DINNER AND AUCTION
OCTOBER 30, 2009
at the ITALIAN CULTURAL CENTRE, 14230 – 133 Ave.
Champagne Reception: 5:30 pm • Dinner: 6:00 pm
Summer is in full swing
President’s Message

Ryan Guenter

Three and a half years ago my only real knowledge of autism was the movie ‘Rain Main’ with Dustin Hoffman. For people who are not somehow affected by autism, this movie may be their only source of information about ASDs. Needless to say, my knowledge and interest in autism have grown immensely by working with the Autism Society of Edmonton Area over the past three years.

In 2006 it was discovered that my oldest nephew, Nicholas, had what was at that time termed a Pervasive Development Disorder, which placed him on the autism spectrum. After overcoming our initial surprise, our family really banded together, and I can report that Nicholas is now doing great as a student at the Janus Academy in Calgary.

Since I was still new to the Edmonton area – I relocated to Edmonton in 2004 after graduating from the University of Lethbridge – I wanted to donate my time to a local volunteer cause. After discovering that Nicholas had autism, it seemed natural to find an organization that helped kids on the autism spectrum.

The first name that popped up in my initial Google search was the Autism Society of Edmonton Area, so I emailed Deb Barrett, who was President at the time, and asked if I could help out. I attended a board meeting one night in March of 2007, and the next thing I knew they had chosen me as the new Treasurer. Numbers are on my brain all day through my work in the investment field, but accounting was not my strong suit, so I found the task a bit daunting. Since we already had a perfect candidate to replace me on the board – Jackie Ryan holds her Certified Managerial Accounting designation and is a top-notch member of the executive – the plan was to relinquish my title of Treasurer but remain on the board as a member-at-large.

That is when the plan went sideways. Somewhere along the line, members on the board decided it would be a good idea for me to take on the Vice-President role, as the VP at the time, Terry Harris, would be stepping up to replace Deb Barrett as President. After talking it over with my wife and family, I decided to take the role with absolutely zero intention of becoming President.

As Terry’s new business really shot off the ground and his time became limited, I would again be asked to step into another role on the executive – this time as President. After speaking with my beautiful and wonderful wife about the matter, we came to the conclusion that it would be an honour for me to accept this role.

Enough about me, however. In the past three years that I have been involved with ASEA, it has been my honour to be a part of the 2007 Gala, the Art of Autism and two great AGM’s. It has also been my pleasure to develop some very wonderful relationships with many great people in the Edmonton area. Most importantly, in the past three years we have seen the implementation of two key staffing roles in the Program Director (Karen Phillips) and Director of Community Awareness and Development (Deb Barrett) who are doing amazing work. With these key staff members, the end result is that we are helping the 7,000 plus families who are affected by autism in the Edmonton area alone. And although not many people know this, ASEA supports many families outside of Edmonton, as well. Families from the Wood Buffalo region or the Athabasca region of Peace district also have ASEA to lean on in times of need. Another initiative we have recently undertaken is to upload Parent and Teacher Info Nights onto our website for members to watch online, no matter where they are. These are just some of the ways that the folks at ASEA are working to help the community.

It’s not easy, though. We need assistance from time to time, like this October, when our primary fundraiser, the 2009 Opening Doors Gala, will be held at the Italian Community Centre (off St. Albert Trail). At this exciting event, host Danny Hooper will have over four hundred guests laughing uncontrollably, and thoroughly entertained. Buy your tickets while they’re still available, or help us out by making a donation or volunteering your time. Your help is appreciated!

Until next issue, thanks very much for your support.
This past school year, a group of teachers from Edmonton Public Schools met four times after school to discuss topics related to teaching students having complex special education needs, including Autism. A teacher network allows teachers who have common interests to share information regarding teaching strategies and best practices. The group consisted of teachers from Interaction, Community Living, Individual Support, and Opportunity classrooms. Each meeting involved a selected topic.

The last session, April 8, focused on issues regarding sensory and movement needs of students within a group format, often of interest to teachers who work with students requiring extra consideration due to difficulties processing and responding to sensory demands. A new resource, “Is it Sensory or is it Behaviour?”, was introduced, and various additional handouts were distributed, including some assessment forms. Many of the teachers have access to a designated Sensory Room as part of their daily programming, but some do not. Some teach students who have had formal sensory integration treatment and interventions in early education or home programming, but not all students have been involved in professionally designed sensory interventions.

Small groups discussed several questions designed to raise awareness and share mutual concerns. Our discussion is presented here to stimulate ongoing planning for learning teams who wish to address the special sensory needs of students for whom they are developing programs for the next school year. As well, the teachers involved will continue to develop strategies and activities which can support sensory management and coping skills for individual students.

1. Who should have a sensory-motor program as part of his or her educational day? How do you know?

Group Responses:
- Any student who has sensory aversions or difficulty coping with the daily schedule, based on individual needs
- Students need assessing regarding sensory needs prior to programming
- All students and teachers need movement “breaks” to stay alert and emotionally regulated
- Sensory breaks should be embedded into the educational schedule rather than separate from academic experiences
- Kids who are more “available for learning” following breaks should have them scheduled frequently
- Staff need to be aware of the differences between general movement and sensory “breaks” and formal interventions directed by trained therapists
- Parents and home therapists sometimes share successes and activities that could be realistically provided in a group context

2. When should sensory-motor programs take place during the school day?

Group Responses:
- As prevention of over- or under-stimulation
- Embedded throughout the day
- Dependent on individual child
3. What activities and experiences should be included?

