



ACT's Resources and Services Survey 2016

"I think it is now CRITICAL for ACT to cultivate and intensify their presence and accessibility to support families to have accurate balance, comprehensive, and unbiased information about a full range of supports available to support children with autism and their families."

"Great organization, but I believe that many families with children with autism do not know about your services, therefore my suggestion would be to try to get the word out as what you do is fantastic."

September 22, 2016

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Executive summary

ACT's Resources and Services Survey 2016 provides a rich source of information about ACT's work for our Staff and Board of Directors. That over 1,000 people took the time to respond is an indication that many people have strong opinions about ACT's services; ACT is encouraged by the generally positive response.

ACT's concern that many parents and professionals are not aware of the range of services we provide has been borne out by the results of this survey - a clear indication that ACT needs to focus attention and resources on promotion.

ACT has also received strong direction on the areas which the B.C. autism community wants ACT to prioritize in developing its information and support services over the next two to five years. ACT's next step will be to find the resources to enable us to meet the challenges we have been set.

Response to the survey and how it was distributed

In August 2016, ACT distributed a survey targeting those who use our information and support services within the autism community of British Columbia. The objective was to understand the perceptions of the consumers of ACT's resources, where we need to improve our services, and to identify the autism community's priorities for future development of ACT's services.

The survey was promoted via ACT's email, Facebook page and website over a three week period. ACT also contacted other community agencies and autism leaders and requested they share with their networks. ACT received 1,051 responses to this survey - a higher return than we expected, especially given the survey was done in the summer.

Most responses were prompted by the announcement that went out to ACT's 8,000 member email list. Not all respondents indicated where they heard about the survey.

- Social Thinking Live Event - 287 hard copy responses from 400 attendees, a 72% rate of return.
- Email - 583 responses, about 6% of the 8,000 person email list.
- Facebook or Website - 79 responses, about 8% of total responses.

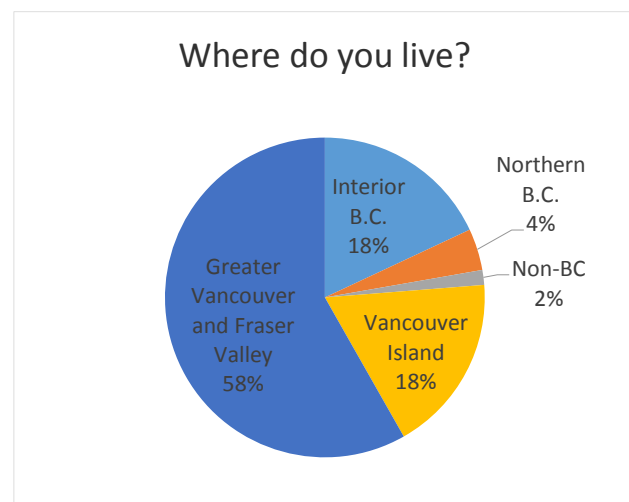
Not all respondents answered all questions. Most responses are presented as the percentage of answers, due to variable responses rates.

Demographic questions

Where do you live?

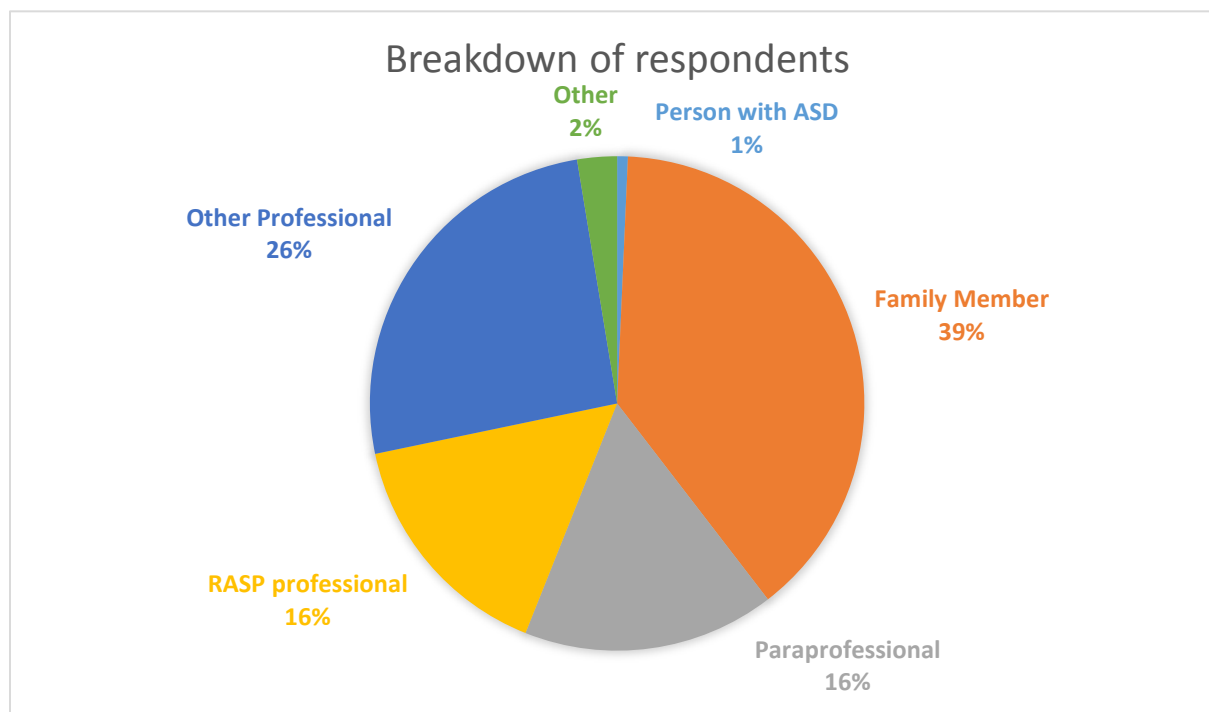
ACT is in contact with parents and professionals around B.C., which is reflected in the response to the survey; 40% of responses came from Vancouver Island, the Interior and the North, which is broadly representative of the province. However, more work needs to be done in the North to promote awareness of ACT's resources.

"I consider ACT our best provincial resource."



Breakdown of respondents

ACT recognises that some respondents have multiple roles; they can be both parents of individuals with autism and RASP professionals, for example. The survey asked respondents to identify their “primary hat” when self-identifying. 39% of respondents identified themselves as Family Members. Nearly half of the respondents (42%) identified themselves as either non-RASP professional or paraprofessionals.



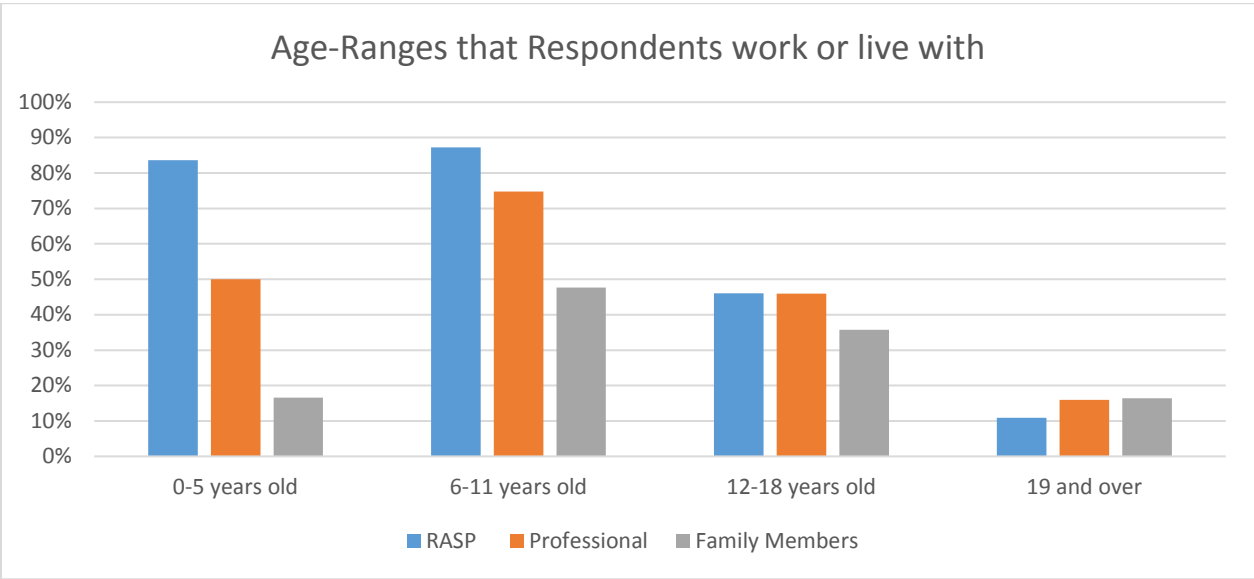
What age range do you support?

This question targeted the age of the person with autism that the family supported or the professional worked with. As respondents could work with more than one age group, or have more than one child with autism, the numbers add to up to more than 100%.

Not surprisingly RASP and Non-RASP Professionals report that they are working mainly with younger children. It was surprising, however, that only 84% of RASP Professionals reported that they work with children under the age of six, given that the RASP is specifically for children under six. Overall, 40% of all respondents are focused on the needs of children under six.

17% of parents who responded have children under six; 65% of family members are supporting children under 12; 36% with children aged 12 -18 years of age. Another 16% of family members are supporting adult children with ASD. This implies that some families are supporting more than one child on the spectrum, which we know is the case.

Only 16% of non-RASP professionals work with adults, which is reflected in parental concerns at the lack of services after the transition to adulthood.

