



Identifying Need, Delivering Service

The Autism Community Satisfaction Survey Report

Commissioned by:

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BACKGROUND

ACT—Autism Community Training is an information, training, and referral service supporting individuals with autism and their families. The organization’s goal is to enable parents, professionals, and para-professionals to support children and adults with autism to live “productive, satisfying lives within their families and communities.” Many of ACT’s services, including maintenance of the Registry of Autism Service Providers (RASP), are funded by B.C.’s Ministry of Child and Family Development (MCFD).

In December 2016, the MCFD announced that it would no longer provide funding to community organizations, such as ACT, to provide autism information and support services. Instead, MCFD will be taking over these services beginning on July 1, 2017.

This report presents results from a community survey regarding the autism community’s perspective on access to autism information and support services. The survey was disseminated via email to ACT’s mailing list on March 9, 2017. Two reminder emails were sent, and the survey was closed on March 29th. The survey was sent to 7,389 people, including individuals with autism, family members, and caregivers, as well as professionals and paraprofessionals who provide services to the autism community. 1,621 responses to the survey were received¹ for a response rate of 22%². To encourage participation, survey completion allowed respondents to enter a draw for a \$100 Amazon gift card.

KEY FINDINGS

- **71% of survey respondents indicated that they prefer to access autism information and services through community non-profit organizations;** 9% indicated that they would prefer MCFD to deliver services, and 20% did not know or were not sure.
- Respondents who indicated that they prefer non-profit service delivery cited the track record, personal experience, and vested interest of community organizations like ACT as reasons to continue service delivery through community organizations.
- Survey respondents who indicated that they prefer information and service delivery from MCFD expressed that centralizing all autism services and information would make it less confusing for families to navigate service providers.
- 86% of respondents indicated that they would be comfortable contacting ACT if they were facing an autism-related challenge, compared to 35% who would be comfortable contacting MCFD.
- 93% of respondents reported being satisfied with their access to services and resources through ACT.
- 96% of respondents reported being satisfied with ACT’s website, compared to 43% who were satisfied with MCFD’s website

¹ While 1,621 individuals responded to the survey, all questions were optional. Therefore, the number of respondents changes throughout the report based on how many answered each question.

² Based on the sample size, responses are accurate within a confidence interval of +/- 2% (95% CI).



SURVEY RESULTS

PREFERENCES FOR ACCESSING INFORMATION AND SERVICES

The core survey question asked respondents to identify their preferences regarding autism information and service delivery. The majority of survey respondents (71%, 1133 of 1590) indicated that they prefer their information and services to be delivered by community, non-profit organizations, while 9% reported that they would prefer to access services through MCFD (Fig. 1). This preference was expressed for all respondents regardless of personal/professional roles (Fig. 2.)

Fig. 1 - How do you prefer services to be delivered?

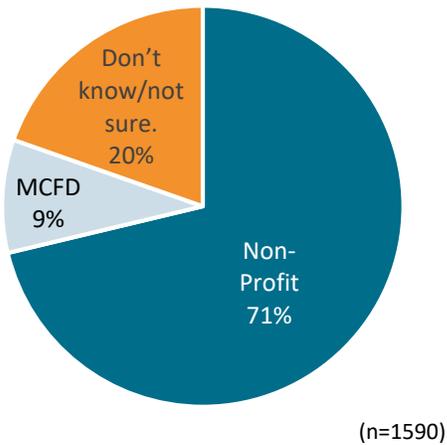
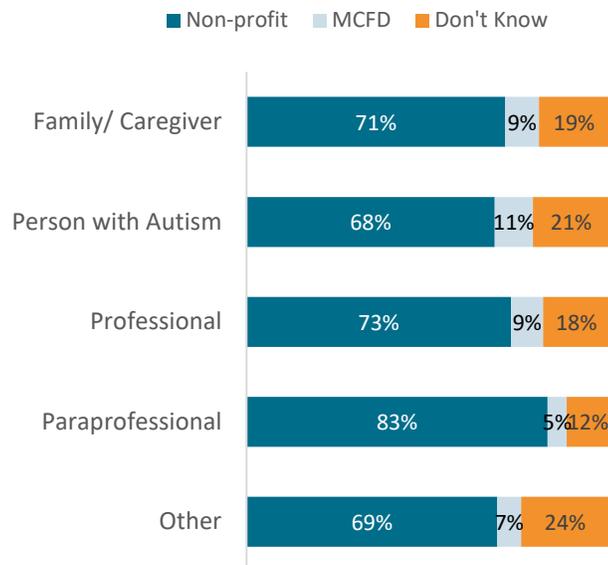