Group Responses:

- Specific activities in the classroom could include push-ups in chairs, sitting on exercise balls to work, action songs, music, a variety of lights, tactile toys, painting or printing in various mediums, therabands, weighted vests, or teacher or peer led exercises
- Suggested sensory room activities include individual sequences set up for each student (such as ten jumps, 3 minutes swinging, deep pressure activities), swinging, tube crawls, colored lights, trampoline, spandex bags, exercise balls, vibrating mats, jumping activities
- Out-of-doors activities included use of playground equipment, walks, guided exercises outside
- Special foods, craft activities, gym programming, science and health activities were also mentioned

4. Where should sensory-motor activities be done? Is it necessary to have a sensory room?

Group Responses:

- Sensory-motor activities can be done anywhere
- Advantages of sensory rooms include having the kids look forward to a break, more equipment, social interactions, supervision advantages, and no need to reorganize classroom
- Disadvantages could include expense, space, cleanliness, anxiety for some, not as natural, the need for extra staff, and safety issues

5. What arrangements must be made to ensure that sensory management programming is practical and beneficial?

Group Responses:

- Staff training to understand benefits and individual programs as required
- Appropriate assessments to identify individual needs
- Consistent rules and routines
- Appropriate use of equipment
- Special cleaning and safety issues
- Planning with extended team if required, especially suggestions from Occupational Therapists trained to work with sensory matters
- Keeping students engaged in appropriate activities
- Communicate needs specifically
- Storage issues for equipment and resources
- Teach students what to do and how to do it
- Be creative and flexible to prevent boredom
6. What safety considerations must be taken into account when developing sensory and movement activities?

Group Responses:
- Define rules
- Consistency by staff
- Evaluating equipment regularly – know weight specifications
- Appropriate supervision
- Appropriate space and padding surrounding equipment

7. How should sensory-motor programs be evaluated? How do we measure outcomes?

Group Responses:
- Decrease in problem behaviour with corresponding increase in classroom participation
- More time on task
- Don’t overuse to the point of wasting time or not meeting needs
- Students learn to monitor their own behaviour and ask for breaks
- Students are calmer
- Students learn to actively engage in their own sensory activities
- An increase in awareness and practice of self-regulation
- Develop appropriate data forms and time involved

As indicated, there were no specific answers to these questions applicable to all students under all circumstances and at all ages. Teachers agreed that each student must be considered individually, with regard to how sensory and movement needs may impact the ability to learn and to perform functional school activities. Teachers must address group goals as well, including various practical challenges such as staffing, supervision and availability of space in a school. Often motor, movement and sensory experiences can be provided within a rich social context, as part of academic programming and the general schedule of a typical school day.

Karen.bain@epsb.ca for AISI Teacher Network

The Cameron Developments Corporation, South Edmonton Common, and Cameron Homes “Opening Doors” for Autism Gala Dinner and Auction

The Opening Doors for Autism Gala Dinner and Auction, to be held on Saturday, October 30th, 2009, this year will be presented by the Naqvi family and is sponsored by their family businesses. This year’s exciting New Orleans style masque event will entertain 400 people at the Italian Cultural Center, with fine food, entertainment, and hundreds of valuable and exciting items for auction!

We invite you to join our host Danny Hooper and our media sponsors, CTV and the Edmonton SUN, in supporting this wonderful cause. The Autism Society continues work daily in our community to reach and assist children, families, teens and young adults affected by autism—thus our theme “Opening Doors for Autism”!

When a child is diagnosed with Autism, families are often devastated by the news that their child’s future may not be the one they dreamed of. They may feel overwhelmed by the demands of caring for and learning how to help their child.

Unfortunately, there has been a dramatic increase in the number of children diagnosed with Autism in recent years. Fortunately, the Autism Society is here to help. For almost 40 years the Autism Society has served families in the Edmonton area as a source of support, resource information, advocacy and most of all hope.

Our previous Gala events have been tremendously successful. With your contribution or attendance, we can continue to provide hope, joy, and quality to the lives of people with autism! Recommended attire for this event is cocktail/semi-formal. For further information, please contact the Autism Society office at (780) 453-3971

Karen.bain@epsb.ca for AISI Teacher Network
TEACHER INFORMATION SERIES –
2009/2010

INTRODUCTION TO AUTISM
Thursday October 22, 2009 6:30 – 9:00 p.m.
Presenter: Karen Bain – Teacher and ERECS Consultant

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

POSITIVE BEHAVIORAL 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@autismedmonton.org

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

Thank You to ASEA’s Amazing Volunteers!
Jean Ashmore
Tracy Baird
Stephen Barrington-Leigh
Amelia Duplessis
Gino Ferri
Rudy Guerra
Terry Harris
Marcy Henschel
Janet Houle
Constable Kevin Kirk
Stephanie Lougheed
Mark Lynch
Sergeant Adrian Marr
Karen Ann Moore
Sabrina Park
Taylor Rankin
Devika Russell
Kelly Sheehy
Andy Sung
Holly Symonds
Gaily Wyatt
Karen Bain
Anthony Barrett
Jeff Belch
Anita Ferri
Heather Guenter
Christian Hansen
Constable Alex Hasham
Anita Homan
David Jardine
Simonne Lougheed
Chelsea Lord
Shane Lynch
Claire McCurdy
Eric Ogletree
Yvette Prefontaine
Terri Robson
Jackie Ryan
Roman Sokolowski
Sara Symington
Alan Wagner

Amazing Volunteers
ASEA’s Annual General Meeting: Taking Stock and Looking Ahead
Roman Sokolowski

ASEA’s Annual General Meeting, held on June 16, 2009, was a chance to catch up on a very busy year. Local autism success stories were shared, and the achievements of educators and employers who are helping to create a better world for people with autism were celebrated.

