



The Nation's Mental Health Advocate for Children and Families

Claiming Children

Winter, 1998

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Family-Professional Relationships

Moving Forward Together

What about family involvement are you afraid of?

“As a parent, I am afraid of losing custody of my child if I make too much trouble.”

“As an administrator, I am afraid I’ll have to answer to my boss for a decision I did not make.”

“As a parent, I am afraid my child’s providers will be angry with me for speaking out and that they will reject us.”

“As an administrator, I am afraid I can’t keep up with all of the changes. When families want so much so quickly, I am afraid I can’t deliver all that they need. I am very afraid of being unhelpful and incompetent.”

“As a parent, I am afraid things will never change. We feel exploited. Every time the program goes after another grant, they showcase us to win their money and then they forget they need us.”

“As an administrator, I am afraid that if this partnering with families doesn’t work, I’ll be seen as incompetent and as a traitor to my profession.”

“As a parent, I am afraid of being blamed for my child’s problems.”

“As an administrator, I am afraid families will take over. No one will want the treatment I have to offer. I’ll lose my job.”

These words were at the heart of a provocative session at the 1997 Federation of

Families’ Annual Conference, conducted by **Charlie Biss, Valerie Burrell-Muhammad, Gary DeCarolis, and Barbara Huff**. The purpose of the session was to introduce the National Peer Technical Assistance Network’s new work, *Family-Professional Relationships: Moving Forward Together*, which presents research and commentary on utilizing family-professional partnership systems approaches in situations involving children with mental health needs. *Family-Professional Relationships* is a work-in-progress, but the initial thinking and basic philosophical tenets described in the work make for a stimulating and powerful conversation. A brief synopsis of the session follows.

New Thinking About Relationships

Despite long-standing recognition of the value of families and professionals working together as partners or allies, the practice has proven difficult. Families and professionals alike experience unprecedented frustration in trying to make things work.

Family members who are veteran to systems change and family involvement have identified many things that interfere with productive relationships. Typical family complaints center on:

- Feeling exploited by provider organizations that use their support to win grants or request public endorsement

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Family-Professional Relationships

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but then fail to include families in decision making, planning, and implementing grant proposals.

- Feeling threatened by professionals who avoid family involvement in the name of maintaining professional distance.
- Feeling vulnerable when they are called upon to publicly share their personal stories for the sake of exposing system inadequacies.

On the provider side, professionals have also voiced concerns. Common among their list of complaints are:

- Feeling inadequate when families request more than the available resources can provide; in fact, requesting perhaps more than anyone has the knowledge or capacity to provide.
- Feeling vulnerable in the face of colleagues' negative attitudes toward including families.
- Feeling devalued as human beings when the systems change and family involvement discussions center on money and power, rather than on their own personal value to the system.

Such concerns result in a sometimes overwhelming level of personal frustration and stress experienced by both professionals and families. Not addressing these concerns can dramatically inhibit reform efforts.

Family-Professional Relationships recommends that families and professionals change the way they look at the problems they are experiencing in developing partnerships. First and foremost, there must be clear agreement that the problem is not family involvement. Families are already involved, and are critical participants in a system that raises and serves children. As Valerie Burrell-Muhammad asserted in the session, "As a parent, we are looked at as the one with the most needs. So it can be assumed in the collaboration process that when we give our input regarding what the service should be and how it should be

delivered, we have those answers. Beyond that, our input into the process generally becomes non-existent."

The solution is not simply to extend membership to families where they have previously not been invited; rather, the task is to fully recognize and honor the membership they already have—a membership that is central to the life of the child. The problem must be reframed as developing and maintaining relationships between families and professionals that make use of family voices in creating better systems of care for children and youth and their families.

In the session, Charlie Biss, state level administrator from Vermont, emphasized the importance of this goal and how professionals need to refocus their thinking.

"Meaningful family involvement is a simple concept that produces profound results. It starts from a place of looking beyond our roles and our credentials to finding the best way to problem-solve with another human being. It begins by developing a relationship of mutual respect, and means that we look at the whole person in their many environments with an emphasis on getting to know them by the things that are going well and that give them hope. As a professional, I think our main strength is our ability to listen—really listen—and then, really, really listen. Only then should we respond with messages of hope and liberation. This attitude will also liberate us to be more effective."

Solutions require a look at why people feel such a relationship is dangerous and risky, not to mention intensely difficult work. Understanding why families and professionals may be fearful of involvement—even when both parties are committed to a partnership—is the first step in initiating a productive dialogue. The second requires a look at what both families and professionals bring to the partnership.

Families bring a rich menu of resources to partnerships with professionals. Among the many resources are:

- Intimate knowledge and understanding

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Family-Professional Relationships

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- of their child, their family system, and where the strengths are.
- A life-long, 24-hour per day commitment.
- A common, jargon-free language.
- Ability to monitor progress firsthand.
- A voice in advocating for the service agency.

