NHS
North East London
Integrated Care Board

NHS North East London ICB

LeDeR Programme Annual Report 2022-2023

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Executive summary

This is the 4th annual report of the Learning from lives and deaths for people with a learning disability and autistic adults (LeDeR) by NHS North east London Integrated Care Board (ICB) LeDeR programme. It is the first report since the start of ICBs in July 2022. The NEL ICB is now responsible for the delivery of LeDeR programme locally.

In March 2021, the LeDeR policy was published introducing a new way of working. NHS NEL ICB has made significant progress toward implementing the requirements of this policy. In January 2022, the LeDeR programme started reviewing deaths of adults known to have a formal diagnosis. Like many other areas, NEL has received a very small number of notifications for autistic adults so far.

126 reviews were received during this reporting period. 62 reviews were completed, achieving 100% completion within 6 months of receipt of the notifications. 48% of these completed reviews received excellent and good care and less than 4% (one case) received poor care.

All 62 reviews received an initial review and 25 (40%) received a focused review compared to 19 (33%) focused reviews last year. 52% were males and 48% were females. Recorded median age of the persons reviewed were 62 years this year. Proportionally, no significant variation recorded in severity of learning disability, ethnicity, living arrangements and place of death compared to last year.

Reviewers have identified many areas of good practice however we continue to record similar gaps as previous years**.** Uptake of national cancer screening programmes remain very low compared to general population and more needs to be done. GPs to offer more face to face appointments and improve the quality of annual health checks. Closer working relationships between professionals and community learning disability teams for support as may be indicated.

The top five recorded causes of death were linked to respiratory problems, heart or cardiac conditions, sepsis, Covid-19, and cancers. Although, nationally, we have seen a significant reduction in the number of Covid-19 deaths, this remains a risk. We will remain mindful of this as we continue to review lives and deaths of people with a learning disability and autism this year and beyond.

Overall, national data show a reduction in avoidable mortality from 54% in 2018 to 49% 2022, London had an average of 48%. Evidence show there is more awareness of the LeDeR programme hence increased number of reported deaths locally and nationally.

The LeDeR review process recognises the pivotal role played by carers and the importance of ‘carer expertise’, in care provision. All families were offered an opportunity to participate and contribute to LeDeR reviews, however, for varied reasons, a small proportion declined this offer.

The LeDeR programme does not replace other statutory investigations and processes for reviewing a person’s death but work alongside these teams. Where there are Safeguarding reviews, serious incidents, complaints or coroners’ inquests, LeDeR review is placed on hold until these processes conclude.

On completion of a focused reviews they are graded and recommendations made. Areas needing improvements are identified and shared with the relevant service provider and the wider teams for the purpose of learning and service improvements.

This report presents analysis of information gathered from 61 people with learning disabilities and one autistic person. Also included are local initiatives and projects as a result of the LeDeR programme.

Introduction

LeDeR programme came into place in 2015 following the confidential inquiry into premature deaths for people with a learning disability (CIPOLD). This report highlighted unacceptable levels of health inequalities faced by people with learning disabilities. The report found that nearly a quarter of people with learning disabilities have poorer health and die younger than other people.

In March 2021, learning from lives and deaths of people with a learning disability and autistic adults (LeDeR) policy was published introducing a new way of working. This meant a wider look into reviews other than focusing on the circumstances around the person's death. The purpose for LeDeR programme remains unchanged, which is to identify learning and affect meaningful change, improve health outcomes for learning disability and autistic people, to live longer, healthier and happier lives.

In January 2022, the LeDeR programme started reviewing autistic adults. NEL, like many other localities has not received many notifications relating to autistic people who do not have a learning disability. Two notifications were recorded and only one had a focused review completed as at the end of the reporting year. Therefore, this report predominately focuses on findings from people with a learning disability.

Poor quality healthcare causes health inequalities and contributes to premature deaths. Statistics show that people with learning disabilities and autism have two or more pre-existing health conditions and more likely to face multiple barriers accessing health and social care services. Due to their complex health and social care needs, they are more likely to experience higher levels of unrecognised and unmet physical and mental health needs.

Diagnostic overshadowing is common in people with a learning disability and can lead to avoidable deaths. It is always vital for clinical teams to explore a physical or psychological reason behind a behaviour change rather than assume its linked to a learning disability or autistic trait. There is need to consider a lower threshold may be required for investigations for people with a learning disability and autism.

Poor communication, inaccessible facilities, absence of support, inflexible procedures, lack of accessible health information or poor awareness of the needs of people with a learning disability and autism are some of the common barriers to accessing services. Most people with a learning disability and autism depend on carers or family members to attend health and social care appointments and to carry out activities of daily living. It is important people providing care have a good understanding of their needs.

NHS NEL ICB understands the needs and experiences of people with a learning disability and autism when accessing health and social care services. Reviewers have documented good practice but also areas needing improvement. Evidence show good progress in terms of learning from completed reviews and service improvement plans, this report presents some of the local initiatives and projects as a result of the LeDeR programme.

LeDeR Programme: Development so far

2013-2015

- Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Led by University of Bristol
- Government response to the CIPOLD report
- National Guidance on Learning from Deaths
- Death by Indifference report by Mencap
- LeDeR Programme initiated

2016-2017

- University of Bristol (UoB) commissioned by NHS England and NHS Improvement to deliver LeDeR programme
- UoB establishment web-based portal and a core dataset for local review teams reviewing the deaths of people with learning disabilities
- National LeDeR programme pilot projects; Tower Hamlets was one of the London's pilot sites

Dec. 2017

- Reviewing of LeDeR cases devolved to Clinical Commissioning Groups
- Training rolled out to all health and social care teams

March 2021

LeDeR Policy was published introducing

- New LeDeR platform hosted by
- ICBs required to appoint SRO and establish LeDeR team
- Governance systems/functions clarified
- New way of working- scope and format: Initial and focused reviews
- New LeDeR Training introduced for all LeDeR workforce
- Name changed to 'Learning from Lives and Deaths of people with a learning disability and autistic adults.
- LeDeR Programme aligned with NHS long term plan

January 2022

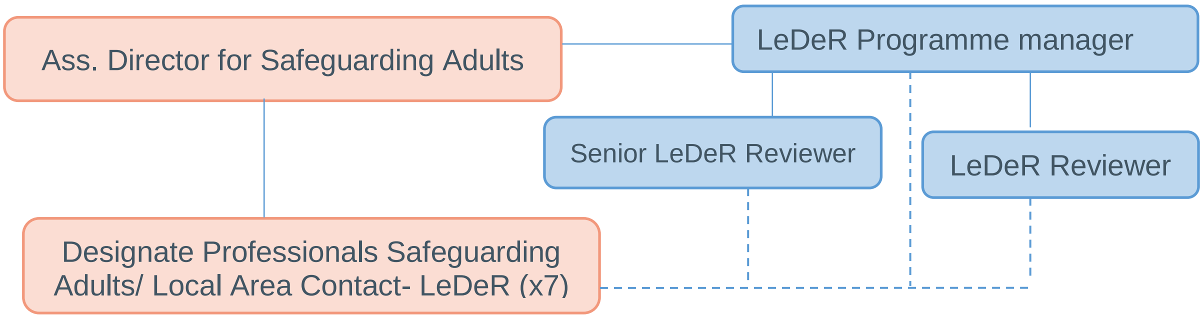
LeDeR Programme started reviewing autistic adults, with a formal diagnosis.

NHS NEL ICB Governance arrangements

LeDeR is a quality improvement tool. The new LeDeR Policy requires that all NHS Integrated Care Boards/ Integrated Care Systems to establish a clear governance process to support effective implementation of the LeDeR programme. ICBs should ensure sufficient resources are available to complete LeDeR reviews.

The NEL LeDeR programme sits within the Nursing & Safeguarding directorate led by the Director of Nursing & Safeguarding with the Senior Responsible Officer (SRO) being Diane Jones, who is the Chief Nursing Officer, supported by a strong LeDeR Programme team. This team consists of a LeDeR Programme Manager, a Senior LeDeR Reviewer, LeDeR Reviewers and a team of Designated Professionals for Safeguarding Adults who are also Local Area Contacts (LACs) for LeDeR.

Figure 1: NEL LeDeR Programme Team

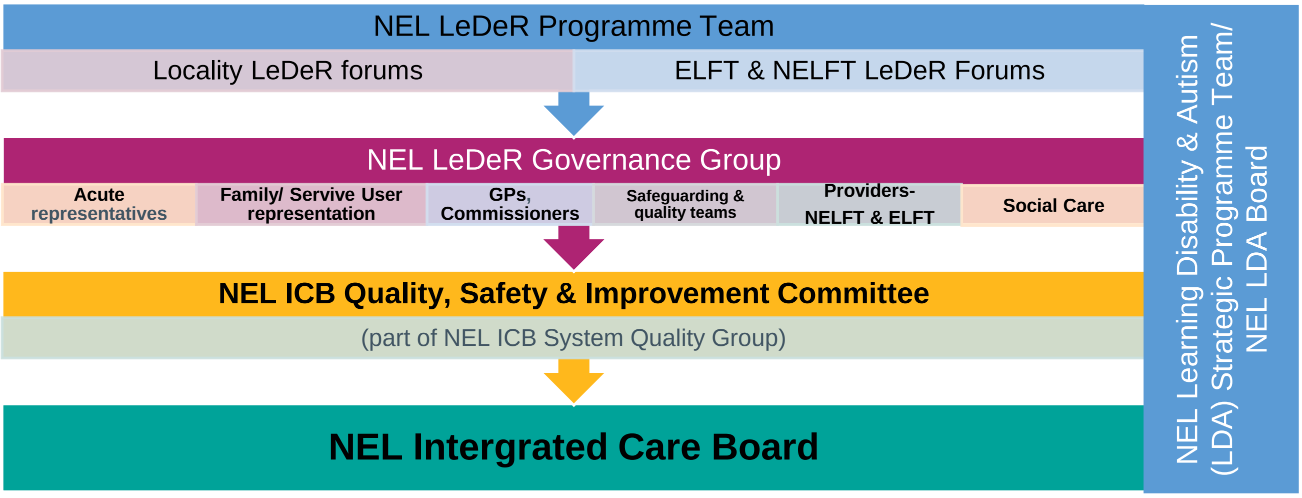


NEL LeDeR Governance system

NHS NEL has setup a LeDeR governance group which meets every quarter and the purpose for this group is to oversee completion of reviews and support learning from these reviews across the NEL footprint. This group has a clear set of Terms of Reference agreed by all participating members. LeDeR programme works closely with key partners, placing experts by lived experience at the heart of what we do.

The group membership comprises of senior colleagues from across health and social care, all of whom have authority to affect change.

Figure 2: NHS ICB LeDeR Governance system



The annual report will be presented to all seven NEL Safeguarding Adults' Boards, NEL Learning Disability and Autism Board, ICB System Quality Group, Quality, Safety & Improvement Committee, NEL ICS System Quality Group and NEL Integrated Care Board.

LeDeR Review Process

Anyone can report a death of a person who has died and was known to have a learning disability or autism or both. This is done vie the LeDeR web platform only. Once a notification is received, it is automatically assigned to the relevant ICB using GP postcode. It is expected that these cases will be allocated to a Reviewer within three months from the receipt date and completed within the next three months thereafter.

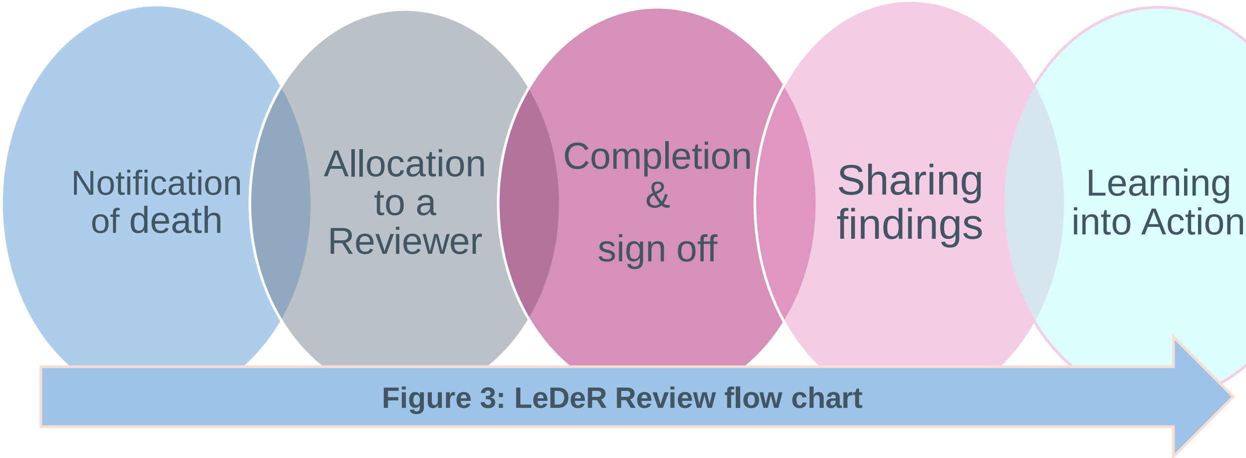


Figure 3: LeDeR Review flow chart

All deaths receive an Initial Review. All people from a global majority groups (also known as Black, Asian and Minority Ethnic groups- BAME), Romany Gypsy, Irish Travellers, Jewish communities and autistic adults without a learning disability must have a focused review. Also, where an initial review indicate that further learning could be gained, a focused review is completed

Where a review has been identified to have significant care gaps or failings, the LeDeR programme team would work with colleagues and families to ensure alignment or escalation with appropriate statutory processes such as Safeguarding reviews or serious incidents. The learning from these processes is then taken forward by all those involved.

