

ANNUAL REPORT 2013



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The mission of ACT – Autism Community Training is to provide excellent information and training, in accordance with international best practices. Our goal is to enable parents, professionals and para-professionals to support children and adults with Autism Spectrum Disorder to live productive, satisfying lives within their families and communities.

ACT – Autism Community Training

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CONTENTS

President's Message	4
ACT – Building Collaboration Across British Columbia & Beyond	6
Real Work for Real Pay	6
Responding to Evolving Needs Transitioning to Adulthood Supporting the Extended Family	7 7 7
Information Services – Reaching Vulnerable Families Registry of Autism Service Providers (RASP)	8 8
Supporting Families Struggling in English "ACT in Chinese" Online Korean Outreach ACT's South Asian Autism Project (ASAAP)	9 9 9 9
ACT's Live Events in 2013	10
Linking Information Resources to ACT's Training Program Sibshop Training	11 11
In Honour of April Autism Awareness Month ACT's 9th Annual Focus on Research Event: Building Community Capacity Across the Rockies	12 12
More Online Videos in 2013	13
New Look for the ACT Website	14
Connecting B.C's Autism Community – Online Social Media Monthly News Round-Up – A Tool for Communication and Collaboration Information in Your Hands Getting the Word Out	15 15 15 15 15
Volunteers are the Heart of the Autism Community	16
Collaboration and Community – ACT Advisory Council 2013	17
ACT's Financial Position in 2013	18
Recognizing our Funders, Donors & Sponsors	19

PRESIDENT'S MESSAGE



In 2013, one in 76 children in British Columbia received Autism Funding from the Ministry of Children and Family Development — more than 8,000 children. This staggering statistic is not an estimate based on research done elsewhere. Each of these children is a resident of

B.C. As their families have gone through the laborious process to access a diagnosis for their child, they are likely to have significant needs.

Given the increased number of children being diagnosed, and the hundreds reaching adulthood each year, ACT is compelled to improve how we provide reliable resources, based on best practices in autism treatment and a commitment to community inclusion. The scale of this increase necessitated ongoing and urgent collaboration with clinicians, agencies, researchers, community professionals, government as well as families and adults with autism.

ACT's overarching goal is to enrich the information and training resources available to members of the autism community. This report presents an overview of 2013 but will also look forward to the necessity of preparing for future demands on our services as the numbers of those being diagnosed with autism continues to mount.

Core to ACT's work is the provision of compassionate support and in-depth information on a rich variety of topics. This includes guiding parents of newly diagnosed children to understand how to use the Registry of Autism Service Providers; helping them to maximize the impact of their child's autism funding. This is part of ACT's focus on empowering families with the information and training on autism that they need. It is the first step of encouraging independence in these children to reach their potential as adults. This strategy makes sense for families and it makes sense for taxpayers who need assurances that the considerable funding that they are spending for autism treatment maximizes positive outcomes.

ACT's work is not limited to information about therapy or therapists. The impact of autism is pervasive. It impacts family life, siblings in particular; the ability of parents to work; opportunities for meaningful inclusion in school and in the community; future employment and the ability to live independently. ACT sees its role empowering parents to build their child's skills, based on an understanding of best practices. This has meant that, of necessity, ACT has had to provide support and information on a dizzying range of topics to families and the professionals who support them: from Toilet Training to Sexuality, from helping families to understand how to encourage language to resources on recreational activities, finding a job, higher education and residential placements. The list is ever growing.

ACT's focus is about supporting a better quality of life for our families; too many remain isolated in their homes without effective support. Children whose families are not supported proactively and whose autism severely impacts their behavior often end up in residential care, far from their family. Such care is expensive; often in the range of \$100,000 a year, a cost that is sometimes necessary across the lifespan. The financial costs to families of substandard treatment are also a heavy burden and should not be overlooked. A recent study by economists at the University of Calgary calculated the cost to families of having a child with autism as ranging from \$3-\$5 million across the lifespan, depending on severity. This does not include the costs to government.¹

ACT's live and online events, which are largely self-supporting through registrations and private

¹ The Value of Caregiver Time: Costs of Supports and Care for Individuals Living with an Autism Spectrum Disorder. www. policyschool.ucalgary.ca/?q=content/value-caregiver-time-costssupport-and-care-individuals-living-autism-spectrum-disorder

sponsorship, play a vital role in inspiring families and professionals to think beyond the here and now, to have courage, to work hard at changing behaviors (both theirs and the children they support) and to dream big. As one parent commented after an ACT conference, "I learned I do too much. It may be easier and faster but it will not set him up for independence."