The meeting opened with reports from ASEA Program Director Karen Phillips and Deborah Barrett, ASEA’s Director of Community Awareness and Development. The Autism Society has plenty of programs on the go, including various support programs, parent and teacher information nights, and a new and improved summer program. ASEA’s recent public education projects have included taking part in Autism Speaks’ Autism Awareness Walk, which also raised over $150,000 for international autism research. ASEA has been working with the Edmonton Police Service to show officers how to best handle situations involving people with ASDs, and to collaborate in finding locator technology that families of wandering children could use from their own computers. Karen Phillips and ASEA board member Shane Lynch have also worked to ensure that the voices of ASEA members are heard by the provincial government during its Setting the Direction consultations.

The Director of Community Awareness and Development is a new position that was created to raise community awareness of ASDs, develop new outreach opportunities, and find new ways to raise money for ASEA’s vital programs. Deborah Barrett has been working to raise awareness through the ASEA web site and newsletter and creating new promotional brochures, as well as building new relationships with the media and with autism foundations and organizations. Deborah is also working to improve community awareness about the needs of adults with autism, and to develop programs and services which continue to lag behind the growing needs of the adult community.

Those in attendance were fortunate to hear the success stories of three local adults with Asperger’s Syndrome. Stephanie Lougheed spoke of the support of her family and the steps she has taken to not only find solid employment, but also to be able to be in a good relationship. In fact, Stephanie revealed that she is now engaged! Alan Wagner talked about the challenges of independent living and overcoming the bureaucratic nightmares of post-secondary education on his way to becoming a teacher. And finally, Roman Sokolowski described the obstacles he had to overcome in growing up with Asperger’s Syndrome before finding his unlikely niche working in Southeast Asia.

The AGM was also a chance to recognize the outstanding achievements of special individuals in the community. Simonne Lougheed received the Outstanding Volunteer Award for her incredible efforts in creating and facilitating ASEA’s support group for adults with Asperger’s Syndrome, a group that now gives local adults with AS a place to share their problems and concerns. ASEA also gave special recognition to the Make A Dream Come True Society (MADCTS), which donated $20,000 to ASEA to support its adult programs—a donation that will make a huge difference. And last but not least, ASEA had the chance to honour local educators and employers for their achievements in helping people with autism (please see the separate awards article in this issue).

The AGM ended with the election of ASEA’s new Board of Directors, who are listed on the inside cover of this issue of Autism Now. The new board will be working with ASEA staff and members to ensure that the coming year will be just as busy as the last one, and even more successful!
ASEA’s 2009 Education and Workplace Awards
Roman Sokolowski and Deborah Barrett

At ASEA’s 2009 Annual General Meeting, awards were presented to honour outstanding educators and employers in the community. Each winner has, in their own way, gone that extra mile to make life better for people with autism and their families.

Workplace Award 2009

Stephanie Lougheed, who has Asperger’s Syndrome, was working at her job in the Learning Resource Centre for several months before she decided to disclose her condition to her co-workers. It wasn’t an easy decision, but once she finally did it, she was overwhelmed by the support and understanding she received from everyone at her workplace. “Their support has increased my self-confidence. My family can hardly believe the change in me,” said Stephanie. This is what inspired her to nominate the Learning Resource Centre for the 2009 WorkPlace Award.

Educator of the Year 2009

Janice Mills, Student Support Specialist, and Kym Keith, Coordinator of Adult Literacy at NorQuest, had faith in Anthony Barrett, a young man with autism who has limited verbal skills but a passion for numbers. They tested him, and in consultation with Anthony’s family, found a math course he would enjoy and, with work, could succeed at. Kym Keith selected Maroro Zinyemba, who had no previous experience with this disability, as the instructor with the right chemistry and enthusiasm to embrace a student with autism in her classroom. Zinyemba and Anthony’s aide, Christian Hansen (winner of the ASEA’s Support Worker 2009 award), worked together to ensure Anthony was able to learn the material. He finished the course with a mark of 91% and a lot of self-esteem, while his classmates gained an appreciation of the person behind the disability.

Teacher of the Year 2009

Linda Robertson was truly amazed by her luck when she got Linda Freeman for her son Aidan’s kindergarten class. Linda Freeman knows how to communicate clearly in a way that Aidan will understand, and knows how to challenge him just the right amount. She closely collaborates with the mental health professionals who work with Aidan, and is always interested in learning the latest cutting-edge teaching methods. Her classroom “should be used as an example of true inclusion,” says Linda Robertson. Part of the reason why Linda Freeman is so good at working with children who have autism is because she herself has a family member with ASD. And even Aidan agrees with the nomination: he recently told his mother that “Mrs. Freeman is awesome!”

