

ACT's Report to Donors 2019



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Introduction

2019 was a successful year for ACT – Autism Community Training thanks to the unprecedented generosity of our donors in 2018, support from our community partners throughout 2019, and the ongoing commitment of our outstanding presenters. We were able to expand our work, meeting the information and training needs of thousands of British Columbians. We are now preparing to meet the challenges of 2020. To do so, we have hired a new member of staff to improve our online resources to better serve the autism community.

What follows is a detailed report on ACT's work in 2019. We hope that you will continue to support ACT in our work, whether as a donor, a sponsor, a presenter or a volunteer. Without government funding we are dependent on the generosity of our supporters. Everyone who supports ACT contributes to providing the resources that make lives better for families affected by autism.

Please let me know if you have any further questions. Feel free to share this document with other individuals or organizations who may be interested in supporting ACT's work.

Deborah Pugh, Executive Director, ACT – Autism Community Training

Program 1: ACT's Live Events

www.actcommunity.ca/events

In 2019, ACT trained more individuals at our live events than ever before. At seven events, all web streamed, we reached 2,700 people delivering nearly 20,000 hours of training. Since 2010, ACT has trained nearly 20,000 professionals, para-professionals, and family members.

The money we raise through registrations subsidizes some of the costs of our online resources. We provided \$11,000 in bursaries in 2019 in the form of reduced registration fees, in order to improve access for low-income registrants.

Simon Fraser University's Department of Psychology has been a long-standing partner providing preferred access to their downtown Vancouver conference facilities. In 2019, ACT has developed new partnerships with the Surrey School District and the Provincial Program for Autism and Related Disorders (a Ministry of Education resource). Together, we were able to reach many educators across the province via web streaming.

As a major priority for families is to have their children taught by those trained in autism, we believe that this is an important initiative. ACT is looking forward to continuing this collaboration in 2020.

"ACT provides services to thousands of families across the province of BC living with children with ASD. They have facilitated access to information, diagnosis, training and services. They provide online training opportunities to remote regions of the province and reach out to families whose first language is not English. The impact of these initiatives on families is tremendous considering the high rates of distress among these families due to lack of information and/or difficulties in navigating the social services system."

Dr. Grace Iarocci, Registered Psychologist, Professor of Psychology, Director of Autism Lab, Simon Fraser University

Program 2: ACT's BC Community Resources Program

www.actcommunity.ca/bcresources

Each year thousands of British Columbians, whose families are effected by autism, consult ACT's BC Community Resources Program (BCCR) – a province-wide resource. Over the last year, there were 70,000 pageviews of a total of 2,600 records created by ACT, linking to reliable online resources.

ACT's website was accessed by over 61,000 British Columbians in the last year, an 8% increase over the previous 12 months.

An Accessible Program Free for All

ACT provides the BCCR Program to meet the diverse needs of those with ASD across a range of issues with free resources. A number of these resources are also relevant nationally and internationally.

This program recognizes that autistic people can range from a gifted child with severe anxiety to an adult with limited ability to communicate. ACT's databases help families, autistic adults and the community professionals who support them, find evidence-informed resources specific to their needs. Topics include:

- Early Intervention
- Positive Behavior Support
- Many aspects of mental health, an important topic in autism.
- Eating Disorders – especially how they affect autistic girls and women.
- Resources for adults seeking help with employment and higher education.
- Resources helpful to immigrant families, including those in translation

Users do not need a password and there is no user fee.

Components of the BCCR Program

The BC Community Resources Program (BCCR) is a comprehensive online information portal available to all British Columbians. No other program in B.C. provides the depth and breadth of information on autism available through a simple keyword search.

A. Community Resources Database

www.actcommunity.ca/aid-search/community/

The Community Resources Database (CRD) provides local information to families across British Columbia by allowing users to filter their search based on their town/city or postal code. There are nearly 1,200 community resources included, from dentists to parent groups.

20,000 users viewed over 42,000 pages on the CRD over the last year.