Professionals also bring resources to their partnerships with families. Examples include:

- A well developed body of knowledge about symptoms, causes, treatment options, and medications.
- Legitimacy and society's sanctioning of their work, which is critical in erasing outmoded beliefs about etiology and treatment success.
- A code of ethics which gives them the power to set standards of acceptable personal and professional behavior, such as confidentiality.
- Power to influence those within their own professional culture.

According to Barbara Huff, *Family-Professional Relationships* provides a stimulus for discussing new ways of thinking about family-professional relationships. The Federation of Families supports efforts to create safe environments in which these conversations might take place.

About the Work

The document, *Family-Professional Relationships*, is a product of the National Peer Technical Assistance Network, which is supported by the following groups:

- Federation of Families for Children's Mental Health.
- National Resource Network for Child and Family Mental Health Services at the Washington Business Group on Health.

- National Technical Assistance Center for Children's Mental Health at Georgetown University.
- Center for the Study of Social Policy.

The writing team for *Family-Professional Relationships* consisted of the following individuals:

- Jane Adams, Keys for Networking (Kansas)
- Charlie Biss, Children's Mental Health (Vermont)
- Valerie Burrell-Muhammad, Private Consultant (Virginia)
- Judith Meyers, Federation of Families Partnership (New York)
- Elaine Slaton, Federation of Families for Children's Mental Health (Virginia).

A number of people contributed to the work as peer consultants. They are:

- Juanita Blount-Clark
- Raymond Crowel
- Angela Diaz
- Karen Gora
- Susan Ignelzi
- Sylvia Johnson
- Martha Kaufman
- Carol Lichtenwalter
- Joan Luzney
- Neal Mazer
- Gerald McKimmey
- Larry Michalczyk
- Kathryn Nicodemus
- Araminta Rivera

A draft version of *Family-Professional Relationships: Moving Forward Together* is available from the Federation for a nominal fee of \$3.50 to cover postage and handling.

In building family-professional relationships, we must go beyond simply extending membership to families and fully recognize and honor the membership they already have—a membership that is central to the life of the child.

Meet Federation Board President, Gail Daniels

Gail Burton Daniels is a single parent of three children, two of whom are adolescents with special emotional challenges. Gail has collaborated with local and national organizations as parent adviser, advocate, panelist, and group facilitator. She has also served the Federation as Board Secretary and Chair of the Diversity Committee. In addition, she is a past president and past legislative liaison for the Federation's DC Chapter, the Family Advocacy and Support Association, Inc.

Here is a glimpse of Gail's vision for the future. These words were taken from her President's Address, presented at the Federation of Families for Children's Mental Health 9th Annual Conference this past November.

"(Our) concern for children and families has evolved into the greatest family movement in the history of the world—the Federation of Families for Children's Mental Health."

Gail Daniels

A Vision for the Future

By Gail Daniels

You are your own self-witness to where you began. You heard what you said, and you saw what you did. You know who came to help you along the path that led you to where you are today and who picked you up when you were down.

I think it's a good practice to keep in mind that everything that we have experienced has everything to do with where we are now and everything to do with the impact that we will make in the future.

It is really fascinating to realize our stage of evolution and how we came to this point. For example, we may be an interior decorator, a Peace Corps worker, a nurse, a welfare mom, an attorney, a travel agent, a preacher's wife. We are male or female, from diverse colors and cultures. Yet, we all bring with us our own unique talents and experiences. We build upon each other's strengths and compensate for each other's weaknesses. But always we bring this common concern—*What about my child?*

From "what about my child?" we have turned to the concern "what about the children?" And that voice has connected with another voice and another until one collective voice called out, "what about the children and their families?" This concern for children and families has evolved into the greatest family movement in the history of the world—the Federation of Families for Children's Mental Health.

It is not just asking this question that brings us together. It is the action we take behind the question—and that action comes with a passion. We were chosen to have this drive and this obsession with children and families. Our actions are motivated by love and that's what we are—a great love story.

We understand that we are not perfect and that we don't have all of the answers all of the time. That is why we need each other. If we didn't need each other, we would not have come together to be a family.

Until we meet again, let me leave you with these words:

We are witnesses of ourselves.
We are witnesses for each other.
And the sun will bear witness to what we do by day.
And the moon will bear witness to what we do by night.
And the leaves on the trees,
And the birds in their flight,
And all that is wet and all that is dry,
Will bear witness to the Mighty Creator of All the universes
That we made a net of our flesh and our bones,
And we tied the knots tight with the energy of our souls...
Our talents, our creativity.
And we threw the net out into the future.
And it transformed into a bridge
Called a culturally competent system of care
For our children and our families to walk across.
Help us...for when the help comes...
Then will come the victory.

