



The Autism NEWSLINK

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the newsletter of autism society ontario

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Toonie for Autism Day Campaign



On April 26, Autism Society Ontario hosted its first annual *Toonie for Autism Day* campaign. This exciting initiative was born out of a ASO's desire to support autism research in Canada, last spring's *CycleUSA* by Sergeant John Keating of Ontario, and the enthusiasm of dozens of volunteers in Durham Region and Toronto (see Durham chapter notes). A committee (Bonnie McPhail, Ron Harrison,

Maria Harrison, and the printing of 10,000 copies of 8 pages of materials was donated by J. F. Moore Inc. With support from most school boards in Ontario and volunteers in ASO



Maria Harrison – Toonie for Autism designer.



Key Toonie for Autism Day volunteers – Ron Harrison and Bonnie McPhail

John Keating, Emmanouela Dimas and ASO staff) was formed, campaign design concept and production was donated by PGE Tools and

chapters, nearly 4000 packages were mailed through mostly internal mail systems to principals in Public and Catholic schools. The packages were recently voluntarily translated into French by Anne Gingras, President of our West Nippising Chapter. Over 241 schools have said "yes" to their participation in this autism awareness and fundraising for autism research event. Over 103,000 students received information about autism that was sent home with them during the campaign. Dozens of offices and places of business around Ontario also joined us in this campaign. All of Durham Region's municipalities officially declared the last Friday in April *Toonie for Autism Day*.



Students of George P. Mackie Public School in Scarborough listen attentively to an autism awareness presentation for Toonie for Autism Day in April.

President's Message

Dear Friends,

It is now three-quarters of the way through the fiscal year for ASO and what a year it has been. We have followed through with the strategic plan by conducting an intensive-working weekend in Bracebridge, now affectionately called "the Bracebridge Summit". The governance model for the organization has been set and board committees are actively working on time frames and strategies with respect to the balance of the plan as developed by all of you with the able assistance of your presidents.

In November, we held the inaugural meeting of the future SEAC (Special Education Advisory Committee) Council. Interested SEAC representatives throughout the province attended and training was provided through workshops conducted by Lynn Ziraldo and Lindsay Moir. We also heard from Alexander Bezzina of the Ministry of Education and from my conversations with the participants, everyone learned from these wonderful and

informative speakers. The basic structure of the SEAC Council has been agreed to and we will continue to move forward with this initiative. A special thanks goes out to the members of the education committee who will form the education resource group to assist this new council with advice on education related problems, initiatives, new government programs and the formation of education policy for ASO.

New fund raising initiatives are in the works as well as the formation of a designated fund (with a view to an eventual foundation) sponsored by ASO to support research into Autism Spectrum Disorders. Research funds have already been donated and we are very excited about the announcement of ASO's Awards of Excellence for Contributions to Autism Research (see announcement in this issue). The Toonie for Autism Day campaign to promote autism awareness and raise autism research funds is in full swing and we anticipate excellent results from this initiative.

As you can see this is a thriving and growing organization; with all of your assistance we can't help but move forward and live up to our new vision and mission statements. I want to thank all of you, the members of ASO, as the completion of these tasks would have been impossible without your support and active involvement. The biggest thanks go out to our marvelous staff including Marg Spoelstra, Ethel Berry, and Susan Oreskovich and dedicated provincial office volunteers Barb Worrall, Joan Lewis and Jean Woolford. Without their ongoing support, organizational skills and knowledge base, we would not have been able to accomplish as much as we have in such a short time span.

Keep involved, keep advocating and our vision will become a reality.

Yours truly,
Hugh Vallee
President of the Board

From Adversity to Diversity: Working Toward a Safe and Inclusive Society



**Annual Conference of the
Ontario Association for Community Living
June 5-8, 2002 - Toronto, Ontario**

Keynote Speaker: Former Ontario Premier Bob Rae
More than 40 sessions on a variety of important themes...

***Freedom from Harm...Diversity...Children and Family
Education and Transition ...Justice***

Sessions are designed for individuals, families, support people,
staff and administrators to meet new people
and to learn from and share experiences with each other.

If you can only attend one day, consider attending our
14th Annual 'Family Day'

Wednesday June 5 (9:30 am - 4:30 pm).

Parent and training consultant Darcy Elks
facilitates a special set of workshops for families
seeking to "Build a Meaningful Day" for their loved ones

For a complete program including registration forms,
contact OACL at 416-447-4348 or visit our website at

www.acl.on.ca

Cycle for Autism is gearing up for September 2002. Watch for details about a potential Northern Ontario route for cycle enthusiasts. Also consider joining Karen Mackay's group.

Are you an avid cyclist? Are you tired of your regular route?

Join us on our 2nd annual 1000 km cycle from Windsor to Ottawa, to raise funds and awareness for Autism. Cycle the full 1000 km or cycle a part of it. Pick up the route anywhere that suits you. We travel 100 km a day, on back roads, through central Ontario, leisurely, with time to smell the flowers and see the countryside. September 9th to 22nd, 2002. For more information contact me at mackay_karen@hotmail.com



Dalhousie and IWK

ASO Education Survey for Parents of Children with ASD

introduce first Joan and Jack Craig Chair in Autism

Families affected by autistic spectrum disorder received encouraging news this month with the appointment of Dr. Susan Bryson as the first holder of



Dalhousie University's Joan and Jack Craig Chair in Autism. Dalhousie University and the IWK Health Centre introduced Dr. Bryson at a joint press conference in late October.

Dr. Bryson is a gifted clinician, researcher and teacher who is recognized nationally and internationally as a leading expert on autism and related disorders of development. She most recently worked at York University and the Toronto Hospital for Sick Children where she founded the Autism Research Unit. Dr. Bryson is no stranger to Halifax nor to Dalhousie, where she taught in the Department of Psychology from 1979 to 1988. During her tenure here she conducted a landmark epidemiological study of autism, the first conducted in North America.

(l-r) Dr. Peter Camfield, head, Department of Pediatrics; Hon. Jamie Muir, Nova Scotia Minister of Health; Dr. Noni MacDonald; Mr. Jack Craig; Dr. Susan Bryson; Mr. Brian MacDougall, Vice President of Operations and Support Services, IWK Health Centre; Mrs. Joan Craig; and Dr. Tom Traves. (Abriel photo)

Educated in psychology at McGill and the University of Guelph, Dr. Bryson's areas of special interest are autistic spectrum disorders, mental handicap, specific developmental learning disorders and developmental neuropsychology. She has published extensively and has presented around the world on topics related to autism and pervasive developmental disorders. She has made distinguished contributions to the community in her capacity as consulting clinician to Woodview Manor and board member for many organizations, including the Asperger Society of Ontario, Kerry's Place, the Geneva Centre, and the Autism Societies of Nova Scotia and Ontario. In 1992 she was honoured with an award for Outstanding Professional Contributions by the Autism Society of Ontario.

"There is no doubt that people living in the Maritimes will benefit from having such a renowned specialist living and working in their midst," said Dr. Tom Traves, President of

Dalhousie University. "An endowed Chair acts as a magnet to attract top-notch faculty and students because of the excellent research and clinical environment such a position provides and nurtures. We are very grateful to the Craigs for their generosity, which has made this possible."

The Joan and Jack Craig Chair in Autism, the first chair of its kind in Canada, was established at Dalhousie in May 1999 with a generous gift from the Craig family. The Chair represents a \$2 million endowment, half of which is donated by the Craigs. The endowment guarantees funding in perpetuity to contribute to the salary of the Chair holder and support her clinical and research efforts. Part of the Chair's salary is also supported by the Dalhousie Pediatric Association. The Chair was created to attract an outstanding individual in the field of autism who would foster new knowledge and treatment practices, and enhance diagnosis, treatment and outcomes for people with autistic spectrum disorder in Nova Scotia and beyond. The Chair will help Dalhousie Medical School and the IWK become leaders in the field of autistic spectrum disorder. Dr. Bryson will be a faculty member of Dalhousie Medical School and of the IWK Department of Pediatrics.

"The Joan and Jack Craig Chair in Autism will help advance scientific research, diagnosis and treatment of autistic spectrum disorder, which is wonderful news for Dalhousie and the IWK and, more importantly, for children and adults with autism, and their families," noted Dr. Noni MacDonald, Dean of Dalhousie Medical School. "There is a great need for outstanding individuals like the Craigs to work hand in hand with Dalhousie, the IWK and government to enhance research and patient care in the Maritimes. Partnerships like this in health care delivery will help us achieve what we cannot achieve alone."