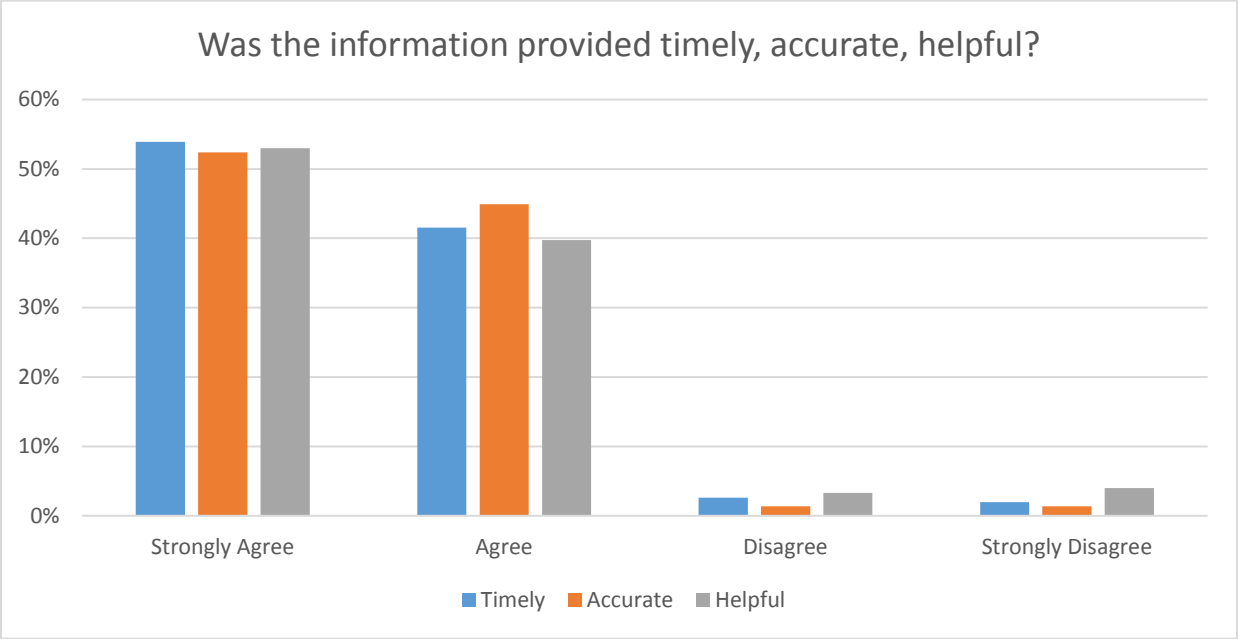


Feedback on the value of ACT’s information services

ACT Information Officers (IOs) are available during office hours to provide individualized, confidential support on all aspects of the resources needed by parents and professionals supporting individuals with autism and other special needs. They also staff information tables at ACT events and at non-ACT events in the community.

Information Officers provide helpful, timely and accurate information

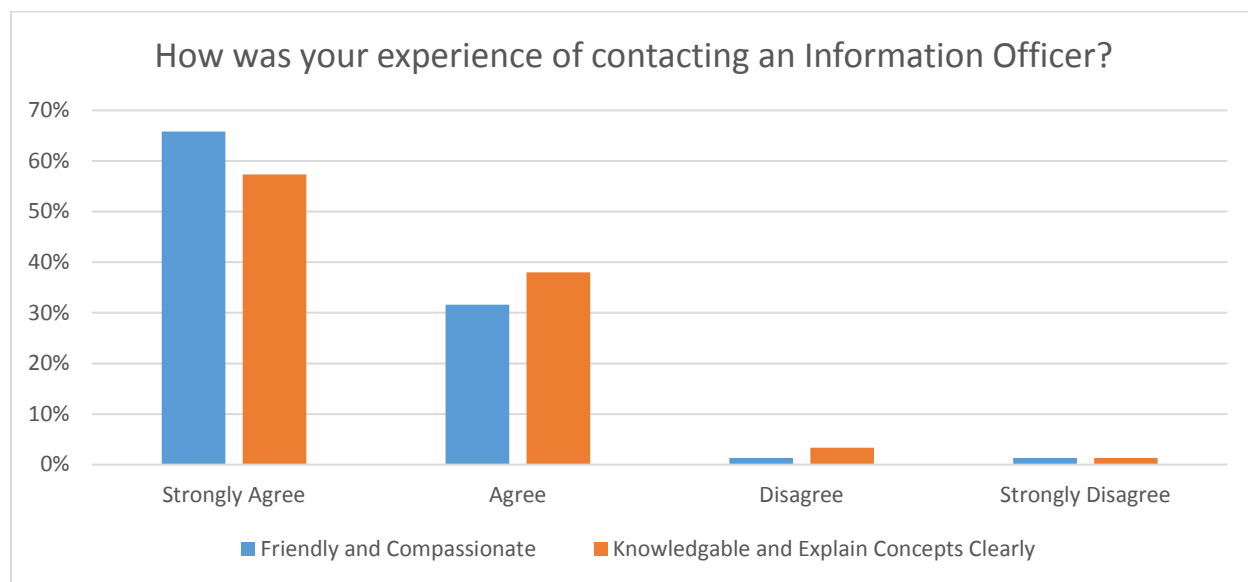
The responses to the quality of service provided by ACT’s IOs were very positive overall. This service is widely regarded as being timely, accurate and helpful. Specifically, 93% of Family Members who have interacted with an ACT Information Officer, found the experience to be helpful and the information provided both accurate (97%) and timely (95%).



“I received a very quick response with all the information I needed.”

Information Officer services are valued by ACT's callers

Many families call the office while under stress; Information Officers strive to be supportive and thoughtful in these interactions. Indeed, of those who responded to this question, 97% of Family Members who called an ACT Information Officer found them to be friendly and compassionate and 95% found that they explained concepts clearly. Many of the comments mentioned specific Information Officers by name, commending them on their warmth.



“Overwhelmingly useful and supportive.”

“Always helpful and responsive - a pleasure to contact”

More awareness of ACT's services needed

Many families are under extremely high stress levels, which puts Information Officers under great pressure to find relevant services. This comment from a parent who has not been in touch with an ACT Information Officer is very concerning:

“I wish we had an advocate. A pioneer who has gone ahead of us on this journey. Someone to help and encourage us parents rather than us just commiserating ‘oh, your child is nonverbal, noncompliant, and aggressive and you can't leave your house too?’ - I think many of us parents feel like we're losing our minds and losing ourselves and we are prisoners in our own homes and have tremendous difficulty understanding autism, or learning how to work with our child, let alone ever seeing the possibility of getting to a point of celebrating autism. 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.”

ACT has taken note that more than half of respondents are unaware that Information Officers offer individualized support, despite ACT's efforts to promote this resource at our live events, via the New Diagnosis Parent Packages and the annual mail out to all parents receiving autism funding. It is evident that we need to find novel ways of promoting the work of ACT's Information Officers.

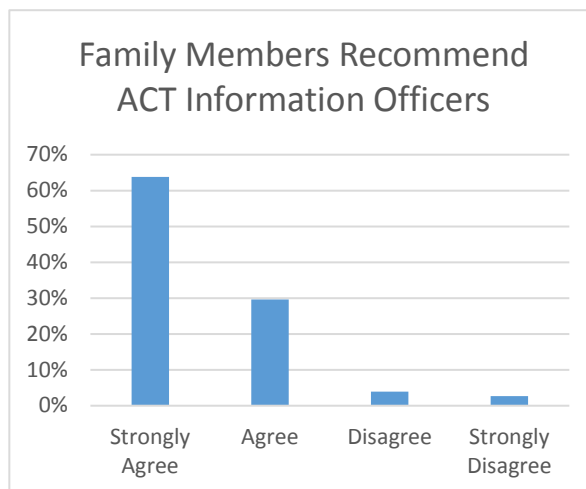
Respondents recommend ACT Information Officers to other families

94% of all family members would recommend other families contact an Information Officer:

“Absolutely, this should be their FIRST phone call.”

Disappointment is almost always due to a lack of availability of services for the Information Officer to share.

“Because we live so far from Vancouver, we have found that ACT has very little to offer our family in help or resources.”



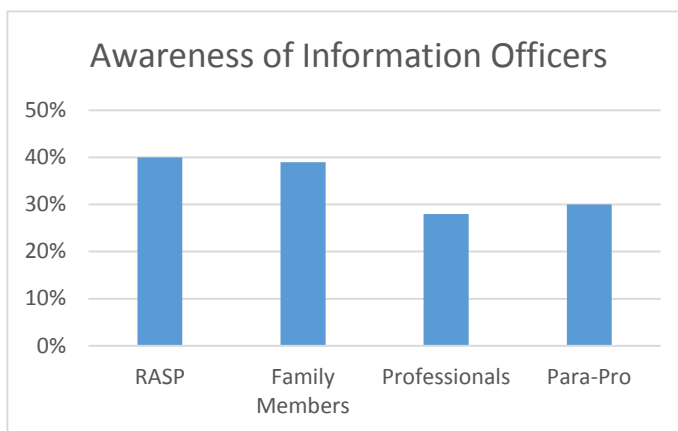
RASP Professionals also contact ACT Information Officers

40% of RASP professionals have contacted an Information Officer, mostly with information questions. Their comments include:

“The individual I spoke to needed to confer with others. She shared that with me and provided a follow up phone call.”

“I left a message and received a phone call back within 15 minutes”

Some of the RASP responses may refer to calls about the RASP application process, and not information support service. This may have inflated the number of responses from RASP professionals - many of their queries were probably answered by the RASP Administrative Assistant who is also a part-time Information Officer, so this is difficult to tease out.