The challenge for ACT in the coming years is how to share our resources effectively, and to do a better job of targeting marginalized families. We are very concerned about individuals with autism and their families living in rural and remote communities; Aboriginal families; those who struggle in English and those impacted by mental illness or poverty. We know that ACT cannot reach all of these families on our own. This is why collaboration is so key. To reach the most vulnerable, who are unlikely to initiate a call to ACT, we must support community professionals, including educators, social workers, health professionals and community agencies, as well as those who provide autism intervention, with the information and training resources they require in their work with the most vulnerable families. Much of what we develop is relevant across special needs and we welcome collaboration across disability organizations.

For this reason, in 2013 we increased our efforts to revamp our services to prepare ourselves to be a knowledge hub for B.C. and for all of Canada eventually. This is a long-term plan which will take until 2015 and beyond to reach fruition. Key to accomplishing this goal is ACT's new website which allows us to integrate more online resources. These include the total redevelopment of the Autism Information Database (AID) to serve as a provincial and, eventually, a national resource, linking to impartial, non-commercial, parent-friendly, best practice resources internationally, as well as a searchable listing of services across B.C.

The British Columbia Ministry of Children and Family Development is the primary funder for ACT's information and support work with families. With MCFD's financial support, ACT has been able to develop one of the most comprehensive, familycentred information hubs on autism available in Canada. MCFD's funding and active collaboration is greatly appreciated.

What ACT has accomplished in 2013 is the result of a dynamic collaborative effort to maximize the impact of our resources to meet the needs of the growing numbers of children and adults with ASD who require services. The role of volunteers is fundamental to what we have been able to accomplish. Our volunteers serve as board members, provide professional and clinical advice to our staff, present on their areas of expertise, register guests at our events, assemble our information materials, and distribute our information across the province through local community groups. They are the backbone of our organization; their contributions are essential to our productivity. I extend my heartfelt thanks to my fellow board members and all the volunteers, sponsors, donors and community partners who contribute to ACT's work.

Finally, I would like to recognize ACT's staff for their efforts to find information, speakers and training resources from around the world, to sustain families and the professionals who support them in British Columbia, to ensure that children and adults with autism have the opportunity to be fully included in community life.

Michael Craig President, Board of Directors ACT – Autism Community Training

ACT – BUILDING COLLABORATION ACROSS BRITISH COLUMBIA & BEYOND

As the number of children in British Columbia being diagnosed with autism mounts year after year, ACT's Board, staff and community partners are constantly analyzing how to offer support more effectively. The challenge is to think strategically about what needs to be put in place for the future to support families with significant needs for which there are few resources available.

In early 2013, ACT's Board and staff spent a day on strategic planning—looking at how to refocus our work over the next several years to maximize our impact on serving the needs of marginalized members of the autism community. The decision was taken to prioritize the needs of immigrant and Aboriginal families who do not make full use of ACT's services. We recognize that we cannot wait for individual families to come to us. ACT must increase its collaboration with agencies serving marginalized families to better communicate what ACT has to offer.

The other group that ACT has committed to serving better is adults with autism, both those who were

diagnosed as children and those who are coming forward seeking a diagnosis as adults. While ACT is not funded to provide services for adults, we have worked both provincially and nationally to focus attention on their needs.

Working on these goals within a climate of government funding cuts and increasing costs has been frustrating, but there has been progress. The adult agenda, in particular, is coming to the fore in response to the reality that few provincial-level services target the needs of adults with autism, especially those who do not qualify for services limited to those with intellectual disabilities.

At ACT we are focused on providing practical, positive supports for families and individuals with autism. Our mandate is province-wide; much of what we do is to connect parents and communities with the information and services they need. In this report we describe what we have accomplished in 2013 with the support of volunteers, government funding, donors and our community partners.

