



ASW MONTHLY UPDATE

PO BOX 165, TWO RIVERS, WI 54241

TOLL FREE 1-888-4AUTISM; 920-553-0278

e-mail: asw@asw4autism.org website: www.asw4autism.org

MARCH, 2007

Jane Pribek, Executive Director

Chris Behnke, Administrative Assistant

The Autism Society of Wisconsin's mission is to promote lifelong opportunities for persons within the autism spectrum, and their families, to be fully included, participating members of their communities through information and referral, advocacy, public awareness, and education and support for local Autism Society of America chapters, professionals and others who support individuals with autism in Wisconsin.

Please feel free to contact the Autism Society of Wisconsin or any local chapter if you have questions or concerns regarding autism spectrum disorders and/or your child.

UPDATES FROM AUTISM SOCIETY OF WISCONSIN LOCAL CHAPTERS

Autism Society of Wisconsin (ASW)

Registration materials for our 2007 Annual Conference are available on our website, www.asw4autism.org. This conference would be a good opportunity for you to learn about autism spectrum disorders, and to meet many others families who have children with an autism spectrum disorder. Some local chapters offer scholarships for parents to attend the conference. Local chapter contact information is listed below. You can also call the ASW office for assistance.

Autism Society of the Fox Valley (ASFV): If you are interested in being on the ASFV mailing list, please contact Kathy Lett at kathy_Lett@hotmail.com or phone her at (920) 582-4724.

Saturday, March 3, from 2-4 pm, Monthly Gym Kids for ASFV Members (free) or \$5 per family for non-members. Contact Steve Brennan for more info.

Monthly Workshop - **Tuesday, March 6**, Kara Van Vooren from WI Facets is doing a presentation on IDEA 2004 at the Goodwill Community Center, 1800 Midway Rd, Menasha from 6-8 pm. Contact Kelly Brodhagen at kjbrod@new.rr.com

Sunday, March 11, 2007 Parent Support Group Meeting, Gullivers Restaurant, Neenah. Contact Kathy Lett for more information or to be added to the email list at kathy_lett@hotmail.com

Tuesday, March 27, ASFV Board Meeting, Goodwill Community Center, 1800 Midway Rd., Menasha from 6-8 pm

For more information on any of the above events, contact Kelly Brodhagen at 920-832-1111.



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Autism Society of Greater Madison (ASGM): ASGM holds Family Support Group meetings on the third Tuesday of every other month (January, March, May, July, September, November). Free childcare is provided during the Support Group. We also have quarterly Autism 101 classes for families of newly diagnosed children. All of our meetings are free and open to the public. Free childcare is provided. ([pre-registration for childcare required](#)).

ASGM is offering limited scholarships, based on need, for those parents, educators and people on the ASD spectrum who live within our service area to attend the Autism Society of Wisconsin Annual Conference. Scholarship applications and details are available on our website, <http://www.autismmadison.org/scholarships/>

March 10:

ASGM Quarterly Birthday Parties at Pump It Up

Join us at [Pump It Up: The Inflatable Party Zone](#) for an autism-friendly birthday party 4 times in 2007! Kids of all ages will love ...Bouncing ...Sliding ... Climbing and ...Tumbling on Pump It Up's giant inflatable play areas. Would you like your child(ren) with autism to receive a birthday party invitation? Please give contact information when you register your child(ren) and we will send a personal invitation to attend that party. If your child has a birthday that falls within the quarter of the party, s/he will be one of the children who will be celebrated. Just let us know when you register. More information at <http://autismmadison.org/pumpitup.htm>

March 20

ASGM PARENT SUPPORT GROUP meets **from 7:00pm-9:00pm** in Fellowship Hall at Midvale Community Lutheran Church, 4329 Tokay Blvd, (corner of Midvale and Tokay) Madison. Sorry, there is no childcare available onsite. For information call (608) 213-8519 or email autismmadison@gmail.com.

