Learning Disability Improvement Standards

Key Findings and Shared Learning Event

02/07/2026

NHS England

Housekeeping

Mute

Please ensure you remain on mute and with your camera off for the presentations, to reduce likelihood of delays.

Interact

We encourage interaction via the Chat function.

Wellbeing First

Please take opportunities to stand, stretch, move about, and keep hydrated.

#NHSBN

#Learning Disabilities

Share

Feel free to share your thoughts about the insight today, especially for colleagues who have been unable to make the session.

Live Recording

The session is being recorded. The session will be available on the LDIS portal post-event.

Agenda

10:00 – 10:05	**Welcome and Introductions**	**Alex Parry-Jones** Delivery Manager, NHS Benchmarking Network
10:05 - 10:40	**Findings from year 8 of the benchmarking project**	**Alex Parry-Jones**
10:40 – 10:50	**NHSBN/LD England: How we worked together**	**Samantha Clark** Chief Executive, Learning Disabilities England
10:50 – 10:55	**Break**	

Agenda

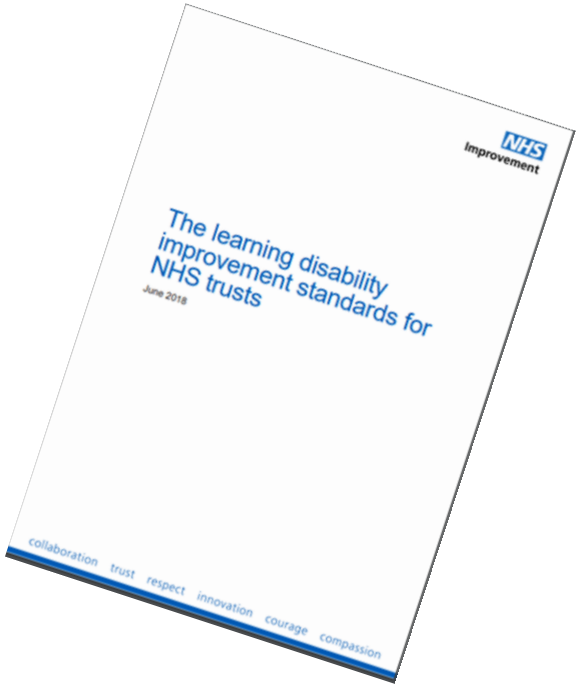
10:55 – 11:20	**Shared Learning Speaker:** From Corporate to Clinical: *Integrating Complex Needs into DOM to Improve Access, Escalation and Care for People with Learning Disability*	**Mid Yorkshire Teaching NHS Trust** **Stephanie Alexander** Clinical Educator - Complex Needs Team
11:10 – 11:25	**Shared Learning Speaker:** A Focus on Patient Participation and Engagement	**St George's, Epsom and St Helier University Hospitals and Health Group** **Dara Shorthall** Group Lead - Learning Disabilities Services
11:25 – 11:40	**Shared Learning Speaker:** Listening, Learning, Improving: *How Incremental Changes Have Enhanced Care and Support for Adults, CYP and Families*	**Birmingham Women's and Children's NHS Trust** **Moses Dube** Lead Nurse for Learning Disability and Autism Liaison Team
11:40 – 11:45	**Next steps**	**Alex Parry-Jones**
11:45 – 12:00	**Data explorer tool demo**	**Giovanny Zapata** Delivery Coordinator, NHS Benchmarking Network

Learning Disability Improvement Standards

Introduction to the project

Alex Parry-Jones
Delivery Manager, NHSBN

NHS Improvement Standards



- Published June 2018

- Four improvement standards against which trust performance is measured cover:
  - **Respecting and protecting rights**
  - **Inclusion and engagement**
  - **Workforce**
  - **Specialist learning disability services**

- The first three ‘universal standards’ apply to all NHS trusts, and the fourth ‘specialist standard’ applies specifically to trusts that provide services commissioned exclusively for people with a learning disability and/or autistic people.

A trust’s compliance with these standards demonstrates it has the right structures, processes, workforce and skills to deliver the outcomes that people with a learning disability, autistic people, their families and carers expect and deserve, as well as commitment to sustainable quality improvement in the services and pathways for this group.

Background and aims

NHS England approached NHS Benchmarking Network in 2017 to assess the implementation of the Improvement Standards

National aims

- Ambition to garner a clear national picture – isolate key themes, celebrate successes, and identify where to target support.
- Identify lack of parity in how policy is interpreted and applied.
- Assess relationship between outcomes/experiences and organisational systems/structures.

Local/organisational aims

- Support Trusts to measure and demonstrate performance against key measures
- Reduce unwarranted variance
- Introduce meaningful patient/family voice to enhance and provide context to the organisational findings
- Inform local improvement planning processes

Respecting & Protecting Rights

- Reasonable adjustments
- Flagging mechanisms
- Learning from deaths
- Protecting liberty
- Anti discriminatory practice

Inclusion & Engagement

- Partners in care
- Values led services
- Co-designed services
- Learning from investigations
- Empowering people

Workforce

- The right staff
- Training and development
- Addressing workforce pressures
- Leadership

Specialist Learning Disability Services

- Community based support
- Reducing admissions & hospital stays
- Reducing over medication
- Evidence based care & treatment
- Reducing restrictive practices

The project

The standards review aims to collect data from a number of perspectives to understand the overall quality of care across services.

- Open to all Acute, Community, Mental Health and Ambulance Trusts.
- Data is collected from four perspectives:

Organisational survey; reviewing activity, workforce, organisational structures and processes

Patient feedback; understanding the experiences people with a learning disability have as they use NHS services

Staff Survey; understanding staff skill, confidence and support when providing care for people with a learning disability and their families

Friends & Family Survey; understanding the experiences and views of relatives and carers as they support someone using NHS services.

The project

- Data collection opened on **3rd November 2025** and closed on the **31st March 2026**

Data collection elements:

1. An **organisational level data collection –** completed for the Trust by a nominated Executive Learning Disability lead.
2. An **online staff survey –** completed by staff members occupying any role, who have experience of working with patients with a learning disability.
3. Seven regional **patient focus groups –** facilitated by LD England
4. An **online patient survey –** completed by people with a learning disability over the age of 18 years old who accessed care in the last year.
5. An **online family/carer survey –** completed by a family member or carer of someone with a learning disability who accessed care in the last year.
6. A **pilot clinical case note review –** Trusts reviewed 5 - 10 clinical case notes of patients with a learning disability who have been seen by the Trust during the last year.

Participation

	Trusts registered	Organisational Surveys	Staff Surveys
Acute	115	107	4,831
Mental Health	34	30	1,021
Community	12	11	339
Ambulance	2	2	8
Total	**164**	**150**	**6,199**

Additionally:

7 Regional Patient Focus Groups

757* Family & Carer Surveys completed

466 Patient Surveys completed (NEW)

719 Case Notes reviewed (NEW - Pilot)

Learning Disability
Improvement Standards

Learning Disability Improvement Standards

Findings From Year 8 of the Benchmarking Exercise

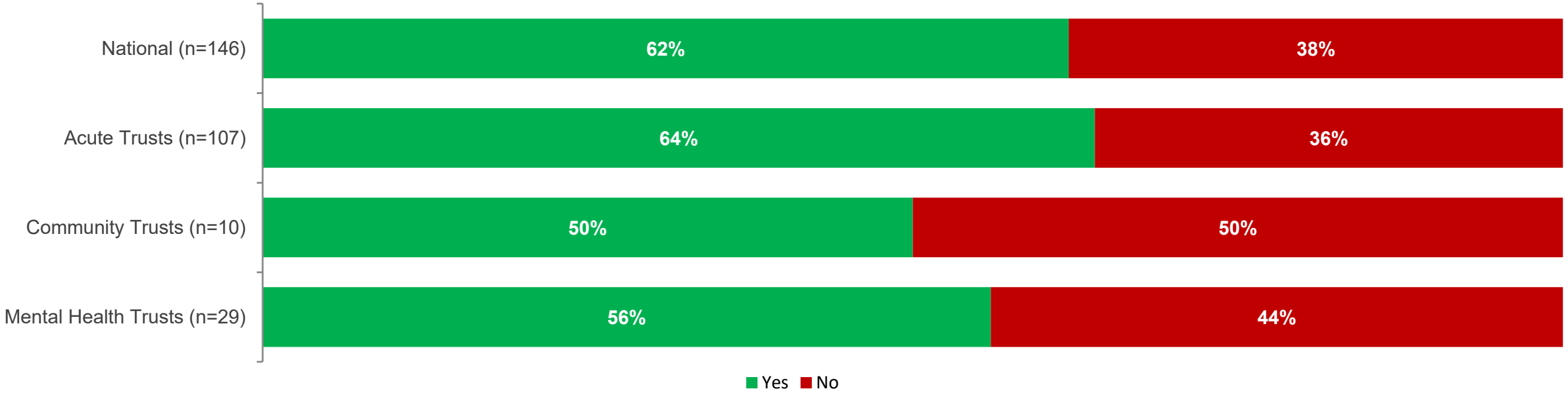
Alex Parry-Jones

Standard 1: Respecting and Protecting Rights

Reasonable Adjustments

62% of Trusts report reasonable adjustments are consistently applied across the care pathway — but patient, family and case note data all tell a more mixed story.

When a reasonable adjustment is identified or requested, does your organisation ensure it is consistently applied across all appointments, procedures, and pre-operative stages?



