



# **Learning Disability Improvement Standards**

Findings From Year 7 of the Benchmarking Exercise:  
Patient Focus Groups

# Patient Focus Groups

As part of a national effort to enhance NHS services, NHS Benchmarking Network partnered with [Learning Disability England \(LDE\)](#), a member led organisation working to improve the lives of people with learning disabilities. LDE supported the delivery of three regional patient focus groups, conducted to gather feedback from individuals with learning disabilities and autistic people. These sessions provided a vital platform for participants to share their lived experiences and offer insights to help shape more inclusive and effective healthcare services.



The discussions were structured around questions related to the **NHS Learning Disability Improvement Standards**, ensuring that the voices of people with learning disabilities and autistic people were central to the conversation. The goal was to reflect these voices in future service improvements, ensuring that NHS care is accessible, supportive, and person-centered.

The focus groups were facilitated by the following organisations:

- [Dudley Voices for Choices \(Midlands\)](#)
- [Skills for People \(North East\)](#)
- [ACE Anglia \(East of England\)](#)



These organisations have extensive experience in supporting individuals with learning disabilities and autistic people, and their expertise was instrumental in creating a safe and welcoming environment for participants to share their feedback.

**46** individuals with learning disabilities shared their experiences of using NHS services. The focus groups were guided by questions covering key areas such as dignity and respect, communication, reasonable adjustments, safety, and support. In total, **176** comments were gathered and carefully analysed to identify common themes, challenges, and areas for improvement.

# What are examples of good care?

Good care for individuals with learning disabilities and autism is characterized by **respect, clear communication, and individualised support**. Key elements of good care include:

**Person-centred approach:** Treating each patient as an individual, listening to their needs, and providing choices in their care. This includes involving family members or support workers as needed and respecting their input.

**Clear and accessible communication:** Ensuring information is explained in a way that is easy to understand, avoiding jargon, and providing **easy read** materials to help individuals grasp important details.

**Adequate time and patience:** Allowing sufficient time for appointments, offering opportunities to ask questions, and being patient when individuals need extra time to process information.

**Respectful interaction:** Treating individuals with dignity, asking for consent before touching, and addressing patients with the same respect as others. Communication should be open, with healthcare professionals checking in regularly to ensure the person is comfortable and informed.

**Inclusion and involvement:** Ensuring that family members and support workers are included in the care process and kept informed, fostering a sense of security and collaboration.

**Reasonable adjustments:** Making accommodations based on individual needs, such as offering quieter spaces for appointments, providing flexible scheduling, and ensuring accessibility in the physical and communication environment.

# What are examples of bad care?



Poor care experiences were marked by a **lack of personalisation**, **poor communication**, **disrespect** towards patients' autonomy, and **inadequate support** for disabilities, leading to a **lack of trust** and increased **anxiety** for patients.

**Lack of choice and control:** Many patients felt they were **not involved in decision-making** regarding their care and reported that decisions were made for them without consultation. Some patients felt **disempowered** and **ignored** when they weren't given the opportunity to express their preferences or ask questions.

**Poor communication:** A significant number of patients reported **confusion** due to **unclear communication**. Information was often provided in a way that was **difficult to understand**, and patients were not always asked if they needed things explained in an accessible format (e.g., Easy Read). In some cases, patients felt **ignored** when they attempted to express concerns or ask for clarification.

**Lack of respect and personalization:** Patients expressed frustration when **staff didn't listen** to them directly, instead speaking to carers or family members. This lack of direct communication made patients feel that their **individual needs** were overlooked. Additionally, some individuals reported being **treated with impatience** or not being given the **time or attention** they needed.

**Long waiting times and anxiety:** Many patients described experiences of **excessive waiting times**, which led to increased anxiety and frustration. In some cases, appointments were **changed or cancelled** without clear communication, leading to confusion. The physical environment, such as **busy and noisy waiting rooms**, also contributed to the stress.

**Inadequate support for disabilities:** There were instances where staff **failed to read or acknowledge hospital passports** and **didn't provide reasonable adjustments** to meet the needs of patients with learning disabilities or autism. This often resulted in patients feeling **unsafe** or **uncomfortable** during their care.

# What can we do better?

6 key themes were identified from 48 improvement suggestions



## **Communication**

Listen to people with a learning disability, involve them in decisions about their own care



## **Reasonable adjustments**

Particularly around waiting times, appointment flexibility and accessible information



