

FAMILY FOOTNOTES

FEBRUARY 2005

Finding Connections & Getting Ready for Summer

Featured in this issue:

- Families share 2004 summer camp stories
- Resources to help you get a head start on summer planning
- Fourth Annual Connecting Families Gathering scheduled for May 15
- Jeanne Sterken talks about why connections among parents matter

Better Together: In FSRC's Inclusion Page, Dennis Granzen's *No Limits* column focuses on parent support groups. Also, two local grants encourage inclusive art programs.

Respite News Page: Provider Tyson Korb talks about summer respite, and the story of one family's use of Respite Care providers to support summer activities.

FSRC's Calendar Page: Dane County Area Events

Naoki's Summer

Naoki had a spectacular summer in 2004 at Eagle's Wings High Fliers program. Naoki, age 11, found the field trips to University sights, local parks, Middleton Pool and "daily adventures" to be a perfect match for his summer needs. The program had a structure each day which Naoki could follow and appreciate.

His mom says they owe the success of the summer to many things, but mostly to the preparation and excitement of the program staff. UCP- Child Care Inclusion Resources staff and Keiko met and consulted with the Eagle's Wings staff before summer started to assist them in understanding not only the impact on Naoki of his autism diagnosis but also the nuances of the disability. The staff was eager to learn and make adjustments to help Naoki be successful. The most important accommodation was Naoki received his own "touch person" for the summer. The center assigned a high school student to be Naoki's ally in the summer adventures. Keiko says "Naoki fell in love with her." She made him feel safe and when he was feeling stress he could go to her and she would help him to regulate with the world around him.

Keiko strongly encourages families to visit centers and camps, as well as to meet with the staff before you commit to the program. Keiko visited a number of places before deciding on Eagle's Wings. If the staff is not open to hearing about the child's support needs during the informational visit - perhaps this is a sign of things to come and a reason to go another way.

Summer Planning: Start Early

The key to planning a great summer is to start early and don't be afraid to be creative. Featured in this issue are the stories of experiences that worked out well last summer for three Dane County kids. We are grateful to Jim Carlson and MC Reisdorf, Bonnie Cate, Keiko Sasahira, Ginger Schwahn, Angela Lazars, Chris Benson, Patti Becker, and Jeremy Sanford for sharing these examples.

Sources of information about summer possibilities:

- **Summer Options for Middle Schoolers**, March 15, 6-8 p.m., at United Cerebral Palsy. For more info call 273-3318.
- FSRC's **Family Support Program** has brochures and application information for a variety of summer camps.
- If you are registered in the **Respite Care Program**, talk to staff about ways respite care workers could help with summer activities (see Respite News insert for more ideas).
- **MSCR** will sponsor summer resource fairs on March 16 & 17 (see Events insert) that are a source of lots of great information about summer options. Also, Madison Newspapers puts out the **K-12 Summer Planner**. Extra copies can be picked up at their office or viewed on-line at www.madison.com.
- **Community Coordinated Child Care** (271-9181, www.4-c.org) and **Satellite** (275-6740, www.Satellitelfcc.com) can help you search for child care providers.





Maggie's Summer

Maggie is a delightful young woman with an engaging smile. She lives with her mother Bonnie and attends high school in a rural Dane County community. In past summers Maggie attended child care programs with younger children and had limited chances to socialize and interact with friends her own age.

Maggie began receiving summer services from UCP's Teen Outreach Program in 2002. Monday through Friday she joined other teens in trips to a Brewers game, picnics in various parks, trips to Devil's lake and many more exciting social outings. Maggie communicates clearly with her smiles and squeals of glee that swimming and boat rides are among her favorite activities. Maggie was eager to leave home to join her friends in the morning and was still smiling when her mom picked her up at the end of the day.

Bonnie made several observations that seemed to sum up her feelings after Maggie's first summer with the Teen Program. "Maggie was happy with life this summer" and "I have never experienced as many positive comments about Maggie as I did this summer from the Teen Outreach staff." The same sentiments were echoed again with big smiles at the end of last summer. Maggie and Bonnie are now eagerly waiting for the chance to participate in more Teen Outreach fun this coming summer.



Keeping healthy/Getting support from other families

4th Annual Gathering for Families of Children with Disabilities "Building Your Tomorrow"

Sunday May 15, 2005 12:30 pm- 4:30 pm
Alliant Energy Center Madison, Wisconsin

Connecting Families is the "non-conference conference." The event and presentations are for and by families of children with disabilities. The intent of the event is to provide families with opportunities to be with and learn from one another.

