

# ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

Joint newsletter of Guelph Services for the Autistic (GSA) and Waterloo-Wellington Autism Services  
Newsletter No 13, November 2001

## VOLUNTEERS MATTER

**volunteer: to enter into or offer oneself for any service of one's own free will.**

2001 is proclaimed International Year of the Volunteer. But a national survey has found that fewer Canadians volunteer now than in the past or give charitable donations.

How important are volunteers for folks who live on the autism spectrum?

Volunteers can make a real difference:

- Serving on boards and committees of organizations devoted to people in need, as do the directors and officers of GSA and WWAS
- Contributing their special abilities to increasing awareness of autism, as Peter McCaskell has for the past 18 months in creating and maintaining the OAARSN website
- Being friends with those who live with autism—opening doors and windows and building bridges to the community. GSA welcomes Heather Baltzer and Cathy Ferguson, University of Guelph students who have volunteered to be such friends.

GSA and WWAS need your time, your creativity, and your donations. We welcome your offers of help. See the Bulletin Board on the back page for contact numbers and addresses.

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## WHY VOLUNTEER?

*Reflections by Cathy Ferguson, 2<sup>nd</sup> year undergraduate student at the University of Guelph*

When asked to explain why it is that I volunteer, I could not give an answer right away. It's not as though volunteering offers immediate, tangible rewards, like having a job and receiving a regular pay cheque, or doing schoolwork and having good grades show up on my transcript. No, volunteering leaves me with a different set of rewards that do not come right away, are not always obvious, and are never tangible.

In my three months with GSA acting as a friend to a person with autism, the main reward for me has been gradually gaining understanding. Each time we hang out, we share just a little bit more of ourselves with each other through activities, and conversation. Each get-together is a little bit more fun than its predecessor, and we gradually come to understand the world of the other, only to find that these worlds are not so different after all.

It didn't take long for his autism to become transparent. Although it is still there, it has become in my eyes more of an attribute than a disability. The friend with whom I spend time can beat me hands down at scrabble, and leave me gasping for air during badminton. He is also flawless when it comes to touch typing, and relentless when there is work to be done. With some encouragement and patience he tells me stories about things he has done, and places he has been - some of which are far greater than any I could tell. He has taught me about manners, friendship, the beauty of silence, and the power of a smile.

Volunteering with GSA is something anyone with a little time and a little patience can do. I know I will never stop learning, and never stop understanding more about autism, and people in general. I also rest easy knowing that my friend is also learning, building skills, and most importantly enjoying himself. These rewards could not be gained any other way.

Thank you GSA!

# *Microboards and other good ideas*

**NOWHERE TO GO...** In late October 2001, the *Toronto Star* published reports on the crisis in Ontario's developmental services, with the titles "Failing our most vulnerable: An investigation into the desperate lives of Ontario's developmentally challenged" and "Adults beaten in group homes: Hundreds of cases may just be tip of iceberg." Cuts and caps in Ontario Government funding have stalled social housing projects and may deter enough good staff and professionals from working in this field. There are acute shortages in good supports and services for the sons and daughters of aging parents and for young people moving from school to adulthood. Many adults with autism are among those who are poorly supported by the traditional social service system. The authors of the *Star* articles pointed to gaps and abuses but did not propose solutions. We would say that, while of course more public funds are needed, our attitudes and values and the ways in which money and other resources are used matter even more. Good ideas and helpful initiatives, mentioned on this page with more information posted on OAARSN, have these qualities:

- ✓ A focus on individual abilities and needs, "one person at a time"
- ✓ Real involvement with and by families and friends
- ✓ Recognition that a person's relationships with others are the most important factor in quality of life
- ✓ Recognition that everyone needs opportunities to choose and to contribute

## *The Quiet Voice*

A message by Judith Snow "to reach as many people as possible who have been labeled disabled...for us to think and explore together what it means for us to be leaders in our own lives, in our communities and as advocates." For the full message click on: <http://www.ont-autism.uoguelph.ca/Snow.PDF>

## **Individualized funding movements**

The Individualized Funding Coalition of Ontario urges the Ontario Government to make disability support dollars directly available to individuals who need them. The IFC website is at <http://www.lefca.com/ifco/> Some additional documents are posted by OAARSN

