

In March 2017 the Forum met to look at making complaints, comments and feedback systems more accessible. This report is a summary of what people told us.

# **NHS England Learning Disability and Autism Forum Event**

## **Complaints, comments and feedback: making it more accessible**



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## Contents

Contents .....	3
1 Thinking about making a complaint .....	4
1.1 What are the problems? .....	4
1.2 What would make it better? .....	4
Everybody needs to understand how to make a complaint so that people know what will happen .....	4
2 Making a Complaint.....	5
2.1 What are the problems? .....	5
2.2 What would make it better? .....	5
3 Staying in touch about a complaint.....	6
3.1 What are the problems? .....	6
3.2 What would make it better? .....	6
4 The end of the complaint.....	6
4.1 What are the problems? .....	6
4.2 What would make it better? .....	7
5 Assessment and Treatment Units (ATUs).....	7
5.1 What are the problems? .....	7
5.2 What would make it better? .....	8
6 Why it is important to make these changes.....	8
7 Glossary .....	9
Next steps.....	9

# 1 Thinking about making a complaint

## 1.1 What are the problems?

People often don't know where to make a complaint, what to expect or how to complain.

- Some people with a learning disability/autism or both find it hard to speak up. This may be because they don't know how to make a complaint or don't know if they will get listened to.
- Often the Language used on the **complaints system** is not easy to understand.
- People can be scared to make a complaint for the reason that they don't want to affect the care they get in the future.
- People can also find it difficult to know who to complain to.

## 1.2 What would make it better?

Everybody needs to understand how to make a complaint so that people know what will happen

- Make an easy read guide on how to make a complaint and what you should expect.
- This would help create a way to make sure the person who is making the complaint, the service and the person handling the complaint all have a good understanding.
- This would make it more likely to be a successful process which benefits everyone.
- People with a learning disability/ autism or both could get better understanding about their rights with the help of the following:
  - Written guidance on knowing your rights
  - Videos online or on DVD about rights
  - Speaking about rights more with patients and in user groups
  - Including patients more when writing their care plans
- Confidentiality is very important. If people want their complaint or concern to be raised without them being identified this should be done.

## 2 Making a Complaint

### 2.1 What are the problems?

We need to improve the process so that it is simpler for everyone to use. This means patients, carers and service providers.

- Forms and process materials are not very accessible.
- There are not enough ways people can make a complaint or raise a concern. It is normally through writing a letter or speaking to someone directly which can be difficult for some people.
- People can feel worried about complaining or raising a concern to the person or service they have had a problem with.
- Sometimes people don't use the word complaint or concern which means their issue doesn't go through the correct process or any process at all.
- The language used around concerns or complaints can make it difficult for services to hear the feedback as they can see it as all negative and not as an opportunity to improve.

### 2.2 What would make it better?

There needs to be lots of different ways available for people to communicate their concerns or complaints. This always needs to be person centred.

- Make sure we are giving people information that they can understand. This could be:
  - Easy read
  - Video
  - Plain English
  - Podcasts
- People could raise their concerns or complaints through:
  - Easy read form
  - In person
  - Video
  - Through an **advocate**
  - Touch screen devices
- Where the complaint or concern is being received needs to have simple systems in place to receive things in different formats and with different words.
- Make sure the system is flexible enough to make it accessible to make a complaint.
- Use information provided by families and carers to help the person make a complaint.
- Ask for feedback at the end of an appointment or the end of an experience of using NHS services. This can feel confrontational, but is also easier for people than remembering how things were after a period of time has passed.

- Having someone independent to investigate the complaint is really important. This needs to be a trusted person who is trained to handle complaints and is confident in working with people with a learning disability, autism or both.
- Make sure the person receiving the complaint:
  - Has patience and listens to people.
  - Doesn't use complicated or leading language.
  - Doesn't influence the complaint in any way based on their experience.

They might need some extra training and support on how to do this.

## 3 Staying in touch about a complaint

### 3.1 What are the problems?

Sometimes the person who made the complaint or raised a concern is not kept in the loop about what is happening. This can make people feel not listened to.

- Feedback sometimes goes to a support worker or family members and not the person who raised the complaint or concern.
- Communication can be sent in a way that is not accessible.

### 3.2 What would make it better?

Make sure the person who made the complaint is receiving feedback all the way along the process as their complaint is being handled.

