

#AskingAutistics about National Autism and Disability Policy

Autistics United Canada is #AskingAutistics for thoughts on national autism and disability policy.

Your responses will help us advocate on the policies that affect our lives.

This survey usually takes **at least 15 minutes** to fill out. There are **4 parts**.

The survey is **ONLY for autistic people living in Canada or autistic people with Canadian citizenship living abroad**. If you need help, you can ask for a trusted person to help you fill it out, but the answers need to be your own.

Instructions:

- You can change the font size or style of this document if that makes it easier for you to fill out the survey.
- You don't have to answer every question, and you can say **as little or as much as you like**.
- You can fill it out using your word processor or print it and scan it.

→ **Please send your completed survey to info@AutisticsUnitedCA.org.**

There is an alternate online form of the survey:

bit.ly/AskingAutisticsCanada

We are asking your **concerns and hopes** on eight (8) topics:

- 1) Autism assessment and diagnosis
- 2) Research
- 3) Therapies and supports
- 4) Employment
- 5) Education
- 6) Housing
- 7) Healthcare
- 8) Government and policy making

We will also ask you which services and supports are most important to you.

You are welcome to share any personal stories on these topics. Everything you say on this survey will be kept confidential and anonymous. That means **unless you give us your permission, we won't share your words with other people.** While we ask for some information about you, we will not ask your name.

If you have trouble filling out the survey, **you can give feedback using your preferred communication method (e.g. video call, audio call, text chat, email).** Please contact us at info@AutisticsUnitedCA.org to set up an interview.

If you have any questions about this survey, please contact us at info@AutisticsUnitedCA.org.

Part 1: Challenges and Changes

1) What challenges do autistic people face in Canada?

Please share your concerns in any or all of these topics:

- a) Autism assessment and diagnosis
- b) Research
- c) Therapies and supports
- d) Employment
- e) Education
- f) Housing
- g) Healthcare
- h) Government and policy making.

Write your answer here:

2) What changes do you want to see in Canada to improve the lives of autistic people? Please share your concerns in any or all of these topics:

- a) Autism assessment and diagnosis
- b) Research
- c) Therapies and supports
- d) Employment
- e) Education
- f) Housing
- g) Healthcare
- h) Government and policy making.

Write your answer here:

3) Can we quote your words in our advocacy campaigns and reports? Your name will not be shared.

- a) Yes
- b) No

Part 2: Therapies, Services and Supports

4) Which services are most helpful for autistic CHILDREN?

Rate each service from very unhelpful to very helpful.

4.1) Behaviour Intervention e.g. Applied Behavioural Analysis (ABA), Discrete Trial Training (DTT), Early Intensive Behavioural Intervention, (EIBI), Pivotal Response Treatment (PRT), Enhanced Milieu Teaching (EMT), Positive Behaviour Support (PBS)

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.2) Developmental / Relationship-Based Therapies e.g. Floortime

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.3) Speech Language Therapy

- a) Very unhelpful
- b) Somewhat unhelpful

- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.4) Occupational Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.5) Physiotherapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.6) Psychotherapy (E.g. services from a psychologist, counsellor and/or psychiatrist, CBT, DBT)

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.7) Music / Art / Equine (Hippotherapy) / Recreational Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.8) Social Skills Classes

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.9) Group Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

4.10) Medication / Psychiatric care

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful

e) Very helpful

4.11) Complementary / Alternative therapies

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

4.12) Educational Assistant in School

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

4.13) Recreational or social groups for autistic people

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

4.14) Autistic peer support or mentorship programs

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

4.15) Respite care / In-home support

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

4.16) Other (please explain below)

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

5) Which services are most helpful for autistic ADULTS?

Rate each service from very unhelpful to very helpful.