54%
of families feel adjustments always made
Family/Carer Survey — All-Age Trusts

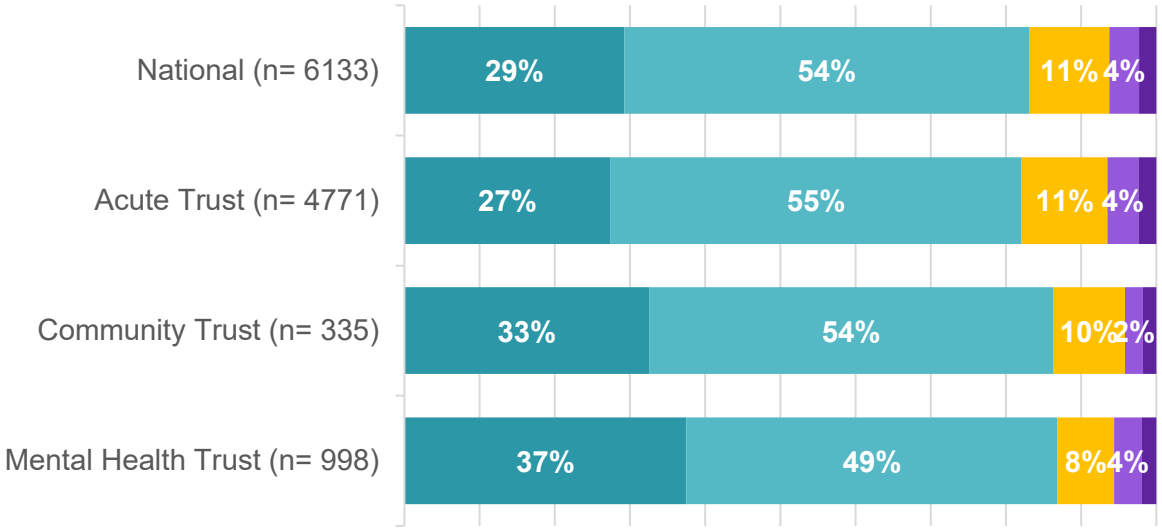
58%
of patients received accessible information
Patient Survey

Standard 1: Respecting and Protecting Rights

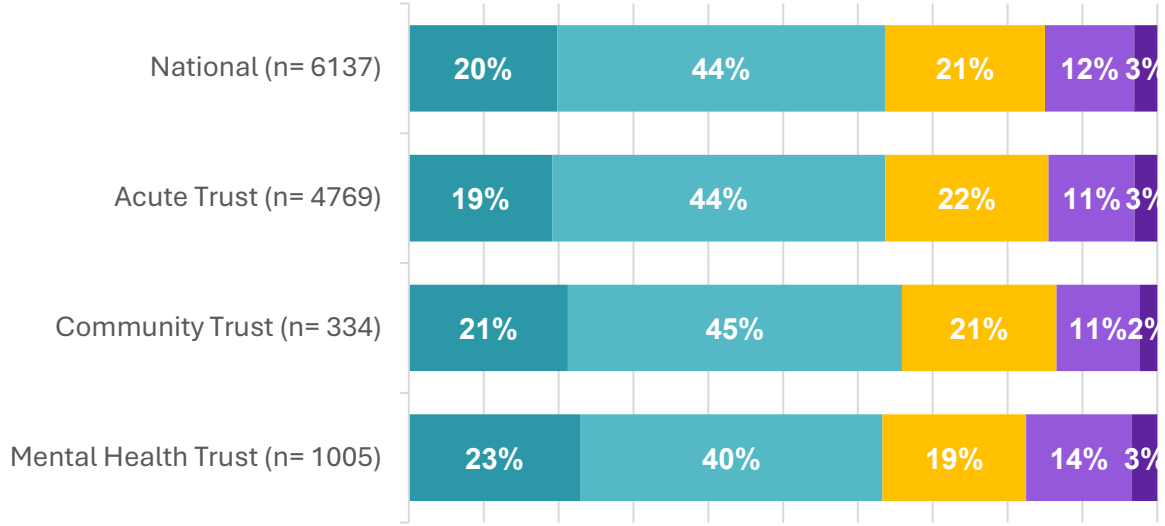
Staff Confidence in Reasonable Adjustments

83% of staff feel able to identify reasonable adjustments — an 11 percentage point increase from last year. However, only **64%** are confident patients always receive the adjustments they need, highlighting a significant gap between identification and delivery.

I feel able to identify what reasonable adjustments are needed for children, young people and adults with a learning disability or autistic people.



I am confident that children, young people and adults with a learning disability or autistic people using my service always receive the reasonable adjustments they need.



Strongly Agree · Agree · Neither Agree nor Disagree · Disagree · Strongly Disagree

75%

of case notes documented reasonable adjustments

Case Note Review

60%

of documented adjustments fully delivered

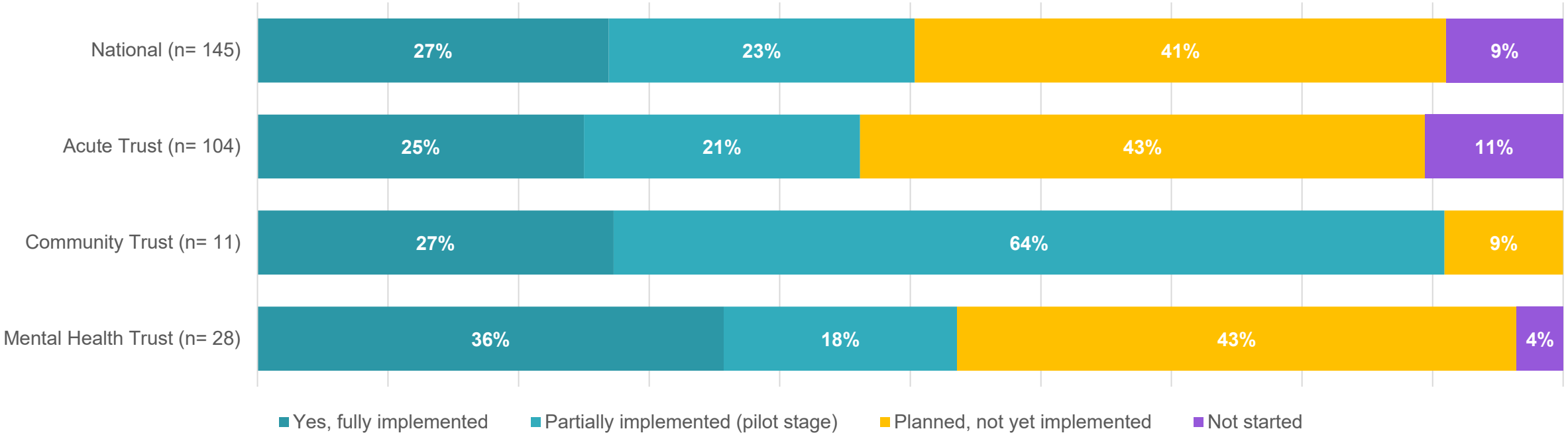
Case Note Review

Standard 1: Respecting and Protecting Rights

Flagging and Identification

Only **27%** of Trusts have the Reasonable Adjustment Digital Flag fully implemented in their EPR. Case notes reflect this: **40%** of notes contained no hospital passport at all, and **4%** had one present but unused — suggesting patient needs are not consistently following them through the system.

Has the Reasonable Adjustments Digital Flag been technically enabled in your electronic patient record (EPR) system?



70%
of Trusts can identify people with LD on waiting lists
Organisational Survey

74%
of staff report an electronic identification system in place
Staff Survey

40%
of case notes had no hospital passport present
Case Note Review

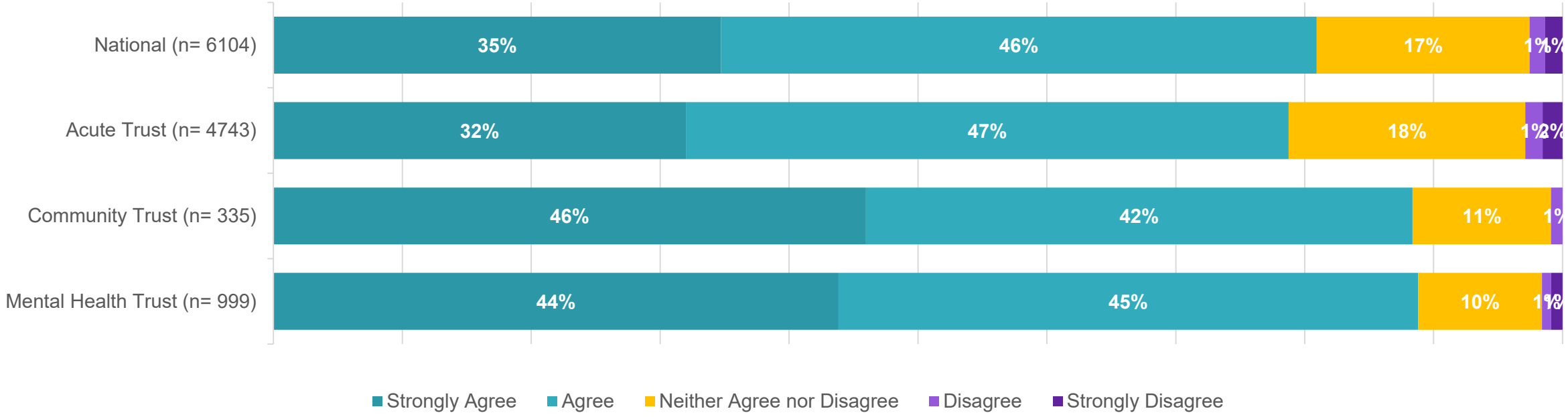
4%
had a passport present but not used
Case Note Review

Standard 2: Inclusion and Engagement

Patient and Family Involvement in Care Decisions

81% of staff report routinely involving patients in care decisions — up from **78%** last year. The patient survey and case note data show the picture is more mixed from the patient's perspective.

I routinely involve children, young people and adults with a learning disability, and autistic people when making decisions about their care and treatment.