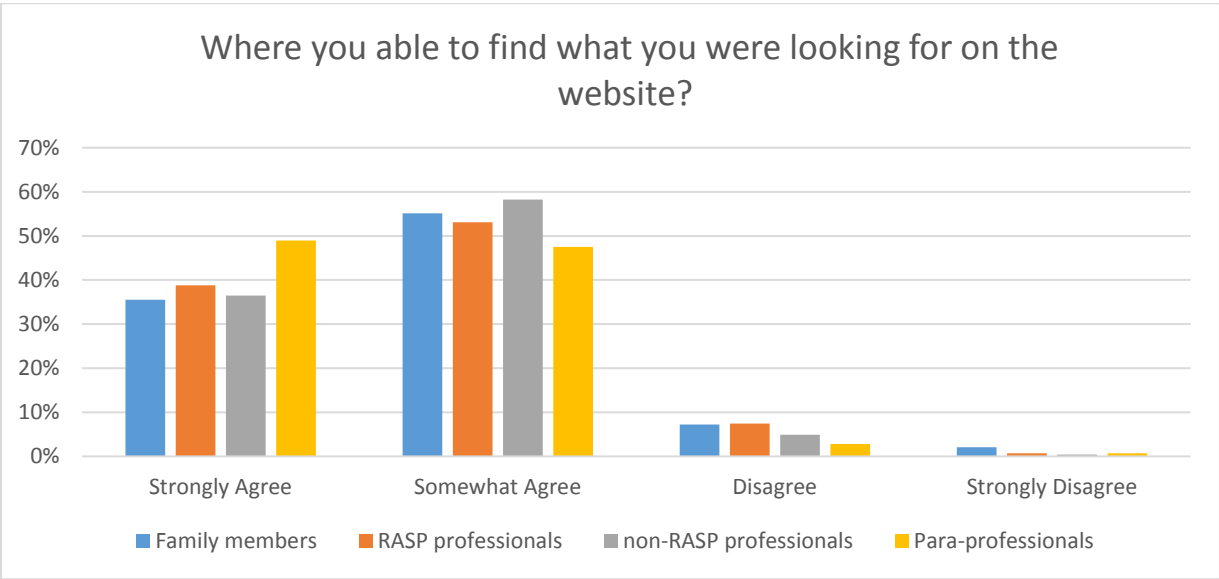


ACT was particularly keen in this survey to determine how our users rate our information resources. Overall, respondents strongly endorse the resources that they are aware of but it is clear that ACT needs to work on increasing awareness of the new resources we have developed in recent years.

The ACT Website: good navigation and clear information

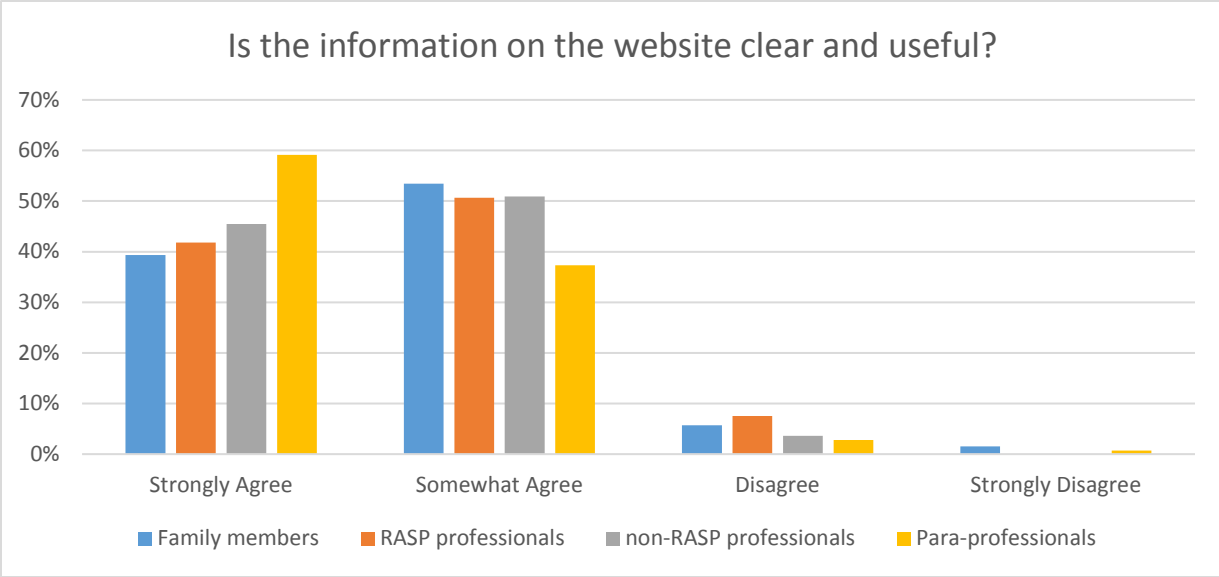
The ACT website acts as an information gateway to many of ACT resources, making information available to anyone with an Internet connection. For many, it provides a source of information that people visit regularly as their needs change.

ACT is aware that the website is complex. We were pleased that 91% of Family Members and 97% of Para-professionals who have visited the ACT website found it fairly easy to find what they were looking for, however, there is clearly room for improvement.



The ACT Website Contains Clear and Useful Information

92% of Family Members and 93% RASP professionals agreed that the information provided is clear and useful. Paraprofessionals especially appreciate the website information (59% Strongly Agree, and 37% Agree).



The ACT Website requires re-development

The request for suggestions for how ACT can improve the website generated a strong response and point to many areas where ACT would like to make a sweeping redesign. Some visitors only go to specific parts and do not browse our other resources, which is a weakness.

“I have only gone to the RASP list.”

“It sounds like I haven't been using it to its full potential!”

Many commented that it was overwhelming, and that they could not find the appropriate information.

"I find it overwhelming and hard to find what I'm looking for, except for the RASP and Live Events."

"The website can be improved to make it easy to navigate. It is so much information; you can easily get lost in there."

"At first glance it appears very 'wordy'"

Navigation and the headers are an area for improvement.

"The information could be better organized. The menus have a lot of information on them and it is not always intuitive as to where to find what."

Others had some very specific suggestions:

"Official policies and guidelines for professionals applying to the RASP. There are no official policies that can be found on the website..."

"List of advocates (who to turn to in specific scenarios), i.e. BC Ombudsperson, BCREP, MLA, Ministry, CLASBC, BCANDS, etc."

"I think it would also be great to discuss, or make accessible, blogs and sites that are written and maintained by folks on the spectrum themselves, although I understand the difficulties in curating a list like that."

Many expressed their appreciation for ACT's online presence:

"Excellent website and newsletter. Keep up the great job!"

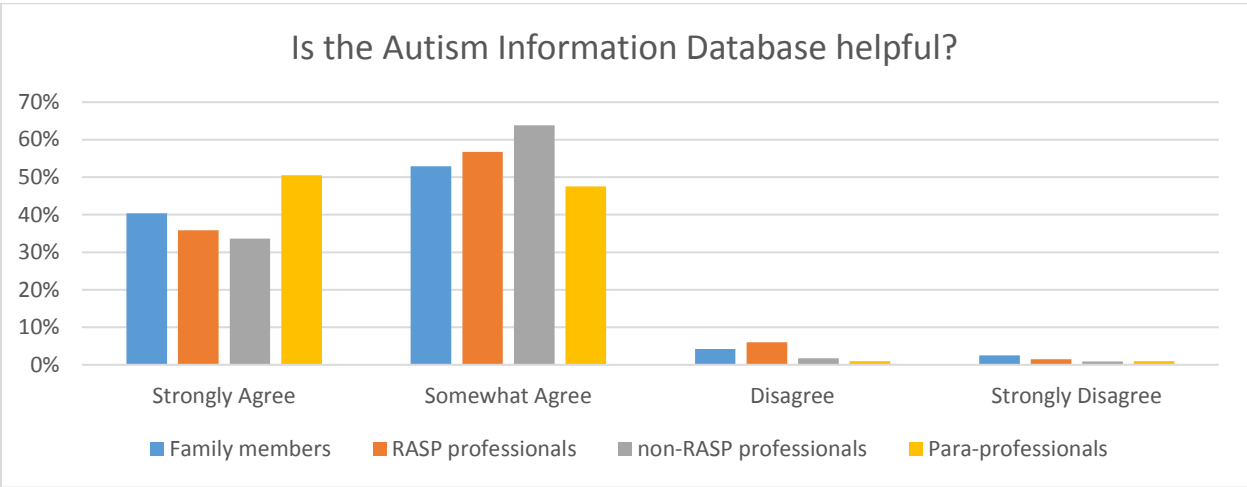
"I haven't visited the home page in a long time - usually just jump straight to the RASP list and get the other info in the newsletter. Just took a peek and it looks good!"

Assessing specific online information resources

The survey also asked about specific resources, to see how aware respondents are of these resources and to what degree they value them.

Autism Information Database (AID)

The AID is a collection of over 2,000 carefully vetted information and community resources which contains information on non-RASP service providers and other community resources as well as helpful online information resources. Of the respondents who were aware of the AID, 93% of Family Members Agreed or Strongly Agreed that the AID is valuable.



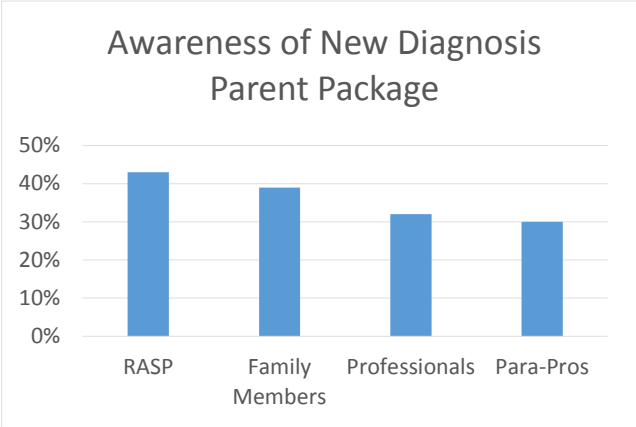
One of the respondents lamented the lack of service providers outside the RASP list, not realising that the AID provides exactly this resource:

“It would be nice to have a database of all service providers for families with kids over 6. I was looking for OT, SLP and art therapy providers.”