Fig. 2 - Preference by Role



In addition to indicating their preference, respondents were invited to provide rationale to support their choice. Eight hundred and six (806) respondents provided a response. Thematic analysis identified key themes according to how respondents preferred to access services.

1. *"I prefer that information and support services on autism-related issues be delivered by a community-based, not-for-profit organization (such as ACT)."*

The majority (71%) of respondents indicated that they prefer autism information and services be delivered by community-based, non-profit organizations. Four general themes were identified in the 614 open-ended responses from these respondents.

1.1 Respondents are highly satisfied with the services provided by community organizations.

Many respondents reported a high-level of confidence in and satisfaction with ACT as the primary provider of autism information and services. ACT's positive track record, expertise/specialization in autism, quick response time, and wide range of education and training services were all cited as reasons for community organizations to continue providing autism information and services. Survey results further indicated that 93% of respondents reported satisfaction with access to autism services and resources through ACT (See "Satisfaction with Services", below).

Respondents also indicated that they trust community organizations like ACT more than government agencies because of their personal, lived experience with autism. As one respondent explained, the information provided by ACT staff is "*disseminated at a more personal level*" because of the close links with the autism community. Another respondent stated that they "*feel safer talking with ACT or a community-based organization who can provide impartial advice and support with how to access services and funding.*"

In summary, many respondents prefer that autism information and services be delivered through community non-profit organizations because of their high satisfaction with the services that are already provided.

"I have been constantly grateful for the cutting-edge quality of information and learning opportunities provided by ACT. While a government department can offer services, I have never known one provide the level of information and continuing education that ACT has supplied, nor one to have such a powerful level of advocacy and openness."

– Autism service provider/ professional

1.2 Respondents lack confidence in MCFD to provide a similar or equal level of service.

Respondents expressed concern with MCFD's decision to take over services that are currently provided by community organizations. Reasons for this concern range from respondents' past negative experiences with MCFD to their present perception of MCFD as a ministry that is "*too slow to respond*," "*too far removed from front line support*," and one that already has "*too much on its plate*." As one respondent elaborated, "*MCFD is already so busy; The social workers are overwhelmed and barely have time to see us as it is.*" In this regard, respondents identified a lack of confidence that MCFD would be able to connect members of the autism community to all the supports and information available to them due to a lack of expertise and capacity.

1.3 Respondents indicated a low level of trust in MCFD.

Respondents expressed a low level of trust in MCFD's ability to provide unbiased information and services to parents. Respondents identified that services provided by the Ministry may be influenced by a political agenda. Other respondents perceived MCFD's decision to take over the provision of autism

resources as a potential conflict of interest since MCFD is also involved in child protection services. As one respondent explained, *“I find that families are more willing to approach outside agencies than MCFD. [...] Some families distrust information provided by MCFD or are concerned that contact with the government / social workers might result in their child being taken away.”*

1.4 Respondents are concerned that adults with autism will not be supported because of the shift in service delivery.

Respondents indicated their preference for a community non-profit to deliver autism services because of a potential gap in services to adults with autism. As the MCFD’s scope of services focus on children and their families, respondents expressed concern that adults with autism will not receive the same level of information and services, including education and employment resources, that they are currently receiving. Furthermore, a shift to MCFD provision of service may mean the loss of advocacy for adults with autism.