57%
of patients felt staff listened to them
Patient Survey

65%
of patients felt things were explained clearly
Patient Survey

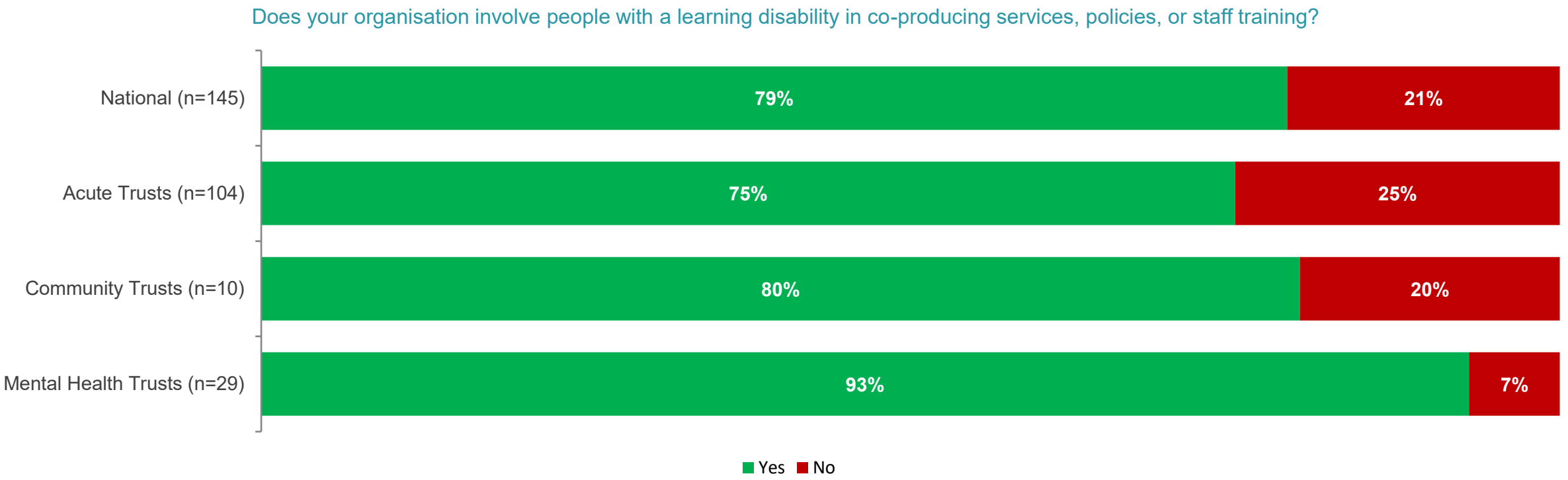
58%
of families agreed staff explained things clearly — All-Age Trusts
Family/Carer Survey

23%
of case notes had no documented patient involvement in decisions
Case Note Review

Standard 2: Inclusion and Engagement

Co-production of Services

79% of Trusts report involving people with learning disabilities in co-producing services, policies or training — but staff and governance data suggest the depth of that involvement is limited.



34%
of staff agree patients are routinely involved in service planning
Staff Survey

32%
of Trusts have a dedicated governance position — down from 38%
Organisational Survey

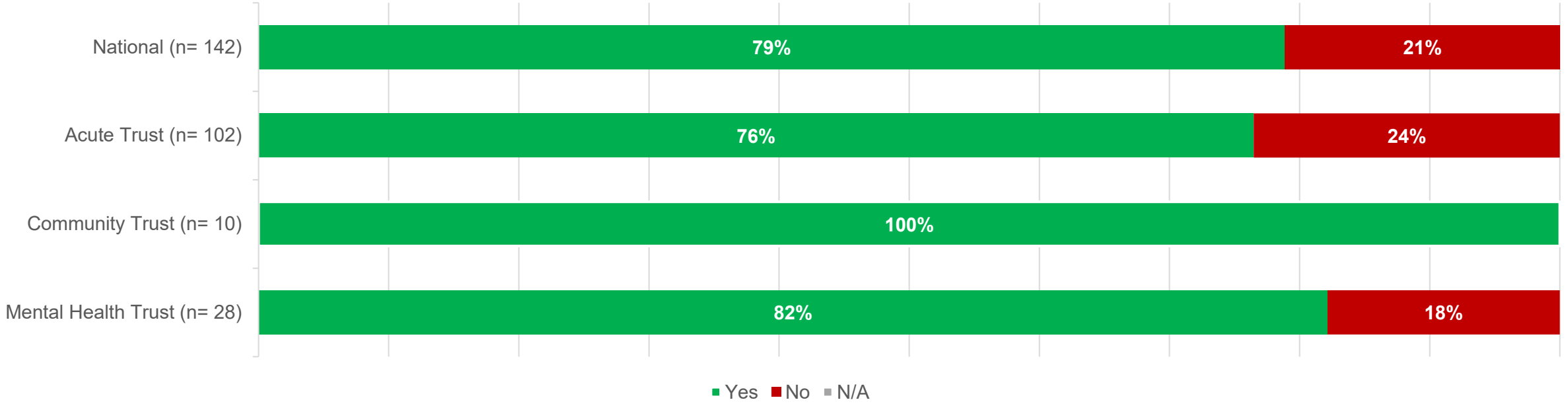
55%
of Trusts involve people with LD in delivering awareness training — up 12 points
Staff Survey

Standard 2: Inclusion and Engagement

Ask Listen Do and Rights Communication

79% of Trusts have an Ask Listen Do process in place for gathering feedback, concerns and complaints — Community Trusts at **90%**. However, the data shows a persistent gap between having the process and staff consistently applying it when it comes to communicating rights.

Does your organisation have a process in place to gather feedback, concerns and complaints for people with a learning disability, autistic people and families using the principles of Ask Listen Do



42%
of staff always inform patients and families of their rights

Staff Survey

80%
of Trusts provide accessible information about rights and services

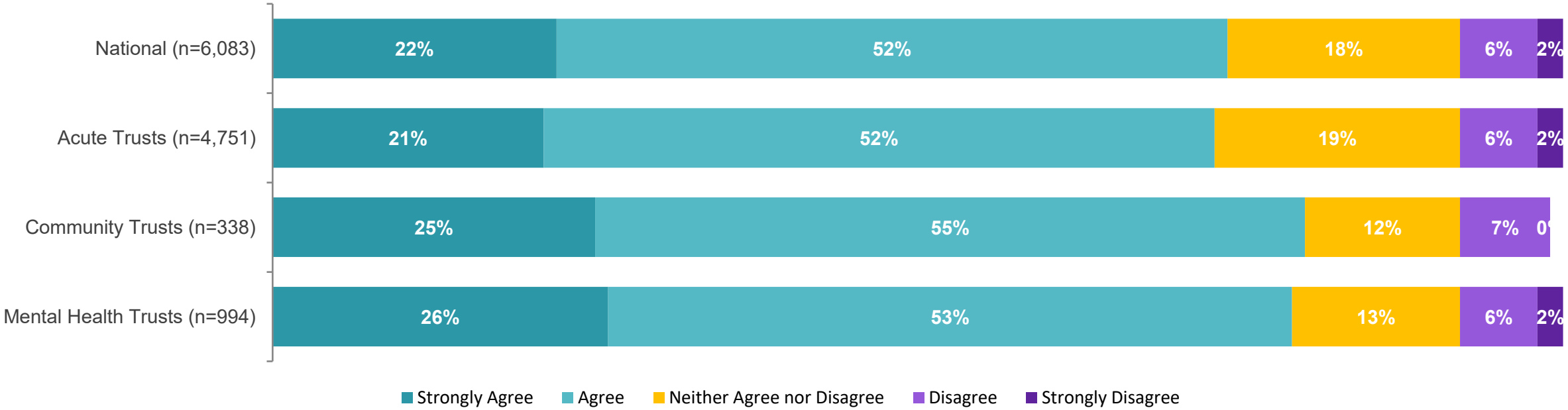
Organisational Survey

Standard 3: Workforce

Staff Knowledge and Skills

74% of staff feel they have the necessary knowledge and skills — a 1 percentage point increase from last year. **90%** have received mandatory training, up from **89%**, which provides some of the foundation for that confidence.

I feel I have the necessary knowledge and skills to meet the needs of children, young people and adults with a learning disability, and autistic people.



55%

of Trusts involve people with LD in delivering awareness training — up 12 points from 44%

Staff Survey

11%

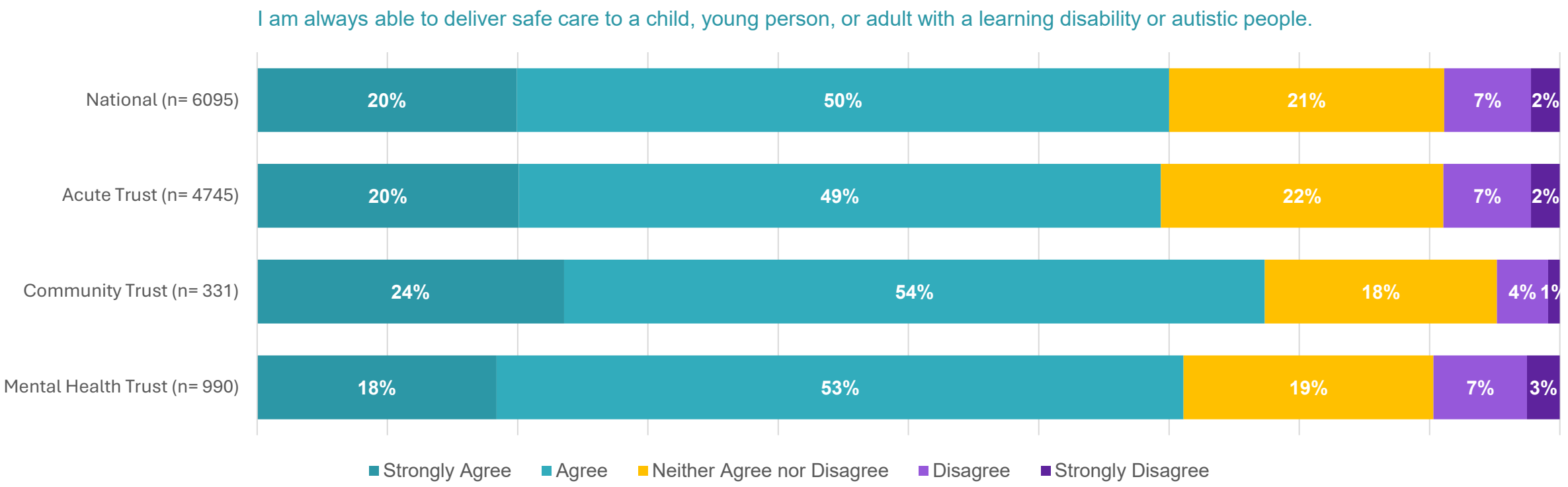
of patients did not feel safe during care

Patient Survey

Standard 3: Workforce

Resources and Safe Care Delivery

70% of staff feel they can always deliver safe care — up from **66%** last year. But consistent with last year only **50%** feel they have the necessary resources, and patient data shows a meaningful gap remains.



