

Comparative Research into the Trends in Lifestyles of Individuals Connected to Autism



A participant-facing snapshot of the 5Qs study

This exploratory study examined the everyday realities, challenges, positive experiences, and support needs of people connected to autism.



HOW WE COLLECTED AND ANALYZED DATA



Five open-ended
questions



Typeform and
social media
recruitment



Qualitative
keyword/theme
analysis



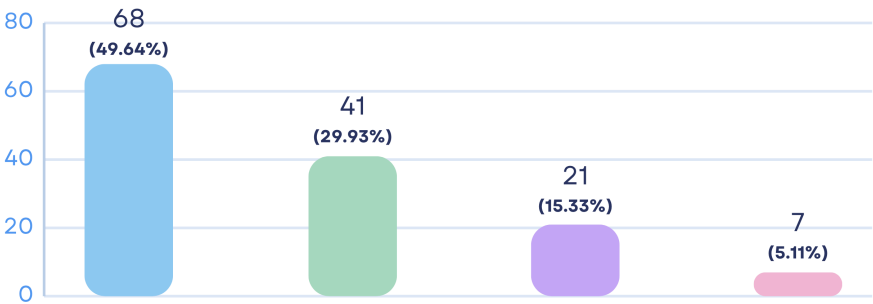
Sentiment
and emotion
analysis

137

total responses

The findings are directional and exploratory.
Responses were concentrated among autistic
adults and parents/guardians, so subgroup results
should be interpreted with care.

WHO PARTICIPATED (COHORTS)



Autistic adults

Autistic
individuals
18+ who self-
identified as
autistic.



Parents & guardians

Parents or
guardians of
an autistic
individual.



Siblings

Siblings of an
autistic
individual, who
are themselves
also 18+.



Indirectly connected participants

Family members,
friends, partners,
or others indirectly
connected.

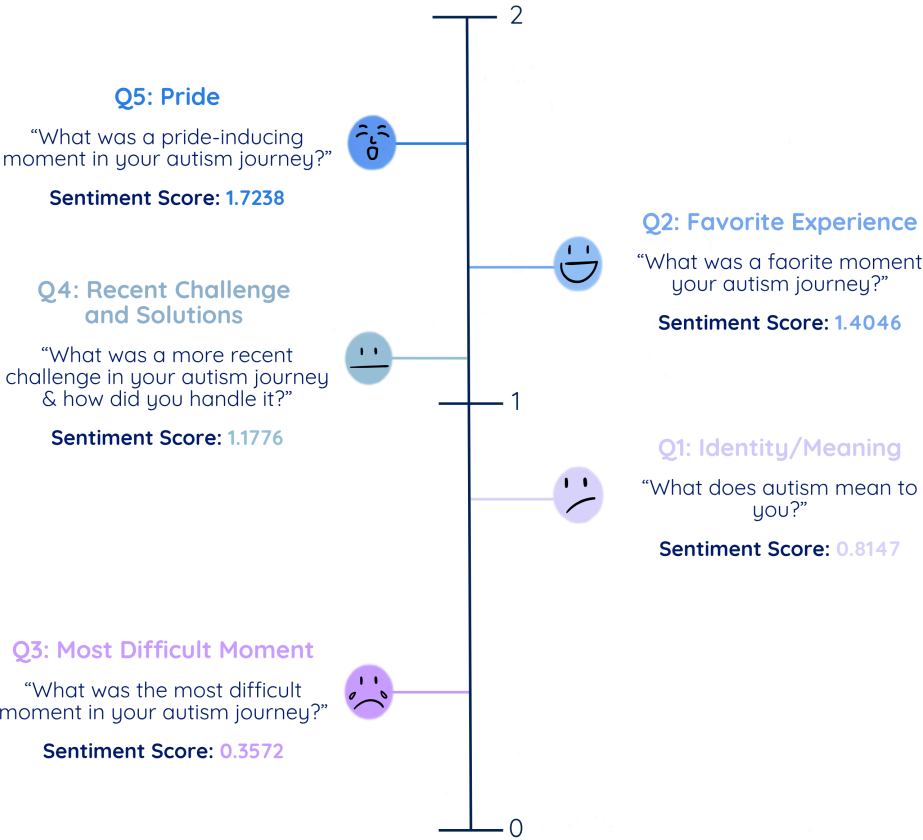
Five Questions, Sentiment Analysis

How did people feel when responding to each question?