“I chose [the community organization option] because these types of organizations cater to children AND adults, as the need for supports often extends beyond childhood into adulthood.” – Self advocate/person with autism

2. *“I prefer that information and support services on autism-related issues be delivered by the Ministry of Children and Family Development.”*

Nine percent of respondents (145 of 1590) indicated that they would prefer to access autism information and services through MCFD. Three themes were identified in the 48 open-ended responses from these respondents:

2.1 Centralizing services with MCFD could simplify the process of connecting families to autism service providers.

Respondents who were supportive of MCFD providing autism support services identified that a key benefit is that information would become centralized, potentially resulting in easier access to autism information. Currently there are several service organisations providing autism information. It was perceived that amalgamating these services would create less confusion and mitigate discrepancies between sources. In addition, respondents perceived that reducing the number of service providers would be more cost effective, potentially allowing excess funds to be redirected to families.

“Navigating all the service providers in the autism community is exhausting and frustrating. If all services and funding was to be controlled by one ministry, perhaps these challenges would be avoided.” – Family member/caregiver



2.2 MCFD is potentially better equipped to reach smaller, harder-to-reach communities than community organizations.

Some respondents, typically those living in harder-to-reach communities, reported having difficulty accessing services provided by community organizations like ACT. Since community organizations do not operate in every municipality, respondents cited the high cost of travel and lodging as a barrier to accessing autism services. As one respondent explained, *“We are ocean-locked. We have to take an \$80.00 ferry to get to Vancouver and back.”* These respondents perceived that centralizing services within MCFD may enable more local and accessible support in all regions of the province.

2.3 Community organizations, including ACT, do not support all alternative autism therapies.

A small segment of respondents (n=5) expressed that they would prefer MCFD because they perceived that community organizations such as ACT are too focused on applied behaviour analysis (ABA) therapies, and do not recognize some alternative therapies. These respondents indicated that having more therapy choices was an important factor in deciding who they want to provide autism information and services.

“ACT has primarily supported only one therapy option for years. Families need choice and individualized treatment options - other than ABA.”

– Family member/caregiver

3. Respondents who selected “Don’t know/Not sure”

Lastly, 20% of survey respondents (138 of 1590) reported that they were unsure of their position in regards to the future of autism service delivery. Two general themes emerged from their responses:

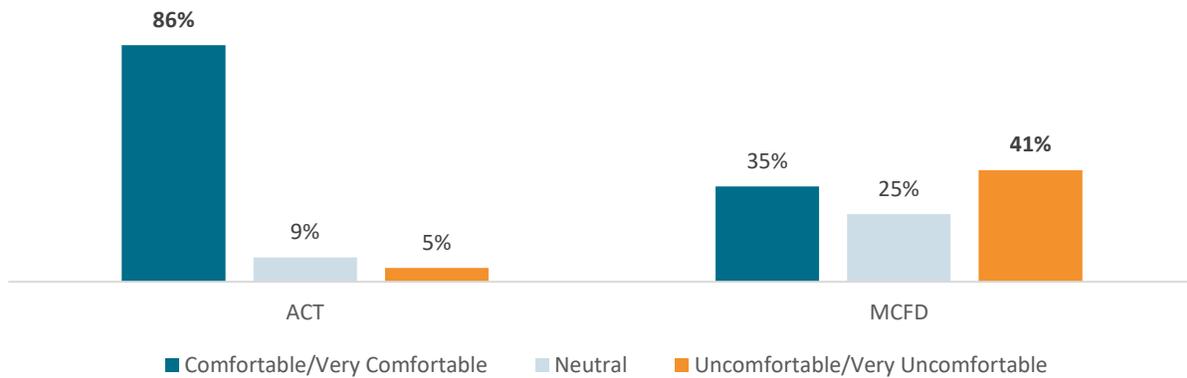
These respondents indicated that they did not understand the difference between ACT and MCFD, nor the exact implications of MCFD’s decision to take over service provision enough to make an informed decision. Other “unsure” respondents expressed ambivalence at the MCFD’s decision as they were *“less concerned with who provides the services than the quality of the service itself.”*

