Performance against the learning disability improvement standards

Findings from the national benchmarking exercise 2019

March 2021

NHS England and NHS Improvement

Contents

Appendices

1. Introduction

There are over 1.2 million people in England with a learning disability and 200,000 autistic people who should be able to expect high quality, personalised and safe care when they use the NHS. Unfortunately, some of these people will receive poorer care and support than the general population. *The NHS Long Term Plan* has pledged to improve services for people with a learning disability, autism or both and reduce inequalities in care and outcomes for this cohort.

The national learning disability improvement standards for NHS Trusts apply to all services funded by the NHS with an aim to promote greater consistency and to ensure Trusts deliver the outcomes that people with a learning disability and/or autism expect and deserve. These were designed by people with a learning disability, autism or both, carers, family members and healthcare professionals to drive rapid improvement of patient experience and equity of care.

There are four standards that Trust performance is measured against. The first three "universal standards" apply to all Trusts, and the fourth "specialist standard" applies specifically to Trusts that provide services that have been commissioned exclusively for patients with a learning disability and/or autism.

The four standards are:

1. Respecting and protecting rights
2. Inclusion and engagement
3. Workforce
4. Specialist learning disability services

The four improvement standards provide Trusts with a benchmark to sustainably improve their services and avoid unwarranted variation in care. Trusts are expected to publish their performance against these improvement standards in their annual quality accounts and demonstrate a sustainable improvement in their quality of service. Each of the four standards has its own respective set of improvement measures.

This report details the findings from the second NHS England and NHS Improvement learning disabilities improvement standards collection. The three-pronged approach of organisational, staff and patient collections provides a holistic view of the workforce, activity, service models and quality of services provided to people with learning disabilities and/or autism.

The data in this report builds on last year's collection and allows the progress of each participant to be measured as well as enabling Trusts to measure their performance with that of their peers.

2. Project process

2019/20 is the second cycle of the learning disability improvement standards project. The collection gathered information on new metrics introduced for the first time this year as well as tracking progress on existing metrics collected in the previous year.

Three levels of data collection were undertaken in the form of: an organisational level collection, a staff survey and a service user survey. For the purposes of this second annual survey, a number of data items and aspects of survey methodology were enhanced, in keeping with feedback elicited by NHS England and NHS Improvement, during a series of "review and refresh" engagement events held in March 2019. These were held with people with a learning disability, their families and healthcare practitioners and managers. The organisational level data collection was further scoped with the NHS Benchmarking Network's Mental Health Reference Group and incorporated a supplementary question set on restrictive interventions, in response to ongoing national concerns regarding such practices. The organisational level questions and staff survey were hosted through an online portal. The service user survey was collected in paper-format in keeping with service user and participant feedback, and a corresponding online questionnaire was made available to allow service users who did not receive a paper survey the opportunity to provide feedback on their experience.

The data collection period was from 18th November 2019 to 17th January 2020. The data collected covered a number of different time points, referencing 2018/19 activity data for Trusts, as well as latest status reports on systems and processes, and current staff and patient perspectives gathered during the November to January data collection period. This year's organisational level collection included a supplementary section which was completed by Trusts providing specialist services specifically for patients with a learning disability. This focussed on the use of restrictive interventions with this cohort, in response to emerging national concerns. The project ran concurrently with the NHS Benchmarking Network's core learning disabilities project that has collected data on specialist learning disabilities services for the past five years.

If you have any questions about this report or would like to be involved in shaping the data collection, please contact Alexander Ng (a.ng1@nhs.net) or Stephen Watkins (s.watkins@nhs.net).

Data collection

Trusts had a three-month data collection window during which to collect and report data for the organisational level survey. Participants could assign multiple staff members to input data through the NHS Benchmarking Network's data collection portal. Participants were also provided with an Excel spreadsheet of the data metrics required for reference purposes.

Trusts were provided with information governance guidance to assist with the identification of patients and staff to complete their respective surveys. Participants were asked to identify up to 50 members of staff who had provided care for patients with a learning disability or autism, and up to 100 service users.

Staff surveys were completed online, with each Trust given a unique URL link that allowed 50 staff members to submit answers anonymously. Service user surveys were collected through a multiple choice paper survey and sent anonymously to a third party provider (Restore Digital) in a freepost envelope.[1]

Data validation, analysis and reporting

The project team analysed and validated the data from the collection and provided participants with a draft interactive toolkit for validation purposes. Where potential discrepancies were flagged, participants were contacted and given an opportunity to review their submission.

---

[1] An experimental online survey replicating the paper-based version was developed and trialled. This attracted very low rates of uptake, with just 70 online surveys being completed; these have consequently been discounted in the current analysis.

Participation

211 organisations from across England participated in the project. Organisations were categorised either as a Specialist Learning Disabilities Provider, where the Trust provides services specifically for patients with a learning disability, or a Universal Provider, where the Trust provides services which may be accessed by patients with a learning disability, for example an outpatients department or Accident and Emergency.

Organisation type	Number
Specialist LD service provider	52
Universal provider	159
Of these:	
Acute	*137*
Community	*10*
Mental health	*7*
Ambulance	*2*
Community Interest Company	*3*

Of the total 211 organisations who participated in the audit:

- **208** completed the organisational-level data collection
  - *An increase of **17** from 2018*
- **205** surveyed their staff, returning **6,132** completed surveys
  - *An increase of **3,964** staff surveys from 2018*
- **190** surveyed their service users, returning **3,819** completed surveys.
  - *An increase of **3,184** service user surveys from 2018*

We thank everyone who provided data for this collection and helped validate their positions in the draft findings. We look forward to working with participants in the next cycle of data collection in 2020.

3. Findings

The three-pronged approach of organisational level, staff level and service user level data collection allows for a comprehensive analysis of how Trusts perform against the national learning disability improvement standards.

Many Trusts reported compliance with the standards and have the correct structures and processes in place to provide high levels of service quality to patients with learning disabilities and/or autism. However, there is still evidence of unwarranted variation across England. The analysis confirms that even the better performing organisations have areas which can be improved when measured against the improvement standards. The most frequently occurring opportunity areas include: Trusts' ability to identify service users with a learning disability and/or autism in order to provide reasonable adjustments to their care, ensuring individuals with a learning disability and/or autism are receiving care as close as possible to their homes/communities and ensuring individuals with a learning disability and/or autism receive the same quality of service as that delivered to other members of society.

The data from Trusts providing universal services showed that an average of 0.3% of people on patient records systems were recorded as having a learning disability. This is slightly less than the data from primary care, where 0.5% of the population are registered as having a learning disability. Without effective electronic flagging to render people visible within systems, Trusts may struggle to provide reasonable adjustments. 77% of staff in Trusts providing universal services felt confident that they could identify the reasonable adjustments that people needed, although around a fifth felt they lacked the resources to meet people's communication needs.

Over half (55%) of Trusts providing specialist learning disability services routinely monitor waiting times for people with a learning disability and/or autism. 38% have policies to maintain frequent contact with people with a learning disability and/or autism to see if their situation is becoming more urgent. 92% of staff in Trusts providing specialist learning disability services agreed they routinely involved children and young people with a learning disability and/or autism when making decisions about their care and treatment. However, when the question was asked of service users, only 77% agreed they were given a choice about how they were cared for.

The headline good performance indicators and areas of improvement have been split across the four improvement standards to evaluate the national picture of services delivered to patients with a learning disability and/or autism. This is the second year the data collection has been conducted and allows certain metrics to be tracked to see the changes that have taken place in the past 12 months.

3.1. Standard 1: Respecting and protecting rights

All Trusts must ensure that they meet their Equality Act duties to people with learning disabilities, autism or both, and that the wider human rights of these people are respected and protected, as required by the Human Rights Act.

To perform well against Standard 1, Trusts must be able to demonstrate that reasonable adjustments to their pathways of care have been made for individuals with a learning disability, autism or both. Additionally, Trusts must have robust mechanisms to identify and flag patients with a learning disability, autism or both, vigilantly monitor restrictions or deprivations of liberty and promote anti-discriminatory practice in relation to people with learning disability, autism or both.

Table 1: Summary of performance against Standard 1

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must demonstrate they have made reasonable adjustments to care pathways to ensure people with learning disabilities, autism or both can access highly personalised care and achieve equality of outcomes.	**79%** of staff agreed they were able to identify what reasonable adjustments were needed for people with learning disabilities and/or autism. **88%** of service users felt safe when they received care from the Trust. **84%** of service users felt that staff listened to them. (74% in 2018).	**68%** of Trusts providing universal services and **62%** of those providing specialist services did not intermittently contact people with a learning disability and/or autism on waiting lists to see if their situation is becoming more urgent. Only **58%** of staff feel that they have the necessary resources to meet the needs of people with learning disabilities and/or autism. **11%** of service users in Trusts providing universal services did not have things explained to them in a way they could understand (16% in 2018).

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must have mechanisms to identify and flag patients with learning disabilities, autism or both from the point of admission through to discharge; and where appropriate, share this information as people move through departments and between services.	**82%** of Trusts could flag a patient with a learning disability on their EPR (79% in 2018). **71%** of staff surveyed, noted that a learning disability would be documented electronically.	**70%** of Trusts providing universal services are unable to recognise if someone on a waiting list has a learning disability (75% in 2018). On average, Trusts providing universal services identified **0.3%** of people with an electronic patient record as having a learning disability. This remains lower than the mean of 0.47% registered as having a learning disability in primary care.[2]
Trusts must have processes to investigate the death of a person with learning disabilities, autism or both while using their services, and to learn lessons from the findings of these investigations.	**83%** of Trusts ensure staff who are trained to be LeDeR reviewers are actively released to undertake these reviews. (86% in 2018).	**60%** of Trusts meet the commitment to ensure staff trained to deliver LeDeR reviews undertake a minimum of 2-3 reviews per year. (71% in 2018). **45%** of staff in Trusts providing universal services and **62%** in Trusts providing specialist services agree that when a person with learning disabilities and/or autism dies, the findings and outcomes from the Trust investigation are shared with staff members.
Trusts must demonstrate that they vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment to people with learning disabilities, autism or both.	**58%** of Trusts undertook an audit of restrictive practices in the last 12 months. **86%** of Trusts have a policy on the use of force to hold/restrain people with learning disability and/or autism who lack the capacity to consent.	**17%** of Trusts providing universal services and **19%** of Trusts providing specialist services do not regularly audit the restrictions and/or deprivations of liberty it places on people with learning disability and/or autism. (18% Universal, 25% specialist in 2018).

[2] NHS Digital (2020) *Health and care of people with learning disabilities, experimental statistics: 2018 to 2019* https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must have measures to promote anti-discriminatory practice in relation to people with learning disabilities, autism or both.	**93%** of service users who received care felt they were treated with respect by staff. (94% in 2018). **83%** of service users said they would recommend their service to a friend of family.	**34%** of Trusts routinely monitor waiting times for people with learning disabilities and/or autism and report concerns to the board regarding waiting times and number of people waiting (26% in 2018). Whilst **56%** of Trusts providing specialist services monitor waiting times of people with a learning disability and/or autism, only **26%** of Trusts providing universal services do. **24%** of Trusts monitor/compare emergency readmission rates of people with learning disabilities with those for people without learning disabilities. **74%** of staff believe that people with a learning disability and/or autism receive the same quality of care as any other person. (74% in 2018)

3.2. Standard 2: Inclusion and engagement

Every Trust must ensure all people with learning disabilities, autism or both, and their families and carers, are empowered to be partners in the care they receive.

Standard 2 requires Trusts to demonstrate their services are co-designed by people with learning disabilities and/or autism and to ensure they feel empowered to exercise their rights. Trusts must also ensure their services are "values-led" in staff training and complaints handling using initiatives such as "*Ask Listen Do*".

Table 2: Summary of performance against Standard 2

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must demonstrate processes that ensure they work and engage with people receiving care, their families and carers, as set out in the NHS Constitution.	**92%** of Trusts providing specialist services produce accessible appointment letters (80% in 2018). However, only **88%** of service users in Trusts providing specialist services said they were told about their appointments/meetings in a way they could understand. **92%** of staff in Trusts providing specialist services agreed they routinely involve children and young people with a learning disability, autism or both when making decisions about their care and treatment	**30%** of Trusts have a dedicated post on their council of governors or board sub-committee for people with a learning disability or their family carer (26% in 2018). **48%** of Trusts providing universal services produce accessible appointment letters (50% in 2018). Only **77%** of service users agree they were given a choice about how they were cared for in trusts providing specialist learning disability services. **46%** of Trusts said people with a learning disability who have multiple long term conditions are assigned an identified coordinator/key worker from the Trust (or from another NHS provider on the basis of a service level agreement).

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must demonstrate that their services are 'values-led'; for example, in service design/improvement, handling of complaints, investigations, training and development, and recruitment.	72% of Trusts note the requirements of "*Ask Listen Do"* and make reasonable adjustments to their complaints process to avoid people with learning disabilities and/or autism from having excessive amounts of form filling	38% of staff in Trusts providing specialist services agreed that people with learning disabilities and/or autism were routinely involved in the planning of Trust services (40% in 2018). 30% of service users who made a complaint were given Easy Read information about how to make a complaint.
Trusts must demonstrate that they codesign relevant services with people with learning disabilities, autism or both and their families and carers.	98% of Trusts providing universal services have on-site facilities to accommodate family carers overnight.	53% of Trusts providing universal services and 40% Trusts providing specialist services have changing places toilet facilities.[3] (45% universal, 36% specialist in 2018)
Trusts must demonstrate that they learn from complaints, investigations and mortality reviews, and that they engage with and involve people, families and carers throughout these processes		43% of Trusts are using "*Ask Listen Do"* good practice resources[4] to improve services after receiving feedback, concerns and complaints for people with a learning disability and/or autism.

[3]http://www.changing-places.org/
[4]https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must be able to demonstrate they empower people with learning disabilities, autism or both and their families and carers to exercise their rights.	**84%** of staff surveyed agreed that people with learning disabilities and/or autism were routinely involved when making decisions about their care and treatment. **81%** of service users said staff listened to what their family thought.	**42%** of Trusts agree they have members of the executive team that regularly meet with, and take advice from people with learning disability/autism, family carers and front line support workers that care for them. **71%** of staff knew their Trust had policies and procedures to ensure the rights of autistic people are respected and protected.

3.3. Standard 3: Workforce

All Trusts must have the skills and capacity to meet the needs of people with learning disabilities, autism or both by providing safe and sustainable staffing, with effective leadership at all levels.

Maintaining workforce is an important challenge for the NHS. The improvement measures highlight the benchmark required to ensure effective delivery of a range of policy ambitions. Trusts must ensure that staff are regularly trained on how to meet the unique needs of people with learning disabilities and/or autism and to have specialist learning disability advice available to staff if required. Additionally, Trusts are expected to have workforce plans to minimise impacts of potential shortages of qualified staff with specialisms in learning disabilities which may include supporting new emerging roles such as allied health professionals, nurses and advanced practitioners.

Table 3: Summary of performance against Standard 3

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Based on analysis of the needs of the local population, Trusts must ensure staff have the specialist knowledge and skills to meet the unique needs of people with learning disabilities, autism or both who access and use their services, as well as those who support them.	**96%** of Trusts have a board level lead who monitors the quality of service provided to people with a learning disability and/or autism. (93% in 2018) **83%** of Trusts agree their staff are trained to recognise their responsibilities to make, record, report and share reasonable adjustment to the delivery of care and support when working with people with learning disabilities and/or autism. (82% in 2018) **76%** of staff have access to specialist learning disability advice when they need it to help meet the needs of people with learning disabilities and/or autism. (74% in 2018)	**75%** of Trusts provide training to people who provide day to day care/support, to learn how to recognise and respond to signs of emerging health problems in people with learning disabilities and/or autism. (87% in 2018)

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Staff must be trained and then routinely updated in how to deliver care to people with learning disabilities, autism or both who use their services, in a way that takes account of their rights, unique needs and health vulnerabilities; adjustments to how services are delivered are tailored to each person's individual needs.	**83%** of Trusts say they provide staff with up-to-date training covering learning disabilities/autism awareness (79% in 2018). **82%** of Trusts agree their staff feel empowered to raise concerns about medication so that people with learning disabilities and/or autism are not over medicated (85% in 2018). Only **4%** of staff would not recommend their trust to a friend of family with a learning disability and/or autism who needed treatment.	**18%** of Trusts have an induction programme that invites people with learning disabilities and/or autism to contribute to staff training (21% in 2018). **22%** of staff in Trusts providing specialist services said they did not receive mandatory training on meeting the needs of people with learning disabilities and/or autism during the course of their work.
Trusts must have workforce plans that manage and mitigate the impact of the growing, cross-system shortage of qualified practitioners with a professional specialism in learning disabilities.	**85%** of Trusts providing specialist services have a workforce plan to support the development of new roles in learning disabilities care (80% in 2018).	**25%** of Trusts providing specialist services do not have a workforce plan that includes data on current and future issues arising from retention/recruitment difficulties in the learning disabilities workforce (29% in 2018).
Trusts must demonstrate clinical and practice leadership and consideration of the needs of people with learning disabilities, autism or both, within local strategies to ensure safe and sustainable staffing.	**67%** of Trusts actively involve people with learning disabilities and/or autism and their families in checking the quality of services being provided and developing improvement plans as a result (67% in 2018).	

3.4. Standard 4: Specialist learning disabilities services

Trusts that provide specialist learning disabilities services commissioned solely for the use of people with a learning disability, autism or both must fulfil the objectives of national policy and strategy

The fourth standard applies to Trusts that provide specialist services specifically for people with a learning disability and/or autism. These Trusts are expected to use Care and Treatment Reviews to assess individuals pre-admission to ensure their inpatient stay is as short as possible or to evaluate if their care is better delivered in the community setting. Trusts must also adhere to conducting regular reviews on psychotropic medications prescribed to people with a learning disability and/or autism in line with NHS England's Stopping The Over Medication of People with learning disabilities and/or autism (STOMP) initiative.[5]

Table 4: Summary of performance against Standard 4

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must have plans for the development of community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.	**82%** of Trusts say they provide intensive community support where staff provide crisis support (74% 2018). **86%** of staff say their Trust has developed effective and new ways to support people with learning disabilities and/or autism to live successfully in the community in recent years.	**51%** of Trusts said they provide a 7 day per week intensive community support service (59% in 2018).
Trusts use the care and treatment review (CTR) and care and education treatment review (CETR) to ensure a stringent assessment is made if admission is anticipated or requested, and that discharge arrangements ensure no individual stays longer than necessary.	**76%** of Trusts monitor target and actual discharge dates for people with learning disabilities and/or autism in hospital (76% in 2018). **75%** of Trusts said they operated a dynamic risk/support register for people with learning disabilities and/or autism in the community setting.	

[5] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts have processes to regularly review the medications prescribed to people with learning disabilities, autism or both. Specifically, prescribing of all psychotropic medication should be considered in line with NHS England's programme stopping over medication programme STOMP.	**94%** of Trusts are signed up to Stopping Over Medication of People with a learning disability and/or autism (STOMP).	**58%** of Trusts have a policy to safeguard people with learning disabilities and/or autism from the inappropriate prescribing of psychotropic medication (62% in 2018). **78%** of Trusts have signed the STOMP pledge.[6] **60%** of staff agree that people with learning disabilities and/or autism are involved in reviewing the appropriateness of psychotropic medications (74% in 2018).
Trusts providing inpatient services have clinical pathways that adhere to evidence-based assessment and treatment, time-limited interventions and measurable discharge processes to ensure inpatient episodes are as short as possible.	**96%** of Trusts agree that a member of staff is identified at the point of admission of a person with learning disability and/or autism who has concerns regarding their behaviour or mental health to work closely on discharge planning with a community based care coordinator.	
Trusts have governance processes for measuring the use of restraint and other restrictive practices, including detailed evidence-based recommendations to support the discontinuation of planned prone restraints and reduction in unwarranted variation in use of restrictive practices. They can demonstrate that alternative approaches are being deployed.	**92%** of Trusts have a restraint reduction programme/policy. **80%** of those have policies that have been reviewed in the last 12 months. **85%** of Trusts say they hold a risk assessment for every physical restraint technique taught to staff. **100%** of Trusts have a medical review following the application of a mechanical restraint.	**10%** of Trusts say they do not hold risk assessments for any physical restraint technique taught to staff. **71%** of staff agree they have received training on reducing the use of restrictive interventions.

[6] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/how-to-support-stomp/#health-care

4.1. Organisational level collection

This year's organisational level data collection collected metrics at a Trust level for the 2018/19 financial year. This is the 2nd year this data has been collected, with 208 submissions from Trusts across England. We would like to thank all contributors for their participation.

The data collection aims to give a holistic view of services provided to people with learning disabilities and/or autism, as well as to measure how Trusts perform against the four standards that NHS England and NHS Improvement expect Trusts to meet.

There have been a number of areas of focus for services provided to people with learning disabilities and/or autism over the last couple of years. These include: the ability to flag people with learning disabilities and/or autism on patient systems, demonstration of reasonable adjustments to care pathways, promotion of anti-discriminatory measures and ensuring people with learning disabilities and/or autism are empowered to exercise their rights.

The 51 organisations that were identified as a specialist learning disability provider were asked to provide data on a number of supplementary questions to explore in greater detail the initiatives set out for reduction of restrictive practices and policies aimed at stopping the over medication of people with learning disabilities and/or autism.

The data included in this bespoke report has been validated by the NHS Benchmarking Network support team together with project leads of participants. The charts show national data, alongside the number of participants that completed the metric.

Alongside this bespoke report, an online interactive toolkit is available containing all the metrics from the data collection. This can be accessed through the NHS Benchmarking Network website (https://members.nhsbenchmarking.nhs.uk/home). If you require a log in, please contact the support team at: nhsbn.nhsildsupport@nhs.net
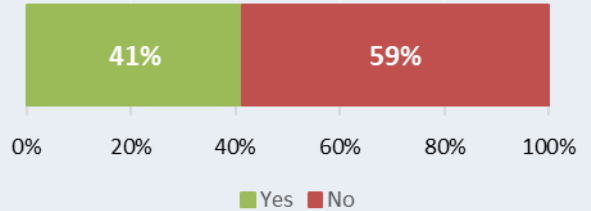
Access

Figure 1: If required, is your organisation able to isolate/disaggregate specific outcome data regarding patients with a learning disability?

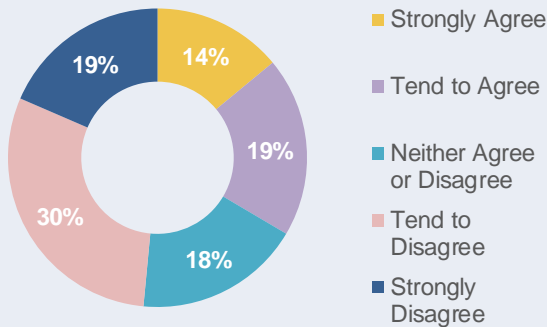| 70%	30%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
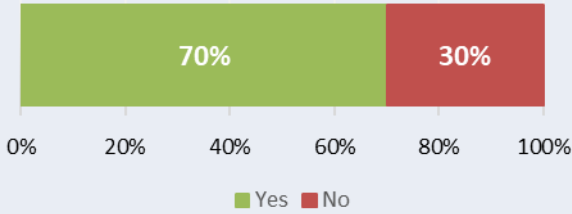
n= 204

Figure 2: Do you currently hold a list of children, young people and adults with a learning disability waiting for assessment and/or treatment?

