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Benchmarking Network



Performance against the learning disability improvement standards

Appendices: Detailed findings from the
2020 collection

January 2022

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Appendix 1: Organisational level collection

We collected metrics from 178 organisations across England, concerning corporate activity in the 2019/20 financial year. The NHS Benchmarking Network (NHSBN) and NHS England and NHS Improvement thank all contributors for their participation.

The country was in national lockdown for just the last eight days in 2019/20 (2.2% of total days), but healthcare services made anticipatory changes ahead of this and the impact of COVID-19 is evident in some of the data.

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.

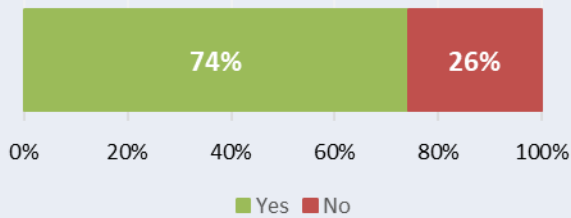
The 50 organisations identified as providing specialist learning services were asked to provide data on supplementary questions to explore in greater detail the initiatives to reduce restrictive practices and policies to stop the over-medication of people with a learning disability and autistic people.

The data included 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.

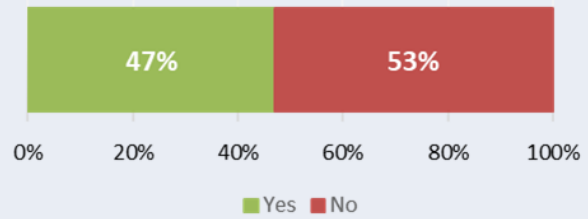
Access

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



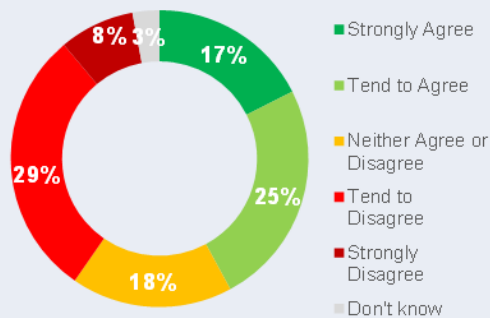
n= 171

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



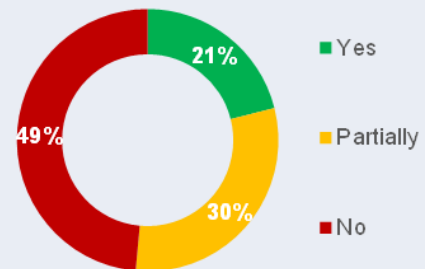
n= 171

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



n= 171

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



n= 171

Figure 5: Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2020

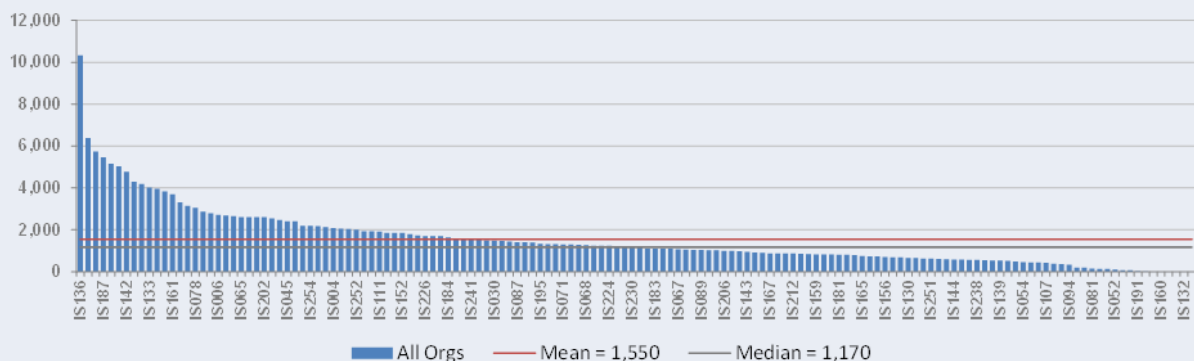


Figure 6: Total number of children, young people and adults who had a learning disability flag on the Trust EPR at 31/03/2020 as a % of total patients on the Trust EPR

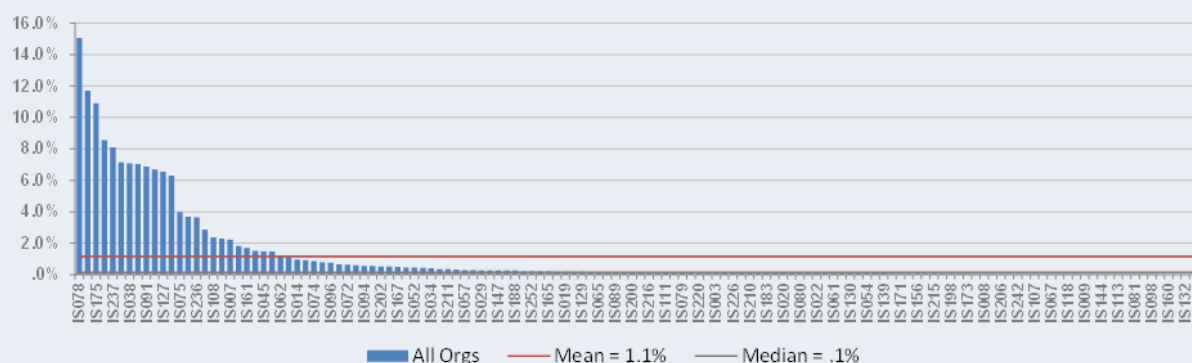
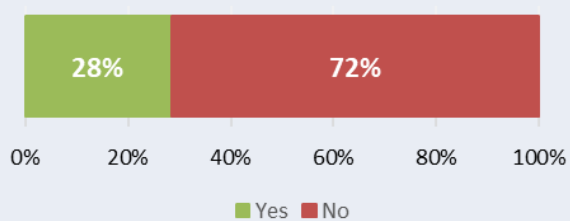


Figure 7: Do you monitor/compare the emergency readmission rates for children, young people and adults with a learning disability, with those of people without learning disabilities?



n = 165

Figure 8: Hospital readmission rate for general population patients in 2019/20

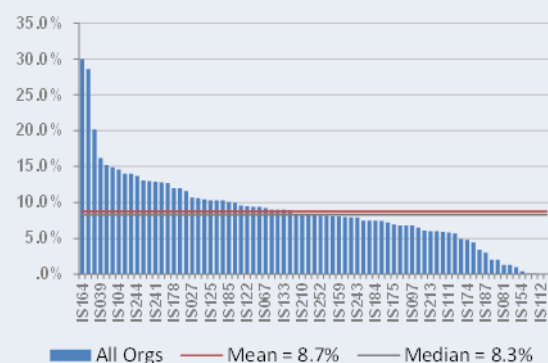


Figure 9: Hospital readmission rate for patients with a learning disability in 2019/20

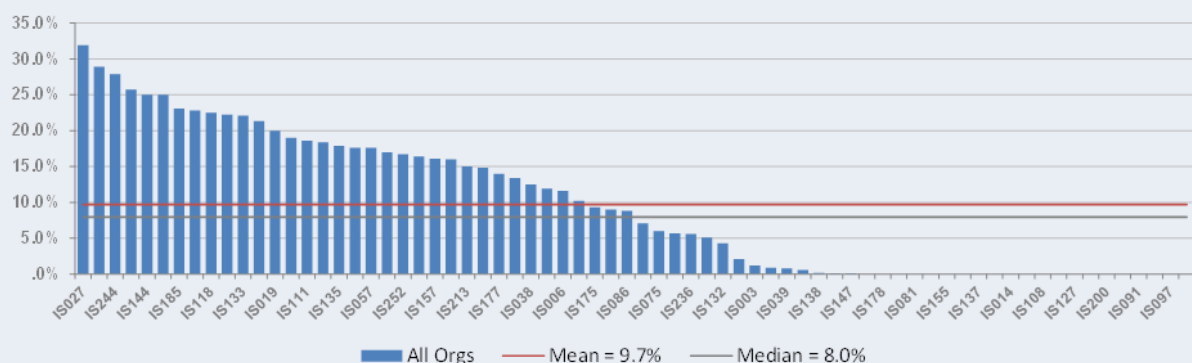
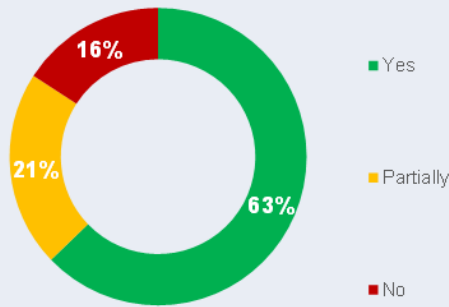
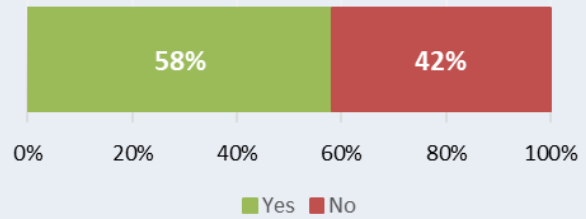


Figure 10: Our organisation regularly audits any restrictions and/or deprivations of liberty it places on people with a learning disability and/or autism



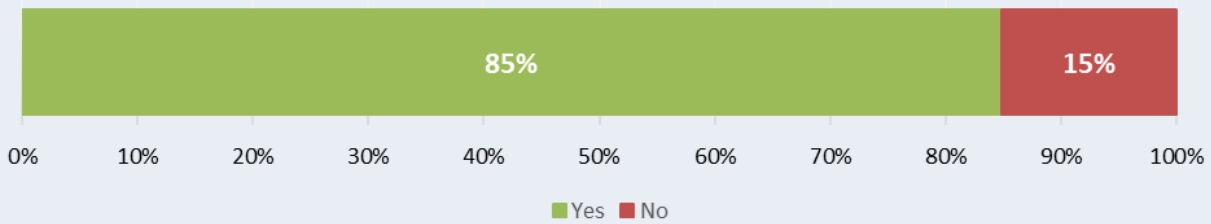
n= 164

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



n= 163

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



n= 171

Figure 13: Total number of patient safety incidents recorded concerning children, young people and adults with a learning disability or autistic people in 2019/20

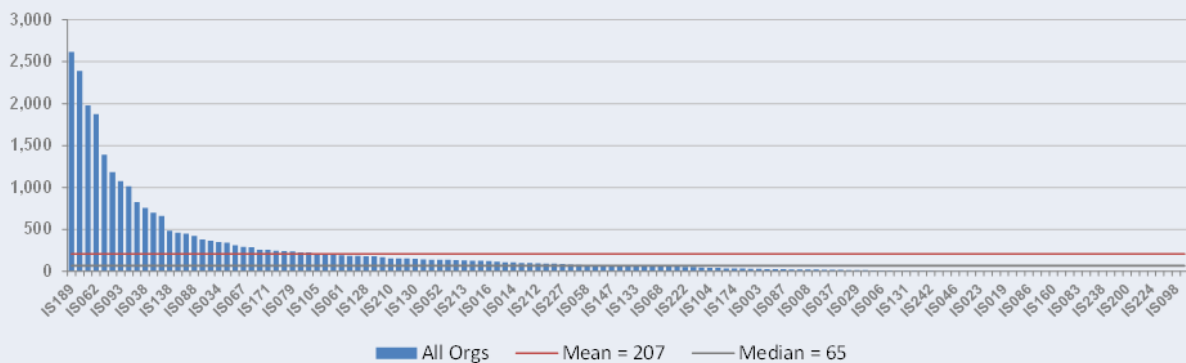


Figure 14: Total number of patient safety incidents recorded for people with a learning disability and/or autism in 2019/20 per 100 children, young people and adults with a learning disability flag on the EPR

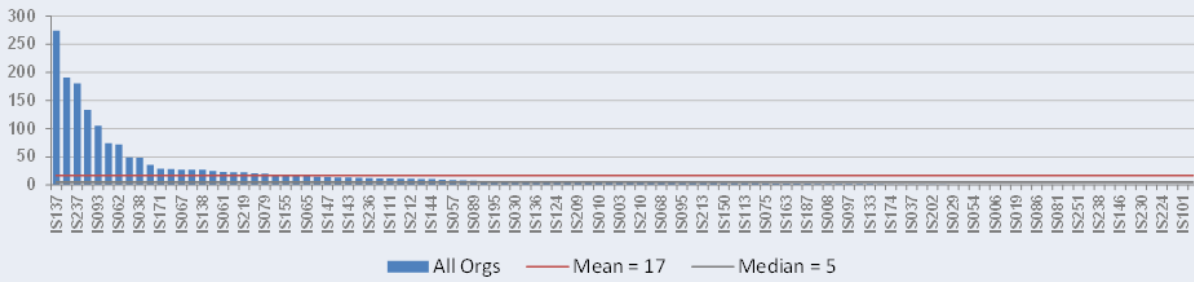


Figure 15: Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2019/20

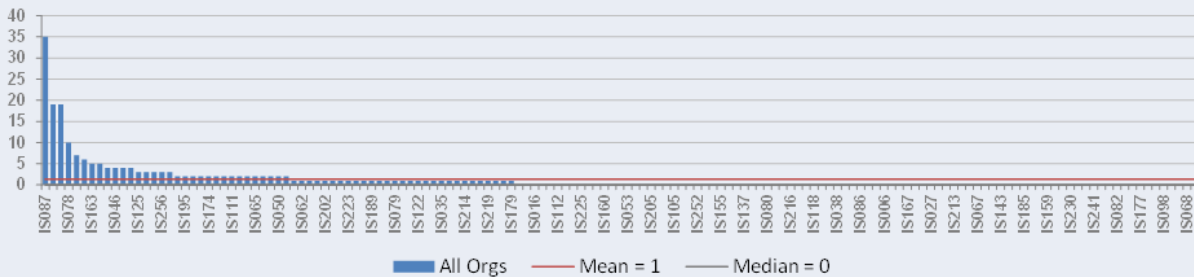


Figure 16: Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2019/20 per 100 people with a learning disability flag on the EPR

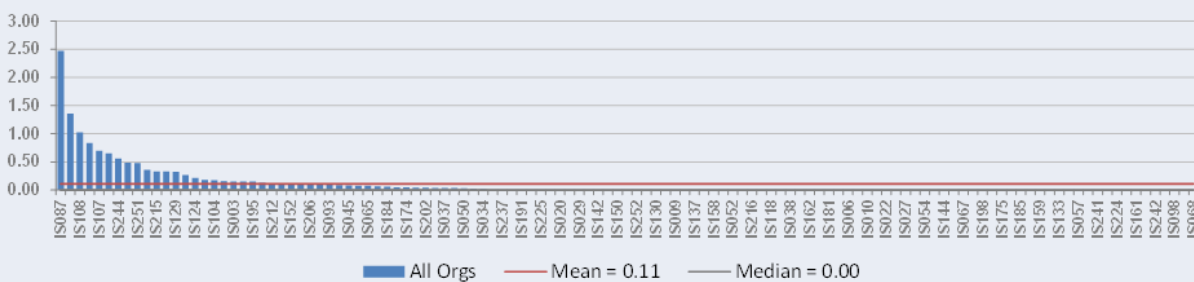


Figure 17: Total number of safeguarding referrals concerning children, young people and adults with a learning disability or autistic people in 2019/20

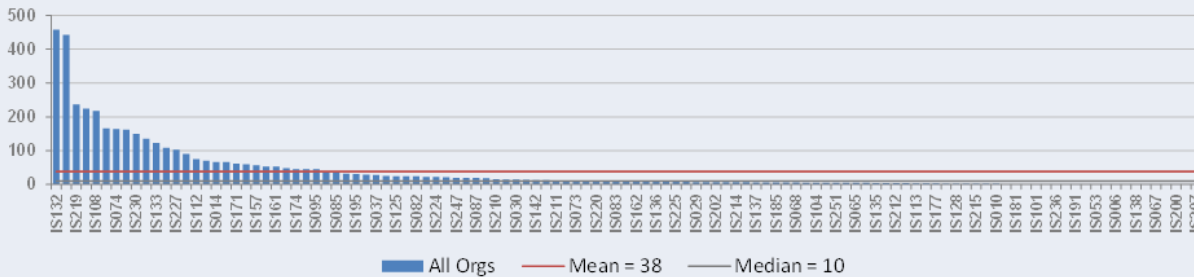


Figure 18: Total number of safeguarding referrals concerning people with a learning disability and/or autism in 2019/20 per 100 people with a learning disability flag on the EPR

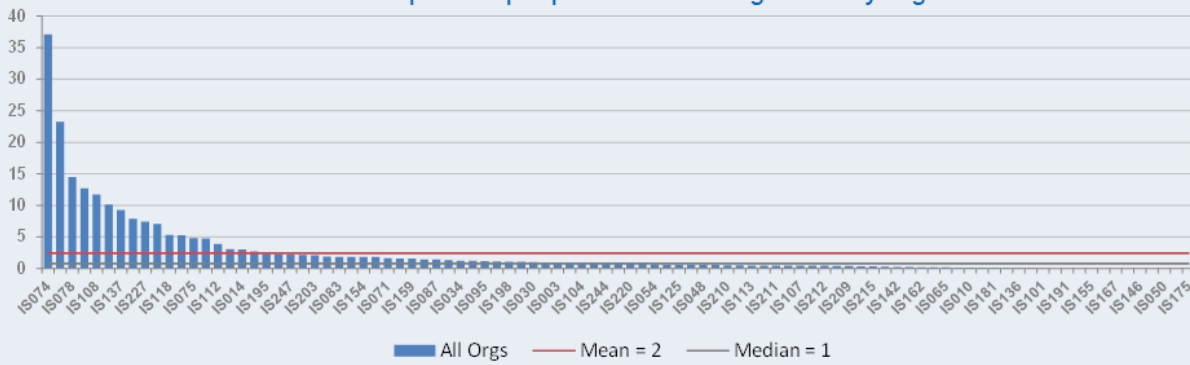


Figure 19: Total number of safeguarding referrals regarding people with a learning disability and/or autism in 2019/20 which met the criteria for a section 42 safeguarding / care act enquiry

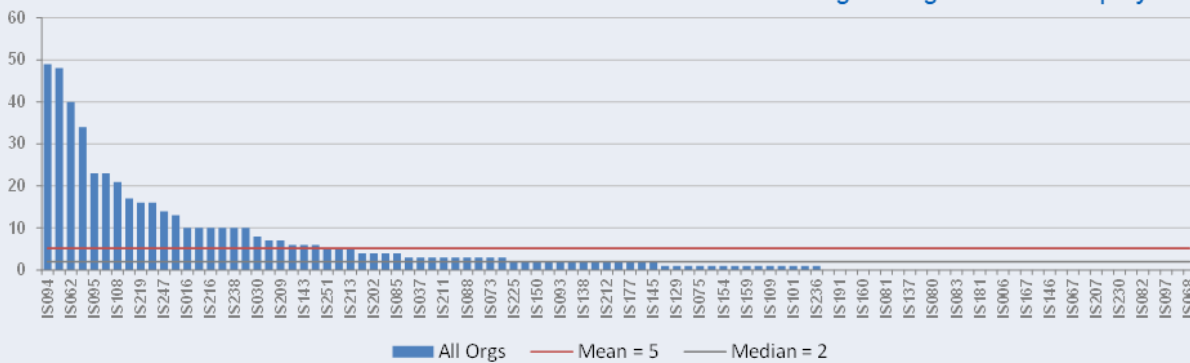


Figure 20: Percentage of safeguarding referrals regarding people with a learning disability and/or autism in 2019/20 which met the criteria for a section 42 safeguarding/care act enquiry

