

Classification: Official

Publication approval reference: PRN00086



Performance against the learning disability improvement standards

Appendices: Detailed findings from the
2021/22 collection

October 2023

Contents

Appendix 1: Organisational level collection.....	2
Access.....	3
Learning Disability Mortality Review (LeDeR).....	10
Engagement.....	13
Reasonable adjustments.....	15
Registered learning disability nurses.....	16
Learning Disability Liaison staff.....	17
Inclusion.....	18
Ask Listen Do.....	19
Leadership.....	19
Workforce plan.....	19
Training.....	20
Specialist learning disabilities services.....	21
Community.....	22
Inpatient.....	22
Positive Behaviour Support.....	23
Specialist learning disability service.....	24
Restrictive practices.....	25
STOMP – STAMP.....	31
Appendix 2: Staff survey.....	32
Appendix 3: Service user survey.....	39
Appendix 4: Data table.....	43

Appendix 1: Organisational level collection

The year 4 improvement standards collected metrics from 189 organisations across England, concerning corporate activity in the 2020/21 financial year. The NHS Benchmarking Network (NHSBN) and NHS England thank all contributors for their participation.

The data collection gives a holistic view of services provided to people with a learning disability and autistic people, and measures how trusts are performing against the four improvement standards.

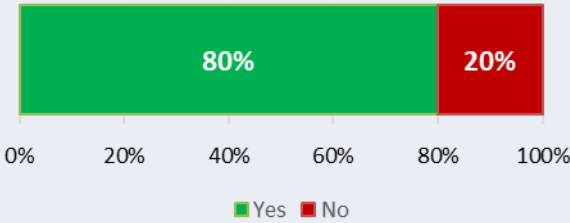
The 56 organisations identified as providing specialist learning services were asked to provide data on supplementary questions to explore the impact of initiatives to reduce restrictive practices and policies to stop the over-medication of people with a learning disability and autistic people.

The data in this report has been validated by the NHSBN support team together with participant project leads. The charts show national data alongside the number of participants who completed the metric.

An online interactive toolkit containing all the metrics from the data collection can be accessed through the NHSBN website (<https://members.nhsbenchmarking.nhs.uk/home>). If you require a log in, please contact the support team at: nhsbn.nhsildsupport@nhs.net

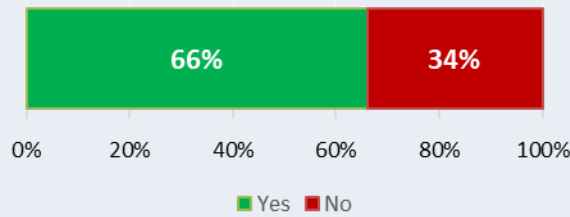
Access

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



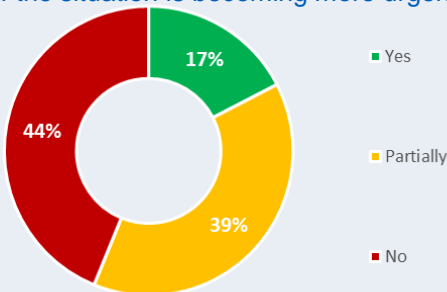
n= 180

Figure 3: Do you currently hold a list of children, young people and adults with a learning disability and/or autistic people waiting for assessment and/or treatment?



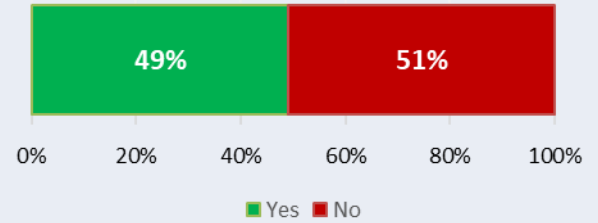
n= 175

Figure 5: 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



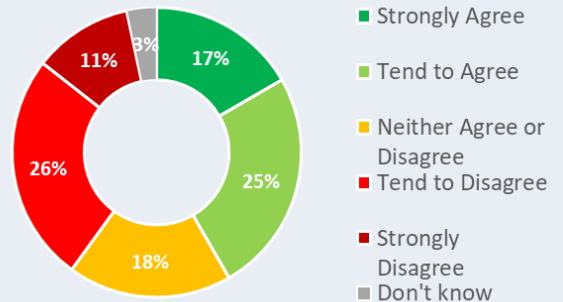
n= 179

Figure 2: If required, is your organisation able to isolate/dissagregate specific outcome data regarding autistic patients?



n= 177

Figure 4: Our organisation routinely monitors waiting times for people with a learning disability and/or autism, and reports concerning waits to the board



n= 180

Figure 6: Total number of patients with a learning disability who were awaiting a first appointment on 31/03/2021

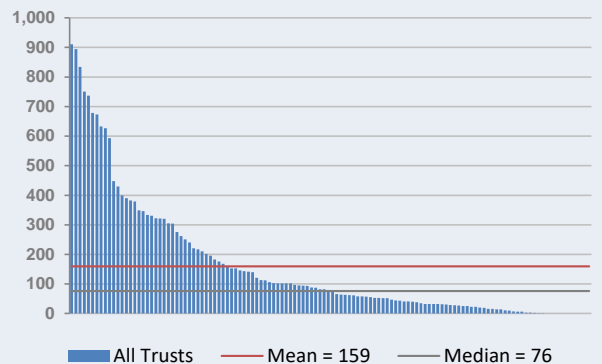


Figure 7: Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2021

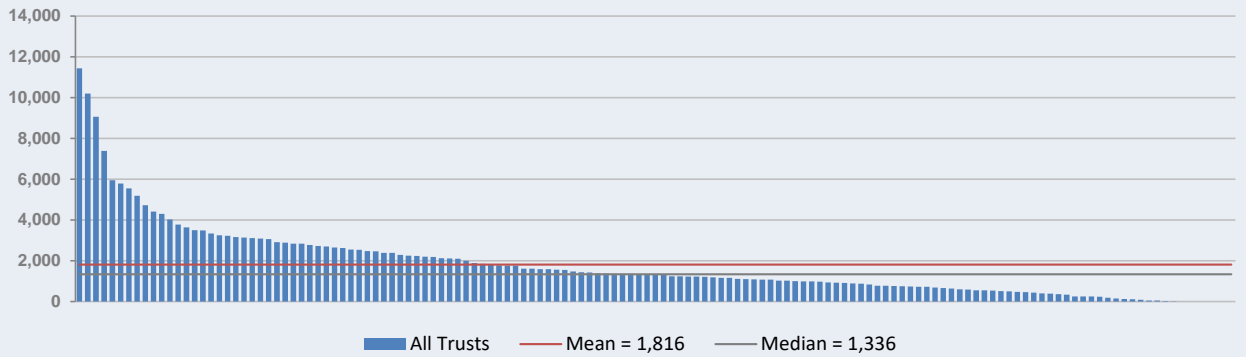


Figure 8: Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2021 as a % of total patients on the Trust EPR

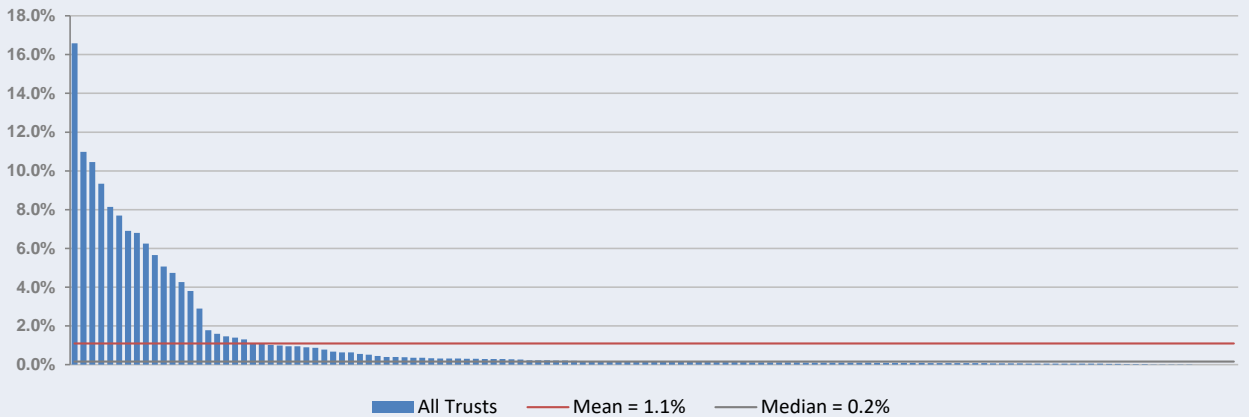
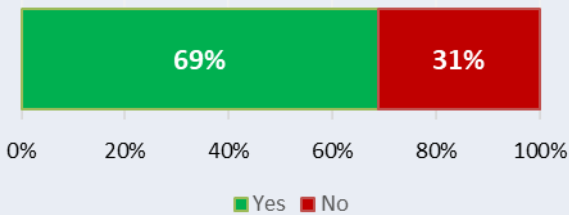
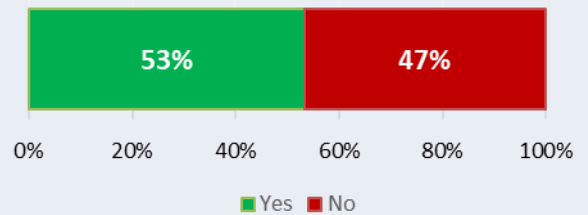


Figure 9: Does your electronic patient record allow you, with the patient's consent, to flag and identify autistic people, who do not also have a learning disability but who may similarly require reasonable adjustments?



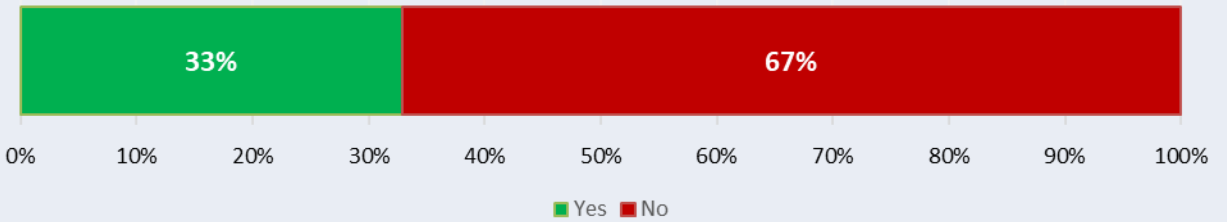
n= 180

Figure 10: Does your Covid recovery plan include specific provision concerning the needs of people with a learning disability and/or autistic people.



n= 151

Figure 11: 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?



n= 170

Figure 12: Hospital readmission rate for general population patients in 2020/21

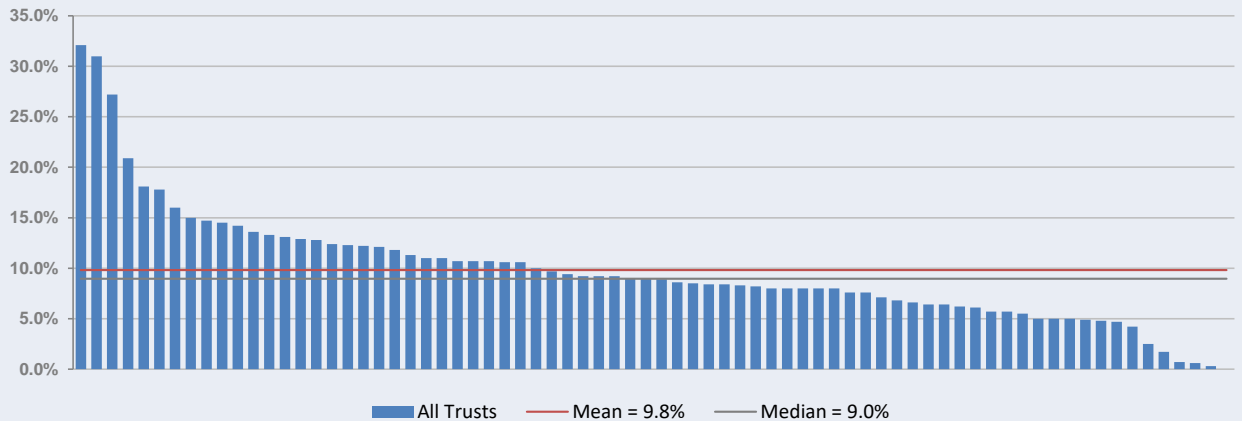


Figure 13: Hospital readmission rate for patients with a learning disability in 2020/21

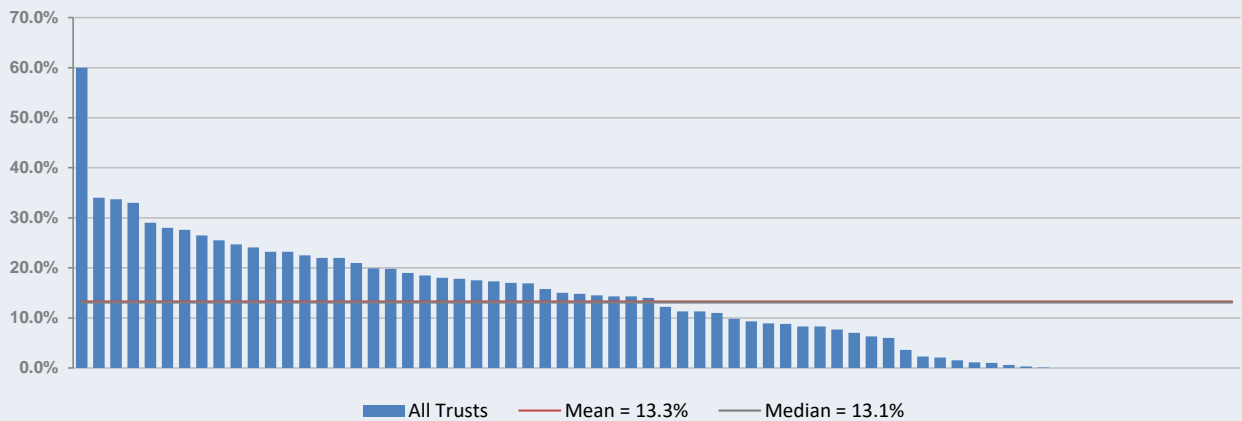
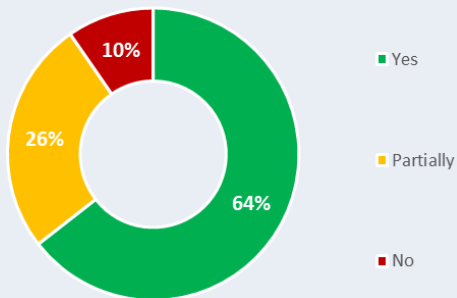
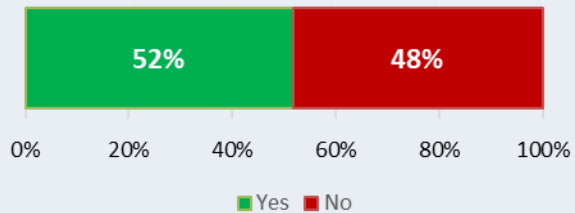


Figure 14: Our organisation regularly audits any restrictions and/or Deprivations of Liberty it places on people with a learning disability and/or autism



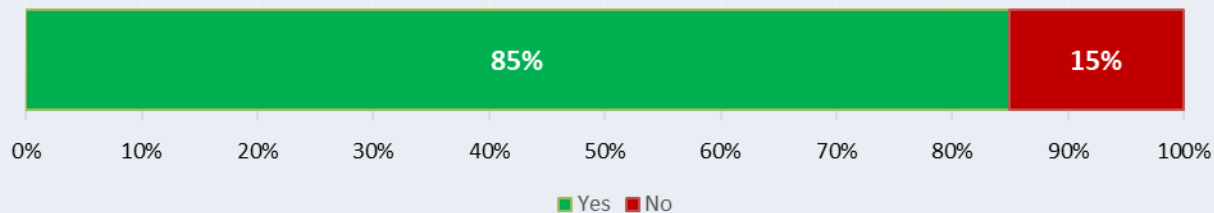
n= 166

Figure 15: Have you undertaken an audit of restrictive practices in the last 12 months?



n= 166

Figure 16: 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?



n= 173

Figure 17: Total number of patient safety incidents recorded concerning children, young people and adults with a learning disability or autistic people in 2020/21

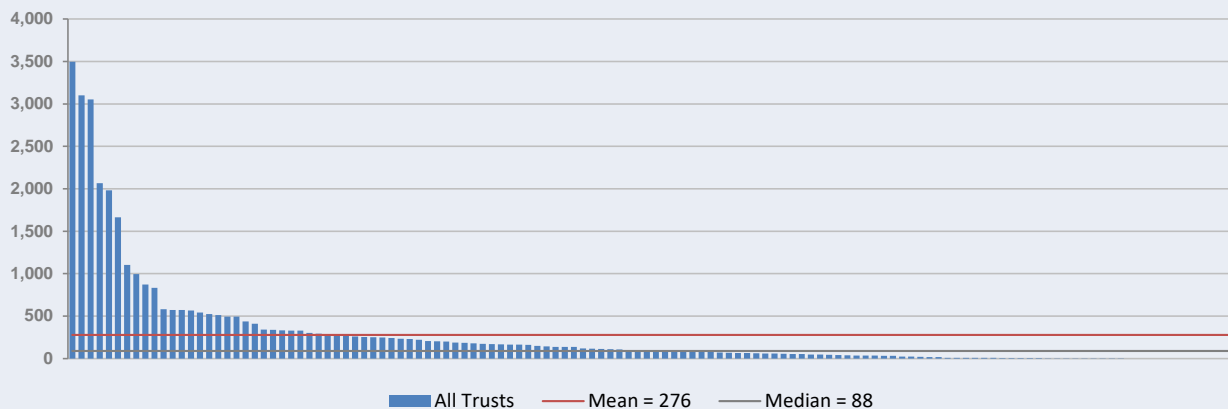


Figure 18: Total number of patient safety incidents recorded for people with a learning disability and/or autism in 2020/21 per 100 children, young people and adults with a learning disability flag on the EPR

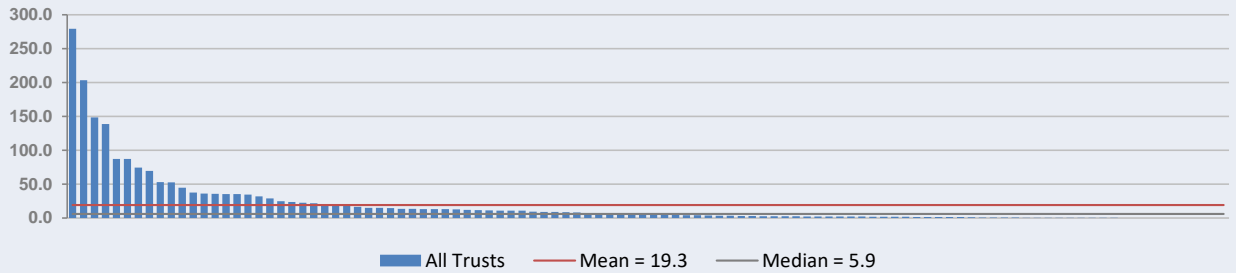


Figure 19: Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2020/21

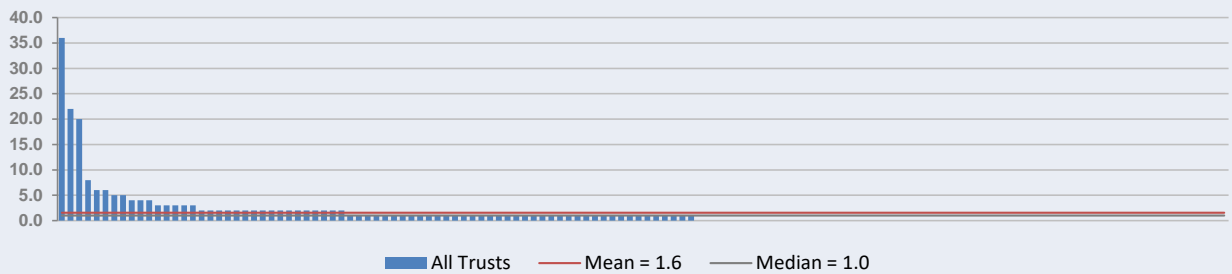


Figure 20: Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2020/21 per 100 people with a learning disability flag on the EPR

