

FAMILY FOOTNOTES

WHAT'S NEW AT FAMILY SUPPORT & RESOURCE CENTER

March 2006



We've moved! On January 30, Family Support & Resource Center moved to new offices at 101 Nob Hill Road. Our previous space didn't work well for an agency of 24 staff; we were divided between two different parts of the building, with crowding in some parts and wasted space in others. Now, we're all together again in a building that has better wheelchair access with continued plentiful parking and easy access to the Beltline. Please stop in to check out our new digs.

Also, please make note of our new phone number: 237-7630.

Welcome Norah!

Last October, Norah Boynton joined our staff:

"Hello! After five months of working at Family Support, I am taking this opportunity to introduce myself and thank staff and families for their patience and support as I have settled into my new position as a Case Manager. I came to Madison eight years ago to attend UW Madison, and graduated with a Masters Degree in Social Work. After completing graduate internships with both Bridges for Families-Birth to Three, and Family Support and Resource Center, I was excited to accept and continue a position for 2 ½ years as a bilingual Service Coordinator with Bridges for Families. It seems fitting that I should round out my experience by returning to Family Support. I am excited to be back and I'm very happy to have the opportunity to join my former mentors in supporting families and children in Dane County."

New Autism Therapy Provider: Maxim Healthcare

There are now three providers of intensive autism therapy in Dane County. General questions and referrals can be directed to:

- ◆ Wisconsin Early Autism Project, Kathy Schutt, 288-9040,
- ◆ Integrated Development Services, Sam Garlock, 441-0123, **or**
- ◆ Maxim HealthCare Services, Mike Bush, 232-1000.

Changes in our Community Inclusion Program

After 11 years as an Inclusion Facilitator, Dennis Granzen is leaving regular employment at FSRC to take on a wider range of consulting roles. The good news is that FSRC will still be able to contract with Dennis for specific person-centered planning and inclusion consultation for the families we serve. He will also continue as a contributor to this newsletter.

Please join us in wishing Dennis success in his new ventures!

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WHAT'S AHEAD AT FSRC

Upcoming Events You Won't Want to Miss:

MSCR Summer Preview Fairs —

March 15 at LaFollette High School & March 16 at Memorial High School. Representatives of over 45 summer programs for kids will be on hand to distribute written information and answer questions. Open from 6:30-8:00pm. Free.

5th Annual Connecting Families

Gathering— It's fun, it's free, and it's scheduled on Saturday, April 8th, from 12:30-4:30pm at The Alliant Energy Center. Exhibitors and free childcare will be available. See the "In Good Company" insert in this newsletter for an interview with this year's keynote speaker Lisa Lieberman.

Allison Smith Bowling Event & Fundraiser—

The Allison Smith Foundation will hold its 5th annual family fun bowling day and fundraiser on Saturday, May 20, at Schwoegler Park Towne Lanes on Madison's west side. Call 237-7630 for more information.

Circles of Life Conference 2006—

This annual conference for families of children with disabilities and the professionals who serve them will be held on May 5-6 in Stevens Point. Parents and professionals will be representing their own perspectives and sharing experiences and approaches they have found helpful. For more information go to www.wfv.org/circle/home.html

Give a Mom a Break

is the name being given to a new initiative to raise awareness of the different needs and challenges that families with children with disabilities face on a daily basis.


The idea is to have families across the state of Wisconsin invite legislators and other elected officials into their homes on **Saturday, May 13, 2006**, the day before Mothers Day. Policy makers at all levels of government will experience a day in the life of a family caring for a chronically ill or disabled child. They will experience firsthand how the decisions they make affect these families.

Efforts are underway now to organize visits around the state. Families interested in meeting with their legislators will work with an area coordinator who will provide the support needed to make their visit positive and successful.

For more information about this effort contact: John Shaw at WCDD at 608/266-7707 or email at shawj2@dhfs.state.wi.us or Fil Clissa at 608/698-0333 or email at: fil@tds.net.

FamilyFunFest: Save The Date!

