aide
canada

Community Consultation Report
January 2019 – August 2020

Introduction

The Autism and Intellectual Disability Knowledge Exchange Network (AIDE Canada) was created to support individuals living with autism and/or intellectual disabilities and their families. AIDE Canada is a national network that helps people in the community we serve to find information that is important to them. Our goals are to improve access to needed information about autism and/or intellectual disabilities for people who live in different regions, who speak either of Canada's official languages, or who are faced with barriers to accessing information.

To achieve these goals, AIDE Canada went straight to the source. We asked the community what they needed and what they wanted to see. Because we wanted to get as much information from our community as possible, we made sure to ask questions in a few different ways and from different groups of people who care about autism and/or intellectual disability resources.

Between January of 2019, when we launched our organization, and September 2020, when we released the full version of our library and website, we held dozens of formal and informal meetings with groups, organizations and individuals. To keep this report focused, we have decided to highlight our 5 largest and/or most formal information gathering projects.

For each of the 5 information gathering projects within this report, we share "Who we spoke to and what we asked" and "What they told us". Following the overview of the top 5 projects is the final section, "How we are using this information". This section outlines the direct links from community consultation to three of our work areas: our on-line platform, our content creation plan, and our in-person library.

It is important to note that the conversation hasn't stopped with this report. AIDE Canada will continue listening to the autism and/or ID community to guide our future plans. It is critical that we continue to engage with the people we serve to build and maintain a strong relationship with our community, and to ensure we continue to provide them with the high quality, trusted resources.

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Community consultation

January 2019

Information needs of self-advocates and families focus groups and interviews

Who we spoke to and what we asked

In January 2019, AIDE Canada hosted several community conversations. We had focus group discussions and interviews with self-advocates and parents from the autism and/or intellectual disability community. Most of the people we spoke to were connected to community organizations including: Autism Calgary, Autism Edmonton, Autism Ontario, Autism Society of Newfoundland and Labrador, Autism Yukon, and the Family Support Institute of British Columbia.

We asked them what they saw as the gaps in current information and the needs and priorities for individuals and families. We also asked the group what principles should guide AIDE Canada's approach to information sharing.

What they told us

Different information gaps exist depending on the stage of a person's journey. The community members spoke about specific information gaps that exist concerning different age groups. For example, when thinking about young children, there are gaps in information about getting a diagnosis, the availably and evaluation of early intervention options, and funding. For slightly older children, there are gaps in information about navigating schools, seeking supports, social inclusion and integration, childcare, advocacy and health issues. We discussed the particular needs of all age groups as well as needs that are consistent across the lifespan. The focus groups also spoke about the difficulty of matching information or services to an exact age, as different people may have similar needs at different ages.

Regarding the principles that should guide AIDE Canada's approach to information sharing, the group said we should pay attention to the tone of the information including the way information communicates messages of respect for individuals and their human rights. They also advised us to consider the range of the materials we will offer in terms of offerings that range: across the lifespan, across different abilities, across languages and across cultures. They stressed the importance of person and family-centredness, accurate and trustworthy information, and the importance of information based on lived-experience.

February 2019

Knowledge and reflection core planning meeting

Who we spoke to and what we asked

In February 2019, AIDE Canada held a meeting with 18 thought leaders and experts from across Canada's autism and intellectual disability community. They included university professors, community organization executives, researchers, and medical experts. Their expertise represented many Canadian regions (Newfoundland, Quebec, Ontario, Alberta, British Columbia and the Yukon). The meeting took place in the form of a round table discussion.

We asked the group to about what principles should guide AIDE Canada in our work. Because the group included many subject matter experts, we also asked for advice around what topics the community in general would need information regarding.

What they told us

The top principles that the expert group urged us to adopt were evidence-informed information, promoting access to support for individuals and families in the autism and/or intellectual disability community, leveraging existing resources, and information sharing through a robust and user-friendly online platform.

The group also suggested specific considerations that should guide AIDE Canada's work going forward. They discussed the importance of different types of knowledge (i.e. lived experience, empirical knowledge, population-level knowledge, and expert knowledge). They suggested that AIDE Canada should adopt an approach that is person- and family-centred, such that it promotes choice and quality of life in addressing the information and support needs of individuals and families. They also suggested that AIDE Canada should work to focus on a full range of ages and regions, and target information to the end-user's needs.

