

Autism Now

Autumn 2009

volume 22, number 3



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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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President's Message

Ryan Guenter



Can you believe the summer has already come and gone? As I write this, it's already October! For those involved with the Autism Society of Edmonton Area, you will already know that October is Gala month. The event takes place at the Italian Cultural Center (on St. Albert Trail) on Friday, October 30th. Tickets for the Gala were gone in no time, as this event has many dedicated attendees - thanks so much for your support. I also want to personally thank *all* of the Gala committee members (you know who you are). Very special thanks go out to Anita Ferri and Holly Brown for stepping up as co-chairs to help make this event the success I know it will be. The next issue of *Autism Now* will have a complete Gala feature, including a full thank-you list, but for now, thank you to everyone who did their part to put together another amazing Gala.

Moving forward, we have much work to do. As most readers are aware by now, September turned out to be a tragic month for the local autism community. By now, I hope that everyone has cried, gotten angry, and has slowly begun coming to terms with the horrible news we heard on September 24th. On behalf of the organization, we send our most sincere condolences to the family. May the road to recovery and happiness be shorter than you might expect. And thank you to Deborah Barrett, Karen Phillips, Linda Dowell and Patricia Terrett at the ASEA office for their swift, diplomatic, caring and insightful responses to the events that saddened us all.

As tragic as this situation was, we can only hope that it helps to catalyze progress in the services offered for individuals and families affected by autism—not only here in Edmonton, but also across Canada and around the world. Hopefully those with the power to make a difference can now empathize and understand that these situations can be beyond difficult.

In my first letter as President, I alluded to the reason why I first got involved with ASEA three years ago: it was because of my

nephew Nicholas, who has autism. At the time I wanted to help him, and joining ASEA seemed to be the best way to do that. Now things are going great for Nicholas, but the reason I have stayed involved with ASEA is because, although the situation that came to a head this September was an extreme and terrible case, it also reflects the fact that there are hundreds of families of people with autism who are facing intense stress and pressure in their daily lives. I encourage anyone with a son, daughter, grandson, granddaughter, niece, nephew, other family member, or friend with autism to get involved. It is well worth it, and your community needs you!

Ending on a positive note, many of the Autism Society's programs for the fall are already underway, including Parent Information Nights, Teacher Information Nights, and Drama Club. Please call our office or visit our website if you want to participate or help out with any of the programs and services we offer. Thank you for your support.



It's Gala Month

Recent Tragedy – Mom's Story and the Resource and Service Issues

Karen Phillips

Many of you will have heard about the recent deaths of a dad and his 11 year old son who had an autism spectrum disorder. The dad took the life of his son and then killed himself.

About a year ago Mom and Dad looked for help for their son because his behaviour was out of control. The problems were serious and it was not safe at home for the boy. The parents took their son to the Royal Alexandra Hospital and he was admitted to the children's psychiatric assessment unit there. The boy was hospitalized for a couple of weeks, his medication was adjusted and he was sent home on a Friday. The parents had a terrible weekend with the boy, his behaviour was much worse than that which had taken them to the hospital in the first place. The boy went to school on Monday and his parents were called within an hour to pick him up, and told not to return him to school until his behaviour was under control. The parents took the boy back to the Royal Alexandra Hospital where he was refused re-admittance. The parents spent 30 hours in the emergency with their child strapped down and terribly distressed. At one point a medical resident came to them and told them to "take their child home, this (the hospital) was no place for him." The mother had to be very loud to get the attention of the entire staff at the nurse's station before they would arrange for the boy to be readmitted to the Royal Alexandra Hospital children's psychiatric unit. Medical staff at the Royal Alexandra Hospital made it clear to the parents that the children's psychiatric assessment unit was not equipped to meet the needs of children with autism spectrum disorders.

The parents sought help from FSCD to put in place an emergency/long term plan for their son, and they were offered the option of being put on a waiting list for an "out of home placement" for at least one full year. Knowing that they could not survive having their son return home until he got help for his severe behavioural problems, the mom started searching and found a service provider in the Edmonton Area who would offer care for their son. Mom and Dad approached FSCD to

arrange to have their son placed with the service provider. FSCD denied the request because they were no longer contracting with that particular service provider. Mom and Dad approached the Alberta Association for Community Living for help and AACL brokered a deal with FSCD so that the boy could be placed with the service provider. Within one week the boy was placed with the service provider and a home was set up for the boy with a two-to-one staff-child ratio. The boy visited home on the weekends and the family felt he was making some progress.

Recently the family was given two weeks' notice that FSCD would no longer fund the specialized placement, and the boy would be moved to a group home, to be placed with one, and eventually two, other children. The family appealed the short notice for moving the boy and the notice period was extended to allow time for a more gradual transition. The family visited the group home and did not want their son to have to move there; the parents found it to be very institutional. There were locks on the doors and the parents were told that if the locks were needed for their son, they would be kept in place. Mom and Dad were devastated to think that this was their son's future.

Mom has shared that her husband felt helpless to get the help their son needed. Mom describes her husband as a loving and caring husband and father.

Many parents and other community members have reached out to support Mom and her remaining son. Many parents of children with autism spectrum disorders have experienced desperation and the helplessness of not knowing what to do and where to go for understanding and help. Many people have been deeply touched by the pain of this family.

The Mom asked me to extend her thanks to everyone who has expressed their support and to those who have kept her and her son in their prayers. Mom said the outpouring of community support has been overwhelming. A special thank you to Tanya and Blaine Stockwell and their fourty friends who made thank cards for Mom. She was deeply touched.

Mom has received in donations about 25% of the amount she needs to cover the cost of the funeral. If you are interested in

making a donation to help Mom cover the costs of the funeral, please contact the Autism Society at 780-453-3971.

Resource and Service Issues

The absence of appropriate services and resources for families who have children with severe behavioural challenges underlie the desperation this family felt.

- 1) Emergency Respite: There is no appropriate place for parents to take their children with ASD and severe behaviour problems if the parent believes they cannot manage their child or the child is unsafe in the home, or even if parents become ill.
- 2) Behavioural Intervention Services: There is no program parents can access to get intensive behavioural help for their child if their child becomes out of control. FSCD offers behavioural help using a consultation model; this is not suitable in a situation where safety of the child or family members is a factor.
- 3) Out of Home Placement: This alternative may be offered to parents by FSCD, but many parents do not want to place their child out of the family home. Where parents do choose this option, there is a long waiting list for out of home placement. One family waited 18 months, finally gave up, and created their own out of home placement, staffing it for the most part by themselves.
- 4) Emergency services: FSCD and the Glenrose Hospital do not offer emergency services. ASEA has been told by government representatives from Health and Children's Services that if a child is out of control and parents feel they cannot cope, they should take the child to the emergency at the Royal Alexandra Hospital (RAH).

Medical staff at the Royal Alexandra Hospital have stated that their staff are not trained to deal with children with Autism Spectrum Disorders. During a recent visit with a parent whose son was placed there, the ASEA Program Director observed that while the staff made every effort to be kind and supportive, the space was small, there were no facilities for the child to get

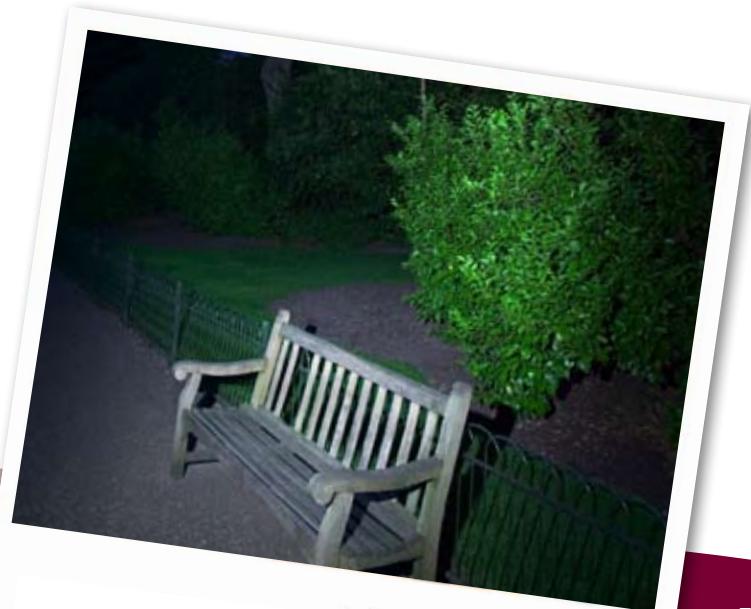
exercise, no occupational therapy support, and not even a TV which played children's programs.

In addition, parents who have requested help in severe situations have been refused help.

One week after the tragic death of a dad and his son, a family took their 16 year old, adult-sized daughter to the emergency at the Royal Alexandra Hospital, after an altercation in which the dad had to shove his daughter, who was in a rage, away from him to get away from her punching, kicking, scratching and biting. The dad was injured. The girl was refused admittance because she was not considered to have a "psychiatric illness". The family took their daughter home and were in crisis. About one week later the parents were surprised, and grateful, to be contacted by the RAH and offered admission for their daughter.

Families who have children with ASD who are behaviourally out of control have incredible pressures placed upon them. Families find themselves in situations where they have to choose between children, where they have to choose between a child and a spouse, or where they have to lock their bedroom door at night because they do not feel safe. Some families have said that it feels like living in a war zone.

I think there is no doubt that we have resource and services issues in Alberta.



A Tribute to a Father and Son: A Eulogy by a Family Member

Author's name withheld by request

Hello everyone, thank you all for joining and supporting us today to listen to a few stories about this amazing family. I am the mother of a wonderful woman who has been an incredible wife and partner, and a super-Mom to two young boys.

My daughter and her partner were a match made from incredible odds.

They both had come from previous marriages, yet each came together bringing with them, their respective loves of their lives, their boys. Lots of boys. Three of them, in fact. A blended family.