- Make sure information is in an accessible format for that person.
- Find out from the person making the complaint how they would like to receive their information about the progress of the complaint.
- Agree regular times to feedback.

## 4 The end of the complaint

### 4.1 What are the problems?

Complaints are not always investigated and a solution given in good time.

- Sometimes the responses are given to a carer or family member instead of to the person who raised the complaint or concern.
- It can be unclear what has happened as a result of the **investigation**.
- It is not always clear what someone can do if they are not happy with the outcomes of the investigation.

## 4.2 What would make it better?

Good and clear feedback on what has happened as a result of the complaint – in a timely manner.

- Be clear about what has happened as a result of the complaint or concern being raised.
- Check that the result has been understood. Possibly ask the person to repeat back what the outcomes are.
- Making sure there is a genuine apology – it's about change and progression, not about blame.
- Keep a log of 'you said we did' and make it available and accessible so that people are clear about what's been done to make improvements to services.
- Create an **appeals process** for if the person who raised the concern or complaint is not happy with the result.
- Give a reference number for the complaint or concern so that people don't have to go through the same process more than once for the same issue.

## 5 Assessment and Treatment Units (ATUs)

### 5.1 What are the problems?

People are scared to complain as they are afraid that this will affect their quality of daily care and that they will be victimised and treated badly. People don't think any positive action will be taken as a result of the complaint or concern being raised.

- Years of complaining can leave people feeling exhausted; run down and sometimes mentally unwell.
- It is not clear how to complain and sometimes people don't know they have the right to complain.
- Sometimes there are communication barriers for the people who want to raise the concern or raise the complaint. These people can be misunderstood.
- Some people are too over medicated to make a complaint or raise a concern.
- Staff sticking together can make it harder to raise concerns or make a complaint.
- There is not enough training for staff on how to listen to concerns or complaints.
- There is not enough independent support to help those who want to complain.
- Families can be scared that complaining will stop them being able to visit.

## 5.2 What would make it better?

- Training for staff on how to hear a complaint or concern and then take positive action.
- Have regular focus groups of people who have raised concerns or complaints or who might want to. This will help people feel less alone.
- Training for parents or families such as **Parent Expert Programme** with a section on complaints.
- Accessible information in plain English and pictures. Role play could be used to show understanding.
- Examples from other **ATUs** of good practice.
- A change in attitude from staff around concerns and complaints. To see them as valuable learning and service improvements.

## 6 Why it is important to make these changes

To make the points raised and solutions suggested work, staff attitudes and the culture towards complaints and concerns needs to change.

- Getting this right will improve people's quality of life.
- Treat me right, Complaints aren't a bad thing. See them as ways to improve.
- Feedback and complaints should actively be encouraged so that services know they are doing a good job.
- Encourage services to be more reactive and proactive. Improve before things reach complaint stage.
- To prevent people going in cycles – deal with the concern or complaint efficiently in the first place will save time and energy.
- Encouraging feedback will also encourage people to give praise about good work services are doing. This will help make relationships better for everyone.
- People need to feel **empowered** and respected.
- Professionals should be accountable for their actions and decisions. Feedback is a very important part of being able to measure performance.



## 7 Glossary

This is an explanation of difficult words in this report, which we highlighted in bold. There is also an easy read glossary in the easy read version of this report.

**Advocate** – Someone who speaks on someone else’s behalf and can support people have their say about what is best for that person.

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**Appeal** – if you don’t like the result of your complaint you can challenge the decision. This means asking for it to be looked at again. There is normally a formal way for how to appeal a complaint.

**Appeals processes**- the way that an organisation does **appeals**.

**Assessment and treatment unit (ATU)** – hospitals that people with a learning disability or autistic people might go to if they have a mental health problem or behaviour that is described as challenging.

**Complaint** – If you think something is bad about a service you can make a complaint. This is a formal process. The service will have a **complaints policy** to deal with your complaint.

**Complaints system** – the way that organisations deal with complaints.

**Empowered**- having the power to do something. For example, someone being in control of their own life.

**Investigation**- looking at the facts of a case or a problem.

**Parent Expert Programme**- training to help parents understand the systems, so that they can get the best care for their disabled child.

## 8 Next steps

NHS England is using what people have told us at this event to make complaints, comments and feedback better for people with a learning disability, autism or both and their family carers. Thank you for sharing your ideas with us.