REAL WORK FOR REAL PAY

In June 2013, ACT organized—with a number of other organizations—a public meeting to explore employment opportunities and barriers for adults with autism. There were 150 participants, including over 20 adults with autism, who spoke with great insight into the challenges they faced looking for employment. Speakers included Dr. Pat Mirenda (UBC), looking at the realities in B.C. for employment services; Dr. Anthony Bailey (UBC), speaking to the vocational abilities of adults with ASD; and Tom Collins (Sinneave Family Foundation, Calgary), providing a national perspective. Co-sponsors included:

- Douglas College Disability and Community Studies Department
- Pacific Autism Family Centre (PAFC) & Century Plaza Hotel
- POPARD Provincial Outreach Program for Autism and Related Disorders
- SFU's Autism and Developmental Disorders Lab
- UBC's Adult Autism Clinic
- UBC's Centre for Interdisciplinary Research and Collaboration in Autism (CIRCA)
- UVic's Centre for Autism Research, Technology and Education (CARTE)

RESPONDING TO EVOLVING NEEDS

Transitioning to Adulthood

The late teen years are frequently a confusing time for individuals with ASD and their families as they transition from support from the Ministries of Education and Children and Family Development and explore what resources are available in adulthood. The diverse needs of adults with ASD require ACT to provide information on resources ranging from university placement to supported employment, to families who contact us from across British Columbia.

"Helping a child with autism transition to an adult world, as an adult with autism, is going to be a challenging and curious time." (Parent – attending the "Real Work for Real Pay" event)

Getting the Word Out on Employment for Adults with Autism

As teens become adults, families who have regularly contacted ACT for support complain that there is no comparable information service for their adult child with ASD. ACT is trying to fill the gap, in collaboration with provincial and national organizations.

ACT applied to Autism Speaks Canada in 2013 for support for a new project, "Getting the Word Out on Employment for Adults." This topic was chosen in response to the concerns of many families and able adults with autism: that the world of adult services is complex and confusing, with few impartial sources of information. ACT was successful in our application. In 2014, thanks to support from Autism Speaks Canada, ACT will employ a new member of staff to map out how employment services are delivered for adults with autism and intellectual disabilities in B.C. ACT will produce a guide as part of ACT's *Autism Manual for B.C.* and identify specific resources on ACT's Autism Information Database. ACT's staff will maintain these resources in years to come.

Supporting the Extended Family

ACT had over 2,000 contacts with families and professionals in 2013 from all over B.C. Eighty percent of the family members who contacted us were mothers, but we saw a noticeable increase in calls from other family members. This is a positive development, as we see that building the capacity and the understanding of the



whole family has a significant impact on reducing family stress and improving the outcomes of the child with autism.

In 2013, ACT focused on highlighting the needs of siblings of children and adults with autism, many of whom have been isolated in very stressed families with little recognition of the reality that having a sibling with ASD has on their childhoods. See page 11 for more about the 2013 Sibshop training.



Courtenay, recent Kwantlen College graduate

INFORMATION SERVICES – REACHING VULNERABLE FAMILIES

In 2013, ACT Information Officers provided support, information and referral services by telephone, email and in-person at our offices and during 40 outreach events across British Columbia. Our staff answered calls in English, Mandarin, Cantonese and Punjabi. Roughly half of all calls were related to a new diagnosis. Increasingly, ACT is making resources available online so they can be used by other agencies supporting families, as well as by families directly.

ACT distributed over 1,200 New Diagnosis Parent Packages (NDPP) in 2013, mostly via public and private diagnosticians who provide them to families. The NDPP is an important information resource for families, presented in a flashy red folder with ACT's logo prominently displayed to help it stand out in the avalanche of materials families receive at the time of diagnosis. The NDPP is key to helping families navigate the complexities of setting up a treatment program.



Top Areas of Parental Concern in 2013

- The diagnostic process in B.C. public and private; in particular, concerns about long waiting lists.
- School issues Individual Education Plans; lack of trained teachers, specialists, one-to-one support.
- Mental health issues especially for those with autism who have "an IQ in the normal range," as no government program takes responsibility for meeting their high level of need.
- Transitioning to adulthood, including education, housing and employment.

Registry of Autism Service Providers (RASP)

The Registry of Autism Service Providers continues to grow. By the end of 2013, there were 519 professionals on the RASP, a net gain of 43 professionals — the largest net increase since 2010. While the RASP list has more than doubled since 2010, the rapid increase in the number of children receiving a diagnosis means the demand for services is growing more quickly than available professionals, especially in rural areas of the province. Two hundred RASP professionals had their status renewed in 2013; ACT confirms professional development and requires new Criminal Record Checks.

RASP Advisory Panel

International standards for autism treatment are increasing every year, informed by research. In 2009, the RASP Panel was established by ACT, at the request of the B.C. Ministry of Children and Family Development, to provide advice to MCFD on future development of the RASP. Panel members play a vital role in protecting the interests of children with autism. Meeting three times a year, they volunteer their time to provide a wide range of professional and parental expertise. Our thanks to Dr. David Batstone, Dr. Karen Bopp, Leslie Clark, Dr. Miriam Elfert, Mary-Ann Fulks, Dr. Laura Grow, Dr. Bonnie Johnson, Dr. Pat Mirenda, Shannon Muir, Dr. Richard Stock and Nicholas Watkins. Their profiles are at www. actcommunity.ca/rasp/.