## **Personal support networks** on the

PLAN model are facilitated as the framework for a good life and a safe and secure future. Look up PLAN's website at <http://www.PLAN.ca> (NB: Use MSN Internet Explorer, not Netscape)

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OAARSN and AAIWW will continue to bring you information on these new initiatives, as well as opportunities to discuss them. Use our Search feature at <http://www.uoguelph.ca/oaar/search1.shtml> and the Discussion Area at <http://www.uoguelph.ca/~gbloomfi/cgi-bin/Ultraboard/UltraBoard.pl>

## **Microboards**

are legally incorporated entities empowered to support an individual with special needs to receive and administer resources, including government funding. Well established in British Columbia, microboards should become an option in Ontario. Check OAARSN site.

## **The Support to Aging Families Project** is

funded by the Trillium Foundation as a provincial project for the next five years and is active in the Region of Durham, Guelph-Wellington and Dufferin County. Families in mainly rural areas are coming together in Family Dialogue Forums to help plan for the future by sharing experiences and supporting each other. A Facilitator in each region/county helps individual families and groups of families to "clarify their visions of how best to support their sons and daughters to become more part of their communities and to lead a meaningful life." Contact Judith McGill, Project Animator (905) 770-2819

## **Adult Autism Needs Survey 2001** is

posted by OAARSN, on behalf of Guelph Services for the Autistic and Waterloo-Wellington Services. People with autism or their representatives can complete the survey online or print it to complete on paper.

Individual information is treated confidentially. To reach the AANS Survey, click on: <http://www.ont-autism.uoguelph.ca/aans2001.shtml> The survey is part of GSA's ASPIRE: Autism Support Project: Information, Resources, Empowerment, described at <http://www.ont-autism.uoguelph.ca/aspire.shtml>

## ***Our Journey Through High Functioning Autism And Asperger Syndrome: A Roadmap***

Edited by Linda Andron. Jessica Kingsley Publishing, 2000. 160 p.

Available in Canada for \$36.40 CDN from Irwin Publishing.

*Reviewed for OAARSN by Lucie Milne*

The stories in this book, written by parents of children with high functioning autism and Aspergers, as well as by their children, are their journeys, their autistic and Aspergers adventures. These experiences have confirmed “the hunches and hopes” of other parents and helped them to apply the authors’ strategies to help their own children. Understanding humour and empathy, speaking neurological speech, making new friendships, fitting into new environments and situations are the topics covered. The stories show those with high-functioning autism and Aspergers have their differences – Do we not all! We see that the children can be comical and creative and that they are very bright. They like themselves just as they are and would like those in the world about them to like them as they are. I wonder how many of us, who are not on an autistic journey of our own, like ourselves as we are!

Who are these individuals and families who share with us their life adventures and learning? What do they give to us?

The first chapter, written by Jeannette Darlington and her two sons Glen and Evan, explores the relatively unknown areas of autism and Aspergers: humour, empathy, and imagination, and shows how this mother guided her sons to be funny and creative. To develop their imagination she drew cartoons, showing, for example, how a favourite toy could be or was already being used in imaginative play. Dramatic play, complete with costume dress up, developed imagination and humour. Videos of dramas enacted reinforced this. “Seeing an old thing in a new way” helps autistic children protect themselves from “getting locked into very rigid patterns of thought.” In a cartoon drawing, Jeannette shows the boys turning their train tracks into pistols. To encourage humour, the boys own many comics. Glen’s and Evan’s commentaries of their responses and perspectives add greatly to this chapter.

Linda Andron is a clinical social worker who specializes in autistic and Asperger disorders. She “incorporates academic and theoretical perspectives with those of parents and individuals with high functioning autism and Aspergers Syndrome.”

Valuable for social workers and therapists are the programs Andron describes.

I especially appreciated young Joshua Mandernach’s taxonomy (I had to look up that word!) of friendship. His listing of definitions of different friendships is one we all should keep for reference as needed.

“Making Friends with Aliens” is the collectively written autobiography of Max with his parents, a creative work so classmates, educators, parents, volunteers and others can know and understand Max. This effort for friendship draws on the remarkable drawing ability of Max and on family snapshots to illustrate the book. In the book are sections for responses and conversation starters for would-be friends. For example: What is your favourite pizza?

