



STAKEHOLDER ENGAGEMENT REPORT

2024

PREPARED FOR THE MINISTRY OF
CHILDREN AND FAMILY DEVELOPMENT

DATE: NOVEMBER 22, 2024

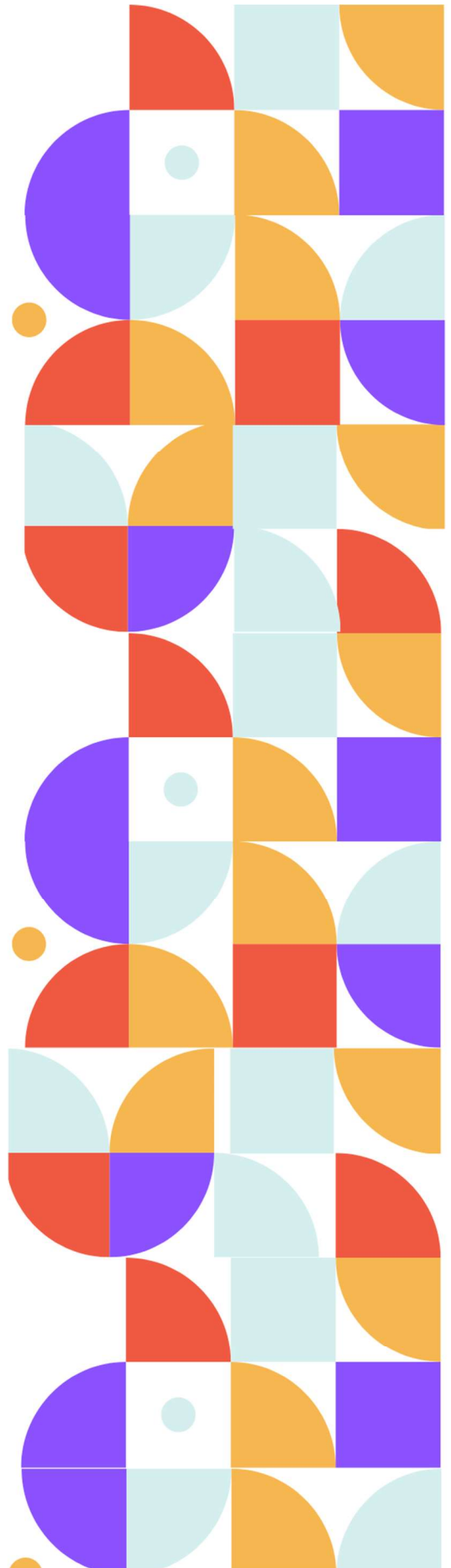


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Language: This report primarily uses person-first language for clarity and consistency in writing. However, we acknowledge and respect that individuals with disabilities may prefer different ways of self-identifying. We encourage readers to recognize the importance of asking each individual their preferred terminology when communicating about or with them. We thank all of those who engaged so passionately in the hope that change will occur to support those with ADHD who feel unsupported.

"The sustained effort required to find appropriate treatment and supports is nearly impossible to maintain."

"ADHD is not a priority in BC public schools and my son has struggled in the environment because of the lack of knowledge and support."

"No funding for services for a child with 'just' an ADHD diagnosis."

A LETTER FROM THE ADHD ADVOCACY SOCIETY OF BC BOARD

What Was Learned and Next Steps



Dear Ministry of Children and Family Development,

On behalf of the board of the ADHD Advocacy Society of BC, we would like to thank you for the funding that has allowed us to reach individuals diagnosed with ADHD who are facing immense challenges and providing them with a platform to share their experiences. Individuals with ADHD and their families were eager to share their experiences, with many being overcome with emotion at the opportunity to be heard and feel less isolated in their journey.

ADHD is a lifelong neurodevelopmental disorder that affects approximately 50,000-70,000 children and youth in BC¹². As of today, children and youth with an ADHD diagnosis are not eligible for services from the Department of Children and Youth with Support Needs (CYSN) within the Ministry of Children and Family Development. This lack of access to services and support is particularly concerning given that ADHD is officially recognized as a disability under both the Canadian Charter of Human Rights and the BC Human Rights Code.

The online survey highlighted the lack of support for ADHD individuals and families negatively affecting them in areas such as: employment (84%), education (90%), mental health (98%) and the justice system (26%). These results go beyond the confines of the MCFD. Research has shown that limited early access to services has a devastating impact on the developmental trajectory of children and youth with ADHD, as well as society as a whole.

When reviewing the results of the interviews, it was heartbreaking to hear the common themes of deep frustration at government systems that provide little to no access to assessments and inconsistent access to services. The financial barriers and lack of understanding about ADHD experienced by families with children with ADHD was clearly communicated with 52% of respondents having to choose between medication and food. We learned about gaps in support across gender, class, income, and ages. IBPOC families and other marginalized groups disproportionately experienced negative interactions with child protection services, compounding their stress.

