The Autistic Experience

*Please only answer these questions if you feel comfortable. Not every question or section needs to be answered. Feel free to use as many words as you’d like. This is your expression of your world, there are no right or wrong answers. The questions we’ve listed are just general ideas, feel free to share any experience you’re willing to tell us, even if it doesn’t match the questions. It is not necessary to have a formal diagnosis to answer our questionnaire. If you are under 18 years old, we will need parental consent in order to publish your testimony. These questions should not be answered by a third party, they should only be answered by the individual themself. Any work you share with us is voluntarily offered for no monetary compensation, but you maintain legal ownership and copyright of it.*

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| First Name: (if you don’t feel comfortable sharing your first name, feel free to write a fake name) |  |
| Age: |  |
| Gender identity: |  |
| Countries you consider home: |  |
| Ethnic background (optional): |  |
| Country of birth (optional): |  |
| Have you received a formal diagnosis? | [ ] No [ ] Yes If yes, at what age: |
| Email address |  |

1. Growing up

What was your experience growing up as an autistic child?

* What was it like for you to be an autistic child? What was great about it? What was tough about it?
* What kind of school did you go to (public school, residential care, special education needs school, university…)?
* What was easy/difficult in your experience at school?
* What subject(s) did you study?
* What was your experience like regarding school/studies?
* Do you feel that the public school system is well suited to you as an autistic person? Does the learning method suit you as an autistic?
* Did you ever get bullied? If so, can you tell us what happened and what impact it has had on you? Also, can you tell us how you survived it? Did you reach out to someone you could trust? Did you move to a different school? Did you stand up to them?
* Do you get along well with your parents? Do you feel that they accept and love you authentically or rather that they try to get you to change? Do you feel that they respect you and listen to your needs? Do they have a positive view of autism?
* Do you get along well with your siblings? Do you feel that they accept and love you authentically or rather that they try to get you to change? Do you feel that they respect you and listen to your needs? Do they have a positive view of autism?

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| Your answer:  |

2. Medical

* What kind of therapy have you had in your life? Did you find it helpful or harmful? What made it helpful/harmful?
* Do you find it easy to go to the GP, dentist, gynecologist, etc. or is it difficult? What makes it easier? What makes it more difficult (scary/painful)?
* Do you feel that doctors generally listen to you and are respectful or are you having a hard time being taken seriously?
* Have you had any interaction with a doctor/therapist that you’ve found particularly helpful/harmful? If so, can you describe it to us?
* In therapy, do you find it easy to talk about the topic you wanted to address in a given session or do you sometimes feel frustrated at the end of a session because you did not get a chance to talk about what felt most important to you? If you find it difficult to bring up a certain topic, what might make it easier for you to express it?

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| Your answer:  |

3. Diagnosis

* Can you tell us about your journey in getting a formal diagnosis (if you’ve gotten one)? Was it easy/difficult to get the diagnosis? Were the doctors/therapists respectful or not?
* If you were diagnosed as a child/teenager, what was helpful about it and what was difficult about it? If you were diagnosed as an adult (or not diagnosed at all), what was helpful about it and what was difficult about it?
* What was it like for you to get a diagnosis? Did you feel relief, fear, anger, pride, …?
* If you do not have a diagnosis, do you feel that it is important to get one? If so, why? If not, why?
* If you were given a diagnosis, which one(s) was it/were they? (You may include self-diagnosis, but please mention it if that’s the case)
* Have you had a diagnosis mistakenly given to you because the therapist did not recognize that you were autistic? For instance, did a therapist/doctor mistakenly diagnose you as ADHD or borderline, bipolar etc. because they did not recognize you as autistic?
* How did your family react to your diagnosis? Were they supportive? Did they seem anxious about it?

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| Your answer:  |

4. Perception of autism

* What is your definition of autism?
* In your opinion, what should be the criteria that define autism?
* Do you feel that autism should be considered as a diagnosis or as a different neurotype?
* How do you feel about the following phrases: “suffers from autism”, “severe autism / mild autism”, “autism spectrum” and “autism disorder”?
* Do you view autism as a disability or a brain type that can cause disabilities or do you rather feel that people who are autistic can also be disabled just like neurotypicals can?
* Do you prefer to say “I am autistic” or “I have autism”?
* Do you feel that autism is a separate medical condition or that it is an integral part of your identity?
* In your experience, what is the best thing about being autistic?
* In your experience, what is the hardest thing about being autistic?
* How do you feel about the way media and pop culture represent autism? Do you find depictions of autism in shows such as The Good Doctor, Atypical etc. accurate and positive? Are there any particular representations you really like/dislike?