The length of time taken to complete a review varies from case to case, some take longer than others depending on the complexity of the case. Ideally, it is expected that all reviews are completed within 6 months of receipt of notification. NHS England completion target is 75%.

NHS NEL ICB has managed to meet this national target and achieved 100%. The six months target excludes reviews on hold due to going statutory reviews or investigations such as safeguarding adult reviews, serious incidents, complaints or coroners’ inquests.

The LeDeR Governance Group is responsible for overseeing the delivery of LeDeR programme while the Local Area Contacts (LACs) for LeDeR are responsible for the quality assurance and sign off of completed reviews.

Findings and recommendations from completed reviews are shared with key partners and care providers and areas needing improvement taken forward. NEL LeDeR Governance Group meets every three months where reviews of significant learning are discussed and care providers provide feedback on service improvements as a result of these completed reviews. Actions, where appropriate, are added on to the governance group tracker to ensure follow up.

The LeDeR reviews process is never complete without involving care providers, families, carers and people who knew the person very well. Whilst the majority of families and carers, were confident that relevant aspects of learning are drawn from reviews with the aim of influencing improvements in the future lives of others, a few did not feel the same. It is not always the case that those families who did not engage had poor care or experiences.

National and local data

In 2017, the responsibility for LeDeR reviews was devolved to Clinical Commissioning Groups (CCGs), now referred to as NHS Integrated Care Boards (ICBs). Since then, 17,149 notifications have been recorded nationally, 550 of which are NHS NEL ICB deaths.

Figure 4: Number of notifications received locally and nationally

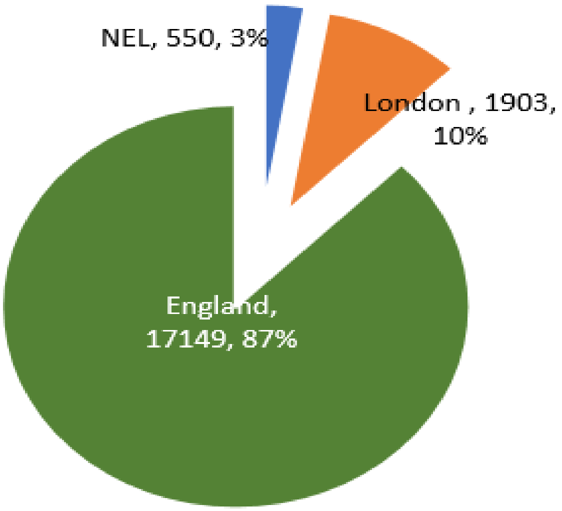


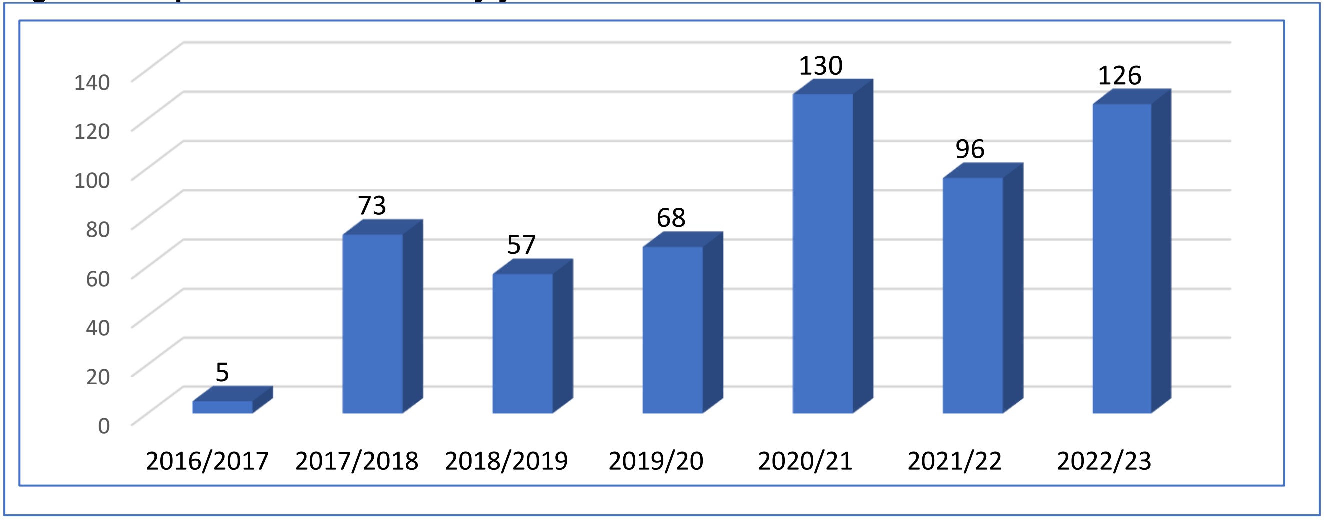
Table 1- National data

Locality	2017-2022 (eligible reviews)
NEL	550
London	1903
England	17149

North East London LeDeR Programme Outlook

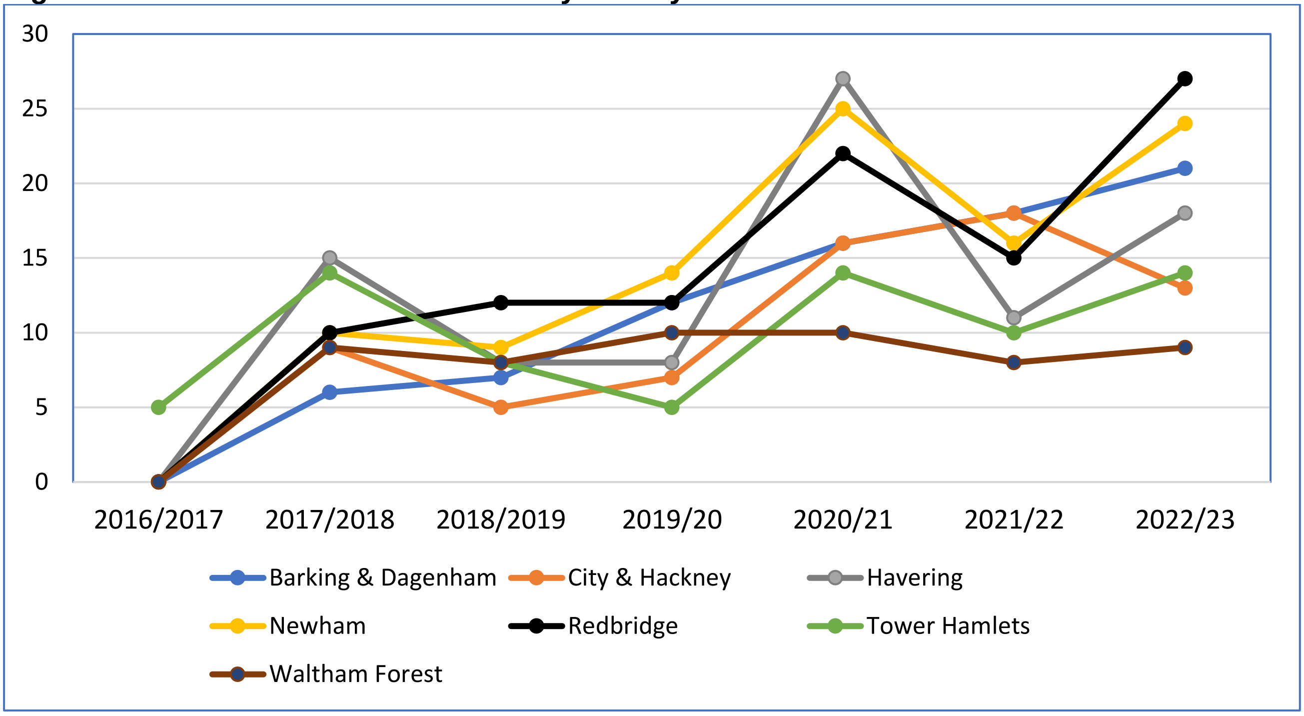
This is the Fourth NHS North east London LeDeR report since the start of the LeDeR Programme. NEL has recorded 550 deaths, accumulative. Most death notifications were reported by Community Learning Disability Nurses or Learning Disability Acute Liaison Nurses and other allied health professionals. This year, a small number of deaths were reported by care staff, London Ambulance Service (LAS) crews and social care teams.

Figure 5: Reported notifications by year since 2016



In 2020-21, NEL recorded almost the same number of deaths as this year's data. Records show, Covid-19 deaths have reduced significantly. Whilst it is not clear why the increased numbers this year, review findings have shown improved level of awareness of reporting of LeDeR deaths. Anyone can notify a death of someone known to have had a learning disability or autism or both via this link: https://leder.nhs.uk/report

Figure 6: NEL notifications since 2016 by locality



Over the past five years, the numbers of notifications received have been consistent across all localities.

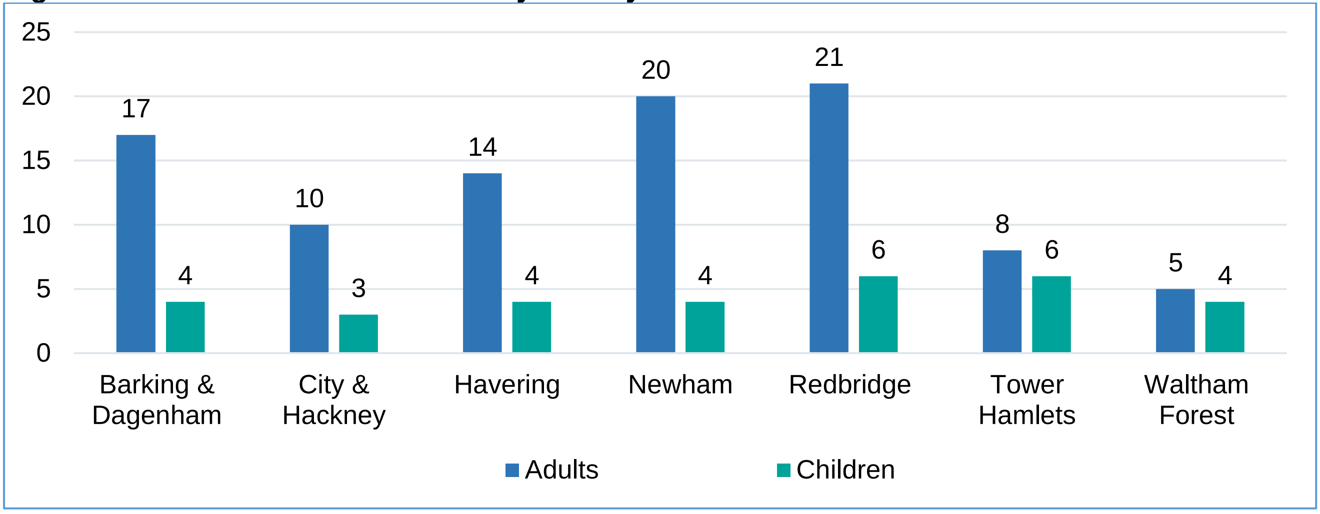
City & Hackney records show a drop while Redbridge has seen an increase in the numbers reported compared to previous years. During the pandemic, Havering recorded the highest numbers of notifications. Barking & Dagenham has had a steady increase over the years while Waltham Forest has remained low.

Redbridge and Newham localities have recorded the highest number of notifications while Waltham Forest has the least during this reporting year, 2022-23.

NEL LeDeR activity and performance- 2022-2023

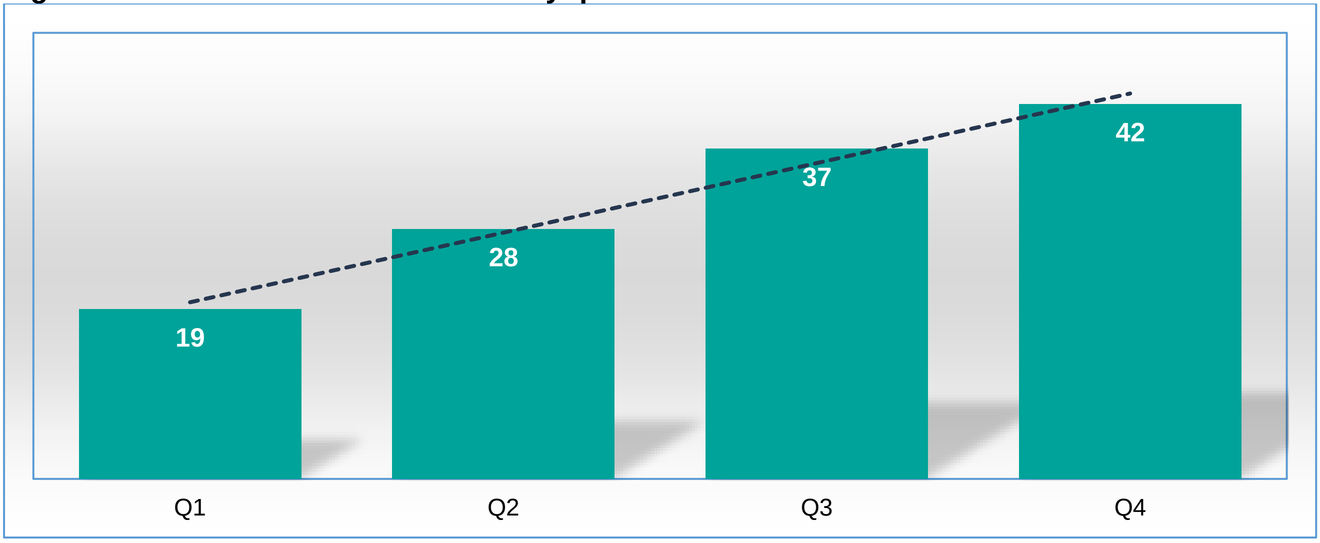
As shown on Figure 5 above, NHS NEL ICB has received 126 notifications; 95 were adults and 31 were children (under 17years old). Below table provides details of these notifications by age and locality.