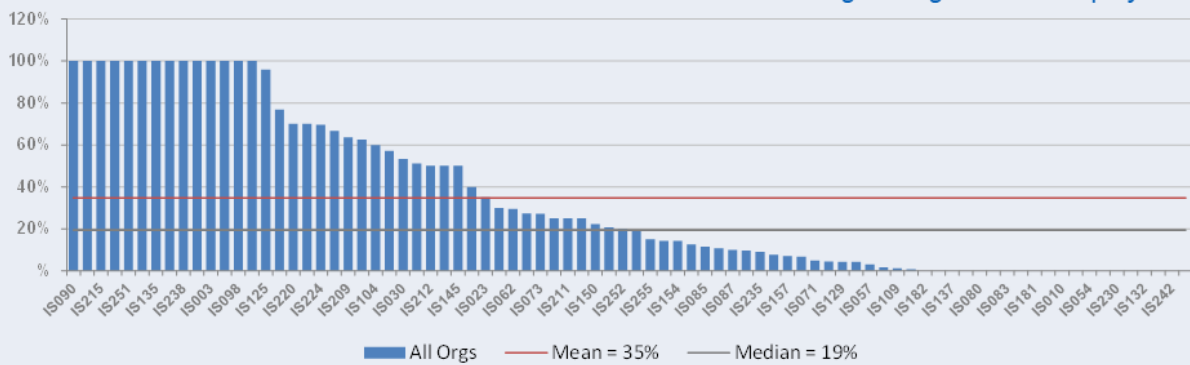


Figure 21: Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2019/20

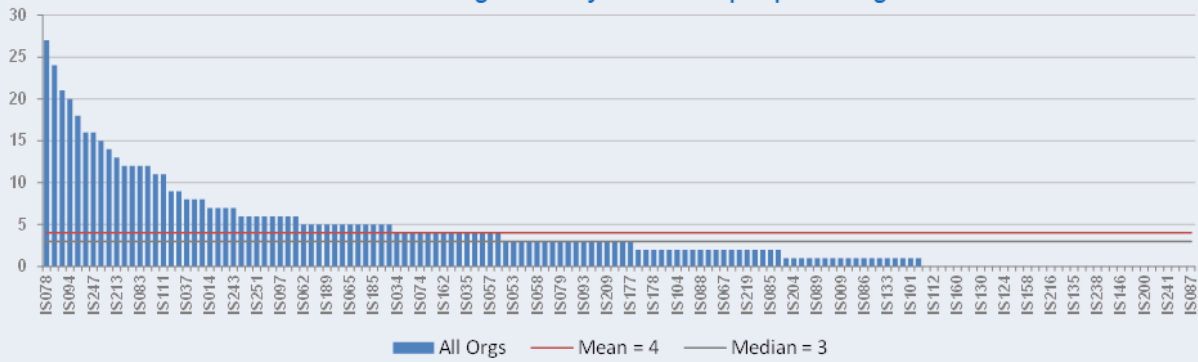
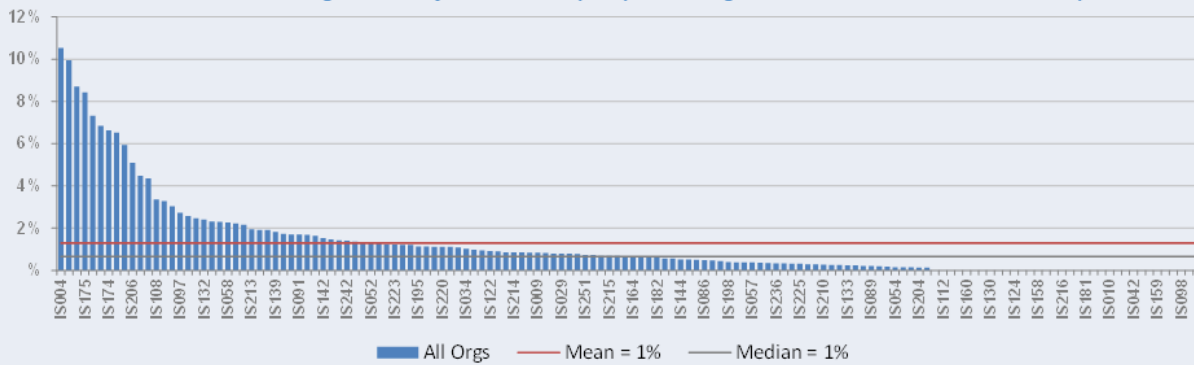


Figure 22: Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2019/20 as a % of total complaints



Learning Disability Mortality Review (LeDeR)

Figure 23: Total number of people with a learning disability who died whilst on an active caseload or within 3 months of the case being closed or discharged in 2019/20

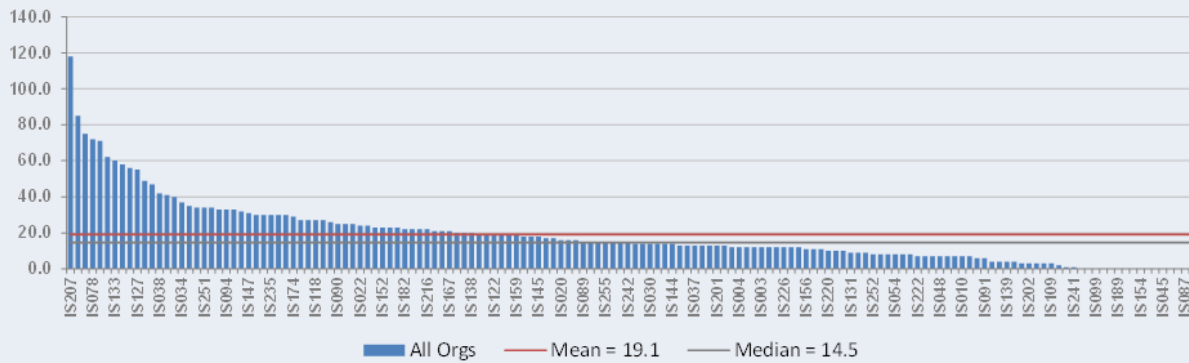


Figure 24: Total number of people with a learning disability who died whilst on an active caseload or within 3 months of the case being closed or discharged in 2019/20 as a % of total deaths

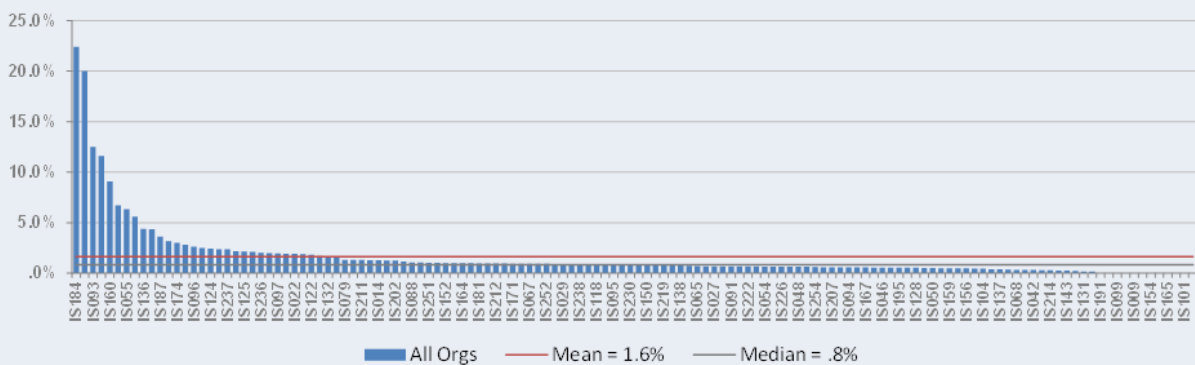


Figure 25: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of choking incidents

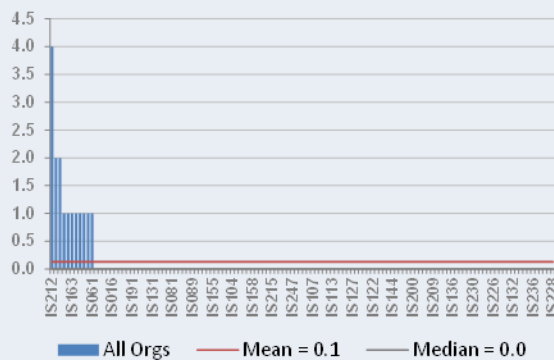


Figure 26: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of choking incidents per 100 patients with an LD flag on the EPR

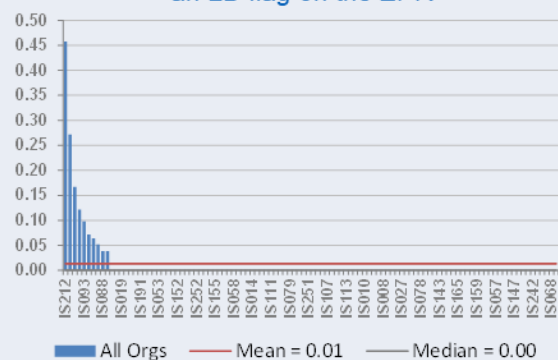


Figure 27: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of sepsis

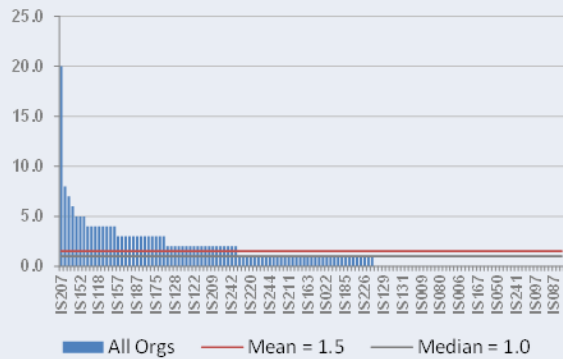


Figure 28: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of sepsis per 100 patients with an LD flag on the EPR

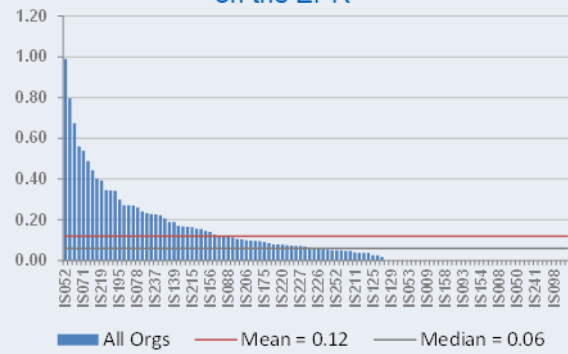


Figure 29: Total number of epilepsy related deaths of people with a learning disability that took place in 2019/20

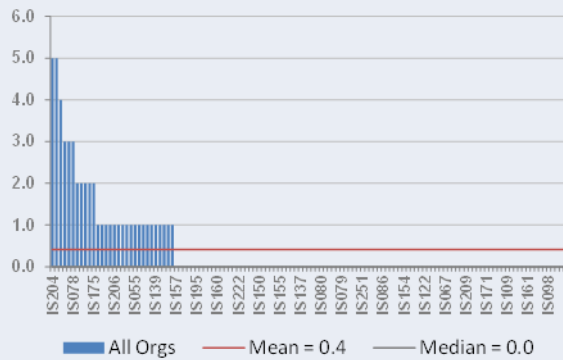


Figure 30: Total number of epilepsy related deaths of people with a learning disability that took place in 2019/20 per 100 patients with an LD flag on the EPR

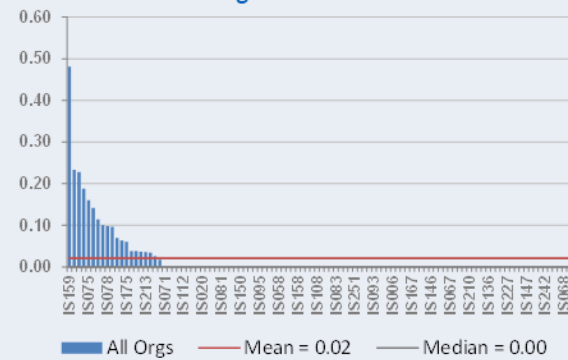


Figure 31: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of gastrointestinal obstructions

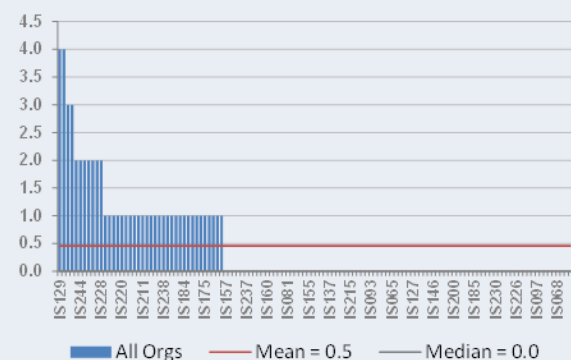


Figure 32: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of gastrointestinal obstructions per 100 patients with an LD flag on the EPR

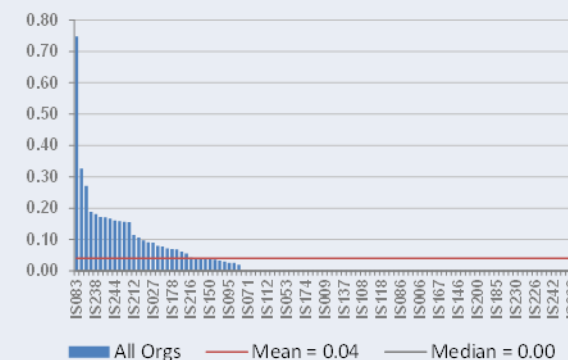


Figure 33: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of a respiratory condition

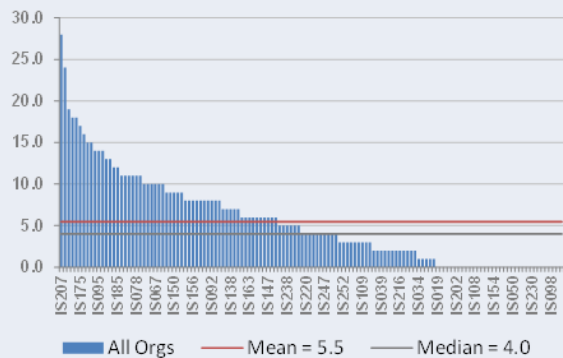


Figure 34: Total number of deaths of people with a learning disability that took place in 2019/20 as a result of a respiratory condition per 100 patients with an LD flag on the EPR

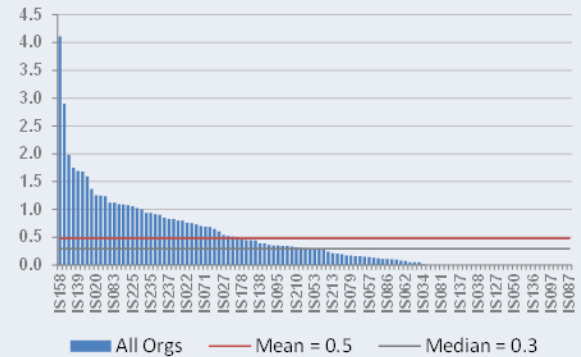
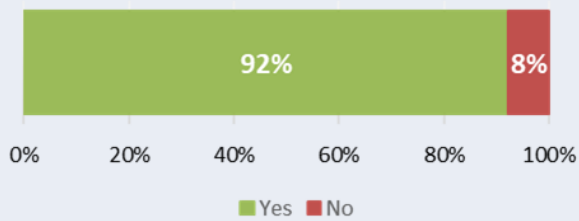
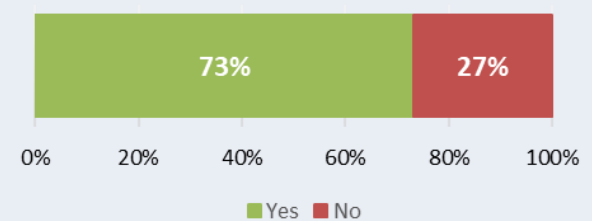


Figure 35: Is your organisation represented on the local Learning Disability Mortality Review Programme (LeDeR) steering group?



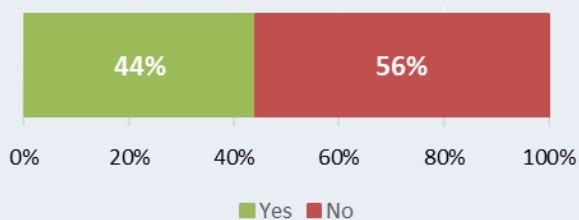
n= 169

Figure 36: 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= 145

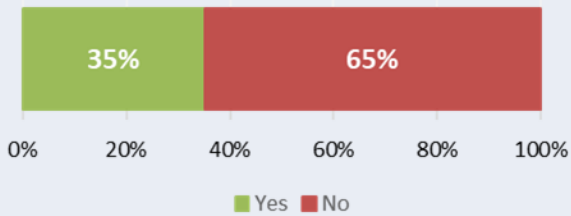
Figure 37: Does your Trust monitor the rates of use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions for people with a learning disability?



n= 161

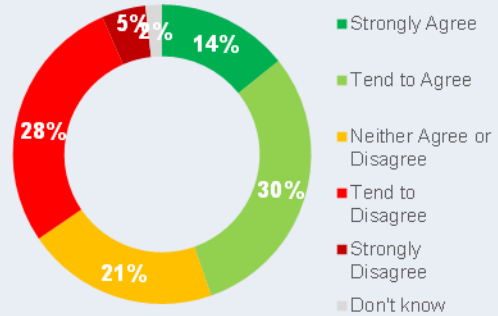
Engagement

Figure 38: 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?



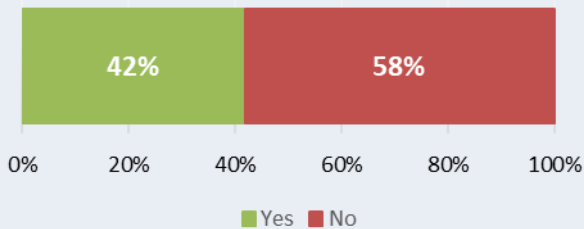
n= 170

Figure 39: 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= 168

Figure 40: 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= 166

Reasonable adjustments

Figure 41: Which reasonable adjustments are offered by your organisation?



