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**How the NHS England Learning Disability and Autism Advisory Group works - the Terms of Reference**

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# Background

The NHS Long-Term Plan includes work to improve the health of people with a learning disability and autistic people in England. It is one of the NHS’ priorities for 2019-2024. At NHS England this work is led by the Learning Disability and Autism Programme.

The NHS is committed to involving people and communities in its work. This means that people’s experiences, expertise, ideas can make a difference. It also helps to challenge thinking, develop new ideas and improve what we do. It leads to making services more responsive to people’s needs, improving access to services as well as improving health outcomes. This commitment is stated in the NHS Long-Term Plan. It is also a legal duty.

The Learning Disability and Autism Advisory Group is one way NHS England works with people with a learning disability, autistic people and their families.

Additionally, there is the Learning Disability and Autism Forum, which is a wider network of autistic people with a learning disability, family carers and supporting organisations who want to be involved, influence and stay in touch with the work of NHS England. We work with the Forum through update emails, easy read newsletters, social media and occasional events.

# Purpose

The purpose of the NHS Learning Disability and Autism Advisory Group is to:

1. **Make a difference to the NHS**

* Impact on NHS strategy and delivery so it reduces health inequalities faced by people with a learning disability and autistic people.
* Influence programmes of work which could most benefit autistic people, people with a learning disability and family carers.

1. **Help people be heard and promote equity**

* Champion issues that are important to people with a learning disability, autistic people and family carers.
* Promote the inclusion of people who are less likely to have their voices heard by the health system and face the greatest health inequalities.
* Link people with different parts of the NHS, where their voice might not otherwise be heard.

1. **Inspire better involvement**

* Connect NHS health professionals and networks of autistic people, people with a learning disability and family carers to promote understanding and involvement.
* Advise on strategies to involve people with lived experience in work, from consultation and focus groups through to coproduction and employment.
* Strengthen how NHS professionals work with, hear from and communicate with people with a learning disability, autistic people and family carers.
* Share good practice and encourage people to get involved.
* Show others what we have made a difference to- build a legacy of change.

1. **Be responsive and proactive**

* Respond to requests for advice from teams across the NHS
* Identify and work on issues faced by autistic people and people with a learning disability in the NHS.

# Members

The group has up to 20 experts by experience, which includes autistic people, people with a learning disability and family carers.

The group is made up of individual people, rather than representatives of organisations. However, advisory group members could be linked to an organisation which can support them to speak up and to link with a wider network.

Being in the group is voluntary. It is not a job, and members are not employed by the NHS.

The group is supported by the following people-

| Name | Role |
| --- | --- |
| Olivia Butterworth- Head of Public Participation | Co-Chair |
| Jodie Williams- Network Manager | Co-Chair and meeting coordinator |
| Gareth Watkins- Network Manager | Co-Chair and meeting coordinator |
| The Learning Disability and Autism Engagement Team | Meeting coordinator |
| Jo Whaley- Public Participation Senior Manager (Learning Disability and Autism) | Deputy Co-Chair |
| Jessica Humphreys- Business Support | Meeting coordinator |
| Debbie Wood- Network Manager | Meeting coordinator |
| Harriet Gwinn- Network Manager | Meeting coordinator |
| Tom Cahill- National Director of the Learning Disability and Autism Programme  Nicola Easey- Head of Health Improvement  Wendy Hicks- Policy team  Rebecca Dewar- Policy team  Jo Skinner- Strategic Communication | Staff with a standing invitation to listen and advise |

We also invite lots of people to come and learn from the group- visitors come to different meetings.

Roles and responsibilities

Each member will:

1. Use your knowledge and experience to make a difference.
2. Support delivery and provide constructive challenge.
3. Work to ensure that views of autistic people, people with a learning disability and family carers are central to policy development at NHS England.
4. Talk to people in your networks about the work of the advisory group and report back what people say.
5. Attend and contribute to all meetings if you possibly can.
6. Let the Engagement team know if you cannot attend a meeting.
7. Talk to the Engagement team if you need support to be involved e.g. if a topic is difficult to understand.