5.1) Behaviour Intervention e.g. Applied Behavioural Analysis (ABA), Discrete Trial Training (DTT), Early Intensive Behavioural Intervention, (EIBI), Pivotal Response Treatment (PRT), Enhanced Milieu Teaching (EMT), Positive Behaviour Support (PBS)

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.2) Developmental / Relationship-Based Therapies e.g. Floortime

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.3) Speech Language Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so

- d) Somewhat helpful
- e) Very helpful

5.4) Occupational Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.5) Physiotherapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.6) Psychotherapy (E.g. services from a psychologist, counsellor and/or psychiatrist, CBT, DBT)

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.7) Music / Art / Equine (Hippotherapy) / Recreational Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.8) Social Skills Classes

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.9) Group Therapy

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.10) Medication / Psychiatric care

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful

e) Very helpful

5.11) Complementary / Alternative therapies

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

5.12) Employment support (e.g. job coach, work accommodations)

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

5.13) Sheltered workshops

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

d) Somewhat helpful

e) Very helpful

5.14) Expanded disability / income benefits

a) Very unhelpful

b) Somewhat unhelpful

c) So-so

- d) Somewhat helpful
- e) Very helpful

5.15) Education support (e.g. school accommodations)

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.16) Recreational or social groups for autistic people

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.17) Autistic peer support or mentorship programs

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

5.18) Respite care / In-home support

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so

- d) Somewhat helpful
- e) Very helpful

5.19) Other (please explain below)

- a) Very unhelpful
- b) Somewhat unhelpful
- c) So-so
- d) Somewhat helpful
- e) Very helpful

Part 3: Demographics

6) Are you an autistic person?

This includes being diagnosed with Autism Spectrum Disorder, Asperger Syndrome, Autistic Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), or self-identification as an autistic person.

- a) Yes
- b) No
- c) Other (please explain):

7) Do you use AAC (Augmentative and Alternative Communication) in your daily life?

AAC includes picture boards, text-to-speech apps, sign language, and other non-mouth ways of communicating.

- a) Yes
- b) Sometimes
- c) No

8) How much support do you need from others for your daily activities? E.g. eating, dressing, bathing, moving from one place to another.

- a) I can do these things on my own.
- b) I need help from others sometimes.
- c) I usually need help from others.
- d) I need help from others all the time.

9) Are you filling out the survey on your own or with someone else's help?

- a) On my own
- b) With someone else's help
- c) Other (please explain):

10) What is your gender?

11) What is your age?

_____ years

12) What is your race or ethnicity? Select all that apply to you.

- Black
- Indigenous
- White
- South Asian
- East Asian
- Southeast Asian
- West Asian
- Latin American
- Arab
- Other (please specify): _____

13) Do you identify as Two-Spirit, lesbian, gay, bisexual, pansexual, queer, asexual, aromantic, transgender, gender non-conforming, non-binary, gender fluid, genderqueer, agender, gendervague, and/or intersex?

- a) Yes
- b) No
- c) Or, fill your own label: _____

14) Do you have other disabilities or health conditions? If so, please list them.

15) What is your employment status? Select all that apply to you.

- Working full time
- Working part time
- Not working and looking for work
- Not working and not currently looking for work
- On disability income / benefits
- Homemaker
- Student
- Other (please specify): _____

16) What is your annual (yearly) income before taxes?

- Less than \$5000
- \$5000 to \$9999
- \$10 000 to \$14 999
- \$15 000 to \$19 999

- \$20 000 to \$24 999
- \$25 000 to \$29 999
- \$30 000 to \$34 999
- \$35 000 to \$39 999
- \$40 000 to \$44 999
- \$45 000 to \$49 999
- \$50 000 to \$59 999
- \$60 000 to \$69 999
- \$70 000 to \$79 999
- \$80 000 to \$89 999
- \$90 000 to \$99 999
- \$100 000 and over

17) Is the income that you rely on to live at least \$2000/month? This can include support from family and household members.

- a) Yes, I live off of at least \$2000/month independently, WITHOUT support from family and/or household members
- b) Yes, I live off of at least \$2000/month INCLUDING support from family and/or household members
- c) No, I live off of less than \$2000/month

d) Other (please explain):

18) What is your experience with obtaining financial supports for disabled people? Select all that apply.