41%	59%

0% 20% 40% 60% 80% 100%

■ Yes ■ No

n= 203

Figure 3: Our organisation routinely monitors waiting times for people with a learning disability and/or autism, and reports concerning waits to the board

14% Strongly Agree
19% Tend to Agree
18% Neither Agree or Disagree
30% Tend to Disagree
19% Strongly Disagree

n= 201

Figure 4: Our organisation has policies which require staff to intermittently contact people with a learning disability and/or autism on waiting lists to see if the situation is becoming more urgent

15% Yes
30% Partially
55% No
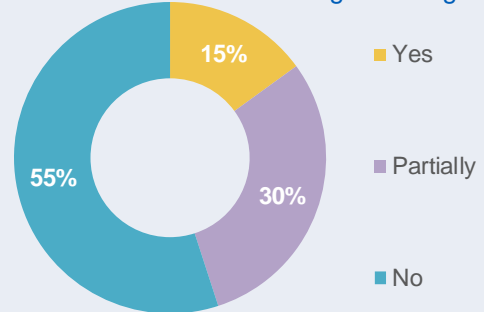
n= 200

Figure 5: Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2019

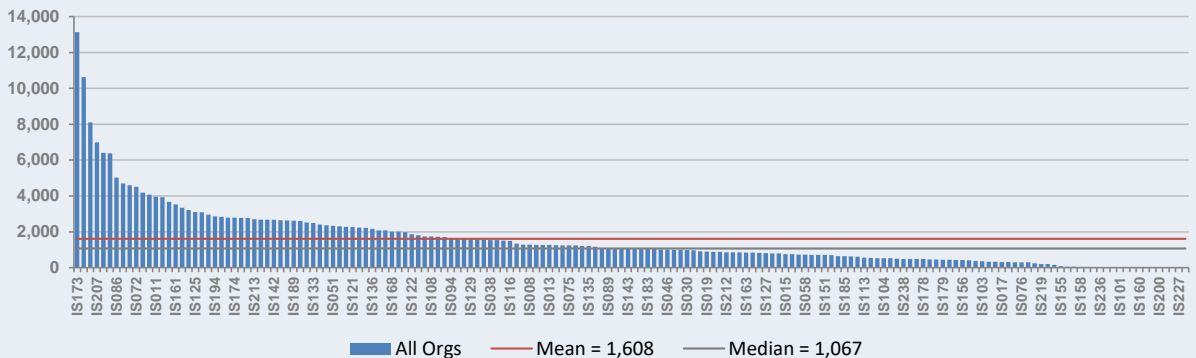■ All Orgs   — Mean = 1,608   — Median = 1,067

Figure 6: Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2019 as a % of total patients on the Trust EPR
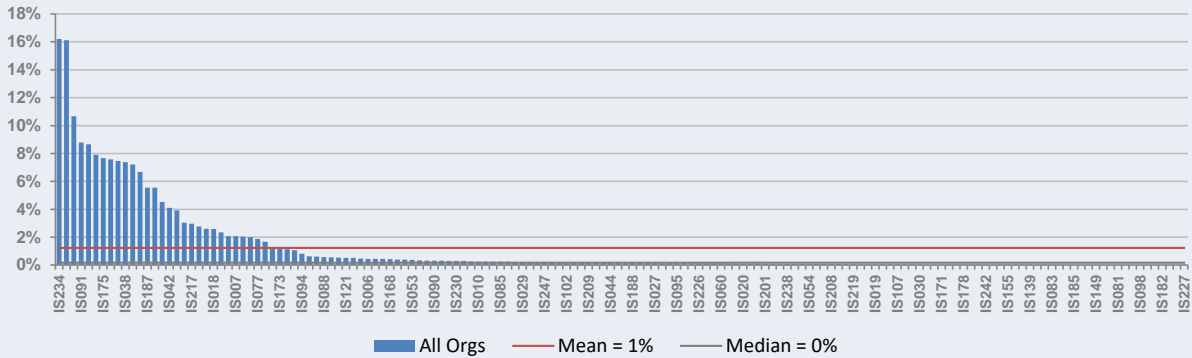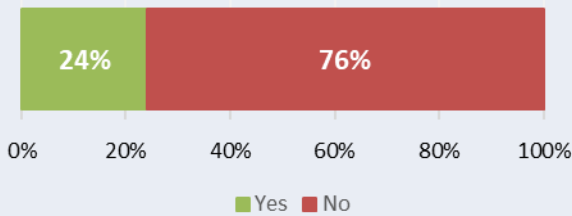

All Orgs — Mean = 1% — Median = 0%

Figure 7: Do you monitor/compare the emergency readmission rates for children, young people and adults with a learning disability, with those of people without learning disabilities?

Yes 24%   No 76%

0%   20%   40%   60%   80%   100%

n= 191

Figure 8: Hospital readmission rate for general population patients in 2018/19

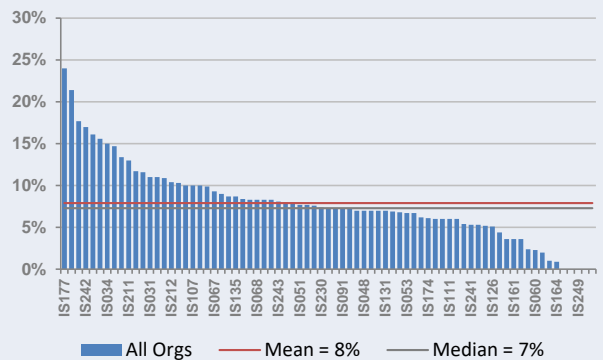All Orgs — Mean = 8% — Median = 7%

Figure 9: Hospital readmission rate for patients with a learning disability in 2018/19
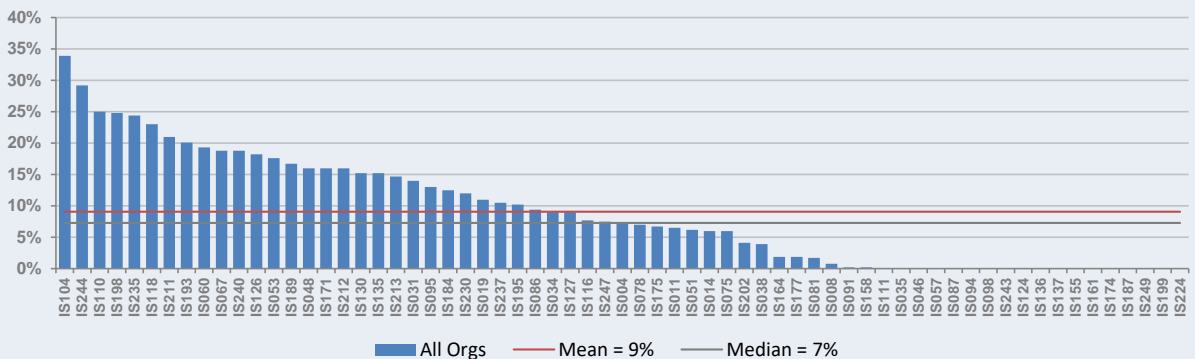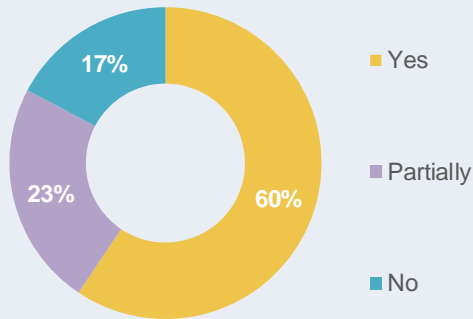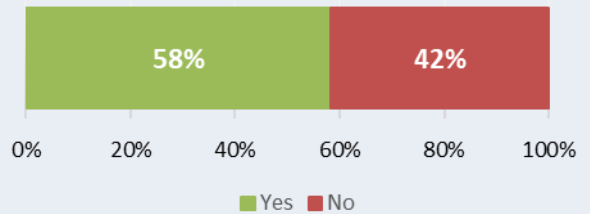

All Orgs — Mean = 9% — Median = 7%

Figure 10: Our organisation regularly audits any restrictions and/or deprivations of liberty it places on people with a learning disability and/or autism

- Yes 60%
- Partially 23%
- No 17%

n= 197

Figure 11: Have you undertaken an audit of restrictive practices in the last 12 months?

- Yes 58%
- No 42%

n= 197

Figure 12: Do you have a policy on the use of force to hold or restrain children, young people and adults with a learning disability and autistic people, who lack the competence of capacity to consent?

- Yes 86%
- No 14%
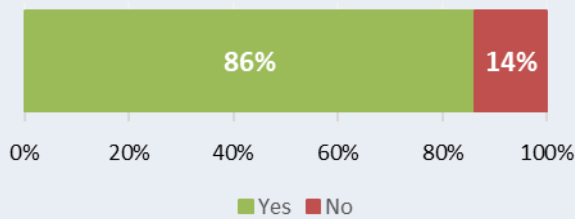
n= 202

Figure 13: If you have a policy on the use of force to hold or restrain people with learning disabilities and/or autism, is it deemed to be in their best interests in order that necessary care and treatment can be delivered?

- Yes 97%
- No 3%
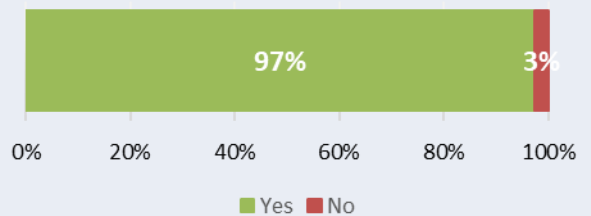
n= 177

Figure 14: Total number of patient safety incidents recorded concerning children, young people and adults with a learning disability or autistic people in 2018/19

- All Orgs
- Mean = 249
- Median = 45

Figure 15: Total number of patient safety incidents recorded for people with a learning disability and/or autism in 2018/19 per 100 children, young people and adults with a learning disability flag on the EPR

All Orgs — Mean = 21 — Median = 5
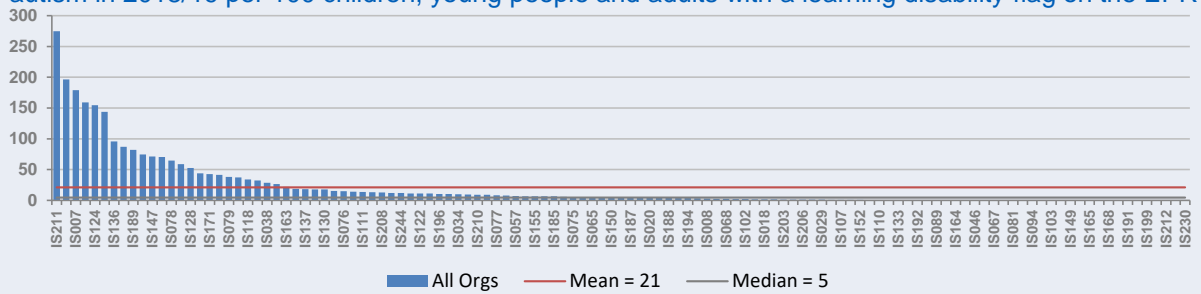
Figure 16: Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2018/19

All Orgs — Mean = 4 — Median = 1
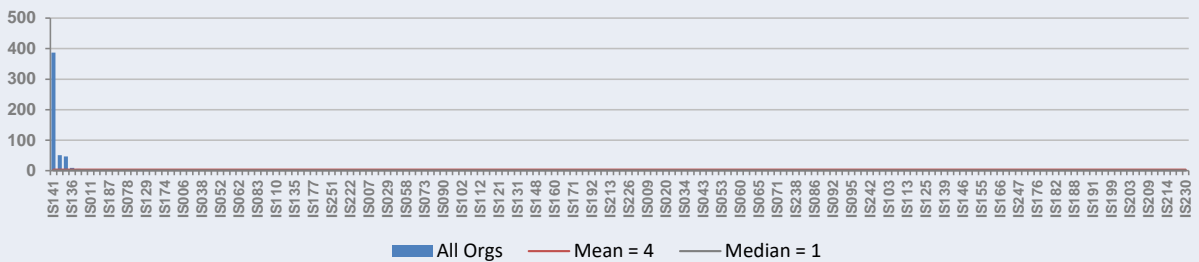
Figure 17: Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2018/19 per 100 people with a learning disability flag on the EPR

All Orgs — Mean = 0.49 — Median = 0.01
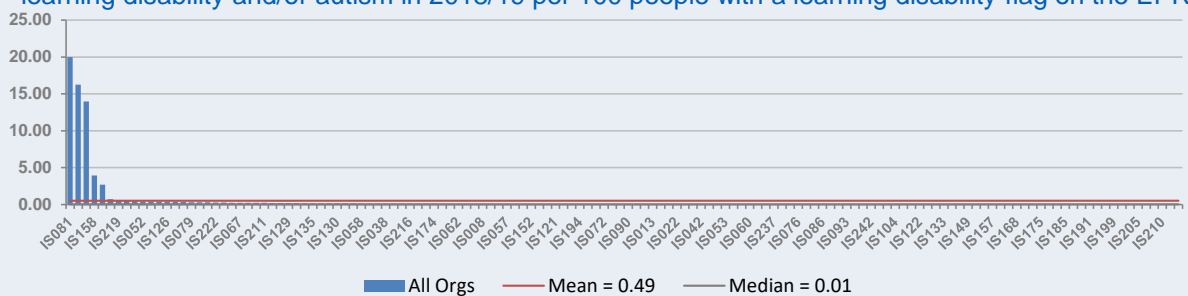
Figure 18: Total number of safeguarding referrals concerning children, young people and adults with a learning disability or autistic people in 2018/19
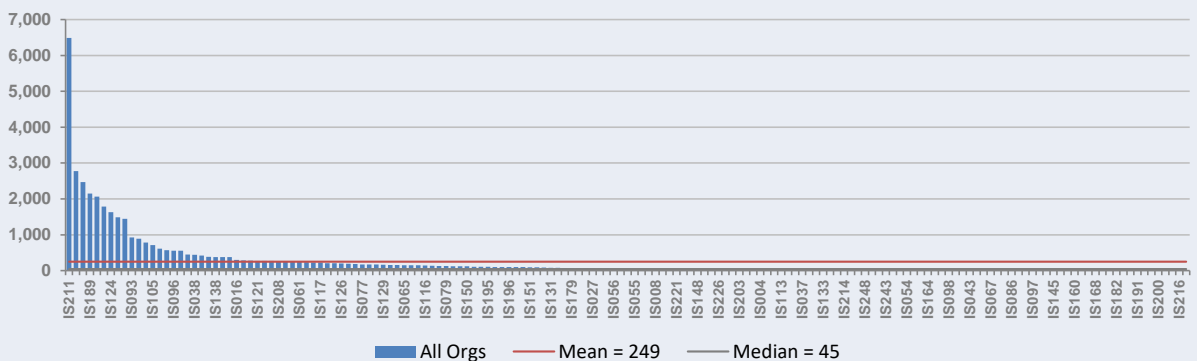
All Orgs — Mean = 27 — Median = 12
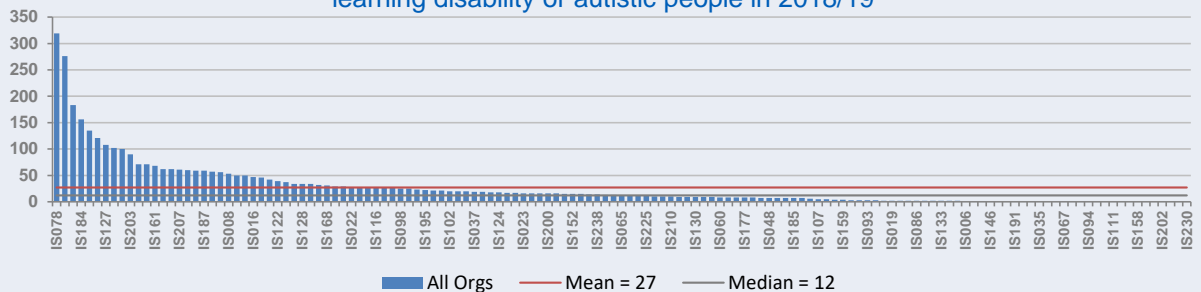
Figure 19: Total number of safeguarding referrals concerning people with a learning disability and/or autism in 2018/19 per 100 people with a learning disability flag on the EPR
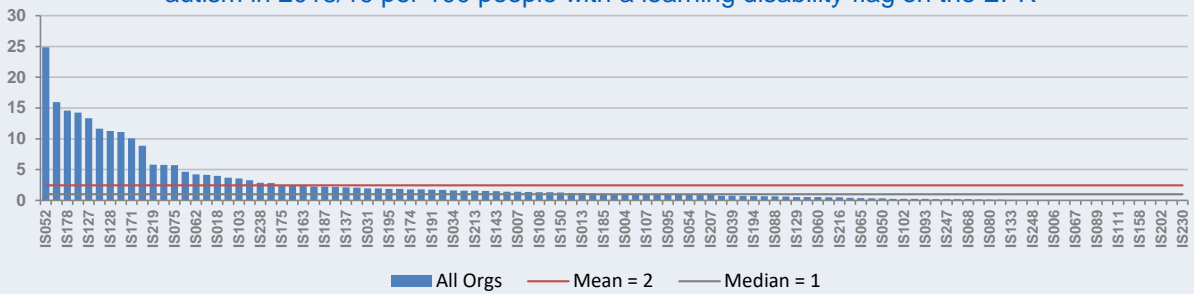
**Figure 20: Total number of safeguarding referrals regarding people with a learning disability and/or autism in 2018/19 which met the criteria for a section 42 safeguarding / care act enquiry**
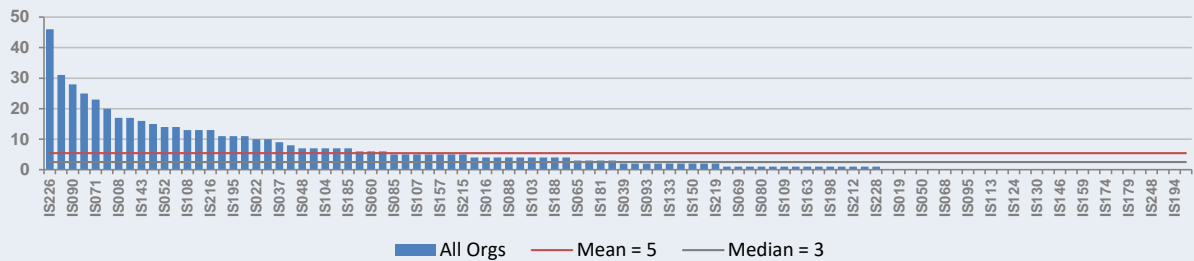
Figure 21: Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2018/19
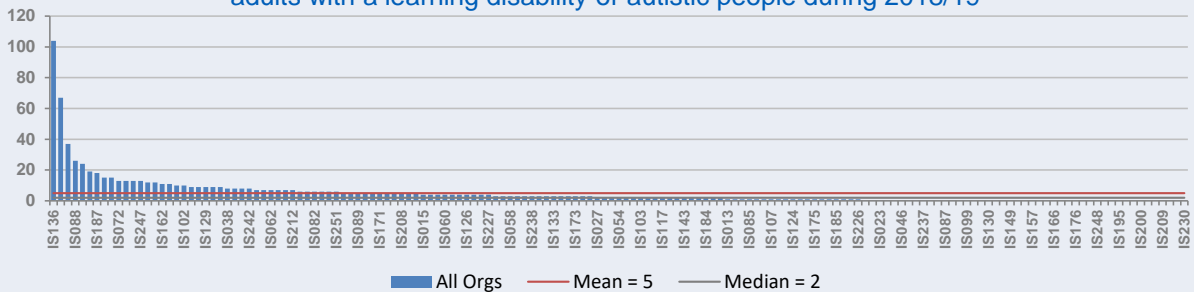
Figure 22: Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2018/19 as a % of total complaints
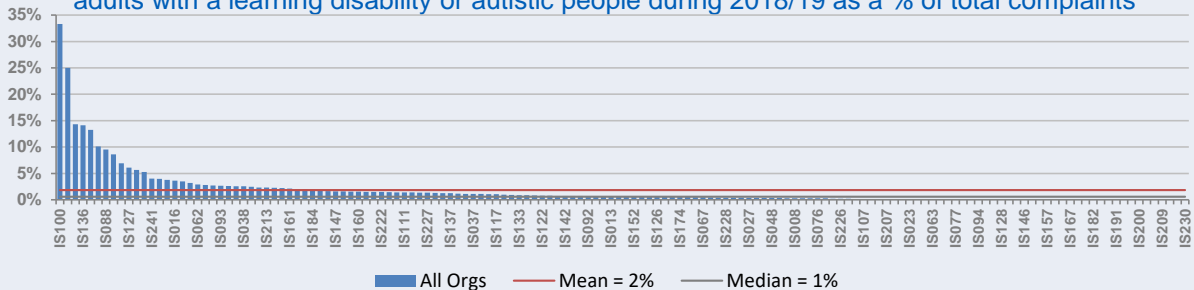
Learning Disability Mortality Review (LeDeR)

Figure 23: Total number of people with a learning disability who died whilst on an active caseload or within 3 months of the case being closed or discharged in 2018/19

Legend: All Orgs — Mean = 16 — Median = 12
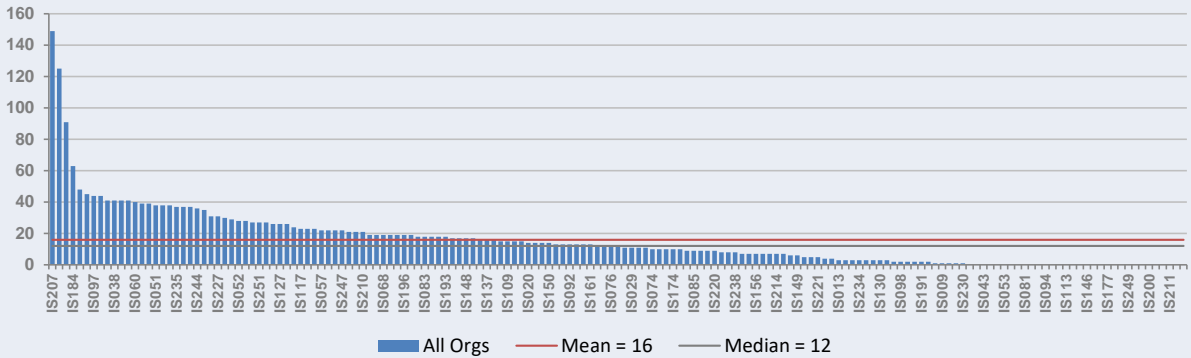
Figure 24: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of choking incidents

Legend: All Orgs — Mean = 0.1 — Median = 0.0
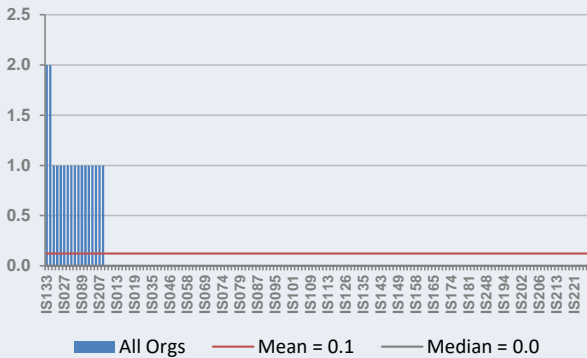
Figure 25: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of choking incidents per 100 patients with an LD flag on the EPR

Legend: All Orgs — Mean = 0.01 — Median = 0.00
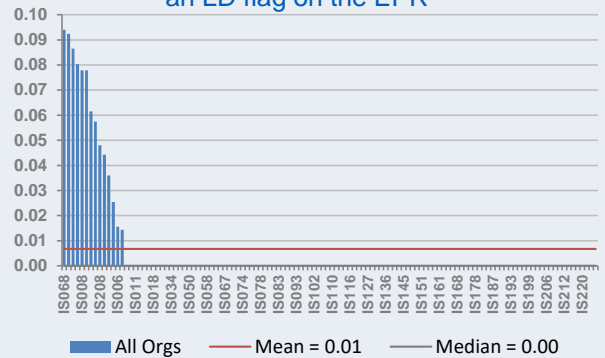
Figure 26: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of sepsis

Legend: All Orgs — Mean = 1.4 — Median = 1.0
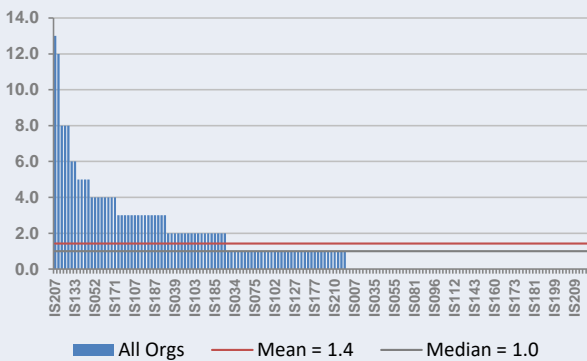
Figure 27: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of sepsis per 100 patients with an LD flag on the EPR