Are responses to the questions more negative or positive?

Average sentiment score (0 = very negative, 2 = very positive)



Summary: Sentiments & Emotions across the 5 questions



Joy was the most frequently identified emotion overall.



Q2 and Q5 were the most positive prompts.



Q3 carried the lowest sentiment and the greatest concentration of challenge-related themes.

Methodology Note

The positive shift in sentiment and emotion for Q2 and Q5 directly reflects the negative shift discussed on Page 3: the models responded differently to positive experience/pride prompts than to autism-related identity terminology.

Interpretation - Does bias in models affect results?

These findings have important implications for language models used to interpret sentiment and emotion in interactions - especially within the autism community. We noticed that across the model comparison, autism-related identity terms were often associated with fear, anger, sadness, disease, or sickness even when sentence structure remained constant, while positive experience and pride prompts received much higher sentiment scores. This prompted our side investigation into confirming this bias, where we asked each model to rate "I am ____" sentences according to sentiment & emotion, detailed on Page 3.

Our suspicions were supported by the results of this investigation, which suggests that model outputs may reflect bias in training-data associations and prompt terminology rather than a person's actual emotional state, and result in potentially misreading neutral or affirming autistic self-identification as negative. This suggests that **the models themselves may be biased towards rating autism-related identity terms (ex. autism, autistic, Autism Spectrum disorder) as more negative**. Sentiment and emotion predictions should therefore be treated as context-dependent signals, not objective judgments, and interpreted carefully alongside the speaker's own meaning and lived experience.

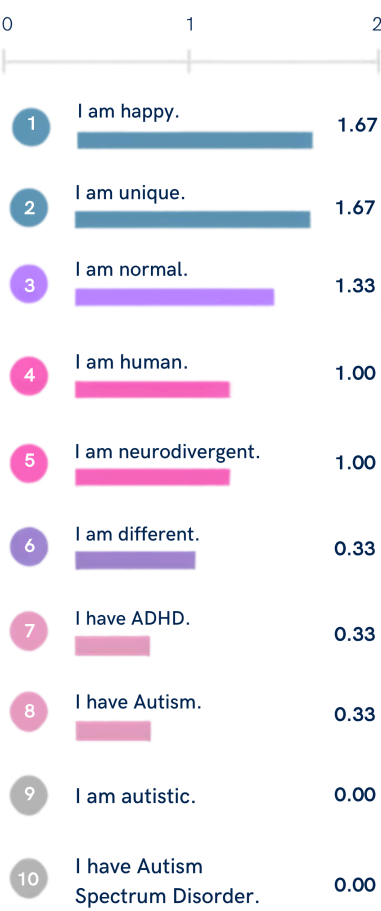
Autism vs. Other Words



Since the models are trained on Tweets, social media posts & literature, by analyzing “I am” sentences, we can see how the general public feels about autism!

Sentiment Model comparison

Average sentiment score (0 = very negative, 2 = very positive)



NOTE: Scores are averages across 3 sentiment analysis models from HuggingFace:

- cardiffnlp/twitter-roberta-base-sentiment
- cardiffnlp/twitter-roberta-base-sentiment-latest
- siebert/sentiment-roberta-large-english

Emotion Model comparison

Across 6 emotions (Joy, Love, Surprise, Anger, Fear, Sadness)

JOY

Positive & neutral identity language such as **happy**, **unique**, and **normal** was most often associated with **joy** across the models.

FEAR **ANGER** **SADNESS**

On the other hand, **autism-related** terms were associated with **fear**, **anger**, or **sadness** across the models.

Ex. “I am autistic.”

“I am autistic.” was associated with **fear**, **sadness**, and **anger** depending on the model.

Ex. “I have Autism.”

“I have Autism.” was associated with **fear** and **anger** depending on the model.

Ex. “I have ASD.”

