

# Can-A-Gen

Canadian Autism Genetics



Hello to everyone . We hope that you had a safe and enjoyable summer and that the transition back to school was a good one. We welcome and appreciate your feedback. You may contact: Bev DaSilva at (905) 521-2100 ext. 74728 or [dasilvb@mcmaster.ca](mailto:dasilvb@mcmaster.ca).

Are you a family (or know of a family) who has two or more children with ASD? How about two or more children with ASD in your extended family or one child with ASD with a known chromosomal abnormality? If this describes your family and you are interested in participating in our study, please call Shannon Werner at (905) 521-2100 ext. 77372 or 1-888-328-8476 or [werners@mcmaster.ca](mailto:werners@mcmaster.ca).

**FALL**



## Reminders

- Are you expecting or have an infant at home? You may be eligible for infant sibling study. If you are interested, please give us a call.
- If you have changed addresses or are planning to move, please let us know so that we can keep our records updated.

## What you will find in this newsletter?

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# What's New at Can-A-Gen?

Canadian Autism Genetics Team

Website: <http://www.offordcentre.com>

Can-a-Gen refers to the Canadian Autism Genetics Team composed of clinicians and scientists at McMaster University and at the Hospital for Sick Children. Our objective is to identify the genes that cause Autism Spectrum Disorders. By identifying these genes we can understand what biochemical pathways lead to the disorder and, from that information, develop new treatments aimed at interrupting the pathway.

Over the last year, we have made a lot of progress in a number of areas. Our study now includes 258 families from all across Canada who have two affected children with ASD. We also have a large number of children with autism who also have chromosomal abnormalities. Children with these abnormalities provide a unique way of trying to identify the genes that cause disorder.

We have not completed collecting all the clinical information from these children and are working hard to finish the blood collection. So far, we have collected DNA from 677 children and their parents and that DNA is stored at the Hospital for Sick Children. Right now, we have identified a number of potential genes that we think might be involved in causing Autism Spectrum Disorders and are looking at those genes base-pair by base-pair to see if any important variants can be identified.

**Myth:** The symptoms of autism can only be recognized by a doctor or other professional.

**Fact:** Parents know their children best and they are the best judge of their child's health. While a diagnosis can be made only by a physician or psychologist, parents should trust their instincts and seek help even if they only suspect there is a problem. Parents need to know about healthy child development and ask for help if their child isn't developing as expected.

As many of you know, we have also joined forces with the other major genetics groups around the world in a collaborative effort called the Autism Genetics Collaboration. This is supported by the National Alliance of Autism Research (NAAR), the National Institute of Health from the US and the Canadian Institutes of Health Research. In total, we have a sample of over 1,600 families with two or more affected children and have combined the DNA from all these families. This represents a four to five-fold increase in sample size over any individual study and I think represents an extraordinary example of how scientists around the world are putting aside their own personal interests in favour of working together for a common cause. At this very moment, the DNA from all our families is being studied and is being put together with the clinical information. Within the next year (before the next newsletter surely) we should have some preliminary information from this collaborative effort.

The other exciting news is that Genome Canada has awarded Can-a-Gen \$15 million to continue our efforts. This money will be put towards establishing a large database to hold all the clinical information, to enlist a large sample of families with one affected child so that we can see if the results we obtained in families with two affected children can be replicated, and to think about the implications of our results with respect to public policy, diagnostic testing, and clinical services. Dr. Steve Scherer who heads up our effort at the Hospital for Sick Children and Jennifer Skaug deserve an enormous amount of credit in putting together this successful application. We were the only Genome Canada application that specifically focuses only on Autism Spectrum Disorders to be awarded funding.

Once again I want to thank all of you for your continued support of our Genetics studies and I hope many of you can come to our Fall Conference to learn some more about our results.

# CAIRN

Sherry Cecil

## ***The sooner you know, the sooner you can help:*** **CAIRN launches awareness campaign to identify autism earlier**

Most parents, and many family physicians, are unfamiliar with the early warning signs that can signal autism. Although new research shows these signs can be observed in infants as young as, or younger than, 12 months, children with autism are typically not diagnosed before the age of 3.

The Canadian Autism Intervention Research Network (CAIRN) hopes its autism awareness campaign will help to lower that age so interventions crucial to improving children's outcomes can begin earlier.

Titled "The sooner you know, the sooner you can help", the campaign targets both parents and family physicians with information designed to improve early screening and referral and a full-color poster highlighting early warning signs that physicians can display in their waiting rooms.

The campaign includes a newsletter for family physicians with on early warning signs, the importance of routine screening and when to refer to a specialist. A list of early intervention resources is also provided for doctors and parents of children who are concerned about a child's development.

The newsletter and posters were sent to 17,000 family physicians across the country. All are members of the College of Family Physicians of Canada. The poster, available in English and French, is also being sent to public health units and early years centres across the country, and can be ordered free of charge from the CAIRN web site, [www.cairn-site.com](http://www.cairn-site.com).

The poster uses knowledge gained from the Canadian Infant Siblings Study to help parents of young children identify possible developmental delays, encouraging them to discuss their concerns with their family doctor.

"It highlights a number of key behavioral signs that our study has identified as being specific risk markers for autism," says Dr. Zwaigenbaum. "It doesn't mean that every child who has one or more of these signs will go on to be diagnosed with autism, but it does indicate that certain developmental milestones are not being met. Our hope is that it will empower parents to seek help."

The campaign is the latest initiative of CAIRN, a group of parents, clinicians and scientists dedicated to promoting early detection and early intervention for children with autism spectrum disorders.