Figure 7: All notifications recorded by locality-2022-23



More details about age distribution will be covered under demographics, on page 13.

Figure 8: Distribution of notifications by quarters

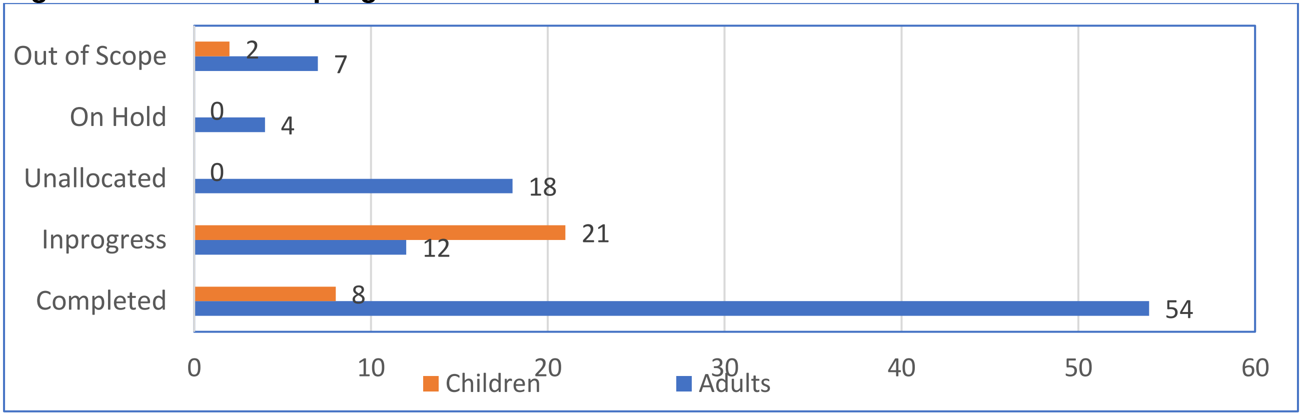


NEL ICB has seen a steady increase in the number of death notifications as shown above. NEL received almost twice the number of notifications during the second half of the year compared to first half (quarter 1 and 2).

During the pandemic, NEL recorded a high number of deaths similar to those recorded this year. Despite that records show a significant declined in the number of covid-19 deaths, the long-term impact cannot be underestimated. It is likely that improved awareness of the LeDeR programme may have contributed to increased reporting.

As at end of this year, 54 adults' reviews are completed, 12 in progress, 4 on hold and 18 were awaiting to be allocated. 'On hold' are those reviews that have been paused due to an ongoing statutory investigation. Seven notifications were considered out of scope, which means these people were not known to have a learning disability or autism or both or were under the age of 4 years, for children.

Figure 9: NEL Review progress status



As seen above, 118 reviews (88 adults and 30 children) were eligible for LeDeR review process. 62 were completed and signed off as at 1st April 2023. The overall performance, by total number of notifications received, is 53%

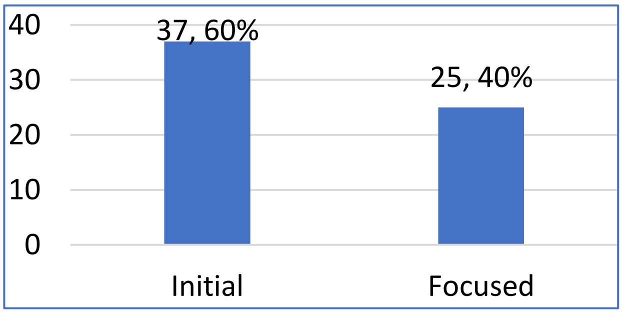
Table 3: Completed reviews by group

Notifications eligible for LeDeR review	Completed	Percentage (%)
Children (30)	8	27%
Adults (88)	54	61%

This year's LeDeR annual report will focus on the detailed analysis of the 62 completed reviews (8 children and 54 adults)

Types of Reviews

All reviews received an initial review. 60% remained as initials while 40% (25) were progressed onto focused reviews. 19 (76%) of the 25 met the set criteria for a focused review, majority of whom were people from minority ethnic groups while six (24%) were of white background. The latter were progressed from initial onto focused reviews following discussions between LACs and the Reviewers. More learning arose from these six reviews which would probably have not been clear had they remained as initial reviews.



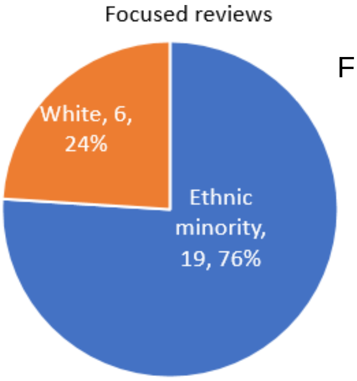


Figure 10

Performance analysis for adults' reviews

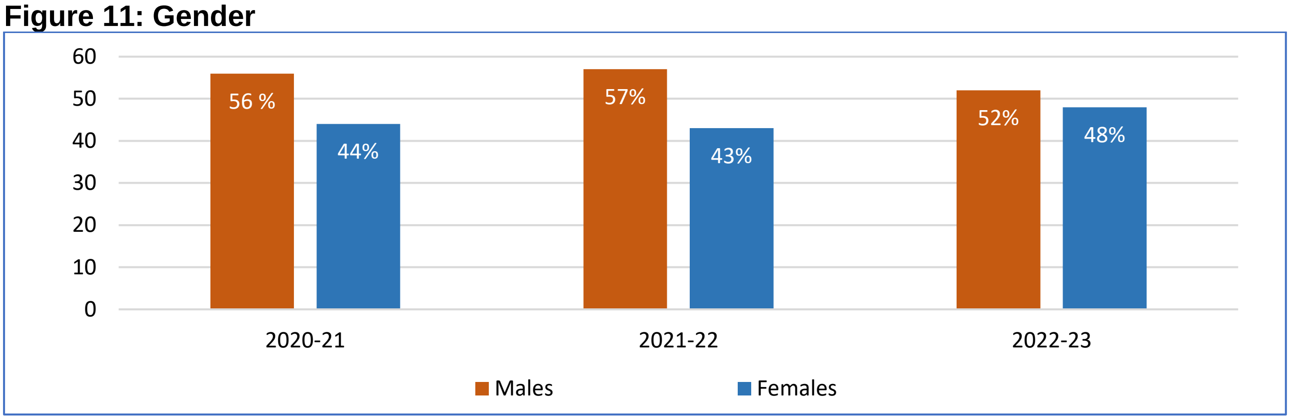
Out of the 88 notifications, 47 of these were received during the first half of the year. All these 47 reviews were completed as at the end of the year, achieving 100% on both allocation and completion, except those on hold due to statutory investigations. For more detailed analysis **about** NHS NEL ICS performance and matrix scoring against national targets, see appendix 1.

Demographics

Gender

This year's data has shown a 5% increase on the number of female deaths compared to the previous year. Overall, more deaths were recorded in males than in females and this was similar across London and nationally.

Figure 11: Gender



Age (all groups)

LeDeR covers people with a learning disability aged 4 years and above and persons over 18 years who have a formal diagnosis of autism. Over half, 52%, of the deaths recorded were of people aged 56 years and above; 24% were between 36-55; 11% were between 18-35 while 13% (8) were children aged between 4 and 17 years of age. The below table provides a comparison to last year.

Table 6: Age groups

	2021-22		2022-23	
Age groups	Numbers	Percentage (%)	Numbers	Percentage (%)
04-17	10	18%	8	13%
18-25	8	14%	4	6%
26-35	2	5%	3	5%
36-45	7	12%	6	9%
46-55	7	12%	9	15%
56-65	8	14%	11	18%
66-75	11	18%	15	25%
76-85	2	5%	4	6%
Over 86	2	5%	2	3%

Recorded age range from reviews was between 4 and 87 years; the median is 62 year, up from 52 years last year and the average age was 58 years compared to 56 years last year. There was a notable drop in the number of 18 to 25-year olds, from 14% to 6% this reporting period.

According to National statistics 2021, 85% of the general population died at age of over 65 years or over. From the above table, 36% of the people who died across North East London were aged 65 and over. This shows that a significant proportion of people with a learning disability living in North East London locality are more likely to die a lot younger compared to those without a learning disability.

Civil partnership (adults aged 18 years and over)

All completed adults' reviews were of persons aged over 18 years old. 84% were recorded as single, slightly lower than last year's data as shown below. 9 (16%) were married or had civil partnership or known to have been in a form of a relationship; 89% (8 out of the 9) of whom were known to have had a mild learning disability.

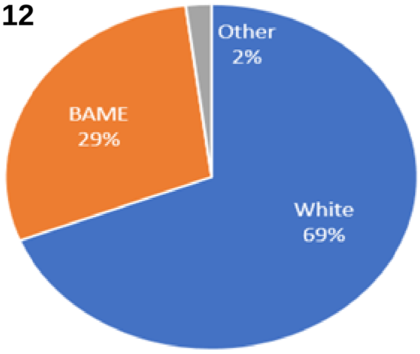
	2021-22	2022-23
Married/Civil partnership	13%	6 (11%)
Single (never married or known to have a relationship)	87%	45 (84%)
Had partners/were in a relationship	-	3 (5%)

Ethnicity

Information about ethnic groups was collected in all of the 62 completed reviews. 69% were of white background, 29% were from global majority groups while 2% preferred not to say their ethnicity or was not recorded. This data is very similar to last year's data which showed, 67% white, 28% ethnic minorities, and less than 3% other. The proportion in ethnicity data remained similar across London localities.

Ethnic group	Numbers
White	43 (69%)
Indian	4 (6%)
Pakistani	2 (3%)
Bangladeshi	4 (6%)
African	2 (3%)
African-Caribbean	3 (5%)
Other Asian	3 (5%)
Prefer not to say	1 (<2%)

Figure 12



Living arrangements of the people who died

Accommodation type	Persons	Percentage (%)
Family home	18	29%
Residential care/ nursing care	20	32%
Extra / Supported accommodation	18	29%
Independent/rented flats	6	10%

68% of people with a learning disability and autism lived with family, independently rented flats and in supported living accommodation. As their needs increased they were cared for in residential and nursing care settings. Most of those who were living in residential and nursing care were aged over 56 years.

Severity of learning disability

Review findings revealed that 85% (53) of the reviews completed had had a learning disability diagnosis, 13% were known to have had a dual diagnosis of both a learning disability and autism while only one (2%) had autism only diagnosis. The 61 persons known to have had a learning disability, were further analysed based on the level of severity of learning disability as shown below:

The most significant statistic shows an increase in the proportion of people known to have had a mild learning disability from 19% to 28% this year. A reduction of 3% was recorded on both those who were known to have had severe and profound learning disabilities compared to last year's record.

Levels of severity		
Mild	16	26%
Moderate	20	33%
Severe	18	29%
Profound/multiple	5	8%
No category recorded	1	2%

Table 7: severity of learning disability

Level of learning disability	NEL data: 2021-22	NEL data: 2022-23	National % (2021-22)
Mild	19%	28%	30%
Moderate	34%	33%	33
Severe	32%	29%	27
Profound	11%	8%	10
Not recorded	4%	2%	0

Place of death

67% died in hospital settings while 29% died in their usual place of residence compared to 56% and 32% in last year respectively.

Table 8: Place of death

Place of death (all ages)	2021-22		2022-23	
Hospital	26	56%	41	67%
Usual place of residence (own home/ family home/ paid accommodation)	15	32%	18	29%
Hospice	4	8%	2	3%
Other	2	4%	1	< 1%

Died in preferred place	8	13%
Not in preferred place	4	6%
No information to indicate their preference	50	81%

In 8 (13%) reviews, reveals that the person died in their preferred place or family's place of choice. They all had end of life care in place and they died either at their family home, hospice or long-term placements surrounded by family, friends and staff whom they had known for long. Four (6%) died in hospital which was not their preferred place of death.

Out-of-Area Placements for people with learning disabilities and autism

It is important that all adults with learning disabilities and autism experience meaningful and fulfilled lives. This means appropriate placement that meets their needs. There are varied reasons why learning disabilities and autistic people live away from home, family and friends. Some of these reasons include availability of beds spaces locally, funding, the person's needs, delayed discharges from hospitals and availability of suitable services to support the person's life choices.

Seven (7) people who died in Redbridge were placed from neighbouring London boroughs of Waltham Forest, Barking & Dagenham and Havering. Newham recorded three people placed in the area from Tower Hamlets while Barking & Dagenham recorded one person from Havering.

Pre-existing health conditions

The data used to inform this next chapters of this annual report was obtained from a smaller set of focused reviews, mainly people from ethnic minority backgrounds', therefore, comparisons between these periods and before 2020 annual reports, should be interpreted with caution.

As clearly demonstrated in Table 9 below most people with a learning disability and autistic adults have 2 or more pre-existing health conditions- physical health and/or psychological conditions. Over half, were known to have respiratory and heart related problems (including high blood pressure). Obesity was noted to be prevalent, 56%, and so was diabetes, 48%, increasing the risk of heart and circulatory disease.

