



The Autism Connection



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Northwestern Counseling & Support Services' Autism Awareness Newsletter

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**NORTHWESTERN
COUNSELING**
& SUPPORT SERVICES



Completely Inspired By This

By Dana Postemski, MA, BCBA

NCSS, Team Leader of the School Based Autism Program

Note to our readers: Sharing this next article (*Boy with Autism's Birthday Goes Viral*) with Franklin and Grand Isle families seemed valuable so you know: you and your child are not alone in how you feel. In my daily work with families and children, a lot of kids experience this feeling of being alone daily; without friends. Many people with Autism feel they are different and find it hard to make friends. It is important for you to know that others are out there that feel this same way. People can make connections in creative ways to support their child with these same feelings. The following article shows one way a family was creative and tried to help her child with his lonely feelings. It is my hope that other people who feel this same way find each other and make a friend. We should move with the times and get creative in our thinking of social integration for people who feel this way.

Being friends with someone today is very different than it was at one time; people have moved to technology to have or maintain friendships not "let's hang out and go do something." Many adults today spend more time on Facebook than they do sitting with people and socializing. If your idea of socializing is being with others, going to movies etc...maybe we should rethink how we are teaching our kids to socialize as this concept of friendship has morphed a lot in recent times. With technology use from everyone on Facebook, Pinterest, fantasy sports, and shared online video games for example, people are making connections in very different ways. When you go out, observe the interactions around you; for some time now it has been observed while out at dinner everyone around us were



not talking to each other they all were staring into their phones. It has been observed when kids hang out these days they are on their video gadgets, phones, basically doing anything but having a conversation with each other. Things have really changed in terms of social life.

A lot of the people we work with excel with technology; as a professional, parent or a person with Autism, we should be thinking of other ways to help them socialize and feel part of a network or community. It is the 21st century, personal relationships have changed drastically. Maybe this change will help support others with social challenges as technology can aide them to find a social group as other people have found. We should try to think outside the box with helping people find ways to feel needed, worthy and make one friend who shares similar interests. Similar interests in life is what drives people to like each other

Continued on page 2

P2

- Completely Inspired By This (cont.)
- Autism Walk

P3

- Heart of Autism

P4

- Conferences, Workshops & Trainings
- Autism Awareness Day
- Light It Up Blue

P5

- Social media and autism

P6

- Autism Awareness Month
- Camp Rainbow
- More Resources

P8

- NCSS Services and Support
- Inside Our Next Issue

Continued from page 1

and want to share more with each other. Providing tools to make connections via technology can help and may take the 'social pressures/nuances' off the person seeking connections. One idea to try is through use of a chat room with the topic of something that interests them. They may feel they make a connection with others that have the same likes as them. Just making connections in this way may help with feelings of loneliness. For those that technology is not of interest, think of other ways such as having a pen pal, or joining an art class, cooking class, bowling league, or forming a small band with a drummer and a guitarist and have a jam night; help them become involved with something of interest with others that have these similar likes. We should try to help people feel like they are making connections. This effort may go a long way with someone.



Our hearts go out to these children/adults who feel this way and hope we can come together to figure out solutions. Relationships/friendships have changed with time, we can use these changes to help us integrate people with Autism in ways they may aspire to make connections. Think of their strengths and find ways to support them finding their social group, think creatively not traditionally. See what this family did in this article. Maybe it will inspire us to think in different ways to have our children feel wanted and liked by someone. It has been said it takes just one person to make someone feel wanted and special.



Happy Birthday Colin
February 2

I am Colin's mom, I created this page for my amazing, wonderful, challenging son who is about to turn 11 on March 9th. Because of Colin's disabilities, social skills are not easy for him, and he often acts out in school, and the other kids don't like him. So when I asked him if he wanted a party for his birthday, he said there wasn't a point because he has no friends. He eats lunch alone in the office everyday because no one will let him sit with them, and rather than force someone to be unhappy with his presence, he sits alone in the office. So I thought, if I could create a page where people could send him positive thoughts and encouraging words, that would be better than any birthday party. Please join me in making my very original son feel special on his day.