I am able to access provincial supports (e.g. Ontario Disability Support Program (ODSP) in Ontario, Persons with Disabilities (PWD) Designation in BC)

I am struggling to access provincial supports (e.g. Ontario Disability Support Program (ODSP) in Ontario, Persons with Disabilities (PWD) Designation in BC)

I am able to access federal supports (e.g. Disability Tax Credit, Canada Pension Plan Disability benefits (CPPD))

I am struggling to access federal supports (e.g. Disability Tax Credit, Canada Pension Plan Disability benefits (CPPD))

I have not tried applying for these supports yet, but want to in the future.

I have not tried applying for these supports, and won't in the future.

Other (please explain): _____

19) What is your current living situation? Select all that apply.

I live in a home that I own (e.g. house, apartment, condo, trailer)

I live in a home that I rent (e.g. house, apartment, condo, trailer)

I live alone; may have a pet

I live in a household with other people

I live in a residential facility where meals and household help are routinely provided by paid staff (or could be if requested)

I live in a residential facility which provides meals and 24-hour medical/nursing care

I am temporarily staying with a relative or friend

I am temporarily staying in a shelter

I do not have stable housing, am underhoused, or am experiencing homelessness

Other (please explain): _____

20) Do you have any concerns about your current living situation? Select all that apply.

- Lack of more permanent housing
 - Condition of housing (e.g. accessibility, hygiene/cleanliness, building construction issues)
 - Struggling to pay for housing and utilities
 - Feeling unsafe
 - None of these
 - Other (please explain): _____
-

21) Select all that apply. In the last 6 months, did you struggling with having enough money to pay for:

- Food
- Housing
- Heat and electricity
- Internet and/or phone
- Medical and accessibility needs (e.g. medication, therapy, assistive devices)
- Transportation
- Care of a dependent (child, elder, person with a disability)

- Debts
 - None of these
 - Other (please explain): _____
-

22) Select all that apply. In the last 6 months, did you face accessibility barriers when trying to obtain any of these?

Accessibility barriers includes issues with organizations, outdoor spaces, buildings, systems, technology, communication, and other people's attitudes that make it more difficult for you because you are autistic or have a disability.

Examples:

A grocery store is too loud and bright.

A website is hard to use and understand.

A government office only allows phone calls and not text communication like email.

- Food
- Housing
- Heat and electricity
- Internet and/or phone

- Medical and accessibility needs (e.g. medication, therapy, assistive devices)
 - Transportation
 - Care of a dependent (child, elder, person with a disability)
 - Debts
 - None of these
 - Other (please explain): _____
-

23) Are you a parent or guardian? Select all that apply to you.

- I am not a parent or guardian
- I am a parent or guardian of a minor child / minor children
- I am a parent or guardian of an adult child / adult children
- I have one or more autistic children
- Other (please explain): _____

24) Which province/territory do you live in?

- a) British Columbia
- b) Alberta
- c) Saskatchewan
- d) Manitoba
- e) Ontario
- f) Quebec
- g) New Brunswick
- h) Nova Scotia
- i) Prince Edward Island
- j) Newfoundland and Labrador
- k) Yukon Territory
- l) Northwest Territories
- m) Nunavut Territory

25) Do you live in an urban, suburban, or rural area?

- a) Urban
- b) Suburban
- c) Rural

Part 4: Follow-Up

26) Do you have anything else to share with us?

27) Do you want to be added to the Autistics United Canada mailing list? (We don't send spam!)

- a) Yes b) No

28) Would you like to be contacted by email for a follow-up interview about your responses? The interview can take place by your preferred communication method (e.g. video call, audio call, text chat, email).

- a) Yes b) No

Thank you for sharing your thoughts to inform autistic self-advocacy and national policy in Canada!

Please email your completed survey to info@AutisticsUnitedCA.org.