

family ties

Winter 2003

A Statewide Publication of Wisconsin Family Ties

Vol. 1, Issue 1

Sharing the Good News

By Ann Hager

So often we hear all the horror stories from families with children in Special Ed that may be diagnosed with behavioral, emotional or mental health disorders. I just wanted to share a success story with you all. Yes...it happens to be my child, but it does attest to the fact that the system does work and children can succeed.

My son Tyler (11 years old, with Bipolar Disorder and Aspergers Syndrome) started middle school this fall in a whole new building with new students and all new teachers. Over the past year Ty had attended an Out Patient Day Treatment Program for 4 hours a day to work on behaviors, anger management, self esteem and coping skills. In August, he graduated with a grade in the 90 percentile. It was exciting! Yet we were concerned about middle school. After having met with his new teachers, we came up with a scoring system to rate Tyler's day. He is rated on cooperation, behavior, quality of work, being prepared for class, homework and general attitude. After a week, Ty has received nothing below a 96% and for the past 3 days he has achieved 100%. He has also discovered the poems of Robert Frost and this past week has already read two whole books. All of this has come from a child that many pro-

fessionals who told us to give up on him and leave him in an institution. We were told, "Kids like this never adapt," "Kids like this will never read or write," and "Kids like this cannot be around others their age because they are too dangerous." Well...he is proving them all wrong thanks to his hard work and the time and effort of some very dedicated teachers. So, yes...the system does work – at least here and now!



By Louise Doescher

I was told that my child would not learn to read. I did not accept this and even though at the time I did not even know what Autism, PDD/NOS, Aspergers, Bipolar, or Tourettes was, I plodded along determined that the child would succeed. HE DID! He has graduated high school, not on top because his IQ is not really high, but he did learn to read and has more common sense than many grown ups I know, is driving a car, has two jobs, lives on his own in his own apartment, and is doing just fine!

Moral of the story?

First educate us, then the teachers and schools and then they can educate our children. Do not give up!



By Pattie Peterson

*Former WFT Family Advocate
(and later, Board President)*

I just had to write you after receiving the most recent Family Ties newsletter (Spring 2002). I enjoyed reading "From the Executive Director." It brought back the memory of meeting you Maggie, Cindy Fahlstrom, Joanne Griesbach and John Franz. We did have foresight didn't we?

We were a very motivated group.

I am still working for the Family Center of Washington County. In fact this year, we have won an award that we will receive in September at our annual Resource Center Conference. I work with nine families in a 25-hour week in their homes and cover Washington County. I teach the Nurturing Program Curriculum. It is a 12-week program. As you will know, there are less and less services available and the families are more complex than ever. I also facilitate a monthly teen parent support group.

Sometimes I feel that I am doing so very little to help families, but a couple of paragraphs can put life back into perspective. One thing I know that does make an impact is a consistent relationship with families. Working at the same place for so many years, parents continually call for support and guidance. So it is with WFT! Thank you for your commitment and congratulations for a job well done.

Refreshing the WFT strategic plan

Two years ago, Wisconsin Family ties initiated a strategic planning process. We are currently reviewing our plan in order to reaffirm our goals and further develop its objectives.

We would like your contribution to this process. Please take a few minutes to complete and return the enclosed survey. The results will be used to help guide the agenda for a planning session to be scheduled early in the new year.

From the Executive Director

By Maggie Mezera

As the year winds down it seems we wind up. Fall is a busy time for us, with school in session again and many opportunities to increase our knowledge at a great number of educational events. We've welcomed new staff as well. Tina Swinford has joined us as our Family Advocate in Waupaca County. We have some new faces in our Madison office as well—Suzanne Martin as Office Manager and Joan Maynard as our statewide Information and Referral Coordinator. Our Board of Directors recently welcomed Cindy Schultz, Financial Manager at Wisconsin Council on Children and Families; Angela Choban, a nurse who is working as a Medical Case Manager and Bonnie Howe, a retired psychiatric nurse. Every one of our employees is a parent of a child with mental health challenges as are over 50% of our Board.

