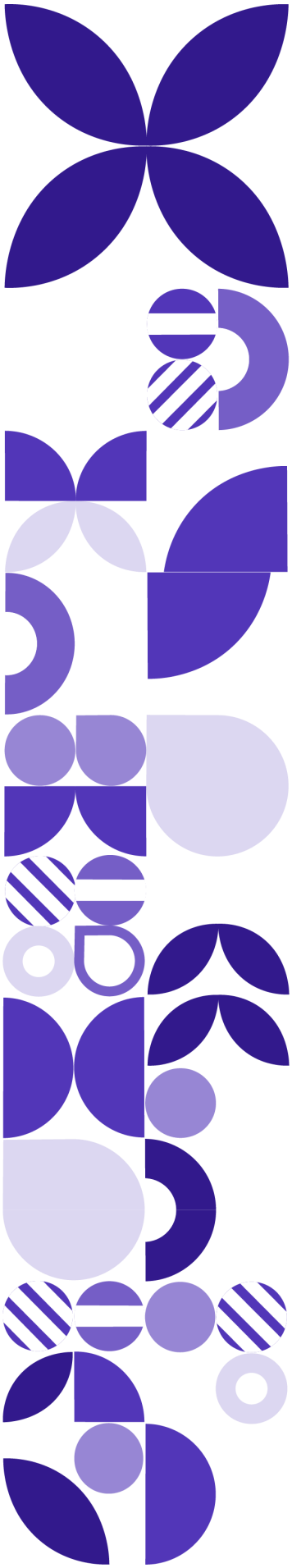
PROGRAM REPORT

JAN. 2019 — AUG. 2023

Funded by:

Public Health Agency of Canada
Agence de la santé publique du Canada

Administered by:
Pacific Autism Family Network



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Executive Summary

Delivering on Promises

The AIDE Canada mandate included 65 deliverables and objectives. They included:

- Develop and establish the AIDE Canada web platform (Completed September 2020)
- Create a free borrow-by-mail and on-line library for the autism and/ or intellectual disability community (Completed September 2020)
- Create a searchable database of Canadian autism and/or ID programs and services (Completed July 2020)
- Develop a cache of knowledge toolkits that address issues across the lifespan for the autism and/or intellectual disability community (ongoing, over 900 resources developed so far)

AIDE Canada has completed, or is on track to completing all deliverables and objectives.

AIDE Canada Resources by Type

5780 Books & library items

921 Articles, courses, and webinars

344 Peer Advice Videos

3274 Programs and services listed

Community Consultation and Evaluation

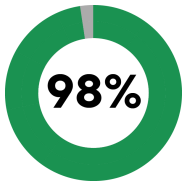
AIDE Canada conducted 17 community consultation and evaluations projects from 2019 to August 2023. The community consultation programs were key to developing AIDE Canada's content, website design, and guiding principles.

Before the AIDE Canada web platform was created:

- 54% of community members found it difficult to locate information related to autism and/ or intellectual disability
- 62% said that they needed more information on important topics.
- Most community members said they needed more information regarding mental health, employment, aging, social skills and other topics related to autism.

After the creation and development of the AIDE Canada web platform

- The website has attracted over 290,000 users and 1 million pageviews since its launch in September 2020.
- 98% of AIDE Canada website users surveyed say that AIDE Canada helped them in some way.
- Third party evaluators confirm that the resources AIDE Canada created respond to articulated community needs.



Say AIDE Canada is helpful

290,000 users

ONE MILLION pageviews

Supporting Equity Seeking Communities:

AIDE Canada worked with many communities within Canada to develop resources specifically to support some of our most vulnerable community members. Projects supporting equity-seeking communities include:

7 resources tailored to support autistic women and girls (viewed 1500 times)

22 resources designed to support individuals in rural and remote communities (viewed over 2700 times).

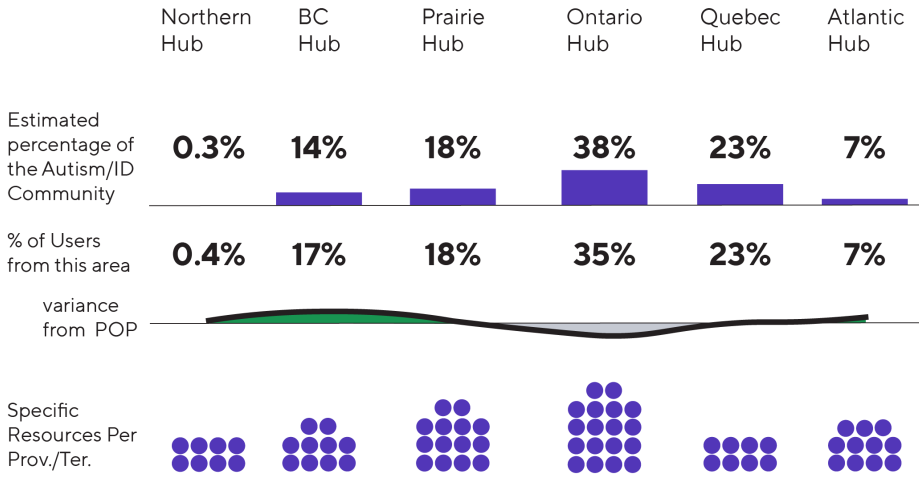
19 resources targeting non-speaking and minimally-speaking individuals who have intellectual disability (viewed over 11,000 times)

6 resources to support the autistic LGBTQ2S+ community (viewed over 1800 times).

7 resources created in partnership with indigenous community members to support their communities (viewed over 1900 times).

National Reach Through the AIDE Canada Hubs

The 6 AIDE Canada hubs are strategically located across Canada and play a pivotal role in our overall success and outreach. The hubs demonstrated unparalleled value by addressing region-specific inquiries through the online chat and developing resources for their communities. This has ensured that our resources are tailored to both regional and national needs.



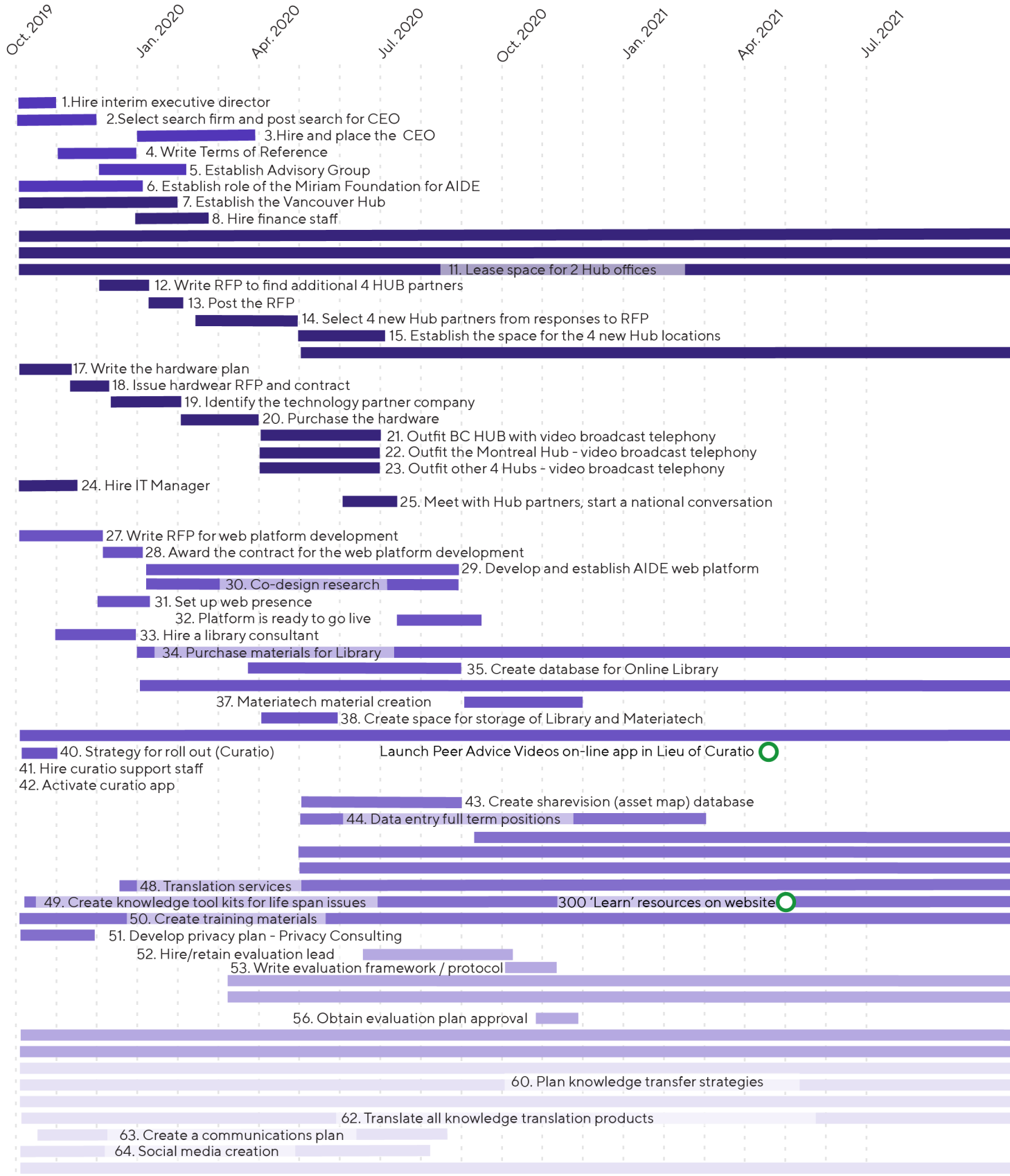
Next Steps

AIDE Canada community members expressed unreserved support for the work of AIDE Canada and the continuation of services including the borrow-by-mail library, and the on-line resources offered for free via the AIDE Canada web portal.

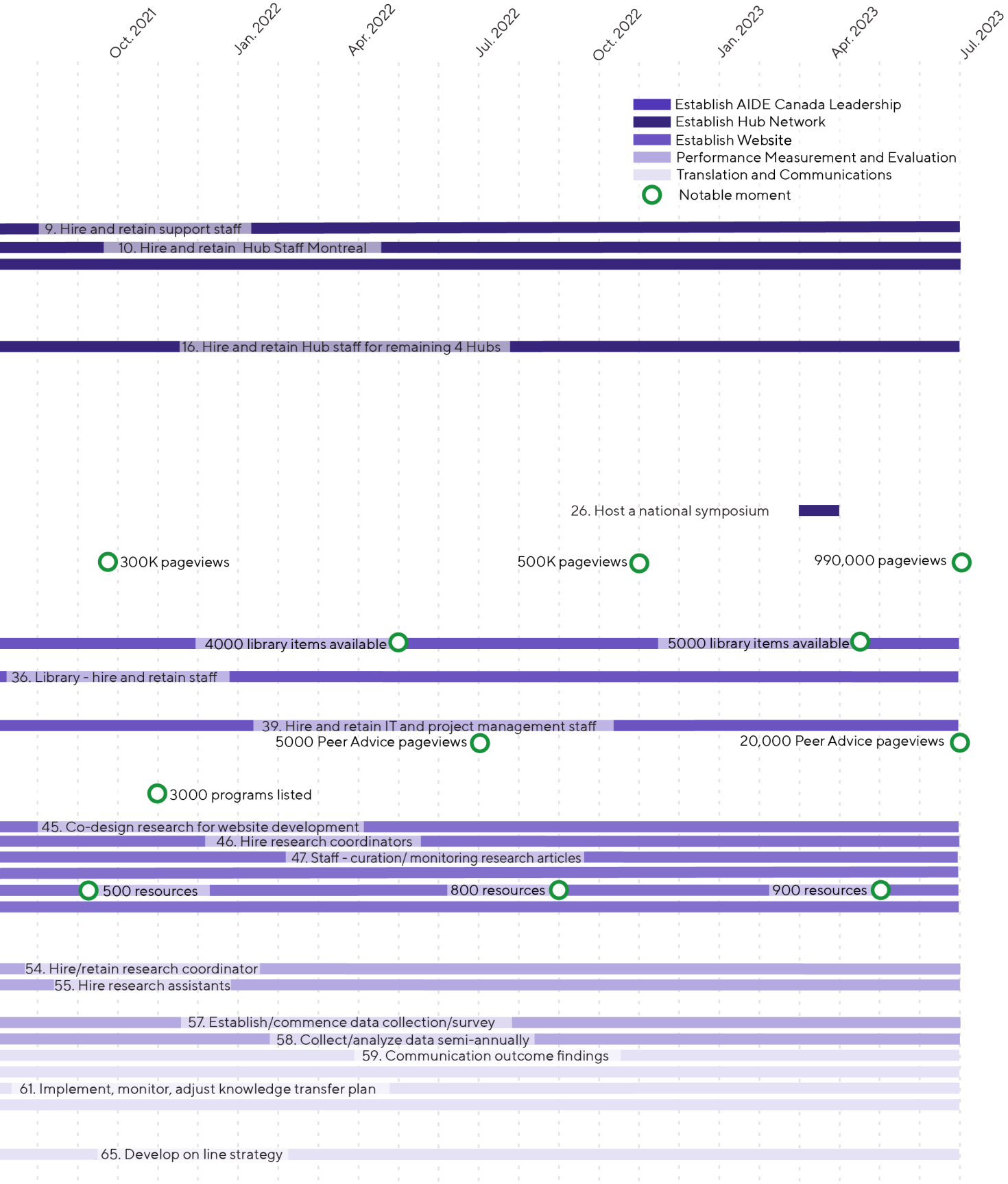
In a national poll, 95% of Autism Community members and 86% of Canadians overall agreed that training more teachers, police officers, doctors and other professionals on working with autistic people will benefit the autism and ID community.

As AIDE Canada looks forward to the next 5 years, our goal is to expand our offerings for professionals and service providers interacting with the autism and/or intellectual disability community.

Delivering on Promises



The AIDE Canada mandate included 65 deliverables and objectives. Take a glance at how we delivered on our promises over the first 4 years. And we are still delivering! Our 22 ongoing objectives are all on track.