COMFORT ACCESSING SERVICES

To further assess the level of trust that the autism community has developed accessing services through ACT, survey respondents were asked to rate their level of comfort contacting either ACT or MCFD when facing an autism related challenge. The majority of respondents (86%) indicated that they would be comfortable contacting a community non-profit service provider, such as ACT, to get support with a challenging situation (Fig. 3). In comparison, 35% of respondents reported that they would be comfortable contacting MCFD when facing a challenging situation.



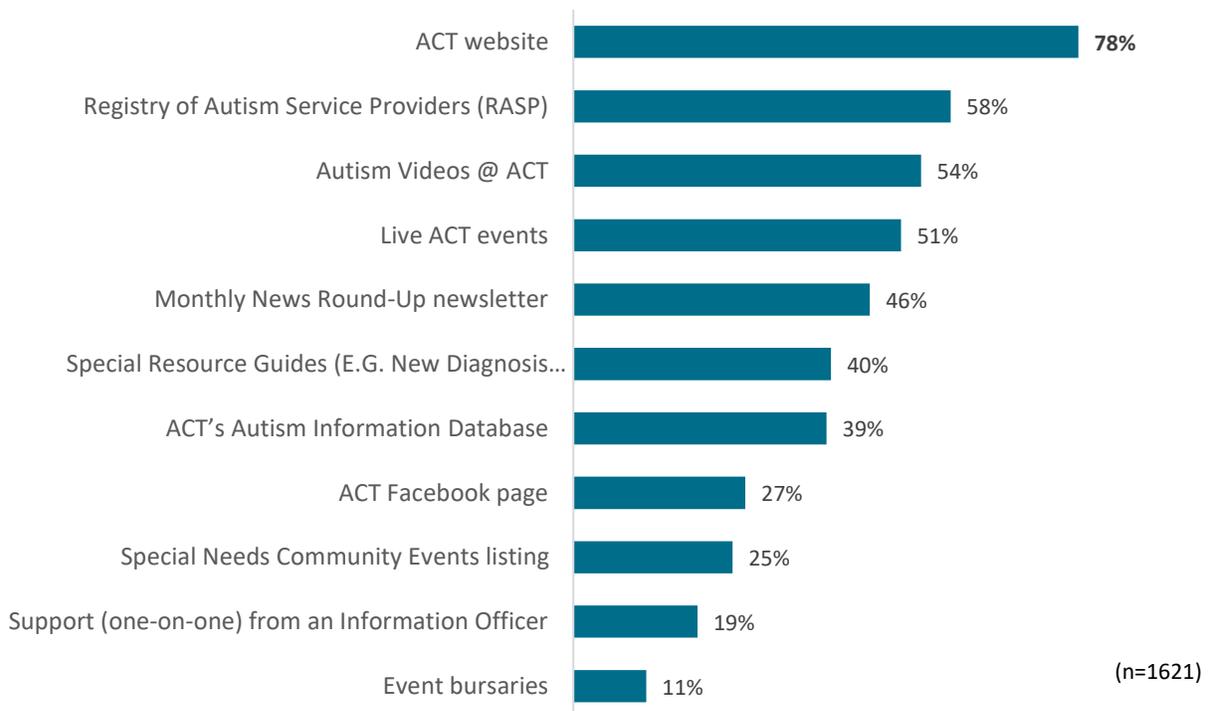
Fig. 3 - If you were facing an autism-related challenge, how comfortable would you be contacting...