It is known that other family members may share symptoms of autism or Aspergers. In his fascinating story “The Aspergers Chronicle” Jim Devine relates how on learning that his son had Aspergers Syndrome he began to realize that he shared some of the same AS characteristics.

More could be said about this book, but personal discovery is a good incentive to read the book. I would like to close with this thought, from the chapter by Fran Goldfarb and Guthrie Devine, that all of us need to learn “how to speak Aspergers.” Here is a book to help us do just that.

*Irwin Publishing is Canadian agent for important titles in Autism and special needs and mental health generally—such as those published by Jessica Kingsley and Paul H. Brookes Publishing, several of which have been reviewed by OAARSN.*

*The Irwin Book Club offers 20 % off various professional titles. [www.irwinpublishing.com](http://www.irwinpublishing.com)*

***Reviews and notes about many more Books on the Autism Spectrum may be found on OAARSN’s site: <http://www.ont-autism.uoguelph.ca/books.shtml>***

## RAISING A CHILD WITH AUTISM: TWO PARENTS' REFLECTIONS

A review essay by John Clifton

*When Snow Turns to Rain: One Family's Struggle to Solve the Riddle of Autism* (USA 1993) by Craig Schulze and *Growing Up Severely Autistic: They Call Me Gabriel* (UK 2000) by Kate Rankin are two fascinating books about raising a child with autism. They are both fine additions to the body of works that includes Josh Greenberg's *A Child Called Noah, Son Rise* by Barry Kaufman and *The Siege* by Clara Claiborne Park. The earliest work of this sort that I know of is Itard's *The Wild Boy of Aveyron* published in the early nineteenth century. Itard was Victor's caregiver and educator. Today there is speculation that the naked and apparently uncivilized child found wandering in a forest in France was autistic and not just abandoned or lost and living in a Rousseauian state of nature. Another work of interest in this area that stands chronologically in between is the published diary of Dawn Powell. Powell was a best-selling novelist of the forties and fifties who, when she wasn't writing some of the most brilliant and scorchingly satirical novels of her time, mothered and raised a son who is now presumed to have had autism. Like Schulze, she managed to afford a residential educational setting for Joseph, but one wonders at the options Powell would have faced regarding such facilities given the times. While her diary is not devoted mostly to her life as lived in relation to her son's autism, her references to his tantrums, her worries and his trips to Bellevue and other hospitals provide glimpses into life with autism at a time when the term was just beginning to be associated with the syndrome we have come to know.

Schulze opens his book with a portrait of his son Jordon as he was

before the onset of autistic symptoms. Jordon is the Schulzes' second son and his above-average development appeared to presage a happy future. Schulze includes some of his diary entries from that time and describes feeling that "our lives are so good that it scares us--seems like something has to go wrong--we love our little boy so much." He is proud of Jordon's apparent achievement of intellectual milestones and this isn't surprising from a man who has made education his life and holds a M.Ed. in Early Childhood Education and a Ph.D. in Human Development. He frequently ponders the state of his spiritual growth by studying great works of the Hindu and Buddhist traditions. There is mention of Thoreau and T.S.Eliot and of a great love for books. His disappointment when Jordon's development begins to stagnate is palpable: "So many consecutive sad days that I've been unable to write. We live in a cloud, with knots in our throats, and again we cry frequently. Jordon is unhappy, alone, and making no progress."

Jordon Schulze began to manifest symptoms of autism when he was two and a half. At first, drug therapies were employed but soon Schulze discovered that "drugs won't be our ticket out of Hell." By the time Jordon was three, the Schulzes had resolved to enrol themselves and Jordon in a two-week stay at the Options Institute owned and run by Barry and Suzy Kaufman. Barry Kaufman is the author of *Son Rise* and *The Miracle Continues* and his family's amazing success in raising and educating their son, Raun, inspires the Schulzes to seek guidance at a farm-like retreat in Connecticut. The cost in 1985 was \$9,000, and the Options Institute was just the beginning of what turned out to be a very expensive attempt to provide

Jordon with what his parents regarded as the best possible education. Schulze is somewhat skeptical of the "get in touch with your feelings" approach: "Does it necessarily follow that responding to an unending string of questions from someone you have just met will put you sufficiently at ease to put you in a happy frame of mind? But even if it's true that I can be made a happier, less judgmental person through this Socratic self-examination process, does that mean that Jordon will, or even can, choose to respond to this loving treatment by emerging from his autism?"