Teaching Assistant of the Year 2009 – April Hart

Primrose and Andy Igonor’s son OJ has been lucky enough to have April Hart for a teaching assistant. Helping OJ learn in the classroom has only been a small part of April’s contribution, says Primrose. Not only has April come up with creative learning aids, such as communication books, and other ways to help OJ, she has also provided crucial emotional supports in class, and even respite care outside of the school. April is truly tuned into OJ’s feelings, and knows how to keep him calm and focused. “April treats OJ as an individual, and as much as possible like a regular kid,” says Primrose. While receiving the
award, April talked about how much she loves working with OJ, and thanked Primrose and Andy for all their support.

**Teaching Assistant of the Year 2009 – Amanda Yakemchuk**

Amanda is a Teaching Assistant who works with Liam, a 9-year-old boy with autism. Liam’s mother Laurel has become so amazed with Amanda’s work that she now calls Amanda their “angel”. Amanda has provided great academic supports, making skilled use of tools like social stories, prompting and cues, and positive reinforcement. But beyond that, Amanda has helped Liam to control his emotions, has taken him on outings, and has also provided respite care. Laurel calls Amanda “a warm, caring, empathetic” person, and believes that her son’s current successes could not have happened without Amanda’s support.

**Outstanding Post-Secondary Teacher of the Year 2009**

Jeff Belch is a student at the University of Alberta, and an adult with Asperger's Syndrome. Recently he signed up for an Earth and Air Sciences course taught by Professor Arturo Sanchez. “Professor Sanchez was totally amazing”, says Jeff’s mother Barbara. “They had an immediate rapport, and Professor Sanchez even lent Jeff his own books.” Professor Sanchez encouraged Jeff’s love of learning by e-mailing him study notes and PowerPoint presentations, tutoring him, and even lending Jeff books from his own personal collection. While accepting his award, Professor Sanchez commented, “In my 25 year career I have received many awards, but I think this is the most important one.”

**Support Worker 2009**

When Anthony Barrett was accepted into a math class at NorQuest College, the only question was, who will support him? Luckily for Deborah Barrett and David Jardine, Christian Hansen came along just at the right time. Christian has always had a passion for working with people with autism, but he and Anthony seem to have a particularly good chemistry. For Christian, accompanying Anthony to NorQuest is more than a job. He sees it as way to ensure Anthony has a life that is full, fun and meaningful. Christian sees beyond the surface to Anthony’s true ability and works very hard to ensure Anthony has opportunities to learn and to participate in all aspects of life.

**Adult Keyworker of the Year 2009**

Kristie-Lee Newton is a pre-school teacher who also works as a tutor, and it was in the latter role that she met Jeff Belch, a 22-year-old with Asperger’s Syndrome. Kristie has worked with Jeff since high school, where she helped him graduate with a high average. “Jeff is not an easy student to motivate,” admits Jeff’s father Andrew, “but Kristie was more than up to the challenge.” Now that Jeff is in university, Kristie continues to work with him, helping him to tackle his courses one at a time. She uses schedules, review notes and special study sessions to prepare him for his exams, and Jeff’s parents believe they have Kristie to thank for Jeff’s continuing good marks. Kristie has also taken Jeff on outings, and even invited him to hang out with her friends. “She has given selflessly of her talents as a tutor,” says Andrew, and she is “a superb person.”
Teacher of the Year 2009

For the last three years, Kerry Faber has been Forrest’s elementary school teacher. During this time, she has always been patient, optimistic and non-judgmental. She has also worked as an advocate, a liaison between teachers and students, and Forrest’s “safe and trusted person”. Kerry has worked hard to teach herself about autism, attending workshops and visiting the doctor with Forrest’s family. She has, in turn, used this new knowledge to educate parents, colleagues and students about ASDs and to promote greater acceptance of people with autism. “Every once in a while you meet child where there’s just something about the child, and you just click,” says Kerry. “We are so grateful to Kerry because she has truly brought out the gifts in Forrest,” says Forrest’s mother Susan.

Excellence in Inclusive Education 2009

Patricia says her son André has been helped by so many staff at École Ste-Jeanne-d’Arc in Edmonton that she couldn’t nominate just one person. So she nominated the entire school staff. The team at École Ste-Jeanne-d’Arc have been united in their commitment to inclusion, and have used different adaptations and teaching aids to achieve it. “I can’t name all the special things they’ve done for André,” says Patricia. From the principal, who attends all of André’s IPP meetings, to the teachers and aides who work with him everyday and regularly attend workshops to increase their knowledge of autism, it has truly been a team effort. And André, in turn, has taught the staff at École Ste-Jeanne-d’Arc a lot: according to one teacher, he “has taught us to be patient, he’s taught us to appreciate every step we take.”
Joe vs. the Boys’ Hockey Team
Shirley (Maher) Williams

Walking around the track tonight with my husband Dave, daughter Sarah and son Joe, I was aware of a hockey game going on underneath us in our local Barrhead Agrena.

We listened to cheers and watched fifteen-year-old boys – the same age as our son – play very well against the visiting team. The cheers, music and noise were too much for our son, so he put on his headphones, the kind that someone would usually wear on heavy equipment. They were bright red, and very noticeable.

