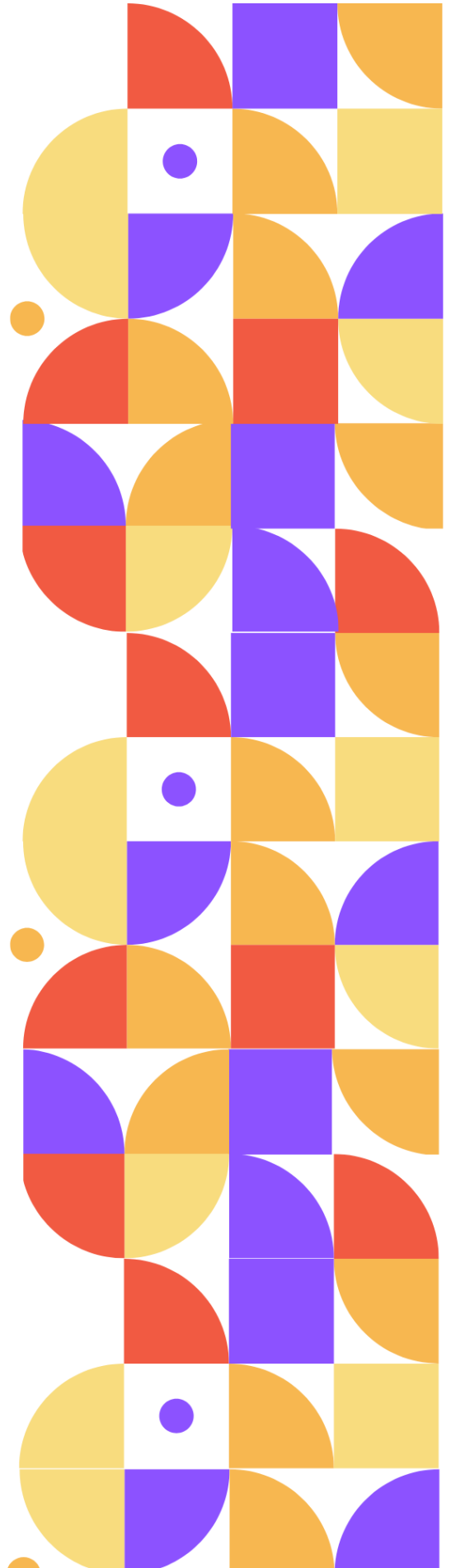


● APPENDIX

RAW DATA - ONLINE SURVEY

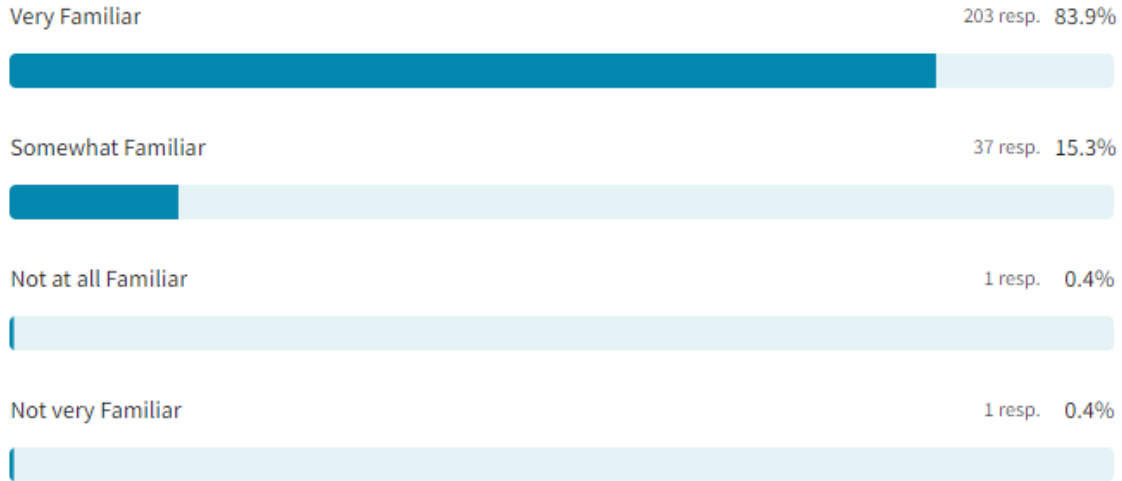


ADHD ADVOCACY SOCIETY OF BC COMMUNITY ENGAGEMENT SURVEY

This engagement is the beginning of a wider conversation on ADHD support, acting as a foundation for future advocacy. Participation is voluntary, confidential, and vital for creating a more inclusive support system.

1: How familiar are you with Attention-Deficit/Hyperactivity Disorder (ADHD)?

242 out of 243 answered

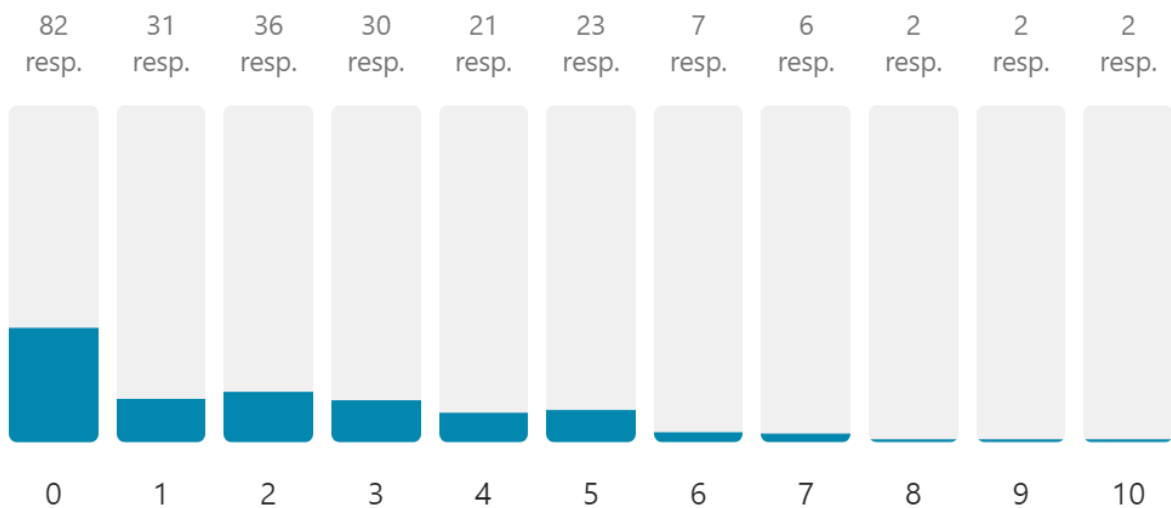


The definition of ADHD as appearing in DSM-5

ADHD is a neurodevelopmental disorder defined by impairing levels of inattention, disorganization, and/or hyperactivity-impulsivity. Inattention and disorganization entail inability to stay on task, seeming not to listen, and losing materials necessary for tasks, at levels that are inconsistent with age or developmental level. Hyperactivity-impulsivity entails overactivity, fidgeting, inability to stay seated, intruding into other people's activities, and inability to wait— symptoms that are excessive for age or developmental level. **Reference:**

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9871920/>

2: How satisfied are you with the current supports and services available for individuals and families affected by ADHD? On a scale of 0 to 10, 0 being very dissatisfied and 10 being very satisfied, select one. 242 out of 243 answered | 2.2 average rating



3: Please select all the categories that apply to you. This will help us understand the diverse perspectives and experiences within our community. 242 out of 243 answered

A Family member/Caregiver with lived experience caring for a child/youth with ADHD 190 resp. 78.5%



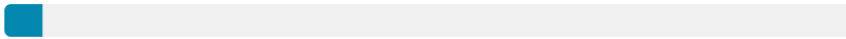
A youth/adult with ADHD 123 resp. 50.8%



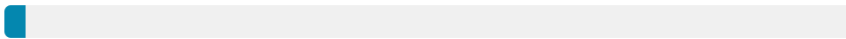
A Service Provider (including medical professionals, social workers, etc.) who works with people with ADHD 79 resp. 32.6%



Part of an organization that can or does collaborate with the ADHD Advocacy Society of BC 11 resp. 4.5%



A volunteer, a staff member, a board member or a Board Director with the ADHD Advocacy Society of BC 6 resp. 2.5%



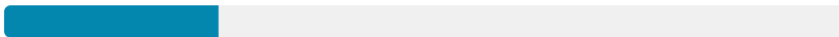
4: From the categories you've selected, please choose one that you feel most strongly aligned with or from which you can provide the most detailed feedback. (If you identify with multiple categories and wish to offer insights from these varied perspectives, you are welcome to retake the survey for each specific category.) Your survey experience will be tailored based on this selection.

243 out of 243 answered

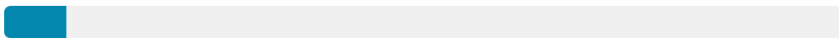
A Family member/Caregiver with lived experience caring for a child/youth with ADHD 160 resp. 65.8%



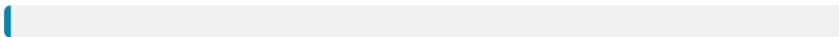
A youth/adult with ADHD 62 resp. 25.5%



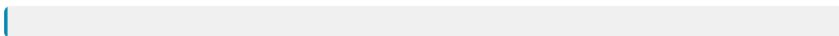
A Service Provider (including medical professionals, social workers, etc.) who works with people with ADHD 18 resp. 7.4%



Part of an organization that can or does collaborate with the ADHD Advocacy Society of BC 2 resp. 0.8%

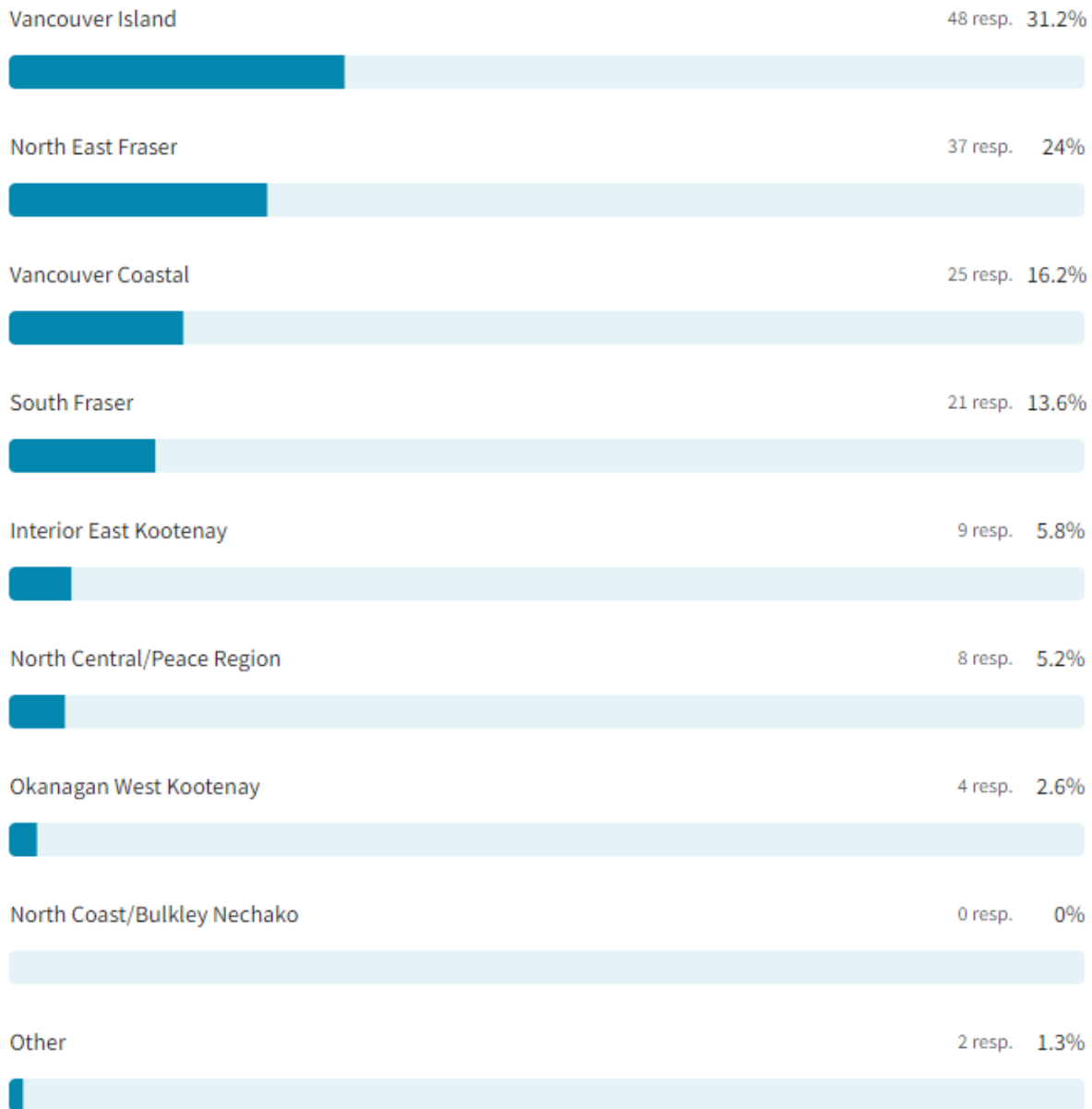


A volunteer, a staff member, a board member or a Board Director with the ADHD Advocacy Society of BC 1 resp. 0.4%



Family/Caregiver w/ lived experience caring for a child/youth with ADHD

1: What region of the province are you from? 154 out of 160 answered



The two responders who selected “other” are from Abbotsford/Fraser Valley and Alberta.

2: How many children or youth in your care have been diagnosed with ADHD?

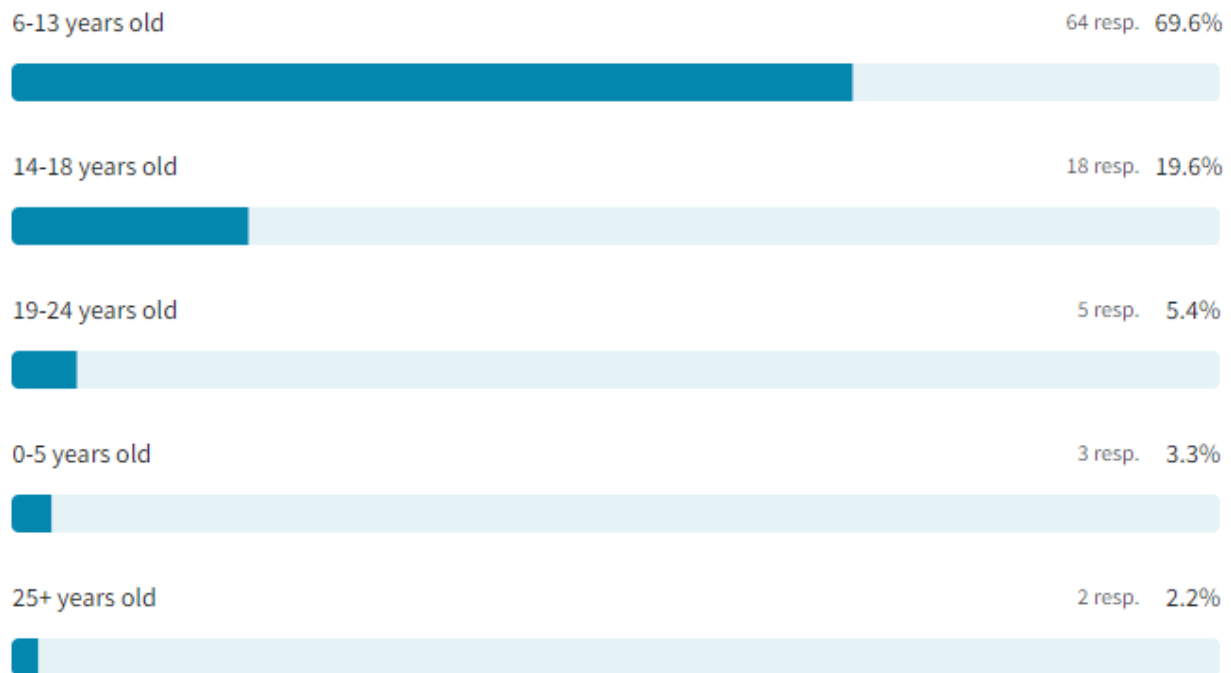
160 out of 160 answered

As many as 98 respondents have one youth or child in their care diagnosed with ADHD.

The non-mandatory demographic questions for them were answered by 93 respondents.

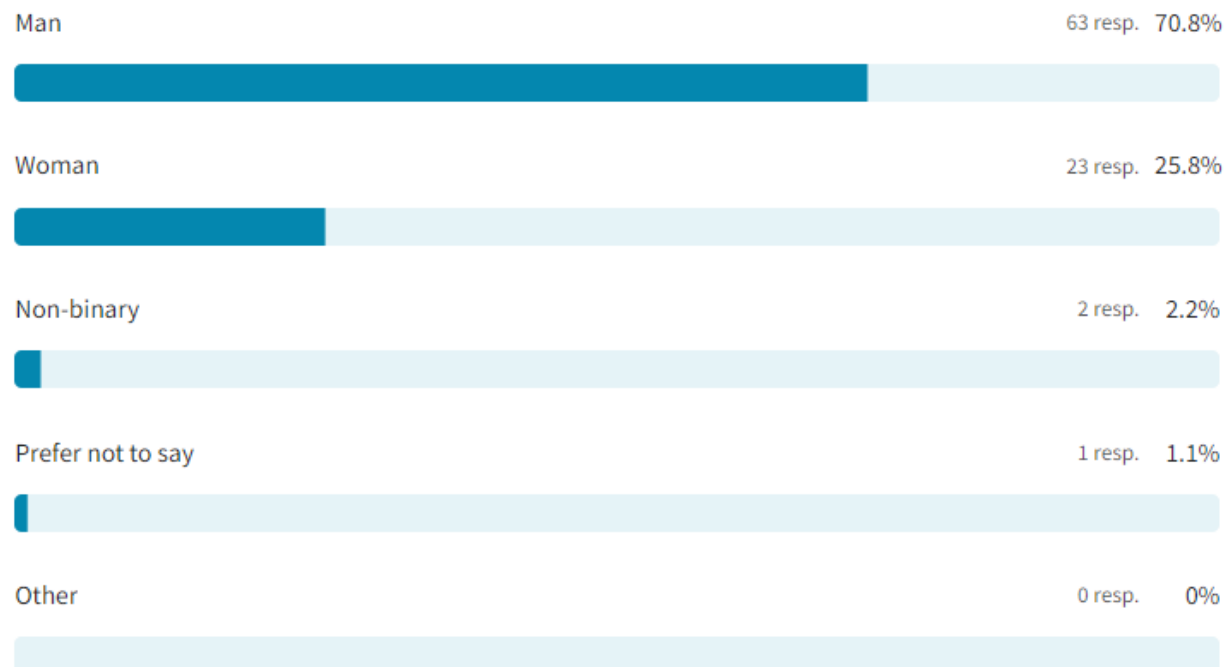
3: What is the age range of the child or youth with ADHD for whom you provide care or support?

92 out of 160 answered Please note



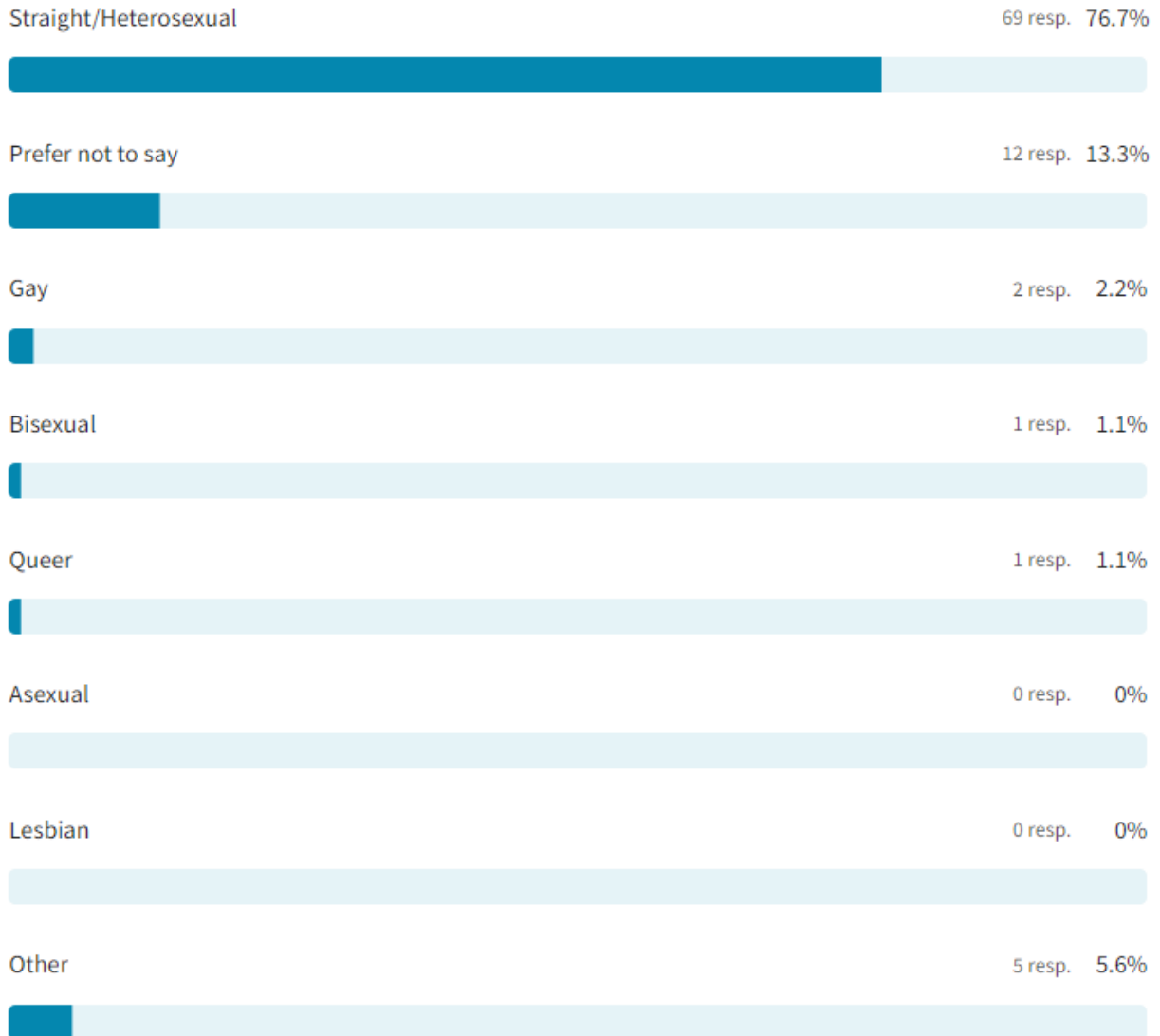
4: Which gender does your child/youth with ADHD in your care most identify with?

89 out of 160 answered Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.



5: How does the child/youth with ADHD in your care describe their sexual orientation?

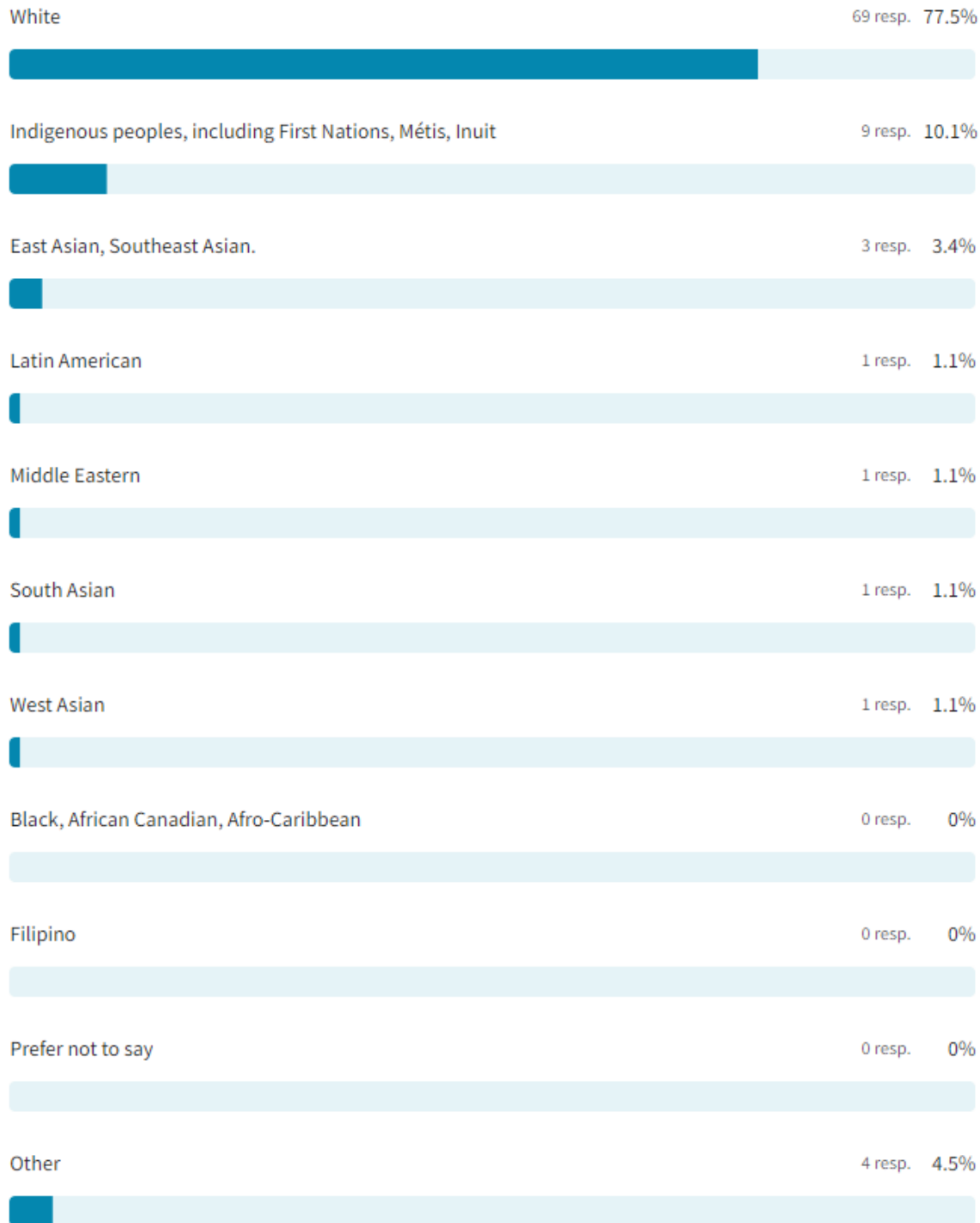
90 out of 160 answered *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*



Other: 5 responses with details >

- Assume straight but he is young
- too young to say
- Not sure yet!
- Too young to have identified
- They do not describe their sexual orientation, too young

6: How do you describe the race or ethnicity of the child/youth with ADHD in your care? 89 out of 160 answered *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*



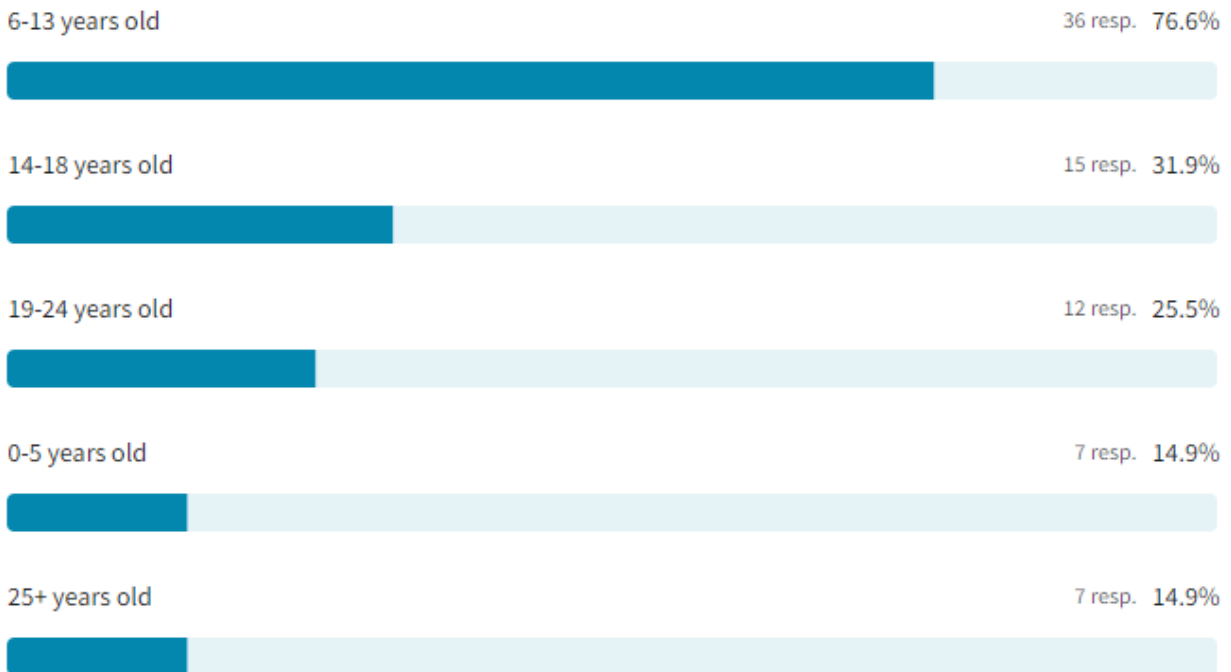
Other: 4 responses with details >

- White and west Indian
- Mixed race
- White & Afro-Caribbean
- Mixed: white & south Asian

A total of 48 responders mentioned having two children or youth in their care diagnosed with ADHD.

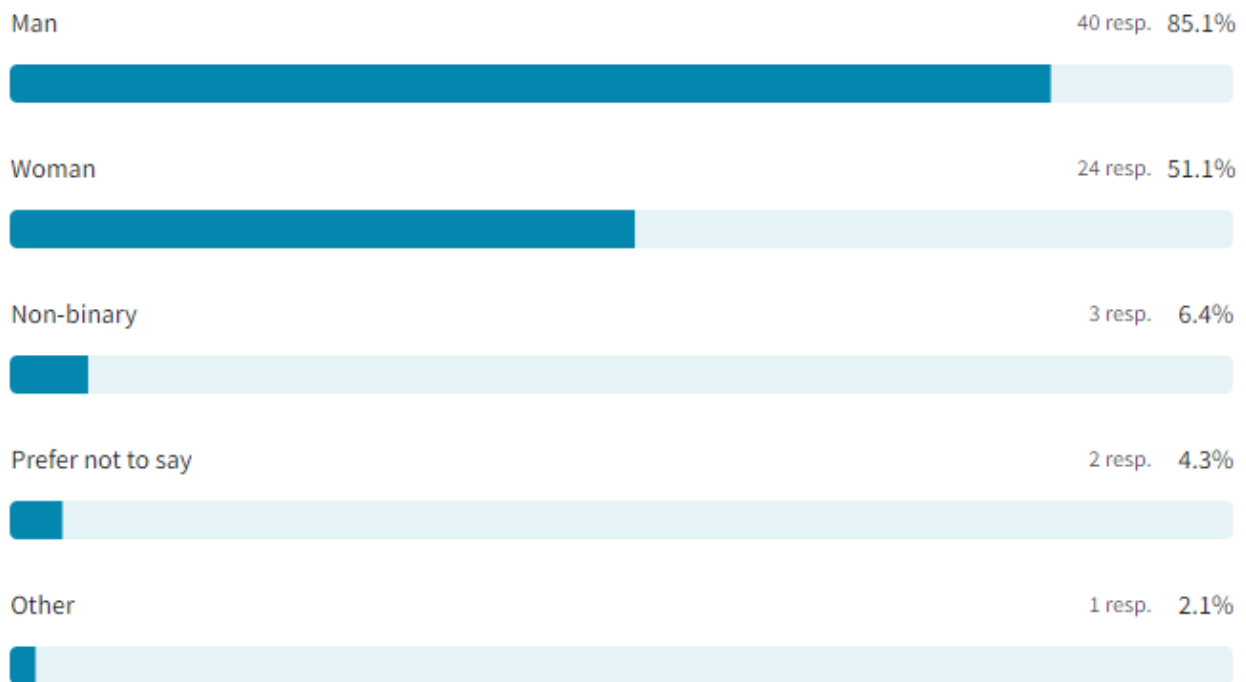
7: What is the age range of the child or youth with ADHD for whom you provide care or support?

47 out of 160 answered (with multiple choice)



8: Which gender does your child/youth with ADHD in your care most identify with?

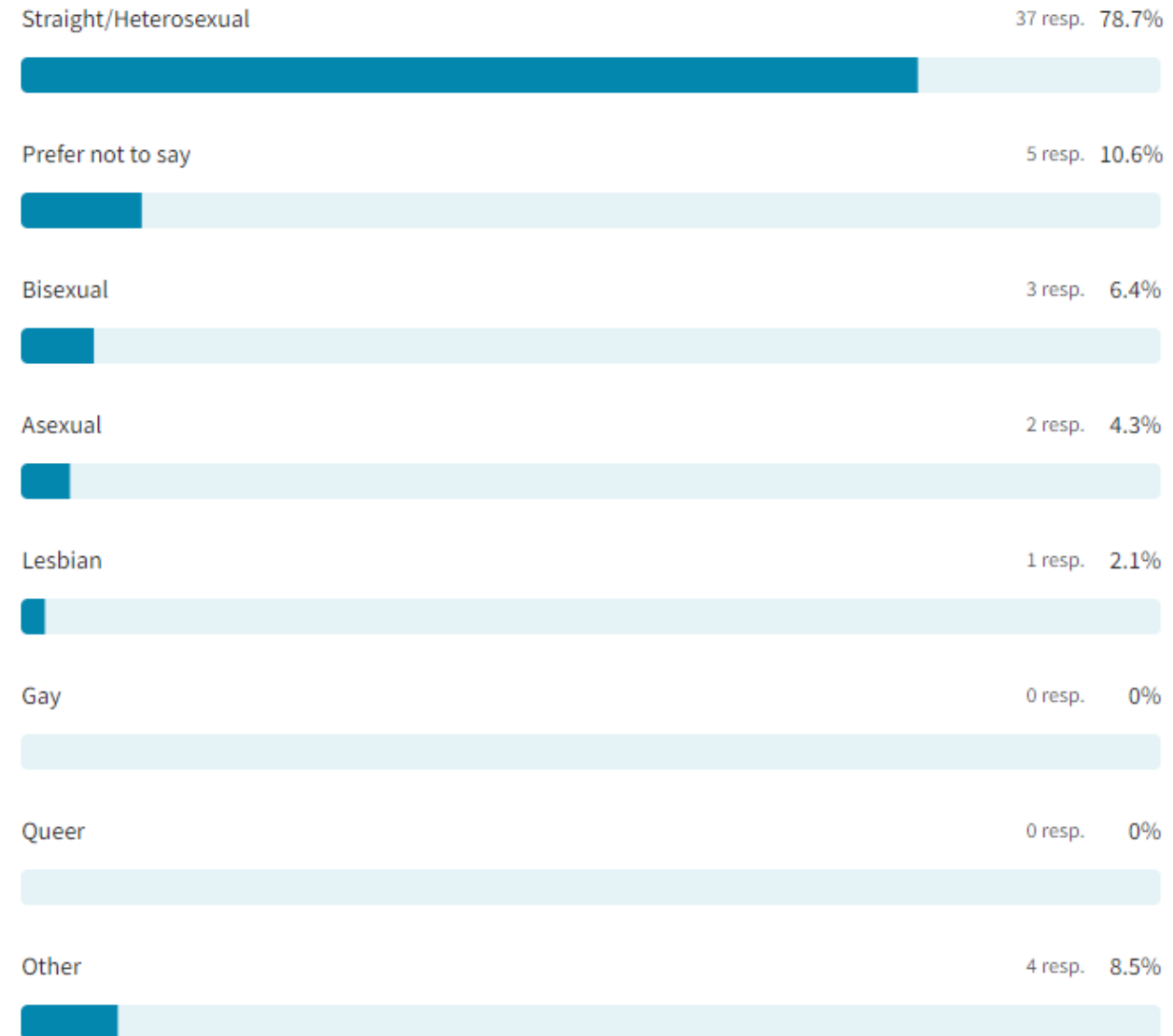
47 out of 160 answered (with multiple choice) *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*



Other Response = girl

9: How does the child/youth with ADHD in your care describe their sexual orientation?

47 out of 160 answered (with multiple choice) *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*

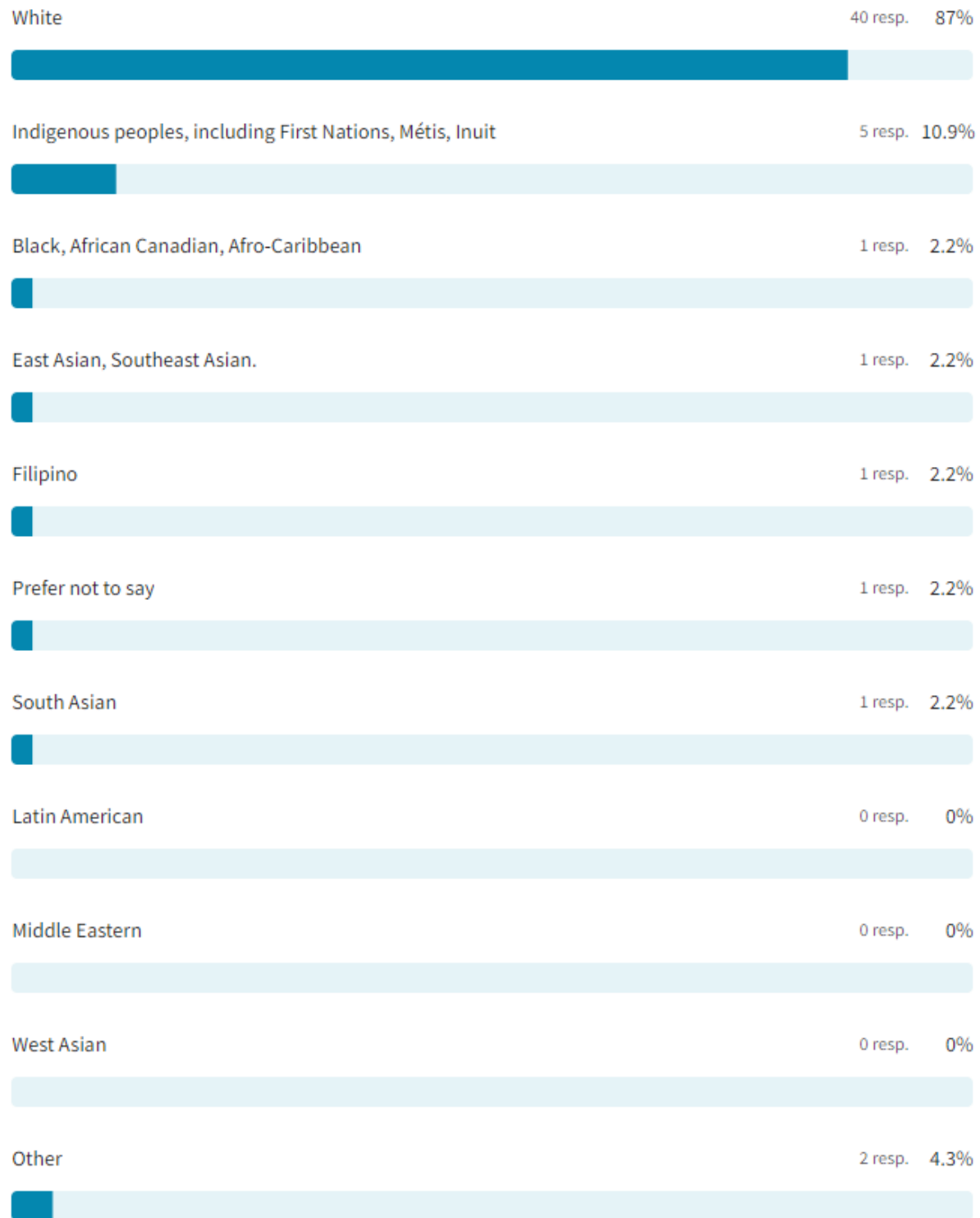


Other: 4 >

- They are young and haven't disclosed a preference yet
- To young to know
- Unknown at this age
- Not yet determined

10: How do you describe the race or ethnicity of the child/youth with ADHD in your care?

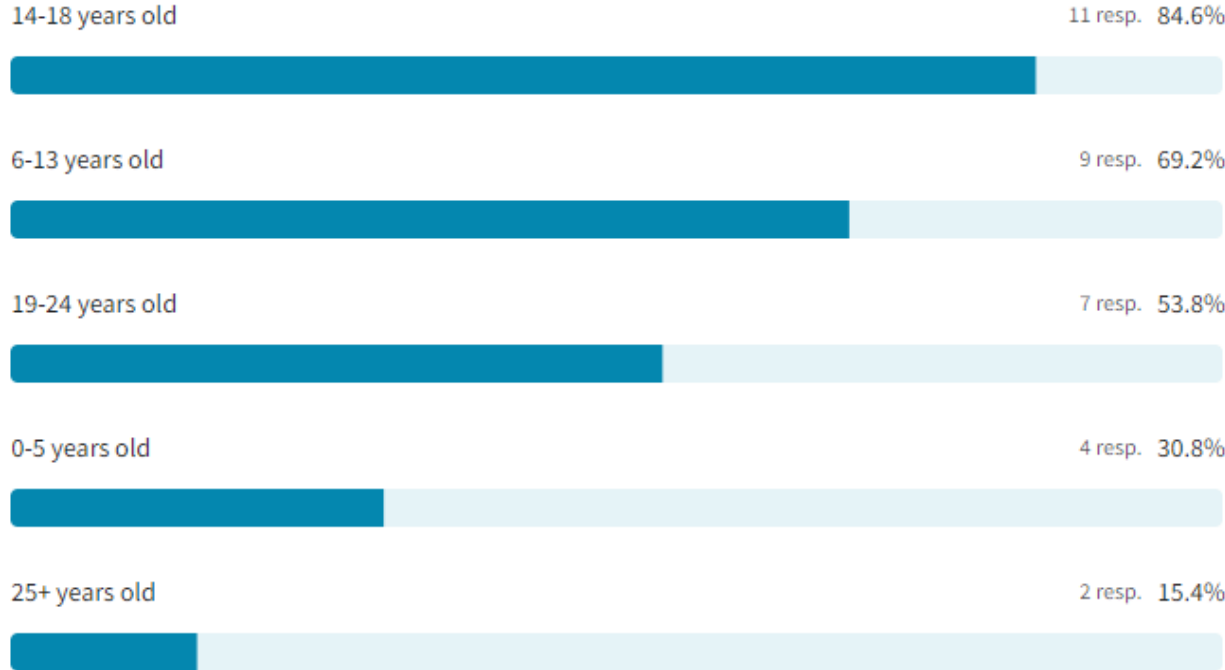
46 out of 160 answered (with multiple choice) Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.



Other: 2 > Recent immigrants | Spanish

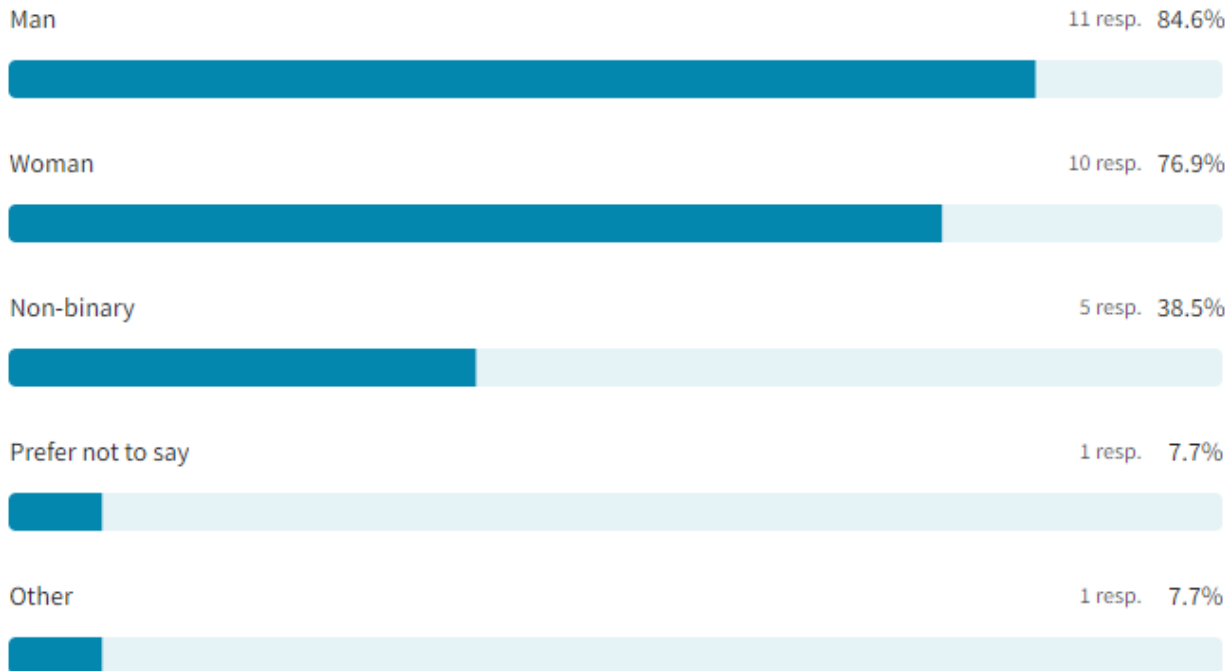
There were 14 respondents who mentioned they had three or more children or youth in their care diagnosed with ADHD.

11: What is the age range of the child or youth with ADHD for whom you provide care or support? 13 out of 160 answered (with multiple choice)



12: Which gender does your child/youth with ADHD in your care most identify with?

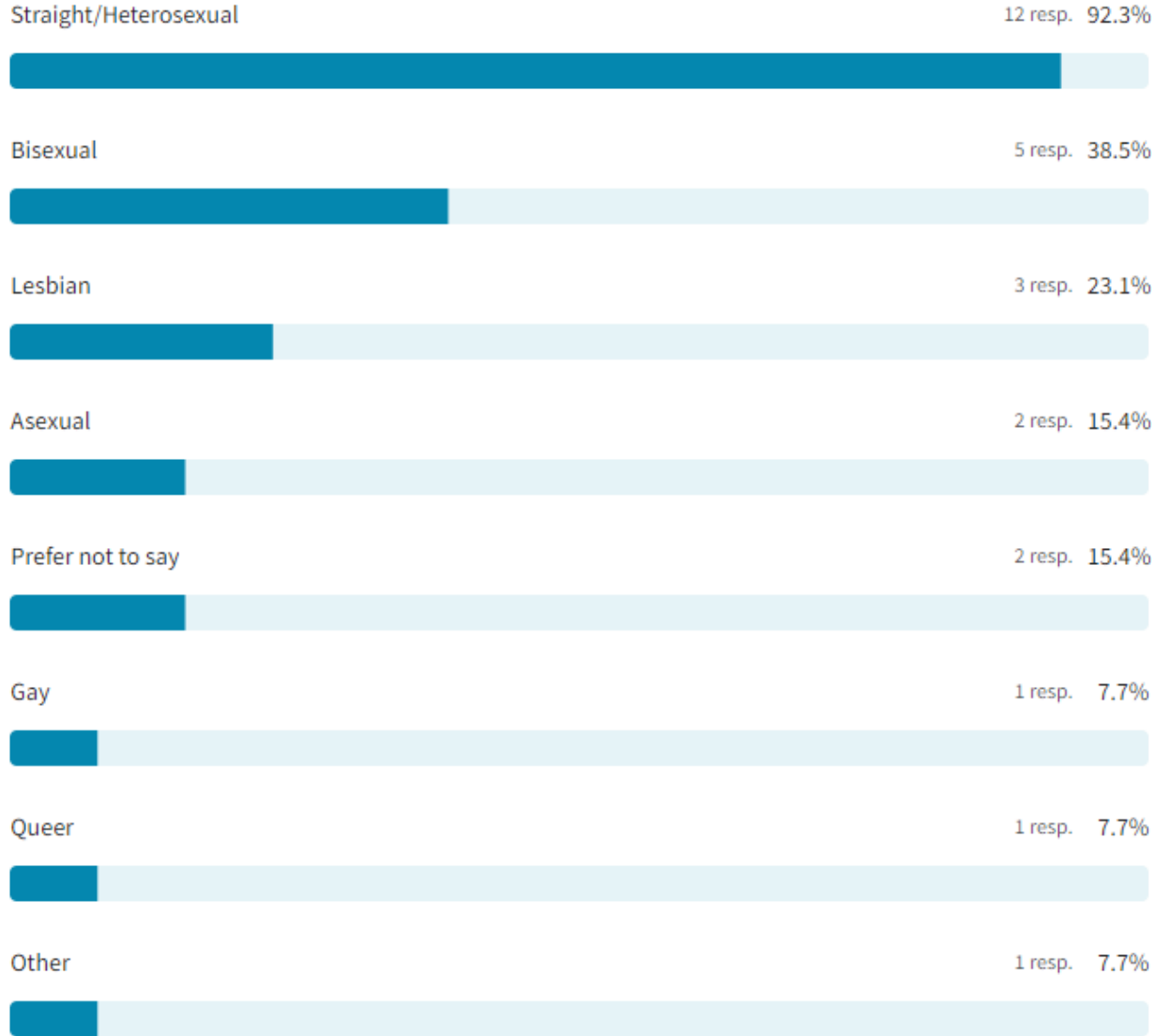
13 out of 160 answered (with multiple choice) *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*



- Other:
- pangender

13: How does the child/youth with ADHD in your care describe their sexual orientation?

13 out of 160 answered (with multiple choice) *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*

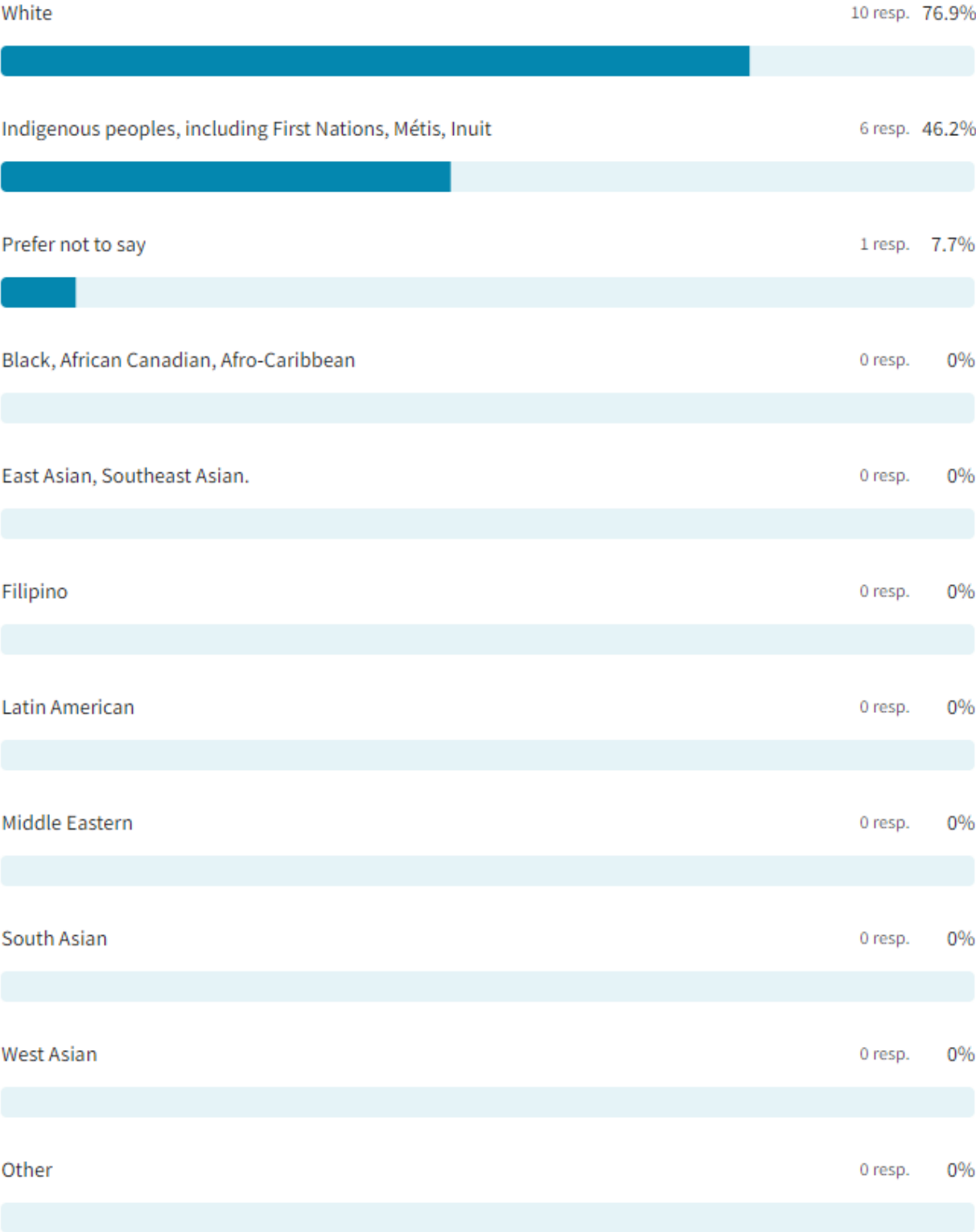


Other:

- panromantic, gynoromantic

14: How do you describe the race or ethnicity of the child/youth with ADHD in your care?

13 out of 160 answered (with multiple choice) *Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.*



15: If you answered any of the Identity Questions, please share if you encountered any barriers to accessing ADHD services as a result of the specific identities. Please elaborate.

67 out of 160 answered

1. No
2. No
3. Not prioritized for Psych Ed assessment at school despite multiple consecutive years of promises that he would be “next”
4. I have accessed supports because I am a white, middle-aged and well educated mother and my son presents as 100% white
5. Many more supports are targeted to minority groups in our schools.
6. none
7. No
8. No
9. No
10. No
11. No
12. Yes, as women/girls who are not thought of as possibly needing support.
13. As new immigrants with diagnosis already, we are really struggling to "break into the system" here for support, and really don't know where to start.
14. Supports for girls with ADHD do not seem to exist. The focus with children is on the hyperactivity, and many girls do not exhibit these traits physically, which leads to them being ignored as also needing support for ADHD.
15. There is an overall lack of services, never mind niche specific services like Indigenous or LGBTQ2+
16. N/a
17. No
18. One barrier would be being a female & having inattentive version of ADHD
19. Lack of support surrounding the family as a whole and how to interact with their siblings and friends.
20. No and curious why so many neurodiverse children question
21. no
22. none
23. Taking too long to access services and no resources for kids with ADHD in the school
24. None
25. no
26. None known
27. Unsure
28. No
29. No barriers as a result of identity
30. My daughter has had significant issues accessing ADHD services due to her gender and the way ADHD typically manifests in girls.
31. no
32. None because of the specific identities
33. Low support for ADHD. If there are any, its geared for autistic children.
34. I find the neurodiverse community very accepting so no barriers
35. No
36. As Great Grandparent I am not involved in accessing ADHD services. I am an intermittent caregiver.
37. No- not in our case
38. Nope
39. N/A

40. We just don't have any ADHD services at all
41. Not enough resources, hard to know where to begin, lost and in the dark, wait lists.
42. No nothing specific to identity
43. Misdiagnosed for 11 years, despite 2 previous psychological assessments. Girls don't present the same way as a boy would
44. Yes, one child has had barriers as a result of being disabled with multiple issues, thus having a complex profile.
45. Being an immigrant, I was not aware of services and resources
46. As son was not native and did not receive an autism diagnosis we left P1 with a diagnosis and referral to CYMH. The other children there left with art, music, horse therapy classes etc.
47. Class related barrier: Low income
48. As a female with ADHD it is not as recognized
49. girls are not expected to have ADHD & neither are "grown-ups". many health professionals dispute the diagnosis of ADHD, & if they do support it, expect people to outgrow it
50. None
51. No barriers encountered based on gender or race.
52. There's barely no services or support from government other than non-profits and good teachers/educators from our public schools who are willing to support. We need a coordinated approach to support all children (and hopefully one day adults too) with all diverse abilities. It's sad to know that the Family Connection Centres are only piloted in limited areas with such a slow timeline of rolling out across the Province for all families - and without long term commitment of supports for families. So many families are struggling. It's time to realign government priorities and ensure we put our children with all diverse abilities and disabilities first!
53. yes
54. No
55. Unsure if ethnicity plays a role in stereotypes of Asian female students needing less educational support.
56. Barrier was doctors, Youth Mental Health, and counsellors telling us "this is in the range of normal behaviour for a 7yr old boy".
57. Services are very long waitlisted and the service is very short lived. A lot of services providers do not have actual or lived experiences. Everything seems hidden.
58. White males are presumed to be as generally able to take care of themselves and "rich", so few supports are given, even if their family is not wealthy.
59. No
60. No
61. Child is trans and we have to spend a disproportionate amount of time at every appointment dealing with pronouns and name issues as well as general education rather than why we are actually there
62. no
63. No
64. I believe there was a delay in identification due to gender identity and lack of information/understanding of atypical presentations of ADHD.
65. The questions used to identify ADHD were developed for those who are born male. We fell through the cracks once, then only received the diagnosis after paying a psychologist \$7500 for a complete assessment.
66. Lack of support from medical professionals (and family members) because "they're just boys"
67. No specific barriers based on identity, but certainly based on availability of services/diagnosis.

DIAGNOSIS

In the following set of questions, we delve into your experiences with the ADHD diagnosis, aiming to capture both its process and its impact on your life.

16: Is the youth or child in your care self-diagnosed? 160 out of 160 answered

Yes 12 resp. 7.5%



No 148 resp. 92.5%



17: If yes, please explain who diagnosed them. 11 out of 160 answered

1. Pediatrician and clinician that did ASD assessments
2. Pediatrician
3. Myself, a few professionals (OT/BC) who could not formally dx. Dr says "not yet."
4. pediatrician
5. Child 1: Paediatrician & then Psychologist Child 2: self diagnosed
6. I (mom) have self-diagnosed my son with ADHD due to symptoms I have noticed. His father has ADHD. Daycare have noticed symptoms as well. We have seen the pediatrician once for diagnosis and she wanted to wait for a confirmed diagnosis until he starts kindergarten in September 2024.
7. Child Psychiatrist, Family Doctor
8. Myself being the mother with ADHD
9. We are in the process of getting the diagnosis. I am his mom and I have ADHD as well so I thought he might have it too. I don't know what we would do if my family doctor wasn't familiar with ADHD already.
10. Was diagnosed as borderline ADHD as a child, being referred back for true diagnosis as teen. Symptoms worsened.
11. Online questionnaire.

18: Was this diagnosis by a medical practitioner/mental health professional, if not self-diagnosed? (Family Physician, Pediatrician, Psychologist, Psychiatrist, Nurse Practitioner)

148 out of 160 answered

Yes 148 resp. 100%



No 0 resp. 0%



19: Please explain how you were diagnosed with ADHD.

0 out of 160 answered A: > no responses

20: Reflecting on your journey toward receiving an ADHD diagnosis, did you encounter ANY barriers? Please consider ANY obstacles or challenges you faced in this process, encompassing any aspect of your experience. 160 out of 160 answered

Yes 124 resp. 77.5%



No 36 resp. 22.5%



21: Please describe ANY challenges or obstacles you faced and/or what stopped you from getting a formal diagnosis. 111 out of 160 answered

1. The other parent was the obstacle
2. Long wait lists to get assessments done
3. Access to services and assessment
4. Teacher not wanting to complete questionnaires. Older pediatrician saying they felt it was unnecessary due to diagnosis of ASD
5. School did not accept diagnosis from pediatrician. Only accepted it from Queen Alexandria hospital in-patient care.
6. Had to pay privately for assessment and go on waitlist
7. It was initially suggested that my daughter had anxiety rather than ADHD (inattentive). It took an additional 2 years for an accurate diagnosis.
8. Lack of educated staff in schools, long wait lists, basic care
9. school initiated the conversation, and then changed their mind about supporting an assessment. a long wait-list for a pediatrician until I travelled out of community (2 hour round trip drive). never received a publicly-funded assessment; had to pay privately
10. Very difficult get the referrals needed and assessments done.
11. It took a long time to get a paediatrician.
12. Minimization and denial by early childhood educators and primary teachers and support workers from the Fraser Valley Child Development Centre
13. It took 4 years for my minor son who is 8 years old to get a diagnosis. It took me 4 years as an adult to get a diagnosis. We don't have Private health care insurance.
14. Teachers don't know enough about female presentation & non-hyper presentation. Dr won't dx with only parent or home study done.
15. So difficult to get the proper testing done. Waited for forever and had to pay crazy out of pocket.
16. We don't have a family doctor, and no clinic I contacted was willing to take an appointment in order 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.
17. Wait time for assessment, once diagnosed it halted/stalled diagnosis for other ND (autism), no real supports or funding for supports (paying out of pocket if able - cost prohibiting), challenges for supports at school
18. Pediatrician would not diagnose so I needed to pay \$3500 for a psych ed. If I went public through the school it would have been a 3 year wait.
19. The psychologist has spent little time with my son and his diagnosis is based primarily on what we tell him.
20. One child was considered too young but later diagnosed
21. The time we had to wait to see a paediatrician to get the ball rolling (close to 7 months) then again had to get a psych educational assessment so the cost of that was \$3450.00 and again another wait for the assessment.

22. we were more given an alphabet soup diagnosis of many different things
23. For the oldest child it was very difficult to access real support other than referral to parenting classes. We reached out for help many ways, and for services from the Alan Cashmore Centre for 2.5 years, before we got an Anxiety (at age 4) ASD diagnosis (at almost 6). We went private for the ASD. Then the ADHD was missed until age 7.5 after we had to leave in-person school due to mental health and not learning and found the child still wasn't able to concentrate and learn even with 1:1 instruction in a homeschool setting. With all 3 diagnoses we were finally able to access real help, but a lot of trauma had already been inflicted on our poor child by a school setting up where she was made to feel she was a failure as a Kindergartener, and so we spent until grade 6 healing and homeschooling before she could return to a private school.
24. Being dismissed by teachers because they are girls who fit in well at school. By some physicians because they are girls who can sit still etc (mask)
25. Personal diagnosis started as self-diagnosis during the diagnosis of my eldest child. Due to undiagnosed and untreated ADHD for more than half of my life I have developed moderate to severe depression and anxiety. My children and myself are inattentive and combined type and as such not disruptive in a classroom setting which meant our issues are routinely ignored and so keep getting worse without the supports and training to manage the ADHD. The sustained effort required to find appropriate treatment and supports is nearly impossible to maintain.
26. School system is indifferent
27. We were not "believed" when our daughter exhibited signs of ADHD. There is a prevalent misconception that ADHD impacts boys and not girls.
28. Getting someone to provide a diagnosis, the perception that ADHD is over diagnosed, and it leads to over medication
29. Struggle to access assessments and knowledgeable medical people in our community has meant out of pocket costs and travel to other communities including the lower mainland and Alberta. It is expensive.
30. Referrals from GP to pediatrician were denied. Paid privately for psych-ed to receive diagnosis
31. The cost of getting a diagnosis through a private clinic is prohibitive. Assessment through school was not available.
32. The wait-list is long and impossible to access even with school reports etc. we were fortunate enough to be able to access private assessment.
33. Timely access to non private psychologist/psychiatrist for assessment, daughter was in university on Vancouver Island. We ended up having to research ourselves & paying out of pocket thousands of dollars
34. The educational system at the time was unaware and it was new in the way they handled the children. The school did not engage with us or let us know in time to try and find help or speed up the diagnosis of ADHD and instead held back the children from progressing into the next grade.
35. Gendered evaluations Limited access to care Uneducated professionals
36. Covid, inability to find a family doctor, inability for family doctor to find a pediatrician. The long wait time for referrals. The first referral I received was private and wanted me to pay 500\$ down immediately or I would lose my spot.
37. not picked up earlier by professionals
38. The system at the time in Alberta was very weak . He was treated along side children with FAS which caused many problems .
39. Dismissive attitude from school administration, long wait list to get a Pediatrician, once diagnosed dismissive attitudes from friends/family about medication awareness,
40. The wait times are challenging for families, the cost of private assessment is very expensive
41. As my son is not a safety risk, the pediatrician would not diagnosis until he starts school
42. Doctor was reluctant to refer to pediatrician based on the fact that boys are "busy" and develop differently than the expectations at school.
43. Referral was very hard to get. For one, we had to book and pay ourselves

44. Too long to see a pediatrician and psychiatrist
45. My son has had obvious difficulties since he was 2 years old. The first doctor I took him to took one look at him and said "he's sitting still, he doesn't have ADHD, ADHD is over-diagnosed these days". The second doctor I took him to said "he's too young to diagnose; he has to be in school before we can diagnose him". The day he started kindergarten, I booked an appointment with a third doctor, who finally diagnosed him but told me he's too young to really treat, we just have to manage until he gets older. When I asked for a referral to a specialist in ADHD (at Children's Hospital), she refused, saying it's only for those with real difficulties.
46. Cost of psych Ed was quite high.
47. Lack of awareness of ADHD by school and medical professionals
48. Wait times to see a pediatrician.
49. challenges based on my child being a "boy" (they all act like that), or trying to diagnose him when he wasn't even 4 yrs old, preschool telling me to pay for support workers out of pocket, dismissive attitudes by administrators at elementary school to provide help for my child, me as a parent looking into hearing tests, sensory processing assessments to rule out ADHD
50. Lack of services and supports
51. Lack of concern from teachers / professionals
52. When he was 2 it was obvious he was different and difficult to manage. However, his family physician told me his behaviour was normal. After several visits, me explaining I have ADHD and me eventually having a breakdown the GP decided to refer to a pediatrician. My son was 3 when he was given the diagnosis and medication from the GP. He is 8 and has since been diagnosed with several comorbidities. 5 years is way too long to drag out diagnosis and therefore accurate care. I quickly realized I needed substantiated proof to get him any help. I know have a binder of proof I bring when I need to advocate for him but it's always a struggle to get assistance
53. it was very challenging to get Doctors to believe that my child was not acting like typical child of her age. The doctors tried to convince us that our parenting style was to blame for any issues. We had to pay privately for extensive assessment and observations to confirm our suspicions.
54. Financial. We paid but it was difficult to find the money. She was not "enough of a problem" in school to warrant a public diagnosis. I (mom) am a behaviour consultant and we worked extremely hard at home to support her at home and school. We DID get a formal diagnosis but we paid privately and out of pocket.
55. Teachers are scared to call out what they recognize as ADHD. It is actively discouraged by admin who do not want to burden the district resources and do not want to deal with parents who may be irate at the suggestion
56. Getting the GP to accept the kids needed assessment. Getting referred to a pediatrician. Getting access to testing beyond basic ADHD testing. Cost of psych-educational assessment. Cost of therapy and ADHD coaching.
57. Lack of knowledge (personal and from professionals)
58. access to a pediatrician. He also diagnosed her solely on my and her teacher's feedback. We were on a waiting list for over a year and she still hasn't seen anyone in person. She is 8.
59. My 20YO child only received an ADHD diagnosis at 17 and autism diagnosis at 20. They presented at an early age as anxiety with select mutism and slipped through the cracks all of their school years. Its been disheartening to be told 'it's just anxiety' by all levels of professionals without any further supports or solutions.
60. School did not believe the diagnosis. Blamed the child as being out of control and not trying hard enough.
61. Waitlist times, access to services, misdiagnosis, improper reporting
62. Lack of education, paediatric availability
63. belief that child will outgrow the behaviours or symptoms of ADHD and not supports needed
64. Price for private help, too long of waitlists. We got lucky due to circumstances
65. length of time to get an appointment

66. N/A
67. It took over a year on a waitlist to even get into a pediatrician to even begin the process of a diagnosis.
68. Not knowing who to ask about it
69. No family doctor to accept my family as patients made getting a diagnosis so hard. We only have access to walk in doctors. And getting medication sorted has been an even bigger challenge. Affording medication even further challenges our family, and without a family doctor we also can't access the disability tax credit to help pay for the medications.
70. Ability to hyperfocus, being a girl
71. Wait times, medical practitioners not noticing atypical presentations (female)
72. GP diagnosed based on basic screen. We needed to pay for psychoeducational assessment to get a detailed evaluation. There is a lack of psychiatrists for fulsome assessment. There is a lack of public psychologists for fulsome assessment.
73. We had to pay privately for an assessment to the psychologist for full diagnostic review as my daughter had multiple disorders concurrently. Being a girl things were masked differently, her school and GP did not recognize ADHD in her it wasn't until her pediatrician was involved as a teenager.
74. The Medical system in BC, didn't diagnose my kid as ADHD despite all the symptoms that I spike of just because the teacher didn't saw symptoms of ADHD in my daughter who has a very high IQ. of course she is masking in school, but medical team dud nit paid any head to my requests to look beyond the observations of teacher. The medical team believes the teacher more who has to watch 30 kids in a class than a mother diagnosed with ADHD and a single kid
75. Co guardian denying any mental health/medical issues, refusing to participate in assessments, appointments, and delaying consenting to treatment/medication.
76. These barriers didn't prevent a formal diagnosis, but they made it difficult to obtain: waitlists, costs.
77. Waitlist, cost. Should be funded and done through school
78. Lengthy waits to get appointments with pediatrician and psychiatrist. At times felt dismissed/gaslit by the pediatrician. Took the school a bit of time to get full support for my child and he often couldn't attend school
79. Lack of publicly funded assessments, long wait time for private assessment
80. teachers, family doctors, psychiatrists
81. Took a crisis before getting diagnosed and only then by a friend who is a doctor
82. 0
83. We paid for a private assessment (psych-ed and ADHD diagnosis) as my child's difficulties were not "significant enough" at the school level to qualify.
84. no support from medical system in getting diagnosis or support. once achieved diagnosis more barriers in schools and finding supports for education and child care
85. '- No coordinated resources or support. - Families are left to navigate on our own. - Public school educators are great, but also has limited abilities to support due to lack of resources, time, chronic underfunding of public education. - Service costs are not covered or supported at all (eg: counselling, therapy, etc.) - families without means are left with no service. - Long wait for assessments. - What is government doing for ADHD families really?
86. Professionals wouldn't diagnose until school age, needed a psych ed assessment and had to go through Jordan's Principle
87. Pediatrician for my older daughter was on maternity leave and we did not feel comfortable with the care being provided by the locum to seem an assessment for your younger daughter.
88. Paid for private assessment as GP and pediatrician did not detect it. School did not provide enough assistance to identify this as underlying issue until we reallllly starting pushing them hard in grade 5. Observations and assessments from school were key to getting pediatrician diagnosis and private assessment diagnosis.