Legend: All Orgs — Mean = 0.14 — Median = 0.04
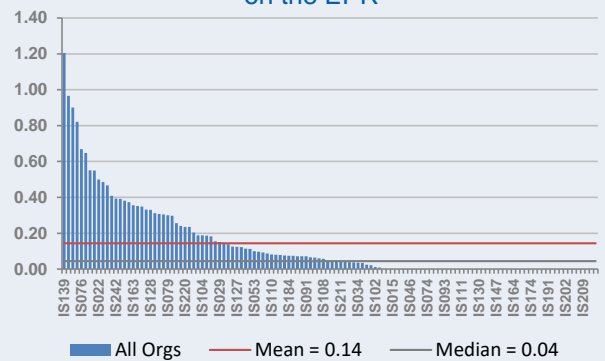
Figure 28: Total number of epilepsy related deaths of people with a learning disability that took place in 2018/19
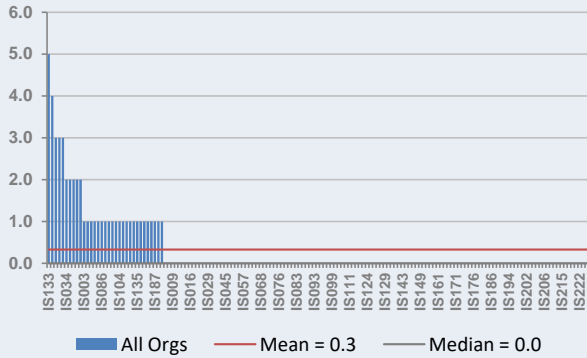
Figure 29: Total number of epilepsy related deaths of people with a learning disability that took place in 2018/19 per 100 patients with an LD flag on the EPR
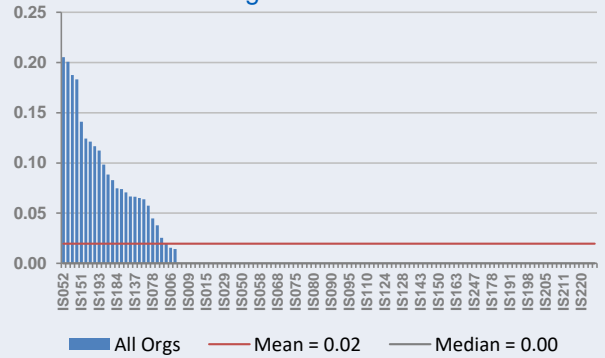
Figure 30: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of gastrointestinal obstructions
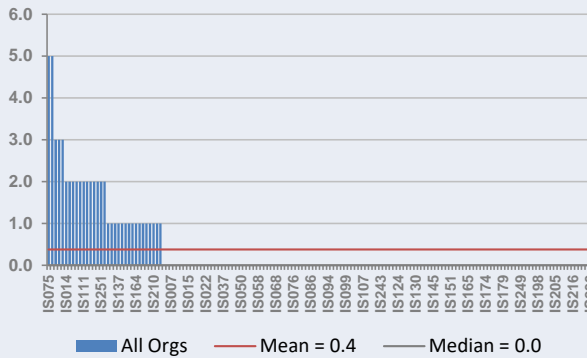
Figure 31: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of gastrointestinal obstructions per 100 patients with an LD flag on the EPR
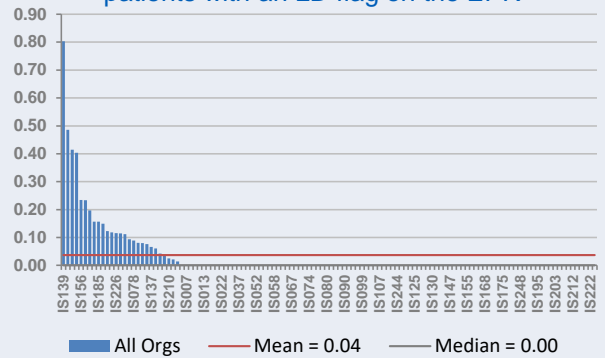
Figure 32: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of pneumonia
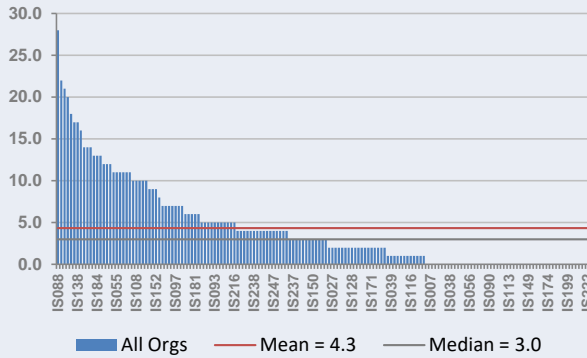
Figure 33: Total number of deaths of people with a learning disability that took place in 2018/19 as a result of pneumonia per 100 patients with an LD flag on the EPR
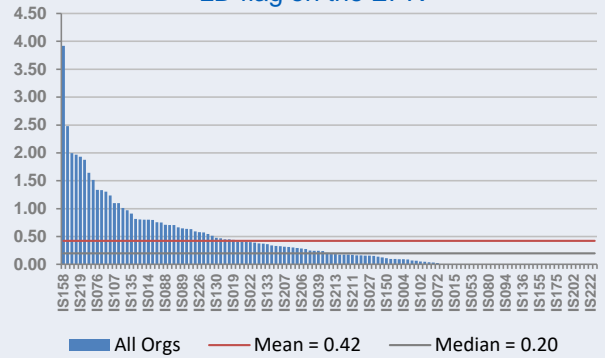
Figure 34: Does your organisation ensure that staff who have trained to be LeDeR reviewers are actively released to undertake these reviews?

83%	17%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
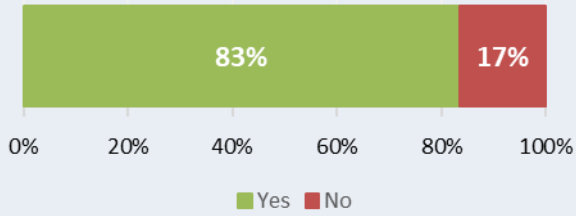
n= 187

Figure 35: Is your organisation currently meeting the commitment to ensure that staff trained to deliver LeDeR reviews undertake the minimum of 2-3 reviews per year?

61%	39%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
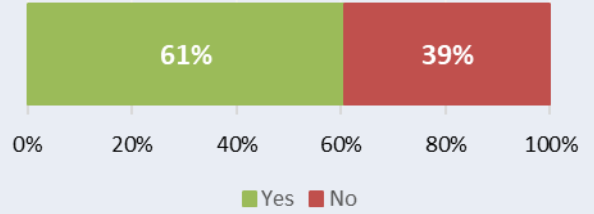
n= 185

Engagement

Figure 36: Do you have a dedicated post/position for a person(s) with a learning disability or their family carers on your Trust council of governors and/or any of your Trust Board sub-committees?

Yes	No
30%	70%
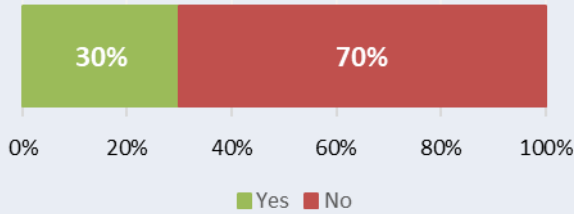
n= 201

Figure 37: Members of the executive team regularly meet with and take advice from people with a learning disability, autism, family carers and the front line workers who support them

- Strongly Agree — 11%
- Tend to Agree — 31%
- Neither Agree or Disagree — 25%
- Tend to Disagree — 23%
- Strongly Disagree — 9%
- Don't know — 1%
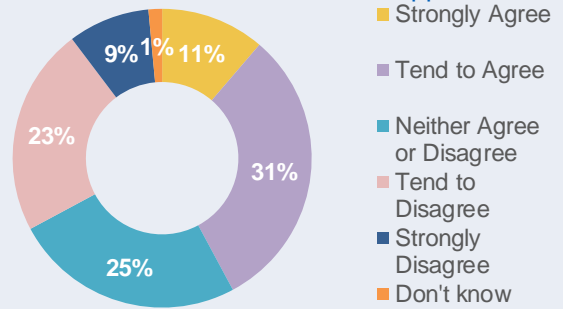
n= 204

Figure 38: Are children, young people and adults with a learning disability, who have multiple long term conditions, assigned an identified coordinator/key worker, either from your Trust, or from another NHS provider, on the basis of a service level agreement?

Yes	No
46%	54%
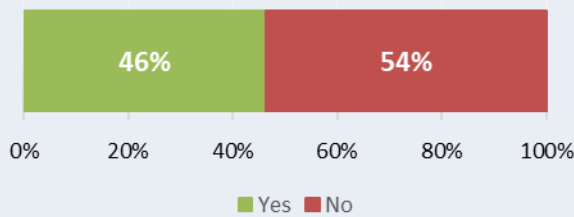
n= 194

Reasonable adjustments

Figure 39: Which reasonable adjustments are offered by your organisation?

Question	Yes	No
Does your organisation provide appointments at times of day and duration to make it easier for children, young people and adults with a learning disability, or autistic people (and their families) to attend?	93%	7%
Is your organisation able to accommodate carers overnight on site (acute hospitals)?	92%	8%
Does your organisation's triage processes prioritise children, young people and adults with a learning disability, or autistic people?	72%	28%
Does your organisation provide a low stimulus area / waiting area?	71%	29%
Does your organisation provide home visits for children, young people and adults with a learning disability, or autistic people, instead of an outpatient appointment?	63%	37%
Does your organisation provide accessible appointment letters?	59%	41%
Do you have a policy which makes it clear that reasonable adjustments should be provided to autistic people?	57%	43%
Does your organisation provide a changing places toilet facilities?	50%	50%

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Yes ■ No

LD Liaison staff

Figure 40: Total number of designated acute learning disability liaison staff employed (WTE)

All Orgs — Mean = 1.47 — Median = 1.00
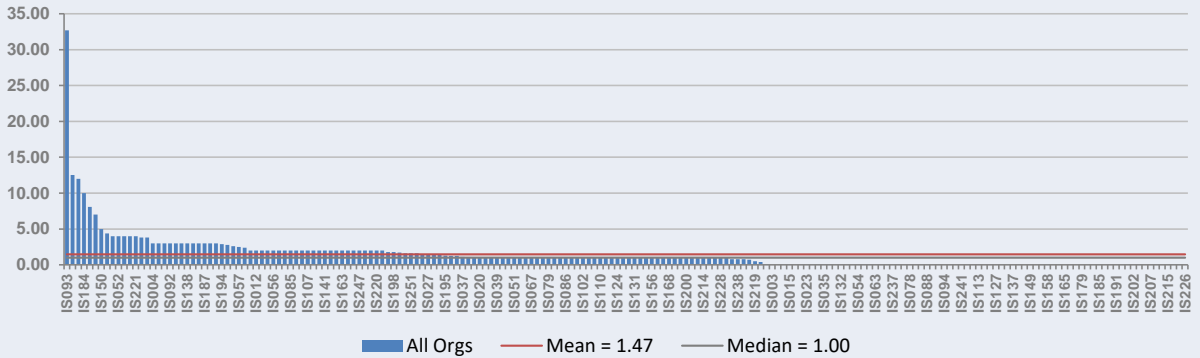
Figure 41: Total number of registered LD nurses as a % of designated acute learning disability liaison staff employed (WTE)

All Orgs — Mean = 81% — Median = 100%
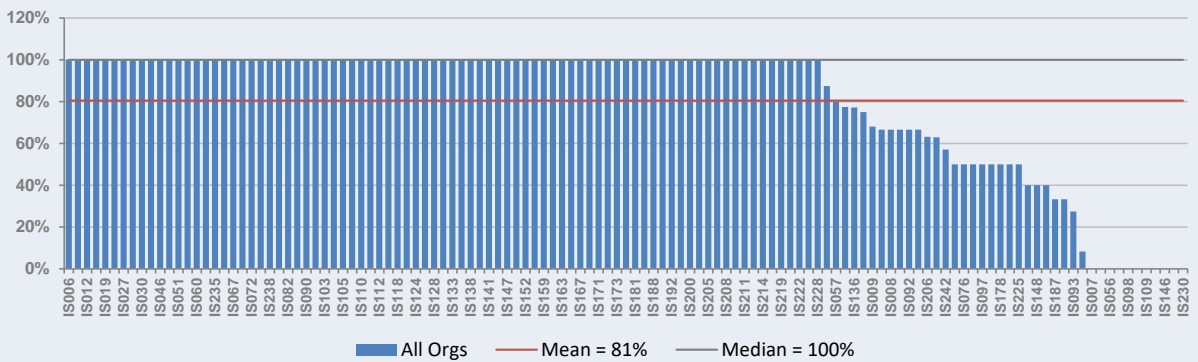
Figure 42: Do you have a partnership agreement with another Trust to provide acute learning disability liaison nurse services?

39% Yes   61% No
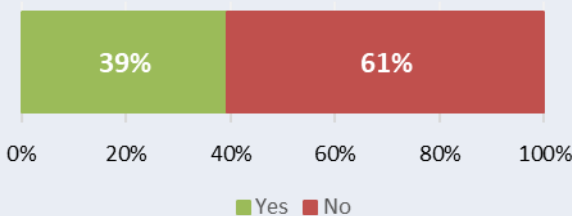
n= 198

Inclusion

Figure 43: Does your Trust employ people with a learning disability or autism?

86% Yes, 14% No

Yes ■ No
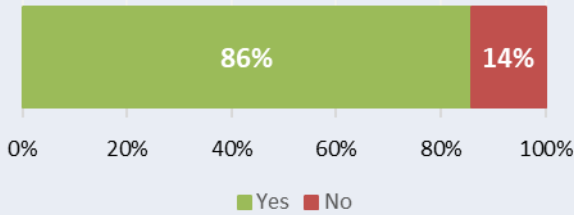
n= 183

Figure 44: Total WTE of workforce employed with a learning disability (paid employment only)

All Orgs ■ Mean = 20 ■ Median = 3
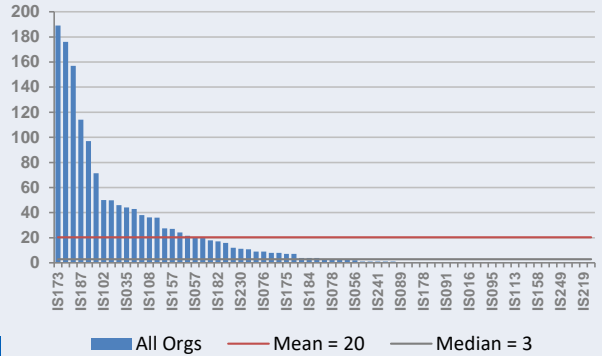
Ask Listen Do

Figure 45: Our organisation uses 'Ask Listen Do', and makes reasonable adjustments to the complaints processes, to avoid people with a learning disability and/or autism having excessive form filling

- Strongly Agree 26%
- Tend to Agree 46%
- Neither Agree or Disagree 14%
- Tend to Disagree 11%
- Strongly Disagree 2%
- Don't know 2%
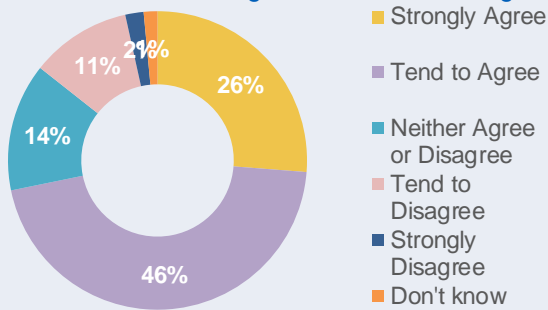
n= 202

Figure 46: Is your organisation using 'Ask Listen Do' good practice resources to improve feedback, concerns and complaints for children, young people and adults with a learning disability, autistic people and families?

43% Yes, 57% No

Yes ■ No
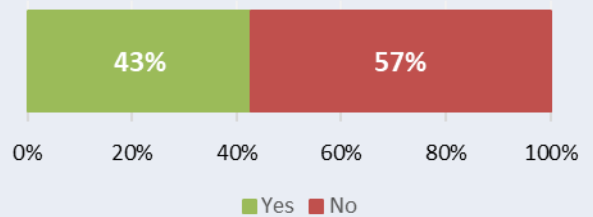
n= 199

Leadership

Figure 47: Does your organisation have a board level lead responsible for monitoring and assuring the quality of service being provided to children, young people and adults with a learning disability and autistic people?

96%	4%

Yes ■ No
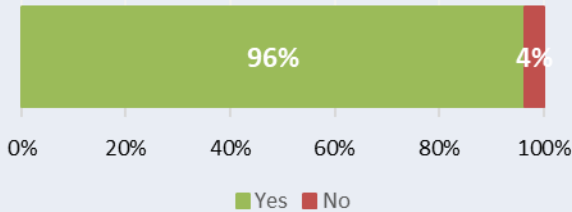
n= 200

Figure 48: Which professional role best describes the executive role of your board member who leads on quality assurance for learning disabilities and autism?

- Nursing
- Quality director
- Operations director or equivalent
- Medical director or equivalent
- Other

74% — 10% — 9% — 5% — 2%
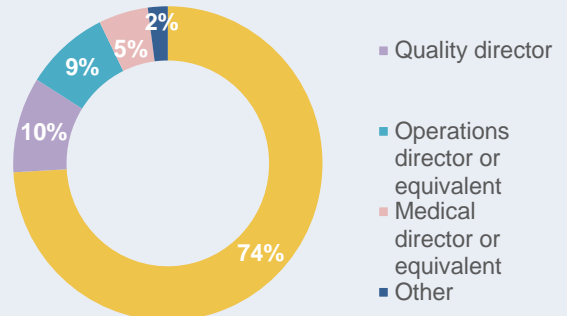
n= 193

Workforce plan

Figure 49: Does your workforce plan include data on current and future issues arising from retention/recruitment difficulties relating to the learning disabilities workforce?

38%	62%

Yes ■ No
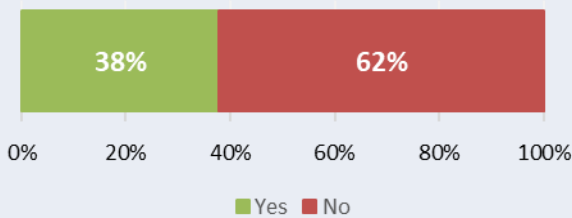
n= 192

Figure 50: Does your workforce plan include provisions to support the development of new roles in learning disabilities care?

53%	47%

Yes ■ No
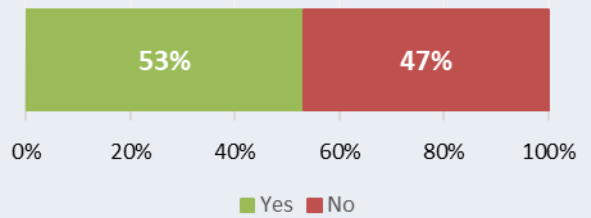
n= 194

Training

Figure 51: Do staff receive up-to-date training covering learning disabilities / autism awareness?

83% Yes
17% No

■ Yes ■ No
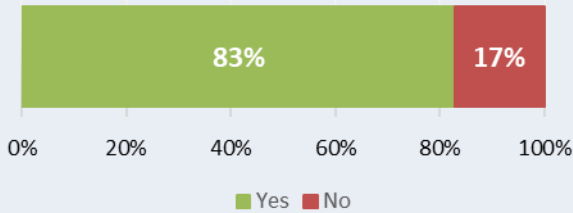
n= 198

Figure 52: Of staff who receive up-to-date training covering learning disabilities / autism awareness, what percentage were trained in this in 2018/19?

■ All Orgs ── Mean = 58% ── Median = 77%
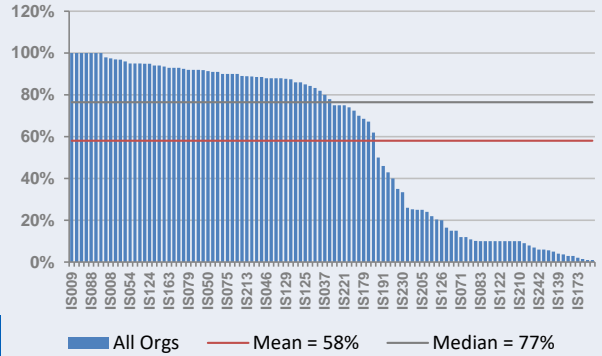
Figure 53: Does your Trust induction programme invite children, young people and adults with a learning disability or autism to contribute to staff training?

18% Yes
82% No

■ Yes ■ No
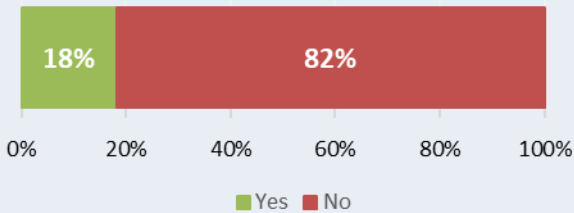
n= 199

Figure 54: Does your organisation provide training to help those who provide day to day care and support, to understand how to recognise and respond to signs of emerging health problems for children, young people and adults with a learning disability or autism?

75% Yes
25% No

■ Yes ■ No
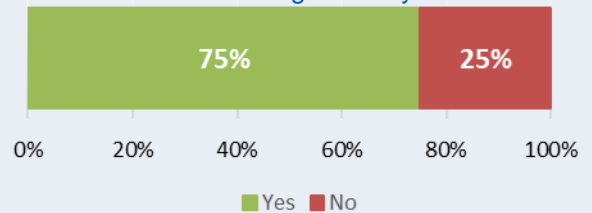
n= 195

Figure 55: Our staff are trained to recognise their responsibilities to make, record, report and share reasonable adjustments to the delivery of care/support, when working with people with a learning disability and/or autism

36% / 47% / 11% / 5% / 1%

- Strongly Agree
- Tend to Agree
- Neither Agree or Disagree
- Tend to Disagree
- Strongly Disagree
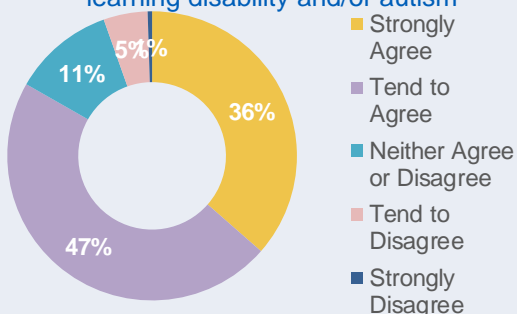
n= 203

Figure 56: Our staff are trained to identify a child, young person or adult at risk of abuse and to help them understand and make sense of safeguarding processes and procedures

87% / 12% / 1%

- Strongly Agree
- Tend to Agree
- Neither Agree or Disagree
- Tend to Disagree
- Strongly Disagree
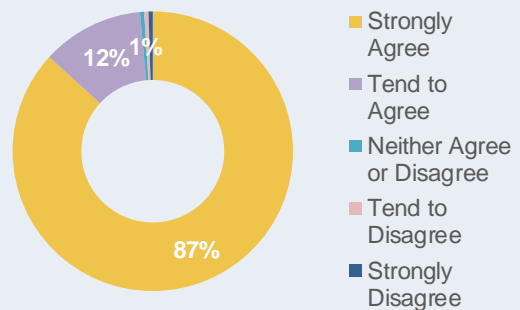
n= 204

Figure 57: Our staff feel empowered to raise concerns about medication, in order to ensure that people with learning disabilities and/or autism are not over medicated

- Strongly Agree
- Tend to Agree
- Neither Agree or Disagree
- Tend to Disagree
- Strongly Disagree

45%
37%
14%
3% 3%
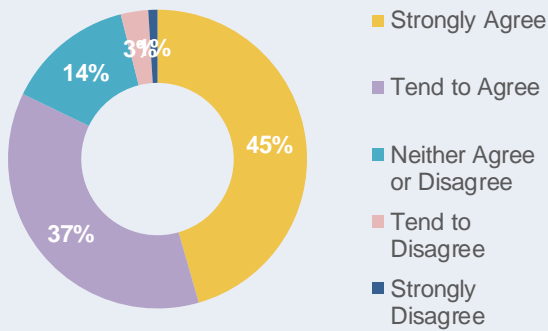
n= 203

Figure 58: Does your organisation actively involve children, young people and adults with a learning disability or autism and their families in checking the quality of the services being provided and developing improvement plans as a result?

67% 33%

0% 20% 40% 60% 80% 100%

- Yes
- No
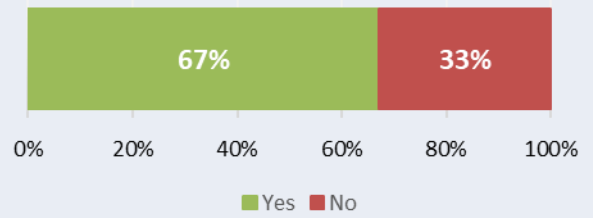
n= 198

Specialist learning disabilities services

Figure 59: Services provided:

Community services:

Service	Yes	No
Specialist community learning disability teams	96%	4%
Autism diagnostic services	84%	16%
Intensive community support teams	82%	18%
Community forensic learning disability team	43%	57%

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Yes ■ No

Inpatient services:

Service	Yes	No
Inpatient Assessment and Treatment Unit (ATU)	56%	44%
Low Secure inpatient unit	32%	68%
Medium Secure inpatient unit	22%	78%
Long term continuing care / rehabilitation inpatient unit	18%	82%
Autism specific inpatient unit	4%	96%
High secure inpatient unit	2%	98%

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Yes ■ No

Community

Figure 60: We operate a dynamic risk / support register with regards to people with a learning disability and/or autism in community settings

- Yes — 75%
- Partially — 17%
- No — 8%
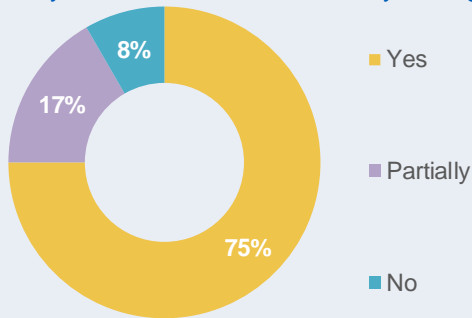
n= 48

Figure 61: If you provide an intensive community support service, do the staff provide crisis support?