Date: Saturday, June 17th
Time: Noon – 4:00 PM
Place: Capital Brewery Family Friendly Bier Garten
Why: Benefit for FSRC



The American Marketing Association rocks! And to prove it, they want to put on a rockin' show for our community and in return raise money for FSRC. AMA is planning FamilyFunFest at the Capital Brewery, and entertainment includes The Gomers live karaoke band, face painting and mascots galore, and tons of great food and drinks. 100% of the proceeds from the event will be donated to FSRC, so be sure to save the date!

Calling All Readers!!

During our recent newsletter committee meeting, we brainstormed ideas for our upcoming May issue. Two topics that arose include:

- 1) How talk to your child about disability (see the "No Limits" column in this newsletter for more info)
- 2) Extracurricular & summer activities you would recommend for special needs children: great activities that are welcoming, inclusive, and well-supported for children

In discussing how to approach these topics, we thought the best way is to ask our most valuable resource directly: our readers. Our assignment to you, our loyal readers, is to e-mail or call us with your stories and ideas. We are looking for perspectives from parents, professionals, siblings, and children themselves. Please help us help other families by sharing your positive experiences.

You can e-mail Becky Ziemba directly at bziemba@fsrcdane.org or call 237-7630 and ask to speak with Becky or Terri by April 1, 2006. We look forward to hearing from you soon!

“In Good Company” Respite Care News

The Respite Care Program is Changing its Name and Approach to Providing Supports by Patti Jo Becker

Our program was developed in the early 1980s, and its structure met the needs of the community very well for a long time. However, much has changed in 25 years, and continuing to provide services in that model in the 21st century will only lead to a longer waiting list and fewer families receiving help. Since March 2005, program staff have been meeting with consultants, families, and providers to talk about and try out various program changes that could expand the availability of respite care resources in Dane County. Throughout 2006, we will be continuing the transition from the Respite Care Program to ***In Good Company*** Respite Care Program, based on conclusions from those meetings.

In Good Company Respite Care Program aims to bring families and individualized care providers together in meaningful and productive relationships. While financial resources remain limited, we are meeting with families at the top of the waiting list and offering an expanded menu of supports. So far, those meetings have confirmed the obvious fact that not all families need the same package of services. For example, a mom who had been waiting for services for over 5 years recently called us. She wasn't expecting long term help, but rather some short term assistance in identifying resources to meet an immediate safety need of her child. In the traditional Respite Care Program days, we would have had to say "sorry, there is nothing we can do; you are on the waiting list." In the *In Good Company* days, we can say "we'll come out, talk and see if we can help you through this for now." A respite staff person met with the family and together they were able to make a successful short term plan using a combination of menu choices that may also have a positive long term effect.

The *In Good Company* Respite Care Program service menu includes;

Care Design: Assisting families in developing a care plan that best meets their goals for their child. It could be a combination of in home, provider home

or community/inclusion based care. It could also include respite events for groups of children.

Employer Role Support: Providing families with assistance in their role as the employer of their in home care providers. This could include providing information and referral to employment tax resources, fiscal agent services, and ongoing employee support assistance.

Provider Identification and Coordination: Offering a range of services from individualized recruitment support, ongoing training opportunities, care coordination and online search resources. The program will continue its efforts to increase the availability of qualified committed care providers.

Resources Identification: Assisting families with identifying sources of funding for care for their family member. Funding resources are available from a variety of sources. Staff assist families in identifying which source is appropriate for them, but can not guarantee availability of any funding source. Staff may assist families in identifying volunteers or other sources for unpaid support.

What does this mean if you are currently receiving supports through the Respite Care Program? There is no change in services for anyone currently in the program, unless you choose to change how you use the program. What does it mean if you are currently on the waiting list? It means that, during 2006, our staff will be working our way through the list, meeting with families and exploring what we might be able to do to help them with their immediate respite needs. As I write this article, the list holds 253 names, and new referrals have not showed signs of slowing in many years. We have a big task ahead of us and change may be slow in coming for those families who have applied only recently. But, we hope that well planned efforts to stretch our capacity will help us to provide more individualized and targeted help to a larger number of Dane County families.



