

Autism Now

Winter 2011

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2011 OPENING DOORS FOR AUTISM GALA SPONSORS

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The Autism Society of Edmonton Area is a non-profit organization founded in 1971 by a concerned group of parents and professionals. The Autism Society of Edmonton Area helps families and communities embrace and support people on the autism spectrum throughout their lives.

AUTISM SOCIETY OF EDMONTON AREA

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PLEASE PHONE THE SOCIETY FOR AD PLACEMENT AND RATES

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President's Message

Arif Khan



When it comes to autism, our provincial government in Alberta has focused on expanding supports to children between the ages of 6 and 17. This has been a major step for Alberta. Many other provinces are still struggling to provide meaningful services to young children. We in Alberta have taken great leadership in creating family-centred services and allowing parents to choose practices they feel best meet their child's best potential.

Over the years, I have observed young children and teens with autism taking part in community activities and fully participating in leisure groups with other children. I have seen families accessing trained community aide workers who help children integrate with others in the community. These efforts have helped children avoid being isolated in their homes, and have empowered parents by making sure that they are not left to care for their autistic children alone. Our province has made great strides in identifying issues and generating solutions. We have proven that we can give children with autism the tools to help them function in society. Now we must take the next step. We must go further.

What happens to a person with ASD when they turn 18 years of age? I wondered about this last year when I joined the ASEA Board, and listened to many parents express their concerns. I especially learned a lot from an e-mail sent to me by Susan Angus. In her message, Susan clearly articulated what families are faced with when their child turns 18 years old. "They face a vast wasteland without opportunities," she wrote. She went on to outline several key points:

- Autism affects 19,000 people in Alberta
- Autism affects 57,000 family members throughout the province
- Alberta has *no long-term strategic plan* for adults with ASD

How do we change this? We need your help. I invite you to share your thoughts and suggestions on this dilemma by e-mailing them to autism@autismedmonton.org and your MLA.

Need A Guide To Adult Life? (Who Doesn't?)

Deborah Barrett

Wondering about adult life for yourself or your child with ASD? Autism Calgary Association, in conjunction with the Vocational and Rehabilitation Research Institute, the Autism Society of Central Alberta and the Autism Society of Edmonton Area, has just released *Adult Life with Autism Spectrum Disorder: a Self-Help Guide*. The Guide is set up to help you get an overview of all areas of adult life for persons with autism, including adult diagnosis and treatment, legal and financial matters for children who will be turning 18, post-secondary educational options, employment opportunities and alternatives, community living, and personal relationships. Beginning with the premise that each person with autism should dare to dream about having a rich, full and meaningful life, the book goes on to provide practical information about resources that will help you or your child put the elements in place to make the vision a reality. The book is available from the Autism Society of Edmonton Area for \$29.95. For more information, please contact the ASEA office at (780) 453-3971.



Education Matters

Positive Behaviour Support Plans

Karen Bain

Designing and implementing Positive Behaviour Support Plans is increasingly common in Alberta schools. A number of recent in-services, workshops and training sessions have addressed the process of conducting Functional Behaviour Assessments and how to use those results to design appropriate behaviour plans. At the same time, there is now more information available about instructional strategies for replacing problem behaviour with more useful, positive skills. The following is a brief, one-page checklist designed to ensure that Positive Behaviour Support Plans are as effective as possible.

Evaluation of Positive Behaviour Support Plans: School Focus

Reflective Questions	Yes	No
Is the problem behaviour defined clearly? Could anyone reading the description count, record, and discuss the problem behaviour objectively?		
Is instruction enthusiastic and properly paced? Are appropriate strategies in place across domains and academic areas?		
Are expectations reasonable, based on an understanding of this student's needs and levels of understanding, not too difficult and not too hard?		
Has the long-term importance of changing or replacing the behaviour been discussed? Does everyone working with the student agree the behaviour needs modification? Have they committed to consistently following agreed-upon strategies and plans?		
Have there been at least five observations of the behaviour which include when, where, how often, how long, and with whom the behaviour is most likely to occur?		
Are there at least five examples of when, where and with whom the behaviour is unlikely or does not occur?		

Has the function or purpose of the behaviour been clearly identified and supported by objective observation as described above?		
Has the problem behaviour been closely matched to an equivalent and appropriate replacement behaviour that will serve the same function or purpose as the behaviour to be replaced?		
Are the replacement behaviours or new skills clearly described, easy to perform, and realistic given the student's abilities?		
Have new skills, tasks, and replacement behaviours been directly taught and mastered, as well as shared across caregivers?		
Are sufficient prompts, natural cues, and other environmental management strategies in place that will promote positive behaviours and decrease problem behaviours? Are prevention and extinction procedures organized well to support behaviour change?		
Is performance of the appropriate new behaviours sufficiently reinforcing? Are proper reinforcement techniques, verbal feedback, and more tangible positive programming strategies in place? Are there positive, natural consequences frequently available following appropriate behaviours? Do reinforcers match the function of problem behaviour?		
Is there an emergency safety plan for aggressive or tantrum behaviour if it occurs? Are staff trained to support and respect the student without reinforcing problem behaviour?		
Is there an appropriate way to collect ongoing data, communicate with all staff, parents and/or caregivers, and maintain positive behaviour change over time? Is appropriate documentation in place?		
Additional information/Discussion/Planning:		

kebain@telus.net

It's a Gala Year!

Deborah Barrett

It's terrific fun, and everyone buzzes about it for weeks afterward. But it only happens every other year. The good news is, this is the year! It's the Opening Doors for Autism Gala, celebrating ASEA's 40th Year, which will be held October 28, 2011 at the Northlands Edmonton EXPO Centre. This year ASEA is proud to welcome back its Gala title sponsors Cameron Developments, South Edmonton Common, and Cameron Homes

The Opening Doors for Autism Gala is ASEA's biggest fundraising event. If you haven't been, it is a dress-up event which includes a wonderful dinner accompanied by live music, a silent auction featuring hundreds of quality items, and a live auction with some unique and exciting items up for bidding. In past years, our auction items have included trips to Greece, a Hockey Night in Canada Trip to Toronto, and a dinner for eight of your close friends prepared by Edmonton's finest firefighters. Newer and more imaginative items surprise us every Gala!