- Yes — 81%
- No — 19%
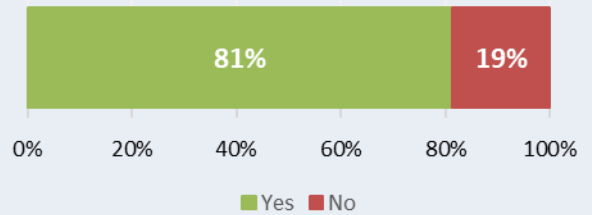
n= 43

Figure 62: If you provide an intensive community support service is it available 7 days per week?

- Yes — 51%
- No — 49%
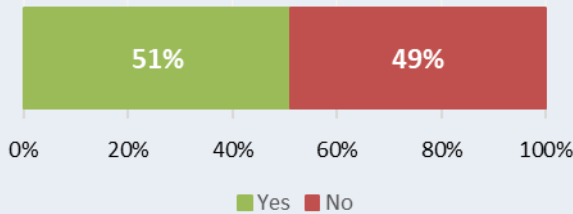
n= 43

Figure 63: Our Community Specialist Practitioners are always able to remain involved and contribute to MDT planning processes when someone on their caseload is admitted to hospital with concerns regarding their mental health or behaviour

- Strongly Agree — 66%
- Tend to Agree — 32%
- Neither Agree or Disagree — 2%
- Tend to Disagree
- Strongly Disagree
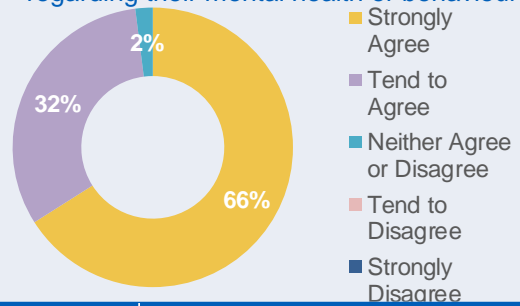
n= 50

Inpatient

Figure 64: Our organisation always considers whether the needs of people with a learning disability and/or autism in inpatient services might be better met in a community setting

- Strongly Agree
- Tend to Agree
- Neither Agree or Disagree
- Tend to Disagree
- Strongly Disagree

8%
92%
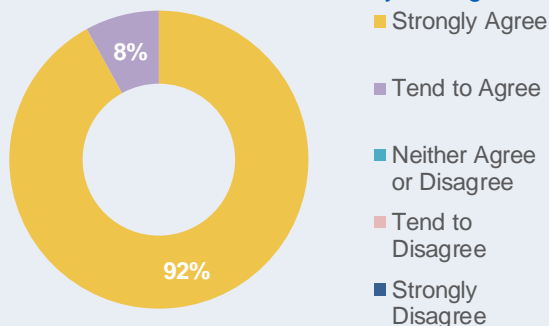
n= 50

Figure 65: Does your organisation ensure that people with a learning disability and/or autism who are in hospital, and family carers are meaningfully involved (as equal partners) in admission, assessment, formulation, care planning, care reviews and discharge planning?

100%

0%   20%   40%   60%   80%   100%

- Yes
- No
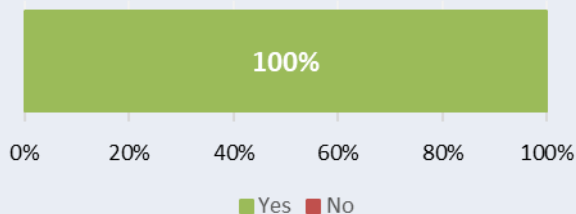
n= 47

Figure 66: Where a person with a learning disability and/or autism is admitted to hospital due to concerns about their behaviour or mental health, a staff members from the hospital is identified at the point of admission, to work closely on discharge planning with a community based care coordinator

- Strongly Agree
- Tend to Agree
- Neither Agree or Disagree
- Tend to Disagree
- Strongly Disagree

4%
35%
61%
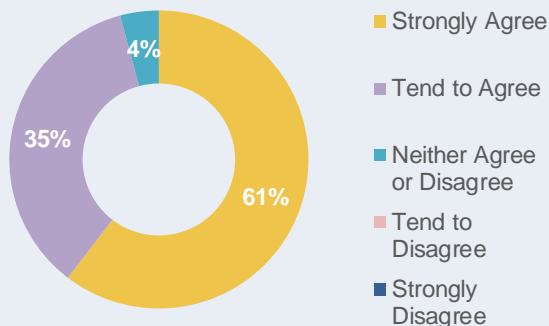
n= 48

Figure 67: Does your organisation monitor target discharge dates and actual discharge dates for children, young people and adults with a learning disability, and autistic people, in hospital?

76%   24%

0%   20%   40%   60%   80%   100%

- Yes
- No
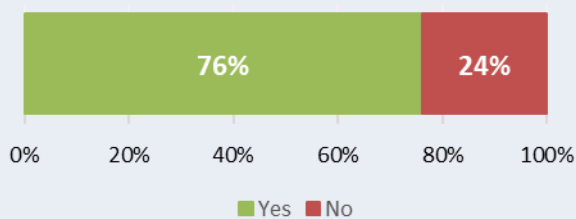
n= 46

Positive Behaviour Support

Figure 68: Does your organisation provide Positive Behaviour Support (PBS)?

100%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
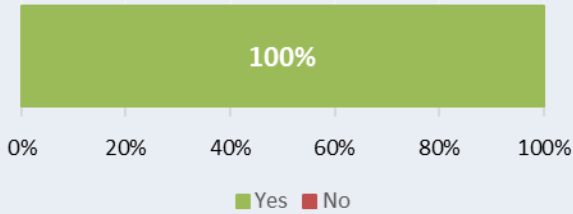
n= 50

Figure 69: Does your organisation provide functional assessments of behaviours of concern, in accordance with NICE guidance?

100%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
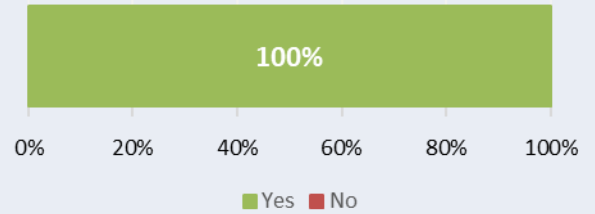
n= 49

Figure 70: Does your organisation train all learning disabilities clinical staff in PBS, in accordance with the competencies associated with their specific role?

86%   14%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
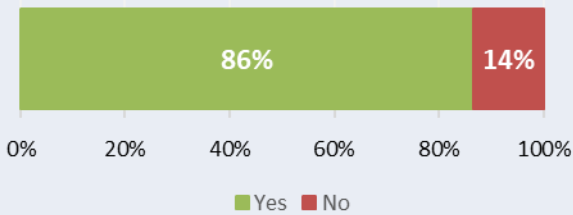
n= 50

Restrictive practices

Figure 71: Restraint reduction programmes/policies

Do you have an organisational restraint reduction programme/policy?
- Yes: 92%
- No: 8%

Do you have a named board level lead for reducing restrictive interventions?
- Yes: 89%
- No: 11%

Has the organisational restraint reduction programme/policy been reviewed in the last 12 months?
- Yes: 80%
- No: 20%

Were people with lived experience of using services involved in developing the policy?
- Yes: 66%
- No: 34%

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Yes ■ No

Figure 72: Restraint reporting

Do you publish an annual report on restraint and restraint reduction?
- Yes: 70%
- No: 30%

Does the report include details of techniques used?
- Yes: 82%
- No: 18%

Does the report include how often the techniques are used?
- Yes: 88%
- No: 12%

Does the report include the number of significant injuries to patients and/or staff as a result of restraint?
- Yes: 63%
- No: 38%

Does the report include the Trust training strategy?
- Yes: 62%
- No: 38%

Is an accessible version of the annual report available?
- Yes: 34%
- No: 66%

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

■ Yes ■ No

Figure 73: Do you hold risk assessments for each individual physical restraint technique taught to your staff?

- All — 85%
- Most — 3%
- Some — 2%
- None — 10%
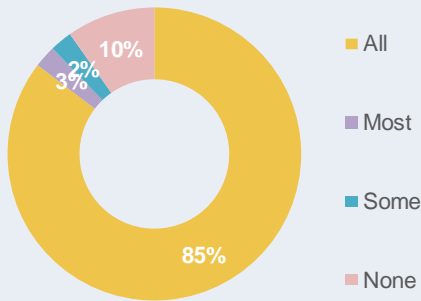
n= 41

Figure 74: Our organisation provides individualised behaviour support plans, for all people with a learning disability and/or autism, who have been assessed as being at risk of being exposed to restrictive interventions

- Strongly Agree — 51%
- Tend to Agree — 47%
- Neither Agree or Disagree
- Tend to Disagree
- Strongly Disagree
- Don't know — 2%
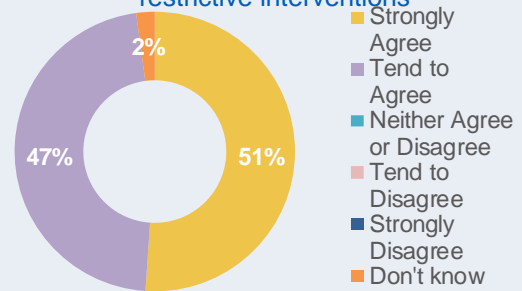
n= 47

Figure 75: Do you provide people who use your services and their families, with accessible information concerning their rights, including in relation to the possible use of restrictive interventions?

Yes 84% No 16%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
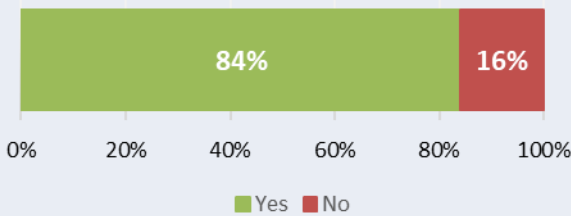
n= 44

Figure 76: With regard to inpatients, do you routinely establish agreements with patients and families, about informing families whenever any form of restrictive interventions have been used?

Yes 81% No 19%

0% 20% 40% 60% 80% 100%

■ Yes ■ No
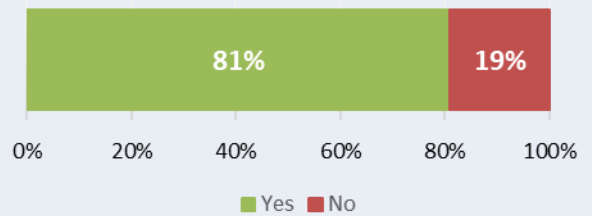
n= 42

Figure 77: Are patients' accounts of incidents and their feelings, anxieties or concerns following the use of restrictive interventions, recorded in their notes?

- Always — 37%
- Mostly — 40%
- Sometimes — 23%
- Never
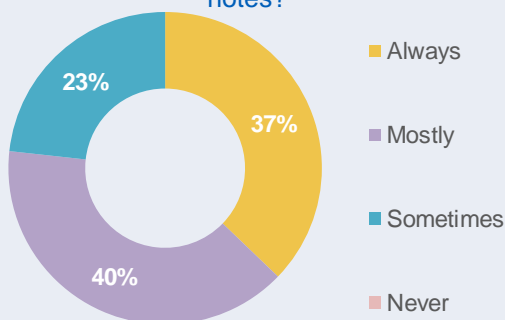
n= 43

Figure 78: Total number of children, young people and adults with a learning disability and autistic people who have experienced the use of physical restraint in 2018/19

■ All Orgs — Mean = 26 — Median = 8
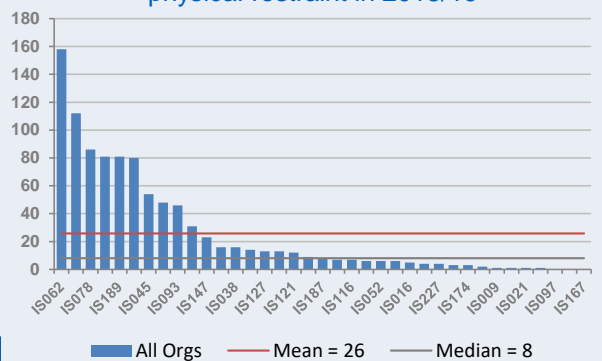
Figure 79: Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2018/19

Legend: All Orgs — Mean = 320 — Median = 115
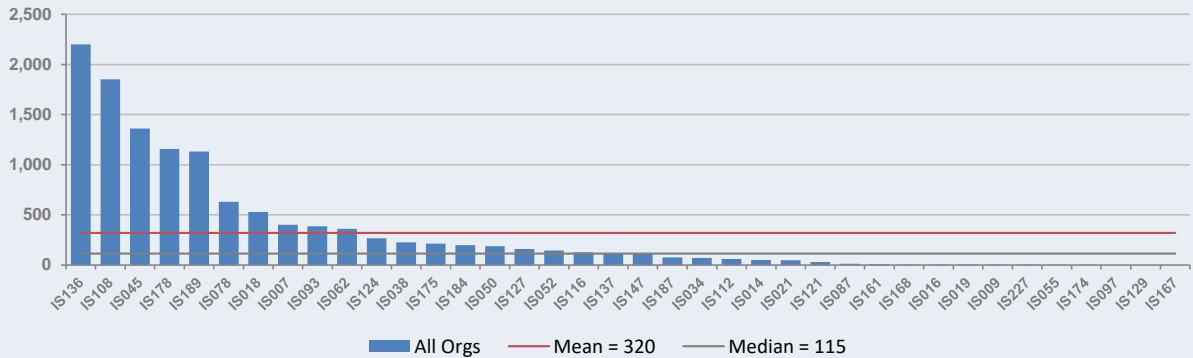
Figure 80: Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2018/19 per 100 children, young people and adults with a learning disability flag on the EPR

Legend: All Orgs — Mean = 27 — Median = 10
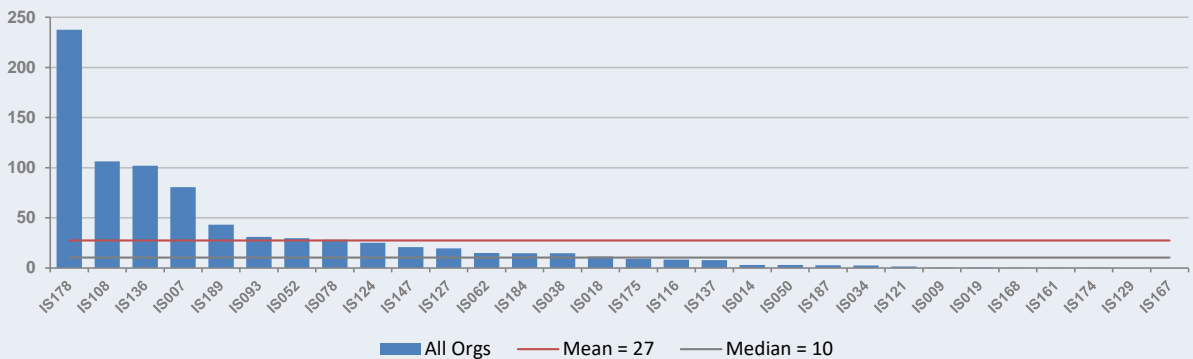
Figure 81: In the exceptional circumstance that there are felt to be cogent reasons to devise a plan for the prone restraint of a patient, are these authorised / signed off by a director of the Trust?

- Always — 29%
- Mostly
- Sometimes
- Never — 71%
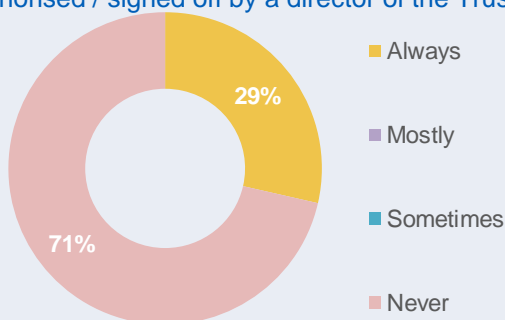
n= 21

Figure 82: Has your board approved the use of mechanical restraint?

Yes 29% — No 71%
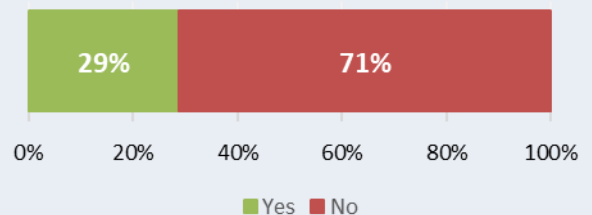
n= 45

Figure 83: Total number of children, young people and adults with a learning disability and autistic people who experienced use of mechanical restraint in 2018/19
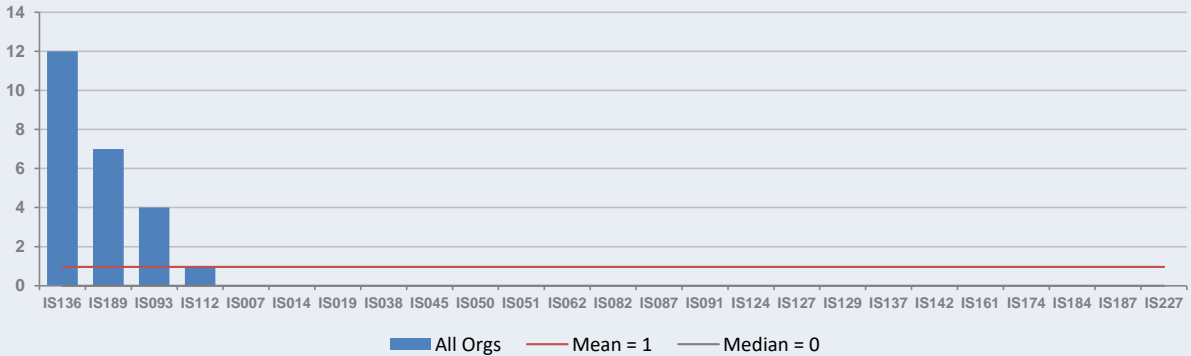
Figure 84: Where a person with a learning disability and/or autism is thought to need a plan for the use of mechanical restraint, is an IMHA consulted as part of the care planning process?

- Always 57%
- Mostly 15%
- Sometimes 14%
- Never 14%
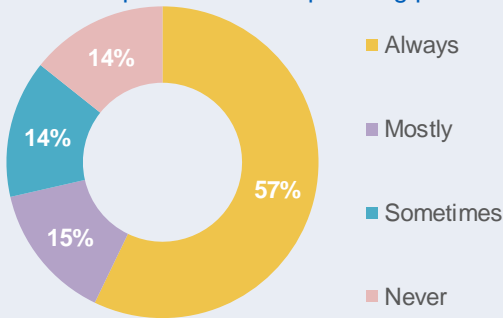
n= 7

Figure 85: Do people with learning disabilities and/or autism who are subjected to mechanical restraint have a specific care plan to reduce the requirement for its use?

- Always 100%
- Mostly
- Sometimes
- Never
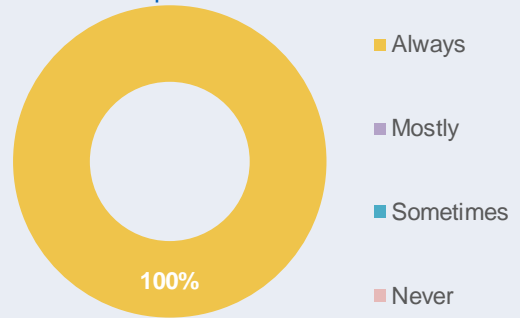
n= 8

Figure 86: Is the RC or duty doctor informed, without delay, each and every time a mechanical restraint device is applied to a patient?

- Yes 91%
- No 9%
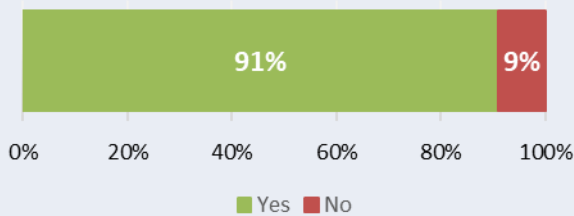
n= 11

Figure 87: Do you have a medical review following the application of a mechanical restraint device?

- Always 100%
- Mostly
- Sometimes
- Never
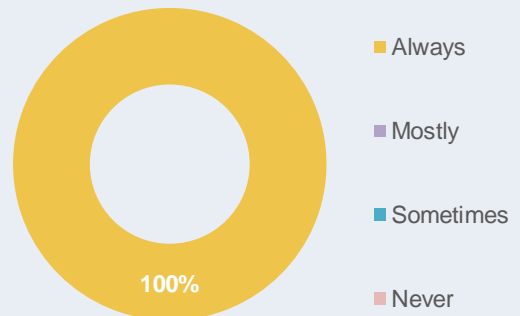
n= 10

Figure 88: Has your board approved the use of long term segregation in your Trust?

Yes: 56%	No: 44%

Legend: Yes, No
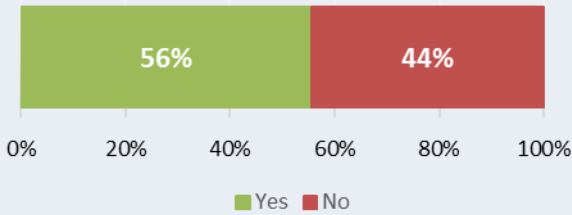
n= 45

Figure 89: Do you routinely notify the local authority safeguarding team when a patient is placed in long term segregation?

Yes: 78%	No: 22%

Legend: Yes, No
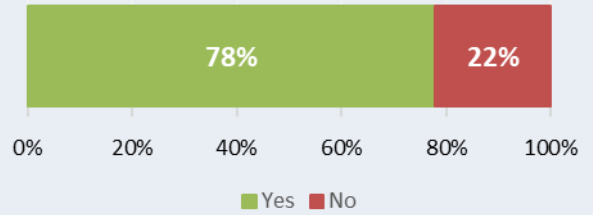
n= 27

Figure 90: Total number of children, young people and adults with a learning disability and autistic people who experienced use of long-term segregation in 2018/19

Legend: All Orgs, Mean = 4, Median = 1
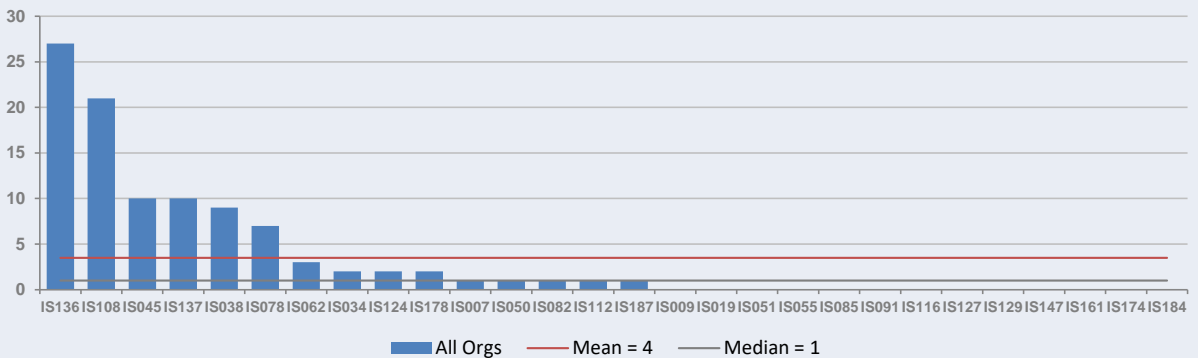
Figure 91: Where a patient is continually segregated for more than 3 months, do they have access to an external hospital review?

Yes: 100%

Legend: Yes, No
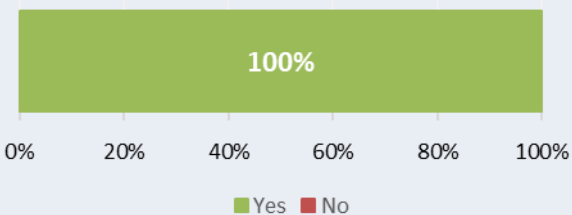
n= 25

Figure 92: Does this routinely include consultation with the patient's IMHA?