“I have Autism Spectrum Disorder.” was associated with **fear** and **anger** depending on the model.

NOTE: Scores are averages across 4 emotion analysis models from HuggingFace:

- bhadresh-savani/distilbert-base-uncased-emotion
- bhadresh-savani/bert-base-uncased-emotion
- bhadresh-savani/roberta-base-emotion
- bhadresh-savani/albert-base-v2-emotion



Both sentiment & emotion analysis machine learning models showed a **strong negative association with autism-related terminology**, even when the sentence structure stayed constant.



Autism-related terminology was most commonly associated with words & phrases such as “**disease**”, “**sickness**”, “**nightmare**”, and “**bad situation**” instead of “**happy**”, “**unique**”, “**human**”, and “**normal**”.

Five Questions - Thematic Analysis

What were the main themes found for each question?



1 Q1 — What does autism mean to you?

Autism carried different meanings: strength and possibility, distinctive experiences, identity, and hardship. The interpretation depends on whose experience is being described.



16.83%

Strengths & possibilities

Some people saw autism as a source of strength, opportunity, or something positive. These accounts make room for valued experiences alongside challenges.

Within these responses: 70% autistic adults, 18% parents, 12% siblings.



36.63%

Unique behaviours & challenges

Many described a collection of unique behaviours and challenges. Autism's meaning emerged through everyday experience as well as a label.

Within these responses: 25% autistic adults, 53% parents, 22% siblings.



2.97%

Identity & self-acceptance

Identity was a small named theme. More broadly, autistic adults emphasized self-acceptance, personal identity, and the possibility of viewing autism positively.

2.97% is the identity theme; it does not measure all self-acceptance accounts.



11.88%

A neutral meaning

Some descriptions were categorized as neutral. Together with the positive and difficult accounts, this shows that autism did not carry one shared emotional meaning.



11.88%

A journey or battle

Journey/Battle frames autism as an experience unfolding over time. The wider interpretation also highlights parents' and guardians' greater emphasis on challenge and hardship.



10.89%

Making room for hardship

Negative accounts were present alongside positive ones. Recognizing difficult experiences matters; no single description captures everyone's relationship with autism.

REPORTED THEME TOTALS			
Parallel Life 22.77%	Positive 16.83%	Definition through Similarities 13.86%	Neutral 11.88%
Journey/Battle 11.88%	Negative 10.89%	Evoked Emotions/Requirements 8.91%	Identity 2.97%

DIFFERENT RELATIONSHIPS, DIFFERENT MEANINGS

Autistic adults	Siblings	Parents & guardians
Self-acceptance, identity, and positive possibilities.	Autism is not something to be ashamed of.	More often emphasized challenge and hardship.

2 Q2 — What is a favorite memory on your autism journey?

Favorite memories included making sense of experiences after diagnosis, discovering talents, and enjoying special interests. Positive moments had personal meaning, not just a theme label.



13.64%

When things made sense

Diagnosis could bring a new way to understand earlier experiences. The report highlights this sense of things making sense as a favorite moment.

Within these responses: 33% autistic adults, 50% parents, 17% siblings.



11.3%

Recognizing personal talents

Realizing an exceptional talent was itself a valued memory. This is a specific interpretation within the broader picture of strengths.

Within these responses: 60% autistic adults, 20% parents, 20% siblings.



15.9%

Passions & special interests

Enjoying a passion or special interest was a source of meaning and pleasure. These memories were described by autistic adults.

All responses in this reported subtheme came from autistic adults.



25.00%

Milestones worth remembering

Milestones also featured among favorite memories. The theme points to progress that mattered to the person or family, alongside discovery and self-understanding.



15.91%

Campaigning as a valued memory

Campaigning appeared as a distinct theme, showing that favorite memories could also involve efforts connected to the wider autism community.



9.09%

No favorite or a negative memory

Not every response offered a positive memory. Keeping these accounts visible avoids assuming that everyone experienced the journey in the same hopeful way.