I am here today to help paint a true picture of this magical family. If any of you here took the opportunity to actually look at the collage of pictures put together, you will see a family. A real family. These boys were the joy of my daughter and my son-in-law's existence. They celebrated life. They enjoyed each other's company. They *truly* loved each other.

Now, quite a few of us know what challenges face us when we blend two families together. Somehow, these two found each other. Despite incredible odds, they naturally connected, and for the past five years of their busy lives, managed to find a way to celebrate how lucky they were to be part of this newly-formed union of strangers and watch as they become an invincible force.

My son-in-law and my daughter embraced the concept of family unity. They worked tirelessly to enjoy time with their kidlets. The collage speaks volumes, and attests to the richness of this family.

Every event mattered. From birthdays to Christmas, from baptisms, to sleepovers for 15 kids, each with his or her own special needs, wreaking havoc throughout the house. I can tell you here and now, I would have lasted all of ten minutes, and at that, would have needed a shot of scotch just to last that long.

Who does that? They did. And they did it with open hearts and tons of love for their boys. This was their purpose in life.

I believe that everyone has a purpose in life. For those of us who knew the true colours of my son-in-law, they knew that he was a vital, vibrant man, whose focus in life was to envelop, protect

and nurture his family. This was his purpose. He was a rational, intelligent, kind, generous, funny and thoughtful person. You knew when he was in the room. He had that smile, and a contagious laugh, one that was heard while goofing around with his boys.

My son-in-law was as determined as my daughter to provide a happy, safe and nourishing environment. With my daughter at his side, they fought the good fight for their child with autism, doing the right thing, and doing the thing right, even if it meant the cost was dear.

My son-in-law tolerated the challenges and struggles facing him head-on, and did his level best to protect his family, especially his wife, from the residual fall-out that raising an autistic child brings.

My guess is that when he saw that he could not attain the same level of quality of life for all of his boys equally, he made a choice. Although it was a choice that some people think they could never make, to me he simply set out to level the playing field for his special son.

He knew the cost of this, in the short term, would be almost unbearable, and seemingly unfair. I think he made this decision knowing that his strong, beautiful partner could carry the torch on his behalf.

He is our hero.

His son is in good hands, and this time the boy's destiny is completely controlled and guided by the love of two great fathers.

I know that some folks feel that this event is a selfish act, but I believe in this case, we have a demonstration of the height of unselfish, giving, caring acts, one that requires a courage greater than the will to live.

As we faced these last few days, I have to tell you from my heart, that we took solace and comfort in knowing that our boy was visited by the very people that helped support, and nurture in his development. To each of you, on behalf of our families, you are the silent force, the ones that are the care-givers, and perhaps now the voice of my daughter's family. We love you, and we thank you.

Last year, our boy with autism deteriorated to the point where he had to be hospitalized for a period of time. He had great difficulties communicating, but once in awhile he would walk

over to the window when the sun was shining in just right and he would close his eyes and look into it. A big smile would spread across his face and he would clap his hands. I am not sure how often the sun shines in Edmonton, but in those rare times, there was no trouble understanding our boy.

Last night my daughter shared a great story about how she bonded with this child, shortly after she and his father met.

His dad took them camping. (Again, I would have lasted 10 minutes, and needed a BOTTLE of scotch.) Dad went off to find fish bait, trusting that he could leave my daughter alone, for the first time, with his special little boy.

So she perched herself on a huge rock and, facing the lake, she picked up the little boy, planted him between her legs facing away from her, and looking at the water. Suddenly, the child simply turned his head, stared up at my daughter, and just snuggled into her chest. She melted. Right then and there, she fell in love. That love flourished.

My daughter took it upon herself to actually potty train this special child. It took her three weeks of standing, sitting, squatting, begging, pleading, force feeding him prune juice, until he finally realized that he could go to the bathroom by himself! Another reason to celebrate!

Well, in no time, word got out, and the next thing you know, the phone was ringing off the hook from families desperate to potty train their children! I told her we could open up a company, and call it "Potty Joy".

I can tell you that his brothers loved him very much. They knew he loved Dora the Explorer, SpongeBob SquarePants, and Blues Clues. They often sat and watched with him, so as to share in his moment, and then go jumping on the trampoline.

For some reason, this incredibly tragic event was somehow paved with kind people. Right from the Edmonton Police Service, ambulance, and hospital folks (a special thanks to Barb and the nurses and doctors who did all that they were able), to the wonderful people at the Rosslyn Inn and Suites, to the store owner at Sobeys who personally delivered the homemade goods for our wake, to this group of able and courteous folks at the funeral parlor (if ever you are in need, ask for Bradley!).

Thanks to the media (believe it or not!), who wrote the truth kindly. You protected our dignity, yet you got the message out.

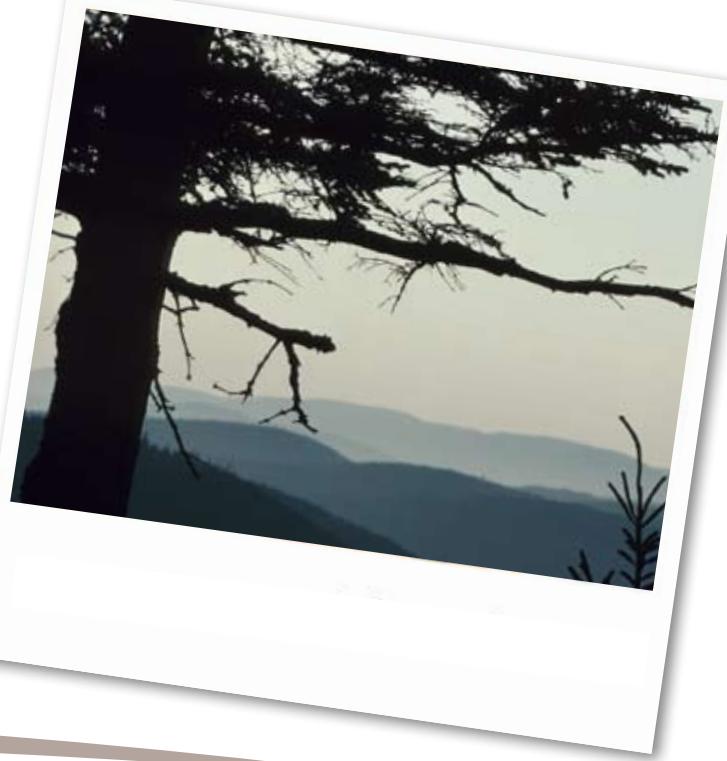
I am truly amazed to see that something of this level of magnitude, so readily available and vulnerable to be misrepresented, was presented with high regards to morals, principals, scruples, and compliance to our privacy. Also, to a very special friend who shall remain anonymous, who cushioned our collective blows by offering his usual kindness and advice, pro bono – I thank you.

To the various causes, societies, associations, and political parties, we know you all have your jobs to do, each of you participating in representing your respective confines and budgets.

Our only wish is that you all get that bonk on your corporate heads one day, all at the same time, much like that V8 commercial, where you will all collectively say, "Wow, I could've financed Autism!"

Finally, to the people of Edmonton, Alberta: We have heard your hearts breaking with ours. We were helpless in our grief, and you all came to help us, lifted our spirits, and made this unbearable pain just a little easier to deal with.

Thank you.



Education Matters: Continue Setting the Direction

Karen Bain

The recent Alberta Education process related to enhancing educational opportunities for students having special education needs, *Setting the Direction*, reportedly involved six thousand Albertans, including many parents and professionals who advocate for children having Autism Spectrum Disorders. The evolving framework designed through that work focuses on inclusive education, a system in which all students are to be respected, participating members of their school communities.

Three central goals and ten key recommendations have been proposed (*Setting the Direction Framework*, July 2009). Goal one involves a **curriculum** that ensures appropriate tools and models to deliver the programs of study, gather essential data, and develop teaching resources. Goal two relates to developing **capacity**, involving parents, school-based expertise to support teachers, instructional excellence, resources and appropriate access to technology. Goal three, **collaboration**, includes provision of special supports and services, an emphasis on school-based learning teams, and ensuring effective transitions for students from early education programming into Grade 1.

Certainly these three central goals and related recommendations are essential for provision of effective programming for students having Autism Spectrum Disorders. Parents and school personnel who are familiar with *Essential Components of Educational Programming for Students with Autism Spectrum Disorders* (Alberta Education, 2007) will recognize that these three components and meaningful inclusion were recommended in that document, as well. The *Essential Components* included meaningful parent involvement (no. 1), professional development and staff training (no. 4), collaboration and coordinated supports (nos. 6 and 7), appropriate curriculum (no. 8), and meaningful inclusion (no. 10).

It was certainly encouraging to see these same components have formed the framework for all students having special needs in Alberta. For the preparation of in-services and supporting teachers, however, I believe students having Autism Spectrum Disorders and other complex social/communication disorders may also require additional consideration within the three general goals. To maintain the “C” framework, these would include a focus on:

Characteristics of autism spectrum disorders and their effects on the learning and behaviour of individual students;

Comprehensive program planning across domains in addition to academics;

Components of Positive Behaviour Supports, including use of Functional Behaviour Assessments and the creation of Individual Behaviour Support Plans, and

Continuity of programming, ensuring appropriate, well-planned transitions between grades and schools

Although inclusion and belonging to a school community should be goals for all students, they are often compromised when school staff are not familiar with the complex special needs that students with ASD may have. Communication, social and behavioural difficulties, along with sensory, attention and learning challenges, characterize these students. Individual assessments and the subsequent matching of needs with instructional methods and materials are often particularly challenging for school staff. Individuals who support, teach, and supervise students having ASD need specific training and ongoing supports to ensure students having autism are well understood, and that they are actively engaged in learning, and not only included physically in a classroom. The specific learning characteristics of each student must be understood and addressed.

