Parent Support and Information
2005 - 2016

Contents

Background to ACT's Information Work 2005 -2016

ACT was first contracted in 2005 by British Columbia's Ministry of Children and Family Development (MCFD) to provide information, support and referral services for families raising a child with autism. From 2005-2010, ACT laid the foundation for serving families across B.C., with Information Officers supporting families via toll-free telephone and by email. During this period, Information Officers began collecting helpful resources for families and developing a series of web-based pdf lists of information resources, such as a list of private diagnosticians.

During this time, ACT recognized the need to develop standardized training for Information Officers (IO) to ensure families across the province were being served with consistent, evidence-informed and professional services. In 2010, ACT began developing a comprehensive Information Officer Manual detailing procedures for IOs to support families including how to access and critically evaluate autism-related information. The IO Manual guides new staff through a series of   information themes and sample resources for answering common questions.

ACT's Family Resource Centre (FRC) opened in 2011, housing a small collection of autism-related print materials and a computer with access to ACT's online resources. Families are encouraged to use the print and online collections during their visit, with Information Officers guiding them to relevant information. As most families who come to the office bring their children, there is also a growing collection of toys and activities to occupy their child while parents meet with an Information Officer.

Role of ACT's Information Officers

> *"The highly sensitive nature of many of these contacts requires staff who are intimately familiar with autism in general, BC autism services, and government autism policies – and the very able, very well trained staff of ACT meet these qualifications superbly."*
> Pat Mirenda, BCBA-D, Professor, Department of Educational and Counselling Psychology and Special Education, University of British Columbia

ACT IOs provide individualized, objective information on autism treatment, funding, and the Registry of Autism Service Providers (RASP) by telephone, email, in-person meetings, at ACT events and outreach activities in community settings. A primary goal of the Information Officer is to build the capacity of parents to manage and negotiate the network of services and resources available by providing information and coaching on how to access services, advocate for needed services, or gain redress if service has not been adequate.

In 2016, over 1000 families, professionals and self-advocates, from across B.C., contacted ACT one or more times for information and support, by telephone and email - a 7.5% increase over 2015. Questions posed by parents are often complex and wide-ranging: from school exclusion, diagnosis across the lifespan, finding a mental health provider to the criminal justice system. (ACT staff answered an additional 400 questions at over 20 community events).

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- 12% of information calls related to adult issues. While ACT has not been funded to provide adult services, we have done our best to answer questions both from families and from adults with ASD.
- Most calls related to some aspect of the autism funding process, ranging from requests for help in accessing MCFD forms, to support in understanding eligible expenses.
- On average, an ACT Information Officer spent 43 minutes helping each family on a "case" inquiry; 3% of cases take over two hours, sometimes involving a number of calls and emails over months.

Information Officers work with a diverse range of individuals, from families with young, newly diagnosed children to those with children who are transitioning to adulthood. Increasingly, ACT is receiving calls from the families of adults with ASD and adults themselves; there is no comparable information service focused on the needs of adults.

In 2016, ACT employed three Information Officers (2.1 FTE) and a Manager of Autism Information Services to provide these services. In addition to supervising the work of the Information Officers, the Manager supports families wishing to make a complaint about a RASP service provider.

ACT's information staff has over 38 years of combined experience in supporting families raising children with autism. One of ACT's Information Officers speaks Mandarin/Cantonese and provides direct support in Chinese to this large population of families living in Greater Vancouver. At the end of 2016, ACT began training a Punjabi-speaking Information Officer.

The work of Information Officers is highly valued by our users as evidenced in ACT's 2016 satisfaction survey, with 87% of family members who have interacted with an Information Officer reporting the experience to be helpful and the information provided to be accurate and timely[1].

Changing needs of families

While the number of children receiving autism funding has more than doubled since 2010, ACT's staffing levels have not increased although the information and support needs of the families contacting ACT has grown increasingly complex. The challenges faced by the families we serve include:

- Those who live in rural and remote areas where few services are available;
- Immigrants and refugees who speak English as a second language and are struggling to find their feet in Canada with the added stress of supporting a child with special needs;
- Parents with mental health issues, exacerbated by the stress of raising a child with special needs.
- Raising children and adults with ASD who have severe challenging behaviors including co-morbid mental health disorders - these children are frequently faced with being excluded from school which has a serious effect on the ability of parents to work;

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[1] ACT's Resources and Services Survey 2016 www.actcommunity.ca/about-us/2016-survey/

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- Funding autism intervention when the amount provided through the Autism Funding Programs is not keeping up with inflation. This is particularly challenging for single parent and low-income families.