REPORTED THEME TOTALS		
Strengths 36.36%	Milestones 25.00%	Campaigning 15.91%
Diagnosis 13.64%	None/Negative 9.09%	

THE MEANING OF DIAGNOSIS MADE A DIFFERENCE



The main differences in viewpoints concerned what diagnosis meant to each person. A shared event could carry different meanings for autistic adults, parents, and siblings.

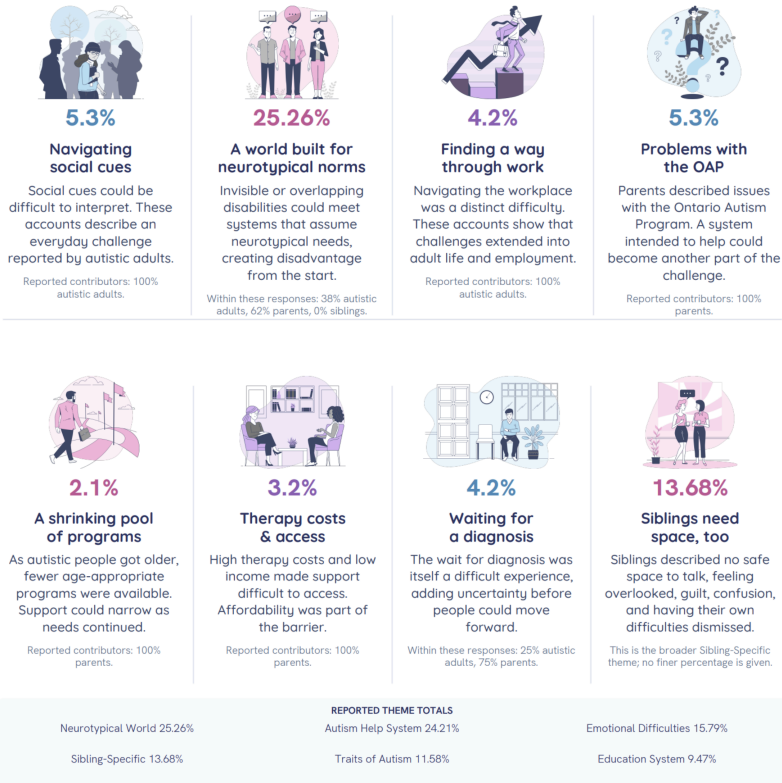
Five Questions - Thematic Analysis

What were the main themes found for each question?



3 Q3 — What was the most difficult moment?

Difficult moments were varied and specific to each group. Many involved a world designed around neurotypical norms, or difficulty reaching the systems meant to offer support.



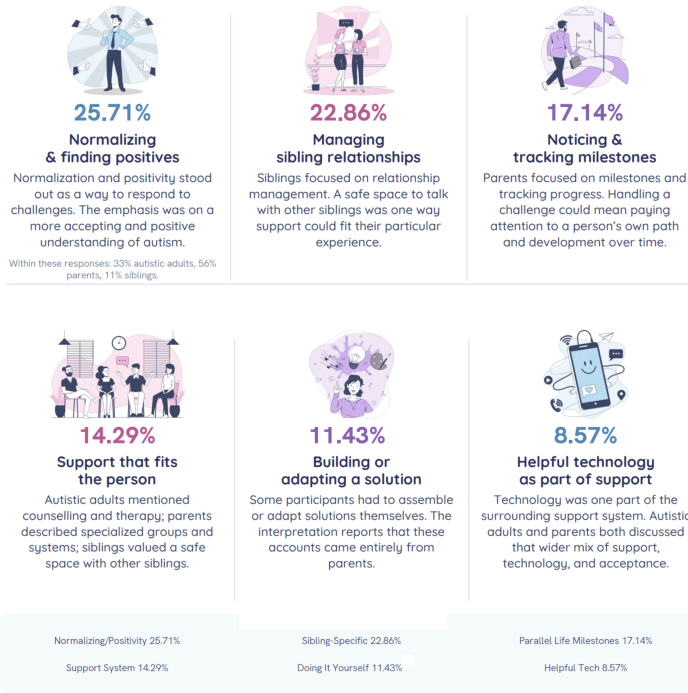
THE LARGEST THEMES CONCERNED THE WORLD & ITS SYSTEMS



The neurotypical world (25.26%) and autism help system (24.21%) were the largest themes. The interpretation points to experiences specific to each group, rather than a single shared “most difficult” moment.