CAIRN's web site has grown to become a trusted source of up-to-date, high-quality evidence-based information on autism for parents, professionals and policy makers, now attracting some 3,000 visitors monthly who log on to learn about the latest findings in autism research around the world.

CAIRN has now published four issues of its highly respected newsletter, the CAIRN Review of Evidence-based Diagnosis and Treatment in Autism, including a special issue on educating children with autism that went to more than 12,000 teachers, principals and other educators.

Another of CAIRN's goals – to develop a national research agenda in early intervention in autism – was advanced this past year when Dr. Peter Szatmari received \$2.1 million in funding from the Canadian Institutes of Health Research (CIHR) for a study that will follow pre-school children with autism spectrum disorders from point of diagnosis to Grade 1 in an attempt to identify those factors that contribute to positive outcomes for these children. Identified by CAIRN conference delegates as the number one priority in early intervention research, this is an exciting development that demonstrates the powerful change that can take place when people pool their knowledge, experience and wisdom for a common cause.

# Research Study: Social Supports for Adolescent Siblings of Children with Autism Spectrum Disorders

Karen Hershenfield, BSc. (medical student), and Wendy Roberts, MD

Parents frequently worry about the impact on siblings and family of having a child with a disorder on the autism spectrum (ASD). Although anecdotal reports suggest that in the long term, siblings may make significant contributions to society due to interest and expertise gained through the experience of growing up with a special needs sibling, research studies with siblings of a child with ASD have identified significant issues which give some a high risk social adjustment status. Review of the limited literature available at this stage suggest that siblings' concerns include: perceived reduced parental attention due to time needed by their affected sibling, embarrassment in public or in the home due to their sibling's behaviour, and the often unpredictable aggressive behaviour of their affected sibling towards them or their belongings. Studies suggest that siblings may have more overall adjustment problems, peer problems, and be at higher risk for anxiety and depression compared to their peers. The studies available however were done with families whose child was diagnosed before current diagnostic criteria and treatment interventions were in place. We have recently completed a pilot study to look at the current situation for adolescent siblings in order to offer parents and siblings themselves coping strategies for frustrating, and at times overwhelming, situations which they may find themselves in.

For this reason, we decided to conduct a study, as part of a University of Toronto undergraduate medicine Determinants of Community Health (DOCH) year II course, to examine the social support needs, the supports available and the barriers to accessing existing support for adolescent siblings of children with ASDs. In-person interviews were conducted with adolescents who have a sibling with an ASD diagnosis. Seven participants between ages 14 and 17 years were recruited from families who had visited the Child Development Centre (CDC) in Toronto. Some were interviewed in their homes and others in the clinic setting. Three major themes were identified concerning siblings' perspectives and potential social support needs. These needs related to the areas of attention, denial, and anxiety. Many overlapping

concepts relating to these themes emerged but consistent messages in these three areas appear to exist.

The first is attention. There was a strong awareness of the demands on their parents' time caused by their sibling's difficulties and needs. However, as would be expected, there was a wish for more of both parents' time for themselves and a sense of the loss of attention which had been theirs or would have been theirs if the situation were more normal. There was also a sense of increased responsibility placed on them due to family needs for babysitting and help with childcare.

At the same time as there was significant awareness of the impact of ASD on themselves and their family, there was denial in some about the reality of their sibling's disorder, a longing for life to just be normal, and not a lot of interest in learning more about autism. Anxiety appeared in many forms and around a number of themes. Several described difficulty in relaxing in front of people outside of the family due to never knowing what might happen that could be very embarrassing. There was also worry about violence, often unpredictable and often based on actual frightening events which had taken place in the past. The unpredictable aspect of incidents and the perceived over reaction to minor events on the part of their sibling were understandably causes of frustration. The future for their family, their sibling, and themselves were all talked about in terms of thinking about their adult status. Few actually anticipated their own role in care in spite of wondering what would happen in the event of their parents being unable to continue to provide for their sibling's care.

Based on our findings, siblings are clearly in need of support and safe places to discuss their feelings without upsetting or adding to their parents' burdens. When we reviewed current community supports for siblings, we found that there are currently few formal programs available, especially for those living outside the Greater Toronto Area. Where programs exist, the main barriers to access identified by participants

included: limited time in their own or their family's schedules, location and the nature of the support available. Only a minority of the students with whom we talked had participated in programs for siblings.

The internet was identified as the location of support which would be most acceptable and the most useful for their age-group although to date no chat line specific to autism has been found. Ability Online is a venue in which an autism and adolescent sibling specific forum could be developed. The recently published book "Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum" by Feiges and Weiss is an excellent and encouraging starting point for parents and adult siblings in their reading.

In conclusion, as a result of our interviews and analysis of the information gleaned from these reports, there are indicators that many siblings are coping well in spite of many frustrations and very different lifestyles than their peers. Challenges exist however and literature specific for their ages and stages should be developed and given to families when they attend clinic visits with their child with ASD. Further development of internet communication pathways specific for siblings of children with ASDs would appear to be the most useful area of focus if we are to reach this very special and often needy group of teenagers.

#### References:

"Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum." Lynne Stern Feiges and Mary Jane Weiss. Autism Asperger Publishing Company. 2004.