Table 9: Summary of pre-existing health conditions

Health Conditions at the time of death	Percentage (%) 2020 - 21 (290)	Percentage (%) 2021-22 (19)	Percentage (%) 2022-23 (25)
Cancers	38 (13%)	4 (21%)	11 (44%)
Cardiac (heart related) conditions	48(16%)	8 (42%)	10 (40%)
Constipation (prescribed laxatives medicines regularly	168 (58%)	12 (65%)	13 (52%)
Dementia/ Alzheimer's	24 (8%)	3 (16%)	6 (24%)
Dental problems	158 (54%)	8 (42%)	2 (8%)
Diabetes (Type 1 & Type 11)	164 (54%)	11 (58%)	12 (48%)
Dysphagia, (swallowing problems)	152 (52%)	6 (32%)	6 (24%)
Epilepsy/seizures	168 (58%)	13 (68%)	10 (40%)
Falls (risk of falls)	175 (60%)	17 (89%)	14 (56%)
High blood pressure (hypertension)	150 (52%)	13 (68%)	15 (60%)
Hyperthyroidism & Hypothyroidism	72(25%)	3 (16%)	2 (8%)
Impaired mobility	181 (62%)	18 (95%)	17 (68%
Incontinence	108 (37%)	8 (42%)	16 (64%)
Iron, Vitamin D and B12 deficiency	142 (49%)	6 (32%)	11(11%)
Mental health needs	99 (34%)	10 (52%)	9 (36%)
Obesity	102 (35%)	14 (75%)	14 (56%)
Renal/ chronic kidney disease	64(22%)	8 (42%)	8 (32%)
Respiratory conditions/problems	174 (60%)	15 (75%)	14 (56%)
Sensory impairment e.g. hearing or visual problems or both	55 (19%)	7 (36%)	4 (16%)
Skin conditions and prescribed medication	207 (71%)	16 (84%)	15 (60%)
Swallowing problem (risk of aspiration)	xxx	xxx	5 (20%)

**Please note that this list of not exhaustive of all pre-existing health conditions.*

36% were known to local mental health teams and common recorded mental health problems or illnesses were paranoid schizophrenia, anxiety, depression, bipolar affective disorders, personality disorders, behaviours that challenge, psychotic episodes, agitation/irritability behaviours and hallucinations.

Over 85% of the people who died were known to have had limited communication or non-verbal and required support with communication. 52% had been treated for constipation and issued with prescriptions, while 60% had been prescribed medication for a skin condition.

68% were known to have mobility issues or at risk of falls, which means support with activities of daily living, appointments, accessing services but also provision of appropriate reasonable adjustments would be important to break the barriers and realise same health outcomes as those without a learning disability and autism or both.

Table 10: National data on top long-term conditions

Condition	London percentage 2021/22 %)	North East London %
Epilepsy	37 %	40 %
Mental health	28 %	36 %
Cardiovascular conditions	23 %	40 %
Sensory impairment	19 %	16 %
Swallowing problem or dysphagia	19 %	20%

Source: National LeDeR report 2021

From the above table 10, people with learning disability and autistic adults living in east London were more likely to have mental health and cardiovascular problems compared to the rest of London.

North east London locality is one of the most deprived localities in London. Office of the national statistics 2022, indicate that people living in deprived areas and with lower incomes have a higher risk of many diseases, including heart disease, diabetes and cancer. Same report indicate that the impact of deprivation is mostly felt by those in vulnerable groups. This risk is driven by reduced access to health care services and lifestyle factors.

Causes of death and avoidable mortality

Mortality reports have established a link between pre-existing health conditions and common causes of death across NEL and nationally. This section focuses on common causes of deaths locally and how this compares to national figures. Also, included in this section are common recorded avoidable deaths.

Cause of Death Certificate is set out in two parts:

I. Part I contains immediate cause of death, tracking the sequence of causes back to any underlying cause or causes.
II. Part II lists other significant conditions, diseases or injuries that may have contributed to the death, but were not part of the direct sequence leading to death.

The table below provides analysis of information obtained from completed reviews on the common primary and secondary causes of death across North East London. The top five causes of death were linked to respiratory problems, cardiac related problems or diseases, cancers, sepsis, and covid-19.

Table 11: summary causes of death and/or related conditions

Causes of death	Primary I (a) (b) & (c)	Secondary II
Respiratory related problems *(bronchopulmonary pneumonia, acute/ bilateral bronchopneumonia, bacterial pneumonia, hospital acquired pneumonia, aspiration pneumonia, chest infection, hypoxic respiratory failure, COPD, asthma)*	24	5
Cancers *(metastatic cancer of the colon, endometrial cancer, cancer of the spine, Prostate cancer, liver cancer, lung cancer, Pancreatic cancer stage 4, breast cancer, leukaemia)*	12	-
Heart related problems	12	-
Sepsis *(half of which were of unknown source)*	8	1
Covid-19 & covid- pneumonia	7	1
Kidney/renal failure	5	3
Cardiac arrest	4	-
Multi organ failure *(related to severe co-morbidity, septic shock, frailty, diabetes, high blood sugars)*	4	1
Epilepsy	3	6
Diabetes	2	-
End stage dementia/ Alzheimer’s	2	1
Frailty/Old age	2	6
Mesenteric Ischemia/small bowel infarction, bowel obstruction	2	1
Mixed drug toxicity	1	-
Myocardial Fibrosis and Anorexia	1	-
Known syndromes *(cerebral palsy, downs syndrome)*	-	4
Learning disabilities/ downs syndrome	-	6

LeDeR findings indicate that our two-thirds of all causes of death were linked to an existing or underlying health condition. Some of the certificates of death read learning disabilities or downs syndrome as a cause of death. These syndromes are commonly known as ‘life limiting conditions’, and are not part of the direct sequence leading to a person’s death.

Avoidable mortality

Avoidable deaths are those deaths that are preventable and or treatable.

Preventable mortality*:* Causes of death that can be mainly avoided through effective public health and primary prevention interventions (i.e. before the onset of diseases/injuries, to reduce incidence).

Treatable mortality: Causes of death that can be mainly avoided through timely and effective health care interventions, including secondary prevention such as screening and treatment (i.e. after the onset of diseases, to reduce case-fatality). Both indicators refer to mortality under age 75.

According to J Natl Med Assoc. 2022, below are some of the examples of preventable and treatable mortality.

Preventable mortality:
– asphyxia, choking, falls, drowning, aspiration pneumonia, covid-19, ischemic heart attack or stroke, diabetes, toxicity, anorexia, bowel obstruction, bowel perforation.

Treatable mortality: sepsis, bacteria pneumonia, infection, and some cancers, such as colorectal, prostate and breast cancers. All these causes of death can be avoided through timely and effective health care interventions

‘Avoidable death’ is a sensitive and debatable subject, however, these causes of death listed above were potentially preventable and/ or treatable if caught early.

National mortality date

National LeDeR report 2021, show that overall avoidable deaths have been decreasing year on year, from 54% in 2018 to 49% in 2021.

Table 12: Avoidable deaths (%)

Year	England
2018	54%
2019	52%
2020	50%
2021	49%

According Office of National statistics 2021, NEL records shows an average of 45% avoidable deaths, this is slightly lower than the national average, 49% and London 48%. The highest rates recorded was North West London at 54%, and the lowest was South West at 42%.

Although, there is evidence of reduced mortality nationally, reports indicate that deaths due to pneumonia, aspiration pneumonia, cardiac arrest and cancers amongst people with learning disabilities and autistic adults remains prevalent. Similar trends have been noted across North East London area.

Medical Examiners roles

LeDeR programme teams across England continue to evidence inaccuracies in the description recorded as cause of death. This report acknowledges that data collated from records may contain errors as a result of incorrectly completed certificates of death or notifications of death.

It is expected that all clinical staff are able to proficiently identify and correctly code causes of death under Part 1 and Part 11. To ensure appropriate training, support and that lessons learnt, the medical examiner offices were established in all acute trusts in England. Their role is to provide independent scrutiny of all non-coronial deaths and ensure certificates of deaths are correctly completed.

Medical examiners should also act as a contact point for the bereaved, providing an opportunity for families and carers to raise any concerns. NEL LeDeR programme team has established close working relationships with medical examiners across the footprint.

Grading of Care

On completion of all reviews, the quality of care of graded; below are our findings and the details of the grading descriptions. 48% of all completed focused reviews received excellent and good care and 4% received poor care.

Table 13: Grading of care

Grade	Description of care provided	2020/21 (92)	2021-22 (19)	2022-23 (25)
6	This was excellent care (it exceeded expected good practice).	1, <1%	0, 0%	3 (12%)
5	This was good care (it met expected good practice	2, 2%	1, 5%	9 (36%)
4	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's well-being).	7, 7%	2, 11%	6 (24%)
3	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.	30, 30%	7, 37%	4 (16%)
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	57, 55%	8, 42%	2 (8%)
1	Care fell far short of expected good practice and this contributed to the cause of death.	6, 6%	1, 5%	1 (4%)

Table 14: Grading of care verses severity of learning disability

Grading	Mild	Moderate	Severe	Multiple /profound	Total
1	1	0	0	0	1
2	1	1	0	0	2
3	2	2	1	0	5
4	2	0	2	1	6
5	2	3	3	1	9
6	0	1	1	1	3

It is clear people with mild and moderate learning disability were more likely to receive poor care compared to those with severe and multiple/ profound learning disability. Two thirds of the people who received poor care (grade 1& 2) were known to have had a mild learning disability. In one review, the care fell short of expected good practice and had impact on the person's health and wellbeing and may have contributed to the person's death. This review was escalated to a safeguarding adults review. No one known to have a mild learning disability received excellent care, grade 6.

Half, 50%, of those who received excellent and good care (grade 5&6) were known to have severe and multiple/profound learning disabilities. In one person with severe learning disability, the care fell short of expected standard (grade 3), this did impact on the person's wellbeing but did not contribute to the cause of death. Learning from this review was taken forward by the relevant care providers.

Also, evidence showed that good quality care was recorded on those on joint health and social care funding and continuing health care (CHC), most of whom were people with severe and profound learning disabilities and or complex health needs. No significant variation in quality of care noted based on type of accommodation.

All 37 initial reviews completed this year were not graded and the person's care was assessed as good or satisfactory and met expected good practice hence not progressed onto a focused review. This is not to say no learning came out of these reviews, of course there was, and these findings were appropriately feedback to the relevant care providers.

Main aspects of care provided to people with a learning disability

Annual Health Checks (AHCs)

Anyone aged 14 years and over and on a doctor's learning disability register is entitled to a free health check once a year. Annual health checks promote healthy living and wellbeing by identifying health issues early, organising referrals, reviewing medication and monitoring ongoing conditions.

Out of the 62 persons who had their care reviewed, 56 were aged 14 years and over and were entitled to annual health checks. Review conclusions indicate that 38 (68%) of those eligible had annual health checks within 12-18 months, 4 (7%) had annual health checks completed between 3-4 years back, before the pandemic, and in 12 (21%) no record of annual health checks found in the records made available to Reviewers. In 2 (3%) reviews, these persons were offered annual health checks but declined, no reasons provided for this.

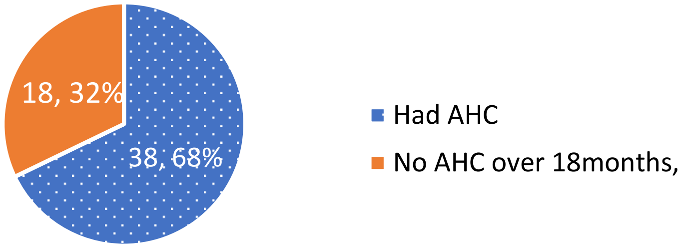


Table 15: Annual Health checks completed

Eligible for AHC	% AHC completed within12-18 months	% HAP updated/ created	Declined AHCs
56	38, 68%	14, 25%	2, 3%

According to Clinical Effective Group (CEG 2022-23) data by Queen Mary University, NEL has achieved 76% annual health checks uptake for over 18 years and 11% for ages under 18 years. The same data sources show that over 65% of all those persons who had annual heath checks also had medicines reconciliation or review.

Reviewers were also able to collected data on how these annual health checks were conducted. 37% (14 of the 38) were completed via telephone while 10 (26%) were completed face to face while the remaining 14 (37%) no evidence to confirm how his was completed.

Table 16: Mode of carrying out Annual Health Checks

Consultation type	Telephone/ video calls	Face to face	Not recorded
38, who had AHC	14, 37%	10, 26%	14, 37%

GPs are expected to carry out face to face appointments to complete annual health checks. Families interviewed during the LeDeR review process, felt that telephone annual health checks were unsatisfactory, GPs were not able to carry out important physical examinations or observations and depended on non-clinical people, carers and family members to provide clinical information.

GPs should complete health action plan at the end of each annual health check. Of the 38 people who had annual health checks, less than half, 14 (37%) had their health action plan completed and/or updated. Without seeing copies of these action plans, it was not possible for Reviewers to comment on their quality. Most of the carers interviewed were not aware whether a health action plan was completed or not.

Although this year's data shows an increase in annual health checks uptake from 57% last year to 68% this year, no person aged between 14-17 years had annual heath check completed. Anyone aged 14 years and over and has not had annual health check, it is advisable to contact your GP for an appointment. More is needed to improve uptake starting.

Although some progress has been recorded indicating increased uptake of annual health checks, further work is required to attain the trajectory set by NHSE of 75% of individuals aged 14 years and over. Annual health checks are an important tool in enabling intervention before issues become more serious.

Mental Capacity Act and Mental Health Assessments

Every adult has the right to make their own decisions and must be presumed to have capacity unless it can be proven otherwise. An individual must be given all practicable help to make their own decisions. Every adult has the right to make what, to other people, may seem like unwise decisions.

Appropriate application of the Mental Capacity Act and assessments is important. Assessing one's capacity helps provide input in different processes and may support interlinked decisions and choices. It helps make sure that people who may lack capacity to make some decisions, about their care and treatment on their own, are empowered, protected and supported to do so. Best interest is applied as needed. https://www.scie.org.uk/mca/

All focused reviews required the Reviewer to complete mental capacity assessment (MCA) questions. 20 (80%) of focused reviews completed had MCA completed and 5 (20%) did not have MCA. 2 (3%) reviews MCA was considered but not progressed. Majority of these reviews were of people from minority ethnic background and not representative of the overall reviews completed.