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| Your answer:  |

5. Day to day life

* What means of transportation do you usually use? Do you feel comfortable taking public transportation?
* What is it like for you to go grocery/food shopping?
* What is it like for you to go shopping for clothes? Do you have certain preferences when it comes to choosing your clothes (fabric, color, labels etc.)?
* Do you find it easy to set boundaries? For instance, are you able to say “no” if you don’t feel like going somewhere or like doing something? Do you find it easy to assert yourself and share your thoughts, needs and feelings?
* Which ways of communicating do you prefer/feel uncomfortable with? Talking to someone face to face / on the phone / written communication (email/chat) / …?
* Do you have any pets? Can you describe your connection to them, the impact they have on you, the importance they have to you?

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| Your answer:  |

6. Special interests

* Do you have any special interests? If so, what are they?
* Can you tell us about how you’ve incorporated those interests in your life (join a club, follow social media groups, made friends who share a common interest, made it your job etc.)?
* Do they affect your social life?
* How often do they change? Monthly, yearly?
* Do you find yourself going back to previous interests or do you stick to the same one constantly?
* In conversations, do you find yourself driving the conversation towards your special interest? Do you find it boring to talk about other subjects?
* Does it help your mental health/mood when you are thinking/doing your special interest?
* How much do your special interests negatively/positively impact your social life and economic life?
* Do you use social media? In what way is it toxic to you? In what way is it beneficial for you?

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| Your answer:  |

7. Professional

* Do you have a job? If so, what is it? At what percentage do you work (how many hours weekly)?
* How do you feel about job interviews? Do you feel that they reflect an accurate and positive image of you? Do you prefer to have them over zoom or in person?
* In your opinion, what makes you good at what you do (what are your professional strengths)?
* Do you feel you are living up to your potential?
* What do you struggle with in the workplace?
* Do your colleagues/managers know that you’re autistic? If so, how did that conversation go (when you informed them you were autistic), how did they react? Did you tell them you were autistic before they’ve hired you or later on? What made you decide to tell them?

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| Your answer:  |

8. Mental health

* What is your mood usually like? Do you usually feel rather happy/enthusiastic/tired/sad/angry/…? Do you feel like your mood changes a lot within a same day or is it rather stable? How would you describe your mood today? How would you describe your mood in the last 3 months?
* Do you feel like you have a good self-esteem and a good self-confidence? What made you improve your self-esteem? What made it difficult for you to have a good self-esteem?
* Have you ever suffered from depression?
* When you suffer from anxiety, does it stop you from living the life that you want to live? What normally triggers it? What kind of anxiety do you feel (phobia, panic attacks, nervousness in certain situations, …)?
* How do you feel your trauma affects your life?

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| Your answer:  |

9. Masking

* Do you know what masking is?
* Do you think you mask? Do you know when you’re masking? Do you feel like you know who you are behind the mask?
* In what situations would you normally mask? Around whom?
* How comfortable are you with eye contact? If no, why? If yes, who with? If you fake it, how do you fake it and why do you fake it? If you do fake it, are there any negative consequences?

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| Your answer:  |

10. Friendships

* Do you have any friends?
* How many close friends do you have? What do you consider a close friend?
* Do you tend to have a small group of friends or a large group of friends?
* What kind of interactions do you prefer to have with your friends (meeting online, going for a drink, doing an activity together…)?
* Do you tend to be closer to neurodivergent people or to neurotypicals? What makes it easier for you to be closer to these people?
* Do you consider yourself to be an introvert or an extravert? Does it depend on the context (who you’re with, for instance)? When do you like to be around people and when do you prefer to be on your own?
* Do you attach yourself to one friend and then put all your efforts into that one person, leading them to become overwhelmed and then no longer wanting to be your friend? Or do you rather tend to have several friends at the same time?