Autism Society of Northeast Wisconsin (ASNEW): ASNEW meets the third Tuesday of the month at the CP Center in Green Bay 2801 S Webster Ave. Call (920)497-1212 for more details.

ASNEW is having a movie party at the DePere Cinema on **Saturday, March 10th at 11 AM**. We're renting out the theater, so bring your whole family. \$3 per person. Contact Vicki Hunt for details dhunt@new.rr.com



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Autism Society of the Lakeshore (ASL): ASL meets the third Thursday of the month at St. Paul's United Methodist Church, 411 Reed Ave., Manitowoc, at 7:00 PM. For more information, call (920) 683-9381.

Chippewa Valley Autism Society (CVAS): CVAS can be reached at (715) 836-9507.

Central Wisconsin Autism Society (CWAS): CWAS meets the first Thursday of each month. They coincide with the school calendar year, taking July and August off. They meet at St. Mark's Lutheran Church, 600 Stevens Drive, Wausau, at 6:30 PM. Meetings are varied, between family support, speakers and business meetings. CWAS can be reached at (715) 845-5524.

CWAS will feature Neuropsychologist's Dr. Michael Wolff and Dr. Rochelle Manor from Grand Rapids, Michigan at our **Thursday, March 1st** meeting at St. Mark's Lutheran Church, 600 Stevens Dr., Wausau at **6:30 PM**. They will address sexual issues related to individual with ASD with their presentations titled: "Helping Adolescents Understand Their Sexual Selves" and "How to Help Adolescents Learn Appropriate Social Behaviors in a Sexually Charged World".

Autism Society of Southeastern Wisconsin (ASSEW):

Autism Society of Southeastern Wisconsin (ASSEW)

9733 W St Martins Road, Franklin, WI 53132

For information on our events, call our office at 414-427-9345 or see our website: www.assew.org

Autism Society of Southeastern Wisconsin

www.assew.org or 414-427-9345

March 2007

Thursday, March 1, 9:30 to 11:30 am, ASSEW office - Morning Coffee support group. Come for a relaxed sharing time with other parents who have "been there." Refreshments provided. Free and open to the public

Saturday, March 10, 9:30 - 11:30 am, Nicolet High School, Glendale.

Parenting Series - Conflict Resolution and Mediation, Presented by Nissan Bar-Lev and Jan Serak
Free and open to the public

Tuesday, March 13th, 6:30 to 8:00 PM - Library Night.



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Saturday, March 17th, Autism Ball, Wisconsin Club. \$75 per person. This is our major fundraiser of the year. Dinner, dancing, silent auction.

Wednesday, March 21st, 6:30 to 8:00 PM - Adults on the Spectrum. Support group for adults 18 and over at the ASSEW office.

Monday, March 26th, 7PM to 9PM ASSEW Board meeting at the Office. All members are welcome.

TWO NEW AUTISM SUPPORT GROUPS:

The La Crosse Area Autism Support Group had its first meeting Wednesday, January 24th, at the La Crosse South Side Neighborhood Center, 1300 6th Street South in La Crosse. This support group will be open to anyone interested in the opportunity to meet and share insight, questions, feelings, and concerns regarding autism spectrum disorders. There is no fee to attend. To be added to the e-mail/snail mail list, contact Steven or Rena Cash at lax-autismgroup@charter.net or 608-519-0883.

Pierce County Area Autism Support Group had its meeting Thursday, January 18th, at English Lutheran Church, 229 West Main Street, Ellsworth, WI 54011. They also have a new group on Yahoo groups for anyone interested in participating from Pierce County or the surrounding area. The link is <http://groups.yahoo.com/group/piercecountyautismsupport>. Anyone is welcome to join! For more information, contact Katie Knutson at knubell@sbcglobal.net or 715-273-4548.

UPDATES FROM WISCONSIN IN-HOME TREATMENT PROVIDERS:

Beyond Boundaries of Autism - Serving in 23 Wisconsin Counties.