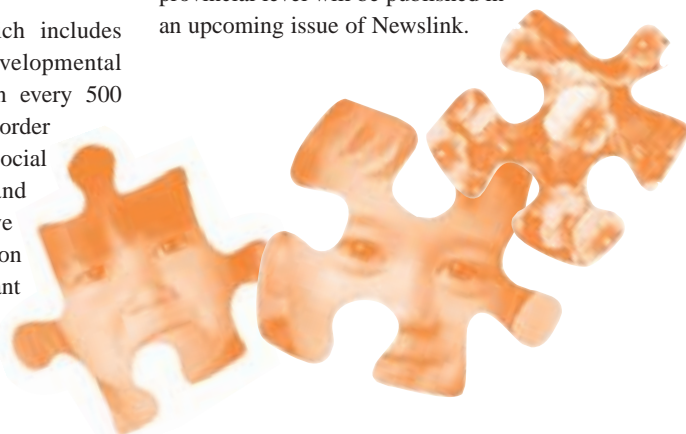
Autistic spectrum disorder, which includes autism and other pervasive developmental disorders, affects at least one in every 500 people. Individuals with this disorder show differences in the areas of social development, communication and behaviour, and typically have learning deficits. Early identification and intervention are very important and can greatly improve the outcome in this lifelong disorder.

"Parent Empowerment" is a strong theme of the York Region ASO Chapter. At a recent chapter meeting, we discussed how we could get better data from parents about their experiences with special education services in York Region. We decided to survey the parents, and wanted to do it electronically to make it easy for parents and inexpensive for the chapter. We approached a leader in web-based survey tools, Perseus Development Corporation, to see if they would consider donating a copy of their SurveySolutions software to develop the survey and to help analyze the results. They not only donated the software, but offered to host the survey as well. Our sincere thanks to Richard Nadler and Perseus Development Corporation for their support.

Parents are invited to participate by going to: <http://www.surveymhosting.net/autism/survey.htm> before June 1st. We will then segment the data by chapter and by board and provide the data to each chapter. The York Region chapter plans to use this information to raise issues at SEAC, and to substantiate those concerns with data. In York Region, we also plan to develop a paper survey and send it to those members who do not have access to the internet. We may also consider telephone surveys for those members as well. Our objective is to get as many to participate as possible. There is after all, power in numbers! If your chapter would like to participate, all you need to do is promote it within your membership.

This survey is confidential. Information will be statistically compiled and graphed, but no names, initials or other identifying information will be collected. The survey does ask the name of your child's school, but this can be left blank.

The data will be analyzed and the results at the provincial level will be published in an upcoming issue of Newslink.



Chapter News

Chapters respond to the question: “What has changed in your community in the last three months because your local ASO chapter exists?”

Cambridge: Working together with the Waterloo Chapter to provide a free workshop, 419 people heard Dr. Lonnie Zwaigenbaum speak on February 15 about new research in autism and coping with frustrations experienced by individuals with Aspergers. That evening Rogers Cable viewers saw a televised interview with Dr. Zwaigenbaum and Victoria McArthur, Cambridge Chapter President.

Chatham/Kent: 90 local people attended an Applied Behaviour Analysis Workshop by Dr. Anne Cummings through the Geneva Centre. Interest and success with this chapter hosted event prompted the scheduling of a second workshop this summer with the majority of local school board staff as anticipated attendants.

Dufferin: 300 people attended a chapter garage sale and saw the chapter's "Autism Awareness" booth. 35 people heard Jackie McMillan - an adult with Asperger's - speak at a chapter meeting. A Local MPP heard concerns about the ageing-out issue in the pre-school IBI programme. Dufferin chapter arranged for ASO Presidents and Board members to hear Kathy Robertson, Lt-Col.(ret) speak about NIDS. There is a NIDS video conference May 18,2002 and Kathy's presentation has become a catalyst for arranging a Toronto-area site to hear Dr. Goldberg, Dr. Galpin, Dr. Griffiths and Dr. Klimas present their theories and their research and to participate in a live Question and Answer session on a potential cause and treatment for at least some of our children.

Durham: About a dozen dedicated volunteers gave up two weekends to gather at the home of Ron & Maria Harrison in Ajax to collate and fill ten thousand Toonie for Autism Day packages for distribution to schools across Ontario.

Grey/Bruce: New conversations have occurred with CPRI's PDD Program and Regional Support Advocates about plans for autism services for children through adults in this region. Toonie for Autism Day has established new contacts with schools in Grey/Bruce about students with ASD.

Halton: The chapter presented its first of monthly 2 day intensive ABA workshops in March. Parents of both younger and older children attended - helping to close the gap of

misconception that ABA is just for the young. Parents came from as far as North Bay to participate in April's workshop, and parents left wanting to set up the same workshops in their area.

Hamilton-Wentworth: Plans are coming together for hosting a much needed summer camp program for high-needs children with ASD in the Hamilton area.

Kingston: An excellent working relationship has emerged between this chapter and the local Early Intensive Behaviour Intervention Provincial Program staff.

London & Middlesex: Autism Awareness continues to increase at many levels in the London area. Physicians are being informed; educators are

Niagara: Puzzle-piece pins promoting autism research and awareness were made by chapter volunteers and purchased by hundreds of people which raised support for chapter activities.

North Bay & Area: Yvette Bellefeuille represented the needs of Native children with ASD and their families at CAIRN in February. The North Bay chapter also continues to highlight serious autism service gaps because of geographical boundaries and catchment area restrictions that have an impact on the Native population.

Ottawa: 50-100 people learned about possible environmental allergies and toxic responses in people with ASD from medical health officers and an environmental allergist in the Ottawa area in March.

Peel: The chapter was revitalized at a recent meeting and 35 people heard about the communication needs of children with autism from Speech Language Pathologist Tracie Lindblad.

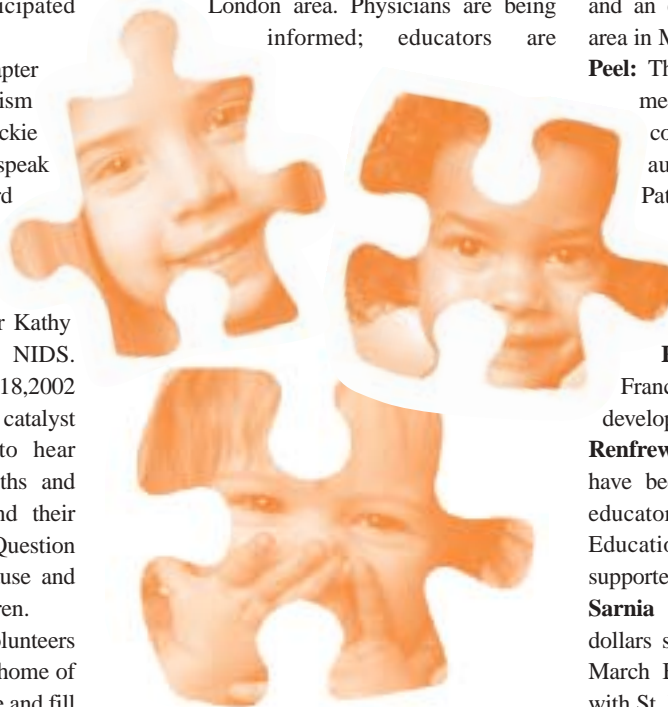
Peterborough: Have set up an office in donated space downtown, complete with telephone, computer and meeting rooms.

Region d'Ottawa: Summer camp for Francophone children with ASD is being developed.

Renfrew: Many parents of students with ASD have been supported in their meetings with educators of their children. The Special Education Advisory Committee has been supported by parents of students with ASD.

Sarnia Lambton: 3000 chapter fund-raised dollars supported ten children with ASD at a March Break program through a partnership with St. Francis Advocates.

Sault Ste. Marie: All interested physicians, psychiatrists, psychologists, behaviour therapists, parents and any other professionals will be invited to attend a one day conference, one day consultation on May 1 & 2 from Dr. Joseph Huggins. Cost is \$20.00 for the day including lunch. Two local agencies have agreed to support this event. Community Living Algoma is helping with distributing flyers and organization along with a financial contribution. Algoma Family Services will provide some financial support.



influenced through 1-1 parent contact and chapter training events, and families experience support through the network of ASO members. New relationships are being formed through the Toonie for Autism Day campaign.