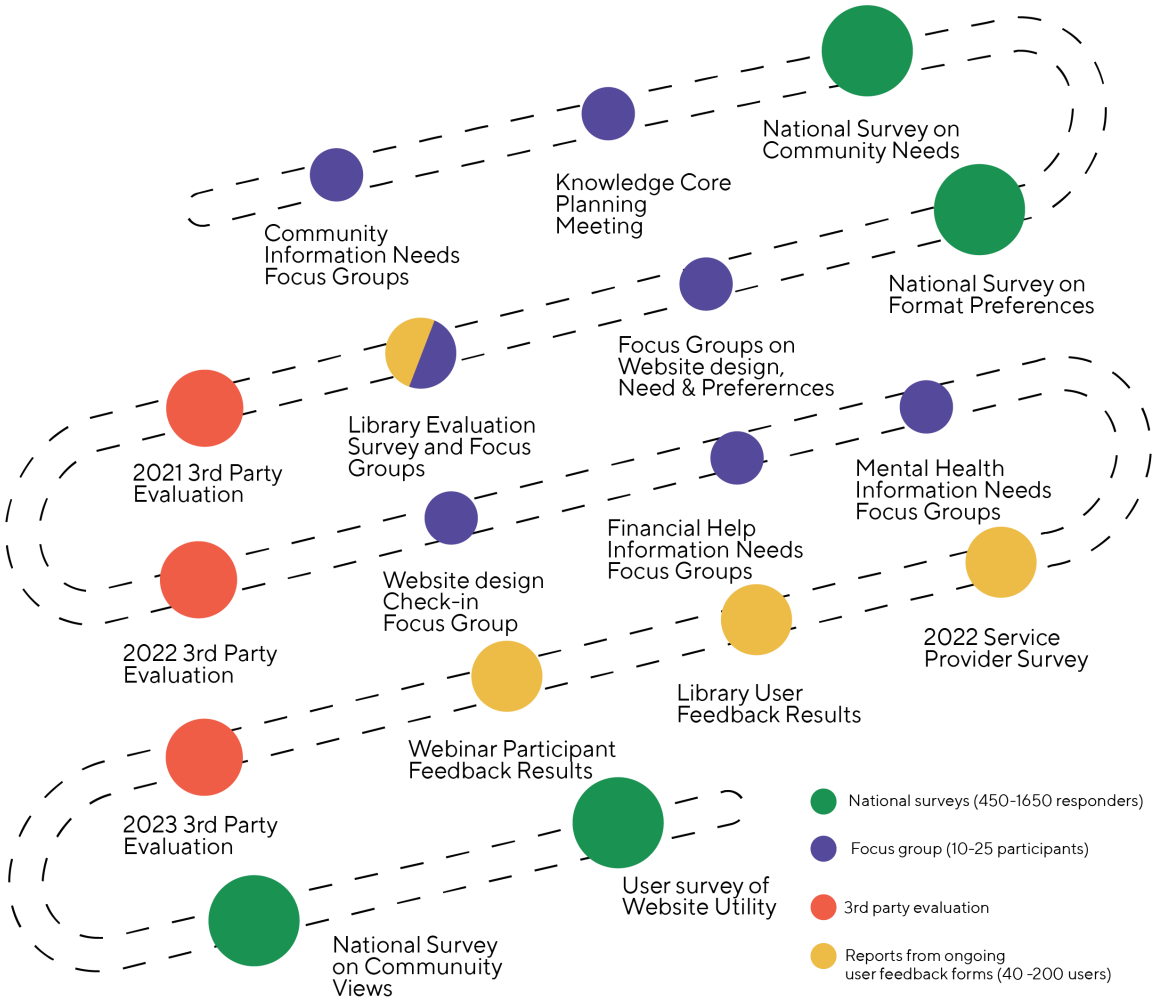


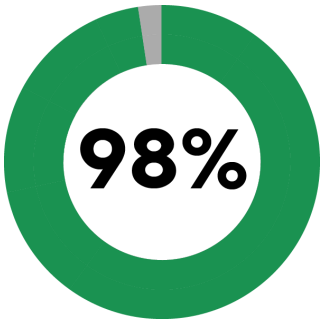
Community Consultation and Evaluation At a Glance

From 2019 to 2023 AIDE Canada conducted 17 community consultation and evaluation projects. These included: national surveys by our own staff, national surveys run by third party polling companies, focus groups run by our own staff, focus groups run by third party evaluators, user feedback forms collected after community members participated in webinars, and community feedback forms from library users. For most of these projects we asked, among other things, the following three questions:

1. Did AIDE Canada help you increase your skills and knowledge about autism and/or intellectual disability?
2. Did AIDE Canada contribute to your well being?
3. Did AIDE Canada help increase protective factors, like your ability to make more informed decisions, increased knowledge about programs or services?

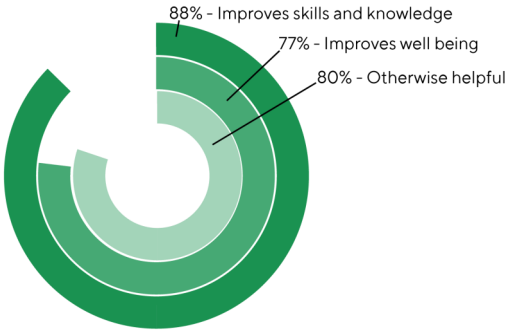
The overwhelming answer to all of these questions was **"Yes, the AIDE Canada site helped me"**. The following pages delve into the individual evaluation projects, but here you can see the aggregate results across all surveys.





98% Say AIDE Canada is Helpful

In surveys involving 1264 AIDE Canada website users, 98% said that AIDE Canada was helpful in some way.



How AIDE Canada Helps

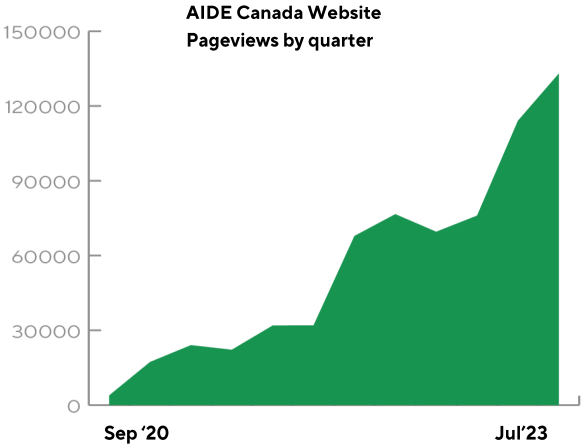
Users of the website who took surveys said that AIDE Canada was helpful in a variety of ways; 88% agreed that AIDE Canada increases skills and knowledge about autism and/or intellectual disability, 77% said we helped to improve their well being, and 80% agreed that we improved one or more protective factors for the autism and/or intellectual disability community.

Listening To the Community

A core tenet of the AIDE Canada project has been the integration of voices from the autism and/or intellectual disability community at every conceivable stage. Recognizing the intrinsic value and importance of firsthand perspectives, we proactively initiated community consultations that spanned an array of critical decision-making areas. From establishing the guiding principles (See pg. 11) to refining website design and all the way to content development, these consultations played a pivotal role in shaping the project's trajectory.

Throughout, our initiative has greatly benefitted from the internal diversity of our team. Approximately one-third of our staff identify as autistic, and an additional 25% are immediate family members of autistic individuals and/or those with intellectual disability. This unique composition ensured that the insights and experiences from the autism community weren't just taken into consideration—they were lived, felt, and deeply understood, leading to a project that was genuinely rooted in the community it aimed to serve.

Demonstrating Results



AIDE Canada Resources by Type

5780 Books & library items

921 Articles, courses,

344 Peer Advice Videos

290,000 users

and

1 MILLION pageviews

January 2019

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

Who We Spoke To

In January 2019, AIDE Canada launched community discussions to address information gaps in the autism and/or intellectual disability community. We engaged self-advocates, parents, and notable organizations such as Autism Calgary, Autism Ontario, the Autism Society of Newfoundland and Labrador, Autism Yukon, and the Family Support Institute of British Columbia.

What They Told Us

Gaps for young children:

- How to get a diagnosis
- How to find early services

Gaps for older children:

- How navigate school
- How to find supports

Gaps for adults and seniors:

- Human rights information
- Life skills and self-care

Community members told us different information gaps exist depending on the stage of a person's journey. For example, for young children, there are gaps in information about getting a diagnosis, the availability and evaluation of early intervention options, and funding. We discussed the particular needs of various age groups as well as needs that are consistent across the lifespan. Individuals 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 way information communicates messages of respect for individuals and their human rights. They also advised us to consider the range of the materials: across different abilities, languages, cultures, and across the lifespan. They stressed the importance of person and family-centredness, accurate and trustworthy information, and the importance of information based on lived experience.

Some of Our Responses

Toolkits on getting a diagnosis and finding funding for every province and territory

Searchable map with over 3000 programs can be filtered by age and need

97 resources on inclusion in school, work, and play cover every life stage

February 2019

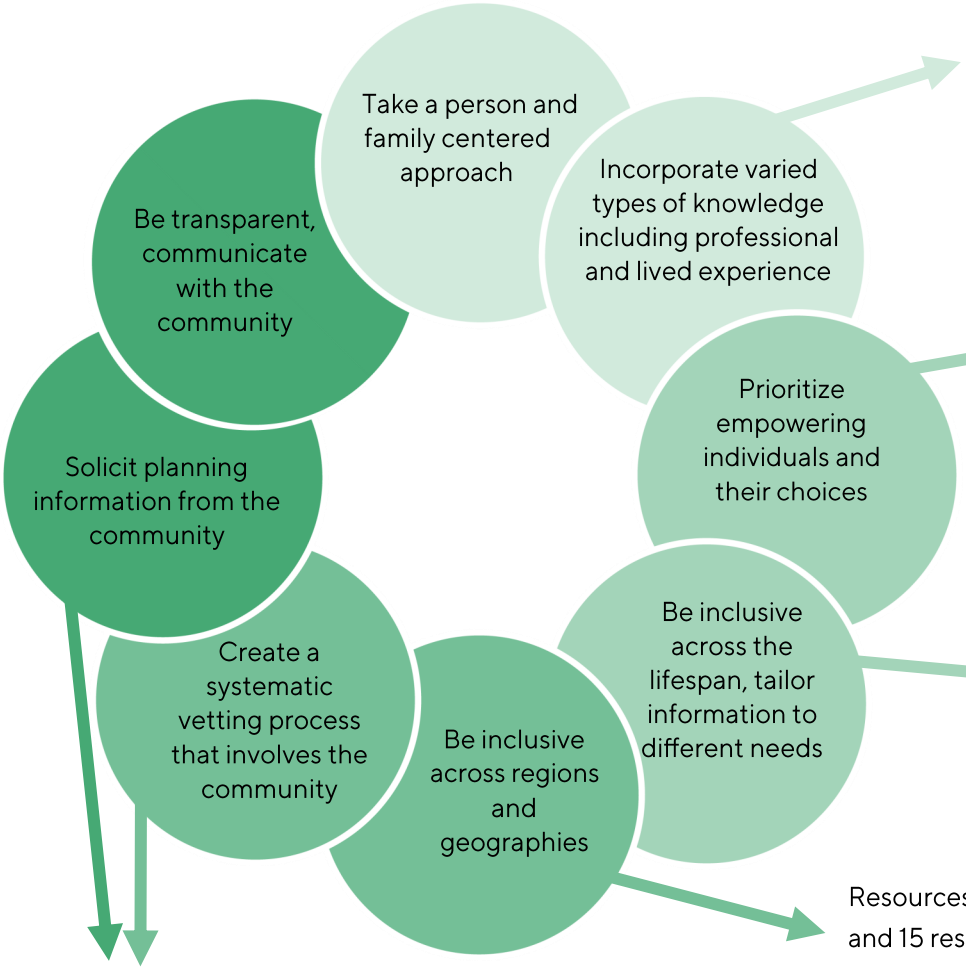
Knowledge and reflection core planning meeting

Who We Spoke To

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 leaders, researchers, and health and social service 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 about what principles should guide AIDE Canada in our work. We also asked for advice about what topics and information would be most valuable to the community.

What they told us:

Some of Our Responses



456 resources available with autistic authors or contributors, additional resources by doctors and other professionals

4 toolkits and videos on making your own decisions, and empowering your children

Resources for every journey stage, **see pg. 27!**

Resources for every Canadian region, and 15 resources focused on rural and remote communities. **see pg. 35!**

Content development based on community input, process posted online. Every resource is reviewed by a self-advocate or parent before publication.

May—July 2019

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

Who We Spoke To

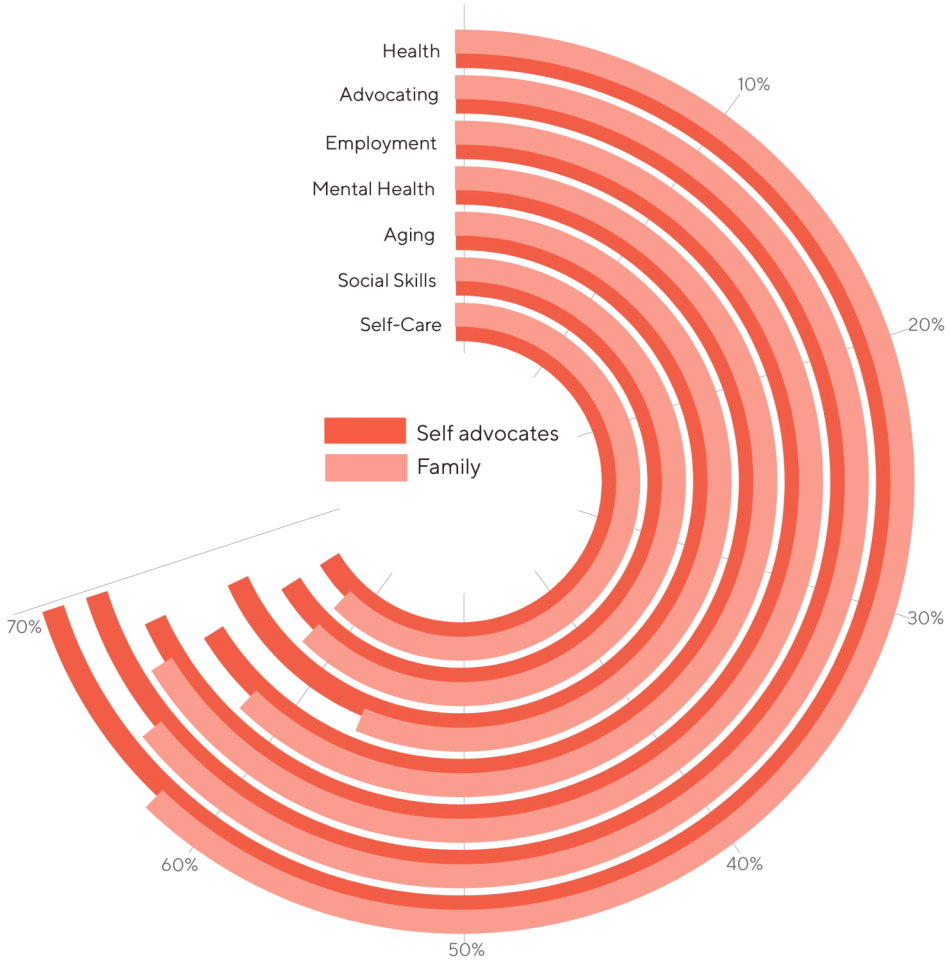
AIDE Canada conducted a national survey with the assistance of a third-party polling firm. There were 742 respondents who qualified to complete the survey. That is, they had been diagnosed with Autism and/or an intellectual disability (ID); and/or, were an immediate family members.

