

# family ties

Summer 2003

A Statewide Publication of Wisconsin Family Ties

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## One Family's Story *From Despair to Advocacy*

By Jodi Bellile

A few years ago I was almost ready to give up on my son. It seemed like he was always in trouble at school or in the community, and life was completely unbearable at home. My son was very angry and I didn't know why or what to do about it.

He had been diagnosed with Attention Deficit / Hyperactivity Disorder and Oppositional Defiant Disorder at the age of seven. He had been on various medications for several years, none of which seemed to help much. I enrolled in every parenting class I could find, trying to learn more about how to handle my son's uncontrollable behaviors. It seemed the harder I tried, the worse things were getting. He had been tossed out of most childcare facilities in town and we were evicted from several apartment complexes due to his destructive and aggressive behaviors. I was paying hundreds of dollars for property damage and lost security deposits. I just couldn't keep up. My youngest son was suffering emotionally as well as physically due to his brother's constant demand for attention and lack of impulse control.

Most people blamed me for my son's behavior problems, claiming it was because I was an unwed teenage mother, or because I must not be disciplining him enough. I was threatened several times that if I didn't straighten him out now, he would end up in jail. Everyone had an opinion, but no one could really help us at all. No one would

dare baby sit and I felt completely alone. Not only was I frustrated, I was exhausted.

Finally, someone told me about "wrap-around" services through Northwoods Alliance for Children and Families (NACF), a federally-funded project serving children with serious emotional disturbances and their families. Their approach was to find out what our needs and strengths were as individuals and as a family, and then to build off of those strengths to accomplish our goals. This was the turning point in our lives.

At an NACF meeting, I met a woman

named Jackie Baldwin. After the meeting, Jackie stopped me in the hall and said she was a Family Advocate with Wisconsin Family Ties (WFT). She assured me I was not alone: She also was a parent of children with special needs and she, too, struggled raising such challenging children. She had felt my pain.

Jackie provided me with support and understanding countless times over the years since I met her. I was able to pick up the phone at any time of day or night and call her when things weren't going so great. She held my hand during some of the most difficult days of my life. She listened to me cry about how hard things were at home. She could sympathize with me like no one else could, as she had been through it too.

Jackie helped introduce me to other parents of children with emotional or behavioral disorders in my community through the local support group she ran. The Wisconsin Family Ties support group also provided childcare during the meetings, which was extremely helpful to me and fun for the kids.

I was able to attend Wisconsin Family Ties' "Family Fun Days," an annual event in Wisconsin Dells where families of children with emotional and behavioral disorders can have a great time doing fun activities with other families. For the first time, I didn't feel embarrassed of my son's behavior. I since have learned to embrace his strengths and celebrate even the smallest successes.

Wisconsin Family Ties and NACF

**Continued on page 3**

### ***We'd Like to Hear From You!***

The *family ties* newsletter is for families and about families. Share your story so others will know they're not alone! Please consider contributing anything that might interest other families, including:

- Your family's story
- A story or artwork by your child
- A poem, written by either a parent or child
- A story from a sibling's perspective

If you're not confident in your writing abilities, don't worry – we can help you edit your story. Names also can be changed if you prefer to remain anonymous. Contact information for Wisconsin Family Ties, including your closest Family Advocate, can be found on the back page of this newsletter.

### **Inside This Issue**

Hager Wins Award . . . . . 2	From the Executive Director . . . . 3	Special Ed Threatened . . . . . 6	Calendar of Events . . . . . 10
Meet the WFT Staff . . . . . 2	Fred Rogers Tribute . . . . . 4	Autism Services Saved . . . . . 7	Family Fun Day Coming . . . . 11

*Bringing hope to families that include children and adolescents with emotional, behavioral and mental disorders.*

## WFT's Ann Hager Named "Parent of the Year"

**A**nn Hager, WFT Family Advocate in Western Wisconsin, received the family member 2003 Children Come First Award at the annual Children Come First Conference in February at Hotel Mead in Wisconsin Rapids. The award is intended for "people who do good things for children with exceptional emotional and behavioral challenges." The recognition is sponsored by the Wisconsin Council on Children & Families, whose mission is to promote the well-being of children and families in Wisconsin by advocating for effective and efficient health, education, and human service delivery systems.

Ann and her husband, Mike, have five sons ranging in age from 6 to 18, which alone should qualify them for some sort of award. Two of the boys, Tyler, 11, and Skyler, 9, have



significant behavioral and emotional disorders. Complicating the situation is the fact that their father also has mental health needs.

Ann was nominated for the award by Donna Gunnarson, a La Crosse County social worker who has known the family since 1995. Donna said that what impresses her most about Ann is her dedication and commitment to her family. "Ann has not been one to sit back and let others do things for her. She seeks out all the information she can get her hands on regarding diagnoses, medications, treatment modalities and interventions."

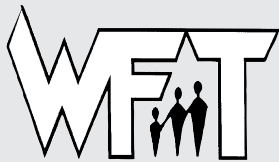
According to Gunnarson's nomination, Ann's work did not end with her own family –

she went on to become an advocate for Wisconsin Family Ties and the Parent Education Project. Through those roles, Ann has become a speaker at conferences and workshops and has been involved with state and federal legislation dealing with mental health issues.

Donna called Ann's role as an advocate "invaluable." "She understands and practices the philosophy that an advocate's role is not to 'do for' the parent, but to empower them to do for themselves," said Gunnarson.

More recognition came when the Hager family and the story of Ann's award were featured in the La Crosse Tribune in March. The article chronicled the challenges faced by the family and their efforts to help other families in similar situations.

Congratulations, Ann!



