



Family Matters

“FULL INCLUSION, FULL LIVES”

Join us for Siblings Day 2005!

WHEN: Sat. Jan. 14, 2006 8:30am-1:00pm

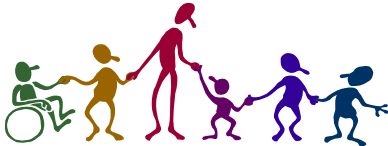
WHERE: Bethany Evangelical Free Church 3936 CTH B, La Crosse

COST: \$6 per child

WHO: Children ages 6-16 who have a brother or sister with a disability or limitation of any type

PRE-REGISTRATION IS REQUIRED

SEE PG. 5 FOR MORE INFO



Would you like to invite others to an accessible and fun community event? You can list your event in *Family Matters* for free. Send your submission to flicck.kari@co.la-crosse.wi.us

A Message from Larry and Keith

Larry Winter and Keith Keller are the Supervisors of the Children with Special Needs Units I & II.

At Christmas time last year Larry received a desk calendar from staff. Each day has a thought that is food for the mind. A recent thought of the day stated the following, “As we continue to grow and mature, we become increasingly aware that all of nature is interdependent, that there is an ecological system that governs nature, including society. We further discover that the higher reaches of our nature have to do with our relationships with others-that human life also is interdependent”.

We have completed a series of trainings to help all of us wrap our minds around the meaning of an “Integrated Systems of Support (ISOS)”. Approximately 150 community partners have increased their knowledge and are ready to move toward action to assist children and families experiencing challenges in La Crosse County. There is consensus in La Crosse County that we are all in this together and that we need each other to accomplish successful outcomes for children and families.

We believe that developing relationships with families, through the Coalition for Children of Differing Abilities and the communities in La Crosse County is the core to meeting the challenges ahead. This is not an **independent** process but an **interdependent** process with each individual assuming responsibility for their part.

As a county we have a wealth of strengths in our system of support for children and their families experiencing challenges. Some of these strengths include; people willing to try new things, a community that is giving, agencies willing to be involved and a desire to listen to parents. We also have areas that we need to strengthen; increased use and development of natural supports, integrated support teams being formed outside of La Crosse County Human Services, building relationships with each other to enhance support activities, involving law enforcement and ensure parents are full partners in system change activities and integrated support teams.

So the challenge for each of us is how do we individually become involved in the ISOS? The answer is finding ways to build relationships, rely on each other to meet the challenges ahead and for each of us to assume individual responsibility for our part in the process. Happy Holiday’s!!!!!!

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Partner Picture

University of Wisconsin-La Crosse Grant Project Entitled, “Active and Healthy Lifestyles for Children and Youth with Disabilities” Program for Children and Youth with Disabilities

The University of Wisconsin-La Crosse works in collaboration with the School District of La Crosse, Gundersen Lutheran, and several youth service agencies to make a difference in the lives of children and youth with disabilities and their families. The project is entitled “Active and Healthy Lifestyles for Children and Youth with Disabilities: A Comprehensive Community-Based Partnership,” and is a 3-year grant funded by the University of Wisconsin Medical School through the Wisconsin Partnership Fund for a Healthy Future (<http://wphf.med.wisc.edu/index.php>). Included among the partnering agencies are the Department of Exercise and Sport Science, and La Crosse Area youth service agencies (i.e., La Crosse Area Family YMCA, La Crosse Area YWCA, Boys and Girls Club of Greater La Crosse, City of La Crosse Parks and Recreation Department, and the UW-L National Youth Sports Program).



The major thrust of the grant is to design, implement, and evaluate physical activity and nutrition education programs for children and youth with disabilities, ages 5-18. Goals of the grant include: 1) increasing the physical activity levels of La Crosse area children and youth with disabilities; 2) decreasing overweight and obesity levels of participants through physical activity and nutrition education; and 3) conducting and disseminating practical and collaborative action-research and best practices related to physical activity and nutrition education.