Tickets for this year's Opening Doors for Autism Gala are \$175, with a table of 10 selling for \$1,750. The last three Galas

have sold out very quickly, so get your tickets as soon as they go on sale.

If you can't come to the Gala, there are other ways you can support this major fundraising event:

- You can become a sponsor. Check out the website www.autismedmonton.org/gala-2011/ to find out sponsorship levels, or call the ASEA office (780-453-3971) for more information.
- You can donate an item for the live or silent auctions. If you aren't sure what to donate, let us know. We can help design a donation package that reflects you and your organization.
- You can volunteer. There are many jobs prior to, during, and after the Gala. Call us at 780-453-3971 to find out how you can help.

The Opening Doors for Autism Gala is a terrific time for a terrific cause – our children and adults with autism. We hope to see you there!



Adult Funding: A Matter of Human Rights

Tanna Somerfield

How is it logical that children are recognized as meeting specific funding criteria in their youth due to a diagnosis of Pervasive Developmental Disorders (PDD), only to be cut off as adults, with no continued supports? Consider the following:

1. Pervasive Developmental Disorders such as autism are not outgrown.

In fact, these conditions, if left untreated and unmanaged, often compound into far more complex and severely debilitating symptoms, illnesses and conditions.

2. Since when is there a statute of limitations on profound neurological abnormalities?

Autism is not an injury, and to discontinue support services for autistic adults based on age and IQ is nothing less than medical negligence.

3. Are there any other severe medical conditions that have requirements for funding and support eligibility based on age or IQ?

Autism cannot be quantified based on who gets funded and who doesn't. Autism is autism. You do not outgrow it. You do not out-think it and – surprise – there is no utopian commune that embraces autistic individuals once they reach a specific chronological age and have IQs over 70.

How can we idly stand by while adults with autism are denied supports and services based on IQ and age? I have never heard of anything so asinine. How is that even legal? Moreover, what do we have to do to rally the government to reconsider this stupidity and change the eligibility requirements to *entitlements*? Here is the only requirement adults with autism should need to qualify for all necessary support and services: *they have autism!*

We are talking about an ever-present exploding population of adults with autism cut loose in a no-man's land. Am I to understand and accept that we, as a society, condone deserting and further marginalizing an entire community of adults with autism and their families because somewhere, someone has written and passed an inhumane, cockamamie bill imposing a restriction on supports, services and funding to adults with autism based on IQ and age?

That is not the future I want for my students. That is not the future I want for my son. This is not a fate that I can accept for countless members of our autistic community. I was not raised that way. I do not parent my child that way, nor do I teach my students that way.

As an Albertan, as a citizen, I cannot accept this unjust and callous dismissal of a marginalized group of highly vulnerable individuals, adults with autism. Tornados level mobile home parks, farming communities and any other areas of least resistance. Is that what this is? Is our community of adults with autism to be leveled and immobilized because they are a marginalized group, and therefore demonstrate *least resistance*?

This is about *human rights*, and not about power, social stratification, nepotism, elitism, favouritism or eligibility. This is not Russian Roulette, a raffle, a contest or a lottery. Adults with autism have the right to live their lives with dignity, and we have responsibilities as a government and society to see to it that this community is served and supported. And if we do not serve and support them, then shame on us for allowing this perpetration of grave injustice against adults with autism to continue.

This error in judgment needs to be formally, publicly and legally reversed, and it cannot happen a moment too soon. For those families and individuals like Michael Frost (*Support Key to Life with Purpose*, Edmonton Journal, Friday, November 19, 2010) who may have already given up hope and believe it is too late, I offer my condolences and my commitment to work towards necessary changes on behalf of our adults with autism and their families. I am talking about inclusion. It is the least I can do, and I *know* I am not alone. It is time we proved to our autistic community and families that they are not alone, either.

A Life in Numbers

Carley Piatt, University of Alberta

If people do not believe that mathematics is simple, it is only because they do not realize how complicated life is.

-John Louis von Neumann

With the support of ASEA's Graduate Researcher Award, I have been studying how children with ASD think about math. As part of the research, I spoke with parents about their child's experiences with numbers and math. I asked questions such as, "Does your child count?" and "Does your child use a calculator?" As with typically developing children, children with autism vary in what they know and in their experiences with numbers and math. Despite the differences, there was one thing shared by all ten children who participated in the study: they all used numbers in one way or another to help structure their world. A few parents even suggested that numbers provided a source of calm and regularity for their children. And for several children, numbers were described as being an important part of the fabric of daily life.

Calendars were mentioned by all of the parents as an example of how numbers gave structure to their children's worlds. For a few children, numbers were also described as a useful way to communicate about more abstract concepts. For example, one six-year-old explains his well-being in terms of percentages. When he is not feeling well, Mom asks "how bad are you feeling?" and he may respond "I feel 30% well", providing useful information to his Mom in a way that makes sense to both of them. A nine-year-old talks to his Mom about stressful experiences at school in terms of a 10-point scale. For many people with or without ASD, the structure of calendars, the rating scales used to judge performances, or numbered lists help impose order on a complex world. It may be that for people with ASD the sense of order and meaning that numbers provide is enhanced. For parents, caregivers, and teachers, being aware of the special role of numbers to help provide structure for people with ASD may be valuable. For example, one suggestion might be to think of ways that abstract concepts, such as feelings or

values, can be made less abstract and easier to talk about with numbers.

With that, a special 110% thanks to all of the parents and children who participated in this study for sharing their insights and experiences with me! This line of research into how children with ASD think about math continues, so please keep an eye out for future updates and presentations.

Teacher Information Night

Positive Experiences in Inclusive Settings –
A Panel Presentation

Tuesday, March 1st, 2010 6:30 - 9:00 p.m.

Presenter: TBA

PLEASE PHONE TO REGISTER: 780-453-3971 or
EMAIL: autism@autismmedmonton.org

Location: 11724 Kingsway Avenue, Main Floor Board Room
Cost: \$5.00 for members, \$15.00 for non-members

Thank You To Our *Autism Now* Contributors!