Everyone noticed our son Joe as he walked around the track with us, wearing his bright red headphones. The ones who noticed him most were other teenage boys. They watched him as he came around to their side of the arena, waiting, it seemed, for a chance to get him alone to tease and ridicule him. This would not be the first time that Joe had been teased on this walking track, or at school, or in our community.

Joe does not have to wear these headphones to get attention as he walks around the track. He walks a little differently from the rest of us. Although he is 15, he walks like a younger child, perhaps a child in elementary school. He skips along, sometimes singing or quoting his favourite videos along the way. Sometimes he walks, sometimes he runs and sometimes he skips along. Joe is different from most teenage boys his age, because our dear son Joseph has autism.

Sometimes reality catches up with me as we walk around the track. Our son is not like other boys his age, and will never be. If he did not have autism, he could be down there playing hockey with the other boys his age. Instead he walks the track with us and needs constant supervision.

Sometimes a tear will come to my eye as I start comparing Joe with the other boys. I walk around the track, noticing the stares at Joe, knowing that he is so easily victimized wherever he goes, and being very aware of our huge lifelong responsibility to him. But soon enough, these thoughts give way to thoughts about how very special Joe is, and how much we love him.

I think of how he can probably recite one hundred different videos at the drop of a hat, and tell you almost every detail of every animal and dinosaur (living or extinct). He is compassionate and innocent. We love his honesty and how he makes us laugh. Joe is an awesome artist, who wants to direct his own animal films one day. Joseph is Joseph all day long. He doesn’t play social or emotional games with anyone. He truly is who he is, and that is so refreshing in today’s society.

Joe skates very poorly, and does not do well on a team. He’d rather do things alone or with just one or two others. His highly responsive senses make it difficult for him to live in today’s world, but live in it he must. He is doing his best to adapt to a world that is too noisy, too bright and generally too overwhelming for him. Joe will navigate the world differently than most of us, but with help and love, he will someday be all that he can be. Thank God, that is enough, regardless of what the rest of the world may think.

While our Joe may never be another Wayne Gretzky or ever play on a boys’ hockey team, I’m sure those boys will never be able to match Joe’s fantastic memory or attention to detail. Although the differences may seem alarming and scary at first, I eventually realize that Joe and each of those boys has different gifts, abilities and purposes. Each has a very different path to follow.

Although there are times when I want to cry from frustration, I still rejoice over Joe’s special abilities, and how well he is doing for a child with autism. I can see that God has a special purpose for Joe, the boys on the hockey team, the hecklers, and for all of us. Each of us is a work in progress. May we all accept, appreciate and be patient with the unique process each one of us goes through, special needs or not.
MIKE LAKE, M.P.
EDMONTON - MILL WOODS - BEAUMONT

You’re invited to our

Pancake Breakfast
in support of the Autism Society of Edmonton Area

WHEN: Saturday, August 22nd
9:00am - 11:30am
WHERE: Mill Woods Town Centre
Professional Building Parking Lot
6203 - 28 Avenue

For more information, call the constituency office at 780.495.2149.

We look forward to seeing you there!

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www.MikeLake.ca

780.495.2149
LakeM@parl.gc.ca
Roommates Help Young Man with Autism Live Independently
Deborah Barrett

What will my child’s adult life be like? For parents of children and teens with autism spectrum disorders, this is often the scariest question we ask ourselves.

It’s a question that fills us with conflict. Concern for our children’s vulnerabilities and dependencies vies with our desire to see them leading fulfilling, increasingly independent lives. Yet the amount of effort we need to put in to help them create meaningful lives is hindered by our increasing awareness of our own aging process as parents. Will we always be tied to their care? Can we ever take a break? How much energy will we have to oversee the many aspects of our adult children’s lives? What will happen to them when we pass on? Who will love them and ensure they continue to grow and live good lives? Will we, and our adult children, be faced with unpalatable living alternatives – a group home or day program that doesn’t work, or caring for our adult children into our very old age?

Many of us hope our children will learn enough through interventions, education and just plain growing up in a family that they will become sufficiently independent to manage their own lives. For some, this is what happens. But for many, we are all too aware that the children we love so much may never become sufficiently independent to live on their own.

One Edmonton area family of a twenty-something man with classical autism has taken a bold step. The family purchased a condo for their son, Matt (names have been changed at the family’s request), and attracted two roommates who live their own lives, but also support Matt. “It’s been 16 months,” says Matt’s mom, “and he’s grown in so many ways. Matt is doing so many things for himself that I hoped might be possible. I’m finally starting to be able to let go and focus more on my own life. I don’t think that would have happened if he had stayed at home.”

When Matt’s older brother moved away, Matt assumed he would live on his own someday as well. Matt’s mom Joan and her husband purchased a three bedroom condominium with Matt’s future in mind. When Matt was old enough, they began implementing a plan for him to live “on his own.”

“Using Family Managed Support (FMS) dollars from PDD (Persons with Developmental Disabilities), I hired a broker,” Joan told me. “She is the person who recruits, interviews, trains and supports the roommates. She also deals with issues that come up with the roommates, so we don’t have to do that. Eventually, she will also replace me as the fund manager for Matt’s FMS monies. Family Managed Supports are very flexible. That’s the beauty of FMS,” says Joan, “You can shape it to suit the future for your child.”