"In Good Company" Respite Care News (continued)

Q&A with Lisa Ackerson Lieberman

Interview by Shauna Foss

Nationally recognized trainer, writer, speaker, and parent, Lisa Ackerson Lieberman will be the keynote speaker at our **5th annual Connecting Families event on Saturday, April 8, 2006 at the Alliant Energy Center.** She is the author of *A "Stranger" Among Us: Hiring In-home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences*, and travels nationally to present issues related to living with disability in the family. Lieberman received her Masters of Social Work in 1977, and has 27 years of professional experience. She has been married for 26 years to a man with multiple sclerosis, and together they parent a teenage son with autism.

As a preview to Lieberman's participation at Connecting Families, and to her book (if you haven't already read it) she answered some questions about how other families can benefit from her professional and personal knowledge of this subject:

Q: What experiences led you to research and write *A "Stranger" Among Us*?

A: I have been hiring in-home providers for my family since 1987. My husband has an advanced case of multiple sclerosis and needs someone full-time to provide all his personal care. Our son, Jordan, has autism (now 17) and had in-home providers until he began high school. Of course, the job description changed dramatically as he developed. When he was very young, providers helped him with personal hygiene, attending therapies, recreational outings. As he grew, they assisted with homework, facilitated independence and social interaction. We have probably employed at least 50 people in our home over the past 19 years, and at some point it dawned on me that I had learned a great deal about how to successfully hire people to support those in my family with disabilities. I learned both from successful hiring as well as from the many mistakes that we made.

Q: What are the most important messages in your book?

A: Although it is hard to pick just a few important messages in my book, I will try to do so.

- 1) Don't allow desperation about finding someone to help your child(ren) ever get in the way of taking all the necessary steps (comprehensive interviews, criminal checks, reference checks, etc.)
- 2) Don't be afraid to get too personal with questions you ask a candidate. You are hiring someone to care of one (or more) of the most precious beings in your life. You cannot afford to allow a fear of offending a candidate get in the way of discovering crucial information that you need to know in order to make an informed decision.
- 3) Trust your "gut." If something doesn't feel right, pay attention and ask more questions until you feel comfortable.

- 4) It is crucial to include your child in the hiring process to as great an extent as possible. Even children who are non-speaking can indicate preferences. As children get older, they will need to have greater input in the decision of who will support them to be as independent as possible.
- 5) Hiring in-home providers is an experience that provides mutual benefits for all people involved; your family, your child(ren) and the people who are supporting your children. You get the comfort of knowing your child is in good hands, your child feels safe and cared for, and the provider gains training and the opportunity to be a significant part of your family. When done correctly, everyone wins!

Q: Who might benefit from reading this book?

A: Obviously, anyone who intends to hire an in-home provider will benefit from using this book as a resource. Parents can use it as a how-to guide, following step by step throughout the process of writing a job description, advertising, screening, interviewing, reference checking, orientation and training, setting up communication processes within the home, and termination. The book includes input from my 19 years of experience, as well as several other families who have successfully hired in-home support.

People who are responsible for consulting with parents would find this book immensely useful. Also anyone who is training people to provide in-home services. I have also been told that people who hire staff for group homes have found this book to be helpful.

Q: What have you found as the most difficult part about hiring in-home support for your child, and how does your book address this problem?

A: I have had many parents tell me that one of the hardest things is finding good candidates to interview. They conclude that there just aren't enough quality candidates out there. My book gives suggestions of many ways to advertise for candidates, including sample ads and job flyers.

People express fear about how to conduct an interview and ask the right questions. This book has an extensive section on how to conduct an interview, including suggestions for questions to ask that aim at those crucial areas that should be explored.

This is a user-friendly book that uncovers the mystery surrounding the hiring process, as well as how to incorporate that provider into the culture of your family in a positive way.

Q: Are there other books you'd recommend for parents looking for care providers for their child(ren) w/ disabilities?

A: In all honesty, one of the reasons I wrote this book is that there was not another book I could find out there that covered this topic in a comprehensive way. I read "how to hire a nanny" books, and in a few cases, there might be a few paragraphs or a short chapter that discussed hiring in-home providers for kids with disabilities.