This year's speakers and panel members will share their experiences in preparing for their child's future. The afternoon will begin with **Deb Wisniewski's** keynote address. Deb is a parent of a child with a disability and works for the Waisman Center. Deb's keynote will be followed by three separate sessions: **Session I: Preparing a Foundation for Adult Life** will give families a chance to hear from an adult consumer and family what you need to know now to prepare that foundation. **Session II: Constructing Connections** will give attendees an opportunity to learn of families' successes in staying connected in school and beyond. **Session III: Blueprint for Advocacy** gives families an opportunity to discover a method of advocacy with which they are comfortable that can help insure future services for their child.

As in years past, all afternoon event attendees will have the chance to connect with each other and visit with exhibitors of local services. The event is free and childcare will be available. For more information see www.LINKdanecounty.org or call Patti Becker at 221-4611 ext 22.

Respite News

Summertime can be a wonderfully relaxing time as well as a challenging time for respite providers. Often, care providers take on more extended, on-going periods of respite during the summer months and it can become challenging to fill all the hours of the day with new and exciting activities. Last summer, **Tyson Korb** did just that. Tyson came to FSRC's Respite Care Program last year with enthusiasm and energy! He jumped right in, doing some serious summertime respite, and here is what he had to say about the experience.

"This past summer I had the pleasure of providing respite care for two teenage boys in the Madison area. When I talked about my future summer job with my friends, most said I was crazy; however, I was looking forward to the challenge. When the summer was over I had helped the boys have a summer they will cherish forever."

"A few tips I would recommend is to plan a fun activity each day, have open communication with family and client, and be yourself. I feel it is important to vary the day. Take advantage of the nice weather and go biking, walk to the library, or have a picnic; anything to make a unique connection. Talking to the individual you are providing care for might sparks some ideas. Keeping an open line of communication with the family is important so both sides can have a positive experience. Lastly, be your self and treat your client the same as you would anybody else. We all grow through challenges; don't be afraid to try new things."

Here are some activities in the Madison area that involve minimal planning and expense.

- ⇒ The Madison Museum of Contemporary Art sponsors the **Art Cart**. The Art Cart is a free traveling art program that allows participants to engage in a creative, outdoor art-making experience.
- ⇒ The **Stagecoach Performances** are a Madison tradition with FREE performances by local middle and high school actors. There are about 25 performances in July and August each summer at various parks in Madison.
- ⇒ MSCR has a **drop-in Playground program** that involves kids in grades 1-5 in initiating, planning and leading various activities. There are roughly 14 venues in the Madison area to choose from and the cost for the entire summer is \$20.

Of course there are many more, and there are many ways to find out more information about the various summer happenings around Madison and Dane County. You may contact the Respite Care Program for more information on ways to find fun things to do!

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. Keep them in mind when planning summer respite, or any time of the year!

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.

Please feel free to contact FSRC if you are interested in utilizing this equipment. Whether you are a family or a care provider, this equipment is here and ready for you! Contact the Respite Care Program at 221-4611.

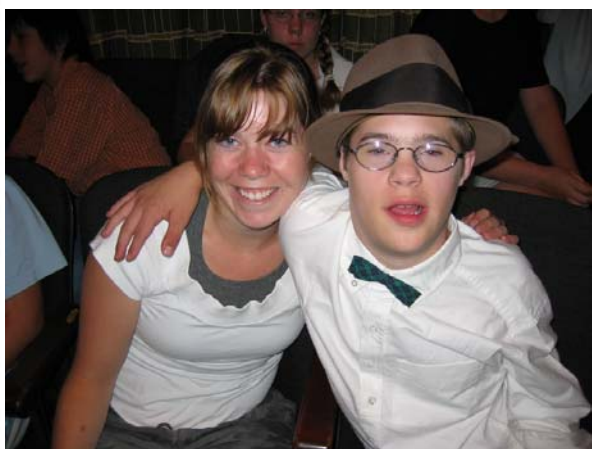


Respite News

Nelson's Summer

It was wonderful for Nelson that we were able to use Respite money and care workers to help Nelson participate in two summer experiences last year.