Ability Online- [www.abilityonline.org](http://www.abilityonline.org)

The Sibling Support Project –

[www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)

Sibling Support Groups (Ontario):

1. Geneva Centre for Autism – [www.autism.net](http://www.autism.net) 416-322-7877

2. In Support of Siblings – Community Living Toronto  
Lori Delzotto 416-236-7621, ext. 230

[ldelzotto@cltoronto.ca](mailto:ldelzotto@cltoronto.ca)

3. Sibshops – Sudbury, Ontario 705-560-8000, ext 226

[jtramontini@hrsrh.on.ca](mailto:jtramontini@hrsrh.on.ca)

4. Sibling Workshops – Waterloo, Ontario 6-12 year olds

519-741-1121, ext. 221 [cbetts@on.aibn.com](mailto:cbetts@on.aibn.com)

5. Sibling group – Thornhill, Ontario

905-889-2690, ext. 2044 or 2112 [dwaring@reena.org](mailto:dwaring@reena.org)

or [aszabo@reena.org](mailto:aszabo@reena.org)

**“If we take people as they are we make them worse. If we treat them as if they were what they ought to be, we help them to become what they are capable of**

**becoming”**

**Goeth**

1. CAIRN: Generating & disseminating evidence-based research on autism.  
[www.cairn-site.com](http://www.cairn-site.com)
2. Geneva Centre for Autism: Outline resources available at The Geneva Centre in Toronto.  
<http://www.autism.net>
3. Asperger's Syndrome Information and Support: A web site dedicated to information on Asperger's Syndrome.  
<http://www.udel.edu/bkirby/asperger>
4. Autism Society of America: Provides a library of information on autism/PDD (click the 'information' tab).  
<http://www.autism-society.org>

# Accommodation Supports

by Lea Pollard at Contact Hamilton

There are various types of accommodation supports available for individuals with developmental disabilities within the city of Hamilton. Some of these services are funded through the Ministry of Community and Social Services (MCSS) while some are privately operated. There is a single point of access for the services funded via MCSS (Contact Hamilton). There are 3 types of *MCSS funded* accommodation supports in Hamilton for adults with a developmental disability. At this time, there are no funded children's accommodation supports within the developmental services sector.

**Group Living:** This kind of accommodation support is staffed fulltime by the agency and is shared by a group of individuals. The actual number of people living in the home varies. Generally speaking, people supported through Group Living options tend to require more structure and staff support.

**Supported Independent Living (SIL):** There are two kinds of SIL support: a) a person may receive several hours a week of staff support to assist them in living in their own apartment/living situation (e.g. assist the person in preparing meals, attending appointments, grocery shopping) OR b) a group of people living together with staffing support in the late afternoon to early morning (this type is similar to a group living model but has less staffing supports available). The emphasis of this kind of accommodation support is to enable the person to live as independently in the community as possible.

**Family or Associate Home:** This type of

Myth: Autism is caused by vaccines.

Fact: There is no good research that shows that autism is caused by vaccines. On the contrary, there is very good research that shows no association whatsoever. In fact, autism can be caused by rubella, a disease that a vaccine prevents. Unwarranted fears about vaccines have led to reduced vaccination rates and have led to epidemics in which children have died.

accommodation is generally available to adults with a developmentally disability who prefer to reside within a family environment. The person participates in various aspects of daily family life.

Private services are also available within Hamilton for both adults and children. There are several kinds of private resources: ***Outside Paid Resources (OPR) and Residential Care Homes/Hostels***. It is important to note that these services are private and the rate of payment varies from home to home. An **OPR** is generally a home or agency that provides services to children at a per diem or daily rate. The home is licensed by the Ministry of Children's and Youth Services and is required to meet certain legislated regulations. Although it may be possible to pay privately for these services, the homes generally operate in partnership with the Children's Aid Societies.

A **Residential Care Facility or Hostel** is also a private service. These homes need to be licensed by the City of Hamilton. They set their own fees and make private arrangements with the individual and/or the guardian or trustee regarding the care they can provide. Many of the Residential Care Facilities are subsidized. For more information about Residential Care Facilities or Hostels, please contact: the City of Hamilton, Residential Care Facilities and Hostels Department at 905-546-2424 ext. 2225.

If you have a child or loved one with a developmental disability and would like to further explore accommodation supports for now or sometime in the future OR if you would like to talk to someone about other services/supports that are available, please call Contact Hamilton at 905-570-8888 and ask to speak with an Intake Coordinator.

**Note: If you reside outside of the Hamilton area, access may be available via a central access site in your home community. Please contact the Provincial Ministry of Community and Social Services for that information toll free at 1-800-561-0369.**

# Balance

By: Michelle Del Duca

Balancing family life with 2 parents working outside the home, and having children with autism (and a child without autism) is an interesting position to be in. My husband and I both went back to school part time this year as well. We never would have considered this if not for the **network of supports** that have been built over the last few years.

We have had the good fortune to employ extremely supportive, and effective in-home workers for our two boys with Autism. In our extended families, we have been able to count on some support as well. In the earlier years I had difficulty with the notion that family offered to take our Neuro-typical son to events, not considering the younger two boys. Slowly I think we have both come around in our thinking. It was hardest for me, but I finally got it! **It should not be “all or nothing”** for our family. Sometimes it's OK if part of our family does something, and part of our family doesn't. We don't all need to loose out on an opportunity to take part in something.

Our oldest son Dominic was invited to go mountain climbing in Alberta for a week with my sister and brother in law. Without hesitation we sent him on what was the vacation of his lifetime so far. I do want Dominic to have the opportunities to do things that we just aren't prepared/able to do at this point in our families' life. I don't want to hold him back from experiencing great things because we can't all go as a family.

We do try to do as much as a family as possible. We have found that Gabriel and Raphael can cross country ski, and toboggan and swim and keep up or exceed the rest of the family. **Letting go** of slightly unrealistic expectations of what the house should look like, gives more freedom to enjoy time with the kids without the guilt. I've never thought back and wished I would have spent more time cleaning the floor and less time playing with the kids.