The grant began April 1, 2005 and since then, the director of the project, Dr. Garth Tymeson, Professor of Exercise and Sport Science and Grant Coordinator Shelley Wetzel have been laying the foundation of the project for the La Crosse community and facilitating programs with local agencies. “This is a great way to enhance health and physical well-being of children and youth with disabilities while they participate in transition programs in our community. This is the ideal time in a child’s life to make a difference” said Grant Coordinator Shelley Wetzel. Some community-based physical activity programs that have included grant participants are modified tee-ball/baseball, modified soccer, and the YMCA Kids Marathon. Parts of the nutritional education component are being planned with the Winning Weighs staff at Gundersen Lutheran. Coming soon will be Hoops for ALL Basketball at the Boys and Girls Club Mathy Center in La Crosse and winter activities held by the YWCA.

The next major step in the grant project is a Physical Activity Mentor Program. The concept is similar to “Big Brothers-Big Sisters”, but with a healthy lifestyle and physical activity participation approach. We began the program on November 7, 2005 and it will be ongoing for the next two and a half years. The mentor program links trained college students with children who have disabilities in the area of physical activity. The time required with a mentee is approximately 2-3 hours per week for a minimum of 6 weeks, or longer if they wish to continue in the program. If your child is between the ages of 5-18 and lives in the La Crosse area and would like to be a mentee in our physical activity mentoring program, or if individuals 18 years or older are interested in becoming a mentor please contact the project staff for an application.

For more information about the grant, the Physical Activity Mentor Program, or to add your name to the family distribution mailing list, contact Shelley Wetzel, Grant Coordinator (608-785-8695; wetzel.shel@uwlax.edu) or Garth Tymeson, Grant Director, (608-785-5415; tymeson.gart@uwlax.edu). Persons are also invited to visit the project website at

<http://www.uwlax.edu/activeandhealthylifestyles/>.



Garth Tymeson
Grant Director

Shelley Wetzel
Grant Coordinator

Radical Resources

Support and Parent Groups



Children of the Heart: A group of parents and families of children with Down Syndrome meet quarterly for a Spring Birthday Party, Summer Picnic, Fall Festival and a Christmas Celebration. Parents meet additional times throughout the year on an informal basis. Children of the Heart sponsors the annual Buddy Walk in October, periodic trainings, and distributes a quarterly newsletter. If you are interested in joining or getting additional information contact Carrie Herrmann at 781-6778.

D.A.D.'s: Dad's assisting Dad's of special needs children is a group of fathers who periodically get together for support. For information on upcoming meetings contact Mike Hager at 784-4567 or Dan Vogelsberg at 788-2139.

Mom's Group: Support group for parents of children with special needs gets together for monthly social and support meetings. Contact Vicki Fruit at 781-9750 for additional information.

LARC: La Crosse Association for Responsible Citizens is a long standing group of parents of children with developmental disabilities. Contact Jane Barnas at 782-4799 for additional information.

Coulee Region Autism Network: A newly formed fun, enriching and uplifting group for families affected by Autism Spectrum/Asperger's. Contact Chris at 526-6451 or Lisa at 526-2962 or hpfam6@centurytel.net

MUMS: National Parent to Parent Network: Assist in forming parent support groups statewide for families with children with any physical, mental or emotional disorders. Contact 1-877-336-5333 or www.netnet.net/mums/

Parent and Caregiver Group: A group for parents and caregivers of children with physical impairments, mobility challenges, gross motor delays and diagnosed disabilities. Contact Jeff and Mindy Reinardy at (507) 454-7501 for additional information.