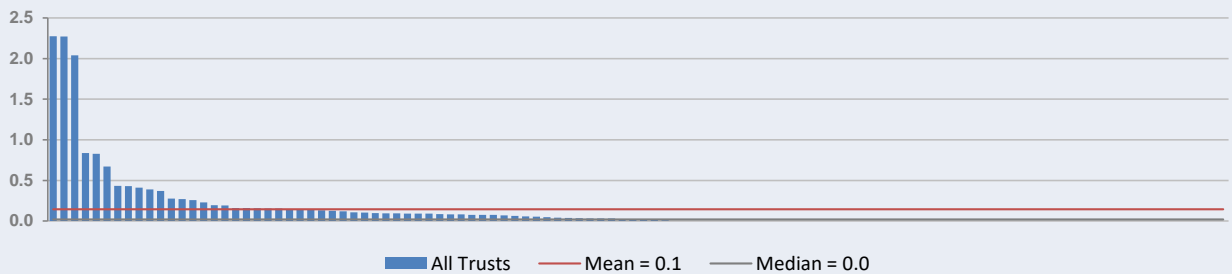


Figure 21: Total number of safeguarding referrals concerning children, young people and adults with a learning disability or autistic people in 2020/21

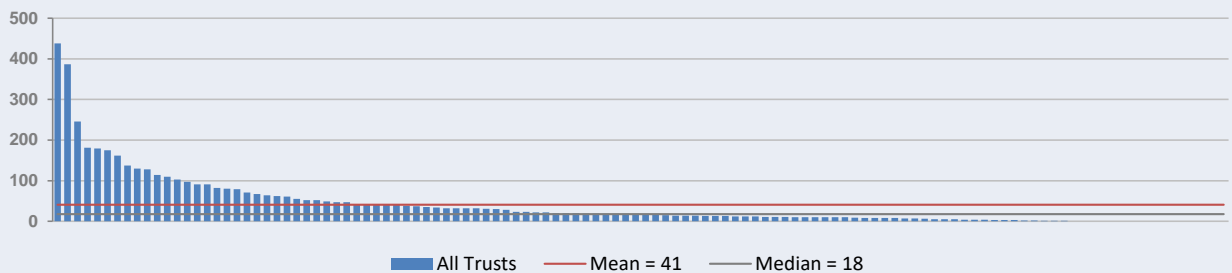


Figure 22: Total number of safeguarding referrals concerning people with a learning disability and/or autism in 2020/21 per 100 people with a learning disability flag on the EPR

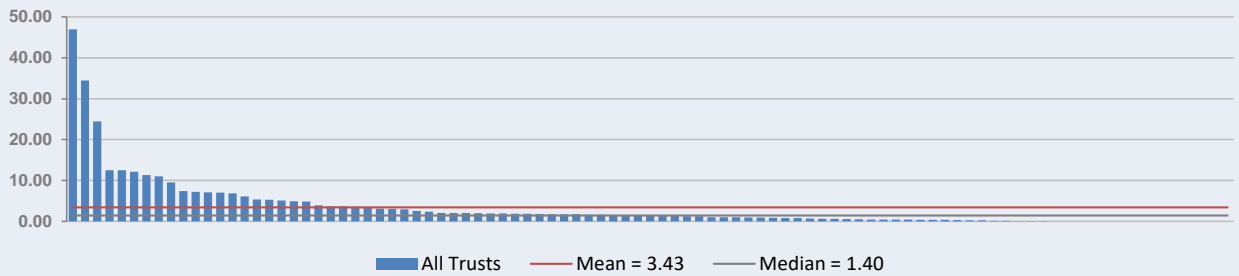


Figure 23: Total number of safeguarding referrals regarding people with a learning disability and/or autism in 2020/21 which met the criteria for a section 42 safeguarding / care act enquiry

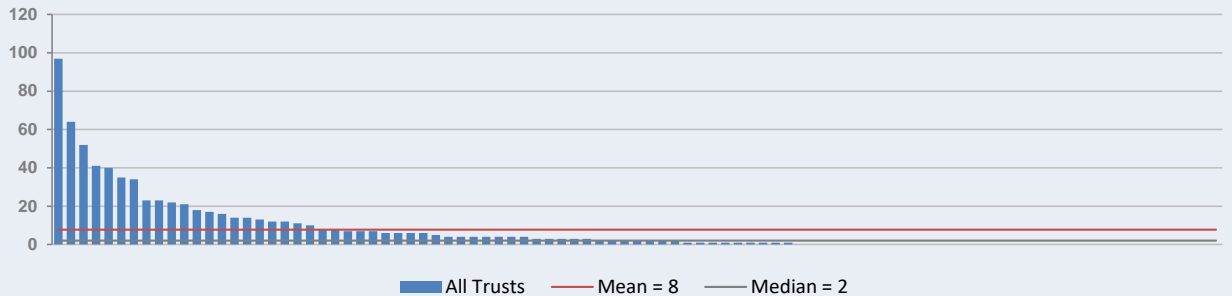


Figure 24: Percentage of safeguarding referrals regarding people with a learning disability and/or autism in 2020/21 which met the criteria for a section 42 safeguarding/care act enquiry

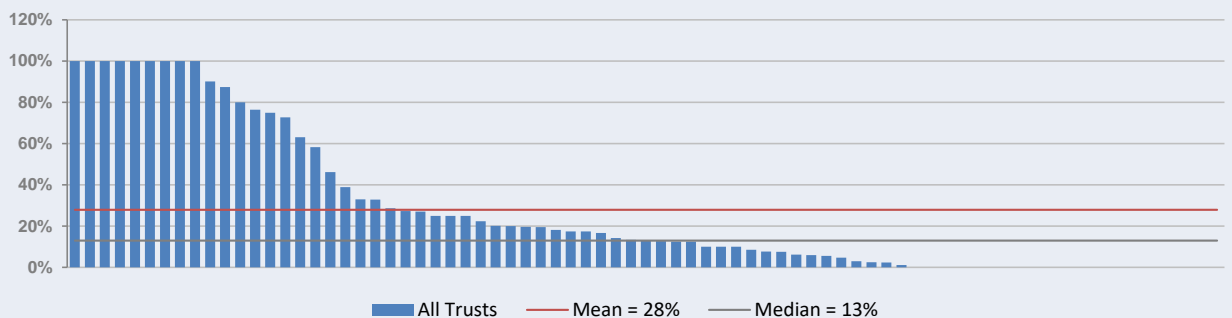


Figure 25: Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability during 2020/21

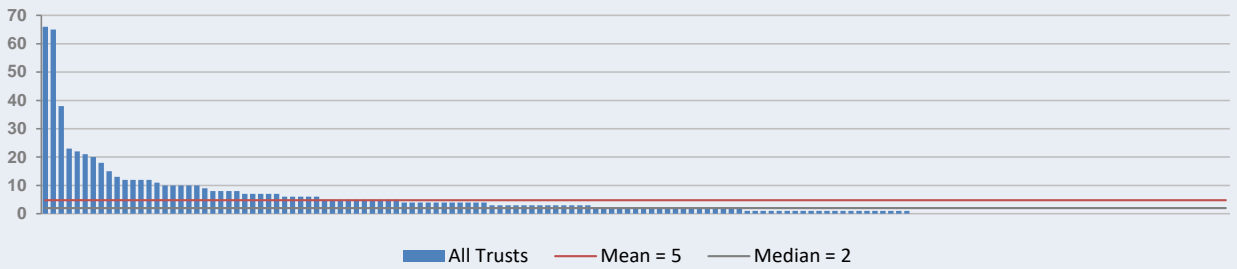


Figure 26: Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability during 2020/21 as a % of total complaints

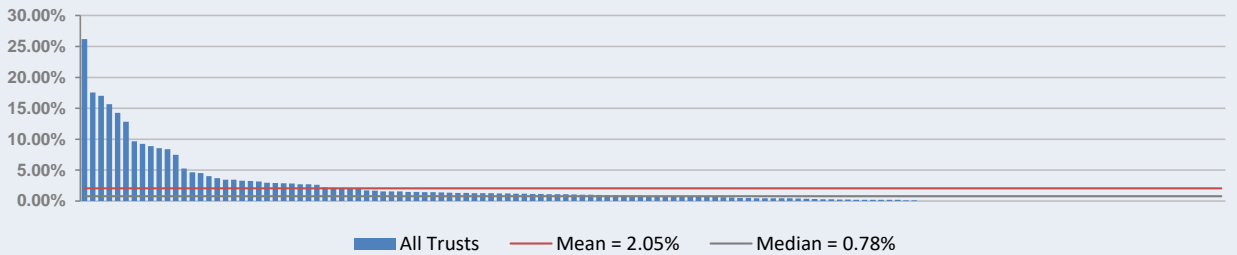
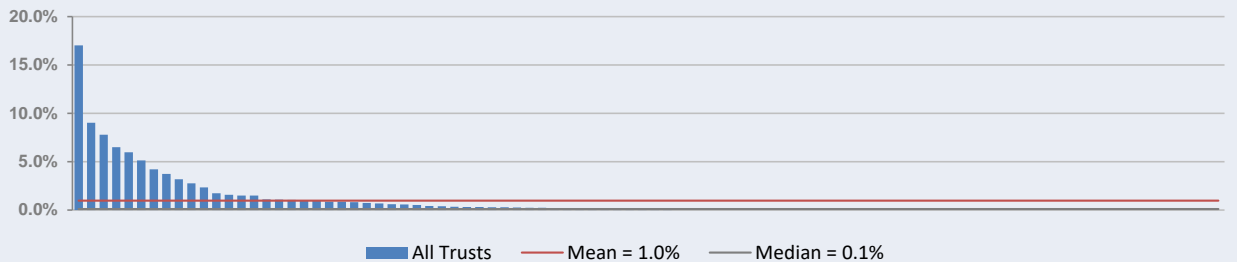


Figure 27: Total number of complaints during 2020/21 concerning the care and treatment of patients with autism who do not also have a learning disability.



Figure 28: Total number of complaints during 2020/21 concerning the care and treatment of patients with autism who do not also have a learning disability as a % of total complaints



Learning Disability Mortality Review (LeDeR)

Figure 29: 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 2020/21

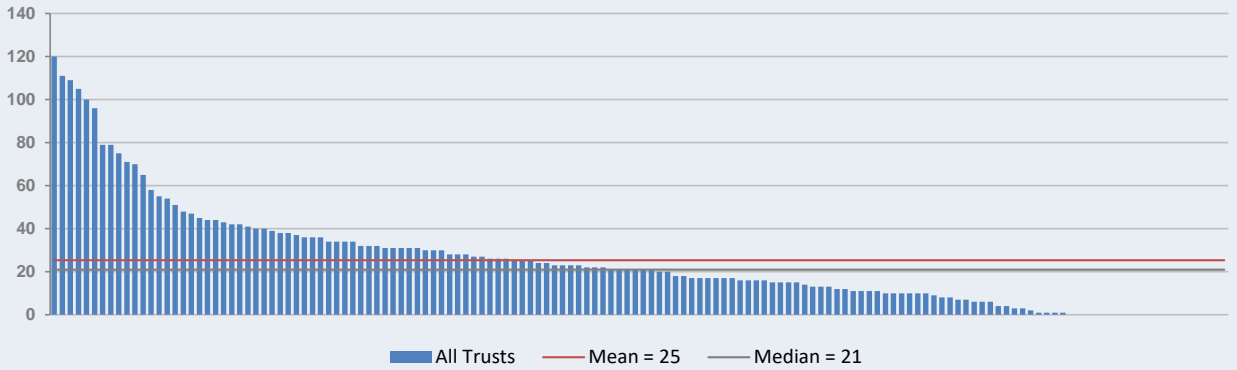


Figure 30: Total number of people with a learning disability who died whilst on an active caseload or within 3 months of the case being closed or discharged in 2020/21 as a % of total deaths

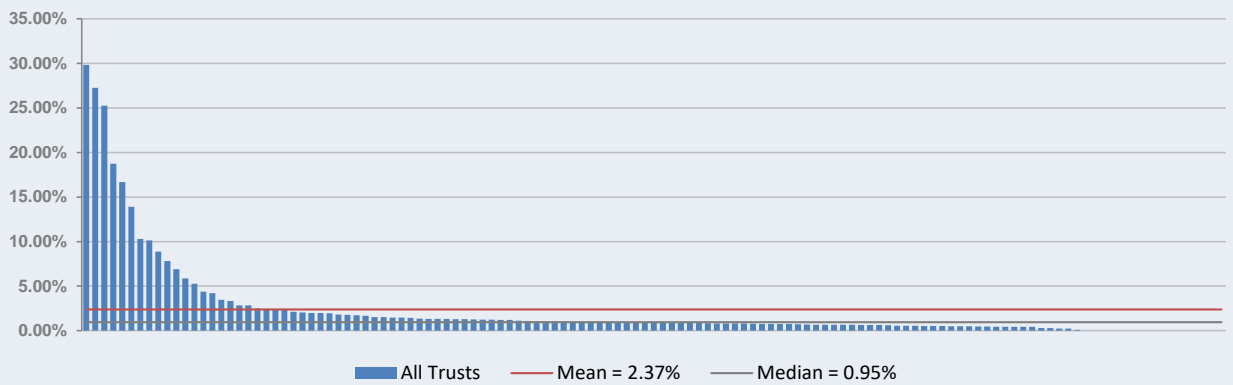


Figure 31: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of choking incidents

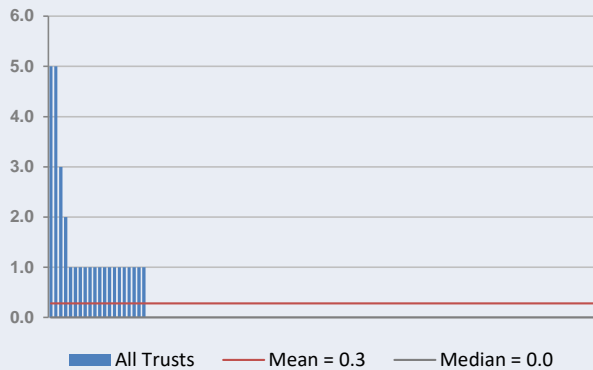


Figure 32: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of choking incidents per 100 patients with an LD flag on the EPR

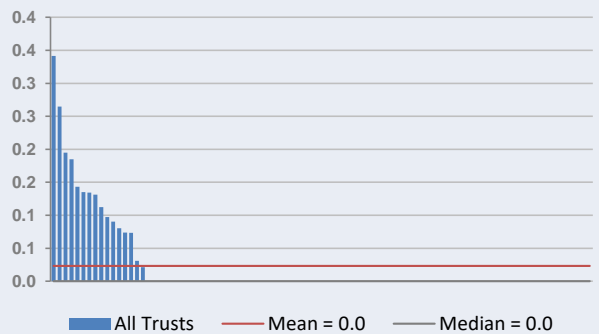


Figure 33: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of sepsis

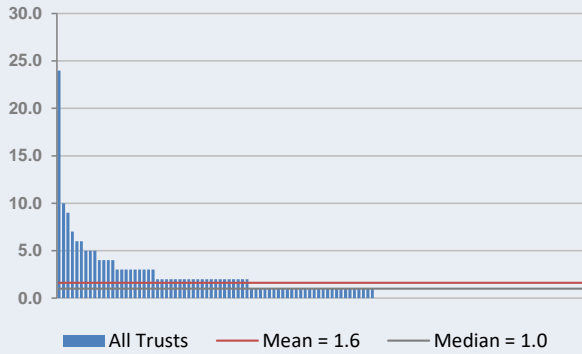


Figure 34: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of sepsis per 100 patients with an LD flag on the EPR

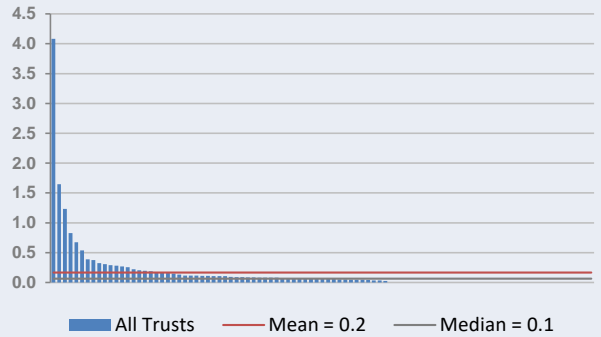


Figure 35: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of epilepsy

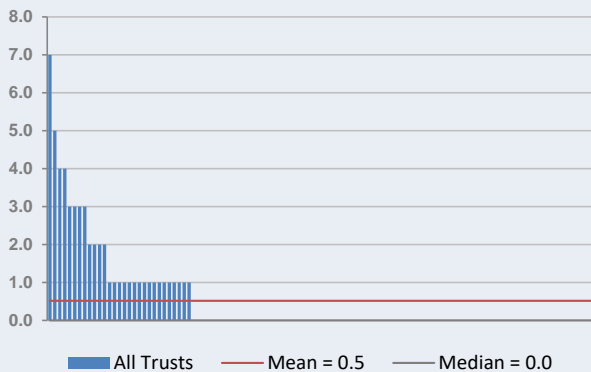


Figure 36: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of epilepsy per 100 patients with an LD flag on the EPR

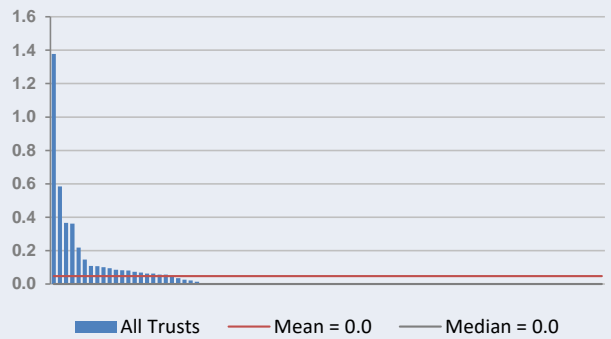


Figure 37: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of gastrointestinal obstructions

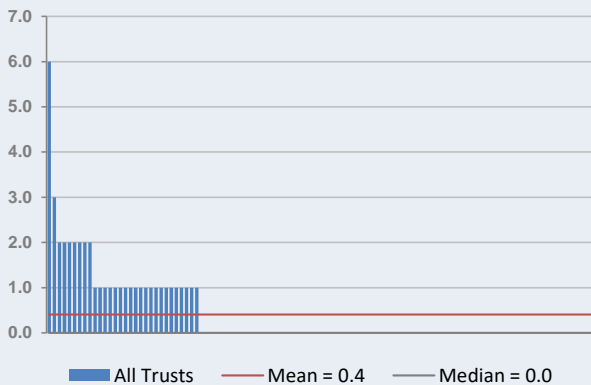


Figure 38: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of gastrointestinal obstructions per 100 patients with an LD flag on the EPR

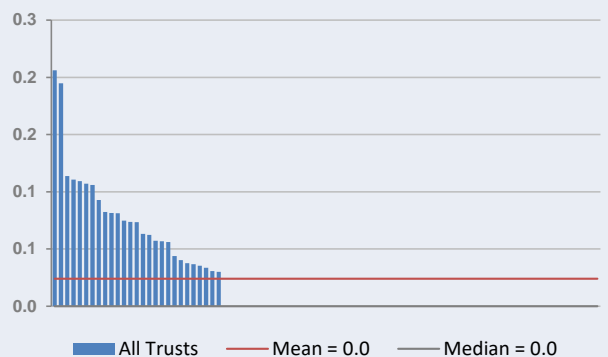


Figure 39: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of non-covid respiratory condition

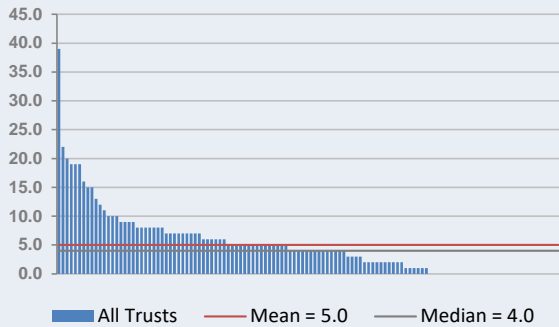


Figure 40: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of non-covid respiratory condition per 100 patients with an LD flag on the EPR