In the last few years we have really focused on **life skills** for the boys. (all 3 of them!) Teaching Dominic to do his own laundry completely has helped considerably. Gabriel and Raphael help with various

stages of the laundry process, including folding and putting the clothes away in drawers and closets. Once a week, the in-home workers spend some time helping them with cleaning and dusting their rooms. While this might not sound like much, it helps my overall workload a great deal, and builds their independence. The kids are proud of themselves and I don't have to dust countless lego airplanes, or jungle animal sculptures.

Claudio and I have also found it essential to **schedule one-to-one time** for each other, and for our oldest son. We work it in to the schedule. Once a month we plan a time for the two of us to go out. It is really a great way for us to recharge/relax and reconnect when life is hectic. Time with Dominic by himself is great too. He has a chance to have our attention and uses it! We often go for a run and I am amazed that he shares wonderful personal stuff and hilarious dirty jokes with his mother. I feel blessed to have the relationship I do with him. I really believe that it is only because we do get the opportunities to go out together by ourselves. When Dominic goes biking or playing racquetball with Claudio, they come back relaxed and happy.

All of our lives have been affected by Autism. We all have varying degrees of stress and joy at different times in our lives. Here's to reducing the things that aren't going to give us and our families' joy, and doing all the little things that do.

Michelle and Claudio Del Duca live in LaSalle (near Windsor) Ontario and have three boys: Dominic - 14, Gabriel - 13, and Raphael - 12. Both Gabriel and Raphael have Autism Both Gabriel and Raphael have Autism



# Preparing Children with ASD for Adulthood

By Rick Ludkin and Robin Brennan

When I was first approached to write this article I had an immediate flashback to last year's Manor Sports Banquet. One of the athletes started off his award acceptance speech with the statement: "I know that dealing with me is a daunting task..." And that's what came to mind in thinking about what to suggest to parents in helping them to prepare their son or daughter for adulthood – it IS a daunting task. This is made especially so when one considers the wide scope of Autistic Spectrum Disorder – advice that might seem very appropriate for one person might be much too complicated or too simple for another. So, specific recommendations are difficult to make.

That being said though, at Woodview Manor (in Hamilton) we have supported a large number of people in making that transition and, so, have developed some...perspective.

There certainly is a lot to think about and a lot for your child to learn. You can't start early enough. We like to break things down into three large general categories (with the understanding that there's a lot of cross-over between them): skills, rules and, for lack of a better word, intangibles.

As an exercise, stop thinking (and probably worrying about) here and now. Think ahead ten or fifteen years and try to picture your child as that young adult. What would you like him or her to be doing (and try to be realistic)? Now, work backward from there and make connections; e.g., in order to eat well (s)he will have to be able to plan a meal, make a shopping list, go to the supermarket, buy food, cook it, clean up afterward, etc. "Life skills" are often referred to as a simple category but there's nothing simple about them. The list of things to know is exhaustive. A life skills inventory that we developed at the Manor to assess this domain contains 229 items alone. The major areas include: personal hygiene, kitchen and cooking skills, laundry skills, cleaning, shopping, budgeting & banking, recreation & leisure, transportation, time management, health care, safety. Each skill can be taught individually. It is important to start this process early and refine the skills as you go. Some of them require a few steps, some take many steps. From our

perspective the important thing about life skills is the level of independence at which they can be performed. Is cuing required to move from step to step or can the youth recognize that it is time to move on and what comes next? If this is difficult, then the important thing is to work out the type of cuing that might be successful in helping the child to cue himself. The level of independence in performing everyday tasks will, to a large extent, determine the level of supervision the person will require as an adult. This isn't necessarily pegged to IQ or verbal acumen – we know some "moderate-functioning" people that are quite successful in living independently and some "more able" folks that are not and require a great deal of daily supervision. [As a rule of thumb, we can predict with confidence that a youth that can set an alarm clock and get up to it without prompts will be much more successful in independent living and in the world of work as an adult.]

Perhaps the most important thing is to expose your child early and often to the tasks (s)he will need in the future. We have been surprised too often at the Manor in meeting young adults who have never had to prepare themselves something to eat, had to do their own laundry, take public transit, clean their rooms, go to the bank or go shopping.

"Social skills" is another catch-all term for a myriad of individual skills, skills that are particularly difficult for people with ASD. Social skills can be taught formally - individually or in small group contexts - or they can be taught opportunistically as the youth takes part in the social milieu around him or her. One of the common problems with formal teaching outside the social context where they are required is that the skills often don't generalize well or at all and so must be taught to cover each possible situation. This can work in situations where the child's activity outside the learning milieu can be readily observed and the performance of the skill(s) reinforced. In most instances you can not expect that the child will generalize from the learning situation to the social situation without this type of support. If this is not the case, teaching the skills in the context of your child's activities may bring faster and more effective results.

Recreational skills, we find, often have been bypassed in the youth's upbringing. These are skills that allow your child to interact with others in a fun and meaningful way – the basis of friendships. Card games and board games are good to know. Turn taking and learning how to win AND lose is important. At Woodview, we have been very surprised by our sports program – the most highly subscribed of all our programs.