SATISFACTION WITH ACT

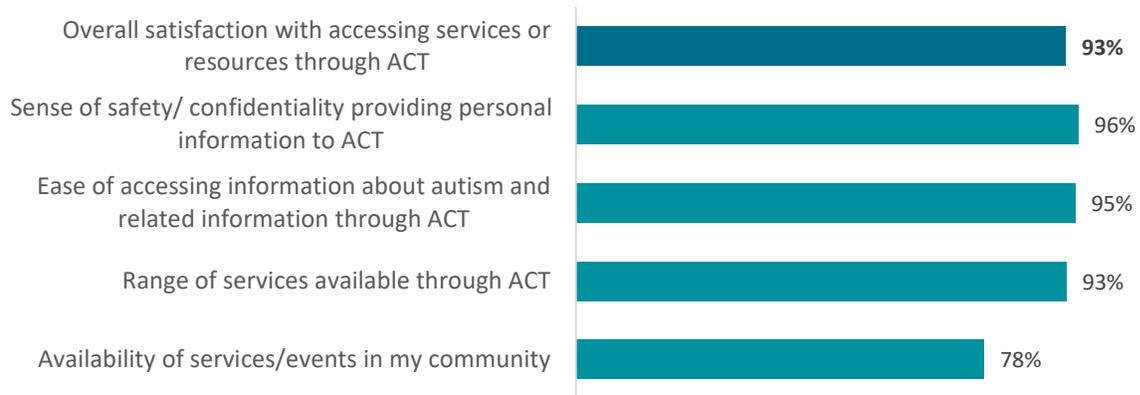
To further explore current access and satisfaction with autism service provision, survey participants were asked to comment on their service use and level of satisfaction with these services. The majority of respondents (98%) had accessed at least one of the services provided by ACT (Fig. 4), and, in general, they reported a high satisfaction with ACT’s information and service delivery (Fig. 5).

Fig. 4 - What supports have you accessed through ACT?



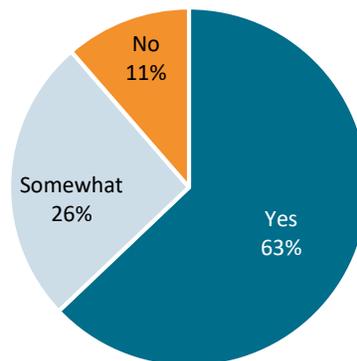
Ninety-three percent of survey respondents (1351 of 1447) indicated that they are either satisfied or very satisfied with access to services or resources provided by ACT (Fig. 4). Respondents reported the highest degree of satisfaction with the sense of safety/ confidentiality of ACT's programs and services (Fig. 5).

Fig. 5 - Satisfaction with ACT's Services
(Proportion of respondents who are "very satisfied" or "satisfied")



In addition, the majority of survey respondents (63%, 924 of 1469) indicated that ACT has contributed to their sense of connectedness within the larger autism community (Fig. 6). It is expected that greater community and social support is beneficial, and therefore that increasing the sense of connectedness improves the well-being of families and individuals living with autism.

Fig. 6 - Has ACT contributed to your sense of connectedness within the autism community?



(n=1469)



ONLINE ACCESSIBILITY

Many autism resources, programs, and services, are advertised, accessed, and delivered online. Most survey respondents (96%, 1308 of 1366) indicated that they are satisfied with the online accessibility of information about autism and related services through ACT's website (Fig. 7). In contrast, 43% of respondents reported being satisfied with MCFD's online accessibility.

Fig. 7 - Satisfaction with ACT Website

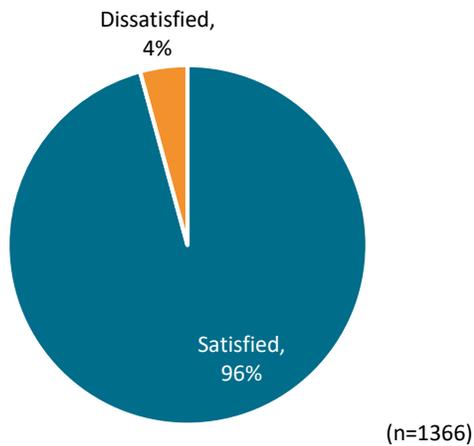
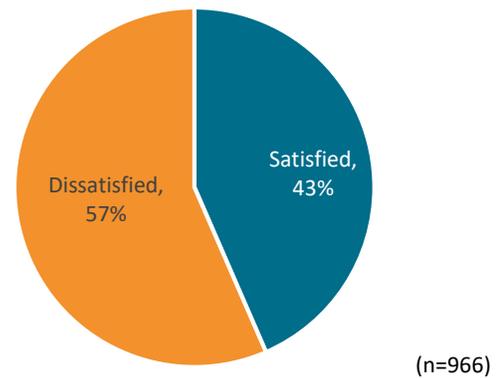