The Schulzes tried to make the best of the program and resolved to follow through by initiating a similar program at home. Since Jordon accompanied them to the Institute and was observed to participate in his own portion of the activities designed for children with autism, the Schulzes had some idea about what was involved. Options was a demanding program which required in their case the help of 16 volunteer and paid staff, some of whom were high school students who could not always be relied upon to show up. Schulze began to wear thin: "Imagine yourself a combination cheerleader, adolescent counselor, housewife, and volunteer coordinator twelve hours a day...This is the stuff of burn-out."

Months later, the Schulzes came to the conclusion that the program was not working and they began to turn their attention to the Higashi school in Japan. After an investigative trip to Tokyo, they enrolled Jordon there and for a year they tried to follow his progress through videotapes sent to their home. Schulze believed that Jordon looked sad and the family was relieved when a Higashi school was founded in Boston and Jordon could be enrolled

there. By this point, Jordon was four and the costs for his education had reached \$25-30,000 per year. The Schulzes began to apply for government subsidies but were initially rebuffed. Finally, after taking legal action, they received a settlement that is not disclosed due to an agreement about confidentiality. Sometimes the Higashi school appeared to have good results and Schulze refused to believe that Jordon's education was not important. To be closer to Jordon, the family decided to move to Massachusetts and had to make decisions about their respective careers. Schulze completed his doctorate and then relocated. Jill managed to work out a deal with her law office so that she could do much of her work at home. For several months, Schulze took on the role of homemaker and Jordon was able to spend more time with the family. Eventually, setbacks and disappointments about Jordon's progress at Higashi resulted in the decision to give Jordon more time at home. Suddenly the Schulzes began to see "fairly substantial changes." Schulze speculated that these changes might have been brought about by any or one of several factors like age, living at home, or vitamin therapy. In any case, with Jordon being more cooperative and his spitting, biting and hitting better under control, the Schulzes were thrilled: "Whatever the reason, his getting somewhat better comes at a critical time, for his continued stagnation could well have pushed us over the edge."

By the end of the book, Jordon is nine. Schulze had temporarily taken a lower-paying job with the Higashi School as a grant writer, but planned to return to his job as a school administrator in Baltimore. The family continued to experience a roller coaster of successes and setbacks. When Jordon experienced a "period of severe tantrums, self-abuse, and aggression that lasts about eight weeks", Schulze

came to realize that "there are substantial limitations to what we can know about him."

*When Snow Turns to Rain* is a moving and informative account of one man and his family's quest to provide the best care and education for a child with autism. Schulze is an introspective and sometimes poetic writer who, though often despairing of a solution to his problems, can describe his situation and that of Jordon in a way that is both terrifying and beautiful. Remembering Jordon's progress before the onset of autism, Schulze writes, "A tiny light, perhaps from the Perseid meteor shower, flickers in the corner of the sky and dies. Here is a perfect metaphor for Jordon. In the backdrop of an empty sky, he moved so brilliantly and then passed from the scene in an instant. Twinkle twinkle little star, now I wonder where you are." As well as being a fine account of some of autism's more devastating effects, the book documents Schulze's profound spiritual journey from a wilderness of grief and disillusionment to, for the time being, sustaining insight. By the end of the book, Schulze has had his vision: "I would come to understand through this trial that pinning my hopes for happiness on Jordon's recovery or on any particular outcome for my life was totally absurd. If the empyrean was to be found at all, it would be located deep within myself, in a core of acceptance and love of life, regardless of its outer dress."