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We would appreciate knowing what kinds of articles you would like to see included in future issues. Please feel free to send your comments or suggestions about this newsletter to:

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Madison, WI 53703

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## Meet the WFT Staff

*We're launching a new feature with this issue of the family ties newsletter. Each quarter, we'll profile a member of the Wisconsin Family Ties staff. First up is Jill Brohmer, WFT Family Advocate in Marinette County. Jill is the mother of three children and has been married for 24 years.*

**• Jill, why do you work for WFT?**

I have two children with special needs. I remember feeling so alone in seeking out services, understanding the services, and just hoped and prayed that the decisions we made for our children were the right ones. Being a Family Advocate has helped me help other parents and families not feel so isolated and intimidated with the process.

**• What's your favorite thing about being a Family Advocate?**

My favorite thing about being an advocate is after meeting and working with families to see the relief on their faces. To hear parents say, "Thanks for listening. It was so nice to talk to someone who is going through the same things we are. It's a great feeling to talk with someone who doesn't judge us."

**• If you had one thing to tell parents, what would it be?**

It's really hard to say just one, so I'll say my favorite three! First I'd say, "Take one day at a time." Second, I encourage parents



**Jill Brohmer**

WFT Family Advocate,  
Marinette County

to keep communication lines open between everyone – yourself and the professionals, yourself and your children. And last, "Always remember, you are not alone."

**• What has helped you cope?**

Over the years I have learned many coping skills. The one skill that has worked the best and kept me on task is humor. When the days would get tough, school would be calling, the meds weren't working, couldn't get a doctor appointment for six weeks – this is

when I would look for the "laugh of the day." I have taught my kids to laugh every day, that it's okay to laugh at themselves, laugh at life, and laugh at their mistakes as long as they don't repeat them.

**• What are some things you like to do outside of work?**

My favorite things to do are walk, read, cook, get together with friends, hang out with my family on a lazy weekend, and work in my garden.

**• How have your child rearing experiences affected your outlook?**

Raising children with special needs has taught me to be humble, grateful for small things, driven in learning all I can about the world our kids live in, and most of all, to be kind and accepting of others.

## From the Executive Director

# My Journey to WFT

By Hugh Davis

My "perfect" world began to unravel about four years ago. I had a great wife, three beautiful kids and made a comfortable living. After many years of working for a major corporation, I had recently joined a small business. Life was good.

But all was not right. My second child, my first son, was showing signs of developmental problems. We had visited the pediatrician several times with our concerns, only to hear reassuring platitudes: "Kids develop at different rates," or "He's a boy; they're slower to develop." We finally pushed for a developmental evaluation and discovered that our son was on the autism spectrum.

## One Family's Story *continued from page 1*

helped me receive funding to attend conferences and workshops to learn more about my son's disability. They helped educate me about emotional and behavioral disorders in children and strategies to help them succeed in school and at home. They provided me with training in the "wraparound" process

### What is Wraparound?

The wraparound process is an approach in which services are highly individualized to meet the needs of children and families. A "facilitator" works with the family to discover their strengths, set goals, determine major needs, and develop strengths-based options.<sup>1</sup>

Jodi says, "One great aspect of the wraparound process is the strengths-based approach. I'll never forget that first meeting when I was asked to list some of my son's strengths. Since everyone up to that time had been so focused on his deficits, I honestly could not think of many!"

Wraparound initiatives for children and families are active or planned in 38 of Wisconsin's 72 counties.

<sup>1</sup> *Finding Families Strengths: A Multiple-Choice Test*, by John VanDenBerg and E. Mary Grealish

I thought I should work harder so we could afford the best treatment, but financial pursuits suddenly seemed trite. The business world became increasingly hollow to me. I felt like a hamster on a wheel – always moving but making no progress. I wanted to make a real, rather than merely financial difference.

In 2001, our 4th child was born. He began missing developmental milestones at the age of 7 months and entered the Birth-to-Three program shortly thereafter. Around that time, I heard a quote from Aleksandr Solzhenitsyn who, after lengthy imprisonment in a Russian gulag, said, "I came to realize that the object of life was not wealth and prosperity as we're led to believe, but the maturing of the human soul." I knew

and how to develop a strength-based plan of care for my family.

Jackie informs me regularly about important state and federal legislative issues regarding children with emotional and behavioral disorders and how I can help make a difference. Wisconsin Family Ties also has provided me with training in advocacy and assertiveness, and has empowered me to want to help other families.

I have now taken over the facilitation of the Wisconsin Family Ties support group in Rhinelander and I work as a Family Advocate for Northwoods Alliance for Children and Families. I provide support and try to help empower other parents as they become familiar with the "wraparound" process. Thanks to the leadership skills WFT and NACF helped me develop, I am also serving as a voice for families on several local committees aimed at helping children with emotional and behavioral disorders.

Today, my son is doing well in school and making new friends. We're still faced with extremely difficult situations, but as I look back at how much our lives have changed and how far we've come, my eyes fill with tears. Thanks to our involvement with Wisconsin Family Ties and NACF, we can look toward the future with hope and anticipation.

right then I could not continue on the same career path.

These events in my life conspired to drive me to do something that I felt was meaningful. These events led me here and I couldn't be happier. I feel I'm where I'm supposed to be.

In my couple of months at WFT, a few things have become apparent:

**The work is difficult:** There is no "cookie cutter" approach – our work is highly individualized for each family. In many instances, we deal with complex and disturbing situations. We also deal with many different organizations – some that share our perspective on family involvement and some that don't.

**The WFT staff is remarkable:** I have been moved by the stories of personal commitment, such as one WFT employee buying groceries for a family after discovering the local food pantry was closed until the next week or another employee who baked a casserole for a mom who had fallen and hurt her back. Despite difficult situations in their own lives, or perhaps because of them, these people go beyond what would reasonably be expected of them on a daily basis. They inspire me.