Beyond Boundaries of Autism wants to celebrate the state of Wisconsin for the wonderful services enjoyed by our Autism Community, which are only available in 2 or 3 other states. We recognize that we are fortunate, but that it is also through the efforts of families like yours that this opportunity was created, through their advocacy. Unfortunately, the need for advocacy and communicating to your legislators is not just a one time endeavor. It is up to families who need the services to keep in contact with Legislators to celebrate what is valued and spotlight what could be better.



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At the time of the writing of this article for all of you, we are awaiting the Governor's Budget Speech to hear if there will be any specifics regarding covering the cost of autism services. On Feb. 9th, Governor Doyle announced his intention to mandate that insurance companies must cover autism care. The impact of focusing on the insurance companies as a possible way to address the waiting list or offset state costs is not really clear. The Governor's intent is stated as addressing the issue in the following ways:

Most children participating in the children's waivers have private insurance coverage through their parent's insurance. If this provision passes as a component of the 07-09 biennial budget, it would be a way to address the speed of the waiting list for intensive treatment as it would draw in private insurance coverage for the most costly aspect of intensive in-home services (lead and senior therapists), thus permitting the next child on the waiting list to move forward. It would also be beneficial to older children in ongoing waiver services as the consultation and intervention that may be needed would be covered by private insurance and could compliment waiver services. The upcoming budget is an agenda item for our February 19th meeting, so I'm certain we will want to discuss this further at that time.

It is a positive point that the Governor recognizes that the length of time that children spend waiting for services needs to be addressed; however, it is also important that the council and the Governor's office hear your ideas, concerns and stories about how the waiting process has impacted your families.

We would welcome the opportunity to hear from you via e-mail to be able to compile your questions or stories. Please e-mail vhazell_bba@gwicc.org your questions or stories. We also want to remind each of you that the Governor has created the autism council to receive input from not just the council members but also from each of you.

All Council meetings are open to the public. The first half hour of each agenda is available for public comment. Anyone wishing to comment must appear in person and register at least 15 minutes prior to the meeting. (The Council will **attempt** to accommodate speakers who are not able to attend until later in the day.) Each speaker will have up to 3 minutes for their comments, regardless of whether they are speaking as an Individual or representing a Group. Email questions can be sent to vhazell_bba@gwicc.org



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NEXT MEETING

May 21, 2007

10:00 AM to 3:00 PM

Meetings are held in the State Office Building at 1 W. Wilson St. Madison

If you have questions about this Council, please contact Sandy Blakeney at 608-261-7651 or by e-mail at blakesn@dhfs.state.wi.us.

Or visit the website at <http://dhfs.wisconsin.gov/bdds/clts/autism/council>

IDS "While You Wait" Services

Waiting for funding does not have to mean waiting for services. If you are wondering what you can be doing while you wait for intensive services to begin, consider our *Family Foundations - While You Wait* program. Our specially trained consultants equip parents with knowledge and strategies to support children's communication, relationships, and cognitive growth. Build a strong foundation for your child's development, and for a more successful intensive therapy experience, regardless of the intensive program you plan to use. Contact IDS Intake Coordinator Sam Garlock at (608) 441-0123 for more information.

ICC FREE MONTHLY PARENT SEMINARS

2 Events for ICC in March

March 19, 2007: What is "Typical" Speech Development?

Presented by Leslie Theys & Brenda Vicen ICC Speech Pathologists

This session will focus on speech and language milestones from birth to age 5 and focus on strategies that can encourage interaction and development.

WHO SHOULD COME?

Immediate Family Members, Extended Family Members, Community Members,
Support Staff

WHERE?

Imagine a Child's Capacity
14 Ellis Potter Court, Suite 200
Madison, WI 53711

TIME?

6:00-8:00pm Refreshments will be served
Space is limited, please reserve your seats today
(608) 204-6242 or mvignali@icc-wi.org



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And as always, we have our ALL-STAR Saturday ON THE LAST SATURDAY OF THE MONTH. It will be a movie experience designed to be enjoyed by all!