“There are minimal to no support services for ADHD. We accessed an information session through CYMH. Information was very basic but likely useful for some parents. GPs only have basic knowledge. There are endless waits to be seen by a pediatrician or psychiatrist. There are no public funded psychologist services available for ADHD cognitive therapy. There is no public funded counselling for expert level parent or child coaching. There is ongoing stigma that this issue is not real, is not disabling, so does not need support. CYSN staff denied my child had an issue and said there were not supports. The province failing to meet the needs of even complex disabled children, so children with ADHD or other concerns are not serviced.” - Parent

¹ <https://caddac.ca/about-adhd/>

² https://www2.gov.bc.ca/assets/gov/data/statistics/people-population-community/population/people_population_projections_highlights.pdf

We heard from families that there is a great need for:

- Parental and family support
- Government funding and policy changes
- Public awareness and training
- Mental health and community integration
- Early diagnosis and comprehensive services
- Social and emotional support

Ultimately, we believe that the information contained in this report highlights that any additions or changes to services and supports for children and youth with ADHD and their families must include collaboration between multiple Ministries and those with lived experience.

A main goal of the ADHD Advocacy Society of B.C is to keep these stories alive and create the change so many families living with ADHD are desperately needing. We will work towards amplifying the voices of families with children and youth with ADHD and working together toward a more equitable and supportive framework for those impacted by ADHD in British Columbia. To this end, we are diligently working on the ADHD Knowledge Translation videos, with filming commencing the 3rd week of November 2024. The estimated completion date is February 2025.

We look forward to further collaboration and progress toward meaningful change, preferably in person. Please let us know what dates and times would be convenient for you.

Sincerely,

The Board of Directors, ADHD Advocacy Society of BC

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EXECUTIVE SUMMARY

ORGANIZATIONAL BACKGROUND AND ENGAGEMENT OVERVIEW

Attention Deficit Hyperactivity Disorder (ADHD) is a complex brain-based disorder that affects many children and adults. According to the Centre for ADHD Awareness Canada, ADHD is a genetic, highly hereditary, life-long neurodevelopmental disorder affecting approximately 1.5 million Canadians, and left untreated, it can have devastating effects on one's life.

The ADHD Advocacy Society of BC (the Society) was established in 2022 by three ADHD advocates who connected through an ADHD Peer Support Facebook group. The Society was formed in response to widespread concerns about inadequate support services for children and youth with ADHD in British Columbia (B.C.). Recognizing systemic failures in ADHD support as highlighted by shared experiences through broader community feedback, the Society sought to address significant gaps in the current support framework.

“Dismissive attitude from school administration.
Long waitlist to get a Pediatrician.
Once diagnosed, dismissive attitudes from friends/family about medication awareness.”

According to the Government of B.C.'s population projections for 2020, approximately **70,000 children and youths have ADHD in B.C.**³, and many experiences share how the current Ministry of Children and Family Development (MCFD) framework for Children and Youth with Support Needs (CYSN) is failing to fully accommodate those with ADHD. Statistics reveal that 32.2 per cent⁴ of individuals with ADHD do not graduate from high school, and many experience mental health diagnoses, such as anxiety, depression, or substance use disorders. These challenges highlight the critical need for enhanced support services and the Society identified an urgent need for improved advocacy.

To tackle these issues, the Society engaged Amplify Consulting Inc., a Kamloops-based firm specializing in communication and stakeholder engagement. A “**Tell Us How You Really Feel**” initiative was launched with financial support provided by MCFD. The initiative kicked off in April 2024 and included virtual and in-person engagement sessions, plus an online survey designed to collect insight and feedback from families impacted by ADHD as well as other key stakeholders.

Definition of a Stakeholder

For the purposes of this report, those who were interviewed are referred to as stakeholders, those who have a vested interest or stake in the decision-making and activities pertaining to the organization or project. In this case, stakeholders included:

- Families and individuals throughout B.C. affected by ADHD
- Service providers throughout B.C.
- Board members of the ADHD Advocacy Society of BC

³ Source: <https://caddac.ca/about-ADHD/>

⁴ Source: https://caddac.ca/wp-content/uploads/policy-paper_seriousness-of-ADHD-final-english.pdf

ENGAGEMENT OBJECTIVES

The Society launched the engagement initiative with three objectives in mind:

1. Assess stakeholder awareness and perceptions around ADHD.

The Society wanted to understand and share with MCFD how much stakeholders, including families affected by ADHD, service providers, and medical professionals, understand ADHD and the efficiency of the existing support framework.

2. Identify gaps in support and recommend solutions.

The Society wanted the survey to uncover any specific weaknesses and strengths in the current support services for individuals with ADHD and explore potential improvements or solutions.

3. Evaluate the Society's reputation and understand how to position it best.

The Society wanted to understand how stakeholders perceive its role, effectiveness, and influence in the ADHD community to identify opportunities for strengthening its position as a thought leader.

SCOPE

The scope of the project was to develop a report providing a comprehensive overview of stakeholder perspectives and actionable insights to guide the development of better supports and services for individuals with ADHD. The report and communication suggestions are intended for the Society's Board of Directors and the Ministry of Children and Family Development (MCFD). This report includes the findings from a multi-faceted stakeholder engagement initiative.