Comprehensive program planning results when there is a focus on looking at the student across domains and matching effective teaching strategies. Typically, cognitive, social, behavioural, academic and communication needs must be met, and a multidisciplinary focus is often required. Appropriate academic achievement is one aspect of that planning, but resources and

inclusive education practices must also include a wide range of opportunities and experiences. Instructional strategies that use behavioural strategies, appreciating functional and life-skill needs, along with reinforcement strategies, direct instruction of social skills, functional communication training, visual supports and assistive technology have been shown to be essential parts of comprehensive educational planning for students having ASD. A comprehensive program must address the range of specialized needs a student with autism may have before the program can achieve the full benefits of an inclusive educational setting.

Students with ASD also require specialized attention to behaviour concerns, functional behaviour assessments, and a behaviour support plan. Selection of a social skills curriculum to directly teach replacement social behaviours, methods of modeling, practicing, and generalizing social behaviours are typically required to make substantial, long lasting behaviour change. While positive behaviour support programming is gaining acceptance and use in Alberta schools, many teachers have not yet mastered this important set of skills, which are often essential for successful inclusion practices.

A final concern relates to continuity of programming. The transition from early childhood programs to Grade 1 is specifically mentioned in *Setting the Direction*. For many students having ASD, however, each major transition can be difficult. Many of these students require extra support, preplanning and predictability to make successful changes to new classrooms or schools. They are often distraught and anxious with simple changes in staff, routines or tasks. There are still examples of students changing schools without necessary information, communication devices, and other supports required. All too often, transition planning has not been effectively completed. As well, many students having ASD are involved in home programs and interventions outside school. The rich information and programming strategies in such programs should at least be reviewed, if not included in school programs.

The framework proposed in *Setting the Direction* provides a wonderful invitation to improve programming for all students requiring specialized supports. How can we ensure that students with Autism Spectrum Disorders will benefit by being more included, reaching higher levels of academic achievement, as well as meeting their unique instructional, social and communication needs?

Kebain@telus.net



The Autism Community in Edmonton Has Lost a Champion

Anita Ferri

Many of us will remember Barbara Stewart, who passed away this October, for her blonde hair and ready laugh. Barbara was small in stature, but she had a huge impact on the autism community at the local, provincial and even national level.

Barbara became involved in the Edmonton Autism Society, as it was called then, in the early 1980's, a few years after her oldest son Bryce was diagnosed with autism. Over the next 20 years, Barbara dedicated her volunteer time to the Autism Society. She was on the board for about 15 years in many roles, including President. Barbara was instrumental in reviving and re-establishing the Autism Society of Alberta in the early 1990's. She knew how critical it is to have a provincial voice for children and adults with autism.

Barbara gained a reputation for being informed: she was always clear on key points, and understood the critical issues affecting people with autism as they related to the educational, social and political situation at the time. Because of her knowledge base and her wonderful advocacy skills, she was often invited or nominated to sit on focus groups, task forces, and working groups with various levels of government to represent the Autism Society and parents and families of individuals with autism.

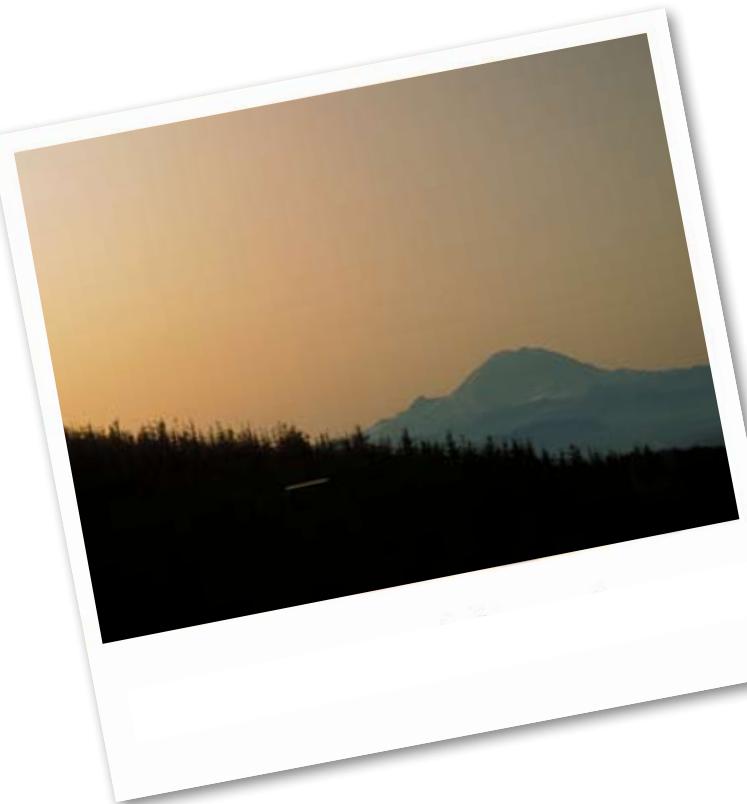
She worked with determination and incredible persistence to improve education and services for children and adults with autism. She also worked on a number of task forces, including one that focused on the needs of adults with autism, that eventually led to the "Protection of Persons in Care" Act.

Barbara had a certain style of advocacy that she used to the advantage of the autism community - a combination of a sharp, focused intelligence, a lovely warmth, and a gracious personality. Barbara's husband, Dr. Neil Roberts, describes her style of advocacy as "firm, persistent, gentle, persuasive"— and I would personally add "effective" to that list. When I think of Barbara, I think not only of what she did, but how she did it - with style, flair and a generosity of spirit that inspired others to get involved. When I think of Barbara, I think of one thing she said on many different occasions: "We need to do something

about this issue, because if we don't advocate for our children, who will?"

We will miss you, Barbara.

Barbara is survived by her devoted husband, Dr. Neil Roberts, and her loving sons, Bryce, Malcolm and Matthew.



TEACHER INFORMATION SERIES – 2009/2010

Introduction to Asperger Syndrome

Thursday November 19, 2009 6:30 – 9:00 p.m.
Presenter: Karen Phillips – Social Worker and Parent
of adult child with AS

Positive Behavioural Support, Part I

Thursday January 21, 2010 6:30 – 9:00 p.m.
Presenter: Shane Lynch – Doctoral Candidate,
Researcher, and Educator

Positive Behavioural Support, Part II

Thursday February 18, 2010 6:30 - 9:00 p.m.
Presenter: Shane Lynch – Doctoral Candidate,
Researcher, and Educator

Working with Parents

Thursday March 18, 2010 6:30 – 9:00 p.m.
Presenter: Karen Phillips – Social Worker and Parent
of adult child with AS
Anita Homan – Teacher and ERECS Consultant

Assistive Technology

Thursday April 15, 2010 6:30 - 9:00 p.m.
Presenter: Sandra Gluth – Teacher and
Technology Consultant

**** Note: PLEASE CALL FOR ALTERNATE LOCATION FOR THIS
SESSION ****

**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

FSCD Tips for Parents

Family Services for Children with Disabilities (FSCD) has been reviewing the way they provide service, and are considering how to best distribute contract funds to the hundreds of families in Alberta. During this time of reduced budgets and changes in how FSCD supports parents, it is wise for parents to keep on top of their child's specialized service contract agreements. Here are a few things to keep in mind:

- Track your FSCD contract expiry date. Call your FSCD caseworker 2-3 months before the expiry date to ask for a Multi-disciplinary Team (MDT) review date. Your service provider, Occupational Therapist (OT), Speech and Language Pathologist (SLP) LP, etc., will need to assess your child and have recommendations (a service plan) prepared for this review. Discuss the recommendations with your service provider to ensure that you, as your child's parents, are in agreement. If you disagree with anything, this is the time to negotiate with your service provider to ensure the plan meets the needs of your child and your family. When you agree, sign the document to show you have reviewed and agree with the plan.
- Let your FSCD caseworker know if you have any problems with your service provider regarding services provided, continuation of services, or service plan problems. If such problems will prevent you from being ready for your MDT review date, request an addendum to be written to avoid an interruption of services to your child, and request to reschedule the MDT review date.
- Let your FSCD caseworker know about any costs you are required to pay related to the agreed specialized services for your child, and ask that the contracted rates for services shown in your agreement are in keeping with market rates and are covered by your FSCD contract. For example: Inform your caseworker if you are charged a higher rate for a service than the amount listed in your agreement.
- If for any reason your service provider recommends that you "transition your child off specialized services" or "terminate service for your child", ask that their reason be put into writing. Is the reason valid? For example, if you are told there are

younger families needing the service, and not that your child does not qualify, be aware that you have options.

If the cause is that your child has not progressed, speak with your caseworker and inform them of any delinquencies on the part of your service provider. For example, mention if your service provider was unable to provide qualified staff (professional or 1:1) or fulfill the recommended hours to properly deliver the recommended service plan to your child.