Saturday March 31st, 2007

Doors open at 9:00am, Show starts at 9:30am

Star Cinema, Madison / Fitchburg, 6091 McKee Rd - Hwy PD

\$5.75 a ticket

(Cash only, no passes accepted)

Featuring:

Lower movie volume, Higher theatre lights, "Break area" available, Accepting and Inviting atmosphere

This months movies **TO BE ANNOUNCED**

Seats are limited:

Please reserve your seats today by calling 204-6246 ex. 62

or e-mailing shammer@icc-wi.org.

Portions of proceeds will go to benefit ICC to continue to make events like this possible.

CESA #7 ON-LINE DISCUSSION

Join CESA #7's On-Line Discussions. The purpose of the "Online Discussions in Special Education" is to provide a platform for parents and school staff to share information, support and expertise in all disability areas. The Online discussion topics change monthly and each month the group is moderated by an autism consultant with expertise in the area of autism spectrum disorders.

There is no cost for this service. You can join the discussion at

<http://www.cesa7.k12.wi.us/sped/chatroom/index.htm>.

Family Voices of Wisconsin is pleased to offer a menu of training opportunities for providers and families on health care and community resources for children and youth with special health care needs and can customize trainings to meet specific learning goals. Our "Did You Know? Now You Know!" training, held in communities throughout the state, offers a comprehensive overview of Wisconsin's health and community support systems for children and youth. For more information,



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please contact Liz Hecht (liz@fvofwi.org) or Barbara Katz (barb@fvofwi.org). Family Voices of Wisconsin, P.O. Box 55029, Madison, WI 53705

Family Respite Care Services, Inc in Janesville, WI serves families that have a child or children with developmental disabilities, mental illness, and/or special health care needs in Rock County. Most families we serve are on a waiting list for funding from programs such as Family Support. We provide four core programs: Respitivity, Respite, Sib's Day Camp (open to kids grades K-12 from within and outside of Rock County), and The Respite Registry (open primarily to Rock County, but may be helpful to parents outside of Rock County). We also have the Reye Jean Timmer Memorial Fund, which is a statewide fund available to families across the state of Wisconsin. To find out more about Family Respite Care Services, please call us 608-758-0956 or check out our website at www.rockcountypressite.org



Advocates: Qualities to Look for and Choosing the Correct One for YOU

Contributed by [Kim Davis](#)

How does this pertain to families who have a son or daughter with a disability? Many times the systems in which families find themselves (e.g., early intervention, school, adult agency) can be overwhelming and confusing. Add increased emotions to the mix, and it is often hard for family members to think clearly and rationally in the heat of a meeting in which they are asked to make crucial life decisions. To make those meetings and situations more manageable and less overwhelming, an advocate may be "employed" to assist, encourage, or educate a family in understanding the ramifications of their decisions. The right advocate at the right moment can have a lasting impact on everyone involved, including the family, the staff of professionals supporting the individual with disabilities, and ultimately, the individual with the disability. That impact can be positive or negative. An advocate is not a person to simply choose without thought and discussion. The wrong advocate can have a serious impact on the relationship between the family and agency. That relationship may likely be longer lasting than the relationship the family may have with the advocate!! Just as finding the right doctor, teacher, or therapist takes time and investigation, so too should obtaining an advocate.



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What is an advocate and what do they do?

According to the dictionary, advocate means “to speak in favor of, one who supports a cause, or one who speaks in another’s behalf” (Webster’s New College Dictionary, 1999). There are several roles or functions that an advocate may play in supporting a child with a disability and his or her family. They may include:

- Listening to all parties in a believing and nonjudgmental manner;
- Clarifying issues;
- Suggesting options;
- Documenting;
- Locating and providing information;
- Modeling appropriate behaviors and boundaries;
- Speaking on the parent/child’s behalf when they cannot speak for themselves;
- Helping the family with written correspondence or phone calls;
- Attending meetings;
- Problem solving;
- Educating families;
- Assisting parents in locating other supports; and
- Following up.

