



WARC's Guidelines for Interviewing Autistic Individuals

This document was prepared for WARC by its parent advisor Beverley Winn in 2015. Beverley is an Autism Consultant & Relationship Specialist with expertise in psychological difference & relationship research. The guidelines for interviewing offer helpful points of advice when carrying out a research interview. They are also applicable for non-research interviews and appointments in other contexts. There are six sections covering; preparation before interview, environment, meeting face-to-face, the interview, after the interview and safeguarding.

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Guidelines for Interviewing Autistic Individuals

Bev Winn

Interviewing Autistic Individuals

Autism often overlaps with other conditions so it is not unusual to meet an autistic individual with dual or multi diagnosis. Some of these conditions include anxiety, depression, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), bi-polar and schizophrenia. It can also overlap with dyslexia and dyspraxia.

Autistic individuals may find it difficult to communicate with others and will struggle with non-verbal communication, such as interpreting body language. They may also find it difficult to understand their own perspective and others' perspectives. Changes in their daily routines may distress them and many autistic individuals may have sensory issues.

The following guidelines can be used when considering and preparing to interview autistic individuals.

Please bear in mind;

- 1) Autistic individuals you contact and interview will have varying degrees of ability, intellect and challenges. Their symptoms will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms.
- 2) Recognise that autistic individuals may use alcohol or drugs and that alcohol and drug use poses high risk because it brings disinhibition but no increase in social understanding which may be magnified in autistic individuals.

Communicating with autistic individuals

Section 1

Before interviewing

First contact:

- Be aware of your tone of voice – autistic individuals can be very adept at identifying when someone is speaking to them in a patronising or condescending voice, tone and manner and may be highly sensitive to this.
- Be explicit – autistic individuals struggle with inference and may not be able to ‘read between the lines’. **They will take what you say literally.**
- Keep your conversation short and the message simple. Avoid using superfluous language and adjectives as some autistic individuals can struggle with slower cognitive processing (they digest information at a slower rate and may only compute chunks of information and not all the information).
- Keep directions and instructions simple with accurate information as most autistic individuals are literal thinkers **and will take anything you tell them as an absolute truth (unless told otherwise).**
- Be precise – try to avoid using estimations e.g. ‘maybe later’ and opt for precise times for example, 10.15 am/pm. However they would expect these precise times to be accurate and run on time.
An appointment booked for 10:15 that doesn’t start till 10:20 is likely to cause agitation and anxiety.
- Some autistic individuals may struggle with abbreviations, idioms and metaphors.
- **Consider contacting by email firstly** as some autistic individuals dislike speaking on the phone.
- Ascertain what way they prefer to communicate.

Section 2

Choosing a suitable environment to interview

- Let them choose the environment for the interview. Some autistic individuals dislike any change to their environment. Therefore, consider conducting an interview from their home or a place of their choice.
- Autistic individuals can become very anxious about new environments. Therefore, if the chosen environment are Cardiff University rooms (e.g. WARC family room), consider including a photo of the room and the front of the building in any correspondence when discussing or arranging an interview. This may minimise anxiety levels.
- Inform the individual of bright ceiling lights (or ability to dimmer the lights), any white noise or noise from fluorescent strip lighting or air conditioning, routine fire drill bells that may go off.

- Inform them of what refreshments will be available and try to provide their preferred choice.
- Inform them to the size of the room e.g. Small or large. This is to avoid choosing the wrong room if someone may be claustrophobic or agoraphobic.

Section 3

Meeting face to face

3.1 Eye contact and physical touch:

Autistic individuals may struggle with giving, maintaining and regulating eye contact. Therefore,

- Expect a varied range of eye contact: minimal eye contact to glaring (sometimes without regular blinking).
- Adjust your eye contact accordingly e.g. If they give minimal eye contact, try to do the same in order they do not feel threatened or the sense that you are looking at them. Divert attention to your voice which should be calm, welcoming and paced.
- Avoid touching the person. Autistic individuals may have sensory challenges which may include a dislike of being touched e.g. Shaking their hand, or a guiding hand towards the interview room. Therefore,
- Wait to see if they reach out to you e.g. offer their hand.
- Put emphasis on a warm smile and greet them by their name

They may fail to read facial emotional expressions and gestures and non-verbal cues.