**The need is great:** There are literally thousands of families in Wisconsin who are not getting the help they need. According to government statistics, there may be as many as 36,000 school age children in our state with emotional or behavioral disorders. Each day, we receive calls from parents who are shattered by their child's diagnosis, unsure of what to do next and in desperate need of someone to take their hand and walk with them for awhile. Unfortunately, our financial resources are limited. We are working hard to find additional funding so we can reach and help these families.

**The rewards are tremendous:** In the business world, rewards are measured by dollar amounts. I have discovered that hearing one family say "thank you" is far more satisfying than closing a multi-million dollar business deal.

The journey I took to WFT has been interesting, but it's only the beginning. I look forward to finding out where the path will lead. I hope you will join us, even in some small way, in our journey to bring hope to Wisconsin's families.

# A Tribute to Fred Rogers: A Champion of Children's Mental Health

By Joan Maynard

Those of us who deemed Fred McFeely Rogers, better known as Mister Rogers, a "breath of fresh air" in the world of children's television, continue to mourn his February 27, 2003 death. Upon hearing the news, I initially felt a strange peace along with sadness. After all, I believed that Mr. Rogers could only have passed from the earth with faith and dignity, for that's how he lived his life. It was clear that the world had lost a clear and bright light, but what soon lessened my sadness was the knowledge that what Fred Rogers had taught us in his patient and loving way, lives on. We can still learn and grow from his gentle wisdom.

In 1969 when his national television program was in its infancy, and as a new kindergarten teacher in Anaheim, California, I purchased all four of Mister Rogers' record albums containing his classic compositions, and used many of those gems in my classroom as well as with my own children a few years later. I remember teaching the names for the days of the week with his simple lyric and tune, and singing about how you can't learn to ride a bicycle by looking at it. Rather, "You have to do it, . . . and when you're through – you will know who did it, for you did it!"

We listened to a song about that unwieldy emotion, anger ("when you feel so mad you could bite"), and learned that it was something we might learn to redirect in other activities or by talking. We sang about love and about the beauty of nature and the fear of going down the bathtub drain. I can't help but believe these songs had an impact on my kindergartners, who are now parents, and even grandparents.

Daniel Lewis, in his front page article in the New York Times the day after Fred

Rogers died, stated that the long-lived PBS program, Mister Rogers' Neighborhood, "was a revolutionary idea. . ." that "remained a thing apart. . ." While "Others would also entertain, Lewis continued, ". . . it was Fred Rogers, the composer, Protestant minister and student of behavior who ventured to deal head-on with the emotional life of children." Be it divorce, disabilities, jealousy and hatred, fear, hospital stays – you name it – it was a topic worthy of an honest and sensitive exploration, hand in hand with the "neighbor," Mister Rogers.

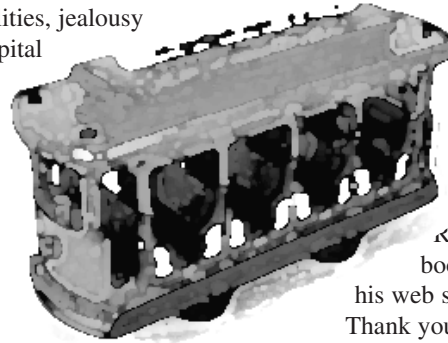
If you ever took the time to slow down and watch (something you HAD to do in order to gain an appreciation for what Mister Rogers was doing), you could see that what he taught his young audience was equally important for caregivers to learn. When Fred Rogers thought about children, his highest priority was to encourage the attributes of "self-

esteem, self-control, imagination, creativity, curiosity, appreciation of diversity, cooperation, tolerance for waiting, and persistence," (Daniel Lewis). He talked directly into the camera, as if in conversation, and through the art of storytelling and make-believe, he underlined the important function of a child's imagination in making sense of it all.

In his conversations and stories, he never let us forget just how very special and unique each of us is, despite our emotional struggles.

Lucky for us, we can still view reruns of "Mister Rogers Neighborhood," read his books, hear his songs, and go to his web site ([www.misterrogers.org](http://www.misterrogers.org)).

Thank you Mr. Rogers, for all you have given, and continue to give, to children and families that help us accept and better understand our emotional lives (as messy and as difficult as they are). The truths you imparted, and the lessons of love you instilled, live on in us as we observe, listen, and work to understand and accept our children – just the way they are.



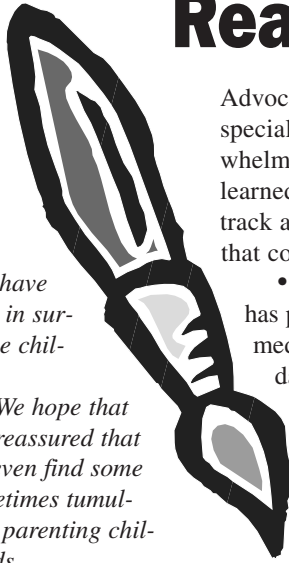
## Ways to Be a Friend to Children

By Catherine Keam

WI Child Care Information Center Newsletter,  
Issue 38, 2000

- Write letters to the editor, to your legislative representative, to policy-makers. Applaud those who help children and families. Blow the whistle on those who hurt them.
- Make your workplace family friendly.
- Be a role model. Children are watching you. They will learn from what you do.
- Make your neighborhood an extended family.
- Encourage parents and other people who care about children to register, become informed and vote.
- Make phone calls about issues that concern you and benefit children and others whose rights are not being respected or needs met.
- Reach out to a parent. Remember that all parents want the same things for their children – a home, education and a chance to succeed.
- Visit your state legislator as well as local government officials.
- Reach out to a child. A smile or word of encouragement can mean a lot.
- Keep an eye on local and national policy decisions that affect children. Find out who's for children and elect officials who put caring into action.

