



## How the NHS England Learning Disability and Autism Advisory Group works

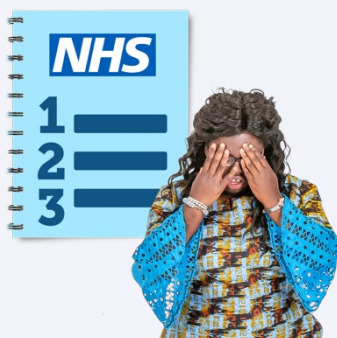


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### 1. Why do we have the Advisory Group



People with a learning disability and autistic people have the same right to good healthcare as everybody else.



But there are lots of ways that people are not getting such good healthcare.



**This leads to many people with a learning disability and autistic people having poor health.**



**We want to improve people's healthcare and health.**



**Improving health and healthcare for people with a learning disability and autistic people is a priority in the NHS Long Term Plan.**



**The NHS must involve people in its work to help it understand people's experiences and how to improve things.**

**The law says this must happen.**



**The Learning Disability and Autism Advisory Group is one of the ways that NHS England involves people with a learning disability, autistic people, and family carers.**



**The Advisory Group is paid for by the NHS England Learning Disability and Autism programme.**



**This is the part of NHS England that works on improving the NHS for people with a learning disability and autistic people.**



**The Engagement Team that run the Advisory Group is part of NHS England's Public Participation team, who work to help the NHS involve people.**



**We also involve people through our Learning Disability and Autism Forum.**



**We stay in touch with the forum through email, Facebook, Twitter and meetings.**

**The aim of the Advisory Group is:**



**1. To improve the NHS for autistic people and people with a learning disability.**



**2. Say what is important to people with a learning disability and autistic people.**



**3. Challenge the NHS on the things it is not getting right and work together with staff to say what would make it better.**



**4. Give a say to people who are often missed out, including people who find it harder to get involved.**

## **2. Advisory Group members**



**The Advisory Group has 20 members.**



**These are people with a learning disability, autistic people, and family carers from all over England.**



**People come from lots of different backgrounds, with different experience.**



**Members do not represent organisations.**



**But they usually have links to organisations and networks which helps them know more about other people's experiences and ideas.**



**Advisory Group members are volunteers.**

**They do not work for NHS England.**





**Members maybe involved in other organisations that might benefit from the work being discussed.**

**This is called a conflict of interest.**



**Members must tell the Engagement Team when this happens.**



**You will be asked to fill in a form saying what other organisations you are involved in.**



**The Engagement Team can help you with this.**

### 3. What the Advisory Group does



**Some of the work in the Advisory Group starts with NHS staff coming and asking for help.**



**The Advisory Group talks about these topics – they share their experiences and ideas.**

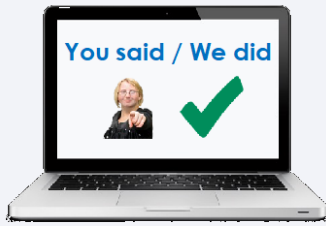


**The Engagement Team writes down what the group says.**



**We do not write down who said what unless that person is happy for this to be shared.**





We write a summary of what the group says on the [NHS England you said, we did webpage](#).



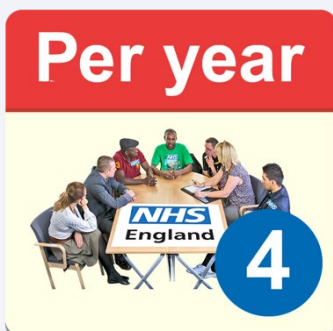
The staff who come to the group to discuss their work, report back a few months later on what they have done with the things the group has told them.



The Advisory Group also can say what they want to work on.

We will try to link with staff who are working on these things.

## 4. The meetings



There are usually four meetings per year.



**Some are in person meetings and some are on online meetings (on Teams).**



**We will let you know the dates of meetings as soon as possible.**



**It is important to attend as many Advisory Group meetings as possible.**



**You should let the Engagement Team know if you cannot attend a meeting.**



**Sometimes there will be chances to get involved in extra work.**



**You can choose if you want to do this.**

## **5. How the Advisory Group is supported**



**The Engagement Team will work with members to make sure you have the right support to have your say.**

**For example:**



- **We give new members an induction – a chance to ask questions about being part of the group.**



- We have a meeting before the group meetings so people can join with any questions.