The roommates the broker hired to live with Matt are ordinary people with regular day jobs, like most people their age. They do not have disabilities. In return for the work the roommates do with Matt, they receive free rent and some additional payment. Matt continues to have supports from an agency that plans and delivers Matt’s day program, which includes working a few hours four days a week. The roommates lead independent lives, as roommates do, but they also ensure that Matt participates in the activities within the condo. They make sure Matt does his fair share of day-to-day living chores. Making dinner, washing dishes, vacuuming, laundry, cleaning the bathroom, tidying up— things that often fell to mom to do when Matt was living at home— are now considered part of his shared responsibilities. The roommates are there to offer support when Matt doesn’t know how to do something or needs direction. And when the roommates have guests over or have a party, Matt becomes part of the group.

“One of the positive aspects of this arrangement is that Matt now has options. He can visit his parents at their home, but he can also go back to his house whenever he wants. “I have a choice. I can go home,” Matt told his mom.

When Matt was in high school, there were so many things I wanted for him, but I didn’t know how they would happen. Now
Matt is helping with meals, doing his laundry, and vacuuming! He has become so much more independent,” says Joan. “After 16 months, I am finally starting to relax. I've always had huge anxieties about leaving Matt to take a holiday, but now Matt is telling me, ‘You've just got to have fun.’”

And what about the roommates? Joan noticed that at first they seemed to speak of Matt in terms of his deficits, but now they talk in terms of the many things he can do. They miss him if they don’t see him for a while, and they check in on one another, because, as one roommate told Joan, “He’s my friend.”

And, as happens in life, roommates are not usually roommates forever. One of the roommates moved on this spring, and the new roommate is female. This will mean negotiating issues of modesty and boundaries with the opposite sex. Joan says the new roommate has a great attitude, and Joan is confident that Matt and the young woman will be able to work things out over time.

I took a lot of hope from my chat with Joan. She has brought together creativity, careful thought, FMS funding, clarity and courage to create a situation that is working for her son, her family, and, I’m guessing, her son’s roommates. It may or may not be a model that will work for my family or yours, but it serves to illustrate what can be done when we start to consider our adult children’s needs, their strengths and talents, and what we can create to ensure their lives are meaningful and growth-filled.

Make a Difference to Families and Individuals Affected by Autism from Your Home

If you have time and interest, and want to make a difference for other families affected by autism, consider joining ASEA’s First Impressions Team. The First Impressions Volunteer Team will help callers get the information they need, or refer them to appropriate individuals and services. First Impressions Team volunteers usually have some experience dealing with a child with autism, must be able to respond to callers in a timely fashion, and will be able to work from home. Training will be provided.

If you are interested in becoming part of ASEA’s First Impressions Team, please call: Patricia Terrett @ 780-453-3971 or email patriciaterrett@autismedmonton.org.
**Book Review: Build Your Own Life**
by Wendy Lawson

Mark Szwender

Wendy Lawson has suffered from Asperger's Syndrome her entire life, but was misdiagnosed as having schizophrenia for over 25 years. She is well aware of all the personal and social difficulties that accompany living with Asperger's Syndrome. However, in her book *Build Your Own Life – A Self-Help Guide for Individuals with Asperger's Syndrome*, the author attempts to draw from her own experiences in helping others with Asperger's Syndrome to realize their individual personal identity and how to build a happy, safe and meaningful life around it. Throughout the book, Lawson describes the many differences between the AS individual and the neurotypical individual. For example, people with AS may find it difficult to practice polytropism or multi-channeling, such as listening to someone speak and looking them in the eyes at the same time. As a result, the AS individual may not make eye contact while listening or speaking to someone, but this does not necessarily mean that they are not interested.

The text is divided into ten chapters, each dealing with separate but interrelated areas of life. These areas are not only specific to people with AS, but are relevant to everyone. Lawson brilliantly compares a person's identity to a house, and explains that, like any house, one's identity is built upon a foundation that consists of many different parts. Each part can be thought of as having its own purpose which is at the same time interrelated with other parts. This metaphor gives the reader a very simple and practical example to think of when considering something as abstract as a personal identity. The author goes on to explain how one can become aware of these parts and how to use that awareness to do many things, such as assessing one's own interests and skills in finding a suitable career, and dealing with unpleasant changes in life.

Wendy is an inspiration for anyone with Asperger’s Syndrome, because she demonstrates the infinite amount of intelligence, potential, and imagination that every individual possesses. *Build Your Own Life* is essential reading for those on the higher end of the autism spectrum who are looking to better understand themselves and the world around them. Since each chapter deals with different areas of life that ring true for everyone, the book also works well for anyone interested in learning about their own identity and the many special characteristics that accompany Asperger’s Syndrome.
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Your generous donations make ASEA’s work possible!

The Cop Show or How We Made A Difference On A Wednesday Afternoon

Sam Varteniuk

Wednesday May 27

1:57 PM
Arrive at the West Division Police Detachment. The lady at the front counter is authoritative and wants to know why I’m here. I tell her I’m with the Autism Society of Edmonton Area, and that we’re here to do a presentation for the police about autism. She demands to know where I’ve parked. I’m taken aback and stammer a bit, then manage to tell her I’ve parked on the street. “Good,” she tells me. She directs me through the door on my left, up two flights of stairs, and then right out of the double doors down to the end of the hallway.