The group discussed the collection and curation of information. They suggested that curation needs to incorporate a systematic and transparent process of vetting information, involving of a range of professional and community stakeholders. Information sharing is more than just considering the content to be shared. Proactive planning is needed to determine how information is identified, who informs it, and how it is conveyed to end users.

The group also discussed topics that the autism and/or intellectual disability community would like to see more of. They identified the following topics: diagnosis, social skills and play, behavioral supports, communication, family/community support, self-care, self-direction, agency and advocacy, home living, housing, community support, health, mental health, safety, social and leisure, education, vocation, livelihood, legal information, taxes and finances, social determinants of health, aging, and broader systems such as stigma, community capacity building, and cultural diversity.

Overall, the expert advisory group recommended that AIDE Canada review existing resources and leverage existing expertise, build advisory networks and partnerships; clarify processes for online architecture and curation of content (for example by organizing content around needs, and by developing a clear vetting process), and apply a lifespan approach with a narrative of hope.

May – July 2019

National survey on informational needs and priorities of Canadians related to autism and intellectual disabilities

Who we spoke to and what we asked

AIDE Canada conducted a national survey with the assistance of a third-party polling and survey firm. The survey went out to over 4,000 people across Canada from May to July 2019.

There were 742 respondents who qualified to complete the survey. These respondents met the following criteria:

- Had been diagnosed with Autism Spectrum Disorder (ASD); and/or,
- Had been diagnosed with Intellectual Disability (ID); and/or,
- Were an immediate family member of the above.

One third of the respondents were themselves a person with a diagnosis or ASD and/or ID. Over three quarters were immediate family members of someone diagnosed with ASD and/or an ID. Eighty one percent of the respondents advised that they themselves or someone in their immediate family being diagnosed with ASD and 52% identified themselves or an immediate family member as having been diagnosed with ID.

Among self-advocates, 65% were men, 29% women, and 6% self-identified as another gender. Among family members, 54% are men, 43% are women and 3% were another gender. Family members were a parent of someone under 18 (40%), a sibling (37%), and/or parent of someone over 18 (13%) who had a diagnosis of ASD or ID.

AIDE Canada used the categories suggested by our earlier focus groups. We asked the survey takers which topics were important to them and how easy it was for them to find information about these topics.

What they told us

While most of the respondents had some information about many autism/intellectual disability subject areas, they stated that they would like to receive more information on most of the subject areas. To find the highest priority topics, we compared how important a topic was to respondents against how easy it was for them to find information on that topic. The high priority topics identified by all respondents were mental health, health, social skills, self-care and behavioral supports.

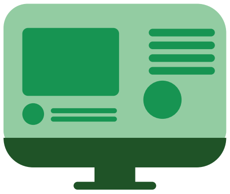
Health + mental health are the most important topics

Self-advocates found health (30%) and mental health (28%) to be the most important topics. They also gave high priority to education (20%) self-care (19%) and social skills (18%). For this group, the topics that were less important but harder to find information on were aging, legal information, taxes and finances.

Respondents between the ages 40-49 years indicated needing more information on all subject areas. About three-quarters among this age group reported needing more information related to livelihood and employment (78%), self-care (76%), and safety (75%).

For parents of a child under 18 years of age, education (26%) and behavioral supports (22%) were important subjects. For those caring for an adult 18 years and above, livelihood and employment (33%), self-care (26%) and self-direction and advocacy (26%) were also important subjects.

Ages 40-49
need more information



51%
Use the internet for information

Regarding sources for information about autism or intellectual disabilities, the majority of respondents use the internet (51%), followed by primary healthcare provider (34%), other healthcare providers (31%), and family and friends with similar experience (29%).

