



ACT'S PROPOSAL IN RESPONSE TO
PROVINCIAL AUTISM INFORMATION AND
SUPPORT SERVICES RFP **XCN2016005RFP**

BURNABY LOCATION OPTION

Submitted September 14, 2016

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ACT'S MISSION

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.

EXCERPTS FROM LETTERS OF SUPPORT—FOR FULL TEXT SEE APPENDIX - REFERENCES

“As a researcher in Autism Spectrum Disorders and a mother, I am impressed with and grateful for the marriage of heart and mind, comfort and practicality, and information and inclusion that ACT provides for the community of autism. Thirty-nine years ago, when my son was born, autism was rarely diagnosed and little understood, and resources were barely there, even in Vancouver, much less across the province. Had ACT been available it would have been a lifeline for our family, as it is for so many now.”

Dr. Deborah Gibson, Parent, Post-Doctoral Fellow, UBC

I have found the ACT staff to be genuine and dedicated in their efforts to ensure families have a listening ear for concerns, a process for addressing complaints, and a mentor for developing self-advocacy skills. In short, ACT protects families from charlatans and misinformation. Where there is funding, there will always be those who misuse the funds or take advantage of the vulnerable. ACT has filled a needed role in monitoring the knowledge, skills and credentials of those claiming to provide autism services.

Dr. Bonnie Johnson, Parent, Registered Speech-Language Pathologist and RASP Panel Member

“ACT was integral in supporting my own successful transition to adulthood.... In 2010, when I was 16 and entering Grade 11, we went to Vancouver for a workshop on transition with Michelle Garcia Winner and Dr. Pamela Crooke. The following year, ACT came to Victoria and organized a workshop on adult issues featuring Dr. Anthony Bailey and a panel of other speakers. These presenters were essential in providing me, my family, and my teachers with the information we needed to plan for my future. I am not sure where I would be now without ACT.”

Patrick Dwyer, Student of Psychology at the University of Victoria; an adult with autism

“ACT recognizes the need to implement more information, training and resources to Aboriginal communities and is making this mandate a priority as much as funding will allow.”

Rona Sterling-Collins, MSW, parent and First Nations Professional

“Our Korean-Canadian families are in double isolation with having a relative with a disability and being in a minority group. ACT has been successful because it has listened to the needs of families across the province and have had the active support of people like us.”

Dr. Bosang Lee, Parent and Executive Director of Here & Now Community Society

“I have come to depend on ACT’s equitable expertise to provide quality evidence-informed information resources. I say this both as a parent of someone on the autism spectrum and as a professional involved in the education and training of practitioners. I believe ACT helps maintain British Columbia’s stellar reputation of a preferred place to live and work if you care about autism.”

Lori Woods, Parent, Co-ordinator, Disability & Community Studies Department, Douglas College

“ACT has been exceptionally innovative and resourceful in bridging the research-practice gap. ACT has been instrumental in disseminating and translating evidence-based information and resources to families and professionals in BC.”

Dr. Grace Iarocci, Professor of Psychology and Director of the Autism and Developmental Disabilities Lab, SFU

“The challenge of supporting people with ASD will only be met with a multi-sectoral and inter-disciplinary approach, and ACT exemplifies this through its commitment to empowering families through the production of quality resources in many forms”

Dr. Jonathan Weiss, C.Psych., Chair in ASD Treatment and Care Research, Associate Professor, York University

1. EXECUTIVE SUMMARY

This proposal provides a description of the achievements of a small not-for-profit society, ACT - Autism Community Training, which has been making a significant contribution to the lives of individuals with autism and their families in British Columbia since 2003.

It makes the case for the Ministry of Children and Family Development (MCFD) to increase funding to ACT to enable it to sustain its excellent services to families of children with autism spectrum disorder¹, who in BC are expected to manage intervention programs for their children, while struggling to understand the diagnosis. ACT's resources are the foundation for building parent competency and supporting MCFD's Autism Funding Programs, ensuring that the taxpayer receives value and children receive quality intervention.

This case is substantiated by *ACT's Resources and Services Survey 2016*² in which a significant majority of over 1,000 respondents have endorsed ACT's approach, commitment and competency while highlighting the extensive work that remains to be done. Further evidence of the high regard in which ACT's work is held is provided by over 20 letters of support, including parent advocates and many parent-professionals in leadership positions within the autism community, as well as the endorsement of three research chairs from British Columbia to Nova Scotia.³

By working collaboratively, and demonstrating compassion, ACT has earned the respect of many marginalized groups within the autism community including: immigrants and refugees; Aboriginal communities; adults who live with autism and families who live in small under-resourced communities throughout the province.⁴

For the past 12 years ACT's highly committed board and staff, have maximized the value of the vital funding provided by MCFD to address our key deliverables. In addition, ACT raises 30-40% of its income from registration fees, sponsorship and donations adding depth to our work by providing an outstanding community education program which has provided training to over 100,000 registrants since 2010 at no cost to government. As well, ACT is addressing the needs of marginalized communities with innovative projects that ACT cannot fund from its MCFD budget.