1:59 PM
I get lost because I turn left instead of right at the top of the stairs. People look at me inquisitively. I eventually sort out the difference between left and right.

2:01 PM
I enter the correct room. Alan and Chelsea are already here. So are Anthony, Christian, Deborah, Patricia, and Karen, along with a few police officers in regular street clothes. Karen is having a difficult time with the computer. It’s an older model from back when they first started trying to make desktops look sleek and sexy, horizontally oriented. Karen is trying to get a DVD to play on it. I help her to get it going, then go downstairs to see if any more of the Autism Society Players have arrived.

2:07 PM
I go downstairs and see Eric entering. He tells me he’s a bit nervous because he’s worried the police will shoot him if he doesn’t do a good performance. I assure him that none of the police officers are in uniform and don’t even have their guns with them. We go upstairs.

Did you know?
You can direct your United Way contributions to the Autism Society of Edmonton Area.
2:08 PM
Eric and I enter the presentation room again and see that a few more police officers have arrived, some of whom are in uniforms. One of them has a gun. I decide not to mention this to Eric. Karen is now having trouble getting the sound to work for her DVD movie. We ask Alex Hasham, the police officer who has organized the event, to help us, but he doesn’t know how to make the sound work either. I trace the cord from the back of the computer to a jack in the wall and realize there must be some sort of central sound system in this room so I start looking for a dial on the wall. I find it soon after and the sound comes on. Karen and Patricia are happy.

2:16 PM
I go downstairs again to see if any more of the Players have arrived, and I see Sara pulling up on her bike. She’s not sure where to lock her bike up because there’s no bike rack, so we decide to lock it to the railing of the stairs. We enter the police building again and the authoritative lady at the desk wants to know why I’m here. I tell her I’m the same person as before, and that I’m still here with the Autism Society of Edmonton Area to do a presentation for the police. She demands to know where I’ve parked. I tell her I’m parked on the street. “Good,” she says, and gives me directions upstairs.

2:28 PM
I check downstairs one last time to see if Adam has arrived. He hasn’t, so I decide to play his part.

2:34 PM
Alex says “let’s get started,” so we do. Karen gets up and talks a bit about autism and what it is. Then she shows her DVD. They can’t get the play menu off the screen once it starts playing, so I help them get rid of it. The DVD is all about five different kids with Autism. We’re here to help the police understand what Autism and Asperger Syndrome look like so that they won’t get confused and think that people with autism are drunk or stoned or just disobedient. This is a mistake that police in Newfoundland made recently.

2:53 PM
The DVD is over. The police have lots of questions. They want to know what it’s like to have autism, what to do if they encounter someone with autism, and how to know for sure whether someone has it. They tell us they can’t just ask someone who’s acting strangely if they have autism, because many people will lie and say ‘yes’ just so that they won’t get in trouble for being drunk or stoned or disobedient. I answer some questions. So do Chelsea and Alan and Karen and Sara and Deborah.

3:32 PM
Time is running out, so Karen says it’s time for the Autism Society Players to take the stage. We do, and perform the script we wrote about a young man who goes into a store to escape the noise on the street. His pockets are turned inside out, he’s wearing his sunglasses even though he’s inside, and he’s acting strangely, so the shopkeeper thinks he might be drunk or stoned. The shopkeeper tries to talk to him but has a tough time communicating. Eventually he grabs the young man, who screams loudly because he doesn’t like being touched. The shopkeeper calls the police. We explain some things about Autism, and then we do the scene again—only this time it’s different, and the shopkeeper tries harder to understand what might be wrong with the young man. The young man also helps the shopkeeper understand by telling him he has autism. They decide to try to call someone to help the young man calm down.

3:40 PM
We finish the scene. The police applaud and then ask us a lot more questions about Autism. They say we have to come back and talk to a larger group. Then a police officer talks about new tracking technology and how it will help with kids with Autism who run away.

4:07 PM
Alex Hasham says the presentation has to stop now because we’ve gone overtime. He thanks us and we leave.
ASEA’s long-running “Fun in the Sun” summer respite program is off to a fabulous start! This year’s program welcomes 33 campers, 6 Junior Youth Leaders, and 10 Summer Workers. Campers between the ages of 6 and 17 with ASD or Asperger’s have been coming to camp and participating in indoor and outdoor activities geared to kids of various ages and ability levels. A few of the exciting things we have done so far include swimming at Millennium Place, playing at Kidz Quarterz, mini golf at Pitch-n-Putt, animal interactions at Dreamcatcher’s Ranch, fun and games with the wonderful staff at Our Lady Queen of Peace Ranch, bowling at Bonnie Doon Lanes, and we have even managed to take in a couple of movies! We have been taking pictures like diligent little shutterbugs, and so at the end of the camp each camper will have a portfolio showing their most fun moments and greatest achievements in both words and photos.