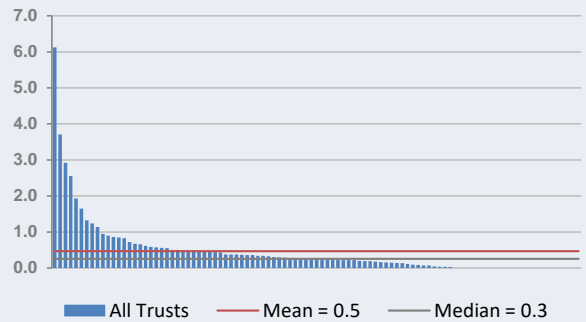


Figure 41: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of Covid-19

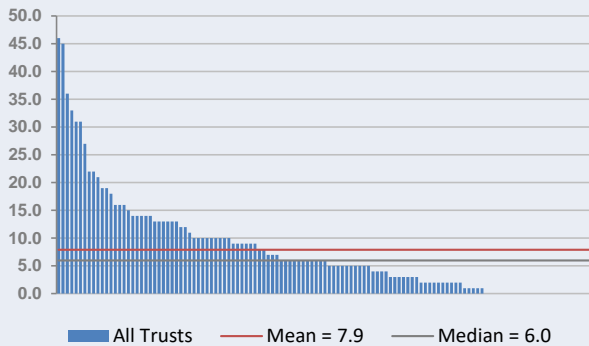


Figure 42: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of Covid-19 per 100 patients with an LD flag on the EPR

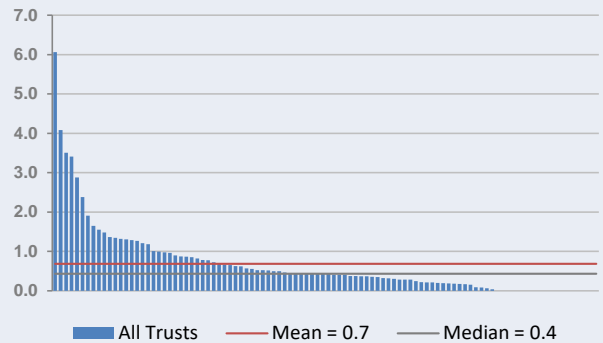


Figure 43: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of other causes

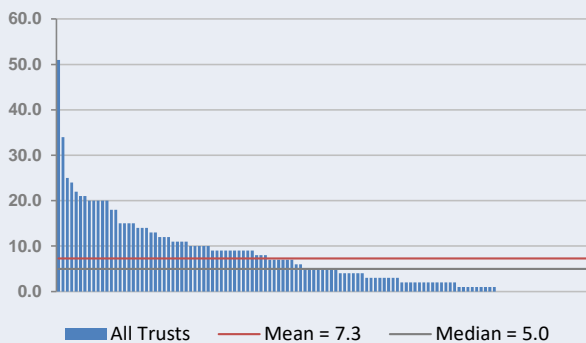


Figure 44: Total number of deaths of people with a learning disability that took place in 2020/21 as a result of other causes per 100 patients with an LD flag on the EPR

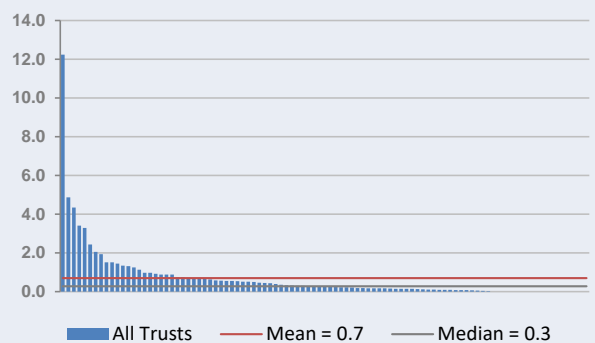
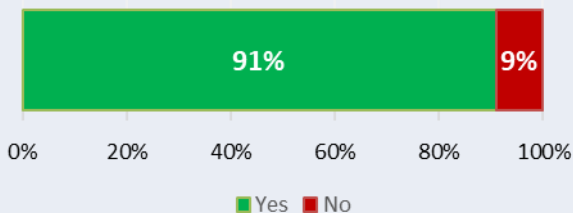
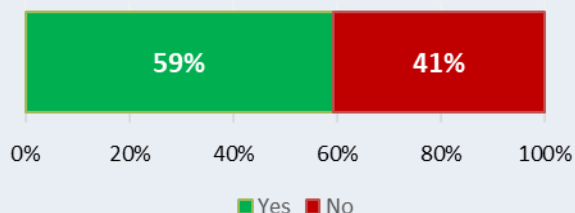


Figure 45: Is your organisation represented on the local Learning Disability Mortality Review Programme (LeDeR) steering group?



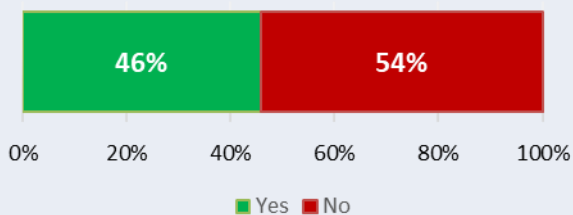
n= 180

Figure 46: 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?



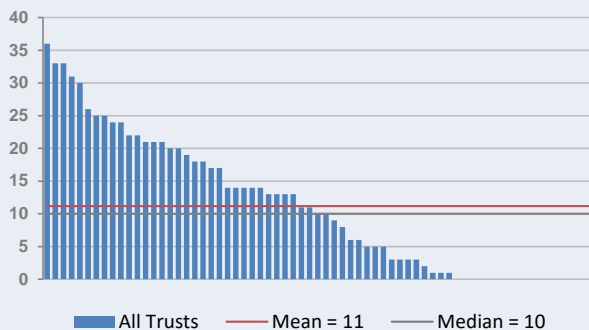
n= 155

Figure 47: Does your Trust monitor the rates of use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions for people with a learning disability?



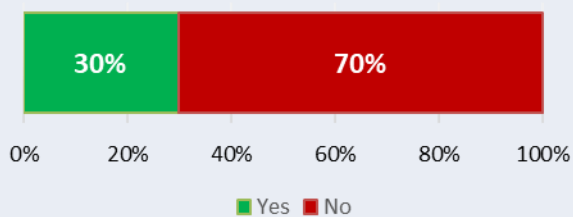
n= 168

Figure 48: Total number of children, young people and adults with a learning disability had a DNACPR authorisation in place at the time of their death, during 2020/21?



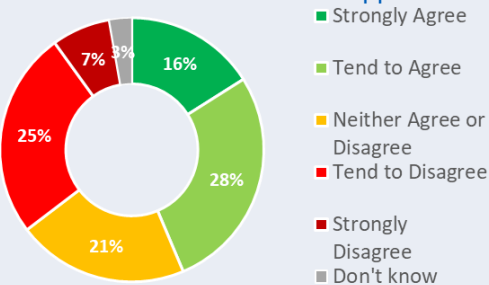
Engagement

Figure 49: 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?



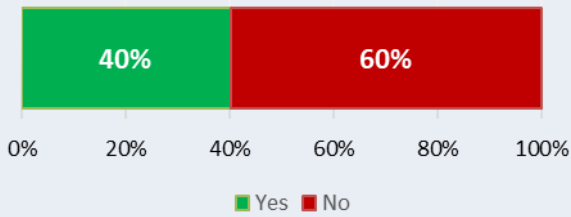
n= 175

Figure 50: 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



n= 181

Figure 51: 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?



n= 163

Reasonable adjustments

Figure 52: Which reasonable adjustments are offered by your organisation?



Registered learning disability nurses

Figure 53: Total number of registered learning disability nurses (WTE)

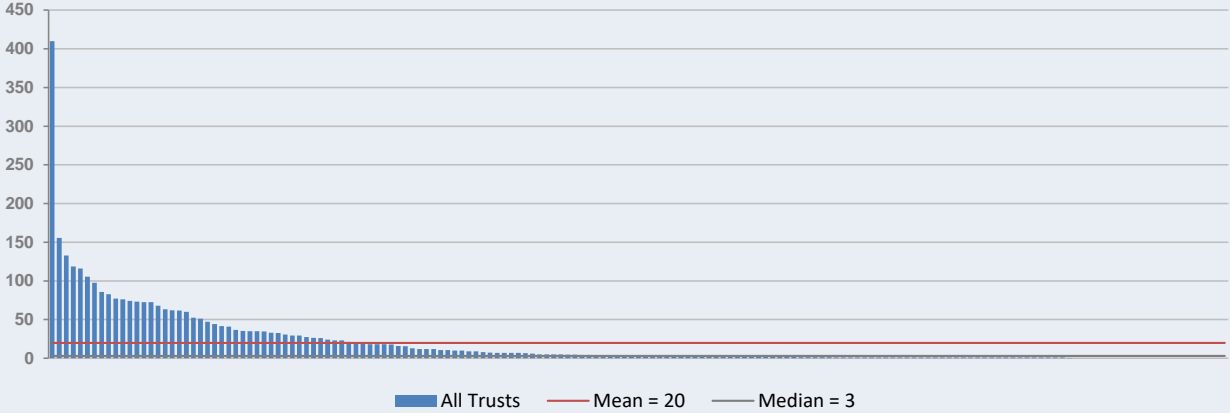
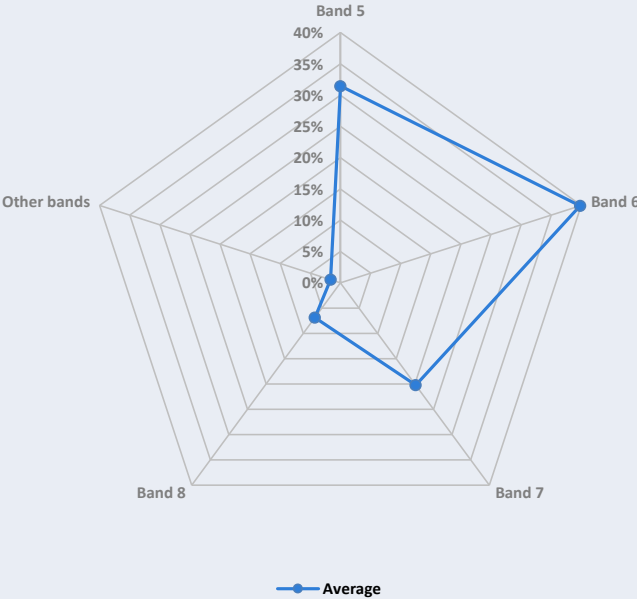


Figure 54: Registered LD nurses skill mix



Registered LD nurses skill mix	National %
Band 5	31%
Band 6	40%
Band 7	20%
Band 8	7%
Other	2%

Learning Disability Liaison staff

Figure 55: Total number of designated acute learning disability liaison staff employed (WTE)

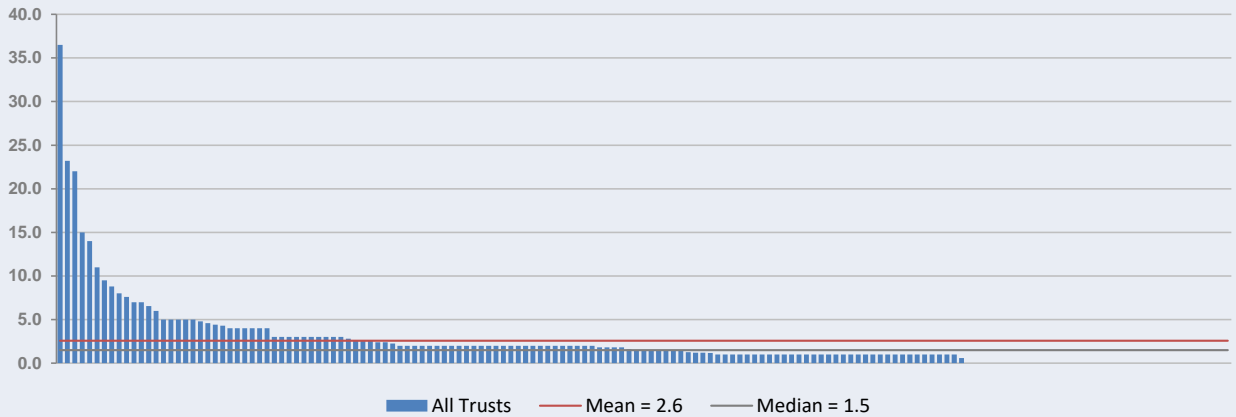


Figure 56: Total number of registered LD nurses as a % of designated acute learning disability liaison staff employed (WTE)

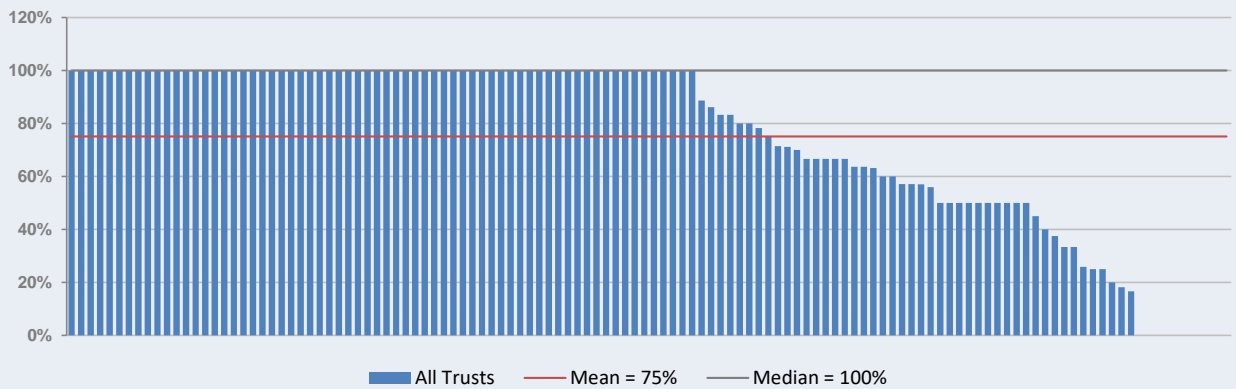


Figure 57: Total number learning disability liaison staff (WTE) provided on the basis of service level agreements with other trusts

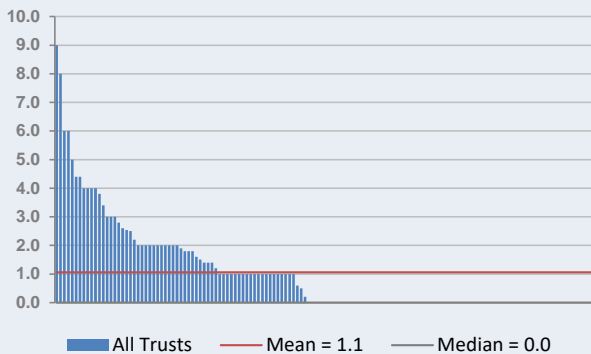
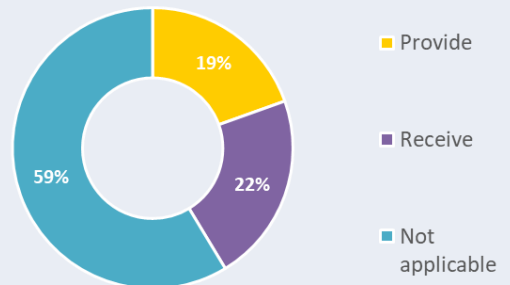
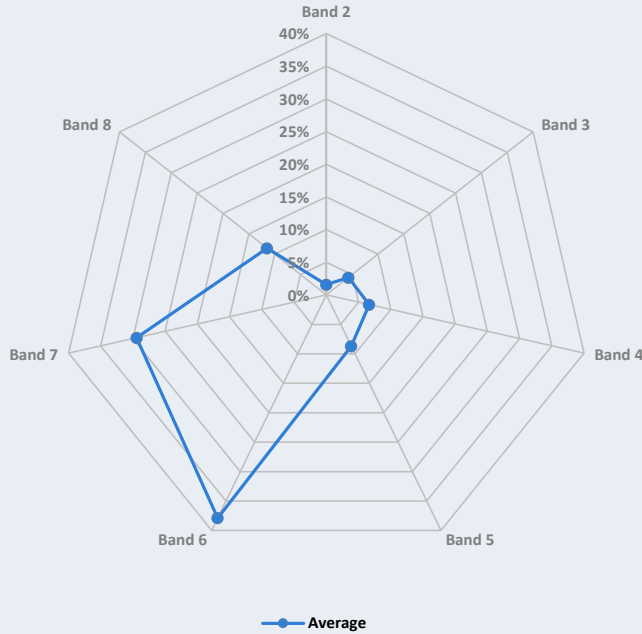


Figure 58: If learning disability liaison services are available in your area, on the basis of a service level agreement with another trust, do you provide or receive these services?



n= 179

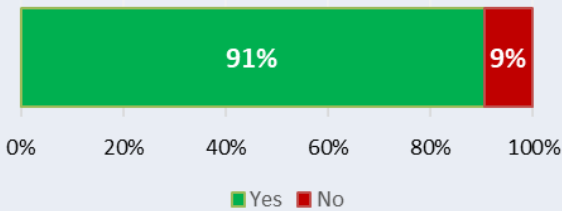
Figure 59: Learning disability liaison service staff skill mix



Learning disability liaison service staff skill mix	National %
Band 2	2%
Band 3	4%
Band 4	7%
Band 5	9%
Band 6	38%
Band 7	29%
Band 8	11%

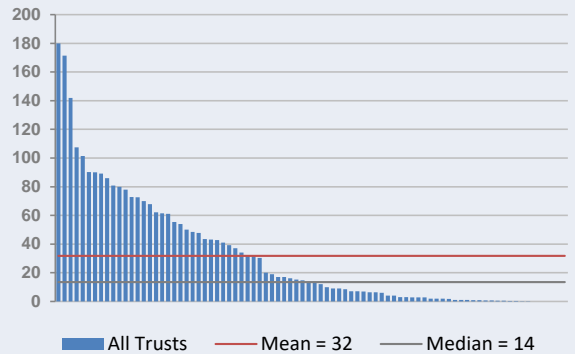
Inclusion

Figure 60: Does your Trust employ people with a learning disability or autism?



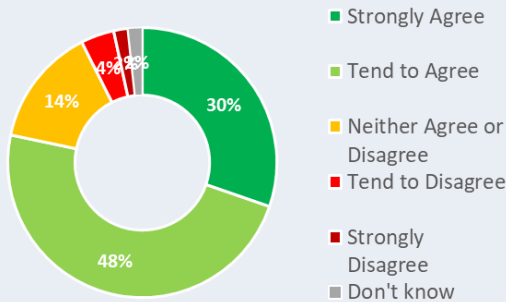
n= 170

Figure 61: Total WTE of workforce employed with a learning disability (paid employment only)



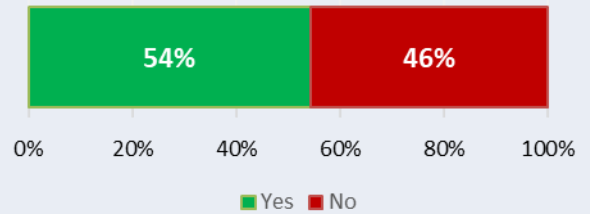
Ask Listen Do

Figure 62: 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



n= 175

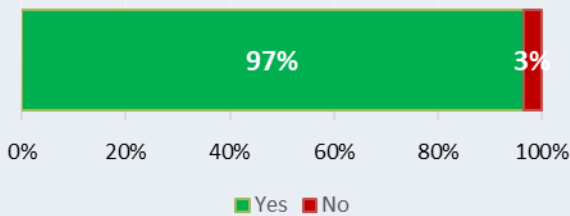
Figure 63: Is your organisation using 'Ask Listen Do' good practice resources to improve feedback, concerns and complaints for children, young people and adults with a learning disability, autistic people and families?



n= 171

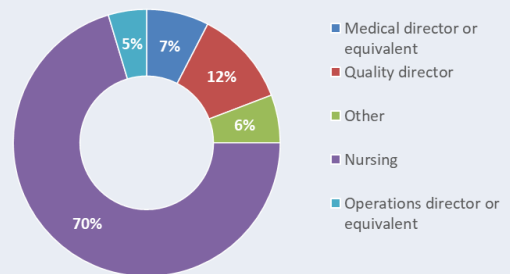
Leadership

Figure 64: 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?



n= 177

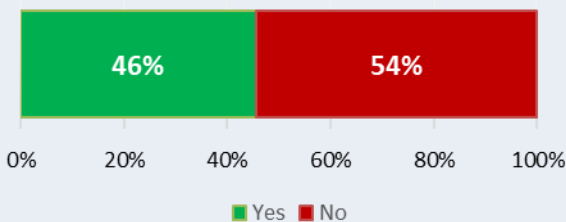
Figure 65: Which professional role best describes the executive role of your board member who leads on quality assurance for learning disabilities and autism?



n= 173

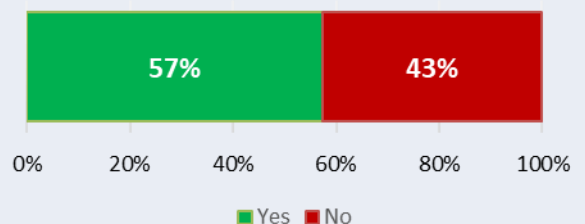
Workforce plan

Figure 66: Does your workforce plan include data on current and future issues arising from retention/recruitment difficulties relating to the learning disabilities workforce?



n= 156

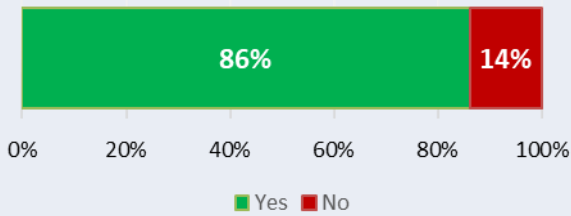
Figure 67: Does your workforce plan include provisions to support the development of new roles in learning disabilities care?



n= 155

Training

Figure 68: Do staff receive up-to-date training covering learning disabilities / autism awareness?



n= 176

Figure 69: Percentage of staff who received up-to-date training covering learning disabilities/autism awareness in 2020/21

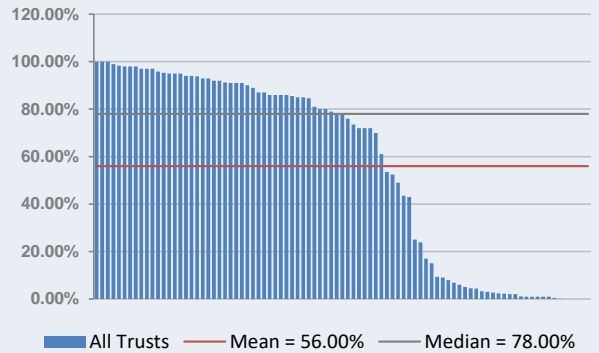
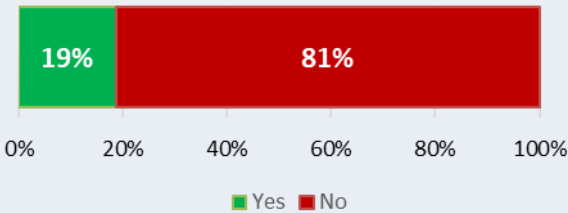
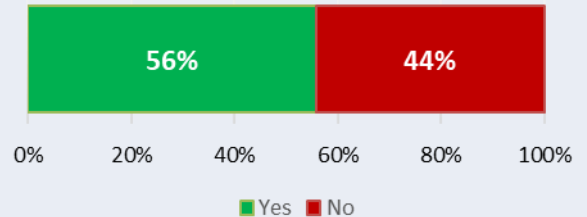


Figure 70: Does your Trust induction programme invite children, young people and adults with a learning disability or autism to contribute to staff training?