Information collected about mental health conditions and illness showed that, 8 (32%) of the focused reviews were known to have had a mental health illness or mental health problem and all had MCAs completed. They were all on prescribed antipsychotic medications for over five years. Four people had a formal diagnosis of mental health illness but no evidence found in records provided to indicate if these people had been seen by a mental health professional, for review, in the last five years. It is also possible that poor record keeping may have contributed to this.

In reviews where MCA was not completed, Reviewers felt that some of these people could have benefited from MCA and best interest assessment, especially where the person was declining care and/or non-compliance with medical or social care support plans. Professional should ensure that the person understands the consequences of their decisions and best interest applied where indicated.

Though some reviews have identified demonstrated good knowledge and understanding of mental capacity act and good application of best interests of the person, it is clear from other reviews completed that further work is required and in particular relating to:

- Mental capacity compliance
- Documentation of mental capacity assessment
- Documentation of Best Interest decision making
- Involving the person as decision making once an individual is over the age of 18 years.

Deprivation of Liberty Safeguards (DoLS) and Liberty Protection Safeguards (LPS).

Deprivation of liberty safeguards (DoLS) is part of the Mental Capacity Act. The purpose is to protect the individual's rights when receiving care or treatment in a hospital or care home and lack mental capacity to consent to those arrangements https://www.scie.org.uk/mca/dols.

Half (10) of all those who has MCA assessments also had Deprivation of Liberty Safeguards (DoLS) applied and implemented to provide legal protection for vulnerable people who are, or may become, deprived of their liberty while in these settings. These were reviewed regularly.

In July 2018, the Government published a Mental Capacity (Amendment) Bill which will see DoLS replaced by the Liberty Protection Safeguards (LPS). LPS is expected to create a new simplified legal framework that is accessible and clear to all affected parties, and that puts the person at the heart of decision-making process.

On 5 April 2023 the Department of Health and Social Care announced the implementation of the Liberty Protection Safeguards (LPS), the Mental Capacity (Amendment) Act 2019, will be delayed.

Source: https://www.scie.org.uk/mca/lps/latest/Oct2022

Weight management (being underweight or overweight)

Out of the 62 completed reviews, 12 (19%) within normal range while 22 (35%) were classified as overweight and/or obese. 18 (29%) had no record to indicate if they had had their weights taken or monitored. The proportion of people classified as underweight has also gone up from 11% to 16% this year. Recommendation was made around staff to monitor weights and make appropriate referrals as indicated.

According to NHS digital 2021, The proportion of people with a learning disability receiving body mass index (BMI) checks has increased from 58.3% in 2017 to 61.5% in 2022. Of those who received BMI checks, 6.4% were classified as underweight (BMI ≤18.4) compared to 4.9% of those without a learning disability. 37.5% were classified as overweight and obese compared to 29.9% those without a learning disability. (NHS Digital, 2021).

Table 17: Weights (BMI data)

	Unknown	Underweight (<18.4)	Normal weight (18.5-24.9)	Overweight (25-29.9)	Obese (>30)
2020/21	17 (36%)	7 (7%)	23 (25%)	13 (14%)	32 (35%)
2021/22	17 (36%)	5 (11%)	9 (19%)	5 (11%)	11 (23%)
2022-23	18 (29%)	10 (16%	12 (19%)	16 (26%)	6 (9%)

NEL has recorded a decrease on the number of people classified as obese and an increase on the number of people recorded as overweight this year. NEL has reported on a number of local initiatives, health living and projects, aimed to improve health and wellbeing of the person and reduce obesity amongst people with a learning disability and autism. It is not clear at this stage if this is linked, in anyway, nonetheless we will continue to monitor this.

According to Queen Mary University- Clinical Effective Group data (CEG 2022-23), more patients are now being weighed. Reviewed records indicate that carers were being asked to support this element and information feedback to GPs. Over 60% of those who had annual health checks, records show they had their nutritional status/diet and level of physical activity was assessed and information about health living provided as indicated.

Flu Vaccination

Flu vaccination is for all those ages 6months and over and in one or more of the clinically risk groups. All people with a learning disability and autism are eligible for flu vaccination.

Table 18: Flu vaccinations

Flu vaccination	2020-21	2021-22	2022-23
% uptake	45%	61%	79%

There is evidence of improved uptake since 2021 from 45% to 79% this reporting period. This report recognises the small data set used over the last two annual reports, hence these results should be treated with caution.

The national target is 75%, however, there are no ground whatsoever for complacency. The risk for serious illness if one is not vaccinated is still there and all eligible groups should be encouraged to continue regular flu vaccination.

DNACPR (Do not attempt cardio pulmonary resuscitation)

A DNACPR decision is put in place to protect people from unnecessary suffering by receiving cardiopulmonary resuscitation (CPR) that they don't want, that won't work or where the harm to them outweighs the benefits.

According to NICE guidelines, DNACPR decision must be made on an individual basis. Clinical staff should always take account of the benefits, risks and burdens of CPR but also consider the individual person's wishes and preferences, the views of the healthcare team and, where appropriate, those close to the person. Hospital trusts and other providers are legally obliged to have a clear DNACPR policy for staff to follow. It must be accessible to patients and/or their families to support them understand the decision-making process.

Reviewers acknowledge that many of the DNACPR documentation and decisions were appropriately completed in the person's, best interest. 61% (38) of the people who died had DNACPR in place before they died while 34% (21) did not have DNACPR in place. Staff and most families were involved and explained the rational for making this decision.

Three of the DNACPR documents were noted to have been completed inappropriately; in one review the DNACPR form was signed by one doctor. It is expected that a DNACPR is signed by two doctors. In the other two reviews, the reasons given for a DNACPR was the person had a learning disability and co-morbidities; this was challenged by the family, supported by staff, and the DNACPR were removed or withdrawn. Clearly, this is unacceptable.

Inappropriate use of DNACPR, including poor clinical decision-making, could be unlawful under the Equality Act 2010 if the decision-making is based on the protected characteristics of age and disability.

The NHS is clear that people should not have a DNACPR on their record just because they have a learning disability, autism or both. The terms "learning disability" and "Down's syndrome" should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death. these conditions are not fatal conditions, NHS digital report, 4th March 2021.

Recommendations made were:

- Doctors to provide accurate recording of DNACPR orders
- Documents to be signed by two doctors as per guidelines
- A capacity assessment should be completed around treatment and escalation plans including ceilings of care. Where the person has capacity, these decisions should be made clear; the person can refuse resuscitation and this should be respected.
- Independent mental capacity advocacy services (IMCA) to be involved, as required, to support the person during this very difficult time.
- The person's best interest to be at the centre of this decision.
- Staff training around having difficult conversations (such as DNACPR and end of life, PEACE Plans), involving the person and or family and where possible.
- A copy of the DNACPR policy, for information, to be made available to families if requested
- Learning disability or other syndromes not to be listed as reasons for a DNACPR decision
- Recognition and earlier decision making which may avoid individuals being transferred to hospital within their last days of life.

Advanced planning or End of life care

End of life care is support for people who are in the last months or years of their life. The aim is to ensure a person receives high-quality care, live as well as possible and die with dignity. It involves thinking and talking about their wishes and preferences.

This could be at home, in a care home, hospice or in hospital, depending on your needs and preference. It is important to ensure that these choices are recorded and applied where appropriate.
Source: https://www.nhs.uk/conditions/end-of-life-care/

60% (37) of all adult reviews had an end of life care plan in place before they died. The period varied from a few hours to a few months. More than half (19) were put in place during the last hospital admission. In 4 (6%) reviews, the person died before the plan could be implemented. 88% of the children were on end of life care, this had been discussed and agreed with their families.

This report recognises that end of life conversation is not an easy subject to hold with families and the person. Reviewers suggested staff training about end of life conversations, to include carers. Working closely with end of life teams and IMCA services for support to ensure people are given the opportunity to participate but also express their wishes when they are able to do so.

Reasonable adjustments (all ages)

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) reviews showed lack of reasonable adjustments (especially in accessing clinic appointments and investigations) as a contributory factor in a number of avoidable deaths.

A lack of reasonable adjustments can be a barrier to accessing healthcare settings and poor health outcomes. Healthcare professionals have a legal duty to provide reasonable adjustments for disabled people. This includes providing information in a format suited to the person (translation and interpretation services, easy-read information, text messaging, avoiding medical jargon), longer appointment times, home visits, home adaptations and suitable support equipment.

Source: (Ali et al., 2013; Heslop et al., 2013).

Almost all people with a learning disability and autism need support in accessing service in one way or the other. They are known to have problems with mobility (some are wheelchair users), visual or hearing impairment, sensory needs and or poor communication. It is everyone's responsibility to provide reasonable adjustments to all those who need this. Quality assessments to identify support needed is very important to ensure access to services and equitable health outcomes.

65% of all completed reviews indicated that the person had been provided with the appropriate reasonable adjustments including home visits, domiciliary phlebotomy services, mobility equipment, good care packages, long appointments and in some cases priority when attending clinics.

In 10% of the reviews, Reviewers highlighted areas where they felt may have impacted on the health and wellbeing of the person and /or carers and in some reviews, this may have contributed to avoidable deaths.

Some of these poor practices included:

- inappropriate mobility equipment (wheelchairs not suited to the person's needs)- in one case the carer was unable to propel the wheelchair to attend clinic. The wheelchair had not been serviced or checked for several years. On one occasion the doctor is said to have attended the patient from the family car.
- delays in home adaptations- in one review the person had waited for over a year to get a lift installed to access upstairs bedroom.

- poor discharge planning; in one review a patient was sent home without appropriate equipment (i.e. a pressure mattresses) and in another review, the patient was transported home before his night care package was in place as agreed.
- not providing information in a format suited to the end user (easy read information) which could have led to missed appointments or low uptake of screening programmes
- not providing interpretation and translation services, hence requiring family members- or friends to provide this service.
- rushed consultations – patients not being provided enough time, long appointments, to express themselves but also the professionals not taking time to ensure they understand the person’s condition
- some professionals (commissioned or contracted to provide home visits) not offering home visits for people with poor mobility
- online appointment booking systems and the blanket assumption that this suits all
- virtual or telephone consultations- clinical staff making decisions without carrying out observations and examinations on the person, a system that is heavily relying on carers for clinical decisions
- some professional, where these services are put in place, not using IMCA services to support patients with key decisions making especially end of care and DNACPR.

National Cancer screening programmes

Breast, prostate and bowel cancers accounted for almost half (49%) of all new cancer cases in the UK. More than a third (36%) of all cancer cases are diagnosed in people aged 75 and over. Incidence rates for all cancers combined in the UK are highest in people aged 85 to 89.

Incidence rates for all cancers combined are lower in the Asian and Black ethnic groups, and in people of mixed or multiple ethnicity, compared with the white ethnic group. Prostate cancer, incidence rates are higher in males of the black minority ethnic group compared with males in the white ethnic group.

Source: British Journal of Cancer volume 126, pages1765–1773 (2022)

a) Bowel cancer screening programme

NHS bowel cancer screening checks for bowel cancer. It is available to everyone aged 60 to 74 years. The bowel programme is slowly expanding to ensure everyone aged 50 years and above will be eligible to receive bowel screening home-test kit by 2025.

24 persons aged over 60 years old were eligible for bowel screening. 8 (33%) had screening done while 11(46%) declined or did not return their testing kit.

Table 19: Bowel screening uptake

Eligible persons, aged >60yrs	% uptake	Did not return kits	No information to indicate if they send kits or not
24	8, 33%	11, 46%	5, 21%

This clearly shows that NEL screening performance of 33%, (slightly up from 31% last year). Reports recorded by Queen Mary University, CEG group shows that 37% of people with learning disability living in North east London had bowel screening. This is very low compared to the general population uptake record at 70.3%. NEL has recruited health improvement specialists to work with people with learning disability and care providers to create awareness and improve bowel screening uptake.

b) Cervical screening

Cervical screening is for women age 25 to 64 years; this is offered every 3 years up to the age of 49 years and every 5 years from age 50 to 64. This is because most cervical cancers develop between these ages. First invitations arrive a few months before people turn 25.

Information gathered from LeDeR reviews indicated that 10 females were eligible for cervical screening; 3 (30%) had cervical screening done, 50% (5) declined while in 2, 20%, no documentation to show if they had had it or not. There was a small movement recorded from 18% last year to 30% this year.

This figure is similar to Queen Mary University, CEG group 2022-23 which shows that 37% of people with learning disability living in North east London had cervical screening. Again, this proportion of uptake is lower than London uptake of 64%.

Some of the reasons recorded for declining cervical screening were that the person was not sexually active and or cultural or religious reasons. There is need for families and carers to be educated to understand being sexuality active increases the risk of cervical cancer but does not take away the risk. However, for a small number of individuals known to have profound and multiple learning disabilities and complex body curvatures, best interests' decisions need to be considered.

c) Breast screening programme

Women aged 50 to 70 are eligible for breast screening programme. From completed reviews, 16 females were eligible for breast screening, 6 (37.5%) had mammograph done while 2 (12.5%) were offered but declined. This number is similar to Queen Mary University, CEG group which showed that 37% of people with learning disability living in North east London had breast screening.

Although, NEL LeDeR data show an increase in uptake from 7% last year to 37.5% this year, this is still low compared to those without a learning disability and autism, in London where records show 50.4% uptake.

According to NHS Breast Screening Programme, England 2021-22 report, 62.3% attended screening appointments (within six months of invitation)– a slight increase on the previous year, (from 61.8%).