If you would like to contact Gail, you can reach her at: P.O. Box 74044, Washington, DC 20056.

Children and Youth Memorial Fund

In August, the Federation of Families Board created a memorial fund honoring our families' children who have died. This fund supports youth activities, including scholarships to the national conference and the Federation's Youth Committee. The first two contributions to the fund were made in honor of Clayton Hunter Huey and Nancy Sheldon, both of whom died in 1997.

The national office welcomes contributions to this fund, which are being received at: Children and Youth Memorial Fund, FFCMH, 1021 Prince Street, Alexandria, VA 22314.

An Autobiographical Remembrance

The following story was written by Nancy Sheldon at the age of 18. She named it *Border Line Kid*, probably, according to her mother, Sharon Sheldon, "because we were always told by professionals and believed ourselves that she was on the border with many of the problems she faced—mental retardation, emotional problems, depression, and mental illness." Please share with us a remembrance of Nancy.

Border Line Kid

Hi, my name is Nancy and I am 18 and I am THE BORDER LINE KID. When I was a baby, the doctor thought I was a normal kid. Then when I was getting older, my teacher and my parents thought that something was wrong. I would not play with the kids in my class. I always wanted to stay with my teacher. So after that my parents took me to the doctor. The doctor said I was mentally retarded, but my parents thought the doctor did not know what he was saying and my parents asked why he would say such a thing like that. He thinks the way I became retarded was because when I was born I lost a lot of oxygen and the right side of my brain was damaged.

Then I went to first grade. I started not understanding what people were saying to me so they had to repeat things they would say. Then, about three years later, they wanted me to go in to special classes but they could not provide what I needed. For the past three or four years, my

parents fought to get me the special classes. After about two years, they finally got me the classes I needed.

I was about in second grade. I was having problems. I would yell and misbehave. So after that they had a meeting. They decided to keep me in the special classes. After that I had a lot of problems. I would not get along with the people in my class. One day I got mad so I hit my teacher and that teacher told my parents that she did not want me in that class. So I went to another class and I was doing just fine. Now I am in the third grade at this moment and we would go outside and run around the school building.

One day my mother came to my school to get me out of that class because my grandfather was dying. My grandfather died and I took it real hard because me and my grandfather were real close. I remember that I would push him in his wheelchair and bring him butter milk. Then in about two to three years my grandmother got remarried.

Now I went to the ninth grade. I spent half of ninth grade in the hospital. At this time I was hearing voices and I was hurting myself. After that we all had a meeting and they put me in a private school. I did not like it. I went to a doctor and they said that I was mentally disturbed and went to a class for that reason. When I went to the class, I would leave out of the classroom without permission. Then after that, I would not talk. I tried to, but the words would not come out. In the ninth grade I had to get tubes in my ears because I could not hear. I had to have this done twice and to this very same day, I still am deaf in my left ear.

I was in the mentally disturbed class. I had so many problems that I had to go to San Marcos treatment center. I stayed there for two years. I would hit people and when I got mad I would try to hurt myself. But when I was at the treatment center I met a wonderful man. His name is Jim. After two years of being at Brown School, I am now a better person and I am still deaf in my left ear. I now live in Austin. I still get mad but now I can control my anger. I hope one day I will get married and have kids. And I am so proud of myself because I love myself. The only way I got here today is my parents' support and love and understanding.

Federation of Families Holds Legislative Awareness Day

A monumental event took place in Washington, DC on November 20, 1997. Over three hundred parents gathered for the first Legislative Awareness Day, sponsored by the Federation of Families. **Teri Toothman**, Federation Board Member and Director of Mountain State Parents CAN, coordinated the event.

Teri encouraged families to prepare for the event long in advance. Families scheduled appointments with their legislators, and reviewed issues that they planned on discussing. Teri tells us that “by the time families arrived in DC, the stage was set for a very intensive day.”

Once in DC, families participated in morning sessions where they heard:

- **Barbara Pryor**, from the office of Senator Jay Rockefeller (D-WV), describe what to expect when visiting the hill.
- A panel discussion outline critical issues affecting families from a national perspective. Panel members included: **Mary Lee Allen**, Children’s Defense Fund; **Barbara Huff**, Federation of Families; **Rhoda Schulzinger**, Bazelon Center for Mental Health Law; **Julie Shroyer**, American Psychiatric Association; **Liz Sweet**, North Dakota Federation of Families for Children’s Mental Health.
- **Liz Sweet** share her personal perspective on getting to know legislators and their staff.

The afternoon was devoted to family visits on Capitol Hill with legislators and/or their staff. **Andrea Price** from the National Mental

Health Association assisted families who did not have appointments in making contacts. “I observed many families leave for the Hill a bit apprehensive—but almost everyone returned excited and full of energy!” Teri reports that “several parents stopped me later and said, ‘I have traveled to Washington (DC) on numerous occasions and have thought that I should visit my legislator—thank you for finally giving me the forum to do so.’”