Many families do not receive the level of service needed to appropriately support their child. When a child goes without treatment, problematic behaviors often increase and they are not able to participate in community activities or attend school. Families become increasingly isolated, with some unable to cope with the stress, they turn to emergency services such as MCFD Child Protection for support. These heartbreaking situations can take several weeks and/or months to resolve with ACT Information Officers, often acting as both information support and advocate for the family.

"I feel like I have PTSD from raising my son to age 6 - and live in a war zone every day. I feel debilitated towards raising my other children as a result of being exposed to his difficult behaviours. And I feel there is no one around to help. His funding is gone and therapy seems to make no difference. I am alone. And so stressed. I wish someone could help[2]."

Developing ACT's Autism Resources

In addition to answering direct requests for information, Information Officers research, evaluate and collect information to produce online resources. Families and professionals have come to rely on ACT to provide timely, trusted and relevant resources to help them navigate autism intervention services for their child.

Autism Information Database (AID)

ACT launched an easy to search, web-based information database in 2012 with over 1,300 vetted resources available to families. In 2015, the database underwent an extensive redesign and was re-launched as the Autism Information Database (AID). Searchable by keyword, the AID functions similarly to other information and library databases with standardized title, author and subject fields. Each record is individually summarized for the user. The AID is unique in that it houses two distinctly different types of resources:

Information Resources

Information resources link to full-text practical and research-based resources which ACT has sourced internationally with the focus on providing information helpful to families, individuals with autism and community professionals on a wide range of topics. A few examples:

- *Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder -* www.actcommunity.ca/resource/2177
- *Toilet Training – A Parent's Guide -* www.actcommunity.ca/resource/488/
- *iPads and Communication Devices -* www.actcommunity.ca/resource/2227

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[2] See ACT's Resources and Services Survey 2016   www.actcommunity.ca/about-us/2016-survey/

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Community Resources

ACT staff collect and index local B.C. community resources on topics such as finding an autism-friendly dentist, local support group or the nearest MCFD Child and Youth with Special Needs office. Community resource records can be searched by subject, city and by postal code which enables a family to find local information.

As of September 2016, the AID has over 2,300 resources. Using the tagline, *like Google for Autism but better!*, the AID has become the primary search tool for Information Officers in supporting families and professionals looking for reliable information. It is a popular tool with over 30% of ACT's website visitors also searching the AID.

A significant advantage of the AID is the ability to create a stable URL for a popular resource that is cited in other ACT resources such as ACT's Autism Manual for B.C. and the Next Steps Guide. For example, the MCFD recently launched a new website with a significant number of URL changes including how to access Autism Funding Forms. Rather than having to change all of the citations in the Autism Manual and Next Steps Guide, it was only necessary to update the URL in the AID record (www.actcommunity.ca/resource/335/). To search the AID go to **www.actcommunity.ca/aid**

Maintaining the AID

Keeping information and community records up to date with relevant content for families is essential to the success of the AID. Unlike maintaining a static database of print resources, AID information records link to full-text sources from authoritative websites. ACT cannot predict if a website will undergo a revision with changed links or new content added. This requires all records to be reviewed every six months to check links and content. The review process can take several weeks. Since launching the AID, ACT has received a grant each summer from the federal government to cover the cost of hiring students to update the AID. Without this support, it would be very difficult for the current staff to maintain existing records and add new resources in a timely manner.

As a custom-built database, troubleshooting and technical upgrades to the AID requires significant and sometimes costly programming from an external contractor. This work is important given that if the AID doesn't function properly, people will stop using it. ACT staff have determined that purchasing an "out of the box" commercial database would be a more cost-effective solution over time. Commercial databases have built-in functionality including multiple modules for searching, acquisitions and ongoing maintenance which can be purchased from the vendor.

Autism Manual for B.C.

ACT's Autism Manual for B.C. was launched in 2008 as a response to families requesting plain language resources from diagnosis to adulthood on autism. Many of the manual chapters have been contributed by experts in their area of practice who donated their efforts to ACT, in order to better support families. Over the last nine years, the Manual has grown to 13 chapters with the most recent chapter added in September 2016, thanks to funding from Autism Speaks Canada. Information Officers frequently direct families to the Autism Manual, often referencing at least one chapter when supporting families and community professionals.