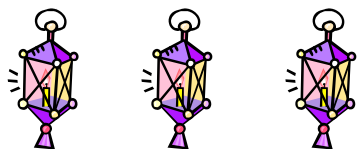
Nelson really enjoyed the Theatre Week at the University Play Circle last summer, sponsored by Children's Theater of Madison. He was cast as the photographer in a shortened version of *Charlotte's Web*. This was performed on the Play Circle stage at the University.



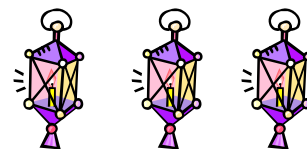
He was able to participate because he had a Respite Care provider with him to keep him on task, modify information, and help him to move around the campus with the group. Sarah was able to help him understand some of the scenes and much of the technical aspects that were taught that week. She was there to help him purchase lunch or treats at the Memorial Union and to help him integrate with the other kids who were taking part in the camp. Sarah helped Nelson listen to the description of the characters and then make a choice about what parts he wanted to try out for. She also was a liaison between the staff of Theater Week and us, the family. Nelson had a fabulous experience.

Nelson also enjoyed a week-long class at the Dane County Humane Society where he learned about the care of pets from cats and dogs to rats. He again was helped by a Respite Care provider who was there to guide Nelson through activities and support him when needed. Without that help, Nelson would not have benefited as much from these summer activities and may have not have been able to participate at all.

We really appreciate the help of FSRC's Respite Care Program and look forward this summer to providing more great experiences for Nelson with the support of Respite Care.



Welcome Path for Neighbors, Friends, and Family



Welcome friends, family, and neighbors to your home for a cup of hot cocoa, tea or coffee and light the path to your door with ICE LUMINARIES

You will need: large, round balloons, H₂O, food coloring, votive candles

How to: Fill the balloons with tap water and tie off. Add food coloring if desired. Place the balloon in the freezer or (if sufficiently cold) outside! Allow enough time for the water to freeze almost completely. When frozen, remove balloon and pour out any unfrozen water. You should have a small well to place a votive candle in. If frozen completely, you may create a well by drizzling hot water onto the top of the ice ball. The well should be deep enough to shield the candle from the wind. Place the luminary along your walkway or on the steps. Light the candles and enjoy the crystal glow. During weather below freezing, they may last for days. Try making the luminary with neighbors and light the entire block...they are environmentally friendly too!



Better Together: FSRC's Inclusion Page

No Limits
By Dennis Granzen

One aspect of my work that I always look forward to is participating in meetings of various sorts of parent groups. Sometimes I attend as a guest to hear about what various members of the group have been up to. Other times I'm there to facilitate the group in developing a plan for their future. Most of the time, I've been invited to address the group about either friendship building or person centered planning.

One reason I like to go to these groups is because the participants come with an interest in the topic, not because they're required to be there. Another is that many of the parents tend to have a great sensitivity for identifying empty words. Talking to a group that you know will keep you on your toes is a great reminder to strive for honesty and relevance.

The Dalai Lama once wrote, "Without the human community one single human being cannot survive." What I hear from the parents who attend useful support groups is that these groups not only offer a better chance at survival, but they and their families have a better opportunity to thrive. Coming together with others who share your circumstances and can recognize the value of your child - while also recognizing each others' differences - brings strength, knowledge and wisdom, among other things. You can both celebrate and commiserate with each other.

Parent support groups can take many forms. Some are tied to a particular school district, others to a particular diagnosis. Some come together for a limited time to accomplish a specific advocacy objective; others are ongoing and develop goals as they carry on. Some - like the popular Parents In Partnership (PIP) and Parents As Leaders (PALS) - include families from a wider geographic area who meet for occasional weekend retreats, with a goal being that the participants return to their communities better equipped and motivated to make a difference for themselves and their neighbors. I've heard several parents draw on their experience with a support group years after the group stopped meeting.

While there are potential pitfalls for some groups - I know of one that faded out because the attendees felt it had become a forum that focused too much on complaints without searching for solutions - the potential benefits make them well worth the risk. They remind us of the necessity of coming together. Going it alone makes everything harder.

Top Ten Reasons to Attend Parent Support Group Meetings:

10. Every meeting has treats.
9. You get to listen to all the entertaining and heartwarming stories about IEP meetings.
8. Between the people doing child care and the other parents, you have a good shot at finding some respite providers.
7. It's more enjoyable than many of the things you'd do if you stayed home.
6. It feels good to be welcomed *because* of your child.
5. There's strength in numbers, even if they're small numbers.
4. You can brag about your child without having to explain anything.
3. Sharing all sorts of things with the other parents, like information, resources, experiences, feelings, even recipes. Or swear words in combinations you've never heard before.
2. It's fun to mock the guest speaker after he/she leaves.
1. Being a little less lonely in the world is a good thing.