In *Growing Up Autistic*, mother, homemaker and occasional writer of articles on autism for the journal of the National Autistic Society (UK), Kate Rankin, tells us that by the time her son, Gabriel, moved out of the family home and into a residential-educational facility, he was seventeen. By the end of her book, Rankin has been dealing with autism for nearly twice as long as the Schulzes. Rankin's husband, Neil, was a carpenter and the family resided near the "high street" in an English town. The Rankins had two other

children, one older than Gabriel and one younger. Rankin tells us nothing about her education but it appears that she was not someone who was able to take time away from her busy life to attain academic credentials. Although she was well aware of the Options Institute and the Higashi schools, she was also equally aware of their costs: "If we'd had 30,000 [pounds] or more to spare I suppose we could have sent him to the Higashi school for some Daily Life Therapy for a year" (p.176). Unfortunately, neither these possibilities nor others presented realistic options.

Still, Rankin is well informed and provides clear and concise accounts of these and other approaches to childhood autism. She writes: "The idea behind the Option method is that by making interaction a pleasurable activity, by making people more attractive than obsessive activities, the child will be encouraged to join 'our world' " (p.152). Regarding the Higashi schools, she explains that they offer "almost military style behaviour control and extensive physical exercise, the idea being that strict routine gives security to these very fearful children and that lots of vigorous physical activity burns up destructive energy" (p.150). Rankin also touches upon the views of Lovaas, Bettelheim, Donna Williams and Temple Grandin. Regarding drug therapies, the Rankins seriously considered them but, in consultation with their doctor, decided that the side effects would outweigh the benefits. At the same time, Rankin does not rule out the use of medications altogether. Gabriel took medication for his epilepsy and reference is made to Temple Grandin's use of an anti-depressant.

Like *When Snow Turns to Rain*, *Growing Up Autistic* vividly portrays many of the everyday experiences that make up a large part of the lives of some parents of children with autism. Without the luxury of a residential-educational facility, the Rankins became daily

more familiar with dangerous and disturbing behaviours: "Gabriel gets more and more furious, pinching his forehead and the back of his neck and letting out bellows of rage as he charges back and forth. He catches sight of a small rolling pin, picks it up and hits his head with it. I try to stay calm and quietly remove a saucepan of hot food from the stove, remembering an occasion not so long ago when in a similar mood he dashed a full pan of hot soup to the floor and over his feet, burning them quite badly" (p.43). Rankin describes several other incidents: he scaled the yard fence and wandered into traffic; he poured washing up liquid into his eyes; and once, after many excursions onto the roofs of the family's home and that of the neighbours, he crashed through next door and narrowly missed a glass table and a television.

By the time Gabriel was thirteen, he had learned to "wee" in the toilet. While Rankin is pleased to announce this as a real accomplishment, she also expresses continued frustration at Gabriel's failure to learn the same skill in regard to his bowels. Several passages in a chapter entitled "Shit Happens" are devoted to this matter. Sometimes he smeared the walls and carpets with feces. Finally, after one more ill-fated attempt at toilet-training resulted in severe constipation, "he has reached a state--there is no way to put this delicately--where he oozes shit more or less continuously" (p.177). Rankin estimates the number of clean-ups in the seventeen years that Gabriel lived with his family at eighteen thousand. She was still asking herself whether it was a question of "can't" or "won't".

On the issue of corporal punishment, Rankin expresses Neil's and her view that while small children understand "smacks", these must be meted out judiciously and not in anger. Although Gabriel frequently appeared to be indifferent to pain, the Rankins did "smack" him and often used a wooden spoon. Eventually, the

mere showing of the spoon to Gabriel was enough to get his behaviour under control. Rankin is candid about one incident when she "snapped" and, enraged by Gabriel's refusal to settle for the night, she bit him. She confesses to a feeling of "everlasting shame."

Sometimes Rankin wondered if she loved her son at all and, with a frankness that is one of the book's chief virtues, she admits that "I felt something closer to hate than love. How often I had wished that this had never happened and I didn't have to endure such turmoil. Dreadful thoughts sometimes crept into my mind, like those of a mother of a Down's syndrome baby I knew who had written: 'There were times when I would return to his cot hoping that the breath of life had gone from him and we could resume our normal lives' " (p.63).