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"Based on my personal experience, this resource alone has saved me countless hours of research when investigating options for my son with autism."
Leslie Clark - Parent

The Manual continues to be a work in progress with new information added on a wide-range of autism topics. ACT staff review the manual chapters annually to update the content and ensure the links are working. Chapters from ACT's Autism Manual of B.C. can be downloaded free of charge at www.actcommunity.ca/ autism-manual

Chapter 1: The Diagnostic Process in British Columbia
Chapter 2: Developing a Treatment Team for a Child with Autism Spectrum Disorder
Chapter 3: Medical Issues in Autism Treatments
Chapter 4: MCFD-funded Services for Children with ASD
Chapter 5: Contracting with Professionals on the RASP
Chapter 6: MCFD Services Available to All Children with Special Needs
Chapter 7: The B.C. Education System – An Introduction for Parents of Students with ASD
Chapter 8: The Role of Parental Advocacy in Navigating the B.C. School System
Chapter 9: Preparing the Transition from School to Work
Chapter 10: Estate Planning for Families Who Have Children with Special Needs in B.C.
Chapter 11: ACT's Guide to Building a Community Group
Chapter 12: Guide to Employment for Teens and Adults with Autism in B.C.
Chapter 13: Guide to Working with South Asian Families Affected by Autism

New Diagnosis Parent Packages and Next Steps Guide

B.C.'s Autism Funding Program is quite different than others across Canada. Parents in B.C. have the responsibility of deciding where to spend the funding set aside for their child. This presents many challenges for the family when deciding what steps to take. ACT's goal is to engage with the family before they have made decisions which could result in wasting the funding and, more seriously, the opportunities of the earliest possible intervention for their child.

This is why ACT has invested considerable time and resources into the development of the New Diagnosis Parent Package (NDPP), often referred to as the "Red Folder", which is distributed to families through public and private diagnosticians.   Developed in 2010, the NDPP contains a number of inserts highlighting ACT's many free services with the goal of helping families understand how to set up a treatment team for their child and reduce the misuse of autism funding by unscrupulous or poorly trained RASP professionals.   Over 12,000 NDPPs have been distributed since 2010.

Next Steps Following an Autism Diagnosis in BC

The 'Next Steps Guide' is the core of the NDPP - it is an easy to follow step-by-by approach to help families navigate autism funding, from the diagnosis to parent training. It is available online and contains numerous links to ACT and MCFD resources. The Guide is available in four languages – English, Chinese, Punjabi and Korean, and ACT continues to actively seek funding to translate the Next Steps into other languages.

The Next Steps Guide is available at www.actcommunity.ca/new-diagnosis-hub/

Autism Videos @ ACT (AVA)

ACT has developed a free online video library of selected ACT workshops available to families and professional in British Columbia and beyond. AVA is funded by sponsorship and donations and funds generated by ACT's live events. Currently, there are over 20 online videos available in English and two in Punjabi. For more details on AVA, see www.actcommunity.ca/videos.

Focus on Marginalized Communities

ACT has made significant progress in developing online resources but this does not address the needs of all families, particularly those living in remote regions of B.C. ACT has undertaken several initiatives to increase the capacity of these families including those who are further marginalized through language and culture.

Families Living in Rural and Remote Communities

Faced with limited supports and services, families living in rural and remote areas feel isolated and underserved. As one respondent wrote in response to ACT's 2016 survey regarding services to underserved regions, "more of everything for rural areas.[3]"   In spite of our small staff, ACT has worked to bridge the gap for families living in rural areas through training initiatives and by reaching out to small communities with low-cost presentations focused on ACT's services and resources.

Training parent facilitators

ACT received a grant from Autism Speaks Canada in 2012 to train parents from underserved community on how to build community-level support groups for parents raising a child with autism. Twelve parents from across the province attended and were also trained on to how to identify local autism-specific services and supports that could be added to the Autism Information Database (AID). Many of the parent facilitators remain in contact with ACT, and their support groups are still active.

Outreach to small communities

In 2016, ACT was invited to provide presentations in three communities – Port Hardy, Squamish and Penticton. These events proved to be very highly effective with positive feedback from the families and professionals who attended, many who were not aware of ACT's services and resources. In smaller communities, there is often a ripple effect arising from these events with attendees sharing what they learned through their own social and community networks. ACT's 2016 satisfaction survey presents evidence that there is a correlation between outreach activities and awareness of ACT services. When asked if they were aware of ACT's information services, respondents from Vancouver Island North (where Port Hardy is situated) were almost as aware of ACT's information services as respondents from Greater Vancouver[4].

The feedback from the presentations along with the survey results provide a strong case for ACT to enhance outreach as an effective and highly valued way to reach families living in rural and remote areas of the province.

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[3] See ACT's 2016 Information and Resources Survey www.actcommunity.ca/about-us/2016-survey/

[4] Ibid.