## Readers Respond



The Fall, 2002 issue of family ties posed the question to our readership: "Is there something that has helped you cope in life with your child?" We asked it in another way as well: "What have you found to be most helpful in surviving your high maintenance children?"

Here are the responses. We hope that in reading them you will be reassured that you are not alone. You may even find some ideas to help you in the sometimes tumultuous and uneven journey of parenting children with mental health needs.

### **From Jackie Baldwin, WFT Family Advocate in Vilas, Oneida, and Forest Counties**

Support from other families with similar challenges has been most helpful to me.

Education about the disability and how it manifests itself at home, school and in the community has also helped. I have benefited immensely from the "Parenting Challenging Children" course facilitated by Family Partners in Rhinelander.

Experiencing understanding from my extended family, and from others in the general public, e.g., schools, teachers, doctors, friends, and the faith community, has helped me cope. But the stressors of stigma are present for many families. We need to erase stigma so that beneficial procedures to help our families can occur.

Breaks to rejuvenate have been helpful in coping. Respite, even for a few hours is vital. But it is hard to find people to watch our children, and the stress can be continual if you don't get a break. As a care taker, I need to find a little time for myself each day!

### **From M. Ann Hager, WFT Family Advocate in Western Wisconsin**

I do not think a day goes by that someone, somewhere does not ask me how I cope with my full life. As the parent of five sons (yes... count them 5!), ages 18, 11, 10, 9 and 6, two with a myriad of mental health and neurological disorders, and the wife of a wonderful man with mental health and physical health issues, my plate is indeed full. I have been blessed. I am also a Family

Advocate for Wisconsin Family Ties and a special education consultant. As overwhelming as some days can be I have learned a few simple things that keep me on track and able to deal with most anything that comes our way.

- **Laughter/humor:** Medical science has proven that laughter is indeed the best medicine. Sometimes a smile can turn the day around or reading a truly funny story can make an otherwise stressful day bearable. This is not something you have to set aside a giant block of time for.... A few sentences here and there or a quick joke always helps restore my ability to cope.

- **Respite Care:** Revive, refresh and recharge – all words we use to describe what respite care used proactively means to our family. No matter how stressful a day is, if we know we have respite down the road we can hang in there and do what has to be done.

- **Looking outside of myself and helping others:** This is pretty self-explanatory. Just when I think my family has the worst things happening, I meet another family who makes my family look blessed.

Concentrating and dwelling on our own hurdles only makes the dark look darker, the improbable look impossible. I have learned to take each day as it comes and celebrate the day at day's end.

- **Prayer:** Many times when I meet families they are very angry with God or their Higher Power. This is very understandable when you have a child with a behavioral, emotional or mental health disorder. But I have discovered that through prayer I have found a serene part of myself that can deal with my children's extreme and troubling behaviors. Daily I pray for the acceptance of their differences, the courage to help them and the rest of my family, and the wisdom to step back and realize I cannot solve all their issues.

- **Taking quiet time for myself:** This is usually done in small breaks..... read a chapter of a good book, take a morning walk, light a candle and take a bubble bath. I have a small box of fun toys that are MINE and mine alone... I play with them! Great stress reliever and always puts a smile on my face.

### **From a Madison mother of a grown daughter...**

The best thing that ever happened to us was finding a professional who said, "You two are having a rough time. What can I do to help?"

### **From a Dane County mother of a daughter in college...**

...a good psychiatrist and a good therapist.

### **From a Madison father of a 17-year-old son with high functioning autism...**

Having an understanding of the disorder so that I can relate to my son on his own terms.

### **From a Dane County mom of a teenage daughter...**

FRIENDS. Without the support of my co-workers and close friends in my faith communities, I don't know how we could face the demands our daughter presents. These loving people have been my strength as we have worked to help our daughter reach her full potential. Also, we've found wonderful medical and psychiatric professionals.

### **From a father of a six-year old with autism from Southeast Wisconsin...**

My wife has been the most helpful. She has an uncanny and natural ability to deal with our son's behaviors. I learn from watching her.

### **From a South Central Wisconsin mother of a teen with a diagnosis on the autism spectrum ...**

Finding a person who could do a comprehensive assessment, and then could meet with my husband and me regularly to explain how the disorder affects our son, has been singularly most helpful. Although we always hated labels, a diagnosis helped in our understanding the language processing differences for kids on the spectrum. And in realizing these differences, my husband and I have been able to make adjustments that have eased our stressors (but not entirely, of course).

If you wish to add to our "What has helped" list, please e-mail or write us. We'll include your comments in the Readers Respond section of future family ties.

# Special Ed Protections Threatened

The Individuals with Disabilities Education Act (IDEA) is one of the most important pieces of legislation for children with disabilities ever passed in this country. Passed in 1975, this law guarantees a free, appropriate public education to children with disabilities. Today, about six million children across the nation receive services under IDEA.

On April 30, H.R. 1350, "Improving Education Results for Children with Disabilities Act," was approved by the U. S. House of Representatives by a vote of 251 – 171. This bill weakens services for children with disabilities and undermines parental rights. Some significant concerns are described below:

## Changes Discipline Provisions:

H.R. 1350 would allow schools to suspend or expel students who violate school rules even if the behavior is caused by the child's disability. It eliminates provisions currently in IDEA that seek to identify and remediate the behavior, such as requirements for manifestation determinations, functional behavior assessments and behavior intervention plans.

## Eliminates Short-term Objectives:

Benchmarks and short-term objectives are slated to be eliminated in the 2005-2006 school year. The rationale for this provision is that starting in 2005, "all parents will receive report cards from schools showing academic progress indicators." Parents and advocates argue that short-term objectives provide useful information about progress on both academic

and non-academic goals. Without them, there is no mechanism to report on a student's overall progress.