Like · Comment · Share

19,599

Usually it's only a celebrity birthday that goes viral but 10-year-old Colin of Kalamazoo, Mich., has become an online superstar. His mom set up a birthday Facebook page after Colin, who has Asperger syndrome, told her that he didn't want to celebrate because he has no friends. His birthday isn't until March 9 but the messages of congratulations came pouring in on the page, which now has over 1 Million likes. Not only that, Colin has received more than 40,000 birthday cards and letters in the mail from all over the world.

This is Colin's mom's original Facebook message that is making his 11th birthday one to remember!

JOIN US!

In an effort to create a stronger community one person at a time, NCSS, with the help of many volunteers will sponsor northwestern Vermont's first walk to increase awareness and raise funds for Autism Programs at NCSS.

NCSS offers supports and programs for individuals and their families with Autism from early childhood to adult. To learn more about our programming call us at **(802) 524-6554**.

Registration and Pledge Forms are available on our website at

www.ncssinc.org/about-us/calendar/eventAutismWalk or by calling: **(802) 393-6406**.

Autism Walk of Northwestern Vermont



Sunday, May 18, 2014

Collins Perley Sports & Fitness Center, St Albans
at 1:00 pm. Registration begins at 12:30 pm.

Heart of Autism: 13-Year-Old Lights It Up Blue!

a post by Kim Jansen, a teacher in Sherman, Conn.

It was just about three years ago when I met the most amazing 10-year-old boy, who has since changed my life. It was the last day of school, and Josh, a 3rd Grader at the time, stopped by my classroom to introduce himself to me. He wanted to say hello and let me know that he may be in my 4th Grade class the next year. Right away, I knew that there was something special about this little guy. September came, and sure enough, Josh was in my 4th Grade class.



Josh had many ups and downs throughout his education, and was diagnosed with Asperger's Syndrome in the spring of 4th grade. His parents could not have been more supportive of this diagnosis and have done everything possible to teach Josh about his diagnosis, as well as educate others about it. They have made spreading Autism Awareness a huge part of their life. They are the reason so many people in the tiny community in which Josh lives, and goes to school in, know what Autism is. Having parents that are so proactive only made Josh more interested in spreading Autism Awareness too.

Last year, Josh had the opportunity to be "The Assistant Principal For The Day", an opportunity for him to make decisions and plan activities for his school. This day took place in April, during Autism Awareness Month. Josh immediately decided he wanted to plan an activity to promote Autism Awareness while he was the Assistant Principal. Josh was now a 5th Grader, but we still had a very close relationship, so together we planned our school's first "Light It Up Blue Day", which was a huge success. Josh was thrilled with the response from our school and community on "Light It Up Blue Day". We immediately began talking about other activities we could do during April of the following year.

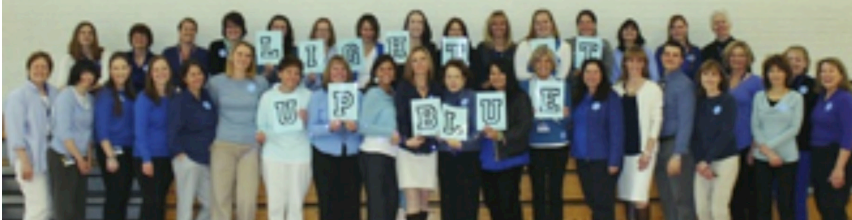
Josh is very passionate about Autism Awareness and had participated in the Greater Waterbury Walk Now for Autism Speaks while he was in 3rd Grade. While working with Josh to organize our Light It Up Blue Day, I joined Josh's Walk Now for Autism Speaks Team. We walked together, in the pouring rain, and began thinking of ways to raise more funds for Autism Research and increase Autism Awareness the following year.

Before we knew it, April was here again, and we were on a mission to spread as much Autism Awareness as possible. We approached our school administrators with several ideas we had for the month. They were very supportive, and so our month began. We started off with "A Light It Up Blue Day". All the students and faculty were decked out in blue, and proudly wore stickers that said, "My School Supports Light It Up Blue Day". It was an amazing day! After that, the month was followed with a school wide "Rise and Shine and Wake Up Autism Awareness Breakfast", a bottle and can drive and a Dunking for Dollars Dunk Tank Fundraiser. It was a very successful month. We managed to raise \$1,800 for Josh's Autism Walk team, but most importantly, every student in our school now has an understanding and awareness of Autism.