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Autism and Aboriginal Families

It has been challenging for ACT to reach Aboriginal communities as many of these families live in remote, underserved areas. In addition, the historical treatment of Aboriginal peoples has led to a lack of trust for mainstream support systems. ACT has made some progress in reaching out to the Aboriginal community. ACT's 2016 Focus on Research conference featured a presentation by Rona Sterling-Collins, a social worker and respected community leader from the Nlha'kapmx Nation on the Aboriginal perspective toward autism services and supports.

"For me, the impact [of the presentation] has been a change in mind-set and action driven by hope…. I shared what I had learned with my coworkers at Interior Health, and we put up a First Nations Peoples of British Columbia map as a step towards making our clinic rooms a safe space to discuss where we come from to improve health service access for Aboriginal People."
Bonnie Johnson, Ph.D., RSLP

Spurred on by this powerful presentation, ACT partnered with Ms. Sterling-Collins and Simon Fraser University to apply for an Autism Speaks Canada grant for 2017, focused on bridging the cultural gap with Aboriginal communities by providing workshops targeted to Aboriginal families and service providers in communities across B.C.

Immigrants and Refugees

Although most new immigrant and refugee families live in large urban areas, many face similar challenges to those living in rural and remote regions in that there are few services and supports available in their language. In addition, there can be cultural misconceptions about disability that further isolates the family.

While ACT offers services in Chinese, via one part-time Information Officer, if a family needs support in other languages, there is limited help available other than from a few dedicated parent volunteers who help with translation. ACT has made a concerted effort to collect and produce more resources in other languages including the Next Steps Guide (available in four languages), over 140 AID resources in other languages and two Punjabi videos produced by ACT, available through Autism Videos @ ACT (AVA).

ACT in Chinese

In 2015, ACT launched a Chinese-language webpage, ACT in Chinese, which has excellent introductory information for families in Chinese including information on therapy approaches, including Applied Behavior Therapy, Positive Behavior Support and Social Thinking. This is extremely helpful for ACT's part-time Chinese speaking Information Officer in supporting families.

ACT in Chinese: **www.actcommunity.ca/ act-in-chinese/**

ACT in Punjabi

In 2013, ACT and a dedicated group of South Asian professionals formed ACT's South Asian Autism Project (ASAAP) to raise awareness within the South Asian community of the need for early diagnosis and treatment of autism. The ASAAP committee works primarily in Punjabi, the third most commonly

spoken language in B.C., after English and Chinese. With a grant from Autism Speaks Canada, ACT has worked with ASAAP's volunteers to:

- Deliver a series of English and Punjabi-language workshops. Two of these workshops were videotaped and are available through Autism Videos @ ACT (AVA)
- Launch a parent support group in English/Punjabi;
- Translate the Next Step Guide into Punjabi;
- Identifying Punjabi-language resources for the AID;
- A member of ASAAP also contributed a new chapter for ACT's Autism Manual for B.C. focused on how professionals can better work with South Asian families affected by autism.

The ACT in Punjabi webpage launched in 2016 with links to the above resources: www.actcommunity.ca/ act-in-punjabi/

Translation of MCFD's A Parent's Handbook: Your Guide to Autism Programs

The MCFD Parent Handbook is an essential resource for families of newly diagnosed children providing information on funding and recommended intervention options. It is featured prominently in ACT publications including the Next Steps Guide. For several years, the Handbook has been available in English only. In 2016, through one-time-only funding from MCFD, ACT is coordinating the translation of the MCFD Handbook into eight languages – Arabic, Chinese, Farsi, French, Japanese, Korean, Punjabi and Spanish. The project is well underway and expected to be completed Spring 2017.

The Value of ACT Parent Support and Information Services

ACT's timely and accurate information support and referral services are widely respected by both families and professionals.

> "ACT serves a critical role…; [t]hey are the first and last place I refer parents to as I am 100% confident that ACT's Information Officers can best advise them on how to proceed in the best interests of their child."
> Richard Stock, Ph.D., BCBA-D, ABA-Autism Department, Capilano University

> "ACT provides a model for organizations nationwide, demonstrating best practices in tailoring and facilitating access to information and training opportunities in the community."
> Mayada Elsabbagh, Ph.D., Assistant Professor, Department of Psychiatry, McGill University

> "I have experience dealing with ASD NGOs [non-government organizations] throughout the world and ACT is one of the most effective organizations I have come across."
> Anthony Bailey, Professor and Chair of Child and Adolescent Psychiatry, University of British Columbia