LD Liaison staff

Figure 42: Total number of registered learning disability nurses (WTE)

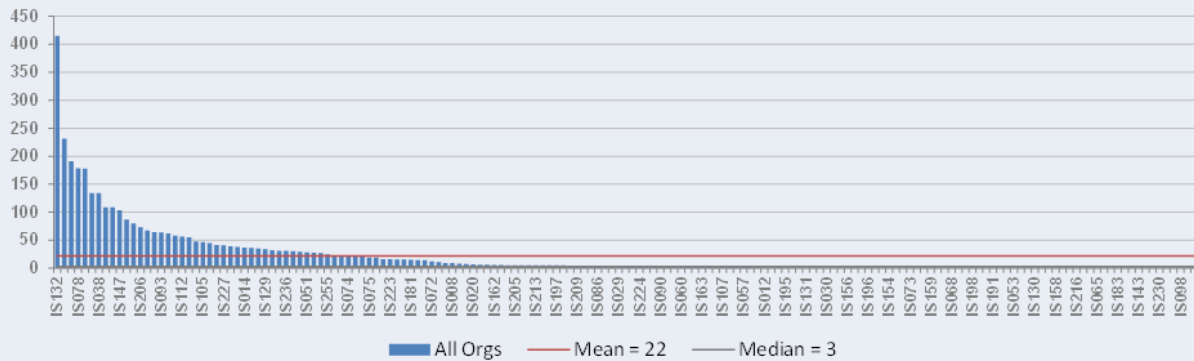


Figure 43: Total number of designated acute learning disability liaison staff employed (WTE)

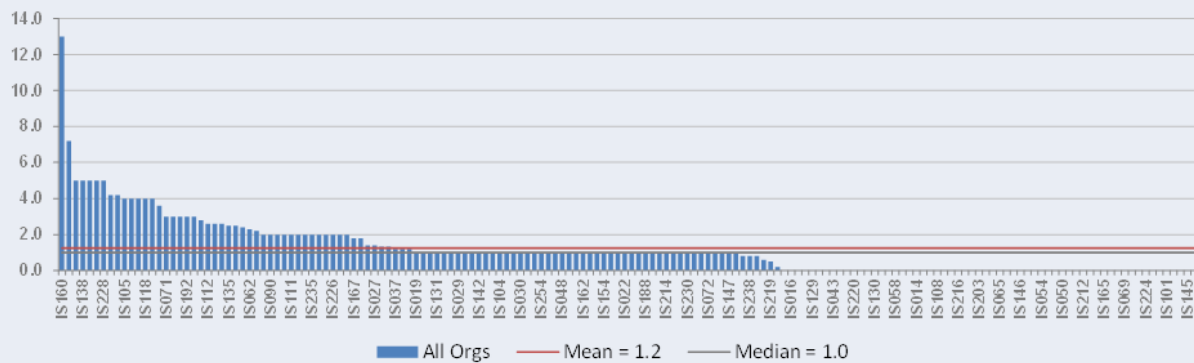


Figure 44: Total number of registered LD nurses as a % of designated acute learning disability liaison staff employed (WTE)

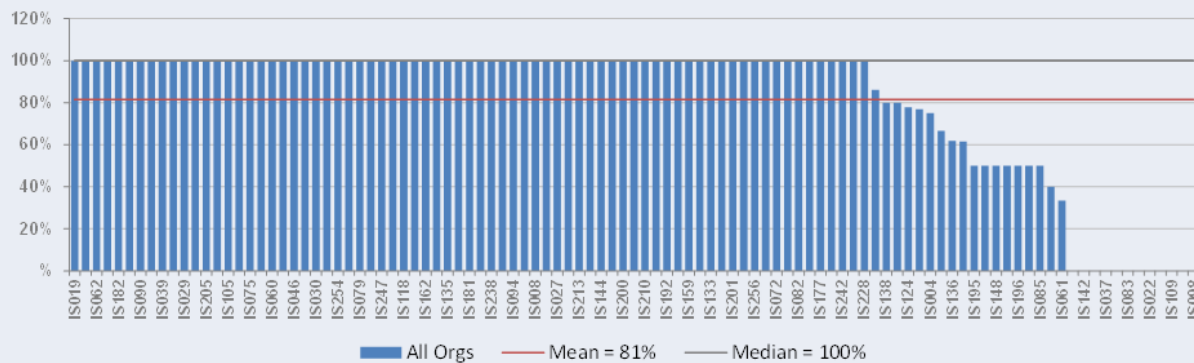


Figure 45: Total number learning disability liaison staff (WTE) provided on the basis of service level agreements with other trusts

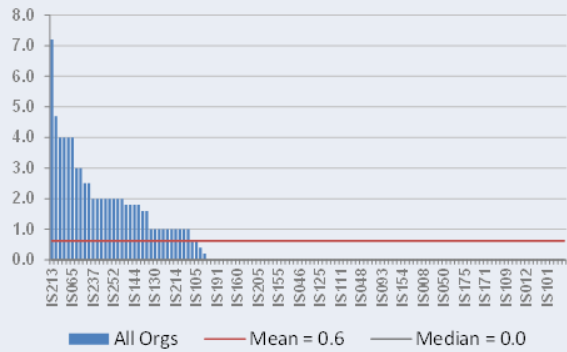
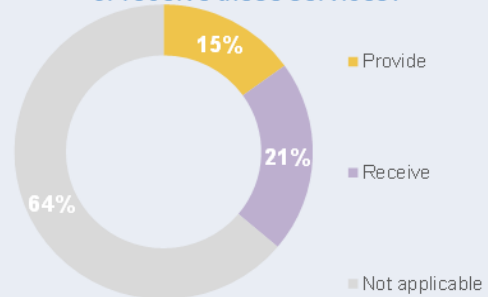
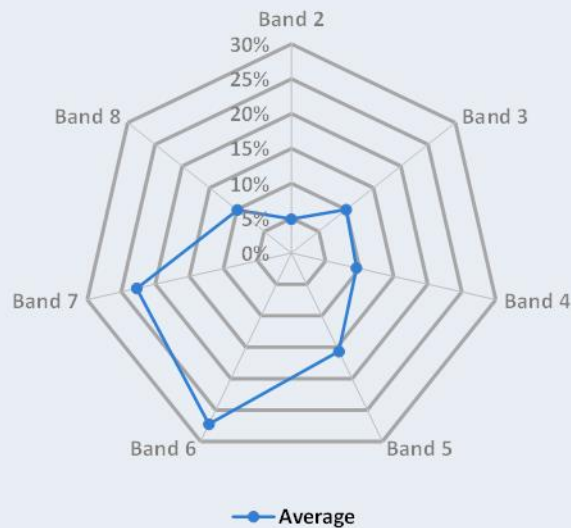


Figure 46: If learning disability liaison services are available in your area, on the basis of a service level agreement with another trust, do you provide or receive these services?



n= 166

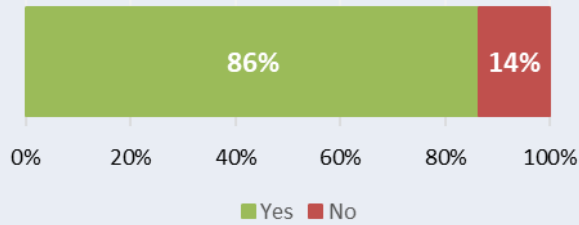
Figure 47: Learning disability liaison service staff skill mix



Learning disability liaison service staff skill mix	National %
Band 2	5%
Band 3	10%
Band 4	10%
Band 5	16%
Band 6	27%
Band 7	23%
Band 8	10%

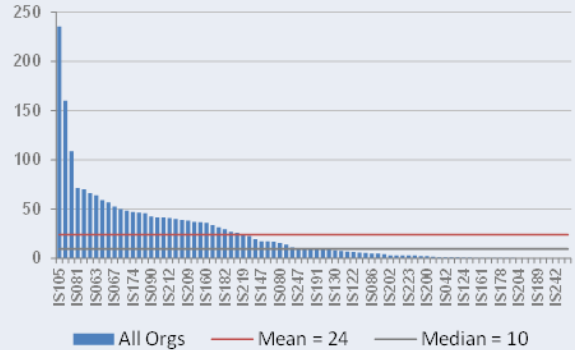
Inclusion

Figure 48: Does your Trust employ people with a learning disability or autism?



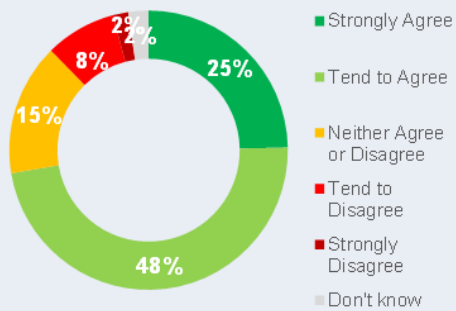
n= 162

Figure 49: Total WTE of workforce employed with a learning disability (paid employment only)



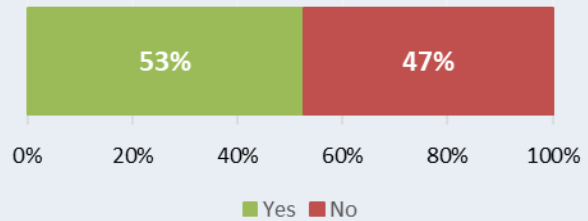
Ask Listen Do

Figure 50: 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= 170

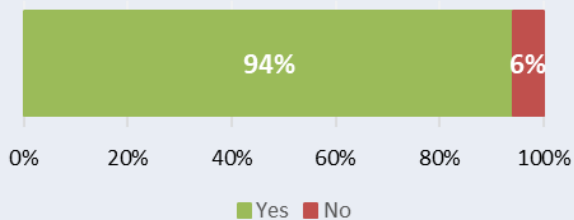
Figure 51: Is your organisation using 'Ask Listen Do' good practice resources to improve feedback, concerns and complaints for children, young people and adults with a learning disability, autistic people and families?



n= 165

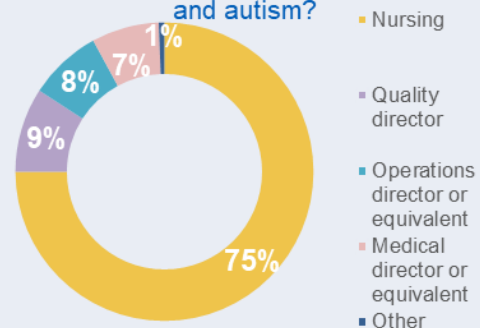
Leadership

Figure 52: 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= 171

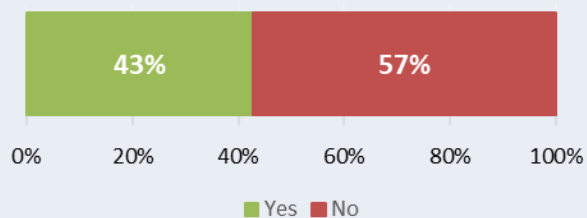
Figure 53: Which professional role best describes the executive role of your board member who leads on quality assurance for learning disabilities and autism?



n= 164

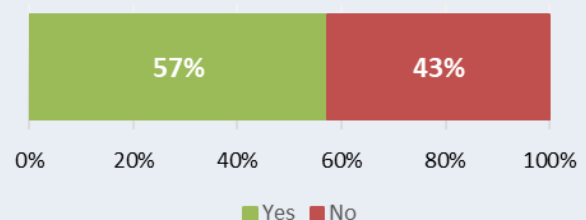
Workforce plan

Figure 54: Does your workforce plan include data on current and future issues arising from retention/recruitment difficulties relating to the learning disabilities workforce?



n= 154

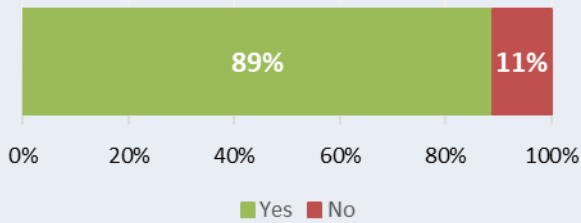
Figure 55: Does your workforce plan include provisions to support the development of new roles in learning disabilities care?



n= 159

Training

Figure 56: Do staff receive up-to-date training covering learning disabilities / autism awareness?



n= 171

Figure 57: Percentage of staff who received up-to-date training covering learning disabilities/autism awareness in 2019/20

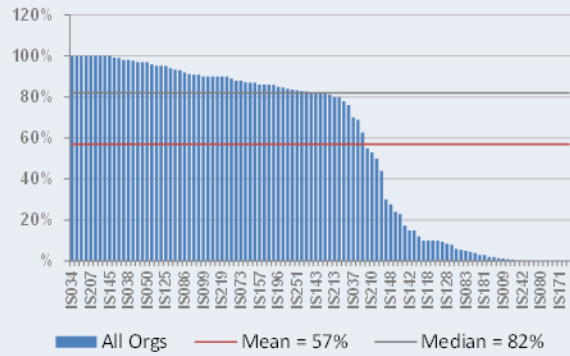
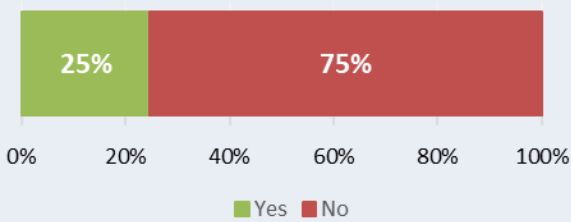
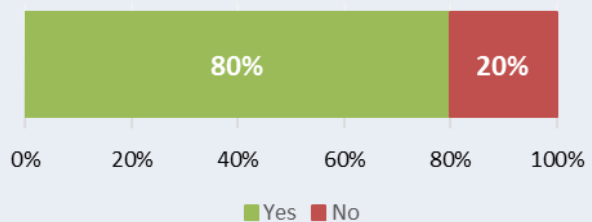


Figure 58: Does your Trust induction programme invite children, young people and adults with a learning disability or autism to contribute to staff training?



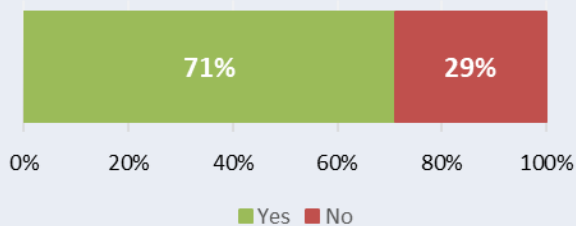
n= 170

Figure 59: 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= 169

Figure 60: 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?

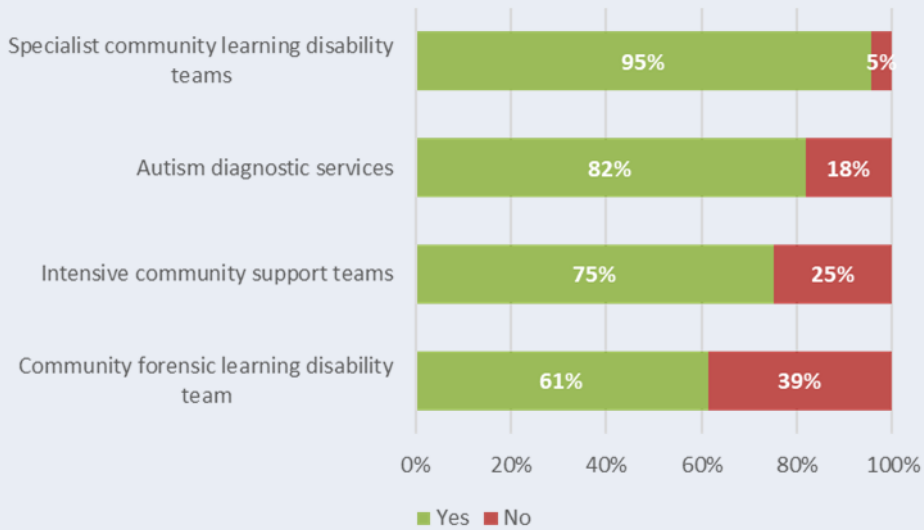


n= 169

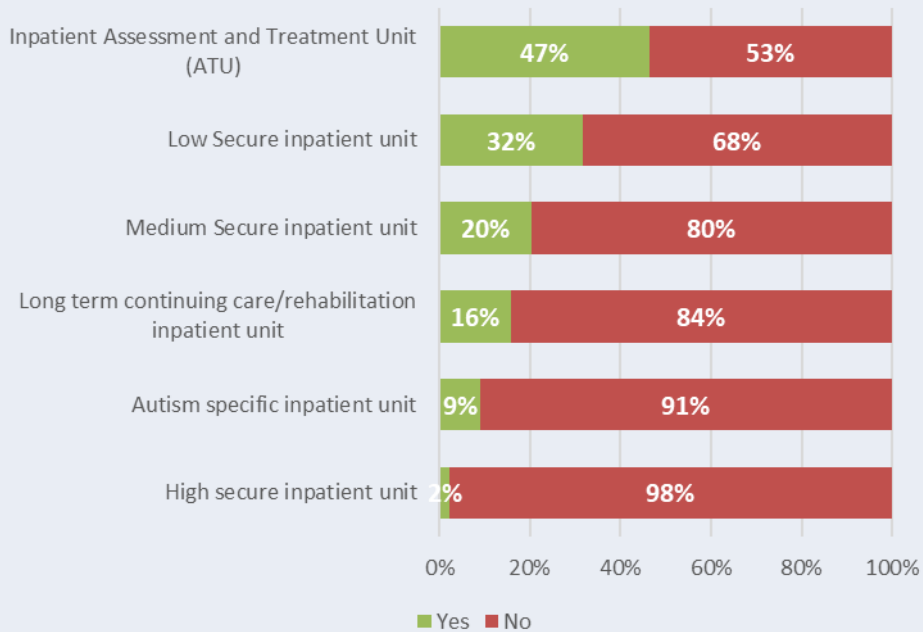
Specialist learning disabilities services

Figure 61: Services provided:

Community services:

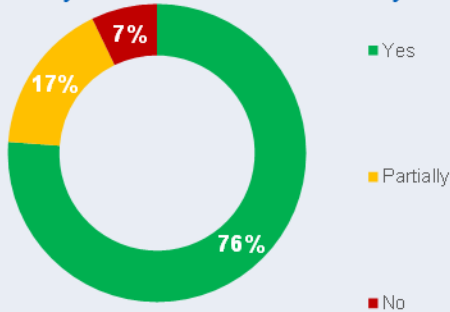


Inpatient services:



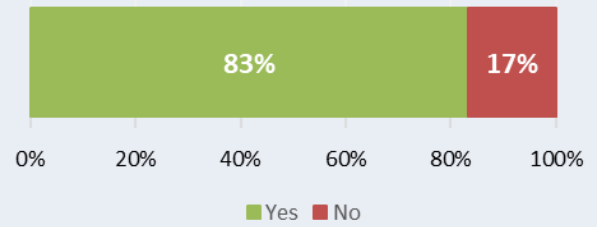
Community

Figure 62: We operate a dynamic risk / support register with regards to people with a learning disability and/or autism in community settings



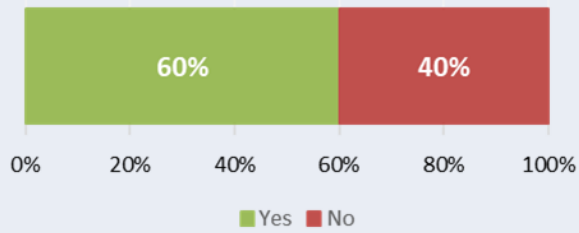
n= 42

Figure 63: If you provide an intensive community support service, do the staff provide crisis support?



n= 43

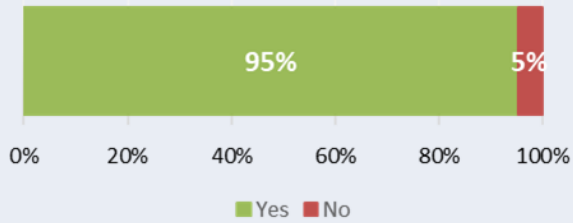
Figure 64: If you provide an intensive community support service is it available 7 days per week?



n= 43

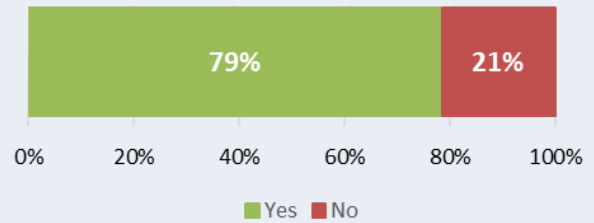
Inpatient

Figure 65: Do your healthcare practitioners provide care coordination in accordance with the provisions of the Care Programme Approach?