February – July 2020

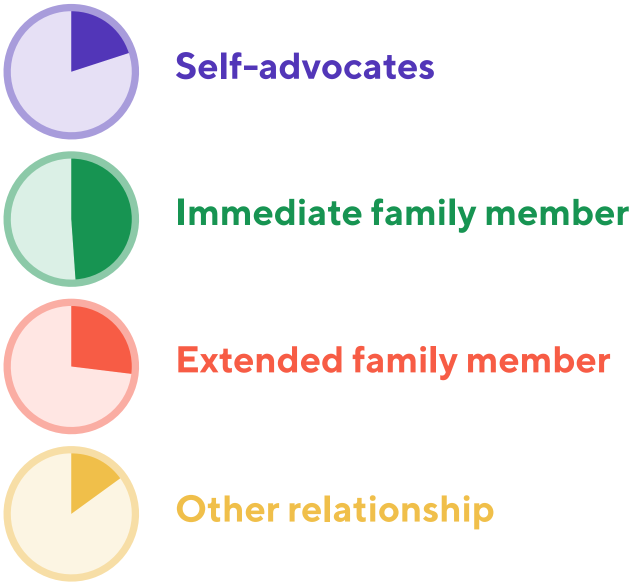
National survey on self-advocates and families' preferences of methods for conveying online information

Who we spoke to and what we asked

AIDE Canada conducted an internet-based survey with the assistance of a third-party polling and survey firm. The survey was posted from February to July 2020 in French and English. It was open to people who self-identified as autistic or as a person with autism and/or as having an intellectual disability. The survey was also open to people who were a family member or had another relationship with someone described above. Other relationships included were caregiver, advocate, healthcare provider, employee of a social service provider, friend, extended family member and social worker.

There were 469 Canadians who qualified to complete the survey:

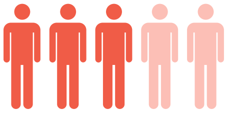
- 22% were self-advocates (that is they self-identified as autistic or as a person with autism or as having an intellectual disability);
- 49% were an immediate family member to someone with autism and/or an intellectual disability;
- 27% were an extended family member to someone with autism and/or an intellectual disability; and,
- 15% had another relationship to someone with autism and/or an intellectual disability.



Most respondents had a primary language of French (18%) or English (77%). The respondents were distributed across Canada, with about 40% coming from Ontario, 34% from Quebec, 16% from British Columbia and the territories, 8% from Alberta and the prairies, and 2% from Atlantic Canada.

We asked people about their preferred methods of receiving information about autism and/or intellectual disabilities, and what topic areas were most important to them. We used the categories of topics established in previous focus groups and surveys. We asked the respondents how they would like to receive different types of information, such as written materials, videos, educational equipment (i.e. games) and maps that displayed the location of different resources available.

What they told us



Say it's difficult to find information

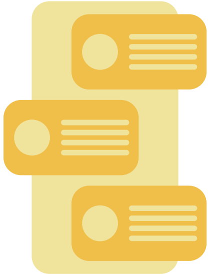
Three-in-five (54%) of respondents said it is difficult to find information related to developmental disabilities. Respondents said they need the most information about topics related to social skills, mental health, livelihood and employment. More than a quarter also need information about family support, self-care and education.

When it comes to preferences for how support organizations should share information such as written materials and videos, most prefer to receive information directly from the organization's website (72%). Some would like to receive information via e-mail (46%), and one fifth (20%) would like to access materials in-person, through the mail. Downloading information from the website was the most preferred option for all groups.

Regarding maps that display resources within the community, many (31%) said they would prefer having a list on AIDE Canada's website and/or for AIDE Canada to partner with other community organizations (19%). About one fifth (17%) advised they would like to be able to talk to a navigator who would assist in accessing this information. Over half (51%) said they would prefer for AIDE Canada to do all of the above.

72%
Check the organization's website

51%
Would prefer AIDE to manage all resources



55%
Want an online listing of equipment

Regarding educational equipment, parents who have a child or children with a developmental disability diagnosis, would prefer to have an online listing of the available equipment, with explanations of how to use the items and their anticipated benefits (55%) rather than physically going to a specific location to try out equipment (19%).

June 2020

Focus groups on stakeholder preferences for online content and ways to access information

Who we spoke to and what we asked

In June 2020, AIDE Canada hosted focus group sessions with individuals from Canada's autism and/or ID community. The 3 sessions were: a parent group (4 participants), a self-advocate group (6 participants), and a service provider group (5 participants). The individuals joined the meeting via video conferencing from across the country, including Yukon, Newfoundland, Nova Scotia, Quebec, Ontario, BC, and Alberta. We asked the focus groups in what format(s) they would prefer different kinds of information be presented, and what features those different formats should include.