Survey Methodology

Online Survey.

Shares an analysis of responses from 243 participants focusing on their awareness of ADHD, the Society, their perceptions of current supports and services, and suggestions for improvement. One person emailed their responses to the consultant directly.

Engagement Sessions. 65 people joined us either via an in-person session or via an online Zoom session.

In-Person Sessions. Shares a summary of discussions held with families affected by ADHD conducted through face-to-face meetings in their communities.

Zoom Sessions. Shares insights gathered from virtual online meetings with stakeholders, including professionals and community members, to discuss ADHD-related issues and supports.

Areas of Focus for the Society in Stakeholder Engagement

Awareness. This includes an evaluation of how well stakeholders understand ADHD and some of the more common misconceptions about the chronic neurodevelopmental disorder.

“I can't even rate the supports and services because I feel there is nothing

Support Gaps. Identifies gaps in existing support systems and potential solutions to fill the gaps.

Reputation. Includes an assessment of the Society’s reputation and its role as a thought leader and advocate for ADHD support.

Project Exclusions

Sample Size Limitations. The engagement activities were conducted through the network the Society has built and that network’s network. The sample size is smaller in scope compared to the provincial population but very targeted to a specific group of people affected by ADHD or those who work with those who have ADHD.

Specific Policy Analysis. The report identifies gaps and suggestions for improvements that can be utilized to help develop policies to bolster support and services specific to ADHD in British Columbia.

Online Survey

Description
An online survey was set up to gather quantitative and qualitative data from a broad audience. The survey aimed to collect insights from individuals affected by ADHD, including families, youth, service providers, organizations working toward similar goals and other stakeholders.
Participants
The online survey received 243 responses from various stakeholders across British Columbia, with one person sending their insight via email.
Data Collection
The survey included questions designed to assess awareness of ADHD, awareness of the Society and the work it does, perceptions of current supports and services, and suggestions for improvement. Data was collected through Typeform, an online surveying platform, and analyzed to identify key trends and themes.
Analysis
Responses were analyzed to determine the level of understanding of ADHD, the gaps in services and supports for those with ADHD and gauge the overall perception of the Society.

In-Person Sessions

Description
In-person sessions were organized to engage directly with stakeholders and gather qualitative and quantitative data through face-to-face, in-person discussions.
Participants
These sessions included families and individuals affected by ADHD.
Data Collection
Through structured and engaging discussions, the team collected detailed feedback on current support services, challenges faced, and potential solutions.
Analysis
Notes from these sessions were reviewed to extract common themes, insights, and suggestions.

Zoom Sessions

Description
Zoom sessions were held to facilitate virtual engagement with stakeholders who could not attend in-person sessions or preferred to engage online.
Participants
The sessions included families with lived experience with ADHD, service providers, and the Board of Directors of the Society.
Data Collection
Like in-person sessions, these virtual meetings used structured discussions to gather feedback on ADHD support and thoughts from stakeholders on the Society's role.
Analysis
Notes from the Zoom sessions were analyzed to include the findings from the online survey and in-person sessions.

Integration and Reporting

Data Integration
Findings from the online survey, in-person sessions, and Zoom sessions have been integrated to provide a comprehensive view of stakeholder perspectives.
Key Themes
The combined data has been used to identify key themes, including awareness of ADHD, gaps in services and supports, and the Society's reputation.
S.W.O.T Analysis
A S.W.O.T analysis (Strengths, Weaknesses, Opportunities, Threats) of the Society was conducted to assess its position and role based on stakeholder feedback.
Recommendations and Next Steps
Actionable recommendations have also been developed to address identified gaps and enhance the Society's advocacy and support efforts.

STAKEHOLDER ENGAGEMENT BEST PRACTICES

It is important to ensure best practices for stakeholder engagement are followed and reported back to the Society. This will provide confidence in knowing how stakeholders were engaged and how information was collected and prepared. The Society's team was responsible for identifying and reaching out to stakeholders, setting up all in-person and virtual sessions, and ensuring that engagement opportunities were accessible across diverse locations throughout B.C.

Identify Stakeholders Fairly

Interviews were done with a range of stakeholders, including the Society's Board of Directors, families with lived experience, healthcare professionals, and collaborative organizations that support those with ADHD.

Treat Stakeholders as Partners

All stakeholders understood the importance of their feedback in helping the Society share insight with MCFD.

Engage with Stakeholders on Their Terms

Engagement was done with stakeholders when, how, and where they were most comfortable. Stakeholders were invited to focus group sessions in Kamloops, Prince George, Chilliwack and Nanaimo. They were provided with the opportunity for one-to-one interviews and were also invited to fill out an online survey.

Disclose Early

Stakeholders were informed that information drawn from these interviews would be provided to MCFD through the Society to help share gaps for ADHD supports and services, as well as to share potential solutions to help support those in B.C. with ADHD. This outlined the important purpose of the project and highlighted the value of their honest, open, and candid feedback.