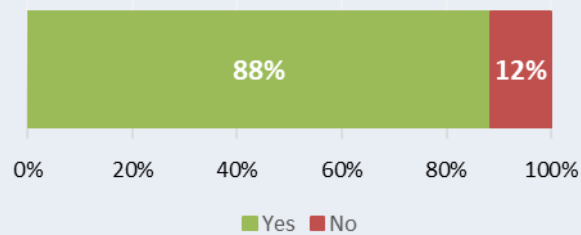
n= 42

Figure 66: Do you continue to provide care coordination, where people are placed in out-of-area inpatient services?



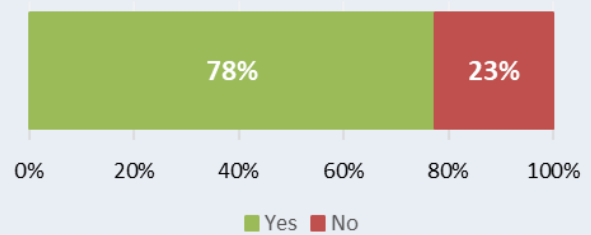
n= 42

Figure 67: Do specialist learning disability practitioners provide in-reach support where people with a learning disability are admitted to universal mental health services?



n= 43

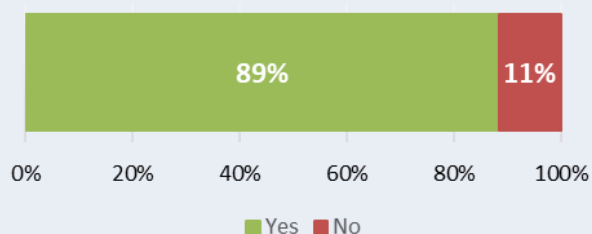
Figure 68: Does your organisation monitor target discharge dates and actual discharge dates for children, young people and adults with a learning disability, and autistic people, in hospital?



n= 40

Positive behaviour support

Figure 69: 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 70: Ethnicity of staff in specialist learning disabilities and/or autism services (headcount)



Ethnicity of staff in specialist learning disability services (headcount)	National %
White / White British / White Other	81%
Asian / Asian British	5%
Black / Black British	6%
Mixed race	1%
Other ethnicity	1%
Unknown / not stated	6%

Restrictive practices

Figure 71: Restraint reduction programmes/policies

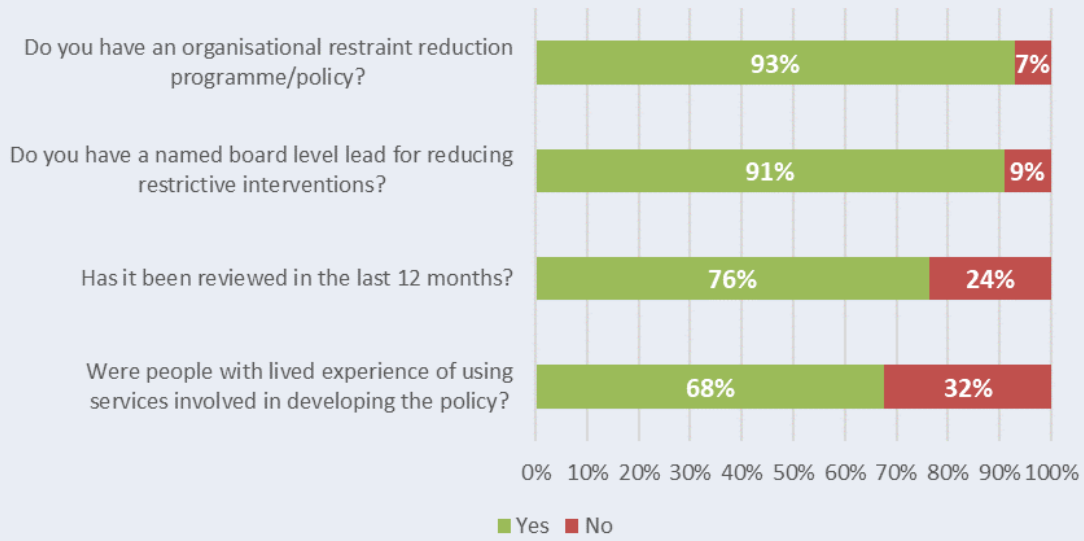


Figure 72: Restraint reporting

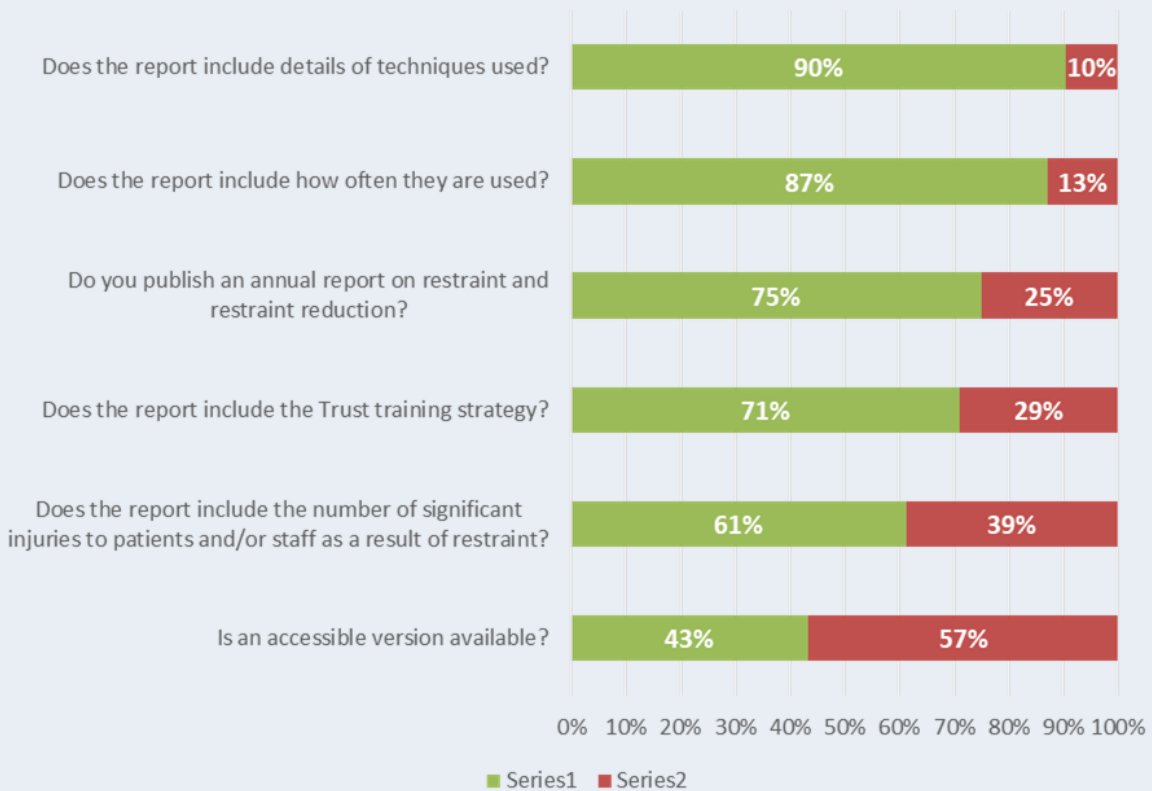
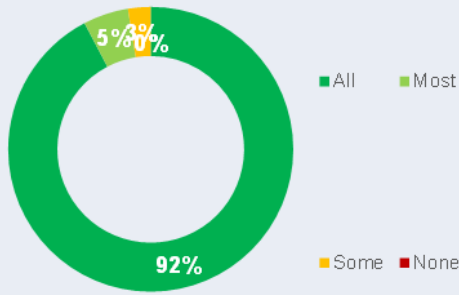
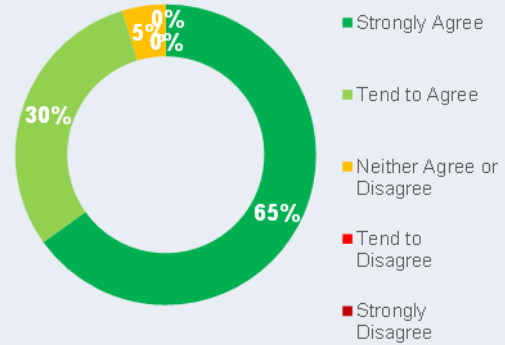


Figure 73: Do you hold risk assessments for each individual physical restraint technique taught to your staff?



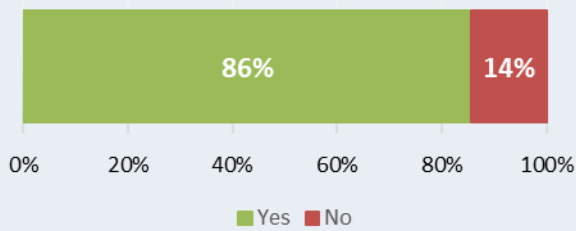
n= 39

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



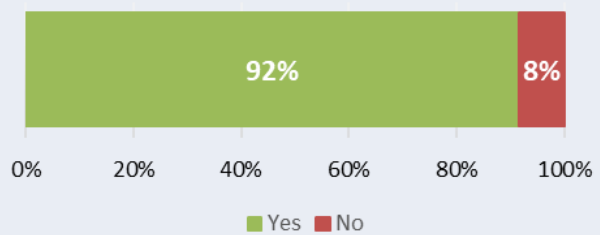
n= 43

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



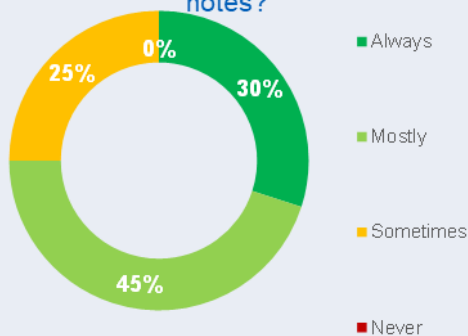
n= 42

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



n= 42

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



n= 40

Figure 78: Total number of children, young people and adults with a learning disability and autistic people who have experienced the use of physical restraint in 2019/20

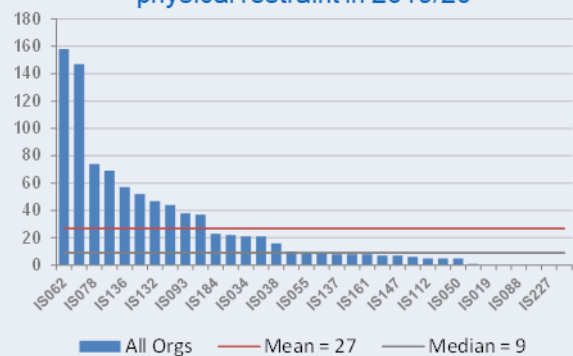


Figure 79: Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2019/20

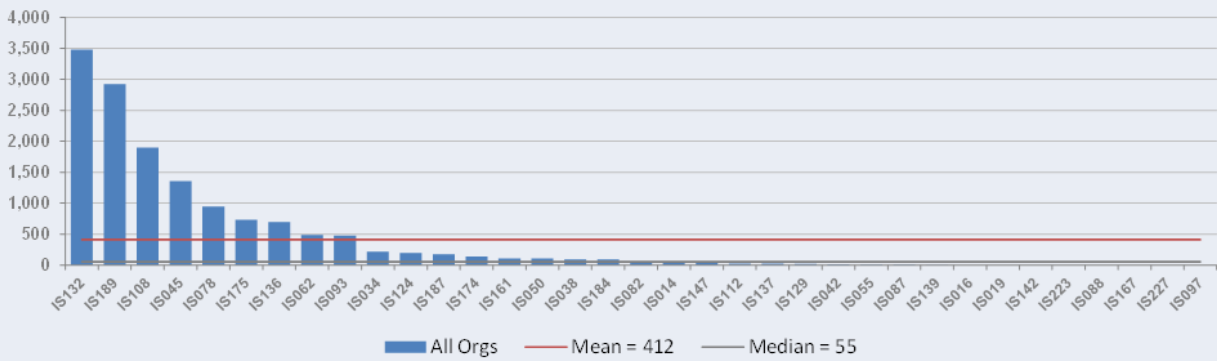


Figure 80: Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2019/20 per 100 children, young people and adults with a learning disability flag on the EPR

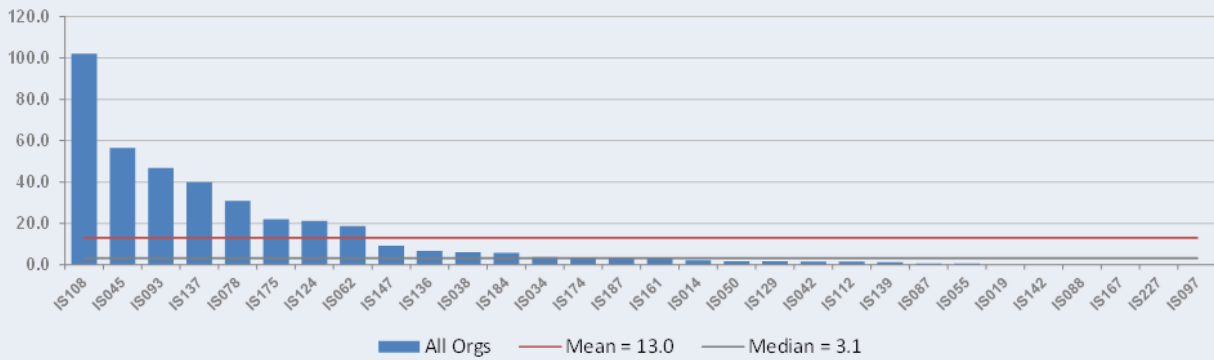
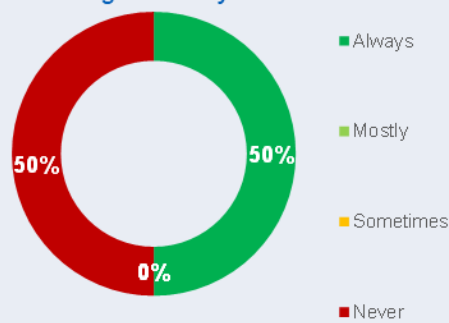
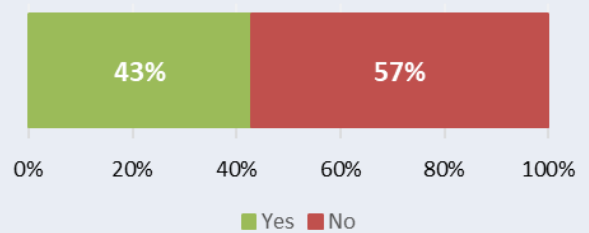


Figure 81: In the exceptional circumstance that there are felt to be cogent reasons to devise a plan for the prone restraint of a patient, are these authorised / signed off by a director of the Trust?



n= 18

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



n= 42

Figure 83: Total number of children, young people and adults with a learning disability and autistic people who experienced use of mechanical restraint in 2019/20

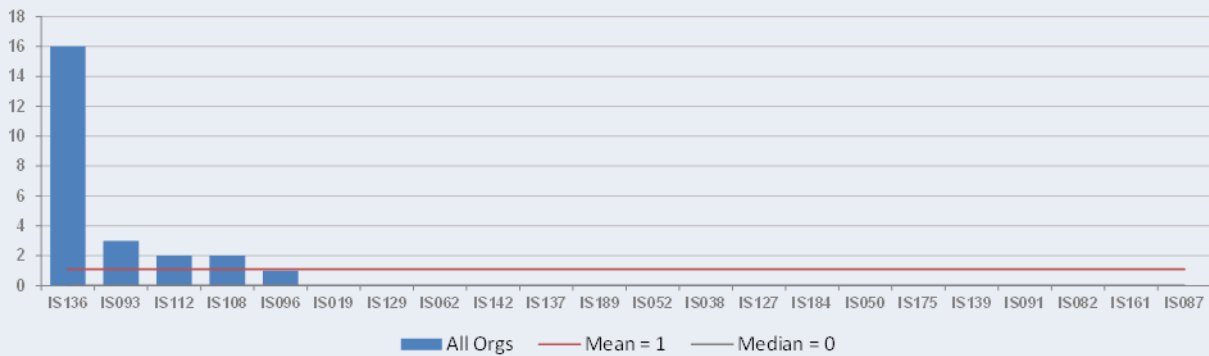
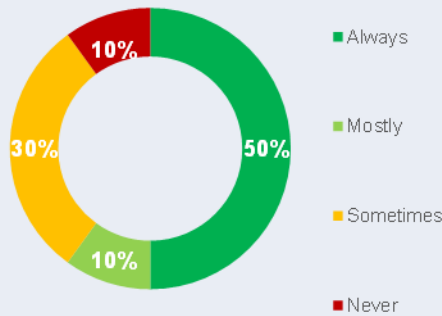
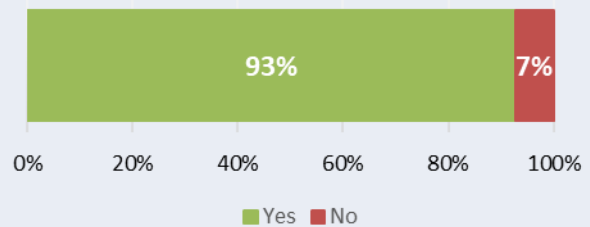


Figure 84: Where a person with a learning disability and/or autism is thought to need a plan for the use of mechanical restraint, is an IMHA consulted as part of the care planning process?



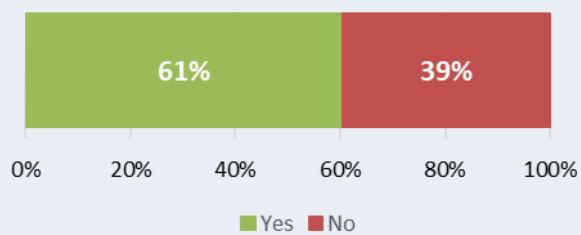
n= 10

Figure 85: Is the RC or duty doctor informed, without delay, each and every time a mechanical restraint device is applied to a patient?