What they told us

The prompts led the groups into robust, in-depth discussions. The different groups went into detail regarding what they would like to see from different types of information. For example, what features made a webinar or an infographic most helpful. While AIDE Canada did take note of all suggestions, only a portion of them are summarized here.

There were several common threads across groups. Participants appreciate information that is practical, brief, credible, and accessible. They also preferred information that was positive and sensitive to identity. All of the groups hoped that information could be filtered for different situations and audiences.

Parents

Parents highly valued information from trusted sources. They also noted that it was important to offering parents information to consider and apply on their own terms. One parent said, "You can't tell parents what to do or how to do it. They have to figure it out for themselves." Another parent noted that if they cannot quickly find what they are searching for, they may give up searching entirely. Parents liked the idea of having multiple levels of depth available for each topic.

Thinking of specific preferences for parents, they valued both research summaries and information from others' lived experiences. Parents advised that they would like to see information presented in different formats for different topics. For example, tax information might be best presented in an article, but education materials should be hands on like a game or application. Thinking about webinars, parents expressed preference for videos that could be watched at a later date, but also could be viewed live so that interaction and questions could be accommodated in real-time. Parents noted that families must be included as an audience for resources, including siblings; family needs should be considered in a holistic fashion.

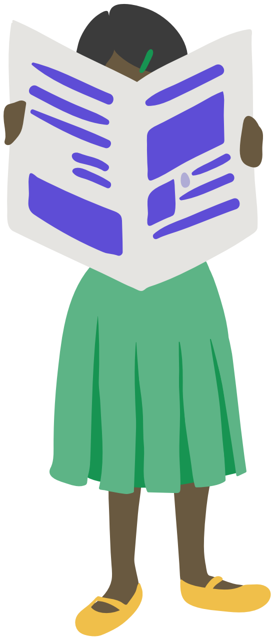
> **"You can't tell parents what to do or how to do it. They have to figure it out for themselves."**

Self-Advocates

Overall, self-advocates expressed a preference for information that is both clear and succinct. Self-advocates also wanted information to be practical in nature. Participants said the internet was most often where they searched for information on topics of interest and suggested it would be helpful if they could filter the information by relevance (i.e. age, region, etc.) Self-advocates also noted that information should be positive in tone and considerate of cultures, genders and other personal identities.

Regarding specific preferences for self-advocates, the group members expressed a preference for research-focused information over personal stories. If personal stories were shared, it was felt that they should convey a specific perspective or theme. Self-advocates appreciated clarity in language and participants preferred overviews over detailed, more lengthy accounts of information. Suggested reading lists were described as a preferred way of accessing more in-depth information. Self-advocates requested brief summaries, like infographics, and workflow charts instead of lengthy journal articles. For legal, tax, finance, self-direction, and advocacy information, participants preferred having an individual to present this information. They suggested that video presentation along with a transcript of the video, would be preferred for these specific topics. Corresponding visual aids and follow-up materials were encouraged.

Prefer clear + succinct information



Want hands-on + evidence-based information

Social Service Providers

Service providers wanted evidence-based information, with methods backed by professionals from trusted sources. They expressed a preference for hands-on information with personal stories from those with firsthand experiences. Participants noted that information should be presented in a respectful and hopeful way, with a sense of partnership and support being conveyed. Service providers noted that content should be uniquely tailored to each audience including those outside of the family, such as teachers or other professionals.

Service providers would like information available in multiple formats: “how to” printouts with action steps, videos with transcripts and closed captioning, firsthand experiences, written materials, flow charts and infographics. Service providers requested information written in simple language available in multiple languages. First-person video stories were also seen as helpful, as were webinars that offer a live question & answer session at the end. They also suggest that first-person narratives from people with lived experience are very helpful. Service providers also noted that connecting people together via webinars or live chat could be particularly helpful for isolated individuals, and those living in rural areas.