SUPPORTING FAMILIES STRUGGLING IN ENGLISH

Many parents who are struggling to understand a new diagnosis for their child, even though they have a good command of English, have shared their concern with ACT at how difficult it must be for new immigrants and refugees. ACT is building our supports for new immigrants and the community organizations who support them, both encouraging community awareness of autism and the need to improve direct support for families.

"ACT in Chinese" Online

Given B.C.'s large community of new immigrants from China, Hong Kong and Taiwan, ACT has been fortunate, since we opened in 2005, to have an Information Officer who can support families in both Mandarin and Cantonese. Christine Hung, who joined ACT in 2009, has been instrumental in translating many documents, which are a part of "ACT in Chinese," a component of ACT's Online Learning Community.

In October 2013, Dianna Yip, BCBA, presented a Positive Behavior Support (PBS) workshop in Cantonese to a group of parents. It was very wellreceived. The level of distress among the parent attendees reinforced ACT's determination to improve its services to families struggling in English. Among the resources added to "ACT in Chinese" online in 2013 is an audio interview on PBS, in Cantonese, between Christine Hung and Dianna Yip.

Christine Hung is also active in responding to requests from the Vancouver-based, Chinese-language media who, in recent years, are showing an increasing interest in highlighting autism awareness. Media outreach is key to building community support for families.

Korean Outreach

In 2013, ACT updated and printed the "Autism Facts" and "ACT's Services" rack cards in Korean. Many thanks to community volunteer and parent, Kyoung Mi Bae, whose skill in translation made this possible.



ACT's South Asian Autism Project (ASAAP)

Developments in 2013 have allowed ACT to reach out to B.C.'s large South Asian community, starting with Punjabi-language speakers. ACT hired a Punjabispeaker, Ruby Bhandal, and brought together a nexus of professionals within the South Asian community who are knowledgeable and respected. They have formed ACT's South Asian Action Project (ASAAP) Committee to focus on raising autism awareness in the South Asian community.

"Building a Bright Future for Children with Autism"

In December 2013, the Surrey School District made their board room available to host ACT's first Punjabi– English event, "Building a Bright Future for Children with Autism." Thirty family members participated; an appearance of the CAN VAN provided by the Canucks Autism Network was a great autism awareness tool. All the panelists volunteered their time; most were members of ASAAP. The severity of the challenges the parents described as they struggled to understand how to get qualified help for their children reinforced the need for more support to the South Asian community.

ACT's South Asian Action Project Members

ACT deeply appreciates the insights and leadership that ASAAP committee members have provided in 2013. Thanks to Nikki Ali, Parbinder Bains, Dr. Vikram Dua, Rina Dulku, Preetinder Narang and Manpreet Singh.

ACT'S LIVE EVENTS IN 2013

ACT held 17 events in 2013, providing 29 days of training in eight communities including Chilliwack, Surrey, Kamloops, Kelowna, Vancouver, Sidney, Nanaimo, and Terrace. Nearly 1,800 people participated in an ACT event



Louise Broadley, Manager of Autism Information Services, staffing ACT's Information Table at the 2013 Focus on Research event; one of 40 ACT Info Tables in 2013

in 2013. We were pleased to hold our first event in Punjabi and one in Cantonese.

Nine ACT events in 2013 were made possible through generous financial cosponsorship. \$12,500 in bursaries was provided in the form of reduced registration fees to encourage participants to attend from across B.C.

Central to ACT's approach to training is to provide a wide-range of training opportunities on topics related to all aspects of living and working with children and adults with autism. Our goal is to encourage families, community professionals and para-professionals, whatever their experience level, to engage in a meaningful opportunity to expand their understanding. We feature leading researchers and clinicians from B.C., Canada and the U.S. to give our registrants the opportunity to attend thought-provoking events that expand our understanding of how to better support individuals with autism, tailored to their needs and interests.

Those who present for ACT and also allow us to video them for our online presentations often donate their time because of their commitment to making life better for families impacted by autism. According to the responses we receive from families, and the professionals who support them , their efforts are deeply appreciated.