Therefore,

- Use words or instructions rather than facial expressions or gestures.

3.2 Their environment:

Autistic individuals may be unused to people in their living space, particularly strangers. They may have certain places or furniture that they will use only but may not be able to communicate that to you.

- Ask them where they would like **you** to sit.
- Be vigilant for signs that they may not want to let you in or go ahead with the interview.¹

3.3 University environment:

Orientation/Navigation:

Autistic individuals upon visiting a new environment may be worrying about where certain areas are in relation to where they will be e.g. Fire exit, toilets, exit and outside. Therefore,

- Orientate them by taking them to where the toilet is or the fire exit etc. Do not point in the direction as some autistic individuals may struggle with spatial awareness and orientation and may panic or become anxious if they take a wrong turn etc.
- Upon entering the interview space ask them:
 - If the lighting is okay?
 - Do they prefer the door open or closed?
 - Where would they like to sit?

With all these requests give space in between for the person to answer

Section 4

The Interview

4.1 Use the guidelines from Section 1.

- Take time to explain the procedure of the interview:
 - Length of time,
 - Breaks,
 - Their right to refuse to answer any question that makes them feel uncomfortable
 - Their right to stop at any time and withdraw from the interview¹
 - Further help, support and signposting
- Pay them the agreed payment for taking part or at the very least explain that you will pay them at the end of the interview. Be mindful that they will take you literally.

4.2 Challenges with Processing Information

Autistic individuals may struggle 'keeping up with you'. When they hear a question they may take longer to process that question, or may ask you to repeat the question. Therefore,

- Give them plenty of time to answer you
- Resist chatting or prompting too soon as this will confuse them.
- Do not bombard them or overwhelm them with questions.
- Avoid speaking hypothetically, making jokes or employing sarcasm

4.3 Challenges with Verbal Communication

Autistic individuals may dislike being interrupted and can go back to recalling their experience from the beginning if interrupted by the interviewer.

Therefore,

- Wait until they finish speaking.

- Ask the question again, if no response
- Ask them if they want to have a break, if still no response
- Ask if they want the interview to stop ¹

4.4 Challenges with Non-Verbal Communication (reading body language)

Some autistic individuals may continue to talk and will not be able to read your non-verbal cues for them to stop.

Therefore,

- Gain their attention by saying their name gently, repeat if necessary until you gain their attention
- Draw their attention to the time you have to interview and the time left.
- Explain you need to move on to the next question

- Explain you have yet to extract enough information from the same question, using prompts be specific on exactly what you want to find out.

- Don't take it personally if the person is rude, blunt, dismissive, or appears to be uncooperative.

Section 5

After the interview

- If you have yet to do it, give any money, voucher to the participant.
- Go through the debriefing procedure **slowly**.
- Point out further information and signposting.
- Ensure you have given your details or ways to contact the project team.
- Make sure the individual knows how to get out of the building and onto transport.
- Book taxi, provide timetable or times of buses nearest to the university premises the interview took place.
- Escort them as far as they want you to e.g. to the door, to their vehicle etc.

Section 6

Safeguarding

6.1 Autistic individuals are often unaware of their own vulnerability.

Therefore,

- Ensure they understand they can withdraw from the study at any time¹

6.2 Recalling unpleasant events may evoke emotional reactions.

Therefore,

- Ensure they are emotionally okay throughout their time with you. If not; give extra time, extra breaks and options to stop the interview.
- Ensure that they are emotionally and physically okay to leave after the interview, if not; **do not let them leave until you are confident they are alright.**

6.3 Meltdown and Shutdown

Some autistic individuals may have challenges with sensory and social situations that may cause a 'meltdown' which may present similarly to a temper-tantrum in children or anti-social behaviour in adults. Meltdowns can be caused by sensory overload or a stressful new social situation. Equally,

shutdown occurs for the same reasons that create a meltdown, but rather than externalising distress, people who become totally non-responsive (shutdown) internalises it. Therefore,

- It is important to remain calm
- Speak with a calming voice with short sentences.
- Do not stand too close or touch the person.
- Once started it has to run its course.
- Allow time for the person to quieten, in a safe environment away from others.
- The individual maybe distressed, embarrassed and apologising repeatedly.
- Be kind, gentle and respectful
- Remember it's **not their fault**. It is a heightened arousal response as a result of autism.

