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ABSTRACT

The Next Steps Conference was one of a series of meetings held for the purpose of increasing the capacity of family members, professionals, and other interested citizens to work together on behalf of children who have serious emotional disorders and to shape an agenda for improved services. The conference was organized around four major issues: family support services; access to appropriate educational services; relinquishing custody as a means of obtaining services, and coordination of services at the individual family level (case management). During the conference, parent-professional teams presented information about the themes, convened into working groups to set goals, held sessions on developing parent organizations and building coalitions, and developed strategies to meet their goals. Participants also discussed establishing a national network to improve services. This proceedings document presents: a conference agenda; introductory remarks; presentations on the four theme issues; guidelines on organization at the national level, state level, and local level; and goals and recommendations. (JDD)

NEXT STEPS

A National Family Agenda for Children Who Have Emotional Disorders

Conference Proceedings

December 10-11, 1988
Arlington, Virginia

Sponsored by:
Research and Training Center on
Family Support and Children's Mental Health
Portland State University

NEXT STEPS

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and Children's Mental Health
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with planning assistance from:

The National Alliance for the Mentally Ill
The National Institute on Disability and
Rehabilitation Research, U.S. Department of Education
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INTRODUCTION

The Next Steps Conference was held in Washington D.C. on December 10 and 11, 1988. It was one of a series of meetings held for the purpose of increasing the capacity of family members, professionals, and other interested citizens to work together on behalf of children who have serious emotional disorders and to shape an agenda for improved services. A conference planning committee (Appendix A) met in October 1988 to establish the purposes and framework for the meeting. These plans were implemented by staff from the Portland Research and Training Center. The conference was attended by parents, professionals and others from 30 states and the District of Columbia.

Conference Objectives. The primary objectives of the Next Steps Conference were:

(1) to unite parents, professionals and other concerned persons in developing five year goals to address key issues of children with serious emotional disorders and their families;

(2) to lay the groundwork for an ongoing national coalition of families, professionals and other citizens concerned with improving services for these children and their families.

Conference Structure. This working conference was organized around four major issues related to children with emotional disorders and their families. During the first conference session, parent-professional teams presented information about the conference themes, and then convened into working groups to set goals. The issues that formed the focus of the meeting were:

- Family support services;
- Access to appropriate educational services;
- Relinquishing custody as a means of obtaining services; and
- Coordination of services at the individual family level (case management).

Presentations during the afternoon general session focused on developing parent organizations and building coalitions at the national, state and local levels. Work groups then reconvened to develop strategies to meet their goals.

Representatives from the work groups presented their goals and strategies for each of the conference themes at the general session on the second conference day. Participants then discussed methods for implementing the work accomplished during the conference and for establishing a national network to improve services for children with emotional disorders and their families.

Both the recommendations of the work groups and the action taken to establish a national network of parents and professionals help to establish a solid foundation upon which to build a comprehensive system of services. These conference proceedings provide a record of the conference; they also serve as a framework for further planning and action on behalf of children with serious emotional, behavioral or mental disorders and their families.

Barbara J. Friesen
September 27, 1989

Conference Agenda

NEXT STEPS: A NATIONAL FAMILY AGENDA FOR CHILDREN WHO HAVE EMOTIONAL DISORDERS

FRIDAY, DECEMBER 9, 1988:

6:00 p.m. - 9:00 p.m. *REGISTRATION*, Board Room, Room 110
Resource Center, Room 104

SATURDAY, DECEMBER 10, 1988:

8:00 a.m. - 8:45 a.m. *REGISTRATION*, Board Room

8:45 a.m. *GENERAL SESSION*, James and Potomac Rooms
Valerie Bradley, Conference Facilitator

8:45 a.m. - 9:00 a.m. *CONFERENCE WELCOME*

Patricia McGill-Smith, Deputy Assistant Secretary
Office of Special Education and Rehabilitative Services
U.S. Department of Education

James W. Stockdill, Director
Division of Education and Service System Liaison
National Institute of Mental Health
U.S. Department of Health and Human Services

9:00 a.m. - 9:15 a.m. *WHY WE ARE HERE: THE CHILDREN AND THE ISSUES*

Ron Norris, Co-chair, National Alliance for the Mentally Ill-Child and Adolescent Network (NAMI-CAN)

Naomi Karp, Program Specialist
National Institute on Disability and Rehabilitation Research
U.S. Department of Education

9:15 a.m. - 10:30 a.m. *PRESENTATIONS*

Family Support Services:	John Baker, Parents and Children Coping Together, Inc. (PACCT) Bonnie Shoultz, Center for Human Policy
Access to Education:	Dixie Jordon, PACER Center Jane Knitzer, Bank Street College
Relinquishing Custody as a Means of Obtaining Services:	Glenda Fine, Parents Involved Network Barbara Friesen, Portland Research and Training Center
Coordination of Services at the Individual Family Level:	Barbara Huff, Keys for Networking Richard Donner, Washburn University

10:30 a.m. - 10:40 a.m.	*BREAK*
10:40 a.m. - 11:50 a.m.	*WORK GROUPS*: Family Support (Monticello) Education (Mt. Vernon) Custody (Jamestown) Service Coordination (Williamsburg)
12:00 p.m. - 1:00 p.m.	*LUNCH*, James and Potomac Rooms
1:00 p.m. - 1:45 p.m.	*PRESENTATION AND DISCUSSION* Priorities and Goals Developed by Work Groups
1:45 p.m. - 2:45 p.m.	*STRATEGIES FOR MEETING GOALS*: Developing Parent Organizations and Building Coalitions
National Level:	Diane Crutcher, National Down Syndrome Congress
State Level:	Samuel L. Davis, Michigan Association for Emotionally Disturbed Children Joanne Griesbach, Wisconsin Family Ties
Local Level:	Christina Kloker-Young, Community Advocate Creasa Reed, Parents Organization Supporting Special Education (POSSE)
2:45 p.m. - 3:00 p.m.	*BREAK*
3:00 p.m. - 4:45 p.m.	*WORK GROUPS*: Strategy Development (continue groups from morning; same meeting rooms)
6:00 - 7:30 p.m.	*RECEPTION AND NO-HOST BAR*, Mt. Vernon and Monticello Rooms
7:30	*DINNER - ON YOUR OWN*

SUNDAY, DECEMBER 11, 1988

8:00 a.m. - 9:00 a.m.	*CONTINENTAL BREAKFAST*, James and Potomac Rooms
9:00 a.m. - 12:00 p.m.	*GENERAL SESSION*: planning "Next Steps": Presentation of recommendations from work group sessions; set future directions.
12:00 p.m.	*ADJOURN*

INTRODUCTORY REMARKS

CONFERENCE WELCOME

PATRICIA MCGILL-SMITH

Patricia McGill-Smith is the Deputy Assistant Secretary for the Office of Special Education and Rehabilitation Services, U.S. Department of Education. She is the former Deputy Director of the National Information Center for Handicapped Children and Youth.

First of all, I want to welcome you all here and tell you how happy I am that you're here, and that you have been willing to come at this time of year when parents and everyone around the world are so extremely busy, and I want to start by telling you "thank you" just for being here.

I bring you the greetings of our new Secretary of Education, Secretary Kavasos, and of Madeline Will, our Assistant Secretary. I have discussed Madeline's intense interest in your issues before, and how she and I both have worked very hard with Barbara Friesen and Naomi Karp, our staff member, to organize these groups and to bring you together. We are aware of the needs of children with mental and emotional problems and extremely concerned about what is happening or not happening in our country. We want you to help us form what is needed to speak on behalf of these children and to have the services around the country that you need.

You mentioned that I have a daughter who is handicapped. I also have three other children who have emotional handicaps due to substance abuse, and you see in me someone who understands some of the issues. Happily, I can tell you that my three children who have substance abuse problems are all sober today, and things are going better for my child who has a mental handicap, even though there are considerable overlays of emotional stress in her.

Yesterday I got a phone call from the principal, and she said at the opening shot, "This is a good phone call. I am calling to report that things are going very, very well, and we have just finished one full week without one complaint." Those stressful things that we parents have to deal with sometimes are so funny that you just about fall apart laughing. It's really good if you can laugh because laughter is a wonderful healing thing, but I must say some of the stresses are not very easy.

As I look across this audience, I see so many of you that I know, and I have met so many of you. I see Bonnie Shoultz over there. I have to tell a story about the last time Bonnie Shoultz came to town because this describes what can happen. My daughter has a problem with telephones and sometimes she makes many phone calls to people. My daughter loves Bonnie Shoultz, and she loves the sound of her voice. As soon as Bonnie went home after the last time we were here together, she received over a hundred phone calls of 18 cents in duration. That's just long enough for Jane to have heard Bonnie's voice on her tape. You know, I could not believe this happened until I got the phone bill. Bonnie couldn't believe it happened either. She wondered who was listening to her tape. We can laugh about that today, but I didn't laugh when I opened the phone bill. I do understand some of the problems that people go through, and you do have, as you have said, a very weighty bit of work today.

We have worked through two meetings that were held in our office with a small planning group. I think and I hope that everyone who was in on those planning groups was able to come today because those deliberations really brought forth a number of recommendations, and we've gone through much problem identification that would lead up to today. The point of today is to set forth an agenda and to strike a series of steps that are going to lead you to some type of a national coalition that is going to speak on behalf of children and youth who have emotional disorders.

It is a considerable challenge to take all those recommendations that we have generated and form them in a couple of days into the next steps that we are going to do. So, without further adieu, I just want to say thank you again for coming at this busy, busy time of year, to give up a weekend to come in and do this work. I must say, as it seems like with all of us in this work, we are motivated by much more than just a job, or just parenthood. It is a motivation that is of much greater extent, and I think that's why you're going to get the fruitful things that you need out of this meeting. Thank you for being here.

JIM STOCKDILL

Jim Stockdill is Director of the Division of Education and Service Systems Liaison at the National Institute of Mental Health (NIMH).

Let me say welcome to all of you on behalf of the National Institute of Mental Health and Dr. Lewis Judd, the Director of NIMH, who could not be with us this morning. It's been a real pleasure for us to collaborate with the National Institute on Disability and Rehabilitation Research (NIDRR) and the Portland State Research and Training Center in planning this conference. Through the Child and Adolescent Service System Program, we've worked with NIDRR for the last four years in supporting two Research and Training Centers on children, as you know, and this, I think, has been a very productive collaborative effort. I hope it can continue for many years to come.

The basic goal of the NIMH Child and Adolescent Service Systems Program is to develop coordinated, comprehensive systems of care for seriously emotionally disturbed children in order to meet the needs of those children and their families. Key to the achievement of that goal is participation of families in the family movement. Since 1985, all states receiving CASSP grants have been mandated to develop and implement goals related to family involvement. NIDRR and NIMH have worked closely with parents; state agencies; professional associations; and national, voluntary, and advocacy groups to keep this process moving forward. Both the National Association of Mental Health and the National Alliance for the Mentally Ill have been key movers in this whole process. Through the Portland Research and Training Center, the Families as Allies concept has grown from a small curriculum development project to a real national movement, and it is our hope that this meeting today will help keep that movement growing and going.

The first Families as Allies regional conference was held in Portland in April of 1986. It included delegations from the 13 western states, and each delegation had a balance of parents and professionals. In 1987 this was followed by four additional Families as Allies conferences across the whole country. Also in 1986, the National Mental Health Association made children the major focus of its annual meeting in Milwaukee.

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The Mental Health Association also initiated the Invisible Children's Project, which was implemented in 1987 and directed at identifying, counting, and describing children with serious emotional disturbance who had been placed out of state because of a lack of services in their own communities.

In September 1987, just one year later, the Virginia Treatment Center and the National Alliance for the Mentally Ill, with support from NIDRR and NIMH, sponsored the first national conference for professionals and parents concerned about children with serious emotional disorders. As we move on during 1987 and 1988, there have been the formation of a number of local and state parent groups focusing on these same populations.

The Portland Research and Training Center has just announced the award of five mini-grants to statewide parent organizations in Hawaii, Montana, Minnesota, Virginia, and Wisconsin. The purpose of these projects is to stimulate and support the development of model statewide parent groups that have the capacity to provide assistance, information, and support to parents and to parent organizations. As this momentum has developed at the community and state level, it seems clear that the need for a national voice for children has become more and more apparent. This conference, which brings together key parent leaders, professionals, and other citizen advocates, can be of critical importance to the development of that national voice, and we hope that this will serve as a key to planning the next steps of the movement.

I want to thank the NIDRR staff and Barbara Friesen from Portland for their leadership in planning this conference. I'm sure our coming together here will give us a strong national coalition, or will at least begin the strong national coalition, that we need to achieve that major goal of vastly improved mental health and education services for children with serious emotional disturbance problems. Thank you all for coming.