50%
of staff feel they have the necessary resources
Staff Survey

15%
of patients felt staff did not listen to them
Patient Survey

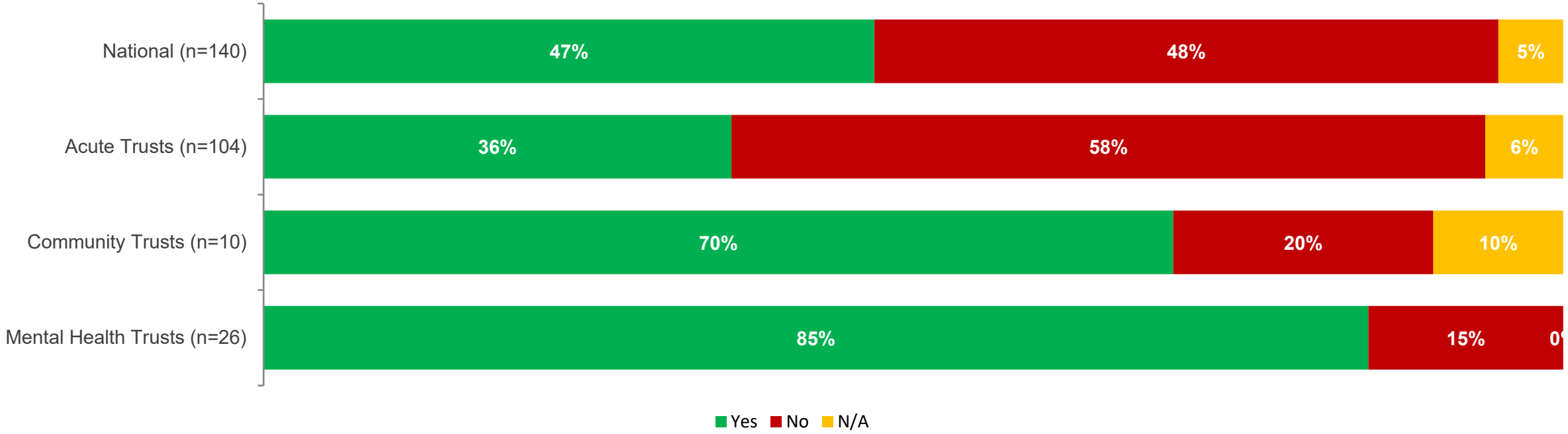
47%
of Trusts include new LD roles in workforce plans — down from 55%
Organisational Survey

Standard 3: Workforce

Workforce Planning

Acute Trusts have fallen from **43%** to **36%** — only around 1 in 3 now include new LD roles in their workforce plans. Nationally the figure has dropped from **55%** to **47%**, with Mental Health Trusts the only trust type holding strong at **85%**.

Does your workforce plan include provisions to support the development of new roles for the care of people with a learning disability?



88%
of Trusts have a board-level lead — down from 90%
Organisational Survey

0.1
median WTE registered LD nurses per 100 patients with LD flag — down from 0.2
Organisational Survey

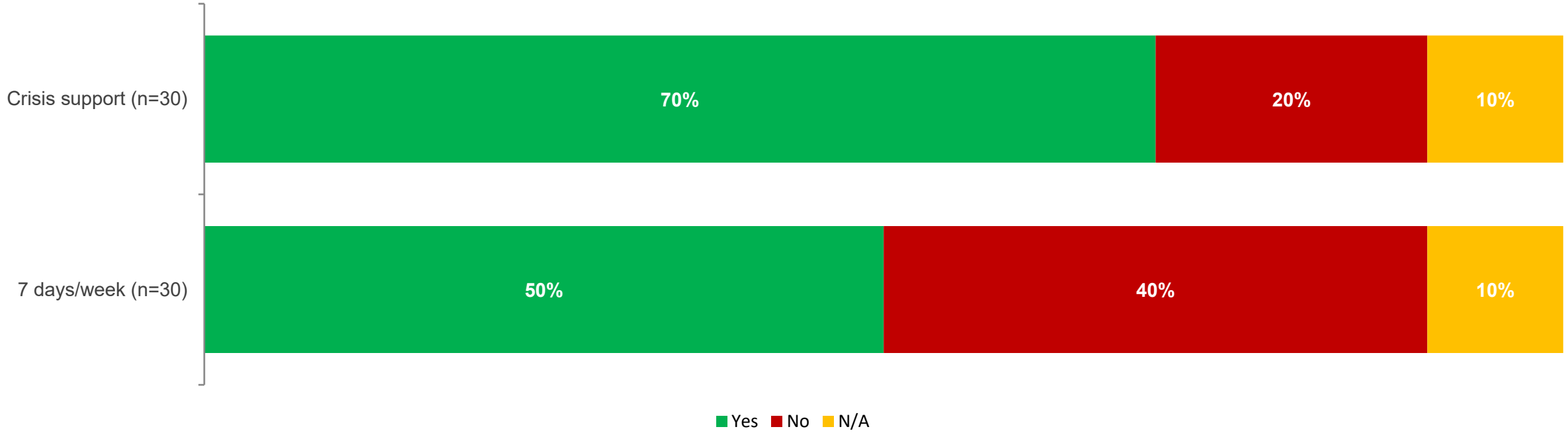
67%
of staff have access to additional specialist LD staff when needed
Staff Survey

Standard 4: Specialist Learning Disability Services

Crisis Support and Community Services

70% of specialist Trusts offer crisis support — down slightly from **73%** but significantly up from **52%** in 2022/23. Only **50%** provide intensive support 7 days a week, a 7 percentage point decrease on last year.

Specialist LD Service Trusts (n=30): Crisis support and 7-day intensive community support



93%
of specialist Trusts monitor target and actual discharge dates — up from 84%
Organisational Survey

90%
have in-reach protocols for LD admissions to universal MH services — up from 80%
Organisational Survey

58%
of specialist service staff agree Trust has developed effective community support
Staff Survey

Standard 4: Specialist Learning Disability Services

STOMP and Medication Reviews

Commitment to STOMP is strong and improving — but patient and family involvement in medication reviews remains persistently low and unchanged from last year.

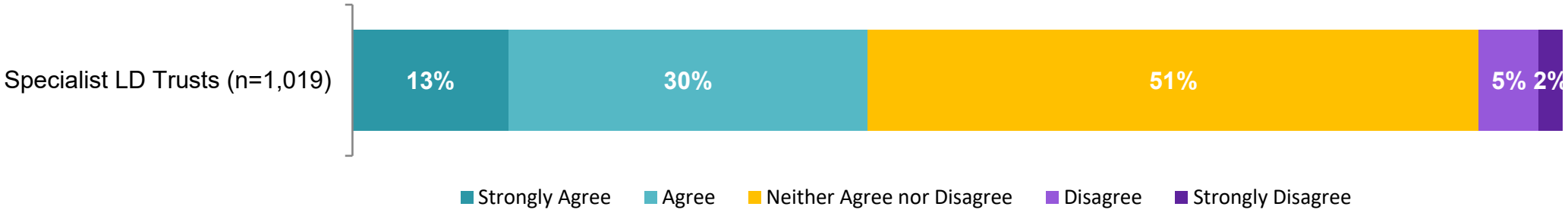
100%

Trusts signed up to STOMP
(up from 95%)

83%

have policy against
inappropriate prescribing
(up from 76%)

People with a learning disability, autistic people and family carers are involved in reviewing the appropriateness of psychotropic medications.



Standard 4: Specialist Learning Disability Services

Restrictive Practices and Behaviour Support

Two near-universal safeguards have declined significantly in a single year. Both were above 95% last year — the drop warrants attention

88%

Risk assessments held (down from 97%)

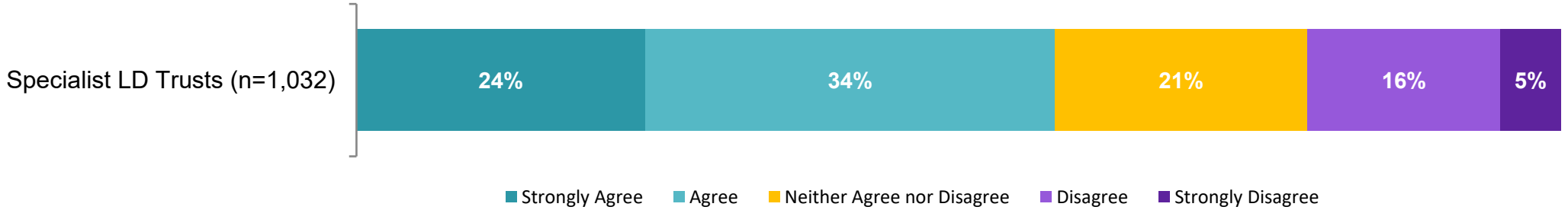
90%

Restraint reduction programme (down from 98%)

96%

Individualised behaviour support plans (up from 93%)

I have had training on reducing the use of restrictive interventions.



