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Blueprint for Autism Community Involvement in Research



Transparency

Communicate clearly about the research
Clarity about involvement role
Shared expectations



Autism-Affirming

Consider physical, emotional and sensory environment
Harnessing individual contributions
Flexible accommodations



Co-Production

Valuing diverse autistic experiences and voices
Research goals informed by the community
"Nothing about us without us"

Russell, A., Lees Thorne, R., Ashwin, C., Brosnan, M, & Bagnall, R. (2025).

Centre for Applied Autism Research (CAAR)

UNIVERSITY OF BATH

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Enhancing Research Culture Through Involvement

Involvement in research means being an active partner to influence and shape the research.

There are different ways of getting involved in research. For example, people can help researchers to identify what research should be about, comment on research materials or be co-researchers, actively carrying out research.

Getting involved in research means that autistic people can bridge the gap between academic research and the lived experience of autism. This can help research to be better, more relevant to and impactful on autistic people's lives.

Getting involved in research should not be a negative experience.

While a positive experience cannot be guaranteed in any life situation, autistic people and their families should feel respected, valued, and enabled when contributing to research.

Through a series of meetings in June and July 2024 with autistic people and researchers at CAAR, we co-produced this involvement blueprint.

It might not always be possible or desirable to implement everything that is in the blueprint.

The blueprint outlines the principles and practices we thought would be helpful as a guide for researchers and autistic people who work together on research at CAAR.

Further Resources

There are lots of published resources available to support researchers and experts by experience in working together. We have listed a few of these at the end of the document.

Transparency



Communication about the research

Clear information should be provided about the research so that autistic people can make an informed decision about if and how they get involved.

Researchers should provide clear information by following these guidelines:

- Communicate clearly what the project is about.
- Explain who is funding the project.
- Describe what has already been done and the plans for future work.
- Describe how this research will help and for whom it will be helpful.
- Describe what the outputs of the research will be.
- Describe the researchers, their strengths and experience of the research topic and involvement activities.
- Describe clearly how the involvement of autistic people will contribute to the research, including what the goal of involvement is.
- Consider the most appropriate way to communicate key information.

Examples of appropriate ways to communicate key information

- Provide written information with icons/images to support the information.
- Use different ways to communicate information about research, for example make a short video or podcast/audio recording as well as providing information in writing.
- Provide information in an easy to read format to increase accessibility.

Clarity about involvement roles

Researchers should provide clear information about the proposed involvement of autistic people. This should include the following:

- **The length of time that people will be expected to be involved.**
  - Include start and end dates.
- **How will involvement occur? Will there be in-person or online meetings?**
  - Provide dates for meetings or other specific activities, ideally at least 2 weeks, in advance.
- **What is the location for any in-person meetings?**
- **How many autistic people will be involved in the project**
  - Aim for an equal balance of autistic people to number of researchers in any meetings or interactive activities.
- **What will the role of autistic people be?**
  - How active will the role be? Will the role be a listener, a co-thinker, advisor, partner or decision-maker?
  - What will the role be called? This will be determined by what the person will be doing and what term they prefer e.g. Advisor, consultant, or co-researcher.
- **Outline the skills and strengths that are being sought.**
  - How close to the topic should an advisor be? What lived experience is important? For example, if it is a study about mental health, does someone need to have had direct experience of the condition being investigated.
  - Can friends and family be involved?
- **Outline how confidentiality will be observed.**
- **What is the policy for payment and expenses and how will this work in practice?**
- **Ending or withdrawing involvement.**
  - Make it clear how people can stop being involved at any stage during the research.

Shared expectations

Autistic people should provide clear information about themselves so that researchers can be confident of a good fit with the involvement role.

- Autistic people can provide as much information as they would like to. They do not have to provide information about themselves if they prefer not to.
    - Autistic people can provide information about themselves in a flexible format. There is a template that can be used that has some supporting examples.