WHY WE ARE HERE: THE CHILDREN AND THE ISSUES

RON NORRIS

Ron Norris is the quality manager for Dupont Corporation. He is a board member and vice president of the Alliance for the Mentally Ill in Delaware and co-chair of the National Alliance for the Mentally Ill nationwide Child and Adolescent Network. He is a contributing author to the book Advocacy on Behalf of Emotionally Disturbed Children. *He is the father of three children, and his oldest daughter has schizophrenia.*

Welcome. I just want to tell you a couple of stories about children that, I think, illustrate why we're here. Yesterday morning a business associate of mine came into my office. She's in her early forties, and she has a 13-year-old daughter named Robin. Robin has had no major problems, but last week, two of Robin's friends went in to their teacher and told the teacher Robin is planning to kill herself. She had made detailed plans of how she was going to do it, she was giving away her prized possessions, and they were really concerned. So this woman came in to talk and we talked for quite a while about what to do, who could help, some people who could provide counseling, how to reach the county crisis team, and, God willing, prevent a tragedy. But you should have seen the look on that woman's face. You've probably all seen that look more than once.

A few days earlier, we got a call at home from a woman in her late thirties. She's the mother of a sixteen-year-old son named Adam. Adam is bright and very talented, but he has been severely handicapped with an obsessive compulsive disorder. When he was younger, the only way he could be educated was in special schools, and because of the stigma of his illness and his strange behavior, the family did not want to put him into a public program or talk to anybody else about what was wrong, so they funded him themselves through years of private school. They spent thousands upon thousands of dollars. Again, that's probably not news to most of you.

The money finally ran out, and this year they tried to place him in a state-run special education program. It's not really a bad program, but in this case it failed within just a few days because the other handicapped adolescents started making fun of this child's obsessive behavior. The mother pulled him out of the program and now he's at home, just sitting. Parents are too tired and too overcome by all this to do anything else. Again, you should have heard that woman's voice over the phone.

I guess, to sum up, I'd say that I'm sick of seeing those situations and hearing about those situations, and I think that probably goes for anybody in this room. I don't think we want to see another family go through these kinds of problems. I don't think we want to see a child get sicker and sicker and not know what's going on, not know what to do about it, and think that the family caused it. Things like that have to stop. I think they will stop, and I think efforts like the one beginning today are part of putting a stop to those problems.

I think this conference is a real milestone. It marks one of the first times we have ever brought together a truly national cross-section of families and professionals to talk specifically about mentally ill and emotionally disturbed children. The results of this conference will help us pinpoint some priority national issues for these children and their families. I think that if we do the job properly over the next two days, we'll have a much better understanding of those issues. That understanding will help the families, the service providers, and the policy-makers to do something about these problems, and doing something is really what it's all about.

In that context, I want to share with you two things that NAMI is doing. First, we're setting up a national telephone network to refer families to support groups and resources and sharing information on what's working and what isn't working for mentally ill, emotionally disturbed children. Second, by 1990, we plan to conduct a state-by-state rating of services for mentally ill children similar to Dr. Torrey's survey for adults, which just came out. We want to continue to update that survey year-by-year. We think both of these steps will make a difference to families in need. It's my hope that by the time we leave this meeting, we're personally motivated to go do some things. I hope we see this as the beginning of a truly effective nationwide network of people willing to stay in touch and stay together to give these children and their families better lives than they've had. Thank you very much.

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NAOMI KARP

Naomi Karp is a program specialist for the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

First of all, I want to thank those of you who are here representing your own families; those of you who are representing other families who were not able to be here; and, most importantly, those of you representing boys and girls who don't have families and who really need our assistance. I also would like to thank Madeline Will, Patricia Smith, and the director of NIDRR, Jim Reswick, for giving me the go ahead and the encouragement and the money to get all of you here today. Barbara, you and your staff, and Lynn Borton and the NAMI people have been most helpful in bringing everybody together. And, Judy, Ira and Jim, we thank you for your efforts and suggestions. I particularly want to thank Val Bradley, Diane Crutcher and Ann Turnbull who really are not touched by emotional problems in their own families, but who know the generic problems that families face and want to bring their experiences and skills to helping us solve some of these problems.

Some of you have heard part of what I'm going to say in the next few minutes, and some of you haven't. I think I'm going to have to keep saying what I say until enough people hear it and say, "Maybe we should do something." I'm going to talk to you both as a professional who has been involved in the field of children with emotional problems since 1963, and as the parent of a son who recently developed a panic disorder.

First of all, the National Institute on Disability and Rehabilitation Research (NIDRR) and Child and Adolescent Service System Program (CASSP) have been funding these two Research and Training Centers for almost four and a half years now. We are about to announce a new priority. We had a proposed priority in the federal register this summer. Both agencies are in the process of internal negotiations about how much money will be put into the centers. I am having a battle royale; NIMH is having a battle royale with decision-makers over funding levels.

We have two Research and Training Centers for children with emotional problems. How many children are there? I don't know. Jane, you say three million. Other people say more than that. Our own Office of Special Education Programs says there are 300,000, and they've got them all. Nobody knows, and nobody's right. Why don't we know? Because there is no organization that can come to our agency and say, "We've got figures to show you that we have x number of kids in these types of settings, and we need this much money to meet the needs of these children and their families."

I'm not pitting disability groups against each other; I just want to show you what it means to have an effective lobby. There are about 200,000 people with spinal cord injuries. We have at least twelve spinal cord injury centers funded by our agency. Why? We've got the paralyzed veterans; we've got Veterans of Foreign Wars; we have spinal cord injured this and that. You name it. They are pounding on our doors constantly, and whoever gets the ear of the decision-makers last is the winner. When you don't have anybody there to find somebody's ear, you're a born loser. We have to do something about that.

Secondly, last September, my son became ill and he decided he could not go to school any more. He couldn't. He was not in any physical or mental condition to go to school and he became very depressed. He started out with a panic disorder, and it was the most horrendous thing our family has ever lived through. I think the fact that we made it without any type of support group that we could consistently rely on, other than our own friends, is a tribute to somebody or something. I don't know what we did, but we were lucky. Fortunately, he's doing much better, but any one of us is extremely vulnerable to being touched by emotional problems and we had all better sit up and do some prevention. I don't want other families to feel the pain and the loneliness that we did.

At our last two meetings, we identified four major areas or concerns facing children with emotional problems and their families. These are by no means the end of the list of problems. In fact, if these four were all of them, we'd probably get our work finished in a couple of years. What we're asking you to do in the next day and a half is to listen to the problems as the participants in this room perceive them, then work on developing some strategies to solve these problems. Then let's lay the groundwork for a firm national coalition that will consistently, articulately, and effectively speak on behalf of these children and their families.

As I said, I started working with emotionally disturbed kids in 1963. We were talking about many of the same issues that we are talking about here today. I personally don't want to be in a room like this in the year 2000, still talking about the same things and saying we really need to do something. We should start planning. If we're not going to do it today, we may not get it done at all, so let's concentrate on it. Thank you all for being here.

PRESENTATIONS

FAMILY SUPPORT SERVICES

BONNIE SHOULTZ

Bonnie Shoultz is the associate director at the Research and Training Center on Community Integration at the Center for Human Policy in Syracuse, New York. She has worked in the field of mental health and developmental disabilities and was associated with the Community Support Program. She is the mother of a 22-year-old son who was labeled "seriously emotionally disturbed" at age four.

I want to talk about family support services and share with you what we've learned at the Center on Human Policy when we've looked at family support services.

Something we often forget is that other countries have national family policies that provide supports to all families with children and they add services for children who have special needs, whether disabilities or other needs. Those supports, such as universal medical care, are lacking in this country. I don't know if universal medical care is something we could ever work toward. One of the things that has occurred in this country is that support services for a child who has special needs are stigmatized in a lot of ways. They are identified with the welfare system and with having low income. I think that in a number of states, families who have a member with a developmental disability are starting to be able to access support services, even when their income falls within the middle range; this is something we need to encourage.

What I want to set forth today is a vision of what kinds of family support services we might really want to be thinking about. I think that too often we think in very narrow terms. For example, we may think that families with children who have emotional disorders really need respite care, or that they really need in-home, intensive, short-term treatment services to fix the family and then move back out. We think in very rigid terms. As we set a national agenda for family support, what we need to do is develop a broader vision and learn from the things that are going on that are very innovative and wonderful in the field of developmental disabilities.

Best Practices

Part of what I want to talk about is "best practices" in family support services today in the field of developmental disabilities. Then I want to correlate that to some of the needs of our families and talk about the barriers that exist and the arguments in favor of family support services.

Some of the best practices have several aspects in common. One is that there is an **ideological commitment to the family**; a firm belief that children belong in families. There is a belief that support should promote integration; integration into the community whenever possible, rather than segregation. For our kids, integration could include supports that help our child become involved with his or her peers in healthy ways, rather than services that only segregate the child with others who have emotional disorders. And finally, innovative family support services should see their job as "whatever it takes" to support the family, not just, "We do this, this, and this and you choose from these things; if those don't work, then that's it."

Another aspect that these services have in common is **family member involvement.** This means not just involving the mother, but all members of the family--siblings, grandparents, aunts--in designing the types of services that this family is going to need to make it in the future. This also means including the child with the disability. Very often that child may know what kinds of supports to his or her family are going to work, and possibly what kinds of supports will be very embarrassing. My son was embarrassed by receiving anything that was different than the ordinary. We need to involve as many family members as possible.

A third aspect of the family-centered approach is **putting the family in charge** of the services they get. Not in the sense that they have to direct the services and manage things, although that is something that is done in some places, but having the family very involved in all aspects of delivery of the services. Professionals who are using this approach see their role as doing things with the family, as being supports to the family, rather than doing things for the family or controlling the family. I still think our professionals are very much in the mindset of controlling families and making families change in order to receive services.

Another aspect of family support services is **individualized and flexible supports.** In many places, family support services are specific and fixed. Families might be offered a certain number of hours of weekly respite care, for instance, or the family might be offered an intensive, but time-limited home treatment service or a parent support group. The family support program feels that it is really offering supports to these families. My feeling is that just offering a specific type of service and calling that family support is not enough. These are worthwhile types of services, but family support should and can encompass much more. Programs need to be built on the premise that families can determine what types of services they most need; services that are flexible and individualized. By individualization, we mean that services are tailored to the family. By flexible, we mean that services can change over time, so that a family doesn't have to decide at one particular point that this is what they are going to need over the next five years and have to stick with that. Instead, we need to realize that families' needs change greatly and services need to change in response.

Innovative family support programs should include the ability to give cash subsidies or vouchers, but I think we have to be careful with providing financial subsidies or vouchers to purchase services because there can be lots of problems. A family shouldn't just get cash from a family support service to go home and purchase the services they need. Often the family can't even locate the kinds of services they really need. There needs to be some sort of family support agency that can make all of this happen; that can arrange for or create services in the community and make those available to the families that need them.

Services could include child care, counseling and therapeutic services, dental and medical care not otherwise covered, specialized diagnosis and evaluation, and specialized nutrition. A lot of our kids may need special diets or at least the families feel that they do. I've met families who feel very strongly that certain diets are necessary and some of those diets are expensive. Other services are homemaker services, home training and parent courses, recreation (especially integrated recreation), alternative activities for the child, services to the siblings or the other kids in the family, respite care, transportation, and services specific to the needs of children with disabilities. These services should be and are provided directly by developmental disabilities agencies or arranged and paid for by the agency.

Another aspect of family support services that I feel we should insist on is **family empowerment**. By this I mean empowering families, rather than controlling families. I think we have to be very careful about that, especially in our field.

Another aspect of family support services is the **use of natural community supports.** This means using the neighborhood and the things that are in the community already; the natural supports that exist, rather than replacing those things with professional services that are part of the formal service system.

Barriers to Family Support Services

I just briefly want to mention some barriers to family support services in this country that I think are especially relevant for our kids, and then go into some of the arguments in favor of family support. Those are the things I think we need to concentrate on.

One barrier to family support services is the **funding mechanisms** that now exist. In most states, current funding mechanisms favor services that keep kids out of the home or services that serve kids out of the home. There are funding mechanisms for outpatient counseling. What about the kinds of things that we need in our home? As an example, the service that I most needed when my son was younger was someone to come into my home at 6:30 in the morning, get him up, and get him ready for school. Just support and encourage him to get ready for school. That would have made a tremendous difference to our family. In fact, I called the local social service agency at one point and said, "Can I get this?" because I knew that the developmental disability agency had that service for families of kids with developmental disabilities. They said, "No, we can give you counseling." We didn't need any more counseling about that issue. Counseling was not solving our problem. Those kinds of funding mechanisms are a real barrier to receiving the kinds of services that we need, so we need to start thinking about what kinds of funding mechanisms we want.

Another barrier to family support services is that **emotional disturbances are still seen as private problems** of the family. We need to make these open, public issues that we're not ashamed of. Family blame is a particular problem for us. Families with other kinds of disabilities don't encounter blaming as much as we do. How can we be asking for support services which will come into our home and actually support us, which we will be in charge of, which we help to determine? We're the people who are blamed for what happened to our child.

A third barrier is the **pressure to maintain the status quo**. That pressure is very strong. The services that are now out there employ hundreds of thousands of people who want to keep doing what they're doing now. True family support services demand a real change in attitude, skills, and in types of work. We need to be thinking about that when we argue it.

A fourth barrier is, **why should the public pay for something that has always been free?** We have always done this ourselves until it became so stressful that our children had to be placed out of the home. Why should somebody suddenly come in and pay money for things that our families have handled themselves?