89. The length of time it took to get a referral was a barrier.
90. Long wait time for assessment, high cost
91. Teacher didn't believe us so wouldn't fill out forms. Had to wait for a new teacher. The new teacher didn't see a problem because my daughter is quiet and he didn't want to fill out forms either. We had to convince him by showing data on girls vs boys with ADHD
92. The cost of getting an assessment for my son was a barrier and delayed our ability to get one.
93. Wait times for getting a diagnosis are a major issue. We were lucky and had an "in" but it still took a while.
94. Early intervention program not believing in the possibility of diagnosis, assumed it was all a result of poor parenting
95. Financial Cost / Huge delays from school testing.
96. Huge waitlist. Doc not willing to make diagnosis without referral.
97. Getting a doctor to listen to my concerns. Then waiting over a year to get a pediatrician and then again not being listen to because the school didn't report enough behavior but the school was closed due to covid and no one was filling out the forms. Then when we got a diagnosis I asked for resources and was told to read books. That was it, again I was on my own. The only help offered was medication.
98. Multiple month to year long wait lists, unclear answers, costly, no funding from Government for schools for ADHD specific
99. It's hard to find affordable providers to help us with the multi generational ADHD that is in our family
100. Ability to see a psychologist to tease out multiple diagnoses. The cost is prohibitive. Ability to see a decent psychiatrist is ridiculous because there aren't enough of them and they will only "consult" and see you once every 6 months, and hand back to your GP - lucky to have one! How are you supposed to figure out all the meds without the ongoing support of a psychiatrist?
101. We had to pay privately because the waitlist for public was too long and our case was not "severe" enough. Further, though I value and respect the OTs we worked with for the 2.5 years leading up to our assessment, I was repeatedly told there was no rush to pursue an assessment, to give it time, it might just be immaturity. Sadly, if I had pursued an assessment after grade 1 as I had been thinking, we would have caught his learning disability much sooner.
102. Caregivers in daycare labelled my child as having behavioural issues, not clearly able to identify ADHD and sensory sensitivity symptoms. Teachers in kindergarten also felt his symptoms were a combination of sensory issues (referred to the school-based team) and behavioural/social-emotional yet we were told our child was a low priority to receive any supports or evaluation through the school board. They informally recommended that we seek OT assessment privately. Which we did at our own expense, and only in the following years sought a pediatrician.
103. It took a long time - since my child originally wasn't "struggling/ struggling enough" in school, it was kind of put off for many years. Anxiety kept being the focus, when I knew it was definitely something more.
104. Wait lists for medical professionals or fees for private assessments
105. Pediatrician thought ADHD was overdiagnosed and wanted to rule out environmental factors. Even though I had already done the work surrounding sleep, diet, parenting, ect. I believe we experienced medical bias from n/m being a low income single mom with a past history of substance abuse disorder.
106. Testing costs
107. School implied that we may be "jumping the gun" looking for a diagnosis so soon. Financial impacts to paying for private assessment. Wait times for private assessment.
108. Three of my children have multiple diagnoses. For one, ADHD was the first and there were minimal barriers. For the others, there were explorations of mental health long before any suggestion of ADHD. Two of these children were assigned female at birth (AFAB) and I suspect

that is why ADHD was not considered for a long time. One was 19 and we could not get our family doctor to refer her to anyone. We managed to gain access to a psychiatrist through our private counsellor because of the barriers.

- 109. 12- 18 month waitlist to see pediatrician. Misplaced first referral. This delayed by 4months. Obstacles in having instructors fill out evaluation forms. Borderline diagnosis and then re-waitlisted.
- 110. We did a screener with our paediatrician (waited more than six months for this appointment). Teacher was asked to fill out similar screener. Didn't pass the threshold for functional impact at that time. All of the questions were oriented for humans born as males/hyperactive.
- 111. Lack of support with initial pediatrician
- 112. Availability.

Care/Support and Services

We're interested in the types of support and services you've accessed, evaluating their effectiveness and identifying gaps in current provisions.

22: Do you have any challenges in accessing support services for your child/youth with ADHD?

160 out of 160 answered



23: If yes, We are sorry to hear that. Please share with us the biggest challenges you have faced or continue to face in accessing support services for your child/youth with ADHD.

129 out of 160 answered

1. Don't know where to look. Schools don't do much
2. Long wait lists
3. Lack of services in our area. Wait lists. Therapists who do not understand that while there is some overlap with one diagnosis, ADHD and it's challenges sometimes need to be looked at as a separate challenge.
4. What services?
5. Publicly funded counselling has been a waitlist nightmare. To the point that again, our family had to pay and source privately. This has been a significant financial burden in both securing a diagnosis and paying for o going private support. Both of these private services have been a requirement of getting a designation for support within the public school system (arg!)
6. Long wait time to see a paediatrician and psychiatrist.
7. Lack of educated staff in schools on all levels in regards to behaviour, executive functioning, and co morbid conditions.
8. No support other than pediatrician for medication
9. Biggest challenge was that the designation was considered behavioral, not recognizing the developmental aspect. Had the supports been in place for middle school, high school would have gone much smoother.
10. They are not available or have long wait lists for services that do not have accommodating hours. Also, very expensive.

11. No educational or learning support in school because ADHD isn't a 'diagnosed learning disability'
12. I have had to advocate multiple times per year for appropriate supports at school. I am continually explaining what ADHD is (not just inattentive behaviour and not just a medically treated diagnosis). Previous encounters with the CDC were dismissive and did not ask for my knowledge base (I work in the field) nor hear what the actual concerns were. Did I not have connections within the field (counselling, psychologist, etc) and if I didn't know how to advocate, my son would have received nothing. All assessments and supports have been paid for privately or through the AHP program (OT and PT). I recognize this is a privilege and not the reality for others/most.
13. In school they won't let him go full days
14. understanding & parental support to navigate consequence effectiveness
15. Expense.
16. Financial and waitlists for services
17. Since it is not a funded designation at school, there is no support provided
18. School support- 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--especially amongst teachers and during free play time with peers. IEPs are not very helpful when the teacher does not have the knowledge or resources on ADHD.
19. FVCDC dropped my child when they were diagnosed with ADHD, with the response "that's a school age thing, we don't help with that"
20. Counselling through the ministry of children was a 6 month wait and my son was deemed high risk.
21. lack of funding & neuro-affirming practitioners/services
22. The help we have been able to access that isn't just medication has only come because our other diagnoses. Autism comes with funding and we have gotten lucky and gotten some help through the public mental health system. We were "lucky" to get the autism diagnosis first. Many of my children's friends got the ADHD diagnosis first and then were able to access very little help—sometimes not even meds. And many later were diagnosed with anxiety (from under treated ADHD) and / or autism that was missed because it was complicated by the ADHD. Treatment and help and support should not depend on getting a magic diagnosis. It should be available to everyone who needs it!
23. There is little to no support at school level
24. During school no support was available for only ADHD. There always had to be further issues such as behavioural issues in order to access support in the school and then the child was often misunderstood and blamed. As a young adults now there seems to be nothing available to support
25. No funding for services for a child with just an ADHD diagnosis
26. Assistance in elementary/junior high. ADHD kids struggle so hard in school and there aren't any resources to help them however if he had it autism diagnosis we'd received funding, I still don't understand why there is no schooling support.
27. Finding any
28. We have struggled to "break into the system" here after moving from New Zealand. Even though both girls also have ASD diagnosis, and I was able to sort their autism funding, I have had a hard time finding support. For example, I was told to email Hollyburn Family Services (local to our area) and they took 3 weeks to reply, only to point me back to their website.
29. The commitment of time to go through each of the hoops required to get support is exhausting.
30. Waitlist for supports (ex. OT) are long. And as working parents we find a lot of therapy / support options are scheduled during hours of work which makes them inaccessible for us.

31. There are no services because the kids with bigger ND concerns have no supports, and they get shuffled down the tunnel, pushing the kids with 'just' adhd so far from services there is very little left
32. Appropriate supports at school and access to respite care. I have to pay out of pocket for respite and all of our occupational therapy and the travel to access both
33. Mental health supports such as cbt or other tools allowing for my dsughter to have better knowledge of what will help her succeed as a youth, teenager, afuld etc. I waited 1 afternoon to speak with someone at the ministry for mental health for children without 1 support available for her.
34. Wait lists for occupational therapists. Thankfully, we found a great ADHD coach.
35. I cannot get my child prescribed ADHD medication without a family Dr.
36. Currently access to psychologist is long wait in university setting
37. There was no support besides the doctor prescribing medication that might not have been the appropriate dosage or brand for the children. Very little guidance on what to expect and how to navigate the coming years
38. There are supports for younger people but not for older folks
39. Our one child that does not have any other diagnosis, gets kicked out of camps, daycares, etc. when we are switching medications or tweaking medications. She has struggled with her behaviours and has not had support & understanding in the community.
40. There are none and the things that are free are not catered to the unique challenges for example OT or social skills training
41. Public school referred me to child/youth mental health services and the wait time for any program was months long. I was referred to a therapist but in order for my child to get help from a therapist immediately I would have to pay out of pocket. Any services that the school offered there would be a wait time. The school psychologist was so overwhelmed that she only could see my so. Once every two weeks. I tried to connect my son to an occupational therapist through the school and was told there is only one per school district and that OT's caseload is so overwhelmed that my son couldn't access the OT through the school. To access an OT privately, I would have to pay out of pocket and there is a wait list of several months.
42. bc ministry of education not recognizing it as a designation with funding attached to support students with adhd despite students overwhelming need of supports including EA supports
43. No supports (staff) or administration agreement (strategies/techniques) in VSB, relies entirely on individual teachers willingness to support the child, no after school care options for children who need more supports, supports from BC Center for Ability for e.g. are reserved for children with more severe needs (on the point scale) when ADHD childs issues are enough to have him excluded from care but not enough to receive any support
44. Supports within the school system in vancouver were very limited. We struggled with what we wanted to include on his IEP because the support would not be realistically possible versus including supports that reflected our child's real need. We were prevented from brining in outside help into school settings despite the school being under-resourced to provide support. It was a frustrating position. The attitude and approach of school leadership was vital to the success and happiness of our child at school. Our experience with school leadership was very mixed.
45. Occupational Therapy near Nanaimo. It is a recommendation in my son's psych Ed and yet I haven't been able to find one and the doctor doesn't know of any either.
46. Respite care and program for kids
47. Getting information about adhd and what it does to the body and brain
48. Availability
49. Waiting too long to get a diagnosis by a professional and also too long to get some therapy person to help my child
50. Getting him diagnosed was a 3 year battle. Now that he's in school and diagnosed, it's even worse. The school keeps telling me how "supportive" they are as they constantly tell me that it's

my fault my son has ADHD and refuse to communicate with me about ways to help. Everytime I insist on a sit-down with them, they tell me he's like this because of me and that we now need to "fix the five years up to now" to see improvement. I'm terrified of sending my son to school because they obviously have no idea how to handle him and the judgement and stigmatism are intense. I've resorted to private doctors to try to get some help, which is insanely expensive but my only viable option at this point.

51. Receiving a subsidized psych-ed assessment from the child's school
52. What support services??
53. Very limited extended health coverage to get psych Ed done, OT and counselling services
54. The total lack of public support services for kids with adhd
55. Counselling supports that are specific to children who are neurodiverse and limited supports specific to social and emotional development within the school district...we have gone through many counsellors trying to find a good fit for our child. Also in person workshops for parents of children with ADHD.
56. there is no funding for further assessment for LD (often occurs in students with ADHD) and to rely on school is a severely limited resource; have to pay out of pocket for any CB therapy for child or parent (therapy plus medication best outcomes); pay out of pocket for any social skill programs (huge social skill deficits and no help to be had, as students with ASD have funding to pay for such programs)
57. Lack of Counselling and Psychiatrist availability
58. inadequacy of supports available - nothing to access
59. There's no central service to coordinate options for diagnosis and services. I learn about most things by talking to other parents. We could find much better services quicker if there was a database or person to assist. Also lack of funding limits our ability to access services as everything is private pay.
60. Kids with ADHD can be very emotionally draining for the family as they need lots of physical/sensory stimulation as well as body support. There is no extra funding for our kids. My child also has ASD which gives us extra support and that is the only way our child and our family is surviving (lots of activities and extra support people). Otherwise our whole family would be exhausted and everyone's mental health will be affected, so we would not be able to support our ADHD child properly.
61. None available unless we pay privately.
62. We sourced and paid for a private psychoed evaluation. The district has recommended a Q designation and that triggers no additional funding or supports. The school staff do their best to support my child but it is all "side of the desk" help
63. It has been IMPOSSIBLE to get an IEP for my daughter as she "only" has ADHD. My older sons got IEPs because they ad co-morbid learning disabilities. One of my son's really didn't, it was a manifestation of his ADHD, but it was caught on psycho-ed assessment so it counted. It's been impossible to get my daughter a PE assessment, too -- they are booking years out now. And the cost!
64. It doesn't seem like there are any support services for ADHD
65. There is very little support for children with ADHD. Lots of stigma and support is geared for autistic children
66. Doctors who specialise in ADHD available to meet with daughter. Availability of child psychologists
67. My younger son was diagnosed with ADHD quite young so we hoped that would provide better in school support. It got him a designation but no funding so he didn't receive much at school for accommodations etc. it took his epilepsy diagnosis to get him a permethrin designation to access in school funding for extra support. Even then, he slips through the cracks as he is not 'manageable' in keeping with the schools IEP goals. It feels pointless

68. Diagnosis not taken seriously, and no supports were really available, even when they said that they were.
69. Receiving some to provide a dx at first. Mental health resources due to age. Social groups. School no on board.
70. Everything is limited. While the teachers have been understanding, their resources including time and money are limited. My child has adverse reactions to medications, and other resources are lacking
71. school IEP doesn't work with ADHD
72. I didn't know there was support available
73. support at school, modification and accommodations for learning very heavily dependent on teacher following IEP or not.
74. School. School doesn't have enough ability or staff to help.
75. time for appointment by qualified doctor and followup
76. I don't know where to get support
77. There are no support services. The ones mentioned at diagnosis, either have year long waitlists or require us to travel 6+ hours
78. Wait lists, Staff turnover, no psychiatrics drs
79. Medical doctor access (no doctors accepting patients in our area, Dawson Creek) Unable to access disability tax credit without a family doctor.
80. Almost no support in schools; no support for community activities; limited support offered through Fraser Valley Child Development in the early years but support not available when the children age
81. Took almost 2 years before a Pediatrician saw our child. Pharmacy hassles. Expense of medication. Lack of CYMH services. Lack of OTs.
82. Family physician not willing to prescribe stimulants, long wait for pediatrician, no other supports other than medications
83. There are minimal to no support services for ADHD. We accessed a 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.
84. She qualifies with all of her diagnosis for accommodations but they can't all be met in school (even being in a privately paid school). Even with multiple diagnosis and qualifying for disability tax credit and an iep she does not qualify for an ea but her school has provided one when necessary.
85. My d7aghter couldn't be diagnosed ADHD.teacher, and medical system should know that ADHD occurs on Spectrum.people with high IQ can have ADHD too and the struggle with these kids are not less. Being gifted with ADHD is not a gift, it's a huge huge challenge.I wish people knew being gifted is not easy, the challenges are real and we need help too.
86. The biggest challenge was getting a formal diagnosis prior to him deregulating to the point of being medically excluded from school and finally admitted to P1.
87. Waitlist and cost
88. Cost of psychologists and lack of free services to teach emotional regulation and executive functioning and social skills
89. Not 100% what's available in the community for us. Took a while to get play therapy with a counselor through MCFD. Paying out of pocket for anything not covered by our insurance was costly (occupational therapy, other play therapy)

90. Unable to access public education in a way that supports child's disability. Had to withdraw from public education due to high anxiety from lack of understanding and support. Long wait time to see pediatrician.
91. mental health supports during teenage years especially during post secondary education
92. Live in a rural area with few resources
93. Our biggest challenge was and still is getting teachers to read and work with our child's IEP. The support services are minimal, especially from grade 7 on.
94. When our GP retired, his replacement did not take our family on (despite his assurances she would). He had previously refused to refer us to a pediatrician so we were without a PCP. I didn't know that prescribing stimulants is highly controlled until I booked a virtual appointment and we were suddenly stranded.
95. It's difficult to get much in-school support as ADHD is not considered a disability or a condition that requires extra in-class support or is considered for an IEP.
96. No coordinated resources or support. - Families are left to navigate on our own. - Public school educators are great, but also has limited abilities to support due to lack of resources, time, chronic underfunding of public education. - Service costs are not covered or supported at all (eg: counselling, therapy, etc.) - families without means are left with no service. - Long wait for assessments. - What is government doing for ADHD families (and other children who require extra support other than autism funding) really? Yes there are some very limited funding to non-profits but we have to search and navigate through everything and advocate for our own children. What happens to families who don't have the ability or time to advocate for their children while struggling to make the ends meet?
97. School having a 1 to 1 support for my child as well as ineligibility to access daycare supports or access programs that other children have regular access too.
98. School and learning supports
99. It's not considered a disability
100. Our oldest daughter is not eligible for a IEP despite her co occurring diagnosis of anxiety. We have paid out of pocket for OT services not fully covered through extended health.
101. Child does not connect easily with other adults / supports. Difficult to figure out and select the right support (i.e. an ADHD coach or other - both the specific person (fit and skill) and the type of support needed).
102. No support in elementary or high school. Constantly blamed for challenging behaviour. Lack of understanding. Low self esteem and hatred of school was the result. Now an adult with poor executive functioning skills who was unable to attend college or get a job. Mental health concerns.
103. Waitlist and searching out appropriate services.
104. Often practitioners say "it's just ADHD" as though it's a minor problem that is insignificant. Other times, they are only interested in helping when the child will go on the medications they are prescribing.
105. School isn't supportive, long wait time to see a paediatrician, no social groups /therapists to get support from, high cost of private therapists
106. Psychologists all have long waiting lists; psych ed testing isn't funded and also have long waits; schools have so many kids with adhd and other diagnoses that there are zero supports; daughter isn't "bad enough" for cymh
107. The biggest challenge has been accessing support in the public education system. My son who has ADHD could be equally as disruptive and challenging as a child with ASD but there was no support to help him to be successful at school. He needed brain and body breaks but there was no support for this. We were forced to leave the public school system to find a school that could meet his needs. Not all families can afford this choice.
108. Financial stress many of the supports necessary for my son are not covered and we pay a high amount out of pocket.

109. School support is inadequate, lack of remedial education supports for learning disability, lack of support for executive functioning limitations, lack of info provided to parents of students diagnosed with learning disabilities and how to support their learning at home. Lack of school support for students with emotional regulation difficulties and relationship skill building.
110. Our son's school does their best, but they have limited resources and are not always able to provide him with the support he needs.
111. Lack of resources available
112. School district has woefully inadequate time, resources and continuity to provide any meaningful support.
113. What support services? If I cannot pay \$150 per hour out of pocket for therapy and \$90 per hour for specialized tutoring there is nothing. The school services are a joke. I have had to find and provide nearly all my kids accommodations. Good thing I happen to change careers and being studying disabilities and modifications or my kids would have received no help.
114. access to a psychiatrist to help with medications. Some teachers have zero understanding of ADHD. Some believe it is not real, others apply stereotypes and since neither of my kids are stereotypical, they fly under the radar for help.
115. EAs in school, my son very much needs a support person to help him at school, for breaks, calming down etc, yet because he hasn't been diagnosed with Autism he does not get an IEP. Yet Autism and ADHD both can require special needs.
116. Financial barriers and wait times for seeing the funded providers to get a diagnosis. We can't access anything for adhd with out it.
117. 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. Also not all service providers are affirming.
118. Financial barriers (there is no funding for ADHD supports), stigma, lack of neuro-affirming options
119. Availability of services and supports.
120. We have sought OT assessment, psych ed assessment, ADHD assessment privately at great expense. Our child's psych ed profile does not qualify for support in the classroom, yet he experiences struggles that prevent him from being able to stay or keep up with the class in many respects. Like many with ADHD, he excels in some areas and is delayed in others; this discrepancy causes much confusion and anxiety for my child, his teachers, and peers. He will be in an intermediate grade next year, and we are concerned about executive function and his ability to continue to keep up.
121. Financial strain. Waitlists.
122. School isn't very supportive in regards to ADHD. He is finally getting a bit more support now that he has also be diagnosed as autistic
123. What services? Everything my children needs (play therapy. Tutoring...) are paid out of pocket
124. Before my son was diagnosed with Autism, the only public. service available was Child Youth Mental Health. This is meant to be a short term service, not ongoing. It also had a long waitlist
125. What type of care to give child who refuses medication
126. Not having a GP for two years. Waiting 7 months for a first appointment with a paediatrician. Trying to discern what kind of therapies might be helpful - play therapy, occupational therapy, parent counselling, etc. All feel like a shot in the dark. Financial impacts to all of these therapies. (Example, play therapy is \$157/session.) Time off work to attend all the therapy appointments.
127. Finding counselling that is affordable or free. CYMH provided basic services and referrals to online programs.
128. We've had to pay large amounts for private counselling. We've had difficulty getting one child's medication covered by pharmacare. We've struggled to advocate for our children's needs in school. We had to pull one child out of traditional school to do an online alternative program.

129. What supports? There is nothing provided in the schools for kids with ADHD. If anything it is tools that the teachers have to purchase for themselves. The teacher has done this, and has also implemented some in-class learning programs for all the kids. We have an appointment to access medication, however I don't know of any supports for "just" adhd.

24: If no, what made the support services accessible to you? 14 out of 160 answered

1. We haven't looked into any or received any
2. School and pediatrician support
3. Now that we have a pediatrician, it is easy to get appointments with them for additional needs. It was just a challenge getting the referral in the first place.
4. The diagnosis
5. Other than medication, I do not know what supports are available.
6. Knowledge of the resources
7. Medication. No other accommodations needed.
8. He is still so young and is more inattentive then hyperactive so extra support has not been required for him yet
9. The school gave us the info 5 years after the report of the psychologist, to register to Child and Youth with Support Needs (CYSN)
10. The information I got from the pediatric and RW
11. Medication
12. Support services have been made accessible by the child's family practitioner and paediatrician. The teacher has been very cooperative with the family.
13. I have a family doctor, who readily agreed to a medication trial while we were on the pediatrician's waitlist. My son received his diagnosis within 5 months of our first family doctor appointment. His school has been fantastic about providing supports and academic extensions for his areas of giftedness
14. I have the financial means to pay out of pocket for Occupational Therapy.

25: Have you interacted with any of the following MCFD departments for support or services for ADHD? 146 out of 160 answered

	Yes	No
Child and Youth Mental Health	72	74
Child Protection Services	18	108
Child and Youth with Support Needs	30	103

26: If you interacted with CYMH and/or CYSN, what were your experiences? 108 out of 160 answered

1. We haven't
2. I was told to not bother with CYMH because the waitlist was so long, cysn worker has largely been unhelpful in the handful of times I have sought specific assistance.
3. Lack of communication from them. Constant changes in staff and forms being "lost" or "misplaced."
4. They were not particularly helpful. They expected him to do things that he was just not developmentally ready for. They washed their hands of him. He is a good 3 years behind in many developmental areas, and the school/mental health system are just not designed for this.
5. Awful waitlist. Filed complaint, then gaslight by a staff who basically said that private providers/ counsellours are the reason the waitlist is so bad, that they can't hire or pay well, because people open their own practice instead of working for an employer at half the wage.
6. Positive once able to see a psychiatrist. Drop ins at the local Foundry have been very helpful.
7. Basic support but only for anxiety conditions

8. no
9. My son only has a CYSN SW because he has the AHP from age 7/8 (has dysgraphia and Developmental Coordination Disorder as well). I have had to ask (politely tell) the SW what I want. I have prefilled the AHP forms for everyone (dr and sw) to sign and submit. I have not received any other supports from CYSN
10. Did not find it helpful. He was not a willing participant, therefore not open to that support.
11. They did not have anything to offer other than parent course suggestions (that we had already taken). No services were offered despite asking for help.
12. Although we participated in play therapy and parenting classes, these activities were prior to an ADHD diagnosis and when I requested support to examine neurodiversity or reasons to explain ALL the challenges, my concerns were often minimized and I was repeatedly told I needed to learn how to coregulate and parent my child where they're at. Since having a diagnosis and receiving medical support (medication) it has been life changing for all of us.
13. Child and youth Mental Health had everything on soon. It was all pretty standard information. Nothing personalized. Child couldn't see anybody in person. For myself, there is no supports as an adult for ADHD and my other Mental Health flash brain concerns
14. Not helpful. Dismissive as child is not high needs.
15. Positive experiences, but difficulty receiving funding for counselling, tutoring, etc
16. N/A
17. Hit and miss. We've had some really great case workers and some not so great.
18. Caseworker has too many files to support (over worked) and caseworker has changed several times due to turn over - get lost in the shuffle, limited abilities to help
19. Not involved
20. They were empathetic and kind but they could not provide much help where needed.
21. The course Riding the Waves of Parenting was fantastic. That is the only resource we have had access to, after rederal from FVDC who then closed our child's file
22. It wasn't the best fit for our son. He wouldn't open up to the counsellor as he didn't feel comfortable with him. We got nowhere with this
23. We have had a variety of social workers involved. The CYSN prior to Covid were more helpful than not. But there is a significant lack of resources and after Covid we have had no contact or support other than accessing autism funding. Our interactions with MCFD child protection were ok, but extremely stressful. I understand we benefited greatly from being a white, 2 parent family who is highly educated and have a middle income (although we are barely surviving in Vancouver). My BIPOC friends have had very different experiences with MCFD child protection and I am have been actively helping keep a family safe for the past year who are Black and Indigenous and have ongoing involvement that basically is a result of being Neurodivergent and low income. Our involvement with CYMH has been okay. We saw the neuro mental health clinic at BCCH and they were helpful. We have been very lucky to have a psychiatrist and a pediatrician not at CYMH to help. I get the impression that many ND kids are denied care with CYMH as being too complex for them.
24. Trying to access support, but being on a waitlist for many many months
25. Cymh was not helpful, no follow up, discharged without discussion or follow up planning
26. Support wasn't related to ADHD but instead mental health, and we felt very supportive by that organization.
27. No issue
28. Fairly neutral so far, we're on the (lengthy) waitlist for services.
29. None of these services are for kids with adhd. They are for kids with other things, and adhd. Kids with adhd get nothing, because kids with higher needs are the fires they focus on.
30. Mainly because my oldest son has ASD and my middle and younger sons with ADHD also have anxiety
31. N/A

32. Have not interacted
33. None - At the time we were completely unaware that there were any services that could have helped us out in this situation.
34. They referred us back to psych and pediatrician. Very nice people
35. Was able to get some support for one child for a short time and my youngest had a psychoeducational assessment where he was diagnosed with dyslexia in addition to confirming the paediatrician's diagnosis of ADHD, but access was outside my community at the time, and we were not able to sustain regular service due to the travel time. Currently on CYFMH waitlist for services, in my community this time, for youngest but it may be too little too late now as he may not be willing to accept services. He has been taught by the school and society that he "should" be able to manage on his own. His sisters are also reluctant to seek out and accept services for the same reason.
36. I had a call with a social worker but she only provided us a list of professionals to try to call & explained the process for trying to use our Autism funding, she couldn't actually recommend anyone specific. As an ADHD adult with 2 Autistic / ADHD kids, this has been to overwhelming to navigate while also trying to survive as a returning Canadian. It would be helpful to have some type of entry point, like an appointment with a psychologist. We have a referral to a paediatrician but I'm told the waitlist is horrendous.
37. A counselor at school felt my daughter was in harm, due to her fathers pstrict parenting style. We were assessed with the worker nort worried about her safety
38. For our one child that has multiple diagnosis. They have recommended we take basic classes to start so they can assist us with other needs, then they forgot to put us in the class twice. Our children have so many different needs that this seems time consuming and exhausting on top of everything we deal with day to day. The classes are at dinner time. 6-7:30pm and we arranged childcare.
39. Theres not the specific services needed within the program no sensory intergration work no social skills training executive functioning training
40. Any program they had was such a long wait list. They also didn't offer any programs outside of working hours. So I would have to take time off work to attend.
41. not great
42. n/a
43. Not much, interacted barely in obtaining AFU
44. great but we registered months before my son turned 18
45. I didnt
46. Can't find therapy but found they offered some interest classes online but my child cannot focus at all in an on line class
47. I felt like I was being judged by the people who were supposed to be helping me and my child.
48. They were not helpful. Blamed parenting.
49. I have not interacted with any of them
50. No interaction with them
51. It's related to childhood trauma rather than ADHD
52. Ok, but very long waitlists
53. I had a lengthy intake during which the social worker laughed about my daughter's violent episodes, provided no real resources and advised adhd is not a mental health concern so outside of their mandate
54. We were offered an anxiety group for my child to attend, which was actually really great! We were also offered a one hour information on anxiety for parents.
55. CYSN support is only for those with ASD or an intellectual disability. CYMH put us on some waitlist, we went through some sort of questionnaire and that was it.
56. We got respite funds after 5 year waitlist but only because I have 2 kids with special needs and no family support

57. No support offered. She was again "not enough of a problem"
58. I received a referral to a ICYT counsellor who met with my child once a week over approx. 4 months
59. No interactions. It's been made clear to use that we are on our own and not to even ask.
60. Focus was not on ADHD, but other diagnoses like Autism, depression, and anxiety
61. Although it's tough to get access, all support was amazing. My only big issue is that they are in such demand that there is no ongoing care, it seems to be emergency or wait list, no long term
62. Counseling was offered, but the counsellors mainly blamed the child, rather than support.
63. Fairly good. Made a good connection who was able to get us into one program. Nothing else since December 2022
64. for another diagnosis not for ADHD, found only when in crisis some supports offered.
65. No. Like I said, we got lucky. We know the right people but I see every day the struggles of families who don't know "the right people"
66. We haven't contacted them
67. First worker was awesome, then she quit and our case seemed to fall through the cracks as we struggled with day to day home and school life and child care
68. Minimally helpful at best.
69. every time we were assigned a counselor they were an intern who would start to build trust with the child but then their contract would be up and we would get assigned a new service person. I was provided with opportunities to attend classes/seminars and this has helped me as a parent however it does not help outside of the home (school/community)
70. Wonderful social worker but only works part-time. Appointment times are not geared to facilitate the child. No supports for home life or family.
71. With one child: on waitlist for 654 days, with other children: no supports offered specific to adhd
72. CYMH support was very limited... I attended a parent information session only. Counsellor at CYMH have generalist education and experience and lack the education and experience to service ADHD children at an expert level. CYSN support is completely absent for ADHD children. The CYSN worker denied my child had the diagnosis, without even meeting my child. They advised that there were no resources available. CYSN staff are not professionals, have not professional accountability and should not have any involvement with disabled children with ADHD or other disability. They lack required education, training and experience managing children with disabilities. They are not experts.
73. CYMH was decent. Son struggled with his assigned psychiatrist. He did well with his play therapist.
74. LONG waitlist, then only 6 months of services provided.
75. Not much interaction for the first few months. Attended zoom sessions for Circle of Security, which was sometimes difficult as they wanted my husband to participate but he has a very busy work schedule. I was also told it was mandatory for me to attend Emotion Focused Parenting workshops, but the dates they offered did not work for me. I had to really advocate for my child to get counseling sessions with them.
76. N/A
77. experiences were with primary care facilities
78. Haha. Impossible to get a response. Took over a year
79. N/A - my child does have anxious tendencies but we have been able to manage this so far.
80. not great, basically said I am not eligible for supports and told me to call mcfd and request support services.
81. Helpful at the beginning but not lately
82. Minimal, not great or helpful
83. We were told about a parent online workshop that was helpful and we attended. Other than that we have not been in touch as we were told since we pay for a child psychologist privately, we can continue that.

84. I interacted with CYMH & CYSN for other diagnosis. ADHD was not considered a strong enough reason for my child to be referred to CYMH or CYSN.
85. NO
86. At the time we did not have any idea we were looking at ADHD. They said they did not have a program or service for us as our child's level of need / struggle was so much less than other kids using their service. They suggesting we read about ADHD not thinking he had ADHD but because these approaches seemed like the closest thing they could recommend that might help us. So one appointment then we were back on our own.
87. Not super helpful. Tried to make me do things that I had done before. Never been offered a cysn for adhd
88. Daughter isn't "bad enough". Need a private psychologist at own expense
89. CYMH was our first interaction on our path to find out why our son was so challenging and aggressive. They fast tracked us to consult us with a psychiatrist, who diagnosed our son with ADHD and helped to support him with medication. This agency's support was vital and effective, however the consulting psychiatrist retired soon after and there was no replacement in the short term and we were bumped to our pediatrician for follow up support.
90. Excellent support provided to both parent and child (counselor had great with knowledge and language for ADHD)
91. No
92. Frustration
93. Okay, super long wait times. Some patchwork service.
94. Only interacted with them for ASD for ine kiddo I have never been told they offer anything for ADHD.
95. N/A
96. Cymh said we didn't fit the mandate and that we needed a diagnosis I had never heard of cysn before
97. We were referred to the Confident Parent program which was SO not affirming and was completely contrary to my parenting values.
98. n/a
99. Support Worker at Elementary School. She was easy to work with but our services didn't go very far beyond implementing ideas.
100. Good experience once we got through the waitlist, was referred to another program from there
101. Other than the long waitlist, we had a positive experience with CYMH. However, if my son had not been diagnosed with Autism, the CYMH services would have ended with no other service for us to access. Kids with ADHD need ongoing support services, not short term.
102. We are seeing a counsellor by my daughter seems resistant to working on any lifestyle change. I would like her to see an occupational therapist, but I can't afford one at the moment
103. N/A
104. Councellors were nice but helped in limited ways. Also child didn't connect well so impact was minor.
105. We had initial visits for three of our children and requested supports for one. We did not hear from them again. We've had our CYSN workers reassigned and not been informed. The workers themselves were kind but we did not feel there was any benefit to working with them.
106. I don't even know where I would find a CYMH or CYSN -- I don't even know what those stand for. My child is inattentive not hyperactive or causing us major crisis. We employ our own play therapist and pay out of pocket, although we can't really afford it.
107. We were told our child didn't qualify for mental health support because of ADHD, offered parenting courses and a recommendation to buy the book "taming the worry dragons" instead.
108. N/A

27: If you have had interactions with Child Protection Services, could you please share your experiences with us? 64 out of 160 answered

1. We haven't
2. My child's needs were not considered or accommodated when they were interviewed, her needs were not considered when a decision was made that she did not need any protection measures in place
3. N/A
4. No
5. None
6. None
7. our son came out of foster care - we have received zero support from any MCFD department
8. Na
9. I am a foster parent and some of by foster children have ADHD
10. N/A
11. Service and support recommendations with long wait times - even when dealing in crisis situation - causes additional trauma
12. Not involved
13. N/A
14. We were reported I believe by our CYSN social worker and a MCFD contracted service provider for having a messy home. It was messy because we were reorganizing and baby proofing for our second child who was going to be crawling soon. We panic cleaned and the child protection worker didn't know why she had been called and cleared us right away. But it was super stressful. It allowed us to access some emergency childcare subsidy, that was open only to people involved in the Child Protection side of MCFD, but it's shameful that reporting us was required for this help to be accessed. I've been working with close friends who are Black and Indigenous for the past year who are involved with child protection for a messy home. The parents have ADHD and physical disabilities (and one is also autistic) and both kids have ADHD (and one and possible both are autistic). The way they have been treated is shameful. They are finally accessing some real help, but it has taken a ton of work and advocacy from many to get there and the status of that help is always precarious. Child protection was just threatening over and over to remove the children from the home without offering any help or support to the parents so they could make the home less messy.
15. One child was put into voluntary care under the promise of the family being able to get better support
16. N/a
17. Best group and easy to navigate with them.
18. Again, not for kids with adhd. Families have struggles that result in cp involvement, and kids have adhd. The focus isn't adhd, and adhd specific services are not the focus, nor are the offered.
19. N/a
20. N/A
21. N/A
22. No contact with Child Protection Services
23. They haven't taken our concerns seriously and think it's a domestic dispute between us & them. We now have multiple community members stating the same concerns and are in a family law action. We are not receiving any support or funding from the government for these children and are advocating to ensure they are safe. Initially, the ministry pursued us to raise our grandchildren because of these same concerns: domestic violence/abuse. This was between our dead daughter & our grandchildren's dad, not us. We are voicing our same concerns.
24. N/a
25. No
26. n/a

27. the social worker was great.
28. Its sad to see that the children in the ministry have many supports though kids not involved with the ministry don't have the same access
29. My experience with child welfare is that they will try their hardest to trip up the parent, so that they can take the child/ children into care. They want to keep the child/ children in care as long as possible. They never tell the parent(s) the truth.
30. They were fine, and understanding to a certain extent.
31. No interactions
32. Horrifying. When my son entered kindergarten, I was very open with the school about his behavioral issues and that I'd been trying to get him diagnosed for almost 3 years without success. They almost immediately reported me to CPS because they believed my being a single mom was too difficult for me and had resulted in him getting ADHD. It was a traumatic experience for my entire family. I no longer trust anyone at the school and desperately regret ever mentioning anything to them. If I'd looked stronger and stood up for my son's behavior, they wouldn't have seen me as "weak" and would have left my family alone. I've been teaching my kids to never trust others anymore and not to *ever* speak with anyone about their challenges unless it's a privately hired doctor who has real experience and knowledge of ADHD. The number of times I was told "it's in the best interest of the child" is disgusting. They traumatized my child and my family. It took weeks for my son to calm down after that happened.
33. n/a
34. no
35. None
36. no
37. Only through other mental health issues in our family and the support we received was very respectful and good
38. Child was taken out of the home for 3 days. This was all they had to offer as help.
39. N/a
40. We haven't contacted them
41. My child was strangled by his father (defined by him as "restraint" for behavior challenges, mcfcd and RCMP together took a statement from my child and the only support offered ever was a notice that my child needed protection from his father and that because I had obtained a protection order they were closing the file. After a few months the protection order was lifted because there was no longer mcfcd involvement and my child's father was given overnight unsupervised access without having to do any parenting or anger training.
42. Several times random strangers said they were going to call CPS when one of my kids would be having a melt down in public however CPS has never contacted me (Thank God). One daycare called the police once because they "couldn't deal" with my child and I missed the daycares call because I was at work
43. N/A
44. Na
45. Extremely traumatic, accusations of "parenting issues" leading to children's difficulties (investigation found "no parenting concerns - 4 times), no helpful supports offered. Mcfd referring to programs that service providers then deemed "not appropriate" or "not eligible", mcfcd not understanding what programs actually are
46. Extremely pointless and frustrating. The social worker had the audacity to indicate son should be assessed for autism simply to justify her unwillingness or inability to help protect my son. They demonstrated a complete lack of insight into how children who are burnt out and showing trauma response combined with a lack of any diagnosis - which turned out to be a developmental language disorder, ADHD, anxiety and undiagnosed as yet learning disorders may react when they attempt to question him about his accusations regarding being abused.
47. None

48. N/A
49. n/a
50. N/A
51. I'm a guardian under the 54.01 transfer of custody. after the 54.01 is granted, receive no support beyond the allocated funds, no respite and again told to contact centralized screening and request a support services file. Did all the steps i needed and to and found supports to get diagnosis as well as apply for the child dissability tax credit/benefit only to find out that I am unable to receive it directly. Very dissapointed in the lack of support from CPS... I was previously a guardianship social worker with MCFD and ICFSA and am very disheartened.
52. N/A
53. No interactions with them.
54. Yes. The social workers don't follow thru and offer services that are not helpful or accessible.
55. N/A
56. NO
57. Had to prove that child's issues were not a result of poor parenting, actually had protection services back me up after seeing first hand what was going on at home
58. N/A
59. n/a
60. n/a
61. N/A
62. No and this doesn't sound like the right fit for us. I think offering services for ADHD through Child protection services is not going to be very popular, it has major implecations
63. N/A
64. N/A

28: Have you ever considered entering into a voluntary care agreement with MCFD, or has your child ever been placed under an involuntary care agreement or similar arrangement with MCFD? 119 out of 160 answered

1. No never
2. No
3. No
4. Unhelpful
5. No
6. No
7. No
8. No
9. No
10. No
11. No
12. No
13. no
14. Na
15. no
16. No
17. No
18. Not involved
19. No
20. Yes
21. No
22. Yes
23. No

24. No
25. No
26. no
27. No
28. No
29. I am considering a vca for one of my kids that has several bahaviour intensive diagnoses, one of which happens to be adhd. In comparison to the other labels, adhd is nothing.
30. No but have more knowledge than most regarding supports etc and are lucky to be able to pay out of pocket for therapy, respite psychology etc so we have been able to avoid this so far
31. No
32. N/A
33. N/A
34. No
35. No
36. No
37. When with their mom, yes.
38. N/a
39. No
40. no
41. n/a
42. No
43. no
44. No
45. no
46. No
47. No
48. Yes
49. No
50. No interactions
51. No
52. No
53. No
54. No
55. n/a
56. Yes and no
57. no
58. She has been place by MCFD
59. No. But life with this child has indeed been very difficult. However we have the capacity to support her at home. But help would have gone a long way.
60. No
61. no
62. No
63. No
64. No
65. No
66. No
67. Yes! I have! There have been moments in the darkest days where I wonder if my son would be better off with another family. Endangering himself, his sibling and his mom. The more I learn about ADHD, the more I find I can handle it
68. No
69. No

70. no
71. No
72. I am not even sure what this means....as no information was passed on to us at any point
73. No, but I know 2 families who have entered a voluntary care agreement for the sole purpose of their child gaining access to the resources that are readily available to foster families.
74. No, absolutely not. These are my kids and my responsibility. I took all available classes and tried to be their advocate through the school system
75. We had our child at Jack Ledger House, Queen Alexandra Hospital.
76. Yes. Youngest currently on a VCA.
77. One of our children has a complex health profile and is in a special needs agreement, which has been a terrible experience. We recognize CYSN staff are unequipped through adequate education, training and experience to be involved in case managing disabled children. The system in providing disabled children services requires complete reform. We support the services for disabled children be moved out of the MCFD ministry immediately given their serious chronic failures and long standing human right breaches and abuse of children and parents. Transfer to Ministry of Health or creation of a new Disability Services ministry with adequate 3rd party oversight needs to be created. We do not believe there is any chance of correction and improvement within the MCFD ministry given the multiple factors involved and the pervasive toxic culture, and we believe the damage caused to the reputation of the MCFD ministry is irreparable.
78. No
79. No
80. I signed up via MCFD/CYMH for Laurel behavior to do home visits with my son after his P1 admission.
81. NO
82. No
83. No
84. No
85. involuntary care inhospital
86. No, never
87. No
88. No
89. No.
90. No
91. i have not considered it, but we did gain custody of our son through MCFD 54.01 permanent transfer of custody.
92. No
93. No
94. No
95. no
96. No
97. No
98. No
99. NO
100. No
101. No
102. no
103. No
104. Yes
105. No

- 106. no - but I can see how many parents would need the help/respice. Sometimes life gets VERY hard.
- 107. No
- 108. n/a
- 109. No
- 110. no
- 111. No
- 112. No
- 113. No
- 114. No
- 115. No.
- 116. No
- 117. No. This question is suitable for a kid needing different kind of help than my kids needs.
- 118. No
- 119. N/A

29: Please indicate if ADHD has negatively affected any of the following areas for you or your child/youth. 149 out of 160 answered

	Yes	No
Employment	69	66
Education	128	21
Mental Health	127	19
Physical Health	75	58
Justic	24	99

30: For any of the areas where you indicated 'Yes,' please share more about how ADHD has affected you or your child/youth in that aspect. Please feel free to include specific stories or details that show your experience. 124 out of 160 answered

1. Not enough Educational Assistants to help students out.
2. I could write a book. I am a single parent and work in the school system. The lack of trained support staff in our schools is astronomical. Lack of understanding, children with no diagnosis that do not generate support but have behavioural issues take the EA support from my children ALL THE TIME.
3. My children struggle in various capacities within the classroom (reading, writing, math challenges, overstimulation in classroom, inability to shut out distractions and hard time focusing, daydreaming, impulsivity, overly talkative). Regarding the child with math struggles, we have requested the school's support in administering level B testing or helping us to pursue a full psyched assessment, which they continue to downplay and avoid. Last year's teacher refused to provide additional support because she claimed that ADHD isn't a diagnosed learning disability
4. Trying to hold full time employment hard
5. All of these areas have given difficulties. Many due to developmental delay
6. Employment, I have been unable to work full time as I often need to take calls and pick up my child from school Education, I have been unable to obtain a better education and better job due to my child's needs and my child has struggled at school due to a lack of supports and understanding of her needs Mental health, we both struggle as there is a lot of stress, anxiety and not many supports in daily life Physical health, My child struggles with anxiety with doctor and especially dental appointments, she gets migraines from anxiety, her anxiety is often triggered

by the overwhelming demands at school and in her Dad's care where she is not adequately accommodated Justice, we had a s.211 report done by an assessor that clearly had no understanding of different needs and my child's diagnosis, her words were taken out of context and questions were not asked in a way she fully understood, her answers were unclear but the assessor did not clarify them and instead interpreted them to fit her own views, in the end the assessor decided my child's views should not be considered at all and that I coached her, the assessor made a recommendation of a parenting schedule and therapies that were not in my child's best interests and did not consider her needs and diagnoses, the assessor implied my daughter just has trauma which is why she has ADHD symptoms, this has destroyed our lives, cost tens of thousands of dollars, endless stress and conflict with her father. My child wants to primarily live with and be catered for by me as she has her 13 years of life, because of this poor assessment her dad is seeking a court order to force her against her will to only see me 2 days a week. The justice system has completely failed us, and destroyed our most basic rights. There is NO judicial or s.211 report writer education on ADHD, anxiety and autism and the approach taken is that caring parents are overprotective and codependent with children and children need to be forced to suffer parenting schedules to fix this. The other parent is permitted to claim the child is not disabled and just difficult and it's ok to physically discipline them, emotionally abuse and control them. I thought our biggest struggle was accessing supports and accommodations in health and school until I separated from my abusive ex-husband. This has been the most traumatizing 2 years of our lives. The family law act needs a clause that requires children's diagnoses be explicitly accommodated and considered and that any assessor conducting a s.211 report for a child with diagnoses have specific education on that diagnosis

7. The school try to enter into a discussion of half days, which I promptly shut down. He was at a nature based public school that had no idea of how to teach him and told me he wouldn't "consent to learning" resulting in him having a gr 1 reading level at the age of 10. He had impulsive behaviour at school, at times. He is disorganized at home and at times unmotivated to care for his physical health which can be a battle of negotiation- everything from brushing his teeth, taking showers regularly, sticking with a sleep schedule etc He is also diagnosed as having "severe anxiety" which is thankfully well managed with meds and counselling at the moment
8. I had to leave a career to care for both children when they were young because of separation challenges and behaviour challenges. My son went through 10 years of schooling before more support was provided and even then it was only provided because we paid out of pocket for a psych-educational assessment for both our children. It took years for my son's diagnosis as we had to wait for paediatrician availability. I've had to cut down hours again at work to help support the children and myself.
9. Mental Health- my son was struggling and was monitored for depression and anxiety. It is always me who has to remind people to check and ensure he is doing well. For physical health, I drive this as well. I found a great OT and PT (again, because I am connected in the field) and we AHP to cover the costs. Otherwise it wouldn't happen. For Education, I initiate the meetings, I lead the meetings and I follow up with teachers directly. I also connect with the administration as needed. For all interventions, I have to find the person/service, pay for it and manage it. I do not receive extra help from CYSN or the school to do so.
10. School stress, stress that manifested itself physically (somatization), bullying and exclusion by peers.
11. Minor child is often excluded at school because he quote can't sit still quote, and as often asked to go to the principal's office because of this. There is no support/ EA support if diagnosed with

ADHD in the BC school system. There are no supports specifically, that we know of for employment help for people with ADHD and other brain-based concerns.

12. I had to leave paid employment to manage the impulse issues
13. Counselling is expensive and prohibitive. Anxiety relating to child not feeling "normal" has resulted in chronic tummy aches and headaches & now stress response illnesses
14. Food obsession
15. N/A
16. Lack of support in school resulting in attempts to force half days, a lot of phone calls for early pick up due to behaviours that could have been supported if there was adequate staff, having concerns dismissed prior to starting kindergarten and then having an extremely traumatic year (leaving kid to hate school and not want to go, being behind in social learning and challenges with making friends with peers)
17. Unable to focus in the classroom and not given any help. Low self esteem and anxiety due to not being supported at school
18. Bullying and isolation at school due to lack of supervision and knowledge re. ADHD at school. My child's not reaching his full learning potential as the way of teaching and learning is not ideal for him.
19. My child was not able to access elementary education with lots of time spent outside of the classroom, no IEP and harassment from a so-called school counselor
20. ADHD has affected our life in many ways. The wait times in BC to be referred to a paediatrician is too long, 6+ months to wait for some type of support with a child struggling with school, life and mentally not able to cope is outrageous. Not enough counseling and barely any support groups to bring your child is very challenging as a parent.
21. Parent unable to work full-time hours due to high support needs, access to education challenging due to lack of follow through on IEP supports from school staff, family mental wellness is impacted on a daily basis due to pervasive demand avoidance, difficult for parents to care for their own physical wellness due to high needs of child/youth
22. I don't know even know how to answer this. The primary factor is schools in BC are not set up to provide inclusive education. The entire system is set up to push kids out who can't just be quiet in a classroom and understand group instruction and independently complete tasks for 6 hours a day. The system is incredibly under-resourced. My older child has significant mental health issues from this lack of support. My younger child is 7 years younger and does not have those mental health issues even though he is also autistic and has ADHD. But he was diagnosed at age 2 due to the family history, provided therapies and support as a toddler and preschooler, and benefited from everything we as parents learned from parenting our eldest kiddo. And he's in a private school that can better meet his needs. Now imagine if all kids got that.
23. Unable to get employment or further education past high school due to challenges. Mental health supports have always been challenging as the cost is prohibitive and free options seem to have huge waitlist or are unavailable and our small community.
24. One falls through all the cracks in every support service area as he presents as smart
25. Being on ADHD medication has reduced his appetite so much I feel he has ARFID (not yet formally diagnosed).
26. I don't know what to write.
27. N/A
28. I can not work outside the home because my child's school can not support him to attend all day. Even with his shortened school days I am frequently called to pick him up. My child is aware at 7 years old that he doesn't have friends at school. It is challenging to have my child play with the

neighborhood children without direct supervision. It is hard for my child to be in sports, extra curricular activities without additional support. So he lags behind his peers.

29. Supporting children with ADHD has certainly had a negative impact on our mental and physical health. As parents we're completely burnt out, but told we don't meet the criteria to receive respite.
30. Systems assume adhd is a character flaw rather than a brain based disability. Prejudice impacts service creation, funding, frequency, variety etc. in every system.
31. As a parent I can only work school hours as finding appropriate after school care for 3 kids with diverse needs is not easy and it is hard to take all the time off I need for all the therapy and appointments we need to attend. My kids' anxiety and depression are directly correlated to their struggles "making good choices" at school and managing to move through the day without appropriate supports.
32. Schooling has been a nightmare with my daughter segregated. We were told she was a safety concern for field trips because she wasn't listening. She goes to a francophone school. They said they wouldn't do anything for her until she was medicated
33. My child cannot properly learn without the support and medication he is not receiving. While we have started and IEP he does not qualify for any extra help.
34. Physical Health - procrastination & need for 'situation to be perfect' affects participation in some physical exercise opportunities. Mental Health - challenges in dealing with stress, social interactions
35. Mental Health for the family and the children. Burnout, frustration, and lack of knowledge on how to deal with these issues. Education was difficult in getting the children to focus on their school work and listening to direction. Being held back a grade impacted the children when their friends moved up and they had to stay behind. The felt loss, and inadequacy. As they grew up they started getting into substance issues and run-ins with the police for fighting and being around the "Wrong crowd" of people.
36. Access to knowledgeable legal help Access to supports in education Access to supports in work (I lost my job due to a meltdown)
37. Mental health is a struggle to be taken seriously sometimes.
38. Since our grandchildren have come to live with us, I have had to take time off of work to care for them. They have high needs. Shortly after they came to live with us, their mom died. We have had both the children diagnosed with ADHD but their needs are great and they require someone to be home with them and be available before and after school or daycare.
39. Education lack of understanding adhd in classrooms or executive functioning deficits and how teachers can better support no designation for adhd
40. At 20 yrs old still not able to secure regular employment. Post secondary education not an option. Struggles with anxiety and depression.
41. It was my nephew and he committed suicide when he was 19
42. Education: lack of proper resources for my son at school so they would send him home when his outbursts would be overwhelming. Lack of proper training for those who had to provide support my son. No full time EA for my son, even though he has an IEP. Sometimes his substitute teachers would find my sons fidgeting and hyperactivity distracting and send him to the principals office, instead of providing him with fidgets or the tools that was discussed on his IEP.
43. He has been excluded from school on multiple occasions, he is currently on anti anxiety medication with struggles alienating friends and almost every single classmate, he is 100% blamed for incidents because he retaliates after being hit/punched by other kids but other kids

are socially aware enough to avoid detection or antagonize when not being watched and then disappearing when authorities come.

44. Education; adhd causes problems with writing, reading comprehension and output
45. I am a senior raising my grandson with a adhd diagnosis and signs of odd as I have a physical disability also it is difficult having no help.
46. Access to responsive, available mental health care within the school setting would have been very helpful. Employers are not aware of the strengths that folks with ADHD bring and how they can often be easily accommodated to find success at work with positive communication. Teachers still struggle to understand and accommodate kids with ADHD and have very little understanding of RSD (which can be huge!)
47. For employment, I felt the need to go down to part time without pay in order to support my children and maintain my own sanity the past few years post pandemic. My son's mental health and ability to develop friendships has been hindered in the school system where he needs to be a part of social experiences with some support. Not enough support in our school to do that.
48. Her adhd is quite severe with her focus time being now at maybe a few minutes - it use to be way less ... teachers have to be completely focused on her and also extremely engaging which is difficult to find. she's 18 and I'm not sure she has the focus to hold down any job because she will continue need reinforcement and redirection at this time
49. Adhd can lead to a great deal of anxiety. This is terrible for mental health. There is a severe lack of self confidence which makes finding employment very difficult.
50. The school educator don't know how to deal with a kid with ADHD
51. My son's school has decided his ADHD is due to my being a single parent and "bad parenting". They've been very clear about this belief. I've had issues with my job because I have to keep taking time off to deal with my son's school because they can't handle him. He's received consistently bad grades despite being very intelligent. His teacher even told me not to be bothered by the poor grades on his report card because she was forced to mark him low; that they're not a real reflection of his abilities and that she suspects he's gifted. I've been reported to MCFD because my "bad parenting" obviously caused my son's ADHD. School has been a horrifying experience, but there aren't many options and I'm now terrified of September coming up again. At least during the summer, I don't need to constantly shield him from being put down by his teachers, told he's a terrible student, told he isn't smart, restricted in his movements, and told to "be like everyone else". School is genuinely horrifying for someone with ADHD.
52. Depression
53. Education, physical and mental health have all suffered due to ADHD. My employment suffers from all the appointments, school calls and missed school of my adhd child
54. School is more challenging. There are issues with personal hygiene and toileting
55. My child seems misunderstood at school as being willfully defiant when he is stuck. He struggles immensely with peer situations at recess as there isn't always supervision close enough to prevent upset and this has resulted in lack of friendships and he struggles with mental health and suicide ideation.
56. His attention and focus is an issue, to be able to absorb a lesson requires both. If he misses the instruction, then he doesn't know what to do, or doesn't retain the info. He did have a psych ed in grade 7 and came out with a written output and math learning disorders. His mental health can be tough for him, often sad he does not have friends; kids teased him at school and pranked him. No true long-term friends despite being at the same elementary school k-7. I think he has some anxiety in new situations involving interactions with new people.

57. Because of late diagnosis, late teen and late 30's, and lack of support services, they both had challenges with education, employment and mental health.
58. Lack of in school support resulting in 2 of my kids barely attending school so missed education. Lack of available services for mental health support. To name a few
59. There is very little self confidence left, and this has lead to fear of many situations including employment.
60. Employment for me, I cant easily return to a job as I cannot place my adhd child in before/after school care. I also feel my adhd will negatively impact my ability to handle additional stress from a job. Physical education is difficult as many places do not have an understanding of how to deal with my special needs child. One karate sensei quite literally picked him up and took him out of the dojo Becuase he felt my son was being disrespectful. When in fact multiple teachers and kids had caused the start of his problems that day. Education is a constant issue. Not enough ea time, lack of education given to staff and teachers on neurodiverse kids, lack of services, lack of effective play options for recess, constant negativity towards him, serious issues with their deficiency in being able to help him with social issues. He's in the public French immersion program Because he's also gifted but they won't give him advanced work
61. My child could no participate in regular activities, we can not go out with kids due to their behavioral issues, my kid needs extra support in school due to her limited ability to focus
62. ADHD had affected her leaning education of the child at school
63. No support educationally at an early age. She was falling behind in school. Not because she has any cognitive impairment but because her ADHD made it difficult to focus and attend to the salient components of her environment. She struggled academically, and no one told us about it during the year. Even when she was diagnosed in grade 4, the school did nothing to support her. There was an IEP which was not taken seriously and not followed through on at school. Thankfully her grade 6 teacher was incredible and saw her for who she was and got her caught up academically. Now, she continues to struggle and we are out of the loop of how to help her because we aren't in the school environment. The IEP is a useless document that does not get implemented.
64. My child receives very little public support for his severe Specific Learning Disorder in all academic areas. In fact, next year, his school of 400 students will have 4 EAs, none of which will offer academic support; behaviour only.
65. See previous comments re: IEP. ADHD has affected all of my cgildren's mental health and wellbeing, and mine as well. It's affectd my oldest son's ability to get and stay employed. It's affected many of my children's ability to finish education. It has affected my ability to work uninterrupted. I spend so much time rescuing, fixing, supporting my kids. And when it comes to support, in ways the system should but does not.
66. school refusal, mental health issues preventing employment, complex needs with multiple diagnoses
67. Lots of support required and I have to take lots of time off work for meetings and appointments for my adhd child
68. School is very pro-medication, even before diagnosis
69. Struggling at school, no supports for learning support or working with her need to wriggle/difficulties with transitions and focus. Major struggles with emotional regulation--cannot deal with disappointment.
70. Having to be called to pick up my child from school due to them not having supports or resources in place to help with his success impacting my work day. Spending most of my time outside of working and parenting looking and vetting resources or supports for my child.

71. Difficulty completing school work and controlling his behaviour in the classroom. Physically he has had difficulty tolerating various medications he has been prescribed including ticks, excessive sleepiness and lack of appetite.
72. He has a different way of learning, and struggles in school because of it. It causes anxiety and other mental health issues. It also effects his friendships
73. additional supports not easily accessible to be successful to participate
74. School. All the way.
75. She takes much more time than the usual to complete the exams. She takes extremely long time to finish her homework. Her skills is much less than the girls in her age.
76. Having a child who is diagnosed with ADHD and clearly has academic and behavioural struggles and gets little to no support at school due to a lack of funding/EA/support teacher is very frustrating. My child is also currently a year into a waitlist to get autism testing as we suspect his ADHD is comorbid with ASD. He is also on a waitlist to be assessed by the school districts psychologist and we were told it could be up to 4 years before he is seen by them. The schools SLP and counsellor are too busy to see my child and we currently don't have an OT. This means a lot of the support my child receives is put solely on our (the parents) shoulders and he is struggling in school. He is a child who will mask and hold it together while at school but when he gets home he falls apart. It is clear that his executive functioning is affected and he would really benefit from interventions happening at school. We are so grateful that he has a phenomenal classroom teacher this year but she cannot be expected to fully support all 5 diagnosed ADHD students that are in that classroom. The BC education system needs to revamp their funding designations to include ADHD. Early intervention is NOT happening. We also live in an area where there are no supports for families. So we are not getting support in the schools nor from the community. It is very isolating and frustrating.
77. Struggles with relationships with other children, emotional dysregulation, getting sent home and removed from daycare/ suspended from school
78. My children have been removed from childcare causing me to lose my job as a single parent and sole provider. All of our mental health has suffered, especially in the way of anxiety and depression. At 4 my son was having suicidal ideation because he thought he was such a bad person for not being able to control himself like other children and CYMH turned us away because we didn't have a pediatrician referral...we waited an additional year after that to get a first appointment with a pediatrician.
79. Im a single mother with 2 kids and not a ton of money; I would register the kids for swimming lessons, gymnastics etc. and be very open about their needs-the kids would get kicked out of lessons within a few weeks. My now 17 year old hasn't gone to school in 2 years because our school board cant find a suitable education center for him (long story, but our "alternative" programs apparently don't have space and they keep trying to get my son to go back to "normal" high school with no support). When my kids were young I was constantly called by school to come pick them up because they couldn't deal with the behaviours. My kids were bullied and picked on constantly however because of the way they reacted my kids were always the ones in trouble (no consequences for the other child involved). Mental health wise, constantly struggling to try and get through a school day without getting in trouble was too much to handle and one of my kids attempted suicide because they felt like no matter how hard they tried they could not live up to everyone's expectations. The ADHD diagnosis is a nightmare because the governement, schools and general public don't recognize how much it can affect people.

80. Too much to type here. Impacts all areas of life. Lack of supports leading to poor self esteem, mental health issues due to feeling “hopeless”, justice issues due to poor impulse control, inadequate/lack of supports in school
81. I have been unable to work due to inadequate government support for my disabled children. Both our children struggle in their ability to perform academically and there is inadequate support for them through the Ministry of Education school district. ADHD is associated with other mental health issues and there is inadequate assessment and treatment services for all mental health concerns.
82. Applying for jobs through websites is difficult for my daughter, she only wants specific jobs and can't make connections with people so she hasn't found employment. School as stated above is access to ea and her full accommodation needs. Mental health, my daughter has concurrent diagnosis of anxiety disorder and depression which is typical with girls with adhd, accessing counselling that doesn't interfere with school hours or extra curricular activities can be challenging and changes to who is covered for billing with benefits makes it that we pay privately due to her connection with her therapist.
83. It's a struggle to get a job and to keep the job.
84. MCFD does not incorporate any informed trauma response dealings with youth. MCFD did not talk with his play therapist or even the district personnel involved at the time. they also did not interview my other teenager who had witnessed her brothers disclosure of abuse. They overstepped by expecting me to continue to work with the other parent who is and has been abusive and continued to block access to treatment of our son simply by using refusal to consent as his own leverage while our son went down hill. They wrote a letter for my sons abuser indicating what a loving father he was despite years of issues of him not attending any medical appointments, participating in evaluations, or even showing any interest in our sons mental and medical well being despite concerns from myself, school, daycare, play therapist etc. They did not acknowledge the additional negative impact it had on my son where various evaluations or medications or appointments were not agreed to until it may have impacted his limited visitation and therefore work schedule. They did not acknowledge how the other parent went from indicating there was nothing wrong with son despite input from multiple other professionals, involvement of START when our young child was talking self harm, input from Kinsight, etc to suddenly claiming he was autistic.
85. She has need of services that are not available for most families in this economy. Free services are too long a wait and too short a service.
86. I had to go on a mental health medical leave from my job for 7 months due to my child having daily meltdowns at school and often being asked to stay home after a big incident. I had missed 45 days of work in the 5.5 months leading up to my leave. My child has missed a LOT of school due to his difficult behaviors in class. He only just returned to full school days 3 days ago, after going for only 2-3 hours a day for 6 months. All of this has negatively impacted myself and my child's mental health.
87. I am unable to work full time. child is unable to access public education (I drive 3 hours per day to send them to an independent school). Family's mental health is often correlated to child's regulation.
88. lack of appropriate & knowledgeable psychiatrists in community & in hospital, weight issues (anorexia & obesity) due to ADHD & meds which impact physical health, lack of understanding among general public leads to difficulty with employment
89. Pulled our kids out of public education after years of advocating and little support but lots of ableism

90. Education: My child has not received adequate education according to his needs throughout his entire education (k-11). He is now in grade 11, and we take him out of school for 1.5 hours a day to work on science and math. He was a late reader/writer, and we are still working very hard at home to help him "catch up," as these services are unavailable in school. His mental health has been a balancing act due to his anxiety caused by the pressures of school. He rarely feels adequately supported in class. Due to this ongoing anxiety, he is fatigued and loses motivation quickly to participate in physical activities, which affects his ability to take care of his physical health.
91. I had to fight with his school to get an IEP in place and I continue to fight daily for that plan to be implemented. I constantly need to educate his school team about ADHD and tie exhibiting behaviour back to the disorder for his team to understand. For mental health: Due to the disorder, my child was unsupported in kindergarten and was labelled a bully. He has since gained some support (see above). Still, the lack of support continues to affect his emotional regulation and social skills and is now impacting his ability to make and maintain friendships. He often is sad and cries as he feels like he has no friends...
92. N/A
93. Economic impacts: - I decided to leave my career of 18 years to better look after my child's needs (ADHD and others). - Often need to leave or change work schedule to look after my child. - Impacts on income and long-term career options and choices. Long-term impacts: - My child's struggles with learning due to ADHD - My child's struggles with social-emotional regulations due to ADHD - My child's self-esteem and self-worth issues (And please note again that while there are supports from amazing educators, but they are swamped with needs of many children and can't provide all the care and attention that are needed to each and every child due to chronic public education underfunding.) Social emotional impacts - Both my child and myself have to find support and resources on our own - creating stress, anxiety and other social emotional impacts.
94. have shared previously
95. School would not provide an IEP or category designation. I ended up homeschooling
96. Middle school has been very challenging of a transition with the reduced support for all kids and the increased demands of all students. There was no plan in place for her transition from elementary because I was told she doesn't have an IEP and wouldn't qualify. Accommodations were not being made for my daughter in middle school. Her teacher didn't even know she had ADHD until we told her and my daughter was still not getting the help she needed from her primary teacher. I only was informed of the inclusive learning teachers and support after I asked my pediatrician to write a letter in support of an IEP. The stress of school worsened my daughter's anxiety and she needed to start seeing her psychologist weekly (her request).
97. Significant academic and social impacts due to undiagnosed and unsupported ADHD. Significantly far behind academically, had to leave French Immersion and friends / peers and move to English as too far behind. Ongoing tutoring plus reluctantly attending counselling sessions. Some mental health struggles resulting from feelings of overwhelm after a life change.
98. Unable to get a job. Poor executive functioning. Attempted but dropped out of college. Mental health and anxiety concerns.
99. My child is being over medicated and soon to be excluded from school. Hard to access further assessments to further learn about comorbid dx
100. My younger son has such trouble focusing that his eyes won't stay on letters long enough to sound them out. Now at the Grade 7 level, he is far behind his peers & never likely to catch up. He struggles with mental health as a result and we have hired a private counselor as we couldn't

get one through CYSN or CYMH. He also struggles to participate in team sports. Coaches don't understand why he "doesn't pay attention" & think he is willfully not participating when he is distracted. This results in him not wanting to participate further (vicious circle).