The Junior Youth Leader position is a new and exciting part of this summer’s program. These young adults on the autism spectrum, aged 16-24, are being paid for their time spent assisting our summer workers to supervise children in their various daily “Fun in the Sun” activities. A work experience coach is working alongside the Junior Leaders as needed, teaching them skills and allowing increasing independence as the Junior Leader is ready for it. The camp runs daily 9:00am to 4:00 pm from June 29th to August 21st, and is based out of St. Timothy’s Anglican Church. So far we have had three exciting, safe and enjoyable weeks, and it will only get better from here!
Ben’s Grad Poem
Eric Giang

Where has all the time gone?
High school, almost time to say so long
Time has flown by so fast
Let’s hope the good times always last

I remember the first time we met
Your smile I will never forget
It has been a joy working with you for the last two years
You have brought us many laughs and tears
Your courage and bravery have battled through the wars
To prove that, you have the battle scars

This journey of yours has taken miles
What keeps us going are your smiles
You have gone through ups and downs
We love it when you make your sounds
You have taught us to see the good in people
You make our lives rich and plentiful
The joy in your smile, the curiosity in your eyes
They certainly do not lie
I think your mom is about to cry
They show the zest for life you have
And you are certainly loved from above
You warm our hearts with your easygoing demeanour
I know this party and your future will be super

Through this wonderful journey
We have seen you grow up so fast
In your mind, I hope this day will always last
From the very beginning, you have had to overcome a lot
The mountains you had to climb, the obstacles you had to go through
The adversity and criticism you had to deal with
To all the people who said you couldn’t do it

Today, you can finally say, “I did it”
I graduated high school
I made it
With the help and support from my family and friends
I have climbed to the top of the mountain
And boy, does it ever feel great
Ben, it is your day, your moment in the sun,
Your time to shine

The way your eyes light up when you hear or see your beads
They are always a great treat (for a job well done)
The joy in your face when you play the piano and guitar
I think you dream of being a rock star
The way you smile when you listen to music
Letting the melody wash over you
Your musical and artistic talents have developed
And improved by leaps and bounds
It fills my heart with joy when you make your happy sounds
These are just some of the things that make you great
Ben, you are absolutely first rate

You surprise us with your spontaneous laughter
You delight us with easygoing personality
You charm us with your wonderful smile
You make us believe that anything is possible
But most importantly, you make us better people
You have taught us to focus on your abilities and not your disability
You have shown us everyday just how special and unique you really are

We are all very honoured and privileged to be a part in the celebration of you graduating high school. We are all extremely proud of you and wish you the best of luck in your future endeavours.

This is truly a monumental and tremendous accomplishment.
Congratulations Ben Kurtz! High school graduate!
Class of 2009!

Keep on smiling, keep on trucking, keep on doing your thing
And we will keep on working, keep on praying, keep on believing in you.
Interactions Program at Belmead School
Kristin Giduk and Treva Lunan

Belmead is an Edmonton Public Elementary School just west of West Edmonton Mall. There are approximately 235 students from Kindergarten to Grade 6, including two Interactions classes. Students in the Interactions Program all have a diagnosis of Autism Spectrum Disorder (ASD).

The Interactions Program at Belmead School prides itself on taking its students into the community and giving them a wide variety of experiences. We generally have two types of outings: one for small groups of students, and another where all students in our program go out together. One of our regular small-group outings is a trip to the bottle depot, where students help sort bottles and wait for the money earned. Each day at school, one student from our program goes around after lunch with a staff member and collects the juice boxes, cans and milk cartons from all the classrooms. The money earned from this helps us buy cooking supplies and other classroom items. Small groups of students also go shopping to buy supplies for the weekly cooking class. Some students have even had the opportunity to go to the bank. Along with the obvious learning opportunities these outings provide, they also give students the chance to learn how to wait and act appropriately in a public setting.

During larger group outings, the Interactions class has had many opportunities to explore West Edmonton Mall, since it is so close to our school. While at the mall students have learned how to order at McDonald’s, visited the pets at PJ’s Pet Center, and watched the sea lions in the big tank. In June we visited the Sea Life Caverns at WEM, which are below the sea lion tank. There is an aquarium with a wide variety of fish, as well as an area with penguins that the students can watch. In November we went to Meadowlark Fire Hall. Before Christmas we went to Toys ‘R’ Us and had each student ask Santa for one item from their Christmas wish list. In April we went to Amazing Agriculture, which is a free field trip where students have the opportunity to see many different kinds of farm animals, as well as things that grow on a farm. Our students also went to see an IMAX show at the TELUS World of Science. Another regular field trip we go on in the fall and spring is to Jasper Place Swimming Pool. Our students thoroughly enjoy their time in the pool. We have some upcoming trips planned, including a trip to the Kinsmen Swimming Pool and Park, visiting the Beaumont Spray Park, and going to Marble Slab, where the students will choose and order their favourite ice cream.

Our group outings generally focus on a special theme or an opportunity for the students to gain some skills that can not otherwise be taught at school. The outings are a lot of fun, while also providing learning opportunities for students and staff alike. If you have questions about any of our outings or have a great idea for us to try, please email Kristin Giduk at kristin.giduk@epsb.ca or Treva Lunan at treva.lunan@epsb.ca.

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.
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.

- Difficulty with social relationships
- Difficulty with verbal communication
- Difficulty in the development of typical play
- Resistance to change in routine
- Extreme responses to sensory stimulation

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.
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 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 ____________ School ______________________
Your child’s name ______________________ DOB ____________ School ______________________
Your child’s name ______________________ DOB ____________ 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

❍ $15 ❍ $25 ❍ $50 ❍ $100 ❍ Other ______________________

Yes! I’d like to volunteer for ASEA – please contact me!

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