A final barrier is a **lack of federal policy**. We probably do need a clear federal policy that mandates family support services. I don't know exactly what shape that policy should take, and in some ways I get really nervous about the government coming in and doing this, but current policies make it difficult for family supports to occur. I meet a lot of families who are on Medicaid and are just having a heck of a time because the kinds of services that Medicaid will fund are restricted and they have such a limited choice of service providers. There are lots of problems that result from a lack of federal policy.

Arguments in Favor of Family Support

Now I would like to talk about arguments in favor of family support services. First of all, **family support services reflect the current ideology**. Current ideology has to do with integration into the community, living harmoniously within families, receiving support in doing so, and the belief that children do belong in families. We say this to all the other disability fields and we need to start saying this real clearly in our field, so that it does reflect the most state-of-the-art ideology.

Family support services are **consistent with existing legislation**. The Education for the Handicapped Act (P.L. 94-142) and the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272) both talk about permanency planning, reunification of families, or, in the case of education, services in a setting that resembles a child's own home as closely as possible. We could argue that family support services are needed based on the intent of these laws.

Another argument is that **family support services do save money**. I get real nervous about money-saving arguments because someday it may be discovered that it doesn't save money. I think we need to talk about values as much as money, but I think this is an argument we can use. A final argument is that **supporting families reflects traditional American values**. We need to capitalize on that, rather than ignoring it.

I feel that the time has come for us to consider and push for family support services that meet the many and varied needs of a diverse population of families. There are lots of advantages to doing this, and I think we're at a key point today to start talking and working on this issue. Thank you.

ACCESS TO EDUCATION

DIXIE JORDON

Dixie Jordon is a parent advocate with the Parent Advocacy Coalition for Educational Rights (PACER). She is on the Governor's sub-committee for children's legislation and is the project director of a statewide effort to establish parent advocacy and support groups. She is the project director of a statewide parent organization funded by a Portland Research and Training Center mini-grant. She is also the parent of a 16-year-old son who has an emotional disorder.

When we talk about access to education, we always talk about special education. The reality is that many children who are emotionally disturbed, as everyone here knows, are not in special education. What I see as a primary responsibility of regular education is to begin to re-establish some of the support staff who have been absent for so long, notably social workers, school nurses, and people who can be effective in medication management. I've seen kids taken off medication because there was no one there to give it to them, and now there are laws which say only specific people can give it. I think that's disgusting. I think that the establishment of parent support groups or support groups made up of children from regular education and special education, along with social workers, are some of the pieces that can help us keep kids out of special education to start with. I guess that's where we're coming from initially. My own child could have benefited from that, but he got progressively worse by not having support at an early age. He is now an eleventh grader and in a nice support group within the school, where the kids simply meet and talk about their issues. I've seen a lot of kids damaged by public schools and that frightens me. I've seen a lot of kids get better in well-established programs and I guess I'm somewhat encouraged by that. I don't mean to be negative, but my experiences have not been positive as we look at some of the issues.

Issues in Education

Certainly one of the major issues is **getting school special education programs to accept psychiatric recommendations and diagnoses**. One of the problems in our state is that we serve children who are emotionally disturbed and we also serve children who are behavior disordered, but we have one service motto and that is behavior disordered, and that's it. There is nothing for those kids who are severely in need of someone to come in and understand and assist, not put the behavioral overlays on them, but provide a more comprehensive base for treatment. Those are the kids who generally get farmed out--ultimately to day treatment programs.

I think there is **federal exclusion of socially inappropriate or maladjusted children**. It's a crime and something has to be done about it. When analysis is done on children, I don't know how there is any way to separate out who is socially maladjusted and who is emotionally disturbed. I do believe that in Minnesota, we have taken steps to distinguish between the two by recognizing behavioral disorders as a separate category, but much more needs to be done on a federal level.

I do believe that the **coordination between schools and treatment programs has never been established**. This is certainly true in our state. Case coordination or case management has to be mandatory and the coordinator or case manager has to work with public schools. I came from a governor's hearing the other day. There were only six parents there, but I had tons of calls from others who couldn't come to testify because they couldn't get respite. From the case providers and from everyone there who testified, it came down to the issue of integration and coordination with public school programs.

Let's look at day treatment programs. Some fine facilities exist. Children are generally remanded to day treatment because they are emotionally disturbed, not because they have educational needs. At least that is the story we get from public schools, so no one takes responsibility for transportation and there can't be any successful reintegration. Some of the kids sent to day treatment programs for short-term basis, perhaps hospital-based for thirty days or less, aren't even eligible under most states' criteria to have an evaluation completed because the timelines are too short. Then they go back to a regular education environment with nothing built in for support. I think that's criminal.

One of the major concerns I have with the thrust of least restrictive environment is that we're in a **failure-based model in the public schools**. We first have to demonstrate we can't be successful, then we'll look at what it takes to make us successful. Then when we reach a certain plateau, we're stuck back out there in the regular education classroom. I'd like to see the least restrictive environment redefined in a manner that is clinically appropriate to the needs of children with emotional disorders.

I think the **extended school year issue** is a critical one for most children who are emotionally disturbed and served by special education in school. The majority of them do not receive outside counseling or outside services through mental health, and when the summer comes, their mental health needs then have to wait until September to be reimplemented or reinstituted. Those are the issues that I see as a parent.

JANE KNITZER

Jane Knitzer is from the Bank Street College of Education in New York. She is the author of Unclaimed Children *and is working on a study focusing on issues of schooling and mental health.*

It's really nice to be here. It is always very humbling for me to be with a group of parents because I've sat with some of you at dinners and some of you have shared your pain, and I stand humbled before you. I am also struck by the progress since *Unclaimed Children.* There is no way this group ever would have come together; there is no way that there would have been these groups five or six years ago and I think that is very nice. The third thing I'm struck by is Bob Friedman, who I think is still putting together the book on advocacy. Two years ago when I first wrote the chapter for the book, I called it, "And Miles to go Before We Sleep." Some of my friends in Vermont have heard me talk about that because it's also stunning how much we have left to do.

Dixie mentioned a lot of the things that we are looking at in this current study. You know, we really didn't coordinate, and I don't have a set of next steps for you yet. In fact I never will. Let me share a couple of images from the study. We are looking at what is being done with kids who are identified in the schools and what is being done with kids who are not yet identified. We are looking at the kids who are at risk of being identified and being pushed into that stream; those kids who cannot get any extra help in their regular education. We're very concerned about that. We're very concerned about the ease with which kids are labeled into special education.

I think there are three focus areas that I'd like to hit. Dixie actually hit them, too, when she talked about schools and the education of children with behavioral or emotional problems or some combination of learning, behavioral and emotional problems.

After making site visits to programs in more than twelve states, my first impression is that **absolutely anything goes.** You are the victims of the communities you happen to live in. There are no standards; there are very low expectations and if you happen to be in a school district where there has been some leadership, you are in luck. If not, you're in trouble. That's the bottom line. Secondly, when you go into these classes for the SED kids, or whatever label you choose, I ask you to look at some issues.

I'll take two minutes to describe to you a visit that I made which will be forever implanted in my head. There were two classrooms. One was third, fourth and fifth graders with a wonderful warm teacher, collages and things all over the classroom and an aide in the classroom; all kids identified as whatever the state equivalent was of seriously emotionally disturbed. In this class, the children started every morning with a meeting to talk about and to make sense of what was going on. They had a teacher who had a real sense of humor. They had a behavior management system. They had a point system which actually had some positive reinforcement, as opposed to negative, and it actually encouraged them to do some group activities, as opposed to individuals earning points. They had made a videotape spoofing their behavior management system. You should show it at every meeting you go to.

These third, fourth and fifth graders had developed a newspaper for the school. They also had an art teacher come in and they had just done papier-mache masks; the masks were all displayed and they had used the project to discuss art and all kinds of interesting things about culture. It was very exciting. Not only that, the teacher said to me, "You know, the parents are really reluctant to come in, so I've raised money to create a one-way observation room so that they come in at their own pace, stay a little bit, leave, learn about their children." He had also gone to the local business people to get some prizes for the parents who came in, sort of like opening a bank account. Needless to say, that was a high.

Then we went to the classroom for children who were in sixth, seventh, and eighth grades. What we found were seven kids sitting in a circle; one or two girls and the rest boys, which is very predictable. A number of kids looked as though they were severely neurologically implicated and some kids did not. They were sitting around in a room and when we walked in, the first thing the teacher said was, "Tell these ladies why you're here." At that point, these ladies, as well as the children, wanted to sink through the floor. It went from bad to worse in that room. I say that because one of the issues that no one has talked about, is "what about the **continuity of experience?**" These are kids for whom change is difficult; change in routines is difficult and predictability is important. The children in that first classroom were going to come into this classroom. When I raised that issue to both the education and the mental health people in this community, they said, "We never thought about that." It was stunning to me and very extreme, clearly, because the good one was so good. I urge you to take a look at issues of continuity; continuity across classrooms and continuity within classrooms.

Mainstreaming has created a monster for some of these children. I have sat in classrooms where I felt like I was in Grand Central Station. One kid was pulled out for art, another for physical education and I said to the teacher, "Do you ever do any group activities?" She said, "Gee I'd love to, but we're in a transition class. There's no way we can do them."

The other thing I urge you to look at is that **behavior management has become defined as special education** for kids with emotional and behavioral handicaps, mostly behavior modification. I have sat in rooms with point systems with kids who are there because they lack social skills. They are sitting at separate desks all around the room and they never have a chance to develop any social skills because they're not allowed to talk to one another. We have set norms for some of these kids that we would never set for kids who don't have serious emotional problems. Look at expectations about behavior. We visited one school where the kids were on their way to recess and the teacher had them lined up for twenty minutes in the hall because they weren't lining up right, and they never got to recess. What I think I'm really saying is that we have spent so much time looking at the procedural aspects of P.L. 94-142. I hope we don't do it with P.L. 99-457.

We need to look at substance and quality. Except very rarely, learning is not used as a way of hooking these kids. Learning can be exciting, even for these kids. Look at management. Look in your own communities, and bring the teachers and the educators in and ask them to describe their systems and continuity. The other thing that we saw much too little of was after-school programs. You talked about the need for extended summer day programs. What about after school? In some cases these kids are rewarded for leaving school an hour early. They don't have a full regular day and then what? Whose problem is it? What happens to the kids? We are not building enriched, extended after-school programs for them. This is very important.

Another issue is the **relationship between education and mental health.** We really need to build in and build back all those mental health support services in a good way in a school. That doesn't mean pulling kids out for individual therapy. It doesn't mean doing family therapy in the school. It means having people available who can help support teachers in crises and people who can help support kids. It provides a buffer so that principals are more willing to have these kinds of kids.

I have to share with you an experience of my own. I have twins and one of my children has lots of stresses due to serious and ongoing chronic physical problems that we are constantly coping with. Though she has emotional problems, she's not seriously emotionally disturbed and I hope we won't get to that point. At one point after we moved back to New York City, she was really becoming school phobic. One morning I could see that it was hard to get her on the bus. I had no idea that there was a school psychologist at her school. That day I got a phone call from the school psychologist, who introduced herself, and said to me that she really didn't think Suzy was sick. (Suzy tends to spend lots of time in the nurse's office. In her school, she's very lucky because she has a wonderful, warm, supportive nurse. I've learned that every time she feels stressed, she goes to the nurse's office. It's terrific. They have a mutual admiration society). The psychologist said "I don't think Suzy is sick." Suzy had been crying. I said "Suzy's not sick." It stunned me when she said to me, "What do you think?" She didn't know I was a psychologist. She didn't know anything about me. She just called and said, "You're the parent, what do you think?" That set the tone for the next four years and for my involvement with this school. I appreciate it deeply and I can see what a difference the lack of that makes, now that we have a new school psychologist there. We need to put back mental health supports into the schools. We need them for kids who are identified as SED and we need them for other kids too. Other kids have crises too, and crises escalate. We need to stop having mental health personnel do all these silly evaluations and reevaluations which don't lead to individualized anything. Everybody knows it, and we don't do anything about it.

We need to get busy, and we need to do a special target on getting education and mental health to collaborate because it would be hard to find two systems less interested in collaborating.

I think the last thing that you need to do is **strengthen your advocacy.** It is really needed. You need to do two things; you need to continue to be the Emperor's New Clothes. There are bad things happening out there, not all is rosy. We found one community where they were building a segregated school for children identified as emotionally handicapped and then they had a more serious label. Building a segregated school starting with the first grade. No justification, they're building it. Somebody's going to get rich building it. It's outrageous.

I know I'm not supposed to talk about custody. Kids continue to be kicked out of schools. Not only that, take a look at your own states in regard to for-profit hospitals and get to the parents so that they don't get their kids needlessly hospitalized in for-profit hospitals for thirty days and then dumped back.

Your voice is needed. The rest of us don't seem to be doing very well. As a group, bring these people in, ask them what they're doing, and open up dialogues with them. You're in a terrific position to do that. Bring the school people in and ask them what their plans are. Do this as a group, not just on an individual basis. We don't have a real vision of best practices that I can share with you. I don't think that you do. We have some individual programs that are dynamite. A lot of caring people out there share your pain and frustration. We need to find ways of defining best practices and a vision for the way the school and mental health should work together. Thank you.

RELINQUISHING CUSTODY

GLENDA FINE

Glenda Fine is a staff member for the Parents Union for Public Schools in Philadelphia. She is director of the Parents Involved Network (PIN) at the Mental Health Association of Southeastern Pennsylvania in Philadelphia. She is the author of a manual on organizing self-help and has co-authored a similar manual for the Georgetown University Child Development Center.