It is important for families to visit their Congress persons. Families present at the Legislative Awareness Day reaffirmed their desire to arrange visits whenever they are in Washington. “As parents, we sometimes do not realize how important it is to have our voice heard by our legislators,” Teri explains. “As a result of the event, now over three hundred parents realize that their voice counts!”

The day was capped off with a legislative reception in the Rayburn Gold Room on Capitol Hill. Legislators and their staff attended, providing yet another opportunity for families to speak directly to them.

According to Teri, the event served to strengthen the Federation’s presence on Capitol Hill. “Our name is now known among some of the top people in our government.”

Julie Shroyer of the Psychiatric Association assisted Teri with planning the event.

The next Legislative Awareness Day is slated for **November 19, 1998**. Watch for updates from Teri in our next newsletter. Or, you can contact her at: Mountain State Parents CAN, P.O. Box 6658, Wheeling, WV 26003-0906; e-mail: MSPCAN@OVNET.COM.

Plan to participate in the Federation’s next Legislative Awareness Day, to be held November 19, 1998.

Meet the Federation's Newest Staff

The Federation is growing. And with that growth, new professionals have joined the Federation's national office staff. Following is a brief introduction to **Patricia Spain** and **Linda Donahue**.

Patricia Spain Joins Technical Assistance Program

The Federation welcomes Patricia (Pat) Spain to its national office staff as a technical assistance specialist.

A parent of a child with depression, Pat began her professional career as a board member with Mississippi Families As Allies (MSFAA), which serves as a statewide organization for the Federation. While in that position, Pat served as a family support specialist. In this role, she responded to requests from families and various organizations for assistance with cases involving children and/or advocacy issues.

"While at Mississippi Families as Allies, I learned a great deal," Pat tells us. She particularly cited support and guidance from **Tessie Schweitzer**, MSFAA director. "Tessie gave me an opportunity to develop my leadership and advocacy skills." Pat found that these advocacy skills were key to her success in working with agencies and organizations around critical issues affecting children and their families. "Often times I needed to call an agency or school and question one of their policies or actions that adversely affected a child or family...knowing how to ask specific questions and frame issues in such a way to support children's best interests was critical to my success." Pat admits that she receives much personal pleasure from helping people "fix" things.

Recently, Pat has specialized in helping grant recipients and agencies think about *real* family involvement. She finds that people often need assistance in making sure that their intentions are matched consistently with their actions. "An important part of my

work has been helping people look beyond what they may have written in a proposal to what it will actually take to achieve their goals."

Pat has served on numerous advisory committees, including the Georgetown Center for Child Development's Cultural Competence Resource Committee. She has lived in Mississippi, Illinois, Louisiana, Maryland, and now, in Virginia. Throughout her life experiences, she has made many wonderful friends as part of the family movement. She will tell you that these dedicated and courageous families have taught her that "no matter what the crisis, we can still get the work done."

Linda Donahue to Provide Administrative Support

The Federation is pleased to welcome Linda Donahue to its national office as a meeting planner/administrative assistant. Linda brings a wealth of experience to the position, including serving as the conference manager for the Georgetown University Medical Center-Imaging Physics Program and project administrator for British Nuclear Fuels.

A person of many talents and skills, Linda is already busy with planning and arranging the logistics for meetings, and assisting staff with writing and editing reports. "Because the position is 'new' I think there will be a lot of opportunities to do a variety of tasks."

According to Linda, she was attracted to the Federation position because it afforded her an opportunity to do something "meaningful." "I am at that point in my life where I want to make a contribution—I can't think of a better way than supporting children's rights."

Linda has two children and has lived in Northern Virginia for over fifteen years. In her spare time, she volunteers at the Smithsonian Institute, gardens and enjoys cooking, especially pastries.

9th Annual Federation Conference a Success!

Nearly every state, province, and tribe was represented in the 9th Federation of Families for Children's Mental Health Annual Conference, which was held last November in Washington, DC. The three-day conference brought together families, youth, and professionals to share insights about preparing systems of care for the next millennium.

From keynote presentations including

Cornel West who spoke on *Race Matters*, to visits with legislators, to over 25 sessions and workshops, there were multiple opportunities to learn and network with other individuals who are committed to providing leadership in the field of children's mental health.

Check out the information on page 9 in this issue on how you can attend next year's conference.

Plan on attending the Federation's 10th Annual Conference—November 19-22, 1998.



*Although the days were packed, attendees still found time to network. As first time conference attendee, **Jo-Anne Morris** of Eugene, Oregon pointed out, "When you have a child with problems, you think you are the only one. Then you look around here and there are lots of people."*



*Awards Dinner-Hawaiian Style! Board member **Angela Nelson** attended the dinner, auction and awards celebration with her new friends. According to Angela, "It was the most fun I have ever had!"*

The Federation of Families for Children's Mental Health Presents Our 10th Anniversary Annual Conference Celebration!