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| Your answer:  |

11. Emotional regulation

* Do you sometimes feel overwhelmed? If so, what can be typical triggers?
* When you’re feeling overwhelmed, how can you regulate yourself? For instance, if you’re having a meltdown, what helps you feel safe and calm?
* If you’re about to have a meltdown, what do you do to prevent it?
* Do you stim? If so, do you move when you stim? What type of stims do you have (physical, verbal, visual)?
* What impact does stimming have on you? Have you ever been forced/asked not to stim? If so, what was that like for you, what happened?
* Do you ever practice self-care? If so, what feels like self-care to you (playing video games, going for a walk, meditating, reading, taking a bath, being creative, …)? How often do you typically practice self-care?
* Do you feel a lot of empathy? Can you describe what it feels like to you when you empathize with someone? In what situations will you tend to feel empathy? How will you express/show your empathy?
* Do you like screens? What impact do they have on you? In what way are they toxic for you? In what way are they beneficial for you? How much time do you spend on screens weekly?

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| Your answer:  |

12. Food

* Do you like to eat various food or do you prefer the same type of food repeatedly? If you prefer to eat similar food repeatedly, what kind of food do you like to eat often?
* Are you a vegetarian/vegan/…? If so, why did you decide to become a vegetarian?
* Do you have any food intolerances/allergies or digestive problems? If so, what kind?

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| Your answer:  |

13. Couple

* Have you ever been involved in a romantic relationship?
	+ If yes:
		- Are they neurodivergent or neurotypical?
		- Can you describe what the communication is like in your relationship? Are there many arguments? Do you confide in them a lot? Do you cry in front of them? Are they supportive?
		- When there is a conflict in your relationship, what is your go-to reaction (get angry / withdraw / …)? Do you rather feel the need to talk about it right away until the issue is solved or do you prefer to process the disagreement on your own and then reconnect once you no longer feel upset?
		- Have you ever been in a toxic relationship? If so, what made it toxic and how did you get out of that relationship?
		- What types of displays of affection do you like? Do you initiate it or do you prefer if your partner initiates it?
		- When your partner is upset, how do you comfort them?
		- How do you show your partner you love them (saying “I love you”, hugging, giving presents, helping them out etc.)?
		- When you’re feeling sexually aroused, how do you let your partner know?
	+ If no: would you like to someday be dating someone? Is there something making it hard for you to date someone? If so, what is it?
* What will make you feel romantically attracted to someone? What will make you feel sexually attracted to someone?
* How do you seduce someone, how do you try to get them to date you?

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| Your answer:  |

14. Parenting

* Are you a parent? If yes, how many children do you have? If no, would you like to be a parent?
* What is it like for you to be a parent? What do you find easy/difficult?
* Is your child autistic?
* Are you a single parent? If so, what is that like?

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| Your answer:  |

15. Gender

* Do you identify as the same gender you were assigned at birth?
* What is your sexual preference? Do you identify as LGBTQIA+?
* How do you feel about gender stereotypes? Do you feel the gender stereotypes attached to your assigned gender match your personality? Do you relate to feminine/masculine stereotypes?
* Growing up, were you encouraged to play games that match the stereotype attached to your gender? Would you have rather played games/been hanging out with people from the other gender? Did you have some liberty around that or was there not much of a choice?

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| Your answer:  |

16. Advice

* Do you have any advice/lifehacks/tips for fellow autistic people?
* Do you have any advice, suggestions or requests you’d like to send to the medical community that could make the medical consultations more comfortable for autistic people?
* Do you have any advice, suggestions or requests you’d like to send to the relatives (parents/siblings) of autistic people?
* Do you have any advice, suggestions or requests you’d like to send to the school system in order to make it more autism-friendly?
* Do you have any advice/tips/suggestions for the two writers of the book (themes to develop, perspectives to include, helpful contacts etc.)?

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| Your answer:  |

17. Other

Is there anything else you’d like to share? Feel free to write here anything you’d like to tell us that didn’t fit in the previous questions!

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| Your answer:  |

*We cannot guarantee your story will be in the book but we’ll try to share as many experiences as possible. Thank you so much for sharing your story with us! We can’t wait to read it and we’re sure it will be incredibly helpful to the autistic community who will be able to relate to your experience and learn from it. It will also help the medical community understand autistic people better and develop a positive view of neurodiversity.*

By sending this paper, I consent to having my story shared in the form of a published book. I understand that I will not be given monetary compensation for this. The use of those testimonies is only allowed in the context of writing this book and cannot be used in any other context or purposes.

Please return this form to the following email address: autisticstories@outlook.com