

Weap: The People

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Welcome to Hope

Jodie Zemp, M.S.W.

Madison, Intake Coordinator, Wisconsin Early Autism Project



As Intake Coordinator at the Madison clinic since May of 2008, I help families begin their journey with us. Although this transition can be a little scary for them, it is ultimately a very exciting and rewarding time. I'm so grateful for the opportunity to be there on the ground floor of their child's time with us and to help soothe any trepidations there may be. I thought I could lay out a little more about the process and my feelings about it for those already in the program and those who haven't joined us yet.

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www.wiautism.com

UPDATE: Autism Insurance Bills

Nissan Bar-Lev and Amy Masek

Co-Chairs, Wisconsin Autism Insurance Now

We are off to a very positive start to the 2009 legislative session!

The Assembly and Senate both held hearings in February on the Autism Insurance Bills, Senate Bill 3 and Assembly Bill 15. Families and advocates from all over the state attended and gave hours of testimony in support of the bills. We would like to thank every person who attended a hearing, gave testimony, wrote letters or emails, or called in support of these bills during the rush of the hearings.

The Senate Committee on Public Health voted unanimously in favor of the amended version of Senate Bill 3. We are still awaiting a vote from the Assembly Committee on Insurance. A vote was scheduled for March 12 but was postponed due to some committee concerns. We are working with committee members on these concerns and will keep everyone informed as more information about a rescheduled vote and "next steps" become available.

In addition to the action on SB 3 and AB 15, Representative Newcomer has introduced AB 141 in response to our initiative. We have analyzed this proposal and, while we support any and all efforts to help families with autism, we do not support it as a substitute for the autism insurance mandate. Instead, we view this proposal as an effort to derail the progress of the autism insurance mandate (SB 3/AB 15) which provides a long term solution to a growing problem. You can access our position on AB 141 at <http://www.autisminsurancenow.org/>.

The amended Senate Bill has received the endorsement of Autism Speaks, an organization that is supporting legislation for autism insurance bills nationwide. We also have support from Wisconsin DHFS, DPI and many other organizations. Thanks, again, to everyone for their ongoing support and especially to those who have spent time traveling to the Capitol for the hearings. Your efforts are appreciated and matter so much more than you know.♦

Our company went through a big change with the introduction of the waiver slot process. The amount of waiver slots that the state gives out is not static, is never guaranteed and can change at any time. The state is now awarding 11 slots a week for all of Wisconsin. We are seeing the wait list speed up to about 1 year from when a child is placed on the list. We have also seen the application process slow down so even though the wait list time has decreased the application process has been taking families longer, anywhere from 1-4 months before they get placed on the wait list. Families often wait 4- 6 months to get an appointment for diagnostic evaluations from a clinician that the state will accept. WEAP-Madison (other clinics may be longer) can usually schedule families in less than a month to 2 months. Some counties can use our diagnostic evaluations alone in the application for the waiver and other counties require families to have an additional report from a psychologist or neurologist who is not a treatment provider.

Previously the state was giving out only 4 slots a week, 16 slots a month, for the state of WI. The wait list was getting really long at that point and we were seeing much older kids coming through, around ages 6-8. Because children are required to be in school full time at age 6 unless there are special circumstances, when we start services at this age it is nearly impossible to get the 35 hours/wk allowed and difficult to meet the minimum requirement of 20 hours a week.

When families first contact me in the intake process, it is a very emotional time. Families may have just received a diagnosis and don't know where to go next. There is a lack of resources out there for families affected by ASD, especially in rural areas. Many times families are relieved to have someone to talk to who is knowledgeable about ASD and familiar with the autism community. One of the main concerns that I hear from families is that their child has a speech & language delay. Parents want their child to develop a form of communication. I see a gap for families after their child is diagnosed. One of the most important aspects of my job as Intake Coordinator is to inform families of what to do next after finding out their child has been diagnosed with ASD to ensure access and efficacy of treatment. Many times families don't get clear direction from professionals and they are on their own to research what treatment options there are for their child. I have spoken with families that are very frustrated with this process. A barrage of terms are thrown at them: intensive in-home programs, gluten-free diets, OT, PT. Families are overwhelmed with what to do.