One third of the respondents were themselves autistic or had an intellectual disability. Over three quarters were immediate family members.

What They Told Us

While most of the respondents had some information about many autism/intellectual disability subject areas, most stated that they would like to receive more information on most of the subject areas. On average, **62% of individuals in the community said that they needed more information.** The high priority topics identified by all respondents were mental health, health, social skills, and self-care and advocating for yourself or others. The graph on the right shows what percentage of self-advocates and family members felt there was a gap in information on the high priority topics. For the most important topics between 70% and 62% of respondents felt they needed more information.

Percentage of community members who felt they needed more information on their highest priority topics



Some of Our Responses

Health	Advocating	Employment	Mental Health	Social Skills	Self-Care
202 resources created	**252** resources created	**152** resources created	**230** resources created	**229** resources created	**53** resources created

February —July 2020

National survey on self-advocate and family preferences for online information

Who We Spoke To

AIDE Canada conducted an internet-based survey in collaboration with a third-party polling firm. The survey was completed by 469 Canadians who spoke French (18%) or English (77%). They were self-advocates (22%), their immediate family members (49%), extended family members (27%), and friends (15%).

What They Told Us

Over half of respondents said it was difficult to find information related to autism and intellectual disability. 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.

Over half (51%) said they would like AIDE Canada to develop:

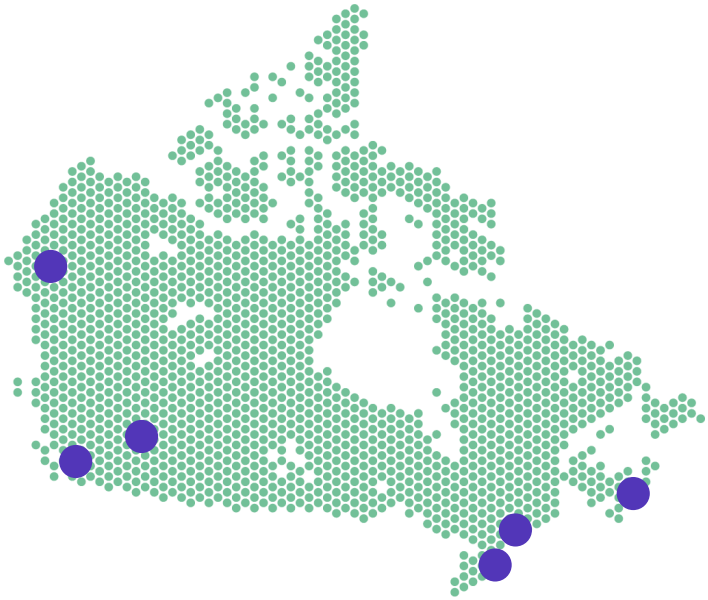
- A list of available community resources in their area, and
- A chat line to assist with finding resources

Difficulty Finding Information: Respondents said they needed the most information about topics related to social skills, mental health, and employment. More than a quarter also need information about family support, self-care, and education, **54% found it difficult to locate information related to autism and/or intellectual disability.**

Some of Our Responses

The AIDE Canada Connection Centre:

- Chat online with a live AIDE Canada staff member
- Communicate in English or French using text or voice call
- Available 12 hours per day from 9am Atlantic to 5pm Pacific
- Local representatives across the country



July 2020

Community Focus Groups

Who We Spoke To

In June 2020, AIDE Canada hosted focus group sessions help shape the development of our content so that resources were formated and targeted to the diverse perspectives of our community. The virtual focus groups included parents, self-advocates, and service providers from the Yukon to Newfoundland. Participants discussed how different types of information should be presented and what features would enhance AIDE Canada's work. In total we spoke to 25 community members across 4 sessions.

What They Told Us

Key insights from the discussions painted a clear picture of community preferences.

Guiding Principles

There was a universal desire for practical and concise information. Participants sought actionable insights that could be seamlessly integrated into daily life. Also across the board, accuracy and trustworthiness were paramount. Accessibility was also key, participants expressed their preferences for clear language, visual aids, and user-friendly formats.

Advice From Parents

Parents stressed the uniqueness of their parenting journey, desiring guidance that respects their autonomy. While guidance was valued, parents sought resources that provide insights to navigate their individual paths. Parents also requested different levels of depth, so that materials could be consumed at a glance, or in depth as time and need permitted.

Parents highlighted the need for adaptability and suggested that the formats should be tailored to the content. For example, parents suggested that webinars would be useful on topics that required real-time engagement, like taxes and finances.

Parents noted that resources should cater to the entire family, considering not only caregivers but also siblings and holistic family needs.

Advice From Self-Advocates

AIDE Canada's commitment to empowering self-advocates within the autism and/or intellectual disability community thrived through focus group engagement.

Self-Advocates endorsed the need for practical, concise information. They also expressed a desire to filter content based on relevance to their individual needs. Self-advocates suggested that respect for individuals and for first voice perspectives was essential. They expressed a preference for visual aids like infographics.

Advice From Service Providers

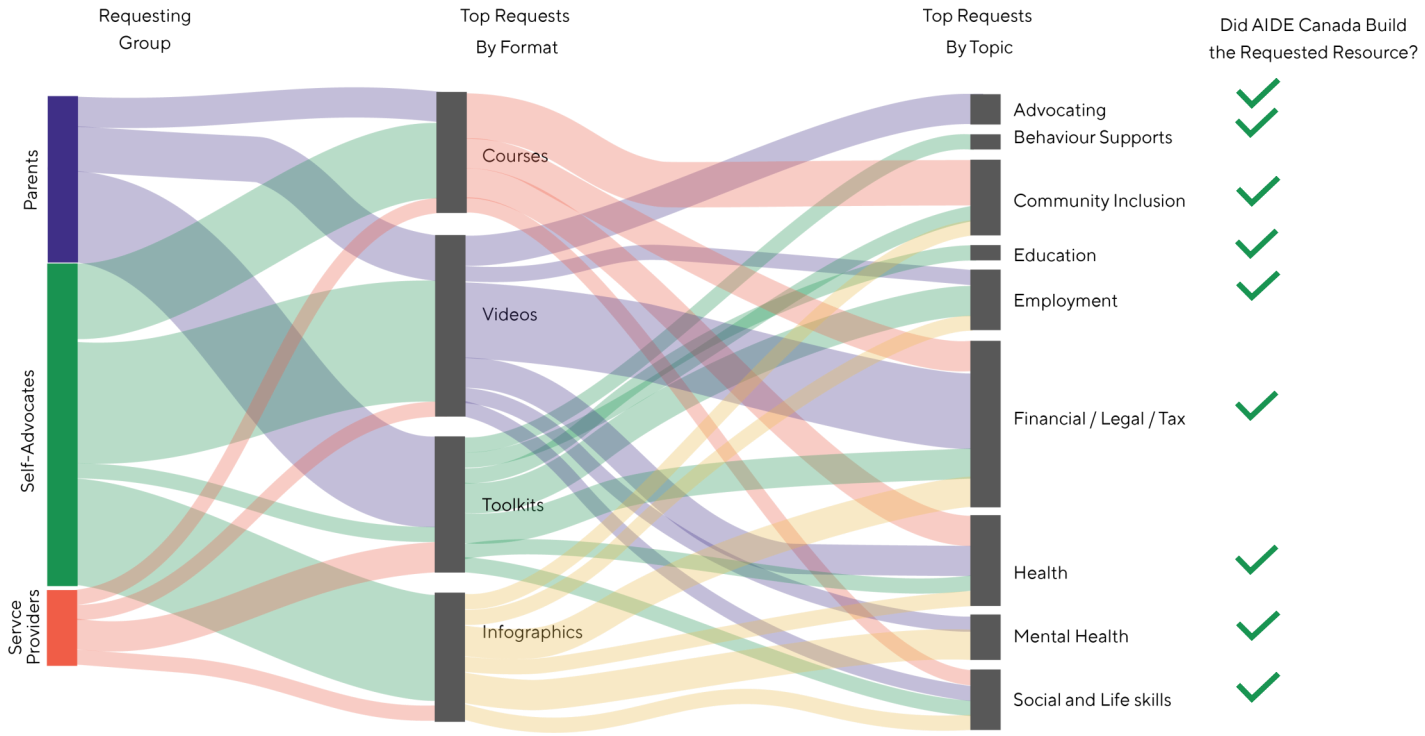
Service providers suggested that content should be evidence-based and rooted in expertise and also valuing the power of human stories.

Service providers stressed fostering a sense of partnership in interactions to create a collaborative environment that uplifts individuals. They suggested that a wide rang of formats would be helpful, videos, articles, and infographics. They noted the importance of inclusivity and accessible language options across languages. Service providers expressed a preference for first-person video stories and interactive webinars, particularly in rural areas to overcome social isolation.

A Path Towards Empowerment

AIDE Canada's focus group sessions were a key step in the development of the AIDE Canda content. The insights gained paved the way for resources rooted the community's expressed needs.

Our Response



January 2021

Library Evaluation Survey and Focus Groups

Who We Spoke To

In January 2021 we spoke to 41 community members about our library. The participants were all new to the Library, and self identified as either : autistic (19%), a person with intellectual disability (2%), parents or guardians in our community (50%), and service providers (36%). Members of the group were from BC Alberta, Ontario, the Maritimes, and Quebec.

What They Told Us

A strong majority of the group (93%) said that they were more likely than not to borrow a book from the library in the future. A Strong majority (76%) said the library was very relevant to their needs and interests.

The self-advocate focus group agreed that the library is a needed resource in Canada, in particular because public libraries and other sources of information often do not have accessible autism and intellectual disability-focused materials.

Participants in the parent and service provider focus groups also described the library as an important resource for the community. One service provider described the library as **"a tremendous gift"** to individuals and families in the community.

February 2021

Third Party Evaluation

Who We Spoke To

In the fall of 2020 AIDE Canada contracted with a third party evaluation team to conduct an independent evaluation of our work. The evaluators reviewed the content of our website and spoke to members of the autism and/or intellectual disability community. The goal was to determine whether what we created was consistent with the feedback and preferences articulated by our community. The evaluation took place from November 2020 to February 2021.

What They Told Us

Parent and Caregiver Impressions

The 3rd party evaluators reported that most parents and caregivers agreed the website is easy to navigate. They generally found the site well laid out and clear. Most agreed that AIDE Canada's website provides useful information and generally responded to their needs.

Most parents and caregivers agreed that the website helped improve their knowledge and skills, and most spoke enthusiastically about it. The majority of them said that they would return to the website to learn more from it. Most believed that using the website had helped improve their well being and/or that of their child. A majority also felt that having information and learning about their child's condition was very important in understanding how to support their child.

Self-Advocate Impressions

The 3rd party evaluators reported that self-advocates in the autism community felt it was easy to find things on AIDE Canada's website. They said the information offered was easy to understand and the language used was appropriate. The self-advocates liked the *Learn* and *Borrow* functions best and were interested in webinars and courses as well as toolkits and other resources.

The self-advocates advised that they enjoyed the ability to search by topic and journey stage. One self-advocate commented that the library:

> **"Looks fun and the books are really specific to people with disabilities, how to help and teach them. Public libraries tend not to have such books."**
>
> - Autistic-self advocate

Most importantly, the 3rd party evaluators reported that the self-advocates not only felt that the information on AIDE Canada's website improved their skills and knowledge but also that it improved their well being. The evaluators wrote:

> **"They seemed to all agree that knowing more about autism builds their self-confidence and helps them acquire confidence in how to do things, the right way to approach people and problems, and how to live their lives more fully".**
>
> - Dandurand, Chin and Associates

June 2021

Focus Group on Mental Health Information Resources

MENTAL HEALTH FOCUS GROUP—JUNE 2021

In June of 2021, AIDE Canada and Partner Hub Autism Ontario conducted a set of 3 focus groups with the purpose of determining what mental health resources would be most beneficial to our community. Twelve individuals participated in the focus groups, which included autistic individuals (5), parents (4), and mental health service providers (3). All three groups spoke to the importance of being able to trust an organization and the resources it promotes, with self-advocates having a strong preference for organizations that have neurodivergent individuals on staff and in leadership positions. The most requested resources were around the topics of trauma, sexual violence, and PTSD, all of which occur at a higher frequency for individuals on the autism spectrum compared to the general population.

Some of Our Responses

TOOLKIT

Neurodivergence and Post-traumatic Stress Disorder from Sexual Assault: A Toolkit for Moving Forward

OVERVIEW

An Introductory Overview of Some Mental Health Challenges and their 'Co-Occurrence' with Autism

TOOLKIT

Autistic Burnout Prevention and Recovery Strategies

RESEARCH SUMMARY

Improving Access to Mental Health Resources in Rural and Remote Regions

VIDEO

Building Resilience, Self-Esteem and Confidence to Support Well-Being

TOOLKIT

Developing Self-Esteem in Teens and Young Adults

June 2021

Focus Group on Financial Information Resources

In July of 2021, AIDE Partner Hub Autism Calgary conducted a set of 2 focus groups with the purpose of determining what financial, legal and tax resources would be most beneficial to our community. Autistic individuals, parents, and service providers from both urban and rural communities participated. There were many pressing questions about trustee and guardianship, human rights, avoiding fraud, and accessing government disability programs and tax credits. Autistic adults were particularly interested in more information about human rights and wanted to hear information from autistic professionals.

Some of Our Responses

AIDE Canada and Autism Calgary partnered to create a series of new resources on finances and taxes for the Autism and/or Intellectual Disability community. These resources are highlighted on **page 43 of this report!**

TOOLKIT

A Guide To Understanding Finances for Adults Who Have Siblings with Disabilities

VIDEO

Estate Planning for People with Disabilities & Their Families

INFOGRAPHIC

The Disability Tax Credit Infographic

January 2022

Website Design Focus Groups

Community consultation on website design was instrumental in the initial design of our website when it launched in September of 2020. Since that time several features and resources have been added to the site. Therefore we hosted an updated series of focus groups and one-on-one interviews in December of 2021 and February of 2022. We consulted self-advocates (6), parents (4) and service providers (5), asking them about the look and feel of our site.

Almost all participants advised that they found the website helpful and easy to navigate. The Peer Advice Videos, Locate Map and the Library were among the most popular resources. Some participants were able to give us valuable insights on how to improve the look and feel of the website.

Our Response

We incorporated the suggestions and preferences into a redesign of the AIDE Canada site that was launched in the autumn of 2022.