101. Has no personal educational plan at school; can not equally participate in sports activities, is very often treated unfairly/misunderstood
102. Need support in school to catch up to peers and can't get any assistance; already answered re mental health
103. My ability to work has been greatly affected based on whether the school was able to manage the child
104. Education ... public school teachers had no clue what ADHD is and how it presents. They need training and support to recognize it since they are asked to fill out diagnosing forms. My daughter also has aDHD but it presents very differently and without my family history I can see how a pediatrician wouldn't reach a diagnosis. Ours was on the fence because the diagnosing criteria didn't fit her presentation (internal hyperactivity in her mind instead of bouncing off the walls physically). The criteria is outdated and lacks a girl's perspective.
105. Living with ADHD makes everything more difficult and there is a lack of systemic supports in place to help individuals with neurodiversity.
106. Our son's education has been impacted significantly by his ability to focus in class, and more importantly, by his struggles with peers. This has caused mental and physical health issues, including burn out last year.
107. Lack of accomodation in school. Frequently harder to take up skills for everyday life and recreation resulting in challenges for participation.
108. It has made school both academic and socially challenging for my kids. Both kids have anxiety. It also masked a learning disability for oldest for a couple years and I had to go private for assessments for both kids. Waiting results for second but I am certain he also has SLD. It has costs thousands of dollars in assessments and then there is no funding or supports in schools everything is put of pocket and/or time from parents at home. This can be exhausting and damaging to relationships when the homework struggle is so hard.as we approach highschool the odds stack against us and the understanding by the professionals (teachers, and school staff) is awful. They say they understand but then don't follow IEPs, don't give accommodations, and blame the student for not trying hard proving they don't really understand.
109. Again - teachers apply stereotypes to your child. One admin for a high school academy wrote off my child from the very beginning of the program, thinking that he would not be able to cope with the program. She put him with the worst students/students with no past experience in the program and provided zero support (despite the IEP). After 2yrs in the program he has decided to drop it because he is getting nowhere because the teachers have written him off. He is fully capable, and a gifted learner in areas that are needed for this academy. They don't care. This experience has led my son to doubt his abilities and feel like he is not good enough. This is not what a teen needs heading into gr 11. ADHD meds already make kids feel down, and teachers making this worse are NOT helpful. TEACHERS NEED TRAINING. Meds make my kids not eat and then they are worried about how others see them as too skinny. The side effect of medications needs to be considered and not stigmatized. They do not participate in anything that will require them to take off their hoodies and show their true body size. The mental health aspect resulting from this is terrible. Yet, they need the meds to be able to focus enough on their non-preferred tasks in school.
110. School system - ADHD is not a priority disability and I have experienced teachers unwilling to try other routes of prevention or accommodations first due to lack of funding, time, energy, etc.

111. I wasn't diagnosed until adulthood. I wasn't able to attend university when I was younger and missed out on years of income I could have made. I have a hard time maintaining healthy habits and i don't want to pass that to my kid
112. My child has significant anxiety but it has lessened with our private and expensive therapist.
113. Employment: I need to pursue paid work to help cover the costs of the expensive programs our son is in (tutoring, OT, counselling, private school ...) and at the same time I don't have the availability to work because parenting a ND child is beyond full-time work. Education: the public education system (VSB) is failing my child and we have decided to move him to a private school that will need his needs better.
114. We have had to modify, create extra supports privately on our own time and expense, or avoid certain activities that are not ADHD affirmative or understand the unique impacts and needs of our child.
115. My son has a difficult time at school. He struggles to be successful at school without adequate supports (an aid), he's had trouble emotionally because he is aware he his "behind" academically and he has frequent outbursts with friends, lastly his physical health has been affected as he struggles to eat healthy food and often goes long periods without eating.
116. There are some teachers who are very mis-educated on ADHD and therefore are not willing to work on providing a supportive environment for children with ADHD. Mental Health has been affected because many families/parents/kids in general are not educated on ADHD can be very not-understanding of the behaviours.
117. Needs extra support at school but an ADHD diagnosis doesn't receive any support
118. School staff have no understanding of what ADHD is and what it is not. Before my son had an Autism diagnosis, the only special needs designation he qualified for in school was a behavior designation. This further confuses the understanding of what adhd is and isn't, as it is not a behavior disorder and behavior is the downstream difficulty. Instead of using surface level strategies to try and modify behavior, they need to look at why the behavior is happening in the first place and how to actively support the upstream needs. Not all medical professionals know how to treat someone with both ADHD and co-occurring conditions.
119. My daughter gets bullied for getting to take breaks, which affects her self esteem. She has been gaslit by teachers who don't understand her symptoms because they do not match the expression of ADHD in boys (which teachers are much more familiar with). Her peers see her as misbehaving when she is really struggling to moderate her attention.
120. His learning at school is disrupted by his ADHD symptoms, his social relationships are impacted by his ADHD symptoms. His mental health has clearly suffered as a result of his experience of constant correction, "getting in trouble" and not being able to get along with with peers.
121. Education. Between ADHD and other LDs, schooling has been difficult. Hes barely meeting grade level expectations. Constant need to supervise and guide child. Organizatin is non existant. Mental health. Adhd has lowered child self esteem. Is being treated for anxiety and depression while waiting on diagnosis and better resources.
122. I wasn't diagnosed until my 30's and was always making mistakes and getting in trouble in my career, and in school prior to that. My career prospects and mental health suffered as a result. I am now in a period of extended burnout and unable to work, and my Long Term Disability plan has cut me off.
123. Bullying and harassment at his employment. Education - we opted for home learning as that was going to be a better choice for his learning style.

124. One child was let go from jobs multiple times for being too slow even though they disclosed their ADHD diagnosis. They were not offered accommodations. ADHD adds to all four children's mental health challenges. They feel frustrated when they can't begin or complete tasks they want and/or need to do. One child finds it very difficult to cook for themselves due to the executive functioning skills required to plan and make a meal. One child often forgets to eat because of medication side effects. Our oldest child was diagnosed while in school. Their ability to focus, manage impulses, transition between activities, and manage their self-care greatly impacted their achievement. One child had frequent panic attacks at school when unexpected changes occurred. They also struggled with time blindness and organization, requiring them to take more time than others to move between classes. They would give up socializing during breaks just to ensure they made it to the next class on time. This child only had a mental health diagnosis at that time. One child is just getting diagnosed now at age 18. They were high achieving in school through lots of hard work but when classes finally got too heavy they could not keep up. They moved out of the academic stream and into a lighter schedule for their final year of high school. They originally wanted to go into sciences but felt they could not focus enough to keep up with their readings and work.

31: What help did you seek when misunderstandings or the lack of support for ADHD made things hard in areas like work, school, employment or health? Please share your experiences.

130 out of 160 answered

1. Not enough EA's
2. CYSN worker, ombudsperson, filing a formal complaint with the health authority, hiring an education advocate, becoming a PAC and DPAC executive, child youth legal center, meetings with all levels of school staff, foundry, FVCDC probably more things I can't recall at the moment
3. Went back to an employer who is more flexible compassionate. Advocating hard within school system
4. Doctors, community resources, our social worker, district staff, private therapies I could go on for days.
5. When the areas of help that you seek don't understand the problem, they are not much use.
6. I work in the field of community living (20 yrs) so I am fully aware of his rights, which I lean into and educate others about when necessary... I have taken concerns at the old school to the district counsellor and the superintendent, leading to a likely early retirement for the last principal.
7. Appointments with GP
8. MCFD, outside counselling services, psychologist services (paid in another province due to lack of availability in BC), parent courses on anxiety and behaviour through BC Mental Health, Occupational therapy
9. There is no help because he is not eligible for any of the supports. Further, I understand his diagnosis better than his SW who we never hear from ever.
10. None
11. I continue to advocate for my children and continue to push for conversations with school staff to appropriately support them so they can be successful at school (teacher, principal, learning support staff), sought counseling, services through the Fraser Valley Child Development Centre, online learning resources, I regularly research and learn more about how to support my children in their unique challenges
12. I feel like I have an ongoing battle with my son's school, to get him the most minimal of support around his ADHD. This has been going on for 4 years. He's in grade four now and is that about a great one level. For myself, I can't advocate too hard or I'll lose my doctor, the only family doctor that my son and I have.
13. My employer, quite frankly, perceived my quitting as my failure to parent.

14. Facebook groups and literature
15. Pediatrician and school
16. Teacher, school-based team meeting
17. Took issues all the way to associate superintendent, a lot of phone calls and meetings, reading books and other materials to better understand and advocate, kept pushing back when told “no” or “sorry, can’t do that”
18. Asking for an EA, asking for 1:1 learning time, asking for flexible seating, asking for a referral to school OT, asking that IEP be followed. None of this was given
19. Contacted the school and school board.
20. Move to OL for schooling
21. Private counseling that cost \$100.00 per hour for our son
22. Requesting/participating in school team meetings to address IEP supports not being provided. Despite multiple meetings/conversations the support staff did not change their practice.
23. We have done a huge amount of things both before and after diagnosis. Accessing what therapies and services were available, in both the private and public system. Advocating with medical providers and social service providers to try to get access to those services. Spending a ton of time researching what is available, and the best source of information is usually not social workers or doctors or educators, it is other parents on Facebook groups or when we find each other out in the world. I have another fulltime job on top of the one that pays me trying to navigate this broken to keep my children as undamaged as possible.
24. Having those who work with him understand that he’s not displaying bad behavior, he is ADHD
25. I tried reaching out through commune community programs, the school and my doctor, but everyone just kept passing us onto the next person and services were rarely received
26. Meetings with school, CYSN, CYMH, social worker
27. I started researching online and discovered parent support services of BC and became a peer support co-facilitator of an ADHD group for children in BC.
28. Any I could find
29. Once my child turned 6 we lost the services of the child development center. I am not aware of other ADHD services.
30. The problem with ADHD is that it can be hard to get organised to get help! We did try speaking to the learning co-ordinator at the school and I asked for an appointment with the social worker when we got our Autism funding.
31. Every possible support in BC. We have worked with them all.
32. Self-study and learning to help educate the people / providers we deal with about ADHD.
33. There is nothing else other than the original nothing I couldn’t get in the first place to support my kids.
34. Constantly advocating for my kids. I bring new and different ideas and research and resources to the team meetings which I ensure happen as needed. I am fortunate to have a reasonable working relationship with the school and also have made use of a local private school when the system couldn’t support appropriately. My new employer has been more than understanding
35. Medication
36. We could not get an assessment through the school because my child is doing well academically, so we had to go to a private clinic.
37. Online sources telehealth sources
38. On recommendation of psychologist who conducted assessment we asked for some academic accommodations through the university assisted learning
39. We sought out help from our doctor in areas where we could try counseling, in school tutor, and medication adjustments. The adjustments took quite a bit of time to sort out which also caused stress on the rest of the household.
40. None There was nothing

41. Our kids have a community counsellor and have integrated her into the school. We have had collaborative meetings with the teachers, school counsellor, principal, etc. We have worked together to figure out what her/his triggers were and what else was going on in their lives and see what could be helpful. Also, including the doctor & paediatrician. We have had to adjust medication for the one child a few times, as needed and I've done an online course from sunny hill about ADHD provided by the paediatrician. We've come up with strategies for school & home that were "somewhat" helpful & behaviour plans and they now have IEP's that are ongoing. I also have a counsellor of my own to vent to that is separate from all these people.
42. Counseling OT and social skills
43. I was in constant communication with the school, making sure they were providing him the tools he needed that was discussed on his IEP. I eventually found a good pediatrician who placed my son on medication that helped with his lack of focus and hyperactivity. I have family who helped bring my son to appointments or extracurriculars that were physical or outdoorsy. As my son has a lot of energy and needs to release his energy outdoors
44. n/a
45. I sought counselling support and zoom groups with people in similar situations.
46. Financially cannot afford respite for my grandson and also activities/programs are expensive
47. School counsellor (we requested but were not given any access), school administration (we were just given a lecture that boys of this age are expected to conduct themselves in a certain manner and to the schools conduct code and behaviour otherwise is not tolerated), we requested IEP and were not given one until 3 years later
48. We relied on the school system advocates to support us, with mixed results.
49. I am worried about my son starting school as he can be very inattentive. I spoke to the school principal to request a teacher who will have patience and understanding. I was dismissed being told that all teachers are fantastic with ADHD which is incorrect. Some teachers do not have the training, experience, or patience to support children with ADHD. We have an older child in school and are aware of teachers that struggle to support her peers that have ADHD
50. go to the doctor continue to get referrals those places refer to other places and so on and so on. The therapist we have contacted don't feel capable to deal with our daughter because she has more than just ADHD going on. She also has Disability. and so we have not found someone who can help her on a biweekly basis
51. I had to go to parenting group and find out online about adhd
52. Spoke with teachers and principal, no help. Total lack of understanding. They felt he needed to apply himself better.
53. I start looking at the libraries to educate myself so I can provide guidance and support to my child
54. I've gone to doctors, to counsellors, to support groups. I've talked to the teacher, the principal, my GP, a paediatrician, a (private) specialist clinical counsellor, a support group at the local hospital. Who haven't I spoken to at this point? The only one who's made any real suggestions is the private counsellor I paid \$2000 to help make recommendations on how to handle my son's behaviour.
55. I changed schools from public to private. It was very expensive but working every penny as educators are not trained on ADHD behavior or alternate schooling methods. It did a lot of damage to my child who developed a distrust for teachers as they treated him like a problem
56. Drs, counselling, OT
57. The child development centre which was not helpful. Private counselling services and play groups for neurodivergent kids have been somewhat helpful. I have essentially reached dead ends everywhere I've gone
58. Constant conversations with school staff, advocating for my child to attend social groups with focused skill building and to access counselling supports at school.
59. I had to advocate and would email teachers to follow up year to year, as well as include the Principal when needed for elementary. I wrote a letter every year to help with class placement

for my child. Currently my child started high school and I check in with teachers here and there to help keep him on track with homework as his executive functioning skills are non-existent. My pediatrician advocates as well so I drop her name when needing follow up with the school. I work for the same school district so I do have higher up people I can complain to...

60. Counselling, I talked with teachers with them and or for them while they were still in the K - 12 education system. Once they reached adulthood, I could only advocate for them with their approval even if they were not in a space where they could advocate for themselves.
61. heavy advocacy on my part with medical practitioners, educators, admin, etc. to ensure a better understanding of the needs of my child and their challenges in approaching these topics adequately
62. Feels like there's not much help for me an adult with adhd. Or at least a massive barrier to getting help and it would make me feel as though the employer disliked me because they had to make accommodations. Im still holding onto the belief that if I try to maintain a good relationship with the school they will help him. The principal is educated well and is sympathetic to his plight so for now I don't want to go over her head.
63. Luckily, with ASD funding we have extra support people. However, finding the right person who understands ADHD is always a challenge. I am stretched very thin trying to support both my kids while maintaining my own sanity as I also have ADHD.
64. I contacted the child's Social Worker, Resource Worker, Pediatrician, School teacher, MCFD mental health.
65. Inclusion and support at all levels of school. Support in the early years with respite and access to services (i.e., OT support would have been extremely useful when she was young, but we could not afford to pay out of pocket).
66. I sought help from his paediatrician, audiologist, developmental optometrist, psychologist, GP doctor, tutors and educational therapists. ALL sourced and paid for by my family. The public education system and Ministry has failed my child
67. I went to the school and asked for an IEP for my daughter. They refused. Teachers often think my daughter shouldn't need help because she is brilliant. They completely don't get how disability works. She is having a hard time finishing her year and graduating -- despite getting 90s whenever she is able to hand in work. They will not let her skip assignments where she has proven knowledge in another way. Keep talking about "fairness." I had to get a PE assessment for my second oldest son to get his teachers to stop abusing and shaming him and instead help him.
68. ADHD seemed to take a back seat to other diagnoses, and I wonder if things might have been different if ADHD symptoms were better explained or support had been more directed towards ADHD
69. Kelty mental health has lots of great online resources
70. talked to the teacher, not much help there.
71. In school iEP meetings. Lots of referrals from our nurse practitioner for specialist and mental health supports
72. Help from pediatrician and counselor for child, as well as counseling for parents. Also parenting courses were taken when offered. A course was also taken in how to get a job, without success.
73. None
74. The parents have dealt with these issues.
75. Teachers, principals, paediatricians, every book I can get my hands on, counselling for myself (mom)
76. emails, meetings, bringing in materials and training supports for teachers, EA's and others who work directly with my child. personal expense to do so for money and time.
77. I just knew the right people who could help us. We didn't get help outside because there weren't any in a timely manner
78. School

79. I had to demand my son's school start a learning plan for him. I believe that if I was not such a strong advocate he would have fallen through the cracks and been left behind by the education system. Due to my son being inattentive ADHD, he tends to not create a lot of fuss in the classroom/around the school so they do not believe he can qualify for any funding under an H diagnosis. Most of the help has had to be source on my own and via the internet. Thank goodness my counsellor was able to start taking my son as a patient because counsellor are extremely hard to find in our area.
80. Family in mental health positions, church, other parents of school children. They were supportive, but mostly I still felt completely alone and lost in this
81. CYSN, CDC, CYMH, WorkBC, resource and referral center, MLP, MP, SD59, and every other option you could possibly dream of.
82. I made sure to get educated about ADHD and the human brain. I went to Childrens hospital to attend several conferences, had my son seen by the ADHD clinic and attended the P1 children's psychiatric until with one of my sons for 5 weeks. I have provided multiple diagnosis documents to the schools, and offered to take time off work to accompany my children on school trips. I have offered to provide additional support to community lessons my kids were attending. There has always been some kind of "red tape" that doesn't allow me to provide the additional support to my child yet they don't have any other way to apparently accommodate the need for extra supervision.
83. Spoke to teachers and principal at the school, applied to private counselling services but was denied because "our case was too complex"!
84. Advocacy supports, leaving public school system, private psych-ed assessments, quit job
85. For the my employment barriers, having 2 disabled children, I looked into program to provide adequate care for my one child but currently there is no government program to meet the specific needs. We have tried to seek support through the school, but there is no funding to support children with ADHD or for children with other complex issues. We have saugh services of the GP, a pediatrician, a child psychiatrist, a BCCH ADHD clinic psychiatrist, Fraser Academy executive function coaching, CYMH, and CYSN. Long-term ADHD counselling and coaching support would be useful for my 1 child, if it existed.
86. Her school has a student support room and the teacher in there has helped support my daughter and helping teachers understand her needs and accommodations, she has connections with some of the ea's. With work I am supporting her to find work. With health I advocate for her, her pediatrician and gp are strong advocates and she is connected with a therapist.
87. I tried to get diagnosis for adhd for daughter, Didn't get.I even paid \$3000 for diagnosis which I didn't got.The struggle takes toll on mental health
88. I reached out to Family smart, the district, his school counsellor, his pediatrician, took rolling with adhd, took confident parent confident child behavior and anxiety courses, attended behavior revolution, read all I could find by Ross Green, asked MCFD for help, took a coparenting class, asked cymh for help, I coordinated with school and daycare and pediatrician for multiple assessments, did another assessment through Brightstar, I amended my schedule to accomplish his reduced hours at school, then being entirely out of school, then took an unpaid leave of absence for his P1 admission driving from the TriCities to B.C. Children's every day for 4 weeks and back and looking after the rest of my family. His father attended remotely a handful of meetings while on speaker on the job site after refusing to attend at the hospital at all to support our son unless I left the building and refusing before and after to do transitions (which son struggles with) at the hospital or see son unless he could take him alone to his home which son would not do and would break down and become violent- hurting me, destroying our home or barricading himself in his bedroom or the bathroom.
89. School meetings, IEP, requested additional servies, looked online for free services and resources, too a parenting course through the government, took online courses on ADHD, joined online support groups.

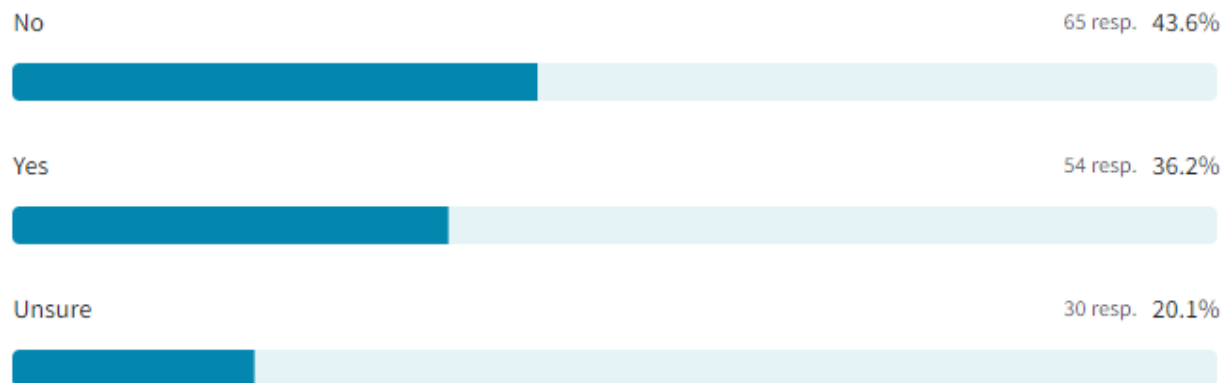
90. Counseling for myself, play therapy for my child, Occupational therapy, connecting with Family Smart, CYMH, connecting with the school psychologist and resource team
91. Consults with family doctor (received referral to pediatrician). Counselling (individual and family) - funded by extended benefits.
92. deep dive into scientific research myself over past 15 years
93. I haven't had any experiences of people misunderstanding ADHD
94. Spoke in the legislature. Formed a parents for inclusive education committee. Joined pac and DPAC. Formed committee at school. Wrote our MLA. List goes on
95. I have contacted the school and the school district for increased support in the classroom. We have also contacted the school counsellor and psychologist for extra support for his anxiety and general mental health. In one instance where things were incredibly challenging, in grade 9, the school district responded to my email by blaming me and refusing to recognize that there was an issue when 75% of the teachers were unwilling to read the IEP and support it.
96. When we were first seeking a diagnosis, I connected with a parenting coach who I later learned had resources that closely aligned with ADHD. This is when I started to bring more ADHD knowledge into my then-current disability background - a two year education I received that did not teach about ADHD! Since receiving our official diagnosis, my child continues to attend monthly OT sessions.
97. N/A.
98. My child's school and teachers/support workers are great, but they are under resourced and overwhelmed without proper public education funding. I have access to counselling through work, but our workplace (like many) definitely need better practices and support for families with diverse needs and abilities.
99. not very many, other parents, family support institute own research, counsellor I have my son seeing.
100. Pushed for a psych ed assessment, accommodations at school
101. I shared my experience or lack of support work my daughter's psychologist and pediatrician, who not said she would benefit from an IEP. The "inclusive learning" teachers at her middle school told us that we are requesting supports available to all students through the ministry education and that she would not qualify for an IEP unless she was non-verbal/severely impaired. We were told her teacher had been following the care plan we shared (co-developed with a private OT and her former elementary after school program in Vancouver).
102. Lots of self learning for primary parent (books, parenting conferences, etc). Paid for tutors. Lots of advocating with teachers to convey the problems and the needs and the suggested strategies.
103. Still looking unsuccessfully.
104. I try to educate
105. We spoke with coaches, resource teachers, class teachers, etc. We hired a counselor privately. However, there is no easy answer and no one seems to have the knowledge or skills to help my child fully.
106. support at school; couldn't find accessible and affordable therapists
107. Spoke to principal, teacher, special support teacher
108. Changed schools and found one that understands neurodiversity and how to support it. Advocated hard for daughter's diagnosis and also lucky to have a pediatrician who is willing to listen and try medication.
109. Reached out to employer, school staff, doctor, MCFD, and private counselors. Tried a new CBT-ADHD program with doctor referral, not happy with online only option and lack of individual phone check-in's.
110. We have a great pediatrician who has monitored our son, and my son is receiving limited help from learning assistance.
111. Therapy

112. None
113. Sought help from school district staff, support groups, private counselling, doctors, MCFD and private tutoring. All had views on the systems in place and some knew things that others didn't so we tried to patch a picture of care together.
114. Lots of communication with instructors. Suggestions about what has worked in past. Contact with school counsellors and student supports.
115. I have asked for assessments of skills and abilities to better understand where support is needed. Got nothing. I have requested support and more communication around school work and struggles. Never last more than a couple weeks. We have IEPs they are never meet the goals are a joke and accommodations are an after thought. I have asked the pediatrician for good resources and got nothing. Everywhere I turn in my community if kids are school aged there are no resources or supports.
116. I have talked to teachers, support workers, vice principals continually for YEARS. I have got written submissions from psychologists to give to support workers and teachers to backup my child. The lack of knowledge and push back resulting from this is exhausting.. and then you start again the next school year.
117. We had to pay for a private assessment for a diagnosis at \$3800 which doesn't include ASD which he likely is as well, we are seeing a parent coach soon, we've read every resource we can come across and talk to other parents, joined FB groups. Had meetings with his current teachers, school staff.
118. From my partner and friends. It's hard on them too.
119. I've had to find my own resources. The parenting Facebook group has been amazing.
120. We have sought private meetings with teachers, we have sought professional support to consult for adaptations (through an OT, psychologist, play-based counsellor, and pediatrician). When misunderstandings have arisen, we have offered to have our professional team be available to speak with teachers to help troubleshoot.
121. Pediatrician-Child is medicated for Anxiety and ADHD. We have used school resources such as the Teacher, Counsellor, Principal. The Principal at our school is amazing so has really helped in making the school a tolerable place for our child who struggles with anxiety to make it through the day.
122. medication for my son when things finally were getting "too hard:
123. Outside tutoring and play therapy (paid for out of pocket)
124. I need help from an educate advocate to help my son get support in the school system. Schools routinely tell parents that children with ADHD are not entitled to any support.
125. We have been in constant contact with teachers and principals to deal with staff and students treating our daughter unfairly or bullying her. Our daughter regularly talks to a counsellor, but has only recently started play therapy as she is not very receptive to talk therapy. She also has a pediatrician.
126. Telehealth appointments (which means different doctor every time, no one who knows us on an ongoing basis), school team implying that we were jumping the gun seeking a diagnosis, when we've been seeing behaviours since the age of three. Teacher sending emails home about kid's behaviour in school and wanting us to "talk to him" about it (kindergarten). Prior to diagnosis, seeking help of clinical counsellor/play therapist, without a clear objective. We just knew we were struggling as a family, our kid was struggling, and we needed help. But we didn't know what we needed help with or how we needed help. So went spent thousands of dollars on therapy, that while some what helpful, was very much floundering around in the dark.
127. When the kids were in school, I communicated with teachers often. There was usually at least one teacher I could rely on to advocate to others on my child's behalf. We found private counsellors to support our children, us as parents, and to advocate with the medical community as necessary. We reached out to WorkBC to help with employment but found the experience

quite frustrating. The child who was trying to find work is also autistic and found much better support through Canucks Autism Network.

- 128. Because I know that nothing is available in the schools, I haven't reached out to the school. I have shared the information with my child's teacher as my born female child is a high masker. This has helped the teacher (who is already massively busy) decide on class-based programs for kids with ADHD -- there are more in the class who are externalizes that cause quite a bit of disruption in the class. So basically, I sought no help because I know that there is not help, except what is put right back onto teachers shoulders.
- 129. Support from the neurodivergent community. No one else seems to understand (or care.)
- 130. Home learning network of parents and support teachers.

32: Have you or your child/youth experienced suicidal ideation as a result of ADHD or the challenges it presents? 149 out of 160 answered



33: What specific support services or resources do you feel are currently lacking for ADHD families in your region? 135 out of 160 answered

1. A starting point for diagnosis, and access to supports, daycare and before/after school care was very challenging when my child was younger, finding availability and accommodations and affordability was impossible
2. Everything! The wait lists in our community are years long. Our children are having to travel to other communities or sit on zoom to get help and that doesn't work for many of them.
3. Any kind of understanding that adhd is not just being a bit busy. It is so much more, and the 'supports' just don't get it.
4. Publicly funded counselling Public awareness campaigns that our kids are biologically different and not just jerks or brats!
5. Long wait times to see paediatrician
6. Advocacy, consultation/coaching for executive functioning deficits (which is the real ADHD diagnosis). There lack of understanding policy makers that ADHD is not just treated by a pill. It is more complex than someone who cannot sit still. This lack of knowledge by policy makers results in lack of services for those with ADHD.
7. All supports. They are put on medication and that's it. No peer support, no life skills, no help managing social skills or impulse control.
8. I cant even begin to list them. I dont know how to describe how significantly this kid was lost in the school system. Taking communication with parents out of the picture will not help for future generations. The new reporting system in schools will not make this better.
9. In the school System

10. Lack of educational supports, socialization supports, mental health supports, social emotional support
11. respite/ parental support for navigation of behaviour/
12. Medically Covered support like OT/counselling
13. Home support
14. Easy access to a pediatrician
15. Funded support
16. Quick and responsive MH services, so much need - needs to be supported sooner, before the crisis point. Financially cost prohibitive for so many, and free or lower cost options with astronomically long waitlists
17. School supports, parenting support and education for kids over 6
18. Teachers and more experts in public schools to support children.
19. Everything. OT would be top of the list, school supports, an ADHD designation, access to medication specialists (my older teen has only seen a GP and I am not confident in the GPs prescribing and that it hasn't attributed to the suicidal ideation
20. Too many to list; -long wait times - Local drop in support for our son and family - more support through public schools - extra funding for services -youth group drop in for children with similar issues
21. Funding!!! The services are available but without funding allocation for ADHD the services are outside of our family budget and cannot be accessed.
22. Schools need to have enough funding to provide all students with access to their education regardless of diagnoses. Schools need to have funds to provide specialized services like OT, SLP, OG reading instruction, EF coaching. OR those need to be turned over to the public medical system and funded there. Accessible childcare needs to be made available to all kids (including before and after school and in the summer) up until the age kids can be home alone (which is likely later for those with ADaHE or other disabilities). The waitlists for mental health care are very long. And in many areas of the province I know it just doesn't exist at all locally.
23. Support in education and mental health support
24. Funding to be able to access supports, available providers
25. We are supported
26. There aren't any at all that I can afford to access.
27. Peer group settings to practice skills.
28. Intake appointments for newcomers and/or newly diagnosed individuals to help with first steps in getting help.
29. There appear to be no or very few services
30. Educational
31. Access to just about any type of service! Every option has a gigantic waitlist. Our paediatrician has advised us to go to Children's Emergency for mental health assessment when things go sideways.
32. Any services at all. There is nothing for kids with just adhd. It's always something much bigger, and adhd.
33. Psychologist and family dr. & pediatrician. tried Cymh but no available supports.
34. Cbt, support for youth
35. Literacy groups
36. Assessments for both ADHD; occupational therapists

37. No way to access medication, referrals are hard to get through telehealth and pediatrician wait-list are long. We cannot find a prescriber and the only solution we were giving was to wait in the ER for 8hrs every month for a prescription, this is unacceptable.
38. Assistance for parents of young adults who have recently been diagnosed providing info on how best to support them . Family physicians to refer to services rather than just prescribing medication- feel there should be more regular in depth follow up with young adults with their physician. We received a referral but no help with who to contact etc and ended up having to search on our own & get recommendations from acquaintances whose young adults had also been diagnosed.
39. Lack of understanding, medical coverage for costs of medication, referrals to counseling, Support groups or activities targeted towards children with ADHD.
40. Employment Education Health
41. None. Medication.
42. Financial, awareness,
43. All kinds- should be funded similarly to autism and every child has different challenges that show up in different areas
44. Lack of access to good mental healthcare facilities or programs - specifically outside of work hours. Courses for parents that teach tools to parents- not over zoom but in person that are taught by occupational therapists, or counsellors, or teachers. Funding for technology free physically challenging extracurriculars.
45. respite, educational supports summer camps
46. I am unsure I cannot comment as this was in Alberta and many years ago now
47. General understanding, the disorders name is ridiculous, 100% of people think it's a discipline issue and we're bad parents
48. School-based training and support for teachers, leadership and staff. We need to meet families where they are already and not require extra time/organizing/cost again and again.
49. Funding in education for extra support. Education for teachers about ADHD
50. OT, general understanding and strategies for how to properly provide accommodations and strategies for skills deficits for my school-aged child. The Montessori program my youngest is in until age 6 is much more equipped, but we pay for the program
51. Finances and respite services
52. All of them. Consistent mental care therapists- not available. Courses for kids with adhd and mid or more are not available
53. Support groups that meet regularly with child care
54. All of them. And even knowing what supports are helpful.
55. Not accessible therapy, everything is waiting list
56. ALL OF THEM. The school is horrifying. The public health system is a joke. The only real help I got was hiring someone privately to walk me through how to handle my son when he's dysregulated. Even now that he's formally diagnosed, his paediatrician keeps saying there's nothing we can really do until he's older. He's suffering from increasing anxiety and when I ask about it am told "it'll go away in time". How is that helpful? When I ask the school for help, they say he's like this because of bad parenting and that I should take courses on how to be a better parent and that I, a single mother, should quit my job to be with him 100% of the time and that this would "fix" him.
57. One on one counselling when going to MCFD.
58. Behaviour intervention and resources for managing difficult behaviours. Respite care. Supports for parents and caregivers resources in schools to support learning and challenging behaviours

59. Parent information workshops and support in creating plans for in the home. We are in a household with one parent who is very knowledgeable on child development and adhd and the other parent is not and has difficulty reading books / watching any kind of recorded webinar. In person support is definitely needed.
60. Any kind of parent training or support group. Social skills programs for ADHD kids that are not thousands of dollars. Strategies and training for teachers to better help their students and understand where they struggle.
61. Counselling, practical life skills education, and relationship counselling
62. Easy access to a central service to help organize local therapies and supports. Services to better education people on adhd and related comorbidities so the whole city is more understanding and available to assist
63. support people who actually understand the need of people with ADHD. Alternative education sites with freedom to roam and purposeful activities where kids with ADHD thrive (forest, farm or other locations outside of traditional classroom)
64. In our region we have a great support services and resources for ADHD families.
65. See above. Education needs to better integrate supports for families of kids with ADHD.
66. Tier 3 reading intervention in schools for severe dyslexics. Continual monitoring of support methods to take data for RTI. IEP goals that are enforced and actually have school principals worried for their jobs if these students are not served.
67. WE NEED IEPs TO BE AUTOMATIC WITH AN ADHD DIAGNOSIS.
68. any
69. Tutoring, social groups, mental health support. School assistance
70. Counseling would be nice, but medication has been a game changer
71. Doctors and psychologists who specialise in ADHD; training for teachers to work more effectively with kids with ADHD.
72. Ongoing supports- everything is intended as short term or emergency
73. First, an understanding that it is no joke. Severe ADHD is life altering, and does not receive the respect it deserves. This is a small, remote area, and I don't know what supports to even ask for.
74. Social groups. Reliable family and school staff education. Mental health resources. Shorter wait times. More info on harder to dx kids.
75. More educational opportunities for parents, teachers and other caregivers. Age appropriate support groups to help children understand ADHD, learn to cope with their difficulties and strategies to help them as well as interactions with others with a similar diagnosis so they are able to learn they are not alone.
76. Money, time, and education
77. support at school + teacher knowledge
78. Awareness of these resources. I was only ever given a website
79. in person options for supports, training for professionals, resources for families and caregivers for respite
80. School !!!
81. Mental support and behavior support
82. All of them. We have none. I was given none when he was diagnosed. There is a huge gap. I have never felt more alone. I am grateful that my profession is an educational assistant so I have knowledge and I have coworkers who have been so helpful. I can't even imagine how families who don't have my background are feeling.
83. Flexible in person parent support, timeliness, support workers and consistency of staff (turnover related)

84. A doctor, disability tax credit, affordable medication so my children can continue to attend school.
85. There is almost no support for kids with ADHD because even with the little bit of support we can possibly access there is a GIANT wait list. All children should be able to take part in community activities and additional supervision needs to be made possible. No student should ever miss a field trip or activity because there isn't enough supervision and children shouldn't be blamed for not being at the same executive functioning level as their peers. All these systems are outdated and do not focus on any type of behavioural needs.
86. More family supports and respite services needed.
87. Primarily supports in schools (ministry special education designation for adhd not funded), education around adhd strategies for youth non-existent, no education for youth on self advocacy, school teams not following IEP, lack of timely mental health supports in the public system, wait times for pediatrician, wait times for public (school based) psych-Ed assessments, family doctor shortage
88. Multidisciplinary assessment service by ADHD experts with pediatricians and psychologists; long-term counselling and ADHD coaching service; adequate school support and accommodation for children with ADHD in the schools
89. Mental health supports in schools, counseling and support that doesn't affect school hours as this created issues with daughter not wanting to go to school, support to find and match with employers, actual support hours for the schools so they have more resources
90. Awareness among Educational institutions and willingness to understand that being Gifted with ADHDer, Autistic is a challenge too. Challenges are faced by 2E kids too. Not getting help also leads to Mental health issues, navigating life becomes difficult. Parenting is not easy too.
91. Any and all supports. All the support goes to children with autism. Any other kids with only ADHD may receive some accommodations at school, only more complex kids that have trauma/stress, a language disorder, undiagnosed learning disabilities are only truly supported in very rare cases. There is no respite, there is no funding, there is no support.
92. Anti-ableist approaches to treating ADHD.
93. Services period, mental health, executive functioning coaching, emotional regulation help, social skills coaching and groups, etc
94. Respite care, in-home therapy of some sort, out of school day camps with specialized staff who can manage my child, and all of this without costing an arm and a leg. My child can't attend a regular summer day camp due to his challenges, unless I pay for my own support worker to attend also. There's no government funding for this like there is with ASD.
95. Awareness, understanding and proper supports in public education system.
96. so many - it starts with real understanding of diagnosis in education and medicine which is still lacking
97. Adequate funding from the ministry of education and child care is severely lacking, to support educators in providing inclusive education
98. Any type of in school support counselling iep teacher awareness. Modifications
99. It would be great to have a family support group to bring families together to discuss tools and ideas for helping our children reach their full potential. We also need this support group to be connected to our local schools to support advocacy and understanding of what a real education for a child with ADHD should look like. We need a facilitated group of like-minded families who can accompany us on our journey to guide and advocate locally.
100. -Professional education/training -Funding (in schools and for family) -School designation for ADHD -up to date information sharing (much of the information continues to reference outdated

info) -Medication not being covered either by pharmacare or by private benefit companies -GPs that can/will confirm a diagnosis. -Parent training (there are many more that I cannot think of right now)

101. Early intervention - most programs will not accept children for ADHD symptoms if there are no developmental delays.
102. I did not even know this ADHD Advocacy Society existed until I saw this survey so even knowing that "you" exists demonstrates a lack of knowledge about what is out there for support and services.
103. There's basically very little support - other than some limited resources provided by non-profits but no stable government funding or commitment to support families with diverse need. We need the family connection centres to roll out across the province asap with proper, long-term funding for ALL children with diverse needs - and hopefully for adults one day too!
104. access to CYSN, support for respite, prevention, lowering costs for recreation programs and community engagement opportunities, daycare needs, support workers in school and outside home.
105. Educational frameworks that enable connection and fun
106. In home support, easy access to assessments/diagnoses, waitlists for these as well as services. A referral to the connected Parenting program was extremely unhelpful, as it had an ableist lens
107. Lack of dedicated support from an EA in class. Lack of information about inclusive learning services and access to the school counsellor for kids with ADHD before transitioning to middle school and/or at the start of middle school. We had to request an IEP before we were told about these services!
108. Early assessment, intervention, and diagnosis through school observations and Psych Eds. Early identification of education gaps resulting from ADHD so that specific explicit instruction, classroom support and interventions can be offered early.
109. Support in school. Support for employment and transition to adulthood.
110. Access to proper assessments and specialists. Waitlists for adhd clinic if you can even get on it
111. A parenting program would be helpful. A Professional Development program for Educators and Coaches would be helpful.
112. therapists, social groups, educational plans,
113. Help in schools (academic support) and support for teachers (more EAs). Teachers need to understand how different kids present and kids with adhd aren't always the loud ones. Need schools to do psych ed assessments and have mental health supports available.
114. Access to pediatrician's for a diagnosis. I understand there are years long waitlists.
115. Need increased access to psych-ed testing for k-12 students, need accommodation support services for all employees to help identify suitable accommodations, need access to executive function supports/training/technology support. Funded services are a must for equitable access.
116. Financial support (funding for things like OT and Orton Gillingham tutoring). Help in advocating for children within the public school system.
117. Some teachers have an understanding of ADHD while others do not. I wish there was more consistency in this area. I wish the physical space of the school allowed for kids to go to when they feel overwhelmed / overstimulated. Activities and groups for families/kids with ADHD would provide more opportunities to get out of the house.

118. When there is already an ASD diagnosis the resources available for adhd are almost nonexistent as all you keep being told is to use the ASD funding- the problem is that the ASD funding doesn't come close to covering services needed for the ASD let alone covering the adhd
119. Academic support in school. Biggest and far reaching challenge. Trickle down effect of significant porportions.
120. Everything and anything. We have nothing.
121. Funding for outside support, extra support at school
122. School support, first and foremost. Long term support parent support and long term counselling for the person with ADHD.
123. How to help them meet other kids like them. How to destigmatize the name. How to inform teachers of what it actually means and how to support kids. How to pay for diagnosis. How to pay for the psychological services my kids need to help them deal with ADHD and all it brings. How to pay for my psychological services to help me deal with my ADHD kids. There is ZERO funding for psychologists. Absolutely astounding. No wonder there are so many drug addicts on the streets. It all begins with unsupported children.
124. Funding for schools for ADHD
125. Funding
126. Family counselling services and resources to support NT siblings; affordable and affirming therapists (music, OT, SLP) without months-long waitlists; resource and classroom teachers with expertise with ND students and how best to meet their needs.
127. School-based resources and recognition of the extent of impact of ADHD in the classroom environment, tutoring for out of school support, access to OT, counselling/psychological support, and ADHD-friendly rec environments/programs for social and physical development.
128. Support Groups/Play Groups/Counselling Services for children with ADHD.
129. Guidance for specific strategies in lifestyle management of ADHD when child refuses medication.
130. Recognition of emotional regulation struggles as part of symptoms. Lack of resources in the health care system (family doctors, paediatricians, therapists for kids and families) cause long wait times. School unable to get funding to support and ADHD diagnosis.
131. Quicker diagnosis. Affordable or free group and one counselling. Classes or supports directly linked to executive functions and how to make them work for the ADHD brain.
132. Education for teachers. Education for medical professionals. Education for parents. Funding from the Ministry of Education and Child Care for more supports at school. Funding for mental health services.
133. Play therapy, tax breaks for therapeutic horse riding, ANY family supports, FUNDING to the schools to provide universal design for learning. The classrooms are JAMMEd with kids with neurodivergent children, and teachers have very little training, and absolutely no funding to buy sensory toys, different seating options etc. And when I say that teachers need training, I mean teachers need to be provided with RELEASE time to both be trained and then to be coached in how to teach the new generation of neurodivergent children. Not one or two optional pro-d's. Coaching and funding of materials is absolutely required.
134. FUNDING! ADHD should be a government funded designation in schools like Autism is. Also, just general understanding of ADHD. Currently our kids (and ourselves) are just treated as "bad" because of our ADHD- bad behavior, bad at our jobs, etc. Parents of ADHD kids are told they are not parenting correctly, and ADHD people are told they are lazy, stupid, not applying themselves, etc. These messages come from teachers, medical professionals, MCFD/CYMH/CYSN, other parents, other students, "experts", and society in general.

135. Availability of timely service and access to programs. Lack of a good information source where you can access information that is trusted. Social media is a challenge with so called "experts."

34: Imagine designing a bold, new provincial support system for children and youth with ADHD: Share your most creative, ambitious and expansive ideas for a system that addresses the unique challenges you've encountered in accessing support and services.

160 out of 160 answered

1. We have way more issues with our child that is also in the spectrum
2. More support in schools
3. Hire as many medical professionals that specialize in diagnosis ADHD and have them all in one building.
4. What is missing is wrap around services, families need a worker that will follow them along each step of the way
5. Can't imagine
6. Having programs that do not take all our AFU or At Home Funding. That funding should be ours to use for direct support. There should be community based programs that are funded by the government to give students early intervention, life skills, community opportunities and TRAINING for EAs, RSW, teachers, district staff on how to work with these students. My children are both highly intelligent and not behavioural kids. They are having their EAs pulled from them to chase after behaviour kids and therefore missing out on the one-to-one support they need in the classroom to achieve their IEP goals. My oldest needs help outside on how to make friends during recess and lunch and he is left outside to run in circles on his own. These children need guidance and they aren't getting it.
7. Easier access to alternative schools. Longer access to alternative school system if child is just not ready to move on. Meet them where they are, not where they should be. Recognize that it is a spectrum, and that extream adhd can be as debilitating as autism. That AuADHD is a thing, you can be both. 'Autistic tendencies' needs to be recognized, particularly by how it actually effects you.
8. Mental health and education supports
9. ADHD on its own should support a designation at schools, if desired by families. I had to lean on his anxiety diagnosis and pay for private counseling to get him a designation (support). Counselling for children, youth and their families or support people. Public awareness campaigns
10. Early screening in primary school for all students. Teachers having comprehensive education on how to spot and support ADHD. Specialized classes for children with ADHD and other neurodivergence.
11. Full in depth training for front line staff, ending the stigma of ADHD through different media challenges, parent support groups that follow a structured routine, a program headed by someone who understands ADHD fully and can relay information in an easy format to all educators/staff in schools. Just one program that is developed but covers all areas of adhd (not just basics) and is taught to every school board so the information isn't conflicting.
12. Proper education for school personnel (everyone - the music teacher, the librarian, janitor, etc) on Executive Functioning deficits. Training for community members (coaches, instructors, etc). ADHD coach and mentors for families who can go into the home, school and work place and bridge the gap. Provide direct teaching and modeling. All paid for by MCFD and MoE. Give financial incentives to dr.s to become developmental peditricians and peditric psychiatrists to assess and treat ADHD.
13. 1:1 workers, free counseling (not cymh) that is not only adhd focused but helps with all the emotional issues that come with adhd, life coach, help teens get on pwd if that is needed, suicidal ideation should not be a means to see a psychiatrist (it is in the interior)

14. Encourage better communication with parents. Make assessments available too ALL kids who need them. Don't wait until grade 12, when it is too late to help them.
15. Equal services for all children that are accessible and affordable. For example, being able to sign up an OT that works outside of school hours or having a centre that your child could go to that supports your child holistically (including support of mental health)
16. In School system
17. Recognition of ADHD as a learning disability, funding for this disability that allows for EA support at school, programs through CYMH or child development centre and school to teach socialization skills and social emotional regulation, self advocacy etc
18. Teachers having training specifically in adhd, EA's specifically trained to work with ADHD kids and adults and enough EA's in the school system, funding. Psychologist that can be accessed by people in poverty who have ADHD.
19. specialized public schooling options, respite opportunities
20. All ND is covered under an umbrella (like AFU, but having all ND able to access help), but NOT like FCC, where you can't choose your service provider and have to physically GET to them for services. Service providers apply for payment under this umbrella and users can choose their SPs in their own area because travel is prohibitive in both time/cost/ability, and also, not every SP has expertise in what is needed.
21. Children with ADHD receiving the same support and funding as those with ASD
22. Unsure
23. Diagnosis services offered at a younger age
24. My son was picked on made fun of by teachers. He was bullied teachers did nothing. Ge was refused a lap top by a horrible principal.
25. Additional staff in schools to support (teachers, EAs, Youth & family counsellors, school counsellors, psychologists); additional mental health professionals, smaller class sizes and school buildings that are safe and accessible, funding for community supports and programs aimed to support inclusion of children with ADHD in camps, daycares, athletics, swimming, arts and other activities
26. ADHD should be a funded designation at school. Kids should automatically get learning support. Small amount of funding similar to AFU for purchase of sensory and regulating materials
27. I would like to see the same support system that they have in high school in the Victoria region in the elementary and Junior high we're a child is assigned a caseworker and has a lot more supports.
28. CBT, support groups, meditation courses, online counseling, outdoor groups, life support skills, confidence boosting support
29. Not separating ADHD children from others but ensuring that all teachers have ADHD training and knowledge and that there are more professionals in class full-time to support those who require an alternative way to learn. It would also be ideal to have a centre, open and available 24/7, to drop by when facing a specific challenge that is more serious or concerning---not in a hospital setting but amongst experts in ADHD.
30. AFU like system expanded to all childhood diagnoses, maintaining parental control
31. More support and groups for families
32. Increased accountability for school staff who do not follow through on IEP supports/accommodations. Parents have a choice in the school support staff assignments. FUNDING!!! Providing life transition support in education & employment. Having a navigator or coordinator to help families plan and manage appointments/services/transitions
33. I want individualized funding for services for all kids with disabilities like the AFU system. It is not nearly enough money, but it is flexible and it makes a huge difference for the families that can access it. And I want a fully funded educational system that is required to provide inclusive education for all kids and can't just push the inconvenient ones out.
34. It's a dream that ADHD be treated and supported like other disabilities

35. in school support for children with ADHD in the form of education, assistance and counselling in particular. Counselling and social programs outside of school. Transition to adult support.
36. Any child with extra support needs will be able to access funding in order to help access the services needed. More providers for services and less "hoops to jump through" for families to get the services
37. Too overwhelmed to come up with anything
38. A school where kids like my child can be accepted and educated. Teachers, and school support staff that have a clear understanding of ADHD and can see that these kids are trying and actually have to work so much harder. Funding for parents that can not work outside the home because schools are understaffed, and overwhelmed and unable to teach my child. Funded occupational therapists that can work with kids past the age of 6.
39. A networks of co-ordinators that work to directly connect families with support.
40. Start with the school system and arm the school system with resources. Make assessments accessible and easy to get
41. The whole system is so flawed that a revamp is not even possible. It needs to be done in stages and the first stage is getting the funding in place for schools who require it. Then look at redesign
42. I think the biggest impact for children would be in the school setting. I'd like to see ADHD get the same funding and needs recognition as ASD. In a dream world, there would required education for all education roles on ADHD. There is a lot of misunderstanding of kids as being "bad" or "lazy" that needs to be combatted. Outside of the school setting, it would also be wonderful to have a social network for ADHD, similar to CAN. For the medical setting, I don't know what can be done about waitlists; I've written to the B.C. Health Minister and didn't even receive a response. There should be a requirement that children must receive treatment /therapy in under a set amount of time (ex. 6 month max wait time). And lastly there should be funding for ADHD needs; it's not fair and is discriminatory that ADHD is neglected while others receive funding.
43. The most useful idea for support is constant, committed funding that increases with the cost of living.
44. My biggest suggestion is access to money for respite and therapies!!! I can find them but even with two incomes I sometimes choose to have my kids go without
45. Bootcamps for physical activity paired with academics
46. A one-stop shop with user friendly, easy to find and follow information. Streamlined and affordable access to ADHD and ASD assessments.
47. I am not an expert in this subject matter and will leave it to those who are. Our medical system is broken and our youth are going to face major mental health issues in the future if they can't be treated now.
48. A referral system that is seamless and not requiring parents to source & pay thousands of \$\$ to get an assessment. Support for young adults at university that can be accessed timely - as it is now, just getting to see a doctor through the university health centre can take over a month. Students are away from their regular support systems and need timely response.
49. It is a system where they walk you through what to expect, what challenges you might face, and other possible diagnoses that might accompany the ADHD diagnosis. Access to medication coverage, support groups or camps for Children with ADHD, Schools with a better understanding of how to deal with children who are ADHD and to make them feel included and a part of the group. Access to Tutors or groups in school to help them with their school work. Not every child learns the same way and with the Diagnosis of ADHD, it's important that they get the same attention that the rest of the regular kids.
50. Educating the educators
51. Medication is a big one. Counseling would be nice
52. I would like to see more support into activities for the children that struggle with activities and not being able to participate in them or remain successful in them. More groups or one on one or trained staff that were able to work with them.

53. Coaching model, executive functioning assessment and support, chronic health designation, school for ADHD kids and social skills training and opportunities
54. Home visits from therapists, occupational therapists, counseling. Talking to parents one on one. Classes taught by play therapists, OTs, teachers, EA's. People who actually work with students on a daily basis. Family outings with occupational therapists, counsellors, teachers, etc that are fun but professionals can work alongside parents and coach them how to deal with things like emotional dysregulation in public, or help with transition from one activity to the next or teaching parents how to advocate for their children in the public school system.
55. recognize and fund programs for this neuro developmental disorder as they do for autism raise awareness in education system and provide funding to support these vulnerable and misunderstood kids!!!
56. n/a
57. A universal resource repository. A widely distributed education campaign disseminated in every school and to school PAC's. Adhesion of ADHD supports for all aged children to the \$10/day childcare plan.
58. Seamless connection between school based need and professional support, where mental health practitioners are able to roll into settings where children already are, work together with teachers and support staff to meet the specific needs of the child in an ongoing manner. That parents are supported through group information and awareness training over time, through the stages of child development. This support is in person and online.
59. Having funding attached to students with ADHD so the schools doesn't need to lean on taking resources from students with ASD who bring in the funding for EAs.
60. don't know
61. A way to get proper assessments done earlier on all children entering the school system and support people to assist in getting the outside agencies required. Proper, paid, mandatory training for educators (I am one) to understand new brain-based research about ADHD, the way to properly teach and prioritize deficit skills in education programs to allow for progress and development before high-school.
62. Everything that the ministry provides
63. I need more time - didn't know I'd have such a huge question and I'm on vacation. Also it's not only my daughter that has adhd but I do as well. There was a course I could access but she couldn't. Off the top of my head we need to make training a lot more accessible for people that are in many different fields so they know how to accommodate the people with ADHD.
64. There should be a support system in place as soon as the child/youth gets diagnosed
65. Change the school system to engage students. The current system simply does not work for sever adhd.
66. It will be nice to have an app to help kids with ADHD and also support group for parents
67. A school that has trained professionals on how to handle someone with ADHD so I'm not terrified every day when I drop him off. A medical system that will help me find ways to handle my son, especially in his most challenging moments. Somewhere to go where they'll actually meet me and my son and HELP US find ways to work through things. My son *knows* he has behaviour issues, but when we talk about it, he keeps saying he doesn't know why he acts like that. There's a switch in his brain that flips between "normal" and "dysregulated", and he's 2 completely different kids depending on which way the switch is flipped. I need some kind of support system to help me handle him to flip the switch back or at least minimize the damage when he's "off". The doctor refuses to help, the school *can't* help, and I'm stuck on my own drowning, terrified of what the future holds for him.
68. Allowing a designation and funding for public schools for those with ADHD
69. Alternative school that is free and provide small class sizes with educators that are highly trained in ADHD and other mental health disorders

70. Child are screened earlier in school, a much better awareness for teachers of what ADHD is. A central hub where families can access counselling, OT, proper medication and various other supports for ADHD
71. Mentorship programs for neurodivergent youth to support younger neurodivergent kids in day camps and extracurriculars. Funding for behaviour supports. Significantly expanding the division within the ministry of education handing special education supports and massively increasing funding for supports in public schools. Canceling all funding for private and separate schools and channeling this money instead into public school supports. Media campaigns around the neurodivergent advantage and which promote understanding about those with ADHD
72. Opportunities for social skill building, frustration tolerance and an overall understanding of kiddos own unique brain. More parent support and information specific to adhd and possibly geared at parents who also have adhd.
73. CYSN to help set up parent support groups that train and teach what can help them manage at home and to advocate better at school. More access to psych ed assessments; depending on school not viable (too underfunded and ELL supports taking priority for support so LD students getting missed because they speak English). ADHD specific social skills training - help these kids find each other and make friends with each other.
74. Thinking outside the box, ONE SIZE DOES NOT FIT ALL, and providing person centered, individualized support services.
75. peer support / family support, better advocacy support
76. Website with multiple options to communicate. le on my own by email/viewing site, chat or phone.
77. System that support child led democratic education where kids can watch adults doing jobs and feel invited into their world to connect and be inspired. System that allow kids to participate in active learning rather than being stuck at the desk. System where adults are ready listen and accommodate the kids interests rather than punish them for non compliance. Access to practitioners who help adults to understand the unique brain activity and how their energy can be harnessed and directed where their body feels regulated.
78. When the child is diagnosed give more support for parents/care givers and schools.
79. Too many to write here. Needs a complete systemic shift.
80. Stop giving public funds to independent private schools for dyslexics. Stop the two tier system in BC where the rich get services and the poor get resource jobs. Kill the Canada Dyslexia Center behind-closed-doors buddy project between Premier Eby and Fraser Academy
81. Would like to see supports such a behavioural therapy in place for kiddos with adhd. And more one on one or small group learning in the classroom- currently there is 0 support with kids with adhd.. they just “borrow” support workers from kids who have other diagnosis
82. I am so exhausted here, I don't even know. But a centre where IEPs and wrap around services are created. No more making parents fight and plead for every little thing. Full PD training for schools!
83. providers who have a more comprehensive understanding of ADHD symptoms, overlap between other diagnoses, and help manage treatment. Resources for children who can't attend school - all the funding goes to the school even if school isn't working for the child
84. Workshops, online classes, online support (chat function), telephone support line, APP for working through challenges/weaknesses and gaining new skills/strategies
85. Extra help during school hours when my child's medication is most effective. Group support on weekends that doesn't break the bank
86. As previously stated, medication and counseling
87. More doctors and practitioners who specialise in ADHD; more PD for teachers
88. I would love to see more skills building and group options for our kids to connect, whether it's for employment training to executive functioning

89. Learning, at a younger age about how to treat those that are different from you. Have all children and teachers learn that there is more than one learning style, and no particular method is the only correct one.
90. Centers with fully knowledgeable staff and supports for families, school members and community members to seek dx, support, education, social groups and Healthcare.
91. I have not accessed services but some of the suggestions in the previous question would be helpful.
92. Respite for caregiver, outdoor learning, one on one time for school, more education for teachers
93. should be an official Ministry designation
94. The diagnosis would have meant something to the school. Instead, we paid 1200 dollars out of pocket to get the diagnosis we were pretty sure was at least one of his issues when he was 15 and doing very poorly in school and life in general. The system would take the diagnosis seriously, and a case manager at the school would make sure the kid got what they needed on an individual basis.
95. Similar to the autism support
96. medication supports, opportunities for other mindfulness tools and training for caregivers to help co regulate
97. Having someone at school with information, TIME and knowledge to help every family
98. don't know
99. We don't know where to find support
100. When a child is diagnosed the family should be given a package that has resources, books, diagrams, brochures, email addresses of professionals that can support them. There should be someone who checks in on the parents and makes sure they are not feeling overwhelmed and alone and if they are then they can guide them in the right direction. A parent support online forum where parents can connect and share resources. Opportunities for children to connect with each other and possibly form friendships with like minded peers.
101. A large indoor space where sensory and physical activity is available on a drop in basis, where parents can meet other parents who are sharing the same challenges. This would mitigate the feelings of isolation for both the children and parents/caregivers. The kids can explore and be kids, and there are staff support workers for them should conflict or incident arise. In our hometown, so we don't have to make a trip out of it.
102. Automatic assignment to a family physician for any child with diverse needs. Other professionals to be able to sign disability tax credit paperwork. Government funded EA support in daycare and preschool programs so parents can work. Remove the age barriers so young children can access mental health support before the age of 6 even if they don't currently have access to a pediatrician.
103. See my previous answer
104. Please train educational and Medical staffs to understand Giftedness. Challenges with 2E is not less. Giftedness can mask ADHD and Adhd can mask Giftedness. Not to completely ignore parents observations. Parents knows their kids better than teacher.
105. Too burnt out to think of anything.
106. Similar to cyn services, but better funded/easier to access, reduced healthcare wait times, public anti stigma campaigns
107. 1-child psychologist in every single school (not 1 shared by all schools in the district) 2- all people employed by schools & who work/run community programs take mandatory training every year regarding children and mental health 3- In elementary school every classroom is given full time support every child diagnosed with ADHD INCLUDING RECESS. 4-Middle and High School- children diagnosed with ADHD get support for the classes where they need it (might be all day, might only need for math class) 5-Every child goes to school full time and is provided with the amount of support they specifically need to make it through the day. 6-the kids get breaks

not punishments 7- Emotional regulation is taught and supported in schools and the community .Basically, focus on the child needs instead of expecting everyone to just go with the flow

108. There is a need for new provincial disability services for all children, youth and adults with any disability need. The service would provide multidisciplinary assessment for individuals drawing from experts in different areas e.g. developmental pediatricians, other medical specialists, psychologists, psychologists, behaviour analysts, etc. The specific experts would be determined and included on a case by case basis as deemed needed by the person's health concerns e.g. ADHD, down's syndrome, etc. This multiple disciplinary assessment would result in a report of the services that the child, youth or adult needs..... While there may be concern that there is a lack of funding for the recommended services, this as a different problem and one that can solved by creating a new separate program (than the assessment program) to fund the required services. The NDIS Australian Disability Service shows promise as a great model for service funding to meet the needs of people with disabilities.... In terms of ADHD management, the multidisciplinary assessment might result in recommendation to be followed by a provincial ADHD physician/psychiatrist team for medication recommendations and engagement in long-term as needed cognitive behavioural counselling and ADHD coaching service to support increased function and problem solving; establishing specific school education support for the person and specific accommodations for the children, youth or adults with ADHD in the school, college or university.
109. MCFD steps in and puts the same pressure on the parent who is a guardian on paper only to step up the way they put pressure on the mother and children being abused. Perhaps MCFD should shift the mandate to having the abusers, deadbeats and disinterested or counterparenting parents actually learn what is necessary to actually support their child(ren) and not let it escalate to the point where the child pays such intense price. Help the parent carrying the weight of the special needs child to get legal ability to move forward if the other party is not lifting a finger to help or be productively involved
110. Anti-ableist, neuroaffirming approaches are required. Medication and non-medication options must be available. Elementary schools must accomodate IEPs and hire enough EAs.
111. Free mental health care for all with ADHD, ADHD is screened in school, support is provided in school, medication is free, wide varieties of executive functioning and social skills and emotional regulation classes and groups
112. See my previous answer. Funding for families is a big piece.
113. Educate all teachers on ADHD, giftedness and 2e! Provided designation, funding and IEPs for ADHD. Offer adhd tailored programs in schools - more outdoor and activity based programs. Provide monthly respite services to parents
114. assessment & support in early years of public education, assessment & support by family doctors, access to psychological support as needed by therapists & psychiatrists for ADHD patient & their family, access to medication as needed (not all ADHD medication works for each ADHD patient)
115. Mandatory parent training would be my first wish
116. Honestly listen to lived experience- individuals and families. Educate teachers and make them accountable for ableism. Educate families, teachers and care providers on the co morbidity that can exist with adhd. Fund more public pysch Ed's
117. I would love to see an in-person travelling advocacy group who would regurly visit schools, families, individuals to check in, keep our system accountable and work to improve what is there, what is missing and increase awareness in general of ADHD.
118. A system that involves everything mentioned in the previous question.
119. Early intervention supports for children and families - learning about ADHD, parenting supports, therapy and more support - learning support, behavioural support - in schools for these students.

120. formal designation, support and accommodations within the public school system, plus support network and occupational therapy
121. More education about ADHD, school support, knowing what is out there for individuals and families to access support and services.
122. We need the family connection centres (or something similar) to be rolled out across the province asap with proper, long-term funding for ALL children with diverse needs - and hopefully for adults one day too!
123. 1 2 1 supports in schools directed specifically for the children who are in identified needs, specialized physical activity room or classroom modifications for kids that need physical outlet, youth care workers to be supports in out of school setting at least once per week, year round before and afterschool care for families that is supported. Having all positions in these suggestions be living wage permanent positions to assist with stability.
124. A place that connects people and enables people to find purpose to contribute. Children feeling connected and valued.
125. Early diagnosis (or even provisional to allow for maturity), so child and system can be ready for the start of school. Support at school and in home if parent requests, more school training on ADHD, acknowledgment that it is a neurodiversity
126. I dream of a public ed system that can manage a child's unique needs in the classroom with adequate supports . I imagine being able to easily access support for tutours , executive functioning coaches
127. There needs to be dedicated funding for kids with challenges like sensory processing disorders which co-occur in kids with ADHD too (not just autistic kids). OT and psychologists would be key. In the school system, OT support for assessing the classroom environment is necessary in elementary, middle and high school. Parents shouldn't have to pay privately for this. Teachers need support know what changes in classroom need to be made to accommodate kids. Parents should not have to tell every single teacher each year that their kid has ADHD. Their ADHD should be considered in class planning! Inclusive learning planning should be happening before each transition to the next grade. There should be dedicated time with an EA based on individualized need of the student, especially those diagnosed with ADHD.
128. School: Early assessments, highly engaged with parents, where teachers / staff and parents ensure they both have same level of knowledge about ADHD. With lots of small group work and learning opportunities and supports. With strong evidence that can be taken to medical field for diagnosis and treatment / management.
129. recognition as a funded diagnosis to get support at school, immediate access for mental health support, executive functioning tools, coverage of medication if needed, supported employment program
130. Access to psychology for differential diagnosis or comorbid diagnosis since anxiety and depression are common. Access to school supports and counselling group programs to grow skills
131. I don't know what that could look like. Having funding for counselling and friendship groups would be helpful. Respite for parents. Support groups that are in person
132. Funding for youth with ADHD that gives families access to specialized tutors & occupational/physical therapists. Experts who could talk to teachers and coaches who work with the youth/children. A parenting program (similar to Thriving Kids one) about ADHD with a coach. Making ADHD a designated disability, so that there will be funding through all school districts for students with ADHD.
133. Access to counseling and play therapy and family counseling that is funded and school support that is funded too
134. i'm not sure
135. Social groups in every region with therapists and psychologists to support. With dedicated facilities and extracurricular activities. Adult and youth Volunteers. Schools to have individual

plans, therapists, psychologist that kids could easily approach. Resources (written, facilities, information sessions) for kids at schools, personal, one on one support from specialists (like shadow teacher). Access to affordable therapists outside the school.