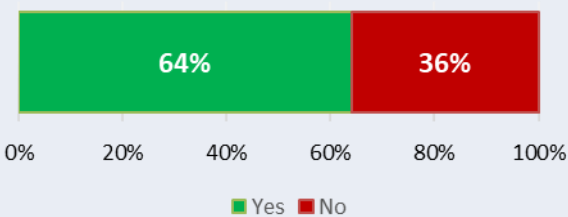
n= 178

Figure 71: 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?



n= 174

Figure 72: 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?

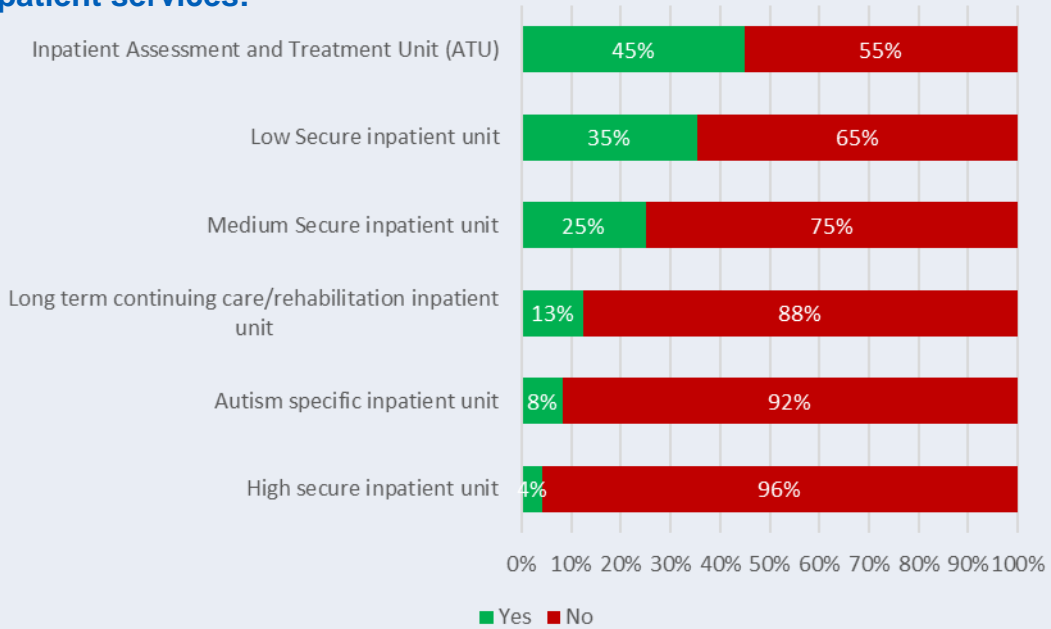


n= 174

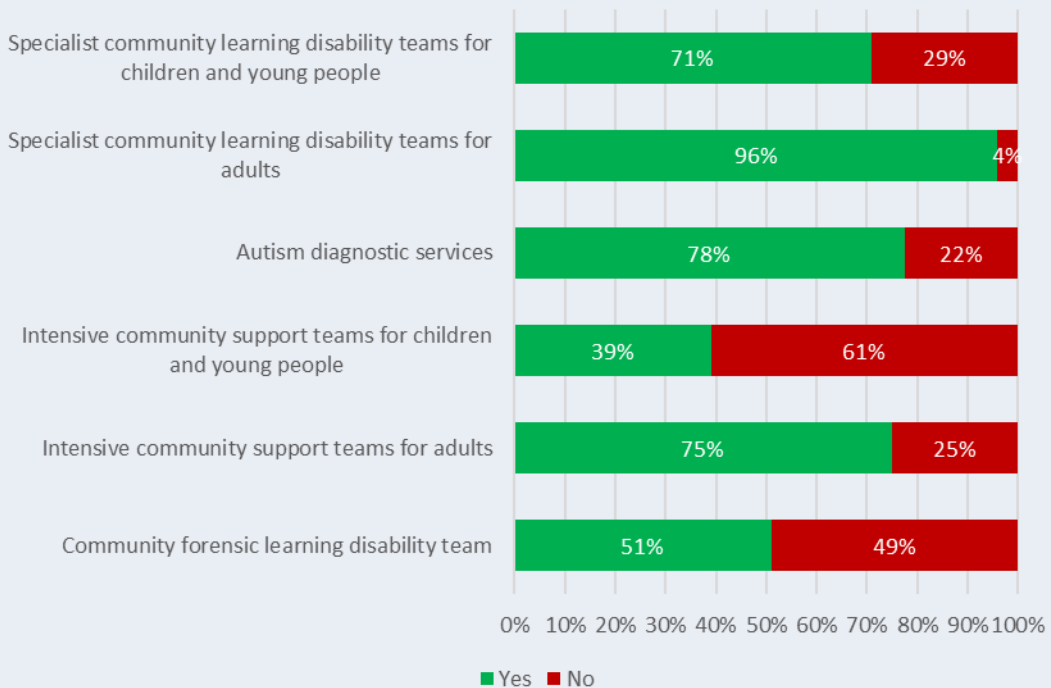
Specialist learning disabilities services

Figure 73: Services provided:

Inpatient services:

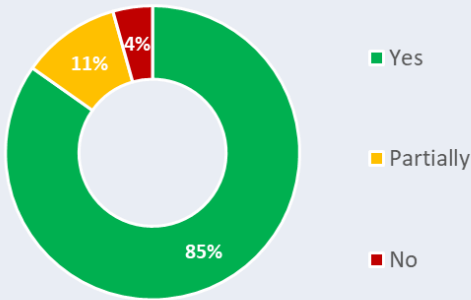


Community services:



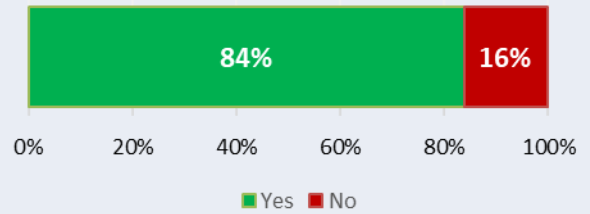
Community

Figure 74: We operate a dynamic risk / support register with regards to people with a learning disability and/or autism in community settings



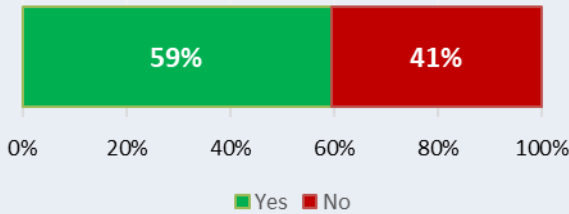
n= 46

Figure 75: If you provide an intensive community support service, do the staff provide crisis support?



n= 37

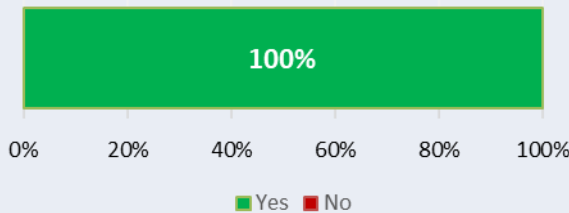
Figure 76: If you provide an intensive community support service is it available 7 days per week?



n= 37

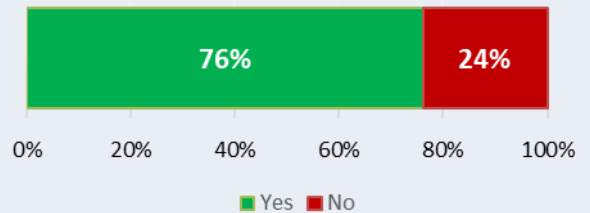
Inpatient

Figure 77: Do your healthcare practitioners provide care coordination in accordance with the provisions of the Care Programme Approach?



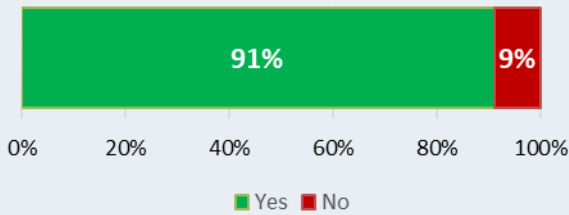
n= 43

Figure 78: Do you continue to provide care coordination, where people are placed in out-of-area inpatient services?



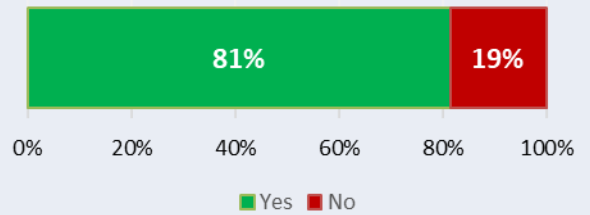
n= 42

Figure 79: Do specialist learning disability practitioners provide in-reach support where people with a learning disability are admitted to universal mental health services?



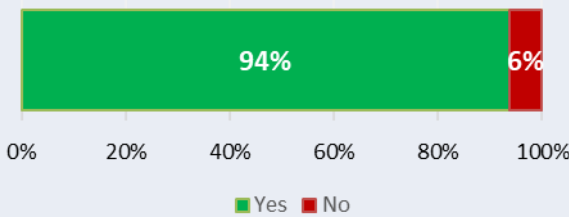
n= 44

Figure 80: 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?



n= 43

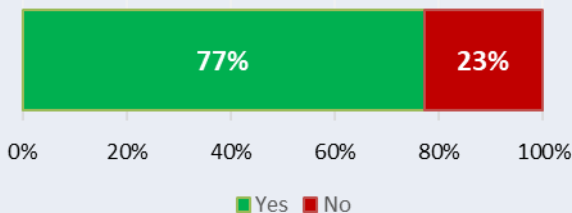
Figure 81: Is there enough availability of independent advocates, in your inpatient settings, to ensure patients can see one, in a timely manner, when they want to?



n= 32

Positive Behaviour Support

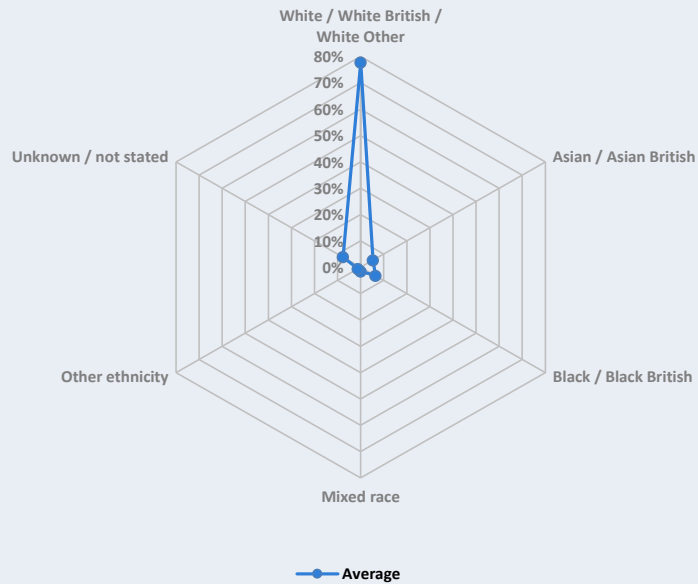
Figure 82: Does your organisation train all learning disabilities clinical staff in PBS, in accordance with the competencies associated with their specific role?



n= 44

Specialist learning disability service staff

Figure 83: Ethnicity of staff in specialist learning disabilities and/or autism services (headcount)



Ethnicity of staff in specialist learning disabilities and/or autism services (headcount)	National %
White / White British / White Other	78%
Asian / Asian British	5%
Black / Black British	6%
Mixed race	2%
Other ethnicity	1%
Unknown / not stated	8%

Restrictive practices

Figure 84: Restraint reduction programmes/policies

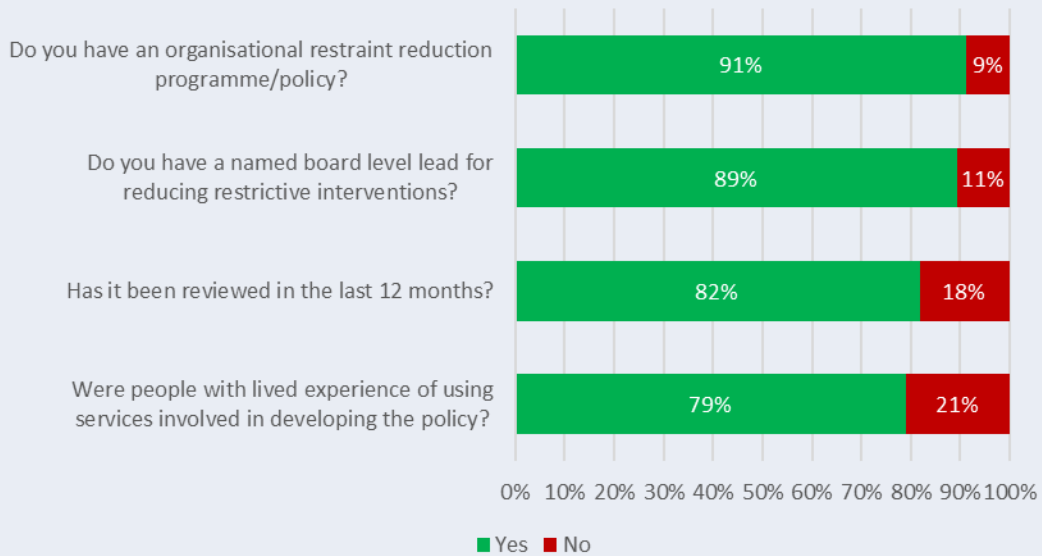


Figure 85: Restraint reporting

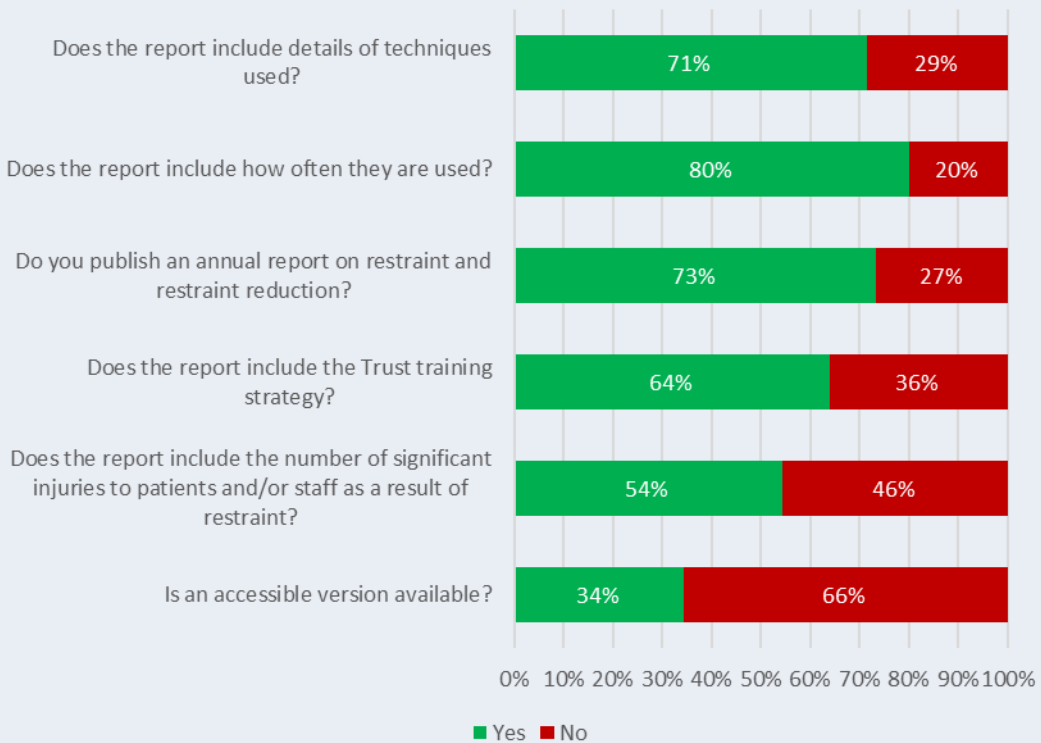
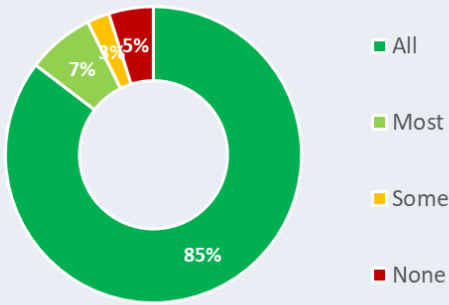
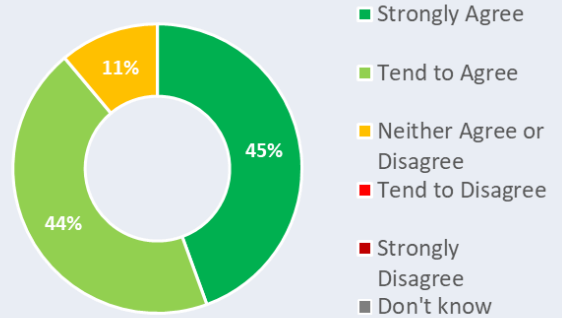


Figure 86: Do you hold risk assessments for each individual physical restraint technique taught to your staff?



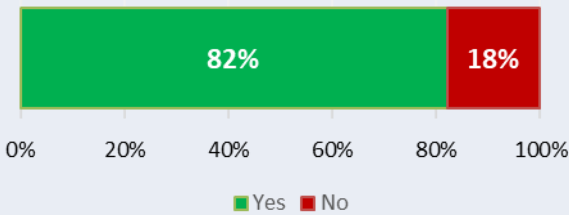
n= 41

Figure 87: 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



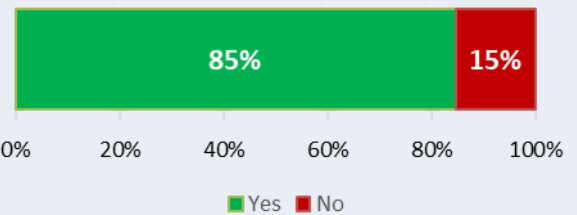
n= 45

Figure 88: 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?