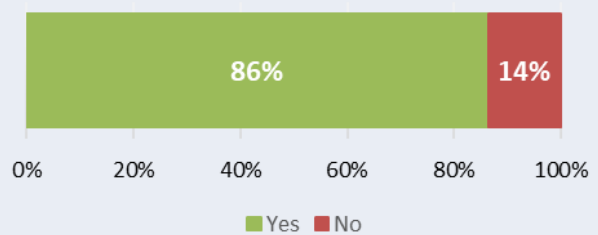
n= 14

Figure 86: Has your board approved the use of long term segregation in your Trust?



n= 38

Figure 87: Do you routinely notify the local authority safeguarding team when a patient is placed in long term segregation?



n= 22

Figure 88: Total number of children, young people and adults with a learning disability and autistic people who experienced use of long-term segregation in 2019/20

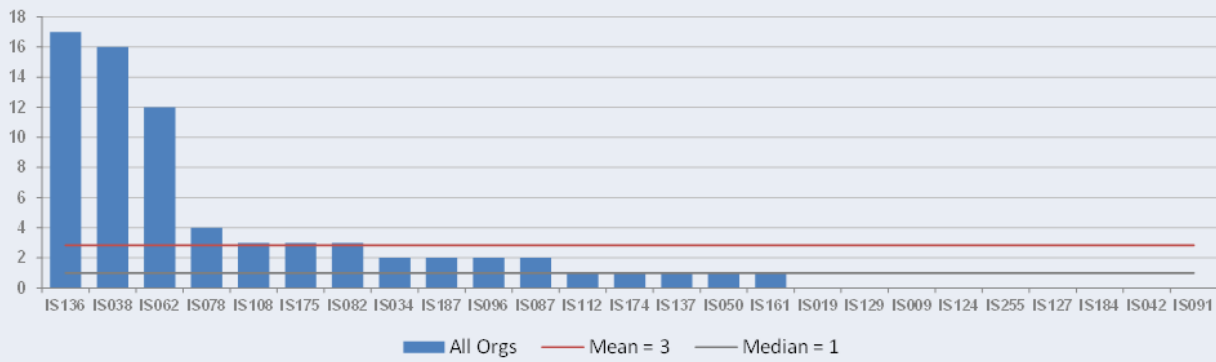
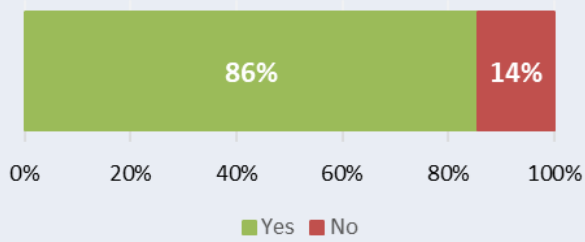
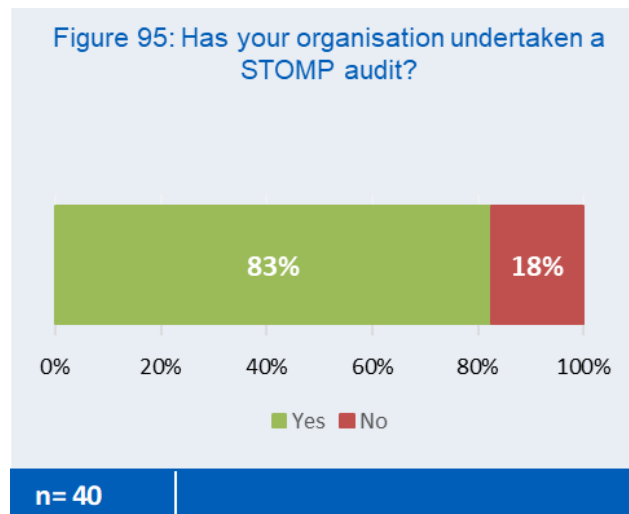
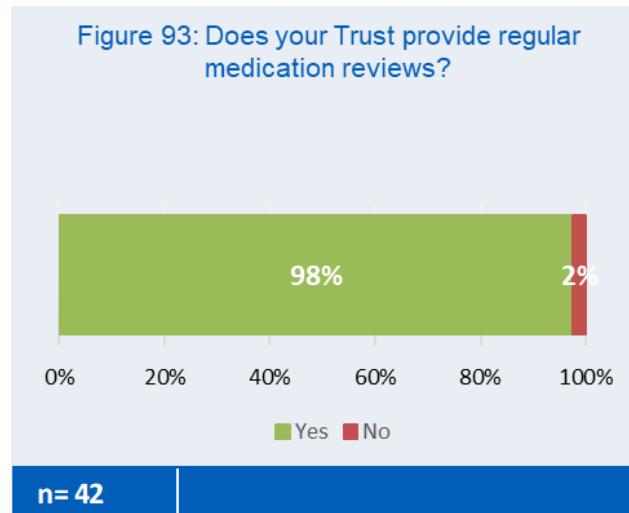
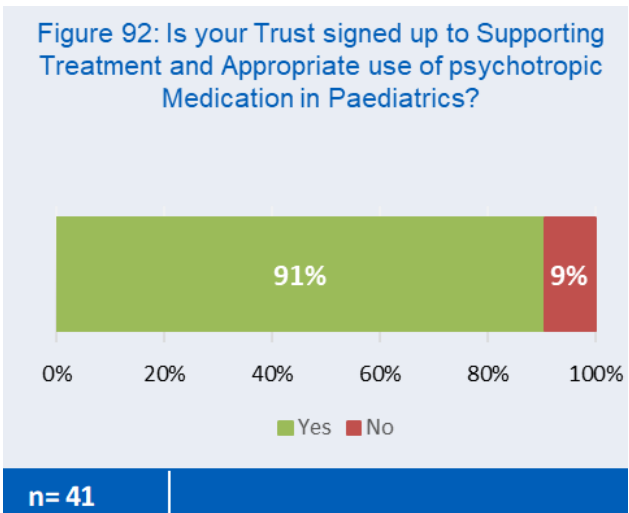
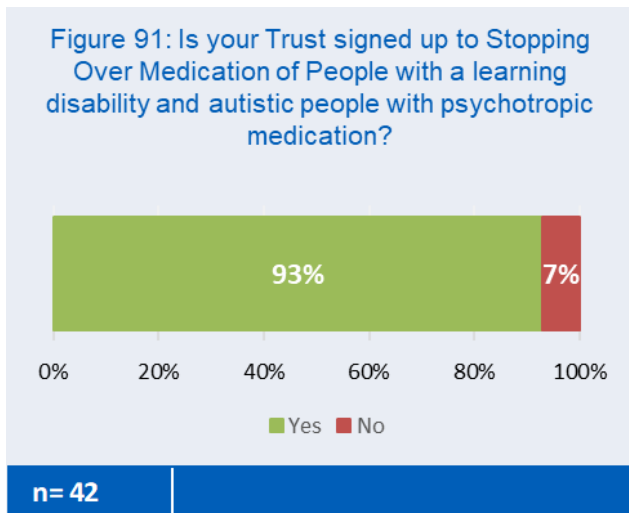
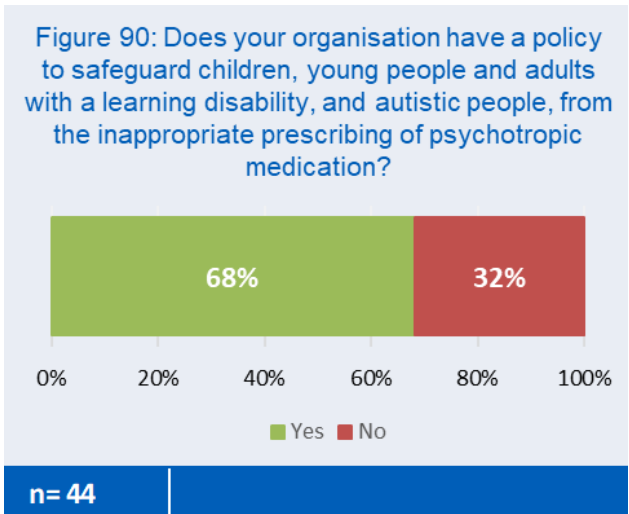


Figure 89: Does this routinely include consultation with the patient's IMHA?



n= 21

STOMP – STAMP



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 the care they provided. Trusts were provided with a single unique URL to share with up to 50 staff members, allowing them to anonymously submit their answers online to the NHS Benchmarking Network.

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, 4,548 staff surveys were completed by 172 organisations; an average 26 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 96: What systems are in place in your Trust for identifying and recording that a child, young person or adult has a learning disability?

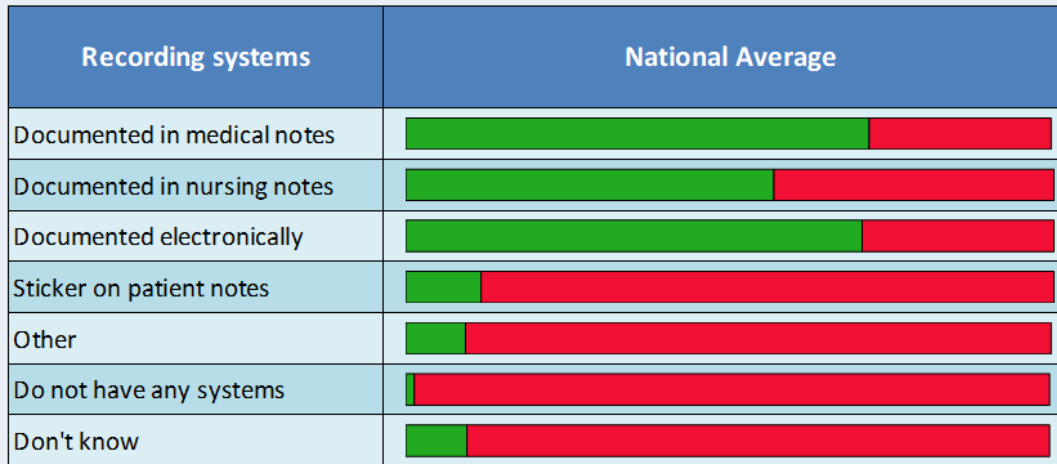


Figure 97: In my Trust children, young people and adults with a learning disability or autistic people have appropriate access to:

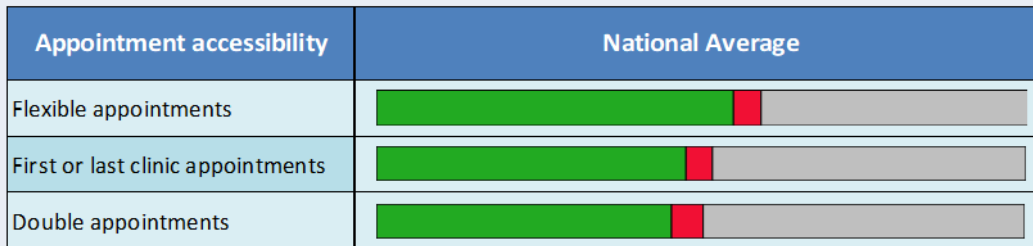


Figure 98: I feel able to identify what reasonable adjustments are needed for children, young people and adults with a learning disability or autistic people

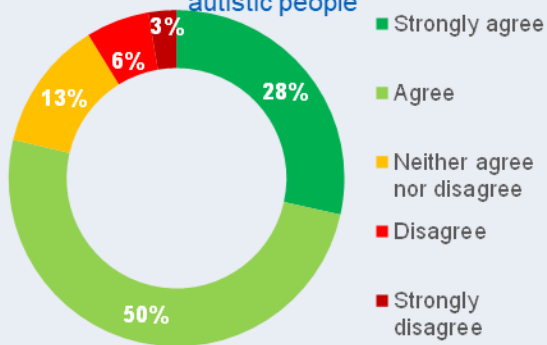


Figure 99: I have the necessary resources to meet the needs of children, young people and adults with a learning disability or autistic people e.g. communication needs or equipment

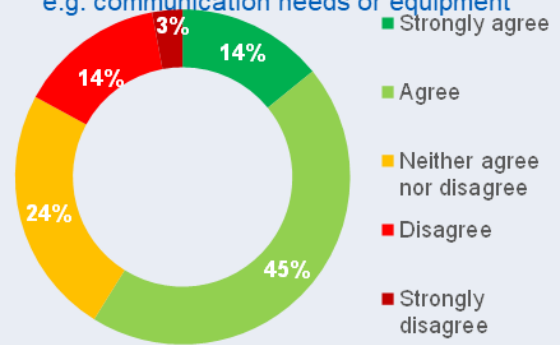


Figure 100: I am confident that children, young people and adults with a learning disability or autistic people using my service always receive the reasonable adjustments they need

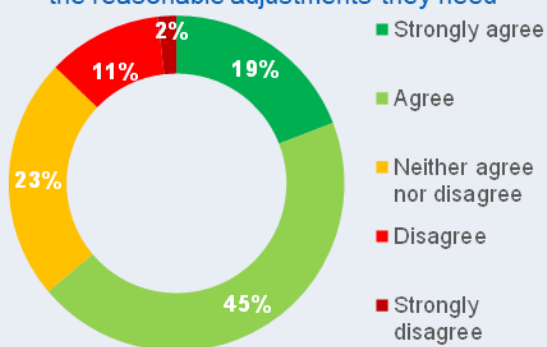


Figure 101: I am always able to deliver safe care to a child, young person, or adult with a learning disability or autistic people

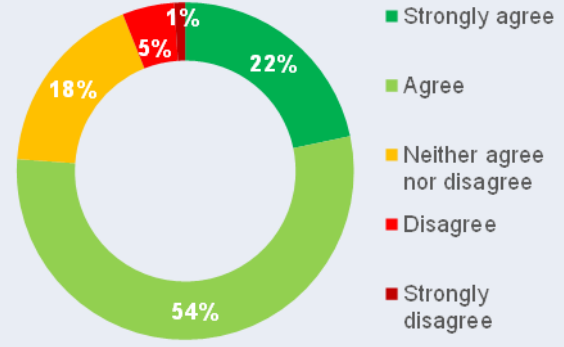


Figure 102: Children, young people and adults with a learning disability or autistic people get the same quality of care as any other person

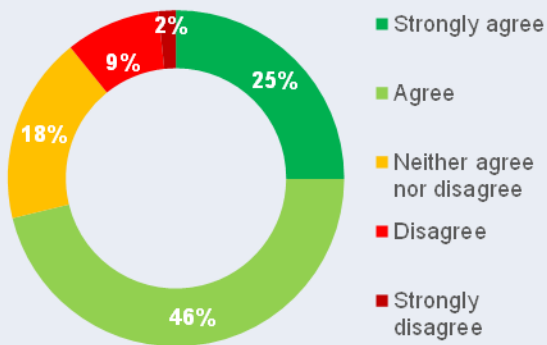


Figure 103: Staff in the Trust always tell children, young people and adults with a learning disability or autistic people and families about their rights when using services

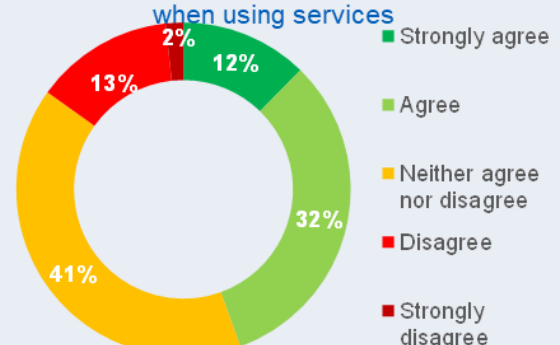
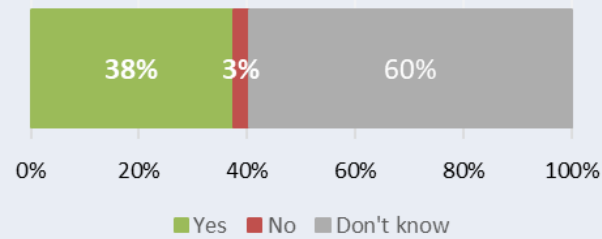


Figure 104: In your Trust, if a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) form (or equivalent) is completed for a child, young person or adult with a learning disability or autistic people, is there a clear policy to double check, to ensure that there is a valid reason?



n= 2881

Figure 105: 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

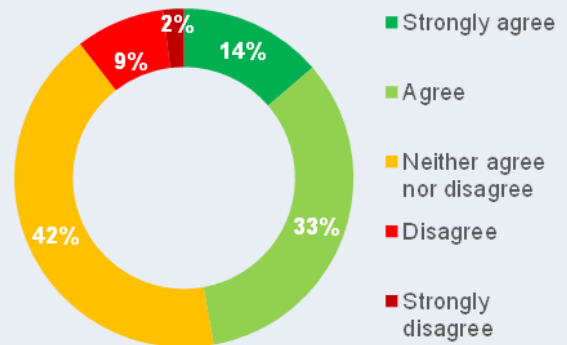
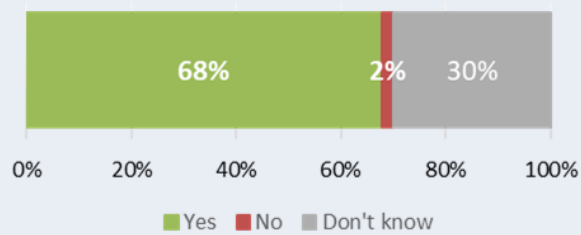


Figure 106: My Trust has policies and procedures to ensure the rights of autistic people are respected and protected



n= 4469

Figure 107: In my Trust, I feel children, young people and adults with a learning disability and autistic people are always treated with dignity and respect

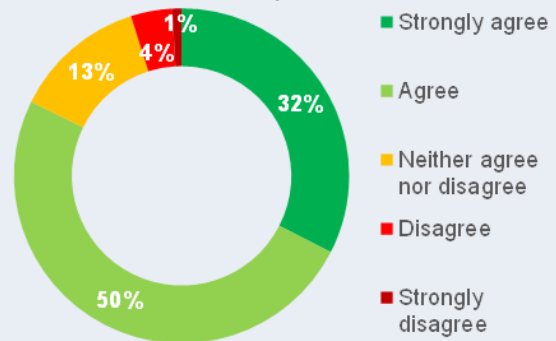


Figure 108: In my Trust, I feel family members of people with a learning disability and/or autism, are always treated with dignity and respect

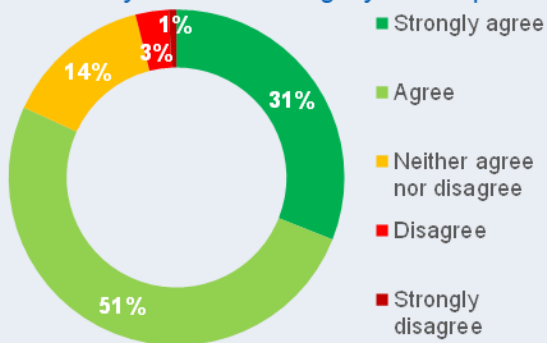


Figure 109: I routinely involve people with a learning disability, and/or autism when making decisions about their care and treatment

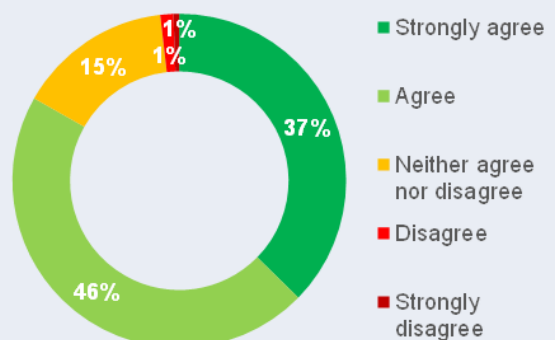


Figure 110: I routinely involve the families of people with a learning disability and/or autism, when making decisions about their care and treatment