This is a group of people who are not supposed to like sports or to have any athletic skills. Our finding is that if you take a group of folks with similarly mediocre skills and modify some of the rules then “sports” become a very attractive option played with gusto and fervor. So don't discount teaching your child how to catch and throw or dribble or shoot a floor hockey ball. Our experience is that youth with ASD spend an awful lot of time playing solitary electronic/computer/internet games (or other focused interests) – sometimes to the exclusion of all else. You might want to think about limiting the time spent in this sort of solitary pursuit or if you can find games that require or can be played with two or more players they would be a much better alternative. We have found it extremely beneficial to include solitary recreation in an individual's daily schedule, if it is meaningful to them. Giving the message that there is time allotted once required tasks are completed sets a good foundation for higher levels of independence in adulthood.

Rules can be a very good thing. They help to clarify what to do when things are confusing or to keep the youth safe in particular situations. Thought needs to be given to the implementation or use of rules. They are important to accomplish tasks, promote family life and safety. But we want to be careful that rules don't become an obsession, promoting inflexible behaviour and thus possibly adding more stress. Most rules in our society are verbally passed down and some youths may well comprehend this information, but some may do better with them written out or shown in pictograms. Find the method that best suits your child. The overall message though is that there are rules which bring rewards when they're followed and consequences when they're not.

The “intangibles” consist of what we've gleaned from years of observing young people with ASD trying to make the leap to adulthood and then trying to determine what it is that has made that move successful or not successful, easier or harder. We would ask you to consider some of the following:

- Young people need to learn that they can, in fact must, make choices. They must also learn that they are responsible for the outcomes of those choices. All too often parents and teachers completely buffer their

children/students from the results of poor choices they have made or don't give them the chance to make choices at all.

- It is important for children and youth to know that there are limits, that no means no.
- They must learn that there are times when gratification must be delayed. [The concept of “first this, then that” is extremely important to learn.]
- You can't win every game or all the time. Everyone needs to learn how to lose (and that it isn't the end of the world).
- It is important that children are encouraged to “grow up” – encourage age appropriate dress, exposure to age appropriate interests and activities. [However, if necessary, allow time for younger interests in a safe environment away from potential scapegoating or bullying.]
- It is OK to limit perseverative behaviours especially when these are getting in the way of what needs to be done.
- “Stress” can sometimes be a good thing that leads to the development of coping skills.
- Work is a good thing; a good work ethic can result in improved self-esteem as well as a sound financial position.

Successful transitions tend to be the cumulative result of exposure to and training in doing the “little tasks” of everyday living. Just look around – there are lots of learning opportunities. There is an interesting article by Roy Brown and Vianne Timmons (*Exceptionality Education Canada*, 1994) in which they looked at differences in experiences of special needs children and those without special needs:

- Fewer adolescents with special needs said they decorated their own bedrooms.
  - They went to bed earlier and more of them were woken by their parents rather than by an alarm clock.
  - They had fewer chores at home.
  - More of them received spending money by asking for it than by earning it.
  - The majority said their parents shopped for their clothes.
- Few picked out their clothes to wear in the morning. All of these (and there are many more) are missed opportunities to learn the things that really count.

To conclude, when considering what your child's life could be like as an adult, it's important to think of building the stepping stones necessary to reach this goal. It's much more difficult to try and build strong steps quickly at the age of 21 than to have slowly and methodically cemented them in place over many years.

# Self care and the Child with Autism Spectrum Disorder

By: Lowana Lee & Julia Lockhart , Occupational Therapists

Children with Autism Spectrum Disorder often have difficulties with self-care skills. This may be due to an inability in processing sensory information correctly from the environment, an inability in initiating and motor planning tasks, an inability in problem solving, and/or delayed development in fine motor skills. These factors can cause concerns in feeding, dressing, personal hygiene and toileting.

## Eating

Eating problem may be due to oral motor difficulties, sensory difficulties and/or behavioral issues. An occupational therapist can help you isolate the particular underlying area of difficulty with your child.

The following are some strategies that can be used:

- Do not make eating an issue.
- Separate the eating goal from other goals eg. developing self-feeding versus increasing tolerance for various textures
- Follow a routine and a schedule
- Modeling – show the child what you are eating and eat with him.
- Present the new food to the child, but do not exert pressure on him to put it into his mouth.
- Provide a pleasant and quiet environment for eating
- If you suspect there is a food allergy, investigate further with health professionals
- If there is an underlying sensory processing component, identify calming strategies that may be able to be used
- Be aware of any motor concerns with seating, especially if the child seems to be moving all the time or falling out of the chair!

## Dressing

Dressing involves many skills: motor planning, balance, visual perception and fine motor skills. If the child has sensory difficulties, he may also have problems with the texture of the clothing eg. he may

dislike collars or turtlenecks, tights or socks, labels, etc. Again, it is important to investigate whether the primary underlying concern is sensory or motor.

The following are some strategies parents can use:

- Turn underwear inside out
- Use loose fitting clothes
- Use fabric softener in the dryer
- Use fleece or flannel material
- Remove labels
- Use simple verbal cues combined with visual cues and hand-over-hand assistance to initiate the dressing process
- Use visual cues to reinforce order of steps
- Maintain the same routine each time

## Toileting

Toilet training in children with ASD can be quite a challenge when there is difficulty registering and initiating the need to go, motor planning getting to the washroom, and managing clothing. The washroom environment can pose sensory challenges for some children eg. echoes, too cold or drafty, overfocus on the flushing, fascination with the taps, hypersensitivity to the toilet paper, or perseveration on tearing off squares of toilet paper. Here are some strategies that parents can try:

- Hand-over-hand assistance, with visual cues to initiate the process
- Padded seat/terry cloth seat/insert to increase sense of security
- Use of soft diaper wipes
- Support under the feet for stability if sitting on the toilet seat, and hand bars to hold on
- A social story or a role model (brother or father) can help to teach boys standing to void. If necessary, fruit loops in the toilet can be used as targets!
- For the child who is fascinated with flushing, prepare them for just one flush
- Use a predetermined number of squares of toilet paper for use when wiping, and count them out

## Personal Hygiene

Face washing is not easy for some children when they have a sensory processing problem.