Free From Manipulation or Coercion

Stakeholders were all asked similar questions. Some of these questions were adjusted depending on the stakeholder group (i.e. Board of Directors and external stakeholders). All stakeholders were encouraged to share openly and freely as the survey was confidential, and all information would be generated into an overall report free from their names attributed to any direct statements or insights.

Documented Fairly

Information was documented fairly and as intended by stakeholders.

Open Process

All stakeholders were provided with time to give comments and feedback on the project. Those who joined the focus groups were invited to take a follow-up survey to see if they had any additional information to share or reach out to Aleece Laird of Amplify Consulting Inc. for a follow-up email and phone call, which some stakeholders did.

**“We don’t have a family doctor,
and no clinic I contacted was willing to
take an appointment to refer to a pediatrician
without being our family doctor.
I called over 100 clinics over 7 months
trying to get a referral to no avail.
It was extremely frustrating and disheartening.”**

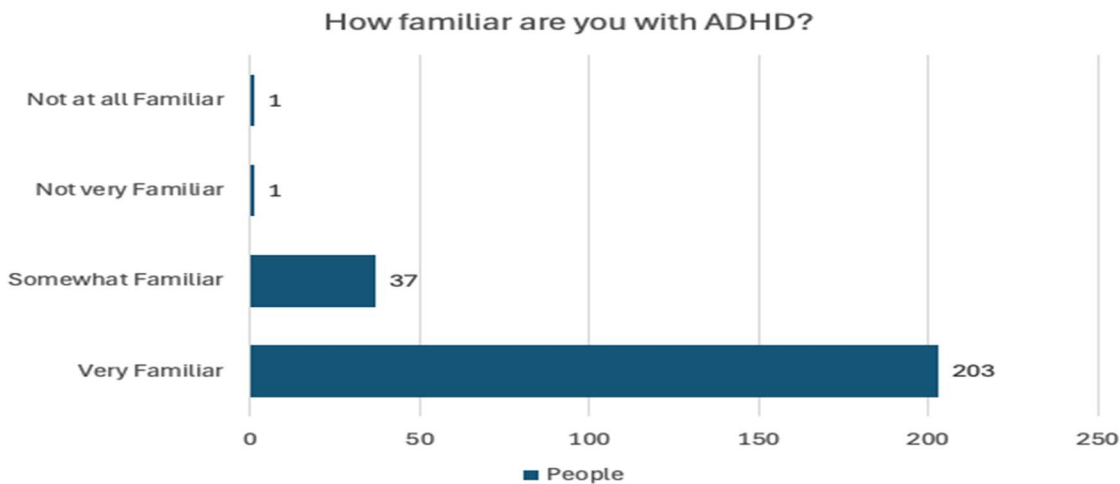
FINDINGS AND INSIGHTS FROM EXTERNAL STAKEHOLDER FEEDBACK

The intention of hosting engagement sessions with external stakeholders was to ensure their voices and experiences were heard to understand a few key items that will help the Society in their work. It will also provide information to MCFD on where gaps exist for those with ADHD looking for support and services. This is a summary of findings from all of the engagement work.

Awareness of ADHD

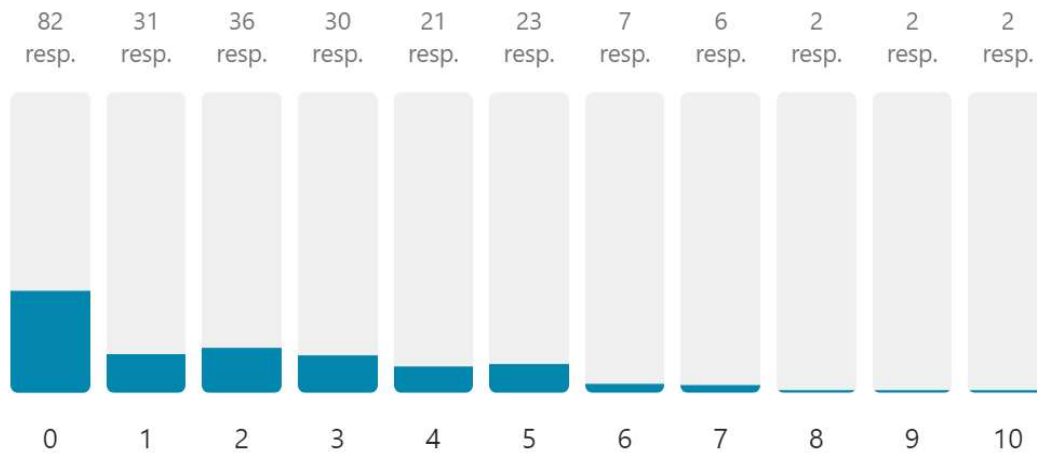
Question (Q): How Familiar Are You with Attention-Deficit/Hyperactivity Disorder (ADHD)?

Answer (A): Of the 242 online respondents, 203 shared they were very familiar with ADHD. There were 37 who shared that they were somewhat familiar with ADHD, while 1 person was not very familiar and 1 was not at all familiar with ADHD.