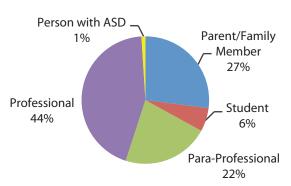
"Great speaker with great ideas-I wish my whole school district was here." (Professional)

"I learned new tools and techniques to share with our team and I gained inspiration to think of and create new strategies at home and at school." (Parent)

DID YOU KNOW?

- Our Social Thinking events are very popular with speech-language pathologists and teachers.
- Parents are the majority of attendees at events featuring Positive Behavior Support and events about transitioning to adulthood.

Who Attends ACT Events (2013)



LINKING INFORMATION RESOURCES TO ACT'S TRAINING PROGRAM

Sibshop Training

For a number of years ACT has been trying to increase support for siblings of children with special needs in B.C. In November 2013, ACT invited Don Meyer, the leading trainer internationally in the area of supporting siblings of children with special needs, to speak. It was a terrific event, co-sponsored by the Down Syndrome Research Foundation. Funding from the Edith Lando Charitable Foundation allowed ACT to provide bursaries for participants from smaller communities outside of Metro Vancouver to maximize the impact across B.C. At the end of the workshop, ten groups identified themselves as being prepared to provide sibling support groups in their communities.



Over 30 children volunteered to be part of the 'Demo Sibshop' on Day 2, making a big contribution to a very fun day.

"I learned the importance of having the typically developing siblings informed, valued and prepared for the future, especially with regards to his/her siblings." (Parent)

"I've never had peers who have siblings with special needs, and it was great to hear about others' experiences and advice." (Sibling)

A highlight of the two-day workshop was a panel of six adult siblings who spoke of their relationships with their siblings with special needs. It was a profound presentation by these impressive young people from a variety of cultural backgrounds, religions, and experiences. They spoke honestly of their love for their brothers and sisters and their stress at considering the future.

ADULT SIBLING PANEL MEMBERS

Jemana Elsharkawi, Marla Folden, Lizzie Goldstone, Erin Laird, Andrew Lusigan, Alice Tai, Yasmin Ullah



'Ready, Set, Coach: Supporting Kids with Autism in Community Recreation Activities' was another great event that focused on building stronger community resources for children with autism and their families. It was presented in Nanaimo in 2013 by Dr. Stephanie Jull, BCBA, Program Director for the Canucks Autism Network (CAN), a strong partner with ACT in several initiatives.



Dr. Pat Mirenda interviews Graeme Gibson, during his presentation at the conference.

THANK YOU TO THE 9TH ANNUAL FOCUS ON RESEARCH PRESENTERS

Anthony Bailey Lauren Binnendyk Christy Cheremshynski Susan Fawcett Brenda Fossett Emily Gardiner Deborah Gibson Graeme Gibson Sandra Hodgetts Tara Hodgson Grace Iarocci Stephanie Jull Joseph Lucyshyn Paul Malette Pat Mirenda Wendy Mitchell Leah Mumford David Nicholas Joseph Z. Sheppard Veronica Smith Joanne Volden Jonathan Weiss

ON THE OCCASION OF APRIL AUTISM AWARENESS MONTH

ACT's 9th Annual Focus on Research Event: Building Community Capacity Across the Rockies

Each April, ACT holds a conference focused on research. Our goal is to support the daily efforts of parents, teachers, and other community professionals with thought-provoking research that emphasizes the practical. In 2013, we were fortunate to have funding from Autism Speaks Canada, which allowed us to strengthen connections with the autism community in Alberta, bringing together researchers, community professionals and parents "across the Rockies."



Participants at the 9th Annual Focus on Research Event at SFU Harbour Centre – Sponsored by Autism Speaks Canada

"The new research areas are inspiring." (Professional)

"Great opportunity to network with other professionals." (Professional)

"[An] important way to connect." (Parent)

MORE ONLINE VIDEOS IN 2013

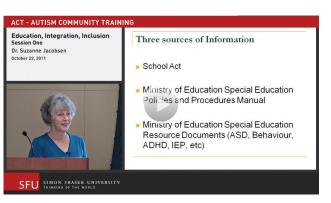
Watch where you like, when you like, and as often as you like

ACT works to reach underserved communities and families by recording selected live events and putting them online. The topics range across the lifespan, and target both new and experienced members of the autism community. ACT's online videos are professionally filmed and edited by Simon Fraser University, and link to additional learning materials as part of ACT's Online Learning Community (AOLC). Seven new online videos were added in 2013, thanks to sponsorship. As ACT has no sustained source of funding to develop the AOLC, support from sponsors is critical to this important part of our work.