Metro Toronto: In February Toronto area parents learned from the Toronto District Board of Education's Catherine Stewart who spoke about "ISA Funding" - Intensive Support Amount. Also, late last fall, hundreds of Canada AM viewers of heard Lee Steele (parent and professional) speak about autism and the impact of autism on families.



Schoolboard – Chapter Co-op

in West Nippising

Simcoe County: A plan to better support families of children with autism through chapter activities from Barrie to Orillia has been organized for May 6 meeting.

Sudbury & District: Over 200 attendees in Sudbury's Autism 2002 conference learned about Sudbury chapter activities and ASO provincial initiatives.

Thunder Bay: Security guards across Thunder Bay received training on understanding and responding to people with ASD with the donated Law Enforcement and Autism videos (from RBC Financial Group) in a training course provided through a Thunder Bay College police training course.

Upper Canada: A partnership with Stormont-Dundas-Glengarry Developmental Services has resulted in a Snoezelen room to be set up in their newly acquired Respite Home. The home will service 2 medically fragile and 4 developmentally challenged individuals at any given time. But the Snoezelen Room will be accessible to the Community. This is a FIRST in this community. The chapter raised \$34,000 through three funding streams: 1. \$25,000 from Ronald McDonald Children's Charities 2. \$3,000 from MCSS 3. Upper Canada's chapter contributed \$6,000. SD&G Developmental Services will provide the additional funding (i.e. renovations costs, fee for engineer, etc.) and will assume administration and on-going costs. I am still involved as I am on the Board for the Respite Home.

Waterloo: See collaboration with Cambridge chapter notes above.

Wellington: Collaboration with Community Living resulted in a planning day on March 28 about the residential needs of adults with ASD.

West Nippising: The Separate School Board and the West Nippising chapter entered into an historical legal agreement about sharing board space and the chapters Snoezelen Room equipment to improve the lives of people with autism and other learning exceptionalities.

Windsor/Essex: Over 500 people saw the faces of children with autism on a huge screen and learned about the impact of autism on families at a wildly successful fundraising dinner in the Windsor area in March.

York Region: Thousands of people are informed by the BBB Autism/ASO York E-News - a collaborative autism website effort of the BBB Autism and York Region ASO Chapter.

Part of a speech that Anne Gingras made in her community about

ASO – School Board Collaboration

Mesdames et messieurs, bonsoir.

Je suis heureuse que vous soyez parmi nous ce soir pour célébrer avec nous le point culminant d'une aventure qui a débuté il y a depuis maintenant près de trois ans.

Je me souviens bien avoir vu la photo en couleur de la salle Snoezelen de l'école John 23d couronner la première page du journal. Et je ressens encore à ce jour, lorsque je regarde NOTRE salle, les premières émotions que j'ai éprouvées quand j'ai dit à mon époux Bill et à mon amie Julie que nous allions, nous aussi, en construire une pour nos enfants.

When I showed my husband the picture of the Snoezelen room and announced that we were going to build one, our lives changed forever. We knew that our group of dedicated members could do it. After reading up on the concept of Snoezelen, finalizing a location for the therapy room, and agreeing on the necessary equipment, we began the long and tedious process of fundraising. Our two families, the Gingras and the Leblancs, with our incomparable dedication, convinced the whole West Nippising Community of our project.

A travers un don merveilleux de la fondation Trillium, des lave-autos, des cyclethons des dons généreux des gens de notre communauté comme Monsieur Paul Goulard, Moe Mantha et les Filles de la Sagesse, pour en nommer seulement quelques-uns, notre salle vit le jour le 4 septembre 1999. Toutes nos heures de travail furent récompensées lorsque les visages de nos enfants Alexandre, Mathieu et Sylvain furent illuminés d'une joie et d'une satisfaction sans pareil.

Living a daily life with autism is NOT easy for the children and their families. Because this disorder is still not well understood by the medical community, there remain many obstacles to be overcome. We must try to find the cause of autism and we hope that someday, it will happen so that families like ours can be spared this tremendous ordeal. But in the meantime, there are wonderful people who are

willing to help us and we are forever grateful for their contributions to our lives. Last August, due to circumstances, we had to find a different location for the Snoezelen room. At that time, I spoke with Cynthia Roveda about the possibility of housing the room in one of the conseil's schools, and finally, this wonderful center was chosen. It took one year to organize and to finalize the details but finally tonight, the dream has become a reality for all the children in our community.

Grâce à ce nouveau partenariat forgé avec le conseil catholique franco-Nord et Autism Society Ontario, nous pourrions donner aux enfants autistes, ainsi qu'à tous les enfants affligés d'un trouble de développement de notre région, une salle merveilleuse et unique qui pourra les faire sourire et alléger leur fardeau quotidien. Trouvant ses origines en Finlande et signifiant <to sniff and doze>, la salle Snoezelen permettra aux enfants de vivre des expériences sensorielles à travers leurs sens. La douce musique, les lumières multi-couleurs, et l'environnement calme contribueront tous au bien-être de nos enfants. Et nous continuerons notre inlassable travail pour ajouter d'autres pièces dans la salle qui pourront favoriser davantage cet apprentissage.

Finally, I would like to thank everybody who helped make this project possible. We have too many volunteers and contributors to acknowledge them at this moment. To do so would perhaps mean forgetting to mention someone. But in that same vein, I can, in the name of our children and families who struggle with autism tell you that we are very grateful for your help, encouragement and continuous support!

Au nom de la société d'Autisme de l'Ontario et de toutes nos familles qui bénéficieront de notre merveilleuse salle, MERCI!

Anne Gingras

President, West Nippising Chapter



Provincial News

What's New? - ASO's Key Areas of Focus

Research:

In February, Autism Society Ontario was privileged to participate in the work of two research groups who also receive funds for autism research from the Canadian Institutes of Health Research. These groups have not only expressed interest in hearing from parents of children with ASDs, but have welcomed their active participation in the formation of research projects and feedback about many aspects of meaningful outcomes in autism research.

On February 2 & 3, The Canadian Autism Intervention Research Network (CAIRN) met in Toronto to talk about exciting autism research that is occurring or being developed in Canada (see article). This meeting was facilitated by Dr. Peter Szatmari of McMaster University in Hamilton.

Autism Society Ontario is a member of another research team known as Autism Spectrum Disorders – Canadian American Research Consortium (ASD- CARC) who gathered in Kingston on February 9 & 10 to review the progress of their research (see article). Led by Dr. Jeanette Holden of Queen's University this group continues its exciting work in looking at a range of issues in understanding autism and effective treatment methods in locations across Canada and the United States.

ASO Research Committee: This new committee has been very busy developing exciting plans for ASO's new Autism Research Fund and for promoting autism research in Canada. (See the Student Grant announcement and application criteria). Membership in this volunteer committee includes Dr. Mehran Alaei – Chair, Doug McCreary, Dr. Jim Bebko, Dr. Rebecca Ward, Nancy Ambrogio, Jennifer Cantello Daw (Geneva Centre representative) and Dr. Jeanette Holden.

ASO Receives Two New Grants:



THE ONTARIO TRILLIUM FOUNDATION
LA FONDATION TRILLIUM DE L'ONTARIO

Autism Society Ontario gratefully acknowledges the financial support of the Ontario Trillium Foundation, an agency of the Ministry of Tourism, Culture and Recreation, which receives annually \$100 million in government funding generated through Ontario's charity casino initiative.

The Ontario Trillium Foundation has just awarded Autism Society Ontario a grant for \$250,000.00 (over three years). ASO is also grateful to Deborah Rossiter for her assistance in writing and submitting this successful grant application.

In partnership with Surrey Place Centre and Geneva Centre for Autism, ASO will produce handbooks of information on Autism Spectrum Disorders for pre-school years, school years and the transition from teen to adulthood. Training will be provided on the content of handbooks through three key ASO chapter regions in the South West, Central and Eastern regions of Ontario. Because of the grant funding, training and support to families in those regions will be provided for the very first time by paid ASO contract workers in local communities. Regular updates on ASO's progress with the grant funds will be available through *Newslink* and ASO's website.



Ontario Ministry of Citizenship. Partnership Incentive Fund: Community ACCESS-Ability Program 2001- 2002: ASO is grateful for funding of \$4000.00 it has received for a project that will facilitate workshop presentations and develop new, up-

to-date resource materials aimed at promoting awareness and reducing social, educational and workplace barriers for persons with Autism Spectrum Disorders. Through ASO's Metro Toronto Chapter, teens and adults with ASD will describe both the barriers and ways they have found to reduce those barriers for successful outcomes in their communities.