Information that can be relevant includes:

- Information about your experience of autism and terms that you prefer to use. This is to help researchers speak to you using the terms that you prefer.
- It is helpful to provide information such as gender and age if you are comfortable to do so. This will help researchers make sure there is a balance and diversity of autistic people supporting the research and can be relevant to some research projects.
- It is helpful to provide some information about your availability for meetings and involvement activities. Are you available during the working day or do your life commitments make this difficult?
- Are you able and willing to travel if this is needed?
- What would you like to do on this project?
- What are your strengths and skills?
- What are you able to do on this project? For example, reviewing study materials carefully and providing feedback, sharing lived experience, chairing meetings etc.
- Do you have interests or experiences that are relevant to the research topic?
- What areas of research are you particularly interested in?

Autism-Affirming



Researchers need to make sure that the research is autism-affirming and inclusive.

Co-production at the very start of the research is the best way to achieve this.

- Autistic people should be involved in identifying research priorities. What changes would people like to see?
- Researchers need to ensure that research involvement and involvement activities are safer spaces for autistic people.

Physical, emotional and sensory environment

- There should be an equal balance of people with lived experience and researchers.
- Offer support leading up to involvement events. This can help to build trust.
- Ask people if they would value a meeting or to observe an activity before deciding whether to take part.
- Ask people what is important to them when attending an involvement event/activity.
- Let people know that it is ok to feel uncomfortable. Agree how they can communicate this.
- Make people aware of any risks to getting involved in the research and co-design and what measures have been taken to reduce these risks.
- Let people know what to expect well in advance. Send information about the agenda, the structure of the event and any questions or discussions points ahead of time.

In-person events

- Consider the location. Autistic people need to arrive able to give their best contributions. Aspects to consider include: Familiar or new location; Central or less busy location; Does the nature of the research topic have any bearing; Do people need a quiet location; Is there a need for access to parking or transport links?
- Provide clear instructions/directions for how to get to the location, including photos of both outside and inside the venue.
- For in-person events, the venue is an indicator of value. Muted colours, calming pictures. A breakout room. Refreshments and facilities are important.
- Welcome people, greet them at the door.
- Consider the structure of the event from the very beginning. What can people do when they arrive?
- Seating – better to have seating set out in a circle rather than rows of chairs. This can support conversations.
- Let people know from the beginning that the space is flexible and they can move around.
- Set some chairs at different levels aside so that people can sit elsewhere, take breaks as needed.
- Adjust the lighting and temperature for comfort.

Autistic people should feel able to be themselves.

- For example, make tactile items such as fidget spinners, Lego or other objects accessible and available for use.
- Tell autistic people in advance that the events are an autism-affirming space where tactile items will be available (or the autistic person can bring their own items).

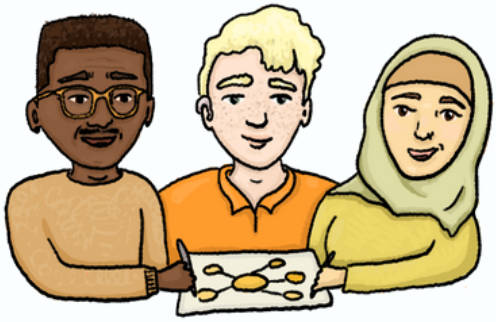
Flexible accommodations

- Timing of events. Consider the working patterns and other commitments of attendees when planning events.
- Structure of the involvement activity/event should be clear. Make this available in advance so that people know what they will be expected to talk about and can prepare.
- Don’t leap straight into the research activity. Let people get to know each other first. Put people at ease.
- Have a facilitator who will manage the event.
- Make it clear that autistic people do not have to lead the event.
- Offer different roles and responsibilities prior to involvement events. Would people prefer to observe, note-take, meet and greet, facilitate etc.
- Enable different ways for people to contribute. Verbally, in writing, drawing, use of colour and other creative approaches.

Harnessing individual contributions

Fostering an autism affirming approach with attention to all aspects of the environment, flexibly, will empower all individuals to make their most effective contributions.

Co-Production



CAAR conducts autism research, and so it is important for autistic people as often as possible to be involved in co-producing this research.

Co-production means autistic people shaping and informing the research carried out at CAAR as much as possible.

