

Oral History of Late-Diagnosed Autistic Adults

Session 2: Main Interview Questions

Hi, my name's Gabby/Joanne, and I'm a research assistant for this project. I'm also autistic and I didn't get my diagnosis until I was [XX years]. In this project, we're recording the oral histories of people who had a late diagnosis of autism. We want to understand what people's lives have been like, before and after their diagnosis.

We're very thankful that you've chosen to meet with us and share a bit about your life.

So, this interview is taking place because you've agreed to share parts of your story, and you can stop or take a break any time. If you do want to take a break, just let me know. We've already talked about possible ways to let me know that, but I just want to check that we're both clear on ways you might let me know you want to stop: [list ways]
_____. I also invite you to just put your hand up, if that's easier.

I'm going to ask some general questions about your life before and after your autism diagnosis. Sometimes I'll ask you to say more about what you've said, to get a clearer idea of the things you're telling me. Just answer at your own pace, there's no rush. You can skip a question or come back to a question at any time.

Please ask me to repeat or re-word a question, if you need to. It's not a problem. That's something I often need to do!

If you need to move your body in any way to be comfortable, then do. Please let me know if you need to move in a way that might mean you're no longer in the video shot, so that I can pause the recording while you move.

As you now, we'll be recording this interview using a video and a voice recorder. The voice recording will be a back-up, if the video doesn't work.

Do you have any questions, before we start? Ok, let's get started!

Start the Interview

My name is _____, and I'm interviewing _____.

Today is the ____ of _____, 2019 and it's ____ o'clock.

We'll start with a few easy questions. Can you tell me your date of birth? And how you prefer to describe your gender identity (as a man, woman, non-binary or another gender identity)?

Primary question 1: Tell me about how things were when you were a child. Maybe to start, you could tell me about your earliest memory?

Prompt questions (not all of these will necessarily be asked by the interviewer):

- a. Where did you grow up?
- b. Who was in your family? Did you have siblings? What were the relationships like??

- c. What was it like at school and with friendships?
- d. What things did you play with, and what games did you like to play?
- e. What were some of your interests?
- f. Can you remember being happy, carefree, anxious, worried, scared, joyful, adventurous, brave, or some other type of feeling?
- g. How was your broader community?
- h. In your family and community, did you feel supported and that you belonged? In what ways?
- i. As a child, did you think of yourself as different from your peers/siblings? Do you remember how others perceived or treated you?

Check if participant needs a break.

Primary question 2: Moving on from your early years, what are some of the things you can tell me about your teenage years?

Prompt questions:

- a. Can you tell me a bit about school?
- b. What sorts of activities did you do? I'm interested to hear about the ones you liked doing as well as the ones you didn't like doing and why you felt that way about them. They might have been solitary activities, social ones, sports ones – either participating or as a spectator.
- c. Are there any specific words you can think of to best describe who you were or what you experienced during your teenage years?
- d. How was your relationship with your family during this time? And your siblings?
- e. We asked you about whether or not you felt different from your peers or siblings during your younger years. Did this change for you as you got older? Do you remember how others perceived or treated you?
- f. How was your mental health? Did you want extra supports. If so were they available or successful?
- g. Do you remember the first time that you heard the term, 'autism' or 'autistic'?

Check if participant needs a break.

Primary question 3: Now moving on to the transition from the teenage years to becoming an adult, can you tell me a bit about what that was like for you?

Prompt questions:

- a. We're interested here about jobs, living situation, friendships, romantic relationships, travel, parenting, gender identity.
- b. How did you feel about this phase of your life? And your sense of who you were in the world?
- c. Education (TAFE, university, other)
- d. Work and career, financial stability

- e. Housing and homes
- f. Moving from your family of origin to chosen families? Children?
- g. Intimate relationships
- h. Friendships
- i. Did your interests shift or intensify? What place did they have in your life?
- j. Did you think of yourself as different during this period? Do you remember how others perceived or treated you?
- k. How has your mental health been?
- l. How has your physical health been?

Check if participant needs a break.