136. Screening tools (not just observation of behaviour) followed by psych ed assessments for those that are flagged. Free mental health supports for kids that don't meet cymh's intake cut off.
137. My issues are with the diagnostic criteria not supporting how some girls (and maybe some boys too) present. It needs to be overhauled, though I recognize that the DSM isn't within the provinces' purview. Training teachers and providing funding for all kids who need it at school regardless of their diagnosis.
138. ADHD center of excellence, offering free support to individuals and overseeing training programs for community organizations/service providers/schools.
139. I think having a system similar to autism funding where there is access to financial support to fund services such as tutoring and occupational therapy, and the purchasing of items to improve people's quality of life when living with ADHD.
140. Public awareness campaigns. Teacher education requirements. REWORK THE EDUCATION SYSTEM. Curriculum design with ADHD / Neurodiversity in mind. Well trained support teachers in every class. Quick ADHD assessments. Additional programs (sports, groups, etc.). Financial support for those families who need it.
141. Access to service in a timely manor- which likely won't happen within the care model that is being proposed. As it is now for ASD services there is an average 18 month wait which will only double or triple in the proposed care model
142. Assigned a government support worker who helps family navigate everything from medical care to academic support. This would be paired with massive changes to resourcing for schools.
143. Sufficient bell to bell support in all classrooms for all learners. No waitlist for diagnosis. No gatekeeping of medications and support strategies. Access to diagnosis and services uniform through all areas of the province. Neurodiversity informed approaches (no behaviourism/ABA style). Individualized approach that respects personal autonomy and family wishes especially cultural needs.
144. Whole health approach. Where medical coverage covers the whole body and all medical treatments even mental health. We're doctors listen and take both preventative and reactive measures, no more wait and see. Where when you get a diagnosis you get good information and links to good resources so you have a starting point to first understand and second seek the services that meet your needs. Not have wait list times measured in years. Have services and resources that help parents and children teach/learn executive functions skills for life including home and school. Therapy for parents dealing with the behaviour, it's hard and we are shamed for bad parenting, we need support too. Also it hereditary so maybe offer parents an assessment. We might not know life shouldn't be so hard. More training and education for education and medical professionals. Not just on the definition of ADHD but also how it presents, how it impacts people in everyday life and the impact it can have in all areas like self esteem, mental health, and development.
145. Start by funding more psych-eds and providing better access to psychiatrists (obvious there are not enough). Pay for psychologist visits. Make teachers learn about various high-incident neurodivergent abilities/disabilities and how to best support those kids. Reduce class sizes. Reduce the stigma of the name.
146. Schools that do not make children sit at a desk all day and read books. Interactive learning with different types of seating arrangements, exercise equipment, stimulation breaks, running breaks, diverse learning. New companies are being set up with different work stations so people don't have to sit at a desk all day to work. Schools should do the same. All we hear is there's not enough staff or money. Schools should get more funding and have better work environments for

staff and students so more people would want to become teachers and EAs and students would want to go to school, especially those with diverse needs.

147. Resource teachers in every classroom, for a start. Co-taught classrooms. More ND content in teacher education
148. Seamless care and communication through a network of ADHD specialized care providers that include services/training to help educate school/program staff, workplaces/employers, and beyond. Also partnerships to further research and best practices.
149. Waitlists for play therapies wouldn't exist. We are a middle-class family with benefits and we still cannot afford financially to have our child in therapy/counselling without needing to give up a sport.
150. Children with an adhd diagnosis get support in school, get funding like autism for outside supports like tutoring and therapy. Funded assessments to know exactly what it is your child needs support for- learning diagnosis or other
151. There is no support in schools, no EA hours assigned etc. often learning disabilities and other diagnosis are co-morbid and do not receive any support for those. OT, play therapy, tutoring are all paid out of pocket by families. It leads to unfair support for those who cannot afford it. ADHD affects all areas of life and supports to assist those of us with it and children should be available and more public funding towards it. Having EA support in schools can drastically help accommodate needs in schools.
152. A known list of resources available online and provided by the diagnosing doc (and familiar with them) - our ped had zero resources to share for local support local support groups for parents local support groups for kids and youth subsidized family coaching subsidies for private or non-profit counseling and/or OT comprehensive assessments to rule out comorbid diagnoses, as well as to point families in direction of a tailored support strategy (may include personality trait testing and coaching youth and families using this information) support and "training" materials for extended family members, to expand family resourcing inside the family
153. That a family gets whatever support services they need throughout the lifespan. Different types of therapy, education, and parenting support. ADHD needs to be recognized as a category of special need in the school system. The Ministry of Education needs to do a thorough investigation into districts support for children with disabilities, including ADHD. They need to look at all areas to improve this; the overall design of our schools/classrooms, number of support staff, staff training, and how Universal Design for Learning can be used in conjunction with special needs service in order to support all students.
154. Something holistic (ie mental health, diet, organization strategies, coaching, medication), and comprehensive (similar to the BC Cancer Centre). The biggest difficulty I have is trying to not only figure out all of the different pieces of ADHD, but how to address them and what specialist to seek help from. After that it is also finding an available specialist or service to even help us once identified.
155. one to one help provided where it is needed in school. Family doctors educated on ADHD in order to better direct parents to supports (not just medications). Access to occupational therapy through MSP.
156. Free counselling. Indepth classes within school districts that focus on executive function, mental health, and acceptance. Quicker and easier access to diagnosis/medications.
157. Multidisciplinary care teams to support diagnosis and education for anyone working with youth. Regular communication and collaboration between the medical and education systems. Engaging awareness campaigns to combat misinformation and stigma. An update to the DSM that looks at neurodiversity and the overlap between ADHD and many other diagnoses.
158. As said above. Deep and meaningful training opportunities for teachers and SSA's that come with ongoing coaching. These trainings would provide the teacher with release time to both train AND plan AND collaborate with coaches. Actual funding for the materials required for our diverse classrooms to achieve universal design for learning (UDL), so all kids can learn inclusively in the

classroom in the way that they can access curriculum. Real and meaningful funding for resource teachers, counsellors and SLPs to create and implement IEPs collaboratively with families and students, so that they feel supported and can access curriculum.

159. A provincial support system would need to be flexible, neuro-affirming, and WELL FUNDED. Something similar to the current AFU model, but for all kids with support needs. This should include adding ADHD as a government funded designation in school so that ADHD kids have access to EA support.

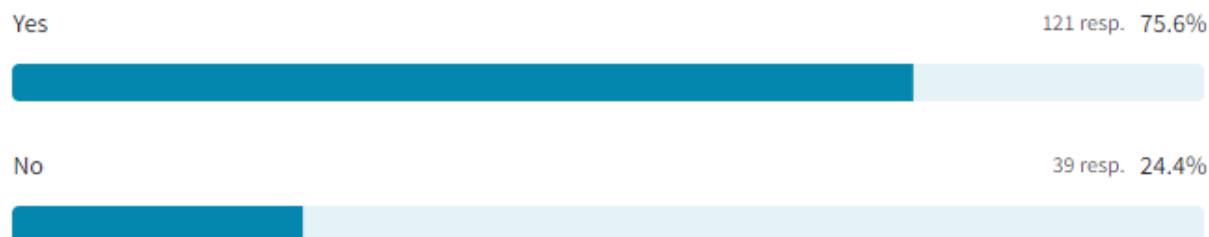
160. A system or environment where ADHD is celebrated more as a gift and an exceptionality that makes the differences of our kids unique to what they can do!

MEDICATION

This part aims to understand participants' experiences with ADHD medication, including accessibility, effectiveness, and any challenges faced. Whether you're currently using medication, have used it in the past, or have decided against it, we're interested in hearing about your journey with medication as a part of ADHD management.

35: Does the child or youth in your care diagnosed with ADHD take medication?

160 out of 160 answered



36: Why doesn't the child/youth in your care diagnosed with ADHD take medication?

33 out of 160 answered

1. The other parent won't allow it
2. We tried it. Never found one that worked that didn't suppress appetite, child was already underweight, it was more important for her to eat, now she is 13 and in crisis with court ordered parenting issues, I don't think we could navigate trying to find one that works and I can't imagine dealing with her dad who makes everything a problem
3. No access to medical oversight
4. They refuse
5. Stimulant medication made anxiety worse.
6. It was not the answer for him. Very adverse response.
7. Wasn't offered
8. He doesn't seem to need medication at this time
9. In large part because since we moved here 6 months ago, we haven't connected into the system. First we had to wait for MSP to kick in, then to get a family dr (which we only got because my mom's dr agreed to take us), and now we are waiting for the paediatrician referral.
10. Child is diagnosed as on the mild end of the spectrum. We have had success with exploring tools and strategies, medication not recommended.
11. We cannot find a prescriber, we have no family Dr, telehealth won't prescribe controlled substances, and we are on 6-12m waiting lists for a pediatrician or psychiatrist.
12. He is only 5 and in daycare. This is something we will re-evaluate when he starts school
13. We used to take it, but found it made her more anxious. So we stayed on her anxiety medication. The ADHD bothers other people more than it bothers her, the anxiety trumps
14. Does not want to take it. Tried to take it but the after effects bothered him a lot
15. He already takes a lot of medications for his other health issues
16. She refuses. We are open to it but she will not. We talk about it regularly.
17. She hasn't started yet. We just received the prescription so she will begin shortly but given lack of real access to work with doctors, I'm a little nervous.
18. not convenient
19. tried and did not work so gave up
20. We're working on skills building and also appetite is poor and I don't want to make it worse.
21. She says it makes her feel not like herself. She has only taken one kind of medication, but she refuses to try anymore.

22. 2 children used to, 1 child has not been prescribed. Child A: now a young adult and no access to doctor and no money for prescriptions, child B: chose themselves to discontinue, child C: practitioners won't prescribe due to concerns around appetite suppression with Conor if eating disorder
23. The system in BC didn't diagnose my kid though she has severe combined ADHD
24. as an adult they no longer with to, but did as a child
25. because i dont think medication is the answer
26. She doesn't want to and I am leery of meds.
27. My son used a medication in the past. It was effective for a time, but then he began to have some significant negative side effects.
28. Medication is a temporary solution, we are more interested in a holistic approach. We're not interested in placing our young child on multiple medications to experiment what works and what doesn't, especially with all the side effects. Also, medication wears off. ADHD does not.
29. They don't have the diagnosis yet
30. Hasn't started yet. Hopefully soon.
31. Not officially diagnosed by pediatrician. Currently taking medications to control anxiety depression as byproduct.
32. We have just received the diagnosis. We did this assessment through private psychologist, \$7500, and now we have to wait for our appointment with our paediatrician.
33. Don't have a formal diagnosis and we have been able to support our child at home through activity, special emotional support, and home learning.

37: Describe your experience accessing medication, from getting a prescription to accessing medication. 108 out of 160 answered

1. We went through over a handful of different meds till we found the one that helped
2. The medication is very expensive and is not covered by some extended medical benefit plans.
3. Many of the newer medications on the market are not covered by our plans and are too expensive to pay out of pocket. My two children have been prescribed medication that costs over \$500 per month/per child. It isn't covered and I cannot afford it so I am left to use something that isn't as effective because I can't pay for what is the best option.
4. Many many prescriptions have been tried. Pills was really all we were offered
5. We took our time and were hesitant in getting him on to meds. At first it just seemed to embolden him/ make him "cocky" for lack of a better term, but that was likely just the adjustment... it's hard/ tricky. I worry about him one day ever getting to fade off the meds since they are a stimulant and often addictive or create dependency
6. Our pediatrician works very well with us, although rushed most times (only 15min) per kid. However, he has always been very open to trying different ideas/meds.
7. Three pediatricians later... we have an amazing doctor. My son is on his third type of medication and it is a balancing act of dosage, symptom management and side effects. We have been able to have the prescriptions covered through extended benefits to 80%.
8. No issues
9. Getting a hold of or making an appointment with our pediatrician can be challenging but we do have consistent prescriptions that are evaluated and changed.
10. Paediatrician immediately noted and recognized ADHD in both children and recommended medication. When one prescription wasn't effective, he quickly switched and is open to trying alternatives
11. it has been good.
12. Only on anxiety meds.
13. amazing
14. Easy. Pediatrician observed behaviour and offered a prescription, if desired.

15. Can be difficult to access follow up appointments, adjustments of Rx (dosing etc), understanding that meds don't "fix" ADHD, but it's one part of a support system to be able to navigate the world
16. Trialing medications is challenging for our son and for us. Having more check-ins regarding side effects and solutions would be helpful.
17. No problems with prescribing for younger child who sees an experienced pediatrician. Already noted issues with teen prescribing. Costs are a significant issue, particularly for Intuniv although biphentin for 2 kids is also a lot
18. Depends... now that we have a paediatrician it's been okay but it took up just about a year to get there between the beginning of seeing our family physician having a paediatrician... we still have long waits to be seen so if your not on top of your next clinic appointment you can potentially run out of prescriptions. And good luck seeing anyone else when your child's paediatrician in on holidays
19. Our family was supported in finding the right medication and dose via our pediatrician and psychiatrist. The cost of one child's medication is quite expensive and that means we have to reduce our budget for other basic needs.
20. Medication access for the older child was mostly okay, although had a rare adverse reaction to the first med. we have not found a med that works yet for the younger child and have opted to wait. Because of the ASD diagnoses we already had a pediatrician and a psychiatrist so it was not difficult to access for us
21. we tried all kinds of medic from grade 2 to grade 7, but nothing seemed to offer the support he needed for the school system. As an adult, he has decided to try medication again.
22. Have had no issues with accessing the medications, thankfully have private insurance coverage for prescriptions otherwise the cost would be prohibitive
23. The only challenge we faced is with our pediatrician being overworked and having prescriptions delayed being filled.
24. I'm sorry, I am too overwhelmed to answer
25. Easy to get on a prescription. Awful trying to find the right one.
26. no problems
27. Getting prescriptions from a doctor is fine, but the pharmacy has been a huge pain. They had archaic rules about refills for ADHD medication as a "controlled substance." We've taken the same medication for six years and we still have stressful times where the pharmacy will not release the medication until just hours before we need a dose.
28. Getting medication hasn't been an issue. Getting special authority for medication has been a ridiculous, time wasting obstacle that is unacceptable and unnecessary
29. We have an amazing pediatrician even if we had to leave to province to find him. Meds are closely followed and even when we started with the wrong one we had lots of support from our locally owed pharmacy and the pediatrician
30. Self directed with support from GP who is learning with us
31. After assessment was recommended that medication could be part of the tool box for our daughter. Saw family physician for request for medication, was surprised at how quickly the request was met & that there was not a lot of discussion about also including other methods, cbt etc. Access to medication has not been an issue to this point
32. It was easy going through the process, what was not easy was trying to find the correct brand and dosage that the difficult part.
33. Not difficult Was misdiagnosed most of my life and given anti depressants and lithium that did nothing Once I was diagnosed and given ADD meds it wasn't a problem
34. Easy peasy
35. It took 3-4 months to get into the pediatrician. Once we did, things moved quickly. Our pediatrician has been great at helping us to understand the process of finding the right medication. Not all the medications were easily accessible at the one pharmacy. We had to go

to a specific pharmacy to get it for her age. Some were not covered by our drug plan. So we paid out of pocket as we were trialing different ones. We would have had to figure out how to get them approved specially. As well, it's been very hard and bumpy road to find the right medication. We had several months of a very angry child, twice. She was hitting, screaming, shouting profanities, punching other children, family members, pets, etc. It was hard to watch as we waited for the medication clear out of her system. I could see how parents would just quit. We have been persistent, knowing once we found the right one, things would be better for her. It has made a world of difference for her in class and for her relationships. We hope to start the next child on medication this month. We've been waiting for this appointment for several months.

36. Easy

37. A complete mess!! It took forever to find a family doctor, then once we found one he had to find a pediatrician that was accepting patients. That pediatrician moved and we had to find a different pediatrician. Then we tried a whole host of medications: concerta, vyvanse, etc. one of the medications gave my son paranoia, another made him really anxious, another gave him insomnia. My son is on a stimulant that helps him focus at school but makes him easily irritable. It's also an appetite suppressant. So now my son is underweight. Because of his adhd and his hatred of different food textures plus his allergies: he has a difficult time finding food that he likes but is also nutritious or that helps him gain weight

38. life changingly positive

39. waitlist, took 6 months to get a pediatrician appointment, we were on 3 different waitlists and chose the drastically poorest reviewed pediatrician just to get in quickly. Once on medication first option sent 6 year old child into a severe depression with suicidal thoughts, dressed all in black, refused to speak to anyone for months. also medication was effective but did not support child in the way needed, he still had the exact same issues and could not stay in school and it was extremely frustrating that so many people on the facebook group had amazing results, life changing etc. and we didn't

40. It has been good although not perfectly responsive, we have found a good match.

41. we transferred our prescriptions from Quebec, didn't know we had to register to fair pharmacare

42. Accessing has been good, but frustrated that extended health is not up to date with newer, longer acting medications and some providers do not cover them (ex: foquest is not covered by Pacific Blue Cross, teachers extended health)

43. First nation health authority lacks in financing newer drugs and lack of medication choices

44. Pediatrician was on over his head and said so. He tried a whole host of things, which was very detrimental in the end. There should have been more access to mental health experts rather than Pediatricians.

45. Perfect, it was a rapid response and my kid is more balance now.

46. It has been horrifying, like every other aspect of life with a kid diagnosed with ADHD. He was put on biphentin when he was diagnosed because the school kept saying he was out of control. This seemed to calm him down in the morning, but the school said it wore off by about 11am. So I went back to the doctor and she increased him to the "max" biphentin. Neither I nor the school noticed any difference. So the doctor switched my son to Foquest. He stopped eating and dropped weight rapidly, so I took him off it before even seeing the doctor again. He was put back on biphentin. The school says the meds do nothing, I see some improvement in the morning, the doctor only sees him every 3 months between medication changes, which isn't quickly enough when things go wrong (like with the Foquest). For the summer, I've completely taken him off of the medication, which has been challenging for me and my family, but at least he's healthier.

47. We didn't have any negative experiences with accessing medication, getting prescriptions refilled can be challenging due to our pediatricians workload. Trying different medication has been challenging as much child is on Max dose and it doesn't help that much

48. Didn't start off well even paediatricians don't seem to have full knowledge. Much improved when connected with psychiatrist

49. Once we had a diagnosis we were immediately able to access medication
50. Great experience alongside our pediatrician
51. Dr's too quick to push it on me, but due to struggles in gr 2 we did trial it. First option was terrible with some success for learning in class, but stopped eating and got very skinny. New pediatrician switched to a different type, much better. Pharmacare and my benefits help pay.
52. Could only get medication prescribed when they finally got in to see a psychiatrist.
53. Once approved by doctor, fairly easy - getting diagnosis, hard
54. We've been lucky to have an excellent provider who has helped us figure out medications. She has medeo so during med changes we don't have to go into office. The hardest part about meds is the expense and that you can only get a limit amount at once. I have to distribute the limit amount of pills between school, home and the backup in my car so it can get confusing to constantly be refilling 3 places without running out.
55. We are lucky to have a Pediatrician who is helpful and accommodating. We tried one medication which worked until side effects started to present. Now we are on the second medication which is less effective so we might need to change it again. It is work in progress.
56. I haven't have any problems accessing her medication.
57. We waited 18 months to see a paediatrician who did not show expert knowledge of ADHD. I learned more from the CADDRA website than I did by talking to this doctor. The med process has been messy as there is no way around the trial and erro nature of it. We are waiting on a referral to see a paediatric psychiatrist with ADHD specialization
58. For us, med problems began the moment the child turned 18. They lost their pediatrician and were tossed off a cliff with no supports. One of my kids is still not properly medicated in his 20s because NO ONE will treat adult ADHD in our community.
59. seemed like an afterthought. prescription given but no clear monitoring of effectiveness or side effects. haphazard
60. It keeps the hyper part down but my child still can't focus.
61. No concerns
62. We have had good support with this but it's due to the fact our son has a neurologist and a paediatrician for all his health condition's
63. Once diagnosed, not a problem to get medication, but the trial of each med was not simple. Titration up and down with each one was very hard. It was almost 8 years to find one that worked fairly well, and at the right dose.
64. Medication was easy to access after dx. Made large improvements. We are privileged to have a very informed and easy accessible pediatrician to work with.
65. Parents obtained the medications.
66. Relatively easy to access. Horrible side effects and we're on the 5th try
67. Straightforward unless my doctor is away then it's impossible to get a refill Rx
68. once he was able to see a pediatrician who is familiar with ADHD easy to access proper medication. GP and walk in clinics not able to support
69. We got Lucky. The first one worked well
70. The doctor prescribes the medication snd we get it from the pharmacy
71. Our pediatrician is amazing.
72. I pay \$560/month out of pocket....as a low income single parent WITH benefits. NOTHING covers the medication that actually works for my kids. It's a common medication yet it isn't covered by benefits, fair pharmacare, bc healthy kids, plan G, special authority, or brand support.
73. both my kids have been on medication; currently, only 1 is taking medication. Like many people, I was nervous and did not want to make my kids take medication when they were younger. After research and education, I changed my mind and we started medication trials. My oldest tried MANY medications before we found one where the benefits outweighed the costs (I think we tried 10 different meds). My younger son who is still on meds has only tried about 6 different ones. Even with his medication he still struggles with emotional regulation and impulsivity.

74. Very challenging!! For a while we were only given a weekly amount. Very frustrating and not cost effective
75. This has been a very difficult journey for our 1 child. Many trial of different medication were tried all without adequate response and significant side effects i.e. crying, panic, sleep disturbance, loss of appetite with weight loss, etc. We eventual opted to stop medication given extreme weight loss. We have recent decided to retry again and are trying our 1st medication. I tool to track the medication and the side effect and decisions would have helped with this. Also, medication alone are less effective than medications and non-medications supports, so we may have had a better response if services were available for the non-medication support.
76. My daughter responded well to medication, we had to play with the dose and it was tricky with her mental health meds. Her pediatrician is amazing and takes emergency calls when needed and calls in rx.
77. Until son was medically excluded from school because his father would not consent but also was not contributing or actively involved in pursuing alternatives there could be no medication. Of course the timing of the schools actions were just after a scheduled pediatrician appointment to discuss medication which of course his father did not attend and did not reply regarding consent meaning I had to again make another appointment to start medication. Then every behavior son exhibited was blamed on it being the “wrong” medication. When Start finally got involved the psychiatrist put son on combination of meds for both anxiety and ADHD. P1 changed meds then altered back to original meds from start psychiatrist. CYMH psychiatrist simply wanted us to say what meds we thought and dose. After being released back to community care pediatrician not comfortable with prescribing combination of medications so awaiting another referral in case son develops tolerance or hits growth spurt etc.
78. Had to wait for a referral to a specialist, then wait for an appointment, then it's trial and error and poorly monitored.
79. We held off on trying meds for a year as we wanted to exhaust other options. We weren't able to get an rx for a stimulant med the first time we tried as my child wouldn't cooperate with the pediatrician to get his height/weight. She bluntly told us we would have to leave then as her next appointment was coming in. We tried 1 stimulant med unsuccessfully, and switched to prozac.
80. Long wait to see pediatrician. Amazing service and support once we got in.
81. It was very easy. My family doctor has the necessary training to prescribe and oversee medication trials
82. Argh. So expensive!! Paying \$150 a month per kid as we have no plan. Took a few tries to get the right medication for both kids.
83. It was easy to get the prescription and access most medications. Getting the insurance to accept that the generic form did not work for my child was a bit tricky. It took a lot of trials to find the proper medication, and it is still far from being perfect.
84. I am a lucky one - it has been easy. With that said, my child's pediatrician whom he has seen since a baby diagnosed him, and our pharmacist has been with my family since before my children were born.
85. When we didn't have a GP, I was able to convince a virtual visit Doctor to refer us to a pediatrician (most virtual doctors will not do this now). While we waited, to see the pediatrician, we found a walk-in clinic (eventually) where we could book the same doctor to do the refills. I was lucky because I had the documentation and I had the skills to advocate successfully.
86. I was lucky to have a family doctor who helped diagnose and refer my child to a paediatrician for further support. I know many families are not this lucky
87. Our Pediatrician has been very helpful and responsive, as has our Pharmacist. That being said, it's been a learning curve to understand how to know when a med is working or not, when to request a change in dosage, and when to try a different med or combination. It's been very self-directed
88. no problem

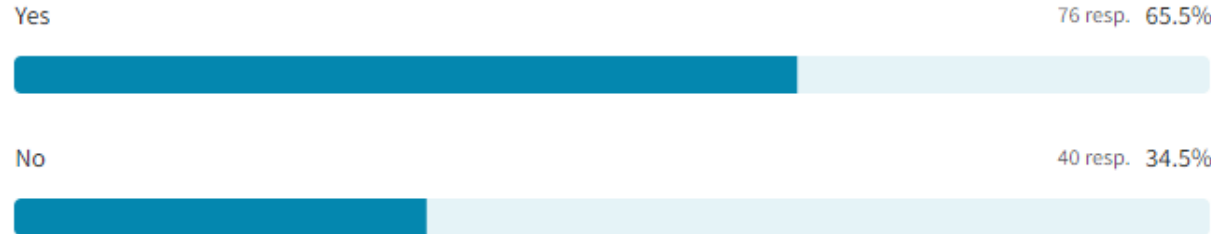
89. Fine when we were in Vancouver. In Victoria there was no counselling from the pharmacist offered when my younger daughter started medication for the first time. Given it was my second child with ADHD I thought perhaps this was assumed that I knew the potential side effects which I did. I did not expect my second daughter to have an adverse drug reaction. My pediatrician was not responsive to my questions I had immediately before starting the medication (shared by email) or after she started. I eventually spoke to the pharmacist that dispensed the medication which was helpful but it was a painful week of little/disruptive sleep for my whole family until we decided to stop the medication.
90. First plan of Intuniv and stimulant was terrible - Intuniv turned him into a zombie. Took a couple of years to get him comfortable with needing / taking stimulant (took some time off). But huge improvements with stimulant, but loss of appetite.
91. Expensive especially when needing to try different types to try to find one that works
92. Easy to assess. Dr pushes it. My children have tried multiple stimulants that have led to suicidal ideation, a hospital stay and self harm. It very much feels like you're in the dark and even if you chart how the medication is working with doctor doesn't believe you and just keeps adding more and more medication's. He has prescribed four pretty heavy medication for my nine-year-old was not a lot of support. Including the ADHD medication we've tried an antidepressant trazodone for sleep and risperidone it doesn't seem very to offer her so many different medication monitoring
93. Long process to get a prescription; if you don't have a family doctor walk in clinics are not willing to help. Family doctor does not check the weight or blood pressure of the child, just refills.
94. Once the teachers participated getting a referral to a pediatrician was easy.
95. No issues. I had to push a bit more for my daughter but I was impatient to start and the doctor wanted to rule out potential other health issues first. So not really an issue, just a delay.
96. Luckily we have extended health benefits and have not faced challenges with medication.
97. Once we had a diagnosis, getting medication was fairly smooth in spite of not having a family doctor. But getting the diagnosis can take years in Vancouver!
98. Accessing medication has been ok, but finding an effective medication has been the issue
99. Improvements but changes in personality that isn't always desired.
100. Meds easy to get. The only support offered. Understanding them, thankfully I have education in that area and was able to seek more information and educate myself.
101. Difficult to see a psychiatrist to help find the right medication and dosage. They give a one appointment "consultation" and that is it. How are parents supposed to figure this all out on our own.. even if we have a GP. Luckily my husband's benefits cover the cost of the medications for the most part, as they are quite expensive. Trying to get refills when they run out and we forgot to get an appointment for a refill with the doctor can be impossible, despite the fact that pharmacists should be able to help. If someone is on a daily medication, they should be able to help when they see the prescription has run out. There are more consequences to our children and parents than the likelihood of a few pills ending up on the street because of an emergency refill. If someone was selling them on the street, they wouldn't be using emergency refills for that.
102. After a year of extensive assessments and creating a baseline of understanding overall health with a pediatrician, including non-medication-based interventions for sleep improvement, checking hearing and sight, etc, our pediatrician suggested that we try medication for classroom use due to the negative impacts our child was experiencing that was impacting their ability to stay with the classroom group (due to punishments from the classroom teacher), strain on social relationships, and lower academic scores.
103. Went very well with the Pediatrician we have.
104. Once he was diagnosed officially we were able to trial different medications and land on the right fit pretty quickly. Getting to the diagnosis took years though.
105. Trial and error

- 106. Prescription was simple to get. However, how the government funds adhd medications does not align with best practice of prescribing. For example, a person needs to try a short acting stimulant first before they will fund an extended release stimulant. However, it is not best practice for doctors to prescribe an extended release stimulant first, and only prescribe immediate release if the extended release isn't tolerated. The government does not fund the medication Intuniv, which is a non-stimulant ADHD medication. The generic only recently came out, so it is still expensive. The only other non stimulant medication available is a different class of medication and works completely differently. So if a family doesn't have extended medical benefits that cover Intuniv, they don't have this medication option due to cost. Many children do well very with Intuniv either in combination with a stimulant or just on its own. Not having as an option for families who can't afford it, with no similar medication to replace it, is unacceptable.
- 107. We were very reluctant with our first child but amazed at the difference it made. It took time to understand the best medication for him and how to deal with side effects. He experienced barriers getting prescription reviews. The first time we had to begin the developmental assessment again, with multiple professionals and long wait lists. The second time he had aged out of the system, stopped taking his medication due to depression and the doctor was reluctant to give him a new prescription because he hadn't taken it for several months. Our second child to take medication had overwhelming mood crashes when the first type wore off. We had to try three types before finding the one that worked best for her. Our struggle now is to get pharmacare to pay for it. Our third child tried one kind while in a severe mental health crisis and did not tolerate it well. We have focused on anxiety medications instead and are cautiously considering adding an ADHD medication. Our fourth child has had few barriers as by now our family doctor knows the family history and understands why we are seeking a diagnosis and medication.
- 108. Our first pediatrician wanted us to wait. New pediatrician was willing to prescribe when our child was 6. It took some trial and error but even in the adjustment period, there was immediate improvement.

38: Do you have extended benefits provided by your employer or through a government program? 149 out of 160 answered



39: Do these extended benefits adequately cover medical care/medication for ADHD? 116 out of 160 answered



40: Have you had to choose between meals, bills, and medications to support a youth/child with ADHD? 136 out of 160 answered

1. No
2. As of now no but if the extra doesn't get covered then I don't know if we can afford it
3. Yes. Had to take my sons off there meds for a month in order to be able to afford food for them.
4. No but if we were to consider medication again it would be a barrier
5. Yes
6. Yes. Some prescriptions we tried were very expensive.
7. No. Thankfully. My heart breaks for the many families in this position
8. No
9. No thankfully and for that I'm grateful!
10. we are lucky as we both work and can make the budget adjustments needed.
11. No
12. No
13. No
14. Mails bills and his medication
15. Not yet, but between one medication vs another because the one that works best is too expensive. Definitely have to adjust our lifestyle (which groceries to buy, activities to put kids in) to be able to afford medication for two kids each month
16. no
17. No, but I know many MANY families with this struggle, and my OWN ADHD medication is prohibitively expensive, even though I have "some" Coverage...
18. no
19. No
20. no
21. Thankfully no
22. No
23. No
24. We have to carefully budget for the \$300/mo not covered by extended benefits. We are also small business owners, so pay the cost of the benefits plan, too
25. No.
26. Yes. Going into debit or not spending in other areas is a real thing!
27. No, but money is always very tight. We are in a huge amount of credit card debt because only one parent can work because our kids ability to attend school and/or childcare is very inconsistent due to lack of support.
28. no but it is expensive
29. No
30. No
31. No because we haven't had any
32. Thankfully no.
33. I quit my job in order to get my child's diagnoses sorted and since then have also sacrificed career promotions and seniority in order to be able to support my children additional needs.
34. No
35. No
36. No. And I am very lucky to be able to say that
37. Medications are covered; therapies run out quickly and respite isn't covered. I wish we could do more but honestly respite wins out over therapy often
38. Yes just medications
39. N/A. Because child is not taking medication, I am not sure if benefits coverage is adequate or not.
40. No

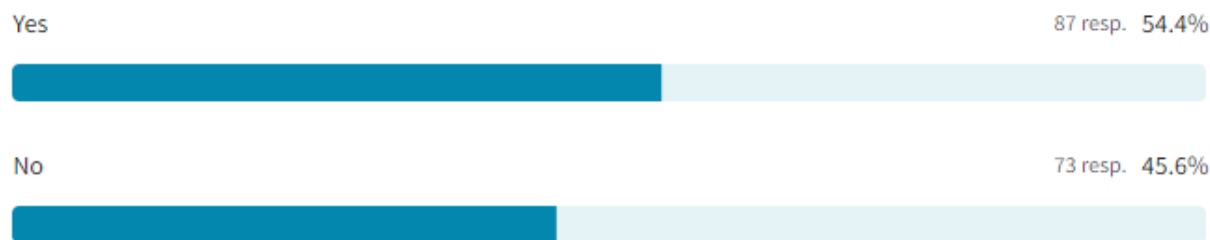
41. Not at this time
42. No
43. Yes
44. No
45. No, but things are tight all the time.
46. Not yet
47. My son's adhd medication is thankfully covered through my work benefits. But things like therapy are only partly covered. So I've already used my sons funding for his therapy and for the rest of the year we will have to pay ourselves.
48. yes
49. n/a
50. No have extended benefits
51. No, thankfully
52. No - he currently is not on medication. My benefits do not cover ADHD medications and it would be a financial burden if he does go on medication and we have to pay out of pocket. We make too much money for Fair Pharmacare coverage
53. no
54. Thankfully no, but we certainly have difficulty getting ahead financially with all of the additional supports and supplies we require.
55. No
56. No
57. Yes
58. No
59. No, but it's been tight sometimes when paying for a private counsellor because the publicly available options weren't producing any real results.
60. Meals but he hardly eats due to the medicine being an appetite suppressant
61. No
62. No
63. No
64. no - I am lucky
65. We have always lived paycheck to paycheck.
66. no
67. No thankfully
68. no, we are lucky to get meds covered. But we do spend big part of our family budget for the kids support (activities and support people)
69. No
70. resulting lack of funds has influenced our meal and grocery shopping choices
71. No, we have been lucky this way.
72. no
73. Yes. Medication is very expensive
74. No
75. We have enough money and insurance so this isn't an issue. Since she hasn't started on meds yet, we're not sure how much of an effect they will have and whether they would be so amazing that we would prioritise them over food and board.
76. Never medication but do not have funds for OT or a nutritionalist
77. Yes. Some of the meds we tried were very expensive.
78. Thankfully with dual coverage we are able to cover most needs. However if school supports due not come (which they haven't in 3 years) I worry that I might have to drop from working full-time which provides me benefits to on call to be accessible to help my child at school.
79. No
80. No, I have not

81. no
82. No
83. I have chosen not to fill my prescription to fill my child's first as his is very expensive without a drug plan
84. No thank God
85. No
86. No thank goodness.
87. Support has been covered through CYMH through two different organizations on a term basis. Term always seems to end and behaviors increase. It is hard to afford without funding, that is, if you want to maintain consistency. Again, I have no idea what's even an option and am having a crash course at this...
88. Yes. Most months. The cost of groceries is only slightly less than the cost of medication. On a single income I often sell my clothes and furniture to be able to afford both.
89. I chose to work for a company and took another role with the company so that I could have the extended benefits they offer so that I could afford the medication. I have had to make some hard choices when paying bills/buying groceries due to time missed at work because of needing to leave and pick up kids from school/daycare when they did not have support
90. Yes. Often.
91. Yes. Living well below poverty line. Access to "plan G" but prescribed meds not covered
92. Luckily no. But we have no medication coverage now, so this will create some financial hardship for us and will prevent us from trying several different medications. Availability of trial medications for no or low cost would help.
93. No
94. No
95. No, my husband and I both have extended benefits. His father will not coordinate benefits or contribute willingly to additional expenses. Play therapy got quite expensive, now thankfully son qualifies for Disability Tax credit so will be easier to cover associated medical expenses.
96. No
97. No
98. No
99. no, we were fortunate
100. No
101. Food first but meds next. We are going in debt as we also pay private school tuition as our kid wasn't getting any support in public. Finally getting support and kind environment
102. No
103. no
104. No - we have good jobs with benefits. We are lucky.
105. I have not had to make this choice, thankfully. I have always been able to afford medication. We have found we need the "brand name" in order for the meds to be effective but many plans do not cover the full cost of the brand name and only pay for the cost of the generic version.
106. no
107. No
108. No
109. no
110. No
111. Yes. The counsellor is not covered under our benefits so we pay out-of-pocket and it is expensive Every 2 weeks it is \$100 or more to see the counsellor Medication is expensive, especially when you're travelling so many that don't work
112. My extended benefits cover medications, but not tutors and therapists.
113. No
114. No

115. We are fortunate to have enough money for medication bills, but it's crazy that we have to pay hundreds of dollars a month for necessary medication.
116. no
117. Yes. We pay out of pocket for tutoring to help my son and it sometimes is a choice in paying down debt
118. We are fortunate enough to have decent medical coverage.
119. I've had to choose between rent and services for the child
120. No, thankfully.
121. No - thankfully. For those that do have to, it is beyond unfair to the child and caregivers to deal without their meds. The risks associated with being unmedicated are too high.
122. No
123. Not yet but I am afraid that might happen
124. No
125. No but our pediatrician provided us with RXHelpOne to reduce the cost.
126. We are lucky enough with benefits to not have to choose because of ADHD but with the high cost of living, we have had to meal-plan, reduce expenses in order to continue to afford basic living expenses and still provide an outlet for our ADHD children (extra-curricular activities)
127. no
128. No
129. Thankfully, no.
130. Thankfully no, but we have been putting a lot of our costs onto a line of credit. So we are slowly going into debt to pay for supports.
131. Thankfully no. We absolutely have had to make some financial adjustments, but haven't had to choose between therapy and those kinds of necessities.
132. No
133. Luckily, we can afford the medications now. I am concerned about whether my daughter will be able to continue with her medication if she decides to move out.
134. no.
135. Fortunately no, but we have had to switch medications to one that is covered even though the original medication was working fine (it was not covered.)
136. No

41: Additional Diagnosis apart from ADHD: If applicable, share any other diagnoses you've received. This helps us understand the complex needs within our community. Except for Autism*, have any additional diagnoses affected the child or youth with ADHD in your care in terms of impacting their ADHD support, treatment or access to ADHD-specific services?*

*An Autism diagnosis allows access to Autism Funding and CYSN services and a designation in school **160 out of 160 answered**



42: Please specify which other diagnosis the child or youth has received in addition to ADHD.

81 out of 160 answered

1. Mild to moderate intellectual disability
2. Anxiety
3. Developmental coordination disorder, hearing loss, apraxia, mental health
4. Extream anxiety, autistic tendencies (which does not get finding) and written output learning disorder
5. Severe anxiety, early puberty
6. Social anxiety, generalized anxiety, dyslexia, dysgraphia, dyscalculia
7. dysgraphia and Developmental Coordination Disorder
8. Fasd, anxiety, depression
9. Anxiety disorder
10. NAS and suspected FAS
11. GAD
12. Anxiety and depression
13. Anxiety, depression, OCD
14. Learning disabilities
15. DCD has contributed to both school and social challenges
16. Dcd (developmental coordination disorder), sensory processing disorder, anxiety
17. FASD, anxiety ,intellectual disability
18. Which child? The various diagnosis include learning disabilities in writing in math, dyslexia, anxiety, depression, IBS, migraines, joint pain.
19. ASD
20. Giftedness; DCD; Learning Disability
21. Tourette Syn, Anxiety, learning dis in multiple areas
22. Anxiety, sleep disorder, and developmental coordination disorder
23. Learning disabilities, anxiety, stress and trauma disorder
24. Anxiety, severe LD including dyslexia, depression
25. Dislexia, dyscalcula
26. Mild anxiety disorder
27. Complex neurodevelopment disorder, intermittent explosive disorder, specific learning disorder with reading & writing,
28. Learning disability
29. Anxiety
30. anxiety learning disorder

31. dysphasia
32. Generalized Anxiety
33. She is intellectual disability, and the therapist often say they are not equipped to work with her and pass her over to someone else. We are still looking for an appropriate therapist.
34. FASD, ODD, PTSD, Anxiety,
35. Sever anxiety, written output learning disability
36. PDA
37. My son has very obvious anxiety, and he has a lisp which he's been receiving speech therapy for.
38. Anxiety , ARFID
39. Ehlers Danlow
40. Separation/social anxiety
41. LD in math and written output. They recommended an ASD assessment which we are waiting for.
42. Anxiety, depression, bipolar disorder
43. Spd, odd, dcd, PDA, tic disorder, social pragmatic communication disorder
44. Written output disorder, anxiety, gifted
45. mild asthma; environ allergies (grass, dust, cat); Circumscribed juvenile-onset pityriasis rubra pilaris (type IV); COVID infection; molar incisor hypomineralisation; Specific Learning Disorder (severe dyscalculia, double-deficit dyslexia, dysgraphia); Sensory Processing Disorder (SPD); Visual Processing Dysfunction; strabismus exophoria (diploplia); Auditory Processing Disorder (APD), decoding and hypersensitivity subtypes
46. Child 1: depression Child 2: dysgraphia, LD of written output and expression. Child 3: anxiety behaviours Child 4: being investigated for dysgraphia.
47. depression, anxiety, dysautonomia
48. Anxiety for both, epilepsy for son
49. Extream anxiety
50. GAD
51. depression
52. ASD, Dyslexia, DCD
53. Anxiety, motor tick
54. OCD, ODD, SPD, PDA
55. Gen Anxiety Disorder, OCD, Trichotilomania, Disregulation Mood Disorder
56. Child A: ptsd, attachment disorder, borderline personality disorder, child B: GAD, MDD, child C: unspecified trauma and/or stressor related disorder, ARFID, unspecified mood disorder
57. Our one child has Developmental Coordination disorder too. Our other child has multiple diagnoses in addition to the ADHD diagnosis resulting in a complex health profile.
58. Anxiety disorder, depression, learning disability (dysgraphia) and cognitive impairments
59. Giftedness, P designation
60. Trauma/stressor related disorder, developmental language disorder, Anxiety, undiagnosed learning disabilities.
61. ODD, anxiety, sensory issues
62. anxiety, Oppositional Defiant Disorder, depression, insomnia, Rejection sensitive dysphoria,
63. Anxiety learning disabilities
64. Developmental Coordination Disorder and Anxiety
65. FASD, Anxiety, high aces scores
66. FASD, sdnsory processing disorder, complex Neurodevelopmental Disorder, dyslexia/other learning disabilities
67. Anxiety and sensory processing disorder
68. Dcd (developmental coordination dis)
69. Both my children also have Developmental Coordination Disorder. My eldest has both to a lesser degree and is therefore classed as "neurotypical" and receives no support. My younger son also has a hearing impairment and learning disability, so he receives support through those.

70. Undiagnosed anxiety, autism
71. learning disabilities
72. Dyslexia and Q- learning disability
73. Asd, dcd, global developmental delay
74. Learning disability
75. Specific learning disability- dyslexia dysgraphia, generalized anxiety disorder. The other kid awaiting psych ed. Assessment
76. Dyslexia, dysgraphia, dyscalculia, giftedness, poor motor skill development
77. High anxiety
78. Specific Learning Disability in written output; Developmental Coordination Disorder
79. Anxiety
80. Dyslexia, Dysgraphia, Discalculia
81. Child 1: autism, OCD, GAD; Child 2: autism, depression, GAD, social anxiety; Child 3: ADHD only; Child 4: autism (PDA), OCD, GAD

43: How has having more than one diagnosis affected your access to ADHD support and services?

77 out of 160 answered

1. It has been hard
2. It's just an extra layer of complexity, people see ADHD as a hyperactive kid so don't understand how there can also be anxiety
3. Significantly. The "specialists" and "therapists" see the ASD and ignore the rest.
4. Have been told he is "very complex", and at that point they seem to stop trying to help.
5. It was actually a blessing to have a "mental health diagnosis" otherwise we would not have had access to a designation at school
6. It's helped in the school system
7. the DCD and its characteristics enabled us to access AHP. other than that, we do not get more supports from CYSN. The DCD has enabled me to successfully advocate for a Chronic Health Designation at school.
8. It just makes it more confusing and hard to get services
9. Challenges with being treated holistically.
10. Surfaces are hard to access, at best they're scattered, not streamlined. There doesn't seem to be anybody that specializes in this area, unless you have good extended health benefits through work.
11. you would think it would be easier -but it isn't
12. Anxiety seems to be the sole thing my dr looks at (anxiety is also a very pervasive symptom for the female presentation of ADHD...again, need more education for others on female presentation)
13. Multiple layers, all interconnected, needing supports
14. Haven't gotten any more support saying that support is only given for the learning disabilities (eg: that is what gets the iep)
15. There is also no support for DCD (outside of BC Children's which is not accessible from the Fraser Valley on a regular basis)
16. We were only able to get some support at school due to some of the other diagnosis and the significant behavioural challenges he had. As an adult to be nothing available.
17. Both have autism diagnosis as well so that has given me access to funding that otherwise would not have been available
18. It makes it more complicated
19. I was provided more community programs for the GAD than I was for Adhd.
20. n/a
21. Still no support and he's so complex

22. I thought it would; BUT even with the funding sorted, I haven't been able to access support. The ASD funding seems nice in theory, but when you get it you have a massive job of actually finding providers to support you (if you even know which ones you need). Once you find someone with space, you have paperwork and wait times to contend with. I've had the funding confirmed for more than 3 months and haven't accessed any support yet. At least this is my
23. It has not
24. It's improved it because we were able to get a school designation of "chronic illness"
25. No one in my family has received support or services solely for adhd (except medication)
26. Without adequate support services (it took 8 months to find a psychologist & it's in another province)
27. Not helped or hindered
28. Hasn't changed anything
29. For this child, it's been a bit helpful
30. Child is often referred to as complex but i tell them most children have an learning challenges and social aDHD
31. probably
32. I find you can find supports, but not necessarily always appropriate for early childhood/primary years. I would like to see more efforts in early intervention
33. Huge-as I just mentioned, therapist keep passing her up. She also in classes she just doesn't have the focus and they are unable to redirect when there is a full class.
34. We have to learn about each individual disability
35. Escalated the complexity greatly
36. It was too overwhelmed to find supports
37. No affect; access is horrible regardless.
38. Doesn't seem to
39. Hesitancy to diagnose pending other diagnoses being confirmed
40. Has opened up the possibility of more support at school due to suicide ideation
41. He gets LST support in school and could have accommodations for post-secondary if he chooses. Doesn't help the ADHD although they impact together.
42. Made it more complicated and more difficult to find the appropriate services from as few sources as possible.
43. it is hard to identify which Dx makes it hard for the child to function and which specialist may help
44. It has only helped us gain the Disability Tax Credit. It has not meaningfully helped in any educational manner
45. Actually, having another LD diagnosed was key to getting an IEP. Without it, my school district refuses to give IEPs for "just" ADHD. It is discrimination.
46. it confuses everything
47. For my son it's helped as it means more specialists monitoring him. My 20YO has been pushed through the system as anxiety so very difficult and now they are an adult so we miss out on a lot of the autism supports
48. The needs of each diagnosis are almost opposite, making finding a good med balance quite hard.
49. more support for ASD as direct funding to choose what is needed.
50. None
51. It mostly seems to amplify the symptoms of ADHD. But no diagnoses other than autism garnish any additional support except DTX and we can't even access that because we don't have a family doctor.
52. Complicated things.
53. Yes, practitioners see adhd as "less urgent" to treat than other diagnoses
54. Our child with ADHD and developmental coordination disorder diagnosis has received physician support only, no counselling. We paid for executive functioning support. Our child with multiple

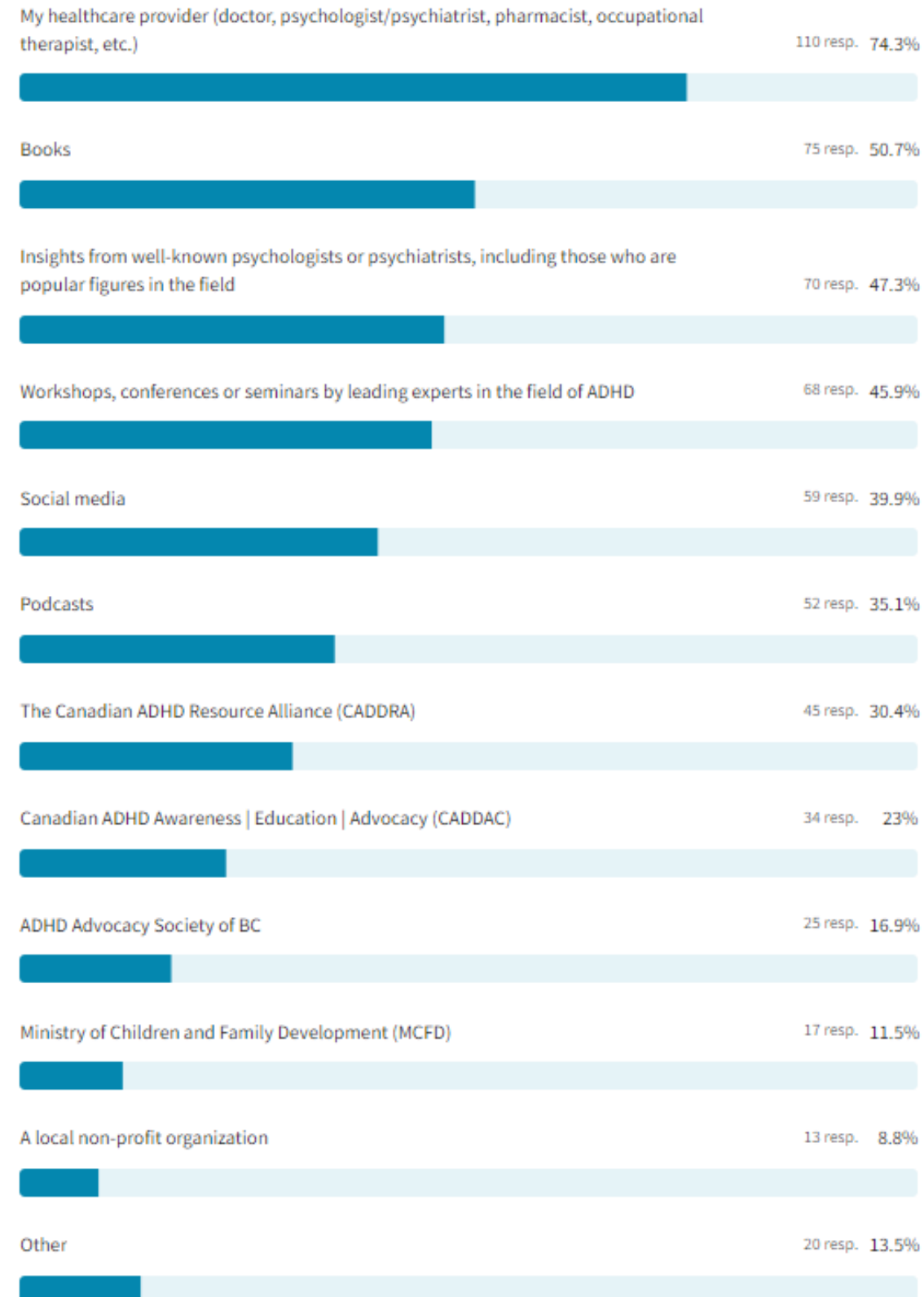
diagnoses has received physician and counselling support through DDMHS, so presumably the presence of the other diagnoses allowed access, however the counselling support was not effective.

55. She has had some additional support at school but the school is still not funded for them as she is not "bad enough"
56. System here couldn't diagnose ADHD if kid has high IQ
57. Fortunately the school and district have been quite supportive. Same with for the most part daycare and Kinsight. However unlike children with autism diagnosis or a combo of alternate ethnic background and autism ev
58. The other diagnoses come with rather aggressive behaviors that is very difficult to manage my child effectively
59. very complex, has taken years to access necessary support plus \$\$\$
60. Before we got autism diagnosis zero support for adhd and anxiety despite multiple doctor notes as it doesn't bring funding.
61. Are there much ADHD support and services that are long-term and stable other than scattered programs here and there?
62. same answer as the others. yes it has affected our access to supports and actually created more barriers in the school and general community for daycare and programs
63. No
64. None. No added support.
65. Still no support
66. Unfortunately, ADHD doesn't receive support and services where my children go to school. My son with multiple diagnosis receives more support due to the other diagnosis.
67. It hasn't
68. became easier to get support from school but still inadequate supports at school level.
69. I think it adds just another barrier and requires more specific support
70. Accessing adhd services hasn't been available
71. Aided it. The secondary diagnosis made the school up support a marginal amount. Cost me a fortune to get as the schools waitng list was over a. year long. That is far to long for a child to fall behind at the early stages.
72. Even with multiple diagnosis we have not got additional anything. Everything has been out of pocket and long waitlist. Most services are online as we can't get any in town.
73. yes - because it requires a psych-ed, which is expensive! Pay for psychologists.
74. Doesnt
75. having a learning disability as well as ADHD has opened the door to a school designation that we wouldn't have received otherwise
76. It means we have had to spend a lot of money to address all of the issues my daughter is struggling with.
77. In one child, ADHD and anxiety masked autism symptoms. In one child, anxiety masked all other diagnoses and they did not get diagnosed with ADHD until adulthood. By the time the younger children were diagnosed, we had a better understanding and were advocating for multiple diagnoses.

Access to Information: Here we explore how you currently find information related to ADHD and your preferences for receiving such information in the future.

44: What are your primary sources or trusted sources of information regarding ADHD support?

148 out of 160 answered (with multiple choice)

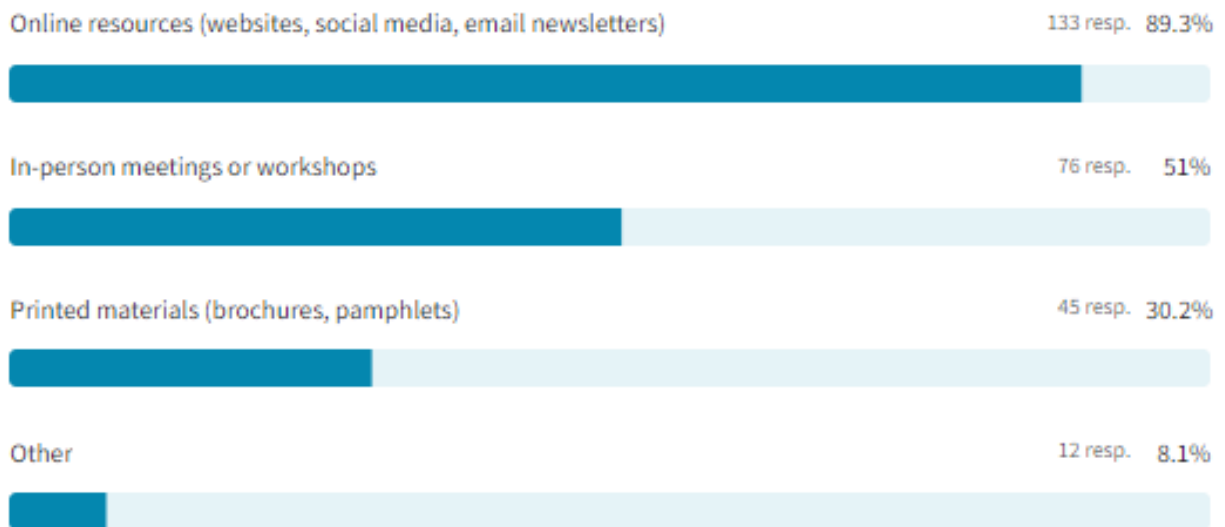


Other (please specify):

- Online searches
- Other parents in social media private groups
- ADDitude online magazine, friends with children with ADHD
- we don't have support for the ADHD
- Parent support services of BC ADHD support group
- ADHDmag
- Me having grown up with it
- peer reviewed research citations
- ADDitude magazine
- Friends in the field
- Parents/caregivers of children with ADHD
- ADDitude Magazine
- Rolling With ADHD online resource
- Research articles
- ADDitude magazine and webinars
- online - various websites from different countries
- The Facebook group/others' lived experiences
- Kelty health
- Research as part of my graduate level coursework
- Home learning network and supports there.

45: How do you prefer to receive information about ADHD and related support services?

149 out of 160 answered (with multiple choice)

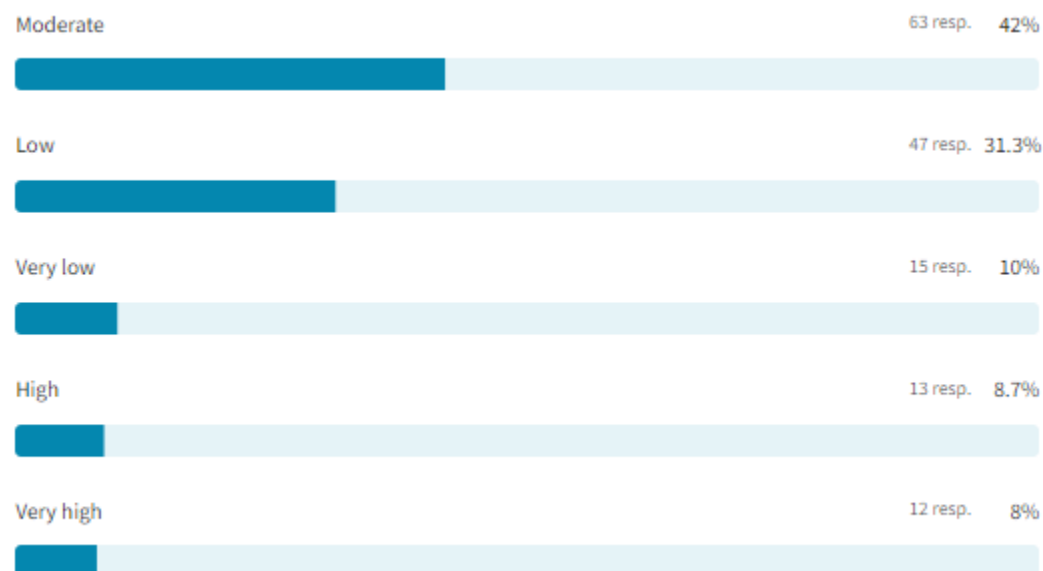


Other (please specify): 12

- Online workshops
- Email Online via zoom/teams
- Doctor office none
- Webinar
- Zoom Doctor From our doctor/pediatrician
- Online workshops and groups
- Webinars
- webinars
- Online/virtual meetings or workshops

46: How would you rate the level of awareness and understanding of ADHD in your community?

150 out of 160 answered



47: What misunderstandings or myths about ADHD have you come across in your community, within your family, schools, workplace, or broader society?

119 out of 160 answered

1. But they're just hyper kids that don't listen
2. Family members not understanding our struggles with my boys.
3. That the person is hyperactive. That it is bad parenting. That it isn't a real diagnosis.
4. "You just need to work harder", "everyone is a little adhd". ..
5. These kids are just brats that need more discipline! Awful people who think that, but not enough education and empathy in the general public
6. If a child is well behaved and does well academically they couldn't have ADHD. That children shouldn't be medicated.
7. That a pill will "fix" them. It's a "choice". Lack of knowledge that ADHD is an executive functioning deficit
8. ADHD does not always mean physically over active.
9. That behaviour is a choice or due to the child being "a bad kid". Sadly this exists very much in the school system. Report cards are a huge indicator of this and say things like "if they tried harder", "if they worked to be a better friend" and "they just don't want to put the effort in"
10. Everyone seems to have ADHD nowadays, ADHD is over diagnosed, medication is over pushed and unnecessary, diet and exercise are more effective at managing ADHD than drugs
11. that everyone with ADHD is at the same level
12. ADHD is hyper & loud. ADHD primarily affects boys
13. Unsure
14. Meds fix the problem, it can be turned off, can grow out of it, "don't look like have ADHD", everyone seems to have it - overdiagnosis, how if you just keep trying then you can do it
15. It's just hyper kids who can't control themselves. Lack of understanding about regulation and sensory needs and that it's on to move your body. Most people are ableist and expect ADHD kids to hide their symptoms and mask all day and meet neurotypical norms
16. That children with ADHD are not smart and able to learn.
17. ADHD behavior is a choice, bad parenting, laziness, doesn't really exist, kids are over medicated

18. Not support for my child in some circumstances
19. that people with ADHD are lazy, defiant, unaware, scattered, unreliable, don't listen,
20. Understanding has improved a lot in the last decade, but the stereotypes that ADHD is the young boy bouncing off the walls persist. People don't understand what a pervasive impact it has on your life.
21. It's a sign of bad parenting
22. Misbehaved children. Lazy parents would won't make kids behave. Kids won't listen and do as they are told.
23. The way that girls and women present differently and have different challenges.
24. That it is not really a huge problem. People who dont know, really dont know.
25. "Girls don't have ADHD", "you're just lazy", "your kids need more discipline aka spanking/punishment", "boys will be boys aka all boys have ADHD"
26. It's not real, they're bad kids, meds are harmful, they can control it, they have no future
27. Kids just need to eat better, get more sleep, and/or be disciplined more and they won't act that way etc. no understanding about sensory involvement and regulation.
28. That all children have behavioral issues when they have adhd
29. Lack of understanding of the challenges with emotional regulation for kids with ADHD
30. That if a child is excelling at school, they can't have ADHD.
31. These kids are problems or out of control or hard to teach
32. That ADHD is hyperactivity
33. That the children are an annoyance or nuisance to the rest of the world, they are wild and uncontrollable, rude. All of the above are not true and I know that the children can't help how they react and interact. The medication does help and keeps them focused. Having a great support system, friends and family alike have helped keep the children in feeling included and normal.
34. That we are hyper That it's not an actual thing
35. That people don't need medication. It's absurd - like telling a schizophrenic their voices are fine, it's everyone else that is the problem
36. Unsure
37. Pill fixes it all
38. ADHD is the result of poor parenting, or too much sugar, or too much technology. ADHD kids are too loud, busy, hyperactive, annoying, etc.
39. that it is not real, not common and not treatable
40. n/a
41. Kids are just not paying attention, parents just need to use strategies like chore charts, obviously the parents are not parenting or disciplining their children correctly
42. I think people don't understand about the complexities of ADHD and how RSD functions along with other more commonly known behaviours. I think folks don't understand about inattentive ADHD as much as other kinds. I think people still don't understand the toll that masking takes on folks with ADHD.
43. Just not fully understanding what ADHD is and making judgements
44. it's in their heads
45. I think they don't understand the level of patients needed
46. That it will go away
47. "You should work harder", "it shouldn't take that long" etc.
48. Only at the schools so far
49. That it's due to bad parenting rather than a physiological condition, that ADHD just means you don't pay attention, that my son is stupid because he won't sit still in class or pay attention, that if I just talked to my son he'd stop behaving like this, that if I punished my son, he'd stop behaving like this, etc.
50. That it means that a kid can't focus or they're hyper.

51. That ADHD is just a child that can't sit still. Low frustration levels, sensory issues, school refusal, anger isn't connected to ADHD
52. People are lazy. Behaviours are a result of poor parenting. It's just a problem ish public schools. Medication is an easy out
53. That certain kids are "too smart" to have adhd
54. Too many have lack of follow up from pediatricians who give medications; parents don't want to try again due to bad experiences. Assumption that my child can regulate his screen use at school (spoiler alert: he can't). That they are 30% younger than their peers and expectations should match them where they are.
55. That they can or should be able to control their emotions and behaviour at all times.
56. laziness, unorganized / messy, unwilling
57. Adhd is a misnomer. My Hyperactivity is in my brain, not always visibly seen outside. I see you focus so how can you have adhd? Ppl think it's more of a quirk and not an actual disability. How can you forget to eat? That's a basic need.
58. "kids can be different", "she will outgrow it", "I don't see any ADHD"
59. Lack of understanding and support of an ADHD child's behaviour.
60. Everyone has a bit - it is no big deal; medication will hurt your child; alternative therapies are an adequate treatment; ADHD is a superpower; ADHD people were valued in hunter-gatherer times; ADHD students are wifful and disobedient; ADHD is a shameful label; ADHD is not common; ADHD is about attention and hyperactivity only; schools and society need to accommodate and include untreated and undiagnosed individuals with ADHD; doctors are over-diagnosing ADHD; wimpy millennial parents who can't parent are seeking a diagnosis when not necessary
61. My kids are wicked smart. So no one in school or the community sees the problems until it's a crisis. And I am overfunctioning to the point of collapse.
62. that it mostly affects boys (hyperactive), that it's not very disabling, that kids grow out of it
63. It's the iceberg. It's so much more than just having too much energy
64. That people who with ADHD are just lazy; that everyone has ADHD
65. Nowadays everyone self diagnosis adhd so it's almost disregarded as not serious or something that needs more support
66. "Isn't everyone a little ADHD"... No, they are not. "He needs to try harder to focus"... does a diabetic need to try harder to use his pancreas more effectively? Neuro-typical people have no idea the extent that a person can be handicapped with this. You may be years behind in development compared to your peers.
67. Either that it's not that big of a deal and meds make it better. That it's not a serious dx that has life long impact. That knowledge on it is not needed to support. That when my child does have meltdowns it's more of a kid who is unruly and put of control then a child with a serious dx thst needs more support and adoptions in life.
68. Only boys have ADHD. These are just "bad" kids. Parents are too lenient and just don't discipline their child.
69. That its over diagnosed. That it doesn't exist.
70. student accommodations at university are sometimes misunderstood
71. fear for medication, exclusion instead of understanding by many with behaviors, lack of accommodation in professional settings to help
72. Just that it's "simple"
73. others NOT believing in the diagnosis thinking ADHA person is using it as an excuse.
74. We don't know where to get help
75. That because my son isn't hyperactive he therefore cannot have ADHD. They he is just "shy" or "weird"
76. That all kids have ADHD, that ADHD isn't real. People who cannot see a barrier are easy to dismiss it as a problem with discipline.

77. That it makes children hyper and that's all. Executive function challenges need to be understood and accepted.
78. People think the kids are "acting out" and that the parents "just don't discipline" the kids. Most people have no idea how much ADHD can affect someone and their ability to do regular everyday activities.
79. Doesn't affect girls
80. That it's "a minor inconvenience and can't be debilitating", that it's a lack of effort, that it is a result of parenting, that it's behavioural, that it doesn't effect girls
81. Most people have a basic stereotypical understanding of what a person with ADHD is like. Many people do not believe it is a valid health concern. Many people blame the parents for poor parenting causing the ADHD behaviours. Many people do not understand that there is usually a combination of challenges associated with ADHD. Many people feel that medication is unnecessary.
82. ADHD happens to people with low IQ only. Girls don't get ADHD
83. The kids are either lazy or unfocused or intentionally disruptive.
84. stereotypes "it's only for children" and "it only affects boys"
85. That she's unintelligent (she's gifted), and rude/unfeeling (she's super emotional and over-sensitive), that she's selfish and uncaring and messy.
86. I hear that it's from bad parenting mostly, or i need to be more strict, change their diets, remove all screens...I've even been told my child just needed a good spanking to smarten up.
87. That adhd is a behavioral disorder that can be treated with discipline. That child should be able to overcome adhd challenges because they are also gifted.
88. too much sugar, too many video games, bad parenting
89. Broader society seems to hold misunderstandings like ADHD = cognitive delay, and prescribed stimulant medication is like illicit drugs.
90. That children/people with ADHD are not as bright and could help it if they wanted to.
91. That all people with ADHD are hyper or get into trouble.
92. Lots - stigma, unfair judgement, macroaggression, etc.
93. have to have medication to be in school, bad kids etc.
94. That it is just hyperactivity or inattentiveness
95. Stigma towards medication. Inability to make appropriate accommodations in class. Teachers assuming my kid is not listening on purpose. Poor communication in school about my daughters ADHD with teachers on call or perhaps just a lack of awareness on the TOC's part on how to support kids with ADHD.
96. That it is always hyperactive. Lack of understanding the emotional overwhelm aspect. My child was disengaged from learning - hyper focused on drawing.
97. People grow out of adhd
98. People think it is an excuse for willful behaviour. Some people think that medication will magically solve the problem. Some people think that it's made up & a result of "bad parenting". Many do not understand how the ADHD brain works and how it can actually be beneficial if guided with the right strategies.
99. That it's not a disorder, it can be controlled/supressed
100. That all kids with adhd are noisy and hyperactive; that adhd is overdiagnosed.
101. That it doesn't really exist. That everyone is a little bit ADHd. That my son isn't bouncing off the walls enough to have ADHD.
102. people often dismiss challenges or minimize them, lack of understanding on emotional regulation difficulties, often bad parenting is blamed.
103. The expectation of how my son should behave verse how he does behave.
104. Most common things I hear are - it's not real, it's caused by bad parenting, the kids are poorly behaved, it means something is wrong with that person, and it's a trend.