Better Together: FSRC's Inclusion Page

"No Limits" By Dennis Granzen

How do we talk to our children about the attributes that make up their "disability" and the labels those attributes bring with them? How should we discuss what makes their needs "special," as opposed to the needs of their peers and siblings which are deemed "typical"? Answering these questions - and following up with these discussions - is vital to both our children's and our own understanding of how we fit into the world, and affects how we envision our future in it. There are no simple or universal answers and very little in writing to guide parents.

As I've learned from the experiences of many families who have and are dealing with these issues, I've seen a wide range of approaches. Some, in an effort to demystify differences and empower the child, have made it a part of ongoing discussions from a young age. Others have decided to not talk about it at all out of concern to avoid unnecessarily creating a sense of difference and isolation that may not otherwise exist. Some wait until they think the time is right to initiate a comprehensive sit down discussion of the condition. Others wait until their child broaches the subject, and then have a series of short discussions. What works in one situation may or may not work in another. Nearly all families struggle with the choice of words that will best explain what they want to say.

Of course, the children's ability to communicate their own concerns and understand what the adults are attempting to communicate to them is crucial to the process. Also, their social experience with peers and siblings often colors their willingness to engage in discussing and understanding issues of difference and disability.

Tony Atwood, recognized worldwide as an authority on Asperger's Syndrome, wrote on this subject, "When do you inform the child that they have Asperger's Syndrome? There is no simple answer. Very young children will not have the maturity to understand the concepts. Older children may be extremely sensitive to any suggestion they are different. Their vehement denial of any inadequacy in social abilities is more an attempt to convince themselves than others. The answer may be to tell the child when they are emotionally able to cope with the information and want to know why they have difficulties in situations that other children find so easy. Sometimes this should be undertaken by parents, sometimes by a professional."

While the specifics may differ when interacting with a child who has a condition other than Asperger's Syndrome, Atwood's idea of finding the right time, place, people and level of ability, interest and maturity strikes me as useful in figuring out how to proceed.

At FSRC, we would like to initiate a way we can all learn from each other about all of this. What has been your experience in explaining these issues to your children, their siblings and their peers? What have they communicated - however they do communicate - to you about their experience of living with a "disability"? How have your discussions of these issues affected how you and they look to the future?

Please let me know what you'd like to share with other families, professionals, educators and other supporters, and I'll put together some of your responses for a future newsletter. Make sure to let me know if it's okay to share your comments publicly and, if so, whether you want to remain anonymous. Here's how to contact me:

e-mail: inclusion@fsredane.org

U.S. mail: Family Support and Resource Center
Community Inclusion
101 Nob Hill Road, Suite 201
Madison, WI 53713

Telephone: 608/237-7639



Better Together: FSRC's Inclusion Page

Parent Group Advocates For More Inclusive Schools

Submitted by Beth Swedeen

Madison Partners for Inclusive Schools began nearly three years ago as a handful of parents who wanted to better connect with other parents and Madison school staff to improve outcomes for all children in the district. The group met at coffee houses and libraries for a couple of years, planning trainings for parents and two resource fairs that included more than 40 booths highlighting programs and resources for Madison families who have children with disabilities.

Over time, a steering committee of 15 or so parents developed to plan activities and make group decisions. We communicated primarily through email because of busy schedules. A larger email list was developed to communicate opportunities to the entire group, which now numbers around 130.

But the group felt the need for more systemic changes. Last spring and summer, the steering committee put together 5-6 message points on ways the group wanted to work more closely with the district to improve outcomes for students. Small groups of us met with individual School Board members, who gave us tips and ideas for working more closely with the district's leadership. They suggested we give a formal presentation to the board, which we put together for a special meeting at the end of November. In the presentation, we called for:

- Closer partnership with the district in sharing resources.
- More say in choosing district principals and other decision-makers.
- Increased high-quality in-servicing on differentiation and other best-practice inclusive strategies.
- Increased partnership to change community perceptions of children and youth with disabilities.

We also worked with the district and local media to place stories in local media highlighting best-practice examples of inclusion for National Inclusion Week in December—an event that one of our members found out about on the internet. As part of that endeavor, the Madison School Superintendent, Art Rainwater, devoted his monthly column to the value of inclusive education: a column that ran in the local newspapers and was highlighted on cable television and in every school newsletter in the district.

