

weap: The People

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Wisconsin Early Autism Project, Inc.

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Families are Heard!

Justin Sallows

Wisconsin Early Autism Project



On February 26th, the Wisconsin State Senate voted to ratify SB 178 to force insurance companies in the State of Wisconsin to cover autism therapy by a vote of 25-8.

On February 28th, hundreds of families rallied at the State Capitol building in support of AB 417. This is the mirror of SB 178 which must be approved by the State Assembly before it can become law.

Karen Sauer of *Friends of Autism* donated t-shirts commemorating the event. WEAP personnel handed them out to families as they arrived. We all greatly enjoyed the opportunity to meet and share experiences.

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WEAP Graduate

Justin Sallows

Wisconsin Early Autism Project

During the week of 2/9/08, Dr. Sallows received an email from the mother of a former client named Peter. She wanted to let us know he was about to enter college and was very well adjusted.

I got together with Dr. Sallows and we came up with some questions for Peter. To our delight, he agreed to update us on how he'd been since those early sessions in 1996.

Justin Sallows: First of all, hello Peter! Dr. Sallows was glad to hear you are doing well. I am his son Justin and I write the company newsletter. We certainly appreciate you taking the time to speak with us today.

Your mother wrote us to say how proud she is of you. She says you are planning to attend the University of St. Andrew's in Scotland. Why did you pick that college?

Peter: I chose to go to St. Andrews for a number of reasons. The most important one was that I am British and I wanted to go to University in the UK, not in America. Going to St. Andrews is kind of like going home in a way. Another reason was because St. Andrews is a small town, just like Princeton, where I live now. I thought that this would make the transition between home and University a little bit easier than if I were going to a place in a bigger city. Another reason I wanted to go there was because it has a good Classics department, which is the field which I will be studying. I've been interested in that type of thing for a while, and going to a place which has a good department for that was a major factor in me choosing St. Andrews. The only other reason I can think of is that St. Andrews is a very old University, so it has a lot

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ABA: A Way of Learning

Christine Wilkins

Wisconsin Early Autism Project



ABA or *Applied Behavior Analysis* is a technique used to observe behavior, analyze why behavior is occurring. A plan can then be designed to change undesirable behavior, and/or teach a desirable behavior.

Quite often *Discrete Trial* is used for this. It begins with providing a direction, such as “Do puzzle”. The child will either respond correctly, incorrectly, or not respond at all. The teacher then follows that up with a response that either reinforces a correct behavior or tries to induce a correct behavior. It can be used for teaching colors, prepositions, simple conversation as well as many other things.

Trying to figure out why a child does something can be tricky because adults communicate differently. For example, a child runs up to another child and hits them. At first glance it may seem as though this child is just mean or naughty. Upon further analysis it is discovered that even though this child has excellent language skills, they do not know how to initiate interaction appropriately. At this point an ABA program made up of social stories, video models, and practice with adults can help change this behavior. One to one play dates can be scheduled to practice in a safe, controlled setting. Soon the child will be walking up to other children and joining into play more appropriately. ABA is really about communicating in a way a recipient can understand and benefit from.

I often find myself using ABA at home with my own

family, not just my children either. I found myself nagging my husband all the time because he was not helping around the home. When this was not working I began to use discrete trial. I would ask him one time, add a prompt (visual list), set up a specific time for the task, then upon completing the task I would praise him for finishing the chore and tell him how much I loved that he helped with the chore. The funny thing is that my husband soon figured out what I was doing and realized how well it worked that he began to use the same techniques on me!

Over the years I have spoken with several senior therapists who utilize ABA techniques with their own children at home and find that the techniques work very well. With my own daughter I find myself saying things like, “time for bed.” If by the third time I tell her to get into bed and she isn’t doing it, I prompt her into bed. This gives her the first two times to be successful independently and then by the third time I help her be successful. If she does it on her own she gets big hugs and praise. If I have to help her and she is upset we discuss choices and how we will have a chance to try again next time. Now that she knows I will follow through on a regular basis she is typically successful by herself the first time. Of course then it is on to the next learning experience and checking to see if mom really means what she says.

ABA is not just for autism, but a way of communication and learning.♦

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Amy Masek, Director of Development and Outreach at WEAP took to the podium and introduced a number of speakers. Both Senators and Assembly persons spoke of their interest in this issue and reinforced their support for the bill before the Assembly.

Governor Jim Doyle spoke to the crowd, relaying his experience traveling the state and meeting families with an autistic member. He was proud of Wisconsin being the leader in autism treatment, but acknowledged the limitations of the waiver system. He called on the State Assembly to bring the matter to a vote.

“It’s whether you’re going to side with some insurance companies in the State of Wisconsin, or whether you’re going to side with families that really need some help”.♦

of cool and quirky traditions that are prominent in student life, such as the academic family, the pier walk, the red gown, etc. These traditions fascinated me, and I was really taken with them when I first heard of them. This is why I wanted to go to St. Andrews; it is a good place to be, both for your studies and for social aspects.