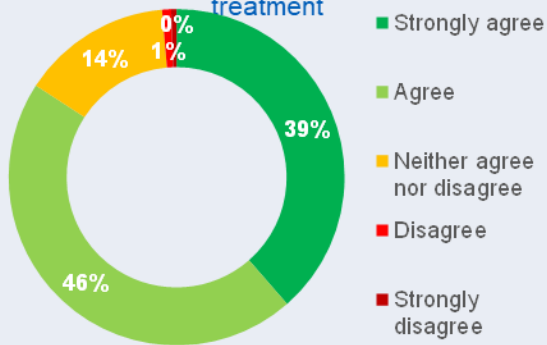


Figure 111: Children, young people and adults with a learning disability are routinely involved in the planning of Trust services

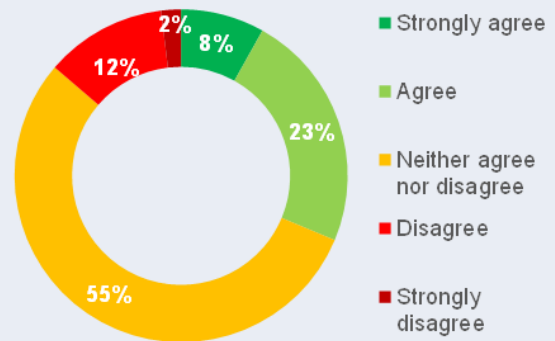


Figure 112: Families of children, young people and adults with a learning disability are routinely involved in the planning of Trust services

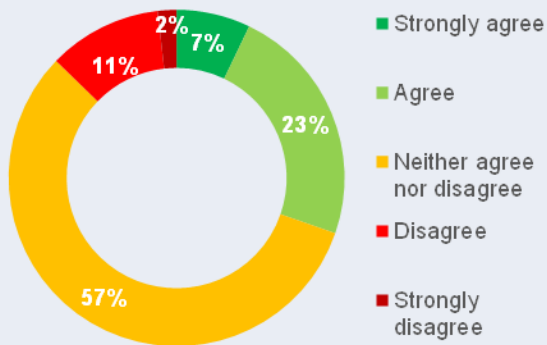
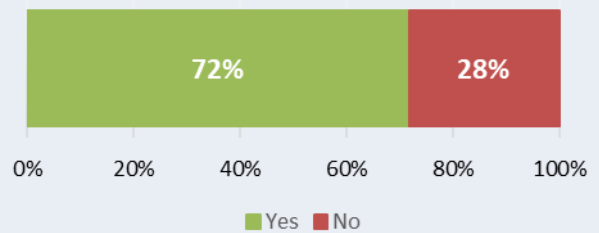


Figure 113: I have received mandatory training on meeting the needs of children, young people and adults with a learning disability, and autistic people, during the course of my work



n = 4492

Figure 114: I feel I have the necessary knowledge and skills to meet the needs of people with a learning disability, and/or autism, during the course of my work

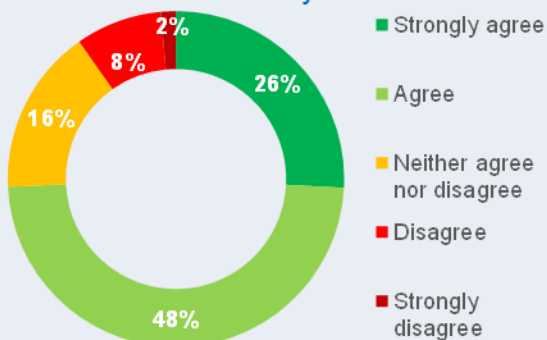


Figure 115: I have access to additional specialist learning disability staff when I need it, to help me meet the needs of children, young people and adults with a learning disability

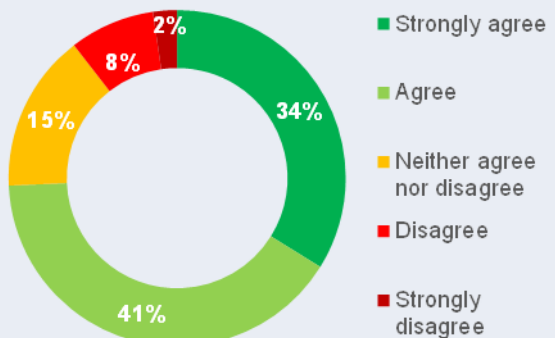


Figure 116: Children, young people and adults with a learning disability are involved in delivering awareness training to staff in my Trust

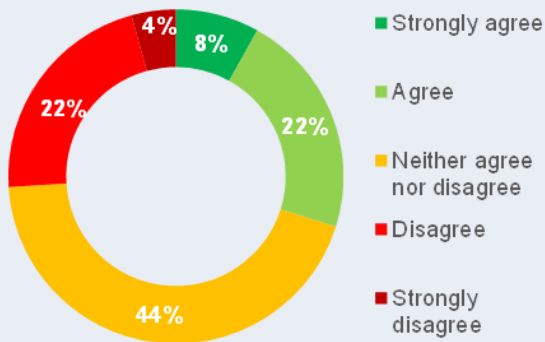


Figure 117: I would recommend the Trust to a friend or family members of a person with a learning disability, and/or autism who needed treatment

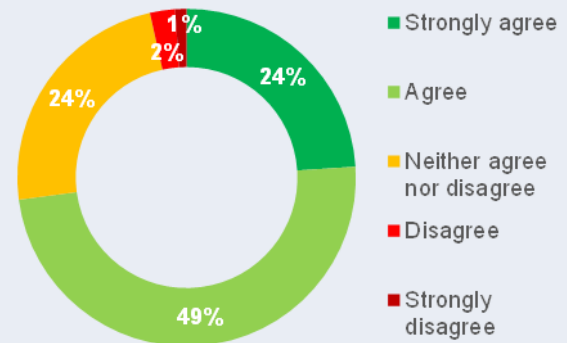


Figure 118: People with a learning disability and/or autism, who are in hospital due to concerns about their behaviour or mental health, continue to be seen by staff from their usual community services

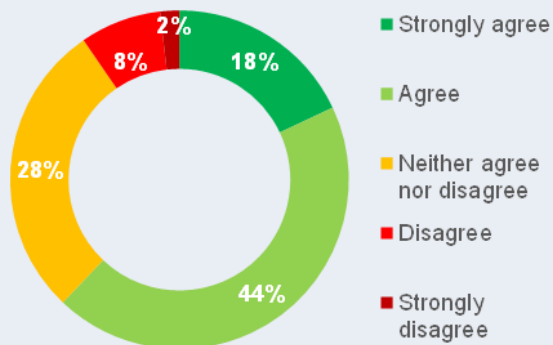


Figure 119: People with a learning disability, and/or autism, who are in hospital due to concerns about their behaviour or mental health, are visited by an external care co-ordinator, case manager, or equivalent at least every 6-8 weeks

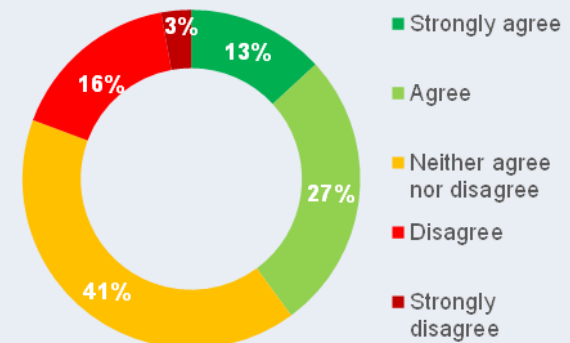


Figure 120: Children, young people and adults with a learning disability, autistic people and family carers are involved in reviewing the appropriateness of psychotropic medications

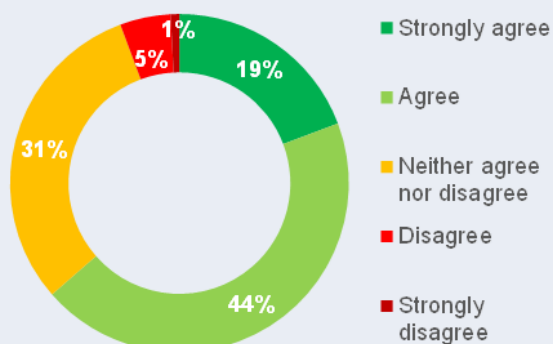


Figure 121: I have had training on reducing the use of restrictive interventions

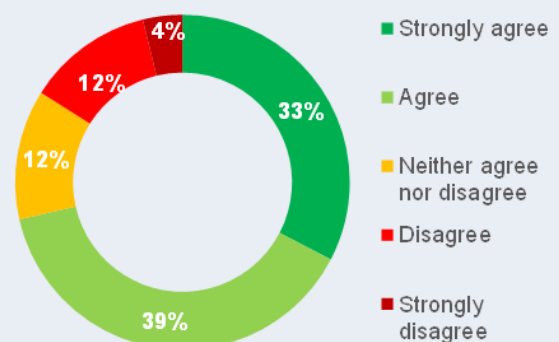


Figure 122: People with a learning disability, and/or autism who are in hospital due to concerns about their behaviour or mental health, have good access to independent advocacy services

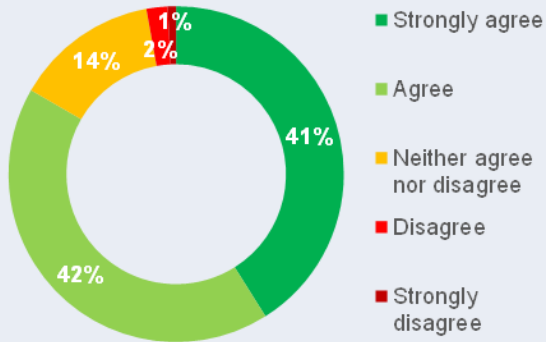


Figure 123: My Trust encourages me to speak out if I have concerns about the wellbeing of children, young people and adults with a learning disability, and autistic people, in our services

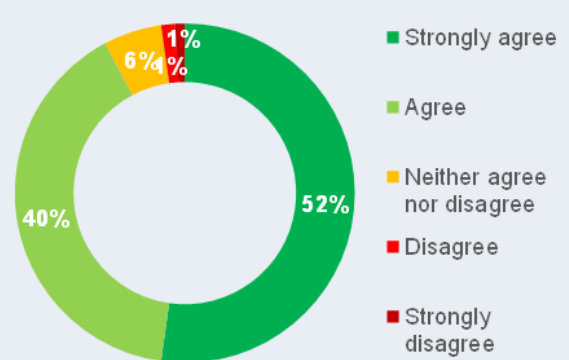
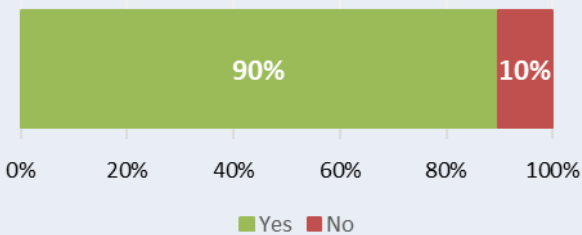


Figure 124: My Trust has developed effective and new ways of supporting children, young people and adults with a learning disability, and autistic people, to live successfully in the community in recent years



n= 1042

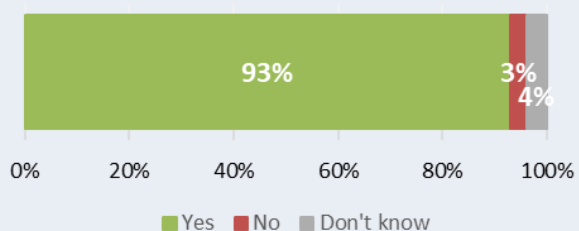
Appendix 3: Service user survey

The service user survey largely followed the same methodology as in the previous year, having then been redesigned and well received by service users and carers. Each trust registering for the data collection received 100 paper surveys along with freepost envelopes to distribute to service users and carers. A total of 152 trusts registered and distributed 15,200 surveys. We received 2,884 service user surveys (completion rate of 19%).

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

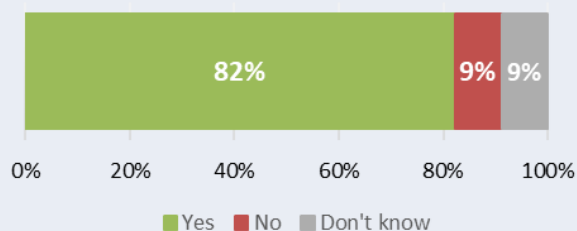
The charts below depict the responses from service users in a series of Yes/No charts, which show the national average for yes/no responses and the number of service users who answered the question.

Figure 125: When you received care from the NHS, did staff treat you with respect?



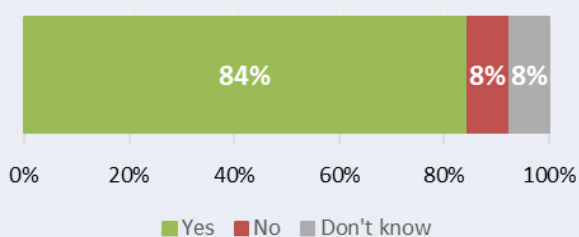
n= 2785

Figure 126: Did staff explain things to you in a way you could understand?



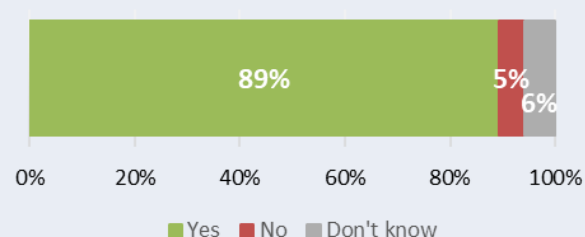
n= 2655

Figure 127: Did you feel like staff listened to you?



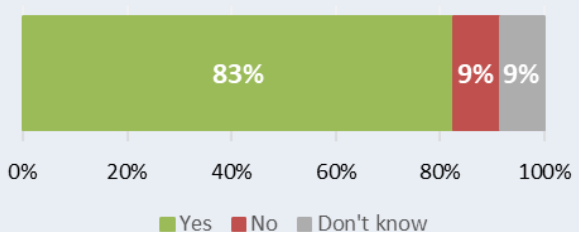
n= 2634

Figure 128: Did you feel like staff cared about you?



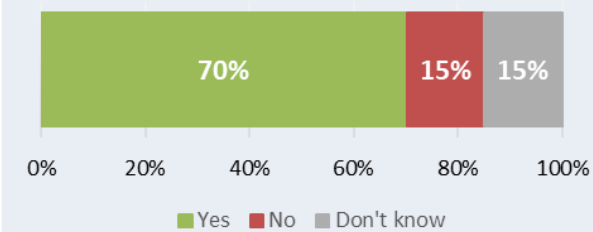
n= 2778

Figure 129: Did staff talk to you about the care you needed?



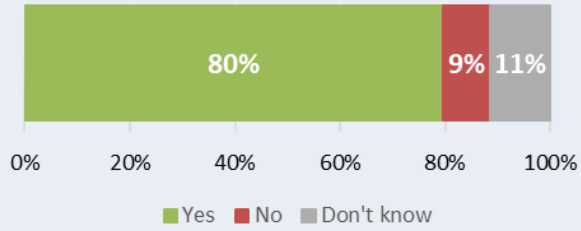
n= 2671

Figure 130: Did staff give you choices about how you were cared for?



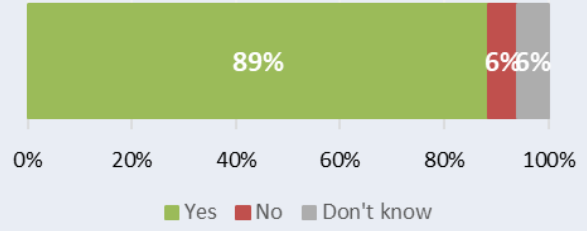
n= 2486

Figure 131: Did staff listen to what your family thought?



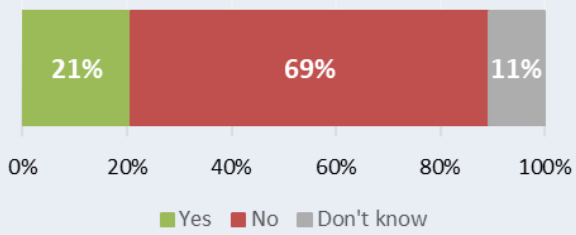
n = 2242

Figure 132: When you received care, did you feel safe?



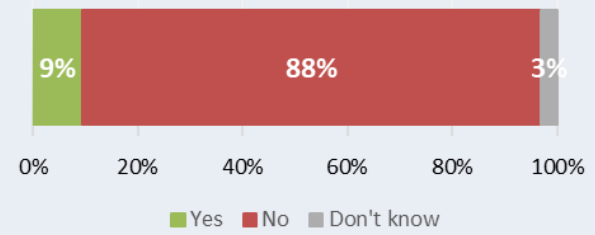
n = 2721

Figure 133: Did you have any concerns about your care?



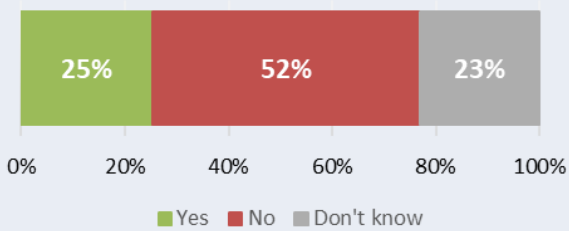
n = 2698

Figure 134: Did you make a complaint?



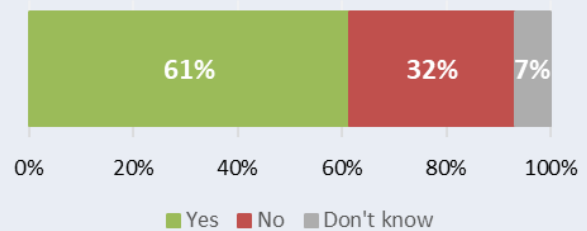
n = 2546

Figure 135: If yes, were you given Easy Read information about how to make a complaint?



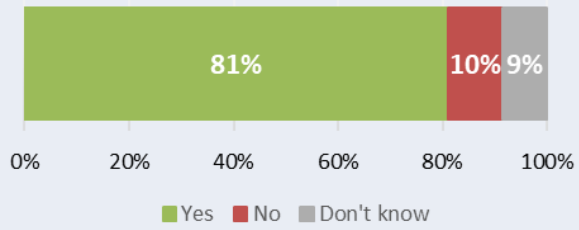
n = 745

Figure 136: If you stayed in hospital, was it easy for your family to visit you?



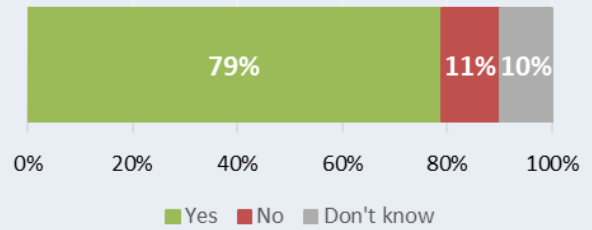
n = 1614

Figure 137: Did staff tell you about your appointments and meetings in a way you could understand?