As a result of our board presentation, our members have also been named to the Madison School District's committees on legislation, equity, and special education. On such committees, we represent the values of inclusive education and how high-quality inclusive practices benefit ALL children.

In January, Madison Partners received a DAWN grant to increase youth involvement in their IEPs and develop trainings for families and staff. The grant also focuses on working with state government to improve financing for school services.

Most recently, we have worked with the Madison School Board and testified at meetings about the value of mixed-ability grouping in schools at a time when the district is under attack by some parents who want more tracking in middle and high schools.

It took our group several years to find its footing, but we feel bolstered by our successes. When families see the direct impact of their advocacy, it's easier to take on the next challenge as it comes along. We welcome your involvement.

If you want to join Partners, please send your email address to Beth Swedeen at swedeen@waisman.wisc.edu. Together, we make a difference.



Dane County Area Events Listing

MARCH 2006

- March 4** **Terrace Town 2006, Monona Terrace 10am to 4pm** - This event highlights how cities are created and planned, and what makes a quality city. Enjoy family-friendly activities. Free event!
- March 5** **Madison Children's Museum Free Family Sunday, Noon to 5pm**
Enjoy free admission all day!
- March 12,19,26** **A-Z Farm Lambing Barn Tours, A-Z Farm, Oregon WI** - See lambs nursing, as well as chicks, bunnies, and other animals. Cost is \$3.50 and children 2 and under are free.
- March 12** **St. Patrick's Day Parade and Shamrock Shuffle, Capitol Square in Madison**
A full day of fun and festivities is planned around this celebration of St. Patrick's Day. For more information see www.stpatsmadison.com.
- March 18-19** **Kids Expo, Alliant Energy Center** - Dozens of presentations and hundreds of exhibitors. This event is a must for kids and parents!

APRIL 2006

- April 8** **Connecting Families 2006, Alliant Energy Center-Expo Hall** - Come join this "non-conference conference", intended to provide families with opportunities to be with and learn from each other! FREE Childcare available (pre-register for childcare requested). For more information call 237-7630.
- April 8** **Oregon Easter Egg Hunt, Jaycee Park, Oregon WI** - Come enjoy breakfast refreshments. The hunt starts promptly at 11am.
- April 9** **City of Madison 150th Celebration, Monona Terrace** - Join Madisonians in celebrating our 150th Birthday! Treats, performances, and activities for all!
- April 29** **The Great Midwest Alpaca Festival Alliant Energy Center** - Come see more than 500 alpacas compete in a full-fleece alpaca halter show and fleece show. Many vendors to see and enjoy. For more information see www.gmaf.info.



Dane County Area Events Listing

May 2006

- May 5-7** **Dairyland Classic Dog Show, Alliant Energy Center** - Come see more than 2200 dogs from over 135 breeds. There will be activities and demonstrations for the public to enjoy.
- May 19-21** **Fitchburg Days, McKee Farms Park, Fitchburg** - Enjoy music, fireworks, dancing and games for all ages. Please call 608-288-8284 or visit www.fitchburgdays.com.
- May 19-21** **2006 Syttende Mai Festival, Stoughton** - This Norse festival has a little something for everyone! Enjoy folk dancing, exhibits, and plenty of food! Don't miss the Ugliest Troll Drawing contest.
- May 26-29** **World's Largest Bratfest, Willow Island at Alliant Energy Center** Open each day from 11am to 7pm, come help break the "Self-Proclaimed" World Record of 189,432.
- May 29** **Oregon Horse Association Annual Horse Show, Triple K Stable, Oregon**
This will be the 30th Annual Memorial Day Show. For more information please call 608-835-9712 or visit www.oregonhorseassociation.org.

June 2006

- June 2-4** **Festa Italia, McKee Farms Park, Fitchburg** - Italian dancers, activities for the kids, and amazing food highlight this weekend of fun. For more information visit www.iwcmadison.com.
- June 17** **Feast with the Beasts, Henry Vilas Zoo, Madison** - This annual event at the zoo features music, face painting, entertainment and great food. For more information call 608-266-4732 or visit www.vilaszoo.org.
- June 22-25** **Oregon Summer Fest, Kiser Firemans Park, Oregon** - A four day event that includes a carnival midway, sport tournaments, live entertainment, family friendly activities, fireworks and a parade.