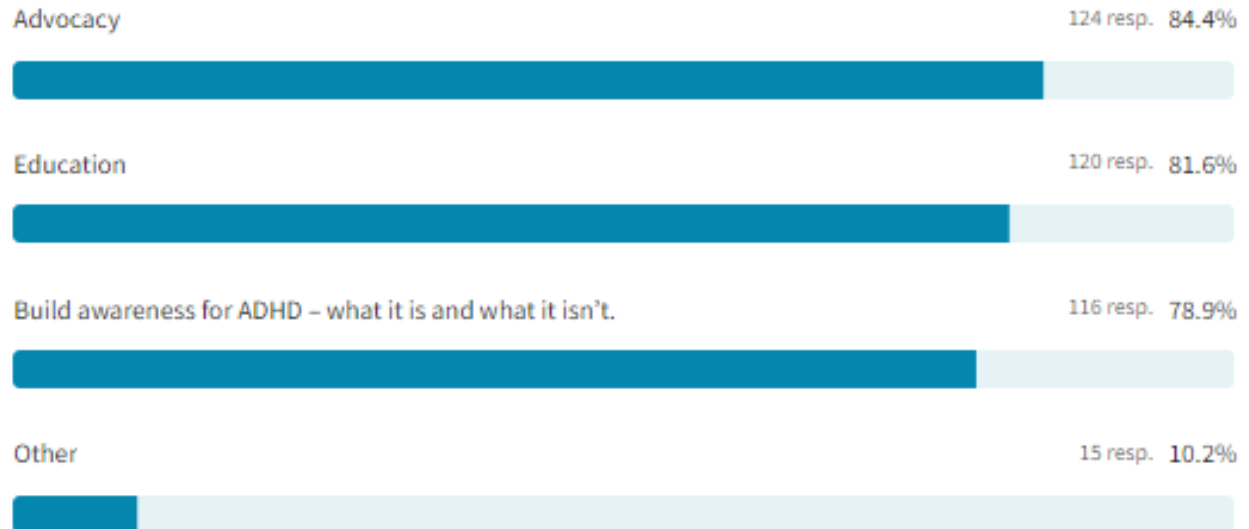
105. Kids with ADHD are incapable of behaving or doing well in school. ADHD doesn't exist. If your kid isn't hyperactive they don't have ADHD.
106. So many You grow out of it Only boys get it Meds make you a zombie It's an excuse It's a result of bad parenting You could/can cure it with____ insert your choice of fad diet, no sugar, no dyes, current trend. It's a super power, so why do you need meds, accommodations, or what ever? Their behavior is their choice, they just need to try harder.
107. Unsure
108. That everyone has this and that it's not a real thing
109. Not understanding how ADHD affects emotional regulation, increases overall stress, and the skills/developmental gaps that may be contributing. They see ADHD as a blanket diagnoses of not being able to concentrate vs the nuance of differing levels of capacity to concentrate depending on the environment and internal factors—also very different handling/understanding of ADHD male children vs ADHD female children.
110. That the behaviours are controllable. People still think kids with ADHD are troublemakers and just need to learn to behave versus the fact that they are impulsive and struggle in the typical educational environment.
111. since my child isn't "hyperactive" he wasn't perceived as adhd. Since my child didnt' struggle academically at first, the adhd possibility was dismissed for too long.
112. It more than just 'not being able to focus'
113. My daughter is continually perceived as 'lazy' or 'rude'. People know about her diagnosis but they don't seem to understand how that makes interaction with her different, or her approach to school work etc.
114. The behaviours associated with emotional dysregulation had caused a lot of misunderstandings. The myth that ADHD is the inability to pay attention, when it is in fact, the inability to regulate attention.
115. NA
116. Not understanding the tendency for hyperfocus on interests. Thinking that individuals just aren't trying. Seeing individuals as lazy. Not understanding the complexities underlying many things neurotypical people do and how ADHD can interfere with ability.
117. Medication will hurt my kid, medication for ADHD is brutal and messes kids up
118. People only recognise "classic boy presentation", they think that ADHD is overdiagnosed, it's "trendy" and people are self-diagnosing for no reason, it's just bad behavior, ADHD kids need strict parents to toughen them up (or worse, need constant punishment and negative reinforcement to "prepare them for the real world.")
119. That "everyone" has ADHD if they are active or distracted. It's a disservice to those who actually do have ADHD.

Engagement and Feedback

This section is your opportunity to tell us how you might like to collaborate with the Society, whether you'd recommend us to others, and if you're open to being contacted for future initiatives. Your feedback is invaluable as we strive to build a supportive community and enhance our services.

48: What roles can the ADHD Advocacy Society of BC take to support you?

147 out of 160 answered (with multiple choice)



Other:

- Please dive into issues in the family justice system and how children and their families are negatively affected, no point in having supports when child is court ordered to experience harm I don't know as I don't know the organization Showing where to access resources/support Individual coaching and support groups with other parents
- None
- Need more therapists and social workers / supports I don't know I have not access that society yet Advocate for more psychiatrists or medical professionals who can diagnose and treat.
- Help within the schools
- We didn't get any support Gender differences
- Email me regarding upcoming events or initiatives.
- These are all interrelated Get funding from government to really invest in our children please!
- Parent knowledge - What supports are available for post-secondary - We are quickly approaching that and I am feeling uncertain.

49: If you would like to play a role in supporting our work, what would it look like? 116 out of 160 answered (with multiple choice) Please note: At the end of this survey, you'll have the option to provide your contact information. Selecting any of the following options alone will NOT result in contact; your details are required for follow-up.

Contribute my knowledge through future surveys, engagement sessions, workshops. 93 resp. 80.2%



Share my story to help others. 52 resp. 44.8%



Host an event in my community to help support other families with ADHD. 31 resp. 26.7%



Other 12 resp. 10.3%



Other:

- I can share my story only with my son's permission.
- PR- This is my profession and I believe that building awareness via media and digital conduits would be beneficial.
- n/a
- community Support for advocacy initiatives
- Band with others in my community to learn better about advocacy, rights and being a part of engagement sessions and workshops in a supportive role Volunteering in a leadership role or for helping organize events in Kamloops and area.
- I honestly want to be involved in advocacy to have the government provide proper ADHD services.
- contribute and support ongoing events--happy to cohost events and engage public also We need to get help first before contributing any role Donate
- I could support an event in my community but not ready to host.
- Could help getting in touch with professionals, organisations

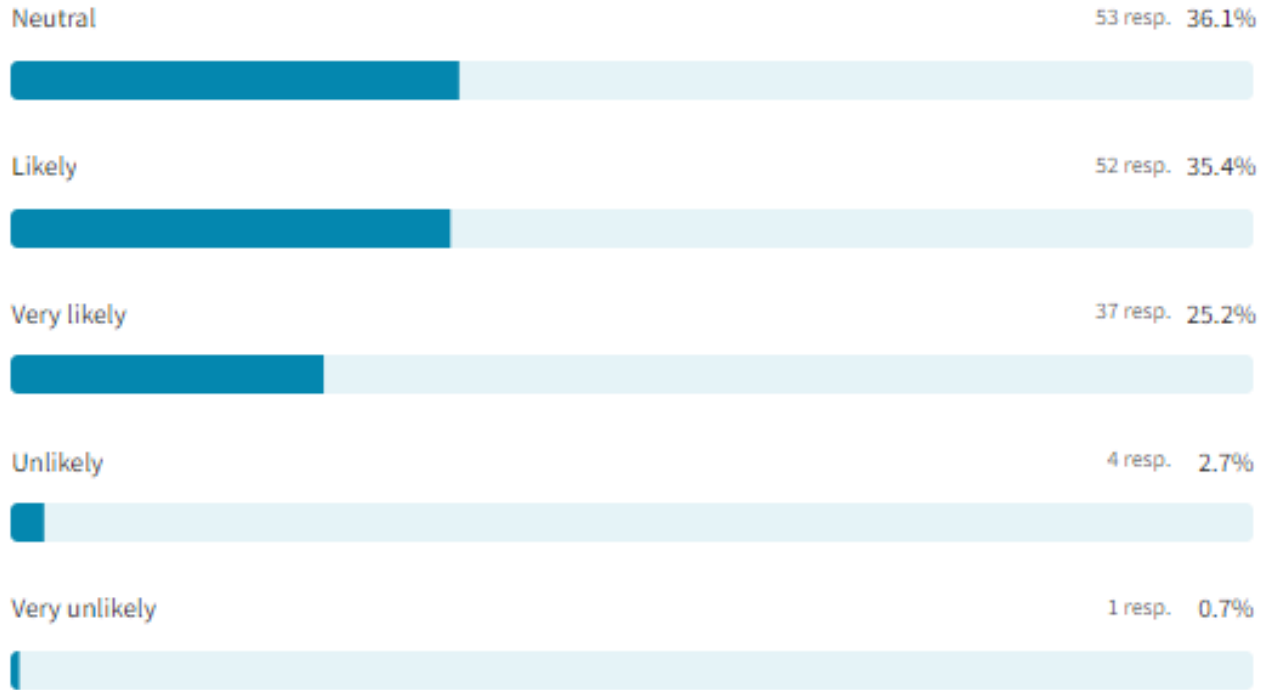
50: Is there anything else you'd like to share or suggest that we haven't covered in this survey?

Your additional thoughts and insights are greatly appreciated. 54 out of 160 answered

1. I also have adhd, so focusing on this has been really hard.
2. Thank you for creating this organization! I am glad that I found out about it!
3. I want to acknowledge that I have a lot of privilege (white, education, skills, career in the field and the connections it brings) and it has enabled me to get a lot of things for my son.
4. Thanks for doing this
5. No
6. No
7. Schools supports, medication affordability and access to other community supports are all needed
8. No
9. I don't know, too overwhelmed to think
10. My experience is that of a recently returned Canadian trying to access services in Canada. Because we didn't get the diagnosis here, **it's really hard to know where to start**. We have already spent years on waitlists etc to get the diagnosis before we moved, and we can't afford to spend years on a waitlists again in order to access support. I imagine similar, and magnified, barriers for recent immigrants.
11. No but thank you for this thorough survey! I can tell a lot of time and effort was put into developing it.
12. I really don't expect any funding body will prioritize this. Mcfd already shot it down when they canceled their 'needs based' cysn eligibility
13. No; thank you for your work
14. Not at this time.
15. Looking at challenges for those with young adults/university students
16. No
17. Personality disorders and related treatment. Research shows ADHD folks have much higher incidences.
18. n/a
19. Thanks for your work on this on behalf of our children and ourselves!
20. Parenting support group
21. There needs to be more education about ADHD in the school system
22. Not at this time
23. Not that I can think of right now.
24. I appreciate all you do to help us understand and deal better with an ADHD child
25. Help women and girls with ADHD. Please. And convince someone, anyone, to provide services for young adults with ADHD. They are absolutely abandoned.
26. More support in schools!!
27. I'm wondering why personality disorders aren't mentioned. There is research that indicates a substantial number have come morbid diagnoses such as narcissism. <https://pubmed.ncbi.nlm.nih.gov/38670059/>
28. Thanks for doing this!
29. When trying to help your child, you don't know what you don't know. There may be all kinds of help out there, but if you don't know how, where, or what to ask for, you don't know what might help. Switching to an alternative school was the best thing we did, but it was not done soon enough, as alternative schools have a reputation as the place where the bad kids go. I know know this is not true.
30. No the survey is very comprehensive.
31. Thank you for your support, and making us feel supported, hopeful, and that we have a community.

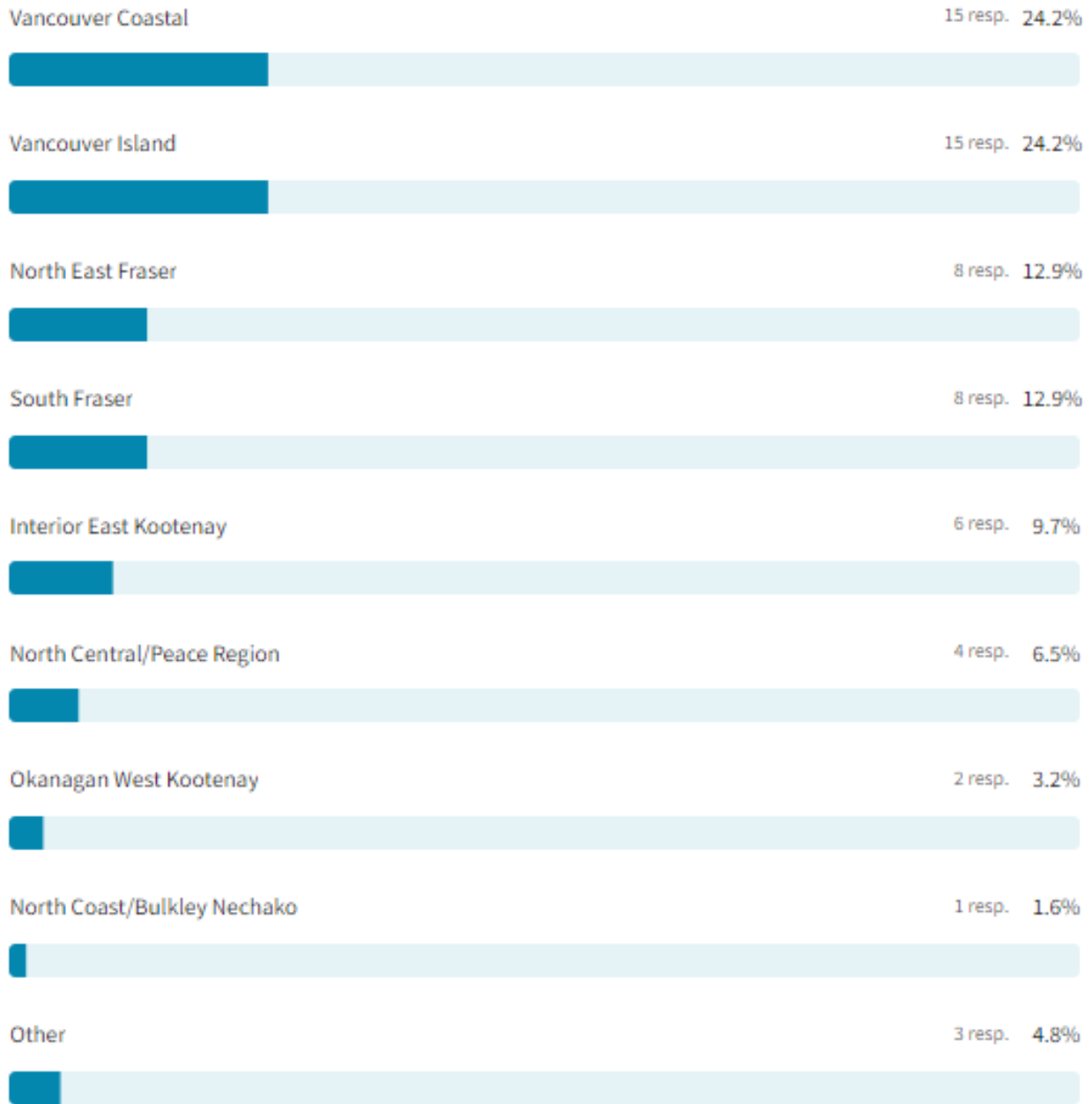
32. more emphasis on the growing number of ADULTS now getting diagnosed and their lifetime prior of struggle.
33. No
34. What an amazing way to hear from parents who are living in the world of ADHD
35. Need to better educate physicians, school staff and other staff who have regular contact with children.
36. It would be amazing to have the different groups that advocate for individual diagnosis group together for more complex cases from an advocacy standpoint to educate MCFD, schools, Representatives for Children and Youth and Judges how different disorders impact these children and how they could more effectively do their job to support these children.
37. FUNDING for services!
38. My gratitude for your efforts and advocacy!
39. In my experience as an educator, the children with adhd who show the most disruptive behaviour are the ones with additional social-psychological vulnerabilities (e.g. poverty, witnessing or experiencing violence at home, other ACEs, excessive and unrestricted access to violent media), and children whose families are openly critical of schools in front of their children.
40. Let's spread the word to dismitify ADHD and hold our school accountable for the lack of support. Thank you for the survey!!
41. Thank you for doing this. It is important.
42. We need the family connection centres to roll out across the province asap with proper, long-term funding for ALL children with diverse needs - and hopefully for adults one day too!
43. n/a
44. No. Thank you.
45. Students and teachers need more support in the classroom - there needs to be funding for ADHD students OR more H (complex behaviour) designations pursued to help get funding for the needed supports.
46. I push to have ADHD recognized by the school system and ministry of education so that there is funding to support students
47. Thank you!
48. I'd like to create an interactive group (whatsapp group or similar) of people who live with ADHD (including parents who have kids with ADHD)to support each other on daily basis.
49. Thank you for asking and listening
50. Thank you for starting the conversation! If I have any further thoughts I will be sure to contact you.
51. i don't think so
52. When I first heard of the organization, I immediately googled and discovered the website. However there are a lot of blank pages.
53. Our kids are in school for six hours a day. We need to put supports into schools. Or these kids drop out.
54. No - thank you for listening and taking this on for the benefit of families with kids who have ADHD.

51: How likely are you to recommend the ADHD Advocacy Society of BC to a friend or family member who has, or is supporting someone with, ADHD? 147 out of 160 answered



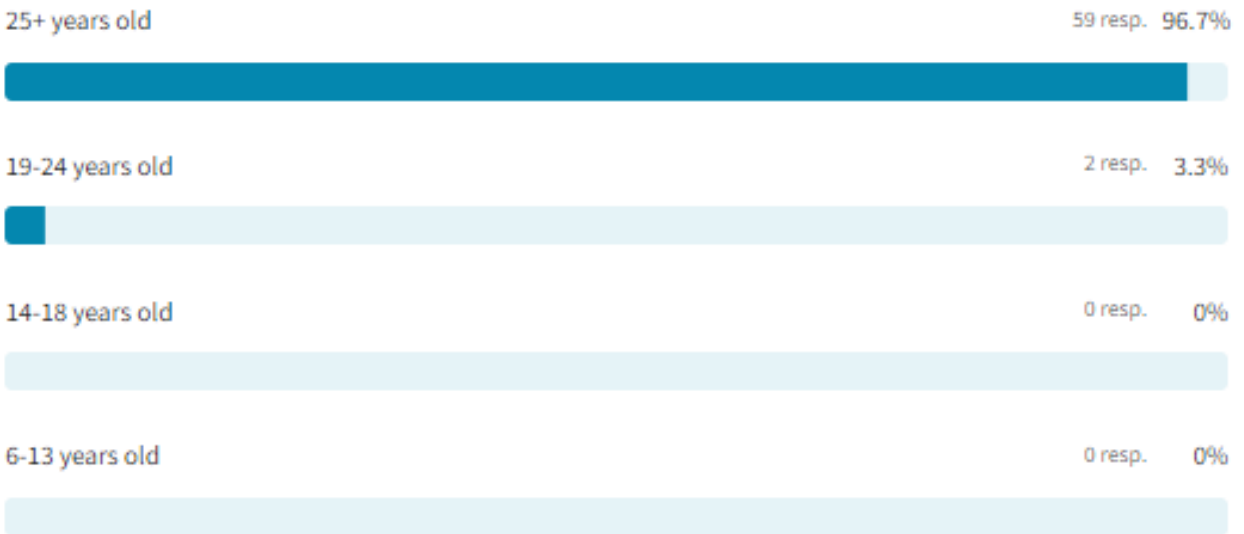
Youth and adults with ADHD

1: What region of the province are you from? 62 out of 62 answered



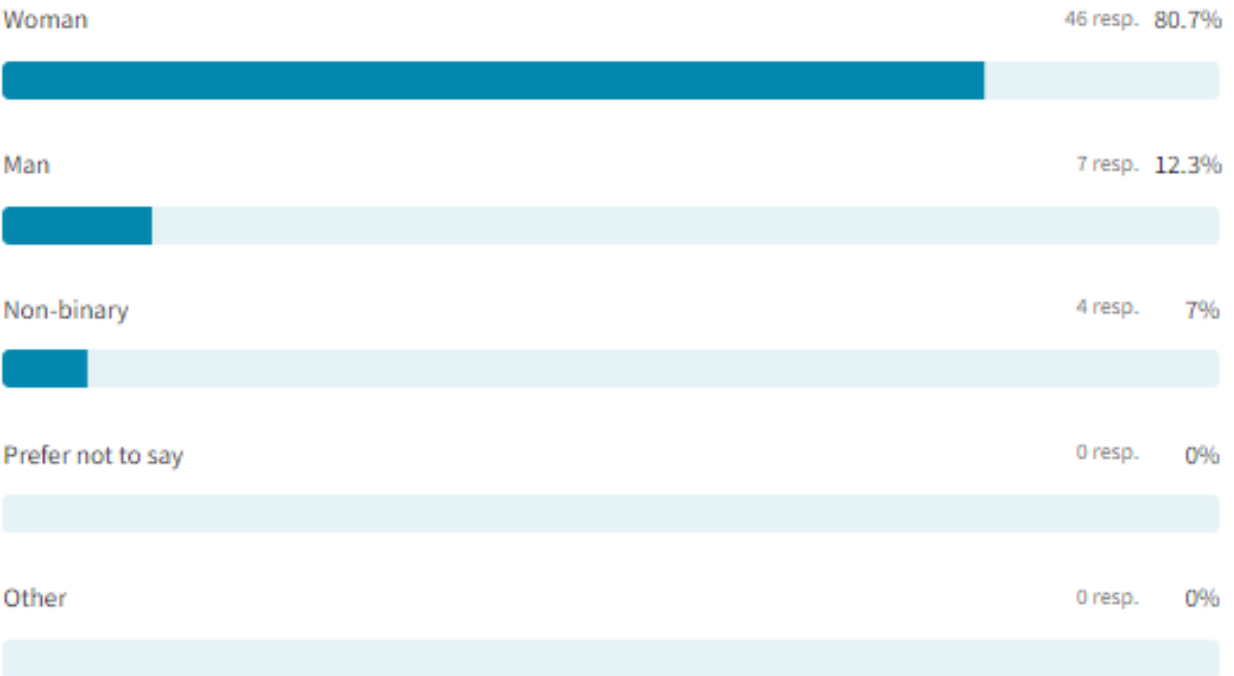
Other: 3 responses > Hope, Bella Coola Valley, Ontario

2: What is your age range? 61 out of 62 answered



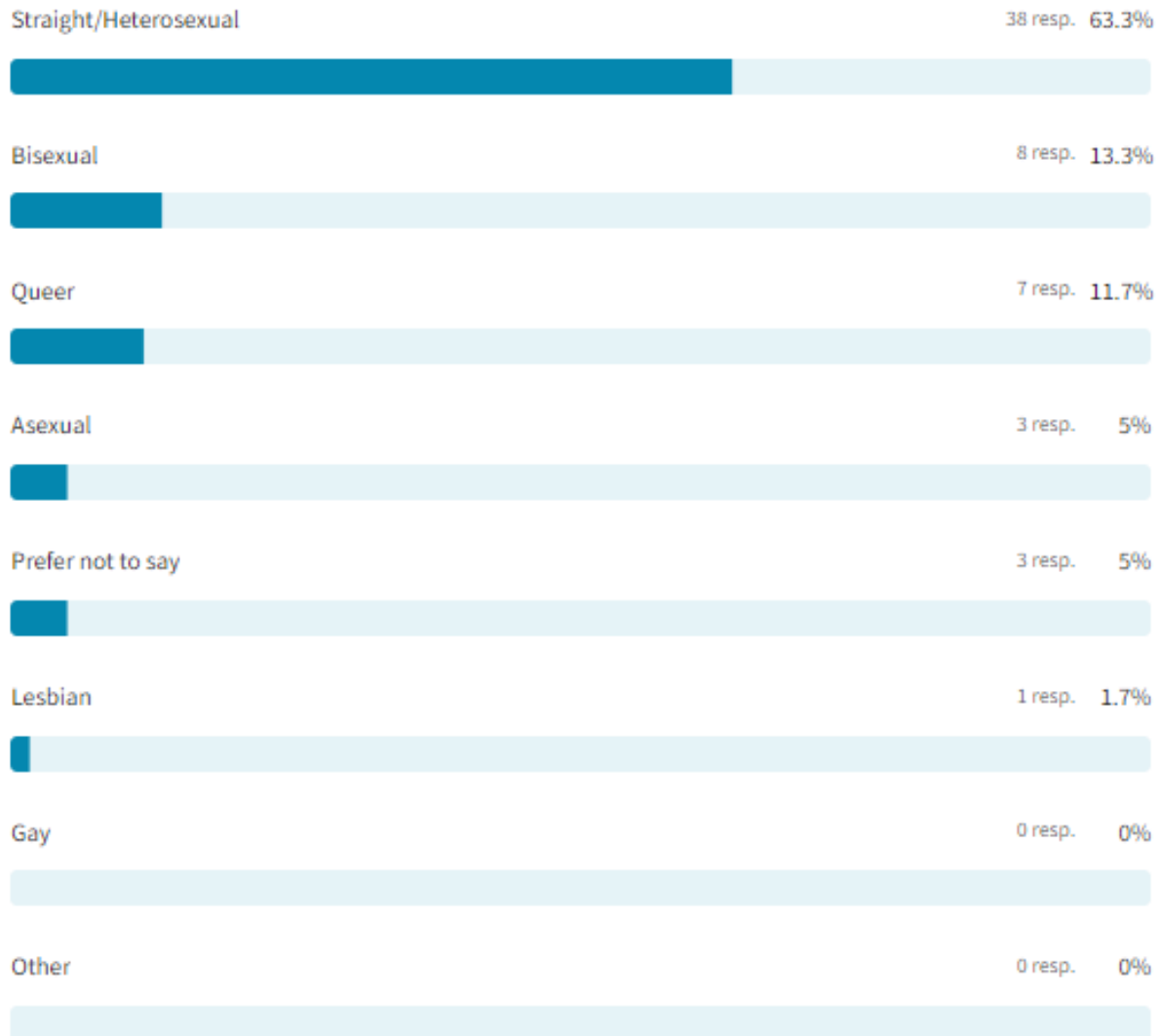
****The following set of Demographic/Identity Questions is voluntary and is being collected to honour and better understand the additional barriers society presents because of historically marginalized identities.***

3: Which gender do you most identify with? 57 out of 62 answered



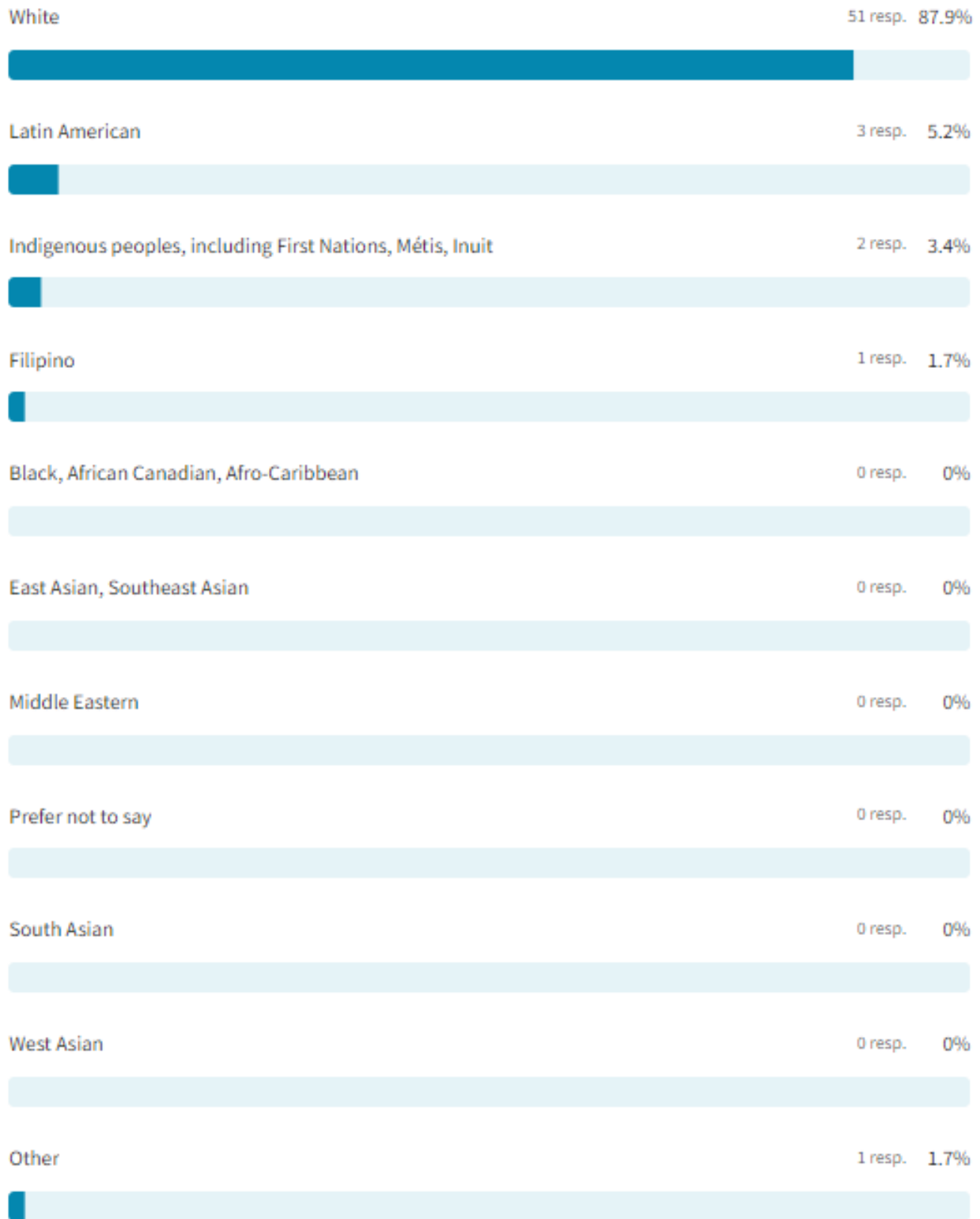
4: How would you describe your sexual orientation? 60 out of 62 answered

Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices and is not meant to be dismissive or reductive of anyone's identity.



5: How do you describe your race or ethnicity? 58 out of 62 answered

Note: our platform's technical limits mean we use 'other' instead of a custom self-describe field. This is a technical workaround to allow participants to self-identify in a manner that might not be fully captured by the preset choices, and is not meant to be dismissive or reductive of anyone's identity.



Other: 1 > Scottish and Native

6: If you answered any of the Identity Questions, please share if you encountered any barriers to accessing ADHD services as a result of the specific identities. Please elaborate.

32 out of 62 answered

1. Frustration with medical system with diagnosis as a mature woman. My doctor had a clear agenda for a depression diagnosis (I am not and have never been depressed) rather than understanding or supporting the ADHD diagnosis I had received. I have therefore avoided medication because I don't trust her to prescribe the appropriate medication for me.
2. I was not diagnosed until I was 43 years old. Very little services in Prince George and not many medical professional recognizing ADHD in adult women.
3. I get denied to every program for some reason, no one is clear with an official diagnosis, my family doctor don't know much and don't refer me to a specialist, medication is super expensive and work have been a challenge
4. No
5. No, it appears that access to care is generally poor
6. Starting the process of getting diagnosed as an adult I was told I don't fit the typical symptoms of ADHD which are based on the stereotypical male experience. Awareness of female ADHD presentation especially as an adult is insufficient
7. Yes, my doctor did not believe I had any issues with my mental health because, and I quote "you went to university". So I made to feel as though my concerns were not real because I was successful in school. I only excelled because that's all I knew how to do. Outside in the 'real world', I struggle and my physician couldn't understand that.
8. As an adult I am struggling to get diagnosed instead of just prescribed meds
9. N/a
10. Being high functioning, I was misdiagnosed until I was 31
11. Only recently learned I have the characteristics of ADHD. Not sure how to access or how it might assist me. (Or others for that matter). I couldn't say how many years it's been since I've been aware of the challenge that I have, as I have some form of time blindness with regards to the passage of time. With a bit of focus, I can work out times based on chronological (saved paperwork, record employment, Pacific years I've attended schools or learning institutions).order of things that I've done, where I've worked, length of friendships with respect to time.
12. As a woman I find I don't get taken as seriously with my diagnosis especially since I am not hyperactive outwardly.
13. My daughters has been diagnosed with adhd, but not me
14. Nothing specific.
15. Adult Basic Education in Community College - barrier to specialized tutor support-learning disability with ADHD
16. As an adult with a late in life diagnosis, services are basically nil.
17. Even though I may be white and male, trying to get help for any services has been hard. A lot of the time, I feel guilty or am made to feel guilty because of who I am if I try to advocate for myself. I have been directly and indirectly told to "suck it up" or "things will pass". People don't look at me and assume that I am struggling or just holding on, they assume that I have it altogether and I don't. I haven't found any groups for men that give me a safe space to talk about things and when I ask about other orgs, no one really knows where to direct me (other than paid groups).
18. I can't access ADHD services
19. I'm unaware of any adhd services for adults
20. As a woman, I was overlooked as a child and not diagnosed until I was 28 years old because I did not present as what most people think of when they think ADHD, which is "Hyper Active Boy"
21. to old and successful to have ADHD and probably a secondary diagnosis of Autism. If you are an adult the key to diagnosis and treatment is having the dollars to pay for it. also, the biggest hindrance is the mental health system itself and the patriarchal, whatever you do, don't question the "System".
22. I was diagnosis as an adult. ADHD was seen more as a boy thing. I grew up being seen as a "bad kid".

23. Late diagnosis , previously diagnosed with depression in my 20's, ppd/ anxiety as a new parent in my 30's, and finally adhd in my 40's.
24. Age: as I was 26 when I began seeking a diagnosis, and was presenting as highly functioning to anyone not in my close circle, I had to strongly advocate for my concerns and struggles to be taken seriously by primary care providers.
25. Being female, being an adult, and no treatment or support for adults in my region or in Canada in general
26. No
27. late diagnosis as a result of being just a 'weird girl'
28. My GP didn't want to help me because ADHD "only affects children"
29. n/a
30. I am self diagnosed ADHD, seeking diagnosis as an adult has proven difficult.
31. N/A
32. ageism

DIAGNOSIS

7: Are you self-diagnosed? 61 out of 62 answered



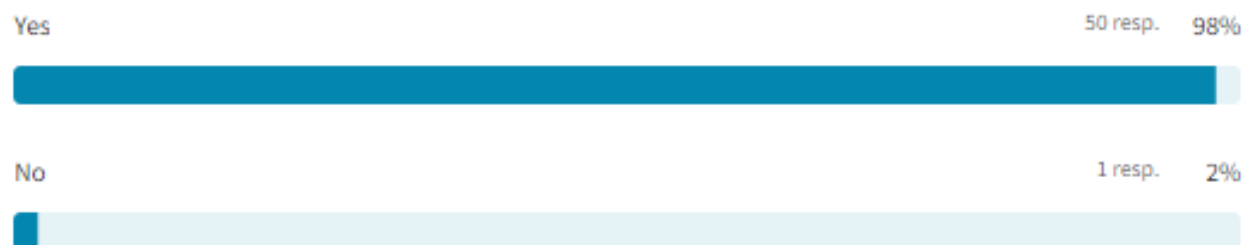
8: Please explain how you were diagnosed with ADHD.

11 out of 62 answered

1. I was tested as a child but didn't have the hyper activity so couldn't get a full diagnosis and was told I'm high functioning. As I got older my concerns increased. I have just finished doing a ADHD assessment through a dr and I'm awaiting my official diagnosis as a woman aged 44.
2. Private doctor from my home country and family doctor agreed
3. By looking at things I struggle with and doing research on how ADHD presents itself in high functioning females and how that matched with me. My GP also thinks I have it but I have not been officially diagnosed. I did lots of research online and can identify with many ADHD issues high functioning women face.
4. I entered into a friendship/relationship with an individual that what's diagnosed with characteristics of ADHD or possibly they were self-diagnosed I don't know but they said that I showed the classic signs of the condition. I was unaware that I was creating psychological work arounds to manage my life with respect to what was going on with me.
5. I self diagnosed then talked to my doctor. She agreed and we started trying medications from there.
6. Because my 2 daughters has been diagnosed, ne only with family doctor.
7. A variety of surveys and self tests and a discussion with my doctor.
8. Self diagnosed
9. My own research, long waits to get formally diagnosed and expens
10. Not diagnosed. Can't access psychiatrist
11. I haven't been diagnosed yet. I keep hitting barriers in getting diagnosed. I currently have no family doctor as well

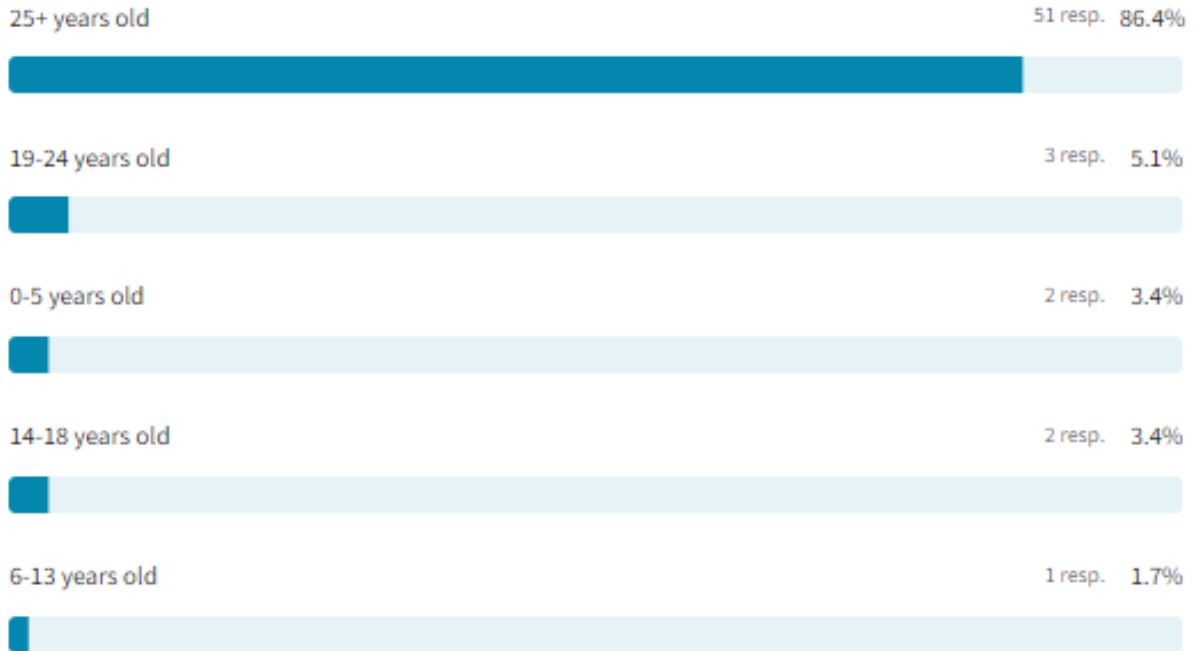
9: If not self-diagnosed, was this diagnosis by a medical practitioner/mental health professional? (Family Physician, Pediatrician, Psychologist, Psychiatrist, Nurse Practitioner)

51 out of 62 answered

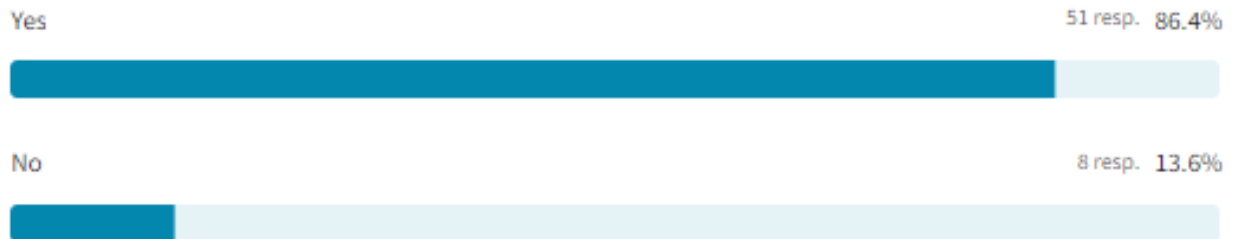


10: How old were you when you were diagnosed with ADHD?

59 out of 62 answered



11: Reflecting on your journey toward receiving an ADHD diagnosis, did you encounter any barriers? Please consider any obstacles or challenges you faced in this process, encompassing any aspect of your experience. 59 out of 62 answered



12: Please describe ANY challenges or obstacles you faced and/or what stopped you from getting a formal diagnosis. 49 out of 62 answered

1. As a girl, my parents, teachers, and doctors overlooked all my symptoms and labeled me as a lazy, over-dramatic, precocious, disorganized, and dawdling daydreamer; berating me constantly for my struggles, until I hit my absolute breaking point at 15. After a childhood of being constantly scolded for wasting my potential by daydreaming and dawdling when I was clearly a very bright child, being placed in the "gifted" program and French immersion to attempt to improve my performance in school by offering more of a challenge, and being encouraged to take accelerated streams in high school that allowed me to skip grade levels in my core subjects to graduate high school early, I began having panic attacks at the age of 15, and suffering from crippling anxiety. I was diagnosed with ADHD and GAD, and put on 300mg of an antidepressant called Effexor (a very high dose, especially for a teen barely weighing 100lbs), and 30mg of short-acting Ritalin 2 to 3 times/day.

2. As noted previously my female GP was not supportive of the adhd diagnosis and was pushing a depression diagnosis. I am and never have been depressed she did not want to support my wish to try CBT before medication - and I had to push to gain access to free or low cost services. I ultimately ended up with counselling services via Sources but it was only because I pushed for this that it was offered as an option
3. My father and brother have diagnosed ADHD I didn't hit all the markers and masked what I thought was "normal" until it was obvious it wasn't in my late adulthood
4. ADHD was missed my whole life. I had many challenges growing up undiagnosed. As an adult, medical practitioners kept telling me I had depression and put me on antidepressants and did not recognize the ADHD.
5. expensive threatement - only self support resources and not people - therapy is expensive and I can't afford - doctors are not clear
6. After finally finding a professional to assess me, I had to pay for the assessment.
7. Doctor not willing to consider diagnosis, psychologist preferring to mis-diagnose, it took over two years to finally see a doctor who would properly refer me.
8. Was diagnosed with other mental health conditions (anxiety, depression, and PTSD) and ADHD wasn't even considered. Once formally diagnosed (which I had to do privately because my doctors didn't feel I was ADHD) there was a resistance to getting medication. I have also been denied for the DTC despite considerable limitations which I am currently appealing
9. I wasn't diagnosed until I was 38 because ADHD in girls and women wasn't a thing. My oldest child was diagnosed and only then did I realize that everything we thought was normal in our family was actually ADHD (and ASD).
10. Was identified as ADHD in my teens, but this was kept from me as my parents felt this diagnosis would hold me back
11. Physician didn't believe I had any issues with my mental health because I completed post-secondary. He only encouraged me to talk to a therapist because "I had a lot to talk about"
12. Diagnosed at 60 years old, after years of interaction with the mental health system in BC. I have received many incorrect/incomplete diagnoses over the years. No one asked the right questions. I randomly got a doctor (with adhd) through Telus Health. She recognized my struggles were potentially ADHD so she referred me to a psychiatrist for an assessment.
13. Cost of private diagnosis was \$1300 otherwise I was expecting a 2 yr wait with the local health authority. I was unaware that there were other options through the Adult ADHD clinic. Obstacles other than costs were social stigma, internalised ableism, lack of consistent and reliable physician care.
14. Being a woman and being misdiagnosed with anxiety and depression since I was 12 years old, even though over the years I never truly felt happy or "normal" now I know that the "normal" I was acting as, was masking my adhd symptoms
15. I was diagnosed in 1990 at 19 years years old and they continually gave me antidepressants. I had to fight at 44 years old to finally get on a medication that actually helps.
16. I don't think I have a formal diagnosis since I've heard it has to be from a Psychiatrist and not a family doctor. And as I'm sure you know it takes years to get an appointment for one, not to mention hundreds of dollars. This has also prevented us from getting our two kids diagnosed
17. Medication is stimulating and doesn't feel good
18. I wasn't aware that my doctor could diagnose me. It was a relief when i found out they could
19. I've been trying to get a diagnosis since I was a child but did not meet the typical ADHD characteristics as they were more focused towards males. My life has been a constant struggle with many visits to doctors, therapists, councillors and psychologists/psychiatrists and

misdiagnoses of anxiety and depression. When I would advise that I wasn't depressed or anxious they wouldn't listen or believe me.

20. Had to get a referral through my university's doctor, who was very skeptical of ADHD diagnoses in general and made me go through all of my symptoms again despite me explaining that the university counselor had strongly suggested I be referred.
21. not enough understanding in women with ADHD- how motherhood can affect- being diagnosed with other illness where the underlying issue was ADHD
22. Education accommodations, access to an ADHD coach because of no government funding or support
23. Lack of support from my family
24. A childhood diagnosis should have been made based on obvious and known symptoms. I instead discovered ADHD and learned about it in my 50s, and then sought a diagnosis through my GP.
25. Resistant GP
26. Being late-identified was an obstacle in itself. Paying out of pocket for an assessment because public psychiatry would take too long was another.
27. Being old, coping, masking, difficulty separating trauma from neurodiversity.
28. Financial barriers: We couldn't afford to get a private diagnosis and so we went further into debt by going with another doctor. Thankfully when I went through the process a second time, it was covered by MSP. Doctors: My family doctor of 30+ years never diagnosed me or brought up ADHD but our new family doctor, she educated herself after I brought up the possibility of my diagnosis. Family: My parents refused to believe me; it took another year to show them that this is real. Even as I contemplate my own Autism diagnosis, how many more people do I have to convince? So, I am hesitant to bring things up with people I know unless I trust them. Friends: Talking with other people, it's that aspect of having to convince them that stopped me. It's just me, quirky ol' me. I tend to feel diminished when I do have to educate and explain.
29. Just not being clear on how to get tested for a possible diagnosis. When I signed up for an appointment at my University, I assumed it would be with a psychologist. I didn't realize any family doctor could do an assessment and diagnosis. Also, associated stigma, having co-existing disorders, and not fitting into the traditional archetype usually associated with males, were barriers to my seeking a diagnosis.
30. Adhd seems to quite a prevalent condition. Any extra supports, outside of a general practitioner's care, such as mental health support is not easily attainable and carries a huge financial burden.
31. I struggled to get a diagnosis, even before I thought it might be ADHD. I was struggling with my mental health (due to untreated ADHD) and faced the "labels" are negative bull tweet. In crude terms the "System" is the problem. The lack of accountability, the arrogance of many within the "System" and how they ignore the very people they are providing treatment for.
32. I'm 37 and just found out about my ADHD from my Psychotherapist. I am 1 yr postpartum and showing more intense symptoms, so that was how we found out. I now realize why I had so much trouble at every job. I always brought ideas and innovation but never finished a project because of the finer details. The listening to people I never even realized. I could be listening but not really listening, causing stress to personal relationships and friendships.
33. The only reasons I received such early diagnosis as a woman was due to: 1) my dad and brother being formally diagnosed so they had the family history to suspect it 2) my mom worked within the schools so they listened to her/trusted her opinion 3) I had very very stereotypical, noticeable symptoms. My entire life I have been told I have ADHD but I do not remember being tested, and think I was actually informally diagnosed at a young age but only received a formal, written assessment diagnosis when I was around 12-13.

34. I didn't know adults could be diagnosis. Felt lost after getting the diagnosis. It was always joked about by people around me.
35. Generally my doctors in the past were unfamiliar with adhd, except for the stereotypical characteristics. Even though I was referred by a female doctor eventually, I had to push for the referral.
36. I ended up paying out of pocket for a private diagnosis through talkwithFrida.com (wonderful and very validating to deal with!) as I felt my primary care provider did not take my concerns seriously and was hesitant to provide referrals to assessment or medication
37. Professionals thinking my symptoms were just caused by depression, life events, or that it was a symptom or connected with my epilepsy
38. Girls didn't behave the way I did
39. I'm 66 ADHD wasn't a diagnosis available during my childhood. So much trauma from acting out, bullied, abused, assaulted etc, etc. Later it was the cost. Now at 66 I finally understand the range of attributes were all ADHD. Very enlightening and empowering. It's never too late.
40. Paid privately; 2+ year waitlist for public diagnosis; Even when diagnosed, faced barriers to ongoing support from multiple GPs - GPs will give out anxiety/depression pharmaceuticals but even with TEO formal diagnosis, I've had two GPs not believe the diagnosis and not want to help me manage the medication
41. No doctors available to do assessment
42. a lack of knowledge of how to get an assessment as an adult.
43. When I was in university I self diagnosed with ADHD and went to a (free) medical professional for help because I felt it was negatively affecting my life. I saw him once and he told me I had dealt with it up until this point so he did not believe I needed any support. He never followed up. I was new to navigating the medical system and was no longer under my parent's medical plans, so I did not think I had any other options for help.
44. Most importantly it was completely unrecognized throughout my childhood and through adulthood until I started to investigate ADHD because I suspected my child to have it. Once I became more aware, it took 3 years of advocating for myself with my GP before they would provide me with a referral for assessment. I believe this was largely due to having a history of depression and anxiety (which was likely secondary to the challenges I was experiencing from Adhd) so my GP thought I was just "being anxious".
45. Access to appropriate psychiatrist. Can't afford the online diagnosis sites
46. No one thought girls could have ADHD, then I was too smart to have ADHD then when I finally sought diagnosis luckily I had the money and access to a professional who would dx an adult. Apparently those are rare and we forget there is a huge generation of people like myself who weren't diagnosed and now are aged out of any kind of support diagnosis or intervention.
47. I had to pay for my first diagnosis in Vancouver. I had one Dr tell me I wasn't ADHD. Later a psychiatrist confirmed my diagnosis.
48. Dr disbelief
49. My doctor wrote me off because I had great grades in school, he said if I had ADHD it would present as a learning disability. I sought another doctor through my university, and it was a very long process to get medicated and diagnosed because many of the doctors at TWU only practice on "youth" (up to 25 y/o) and the doctors who affirmed my adhd were only available in the school year when I was busiest.

CARE/SUPPORT AND SERVICES

We're interested in the types of support and services you've accessed, evaluating their effectiveness and identifying gaps in current provisions.

13: Do you have any challenges in accessing support services for ADHD? 61 out of 62 answered



14: We are sorry to hear that. Please share with us the biggest challenges you have faced or continue to face in accessing support services.

49 out of 62 answered

1. Medication, even with decades of adjustments and changes, has not been able to adequately reduce or relieve my symptoms enough to function adequately day to day, and most medications exacerbate my symptoms or have severe side effects that are intolerable. My early struggles with anxiety triggered frequent chronic bouts of severe depression, and I have been suffering since with debilitating mental health issues that have caused me to fail repeatedly at attending university to complete my degrees for teaching or early childhood education - my passions - even part-time as a 'student with a disability'. Despite decades of persevering, I have been unable to work full time, and struggle with even part-time employment without burning out. I always start off with incredible performance, and then gradually wear down until my employers are fed up with my increasing absences, lateness, and mistakes made due to poor executive functioning. I have attended numerous free classes and groups on CBT through the years, gone for counselling and worked with a number psychiatrists for the limited number of visits allowed for free through mental health services, trying to become stabilized enough to maintain regular employment, but I was eventually encouraged to apply for CPP disability in my early thirties to help reduce my levels of stress, as I had recently become a mom, and my symptoms had become unbearable. With my current mix of medication, my anxiety and depression are usually adequately under control as long as I am careful to keep up with my self-care and avoid stressors. My ADHD is not under control, though, and I struggle to function day to day.
2. Financial
3. There aren't any other than your society.
4. I have been denied for everything I applied, and I don't even know if my doctor is actually sending because she conflicts with the other doctor diagnosed (I have two family doctors)
5. I would like more mental health supports. Even a group therapy session for adults with ADHD
6. I had to convince my family doctor to give me an ADHD medication rx
7. a good example is only finding out about this advocacy group just now - diagnosed two years ago.
8. There is no financial assistance for ADHD and counselling is expensive.
9. It took some time to convince my doctor. Refilling my ADHD prescription is a challenge because it can't be renewed until the day I run out due to insurance.
10. There are no 'true' services for ADHD. There are no accommodations in the work place, no acceptance or understanding of executive dysfunction, and no support or assistance for adults with ADHD
11. medications

12. Biggest challenges are financial. I've worked with a coach for a while but it's not sustainable. Even the online apps that would (allegedly) help are expensive. I have no extended health benefits so the meds also add up.
13. Accessing knowledgeable experts regarding adult adhd, late-age diagnosis, common ADHD comorbidities with disordered eating, addiction, intestinal disease and hormonal balances particularly with those experiencing menopause. It seems that most resources are for parents and children and center around education.
14. I had to fight to get the right medication people think your pill seeker
15. Beyond my family doctor helping find medications, everything else including much needed counselling services are an expensive and out of pocket expense. I have also tried hard to advocate for getting the disability tax credit but have been essentially laughed off despite my severe ADHD, anxiety and suspected autism diagnosis which prevent me from being able to function fully or work more than 24 hours per week without major burnout.
16. My life has been on and off in a "special way" now after so many years I understand the reason.
17. I am an adult and most of the supports are geared towards kids.
18. Unsure if what supports there are for an adult female or how to gain access to them.
19. ACCUPUNTURE covered services- help to manage nervous system
20. Access to an ADHD Coach due to lack of government support or funding
21. They are hard to find. Self management apps all cost to subscribe.
22. The only specialist in BC has a tremendous wait list, and when I met with him (one time only) all he seemed to have time for was to refer me to the resources on his website.
23. Lack of Dr's willing to provide medication. No free counselling
24. Accessing medication is incredibly difficult.
25. There are none for adults.
26. There are no support groups for just men in Canada for ADHD. I don't have many guy friends either. If there is anything support group wise out there, I know I'd have to pay out of pocket for that and we can't afford that.
27. I do not hve a doctor. I used to get my medication from a clinic but 3 years ago they decided they would no kong preselceibe stimulants to walk ins. I've tried other walks in but they have told me to get it from my regular walk in, which no long prescribes to walk on patients. I've tried everything to get a prescription. It has drastically affected my self esteem
28. I don't have a doctor and the one walk in clinic in town doesn't deal with that. They have told me there's a facility in Victoria but they aren't taking new patients at this time.
29. Finding free coaching and therapy ongoing (other than when I was a grad student). There don't seem to be many services available beyond medication. Currently I am having challenges applying for my Disability Tax Credit, as my doctor wrongly believes it's only for more severe conditions "like schizophrenia."
30. Lack of awareness about what's available for adults especially 50+ when diagnosed
31. I don't know where to start, what's available to me and where to look.
32. Seems like the only people that get any real help are those with money
33. Money! Those with the means can access the treatment.
34. No one is helping me get care or medication. I need help! I was told I have to pay for assessments and services but I cannot afford that. I'm on maternity leave!
35. I do not receive any supports whatsoever. As a child I only received minor in class supports and was more-so treated as a behavioural problem/disturbance than a hyper kid who wasn't trying to be disruptive.
36. Other than medication, I don't know of any supports in my area.
37. There are not many care providers who are affirming, familiar with adhd and/or neurodivergent themselves, and then if there are, they are in demand and wait lists are long.
38. I live in a fairly small, rural community and we do not have support services for adults with ADHD available, only for children and youth.

39. No support or services for adults over the years. There is CADDAC in Ontario, but I've found they don't have much support beyond information about ADHD. I'm looking for tools, how to implement changes in my daily life such learning tools on things like organization
40. Lack of accommodations
41. Nothing available
42. lack of knowing where to go and being aware that there are supports outside of medication
43. Stigma and lack of understanding-- many people still say/think that ADHD is not real, or that it is over-diagnosed and over-prescribed which is a major problem for being able to disclose and request supports. My own boss once said openly in a staff meeting that "ADHD is not a thing, it's just anxiety". There are not enough (any?) specialized supports such as OT or support workers/coaches to help people figure out the ways that ADHD is dis-abling them in their daily lives and to help find interventions and strategies that actually work for them (individualized, not just "10 ways you can stay organized" from pintrest or something). And then, if we did have those kinds of specialized supports, there is no funding/subsidies/coverage to pay for them (other than if a person is receiving Disability Tax Credit which most are not unless they also have other diagnoses).
44. Affordability. Availability in my location
45. Im too old, period. There are no supports for me.
46. Being self diagnosed is not recognized in any organizations
47. Well, actually, I don't. I am an ADHD coach, but so many of the women I talk to cannot afford coaching. I think this is a real shame.
48. Working in education where it is believed this is not an issue in females.
49. I mask and function as a "normal" adult so I'm not considered for supports or extra assistance. When I have asked, I have been told "you seem like you can handle it." Which usually leads to burnout and my mental health suffers greatly.

15: What made the support services accessible to you? 8 out of 62 answered

1. Wait times. It took me 2 years to get an appointment with a specialist to do an ADHD assessment
2. in my work, I have many resources for neurodivergent children, and have learned A LOT through my work place. But would like to learn more of adult services, which are harder to obtain that are provincially funded. I did find a local CBT group through a referral from my GP that is covered through MSP, that is yet to start.
3. I haven't yet accessed any formal organization with regards to assistance. I'd also like to note that I didn't answer a few of the questions because a simple yes or no did not effectively or efficiently describe my answer to that particular question. It kind of reminded me of like a lawyer that wanted to have a yes or no answer to a question that was extremely more complicated and definitely more detailed in nature
4. Haven't specifically sought any out.
5. I had a good psychologist and a speech pathologist. I had support once I got my diagnosis.
6. I paid for them. I am now mature enough, self aware enough to cope well, and have wonderful friends and family.
7. Money
8. Online, Reddit forums always active and available, friend who have been diagnosed as adults, my university offers ADHD support groups

16: In your opinion, how do you think some of the challenges you've experienced could be addressed? 62 out of 62 answered

1. Just like AA or other ongoing support groups that are easy to attend regularly or find and drop in on in times of need, we need this for people struggling with executive functioning, to help support and teach us strategies for coping and succeeding at performing basic daily tasks without getting distracted, overwhelmed, and hopelessly behind in everything.
2. Information made more readily available - and GPs being willing to share free or low cost services or otherwise rather than pushing costly medication routes - and pharmaceutical agendas
3. More awareness and testing
4. Earlier recognition
5. A location where I can physically go to ask for help and find what support I can ask. Plus financial support for medication and therapy
6. Actual programs for high functioning adults
7. Trusting patients. Doctors being better informed. Having more professionals able to diagnose ADHD
8. better education about the disorder in all areas: medicine, education, businesses
9. Treat ADHD as seriously as other neurodivergent diagnoses and put more research into presentation in females (especially adults). Many adult women are only finding out now in their 30's and 40's that the reason they have struggled so hard is because they are undiagnosed. We were never even considered for ADHD as kids because the "profile" of a kid with ADHD was a hyperactive boy with impulse control issues who couldn't sit still.
10. laws and policies around prescription renewal for controlled substances used to treat ADHD should be changed.
11. By actually supporting adults with ADHD in the workplace
12. seeing a specialist who understands my needs, not a general psychotherapist who sees everyone in 3 different communities/doing basic work
13. I feel like because I am not a kid in school (I did well in school because I liked school so could focus on it and excel easily but in subjects I did not like like math I struggle all the way through horribly, it was like trying to learn to speak Chinese and having to read characters that are not even in an alphabet I understand) there are no resources and they don't care and would rather just try to push meds.
14. To make the disability tax credit more accessible to those with ADHD - the bar is very high to qualify and I frankly don't have the bandwidth to deal with the application process
15. Increased accessibility to medical professionals for timely diagnosis as well as treatment. Not having a GP means not having access to medication due to the stigma associated with stimulants. Losing a GP often means losing your mental health and access to your medications. Awareness campaigns that target myths around ADHD and the supposed "everyone has it" phenomenon, resources with gendered perspectives, resources specific for those diagnosed late in life. Having better access to these resources would help with feelings of isolation.
16. Access to low-no cost services. Shorter wait times for diagnosis. More research on women and ADHD
17. better education for doctors
18. Having an organization available that can help you traverse the difference between situations where you have not taken the responsibility for the choices that you made opposed to having actual barriers because of the way you learn and the way that you process information. To learn to understand the difference between the two or if there is in fact a difference between the two
19. Having counselling services available for lower fee AND by counsellors trained and proven to be supportive of ADHD clients (in my many years it took countless ones until I found someone who legitimately understood, empathize and helped me instead of just giving me solutions that would only work for neurotypicals).
20. I think so

21. I would love more groups - like accountability circles, getting organized, so you want to be an entrepreneur but you have ADHD, talking through emotional impacts of ADHD
22. I'm unsure. I hate having to explain my ADHD and am also worried about the stigma behind volunteering that information to those that don't understand it. It's very overwhelming.
23. Better education, breaking down the stigma around ADHD, better non-medication supports.
24. covering some therapies or OT
25. Give adults with invisible disabilities (ADHD, etc.) the necessary support such as ADHD coaching, just like giving a guide dog to a visibly disabled adult person.
26. Offering bursaries or benefits coverage for self management apps and mental health supports
27. A school-age diagnosis would have made a significant difference to my life.
28. Counseling groups for free
29. Increase the amount of family doctors, continuing ed for doctors to increase their competency regarding ADHD medication.
30. Add supports for adults.
31. The government and organizations need to do a better job at advertising what is available and making services available to a wide range. The sense I get is that the typical vulnerable population is addressed first but then everyone else must beg for a service. If there is a service out there, it's poorly advertised, and you have to know OF that group as opposed to that group making themselves known to the general public. Government agencies should aim to reach out to everyone, not just stop part of the way.
32. I need a doctor. Or at the very least, a walk in clinic that doesn't make accessing stimulant meds impossible. Even Telus health won't write a prescription for stimulants.
33. I have read that medication makes a significant difference.
34. More education for family physicians. More support services in the context of mental health for ADHD.
35. Make it easier to get assessed
36. Make services more accessible and covered by BC MSP
37. Long wait times and expensive
38. I think that psychologists would be beneficial at a lower price, so that people of all walks of life can experience a diagnosis.
39. Educate physicians, therapists and pharmacists about services
40. More readily available information. In Dr's offices, work places and schools.
41. Free access to all
42. Yes.
43. Getting diagnosed when I was a child when this started could have saved me a lot of stress and anxiety all my life.
44. I wouldn't know, I don't have a basis of what I should've received to govern what was lacking. I'd say having teachers understand ADHD, burnout, executive dysfunction, etc and not have it treated as an individual and educational failure would be a start.
45. More awareness about ADHD. People that don't have it seem to think it's all fun and games but don't realize how difficult it is when you live with it.
46. I would like more health care providers to be educated and affirming, even my massage therapist said to me that everyone is a little adhd, and my dentist did not seem to understand my struggles with dental hygiene are related directly to my adhd.
47. More open dialogue about different presentations of ADHD/ADD to decrease stigma. More education for primary care providers. More coverage for supports through BC Medical Coverage
48. 1st not being in the DSM as it's NOT a mental health issue. It's neurological based. That's similar to putting epilepsy in the DSM as some epileptics also struggle with the same or similar symptoms. And is also common to have depression as well. 2nd. Also focusing on the many strengths associated with ADD/ADHD. 3rd many family doctors are still clueless that women can have this, the difference in how it presents in women vs men (or girls vs boys). To have testing

covered by provincial health coverage. To have treatment covered - as long as by a certified clinician, etc. SO many more answers but too little time

49. Inclusion would reduce the barriers that exist when you have a disability that people can't "see".
50. Be more aware that girls present differently. I think the shame and people pleasing trauma is more acute in females. They can also go unnoticed because they mask their symptoms. For example I often lied to cover the shame of some of my impulsive blurts or actions. Research compassionate therapies and nutrition more. While drugs can provide real relief, not enough research and care ever goes into any 'disorder'. Also, provide more opportunities for enrichment. ADHD and giftedness often go hand in hand. The ADHD kid will often get 'in trouble' as I did, because they complete tasks faster and are BORED.
51. Better doctor education about ADHD; teach them to be more willing to work with patients to manage medication; it is simple - listen to the patients experiences, offer opportunity to try different medication; this is the same for ALL medication. Why is ADHD medication different?
52. Need free therapy and medication for adhd, just as there is for cancer or long covid etc
53. general knowledge of ADHD as it is shown in women/persons raised as female.
54. I think more education at a high school level should be taught to students (by a professional, non teacher) Maybe an optional school assembly outlining common struggles other youth have and where to go for help. When I was a teen I didnt know that what I was struggling with was something that could be helped - I thought everyone was just coping better than I was.
55. Maybe having organizations like this one and CADDAC, and other specialists such as Kelty/ADHD clinic at BCCH do workshops, speak at events, conferences geared towards physicians (GPs, pediatricians, etc.) to get them up-to-date on research, interventions, lived experiences about ADHD. I think there is too much "preaching to the choir"-- more work is needed in the spaces that do not acknowledge the issues and challenges. Support groups are great too though!
56. A list of resources available in mu area. MSP to cover online diagnosis
57. Have more supports for older people too. I suspect I have autism as well and currently there are no practioners in BC giving adults a diagnosis. So that sucks because Id like to go to university but Ill need accommodations but guess what? No accommodations unless there is a dx.
58. Doctors with more compassion and more understanding of ADHD, undiagnosed ADHD adults and the medication
59. Coaching and counselling
60. The only way is with gentle confrontation
61. More education on ADHD, especially for GPs. We are continually discovering more about ADHD and it's presentation in women, and I was overlooked because I didn't meet the "standards" that are attributed to males.
62. If ADHD was not stigmatized or told that the symptoms don't last into adulthood. If anything, they've got worse with transitioning to parenthood and working fulltime. The assumption someone is able to function normally is my biggest obstacle as I've always been taught to "prove them wrong." Instead of "how can they work with me. "

17: Have you interacted with any of the following MCFD departments for support or services for ADHD?

61 out of 62 answered

	Yes	No	Don't know
Child and Youth Mental Health	6	52	3
Child Protection Services	1	56	2
Child and Youth with Support Needs	2	55	4

18: If you interacted with CYMH and/or CYSN, what were your experiences?

28 out of 62 answered

1. I grew up in Ontario, so accessed support for myself as a youth through their systems, specifically NCYC, which seems to not exist anymore.
2. Education opportunities
3. None because I was told there is limited to no supports for children with ADHD
4. I've interacted with them on behalf of my children for their anxiety and ASD. Never for the ADHD.
5. N/A
6. I should note, the year I was diagnosed. I was working in administrative role for mcfd. It was notable the lack of awareness and education that social workers had around those with special needs.
7. Misdiagnosed with depression and anxiety by psychiatrist through CYMH in early 2000s. Requested records through FOI request to gain insight, very little to no case notes or file documentation was made. So it was hard to use this to make a medical history for my mental health.
8. I find child and youth mental health has very limited resources. I have two children with ADHD and they have been a very little support aside from getting us diagnosis. For the first time in almost 10 years this year we have received support by way of a DBT group
9. Although I can learn letter identifiers to mean a full sentence of words. Whether they are an acronym or, The other one I can't remember at this time. I actually don't know what you're referring to with the letters about. A friend gave me the pamphlet and encouraged me to complete this survey. So with regards to the letter identifiers I either did not understand I needed to pay attention, and or, I don't have enough experience to understand what their letters were supposed to mean.
10. Not applicable
11. I don't know if these answers are for me or my daughters?
12. did not interact
13. None
14. N/A, diagnosed as an adult.
15. Not applicable.
16. na
17. This is just for me and I've never been through those groups
18. n/a
19. No
20. They helped a bit in advocating for better accommodations within the school system/my IEP but even then it was minimal and only to the extent it could be done silently and within the classroom. Most of the accommodations I received, the responsibility fell on me to self-serve/administer. MCFD never personally addressed my ADHD in a clinical/therapeutic setting. They focused on my other issues like anxiety.
21. I have 2 children with autism but have not accessed the supports for ADHD. CYSN workers have never been helpful for me and change so often.
22. N/a

23. Have not interacted on a personal basis as I am too old to qualify for these services.
24. I was a CYSN Social Worker for 3.5 years....i know there are zero supports for families with kids with adhd. There is barely support available for CYSN eligible children .
25. n/a
26. Terrible. Lots of parent blaming and very little follow up. They only offered parent groups that were being run during daytime week days (working hours) and these were groups for supporting emotion regulation. While learning about how to co-regulate with our kids is certainly important, it is not always the issue at hand for kids with ADHD who are struggling. They need more therapeutic validation for how hard it can be for them to manage in a neuro-typical world (especially school). The answer isn't always teaching parents how to de-escalate a meltdown. I cannot stand the one-size-fits-all approach at CYMH. It is not a useful service for the children and youth who actually need it the most.
27. N/A
28. Asking for support and receiving none.