Fig. 8 - Satisfaction with MCFD Website



CONCLUSION

The survey results provide an understanding of the general preferences for the future of autism service delivery from the perspective of the autism community. Responses to the survey demonstrated that the majority of individuals with autism, their family members and caregivers, as well as the professionals/paraprofessionals who serve them would prefer to continue to access information and services through non-profit, community-based providers, such as ACT.

In particular, survey respondents expressed a high level of trust in ACT, as demonstrated by the proportion of respondents who would be comfortable contacting ACT versus the proportion who would be comfortable contacting MCFD when facing a challenge. Survey respondents also expressed a high level of satisfaction with current service delivery, and cited high satisfaction in their rationale for preferring information and services that are provided by community organizations.

RESPONDENT PROFILE

Survey respondents primarily represented family members/caregivers of individuals with autism (53%), professionals and paraprofessionals who support individuals with autism (39%), as well as self-advocates or individuals with autism (1%) (Fig. 9).

Of the professionals who responded to the survey, 38% (154 of 410) are listed in the Registry for Autism Service Providers (RASP). The survey was completed by individuals across the province with the Fraser Region accounting for the largest number of respondents (34%; 486 of 1415) followed by the Vancouver/Coastal Region (25%, 355 of 1415) (Fig. 10).

Fig. 9 - Primary Role of Respondents

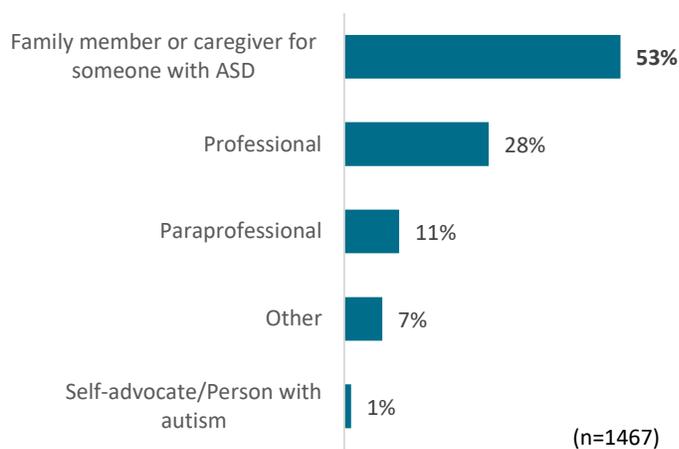
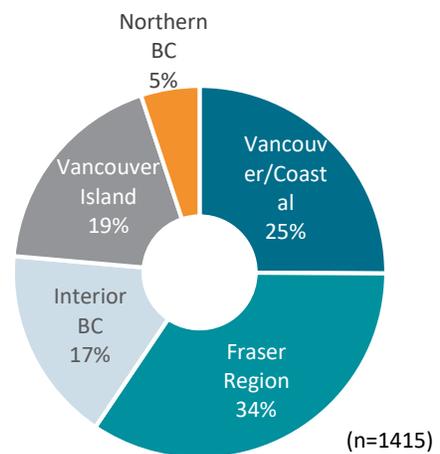


Fig. 10 - Location of Respondents



Survey respondents represent and care for individuals with autism of all ages (Fig. 11).

Fig. 11 - "I mostly support individuals with autism who are..."
(Respondents could select more than one option; totals do not equal 100%)