Uptake was highest in the South East of England at 67.7% ***and lowest in London at 50.4%.***

Mobile Units

LeDeR programme recognises that mobile clinics have provided breast screening access to many women, however, there are some challenges for people with a learning disability and autism:

- limited options for their siting space due to the size of the mobile unit
- lack of amenities for staff and women attending screening such as accessible toilets and changing spaces.
- limitations on the timings and duration of visits imposed by organisations that own these sites

For those caring for people with a learning disability and autism, it is always advisable to speak with the nurse or doctor if nervous about screening who can talk through any questions or concerns one may have. The nurse or doctor should put in place reasonable arrangements to help you feel more confident and comfortable and or refer to appropriate teams or services for support as needed.

d) Prostate Cancer Screening

Prostate cancer screening is not a national screening programme but it is recommended for males over 55 years of age. Research findings by Cancer UK, show that prostate cancer is the second most common cause of cancer deaths among males worldwide. Prostate-specific antigen (PSA) test is a blood test that measures the amount of prostate specific antigen (PSA) in blood. A raised PSA level may suggest a problem, but not necessarily a cancer.

General guidelines recommend PSA testing from ages 55 to 69, however a person can request a PSA test earlier between the ages of 40 and 54 if:

- there is immediate family history of prostate cancer (father or brother, has had prostate cancer)
- at least two extended family members who have had prostate cancer
- are African-American, an ethnicity that has a higher risk of developing more aggressive cancers

LeDeR review findings shows that 12 males were eligible for prostate screening, 1 (8%) had screening and two (17%) were offered and declined; no reason given and no evidence of discussions to explain to the person why this is important. Two people were recorded to have had prostate cancer, both were of white background and no record indicating that they had had prostate screening before diagnosis.

PSA testing rates have increased from 1.4% in 2019 to 11.3% in 2021. PSA testing has remained low, and information gathered so far do not appear to reflect a need to change the current policy to consider prostate screening as a national screening programme.

It is important people are made aware of the advantages of earlier diagnosis and the positive news about high survival rates for prostate cancer. According to Cancer UK, more than 95 out of 100 (more than 95%) will survive their cancer for 1 year or more. More than 85 out of 100 (more than 85%) will survive their cancer for 5 years or more. Almost 80 out of 100 (almost 80%) will survive their cancer for 10 years or more.

Why most people do not access national screening programmes

There are lots of reasons and considerations why people might not want to come forward for screening. Whilst most of these reasons may apply to general population, they are most felt by people with a learning disability and autism. These may include:

- cultural/traditional and religious barriers; norms and traditions practiced by their families, and expectations
- health system barriers; factors in the design, function and implementation of health systems that make it difficult for some individuals to access, especially those that require provision of reasonable adjustments to benefit from these services. For example, mobile units.
- an informed decision not to attend or not thinking they are at risk of cancer.
- not understanding the information that has been sent to them (not user friendly)
- fear, both of the possible pain caused from the procedure and of cancer
- structural barriers associated with anxiety or stress
- embarrassment or modesty or apathy towards attendance
- accessibility issues (not user-friendly) and fixed timings

How can we improve attendance to screening programmes?

i. Provision of reasonable adjustments: Understanding the needs of people with a learning disability and autism helps provide them with facilities and support they need to attend these clinics.

ii. Understanding your population: It is important to know your population and provide information resources that is appropriate and suited to their needs such as alternative languages rather than English, and working with community groups to further understand cultural and other barriers to attendance.

   People with learning disability needs to be supported to understand the importance of participating in screening programmes.

iii. Screening services should ensure screening clinics are held in accessible places with facilities but also changes to policies, procedures and staff training to make sure the service works equally well for all people including those with physical, learning disability and autism.

Covid-19 Pandemic

In 2020 covid-19 was recorded as the top leading cause of deaths for people with a learning disability and autism, accounting for 22% of all deaths nationally. NHS NEL recorded the highest number of deaths, almost twice as many deaths, compared to the numbers reported before the pandemic.

Research has shown the vaccines help reduce risk of getting seriously ill or dying from Covid-19. The proportion of deaths due to Covid-19 has significantly decreased. However, we continue to record a small number of Covid-19 related deaths either directly or Covid-19 contributing to the cause of death.

Reviewed information continues to evidence that a greater proportion of males than females with learning disabilities died from Covid-19. NHS NEL LeDeR annual report 2020 data reported similar trends; more males died from Covid-19 compared to females. This year's report findings indicate, 4 (58%) out of the seven covid-19 related deaths were males.

Covid-19 has continued into 2023 impacting on the lives and deaths of the entire population, including people with a learning disability and autism who continue to be affected in multiple ways.

Covid-19 vaccination

Covid-19 vaccinations is also referred to as SARV-CoV2 (where SARV stands for severe acute respiratory Syndrome). It is aimed to reduce the risk of people getting seriously ill or dying from Covid-19**.** 46 (74%) of all persons whose care was reviewed had had 2 or more of the covid vaccinations. 2 people had had one dose of covid vaccination; 4 people declined the vaccination. They were all noted to have significant needle phobia. Recommendations were made around systematic desensitisation to break the cycle of worry and support them to gradually cope with their fears and access treatment.

NHS England data, December 2022, the 88.9 % of all eligible adults received Covid-19 boosters, (https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-vaccinations/).

50% (26) of reviewed cases received covid booster in 2022. This figure is significantly lower than 88.9% recorded nationally on those without a learning disability and autism.

This year's report has recorded 8 deaths linked to covid-19 or where Covid-19 contributed to the cause of death. In one review, the person declined vaccination and died of covid-pneumonia. In all the other six deaths, the persons had had 2 or more of covid vaccinations.

Covid-19 is still circulating within the community and remains a risk. It is still possible to catch and spread Covid--19, even if you are fully vaccinated.

Research findings indicate that people with learning disabilities and autism are extremely vulnerable to the effects of SARS-CoV-2 infection. They are five times more likely to be admitted to hospital and eight times more likely to die from Covid-19. Inaccessible health facilities and health information, poorly trained health staff, not following public health advice are some of the failings that make people with intellectual disabilities clinically vulnerable to Covid-19. By understanding the risks, and making safer choices can help reduce the risk of catching or spreading Covid-19 in the community.
source: https://www.scie.org.uk/care-providers/coronavirus-covid-19/

Use of Urgent care and Emergency Departments by people with a learning disability and autism

People with learning disabilities are more likely to have a wide range of physical and mental health problems, hence more likely to attend Emergency Departments or Urgent care centres than the general population. Information gathered from completed reviews, showed that people with learning disabilities and autism attended Emergency Departments, on average 4 times, in some reviews the persons attended more than 10 times, during the last 3 months of their life.

LeDeR programme has recorded lots of good practices about our acute services, Emergency Departments as well as urgent care centres. In some reviews, the care provided was above expected standard, there was evidence of good clinical care and outcomes once seen and well-planned care on the wards.

There was evidence of excellent liaison and support provided by acute learning disability and autism nursing teams. some families reported excellent communication and support during end of life care and positive bereavement support.

During the pandemic, continuity of care was crucial; some services were delivered virtually (via video or by telephone). After the pandemic, virtual consultations seem to continue despite the drive to get back ‘to normal’.

Review findings show that most GPs continue to provide virtual and/or telephone consultations and this has been noted as inadequate as examinations and observations cannot be done online, increasing the risk of missed or wrong diagnosis. This has resulted to many attending Emergency Departments and Urgent Care centres for face to face consultations.

Due to high demand for Emergency Departments and Urgent Care services, the waits are too long; most departments have restricted spaces putting huge pressure to both staff and patients. High workload and time pressure have reduced the attention devoted by clinical staff to ‘safety-critical tasks’, thus creating conditions for errors and increased likelihood of serious consequences.

Example: Patient X
X was 65 years old, attended Emergency Departments three times within 8 days. Presenting complaint was abdominal pain. Records show observations were done, bloods taken and the results were unremarkable, treated for constipation and discharged home, twice, with a plan to return if symptoms do not improve. On the 3rd attendance, an x-ray was considered but this was not done because X was agitated after a long wait, Record reads “patient not cooperating, cannot stay still.” ? learning disability”. Again, discharged home.

Two days later, X was found on the floor by staff unconscious (unwitnessed fall), he was brought to emergency department via ambulance for his fourth time in 8 days. Working diagnosis; ? query sepsis. An x-ray was requested which revealed a twisted perforated bowel. At this stage, X was too unwell, and passed away a day later. Cause of death (1a)- Bowel obstruction. This was considered as ‘avoidable death’.

Communicating with people with learning disability and autistic adults

LeDeR findings indicate that, the quality of patient-care provider communication varied depending on level of learning disability and support available. People with severe or profound learning disabilities are less likely to receive crucial elements of effective patient-provider communication such as detailed explanations on subsequent treatment steps or side effects of medication prescribed, compared to those with mild learning disability. This is because information is usually directed to a family member or carer, the later may not be the usual carer who knows the person well.

Communication barriers can make diagnosis and even the recognition of symptoms more difficult. Review findings indicate that hospital staff reported difficulties when dealing with patients with learning disabilities and autism due to reservations, a lack of experience with or ignorance of this group of patients. In some cases, reservations manifested in reasons given for the omission of examinations or treatment for patients with severe or multiple disabilities in which judgments about their quality of life become apparent. Some of the reasons given by staff would be, “patient declined or refused care or not cooperative” and this is independent of the patients’ individual will.

Without doubt, it takes time and patience to get quality information from patients with learning disabilities and autism; however, without this information, clinical teams are more likely to misdiagnose these patients and/or often resulting to delayed diagnosis, some with fatal consequences.

Evidence show that most emergency departments and urgent care centres do not have accessible information suited to people with a learning disability and autism, for example- an easy read registration document. Often, no support is readily available for carers whose English is not first language, resulting to families being supported by relatives and/or friends. Where translation and interpretation services were requested, these took long to arrive or did not turn up at all.

There is no evidence to indicate that most people who attended emergency departments and or urgent care centres presented with an hospital passport. Use of urgent care plans or hospital passports is recognised as useful tool in understanding the person’s needs, medications, allergies, medical history as well as mode of communication; especially when the person is accompanied by a carer who is not the person’s regular carer.

Recommendations were made around close working relationships with hospital learning disability nurses; providing suitable reasonable adjustments including information in formats that are suited to the person such as pictorials and/or easy read; longer appointments as well as provision of translation and interpretation services to support families as needed. Also, carers should ensure they bring hospital passports with them while attending hospitals appointments and or emergency departments to aid delivering of the right and effective care.

Online Universal Care Plan have been reported as a very useful tool and working well. They bring together multiple electronic patient records, personal health records, or electronic palliative care coordination systems in standardised data fields and is accessible to all emergency departments and urgent care services. It is based on the openEHR standard health record, a tool used to pull together patient information, and enables sharing with different services or teams. Universal Care Plans are easy to update and provide more accurate information about the person.

Diagnosis overshadowing, Behaviours that challenge and Pain Management

Emergency Departments and Urgent care centres are mostly busy, crowded and noisy. As we all know, busy crowded areas can cause people with learning disabilities and autistic adults to be anxious and trigger behaviours that challenge. LeDeR Reviewers recognises that behaviours that challenge and pain management can be so intertwined, making it very difficult for emergency staff to deliver the appropriate care and often some tests or examinations may not be done or carried out to help reach a conclusive diagnosis.

Diagnostic overshadowing can occur when healthcare professionals assume that a behaviour is related to a learning disability rather than a real problem. In some reviews there was evidence assumptions and judgements were made based on the ‘learning disability’ element and not the person. For example, in one review, the person was restless, pacing up and down holding his tummy, this was believed to be a ‘symptom of a learning disability’, rather than a sign of distress or pain.

The above example and many more indicate that anxiety and behaviours that challenge are more likely to be associated with a learning disability and not related to pain or a new physical problem that may require detailed assessment or consideration.

Reviewers suggested clinical staff should undertake detailed assessments on people with learning disabilities to ensure they pick up any unidentified physical health issues. They should not assume change in behaviours, which could be an expression of indeterminate pain, is primarily due to learning disability or autism or dementia.

Also suggested was, services to ensure staff complete the mandatory learning disability and autism training to improve their understanding of the needs of people with a learning disability and autistic adults. Appropriate referrals for one-to-one practical advice and emotional support (positive behavioural services) or further assessment or treatment, such as cognitive behavioural therapy, talking therapy, psychodynamic therapy or medication prescribed as may be indicated.

Emergency Departments and urgent care centres have long waiting times. Most people with learning disabilities have complex health needs requiring regular pain management or some have difficulties sitting long hours or at risk of pressure sores.

People with learning disabilities find it difficulty or struggle to express feeling unwell and clearly verbalise their levels of pain or site of pain. They talk about anxiety different to how people without a learning disability do. Some describe physical feelings rather than using words we often associate with anxiety such as ‘anxious’ and ‘worried’. They could say words such as – ‘I do not want it’ or ‘shooting’ to describe pain.

The common tool used to assess pain is ‘on a scale of 1-10 how do you rate your pain’. Whilst this may work for some people it is a challenge for most people even those without a learning disability, as different people will have different pain thresholds. This calls for a special consideration when assessing pain in people with learning disabilities and autism.

Suggestions were made around, staff ensuring patients do not suffer pain while waiting for treatment. Making courtesy calls or quick rounds every so often to check if the person is in pain and make then comfortable, volunteers have played a key role in these circumstances. Important, considerations should be made to see this group of patients quicker.

Unsafe discharges from hospitals

A failed discharge is realised when the person’s condition suddenly worsens when released from hospital, and or return to the hospital shortly after discharge (within 48hours). Below are some of areas Reviewers identified as ‘a failed discharge’:

- when the person is sent home before all the test results are reviewed, resulting to incorrect diagnosis
- absence of appropriate care package and or follow up care plans to support the person at home
- taking incorrect history of the person and poor documentation
- when the treating team does not fully understand the extend of the person’s medical condition, discharge home when the person still needed ongoing hospital support
- missed symptoms indicating the persons condition is worsening or the person is at risk of an adverse medical event if released from the hospital or errors suggesting that the person’s condition has improved when this is not the case
- not involving the person who knows the unwell person well, a regular or main carer.