November 19 – 22, 1998

J.W. Marriott Hotel • Washington, DC

Here is a sneak preview of what's on the agenda. Register today!

November 19 FFCMH Legislative Awareness Day - Chapters & State Organizations encouraged to attend!

- ◆ Morning training session on techniques for successful lobbying with your congressional representatives.
- ◆ Afternoon appointments (pre-arranged) with your congressional representatives & evening reception on the Hill!

November 20 - 22 (Opening session begins at 12:30 PM – Don't miss it!)

- ◆ *Our Young Black Men are Dying and Nobody Seems to Care*— an original musical play by James Chapman
The Critics Agree
- ◆ "The most important play in America"
Dan Freedman, New Alliance Press
- ◆ "One of the best plays in New York"
Scott Poulson-Bryant, The Village Voice
- ◆ "Passionately articulate"
Pamela Sommers, The Washington Post
- ◆ "Challenges audience to start caring again"
C.J. Clemmons, The Virginian Pilot
- ◆ Geoffrey Canada, acclaimed author of *Fist Stick Knife Gun: A Personal History of Violence in America*, delivering an unforgettable keynote presentation.
- ◆ Twenty-eight of the finest workshops you will attend this or any year.

___ FFCMH member registration = \$145.00
 ___ Non member registration = \$205.00
 ___ On-sight registration = \$225.00
 ___ One day registration (Friday or Saturday)
 ___ FFCMH members = \$95.00 ___ Non members= \$120.00

Check the registration amount that applies to you. (Be sure your membership is current.)

Yes, I will be attending the free FFCMH Legislative Awareness Day

Name: _____
 Address: _____
 City: _____ State: _____ Zip: _____
 Phone: (home) _____ (work) _____
 VISA or Mastercard # _____ Exp. Date _____
 Signature _____ Date _____

Mail Registration form with payment to:
 FFCMH Conference
 c/o B-C Family Productions
 16 Sagamore Place
 Hillsborough, NC 27278
 Phone: 919-477-3677
 FAX: 919-479-5247

Make checks payable to: Federation of Families for Children's Mental Health

Capitol Connection

Trina Osher

Following is a brief update on the *1997 Amendments to the Individuals With Disabilities Education Act (IDEA)*, Congressional initiatives, and opportunities for advocacy.

IDEA Update

October 22, 1997, the US Department of Education published a notice of proposed rule making (NPRM) containing draft regulations for implementing IDEA. The Federation worked closely with the Coalition for Citizens With Disabilities (CCD) Education Task Force to insure the interests of children and youth with emotional disturbances and their families were addressed in their comments.

The Federation also submitted comments and suggestions of its own. Our focus was to insure the protections of the law are maintained and enforced so that the promise of a free appropriate, public education becomes reality for children with emotional disturbances.

If you would like a copy of the full text of these comments, please contact the Federation office and ask Marion Robinson to send you a copy. You can review the proposed regulations, as well as comments from a variety of sources, at the Center for Effective Collaboration and Practice's website <http://www.air-dc.org/cecp>.

The Current Status of IDEA

Public Law 97-105 (IDEA) is a carefully crafted compromise protecting children and youth with disabilities and promoting safe and productive school environments. The Department's draft regulations closely followed the dictates of the statute. They received over 2000 comments on the draft. The Department is expecting to issue *final regulations* sometime in May 1998.

Presently, the IDEA continues to come under attack. While the official comment period ended on January 20, 1998, the Federation has learned that Congressional leaders are still receiving literally thousands of calls and letters from school boards and school administrators complaining about the regulations. Secretary of Education, Richard Riley, has been under heavy attack by groups that want to reopen the debate. For example, Riley received a letter from key Republican Congressional leaders (which you can read on the Internet at <http://www.npnd.org>) which reveals their intent to undermine the fundamental protections in this law through weakened regulations that would contradict the statute and Congressional intent. As recently as March 18th, Senator Gorton (WA) publicly claimed the new law would require enormous amounts of paperwork and that students with disabilities would endanger the lives of general education students.

Advocates and parents who value the 1997 Amendments to IDEA must take action now. Contact Secretary Riley, Senator Jeffords, Congressman Goodling, and your own Congressional delegation. Get in touch while they are at home during the April 2-20, 1998 recess. Here are some areas that they need to hear about:

- Tell them that you support the 1997 Amendments and secure their promise not to allow the law to be weakened.
- Remind them that it took two years of debate and consensus building to create this law and secure their promise to see that it is upheld.
- Ask them to insure that IDEA is not destroyed by a few vocal and well-funded special interest groups that are subverting the rule making process by continuing to bombard the Department with comments and demands.