It has been a wonderful experience working with Josh to spread Autism Awareness and becoming involved in the Greater Waterbury Walk Now For Autism Speaks. I look forward to working with Josh on this journey for years to come!

The Heart of Autism series highlights individuals with autism giving back to the autism community. Read more about these inspiring people here! If you have an idea for a Heart of Autism story, we would love to hear from you!

Email us at heartofautism@autismspeaks.org.



The teachers at Josh's school Lighting It Up Blue!



Kim Jansen with Josh



Josh cutting the tape with his mom at the Greater Waterbury Walk Now for Autism Speaks!



Josh and his parents

Conferences, Workshops & Trainings:

Vermont Family Network's Annual Conference

at Burlington Hilton

When: Tues. April 1; 8 am - 4:45 pm

Limited parent scholarships are available upon request. Questions? Contact Kathleen Burdo or 1-800-800-4005, x246

Contact Vermont Family Network to Schedule a Workshop: VFN can provide a wide variety of free training opportunities to your group or organization upon request. To request a workshop or to receive more information about the workshops offered, email Janice Sabett, or call 1-800-800-4005 ext. 218.

- Communication
- Health
- Education
- Parent Volunteers
- Transition to Adulthood

See this website for more:

www.vermontfamilynetwork.org/training/workshops

**APRIL 2ND IS
WORLD AUTISM
AWARENESS DAY!**



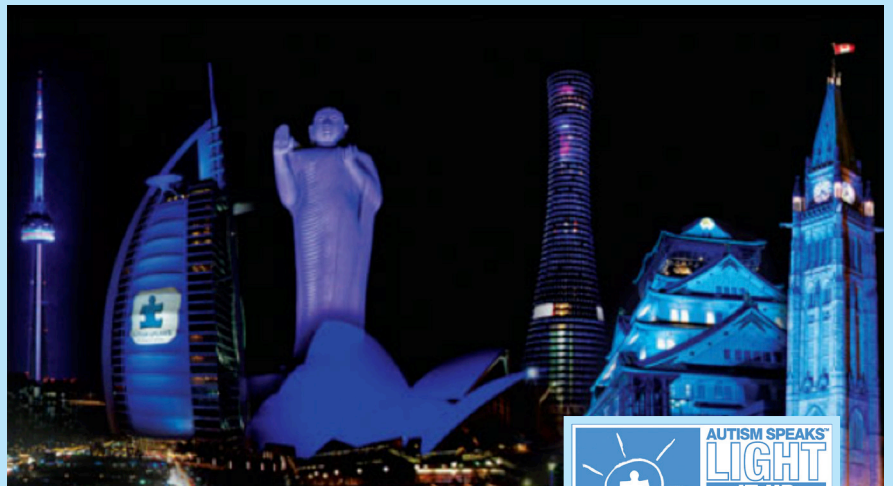
Join Us to Light It Up Blue for World Autism Awareness Day

Each April 2, Autism Speaks celebrates Light It Up Blue along with the international autism community, in commemoration of the United Nations-sanctioned World Autism Awareness Day.

Light It Up Blue is a unique global initiative that kicks-off Autism Awareness Month and helps raise awareness about autism. In honor of this historic day, many iconic landmarks, hotels, sporting venues, concert halls, museums, bridges and retail stores are among the thousands of buildings lit blue to raise autism awareness.

The Light It Up Blue site for 2014 is now available at www.autismspeaks.org/LIUB. Join us on World Autism Awareness Day April 2nd, and throughout April by signing up today!

www.autismspeaks.org/news/news-item/join-us-light-it-blue-world-autism-awareness-day



Social media and autism: A life line

*Autism Unexpected by Jean Winegardner
A life line Sunday, May 30, 2010*

Social media is all the rage these days. Twitter, Facebook, Foursquare, Digg, StumbleUpon, Kirtsy, blogs, and the myriad of other ways that individuals around the world connect online these days have changed the face of the world.