In this proposal, ACT demonstrates conclusively that it can deliver basic services with the \$670,000 outlined in the RFP, the same amount it has received since 2010. We will also provide analysis of the corroding effect of inflation and the explosion in the number of children receiving autism funding in B.C. on the value of MCFD funding in real terms and request MCFD to consider where it may be necessary for ACT to reduce the services MCFD funds so as to remain fiscally responsible. Indeed, the disconnect between MCFD funding levels and the real cost of the increased deliverables MCFD requires, if ACT is to maintain its current high level of productivity, is the reason why ACT has been requesting MCFD for the past three years to reissue this RFP. MCFD's funding of the Autism Funding Programs is now \$68 million. We will argue that not to invest in parent information and training ignore the crucial role that families play. We look forward to negotiations with MCFD as to how to prioritize deliverables given the limitations of the funding envelope.

¹ Throughout this proposal, ACT will use autism in the place of autism spectrum disorder to promote clarity.

² *Appendix: ACT's Resources and Services Survey 2016*

³ *Appendix: References and Letters of Support*

⁴ *Appendix: References and Letters of Support: Kamat, Sterling Collins, Lee, Garreck, Dwyer*

DEMOGRAPHIC AND INFLATIONARY REALITIES

According to unpublished MCFD statistics, in 2007 the prevalence of autism in B.C. was 1 in 181; in 2016 MCFD has identified that 1 in 61 children in B.C., nearly 12,000 in total, is diagnosed with autism and is receiving autism funding.

Table 1 provides a breakdown of how ACT is funded by MCFD to support children with autism:

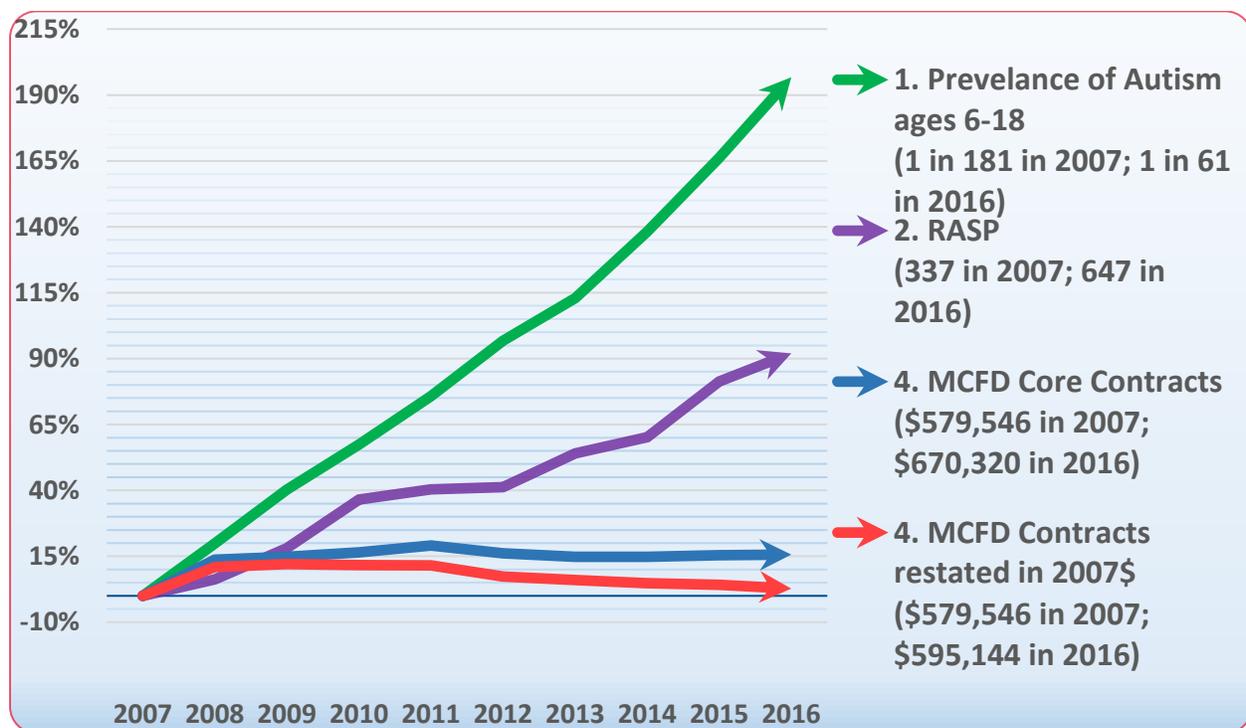
- 2007 - ACT received \$579,000 to serve the families of 4,360 children = \$133 per child.
- 2016 - ACT receives \$670,000 to serve families of 12,000 children = \$56 per child.

Taking into account inflation since 2007 (\$670,000 in 2016 equals to \$595,000 in 2007 dollars):

In 2016 ACT is receiving \$50 per child in real terms as compared to \$133 per child in 2007.

Another significant workload factor for ACT has been a 92% increase in the number of RASP professionals that ACT must monitor since 2007, from 337 to 2007 to nearly 650 to date.

TABLE 1 - COMPARING ASD RATES IN BC WITH MCFD FUNDING FOR ACT YEAR 2007 TO 2016: PERCENTAGE CHANGES SINCE 2007



This proposal makes a compelling case that, to continue with the innovations and the stability that have been a hallmark of ACT's work, MCFD need to invest in ACT's human, information and technological resources. The funding envelope attached to this current RFP extends the \$670,000 budget for a further three years. While it is unknown what will be the impact of inflation, and the possible increase in children being diagnosed in B.C., clearly the decline in funding per child is a serious issue which will require further discussions with MCFD. We are now at the point where even ACT's considerable capacity for innovation and efficiency can't maintain the current level of services indefinitely without increased MCFD support.