Remember that your voices count!

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IDEA continues to come under attack—Contact your congressional leaders and secure their promise to uphold the law.

Capitol Connection

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Congressional Horizon

The Federation has been following several Congressional initiatives that will have a significant impact on children and youth with mental health needs and their families. A brief summary of these measures and the Federation's activities and positions follows.

S. 10, the Violent and Repeat Juvenile Offender Act of 1997

This bill would create a new \$500 million state block grant to build juvenile facilities and establish sanctions, develop record keeping and reporting systems for juvenile offenders, and conduct drug testing upon arrest. This measure also:

- puts many juveniles at great risk for physical and sexual abuse in adult jails and prisons by no longer requiring that children be separated from adult inmates;
- treats runaways and truants like criminals rather than children who need services and supports, by allowing some of them to be locked up with adults for up to 14 days;
- fails to provide funding for sound prevention programs; and
- does nothing to keep guns out of the hands of children.

The Federation has been actively working with a broad coalition strongly opposed to this bill. We have signed on to six coalition letters each criticizing and opposing a specific feature of the bill. We have issued action alerts to our membership urging them to tell their Congressional delegations to "Stop S. 10."

According to the coalition, grass roots advocacy is working to influence behind-the-scenes discussions about this bill. Keep it up! Get in touch with your Congressional delegation while they are at home for the

Spring recess (April 2-20, 1998) and tell them that no amount of tinkering will make this bill acceptable. See the Children's Defense Fund's website at <http://www.childrensdefense.org> for more details and regular updates.

H.R. 3206, the Fair Housing Amendments Act of 1998

This bill is strongly supported by a handful of municipalities that have been found to be discriminating on the basis of familial status and disability. It would virtually repeal many of the current civil rights that protect individuals from discrimination in housing based on race, ethnicity, and disability.

The bill contains provisions that could jeopardize housing for many families simply because they are raising a child with a disability. It could also make it difficult for specialized foster care and group homes to locate in communities where there is opposition by local residents. Specifically this bill will:

- Make it more difficult to file a complaint about discrimination in housing and have it investigated by the Department of Housing and Urban Development.
- Make it more difficult for people with disabilities to have their discrimination claims heard in federal courts. This is because the bill will require them to first exhaust all administrative and state level judicial remedies. The cost and time involved would effectively strip people with disabilities of the opportunity to get a federal court hearing.
- Change the definition of "familial status" and "family" to refer only to individuals related by blood, marriage, or adoption. This could exclude individuals in group homes (especially unrelated adults with disabilities) from the fair housing protection.

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Capitol Connection

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- Permit localities to adopt quotas on the number of unrelated people with disabilities living together and impose spacing requirements that could make it virtually impossible to find housing. Localities could also repeal current protections enabling individuals recovering from addiction to live in the community and legislate against community housing for juvenile offenders.

The Federation is actively working with a broad coalition strongly opposed to this legislation. We have issued action alerts urging our membership to inform their Congressional delegations of their opposition to this bill.

This is another issue to discuss with your Congressional Delegation during the Spring recess. For more details and up to date information see the Bazelon Center for Mental Health Law's website at <http://www.bazelon.org/housing.html>

S. 1492, the Healthy and Smoke-Free Children Act

This bill, which has widespread support among children's advocates, would utilize funds from any tobacco settlement to provide child care, after school care, and supervised summer activities for millions of children. The Federation has signed on to a Children's Defense Fund letter to Senator Kennedy strongly supporting this measure. The Children's Defense Fund has initiated a major child care campaign seeking a comprehensive child care investment package in 1998.

The Federation's Point of View

There are a number of child care bills in Congress. From the Federation's point of view, the important things are to:

- Make sure any enacted child care bill contains protections to insure children with mental health needs get equal access to child care.

- Make sure that mental health needs are appropriately identified and addressed.
- Make sure that staff have training in proactive discipline.

For example, S. 1151 and H.R. 3296 are initiatives that will significantly improve the chances of all low income and other student parents finding campus-based child care while they attend college. However, neither measure specifically address equal access for children with disabilities. Advocacy leaders for campus-based child care doubt that they will have much opportunity to make revisions even though addressing the needs of children with disabilities is extremely important to the members of the National Coalition for Campus Children's Centers and a high percentage of campus-based child care programs regularly serve children with disabilities.

The Federation has notified both the Children's Defense Fund and the National Coalition for Campus Children's Centers of our general support for child care legislation and that we could really get behind these efforts if they contained provisions requiring that: children with disabilities - especially children with emotional or behavioral disorders - have equal access to campus based child care; and that staff of these facilities receive training and technical support to address the mental health needs of children in their care to insure they appropriately, proactively, and constructively deal with any problem behaviors that come up.