I'm pleased to be here today to participate in this meeting. Before our discussion on custody occurs, we'd like to say two things. Number one, although we are all advocating for community-based services, it is important to always keep in mind that there are children who need residential services also. And second, Barbara and I are not attorneys. The custody laws and regulations are very complex and very confusing. The purpose of our discussion today is to give you a very focused overview of the problem and some of the consequences, from the parents' perspective, when we must relinquish custody as a means of obtaining services for our children with mental health problems.

Not too long ago, the need to relinquish custody for service was not a very big topic of interest and concern in Pennsylvania and other states, except to parents and families involved in this process and to some very concerned child mental health advocates. It has come to the forefront as a critical issue because parents and other interested professionals and individuals have begun to articulate their concerns about this practice. Today, more and more interested people are in agreement that we must work to change this situation.

I'm going relate to you some comments that parents have made to me about the custody issue. "Why do I have to give up custody of my child in order to get services? I have not abused my child. I have not neglected my child. I have worked very hard to provide everything that my child needs. Do you mean that I have to go before a judge and state that I cannot control my child in order for him to get the treatment he needs?" Another statement I often hear is, "I was told that relinquishing custody is just a formality, but other parents have told me that I may not be able to get my child back when I want to. Is that true?" These and other statements by parents reflect their concern about relinquishing custody of their children for mental health services. You will hear me say relinquishing custody many times, so that those of you who are not aware of this problem will remember those words when you leave here.

What are some of the consequences of relinquishing custody? Relinquishing custody of a child means relinquishing your rights as a parent. Although it varies from state to state, parents may lose the right to choose the place that their child will have to go. They will lose the right to take their child out if they are not satisfied with the program. In many states, parents lose the right to be involved in the treatment planning process. In some states, parents lose the right to participate in the education process. In some states, there are visitation stipulations so that a parent may not get to visit a child or the child may not be able to come home and visit as often as the parent might like.

What happens to parents? How do they feel? What are they told? How are parents perceived by places that do have children in their care? Parents are rarely viewed as a valuable resource and are very quickly labeled as parents who couldn't do the job. When they ask questions and want to be involved either by phone or in person, they are often viewed as intrusive and very over-protective. Whenever I called the place that my son was at, they said, "She's calling again". This was very disconcerting to me. If I didn't call, who would call to find out how my son was? I was and still am his mother. If parents back off, they are viewed as being uncaring and uninvolved and just wanting to get rid of their kid. These are some of the situations that parents have to put up with.

In order to get services, many parents are told that relinquishing custody is just a formality. "It doesn't mean a thing, just sign on the line." Doesn't mean anything. After the child is in placement, parents find that this formality leads to attitudes such as, "we're not interested in what you, the parent, have to say because, after all, if you were so interested and you know so much, then why are you letting the state pay for your child's living? Why is your child here if you know so much?" The attitude is, "we will fix your child because you could not do so. The state is taking care of everything."

In some states, residential placement means that the child's school program becomes a special education placement. It appears that there are several states that may be excluding parents from their child's education. Again, I am not an attorney. However, this practice sounds rather inconsistent with federal law, particularly if the state is acting in place of the parent. Public Law 94-142 specifically uses the term parent and defines parent as a parent, guardian, person acting as the parent or an appointed surrogate. The term "parent" expressly excludes the state, so that if the child is a ward of the state, the state cannot both propose the service and consent to it.

Another issue with education is that parents are not invited to participate in the special education process, the individual program planning, and are often upset to find that they have received an IEP in the mail without their participation. As one parent said to me, "I called the school where my son was in residential placement and asked for a weekly progress report on how he was doing in school. What parent would not want that information? But I was told that since the state had custody and was paying for him, I wasn't really able to get that information and it wasn't important for me to get it."

What happens when we have our own medical insurance and we want our child to continue with our family physician and with his or her dentist? This right is also denied in some states. Does that make sense? Parents are often not told if their child is put on medication. They do not have to discuss it with the parents in some states. Who would want their child to be put on some type of medication and not be part of that planning? Would your pediatrician do that at home? No. If a parent is dissatisfied with the placement and with the inability to be involved with the child's treatment and education and wants to remove the child, new problems arise. The parent may not be able to get that child back. There may have to be a judicial process. There may have to be other processes involved. Who knows when the parent might get that child back?

We must at least look for ways to make things more reasonable and less debilitating for caring, involved and interested parents. We must begin to look at specific strategies for change. A more positive approach to residential services is essential for both parents and for their children. Thank you.

BARBARA FRIESEN

Barbara Friesen, Ph.D., is the director of the Portland Research and Training Center.

The problem of parents having to relinquish custody in order to get services is a very complicated issue, and we can't possibly tell you all the nuances. Part of the problem is that every time we talk about it, and when we talk with attorneys about it, we all get hopelessly confused.

One of the problems with this issue is that it's very difficult to sort out what is law and what is practice. The circumstances of parents having to relinquish custody usually arise out of out-of-home placement, residential treatment, or placement in special schools. Why does this happen? It happens partly because Public Law 96-272, the Adoption Assistance and Foster Care Act of 1980, sets out the conditions under which states can receive money. So, at one level, receiving money for out-of-home placement makes this a financial issue. The Act says that states have to have some kind of an agreement with parents, but what the Act does not say is that the state has to take custody. It says they have to have an agreement and it specifically says that they may have some kind of informal written agreement, but it does not say that states must take custody. However, many states have built into their state laws, or their administrative rules which have the force of law, or at least into their informal practices, the taking of legal custody.

In my home state of Oregon, I was told, "Well you know, it is true that our state law specifically says that parents should not have to give up custody in order to get services, but we talked to the Attorney General and he said, 'Well, if you're going to have physical custody, you probably better have legal custody.'" So at this point, the state has not changed the law, but has written a set of administrative rules which have the same effect.

Finances are an issue and when we talk to child welfare people around the country, many of them believe that if they don't have legal custody, they can't get paid. That is one explanation that is given.

Another explanation is a therapeutic one, and we hear this one a lot. "If we don't have custody and these kids are in residential care, those parents will yank them out of treatment prematurely. So for the sake of the child and for the sake of the child's treatment and education and to maintain consistency, if we have custody, then we can say when the child enters residential treatment and when the child leaves residential treatment." These are well-meaning people who really believe what they're saying, so a therapeutic explanation is another reason for relinquishing custody.

We did an informal survey of 50 states and asked about their provisions for out-of-home placement specifically for these kids. Forty-one states responded. What we got back was a variety of answers. Twenty-nine states do have an arrangement by which they can do voluntary placement agreements that stop short of legal custody. What we don't know is how often they use them. Glenda and I know of two states, Pennsylvania and Oregon, that do have such a legal possibility, but don't use it very often. If you move across from one state border to another, there are changes in the rights that parents relinquish and the rights that parents keep. The variation makes it very difficult to sort out law from practice.

Glenda alluded to another piece of practice that often gets interpreted as law, but isn't. That's how the residential treatment centers behave and the policies that they have about how often parents can visit their children or whether or not they can receive phone calls. In this day and age, we still have residential treatment programs that earnestly and honestly believe that parents will upset their children by visiting and that it's really best to separate them, at least for a while. Many residential facilities have very restrictive communication policies during the first week, the first month, and sometimes throughout the span of residential treatment.

We also have responses from a survey of 966 parents from around the country. We asked the question, "Has it ever been suggested to you that you give up custody in order to get services?" Twenty-five percent of those parents answered, "Yes, it has been." We asked them about some of the reasons and most of them have to do with funding, or "It was just explained to us that that's the way we do things in this state." A few parents said, "We pushed it farther. We didn't want to do it. We decided against residential placement." Other parents stated, "We didn't want to relinquish custody, so we decided to take on the cost of the services that our child needs, and we're glad we did that."

In terms of the scope of the problem, 25% of the people surveyed said they had been asked to relinquish custody and about 35% of those had actually relinquished custody. This was not a random sample of the population, so I don't want you to conclude that 25% of all parents in the whole country have been asked to relinquish custody. We don't really know that and the lack of information is very difficult. At least now we have more information than we used to have. Before, for years, all we had were anecdotes from parents who were upset about this issue. Thank you.

SERVICE COORDINATION

RICHARD DONNER

Richard Donner, M.S.W., is an instructor and training coordinator in the Human Services program at Washburn University in Topeka, Kansas. He is also a doctoral candidate at the School of Social Welfare, University of Kansas, where he is conducting research on family support issues. He has a clinical private practice and consultation regarding children and family mental health services.

BARBARA HUFF

Barbara Huff is the executive director of Keys for Networking, a statewide parent organization based in Topeka, Kanasa that provides information, support, and advocacy *services to families whose children have emotional, behavioral, or mental disorders. She is the parent of two daughters, one of whom has required treatment for serious physical and emotional problems over the last ten years.*

Richard:
We're going to try something a little bit different than the other presenters. We're going to do something Barbara and I do very well. We keep following each other and collaborating with each other. She'll say something and I'll add to it and vice versa. We hope we'll be able to present to you today some of the issues as we see them and as they relate specifically to case coordination at the individual level. We're going to encompass all of the stuff that goes into case management.

I want to clarify what we mean by case management and we hope to do that best by describing to you a specific case that Barbara and I have been involved with for the past six months. It is the case of a young boy named Sam and his family. Sam was being released from a residential treatment program last spring after two years. Through the case management discussion with you, we hope to be able to identify some of the problems his family and he identified, what the case manager was and wasn't able to do to assist them in meeting their needs. We hope that using this example will highlight the specific issues for you that relate to the benefits of case coordination, barriers to it, and the necessity that it be available for all families.

Barbara:
I would like to start out by giving you a brief idea of how I came into contact with this family. All of you who work with families know how this is; the phone rang at 11:30 at night and I thought, "Do you people not ever think I sleep?" I picked up the phone, (I immediately mellow every time it's a family) and the next thing I did was say, "I have time to listen, it's okay." This parent, Amy, is Sam's mother, and Amy and Tom, her husband, were obviously in a real crisis. Sam was being released from an institution and they were suffering from the fears that many of us suffer when that happens. She began to visit with me and after she found out that I was a parent, I think she found it even easier and more comfortable sharing her pain and frustration and what had gone on with the family in the past when Sam was living at home before he was institutionalized. She began to reveal a lot about her family's suffering and I decided to just take some notes after I awoke enough to begin to listen to all this. I began writing down different things that Amy told me and later I was able to kind of categorize that, so that's how Richard and I are going to focus on this particular case today.

Obviously this is real life and it's real close to our hearts because we have seen many successes as we have gone along in the last several months with this case. Amy talked a lot about her feelings of guilt, about wanting Sam to come home and not wanting him at home, and all the overwhelming feelings that went along with that. She talked about how he had just consumed their entire family life in the past and she wasn't willing to have that happen again. As she began to describe Sam to me, I also realized exactly how serious this young man's disability was and I think that it is important for you to know that we were not working with a mild or moderate child, but we were working with a child who has really serious, serious emotional disabilities. A very aggressive child. Three different times he attacked members of the family. She began to describe a child who was very, very troubled. The actual diagnosis was schizoid personality of adolescence with problems, depressive features, whatever that means. In fact the family actually did not agree with any of the test results or the diagnosis this professional came up with. It seems that their son was much different from how the professionals saw him, but then he had been institutionalized a couple of years, so it was hard to have a very clear picture of him. No one was really sure of his capacity or his capabilities because of the amount of time he had been in the institutional setting.

Richard:
At that time, we were in a kind of fortunate position because Amy had called Barbara and Barbara is real good at having the right connections and knowing whom to call. She got in touch with me and we were able to get in touch with the project that I had been involved with in developing a case management system. The very first thing we did was access a case manager. This case manager happened to be a person who has an associate degree in licensed mental health technology and had some experience working with families, but had never worked with them in this kind of capacity. What she and we did with the family within the next week was meet with them and underscore the strengths and well as the needs this family could identify. It was critical to us and it is critical when we think in terms of case coordination that we begin to look at successes; we begin to look at strengths.

What Barbara described to you is typical of most families. They are focusing on the "God, what are we going to do?" problem. It is also what most professionals do and most of us, as trained professionals, know that is what we are supposed to do. We are supposed to look at pathology. We are supposed to look at illness and we are supposed to look at problems.

It seems to us that if this kind of model is going to work, it would have to focus on what people do well. We sat down with the family and Sam and said, "All right, what do you want and what will make it work?" This was the very first time this family had even considered that Sam might be able to come home. They were looking at the possibility of placing him in the state institution because the other residential care wasn't going to keep him anymore. We began to look at what they thought they could offer and what they thought they needed. What would it take for us to help them be able to maintain him in his own home, in his own community, in his own school?

We found out that Sam had a lot of strengths and was a very loving and caring son. He was a person who cared about young children very, very much. He happened to be very good at soccer and he liked other sports. He was becoming quite proficient at skateboarding. He liked to wear camouflage clothing. Although he was 16 1/2 years old, he was in many ways mentally developed at about 13 or 14 years of age, but he did get along with friends about that age and he really did like people. His aggression was very minimal and it had happened only three times in three years. Two of those instances were provoked, according to Sam, and yet were being used by the people at the institution as an indication that this child needed to be released from the institution because he had homicidal tendencies. After this very first meeting between the family and the case manager, we began to address some of the major issues and some of the major goals that the family wanted and began to design a program that was specific for him.

