

Peer Research and Participation Involving Autistic Young People

We are:



Caroline



Louise

We work for:



We have been researching the involvement of autistic young people in peer research and participation. We have gathered information and advice from a range of different academic and charity sources. This is some of the information that we have found out:



What is peer research and participation?



Peer research and participation involves people with lived experience directing and participating in research.



Peer researchers can be involved at different levels. For example, it might involve running focus groups, writing questionnaires or setting research questions.

Why is peer research and participation important?



Ensures that findings are relevant, accessible and reflect the lived experience of autistic people.



Allows autistic people to have their voices heard on issues which directly affect us.

Why is peer research and participation important?



Participants can relate to peer researchers and may feel more confident to take part.



Those involved in peer research and participation have the chance to develop employability skills.

Autism in peer research and participation



Reflect the language autistic people use about autism. E.g. some autistic people prefer to be called 'autistic person' rather than 'person with autism.'



In this infographic, we use the term 'autistic person' to reflect the preferences of the community.

Autism in peer research and participation



Not all the stereotypes about autism are accurate, so it is important to not make assumptions. For example, not all autistic people are good at maths.



Be mindful that autistic people may be distrustful of research. For too long, autism research hasn't involved autistic people or reflected priorities of the community.

Autism in peer research and participation

Recognise that lots of autistic people describe being autistic as an essential part of who they are. Focus on the strengths as well as the difficulties of being autistic. Every autistic person is different but these are some strengths which autistic people may have:



Communication with autistic young people in peer research and participation

Give young people the chance to respond to information in different ways. e.g.

Using:



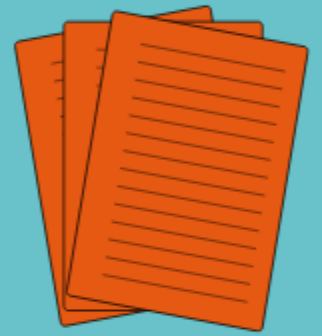
Emojis



Drawings

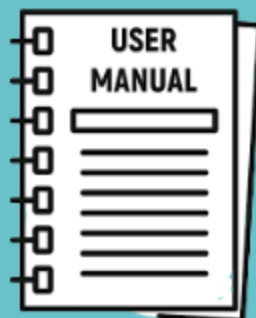


Audio notes



Writing

Provide clear information and instructions in advance.



Communication with autistic young people in peer research and participation

Ask young people how they like to receive information. This might be:



through video or audio formats.



through easy read information (with pictures).



Avoid using jargon and acronyms. Use literal language.

Ways of working effectively with autistic young people in participation and peer research



Set guidelines with young people at the beginning of the project and review them throughout.



Spend time building relationships with young people before starting the research process.

Ways of working effectively with autistic young people in participation and peer research



If meeting in person, consider the accessibility of the venue. Give young people information about the venue in advance.



Make research findings accessible online.



Consider sharing one page profiles of researchers joining the meeting.

Ways of working effectively with autistic young people in participation and peer research



Provide training for everyone involved with the research process. When working with autistic young people, staff should have autism training.



Set up a buddy system to link young people involved with the research to each other for support.

Ways of working effectively with autistic young people in participation and peer research



Consider recruitment - are you recruiting young people furthest away from power? E.g. including minimally speaking autistic people and autistic people from marginalised backgrounds.



Be mindful of young people's energy levels and sensory needs.