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**Your talent and hard work have made this issue
of *Autism Now* possible!**

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Your generous donations make ASEA's work possible!

Who, Me? I Don't Need PDD Funding, Do I?

Cathy Lamoureux

I have been contacted on several occasions by Dr. Deborah Barrett to help her get the message out about the need to continue PDD funding. I diligently passed the information on to families who I thought would support Deborah in her efforts. But at the time, I felt that this would probably not be something I needed to worry about myself, as my son is high-functioning and would be fine.

For those of you not familiar with my family, I have two boys. Jake is my 10-year-old son with ASD, and Clay is my neuro-typical 9 year old. I have written many comical tales about my off-the-wall and chaotic family, but I never thought I would have to take the next step into the ever-changing world of autism. This is the story of an experience that once again challenged me and made me rethink how much support Jake truly needs.

My husband Kent and I left one Tuesday for three fun-filled days at the PGA Conference. No, this does not have anything to do with professional golf or warm weather – this was an all-expense-paid trip to the Potato Growers of Alberta's annual trade show in sunny (and snowy) downtown Red Deer! Yes, I was desperate for a couple of days away, and my father volunteered to stay with the boys. This was the first time Kent and I have gone anywhere without the kids, as we had never had anyone brave enough to take care of Jake for us! For anyone who does not know me, understand that I have always been very comfortable with my son's diagnosis, and have given many talks and presentations with a very matter-of-fact view of things. I would never let Jake's behaviours or his prospects for the future impact me emotionally, or so I thought. My father, on the other hand, has never been able to accept that Jake was "different", and in his *generational* ways – he's almost 70 – has never been shy about arguing with me that all Jake really needs is more discipline! After years of struggling to convince my father that autism is real and not just "spoiled child syndrome",

I was secretly hoping he would run into trouble trying to “properly” parent this seemingly “normal and spoiled” child.

Kent and I left town around 3:00 PM, and by 3:30 we received our first phone call from Jake. It appeared that Jake had second thoughts about *letting* us go away, and decided that we needed to come home. After an hour or so on the road and roughly 30 phone calls, we decided to just shut our phones off. I will not go into detail about the rest of the two days (let’s just say we ended up having to leave the conference early), but I will tell you about one of my father’s battles with my apparently “normal” child.

It was Wednesday evening, and the boys had to deliver their Gazettes just as the snow started to fall and the thermometer plunged to -20 degrees. My father was driving our two sons in his truck when Jake came to the window and asked, “Grandpa, why do you get to sit in the warm truck and I can’t?” My father responded that it was because delivering the newspapers wasn’t *his* job, it was *Jake’s*. Being a logical thinker, Jake pondered this for a while, and then said to Grandpa, “Then I quit!” My father said Jake couldn’t quit, because that wouldn’t be fair to Clay. A struggle ensued, and my Father finally cried uncle and called me up on the phone, sounding positively exasperated. The next day the school called my cell phone to ask where Jake was. Turns out my Father could not get him to go to school, as Jake was in a “defiant” mood that no amount of discipline could change! That day we had to leave Red Deer early. I counted 160 phone calls and text messages from Jake. It appears his OCD kicked in, and the more he thought about us not answering, the more anxious he became and the more he called.

I had just finished a half-hour conversation on the way home, reassuring Jake I would be there before bed, when I walked through the door and was greeted by my dog, two cats, Clay and my father (who already his jacket on and truck running). The one person who I most expected to be running to greet me was busy hammering a nail into a piece of wood on my dining room table! My father looked exhausted, so I did not question why my son had a hammer, nails and other tools. Instead, I quietly asked Jake to put them away. He proceeded to line up his toy cars, appearing oblivious to the fact that I was even home. This is only the second time I realized the impact this disorder will have on

Jake in later years. Will he be able to hold down a job? Will he ever be able to feel compassion or have a healthy attachment to people? These are only a few of my seemingly endless worries.

I will be supporting Dr. Deborah Barrett in getting the word out to our politicians because I am awakening to the possibilities that many MLAs are from my father’s generation. They may believe that autism is more of a parenting issue, and should not be the government’s problem. My father now has a new appreciation of the struggles my family faces daily. Hopefully I can show others that this is a serious disability that will need further support through PDD funding if individuals like my son are going to become contributing members of our society and develop to their full potential. Let’s all support Dr. Deborah Barrett and start writing letters to the appropriate people for the sake of our children and their *successful* futures in our communities.

Graduate Student Pilot Grants Available For 2011-2012

The 2011 Graduate Student Pilot Grants (minimum of two in a 12 month period) will support individuals conducting graduate research in any field related to Autism Spectrum Disorders to begin May 2011. These Scholarships are jointly funded by the Autism Society of Edmonton Area, and the Autism Research Centre at the Glenrose Rehabilitation Hospital (affiliated with Alberta Health Services and the University of Alberta). Each pilot grant (maximum \$5,000) is to be applied towards the operating costs of the successful applicant’s graduate research project.

Applications will be judged on the quality and originality of the proposed project, and on the potential of the research to contribute to the well-being of persons with ASD and their families. Each successful applicant will provide a written progress report at 6 months and a final report and presentation of study findings at the conclusion of the project.

For complete application instructions, please visit www.autismedmonton.org/news/2011-grad-student-pilot-grants/



City Health Services is the only company in Edmonton specializing in home care and respite care for those diagnosed with **Autism and Aspergers**.

At City Health Services our aim is to increase **functioning and behavior** of the client, and improving quality of life, not just maintaining the status quo. We offer these services with **trained staff** that understand the needs of this population, and by implementing **nursing plans and behavioral programs**.

Authoritative research has shown that this population lacks **specialized quality care**, which prevents them from reaching their full potential. By using **behavioral programs** and the continuum model of care we ensure client's specific needs are met and that they are always **growing as individuals**. Our services are "needs-led" and based on a **thorough assessment** of each individual client, using a **tailor made care-plan**. Care-plans are reviewed as needed at anytime to accommodate the client's **current needs**. Specifically City Health Services offers the following services:

- **Personal Care**
- **Medication administration**
- **Daily activity programs such as recreation outings**
- **Escorts to school or simply a place of interest**

City Health Services is the brain-child of two nurses with extensive psychiatric experience. **Ben Akowuah**, a UK trained nurse who managed Brookdale, a 70 bed hospital designed exclusively for those living with Autism and Aspergers, the only one of its kind in the UK. **Vinay Jhass** a University of Alberta graduate in nursing and has worked exclusively in psychiatry since graduation.