This events listing is gathered from information provided by www.visitmadison.com





FRIENDS OF OUR FAMILIES

Local Businesses Brighten the Holidays for Kids and Families

A holiday tradition at FSRC is the delivery of gifts to many of the children we serve. This year, due to the generosity of employees of **American Transmission Co.**, **Capitol Indemnity Corp.**, & **Meriter Retirement Center**, as well as the members of **Unity Church of Madison**, we were able to provide individually selected gifts and certificates for holiday groceries to over 150 children in our programs. Thanks also to **The Pleasant Company** for donating dolls and **Playthings** at Hilldale Mall for sponsoring FSRC in the Holiday Tree Walk.



In December, FSRC staff offices were quickly filled with presents, even bicycles, donated by generous donors.



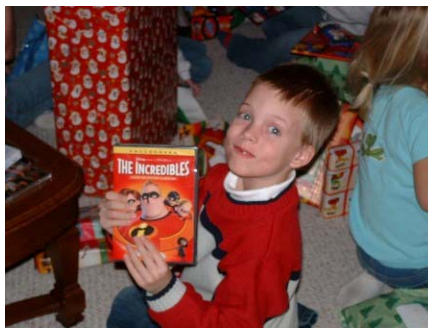
The Perez-Wilson family gets a visit from Santa. Amy DeWald, the family's case manager, tells this story: "The children received gifts last year and have come to believe that I know Santa personally since I have been able to take their wish lists with me and return near Christmas with brightly wrapped packages filled with many of their favorite things. This year, after the children finished opening their gifts, the doorbell rang and suddenly Santa himself appeared at their door to wish them a Merry Christmas. The children were amazed. I didn't realize that Santa would be making a personal visit, but the timing of the delivery of gifts was a perfect fit!



Hailey Disch-Smith was especially pleased with her new American Girl doll.



Playthings in Hilldale Mall was awarded second prize for tree decorations at the annual Hilldale Holiday Tree Walk. As the non-profit agency sponsored by Playthings, FSRC was the lucky recipient of the prize money!



Two children in the Schwichtenberg family have an extra special Christmas, thanks to employees at American Transmission Co.

Thanks to these businesses and foundations which made generous donations to FSRC at the end of 2005:

- **UW Medical Foundation**
- **Ella Mae Siebert Foundation.**
- **Jenni & Kyle Memorial Fund**
- **Phoebe & John D. Lewis Foundation**
- **Knights of Columbus, Council 6371, Waunakee**
- **Madison Investment Advisors**
- **Playthings**



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 1945 W. Broadway
 Madison, Wisconsin 53713
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Patti Jo Becker-Director
 Shauna Foss Jeremy Sanford

Inclusion Facilitators:

Dennis Granzen Fil Clissa

Website: www.fsrdane.org

FAMILY FOOTNOTES-BACK PAGE

*We Recognize
 Sexual Assault Awareness Month
 April 2006*



Rape Crisis Center provides
free 24-hour Services for survivors
 of sexual violence and supportive
 family or friends.

Rape Crisis Center
 128 E. Olin Avenue, Madison, WI 53713
 24-hour crisis line (608) 251-7273
 administration (608) 251-5126
www.danecountvrcc.org

Wheelchair Accessibility Loan Program

A reminder that the Respite Care Program has **2 portable ramps for loan free of charge!** These ramps are intended to provide short-term accessibility for respite provider homes, houses of friends, and other community settings. Each set of equipment includes a 6 foot ramp which folds up to the size of a large suitcase and a 1.5" threshold ramp.

You're receiving this newsletter because your name is on FSRC's mailing list. We do not share our mailing list with other organizations. However, if you would prefer to be taken off our list, please let us know by calling 237-7630 or emailing us at fsrc@fsrdane.org. Thanks!

"Family Footnotes" is a quarterly publication of the Family Support and Resource Center, a non-profit organization serving Dane County families who have members at home with developmental disabilities. For more information, call us at 608/237-7630 or email us at fsrc@fsrdane.org. Current and back issues are posted on our website at www.fsrdane.org.