La Crosse Area Asperger Support Group: The purpose is to provide direct instruction in social interaction and pragmatic skills, provide planned and organized social activities, provide an accommodating environment for individuals with AS to experience successful social interactions and to facilitate possible friendships. Meets 2 Thursdays a month at Catholic Charities in La Crosse from 5-7 PM for children ages 10-15. There is a fee of \$28/hr plus occasional fees for planned activities. Facilitators are Diane Hietpas, MSE and Keith Braunreiter, BS. Call (608) 782-0710



Net Connections: Any web links you have found helpful can be forwarded to Amy Burkhalter at aburkhalter@effectivebehavior.com.

blvd.com The Boulevard is a disability resource directory of products and services for the physically challenged, elderly, caregivers and healthcare professionals. At this website you can sign up to receive their free newsletter and post messages or questions on a message board to others who visit the site. The November 2005 newsletter featured an article titled **"MIT Launches Major Autism Initiative."** MIT brain researchers received a \$7.5 million grant from the Simons Foundation in New York in which they are undertaking a multi-faceted approach to understanding the genetic, molecular and behavioral aspects of autism. Autism's symptoms involve many different dimensions of the brain including social, cognitive, visual, motor, and language. To develop a full understanding MIT will analyze the range of dysfunctions and their probable causes. The president of MIT says they are entering a new era of neuroscience and cognitive science which will help them apply new ideas and technologies to the understanding of brain disorders.

www.eparent.com Check out the Exceptional Parent Magazine website where you can access eparent services such as archived articles and a search and respond section where parents can exchange information about their experiences with having a child with a disability. There may be a fee for some articles but there is also lots of free information.

Family to Family

Ten Things Every Child with Autism Wishes you Knew

By Ellen Notbohm
South Florida Parenting

- 1.** I am a child with autism. I am not “autistic.” My autism is one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)?
- 2.** My sensory perceptions are disordered. This means the ordinary sights, sounds, smells, tastes and touches of everyday life that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you, but I am really just trying to defend myself. A “simple” trip to the grocery store may be hard for me. My hearing may be hyperacute. Dozens of people are talking at once. The loudspeaker booms today’s special. Muzak whines from the sound system. Cash registers beep and cough. A coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input, and I’m in overload! My sense of smell may be highly sensitive. The fish at the meat counter isn’t quite fresh, the guy standing next to us hasn’t showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they’re mopping up pickles on Aisle 3 with ammonia. ...I can’t sort it all out, I’m too nauseous.
- 3.** Please remember to distinguish between won’t (I choose not to) and can’t (I’m not able to). Receptive and expressive language are both difficult for me. It isn’t that I don’t listen to instructions. It’s that I can’t understand you. When you call to me from across the room, this is what I hear: “*^%\$#@, Billy. #%^*^&^%\$&*.” Instead, come speak directly to me in plain words: “Please put your book in your desk, Billy. It’s time to go to lunch.” This tells me what you want me to do and what is going to happen next. Now it’s much easier for me to comply.
- 4.** I am a concrete thinker. I interpret language literally. It’s very confusing for me when you say, “Hold your horses, cowboy!” when what you really mean is “Please stop running.” When you say, “It’s pouring cats and dogs,” I see pets coming out of a pitcher. Please just tell me, “It’s raining very hard.” Idioms, puns, nuances, double entendres and sarcasm are lost on me.
- 5.** Be patient with my limited vocabulary. It’s hard for me to tell you what I need when I don’t know the words to describe my feelings. I may be hungry, frustrated, frightened or confused, but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation, or other signs that something is wrong. There’s a flip side to this: I may sound like a little professor or a movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits, because I know I am expected to respond when spoken to. They may come from books, television or the speech of other people. It’s called echolalia. I don’t necessarily understand the context or the terminology I’m using, I just know it gets me off the hook for coming up with a reply.
- 6.** Because language is so difficult for me, I am very visually oriented. Show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of patient repetition helps me learn. A visual schedule is extremely helpful as I move through my day. Like your day planner, it relieves me of the stress of having to remember what comes next, makes for smooth transitions between activities, and helps me manage my time and meet your expectations. Here’s a great web site for learning more about visual schedules <http://www.cesa7.k12.wi.us/newweb/content/rsn/autism.asp>
- 7.** Focus and build on what I can do rather than what I can’t do. Like any other human, I can’t learn in an environment where I’m constantly made to feel that I’m not good enough or that I need fixing. Trying anything new when I am almost sure to be met with criticism, however constructive, becomes something to be avoided. Look for my strengths and you’ll find them. There’s more than one right way to do most things.
- 8.** Help me with social interactions. It may look like I don’t want to play with the other kids on the playground, but sometimes it’s just that I simply don’t know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, I may be delighted to be included.