Example of a BC Community Resources Database record

Developmental Disabilities Association of British Columbia Berwick Child Development Centre

Mandate (from the organization website)

"DDA's Children's Services offer quality inclusive childcare programs in Vancouver and Richmond for both typical and special needs children. Children and their families develop understanding and respect for diversity in our programs guided by our caring and well qualified staff." [Website]

Summary

An inclusive child care program that welcomes children of all abilities (with or without developmental disabilities) operated by Developmental Disabilities Association providing preschool for children 3 to 5 years old in Vancouver.

For full text or more information

Visit www.develop.bc.ca/for-families/children-and-youth/

Subject(s)

- Childcare
- Education

Berwick Child Development Centre is located at

2765 Osoyoos Crescent
Vancouver, BC
V6T 1X7

berwick@develop.bc.ca
604-822-6616



B. ACT's Autism Information Database (AID)

www.actcommunity.ca/aid-search

- The AID is a unique online portal that allows users to keyword search over 1,400 curated records for evidence-based practical information resources:
- AID records are available in multiple languages to benefit BC's immigrant communities.
- Submissions are screened by ACT's staff with support of the [AID's International Advisory Panel](#).

Over 8,000 individuals searched the Autism Information Database over the last year.

C. Special Needs Community Events Listing Database

www.actcommunity.ca/special-needs-community-events

The Special Needs Community Events Listing is a free service.

Over 1,000 users consult listings on events/training across B.C. monthly

D. ACT's Autism Manual for BC

www.actcommunity.ca/information/autism-manual-for-bc/

13 chapters developed for B.C. parents providing practical information on diagnosis, treatment, education and transition to adulthood.

Over 2,000 British Columbians consulted the Autism Manual for BC in the last year.

E. ACT's Specialized Webpages:

- New Diagnosis Hub for BC:**
www.actcommunity.ca/information/new-diagnosis-hub
- School-Age Children:**
www.actcommunity.ca/information/school-children-autism
- Transition to Adulthood:**
www.actcommunity.ca/information/transition-adult
- Opportunities for Individuals with ASD – Post-Secondary:**
www.actcommunity.ca/education/post-sec-asd-opportunities
- ACT in Chinese:**
www.actcommunity.ca/information/act-in-chinese

Nearly 5,000 individuals consulted ACT's specialized webpages in the last year.

"ACT made it possible for me to guide two autistic sons through the pitfalls of childhood and adolescence, and the often problematic transition to adulthood, toward a future that gives me every reason to hope they will enjoy solid mental health and be able to make successful contributions to society through their work."

Dr. Mary Ellen Ross, Parent, ACT's Volunteer Facebook Manager and Donor

"Over time, ACT's "BC Community Resources Program" has truly become exceptionally well developed. These resources are thorough and regularly updated. Important to me as a health professional, ACT takes great care to present only evidence-based practices and reliably researched and proven content in their web presence. That is the exception, these days, as a substantial amount of incorrect and unfortunate information specific to autism has migrated onto the internet."

Kenneth Cole, Registered Psychologist, BC Children's Hospital

Program 3: Autism Videos @ ACT

www.actcommunity.ca/videos

Free and No Passwords Required – Truly an Accessible Resource for B.C. and Beyond

Autism Videos @ ACT (AVA) is a library of 60 free online presentations by internationally recognized autism specialists and those with lived experience: both autistic adults and family members. The videos cover many aspects of living with autism.

No other organization in B.C., or internationally, provides a resource equivalent to AVA's offerings, available thanks to the willingness of presenters to allow ACT to record their presentations and make them available online. This generosity allows AVA to provide B.C. families access to presentations on important topics, by leading researchers and clinicians from around the world, available on their schedules, without having to leave their homes.

ACT developed AVA to meet the needs of the autism community across B.C.; it is particularly appreciated in smaller communities where few training opportunities are available. AVA is also accessed internationally to meet the huge knowledge deficit world-wide.

In the last year:

- Over 11,000 individuals accessed an AVA video;
- 4,600 hours of video were watched on streaming video;
- 80% of our users were in British Columbia.

ACT adds new content regularly:

- 21 new videos were added in 2019, in addition to the 12 added in 2018.
- There are 96 hours of video available for viewing on AVA.