Fundraising

Attention Art lovers and collectors: *ASO's Annual Art Auction* will be held in Toronto on Wednesday, May 29, 2002 beginning at 6:00pm at St. Lawrence Hall at 157 King Street East. All are welcome. Admission is \$10.00/person. Come out for a great evening which includes good food and great art at bargain prices. Help us reach our goal to raise \$20,000.00. All proceeds support the work of Autism Society Ontario. Call 416-246-9592 for more information.

Government Relations

Anyone who lives in Ontario cannot help but notice the unprecedented amount of media coverage about autism in the last year. Recently, there has been an enormous pressure placed on Ontario's leaders to increase services to the Provincial Early Intensive Behaviour Intervention program. This program is a critically important initiative that is still building capacity, but that also has hundreds of children waiting or aging out of the program prior to ever receiving services. Most children with autism under the age of six are not even eligible for this particular program and may not be receiving any support at all in their communities. For children turning six and no longer eligible for the program, few schools have trained and supported staff who understand and are able to provide students with ASD the support they require in order to learn. Other media attention has been drawn to the need for respite services, residential and independent living needs of adults with autism and the challenges faced by families in getting a clear and early diagnosis.

Ontario Pre-Budget Consultation: In March 2002 Autism Society Ontario met face-to-face with the then Minister of Finance, James

Provincial News

Flaherty, in a Pre-budget consultation for Ontario. ASO Board member Dr. Rebecca Ward and Executive Director Margaret Spoelstra presented the minister with an eleven page document identifying key areas of focus for our provincial leaders to consider in providing much needed services and support to all individuals with Autism Spectrum Disorders in Ontario. Key items requested by ASO:

- Increase funding for intensive early intervention for all young children with autism by forty million dollars
- Inter-ministerial Coordination of Autism Services through an Autism Secretariat (Health, Social Services and Education), with Social Services as lead ministry
- Invest in services and support to families in their communities through respite care programs, transition funds and training for service providers across Ontario.
- Invest \$ 1 million per year over the next 5 years to Autism specific research projects
- Reduce the Financial Burden on families with children and dependent adults with Autism Spectrum Disorders through changes to tax policy to reduce the financial burden on families

Advocacy and Support:

2001/2002 Gerry Bloomfield Award: ASO is accepting nominations for this annual award. Nomination forms are printed on the last page of this newsletter. This award for excellence in professional contributions to the field of autism and for outstanding volunteer

service will be presented at ASO's Annual Autism Conference and General Meeting in Peterborough on June 21 & 22. Ballots for ASO members to vote for nominated recipients will be available in May on ASO's website and through the chapters or the provincial office.

ASO's 2001/2002 Autism Conference and AGM will be hosted by the Peterborough Chapter at the Holiday Inn in Peterborough on June 21 & 22, 2002. Conference speakers are Dr. Marcia Gragg and Dr. Tara Kennedy. The winner of ASO's Gerry Bloomfield award will also be presented. Details about conference registration will be available in May. Everyone is welcome to attend the conference.

Public Awareness:

Education Committee Report:

The main focus for the Education Committee this year is to update and expand "Navigating the Special Education System in Ontario – A Handbook for Parents of children with Autism/PDD". This process is well underway and we expect to have a draft version of the main sections by the end of February. The sections on the IPRC and IEP are being brought in line with current legislation. The section on Advocacy will be considerably expanded. New sections will include Secondary School Issues, Use of Computers



Connie Kuipers of Global Learning Partners facilitated the April 13, 2002 session.

and Software, some basic information on ISA funding and a glossary. The first Hand Accounts section will also be updated. We hope to have a finished product by this summer.

Governance and Advocacy:

ASO Education Policy & SEAC Council formation: ASO is in the process of forming an ASO Special Education Advisory Council to develop ASO's policies and positions on issues related to the education of students with ASDs in Ontario. Regional representation will



ASO Chapter Presidents, Education Committee and Board members develop new education policies.

form a 12 member Council that will work with ASO's Board of Directors, ASO's Education Committee and ASO staff in forming ASO education policy and responding to key issues effecting students with ASDs in Ontario. On April 13, 2002 members of ASO's Board, President's Council and Education Committee met in Mississauga to form a Global Education Policy and identify key policy statements that will form the basis for the ongoing work of ASO through its advocacy efforts and promotion of autism awareness in Ontario's education system.



Recipients of the *Gerry Bloomfield Awards*

Professional: For outstanding professional contributions to the field of autism

Volunteer: For outstanding contributions to the society by a volunteer

Year	Professional	Volunteer	Special Award
1991	Dr. Susan Bryson	Eleanor Ritchie	Adult Task Force
1992	Martha Leary	Claire Zeijdel	
1993	Dr. Peter Szatmari Susan Honeyman	Don Dalton	
1994	Catherine Hanna	The Rain Family	
1995	Dr. Joseph Huggins	The Awad Family	
1996	Carrie Augustine	Arthur and Rhonda Shlanger Natalie Whatley	
1997	Dr. Jeanette Holden	Claudio & Michelle Del Duca	
1998	-	-	Art Auction Committee
1999/00	Sheila Bell	Karen MacKay	
2000/01	Jennifer Cantello Daw	Eddy and Lilian Lloyd	



Metro Chapter Advocacy

Open letter to Toronto District School Board

Dear Sir/Madam:

As you are aware, the Toronto District School Board has informed the Special Education Department that they will be cutting the Itinerant Resource Teaching Positions for September 2002. The Metro Chapter of the Autism Society opposes this cut. We fear the negative impact these cuts are going to have for all special needs students and, in particular, children with autism. We feel the IRTs provide key services and support through:

- Offering programming modification strategies to teachers
- Working in partnership with Special Education Consultants to service each of the Family of Schools
- Supporting teachers with hard to serve students in regular and special education classrooms
- Providing resources for the classroom teachers and parents

- Supporting the self-contained classrooms
- Working directly with students
- Conferencing with parents, teachers, S.E.R.T.s, outside agencies and administrative staff
- Problem solving difficult situations arising in the school environment
- Advocating for student's needs in team meetings
- Planning and delivery of Professional Development Workshops
- Working directly with teachers, administrators and parents to ensure our hardest-to-serve students receive the support they require and deserve through the ISA process.

Concerns:

Who is going to support new teachers in classrooms where there are increasing numbers of students with specific and special needs? There are no longer any General Consultants.

Principals and Vice Principals are so busy with administrative tasks that they are unable to fully support teachers. S.E.R.T. teachers are already supporting a large number of students and cannot be stretched any further. Special Education Consultants are extremely busy with meetings and administrative tracking that they simply cannot provide the support.

The role of the Itinerant Resource Teacher has been essential to the delivery of support given to students, teachers, parents and administrative staff. Please consider reinstating the role of Special Education Itinerant Resource Teacher for the 2002-2003 school year.

Thank-you for your attention in this matter.
Sincerely,

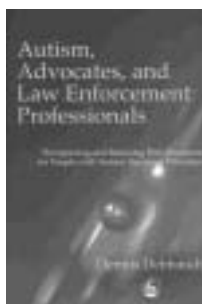
Luc VanderMeeren
Vice President – Autism Society Ontario,
Metro Toronto Chapter

Book Review

Autism, Advocates, and Law Enforcement Professionals

By: Dennis Debbaudt

Autism, Advocates, and Law Enforcement Professionals is a book that should be read by everyone with a loved one with an Autism Spectrum Disorder (ASD). The real life stories that are communicated in this must read book are chilling in the extreme. Those of us who live with a young person with an ASD must look to the day when they will be out in the community away from our mediating skills. What skills do our loved one possess that would enable them to deal with a situation of legal crisis? Whether they are the accused or the victim, Dennis Debbaudt gives sound advice on what to teach and how to teach it. He also goes into detail on how advocates or



groups such as our own Autism Society Ontario can go about identifying and then educating the professionals in our community.

The book is written in an easy to follow, well documented fashion. This leads the reader to understand what Autism is and how it affects those living with it. It also makes the reader aware of the immediate necessity for preparing our loved ones for life in the community at large as well as preparing our community for life with our loved ones.

There are two distinct perspectives taken in this work. The first half of the book is written with law enforcement professionals in mind. It clarifies for them how to recognize and respond to a person with ASD. How to interview and interrogate as well as deal with a victim of a crime who has an ASD. The last chapter deals with training programs that are available or how to go about setting up a training program for the professionals in your community.