It's easy to make fun of social media. How many ways do you need to broadcast what you are doing right this second? For parents of children with autism and people with autism themselves, however, social media can be a lifesaving conduit to a social world that is too difficult to interact with IRL—in real life. For people like us, social media is real life.

Having a child with autism can be extremely isolating. Friends who don't understand what you're going through or who don't want to be around a difficult child may fall away. It gets harder to take an unpredictable child into public. It can be hard to plan playdates ahead of time if you don't know how your child will be feeling at a specific time in the future.

Activities that typical kids enjoy may be too overstimulating for a child on the spectrum. Sometimes even when your child wants to and is capable of participating in the social sphere, the invites just don't come. Some days it's just too hard to face the stares and judgments of onlookers, so parents end up staying home.

This is where the beauty of social media lies. When there is no one in your life to turn to in the middle of the day (or the middle of the night), Twitter is there. When you have a question about a treatment and you want to know others' experiences, blogs are there. When you just need some adult contact to take your mind off of all that is so difficult, Facebook steps up.

For people on the spectrum themselves, online communication eliminates the pressure to respond immediately in conversation and lets an individual choose what conversations they want to take part in. Web conversation is also more black and white, reducing the need to understand all the non-verbal parts of communication that can be so difficult for those with autism.

I started blogging coincidentally at almost the same time I started to suspect that my son Jack was autistic. I know for a fact that my and Jack's paths would have been radically different without the social media to which my blogging introduced me. Social media helped me get to the accepting, knowledgeable place I am far more quickly than I could have gotten there myself.

There is a lot of division in the autism community—and the autism social media community is no different. Much of what I initially found online terrified me. But more than that, I found people like me. I found women going through exactly what I was going through. Even more

importantly, I found women who were a few steps ahead of me in the autism journey. Not only will you find support for yourself if you put yourself out there, you will often find that you are offering comfort to those who follow you.

There are a tremendous number of autism bloggers who offer comfort, ideas, and practical advice. While I would not recommend taking as gospel anything that you read online in terms of treatment or medical advice, I will say that with a little bit of work you can find a supportive group of parents who can help hold you up.

There have been times that I haven't felt confident in my knowledge about developmental disabilities and have had my tribe of online friends reassure me—and offer me practical advice. There have been times I have felt destroyed by something that happened at my son's school and have had that same community help me hold it together. Some days that happens on my blog, some days it happens on twitter, but regardless, I know that if I need someone who gets—really gets—what I am going through, they are there almost immediately. This is something that is very hard to find in real life.

There are, of course, dangers with publishing so much information online. You have to be careful about your own privacy and that of your child. Many people write anonymously for this very reason. Needless to say, you should assume that anything you write online, even without your name attached, will be found and attributed to you. Just as the best things about social media are its sense of community and interconnectedness, those very things can turn into negatives if you write things you wouldn't say to someone in person.

I try to write as if the person I am writing about is standing behind me, reading over my shoulder. This includes teachers, administrators, and a potential court of law. Understand that if you do take advantage of this incredible online resource, your words are permanently available should you have need to sue the school district or even go through a divorce.

The down sides are strongly outweighed by the benefits

if you use these social media tools carefully. In a very

real way, social media matters. Blogging, Twitter,

Facebook, and the others can be a very real

lifeline that is inaccessible in your concrete

life. Online friends are real friends.

Sometimes the fact that you spend

time and effort invested in these

social media arenas without

tangible paybacks obscures the

fact that you are getting something

far more valuable: community and

support.

Up next on Autism Unexpected:

Some sites to start with in your autism

social media journey.

Read more: <http://communities.washingtontimes.com/neighborhood/autism-unexpected/2010/may/30/social-media-and-autism-life-line/>

Follow us: @wtcommunities on Twitter





April is Autism Awareness Month

- Autism now affects 1 in 88 children and 1 in 54 boys.
- Autism prevalence figures are growing
- Autism is the fastest growing serious developmental disability in the U.S.
- Autism costs a family \$60,000 a year on average.
- Autism receives less than 5% of the research funding of many less prevalent childhood diseases.
- Boys are nearly five times more likely than girls to have autism.
- There is no medical detection or cure for autism.