All videos are free, with no password required. We know from experience, because many of our families face financial and other challenges, if we charged for our online resources, with the added complication of membership requirements and passwords, many families are likely to engage in random internet searches instead. Such searches often lead to questionable resources and inaccurate information, making families vulnerable to exploitation, unlike the carefully vetted information that ACT provides on AVA.

Addressing Family Priorities

AVA videos reflect the range of concerns facing families. These include diagnosis, choosing therapies, toilet training, sleep issues, positive behavior support and promoting inclusion in community recreation. As their child ages, caregivers need to learn about transition to adulthood, mental health

[Download the Special Needs Resources Guide for Schools](#)



The cover page for 'ACT's Special Needs Resources Guide for Schools' features the ACT logo (a red square with 'act' in white) and the text 'Autism Community Training'. Below the logo, it states 'Fall 2019' and 'ACT is Canada's leading independent not-for-profit specializing in free evidence-informed resources for the autism and special needs community'. The title 'ACT's Special Needs Resources Guide for Schools' is prominently displayed. Below the title, there are four sections: 'AUTISM VIDEOS @ ACT' with the URL 'www.actcommunity.ca/videos', 'ACT'S LIVE & WEB STREAMED EVENTS' with the URL 'www.actcommunity.ca/events', 'AUTISM RESOURCES FOR B.C.' with the URL 'www.actcommunity.ca/bcreources', and 'AUTISM INFORMATION DATABASE' with the URL 'www.actcommunity.ca/sid'. At the bottom, there is a photograph of a group of people, including children and adults, looking at a book together in a garden setting. The URL 'www.actcommunity.ca' is printed at the bottom right of the page.

"To the best of my knowledge, the online video resource curated by ACT is unique. It covers an impressively large range of topics related to ASD, with high quality information delivered by professionals with considerable relevant experience.... it is an indication of the esteem in which I hold this material that I recommend viewing not just to affected individuals, their families, and professionals within BC, but also with the much wider audience with whom I interact internationally. In my experience, people who interact with this resource consistently find it to be relevant and useful."

Professor Anthony Bailey, Chair in Child and Adolescent Psychiatry, University of British Columbia

and employment. ACT chooses topics and presenters that focus on evidence-based information to enable families to make informed decisions.

As parents try to help their complex children, while navigating B.C.'s system of service provision across a number of government ministries, they deeply appreciate the practical information and insights shared by clinicians and researchers. They also find it very helpful that they can share our presentations easily with others who serve their children, simply by sending a link.

In addition, ACT has found that there is a powerful effect on audiences when those on the autism spectrum and their families share their experiences of 'life with autism'. The right speaker can build understanding and hope, along with providing insights to families as to why evidence-based practice is so essential, by helping to translate research into concrete steps to improve lives.

Increasing Accessibility

In 2019 ACT began closed captioning and translating our most popular videos to increase access for the hearing impaired and those for whom English is a second language. Many of our videos have been uploaded to YouTube to increase accessibility.

Autism Videos @ ACT is Indebted to our Presenters

As of 2019, 75 presenters are contributing their intellectual property to ACT annually by allowing us to post their presentations on the ACT website. Some are contributing a 30-minute presentation, others have allowed us to provide an edited version of a two-day workshop. These contributions are invaluable. When a parent can enable their child to learn how to swim by watching an AVA video, given that drowning is the leading cause of premature death in children with autism, the impact is beyond measure. When a parent can take their child to the grocery store without a tantrum or fear they will bolt, the family's well-being and the child's safety is improved long-term. When a family learns how to encourage the development of language in their child, there is lifelong value for that child and for our society.

"In my studies in the autism field, I have seen numerous examples of much larger and better-resourced organizations around the world that have done far, far, less to reach diverse communities than ACT."

Patrick Dwyer – autistic adult, ACT volunteer, Ph.D. Student, Center for Mind and Brain, University of California Davis

"As a professional who has provided numerous workshops on behalf of ACT, I am proud to have them share my work via their online platform, making information accessible to families and professionals worldwide."

Dr. Brenda Fossett, BCBA-D, Faculty, Capilano University

"It cannot be overstated how impactful these videos are on the daily lives of families. I have met families who (after decades of diapers) have toilet-trained their adult children because they followed a workshop provided free by ACT. I have met other families who have been successful in ensuring their children receive the services they need in the public-school system because ACT taught them how to advocate effectively."