ASEA Receives Autism Speaks Canada Grant

Deborah Barrett

From the point of view of parents, the future for adults with autism is currently anything but bright. Approximately 60% of children who currently qualify for FSCD funding will not qualify for any sort of funding starting on their 18th birthday. Young adults who *do* qualify for PDD (Persons with Developmental Disabilities) funding may not be able to find appropriate services with qualified workers. ASEA is working hard to make changes, but the changes we need are huge and systemic.

Funding received from Autism Speaks Canada for ASEA's "Working Effectively with Adults with Autism" program will help make a difference. ASEA received \$24,305 to create a DVD and prepare workshops to help those who work with adults with autism understand autism and provide effective assistance to the adults they work with. ASEA will turn to our resident experts, the adults with autism who make up our own Autism Society Players, to assist in the creation and production of the DVD. Sam Varteniuk, ASEA's dramaturge, will oversee all parts of the project.

Autism Speaks Canada was pleased to fund this project, citing its creativity and potential for use across Alberta and potentially across Canada.

Workshops for Siblings of Children with Special Needs!



Join us! These workshops will provide opportunities for brothers and sisters of children with special health, mental health and developmental needs to obtain peer support and education within a recreational context.

Sibshops are lively, pedal-to-the-metal celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so-good thing and for many somewhere in between. They reflect a belief that brothers and sisters have much to offer one another, if they are given the chance.

The Sibshop model intersperses Information and discussion activities with new games (designed to be unique, offbeat, and appealing to a wide ability range), cooking activities, art and recreational activities and special guests.

Sibshops seek to provide siblings with opportunities for peer support. Because Sibshops are designed (primarily) for school aged children, peer support is provided within a lively, recreational context that emphasizes a kid's-eye view.

Sibshops are not therapy, group or otherwise, although their effect may be therapeutic for some children. Sibshops acknowledge that most brothers and sisters of people with special needs, like their parents, are doing well, despite the challenges of an illness or disability.

For more info, contact Debi Currie at 780-496-7318 or debi.currie@edmonton.ca

9 – 12 year olds Saturday, February 12
11:00am – 3:00pm #379093 \$32.10
Terwillegar Community Recreation Centre 2051 Leger Rd. NW

13 – 15 year olds Saturday, March 19
11:00am – 3:00pm #379094 \$32.10
Terwillegar Community Recreation Centre

To Register call 311 or www.edmonton.ca/ereg
Registration begins Nov 1, 2010



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A Different Vacation

Gail Wyatt

It was time to plan another family vacation for my husband Gord, my children Lauren (19), Ian (17) and Graeme (14), and myself. Ian has autism and could be the poster child for Disneyland. He loves the place, and his Special Friends Pass enables him to cope with the very busy, loud Disney environment by ensuring frequent sensory breaks on some of the wild rides. Lauren and Graeme were feeling a little less enthralled with the magic kingdom, and were anxious to see a country outside of the USA. Disneyland will always be special to my husband, Gord and me, as we have enjoyed our most successful family vacations there. After all, if Ian is happy, it's much easier for the rest of us to be happy.

This year, I came up with another option, and that was to travel to Costa Rica. Lauren was immediately on board: being 19 years old and having your parents offer you an all-expenses-paid vacation has a way of motivating you! The boys, however, did not buy in so enthusiastically. Gord studied up on the hot weather in Costa Rica at that time of year and really began to have second thoughts. It occurred to me that another option would be for us to split up and travel in different directions. It was kind of a touchy thing to suggest, but either I got up the courage or Gord brought it up, and we decided to have a family holiday, *but just not the same one for the whole family*. Graeme was on the fence for a bit, deciding whether to stick with the boys in California or join the girls in Costa Rica. In the end, he decided he needed to stick to his original plan to see some new territory.

In our family, Gord is the planner. He loves to plan out our holidays, making sure everything is booked and in place. In no time, the California 10-day itinerary was established, with flights, hotel, rental car, and ball game tickets booked or purchased. I, on the other hand, prefer to consider myself more of a free spirit, reliving my early days as a backpacker. Now I would be the first to admit that having things planned worked well for us when the kids were young, and especially since autism joined the family. After all, Ian's day is not complete without a pretty detailed plan

of what's coming up next. Clearly, the schedule thing is Gord and Ian's forte, but doesn't work so well for myself and our other two children.

Lauren and Graeme provided little input into the trip despite my repeated requests to read the many books I had gathered, books that presented us with oh so many options. The most I got from them is when I had narrowed down our choices to A or B and they contributed to the final decision. I really debated whether to rent a vehicle and drive while there. I would need to rely on the kids for navigation, and having them look out the window would be a new experience, since their eyes tend to be keenly focused on electronics while in the vehicle. I wasn't too sure of their ability to help us get around, but in the end we decided to brave it and add to our adventure.

Eventually the big day of departure arrived, and we were off. One week later, Gord and Ian left on their trip. I think Costa Rica was an absolutely fabulous destination. The people were friendly, the countryside was beautiful and there was so much to see and do. We went to four areas in our two-and-a-half weeks there, and felt like we had four separate vacations. But even though Costa Rica was a wonderful place, I felt that this holiday was more about what this experience meant for our family. I can't remember when I last spent so much time with my children. The truth is Lauren and Graeme have had limited opportunities for their needs and interests to come first and not be overshadowed by Ian's needs. Various incidents reminded me of this over the duration of the trip.

One place we traveled was particularly rugged, and it was hotter than any of us had ever experienced. Our lodging was sparse. It was important to me that my kids experience this. I wanted then to understand the privileged life we live here in Canada and take so very much for granted. I also knew that if they complained I would have no problem telling them to "suck it up", and was confident that they would respond appropriately. Generally that worked, although I've already mentioned that Graeme is 14, so most of you will know

that means he follows the “I’m a teenager” clause. I would also mention that “suck it up” is totally ineffective on Ian, so I took advantage of using it while I could.