Link up your autism posts at
www.singingthroughtherain.net



Get ready for Camp Rainbow!

Creating an exciting Summer Camp Experience for children with a diagnosis of autism or other developmental disability

Activities addressing five core areas: sensory exploration / fine and gross motor skills / communication skills / academic skills / social skills

Fridays this July and August at the Georgia Beach Pavilion in Georgia, VT

For more information contact Tina Cross at 393-6650 or email tcross@nccsinc.org

More resources for you and/or your child/teen.

www.autismsupportnetwork.com/chat

Our Support Community

Join our free support community and connect with thousands of other families and individuals touched by ASD. Find out what's working for others, coping strategies, and life guides from others living what you're going through now. Click here to join for free!

Read more: www.autismsupportnetwork.com/#ixzz2tDqRjJMz

What is SquagTM?

www.squag.com

SquagTM [skwag] is a curated, online experience for kids on the autism spectrum (and their siblings!) that allows them to initiate, explore, and self-discover. Our SquagpadsTM give parents an opportunity to learn about their kids and give kids a new way to learn about the Squag: Social media for teens and tweens with autism

Squag: Social media for teens and tweens with autism

SILVER SPRING, Md., February 20, 2012 — Two years ago, Sara Winter's nephew got in a skirmish at recess and was very upset. Winter suggested that the boy, who is on the autism spectrum, write a note to his parents on her Blackberry to tell them what he was feeling.

Astounded by the way he was able to express himself, Winter began searching for software that could help him do so more. Finding none, she eventually created a social networking-style interface for kids on the spectrum called Squag.

Officially launched in January of this year, Squag is a curated space for kids to build ideas about themselves and communicate with their parents and, eventually, their peers. What that means is that kids create their own Squagpad, a virtual bedroom full of photos and videos they like, alongside prompts that encourage them to write about their feelings and wishes.

Parents have access to all of the content uploaded, and once the full version is launched in late spring, users will be able to connect with each other in a manner intended to keep everyone safe and happy.

Winter had never planned on working with special needs children. Working in theater, she was living her dream as a professional dancer in New York, when a knee injury in 2001 left her looking for a job as she recovered from surgery.

She moved home shortly after her nephew got his diagnosis and ended up becoming his aide and therapist, working with him at home and school every day, a move that was supposed to be temporary, but that lasted for nine years.

"I got to be with him every day and I was totally hooked," says Winter, who received training in many therapies and interventions to help her nephew. Then came that skirmish at recess. As her nephew typed a note to his parents, she says she was astounded by his level of sophistication in expressing himself that way.

"I realized in that moment that I had been underestimating him," she said, "and if I was underestimating him, who else in his immediate community was and what opportunities was he missing out on in result?"

Winter wanted to find software for kids like her nephew that wasn't therapy and wasn't a game, but something that took his communication style into consideration and made it safe to communicate with parents, peers, and himself. Not finding that software, Winter and her family took a leap of faith and decided to build it themselves.

"I decided to build something in the space that I'm passionate about: social and creative opportunities for underestimated kids," she says. Winter, who has two young sons of her own, consulted with therapists and individuals with autism, both adults and children, when seeking feedback on Squag.

"I've met so many incredible self-advocates," she says, "and they have not been shy in telling me what works and what doesn't." Through a prototype test last year, she was able to get feedback from kid users whom she says were "very clear" about what they wanted to see in their Squagpads.

The Squagpad

So what is it that kids can put in their Squagpads? The pads are a virtual room that kids can use to express themselves. At the center of the room is a mirror, where kids can take photos of themselves through their computer's camera. The mirror section prompts Squaggers to reflect on their feelings and self-image.

There are also sections of the pad, where kids can make wishes, choose photos and videos (selected by the team behind Squag) to mark as favorites. All their photos and videos are collected in a virtual scrapbook that they can look back on.

One of the most interesting aspects of the Squagpad is the journal, where kids can write down their feelings and thoughts. Jack Hampton, a young man who has been using Squag since its launch, says he likes the journal aspect best. "I can write in my journal and be by myself to talk about things I like," he says. "I like my journal because I get to write about things I hope to do."