New Diagnosis Parent Package

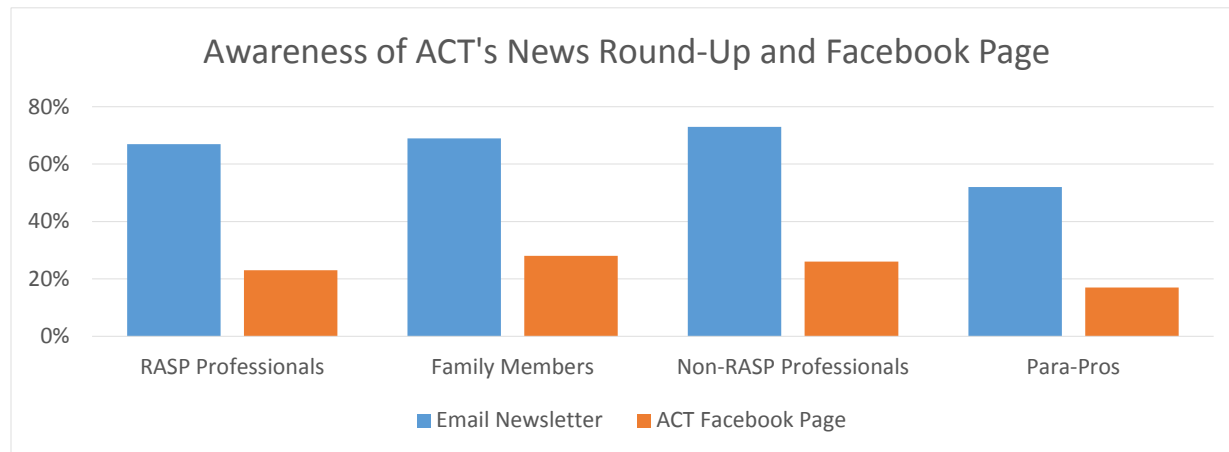
The New Diagnosis Parent Package (the “Red Folder”) is distributed by ACT to private and publically funded diagnosticians across B.C. - not to professionals generally. Of family members with a child under six, 60% were aware of this important resource which is aimed at alerting parents of newly diagnosed children about ACT’s resources.

“I had the opportunity to give a parent the ‘red folder’ package.... It was extremely helpful and it gave us both a good starting point. Thank you.”



Monthly News Round-Up and Facebook

Each month ACT sends out the ‘News Round-Up’ (an emailed newsletter) and issues Facebook postings daily to share resources developed by ACT and other reputable organizations, as well as news items. The News Round-Up is better known to family members and professionals; there is less awareness of Facebook.



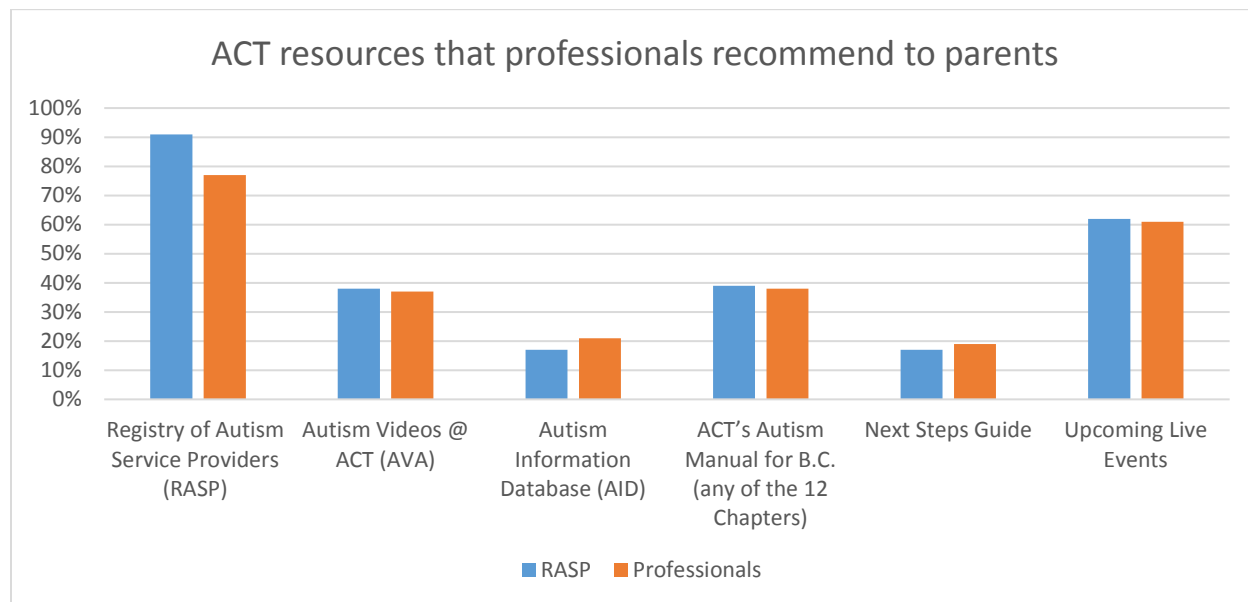
“I think ACT does an amazing job. I absolutely love the newsletter – it helps keep me linked in so many ways.”

“The email newsletter has been very valuable information to share with families.”

“I do like the social media expansion as the newer generation of parents really use these resources – often first.”

Promotion of ACT resources by RASP and non-RASP Professionals

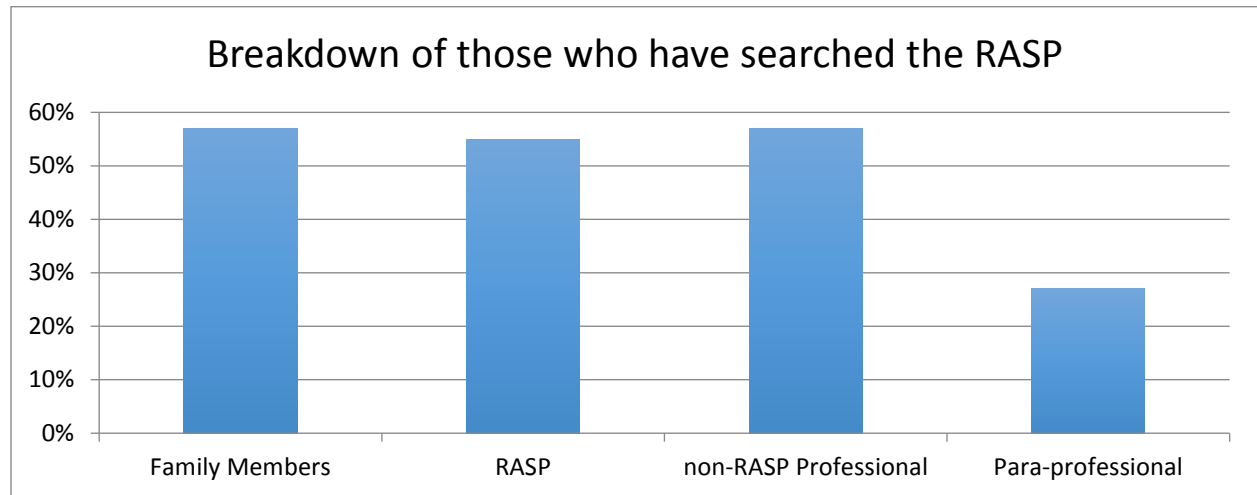
Non-RASP professionals who responded to the survey are strong users of ACT’s resources and just as likely to recommend them to families as RASP Professionals are - with the exception of the RASP itself.



Perceptions of the RASP

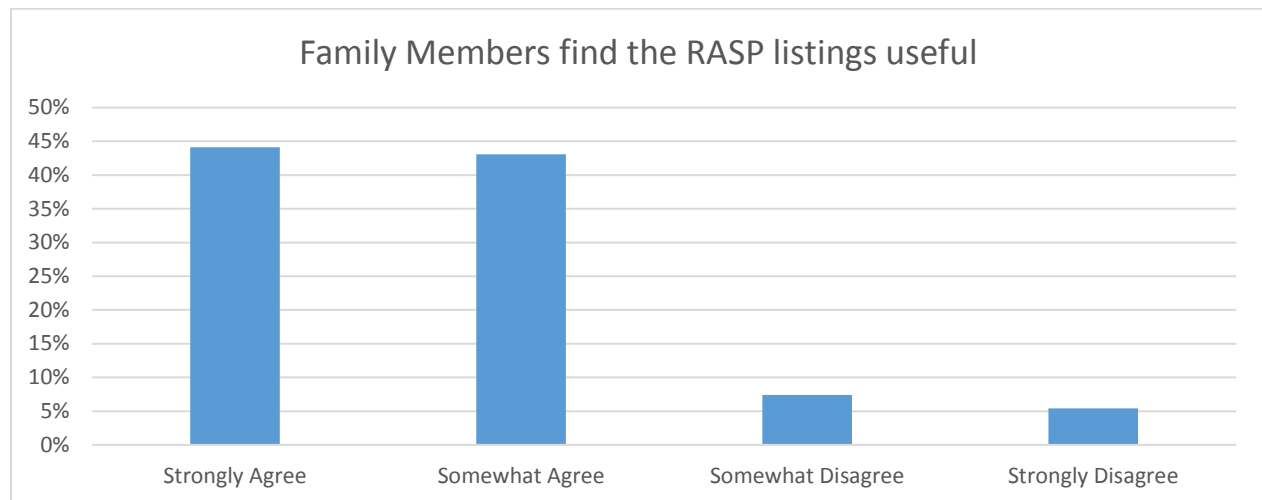
What percentage of respondents use the RASP?

The RASP area of the ACT website is widely used, as parents are required to use RASP professionals for children under the age of six when using Autism Funding. The RASP list is also used by those who support children with other special needs and children with autism six and over, as it provides a comprehensive starting point to find professionals with strong qualifications in behavior analysis and other evidence-based approaches.



"I sometimes refer families to the RASP list even if their children don't have a diagnosis of ASD but need the type of services listed. It is easy for them to navigate and all in one place."

Overall, 87% of Family Members who use the RASP Agree or Strongly Agree that the RASP listings that ACT provides are useful. 13% do not find it helpful which may reflect frustration that they cannot find professionals available to meet their child's needs.



Speaking out on service quality issues

Many comments, from parents, professionals and RASP Professionals themselves, addressed service quality issues. MCFD, with ACT's support, is undertaking initiatives to rectify this critical area of concern. In the meantime, these comments reflect widespread perceptions of the current limitations of the RASP:

"There needs to be more checks or somebody governing the RASP list. Providers should have to be ethical in the treatment and communication with families."