Q: How satisfied are you with the current support for ADHD?

A: The question asked the online survey-takers to respond between 0-10, with 0 being very dissatisfied and 10 being very satisfied.



Challenges in ADHD support and services

These are key themes of information shared by online and in-person respondents. To summarize the findings, while there were pockets of positive experiences, the overall sentiment expressed by respondents was one of **frustration** with long wait lists, a lack of ADHD-specific services, overworked staff, and systemic gaps in care coordination. The need for better communication, more targeted ADHD support, and a holistic, family-centered approach was a recurring theme.

Systemic Challenges with the Ministry of Children and Family Development

Varied Experience Levels

Experiences with MCFD range from ‘nothing’ to ‘extensive’, reflecting a broad spectrum of engagement with MCFD. Individuals with ‘extensive’ experience have often faced difficulties due to their history with the system, while those with limited interaction lack understanding of the services and supports offered.

Inadequate Support and Accessibility

Many participants expressed frustration with MCFD due to inadequate support or availability for ADHD diagnoses. Experiences included difficulties in accessing services, delays, and inadequate responses to their needs from those within MCFD and other healthcare providers.

Inconsistent Quality of Support

Feedback indicates a wide range of quality in services and supports. Some respondents have found MCFD staff helpful, while others shared they have experienced a lack of help and even bullying. The overall sentiment suggests that navigating MCFD can be complex and frustrating.

Systemic Failures

Participants noted that the MCFD framework does not adequately address the needs of individuals with ADHD, particularly those without additional diagnoses. This gap often results in families falling through the cracks or struggling to obtain necessary support.

Reactive rather than Proactive

The system is perceived as largely reactive, addressing issues only after they arise or reach a crisis rather than providing proactive support or preventive measures.

Lack of Awareness and Understanding

Unawareness of Family Connection Centres (FCC) and CYSN Services

Many participants were unfamiliar with FCCs and CYSN services, highlighting a broader issue of a lack of awareness of these resources. It should also be noted that if there is more awareness among those who need help, this will put an additional strain on services, which must be considered.

Concerns About Resource Allocation

Some participants expressed concerns about the potential negative impact of FCCs on existing autism funding, indicating a lack of clarity about how these services are integrated and their implications for ADHD support. It also shows a need for clearer communication from MCFD.

Misunderstanding of ADHD

Many individuals reported a lack of understanding and awareness about ADHD among both service providers and those within the broader community. This includes misconceptions about ADHD being a ‘legitimate’ disability and inadequate support for individuals with ADHD.

Dissatisfaction with Current Services

Service Accessibility Issues

Many respondents reported a low level of satisfaction with the current ADHD support services. Common issues included long wait times for diagnoses, difficulty accessing medication, and inadequate support within educational settings.

“Just incredible waitlists - there aren’t enough service providers for the number of kids who need support. We’re fortunate that we can pay privately. The costs are exorbitant.”

Underfunded and Overstretched Resources

There is a general dissatisfaction with the availability and quality of current support and services to support those with ADHD. Respondents noted that resources are limited, leading to long wait times and inadequate, timely assistance.

Reactive Support

Support services are seen as failing to address the needs of those affected with ADHD proactively. Many shared that MCFD and others only engage when problems escalate, reaching a crisis stage rather than providing proactive, preventative, or ongoing support.

Fragmented Support

Respondents noted a lack of comprehensive, coordinated support, leading to feelings of frustration and inadequacy in managing their or their child/youth’s ADHD. Additionally, there is a significant strain shared by those parents/guardians who do not have ADHD but are caring for children/youth with ADHD.

Impact of ADHD on Daily Life

The percentage of respondents who shared how ADHD has negatively affected them/their families:

Employment	Education	Mental Health	Physical Health	Justice
84%	90%	98%	81%	26%

Educational Difficulties

Respondents frequently reported that ADHD has negatively impacted their child’s or youth’s education. This included academic struggles, insufficient school support, a lack of mandatory teacher training and a supportive environment which resulted in behavioural challenges and exclusion. Many families have moved to home learning to ensure those supports, but then also experience a challenge with one parent required to be at home and not working, drawing down the amount of household income.

Mental and Emotional Strain

Respondents share that ADHD has contributed to significant mental health challenges for both individuals with ADHD and their families. This included burnout, stress, and mental health issues exacerbated by the lack of support, services, or a network of support.

Strain on the Family Unit

Respondents share that ADHD creates considerable strain on family life, from managing impulsivity and behavioural issues to the financial burden of medication and therapy. The emotional toll on families is significant, with some feeling judged, alone, and unsupported.

Employment

Barriers shared by respondents include filling out paperwork and a general lack of understanding or accommodation from employers for those with ADHD. Some respondents emphasized the need for better ADHD awareness and support in the workplace.

Summary of Interactions with MCFD

Survey respondents' experiences with MCFD services, including CYMH (Child and Youth Mental Health) and CYSN (Children and Youth with Support Needs), reveal several key insights:

Long Wait Times and Delayed Services

Many respondents expressed frustration with the long wait times to access CYMH and CYSN services. In some cases, families waited months or even years for support, which led to delayed diagnoses and opportunities for early intervention. For some, services arrived too late to be fully effective or were no longer necessary as the child had aged out of certain programs.