January - March 2022

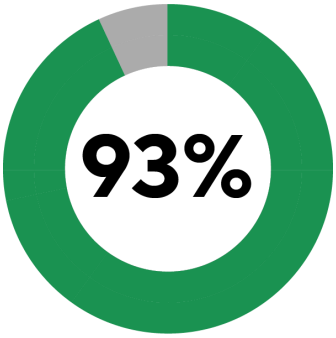
Partner and Service Provider Survey

Who We Spoke To

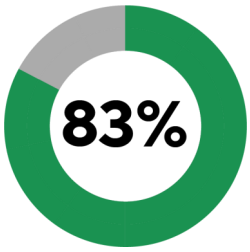
From January to March 2022, AIDE Canada hosted an online Survey for service providers from the autism and/or intellectual disability community. We received 185 responses from individuals representing 109 different Canadian autism/ID organizations. All of the respondents were service providers. Respondents also had the opportunity to identify as autistic individuals (13), individuals with intellectual disability (7) parents or caregivers (29) or immediate family members (52). Their responses indicate how AIDE Canada is succeeding when it comes to increasing community capacity.

109

different Canadian autism and/or intellectual disability service providers.



93% of surveyed users said AIDE Canada helped them give better support to the community



83% of surveyed users said AIDE Canada helped to increase their own knowledge and skills

What They Told Us

"Quite impressed with your website and all that AIDE Canada does to support folks with Autism and/or ID".

– Educator at Saanich BC School District

"AIDE appears to be a really well thought out initiative. I really like how it has a lifespan approach and incorporates the voices of autistic individuals and their loved ones. The lending library has a wide selection of books. I think the site does a really good job translating complex scientific research into accessible content. Well done!"

- Service Provider at Dori Zener & Associates

"Your lending library and online courses are fantastic."

- Self-employed Education Assistant

"I appreciate the fact that AIDE is applicable to all in Canada and beyond - no matter where one resides. This is a wonderful resource to Canadians!"

- Researcher at the University of Calgary

February 2022

Third Party Evaluation

During the 2021/22 fiscal year AIDE Canada engaged a third party organization to review its website and ensure that the services provided through the platform are responsive to the evolving needs of its users. The same firm was engaged to examine the process through which AIDE Canada identified priorities for content development. They were asked to determine whether AIDE Canada consulted with prospective users, as how well we tracked and managed of projects.

Substantive Analysis

The auditors looked at several key factors for a substantive analysis of the AIDE Canada website. These included language balance, balance by types of users, types of knowledge products, cultural relevance, gender balance, and reliability of evidence as a basis of information. The auditors noted: "Our own review of some of the more recently developed resources (including webinars) developed or commissioned by AIDE Canada persuaded us that they had been well planned and submitted to careful and meticulous review, and continued to be of outstanding quality".

"There have been regular and meaningful consultations with users since [the previous] review to genuinely obtain the views and feedback of a range of users, as well as a real effort to implement the suggestions and ideas that users shared with the organization"

- Dandurand, Chin and Associates

Community Responses

Eighteen community members were interviewed one-on-one by the auditors. They were autistic self advocates (11), parents (5) and service providers (8). During the consultation, users were asked to comment on the overall usefulness of AIDE Canada's web platform. They were also asked whether the website helped them improve their knowledge and skills and improved their wellbeing. According to the auditors: "the responses were uniformly positive and on the whole interviewees were very pleased with the content and relevance of the information available on the website".

The Peer Advice videos under the *Connect* function were extremely popular and all the self -advocates interviewed felt they were relevant and very informative. The auditors noted that: "During the initial review, overall users felt that the information on the website was trustworthy and reliable. During the current review, this general perception still held true for everyone who was interviewed".

Community stakeholders expressed an interest in receiving even more materials developed by AIDE Canada. The topics they suggested and their insights into the web platform informed the content development plan.

September 2020 - July 2023

Webinar Participant Feedback

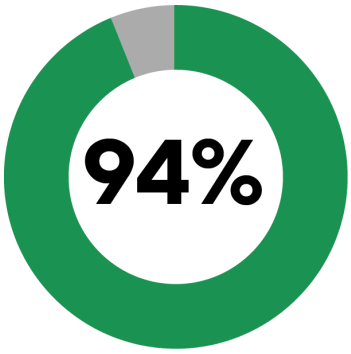
Who We Spoke To

AIDE Canada's commitment to disseminating valuable information and fostering inclusive dialogue was exemplified through its robust series of webinars. A total of 78 webinars have been meticulously curated so far, each addressing a diverse range of topics with varying target audiences in mind. Collectively, these webinars have attracted an impressive 9,753 pageviews, evidencing their widespread appeal and impact.

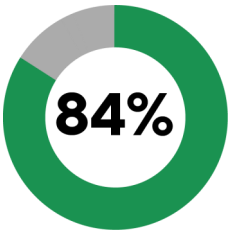
Particularly notable was the resonance of topics like Autistic Burnout, the journey to getting a diagnosis, comprehensive estate planning for individuals with disabilities, and indispensable strategies for supporting children in geographically remote areas. The breadth of topics ensured that the webinars were not just universally relevant but also specifically tailored, as reflected in the audience demographics: 53% were parents and family members, 33% were service providers, and a significant 14% were self-advocates. This vast outreach underscores AIDE Canada's dedication to engaging and empowering every stakeholder within the autism and/or intellectual disability community.

After each webinar, participants were invited to take a survey about their experience.

What They Told Us



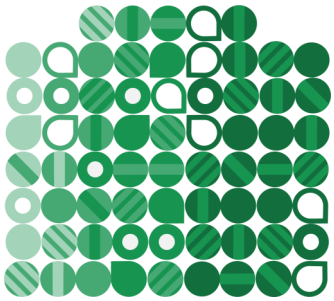
94% of surveyed users said the webinar was helpful



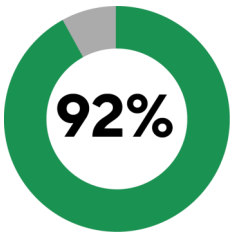
84% said the webinar improved their sense of well being

"This is a wonderful resource, I'll be sure to pass it along to folks who would benefit from it, thanks so much!"

- Kaleidoscope Help Group



77 Webinars



92% said the webinar improved their skills and knowledge

We're so impressed with the level of neurodiverse-affirming content, the inclusion and prioritisation of Autistic voices and the conscious effort to eliminate ableism in your content.

- Kimberly M., Service Provider

September 2020 - July 2023

Library Users Feedback Forms

Who We Spoke To

The AIDE Canada Library stands as a testament to our unwavering dedication to knowledge dissemination and community support. Boasting a rich collection of over 5,000 items all related to autism and/or intellectual disability, the library offers a plethora of resources that community members can borrow without incurring any cost. Since its inception in September 2020, the library's significance has resonated widely, amassing 1,304 members and facilitating the lending of more than 4,000 items. Notably, our member base is geographically diverse, representing every region of Canada. A heartening observation has been the library's soaring popularity among individuals in rural and remote communities, underscoring its role as a beacon of information and support in areas where such resources might be scant. We deeply value feedback and continually aim to refine our offerings. As such, every user of the library is encouraged to fill out a feedback form, the results of which are shown below. This iterative approach ensures that AIDE Canada Library remains in tune with the evolving needs of its vast community.

What They Told Us

"This is the most wonderful resource! So glad I found it!!"

- Mary M.

"Thank you for providing this wonderful service. Nice to see information that is inclusive of the Autistic Perspective "

- Debra R.

100% of surveyed users said the Library was helpful in some way

"I feel like I won the Autism lottery coming here! "

- Library Member

Reading these books has increased my knowledge and has lessened the stress for [my daughter] and our family. Thank you!

- Rena F.

It's AMAZING! I'm an SLP and have shared it with so many clients already.

- Library Member

August 2023

National Survey on the Utility of Autism and ID-focused resources

In August 2023, through a national polling organization, AIDE Canada commissioned a national poll specifically focusing on evaluating the perceived impact and effectiveness of our initiatives within the both the autism and/or intellectual disability community and in the general population of Canada overall. 1604 individuals participated giving a national margin of error at 2.5%. We are proud of and excited by the informative results that emerged.

Who We Spoke To:

What They Told Us:

"Training more teachers, police officers, doctors and other professionals on working with autistic people will benefit the autism and ID community." **95% of Autism Community and 86% of Canadians overall agree**

"A free borrow-by-mail and online library service for those in the autism and ID community is beneficial service for this community." **93% of Autism Community and 83% of Canadians overall agree**

"Offering free articles, toolkits, and courses for those in the autism and ID community is beneficial service for this community." **96% of Autism Community and 86% of Canadians overall agree**

"Offering a free national chat line that helps the autism and ID community to access existing services and programs is beneficial service for this community ." **91% of Autism Community and 84% of Canadians overall agree**

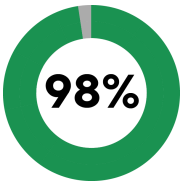
August 2023

Evaluation of AIDE Canada by Website Users

In August 2023, AIDE Canada launched a survey for users of our website. The survey focused on how our website users feel about the utility of the resources we created. 938 individuals completed the survey. Of those, 699 reported being connected to the autism and/or intellectual disability community. The insights that emerged from the survey give an excellent picture of the thoughts and feelings of our community about the work that AIDE Canada has accomplished.

Who We Spoke To:

What They Told Us:



Say AIDE Canada is helpful

Almost all (98%) of the website users who took the survey agreed that the AIDE Canada website was helpful in some way. 87% felt that AIDE Canada resources help to improve users' skills and knowledge about autism and/or intellectual disability. 82% felt that AIDE Canada helps the autistic community connect to relevant resources and materials. 80% felt that AIDE Canada contributes to the wellbeing of members of the autism and/or intellectual disability community.

97% of surveyed website users felt that the articles, videos, toolkits and courses on the AIDE Canada website were helpful. 96% of surveyed website users felt that the AIDE Canada library was helpful. Some comments from the survey capture community members' feelings about AIDE Canada:

"I like that you have so many free helpful resources to help anybody educate themselves on ASD and on how to be supportive to us autistic individuals."
- Lilly Y. (Self-advocate)

"Love how easy it is to navigate and find things. Love the variety of materials"
- Kathleen M. (Parent)

September 2023

Third Party Evaluation

From July to September 2023, AIDE Canada engaged a third party organization to review its website and make suggestions on how our services might be enhanced or improved upon.

The review of AIDE Canada's web platform and services drew from a multifaceted approach. This included studying annual reports, examining the platform's analytics, considering findings from a user survey, and analyzing the platform's present resources and offerings. Critically, feedback was sourced from focus group sessions conducted via video conferences with three distinct user categories: self-advocates, parents of children with ASD or ID, and service professionals. These groups provided insights into the quality, experience, accessibility, and potential areas of enhancement regarding AIDE Canada's resources. Additionally, interviews were held with representatives from AIDE Canada's HUB Network partners, which delved into topics such as the platform's evolution, its usefulness, and potential future directions for the organization.

AWARENESS, KEY FINDING:

"Awareness, within the ASD/ID community, of the existence of AIDE Canada's platform and resources have increased significantly over the last two years..."

AWARENESS, ROOM TO GROW:

AIDE Canada could aim to improve marketing and reach out more proactively to potential users

ACESSIBILITY, KEY FINDING:

"There is an enormous number of varied resources available on the platform. The quality of these resources is rarely disputed."

ACCESIBILITY, ROOM TO GROW:

AIDE Canada could update its management system to further improve the website's navigability and search functions

CREDIBILITY, KEY FINDING:

"The credibility and trustworthiness of the resources found on AIDE Canada's platform is quite high."

CREDIBILITY, ROOM TO GROW:

Aide Canada may wish to be more explicit and transparent about the process to curate information.

HUB PARTNERS, KEY FINDING:

"The HUB network of partners has functioned well so far"

HUB PARTNERS, ROOM TO GROW:

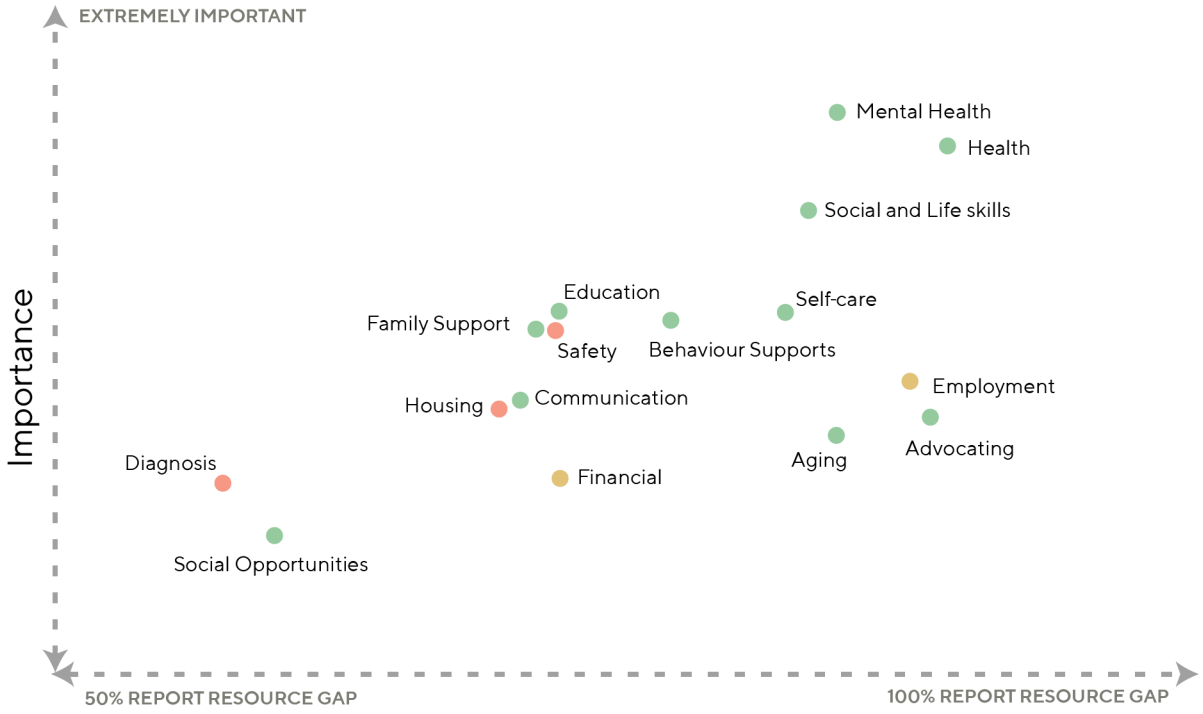
The collaboration in the hub-to-hub network could be further enhanced by increasing hub participation in all AIDE Canada activities.

Meeting Needs

At the launch of the AIDE Canada initiative our dedicated team embarked on a series of community consultations, specifically targeting Canadian stakeholders, to deepen our understanding of the existing gaps in autism information. These consultative sessions provided invaluable insights that allowed us to tailor our offerings more effectively to the real-world needs of the community. In the table below you can see the articulated needs of the autism community in 2019 and compare it to the number of resources that we built to meet that need in the following years.