Two days after the interview

6.4 Aftercare:

- Follow up with an email, phone call to ensure the individual is okay.
- Point out in your communication with them where they can get further help e.g. Counselling support, adult support services.
- If you have stated that you will keep them informed about the outcome of the research, ensure that is carried through. Autistic individuals will take it literally and are likely to hold you to your word.

¹ Mental Capacity Act 2005 (c.9) London: HMSO:

A researcher must withdraw someone from a project if: 1) they indicate in any way that they want to be withdrawn from the project (for example, if they become upset or distressed), or 2) any of the Act's requirements are no longer met.

http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

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<http://psych.cf.ac.uk/contactsandpeople/pgs/winn.php>



<http://www.autismrpphub.org/>

Checklist

- ❖ **Autistic individuals may have varying degrees of ability, intellect and challenges.** Their symptoms will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms.
- ❖ **Recognise that autistic individuals may use alcohol or drugs** and that alcohol and drug use poses high risk because it brings disinhibition but no increase in social understanding which will be magnified in autistic individuals.
- ❖ **Be aware of your tone of voice** – autistic individuals can be very adept at identifying when someone is speaking to them in a patronising or condescending voice, tone and manner and may be highly sensitive to this.
- ❖ **Be explicit** – autistic individuals struggle with inference and may not be able to ‘read between the lines’. They will take what you say literally.
- ❖ **Keep your conversation short and the message simple.** Avoid using superfluous language and adjectives as some autistic individuals can struggle with slower cognitive processing (they digest information at a slower rate and may only compute chunks of information and not all the information).
- ❖ **Keep directions and instructions simple** with accurate information as autistic individuals are literal thinkers and will take anything you tell them as an absolute truth (unless told otherwise).
- ❖ **Be precise – try to avoid using estimations** e.g. ‘maybe later’ and opt for precise times 10-11. However, they would expect these precise times to be accurate and run on time. An appointment booked for 10:15 that doesn’t start till 10:20 is likely to cause agitation and anxiety.
- ❖ **Some autistic individuals may struggle with abbreviations, idioms and metaphors.**
- ❖ **Consider contacting by email firstly** as some autistic individuals dislike speaking on the phone.
- ❖ **Ascertain what way they prefer to communicate** e.g. Face to face, Skype, telephone interview
- ❖ **Let them choose the environment for the interview.** Some autistic individuals dislike any change to their environment. Therefore, consider conducting an interview from their home or a place of their choice e.g. Parents home, favourite coffee shop, online (Skype).
- ❖ **Autistic individuals can become very anxious about new environments.** Therefore, if the chosen environment is Cardiff University rooms, consider including a photo of the room and

the front of the building in any correspondence when discussing or arranging an interview.

This may minimise anxiety levels.

- ❖ **Be aware of sensory issues:** Inform the individual of bright ceiling lights. (or ability to dimmer the lights), any white noise or noise from fluorescent strip lighting or air conditioning, routine fire drill bells that may go off.
- ❖ **Inform them to the size of the room** e.g. Small or large. This is to avoid choosing the wrong room if someone may be claustrophobic or agoraphobic.
- ❖ **Inform them of what refreshments will be available** and try to provide their preferred choice.
- ❖ **Expect a varied range of eye contact:** minimal eye contact to glaring (sometimes without regular blinking).
- ❖ **Adjust your eye contact accordingly** e.g. If they give minimal eye contact, try to do the same in order they do not feel threatened or the sense that you are looking at them. Divert attention to your voice which should be calm, welcoming and paced.
- ❖ **Avoid touching the person.** Autistic individuals may have sensory challenges which may include a dislike of being touched e.g. shaking their hand, or a guiding hand towards the interview room. Therefore, wait to see if they reach out to you e.g. offer their hand.
- ❖ **Use words or instructions** rather than facial expressions or gestures. Put emphasis on a warm smile and greet them by their name
- ❖ **Ask them where they would like you to sit.**
- ❖ **Be vigilant for signs** that they may not want to let you in or go ahead with the interview
- ❖ **Orientate them** by taking them to where the WC is or the fire exit etc.
- ❖ **Do not point in the direction** as some autistic individuals may struggle with spatial awareness and orientation and may panic or become anxious if they take a wrong turn etc.
- ❖ **Ask them if they prefer the door open or closed?**
- ❖ **Ask them where would they like to sit?**
- ❖ **Take time to explain the procedure of the interview:** Length of time, Breaks,
- ❖ **Ensure they understand their rights** to refuse to answer any question that makes them feel uncomfortable.
- ❖ **Ensure they understand** their right to stop at any time and withdraw from the interview.
- ❖ **Autistic individuals may struggle 'keeping up with you'.** Give them plenty of time to answer you
- ❖ **Resist chatting or prompting too soon as this will confuse them.**
- ❖ **Do not bombard them or overwhelm them with questions.**