We've included some pictures in this

issue taken at our annual Family Fun Day at Family Land Waterpark, held on July 16 in Wisconsin Dells. We fed lunch to 795 family members who journeyed from all over the state. Many of the county Integrated Services Programs supported the cost of family attendance, provided chaperones and transportation to the park. We are very appreciative of the collaborative spirit that has developed between these programs, the people who work in them, and WFT over the years. The Wisconsin State Journal once again provided financial support in the form of a generous Youth Services grant. Thank you to all who made the day such a good day for families!

We received a thank you note from an Integrated Services Project Director follow-

ing the event which described the experiences of a probation officer who came as a chaperone. He brought a child that had never appeared to enjoy past activities, but who had a great time and was very appreciative to be given the opportunity to attend. The chaperone offered to be there any time a male chaperone was needed in the future.

We have included an insert, "WFT Planning Survey," in this issue. What we do with and for families is based on expressed family needs. We need your input to help us determine how we will direct our energies over the next several years. Please take a moment to respond to the survey, fold it, stamp it, mail it, and we'll take it from there. Thank you for your interest and support.

Conferences and Workshops

October 22-23

A Special Training on Early Childhood Brain Research, Levels I – IV, Hotel Mead, Wisconsin Rapids. For information: jerickson@wccf.org or call Jeanne Erickson, WCCF, 608/284-0580

November 13-14

11th Annual Conference "Emerging Issues in Mediation", Concourse Hotel, Madison. For information: wam@mailbag.com and www.wamediators.org or call 800/752-9692 or 608/262-7942

November 14-15

26th Annual WI Assn. for Children with Behavior Disorders Conference, Marriott West, Middleton, WI (Ann Hager, WFT Family Advocate will present "The Behavior Blues and Boo Hoos.") For information: 608/773-2664

November 15

Autism Society-Madison Chapter is presenting a one-day workshop with Dr. Kathleen Quill, author of Do-Watch-Listen-Say: Social & Communication Intervention for Children with Autism. Marriot Madison West. Register by mail or on ASW web site no later than November 8; early registration fee by Oct. 15. For information: www.asw4autism.org or 608/222-4742, mllarson@wisc.edu

November 19

Mental Health Association, Milwaukee County, "Creating Environments that Foster Mental Health: A Prevention and Early Intervention Training," Best Western Midway Hotel, Appleton. For information: <http://www.mhamilw.org> or call Theresa Grove at 414/276-3122

November 22-24

"Raising Children with Mental Health Needs: Families/Call for Action" 26th Annual Federation of Families for Children's Mental Health Conference, Washington D.C. For information: www.bcfamily.com; 919/477-3688

February 12-13, 2003

13th Annual Children Come First Conference, Hotel Mead, Wisconsin Rapids. For information see page 5.



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An Overview of Family Involvement

A Birdseye View of Wisconsin Family Ties

By Maggie Mezera

Parents of children with disabilities are increasingly taking advantage of opportunities to network with other families, not only to improve the quality of their own family life but to join forces to advocate for all families.

In the early 1960's parents of children with developmental disabilities began influencing state systems to improve services for their children. The Association for Retarded Citizens was an early leader. The passage of the Education for All Handicapped Children Act in 1975, PL 94-142, (today known as the Individuals with Disabilities Education Act or IDEA), which provided for a free and appropriate education for all children with disabilities, made family involvement in the education process part of the law. Families in the disability areas of cognitive and physical disabilities and sensory impairments have been organized longer than families of children with emotional or behavioral problems, and their lobbying efforts 27 years ago were instrumental in getting that law passed.

In 1985-86, the Technical Assistance for Parent Programs (TAPP) and the Research & Training Center on Family Support & Children's Mental Health at Portland State University in Oregon, carried out a study of existing organizations of and for parents of children & adolescents with serious emotional disabilities. There was an interest in learning the extent to which these families were separately organized or were included in multidisciplinary organization. At the completion of the study, a national directory was published. Two hundred seven parent organizations were studied. Only 4% of the organizations focused exclusively on emotional disorders and didn't include other disabilities.