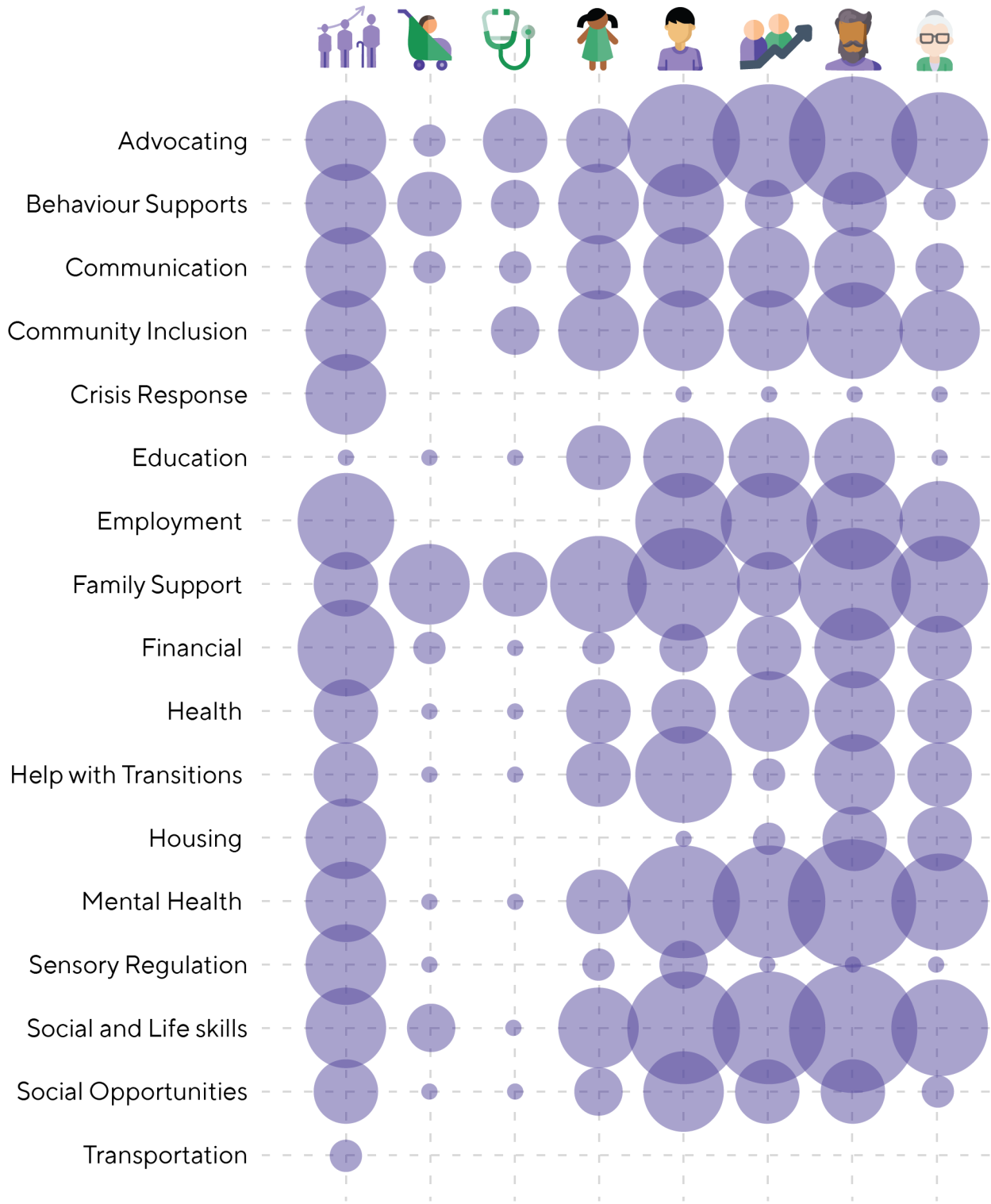
In the image to the right you can see the community response to the resources that we built. Our commitment to bridging the information gaps remains unwavering, and we are excited to share our progress with our community.

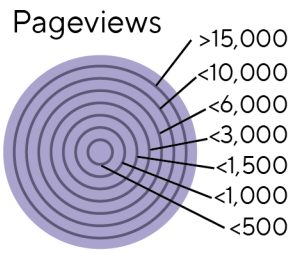
2019 AIDE Canada National Survey on Information Needs of the Autism Community in Canada vs. Number of AIDE Canada Resources Created 2019-2023



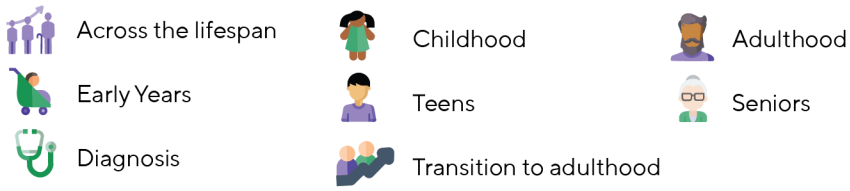
Number of Resources Created by AIDE Canada 2019 - 2023

- 15 - 25 resources created
- 26 - 50 resources created
- 50 or more resources created





Resource focus



The 50 Most Popular AIDE Canada Resources

AIDE Canada has developed hundreds of resources on a huge range of topics for the autism and/or intellectual disability community. Here are the top 50 most popular.

- Toolkit
- Research Summary
- Webinar
- Video
- Course
- Infographic

- Autism and Anxiety
- Autism Tests in Canada: Steps to getting a diagnosis as an adult
- Autistic Burnout Toolkit
- Co-occuring Mental Health Conditions and Autism
- Developing Independent Living Skills for Adults with Intellectual Disability
- Elementary and Secondary Education Supports and Services
- Finding What Your Child Needs with Little to No Cost
- The Gift of Being Different: Autism in an Indigenous Community
- Improving Housing Opportunities
- Peer Advice Videos, Self Advocates & Parents
- Police and Autism Training Video
- Post-Secondary Education Disability Funding By Province & Territory Toolkit
- Recognizing Autistic Girls: an Infographic for Professionals
- Saskatchewan Am I Autistic? Video Essay
- The Self-Care Toolkit
- Sibling Guide On Mental Health for Adults with Siblings with Disabilities
- Signs and symptoms of aging
- Sleep Solutions Toolkit
- Teens Toolkit: From Just Surviving to Thriving in High School
- Teens Toolkit: Mental Health and Sensory Challenges for Teens
- Transition to Adulthood
- Understanding what is happening inside your body: Interoceptive Training for All Ages
- What Autism Looks Like for Girls & Non-Binary Individuals
- What is Job Coaching?: A Toolkit to Support Access to Employment

Autism Campus Prep

Autism Diagnosis in Adulthood

Autism Funding Programs for Children Under 18

Autistic Burnout Webinar

Being Diagnosed as an Adult: What to do while you wait for a formal diagnosis

Caring for the Caregivers of Those with Developmental Disabilities

Ensuring Safety: A Parent's Perspective

Estate Planning for People with Disabilities & Their Families

Feeding and Eating Issues

Intersectionality: Developmental Disability and LGBTQ2S+ Toolkit

Launch into Life! QuickStart Planning Tool

Parenting a Teen with ASD Toolkit

Post-Secondary Education Disability Funding By Province/ Territory Infographic

Promoting Self-Determination Across the Lifespan

Receiving an Autism Diagnosis Later In Life: a self-advocate perspective

Self-Regulation Toolkit

Sensory Processing Differences Toolkit

Sensory Processing in Autism: The Neuroscience & Practical Strategies

Supporting Children with Autism and ID during COVID-19

Supporting Children in Rural and Remote Areas

Supporting Individuals with Limited Speech

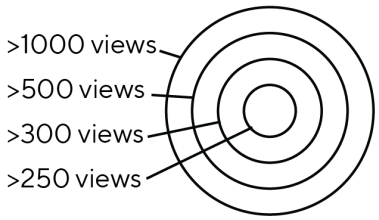
Treating Mental Health Conditions in Autistic Individuals

Understanding Self-Injerious Behaviours

Understanding Social Situations Interactive Video Course

What to Expect When You Get Older, How to Prepare Well

Why More People Weren't Diagnosed with Autism as Children



Community Spotlight:

Rural and Remote Communities

New Resources

Members of the autism and/or intellectual disability community living in rural or remote Canadian communities received much-needed help through AIDE Canada's efforts. Since 2019, AIDE Canada has built **22 resources focused on rural and remote communities.** The unique challenges that rural and remote community members face were key considerations when developing theses toolkits, webinars, and courses.

Fulfilling a Commitment

These 22 new resources were developed as part of AIDE Canada's commitment to reach Canadians in rural and remote areas. During community consultations community members described their unique challenges and AIDE Canada listened. Among other resources, AIDE Canada worked with our Hub partner Autism Yukon to develop a guides on accessing diagnosis and supports for the Yukon, Nunavut and Northwest Territories. We also developed a 6-part course that focuses on teaching practical strategies to support autistic children in communities where no professional autism supports services are available. Together the resources have been viewed over 2700 times.

Canada's Largest Autism Library Delivered to Your Door

The AIDE Canada Library contains over 5000 items all focused on autism and/or intellectual disability. This is over twice the number of autism and/or ID related titles available at the Toronto Public Library. Community members living in rural and remote areas particularly requested the borrow by mail service as they found that the local library offerings on these topics were often small and out of date. Our AIDE Canada Library site is deliberately streamlined to allow for faster load times in areas without highspeed internet.

Rural and Remote Community Members Respond

Website analytics show that in users from over 829 communities accessed our web platform. Of these, 469 (shown in red on the map) were Canadian communities with a population of 10,000 or less. There were a combined, 16,123 users from these communities.

Many community members have written to us when responding to surveys and through email and social media expressing their perspective from rural and remote communities. Read these impressions all from AIDE Canada library members.

"I feel empowered and prepared to face difficult situations...We live on Vancouver Island... We love your library and hope that you will continue to offer your 'Borrow by Mail' service."

- Elena

"Thank you so much for providing this service. It can be really difficult to obtain materials, especially if you live rurally. Thank you again, this really helped me!"

- Library Member

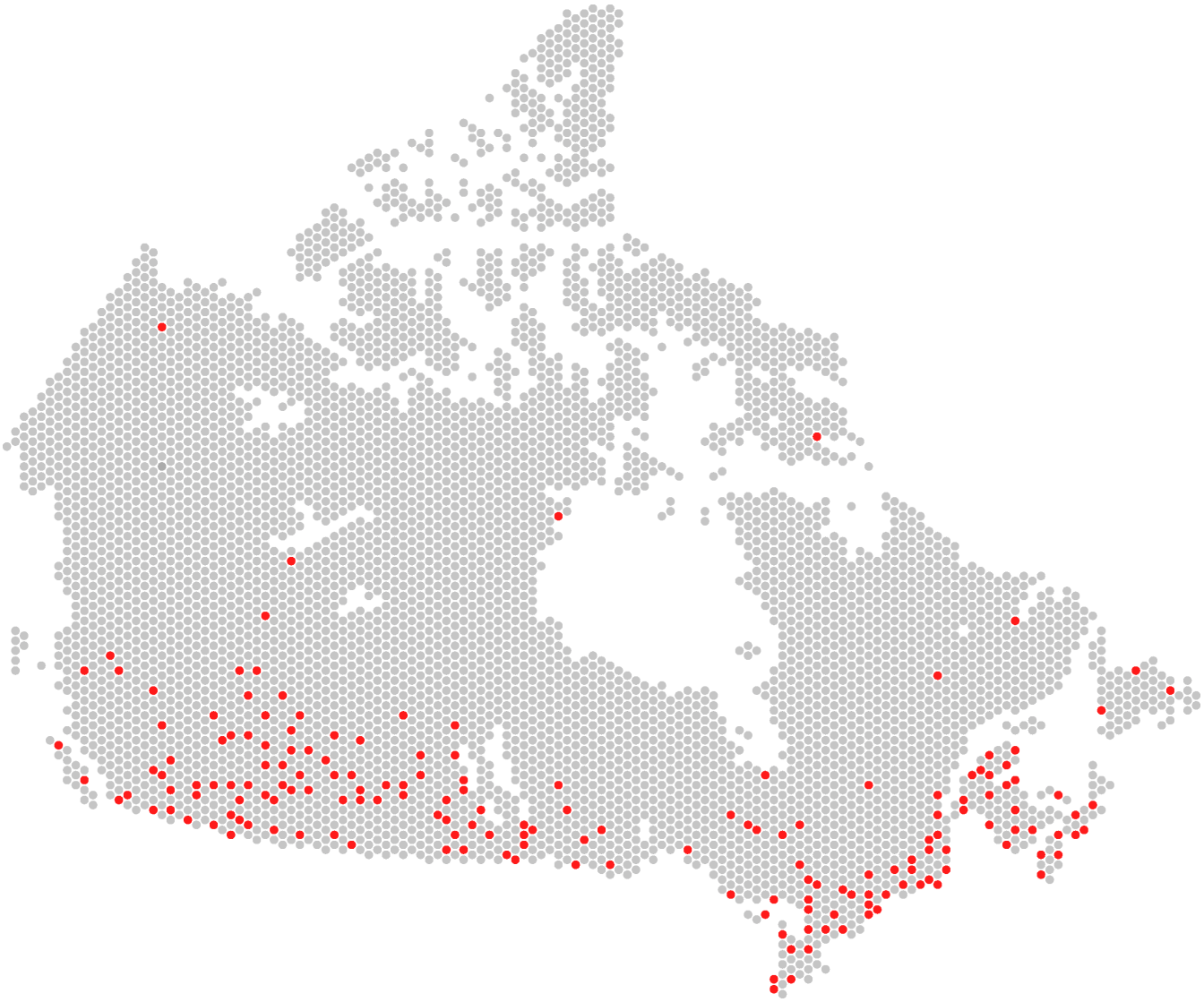
"Thank you so much. I just found out about this amazing resource - I live in a rural small town in NB, so not a lot of resources here!"

- Library Member

22
resources built for remote communities

469
rural/remote communities reached

Accessed by
16,123
different users

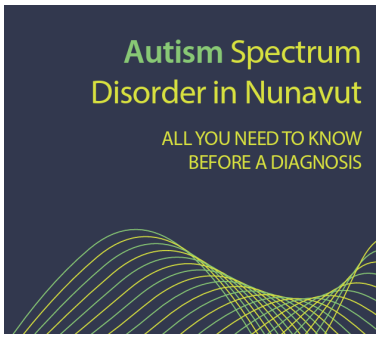


RESEARCH SUMMARY

Improving Access to Mental Health Resources in Rural and Remote Regions

VIDEO

Supporting Children in Geographically Rural and Remote Areas



TOOLKIT

Autism in Nunavut: All You Need to Know Before You Get a Diagnosis

Community Spotlight:

Non-Speaking and Minimally-Speaking Community Members

With a vision to support and empower non-speaking and minimally speaking individuals, AIDE Canada created several projects aimed at the development and dissemination of resources tailored specifically for this community. We are proud to report that a total of **19 new resources** were successfully developed, each designed to address various needs and challenges faced by these individuals and their families .