The good news is that ABA therapy, the most effective intervention for children with ASD, is available

through our program. Many states don't have ABA programs. We have amazing therapists who are devoted to the treatment of children with ASD. Our individualized curriculum is fun, builds skills, and is backed by over 30 years of research.

Other families contact me looking for a diagnostic evaluation. Some families know something is wrong and are looking to get some answers, or have read a book or article about autism that reminded them of their child. Others were referred by a friend or other professionals.

I meet with families after their child has been diagnosed. Parents are devastated and often in shock. They may feel a variety of different emotions. Many times families are experiencing feelings of loss. It is not the loss of their child, but a loss of the dreams and expectations they have for their child as these dreams and expectations may shift to accommodate a child with special needs. A lot of times we get questions like, "is my child higher or lower functioning on the spectrum and how will this disorder affect my child in the future?" Parents want to know the quality of life their child will have.

The evaluation is really a roller coaster of emotions for families in a short period of time. The diagnostic evaluation usually takes about 2 hours and during that time period parents find out:

1. Their child has ASD
2. Treatment for ASD includes intensive in-home therapy where therapists are in your home anywhere from 20 to 40 hours/week.
3. Early intervention is critical to treatment, but neither insurance nor medical assistance will cover treatment, so they will have to wait over 1 year for funding.

The hardest part of my job is telling families that we have effective treatment available for their child, but that they will either have to wait for funding or do the nearly impossible and pay out of pocket. A full program can cost around \$35,000.00 per year.

Hopefully this will all change in the future with the Insurance mandate. I hope to one day soon be able to talk with families about treatment options and be able to simply say, "Here's what is recommended, Let's get started with treatment."

While families wait for their waiver slot to come up, WEAP offers preliminary services such as: outpatient therapy, social skills classes, parent training classes, speech therapy, and modified in-home programs. Since insurance does not cover autism related services, parents must pay for these services but we try to keep the costs as minimal as possible.

After their waiver slot has been approved, the next step is Parent Orientation. Parents are very excited at these introductory events. Calling parents and inviting them to Parent Orientation is one of the best parts of my job. I love being able to tell them that what they've been waiting for has happened and their child can start benefiting from our full program with state funding. It is so rewarding to be able to give that kind of news and to hear the emotion in their voices as they realize that after such a lengthy wait, help is on the way.

It is really great to see families at parent orientation. Many times they come together and are able to share a little bit about their story with others. I see a lot of bonding between them over different life experiences of having a child with ASD. Parents enjoy meeting each other and having that mutual support.

Usually we have anywhere from 3-10 families attend parent orientation. Parents get an overview of what therapy is, what to expect, and what therapy will mean for their family. We also discuss billing procedures and staffing.

WEAP recommends 40 hours per week of therapy based on research by Dr. Sallows and Tammy Graupner (For more information you can find their research article on our website: <http://www.wiautism.com/research.php>). Children must have 20 hours of 1:1 therapy per week in order to maintain eligibility for funding through the state. Because of this we try to get as much availability as we can. Morning and day hours are the easiest hours to staff and the best time for kiddos to learn. Sometimes we have to work around school schedules. There has to be an adult in the home for therapy so sometimes we have to take into consideration parents' work schedule.

We can basically work on anything through therapy, so if parents want to work on morning routines we can certainly schedule line therapy before school or in the morning to target these skills. If kiddos need help with a nightly routine, we can be there at night to work on those things. There are usually 3-4 line therapists on a team and Senior Therapists go out to the home about 4 hours/wk. The Senior Therapist is responsible for running a child's program. They are the family's main go-to person. Among many job duties that Seniors have, they supervise and train line staff, develop programs and treatment plans for the child and run weekly team meetings.