## Paperwork Reduction Dangers:

The bill contains a provision allowing the U.S. Department of Education to approve 'demonstration' projects for up to 10 states to remove paperwork burdens. In these cases, IDEA statutory and regulatory requirements would be waived with no public review process.

## Optional 3-year IEPs:

The bill allows for development of 3-year Individualized Education Programs (IEPs) instead of the current annual review. While this is an optional choice for parents, there is concern that some parents will be confused or feel coerced to accept this option.

## Reduces Due Process Protections:

The bill contains several procedural provisions that may reduce parents' ability to ensure that their children receive appropriate services.

- It provides for voluntary binding arbitration to settle issues between parents and the school. While this sounds innocuous, it means that parents will give up their rights to appeal. Since a child's needs change over time, questions may also arise about how long the arbitration is binding.
- The bill mandates a one-month waiting period before any parent complaint can go to due process, regardless of the problem or issue.
- It establishes a one-year statute of limitations for filing a complaint of violation.

## Funds Used for Other Purposes:

H.R. 1350 allows 15% of the federal funding to be diverted from direct services to children with disabilities and used for other purposes. Some of these funds will go for pre-referral services, which are necessary, but according to many advocates, should not be funded at the expense of direct special education services.

WFT Family Advocate Ann Hager, who has extensive training and experience in special education law, states, "I have several concerns with H.R. 1350 as it stands, but the one I feel will impact our children the most is the provision doing away with a manifestation hearing for behavioral issues." Quite often, the

child's behavior can be dramatically improved through simple intervention strategies or environmental changes.

## What can we do now?

As we go to press, there is still time to make a difference. The Senate is expected to introduce its bill to reauthorize IDEA in early June, with voting by the full Senate about two weeks after introduction. If you're concerned about this issue, you can call, fax or email your Senators (contact information for Wisconsin's Senators is listed below). Tell them how the changes proposed by H.R. 1350 would affect your child. You don't need to cover every issue - focus on those most pertinent to your situation.

You may also wish to tell your Senators that any bill to reauthorize IDEA should:

- Maintain all current provisions on parental involvement
- Maintain all current procedural safeguards and due process protections
- Protect the rights of students with disabilities involved in discipline cases
- Limit the amount of IDEA funds that can be used for purposes other than the delivery of special education services
- Address excessive paperwork issues in ways that do not undermine accountability and parent involvement

For more information on the IDEA Reauthorization, visit the following websites.

- United Against House Bill HR 1350: IDEA Reauthorization  
[www.geocities.com/vshr1350](http://www.geocities.com/vshr1350)
- The Arc of the United States:  
[www.thearc.org](http://www.thearc.org)
- Council for Exceptional Children:  
[www.cec.sped.org](http://www.cec.sped.org)
- Council of Parent Attorneys and Advocates:  
[www.copaa.net](http://www.copaa.net)

## Wisconsin's Senators:

- **Senator Herb Kohl**  
330 Hart Senate Office Building  
Washington, D.C. 20510  
(202) 224-5653  
[senator\\_kohl@kohl.senate.gov](mailto:senator_kohl@kohl.senate.gov)
- **Senator Russ Feingold**  
506 Hart Senate Office Building  
Washington, D.C. 20510  
(202) 224-5323  
[russell\\_feingold@feingold.senate.gov](mailto:russell_feingold@feingold.senate.gov)

## How Did Your Representative Vote?

This table shows how Wisconsin's House delegation voted on H.R. 1350. Remember, a "yes" vote on this bill removes many of the safeguards currently found in IDEA.

District	Representative	Vote
1	Paul Ryan (R), <i>Janesville</i>	Yes
2	Tammy Baldwin (D), <i>Madison</i>	No
3	Ron Kind (D), <i>La Crosse</i>	Yes
4	Jerry Kleczka (D), <i>Milwaukee</i>	No
5	Jim Sensenbrenner (R), <i>Menomonee Falls</i>	Yes
6	Tom Petri (R), <i>Fond du Lac</i>	Yes
7	David Obey (D), <i>Wausau</i>	No
8	Mark Green (R), <i>Green Bay</i>	Yes

# Advocacy in Action

## *Autism Treatment Compromise Reached*

**W**hen Governor Jim Doyle submitted his 2003-05 state budget proposal this past February, one item shocked families of children who have autism: The budget, based on information that federal Medicaid funding would no longer be available, eliminated Wisconsin's intensive in-home autism treatment program.

A proven intervention that has transformed the lives of children with autism for over ten years, Wisconsin's intensive services program currently serves over 1000 children. It is backed by strong research which shows that behavioral therapy – applied during crucial stages of a child's development and with adequate intensity – can make a significant difference in the lives of children who have autism. Many children make remarkable breakthroughs in intellect, behavior and social functioning.

Spurred on by the potential loss of this crucial service, parents, many of whom had never been involved in the political process, began contacting the Governor and their legislators. Hundreds of families wrote letters describing the dramatic and long-term gains made by their children receiving this therapy and asking for the service to be restored. They contacted media outlets, spoke at rallies and testified at budget hearings held

around the state by the legislature's Joint Finance Committee.

The outpouring was so forceful and the stories so compelling that the Governor, much to his credit, quickly acknowledged that he would try to find a way to restore the program. He asked the Department of Health & Family Services (DHFS) to research alternatives.

At the same time, a newly-formed "Autism Coalition" emerged to deal with the crisis and began negotiations with DHFS to find an alternative. The Autism Coalition is a group of over 50 organizations including parents, disability advocates, school groups and service providers. One of the issues with which the parties had to wrestle was the reality of a \$3.2 billion deficit. It also was unclear if the federal government would continue to provide funding for the service as an entitlement as it had in the past. In light of these difficulties, it quickly became apparent that compromise would be required if any of the program was to be saved.