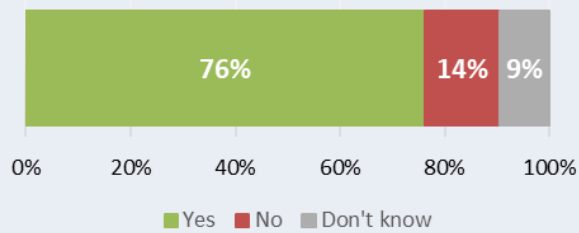
n= 2386

Figure 138: Were your appointments and meetings arranged to suit you?



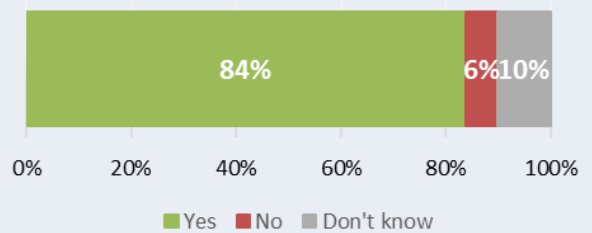
n= 2489

Figure 139: If you needed to be seen in an emergency, were you seen quickly?



n= 1972

Figure 140: Would you recommend this service to a friend or family?



n= 2716

Data tables

Figure	Respecting and protecting rights – Organisational level	Response	Specialist National	Specialist N=	Universal National	Universal N=	All trusts National	All trusts N=
1	If required, is your organisation able to isolate/disaggregate specific outcome data regarding patients with a learning disability?	Yes	76.7%	33	73.4%	94	74.3%	127
		No	23.3%	10	26.6%	34	25.7%	44
		Total		43		128		171
2	Do you currently hold a list of children, young people and adults with a learning disability waiting for assessment and/or treatment?	Yes	75.0%	33	37.8%	48	47.4%	81
		No	25.0%	11	62.2%	79	52.6%	90
		Total		44		127		171
3	To what extent do you agree or disagree with this statement: Our organisation routinely monitors waiting times for children, young people and adults with a learning disability, and autistic people, and reports data concerning waiting list numbers and lengths of wait to the board.	Strongly Agree	41.9%	18	9.4%	12	17.5%	30
		Tend to Agree	34.9%	15	21.1%	27	24.6%	42
		Neither Agree or Disagree	14.0%	6	18.8%	24	17.5%	30
		Tend to Disagree	4.7%	2	37.5%	48	29.2%	50
		Strongly Disagree	2.3%	1	10.2%	13	8.2%	14
		Don't know	2.3%	1	3.1%	4	2.9%	5
		Total		43		128		171
4	Does your organisation have policies which require staff to intermittently contact children, young people and adults who have a learning disability and autistic people, on waiting lists to see if the situation is becoming more urgent?	Yes	50.0%	22	11.0%	14	21.1%	36
		No	18.2%	8	59.1%	75	48.5%	83
		Partially	31.8%	14	29.9%	38	30.4%	52
		Total		44		127		171
5	Total number of children, young people and adults who had a learning disability flag on the trust EPR at 31/03/2020	-	2135.0	41	1322.0	105	1550.3	146
6	Total number of children, young people and adults who had a learning disability flag on the trust EPR at 31/03/2020 as a % of total patients on the trust EPR	-	3.0%	40	0.3%	94	1.1%	134
7	Do you monitor/compare the emergency readmission rates for children, young people and adults with a learning disability, with those of people without learning disabilities?	Yes	40.0%	16	24.8%	31	28.5%	47
		No	60.0%	24	75.2%	94	71.5%	118
		Total		40		125		165
8	Average hospital readmission rate for the general population in 2019/20	-	8.3%	27	9.0%	50	8.7%	77
9	Average hospital readmission rate for learning disability patients in 2019/20	-	3.1%	26	13.6%	44	9.7%	70
10	Does your organisation regularly audit any restrictions and/or deprivations of liberty it places on children, young people and adults with a learning disability and/or autistic people?	Yes	70.0%	28	60.5%	75	62.8%	103
		No	10.0%	4	17.7%	22	15.9%	26
		Partially	20.0%	8	21.8%	27	21.3%	35
		Total		40		124		164
11	Have you undertaken an audit of restrictive practices in the last 12 months?	Yes	85.4%	35	49.2%	60	58.3%	95
		No	14.6%	6	50.8%	62	41.7%	68
		Total		41		122		163
12	Do you have a policy on the use of force to hold or restrain children, young people and adults with a learning disability and autistic people, who lack the competence of capacity to consent?	Yes	93.2%	41	82.7%	105	85.4%	146
		No	6.8%	3	17.3%	22	14.6%	25
		Total		44		127		171
13	Total number of patient safety incidents recorded concerning children, young people and adults with a learning disability or autistic people in 2019/20	-	506.7	34	108.1	103	207.0	137

Figure	Respecting and protecting rights – Organisational level	Response	Specialist National N=		Universal National N=		All trusts National N=	
14	Total number of patient safety incidents recorded for people with a learning disability and/or autism in 2019/20 per 100 children, young people and adults with a learning disability flag on the EPR	-	38	29	9	81	17	110
15	Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2019/20	-	2.7	40	0.8	109	1.3	149
16	Total number of Serious Incidents Requiring Investigation (SIRIs) concerning people with a learning disability and/or autism in 2019/20 per 100 people with a learning disability flag on the EPR	-	0	33	0	86	0	119
17	Number of safeguarding referrals concerning children, young people and adults with a learning disability or autistic people in 2019/20	-	82.4	31	21.3	84	37.7	115
18	Total number of safeguarding referrals concerning people with a learning disability and/or autism in 2019/20 per 100 people with a learning disability flag on the EPR	-	3	24	2	71	2	95
19	Total number of safeguarding referrals regarding people with a learning disability and/or autism in 2019/20 which met the criteria for a section 42 safeguarding/care act enquiry	-	5.6	17	5.1	82	5.2	99
20	Percentage of safeguarding referrals regarding people with a learning disability and/or autism in 2019/20 which met the criteria for a section 42 safeguarding/care act enquiry	-	14%	15	39%	67	35%	82
21	Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2019/20	-	5.5	42	3.5	106	4.0	148
22	Total number of formal complaints regarding the care and treatment of young people and adults with a learning disability or autistic people during 2019/20 as a % of total complaints	-	2%	42	1%	102	1%	144
23	Total number of people with a learning disability who died whilst on an active caseload or within 3 months of the case being closed or discharged in 2019/20	-	29.2	41	15.3	111	19.1	152
24	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 2019/20 as a % of total deaths	-	3.2%	34	1.1%	100	1.6%	134
25	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of choking incidents	-	0.2	32	0.1	94	0.1	126
26	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of choking incidents per 100 patients with an LD flag on the EPR	-	0.0	29	0.0	77	0.0	106

Figure	Respecting and protecting rights – Organisational level	Response	Specialist National N=	Universal National N=	All trusts National N=
27	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of sepsis	-	1.0 34	1.7 99	1.5 133
28	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of sepsis per 100 patients with an LD flag on the EPR	-	0.1 31	0.1 81	0.1 112
29	Total number of epilepsy related deaths of people with a learning disability that took place in 2019/20	-	0.6 32	0.4 93	0.4 125
30	Total number of epilepsy related deaths of people with a learning disability that took place in 2019/20 per 100 patients with an LD flag on the EPR	-	0.0 29	0.0 77	0.0 106
31	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of gastrointestinal obstructions	-	0.4 32	0.5 92	0.5 124
32	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of gastrointestinal obstructions per 100 patients with an LD flag on the EPR	-	0.0 29	0.0 77	0.0 106
33	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of respiratory condition	-	5.3 34	5.6 100	5.5 134
34	Total number of deaths of people with a learning disability that took place in 2019/20 as a result of respiratory condition per 100 patients with an LD flag on the EPR	-	0.4 31	0.5 82	0.5 113
35	Is your organisation represented on the local Learning Disability Mortality Review Programme (LeDeR) steering group?	Yes	100% 43	89.7% 113	92.3% 156
		No	0% 0	10.3% 13	7.7% 13
		Total	43	126	169
36	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	82.1% 32	69.8% 74	73.1% 106
		No	17.9% 7	30.2% 32	26.9% 39
		Total	39	106	145
37	Does your Trust monitor the rates of use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions for people with a learning disability?	Yes	32.5% 13	47.9% 58	44.1% 71
		No	67.5% 27	52.1% 63	55.9% 90
		Total	40	121	161

Figure	Inclusion and engagement – Organisational level	Response	Specialist		Universal		All trusts	
			National	N=	National	N=	National	N=
38	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	40.5%	17	33.6%	43	35.3%	60
		No	59.5%	25	66.4%	85	64.7%	110
		Total		42		128		170
39	To what extent do you agree or disagree with this statement: Members of the executive team regularly meet with and take advice from children, young people and adults with a learning disability, autistic people, family carers and the front-line workers who support them.	Strongly Agree	19.5%	8	12.6%	16	14.3%	24
		Tend to Agree	46.3%	19	25.2%	32	30.4%	51
		Neither Agree or Disagree	12.2%	5	23.6%	30	20.8%	35
		Tend to Disagree	17.1%	7	31.5%	40	28.0%	47
		Strongly Disagree	2.4%	1	5.5%	7	4.8%	8
		Don't know	2.4%	1	1.6%	2	1.8%	3
		Total		41		127		168
40	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	35.5%	44	42.2%	70
		No	38.1%	16	64.5%	80	57.8%	96
		Total		42		124		166
41	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	95.5%	42	97.7%	125	97.1%	167
		No	4.5%	2	2.3%	3	2.9%	5
		Total		44		128		172
41	Is your organisation able to accommodate carers overnight on site (acute hospitals)?	Yes	46.2%	6	97.4%	113	92.2%	119
		No	53.8%	7	2.6%	3	7.8%	10
		Total		13		116		129
41	Does your organisation provide a low stimulus area/waiting area?	Yes	65.1%	28	75.2%	94	72.6%	122
		No	34.9%	15	24.8%	31	27.4%	46
		Total		43		125		168
41	Does your organisation's triage processes prioritise children, young people and adults with a learning disability, or autistic people?	Yes	60.5%	26	75.6%	96	71.8%	122
		No	39.5%	17	24.4%	31	28.2%	48
		Total		43		127		170
41	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	93.2%	41	58.1%	72	67.3%	113
		No	6.8%	3	41.9%	52	32.7%	55
		Total		44		124		168
41	Do you have a policy which makes it clear that reasonable adjustments should be provided to autistic people?	Yes	65.0%	26	65.4%	83	65.3%	109
		No	35.0%	14	34.6%	44	34.7%	58
		Total		40		127		167
41	Does your organisation provide accessible appointment letters?	Yes	93.3%	42	55.9%	71	65.7%	113
		No	6.7%	3	44.1%	56	34.3%	59
		Total		45		127		172
41	Does your organisation provide a changing places toilet facilities?	Yes	44.2%	19	52.8%	67	50.6%	86
		No	55.8%	24	47.2%	60	49.4%	84
		Total		43		127		170
42	Total number of registered learning disability nurses (WTE)	-	73.7	40	5.5	125	22.0	165
43	Total number of designated acute learning disability liaison staff employed (WTE)	-	1.1	38	1.3	126	1.2	164
44	Total number of registered LD nurses as a % of designated acute learning disability liaison staff employed (WTE)	-	83.5%	18	81.0%	85	81.4%	103
45	Total number learning disability liaison staff (WTE) provided on the basis of	-	0.6	29	0.6	96	0.6	125

Figure	Inclusion and engagement – Organisational level	Response	Specialist		Universal		All trusts	
			National	N=	National	N=	National	N=
	service level agreements with other trusts							
46	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	39.0%	16	7.2%	9	15.1%	25
		Receive	7.3%	3	25.6%	32	21.1%	35
		Not applicable	53.7%	22	67.2%	84	63.9%	106
		Total		41		125		166
47	Learning disability liaison service staff skill mix	Band 2	5.9%	35.9	1.5%	2.95	4.9%	38.9
		Band 3	12.5%	75.3	2.3%	4.5	10.0%	79.8
		Band 4	11.2%	67.7	4.3%	8.3	9.5%	76
		Band 5	17.0%	103	11.3%	21.6	15.6%	125
		Band 6	25.5%	154	32.8%	62.9	27.3%	217
		Band 7	18.1%	109	37.4%	71.7	22.7%	181
		Band 8	9.8%	59.1	10.4%	19.9	9.9%	78.9
	Total		604		192		796	
48	Does your trust employ people with a learning disability or autism?	Yes	85.4%	35	86.8%	105	86.4%	140
		No	14.6%	6	13.2%	16	13.6%	22
		Total		41		121		162
49	If yes, what is the WTE of workforce employed with a learning disability (paid employment only)?	-	16.9	26	27.3	58	24.1	84
50	To what extent do you agree or disagree with this statement: 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	21.4%	9	25.8%	33	24.7%	42
		Tend to Agree	47.6%	20	47.7%	61	47.6%	81
		Neither Agree or Disagree	21.4%	9	13.3%	17	15.3%	26
		Tend to Disagree	7.1%	3	8.6%	11	8.2%	14
		Strongly Disagree	2.4%	1	1.6%	2	1.8%	3
		Don't know	0.0%	0	3.1%	4	2.4%	4
	Total		42		128		170	
51	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	45.2%	19	55.3%	68	52.7%	87
		No	54.8%	23	44.7%	55	47.3%	78
		Total		42		123		165

Figure Workforce – Organisational level		Response	Specialist National	Specialist N=	Universal National	Universal N=	All trusts National	All trusts N=
52	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	97.7%	42	93.0%	119	94.2%	161
		No	2.3%	1	7.0%	9	5.8%	10
		Total		43		128		171
53	Which professional role best describes the executive role of your board member who leads on quality assurance for learning disabilities and autism?	Nursing	47.6%	20	84.4%	103	75.0%	123
		Quality director	16.7%	7	6.6%	8	9.1%	15
		Operations director or	14.3%	6	5.7%	7	7.9%	13
		Medical director or	19.0%	8	3.3%	4	7.3%	12
		Other	2.4%	1	0.0%	0	0.6%	1
Total		42		122		164		
54	Does your workforce plan include data on current and future issues arising from retention/recruitment difficulties relating to the learning disabilities workforce?	Yes	80.0%	32	29.8%	34	42.9%	66
		No	20.0%	8	70.2%	80	57.1%	88
		Total		40		114		154
55	Does your workforce plan include provisions to support the development of new roles in learning disabilities care?	Yes	90.2%	37	45.8%	54	57.2%	91
		No	9.8%	4	54.2%	64	42.8%	68
		Total		41		118		159
56	Do staff receive up-to-date training covering learning disabilities / autism awareness?	Yes	90.5%	38	88.4%	114	88.9%	152
		No	9.5%	4	11.6%	15	11.1%	19
		Total		42		129		171
57	If yes, what percentage of staff were trained in this in 2018/19?	-	70.3%	26	52.7%	81	57.0%	107
58	Does your trust induction programme invite children, young people and adults with a learning disability or autism to contribute to staff training?	Yes	19.5%	8	26.4%	34	24.7%	42
		No	80.5%	33	73.6%	95	75.3%	128
		Total		41		129		170
59	Does your organisation provide training to help those who provide day to day care and support, to understand how to recognise and respond to signs of emerging health problems for children, young people and adults with a learning disability or autistic people?	Yes	88.4%	38	77.0%	97	79.9%	135
		No	11.6%	5	23.0%	29	20.1%	34
		Total		43		126		169
60	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	83.7%	36	66.7%	84	71.0%	120
		No	16.3%	7	33.3%	42	29.0%	49
		Total		43		126		169

Figure Specialist learning disability – organisational level		Response	Specialist National	Specialist N=
61	Specialist community learning disability teams	Yes	95.5%	42
		No	4.5%	2
		Total		44
61	Autism diagnostic services	Yes	81.8%	36
		No	18.2%	8
		Total		44
61	Intensive community support teams	Yes	75.0%	33
		No	25.0%	11
		Total		44
61	Community forensic learning disability team	Yes	61.4%	27
		No	38.6%	17
		Total		44

Figure Specialist learning disability – organisational level		Response	Specialist National	N=		
61	Inpatient Assessment and Treatment Unit (ATU)	Yes	46.5%	20		
		No	53.5%	23		
		Total		43		
61	Low Secure inpatient unit	Yes	31.8%	14		
		No	68.2%	30		
		Total		44		
61	Medium Secure inpatient unit	Yes	20.5%	9		
		No	79.5%	35		
		Total		44		
61	Long term continuing care / rehabilitation inpatient unit	Yes	15.9%	7		
		No	84.1%	37		
		Total		44		
61	Autism specific inpatient unit	Yes	9.1%	4		
		No	90.9%	40		
		Total		44		
61	High secure inpatient unit	Yes	2.3%	1		
		No	97.7%	43		
		Total		44		
62	Do you operate a dynamic risk/support register with regard to children, young people and adults with a learning disability, and autistic people, in community settings?	Yes	76.2%	32		
		No	7.1%	3		
		Partially	16.7%	7		
		Total		42		
63	If you provide an intensive community support service, do the staff provide crisis support?	Yes	83.3%	30		
		No	16.7%	6		
		Total		36		
64	If you provide an intensive community support service is it available 7 days per week?	Yes	60.0%	21		
		No	40.0%	14		
		Total		35		
65	Do your healthcare practitioners provide care coordination in accordance with the provisions of the Care Programme Approach?	Yes	95.2%	40		
		No	4.8%	2		
		Total		42		
66	Do you continue to provide care coordination, where people are placed in out-of-area inpatient services?	Yes	78.6%	33		
		No	21.4%	9		
		Total		42		
67	Do specialist learning disability practitioners provide in-reach support where people with a learning disability are admitted to universal mental health services?	Yes	88.4%	38		
		No	11.6%	5		
		Total		43		
68	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	77.5%	31		
		No	22.5%	9		
		Total		40		
69	Does your organisation train all learning disabilities clinical staff in PBS, in accordance with the competencies associated with their specific role?	Yes	88.6%	39		
		No	11.4%	5		
		Total		44		
70	Ethnicity of staff in specialist learning disabilities and/or autism services (headcount)	White / White British / White Other	80.8%	6066		
		Asian / Asian British	4.6%	347		
		Black / Black British	5.8%	435		
		Mixed race	1.2%	93		
		Other ethnicity	1.1%	84		
		Unknown	6.4%	481		
		Total		7507		
		71	Do you have an organisational restraint reduction programme/policy?	Yes	93.0%	40
				No	7.0%	3
Total				43		
71	Do you have a named board level lead for reducing restrictive interventions?	Yes	90.9%	40		
		No	9.1%	4		
		Total		44		