Barbara:
One of the things that came out loud and clear as I began to work with this family was their lack of support. Lots of things fall into the category of lack of support, but I think Amy was able to tell me how she felt because I felt the same way. My marriage had dissolved under all the crisis and theirs had been on the verge of falling apart when their son had been home before, so she was real upfront in saying to me, "I don't know that I can take that risk and I don't know what kinds of support I need in

order for that not to happen." They had never had an opportunity to network with other families that were going through the same kinds of feelings and problems. They had no extended family nearby because they had moved into the Topeka area from rural Eastern Kansas in order to have services.

After they made this major move, there were no services available, so they had no extended family and not a lot of close friends for themselves or for their son. They also were feeling that it was real unfair to their other children. Their oldest daughter said that she just couldn't take it again and wouldn't take it again and she moved out at just the idea that Sam was moving back. Sam had physically threatened the younger daughter's friends at one time and so she was afraid for him to be around her friends. She was really apprehensive and they were all feeling so guilty about feeling apprehensive. Also, they all knew that there was no way to get away from this and we all know that. They knew that before Sam had been overwhelming and they had no time to themselves and no time with the other girls in the family. They were really frightened about that and the effects it would have on the rest of the family members. We can all relate to that.

Richard:
One of the things the case manager did early on, due to the support needs of the family, was to hook them up to the parents' support group. It was one of the first groups established in our state and we were fortunate enough to be able to access that immediately. Another thing the case manager did was provide the family with written information about Sam's disability. During the years of treatment, they had never received an understanding of the mental health issues and what it all meant or the medications he was on. The case manager provided them with that information. She was also able to provide the opportunity for respite care. We happened to be in the midst of developing a respite care training pilot project, so we had a few students who were trained and were willing to provide respite should the family want it. We told the family that we could get it for them if they needed it. The other thing the case manager did, and continues to do, is spent a lot of time with Sam's two sisters. We did not and do not provide case management only for the child with the emotional disability. We have to look at providing it for the family and this includes his sister, who was away from home. That was accomplished by the case manager talking with the two sisters, spending time with them, finding out what they thought was going on, and getting their support for what they needed as well.

Barbara:
The family had not utilized services for Sam within the Topeka area. They had no idea who to connect with for a therapist. They were going to need a psychiatrist for the medication check and they were going to need some type of crisis intervention plan in case of an emergency. They needed a way to access services, possibly on a home-based model, without relinquishing custody to the social rehabilitation services.

Richard:
And as a result of those needs, the case manager was able to access formalized resources. The key in these case management models is that we not just use formalized resources, but that they are essential and accessible. We were able to quickly locate a therapist who was willing to work with the family and see Sam on a regular basis in his regular home environment, without being constrained by agency rules which would require the therapist to see him in the office. We also were able to set up a meeting quickly with a child psychiatrist, who was willing to see Sam only for medication and to provide the necessary backup support in case of an emergency hospitalization. This was something the family was very scared and concerned about.

Barbara:
Of all things, they released this young man from the institution in mid-May with no summer plans. Both parents worked and there was absolutely nothing in line or in order for the summer, so there was no supervision. If there had been some type of program for him, there was no transportation to get him there. At that time, he had no friends and no peers in the community, so we began to have to think in terms of what we were going to do for summer plans.

Richard:
The case manager acted in an aggressive outreach to the community at large, which is another essential component of case management. In a very short period of time, she accessed the kinds of services that all the other kids of Sam's age could have access to in the community. He attended a basketball camp; he was able to be in a recreation program. He was also a volunteer, teaching children who are severely multiply handicapped to swim, because Sam really enjoyed helping other kids and being able to do some of those things.

Barbara:
I'm just going to mention one quick thing about school because I don't think I have to tell you what schools might have been like, other than to tell that they didn't want him. Richard and I set up a meeting with them and they locked us out, mainly because we invited the parents to come to the meeting. I had been clear with the special education director in saying that I had invited these parents, so they had the parents locked in and us locked out. It was rather tense, so school problems just went on and on. We weren't asking them to pay for anything. We just wanted them to cooperate and let this young man go to school in his own district. I won't go into all the details about that because it was fairly incredible. But the benefits of this relationship to all can be spelled out by my just saying that the best word I can think of is "relief". Relief to the family, relief to the child, relief to everyone. We talked about adjectives that might best describe the case management role and I think they would include companion, coordinator, communicator, collaborator, and creator. She or he must be flexible, available, empowering, consistent and caring.

Richard:
And most importantly, involved in the work. I put up on the board all those principles which we feel are essential if case management is to be offered to families. We do have copies of these for people who are interested in them. Case management should be based on the values that you've heard from other presenters here this morning. We think that is the only way that it is going to be implemented in a way that is responsive to individuals and to families according to their definition of what they want in a case manager. The case manager is the person who is there to help them access services and get it done.

Barbara:
Richard and I both agree that when case management is implemented in the way that we have described, it can be the backbone in the system of care to families and to children. We see it as a way to coordinate and appropriate resources and services, particularly services that change in time. We believe that it has that kind of strength to it. In conclusion, I'd just like to say that case management is an essential service that needs to be available to every family and to every child who has an emotional disability. Thank you.

STRATEGIES FOR MEETING GOALS

ORGANIZING AT THE NATIONAL LEVEL

DIANE CRUTCHER

Diane Crutcher is the executive director of the National Down Syndrome Congress in Chicago, Illinois. She is a consultant to the Federal Department of Education for Health and Human Services. She is also the mother of a fifteen-year-old daughter with Down Syndrome.

I'm really here to tell you about the formation of the National Down Syndrome Congress, and in doing so, offer you no pressure whatsoever to form whatever it is you choose or choose not to form. I merely want to offer you some background on the formation of a national parent organization about 16 years ago that spun off of a very powerful advocacy group, the Association for Retarded Citizens (ARC). Sixteen years ago, 800 parents of children with Down Syndrome met during an ARC U.S. convention and called their own side meeting. They felt the need to address the things that are most alike about their children; not that the ARC U.S. was not addressing them wholeheartedly, considering the gamut of disabilities that they did address.

The parents decided that they wanted their own particular interest group that could specify the likenesses about the children with Down Syndrome educationally, psychosocially, biomedically, and the likenesses of the families. From that came a steering committee, which had three members who happened to live in Chicago, Illinois. Since they were close to one another, those parents met more often than the rest of the steering committee could actually come together and join with them. They began formulating a constitution and bylaws and making decisions about directors, officers, and meeting dates. They actually included a mechanism for electing board members and officers. They got into the question of a specific location, and as you might guess, decided to locate in Chicago. So there is nothing magical about Chicago, IL. They were just being logical. There was no money to fund any of these efforts. All of these people were traveling on their own and doing these things because they were caring parents and they wanted to help the kids.

One of the parents happened to be married to an attorney, which is useful when a group is trying to get a not-for-profit charter. They were able to get the charter once the constitution and by-laws were adopted, board members chosen and officers elected. That was also chartered in the state of Illinois and the organization remains in Illinois. We are still in Chicago, although we find ourselves in Washington, D.C. quite a bit. We've opted to remain in Chicago because we find that when we come to Washington, we are able to be what we call "care advocates." We don't provide services and we don't run adult training centers or programs for day camps. We advocate on behalf of people with Down Syndrome and their families. That's all we do.

At this point, members of the steering committee transferred themselves into officer positions. They set up the next meeting for the fall of 1972 and there has been an annual meeting each year since.

In 1973, the group met again and I'll remind you that they were still volunteers, only now their numbers have grown, and they have more people on their board of directors. People actually have titles at this point, although the board is still made up of volunteers. Initially, meetings of this group were still attached to the ARC U.S. annual convention. The day before or after the ARC meeting was just for the Down Syndrome Special Interest Group, an arm of the ARC U.S.

Over the years, it was decided that the ARC U.S. and the National Down Syndrome Congress (NDSC) could probably best go their own ways, but still remain close to one another as far as being interested and supportive in one another's endeavors. That's really what has happened. The NDSC made the break when we opted not to go to Hawaii for our annual convention. We knew that our membership, with just a few years into the NDSC formation, could not afford such a trip. The board, the officers, as well as attendees and members alike, were paying out of pocket. With the group still in its infancy, we just could not afford the probable poor attendance. We opted not to go to Hawaii. That was really the beginning of the more formal organization, National Down Syndrome Congress, separate from the ARC U.S.

Over the years, the conventions have been held separately from ARC U.S. We make sure not to step on one another's dates because we do not want attendees who would like to go to both programs to be prohibited from doing so. Often our conventions are in the same part of the country. A couple of years ago, in fact, we were within three or four hundred miles of one another and just a weekend or so apart. Hopefully, people were able to make a long week of it and attend both conventions. That would certainly be our goal. We have coordinated with the ARC U.S. on a variety of things over the years and our relationship has improved. Our relationship has been particularly enhanced in the last five or six years and we do a lot of cooperative efforts, especially with regard to legislative issues.

We have our own brochures now and a national headquarters, which is in Chicago. The headquarters office is actually in Park Ridge, out by O'Hare, and we have a hired staff that is growing as the organization grows. We currently have about a five-thousand family membership base. There are five hundred parent groups across the country, which represent about two million members. Our last convention was held a couple of weeks ago in Cincinnati and 2,300 people attended. Eleven or twelve years ago was the first convention for which we kept attendance numbers; it drew 650 people, so we are seeing growth in the organization. Obviously, we are meeting needs of these families. We also have side conferences for brothers and sisters of those with Down Syndrome, as well as youth and adults who have Down Syndrome.

I brought a few handouts with me, though certainly not enough for a group of this size. I will leave them with Dr. Friesen and she can choose to use them as she will. They are brochures on the National Down Syndrome Congress, which state its purposes, goals, objectives, and a little bit about its history. There is also a brochure that I brought from one of our local organizations. As I said, there are five hundred of these across the country. One of them happens to be in my home town of Wilmington, Illinois, so I brought its brochures for you to get a sense of what the local chapters do in tandem with the national organization.

The bottom line is that the NDSC is a parent support organization promoting public awareness about all aspects of Down Syndrome. We have a clearinghouse now in our national headquarters office and we are gathering a gamut of information on all aspects of Down Syndrome, which we offer to parents and professionals and any other interested persons. We have sixteen standing committees with the organization and those are chaired by the board of directors. Six of those standing committees are what I call operational committees; the ones that you have to have in order to maintain your organization. The other ten are service-oriented committees, which actually provide information and service to constituents. We also have five ad-hoc committees that tend to come and go as the needs of the organization change.

Rather than eating up more time, I'm going to stop here and offer to answer questions that anyone might have on any aspect of formation of a national organization.

People like Barbara, Ann and others have come to present for us over the years and taken their precious weekends and evenings. They offer their time and their expertise and it's with that kind of support that we're allowed to do the things that we need to do. When we come to Washington or meet nationally on any level, it's very important for us to be sophisticated and to represent people with Down Syndrome and their families in a fashion that we all would like to be remembered.

Underlying that at all times, there is the message that I'm a parent of a child with Down Syndrome. When I do presentations, sometimes I don't have it announced that I am a parent. I announce that myself about halfway through a presentation, after allowing the audience to get to know me first and have some kind of acceptance of the message that I'm presenting. Then all of a sudden, I drop it on them and you can see many people in the audience say, "Oh my goodness, I can't believe this." However, the parents will come up to me afterwards and say, "We could tell all along that you were, even though you never said it, but there was an underlying tone." I think that's what we never forget in our service provision for constituents, either here in Washington, nationally, in parent group meetings at home, or in our conventions. We never forget the people that we serve because we are those people.

There are a lot of people who have stood with me. I have two children, who are now 20 and 15, and I have a husband and that is what has really made it possible for us to do what we've done over the years. The doctor said not to bring Mindy Crutcher home because she'd never be anything more than a vegetable. We should tell our friends that she had died, then we could go home ready to have another child. When we decided to bring her home, we told our four-year-old daughter about her new sister and said, "Your sister has something called Down Syndrome. It's nothing anyone did or didn't do; it's how she was born and she's going to be slower than other kids and we're all going to have to help her. We don't really know what that means, but we feel we have to try." My four-year-old daughter said, "Mommy, if something happened to me, we would try." It was at that point we knew we would be serving everybody in our family very well if we all put forth an extraordinary effort.

Actually, we don't live with Down Syndrome every day in our house. We live with two kids and a mom and a dad; our life is more like everybody else's than different, but we've done this on her behalf because she is a worthy individual. There were many people standing with us as we formed and saw the National Down Syndrome Congress grow to the point where we have salaries and we're able to pay for help. Those salaries are much lower than typical Chicago salaries and that's because we would rather have service to families than to have typical Chicago salaries.

We call ourselves a parent organization, although we certainly have professionals among our membership. Probably about twenty percent are "just professionals." Now, there is crossover because many parents also get into the field, or some were in a related field before. It is not unusual to find parents going into a related field once they have a child with a problem because you do become very knowledgeable and very interested in helping not just your own children, but others. This means that our actual membership is probably about 50-50; about fifty percent who are just parents and fifty percent who either crossover or are just professionals. In the actual formation of the organization, however, it was primarily just parents and a few who had crossed over into the field. Over the years, we have picked up a lot more professional support and I think that has to do with our ability and willingness to retain, maintain, and obtain professionals as our partners.