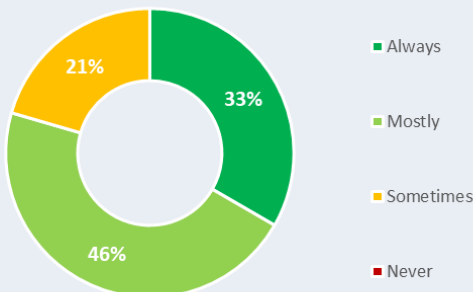
n= 45

Figure 89: 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?



n= 39

Figure 90: Are patients' accounts of incidents and their feelings, anxieties or concerns following the use of restrictive interventions, recorded in their notes?



n= 39

Figure 91: Total number of children, young people and adults with a learning disability and autistic people who have experienced the use of physical restraint in 2020/21

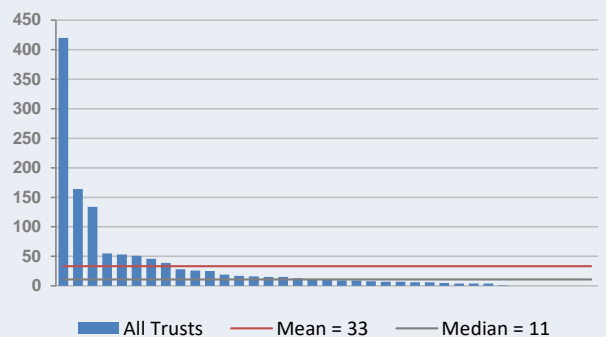


Figure 92: Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2020/21

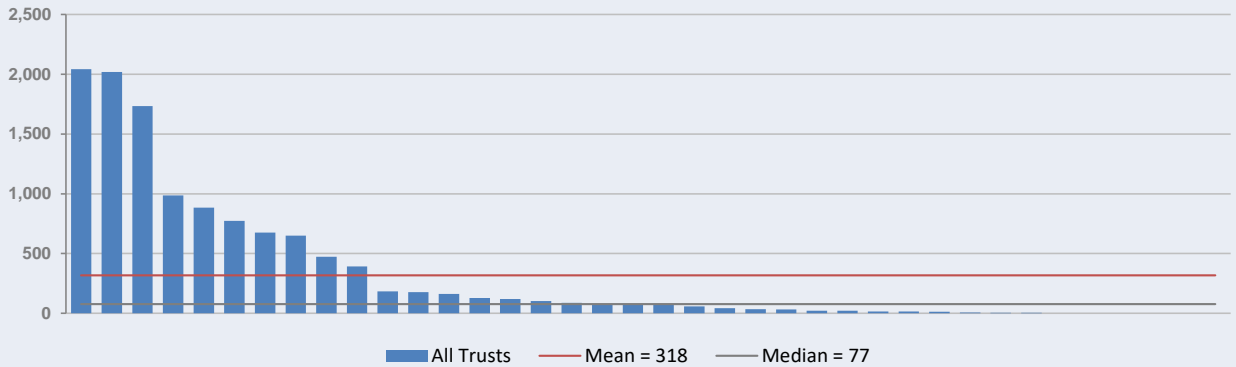


Figure 93: Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2020/21 per 100 children, young people and adults with a learning disability flag on the EPR

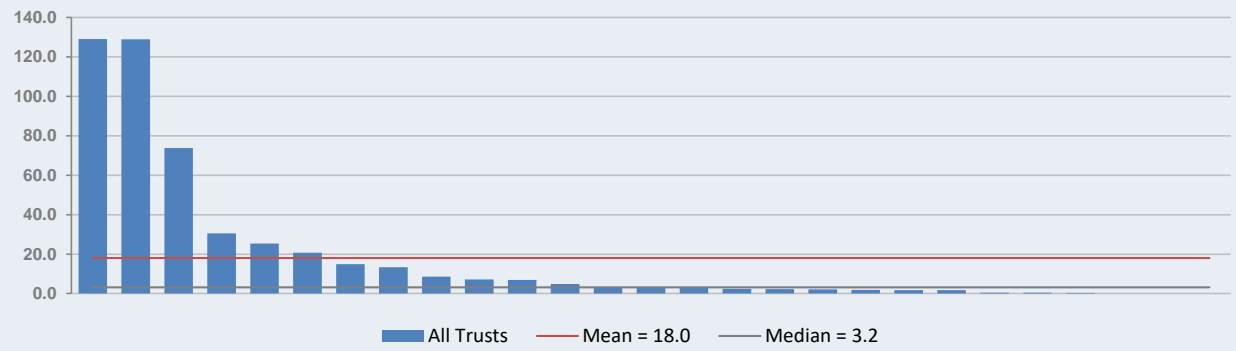
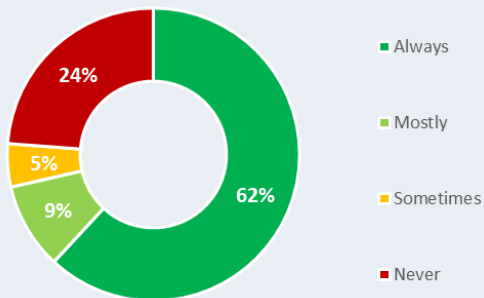
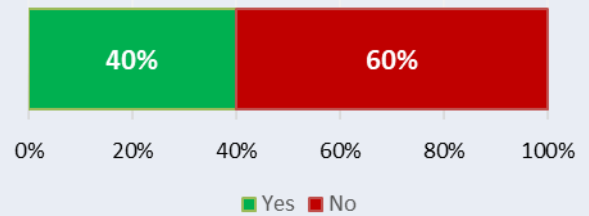


Figure 94: In the exceptional circumstance that there are felt to be cogent reasons to devise a plan for the prone restraint of a patient, are these authorised / signed off by a director of the Trust?



n= 21

Figure 95: Has your board approved the use of mechanical restraint?



n= 45

Figure 96: Total number of children, young people and adults with a learning disability and autistic people who experienced use of mechanical restraint in 2020/21

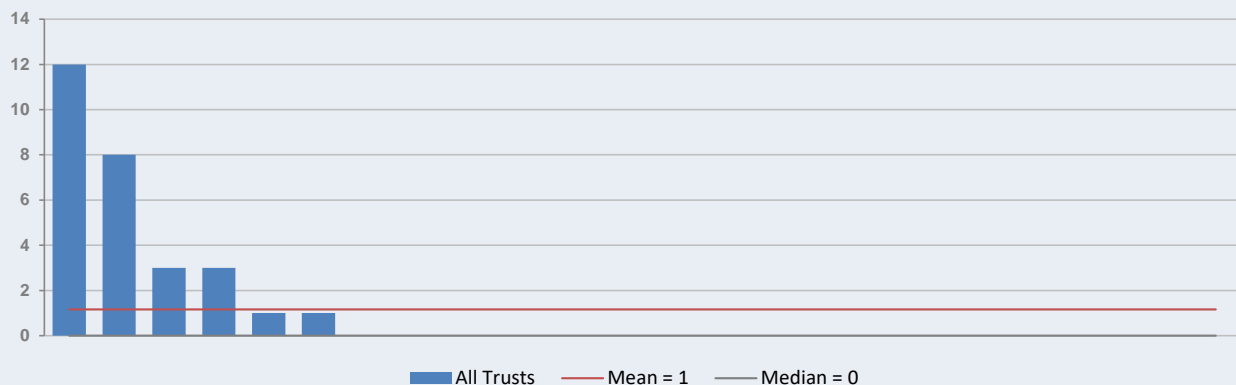
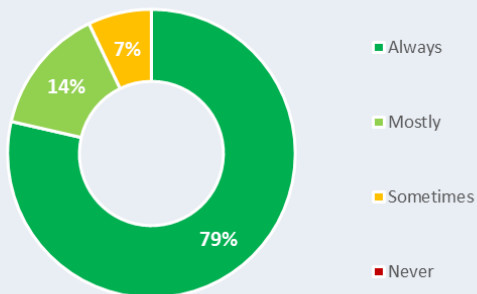
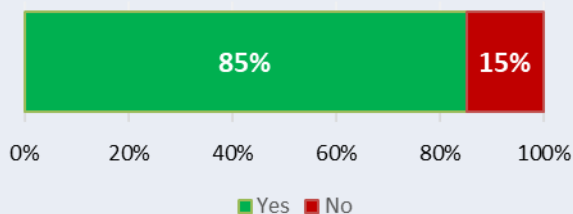


Figure 97: Where a person with a learning disability and/or autism is thought to need a plan for the use of mechanical restraint, is an IMHA consulted as part of the care planning process?



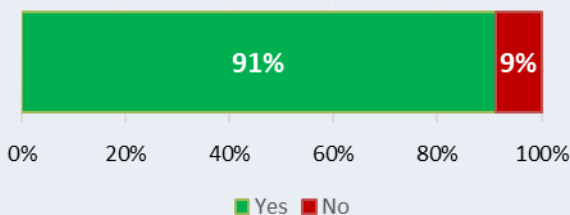
n= 14

Figure 98: Is the RC or duty doctor informed, without delay, each and every time a mechanical restraint device is applied to a patient?



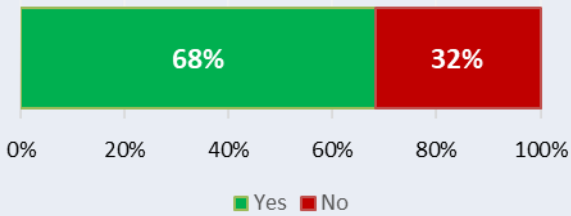
n= 20

Figure 99: Do you use a provider of training in restraint, across your workforce, who is certified as complying with the Restraint Reduction Network Training standards?



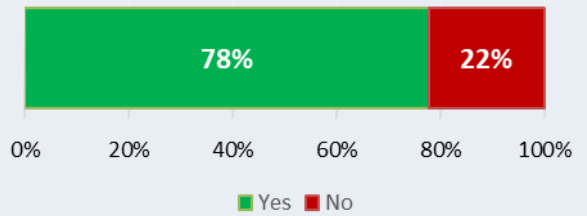
n= 46

Figure 100: Has your board approved the use of long term segregation in your Trust?



n= 41

Figure 101: Do you routinely notify the local authority safeguarding team when a patient is placed in long term segregation?



n= 27

Figure 102: Total number of children, young people and adults with a learning disability and autistic people who experienced use of long-term segregation in 2020/21

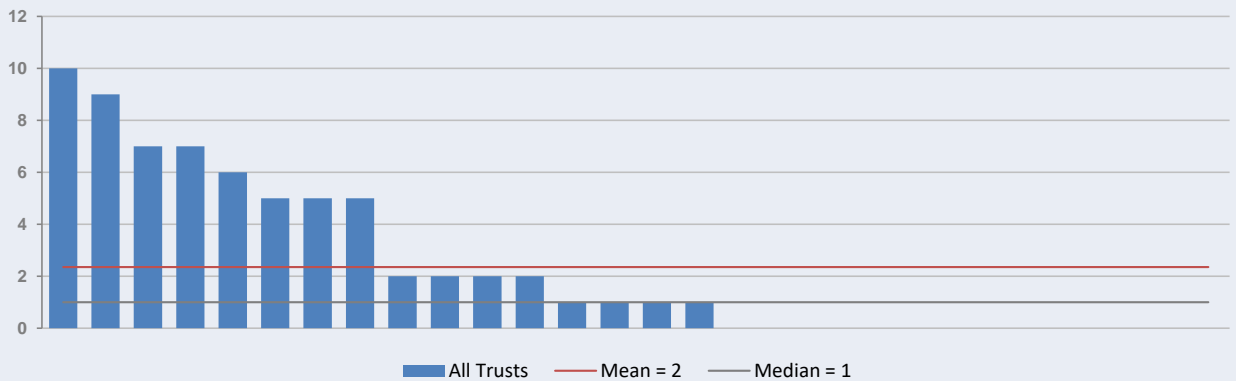
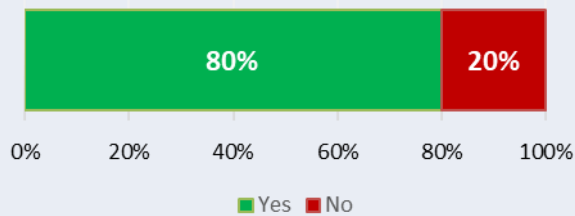
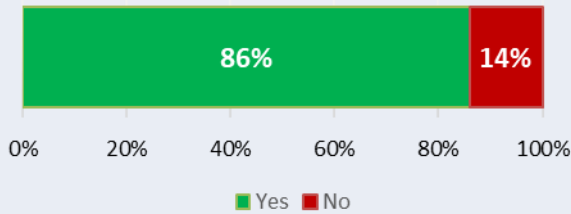


Figure 103: Does this routinely include consultation with the patient's IMHA?



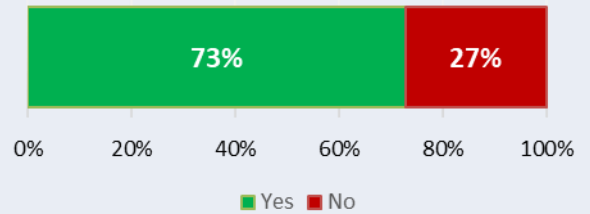
n= 25

Figure 104: Is seclusion approved for use in your service?



n= 43

Figure 105: Does seclusion always take place in a dedicated area of the ward / service, that is not used for any other purpose?



n= 33

Figure 106: Total number of children, young people and adults with a learning disability and autistic people who were subjected to seclusion during 2020/21

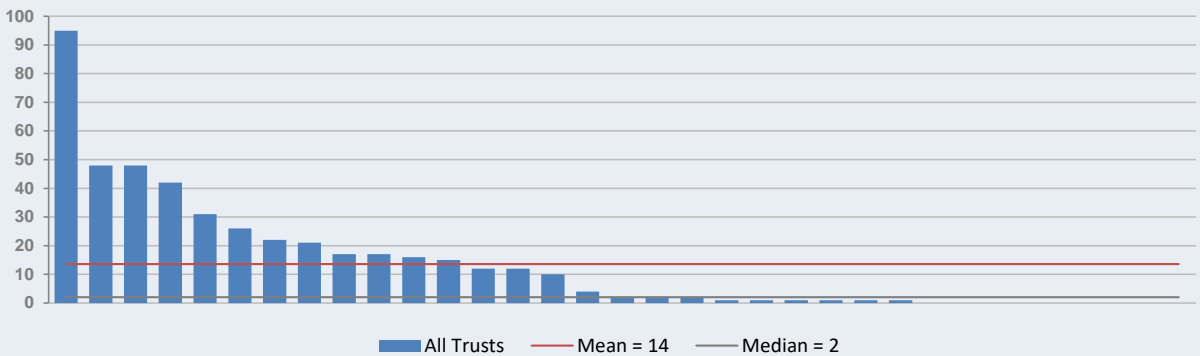
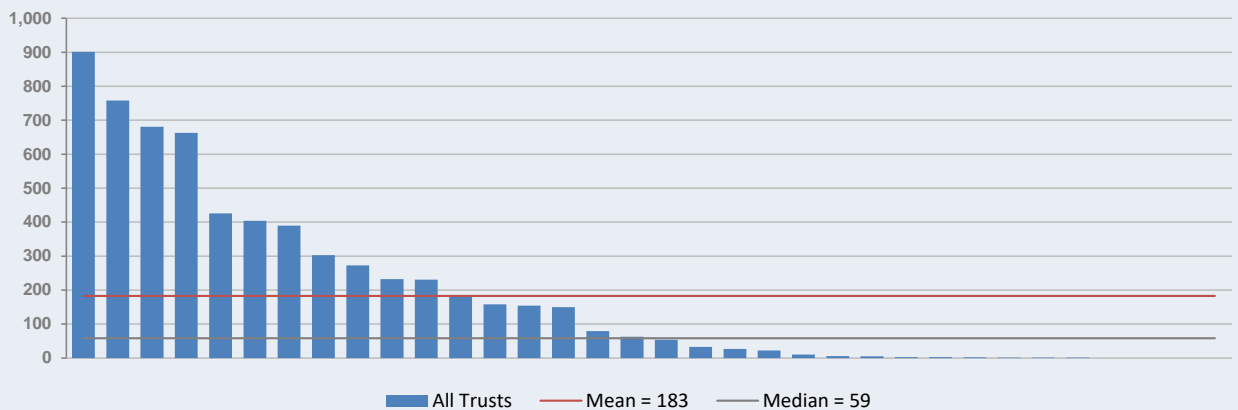
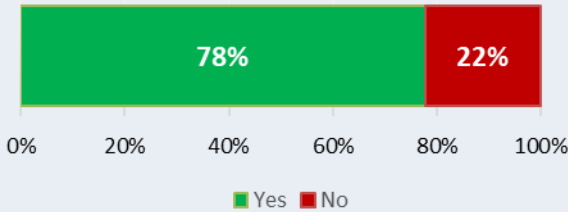


Figure 107: Total number of episodes of seclusion took place during 2020/21



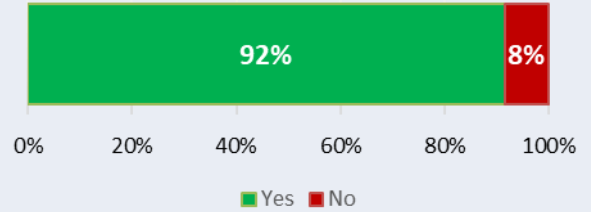
STOMP – STAMP

Figure 108: 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?



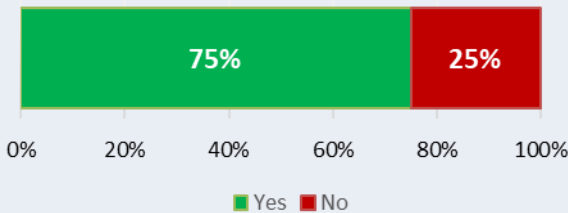
n= 45

Figure 109: Is your Trust signed up to Stopping Over Medication of People with a learning disability and autistic people with psychotropic medication?



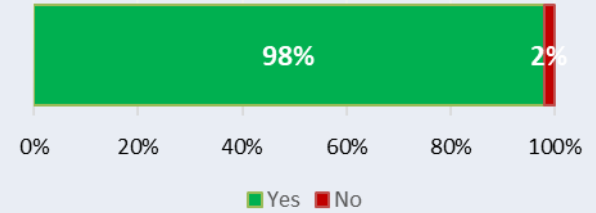
n= 48

Figure 110: Is your Trust signed up to Supporting Treatment and Appropriate use of psychotropic Medication in Paediatrics?



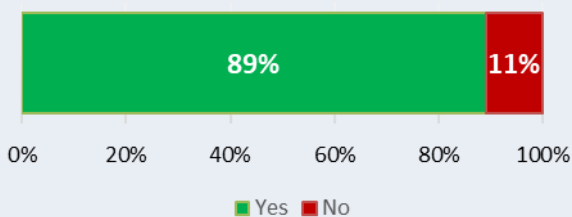
n= 36

Figure 111: Does your Trust provide regular medication reviews?



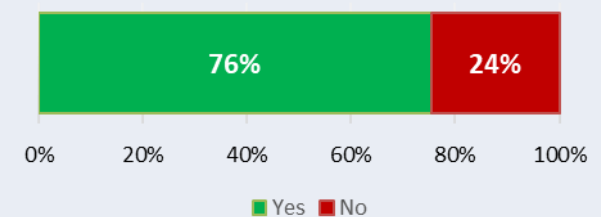
n= 47

Figure 112: Has your organisation signed the STOMP pledge?



n= 46

Figure 113: Has your organisation undertaken a STOMP audit?



n= 45

Appendix 2: Staff survey

Trusts across England asked staff who had provided care for patients with a learning disability and autistic people to complete a short survey on that care.

Trusts were provided with a single unique URL to share with up to 50 staff so that they could anonymously submit their answers online to the NHSBN.

The unique URL also allowed the bespoke analysis of each organisation's staff views. Trusts were provided with information governance guidance and GDPR guidance to assist with the data collection.

Overall, 3,608 staff surveys were completed by 164 organisations, with an average 22 staff surveys completed per trust.

The survey predominantly asked multiple choice questions to minimise the time staff needed to spend away from their day-to-day duties to complete it. The charts show national data alongside the number of participants who completed the metric.

The topics explored through 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 to meet the needs of people with a learning disability and autistic people.