After a week of travel when all decisions about where to go and what to do were left to me, I was completely exhausted and really missing the family planner. Graeme is a homebody, and by the end of the trip he was so glad to be coming home. Lauren is ready to conquer the world, so she soaked up every minute of the trip, but she was still glad to come home and see her friends. I reacquainted myself with travel somewhat like I’d experienced long before marrying and having children. Okay, I’ll admit there were a few upgrades that I definitely couldn’t have afforded when I was traveling on a shoestring budget. But mostly, I feel privileged to have shared this experience with my kids.

Our separate flights back home happened to arrive in Edmonton within five minutes of one another. We were all so excited to see one another. It was great to learn that an equally thrilling, exciting and satisfying time had been had by Gord and Ian in California. Ian had done his best to set records for the most number of consecutive trips on the wildest rides. Good thing Ian had his Dad with him for this! Usually I’m used to rating pretty high on Ian’s list of favourite people, but I was definitely second fiddle when we returned home. I guess I can understand, since I disappeared for two and a half weeks while Dad took him on the trip of a lifetime! Family holidays in different locations might not work for everyone, but this year, it certainly was the right decision for us.



My Newspaper

Tanna Somerfield

Recently I took my ten-year-old son to the south side for a medical appointment. On our way home we passed through downtown Edmonton and noticed a crowd of people around a busy intersection and a bottleneck of cars. Traffic was backed up like Jasper National Park on a long weekend. In Jasper, tourists would be observing the law by yielding to crossing wildlife such as meandering mountain sheep or panicked mule deer and their calves. But this local disruption to motorists and pedestrians was due to another marauding, displaced inhabitant, indigenous to these parts: a man, apparently homeless, but not just any homeless man. He was, clearly, a man in need of some specific interventions.

The crowd dispersed as the lone figure thrashed his way through the loose wall of people, muttering laconically to himself, “That’s my newspaper, that’s my newspaper, that’s my newspaper; not garbage, not garbage, not garbage...” My ten-year-old son said, “Mom, that man’s autistic. We can’t just leave him there, we need to help him.”

Before I could say a word, my little boy jumped out of the car and bolted toward the man. “It’s OK,” my son said, “We’ll get you another newspaper. That’s my mom, she’ll get you another newspaper.”

Be careful what you wish for! I have tried to raise my son to be his brother’s keeper, but not at the expense of risking being killed in stop-and-go traffic. In this case, the man my child ran to was indeed a brother, as they both had autism. My son recognized a kindred spirit immediately.

“We’ll get you a newspaper. Just come with us...” My little boy offered his hand to the man and, slowly and cautiously, the man took it. Another kind bystander stepped up and said, “Yes, we’ll get you a newspaper – a better newspaper – a new one!”

The crowd lapsed into collective sigh of relief as my boy and the stranger led the autistic man safely to the sidewalk, and my son sat next to him on a bus stop bench to flip through his *Diary*

of *A Wimpy Kid* book. He regaled the man with stories and pictures from the book, and soon enough the man was totally engrossed in my son's graphic novel.

The wife of the helpful stranger told me to go park my car at the meter parking spot near the bus stop, and she would keep a close eye while her husband picked up a new paper. That's what I did, and soon enough all the people got back on their way, resuming their daily routines. In short order, a newspaper was given to the man, and the kind couple thanked my son and me. They said their goodbyes, and continued on their way.

"Mom we can't just leave him here – he's autistic! Should we bring him home?"

"Well, we'll see. I don't think bringing him home will be necessary. I'll make some phone calls. Don't worry, we won't just leave him here."

I began calling and calling and calling, until my cell phone battery finally died. *This is not good*, I thought to myself. *No one is picking up. No one is calling back.*

Moments later, a police car pulled up and an officer came out. Evidently, a merchant or citizen had called the police. I learned that this was not the first incident. Apparently this man, who the police confirmed was indeed autistic, was currently in between caregivers, as his elderly father was in the hospital being treated for a stroke and his mother was in a palliative care unit. Needless to say, the man was not receiving around-the-clock care and supervision, which often resulted in situations such as today's. The officer did tell me the family was doing their best, but they were kept busy by their jobs and children. They had been attempting to contact resource people to try to get support and respite, but it had been tough.

Within a day or so I did get some callbacks, and this is the information I was able to gather from some active advocates for autism:

- 1) By the year 2012, the number of adults with autism is going to skyrocket.

- 2) We, as a province, have done very little planning to create programs and opportunities to ensure these adults can participate in and make contributions to the community.
- 3) Post-secondary programs with appropriate supports are needed.
- 4) Appropriate employment training and employment support programs are necessary for this population.
- 5) We cannot only fund those with IQs below 70. We need to give support to the adults with autism (the largest portion of the autistic population) who will not qualify for PDD funding.

Lastly, I was advised to Google CTV Edmonton and check out their online videos from a special feature series on autism.

Well, if Jasper can preserve, protect and honour its wildlife, surely we Albertans can organize ourselves well enough to look after our autistic population in time for the explosive influx of autistic adults.

I hope that, one day soon, the autistic man we met that day and others like him will have a sanctuary and protection so they are not in danger of wandering aimlessly through the dangerous roads of life, at high risk for exclusion, injury, and worse.

Autism

A Poem by Kristian Hooker

Kristian is a young adult with Asperger's and the chair of the Advisory Committee for Autism Society Canada.

Often burdened by false presumptions that are
DISABLING

Misunderstood due to intolerance that desperately
NEEDS A CURE

Unaccepted by the majority of society to make us feel
SOCIALLY AWKWARD

A target of abuse, neglect, and cruelty described as
SICK

The tool that strengthens my voice to abolish these
BARRIERS



Parent Information Nights: 2011

Positive Behavioural Support – Part II

Thursday, February 17th, 2011

7:00 - 9:00 p.m.

Presenter: Dr. Shane Lynch, Educational Psychologist,
specializing in ASD

Search Management; Pro-active and Reactive Response (What happens when children go missing?)

Thursday, March 17th, 2011

7:00 - 9:00 p.m.