The organizations serving families of children with a wide range of disabilities (71%) tended to have developed in response to PL 94-142 and had an emphasis on public schools and special education services. Disabilities addressed by the greatest number of organizations were cognitive disabilities/developmental disabilities (65%) and learning disabilities (64%). Other disabilities served by about 55% of organizations were autism, physical disabilities, chronic

physical illnesses and hearing & visual impairments. The goals of the organizations studied included an emphasis on community education, parent education and providing training, support, advocacy and information. It is interesting that when program operation issues were identified that were problematic

faculties as the source of the child's problems.

In 1986, the Research & Training Center in Oregon began a series of regional conferences, called "Families as Allies." Several of the parents who ultimately were members of the steering committee that formed Wisconsin Family Ties attended the regional conference held in Indiana. There, concepts of parent-professional partnerships and family advocacy were introduced. These conferences were an important milestone. Family members and members of the professional community met to discuss ways to improve services for themselves and their children. A natural outgrowth of these meetings was the realization that families needed to organize.

Early in 1988, a Conference entitled "Next Steps – A National Family Agenda for Children Who Have Emotional Disorders" was held in Washington D.C. Among the recommendations that came from the participants was to form a national organization, which became The Federation of Families for Children's Mental Health, of which WFT is the Wisconsin statewide organization.

In the summer of 1988 the National Institutes on Disability and Rehabilitation Research and the National Institute of Mental Health jointly allocated \$100,000 to support the development of statewide parent organizations that would focus on serving families that included children with serious emotional and behavioral disabilities. The request for proposal included the following goals: (1) to stimulate and support the development of model statewide parent organizations that can provide technical assistance, information and support to parents within the state and (2) evaluate the implementation and outcome of these models to promote effective approaches. Forty-seven organizations applied and five \$20,000 grants were awarded. Wisconsin Family Ties received one of those grants.

What enabled a group of Wisconsin parents to successfully compete was a series of events that began in 1985, when the state of Wisconsin was awarded one of 10 CASSP (Child and Adolescent Service System) federal grants to begin developing a system of care

...being a part of the family movement and Wisconsin Family Ties in particular, has made a positive impact on their family, including positive changes in services, children's behavior, family well-being and personal growth.

for parent organizations, in addition to recruitment, developing parent leadership was identified as an important issue. 37% of the respondents said they had difficulty in helping parents build the skill and confidence to assume leadership roles.

I believe that reasons why the development of formal organizations of parents of children with emotional and behavioral disabilities lagged behind other disabilities included the following:

It is only relatively recently that it has been widely recognized or accepted that kids have mental health problems.

Stigma is a big barrier. Professionals have viewed parents as more troubled than their children or as the "source" of the child's problems. Professionals often looked for child abuse, neglect, substance abuse or marital dif-

Family Involvement *Continued from page 3*

for children with serious emotional and behavioral disorders. CASSP required grantees to address the need for family involvement and advocacy. From **1985-7**, with CASSP money, NAMI of WI facilitated the Child Advocacy Project, with the goal of organizing parents into a support, education and advocacy network in the state. In **1987**, parents from 9 local support groups formed a steering committee. In **June 1987**, WFT was formed. In **1988**, we were awarded the federal Statewide Demonstration Project grant previously described. We used the grant to open an office in Madison and hire a part time employee. Since that time, WFT has been awarded 4 consecutive additional statewide Family Network Grants and now receive funding from 9 major sources.

Structurally, we are a statewide, not-for-profit agency. Our mission is to work to create greater understanding, respectful acceptance and support in the community for families that include children and adolescents with emotional, behavioral, and mental disorders. Our organizational goals are:

To assist parents in forming community-based support groups in which they can share problems, exchange ideas and receive information

To advocate in the public forum for comprehensive, coordinated, community-based, family-centered services.

To exchange information on medical and research findings, available social services, education, legal and public policy issues.

To foster a collaborative working relationship between parents and the professionals working with children and their families

To increase awareness of our children's special problems and needs.

We have seen the critical impact families can have in the effort to achieve a mental health system that is sufficiently funded, coordinated, comprehensive, family centered, strength and community-based. An example of our early systems advocacy efforts was grassroots support for The Integrated Services Program for Children with Severe Disabilities legislation, passed in 1989. We are currently

working with other advocacy organizations to get mental health insurance parity legislation passed in Wisconsin.