Better Together: FSRC's Inclusion Page

WCDD Awards Grants to Local Groups for Inclusion

By Fil Clissa

The Wisconsin Council on Developmental Disabilities has recently awarded two local groups grant money to fulfill their goals for inclusive art experiences for kids with disabilities.

Monroe Street Fine Arts Center received a QCue (Quality Communities Utilize Everyone) grant. The grant money will be used to fund a pilot class that would enable children with autism to join with their typically developing peers in a rich art curriculum, with the additional supports needed to ensure their success.

The Everybody Learns More (ELM) Art Explorations class will include approximately 8 students. The students will be paired in the class (one student with autism paired with a non-disabled peer). They will work on joint projects and individual assignments, with interaction encouraged among students in all activities. Collaboration will be required, particularly for the joint projects. The instructor and the in-class aides will facilitate this collaboration as needed. At the completion of the class, the ELM students will create a gallery at the Monroe St. Fine Arts Center, displaying highlighted pieces of their art. A gallery night will be held at the Center, with classmates, friends and families invited to see the work the students created.

The idea for the class came from Jane Boutelle. Jane is a parent and an Art Center Board Member. The Monroe St. Fine Arts Center folks embraced this idea and have been very enthusiastic about making it happen. Medora Ebersole, Interim Executive Director, said, "We are so glad to be able to extend our definition of community with this offering. We have gotten great response so far from families of 'typical' students."

The class will begin Thursday February 8 and run for 8 sessions (no session during the spring break week). It will culminate in an art exhibit at the Fine Arts Center on Thursday April 7 from 5-6 p.m. You can contact Medora Ebersole at 608-232-1510 for more information about the ELM classes.

Individuals, community groups, neighborhood centers, faith communities and others are eligible to win up to \$500.00 to "spark" innovative methods of creating more inclusive neighborhoods and communities by recognizing the importance of utilizing the assets of ALL people, including people with disabilities. QCUE Grants are available on an ongoing basis. To apply for a grant in your community or for more information about QCUE Grants, contact Kathryn Mazack at 266-5395.

Madison East High School Art Club received a Project T.E.E.N. (Teen Energy and Empowerment Network) Grant. Funding through the Project T.E.E.N. Grant will provide an opportunity to involve students with disabilities in the after-school Art Club. Students will be matched with typically developing peers to complete the art projects. Those students will also participate and attend the reception and placement of the projects for display or use. Staff will assist in facilitating relationships among the students, providing necessary support.

Project T.E.E.N. Grants offer funding and support to student leaders who want their school to be a better place for students with disabilities. Grants of between \$250 and \$500 are awarded to schools who have students interested in creating a project to improve their school for students with disabilities.

Grant information is also available online at the WCDD website: www.wcdd.org.



Dane County Area Events Listing

Middle School Socials at Warner Park Community Recreation Center:

Includes open gym, game room, DJ, and pizza. Students must present a current middle school ID for admission to the social.

2005 Dates: March 18, Apr. 15, May 20

- Time: 7-9:30 pm
- Staff and chaperones: MSCR

Cost: \$3 without WPCRC ID

Free with WPCRC ID

Overture Center Vouchers provide access to great performances:

Family Support and Resource Center periodically receives vouchers to the Overture Center for various performances. Please feel free to contact us at 221-4611 to inquire about availability. We currently have vouchers for: **"Dan Zane and Friends"** 4/9/2005 at 11am.

MARCH 2005

March 5, 12, 19, 26: Kids in the Rotunda (formerly Kids in the Crossroads) Join Overture Center for the Arts each Saturday for free performances presented on the Rotunda Stage. Performance times are at 11am and 1pm.

- * March 05 Goongoo Peas- Caribbean folk music
- * March 12 Cheney & Mills- magician
- * March 19 Art Shegonee- Native American dance and storytelling
- * March 26 Stuart Stotts- folksinger/storyteller

March 1, 8, 15: Toddler Story and Stroll at Olbrich Gardens introduces toddler to nature through stories and a stroll through the tropical environment that is the Boltz Conservatory. Start time is 10am. Cost is \$3 per child and adults are free.