Five presentations taped at the 9th Annual Focus on Research were released as online videos in 2013. Funding to make this possible came from Autism Speaks Canada, NeuroDevNet and the Sinneave Family Foundation. Particular thanks to the researchers who volunteered their time to present their work.

- 1. Understanding the Decision Making Process of Parents Who Choose Complementary and Alternative Medicine for their Children with ASD.
- 2. Blueprint for University Transition Year Programs for Persons with Autism.
- 3. Emergency Services, Hospitalizations and Mental Health Care for Adolescents and Adults with ASD.
- 4. Quality of Life Among Families Living with ASD.
- 5. A Review of Emerging Considerations for Vocational Support in ASD: Challenges and Opportunities.





Helping families and community professionals understand how services are delivered in B.C. is a crucial area of ACT's work. In 2013 ACT added two full-length online videos with a focus on B.C. services:

- 1. Best Practices in Early Intervention Helping Families Build the "Team." Released January 2013.
- 2. Education, Integration, Inclusion: Key Information for Parents of Children with Special Needs. Released May 2013.





NEW LOOK FOR THE ACT WEBSITE

In August 2013, ACT launched a new website:

- Improving navigation to the RASP List and ACT Events the two most popular sections of the website;
- Adding a rotating banner and news feed so that the front page is always fresh;
- Moving to an easier-to-remember URL at www.actcommunity.ca.

The number of visits to ACT's website increased by 13% in 2013 over 2012. Most of our visitors come during the day, but there is a definite bump in visitors after dinner!

a c t Autism Commu					E F Login to Online Videos
HOME AUTISM INFORMATION	RASP	AUTISM EDUCATION	NEWS	SUPPORT US	ABOUTACT
Autism Manual for BC				Diagnostic process Medical issues Developing a treatment team & more	Recent News ACT June News Roundup - All ACT videos free, job postings, anti- spam laws & more Jun 30, 2014 ACT is looking for qualified vendors for database Jun 13, 2014 News from the International Meeting for Autism Research (IMFAR 2014) May 20, 2014
Registry of Autism Service Providens	Search ACT's	1 Information Database	act Online Learning Comm		Upcoming Live Events
Need individualized inf ACT - Autism Community Training is a Spectrum Disorder and their families a professionals. If you need help finding resources rele for individualized support. Edit	n information a across British G	and referral service that s olumbia. We also welcom	e calls from comm	unity	Phone 604-205-5467 Toll-free 1-866-939-5188 Email Info@æctcommunity.ca Office Hours Office Hours Monday - Friday 8:30am - 4:30pm full contact details

The 111,050 visits to ACT's Website in 2013 is the equivalent of over 30 visits a day, 365 days a year, 24 hours a day.



ACT's Autism Manual for B.C. is a free online resource. New in 2013: Chapter 11, "ACT Guide to Building Community Groups."



MANY THANKS FOR YOUR PHOTOS

ACT receives terrific feedback on the photos of children and adults with autism having fun with their families and their peers that we use in our autism awareness materials and on our website. "After my son's diagnosis, it gave me a huge boost to see the wonderful photos on your website," one mother told us. ACT rarely uses agencies photos on our website or in print publications; 95% percent are sent to us by families. Share your photos: www.actcommunity.ca/ sharephotos.

CONNECTING B.C.'S AUTISM COMMUNITY – ONLINE

One of ACT's strategic priorities is to share information widely on our activities and to communicate in ways that are easy to access.

Social Media

Find ACT on Facebook! We appreciate it when a post is widely shared and commented on. ACT's Facebook page had 788 followers at the end of

2013, and is an increasingly important part of our communications strategy. We share pieces (like the one to the right) that reflect on autism, parenting, teaching, transitioning and living within the community. We also have Twitter and LinkedIn accounts.

ACT-Autism Community Training November 6, 2013 · Vancouver · @

Do you know someone who has autism and is looking for a job in IT? Specialisterne has come to Canada and is hiring! Those from our office who saw founder Thorkil Sonne speak last night were blown away by his vision



Monthly News Round-up – A Tool for Communication and Collaboration



There are many organizations and individuals doing great work around B.C. ACT's News Round-Up promotes information sharing around the province, including research and courses at B.C. colleges and universities, MCFD initiatives, the latest from CAN, Autism Speaks Canada and new resources provided

by ACT. Sign up for ACT's confidential email list to get the latest news from ACT and join 7,000 individuals and agencies across B.C. Visit www.actcommunity.ca/mailing-list to sign up.