AIDE Canada developed animated videos with accessible language that demystify complex subjects, like sleep hygiene and mental health. We also introduced infographics in accessible language, targeting financial safety and online protection.

For service providers, we developed a series of articles on how to enhance healthcare delivery for non-speaking patients with intellectual disabilities.

To support the families of our community members we developed resources on representation and capacity issues.

Throughout our work AIDE Canada consulted with individuals with intellectual disabilities and solicited their feedback. One community member told us:

"[The AIDE Canada ID Inclusion Project] gave me more hope that things will improve and that we are being heard and respected"

- Jamie H.

Community Spotlight:

Indigenous Communities

AIDE Canada, in its mission to champion diverse voices, embarked on a significant project to amplify the experiences of Indigenous individuals within the intellectual disability community, particularly those residing in remote regions. In partnership with several indigenous community members we crafted a total of **7 new resources to bridge understanding and foster inclusivity.** This includes 3 enlightening webinars and 3 evocative short video essays, which effectively showcased the unique challenges and triumphs faced by these Indigenous community members. One of our most poignant efforts was the collaboration with Indigenous community members to produce a documentary titled "The Gift of Being Different." This documentary delves into the journey of an Indigenous family's navigation and understanding of autism. The reception and impact of these resources have been commendable, with a **collective viewership tallying up to 1900 pageviews.** Through such endeavors, AIDE Canada remains committed to fostering inclusivity, understanding, and awareness across diverse communities.

VIDEO

The Gift of Being Different

Community Spotlight:

The Autistic LGBTQ+ Community

The autism community includes an intersectionality of identities. To celebrate this diversity AIDE Canada turned its focus toward the experiences of the LGBTQ+ community. With an emphasis on understanding, representation, and support, we crafted **6 new resources** which include practical toolkits, engaging webinars, and insightful infographics. One important topic we explored is the unique presentation of autism among individuals who identify with non-binary genders.

Recognizing the multifaceted nature of identity, we introduced a toolkit dedicated to celebrating intersectionality and gender diversity. Our efforts were enriched by collaborating with esteemed personalities in the community, notably Dr. Wenn Lawson, an international researcher and the author of many books on autism and the LGBTQ+ community. These partnership helped to amplify the authenticity and depth of our content.

The impact of these resources has been felt in our community. **The resources have been viewed over 1800 times**.

Community Spotlight:

The Autistic Women and Girls

Recognizing the persistent disparities in the diagnosis and understanding of autism among women and girls, AIDE Canada championed the creation of targeted resources to bridge this gap. Historically, women and girls have been underdiagnosed, often receiving a diagnosis later in life, or misdiagnosed with other conditions instead of autism. This delay and misidentification can be attributed to prevailing biases, gender stereotypes, and a predominant diagnostic model based largely on male presentations.

To counteract this and ensure a holistic representation, we not only developed resources to assist professionals in recognizing autism in women and girls but also took the essential step of hiring numerous autistic women in this work.

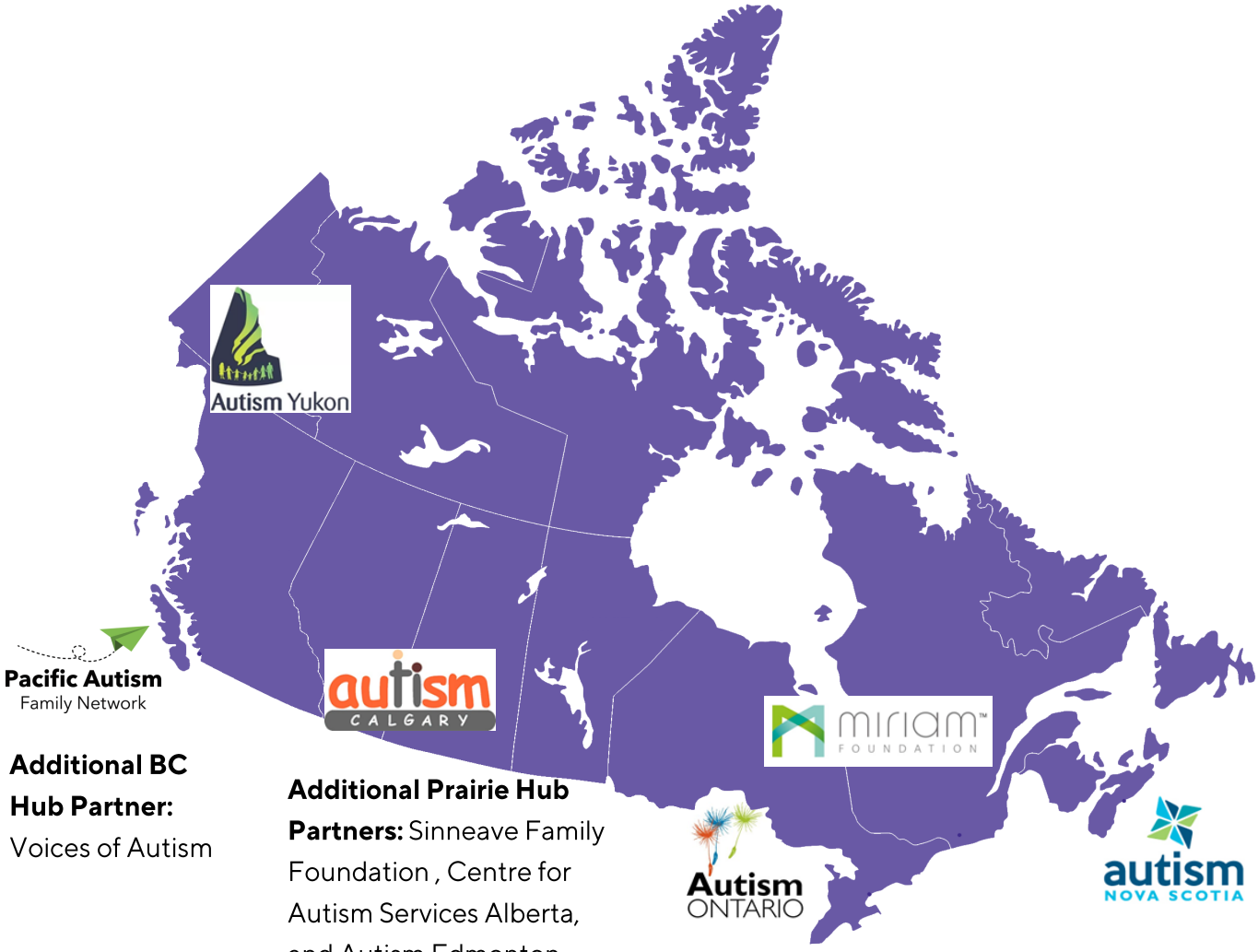
By centralizing autistic women's perspectives, we've ensured that the resources resonate with genuine experiences and insights. These talented women have been instrumental in guiding the creation of tools that debunk myths, clarify misconceptions, and emphasize the nuanced manifestations of autism across genders.

Through these initiatives, AIDE Canada reiterates its commitment to inclusivity and equity in the autism community.

AIDE Canada Hub Network

Overview

The 6 AIDE Canada hubs are strategically located across Canada and play a pivotal role in our overall success. These hubs, beyond serving as focal points for information dissemination, have demonstrated their unparalleled value by contributing hundreds of thousands of dollars in the form of in-kind donations to the AIDE Canada initiative. In addition, the hubs address region-specific inquiries through the online chat platform. Their presence allows for a nuanced understanding of individual regional needs, programs and services, ensuring that recommendations are tailored and relevant. The interconnectedness and regional specificity provided by the AIDE Canada hubs strengthens the project's mission to serve and support the diverse Canadian community.

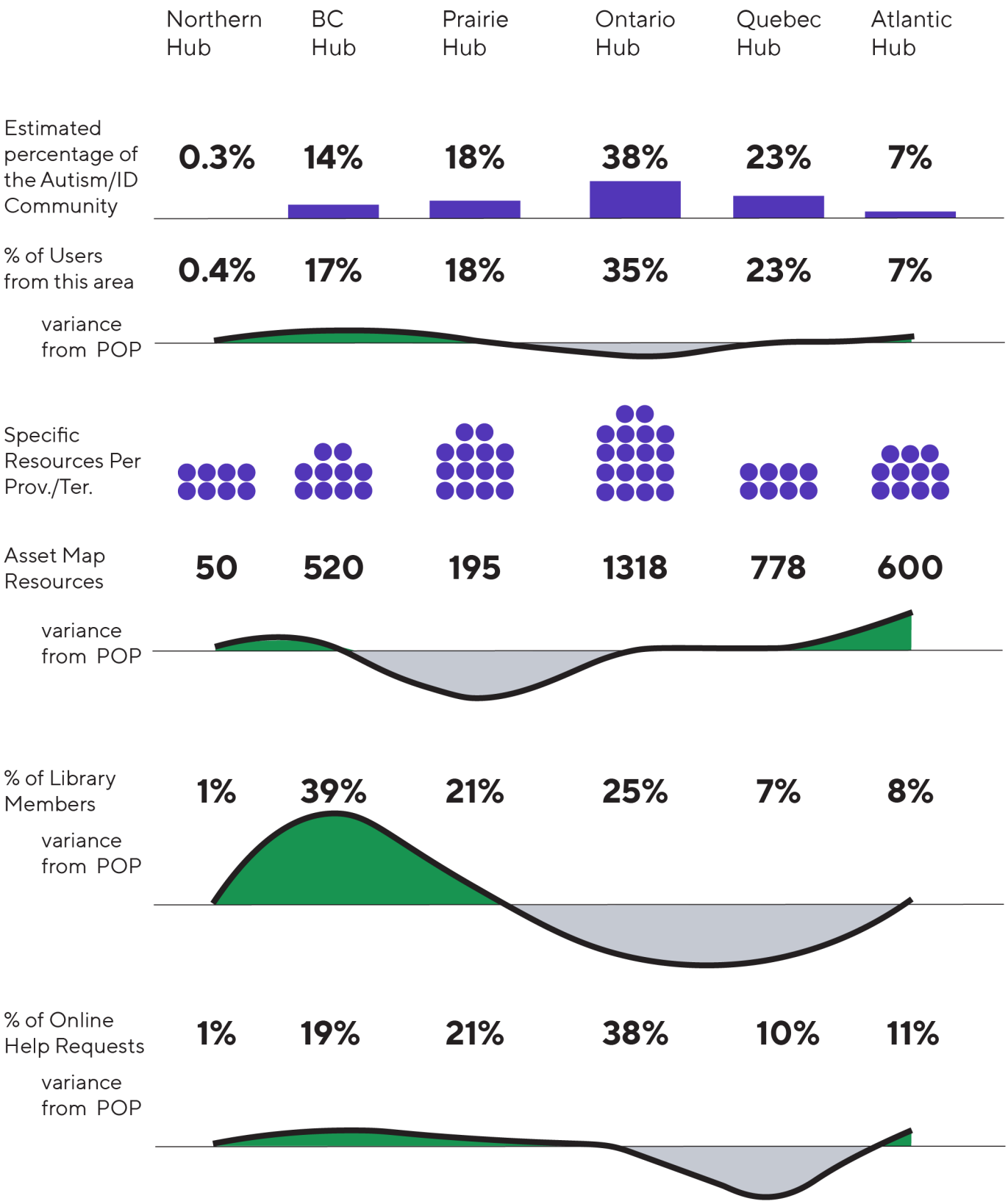


Additional BC Hub Partner: Voices of Autism

Additional Prairie Hub Partners: Sinneave Family Foundation , Centre for Autism Services Alberta, and Autism Edmonton.

Additional Ontario Hub Partners: Holland Bloorview Hospital, Reena, Empowered Kids Ontario, SAAAC Autism Centre, and Pooran Law

Resources Used and Needs Met By Region

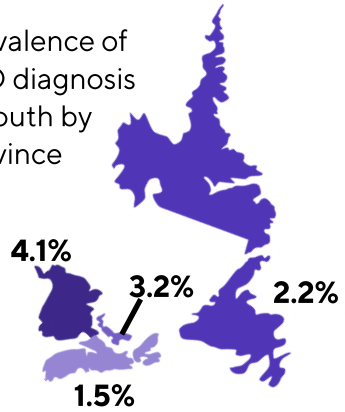


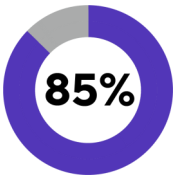
*Community members include autistic individuals, individuals with intellectual disability, their families and service providers working with the Autism/ID community. This estimate assumes consistent prevelance of autism across Canada.

Reaching the Maritimes

Quick Facts:

Prevalence of ASD diagnosis in youth by province





of neighbourhoods have 1 or more autistic kindergarten students

1 of every 3 people identifies as being part of the autism and/or ID community

15,054

people from the Maritimes use AIDE Canada resources

47 unique resources created by the Maritime Hub

AIDE Canada and Autism Nova Scotia are building a bright future for the Maritime Autism and/or Intellectual Disability community.

In an era where collaboration is key to fostering change, Autism Nova Scotia has led AIDE Canada's work in the 4 Maritime provinces to provide much-needed information and resources for our community.

Since 2019 the Maritime Hub has co-delivered an impressive lineup of 19 webinars, targeting diverse topics such as trauma, occupational therapy, and mental health, that cater to the unique needs of our community.

Autism Nova Scotia also showcased its leadership by pioneering the development of 28 additional resources.

One of the highlights of the collaboration was the development of a series on 'Healthy Relationships and Sexuality.' This significant initiative filled an gap that was a point of concern for parents and self-advocates alike during our community consultations . The Autism Nova Scotia team delivered the resources in multiple formats to cater to diverse audiences about this sensitive and important topic. Infographics for young adults, comprehensive toolkits for parents, and an enlightening webinar series ensured that no member of the community was left out.

One autistic self-advocate expressed her gratitude, saying, **"There is a lot of stigma that people on the spectrum can't date or can't have relationships, and it's wrong. This program helps people develop skills, like dealing with emotions and communication ."**

For many like this community member, the collaborative efforts of AIDE Canada and Autism Nova Scotia provide more than just resources—they offer hope, understanding, and a sense of belonging.

Cynthia Carroll, the Executive Director of Autism Nova Scotia, remarked on the partnership's profound influence, stating, **"This collaboration is a testament to what can be achieved when two organizations, both deeply committed to a cause, come together. Our shared mission has always been to uplift, support, and advocate with the autism community. The feedback we receive daily is a heartening confirmation that we're on the right path."**

The trailblazing partnership between AIDE Canada and Autism Nova Scotia illustrates how a shared vision can effect monumental change.

Maritime Hub Resources Spotlight:

Healthy Relationships and Sexuality Collection

What we heard:

"There are no accessible language resources for adults with intellectual disabilities about sex, relationships, and the things you need to know when you have an adult body."

AIDE Canada and Autism Nova Scotia partner to develop a comprehensive set of resources on healthy relationships and sexuality for the autism and/or intellectual disability community.