- ❖ **Avoid speaking hypothetically, making jokes or employing sarcasm**
- ❖ **Autistic individuals may dislike being interrupted** and can go back to recalling their experience from the beginning if interrupted by the interviewer.
- ❖ **Wait until they finish speaking.**
- ❖ **They may however stop in mid speech without giving a reason why.** Ask the question again, if no response, ask them if they want to have a break, if still no response! Ask them if they want the interview to stop
- ❖ **Some autistic individuals may continue to talk and will not be able to read your non-verbal cues for them to stop.** Therefore, gain their attention by saying their name gently, repeat if necessary until you gain their attention
- ❖ **Draw their attention to the time you have to interview and the time left:** explain you need to move on to the next question or if you have yet to gain enough of the same question, using prompts be specific on exactly what you want to find out.
- ❖ **Don't take it personally if the person is rude, blunt, dismissive,** or appears to be uncooperative.
- ❖ **Go through the debriefing procedure slowly:**
 - ❖ **Ensure you have signposted** and discussed/ shown them where to get further help, support.
 - ❖ **Ensure you pay them the agreed payment for taking part** e.g. Money, voucher.
 - ❖ **Ensure you have given your details or ways to contact the project team.**
- ❖ **Recalling unpleasant events may evoke emotional reactions.** Therefore, ensure they are emotionally okay throughout their time with you. If not; give extra time, extra breaks and options to stop the interview.
- ❖ **Ensure that they are emotionally and physically okay to leave after the interview,** if not; do not let them leave until you are confident they are alright.
- ❖ **Some autistic individuals may have challenges with sensory and social situations that may cause a 'meltdown' or 'shutdown' whilst in your care.** A meltdown may present similarly to a temper-tantrum in children or anti-social behaviour in adults. Shutdowns when people internalize their distress and become completely unresponsive. Meltdown and shutdown can be caused by sensory overload or a stressful new social situation:
 - ❖ **It is important to remain calm.**
 - ❖ **Speak with a calming voice with short sentences.**
 - ❖ **Do not stand too close or touch the person.**
 - ❖ **Once a meltdown/shutdown has started it has to run its course.** Allow time for the person to quieten, in a safe environment away from others.

- ❖ **Keep them with you until you are satisfied they are safe to leave.**
- ❖ **After the meltdown/shutdown the individual maybe distressed**, embarrassed and apologising repeatedly.
- ❖ **Be kind, gentle and respectful**
- ❖ **Remember it's not their fault.** It is a heightened arousal response as a result of autism.
- ❖ **Be aware of your duty of care:** Autistic individuals are often unaware of their own vulnerability, ensure they are safe to leave your care.
- ❖ **Make sure the autistic individual knows how to get out of building and onto transport:** book taxi, provide timetable or times of buses nearest to CU premises where you conducted the interview.
- ❖ **Escort them as far as they want you to** e.g. to the door, to their vehicle etc.
- ❖ **Aftercare:** Follow up with an email, phone call to ensure the individual is okay.
- ❖ Point out in your communication with them where they can get further help e.g. Counselling support, adult support services.
- ❖ **Keep them informed:** If you have stated that you will keep them informed about the outcome of the research, ensure that is carried through. Autistic individuals will take it literally.
- ❖ **Remember to follow CU's safe-guarding and Risk Assessment procedures and protocols.**

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