4 Q4 — What was a recent challenge, and how was it handled?

Responses described how people handled challenges: acceptance, tailored support, relationships, technology, and solutions they assembled themselves. What helped depended on the person and context.



DIFFERENT PEOPLE NEEDED DIFFERENT RESPONSES



Parents emphasized milestones; siblings emphasized relationships. The “Other” group wanted to understand autism better from a non-autistic perspective. Support needs to reflect these different starting points.

Five Questions - Thematic Analysis

What were the main themes found for each question?



5

Q5 — What is the proudest moment?

Pride often came from progress whose significance was personal: reaching a milestone, communicating, advocating for yourself, helping someone, or seeing growth over time.



56.14%

Ordinary to others, meaningful to you

Good grades, managing overwhelm, trying a new food, or leaving a comfort zone could mark major progress. The effort behind the milestone gave it meaning.

Within these responses: 31% autistic adults, 41% parents, 19% siblings, 9% other.



12.3%

Finding a way through neurotypical systems

Some accounts celebrated getting through systems designed around neurotypical expectations in distinctive ways connected to autism.

Within these responses: 0% autistic adults, 71% parents, 29% siblings.



10.5%

Stepping beyond a comfort zone

Expressing feelings, standing up to bullying, self-advocacy, and making friends could become sources of pride.

All responses in this reported subtheme came from autistic adults.



1.8%

A first moment of communication

A child communicating or expressing themselves for the first time was highlighted as a meaningful achievement.

†Percentage reproduced as reported. The subgroup breakdown is incomplete.



5.3%

Making a difference in someone's journey

Being part of another person's journey could bring pride through a sense that your contribution mattered and had an impact.

All responses in this reported subtheme came from the "Other" group.



15.8%

Seeing who someone has become

Pride could come from personal growth, from seeing a child or sibling grow, or from both. The relationship and the journey mattered.

Within these responses: 11.1% autistic adults, 44.4% parents, 44.4% siblings.

REPORTED THEME TOTALS

Achieving Unique Milestones 56.14%

Resilience 22.81%

Discovery 10.53%

Dreams 8.77%

Nothing 1.75%

PRIDE MAKES SENSE IN THE CONTEXT OF A PERSON'S LIFE



The same achievement can carry very different weight for different people. These responses connect pride to effort, self-expression, relationships, and growth along an individual path.

(NOTE: All images/illustrations from Pages 4-6 came from Storyset/Freepik)



One autism journey, many characters, shared barriers.

1



Autism is lifelong and highly individual, but with recurring themes, viewpoints, and issues across groups.

2



Autistic adults emphasized identity and self-understanding; parents/guardians emphasized milestones, systems, and supports; siblings emphasized relationships.

3



Across groups, many people described navigating a world that is not sufficiently informed about autism.

4



Autism has a negative stigma within and outside the autism community; normalizing autism & seeing the positive aspects of the autism journey is critical.

5



People and families often have to fight systems that should be fighting for them & navigate a world; age-appropriate support can shrink across the lifespan.

IMPLICATIONS



For governments: plans should incorporate findings from this study (ex. the *Ontario Autism Plan*, explicitly mentioned by participants as needing *significant improvements*)



For partners: design accessible, specialized tools and promote solutions that already help - especially sibling support & older groups!



For the wider community: replace stigma with informed, balanced, and hopeful representation.

LIMITATIONS

Exploratory sample; response imbalance across cohorts; automated sentiment/emotion outputs may contain model bias; findings should not be generalized beyond the study.

The research team aims to repeat the study annually, with improvements to the methodology & expanded scopes (ex. geographically, the "Other" category, intersectional conditions & systematic barriers). Hopefully, we see trends towards a **more truthful, hopeful, and positive view of autism**. and **solutions that genuinely help members of the autism community**.

See full research report (*coming soon*) at autinerary.ca/autism-is, as well as the campaign that surrounded the research!