- Use a softer texture facecloth. Start with a dry cloth, then a damp cloth, and then a wet cloth
- Do not use a large towel on the face
- Maintain a medium temperature
- A mirror can help the children to see and to get prepared
- Use heavy pressure, as light pressure can be irritating for some children especially when the facecloth is wet
- Have the child model another person
- Use hand-over-hand assistance if the child has motor planning problems. Structure the task into different steps, and divide the face into sections with a specific number of strokes per section
- You can also provide visual pictures, for example PECS (Picture Exchange Communication System)
- Provide a pleasant environment

Tooth brushing is another area that children with ASD have difficulty with. This often stems from a sensory concern, and your occupational therapist may be able to provide some oral desensitization for you to work with your child.

- Use a softer brush or sponge brush in the oral cavity
  - Use a facecloth on the teeth and use of milder toothpaste
  - Use a mirror to provide visual feedback
  - Let the child hold his own toothbrush
- .Again, provide a pleasant environment.

Hair Brushing can also be a struggle for some children.

- Massage the head before brushing, using firm strokes
- Use soft bristles with a high number of bristles per square inch
- Using a mirror can also help to prepare the child and provide feedback
- Support longer locks while combing them

- Use anti-tangle spray on the hair to detangle it first before the combing
- Give the brush to the child to hold so that he can have some control
- Use a social story before a hair cut
- Use a quiet razor or have him use headphones while the razor is being used

Bathing/Showering can be a challenge for some when there is increased focus on the water or with the opposite (avoiding water).

- Use a removable showerhead with a gentle flow and adjust it to mid temperature
- Have the child hold the showerhead so he has the control of the task
- Have the child apply the shampoo (you can also try a milder shampoo)
- A shampoo with built in conditioner helps to decrease the tangles.
- Massage the head before washing the hair.
- Use a facecloth on the face to keep water off.
- Have the child lean back in the tub keeping his ears free of water.

The above strategies are some that we have found useful when working with children with ASD. Not all of them will apply to your child. If your child struggles with some functional activities and there is a strong sensory component underlying his difficulties, your occupational therapist may be able to offer some strategies to make the activity go more smoothly and make life easier for all!



## Keep us up to date

Please keep in touch with us so we have an up-to-date record of your address and phone number. This helps us to keep you informed. If you have received questionnaires from us, we would ask that you return them as soon as possible. If you have misplaced the forms or the return envelope, please contact **Bev Da Silva** at **x74728**. Messages can be left on her voice mail in the evening, if this is more convenient for you.

# Brief summary of the presentations from the Parent Conference November 2004

## Infant Sibling Study Update

Dr. Lonnie Zwaigenbaum Presentation

Dr. Zwaigenbaum presented an update on the Infant Sibling Study. The main goals of the study are to: a) better understand the early development of siblings of children with ASD, and b) identify early 'risk markers' that predict status of child development at age 3 years. Currently, there are 176 siblings and 70 comparison infants participating in the program.

Initial Findings from the study show that 11 out of 90 siblings followed to age 2 years have a clinical diagnosis of autism and an autism classification based on the ADOS. According to Dr. Zwaigenbaum, the features that characterize this group of children at age 6 months can be divided into two categories: a) *Subtle differences* such as decreased vocalization, somewhat passive, motor delays (low muscle tone), and b) *No obvious social concerns* such as eye contact present, reciprocal social smiling, social interest and affect. At 12 months of age children with autism present the following features: poor visual tracking (and overall engagement), quiet, lack social babbling, decreased social behaviors (smiling, response to game of peek-a-boo, interest and affect), lack basic imitation skills, extreme reactivity, atypical motor and sensory behaviors, and variable language and cognitive delays.

Dr. Zwaigenbaum then described some of the ongoing research projects related to the Infant Sibling Study: There will be a follow-up assessment of younger siblings to age 5 years as part of the newly funded CIHR project "*ASD: Pathways to Better Outcomes*". Future research will include assessment of the child with ASD (proband). On another study, Dr. Jessica Brian and Shelley Mitchell are conducting an intervention study aiming to assess autism treatment strategies in 12-24 month-olds with early signs. The study focuses on early communication, joint attention, social engagement/disengagement, imitation, and attention to the environment. Finally, the research team will conduct a new study of early head growth in autism. Evidence show that increased head growth

previously noted in some children with autism. This study will evaluate early patterns of head growth as a possible risk marker for autism. Based on a direct measurement and review of growth records for Sibs and Probands, the study will correlate early head growth with other early features of autism.

Dr. Zwaigenbaum noted that this research program is part of an international collaboration called "*Baby Sib Research Consortium*". Research groups from across North America are teaming up for this consortium: Yale Child Study Group (A. Klin), Johns Hopkins University (R. Landa), Vanderbilt University (W. Stone), UC Davis –UCLA (S. Rogers, M. Sigman, S. Ozonoff), U. Washington (G. Dawson), U. Connecticut (D. Fein), U. Pittsburgh (J Iverson), Boston Medical Centre (A. Carter, H Tager-Flusberg), U. Michigan (C. Lord), and McMaster/U Toronto/Dalhousie U (S. Bryson, L. Zwaigenbaum).