Remember your child qualifies for specialized services if he or she “has a severe disability resulting in significant limitations and service needs in two or more of the following areas:

- (i) behaviour;
- (ii) communication and socialization skills;
- (iii) cognitive abilities;
- (iv) physical and motor development;
- (v) self help skills and adaptive functioning;

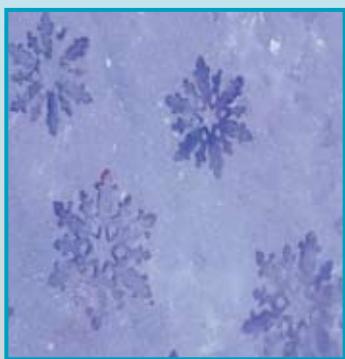
and if

- (vi) the level and complexity of the child’s needs require an array of integrated and coordinated services, including one or more specialized services,
- (vii) a multi disciplinary team has completed an assessment that identifies that the child has a critical need for a specialized service and recommends to the director that a specialized service be provided,
- (viii) an individualized plan, satisfactory to the director, has been developed to coordinate and direct the delivery of services, including a specialized service,
- (ix) the proposed specialized service is likely, in the opinion of a multi disciplinary team, to achieve measurable improvement in a reasonable and predictable period of time or to sustain or to prevent a regression or dependency in the child’s activities of normal daily living,
- (x) the proposed specialized service is based on established rehabilitative practices, strategies and approaches that are reasonable, least intrusive and demonstrated to be effective, and other available programs and services are not appropriate or are insufficient to meet the child’s needs”

- Your choice of service providers is not limited to those agencies located in Edmonton and area. There are other service providers both within and outside of Canada that currently provide services for families in the Edmonton area. These providers are also an option, especially for families that are finding it difficult to gain specialized services and appropriate intervention programs for older children. Travel costs associated with program supervision become part of your contract agreement with FSCD. A few examples of notable service providers outside of Edmonton are Autism Partnership – Calgary and the Centre for Autism and Related Disabilities (CARD) – California (their web site notes they work with older children).
- Sometimes one of your specialized service professionals (for example, Occupational Therapist) may be able to supervise your in-home program, in effect acting as your program coordinator. Check with your FSCD caseworker to see if this is a workable option for you. For example, your OT with your service provider may also do some private consultation. This private consultation is the model used by Autism Partnership and CARD.
- Be prepared to speak with your FSCD caseworker about the specialized services and hours of service your child needs. Ask and discuss possible options at your disposal to negotiate (save) contract expenses, such as other ways of coordinating services or supervision of services – for example, a parent-monitored model similar to the one currently being used by PDD.
- Familiarize yourself with the Family Support for Children with Disabilities Act and Family Support for Children with Disabilities Regulations at www.autismedmonton.org/fscd-links. The web page includes links to the original documents on the Government of Alberta web site. Check the Government web site periodically for changes and updates.

Art of Autism Christmas Cards Available Now!

ASEA is proud to offer a brand new series of Christmas cards, featuring some amazing art by local artists with autism! Four different sets of eight cards are available, with each set featuring four different full-colour designs. Proceeds from the cards are used to support programs for children and adults. To order or to find out more, please contact the ASEA office at 780-453-3971 or visit www.autismedmonton.org!



Educating Our Son with Autism (If I Had To Do It All Over Again...)

Shirley (Maher) Williams

They say hindsight is 20-20, and I think that's true for many areas in our lives. It's certainly true for our experience educating our son Joseph, who has high-functioning autism. Joseph is in Grade 12 this year, and is finally doing much better than he has ever done before. This is due to a combination high school and home school program in his IPP that we implemented last year.

We live in rural Alberta and Joe has attended two public schools in our area. If we had to educate Joe over again, this is the plan we would follow:

Kindergarten–Grade 1: During the first few years we would have home schooled Joseph, because at his school he was constantly getting sick with the flu (common with ASD kids). In fact, Joe got the flu so often that he ended up staying home half the time, anyway. Another reason to choose home schooling is the many health and professional appointments that are needed to get your child into “the system”. All these appointments ensure that you are constantly running around, and this is stressful for the whole family.

Grade 2–Grade 4 or 5: A public elementary school is good for socializing and learning during these years, as the school staff try many different ways to teach the child. Bullying starts around Grade 5, so I would pull the child out before Grade 5 or 6 if it starts to be a problem. Bullying severely, and sometimes permanently, damages the child. If the school deals well with bullying, then by all means keep the child in school until high school. If not, I would home school Grade 5 and possibly Grade 6, as it's not worth the extra troubles on top of everything else you're going through with your child and family.

High School: In high school we found that the teachers don't really want to get involved with your child, and that they want

the aide to have the full responsibility. This is probably because of their class sizes, among other reasons. There are exceptions, but don't hold your breath. The system also tends to lead your child to less academics and more life skills programs. Many teachers seem to give up on finding ways to help the child move ahead in academic areas of struggle. This may be good for some kids, but not for others. High school teachers generally want to get their students with ASDs through the system without much trouble. This is why we have opted for the following, as we knew our son had more academic potential.

Combo Home Schooling & High School: Let your child take their favourite classes or options through the high school, and home school the rest of their subjects. The child gets the best of both worlds with the flexibility this provides. They still get the benefits of high school, routine, independence, socialization, and education. But in areas where they struggle, it is best to go home and have focused time to work and learn. There is little or no bullying, they are less stressed, more productive and happy. Everyone wins.

Feel free to fine-tune your educational program to your child's needs!

Be positive and work as a team with your educational staff. If something isn't working, bring up the problems in positive ways. If results do not get better, brainstorm for something better and keep working at it, until the absolute best is done for your child. If the staff are too busy for this, work out a creative plan with your spouse and go in and present it to them. Sometimes they are happy to have this done for them, as their time is limited.

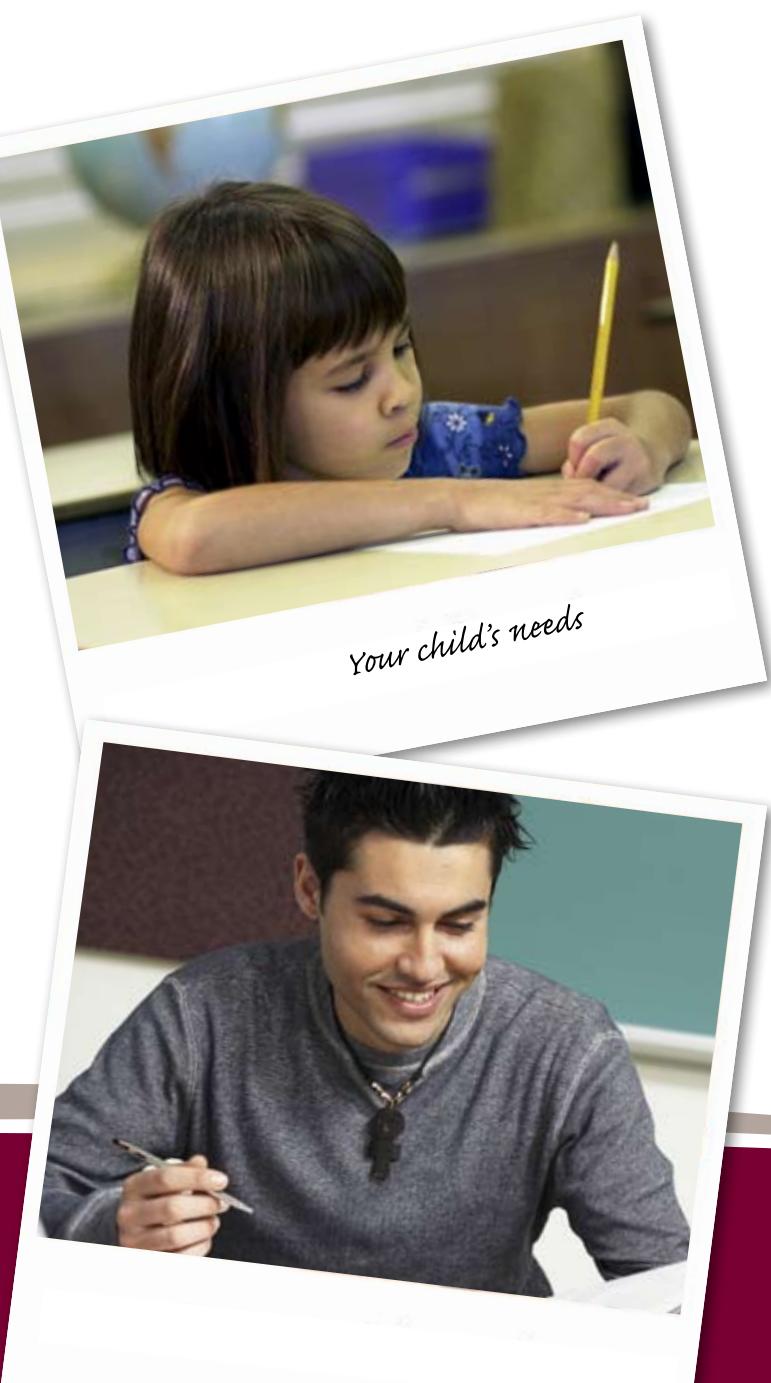
Other Tips We Have Learned:

- We do not allow an aide to work with our child unless they are willing to eagerly learn about his disability, or unless they have at least 2 years of experience. We stand firm on this, as a good aide is essential in your child's progress. An aide communicates and adapts verbal and written communication and learning materials for your child throughout the day, and also helps them deal with social challenges.

- If you have a "gut feeling" about an aide or teacher who is not working out or clashes with your child, check the facts (in most cases the child cannot verbalize these problems) and deal with it quickly. Get a new aide—don't try and accommodate the school, because they are there to accommodate YOU. Ask for another aide, and stand your ground!
- If the aide and the teacher treat your child with respect and care, then the children in the class will do the same. If they do not, then neither will the rest of the children in the class.
- Make sure that your aide and/or teachers are allowed to take in at least one autism conference per school year.
- Provide a tip sheet on your child to everyone who works with them. Make sure it includes things like their sensitivities, health challenges, or what to do in problem situations. This will go a long way toward getting everyone on board to help your child learn and socialize.
- Even if you are exhausted and have no extra time, try to get involved in some small ways to support your school and get to know your staff—it will pay off in the long run.
- Compliment and give thank-you cards or small gifts to your staff who are working and doing their best to help your child move forward. Always be honest and apologize when you make mistakes. Keep the lines of communication open.
- People are sometimes scared to home school because they think it will lack socialization. This is not a problem if you are a "social" family and visit with other families. Socializing is not a challenge if you combine homeschooling and high school. Let's face it: kids with ASDs are usually loners, whether they stay at home or at school, but it's still worth it to keep trying.
- Model treating your child with love and respect as a person, regardless of their disability. Look at the child first, and the disability afterward.
- Don't forget to teach your child manners. Please and thank you still go a long way, even if they can't say the words properly. This is good everywhere, including the school system.