It has been interesting to observe that how the effort to improve mental health service delivery over the years has developed. Some of the changes in approach are reflected in the language and words used. For example:

- From a family organization "parent" target group to an emphasis on "family"
- From "child centered" to "family centered"
- From a diagnosis based medical model to a strength-based model
- From discussing service provision as "flexible and individualized" to identifying it as the process of providing "wraparound" services
- From simply partnering with professionals on an individual therapeutic level to a being partner with policymakers in designing system change

As the parent support, education and advocacy movement has matured, several benefits have been identified by family members that have been involved in the movement. These include:

Being able to receive information on legal rights, specific disorders and resources. One family member said, "I've learned a lot about different types of learning disabilities and emotional disabilities. I've learned to identify what may be considered normal childhood behavior and what could possibly be a problem."

Receiving support from peers, which comes in many forms, including parent-to-parent sharing, understanding, staff as advocates and providing training for advocacy at a

higher level. A family member said, "The kind of help that I received that was the most helpful for me was at the support meetings because there wasn't a single thing I could say that frazzled anybody or surprised anybody. It was the only place ever where I could say things that one of my kids has done and there is always someone there that will relate that their child also went through that phase. When he did things, it helped to call the police or whatever."

Being able to take advantage of "practical services", including workshops, financial support and respite care.

Helping to access culturally appropriate services and broaden appreciation for cultural differences. A family member said that, "We are encouraged to go to a variety of workshops so that we can learn and grow. I've learned that there are different life styles, different cultures. I've learned how to show others respect. We are a part of this great big mix."

In summary, families relate that being a part of the family movement and Wisconsin Family Ties in particular, has made a positive impact on their family, including positive changes in services, children's behavior, family well-being and personal growth. In addition, family members have felt an increased ability and confidence to advocate for their own children as well as for other children and families. Families, from the beginning, have advocated to receive services and supports needed to keep their children at home and in the community. They have wanted to be involved as full partners in the planning, development, implementation, management and evaluation of services their children receive, and to have their voices heard when policies that impact their families are developed. Families want to be involved!

What would you say to this question?

Is there something that has helped you cope in life with your child?

Or another way of asking this is:

What have you found to be most helpful in surviving your high maintenance child(ren)?

It can be anything you wish to identify (person, program, situation, whatever). We'll publish the results to this question in our next newsletter identifying you, for instance, as "mom in Rusk County," "grandparent in Milwaukee, etc." Write your short paragraph or sentence on a post card, if you wish. Or if it's longer, send it in an envelope. It could become a feature article if it's around 500 words long. We look forward to hearing from you!

“A Beautiful Mind” donation to help educate Wisconsinites about mental illness

Wisconsin United for Mental Health donates approximately 300 copies of movie to Wisconsin libraries

Wisconsin residents can now check out a great movie on DVD or video from their local library and learn more about mental illness at the same time. Nearly 300 copies of the Academy Award-winning movie "A Beautiful Mind" were donated to more than 200 libraries around Wisconsin by Wisconsin United for Mental Health to help bring attention to mental illness and the support resources that are available to those who suffer from it.

"We want to provide everyone with the chance to view 'A Beautiful Mind' because it is a great mainstream tool that helps bring the issue of mental illness to the forefront," said Nino Amato, co-chair of Wisconsin United for Mental Health. "Mental illness is a disease that many people don't like to talk about, but one that needs to be brought out in the open. Through this donation, we hope more people will learn about mental illness and understand that it is a real, common and treatable disease."

"A Beautiful Mind" is based on the real life challenges that John Forbes Nash Jr. (played by Russell Crowe) faced and how he overcame those struggles. Nash, who won the Nobel Prize in Economics in 1994 for his Game Theory of Economics, suffered from paranoid schizophrenia. The winner of four Academy Awards, including Best Picture, the movie depicts Nash's life and shows how he overcame the debilitating mental illness.

Copies of the movie are available at fourteen library systems around Wisconsin, including the Arrowhead, Eastern Shores, Indianhead Federated, Kenosha County, Lakeshores, Manitowoc-Calumet, Milwaukee County

Federated, Nicolet Federated, South Central, Southwest Wisconsin, Waukesha County Federated, Winding Rivers, Winnefox and the Wisconsin Valley Library Systems. Wisconsin residents can check out the movie from their local library with their library card.