Family to Family

9. Try to identify what triggers my meltdowns. This is termed “the antecedent.” Meltdowns, blowups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented.

10. If you are a family member, please love me unconditionally. Banish thoughts such as, “If he would just...” and “Why can’t she ...?” You didn’t fulfill every last expectation your parents had for you, and you wouldn’t like being constantly reminded of it. I didn’t choose to have autism. Remember that it’s happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you I’m worth it.

It all comes down to three words: Patience. Patience. Patience.

Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. I may not be good at eye contact or conversation, but have you noticed I don’t lie, cheat at games, tattle on my classmates, or pass judgment on other people?

You are my foundation. Think through some of those societal rules, and if they don’t make sense for me, let them go. Be my advocate, be my friend and we’ll see just how far I can go. I probably won’t be the next Michael Jordan, but with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gough. They had autism too.

*Freelance writer and consultant Ellen Notbohm is a columnist for Autism/Asperger’s Digest and co-author of 1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders (Future Horizons). She favors “common sense” approaches to raising her sons with autism and AD/HD. She lives in Oregon.

Awesome Activities

The Epilepsy Foundation South Central Wisconsin will be hosting “Siblings Day 2006” - in the La Crosse, Wisconsin area on **January 14th**. This program is based on the experiences and feedback received from similar sibling workshops that have been held for the past 7 years by the Epilepsy Foundation of South Central Wisconsin in Madison. Close to 250 children have participated in past events, and the response from both the children and the parents in post-event surveys was overwhelmingly positive, with over 90% of the respondents requesting future programs like this. Survey results are available upon request.

The workshop is modeled after the Sibshop program developed in Seattle. The program was co-developed by Donald J. Meyer, Director of the Sibling Support Project at The Children’s Hospital & Medical Center, and Patricia F. Vadasy, Research Associate at the Washington Research Institute. Sibshops provide opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education while playing games and making new friends. Typical activities include educational discussions and games designed to be unique, offbeat, and appealing to children with a wide range of ages and abilities.

Our goal is to provide brothers and sisters of children with disabilities or special needs an opportunity to have special events of their own and to facilitate their long-term support. These children have a unique need for social and emotional support. Siblings are likely to have the longest-lasting relationship with a family member with a disability and often are responsible for their brother’s or sister’s well-being in later life. Programs that deal with disabilities frequently overlook them. Siblings of children with special needs have much to offer one another if they are given the opportunity to express themselves and to meet and begin long-term friendships with their peers.

8:30 - 9:00	Check-in
9:00 - 9:45	Get Hoppin’ with Welcomes & Warm-ups
9:45 - 10:00	Snack
10:00 - 10:30	Dear Aunt Blabby
10:30 - 12:00	Adventures in Art
12:00 - 12:15	Family Program
12:15 - 1:00	Family Pizza Lunch



CALL 800-657-4929 FOR REGISTRATION FORMS OR MORE INFORMATION

“In the News”

CRISIS PLANNING By Eleanor Shaffar MA LPC



Webster defines a “crisis” as a “turning point in the course of anything, for better or worse; a decisive or crucial time, stage, or event; a time of great danger or trouble, often one which threatens to result in unpleasant consequences.” More simply a crisis could also be defined as “a fork in the road, where one must choose which direction to take”. Webster defines a “plan” as “any detailed method formulated beforehand, for doing or making something; a method of proceeding”. Putting these definitions together, crisis planning becomes “The process of choosing beforehand the path to take when one encounters a time of trouble which might result in unpleasant consequences.”