Presenter: Corps Sergeant Major Adrian Marr,
Edmonton Police Service

PLEASE PHONE TO REGISTER: 780-453-3971 or
EMAIL: autism@autismedmonton.org

Location: 11724 Kingsway Avenue
Main Floor Board Room

Cost: \$5.00 for members
\$15.00 for non-members

What Hippocratic Dads Would Do

Y.C. Ghimn

Unlike our modern doctors, Hippocrates worked on classifying pathological data, rarely to label (i.e. diagnose) each separate syndrome quickly, but to identify *the seat of pain*. When hacking coughs occur, for instance, a Hippocratic physician may suspect none of those catalogued entities such as tuberculosis – a

19th century invention – but would instead look to a throat irritation or chest discomfort identified simply with *the seat of pain*. Certain diseases we have named after the body part sound ridiculous: heartburn is not cardiovascular, and stomach flu is not influenza!

Experts think my little one has a *spectrum* disorder called autism; contrary to other kids who are similarly stigmatized, however, she never developed qualitative sensory or fine motor-related impairment. Her friend with ASD, too, seems über-verbal. She is emotionally nonreciprocal, but seems to have no other symptoms. Hence, both daddies are left to wonder: do our daughters belong under autism, the presumed umbrella concept? Indeed, scientists have coined lower terms – for example Asperger's, high-functioning autism, etc. I believe my daughter is just a bit *nerdy*, just as her parents were!

Hippocrates nonetheless taught us: if cases got distinguished whenever there is variation, the number should become incalculable. But neither would Hippocrates prefer big-word constructs like SIDS to describe a mere fact that Suddenly the Infant has Died, period. It seems that clinicians today prefer labels like “syndromes” or “disorders”, but these labels seem to disregard much of the essential person that is hiding behind discernible symptoms. My daughter, for instance, avoids eye contact. But is this, perhaps, part of her cultural tradition?

Whatever is found *in* any name – whether it be autism, or even “dog”, as Friedrich Nietzsche metaphorically referred to his obtrusive pain so he could scold it – matters. What's important is undoubtedly my creative girl. She thrives upon routine – not deduced or resulted from being autistic; thus I hardly accept or equally deny this ASD filing. (And why bother? After all, it opens the door to new services for her and for our beloved family!) Hippocrates might have done neither, but he would have still supported her in terms of her symptoms. And in the end, isn't that what we should all be doing?

ASEA's 2010 Christmas Party!



ASEA Facebook Community

ASEA has a Facebook Community site that was started so Edmonton families with members on the Autism Spectrum could find and get in touch with each other. Members can use the group to

- set up coffee meet-ups, play dates, and more
- keep an eye on each other's status and encourage each other when they're feeling discouraged
- make announcements about activities and the new Aspire committee

Anyone with a personal relationship with someone on the Autism Spectrum is welcome to request an invitation. Please send an e-mail to patriciaterrett@autismmedmonton.org and ask to be invited to this community site.



Cycle for Autism 2011 Now Accepting Pre-Registrations!

On your mark, get set, go! Father's Day (June 19) 2011 marks the date of the 2nd Annual Cycle for Autism at Gold Bar Park. It's your chance to cycle, walk or run to raise funds for *local* autism programs and services. Invite your friends, family or co-workers to join your team and join in the fun, or strike out on your own. Either way, it will be a day of sunshine, fresh air and fun – and all for a good cause! Plus, there will be plenty of snacks and games to keep the whole family entertained!

You can pre-register your team or yourself by visiting www.cycleforautismmedmonton.com. And keep checking the site for more event news and info!

WeBA Gala a Classy Event

The River Cree Resort was elegant, the room stylish, the atmosphere smooth and sophisticated as the West Edmonton Business Association (WeBA) hosted its 2010 Gala. The Gala, a well-organized but informal procession of hors d'oeuvres, entrée, dessert and wine, followed by a lively dance, was accompanied by a silent auction, the proceeds of which (\$4,285) went to the Autism Society of Edmonton Area.

Vince Caputo, a director of WeBA and organizer of the event, spoke from the heart about autism, because he has a nephew with the diagnosis. John Su, President of WeBA, spoke about WeBA and their support for ASEA. Deborah Barrett, Director of Community Awareness and Development for ASEA, gave a moving presentation about autism and how it affects families. She also spoke about how businesses can make a difference, especially for adults with autism. Many of those in attendance had someone they love who is affected by autism.

The Gala was well-run, fun, and stylish. The cheque itself was presented to ASEA a month later, just after Premier Ed Stelmach spoke at WeBA's Premier's luncheon on December 6 at the Hilton Garden Inn – an event that gave ASEA another opportunity to highlight the challenges facing individuals and families with autism. Nicely done, WeBA!



Vince Caputo, WeBA Events Director and Team Leader

Aspire Parent Group

Cathy Girard and Kelly Sheehy

Raising a child with Aspergers Syndrome (AS) can be a rewarding, yet challenging, situation for any family. Once children reach school age, the challenges seem to multiply, and as parents, we suddenly need to develop keen skills in negotiation and advocacy. Many families find themselves in a school situation that changes from year to year – the classroom and teacher that worked so well are gone, and a new situation must be met head-on. Where do our children go when the regular classroom is not successful? There is no “Asperger Program” that will meet their social, emotional and academic needs.

Both our families struggled finding the right fit for our children in the public school system. In the end, there was no right place, no program that would meet all their needs, so we both made the choice to educate our children at home. This has turned into an amazing opportunity for our kids to thrive, and a chance for us to positively impact their education and development. But the problem remains that there is no appropriate public or private school setting in Edmonton and Area that will meet the unique needs of children with AS or High Functioning Autism (HFA).

In September, we started talking about the idea of creating an alternative school program for our children – Aspire Academy – a school program that would address the social, emotional and academic needs of children with AS, HFA and PDD-NOS. From this idea, we decided to develop the Aspire Parent group to gather the support of parents who wish to make a better educational environment for our children.

We have been busy with a couple of initiatives that are currently underway. First, we met with the staff and administrators at Argyll Centre, the Edmonton Public School Board site for home education. We pitched our idea of what an ideal school environment would look like, and asked if they could support us in initiating a program. We also needed to find out if there were enough parents who would support the development of a school program for kids with AS/HFA. In

order to determine this, we created an online survey to collect feedback from parents on the school experiences of their children. To date we have received 65 responses, the majority of which indicate there are challenges and barriers in the current education system.