In some of the failed discharge cases, Reviewers could not find evidence of MDT approaches, nor capacity assessments and application of best interest recorded. Reviewers recommended a wholistic assessment and senior clinical review to certify ‘medical fitness to discharge’ before sending home a person with learning disabilities or autistic adults or both. The discharging team to ensure follow-up information is clear and easily understood.

Mental capacity assessment is important to identify areas of support and where appropriate, involve IMCA to support the patient and family was also recommended. Application of best interest for those who lack capacity should be at the heart of clinical practice.

Table 20: Areas of good practice and areas needing improvement

✓ Good practice gathered from completed reviews	✗ Reviewers recommendations on areas needing change
Good quality annual health checks and heath action plans. Fit for purpose health action plans to support people on varied health and social care issues	Improved quality annual health check to pick up unidentified problems -meaningful health action plans. -face to face to consultations -more health facilitator roles/ nurse practitioners to support GPs with Annual health checks audits and uptake starting 14 years. -Proactive approaches to follow up missed appointments and delayed referrals
Excellent provision of reasonable adjusted tailored to the person/ home visits/ environment adaptations.	
Evidence of good understanding and applications of Mental capacity act- good quality mental capacity assessments (specific to task), DoLS and application of best interest within acute teams and some community teams	Clinical teams taking a deep dive into avoidable causes of death to learn more
	Closer working relationships between health and social care teams/ information sharing
	Fit for purpose quality assurance process for implementation of MCAs and more use of IMCA services
Good communication between professionals, families and service user	Accessible and appropriate services to support autistic people post diagnosis.
Positive culture of continual learning across services	Improved documentation, patient records, to support delivery of care; accurate recording of causes of death and SJRs.
Good liaison between acute learning disability teams, families and community teams	More targeted and proactive campaigns to increase uptake of cancer screening programmes
Some GPs going up and above to provide home visits, care coordination, long and flexible appointments, regular medical reviews and health and wellbeing advice.	More patients supported to access regular antipsychotic reviews and support offered to stop overmedication where appropriate
Some very good care packages and social care reviews meeting the person's health and social care needs.	MDT approaches and wholistic assessments/reviews to inform fit for discharge hospital process
Multidisciplinary meetings to support patients with complex care needs, including safe discharges.	Closer working relationships with end of life care teams to support advanced care planning when one is able to do so.
Appropriate and effective application of process and protocols such as DNACPR, patient pathways, referrals and fast tracking of cancer patients	DNACPRs are correctly completed and the right clinical reasons provided and not learning disabilities or a syndrome.
Excellent care provision at end of life of the person, family and staff bereavement support	Provision of bereavement support to people with learning disability and autism when they lose their family members and or close or long-term friends

Lived Experience

Case 1: An example of good quality of care

PP was 76 years at the time of her death. she was known to have moderate learning disability, down syndrome, from early childhood, hypertension and poor vision. PP had history of difficult and challenging behaviour but this was well managed. She enjoyed going on regular holidays, visited Disneyland Paris, Spain, she was very social and liked visiting the local pub. PP was supported to attend day centres, day trips and to travel abroad.

Later PP was diagnosed with Chronic Kidney Disease stage 3, Epilepsy, Alzheimer's and Osteoporosis. She received regular reviews from psychiatry team, neurology team, and received physio support with her transfer equipment and a specialised wheelchair. An epilepsy care plan was in place and was followed. It is recorded that the epilepsy nurses' number was provided to the carers for support as needed. PP was supported to attend all clinic appointments and annual health checks.

Records show evidence of regular MDTs to discuss PP's dementia, health and wellbeing and deterioration. She had an advocate, social worker, GP, care manager and a trustee, all attended MDT meetings. The social care team tried to move PP into a nursing home when she was put onto an end of life pathway. The care manager, the advocate and the trustee all agreed it was in PP's best interest to remain in her residential care home and have end of life care come to her.

Arrangements were made to ensure PP remained in her residential care with 2 waking night staff on shift. Her GP visited her on a weekly basis, sometimes as requested, and she was kept comfortable up to her death. Staff were provided with bereavement support following her death. PP's care manager believes she had a very peaceful and dignified death and in a place of her choice.

Grading of care was excellent. There was clear evidence of good care coordination and support systems; MDTs, care plans, application of the Mental Capacity Act and her wishes were considered and services involved all the people who knew her well. PP was provided with personalised reasonable adjustments including wheelchair and transfer equipment. PP died with dignity at her home, surrounded by the people/ staff who knew and cared for her.

Case 2: An example of care that fell short of expected standard

PS lived with his family, last born in a family of five siblings. He was known to have had severe learning disability, history of complex health needs; severe depression, high blood pressure, dyslipidaemia, diabetes, asthma, COPD and epilepsy. His main carer was his mother who was also known to have health problems. Some records state he had autism traits, but Reviewer found no evidence to show PS had a formal diagnosis of autism.

During the last 3 years, PS presented with sore throat and chest infections eleven, (11) times. PS's reoccurring chest infections were treated with antibiotics, to which he developed an allergy to penicillin. No antibiotic medical review recorded.

His last BMI was over 37kg/m2 and his weight seemed to have increased over time. A concern was raised with social care team regarding his weight management and lack of activity. Records show this was unsubstantiated and not followed up. No evidence of annual health checks but invites were sent out and no follow up.

Last 2 years, PS suffered increased episodes of seizure activity due to probable, levels of anxiety and stress. His mood changed, was low and withdrawn. Reviewer found no neurology referral on his records and no mental health team to deal help with his low moods and anxiety. PS's was known to feel stressed and GP advised him to buy over the counter medicines. He was also referred to social prescribers for low mood and healthy lifestyles but no evidence of attendance or recorded outcome as a result.

PS was not known to community learning disability team and no evidence of visiting epilepsy team to help support him manage his seizures. No evidence of referral to dietician to support with health eating.

It was noted that for several years, PS had stopped attending day centre. At the end of the pandemic, a risk assessment and safeguarding plan was completed to support PS to access the community services and engaging with outdoor activity to minimise risk of isolation but no evidence this plan was implemented or followed.

Mum informed social worker of ongoing issues within the family but no action taken as she declined to raise this matter as a safeguarding concern. Mum reported that she was coping well with care provision despite ill-health and declined extra support.

A few months later, mum raised issues, again, about her family. It was recorded that some members of the family were not allowed to visit PS but evidence showed they continued to visit. Three safeguarding alerts were raised by visiting care staff but were not investigated, due to lack of sufficient information. As part of the safeguarding enquiry mental capacity assessment was carried out and PS was deemed to lack capacity and unable to understand, give information and articulate his views or make decision. There is no evidence to indicate that an independent advocate, IMCA, was considered for PS despite ongoing family issues and mum's ill-health.

During his last few months, his seizures increased as reported by family but no contact with GP or clinical services noted on his records. One morning, PS was found at home unresponsive; admitted via the emergency department onto ICU with suspected sepsis, acute kidney injury (AKI) and diabetic ketoacidosis (DKA), a serious complication of diabetes. Two days later he stabilised and was moved onto the ward.

On the ward, records show he had missed his medicine. Reviewer found no explanation or follow up recorded nor was there an incident raised as a result of this omission. An MRI scan was requested by one of the attending doctors on the ward, records show this was not done nor followed up during his stay at the hospital. It would appear, PS was not supported to eat, one carer stated '*the food was left there and no one bothered to support him to eat.'*

On his last day, PS's seizures increased, he went into cardiac arrest. Despite resuscitation attempts PS continued to deteriorate. Best interest decision was made by his doctors, nurses and the resus team due to prolonged cardiac arrest to stop resuscitation (DNACPR). It is not clear if the mum was involved in this decision. Sadly, PS passed way. Cause of death was pulmonary thromboembolism, epilepsy and sepsis (treated).

During the review process, there was no evidence of a recent care plan for PS, the last care plan was dated seven years ago, and no carer's assessment for mum. Mum is recorded as declined assessment.

This level of care was graded as below the expected standard, impacted on the person's health and wellbeing and may have contributed to the person's death.

Learning into Action: Local Initiatives 2022-23

NEL LeDeR programme has recorded a number of local initiatives and projects as a result of completed reviews during this reporting period. These initiatives were aimed at creating awareness of the LeDeR programme while addressing gaps identified in this LeDeR report and previous reports.

Working closely with key partners, below are some of the activities documented.

Figure 13: Local Initiatives

All ED departments have set up flagging system to monitor people with a learning disability and autistic adults when attending these departments.
Out of hours support and learning disability check list to ensure safe discharges

Supported by Public Heath Teams across NEL, all boroughs have established obesity and health living projects to raise awareness of health living. Regular workshops are taking place and the numbers are noted to go up.

All acute teams have undertaken work to develop or review their learning disability and autism strategies aligning them with local service delivery plans

Led by local pharmacy teams, STOP clinics & Structured Medicine Reviews (SMRs) happening across NEL

Improved learning disability & autism trainings, raising awareness of needs of people with a learning disability & Autism. Increased learning disability & autism workforce

Staff training on Dysphagia, constipation, diabetes and mental capacity assessments continue

Significant 7 trainer (BHR locality) to training care staff in care homes and supported living placements about recognising deterioration and acting early

Tower Hamlet is championing the implementation of Urgent (universal) care plans. While ELFT is piloting a health app, service user held app which would help people can track their own health conditions

Health Facilitation Team working with GP practices to improve uptake of AHC and health action plans, aimed to improve uptake and quality of starting 14years

A review of bowel screening pathway for people with a learning across NELFT. Breast screening campaigns across Hackney and Newham teams

LeDeR workshops continue across all our local areas, sharing findings and recommendations from completed reviews aimed to support service improvement hence improved quality of care

Appendix 2 for more details about individual partners/ care providers are doing to improve the quality of care for people with a learning disability and autism.

Evaluating the Impact

It is the responsibility of NHS NEL ICB to monitor and review service improvement plans to ensure that they are implemented and effective in improving the quality of care provided to people with learning disability and autism; reducing inequalities and saving lives.

In order to achieve this, NHS NEL ICB has put in place the following:

- a strong NEL ICB wide governance and quality assurance system to make sure that learning is imbedded into services to address inequalities facing vulnerable groups including people with learning disabilities and autistic adults while improving their health and wellbeing

- a NEL wide LeDeR Governance Group not only to oversee the completion of the reviews but to ensure actions are taken forward into service improvement and to hold services to account

- implemented a three year- NEL LeDeR strategy 2022-25 which sets out a commitment to service improvement in relation to the LeDeR findings. This includes, an implementation and monitoring plan for the strategy. This plan will be reviewed annually to ensure improvement are captured and any challenges mitigated in good time

- established local LeDeR forums to improve awareness of LeDeR programme and share findings and recommendations from completed reviews and support services put in place actions to address local issues

- NHS NEL Learning Disability and Autism Delivery Plan which sets out a critical mechanism by which the Integrated Care Board will hold care providers and localities to account for progress in helping to reduce premature mortality.

How will we evidence that service improvements are making a difference to people with a learning disability and autism and their families?

- NHS NEL ICB quality leads will continue to engage with providers to monitor the implementation of service improvements in response to the learning from LeDeR reviews

- The NEL Governance Group and LeDeR forums will monitor the themes and trends from completed reviews within their meetings

- Good quality grading of care in future LeDeR reviews. It is expected that Reviewers will continue to monitor and report improvement in grading of care

- Local service user groups will be consulted on their experience of using local services. This will be through Healthwatch reports, open events, patient/carer feedback reports and or patient surveys

- Regular audits will be undertaken to monitor any changes implemented as required, for example on the quality of annul health checks.

Conclusion

From the findings and learning identified within the 62 reviews completed between 1st April 2022 to 31st March 2023, the following recommendations have been made as areas of work to be continued going forward:

- Continue to build and strengthen links between key partners and care providers to ensure all findings and recommendations from reviews are shared and reflected in transformation work streams to further improve the lives of individuals with a learning disability and autistic adults living within our areas

- Further develop Local LeDeR forums and NEL-wide LeDeR Governance Group to ensure findings from completed inform local service delivery plans across North east London

- Continue to raise awareness of the LeDeR Programme within all health and social care partners to ensure all individuals with a learning disability or autism who sadly die within NEL are notified to the Programme and their death reviewed

- Continue to promote uptake of annual health checks to ensure persons age 14 years and over are invited and supported to attend annual health checks; annual health checks are robust and meets the needs of the individual in line with the required NHS England trajectory. Each annual health check ends with a SMART health action plan to make sure the person benefits from these checks and it is not a tick box exercise

- Commissioners to continue already on-going work with GPs to ensure all learning disability GP registers are up to date to ensure identification of these individuals within our communities

- Continue advocating and creating awareness of the needs of autistic adults and that autistic people have access to services that appropriately support their specific needs.

- support education and training for all health and social care staff in respect of their responsibilities in ensuring compliance with the Mental Capacity Act (2005), Deprivation of Liberty Safeguard (DoLs) and application of best interest as indicated.

- Support screening services to build on the small progress made in ensuring individuals with a learning disability have equal access to all health screening programmes, including cancer screening and follow ups on missed appointments and support is provided to those who have ‘not attended’ or not partaken in screening

- Support ongoing education and training amongst care staff on recognising deterioration and end of life care, to ensure staff are able to seek help in good time, minimising hospitalisation

- Empowering staff to hold end of life care conversations both in hospital and community settings; allowing early planning with the individuals and their families and those who care for them

- Continue rising awareness of the importance of provision of reasonable adjustments for people with a learning disability and autism; this would help remove barriers to accessing services, which could potentially contribute to avoidable deaths, hence improved health outcomes, enabling them live longer, healthier and happier.