March 3-5: A Little Night Music is presented by Strollers Theatre. Performances 3/3 at 7:30pm, 3/4 at 8pm or 3/5 at 4pm or 8pm. For more information contact Bartell Theatre at 661-9696 or at <http://madstage/companies/strollers>

March 6: MSCR Summer Program Guide circulation begins. Available in the Sunday WSJ. Also will be mailed to MMSD residents week of March 7-11. ****Registration for Summer Programs begins March 14 for MMSD residents and March 28 for non-residents of MMSD****

March 11-13: Canoecopia Alliant Energy Center. Largest paddle-sport expo in the world. Find the newest, best, and most of anything that is even remotely related to paddling! Find more information at www.canoecopia.com.

March 13: Madison's 8th Annual St. Patrick's Day Parade Many musical acts, dance troops, and other performances to enjoy! Location to begin is St. Patrick's Catholic Church in Madison. More information may be found at www.stpatsmadison.com.

March 16-17: MSCR Summer Programs Previews Two opportunities to find out more about all the summer programs that are available through MSCR. Memorial HS will host the Preview on March 16 and LaFollette will host on March 17. The hours for both opportunities are from 6:30 to 8pm.

March 26: Jaycee Easter Egg Hunt Oregon, WI. Games and prizes for children of all ages.



APRIL 2005

April 2, 9, 16, 23, 30: Kids in the Rotunda (formerly Kids in the Crossroads) Join Overture Center for the Arts each Saturday for free performances presented on the Rotunda Stage. Performance times are at 11am and 1pm.

- April 02 Co'Motion Dance- modern dance
- April 09 Greg Percy- "Songs in the Key of Art"
- April 16 Bovee and Heil- traditional American music
- April 23 Bob Kann- juggler/comedian
- April 30 Ace Willie- magician

April 15: Midwest Horse Fair Alliant Energy Center. More information is available at www.midwesthorsefair.com.

April 16: Opera for the Young's "Hansel & Gretel" Stoughton Opera House. Performance time is 2pm to 3pm.

April 22-23: Midwest Spring Holstein Show Alliant Energy Center

April 23-24: Kids Expo Alliant Energy Center. An incredible celebration featuring the very best entertainers, exhibitors and interactive fun for kids 0-15.

MAY 2005

May 7: Kids in the Rotunda (formerly Kids in the Crossroads) Join Overture Center for the Arts each Saturday for free performances presented on the Rotunda Stage. Performances at 11am and 1pm

- * May 7 Playtime Productions Children's Theatre- "If the Shoe Fits...A Cinderella Story"

May 6-8: Dairyland Classic Dog Show Alliant Energy Center.

May 8: Mother's Day Concert Olbrich Gardens. Bring your mother to the gardens for a stroll through the spring blossoms. Also enjoy a concert by the New Horizons Concert Band in the Evjue Commons.

May 15: Connecting Families Alliant Energy Center.

May 20-22: Fitchburg Days Festival McKee Farms Park, Fitchburg. This event features live music, fireworks, Irish dancers, a carnival, food, and kids' activities.

May 20-21: ALL BABY EXPO Alliant Energy Center-Exhibition Hall All Baby Expo will provide a unique one-stop shopping consumer show that will emphasize the ever-expanding parenting market.

Information collected from Greater Madison Convention and Visitor Bureau www.visitmadison.com

Waisman Center Children's Theatre

Feb. 27-1 & 3 p.m. Reed Marionetts Science and Puppets 2005-learn about science from history's greatest minds as puppets take over the stage for an entertaining & informative afternoon.

March 6-1 & 3 p.m. Dance Wisconsin *Alice in Wonderland*-join Alice & all the classic characters. Ballet.

March 13-1 & 3 p.m. Atimevu Drum and Dance Rhythm, drumming, dancing & more. A wonderful interactive performance with a world beat.

April 3-3-1p.m. Banana Productions *The Bananaland Review*-join six foot Banana as she helps a little girl realize her dreams in this engaging high energy musical and fun vaudeville style show. Audience participation!

April 16-1:00 only April 17-1 & 3 p.m. PlayTime Productions *If the Shoe Fits...A Cinderella Story*- the classic & magical fairytale with fun & comedic new twists brought to life by an all-children cast with music, songs, & costumes.