Children may be eligible to receive a total of 35 hours/wk of therapy through the state waiver program. This total is set by the state, not WEAP. Some of these hours go towards supervision, team meetings and

travel time. Usually they can utilize 25-26 hrs/wk of 1:1 therapy.

The County Caseworker helps families apply for funding and determines children's eligibility for services. Caseworkers are invited to progress reviews and workshops. It is up to the Caseworker whether or not they attend. We see varying degrees of involvement from County Caseworkers. They are also involved in the recertification process for services which happens once a year. Every year children have to meet certain criteria to maintain funding. Caseworkers are also involved in the transition between intensive and post-intensive services.

Families can receive up to 3 years of intensive therapy (35 hrs/wk) and can receive post-intensive services. In this phase parents can use funding more flexibly. It doesn't have to be in-home therapy, but if it is, it usually ends up being funding for about 6-7hr/wk of therapy. Every child is different so we can't really say what kind of progress to expect on an individual basis. However our research has shown that about half of the children that go through our program sustain at least average IQ scores when compared to their peers. Common deficits that therapists target include understanding language, communicating with and relating to peers, building age appropriate and symbolic play skills, and increasing conceptual thinking and cognitive skills.

One thing that I notice is that a lot of families are initially concerned with the amount of therapy hours children do, thinking that their child may not be able to handle it. When I talk to families after their child has started, they are amazed at how well their child is doing, how much fun they are having, and how excited they get to have therapy. One family I worked with was doing out of pocket services for about a year and then discontinued services. This family saw a lot of regression and a lot of increased behaviors and non-compliance. They decided to return to WEAP and are starting to see him flourish in therapy once again. There are many gains to experience in working with our kiddos. I had the pleasure of being a line therapist before my job as Intake Coordinator. It was a very rewarding job to be part of something that helps a child build skills that they will use for the rest of their lives. From my experience as a line therapist I know first hand that our program is fun and works for kids. This definitely motivates me in my job to help families gain access to services. More often than not I work with families that have a diagnosis for their child but don't know where to turn next. The most rewarding part of my job now is to help families bridge the gap between having their child diagnosed and giving them the information and resources to access the appropriate services for their child.♦

Summer is Coming!

Wendy Copus

Madison HR Director, Wisconsin Early Autism Project

Due to the flexible scheduling and relevance to many college majors, WEAP employs a large number of college students. Often, students will leave their work area to return home for the summer.

We are currently looking for therapists who will be remaining in their work area during summer and who could work some extra hours during that time. If you would like to pick up extra hours during the summer, and help us in our efforts to maximize our children's hours, please call the Human Resources department in your clinic. Listed below are the people in each clinic that you can contact.

It is also important to note, that any Line Therapist interested in working more hours either temporarily or on a permanent basis, should contact their Human Resources department to arrange for more hours. Senior Therapists cannot make such placements and are not responsible for relaying messages to Human Resources regarding hours on other teams or other employment issues. Your Human Resources Representative is the appropriate

person to talk to about placement and any other questions or concerns you may have regarding your employment with WEAP.

Call your HR department early to line up work for the summer. We look forward to helping you with this.♦

Milwaukee Clinic
150 N. Sunnyslope Road
Suite #100
Milwaukee, WI. 53005
(262) 432-5660
Contact:
Carrie Rose
Lindsey Baker

Green Bay Clinic
1141 W. Main Ave.
Suite #201
De Pere, WI 54115
(920) 338-1610
Contact:
Angela Bartol

Madison Clinic
6402 Odana Rd
Madison, WI 53719
(608) 288-9040
Contact:
Wendy Copus

La Crosse Clinic
1113 Riders Club Road
Onalaska, WI. 54650
(608) 781-6500
Contact:
Karin Wessel



Eau Claire Clinic
2125 Hieghts Dr.
Suite 2F
Eau Claire, WI 54701
(715) 832-2233
Contact:
Karin Wessel

Upcoming Events

Rock for Autism

Rock Concert for Autism. A.N.G.E.L., Inc. Raising awareness & funds for WI. children affected by Autism. Silent Auction, kids raffles, Beatles memorabilia & autism merchandise! Igneous sings 60's, 70's, 80's music at 7pm & Stockwood sings Beatles songs at 9pm. Support a great cause 1 in 150 have autism.