19: If you have had interactions with Child Protection Services, could you please share your experiences with us? 26 out of 62 answered

1. I have not.
2. None
3. none
4. N/A
5. N/a
6. No
7. Okay so now I understand you're saying child protective services or something like that. I'm probably much older than the average individual that would fill out this form. I do not have a challenge with this organization knowing that I am 60 years old. When I was a child my mother took me to a psychiatrist. If I was on any medications at the time I am unaware of them and I don't remember them. I don't remember what I talked about with the doctor other than vaguely remembering looking at pictures of ink blots.
8. N/a
9. No
10. None
11. N/A
12. Not applicable.
13. na
14. Not applicable in my life
15. My children were removed from my home to their father's when things were getting out of my control
16. n/a
17. very negative. the very definition of "shot first, ask questions second" mentality.
18. No, but a social worker once did interview me within the school when I was around 7 without parental consent for no known reason/report and my mom had a field day with them. I also definitely didn't help the situation because I, as a young kid with ADHD and no filter, told them I wouldn't respond to them because "my mommy told me that you guys take kids away."
19. Had MCFD called when my children were young because they were loud and had lots of behaviours. Neighbours don't what was going on or that they were neurodivergent. My son was first diagnosed with adhd and then later the autism diagnosis was added. There were no supports I knew of for adhd. Kids can't even get an IEP based on an ADHD diagnosis.
20. N/a
21. N/A

22. I was an MCFD child protection social worker for 13+ years. There is little understanding about ADHD in general.
23. n/a
24. When my son was born we were contacted by CPS due to a medical issue he suffered. It was unrelated to my ADHD diagnosis
25. n/a
26. N/A

20: Have you ever considered entering into a voluntary care agreement with MCFD, or have you ever been placed under an involuntary care agreement or similar arrangement with MCFD?

32 out of 62 answered

1. No
2. No
3. No
4. No
5. No
6. no
7. No
8. n/a
9. No
10. Again I'm aware that the letter signify something. If I answer honestly I'd have to say I don't really know what you're asking me, but I do know that I could stop the survey and look it up and then, . Give you the impression that I was aware of it at the time of doing the survey specifically.
11. N/a
12. It's possible
13. No
14. N/A
15. No.
16. I'm not familiar with voluntary or involuntary care agreements.
17. na
18. Not applicable in my life
19. No
20. n/a
21. No. MCFD is the problem. Mental health should be separate from children services. Especially for those within marginalized groups.
22. I do not know what that is, so no
23. No
24. N/a
25. No
26. NO. Foster care does not NOT fix children. The system is so broken, it's beyond repair.
27. n/a
28. When I was in university I was struggling so badly with my mental health that I considered going to a location to help me. I talked myself out of it because I didnt think my problems "were significant enough"
29. No
30. Never
31. N/A
32. no

21: Please indicate if ADHD has negatively affected any of the following areas for you or your child/youth. 62 out of 62 answered

	Yes	No
Employment	52	9
Education	56	6
Mental Health	61	1
Physical Health	50	9
Justice	16	36

22: For any of the areas where you indicated 'Yes,' please share more about how ADHD has affected you in that aspect. Please feel free to include specific stories or details that show your experience. 50 out of 62 answered

1. I did in earlier responses.
2. My adhd was undiagnosed for many years and came about following an extended period of burnout.
3. Binge eating, easily distracted and not able to retain what I should be listening to
4. Always in trouble at school and work. Trouble making friends, keeping relationships
5. Mental health services that would be covered under our medical program
6. adhd, undiagnosed, essentially destroyed my life in all the indicated areas. Unable to finish college, poor experience in University (graduated... barely), multiple failed marriages and relationships, inability to create a career path or to remain employed, inability to cope with retirement which led to my diagnosis after years of being misdiagnosed for depression, anxiety
7. Employment - I have never had medication for ADHD so I have always struggled to stick with tasks and apply appropriate amounts of detail which has made working in certain professions extremely difficult. Education - I have always done well in school (another reason I was overlooked) but struggle so much with the traditional lecture format. I can't listen and take notes at the same time which means I can either listen (and forget it all later) or take notes and not understand it and have to teach myself through extensive textbook reading, YouTube videos/tutorials etc so it takes me an unreasonable amount of time to learn and study. Mental Health - I have had sever generalized anxiety and depression and suffer from ptsd. I have tried varieties of medications and antidepressants which have made my ADHD worse. Now that I'm on the correct medication, I am better able to understand and mitigate downsides.
8. I'm reasonably smart, but completed an easier degree at university because my ADHD made it impossible to concentrate. I have dealt with shame at work repeatedly when I've dropped the ball due to my ADHD. Untreated ADHD has left me with persistent anxiety.
9. Employment: I have been overlooked for promotions I have been more than qualified for because I do not 'fit the norm'. Education: has always been incredibly stressful due to my executive dysfunction and although I am incredibly intelligent, I do not appear so because I am late/forgetful/absentminded/inattentive/etc. Mental Health: I spent my youth, teen, and early 20's in various states of anxiousness and/or depression due to the fact that I didn't fit in and struggled to connect with my peers. My diagnosis led to an immense amount of relief, as I finally understood my brain, but also a sense of loss at what I had missed out on in my younger years, as I had strong feelings something was wrong with me, when in fact I was just wired different. Knowledge is power and I esent not having that power as a child.
10. Once I had a job, I locked my keys in my car three times in one week and was too embarrassed to tell them. Who would believe that someone we uld do that who otherwise presents as capable? Education I've always had to do part time. I dropped out of school in grade ten but was able to get more secondary education when I was older. Took 8 years for me to get my degree.
11. I've have a hard time holding a job. I never finished school. I have had depression and felt crazy my whole life. I am extremely unorganized

12. Struggles with math all through elementary to university even though I was honored roll in everything else, I had to change the degree I wanted which would have set me up with a job because of 1 math class. I spent many nights at the kitchen table in tears with my dad trying to help me (he gets math easily). So it is not that I am not smart, I am very smart I just can't stand math and so can't focus on it and therefore cannot figure it out. I also struggle with depression, anxiety and have been diagnosed with PTSD and have a permanent disability because of it, so add ADHD in there when you are depressed or going through an unnecessary fight or flight response and it is just a recipe for nothing to get done and me to fall apart.
13. I find many people simply don't believe ADHD is a real problem. The problem is laziness, flakiness or any other number of personal shortcomings.
14. I also have Crohn's and I have a really hard time remembering what I can and cannot eat and controlling my urge to eat things that I know I shouldn't. I have a hard time at work. My work needs to be tailored to me to be able to keep me interested.. I suffer with anxiety. I suffer with mental health issues and self-esteem..
15. Employment: ADHD has affected me in every aspect of employment. I've always struggled with work, I have never had 1 clear idea of what I wanted to do for work and any ideas I did have, I never had a coach, or anyone coach me how to be better. I've been fired twice, laid off twice and mutually separated with 1 employer. I've been bullied and harassed at many of my jobs. Trying to start my own business has been tough as well, I keep putting it off, ADHD is part of this, rejection is another, feeling validated is another and so many reasons in my head keep popping up and stop me. In specific jobs, there are details that I would miss because people aren't clear with their expectations. I am magically supposed to know everything that someone is looking for, instead of following a standardized process. I have gone into managers offices and told them point blank their mistakes because of that sense of justice, black and white, right and wrong sense I have. I found ways around this by coming up with my own work processes and also leaning into automation to automate my work. I also struggled to convey my ideas, not realizing that the way my mind works, confuses people. I think in terms of a mind maps, connections that I make I understand but I have to explain these connections to others. People think I am the crazy one. One thing I noticed is that anytime I bring up bullying or harassment in a work environment, there tends to be a lot of victim blaming and I am being forced to look and see how many actions contribute to the situation, not what the bully did. Education: ADHD has affected me in every aspect in my education. I always struggled in school. My grades were usually C or C-. My mind would just wander, I could never focus. There were very few classes that kept my interest. I struggled with all my life, to the point where I wonder about a learning disability, I know I have one, just which one(s). I was never the troublemaker in school, I wasn't hyper, I always flew under the radar, I was just told to try harder and better luck next time. Mental Health: ADHD has affected me in every aspect in my mental health. I have anxiety and depression. This is the result of trauma, being bullied, whether at school, at home or at work and traumatic events I've been a part of like plane and car crashes. The bullying at work destroyed my self-confidence. Physical Health: ADHD has affected me in every aspect in my physical health. ADHD is part of the reason that I have struggled with my weight for all my life. I've been obese and I've been very fit. ADHD does not give me a middle ground, I am never satisfied with 1 lap, it has to be 2. When it comes to food, I feel like I'm an addict, I can't just enjoy 1 Slurpee, I need more than that. I did develop a non-alcoholic fatty liver as a result of the life I've led but so far diabetes has not emerged. I can never just be comfortable in my own skin, I have a poor self-image of my own body and regardless of how much or how little I weigh, I never have a positive body image in my head. Justice: I've never been arrested for anything and never been in front of a judge or to court (thank goodness) I know my ADHD caused 1 car accident. Someone in front of me had stopped in a yield, I expected them to go, they hadn't, and I ran into their bumper. My brain impulsively got frustrated and I went, even though I told myself to stop. That affects my insurance and driving record. The person wasn't hurt but I wish I could have stopped myself.

16. Most notably, the lack of updated education and training for medical professionals on ADHD is harmful. The overwhelming majority still operate on myths about the condition and neurodiversity in general. Lived experiences are not given much clout. There is so little understanding around how ADHD interacts with other medical issues mentally and physically. Currently I am trying to finish a master's degree, but have been banned from accessing further student loan funding because I didn't have a diagnosis during my undergrad for the monies that were borrowed. Had I been diagnosed in previous years, I would not be designated as restricted due to receiving too many months of repayment assistance - assistance that was needed due to chronic illness and ADHD. I am trying to appeal that designation, but it's been a terrible experience and the National Student Loan Service Centre seems to have disregarded.
17. There's barriers in all areas as most structures and systems are built for NT people. Until there are options in place for Nad's it will always be a struggle.
18. I have always been made to believe that I am "different" and this has affected many relationships from coworkers, supervisors and friends and family. I had been made to think that I was just a "unique" person and many people just didn't like me. Now I realize with my adhd diagnosis, that I was masking to fit in. Had I known of my diagnosis when I was a child, perhaps I would have been able to maintain better relationships and hold jobs for longer periods of time. I had young parents who thought it was my job to apply myself as a child, so now I am an uneducated and overweight adult trying to figure things out on my own as I support myself in my independence. Had I been able to apply myself as a child, perhaps I would have been able to educate myself with bursaries and/or grants and now I feel helpless to obtain an education as I can't afford it and need to continue working full time to support myself.
19. The reason that I checked know for all of the questions that you asked, is because I believe I have learned that the majority of the challenges in life are ones own responsibility to manage. It took far too many years then I'd like to count to get to the point where I understood some of these concepts either because of the way that they were being presented to me or for some reason my inability to retain the information and to connect the dots. I believe in some of these cases my workaround has been learning the information understanding the information hopefully from the perspective that the individual writing it would like to have me answer it based on the average expected outcome to have me seen as a rational competent individual. It took me a while to learn the difference between learning and understanding a topic opposed to offering the answer that is most popular to gain a more desirable criticism from the individual marking the test or exams to get the certification. Sometimes set aside what I think is my personal opinion on the topic. Have I had difficulty getting to this point Yes
20. Unable to work full time hours especially since becoming a mom, which makes it very difficult financially especially when we have to spend so much on medication, supplements, counselling, Occupational therapy for our kids, as well as my husband has bipolar type 2. We cannot get out of debt because of this
21. Barriers are everywhere, I was born and raised in Mexico, moved to Canada few years ago, my 2nd child has born here, I realized since my pregnancy something was different, I got pregnant at age of 44, my daughter was diagnosed when she was 6, pediatrician was not convinced that my daughter is ADHD, my 1st daughter also was diagnosed here in Canada when she was 18 I think, for 3 of us the difficult path has been more difficult for my youngest daughter and mine.
22. being late diagnosed it has impacted everything - confidence, feelings of shame, feeling like I am never accomplishing what i want to do, having goals but no idea how to plan, impacts on relationships with the emotional dysregulation and rejection sensitivity disorder. And how it is always seen as a negative - how much of a problem are you to others - as opposed to looking at the strengths
23. Harder to keep my house in order, focus at work, convince myself to exercise, relax, do things that I'm interested in doing, which complicates mental health.
24. Access to tutoring support for adult education, and access to ADHD coaching.

25. I was undiagnosed during school. Struggled in many subjects. This limited my post secondary and career options. Struggled in jobs too. Got fired or quit because I lacked planning and self management skills. Low self esteem. Bad life choices. Addiction.
26. Ableism is rampant in the education (including post-secondary) system, health care systems, and employment. Getting accommodations is difficult (costly, emotionally taxing, etc) and you are not always granted accommodations despite duty to accommodate.
27. I think my experience is consistent with others my age receiving a diagnosis. Even this survey is odd, as the demographics only differentiate age ranges under 25. What I need as a 50-year old is very different from what a 29 year old needs.
28. Studying, education struggles, depression and anxiety
29. I have had mental health issues and it can be difficult to focus sometimes.
30. Clearly having ADHD is a barrier to focusing and advocating for yourself
31. I am 35 and I have never held a job longer than 9 months. My mental health has always been bad and it just keeps getting worse. I feel like a child stuck in an adult's body with all the adult responsibilities that go along with it and I am seriously drowning
32. If someone wants to interview me about my experiences I'd be more than happy. However, writing at times can be very painful and lengthy process.
33. Education - not being able to settle on a major so took a bunch of random classes. Work - performance reviews always showed how I could not complete projects.
34. I have too many to list. Over 40 years of navigating the world without a dx led to a lot of trauma. Now picking up the pieces.
35. Education is a big one, I was always in trouble and being punished as a kid, I had a designated seat in the principal's office for when I was sent out of the class for being 'disruptive' my entire elementary school experience. I am deeply insecure about being a burden due to my ADHD and fear work/have not ever had a job. As a kid I was excluded from physical activity because I was 'loud and boisterous.' I often was left out of teams in gym due to social alienation. I wasn't on any team sports outside of school because the coaches found me difficult. I also got kicked out of swimming lessons and failed my level 3 swim tests 4 different times because I "kept talking during instruction" even though I was a very strong swimmer. It got to the point my mom took me on hour long drives to other pools to try and take the tests there, only for me to fail again before we gave up and she just started taking me to the pool by myself because I loved swimming but wasn't welcome in any of the swimming classes. Mental health wise, I was definitely a sad kid as I had no friends, I could tell the adults around me and my teachers didn't like me, etc. As a teen I experienced a lot of depression and anxiety from feeling like a freak and trying my best but failing to succeed in classes and in making relationships with peers.
36. I am always in trouble at work for acting too fast.
37. I struggled mostly in post-secondary, took longer than my peers to graduate. My mental health was ignored except for anti-depressants that had more negative side-effects than positive. My employment suffered as I was unable to perform to the expectations that were placed on me. Although I did not receive my diagnosis until after my struggles, it made them make sense finally. My physical health has suffered as a result, as I struggle with personal hygiene and shame over my body.
38. I feel like most of my life I was stuck in this void where I was full of potential but would not be able to fulfill it. The world was waiting for the great stuff that I wanted to do, but then I couldn't focus the work.
39. I have worked with a therapist for many years now and I believe that my undiagnosed ADHD led to an anxiety disorder. I also think it was a big challenge to my mental health because I was not "as good" as my friends and peers. I thought I was less capable and less intelligent because I struggled in areas they did not
40. Criticism, lack of accommodations, lack of understanding, overlooked for promotions, awards etc.

41. Physical - knowing that being active help, yet procrastination and low motivation an issue. Also, I have daytime sleepiness issues, partly related to ADHD (ADD, inattentive subtype), I am so sleepy at times that it compounds the other ADD issues. Employment: being late, forgetful, and especially difficulty absorbing training material / classes which can be a lot of information and/or reading. Also difficult to understand it without knowing the "big picture" as well. Or understanding as well - especially things like learning and applying policies and procedures. Getting extremely sleepy during sitting, being inactive etc during this also makes it worse. This applies not just to work training. Education - I feel so much grief and sense of loss because I am 56 and my learning challenges led to not completing my degree - just need another course but had to quit, plus my marks were horrible. Same in high school. So much lost or wasted potential in my life. Mental Health: periods of depression. One experience of severe depression for at least 2 years. Other contributing factors, but ADHD also made it very very difficult to get out of it.
42. Employment: when I was much younger fired for blurting, problems with reckless behavior and impulsivity. Education: took me 7 years to get a 4 year BA. again, impulsivity led to reckless behavior, especially at the bar I worked at to put myself through school. Hung over alot. Good student but no focus or discipline. I did get it because I was smart. I could have done so much better though had I known what I was dealing with! Mental Health: Always feeling like there is 'something wrong' with me. Lost friends due to blurting then, lots of shame. Physical health. lack of spatial awareness has cause some falls, broke my foot in January because I wasn't 'watching' where I was going. I think impulsive eating also plays a role in the ADHD eater's life.
43. No accommodations available in school or work
44. Already answered in previous questions
45. Undiagnosed adhd contributed greatly to several burnouts, loss of jobs, inability to focus on an education and/or career plans. Inability to focus on exercise/health plans. Huge carb cravings led to 9besity.
46. It is hard to explain everything. I can do really good at a job and then lose interest so I quit and I'm currently unemployed. I could not and did not study or do homework in school. I almost did not graduate high school. My mental health is suffering because I have no access to help with this. And I've forgotten what else was asked how it affects me
47. Just being undiagnosed for so long made everything so much harder.
48. Not being believed and being judged negatively.
49. I was misdiagnosed with generalized anxiety disorder when I was in grade 9, but now that I have an ADHD diagnosis, I am quite sure my anxiety is purely a product of unregulated ADHD. This level of anxiety was harsh during my education, because it always seemed like I couldn't catch up/keep up, and assignments took 10x longer for me to complete than others. My anxiety as a result of my adhd has also been a contributor to a few depressive episodes I've had.
50. I have lost jobs or been unable to keep up with job demands due to inattentiveness or lack of attention to detail. Same issue with education, I struggle to stick to deadlines and struggle with task paralysis. This affects my mental health as I feel I am inadequate because of how my brain functions. I've learned to mask and deal so I can present better to my employer but my mental health is garbage.

23: What help did you seek when misunderstandings or the lack of support for ADHD made things hard in areas like work, school, employment or health? Please share your experiences.

53 out of 62 answered

1. Crisis lines, mental health center, doctor, counseling, psychiatrist, family and friends
2. At the time my adhd was impacting work and or school I did not know that I had adhd. I had never understood my hyperactive brain and RSD and anxiety were from adhd. The challenges experienced were resultant from symptoms I did not understand to be adhd related
3. I didn't. I masked it and rebelled
4. I didn't seek help. just accepted the consequences even tho I felt they were very unfair.

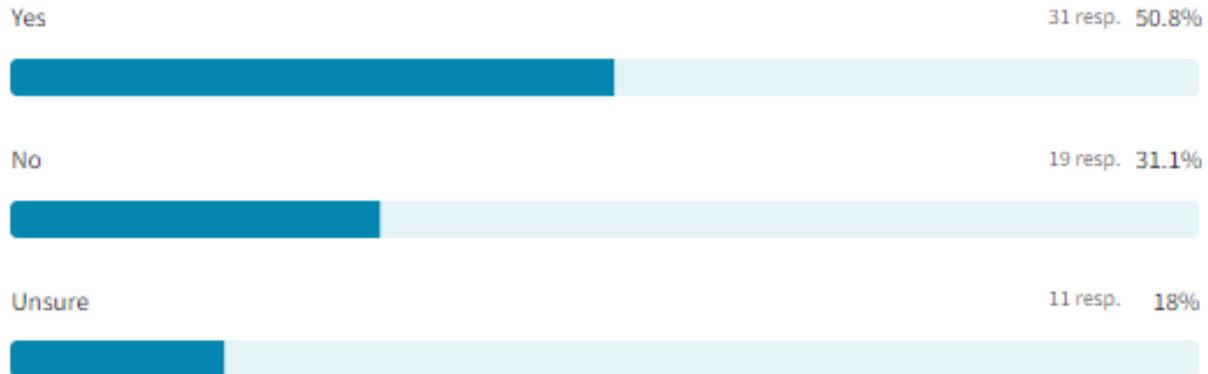
5. Help to be better and not morr barriers.
6. Only recently diagnosed. Still trying to do a lot of the discovery and work on my own. Was told to go to websites to look for help
7. None. I didn't know why I was suffering for most of my life
8. School counsellors, physicians, counsellors, psychiatrists, and psychologists who all missed obvious symptoms. To be fair in my early years I was simply labelled lazy and distracted, then depressed and anxious. I don't think the proper diagnosis even existed when it would have helped me moset
9. None because I assumed it was just me and in my head. No one seemed to understand my struggles and I didn't attribute it to ADHD because I didn't fit the profile
10. none. I just thought I had a character flaw until I was diagnosed.
11. I learned grittiness and perseverance, as I did not get the help I was seeking
12. Felt like my concerns were only from depression, anxiety, PMS, etc. When actually, depression and anxiety were the symptoms to the ADHD
13. None because I can't even get a proper diagnosis.
14. I did not seek help because I was diagnosed so late in life. When I was really struggling with anxiety and depression I sought help from the community health team.
15. Formal diagnosis, personal counselling, and medication (which was a unnecessarily long process due to my physician's personal opinions with male patients.
16. Seeking therapy for the most part
17. For myself, I don't have too much of a hard time advocating for myself. I'm pretty voc.. in regards to my two children who also have ADHD I have had to continually fight for them to get the support. They deserve. It seems the schools are very happy to fill out the forms so they get the extra funding, but they are not happy to actually provide any extra help
18. Because I went through most of my life not understanding that I was neurodivergent the way that I think and understand things and how I process information it was never an option for me I simply found ways to work around it or to mitigate it to be able to be a part of the group or the organization for the short periods of times that I was involved
19. Medication (still not helping a ton), counselling, private ADHD coaching to help me personally and work wise. Alternative medicine such as naturopathic care, essential oils, supplements
20. The way I perceive everything, issues at school, work, health are currently being addressed
21. As an adult, I would say following people on social media who talked about adult ADHD was really helpful for me understanding how it has impacted every aspect of my life. I've also read a tonne of books, attended some ADHD groups through ADDA and one based in Ontario. I'm still learning. would love an accountability partner to have regular body doubling sessions with. Same with health - as I am unmotivated to do the thing for myself, but would if others are. an external locus of control
22. I have not sought help. It's too difficult. Even though my work is understanding for some things, even asking for a privacy or quiet area to work is difficult when they have an open office structure. They have policies for how officers are designed and one request was bounced to 5 people l. Why should I have to explain my needs to 5 different people?
23. Other people's experiences online and their suggestions, medication.
24. I asked help and support from the disability services office of the college. I asked for tutoring support from a non-profit charity organization.
25. Found a Neurodiversity therapy group for my kid. Started going myself.
26. Well, it didn't really exist beyond meds, therapy, and YouTube videos. Still doesn't.
27. I didn't know where to seek help. I was unaware of ADHD at the time. After my children were gone, I ended up on the street and in jail.
28. Anti depressants
29. I read a lot of books while I was on medication. I spoke with a therapist
30. I self advocate by asking questions if I am unclear, so I can get the accommodations I need.

31. I had no help. There was no support for me. I had no one to talk too. For work, I was terrified to act against my bully's and so even when I tried, I talked myself out of it, like I was the one at fault. In education, I only had 1 teacher ever wonder if I had a learning disability, but I never had anyone suggest anything or give me an avenue to pursue, I just thought that I was dumb. I didn't have a name for this until I was 46 and even now, even after all this advocacy, I still don't feel like I have support.
32. Therapy. Help at work is nonexistent due to their lack of understanding about adult adhd
33. I have always struggled to ask for help and have always been over looked because I appear normal on the outside. I wasn't diagnosed with adhd until my 30's but I have always felt like there was something wrong with me
34. self education, submitting grievance through Union, currently have a complaint in with BC Human Rights Board. I didn't get a formal diagnosis until I was 58. Am self diagnosed secondary condition of Autism. Currently not sure if Autism should be the primary diagnosis or ADD. Usually I either quit, dropped out and/or got fired.
35. I didn't know, so none.
36. My mom advocated for me as a kid to try and get me more one on one help from teachers and EA's, in highschool she connected me with MCFD for their help in IEP advocacy. My mom also helped me navigate psychiatrists to get me ADHD med, and helped fight her insurance to cover the more expensive one I needed when every other medication didn't work.
37. None. I was told it was me and I was bad.
38. I didn't know at the time I had adhd, but to save my mental health I switched jobs and fields completely, taking a less demanding position for less pay. My mental health has improved and I have found a family doctor that is supportive and affirming. I do not disclose my adhd at work.
39. I did not know at the time I was ADHD
40. I could not find any support
41. Family doctors in my late 30's and early 40's. One doctor still thought it was just in boys and sometimes in men. No ADD specific place in Kingston ontario. Still isn't. I tried to return to university to finish but tye disability accommodation centre couldn't grasp that I needed support with all the steps and paperwork involved in registering. I gave up. I tried again later but my adhd prevented me from understanding the information. I'm thinking about applying for an accommodation at work, but given the challenges I've had with getting an accommodation for my epilepsy symptoms, I don't know how the adhd request will go over. Plus, I don't want them to know that I have these challenges since I'm about to start training for a management role
42. Advocacy: however, eventually this led me to burnout (I have 5 kids who also have ADHD. The advocacy has been endless).
43. Nothing, masked and soldiered on. Eventually knew to surround myself with people who appreciate some of the gifts than come with ADHD and have compassion for the rest.
44. Trying to access Sickness EI because I need to change jobs. It's dufficult
45. Did research what is available, but not anything that would be enough to make any difference
46. Social Media helped with knowing that I wasn't alone and that I had the ability to reach out and get support and community
47. I tried NOT to seek help because I did not know that I could get help. I didnt know that I had any options
48. I looked for more information through agency websites and other materials such as the ADDitude Magazine, CADDAC. I attended a workshop hosted by the school district that was facilitated by a clinical counsellor with special interest in ADHD (specific to seeking support for my child with ADHD)-- and then I saw this counsellor for a couple of private sessions for further support, consultation, and advice on how to get GP on board with referrals and potential medication trials,, once I had my diagnosis and when I returned to post-secondary I got support for accommodations through the university, have not made any direct requests to my employer although it would probably be beneficial because there isn't really anything concrete to ask for.

49. 8 didn't because I didn't know I had it.
50. There was no help to seek! There was nothing and still is nothing for me.
51. I haven't reached out for help. I don't want to be even more misunderstood
52. My friend was diagnosed about a year before me, she sent me podcasts and research to peruse that has been very informative. I just make sure I educate myself well so that I can educate others so the neurotypical world may understand the neurodivergent world.
53. I have sought accommodation for my education but have been unsuccessful in receiving accommodations for work.

24: Have you experienced suicidal ideation as a result of ADHD or the challenges it presents?

61 out of 62 answered



25: Have there been any support services that have been most helpful to you in managing your ADHD? Please share. 51 out of 62 answered

1. Apps like Finch that help me stay on track of daily tasks and reward me for completion. Hard to focus on making a complete list of tasks, though.
2. Sources counselling was excellent
3. No
4. The book Scattered Minds has been insightful. It is nice to hear that other people have had similar life situations.
5. Just great reading material
6. Did not realize that past incidents were most likely attributed to ADHD, due to my late diagnosis
7. Medication, counselling, education of others
8. Still looking
9. DTC Solutions on Facebook has been invaluable and other facebook groups for neurodivergent moms. I started noticing my ADHD when people started pointing out things about my son's difficulties (also ADHD).
10. No
11. Just chatting with my friend who also has it.
12. Nope.
13. Counselling
14. Counselling and family support
15. this has been a running theme in my life or I just think it would be just better if I just went away
16. This time in life. This particular survey and this group trying to find real answers to why we have such a ineffective approach to helping individuals with psychological divergence, relating to how we learn. And of course experience the world. Does that work could also be replaced with environment etc etc

17. ADHD coaching program and personal counselling have been the most helpful and all at 100% out of pocket cost.
18. No
19. social media, some friends, ADDA, I did have a coach for a bit but that wasn't helpful. now i'm seeing a counsellor who has knowledge of ADHD which is so helpful. I was seeing someone for years before and every thing i spoke to her about, that I was struggling with, was a result of ADHD. When I came across a twitter thread talking about ADHD and saw myself there so clearly, I went back to that therapist to ask for a diagnosis and she admitted she did not know much about ADHD. I just think of the years I didn't need to be in anguish if she had known more.
20. None that I am aware of
21. Nothing formal outside of medication.
22. courses, education free. Acupuncture, exercise
23. Tutoring support, CBT.
24. Podcasts and youtube channels.
25. No
26. No services, I don't have anyone to really talk too other than my wife. ADHD medication and my anxiety/depression medication has been massively helpful.
27. Only the disability services at my university
28. No
29. Business coaching suitable for creative entrepreneurs. Life coaching. Anxiety therapy. Therapeutic expressive arts.
30. No
31. VIHA and Psychologist
32. Therapy
33. Mostly my own systems and coping mechanisms. Educational had accommodations in place to ensure I recieved my diploma like being able to have extended time for tests, written notes, and 1on1 support for organizing tasks in priority and next step action. Since then I have never had the same supports.
34. Certain Counsellors have helped. I am mostly self educated and have researched extensively about ADHD & Autism; not by choice because the "System" has not provided the diagnosis and/or supports needed. I have told the following my various medical professionals (psychologists, psychiatrists, clinical counsellors, different Doctors; adjustment disorder, OCD, BPD, Bi-polar, anxiety disorder, avoidant personality disorder) What is ironic is that the medical professionals that came forth with the preceding "labels" is that not one of them would actually do a formal diagnosis.
35. None yet
36. Medication and having a youth worker through MCFD who would negotiate on my behalf with the schools. The internet has also been really helpful as it has taught me symptoms I didn't even know wasn't normal and given me a sense of community with other adult women ADHD'ers
37. I see a psychiatrist once every 6-12 months to go over how my meds are working. That's it. Doesn't seem like enough.
38. Online resources, like How to ADHD/Jess McCabe
39. talkwithFrida.com and honestly, watching videos on TikTok of others describing their own experiences with ADHD and what worked for them
40. No
41. Peer groups that have formed naturally
42. not really, my colleagues, friends and family are all very accepting and loving. I'm lucky
43. Dr Sarah Adams Vancouver online executive function workshop for ADHD. (Covered by MSP!) CBT and mindfulness support groups through Cognito Health (private). MBSR workshops (private).
44. Medication and time off work

45. Getting a diagnosis and learning about what ADHD is and how it affects people had made me feel less alone
46. I did get some coaching/counselling help through the student services department of my university with a psychologist whose focus was on ADHD/neurodiverse students in the first or second semester of my program and he was extremely helpful. He provided space for me to talk through my anxieties about asking for supports while feeling like I was asking for favors or "special treatment" and helped me to reframe and unlearn some of the ableist thinking. He also provided some concrete strategies to try and offered ideas about how to advocate for myself.
47. No
48. Medication has been somewhat helpful but I could use counselling but can't afford it. Can't get a family dr to get meds now either and no walk-in clinics where I am.
49. No
50. Coaching and counselling
51. No

26: Going forward, what support services or accommodations would help you manage your ADHD? 54 out of 62 answered

1. Answered in previous responses
2. Access to free counselling and support services / I am a low income single parent and suspect that one or both my daughters have adhd - we have not sought diagnosis yet but CBT services would be very helpful for them both and myself.
3. Disability Tax Credit would be beneficial to help pay for counselling supports.
4. Therapy outside of business hours ideally
5. A little bit easier access to medical care.
6. Support children in school with executive function teaching and tools
7. affordable coaching or therapy - at present it is not possible for me to access the help I feel I need simply due to my financial situation
8. More awareness in the medical community. More understanding by the public about what ADHD is and the difficulties/limitations it can create. Funding similar to autism at least for kids because they require additional help and support in school and are currently being left behind because there are no supports budgeted for them. Provincial health coverage for ADHD counselling and mental health/ neurodiversity counselling. Better inclusion regarding disability and support - it may not be a visible disability but it still greatly impacts those affected and their families.
9. I would like diagnosis in BC to be more straightforward for adults and children. All GPs should be able and willing to diagnose and treat ADHD.
10. 1:1 coaching/support in the workplace Counselling Support groups Life coaching for everyday tasks and/or routine building
11. Occupational therapists who come in and help me figure out a game plan to get things done.
12. On going low/no cost counselling services specific to challenges of ADHD including CBT and ACT approaches.
13. Because medical services are so siloed those of us with ADHD have to try to connect every piece together when so many things interrelate. Finding ways to connect health professionals in a way that doesn't burden the individual who is already less able to take on such responsibility is so needed. Counseling has been the most important piece but it is very cost restrictive. Walk-in counseling and brief counseling are not usually appropriate for addressing ADHD, unless somebody is already well versed in their condition.
14. I am currently struggling with my employer and asking for an accommodation to work from home while I seek out treatment to manage my symptoms with my GP

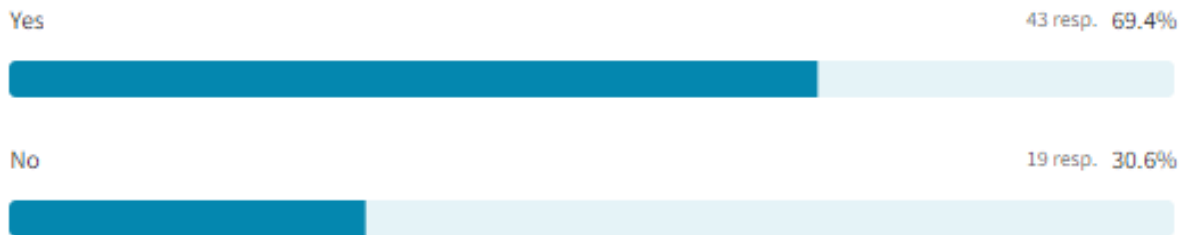
15. Honestly honestly, I would give my left arm to have one on one coaching somebody that I can trust and then approaches me in a manner that I don't automatically do the opposite that they ask to help coach me through the things that I need to be getting done.
16. Having well trained individuals who have either experienced some form of challenges in life, with respect to this particular diagnosis. To be willing to talk to other individuals and help them correct their program if you will. Fill in the blanks of all the different things that they feel they haven't properly learned in life.
17. Having literally anything covered by our provincial or federal government services... Especially counselling and or ADHD coaching and education programs to help support and heal from all the trauma life has thrown our way as a result of not being neurotypical.
18. First being well diagnosed
19. Accountability groups, groups to discuss impacts, groups for different challenges or areas (i'm thinking entrepreneurs). Courses geared towards the ADHD mind - finances, scheduling, turning a goal into reality -- all of these with work blocks worked in. having body doubling sessions.
20. Access to things like: help with taxes, assistance with accommodations for work, assistance with disability tax credit application, etc
21. More community support and education focused on the lived experience of folks with ADHD - while caregivers need support too, the criteria for diagnosing ADHD generally reflects the experience that other people have with us, not our own internal lived experience. The disorganization or distraction is a symptom, but so is the ability to specialize in a topic and retain information, work well under pressure, and empathize strongly. Meet us on our level and everything becomes more manageable.
22. acupuncture, exercise, OT
23. ADHD Coaching and also access to government support or funding for ADHD counseling therapy.
24. Apps or tools to help me break down tasks or motivate myself. A support coach to help me build skills.
25. Awareness is key, especially in the workplace and how accommodations can allow for personal success.
26. Support services that recognize co-occurring conditions such as autism from a non-pathologizing lens.
27. Money for support. It's barely acknowledged, even among third-party medical suppliers.
28. A group for men that can just be a place to talk. It would be good to find some male doctors or counsellors etc...as well.
29. Access to medication. Accomodation of fidgeting would be great too. My job often has meetings and I like to have something to fidget or play with that I'm not trying to hide. A previous job allowed me to crochet, color, or have putty during long training and meeting
30. I've read medication really helps
31. More of the previous answer! But these services easily accessible and affordable (for people with low or very low income). I sometimes spend hours researching possible options, but most things I find are private-pay or DIY courses I don't have capacity for.
32. One on one therapy
33. Knowing my self well. Knowing that there are strategies such as Dialectical Behavioural Therapy and people that I can talk to.
34. Employers (especially HR) being better educated about adhd in adults.
35. Free access to all services available would be a good place to start.
36. talk therapy & some form of Coaching.

37. A free and accessible assessment. Medication that I can take while breastfeeding. Cognitive behavioral therapy. Therapy in general. Some sort of support for school and work.
38. I don't know, I wish there was a list of things I'm entitled to and things that might help me to look into but I've never been presented one.
39. For ADHD to not be seen as a joke. For employers to understand that I do have challenges and am not purposely causing trouble.
40. Counselling specific to late diagnosed women
41. "Training" in organizing, time management, daily living skills ie developing and maintaining routines and habits (I'm embarrassed to share the basic daily things I forget to do. Or I lose sense of time as to when I last did it. Or time awareness... and accountability and follow up after.
42. Recognition and understanding that adhd can be debilitating for many.
43. better diet, i think
44. Free therapy, accommodations that are meaningful at work, no barriers to medication- access to doctors that understand and prescribe without bias
45. There needs to be better screening for ADHD in AFAB persons and then being able to create the specialized resources for children.
46. unsure
47. I would love to be able to have a similar support to the one I received at my university, or maybe through an OT who could offer assessment and periodic follow up.
48. Access to a coach and/or body double. A bookkeeper for my finances. Access to a cbt practitioner
49. I dont even know what could be available to start answering. Access to actual doctors and diagnosis and followup aftwr diagnosis would be nice. Navigating the disability tax credit and applying for disability benefits.
50. Any type of empathy from health care providers. I know I need medication
51. Coaching and counselling
52. Advocacy
53. Accommodations for allotted time and exam procedures in my classes, I also struggle to see movies in the theatre when there are not closed captions on the screen. My auditory processing skills are low.
54. Task management assistance, counselling, noise canceling headphones (like loops), visual updates/reminders app, a life coach to remind for basic necessities

MEDICATION

This part aims to understand participants' experiences with ADHD medication, including accessibility, effectiveness, and any challenges faced. Whether you're currently using medication, have used it in the past, or have decided against it, we're interested in hearing about your journey with medication as a part of ADHD management.

27: Do you take medication? 62 out of 62 answered



28: How does taking medication help you? 38 out of 62 answered

1. It occasionally helps with energy and focus, but side effects make it hard to take regularly
2. Helps me focus and stay on task.
3. I'm still testing
4. Helping me organize my life and function
5. It allows me to hyperfocus on a task and turn down some of the noise that causes distractions and overwhelm/overstimulation
6. Helps Minimize distractions
7. Most of the day, tappers off around dinner
8. It allows me to not act upon impulsive thoughts and stay (slightly) more focused.
9. I am unsure of how effective my current medication is. It seems to help a little bit with reducing the constant inner dialogue/repetitive buzz of thoughts. I have not noticed any improvements with regards to executive dysfunction, memory loss, mental overwhelm.
10. It seems to calm my mind down and slow down my thinking. But it also helps me be motivated for the day and my tasks in ways I couldn't manage without meds
11. I'm taking a medication with the help of my naturopath. There hasn't been significant studies to show the effectiveness of the medication that I am currently taking. But apparently it's supposed to help with the energy drain I have during the day, which I've been overriding with pure determination and excessive coffee. I actually don't know if whether or not the symptoms have simply be getting more pronounced or my workarounds have been becoming less effective and I don't know how to differentiate between the point at which that occurred. I've only been aware of the term neural typical opposed to neural divergent recently within say the last year.
12. It helps somewhat.... After trying almost every medication out there with hardly any positive effects, we found one that somewhat helps with emotional regulation and impulse control. None seem to help me with focus or anything else
13. makes my brain less loud so it is easier to focus
14. It calms my mind and helps me focus. I am much more relaxed and level-headed.
15. Clears the brain fog, makes focusing easier, or transitioning back into my task easier when I get distracted
16. It helped me to concentrate and focus well and most especially to inhibit impulsive actions.
17. Helps my brain focus.
18. Keeps me from being sleepy and lethargic all day.
19. Helps me focus.
20. Focus, attention, less distractions and I can complete tasks in a timely manner.
21. Makes it possible to work

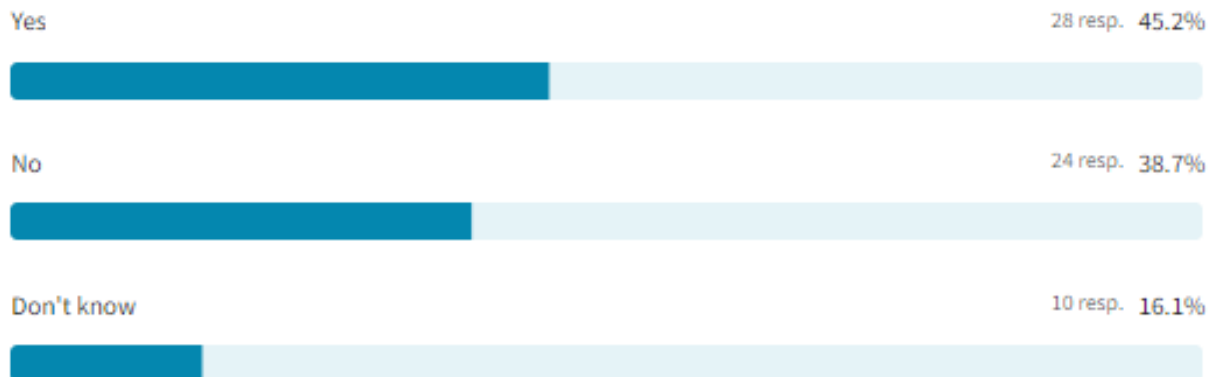
22. ADHD Meds help me in every aspect of my life; home, work or life. I have far less unwanted thoughts going in and out and can put thoughts to the side for later in an easier way. Medication has brought me clarity in many aspects, like tasks that I need to complete and breaking those down. I can manage family things easier on meds as well, paying bills, groceries etc...
23. I take medication occasionally for anxiety which helps me be regulated and able to participate in work and life events that are triggering or overly activating. I have tried one kind of ADHD medication thus far which I didn't love, and even though I would like to try other types, I have anxiety about this so keep putting it off.
24. I can plan my day and focus on various tasks. My conversation skills improved and I now understand why I loathe small talk. I also do not pace, no more chewing my nails or cuticles, I finally sleep more than 4 hours a night! I have been an insomniac for as long as I can remember (about 3 yrs old), I now show up close to on time for events, don't interrupt every conversation (I can actually listen now!).
25. Helps me focus
26. It calms my brain enough to where I can feel relaxed, focused and less stuck when trying to get important tasks done. I am also in a over all better mood.
27. My anxiety has drastically decreased as my brain has stopped spiralling to the level it constantly did before. I can focus a lot better, I was able to go to collage. I can break through my executive dysfunction more often, I feel motivated to try new things and to address issues instead of putting them off, I get overwhelmed less often, I can actually be semi productive at times. It's all around really drastically improved my quality of life and productivity
28. It makes my daily life more manageable, helps me to feel less overwhelmed by everything
29. I am able to focus more clearly on the task at hand, and actually start into a task without it feeling like a mountain to climb! It has helped me establish healthy routines that make my ADHD symptoms more manageable.
30. I take determine which is also for my excessive daytime sleepiness. It helps me stay alert, awake, and focus on difficult tasks such as organizing, focusing on even small tasks such as basic personal paperwork.
31. It helps with staying focused and quieting down the background noise in my brain
32. It helps me to be motivated to start tasks faster. It helps be to stay focused on one task and not be as anxious about forgetting to do something (or forgetting something that is a safety concern, aka leaving the curling iron on) It helps me regulate my emotions and reduce outbursts of anger and sadness
33. Focus
34. Allows focus and some clarity while working
35. Allows me a moment of peace and focus
36. Stops me from being so reactionary
37. In every single way. It flipped my life 180. I can be alone with my thoughts, and just BE. The first time I took medication, I watched a three hour dialogue-heavy play for a class, all in one sitting. I understood everything. I wept after. I could not believe this is how other people experience the world. It helps me regulate my nicotine addiction as well, and my thoughts and ability to write is much clearer and easy.
38. Quiets the many tasks bouncing around, gives clarity and provides regulation for triggers of anxiety

29: Why don't you take medication for your ADHD? 18 out of 62 answered

1. Because I don't trust my doctor to prescribe the correct medication. She is too focused on pushing depression medication and diagnosis when I have no history or symptoms of depression. Anxiety yes but not depression.
2. No official diagnosis yet
3. I've tried 2 separate medications with proper titration periods. The medication caused other problems that started to impact my life as much as, or more than the adhd
4. present doctor will not prescribe
5. Haven't found anything that really helps
6. Stimulant, racing my heart so bad
7. breastfeeding , worry of efficiency and costs
8. It is difficult to obtain
9. I can't get medication cause I don't have a doctor. I have even offered to take medication every morning at a pharmacy if doctors aren't comfortable prescribing stimulants to walk in. But no.
10. Can't find a doctor
11. It make me shaky.
12. I tried one and it didn't work for me. My doctor said there's no point in trying any of the other ones since the one I tried didn't work
13. the impact of meds given my age, the lack of clarity in the full pro's & con's of using medication because Canada does not have a legally binding informed consent policy such as the USA has. the fact that a person will not receive adequate monitoring of the impact of using meds, whether positive and/or negative. Meds are only one part of the solution and can cause more problems then they solve. We need holistic treatment.
14. No doctors have seen me since self-diagnosis
15. prefer to manage with herbs, diet and acceptance. I'm 66 and have never been medicated
16. I am hypersensitive to stimulants. I tried Vyvanse for 15 months and it was an awful experience. I am unsure if I will try stimulants again, or a non stimulant. But I would need to pay for private support if I do, because my GP won't medicate for ADHD. She referred me to a private paid clinic for management.
17. I am undiagnosed professionally, it would be illegal
18. I manage my symptoms naturally

30: Is your medical care for ADHD covered under your caregiver's benefits?

62 out of 62 answered



31: Have you or your family had to choose between meals, bills, and medications for ADHD?

62 out of 62 answered



32: Please elaborate further and share why you or your family had to choose between meals, bills and medication for ADHD. 12 out of 62 answered

1. Part of my medication is covered but not all. I do not get it when it is not covered, unless I get approved for Plan G
2. benefits only cover so much
3. This is a triggering question to answer. As a single person living on low income, the cost of living (namely food and housing) has gotten to the point where MAID is something I think about often. I am doing everything I can to improve my education, therefore access to a living wage, but having a lower standard of living is quickly translating to additional mental health and physical challenges.
4. I have partial coverage. The meds are quite expensive and there have been gaps of a few days between paydays where I needed my meds, but also needs groceries or a bill to be paid, and i would choose to pick up my meds instead of groceries or bills.
5. Even with coverage it doesn't cover the whole cost and my medication is only covered 50%. The our of pocket cost is approximately 100 dollars per month. I also have anxiety medication, my husband is on 4 medications for his bipolar disorder, and the fact that I am unable to work more than about half hours per week coupled with child care limits and the insane cost of living has meant not filling my prescription at times.
6. I have experienced financial anxiety for much of my life.
7. When making the switch to certain medication, our extended health plan didn't cover that particular drug, so we had to use Innovicare to cover it. Since we live in bank overdraft, we don't have much money coming in, we need to know where our overdraft limit is and there is a constant battle of approved and declined. The credit cards are at their max too.
8. Knowing the cost of medication, I don't think we could afford if. We have a new baby and I'm not working.
9. The cost of my medication is not covered through MSP
10. I am a full-time mature graduate student. My school does not provide medical coverage. I am not currently paying more support because because I am bleeding money.
11. Everything is too expensive in BC
12. I cant work right now so dont have money for medication.

33: Below are some statements about getting medication and services for ADHD. For each one, please check 'True' if it matches your experience or 'False' if it doesn't. 61 out of 62 answered

	True	False
I understood or was clearly explained how to get a prescription for ADHD medication	41	20
I could easily access my ADHD medication from the pharmacy	35	25
Finding and seeing a physician for ADHD was simple.	9	52
I have not faced challenges getting the services & care I need for ADHD.	4	56

34: If you answered 'False' to any of the questions. Please share with us what happened, and how the process of getting that particular service was. 45 out of 62 answered

1. It is very difficult to reliably get prescription renewals for ADHD medication because of the idiots who abuse these medications. Getting in to see my psychiatrist or GP, if I even had one at the time, took a very long time, and remembering to make an appointment in time to get in before my prescription ran out was always challenging, especially if appointments were cancelled or postponed for various reasons, or forgotten by me occasionally. Clinic doctors can not prescribe any of my ADHD medications. Occasionally even my own doctor/psych wasn't allowed to prescribe anymore. Very challenging to adjust and go without.
2. As noted previously - my doctor did not want to support my adhd diagnosis. I had to self diagnose and then insist on being tested. She did not want to do that but I insisted as I had had several people recommend I consider adhd as a possibility. I had to fight hard to have the GP even consider it, she was not sympathetic nor supportive -ore irritated, and kept trying to push a diagnosis of depression
3. Not enough DRs to provide assessment
4. It was hard to find a doctor who actually took me seriously and didn't just dismiss my symptoms as depression.
5. I can't type so much, I get distracted, if you need you can call me. 778-680-2481
6. Any type of treatment outside of medication is not covered
7. Doctor will not consider prescribing - believes I am simply "anxious" and fears drug interactions
8. Needed a referral to get an assessment and doctors didn't believe I fit the ADHD profile. Finally I asked to be referred to private ADHD assessment and pay privately
9. Your questions are too skewed. It wasn't easy, but it wasn't impossible because I have white middle-aged, middle class mom privilege.
10. Beyond medication, there are no services available for adults with adhd
11. Renewing my prescription cannot be done online like all my other meds. So I have to go in for some reason and renew in person and then come back the next day to pick it up. It is time consuming and annoying.
12. Because I don't have a family physician, I must renew my meds through an online service. Not all of the doctors are comfortable with prescription methylphenidate to folks who are not regular patients. This has led to being unable to get refills in a timely manner — doses are missed.
13. In order to save emotional energy, I will just say that the lack of awareness around ADHD and stimulants is in every system. Educationally, whether it be k to 12 or post-secondary, in all areas of our health and wellness institutions and in all employment and economic sectors, those are us with ADHD must face constant barriers due to ignorance and stigma, individually and systemically.
14. The extensive wait lists, and then misdiagnosis' I received over the last 3 years alone was enough to drive a person mad. I'm glad I advocated for myself and got an official diagnosis

15. Refilling my prescription is a big hassle, as I have to book an appointment with my doctor every few months to review my medication, then I have to wait for the pharmacy to refill it.
16. I answer no only because I've only been aware of symptoms of ADHD for the last few years, And I've only recently been focusing more on the subject to determine whether or not if and how much of this divergence I have been experiencing throughout my life and didn't even realize it. One example might be a situation during my elementary years where I would fail a test. And then create some form of work around in my brain and then the next day the teacher would be kind enough to allow me to take the test over and I would get an extremely high mark and would be accused of cheating. As to whether or not those marks are actually given to me in the end I don't know what my mother may or may not have done to mitigate any of this as I often found myself in situations where I was one of the few kids in the class that had to put up their hand after the roll call. When the teacher would say did we miss anybody.
17. Luckily our family doctor is great and has been very supportive in getting me ADHD medications. However finding the right dose and one that works for me and actually makes a difference has been difficult and I have had to research and bring ideas and other medication options to her as she is not a psychiatrist or expert in ADHD.
18. To diagnose my young kid was a huge process with pediatrician, after few years finally referred my daughter to Sunny Hill Hospital.
19. trying to get an appointment with the doctor to renew a script to get it filled is really a challenge - both because of the lack of executive functioning but also because it is really hard to see your doctor. I can only get scripts with one refill at a time.
20. I had to pay to get my appointment for diagnosis. Regular wait time was one year minimum.
21. There are specific rules about how the dosing requirements for medication have to be phrased, which my doctor didn't know and meant I couldn't get the refills he had ordered. Walk-in clinics also don't like prescribing ADHD medication - I lost my prescription for over two years because I lost my provider through the university and none of the walk-in doctors I spoke with would help. One of them drug-tested me without my knowledge or consent, despite the fact that I'd been on ADHD medication for four years at that point and it was visible in my Health Gateway file.
22. Getting an assessment was difficult as there were not enough specialists who were credible enough to conduct an assessment. The cost of getting an assessment is too high and unaffordable. Doctors/practitioners, etc. are not educated about ADHD.
23. I had to figure it out then advocate for myself.
24. It's more complex than that.
25. I was not sure if my doctor was able to prescribe meds or how medication actually worked. It's only been through years of advocacy that I have learned this. The pharmacy is extremely watchful on ADHD meds, they won't do anything outside the extended health plan. If you have enough medication for 1 week, they will claim your plan has to wait for that 1 week to expire and then you can refill. We were lucky our GP learned as much as she has but seeing an actual specialist, that has been brutal. So many out there don't understand what ADHD or that ADHD is all about 1 area and that isn't the case; even in our own group I see misconceptions that need to be corrected.
26. I can't find a doctor who deals with ADHD
27. My physician has refused to fill out my Disability Tax Form because she doesn't believe ADHD is eligible, or considered a disability. She was not the one who diagnosed me, and we have not had any in-depth conversations about my mental health and the ways that ADHD negatively impacts my life. So I am feeling lost about what to do. Also at one point she referred me to a psychiatrist to explore medication options beyond what she was familiar with, but they wanted to charge me \$2000 to do a new ADHD assessment, even though I already have a diagnosis. So it seems that many medical professionals are either uninformed or taking advantage of people - charging them HIGH amounts of money when ADHD medical care is supposed to be free.
28. Pharmacy's rules regarding refills are ridiculous.

29. not available unless I paid for the diagnosis. meds are easy to access, they give them out like candy.
30. I still haven't been able to see a doctor who will help me diagnose and get medication.
31. I wasn't able to get a psychiatrist for years, I only received one through Vancouver coastal's telehealth program during quarantine because the only psychiatrist we had in my area was old school, bad at his job and suddenly left without a replacement or any warning. The psychiatrist I saw virtually changed my life but she and my mom had to fill out a ton of forms to have my meds covered by insurance and get me on special plans to cover psychiatric medications
32. Was seeing the doctor for Other stuff. Two of my children were diagnosed with autism and I questioned myself. Doc said I just have ADHD.
33. I answered these earlier (I'm running out of time yo finish this survey...it's taken me much longer than 7 mins but want to give good details
34. You learn from others; there is no prescribed path
35. I never needed that explanation and found the test cost by the practitioners I sought out were very pricey. It was worth it though and I have a good job to pay.
36. 1st GP didn't believe ADhD affected adults. She was reluctant to accept my private-pay diagnosis, and when discussing side effects of the , dismissed me and was clearly unable to provide support. 2nd GP was similar, told me to go to a orivate-pay clinic. She doesn't want to manage ADHD. I have a formal diagnosis from a psychiatrist. It was very thorough. But the doctors think I just want to shoot for stimulants. I hate stimulants. I just want help managing my life.
37. Almost impossible to find adhd assessment for an adult. Walk in doctors won't give meds and family doctors not available. Can't even find a family doctor
38. I was only able to start the process to get medication when my sibling shared her own ADHD experience with me and explained the steps I needed to take
39. Already answered in previous question
40. Waiting a year to see a specialist in Victoria. I'm in Nanaimo
41. No doctors means no access.
42. N/A
43. The pharmacist treats me (a 64 year old) like I am a drug pusher whenever I ask for a refill of my meds.
44. I was seeing a personal therapist, who noticed that my patterns of adhd sounded a lot like his wife's, and he asked if I also had adhd. I said I had presumed so, but my GP always wrote me off. He was able to refer me to a doctor at my university who was willing to hear me out, and then have me try medication. Getting refills on these outside of the school year was a very difficult.
45. I have never seen anyone specific in adulthood specifically for adhd challenges. I have been lead to believe that the medication is supposed to do the heavy lifting without a real explanation of what it does. I believe I assumed I am to be managing my own ADHD symptoms and make people aware.

Additional Diagnosis apart from ADHD: If applicable, share any other diagnoses you've received. This helps us understand the complex needs within our community

35: Except for Autism*, have any additional diagnoses affected your care in terms of impacting their ADHD support, treatment or access to ADHD-specific services? *An Autism diagnosis allows access to Autism Funding and CYSN services and a designation in school

59 out of 62 answered

Yes 29 resp. 49.2%



No 30 resp. 50.8%



36: Please specify which diagnosis have you received in addition to ADHD. 27 out of 62 answered

1. Generalized Anxiety disorder, Major Depressive disorder, Obsessive Compulsive disorder (by one doctor, but others disagreed) Social Anxiety disorder, Panic Disorder (now thought to be temporary symptoms of untreated GAD) Orthostatic hypotension, Ehlers-Danlos hypermobility
2. Possibly Bipolar
3. Depression, Anxiety
4. Severe generalized anxiety, depression, and PTSD
5. Obesity, endocrine disease, Anxiety and Depression
6. Generalized anxiety disorder
7. Neurodevelopmental disorder, developmental language disorder, specific learning disorder with impairment in Mathematics.
8. General anxiety
9. Major Depressive Disorder and Generalized Anxiety Disorder.
10. Rheumatoid Arthritis Fibromyalgia Anxiety based depression Severe depression
11. Depression, anxiety
12. Learning disorder in reading and math reasoning
13. Anxiety disorder
14. anxiety and varying levels of depression
15. Autism
16. Anxiety and depression
17. Major depression
18. Severe anxiety disorder, learning disability in math, severe panic disorder, depression. (I also have ASD)
19. Epilepsy, idiopathic hypersomnia, depression, complex PTSD(all correct diagnoses) misdiagnoses: bi polar 1 or 2, borderline personality disorder, brain damage (thinking my cognitive challenges were caused by seizures!), generalized anxiety disorder, oh... and the early stage I took determine, I broke our on a bad skin condition - mostly spots on my face, i went to the emergency dept and was assumed to be a meth addict especially upon mentioning i take dexedrine (also maybe Dr was influenced by my other appearance due to being overwhelmed by daily living due to ADHD, severely depressed and exhausted, so my ability to keep up with good personal hygiene, i looked like shit at that time in my life!) But mentioning the dexedrine was the kicker. And, as such, I was kicked out of the emergency dept! Also, because those misdiagnoses were in my medical file, anytime I went to a specialist (including a dermatologist) I was further misdiagnosed or neglected care
20. Oppositional defiance disorder, major depression, PTSD, anxiety and a PDA profile

21. PTSD, Fibromyalgia, POTS, Bi-Polar
22. Anxiety and depression
23. celiac disease
24. I have suffered with depression and anxiety in the past. I had a doctor tell me it wasn't ADHD, but it was manic depressive disorder.
25. I'm AuDHD and there is no autistic support for adults.
26. Depression, anxiety, bipolar, borderline personality traits - the only ones that are a true diagnosis are depression and anxiety.
27. General Anxiety Disorder and Depression

37: How has having more than one diagnosis affected your access to ADHD support and services? 25 out of 62 answered

1. It makes it very confusing with so many overlaps and differing opinions on diagnosis.
2. No
3. There seems to be a belief that depression and anxiety are real and the causes of my problems, not results of my adhd
4. My symptoms and struggles were brushed aside as poorly managed anxiety and depression. I was put on medication that wasn't right for me, and was made to feel like my struggles were "in my head" or over exaggerated
5. Health services and institutions are siloed therefore, all responsibility is on the person with ADHD to manage communications between service providers, which is especially challenging when we have very almost no control as individuals. Literally all medical condition will be worsened if somebody has ADHD, particularly because Canadian Healthcare requires that individual to be their own advocate, their case manager, their own record keeper, their own financial manager, while trying to balance having an income and having family and social relationships.
6. So many of my ADHD symptoms were attributed to my anxiety, so I had to really research and self diagnose then advocate for myself.
7. Yes
8. confusing
9. It greatly affected my overall mental health.
10. Limited it. Affected my understanding of how things can cause or be caused by other things
11. Sometimes ADHD concerns are assumed to be because of other diagnoses and this is incorrect
12. Because I didn't get a diagnosis until much later in life, I am where I am because no one explained my brain. There is no way that when I was younger, that I had the language I have now, I didn't know how to advocate, I was told to sit down, just be a good kid and try harder, I was the problem. I know I'm not crazy, my brain just works different. If I could re-do life with this knowledge, things would be drastically different.
13. It hasn't
14. easily triggered, despondence, overwhelm
15. I am autistic and have ADHD. This has not impacted by ability to accept services.
16. Everything is blamed on anxiety
17. in all honesty, this is a dumb question.
18. trying to figure out what is causing what and what is exasperating what is extremely difficult and frustrating. Trying to fix the whole when you can't even identify the individual disturbance is hard and makes figuring out where to start and what to do very difficult
19. Its the same no doctor no supports
20. It gets used as a more acceptable method of describing me and hinders any help I need.
21. Usually my other issues with mental health overshadow my struggles with ADHD as they are usually more severe.
22. Yep

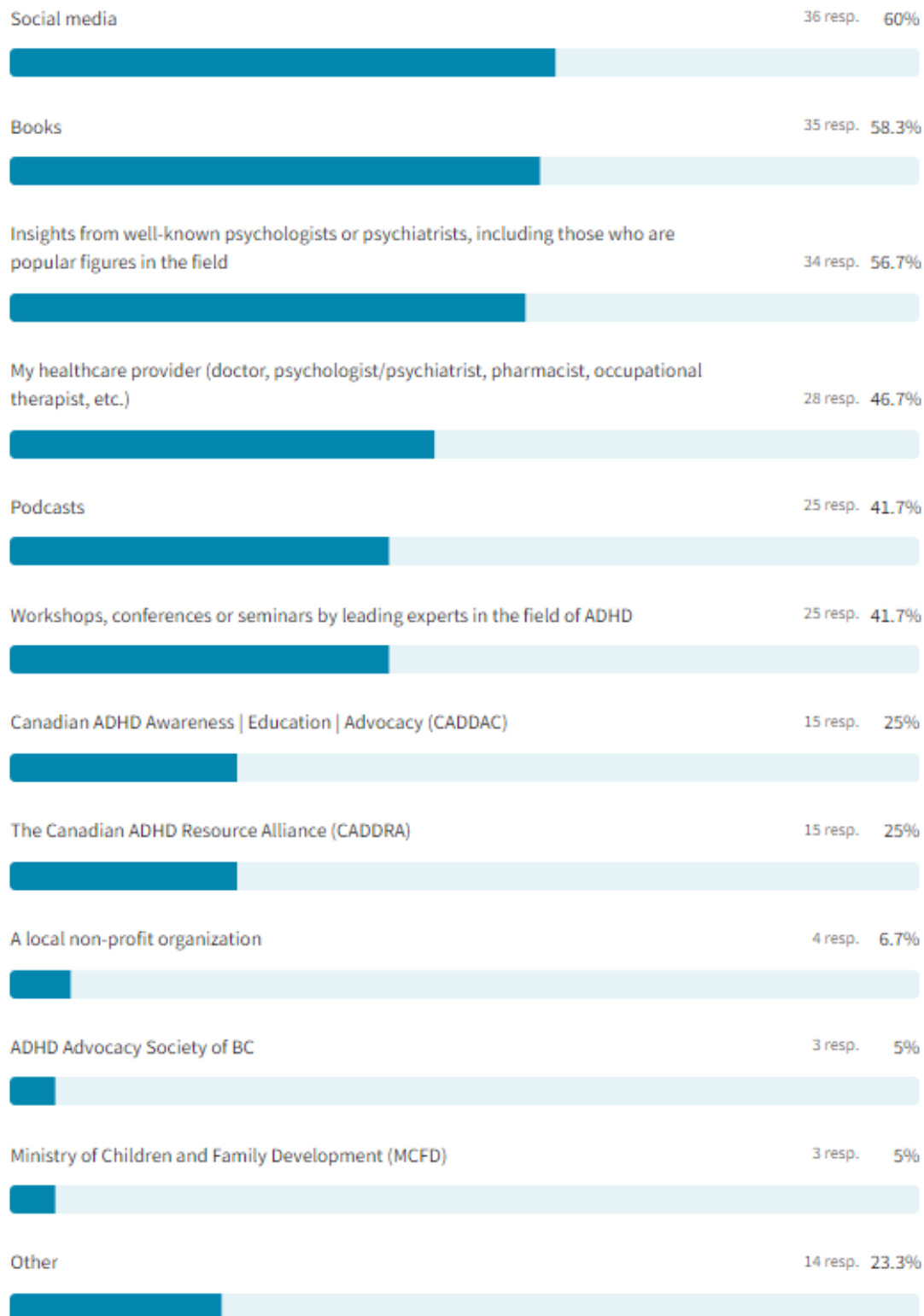
23. it has made it harder to successfully assess what is a support for ADHD or other things.
24. Bring offered meds I didn't need, referred to social workers or therapists who tried to fix me in other ways, didn't believe me or understand the information I was trying to educate them with. I was referred to an optional outpatient psychiatric facility for 2 weeks. I was grieving a major loss in my life as well. They tried to put me on Seroquel, which I refused. I was told I'd end up like my dad if I didn't (he was bipolar 1), I asked and asked for some kind of support or referral to something to help with adhd (I'd been diagnosed at 30, at this time o was 40-ish) I was neglected proper care, verbally and mentally abused by most of the health care staff, and signed myself out. The referring psychiatrist, who didn't have "floor rights" the that facility, was disgusted with what happened. He wanted to help, but nothing available! This was approx 2010?
25. It delayed my access both in getting an assessment and diagnosis, and then in getting medication. Although the diagnosing specialist's report made recommendations for medication based on what I was already taking for depression and anxiety, my GP declined (told me I didn't need it and it would be complicated because of the medications I was already taking). I went back to see her a second time several months later and asked again and she told me to get an ECG first. By the time I had completed the ECG and was able to get back in for another Dr. appointment it had been almost a year since I received the diagnosis before getting my first prescription. Then it of course took some time to adjust and change dosages, etc, before I could tell if I had found the appropriate medication and amount.

Access to Information

Here we explore how you currently find information related to ADHD and your preferences for receiving such information in the future.

38: What are your primary sources or trusted sources of information regarding ADHD support?

60 out of 62 answered (with multiple choice)

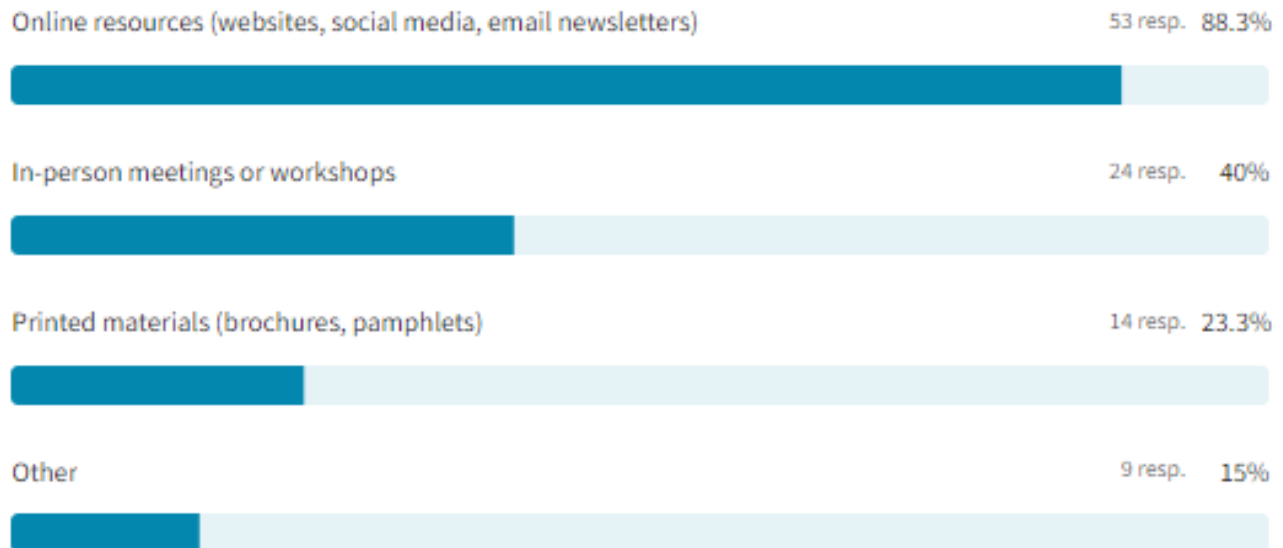


Other (please specify):

- My partner has an adhd diagnosis and we support each other and read up on it
- Research for reputable sources on the internet.
- Specifically your friend that had the diagnosis and told me that I displayed the character six of the condition
- ADHD coaching program online
- ADDA
- Myself. Reading online journals.
- ADDitude magazine articles
- legitimate sites via the internet
- Peer reviewed literature
- Not really much else. Too disorganized and busy keeping up with life to search for appropriate info. I hadn't heard of your organization until today. I'll start looking into it today
- CADDAC
- Friends/family
- ADDitude online magazine, Kelty MH (BCCH)
- Websites online, Additive newslettwe

39: How do you prefer to receive information about ADHD and related support services?