Finally, Dr. Zwaigenbaum described some projects that are under development. More specifically, one project will involve brain imaging of high risk infants (with Dr. Joe Piven, UNC). Another project will involve developing and evaluating diagnostic criteria for ASD in children under 2 years of age (with Dr. Cathy Lord and Sib Consortium). A third *Autism and Language Genetic Study* will examine speech delay, mild difficulties in processing speech sounds, and in reading and spelling within families of individuals with autism. Results from this study may help identify genes involved in both language abilities and in autism.

**Myth:** Autism can be diagnosed only after age 3.

**Fact:** Current research is showing that there are signs and symptoms of autism clearly recognizable in a child in his/her first year after birth and certainly before age 2.

# MEG in Specific Language Impairment and Autism Spectrum Disorder: Research in Neuroimaging

By Janis Oram Cardy, PhD, S-LP(C)

According to Dr. Oram Candy, children with language disorders (Autism, SLI) have impaired understanding and/or use of language and are at high risk for life-long academic, behaviour and social problems, which has far-reaching health and social implications. Little is known about the basic brain differences underlying developmental language disorders in children. Dr. Oram Candy believes that these children may have a basic problem in the parts of their brain involved in perceiving speech sounds, which leads to difficulties acquiring language early in development.

Dr. Oram Candy and her group are using a state-of-the-art, non-invasive brain imaging technique (MEG) to establish whether children with language impairments, either found alone (SLI) or in association with Autism, have problems in distinguishing sounds as compared to children on the autism spectrum who have communication problems that are only socially based (Asperger Syndrome) or children who have no developmental problems (controls). This project also seeks to determine whether children with Autism and SLI differ in the specific point in time and place in the brain they have problems distinguishing speech sounds. Dr. Oram Candy hopes that this kind of approach will allow for earlier identification, suggest more specific and focused treatment regimens, and lead to discovery of new therapeutic interventions for children with autism and other language disorders.

For the specific project, participant recruitment is underway involving four groups: a) Autism (+ASD, +SLI), b) Asperger Syndrome (+ASD, -SLI), c) Specific Language Impairment (-ASD, +SLI), and d) Typical Development (-ASD, -SLI). The goal is to enroll at least 20 children in each group. Inclusion Criteria for the study are: a) 8-to 18 years old, b) no metal (e.g., braces, permanent retainer, pins), c) no known neurological or sensory impairment (e.g., CP, epilepsy, hearing impairment, etc.), d) nonverbal/Performance IQ =16th%ile, and e) able to lie still for 5-10 minutes. The study requires two visits to the Hospital for Sick Children. The first visit is at the Child Development Centre and includes a standardized assessment (WISC-IV, CELF-4, WRMT-R, CTOPP, ADOS, ADI-R). This usually takes one-half to full day and a short report on child's performance is given to parents. The second visit is at the MEG Lab. This usually takes 2 to 2.5 hours. During this experiment, three sensors are taped at nose and ears, sponge earphones are inserted into ears, while the child lies still on bed with head in helmet, watching a video. The experiment is repeated 6 to 8 time (3-12 minutes each).

For more information about this study visit [http://individual.utoronto.ca/oram/MEG\\_1.html](http://individual.utoronto.ca/oram/MEG_1.html)

## Blood Collection

For those **multiplex families** who are in Dr. Szatmari's Genetic Study, if we have not yet collected your child's blood, and your child is having his/her blood tested for any other reason, please contact *Ann Thompson* at **(905) 521-2100 ext. 77831**. We may be able to arrange to have our research blood collected at the same time.

# Social Communication Programming for Children with Autism

By Shelley J. Mitchell, B.Sc., MSLP (C)

Shelley J. Mitchell presented very interesting information regarding the many complex elements of “Social Skills” in children with ASD. According to Mitchell it is important for parents to understand that there are four main categories of their child’s skills/functions:

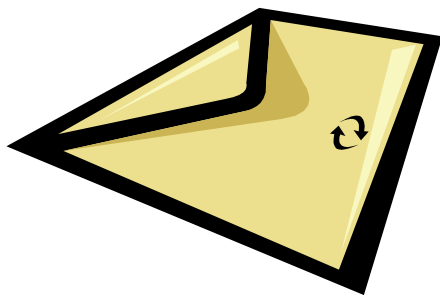
- 1) Communication Functions include requesting (objects, actions, and information), directing, commenting, protesting, and greetings/salutations.
- 2) Social Interaction includes response to social initiations, response to play initiations, initiation of social routines, initiation of play, showing, and sharing emotion.
- 3) Play includes functional actions with toy (solo/with a partner), selecting appropriate toy for solo play, pretend play (miniatures), imaginative play (representational), and turn-taking in play.
- 4) Imitation includes actions (in songs, in play/ social/ communication context), actions with object, oral movements, vocalizations, words, and social/play sequences.

According to Mitchell, when parents are trying to answer the question “How do I decide what to teach my child?” they should use the following guidelines:

- 1) Increase frequency of appropriate emerging behaviours
- 2) Increase complexity of social and/or communicative behaviours
- 3) Increase sophistication of social and/or communicative behaviours
- 4) Establish new behaviours

According to Mitchell, teaching a child can be direct (i.e. structured, supervised, has a specific goal, has specific cues provides practice with the skill) or incidental (i.e. less structured, shadowed, has opportunities for new skills to be used, uses cues and then fades them, provides “test” situation). Mitchell also noted that imitation is not enough and that children need a chance to practice the skill correctly but spontaneously.