JS: Your mother also mentioned that she struggled with how to tell you about your previous diagnosis of autism. Do you have any advice for other parents out there who may be feeling the same way?

P: When my parents first told me that I was autistic when I was young, I was really taken aback, but I never really thought about how difficult it was for them to tell me. All I can say is that my mom and dad just told me about it straight out, and that did seem to work; there was no prelude or anything, it was just the nitty gritty. However, they told me about it when I was 17, and I was diagnosed with autism when I was around 3 or 4, so choosing the right time to tell your child is quite difficult. I reckon that I was told at a good time because I was definitely better at 17 than at 4, so it wasn't as if someone was telling me "you have this NOW", it was like "you USED to have this". My advice is that you have to pick the right moment, when you know you're going to upset your child the least (the news will be upsetting to some, but it can come as a relief to others, as a sort of explanation for the behavior; I can safely say that it came as a relief to me sort of, but I was upset too). Tell the news to them as directly as possible, but some moments might be better than others.

JS: Most people have difficulty remembering things from their childhood, but do you remember therapy at all?

P: I remember going to therapy and a school that would help me get better. I sometimes remember people holding different objects, like a toy sword or boat, and asking me what it was, but apart from that I don't remember much at all. It was a long time ago.

JS: How did you interact with other children in grade school?

P: In elementary school I had good friends whom I could talk to if I had something on my mind; I can say the same about middle school too, but in my first few years of high school I did not have many friends. It was sometimes very difficult to talk to people about

problems because I did not feel as if I knew them all that well, so I could only talk to my family, something that an ordinary teen doesn't really do. It was as if my family had become my personal psychiatrist! Now I do have close friends whom I can talk to, but from the end of middle school to the middle of high school it was quite difficult in that respect. As far as interacting with other people goes, I have always found that challenging, though I've been a bit better at it over the past year or so. I usually just hung around with people and did whatever they were doing, but I never really talked much, only when I was spoken to. Basically, I just stuck with people but kept quiet. I remember in the first few years of high school just wandering around the hallways at break doing nothing at all because I had no one to sit with. It was as if that time went on and on repeating itself, loneliness all the time. This continued outside school as well; sometimes I went to parties or the theatre by myself because I had no one to go with. The situation has now changed greatly, both in school and outside of school, but sometimes I still chill in the library or the Idea's Center by myself during break because I can't find my friends or because they're busy. However, I don't feel bad about this because I know that I'm not an outsider any longer, I do have friends. Overall, though, things have been much better.

JS: Tell me about the time you first felt different from other children. Did you find there were people that could help you with these feelings? Did you come up with ways to feel more like the other children?

P: I first began feeling different from other kids when I was in 5th or 6th grade. This, I think, was mainly due to the fact that my family and I had recently just moved to Princeton the summer before from England. The two cultures are quite different, and this culture clash made me believe that I was different.

In England, I had two good friends at my school and I did not consider myself weird or different. However, halfway through 5th grade I began to notice that I didn't really fit in with most other kids because of my mannerisms, my accent, my "look", basically everything. We had moved many times before, but this one really changed my outlook of myself as a person overall. I didn't seek help about this until the summer before my sophomore year. I remember having a long talk with my parents about it and I went to bed that evening feeling much more assured

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because they said that I had no problems; I was myself and that was fine. However, I kept feeling doubtful and upset over the next year or so, partly due to the fact that I was finding similarities between myself and "troubled" characters in books.

For example, when I read *The Curious Incident of the Dog in the Night Time*, a book about a teen with a disorder similar to Asperger's Syndrome, I was quite freaked out because I could identify with this boy. Was I "different" like this boy? Was I "normal"? Since talking with my family wasn't enough help for me I began seeing a psychologist and I talked with her about the feelings I was having; am I weird or not? Why don't I fit in? She also helped me deal with my feelings when I found out about my autism as a child, which was really helpful.

By the end of my junior year of high school, I had finished seeing the psychologist and I was feeling much better. Over the summer I hung out with new found friends a lot more. Since the beginning of senior year I have been feeling much better on a social level. This all happened because of not only having extremely deep and thoughtful talks with the family and this psychologist, but also making efforts to act like other kids, like having a facebook account (this was the most useful, I think; it really allows people to contact each other without meeting them face to face which, for a autistic/asperger kid, is really difficult), using phrases as "what's up?" instead of "how are you?", giving someone a pound or a high five instead of a handshake, using AIM every now and then, doing stuff which I never really did before. The phrase "following the crowd" is prominent in this day and age as a barrier against being yourself and unique, but I found it useful to become more accepted.

JS: Did you have friends you could spend time with and share how you were feeling?