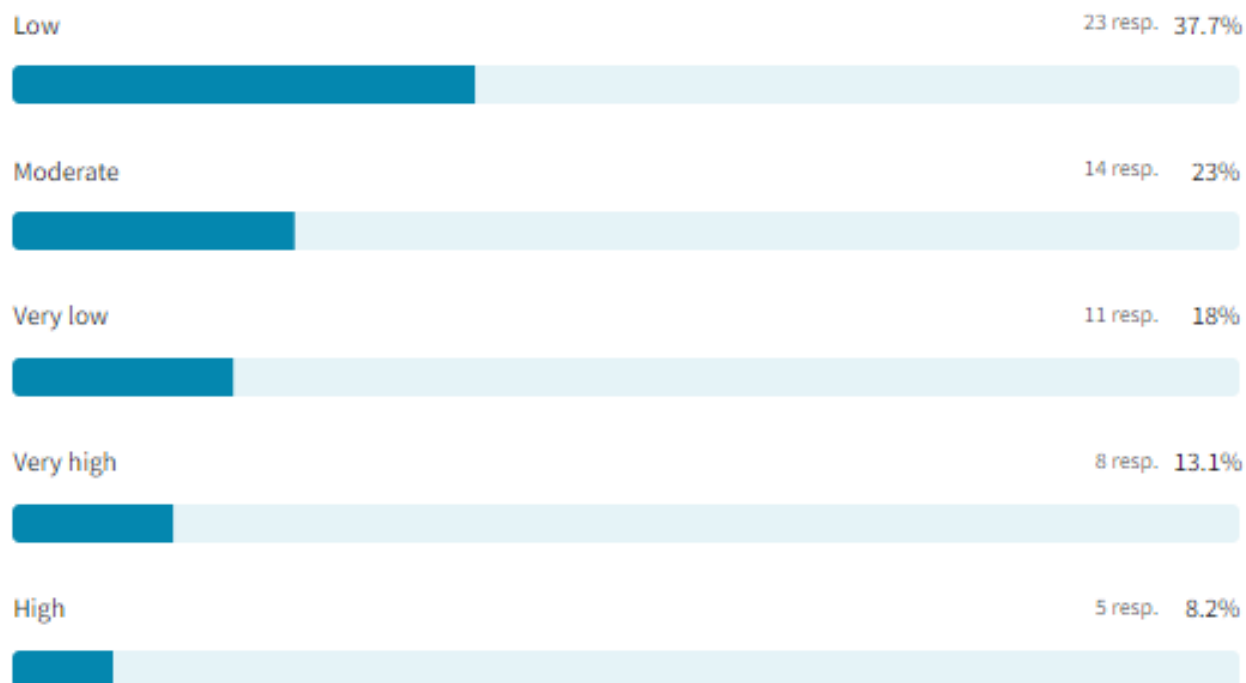
60 out of 62 answered (with multiple choice)



Other (please specify):

- online workshops, podcasts, books,
- Email
- Peer-reviewed journals.
- All of the above work
- Medical professionals
- online forums. we all don't live in major centres.
- Online classes, workshops, peer support etc
- Current peer reviewed research
- Audiobooks

40: How would you rate the level of awareness and understanding of ADHD in your community? 61 out of 62 answered



41: What misunderstandings or myths about ADHD have you come across in your community, within your family, schools, workplace, or broader society? 49 out of 62 answered

1. No one understands; even mentioning ADHD gets an eye-roll because everyone claims to be affected No one understands; even mentioning ADHD gets an eye-roll because everyone claims to be affected by it, so actual sufferers aren't listened to.
2. The biggest challenge I've faced is the diagnosis as an adult woman is dismissed because I don't display what has traditionally been understood to be adhd characteristics. I have a hyperactive brain - and struggle with executive functions, have some anxiety - I do not outwardly "display" what people think adhd looks like. So socially people think it's a "trendy" diagnosis rather than a real one.
3. That it is a childhood thing that little boys have
4. That everyone have
5. When I was diagnosed with ADHD , the first words out of my mouth were, "But that's not even a real thing.". My ignorance and lack of understanding was very real, and I'm now realizing that there is a large percentage of people out there who are as blind to ADHD and its symptoms as I was.
6. not real, excuse for poor performance
7. That if you are good at school you can't possibly be ADHD. That ADHD looks the same in males and females. That medication is bad/harmful. And that my symptoms are caused by anxiety not that ADHD contributes to my anxiety
8. Many people believe that they can treat their ADHD by trying harder, with food/vitamins, or through any means except medication.
9. There is a general sense that it is not a 'real' medical issue
10. it's not real, it's all in your head, buck up and keep working
11. People throwing the term around drives me nuts. Like saying 'oh my gosh I forgot something it's like I have adhd'

12. It's not real. I'm not trying hard enough. It's a "fashionable" diagnosis (and therefore not real). Everyone has problems with ____ (memory, emotions, etc). Just learn to do it, with practise you'll be okay.
13. The ADHD is primarily found in boys, that ADHD is an issue with laziness and discipline, that individuals with ADHD will behave hyperactively physically, you can't have ADHD if you get good grades, adhd is specifically caused by trauma, adhd can be cured or grown out of... just to name a few.
14. I have been told I am lazy my whole life because I get stuck in thought paralysis. Now I know it was just the way my brain was wired and now I have debunked the myth that I am just lazy and am starting to enjoy life, slowly but surely
15. People that just don't believe that it's even an actual thing you think you're just full of it. especially as a female who is not overly hyperactive people just don't even believe that you have it. They think you're taking pills to get skinny or high. I also find it worked that when I've made a mistake or something hasn't gone quite right that they think it's an excuse I use
16. I'd have to say I don't specifically know because of how I'm processing information. I may be harboring some of the myths just because of how I processed information throughout my life. For example creating self-talk within my mind's eye saying that it's my responsibility it's my choice and if I choose to learn it and understand it and it benefits me then it's okay but if I'm not able to comprehend it or understand it I don't know who I'm supposed to talk to to correct that or if it's just somebody's opinion or or misinformation etc etc
17. That you have to be overtly hyperactive That you can't have ADHD if you had good grades in school That "everyone thinks they have ADHD now* because of the internet That medication solves everything That you "should" be able to work full time and manage everything, you're just not trying hard enough That ADHD is not a disability
18. People need more resources and understanding for neurodivergent people
19. That it's only kids - specifically boys - who are affected. That you grow out of it as an adult. That you can't have ADHD if you went to grad school or could hold a job.
20. Slow, stupid, inattentive, can't finish anything.
21. It's just about not focusing, you're only hyperactive, you're too smart for ADHD, you'll grow out of it, being on medication for the rest of your life is bad, you're just not trying.
22. only happens in boys
23. Stigma about ADHD.
24. It's all about hyper kids
25. "You're just lazy."
26. So, so many.
27. I've come across and experienced every single myth. I'm not dumb, my brain is wired differently. I am allowed to have lots of ideas and my ideas are valid and have value. ADHD isn't a big deal, ADHD is only for kids, you can't have ADHD you have it altogether, ADHD isn't real, you just need to try harder, ADHD brains can't focus, you're not hyper, girls don't get ADHD, ADHD is a learning disability, you've outgrown ADHD, You can't be ADHD, you're so organized, your parents should have been more strict on you
28. That all people who have ADHD can't focus and are hyper.
29. That if I try harder I can accomplish all things
30. In general, assumptions that aren't true about intelligence, hyperactivity, attention, and the ability to be employed/run a business/achieve higher education etc. Judgmental perspectives on things like "procrastination," "laziness," time management and time blindness etc.
31. Common perception that it only affects boys and that it only shows up as being hyperactive or scatter-brained
32. "Everyone's a little ADHD" People not understanding how emotionally & physically taxing it can be. People thinking you're lazy, or a procrastinator, because you struggle to get important tasks done.

33. very much the usual gamut of the ignorant and the uneducated.
34. People think I just don't care to listen or concentrate - excuses
35. People assume I don't have ADHD or that it "isn't that bad" because I am able to hyperfocus at times.
36. That it's not all fun and games.
37. Only young boys are affected. It looks like 'bouncing off the walls', or that everyone has it to some degree. That it's an excuse for laziness. It doesn't exist. It's trendy. It leads to drug abuse (I can't even remember to take it or refill my prescription).
38. That it only presents as visible hyperactivity
39. Several. No time to go into detail now
40. that we are 'all a little adhd' is the one that upsets me the most, i think. or I 'just need a system'...ugh.
41. That it is med seeking. That it should not be accommodated or that people with adhd can't be as good at their jobs.
42. how hard it is to be on top of the things I need to be on top of
43. I think that the stereotype of an active young boy is still prevalent. I think many women who have ADHD struggle because they struggle internally and are not a disturbance to the classroom so they do not receive support
44. I regularly hear comments from schools/teachers, doctors, mental health practitioners, child development consultants, friends, family, etc., etc., that ADHD is over-diagnosed, that it is not "real", that it is actually "trauma" (thanks for nothing doctor), that it is/was a fad, that it is part of the pharmaceutical industry's way of making money and that doctors over-medicate. People are so afraid of looking like the fool who believed in the fad of the day that they resist acknowledging that they/their child may have ADHD.
45. That we are dumb, disorganized, incapable, impulsive
46. ADHD is an excuse to be lazy, made up, and over diagnosed
47. That females don't suffer from this, that you outgrow it as you age, that it is consistent across all environments, that I am just an emotional person with no control, that I am crazy, and on and on and on.
48. That if one has ADHD, it naturally should present as a learning disability. Many people still believe that hyperactivity needs to be present for diagnosis.
49. Something you grow out of, very easily distracted/aloof, only people who are stupid have adhd, no ambition or follow through, lazy and hate learning/classrooms

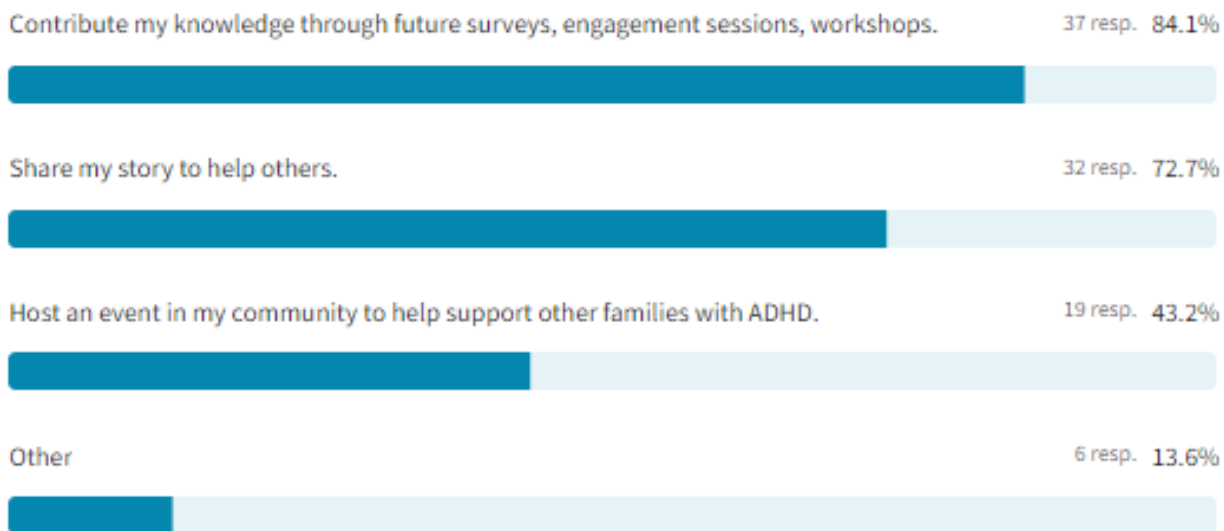
Engagement and Feedback

This section is your opportunity to tell us how you might like to collaborate with the Society, whether you'd recommend us to others, and if you're open to being contacted for future initiatives. Your feedback is invaluable as we strive to build a supportive community and enhance our services.

42: If you would like to play a role in supporting our work, what would it look like?

44 out of 62 answered (with multiple choice)

Please note: At the end of this survey, you'll have the option to provide your contact information. Selecting any of the following options alone will NOT result in contact; your details are required for follow-up.



Other:

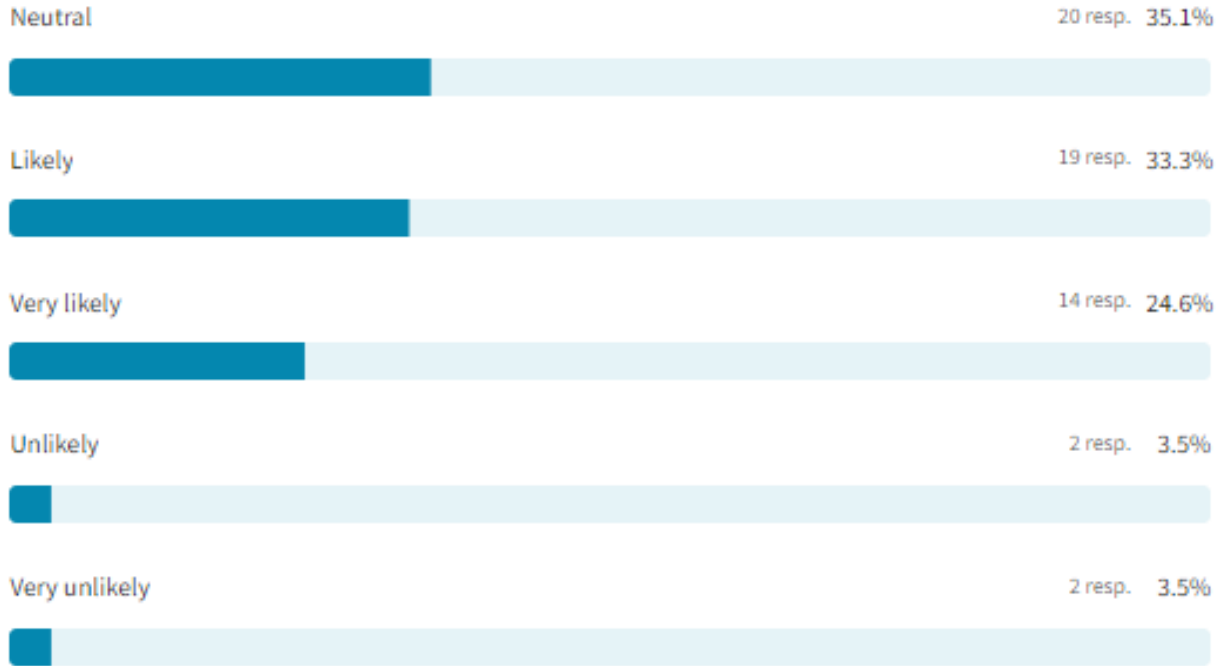
- advocate for better mental health options
- I am an Expressive Arts Therapist moving into a specialization of ADHD and neurodivergence. I am also a sound healer and musician, and would be happy to share more about how creative expression and music help us to regulate our nervous systems, express emotions gently, and activate neurotransmitters.
- advocate for equal access for all individuals regardless of race, sexual orientation, where they live and financial means; to a full range of treatment options, respecting an individual's right to choose.
- Whatever would be helpful
- Sensory Friendly Story Times that I offer at the Ocean Park Library. Once a month.
- I give workshops on Neuro-diversity.

43: Is there anything else you'd like to share or suggest that we haven't covered in this survey? Your additional thoughts and insights are greatly appreciated. 22 out of 62 answered

1. the difficulties faced with a very late diagnosis - 65+
2. There needs to be so much more awareness surrounding invisible disabilities. Medical professionals, the government, etc to understand that even though we look normal on the surface, there is so much underneath that can be absolutely debilitating.
3. It should cost a lot to be diagnosed, nor should I have to wait months and months to be.
4. It seems from the questions that the focus may still be just on parents and children. I hope to see More content and at adult individuals, namely women over 30 yrs.

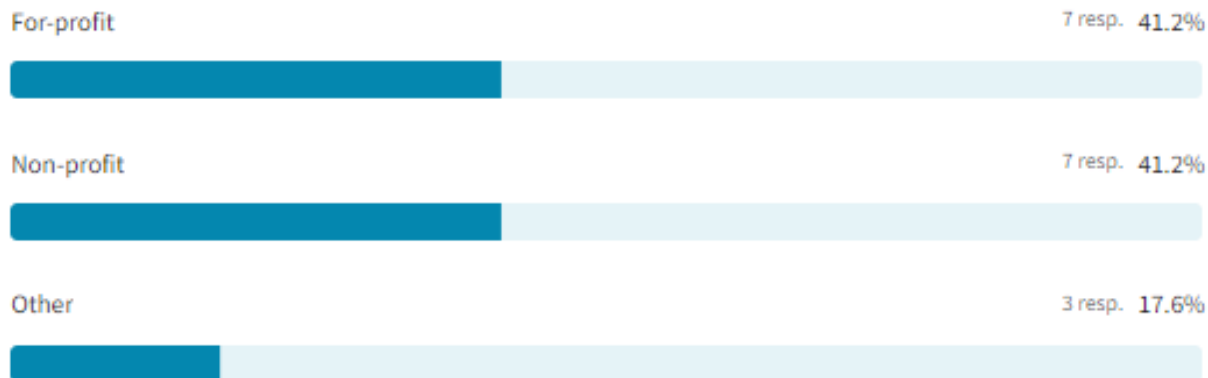
5. I am the Pacific region representative for the federal public service for the representation of neurodivergent public servants. This is a national working group and I'm very proud of the work that we're doing and I would love access to more resources in order to be able to share her broader audience. One of our goals is to work with the federal Public service on putting together for managers. What accommodations should look like for neurodivergent workers. This is a fairly new group and we are already over 3500 members across all arms of the federal government.
6. I think I mentioned a bit about figuring out how some of the challenges that we have in life, our choices that we may not have taken responsibility for, differ or similar to some of the symptoms that ADHD individuals have. I keep being told that an individual the ADHD may not necessarily have the ability to do some things. So how do I know that I just simply haven't filled in all the gaps with regards to all the information that I have learned or is it that somehow my brain doesn't have the ability to process the programming that's being offered to me by the institutions or somehow because of my neural Divergent brain, I can see the inconsistencies of all the information that we're inputting into what I consider our biological hard drive.
7. No
8. N/A
9. None.
10. Nothing further to add
11. I've had absolutely no support for ADHD. I struggle with it every day and don't know how I could support your work, although I'm very interested in doing so.
12. You could include something like barriers to accessing financial supports, including having a medical professional fill out your Disability Tax Credit Form. Many things it seems rely on having this piece completed, but if your medical professional is unaware, this becomes a barrier.
13. This survey is long and hard for someone with ADHD
14. The age range should've been expanded. I'm 54 and was diagnosed at age 50. ADHD in menopause has additional difficulties. Having your survey age range stop at 25+ is unfortunately very limiting.
15. probably, but.....
16. I would like to see more on your social media page and more on your website. How do we get the support we need.
17. No.
18. I am not getting much traction for my story time and wondering if you'd be able to support/promote it in some way? The last one of this season is on May 25 at 10:30. They will begin again in Sept.
19. When I answered some questions in the type box I could see everything I had written because the text box expanded. I did not like when my writing just disappeared off the page because I could not see/remember everything I had written
20. Help!!!! I'm 64 and a poster child for undiagnosed ADHD in women. My biggest regret is not being able to convince my mother that adhd is a thing I have it, and that's why I'm a failure by her standards. I need a simple overview document that I can give her about adhd
21. So much discourse is focused around kids and their dx and there are women my age that have never had supports or even a diagnosis and even after a dx aren't given counselling to challenge the grief of a lifetime of being told you are making things up. If I suspect ADHD or Autism I should be able to bring it up to a dr, get assessed then get referred for triage in a system to know what's available.
22. No, I think it's all been covered

44: How likely are you to recommend the ADHD Advocacy Society of BC to a friend or family member who has, or is supporting someone with, ADHD? 57 out of 62 answered



A Service Provider who works with people with ADHD

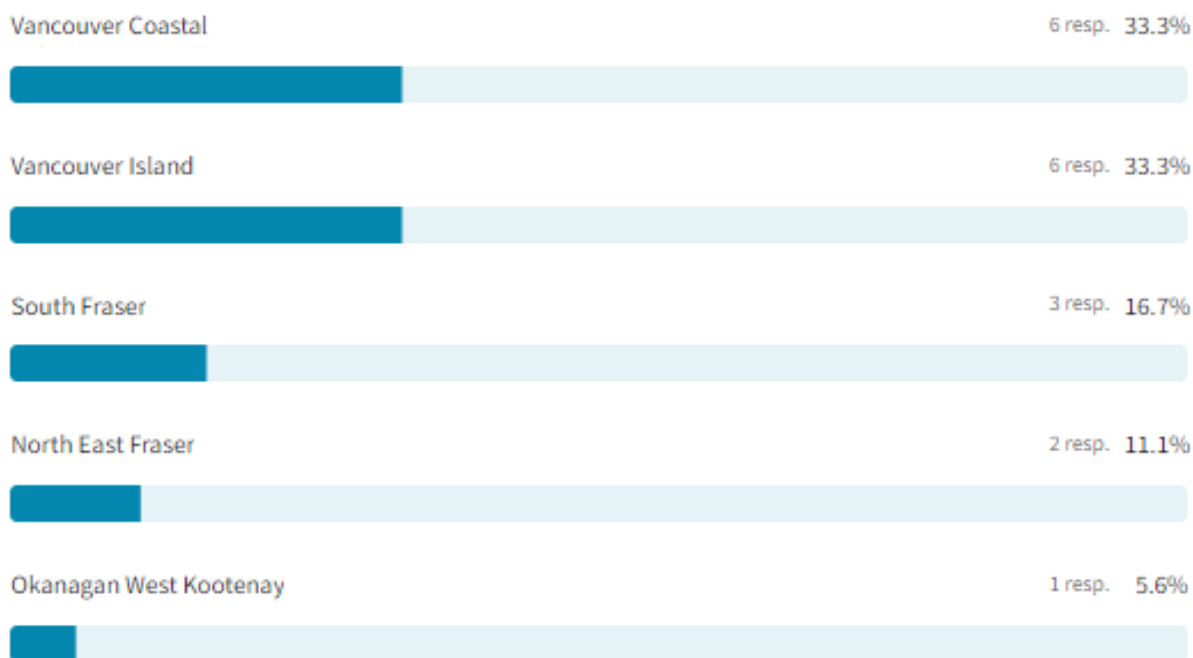
1: Is your organization/service primarily operated as a for-profit or non-profit entity? Please select one. 17 out of 18 answered



Other, please specify:

- University
- Private practice
- Respite

2: What region of the province are you from? 18 out of 18 answered



3: What types of services or interventions do you offer to individuals with ADHD?

17 out of 18 answered

1. Neuro affirming play therapy and child and family consultant
2. RCC
3. ADHD assessment
4. I instruct post-secondary students and have found an increasing number have focusing and time-management challenges. We have a centre for assisted learning, but I don't find they offer any active supports --just exemptions from time requirements on assignments.
5. Occupational Therapy
6. Counselling
7. Supported Child Development, Family Support
8. behaviour analysis, inclusive day camps
9. consulting pediatric services - assessment and treatment
10. Parent management training (PMT) intervention.
11. assessment and treatment services
12. Paediatrician who diagnoses and treats ADHD and other neurodevelopmental disorders
13. Speech services/school support
14. Pediatrician- diagnosis, management
15. Respite for the youth so their parents can have a break.
16. Nursing Services
17. Therapeutic Education, spring and summer camp, behaviour intervention

4: As a service provider, what challenges do you encounter when providing support to individuals with ADHD? 18 out of 18 answered

1. Lack of education on ADHD and how it presents differently in girls and boys. Lack of education that ADHD is a spectrum Little or lack of support for kids in the education system
2. No funding beyond insurance
3. Lack of referrals to supports for adults, unless they also have an intellectual disability and/or are CLBC eligible
4. It's difficult to know where they can turn to for support, aside from private for-profit services (e.g. ADHD coaching). I also believe that schools do not support ADHD as they do other neurodevelopmental disorders, and I often feel that parents have to advocate harder for their kids, and they are already burnt out.
5. Not enough reputable, evidence-informed supports for post-secondary students who are willing to make use of them, and could benefit from them. I am not an expert in this area, and my time for providing these supports is limited. I also have some undiagnosed focusing challenges of my own, and so I do appreciate that the struggle for my students is real...
6. Lack of funding within the school systems, lack of education for caregivers (including teachers) resulting in misperceptions of what is/isn't ADHD, and lack of structured intervention frameworks (this last one is changing a bit now!)
7. Late diagnosis, lack of support, accommodations not be utilized at school, sensory overload, impulse control.
8. Not associated with funding or consistent formal supports at school. Families with young children are told they are "too young to diagnose" but the challenges are present
9. lack of understanding from others (caregivers, teachers etc.), lack of funding - many kids have ASD/ADHD and only have my support because of ASD funding while siblings with ADHD don't. Lack of solutions offered beyond meds.
10. Finding resources to support families navigating the system
11. Need for more time to be responsive to individual needs. Less program strict structure. More practitioners- the waitlist is too long.
12. lack of government support (e.g., MOE, MCFD)

13. There are very few resources available to support children at school and in the community unless families have financial means to pay privately.
14. No or little funding. We are often taking funding from others that need it to provide it to students with ADHD. We are putting them in categories to try and get them support based off of behaviour
15. Suboptimal school supports, parent supports
16. Parents not willing to get correct supports in place.
17. Difficulty with assessment due to distractions, inability to stay still, non/compliance with medications, other mental health challenges concurrent with ADHD
18. Our biggest barrier to services is funding and access to support services. Children with ADHD do not come with any funding to support the child and their family, and no access to a social worker - which then means no access to additional services (respite, funding, counselling etc).

5: In your personal opinion, what are the most pressing needs or challenges faced by children/youth or families affected by ADHD? 17 out of 18 answered

1. Education on ADHD and funding for families to be eligible to have access to support
2. For school aged children both the child and parents need help to understand how to support
3. Need for publically funded support (e.g., CYSN) and IEP support at school (possibly a separate designation for ADHD specifically). I also think that expecting everyone to be able to access private assessment services to obtain a formal diagnosis is unrealistic. I don't think the answer is acceptance of self-diagnosis, but if pediatricians are making referrals for private psychoeducational assessments, then MSP should pay for it.
4. Not understanding what the learning style involves, seeing it as a deficit only, and not having enough support or ideas for how to work with an ADHD thinking style.
5. There needs to be a shift in understanding what ADHD IS, and establishing supports based on this diagnosis. The most pressing need is to support children and youth struggling with ADHD symptoms, as the inability to do so is resulting in severely impaired self-esteem and internalized feelings of anxiety/depression/negativity. The biggest challenge is a lack of funding, which further perpetuates misunderstanding and the idea that kids with inattention should just 'try harder.'
6. Mental health supports, understanding, diagnosis, accommodations, stigma
7. Options other than medication; funding for support
8. education for caregivers, funding for support, educational rights for accomodations in school
9. Lack of education for parents on how to improve their child's executive function and no public resources to support them to do so.
10. Parent support to understand non-coercive practices.
11. Lack of government supports
12. Greater understanding of the strengths and challenges faced, so that appropriate supports and services are available. We also need more trained doctors to diagnose and treat, as well as teachers that have the training to teach children with ADHD in a way that serves their diverse brain best.
13. Executive functioning, misleading information around medication, need for one on one support in classrooms
14. School supports, transition to adult care supports
15. They need updated information and to not rely on what they know from 30 years ago.
16. Funding! And better school supports. Currently, the support goes to children who are lower functioning, whereas children with learning challenges and ADHD are not given any support because they appear “high-functioning”
17. Their lack of support in the school system. Again the barrier is funding, as ADHD is not attached to any funding with the ministry of education designations. Funding and lack of support in the community.

6: From your perspective, what might be some solutions to address these challenges?

17 out of 18 answered

1. School districts having educational seminars on what ADhD is and how to support it MCFD funding the same as ASD
2. MSP should cover RCC services for adhd support
3. More psychologists adept at ADHD assessment in the public health care system and the cost of assessment paid for through MSP. IEP designations should be updated and revised to include ADHD specifically.
4. In my industry (post-secondary education), some consolidated, evidence-supported ideas and advice for students themselves as well as for instructors. There is a willingness to guide students to robust materials and supports--we just don't have a one-stop shop for accessing good quality materials and supports.
5. Teacher Education, Government Funding, Parent Support groups, Implementation of ADHD-specific frameworks in intervention (ex. Lori Flynn's EASE framework).
6. Easier access to diagnosis, societal understanding, mental health support, accommodations,
7. Contracted organizations to provide ADHD-specific support or funding
8. more professionals specializing in ADHD, more info for caregivers on parenting tips, funding for support, training for schools and teachers
9. Government funded commitment to establish and fund organizations to provide executive function coaching to children, youth and families
10. Wider funding, more skilled practitioners, family conflict support, teacher ed. on strength based approaches to behaviour
11. More awareness and support (financial) at the government level
12. Training about ADHD at the medical school level. More public funding for allied health including ADHD coaching, OT, social work and counselling, and tutoring. More opportunities for teachers to learn how ADHD children learn.
13. More funding to provide more EA support and classroom strategies. Reading support
14. Additional funding for schools
15. Education services, in home observations and medication option resources.
16. Better funding, better distribution of school supports.
17. Funding for more support services.

7: What are the recurring themes or feedback you've heard from children, youth, or families with ADHD about their experiences with support services? 17 out of 18 answered

1. There is no funding for support services and little to none in the school system
2. Insurance funding doesn't go far enough
3. How difficult it is to access assessment services. And what to do after they receive a diagnosis. They aren't sure where to access supports, and are concerned about the cost, as most services are private.
4. Inaccessible.
5. Lack of funding within the schools leading to no support for either in school or out-of-school services, persistently being seen as 'lazy,' focusing on a lack of effort in each student rather than a lag in skills
6. Female late diagnosis, lack of understanding, failure to use accommodations, having to advocate for self in school/university,
7. Day to day is hard, they just do what they can to survive
8. many of my clients with ADHD also have parents with ADHD and the caregivers have trouble seeking, scheduling and managing support
9. there aren't any public services. waitlists are long for therapy but what they need is executive function coaching

- 10. Waitlists too long. Need for mediating parenting disputes on approaching parenting with a united front. Parental conflicts make family stress worse- making the child more stressed. Not helpful for executive functions at all!
- 11. They feel alone and unsupported
- 12. There is no one to help, services are too expensive, parents and family members need support as well as the child.
- 13. They often tell me they hate school because it's too hard
- 14. Frustration with school supports
- 15. Not much available
- 16. Lack of support, lack of funding, difficulty with the school system.
- 17. That they have to pay out of pocket to gain access to services. How alone the families are because these children are not included in all activities.

8: Have you interacted with MCFD for any of the following services? 18 out of 18 answered

	Yes	No
Child and Youth Mental Health	15	2
Child Protection Services	13	3
Child and Youth with Support Needs	15	2

9: How has your relationship with MCFD been? Please share any experiences you've had with MCFD and its services. 15 out of 18 answered

- 1. My interactions have been frustrating at times as the child needs to be actively hurting themselves or someone else to maybe get help
- 2. Poor. Don't take long term approach. Don't work in prevention, only crisis mode. Racist system.
- 3. I often find for families that I work with, access to programming or services through mcfd seems to be dependent on the worker they are assigned to. Parents are often concerned about accessing mcfd services because they have an idea that mcfd is only for matters of child protection.
- 4. N/A
- 5. Reactive not proactive, there has to be a crisis for certain supports to kick in in a timely manner.
- 6. mixed. Most MCFD staff have high caseloads and it's varied how much tangible support they actually give
- 7. rarely has MCFD been able to provide what families need
- 8. Few resources that directly enhance skills for parenting and stress reduction. Prevention of systemic oppression.
- 9. Frustrating
- 10. Individuals have been helpful for the most part, but the ministry as a whole sees no benefit to funding support services for "just ADHD", which is very frustrating.
- 11. Good. They are limited in the amount of support they can provide
- 12. Good overall, however long wait times through CYMH
- 13. Very positive
- 14. Mostly positive, though I have had to wait a long time on the phone in order to report abuse, and we have had children waiting a long time in the ER for MCFD to show up
- 15. Overall it has been okay, although my expectations are low. Often the social workers are changing frequently so it is difficult to build a relationship with them. When I put in a call and ask for support, the family is usually in crisis so they will work hard to get support services for them.

10: How could a new support system led by MCFD improve the integration and coordination of ADHD services for children and youth? Based on your experience, what are the essential components that should be included to effectively support individuals with ADHD and their families? 16 out of 18 answered

1. An accessible list of helpful services and funding to make them accessible to all
2. Put adhd supports under ministry of health. Msp funded counselling. This often goes hand in hand with getting medications right.
3. Advocacy to schools, parent support groups, ADHD coaching, connection with psychiatry or pediatrician for medication management. Overall, an individual case worker who understands the nuances of ADHD and can help the family navigate services. That burden needs to be taken off of parents.
4. Not sure. In my industry (post-secondary education for youth), MCFD is not a natural partner, and there may be a lot of stigma attached to services that are located there.
5. Parent and Teacher Education re: executive dysfunction and how to support building these skills in kids, Support/Social groups for individuals with ADHD to develop skills in how to improve their occupational performance issues
6. Proactive support, ongoing programming without gatekeeping OR at least shorter waitlists
7. Families shouldn't have to prove how bad their lives are to get access to respite. They shouldn't have to hound their social worker to get information or supports. Many supports are available but not readily offered and a parents can sometimes get them if they hear about it from someone else and know to ask for it. This information should be readily given with follow through from MCFD
8. navigators, funding for assessment and treatment, educational opportunities, parent coaching, executive function coaching, counselling including CBT for ADHD
9. Parenting mediation, citizen engagement to give voice for lived experiences of institutional stress, open feedback, answer 94 TRC Calls to Action. Especially Call To Action 6-
10. Offer programs for families impacted by ADHD
11. Multidisciplinary services that can diagnose, treat, follow, and support not just children with ADHD, but their family, school, and community.
12. Educational support, executive functioning support, family support, de-stigmatization
13. Funding for medication coverage not covered by special authority, integration within the school system
14. Individualized supports for families. Resources on setting up schedules and implementing changes within the home.
15. More support and funding for families. More support, funding, and education about ADHD in schools
16. Actually giving them a CYSN social worker.

Part of an organization that can/does collaborate with the Society

1: What region of the province are you from? 2 out of 2 answered

There were only two responses for this category, and both were from North Coast/Bulkley Nechako.

2: What types of services or interventions does your organization offer? 2 out of 2 answered

- We are currently in development
- Early intervention, therapy and behavioural interventions

3: Has your organization had any involvement or experience working with individuals or families affected by ADHD? 2 out of 2 answered

Yes: 2 | No: 0

4: In what ways do you currently support, or have supported in the past, individuals with ADHD or their families? 2 out of 2 answered

- Currently in development
- Seeking resources to educate and behaviour intervention

5: What feedback or common concerns do you hear from individuals or families affected by ADHD in your interactions or collaborations? 2 out of 2 answered

- Lack of services and supports and lack of education
- Lack of resources in community and schools

6: What unique perspectives or resources does your organization currently offer to help address the needs of ADHD families, children or youth? 2 out of 2 answered

- We are currently in development
- One of the few centres that is open referral system to help connect families/caregivers with services

7: Have you interacted with MCFD about any of the following services?

2 out of 2 answered

- Both responders said yes to all three: CYMS, CPS and CYSN,

8: How has your relationship with MCFD been? Please share any experiences you've had with MCFD and its services. 2 out of 2 answered

- We have a signed agreement with MCFD to create a pilot program to support CYSN
- Strenuous

9: What existing programs or initiatives within your organization could be expanded or adapted to better support ADHD families, children, or youth in British Columbia? 2 out of 2 answered

- Our Health, Education and Social departments could and are expanding
- Social learning groups, parent supports, individual supports, educational support, advocacy for children and youth in schools

Volunteer, a staff member, a board member or a Board Director with the Society

1: What region of the province are you from? 1 out of 1 answered

Only one response from this category from North East Fraser

2: What do you perceive as the primary role and mission of the ADHD Advocacy Society of BC? 1 out of 1 answered

Our goal is educating and supporting and advocating for all ADHDers. We advocate in all aspect government for better ADHD recognition and support.

3: Have you or someone you know been diagnosed with ADHD? 1 out of 1 answered Yes.

4: Please share your insights and/or personal experiences related to ADHD diagnosis and management. 1 out of 1 answered

I was diagnosed at age 12 in the 90s when it was extremely unusual for girls to be diagnosed. My mum did have the psychologist present the diagnosis to me and what that meant in a personal meeting for just me and had a different one for her as well. I was given the option to try medications as management and I made the choice not to. I worked very hard with the help my mum and outside skills courses and things to learn at least school skills and some EF skills. My mum told me that even if I had chosen to try meds only a psychiatrist could prescribe at the time and that would have been very challenging to get in to one. There was no school supports at all offered by the school.

5: What is your understanding of the current support services available for individuals with ADHD? 1 out of 1 answered

There are still not a lot of supports available. Today it is still not designated at school and teachers still know very little about it. Most students with just ADHD have no designation and not entitled to supports or even an IEP. Outside supports these days I would say are OT and Psychology as some options and maybe ADHD coaches or Executive function skills coaches. All of these are out of pocket for payment and there is no funding and so are out of reach of a huge number of people. Support networks of parents on social media are a go to for many, for resources, education and understanding. There is nothing offered by the government for help and support either. There is still a lot of stigma everywhere and is extremely unhelpful. Many doctors are uneducated.

6: In your opinion, what are the strengths of existing ADHD support services? 1 out of 1 answered

There are no real supports so no real strengths. If picking say a support that is paid for out of pocket possibly like OT or ADHD coach the strengths are that these deal with things specific to certain struggles with ADHD like executive function skills and sensory challenges and or with an ADHD coach they are often ADHD themselves and can help with ADHD specific things. There are no public supports for kids or adults so no strengths.

7: In your opinion, what are the weaknesses of existing ADHD support services? 1 out of 1 answered

The fact there isn't really any supports at all. Very little for kids in school. No designation and no IEP. Lack of knowledge by everyone that works with them. There is even less for adults, no supports at all and none at work, if you have a decent boss you could ask for some accommodations but because of stigma it may or may not go well.

8: How can the ADHD Advocacy Society of BC better advocate for the needs of children, youth or families with ADHD? 1 out of 1 answered

Advocacy and education needs to happen at all levels. We need the general public, all people who work in schools or with kids in any situation to know what ADHD really is and how to support it. We need all medical professionals to be up to date on their knowledge about ADHD and about its treatment. Education on what it is and how it affects us and that it is not a choice and ADHD people are not doing it on purpose and are not bad. That we are very smart and outside the box thinkers and innovators and valuable people with differently wired brains. They need to know how to support us and how they can make changes to every day things everywhere that would greatly benefit us and at the same time it will benefit everyone else too. Helping end stigma.

9: Advocacy is one of the key roles of the ADHD Advocacy Society of BC. What other roles do you see emerging for the Society in the future? 1 out of 1 answered

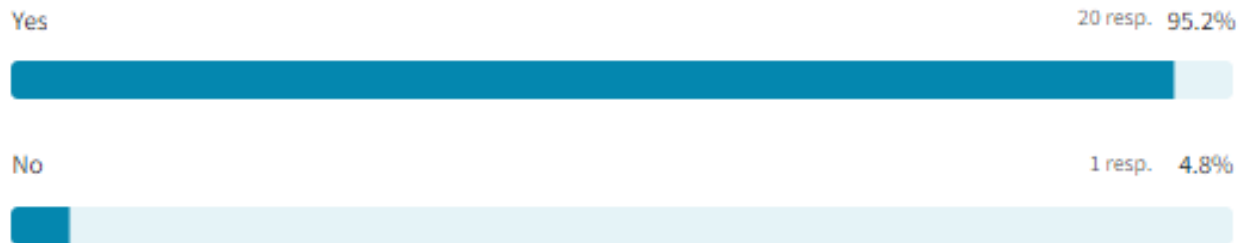
A place for resources and information that families need and can find in one place that are ADHD related.

Common questions for these Stakeholder groups including

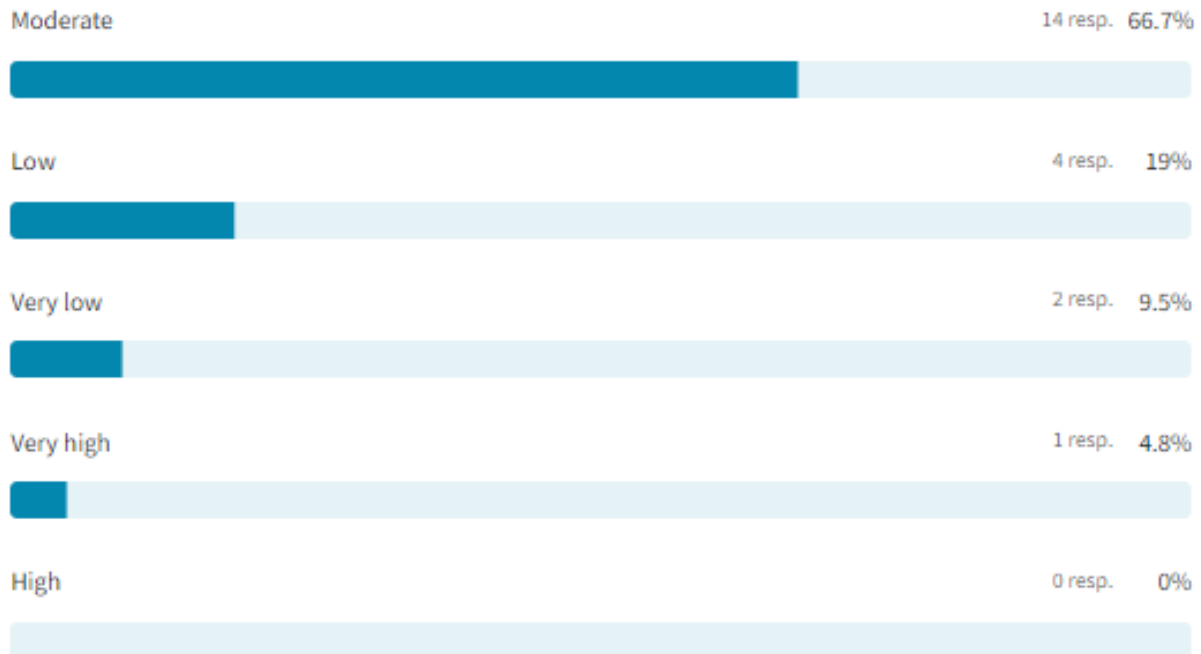
- A Service Provider who works with people with ADHD
- Part of an organization that can/does collaborate with the Society
- Volunteer, a staff member, a board member or a Board Director with the Society

1: Are there some common misconceptions you've encountered about ADHD in your community. (in your family, at school, at work or in the general society around you)?

21 out of 243 answered



2: How would you rate the level of awareness and understanding of ADHD in your community? 21 out of 243 answered

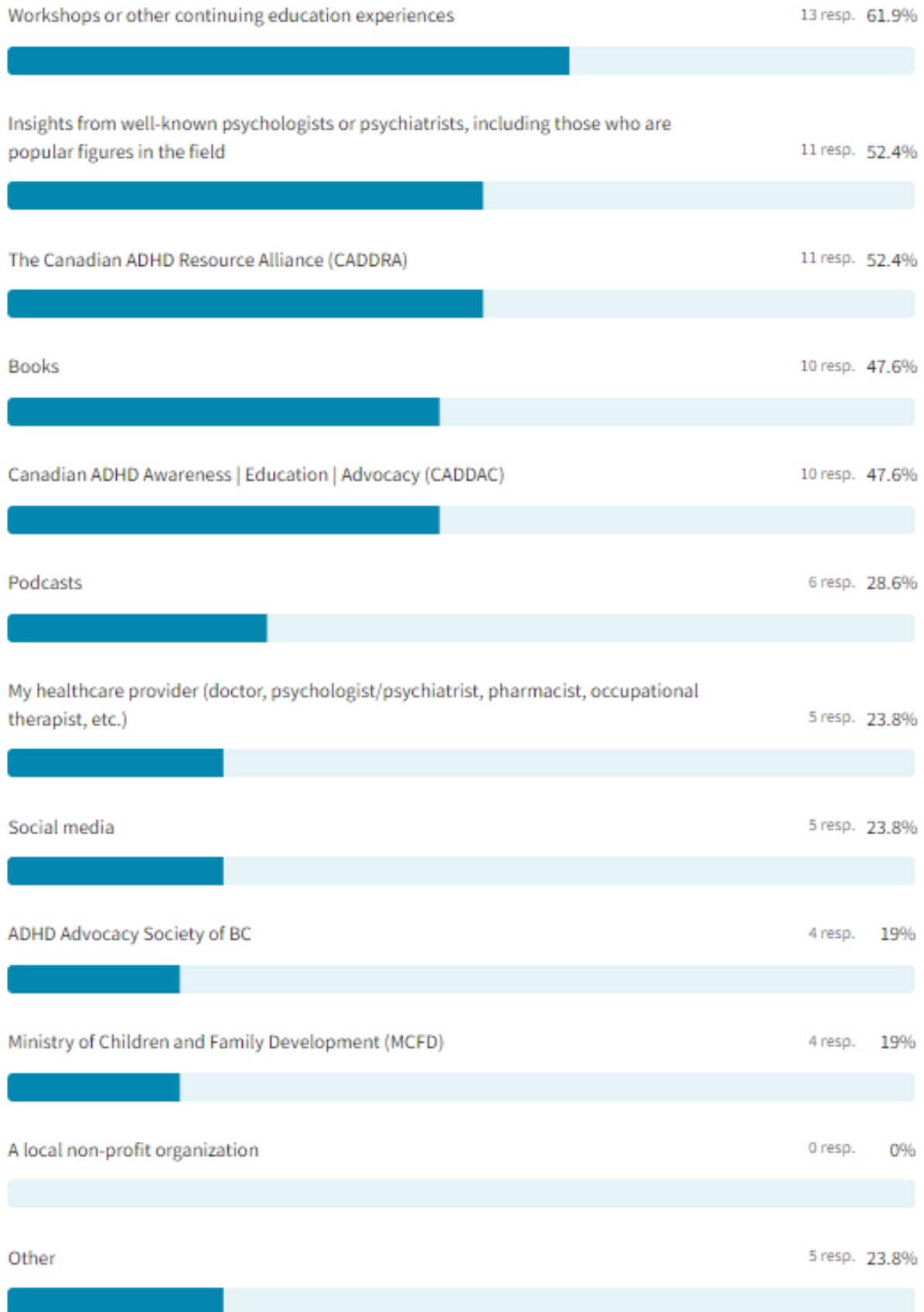


3: Please elaborate on what some of the misconceptions are that you have encountered about ADHD. 19 out of 243 answered

1. People not educated on the different strategies to help with focus People think you can turn it on and off. Not understanding the anxiety that comes with ADHD
2. People with ADHD are wild
3. Lazy, can't change.
4. misconceptions: that people grow out of it, that it only affects boys, that it means people are hyper, that it means it only affects concentration
5. Some people assume that students with ADHD are lazy or apathetic. This is not the case --they want to make progress.
6. Kids are lazy, ADHD is just hyperactivity, if we make a kid try harder they'll do better, kids are too 'old' or too 'smart' to need increased levels of support
7. Don't pay attention and can't learn
8. That folx with adhd are simply inattentive or lazy.
9. The children just have to "try harder." Many families do not understand there is a neurological difference, rather than just behavioural presentations. Medication is not well understood.
10. ADHD mistaken as laziness, apathy etc. People truly don't understand the impact it has on impulse control and think lectures and punishment are the answer. People don't understand that movement and adding stimulation can help focus and attention. Kids are often told to try harder, when it's not recognized how hard they are actually trying. Parents and teachers have age typical expectations on independence, organization, and responsibility without realizing these are deficits and delays they wouldn't expect of a younger child. Presuming competence while understanding real support needs has to occur simultaneously!
11. My grade 6 teacher thought I would not make it to university. (I was diagnosed that year). Little did she know that gave me the drive to say watch me and I did, but it stuck and it stung. I did not like that teacher much. I have also heard the standard about not meeting potential or are lazy etc.. as well.
12. People don't understand the complexity of it; people think the challenges of ADHD are not brain-based "just do it"; people with adhd are "lazy, don't apply themselves"; lack of awareness of the comorbidities
13. That the behaviour profile is untreatable.
14. That ADHD is a disruptive behaviour disorder, that it's not a real disorder (everyone has the symptoms), that the medications for ADHD are dangerous
15. That "everyone has it"; that it's not disabling - people can just try harder to focus and behave; that pills cure it so no support services are needed; that symptoms are willful - kids are bad
16. That it is a behaviour issue. Medication is not good.
17. You need to make people sit and do school or activities like everyone else. You dont care because you forgot.
18. Attention-seeking, they are faking it and able to control their hyperactivity.
19. That they are all hyperactive. Especially when it come to females with ADHD.

4: What are your primary sources or trusted sources of information regarding ADHD support?

21 out of 243 answered (with multiple choice)

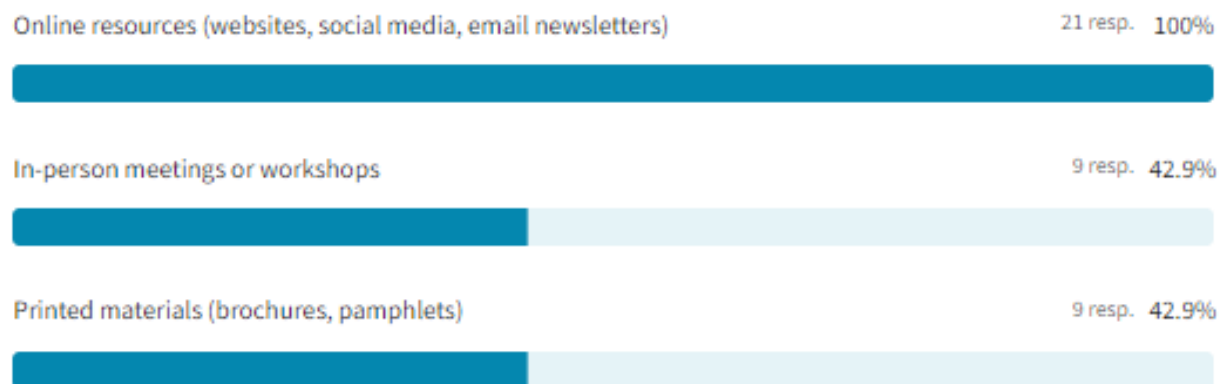


Other (please specify):

- <https://www.additudemag.com/>
- ADDA, ADDIVA network, many well known ADHD coaches and professionals of various types and their websites, ADHD summits, Scientific studies, CHADD
- ADDITUDE website/podcast/magazine
- Current research
- the internet - google

5: How do you prefer to receive information about ADHD and related support services?

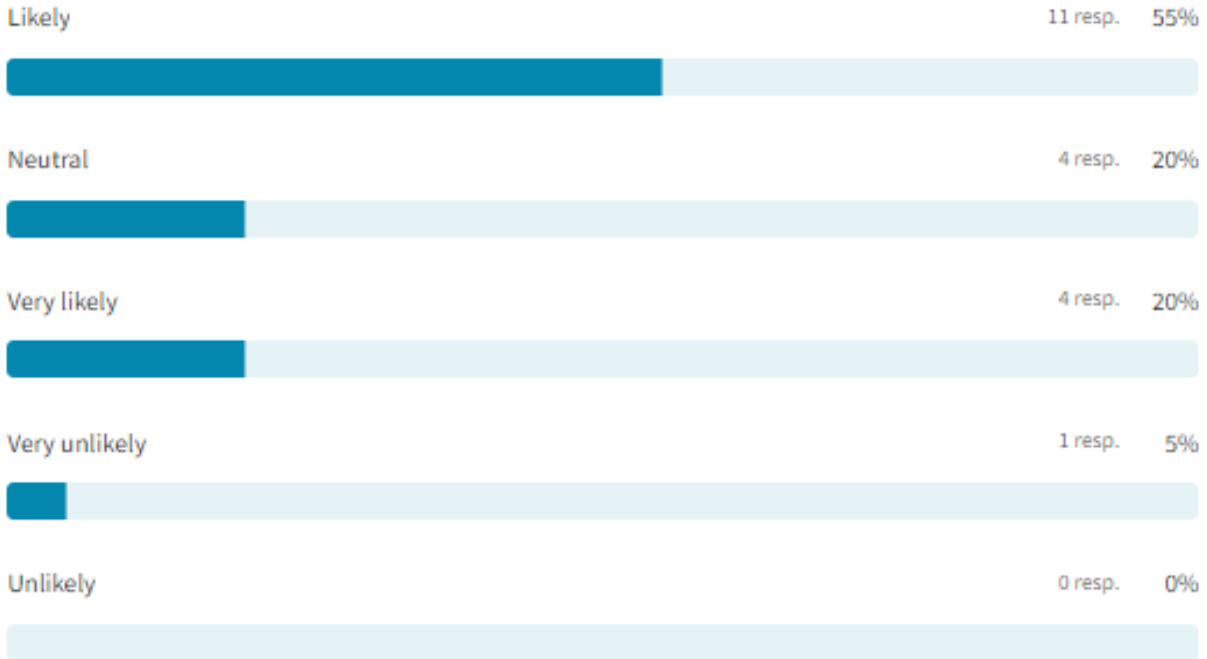
21 out of 243 answered (with multiple choice)



6: How do you think you or your organization can contribute to the development and implementation of a new provincial support system for ADHD children, youth or families provided by MCFD? 15 out of 243 answered

1. Unsure
2. Providing insight into indigenous people with ADHD perspectives, as well as those living in rural communities.
3. We could be a contracted assessment provider. We can also provide psychoeducation to families
4. not sure.
5. Providing education to larger government bodies (ex. schools), direct service provision and consultative services for families with children with ADHD
6. Sharing information with individuals and or other agencies, gaining knowledge on ADHD to better understand to support
7. Providing counselling support
8. advocacy, education
9. Helping develop educational training to the people running the support system so ADHDers needs are heard and met appropriately and not dismissed.
10. I really don't know
11. Joining a collective voice
12. I approached MCFD several years ago with just such a proposal and was told there was no funding. I haven't given up, and continue to build my network of allied service providers. If MCFD is willing and able to collaborate on a multidisciplinary service, I am happy to be a part!
13. They need the support from the school districts
14. panels and discussion with provincial stakeholders
15. Most of our children that we support are autistic - often because of the barriers of funding. Many of our autistic students also have ADHD. We do not have as much experience support children with just ADHD and so it would be great to support more children that need it and are not receiving services due to the funding barrier.

7: How likely are you to recommend the ADHD Advocacy Society of BC to a friend or family member who has, or is supporting someone with, ADHD? 20 out of 243 answered

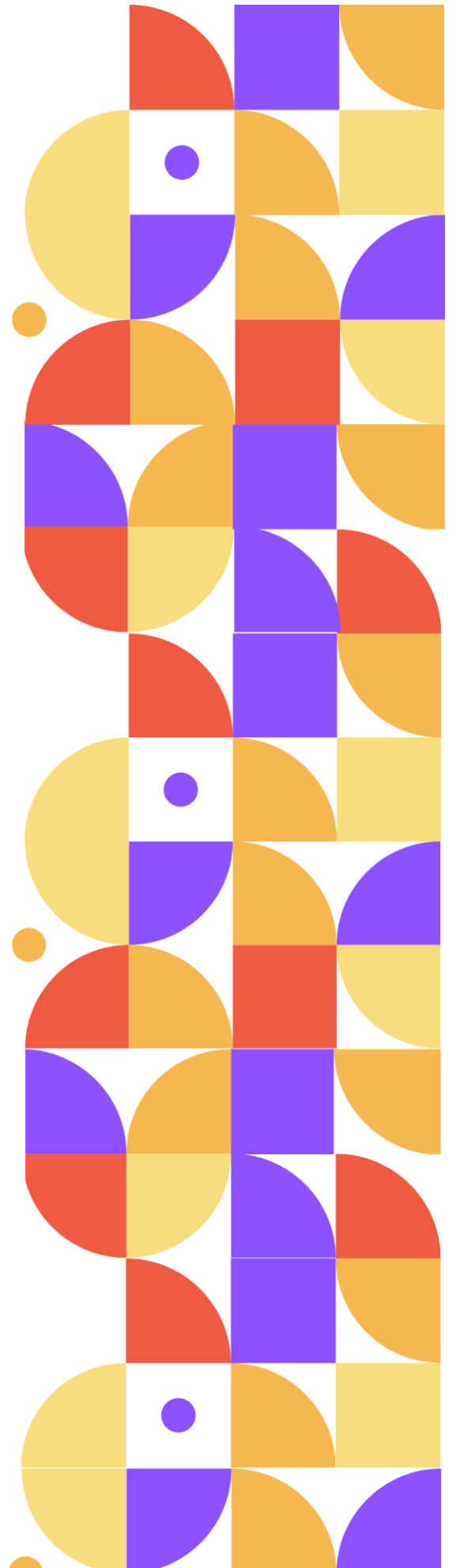


8: Is there anything else you would like to add? 8 out of 243 answered

1. I am the CYSN Coordinator for Nak'azdli Whut'en First Nation. Our CYSN services are still in development. We are the only First Nation currently in agreement with MCFD to develop an indigenous led support service framework.
2. I appreciate what you're doing for families, and I wish I knew about your organization sooner.
3. I am interested in this project, just not sure of how much time I would have to be involved. Please keep us informed.
4. Thank you for doing this- I'm sorry for my late submission!
5. Thank you!
6. N/A
7. Thanks for what you are doing.
8. More funding and access to support services would be amazing!

● APPENDIX

RAW DATA - IN PERSON AND
ONLINE FOCUS GROUPS



Q: Have you ever had experience with MCFD and if so, with what?

Our kids were taken away legally, and we did everything we could to get our kids back. The social worker with MCFD was very helpful.

Our kid – who is very clumsy – broke a bone, and based on what he was saying, the doctor reported my ex-wife to MCFD, so there was follow up.

MCFD is the closest thing we have to a training manual for kids in the support they offer to our family.

I was signed over at the age of 17 and lived independently through them for two years. There was not the support I needed at home as my parents had major issues with their own mental health and addiction. Despite my circumstances, it was a good experience to help me find freedom and support me. Fast forward to now, years later, I had someone called MCFD on me when my daughter was two. Instead of supporting me, they made me feel shame. I have reached out over the years, but I have had no positive experience or others services offered. No direct support of counselling and a lot of shame. Persons With Disability (PWD) has actually been more helpful to me than anything. I thank them whenever I can.

I don't feel the support by MCFD. I feel they are so busy and so inundated with a lot of stuff.

No experience. I do have close personal friends who are social workers with MCDF. They talk about the system having so much red tape, that they feel like they are not helping anyone. It's a pretty challenging situation from the sounds of it and their experience.

Q: How satisfied are you with the current supports and services available for individuals and families affected by ADHD in B.C.?

I was diagnosed at 55 years of age. When I had medication, things were clearer for me and I went a little easier on myself. It was very challenging to find resources for women with ADHD. I have done a lot of research and listening to books on Audible. I have talked to different mentors in business, and I have a great nurse practitioner who helped with a diagnosis.

Getting a psychologist is a financial barrier to getting a diagnosis.

Most people don't think ADHD is a real thing, but rather an excuse for behaviour. I did a series of testing with a nurse practitioner and did a lot of research in terms of supports and medications.

No. I had a late diagnosis at 36 year of age after five years of getting through the process. It was long and challenging.

Not happy. We have two boys with ADHD and their dad has ADHD too. After a child is diagnosed, parents should be offered assessment automatically.

There is such a barrier to getting an assessment. Our doctor said to fill out a form online and bring it in, but filling out forms is such a barrier to someone with ADHD to fill out the form, print them off. It took me 4 or 5 months to just fill out the forms.

I don't think there is much in terms of supports and services. I do a lot of research and advocacy for myself, but information is still hard to find. I'd love to develop a support group for women as we go through a special sort of hell with expectations, hormones, etc. I avoid social media at all costs because of the negativity, I would never do a support group online. I mainly find information in the U.S. and I am looking for big, trusted sites – recommended by the nurse practitioner. The financial burden for an assessment partially covered by extended health, it's still expensive. There are a lot of health challenges that can arise such as substance use addiction – I used alcohol. Paperwork support would be helpful, because that makes me stressed and it is paralyzing.

It takes so long to get any assessment and a diagnosis.

Finding resources is challenging as they are not easy to find.

Had to go privately and had to wait 2 years to get an assessment for autism. We're watching our child fall behind in school and the school is just letting him slide.

Q: Has there been a negative impacts in the following areas: employment, education, mental health, or physical health?

Education. Our son's EA had surgery, so our son was disconnected to their EA and had to change teachers which was hard. The Principal has been amazing and is helpful to our son and being accommodating.

Education. Access to the Individualized Education Plan (IEP) through our young son's cancer diagnosis because he missed so much school – but not from his ADHD. There's not enough follow up after diagnosis of ADHD to support.

Education. Schooling has been impacted by being excluded in school. The spread between him and his peers is growing larger and larger as he gets older.

Education. Elementary school in the early 90s they were pushing the medication and that is all they were pushing. I can remember being bored a lot of the time – I couldn't stay focused. My Mom was feeling criticized by people in the school for how I was raised.

Healthcare. The lack of follow- up care with their pediatrician is a challenge. There is no time or interest to find out what is going on to be proactive.

Personal Relationships. My marriage fell apart – my wife is neurotypical, and I have ADHD. We were not compatible. Both our kids have ADHD, and she doesn't know how to raise them, which creates more divisions in our family. I reference the movie Hook when you have the first stimulant – “There you are Peter!” I was focused after medication, and it helped me and could have helped me a lot earlier.

Employment. I always wanted to be a doctor, but what stopped me was applying for paperwork because it was paralyzing. My parents allowed me to do everything I wanted to do; they were supported in to keep me busy. A lot of parents that can't put their kids into activities like sports because they can't afford to.

Employment. My staff, many whom have ADHD, are negatively impacted as they get frustrated in not having autonomy. I tell them, "You all have a voice here – bring your ideas, you have a say." They enjoy that aspect and that we implement their ideas. They can take ownership at the business.

Employment. I would love to see some change in employment situations where things can be learned in a different format.

Mental Health. People are quick to judge and think you have a mental illness – the stigma exists.

Mental Health. I was 33 years old when I was diagnosed. I have a family doctor, and I am privileged. Could talk to my doctors with my mental health. My family is open about medication and mental health. I also have anxiety with death and dying. My anxiety got a little better after that, so I started seeing a counsellor. My doctor agreed to put me on medication to see if my symptoms subside. The medication is working well for me. I don't know where I would be without the support that I have.

Mental Health. Criticized by family for medicating my child and criticized by school for not medicating my child. I couldn't win.

Q: Share what gaps you've experienced. What solutions would help you?

Peer Group. I want to network with those in the business community or high achieving because I relate to them. That would be beneficial – a peer group of women ADHD Entrepreneurs would be great.

Support Group. There are tons of support groups, but not in B.C., and there is nothing for adults.

Resources. There are not enough resources for medication information.

Support Group. I grew up my whole life thinking I'm a bad person.

Remove Stigma. There is a stigma around surrounding ADHD that wrongly associates it with stupidity.

Support in Healthcare. I didn't know what to do with the information about having ADHD and what the next steps would be on how to get an assessment. I was told I didn't have ADHD because I graduated high school and had a job.

Support in Healthcare. Telehealth people were not helpful. The more I researched and the more organized I was, the more people said I didn't have ADHD. I was on a call with my doctor, and she was so dismissive that I as really stressed.

Support in Healthcare. Medical professionals who are not aware of what ADHD is and don't take people seriously. You need to be a strong advocate for yourself, and we need to provide them with training and information.

Support in Healthcare. Shorten the delay of time to get an appointment for a diagnosis.

Support in Healthcare. There are so many barriers: because you know, and you've done the research and the barriers come up because medical people think you are looking for drugs.

Support in Healthcare. Have something like you can get for an STI with Get Checked. An online portal which helps you narrow things down specific to ADHD. Advocating for the support you deserve.

Support in Education. Elementary school was the biggest challenge for my daughter. High school was better and moving around classrooms and teachers and subjects. They excluded my daughter in elementary school to a class trip to a camping trip and there was a history of exclusion at school. The counselling office a bit more supportive in high school. I don't want people to go through that as a single parent. Report cards changed from letter grade to proficiency scale and that was not good for my daughter who wants to see that what she does sees the benefits.

I don't know how I can help fix things. I'm just one person.

I was too emotional, and people didn't want to deal with me – I cried all the time.

I'm a single parent and MCFD pounds on my door that minute. I am struggling to look through your house.

Tax support. Have an ADHD tax place for you to file your taxes. Someone who has that all organized for you.

Financial navigator. Financial education.

Drop-In Centre. Access to assessment and diagnosis not just for adults but for kids too. A place to go – an ADHD drop- in centre. I went to Interior Community Services, but there wasn't anything specific for ADHD.

Reduce Stigma. This makes ADHD challenging and you don't want to ask for support. People believing me and that ADHD does impact me. Stigma around taking medication. More information and making it more common or more accepting.

Medication Support and Education. It's hard to pick a medication to have more information about the different medications. More options for coverage for medication that is not covered – access to affordable medications. More support in getting those medications and supports.

Access to Medication. Access to free medication would be important. If I didn't have benefits I could not afford them.

ADHD Employer Supports. More businesses having access to ADHD workshops and training. Ongoing training if their employees need it or want it. More inclusion information. Better tools for communicating better. Easier access to information.

Home Support. The opportunity to hire someone to come in and help me organize. House cleaning and daily living support. Access to therapeutic sessions. More support and access to support in-home. More access to Persons with Disabilities (PWD) – that’s what saved me out of the pay day loan cycle.

Support for Adults. Nothing is geared toward adults in terms of supports; it’s even more challenging for women or minorities.

Health Navigator. One stop shop for phoning someone - a navigator who can help you and direct you.

Healthcare Support. Consistent access to a psychiatrist without asking for a referral every single time. And it should be covered by medical. Coaching and counselling – it was so great and good for me, but I don’t have the funds to continue that.

Early Support. Make it so people don’t have to be in crisis in order to have access to help.

Healthcare support. More education for people who are diagnosed. You shouldn’t leave a doctor’s office with a prescription without good information and follow up care to a counsellor or others who can help you know what to expect.

Education for those in healthcare. Informed care from secondary providers and training for these people.

Parental Support. Support for the parents too.

Health Navigator. Having kids with ADHD and helping them find supports is like a shitty treasure hunt.

ADHD Coaching. Not everyone can access it but it’s helpful.

Q: Have you ever had experience with MCFD and if so, with what?

Yes – my son was upset once and told his teacher that his Dad yelled at him. MCFD came in and did a complete investigation and recommended that his Dad take parenting classes. It was a ‘Dads supporting Dads’ group.

I have limited experience with MCFD.

We have had no connection with MCFD. We have received a new diagnosis for our child, so we are new to all of this.

No experience with MCFD but that’s because I fell through the cracks like many people and have never received services or help.

We have had good outcomes with MCFD but that’s because I’m very bull headed and strong and I keep going until we get what we need. I know that’s not the same experience for others who I’ve talked with.

Zero. But my daughter is only 5 years old so we’re likely new to everything and will likely encounter MCFD.

No interaction with MCFD.

Not in my personal life with my own family but I did when I was growing up with my parents’ relationship.

The Ministry has been great to us - our son has many diagnoses. We get direct funding to pay for the many therapies he needs. Unfortunately though, we have gone through a number of social workers. ADHD does nothing as far as a diagnosis goes to get any supports. We are medicating our son and that has made a difference in his life. Generally good experience.

We are low income, so all medication is covered except ADHD medications. It’s very expensive.

MCFD has not been helpful. They were at first when we got our grandkids after our own child had passed away. Initially they were great but then it changed. They did not care about the care of our children. We didn’t feel we were well supported by MCFD. The kids were apprehended from our care after living with us. We believe the Ministry has left our grandkids in a perilous situation with no support. The system has full control and there is nothing that gives families the power. The call is made based on procedures and protocols – not a careful look at scenarios.

Q: How much do you know about Family Connection Centres and CYSN (Children and Youth with Support Needs) Services?

No experience and I don’t know anything.

I have no experience and do not know what this is.