In one fashion or another we all plan for crisis. We “save for a rainy day”. We take out health and life and accident insurance “just in case”. When we hire a babysitter we leave a list of phone numbers by the phone “in case of emergency”. Some stash food, water, flashlights and batteries in their basement “for a weather emergency”. If we’re smart, while living in Wisconsin, we carry a blanket, snacks and candles in our cars during the winter storm season. Most people write a Last Will and Testament spelling out their final wishes for their property and children. We want to make sure our wishes are followed. After all we don’t want a stranger deciding who gets grandma’s silver or more importantly, who will be caring for our children after we’re gone. As much as we are able we want to be in control of what happens to our families or our possessions when we are no longer around.

Planning ahead is a good thing, a very wise thing to do! In fact, some would consider it shortsighted if not even foolish to fail to plan ahead for emergencies.

For the past five years La Crosse County Human Services has been operating a Crisis Intervention Program designed to intervene in situations where La Crosse County residents are experiencing a “mental health crisis”. Much of the time, these crises involve people who for various reasons, want to hurt themselves or end their lives. For some it involves being out of control behaviorally. Still others might be having difficulty thinking clearly, rationally. In all cases our interventions are meant to prevent, or at the least attempt to minimize the unpleasant consequences of the particular crisis.

Often a crisis is unforeseen. We cannot always predict the loss of a loved one, or the serious depression it might induce. Postpartum depression is another example of a crisis not easily predicted. For these unforeseen kinds of crises we must simply respond in the here and now, doing the best we can to resolve the situation.

Many times however, we are able to predict that a crisis is likely to occur. For example, if we know an individual suffers from depression and has recently lost a loved one, we can be reasonably sure that their depression may become more pronounced during their time of grief. Or, perhaps a child has autism and we know that changes in their environment cause them great distress. We can reasonably predict that changing the classroom teacher may result in behavior management problems. For the victim of abuse who has a pattern of self-injurious behavior, we can predict that during times of greater stress, their self-injurious behaviors may increase.



Because we can predict the likelihood of crisis, for all of these individuals we can plan ahead to minimize the impact of their crisis situations when they do occur. For the depressed individual, we can intensify their support system possibly preventing another hospitalization. For the autistic child we can ease their transitions, or introduce them to new staff gradually and possibly prevent a behavioral outburst leading to use of physical restraints. For the abuse survivor, we can choose to not over react to their behaviors, and provide additional supervision or other safety measures during their stressful times, again preventing serious injury or an unnecessary hospitalization.

In many situations, the process of planning ahead for a crisis can actually prevent a crisis from occurring in the first place. Take for example the autistic child we have been discussing. The child has had several behavioral outbursts that are difficult for the teachers to manage. During the process of writing his crisis plan it is discovered that these behavioral outbursts occur every time his schedule is abruptly changed.

“In the News”

It then becomes apparent to his teachers that if they either avoid changes in the schedule or give him a series of advanced warnings about the upcoming changes, then the child may not react so negatively. The teachers might even choose to implement a new behavior plan to gradually increase his tolerance for change by shaping his behavior with small, incremental changes to his daily routine. In the process of planning for the crisis, the staff choose to make certain changes in the child's environment, that will ultimately prevent behavioral outbursts in the future.

I have worked with a number of children who have engaged in self-injurious behaviors. Initially those around them have often considered the act of cutting a crisis situation which then resulted in a trip to the emergency room and a Chapter 51 detention. During the process of crisis planning it was determined that the “cutting” was not suicidal in nature or life threatening. Rather it was seen as more of a coping strategy used by the individuals to relieve their emotional distress. So the “crisis” of cutting ceased being seen as a “crisis” and became more of an opportunity for teaching different coping strategies. (Obviously, the client's medical needs must always be evaluated and attended to. But the unpleasant consequence of hospitalization under a Chapter 51 detention can be avoided in some cases.)