Each child and situation are unique and different, but I hope these words of experience will help you to develop a creative program that is fine-tuned to your child's unique challenges and abilities. You only have one chance to do the best for your child with the information and resources that you have. Go for it, be creative, be courageous, and do whatever is needed to help your child achieve their greatest potential. You will never regret it, and neither will they. Most of all—for goodness' sake—keep praying!

To Your Child's Success!



The "Nature Nut" Meltdown

Cathy Lamoureux

I recently received an email from Deborah Barrett asking for another article. If any of you read the last *Autism Now*, I wrote an article on "The Quirky Mom's Group". I initially declined, as I am inundated with schoolwork, but as I sat here with my very sick son lying next to me, I decided I needed to write about the day's events that led up to why I am lying here now.

The highly anticipated day had finally arrived. We were going to see John Acorn, "The Nature Nut", at the Museum one fine Saturday. Our family are HUGE fans, and we had eagerly awaited this day. Jake, my 8 year old boy with Asperger's, was particularly excited to see "The Nature Nut", not because he is particularly fond of bugs, but because he wanted to have his guitar signed by Mr. Acorn. Jake does not exactly play guitar, but he has it in his mind that one day he will be a great performer. He has been known to try busking in the local Starbucks at the corner of our street, but so far he hasn't made much of a living at it!

We packed up the family, which consists of me, my son Jake whom I have already introduced, my 7-year-old neuro-typical budding entomologist Clay, and my husband Kent, who struggles desperately to understand the complexities of Jake's disorder and becomes quickly frustrated with many of Jake's quirky antics. We were already heading down the road when I made the terrible mistake of deciding to go to the Starbucks with the hottest coffee instead of the agreed-upon Starbucks by the video store. This was enough to start the family feud. Jake could not let go of the fact that we would not be sticking to the original plan, and Kent couldn't handle the fact that Jake was melting down over something as ridiculous as changing which Starbucks we were going to.

Kent and I made the executive decision that if Jake could not pull it together by the time we arrived at the video store, he would have to go back home. After all, if he was already upset about the Starbucks switch, he would not be in any condition to handle a day at the museum, and everyone's experience

would be ruined. Jake persistently carried on, so I was forced with that moral dilemma: whether to follow through with the consequences or let him have his way and make things better for a minute, or ten, minutes, or maybe an hour. We ended up heading for home with one boy, Jake, *pleading* so remorsefully that I was about to start crying, Clay in tears as he was feeling so bad for his brother whom he didn't want to see miss this event, and Kent staring me down, wondering if I was truly going to follow through with what I said. I must say, it was the longest ride home I have ever had to endure.

As I pulled into the driveway, Jake was already in a full-blown meltdown, and any of you with Aspie kids know how intense these meltdowns can be. As luck would have it, the nosy neighbour from across the street just happened to be out pulling weeds. This would be the only neighbour on the whole block who should not witness the next bit of events, as she already thinks our family is crazy, and believes that Social Services should be ringing our doorbell on most days! As I came screaming around the corner and onto the driveway, Kent flung his door open and ran to Jake's side to drag him out of the car while Jake kicked and screamed. He cried out for me to please let him hug and kiss me goodbye. I opened my door for our goodbye and he grabbed onto the steering wheel, wailing at the top of his lungs: "PLEASE, PLEASE MOM, DON'T LEAVE ME! PLEASE, I WILL BE GOOD!" My neighbour looked mortified as Kent peeled Jake off the car, and I quickly slammed the door and took off with Clay. As I looked back thru the mirror all I could see was Kent holding onto Jake's shirt as he tried to run after the car. Now, from an outsider's view we must have looked abusive parents denying our child his mother, but, as we all know, once a meltdown begins you really have to have an ASD child to truly understand the events that are unfolding.

As the day ended I gave myself a huge pat on the back. First, for being able to follow thru with the consequences we had promised, and second, for not letting myself get upset that I was once again in the hot seat with the neighbour as she continued to judge me on my inability to parent this poor, neglected child. Ironically, I am usually faulted for spoiling Jake, and it is almost refreshing to be viewed as neglectful. Maybe one day outsiders will understand how complicated

it is to raise our children, and instead of being so quick to judge us, they will seek to understand and then offer us help. Of course, if that happened we would have no need for the Quirky Moms Group, and I would have less to write about.

As the evening creeps in I take my usual spot after such an emotional day. I lay beside Jake as he sleeps next to me. Unfortunately my dear Jake becomes very ill after his meltdowns, and I always lay with him remembering why I love him so much. As we all know, our kids do not want to engage in such behaviour; they are just wired differently, and it takes a bigger toll on their little bodies than it does on ours. But as complicated and frustrating as Jake can make my days, I wouldn't want him any other way!

Goodnight, everyone.



The Meltdown

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OPENING DOORS

for AUTISM GALA

Thank you to our wonderful financial sponsors who have contributed greatly to the Gala and Auction held October 30, hosted by Danny Hooper.

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As we go to press, we do not yet have a full list of Gala donors. The full donor list will be published in the next issue of Autism Now. Thank you for your generous donations!

Thank You to ASEA's Amazing Volunteers!

ASEA's major fundraiser is the Opening Doors Gala, held every other year. The Gala provides the bulk of our funding at present, and continues to be volunteer-organized and run. In addition to our incredibly generous sponsors, we are also tremendously indebted to our hard-working Gala Committee and volunteers. Thank you to all who make this year's Gala a huge success.

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Deborah Barrett

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Family Managed Supports (FMS): Is It The Right Funding Option for My Family?

Allison Jiminez

If you are considering hiring staff to provide supports for your family member with a developmental disability, then you will probably want to choose a PDD funding option. Family Managed Supports (FMS), also referred to as “Private Hire”, has been a PDD funding option since 1999. This option has become very popular over the years, and the number of families who are currently choosing FMS is increasing rapidly. The 300 families who have chosen this option are encouraged to develop creative supports which focus on community inclusion for their adult family member. Some testimonials from families indicate they like FMS because they have total say in the choice of staff; control of the funding dollars; and the ability to develop a unique program that meet the needs of the individual, and is not limited to just respite, but also includes all the supports that PDD funds.

Families who choose this option become responsible for hiring, directing, supervising and paying the support staff hired to assist their family member. Families are in essence choosing to become the employer. FMS is not for everyone. Families who chose to become the employer or Funds Administrator, as they are referred to by PDD, are aware that this option requires their commitment to complete all of the administrative and reporting functions without remuneration for their time. The role of the Funds Administrator includes monitoring the quality of the supports that are provided, developing goals that focus on inclusion and outcomes for their family members, completing financial requirements, understanding the abuse reporting and response processes, adhering to applicable provincial legislation and regulations for employers, maintaining records, and attending the necessary training sessions that PDD offers.

What should you expect if you should choose this option? There is a lot of support to assist you with this journey as you navigate through FMS processes. Once you have completed the intake process you will be assigned a Community Support

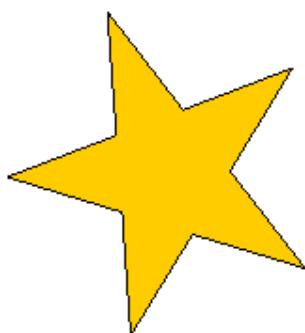
Coordinator (CSC) whose role is to assist and guide you through the steps required to do FMS. Your CSC, who is knowledgeable about FMS, will meet with you and your family member to discuss your unique service requirements. Your coordinator will translate your service requirements into a budget, submit an application for funding on your behalf, and explain the funding approval process. Once you have been approved for FMS funding, you will be required to complete a Family Managed Service Agreement, which is a contract between you and PDD. Your CSC will review and explain the agreement, the process for making changes to the agreement, and invoicing procedures.

Are there other supports aside from your PDD community support coordinator to assist you with FMS? Yes; PDD is committed to providing flexible supports to families who choose FMS and have contracted with a variety of community agencies to provide supports to families. These supports include access to a Payroll company to assist you with the payroll requirements, such as Revenue Canada source deductions, T4 slips, etc. Another agency provides learning opportunities to families which focus on individual service planning, abuse prevention and response protocol, individual rights and restrictive procedures, and employer-related responsibilities. Supports are also available to families who require positive strategies to manage challenging and complex behaviours. Support is also available to FMS families who would like to connect with each other for mentoring or sharing knowledge.

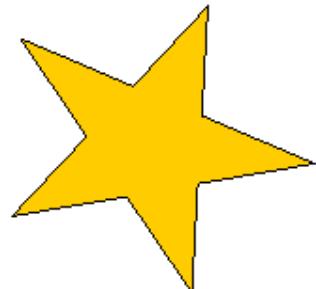
How can families' help impact the course that FMS takes? PDD believes in continuous improvement and believes that the users of this program should be involved in shaping and developing it. Families have told us that they would like a Family Resource Centre, a new model for FMS funding delivery, an improved intake process to enable a smooth transition to the FMS program, the provision of more knowledge about FMS through educational and outreach activities, and a review of PDD policies to ensure this option is flexible for families. If you decide that FMS is the right funding option for your family, we look forward to having you join a group of families who have taught us over the last ten years that families know what is best for their family member.

Riverbend Junior High

Welcomes All To Its 5th Annual...



*Past,
Present and
Future
Talent Show*



Location: Royal Alberta Museum Auditorium

Tickets: \$10.00

Date: Thursday, December 17, 2009

Doors Open At: 6:30 pm

Show Starts At: 7:00 pm

There will be a silent auction during intermission. All proceeds from the auction and ticket sales will go to:

Autism Society of Edmonton Area

FOR TICKETS CALL RIVERBEND JUNIOR HIGH:
780-434-7914



An Open Letter to the Autism Society of Edmonton Area

Claude Benevent-Loven

My husband and I are newcomers to your community, but you have already given us much inspiration and hope. I have an adult daughter with Asperger's Syndrome, and I am appealing to the community for interested people of like minds and hearts to come forward to form a holistic residential program, based on the Camphill model, for our loved ones.