In my sophomore year, I befriended a girl (whose name I will leave unknown) and I have been very good friends with her ever since. It was hard making friends with her, but I am certainly glad that I did. She is one of my good friends with whom I can truly speak my mind. If she asks me, "what are you thinking of right now?", I will say whatever I'm thinking of, no matter how personal it is. There are no barriers between us. Gradually, I have come to know her friends and become friends with them too, so I am happy to say that I have made a good group of friends whom I can rely on and stick with (it might be worth mentioning here that this group of friends is all girls; not really sure why it's this way, but I can't exactly complain...). However, I have had my share of meeting

people and then just not talking with them anymore because we don't click; it must happen to everyone. It is certainly true that friendships during the teen years are important, and meeting this very good friend of mine has certainly proved that.

JS: I also remember high school to sometimes be very stressful. At times I found myself getting angry at people and situations. How were you able to cope with these feelings?

P: One of my great faults is keeping most of my feelings bottled up (except if it has to do with girls ha ha!). Therefore, if I find myself becoming angry at something, I tend to keep it inside. If I am feeling stressed, however, I usually complain about it to anyone who will listen, which is friends and family most of the time. Usually I find that if I talk with someone about something that is bothering me, it makes me feel better, much better. It is strange, though, that I do not speak my feelings when I am angry (most of the time, that is). I don't know why this happens really. I suppose I think that I can fix it by myself, but when I am stressed I need someone to help me. This pretty much sums it up, I'd say.

JS: Well thanks again Peter for sharing with us. Before we go could you tell us what your hopes and dreams are for the future beyond college?

P: Once I leave University I would love to go to graduate school and get a Ph.D., and then become a classical archaeologist. It would be nice to marry someone and have a family too. Whether this will happen or not though, I can't really say.♦



Upcoming Events

(Courtesy of sarnet.org)

PECS Basic Training

(Formerly called Two-Day PECS Training Workshop) This intense two-day training is designed to teach participants to appropriately implement the Picture Exchange Communication System. It begins with an overview of the Pyramid Approach to Education to explore the key components of designing effective educational environments. A historical overview of language training programs used with non-verbal individuals is discussed.

Apr 21 - Apr 22

Milwaukee

8a-4PM

\$295/Professional - \$195/Parent

Stefanie Levendis

www.pecs.com Slevendis@pecs.com

888-732-7462

Autism Society of Wisconsin Annual Conference

Brenda Smith Myles PhD, Paula Kluth PhD, Dr. Eric Courchesne

May 1 – 3

Green Bay

Varied Fees

Regency Suites / KI Convention Center

Jane Pribek

www.asw4autism.org asw@asw4autism.org

920-553-0278

La Crosse Area Parent Group

Join this vibrant group of parents to discuss topics of interest, create change & find comeraderie. Childcare provided.

Feb 20 Mar 10 Apr 16 La Crosse 3rd Wed

6:30-8:30PM

Free

1825 Victory Street

Steven or Rena Cash

health.groups.yahoo.com/group/AutismFYI-LaCrosse/

lax-autismgroup@charter.net

608-782-6480

Groups and Classes

| Location | Group | Age/Level | Facilitator | Fee | Days | Time | Start Date |
|------------|---------------------|----------------------------------|------------------------------|--|---------------------------------------|-------------|-----------------------|
| Eau Claire | Social Skills | 5-8 YRO | Michelle S Shelly B | \$30/session | Tuesdays | 4:00-5:30PM | Feb 5- Mar 25th |
| La Crosse | Social Skills | 5-8 YRO | Kally Angell John Nicklay | \$30/session | Thursdays | 4:00-5:30PM | Feb 28- April 17th |
| Madison | Sibling Class | Open to Community 8-14 | Chris W Michelle S | \$30 first child, Prorated for additional | 1 st Tues each month | 4:00PM | Feb. 5- June 3 |
| Madison | Parent Group | Open to Community | Chris W | \$30/session \$4/child daycare (register 2 wks in advc.) | 2 nd Tues ea.Month | 4:00-5:30PM | continuing |
| Madison | Teen Group | Open to Community 12 + YRO | Matt N | \$40/session | Thurs E/O Is outing | 4:00-6:00PM | continuing |
| Green Bay | Caregivers Group | Open to Community | C. Van Dyke | \$30/session \$4/child daycare (register 2 wks in advc.) | Mondays | 5:00-6:15PM | Feb 4- May19 |

Current Openings

| GREEN BAY 920-338-1610 | MILWAUKEE 262-432-5660 | MADISON 608-288-9040 | EAU CLAIRE 608-781-6500 | LA CROSSE 608-781-6500 |
|---|---|--|--|--|
| Oneida Clintonville Pembine Manitowoc Sheboygan | Milwaukee Racine Kenosha Milwaukee Waukesha | Pewaukee Mukwonago Muskego New Berlin Juneau | Madison Lake Mills Watertown Monroe Sharon | Somerset Steven's Point Marshfield La Crosse Steven's Point Nekoosa |