Planning ahead for crisis situations also helps to ensure more positive outcomes. If all parties involved know what to do, who to call, where to go, when a crisis actually occurs they tend to remain more calm and rational. Panic does not set in. The person in crisis gets the assistance they need, and those around them don't over or under react to make the situation worse.

If the individual has been involved in the crisis planning process, it is more likely that the treatment team will discover more effective strategies in dealing with the crisis. We ask individuals what works for them and what doesn't. It does little good to advise an upset teen to write her thoughts in a journal if that isn't something she finds helpful. I have known individuals who have advised staff never to touch them when they are “steaming”. Many of us helpers want to comfort, touch, put an arm around someone who is upset, but sometimes it is the worst thing we could do for that person. If we know what is helpful and we do what is helpful, we will most likely experience a more positive intervention. At the very least we will avoid causing more harm.

Planning ahead for crisis intervention is a process. Our crisis program uses a two page form that covers a number of areas. We gather demographic information, emergency contact names and numbers, resource persons, and medical and mental health provider information. But more importantly, we explore what works and what doesn't work and what personal strengths the individual possesses that can assist them in coping with their crisis situation. We then formulate a step by step plan of action to be implemented when a crisis occurs. Everyone involved with the individual on a regular basis is given access to the crisis plan. Our Mobile Crisis Intervention Program has made it possible for our crisis responders to have access to plans as well, so that they are able to respond appropriately when called out.

If you or a loved one have special needs that might predictably lead to crisis situations, I would like to encourage you to PLAN AHEAD! It is the best way to ensure a more positive outcome for you when a crisis does occur. Take the time to plan carefully. **If you would like assistance please contact your social worker or the La Crosse County Crisis Intervention Team at 784-HELP.** We will be glad to help!

WANTED: Caring, compassionate, consistent individuals and/or families to provide Emergency Respite in own home for children experiencing a crisis. Candidates must be willing to be certified under HFS 34 as crisis responders. This involves obtaining training in crisis intervention skills, Chapter 51 mental health commitments, Ch.55 protective placements, Ch. 48 child protective services and Ch. 938 delinquency policies and procedures. Position involves working collaboratively with crisis intervention staff, children, and parents in crisis situations. For further information, please contact Eleanor Shaffar MA at 789-4857 weekdays.



Family Matters
Attn: Kari Flicek

La Crosse County Human Services
300 4th St. N.
La Crosse, WI 54601

Coulee Coalition for Children of Differing Abilities



Be a part of an exciting new coalition in La Crosse County! The Coulee Coalition for Children of Differing Abilities seeks to identify the unique challenges of children with special needs and their families. We promote access to community resources, supports and services through collaboration and advocacy. We do this through a strong emphasis on family involvement. We feel it is important that no matter what avenue a family takes to seek help for their child, they have a complete array of strength based and family focused programs to help support that child and, in turn, the family. Our coalition has identified several areas of support and concern and formed several subcommittees to meet the needs of families and professionals

working with families. **We usually meet the 4th Monday of every month from 12:00-2:00pm at the La Crosse County Administration Building, 400 N. 4th Street, La Crosse, WI in the basement auditorium (B190). If you would like to join or would like more information call Kristine Buehler at 785-6225. Hope to hear from you!**

<http://www.co.la-crosse.wi.us/humanservices/fc/docs/specialneeds/coalition.htm>

Monies donated to the coalition go towards efforts to support families who have children with differing abilities.

Please cut out and return this form to...

Independent Living Resources
Attn: Michelle Olson
4439 Mormon Coulee Road
La Crosse, WI 54601

Yes, I am interested in making a tax-deductible donation to the coalition!

Name _____

Address _____

Telephone _____

Amount: \$10 \$20 \$50 Other

Check here to have receipt mailed to you