Learning Disability Improvement Standards

Findings From Year 8 of the Benchmarking Exercise: Patient Focus Groups

Learning Disability England

Patient Focus Groups

- 7 regional workshops held
- 218 people with a learning disability shared their experiences of using NHS services over the last year.
- Questions asked on dignity and respect, communication, access to appropriate care & support, inclusion of family & support
- Overall, 893 experiences of care comments were analysed.
- Additionally, 172 suggestions for improvement were submitted.

Skills for People (North East & Yorkshire)

ACE Anglia (East of England)

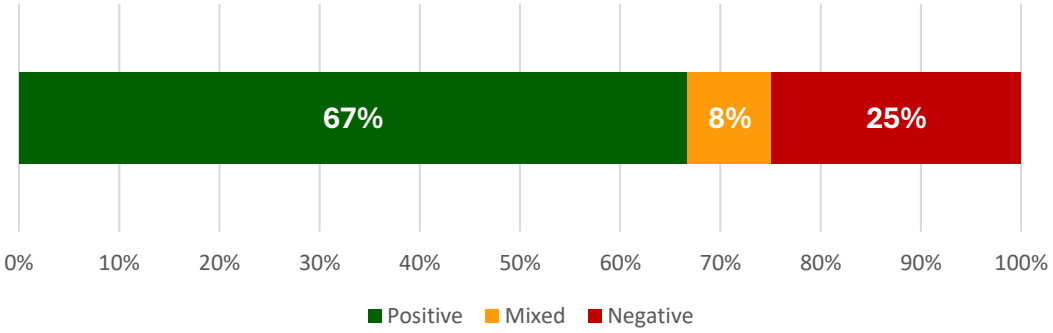
Dudley Voices for Choice (Midlands)

Pathways Associates (North West)

People First Forum (South West)

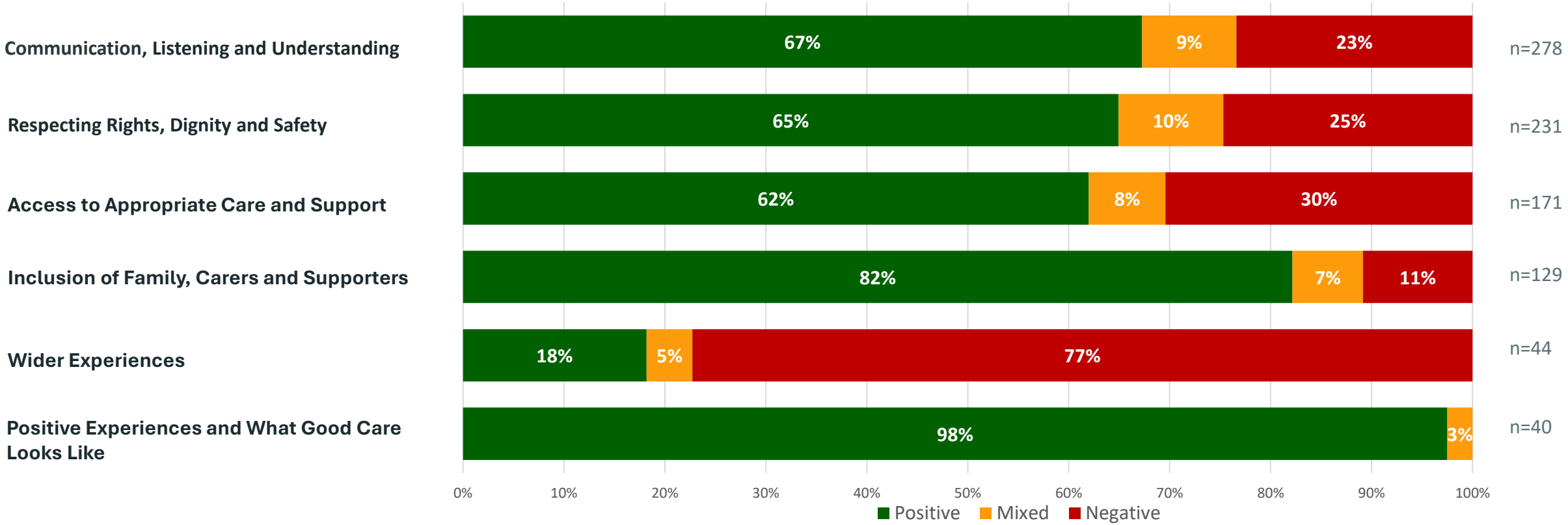
Lewisham Speaking Up (London)

Active Prospects (South East)



Key themes from regional focus groups

The chart below shows how positive, mixed and negative responses were distributed within each of the six themes, ordered by the number of responses they attracted.



Learning Disability Improvement Standards

Each bar shows the share of positive, mixed and negative responses within that theme. Percentages may be greater than 100% due to rounding

What can we do better?

An additional **172** suggestions for how the NHS can do better were also received, highlighting **5** key themes

Accessible information, provided as standard With Easy Read and plain language by default, not only when asked.

Use hospital passports and act on reasonable adjustments
Read and use passports every time, and make adjustments without being asked repeatedly.

Listen to patients, communicate directly, and allow time
Speak to people directly, not just carers, and allow time to understand.

The right staff, trained and informed by lived experience
With more liaison nurses, and people with lived experience involved in training and quality checks.

Access, Environment and Hospital Processes
Cut waiting times, improve parking, signage and transport, and make discharge safer.

Learning Disability Improvement Standards

How we worked together

Samantha Clark
Learning Disability England

Learning Disability
Improvement Standards

Learning Disability England

Learning Disability England exists to make life better for and with people with Learning Disabilities and their families.

Learning Disability England

How we work

Support others work

Celebrate others action or achievements

Lead when taking action together is best

We do this through

1. **Membership – for people and organisations creating stronger links together**
2. **Influence and campaigning – speaking up and sharing others important work**
3. **Solving problems together & sharing what works**
4. **Share information and build networks so we learn together**

Learning Disability England

Members work together to build a world where people with learning disabilities have good lives with equal choices and opportunities as others.

At the end of May 2026 there were

209 organisation or group members

576 individual members

Why we think this matters

Cameron works at Dudley Voices for Choice

Community Partners

In 2025 we worked with 3 community partner groups

This year we were able to recruit a partner organisation in each region

ACE Anglia (East of England)

Dudley Voices for Choice (Midlands)

Pathways Associates (North West)

Skills for People (North East & Yorkshire)

People First Forum (South West)

Lewisham Speaking Up (London)

Active Prospects (South East)

The groups were offered a flat fee for:

- Coming to an on line briefing session at the start and a reflection / learning session at the end
- Capturing the experiences and feedback of 20 people
- Promoting the survey and Standards work
- Sharing the feedback in formats we agreed

What we did

To support them Learning Disability England:

- Created a resource pack, presentations and feedback templates
- Facilitated the briefing session with NHS Benchmarking colleagues
- Offered any support or helped problem solve as they did the work
- Facilitated the reflection and learning session at the end of the process

Different perspectives

Learning – my reflections

Trusting relationships

Flexibility

Stories – rich and varied information

Honesty – frustration at the pace or kind of change

Challenge to us and NHS Benchmarking on accessibility and inclusion

People want to be part of the solution

Break

NHS
Mid Yorkshire Teaching
NHS Trust

From Corporate to Clinical:

Improving Care for People with Learning Disability and Autism Through Integration into the Division of Medicine

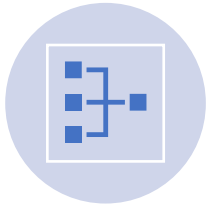
The Complex Needs Team

Working together
making a difference

Aim of the Quality Improvement Plan

Improve	Improve the quality, safety and equity of care for people with Learning Disability and Autism
Reduce	Reduce variation in care, access and escalation processes
Strengthen	Strengthen clinical integration and accountability
Ensure	Ensure timely identification and support for patients with complex needs
Embed	Embed consistent delivery of reasonable adjustments