The second half of this book is written for the citizen. It discusses safety issues at home, how

to make our loved ones aware of law enforcement and how to deal with them should they ever be the victims of a crime. Advocacy for offenders with ASD and ideas for collaborative Autism awareness campaigns are given.

All in all I gained a lot of new information about who we need to add to our list of those in need of education about ASD, and how to go about getting them to buy into these programs, once you actually get them set up. I always say a silent prayer for my children when I leave them in the care of others, for both safety and understanding. This book has helped me to realize that I must go further in being sure that I have done my part in preparing my boys for the world without me, and visa-versa. For as the author points out, our loved ones are seven times more likely to come in contact with the law than an individual without an ASD.

Respectfully submitted by Victoria McArthur
President,
Autism Society Ontario
Cambridge Chapter

Unraveling The Mystery of Autism Spectrum Disorders

Dr. Jeanette Holden (Queen's University) is leading a group of over 60 researchers, clinicians and parents from across Canada and the US who have formed a multidisciplinary research team called the *Autism Spectrum Disorders - Canadian American Research Consortium (ASD-CARC)*. This group has secured funding from the Canadian Institutes of Health Research (CIHR) and the Ontario Mental Health Foundation (OMHF) to:

gain a better understanding of the biological basis of ASDs, determine the very earliest of signs of ASD during infancy, identify genes important in determining risk for ASDs, and develop methods for identifying individuals at risk for ASD during infancy so that treatments can be introduced even earlier, optimizing outcomes for children with ASDs.

How You Can Participate. You are invited to participate in several different studies:

- 1) Autism Spectrum Disorders Research Registry.** If you have one or more children with ASD, please register your family at www.autismresearch.ca. Through the Registry we will inform families of various studies and invite your participation. We are asking for basic information, which may help us to identify child and family factors that may be shared with many other families with a child with ASD, including ASD symptoms, obstetrical history, family history, etc.
- 2) Genetics of ASDs.** We invite families on the Research Registry with **two children with ASD** or **with one affected child and another affected family member in the extended family** (e.g. parents, cousins, nephews, etc.) to participate in genetics research. By identifying the genetic factors across a large number of families, we hope to be able to (a) develop a simple blood test that will predict who is likely to develop ASD, (b) learn how these genes work to predispose an individual to ASD, and (3) contribute to the development of dietary, pharmacological or other treatments that could reduce or eliminate symptoms. We will also notify families on our Research Registry when we extend genetic testing to families with one affected member.
- 3) Clinical and Behavioural Studies in ASD.** We invite **all families** on the Research Registry to participate in a variety of **on-line questionnaires** about ASD symptoms or

other related factors. Families living close to one of our Regional Centres may also be invited to participate in **direct assessments**. All clinical and behavioural information about the affected children and their families will be associated with genetic information to determine whether families who share the same genetic patterns also share some of the same behavioural and family characteristics, thus forming a **"genetic subgroup of ASD"**.

- 4) Prospective Study:** Families with **one or more children with autism who have a new baby (under 1 year of age)** are invited to participate in a Prospective Study of Autism in which they will be asked to track their infant's development over the first three years of life. Our goal is to develop an early detection tool for identifying autistic symptoms before one year of life. **With early detection of ASD** in children at-risk, our plan is to develop **very early intervention strategies** to prevent the full expression of autistic symptoms in these infants.
- 5) Epidemiology of Autism Spectrum Disorders in Canada.** The Epidemiology study will examine specific regions of

Canada in great detail to determine the prevalence and incidence of ASDs in Canada, in order to help plan services and to determine whether changing incidences are due to specific causative factors.

Contact Information: Please register your family in our Research Registry at www.autismresearch.ca. For more information, contact Dr. Becky Ward by email (autism@post.queensu.ca), phone (613) 548-4417, ext. 1130, or mail (see below). We are very grateful to all families who consider participating in our studies. We know that your time is valuable and that by participating you are helping not only your own families, but future families as well.

Thank you.

Becky Ward, PhD, C. Psych.
Clinical Research Coordinator
Autism Research Program (ASD-CARC)
Ongwanada Resource Centre
191 Portsmouth Avenue,
Kingston, Ontario K7M 8A6



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Or visit the Geneva Centre website www.autism.net



The Canadian Autism Intervention Research Network (CAIRN) is a network of researchers and stakeholders from across Canada interested in early intervention in autism. The membership of CAIRN includes parents, scientists and front-line clinicians from several different disciplines including psychiatry, pediatrics, psychology, education, health policy, speech and language pathology, occupational therapy and early childhood education. The purpose of CAIRN is to develop a research agenda in early intervention in autism based on community input. This includes conducting high quality research studies, disseminating the evidence, developing evidence-based policy and advocating for more services and better training in early intervention in autism.

The impetus behind the development of CAIRN is a recognition that the delivery of services for young children with autism spectrum disorders in Canada is in crisis. The number of children coming to clinical attention has mushroomed but diagnostic and treatment services have not kept pace with this increased demand. Agencies and governments have been inundated with requests for services but there is little guidance in the field or the research literature as to the most effective and efficient forms of early intervention. It is clear that early intervention for young children with autism spectrum disorders works but it is also true that the quality of that evidence is weak and many unanswered questions remain. Key questions that require answers include the size of the treatment effect, the identification of the active ingredients in treatment and some knowledge about which form of early intervention works for what type of child with autism. A second generation of research studies in early intervention in autism is desperately needed but we believe that the research agenda must be based on input from parents, service providers and health policy analysts from provincial governments. Otherwise the results of these research studies have little chance of being implemented in communities across Canada and of improving the life chances of young children with autism spectrum disorders.

An initial meeting was held in November 2000. CAIRN provided a forum in which individuals from different areas in the autism community involved in early intervention came together to discuss research issues and ideas in an open and collegial atmosphere. Researchers

genuinely listened to suggestions from members of the group and incorporated new ideas into their current projects.

Three important outcomes emerged from that initial meeting: 1) a consortium of researchers was established that will submit research proposals on early intervention to the Canadian Institutes of Health Research, the federal research funding agency; 2) a partnership of stakeholders was established to advocate for the provision of high-quality early intervention services for children with autism, and 3) some priorities for immediate action were identified. These priorities included advocating for more research in early intervention, promoting better education and training for physicians, front line clinicians and the general public about the benefits of early intervention, and demanding better early intervention services across Canada for children with autism/PDD that incorporate practices based on the best available evidence.

The working group held a second meeting in February 2002 to assess the progress being made with respect to priorities identified. A number of scientists gave brief presentations on their research projects and received very useful feedback from parents, clinicians and other scientists. The format of this meeting consisted of several presentations in four key areas: community screening for autism, measurement of the benefits of treatment, types of early intervention and education for professionals. The possibility of setting up sub-committees of CAIRN was discussed, and 6 key areas were identified: 1 – screening; 2 – measurement; 3 – intervention; 4 – training and education; 5 – policy, advocacy; 6 – website. Each sub-committee would be a knowledge-sharing group that will define their own objectives to be discussed at the next CAIRN meeting.

This meeting was very successful, and the progress being made in research was substantial and promising. CAIRN is motivated and energetic, and the possibility of becoming the voice of “evidence-based” care in early intervention in autism is within reach. A web site will soon be set up, please check our web address for updates.

The Steering Committee Members of CAIRN are Peter Szatmari, Psychiatry and Behavioural Neurosciences, Lonnie Zwaigenbaum, Pediatrics and Cathy Charles, Clinical Epidemiology and Biostatistics, McMaster University; Susan Bryson and Isabel Smith,

Pediatrics, Dalhousie University; Mary Lyon, Professional Studies, Mount Saint Vincent University; Paul McDonnell, Psychology, University of New Brunswick; Sheila Laredo, Endocrinology and Metabolism (and parent of a child with PDD), University of Toronto; Elizabeth Starr, Faculty of Education, University of Windsor; Sherry Thompson, Children’s Services, Government of Alberta; and Joanne Volden, Speech Pathology and Audiology, University of Alberta. The CAIRN website is located at www.cairn-site.com.