Yes: 96%	No: 4%

Legend: Yes, No
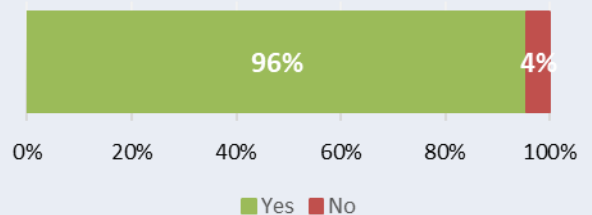
n= 23

STOMP – STAMP

Figure 93: Does your organisation have a policy to safeguard children, young people and adults with a learning disability, and autistic people, from the inappropriate prescribing of psychotropic medication?

Yes	No
58%	42%
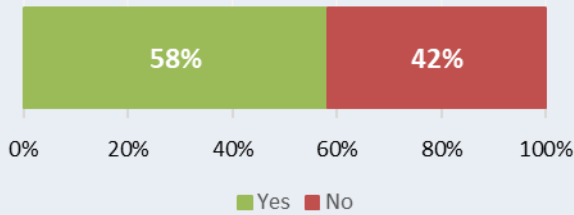
n= 48

Figure 94: Is your Trust signed up to Stopping Over Medication of People with a learning disability and autistic people with psychotropic medication?

Yes	No
94%	6%
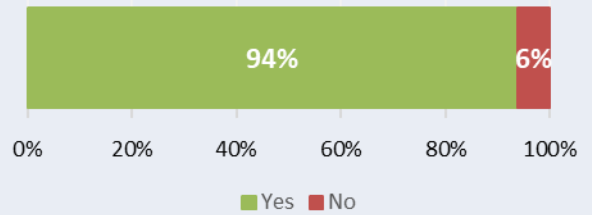
n= 48

Figure 95: Is your Trust signed up to Supporting Treatment and Appropriate use of psychotropic Medication in Paediatrics?

Yes	No
91%	9%
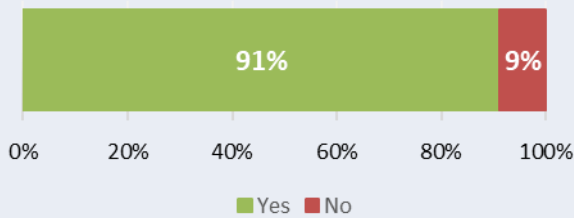
n= 34

Figure 96: Does your Trust provide regular medication reviews?

Yes	No
94%	6%
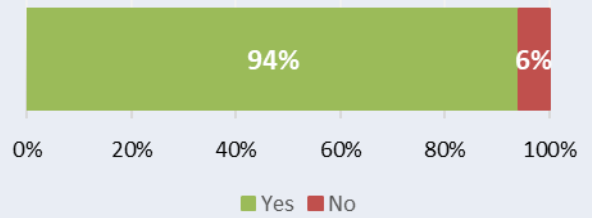
n= 50

Figure 97: Has your organisation signed the STOMP pledge?

Yes	No
78%	22%
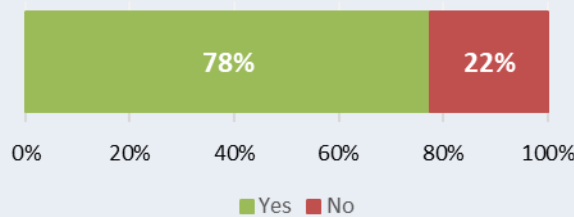
n= 49

Figure 98: Has your organisation undertaken a STOMP audit?

Yes	No
83%	17%
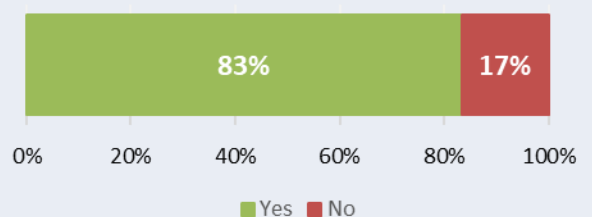
n= 48

4.2. Staff survey

The staff survey expands on the collection undertaken in the previous year with participants asked to identify up to 50 members of staff who had provided care for patients with a learning disability and/or autism. Participants were given a unique URL link which could allow up to 50 staff members per organisation to anonymously submit their answers online to the NHS Benchmarking Network.

Trusts were also provided with information governance guidance and GDPR guidance to assist with the data collection. The unique URL links provided to participants allowed the Trust to be identified for bespoke analysis but the individual staff to remain anonymous.

6,132 staff surveys were completed by 205 participating organisations. This resulted in a 60% completion rate, with an average of 30 staff surveys completed per Trust.

The questionnaires were multiple choice and predominantly used a 5-point Likert scale to minimise the amount of time staff were spending away from their day-to-day duties. Results from the 5-point Likert scales have been formatted into donut charts.

The topics explored throughout the survey include: the ability of staff to identify what reasonable adjustments patients required, the involvement of patients and family carers in how care was delivered, and whether staff had received the necessary training required to meet the needs of people with a learning disability and/or autism.

Figure 99: What systems are in place in your Trust for identifying and recording that a child, young person or adult has a learning disability?

Recording systems	National Average	National Average	
		Yes %	No %
Documented in medical notes		71%	29%
Documented in nursing notes		57%	43%
Documented electronically		71%	29%
Sticker on patient notes		12%	88%
Other		9%	91%
Do not have any systems		1%	99%
Don't know		6%	94%

Figure 100: In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to:

Appointment accessibility	National Average	National Average		
		Yes %	No %	Don't Know %
Flexible appointments		54%	6%	40%
First or last clinic appointments		49%	6%	45%
Double appointments		46%	7%	47%

Figure 101: I feel able to identify what reasonable adjustments are needed for children, young people and adults with a learning disability or autistic people

- Strongly agree: 28%
- Agree: 51%
- Neither agree nor disagree: 12%
- Disagree: 6%
- Strongly disagree: 3%
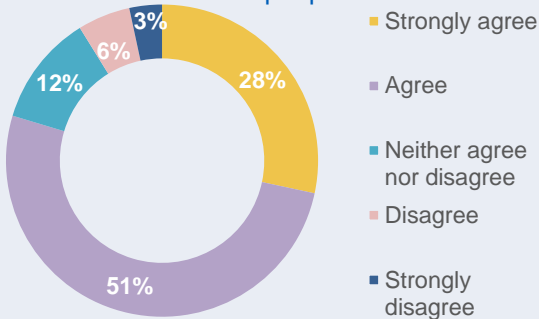
Figure 102: I have the necessary resources to meet the needs of children, young people and adults with a learning disability or autistic people e.g. communication needs or equipment

- Strongly agree: 13%
- Agree: 46%
- Neither agree nor disagree: 23%
- Disagree: 15%
- Strongly disagree: 3%
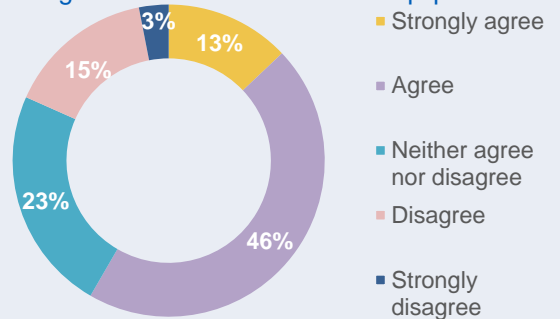
Figure 103: I am confident that children, young people and adults with a learning disability or autistic people using my service always receive the reasonable adjustments they need

- Strongly agree: 18%
- Agree: 47%
- Neither agree nor disagree: 21%
- Disagree: 12%
- Strongly disagree: 2%
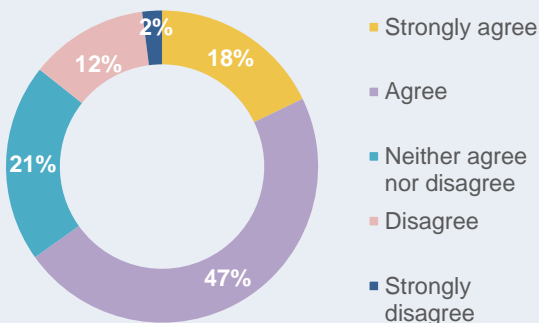
Figure 104: I am always able to deliver safe care to a child, young person, or adult with a learning disability or autistic people

- Strongly agree: 21%
- Agree: 55%
- Neither agree nor disagree: 17%
- Disagree: 6%
- Strongly disagree: 1%
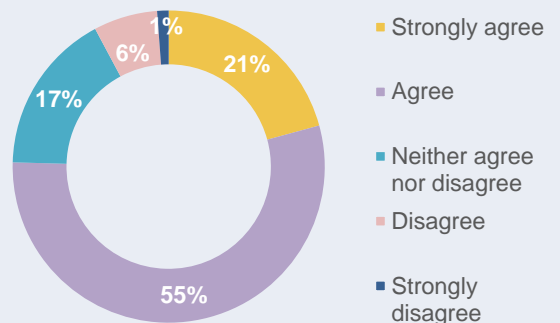
Figure 105: Children, young people and adults with a learning disability or autistic people get the same quality of care as any other person

- Strongly agree: 28%
- Agree: 46%
- Neither agree nor disagree: 15%
- Disagree: 9%
- Strongly disagree: 2%
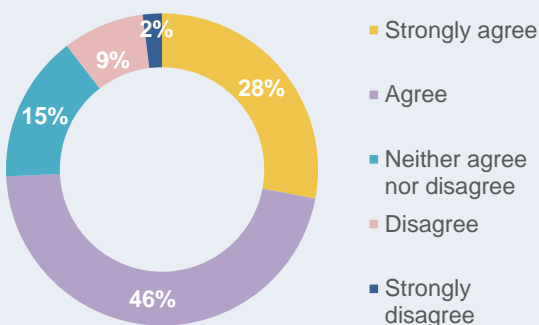
Figure 106: Staff in the Trust always tell children, young people and adults with a learning disability or autistic people and families about their rights when using services

- Strongly agree: 13%
- Agree: 36%
- Neither agree nor disagree: 36%
- Disagree: 13%
- Strongly disagree: 2%
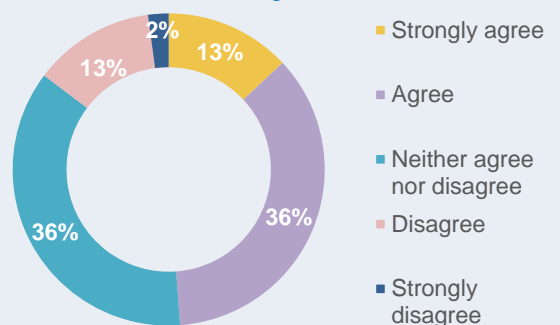
Figure 107: In your Trust, if a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) form (or equivalent) is completed for a child, young person or adult with a learning disability or autistic people, is there a clear policy to double check, to ensure that there is a valid reason?

Yes	No	Don't know
40%	4%	56%
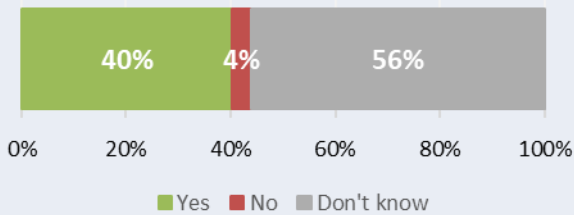
n= 3879

Figure 108: If a person with a learning disability and/or autism dies under the care of our service, the findings and outcomes from the Trust investigation are shared with staff team members

- Strongly agree: 14%
- Agree: 35%
- Neither agree nor disagree: 40%
- Disagree: 9%
- Strongly disagree: 2%
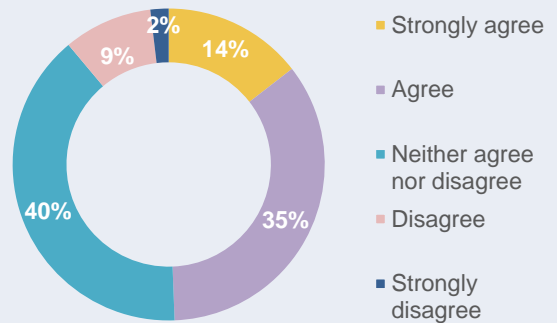
Figure 109: My Trust has policies and procedures to ensure the rights of autistic people are respected and protected

Yes	No	Don't know
71%	3%	26%
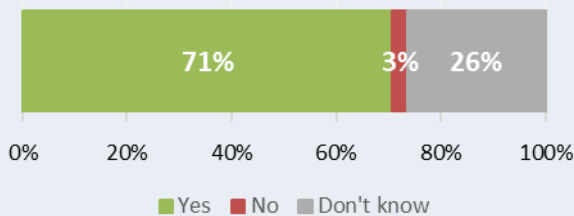
n= 5967

Figure 110: In my Trust, I feel children, young people and adults with a learning disability and autistic people are always treated with dignity and respect

- Strongly agree: 33%
- Agree: 51%
- Neither agree nor disagree: 11%
- Disagree: 4%
- Strongly disagree: 1%
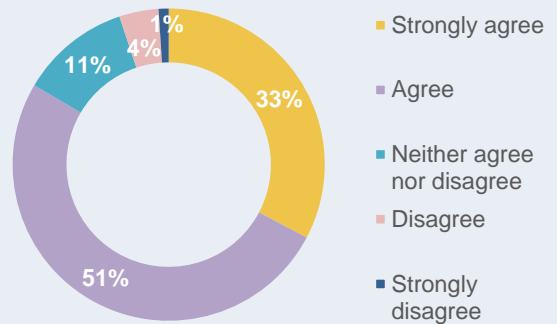
Figure 111: In my Trust, I feel family members of people with a learning disability and/or autism, are always treated with dignity and respect

- Strongly agree: 31%
- Agree: 52%
- Neither agree nor disagree: 13%
- Disagree: 3%
- Strongly disagree: 1%
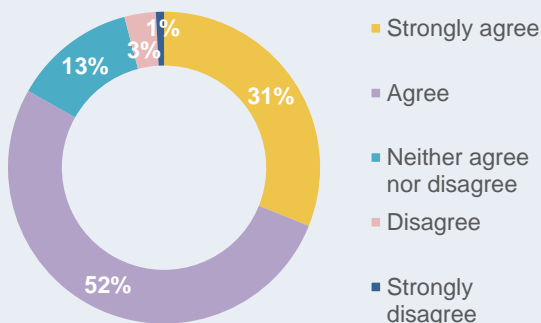
Figure 112: I routinely involve people with a learning disability, and/or autism when making decisions about their care and treatment

- Strongly agree: 37%
- Agree: 47%
- Neither agree nor disagree: 14%
- Disagree: 1%
- Strongly disagree: 1%
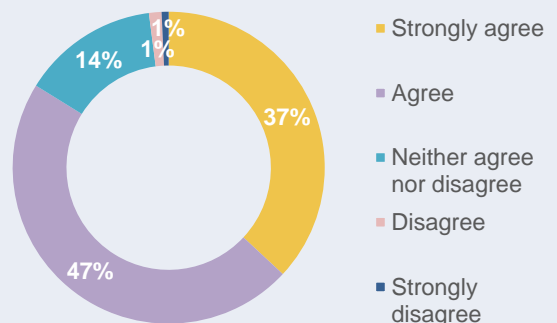
Figure 113: I routinely involve the families of people with a learning disability and/or autism, when making decisions about their care and treatment

- Strongly agree — 38%
- Agree — 48%
- Neither agree nor disagree — 12%
- Disagree — 1%
- Strongly disagree — 1%
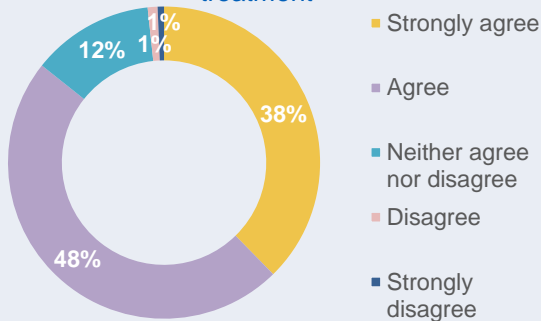
Figure 114: Children, young people and adults with a learning disability are routinely involved in the planning of Trust services

- Strongly agree — 8%
- Agree — 25%
- Neither agree nor disagree — 54%
- Disagree — 11%
- Strongly disagree — 2%
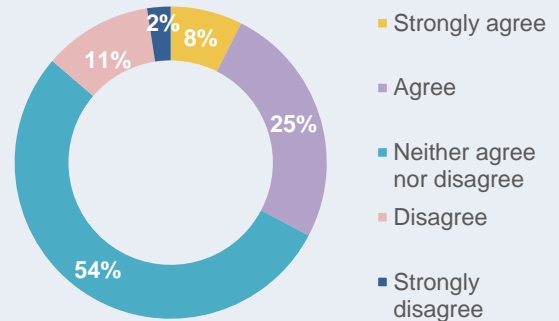
Figure 115: Families of children, young people and adults with a learning disability are routinely involved in the planning of Trust services

- Strongly agree — 7%
- Agree — 26%
- Neither agree nor disagree — 54%
- Disagree — 11%
- Strongly disagree — 2%
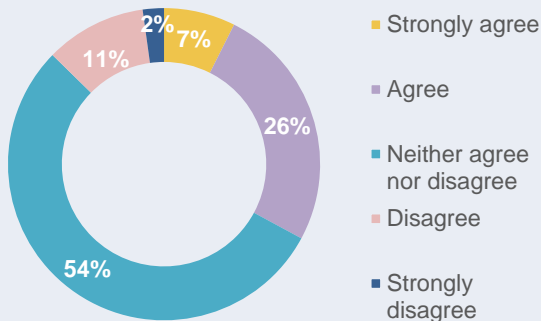
Figure 116: I have received mandatory training on meeting the needs of children, young people and adults with a learning disability, and autistic people, during the course of my work

Yes	No
69%	31%
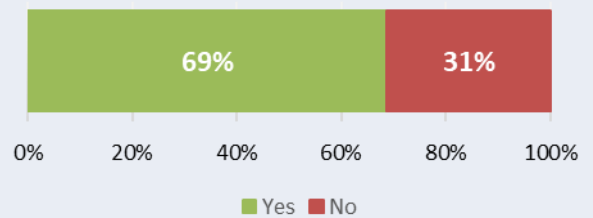
n= 6027

Figure 117: I feel I have the necessary knowledge and skills to meet the needs of people with a learning disability, and/or autism, during the course of my work

- Strongly agree — 26%
- Agree — 49%
- Neither agree nor disagree — 15%
- Disagree — 8%
- Strongly disagree — 2%
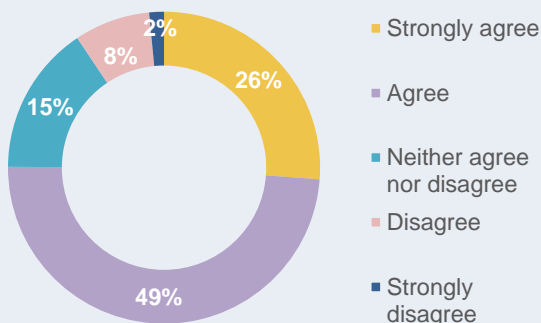
Figure 118: I have access to additional specialist learning disability staff when I need it, to help me meet the needs of children, young people and adults with a learning disability

- Strongly agree — 35%
- Agree — 41%
- Neither agree nor disagree — 13%
- Disagree — 9%
- Strongly disagree — 2%
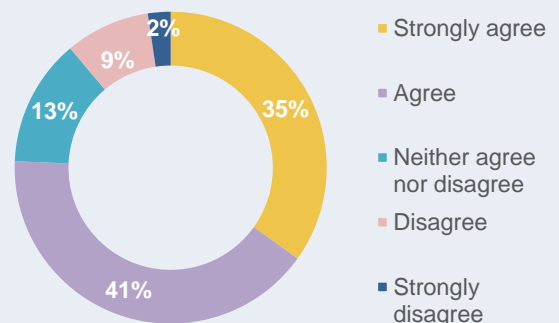
Figure 119: Children, young people and adults with a learning disability are involved in delivering awareness training to staff in my Trust

- Strongly agree: 9%
- Agree: 22%
- Neither agree nor disagree: 42%
- Disagree: 22%
- Strongly disagree: 5%
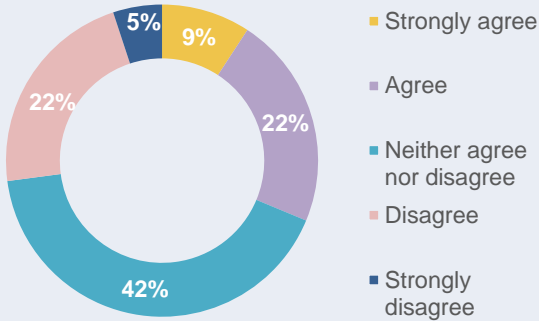
Figure 120: I would recommend the Trust to a friend or family members of a person with a learning disability, and/or autism who needed treatment

- Strongly agree: 23%
- Agree: 50%
- Neither agree nor disagree: 23%
- Disagree: 3%
- Strongly disagree: 1%
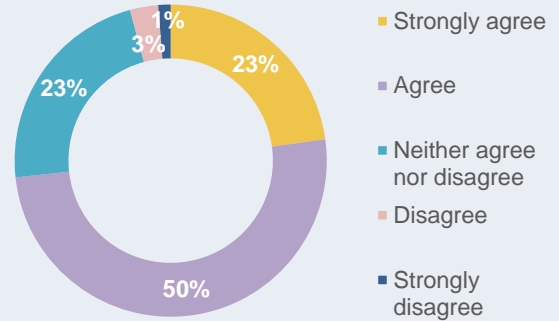
Figure 121: People with a learning disability and/or autism, who are in hospital due to concerns about their behaviour or mental health, continue to be seen by staff from their usual community services

- Strongly agree: 21%
- Agree: 41%
- Neither agree nor disagree: 28%
- Disagree: 8%
- Strongly disagree: 2%
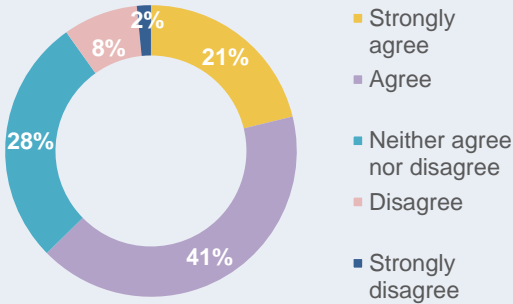
Figure 122: People with a learning disability, and/or autism, who are in hospital due to concerns about their behaviour or mental health, are visited by an external care co-ordinator, case manager, or equivalent at least every 6-8 weeks

- Strongly agree: 10%
- Agree: 34%
- Neither agree nor disagree: 39%
- Disagree: 12%
- Strongly disagree: 5%
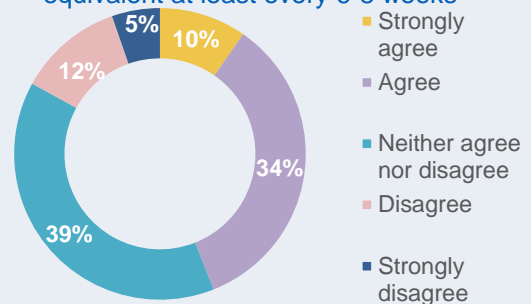
Figure 123: Children, young people and adults with a learning disability, autistic people and family carers are involved in reviewing the appropriateness of psychotropic medications

- Strongly agree: 17%
- Agree: 43%
- Neither agree nor disagree: 34%
- Disagree: 5%
- Strongly disagree: 1%
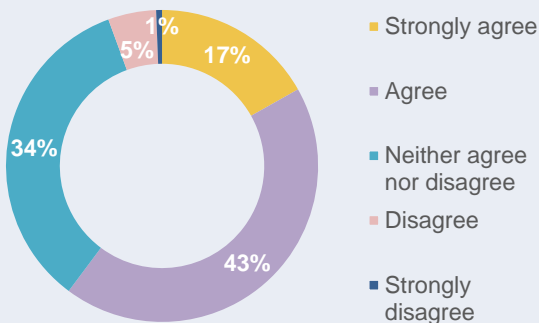
Figure 124: I have had training on reducing the use of restrictive interventions

- Strongly agree: 34%
- Agree: 37%
- Neither agree nor disagree: 13%
- Disagree: 13%
- Strongly disagree: 3%
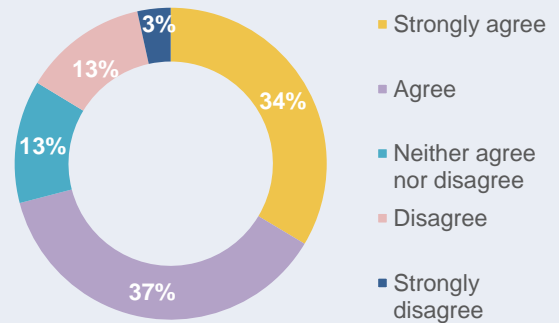
Figure 125: People with a learning disability, and/or autism who are in hospital due to concerns about their behaviour or mental health, have good access to independent advocacy services

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

0%
3%
14%
39%
44%
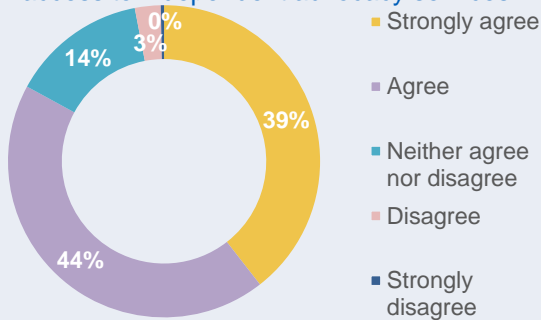
Figure 126: My Trust encourages me to speak out if I have concerns about the wellbeing of children, young people and adults with a learning disability, and autistic people, in our services

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

1%
6%
1%
40%
52%
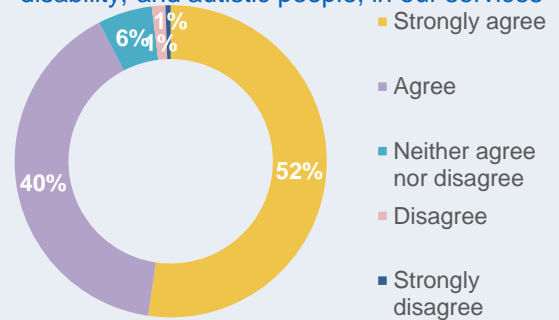
Figure 127: My Trust has developed effective and new ways of supporting children, young people and adults with a learning disability, and autistic people, to live successfully in the community in recent years

86%   14%

0%   20%   40%   60%   80%   100%

■ Yes ■ No
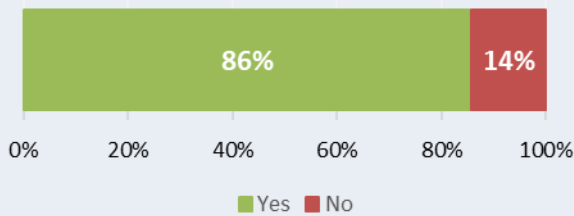
n= 1270

4.3. Service user survey

The service user survey received a redesign following last year's pilot survey. Upon feedback from participants, the process was simplified to improve accessibility. The survey was conducted on a paper form and submitted through an accompanying freepost envelope.