Jemana Elsharkawi, BCBA, Behavior Consultant, Vancouver Island, Member & Donor

Meeting the Needs of a Rapidly Increasing Population

Helping families to help themselves via a service that is always accessible is vital in the context of the increasing rate of ASD diagnosis. Twenty years ago, ASD was considered a rare condition. This has changed dramatically. In 2018, the Public Health Agency of Canada reported that 1 in 66 Canadian children has been diagnosed with ASD.¹ According to the B.C. Ministry of Children and Families, over 16,000 children are enrolled in its Autism Funding Program.² These families use government funds to hire professionals and para-professionals to work with their autistic children. ACT's resources help them to understand autism, therapeutic interventions, and how to assess progress.

Addressing BC's Geographical, Social and Cultural Realities

ACT's online resources benefit the autism community by removing the barriers of geographic isolation, cost and time, as they can be used on the user's schedule, from their home or office.

While autism affects all communities in our province, the impact on families who live in rural and remote communities or in poverty - especially Indigenous families on reserve and recent immigrants - is disproportionately negative.

Those from diverse cultural and linguistic backgrounds require professional support informed by sensitivity and respect. In 2017, ACT developed a learning stream within AVA devoted to building understanding of linguistic and cultural diversity. In addition, AVA added two videos in Punjabi for parents.

In 2018 and 2019, with the support of our sponsors, ACT has developed three important learning streams within AVA:

- Autism & Mental Health – 14 videos
- Women & Girls with ASD – 10 videos
- Positive Behavior Support – 11 videos

Community Engagement Via Social Media

ACT is extremely fortunate to have a volunteer social media manager who leads our efforts to ensure that evidence-based information is promoted on ACT's Facebook page. In the context of the fear and misinformation which permeates the online environment, ACT's Facebook page has a refreshing focus on the positive - but the page also tackles the difficult topics that concern our community:

www.facebook.com/AutismCommunityTraining

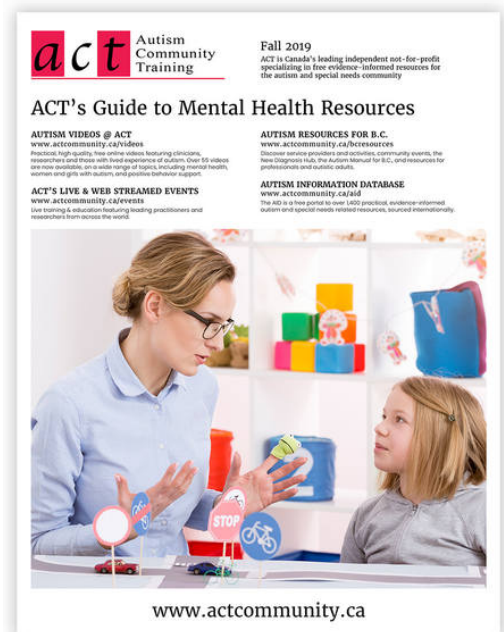
Promoting ACT's Resources Encourages Access

We promote the BC Community Resources Program and Autism Videos @ ACT across many platforms to reach those who may be unaware of

"In my studies in the autism field, I have seen numerous examples of much larger and better-resourced organizations around the world that have done far, far, less to reach diverse communities than ACT."

Patrick Dwyer – autistic adult, ACT volunteer, Ph.D. Student, Center for Mind and Brain, University of California Davis

[Download ACT's Guide to Mental Health Resources](#)



¹ www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html

² <https://mcf.gov.bc.ca/reporting/services/children-and-youth-with-special-needs/case-data-and-trends>

the excellent evidence-based resources that are available. This work is essential to countering the false information that dominates random internet searches on autism-related topics. These are some of the ways that we reach families:

- Via Facebook (6,600 followers) - www.facebook.com/AutismCommunityTraining
- ACT's online newsletter (8,000 subscribers) - www.actcommunity.ca/mailling-list
- At ACT's regular, live and web streamed events. In 2019 we registered 2700 attendees for seven events.

Measuring Impact

Thousands of British Columbians consult ACT resources each year, benefiting from free resources on health care, education and community inclusion. In terms of public health, this information is vital.

