

Identifying Actions to Improve the Physical and Mental Health of Autistic People, People with Learning Disabilities or Both

Part A: Focus Group Information Sheet

About the project

Autistic people, on average, experience poorer physical and mental health than non-autistic people. National legislation, policies and guidance have been put in place to try to address this. However, there is an ongoing need to reduce the health inequalities that autistic people face.

NHS England and Improvement have asked [The Strategy Unit](#) to help identify key actions for improving autistic people's health. To do this, we will:

- Speak with autistic people and carers of autistic people
- Speak with a range of healthcare professionals
- Analyse data collected by healthcare services.

We will use this information to understand:

- Why autistic people experience poorer physical and mental health
- Autistic people's experiences of accessing healthcare services, and
- What services can do to improve the health and experiences of autistic people.

The project will also explore health inequalities for people with a learning disability. We will combine our findings to develop key recommendations for improving the health of autistic people, people with a learning disability, or people with both.

Why am I being contacted?

We want to work together with autistic people to ensure that the recommendations we develop reflect what is most important, and will make the most difference, to autistic people.

What am I being invited to do?

We are inviting you to an online focus group discussion. This will involve coming together with other autistic people to talk about what matters to your health and wellbeing. We would like to hear about your experiences of accessing healthcare services and your ideas for improving them.

Focus group details

Date: Tuesday 11th January 2022
Time: 1pm – 3pm with breaks
Location: Online via Microsoft Teams

There will be approximately 12 people in the group.

We will share the discussion topics with you before the focus group so that you know what we are going to ask you.

For those of you are not NHS staff, we will send you a £50 voucher after the focus group to thank you for your time.

Who will be at the focus group?

The focus group has been organised by a research organisation called [The Strategy Unit](#). The Strategy Unit is part of the NHS. We help NHS services to learn and improve.

We will work together with other people to deliver the focus group. At the focus group, you will meet:



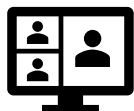
David Gill. David is autistic and is a Lived Experience Adviser in the national children and young people’s team at NHS England and Improvement.



Fiona Ritchie. Fiona works with people with a learning disability and/or autism to help their voices to be heard.



Ellie Moore. Ellie is a researcher from the Strategy Unit.



Other autistic people who have been invited to share their views (up to 12 people).

What we will we do with the information?

We will record the focus group discussion to help us write up the information and ideas you have shared. Before the discussion, we will check that everyone is happy to have their voice recorded.

The recording will be stored securely. Only the researchers from the focus group will be able to listen to the recording.

We may use quotes from the focus groups in our reporting, but we will not use your name or any other details that could link any quotes to you.

We will use what we have learned from the conversation to make recommendations to the NHS about how to improve health services for autistic people and people with a learning disability.

Important information

It is your choice whether you participate in the focus group. You can change your mind at any time. If you decide not to take part in the focus group, or to stop taking part, you do not have to give a reason why. However, as the information collected from the focus group will be anonymised, it will not be possible to withdraw your comments once the discussion has been written up.

Your decision about whether to take part in the focus group will not affect your care or support in any way.

Who can I contact for more information?

If you are unsure about any of the information or would like to ask a question about the focus group, please contact:

Name: Ellie Moore (Researcher at the Strategy Unit)

Email: ellie.moore9@nhs.net

Mobile: 07423794371

Part B: Participant Consent Form

I have read and understood the participant information sheet.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I can ask questions at any time.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I am happy for my voice to be recorded.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that the things I say might be included in a report, but that no personal details will be used.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I should not share any personal information that other people share during the group outside of the group.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I can change my mind about taking part at any time.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that as the information collected from the focus group will be anonymised, it will not be possible to withdraw statements once the discussion has been written up.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that my decision whether to take part will not affect my care or support in any way.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that if something I say makes the researchers concerned that someone is at risk of harm, they might have to tell someone else what I have said.	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Contact preferences

1. I would like to be sent a reminder about the focus group.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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If you answered 'yes', please complete boxes 2 and 3 below. If you answered 'no', please skip boxes 2 and 3.

2. I would like to receive a reminder about the focus group by:	<input type="checkbox"/> Text	<input type="checkbox"/> Call	<input type="checkbox"/> Email
3. Please provide the telephone number or email address you would like the reminder to be sent to:			

We will also share the discussion topics with you the week before the focus group, using the email address you use to return this form.

If you are unable to complete and return this form electronically, please contact Ellie Moore for assistance - 07423794371 / ellie.moore9@nhs.net.

Name: _____
 Signature: _____
 Date: _____

Please email your completed consent form to ellie.moore9@nhs.net by 9am on Tuesday 4th January 2022.