- We give you information about meetings in advance to help you prepare.



**We will always try to give you this information at least two weeks before meetings.**



**Usually you will be able to share the information with your networks.**



**This will help you speak up for other people as well as for yourself.**



- **You can bring support staff to help you have your say.**



**Your support staff are there to help you, not to have a say themselves.**



- **Some things we talk about can be upsetting because they affect people's lives.**



**We will have staff available to support you if you are upset by discussions. They are called Mental Health First Aiders.**



**You do not have to share things that you want to keep private.**

## **6. Rules of the Advisory Group**



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



**We ask everyone involved to show respect to others to make meetings safe and supportive.**



**These rules help everyone do this:**

**Easy words**



1. To make the meetings work for everyone we ask that people use easy words and use preferred words around learning disability and autism.



2. Everyone has an equal right to take part in meetings.



**People should not be treated badly because of their background, for example ethnicity or gender.**

**This is not allowed.**



3. Everyone has a right to their own views.



**If people disagree it is important to be respectful.**



**4. We understand that people can get quite cross about the things we discuss.**



**It is OK to tell people how you are feeling.**

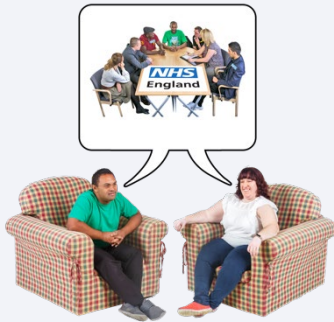


**But it is not okay to direct anger at other people.**



**Talk to the Engagement team if you want to talk about these things.**

## 7. Sharing information and privacy



**You can usually talk to other people about the Advisory Group discussions.**



**This helps bring in lots of different ideas.**



**Sometimes you will be told that a discussion cannot be shared with people outside the meeting – that it is confidential.**



**You must not share personal things about other group members without their permission.**

**For example -**



- **Phone numbers of other group members**



- **Personal things other group members share at meetings.**



**The Engagement team will keep your personal information safe.**

## **8. Expenses and involvement payments**



**We pay expenses of members coming to meetings.**



For example, travel, meals and hotels.



You can find out more in the [easy read expenses policy](#).



Usually, we will book travel and hotels, so you do not have to spend money.



For other expenses like meals, you will need to pay for them, keep the receipt and claim the money back.



**You will get involvement payments for your time and expertise.**

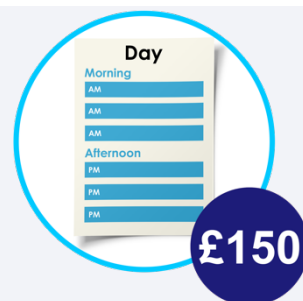


**These are paid into your bank account.**

**Involvement payments are -**



**£75 for half a day**

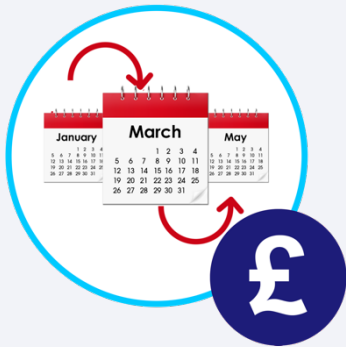


**£150 for a full day**



**Tax and National Insurance are taken from this, depending on what other money you have coming in.**





**Every three months you will get a small extra payment for any involvement payments you have had.**



**If you get benefits, involvement payments might affect this.**



**We can get the Citizens Advice Bureau to give you advice about this.**



**Ask the Engagement Team to arrange this.**

## 9. Leaving the group



**Advisory Group members can be in the group for up to 6 years.**



**You can choose to leave before this if you want to.**



**Every 2 years some members leave at the end of their 6 years, and new members join.**



**Advisory Group members might be asked to leave the group early for these reasons:**



- **For missing meetings without a good reason**



- **For not following the rules of the group**



**The Engagement Team will always discuss this with the group member first.**



**This is to give us chance to work out any problems together.**



**If you have any problems or worries about the Advisory Group you can ask the Engagement Team to help at [engage@nhs.net](mailto:engage@nhs.net) or telephone 0113 824 9686.**



**If you do not want to ask the Engagement Team to help you can ask the Public Participation team at [england.engagement@nhs.net](mailto:england.engagement@nhs.net)**