What were we trying to accomplish



Transition from a **corporate service → clinically embedded model (DOM)**

Improve **access to specialist complex needs support**

Introduce **clear, structured referral and triage processes**

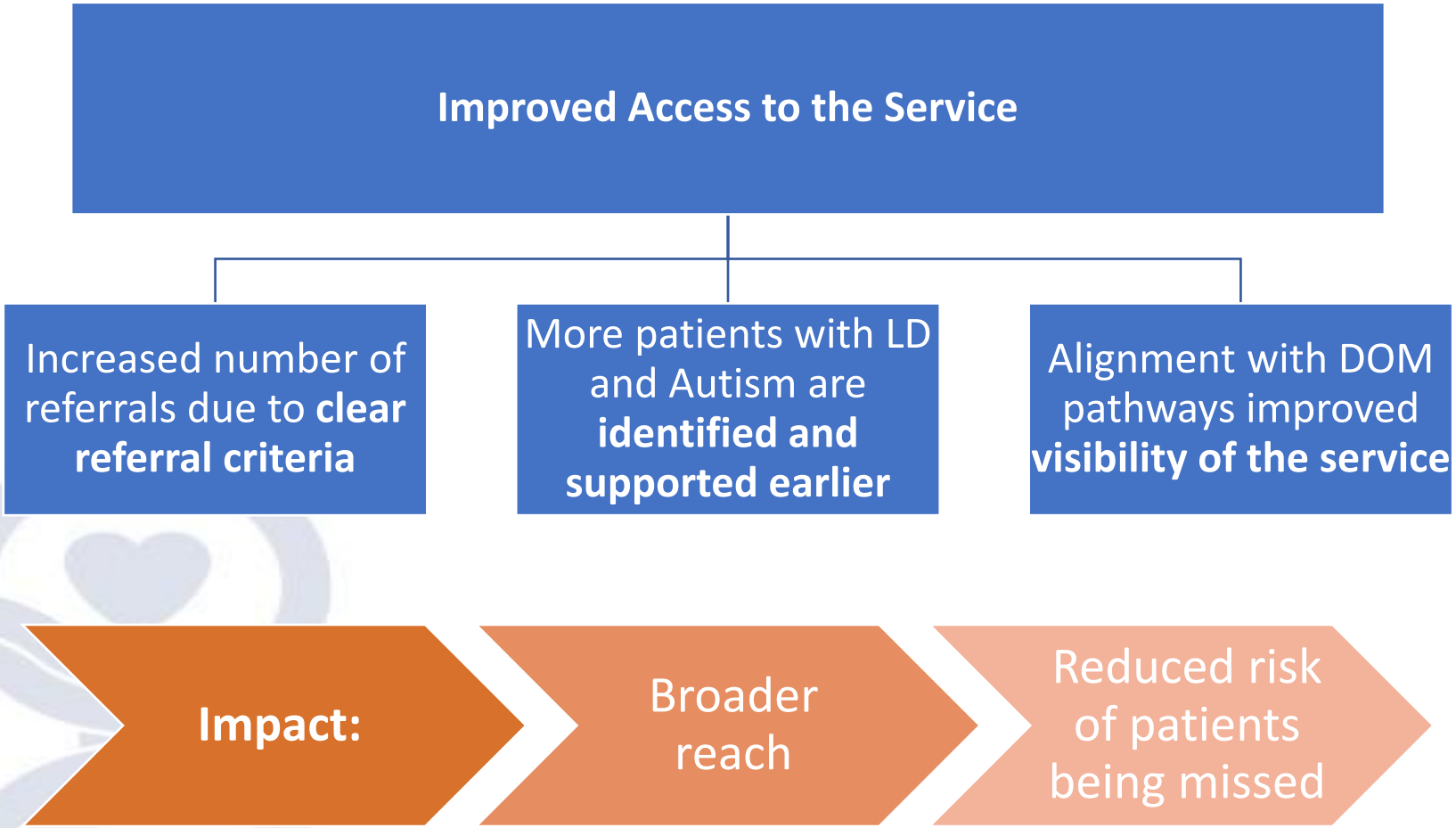
Strengthen **clinical escalation pathways linked to MDT working**

Enable **closer, day-to-day working with frontline clinical teams**

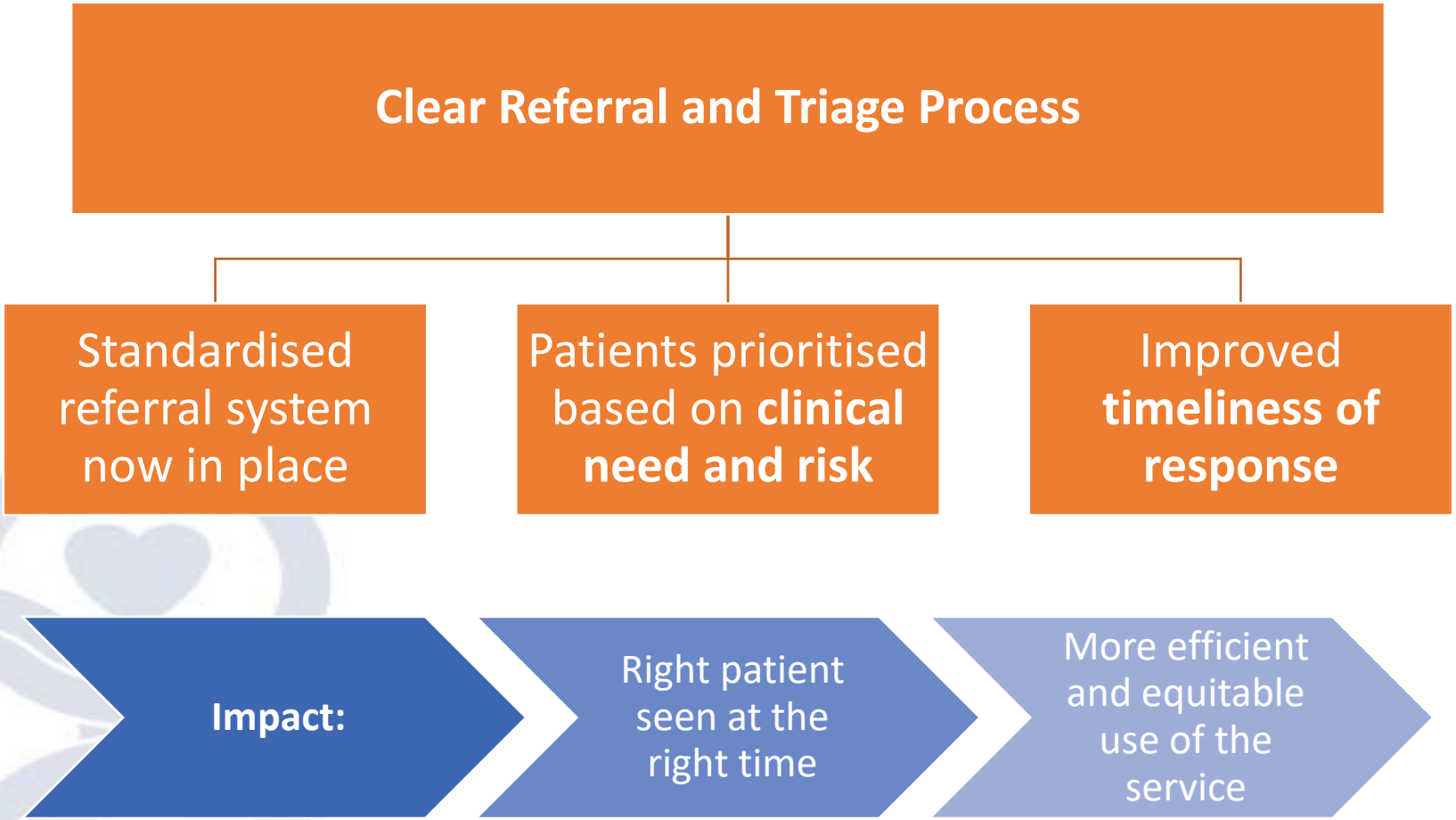
What changes did we implement?

- **Moved from Corporate into Division of Medicine (DOM)**
- **Introduced a formal referral and triage process**
- **Established clear escalation pathways**
- **Embedded multidisciplinary working**
- **Shifted to pathway-based working across care settings**