Primary question 4: Can you tell me some the things that happened in later adulthood, that brought you to a diagnosis? When exactly did you get your diagnosis?

Prompt questions:

- a. Life circumstances, another person, health professional, something you read or heard, child's diagnosis
- b. How was this process for you?
- c. What did you know or think about autism at the time?
- d. Looking back, can you recall how medical or other professionals treated you during this time? Was diagnosis an empowering experience for you or one that left you feeling overly vulnerable? Or both?

Check if participant needs a break.

Primary question 5: How has life been after diagnosis? Can you tell me about the impact of having a diagnosis on your life and well-being?

Prompt questions:

- a. What do you know or think about autism now?
- b. How important is being autistic to you? How has being autistic impacted upon the different aspects of your life (family, work, friendships/relationships/wellbeing)?
- c. How do you see yourself now, and has your understanding of your past changed?
- d. What have been helpful or unhelpful sources of information or support?
- e. Have you engaged with the autism community? If so, how? If not, can you tell me a bit about why that is (e.g.,) lack of opportunity, not interested, don't know how to make contact, don't think it would be helpful)?
- f. How do you think your closest people and society treat and understand autistic people?
- g. Do you talk about your diagnosis with others?
- h. Do you take care of yourself in different ways now, or make different choices in your life?
- i. How is your life different now that you have an autism diagnosis?

- j. If you hadn't gotten the diagnosis, how might your life be worse today? Or better?
- k. Given the lateness of your diagnosis, how has the diagnosis impacted your relationships? With parents/family? Friends? Other autistic people?
- l. On the whole, do you believe having been diagnosed is a good thing for you? Why?
- m. How has having the diagnosis changed the community/communities you are a part of?
- n. Do you feel stigmatized in any way since being diagnosed?

Check if participant needs a break.

Primary question 6: Thinking about the next 5 years, what sorts of things do you think will happen for you during that time?

- a) What are your hopes for you? Your family? And your community?
- b) What are your concerns for you? Your family? And your community?
- c) Is there a dream – something you've always wanted – that you'd like to achieve, or begin working towards?
- d) What will help to make them happy years?

Primary question 7: Almost done! Is there anything else you think it's important that I should know?

Next steps

That's all my questions. Thanks so much for speaking with me and for sharing your life history – it was wonderful to be able to hear it. I hope that you are feeling ok about it too.

Regarding next steps, we are going to send the recording of your interview to a transcription service, who will write it out. And I will send you the transcript (the written-out version) of your interview in about one month's time for you to review – to look over and make sure that you are happy with everything being included (and if you're not, that's fine, you can delete bits!). At the same time, I'll check whether you would still like any visual materials (like photos or objects) to be included as part of your life history.

In the meantime, is it ok if I contact you with questions I might have to clarify some of the topics we discussed today?

Finally, I hope that you enjoyed our conversation. But if you feel worried or upset as a result of what we've spoken about today, please get in touch with your support person and/or see your GP. I've also included the phone numbers for beyondblue and Lifeline in your Support Person letter, in case you'd like to speak to someone anonymously about any concerns you have following this interview.

Thanks so much again and I look forward to being in touch again soon.

LIST OF DIFFERENT WAYS TO LET THE INTERVIEWER KNOW THAT YOU WANT A BREAK

- Make a 'T' sign with your hands, like this:

You might have seen this in baseball or basketball games when someone wants a 'Time Out' from the game.



- Say words to state that you need a break, like "I'd like a break now" or "I'm done for now".
- Show me the 'Break' sign (we will email you this sign after Session 1, before the interview begins, so that you can use if you become non-verbal).
- Use a hand signal of your choice. The Interviewer will check with you before the interview begins to make sure that they know what it is.
- Get up and walk to a different part of the room or go into a different room. Let us know before you do this, if possible (we might need to make some changes to our recording equipment if you move).
- Signal to someone else in the room. They can let the Interviewer know that you'd like to take a break.
- Tap your watch (or your wrist where a watch might be, if you don't have one).
- Stay silent. When the interviewer notices, they will ask if you need a break. You can nod your head to show that you do.