Movie Review

I Am Sam

Finally, a film about people with disabilities that has integrity! I only wish that the larger community was more receptive. Some movie reviewers have panned it before even seeing the film. Sean Penn and Michelle Pfeiffer give very credible performances (strong enough to cause 8 people with an extensive history of working with individuals with autism, to alternately weep and laugh with delight.) Sean Penn is Sam, an individual with a developmental disability and “autistic tendencies” who, very early in the film, discovers that he is to be the single parent of a baby girl, Lucy (in the sky with diamonds.) Yes, Sam is a foremost authority on the Beatles, and the film’s wonderful soundtrack attests to this interest. The heartaches and joys of raising a child are sensitively portrayed. We are given pause to consider the qualities involved in being a good parent. The supporting cast includes individuals with developmental disabilities who continuously demonstrate their abilities as fine actors and true friends! Starbucks, Pizza Hut, Big Boy and IHOP (International House of Pancakes) figure prominently in this movie. One can only hope that their being portrayed as understanding employers of individuals with disabilities is in fact, reality. Although there are still many barriers to be overcome, this film attempts calls upon the community to become more open minded. If you have ever felt alone in your role as a parent or have worries about your child’s future, you will find this film reassuring in its message. A community is involved in raising a child AND it’s possible to do it well with one another’s support.

Anna-Marie Teasdale

Opinion

Guest Editorial

by Kathryn Everest



It's hard to believe how much things have changed since my son James was diagnosed with autism in 1993. ABA was synonymous with Lovaas and not widely practiced. There were autism treatment centres that still used aversives, some stronger than others. The web was predominately an academic resource, and access to Internet email was rare. The Geneva Centre and Autism Society Ontario was busily organizing for an International Symposium on Autism and wasn't particularly responsive to my requests for information. My local library had two books on autism: *The Empty Fortress* by Bruno Bettelheim, and another dreadful book called *Bobby*, about a self-proclaimed heroic professional (the author) who saves this child from his horrible parents. In 1993 there really wasn't much.

At the 1993 symposium, I met a friend who told me about an Internet newsgroup - bit.listserv.autism, and I eagerly joined. I not only read every piece of information published on this forum, but I consumed everything in the archives. I also became associated with Kerry's Place and finally had access to a decent library. Once I exhausted Kerry's Place library, I moved into The Geneva Centre's and then begin to develop my own (which has grown into quite a collection).

The more I learned, the more I comfortable I became expressing my opinions on many newsgroups or anywhere where parents or professionals congregated. I tried not to be obnoxious but I felt pretty confident that I had a good understanding of the issues, and that I had a path, a way through this labyrinth. I didn't want to get into "analysis paralysis" and not take action, as the one thing everyone agrees with was that the worst thing was to do nothing. We tried a number of interventions including ABA, and determined that what worked for James was a program that focused on his sensory issues.

While many of the programs that I researched each had successes, none of them were available in Toronto. Most of the services in the Greater Toronto Area used a "mediator" model, meaning that they didn't provide services directly to the kids, but rather consulted to parents. At that point, I didn't need more information - I needed services! So, like many

parents before me, I joined up with other frustrated parents to bring a specific program to Toronto.

As this group of very dedicated parents worked tirelessly to raise money and seek support, it came to our attention that we had some opposition. I was prepared to deal with skeptics, but I can't express my devastation and sadness when I learned that the biggest opposition was coming from other parents of kids with autism. How could another parent, who knew how bad things were and how hard it was to raise money, and to get support, be so thoughtless as to pull the rug out from under us, and to destroy what I thought was my son's best chance? Certainly they weren't suggesting that their child's needs were more important than mine? Is that how we are going to go forward - by getting what our child needs at the expense of each other?

I suddenly realized how destructive these "debates" were. I realized how this fragmentation could really weaken our position, and tear us apart. If we as parents are working against each other, how will this look to the government and to corporate sponsors? Both these groups are not interested in being involved in controversy, and will not devote much time to understanding the issues.

And what are the issues? One central issue is that autism spectrum disorder does not describe a homogeneous group, but for some reason, many of us choose to ignore this. The reality is that there isn't one program that addresses the complexity of autism. If you believe that all children with ASD can maximize their potential from one particular intervention - you need to meet more kids. All children benefit from intensive intervention - the earlier the better. After that - all bets are off. We don't know which kids will do best in which programs. The best way to address that is to have a range of programs. I wish everyone could proactively fight for the services that their children need, rather than trying to interfere with programs that other parents fought so hard to get.

I know that in some smaller communities, there are limited resources so maintaining several different programs could be difficult to justify, so parents need to actively advocate for what they want. In our case, this was Toronto, and there is no reason why we should settle for anything less than meeting the needs of all our

kids. Why are we convinced that we have to present our situation simplistically? The reality is that autism is a huge spectrum, and there isn't a "one size fits all" approach.

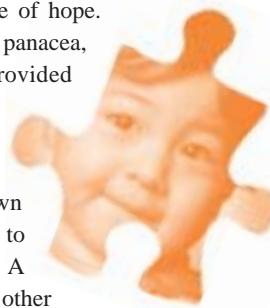
As James has gotten older (he'll be 13 this October), I've learned a lot (with still a long way to go). I regret many of the comments I made, and my arrogance. I didn't mean to hurt anyone - I really thought I was doing it for the right reasons.

So today, I support anybody who is trying to get more services for kids with autism. I'm more humble about what I know and what I don't know. I'm more patient when parents who use ABA suggest that it didn't work for me "because I didn't do it right". I understand how strongly we believe in what we are doing, and how difficult it is to hear that it didn't work for someone. This is true of many interventions - not just ABA. Especially if the intervention you are using is your source of hope.

It's hard to hear that it isn't a panacea, and even that it only provided limited success.

We take so much flack from the larger community and even often from our own families; we shouldn't have to deal with it from each other. A little more respect for each other would go a long way towards bringing us together as a supportive community. Whether you choose ABA, Miller, Floortime, TEACCH, SI, Giant Steps, integration, segregation, residential, etc. should not be important to anyone other than you. What's important is that the person with autism is getting the support they need in the form of the best their community can offer. That's certainly something I can rally around. And while the intervention that you select for your child may not be effective for mine, I can still support you. All I ask is that you support me.

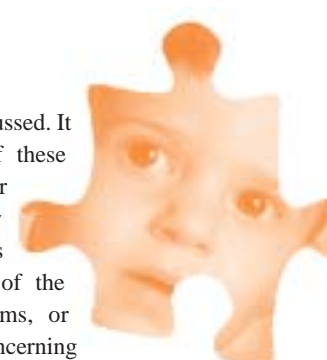
Respect that I've done my homework if I say I have. Trust that I'm fighting for a program for my son because I think it's what he needs, and not because I don't have all the facts. Don't be threatened by the fact that we are not all advocating for the exact same program. By fighting for only one program, we may be only addressing the needs of some of the kids. By insisting that one technique is superior to all others, you may inadvertently destroy the perfect program for someone else's child.



Frequently Asked Questions:

Getting a Diagnosis of Autism, Asperger's or PDD

Kevin P. Stoddart, M.S.W., Ph.D. (Cand.), R.S.W.



1. What characteristics does a person have if they are diagnosed with Autism, Asperger's, or PDD?

The characteristics required for a diagnosis of any Pervasive Developmental Disorder are listed in The Diagnostic and Statistical Manual of the American Psychological Association (1994). The three major characteristics are: problems in communication or use of language, poor social skills, and a restricted range of interests and/or repetitive behaviours. The severity and number of the problems in these three areas determine what specific diagnosis under the “umbrella” of PDD an individual is given.

2. Are a person's intellectual abilities affected if they have Autism, Asperger's or PDD?

Intelligence, as measured by an IQ test, may be below average if somebody has been diagnosed with PDD or Autism. However, this is not necessarily the case and testing may show average or even above average skills. If somebody is diagnosed with Asperger's, according to current diagnostic criteria, there is no cognitive delay. What is a common cognitive profile among the three diagnoses is that the individual's skills and abilities are uneven, with areas of great strength existing alongside puzzling skill deficits.

3. Who is allowed to diagnose a person with Autism, Asperger's or PDD?

Medical doctors (GP's, psychiatrists, pediatricians) and psychologists are permitted to give a formal diagnosis of any type of PDD. Social workers, occupational therapists, and speech-language pathologists may provide a professional opinion as to the likelihood that a child or an individual has the disorder. However, this impression must be confirmed by one of the previously mentioned professionals in order for this to be a formal diagnosis.

4. Will my family doctor know about Autism, Asperger's, or PDD?

Most doctors will be familiar with the terms "PDD" and "Autism", however some may not have heard of the labels more recently included under the umbrella of PDD in 1994 (such as "Asperger's Disorder"). Physicians who

commonly work with children or adults with developmental delays will be more familiar with Asperger's Disorder. Because the symptoms of Asperger's Disorder are much more subtle than other forms of PDD (such as autism), a diagnosis may be more difficult to give, even if the doctor is familiar with Asperger's.