After years of worry about the family's ability to ensure Gabriel's safety, and after the death of her adored husband Neil in a bicycle accident, Rankin began to feel desperate and begged seemingly indifferent social service agencies for additional money for preventative measures. Gabriel was seventeen when a suitable residential-educational facility was found. Although Rankin worried about the possibility of abuse in such facilities, she was also relieved to think (perhaps over sanguinely) that institutional care for people like Gabriel has improved "immeasurably" in recent years.

In the book's final pages, like Schulze, Rankin searches for a summing up and, as it turns out, she has been on a sort of spiritual journey herself. From being a mother who had to admit she was often feeling more hate than love for her child, and who found it impossible to see him as a "blessing", she ends with a vision of her own. She tells us that Gabriel has touched the lives of many people and they have extended their kindness to him. He has taught them about

"patience, tolerance, different perspectives and new ways of looking at others and themselves...he has generated an enormous amount of unconditional love." When she thinks back to when asked if she thought that having a child like Gabriel was a "blessing", she concludes, "Now I think I have some small idea of what that means and I'm grateful."

*Growing Up Severely Autistic* is an often stark and realistic portrayal of life with a child who has profound behavioural problems. Rankin has written a plainspoken and courageous account. It should prove to be an invaluable resource to other parents, siblings, caregivers and educators. Yet, on the issue of corporal punishment, one wishes that Rankin had said more. She confesses to having snapped and bitten Gabriel. Isn't the existence of this possibility one of the reasons why educators have counseled against corporal punishment? Once it is okay to "smack", it becomes more likely that the adult might "go too far"? And what of corporal punishment in a residential or educational setting? Rankin worried that Gabriel's bruises and scrapes might have originated at school. She omits to mention that teachers are sometimes wondering too.

The concluding insights reached by the two books considered here are interestingly different. Schulze seems to achieve a sort of Vedantic release from the vicissitudes of life in general through an insight about the interior source of human happiness and the ultimate irrelevance of results in the material world.. For her part, Rankin finds happiness in the joys of human interaction. Despite his problems, her son has made a wonderful difference in the lives of the people around him. But whatever philosophical differences may separate them, both writers seem to arrive at a place that stresses love and acceptance. Both will offer hope to others who are still confused and stumbling in the dark.

## **"Dear Family and Friends"**

*This article appeared in the holiday 1999 issue of ASAP News! (Volume 3.5), the Autism Support and Advocacy Project and Potential Unlimited Publishing. It was originally reprinted by permission of editor/author, Viki Gayhardt, in the FEAT Daily Newsletter November 28, 1999. The article was written to be sent to relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with autism.*

I understand that we will be visiting each other for the holidays this year! Sometimes these visits can be very hard for me, but here is some information that might help our visit to be more successful.

As you probably know, I am challenged by a hidden disability called autism or what some people refer to as a pervasive developmental disorder (PDD). Autism/PDD is a neurodevelopmental disorder which makes it hard for me to understand the environment around me. I have barriers in my brain that you can't see but which make it difficult for me to adapt to my surroundings.

Sometimes I may seem rude and abrupt, but it is only because I have to try so hard to understand people and at the same time, make myself understood. People with autism have different abilities: some may not speak, some write beautiful poetry. Others are whizzes in math (Albert Einstein was thought to be autistic), or have difficulty making friends. We are all different and need various degrees of support.

Sometimes when I am touched unexpectedly, it might feel painful and make me want to run away. I get easily frustrated, too. Being with lots of other people is like standing next to a moving freight train and trying to decide how and when to jump aboard. I feel frightened and confused a lot of the time, like you would if you landed on an alien planet and didn't understand how the inhabitants communicated. This is why I need to have things the same as much as possible. Once I learn how things happen, I can get by ok. But if something, anything changes, then I have to relearn the situation all over again! It is very hard.

When you try to talk to me, I often can't understand what you say because there is a lot of distraction around. I have to concentrate very hard to hear and understand one thing at a time.

You might think I am ignoring you--I am not. Rather, I am hearing everything and not knowing what is most important to respond to. Holidays are exceptionally hard because there are so many different people, places and things going on that are out of my ordinary realm. This may be fun and adventurous for most people, but for me, it's very hard work and can be extremely stressful.

I often have to get away from all the commotion to calm down. It would be great if you had a private place set up to where I could retreat.