The library donation is one way the new organization is working to educate the public and improve everyone's knowledge and perception of mental illness.

"Mental illnesses are very real diseases that affect one out of five Wisconsinites," said Amato. "If we can help to educate people on this issue through this Hollywood movie, then it was a worthwhile effort."

Wisconsin United for Mental Health is a non-profit group made up of health organizations dealing with mental illness that was launched in May to provide information about mental illness to the general public and to reduce stigma associated with mental illness. Additional information about mental illness can also be found on the organization's Web site at www.wimentalhealth.org. Wisconsin United for Mental Health is being funded through an educational grant from Eli Lilly & Company.

The group's steering committee is made up of: National Alliance for the Mentally Ill-Wisconsin; Wisconsin Coalition for Advocacy; Wisconsin Council on Mental Health; Mental Health Association in Milwaukee; Mental Health Center of Dane County, Inc.; Grassroots Empowerment Project; Helping Others Prevent and Educate about Suicide; Wisconsin Family Ties; Wisconsin Women's Health Foundation; and Wisconsin Dept. of Health and Family

Services, Division of Public Health, Division of Supportive Living, Bureau of Community Mental Health. The co-chairs of Wisconsin United for Mental Health are Sinikka McCabe, administrator for the Wisconsin Department of Health and Family Services, Division of Supportive Living, and Nino Amato, president of Nino Amato & Associates.

Mark your calendars!

13th Annual Children Come First Conference

February 12 – 13th, 2003
Hotel Mead & Conference Center,
Wisconsin Rapids, WI

A Program For All Seasons

This year's conference will highlight entry level and advanced workshops in the areas of the principles of wraparound, juvenile justice competency, AODA and mental health, educational concerns, early childhood brain development. Workshops focusing on the issues and concerns of alternative family placements and extended families will be offered.

The 6th annual Children Come First Awards luncheon will be held on February 12, 2003.

Cost of this two-day conference is \$125.00. Make hotel reservations directly with the Hotel Mead by calling 1-800-943-6323.

Specify the Children Come First Conference.

For more information contact
Jeanne Erickson: jerickson@wccf.org,
or 608-284-0580 ext 301 at WCCF
or visit the WCCF website at
<http://www.wccf.org>.

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Contact Jeanne Zimmerman or Susan Maslack at the SNHU Vermont Center at 800-730-5542 or 802-655-7235 or e-mail Jeanne at j.zimmerman@snhu.edu. Visit their website at www.snhu.edu/pcmh.

Trust is built on constructive parent, professional communications

As the parent of a child with disabilities, Kay (not her real name) knows the importance of working closely with school professionals - and how communication can affect the relationship. She has experienced the breakdown of communication with school personnel - as well as the smooth success of collaboration.

Kay's son Thomas has an attention deficit disorder and learning disabilities. Kay remembers many meetings with school professionals to write Individualized Education Programs (IEP's) and discuss academic or behavior issues.

Trust is one of the most important aspects of establishing good working relationships

between parents and professionals, Kay said, and honest communication helps build trust.

For her, building trust through effective communication can be as simple as returning a phone call within a few days, Kay said. She lost trust when it took two to three weeks for her son's case manager to return calls. Because of the experience, she follows through when professionals call her.

In another situation, Kay and school personnel worked together to address a problem affecting Thomas. The school then kept Kay informed about her son's progress. The situation encouraged her to trust the professionals.

At a recent PACER workshop, Al Blixt, a nationally recognized speaker on collaboration and himself the parent of a child with a disability, stressed the importance of good parent-professional working relationships. He agrees with Kay on the importance of building trust through good communication.

Commitment to sharing information builds trust over time, he said.

The following tips from PACER's parent advocates and Blixt may help parents build trust and good parent-school relationships through effective communication:

1. Be confident. Always remember that you, the parent, probably care more than anyone else in the world about your child. A parent never has to feel guilty or embarrassed asking questions or assertively pursuing the appropriate services for the child. It is your role, responsibility, and right.