Our goals for the Aspire Parent Group include the advocacy for and development of alternative learning environments for children with AS, HFA or PDD-NOS who have average or above-average cognitive abilities. This includes support for families who homeschool, as well as an appropriate public school program that would respect and address the needs of our kids. In order to achieve this goal, we need to create a working committee of parents who wish to advocate for change and different educational options for our children. In addition to the school program, we also have the goal of creating a stronger community of families who have children with AS and HFA by initiating Family Social Evenings and supporting home educating families with a Homeschool Activity Group.

Our first Family Social Evening will be held on February 12th, 2010. A potluck and games night is planned, and all members of the family are encouraged to attend. Our first Homeschool Activity Group will be held on February 18th. This will be an opportunity to meet other families who are homeschooling, as well as plan ideas for activities that we can do as a group.

If you are interested in any of these events, would like to get involved, or want to find out more about the Aspire Parent Group, please visit our blog at <http://aspireparentgroup.blogspot.com/> or email us at aspireparents@gmail.com.

Power Islands: A Playwriting Adventure

Sam Varteniuk

On Friday, December 10, the Autism Society Players (ASP) had the distinct pleasure of hearing their second full-length play, *Power Islands: Adventure Two*, read aloud by members of Edmonton's professional theatre community. The reading was presented to a small but enthusiastic crowd of friends and family.

The ASP have been meeting since 2005, collectively writing and performing plays. Their initial efforts, *A Room* and *Autism vs. Mitchism*, were sometimes humorous but ultimately sincere investigations of Autism Spectrum Disorders (ASD) where the players could explore difficulties they encountered in their own lives from the relative safety of dramatic fiction. However, in 2008 the group took a different direction: rather than focus on the disorder which united them, the Players opted to throw off the limitations of autism and simply write a story they found compelling. The result was *Power Islands*.

“I like writing because it allows me to escape my everyday life,” says Neil Mikalonis, a member of the group since it began five years ago. Neil plays the role of Tammy Trouble, a tough single mom who can control the weather with her mind. She is joined by a number of other super individuals who can fly, turn invisible, teleport through phone lines, read minds, erase memories, create and cure infectious diseases, and create simple objects out of thin air. Epic battles between good and evil are fought on a chain of islands worthy of their superhuman inhabitants: from the Island of Tough Single Moms to the Island of Team Sports, from Manufacturing Isle to the Artistic Archipelago, there’s a land mass for every situation and a limitless sky of creativity.

It was nearly a year ago that actors from the professional community first agreed to come together for a workshop reading of *Adventure One*; many of the same people responded eagerly to the invitation to read the sequel. “We were all curious to know what happened next,” said Taylor Chadwick, a local actor who has lent his services to both readings. He was joined by Amber Bissonette, Ellen Chorley, Matt Kloster, Amelia Maciejewski, Sarah Polkinghorne, Cat Walsh, Stephanie Wigston, and Dave Wolkowski. Though they’d never read the play together in rehearsal, these talented actors delivered a performance that was almost as good as seeing a full-scale production.

Originally conceived as a drama group, the focus for the ASP has shifted to writing in recent years. Beginning with a wish list of ideas and impulses (Aaron searches for his father; aliens

burst out of someone’s chest; etc.), the Players begin to string together a plot packed with conflict, plot twists, and character development. Good people turn evil, evil people have their memories erased, time travel goes wrong and alters the future, and heroism saves the day. Structured similarly to radio serials of the '30s and '40s, each Adventure is comprised of four half-hour episodes, beginning with a bang and ending on a cliff hanger; the idea is to generate an exciting narrative that will make audiences eager to “tune in next week”.

While the fundamental value of art is not something the writer of this article is prepared to debate, there is real therapeutic value for a group of persons with autism to write something that has nothing to do with autism. Discussions of character motivation, where writers empathise with characters in an effort to generate dialogue for a scene, enhance understandings of social situations. However, unlike traditional therapy, in a writing situation the focus is taken off of the individual. The Players are invited to consider social interaction from a position of power; they are omnipotent, controlling the actions of people they create. For a person accustomed to having obstacles thrown in his or her path, writing is a tremendous way to empower and build confidence. But, most importantly, it’s a lot of fun.

And what does the future hold for the Power Islands? There’s been talk of a full-scale production, but the complexities of live performance are daunting. The piece feels more like a cartoon than anything, and the ASP have begun to bounce around the notion of creating animated versions of individual episodes for an Internet audience. But for now, we’ll keep writing. After all, who knows what dangers our heroes will encounter? Will Aaron and Sarah manage to rejoin the sundered halves of the former Yvette? Will Alan overcome his fear of time travel? What will become of Bob and Bill? And who the heck is the new super villain who’s just sprung up from the Earth? Find out in the next amazing adventure of...

THE POWER ISLANDS!

Oughtisms

Tanna Somerfield

We *ought* to honor abilities
not disabilities.
We *ought* to able-ise,
enfranchise,
recognize,
humanize
and capitalize
on
mindful,
ingenious,
ears
and
eyes
that blaze trails
of new enterprise
and break endless ground to fertilize.
If only companies would realize,
*there is so much to expect from
autistic employees
from all over the spectrum.*

Tailored Mortgage Inc.: Mortgage Brokerage Joins Fight to Aid Charities

With today's ever-changing economy, charities and schools are always looking for new ways to raise money. And we all have a special charity that is close to our hearts.

This is what inspired Tailored Mortgage Inc. owners Dea Bullis and Eva Neufeld to come up with the idea of the TM 500 Charity Event. They decided they wanted to use their expertise to give back to the community that has given them and their families so much over the years. They decided to support families and children in need.

"Everyone either needs or has a mortgage," says Eva Neufeld. This is true whether you're purchasing your first home, moving up to a larger one, refinancing, setting up a Home Equity Line of Credit, or your current mortgage is up for renewal. When someone purchases a mortgage of \$200,000 or more through Tailored Mortgage Inc., TM will donate \$500 to that client's school or charity of choice. It's that simple. That's the TM 500 concept.