Figure 114: 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
Documented in medical notes	71%
Documented in nursing notes	56%
Documented electronically	71%
Sticker on patient notes	13%
Other	10%
Do not have any systems	
Don't know	9%

Figure 115: In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to:

Appointment accessibility	National Average
Appointments	70%
Flexible appointments	53%
First or last clinic appointments	47%
Double appointments	46%

Figure 116: I feel able to identify what reasonable adjustments are needed for children, young people and adults with a learning disability or autistic people

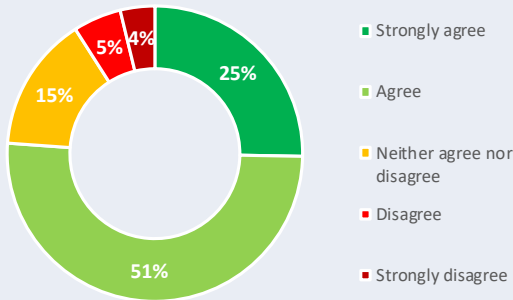


Figure 117: I have the necessary resources to meet the needs of children, young people and adults with a learning disability or autistic people e.g. communication needs or equipment

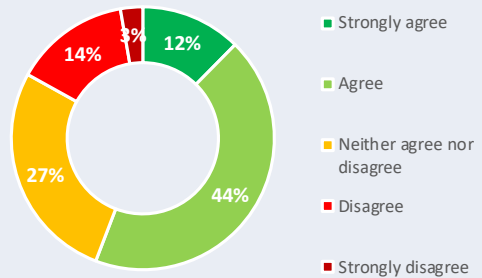


Figure 118: I am confident that children, young people and adults with a learning disability or autistic people using my service always receive the reasonable adjustments they need

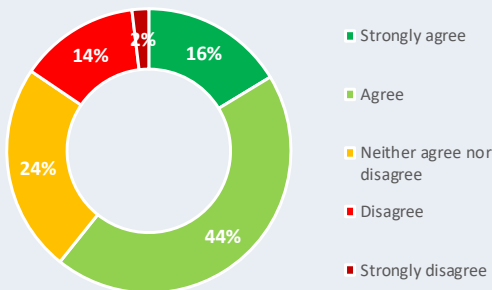


Figure 119: I am always able to deliver safe care to a child, young person, or adult with a learning disability or autistic people

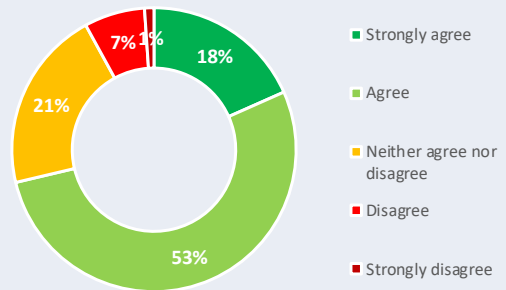


Figure 120: Children, young people and adults with a learning disability or autistic people get the same quality of care as any other person

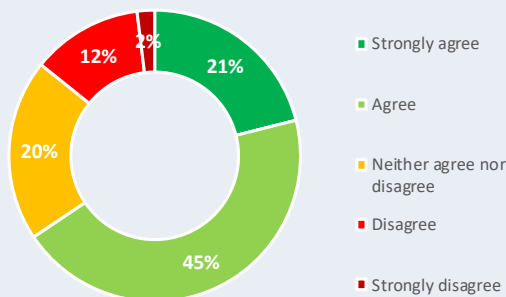


Figure 121: Staff in the Trust always tell children, young people and adults with a learning disability or autistic people and families about their rights when using services

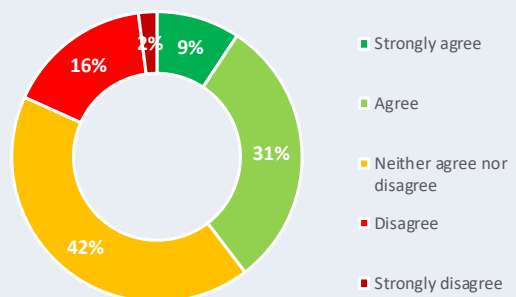
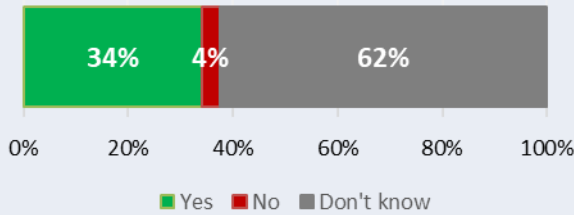


Figure 122: In your Trust, if a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) form (or equivalent) is completed for a child, young person or adult with a learning disability or autistic people, is there a clear policy to double check, to ensure that there is a valid reason?



n= 2402

Figure 123: 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

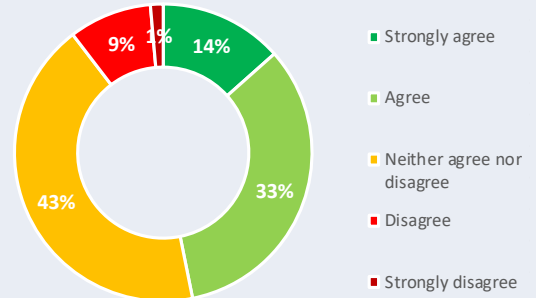
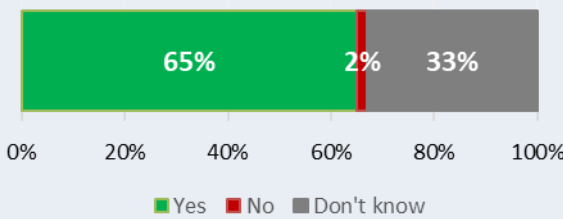


Figure 124: My Trust has policies and procedures to ensure the rights of autistic people are respected and protected



n= 3560

Figure 125: In my Trust, I feel children, young people and adults with a learning disability and autistic people are always treated with dignity and respect

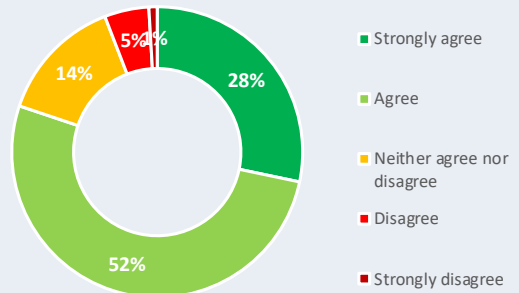


Figure 126: In my Trust, I feel family members of people with a learning disability and/or autism, are always treated with dignity and respect

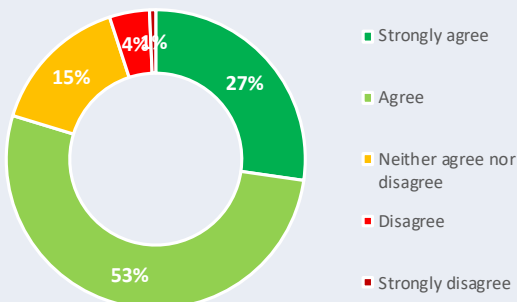


Figure 127: I routinely involve people with a learning disability, and/or autism when making decisions about their care and treatment

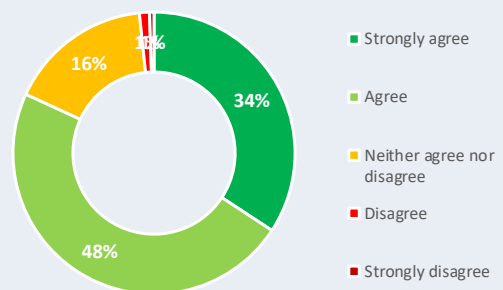


Figure 128: I routinely involve the families of people with a learning disability and/or autism, when making decisions about their care and treatment

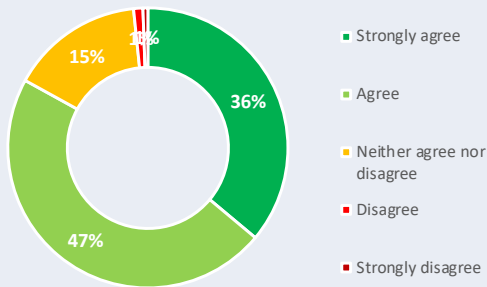


Figure 129: Children, young people and adults with a learning disability are routinely involved in the planning of Trust services

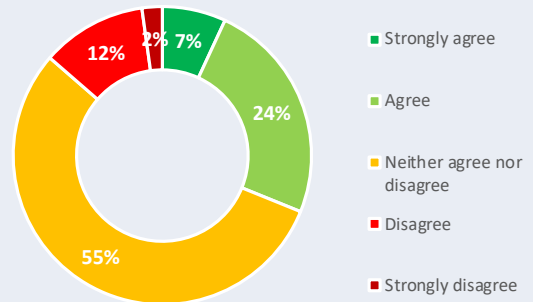


Figure 130: Families of children, young people and adults with a learning disability are routinely involved in the planning of Trust services

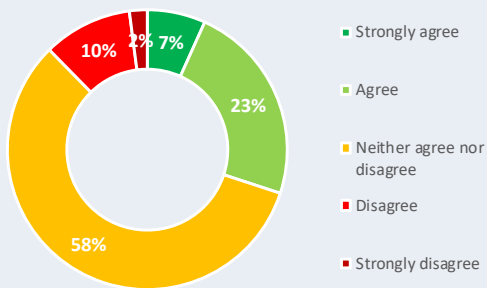
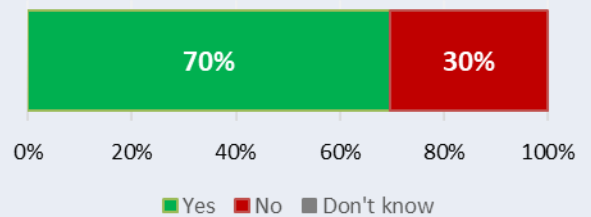


Figure 131: I have received mandatory training on meeting the needs of children, young people and adults with a learning disability, and autistic people, during the course of my work



n= 3574

Figure 132: I feel I have the necessary knowledge and skills to meet the needs of people with a learning disability, and/or autistic people, during the course of my work

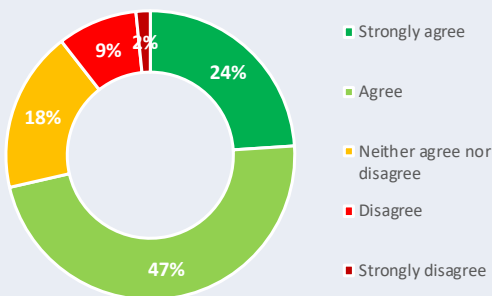


Figure 133: I have access to additional specialist learning disability staff when I need it, to help me meet the needs of children, young people and adults with a learning disability

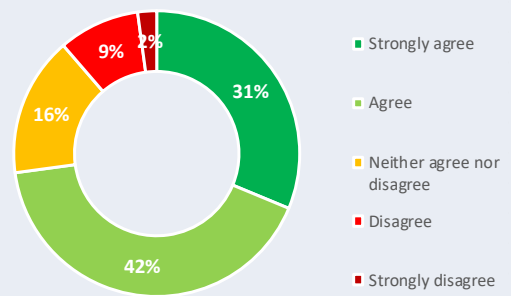


Figure 134: Children, young people and adults with a learning disability are involved in delivering awareness training to staff in my Trust

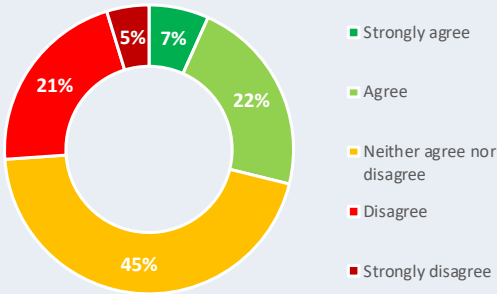


Figure 135: I would recommend the Trust to friends or family members of a person with a learning disability, and/or autistic people who need treatment

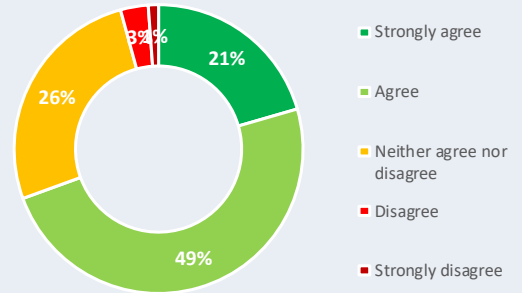


Figure 136: People with a learning disability and/or autistic people, who are in hospital due to concerns about their behaviour or mental health, continue to be seen by staff from their usual community services

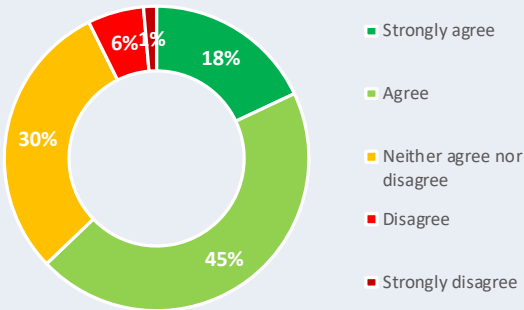


Figure 137: People with a learning disability, and/or autistic people, who are in hospital due to concerns about their behaviour or mental health, are visited by an external care co-ordinator, case manager, or equivalent at least every 6-8 weeks

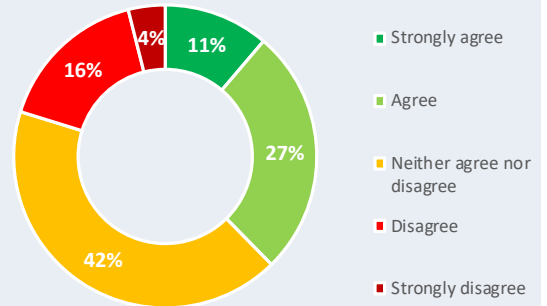


Figure 138: Children, young people and adults with a learning disability, autistic people and family carers are involved in reviewing the appropriateness of psychotropic medications

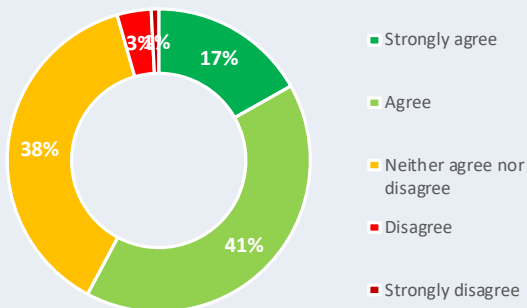


Figure 139: I have had training on reducing the use of restrictive interventions

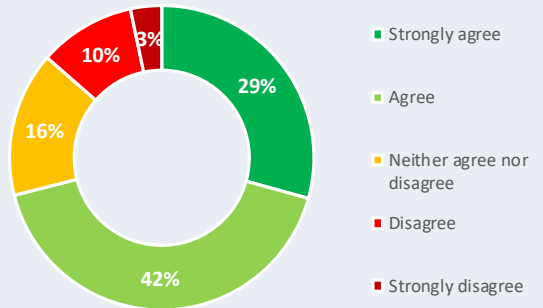


Figure 140: People with a learning disability, and/or autistic people who are in hospital due to concerns about their behaviour or mental health, have good access to independent advocacy services

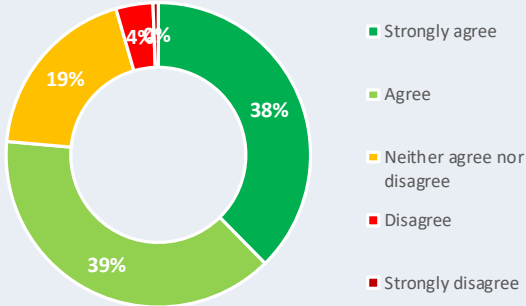


Figure 141: My Trust encourages me to speak out if I have concerns about the wellbeing of children, young people and adults with a learning disability, and autistic people, in our services

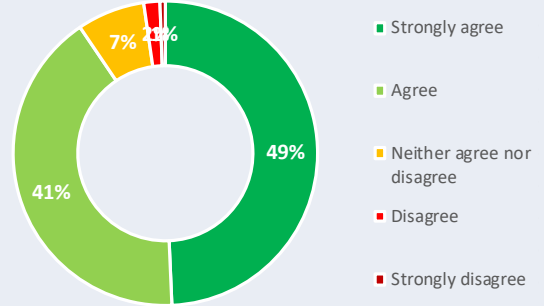
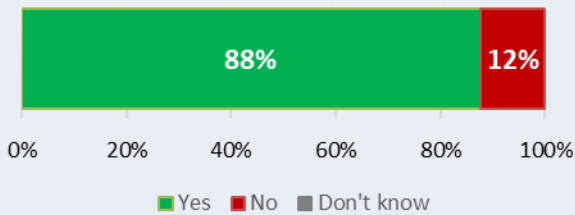


Figure 142: My Trust has developed effective and new ways of supporting children, young people and adults with a learning disability, and autistic people, to live successfully in the community in recent years



n= 737

Appendix 3: Service user survey

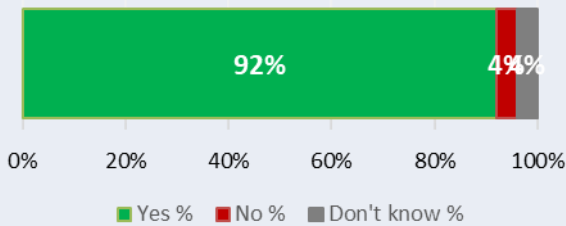
The service user survey largely followed the same methodology as in the previous year. Each trust that registered for the data collection received 100 paper surveys along with freepost envelopes to distribute to service users and carers.

A total of 169 trusts registered for the data collection, with 16,900 surveys distributed to service users and 2,675 returned.

Participants were provided with information governance guidance to alleviate any concerns regarding GDPR. Each survey contained a barcode unique to the trust, allowing trusts to be identified but the patient to remain anonymous.

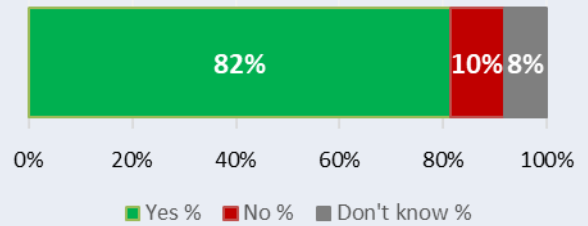
The charts below show the national average for yes/no responses and the number of service users who answered the question.

Figure 143: When you received care from the NHS, did staff treat you with respect?



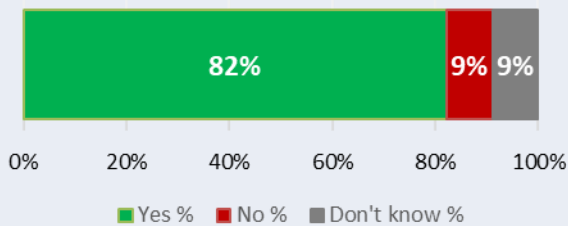
n= 2575

Figure 144: Did staff explain things to you in a way you could understand?



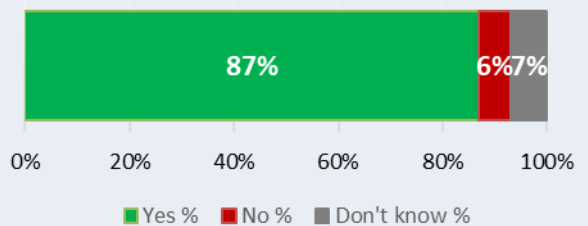
n= 2435

Figure 145: Did you feel like staff listened to you?



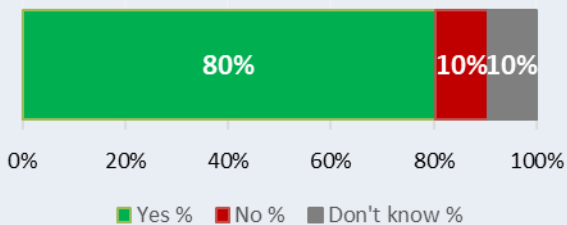
n= 2408

Figure 146: Did you feel like staff cared about you?



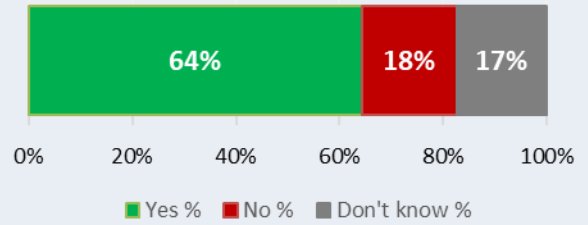
n= 2558

Figure 147: Did staff talk to you about the care you needed?