2. Ask for a setting in which you are comfortable and can do your best in communicating with the school about your son or daughter. For example, tell school personnel if you feel awkward sitting in a tiny elementary school desk while discussing important information about your child.

3. Tell school personnel how you want to be addressed as you interact. Do you prefer to be called, "Mr. Smith," instead of "John?" In turn, ask the people from school how they want to be addressed.

4. Think about the important points to discuss and questions to ask before a telephone call or meeting. Write them down and check them off as they are addressed. At the end of the call or meeting, summarize actions to be taken and who will be responsible for each action. Write it down.

5. Ask questions, ask questions, and ask questions. It is an effective way to clarify points

and keep the line of communication open.

6. Make sure you have the same information as the school professionals. For example, if the school evaluated your child, read and be sure you understand the evaluation. Ask until you do understand.

7. At meetings, direct comments and questions to the persons who can best address or answer them. (Be sure a school district representative, someone who knows the district's resources and is authorized to make decisions, attends each IEP meeting.)

8. In all communications with the school, speak or write in an honest, respectful, and direct manner. When speaking, try to state your issues clearly. Restate your concerns if you think you were not heard the first time. Listen, as well. It will help you gather information about your child and understand other viewpoints.

9. Focus communications on the child. For example, at an IEP meeting, include your child as much as is possible and appropriate. Request that he or she attend some or all the meeting. If that is not feasible, bring pictures of your child to show. It is a way to remind the group that the child is the reason for the meeting.

10. Keep the communication lines open. Remember that neither you nor the professionals have all the answers. Work as a team to find solutions. Everyone has the same goal - to provide an appropriate educational program for the child.

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The Childhood Depression Sourcebook

Jeffery A. Miller, Ph.D.

John Wiley and Sons: 1998

This book provides a comprehensive up-to-date summary of this common emotional disturbance in children. It is a valuable resource for teachers, parents, and providers of mental health services. Dr. Miller presents the issue in straightforward, clear style and provides easy-to-understand, practical recommendations ... an essential addition to the library of anyone who works with children.

Communication tips for professionals

Al Blixt and PACER advocates offer the following tips for professionals wanting to better communicate with parents of children with disabilities:

■ Practice empathy, not sympathy.

Empathy means to identify with and understand another's situation. Sympathy can mean pity. Parents need to know you respect them as persons - even in difficult circumstances. Knowing they are respected can lead to trust.

■ Balance helping with listening.

Sometimes the best help is listening.

■ Level the playing field. Use plain, clear language so that parents can understand all the information you are giving.

Mutual understanding is key for communication.

■ Be trustworthy. Follow through.

For example, if you say you will contact a parent at a specific time, do so. Even if you cannot provide complete information, let the parent know you haven't forgotten him or her and are working on the situation.

■ Don't take negative comments personally.

Parents can be frustrated, angry, or anxious because their child is not doing well in school.

Family Fun Day 2002



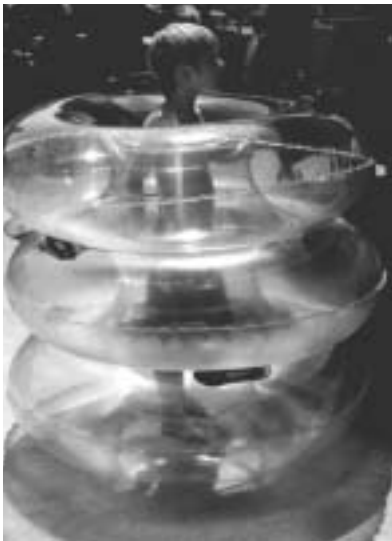
Cody Schwoch of Altoona, WI worked up quite an appetite!



Julie and Kristan Heaps, of Eau Claire, WI, were among the 795 who participated in Family Fun Day on July 16 at Family Land Waterpark in Wisconsin Dells.



The lunch line was well worth the wait!



Cody Schwoch or the Michelin baby?

family ties newsletter

Please complete and mail or FAX this form to:

Wisconsin Family Ties
16 N. Carroll St., Suite 640
Madison, WI 53703

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