Each Trust who registered for this element of the audit received 100 paper forms for distribution to service users and carers. A total of 205 Trusts registered for the service user survey creating an overall sample size of 20,500 survey forms made available for Trusts to distribute.

Participants were provided with information governance guidance to alleviate any concerns regarding GDPR. Each survey contained a barcode unique to the Trust, which allows bespoke analysis of the service user surveys in which the Trust could be identified but the patient remained anonymous.

Following the adoption of the feedback, the results showed significant increases in participation, with 3,819 surveys being completed by service users and carers receiving care in 190 participant Trusts, giving an overall survey completion rate of 19%.

An additional online survey with the same set of questions was also launched to accompany the paper-format surveys. This allowed increased access to the audit for service users who wanted to have their opinions on the service they received taken into account, but were not included in Trust's 100 sample patients who received paper survey forms. The participation in the online questionnaire was lower, with 81 service users participating. The results from the additional online survey therefore have lower significance compared to the paper-format but can be viewed in parallel to form a basis of all service user opinions on learning disability services. These additional results can be found in Appendix 3.

Figure 128: When you received care from the NHS, did staff treat you with respect?

93% Yes, 4% No, 2% Don't know
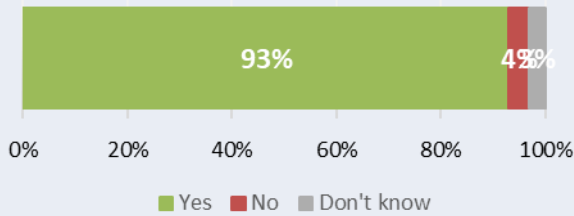
n= 3766

Figure 129: Did staff explain things to you in a way you could understand?

83% Yes, 10% No, 7% Don't know
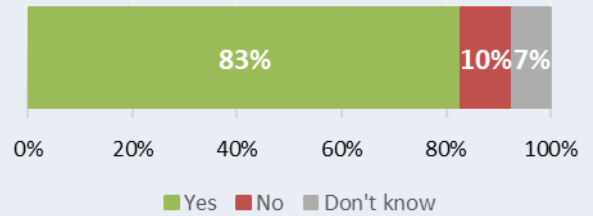
n= 3748

Figure 130: Did you feel like staff listened to you?

84% Yes, 9% No, 7% Don't know
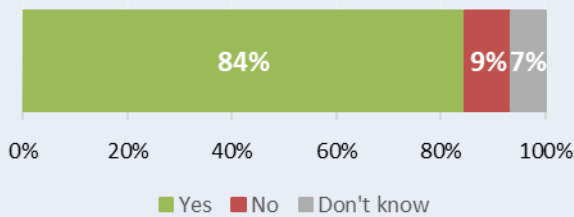
n= 3741

Figure 131: Did you feel like staff cared about you?

88% Yes, 6% No, 6% Don't know
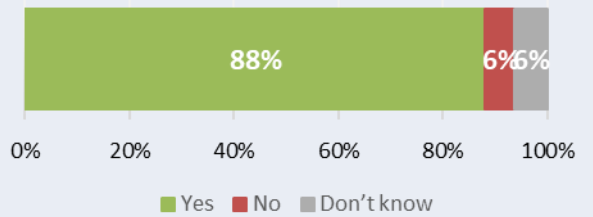
n= 3765

Figure 132: Did staff talk to you about the care you needed?

84% Yes, 9% No, 7% Don't know
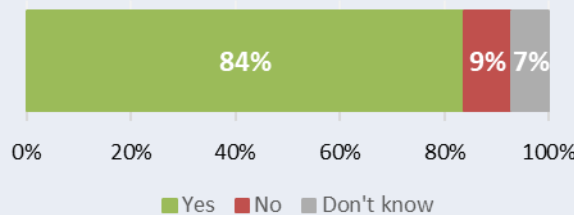
n= 3755

Figure 133: Did staff give you choices about how you were cared for?

68% Yes, 17% No, 15% Don't know
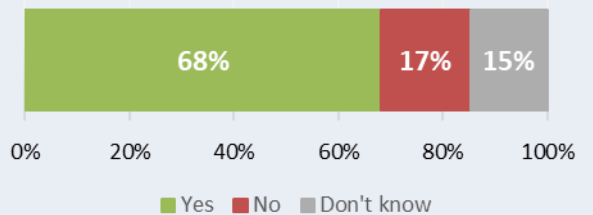
n= 3725

Figure 134: Did staff listen to what your family thought?

	Yes	No	Don't know
	81%	8%	10%

Yes ■ No ■ Don't know
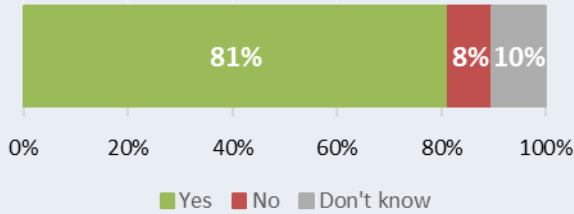
n= 3728

Figure 135: When you received care, did you feel safe?

	Yes	No	Don't know
	88%	6%	6%

Yes ■ No ■ Don't know
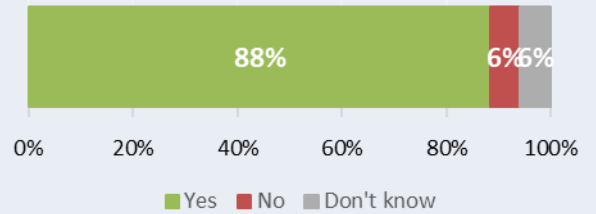
n= 3766

Figure 136: Did you have any concerns about your care?

	Yes	No	Don't know
	22%	68%	10%

Yes ■ No ■ Don't know
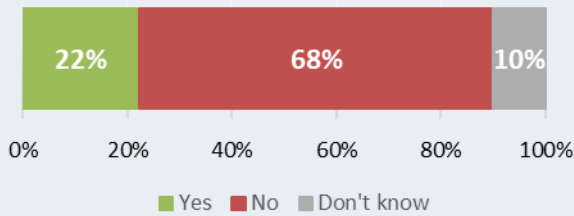
n= 3738

Figure 137: Did you make a complaint?

	Yes	No	Don't know
	10%	87%	3%

Yes ■ No ■ Don't know
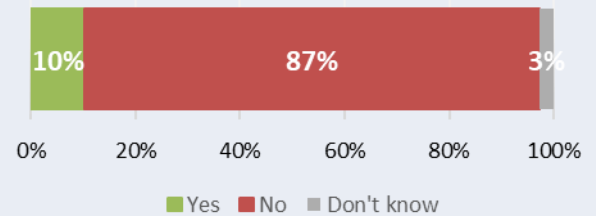
n= 3757

Figure 138: If yes, were you given Easy Read information about how to make a complaint?

	Yes	No	Don't know
	30%	52%	17%

Yes ■ No ■ Don't know
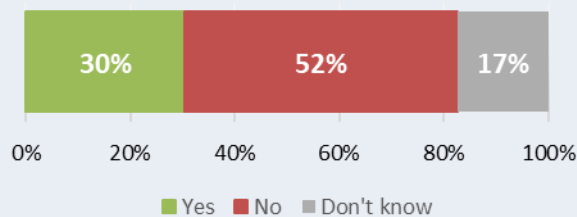
n= 2904

Figure 139: If you stayed in hospital, was it easy for your family to visit you?

	Yes	No	Don't know
	86%	10%	5%

Yes ■ No ■ Don't know
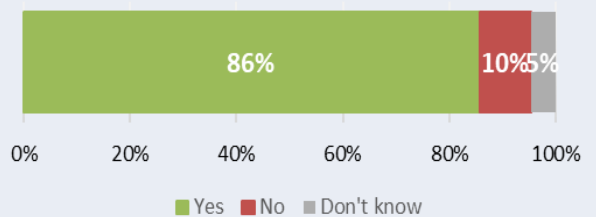
n= 3729

Figure 140: Did staff tell you about your appointments and meetings in a way you could understand?

Yes	81%
No	11%
Don't know	8%
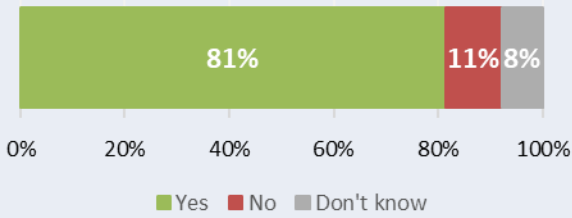
n= 3721

Figure 141: Were your appointments and meetings arranged to suit you?

Yes	78%
No	13%
Don't know	8%
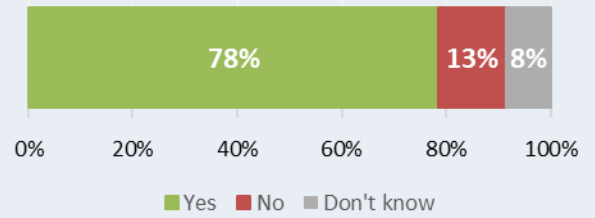
n= 3723

Figure 142: If you needed to be seen in an emergency, were you seen quickly?

Yes	72%
No	19%
Don't know	9%
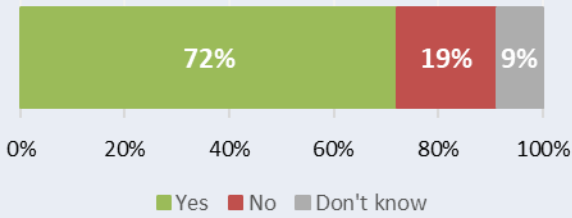
n= 3708

Figure 143: Would you recommend this service to a friend or family?

Yes	83%
No	7%
Don't know	10%
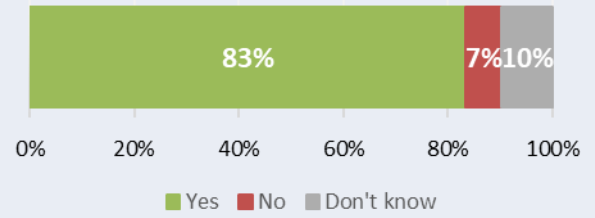
n= 3759

5. Conclusion and next steps

The report highlights the detailed findings from the second year of the NHS England and NHS Improvement learning disabilities improvement standards project and builds upon findings from last year's report.

The Long Term Plan target to ensure Trusts have a "digital flag" for patients with learning disabilities and/or autism by 2023/24 is evident, with more Trusts having the ability to identify patients on their EPR systems than in the previous year's survey. This is vital to enable staff to provide reasonable adjustments and highly personalised care to relevant service users. The growth in the proportion of Trusts providing reasonable adjustments such as accessible appointment letters, changing places toilet facilities and low stimulus waiting areas is welcome, but there is still scope for improvement. Staff also felt confident in their ability to provide the reasonable adjustments required and deliver the same quality of care as to any other person.

The increased participation in this year's service user survey has allowed more detailed analysis on patient feedback. The majority of service users felt they were listened to by staff, treated with respect and spoken to about appointments and meetings in a way they could understand. The proportion of service users that would recommend the service provided to family or friends is in line with other services provided in the NHS, which shows that the majority are satisfied with the quality of care received.

The NHS Benchmarking Network would like to thank all participants who provided their data for the 2018/19 collection and helped validate their positions in the draft findings. We look forward to working with participants to develop the project further in the next cycle of data collection in 2020.

If you have any questions about this report or would like to involved in shaping the data collection for future iterations, please contact Alexander Ng (a.ng1@nhs.net) or Stephen Watkins (s.watkins@nhs.net).

Appendix 1: Data tables

Figure	Respecting and protecting rights - Organisational level	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
1	If required, is your organisation able to isolate/disaggregate specific outcome data regarding patients with a learning disability?	Yes	70.6%	36	69.9%	107	70.1%	143
		No	29.4%	15	30.1%	46	29.9%	61
		Total		51		153		204
2	Do you currently hold a list of children, young people and adults with a learning disability waiting for assessment and/or treatment?	Yes	75.0%	39	29.8%	45	41.4%	84
		No	25.0%	13	70.2%	106	58.6%	119
		Total		52		151		203
3	Our organisation routinely monitors waiting times for people with a learning disability and/or autism, and reports concerning waits to the board	Strongly Agree	35.3%	18	6.7%	10	13.9%	28
		Tend to Agree	19.6%	10	19.3%	29	19.4%	39
		Neither Agree or Disagree	21.6%	11	16.7%	25	17.9%	36
		Tend to Disagree	15.7%	8	34.7%	52	29.9%	60
		Strongly Disagree	7.8%	4	22.0%	33	18.4%	37
		Don't know	0.0%	0	0.7%	1	0.5%	1
		Total		51		150		201
4	Our organisation has policies which require staff to intermittently contact people with a learning disability and/or autism on waiting lists to see if the situation is becoming more urgent	Yes	38.0%	19	7.3%	11	15.0%	30
		No	18.0%	9	67.3%	101	55.0%	110
		Partially	44.0%	22	25.3%	38	30.0%	60
		Total		50		150		200
5	Average number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2019	-	1773	41	1556	129	1608	170
6	Average number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2019 as a % of total patients on the Trust EPR	-	3.8%	41	0.3%	113	1.2%	154
7	Do you monitor/compare the emergency readmission rates for children, young people and adults with a learning disability, with those of people without learning disabilities?	Yes	31.1%	14	21.9%	32	24.1%	46
		No	68.9%	31	78.1%	114	75.9%	145
		Total		45		146		191
8	Average hospital readmission rate for general population patients in 2018/19?	-	7.5%	20	8.1%	55	7.9%	75

Figure	Respecting and protecting rights - Organisational level	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
9	Average hospital readmission rate for patients with learning disabilities in 2018/19	-	5.5%	20	10.7%	45	9.1%	65
10	Our organisation regularly audits any restrictions and/or deprivations of liberty it places on people with a learning disability and/or autism	Yes	67.3%	33	56.8%	84	59.4%	117
		No	18.4%	9	16.9%	25	17.3%	34
		Partially	14.3%	7	26.4%	39	23.4%	46
		Total		49		148		197
11	Have you undertaken an audit of restrictive practices in the last 12 months?	Yes	77.1%	37	52.3%	78	58.4%	115
		No	22.9%	11	47.7%	71	41.6%	82
		Total		48		149		197
12	Do you have a policy on the use of force to hold or restrain children, young people and adults with a learning disability and autistic people, who lack the competence of capacity to consent?	Yes	94.0%	47	83.6%	127	86.1%	174
		No	6.0%	3	16.4%	25	13.9%	28
		Total		50		152		202
13	If you have a policy on the use of force to hold or restrain people with learning disabilities and/or autism, is it deemed to be in their best interests in order that necessary care and treatment can be delivered?	Yes	100.0%	47	96.2%	125	97.2%	172
		No	0.0%	0	3.8%	5	2.8%	5
		Total		47		130		177
14	Average number of patient safety incidents recorded concerning children, young people and adults with a learning disability or autistic people in 2018/19	-	540.77	39	156.18	122	249.34	161
15	Average number of patient safety incidents recorded for people with a learning disability and/or autism in 2018/19 per 100 children, young people and adults with a learning disability flag on the EPR	-	43.82	29	13.98	90	21.26	119
16	Average number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2018/19	-	3.37	46	3.64	138	3.57	184
17	Average number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2018/19 per 100 people with a learning disability flag on the EPR	-	0.62	36	0.45	102	0.49	138

Figure	Respecting and protecting rights - Organisational level	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
18	Average number of safeguarding referrals concerning children, young people and adults with a learning disability or autistic people in 2018/19	-	54.30	33	18.75	106	27.19	139
19	Average number of safeguarding referrals concerning people with a learning disability and/or autism in 2018/19 per 100 people with a learning disability flag on the EPR	-	4.47	26	1.78	81	2.43	107
20	Average number of safeguarding referrals regarding people with a learning disability and/or autism in 2018/19 which met the criteria for a section 42 safeguarding/care act enquiry	-	5.42	24	5.43	76	5.43	100
21	Average number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2018/19.	-	8.88	41	3.63	115	5.01	156
22	Average number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2018/19 as a % of total complaints	-	4.1%	40	1.0%	107	1.8%	147
23	Average number of people with a learning disability who died whilst on an active caseload or within 3 months of the case being closed or discharged in 2018/19	-	25.38	45	12.45	120	15.98	165
24	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of choking incidents	-	0.18	40	0.10	115	0.12	155
25	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of choking incidents per 100 patients with an LD flag on the EPR		0.01	31	0.01	89	0.01	120
26	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of sepsis	-	1.15	41	1.53	120	1.43	161
27	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of sepsis per 100 patients with an LD flag on the EPR	-	0.13	32	0.15	92	0.14	124
28	Average number of epilepsy related deaths of people with a learning disability that took place in 2018/19	-	0.51	39	0.27	115	0.33	154
29	Average number of epilepsy related deaths of people with a learning disability that took place in 2018/19 per 100 patients with an LD flag on the EPR	-	0.03	30	0.02	90	0.02	120

Figure	Respecting and protecting rights - Organisational level	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
30	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of gastrointestinal obstructions	-	0.45	40	0.35	116	0.38	156
31	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of gastrointestinal obstructions per 100 patients with an LD flag on the EPR	-	0.04	31	0.03	91	0.04	122
32	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of pneumonia	-	4.88	42	4.13	122	4.32	164
33	Average number of deaths of people with a learning disability that took place in 2018/19 as a result of pneumonia per 100 patients with an LD flag on the EPR	-	0.35	33	0.45	93	0.42	126
34	Does your organisation ensure that staff who have trained to be LeDeR reviewers, are actively released to undertake these reviews?	Yes	88.0%	44	81.8%	112	83.4%	156
		No	12.0%	6	18.2%	25	16.6%	31
		Total		50		137		187
35	Is your organisation currently meeting the commitment to ensure that staff trained to deliver LeDeR reviews, undertake the minimum of 2-3 reviews per year?	Yes	67.3%	33	58.1%	79	60.5%	112
		No	32.7%	16	41.9%	57	39.5%	73
		Total		49		136		185

Figure	Inclusion and engagement - Organisational level	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
36	Do you have a dedicated post/position for a person(s) with a learning disability or their family carers on your Trust council of governors and/or any of your Trust Board sub-committees?	Yes	32.0%	16	29.1%	44	29.9%	60
		No	68.0%	34	70.9%	107	70.1%	141
		Total		50		151		201
37	Members of the executive team regularly meet with and take advice from people with a learning disability, autism, family carers and the front line workers who support them	Strongly Agree	7.84%	4	12.42%	19	11.27%	23
		Tend to Agree	50.98%	26	24.18%	37	30.88%	63
		Neither Agree or Disagree	23.53%	12	25.49%	39	25.00%	51
		Tend to Disagree	15.69%	8	24.84%	38	22.55%	46
		Strongly Disagree	1.96%	1	11.11%	17	8.82%	18
		Don't know	0.00%	0	1.96%	3	1.47%	3
		Total		51		153		204
38	Are children, young people and adults with a learning disability, who have multiple long term conditions, assigned an identified coordinator/key worker, either from your Trust, or from another NHS provider, on the basis of a service level agreement?	Yes	66.0%	33	39.6%	57	46.4%	90
		No	34.0%	17	60.4%	87	53.6%	104
		Total		50		144		194
39	Does your organisation provide appointments at times of day and duration to make it easier for children, young people and adults with a learning disability, or autistic people (and their families) to attend?	Yes	93.9%	46	92.1%	140	92.5%	186
		No	6.1%	3	7.9%	12	7.5%	15
		Total		49		152		201
39	Is your organisation able to accommodate carers overnight on site (acute hospitals)?	Yes	43.8%	7	97.8%	131	92.0%	138
		No	56.3%	9	2.2%	3	8.0%	12
		Total		16		134		150
39	Does your organisation's triage processes prioritise children, young people and adults with a learning disability, or autistic people?	Yes	63.0%	29	74.3%	110	71.6%	139
		No	37.0%	17	25.7%	38	28.4%	55
		Total		46		148		194
39	Does your organisation provide a low stimulus area/waiting area?	Yes	70.0%	35	71.8%	107	71.4%	142
		No	30.0%	15	28.2%	42	28.6%	57
		Total		50		149		199
39	Does your organisation provide home visits for children, young people and adults with a learning disability, or autistic people, instead of an outpatient appointment?	Yes	96.0%	48	52.3%	79	63.2%	127
		No	4.0%	2	47.7%	72	36.8%	74
		Total		50		151		201

Figure	Inclusion and engagement - Organisational level	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
39	Does your organisation provide accessible appointment letters?	Yes	92.0%	46	48.3%	72	59.3%	118
		No	8.0%	4	51.7%	77	40.7%	81
		Total		50		149		199
39	Do you have a policy which makes it clear that reasonable adjustments should be provided to autistic people?	Yes	55.3%	26	57.1%	84	56.7%	110
		No	44.7%	21	42.9%	63	43.3%	84
		Total		47		147		194
39	Does your organisation provide a changing places toilet facilities?	Yes	39.2%	20	53.3%	80	49.8%	100
		No	60.8%	31	46.7%	70	50.2%	101
		Total		51		150		201
40	Average number of designated acute learning disability liaison staff employed (WTE)	-	2.39	45	1.19	151	1.47	196
41	Average number of registered LD nurses as a % of designated acute learning disability liaison staff employed (WTE)	-	78.3%	25	81.1%	98	80.5%	123
42	Do you have a partnership agreement with another Trust to provide acute learning disability liaison nurse services?	Yes	52.1%	25	35.3%	53	39.4%	78
		No	47.9%	23	64.7%	97	60.6%	120
		Total		48		150		198
43	Does your Trust employ people with a learning disability or autism?	Yes	82.6%	38	86.9%	119	85.8%	157
		No	17.4%	8	13.1%	18	14.2%	26
		Total		46		137		183
44	Average WTE of workforce employed with a learning disability (paid employment only)	-	14.27	21	23.08	50	20.48	71
45	Our organisation uses 'Ask Listen Do', and makes reasonable adjustments to the complaints processes, to avoid people with a learning disability and/or autism having excessive form filling	Strongly Agree	34.00%	17	23.68%	36	26.24%	53
		Tend to Agree	44.00%	22	46.05%	70	45.54%	92
		Neither Agree or Disagree	14.00%	7	13.82%	21	13.86%	28
		Tend to Disagree	4.00%	2	13.16%	20	10.89%	22
		Strongly Disagree	4.00%	2	1.32%	2	1.98%	4
		Don't know	0.00%	0	1.97%	3	1.49%	3
		Total		50		152		202
46	Is your organisation using 'Ask Listen Do' good practice resources to improve feedback, concerns and complaints for children, young people and adults with a learning disability, autistic people and families?	Yes	40.0%	20	43.6%	65	42.7%	85
		No	60.0%	30	56.4%	84	57.3%	114
		Total		50		149		199