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Appendix 1: NHS NEL ICS performance and matrix scoring against national targets

LeDeR performance is based on two indicators (KPIS), the percentage of reviews allocated within three of the receipt of the notification and percentage of completed within the next three months. It is expected that a review would be completed and signed off within six months of receipt of the notification. Some reviews take short than others depending of the complexity.

Performance analysis for adults' reviews

Out of the 88 notifications, 47 of these were received during the first half of the year. All these 47 reviews were completed as at the end of the year, achieving 100% on both allocation and completion, except those on hold due to statutory investigations.

Table 4: Scoring matrix- adults

Metric Description	Frequency of data collection	* Scoring Matrix		
		Red	Amber	Green
% notifications assigned within 3 months	Monthly	0%	Amber: 0%	100%
% of notifications completed within 6 months	Monthly	0%	Amber: 0%	100%

Performance analysis- Child death reviews

All children deaths (under 17years of age) are reviewed via the child death review panel (CDOP) process. CDOP is a multi-disciplinary process with includes all health and social care professionals involved with the child. The LeDeR programme team attends CDOP and CDR meetings and relevant information (Forms B and C) are obtained to support completion of the LeDeR reviews.

Out of 31 notifications, eight (26%) were completed as at the end of the year. All CDOP reviews are allocated to the relevant CDOP team immediately a child has died, achieving 100% on allocations.

22 (70%) of the children open reviews, 48% of which were notified more than six months and are a breach while seven (22%) are within 6 months of notification.

Table 5: Matrix scoring- children

Metric Description	Frequency of data collection	* Scoring Matrix		
		Red	Amber	Green
% notifications assigned within 3 months	Monthly	0%	0%	100%
% of notifications completed within 6 months	Monthly	48% (over 6 months)	Amber: 22% (less 6months)	26%

Appendix 2: Learning into action

NHS NEL Integrated Care Board (ICB)

Initiative/Project	Areas of focus and achievements / progress	
Implementation of LeDeR Policy	✓ Established LeDeR programme team ✓ Appointed Senior Responsible officer for LeDeR Programme ✓ Established LeDeR Governance group ✓ Established LeDeR local groups ✓ Continue completion of LeDeR Reviews	– Ensure effective deliver of the LeDeR programme work – Share findings and recommendations from completed reviews
LeDeR Conference in September 2022	✓ Create awareness of LeDeR programme activities	– Improve awareness and reporting of deaths to LeDeR programme across NEL

NHS North east London Foundation trust (NELFT) workstreams

Initiative/Project	Areas of focus and achievements / progress	Expected outcome
Recognising deteriorating patient (Restore mini2/ Significant7 Training)	✓ Successful recruitment of band 7 Nurse trainer ✓ Training package developed and approved ✓ Scoping work completed and KPIs agreed ✓ 26 staff trained in three care homes ✓ .	– Improving staff confidence in recognising deterioration and seek help in good time – Improved awareness of the needs of people with learning disability and autistic adults – possible reduction in hospital admission
Bowel screening pathway for people with a learning disability	✓ Pathway document shared with all relevant services for implementation	– Improve uptake of bowel screening

Obesity and health living project	**NELFT wide** ✓ raising awareness of health living and developing resources pack for people with learning disabilities ✓ NELFT wide Dietician post agreed to support people with learning disability. Post to start in 2023-24 financial year. ✓ Established working groups with Health teams, public health teams and community LD teams ✓ System wide approach adopted ✓ Outcome measure identified for NELFT Health living and in final stages of ratification Working closely with Public Health teams, all four boroughs (Barking & Dagenham, Havering, Redbridge and Waltham Forest) have now established health living programme. In some localities, records show reduction in weight of the participants.	– Improved health and wellbeing of the person – Reduced rate of obesity and ensure regular monitoring of weights.
DNACPR review conducted jointly by BHR teams including acute teams	✓ NELFT has reviewed DNACPR pack and this has been shared with all Community learning disability teams, acute learning disability liaison nurses and Primary care teams. ✓ Jointly with mainstream End of life care (EoL) teams in ensuring appropriate application of DNACPR	– Ensure appropriate application of DNACPR – Improve family engagement in key decision making
Diagnostic overshadowing	This involves imbedding good practices around annual health checks and health action plans, vaccinations and provisions of reasonable adjustments, Main areas of focus: ✓ Validation of GP registers- strengthen the role of learning disability link workers ✓ Joint working with primary care and community services. ✓ Consent to share information/ communication between systems and teams ✓ Easy guide to flag patients on Rio ✓ Liaison with urgent care pathway ✓ Health facilitation role/ physical health ✓ Appropriate use and application of MCA/DoLS and LPS ✓ My health guide app update, Urgent Care Plans/ Hospital passports	– Minimise risk of missed diagnosis – Improved communication between teams – Avoid duplication of tasks – Efficiency in delivery of care – Improved vaccination uptake – Effective provision of reasonable adjustments
STOMP and SMR	✓ STOMP clinics in place across all four NELFT London boroughs.	– Reduced and where appropriate, STOP overmedication – Ensure regular medical reviews

Dysphagia: Raising awareness regarding identifying red flags	✓ Dysphagia Training available via NELFT e-learning platform ✓ Webinars for carers, GP and CLDT staff to continue	– Improved awareness – Minimise risks of aspiration pneumonia
Diabetes and constipation	✓ raising awareness of diabetes and constipation.	– Improved awareness and management of diabetes and constipation
Dentistry	✓ Established liaison with community dentistry provider to develop seamless referral process. (ongoing)	– Improved dental care for people with learning disability and autism
Other key work streams	✓ Establishment of a clear LeDeR governance system within NELFT and a review of LeDeR SOP to reflect changes in process	– Align system in support of the LeDeR Programme
	✓ Established Safe discharges working group	– Ensure Safe discharges to the community

NHS East London Foundation Trust (ELFT) projects

Initiative/Project	Areas of focus and achievements / progress	
Governance & LeDeR Information	✓ Established (approved) a clear governance system for reporting LeDeR information. This has been emended into the patient safety systems	– Align system in support of the LeDeR Programme
Flags and diagnostic codes on all records	✓ Review of patient coding systems to ensure alerts and ICD10 codes	– Easy to flag up learning disability and autistic patients on the system
Cancer Screening	✓ Breast Screening campaigns	– Improved uptake of breast screening
weight management programme	✓ health and wellbeing programmes across Tower Hamlets and Newham for people with learning disabilities (jointly funded through personal budgets and Public health)	– Improved health and wellbeing
STOMP	✓ STOMP programmes or QI projects– focusing on identifying those from `black ethnic minority background on higher levels of antipsychotic medication	– Reduced and where appropriate, STOP overmedication
Local LeDeR Workshops/ forums	✓ LeDeR workshops happening across all localities- sharing findings from completed LeDeR reviews and supporting local action plans.	– Improve awareness of LeDeR, learning into action

Annual health checks & Health action plans	✓ Health Facilitation Team working with GP practices to improve uptake of annual health checks and health action plans.	– Improve quality and uptake of annual health checks starting 14 years; minimise diagnosis overshadowing or delayed diagnosis
Health App / Urgent Care plans	✓ ELFT working on pilot for Medii – service user held app aimed to help people track their own health conditions	– Empowering the person to take control of their health and wellbeing
Staff training/ Learning disability events	✓ Learning disability and Autism awareness training for all staff ✓ Smoking Cessation and Physical Health Teams ✓ Quarterly Trust wide Safeguarding Event with a focus on Learning Disability and Autism, including LeDeR outcomes, and Suicide Prevention for Autistic people	– Improved awareness of the needs of people with a learning disability and autism
Autism strategic lead role	✓ Autism strategic lead role in place	– To provide leadership

NHS Barts Health workstreams

Initiative/Project	**Areas of focus and achievements / progress**	
Emergency Department (ED)D Standard Operating Procedure	✓ Developed and now being rolled out and to be embedded across all Barts Health hospital sites This policy would ensure all learning disability patients' results are reviewed by a senior clinician, before they are discharged home)	– minimise failed discharges – minimise delayed or misdiagnosis – improved awareness of LeDeR and the needs of people with a learning disability and autism – embed Learning disability care provision within Systems and Processes
Teaching and Training in Emergency departments	✓ Learning disability and autism awareness training with a rolling program in place ✓ Learning Disability daily reporting - to strengthen the report system and passed to the Medical Directors on each site to ensure they are aware of patients on-site, and their whereabouts, including A&E	
Trust-wide Learning Disability vision and strategy	✓ Working on a Trust-wide Learning Disability vision and strategy	
Regular report to Trust Mortality and Morbidity Review Group	✓ Regular Mortality and Morbidity Review Group meetings, reporting every other month to the Trust Committee group. LeDeR reviews and serious incidents to be included in the agenda	– embed learning from MMR reviews/ informed service improvement plans – improved patient experience

Specialist Staff	✓ increased specialist learning disability staff from and a staff available at all sites.	– Improved staff capacities to support people with learning disability and autism. – Joint working relationships between teams
Strengthening trust-wide assurance	✓ Strengthen learning disability agenda, including patient quality of care and experience throughout the trust. ✓ A review of the Integrated Safeguarding Committee to include learning disability dashboards ✓ ensuring safeguarding, is not a standalone	

NHS Barking Havering and Redbridge University Hospitals (BHRUT) Trust workstreams

Initiative/Project	Areas of focus and achievements / progress	
Learning Disability & Autism Strategy:	✓ In conjunction with Learning Disability patients and their carers, BHRUT implemented Learning Disability & Autism Strategy. ✓ developed a detailed workplan that is refreshed regularly and reported via safeguarding governance processes, to ensure new initiatives are considered and appropriate actions added onto the workplan.	– ensure clear processes are in place to minimise failed discharges – improved awareness of LeDeR – improved disability awareness
Service User Engagement	✓ A Trust Learning Disability & Autism Working Group, meets every two months (face-to-face); the purpose is to listen and work with people with lived experience on key projects/ areas that matter to them. ✓ Support production of easy read documents.	– Improved patient-carer experience – Informed service improvement plans- service user lead. – Improved awareness of the needs of people with a learning disability and autism.
Learning disability and autism mandatory training	✓ Implemented mandatory Learning Disability Awareness Training ✓ Development of Practice Development nurse post created to support training and workforce development across all trust sites	
Workforce/ Learning disability team	✓ The Trust has expanded Learning disability and autism team to support more patients across the Trust services.	
Out of Hours Support and Learning Disability Checklist	✓ Working closely with our Emergency Departments and wards, a learning disability check list was developed and implemented to ensure staff carryout all necessary safety-critical tasks on all patients attending ED ✓ Aims to minimise the risk of diagnosis overshadowing, ensure considerations for making reasonable adjustments, improve communication and recognising pain. ✓ Introduction of an on-call Safeguarding and Daily Checks Manual to the Trust managers' on-call	– Improved quality of care – Minimise delayed provision of care and treatment – Minimise inappropriate discharges – Ensure support for those missing appointments

Referrals and daily checks	✓ Established referral pathway for Emergency Department clinical staff to refer to specialist teams than sending a patient back to GP ✓ Electronic referrals via 'Careflow Connects' – to aid in early identification of patient admitted and requiring assessments and discharge planning. ✓ Learning Disability Team visit the ED 's on a daily basis (Monday-Friday, 09.00 – 17.00hrs).	
Learning Disability Career Map	✓ The Trust has produced a Learning Disability Career Map to enhance the quality of patient care by promoting supportive Learning Disability Nursing careers. ✓ The Career Map looks at the career development required to achieve the vision of having one Learning Disability Nurse on every ward. ✓ The Learning Disability and Autism Team supports experiential placements of year 2 and year 3 Learning Disability Student Nurses – key placement to the students learning in practice	– Improve awareness of the needs of people with a learning disability and autism.
Flags on all learning disability patients	✓ Implementation of Learning Disability and Autism flags on patient records to monitor hospital admissions and ensure early recognition and referrals to the Learning Disability Team	– Improved support by Acute LD nurses
Learning Disability and Autism Resource packs	✓ Learning Disability and Autism resource folders are available on both EDs and all ward areas providing easy access to a wide number of easy read resources as well as all Learning Disability and Autism pathways.	– Improve awareness of the needs of people with a learning disability and autism
LeDeR review meetings	✓ Monthly meetings with the local LeDeR team to discuss reviews' progress and address any issues that could delay completion.	– Support LeDeR reviewing process and share learning as indicated
Learning Disability Champions	✓ The Trust runs quarterly Learning Disability Champions workshops aimed to share information and act as an advocate for people with Learning Disabilities across the Trust services.	– Improve awareness of the needs of people with a learning disability and autism

NHS Homerton University Hospitals workstreams

Initiative/Project	Areas of focus and achievements / progress	
Reviewing & Implementing Emergency Department SOP	✓ Review of Emergency Department Standard Operating Procedure (SOP) to ensure processes are imbedded in all places as expected; identifying the needs of these patients and supporting clinicians who work in these	– Ensure system and process are fit for purpose and – improved awareness of the needs of the person and addressing these needs.
Learning disability Training	✓ Targeted Learning disability Training for staff to improve awareness of needs of this group of patients, including how they communicate, diagnostic overshadowing and provision of reasonable adjustments	– improved awareness of the needs of people with a learning disability and autism.
Flag on all learning disability patients	✓ Addition of flags on patient records to monitor hospital admissions and inform the system on how to improve the processes to ensure positive outcomes	
Workforce	✓ Extra resource has been agreed – a new member to join soon	– Improved capacity to provide support/ liaison
DNACPR audit	✓ Completed DNACPR audit to ensure documentation is appropriate and any lessons, if any, are leant	– Ensure appropriate application of DNACPR
LDA Strategy	✓ First patient participation group established to co-review current Learning disability strategy	– Ensure service user engagement/ participation