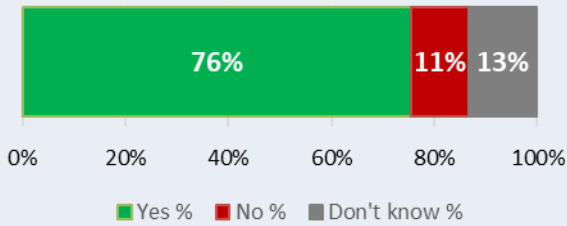
n= 2454

Figure 148: Did staff give you choices about how you were cared for?



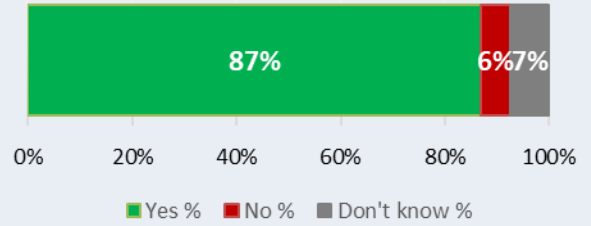
n= 2295

Figure 149: Did staff listen to what your family thought?



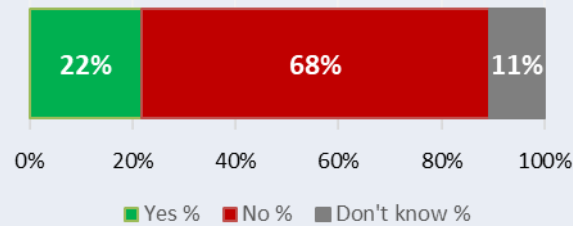
n= 2095

Figure 150: When you received care, did you feel safe?



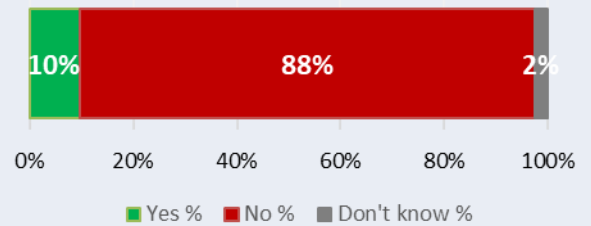
n= 2500

Figure 151: Did you have any concerns about your care?



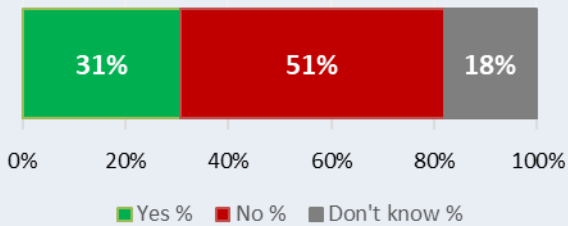
n= 2472

Figure 152: Did you make a complaint?



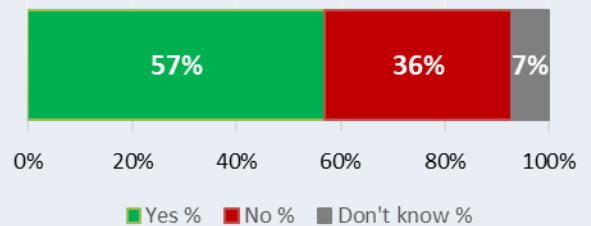
n= 2386

Figure 153: If a complaint was made, were you given Easy Read information about how to make a complaint?



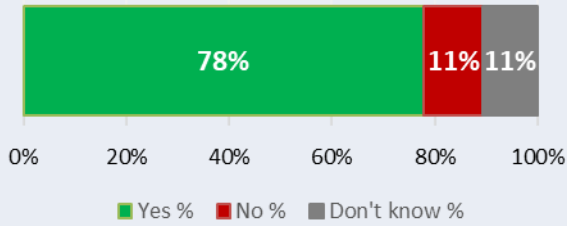
n= 675

Figure 154: If you stayed in hospital, was it easy for your family to visit you?



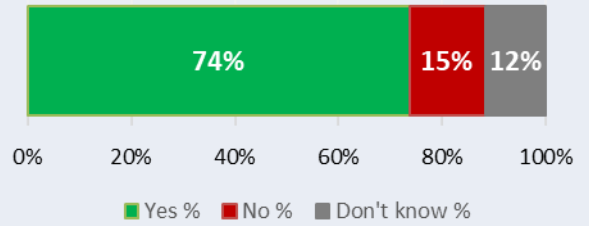
n= 1470

Figure 155: Did staff tell you about your appointments and meetings in a way you could understand?



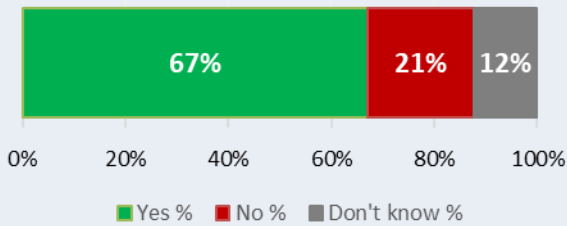
n= 2169

Figure 156: Were your appointments and meetings arranged to suit you?



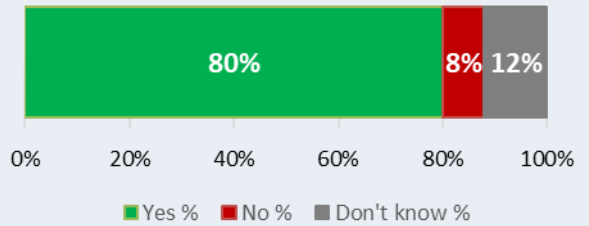
n= 2265

Figure 157: If you needed to be seen in an emergency, were you seen quickly?



n= 1764

Figure 158: Would you recommend this service to a friend or family?



n= 2495

Appendix 4: Data tables

Figure	Respecting and protecting rights -	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
1	If required, is your organisation able to	Yes	84.8%	39	78.4%	105	80.0%	144
		No	15.2%	7	21.6%	29	20.0%	36
		Total		46		134		180
2	If required, is your organisation able to	Yes	51.1%	23	48.5%	64	49.2%	87
		No	48.9%	22	51.5%	68	50.8%	90
		Total		45		132		177
3	Do you currently hold a list of children, young	Yes	80.0%	36	61.5%	80	66.3%	116
		No	20.0%	9	38.5%	50	33.7%	59
		Total		45		130		175
4	Our organisation routinely monitors waiting	Strongly Agree	38.3%	18	9.0%	12	16.7%	30
		Tend to Agree	36.2%	17	21.1%	28	25.0%	45
		Neither Agree or Disagree	6.4%	3	22.6%	30	18.3%	33
		Tend to Disagree	14.9%	7	29.3%	39	25.6%	46
		Strongly Disagree	4.3%	2	13.5%	18	11.1%	20
		Don't know	0.0%	0	4.5%	6	3.3%	6
		Total		47		133		180
5	Our organisation has policies which require staff	Yes	43.5%	20	8.3%	11	17.3%	31
		Partially	43.5%	20	36.8%	49	38.5%	69
		No	13.0%	6	54.9%	73	44.1%	79
		Total		46		133		179
6	Total number of patients with a learning disability who were awaiting a first appointment on 31/03/2021	-	218	42	129.4	82	159.4	124
7	Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2021	-	2409.9	38	1597	103	1816.1	141
8	Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2021 as a % of total patients on the Trust EPR	-	2.8%	37	0.4%	94	1.1%	131
9	Does your electronic patient record allow you,	Yes	55.1%	27	74.0%	97	68.9%	124
		No	44.9%	22	26.0%	34	31.1%	56
		Total		49		131		180
10	Does your Covid recovery plan include specific	Yes	76.2%	32	44.0%	48	53.0%	80
		No	23.8%	10	56.0%	61	47.0%	71
		Total		42		109		151
11	Do you monitor/compare the emergency	Yes	39.1%	18	30.6%	38	32.9%	56
		No	60.9%	28	69.4%	86	67.1%	114
		Total		46		124		170

Figure	Respecting and protecting rights - Organisational level	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
12	Hospital readmission rate for general population patients in 2020/21	-	8.6%	19	10.2%	55	9.8%	74
13	Hospital readmission rate for patients with a learning disability in 2020/21	-	8.7%	17	14.8%	51	13.3%	68
14	Our organisation regularly audits any restrictions and/or Deprivations of Liberty it places on people with a learning disability and/or autism	Yes	69.8%	30	62.6%	77	64.5%	107
		Partially	27.9%	12	25.2%	31	25.9%	43
		No	2.3%	1	12.2%	15	9.6%	16
		Total		43		123		166
15	Have you undertaken an audit of restrictive practices in the last 12 months?	Yes	79.1%	34	42.3%	52	51.8%	86
		No	20.9%	9	57.7%	71	48.2%	80
		Total		43		123		166
16	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	95.2%	40	81.7%	107	85.0%	147
		No	4.8%	2	18.3%	24	15.0%	26
		Total		42		131		173
17	Total number of patient safety incidents recorded concerning children, young people and adults with a learning disability or autistic people in 2020/21	-	641.2	41	104.5	87	276.4	128
18	Total number of patient safety incidents recorded for people with a learning disability and/or autism in 2020/21 per 100 children, young people and adults with a learning disability flag on the EPR	-	37.6	29	12.4	77	19.3	106
19	Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2020/21	-	3.1	39	0.9	95	1.6	134
20	Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2020/21 per 100 people with a learning disability flag on the EPR	-	0.2	28	0.1	82	0.1	110
21	Total number of safeguarding referrals concerning children, young people and adults with a learning disability or autistic people in 2020/21	-	72.3	37	26.5	81	40.9	118
22	Total number of safeguarding referrals concerning people with a learning disability and/or autism in 2020/21 per 100 people with a learning disability flag on the EPR	-	5.4	27	2.7	68	3.4	95
23	Total number of safeguarding referrals regarding people with a learning disability and/or autism in 2020/21 which met the criteria for a section 42 safeguarding / care act enquiry	-	12.3	24	6.2	69	7.8	93
24	Percentage of safeguarding referrals regarding people with a learning disability and/or autism in 2020/21 which met the criteria for a section 42 safeguarding/care act enquiry	-	19.3%	21	31.1%	56	27.9%	77
25	Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability during 2020/21	-	6	43	4	106	5	149

Figure	Respecting and protecting rights - Organisational level	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
26	Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability during 2020/21 as a % of total complaints	-	3%	41	1%	97	2%	138
27	Total number of complaints during 2020/21 concerning the care and treatment of patients with autism who do not also have a learning disability	-	3	28	2	70	2	98
28	Total number of complaints during 2020/21 concerning the care and treatment of patients with autism who do not also have a learning disability as a % of total complaints	-	2%	26	1%	66	1%	92
29	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 2020/21	-	42.9	43	17.9	103	25.3	146
30	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 2020/21 as a % of total deaths	-	4.6%	36	1.5%	91	2.4%	127
31	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of choking incidents	-	0.6	29	0.2	83	0.3	112
32	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of choking incidents per 100 patients with an LD flag on the EPR	-	0	22	0	69	0	91
33	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of sepsis	-	1	30	1.8	88	1.6	118
34	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of sepsis per 100 patients with an LD flag on the EPR	-	0.1	23	0.2	72	0.2	95
35	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of epilepsy	-	0.8	29	0.4	81	0.5	110
36	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of epilepsy per 100 patients with an LD flag on the EPR	-	0.1	22	0	67	0	89
37	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of gastrointestinal obstructions	-	0.4	29	0.4	79	0.4	108
38	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of gastrointestinal obstructions per 100 patients with an LD flag on the EPR	-	0	22	0	65	0	87
39	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of non-covid respiratory condition	-	5.9	31	4.7	91	5	122

Figure	Respecting and protecting rights - Organisational level	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
40	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of non-covid respiratory condition per 100 patients with an LD flag on the EPR	-	0.4	24	0.5	75	0.5	99
41	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of Covid-19	-	10.6	30	7.1	93	7.9	123
42	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of Covid-19 per 100 patients with an LD flag on the EPR	-	0.7	23	0.7	77	0.7	100
43	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of other causes	-	12.4	31	5.5	90	7.3	121
44	Total number of deaths of people with a learning disability that took place in 2020/21 as a result of other causes per 100 patients with an LD flag on the EPR	-	0.8	24	0.6	73	0.7	97
45	Is your organisation represented on the local Learning Disability Mortality Review Programme (LeDeR) steering group?	Yes	95.7%	45	89.5%	119	91.1%	164
		No	4.3%	2	10.5%	14	8.9%	16
		Total		47		133		180
46	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	76.2%	32	53.1%	60	59.4%	92
		No	23.8%	10	46.9%	53	40.6%	63
		Total		42		113		155
47	Does your Trust monitor the rates of use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions for people with a learning disability?	Yes	30.4%	14	51.6%	63	45.8%	77
		No	69.6%	32	48.4%	59	54.2%	91
		Total		46		122		168
48	Total number of children, young people and adults with a learning disability had a DNACPR authorisation in place at the time of their death, during 2020/21?	-	4.5	11	12.5	56	11.2	67

Figure	Inclusion and engagement - Organisational level	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
49	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	37.8%	17	26.9%	35	29.7%	52
		No	62.2%	28	73.1%	95	70.3%	123
		Total		45		130		175
50	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	29.8%	14	11.2%	15	16.0%	29
		Tend to Agree	38.3%	18	23.9%	32	27.6%	50
		Neither Agree or Disagree	12.8%	6	23.9%	32	21.0%	38
		Tend to Disagree	14.9%	7	29.1%	39	25.4%	46
		Disagree	2.1%	1	9.0%	12	7.2%	13
		Don't know	2.1%	1	3.0%	4	2.8%	5
		Total		47		134		181
51	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	61.9%	26	33.1%	40	40.5%	66
		No	38.1%	16	66.9%	81	59.5%	97
		Total		42		121		163
52	Does your organisation's triage process prioritise children, young people and adults with a learning disability, or autistic people?	Yes	61.4%	27	72.3%	94	69.5%	121
		No	38.6%	17	27.7%	36	30.5%	53
		Total		44		130		174
52	Does your organisation provide a low stimulus area/waiting area?	Yes	51.1%	24	74.8%	98	68.5%	122
		No	48.9%	23	25.2%	33	31.5%	56
		Total		47		131		178
52	Does your organisation provide a Changing Places toilet facility?	Yes	48.9%	23	59.5%	78	56.7%	101
		No	51.1%	24	40.5%	53	43.3%	77
		Total		47		131		178
52	Does your organisation produce accessible appointment letters?	Yes	86.4%	38	62.9%	83	68.8%	121
		No	13.6%	6	37.1%	49	31.3%	55
		Total		44		132		176
52	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	95.7%	44	95.5%	126	95.5%	170
		No	4.3%	2	4.5%	6	4.5%	8
		Total		46		132		178
52	Is your organisation able to accommodate carers overnight on site (acute hospitals)?	Yes	33.3%	3	100.0%	119	95.3%	122
		No	66.7%	6	0.0%	0	4.7%	6
		Total		9		119		128
52	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	97.8%	45	52.3%	69	64.0%	114
		No	2.2%	1	47.7%	63	36.0%	64
		Total		46		132		178
52	Do you have a policy that makes it clear that reasonable adjustments should be provided to autistic people?	Yes	50.0%	21	57.8%	74	55.9%	95
		No	50.0%	21	42.2%	54	44.1%	75
		Total		42		128		170
53	Total number of registered learning disability nurses (WTE)	-	62.4	44	4.5	123	19.8	167

Figure	Inclusion and engagement - Organisational level	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
54	Registered LD nurses skill mix	Band 5	32.5%	892	26.4%	147.3	31.4%	1039
		Band 6	40.8%	1120	35.1%	196.3	39.8%	1316
		Band 7	19.4%	534.2	24.0%	134.1	20.2%	668.2
		Band 8	6.2%	170.4	10.3%	57.3	6.9%	227.7
		Other	1.1%	30.39	4.2%	23.5	1.6%	53.89
55	Total number of designated acute learning disability liaison staff employed (WTE)	-	3.9	37	2.2	122	2.6	159
56	Total number of registered LD nurses as a % of designated acute learning disability liaison staff employed (WTE)	-						
57	Total number learning disability liaison staff (WTE) provided on the basis of service level agreements with other trusts	-	1.4	35	0.9	104	1.1	139
58	If learning disability liaison services are available in your area, on the basis of a service level agreement with another trust, do you provide or receive these services?	Provide	42.6%	20	11.4%	15	19.6%	35
		Receive	10.6%	5	25.8%	34	21.8%	39
		Not applicable	46.8%	22	62.9%	83	58.7%	105
		Total		47		132		179
59	Learning disability liaison service staff skill mix	Band 2	0.0%	0	2.4%	6.41	1.6%	6.41
		Band 3	7.7%	11	2.4%	6.49	4.3%	17.49
		Band 4	7.7%	11	6.1%	16.2	6.6%	27.2
		Band 5	10.4%	14.8	7.8%	20.8	8.7%	35.6
		Band 6	44.3%	63.2	34.5%	91.8	37.9%	155
		Band 7	22.5%	32.1	33.1%	88.3	29.4%	120.4
60	Does your Trust employ people with a learning disability or autism?	Yes	84.4%	38	92.8%	116	90.6%	154
		No	15.6%	7	7.2%	9	9.4%	16
		Total		45		125		170
61	Total WTE of workforce employed with a learning disability and/or autism (paid employment only)	-	24.9	30	35.6	54	31.8	84
62	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	40.9%	18	26.7%	35	30.3%	53
		Tend to Agree	45.5%	20	48.9%	64	48.0%	84
		Neither Agree or Disagree	13.6%	6	14.5%	19	14.3%	25
		Tend to Disagree	0.0%	0	5.3%	7	4.0%	7
		Strongly Disagree	0.0%	0	2.3%	3	1.7%	3
		Don't know	0.0%	0	2.3%	3	1.7%	3
		Total		44		131		175
63	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	55.6%	25	54.0%	68	54.4%	93
		No	44.4%	20	46.0%	58	45.6%	78
		Total		45		126		171

Figure	Workforce - Organisational level	Responses	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
64	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	95.5%	42	97.0%	129	96.6%	171
		No	4.5%	2	3.0%	4	3.4%	6
		Total		44		133		177
65	Which professional role best describes the executive role of your board member who leads on quality assurance for learning disabilities and autism?	Medical Director or equivalent	14.0%	6	5.4%	7	7.5%	13
		Quality Director	27.9%	12	6.2%	8	11.6%	20
		Nursing	34.9%	15	82.3%	107	70.5%	122
		Other	7.0%	3	5.4%	7	5.8%	10
		Operations Director or equivalent	16.3%	7	0.8%	1	4.6%	8
		Total		43		130		173
66	Does your workforce plan include data on current and future issues arising from retention/recruitment difficulties relating to the learning disabilities workforce?	Yes	76.7%	33	33.6%	38	45.5%	71
		No	23.3%	10	66.4%	75	54.5%	85
		Total		43		113		156
67	Does your workforce plan include provisions to support the development of new roles in learning disabilities care?	Yes	86.0%	37	46.4%	52	57.4%	89
		No	14.0%	6	53.6%	60	42.6%	66
		Total		43		112		155
68	Do staff receive up-to-date training covering learning disabilities / autism awareness?	Yes	90.9%	40	84.8%	112	86.4%	152
		No	9.1%	4	15.2%	20	13.6%	24
		Total		44		132		176
69	Percentage of staff who received up-to-date training covering learning disabilities/autism awareness in 2020/21	-	60.2%	18	54.9%	71	56.0%	89
70	Does your Trust induction programme invite children, young people and adults with a learning disability or autism to contribute to staff training?	Yes	22.2%	10	18.0%	24	19.1%	34
		No	77.8%	35	82.0%	109	80.9%	144
		Total		45		133		178
71	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?	Yes	81.8%	36	46.9%	61	55.7%	97
		No	18.2%	8	53.1%	69	44.3%	77
		Total		44		130		174
72	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	71.4%	30	62.1%	82	64.4%	112
		No	28.6%	12	37.9%	50	35.6%	62
		Total		42		132		174