Here is Sophie's story: It was first determined that Sophie was autistic at age five-and-a-half. She was diagnosed by Dr. Tomatis in Paris, who treated her with a method that gave her the capability to communicate with language. After that, she was able to learn both English and French. We had a follow up program with Dr. Tomatis a year later at his Toronto clinic, the CALL Centre. Except for her first two years in a Waldorf program in Edmonton, Sophie's experiences with inclusive education were painful. She finally enjoyed her studies at Grant MacEwan's College Connection Program, a place where she was respected by both students and teachers.

When Sophie turned nineteen, she suffered the onset of bi-polar disorder. In our quest to help Sophie be all that she can be, and following her leads, we have explored group home settings, and programs through Nina Haggerty, Chrysalis, and EmployAbilities, to name a few. So far, the only program in Edmonton that Sophie truly enjoys is the Little Bits Therapeutic Riding Program at the White Mud Equine Centre. Sophie's well-being is supported by her love for artistic expression, piano and singing.

At the end of the College Connection Program, Sophie was bored in the group home setting and returned home to live with us. We had to regroup to give Sophie an interesting life. This is when I met Kathleen Thompson, who is a Waldorf Teacher (Grades 1 to 12) with a remedial education specialty. She invited me to work with her to home school two children in a Waldorf program for a year, with very good results. Then Kathleen agreed to create a program for Sophie. The program was very inspirational and enlivened Sophie. Kathleen also

started us on the path to explore the Cascadia Program in North Vancouver (www.cascadiasociety.org) and the Glenora Farm on Vancouver Island (www.itawegmanassociation.org). In the end, Sophie did not move there because Cascadia had no openings, because Glenora Farm was short-staffed, and because our family is here in Edmonton. And yet, as the advancing years press in on me, I know in my heart that I must create a suitable lifestyle for Sophie for her care now and after I am gone.

I have been encouraged to find ways to start a Camphill-inspired Program in Alberta. A year ago, Persons with Developmental Disabilities (PDD) had verbally offered support to get this project off the ground. We have met some wonderful people who have helped so much along the way—notably George Bengtson and Heidi Krieger, who have been working with Sophie, with the spirit of Camphill in mind, for the past five years in our home. And yet, Sophie needs true community because she feels so isolated.

Many of us who have adult children on the autism spectrum are faced with the need to create suitable residential care and adapted programs. In Camphill communities, companions (people with developmental or intellectual disabilities) and co-workers (caregivers) "live and work together to create a life that is healthy, abundant in cultural opportunities, and vocationally and socially fulfilling for all."

In Alberta, we could start with a day program in a vacated school, perhaps. Initially, we would look for ways to utilize existing talents and gifts to share among ourselves, as people with Autism/Asperger's, as parents, and as current trusted caregivers. We could all build on a vision for the future as we learn about Rudolf Steiner's philosophy and Karl Konig, the founder of the Camphill movement. The focus of the program is to provide healthy rhythms of life, good nutrition, a sense of purpose, and the gratification that comes from contributing to society in a meaningful way. Beauty, truth, and a love of nature complete the holistic mandate.

If you find you have a similar vision and are interested in pursuing this conversation, please contact me at 780-469-8860.

Walk Now for Autism Speaks

Deborah Barrett

Rundle Park had a carnival-like atmosphere on Sunday, September 13. The CHICKadivas performed their crowd-pleasing tunes, balloons were handed out, and hundreds of adults and children strolled through the resource fair table displays as they prepared to walk for autism research. A tent and amusements for the kids were hosted by Children's Autism Services, while ASEA hosted a tent for teens and adults with autism, and gave balloons to anyone who asked. Young or old, everyone was there because they are connected to someone with autism, and everyone wanted to do something to raise money for autism research.

Suzanne Lanthier, Executive Director of Autism Speaks Canada, introduced Deb Samagalski, one of this year's top fundraisers. Dr. Lonnie Zwaigenbaum spoke about autism research and Mike Lake, Member of Parliament for Edmonton – Mill Woods – Beaumont, talked about the need to support families with autism by supporting autism research. And then the walk began. Later that morning, when the happy walkers returned, we learned that about \$120,000 had been raised for autism research. Congratulations to all who helped!



Thank You to Our *Autism Now* Contributors!

Backstreet Communications	Marcy Henschel
Karen Bain	Allison Jiminez
Deborah Barrett	Cheryl Kerr
Claude Benevent-Loven	Cathy Lamoureux
Kurtis Connell	Mark Middaugh
Erin Dewar	Yolan Parrott
Linda Dowell	Karen Phillips
Amelia Duplessis	Roman Sokolowski
Anita Ferri	Shirley (Maher) Williams
Ryan Guenter	

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

Pro-Active Strategies for Finding Lost Children

Cheryl Kerr

What would you do if your child were lost? It can happen so easily and unexpectedly. It's a situation every parent fears, especially if their child has special needs. Time is critical when searching for a lost person, so earlier this year ASEA invited Constable Adrian Marr, Search Manager with the Edmonton Police Service, to discuss the role of search management operations in finding lost children, as well as pro-active strategies for parents. Here are some preventive measures that parents can take before their child goes missing:

- **Start a Lost/Missing Person Questionnaire**

- Obtain a copy of the questionnaire from ASEA.
- Complete the parts of the questionnaire that are relatively static, such as doctor information, general description of the child, places frequented, medical health, habits and personality. This will save valuable time if the form is ever needed to be completed entirely.

- **Update your emergency contact information**

- Choose people who would be available if called.
- Share a copy of your Lost/Missing Person Questionnaire with your emergency contacts. Include a photo.

- **Be aware of the child's behaviour, schedules, contacts and conversations**

- Monitor the child's behaviour, schedules, contacts and conversations. Detailed information saves time by providing clues as to where the child may be.
- Note clothing. If possible, establish a clothing schedule so you can determine what they were wearing when they got lost, in case you do not know or remember.
- Establish networks of people who know your child and would be able to assist in a search.
- Formalize an alert process with your network so they would know what to do if contacted.
- Learn from the past so you can narrow down the search area.

- **Visit your community police station**

- Take your child to your community police station and introduce yourselves. Tell them Constable Adrian Marr gave a talk at ASEA and suggested you make yourselves known to them in case your child ever went missing. The more known your child is to the police, the easier it will be to find him or her.

As diligent as you can be, you can't always prevent your child from bolting or wandering off. Therefore, the best strategy is to be prepared so your child can be found quickly. The strategies listed above will aid the search process. If you would like more information about lost or missing persons, please contact Patricia Terrett at ASEA.

Thank You to ASEA's Amazing Volunteers!

Jean Ashmore	Karen Bain
Stephen Barrington-Leigh	Tracee Baird
Jeff Belch	Amelia Duplessis
Nan Edmond and daughter	Anita Ferri
Gino Ferri	David Jardine
Heather Guenter	Rudy Guerra
Marcy Henschel	Anita Homan
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Dramamama

Amelia Duplessis

I'm sleep-deprived and mentally exhausted. I am trying to think of something to say about the summer parent/child group we held this summer, and it probably won't make much sense. Sound familiar? Hal is a night-waker. She has been up for virtually every night since she was born three-and-a-half years ago. Add a teething 14-month-old into the mix and Mommy is delirious on sprint sleeping. Mom's lack of energy is complemented by her children's hyper-energy: climbing on tables and chairs, never-ending exploration, requests for assistance to do something they aren't supposed to be doing...

That energy level has never been good for play groups. Hal also has sensory issues which made singing in circle time or music lessons torture for her. I have enrolled in dozens of play groups of all kinds, and have had to drop out of every single one.

About a year ago, driven by failure, I began thinking about what I can do to help my daughter. What I had was degree in Drama and experience participating in dozens of failed playgroups. Finally, I got an idea, and this past spring I piloted my Dramamama group at a community parent/child group. We had a blast! We worked together to make costumes and sets. I would read the lines to the kids, and they would repeat them aloud.

The plan was to do the same over the summer with the Autism Society. The first day of the summer group was a free-for-all, so I could get to know the kids and find out what they were interested in. They liked aliens, so I planned on an alien-themed class, complete with alien surveys for their alien characters. The second day I was surprised with an entirely different group of people who liked farms. Each week had different people, so it was time for a change of plans, since the old plan relied on consistent membership. What ended up evolving was a casual get-together where parents could meet and 'compare notes', and the children could do activities or play together. Coming from someone like me, who had taken a month to write a page, the latter was much easier to prepare for! Friendships were made, and parents had an excuse to get out of the house.

My own personal experience with the group involved my daughter, Hal, going from screaming and not wanting to go into the room to sitting and colouring for the entire 45 minutes, and then some, by the end. We also got to hang out with adults who are on the spectrum, and who were able to corroborate a lot of things I have noticed about my daughter that the doctors said aren't related to autism. Hal started playschool a few weeks ago and has surprised me by consistently staying the entire 2 hours, 3 days a week, without incident. I chalk some of that up to being able to practice in a hospitable environment with many positive adults and children over the summer. (She also has a good aide.)

The summer was incredibly positive, and it would be great to continue holding get-togethers. Not just with parents of recently diagnosed children, but everyone. Adults are great mentors, not just for the kids, but to the parents, too. And older kids on the spectrum are great role models for younger kids. It would be great to build a community within the Autism Society where we can offer support to each other.

Unfortunately for me, the regular day-to-day stressors and business (and an actor husband who is busy, on the heels of being nominated for a Gemini Award!) have left little time for planning and implementing much other than meals. But if you would like social gatherings for the society, I would very much like to continue to work with people like you to help build a community that can strengthen the bond that we all have.