"The RASP contains too many providers of questionable therapies. Needs to focus on evidence-based practises."

"I would find it helpful if there was capacity to conduct random 'service audits' to review the quality of services/interventions being purchased. As a CYSN Social Worker, I'm aware of situations where we get involved after several years of intervention, only to discover that the services have been ineffective and thus not the best use of funding."

"Given some recent ethical issues I am aware of, I'm concerned that some on the RASP are not a part of a professional regulatory body that has legislative authority."

"It would be great to have the RASP providers rated."

Seeking more detailed and accurate information on RASP Professionals

The RASP list contains information on the region where a professional works, professional qualifications and, if applicable, supervisory information. Many parents, however, seek more detailed information on RASP professionals, asking for profiles where professionals can detail their approach to autism treatment. Historically, detailed profiles have only been available for Behavior Consultants; ACT would like to re-develop the profile tool which is no longer functional and make it available for all RASP Professionals to provide profiles if they so choose.

"Wish the RASP list can provide more detailed information about professionals' profiles."

"RASP list needs to be kept more up to date with respect to specific approaches used by the professionals on it."

"The RASP doesn't help me find a fit for my child. It just shows me how much supply-demand situation exists in Victoria."

See page 22 for further discussion on the desirability of a RASP for six and over and for detailed profiles for RASP professionals.

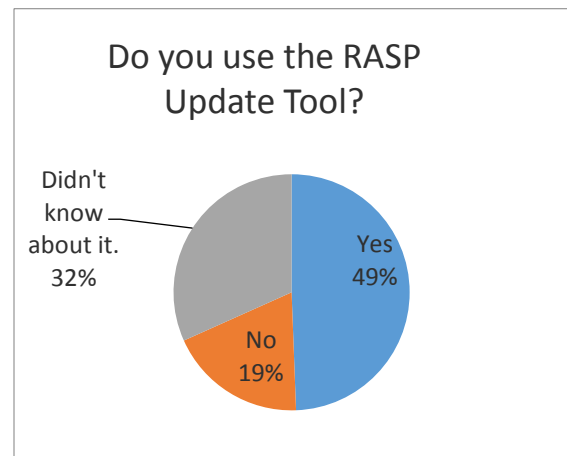
Questions specific to RASP Professionals

The RASP listing service is directed specifically towards the families of children diagnosed with autism under the age of 6.

The update tool for RASP Professionals

The online RASP Update Tool was developed in 2015 to make it faster and easier for RASP providers to update their contact information and availability. Nearly 70% of RASP Professionals indicated they knew about this tool but ACT needs to work on promoting this tool to those who don't. It is not clear why 19% of RASP respondents who know about the tool choose not to use it.

It is clear that there is significant parental frustration at not receiving responses from RASP Providers who indicate they are taking new clients.



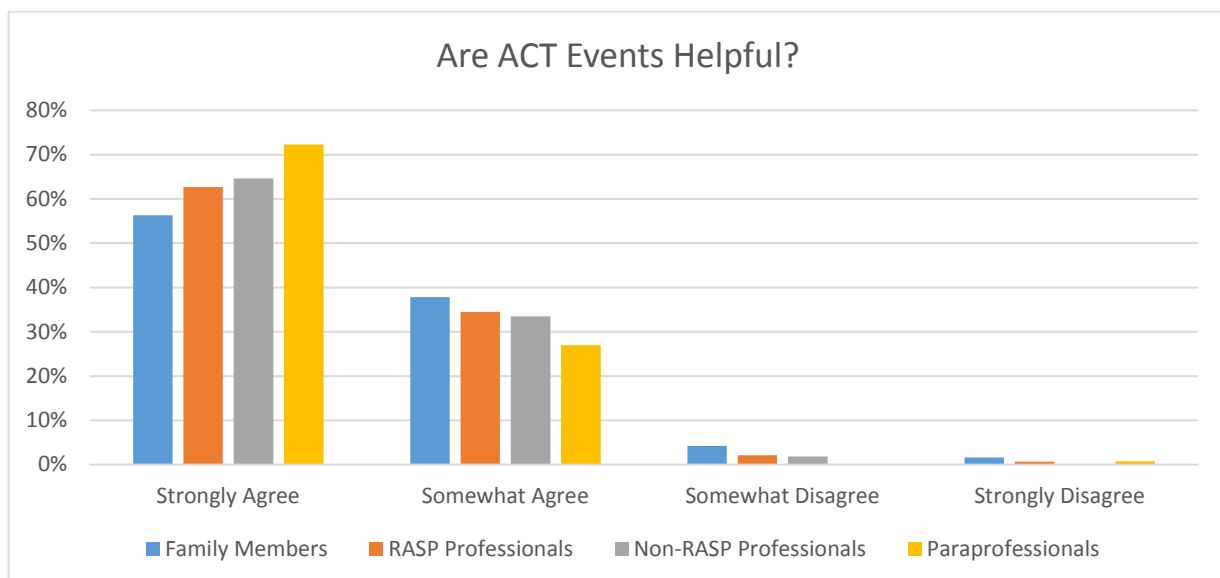
"Every single provider I contacted where the list had indicated "is accepting new clients" -- and not a single one of them were accepting new clients."

Positive feedback on ACT's training

ACT provides both live and online training opportunities for parents and professionals across British Columbia. This is one of the most valued services that ACT provides

Strong support for ACT's Live Events

ACT's Live Events are given a very high rating by survey respondents. In general, respondents consider them to be professional, well-organized and relevant. 98% of RASP Professionals and 94% of Family Members agreed or strongly agreed that that ACT's Live Events are helpful. Many respondents report attending multiple events and remark on the accessibility of events for both parents and professionals.



“The live events are the best professional development opportunities I have attended. I always learn something, and get more insight in how to work with students. Keep it going!”

“I’ve attended several excellent ACT events. It’s nice to be able to register online.”

“The ACT events that I’ve attended have been very relevant and well organized. Quality is more important than quantity in my opinion.”

“I am impressed that ACT keeps live events open to parents and para-professionals. Parents really value the information they receive and that they are included.”

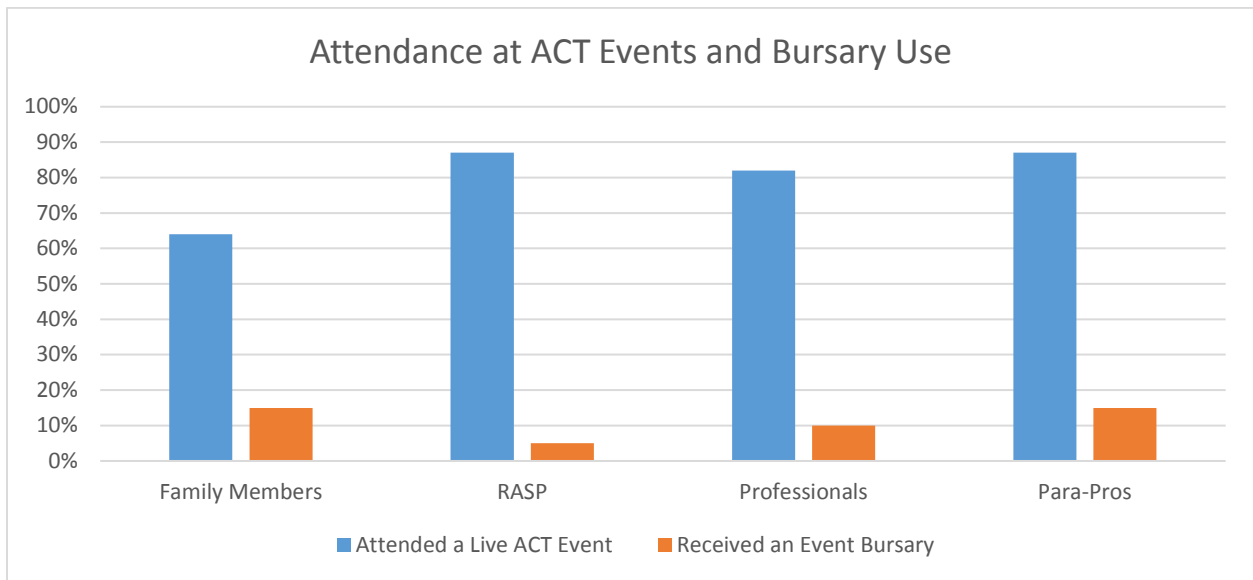
Awareness and use of ACT’s bursary program

ACT provides bursaries, in particular for those living outside of Metro Vancouver, to promote accessibility. \$24,000 in bursaries was provided in 2015, to encourage participation from those with low income or who have to travel to attend:

The chart on page 18 ‘Live Events and Bursary Use’ demonstrates that applicants from Northern B.C. receive proportionally more bursaries than those from other regions, in recognition of the difficulties they face in accessing training locally.