## **Tailored care**

Treat everyone as an individual, don't assume needs



## **Hospital passports**

Review, use and update



## **Patience**

Allow time to process information and ask questions



## **Staff knowledge and availability**

Including provision of training and availability of Learning Disability nurses



# Breakdown of feedback

## Overall comments

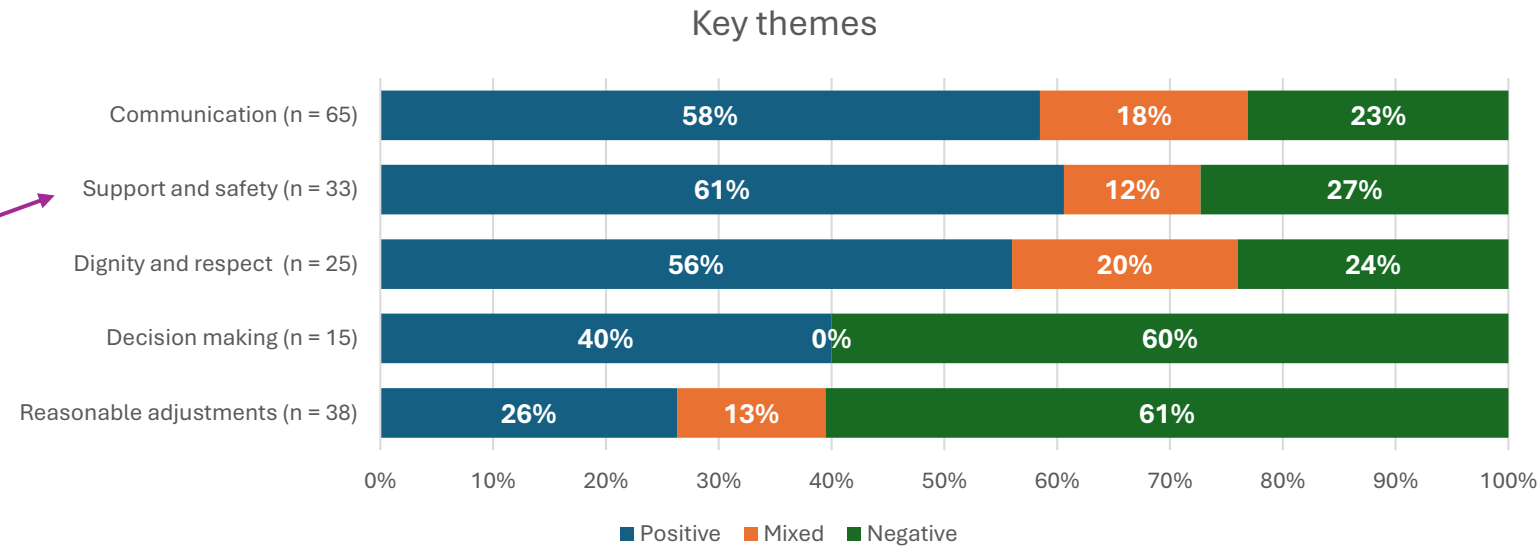
Overall, we received **176** comments back to analyse. The split of comment type can be found in responses table.

**54%** positive, **13%** mixed and **33%** negative.

The theme of communication (**37%**) reasonable adjustment (**22%**) came on top. However, the reasonable adjustment theme was predominately negative comments and communication predominantly positive (see key themes table)

Responses	
Positive	88
Mixed	26
Negative	62

Themes	Positive	Mixed	Negative	Total
Reasonable adjustments (n = 38)	10	5	23	38
Decision making (n = 15)	6	0	9	15
Dignity and respect (n = 25)	14	5	6	25
Support and safety (n = 33)	20	4	9	33
Communication (n = 65)	38	12	15	65
TOTAL	88	26	62	



# Breakdown of feedback

## Improvement feedback

An additional **48** suggestion for how the NHS can do better were received.

Being listened to and communicated with was the top response (**29%**). Participants wanted to be involved in decision about their care. Feedback reflected frustration that family and carers were consulted before the patient themselves. Not everyone needs to be treated the same and participants wanted to care to be tailored to their needs and abilities (**10%**).

There was a notable request from participants for more staff training (**19%**), including how and when to provide reasonable adjustments (**33%**) .

Theme	Number of comments	%
Listen to and communicate	14	29%
Staff training and availabilty	9	19%
Resonable adjustments - appointments	6	13%
Treat everyone as an individual	5	10%
Resonable adjustments - easy read/accesssbile information	5	10%
Resonable adjustments - waiting times	4	8%
Hospital passports	4	8%
Resonable adjustments	1	2%

# Breakdown of findings

## Breakdown by organisation

Theme	Question	ACE			Skills for people			Voices for choice		
		Positive	Mixed	Negative	Positive	Mixed	Negative	Positive	Mixed	Negative
Communication	Did staff explain things to you in a way that you could understand	2	3	0	2	1	3	5	1	4
Communication	Did staff listen to your family/supporter/friend	4	0	0	1			9		1
Communication	Did staff talk to you about the care you needed	2	0	0	5			1	3	4
Reasonable adjust	Did staff tell you about your appointments and meetings in a way that you could understand	0	0	0	3		3	1	1	4
Communication	Did you feel like staff listened to you	1	1	0	3	1		3	2	3
Support and safety	If you stayed in hospital was it easy for family/friend/support to visit?	0	0	0				2	1	
Dignity and respect	Treatment with dignity and respect	4	0	1	1	2	4	9	3	1
Support and safety	when you were at hospital did you feel safe?	0	0	0	7	1	2	5		2
Support and safety	Did you have any concerns about your care	0	0	0				3		3
Support and safety	Did you make a complaint	0	0	0				3	2	2
Reasonable adjust	If yes, were you given easy read info about how to make a complaint	0	0	0					3	
Reasonable adjust	If you were seen in an emergency, were you seen quickly	0	0	0				2		4
Decision making	Choices about how you were cared for	0	0	0	1		1	5		8
Reasonable adjust	Were your appointments arranged to suit you?				1		8	3	1	4
		13	4	1	24	5	21	51	17	40
	<b>TOTAL</b>	<b>18</b>			<b>50</b>			<b>108</b>		
	What could be made better	<b>12</b>			<b>22</b>			<b>14</b>		