Figure	Workforce - Organisational level	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
47	Does your organisation have a board level lead responsible for monitoring and assuring the quality of service being provided to children, young people and adults with a learning disability and autistic people?	Yes	96.0%	48	96.0%	144	96.0%	192
		No	4.0%	2	4.0%	6	4.0%	8
		Total		50		150		200
48	Which professional role best describes the executive role of your board member who leads on quality assurance for learning disabilities and autism?	Nursing	44.00%	22	84.62%	121	74.09%	143
		Quality director	20.00%	10	6.29%	9	9.84%	19
		Operations director or equivalent	24.00%	12	3.50%	5	8.81%	17
		Medical director or equivalent	6.00%	3	4.90%	7	5.18%	10
		Other	6.00%	3	0.70%	1	2.07%	4
		Total		50		143		193
49	Does your workforce plan include data on current and future issues arising from retention/recruitment difficulties relating to the learning disabilities workforce?	Yes	73.5%	36	25.2%	36	37.5%	72
		No	26.5%	13	74.8%	107	62.5%	120
		Total		49		143		192
50	Does your workforce plan include provisions to support the development of new roles in learning disabilities care?	Yes	85.7%	42	42.1%	61	53.1%	103
		No	14.3%	7	57.9%	84	46.9%	91
		Total		49		145		194
51	Do staff receive up-to-date training covering learning disabilities / autism awareness?	Yes	81.3%	39	83.3%	125	82.8%	164
		No	18.8%	9	16.7%	25	17.2%	34
		Total		48		150		198
52	Of staff who receive up-to-date training covering learning disabilities / autism awareness, what percentage were trained in this in 2018/19?	-	70.07%	21	55.17%	87	58.07%	108
53	Does your Trust induction programme invite children, young people and adults with a learning disability or autism to contribute to staff training?	Yes	24.5%	12	16.0%	24	18.1%	36
		No	75.5%	37	84.0%	126	81.9%	163
		Total		49		150		199
54	Does your organisation provide training to help those who provide day to day care and support, to understand how to recognise and respond to signs of emerging health problems for children, young people and adults with a learning disability or autistic people?	Yes	85.7%	42	71.2%	104	74.9%	146
		No	14.3%	7	28.8%	42	25.1%	49
		Total		49		146		195

Figure	Workforce - Organisational level	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
55	Our staff are trained to recognise their responsibilities to make, record, report and share reasonable adjustments to the delivery of care/support, when working with people with a learning disability and/or autism	Strongly Agree	46.00%	23	33.33%	51	36.45%	74
		Tend to Agree	42.00%	21	48.37%	74	46.80%	95
		Neither Agree or Disagree	12.00%	6	11.11%	17	11.33%	23
		Tend to Disagree	0.00%	0	6.54%	10	4.93%	10
		Strongly Disagree	0.00%	0	0.65%	1	0.49%	1
		Don't know	0.00%	0	0.00%	0	0.00%	0
		Total		50		153		203
56	Our staff are trained to identify a child, young person or adult at risk of abuse and to help them understand and make sense of safeguarding processes and procedures.	Strongly Agree	92.16%	47	84.97%	130	86.76%	177
		Tend to Agree	7.84%	4	13.07%	20	11.76%	24
		Neither Agree or Disagree	0.00%	0	0.65%	1	0.49%	1
		Tend to Disagree	0.00%	0	0.65%	1	0.49%	1
		Strongly Disagree	0.00%	0	0.65%	1	0.49%	1
		Don't know	0.00%	0	0.00%	0	0.00%	0
		Total		51		153		204
57	Our staff feel empowered to raise concerns about medication, in order to ensure that people with learning disabilities and/or autism are not over medicated	Strongly Agree	62.00%	31	39.87%	61	45.32%	92
		Tend to Agree	36.00%	18	36.60%	56	36.45%	74
		Neither Agree or Disagree	2.00%	1	17.65%	27	13.79%	28
		Tend to Disagree	0.00%	0	3.92%	6	2.96%	6
		Strongly Disagree	0.00%	0	1.31%	2	0.99%	2
		Don't know	0.00%	0	0.65%	1	0.49%	1
		Total		50		153		203
58	Does your organisation actively involve children, young people and adults with a learning disability or autism and their families in checking the quality of the services being provided and developing improvement plans as a result?	Yes	74.5%	35	64.9%	98	67.2%	133
		No	25.5%	12	35.1%	53	32.8%	65
		Total		47		151		198

Figure	Specialist learning disability - Organisational level	Response	Specialist National	n=
59	Does your service provide: Specialist community learning disability teams?	Yes	96.0%	48
		No	4.0%	2
		Total		50
59	Does your service provide: Autism diagnostic services?	Yes	83.7%	41
		No	16.3%	8
		Total		49
59	Does your service provide: Intensive community support teams?	Yes	82.0%	41
		No	18.0%	9
		Total		50
59	Does your service provide: Inpatient Assessment and Treatment Unit (ATU)?	Yes	56.0%	28
		No	44.0%	22
		Total		50
59	Does your service provide: Community forensic learning disability team?	Yes	42.9%	21
		No	57.1%	28
		Total		49
59	Does your service provide: Low Secure inpatient unit?	Yes	32.0%	16
		No	68.0%	34
		Total		50
59	Does your service provide: Medium Secure inpatient unit?	Yes	22.0%	11
		No	78.0%	39
		Total		50
59	Does your service provide: Long term continuing care / rehabilitation inpatient unit?	Yes	18.4%	9
		No	81.6%	40
		Total		49
59	Does your service provide: Autism specific inpatient unit?	Yes	4.1%	2
		No	95.9%	47
		Total		49
59	Does your service provide: High secure inpatient unit?	Yes	2.0%	1
		No	98.0%	48
		Total		49
60	Do you operate a dynamic risk/support register with regards to people with a learning disability and/or autism in community settings?	Yes	75.0%	36
		No	8.3%	4
		Partially	16.7%	8
		Total		48
61	If you provide an intensive community support service, do the staff provide crisis support?	Yes	81.4%	35
		No	18.6%	8
		Total		43
62	If you provide an intensive community support service is it available 7 days per week?	Yes	51.2%	22
		No	48.8%	21
		Total		43
63	Our Community Specialist Practitioners are always able to remain fully involved and contribute to MDT planning processes when someone on their caseload is admitted to hospital due to concerns regarding their mental health or behaviours.	Strongly Agree	66.0%	33
		Tend to Agree	32.0%	16
		Neither Agree or Disagree	2.0%	1
		Tend to Disagree	0.0%	0
		Strongly Disagree	0.0%	0
		Don't know	0.0%	0
		Total		50

Figure	Specialist learning disability - Organisational level	Response	Specialist National	n=
64	Our organisation always considers whether the needs of people with a learning disability and/or autism in inpatient services might be better met in a community setting	Strongly Agree	92.0%	46
		Tend to Agree	8.0%	4
		Neither Agree or Disagree	0.0%	0
		Tend to Disagree	0.0%	0
		Strongly Disagree	0.0%	0
		Don't know	0.0%	0
		Total		50
65	Does your organisation ensure that children, young people and adults with a learning disability and autistic people who are in hospital, and family carers are meaningfully involved (as equal partners) in admission, assessment, formulation, care planning, care reviews and discharge planning?	Yes	100.0%	47
		No	0.0%	0
		Total		47
66	Where a person with a learning disability and/or autism is admitted to hospital due to concerns about their behaviour or mental health, a staff members from the hospital is identified at the point of admission, to work closely on discharge planning with a community based care coordinator	Strongly Agree	60.4%	29
		Tend to Agree	35.4%	17
		Neither Agree or Disagree	4.2%	2
		Tend to Disagree	0.0%	0
		Strongly Disagree	0.0%	0
		Don't know	0.0%	0
		Total		48
67	Does your organisation monitor target discharge dates and actual discharge dates for children, young people and adults with a learning disability, and autistic people, in hospital?	Yes	76.1%	35
		No	23.9%	11
		Total		46
68	Does your organisation provide Positive Behaviour Support (PBS)?	Yes	100.0%	50
		No	0.0%	0
		Total		50
69	Does your organisation provide functional assessments of behaviours of concern, in accordance with NICE guidance?	Yes	100.0%	49
		No	0.0%	0
		Total		49
70	Does your organisation train all learning disabilities clinical staff in PBS, in accordance with the competencies associated with their specific role?	Yes	86.0%	43
		No	14.0%	7
		Total		50

Figure	Supplementary - Organisational level	Response	Specialist National	n=
71	Do you have an organisational restraint reduction programme/policy?	Yes	91.7%	44
		No	8.3%	4
		Total		48
71	Do you have a named board level lead for reducing restrictive interventions?	Yes	89.4%	42
		No	10.6%	5
		Total		47
71	Has the organisational restraint reduction programme/policy been reviewed in the last 12 months?	Yes	79.5%	35
		No	20.5%	9
		Total		44
71	Were people with lived experience of using services involved in developing the policy?	Yes	65.9%	27
		No	34.1%	14
		Total		41
72	Does the report include how often the techniques are used?	Yes	87.9%	29
		No	12.1%	4
		Total		33
72	Does the report include details of techniques used?	Yes	82.4%	28
		No	17.6%	6
		Total		34
72	Do you publish an annual report on restraint and restraint reduction?	Yes	70.5%	31
		No	29.5%	13
		Total		44
72	Does the report include the number of significant injuries to patients and/or staff as a result of restraint?	Yes	62.5%	20
		No	37.5%	12
		Total		32
72	Does the report include the Trust training strategy?	Yes	61.8%	21
		No	38.2%	13
		Total		34
72	Is an accessible version available?	Yes	34.4%	11
		No	65.6%	21
		Total		32
73	Do you hold risk assessments for each individual physical restraint technique taught to your staff?	All	85.37%	35
		Most	2.44%	1
		Some	2.44%	1
		None	9.76%	4
		Total		41
74	Our organisation provides individualised behaviour support plans, for all people with a learning disability and/or autism, who have been assessed as being at risk of being exposed to restrictive interventions	Strongly Agree	51.06%	24
		Tend to Agree	46.81%	22
		Neither Agree or Disagree	0.00%	0
		Tend to Disagree	0.00%	0
		Strongly Disagree	0.00%	0
		Don't know	2.13%	1
		Total		47
75	Do you provide people who use your services and their families, with accessible information concerning their rights, including in relation to the possible use of restrictive interventions?	Yes	84.1%	37
		No	15.9%	7
		Total		44

Figure	Supplementary - Organisational level	Response	Specialist National	n=
76	With regard to inpatients, do you routinely establish agreements with patients and families, about informing families whenever any form of restrictive interventions have been used?	Yes	81.0%	34
		No	19.0%	8
		Total		42
77	Are patients' accounts of incidents and their feelings, anxieties or concerns following the use of restrictive interventions, recorded in their notes?	Always	37.2%	16
		Mostly	39.5%	17
		Sometimes	23.3%	10
		Never	0.0%	0
		Total		43
78	Average number of children, young people and adults with a learning disability and autistic people who have experienced the use of physical restraint in 2018/19	-	25.89	37
79	Average number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2018/19	-	319.68	38
80	Average number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2018/19 per 100 children, young people and adults with a learning disability flag on the EPR	-	27.34	30
81	In the exceptional circumstance that there are felt to be cogent reasons to devise a plan for the prone restraint of a patient, are these authorised / signed off by a director of the Trust?	Always	28.6%	6
		Mostly	0.0%	0
		Sometimes	0.0%	0
		Never	71.4%	15
		Total		21
82	Has your board approved the use of mechanical restraint?	Yes	28.9%	13
		No	71.1%	32
		Total		45
83	Average number of children, young people and adults with a learning disability and autistic people who experienced use of mechanical restraint in 2018/19	-	0.96	25
84	Where a person with a learning disability and/or autism is thought to need a plan for the use of mechanical restraint, is an IMHA consulted as part of the care planning process?	Always	57.1%	4
		Mostly	14.3%	1
		Sometimes	14.3%	1
		Never	14.3%	1
		Total		7
85	Do people with learning disabilities and/or autism who are subjected to mechanical restraint have a specific care plan to reduce the requirement for its use?	Always	100.0%	8
		Mostly	0.0%	0
		Sometimes	0.0%	0
		Never	0.0%	0
		Total		8
86	Is the RC or duty doctor informed, without delay, each and every time a mechanical restraint device is applied to a patient?	Yes	90.9%	10
		No	9.1%	1
		Total		11

Figure	Supplementary - Organisational level	Response	Specialist National	n=
87	Do you have a medical review following the application of a mechanical restraint device?	Always	100.0%	10
		Mostly	0.0%	0
		Sometimes	0.0%	0
		Never	0.0%	0
		Total		10
88	Has your board approved the use of long term segregation in your Trust?	Yes	55.6%	25
		No	44.4%	20
		Total		45
89	Do you routinely notify the local authority safeguarding team when a patient is placed in long term segregation?	Yes	77.8%	21
		No	22.2%	6
		Total		27
90	Average number of children, young people and adults with a learning disability and autistic people who experienced use of long-term segregation in 2018/19	-	3.5	28
91	Where a patient is continually segregated for more than 3 months, do they have access to an external hospital review?	Yes	100.0%	25
		No	0.0%	0
		Total		25
92	Does this routinely include consultation with the patient's IMHA?	Yes	95.7%	22
		No	4.3%	1
		Total		23
93	Does your organisation have a policy to safeguard children, young people and adults with a learning disability, and autistic people, from the inappropriate prescribing of psychotropic medication?	Yes	58.3%	28
		No	41.7%	20
		Total		48
94	Is your Trust signed up to stopping over medication of adults with a learning disability and autistic people with psychotropic medication?	Yes	93.8%	45
		No	6.3%	3
		Total		48
95	Is your Trust signed up to supporting treatment and appropriate use of psychotropic medication in paediatrics?	Yes	91.2%	31
		No	8.8%	3
		Total		34
96	Does your Trust provide regular medication reviews?	Yes	94.0%	47
		No	6.0%	3
		Total		50
97	Has your organisation signed the STOMP pledge?	Yes	77.6%	38
		No	22.4%	11
		Total		49
98	Has your organisation undertaken a STOMP audit?	Yes	83.3%	40
		No	16.7%	8
		Total		48

Figure	Respecting and protecting rights - Staff survey	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
99	What systems are in place in your Trust for identifying and recording that a child, young person or adult has a learning disability?	Documented in medical notes	-	-	71%	3256	71%	3256
		Documented in nursing notes	-	-	57%	2605	57%	2605
		Documented electronically	-	-	70%	3231	71%	3231
		Sticker on patient notes	-	-	11%	526	12%	526
		Other	-	-	9%	425	9%	425
		Do not have any systems	-	-	1%	66	1%	66
		Don't know	-	-	6%	256	6%	256
		Total	-	-	-	-	-	-
100	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to appointments	Yes	87%	1301	67%	2922	72%	4223
		No	5%	73	3%	109	3%	182
		Don't know	9%	130	30%	1324	25%	1454
		Total		1504		4355		5859
100	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to flexible appointments	Yes	75%	1112	47%	2004	54%	3116
		No	6%	84	6%	265	6%	349
		Don't know	19%	285	47%	2003	40%	2288
		Total		1481		4272		5753
100	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to first or last clinic appointments	Yes	66%	936	44%	1836	49%	2772
		No	6%	82	6%	237	6%	319
		Don't know	28%	400	51%	2147	45%	2547
		Total		1418		4220		5638
100	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to double appointments	Yes	65%	919	40%	1672	46%	2591
		No	6%	90	7%	293	7%	383
		Don't know	29%	411	53%	2250	47%	2661
		Total		1420		4215		5635
101	I feel able to identify what reasonable adjustments are needed for children, young people and adults with a learning disability or autistic people.	Strongly Agree	48%	747	22%	985	28%	1732
		Agree	41%	639	55%	2493	51%	3132
		Neither agree nor disagree	5%	77	14%	627	12%	704
		Disagree	2%	31	7%	302	5%	333
		Strongly Disagree	3%	47	3%	159	3%	206
		Total		1541		4566		6107
102	I have the necessary resources to meet the needs of children, young people and adults with a learning disability or autistic people e.g. communication needs, equipment.	Strongly Agree	19%	295	11%	490	13%	785
		Agree	49%	751	44%	2005	45%	2756
		Neither agree nor disagree	15%	236	26%	1178	23%	1414
		Disagree	13%	198	16%	729	15%	927
		Strongly Disagree	3%	52	3%	134	3%	186
		Total		1532		4536		6068
103	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	29%	441	14%	645	18%	1086
		Agree	48%	735	47%	2142	47%	2877
		Neither agree nor disagree	13%	203	23%	1046	21%	1249
		Disagree	9%	134	14%	614	12%	748
		Strongly Disagree	2%	24	2%	100	2%	124
		Total		1537		4547		6084

Figure	Respecting and protecting rights - Staff survey	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
104	I am always able to deliver safe care to a child, young person, or adult with a learning disability or autistic people.	Strongly Agree	30%	458	18%	802	21%	1260
		Agree	52%	793	56%	2525	55%	3318
		Neither agree nor disagree	11%	174	19%	843	17%	1017
		Disagree	6%	88	7%	314	7%	402
		Strongly Disagree	1%	14	1%	58	1%	72
		Total		1527		4542		6069
105	Children, young people and adults with a learning disability or autistic people get the same quality of care as any other person.	Strongly Agree	-	-	28%	1251	28%	1251
		Agree	-	-	46%	2084	46%	2084
		Neither agree nor disagree	-	-	15%	688	15%	688
		Disagree	-	-	8%	378	8%	378
		Strongly Disagree	-	-	2%	89	2%	89
		Total	-	-		4490		4490
106	Staff in the Trust always tell children, young people and adults with a learning disability or autistic people and families about their rights when using services.	Strongly Agree	24%	365	9%	425	13%	790
		Agree	46%	704	32%	1468	36%	2172
		Neither agree nor disagree	21%	324	42%	1887	36%	2211
		Disagree	8%	126	14%	637	13%	763
		Strongly Disagree	1%	13	3%	116	2%	129
		Total		1532		4533		6065
107	In your Trust, if a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) form (or equivalent) is completed for a child, young person or adult with a learning disability or autistic people, is there a clear policy to double check, to ensure that there is a valid reason?	Yes	41%	118	40%	1433	40%	1551
		No	4%	11	3%	125	4%	136
		Don't know	55%	160	57%	2032	57%	2192
		Total		289		3590		3879
108	If a child, young person or adult with a learning disability or autistic people dies under the care of our service, the findings and outcomes from the Trust investigation are shared with staff team members.	Strongly Agree	21%	321	12%	557	14%	878
		Agree	41%	627	33%	1487	35%	2114
		Neither agree nor disagree	28%	428	43%	1965	40%	2393
		Disagree	9%	130	9%	428	9%	558
		Strongly Disagree	1%	22	2%	92	2%	114
		Total		1528		4529		6057
109	My Trust has policies and procedures to ensure the rights of autistic people are respected and protected?	Yes	76%	1144	69%	3097	71%	4241
		No	4%	58	3%	113	3%	171
		Don't know	20%	304	28%	1251	26%	1555
		Total		1506		4461		5967

Figure	Inclusion and engagement - Staff survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
110	In my Trust, I feel children, young people and adults with a learning disability and autistic people are always treated with dignity and respect.	Strongly Agree	41%	628	30%	1364	33%	1992
		Agree	47%	717	52%	2371	51%	3088
		Neither agree nor disagree	8%	122	13%	571	11%	693
		Disagree	3%	51	4%	197	4%	248
		Strongly Disagree	1%	13	1%	50	1%	63
		Total		1531		4553		6084
111	In my trust, I feel family members of children, young people and adults with a learning disability, and autistic people, are always treated with dignity and respect.	Strongly Agree	38%	576	29%	1315	31%	1891
		Agree	49%	749	53%	2420	52%	3169
		Neither agree nor disagree	10%	159	13%	614	13%	773
		Disagree	2%	37	4%	161	3%	198
		Strongly Disagree	1%	12	1%	39	1%	51
		Total		1533		4549		6082
112	I routinely involve children, young people and adults with a learning disability, and autistic people when making decisions about their care and treatment.	Strongly Agree	52%	800	32%	1440	37%	2240
		Agree	40%	607	49%	2235	47%	2842
		Neither agree nor disagree	7%	110	17%	748	14%	858
		Disagree	0%	4	2%	75	1%	79
		Strongly Disagree	1%	10	1%	34	1%	44
		Total		1531		4532		6063
113	I routinely involve the families of children, young people and adults with a learning disability, and autistic people, when making decisions about their care and treatment.	Strongly Agree	49%	743	34%	1542	38%	2285
		Agree	42%	640	50%	2273	48%	2913
		Neither agree nor disagree	8%	122	14%	644	13%	766
		Disagree	0%	7	1%	55	1%	62
		Strongly Disagree	1%	10	1%	30	1%	40
		Total		1522		4544		6066
114	Children, young people and adults with a learning disability are routinely involved in the planning of Trust services.	Strongly Agree	10%	148	7%	303	7%	451
		Agree	30%	449	24%	1079	25%	1528
		Neither agree nor disagree	42%	641	57%	2597	54%	3238
		Disagree	15%	227	10%	454	11%	681
		Strongly Disagree	4%	54	2%	93	2%	147
		Total		1519		4526		6045
115	Families of children, young people and adults with a learning disability are routinely involved in the planning of Trust services.	Strongly Agree	8%	129	7%	320	7%	449
		Agree	29%	446	24%	1097	25%	1543
		Neither agree nor disagree	45%	693	58%	2605	54%	3298
		Disagree	14%	214	9%	421	10%	635
		Strongly Disagree	3%	50	2%	83	2%	133
		Total		1532		4526		6058

Figure Workforce - Staff survey	Response	Specialist National	n=	Universal National	n=	All Trusts National	n=
116 I have received mandatory training on meeting the needs of children, young people and adults with a learning disability, and autistic people, during the course of my work.	Yes	78%	1196	66%	2960	69%	4156
	No	22%	331	34%	1540	31%	1871
	Total		1527		4500		6027
117 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, during the course of my work.	Strongly Agree	45%	698	20%	896	26%	1594
	Agree	41%	634	51%	2342	49%	2976
	Neither agree nor disagree	8%	120	18%	825	16%	945
	Disagree	4%	67	9%	411	8%	478
	Strongly Disagree	1%	18	2%	75	2%	93
	Total		1537		4549		6086
118 I have access to additional specialist learning disability staff when I need it, to help me meet the needs of children, young people and adults with a learning disability.	Strongly Agree	48%	737	30%	1388	35%	2125
	Agree	35%	542	43%	1941	41%	2483
	Neither agree nor disagree	9%	133	15%	671	13%	804
	Disagree	6%	93	10%	442	9%	535
	Strongly Disagree	2%	27	3%	116	2%	143
	Total		1532		4558		6090
119 Children, young people and adults with a learning disability are involved in delivering awareness training to staff in my Trust.	Strongly Agree	11%	174	8%	386	9%	560
	Agree	26%	400	21%	940	22%	1340
	Neither agree nor disagree	35%	537	44%	1992	42%	2529
	Disagree	22%	335	22%	1003	22%	1338
	Strongly Disagree	5%	80	5%	228	5%	308
	Total		1526		4549		6075
120 I would recommend the Trust to a friend or family members of a child, young person or adult with a learning disability, or an autistic person, who needed treatment.	Strongly Agree	31%	477	20%	913	23%	1390
	Agree	49%	756	51%	2318	50%	3074
	Neither agree nor disagree	16%	238	25%	1134	23%	1372
	Disagree	3%	42	3%	136	3%	178
	Strongly Disagree	1%	21	1%	57	1%	78
	Total		1534		4558		6092