Years ago, when Mindy was quite young, I thought that my husband and I were the only ones who could be Mindy's advocates; we were her best friends and her best teachers and we would go through life being that for her. We discovered relatively early in Mindy's life that we were going no place in Mindy's life without professional expertise. In fact, we might even be going backwards because we were spending time fighting people who could help us. After learning that lesson, and it was a painful one to learn, I became a strong advocate of parent-professional partnerships and working together on behalf of the kids that we all care about. That's the attitude of the national organization and with that kind of attitude, you tend to draw people to you.

We hope our conventions offer a host of opportunities for people to learn, both professionals and parents. We find a lot of professionals coming to our conference because they also need to learn about parents and families, not just some more techniques to take back and use on their particular clients. They know that they need to learn about families and there is no better place to do that than where you have nursing mothers and babies on the floor in an informal atmosphere that we seem to have been able to create. We have had professional partners with our parent organization since its inception. The only place where we draw the line is on our board of directors, where we make sure that we have an abundance of parents. They may be professionals, but at least 17 of the board members will be parents of a child with Down Syndrome. The parent does not necessarily need to be a biological parent and the child does not necessarily have to live at home. There will never be a president of our organization who is not a parent. Our organization will always be led by a parent.

If there is a nucleus of parents and professionals here who are interested in pursuing formation of a group for parents of children who have an emotional disorder, then I would say that this is an opportune time because you're here together. That's really the key. You also have something that we did not have seventeen years ago and that is the support of some federal agencies and a Research and Training Center to continue to bring you together and to help focus.

My caution is that if this is what you choose to have, this is your group. It is not a group from the Research and Training Center or a parent group from the National Institute on Disability and Rehabilitation Research. This is your group. If that is the intent, then it needs to be maintained by parents and eventually you need to break out on your own so that you can handle your group yourself. That is after brochures are developed, membership is available, and there is somebody to handle that whole routine. Our membership was handled for years on a volunteer basis in somebody's house. It can be done. It's tough. It takes a lot of good, devoted volunteers.

The similarities among parents with children who have disabilities are amazing to me. I was thinking about the critical health care needs that the parents of children with Down Syndrome face every day and the number of cancellations that we have for our convention because of a heart problem that has worsened at the last minute or respiratory infections that seem to strike at a moment's notice. What often happens at our convention is that one parent comes because the other parent is home with a child that they were unable to leave with anyone else because one cannot leave this child with just anybody. There's a similarity there.

Regarding grassroots efforts, we obviously consider it quite vital or we wouldn't have 500 parent groups across the country. Ironically enough, the parent groups began to come together when the national group formed. It was not the other way around. It seemed to need an impetus on a national level. Committees formulated a parent group formation packet that has a sample constitution and bylaws and some grassroots fundraising ideas. You need money on a local level. You can't continue to meet and contribute out of your pockets. We're nickeled and dimed to death as parents of kids with disabilities and I know that as well as anybody in this room. For us, it worked by formulating on a national level and I will be the first to admit that those who are able to participate on a national level probably had a different economic situation than many of the folks back home. The national participants were the folks that were able to pay for care providers for a weekend, buy an airplane ticket and go and stay some place for a couple of days.

We were part and parcel of the Association for Retarded Citizens and actually formulated from them. They were certainly the service provider and the advocate for all persons with retardation and remain that today. We felt it was appropriate to separate only because of the very specific needs and the numbers of persons with Down Syndrome who have distinct likenesses amongst them. We didn't do this immediately. It was a few years before we made the cut because we were really infants at that time and we needed that umbilical cord to even be able to investigate the feasibility of the organization.

So it was with growth that we began to see the feasibility of the organization and how the two could complement one another. If an organization is formed to serve the needs of children and adolescents with emotional disorders, I would hope that the endeavor never, ever stops being one that continues to work with the Alliance that is already well-formulated and serving many people with this particular kind of disorder. In our opinion, ARC U.S. had a concentration in the area of adults and older adolescents. We were kind of growing out of that, particularly for Down Syndrome. The other forms of retardation are served very well under the ARC U.S. and certainly Down Syndrome is also served as kind of an overlay, but we feel that the NDSC specifically addresses the needs that we feel are not capable of being addressed as we would have wished under our old umbrella. It's very difficult to break away from a loved one and retain a good relationship and I would just like to close by saying that I hope you all are able to do that if you choose to. It will benefit everyone, I'm sure. Thank you for the invitation to speak here today. I wish you all well.

ORGANIZING AT THE STATE LEVEL

SAM DAVIS

Sam Davis is the executive director of the Michigan Association for Disturbed Children.

I mentioned this morning that the Michigan Association for Emotionally Disturbed Children may be the oldest of all the parent organizations for disturbed children. We were formed in 1957. A group of parents from different parts of the state got together and decided to create an organization and did pretty much what the earlier speaker was describing in terms of bylaws and all that business. I was hired in 1960, so I've been with the organization a long time and I think I know a lot of the problems and a lot of the ideas that affect the maintenance of an organization like this. What I'm going to try to do is describe what I feel are strategies for survival. I think the topic is strategies for meeting goals and one goal is to survive. That has really been an ongoing goal for our organization. From the very beginning, our goal has been survival and advocating a mandatory special education law, which was passed in Michigan prior to the federal law to promote changes in the mental health system. This involves money survival and factionalism survival.

First of all, let me talk about our name: the Michigan Association for Emotionally Disturbed Children. There has been a lot of discussion for the last twenty-five years about changing the name. We could find a euphemism so that people would find it easier to join. Well, our name is our name. We have had some fascinating discussions among new parents who come into the organization, get on the board of directors and say, "Let's change the name." Of course, what usually happens at the end of hours of discussion is, "Never mind what the name is, never mind what the diagnosis is, what we need is service. We need help. Let's not dance around nomenclature."

I think that the use of our name, Emotionally Disturbed Children, is very meaningful and effective. I think the parents sometimes have an easier time joining the organization and participating than some of my professional colleagues and I hope to touch on that point a little bit later.

The second thing I'd like to mention is parent leadership for our organization. It's not written in the bylaws, but the tradition is parent leadership and professional involvement. We make every effort to have a parent as president. The majority of the board of directors are parents. We have local chapters throughout the state and we make every effort for the local chapters to be run by parents, with strong professional involvement. I guess to do that effectively, it is helpful for both sides to understand what resistance there may be in terms of equality, togetherness and peer relationships in the organization. I drew a lot of material from the Families As Allies Conference. It spoke very much to what I'm talking about here. Parents understand how professionals sometimes view them and vice versa; if they talk about it a little and handle that, I think it makes it easier to work together as partners.

I think it is important for a statewide organization to have a variety of projects available. I know that when I first met Glenda, we were in Erie, Pennsylvania, talking to a group of people who wanted to form a parent group. We met somebody today from Erie who's representing that group. There may be a difference of opinion about this, but I think that when we talked in Erie, there was the thought of just having a parent support group to let the parents come together and share. I am talking about having a variety of projects in a statewide organization; I'm in favor of that because greater variety will make it easier to assign people to something they're interested in. Not everybody is interested in marching on Lansing (Michigan's state capitol) or Washington. Not everyone is interested in fundraising; some people may want to take the kids on a trip for the weekend. Somehow we've tried to have a variety of projects. It's open and this concept fits also with those mentioned by other people. We all have strengths and the organization can find a way to utilize everybody's strength. That principle does work most of the time and I think that's very important.

Next I want to discuss issues. Our organization presents itself as having two major functions: parent support, whatever that phrase means; and dealing with issues. When I started, we called it "social action." We're not allowed to call it "advocacy" and retain freedom from government control and intervention or United Way priorities. Advocacy is a tricky area. And somebody used a nice phrase this morning: "legislative awareness." Paul VanderVelde from the Michigan Department of Mental Health knows that we don't do any lobbying; we only do "legislative awareness."

There are some interesting things that I think are important in this area. The first is the use of data. I think it's important to use hard information. We also try, or at least I try, with my membership, my staff and my colleagues, to be very conservative in the numbers that I use. We try to be relatively conservative because it's easier to sell your argument that way.

We try to maintain a somewhat adversarial posture with decisionmakers, but in a polite way. Naturally, we try to maintain a nonpartisan posture and we try to maintain at least an arm's length relationship with leaders, legislators and decisionmakers. Sometimes you can get seduced into a relationship and it can really create a problem. This is business. This organization is here for a purpose and I think these are techniques that may help.

Next I want to talk just briefly about expertise. I think organizations like ours need expertise desperately. We need it from the professional community. It's fine if parents can become knowledgeable; I'm just saying we need expertise. We need good writers; we need the professional good literature. The organization must make a special effort to hire and retain individuals who have these skills.

The next point relates to language. We try not to abuse anyone by our use of language, but in working with the professional community, some are in "community mental health" and some are in "state programs." I don't like the word and we try not to use the word "institution." I don't like "suspected emotional impairment"; "suspected" sounds like criminality. We try to get a message across in the way we talk and write, so that language doesn't remain a barrier. I think language is a barrier among professionals themselves and certainly between professionals and parents.

Lastly, stability is important. The resources for maintaining a group, obviously, are two: people and money. Our organization is fortunate that we were able to receive United Way financial support, not right from the beginning, but in the mid-'60s. So we have had financial support; that's been helpful. There are other sources for funds, but certainly money is necessary to maintain an effective statewide organization and for going into the national arena, which I hope everybody wants. Thank you very much.

JOANNE GRIESBACH

Joanne Griesbach is the president of Wisconsin Family Ties and the mother of an eight year-old daughter with autism.

I should say that on behalf of all the families around the state who comprise Wisconsin Family Ties, it is really an honor for us to be represented here and to consider that you value what we have done in Wisconsin. As I understand it, the main interest is the factors that led to the formation of Wisconsin Family Ties and have contributed to its ongoing success. I think of Wisconsin Family Ties as an experiment in which factors are continually changing; we try a little bit here, bump into a wall. Then we'll change directions and see what happens.

I've put together a formula of the factors that led to the successful formation of the group; the first factor, of course, is the parents. There is no question that you have to have enthusiastic, dedicated, committed parents who are willing to give up a lot of time and put up with a lot of aggravation to get these things started and do a thankless job. Many times, they just are not given credit for a lot of the work, primarily because they end up being thorns in people's sides. The reaction is often: "Oh, it's her on the phone again."

Of course, there are other people who are supportive of these children and have a vision. These are folks who are either in the bureaucracies or professionals working within the field. Some are teachers willing to get in there and give the parents a lot of moral support; that's really valuable.

The second component is the CASSP Initiative, and much of the effort of the Portland Research and Training Center. There is no question that the family advocacy movement in Wisconsin would not be where it is today without the CASSP Initiative.

The third component is the Office of Mental Health in Wisconsin. It was in the Office of Mental Health that the decision was made to dedicate some of the state CASSP effort to establishing a family support and advocacy organization. This is ironic because the mental health folks are the folks who are going to end up at the short end of the stick with all this. They're the ones we're going to monitor. So, how do you start a group that's going to come and sit on your doorstep? That problem was solved by contracting, which is the fourth component: the Alliance for the Mentally Ill (AMI).

Wisconsin is the birthplace of the AMI movement; AMI agreed to sign a contract with the Office of Mental Health and hired a part-time person whose sole duty was to go to the community and recruit parent leaders and get the local support groups going. AMI exercised a great deal of wonderful judgment and hired an absolutely marvelous man, Mr. Howard Mandeville. Although he was not a parent, he thought like a parent. He had a deep commitment to family involvement in children's lives and he had his own agenda of creating a statewide parent support group or a statewide initiative. He didn't tell parents when he was recruiting them on a local level. He sprung that when he got us all together in one room.

The fifth, and very crucial, factor is our state protection and advocacy agency: the Wisconsin Coalition for Advocacy (WCA). They are a particularly aggressive and notorious group within the state and are not welcome in many corners of the service system. Together with the Alliance for the Mentally Ill, the WCA was very instrumental in whipping Wisconsin into shape, as far as its adult mental health system is concerned. They were very instrumental in securing the passage of many legislative initiatives and can take much of the responsibility and credit that Wisconsin gets for its adult mental health system. About three years ago, the WCA was approached by CASSP and asked to spearhead a task force to study the children's mental health system in Wisconsin. In 1987, the report called "Kids in Crisis" was issued, which documented the available services, the service gaps and the types of things Wisconsin was doing for the children who needed mental health services. Needless to say, the report essentially said, "We're in big trouble because we're not doing a lot for our kids and something needs to be done about it." As a result, the WCA has made children's mental health services one of its priorities and they're now working on legislation with our state group to improve mental health services for kids, as has been done for adults. In fact, the WCA went so far as to secure an office for us next to theirs. We're right there when they need us and they can parade us out when they need parents to talk about experiences.

I'll give you a little bit of history to give you an idea of how quickly things came about. Our heads are still spinning and we're still not sure where we are. Events like this give us an opportunity to stop, look and consider what we had done. Wisconsin was one of the very first states to get a CASSP grant, in 1983. In 1984, the Office of Mental Health made its contract with AMI and began the Child Advocacy Project.