Admission: \$2.00 adults; \$1.00 children Questions?: Call Teresa at 263-5837 weekdays or palumbo@waisman.wisc.edu.





SPECIAL CONNECTIONS

By: Jeanne Sterken

Connections are important in life. When you are the parent of a child with special needs, connections are invaluable.

I choose to approach life with an optimistic outlook. The realization that our beautiful daughter would forever be challenged by her special needs changed me forever, testing my optimism. I searched for ways to gain control. Instead, I found a means to cope with the unknown and gained a support system for our family; I connected with other parents of children with special needs. The isolation I had known dissolved. These parents knew firsthand the feelings of worry, despair, sadness, hope & acceptance. These parents with special children understand having to adjust and adapt a dream for a child, while family and friends seek to relate to our changing lives. These parents of special children offer support when we become discouraged or full of doubt; information about resources overlooked by others; and insights into the educational system that no book would cover. These families share the experience of raising a child with special needs.

Over the years, parents have shared which resources are helpful and which to avoid, including which physicians to use; which therapies to consider and where to get them; and information on respite care, schools, inclusion, IEPs and more. Networking with other parents provided resources that professionals never had.

"By sharing knowledge and practical experiences with other parents, we ease the way for each other through the maze of resources and roadblocks encountered in the life of a special child."

My reliance on a pediatrician for information and guidance with my typically developing child has been tempered by a realization that special needs children have **unique needs** unfamiliar to most doctors. Medical school devotes little attention to the special needs population, and most pediatricians have only a small number of children with special needs so their practical experience is limited. On a quest for answers, parents become experts on their child's particular condition, gathering information after extensive searching. By sharing knowledge and practical experiences with other parents, we ease the way for each other through the maze of resources and roadblocks encountered in the life of a special child.

"The part of me that is entwined with my child wants to connect with other parents, creating a community which embraces my child as their own— sheltering her, loving her, accepting her, and valuing her contribution to their life."

Raising a child with special needs has distinct challenges and concerns for a parent. We face the reality that when our children grow older they may not move out, get a job or go to school as their peers are doing. We ask questions of the future, such as: "Who will love

my child when I am gone? Who will make sure my child is dressed in clean clothes, with hair clean and combed? Who will wipe her face clean so she doesn't disturb others with her drool? Will she have a suitable living situation?" The part of me that is entwined with my child wants to connect with other parents, creating a community which embraces my child as their own— sheltering her, loving her, accepting her, and valuing her contribution to their life. Connecting families together builds a community where people are enriched by the experience of caring about our children and our children's future.

Call for information on parent support groups:

Family Support & Resource Center would like to update and disseminate our information about parent support groups for families of children with developmental disabilities that are currently active throughout Dane County. If you would like your group to be included on our list, please email (fsrc@fsrcdane.org) or call us (221-4611) with the name and purpose of the group and contact names, phone numbers or email addresses.



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Inclusion Facilitators:

Dennis Granzen Fil Clissa

FAMILY FOOTNOTES-BACK PAGE

Family——>Family

For Sale (Call 221-4611 for more information)

- 1994 Chevy Van, Handicap accessible. Good/fair condition with no mechanical problems....\$4000
- 1999 extended Dodge Ram van with lift, extended top and 2 tie downs. Good condition.....\$15,000

DID YOU KNOW???? Family Support and Resource Center can benefit from you buying groceries at Pick-N-Save? Yes, if you go to the service counter and let them know FSRC's account number **225375**, they will issue you a new Advantage Plus Savers Club Card and each time you buy groceries a portion of your purchase will be donated to FSRC. Pick-N-Save plans to give a total of 2.5 million dollars to this "We Care" Program. There are Pick-N-Save stores in Stoughton, McFarland, DeForest, and on McKee Road in Madison. Please participate when possible. Thank you!!!

THANKS!

- To the wonderful people at the following organizations, who shopped for and wrapped holiday gifts for children and parents served by FSRC: **American Transmission Co., Capitol Indemnity Corp., Meriter Retirement Services, and Unity Church of Madison.**
- To The Evjue Foundation, SBC Foundation, Alliant Energy Foundation, Phoebe & John R. Lewis Foundation, Playthings at Hilldale, Ed & Betty Garvey, Sally Wilmeth & Terry Geurkink, and the Ellamae Siebert Foundation for end-of-year gifts and grants to FSRC.

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 608/221-4611 or email us at fsrc@fsrcdane.org.