If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control

over me. Sitting in one place for even 5 minutes is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people--I just have to get up and move about. Please don't hold up your meal for me--go on without me and my parents will handle the situation the best way they know.

Eating in general is hard for me. If you understand that autism is a sensory processing disorder, it's no wonder eating is a problem! Think of all the senses involved with eating: sight, smell, taste, touch AND all the complicated mechanics that are involved with chewing and swallowing that a lot of people with autism have trouble with. I am not being picky—I literally cannot eat certain food as my sensory system and/or oral motor coordination are impaired.

Don't be disappointed if mommy hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggy! I have to feel comfortable in my clothes or I will just be miserable! Temple Grandin, a very smart adult with autism, has taught people that when she had to wear stiff petticoats as a child, she felt like her skin was being rubbed with sandpaper. I often feel the same way in dressy clothes.

When I go to someone else's house, I may appear bossy and controlling. In a sense, I am being controlling because that is how I try to fit into the world around me (which is so hard to figure out!)

*....continued on page 8...*

## AAIWW BULLETIN BOARD

### GUELPH SERVICES FOR THE AUTISTIC

functions as a housing trust, to help adults with autism to live happier and more fulfilling lives in homes of their own. GSA also encourages individuals, with their families and friends, to plan for good lives as adults in their home communities. See GSA pages on the OAARSN website:

[http://www.ont-autism.uoguelph.ca/gsainfo\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsainfo_new.shtml)

[http://www.ont-autism.uoguelph.ca/gsafaq\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsafaq_new.shtml)

Tax-creditable receipts are issued for donations of at least \$10. Please mail to Guelph Services for the Autistic, P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9.

### ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK

<http://www.ont-autism.uoguelph.ca>

OAARSN offers a rich and expanding collection of up-to-date information and communication tools that can put you in touch with others. We can all benefit from the opportunities for mutual support, encouragement and information sharing. We hope that OAARSN's efforts to draw attention to positive approaches and best practices in supporting adults with autism can help all who live and work on the front lines. We welcome news items, new information, discussion questions and comments, and accounts of experience.

Check out the News Scroller and What's New on the opening page for new additions to the site. You may request to be on the OAARSN List to receive regular e-mail bulletins of autism news and announcements of events. You may also look at the **Adult Autism Needs Survey 2001** and, if you wish, complete and submit it. Click on:

<http://www.ont-autism.uoguelph.ca/aans2001.shtml>

### WATERLOO-WELLINGTON AUTISM SERVICES

Information about WWAS may be found at

<http://www.ont-autism.uoguelph.ca/wwasinfo.shtml>

Become a member with a donation of \$25 or more. Or subscribe to AAIWW for \$5 a year (to cover printing and postage costs).

Make cheques payable to WWAS and send with your name, full address and phone number, to William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2. For more information, call our answering machine at (519) 742 1414, leave your name, number and request.

(*"Dear Family and Friends" continued from page 7*)

Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things--just please be patient with me and understanding of how I have to cope...mom and dad have no control over how my autism makes me feel inside.

People with autism often have little things that they do to help themselves feel more comfortable. The grown ups call it "Self regulation," or "stimming". I might rock, hum, flick my fingers in my face, flap my arms or any number of different things. I am not trying to be disruptive or weird. Again, I am doing what I have to do for my brain to adapt to your world.

Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grown ups call this "perseverating" which is kind of like self-regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable, and I don't want to come out of that comfortable place and join your hard-to-figure-out-world. Perseverative behaviors are good to a certain degree because they help me calm down. Please be respectful to my mom and dad if they let me "stim" for a while as they know me best and what helps to calm me.

Remember that my mom and dad have to watch me much more closely than the average child. This is for my own safety, preservation of your possessions, and to facilitate my integration with you tippies (what we autistics fondly call you neurotypical folk!) It hurts my parents' feelings to be criticized for being over-protective or condemned for not watching me close enough. They are human and have been given an assignment intended for saints. My parents are good people and need your support.

Holidays are filled with sights, Sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you tippies but it's very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate, please remember that I don't possess the neurological system that is required to follow tippy rules.

I am a unique person--an interesting person. I will find my place at this celebration that is comfortable for us all as long as you'll try to view the world through my eyes!