Community response:

Together resources have been accessed

3,075

times

The team developed accessible language infographics on topics like puberty, menstruation, dating, consent, rejections and protection from STIs.

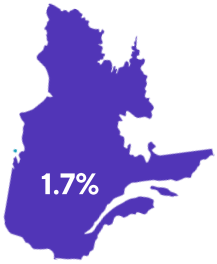
Interactive webinars for parents about the caregiver's role in providing sexuality education to their child or family member

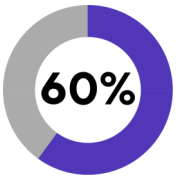
Guides for parents on talking to your adult children about healthy relationships and sexuality. Teaching how to help develop personal skills, and support healthy knowledge acquisition.

Reaching Quebec

Quick Facts:

Prevalence of ASD diagnosis in youth





60% of neighbourhoods have 1 or more autistic kindergarten students

1 of every 5 people identifies as being part of the autism and/or ID community

43,010

people from Quebec used AIDE Canada resources

50 MateriaTech ™ resources available through the Quebec Hub

AIDE Canada and Miriam Foundation are bridging linguistic Gaps for the Canadian Autism and/or Intellectual Disability Community.

Amid the cultural mosaic that is Canada, the fusion of English and French-speaking populations highlights the importance of ensuring services are accessible to both linguistic groups. In the realm of autism support, AIDE Canada found an unparalleled ally in the Miriam Foundation of Montreal.

Miriam Foundation, rooted deeply in Montreal, led the Quebec hub of the AIDE Canada initiative. Their knowledge of the region and its specific needs positioned them as the ideal leaders to ensure AIDE Canada's outreach was effective and comprehensive.

One highlight of this collaboration was the AIDE Canada's improved availability to offer the online chat connection centre resource in French. Recognizing the immense linguistic diversity of the nation, and with the instrumental push and support of the Miriam Foundation, this initiative ensured that the Francophone population was not sidelined. This inclusion was not just about translation; it was a testament to the commitment of both organizations to ensure every individual, irrespective of language, felt heard and supported.

Miriam Foundation also championed the 'Materiatech' program. A revolutionary concept, Materiatech offers free hands-on learning activities through a 'borrow by mail' format. This initiative addresses the varied learning needs of individuals with autism and/or intellectual disability and ensures that resources are within arm's reach, no matter the distance.

As *Consuelo C.,* a ESDM service provider from Montreal told us:

"Many families I service don't have the financial resources to purchase items used in our sessions, *Aide Canada MateriaTech* has allowed them to continue the work on their own. In the last 18 months, I can report that 50% of the families I worked with have since borrowed resources in both official languages. I can say with confidence that *Aide Canada* has been crucial for their ability to promote the welfare of their children."

The Miriam foundation also took the lead on the development of toolkits for our community on the topics of social inclusion and menopause.

The alliance between AIDE Canada and Miriam Foundation serves as a testament to the potential of collaborative ventures.

Quebec Hub Resources Spotlight:

Promoting Social Participation in Autistic Children

What we heard:

> "My child was just diagnosed with ASD. All of the advice online seems to be about professional services, but also I want to know what I can do at home to help my child succeed."

We partner with a parent and a PhD psychologist from the University of Quebec in Montreal to develop a toolkit that gives parents practical at-home strategies to support their child.

Plain language description of different diagnosis

- Intellectual Disability
- Autism Spectrum Disorder
- Attention Deficit Hyperactivity Disorder

Recommendations for at-home interventions for each diagnosis emphasising social participation in activities like meal times, and playing with peers.

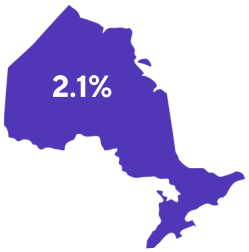
1-2-3

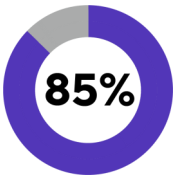
Plain language description and at-home strategy recommendations for the 3 recognized levels of support for Autism Spectrum Disorder.

Reaching Ontario

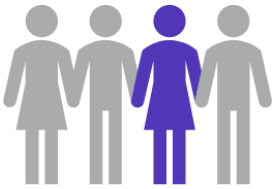
Quick Facts:

Prevalence of ASD diagnosis in youth





of neighbourhoods have 1 or more autistic kindergarten students



1 of every 4 people identifies as being part of the autism and/or ID community

65,923

people from Ontario use AIDE Canada resources

45 unique resources created by the Ontario Hub

Ontario,'s cultural diversity brings with it a myriad of needs and perspectives, especially in the sphere of autism support. Amid this kaleidoscope of voices, Autism Ontario is the leading force, as the AIDE Canada Hub leader. Collaborating closely with Reena Foundation, Holland Bloorview Hospital, Empowered Kids Ontario, SAAAC Autism Centre, and Pooran Law, Autism Ontario has set an exemplary standard in unified effort and vision.

Together, under the umbrella of the Ontario hub, these partners developed 45 unique resources to amplify the voices of and lend support to the autism community. Together these resources have been viewed over 8,300 times.

Autism Ontario played an instrumental role in the development of the 'Peer Advice Videos' initiative. A project that centralized the experiences of non-speaking self-advocates in the autism and/or ID community. The outcome? A web application that not only bridges understanding gaps but also celebrates voices that are often unheard. The popularity of this application, with over 20,000 pageviews, speaks volumes about its impact and relevance.

In the words of Bethany, a community member from Ontario,

"I was grateful to find AIDE Canada's "peer advice" videos addressing questions about sensory challenges. As an Occupational Therapist who often shares information about sensory processing and sensory-based strategies, I feel it is important to include the perspectives of those with lived experience to inform and validate any of my clinical recommendations. I plan to share these videos with autistic individuals and their families so they can hear the ideas and perspectives of autistic peers."

In further testament to the Ontario hub's commitment to embracing Canada's diverse fabric, they develop culturally specific resources tailored for newcomer Canadians and curated the 'Cultural Experience Video Essays'. This series poignantly captures the narratives of three families from the autism community, newly integrated into Canadian society. Additionally, with a keen insight into the specific needs of newcomer families originating from Asia, the hub pioneered resources designed exclusively for them, reinforcing the ideal that every voice, every story, and every experience has a place and value in the wider autism community.

Ontario Hub Resources Spotlight:

Peer Advice Videos - Intellectual Disability

What we heard:

> "There are almost no resources that centralize the thoughts and opinions of self-advocates who are non-speaking. I want to hear from people like me."

AIDE Canada partnered with Autism Ontario and others to develop the peer advice videos: Questions asked and answered by self advocates and partied in the autism and/or intellectual disability community.

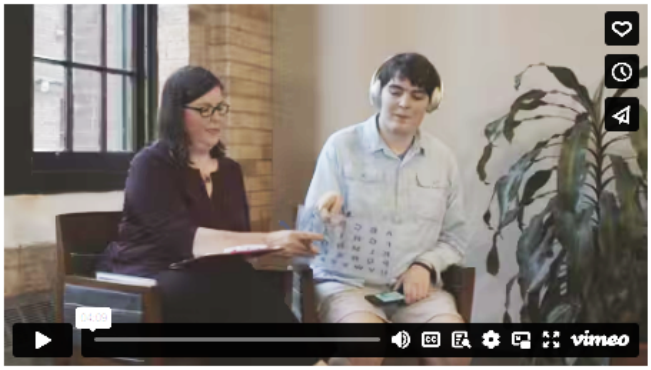
1 **Focus group research revealed the questions in demand**

Select category and/or type keyword to search

Search by Question: Enter a question

- Can I ask for accommodation at work?
- How do I create and maintain belief in myself in a world focused on the typical experience?
- How can I do challenging things with an uncooperative body?
- How can I face my fears? Where can I go to practice being with dogs?
- Do I have to disclose my diagnosis?
- Being different is okay. How can I encourage others to embrace their individuality?
- What should I wear to a job interview?

2 **Onboard 9 advice-givers to answer the questions of fellow non-speakers in the autism and/or ID community**



How can I do challenging things with an uncooperative body?

3 **Onboard an autistic self-advocate directed production company to record the responses**

4 **Publish videos onto the AIDE Canada Peer Advice Video web application.**

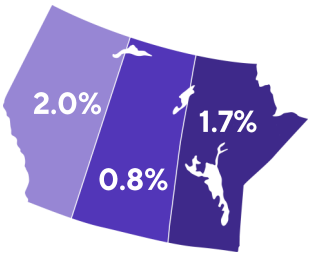
Community response:

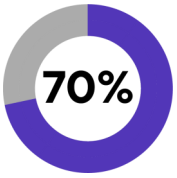
Peer Advice Video web application has been accessed over 20,000 times

Reaching the Prairies

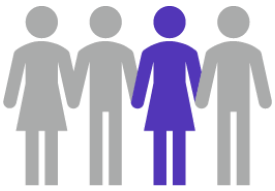
Quick Facts:

Prevalence of ASD diagnosis in youth by province





70% of neighbourhoods have 1 or more autistic kindergarten students



1 of every 4 people identifies as being part of the autism and/or ID community

34,252

people from the Prairies use AIDE Canada resources

52 unique resources created by the Maritime Hub

Autism Calgary and AIDE Canada are pioneering change through collaboration in the prairies.

Under the banner of the AIDE Canada Prairie hub, Autsim Calgary has created synergic collaboration with esteemed partners the Sinneave Family Foundation, Centre for Autism Services Alberta, and Autism Edmonton.

These organizations have harnessed their combined expertise to produce a amazing 52 unique resources tailored to the needs of the Canadian autism and/or intellectual disability community. Among these are 22 webinars that delve into crucial subjects such as employment, executive functioning, and housing. Not forgotten were more nuanced parenting challenges such as managing sleep patterns, addressing picky eaters, guiding toilet training, and fostering early engagement.

A standout among their initiatives was a groundbreaking series of toolkits and videos developed entirely by self-advocates from Alberta, Manitoba, and Saskatchewan. This series took a deep dive into housing, social inclusion, and the intricacies of diagnosis in the prairie provinces. Their voices lend authenticity, adding immense value to the resources.

Tuned into the community's pulse, the Prairie hub took note of an overwhelming request for resources on financial management. Addressing this, they curated a series on finances, resonating deeply with community members and proving the hub's commitment to addressing their genuine concerns.

Recognizing a pronounced need from the community's feedback, the Prairie hub responded with a comprehensive resource series on finances. These resources, which were conceived following community consultations, have proven invaluable, speaking volumes about the hub's commitment to addressing community needs.

Autism Calgary also played a pivotal role in staffing the online chat line, ensuring the community's inquiries and concerns receive prompt attention.

Heidi, an engaged parent and community member from Manitoba, encapsulated the sentiment of many when she shared**:**

"I really like the articles, courses & videos that are so important for the autistic community and also others involved like teachers, the community at large & those serving in other fields that may come across those in the autistic community."

Lyndon Parakin, the Executive Director of Autism Calgary, reflecting on their work, mentioned, **"Our alliance with AIDE Canada and our esteemed partners within the Prairie hub has been transformative. We've bridged knowledge gaps, fostered innovation, and above all, empowered our community. These resources aren't just about information; they're about meaningful change."**

The Sinneave Family Foundation remains essential in the AIDE Canada Library program, hosting the Calgary branch of the successful service and adding over 500 books to the available collection.

With the continued dedication of Autism Calgary and its partners, the autism and/or intellectual disability community in the prairies can look forward to a future filled with even more tailored resources, support, and understanding.

Prairies Hub Resources Spotlight:

Financial Resources Collection

What we heard:

"Our community needs access to plain language information and resources about taxes, finances and understating legal matters."

AIDE Canada and Autism Calgary partner to develop a plain language set of resources on taxes, finances and legal matters for the autism and/or intellectual disability community.

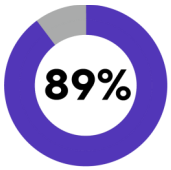
Community response:

Financial resources collection accessed 3,075 times

The team developed accessible language infographics and toolkits and videos on topics like provincial disability funding programs, the Disability Tax Credit, financial abuse and protecting yourself from cyber crime.

Reaching the North

Quick Facts:



of neighbourhoods have 1 or more autistic kindergarten students

18 unique resources created by the Northern Hub

705

people from the territories use AIDE Canada resources

In an area where services are limited and accessing essential resources is a challenge, Autism Yukon and AIDE Canda partnered to support the autism and/or intellectual disability community. Steering the Northern Hub's mission, Autism Yukon has been instrumental in devising strategies and initiatives that address the distinct hurdles faced by families and individuals in the Yukon, Nunavut and Northwest Territories.

Autism Yukon took a hands-on approach to staffing AIDE Canada's chat service. This direct line of communication ensured that families and individuals in the North had real-time access to crucial support and resources.

Recognizing the unique hurdles of the three Canadian territories, Autism Yukon embarked on an ambitious project. They crafted two unprecedented guides for each territory. The first guide provides a roadmap for obtaining a diagnosis, while the second offers insights into accessing essential supports. These guides, tailored to the specific needs of each territory, have become invaluable companions for families embarking on their autism journeys.

Furthering their commitment to addressing the distinct challenges of the North, Autism Yukon pioneered a six-part course focusing on supporting neurodiverse children in rural and remote areas. Given the inherent challenges of limited services in these locations, this course provides vital guidance to families and educators.

"Canada's North has its unique set of challenges, particularly for families in the autism community" said Rebecca Fenton, the Director of Autism Yukon. "Our collaboration with AIDE Canada is about bridging those gaps, ensuring that every individual feels connected and empowered. We want to show that being remote doesn't mean being alone or without support."

Autism Yukon has developed 18 resources under the aegis of the Northern Hub. Their impact is clear, having been accessed an impressive 2,262 times, demonstrating their importance in the community of the territories where 705 of the users lived, but also other remote and rural communities across Canada.

Reflecting on the transformative power of AIDE Canada in the north Sarah, a sibling of an autistic adult shared: **"The AIDE library is a fantastic resource for research...There are also a nice variety of testimonials from other families and self-advocates, which, by reading, I have learned a great deal and realized that the ups and downs I experience are not unique.**

Autism Yukon, in collaboration with AIDE Canada, paints a hopeful future for the Northern Hub, a vision where geography and service limitations don't impede access to essential resources and community support.

Northern Hub Resources Spotlight:

Supporting Children in Rural Areas

What we heard: "Almost all the resources to help parents in the autism community focus on connecting with professional supports. I live in a rural community where those services just don't exist. There aren't any resources out there for communities like mine."

AIDE Canada and Autism Yukon partner to develop a set of resources for parents in remote communities.

Community response:

Resources have been accessed

1,005

times

1. From Goals to Outcomes supporting individuals working with young children with special needs in rural and remote areas.