How we are using this information

We are extremely grateful for all of those who participated in our focus groups workshops and surveys. Their insights and advice have been instrumental in our work. This section of the report will outline the direct links from community consultation to three of our work areas: our on-line platform, our content creation plan, and our in-person library.

Learn

Locate

Connect

Borrow

On-line platform

The AIDE Canada on-line platform contains many features that were in express response to community preferences and requests. It has 4 main sections: Learn, Locate, Connect, and Borrow. All of our web platform applications allow users to filter information according to "Needs" and "Journey Stage".

The "Needs" filters are directly taken from the list of topics suggested by experts at the Knowledge and Reflection Core Planning Meeting as ranked by the community in the 2019 National Survey on Informational Needs and Priorities of Canadians related to ASD and IDs. These priority needs categories were later confirmed by the subsequent groups and survey. The needs filters include all of the priority topics (mental health, health, social skills, self-care and behavioral supports), along with other topics that community members indicated they valued.

All of the resources on the AIDE Canada platform can be filtered according to "Journey Stage". These filters are taken from the community's request for information to be searchable not just by age, but according to a person's unique situation. The Journey Stage filters are: Early Years, Diagnosis, Childhood, Transitioning to Adulthood, Adulthood, Seniors, and Across the Lifespan. By using these filters people can find the information that is most relevant for them.

The "Learn" section of the AIDE Canada platform contains a library of on-line resources such as articles, videos, courses, research summaries and infographics.

The "Locate" section of the platform contains a clickable resource map of programs available across Canada related to ASD and/or IDs. We took seriously the community's request regarding finding resources quickly. If a person were to search using Google, for example, the results are organization-based so the user must further search each organization's website to determine if it has relevant programs. That is why the resource map is searchable by program, rather than organization. Our community members can go to one map to search thousands of programs across Canada, and filter the results by location, need journey stage and program type.

The "Connect" section of the platform is where users can find a live on-line chat feature. This feature responds to the community request for assistance navigating the resources that was articulated through the focus groups and the surveys. Now community members can chat (via text, or computer audio or video) with AIDE Canada staff, from 9am Atlantic time to 5pm Pacific time every weekday. The connect section of the platform also hosts events listings that are searchable by keyword, need, journey stage and location.

The content development plan

Following the recommendations of the experts at the Knowledge and Reflection Core Planning Meeting, AIDE Canada assembled a team of experts with lived experience as self-advocates, family members and service providers as well as strong academic and project management backgrounds. This team worked together to create the content development plan. The plan elements include reviewing existing resources to and leveraging existing expertise. The plan is based on the priority of needs articulated by our community in the 2 national surveys and in the focus groups on stakeholder preferences for online content. The topics of the projects were selected to coordinate with the expressed priorities and delivery method preferences of the different intended audiences.

The 2020/21 content development plan includes over 70 projects. As requested by the community the format of each project is geared towards specific audiences, offer varying levels of depth on in different pieces about the same topic, and all projects will be vetted by persons with lived experience as well as by experts in subject matter.

The priority order of the projects was built on the priority order expressed by our community. AIDE Canada is working to contract with a wide range of authors from across Canada in order to build our networks and partnerships. In addition to content creation AIDE is also in the process of cataloguing all recent and publicly available information on autism and/or intellectual disabilities that is available from credible Canadian sources. In the coming year we will be working with these authors and organizations to bring their materials into the AIDE Canada on-line library so that our community members can access information more easily.

In-person library

AIDE heard through the surveys and feedback groups that if we focused only on on-line resources we would be leaving some people behind, particularly community members who live in remote areas without access to high-speed internet. With this in mind AIDE created a nation-wide lending library with over 3000 items. Our library includes books and DVDs. It also includes hands-on learning materials such as games and other educational tools that teach motor skills and language foundations. The library has 3 in-person locations; (Vancouver, Whitehorse, and Calgary) and accommodates low-bandwidth connections. Using the on-line catalogue, members of the library can request materials from anywhere in Canada. AIDE will ship the materials free of charge along with a pre-paid postage slip so that the items can be returned once our community members have finished using them.

Moving forward, AIDE will remain committed to ongoing input and guidance from our community. Understanding the wide range of individual, family and community needs and priorities is integral to our work.