Figure Specialist services - Staff survey	Response	Specialist National	n=
121 Children, young people and adults with a learning disability, and people with autism, who are in hospital because of concerns about their behaviour or mental health, continue to be seen by staff from their usual community services.	Strongly Agree	21%	314
	Agree	41%	614
	Neither agree nor disagree	27%	407
	Disagree	8%	123
	Strongly Disagree	2%	23
	Total		1481
122 Children, young people and adults with a learning disability, and autistic people, who are in hospital because of concerns about their behaviour or mental health, are visited by an external care co-ordinator, case manager, or equivalent at least every 6-8 weeks.	Strongly Agree	10%	29
	Agree	34%	103
	Neither agree nor disagree	39%	117
	Disagree	12%	35
	Strongly Disagree	5%	16
	Total		300
123 Children, young people and adults with a learning disability, autistic people and family carers are involved in reviewing the appropriateness of psychotropic medications.	Strongly Agree	17%	250
	Agree	43%	644
	Neither agree nor disagree	34%	508
	Disagree	5%	74
	Strongly Disagree	1%	9
	Total		1485
124 I have had training on reducing the use of restrictive interventions.	Strongly Agree	34%	498
	Agree	37%	554
	Neither agree nor disagree	13%	189
	Disagree	13%	191
	Strongly Disagree	3%	51
	Total		1483
125 Children, young people and adults with a learning disability, and autistic people who are in hospital because of concerns about their behaviour or mental health, have good access to independent advocacy services.	Strongly Agree	39%	118
	Agree	43%	130
	Neither agree nor disagree	14%	42
	Disagree	3%	8
	Strongly Disagree	0%	1
	Total		299
126 My Trust encourages me to speak out if I have concerns about the wellbeing of children, young people and adults with a learning disability, and autistic people, in our services.	Strongly Agree	52%	780
	Agree	40%	598
	Neither agree nor disagree	6%	84
	Disagree	1%	21
	Strongly Disagree	1%	8
	Total		1491
127 My Trust has developed effective and new ways of supporting children, young people and adults with a learning disability, and autistic people, to live successfully in the community in recent years.	Yes	86%	1098
	No	14%	172
	Total		1270

Figure	Service user survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
128	When you received care from the NHS, did staff treat you with respect?	Yes	94.5%	788	92.5%	2689	92.9%	3477
		No	3.2%	27	4.2%	121	4.0%	148
		Don't know	2.3%	19	3.3%	96	3.1%	115
		Total		834		2907		3741
129	Did staff explain things to you in a way you could understand?	Yes	88.7%	719	81.0%	2240	82.7%	2959
		No	5.5%	45	11.1%	306	9.8%	351
		Don't know	5.8%	47	7.9%	219	7.4%	266
		Total		811		2766		3577
130	Did you feel like staff listened to you?	Yes	89.3%	725	83.0%	2276	84.5%	3001
		No	6.9%	56	9.6%	263	9.0%	319
		Don't know	3.8%	31	7.3%	201	6.5%	232
		Total		812		2741		3553
131	Did you feel like staff cared about you?	Yes	89.6%	746	87.6%	2547	88.1%	3293
		No	4.4%	37	6.0%	173	5.6%	210
		Don't know	6.0%	50	6.4%	185	6.3%	235
		Total		833		2906		3739
132	Did staff talk to you about the care you needed?	Yes	86.8%	700	82.7%	2303	83.6%	3003
		No	7.2%	58	9.8%	274	9.2%	332
		Don't know	6.0%	48	7.4%	206	7.1%	254
		Total		806		2784		3590
133	Did staff give you choices about how you were cared for?	Yes	76.7%	603	65.4%	1686	68.1%	2289
		No	10.8%	85	19.1%	491	17.1%	576
		Don't know	12.5%	98	15.5%	399	14.8%	497
		Total		786		2577		3363
134	Did staff listen to what your family thought?	Yes	80.9%	556	81.4%	1925	81.3%	2481
		No	7.3%	50	8.6%	203	8.3%	253
		Don't know	11.8%	81	10.0%	237	10.4%	318
		Total		687		2366		3053
135	When you received care, did you feel safe?	Yes	89.6%	731	88.0%	2511	88.3%	3242
		No	6.3%	51	5.5%	157	5.7%	208
		Don't know	4.2%	34	6.5%	185	6.0%	219
		Total		816		2854		3670
136	Did you have any concerns about your care?	Yes	20.6%	166	22.8%	637	22.3%	803
		No	70.6%	569	66.9%	1870	67.8%	2439
		Don't know	8.8%	71	10.2%	286	9.9%	357
		Total		806		2794		3600

Figure	Service user survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
137	Did you make a complaint?	Yes	12.7%	96	9.5%	254	10.2%	350
		No	83.7%	633	87.9%	2343	86.9%	2976
		Don't know	3.6%	27	2.6%	69	2.8%	96
		Total		756		2667		3423
138	If yes, were you given Easy Read information about how to make a complaint?	Yes	44.8%	117	25.3%	185	30.4%	302
		No	37.5%	98	57.5%	420	52.2%	518
		Don't know	17.6%	46	17.2%	126	17.3%	172
		Total		261		731		992
139	If you stayed in hospital, was it easy for your family to visit you?	Yes	77.3%	337	87.7%	1617	85.7%	1954
		No	17.2%	75	7.8%	144	9.6%	219
		Don't know	5.5%	24	4.4%	81	4.6%	105
		Total		436		1843		2279
140	Did staff tell you about your appointments and meetings in a way you could understand?	Yes	88.1%	651	79.2%	1922	81.3%	2573
		No	6.5%	48	12.1%	294	10.8%	342
		Don't know	5.4%	40	8.6%	209	7.9%	249
		Total		739		2426		3165
141	Were your appointments and meetings arranged to suit you?	Yes	86.0%	667	76.2%	1923	78.5%	2590
		No	8.1%	63	14.6%	368	13.1%	431
		Don't know	5.9%	46	9.2%	233	8.5%	279
		Total		776		2525		3301
142	If you needed to be seen in an emergency, were you seen quickly?	Yes	77.2%	426	70.6%	1448	72.0%	1874
		No	13.0%	72	20.8%	427	19.2%	499
		Don't know	9.8%	54	8.5%	174	8.8%	228
		Total		552		2050		2602
143	Would you recommend this service to a friend or family?	Yes	83.4%	674	83.2%	2377	83.2%	3051
		No	8.8%	71	6.5%	185	7.0%	256
		Don't know	7.8%	63	10.3%	294	9.7%	357
		Total		808		2857		3665

Appendix 2: Participants

Organisation Name	Peer Group	Organisational level	Staff survey	Service user survey
Airedale NHS Foundation Trust	Universal	✓	6	31
Alder Hey Children's NHS Foundation Trust	Universal	✓	31	0
Ashford and St Peter's Hospitals NHS Foundation Trust	Universal	✓	14	0
Avon and Wiltshire Mental Health Partnership NHS Trust	Specialist	✓	23	8
Barking, Havering and Redbridge University Hospitals NHS Trust	Universal	✓	40	37
Barnet, Enfield and Haringey Mental Health NHS Trust	Specialist	✓	20	1
Barnsley Hospital NHS Foundation Trust	Universal	✓	16	0
Barts Health NHS Trust	Universal	✓	52	28
Basildon and Thurrock University Hospitals NHS Foundation Trust	Universal	✓	17	19
Bedford Hospital NHS Trust	Universal	✓	9	19
Berkshire Healthcare NHS Foundation Trust	Specialist	✓	20	18
Birmingham and Solihull Mental Health NHS Foundation Trust	Universal	✓	51	8
Birmingham Community Healthcare NHS Foundation Trust	Specialist	✓	21	18
Birmingham Women's and Children's NHS Foundation Trust	Universal	✓	52	13
Black Country Partnership NHS Foundation Trust	Specialist	✓	33	12
Blackpool Teaching Hospitals NHS Foundation Trust	Specialist	✓	24	27
Bolton NHS Foundation Trust	Universal	✓	21	25
Bradford District NHS Foundation Trust	Specialist	✓	28	28
Bradford Teaching Hospitals NHS Foundation Trust	Universal	✓	22	4
Bridgewater Community Healthcare NHS Foundation Trust	Universal	✓	40	0
Buckinghamshire Healthcare NHS Trust	Universal	✓	43	32
Calderdale and Huddersfield NHS Foundation Trust	Universal	✓	52	40
Cambridge University Hospitals NHS Foundation Trust	Universal	✓	51	14
Cambridgeshire and Peterborough NHS Foundation Trust	Specialist	✓	13	19
Central and North West London NHS Foundation Trust	Specialist	✓	38	6
Central London Community Healthcare NHS Trust	Universal	✓	51	22
Chelsea and Westminster Hospital NHS Foundation Trust	Universal	✓	27	19
Cheshire and Wirral Partnership NHS Foundation Trust	Specialist	✓	16	0
Chesterfield Royal Hospital NHS Foundation Trust	Specialist	✓	4	13
Cornwall Partnership NHS Foundation Trust	Specialist	✓	20	2

Organisation Name	Peer Group	Organisational level	Staff survey	Service user survey
Countess of Chester Hospital NHS Foundation Trust	Universal	✓	11	3
County Durham and Darlington NHS Foundation Trust	Universal	x	0	4
Coventry and Warwickshire Partnership NHS Trust	Specialist	✓	29	5
Croydon Health Services NHS Trust	Universal	✓	1	0
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	Specialist	✓	51	1
Cygnet Health Care	Specialist	✓	43	29
Dartford and Gravesham NHS Trust	Universal	✓	5	29
Derbyshire Community Health Services NHS Foundation Trust	Specialist	✓	27	6
Derbyshire Healthcare NHS Foundation Trust	Specialist	✓	17	2
Devon Partnership NHS Trust	Specialist	✓	27	13
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	Universal	✓	44	25
Dorset County Hospital NHS Foundation Trust	Universal	✓	14	27
Dorset HealthCare University NHS Foundation Trust	Specialist	✓	20	25
Dudley and Walsall Mental Health Partnership NHS Trust	Universal	✓	3	10
East and North Hertfordshire NHS Trust	Universal	✓	51	32
East Cheshire NHS Trust	Universal	✓	29	10
East Kent Hospitals University NHS Foundation Trust	Universal	✓	50	21
East Lancashire Hospitals NHS Trust	Universal	✓	10	16
East London NHS Foundation Trust	Specialist	✓	35	26
East Of England Ambulance Service NHS Trust	Universal	✓	0	0
East Suffolk and North Essex NHS Foundation Trust	Universal	✓	53	41
Epsom and St Helier University Hospitals NHS Trust	Universal	✓	51	21
Essex Partnership University NHS Foundation Trust	Universal	✓	9	20
Frimley Health NHS Foundation Trust	Universal	✓	18	26
Gateshead Health NHS Foundation Trust	Universal	✓	0	0
George Eliot Hospital NHS Trust	Universal	✓	8	0
Gloucestershire Health and Care NHS Foundation Trust	Universal	✓	22	11
Gloucestershire Hospitals NHS Foundation Trust	Universal	✓	28	35
Great Ormond Street Hospital for Children NHS Foundation Trust	Universal	✓	51	0
Great Western Hospitals NHS Foundation Trust	Universal	✓	52	13
Greater Manchester Mental Health NHS Foundation Trust	Universal	✓	63	2
Guy's and St Thomas' NHS Foundation Trust	Universal	✓	21	6
Hampshire Hospitals NHS Foundation Trust	Universal	✓	40	0
Harrogate and District NHS Foundation Trust	Universal	✓	51	41
Hertfordshire Community NHS Trust	Universal	✓	17	24
Hertfordshire Partnership University NHS Foundation Trust	Specialist	✓	51	46
Homerton University Hospital NHS Foundation Trust	Universal	✓	47	29
Hounslow and Richmond Community Healthcare NHS Trust	Universal	✓	41	30

Organisation Name	Peer Group	Organisational level	Staff survey	Service user survey
Hull University Teaching Hospitals NHS Trust	Universal	✓	25	0
Humber NHS Foundation Trust	Specialist	✓	26	12
Imperial College Healthcare NHS Trust	Universal	✓	14	32
Isle of Wight NHS Trust	Specialist	✓	18	25
James Paget University Hospitals NHS Foundation Trust	Universal	✓	7	21
Kent and Medway NHS and Social Care Partnership Trust	Specialist	✓	4	26
Kent Community Health NHS Foundation Trust	Specialist	✓	36	13
Kettering General Hospital NHS Foundation Trust	Universal	✓	17	7
King's College Hospital NHS Foundation Trust	Universal	✓	51	28
Lancashire Care NHS Foundation Trust	Specialist	✓	53	21
Lancashire Teaching Hospitals NHS Foundation Trust	Universal	✓	52	17
Leeds and York Partnership NHS Foundation Trust	Specialist	✓	51	18
Leeds Community Healthcare NHS Trust	Universal	✓	51	0
Leeds Teaching Hospitals NHS Trust	Universal	✓	21	17
Leicestershire Partnership NHS Trust	Specialist	✓	35	7
Lewisham and Greenwich NHS Trust	Universal	✓	0	7
Lincolnshire Community Health Services NHS Trust	Universal	✓	39	16
Lincolnshire Partnership NHS Foundation Trust	Specialist	✓	43	18
Liverpool Heart and Chest NHS Foundation Trust	Universal	✓	50	1
Liverpool University Hospitals NHS Foundation Trust	Universal	✓	32	26
Liverpool Women's NHS Foundation Trust	Universal	✓	7	6
Livewell Southwest	Specialist	✓	18	16
Locala Community Social Enterprise	Universal	✓	22	0
London North West University Healthcare NHS Trust	Universal	✓	51	57
Luton and Dunstable University Hospital NHS Foundation Trust	Universal	✓	3	20
Maidstone and Tunbridge Wells NHS Trust	Universal	✓	52	20
Manchester University NHS Foundation Trust	Universal	✓	51	20
Medway NHS Foundation Trust	Universal	✓	18	30
Mersey Care NHS Foundation Trust	Specialist	✓	51	58
Mid Cheshire Hospitals NHS Foundation Trust	Universal	✓	15	13
Mid Essex Hospital Services NHS Trust	Universal	✓	51	29
Mid Yorkshire Hospitals NHS Trust	Universal	✓	43	80
Midlands Partnership NHS Foundation Trust	Specialist	✓	51	13
Milton Keynes University Hospital NHS Foundation Trust	Universal	✓	24	1
Moorfields Eye Hospital NHS Foundation Trust	Universal	✓	23	50
Norfolk and Norwich University Hospitals NHS Foundation Trust	Universal	✓	49	29
Norfolk and Suffolk NHS Foundation Trust	Specialist	✓	10	13
Norfolk Community Health and Care NHS Trust	Universal	✓	9	25
North Bristol NHS Trust	Universal	✓	52	23
North East London NHS Foundation Trust	Specialist	✓	17	15
North Middlesex University Hospital NHS Trust	Universal	✓	53	16
North Staffordshire Combined Healthcare NHS Trust	Specialist	✓	23	31
North Tees and Hartlepool NHS Foundation Trust	Universal	✓	11	3

Organisation Name	Peer Group	Organisational level	Staff survey	Service user survey
North West Anglia NHS Foundation Trust	Universal	✓	24	27
North West Boroughs Healthcare NHS Foundation Trust	Specialist	✓	31	9
Northampton General Hospital NHS Trust	Universal	✓	47	43
Northamptonshire Healthcare NHS Foundation Trust	Specialist	✓	50	17
Northern Devon Healthcare NHS Trust	Universal	✓	51	33
Northern Lincolnshire and Goole NHS Foundation Trust	Universal	✓	5	0
Northumbria Healthcare NHS Foundation Trust	Universal	✓	7	8
Nottingham University Hospitals NHS Trust	Universal	✓	51	4
Nottinghamshire Healthcare NHS Foundation Trust	Specialist	✓	45	7
Oxford Health NHS Foundation Trust	Specialist	✓	14	16
Oxford University Hospitals NHS Foundation Trust	Universal	✓	5	20
Oxleas NHS Foundation Trust	Specialist	✓	46	18
Pennine Acute Hospitals NHS Trust	Universal	✓	47	17
Pennine Care NHS Foundation Trust	Specialist	✓	29	10
Poole Hospital NHS Foundation Trust	Universal	✓	16	26
Portsmouth Hospitals NHS Trust	Universal	✓	10	26
Provide	Universal	✓	52	0
Queen Victoria Hospital NHS Foundation Trust	Universal	✓	46	37
Rotherham Doncaster and South Humber NHS Foundation Trust	Specialist	✓	44	27
Royal Berkshire NHS Foundation Trust	Universal	✓	9	27
Royal Brompton and Harefield NHS Foundation Trust	Universal	✓	51	12
Royal Cornwall Hospitals NHS Trust	Universal	✓	51	19
Royal Devon and Exeter NHS Foundation Trust	Universal	✓	17	28
Royal Free London NHS Foundation Trust	Universal	✓	50	13
Royal National Orthopaedic Hospital NHS Trust	Universal	x	51	21
Royal Papworth Hospital NHS Foundation Trust	Universal	✓	39	0
Royal Surrey NHS Foundation Trust	Universal	✓	32	29
Royal United Hospitals Bath NHS Foundation Trust	Universal	✓	21	26
Salford Royal NHS Foundation Trust	Universal	✓	7	19
Salisbury NHS Foundation Trust	Universal	✓	14	20
Sandwell and West Birmingham Hospitals NHS Trust	Universal	✓	51	19
Sheffield Children's NHS Foundation Trust	Universal	✓	18	0
Sheffield Health and Social Care NHS Foundation Trust	Specialist	✓	25	5
Sheffield Teaching Hospitals NHS Foundation Trust	Universal	✓	51	26
Sherwood Forest Hospitals NHS Foundation Trust	Universal	✓	10	23
Shrewsbury and Telford Hospital NHS Trust	Universal	✓	12	9
Shropshire Community Health NHS Trust	Universal	✓	35	25
Sirona Care & Health CIC	Universal	✓	51	12
Solent NHS Trust	Specialist	✓	9	18
Somerset Partnership NHS Foundation Trust	Specialist	✓	16	29
South London and Maudsley NHS Foundation Trust	Universal	x	0	9
South Tees Hospitals NHS Foundation Trust	Universal	✓	50	32
South Tyneside and Sunderland NHS Foundation Trust	Universal	✓	0	23

Organisation Name	Peer Group	Organisational level	Staff survey	Service user survey
South Warwickshire NHS Foundation Trust	Universal	✓	27	38
South West London and St George's Mental Health NHS Trust	Specialist	✓	21	21
South West Yorkshire Partnership NHS Foundation Trust	Specialist	✓	11	18
South Western Ambulance Service NHS Foundation Trust	Universal	✓	51	0
Southend University Hospital NHS Foundation Trust	Universal	✓	30	41
Southern Health NHS Foundation Trust	Specialist	✓	52	17
Southport and Ormskirk Hospital NHS Trust	Universal	✓	23	21
St George's University Hospitals NHS Foundation Trust	Universal	✓	51	55
St Helens and Knowsley Teaching Hospitals NHS Trust	Universal	✓	51	17
Stockport NHS Foundation Trust	Universal	✓	13	22
Surrey and Borders Partnership NHS Foundation Trust	Specialist	✓	35	7
Surrey and Sussex Healthcare NHS Trust	Universal	✓	27	0
Sussex Community NHS Foundation Trust	Universal	✓	52	15
Sussex Partnership NHS Foundation Trust	Specialist	✓	39	14
Tameside and Glossop Integrated Care NHS Foundation Trust	Universal	✓	51	14
Taunton and Somerset NHS Foundation Trust	Universal	✓	0	0
Tavistock and Portman NHS Foundation Trust	Universal	✓	8	32
Tees, Esk and Wear Valleys NHS Foundation Trust	Specialist	✓	51	19
The Christie NHS Foundation Trust	Universal	x	6	1
The Clatterbridge Cancer Centre NHS Foundation Trust	Universal	✓	51	12
The Dudley Group NHS Foundation Trust	Universal	✓	35	27
The Hillingdon Hospitals NHS Foundation Trust	Universal	✓	8	20
The Newcastle upon Tyne Hospitals NHS Foundation Trust	Universal	✓	18	26
The Princess Alexandra Hospital NHS Trust	Universal	✓	15	7
The Queen Elizabeth Hospital, King's Lynn. NHS Foundation Trust	Universal	✓	25	9
The Rotherham NHS Foundation Trust	Universal	✓	19	9
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Universal	✓	13	31
The Royal Marsden NHS Foundation Trust	Universal	✓	7	0
The Royal Orthopaedic Hospital NHS Foundation Trust	Universal	✓	27	4
The Royal Wolverhampton NHS Trust	Universal	✓	28	9
The Walton Centre NHS Foundation Trust	Universal	✓	49	16
Torbay and South Devon NHS Foundation Trust	Universal	✓	7	4
United Lincolnshire Hospitals NHS Trust	Universal	✓	37	26
University College London Hospitals NHS Foundation Trust	Universal	✓	0	25
University Hospital of Derby and Burton NHS Foundation Trust	Universal	✓	18	22

Organisation Name	Peer Group	Organisational level	Staff survey	Service user survey
University Hospital Southampton NHS Foundation Trust	Universal	✓	51	27
University Hospitals Birmingham NHS Foundation Trust	Universal	✓	26	24
University Hospitals Bristol NHS Foundation Trust	Universal	✓	17	31
University Hospitals Coventry and Warwickshire NHS Trust	Universal	✓	30	24
University Hospitals of Leicester NHS Trust	Universal	✓	13	37
University Hospitals of Morecambe Bay NHS Foundation Trust	Universal	✓	21	27
University Hospitals of North Midlands NHS Trust	Universal	✓	31	19
University Hospitals Plymouth NHS Trust	Universal	✓	22	24
Walsall Healthcare NHS Trust	Universal	✓	51	7
Warrington and Halton Hospitals NHS Foundation Trust	Universal	✓	14	21
West Hertfordshire Hospitals NHS Trust	Universal	✓	57	19
West London NHS Trust	Universal	✓	13	13
West Suffolk NHS Foundation Trust	Universal	✓	36	1
Western Sussex Hospitals NHS Foundation Trust	Universal	✓	23	2
Weston Area Health NHS Trust	Universal	✓	18	23
Whittington Health NHS Trust	Universal	✓	16	0
Wirral Community Health and Care NHS Foundation Trust	Universal	✓	29	39
Wirral University Teaching Hospital NHS Foundation Trust	Universal	✓	11	6
Worcestershire Acute Hospitals NHS Trust	Universal	✓	52	29
Worcestershire Health and Care NHS Trust	Specialist	✓	32	5
Wrightington, Wigan and Leigh NHS Foundation Trust	Universal	✓	2	9
Wye Valley NHS Trust	Universal	x	15	24
Yeovil District Hospital NHS Foundation Trust	Universal	✓	22	20
York Teaching Hospital NHS Foundation Trust	Universal	✓	10	28

Appendix 3: Online Service User results

Online service user survey	Response	National	n=
1. When you received care from the NHS, did staff treat you with respect?	Yes	70%	54
	No	23%	18
	Don't know	6%	5
	Total		**77**
2. Did staff explain things to you in a way you could understand?	Yes	56%	43
	No	38%	29
	Don't know	6%	5
	Total		**77**
3. Did you feel like staff listened to you?	Yes	55%	42
	No	39%	30
	Don't know	6%	5
	Total		**77**
4. Did you feel like staff cared about you?	Yes	65%	51
	No	28%	22
	Don't know	6%	5
	Total		**78**
5. Did staff talk to you about the care you needed?	Yes	59%	44
	No	37%	28
	Don't know	4%	3
	Total		**75**
6. Did staff give you choices about how you were cared for?	Yes	36%	27
	No	57%	42
	Don't know	7%	5
	Total		**74**
7. Did staff listen to what your family thought?	Yes	59%	43
	No	36%	26
	Don't know	5%	4
	Total		**73**
8. When you received care, did you feel safe?	Yes	57%	44
	No	35%	27
	Don't know	8%	6
	Total		**77**
9. Did you have any concerns about your care?	Yes	53%	41
	No	38%	30
	Don't know	9%	7
	Total		**78**

Online service user survey	Response	National	n=
10. Did you make a complaint?	Yes	27%	20
	No	70%	52
	Don't know	3%	2
	Total		**74**
11. If yes, were you given Easy Read information about how to make a complaint?	Yes	19%	7
	No	78%	29
	Don't know	3%	1
	Total		**37**
12. If you stayed in hospital, was it easy for your family to visit you?	Yes	65%	30
	No	33%	15
	Don't know	2%	1
	Total		**46**
13. Did staff tell you about your appointments and meetings in a way you could understand?	Yes	48%	33
	No	51%	35
	Don't know	1%	1
	Total		**69**
14. Were your appointments and meetings arranged to suit you?	Yes	43%	32
	No	53%	39
	Don't know	4%	3
	Total		**74**
15. If you needed to be seen in an emergency, were you seen quickly?	Yes	41%	22
	No	57%	31
	Don't know	2%	1
	Total		**54**
16. Would you recommend this service to a friend or family?	Yes	45%	34
	No	37%	28
	Don't know	17%	13
	Total		**75**