Figure	Specialist Learning Disability Services - Organisational level	Responses	Specialist	
			National	n=
73	Inpatient Assessment and Treatment Unit (ATU)	Yes	44.9%	22
		No	55.1%	27
		Total		49
73	Low Secure inpatient unit	Yes	35.4%	17
		No	64.6%	31
		Total		48
73	Medium Secure inpatient unit	Yes	25.0%	12
		No	75.0%	36
		Total		48
73	Long term continuing care/rehabilitation inpatient unit	Yes	12.5%	6
		No	87.5%	42
		Total		48
73	Autism specific inpatient unit	Yes	8.3%	4
		No	91.7%	44
		Total		48
73	High Secure inpatient unit	Yes	4.2%	2
		No	95.8%	46
		Total		48
73	Specialist community learning disability teams for children and young people	Yes	70.8%	34
		No	29.2%	14
		Total		48
73	Specialist community learning disability teams for adults	Yes	95.9%	47
		No	4.1%	2
		Total		49
73	Autism diagnostic services	Yes	77.6%	38
		No	22.4%	11
		Total		49
73	Intensive community support teams for children and young people	Yes	39.1%	18
		No	60.9%	28
		Total		46
73	Intensive community support teams for adults	Yes	75.0%	36
		No	25.0%	12
		Total		48
73	Community forensic learning disability team	Yes	51.1%	24
		No	48.9%	23
		Total		47
74	We operate a dynamic risk / support register with regards to people with a learning disability and/or autism in community settings	Yes	84.8%	39
		Partially	10.9%	5
		No	4.3%	2
		Total		46
75	If you provide an intensive community support service, do the staff provide crisis support?	Yes	83.8%	31
		No	16.2%	6
		Total		37
76	If you provide an intensive community support service is it available 7 days per week?	Yes	59.5%	22
		No	40.5%	15
		Total		37
77	Do your healthcare practitioners provide care coordination in accordance with the provisions of the Care Programme Approach?	Yes	100.0%	43
		No	0.0%	0
		Total		43

Figure	Specialist Learning Disability Services - Organisational level	Responses	Specialist	
			National	n=
78	Do you continue to provide care coordination, where people are placed in out-of-area inpatient services?	Yes	76.2%	32
		No	23.8%	10
		Total		42
79	Do specialist learning disability practitioners provide in-reach support where people with a learning disability are admitted to universal mental health services?	Yes	90.9%	40
		No	9.1%	4
		Total		44
80	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	81.4%	35
		No	18.6%	8
		Total		43
81	Is there enough availability of independent advocates, in your inpatient settings, to ensure patients can see one, in a timely manner, when they want to?	Yes	93.8%	30
		No	6.3%	2
		Total		32
82	Does your organisation train all learning disabilities clinical staff in PBS, in accordance with the competencies associated with their specific role?	Yes	77.3%	34
		No	22.7%	10
		Total		44
83	Ethnicity of staff in specialist learning disabilities and/or autism services (headcount)	White / White British / White Other	77.7%	6568
		Asian / Asian British	5.3%	449.8
		Black / Black British	6.4%	543.8
		Mixed race	1.6%	133.3
		Other ethnicity	1.2%	104.6
		Unknown	7.7%	648.2

Figure	Supplementary Questions - Organisational level	Responses	Specialist	
			National	n=
84	Do you have an organisational restraint reduction programme/policy?	Yes	91.3%	42
		No	8.7%	4
		Total		46
84	Do you have a named board level lead for reducing restrictive interventions?	Yes	89.4%	42
		No	10.6%	5
		Total		47
84	Has it been reviewed in the last 12 months?	Yes	81.8%	36
		No	18.2%	8
		Total		44
84	Were people with lived experience of using services involved in developing the policy?	Yes	79.1%	34
		No	20.9%	9
		Total		43
85	Does the report include details of techniques used?	Yes	71.4%	25
		No	28.6%	10
		Total		35
85	Does the report include how often they are used?	Yes	80.0%	28
		No	20.0%	7
		Total		35
85	Do you publish an annual report on restraint and restraint reduction?	Yes	73.3%	33
		No	26.7%	12
		Total		45
85	Does the report include the Trust training strategy?	Yes	63.9%	23
		No	36.1%	13
		Total		36
85	Does the report include the number of significant injuries to patients and or staff as a result of restraint?	Yes	54.3%	19
		No	45.7%	16
		Total		35
85	Is an accessible version available?	Yes	34.3%	12
		No	65.7%	23
		Total		35
86	Do you hold risk assessments for each individual physical restraint technique taught to your staff?	All	85.4%	35
		Most	7.3%	3
		Some	2.4%	1
		None	4.9%	2
		Total		41
87	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	44.4%	20
		Tend to Agree	44.4%	20
		Neither Agree or Disagree	11.1%	5
		Tend to Disagree	0.0%	0
		Strongly Disagree	0.0%	0
		Don't know	0.0%	0
		Total		45
		88	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
No	17.8%			8
Total				45

Figure	Supplementary Questions - Organisational level	Responses	Specialist	
			National	n=
89	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	84.6%	33
		No	15.4%	6
		Total		39
90	Are patients' accounts of incidents and their feelings, anxieties or concerns following the use of restrictive interventions, recorded in their notes?	Always	33.3%	13
		Mostly	46.2%	18
		Sometimes	20.5%	8
		Never	0.0%	0
		Total		39
91	Total number of children, young people and adults with a learning disability and autistic people who have experienced the use of physical restraint in 2020/21	-	33.2	37
92	Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2020/21	-	318.2	38
93	Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2020/21 per 100 children, young people and adults with a learning disability flag on the EPR	-	18	27
94	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	61.9%	13
		Mostly	9.5%	2
		Sometimes	4.8%	1
		Never	23.8%	5
		Total		21
95	Has your board approved the use of mechanical restraint?	Yes	40.0%	18
		No	60.0%	27
		Total		45
96	Total number of children, young people and adults with a learning disability and autistic people who experienced use of mechanical restraint in 2020/21	-	1.2	24
97	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	78.6%	11
		Mostly	14.3%	2
		Sometimes	7.1%	1
		Never	0.0%	0
		Total		14
98	Is the RC or duty doctor informed, without delay, each and every time a mechanical restraint device is applied to a patient?	Yes	85.0%	17
		No	15.0%	3
		Total		20
99	Do you use a provider of training in restraint, across your workforce, who is certified as complying with the Restraint Reduction Network Training standards?	Yes	91.3%	42
		No	8.7%	4
		Total		46

Figure	Supplementary Questions - Organisational level	Responses	Specialist	
			National	n=
100	Has your board approved the use of long term segregation in your Trust?	Yes	68.3%	28
		No	31.7%	13
		Total		41
101	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
102	Total number of children, young people and adults with a learning disability and autistic people who experienced use of long-term segregation in 2020/21	-	2.4	28
103	Does this routinely include consultation with the patient's IMHA?	Yes	80.0%	20
		No	20.0%	5
		Total		25
104	Is seclusion approved for use in your service?	Yes	86.0%	37
		No	14.0%	6
		Total		43
105	Does seclusion always take place in a dedicated area of the ward / service, that is not used for any other purpose?	Yes	72.7%	24
		No	27.3%	9
		Total		33
106	Total number of children, young people and adults with a learning disability and autistic people who were subjected to seclusion during 2020/21	-	13.6	33
107	Total number of episodes of seclusion took place during 2020/21	-	182.9	34
108	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	77.8%	35
		No	22.2%	10
		Total		45
109	Is your Trust signed up to Stopping Over Medication of People with a learning disability and autistic people with psychotropic medication?	Yes	91.7%	44
		No	8.3%	4
		Total		48
110	Is your Trust signed up to Supporting Treatment and Appropriate use of psychotropic Medication in Paediatrics?	Yes	75.0%	27
		No	25.0%	9
		Total		36
111	Does your Trust provide regular medication reviews?	Yes	97.9%	46
		No	2.1%	1
		Total		47
112	Has your organisation signed the STOMP pledge?	Yes	89.1%	41
		No	10.9%	5
		Total		46
113	Has your organisation undertaken a STOMP audit?	Yes	75.6%	34
		No	24.4%	11
		Total		45

Figure	Respecting and protecting rights - Staff survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
114	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%	1932	71%	1932
		Documented in nursing notes	-	-	56%	1510	56%	1510
		Documented electronically	-	-	71%	1931	71%	1931
		Sticker on patient notes	-	-	13%	354	13%	354
		Other	-	-	10%	258	10%	258
		Do not have any system	-	-	1%	39	1%	39
		Don't know	-	-	9%	239	9%	239
115	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to appointments	Yes	84%	730	65%	1725	70%	2455
		No	5%	44	2%	62	3%	106
		Don't know	11%	97	32%	848	27%	945
		Total		871		2635		3506
115	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to flexible appointments	Yes	74%	633	45%	1181	53%	1814
		No	5%	43	5%	120	5%	163
		Don't know	21%	182	50%	1295	43%	1477
		Total		858		2596		3454
115	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	65%	542	41%	1074	47%	1616
		No	5%	42	5%	119	5%	161
		Don't know	30%	248	54%	1399	48%	1647
		Total		832		2592		3424
115	In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to double appointments	Yes	64%	528	40%	1039	46%	1567
		No	6%	48	6%	162	6%	210
		Don't know	31%	253	53%	1380	48%	1633
		Total		829		2581		3410
116	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	40%	356	20%	547	25%	903
		Agree	47%	411	52%	1405	51%	1816
		Neither agree nor disagree	8%	67	17%	462	15%	529
		Disagree	2%	17	6%	171	5%	188
		Strongly disagree	4%	31	4%	104	4%	135
		Total		882		2689		3571
117	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	21%	189	9%	254	12%	443
		Agree	48%	427	42%	1127	43%	1554
		Neither agree nor disagree	19%	171	30%	803	27%	974
		Disagree	9%	84	16%	424	14%	508
		Strongly disagree	2%	18	3%	80	3%	98
		Total		889		2688		3577

Figure	Respecting and protecting rights - Staff survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
118	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	27%	240	13%	343	16%	583
		Agree	46%	405	44%	1183	44%	1588
		Neither agree nor disagree	17%	153	26%	695	24%	848
		Disagree	9%	81	15%	406	14%	487
		Strongly disagree	1%	11	2%	57	2%	68
		Total		890		2684		3574
119	I am always able to deliver safe care to a child, young person, or adult with a learning disability or autistic people	Strongly agree	27%	242	15%	412	18%	654
		Agree	54%	479	53%	1408	53%	1887
		Neither agree nor disagree	13%	115	23%	624	21%	739
		Disagree	5%	45	8%	201	7%	246
		Strongly disagree	0%	4	1%	34	1%	38
		Total		885		2679		3564
120	Children, young people and adults with a learning disability or autistic people get the same quality of care as any other person	Strongly agree	-	0	21%	564	21%	564
		Agree	-	0	45%	1192	45%	1192
		Neither agree nor disagree	-	0	20%	540	20%	540
		Disagree	-	0	12%	329	12%	329
		Strongly disagree	-	0	2%	52	2%	52
		Total	-	0		2677		2677
121	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	18%	155	7%	176	9%	331
		Agree	44%	391	26%	688	30%	1079
		Neither agree nor disagree	28%	249	47%	1249	42%	1498
		Disagree	9%	78	19%	499	16%	577
		Strongly disagree	1%	11	2%	62	2%	73
		Total		884		2674		3558
122	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	47%	81	33%	735	34%	816
		No	2%	4	4%	81	4%	85
		Don't know	51%	89	63%	1412	62%	1501
		Total		174		2228		2402
123	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	22%	190	11%	285	13%	475
		Agree	41%	359	31%	823	33%	1182
		Neither agree nor disagree	29%	253	47%	1260	43%	1513
		Disagree	8%	67	9%	252	9%	319
		Strongly disagree	1%	12	1%	37	1%	49
		Total		881		2657		3538
124	My Trust has policies and procedures to ensure the rights of autistic people are respected and protected	Yes	71%	626	63%	1689	65%	2315
		No	2%	19	2%	54	2%	73
		Don't know	27%	233	35%	939	33%	1172
		Total		878		2682		3560

Figure	Inclusion and engagement - Staff survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
125	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	38%	335	25%	674	28%	1009
		Agree	48%	427	53%	1423	52%	1850
		Neither agree nor disagree	9%	79	16%	420	14%	499
		Disagree	4%	36	5%	140	5%	176
		Strongly disagree	1%	5	1%	28	1%	33
		Total		882		2685		3567
126	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	36%	318	24%	658	27%	976
		Agree	49%	436	53%	1440	52%	1876
		Neither agree nor disagree	10%	92	17%	455	15%	547
		Disagree	4%	36	4%	119	4%	155
		Strongly disagree	0%	4	1%	20	1%	24
		Total		886		2692		3578
127	I routinely involve people with a learning disability, and/or autism when making decisions about their care and treatment	Strongly agree	51%	448	29%	769	34%	1217
		Agree	41%	361	50%	1331	48%	1692
		Neither agree nor disagree	7%	66	19%	520	16%	586
		Disagree	1%	6	1%	35	1%	41
		Strongly disagree	0%	2	1%	16	1%	18
		Total		883		2671		3554
128	I routinely involve the families of people with a learning disability and/or autism, when making decisions about their care and treatment	Strongly agree	46%	405	33%	873	36%	1278
		Agree	42%	370	48%	1292	47%	1662
		Neither agree nor disagree	10%	87	17%	457	15%	544
		Disagree	1%	12	1%	26	1%	38
		Strongly disagree	0%	3	1%	17	1%	20
		Total		877		2665		3542
129	Children, young people and adults with a learning disability are routinely involved in the planning of Trust services	Strongly agree	8%	73	6%	172	7%	245
		Agree	31%	270	22%	590	24%	860
		Neither agree nor disagree	47%	415	58%	1546	55%	1961
		Disagree	12%	103	11%	302	11%	405
		Strongly disagree	2%	21	2%	57	2%	78
		Total		882		2667		3549
130	Families of children, young people and adults with a learning disability are routinely involved in the planning of Trust services	Strongly agree	9%	76	6%	163	7%	239
		Agree	27%	240	22%	587	23%	827
		Neither agree nor disagree	52%	458	59%	1586	58%	2044
		Disagree	10%	87	10%	278	10%	365
		Strongly disagree	2%	21	2%	52	2%	73
		Total		882		2666		3548

Figure	Workforce - Staff survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
131	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	79%	698	67%	1795	70%	2493
		No	21%	185	33%	896	30%	1081
		Total		883		2691		3574
132	I feel I have the necessary knowledge and skills to meet the needs of people with a learning disability, and/or autistic people, during the course of my work	Strongly agree	40%	356	19%	499	24%	855
		Agree	46%	411	48%	1281	47%	1692
		Neither agree nor disagree	8%	70	21%	573	18%	643
		Disagree	4%	38	10%	281	9%	319
		Strongly disagree	1%	9	2%	48	2%	57
		Total		884		2682		3566
133	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	43%	382	27%	727	31%	1109
		Agree	40%	355	42%	1121	42%	1476
		Neither agree nor disagree	9%	81	18%	480	16%	561
		Disagree	6%	51	10%	275	9%	326
		Strongly disagree	1%	11	2%	65	2%	76
		Total		880		2668		3548
134	Children, young people and adults with a learning disability are involved in delivering awareness training to staff in my Trust	Strongly agree	10%	85	6%	153	7%	238
		Agree	29%	261	20%	526	22%	787
		Neither agree nor disagree	41%	359	47%	1242	45%	1601
		Disagree	17%	147	23%	612	21%	759
		Strongly disagree	4%	33	5%	135	5%	168
		Total		885		2668		3553
135	I would recommend the Trust to friends or family members of a person with a learning disability, and/or autistic people who need treatment	Strongly agree	28%	248	18%	486	21%	734
		Agree	49%	429	49%	1321	49%	1750
		Neither agree nor disagree	19%	166	29%	775	26%	941
		Disagree	4%	32	3%	79	3%	111
		Strongly disagree	1%	8	1%	33	1%	41
		Total		883		2694		3577

Figure	Specialist services - Staff survey	Response	Specialist	
			National	n=
136	People with a learning disability and/or autistic people, 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	18%	157
		Agree	45%	391
		Neither agree nor disagree	30%	260
		Disagree	6%	52
		Strongly disagree	1%	12
		Total		872
137	People with a learning disability, and/or autistic people, 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	11%	20
		Agree	26%	47
		Neither agree nor disagree	42%	75
		Disagree	16%	29
		Strongly disagree	4%	7
		Total		178
138	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%	148
		Agree	41%	360
		Neither agree nor disagree	38%	332
		Disagree	4%	32
		Strongly disagree	1%	7
		Total		879
139	I have had training on reducing the use of restrictive interventions	Strongly agree	29%	257
		Agree	42%	366
		Neither agree nor disagree	15%	135
		Disagree	10%	90
		Strongly disagree	3%	29
		Total		877
140	People with a learning disability, and/or autistic people who are in hospital due to concerns about their behaviour or mental health, have good access to independent advocacy services	Strongly agree	38%	67
		Agree	39%	69
		Neither agree nor disagree	19%	34
		Disagree	4%	7
		Strongly disagree	1%	1
		Total		178
141	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	49%	432
		Agree	41%	361
		Neither agree nor disagree	7%	63
		Disagree	2%	15
		Strongly disagree	1%	5
		Total		876
142	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	88%	645
		No	12%	92
		Total		737

Figure	Service user survey	Response	Specialist		Universal		All Trusts	
			National	n=	National	n=	National	n=
143	When you received care from the NHS, did staff treat you with respect?	Yes	94%	648	91%	1721	92%	2369
		No	3%	21	4%	81	4%	102
		Don't know	3%	24	4%	80	4%	104
		Total		693		1882		2575
144	Did staff explain things to you in a way you could understand?	Yes	86%	563	80%	1422	82%	1985
		No	8%	51	11%	202	10%	253
		Don't know	7%	44	9%	153	8%	197
		Total		658		1777		2435
145	Did you feel like staff listened to you?	Yes	86%	567	81%	1412	82%	1979
		No	6%	41	10%	173	9%	214
		Don't know	8%	55	9%	160	9%	215
		Total		663		1745		2408
146	Did you feel like staff cared about you?	Yes	90%	618	86%	1603	87%	2221
		No	5%	36	7%	125	6%	161
		Don't know	5%	36	7%	140	7%	176
		Total		690		1868		2558
147	Did staff talk to you about the care you needed?	Yes	84%	556	79%	1416	80%	1972
		No	7%	46	11%	201	10%	247
		Don't know	9%	62	10%	173	10%	235
		Total		664		1790		2454
148	Did staff give you choices about how you were cared for?	Yes	70%	440	62%	1034	64%	1474
		No	14%	89	20%	332	18%	421
		Don't know	16%	99	18%	301	17%	400
		Total		628		1667		2295
149	Did staff listen to what your family thought?	Yes	78%	441	75%	1143	76%	1584
		No	8%	46	12%	186	11%	232
		Don't know	14%	77	13%	202	13%	279
		Total		564		1531		2095
150	When you received care, did you feel safe?	Yes	89%	600	86%	1575	87%	2175
		No	4%	30	6%	108	6%	138
		Don't know	7%	44	8%	143	7%	187
		Total		674		1826		2500
151	Did you have any concerns about your care?	Yes	20%	135	22%	402	22%	537
		No	69%	461	67%	1210	68%	1671
		Don't know	10%	68	11%	196	11%	264
		Total		664		1808		2472
152	Did you make a complaint?	Yes	12%	74	9%	157	10%	231
		No	85%	531	89%	1566	88%	2097
		Don't know	4%	23	2%	35	2%	58
		Total		628		1758		2386

Figure	Service user survey	Response	Specialist		Universal		All Trusts	
			Nationa	n=	Nationa	n=	Nationa	n=
153	If a complaint was made, were you given Easy Read information about how to make a complaint?	Yes	45%	93	24%	114	31%	207
		No	40%	81	56%	265	51%	346
		Don't know	15%	31	19%	91	18%	122
		Total		205		470		675
154	If you stayed in hospital, was it easy for your family to visit you?	Yes	59%	179	56%	659	57%	838
		No	30%	91	37%	433	36%	524
		Don't know	10%	31	7%	77	7%	108
		Total		301		1169		1470
155	Did staff tell you about your appointments and meetings in a way you could understand?	Yes	82%	507	76%	1183	78%	1690
		No	9%	54	13%	195	11%	249
		Don't know	10%	59	11%	171	11%	230
		Total		620		1549		2169
156	Were your appointments and meetings arranged to suit you?	Yes	79%	521	71%	1147	74%	1668
		No	10%	68	16%	264	15%	332
		Don't know	10%	69	12%	196	12%	265
		Total		658		1607		2265
157	If you needed to be seen in an emergency, were you seen quickly?	Yes	70%	304	66%	878	67%	1182
		No	17%	76	22%	289	21%	365
		Don't know	13%	55	12%	162	12%	217
		Total		435		1329		1764
158	Would you recommend this service to a friend or family?	Yes	81%	543	80%	1456	80%	1999
		No	7%	48	8%	148	8%	196
		Don't know	11%	76	12%	224	12%	300
		Total		667		1828		2495