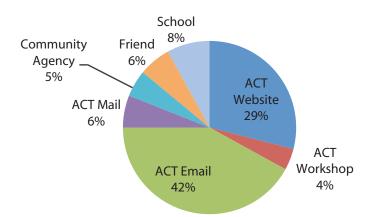
Information in your Hands

In 2013, in addition to updating our rack cards in Korean, Punjabi and Chinese, ACT published a new chapter of ACT's *Autism Manual for B.C.*: "ACT's Guide to Building a Community Group." This was the result of a 2012 project funding by Autism Speaks Canada and is relevant across special needs. It is available as a free PDF downloadable at www.actcommunity.ca/autism-manual-for-bc.

Getting the Word Out

Beyond ACT's monthly News Round-Up; annual mailouts, New Diagnosis Parent Packages, social media and information tables, we rely on community connections to spread the word on our services! See page 17 for more information on our community partnerships.

How Attendees Hear About ACT Events



2013 EVENT VOLUNTEERS

Brenna Boland Wendy Clark Heather Clarke Iemana Elsharkawi Katherine Gantz Corinne Hansen Erin Hibb Vivian Huen Susan James Katie Janzen Niaz Javid Bonnie Johnson Collin Johnson **Chantal Juilfs** Iryna Kolesnyk Samantha Kwon Sean McKenzie Anne Millerd Terri Nakayama Sherry Nassrin Sara Nicol Kim Nicol Kaori Ohashi Nicole Page Laurie Phipps Penny Poitras Jenny Poulin Ben Reiman Sophia Schweitz Heather Shaw **Darlene Stevens** Cherry Truong Rita Yeung Kate Zhao

> "It's always a pleasure to be part of the ACT community." (Volunteer)

VOLUNTEERS ARE THE HEART OF THE AUTISM COMMUNITY

Volunteers make a huge contribution to ACT's effectiveness. They compile information folders, register people at events, provide expertise. This all helps ACT extend our reach across the province. Many thanks to all who have enabled ACT to serve the autism community more effectively in 2013.

Event Volunteers

If you have attended an ACT event, you have been helped by an ACT volunteer. Event volunteers are usually students or parents; they register attendees, help with book sales, and hand out attendance certificates and evaluations forms. ACT could not run our events without their support.



Three event volunteers prepared for registrants! Nanaimo, 2013

Office Volunteers

Deborah Broadley, Adam Elsharkawi and Steve Lo are regular office volunteers. The next time you see one of our New Diagnosis Parent Packages (the red folders), think of our office volunteers, who prepared 1,200 in 2013.

Information Officer Christine Hung and Steven Lo, ACT's most experienced office volunteer and ardent Canuck fan!



COLLABORATION AND COMMUNITY – ACT ADVISORY COUNCIL 2013

ACT's Advisory Council is drawn from around B.C. and from a variety of professional backgrounds; they all volunteer their expertise to enable ACT to provide an effective service to families and individuals with autism. Many of our Advisory Council members are parents. They represent a diverse resource of experience, enabling ACT to keep in touch with the needs of families living in very different circumstances. Our professionals play an essential role in ensuring that we continue to keep current with best practices in the diagnosis and treatment of autism and provide unbiased and credible information to families. For biographical information on the members of the ACT Advisory Council, see www.actcommunity.ca/about-us/advisory-council.

- David Batstone, Ph.D. Steve Blackwell Dana Brynelsen Margaret Clark, M.D. Kim Dragseth Vikram Dua, M.D. Blair Dwyer Mary-Ann Fulks Betty-Ann Garreck
- Sarah Goudal Elizabeth Hartney, Ph.D. Janice Harvey Sue Henke Suzanne Jacobsen, Ed.D. Randy James Gerry Kysela, Ph.D. Joseph Lucyshyn, Ph.D. Chris McIntosh
- Anne Millerd Pat Mirenda, Ph.D. Shannon Muir Jo-Anne Seip Sue Wastie Catrin Webb Carol Ywan



Three members of the BC Association for Behaviour Analysis (BC-ABA), Richard Stock, Ben Reiman and Judy Bui, staff a BC-ABA information table at an ACT event. BC-ABA co-sponsored several ACT events in 2013, helping ensure that their membership gained Continuing Education Units.



Professor Joseph Lucyshyn (UBC), Member of ACT's Advisory Council, shares a joke with Sophia Schweitz, volunteer.