The recruitment of leaders was an interesting process because there were several methods used. Many communities in Wisconsin had very active AMI groups. Howard would target certain folks to help initiate support groups; these folks either had children or were interested in children. Wisconsin is real good at getting grassroots movements going and there are all kinds of movements throughtout the state. We went to folks in groups representing people who have some type of disability and looked for parents whose kids fit these categories and were willing to put in time and effort. A strategy that was very useful was to go through the special education system in the state, talk to district school directors and tell them about the organization we planned to establish. They would give us permission to contact parents through letters; they would mail the letters out themselves or we would give them material to be sent home with the children. We found this to be a very successful means of recruiting parents.

By June 1987, we had about ten local groups functioning at various levels of sophistication because some had not been in existence very long. At that time, the state AMI dedicated one day of its state conference to children's issues. It was here that parents from all over the state formed a steering committee, which decided to talk about having a statewide network. The steering committee met later on that month and moved very quickly; we appointed officers. One poor man showed up at that conference out of curiosity and next thing he knew, he was treasurer of a state organization. The formation of the parent support organization actually took place about the end of June or beginning of July. This was a pivotal point in the development of the whole movement because it was at this time that the contract ended with the state-level Alliance for the Mentally Ill. It was decided that it was time for the parents themselves to take up the initiative and direct the movement of the organization. A good portion of the year was spent in thinking up a name, which was rather difficult. We developed a purpose statement and some bylaws, which have already been amended. Our board of directors meets monthly. Essentially, we have worked out a mode of operation.

How do you get people working together towards one purpose in a relatively large state? The contact between the CASSP initiative and the parent group fortunately was moved back into the Office of Mental Health and one half-time person was devoted to be the liaison with the parent support group. It's the function of the people you have helping you. Oren Hammes has been a tremendous help to our group. Without him and his enthusiasm, I don't think we would have had the impact that we have made. He is just tireless in his efforts on our behalf. He and Maggie Mezera are also in charge of the outreach aspect of the group and they have gotten several new groups going within the state and recruited some wonderful people.

The next highlight was that we were one of the groups that were awarded the mini-grants that came out of Portland. This is very exciting and is going to give us a chance to actually implement some of the ideas we've been discussing.

For the second year, we've been working on achieving the goals that we have set for ourselves. We have opened a state office next door to the Coalition (WAC) on Capitol Square, across the street from all the legislators and the governor. We are trying to set up a communication system. Wisconsin is a relatively large state and if you're going to have a state organization, you have to have some means of allowing folks on the local level to identify with the state group. They need to feel that they have input and a sense of belonging with this group. We have a toll-free number now and we are putting answering machines in all of the homes of the local leaders, so that we don't have to spend time trying to contact people who work and are involved in other activities and with their families.

Right now, we're also engaged in planning four regional conferences. We have targeted four different areas of the state to give folks an opportunity to get information about programs in other places and training necessary for caring for these kids. The conferences are for folks who don't have a chance to come to Washington D.C. or to Madison, our state capitol. This includes parents and professionals. I would say that a good portion of the folks in the mental health and social service system don't know what CASSP is. We hope to spread the word abut Wisconsin Family Ties, disseminate CASSP goals and talk about many of the legislative initiatives and engender support for those. We have gotten the support group leaders together so we can meet and talk about what's going on with our groups. Also, a four-part children's mental health act will be introduced into the legislature, Children Come First, and we're going to be working on that.

I have just three points that I want to make regarding an underlying philosophy that we always want to keep in mind as we're running our group. The first is inclusiveness; we're not real worried about diagnosis or labels or anything of that nature. We accept whoever comes to us; we will do the best that we can for you.

Second, we always have to remember that the local affiliates do the work and the most important work is to support them because that is where direct service is provided to parents.

Third, leadership will always be a problem. Members of the executive committee have realized that we're committed to this for a long time. Given the particular problems for families who have these types of kids, a lot of people are not going to be able to devote a lot of time to developing the organization. It's an ongoing experiment and we'll let you know what happens in a year. Thank you very much.

ORGANIZING AT THE LOCAL LEVEL

CHRISTINA KLOKER-YOUNG

Christina Kloker-Young is a child advocate and the chair of the Advisory Board of the Florida Research and Training Center. She is also a board member of the Advisory Committee of the Technical Assistance Center for the Georgetown University CASSP project. She is past director of the Summit County Mental Health Association in Akron, Ohio and the founder of Summit Parents Involved Network (SPIN). In 1988, she received the Howard Safer Award from the National Council of Community Health Centers for child advocacy efforts.

The purpose of my presentation is to provide the principles and examples of benefits, pitfalls, and successes associated with organizing a parent support group, an education and advocacy group at the local level. Then I will share with you some suggestions and strategies that parents can apply toward meeting their goals.

Let me tell you the background of SPIN, which stands for the Summit Parents Involved Network. SPIN was started in March of 1986 and is patterned after Parents Involved Network, which has been so successful in the Pennsylvania area. Frankly, if I was going to serve on the CASSP advisory board and the state of the art for the future was parent support groups, I would say you had better get in gear and figure out if you can do this locally. I want you to know that SPIN has been in existence twenty months and has had a budget of $21,000 from Ohio CASSP, United Way, Mental Health Association fundraising, and lots of nickles and dimes. We hired a part-time director for fifteen to twenty hours per weekand paid for office space, phone, travel for parents to state and national conferences; we also put out a newsletter. We had bi-monthly meetings and parents, teachers, clinicians and advocates attended.

The purpose of SPIN is to be a self-help advocacy organization. SPIN was developed to provide support, education, advocacy, training to parents and others concerned about children with behavioral and emotional problems. We welcomed anyone who wanted to attend. We held support group meetings. Initially, we had an education and advocacy meeting and a support meeting each month. The support meeting meant sharing your problems and the ways you got through that time. We sent monthly newsletters to 330 people and we established goals for meetings and advocacy efforts.

The benefits of SPIN have been to place parents together so they could understand that they are not alone. We saw a special benefit for single parents who were extremely alone in these problem times. We had a telephone network called "Lend an Ear, Bend an Ear," as well as advocacy training, letter writing, and testimony at the capitol. Members attended local mental health and education system meetings and spoke out about our issues. We taught parents their rights and the ways in which they can be their own advocates.

The group was well-received by clinicians and administrators. We also had a close connection with the Mental Health Association's Ombudsman Program. The parents took an active role in the IEP process and were able to work together and support each other. Parents got monitors on a bus; that hadn't happened after years of trying, but it happened after this group put their efforts toward it. They also got appropriate testing in the school for some children who had been misdiagnosed. Parents also provided advocacy for respite care services, when that wasn't even a word the Mental Health Board seemed to have in their vocabulary.

Another benefit was that members participated in local, state and national conferences. There is nothing so heartening as watching a group of parents come together on a national level and go into a room and share with each other. It's very powerful and we felt proud to be able to make those meetings happen. SPIN parents participated in the formation of a new, local children's emergency services through our Mental Health Board. They also participated in the development of a home intervention services curriculum that's being developed at Akron University. Parents were asked what they thought the curriculum should include. The formation of other parent groups was encouraged to meet parents' personal and advocacy needs. The newsletter was excellent and benefited 330 people monthly. Staff and parents participated in local coalitionsto make the community more aware of SED children and their needs. The parents were asked to serve on some local boards, which had been comprised of "Who's Who" in the local community, rather than based on consideration as to who should be on those boards.

A letter went out November 3, 1988 saying, "It is with some sadness, but also with much enthusiasm, that I (Veronica Butell, the SPIN coordinator) am sending this letter to you today. The sadness revolves around SPIN and its present form. Due to lack of funding and lack of participation, SPIN is now disbanded as a support group for parents of children with emotional or behavioral difficulties. Thus, there will be no more meetings, nor will there be any publications of the *Child Advocate*. However, SPIN will continue to exist. As in the past, SPIN will provide referrals to parents in need of services for themselves or their children. In addition, SPIN will provide technical assistance to any newly forming parent group."

One of the pitfalls was that as the meetings went on in the twenty month period, very few parents attended. Margaret Burley spoke before 65 people at our first meeting; she's one of the four finalists that Bush and Quayle are interviewing for the job of Assistant Secretary in the Office of Special Education and she has spoken at some of our previous conferences as a parent. The very first year, we averaged 7-10 people at our meetings; the second year, it was 3-4 people. In the last few months, we sometimes had one person show up.

Another pitfall was that there was little or no reliable assistance available to staff for many jobs. There was an attitude of apathy, with parents centering on their own needs and lacking willingness to carry out the mission for other children. Initially, parents resented the advocacy focus and requested to talk about their problems and wait awhile before getting further involved.

One suggestion is to have an independent advocacy group or organization as a sponsor, like our Mental Health Association, so there will be support when the ball is dropped. Hold group meetings in the schools or in the churches to make it easier to reach parents. Provide services, such as child care or gas money. Check expectations frequently in the group; teach them how to be a group and don't expect advocacy too soon. Sometimes a staff member is needed to advocate, as when parents have difficulty questioning the professional. This is particularly difficult when the professional is asking the parent to change their behavior as part of the child's treatment plan.

In my personal experience, a parent support group is not easy and not a single solution to supporting the movement for these children. A national organization can come from strong local organizations, but needs to come from strong advocacy groups and strong services. Parent and staff leaders are needed to make this happen; you need a high level of commitment and dedication. In our experience, these groups always seem to be in a start-up mode. We found that we needed about $16,000 to run the group effectively without exhausting parents or the staff. Strong local coalitions have become very effective in our area and the parents working with these coalitions has helped increase awareness in our community. In that respect, we have put parents in important positions and have served as the public relations agent for parents.

One of the most positive forces for change in my county has been the Summit Meeting, which came after the most tragic case of child abuse that I have ever seen in the thirteen years I've been working. We asked how we could prevent this tragedy from happening again. The executive directors met from every one of the systems that had to deal with those children; they formed the Summit Meeting. The meeting is now funded, so it is held four times a year. We have been meeting since January 1984 and we will meet again on Monday. Looking at the way all children are served in our community has proved far more powerful than just looking at one particular case.

When the judge sits from 10:00 a.m. to 1:00 p.m. with the head of the Department of Education or other departments, they get to know each other and they have an agenda that's very revealing. It's confidential among them, but we found that has been a successful way of making things happen. The strength and the communication when those executives meet helped to break down the turf and has resolved some of our large system problems. Thank you.

CREASA REED

Creasa Reed is the founder and president of Parents Organization Supporting Special Education (POSSE) in Kentucky. She is a panel member for Kentucky's Special Needs Adoption Program and is active in the Kentucky Coalition for People with Handicaps. She is also the mother of a ten-year-old boy who has an emotional disability.

POSSE was formed by a group of parents in Georgetown, Kentucky in the spring of 1987. Initially, its primary objective was to assist the school systems in developing Individual Educational Plans (IEPs) with emotionally disturbed children in the school's behavior disorder unit. Although POSSE is still active in the development of schools, its focus has changed, as the needs of its members became apparent and the educational needs of children were met. The parents of POSSE have now identified respite as their number one need. The children of POSSE have identified recreational programs as their number one need.

In response to those needs, POSSE designed a program with the dual objective of meeting needs of parents and children. Upon collaboration with the local community mental health center, the comprehensive care center and great technical assistance from Dr. Paul Stratton, funding was obtained to initiate our program. Our program will provide respite for the family, but, in my opinion, it will be even more important in providing an opportunity for children to participate in programs that they've never participated in before. My child will wear a uniform and may even get a trophy. This has not happened before. We're very excited and we hope to implement this in the spring.

The original impetus for POSSE will remain to improve educational services for emotionally disturbed children. Encompassed within that task is proactive outreach for identified children within the school system and to advocate for appropriate services and placements for them. The members of POSSE seek to remain focused on our true mission: to provide support to one another. Within that mission, one of our strongest efforts is to navigate the system sufficiently to allow our children to remain in our homes. Not only are we seeking to change the system, but we want to become a vital part of that system.

We've become advocates and developed basic principles for providing members security, comfort and increased family health. One of the principles that evolved from POSSE is that parents are responsible for the identification of needs and setting goals and objectives to accommodate those needs. All members have equality of voice and need. The welfare of a parent or family in crisis takes precedence over group activities and plans; structure is not as important as meeting needs. Parents are responsible for deciding the group's mission. Although attendance is encouraged, it is not a determinant in providing support and advocacy services. Parents' and children's needs are equal whenever possible. If this is not possible, parents' needs are secondary. POSSE's core principle is to put the welfare of the children first.

Some of the benefits derived from POSSE and our families are: (1) to strengthen family life through social ties that provide comfort, familiarity, understanding and support; (2) to improve advocacy efforts; (3) to share knowledge and information; (4) to offer hope and techniques for accessing services; (5) to support children through total family effort and involvement; and, (6) to offer parents a healthy outlet for frustration and stress. Parental involvement in advocacy efforts influences the quality of services universally.