Co-production can involve a wide variety of tasks, including the development of research topics/questions, reviewing research materials, and analysing data. Co-production can help to make CAAR's research better and more relevant to autistic people's lives.

Researchers should therefore aim to conduct research that is informed by the autistic community and reach a diverse range of autistic people to take part in co-production.

This blueprint can help to achieve these aims and support co-production. Researchers should also consider the following:

- Autistic people do not need to have a formal diagnosis of autism (e.g., co-production should also be open to people who self-identify as autistic or are awaiting a formal diagnosis).
- Use identity first language (i.e., "autistic person"). Though check with individuals what their preference is.
- Seek diversity amongst advisors, such as people from under-represented groups and different communities.
- Where needed, work with other agencies to bridge cultural and other inter-sectional gaps.
- Share useful tools and resources with autistic people getting involved in research so that they can be empowered to contribute fully.

Resources and information about involvement

This blueprint for autism community involvement in research has been co-created between the Centre for Applied Autism Research (CAAR) and members of the autistic community.

More resources are available from CAAR here: https://www.bath.ac.uk/research-centres/centre-for-applied-autism-research/

A digital version of the blueprint for autism community involvement in research is available here (pdf and word): https://www.bath.ac.uk/publications/resources-for-researchers-and-the-autism-community/

Everyone is welcome to use the blueprint for autism community involvement in research, free of charge for non-commercial purposes. If you do use it, please let us know by emailing: CAAR@bath.ac.uk.

If you need to cite the blueprint for autism community involvement in research, please use:

Blueprint for autism community involvement in research (Centre for Applied Autism research, 2025). https://www.bath.ac.uk/publications/resources-for-researchers-and-the-autism-community/

Other resources

- The National institute for Health Research (NIHR) resource for involvement: https://www.learningforinvolvement.org.uk/topic/getting-started-being-involved/
- The involvement matrix, manual and checklist are really helpful tools: https://www.kcrutrecht.nl/involvement-matrix/

Template to provide information about yourself

What information would you like to provide about your personal profile, strengths and abilities for research involvement?

My experience

- Do you have a formal diagnosis of autism, or do you self-identify as autistic?

- If you have a formal diagnosis of autism, how old were you when you received this?

- What term do you prefer to use to refer to autism? (This information will help researchers to use terms that you prefer when communicating with you about the research.)

- Do you have additional conditions?

- Please detail these if you are comfortable to do so.

- Are you a family member of an autistic person?

Personal profile

This information will help the researcher to make sure there is a balance of different voices and perspectives involved in the research. You can provide as much information as you are comfortable with.

- Name:
- Age:
- Gender:
- Where do you live?
  - (knowing your location can help researchers understand if they can fund travel for in-person attendance)
- What is your highest level of education?
  - (knowing this can help the researchers to try and find experts by experience with diverse education histories)
- Are there any times of the day or week (e.g., Tuesday mornings) that would be difficult for you to attend meetings? If so, please tell us what these are.

Your research involvement

People can be involved in research in different ways and at different phases of a research study.

- Please give some information here about what you like to do on this project.
- What are your strengths and areas of interest?
    - (There is some information on the next page that might be helpful when thinking about this question).

Phases of research

Research projects typically have a

- preparation phase (e.g. identifying a research question, ethics approval)
- an execution phase (e.g. recruiting participants, choosing measures)
- and an implementation phase (e.g. reporting the research, sharing findings more widely).

Autistic people can be involved throughout any or all of these phases.

Roles

People can have different roles when they get involved with research. These roles can vary in how active they are.

For example, a less active but important role would be to receive information about the research and provide feedback.

More active roles might include asking the research team questions about the research, providing advice to the researchers, working as an equal partner in the research e.g. collecting and analysing data or leading the research and making decisions.

Skills, abilities and interests

- Please list any skills, abilities and interests that you think are relevant and important for the researcher to know about.

- Some examples could include:
- Being able to break things down into smallest elements.
- Personal experience to empathise with difficult subject areas.
- Efficient and focused chairing of meetings.