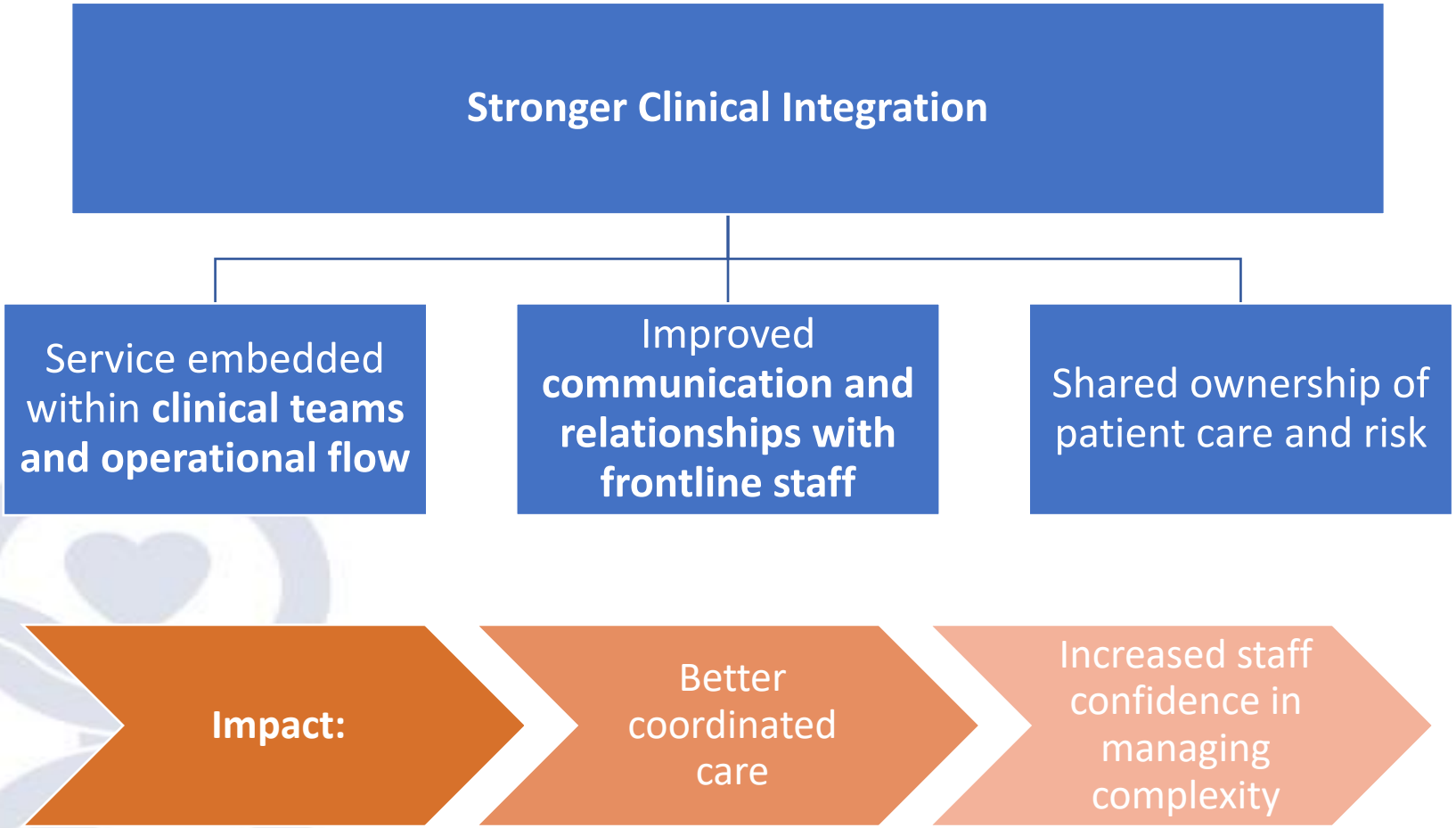
Improvement 1: Improved Access



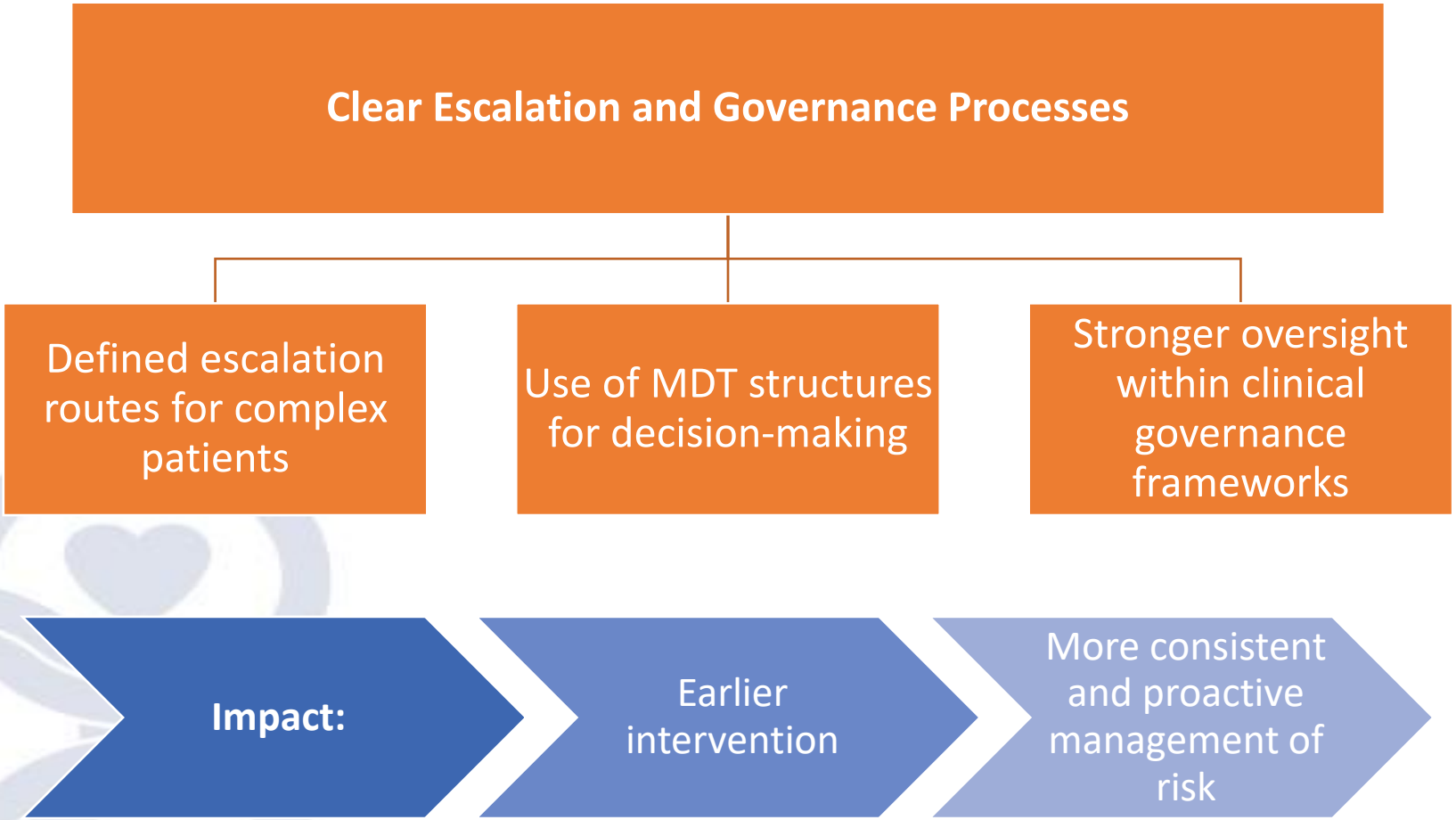
Improvement 2: Referral & Triage



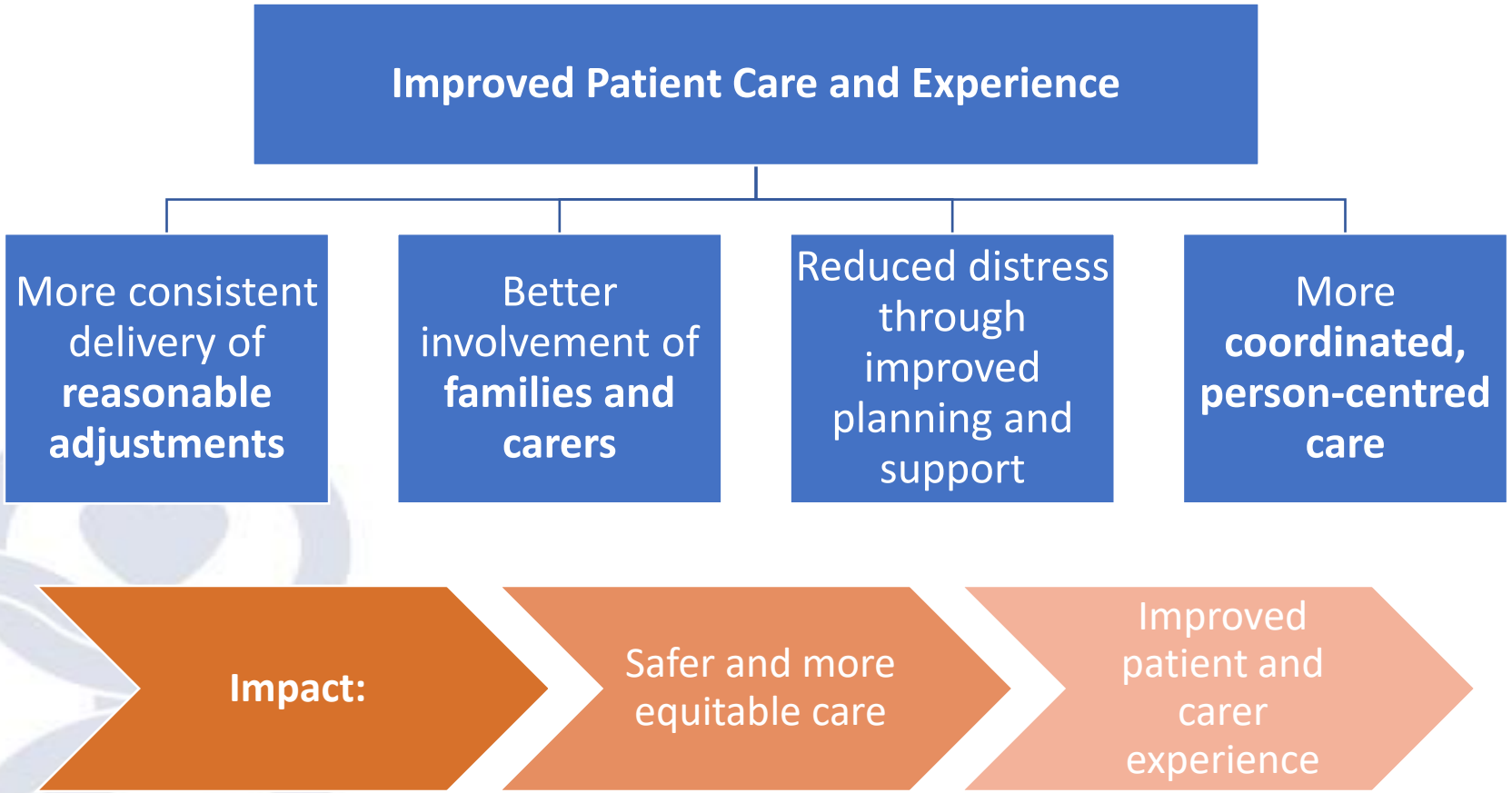
Improvement 3: Clinical Integration



Improvement 4: Escalation & Governance



Improvement 5: Patient Care & Experience



Key Learning

- Embedding services within **clinical divisions is critical**
- Operational clarity enables **consistency and equity**
- Referral and triage systems improve **access and prioritisation**
- Close working with clinical teams improves **outcomes and safety**

Closing Message

Integration, structure and clinical partnership are key to delivering equitable care for people with Learning Disability and Autism.

Thank You and Questions

If there are any further follow up questions or networking opportunities, please contact:

Richard Bunn, Complex Needs Team Head of Service.

Email: richard.bunn1@nhs.net

NHS England Learning Disabilities Improvement Standards Shared Learning Presentation

A focus on Patient Participation and Engagement

Dara Shortall – BSc RNLD, MSc
Advanced Clinical Practice

Group Lead for Learning Disabilities Services – St Georges, Epsom & St Helier Hospitals Health Group (GESH)

Limitations of Traditional Approaches to Patient Participation and Engagement

Often involves a small, regular group of patients, parents and carers, limiting the diversity of perspectives.