Resource Gaps and Overburdened Staff

Numerous respondents mentioned caseworkers are overworked, which has limited their ability to provide consistent and effective support. Some respondents shared they do much of the research and 'legwork' themselves, including pre-filling out forms or advocating for necessary services. Limited staffing and high turnover among workers seem to compound the challenges.

“No family doctor to accept my family as patients made getting a diagnosis so hard. We only have access to walk-in doctors. Getting medication sorted has been an even bigger challenge.”

Inconsistent and Limited Supports

Respondents highlighted inconsistencies in the quality of service provided. Some described positive experiences, particularly with individual workers or programs like “Riding the Waves of Parenting” or services provided through The Foundry. However, others noted that caseworkers have frequently changed, leading to a lack of continuity and lost progress for their child/youth. Additionally, some families found CYMH services to be dismissive of ADHD, focusing on diagnoses like anxiety or autism instead, which limited the relevance of the support provided.

Lack of Tailored Services for ADHD

Many families shared that ADHD-specific services were either nonexistent or insufficient. CYMH and CYSN often focused on autism, anxiety, or other conditions, leaving ADHD-related challenges under-addressed. Respondents expressed a desire for more targeted ADHD services, including sensory integration work, executive functioning training, and social skills development, which were largely unavailable.

Frustration with the Lack of Holistic Support

“Services are very long waitlisted, and the service is very short lived. A lot of services providers do not have actual or lived experiences.”

Respondents shared that the services provided by CYMH and CYSN were too narrow in scope, focusing primarily on parenting classes or basic mental health interventions. Families expressed a desire for a more comprehensive and proactive approach that includes emotional support, respite care, and guidance on navigating the complex system of ADHD-related services.

Challenge in Interactions with Child Protection Services (CPS)

Several respondents had interactions with CPS and reported stressful or traumatic experiences. CPS involvement was often triggered by concerns unrelated to ADHD, such as messy homes or behavioural issues. Families noted that CPS often failed to consider ADHD and related neurodiversity as contributing factors, and instead, parenting was blamed. There were reports of children being removed or families being investigated without proper support being offered.

Systemic Inequality and Discrimination

Respondents from marginalized communities, particularly BIPOC families, noted their experiences with MCFD were disproportionately negative. Some families felt targeted or discriminated against based on race, neurodiversity, or socioeconomic status, which compounded the stress of interacting with child protection and mental health services.

Lack of Communication and Follow Up Care/Support

Consistent concerns were shared about poor communication between families and MCFD. Forms were often lost or misplaced, and follow-up was inconsistent. Some respondents reported feeling abandoned by the system, with no clear guidance on how to move forward or access appropriate support.

Identified Gaps in Support

One of the goals of the engagement initiative was to determine if the identity of the respondent, such as gender, sex, race, etc., impacted access to ADHD services. The analysis of responses showed that while many respondents reported no identity-based barriers to accessing ADHD services, several significant identity-related challenges were highlighted by others, particularly related to gender, race, and immigrant status. Barriers identified include:

Gender-Based Biases

Delayed Diagnosis for Women and Girls

Several female respondents reported they were diagnosed late in life, often as adults, due to ADHD being stereotypically viewed as a disorder affecting hyperactive boys. Women often have inattentive ADHD, which is less understood, leading to their symptoms being ignored or misdiagnosed with other conditions like depression or anxiety. Specific examples from respondents included diagnoses delayed until their 20s, 30s, or 40s. One respondent shared they were misdiagnosed for 11 years.

Not Taken Seriously

Female respondents described facing dismissive healthcare providers who underestimated their symptoms because they did not fit the 'typical ADHD profile'. One respondent was dismissed because she had excelled in school, while another noted that being 'high functioning' led to her symptoms being downplayed.

"Girls are not expected to have ADHD, and neither are 'grown-ups'. Many health professionals dispute the diagnosis of ADHD, and if they do support it, they expect people to

Systemic Ignorance of 'Female ADHD'

Many respondents shared that the healthcare system is not equipped to recognize ADHD in women and girls, with some respondents sharing that support for girls with ADHD is almost non-existent in schools and other health services. Others pointed out that doctors often had a male-centric view of ADHD, making it harder for women to get appropriate care.

Class and Income Barriers

Financial Barriers to Care

Several respondents mentioned accessing ADHD services, particularly for adults, often requires the financial ability to pay for private assessments or medication, which can be prohibitively expensive. This lack of affordability for assessments (costing thousands of dollars) or proper treatment is a significant barrier for individuals.

"Publicly funded counselling has been a waitlist nightmare. Our family had to pay and source privately. This has been a significant financial burden in both securing a diagnosis and paying for ongoing private support."

High Cost of Private Assessments

Due to long wait times in the public healthcare system, many respondents were forced to seek private assessments, which can cost between \$1,300 and \$3,500. This was a major financial burden for families and individuals, and in some cases, families have gone into debt to cover these costs.