While your Congressional delegation is home for recess April 2-20, 1998, let them know of your support for child care and your concern that legislation on this issue afford children with disabilities and mental health needs adequate protections. For more information and details about child care initiatives see the Children's Defense Fund's website at <http://childrensdefense.org> or the National Coalition for Campus Children's Centers web page at <http://ericps.crc.uiuc.edu/n4c/n4chome.html>.

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Let your congressional know that all new initiatives currently under discussion must contain protections to insure that children with mental health needs get equal access to child care, and that mental health needs are appropriately identified and addressed.

Capitol Connection

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Opportunities for Advocacy

The Federation has been given a grant from the National Technical Assistance Center for State Mental Health Planning (NTAC) at the National Association of State Mental Health Program Directors (NASMHPD) to design and conduct four workshops with a children's focus at the Performance Outcomes National Technical Assistance Workshop in May 1998. This is a federally sponsored meeting for state mental health block grant advisory councils. The grant also includes funds to pay for up to twenty family members to attend the meeting.

The Federation has a contract with the National Mental Health Association to help them develop a curriculum for leadership development for children's mental health care reform. It will be field tested in full day workshops held for family members and advocates in Utah and West Virginia. This initiative is funded by the Center for Mental Health Services.

While there is both hope and concern about how the new special education law (the Individuals With Disabilities Education Act known as IDEA) is being implemented, no one is collecting data about how it is affecting children. The Federation, therefore, is currently developing a simple format for collecting information about how children with mental, emotional, or behavioral disorders are doing under the IDEA. Look for this one page form in the near future. Distribute it and urge families to fill it out and send it to us.

In 1997, Congress enacted the State Children's Health Insurance Program or SCHIP. Early in 1998, the Federation sent information packets to our statewide organizations. States are currently in the process of developing their plans for this program. They must have a federally approved plan approved by the end of September 1998 in order to access these new funds. Advocates for children should get involved in developing their state plan and insist that mental

health and substance abuse prevention and treatment are included in their state's benefit package.

There is also a new opportunity for family involvement in state and local planning for special education. States will have the opportunity to apply to the U.S. Department of Education for State Improvement Plan funds and local education agencies will be developing local improvement plans to submit to the state. Both are required to seek input from the public and families who are raising children receiving special education. Advocates need to find out who is responsible for the process, and seek appointment to the planning team to represent the interests of children with emotional or behavioral disorders and their families.

Contact Trina at tosher@ix.netcom.com.

Scholarship Available

The Federation is pleased to announce that the **Michael K. Scholarship** has been established at Texas A & M University by an anonymous donor. The scholarship is designed to support an individual with a neurological disorder in pursuing a college education. The one-time scholarship amount is \$20,000, and is awarded in increments of \$5,000 over a four-year period.

The Michael K. Scholarship acknowledges the potential of individuals with neurological disorders to fulfill their dreams of a college degree. Applicants for the scholarship must have a history of a neurological disorder (with preference going to an individual with Bipolar disorder) and be accepted at Texas A & M University. For more information, contact Karen Pearce in the Financial Aid Office at Texas A & M University, College Station Branch, (409-845-3236).

New scholarship acknowledges the potential of individuals with mental health needs to fulfill their dreams of a college degree.

Internet LISTSERV Up and Running

New Internet LISTSERV is established to facilitate networking and information exchange among families and family-run organizations concerned with the mental health needs of children and youth with mental health needs.

In collaboration with the Center for Effective Collaboration and Practice (CECP), the Federation has set up a LISTSERV on the Internet specifically for families. The LISTSERV is public—note that it is not a Federation LISTSERV—and is open to all family members who are raising children with mental health needs.

A LISTSERV is a computer program that receives e-mail sent to a central address and then sends it out to a list of “subscribers.” A subscriber to the LISTSERV can pose questions and distribute information in a quick and efficient manner.

The LISTSERV is designed to facilitate networking and information exchange among families and family-run organizations concerned with the mental health needs of children and youth with emotional/behavioral problems. Anyone who has subscribed

to the list will automatically receive all messages sent by other subscribers. There is no charge for this “subscription” service.

The Federation recognizes that not all families or family-run organizations have access to the Internet. However, the number who do grows daily. Nearly one-third of Federation chapters have access to the Internet. In addition, access to the Internet is increasingly available to the public in schools and libraries.

If you have access to the Internet and would like to become a subscriber, please send an e-mail to: <owner-families-ebd@lists.air-dc.org>

If you would like to receive more information on locating public access to the Internet, please call **Stephanie Snow** at the Center for Effective Collaboration and Practice, 1-888-457-1551 (toll-free).

Leadership Program Seeks Candidates

The Robert Wood Johnson Community Health Leadership Program (CHLP) is accepting nominations for its leadership awards. CHLP honors ten outstanding individuals each year for their work in creating or enhancing healthcare programs serving communities in which needs have been ignored and/or unmet.