5. What is an “Autistic Spectrum Disorder”?

Some people refer to Pervasive Developmental Disorders in this way as it is thought to be more descriptive than the term “PDD”, and it emphasizes the perception that all of the Pervasive Developmental Disorders fall along a continuum from more severe language, cognitive, behaviour, and functional skill deficits to very mild needs in these areas (e.g., those with Asperger's).

6. Is a diagnostic assessment covered under OHIP?

If a diagnosis is provided by a medical doctor (e.g., pediatrician, psychiatrist), then it is covered under OHIP. The services of a psychologist are covered under some employee benefits plans. These plans however may not cover the entire cost of a diagnostic assessment.

7. Is it useful for an adult to be diagnosed with PDD, Autism, or Asperger's?

In most cases it is useful for an adult to receive a diagnosis. This process may mean that any previous less useful, inclusive, or inaccurate diagnoses can be discarded. A diagnosis in adulthood may also mean access to new services. Some adults come to the realization that they have symptoms of PDD themselves. If they are functioning well without a “formal diagnosis” from a professional, or if a diagnostic assessment would not mean any change in their self-perception, services available to them, or treatment approach used, a full assessment may not be necessary.

8. Should I do anything to prepare for my child being assessed?

The doctor may want to see any previous assessments that your child has had. If you have them, bring them along to the appointment or mail them beforehand. As a part of the assessment, developmental

milestones will be discussed. It is helpful to think of these beforehand and gather any records you may have (e.g. "My Baby's Book"). Make a list of the characteristics, problems, or behaviours that are concerning you before the appointment. As well, write out any questions that you may have for the doctor. Reviewing family videos may help you see characteristics that are now problematic or notice changes that have occurred in your child. It may be helpful for you to read further on PDD, talk to other parents who have a child with PDD, or view videotapes on PDD before the appointment.

9. The waiting lists are long to get a diagnosis. What can I do in the meantime?

Although some services in Ontario require a diagnosis of PDD before you can get help from them, many do not. Begin to explore those that do not require a diagnosis. Reading the literature on PDD or attending workshops is helpful. Finally, begin to explore strategies that may be useful in interacting with an individual with PDD (for example, presenting information visually when teaching) and try them out. The success or lack of success of these interventions is useful in helping you better understand the individual, and is important information for the eventual diagnostic assessment.

10. What is involved in the assessment process?

It depends on the professional completing the assessment and the individual being assessed. Some doctors may not make a diagnosis immediately and will prefer instead to wait and see how a young child progresses over time. Those who are very familiar with PDD may feel confident making a diagnosis immediately. During the interview(s) the assessor will want to know the characteristics that are concerning and the child's or adult's developmental milestones. Standardized tests (such as tests of intelligence and language abilities) may be a part of an assessment, especially if the diagnostician is a psychologist. Parents may also be asked questions in order to complete

standardized questionnaires (such as an Autism Rating Scale). Adults are diagnosed in a similar way to children, although usually a diagnosis is easier to make at this point, given that the individual's developmental deficits and characteristics are more obvious and long-standing.

11. My child does not usually do well in testing situations. What should I do about this?

Many children and adults with PDD do not function optimally in a testing situation for a variety of reasons such as anxiety, inability to focus, or sensory distractions. Tell the individual that is assessing your child what your experience has been, and if there are any strategies that have helped to address this problem in the past. A good assessment will usually contain a statement by the assessor as to whether or not they feel the test results are representative of the child's true abilities.

12. What if I don't agree with the Doctor's diagnosis or opinion?

Most doctors are open to their patients getting a second opinion, and it is your right to do so.

13. Where can I go to get a diagnosis?

Start with your family doctor. They may be able to refer you to a local specialist in the field. Many local children's mental health agencies are becoming more familiar with all forms of PDD and provide diagnostic assessments. As well, some local hospitals have specialized clinics for children experiencing developmental, behaviour, or mental health problems. Adults can receive diagnostic assessments at local centres for developmentally delayed adults or for adults with autism, although these resources are limited.

14. Is it possible that more than one person in my family has a form of PDD?

Yes it is. Studies are increasingly pointing to a genetic basis for autism and other Pervasive Developmental Disorders. Multiple occurrences of the disorder may occur in the same generation or across generations, and be seen with varying degrees of severity. Addressing this openly as a family may sometimes be stressful, or alternatively, bring feelings of relief and greater understanding from family members. If you know or suspect that there is a history of PDD or other similar symptoms in your family, this is useful information for the diagnostician to know.

15. Does it matter if my child is diagnosed with a specific PDD (such as Autism or Asperger's) as opposed to PDD generally?

If your child is young (i.e., under three years of age), it may be difficult to determine the specific Pervasive Developmental Disorder that is most appropriate. Knowing that your child has some form of PDD is most important initially; in later years questions about the specific diagnosis under the umbrella of PDD can be revisited, and the label can be "fine-tuned" if needed. It is important to remember though that eligibility for certain services may be in part determined by the specific diagnosis a child or adult has been given.

16. Will a diagnosis of Autism, PDD or Asperger's work against my child in the future?

Probably not. Unfortunately, inappropriate use of diagnoses has occurred in the past with other childhood disorders and many parents are understandably leery about having their child "labelled". A diagnosis of PDD will hopefully help you to get the most appropriate services and treatment for your child. As well, it is critical that your child's treatment and educational plans are made with this diagnosis in mind.

17. My child already has another diagnosis. Will that diagnosis remain if they are diagnosed with PDD?

Sometimes, a diagnosis that is given before a diagnosis of Autism, PDD or Asperger's is given, addresses some of the specific problems that may be evident (for example, a learning disability or attention deficit problem). But this label may not account for the many behavioural, learning or emotional characteristics that a label of PDD encompasses. It is therefore most helpful to think of your child as having the diagnosis that is most inclusive of all the symptoms that s/he exhibits. If an individual has symptoms that are not fully explained by a diagnosis of PDD (such as severe depression or severe anxiety), these labels may be appropriately maintained in addition to a diagnosis of PDD. In this case, they may need special attention in the individual's treatment plan.

18. Who should I tell my child's diagnosis to?

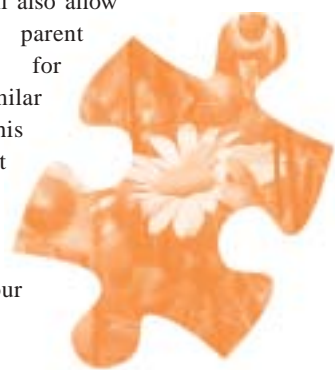
Any professional involved with your child (teachers, doctors, social workers, therapists) should know that your child has been diagnosed with PDD. In some cases, if your child is very mildly affected by PDD or Asperger's it may not be necessary to tell others involved with your child (such as camp counsellors, swimming coaches, etc.). However, in most cases, telling these people helps them understand your child better and interact more effectively with them.

19. It was recommended that I get further assessments after the diagnosis. Is this necessary?

A question that should be asked prior to agreeing to any assessment is: "What specifically can this process add to the treatment plan or approach that I already have for my child?" In a desire to get as much help for their child as possible, some parents get many assessments around the time of diagnosis; they may as a result either be overwhelmed with the information, or find the assessments uninformative. Searching for assessment services may also delay active treatment. The major benefit of multiple assessments is that specific issues and concerns can be looked at from a multi-disciplinary perspective.

20. My child has now been diagnosed. What's next?

When your child is diagnosed, the most important next step is for you and professionals involved with your child to learn about the many methods of intervention used with individuals with PDD and apply them to their interactions with your child. Local agencies specializing in developmental disabilities, or PDD, along with resources on the Internet are excellent places to look for this information. The diagnosis will also allow parents to find parent support groups for parents in similar situations. This diagnosis does not need to be just "another label"- make it work for you and your child.



News Release

Autism Society Ontario and Geneva Centre for Autism
Announce the Establishment of

Student Awards of Excellence for Contributions to Autism Research

March 21, 2002

In recognition of significant contributions by students to research and advancement of knowledge in Autism Spectrum Disorders, Autism Society Ontario and the Geneva Centre for Autism announce the establishment of "Student Awards of Excellence for Contributions to Autism Research". These awards will be presented every two years to students registered in Ontario colleges and universities in recognition of their contribution through publication of articles in peer-reviewed journals. Recipients will be honoured at an event coinciding with the Geneva Centre Symposium starting in 2002. Awards will include registration for the Symposium, as well as economy travel and accommodation for the Symposium.