Breakdown of Bursary Respondents:

- 15% of parents
- 15% of para-professionals
- 10% of professionals



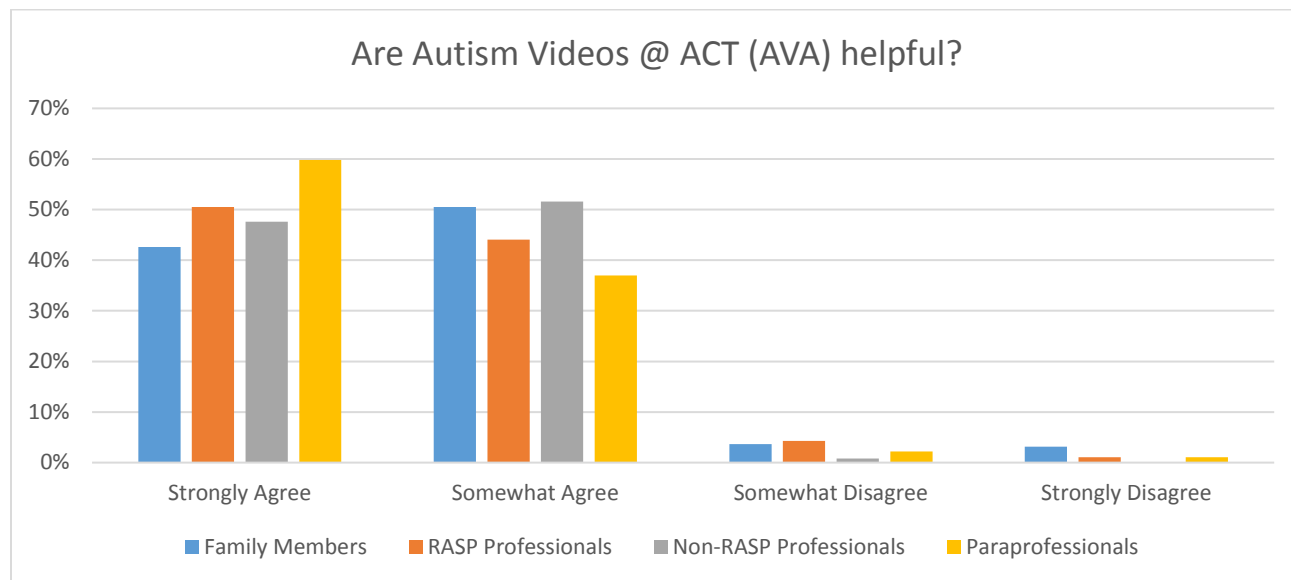
“I am grateful for the bursary fund that I have used in the past. It has given me the chance to come to live events and learn so much when I absolutely couldn’t afford it. Thank you.”

While bursaries are appreciated, many respondents would prefer more training in their own communities:

“I recognize the population base is in the lower mainland, however it is always exciting when a workshop or event comes anywhere near the Okanagan.”

Autism Videos @ ACT: Making learning opportunities more widely accessible

Autism Videos @ ACT (AVA) is a newer ACT service that was re-launched in 2015 after ACT made all online videos free in 2014. AVA is developing an audience, and is perceived as helpful by those who know of this service. Of those who know of AVA, 95% of RASP Professionals and 97% of Para-Professionals Agree or Strongly Agree that the free online videos that ACT provides are useful. These videos are available at home, and at any time convenient to the user.



Videos are popular especially for those who do not live in Metro Vancouver:

“More events need to be by video. I am unable to attend events in Lower Mainland.”

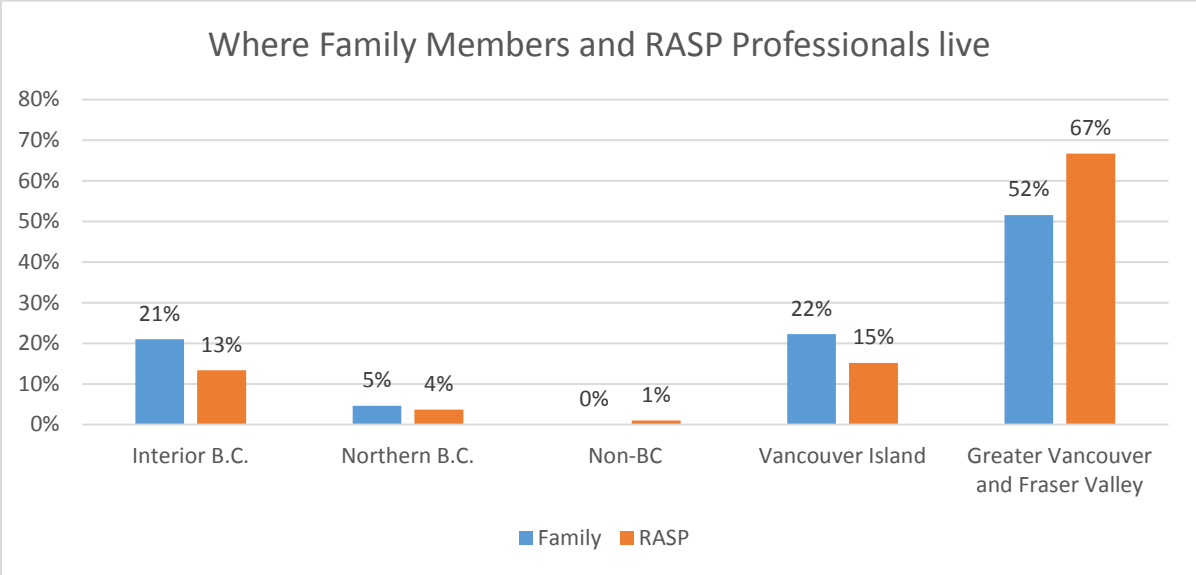
“I appreciate being able to watch autism videos at home as I have to travel far to attend events in Vancouver.”

“I do love the online videos that I can access all the time”

“As somebody who lives in the B.C. interior, I would greatly appreciate more online resources, particularly recorded videos, so I don't need to spend as much time and money travelling to learn.”

Perceptions of users outside of the Lower Mainland

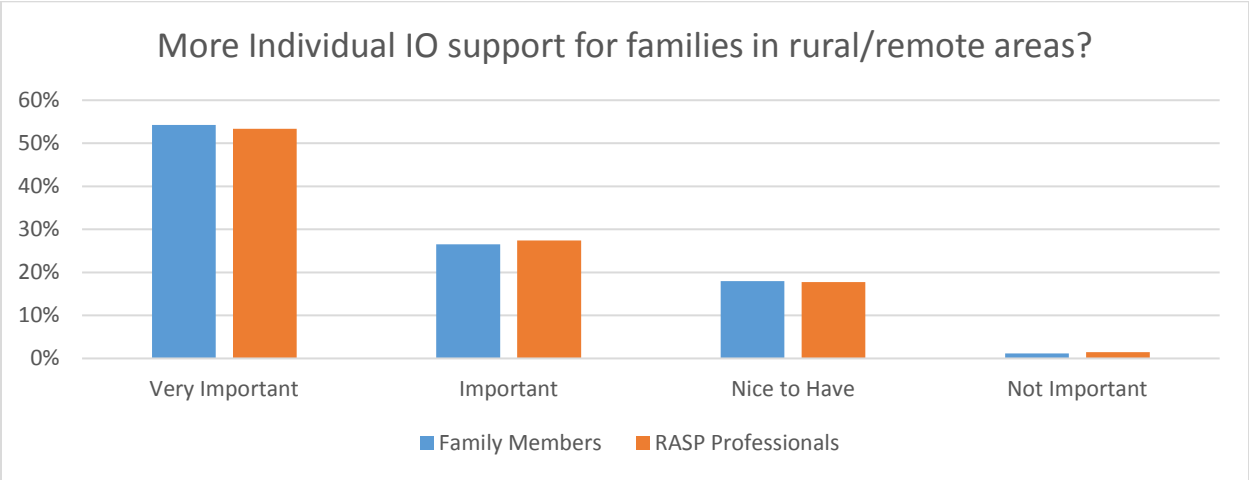
Survey respondents frequently mentioned the lack of services and resources outside of Metro Vancouver. ACT has worked to develop innovative approaches to address this (Autism Videos @ ACT, the Autism Manual for B.C and the AID are all available to anyone with an internet connection).



More information support requested

Rural areas are less aware of Information Officer support: only 26% of respondents from the North and 24% from the Kootenays were aware of the service Information Officers provide, compared to 39% of responses from Greater Vancouver and 36% in the Okanagan. Interestingly, Vancouver Island North had a 34% awareness of Information Support. This is probably the result of training ACT provided to MCFD Children and Youth with Special Needs Social Workers from across Vancouver Island in 2016 and an information session in Port Hardy.

Respondents would like more information support in rural areas; those who did call an Information Officer would recommend the service to other parents. 55% of all respondents think that it is Very Important to provide more IO services to those in rural and remote areas. Unsurprisingly, this is rated even higher in the North (78% rate it as Very Important, and none ranked it as Not Important).



Lack of local RASP professionals

Many families in rural areas indicated that they do not use the RASP because they do not think they will find RASP professionals in their area to serve them. Those in rural areas who have used the RASP agree that it is useful (77% from the Interior Agree or Strongly Agree, but 15% answered Not Applicable. 25% from the North felt the RASP listing was Not Applicable to them)

“There are very few RASP people out in the Eastern Fraser Valley”

“Not enough service providers in my area.”

“We barely used my son's funding because there were no available professionals in our area that were on the RASP”

“I live in a rural area where there a few professionals on the RASP that live in the area.”

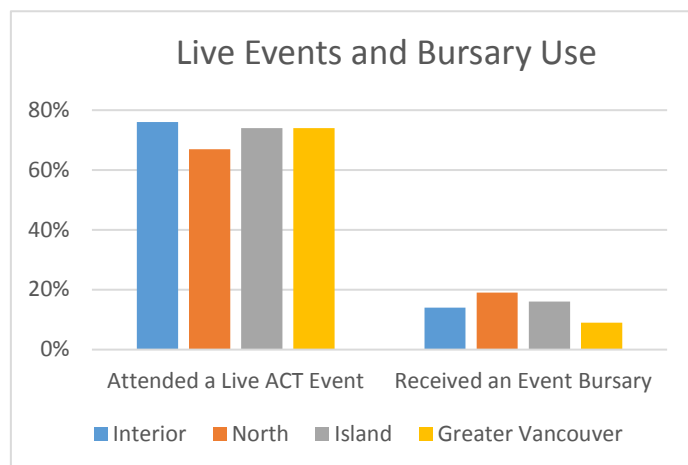
“Not a lot of options in the Cariboo, but that isn't ACT's responsibility”

More live training wanted

ACT's live training is an important part of ACT's services and an opportunity for ACT's staff to share resources. For many attendees it is a first introduction to ACT. While many respondents from smaller communities had attended an ACT Event, they wanted more events in their home communities.