2. Overview of development ASD, Fetal Alcohol Syndrome, ADHD and Global Developmental Delay

3. From Theory to Practice: Using Therapists' Goals in a Culturally Responsive Way

4. Increasing Childrens' Language

5. Sensory Processing Differences and Self-Regulation

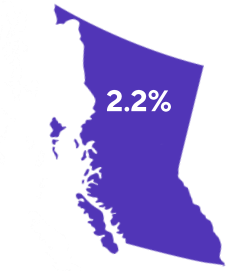
6. Filling their Toolbox, Guiding Children's Behaviour

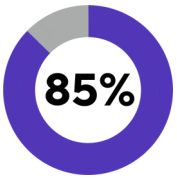
Autism Yukon

Reaching British Columbia

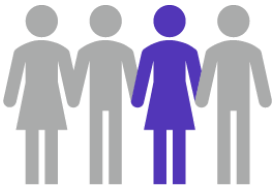
Quick Facts:

Prevalence of ASD diagnosis in youth





of neighbourhoods have 1 or more autistic kindergarten students



1 of every 4 people identifies as being part of the autism and/or ID community

31,516
people from BC use AIDE Canada resources

371
unique resources created by the BC Hub

AIDE Canada is hosted and administered by the Pacific Autism Family Network (PAFN) in British Columbia. Voices of Autism, a self-advocate advisory group, combines with PAFN to make up the BC hub of AIDE Canada.

The BC hub has been instrumental in pioneering hundreds of projects on every topic articulated as a need through the AIDE Canada community consultations. Some truly innovative and useful resources have resulted from the hard work, expertise and dedication of the BC Hub staff.

One notable accomplishment was the development of an interactive video series that used the most current, evidence based techniques together with cutting edge technology. The result was a series of videos, that can be controlled by the user, to help autistic adults understand and navigate social situations.

In this project, as well as the 370 other projects headed by the BC hub, PAFN and Voices of Autism prioritized the voices of those with lived experience as autistic self advocates and the caregivers of non-speaking autistic individuals and those with intellectual disability. This was the central theme behind the extremely popular Peer Advice Video series, the first two phases of which were completed by the BC Hub.

Listening to the needs of our community, the BC Hub also embarked on several ambitious projects that made AIDE Canada among the first in the world to provide resources developed specifically about autistic burnout. Recognizing the need, PAFN stepped up to provide comprehensive materials that not only help individuals understand autistic burnout but also offer guidance on developing both prevention and recovery strategies.

The successful suite of resources on autistic burn out have been viewed over 2400 times in the short months since their release.

The PAFN and AIDE Canada also emerged as thought leaders on the topic of autism and aging, and will host the world's first international conference on autism and aging in November 2023.

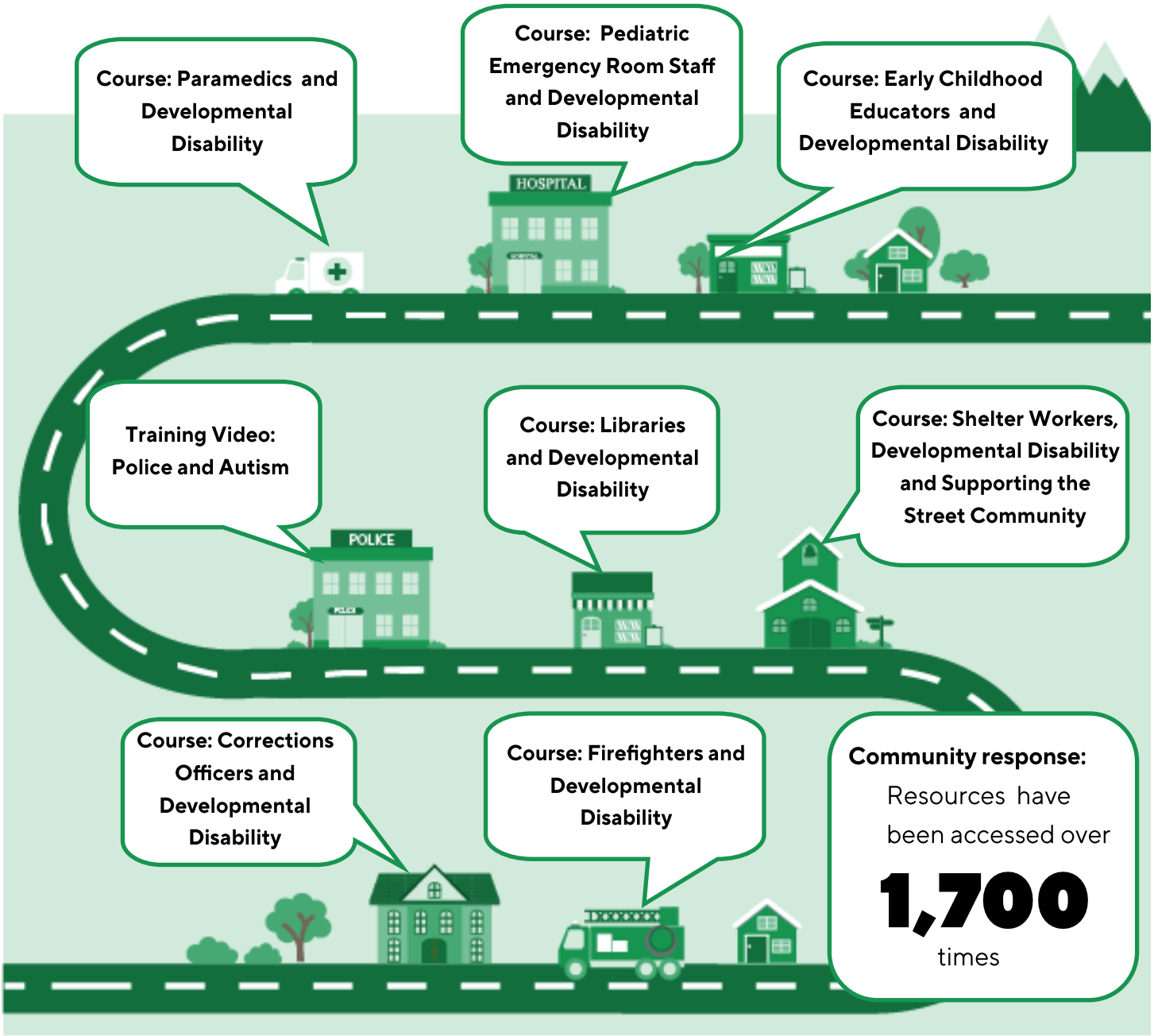
The scale and impact of PAFN's work can be seen in numbers: an astounding 371 resources have been developed under the aegis of the BC hub, amassing a total of 56,588 pageviews. Each resource is a testament to their commitment to making relevant information accessible to all who seek it.

In the words of a Bjorn J., a firefighter who took AIDE Canada's course on firefighters and developmental disability: **"Your knowledge, enthusiasm, and love for your job is very evident in your course."**

British Columbia Hub Resources Spotlight:

Courses that Make a Better Society

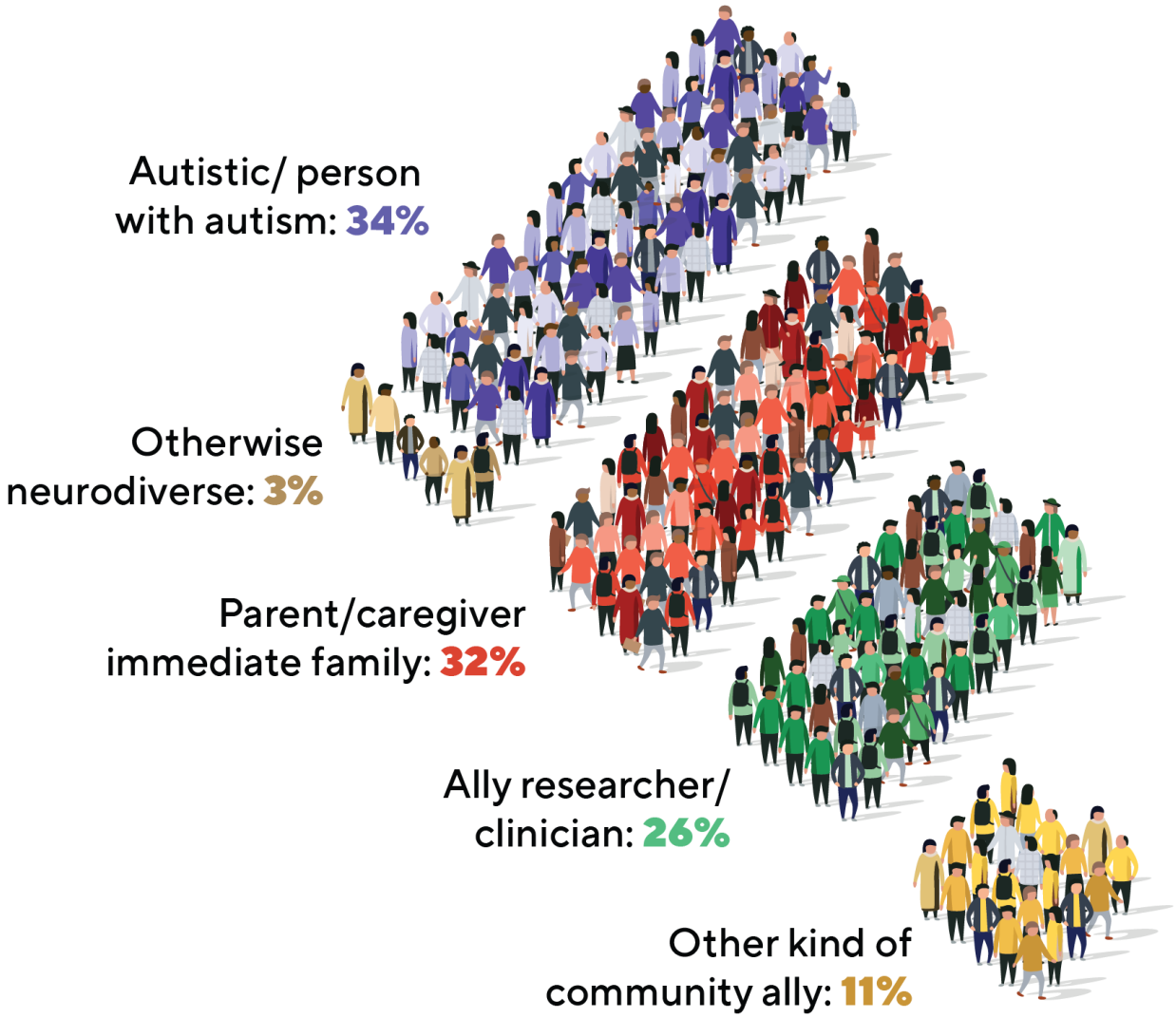
What we heard: "Interacting with professionals is extremely stressful. Particularly police officers and other first responders. I so am worried that they will not understand. I am worried autism will prevent me from getting the help I need in an emergency, or worse, that a misunderstanding will cause the situation to escalate."



Diversity at AIDE Canada

From April 1, 2020 to July 31, 2023 AIDE Canada worked with over 200 different individuals to create content related to autism and/or intellectual disability for the AIDE Canada website. Many people have asked us about the diversity of our staff, partners, and contractors. The following is a snapshot of who we worked with over the first 3 years of the initiative and the diversity of our community.

All Staff, Partners, and Independent Contractors:



All Full and Part Time Staff:

Autistic/ person with autism: **33%**

Otherwise neurodiverse: **8%**

Parent/ immediate family: **26%**

Other kind of ally: **33%**

Black, indigenous, or person of colour: **37%**

Gender identity female: **67%**

Leadership and Management Staff

autistic person / person with autism: **25%**

parent or immediate family member: **25%**

otherwise neurodiverse: **17%**

other kind of community ally: **33%**

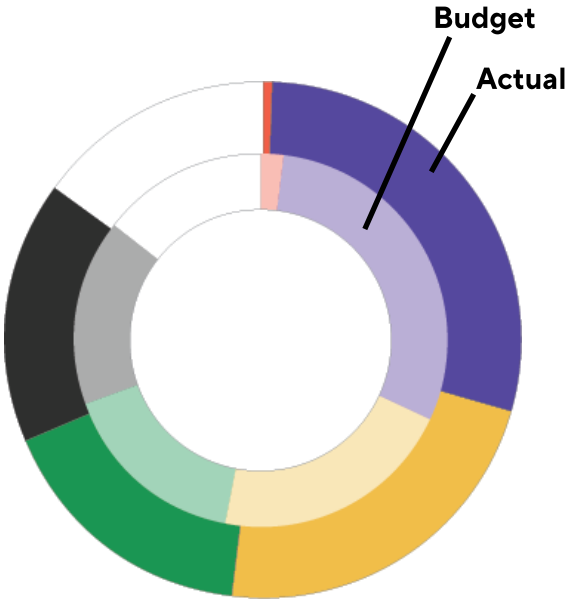
Financial Stewardship

Funding for the AIDE Canada initiative was announced in the 2018/19 Federal budget. The Public Health Agency of Canada committed to funding the project from 2019 to 2023.

Three million dollars of the total project funding is being donated in-kind by the Pacific Autism Family Network, the Miriam Foundation, and the hub partner organizations. The total cash budget for the project was estimated at $11,959,095. That amount is scheduled to be distributed over 5 years, and includes $800,000 to cover an extension of the project from September 2023 to March 2024. The table below compares actual to budgeted expenses throughout the project.

Throughout, AIDE Canada has remained within budget while delivering on all of the project promises and deliverables.

Fiscal Year	Budget	Actual
2018/19	253,700	86,753
2019/20	3,597,800	3,344,758
2020/21	2,503,300	2,607,090
2021/22	1,957,210	1,953,329
2022/23	1,926,210	1,901,933
2023/24	1,720,875	-



Next Steps

AIDE Canada community members expressed unreserved support for the work of AIDE Canada and the continuation of services including the borrow-by-mail library, and the on-line resources offered for free via the AIDE Canada web portal.

In a national poll, 95% of Autism Community members and 86% of Canadians overall agreed that training more teachers, police officers, doctors and other professionals on working with autistic people will benefit the autism and ID community.

The self-directed courses for first responders and other professionals have been extremely well received by community members. We have had frequent requests, however, for in-person and facilitated on-line courses led by an instructor. These offerings would be outside our current mandate, however, as AIDE Canada looks forward to the next 5 years, one of our goals is to expand our offerings for professionals and service providers interacting with the autism and/or intellectual disability community.

Our Thanks

AIDE Canada is funded by the Public Health Agency of Canada. None of the progress and community impact described in this report would be possible without their generous support. We would also like to thank the many additional individuals and organizations that have contributed to our success. We are grateful for your support and expertise and your roles in helping us make Canada a more inclusive place for the autism and/or intellectual disability community.

Public Health Agency of Canada

Agence de la santé publique du Canada

Funded by:

Public Health Agency of Canada

Agence de la santé publique du Canada

Administered by: