

Missing People Autism Research – Interview Information Sheet

About this document

This document provides more detail about Missing People’s research exploring the links between autism and missing, and describes how you can be involved as a participant in this research by sharing your experiences with us in an interview¹. We know that the word “interview” alone carries negative connotations for many people, so please make sure to read the footnote at the bottom of this page clarifying what we mean by “interview” in the context of this research.

Participants’ wellbeing is our number one priority, and we are committed to ensuring that those who take part feel sufficiently prepared and comfortable chatting to us. This document provides as much detail as possible to ensure you are fully informed about the interview process and the research project in general. This includes:

1. Purpose of research
2. Research methods
3. How we will use the findings
4. Interview formats, accommodations and adjustments
5. How we will use your data – confidentiality and anonymity
6. Safeguarding
7. Right to withdraw
8. How to sign up

Please note that reading this document is entirely optional – if you already know that you would like to take part in an interview, please email Ross Paterson at ross.paterson@missingpeople.org.uk to express your interest and he will get back to you about next steps.

However, we know that many people would like to know as much information as possible before agreeing to be interviewed. If that applies to you, this document is primarily for your benefit. If there is anything not mentioned here which you would like to know before agreeing to take part, please do not hesitate to reach out to Ross via the above email address. We are happy to answer any questions you might have, no matter how big or small they might seem, and there are no silly questions. In the meantime, if you would like to, please read on for more details about the study.

¹ We acknowledge that the word ‘interview’ may sound quite formal and potentially intimidating to some, but please note that we approach our interviews more in the style of an informal chat as we want you to feel as relaxed as possible. While the term ‘interview’ will feature throughout this document and others, please keep in mind that it would feel much more laid-back and casual than the term suggests. Furthermore, we hope you will feel reassured by the fact that the lead interviewer and main point of contact, Ross, is autistic himself and so can personally relate to many of the challenges or anxieties you might experience. Please do not hesitate to reach out to him if you have any worries or concerns about the interview. We are also sending the interview questions to all participants several weeks in advance so you know exactly what to expect and have time to think about your responses. Additionally, you can request any adjustments which would make the interview more accessible to you, and choose from various alternative, non-verbal interview formats such as text-based or picture-based interviews (for more on this, see Section 4 of this document).

1. Purpose of research

Missing² as an issue encompasses a broad spectrum of experience and intersects with a variety of other social issues, including mental health, criminal and sexual exploitation, and homelessness amongst others.

Of course, no two autistic people are the same, each with unique personalities and needs. However, it is also true that autism is associated with several traits that may put autistic people at greater risk of harm before, during, and after a missing episode. These include, for example:

- Communication difficulties
- Sensory processing differences
- Repetitive behaviours and routines
- Anxiety related to change and transitions

To date, however, there has sadly been very little research in this area. Autism is therefore an important piece in the jigsaw of missing, and as a charity we feel it is important for us to better understand the experience of autistic people who go missing.

If you are interested in taking part in this research, please check that you meet the necessary criteria:

- You are age 18 or older
- You are based in the UK
- You are autistic (whether formally diagnosed or self-diagnosed)
- You have lived experience of going missing at some point in your life (see footnote below for what we mean by 'missing'). You still meet the criteria for being 'missing', regardless of:
 - How long you were away for (e.g. one hour, two days, several weeks, six months etc.)
 - How old you were at the time (e.g. if you were a child or an adult at the time)
 - How many times you went missing in total (e.g. once or multiple times)
 - Where you went missing from (e.g. home, a care setting, school, work, a hospital, etc.)
 - Whether or not you were reported as missing to the police

2. Research methods

Our research comprises five main elements:

1. Desk research into the relationship between autism and issues we know have strong links with missing
2. Qualitative research analysing Missing People's records of support provided to autistic missing people
3. Surveys, qualitative interviews, and focus groups with professionals who work in relevant organisations, including charities, the police, care settings and other frontline services
4. Surveys and qualitative interviews with family members of autistic people who have been missing
5. Surveys and qualitative interviews with autistic people with lived experience of being missing.

² By 'missing', or 'run away', we mean when you leave somewhere you are expected to be, without telling or being able to tell other people where you have gone, and your whereabouts are unknown to others. This can be for any length of time, from a few hours to several days, months or years. This typically involves being reported to the police as a missing person, but it can also include situations where you were not reported missing. Some people might use different terms to describe their experience such as 'going away', 'disappearing', 'going absent', 'taking time out', or something else, and you may never have thought of yourself as 'missing'.

Having finished collecting data for stages 1 to 3, we are now collecting data for stages 4 and 5. As a charity, we recognise the importance of centring the voices of people with lived experience of missing, and strongly value your opinions and insights.

If you are interested, you can also learn more about, and complete, our lived experience survey by [clicking here](#). You are welcome to complete our survey and take part in an interview if you would like to – one does not disqualify you from the other.

3. How we will use the findings

We intend to use the findings of this research to:

- Better advocate on behalf of autistic people who go missing
- Ensure our own services are best meeting the needs of autistic people (to learn more about our full range of services, [click here](#)), and
- Publish a public facing research report outlining our key findings

The report will also offer good practice guidance to families and carers of autistic people at risk of going missing, as well as to professionals who may have a role in supporting autistic people. We hope that the publication of the report will influence the policies and practices of the key agencies and groups typically involved when someone goes missing to ensure that the needs of autistic people who might be at risk of going missing are being properly met across the UK, that they can access the support they need, and that they are safeguarded as effectively as possible.