Once the full version is launched, kids will be able to communicate with their peers, but personal photos will remain invisible to others. In order to keep Squag's young users safe, members who use the peer-to-peer enabled features will go through an application process and must provide a credit card number.

The Squag staff will also moderate all of the activities.

Furthermore, parents have access to everything kids do on Squag. They will have transcripts from every peer-to-peer Squag session and are able to see all the choices their child makes in his or her Squagpad from their very own parent dashboard, hopefully sparking communication between the parents and children.

Based on feedback from teenagers, Winter and her team are considering giving parents an option to fade back in how much they have access to.

So far, parents have been very happy with Squag. Deanna Pidwerbeski uses Squag with her 11-year-old son Ben. She says that her son struggles with both social relationships and gets addicted to technology, especially games. "This seemed like a healthy thing for him to be doing online

while also giving him a safe space to meet and chat with people," she says.

She also likes that the Squagpad is full of things the users like and take comfort in—including positive messages from their parents. "These children can get a lot of negative feedback about themselves on a daily basis from peers, teachers, and yes, even their parents." Pidwerbeski says. "But Squag can help to repair that somewhat."

Lauri Swann Hunt is also a fan. Her 12-year-old son Henry uses Squag and thinks it is very cool. Swann Hunt herself likes the aesthetics and language used in the Squagpad.

"I like that it's very calm and soothing," she says. "Henry uses it differently than he does other things on the computer. He doesn't get 'stuck' on what he's doing in the Squagpad, which I love."

All of this, of course is very interesting, but what is with the name? What does Squag mean?

Winter says that it comes from her nephew's earliest days of therapy when they were trying to get him to name different shapes that she saw. "Squag" was his name for square.

Winter says that her sister ultimately came up with the name for Squag, which, according to Winter, is both "super meaningful to us and, in one word, reminded us of how far he's come."

"I like the name now too because it is free of diagnostic labels, which is important to us," she says.

Squag is currently in a free beta testing period, during which time nearly 300 users have joined. Once the full version is launched this spring, users will have a 30-day free trial before a small membership fee (think less than \$10 a month) goes into effect.

Winter says that at least 10% of each monthly membership fee will go to charitable organizations that serve ASD and other special needs communities. She hopes to make those donations reflect the usership, so it generates more services in their area.

As for Winter's original inspiration for Squag? She says her nephew, now 12, loves certain features of the Squagpad, such as the mirror and finding messages from Winter herself in his Squagpad.

"He has very firm ideas about which videos are good and which are 'boring,'" she says. "We have some new features in the works that I think he will love. He is our toughest critic, so I will keep you posted!"

You can sign up for Squag on their website. You can also find them on Facebook and Twitter.

Read more: <http://communities.washingtontimes.com/neighborhood/autism-unexpected/2012/feb/21/squag-social-media-teens-and-tweens-autism/#ixzz2tDv8yy00>

Follow us: @wtcommunities on Twitter

Donna Williams Web site:

<http://www.donnawilliams.net>

This Web site was created by Donna Williams, an adult with autism who has written extensively on her personal experiences. The website features useful articles, an online gallery and connection to a global (free) self employment register for teens and adults with ASD where they can also list dinner clubs and activities clubs.

Support Where You Need It



Given the sharp increase in autism spectrum disorders and increased need in the community, NCSS has created wrap around services to accommodate the entire spectrum.

Early Intervention Services (Birth - 3 Years Old)

This program brings together families and service providers from many aspects of the community, including public and private agencies, parent child centers, local school districts, and private providers. Supports and services come together to meet each child's unique needs and the needs of their family in their home and community.

School Based Services (3 - 21 Years Old)

Training and support services will be provided in all settings, as determined by each child's team.

Family Support Program (Lifetime)

The Family Support Program provides support in the home and community for families raising children with ASD.

Program for Adaptive & Expressive Arts (Lifetime)

Communication, physical, social and emotional skills building program.

**For more information about the services above,
please call 802-524-6554**



The **Autism Connection**

Inside the next issue:

- Autism in the News
- More from Recipe Corner
- NCSS Services

NORTHWESTERN COUNSELING & SUPPORT SERVICES

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fgiunitedway.org

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