Puberty, Sexuality and You: Providing Your Child with a Sexual Health Education

Yolan Parrott

Quite often the parents that come to the puberty and sexuality parent group at the Glenrose Rehabilitation Hospital's Autism Follow-Up Clinic arrive with a mix of curiosity and anxiety. On occasion I have seen parents cringe when I ask about sexuality education, while the majority of the time I am met with a gaze that conveys a mixture of fear and panic. Those parents who seek me out usually want a solution to a sexually-based "problem behaviour" such as inappropriate touching or stripping in public. For many parents, behaviours such as these are not a concern, making the topic easy to forget. But even if you never need to address specific sexually-based concerns with your child, all of your children will, one day, experience puberty. It is important to understand that your child will mature at the same physiological rate as same-aged peers (Koller, 2000). Additionally, your child will have curiosities and deserves to be informed of the physiological, social and emotional changes they are likely to experience. Sexuality education should address physiology and anatomy, as well as sexual behaviours, attitudes, values, emotions, body image, physical expression and much more. By providing your child with appropriate sexuality education early, you prepare them for future relationships and healthy sexual decision making. I always tell the parents I work with to "think about your child's future and what you want them to know when they are 18, 25 and 30". These are the things we need to start teaching them now, so they will have the foundation skills to engage in healthy relationships and lifestyles in the future.

Although children with autism typically follow the same physical growth and development as their peers (Koller, 2000), they may not have the same opportunity to learn information and skills associated with sexual development. This may result from not having the same access to sexual health education, or not receiving sexual health information in an appropriate format. To prepare your child for puberty as well as sex education in school, it is best to start early. Although there is no established "correct" time to begin addressing the topic of sexuality, there

seem to be two logical places to start; which one you choose is up to you. One option is in the years prior to puberty. Although children begin puberty at different ages; on average, girls begin puberty at age 10 or 11, and boys at age 11 or 12 (<http://sexualityandu.ca/professionals/sexuality-child-4.aspx>). Keep an eye out for signs of secondary sex characteristics (voice changes, development of breast buds, etc.), as these are signs of puberty. By providing sexuality education prior to the onset of puberty, you can help your child through this difficult transition. Physical and emotional changes are a scary thing, especially if you don't know what is happening to your body. Starting sexuality education early also allows children to master the new skills required for managing puberty. Information on hygiene, menstrual management, masturbation, etc., allows children to learn these tasks prior to them becoming necessary components of daily living skills.

The second appropriate option for initiating sexuality education is just prior to receiving school-based sex education. If and when school based sex education is provided will depend on your school program. If it is being instructed to your child, it is important that you discover when it is being taught and what the curriculum contains. Introducing your child to sex education will give them a "heads up" on the topic and help prepare them for the topic at school. Unlike peers who may have acquired knowledge regarding sexual health through incidental learning, children with autism are less likely to have picked up on informal sexual health education through social cues, informal information shared on school grounds, or by TV or music media.

We all know sexuality is a sensitive topic, and is often difficult to broach. Many parents report their children do not show an interest in the topic. Trust me, this is normal, and by no means does it indicate that the topic should be ignored. When broaching the topic, a good place to start is by looking for available opportunities in everyday life: scenes from TV shows or movies, or even couples on the street, can serve as examples for conversation about relationships. Books can be used as a tool to engage in conversation— just be sure to find ones that are both age-appropriate and at the cognitive level of your child. Using the school curriculum is also a great way to engage your child in

the topic of sexuality: by finding out lesson plans you can review the information covered at school with your child later on at home. Lastly, remember to welcome your child's questions by indicating your openness about the topic. The more comfortable and open you are, the more likely they are to voice questions and concerns.

Always remember that you are the best source of sexuality education for your child. Without knowing it, you have been modeling social relationships, attitudes, values and behaviours for your child for many years now. By broaching the topic of sexuality with your child you can share information which will encourage a healthy, happy and safe lifestyle.

*Yolan Parrott MSc OT
Occupational Therapist
Glenrose Rehabilitation Hospital – Autism Follow-Up Clinic*

References:

Koller, R. (2000). Sexuality and Adolescents with Autism. *Sexuality and Disability*, 18 (2) Pg. 125 SexualityandU. Sexuality and Child Development. (2006) [Online] Available <http://sexualityandu.ca/professionals/sexuality-child-4.aspx>. Accessed on January 10th 2009.



social and emotional changes

A Parent's Perspective: Looking through the lens of the SCERTS Model

Marcy Henschel

My fraternal twin sons were diagnosed with autism when they were 3 years and 2 months old. I feel that our boys have made wonderful progress over the years, but there came a time when I began to notice a large gap in the functional use of all the skills they were learning, and in their ability to transfer what they learned into everyday life. Even though this gap was becoming very apparent to me, I didn't know what to do about it.

In 2007, after attending a presentation at an autism conference with one of the founders of the SCERTS model, Dr. Barry Prizant, I realised how to fill the gap! I knew where I wanted and needed our son's educational and therapy programs to go. Wearing both of my 'hats'— the first being a university trained educator and the second being a parent— I knew I had found the treatment framework and methodology I had been searching for and trying to put into words for all of our current therapists: it was the SCERTS model. I immediately rushed to the conference bookstore and bought the comprehensive manuals. I then began helping my son's teams at school shift focus, and I started working with a service provider using the SCERTS model, Children's Autism Services of Edmonton.

What I love about the SCERTS model:

- It is extremely family-centred and focuses on the child's development.
- It provides a framework of detailed goals to work from, but it is very flexible.
- It focuses on enhancing our children's core underlying developmental abilities.
- It includes pretend play and addresses the domains of "Joint Attention and Symbol Use, Mutual Regulation and Self-Regulation, Interpersonal Supports and Learning Supports"¹
- It has excellent tools to help the team determine where the child is presently functioning and provides an organized progression for goals.

- It focuses on the development of functional skills that are individualized for children; skills that enhance our daily lives as a family and allow our children to increase their independence and self-esteem.
- It doesn't exclude other approaches and teaching strategies as long as they are in line with the SCERTS goals for our children.
- It doesn't focus solely on training skills in a linear, rigid manner. The model facilitates the generalization of skills.

Over the past three years, through our work with the qualified professionals both in the education system and via our FSCD-funded Specialised Services home program with Children's Autism Services of Edmonton, we have kept our SCERTS lens at the forefront of everything related to our sons' education and therapies. What a difference it has made to us and them! We have seen a significant increase in their ability to socially communicate and engage, regulate their arousal and communicate their emotions. Transactional supports have become an everyday part of every aspect of our lives. We have had many successful community outings, attended many community programs and events, and had two wonderful, very successful family vacations, both including airplane rides! We even used everything we have learned from SCERTS to help us get our sons through serious major medical procedures, successfully helping them understand what was going on. I have found the Learning Supports to be key in achieving success in whatever we are doing. There are a few things we don't leave home without: social stories, visual supports or schedules of some sort!

"The SCERTS® model is a comprehensive, multidisciplinary approach to enhancing communication and social-emotional abilities of individuals with ASD and related disabilities. The model addresses three domains: Social Communication, Emotional Regulation, and Transactional Supports"²

** For more information, check out www.scerts.com or www.childrensautism.ca

1,2 Prizant, B. M., Wetherby, A. M., Rubin, E., Laurent, A., & Rydell, P. (2006). The SCERTS Model: A Comprehensive Educational Approach for Children with Autism Spectrum Disorders. Baltimore: Brookes.

ASEA Casino – Volunteers Needed!

Wednesday & Thursday, January 27 & 28, 2010
Palace Casino, West Edmonton Mall

It's time for another casino, and we need your help! Casinos are a HUGE fundraiser for ASEA's programs and services – the last one brought in over \$75,000 from just two days of work! But when you volunteer, you won't just be helping people with autism and their families—you'll also have the chance to meet great people from the autism community, share stories, and make connections that could last a lifetime.

We need 40 volunteers to make this another successful casino.

- Anyone who is 18+ years old and can pass a security screening is welcome to volunteer
- If you'd like to help out, contact Greg Morrison at 780-436-3875 or gregmorrison@shaw.ca
- Please tell Greg which day and which shift you would prefer (first shift: approx. 11 AM-6 PM; second shift: approx. 6 PM to 3 AM)



Volunteers Needed

Thank You to All of Our Recent Donors!

MOSAIC SPONSORS – \$1000-\$4999

CIBC World Markets (Children Foundation)
Collins Industries Ltd.
The Retreat Hair & Esthetics Inc.
TIC Canada, Cloverbar Site Building Trade
Union 52 Benevolent Society
United Way of Alberta Capital Region

KALEIDOSCOPE SPONSORS – \$500-\$999

Deborah Barrett & David Jardine
Ric Forest
Meloche Monnex Edmonton Social Club
Universe Machine Corporation

TIFFANY SPONSORS – \$100-\$499

Robin Adkins	Johannes Koopmans
Claire Derochers & Doug McConnell	Brian MacDougall
Carol Grierson	Glen Resler
Mark Lynch	Wayne Shaw
Place-Crete System Inc.	Marcel Van Hecke
Brian Robinson	William & Ruth Wyatt
United Way of York Region	
Alex & Beverly B. Young	

COLLAGE SPONSORS – \$0-\$99

Monika Anderlic	Gerald Anderson
Donald & Catherine Beer	Leon Carlson
Robert Chromyc	Carlos Escoto
Morley & Paula Hagan	Terry & Ruth Harrold
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Leonard & Oxanna Lozowy	Jean MacKenzie
Claudette & Brian Maclean	Margaret Marshall
Kim McCool	Albert & Jane Medcke
Peter Mergl	Roy Merritt
Raha Munawwar & Shawkat Shareef	Olin Murray
Kimberly & Dallas Perreault	Catherine Perry
Jay & Vanessa Reinett	Dave Riffle
Marcel Royer	Casey & Alexandra Skakun
Diane Skoetsch	Helen Underwood
Carrie Weich	Melanie & David Yourechuk
Tammy Zeman	

My Time As a Junior Youth Leader

Kurtis Connell

Because of my lack of experience in a working environment and in a leadership position, being a Junior Youth Leader was, at first, a significant challenge for me. At first I was not willing to accept the position, as I lacked any confidence in myself as a responsible and dependable person; it did not sound like a job that would suit me. Yet over time, as I had gained experience in dealing with both the staff members and the campers, I began to realize that I had greater potential than I'd thought. I began to overcome my feelings of angst and self-doubt, and started to feel like I could actually handle a high level of responsibility. It was a pleasure to have gotten to know such friendly and interesting people, and I am grateful for all the help they had given me.

