

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

Part A: Bereaved Carers Focus Group Information Sheet

About the project

Autistic people, people with a learning disability, and people with both experience poorer physical and mental health than people without a learning disability and/or autism. National legislation, policies and guidance have been put in place to try to address this. However, the COVID-19 pandemic has highlighted the need for faster progress towards reducing the health inequalities that people with a learning disability and autistic people face.

NHS England and Improvement have asked [The Strategy Unit](#) to help identify key actions for improving the health of people with a learning disability and/or autism. To explore what contributes to poorer health, people's experiences of accessing healthcare services, and how healthcare services can be improved for people with a learning disability and/or autism, we will:

- Speak with people with a learning disability and autistic people
- Speak with carers of people with a learning disability and/or autism, including carers who have lost a loved one
- Speak with a range of NHS healthcare professionals
- Analyse data collected by NHS healthcare services

Our findings will be used to develop key recommendations for improving the health of autistic people and people with a learning disability.

Why am I being contacted?

Autistic people, people with a learning disability and people with both are at higher risk of dying prematurely, in part due to health inequalities. As someone who has cared for and lost a loved one with a learning disability and/or autism, we are inviting you to share your views and experiences. We want to ensure that the recommendations we make about reducing health inequalities are led by the lived experience of the people they affect, including carers who have played a critical role in advocating for and supporting the physical and mental health of their loved ones.

What am I being invited to do?

We are inviting you to an online focus group discussion. This will involve coming together with other carers who have lost a loved one with a learning disability,

autism, or both, to talk about what matters most to them. We would like to hear about your experiences of accessing healthcare services, and your ideas for improving health services for people with a learning disability, autistic people, and those who support them.

Focus group details

Date: Monday 17th January 2022
Time: 10am – 12pm
Location: Online via Microsoft Teams

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

There will be two facilitators for the group who will enable safe and sensitive discussions. One of the facilitators is also a carer who has lost their loved one. We can also provide information about services you can contact should you need support during or after the group.

For those of you who 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 [The Strategy Unit](#) – an organisation leading research, analysis and change from within the NHS. We will work together with other people to deliver the focus group:



Gabriella Walker. Gabriella has worked in health inequalities and improving access to services in the NHS for over 15 years. Her youngest child, Thea, had profound and multiple disabilities and died in 2019.



Fiona Ritchie. Fiona works with people with learning disabilities and autistic people to enable them to get their voices heard.



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

What we will do with the information?

The focus group discussion will be audio-recorded 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 and will only be accessed by the research team.

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 as an individual.

We will use the information gathered from the focus groups to make recommendations to the NHS about how to improve health services for autistic people and people with a learning disability.

Do I have to take part?

It is your choice whether you participate in the focus group and you are free to withdraw at any time, without giving any reason. However, 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.

Your decision to take part, or to stop taking part, will not affect yours or any person you care for's healthcare and support in any way.

Who can I contact for more information?

If you have any questions about the focus group, please contact:

Name: Ellie Moore (Researcher at the Strategy Unit)

Email: ellie.moore9@nhs.net

Mobile: 07423794371

Or

Name: Gabriella Walker (Lived Experience Facilitator)

Email: gabriella.walker@nhs.net

Mobile: 07970731114

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 mine or anyone I care for's access to care or support.	<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 Monday 10th January 2022, 9am.