Feedback can become repetitive and may not always reflect the wider experiences and priorities of people with learning disabilities.

Can be less accessible for many people with learning disabilities, as well as their families and carers, limiting opportunities for meaningful involvement.

New Approaches to Patient Participation and Engagement

Reaches a broader range of individuals with learning disabilities, including those with severe and profound learning disabilities.

Increased engagement with people who may not otherwise attend patient participation and engagement groups.

Creates opportunities for informal conversations that encourage honest feedback and shared learning.

Access to established networks representing a wider demographic and geographical area.

Broader representation across health, social care, voluntary and independent sector organisations.

Parent and Carer forums

1

2

Tea and Cake Sessions

Day services workshops

3

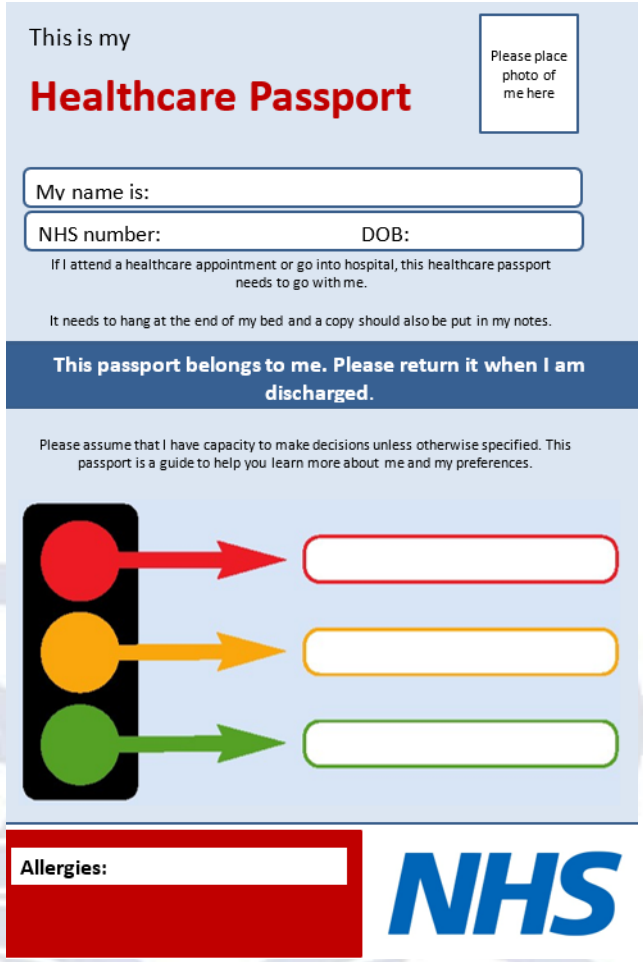
4

Hospital Patient Participation and Engagement Sessions

Peer Reviews of our Services

5

From Engagement to Co-production – Co-producing the Hospital Passport


This is my

Healthcare Passport

Please place photo of me here

My name is:

NHS number: DOB:

If I attend a healthcare appointment or go into hospital, this healthcare passport needs to go with me.

It needs to hang at the end of my bed and a copy should also be put in my notes.

This passport belongs to me. Please return it when I am discharged.

Please assume that I have capacity to make decisions unless otherwise specified. This passport is a guide to help you learn more about me and my preferences.

Allergies:

NHS

Sutton Mencap

Sutton Mencap film club

NHS South West London

Sutton Health & Care

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From Engagement to Co-Production – Independent Voices Driving Improvement

Road show report

Speak up Sutton and Action Voices are self advocacy groups. We do roadshows so we can **include more people** and help them to to speak up.

From October to December 2024, we spoke to **47 people.** They were from:

- **Mencap Metime** in Cheam
- **Sutton Mencap** tea and cake group
- **Orchard Hill College**
- **Burgess Road, Orchard House and Fairview supported living homes**

We asked everyone about their **experience of hospital.** We took questions from Dr Bob Calverley and Dara Shortall, the Learning Disability nurse.

At Mencap Metime and with supported living residents, we also asked people about **activities at home.**

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Make staff more aware to talk to the actual patient instead of those supporting them like carers

I found it difficult to communicate with them, I felt like they could not understand me

The nurses were very approachable and caring but they could have explained things more.

From Engagement to Co-production – Community Partnerships in Action

Pictured is Nickel Support hosting a stand on Learning Disability Awareness Week at St Heliers Hospital, selling their jams, chutneys and home accessories that are made in their day services, where individuals with learning disabilities sell at their 'interestingly different' shop and independent cafes locally.

Positive outcomes from Patient Participation and Engagement

Priority triage and assessment for patients with Learning Disabilities in A&E

Introduction of mandatory Learning Disabilities specific fields in Emergency Departments initial triage and assessments form

Introduction of a group-wide Learning Disabilities Steering Group meeting

Shared experiences from parents, carers and individuals with learning disabilities at the recent local annual learning disabilities conference

Shared experiences of individuals with learning disabilities at Learning Disabilities Champions networks

Development of Learning Disabilities peer reviews

Special Guest...

Thank you

Questions

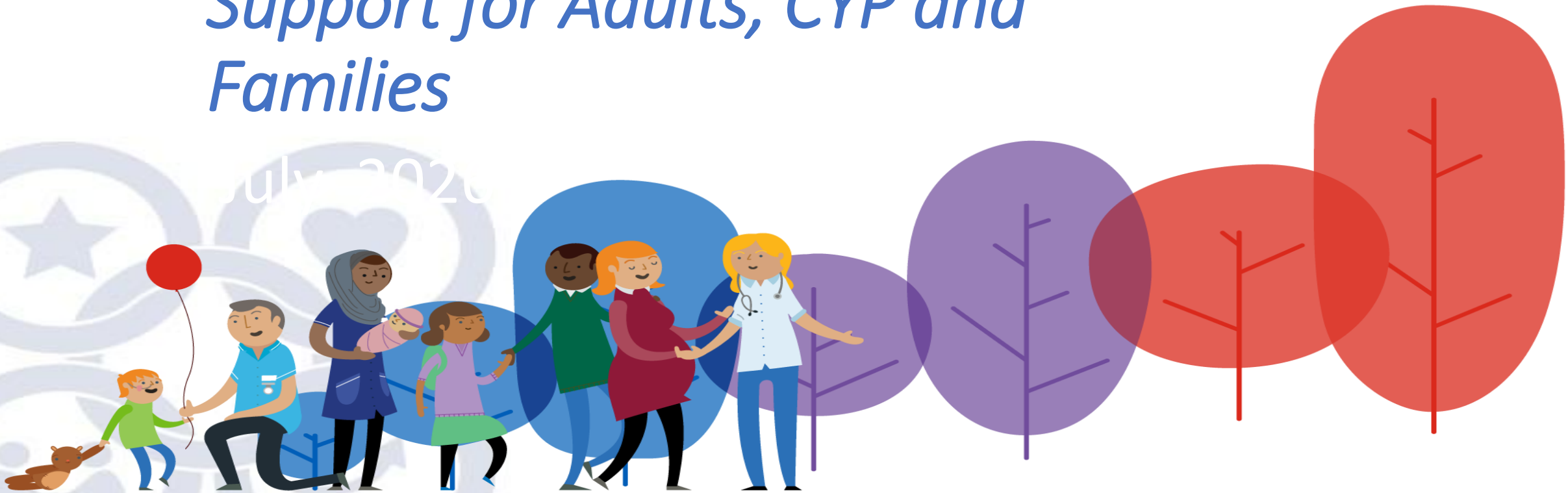
Dara Shortall – Group Lead for Learning Disabilities Services

St Georges, Epsom and St Helier University Hospitals and Health Group

Email: d.shortall@nhs.net

Listening, Learning, Improving: *How Incremental Changes Have Enhanced Care and Support for Adults, CYP and Families*

July 2020



Aim of the Quality Improvement Project

- Improve experiences and outcomes for CYP and families
- Improve access to specialist support
- Personalised reasonable adjustments
- Strengthen MDT working
- Improve transition to adult services

Changes Implemented

- Workforce expanded: Band 8a Lead, Band 7 CNS, Band 6 LDLN, Clinical Educator, Mencap Play Therapist & Facilitator
- Electronic Patient Record (May 2025)
- Shared documentation
- Reasonable adjustment flags
- Hospital Passports
- Oliver McGowan Training rollout
- Improved staff awareness and referrals

Impact on Practice

- Earlier and increased referrals
- Better triage and planned admissions
- Weekly MDT participation
- Complex discharge support
- Families feel heard and supported

Top Five Improvements

- Expanded specialist workforce
- Electronic Patient Record
- Embedded Oliver McGowan Training
- Improved patient and family experience
- Stronger transition to adult services

Looking Ahead

- Autism Accreditation Inclusion Award
- Embed training into practice
- Co-production with families
- Annual Health Checks from age 14+
- Partnership with NHS England, BCHC, UHB and ICB

Thank You

- Listening. Learning. Improving.
- Questions?

Learning Disability Improvement Standards

Next Steps

Alex Parry-Jones

Next Steps

- Reporting
  - Data and Improvement Tool is live
  - National report
  - Bespoke reports – Mid July
- Good practice compendium
- Patient focus group feedback report and resources available on LDIS portal
- Year 8 feedback survey
- NHSBN LDSS project launching September

Learning Disability Improvement Standards

Data & Improvement Tool Demonstration

Giovanny Zapata
Delivery Coordinator, NHSBN

Learning Disability Improvement Standards

Thank you for attending!

Contact us: nhsbn.nhsildsupport@nhs.net