Figure Specialist learning disability – organisational level		Response	Specialist National	N=
71	Has it been reviewed in the last 12 months?	Yes	76.3%	29
		No	23.7%	9
		Total		38
71	Were people with lived experience of using services involved in developing the policy?	Yes	67.6%	25
		No	32.4%	12
		Total		37
72	Does the report include details of techniques used?	Yes	90.3%	28
		No	9.7%	3
		Total		31
72	Does the report include how often they are used?	Yes	87.1%	27
		No	12.9%	4
		Total		31
72	Do you publish an annual report on restraint and restraint reduction?	Yes	75.0%	30
		No	25.0%	10
		Total		40
72	Does the report include the trust training strategy?	Yes	71.0%	22
		No	29.0%	9
		Total		31
72	Does the report include the number of significant injuries to patients and/or staff as a result of restraint?	Yes	61.3%	19
		No	38.7%	12
		Total		31
72	Is an accessible version available?	Yes	43.3%	13
		No	56.7%	17
		Total		30
73	Do you hold risk assessments for each individual physical restraint technique taught to your staff?	All	92.3%	36
		Most	5.1%	2
		Some	2.6%	1
		None	0.0%	0
		Total		39
74	To what extent do you agree or disagree with this statement: Our organisation provides individualised behaviour support plans, for all children, young people and adults with a learning disability or autistic people, who have been assessed as being at risk of being exposed to restrictive interventions.	Strongly Agree	65.1%	28
		Tend to Agree	30.2%	13
		Neither Agree or Disagree	4.7%	2
		Tend to Disagree	0.0%	0
		Strongly Disagree	0.0%	0
		Don't know	0.0%	0
		Total		43
75	Do you provide people who use your services and their families, with accessible information concerning their rights, including in relation to the possible use of restrictive interventions?	Yes	85.7%	36
		No	14.3%	6
		Total		42
76	With regard to inpatients, do you routinely establish agreements with patients and families, about informing families whenever any form of restrictive interventions have been used?	Yes	91.7%	33
		No	8.3%	3
		Total		36
77	Are patients' accounts of incidents and their feelings, anxieties or concerns following the use of restrictive interventions, recorded in their notes?	Always	30.0%	12
		Mostly	45.0%	18
		Sometimes	25.0%	10
		Never	0.0%	0
		Not applicable	0.0%	0
Total		40		
78	Total number of children, young people and adults with a learning disability and autistic people who have experienced the use of physical restraint in 2019/20	-	26.9	34
79	Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2019/20	-	411.8	35
80	Total number of incidences of physical restraint specifically applied to children, young people and adults with a learning disability and autistic people in 2019/20 per 100 children,	-	13.0	30

Figure Specialist learning disability – organisational level		Response	Specialist National	N=
	young people and adults with a learning disability flag on the EPR			
81	In the exceptional circumstance that there are felt to be cogent reasons to devise a plan for the prone restraint of a patient, are these authorised/signed off by a director of the trust?	Always	50.0%	9
		Mostly	0.0%	0
		Sometimes	0.0%	0
		Never	50.0%	9
		Not applicable	0.0%	0
		Total		18
82	Has your board approved the use of mechanical restraint?	Yes	42.9%	18
		No	57.1%	24
		Total		42
83	Total number of children, young people and adults with a learning disability and autistic people who experienced use of mechanical restraint in 2019/20	-	1.1	22
84	Where a child, young person or adult is thought to need a plan for the use of mechanical restraint, is an IMHA consulted as part of the care planning process?	Always	50.0%	5
		Mostly	10.0%	1
		Sometimes	30.0%	3
		Never	10.0%	1
		Not applicable	0.0%	0
		Total		10
85	Is the RC or duty doctor informed, without delay, each and every time a mechanical restraint device is applied to a patient?	Yes	92.9%	13
		No	7.1%	1
		Total		14
86	Has your board approved the use of long term segregation in your trust?	Yes	60.5%	23
		No	39.5%	15
		Total		38
87	Do you routinely notify the local authority safeguarding team when a patient is placed in long term segregation?	Yes	86.4%	19
		No	13.6%	3
		Total		22
88	Total number of children, young people and adults with a learning disability and autistic people who experienced use of long-term segregation in 2019/20	-	2.8	25
89	Does this routinely include consultation with the patient's IMHA?	Yes	85.7%	18
		No	14.3%	3
		Total		21
90	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	68.2%	30
		No	31.8%	14
		Total		44
91	Is your trust signed up to stopping over medication of adults with a learning disability and autistic people with psychotropic medication?	Yes	92.9%	39
		No	7.1%	3
		Total		42
92	Is your trust signed up to supporting treatment and appropriate use of psychotropic medication in paediatrics?	Yes	90.6%	29
		No	9.4%	3
		Total		32
93	Does your trust provide regular medication reviews?	Yes	97.6%	41
		No	2.4%	1
		Total		42
94	Has your organisation signed the STOMP pledge?	Yes	85.7%	36
		No	14.3%	6
		Total		42
95	Has your organisation undertaken a STOMP audit?	Yes	82.5%	33
		No	17.5%	7
		Total		40

Figure	Respecting and protecting rights – Staff survey	Response	Specialist National	Specialist N=	Universal National	Universal N=	All trusts National	All trusts N=
96	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	-	0	72%	2386	72%	2386
		Documented in nursing notes	-	0	57%	1885	57%	1885
		Documented electronically	-	0	70%	2338	70%	2338
		Sticker on patient notes	-	0	12%	385	12%	385
		Other	-	0	9%	309	9%	309
		Do not have any systems	-	0	1%	44	1%	44
		Don't know	-	0	10%	320	10%	320
		Total	-	0		7667		7667
97	In my trust children, young people and adults with a learning disability or autistic people have appropriate access to flexible appointments	Yes	75%	888	46%	1485	54%	2373
		No	5%	60	4%	126	4%	186
		Don't know	20%	238	50%	1593	42%	1831
		Total		1186		3204		4390
97	In my trust children, young people and adults with a learning disability or autistic people have appropriate access to first or last clinic appointments	Yes	66%	761	41%	1304	48%	2065
		No	4%	42	4%	136	4%	178
		Don't know	31%	354	55%	1742	48%	2096
		Total		1157		3182		4339
97	In my trust children, young people and adults with a learning disability or autistic people have appropriate access to double appointments	Yes	62%	708	40%	1265	46%	1973
		No	5%	53	5%	161	5%	214
		Don't know	34%	387	55%	1762	50%	2149
		Total		1148		3188		4336
98	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	49%	594	21%	689	28%	1283
		Agree	42%	512	53%	1752	50%	2264
		Neither agree nor disagree	4%	51	16%	514	13%	565
		Disagree	2%	22	8%	252	6%	274
		Strongly Disagree	3%	36	3%	86	3%	122
		Total		1215		3293		4508
99	I have the necessary resources to meet the needs of children, young people and adults with a learning disability or autistic people eg communication needs, equipment.	Strongly Agree	22%	273	11%	364	14%	637
		Agree	50%	605	43%	1410	45%	2015
		Neither agree nor disagree	14%	168	28%	917	24%	1085
		Disagree	11%	128	15%	509	14%	637
		Strongly Disagree	3%	42	3%	90	3%	132
		Total		1216		3290		4506
100	I am confident that children, young people and adults with a learning disability or autistic people using my service always receive the reasonable adjustments they need.	Strongly Agree	29%	356	15%	507	19%	863
		Agree	46%	562	44%	1456	45%	2018
		Neither agree nor disagree	14%	175	27%	878	23%	1053
		Disagree	8%	103	12%	395	11%	498
		Strongly Disagree	2%	24	2%	57	2%	81
		Total		1220		3293		4513
101	I am always able to deliver safe care to a child, young person, or adult with a learning disability or autistic people.	Strongly Agree	32%	389	18%	581	22%	970
		Agree	51%	618	56%	1819	54%	2437
		Neither agree nor disagree	12%	142	20%	656	18%	798
		Disagree	4%	44	5%	179	5%	223
		Strongly Disagree	1%	16	1%	31	1%	47
		Total		1209		3266		4475
102	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	25%	818	25%	818
		Agree	-	0	46%	1505	46%	1505
		Neither agree nor disagree	-	0	18%	588	18%	588
		Disagree	-	0	9%	297	9%	297
		Strongly Disagree	-	0	2%	55	2%	55
		Total		0		3263		3263
103		Strongly Agree	22%	266	9%	286	12%	552

Figure	Respecting and protecting rights – Staff survey	Response	Specialist National	Specialist N=	Universal National	Universal N=	All trusts National	All trusts N=
	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.	Agree	45%	546	27%	894	32%	1440
		Neither agree nor disagree	24%	296	46%	1514	40%	1810
		Disagree	7%	90	16%	510	13%	600
		Strongly Disagree	1%	11	2%	66	2%	77
		Total		1209		3270		4479
104	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	48%	117	37%	964	38%	1081
		No	2%	5	3%	76	3%	81
		Don't know	50%	121	61%	1598	60%	1719
		Total		243		2638		2881
105	If a child, young person or adult with a learning disability or autistic people dies under the care of our service, the findings and outcomes from the trust investigation are shared with staff team members.	Strongly Agree	21%	255	11%	354	14%	609
		Agree	40%	476	31%	1012	33%	1488
		Neither agree nor disagree	29%	346	47%	1535	42%	1881
		Disagree	9%	105	8%	273	9%	378
		Strongly Disagree	1%	16	2%	72	2%	88
		Total		1198		3246		4444
106	My trust has policies and procedures to ensure the rights of autistic people are respected and protected?	Yes	72%	875	66%	2155	68%	3030
		No	3%	37	2%	68	2%	105
		Don't know	24%	295	32%	1039	30%	1334
		Total		1207		3262		4469

Figure	Inclusion and Engagement – Staff survey	Response	Specialist		Universal		All trusts	
			National	N=	National	N=	National	N=
107	In my T trust, I feel children, young people and adults with a learning disability and autistic people are always treated with dignity and respect.	Strongly Agree	43%	516	29%	943	33%	1459
		Agree	44%	533	52%	1699	50%	2232
		Neither agree nor disagree	9%	106	14%	470	13%	576
		Disagree	4%	45	4%	134	4%	179
		Strongly Disagree	1%	8	1%	32	1%	40
		Total		1208		3278		4486
108	In my trust, I feel family members of children, young people and adults with a learning disability, and autistic people, are always treated with dignity and respect.	Strongly Agree	40%	487	28%	907	31%	1394
		Agree	46%	550	53%	1734	51%	2284
		Neither agree nor disagree	10%	126	16%	513	14%	639
		Disagree	3%	37	3%	107	3%	144
		Strongly Disagree	1%	8	1%	25	1%	33
		Total		1208		3286		4494
109	I routinely involve children, young people and adults with a learning disability, and autistic people when making decisions about their care and treatment.	Strongly Agree	51%	612	32%	1050	37%	1662
		Agree	40%	486	48%	1554	46%	2040
		Neither agree nor disagree	7%	90	18%	576	15%	666
		Disagree	1%	12	1%	44	1%	56
		Strongly Disagree	1%	8	1%	17	1%	25
		Total		1208		3241		4449
110	I routinely involve the families of children, young people and adults with a learning disability, and autistic people, when making decisions about their care and treatment.	Strongly Agree	49%	585	35%	1132	39%	1717
		Agree	40%	477	48%	1554	46%	2031
		Neither agree nor disagree	10%	121	16%	521	14%	642
		Disagree	1%	10	1%	29	1%	39
		Strongly Disagree	1%	8	0%	15	1%	23
		Total		1201		3251		4452
111	Children, young people and adults with a learning disability are routinely involved in the planning of trust services.	Strongly Agree	9%	111	8%	251	8%	362
		Agree	28%	340	21%	693	23%	1033
		Neither agree nor disagree	45%	540	59%	1910	55%	2450
		Disagree	15%	184	10%	341	12%	525
		Strongly Disagree	3%	31	2%	55	2%	86
		Total		1206		3250		4456
112	Families of children, young people and adults with a learning disability are routinely involved in the planning of trust services.	Strongly Agree	7%	86	7%	229	7%	315
		Agree	27%	320	22%	707	23%	1027
		Neither agree nor disagree	49%	588	60%	1932	57%	2520
		Disagree	14%	171	10%	313	11%	484
		Strongly Disagree	3%	30	2%	50	2%	80
		Total		1195		3231		4426

Figure Workforce – Staff survey		Response	Specialist		Universal		All trusts	
			National	N=	National	N=	National	N=
113	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	83%	1009	68%	2219	72%	3228
		No	17%	203	32%	1061	28%	1264
		Total		1212		3280		4492
114	I feel I have the necessary knowledge and skills to meet the needs of children, young people and adults with a learning disability, and autistic people, during the course of my work.	Strongly Agree	43%	521	19%	636	26%	1157
		Agree	45%	549	50%	1620	48%	2169
		Neither agree nor disagree	6%	75	20%	641	16%	716
		Disagree	4%	49	10%	323	8%	372
		Strongly Disagree	1%	13	2%	52	1%	65
		Total		1207		3272		4479
115	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	49%	589	28%	925	34%	1514
		Agree	36%	435	42%	1374	40%	1809
		Neither agree nor disagree	8%	95	18%	586	15%	681
		Disagree	5%	66	9%	300	8%	366
		Strongly Disagree	2%	24	2%	79	2%	103
		Total		1209		3264		4473
116	Children, young people and adults with a learning disability are involved in delivering awareness training to staff in my trust.	Strongly Agree	10%	125	7%	234	8%	359
		Agree	25%	305	20%	664	22%	969
		Neither agree nor disagree	38%	460	46%	1504	44%	1964
		Disagree	21%	256	22%	711	22%	967
		Strongly Disagree	5%	54	4%	136	4%	190
		Total		1200		3249		4449
117	I would recommend the trust to a friend or family members of a child, young person or adult with a learning disability, or an autistic person, who needed treatment.	Strongly Agree	31%	382	21%	699	24%	1081
		Agree	49%	593	49%	1613	49%	2206
		Neither agree nor disagree	16%	190	27%	875	24%	1065
		Disagree	3%	35	2%	73	2%	108
		Strongly Disagree	1%	13	1%	36	1%	49
		Total		1213		3296		4509

Figure Specialist services – Staff survey		Response	Specialist National	Specialist N=
118	Children, young people and adults with a learning disability, and people with autism, who are in hospital because of concerns about their behaviour or mental health, continue to be seen by staff from their usual community services.	Strongly Agree	18%	216
		Agree	44%	529
		Neither agree nor disagree	28%	340
		Disagree	8%	93
		Strongly Disagree	2%	22
		Total		1200
119	Children, young people and adults with a learning disability, and autistic people, who are in hospital because of concerns about their behaviour or mental health, are visited by an external care coordinator, case manager, or equivalent at least every 6-8 weeks.	Strongly Agree	13%	32
		Agree	27%	65
		Neither agree nor disagree	41%	99
		Disagree	16%	40
		Strongly Disagree	3%	7
		Total		243
120	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	19%	231
		Agree	44%	531
		Neither agree nor disagree	31%	369
		Disagree	5%	58
		Strongly Disagree	1%	10
		Total		1199
121	I have had training on reducing the use of restrictive interventions.	Strongly Agree	33%	393
		Agree	39%	467
		Neither agree nor disagree	13%	151
		Disagree	12%	147
		Strongly Disagree	4%	46
		Total		1204
122	Children, young people and adults with a learning disability, and autistic people who are in hospital because of concerns about their behaviour or mental health, have good access to independent advocacy services.	Strongly Agree	41%	101
		Agree	42%	104
		Neither agree nor disagree	14%	34
		Disagree	2%	5
		Strongly Disagree	1%	2
		Total		246
123	My trust encourages me to speak out if I have concerns about the wellbeing of children, young people and adults with a learning disability, and autistic people, in our services.	Strongly Agree	52%	631
		Agree	40%	483
		Neither agree nor disagree	6%	67
		Disagree	1%	16
		Strongly Disagree	1%	11
		Total		1208
124	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	90%	935
		No	10%	107
		Total		1042

Respecting and protecting rights – service user survey		Response	Specialist National	Specialist N=	Universal National	Universal N=	All trusts National	All trusts N=
125	When you received care from the NHS, did staff treat you with respect?	Yes	90%	599	94%	1989	93%	2588
		No	4%	29	3%	62	3%	91
		Don't know	5%	34	3%	72	4%	106
		Total		662		2123		2785
126	Did staff explain things to you in a way you could understand?	Yes	81%	515	83%	1667	82%	2182
		No	10%	63	9%	177	9%	240
		Don't know	9%	57	9%	176	9%	233
		Total		635		2020		2655
127	Did you feel like staff listened to you?	Yes	81%	503	85%	1721	84%	2224
		No	10%	61	8%	151	8%	212
		Don't know	9%	57	7%	141	8%	198
		Total		621		2013		2634
128	Did you feel like staff cared about you?	Yes	89%	583	89%	1896	89%	2479
		No	6%	37	5%	102	5%	139
		Don't know	5%	34	6%	126	6%	160
		Total		654		2124		2778

Respecting and protecting rights – Figureservice user survey		Response	Specialist		Universal		All trusts	
			National	N=	National	N=	National	N=
129	Did staff talk to you about the care you needed?	Yes	82%	520	83%	1684	83%	2204
		No	9%	59	9%	179	9%	238
		Don't know	9%	57	8%	172	9%	229
		Total		636		2035		2671
130	Did staff give you choices about how you were cared for?	Yes	68%	398	71%	1349	70%	1747
		No	16%	95	14%	273	15%	368
		Don't know	16%	94	15%	277	15%	371
		Total		587		1899		2486
131	Did staff listen to what your family thought?	Yes	77%	399	80%	1385	80%	1784
		No	10%	52	9%	151	9%	203
		Don't know	12%	64	11%	191	11%	255
		Total		515		1727		2242
132	When you received care, did you feel safe?	Yes	87%	558	89%	1851	89%	2409
		No	7%	43	5%	107	6%	150
		Don't know	6%	40	6%	122	6%	162
		Total		641		2080		2721
133	Did you have any concerns about your care?	Yes	23%	149	20%	412	21%	561
		No	67%	429	69%	1423	69%	1852
		Don't know	10%	64	11%	221	11%	285
		Total		642		2056		2698
134	Did you make a complaint?	Yes	12%	72	9%	169	9%	241
		No	86%	515	88%	1713	88%	2228
		Don't know	2%	14	3%	63	3%	77
		Total		601		1945		2546
135	If yes, were you given Easy Read information about how to make a complaint?	Yes	31%	52	24%	136	25%	188
		No	50%	85	52%	301	52%	386
		Don't know	19%	32	24%	139	23%	171
		Total		169		576		745
136	If you stayed in hospital, was it easy for your family to visit you?	Yes	57%	223	63%	769	61%	992
		No	35%	138	30%	372	32%	510
		Don't know	8%	32	7%	80	7%	112
		Total		393		1221		1614
137	Did staff tell you about your appointments and meetings in a way you could understand?	Yes	79%	443	82%	1492	81%	1935
		No	13%	75	9%	173	10%	248
		Don't know	7%	40	9%	163	9%	203
		Total		558		1828		2386
138	Were your appointments and meetings arranged to suit you?	Yes	76%	445	80%	1519	79%	1964
		No	14%	83	10%	196	11%	279
		Don't know	10%	60	10%	186	10%	246
		Total		588		1901		2489
139	If you needed to be seen in an emergency, were you seen quickly?	Yes	72%	353	78%	1151	76%	1504
		No	18%	86	13%	196	14%	282
		Don't know	10%	48	9%	138	9%	186
		Total		487		1485		1972
140	Would you recommend this service to a friend or family?	Yes	80%	518	85%	1756	84%	2274
		No	9%	61	5%	107	6%	168
		Don't know	11%	70	10%	204	10%	274
		Total		649		2067		2716

Contact us:

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If you have any questions about this report or would like to be involved in shaping the data collection, please contact the NHSBN support team at

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