Ongoing Expenses for Care

Beyond the assessment and diagnosis, the costs of therapy, ADHD coaching, medications, and other services are frequently out-of-pocket, further adding to a family's financial strain. Many families without insurance and those in a diverse range of income brackets shared that they have faced significant obstacles in accessing necessary support.

Age-Related Barriers

ADHD Perceived as a Childhood-Only Disorder

Several adult respondents reported being dismissed by healthcare providers because ADHD is seen as a 'condition' that only affects children. This, in turn, has led to late diagnoses for many respondents, with several not receiving a diagnosis until they were in their 30s or 40s. Some were misdiagnosed earlier in life with depression, anxiety, or behavioural issues.

Limited Services for Adults

Adults participating in the engagement initiative expressed frustration with the lack of services or support tailored to adults with ADHD, particularly in more rural regions in northern B.C. Several noted that accessing services required financial resources for private assessments or specialist care, as public services were insufficient or non-existent.

Transgender Identity

Focus on Gender Identity over ADHD

One respondent noted that their transgender child struggled to access ADHD care because appointments often focused more on pronouns and gender identity issues, which detracted from the ADHD-related care they needed. In one of the in-person sessions, a transgender person also noted the challenges they've had trying to access healthcare and ADHD diagnosis.

“Our pediatrician thought ADHD was over diagnosed and wanted to rule out environmental factors even though I had already done the work surrounding sleep, diet, parenting, etc.”

Systemic Issues with Medical Professionals

Dismissive Healthcare Providers

Respondents expressed frustration with doctors who were either dismissive of ADHD as a diagnosis or focused on other conditions, such as depression. Others mentioned that general practitioners lacked the expertise to diagnose ADHD or provide appropriate referrals to specialists. Some reported being told by doctors that ADHD only affects children or being misdiagnosed with other conditions (e.g., depression, anxiety, PTSD) for years. Others encountered skepticism from doctors who minimized their symptoms based on the person's academic success or outward functionality. These systemic issues have contributed to delays in diagnosis and proper care for respondents.

Reluctance to Diagnose or Prescribe Medication

Several respondents noted that even after receiving a diagnosis, doctors have been resistant to prescribing ADHD medication or supporting alternative treatments like Cognitive Behavioral Therapy (CBT).

School Related Challenges

Lack of Support and Understanding from Schools

Respondents shared that schools often failed to recognize ADHD, especially in girls and quieter students. In some cases, schools did not accept diagnoses from family pediatricians and insisted on assessments from specific institutions, causing further delays.

Teachers and Administrators Dismissing Concerns

Respondents shared their experiences with teachers who were sometimes reluctant to complete ADHD questionnaires, particularly if the child wasn't disruptive in class. Others downplayed the severity of the symptoms, making it difficult for parents to advocate for their children's needs.

Geographical and Accessibility Issues

Limited Access to Specialists

Families in rural or remote communities shared that they face significant challenges accessing ADHD specialists. Many respondents have had to travel long distances to access care, adding logistical and financial burdens to an already complex process.

Lack of Family Doctors

Some families and individuals, particularly those relying on walk-in clinics, struggled to begin the diagnostic process due to a lack of family doctors, who are often one of the trusted pathways to make the necessary referrals to pediatricians or specialists.

Social Stigma and Internalized Ableism

Stigma surrounding ADHD

Some respondents expressed hesitation in seeking a diagnosis due to the stigma surrounding ADHD. This included internalized ableism, fear of being judged by others, or concern about being perceived as lazy or incapable.

Stereotypes About ADHD

The widespread belief that ADHD is ‘over-diagnosed’ or only affects hyperactive boys has further complicated the process of getting diagnosed for respondents, particularly for girls and adults.

Obstacles for Parents and Families

Lack of Agreement Between Parents

A few respondents faced resistance from a co-parent or family member who did not support the diagnosis of ADHD or refused to participate in the assessment process. This added a layer of difficulty in advocating for the child/youth.

Family Misunderstandings

Several respondents mentioned that their family members, such as grandparents or parents, don’t believe ADHD is real or dismissed their concerns, making it harder to get a diagnosis and seek support.

Immigrant Status

Struggles Navigating the Healthcare System

Immigrants reported difficulty accessing ADHD services due to unfamiliarity with the healthcare system. They often felt lost and uncertain about where to begin, which created a barrier to getting support for their ADHD needs for their children.

Race and Ethnicity

Racial Biases

A few respondents noted racial factors impacting their access to ADHD services. One respondent felt that being ‘white and well-educated’ provided them with easier access to support, while another felt that certain minority groups were more targeted for support in schools. A third respondent raised concerns

about stereotypes affecting Asian female students, who may stereotypically be seen as not needing educational support.