The advocate is NOT a therapist, a lawyer, or the primary decision maker (IN-Source correspondence, December 2005).

Why would one obtain an advocate?

As suggested by the list of functions an advocate may play, a family might consider working with an advocate when they feel overwhelmed with the amount and type of information they are receiving, if they need assistance in correspondence or locating additional supports, and/or if they need help with problem solving when issues are challenging and it becomes hard to maintain emotions while attending meetings. Clearly, an advocate can become an invaluable asset to a family and a child with a disability. At the same time, an advocate can also become a detriment or disadvantage unless the family is careful and thoughtful in choosing their advocate and maintaining their services.

Choosing an advocate

Since an advocate has the ability to become an integral part of a child’s educational team, it is vital for the family to do research prior to obtaining an advocate. Simply because someone calls him or herself an advocate, does not mean he or she always represents the family and child in the best possible manner. Research can assist in finding the right person who ultimately can help or hinder the future of your child. Consider the following information seeking guidelines:



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What type of training in special education and school systems has this person received?

Training is available to advocates. It would be useful to find out what training the potential advocate has received. What topics were covered that would make someone an advocate? What skills were stressed? Skills such as communication, collaboration, presentation, and maintaining a professional relationship are important skills needed by anyone who is an advocate. When and where were the trainings and how long were they? How frequently does the advocate attend trainings? They should have current information and a good knowledge of special education in general as well as special education law. Care must be taken to ensure that their information is current and accurate. Practical experience such as attending IEP meetings or case conference participation should also be expected. Remember, knowledge alone does not make an effective and good advocate, interpersonal skills are essential in order to create and maintain a good working, collaborative relationship.

How long has this person been involved in advocacy?

When did he or she become an advocate? If the person has been involved for a long time they may have established relationships with certain school districts; this can be good or bad depending upon the advocates approach. There are advantages to being an advocate for a long time such as getting to know the systems as well as people within the systems. However, reputations can be positive or negative. Someone who is new to being an advocate will not have a reputation that can either tarnish or enhance their usefulness, but he or she can bring along the current training and knowledge that is needed.

Does this person understand YOUR child and your child's needs?

It is important for any advocate to get to know YOUR child and YOUR child's needs and not compare your child to another. Even children who have the same or similar diagnosis deserve to be treated as individuals. It may be wise to have the advocate meet your child and spend some time together before any conferences. In that way, the advocate can better assist you in tailoring your requests to the unique needs of your child. There are no recipes or simple methods that can be used with every child. Each situation is different and requires open minds to come up with solutions for the distinguishing features of your child. The advocate should be able to explain how your child's disability may impact their learning and then work with you to help prioritize your child's needs. Each child is an individual and therefore, deserves to be considered as an individual and not as a part of a group who share a label.



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Will this person be sensitive to the fact that YOU have the ultimate final decision making power?

An advocate can offer options for different situations but must respect you to make the final decision. An advocate who interjects too much personal preference is overstepping his or her role. Ultimately, decisions are for the parents to make when given options. An advocate knows and expects this. The parent makes the final decision, not the advocate.

Can this person be objective? What evidence is there of this fact?

Having an open mind is an asset for everyone participating in meetings that discuss the future of a child. There are many options. An advocate should not be influenced by personal experiences or relationships with a school system that would impact his or her emotions and reason. This is not about them and their history, but it is about YOUR child.

If there is a history and the advocate cannot be objective, it may not be a good match for you and your child. (See appendix for IN-Source contact information.)

Can this person maintain a professional demeanor?

Professional demeanor may be hard to define in exact terms, but most of us would think of words such as respectful, courteous, competent, open-minded, or considerate as part of the definition. An advocate should embody all of those traits when supporting you and your child. Once again, it would be imperative for the advocate to separate “personal” from “professional” issues when working with you, in order to keep your child’s best interest foremost and not their personal agenda. If an advocate performs in an un-professional manner, it can do more harm than good for your relationship with the school and, ultimately, for your child.