We know about them as both our boys have autism diagnoses. Our psychologist before said there was no need to get an ADHD diagnosis because it was useless. After we fired them, we got our kids diagnosed, got them on medication and then they were not suicidal.

We work with them because our child has been diagnose with autism. We want the best for all children, but when we learned that funding could be removed from children with autism to go into the FCCs, we were very nervous for what this could mean for lack of support.

I have no idea of what these are and we have never had a connection before.

I know very little about FCCs or CYSNs so I don't know if they could be helpful or not.

Q: How satisfied are you with the current supports and services available for individuals and families affected by ADHD in B.C.?

We are not satisfied because we don't know how to identify what services are there. It took so long to find the support we have found.

Not satisfied. Even our own doctor does not support medication.

Not satisfied. It has been so hard to get my prescription refilled for ADHD medication. It has to be filled on the day and they don't give you more than one month, and I can't go without them.

Not satisfied. My 9 years old does not have a diagnosis yet and we're still waiting and waiting. It's hard to find another doctor or anyone who can help us.

When you don't have a diagnosis, they send the parents to training and coaching instead which doesn't help the child. We are not happy with the supports and services.

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

It's hard to find resources and supports. I took my child to the Child Development Centre, but I feel like we're doing all we can to find help and support, and we're not getting it. Meanwhile, our daughter continues to suffer and not get the help she needs.

I feel quite lost, but the school we attend – Heritage Christian Online School – has really helped us access service and supports.

I don't know, I hear the stories of those families with ADHD, and they don't have an Education Assistant in their school for their child and therefore they don't have supports.

There is an Autism group in Chilliwack which has been great. The only other resource was the doctor who gave us a diagnosis. Other than that, we do not feel supported or that we have the resources we need. I am on a waitlist to be first on a 2025 waitlist for a certain doctor to get support. There are not enough doctors out there to support our families and children.

Very low in terms of support.

We get zero support. There is nothing for my child. We to figure everything out ourselves.

Very low in terms of satisfaction. I don't feel there are good supports. We were referred to a course online – Rolling with ADHD – as we were hitting issues with medication with our grandchild. You need to do a lot of self-advocacy. We were told we needed to self educate ourselves.

Q: Have they been negatively affected in any of the following areas: employment, education, mental health, physical health?

Yes – education and schooling. We are not supported, and our child is constantly in trouble.

I am on disability now because I am burned out. If there were supports for me back years ago, I could have found the help that I need to be a productive and contributing citizen. Now, I spend hours in my room in the dark because I'm so exhausted and burnt out. I feel there is no hope and I don't have any aspirations.

In society in general. I am a trans woman and I do not feel there is support for those in our community. I believe so many trans people have ADHD, and they have been left for so long without support.

The school system is terrible. My child is five and supposed to go to Kindergarten this year and I think we'll be doing home schooling. They don't want to go and the supports we would need are not available.

Our kids have not done well in school. There is no supports for them there and they get in trouble. It have been a challenge.

We homeschool our kids and it's been great for them, although it's a big sacrifice for our family as we are low income and we only have one income for our family. My husband was doing construction but hurt his back, so for a while there, we had no money coming into our home. But we continue because we believe it's the right thing for our kids who are brilliant.

The healthcare system is a nightmare. I spent most of my life on an anti-depressant, although that wasn't working because that wasn't the problem. It wasn't until I was 47 until I was diagnosed.

Education. Being at home with our kids for home learning has been a top priority and has worked out so well for our kids. They are excelling in so many ways from being home learners.

Q: Share what gaps you've experienced. What would be some solutions that would help you?

I wanted to make a note that if you have PDA, I have heard that it is likely you will get an Autism diagnosis. The is slowly opening the doors for more funding.

This is multigenerational and we have so much stigma attached to ADHD. If we can reduce the stigma and build understanding, that would go a long way in helping people reach out for help and not feel like they are alone.

I think that we should have the special needs classrooms again – I know that's an unpopular opinion, but we lose the focus for kids who need help and the kids who are ADHD and have dyslexia are no longer supported. The kids are all in one classroom, so in some ways it works and some ways it doesn't. Why is my kid in grade 4 science when he can't even read.

Finding the right people to help. You have to push to get into the system, but once you find the right people – that can help launch you and your children forward.

Strong Start – a great way to get families connected where they may not get the connection with others if they're not leaving the house or not engaged in their communities. Having kids assessed there would be great so that they get diagnosed and help when they're younger.

Better resources before diagnosis. Information that is helpful for families who have no idea what they're getting into.

Public advertising on what ADHD medication is and does to try and reduce the stigma around it.

More education for those who are teachers and medical professions for greater understanding of what ADHD is. It's challenging having these leaders not be aware of ADHD and having to push for a diagnosis, help/assistance, or guidance because they don't know.

More support groups. I never had supports when I was a kid – and I still struggle – and would benefit from more support groups. Talk about you've been through so you know you're not alone. That would even be helpful.

Free universal training on what ADHD is that you can take at your own pace. The issue, I believe, is that the government doesn't want us to become aware because that takes away jobs from those in healthcare. Fraser Health, for example, is unionized so if people are better educated, it lessens the demand for help.

Resources that resonate with the next generation. My generation is going to watch Tik Tok so having information and supports relevant to how these audiences access information and understanding that people access information in many different ways.

Communications that are targeted to specific generations to build awareness and understanding.

Neuro-friendly rooms and spaces. For example, we have rings and a bullet bar in our house. It would be amazing if they could do this in other areas like restaurants or other spaces to help kids.

Added funding to help purchase the specialized food our ADHD kids will only eat. Our pediatrician said our son is not growing, but that's because he will only eat certain things, which are also more expensive. Having a funding to help with this would be huge.

Help to fill out paperwork. For some, there is money and funding available, but they'll only apply for one or two pots of money because the paperwork is a barrier.

Respite for families.

Supports to fill out paperwork.

Places with trained facilitators who know how to work with youth who then know how to work with these kids. Summer camp, for example, would be great to have the youth trained to work with kids who have ADHD so that they know how best to work with them.

Stopping the cycle of stigma. Share what ADHD is and is not. ADHD does not mean that people are lazy.

Having a peer mentor for those getting a diagnosis. Once you get a diagnosis, you feel like you're the only one and there are limited places to go for help to get to the next steps. Having another person who has gone through this already would be so helpful to provide that guidance and reassurance.

Money for ADHD medications because they are not covered by the government. Medication for ADHD is currently out of pocket for parents.

If there was a counselling or training for families when the diagnosis happens on how to cope with this.

Training for those in medicine and teaching. Having these people who interact with our kids understand more about ADHD would be amazing.

A clear understanding of the pathway to a diagnosis and then what's next. People are just not aware.

Awareness of symptoms and things to look out for with ADHD. Also look for symptoms of what to look for that is more gender specific. Without a lot of testing in the past for girls, there is not as much information and you can't test a girl with the same test as a boy as there are differences.

Unlimited school support! One on one assistance and support for our kids with ADHD. Equal support as for those with Autism.

Covered medication for ADHD.

Coping mechanisms: support groups | respite | general tools to cope with ADHD.

Support groups where people can share relatable stories.

Support for parents to help their kids. For those parents with ADHD and those who do not have ADHD.

Job opportunities for those with ADHD who would be amazing and support on the job. Employer training would be excellent to help really make inclusive employment inclusive.

Help reduce the gender bias in the medical/healthcare system.

More public awareness campaigns to help reduce stigma. More understanding and the normalization of the ways you're different, but that's good.

Better support for stepparents. Being a stepmom, I don't have the same voice as the biological parents. Being a stepparent, we don't have the same voice to advocate for our kids in the system, but we're trying to help find them supports and services.

Gender bias is a big gap in getting a diagnosis and getting help. There is a bias toward the way you present and how you function which could prevent you from getting a diagnosis.

Money is a huge challenge – any financial investment in those with ADHD is money well spent.

Proper diet and we react to the food we eat. Having money to help create eating plans to help us regulate ourselves.

Coaching and counselling for couples for those who have ADHD and those who don't.

Make things more accessible for those with ADHD taking into consideration how our brains work.

Holistic planning and support. I don't have hope – I feel like my life has been wrung out of me. I don't have any aspirations anymore. I would like someone to be able to help with holistic planning. We need the same thing that Alcoholics Anonymous has – a holistic approach with peer support, training, tools, networks.

Mindfulness practices to help us track back to why we are having these thoughts. I have had to manage my own shit, and if I didn't, I wouldn't make it. Having a counsellor who is neurodivergent who can offer free counselling.

Education for people who work with kids with ADHD. The education system doesn't recognize what is going on with those with ADHD and how to support. Kids are growing up in a world where they don't know why they are different, and they don't have the supports. It's been a constant cycle of hell for me.

We have a system that tries to help fix people instead of fixing the environment.

Support groups. When we find our tribe, it's amazing.

Having the voice of trans people being heard. The voice of trans people have not been heard and there are so many challenges with transgender people as such a big part of this group of people have ADHD.

Peer support is huge for people who have lived experience to help people with ADHD and for those going through transitioning.

Testing is given to you based on the gender evaluations which are a challenge because the testing is different for males and females.

Giving people the support they deserve. Until I was given the right medication, I thought my life was over. A lifetime of masking has led to burn out – and now I'm on disability. My entire life battling with people because it wasn't treated or recognized, my life was a rollercoaster.

More access to apps. We use the Moshi Twilight Sleep stories that are set to music – not a free app – and this would be great for other families too.

My dream for my son is to have someone who could come alongside him to help him learn how to regulate. I can't teach him that because I as the parent (with ADHD) don't know how to regulate. He is doing Occupational Therapy but we have to drive a few hours so it is costly and time consuming. His school is also getting him an EA to help him, because we can't.

My children are so smart and are way ahead and need support in school. My daughter needs help with emotional regulation and doesn't have the supports she need. We don't know where to go to get our kids tested for his giftedness – we need to learn where there are supports for our kids. We don't have space for much in our home, but we would love to have something like a therapy room in our home to help them.

I need more resources.

A body double. As a parent with ADHD, having a body double who works on the same project as me, in the same room, and works so that they help me stay on track and on focus.

I need a network of supporters.

Support for my child who has food aversions. They are very young and not growing because they can't sit still long enough to eat food.

It's a hard time to balance screen time. I would like some tools to help with this.

For myself (adult woman): I went to my GP who gave me the assessment quiz to take and said I have ADHD. I have been working to find a medication that works for me with no major side effects. The GP said that he cannot give me an official diagnosis and I need to see a psychologist. I would like some Occupational Therapist.

Support to help pay for a therapist who works with parents who have ADHD and who have kids who ADHD to come to my house for two hours to help me make my house function.

My kids do the outdoor education through Heritage Christians Online School's Community Connections and it's so good for them.

Q: Have you ever had experience with MCFD and if so, with what?

Several neighbours and the school have called MCFD on us for various reasons. It was a scary and frustrating experience because my parents were foster parents, and I know that MCFD has the power to take away your kids. We've had multiple times where MCFD has been called on us. The sentiment is from friends and those who are social workers, "Just comply with everything MCFD requires."

I'm First Nations and know someone taken by MCFD. That is the biggest fear thinking they are you here to take my kids. This thought is in my DNA as a First Nations person.

When they were called for our kids, MCFD contacted me via the phone and looked to set up an appointment. They came to the house, and it was pleasant. They wanted to talk with each of the kids separate from us – the kids were interviewed at the school for the same instance. We asked for a copy of the report and received a letter back, but no report.

During COVID, there was a health and wellness check for us medically neglecting our child, which wasn't the case but they had to investigate regardless. I ask for a letter every time. I'm glad we have a system to help those families that need the help.

The systemic racism is still here in MCFD and we are impacted as First Nations people and I also feel we get this as people with ADHD too. People think we're lazy and incompetent as ADHDers.

No follow up contact, only a letter when our social worker changes.

As far as MCFD goes, I'd like to see the right supports for kids.

No experience.

No understanding of the services or what MCFD does.

I tried to reach out for assistance for my son with ADHD and he was aging out and I was told no we cannot help your child, he's too old (at 7 years of age). I was told that they can help me as a parent where I can share insight with someone, but I don't need the help for me, my child needs it.

My daughter received physio and that was a positive but that was the end of the road for support.

80% of the kids I work with at a local shelter I provide mentorship for. It's been by fluke working with the Ministry and MCFD. I got to work with MCFD and they thanked me for the work I do because of what I was doing, which was different for kids in terms of mentorship, and it was making a difference for youth.

Adopted my son when he was a baby and had weekly meetings with MCFD. I have worked for nonprofits that support kids and youth and we intersect with the Ministry. I feel that my experiences are mostly negative because it's a broken system and you're always trying to bridge the gaps. MCFD staff's hands are tied because of protocol, or they are overworked – there is no room for them to look after people because they are so overworked. I feel like MCFD staff are an "if only" organization who can't do what they want or need to make a difference and help but could "if only" they had the resources they needed. We see a lot of people from an HR perspective who want to make change but can't and burn out.

I have had experience through work as I work within the system in a ministry. MCFD in my opinion is broken and doesn't lend the support that kids and youth need. There is not a lot of support – I found out about the \$150 support benefit in a gossip group on line.

I've had experience personally, trying to reach out for support. I have written lots of communication to the Ministry. The system has been tricky. The system is also so frustrating. The responses back have been that there are engagement surveys that go out, so fill those out.

When you have ADHD yourself, it's hard to advocate for yourself.

55 doctors attended a session with Dr. Francis – a colleague said that B.C. is 10 years behind. My doctor didn't go because they don't believe ADHD is real.

I have had experience to report in my job. It's been a neutral experience and professional. It helped me personally.

Many occasions in my job and I can share that the wait times are high. MCFD has been supportive in terms of what I would have expected from government.

I accessed services for our kids with mental health and went into the intake process. I was laughed at by the MCFD staff worker who was not helpful at all to our family. I was told that our kids have behavioural challenges, and they did not have mental health challenges. We were given parental coaching, but it wasn't helpful to our family. They don't ever meet with the kids to offer them help to understand them and their challenges. It seems more like for people with parenting issues who don't have the skills - this could be helpful for some, but if your kid has a diagnosis, this is not helpful for them directly.

The School District life skills program is available at our school has been very supportive of the kids and has been so helpful. The staff have been beyond amazing because our school is considered a "problem" higher needs school.

We were accepted by Child Development Centre (Nanaimo) and they told us that we were getting duplicate services and MCFD said they would close our file. We didn't feel any support for what we needed.

I have had no experience.

When we first arrived in B.C. from the east coast, our child had autism funding, but he needs support for ADHD. We moved out from the East Coast to the West Coast because there are more services here for our child. I have never heard from my case worker/social worker past the initial interview, and that was three years ago.

I would have not thought to reach out to MCFD for help for my kids and the mental health challenges they are struggling with.

We are paying privately to get our child an autism diagnosis because we aren't interested in waiting for MCFD and the system to help us.

You have to get your diagnosis validated moving from province to province. I feel the balls have been dropped time and time again for my child in the system, and I've been screaming out for help since

he was a baby. I don't know if his needs are being met and if he'll be a competent person. We went through the Child Development Centre in Nanaimo but then never heard back so we have felt a real lack of support. I'm watching this beautiful child suffering socially and for learning.

A lot of the stuff we're supported for is broad strokes – not situation specific. MCFD can't pivot and provide that support families need.

Assessments should not be something we have to pay for ourselves and should be provided. If that happened, there would be people who would have earlier intervention.

There is a lack of early intervention in the school system, so by the time they get a diagnosis, they are already behind and not supported well.

Our children are high functioning, and we have been told that they will likely not get a diagnosis if we go through the public system - so we went privately.

Q: How much do you know about Family Connection Centres and CYSN (Children and Youth with Support Needs) Services?

Some of the clinicians were good – some were not as good. It's very hit and miss in terms of services.

Everyone in the system who wants to help but they get burned out because of the red tape and bureaucracy. It makes good people leave the system.

Thriving Child - Confident Parent – has not been good for our family – this was recommended by our clinician. Some help but not worth our time. It's something that is pushed on you and if you jump through these hoops, you can get these different services. I'd like to see what the autism families have done to advocate for kids with autism

Zero – have never heard about this.

Zero – never heard.

Zero – no idea.

Have heard – but don't know a lot about them.

Zero – I really know nothing.

I barely know anything and have no experience.

Zero – I have never heard anything about this.

I know that there was the change with the hubs, but I don't really know anything about them.

The hub systems is only catering to the highest needs because government services are meant to be specific and generic to help the masses.

Q: How satisfied are you with the current supports and services available for individuals and families affected by ADHD in B.C.?

Play therapy and then the person left and that was the end of it. They only work with the high profile and challenging cases and our family isn't in a desperate situation.

If it weren't for my grade 1 teacher, my son would not have made it through. My teacher's communication was incredible, and the teacher was so understanding and supporting – “go run around on the playground.” I had no idea, but this teacher connected me to people and services and now I'm working on what I need to do for the next year for my son.

This is something that people in teaching don't know about – ADHD, etc. – there is stigma involved. There are some teachers that do understand, but they are not set up for success.

Teacher for our kid in grade 1, the teacher had been there for a long time and set in their process and ways and anything that didn't fit, was too challenging to support.

For teachers, the lack of professional development for ADHD is just a drop in the bucket. So much retraining needs to be redone and there needs to be an overall overhaul to teach inclusion support as an addition, but not everyone has the means to do that. Professional development is not looking at the roots and understanding of the 'why' for professional development for those who have been teaching for a long time. Teachers are afraid to say they don't have the understanding and need the help.

Schools don't have the time to help kids – the teachers are so strapped for time and don't have the understanding they need to help people. The help our kids get is primarily from home.

No support. I am on medical leave because it's so stressful at our home and I don't know what to do.

None of the funding for my son goes to him in the school system.

The 'ADHD tax' is higher than you can imagine.

My doctor shamed me – he said I could not get a diagnosis, but I could get drugs. We don't have this service anymore – the lack of care in our medical system is terrible.

The people who work in the healthcare system and with families should be educated

We had to fight to get one on one support for our child. We were lucky to get the right person for our daughter and the care for her education. Understanding of children's behaviour indicates what kids can't communicate with words. I love seeing the First Nations people, for example, who have such respect for children as a gift. I wish our system could take this same attitude.

Not satisfied. FSA and standardized testing, for example, is only for normal people.

There were exercise balls in the classroom but not on for me because I didn't have a diagnosis.

I feel like I've been failed by our system: health, medical and justice. You name it, I feel failed. I can't get a doctor. My doctor thought I was seeking drugs – when I was just trying to get ADHD medication to help. She told me to get the “F***” out of her office. My medical system tells me that I'm just being

dramatic when I'm trying to get help. There are doctors out there that to care but can't do anything for me – the bureaucracy of this. There is a huge room for improvement.

I have a family doctor – so I feel lucky. There is a mass exodus of doctors out of BC because they can get more money in other parts of the country.

Q: What are your hopes and dreams – no barriers!

The second our children are diagnosed; we need mental health supports for parents and guardians.

ADHD is your superpower – especially if something interests you. There needs to be more awareness of this for others who don't have ADHD.

A building for ADHD'ers that has all of the things that would be helpful: paperwork services, a wall of fidgets, nap pods, we need to create a safe space where we can unwind and get help. Adult jungle gym or a rage pit.

We must be “closet weirdos.” I would love it if there was a campaign that talked about ADHD to help people understand what it is and what it isn't.

We need the individualized services we can walk into, and it has to be a physical space, not just something online. A safe space where you can go with someone trained to enter the world of those with ADHD instead of escorting them out.

There is no support – the system is run by people who don't understand the overwhelm. We need more people in decision-making positions who understand. Less top-down solutions.

A system where everyone is represented and show up as who they are.

An ADHD coach would help. I have an ADHD buddy system where I talk to a friend as we do our laundry.

So much better mental health services and watch ADHD people soar.

An advocate at work to help at work. Help in the employment field for there to be accommodations.

Advocacy to teach the public with proper information. Workplace advocate to help you and represent you communicate to your employers.

Access to resources and proper diagnosis.

ADHD mentorship groups. Stuff like opportunities to chat with people. AVI – is a place in Nanaimo and Victoria – which has resources for people who are dealing with psych ed evaluation.

Balance between awareness and you can't do stuff because you're disabled.

Funding for post-secondary resources for those with disabilities.

Help for accessing harm reduction because I am self medicating for my ADHD to be 'normal'.

Edgewood in Nanaimo is great, but we don't have access to these kinds of resources to diagnose people with substance use issues and mental health. Places like Edgewood for people to access but free or at least accessible.

90% of people on the streets would not be homeless if there were services to support them. Support for people before they become homeless.
Understanding in the workplace.

More places like Wingspan + arts and disability who are teaching disability through art. Awareness and education for the next generation to bring understanding. Bring that awareness and education. More understanding of invisible disabilities because there are differences.

Support groups for elderly or retirees for parents to get their brain around ADHD and what it is – not thinking it's not real or feeling bad because they never had our generation diagnosed and we lived through hell.

More physical, accessible solutions and resources. There isn't support for people who are self medicating. There are things that can help with impulse control, but you can't access them. There needs to be a middle ground and a desire to change.

People make a lot of assumptions about me. I would love it if I was seen as 'normal'.

Assistants for people with ADHD to handle the executive function tasks.

Mobile services to come to our family to support us.

Walking therapy opportunities for parents to utilize.

So easy for people to come from top down to come up with solutions that don't resonate with those who need services and then those solutions don't work on the ground.

The balance of power for those who are experiencing the challenges who need to be involved in creating the processes and solutions. Ensuring that engagement happens with the people who are living the experience.

A one stop shop. Something like CDC (Nanaimo), MCFD, Island Health, and School District in one building because they don't know all that is going on for families to best support them. To be able to go to one place that can provide help to families.

Navigators who know everything because I find I'm sharing things with them they don't know, and it doesn't give me a lot of hope.

More accountability for daycare providers who are getting gov't funding – they get funding through the fee reduction system – they get that for their own in-house training for autism and mental health. But the training for staff isn't happening and someone needs to make sure it is happening.

Accountability to follow up on the training that needs to happen and holding people to account.

Having training that truly works for people with testing and building competencies. There needs to be standards for people to have to redo it. Do this like First Aid – not just a refresher course but ensuring people get the full training because some much changes. Having accreditation and assessments to ensure learning is happening.

Accountability in our system in general to support children and families who are falling through the cracks.

Councillors that can help our kids because they need help and follow up to ensure that they are on track.

Support because we have ADHD parents trying to help our ADHD kids. A place where all of this can be supplied and carries those answers in one place. An organization that puts this all together for us.

Education and awareness for your own parents (Boomer Generation) who don't believe ADHD is true to help them understand what is happening with their grandchildren. I wish there was more that I could share with them to provide that education campaign and that it's not just hyper kids.

More prevention instead of reaction.

MCFD to mandate one ADHD training on a Pro-D day each year for teachers. Sell this as how much more empowering it will be to teachers in the work they can do.

Give teachers the freedom to be flexible with schedules for the kids ie letting kids run outside, doing things in less of a structured way.

Individualized support for children.

There is so much red tape for people to understand what my kid's needs truly are. Then that leads to a lack of help.

Having the support and believe believing me when I say, "these are the ways my child is presenting, what do you recommend?" and having someone share what are the next steps. A pathway for us so there is understanding.

Having someone sit down with our family to come up with an action plan to help. I'd love to sit down and brainstorm ideas with professionals, teachers, other ADHD parents and families.

Early intervention.

Kids to be fully assessed.

Educators to have education on things to understand about ADHD. For the new grads coming out from university to have the training they need before they enter the schools to teach our kids.

Funding to include those with ADHD – like special tutoring, EAs, and other supports for physical things.

Educational campaign for some sort of effective education for the public on what ADHD is and what it is not – there is a stigma and a lack of understanding.

Training for those in the workforce – training for employers to know how to find a fit and providing a safe environment for employees.

Help with paperwork and administrative work in my job.

ADHD to be on par with autism in this province and recognized what it is.

I would love for my kid to go back to public school.

I want the support in the public school for our kids.

Before and after school care – inclusive childcare.

Ministry of Education who can allocate funding for special education – they need another division in government who deploy that funding strategically.

Sitting down at a table with people to help solve specific problems in our education system.

Programs within schools that are helpful for our kids to learn well.

Q: Have they been negatively affected in any of the following areas: employment, education, mental health, physical health?

Home life: The functionality of our home and our homelife. We are looking at the autism diagnosis just so we can get support for our children because there is nothing for ADHD supports with funding and information.

Employment: Being a neurodiverse person in a neurotypical job – you do anything that is different and you're suddenly unemployed. This was before I got diagnosed. They thought I was special. Even though I could perform on the job, I still was treated differently. In work, dislike turned into distrust and turned into workplace harassment and bullying. I was given terrible treatment at work and my co-workers could not believe some of the crap that happened to me.

Less job issues because I've always been in STEM fields – they're generally more friendly as those are more neurodiverse fields. I received a diagnosis when I was 6, but I really didn't have any supports for next steps and how to help me.

Q: Have you ever had experience with MCFD and if so, with what?

Zero experience. Before I had my kids, I looked them up as I was considering adoption.

Lots of experience as I am a former foster child as was my husband. I have also provided care to foster kids when I was in care as a youngster. I also worked at Intersect Youth & Family Services in Prince George. My family has had two contacts with the Ministry and the experiences ranged from good to not so good. Having to advocate for yourself and your family is a challenge, as there are many blurry lines. There is a lot of bullying by MCFD staff, especially when I was younger and a first time Mom. We feel lucky, though, because we know the system, so we call our friends who are social workers and figure out how to navigate things.

I had a foster son for 8 years. He had ADHD, but it was a long time ago when there wasn't a lot of support. The school system called MCFD on me because my son wore pjs to school, his hair wasn't brushed, and nails were long. Teachers thought he wasn't a good placement in our family. There wasn't a lot of support from MCFD. It was more accusatory, and when there was engagement, it was hands-off because they were so short-staffed. Essentially, we had yearly inspections and no proactive support, and this was more than 15 years ago.

I approached MCFD to figure out how to approach a situation with my daughter's father. They've been very supportive in the past, but as time goes on, I feel like they are getting sick of me and sweep my concerns under the rug. I continue to call, though, because I want to make sure things are documented. I have been told to go and get a protective order for my daughter. I fear that if I go the court route – I won't be recognized as the parent, and there has been no help in sharing what going through court means and how to go about it.

The system is overtaxed, and resources are limited. There are videos and tutorials, but MCFD has never shared those with me. I found good information, but only after a friend and I discovered it.

I don't have any experience with MCFD.

My experience was when an individual I trusted phoned MCFD on me. It was a big challenge. When I tried to solve some of the challenges with my child and get him into counselling, I was told that he was not "broken enough."

I have had experience with Child and Mental Health with my oldest (not ADHD) when I reached out to them, and they did an intake and turned us away. They said our 7-year-old daughter wasn't struggling enough. We were screaming for help, but none came.

We have used CYSN for our oldest with autism. He had a mental breakdown, and it spiraled out of control to the point our son was hospitalized for 6 months. He attacked me and was removed from our care. We were given the choice to surrender our child voluntarily, which means that we did not get any funding when he came back in our care. When he was in care, we had to pay for it because it was a voluntary surrender, and the cost was three times our mortgage. Now, we have tried to apply for funding, but our child is not recognized as our dependent by the Federal government, so we're doing everything on our own.

We have worked with Intersect in Prince George, and we have had a lot of problems getting in there. I feel like we had to be broken before we got to access to services. MCFD was called on my parents twice, and in the end, not much came from it.

Q: How much do you know about Family Connection Centres and Children and Youth with Support Needs Services?

Nothing – I don't understand what this is at all.

Nothing – I have never heard of it.

Not much good as I was told my kid wasn't bad enough to get help. There has to be some kind of trauma before something happens. Our system is very reactive.

Didn't know about CYSN until we were given help. We have had three different workers assigned to us so far, and I can tell you that their training is inadequate. I find people assume you would know the process. They are not advocates, and my experience with them makes me feel like they are in the business of saying "no." I find the challenge is that they don't know a lot about the kids that they are supposed to be working for and with. They have a surface knowledge about the kids, which doesn't help provide the support they need. Workers don't understand the systems they are supposed to be referring people into. Any help or support workers are, sadly, the last people I call.

Overall, access to everything is very limited. We moved to Prince George a few years ago and waited 18 months to get a pediatrician. We have no family doctor. When we moved, we lost everything and tried to get an autism diagnosis for three years. I don't know how to access these things, and I can't even get a doctor's appointment. And the doctors don't know where to move you into the system. I am so frustrated. It took me 14 hours one day to get my kid's prescription filled. I feel like I'm winning if we get our daughter to school.

Our kid was beat up daily, and our school said it was "normal." The solution was to send our kids back to the publicly funded "daycare" system aka school.

Q: How satisfied are you with the current supports and services available for individuals and families affected by ADHD in B.C.?

Not satisfied. The message you get from MCFD is that medication is the way – "medicate them."

I have had both good and not good experiences. For our young son, we have seen good changes and progress that have been made for him. The sad part is that there are no financial resources, and there is more knowledge and experience out there, but the limitations are a big struggle. Our teachers and principal have been tremendous in providing support. I thought my child was wild and "just a boy," but our teacher tried many things and then shared that the next step might be to talk to our doctor. Our doctor was extremely knowledgeable. They did not make assumptions, did not use labels, and talked to our child to answer questions.

The school's support staff is open, collaborative, and willing to try different things, but the resources are underfunded and understaffed. It's not that they don't want to help; they just can't. The knowledge and willingness are there.

I feel like I have been judged and not supported. My perspective comes from my husband's terrible experience of having ADHD. Part of the reason we have success is that I am open-minded, and a reader, and I dig deep for solutions and resources where I can find them, but it's not easy.

Not good. There are a lot of support staff who want to help, but the funding limits this. I have to say, there are many special people in the system who want to do all they can to help.

In terms of support, the shift from elementary to high school has been a big challenge. We have seen that there is a huge lack of staffing and funding. Teachers and administrators are putting out so many fires they're dealing with the challenges. Classroom management plays a big role – there are so many students in a class, and it's hard for kids to get the support they need.

It's a triage system right now – we were told our kid just has ADHD, and there are kids who are worse off, so we should consider not going for a diagnosis. This is frustrating because it doesn't mean he doesn't need support or deserve it – kids are falling through the cracks.

I am not very satisfied.

What services? Please make sure you note that for me as the services are terrible.

In elementary school, I was diagnosed, and it was a taboo thing. I feel like I was one of the first groups pinpointed for ADHD. I had so much support in elementary school and then felt like I was dropped in high school. It was so hands off, and I got no help, so I skipped school. I feel like I was set up to fail.

Too many neurodivergent kids in one room, it escalates, and teachers are not well equipped to handle this.

I have seen some teachers who provide great support as they account for the needs of all elementary school kids. Once they move from elementary to high school, they come out of a place with freedom and support and move to high school with very little support. It's a bit shocking for kids.

In Prince George, we have two Psychoeducational assessment teachers for the district, and there should be seven. Our kids are told they don't get help because they aren't bad enough.

Teachers are not equipped with the information on the students to support them or the knowledge to help support them. Most of them struggle with how to deal with ADHD, and as a result lack empathy for the kids. Teachers need the education.

I had a teacher say to me, "I cannot handle you." It makes it hard for families to have their kids in the school system.

There is nothing available for our family.

Our school won't do anything. The doctor won't do anything. The counselling wait list is too long. Counselling on zoom won't work for my kids.

I wonder if there was funding to fill positions, do we even have the people to fill those positions?

The challenge with our schools is that there is funding, but it's shared and some kids don't get the support they deserve or are funded for.

Two thumbs down.

Q: According to the gaps you've experienced, what are some of the dreams you have for supports?

Resource teacher to help the kids in secondary school so they have more time to spend with kids.

Parent group that can help you get connected. So many people would stop on the journey if they don't know what the steps are. I feel like some parents are close to the solution but give up because they don't know how close they are to getting help.

Outside learning – learning outside and being in nature. Less distractions, and less screen time – a good way to learn for all kids, including those with ADHD.

One-on-one attention for our kids.

Respite for some time. When I do get respite, I realize how tired I am.

A great Facebook page with information and a group of like-minded people.

The opportunity to be honest and say I'm struggling and have people come around you to support you. I've created a community of like-minded people that I can lean on.

Respite which is a huge piece of how parents recover.

Supports for more introverted people. If you're not extroverted, you can be left out of a lot of things.

Childcare that aligns with external events for parents so they can attend and get access to the services they need.

Alternative learning, like art wellness classes. Creating spaces for kids to thrive with lamps instead of overhead lights and bean bag chairs. Meeting kids where they are at and getting alternative classes to get kids moving.

Think outside of the box.

Getting to truly know the kids and finding alternatives for them within the systems – education and healthcare.

Alternatives to medication. There don't seem to be alternatives with physicians for non-medication options and alternatives.

Would like to know about my actual diagnosis since it happened so long ago. No one has sat down and talked to me about ADHD and how changes may have occurred for me over my lifetime. A reassessment would be helpful.

More knowledge on medications and knowing what they impact and affect.

More education for staff and teachers to know the impacts of ADHD on kids so they can better understand and support.

Ending the stigma on ADHD and increasing the awareness for what it is and isn't.

DELS (District Elementary Learner Support) program to be expanded. This is not in our school, so for him to be in this program, I drive him in the morning for a half-day. It's not budget friendly. It's just a 2-year program, and you can only do that for two years until you graduate, whether you're ready or not.

Some funding help for gas money would be helpful to make appointments to offset the costs to our household.

Access to assessments.

Funding for OT or behavioural help for my daughter and ability to access that.

To have a navigator who could make recommendations with a menu of options for supports I'm not aware of.

Help for my kid to not end up in jail – he doesn't use his brain.

Respite for our family.

I would like to not fear my kid and that they're going to do something to me.

Proactive supports, not the reactive supports after something has happened. I'm afraid of what is going to happen to my kid when he turns 19.

Someone believing you when you need help.

Feeling like you can trust those people to be honest – I'm afraid of the consequences of being truthful. The can or worms I would be afraid of opening. I've seen it happen – kids being apprehended.

Money and funding for programs and supports that would be helpful.

Counselling for kids who are aged out or about to be. Transition of people from counselling to another support service.

Continuity of care is critical.

Ease to transfer records for our child. Nothing transferred through the systems, medical files or school files. How can this not be accessible – it's like we transferred to another planet.

Q: Is there anything else you'd like to add?

There are major financial implications of trying to provide supports:

My husband works 14 hours out of the house to support our family and I homeschool our kids.

We don't have extended medical, so we're paying for everything.

We continue to be on the waiting list for a diagnosis.

I am self-employed, so I have flexibility, but I can't imagine the cost of lost opportunity in caring for my

kids. Our accountant figured that over time, it was \$150,000 in medication counselling, etc., that is not covered. Childcare is very difficult to find.

Medication wise has been very expensive. \$950 for a 3-month supply of ADHD meds.

Special authority is very challenging to get access too.

The hardest thing about having a kid with ADHD is not personally understanding my kid with ADHD. Everything I'm learning from a book – as a parent who does not have ADHD, it's a struggle to relate. I'm lucky to have a job with extended medical.

We're on the 4th medication that we're trying with crazy side effects.

I struggle with my child's impulsivity. They are destructive, and everything is wrecked, so it's very costly to replace everything.

Anything (toys, materials, etc..) with special needs is triple the cost.

Services such as behaviour support plans should be across the board.

Sometimes the plans are not followed through, so you're on the right path, and then you're off it.

As a teenager with ADHD, I would have benefitted from counselling. I was always fighting myself... why am I not good enough and not normal. I had major self-esteem struggles.

Standard tracking so we can see how our kids are improving or not and be proactive. Needs-based support instead of diagnosis-based.

Families with Lived Experience
Summary of Seven Online Sessions

Q: Have you ever had experience with MCFD and if so, with what?

Have not any experience with the MCFD at all. No direct connection.

Never had experience.

CMYH is where we started. Dealing with them for 10+ years. It was frustrating as soon as we got an autism diagnosis, they stopped contacting us which is not how it's supposed to be. They have so many clients – what we have now is not a feasible model. Frustrating the lack of supports when we only had an ADHD diagnosis. There is a terrible parent courses for neurodivergent families: Connect Parenting.

Respite has been helpful, but group respite has been challenging.

They are helpful to a point. They tend to, post-COVID, have made many changes to the programming. For some kid support programs, with lack of staff, they have too many kids in a group which is not effective.

They dropped the ball in terms of the transition to CLB for my child – his paperwork was lost and we had to wait longer than we should have.

Resources are something that I'm struggling. Most places reply with a gigantic email with several links. It feels like a Google search only. I am a career advisor so when I send information, I tell them what the resources are and then provide links. What is sent out is not helpful.

I don't have a diagnosis. My home country in Brazil, but I am a Canadian citizen. I have to beg my family doctor for a diagnosis, but I've been told no.

Not directly – I don't have kids myself – but my niece has been diagnosed. Got diagnosed in Ontario at 45 years.

Disconnect from MCFD because there is a lack of staff and the communication at various levels is terrible. I have been involved for decades as an employee of MCFD. I was involved in protection system with my own kids. The protection system has been problematic for me. Was involved in CYMH with my kids and there have been a lot of problems. Respite has been one of the biggest issues. I have issues as a kinship caregiver and policies that are discriminatory. I am fighting for paradigm shifts with mcfcd.

Mitzi Dean used to be the head of MCFD – my experience is her lack of leadership. I have actively tried to speak with her as my MLA and she just refuses to meet with me after super polite communications to her team to share my experiences. Met with a solid “no” or form letters.

Some involvement but was told that your kids are too much in a program in Vancouver. When we needed to access support were taken off the wait list and the after-school program – got them back on the list when they were school age. Got support at the end of grade 3. The system is confusing.

We cost shared an EA for childcare for the summer – and then they changed that were the kids had to do camps which weren't a fit. Our consultant is open to hearing but now change is happening.

Recently contacted the representative for children and youth engagement advocating for ADHD. Did one as a professional and one as a parent.

Had a drop-in session with them. They're not sure what they can do with us. It's been some time, and we still haven't heard from them. We have no clue as to what is next.

Wrote them to advocate for ADHD on our family's experience – got a form letter back. Disappointing.

Both my kids have an autism diagnosis – I advocate for our family through MCFD. It's hit and miss.

I have supported a child development survey and wrote a candid response which got me a call and a form letter back.

Not personally – but involved in many cases where parents/guardians had to interact with MCFD. It's been a negative experience for them. MCFD doesn't understand the complexities and nuances of ADHD and as a result they can't communicate well with families.

MCFD has limited clinical knowledge and don't know how to listen or don't understand. They're the ones in charge but they're not experienced clinicians on the front lines. Many from MCFD don't have a grasp of what these families are dealing with.

I feel with MCFD they're about assessing the environment, not about empowering these families. Their foundation is that "this child doesn't fit" our process. Round peg into that square hole. I feel with MCFD, their focus is on "What do we shave away of this child so that they can fit into society better."

This is the last place I would go for services or support or help.

Q: How much do you know about Family Connection Centres and CYSN (Children and Youth with Support Needs) Services?

I assume at one point I will be accessing services as my daughter's teacher has recommended we get our child diagnosed. I'm not sure what is out there for adults with ADHD.

I know a lot and I don't like what I hear from others in this focus group.

I have heard about them but am not familiar. My son is 11 and diagnosed in Ontario and we came here to find no support. The school doesn't want to do anything so you're out of luck unless you go privately for services which can be very expensive.

I am learning about ADHD and on my initiative. It is hard to find information and I have not heard about these organizations.

I find I am trying to get straight answer but it's a challenge.

A friend of mine has a daughter who is high support needs and I only know about them indirectly through watching and then what my friend went through as her daughter was aging out.

I'm a social worker so I know a lot.

I have a good understanding of both FCCs and CYNs and have been challenging their systems. The Kelowna pilot project funding is not working for a lot of families currently. It's not enough.

I have heard about the pilot project in Kelowna – but my knowledge is very limited. I feel like I know nothing about them or what they can do for our family.

When they were going to put the FCCs out there, they didn't build up the capacity for these. They had to bring contractors in from outside communities. We don't have the infrastructure built up and the trained people to be able to help. There needs to be a subsection of people with lived experience – those who can share peer experience.

It's been a challenge. Went to a drop-in day and had to come back and bring their child – their website doesn't share that your child needs to be present so that's frustrating. Very limited intake opportunities for kids. After our assessment, I understand that my child would need to see a psychiatrist but can't because my child is too young. I got a call back and I had to reach out to my pediatrician and we're on a waitlist, but I don't know how long for. Psychiatrist will assess for other things that might be going on and reassess the medication.

Similar to the model in Ontario that is not working. Not good quality. Groups I'm in in B.C. are working okay because there are still options outside of FCCs. My question is will they be culturally sensitive facilities. Doing whole new assessments is hard on our kids and it's frustrating.

I have little faith in the assessment process and that there won't be the support available for those who need it. This just addresses one piece – we need a holistic view. I was at first excited about a needs-based (rather than a diagnosis model) support model, but it hasn't materialized into what they need. Kids are on a spectrum and need a spectrum of supports.

I also think that they have "dangled the carrot" in front of families that currently have no support, needs based sounds great in theory but if there isn't additional funding to pay for a system that supports all kids with support needs, we will all basically get nothing.

I don't know where they're going to get all of the staff from that they need. Many service providers will be put out of business by the FCCs, mainly small businesses and I think the statistic was that up to 90% of these businesses are women owned small businesses.

What I do know is that they are compensating for the lack of diagnosis and support – there is a catchall at the end when they're adults. It's done nothing to solve the problem. It's appalling.

I am aware that if you lack specificity, these places are not going to help people with ADHD at all. It's a system where you lump everyone all in together. It's like, "Here's a little book on how to be a person." It's inadequate and a band aid solution, and not a good one at that.

Q: How satisfied are you with the current supports and services available for individuals and families affected by ADHD in B.C.?

Unsatisfied. I'm new to accessing any support. I started looking things up through Google and joined a Facebook group "Parents of Children with ADHD in B.C." Got recommended to have my daughter assessed and I stayed in the group to get information from my peers and good to connect with people. When I was researching for things, I was surprised with how much information there was for adults with autism and other diagnoses, but there wasn't anything for ADHD until I found a group that has a six-week coaching program. They talked about what ADHD is and isn't and common traits so I know what parts of me are me, and what parts are ADHD. CADAC was great. The fact that it was Canadian focused was great with things like employment law in Canada in the event you need to make a human rights claim. It's been a lot on me to do the research and there isn't a lot provincially for me. It's a challenge to find information. First dozen link on Google are top level posts but all very nebulous and not easy to understand and blog posts from people trying to sell something.

Too many still do not "believe" in ADHD.

I was in Prince Rupert and still didn't receive a referral after six months – I had to follow up. There is an unavailability of specialists to even see us – we had to wait a year to access an appointment with a specialist.

ADHD rarely comes alone, too. There are usually other challenges people have and the system is not set up well.

So many people are struggling, and I don't know why. I feel so sad for so many people who don't have a diagnosis.

Our first pediatrician was 1.5 hours away. We've had to drive 4.5 hours to get to Prince George for an assessment and it was terrible. We've also driven 13 hours to get to a specialist appointment. We do appointments via zoom.

I literally want to do face palm all the time.

Zero (can I give a minus score) I could go off on the deficiencies of the system – there are no supports to comment on to be honest. I'm able to do a lot of self-advocacy, but it's exhausting. It's always a shut door – sometimes you think there is a glimmer of hope – that in the end it's always been a closed door. It was a huge relief to find out eventually that I wasn't a defective person. I burned out really badly, but I at least knew what my challenge was.

It is like MCFD/Government refuse to acknowledge ADHD as the disabling disorder it is. Even in all their collecting of feedback over the past 6 or so years; ADHD is left out, never even mentioned.

Can I put a negative number on the supports and services because that's how I feel.

I live in a rural area and drive 2 hours to get to doctor. He was incredibly dismissive of my ADHD and his in his opinion was that big pharma was pushing adult ADHD. This was a mental health professional – I felt humiliated, insulted and gas lit – I wondered if I forgot to mention things and was crazy. I worked in a mental health office for a number of years – I think of all of the people who go into an office and how vulnerable they are – I actually filed a formal grievance because I didn't want others to experience the same thing.

I live so close to a boundary of a health region so I'm stuck and cannot go to someone else. I do what I can on my own – I have found a really good therapist. The saving grace is that this ADHD community is so grateful and supportive - we have each other's back. It's a massive burden.

I can literally echo your entire story. For my entire life I have been overworked – in the beginning I was taking medication because I thought I had depression. Then that didn't work so I got anxiety medication – then hired a psychologist and psychiatrist. In Canada the wait list is 2 years – and my doctor said I would take the spot of someone who really needed help so should really consider if I needed the appointment or not. It was terrible.

I would give a 1 out of 10 because we do have reliable resource on websites, but having such a confusing system, it's hard to navigate. I would love to see a formal blog post from a credible source, otherwise I don't know what is true or real.

It seems like everyone who doesn't understand ADHD (which is most people) leaves us feeling like we've done something wrong, it's our own fault that we're struggling.

Support and programs are non-existent for me.

I had brought the information to our school when we got a diagnosis and was told that "it's just ADHD" like I had a cold and that it doesn't impact the world. They don't understand the excessive challenges that come with ADHD.

Zero services but I thank the ADHD Advocacy Society of BC for spearheading this. It is a lot of work, it is much needed. And it's always such a relief to spend some time with people who face the same struggles. Going into the system I didn't understand and those that work in the system don't understand it either.

We need a paradigm shift needed in child welfare: From child focus to family focus: It is time to shift the child-as-client paradigm - Casey Family Programs "...move our social welfare system from a focus on child welfare to a focus on family welfare. That's not to suggest that the welfare of children is not an important focus. But it is to suggest that children should be seen in a larger context. I will discuss some of the functional changes needed to implement this concept as well as some of the challenges that may impede making those changes. <https://www.casey.org/must-shift-paradigm/> Paradigm Shift aims to interrupt and lessen the cycle of trauma that occurs for children, youth, and families. This new curriculum is a vital form of justice. In this context, we refer to justice as the justice of being heard, seen, and valued; that each person's voice and perspective at the table is important and needed.

Shift to strength based, neuro affirmative model in disabilities. Identifying and Shifting Disempowering Paradigms for Families of Children With Disability Through a System Informed Positive Psychology Approach - PMC (nih.gov) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8734639/> and <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8734639/bin/fpsyg-12-663640-g001.jpg>

The hardest part is that we have tried to manage our children's ADHD through various medications – there is no guided systems. Found an awesome pharmacist who was able to help - my pediatrician didn't have the time or the experience to help. We pay \$400/ week for tutoring and wanted to go private because we didn't want to rely on the public system. We wanted these services in school so that kids could be kids after school where they had down time. Joined the school board and school council so these opinions can be heard to have my best foot in the door. ADHD kids are 10x more likely to have other diagnosis.

Parent support services offer ADHD support for parent, very supportive. The support groups of people with lived experience. I do have the benefit of AFU funding and special funding through online schooling. Parents have to join board to advocate for their boards. They must give up their time to do the advocacy work. If I'm not on that board – the voice isn't there for kids with ADHD.

We don't have enough people who need to be trained and the professionals need to be trained on neurodiversity, neuro-affirmative,

Individualized funding, for our kids in school system. Online school is individualized, \$14,800 per child.

There are a lot of barriers and invisible work being done.

Very involved in the ADHD community.

Family doctor and pediatrician don't have any help they can provide. Medical professionals I work with don't have ideas either. The school doesn't feel like he can help him. The supports aren't there. My pediatrician is not open to trying new things and took away the medication.

Not satisfied at all – health professionals don't have any place of where to go. Or supports to find these places. I work during the day so it's hard to get to these appointments with my son. In urgent care, which is where I work, I see people come in and mainly for those who need prescription refills – doctors are reluctant to see patients with ADHD.

Not at all satisfied – zero. Rolling with ADHD has heard not great things about it – one size fits all. Didn't get support at all. No designation for ADHD = no support in the schools and pull funding from those who have support.

First reaction: What services and supports?

There is a void that no other parent can understand. There is no mentorship for families. Lack of support and training for ADHD. No helpers and our kids are left behind.

I have had a similar experience – fight to get a diagnosis – no support for the schools. EAs are stretched thin. Anything available is hard to find out there.

Disability tax credit – I had no idea of that until I heard about it in a support group. You're kind of on your own to figure things out. Sure, the basics are out there but you don't get a lot out of it.

The system is hard to figure out. I have been asking questions and my whole life changed and I ask how is this so broken? 5% help in the classroom every day is nothing. ADHD is an invisible disability that doesn't get the attention, but kids are labelled “problem causers.”

I am in a support group and leading this because I'm passionate about helping other families. I thank God for the support group – helped me to figure out how I could support my child.

Daycares can apply to supportive child development. They can put the funding toward a new resource – but this means that they need to identify kids who would struggle so they follow the kids around and provide daily reports of what happens to build up a case for funding. So detrimental to the mental health of the whole family and long-term damage. Funding model is meant to target you kids.

“Support” had to wait for an OT to go in and it took years. The conclusion is that they were high energy even though they knew they had ADHD. They see the behaviours and bullying is such a problem. Kids refuse to wear pink shirts as the ones who are the worst bullies are the ones wearing those pink shirts. My son stays inside for breaks because there is no social support on the playground and he keeps ending up in trouble... great inclusivity.

Non-existent services – tell me what they are, please and I'll access them!

They have not availed themselves to our families and we feel very isolated. There are crickets. We are left to find supports on our own.

Kids could be trained to be leverage the asset of ADHD as an exceptionality and these cognitive assets they have. They are not tapping into the solutions that kids with ADHD can solve – it's a superpower that is not being used due to lack of training from the professionals. The system is letting people fall through the cracks which become bigger issues as time goes on – alcoholism, divorce, homelessness.

When you're a kid you don't want to be "disabled." Our system is set up as "Here are things you can do to survive," – frame it differently so that kids can thrive.

Our youngest is 7, with ADHD – there is no help at all, but he's doing well because we both get it as parents with ADHD. Other than that, there would be nothing if we didn't understand what he was working with. We can't have this beautiful child suffer in the classroom. We don't know as parents where we should go although ADHD has been around for 40+ years and the supports are not there. People think ADHD is still "made up."

Q: Have they been negatively affected in any of the following areas: employment, education, mental health, physical health?

Employment for me as an adult has been a challenge. My employer didn't understand how my brain worked and what commendation I would need. I was laid off. With a new employer, I want to make sure my new employer understands. A resource for employees and the employer would be helpful to have so that we all know how to work together and utilize each others' strengths and help with each others' weaknesses. A resource for employers. Provide a resource to an employer – like a checklist.

Everyone with ADHD is different and are impacted differently and there needs to be many supports offered.

All of our stories are **our shared stories** and **our collective voice together**.

Education for sure – not being recognized as needing additional supports. It's been a big challenge for my child who gets sent out of his class, and then we are called by the school to come and get him because of his behaviour.

Mental health suffered in a way of coping until I just couldn't cope anymore.

Our son is 7 and in school – he has been bullied a lot. We had to pull him out of the school because it's hard to watch his spark disappear. We are on top of that for mental health with our kids.

There was a generalized want of understanding for what I was going through with ADHD. Those caused serious problems with my progress forward and was disruptive of my social connections.

Exhausting that is self-afflicted because we work like beasts for five days a week because of our ADHD and then crash on weekends.

Socially impacted mental health and self esteem – being a boisterous boy – you get picked on a lot. It does wear on you. We teach coping mechanisms and not strategies. The ones who do have strategies are able to handle things well.

Personal experience – built a website, did a bunch of apps, did the work in 2 to 3 days in something that could have been done in a month. They asked me to proof it and check links but that's not where I have my giftings. We look at it as everyone like they should function the same.

How often our kid is misunderstood – is this willful behaviour or not – once you're grounded in understanding, everything could be reachable.

Q: Share what gaps you've experienced.

Education: my son doesn't qualify for an Individualized Education Plan – doesn't get an individualized plan because he doesn't have a designation. We are told time and time again that there isn't support – we know he would succeed if he had more support. We have had team-based meeting but not a school based meeting because he doesn't have a diagnosis for something else. The resources they provided were the Confident Parents and Thriving Kids course and recommended our son see a counsellor and recommended some books. They didn't recommend a FCC or the Ministry.

I stumbled upon a parent support group that meets every second Sunday. Parents support systems of B.C. and have different groups and one for ADHD.

Q: What would be some solutions that would help you?

For having my daughter assessed, I want to know what type of support my daughter needs to succeed in school. I want a clear diagnosis for her and what the next steps are, the supports are. What are her top needs and what supports can I access. It's one thing to be told you have this "brain condition" but it's another to have clear support and where I can go. Who can I go to to learn more about my brain.

There are limited supports for adults with ADHD and it's hard to find useful information. I would appreciate someone to help me navigate the system. Here is where we are now, here's a list of resources you can look at, and guidance on how to access support.

Tools to give back to my daughter's teacher to help them help my child in the classroom.

Disability tax credit for people with ADHD is available but I've heard that it's very challenging to fill out. It would be great to have access to support groups and have them be easy to find.

Figuring out a way to navigate my own brain and learning about those work arounds and then learning how to implement them.

A dedicated provincial funding stream, the qualifier being ADHD, FAS, etc... Intake including assessment for ADHD.

Access to training/ workshops/ art therapy too.

The ADHD Clinic at BCCH/Sunnyhill having outreach clinics across BC.

MCFD finally acknowledging ADHD as a disabling disorder.

Making sure that any doctors do have the proper training.

Services closer to home.

Sensitivity training for medical professionals.

Sounds simple, but I would like to talk to a person to ask for resources. Just someone who can listen and suggest something that it is for me.

Appropriate training for schools.

Access to mental health supports.

Social groups of therapists – learning social skills in a peer group – we had that in Ontario and not in B.C. A free app. They had one that was like a mental health check up. It would be cool to have something for habits etc. They have many, but all pricey.

Awareness campaign at a provincial level to what ADHD is. The biggest thing lacking is awareness about ADHD – still prevalent in our society that this is a trendy thing from the 90s that kids were prescribed Ritalin for.

Public education. Yes, an actual awareness campaign that helps people understand. And that doesn't stigmatize self-diagnosed people, considering what a privilege it is for people to even be able to get a diagnosis. There has been a great job done for autism.

Government recognizing this so that the health care providers know it's important.

An awareness campaign would help those who have a diagnosis feel able to stop gaslighting themselves, too. The self-criticism is hard to unlearn, especially when surrounded by people who don't understand. I see promotion of drug addiction – a one stop shop – you have all that you need but somewhere for people with ADHD to go as a one stop shop. There are days you cannot take it and it is draining.

A mental health safe space.

Even the resources that do exist, all the steps to access them are the exact things that are barriers for people with ADHD.

Quality professional development for the mental health, school, family health, etc. resources that already exist. And as everyone knows - more resources, period.

In-person support-type groups.

Financial supports for therapies, medications, etc. that don't require so much paperwork and gatekeeping. I want to see individualized funding. In the long run it will cost gov't less – with a peer navigator system running alongside the individualized funding to provide help, guidance, and next steps.

Create a system that can work for everyone – inclusive and meets the needs of neurodivergent and neurotypicals see that all are equal and celebrated. Complete paradigm shift.

Need to fight so hard to get the supports of what my family needs. Because there is so much stigma – Able Mothers report <https://westcoastleaf.org/work/able-mothers-report/> – MCFD is discriminated against neurodivergent people starting families.

There is also a need for greater consideration of directly incorporating child voice and participation in both the development and delivery of programs and care. Our case study arose from data collected as part of action research, resulting in an intervention co-designed by parents/carers, professionals, and researchers. The intervention aimed to identify and value the child's strengths, but the children themselves were not included in the design itself. The inclusion of the child's voice is increasingly being considered as possible and necessary from the earliest possible age (Carroll and Twomey, 2020; Parsons et al., 2020; Rix et al., 2020). For instance, our experiences here have led to the development of the Child Voice model and program (Mahmic and Janson, 2019). Future work should continue to consider strategies

for including the entire family within the care process – including parents/carers, siblings, and the children with disability themselves.

Systems in BC tend to micromanage us, individualized funding is not even considered. The government has to control and has little trust in families. There are too many children who end up in special needs voluntary care agreements because mcfcd/health does not provide enough supports to keep them in home. Instead, they come into care and the cost is triple. Transforming Respite (health.govt.nz) This requires a new way of thinking; in particular, to trust that families/whānau will access supports that meet their needs, whatever those needs are and in ways that may be unique to them. Respite support needs to be available early, before families/whānau start to feel that they cannot cope. Respite should be age appropriate and a best match for the family/whānau. Respite needs will change throughout the stages of life. Respite is a lifelong investment in the wellbeing of the disabled person and their family/whānau. The high-level outcomes we seek through this strategy are to ensure that the respite model:

Offers choice, control and flexibility about how disabled people and their families/whānau take a break – this includes offering disabled people and their families/whānau a flexible respite budget that allows them to take breaks in the ways that suit them best

- enhances the range of quality respite options that families/whānau who need them most can access – this includes developing new and expanded respite services, in line with what people want
- recognises the value of respite and takes a lifelong approach to respite allocation and funding

is easy to use and to access – this includes easier administration and payment methods, better access to information about the respite options available and support to find and use these options. principles The principles of this strategy are based on those developed for Enabling Good Lives (EGL) (Enabling Good Lives 2017). They are as follows. Self-determination Disabled people are in control of their lives. In the respite context, families/whānau feel empowered and able to take the breaks that they need from caring.

Beginning early, we take an investment approach to respite and recognise that supporting families/whānau to have a break may prevent a crisis and sustain the family unit.

Person-centred Disabled people and their families/whānau use respite supports that are tailored to their individual needs and goals and that take a whole-life approach. Ordinary life outcomes We offer respite options that support disabled people and their families/whānau to access everyday life, learn, grow social networks, increase independence and integrate with their communities. Mainstream first Everybody experiences full participation and inclusion within their community (people, places, assets, infrastructure and supports) as of right and can choose funded supports to enhance and facilitate this.

Mana-enhancing We recognise and respect the abilities and contributions of disabled people and their families/whānau. Easy to use Supports are simple to use and flexible. Relationship building Supports build and strengthen relationships between disabled people, their families/whānau and their communities.

In addition, it is essential that disabled people feel safe while accessing respite services.

Some ideas for respite:

CHEO respite and home-care programs providing extra support to families

In-home respite care

Extra Personal Support Service hours for existing home care patients, which can be used as companionship for the child or youth (reading, playing games, doing crafts, etc.), homemaking (laundry, dishes, light cleaning, small meal preparation), or other agreed-upon activities.

MCFD policies are ridiculous – re: kinship support or enhanced funding, if your daughter or son is in your home, you're not eligible. The policies need to be understood in the context of our families with the recognition of the inclusion of our disabilities.

Funding available on an individual level – it would be challenging for the gov't.

Love to see more supports offered in the school and community resources accessible in our schools. Schools are such a logical place for these supports to exist - more funding for our schools with a community resource person who can advocate for the kids and their needs.

Changing the way we teach children how to read – teachers need to be better educated – offering our schools more support.

If you have a neurodiverse child, you should be wealthy – we have those resources to help with our kids' development would not be available – time, money, and resources. Mental capacity and the perseverance to advocate for their kids because it's a luxury. The pool is only so large in terms of resources and the struggles it puts on families.

What happens at home and school cross – separate ministries makes it problematic and more gaps overall.

MCFD and the schools working together to find solutions. Have a resource person who is not the teacher. I was a school social worker back in the 1990s and we no longer have that and we need that back.

Individual funding the match what families need. Some of the teens complain that their parents are just putting them in programs to use up the funding – more about the fit and meet the needs in a neuro diversity kind of way to move forward.

The importance of neurodiverse people in our school – build a culture that surrounds our kids.

Family Support Institute. These are volunteer roles (Resource Parents), but with training. There is an amazing gathering once per year. The focus is on developmental disability but also includes mental health. Family Smart – with paid roles. These are parent peers, they did have youth peers for awhile, I am unsure why it was dropped. This is all around mental health. <https://familysmart.ca/parent-peer-support/bc-parent-peer-support/>

A resource tool – the professionals that families are going to see have information for these resources available because they don't. They have no idea on what resources are available.

Educating the school system on ADHD supports and the resources available.

Support groups although I've only gone the once.

Advertising and being more visual would be helpful and provide more opportunities to learn would be good through channels like social media. Share more about MCFD and places where families might go.

Someone like Dan Duncan in the Interior is great and I was on a call and there were 900 participants involved.

Use plain language to make some complex terms more accessible.

A Facebook group would be helpful like ADHD and Neuro divergent of BC.

Share details like that you can fill out disability tax credit information and more successful on your application.

Help in crisis: when behaviours are big and aggressive and scary, it's hard to read a book in 5 minutes to get strategies. I feel very sad in how my son is feeling and reacting. Having a number to call to talk to someone would be helpful. Some kind of support available in real time.

Peer support from the FCCs would be good – my situation has gotten worse – so ideas on who I can call in the moment would be good.

I would love someone who can help with behavioural intervention like an OT.

Have a set up similar to AA or NA and meet other people in person to facilitate these conversations.

I would appreciate a play group for my son with other kids who are similar with a drop in and talk with other kids opportunity and guided conversations.

Class dedicated to kids that are ADHD – there are kids that understand.

Better guides for the parents to build understanding.

Having ADHD be a funded designation to get some support and would go a long way.

If people just understood ADHD – reduce the stigma in society.

Education and awareness are the way forward.

The school system is broken – not meeting the needs of communities – needs to be overhauled.

Help parents better advocate for their kids. Educating the parents showing them the next steps. Better training for teachers in general in their curriculum.

Set up the groundwork for advocacy. There is disability funding for their child and I only learned about this through the person at HR Block!

There are good resources people don't know about like Coursera for ADHD.
www.coursera.org/courses?query=ADHD

Programs to help reach kids earlier to help build out strategies – training them to be more effective to the way they operate. More thinking strategies and not coping mechanisms.

You have someone assist or manage the things you are not good at – delegate your weaknesses. We should do the same with those with ADHD and use their superpowers.

Bring together the knowledge sets that would help ie: nutrition. Info, support, and events geared toward kids to help them learn they're not alone and provide that help and insight for families too!

I love that a teacher in our district has the kids outside every single day to help the kids. Looking at education differently and how to work with all kids. In order to find the solutions in school, we need to abandon the Prussian model of education.

We come from a punitive place first and there isn't the room for self-reflection that I believe it necessary to help those with ADHD.

Teaching parents how to have the patience to help our children. A series of videos on how to best practices in supporting our child in the following areas where they are likely to struggle early on. Not give them additional disadvantages of parenting. They're not easy to find for what a person's typical resources are.

Family centred care – not broad spectrum – client driven support.

Transitional pathways – provide people with all of the options that will work for families based on stats and draw backs and advantages.

Service Providers Who work with People with ADHD

Q: Do you have experience with MCFD and what has that experience been like.

Yes – it's never been good. I don't think I've ever had a great relationship with MCFD. They're very much like enforcement. They are not regulated like nurses, for example with a governing body, so there are not a lot of high standards for their workers. There is so much turnover, so it's hard to create relationships.

I am a privileged white woman, and even I had a terrible experience with them. There is no accountability within their reporting structure. It's basically a broken system trying to solve problems for some of the most vulnerable.

Yes, when new MCFD people start, they attend seminars I host, and they are eager to learn. That's been a positive. I would recommend providing education on ADHD for those in MCFD. They have no sense of community and feel very empty about what their role is.

A variety of answers because I live in both worlds with my role – one that provides this service and works with foster families as an advocate. The lack of child development education for social workers is terrible. Social workers know nothing about ADHD which is terrifying. They're making decisions when they don't know a lot about what children need. Policies look good on paper but don't work.

There is no training for foster families on kids with ADHD unless they have a good clinician involved. Tips and strategies are what I share. There is more funding for key workers for FASD. I must say that in this system, you become jaded - if you have ADHD and another thing that's the best-case scenario to get support. Children who have traumatic upbringing exhibit symptoms of ADHD and understand the connection. Often, parents with undiagnosed kids with ADHD have ADHD, so it's a struggle for them to give support.

Q: How satisfied are you with the current supports and services available for individuals and families affected by ADHD in B.C.?

I feel like there is nothing. You can't get a diagnosis – no one has a GP to refer you. Your best bet is TELUS Health (which, to me, is a crapshoot) and a thoughtful General Practitioner or Nurse Practitioner that would refer you. You could get help at [Central Island Services at Brooks Landing](#) in Nanaimo. If there is a crisis, you could get a referral.

To get a diagnosis is next to impossible – you'd be more likely to find a unicorn in the forest. Then, in terms of support and services, once you get the diagnosis, there is minimal help available.

Systemically 0% - negative.

You can find folks to support you but it's a real challenge. Our system is broken.

Q: Share what gaps you've experienced as a service provider.

I don't think there are any services for some of the community's most vulnerable – unhoused and substance users. There is no open door. You're in complete crisis or you're grinding it out – there is no middle ground.

There isn't a clear diagnostic pathway for ADHD – no one to walk families through the process to give people services and tips for autism or other diagnoses. Who can do this? Where do I go for a diagnosis? That's what I hear from families all the time.

Children & Youth with Support Needs (CYSN) social workers have 200-300 people on their caseloads. I know more about the child than they do – i.e., they didn't know about an allergy – the legal guardian doesn't know key things. I have a caseload of 28 kids, which is a lot. Part of this is funding and retention rates of staff and a revolving door. How do you maintain the unmanageable?

Asked for our organization with \$10/day daycare and all childcare with inclusive spaces and wanted more information on ADHD. 97% of people in the room know someone with ADHD. How many received training? 0% in that room. We have so much more information, yet we are so ill-equipped to understand the system. We have parents and foster parents who want to go to the autism root because there is funding. They're told to "Say this," so that you get a better outcome. Why is there this gap? Because there is a system of reactive management that provides a holistic solution to what is needed.

There are multifaceted pieces and parents don't know what the process is.

What is the training for teachers? There is a 100% chance you are going to have kids with ADHD. There is not a lot of training to prepare teachers. Unfair expectations for teachers.

Q: Are you familiar with the ADHD Advocacy Society of BC?

Not too aware of them before meeting their Board chair in community.

I wasn't aware of this before this session.

Q: How might you want to contribute to their work?

Provide connections, include them in my workshops, and help them spread their networks. Collaborate with workshops/education. People are hungry for these events.

I don't know. I really see this where my focus is right now. Curious about what it looks like – didn't know about the society before and share with foster caregivers and easy start.

Q: How might you want to gain greater support from them?

Have a navigator who can help people try and find services. Connect with Child/Youth Mental Health in Nanaimo. Follow up for support and support groups and send people home with information. Host a diagnosis clinic for people so they can at least figure out if they have ADHD or not so they can move forward.

Create a standard of diagnosis for people.

Training to foster caregivers – show what I currently teach – best practices and current information to make sure what I'm sharing is accurate. "How to ADHD". "Am I on the right track – am I missing something."

What would you love to see on the website?: kids asked to do an assessment. At age 4 ADHD, trauma, Mom had significant experience of abuse and trauma, chaos for home life. The kid comes to me and loves to play big and see how people react. Simple – yes, you can and improve. Video on helping parents and teachers with the yes and mentality.

Q: What roles do you believe they should take as a Society focused on ADHD advocacy?

For those you work with do there appear to be consistencies in challenges in the following areas: employment, education, mental health, physical health?

Are there services you know that provide help in addressing issues with employment, education, mental health, and/or physical health?

Q: Is there anything else you'd like to add?

Glad you're doing the work for MCFD – it's important to do this to effect change.

Email Response from an Individual

This individual asked to email their thoughts instead of filling out the online survey.

I am not aware of anything pertaining to ADHD in the community specifically. Things like this are not well communicated at least to me. I would be very interested in not only existing programs, but I have even been thinking about starting a support group for neural divergent to get together and talk about the difficulties of trying to do it "their way". I think one of the best solutions we have is just talking it out with each other in a safe space. Just hearts and brains.

I think a lot of the help is focused to people in educational programs, but there could be a much bigger push with the work force.

Corporations already see this, but if you can properly motivate a ADHD person, you can get a lot more productive and creativity than with most staff. It only makes sense that there should be resources available to help us develop our strategy's and communicate it with our employers for the betterment of everyone. This goes with community work, being natural people pleasers, a little help getting over our blockers and we could do a lot of good.

Tearing down communication issues between those with ADHD and their employers would probably make a world of difference.