Finally, Mitchell pointed out that when parents are setting up structured social interactions for their child they should a) know what skills the child has in terms of language, communication, play and imitation, b) provide enough support for your child to be successful with some spontaneity, and c) know the demands of the activity.



## Clinical Concerns? Who Do You Call?

When you wish to consult Dr. Szatmari regarding a clinical concern (medication, behaviour, etc.), please call his personal secretary, *Joan Whitehouse* **521-2100 ext. 77367**. She knows Dr. Szatmari’s schedule and can see he gets the message promptly and arrange a time when you can talk to him. Even if you live outside of the Hamilton area Dr. Szatmari and Dr. Zwaigenbaum will see families involved in our studies for clinical reasons.

# Suggestions for Strategies to Enhance the Socialization of Children and Youth with Asperger Syndrome: Caution, One Size Does Not Fit All

By Barbara Muskat M.S.W., R.S.W.

Barbara Muskat's presentation had three main objectives: a) review some of the social and emotional difficulties which are distinguishing features of individuals with Asperger Syndrome, b) review the importance of promoting social and emotional well-being, and c) discuss individual, group, and family-based strategies to address these concerns.

According to Muskat, social difficulties common to individuals with Asperger Syndrome are usually described using three major theories: a) Central Coherence Theory (difficulty relating parts-to-whole), b) Executive Dysfunction Theory (difficulty creating organizational structures that allow for flexibility and prioritization, and difficulty planning, breaking down information into steps, managing time), and c) Theory of Mind (difficulty thinking about and acting on information about one's own or others' mental states such as beliefs, desires, and intentions).

According to Muskat the development of social competence is a protective factor for the mental health and well being of children and youth since there is evidence for a high correlation between poor peer relations and psychosocial problems.

Muskat then presented some basic principles of intervention:

- Model self-talk (i.e. talk aloud through activities that rely on non-verbal cues such as visual-spatial-organizational abilities or social perception)
- Label feelings and emotions as they occur
- Provide opportunities to recognize and understand nonverbal patterns (make them explicit as they occur)
- Break tasks down into steps
- Work together to develop strategies to assist in adapting to change
- Create a supportive home environment in which the individual is able to feel accepted and successful

Muskat noted that most individuals with Asperger Syndrome are not loners by choice. There is a tendency for these individuals as adolescents to become despondent, negative, and sometimes, clinically depressed, as a result of their increasing

awareness of difficulties in social situations, and repeated experiences of failure to make and/or maintain relationships.

Muskat then presented some general points that should be considered when trying to address social difficulties in individuals with AS:

- Individuals with Asperger Syndrome have difficulty learning about socialization in the midst of large, complex social situations
- Individuals with nonverbal learning disabilities need to learn to recognize situations that are potentially problematic and develop strategies to deal with them (i.e. recognizing that large groups are too stimulating, and requesting permission to be in a smaller group)
- Model and practice the use of language that is similar to age-peers, rather than relying on "adult" language
- Do not ignore or explain away inappropriate behaviours
- Individuals with Asperger Syndrome are not "rude" or "insensitive" on purpose. Offer them assistance, support and protection, NOT criticism
- Individuals with Asperger Syndrome may need help to understand why it is important to consider the needs and feelings of other people
- Individuals with Asperger Syndrome often need explicit help to observe and notice others
- Intervention with individuals with nonverbal learning disabilities is found to be most effective when the individual, family, school and clinic are working on the same issues. Generalization is best achieved when the same issues are being addressed and similar approaches are being used
- Monitor progress jointly with the individual. Find out which situations have been more easily managed and which are more troublesome. Self-evaluation should be used in a manner that strengthens self-esteem.

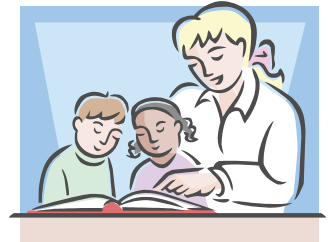
Finally, Muskat briefly described some of the most popular intervention techniques for individuals with Asperger Syndrome such as social skills training, socialization groups, self-esteem building, and cognitive behaviour therapy.

# Autism & Language Genetics Study

**Investigators:** Dr. L. Zwaigenbaum (Principal Investigator), Dr. P. Szatmari and Dr. J. Goldberg, McMaster University, and Dr. S. Scherer, University of Toronto.

**Do you have a relative who has speech delay or who has had difficulty with language in writing, reading and spelling?**

This study explores the language abilities of relatives of children with Autism Spectrum Disorders (ASD) and the specific genetic factors that may be involved.



If you think your family and your relatives might be interested in participating, please contact Ellie Deveau at 905-521-2100 #74906 or by e-mail: [deveau@mcmaster.ca](mailto:deveau@mcmaster.ca)

## Understanding the Conversation Abilities of High Functioning Adolescent Children with an Autism Spectrum Disorder (ASD)

### Principal Investigators

Dr. Peter Szatmari, Dr. Jessica de Villiers, Dr. Robert Stainton, Dr. Larry Tuff, and Dr. Melissa Rutherford

**Objective of the Study:** To determine the how an adolescent with an autism spectrum disorder's ability to carry on a conversation is related to their information processing style.

**We are looking for:** Adolescent Children between the ages of 13-18 who have a diagnosis of Autism or Asperger syndrome. All participants must be able to carry a conversation and read at a grade 4 level.

All participants will receive a psychometric summary report of their cognitive performance.

For further information regarding the study or to inquire about participating, please contact the project coordinator: Liezanne Vaccarella at (905) 521-2100 ext. 74356, E-mail: [vaccarel@mcmaster.ca](mailto:vaccarel@mcmaster.ca)