I honestly feel that I could have simply volunteered to help without being employed, and would have still felt just as satisfied. It was my first ever job, and I definitely enjoyed the feeling of earning my own money, but any monetary gain was totally secondary to all the other wonderful opportunities and experiences I gained during the past summer. It's been a great time.



Responsibility

Pancake Breakfast Raises Money and Awareness for Autism

Deborah Barrett

A sunny Saturday morning, a delicious pancake breakfast, and a cheque to the Autism Society for over \$3000 – what could be better? That was the feeling on August 22, when Mike Lake, MP for Edmonton- Mill Woods-Beaumont, held his second Pancake Breakfast Fundraiser for the Autism Society. On this sunny August morning, Mike, along with his wife Debi, daughter Janae, and son Jaden, hosted a number of families of kids with autism and many Mill Woods-Beaumont constituents.

Mike knows about autism firsthand, because his handsome young son, Jaden, has an autism spectrum disorder. Because of Jaden, Mike has helped raise awareness of autism in Ottawa. And the Pancake Breakfast was a great opportunity for ASEA to help Mill Woods-Beaumont constituents learn more about autism. One tiny, grey-haired lady told me, “I don’t know anything about autism. I just want to understand.” “Wow,” I told her, as I offered her a brochure, “what a great attitude. Learning more about autism is an important way to help build community support for our children and adults with autism.” So thanks, Mike, for supporting ASEA and for helping us build more awareness and stronger community connections. We sure appreciate it!



Parent Information Nights

Negotiating Contracts with FSCD and PDD

Date: November 24, 2009, 7 PM-9 PM

Tips from Experienced Parents. Feel free to ask questions.

Presenters: Roma Kurtz (Parent and Teacher) and David Jardine (Parent and Lawyer)

Caregivers Taking Care of Themselves

Date: January 26, 2010, 7 PM-9 PM

Presenter: A representative from the Alberta Caregiver’s Association

FSCD – Changes

Date: TBA

Presenters: Marcy Henshel and a representative from FSCD

For each Parent Information Night:

Location: 11724 Kingsway Avenue, Main floor boardroom

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

To register: Phone 780-453-3971 or E-mail autism@autismedmonton.org

For more info, check ASEA's web site, www.autismedmonton.org

A Junior Leader's Experience at ASEA's Fun in the Sun Camp

Mark Middaugh

This summer, I had the opportunity to work as a Junior Youth Leader for the “Fun in the Sun” camp for children with autism spectrum disorders. I have to applaud the Autism Society for inviting staff who were affected by autism to work alongside people who were educated to work with children with ASD. It was a great experience to work with this delightful and unique group of people. My own experience as an individual with autism proved to be very helpful to the team, as it helped the staff to anticipate

and interpret the campers' behaviour. The campers seemed comfortable working with me, and I hope I made a positive impact by working with them. Even after the camp ended, I've continued to mentor a youth who attended the camp—not as a job, but as a relationship.

One thing I learned from this experience is that the most important aspect of working with these children is making a connection. This is the basis of all success for both the camper and the leader. There is nothing more important to a child with ASD than the opportunity to connect with people in a positive and personal way. That may be true for all people, but people with ASD have fewer opportunities to socialize in a safe, welcoming environment, and that's why a camp like this one is so important. I'm also pleased that the media got involved and produced a story on the "Fun in the Sun" experience. Hopefully, through public awareness, there will be many more opportunities for people with Autism Spectrum Disorders. All in all, the camp was a great experience for everyone, and I hope that I will have another opportunity to participate in "Fun in the Sun" next summer!

ASEA Receives Community Spirit Donation Grant

Roman Sokolowski

The Autism Society of Edmonton Area is excited to announce that it is the recipient of a \$14,813 Community Spirit Donation Grant from Alberta Culture and Community Spirit. The grant money will help ASEA to serve individuals with autism and their families in new and better ways. ASEA receives many phone calls from families and professionals who want to access our services or even require emergency assistance. That's why a portion of the grant money will be used to set up an improved phone system in our office. The grant money will also be used to develop a foundation for ASEA's volunteer program, so that we can better connect with people who want to help their community. The Autism Society would like to sincerely thank Alberta Culture and Community Spirit for this valuable grant, with all the exciting new opportunities that come with it.

Events at a Glance

For a complete, up-to-date listing of events from ASEA and within the autism community, please see ASEA's web site. Just visit www.autismedmonton.org and click the "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?

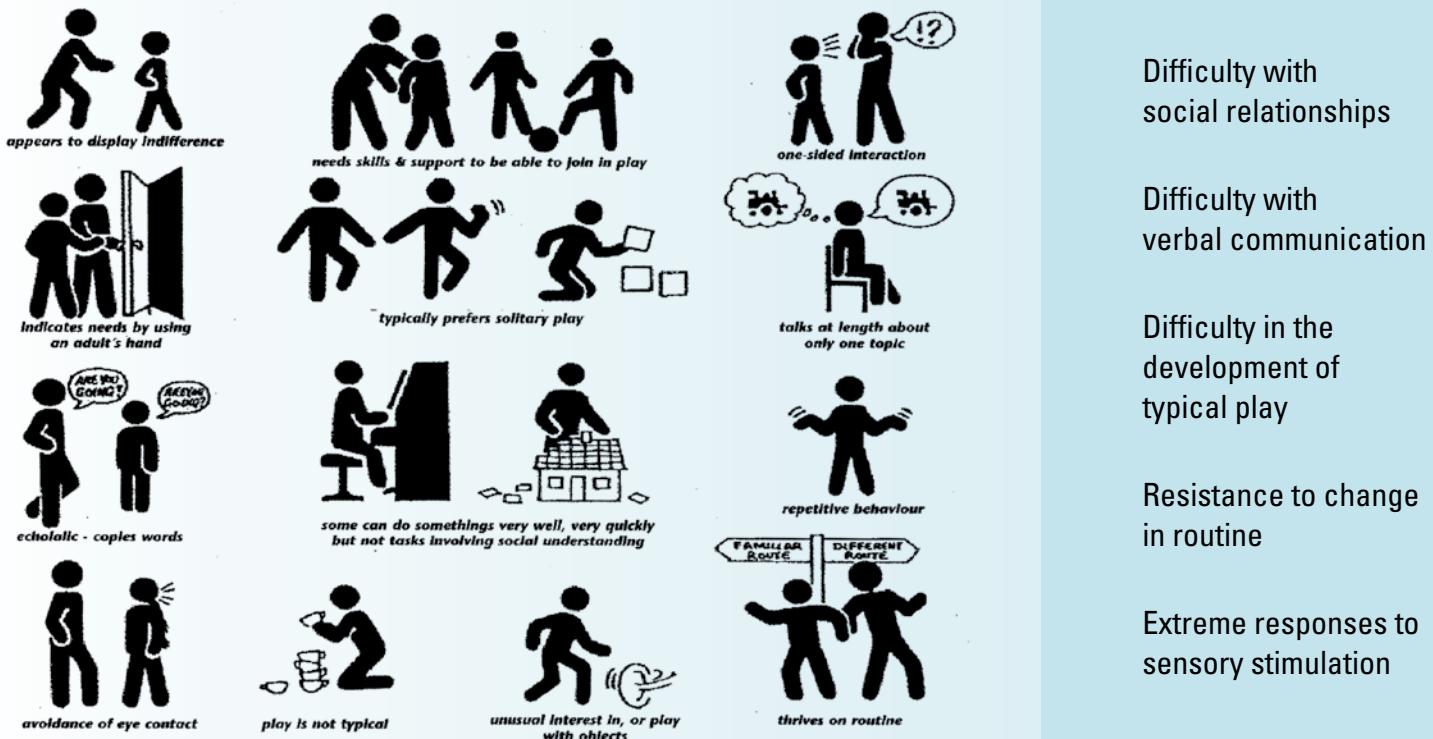
Autism Now would love to hear your stories - about your kids, your concerns, your family. If you have time to write, please email your articles to submissions@autismedmonton.org. If writing isn't your thing, send us an email—we will be happy to talk with you and write an article based on your experiences. Autism Now would love to include a full spectrum of stories about living with autism.



share your story

Autism is:

These figures illustrate some of the manifestations of autism. Not all persons with autism experience each of these symptoms and they vary in severity.



Early diagnosis is essential if people with autism are to achieve full potential. It is only when their disability is understood that they can be helped to maximize skills and minimize problems.

Please return your completed form and/or donation to:

AUTISM SOCIETY OF EDMONTON AREA
#101, 11720 Kingsway Avenue, Edmonton, AB T5G 0X5



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

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 Are they autistic? School _____

Your child's name _____ DOB _____ dd/mm/yy Are they autistic? School _____

Your child's name _____ DOB _____ dd/mm/yy Are they autistic? School _____

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

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

\$40 New family membership \$100 professional / agency membership

\$40 renewing family membership \$40 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 AMEX Cheque

Card number _____ Expiry date _____ mm/yy

Signature _____

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

\$10 \$25 \$50 \$100 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
\$10 are eligible for a
charitable tax receipt.

Please return your completed form and/or donation to:

AUTISM SOCIETY OF EDMONTON AREA

#101, 11720 Kingsway Avenue, Edmonton, AB T5G 0X5

E-mail: autism@compusmart.ab.ca



www.autismedmonton.org



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Return undeliverable Canadian addresses to:

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