To be eligible for the next award (2002) the student must:

- be enrolled in or recently graduated from (after September 1, 2001) an Ontario University or College
- have published a scientific manuscript with his/her name as either the first or second author during the period September 1, 2001 to July 31, 2002

The topic of the manuscript must be directly related to Autism Spectrum Disorders. Students with manuscripts accepted for publication during this time interval are also eligible.

Application for the awards must be received by 5:00 p.m. Wednesday, July 31, 2002 at the ASO office, 1 Greensboro Drive, Suite 306, Toronto, Ontario, M9W 1C8. For additional information, please refer to the award criteria posted at www.autismsociety.on.ca or contact Autism Society Ontario at mail@autismsociety.on.ca

**Student Awards of Excellence for
Contributions to Autism Research
sponsored jointly by
Autism Society Ontario and the Geneva
Centre for Autism**

All students enrolled in or recently graduated from (after September 1, 2001) an Ontario University or College are invited to submit applications for an award jointly presented by

Autism Society Ontario and the Geneva Centre for Autism. The award will be presented during the Geneva Centre for Autism Symposium in 2002 and will include registration, as well as economy travel and accommodation for the Symposium.

To be eligible, the student must have a published or accepted scientific manuscript in a peer-reviewed journal, with his/her name as either the first or second author during the period September 1, 2001 to July 31, 2002. The topic of the manuscript must be directly related to Autism Spectrum Disorders. The student must send a two page letter of application including:

- a half page summary of the major findings of his/her research paper in lay language
- a statement of why research in the student's area of study is important to our understanding of autism
- a description of how the student has been influenced by his/her exposure to the field of autism and/or to individuals with autism.

In addition, two letters of reference describing the student's qualifications and merits must be submitted directly to Autism Society Ontario from professionals familiar with the student's work. One of these must be from the student's immediate supervisor who should describe the student's role in the study described in the published manuscript as well as attributes that make the student a suitable candidate for the award.

The deadline for receipt of all materials is July 31, 2002.

In Memory of E. Louise Morgan

It is with deep regret that we acknowledge the passing of E. Louise Morgan on Dec. 21, 2001. Ms Morgan was a founding member of Autism Society Ontario and a loyal and generous supporter of our organization. Autism Society Ontario expressed appreciation for Ms. Morgan's contributions to her family at the funeral held on December 27, 2001.

ASO Chapter Presidents

Brant & County	
Clifford B Gowan	(519) 759-8891
Cambridge	
Victoria McArthur	(519) 658-4906
Chatham-Kent	
Marianne and Tony Knox	(519) 352-7945
Dufferin	
Doug McCreary	(519) 942-2348
Durham Region	
Sandra Weichel	(905) 666-6870
Grey-Bruce	
Linda Dow-Sitch	(519) 371-7180
Halton	
Cindy Faria	(905) 825-1344
Hamilton-Wentworth	
T. Simms-Obidi	(905) 545-9643
Kingston	
David Parkhill	(613) 389-2285
London	
Patricia Gallin	(519) 473-5999
Metro Toronto	
Chapter office	(416) 489-0702
Niagara Region	
Mike Gowan	(905) 735-9186
North Bay & Area	
Yvette Bellefeuille	(705) 472-6807
Ottawa	
Elizabeth McRae	(613) 692-1052
Région d'Ottawa	
Huguette Boisvert	(613) 722-2482
Peel Region	
Jacky Sheppard	(905) 820-8698
Peterborough	
Joyce Fee	(705) 743-9315
Renfrew County	
Susan Sullivan	(613) 584-4207
Sarnia-Lambton	
Lily Verhoeven	(519) 899-4348
Sault Ste. Marie	
Barbara Gjos	(705) 782-6379
Simcoe County	
Helen Aitken	(705) 686-3911
Sudbury & District	
Joanne Thistle	(705) 682-0983
Thunder Bay & District	
Sheila Waywanko	(807) 473-4666
Upper Canada	
Heidi Kaack	(613) 346-5745
Waterloo	
Alan Coughlin	(519) 742-1414
Wellington County	
Louisa Kuitert	(519) 787-8701
West Nipissing	
Anne Gingras	(705) 753-5326
Windsor-Essex	
Laurie Golocevac	(519) 250-1893
York Region	
Cindi Buick	(905) 780-1590

Gerry Bloomfield Award

Gerry Bloomfield was a founding member of what was then OSAC (Ontario Society of Autistic Children) as well as a founding member of the Wellington Chapter. Not only was Gerry actively involved in formulating and developing policies which allowed ASO to grow but he also was instrumental in obtaining the Trillium Funds which have been such an integral part of our growth.

Gerry, through his many years of service, was and still is totally dedicated to the public awareness and importance of diagnosis at an early age. He has provided leadership, advocacy and a tremendous amount of time to furthering the development of our Society.

Gerry retired from the ASO Board of Directors in 1989, after many years of dedicated service. An award in his honor has been developed to recognize his outstanding contributions over the years to the Society and to the case of autism.

Nominations will be reviewed by the Executive Committee. Finalists will be presented to the Board of Directors for short list selection. The

selected candidates will be presented to the ASO membership for final voting. The 2001 Awards will be presented at the Annual General Meeting on June 22, 2002.

Professional Award The Gerry Bloomfield Award for outstanding professional contributions to the field of Autism or Autism Society Ontario

In recognition of the critical role played by professionals in the lives of people with autism and their families:

- May be awarded to an individual or group of individuals whose efforts have contributed to improving the quality of life for a person or persons with autism and pervasive developmental disorders through:
 - improving programs
 - research
 - establishing guidelines and policies
- May be awarded to someone whose efforts have had direct influence in making a significant change in the lives of the people with autism and their families.

Volunteer Award

The Gerry Bloomfield Award for outstanding contributions to the Society by a Volunteer

- May be awarded to an *individual* or group of *individuals* whose efforts have contributed to improving the quality of life for a person or persons with autism and pervasive developmental disorders through:
 - promoting public awareness and understanding
 - advocating on behalf of
 - supporting the families and communities through outstanding work at the chapter level
- May be awarded to someone whose efforts have created a greater profile for the Chapter or the Society with the community at large.
- The recipient(s) should be a past or present member of the Society.
- The recipient(s) should have demonstrated integrity, commitment and loyalty over a sustained period of time to the lives of people with autism and pervasive development disorders.

GERRY BLOOMFIELD PROFESSIONAL AWARD NOMINATION FORM 2001

*Nominations must be received by
May 15, 2002*

Names(s) of Candidate(s) _____

Address _____

Telephone: (H) _____
(B) _____

Synopsis of candidate's contributions to Autism Society Ontario
(attach any additional comments to nomination form)

Is the candidate a past or present member of the Society? _____

Nominator's Name: _____

Address: _____

Telephone: (H) _____
(B) _____

I hereby affirm that the above information is accurate.

Signature

Date

**GERRY BLOOMFIELD VOLUNTEER AWARD
NOMINATION FORM 2001**

*Nominations must be received by
May 15, 2002*

Names(s) of Candidate(s) _____

Address _____

Telephone: (H) _____
(B) _____

Synopsis of candidate's contributions to Autism Society Ontario
(attach any additional comments to nomination form)

Is the candidate a past or present member of the Society? _____
Nominator's Name: _____

Address: _____

Telephone: (H) _____
(B) _____

I hereby affirm that the above information is accurate.

Signature

Date



Autism Society Ontario
1 Greensboro Drive, Suite 306
Etobicoke, ON
M9W 1C8

Check out our website at: www.autismsociety.on.ca

Autism Society Ontario is a registered charitable non-profit organization (# 11924 8789 RR0001).

Our Vision: Acceptance and opportunities for all individuals with Autism Spectrum Disorders.

Our Mission: To ensure that each individual with Autism Spectrum Disorder is provided the means to achieve quality of life as a respected member of society. *Newslink* is produced 3 to 4 times per year. Subscription to *Newslink* is included with ASO membership. *Newslink* welcomes contributions from its readers.

Send your articles, reviews, letters, comments, announcements, etc. to Newslink Editor, 1 Greensboro Dr., Suite 306, Toronto, Ontario, M9W 1C8. Phone: 416-246-9592

Fax: 416-246-9417 email: mail@autismsociety.on.ca. Inclusions of information not directly related to ASO are for your information only and individuals, events, therapies, treatments, etc. are not necessarily endorsed by ASO.