Recipients of the leadership award receive \$100,000, \$95,000 of which is to be used for program enhancement over a three year period, and \$5,000 of which is to be used as a personal stipend.

CHLP seeks individuals who have demonstrated leadership skills that enable them to overcome complex obstacles and find creative ways to bring healthcare services to

their communities. Typically, leadership nominees are in mid-career, with no less than five years and no more than fifteen years of community work experience. Most nominees have not been “officially” recognized for their work by other major organizations.

Nominations can be made by consumers, community health leaders, health professionals, and government officials who have been personally inspired by the nominees. Nominators should write CHLP for a brochure and a letter of intent form. The nomination is due to CHLP’s program office by September 16, 1998. Early submissions are guaranteed a prompt response.

Contact: CHLP, 30 Winter Street, Suite 920, Boston, MA 02108.

A Message From the Executive Director

Barbara Huff

Things are happening. Here at the national office, the Federation has just experienced a tremendous growth and building period. We have taken on new projects, expanded our professional staff, and have made plans to enhance our ongoing programs. I am optimistic that all of these changes will further advance our mission of providing leadership in the field of children's mental health.

One change that I am very excited about concerns the newsletter. Repeatedly, I have heard from many of you how useful it is. I know what an important tool it is for keeping us connected, not to mention spreading the word about the important work that we are doing. We decided to take a look at the newsletter, and see how we might make it even better.

I began talking with the Board of Directors. We established a working group to advise us on changes we might make to the newsletter. These advisers include myself and:

- Gail Daniels
- Al Duchnowski
- Trina Osher
- Angela Nelson
- Dixie Jordan

As a result of discussions, we have decided to make a few changes I'm sure you will like. First, we are going to redesign the newsletter. Expect a totally different look with your summer issue!

Second, over the years, we have entertained suggestions such as, "it would be nice to have regular columns in the newsletter." I know myself when I pick up a newsletter, I immediately turn to the page featuring my favorite column-columnist to get an update. I actually look forward to seeing what information the particular column will feature each issue. So, in response to this suggestion, we decided to add some regular columns. Currently, we are exploring several column

topics, which include:

- Research Updates.
- Legislative and Policy Updates.
- Youth Issues from the Youth Perspective.
- Tips for Chapter Leaders and State Organizations.
- State Round-Up.

Of course, we will always include a message from our president, and news from the national office.

Finally, we have decided to try something a little different with our feature story. Beginning with the summer issue, we are going to pick a topic and cover it thoroughly from the Federation perspective. Here a few of the topics we are considering:

- Research and Evaluation.
- Youth in Transition.
- Cross-System Collaborative Efforts.
- Early Intervention.
- Juvenile Justice.

I hope that you are excited about these changes. Please let us know if you have suggestions or ideas. If you'd like to be in the planning "loop," we'd be delighted! In fact, we need contacts from our state and local Federation offices who would be willing to share information on a regular basis. I encourage you to contact the newsletter editor, Cynthia Warger. She can be reached at: Box 3836, Reston, VA 20195; (703)437-6542; FAX (703)435-2656; e-mail: clw001@tomco.net

In the meantime, I look forward to an even more productive and satisfying year. And don't forget, it's never too early to plan on attending the Federation's Annual Conference, to be held this year on November 19-22 (see page 9). This is the Federation's 10th Anniversary, so we hope that all of you will join us for the celebration.

Nomination Process for Board Positions

TRAINING INSTITUTES

*Developing Local Systems of
Care in a Managed Care
Environment for Children and
Adolescents with Serious
Emotional Disturbances and
their Families*

*June 13-17, 1998
Omni Rosen Hotel
Orlando, FL*

*For information, contact
Georgetown University Child
Development Center
202-687-5000.*

Have you ever thought about running or nominating someone for the Federation's Board of Directors? Do you know an individual with fund raising experience who has a strong commitment to children with mental health needs and their families? If yes, the Federation would like you to participate in its nominations and elections. The first step is understanding how the nomination process works.

Members from the Diversity, Newsletter, and Nominating committees of the Federation have been working diligently over the past several months to make the election and nominations process more visible and easier to understand. One of their suggestions is to include information about the nominations and elections process in each issue of *Claiming Children*.

Look to the Spring 1998 issue for the following information:

- Detailed explanation of the nominations process according to the Federation's by-laws.
- Description of board members' roles and responsibilities.
- Upcoming board vacancies.
- Nomination form.

The Summer 1998 issue will present a slate of nominees, including a profile and photograph of the candidates. Only members are allowed to vote, so now would be a good time to check your membership status to ensure that your vote counts.

We will announce the election results in the Fall 1998 newsletter issue.

FEDERATION OF FAMILIES
FOR CHILDREN'S MENTAL HEALTH

1021 Prince St. • Alexandria, VA 22314-2971