## What the Engagement Team will do- as coordinators for the group

1. Let group members know at least two months before, if possible, when a meeting will be and the broad topic area.
2. Develop accessible meetings, meeting all the members’ and presenters’ support needs. For example-
   1. We aim to ensure the information is in easy read for people who use that and with additional information for people who prefer more detail.
   2. Because of coronavirus, for people who can’t travel to the in person meetings we also offer online meetings instead of meeting in person.
3. Share the papers with the group two weeks before so that group members have time to prepare and talk with their networks before the meeting.
4. Record the advice of the Advisory Group during the meetings. Meeting notes will be used to influence policy.
5. Meeting notes will be distributed to policy leads and group members as soon as possible following each meeting. They will also be published on the group’s [You Said, We Did webpage](https://www.england.nhs.uk/learning-disabilities/about/get-involved/you-said-we-did/).
6. Invite leads of policy topics that have come to the group to return, to update the group on progress- to show what difference the group has made.
7. Use what the group has said to impact on strategy and policy development at every opportunity, including new policy areas.
8. Make sure speakers and policy leads who visit the meetings are aware of the groups purpose, history, preferred language, communication and meeting style.
9. Provide a mental health first aider and space to talk if the subject is upsetting.

## Rules of the group

We aim to make the group accessible and safe for all members, staff and guests.

1. We ask that everyone involved to show respect to others to ensure meetings are safe and supportive
2. To make the meetings work for everyone we ask that people avoid jargon and acronyms and [use preferred words around learning disability and autism](https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/).
3. All members of the network have the right to participate in meetings and workshops without fear of discrimination or prejudice based on ethnicity, sexuality, nationality, class, age, gender, disability or religion. Discriminatory behaviours will not be tolerated.
4. We understand that people are passionate about the issues we discuss. The expression of feelings is fine as long as this is not directed at individuals or groups of people.
5. Constructive criticism and disagreements are welcome but should be focused on the issue not the person. Everyone is entitled to their own views and beliefs and every member is asked to be respectful when there are personal differences.

We offer opportunities to discuss issues outside of meetings, to help smooth running of meetings.

## Confidentiality and information sharing

Advisory group members are chosen for their own experience and also for the networks of people they are linked to. Group members will be given information in advance about what will be discussed at meetings. This means they can also discuss things with their networks.

Sometimes the information about a discussion cannot be shared, for example because it is not developed enough to be made public. It will be made clear if any information cannot be shared outside the advisory group.

Group members might discuss things that are confidential, such as their personal experiences. These must not be shared outside the group. The Engagement Team will make sure the notes from the group do not reveal who people are who have shared their experiences, unless that person has given us permission.

Group members might also share things like their email address or telephone number. Group members and the Engagement Team must not share these without permission.

## Induction, training and support

When new members join the Advisory Group we want to get to know you and for you to get to know us. We will-

* Give you a welcome pack, in a format that is accessible to you
* Arrange meetings to get to know you – induction meetings
* There are a range of [learning and development opportunities](https://www.england.nhs.uk/participation/learning/) available to people involved in our work (for public and patient voice partners- PPVs), details can be found on the [Involvement Hub.](https://www.england.nhs.uk/get-involved/about/)
* We will also share opportunities for you like training and coaching.

If you need support with digital technology such as computers to join online meetings we will help you. If you need IT equipment we work with an organisation called Starting Point who can help with this. For more information or to ask for support, please email [england.engagement@nhs.net](mailto:england.engagement@nhs.net)

## How we pay people

We pay people for their expenses and involvement according to the [NHS England public participation expenses policy](https://www.england.nhs.uk/publication/working-with-our-patient-and-public-voice-partners-reimbursing-expenses-and-paying-involvement-payments/)

1. We will pay travel expenses involved in attending meetings.
2. We will pay the costs of support workers, according to policy, as long as these costs are agreed with the Engagement Team in advance.
3. Involvement in Advisory Group meetings attracts a public involvement payment.

This payment is paid straight to your bank account. Any tax or National Insurance contributions will be taken from this payment before it comes to you.

Accepting the payment may affect your benefits, so you may choose not to accept it. Before accepting an involvement payment it may be useful to get advice. NHS England has asked Citizens Advice to give free advice to advisory group members about public involvement payments. For details of how to contact them please email [england.engagement@nhs.net](mailto:england.engagement@nhs.net) It may also be useful to talk to the job centre.