Does this person seek win-win solutions?

When an advocate is utilized, there is usually a perceived need on the part of the family for additional support in understanding systems or working with the school to create an acceptable program. Can your advocate work collaboratively to achieve a win—win solution that supports your child, but does not put the school in a financial or personnel strain? While you may want “everything” for your child, every other parent who has a child in special education does too. It is impossible for any school district to give “everything” to every child.

Does the advocate recognize the limits of the system, as well as the limits of the family, or ask questions that would lead to a mutual satisfactory solution? Does the advocate work to avoid the “us/them” situation which only creates tension and ill will? That is a more collaborative and reasonable way to achieve a desired goal. Suggesting the tabling of a toxic issue until more information can be generated and gathered may prove to be more helpful than pushing forward



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when an issue becomes questionable. Ultimately over time, working collaboratively will garner more for your child and your family.

Does this person understand his/her professional limits?

An advocate is not an attorney. An advocate should know when to stop, because their role has started to switch from being a support person to someone giving legal advice. Then it is time to suggest an attorney. Most advocates should have an attorney who they are familiar with and who they can recommend to families.

What references are available and what is the reputation of this advocate?

Just as families would seek references and reputation information for medical or other personnel, seeking information about an advocate is wise. Simply because someone calls him or herself an advocate, does not mean they are qualified.

You may want to seek information from other families and the school districts where the advocate has been working. Questions to ask may be: How many meetings has the advocate attended and how did they work in those meetings; collaboratively or as an adversary? Do schools see the advocate as someone who complains, always finds an issue because the schools are out to “get” students with disabilities, generates undue stress, and threatens lawsuits? Do families feel comfortable with the demeanor and manner in which the advocate “represents” them to the school? Do families and schools see the advocate as someone who is open-minded and willing to negotiate or someone who has an agenda in each instance? Careful consideration of the choice of an advocate can make or break the relationship between the school and your family.

Can this person help you build and maintain a good, trusting, positive relationship for YOU with your child's school?

Your child will be in his or her school daily for many years to come. Teachers and staff talk to one another and share their insights and feelings, just as families do. Teachers want to do what is best for all of the students they serve. But, a strained relationship can “drain” their physical and emotional resources and thus impact the type of care and services a student receives. A fear-based relationship may not be the best way to achieve the goals set forth for a child! This happens not because teachers/staff are bad people, but because they are human and the added stress and tension can adversely affect their work with a child. It is not intentional, but it can happen.

As in life, an advocate should help you achieve a positive relationship with your child's school. The saying, “you can get more with sugar than you can with vinegar” holds true in so many ways. If you work with the school, realize their limits and try to collaborate with them for the good of your child, you will achieve more in the long run than if you make unreasonable demands simply because an advocate says to do it. When we have positive and healthy relationships in our lives, we are more



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apt to get things accomplished and done for us because others genuinely care about our welfare and that of our child and family.

We need to have positive, strong, and nurturing relationships all of our lives to assist us in meeting our needs and those of our children. Without strong and positive relationships, achieving our goals may be challenging. The future of your child is in your ability to choose your battles wisely, understand constraints, and seek ways to "add a little sugar" to the relationships you create. Let's make this relationship work to your child's advantage.

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Advocacy information page from The Advocacy Learning Center (TALC). Retrieved December, 2005 from <http://pages.zdnet.com/ourorhskids/id29.html>.

Bollero, J.L. Esq. (n.d.). *Before you retain a lay advocate*. Retrieved December 2005 from www.wrightslaw.com.

Contact information for IN*SOURCE: 809 North Michigan Street, South Bend, IN 46601-1036. You can also contact IN*SOURCE via phone at 1-574-234-7101, toll free at 1-800-332-4433, or by fax at 1-574-234-7279.

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