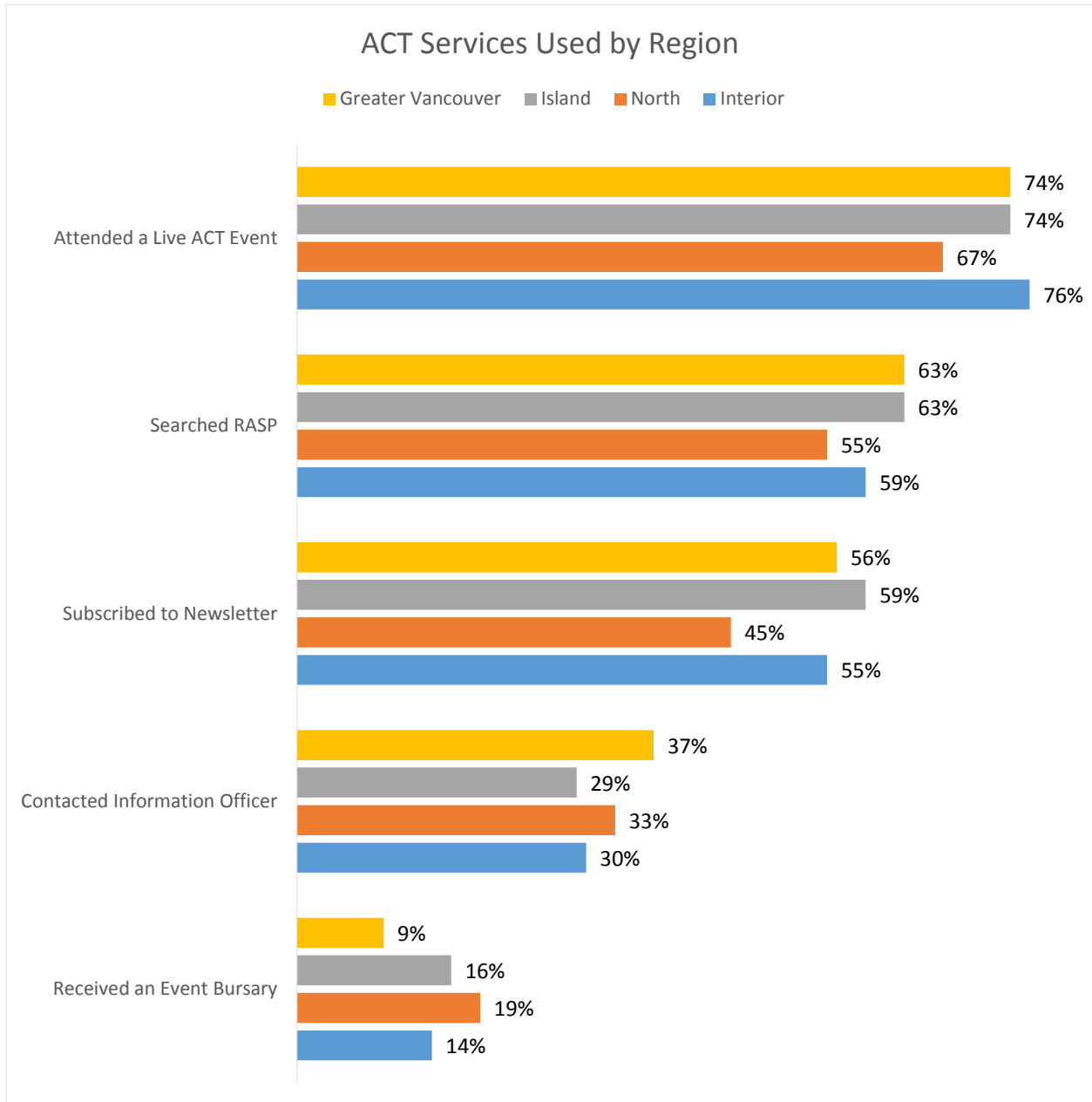
“Living in a rural area I find most of the ACT events and information not relevant or am unable to attend (or my families are unable to attend) as too far away. The closest one I have seen is in Kelowna is a 7 hour drive away.... Just not accessible!”

“Resources are limited because we live in Chilliwack.”



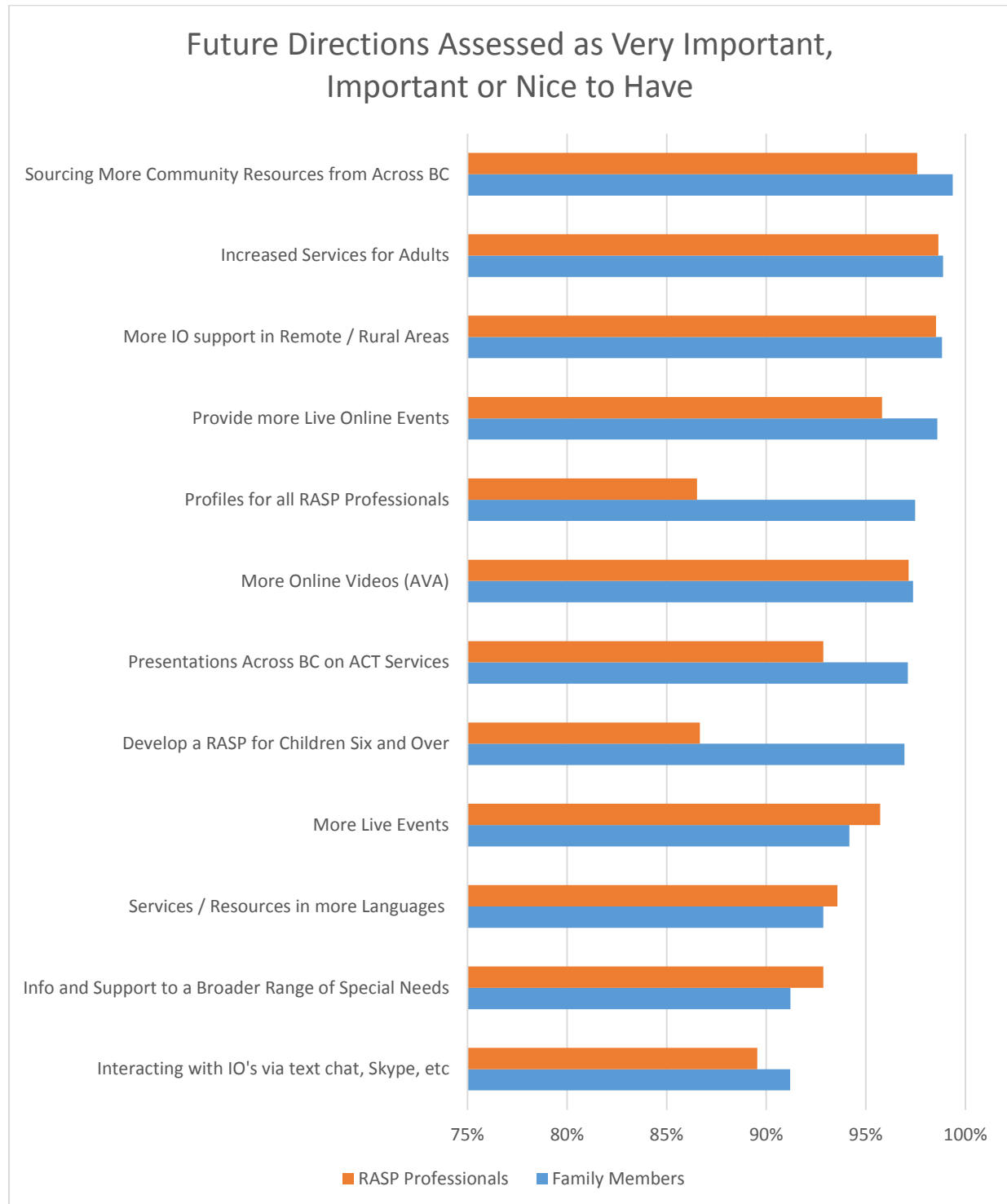
ACT services used by region

Overall, ACT's services are used across British Columbia but the North is a region where ACT needs to focus more promotion of our services.



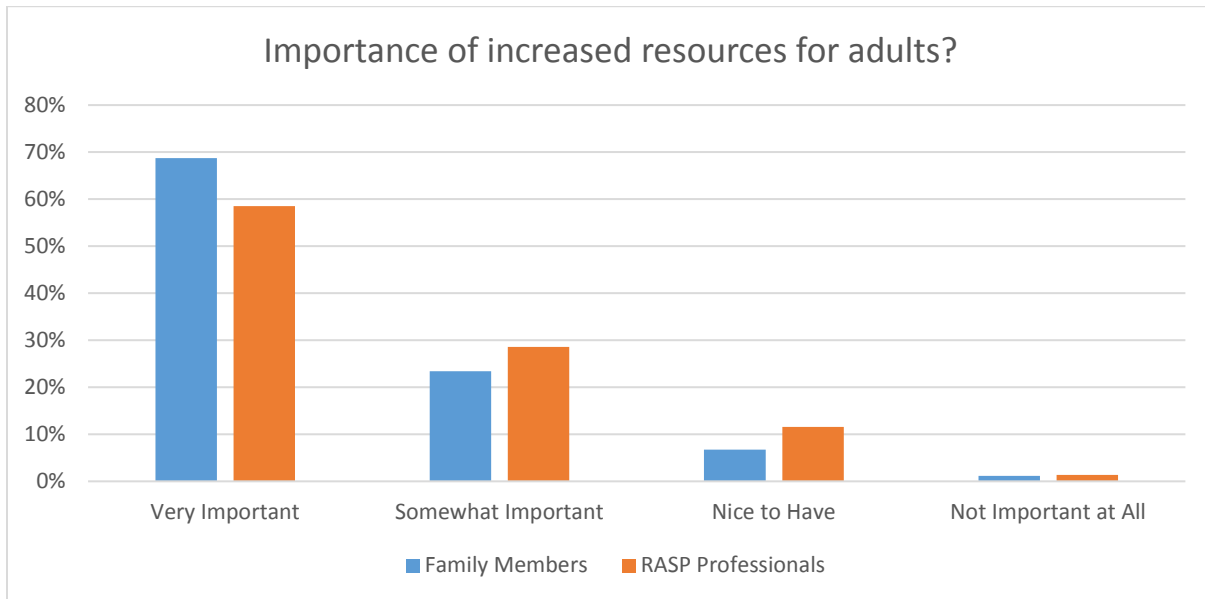
Prioritizing future directions

As a result of ACT's 12 years of providing parent support, we recognize that there are many needs that are facing families who have children with ASD. In order to gauge priorities, the survey asked the question: "If ACT had the resources, where should it focus its efforts over the next two to five years?" Some of these priorities are discussed in detail below.