1. If you accept the public involvement payment, every 3 months you will receive a small additional payment, worth 12.5% of the payments you have received.

# About the meetings

The Advisory Group usually looks at 6 topics per year. Meetings are sometimes online and sometimes in person. For example, we are aiming to have two meetings in person in 2022/23 and 2 meetings online. For people unable to meet in person, the in person meeting will be repeated online.

Meetings in person are usually all day meetings. Online meetings are usually just for half days and are on Microsoft Teams. If you find this hard we can help you.

## Preparing for meetings

Before meeting advisory group members will

* Read papers in advance
* Liaise with networks where appropriate
* Think about the topics to be discussed
* Let the Engagement team know if there are any problems or queries
* We hold a meeting a few days before the meeting if anyone has any questions.
* We hold a meeting a few days after the meeting if anyone thinks of anything else they would like to say on the topic

## Involvement in other NHS work as an Advisory Group member.

From time to time opportunities arise for group members to share their expertise or represent the group outside of the regular meetings. These are optional for group members.

We will share these opportunities with members, matching skills and interests to the work that arises. The group’s personal profiles will help with this.

Different types of additional work might include-

1. The Engagement Team may invite members to a meeting, strategic and directly related to our work, such as being a representative on the Citizens Advisory Group, giving a presentation or joining a working group.
2. Based on things group members tell us they are interested in, we seek opportunities for members to influence those topics and make connections
3. Policy leads may ask members to join meetings that they are holding e.g. follow up meetings to a topic they have brought to the Advisory Group.

Extra pieces of work may attract a public involvement payment. This will be decided on a case-by-case basis and communicated with the group when the opportunities are advertised.

# How the Advisory Group fits into NHS England (governance)

The Advisory Group is funded by the NHS England Learning Disability and Autism Programme Board.

The work of the group is overseen by, and accountable to, the Public Participation team in the Equalities, Participation and Experience Division.

The group reports to the policy leads who attend the meetings for advice, to the Public Participation team and to the Learning Disability and Autism Programme.

# Leaving the group

## Length of time people can stay on the group (tenure)

The Advisory Group will replace its membership over time to get a wide diversity of ideas.

Members can be on Advisory Group for up to 6 years. ​

This is longer than standard for public and patient voice (PPV) partners policy. This allows people get to know each other and get confident to speak out. ​

We will phase new members in and older members out gradually, so we do not lose everyone at the same time to-

* support new members to settle in
* keep memories of what has happened before in the group

We replace a third of the members every 2 years.

People will not be able to reapply to join the group again after they have finished on the group.

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## Being asked to leave the group

A member might be asked to leave the group if they-

* Do not attend meetings, without a good reason
* Do not follow the rules of the group

We will always talk to the group member to understand and resolve any problems before asking anyone to leave the group.

# Raising concerns and resolving issues

If you have any concerns about things that happen in the advisory group we will try to resolve this. We will involve other people if we need to, including if your concerns are about the staff of the Engagement Team.

If you have any concerns please email the Engagement Team at [engage@nhs.net](mailto:engage@nhs.net) or telephone 0113 824 9686. If it is not appropriate to do this you can email the Public Participation team at [england.engagement@nhs.net](mailto:england.engagement@nhs.net) and ask for someone outside the Engagement Team to get involved.

# Conflict of Interest

Members must let us know if they have a conflict of interest. This is if we are discussing something that if they or an organisation they work for will benefit from.

All members are required to fill in a declaration of interest form when they join the group.

Group members’ “interests” will be published on our website.

If a decision is to be made in a meeting that may be conflicted, the Co-Chairs will ask if anyone has a conflict of interest. This will be recorded.

If any member has reason to believe a conflict of interest situation has arisen or may arise, this should be drawn to the attention of the meeting Chairs or the Engagement team, as soon as possible.

# Review

We will review how the group works, the membership and the terms of reference every year to ensure continued fitness for purpose. This will be done in two ways-

* Meeting with the group to discuss how things are going
* Annual public participation survey

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