Sustainability: Support from the Autism Community is Key

ACT has a small staff of three full-time and two part-time staff. Our overheads are minimal. We accomplish a great deal more than our staffing allows because of the number of people who volunteer their expertise. ACT relies on dozens of supporters across B.C., and internationally, including autistic adults, clinicians, researchers and family members, to inform and support our work. Many are members of ACT.

Supporters donate money, skills and knowledge to help us produce far more value for the autism community than we could if we were depending only on our small staff. Collectively, our community supporters serve on ACT committees, proofread and translate our materials, recommend resources to us, manage our Facebook page and provide a depth of expertise and advice that we could otherwise not afford.

Why Community Support for ACT's Online Resources are Key to their Survival

ACT does not charge for our online resources because we are committed to open access as the only way to promote the evidence-based resources we support. Our fundraising efforts for 2020 will be focused on partnering with other agencies, that share ACT's values so that we can continue our work. However, we do rely on individual donors, most of whom are parents or community professionals who work closely with autistic individuals and their families. Given autism's status as an invisible disability, the support of families and community professionals who really understand the significance of our work, is crucial.

"Three years ago, my husband and I chose to support ACT in another way, as donors, by organizing an annual herring sale through our company, Oceanside Fisheries, with 100% of proceeds going to ACT. The success of this event grew dramatically in year two, and we look forward to continuing this fundraising effort. It is only a small contribution to the overall operation of maintaining ACT's online resources, but we feel good about doing our part in helping others access help like we have had for our daughter."

Anne McCaw, Parent, Donor, and Member of ACT

"In a desire to give back to the community, I have volunteered my time to captioning the audiovisual recordings that ACT has made of the courses and conferences it organizes.... it is no less than awe-inspiring that ACT reaches beyond barriers of financial constraints and geographical distance by putting this knowledge online for free. Moreover, captioning the videos makes them accessible to the hard of hearing as well as the many immigrants to British Columbia for whom English is a second language and who can grasp the content better if they are able to both hear and read it. "

Jian-Xing Too, Parent, Volunteer, Member

ACT's Goals for 2020

Live Events and Web Streaming

ACT is planning ten events for 2019 with at least 80% to be web streamed. Details will be announced in the New Year.

BC Community Resources

To improve the experience of those who use the BC Community Resources Program, and if we have sufficient funding, ACT intends to:

- Upgrade our technology to improve the experience of our users. For example, creating a searchable map listing all BC Community Resources.
- Add new information resources to the Autism Information Database. For example, we have over 400 AID records waiting to be finalized.
- Increase by 200 the records on the Community Resources Database – focusing on smaller communities.
- Revise ACT's Autism Manual for BC to update information on government programs.
- Update ACT's specialized webpages.

AVA Projects for 2020:

Our broad goal is to develop more videos to support diverse groups within the autism and special needs communities, along with improving access through captioning, translation and promotion. With sufficient funding, we will:

- Prepare a video from ACT's 2019 Focus on Research conference focused on the needs of Indigenous families: *'Supporting Indigenous Families Affected by Autism Through Engagement and Research'*
- Record and edit a full day advocacy workshop to help families who have autistic children understand the policies of the Ministry of Children and Family Development and the Ministry of Education.
- Prepare a series of videos based on an ACT conference scheduled for October 2020 on models of parent coaching to support early intervention in autism.
- Continue our work to close caption thirty of ACT's videos to benefit BC communities who are hearing impaired or speak English as a second language.
- Translate five key practical videos in several languages to support immigrant families who have children with autism.
- Maintain and enhance our current video platform.

"Because we feel a debt of gratitude to ACT and want other parents to benefit from ACT's work, my husband and I have also been happy to support ACT's work as donors. Blair's law firm, Dwyer Tax Law, has sponsored a number of ACT workshops. And when Blair's mother died in October 2018, we used our bequest from her estate to launch a fundraising campaign for ACT, matching others' donations to a maximum of \$50,000. The campaign raised close to \$100,000. We know Blair's mother, who dearly loved her grandsons, would have approved of this use of her savings."

Mary Ellen Ross, Parent, Member, Donor