Apr 17

Milwaukee

Doors open at 6pm Concert starts at 7pm

\$10 in advance, \$15 at the door, Children 10 & under \$5

American Serb Hall 5101 Oklahoma Ave.

Cindy Schultz

262-639-3041

angelofautism@hotmail.com

www.angelautismnetwork.org

SEE COMPLETE LISTINGS ON OUR WEBSITE

WWW.WIAUTISM.COM



ASW Annual Conference

Michelle G. Winner, Scott Bellini,
Morton Gernsbacher

May 7-9

Wisconsin Dells

Kalahari Resort & Convention Center

Jane Pribek

920-973-4080

jpribek@asw4autism.org

www.asw4autism.org

The 5th Annual Autism Open Golf Scramble

Join us for a great day of fun and awareness!! We are doing our annual golf outing to raise money for our autism summer program. The Social Summer Experience (SSE) is for kids with ASD entering grades K-6th Enrolling now!!

Jun 6

Waupaca

Foxfire Golf Course

\$75 per person

Autism Matters (Nicole Lannyk)

920-867-2847

info@autismmatterswaupaca.com

www.AutismMattersWaupaca.com

Groups and Classes

Location	Group	Age/Level	Facilitator	Fee	Days	Time	Start Date
Madison	Parent Group	Open to Community	Chris W	\$30/session \$4/child daycare (rgstr 2 wks in advc.)	2 nd Tues ea.Month	4:00- 5:30PM	Ongoing
Madison	Parents/ Caregivers	Open to Community	varies	\$30/session \$4/child daycare (rgstr 2 wks in advc.)	2 nd Tues ea.Month	5:30- 7:00PM	Ongoing
Milwaukee	Play group	Ages 3-5	Stephanie B	\$30/session	Wednesdays	9:00-10:00 AM	Apr 1- May 27
Milwaukee	Social Skills: Problem Solving	Ages 4-6	Stephanie B	\$30/session	Mondays	2:30- 4:00PM	Apr 6- May 4
Milwaukee	Social Skills: Girls' Club	Ages 7-9	Stephanie B	\$30/session	Tuesdays	4:30- 6:00PM	Apr 7- Apr 28
Milwaukee	Social Skills: Boys' Club	Ages 7-9	Stephanie B	\$30/session	Tuesdays	4:30- 6:00PM	May 5- May 26
Milwaukee	Kids' Group	Ages 8-12	Stephanie B	\$30/session	Mondays	4:30- 6:00PM	Mar 30- May 18
La Crosse	Daily Living Skills	Parents & Care Givers	Chris W	FREE	Thursday	5:30- 7:00PM	March 26
La Crosse	PECS	Parents & Care Givers	Chris W	\$5 materials fee	Thursday	5:30- 7:00PM	April 9



Current Openings

GREEN BAY 920-338-1610	MILWAUKEE 262-432-5660	MADISON 608-288-9040	LA CROSSE 608-781-6500	EAU CLAIRE 715-832-2233
Fox Cities Green Bay Luxemburg Sturgeon Bay Wautoma	Brookfield Burlington Cedarburg Ixonia Juneau Mequon Milwaukee Mukwonago Nashotah	Oak Creek Oconomowoc Racine South Milwaukee Watertown Waukesha West Allis	Beaver Dam Dodgeville Janesville Portage Richland Center Sauk City Waunakee	Seneca Wauzeka Colfax Hazelhurst Marshfield Medford Rice Lake Wheeler