4. Interview formats, accommodations and adjustments

We would like to hear from you about your own experiences of running away or going missing as an autistic person by conducting an interview. However, as mentioned previously, we are aware that different people will have different accessibility needs. We want to be as flexible as possible to ensure the interviews are accessible to all, so you can choose which interview format suits you best and request any accommodations that would make it easier for you to participate.

Below is some basic information about different formats, along with some examples of accommodations that can be made for each. Please note that this is not an exhaustive list, and you are welcome to request any other accommodations or interview formats that are not included here but would help you to participate.

Verbal interview (online or by phone)

- We ask you questions via online platform (e.g. Teams or Zoom), or via telephone call, and you respond verbally
- Calls recorded (with your consent) so we can produce an accurate transcript
- The interview would likely last around one hour, but may be slightly shorter or longer
- Two members of the research team would conduct the interview, led by Ross who is autistic himself

Possible accommodations / adjustments

- Interview questions sent to you in advance so you know what to expect and can prepare responses (we do this for all participants – no need to request)
- Regular breaks throughout call if needed
- Several shorter calls rather than a single one-hour call
- Cameras can remain switched off if using video call platform
- Somebody can join you during the call for support, or to help with communication
- We can send any follow-up questions we might have in written form after the call rather than asking during the interview

Text-based or picture-based interview

- We send you a list of written questions
- You reply to our questions by sending typed responses, images, drawings, videos, or any other non-verbal format you like
- You choose which platform we use to communicate. For example:
 - Email
 - Text message
 - WhatsApp
 - Zoom or Teams chat function
 - Other (on request)

Possible accommodations / adjustments

- You can request not to be sent any follow-up questions
- You decide how much time you need to return your responses to our questions
- You can skip any questions you're unsure about or don't want to answer
- You can have a family member, carer, friend, or other trusted person help you with your responses if necessary

If you are interested in taking part, we will send you a 'Research Preferences Form' in advance in which you can indicate your preferred format and any accommodations you would like us to put in place. Regardless of format, to give you a general idea of the type of things we would like to explore, our questions will centre around the following broad themes:

1. Your background, autism, and any other comorbid conditions you might have
2. Circumstances around why you went missing
3. What happened to you while you were away
4. How/why you returned from being missing
5. What support you were given when you returned
6. What support you wanted
7. Your experiences with agencies like the police, social services, healthcare workers, charities, and any others

5. How we will use your data – confidentiality and anonymity

We will ensure that your confidentiality and anonymity, and that of any other people you mention during your interview, are protected at all times. We will carry out the interview in your preferred format.

If you choose a verbal interview format, we would like to produce a transcript of the conversation. This would involve us recording the conversation, with your consent, so we can listen back later and ensure the accuracy of the transcript. These files, along with any other documents you send us, will be stored in an internal, password-protected cloud storage system in a folder which only our research team have access to.

The same is true for any data or documentation shared with us via alternative interview formats, such as text-based and picture-based formats. All data you share with us will be deleted from our end on your chosen communication platform. However, please be aware of your chosen platform's data storage and privacy policies as these sit outside of the control of Missing People.

All interview data will be fully anonymised, with all names, places and other sensitive information being redacted from any output from this research. Your name, contact details, and the fact that you took part in the research, will be stored on our internal case management system. However, no details of what you disclose in this research will be stored there, simply the fact that you took part.

All interview data will then be analysed for:

1. Key takeaways and findings, such as common themes shared by multiple participants, as well as more unique and individual experiences, thoughts or opinions, and

2. Useful or impactful direct quotes for potential inclusion in the final report (again, any quotes used will be completely anonymised).

We will not share participants' interview data with anyone internally or externally, except of course for the final report where any information we do include will be fully anonymised. However, if you are planning to have someone accompany you during the call, please be aware that Missing People cannot control what your accompanying person chooses to do with the information you share in their presence.

6. Safeguarding

It's possible that certain questions or topics we intend to ask might be triggering for some. We understand the sensitivity of certain topics and want to ensure participants that their wellbeing is our number one priority. This is one of the reasons why we intend to share the interview questions with you in advance, to allow you to let us know if there are any topics that you do not want to discuss. You can let us know about this in your 'Research Preferences Form', via email, or immediately before we start the interview.

If you become distressed during the interview for any reason, please just let us know. We can take a break, reschedule the interview for a later date, or even terminate the interview altogether.

If you are affected in any way during your interview and need someone to speak to, our Helpline team are available to chat and offer you any support you need. You can contact them by phone or text message via 116 000, or send an email to 116000@missingpeople.org.uk. We will remind you of this again at the end of the interview.

For safeguarding reasons, please note that if disclosures are made during the interview which identify you or any other individual to be at risk of serious and immediate harm, or identify detailed information about serious crime that has not previously been disclosed to the correct authority, we may have to break confidentiality and inform a Director at Missing People in line with the organisation's Safeguarding Policy. If this happens we will inform you of potential next steps.

7. Right to withdraw

At any point during the interview, if you do not want to continue, please just tell us and we can end the call immediately. You have the right to withdraw your consent to take part at any time. If, following the interview, you decide that you do not want us to use your contributions to this research in our final report, please let us know and we will delete all of your data.

8. How to sign up

This form was intended to ensure that people are fully informed about this research project and the interview process so they can make an informed decision about whether they would like to take part. If you are interested in taking part in an interview, or have any questions at all, please email Ross Paterson at ross.paterson@missingpeople.org.uk.