SOLUTIONS UNCOVERED THROUGH STAKEHOLDER FEEDBACK

Through the survey, as well as the in-person and Zoom engagement sessions, the goal was to understand what big-picture solutions respondents had in mind and what their priorities were. The responses suggest a variety of improvements to better support individuals with ADHD, focusing on the **education systems**, **healthcare**, and overall **community support**. Here are the seven key areas, each with additional ideas to further expand on the solutions:

1. **School-Based Support**
2. **Parental and Family Support**
3. **Access to Early Diagnosis and Comprehensive Services**
4. **Mental Health and Community Integration**
5. **Public Awareness and Training**
6. **Government Funding and Policy Changes**
7. **Social and Emotional Support**

The overarching themes suggest a need for **better training** for educators and medical professionals, **earlier and more accessible diagnosis**, **continuous wrap-around services**, **increased government funding**, and **stronger parent/guardian and community support systems**. Respondents envision a holistic, well-funded system that supports ADHD across all stages of life, reduces stigma, and provides individualized resources tailored to each child's or adult's unique needs.

The following is a summarized list of the key areas identified:

"School did not believe the diagnosis.

Blamed the child as being out of control and not trying hard enough."

School-Based Support

More Trained Staff and Resources in Schools

Respondents emphasized the need for more teachers, educational assistants (EAs), and mental health professionals trained to support ADHD. Solutions include smaller class sizes, full-time in-class support, and better-trained staff across all school roles, including teachers, EAs, administrators, coaches, etc.

ADHD as a Designation for Learning Support

Many respondents suggested that ADHD should be recognized as a funded designation, like autism, providing students with additional resources, including educational and learning supports and access to social-emotional learning programs.

Specialized and Inclusive Learning Environments

In the feedback, there was significant support for alternative schools, home learning, or specialized classes for children with ADHD, as well as training educators on ADHD-specific teaching strategies and how to provide inclusive learning environments.

Parental and Family Support

Parent Training and Support Groups

There was a call for more accessible training for parents and guardians to help them manage their child or youth's ADHD. Respondents wanted to see structured parent support groups, respite care, and family coaching programs, especially for those who have ADHD themselves.


Access to Resources and Guides

Respondents shared that families should be given comprehensive resource guides upon diagnosis, including information on support services, financial assistance, and educational strategies. Online support systems and community connections were also emphasized to help parents feel less isolated.

Access to Early Assessment and Comprehensive Services

Earlier and More Accessible Diagnosis

Many respondents wanted earlier ADHD screenings in school or as soon as children enter the education system. They also called for easier access to assessments, including reducing wait times for psychological evaluations. Many respondents also suggested that when a child/youth is assessed, biological parents should also be assessed.



“There is a lack of funding and neuro-affirming practitioners/services.”

Comprehensive, Multidisciplinary Services

Several respondents suggested a one-stop shop or ADHD-specific centres offering diagnosis, therapy, and support services. These centres could provide holistic care, including mental health services, occupational therapy, and life skills training covered by government funding.

Support for Vulnerable Populations

An emphasis on providing targeted ADHD services for vulnerable populations, such as those experiencing homelessness or substance abuse issues, was a unique focus in the responses.

Mental Health and Community Integration

Wrap-around and Continuous Services

Respondents stressed the need for wrap-around services that follow children and families throughout their ADHD journey, including caseworkers or navigators who help coordinate appointments, school support, and transition into adulthood.

Mental Health and Life Skills Programs

Many shared they wanted to see advocacy for free or subsidized counselling, ADHD coaching, and life skills programs that address both ADHD and related emotional or social challenges, such as anxiety and depression.

Public Awareness and Training

“Everything is limited. While the teachers have been understanding, their resources, including time and money, are limited.”

Public Awareness Campaigns

Respondents suggested that media and ongoing campaigns can help reduce stigma and educate the public about ADHD – what it is and what it isn’t. Respondents believe these campaigns could help improve understanding, dispel myths, and promote acceptance and support.

Training for Educators and Healthcare Professionals

Respondents shared that education and healthcare staff need better, mandatory training on ADHD, including understanding executive functioning deficits and how ADHD affects emotional regulation, learning, and social interactions.

Government Funding and Policy Changes

Increased Funding for ADHD Services

Many respondents stressed the need for consistent government funding for ADHD support, including educational programs, mental health services, and medical care. They wanted ADHD to be treated like other disabilities, with access to individualized funding systems like Autism Funding (AFU).

Flexible, Individualized Support Models

Respondents want to see advocacy for funding models that allow families to choose service providers, ensure access to local services, and reduce travel and financial burdens. They also wanted to see support for policies that ensure timely access to diagnosis and ongoing support.

“The commitment of time to go through each of the hoops required to get support is exhausting.”

Social and Emotional Support

Programs to Build Social Skills

Respondents emphasized the need for more programs focused on social-emotional learning, including opportunities for children/youth with ADHD to build friendships and work on emotional regulation and frustration tolerance.

Support Networks for Adults with ADHD

Respondents shared a desire for more support for teens and adults with ADHD, including life transition programs, employment training, and continued access to therapy and coaching.

Creation of Safe Spaces

Respondents suggested physical safe spaces tailored for individuals with ADHD, which could include sensory-friendly environments, therapeutic services, and community support systems.