In early May, the administration and the Autism Coalition issued separate press releases announcing that an agreement in principle had been reached. The Governor indicated that he would restore 26.5 million dollars of state funds over the two-year

budget period for this important program. Some of the key aspects of the proposed program include:

- Services will be provided under a Medicaid "waiver". With a waiver, there are a number of "slots" allotted for the program. The proposed level of funding will result in approximately 250 new kids entering the program in each year.
- Children will be allowed three years of intensive-level (25-35 hours per week) services.
- Once a child has completed 3 years of intensive services, he/she would receive other supports and services. One of the advantages of a waiver is that it enables creation of tailored long-term support for children who need it.
- Implementation of a family cost-sharing system based on the ability to pay.

While the final outcome is not yet known – the state legislature still must approve the revised budget proposal – it's clear that parents and families advocating for their children have made a multi-million dollar difference. "Parents helped saved this program," said a member of the Autism Coalition. "Without their voices, it's likely that no services would have been restored."

## **Advocacy: Whose Job Is It?**

*(from the ABC's of Advocacy, published by CAUSE, Lansing, Michigan.)*

This is a story about four people named Everybody, Somebody, Anybody and Nobody. There was an important job to be done and Everybody was sure Somebody would do it. Anybody could have done it, but Nobody did it. Somebody got angry about that, because it was Everybody's job. Everybody thought Anybody could do it but Nobody realized that Everybody wouldn't do it. It ended up that Everybody blamed Somebody when Nobody did what Anybody could have done.

# *Thank You*

WFT would like to thank

**Chris Arenas,**  
Sedona Consulting

**AnchorBank,**  
West Towne Branch

*for recent contributions of time and facility space.*

# Book Review

## *"Parenting Your Out of Control Teenager: 7 Steps to Reestablish and Reclaim Love"*

By: Dr Scott Sells, Ph.D.

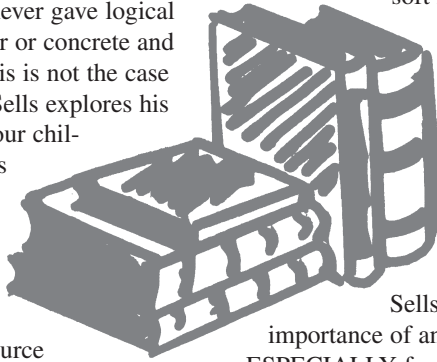
By **M. Ann Hager**

Over the years I have read hundreds of books on parenting and particularly on parenting a "difficult" child. Many were passable but never gave logical reasons for behavior or concrete and specific consequences. This is not the case with Dr. Sells' book. Dr. Sells explores his theory of the 7 Aces that our children use with us as well as the behaviors we use with them that actually reinforce negative activity. His book is full of innovative and effective responses and a great resource for a family that has tried EVERYTHING to no avail.

Dr. Sells goes one step further. An entire

chapter is dedicated to learning to nurture the "difficult" child/teen. He says, "Some parents demonstrate tough love through discipline but have failed to show what I call "soft love" through special outings, warm hugs or words of praise. A lack of structure allows teens to act out because they are angry and bitter inside. Over the years this anger grows like a cancer and is taken out on you and the rest of the world." Dr.

Sells goes on to explain the importance of an abundance of nurturing ESPECIALLY for the difficult child or teen. Dr. Sells speaks of very clear guidelines and a concise written contract system to be used



with your child or teen. As a parent who has worked with this model for more than a year, I can attest that it does work! And it works very well!

Dr. Sells will be speaking in Madison on June 10, 2003. He is an associate professor of social work at Savannah State University and Clinical Director of the Savannah Family Institute, Savannah, Georgia. He has personally treated over 300 difficult children and adolescents, and is a consultant for the Department of Juvenile Justice. For more information check out [www.difficult.net](http://www.difficult.net).

## Count on Me!

*I'll help WFT bring hope to Wisconsin families that include children with emotional and behavioral disorders.*

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

- Parent / Caregiver     Professional  
 Legislator             Other

### *I wish to be a:*

- "Family Advocate" (\$500 or more)  
 "Family Friend" (\$100 - \$500)  
 "Family Supporter" (up to \$100)

- I wish to receive *family ties*,  
WFT's quarterly newsletter

*Donations to WFT are tax-deductible.*

## *Embrace*

*A Support Group formed by parents of children with special needs.*

Serving Outagamie / Waupaca County Area

**When:** First Thursday of each month

**Where:** New London Family Medical Center,  
Main Entrance

**Time:** 6:30 p.m.

Families of children with special needs getting together to support each other. We can share stories, develop strengths, learn how to advocate and learn from each other.

### **Come Join Us!**

We will have occasional guest speakers; refreshments and snacks will be available. If you need childcare, please let us know.

**For more information, call:**

**Lori Prahl, (920) 982-6143**

or

**Tina Swinford, (920) 982-6469**

**Wisconsin Family Ties**

**Family Advocate**

# Project Med:

## *Booklets Aim to Educate Consumers*

Do you have questions about your child's meds? Does your child have questions about their meds that you have a difficult time answering? Are you wondering what kinds of questions you should be asking your doctor about medications?

A set of eight booklets on basic patient rights and on the most common behavioral and anticonvulsant medicines are now available through Ohio State University's Nisonger Center. The booklets are innovative because they were developed especially for people with language, learning, or sensory disorders. The eight books in the series are as follows:

1. Patients' Rights and Responsibilities
2. Anticonvulsant Medicines

3. Antipsychotic Medicines
4. Antidepressant Medicines
5. Antimanic Medicines
6. Antianxiety Medicines
7. Stimulant Medicines
8. Other Behavior Medicines

The medication booklets discuss the most common uses for a drug, the possible side effects, doses, and common interactions with other food and drugs. Written in simple words with pronunciations and explanations of more challenging words, the booklets also contain lots of illustrations, and are actually interesting and informative for people of all reading levels. WFT agrees that these booklets could be useful in helping a child and/or adolescent, as well as a concerned parent,

understand the reasons behind taking the medication(s). The cost of each of booklet is \$1.50, plus \$1.50 for shipping and handling (or 8% of total order, if ordering in bulk).

It is highly recommended that those interested purchase the first booklet, Patients' Rights and Responsibilities, along with any others specific to individual needs. Cutout cards with a list of questions to ask your doctor when receiving new medication for yourself or child are included in this booklet. Spanish version booklets will be available this summer!

Visit the website at <http://www.project-med.org>, or interested readers may phone Krista Pappas, the project coordinator, at 614-688-3375. E-mail should be addressed to [proj.med@osu.edu](mailto:proj.med@osu.edu).

## New Faces at WFT

**W**FT recently welcomed four individuals as they assumed new positions with the organization. Two new staff members joined WFT in February and two new board members were elected in March.

**Kimm Hurley-Smith** was recently elected to her first term on the WFT Board. She has worked as a national consultant on domestic violence, child protection, cultural competency, parenting and program development. She currently is president and CEO of a managed-care program in Madison entitled Community Partnerships. This program enrolls children and youth that have been identified as severely emotionally disturbed, and works with the families within teams in a wraparound approach to keep children and youth out of institutions. Additionally, she is an Adjunct Professor at UW-Madison in the graduate School of Social Work.

**Doris Kontos** is returning to the WFT Board of Directors after a one year hiatus. She has six years of previous WFT Board experience, serving two years as Board Secretary. Doris is the parent of teenage twins with autism, one of whom also has bipolar disorder. Doris has a wealth of experience in the world of developmental disabilities advocacy. She has been involved in the Birth-to-Three program, school issues and in the area of family support. Doris will be serving as President of the WFT Board.

**Christine Richardson** joined WFT as a Family Advocate serving Washburn County. Chris is particularly interested in Attention Deficit Disorder and its associated issues, as she and her two children are challenged by ADD. Chris' work as a Parent Liaison for both CESA #11 and #12 has given her a strong background in the Special Education system, IEP process and development, conflict resolution and mediation. She also works with incarcerated youth, many of whom have various types of social and emotional issues.

**Hugh Davis** is the new Executive Director of WFT. He has four children, two with special needs. His background is described in the article "My Journey to WFT," which can be found on page 3 of this newsletter

WFT would also like to recognize two very special individuals who recently retired from the organization: **Maggie Mezera**, a co-founder of WFT who ably guided the organization as Executive Director for most of its existence, and **Karen Robison**, who deftly led the Board of Directors as its President. We will always consider you part of the WFT family.

# Conferences *and* Workshops

## June 10

"Transforming the Difficult Adolescent: A Step-by-Step Approach to Restoring Love and Limits," 9 a.m. – 4 p.m., Radisson Hotel, Madison. Scott P. Sells condenses his six-week parent training program based on his book *Parenting Your Out of Control Teenager* into a one-day workshop. (See review on page 8 by Ann Hager.) Parent rate is \$40. Call our office for a brochure, or register on-line at [www.uwlax.edu/cont-ed](http://www.uwlax.edu/cont-ed).

## June 10

"Perinatal Mood Disorders – You Can't Tell By Looking," 8:30 a.m. – 4 p.m., Monona Terrace Convention Center, Madison. Contact Ann E. Conway, 608-267-6200; [foundation@perinatalweb.org](mailto:foundation@perinatalweb.org).

## June 23-24

"Networking Neurons: Making Connections – Healthy Kids + Healthy Families = Healthy Communities," Monona Terrace Convention Center, Madison. Contact Jeanne Erickson at 608-284-0480 ext. 301 or 877-232-7246 ext 301; [jerickson@wccf.org](mailto:jerickson@wccf.org). Further information will be posted on the web site at <http://www.wccf.org/whatsnew/index.html> as it becomes available.

## June 23-26

"Positive Approaches to Solving Severe Behavior Challenges." 9 a.m. – 4:30 p.m., Radisson Hotel Lincolnwood Chicago Northshore. Four seminars by the Institute for Applied Behavior Analysis. \$125/day before 5/23/03 or \$150 after. Call 1-800-457-5575 or [www.iaba.com](http://www.iaba.com).

## June 26-28

"Building on Family Strengths" Showcases programs that are innovative, family-centered, and culturally competent in helping to improve services for families and children affected by emotional, behavioral, or mental disorders. Hilton Hotel, Portland, OR. \$305 before 5/24 or \$335 after. Contact Lyn Gordon at 503-725-4114; [gordonl@pdx.edu](mailto:gordonl@pdx.edu). Visit: [www.rtc.pdx.edu](http://www.rtc.pdx.edu).

## Aug 4-5

"Issues, Trends & Effective Practices for Children & Youth with Autism Spectrum Disorders," 9 a.m. – 4 p.m., UW Whitewater. Fee: \$150 for non-credit. Contact Continuing Ed Svcs 262-472-3165; [cesevents@uww.edu](mailto:cesevents@uww.edu) Visit: [www.uww.edu/conteduc](http://www.uww.edu/conteduc).

## Sept 14-17

"National Conference on Addiction & Criminal Behavior," Marriott Pavillion Hotel, St. Louis, MO. 1-800-851-5406; [www.gwcinc.com](http://www.gwcinc.com).

## Sept 16-19

"A Universal Break: Respite for Caregivers," Orlando, FL. ARCH and Natl Respite Network; \$325 before 8/22 registration; reduced rate for NRN members. Contact 517-339-5695 or 339-0640; or [cccincreno@aol.com](mailto:cccincreno@aol.com).

## Sept 26-27

+ four more weekends until April "Parents in Partnership" provides training for parents and caregivers of special needs children 6-14 years. Meeting site is Wintergreen Resort, Wisc Dells. Excellent opportunity to develop leadership skills, improve parent-professional relationships, and join a network of parents. Cost is your time – a commitment to attend all five weekends (9/26-27; 11/14-15; 1/16-17; 3/12-13; 4/16-17). Enrollment is limited. Reimbursement for a portion of expenses. Contact Martha DeYoung at 608-742-8814, ext. 255; or [dyoungm@cesa5.k12.wi.us](mailto:dyoungm@cesa5.k12.wi.us).

## Oct 20-23

"Child Sexual Abuse," Marriott-Madison West. UW-Madison Division of Continuing Studies. Brochure out in July. Contact 608-263-5130 or 800-442-7107; E-mail: [midwest@dcs.wisc.edu](mailto:midwest@dcs.wisc.edu).

## Fall (dates TBD)

"Visions for Tomorrow: Education Course for Caregivers of Children with Brain Disorders" NAMI Dane County. Call 608-249-7188.

## Donate to WFT When You Shop for Groceries!

Wisconsin Family Ties has been selected to participate in Pick 'n Save's electronic "We Care" donation program. WFT benefits if you list our account number on your Advantage® Savers Club card. Our account number is 941085. Each time you present your Pick 'n Save Advantage card at

the check out, a donation from your grocery purchase is added to our account. If you already have a Savers Club card, simply complete a change form and designate Wisconsin Family Ties' number on the form. THANK YOU for supporting WFT!





# Annual WFT Family Fun Day at Wisconsin Dells

Here we go again!! Plans are well in hand for the 8th Annual Family Fun Day at Family Land Waterpark. Join families from all over the state at Wisconsin Dells on Tuesday, July 15 for this much anticipated event. What makes it really sweet is the discounted tickets and lunch we are able to provide.

This tradition began in 1996 with about 30 family members in attendance. Word got out about how much fun we had and how good the food was. In the following years, the attendance grew: First to 146, then to 221, to over 400, and then to over 700. Last year, we distributed nearly 800 tickets!

We greet families at the entrance at about 9 a.m. and all gather at a cabana reserved for WFT. We provide a picnic lunch for all in attendance at noon. In between, we have fun in the water and sun. Set aside the date and expect to meet families like yours from all over the state.

You may register for Family Fun Day by completing the form on this page. Mail the form to us with your payment by Thursday, July 3, so that you will be assured of receiving your tickets before the event. You may also call the WFT office to request tickets. Please remember, however, that we need your payment before the tickets can be sent to you. Whichever way you choose to register, please do so well before the deadline. Then, gather your kids, swimming suits and towels and head for the Dells on July 15. See you there!



### Familyland Ticket Request

Please print clearly. Mail with payment to: WFT, 16 N. Carroll, Ste. 640, Madison WI 53703  
MUST BE RECEIVED IN OUR OFFICE NO LATER THAN THURSDAY, JULY 3. Please Print Legibly.

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Address \_\_\_\_\_

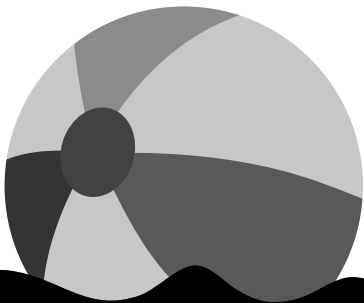
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone (      ) \_\_\_\_\_ - \_\_\_\_\_

Number of Tickets Requested: ) \_\_\_\_\_ Amount Enclosed \$ \_\_\_\_\_

(ages 3 - adult \$10/ticket; ages 0 - 2 Free)

(Payment by Personal check, Money Order or Cashier's Check Only)



# family ties

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

608/267-6888  
(Madison office)

800/422-7145  
(Parents outside the Madison calling area)

FAX: 608/267-6801  
www.wifamilyties.org

Hugh Davis  
*Executive Director*

Christine Pavelko  
*Graphic Designer*

*Wisconsin Family Ties (WFT) is a statewide organization run by families for families that include children and adolescents with emotional, behavioral, and mental disorders. An Equal Opportunity Employer, WFT is funded by individuals, corporations, grants and an allocation from Community Shares of Wisconsin. Contributions to WFT are tax deductible.*

## Wisconsin Family Ties Board of Directors

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Angela Choban, *Waukesha*

Don Rosin, *Lac du Flambeau*

John Grace, *Vice President, Madison*

Bill Griesbach, *Green Bay*

Bonnie Howe, *Waunakee*

Ginny Stuesser, *Secretary, Waukesha*

Kimm Hurley-Smith, *Madison*

Cindy Schultz, *Madison*

## Wisconsin Family Ties Madison Office Staff

■ Hugh Davis, *Executive Director*

■ Suzanne Martin, *Office Manager*

■ Joan Maynard, *Information & Referral Coordinator*

## Wisconsin Family Ties Family Advocates

*Dane County:*

Bonnie Schoeneman-Lubet, **608/277-0996**

*La Crosse County:*

Ann Hager, **608/787-7400**

*Washburn County:*

Christine Richardson, **715/635-8778**

*Mendota Mental Health Institute:*

Beryl Gribbon Fago, **608/301-1190**

*Lincoln County Support Group Leader:*

Louise Doescher, **715/536-3094**

*Waukesha County:*

Kathryn Jalas Franke, **262/646-4455**

*Forest County:*

Alberta Hatmaker, **715/478-5965**

*Marinette County:*

Jill Brohmer, **715/732-0951**

*Waupaca County:*

Tina Swinford, **920/982-6469**

*Kenosha County:*

Ginger Fobart, **262/652-3031**

*Vilas County:*

Jackie Baldwin, **715/542-3535**

*Waushara County:*

Donald Sittig, **920/787-0018**