ACT'S FINANCIAL POSITION IN 2013

Overall, 2013 was a stable year financially for ACT, thanks primarily to very tight controls over expenditure on staffing and on expenses associated with training. ACT ended 2013 with a small surplus of \$4,500.

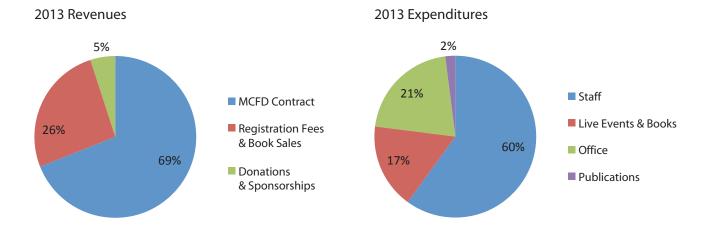
ACT's revenues dropped by 13% in 2013, from \$1.2 million to \$1.04 million. A small part of this (\$13,000) was related to a cut in ACT's revenues from MCFD which fell to \$721,000. As the cost of ACT's MCFD-related expenditure rose in 2013, this cut required careful financial management.

ACT also decided to seek more sponsorship to allow us to continue to travel to smaller communities across B.C. and to put on larger events while keeping fees down. In 2013 sponsorship income increased to \$39,000, a 34% increase over 2012.

The most significant change in ACT's financial picture in 2013 came in the area of training. This part of ACT's work is largely self-financing from the fees we charge to registrants. The continuing increases in the cost of travel, venues, catering and speaker fees in 2013 required a reassessment of our training program:

- We reduced the scale of our events, holding 17 in 2013, the same number as 2012, however, fewer were multi-day events. ACT provided 29 training days in 2013 as compared to 38 in 2012.
- The number of registrants dropped to 1800 in 2013 from 2200 in 2012.
- While registration income dropped by 40%, expenditure on events was reduced by 49%.
- While we pulled back on live events, we increased our efforts to expand our online videos — from 8 to 14—to improve access to underserved communities.

In 2013, ACT continued to prioritize the needs of low-income registrants and those coming from outside Metro Vancouver. ACT maintained the level of bursaries at the same level as 2012; providing over \$12,000 in bursaries in the form of reduced registration fees in 2013.



ACT's audited financial statements for 2013 are available upon request.

RECOGNIZING OUR FUNDERS, DONORS & SPONSORS

ACT thanks the British Columbia Ministry for Children and Family Development for the funding which supports the core of ACT's information and support work, as well as the management of the Registry of Autism Service Providers (RASP). The rest of ACT's work in 2013 was made possible by a dynamic mix of donations from individuals and organizations, as well as the provision of facilities and expertise (in particular from our presenters). A special thanks to Dr. Grace Iarocci and Simon Fraser University's Department of Psychology which has supported ACT's live and online training by providing their facilities to ACT, including production of ACT's Online Videos, since 2004.

- \$10,000 \$25, 000 Autism Speaks Canada
- **\$5,000 \$10,000** The Edith Lando Charitable Foundation
- \$1,000 \$5,000 Dwyer Tax Lawyers; NeuroDevNet; Tony Yue
- **\$500 \$1,000** Mackenzie Financial (Ting Ying Zhong); Vivian Walker "in memory of Richard"; Sinneave Family Foundation; Telus Corporation
- \$100 \$500 Jill Bert; The Coast Capri Hotel; Deborah Pugh; Amy Severson; Dr. Lee Tidmarsh; numerous anonymous individual donations via Canada Helps and the United Way of Ottawa and Calgary
- Under \$100 Sarah Alvarez; Joanne Flowerdew; The Hydrecs Fund; Sharon Randhawa; Michael Alvin Reimer; individual anonymous donations via United Way of Greater Victoria, Lower Mainland and Calgary and via Canada Helps

Bursaries

Donations help fund bursaries for parents, para-professionals and professionals who are either low-income or who must travel outside their home region in order to attend an ACT event. In 2013, ACT provided over \$12,500 in bursaries to 140 event attendees, half of them parents of children with autism. ACT believes that providing more equitable access to training is essential to ensuring that families and professionals in B.C. can effectively support the children and adults whom they work or live with.

ACT WELCOMES YOUR DONATIONS OR SPONSORSHIP

ACT can receive donations via CanadaHelps.org, the United Way, or by contacting the ACT office. We also welcome donations of shares. We are a federally registered Canadian charity; ACT's Charitable Tax Number is #861691236RR0001. Tax receipts are provided for donations over \$10. For details of ACT's current projects, see www.actcommunity.ca/donate/.