When children grow up: services for adults

Both parents and RASP professionals are looking ahead to adulthood – 99% of parents and RASP professionals rank more resources for adults as Very or Somewhat Important. While ACT is not funded for this service, we do the best we can to provide information on the services available.



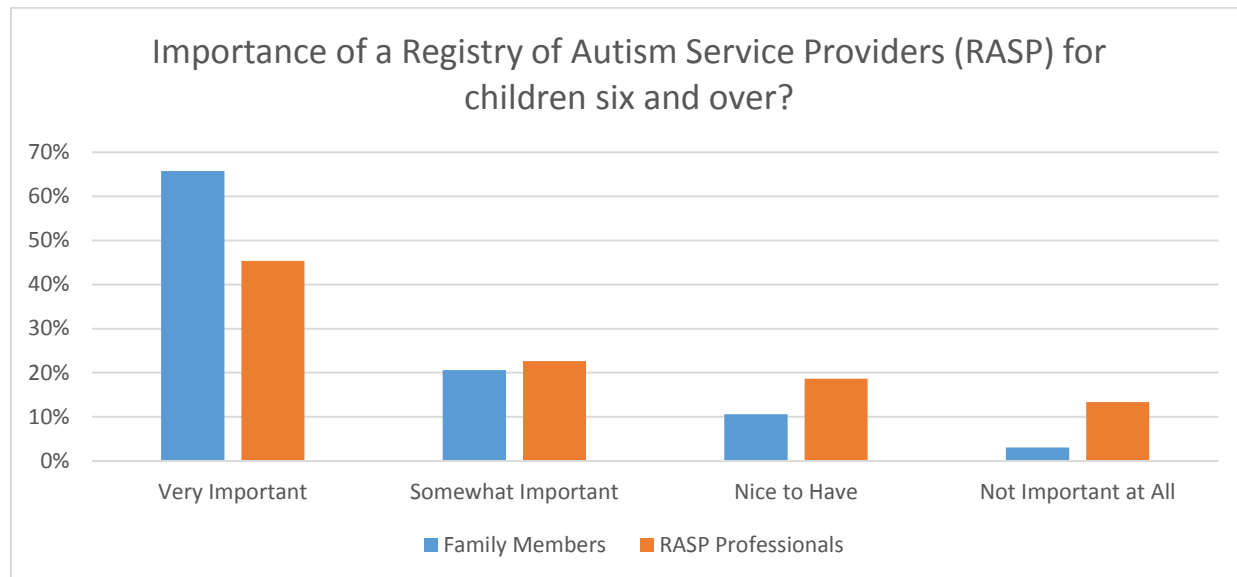
“There's a real lack of services for teens, youth, young adult everywhere!”

“Diagnostic services for adults are lacking in BC. Therapy services for adults with ASD need development.”

“Adulthood is coming faster than I like to think (it has been 11 years - in another 11 years - he'll be 22!). Resources and information for adults on the spectrum would be very helpful.”

Parents support a RASP for children six and over

The RASP is also used widely for those seeking professionals for children six and over. Comments and responses to Question 14: “If ACT had the resources, where should it focus its efforts over the next two to five years?” point to a demand for a RASP for children six and over. 97% gave this a positive rating, as compared to 87% of RASP professionals.



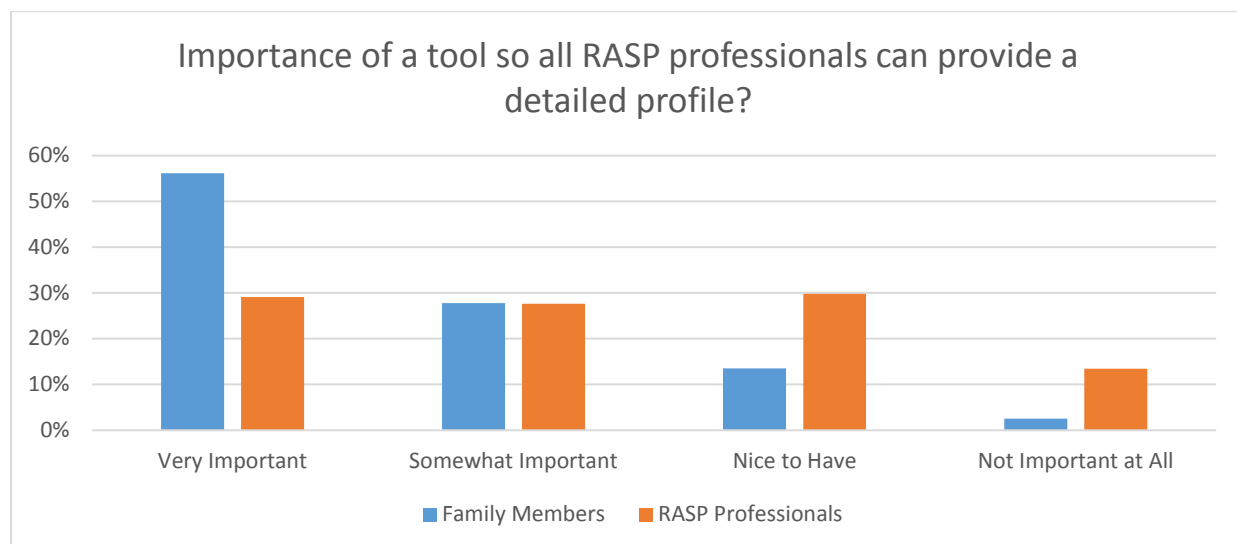
“I found the gap of RASP for over 6, lack of regulation for BI very concerning”

“(Families of) Children of all ages accessing autism funding should only be able to use the funds towards service providers on the RASP just as with the under 6.”

“No RASP for kids over 6 sends the message that we don’t care as much about the quality of care for them.”

Strong support for a RASP Profile Tool

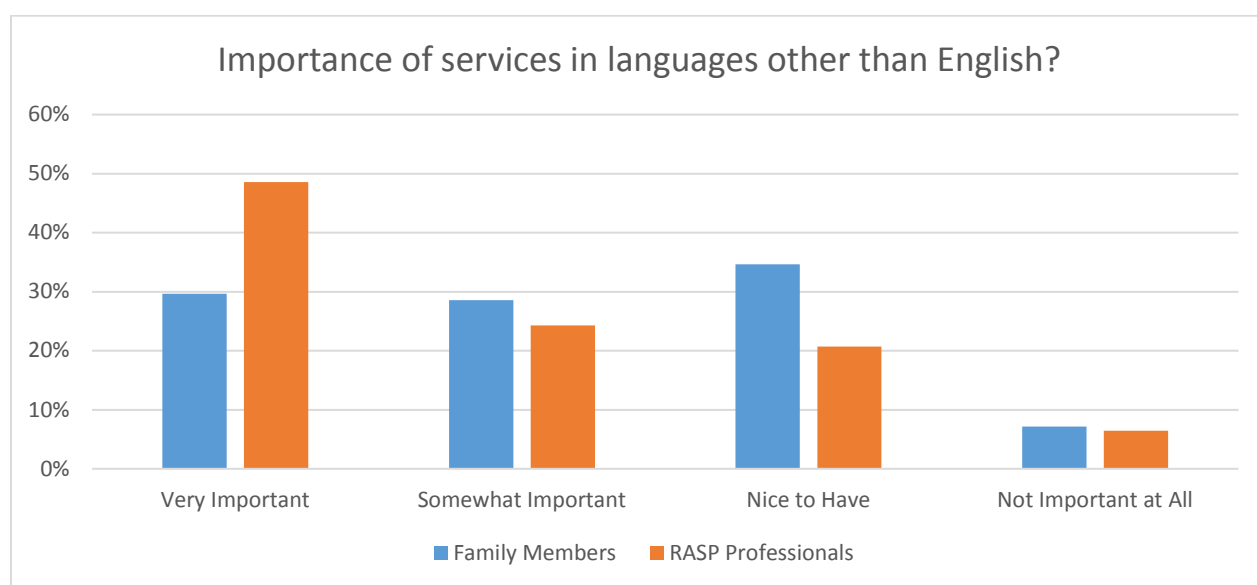
There was strong support for a RASP Profile Tool; 97% of parents indicated that detailed profiles of RASP professionals would be a positive resource; 87% of RASP professionals agreed.



Immigrants and refugees: services for non-English speakers

The need for more resources in languages other than English and Chinese (ACT currently has a part-time Chinese-speaking Information Officer) was rated as valuable by 93% of Family Members, and 94% of RASP professionals who answered this question. Many respondents are sensitive to the needs of those who struggle in English.

“I am an English speaking, Canadian born mum of an autistic boy. I am also a health care professional (albeit in a vastly different area than pediatrics or developmental disabilities and neurological differences). Frankly, I had trouble navigating information and needed services for my family and my child. I can't imagine what it is like for someone who is not a native English speaker and whose cultural background cause barriers that I never dreamed of. Services in languages other than English (with cultural sensitivity) is truly needed to make ACT inclusive for all.”



“Presentations [should] be offered to families of different languages. I feel these families are often lost and trust the first resource that explains in their language. These resources are not always serving the families and children's needs; more so; their own agenda.”

“I'm concerned about how difficult it is for marginalized families to access services. Language and culture is one barrier but I think poverty and limited education is an even bigger barrier.”

Thank you to all who participated in the survey

Overall the survey results provided ACT with clear feedback and direction for the future. We will share the results with our funders and try to rise to the expectations that have been shared with us through this survey. Above all we recognize that we need to promote the services and resources which we have developed more creatively.