Some pitfalls are: *whiners*, or parents who attend the meetings just to gripe. *Takers* are parents who have not learned how to give or are temporarily unable to give. The *"me syndrome"* involves the parent who always has the worst experience, the biggest problem and the hardest time. *The user* is a parent who is a member of another agency and may try to use the parent group to serve the interests of the other agency. Parents have to maintain control over group policies and actions. *The little red hen syndrome* occurs when one member does all the work. *Growing pains* involve the inevitable shift that occurs when new members join the group; everybody has to find their place again. *Personality clashes* may happen among members and among the professionals involved with the group. *The angry parent* has to strike out and the group becomes an easy target. *The absent parent* is one who never attends a meeting, yet calls you at home and wants two hours of your time. *The non-compliant parent* disappoints the group's super advocacy efforts by sending the child for an out-of-home placement.

A suggestion is to focus on solutions, rather than dwelling on the problems. When a member comes to POSSE with a problem, we let that member talk, but we plan to initiate an action before that member leaves. Different opinions can be healthy, but keep sight of your long term goals and objectives. *Be persistent*; do not accept "no" when it counts. When POSSE began, some children were riding the bus for over an hour and a half. We had two special transportation buses in our whole county; now we have five buses and another ordered.

Do not let one member dominate the conversation of the group. Interrupt the "me person" if necessary and ask a member with success on that issue to speak to that person's concern.

Be sure that the goals of the organization serve the needs of the members. Watch for conflict of interest in members who represent other systems. *When personality clashes occur, try to remain neutral* and allow the members to handle it themselves. *Don't take it personally when a member strikes out* at you in anger; separate yourself from the system with whom the parent is really angry.

Learn how to navigate the system a step at a time. For example, POSSE parents managed to obtain additional staff for the Behavior Disorder Unit by developing an IEP that was impossible to implement with existing staff. An aide was hired. *Be willing to work behind the scenes and give somebody else the spotlight.* POSSE worked with a special education director to change a proposed medication policy. When the director presented the proposal to the board of education, it passed without dissent. *Be creative*; have brainstorming sessions where you dare to dream "what if."

Become a partner with the agencies that serve your group. We have three projects going now and one is collaborating with the Department Director for Human Resources and the Special Education Director to present a workshop on non-violent restraint techniques. Hopefully, this will teach parents and school staff how to physically restrain our children without harming them or becoming harmed.

We're also working with the Special Friend Project, in which POSSE mothers go into the schools with handicapped puppets; we hope to sensitize some of the younger kids in the schools and preschools. We also worked with parents in the project in using a video for identifying school children with special needs. POSSE parents starred in the video and we supplied the dialogue.

Ask questions and stay informed when an agency offers your group tangible or intangible benefits. Do not accept gifts that have conditions that do not agree with your principles. *Be realistic about expectations from parents*; everyone who joins the group won't stay. Keep in mind that everyone needs as much support as possible. *Keep yourself well and empathize with others*, but remember that you're not in charge of their lives.

In summation, I guess I'd like to express my personal wish that all families of children with serious emotional disorders had access to a parent support group and that professionals acknowledge the therapeutic value of this type of influence on families. I'd like to thank CASSP for their friendship; CASSP has offered POSSE information, training and a lot of support. Thank you.

ADDRESS

NAOMI KARP

This meeting is not intended to preclude any group or person from membership or participation. This meeting is not intended to halt any ongoing activities on behalf of children or families. This meeting also is not intended to develop any type of organization under the auspices of an existing research and training center or a federal agency.

The meeting is intended to unite groups and individuals concerned about issues, policies, practices, regulations and laws that affect children and youth with emotional problems and their families. This meeting is to lay the groundwork for a cohesive, enduring coalition of groups and individuals who will consistently, articulately, and effectively speak with policymakers, professional organizations, legislators and the general public about the needs of children with emotional problems and their families. It is intended to begin to develop strategies for coordinated local, state, and national efforts to address inequities and inconsistencies in policies, practices, regulations and laws and improve services and programs for children with emotional problems and their families.

I think we have to look at the definition of coalition in order to understand what we're talking about. I looked up the definition for "coalition" in an unabridged dictionary last night; it has four different definitions. One definition is the act of coalescing or the state of being joined by coalescence. The second definition is a combination, a union. "Coalition" is also defined as a temporary alliance of factions for some specific purpose. The fourth definition is an alliance, confederacy, combination, league or union. A coalition in social services and social sciences connotes banding together of formally structured groups and organizations to influence decisions. We're talking about children who have non-traditional behaviors, so we need to think about a non-traditional definition for a coalition. Therefore, formal groups and private citizens and individuals should be united to share their concerns for improving services and supports for children with emotional problems and their families.

I think we also need to ask certain questions. The first is: what is missing in this field in the area of family supports and why have these elements been missing for so long? Secondly, what is missing in this field to prevent Medicaid reform? What has impeded the delivery of community-based services to boys and girls with emotional problems? And, lastly, why does this field lag so pitifully behind the mental retardation, developmental disabilities field in services, integration and support services? Also, who can best address these questions and how can the questions best be solved?

I think that's what we're here today to decide. We need a voice to speak for children and until we have that voice, Judy and I are always going to have problems in our agencies. Most importantly, families and children are going to have major problems. I don't think we want that and I don't want to be in a room like this in the year 2000, saying that we need to start planning. In the year 2000, we should be meeting to discuss accomplishments that began here today.

GOALS AND RECOMMENDATIONS

FAMILY SUPPORT

Position statement: Every family has a basic right to an appropriate, available and accessible support base to meet family-identified needs.

Goals

- There should be an appropriate, available, and acceptable support base to meet family-identified needs.
- Service systems should be built on empowering families and utilizing their strengths by ensuring that families are equal partners in the planning, implementation and evaluation of programs.
- Policy, legislation and funding should mandate family and professional collaboration in the development and integration of services and provide incentives through legislation and funding to encourage the development of innovative programming which includes increased service options and choices, service integration and collaboration, and family involvement.
- The focus should not be on the disability, but the child should be viewed as a whole person and the family should be viewed as a whole unit, and families and children should be empowered to make decisions about their own lives.

Recommendations

- Develop a single point of entry in the community.
- Develop a state and national clearinghouse.
- Funding should be flexible to provide for a variety of services in multiple settings.
- Family member participation on boards and advisory committees.
- Legislation should create financial incentives for creative and effective service integration.
- State policies should be developed regarding professional training.
- A national family policy should be developed.
- Professional training for parent skills development, leadership skills development, knowledge of the current technology, advocacy.
- Advocate for funding which creates incentives for developing effective and creative services.

EDUCATION

Position statement: Children and families will be actively involved in a natural, culturally sensitive, supportive environment. Support systems will promote social integration which to lead to the achievement of academic, developmental and vocational goals.

Goals

- Parents should receive basic education regarding the services available for children, how to access services, and their rights regarding involvement in the planning and implementation of services.
- There should be a universal definition of "best practices."
- There should be a clear definition of "related services"; effective means should be developed for implementing these services for children with emotional disturbance.
- The education and treatment of emotional disorders in children should be included in undergraduate, graduate, and continuing education programs for teachers, administrators, and support personnel. This training should be updated to incorporate state-of-the-art practices.

Recommendations

- Local parent resource centers and advocacy groups should provide parent education regarding basic services, rights, and treatment models.
- State parent training centers should develop informational material for parents.
- National organizations should develop and disseminate informational material for parents.
- A national newsletter should be developed.
- Parents, teachers, and children should provide the information about what constitutes "best practices."
- Parents should become members of boards and decision-making bodies involved in educational services and practices.
- Local forums should be held for parents and teachers to discuss important service issues.
- Public hearings should be held when research proposals are made.
- There should be a national subcommittee to focus on the issues of "best practices" in education.
- An array of community-based services should be developed for parents and advocates to demand access to services available in the community.

- There should be advocacy at the state level to improve university curriculum and field service to teach professionals how to provide appropriate treatment and service.
- A national parent training center should be established to provide technical service and training about mental health issues.
- There should be interdisciplinary in-service training at the local level.
- There should be parent advocacy at the federal level to set training priorities for accreditation and certification requirements.

CUSTODY

Goals

- Services should always see children as members of family units and should provide services as close to the child's home as possible. Services should be funded based on the needs of the family unit and the issue of family bonds and unity should be considered separately from the issue of custody.
- Service providers shall not require the relinquishment of legal custody as a requirement for obtaining services.
- The national organization shall obtain information and expertise needed to preserve family bonds in the practices, policies and laws governing mental health services.

Recommendations

- Create a national policy on children and families across categories of service and diagnostic labels. The value of family preservation should be integrated into every law, policy and action developed and implemented on behalf of children who need mental health services.
- Provide education to inform parents of the way the system operates, the nature and effect of treatment and the options for mental and emotional disorders.
- Conduct multi-disciplinary research regarding relinquishment of parental custody to determine the attitude of professionals toward custody, the statutory provisions regarding relinquishment of custody, the scope of the problem, model statutes and programs, the impact of custody on the family and child, and current practices.
- Develop a clear statement of the problem which can be understood by a range of audiences and find a position to support policy and advocacy in a variety of areas.
- Inform parents of the issues and their rights with regard to custody.
- Educate professionals regarding the importance and trauma of custody transfer.
- Influence public opinion regarding custody issues by using the media, lawsuits, and letters to state and federal agencies.
- Emphasize exemplary programs.
- Develop funding mechanisms contingent upon appropriate use of custody relinquishment.
- Change federal and state policies to emphasize the priority of preserving family bonds.
- Include custody awareness in funding patterns, child welfare laws and clinical education.
- Encourage research funding for study of the custody issue.
- Encourage local researchers to apply for funds to explore the custody issue.

SERVICE COORDINATION

Goals

- Services should be mandated with intensive case management at the core. Families should also have access to a full array of services without regard to family resources and the services system should be driven by a universal set of values, reflecting the importance of family unity and involvement.
- Professional training must build in respect for the family.
- Professionals shall be trained in parent-professional collaboration and promotion and licensure of professionals shall require evidence of collaborative teamwork with parents.
- Gaps in service provision must be identified, resources provided, and inter-agency collaboration mandated to provide coordinated, comprehensive services.
- A national political agenda must be developed to address all the needs of these children and their families.

Recommendations

- Develop a clear definition of case management.
- Define the target group and the services that should be provided to children and families.
- Encourage parents, professionals, and community leaders to be involved in advocacy for mandated services.
- Ensure that promotions and licensure of professionals be based in part on evidence of collaborative teamwork.
- Provide community education so that the community accepts responsibility for the child.
- Develop a national political agenda.
- Develop a national clearinghouse.
- Educate the public, so that this illness receives the attention and concern given to other types of illness.

CONCLUSION

Parents and professionals were involved in extensive discussion about whether or not to form a national organization. Discussion also focused on the type of organization that should be developed and who should be a part of that organization. Concerns were expressed about the work and expense involved in forming a new organization and the amount of work the organization would have to do after its formation.

Throughout the discussion, many parents kept returning to the theme that adequate service would never be provided and their needs would never be given recognition without a separate organization to focus exclusively on children with severe emotional disorders and their families.

There was also concern about how such an organization should be structured and governed. Opinions were expressed that the organization should be parent-driven, but both parents and professionals should be a part of the organization. Another concern was identification of the population that the organization would be representing. In response several people gave examples of existing local organizations and their structure, membership, and the populations represented.

Following the discussion, a motion was made and seconded:

> We move that a steering committee be appointed to develop a plan to establish a parent-run coalition to address the needs of children with emotional problems to promote their healthy development as children and in their transition to adulthood.

Following presentation of the motion, it was approved by a majority vote of the parents. It was agreed that the steering committee, made up of parent volunteers, would meet by March 1989.

The conference concluded with general discussion regarding the tasks to be undertaken by the steering committee.

APPENDIX A

NEXT STEPS CONFERENCE PLANNING COMMITTEE

John Baker, Parents and Children Coping Together (PACCT), Co-convener, National Alliance for the Mentally Ill Child and Adolescent Network, NAMI-CAN, VIRGINIA.

Lynn Borton, National Alliance for the Mentally Ill, VIRGINIA.

Gary Brunk, Beach Center on Families and Disability, University of Kansas, KANSAS.

Albert Duchnowski, Director of Training and Dissemination, Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, FLORIDA.

Glenda Fine, Director, Parents Involved Network (PIN), Mental Health Association of Southeastern Pennsylvania, PENNSYLVANIA.

Barbara J. Friesen, Director, Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute, Portland State University, OREGON.

Carol Garvin, President, National Mental Health Association, SOUTH CAROLINA.

Barbara Huff, Executive Director, Keys for Networking, KANSAS.

Dixie Jordon, Parent Advocacy Coalition for Educational Rights (PACER) Center, MINNESOTA.

Naomi Karp, Program Specialist, National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

Judith Katz-Leavy, Deputy Chief, Child and Family Support Branch, National Institute of Mental Health, U.S. Department of Health and Human Services.

Chris Koyanagi, Director of Federal Relations, National Mental Health Association.

Ira Lourie, Chief, Child and Family Support Branch, National Institute of Mental Health, U.S. Department of Health and Human Services.

Maggie Mezera, Wisconsin Family Ties, WISCONSIN.

Ron F. Norris, Co-convener, National Alliance for the Mentally Ill Child and Adolescent Network, NAMI-CAN, DELAWARE.

Patricia McGill Smith, Deputy Assistant Secretary, Office of Special Education and Rehabilitation Research, U.S. Department of Education.

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