To help aid your charity or school of choice, visit www.tailoredmortgages.com or call 780-757-1107.

Thank You to Our ASEA Volunteers!

Susan Angus
Jeff Belch
Charlene Cheung
Laura Dumas
Cathy Girard
Lynn Hughes
Chris Kish
Ben Kurtz
Mark Lynch
Kirsten Nadeau
Karen Phillips
Jaspreet Rai
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Jordan Morgan
Omair Peracha
Charlene Prochnau
Christina Shea
Andrew Sung
Leanne Weidmann



**Do you have a child with
Aspergers Syndrome,
High Functioning Autism or
PDD-NOS?**

Aspire Parent Group

"Aspiring to create a better learning environment for our children"



Our goal is to create a learning environment that is designed to meet the needs of children with Aspergers (AS), High-functioning autism (HFA), and other similar disorders (such as PDD-NOS, General Anxiety Disorder, Sensory Processing Disorder, and Non-verbal Learning Disorder), who have average to above average IQ.

It is our belief, that by providing a program that addresses the unique needs of these students, we can build confidence and promote self-advocacy skills, enabling them to reach their true potential and successfully transition into adulthood.

In addition to the goal of achieving a school program, we aim to:

- build a supportive community for families who have children with AS, HFA, PDD-NOS
- build a network of families who are home educating their children to share resources and create educational opportunities
- create an awareness of the challenges and issues faced by children and adults with a diagnosis of Aspergers Syndrome/High Functioning Autism.

**For more information, please contact aspireparents@gmail.com
or visit <http://aspireparentgroup.blogspot.com/>**

Events at a Glance

For a complete, up-to-date listing of events from ASEA and the local autism community, please see ASEA's web site. Just visit www.autismedmonton.org and click the "News and Events" button at the top of the screen! Special events will continue to be sent to members via e-bulletin.

Do You Have A Story To Share?

Autism Now would love to hear your stories - about your kids, your concerns, your family. If you have time to write, please email your articles to submissions@autismedmonton.org (All submissions must follow the submission guidelines posted at www.autismedmonton.org/autism-now-submission-guidelines/). If writing isn't your thing, send us an email or give us a call—we will be happy to talk with you and write an article based on your experiences. Autism Now would love to include a full spectrum of stories about living with autism.

We Welcome Your Feedback

Want to let us know what you think of the latest issue of *Autism Now*? Do you have an idea for something you'd like to see in the next issue? Feel free to drop us a line at autismnow@autismedmonton.org

In Case You Don't Know, Here's What ASEA Does For You

ASEA offers a wide range of programs and services to improve the lives of people with autism, their families, and our entire community. Check them out at www.autismedmonton.org/our-programs-and-services. Some of these programs and services are only available to members. If you aren't one yet, you and your whole family can join for as little as \$50 a year— just fill out the membership form on the next page, or visit www.autismedmonton.org to sign up online! ASEA relies on people just like you for the funds that keep us working in the community. We don't receive any

money from the United Way. All our revenue comes from memberships, donations, and fundraising events like our Opening Doors Gala and Cycle for Autism. We hope you will make use of our programs and services, and if you do, please consider making a donation or volunteering at our next fundraising event.

For a complete listing of ASEA's programs and services, please visit www.autismedmonton.org/our-programs-and-services

But Wait! There's More: Services You May Not Know About

ASEA has many programs and services, but we also work behind the scenes to increase community awareness about autism and provide information to families who suspect or have just received a new diagnosis. We speak to a variety of organizations to help them learn about autism, and get media coverage for autism issues, concerns and programs. ASEA also initiates and publicizes research projects to benefit persons with autism and their families.

ASEA also works with community partners, government and families to ensure that quality programs and services will be in place for children and their families throughout their lives, from childhood into adulthood. This year, we are focusing on creating appropriate community options for older children, teens and adults.



MEMBERSHIP APPLICATION

1. THANK YOU FOR YOUR ASEA MEMBERSHIP

Thank you for joining ASEA. Membership fees contribute directly towards the Society's ability to provide informational resources and services to families and professionals who support individuals with Autism Spectrum Disorders.

2. NAME & CONTACT INFORMATION *All information gathered will not be sold, traded or used for any purposes not directly related to ASEA*

Dr. / Mr. / Mrs. / Ms. (First) _____ (Last) _____

Dr. / Mr. / Mrs. / Ms. (First) _____ (Last) _____

Mailing Address: _____ City _____ PC _____

Telephone: (h) _____ (w) _____ (c) _____

E-mail: _____ 2nd/work e-mail: _____

Occupation / Workplace: _____ Occupation / Workplace: _____

I am: an individual with autism a parent a relative: _____
 a teacher/teacher's aide an agency a professional other: _____

3. ABOUT YOUR CHILDREN *Knowing the ages, situations and schools of your children helps us notify you about programs available and scholarships for siblings.*

Your child's name _____ DOB dd/mm/yy School _____

Your child's name _____ DOB dd/mm/yy School _____

Your child's name _____ DOB dd/mm/yy School _____

Diagnosis (Optional) 1) _____ 2) _____ 3) _____

4. TYPE OF MEMBERSHIP *ASEA has simplified its membership offerings for your convenience*

- \$50 New family membership \$100 professional / agency membership
 \$50 renewing family membership \$50 teacher / teacher's aide membership
 *\$0 assisted family membership *ASEA recognizes that some families are unable to afford annual fees. ASEA will consider requests for assisted family membership on a case by case basis. All inquiries will remain confidential.

I would like to receive Autism Now by email by mail

5. PAYMENT *Memberships are renewed annually. Donors and volunteers play an vital role in sustaining services and creating new programs.*

Visa MasterCard Cheque

Card number _____ Expiry date (mm/yy)

Signature _____

Yes! I'd also like to make a donation to ASEA

- \$25 \$50 \$100 \$200 Other _____
 Yes! I'd like to volunteer for ASEA – please contact me!

Please consider giving of your time or financial resources in addition to your membership.

All donations over \$25 are eligible for a charitable tax receipt.



www.autismedmonton.org



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