



Learning Disabilities Mortality Review  
(LeDeR) Programme



**North East London**  
Clinical Commissioning Group

# North East London LeDeR Annual Report 2020-21

*Kivengea, Beatrice, North East London LeDeR Coordinator*



## Foreword by Dr Jyoti Sood

We welcome this second report from the North East London LeDeR programme team. 2020/21 has been the most challenging year for the NHS to date, and has notably shone a light on the health inequalities experienced by some of our most vulnerable populations. It has never been more clear that we have significant work to do to ensure that people with a learning disability have equitable access to health care, and the LeDeR programme remains a key part of delivering this goal.

This second report has evidenced some areas of improvement in our offer for people with learning disabilities, which should be lauded; it is wonderful to see that the number of reviews identifying good and excellent care has increased, and our hospitals, community teams and voluntary sector must be recognised for their passion for and commitment to improving the experience of people with a learning disability.

We must however also acknowledge that the report identifies a number of areas of improvement. The experience of our BAME patients, for example, will need to be a key focus in the coming months; as will considering how people with a learning disability can be supported with weight management, dental care and cancer screening. We have seen improvements in the number of people with a learning disability having their Annual Health Check, but we will continue to focus on increasing these numbers and ensuring our Annual Health Checks are of a high quality and standard.

As we move into 2021/22 and focus on imbedding [Learning From Lives and Deaths – People with a learning disability and autistic people](#), the recommendations from this report will be a key factor in shaping our plan to put action into learning.

I would like to acknowledge the incredible efforts of our LeDeR team and reviewers this year, and their response to the Covid-19 pandemic. NEL CCGs led on the development of a rapid review at the outset of the pandemic that allowed professionals to swiftly implement recommendations to benefit people with a learning disability at the start of the first wave. We also sadly received an unprecedented number of notifications of death; our reviewers delivered an incredible response to this in order to ensure that reviews continued to be completed to a high standard and within expected timescales.

Completing reviews within six months is one aspect of the LeDeR review process, however the most important part is the changes that are made as a result of that learning. We remain committed to the LeDeR review process in driving local change, and working closely with all partners to understand what is working well and what is needed to improve access and the quality of health and social care outcomes.

The success of the LeDeR process is hugely dependent on the support of the family members and carers of those who have died. I would therefore like to end with my heartfelt thanks to everyone who has contributed to and helped shape this important piece of work in this most difficult of years, especially the people with lived experience; the inclusion of personal stories in this report is a testimony to them and their loved ones.

A handwritten signature in black ink that reads "Jyoti Sood" with a checkmark below it.

Dr Jyoti Sood  
Clinical Lead for Learning Disabilities and Autism  
NEL CCGs

## Acknowledgements

We would like to acknowledge the many people who have contributed and supported the implementation of the LeDeR programme during a challenging year.

Special thanks all our LeDeR reviewers, health and social care providers, carers and families who have been central to supporting the reviewing process and delivering the programme. A special gratitude to families and carers who have provided a lot of useful information about the care provided to their loved ones and their contribution on best practice and also some of the areas that need improvements.

We would like to thank those families who have given us permission to share the stories of their loved ones with the view to bring much needed changes for other people with learning disabilities.

We would also like to acknowledge with much appreciation the crucial role of the acute teams at Barts Health, Homerton Hospital and Barking Havering Redbridge University Hospital Trust who diligently delivered quality care to people with learning disabilities during a very challenging time. The Acute Learning disability Teams were praised for their good communication and support to families and community services throughout the pandemic.

A big thank you to North East London Foundation Trust (NELFT) and East London Foundation Trust (ELFT) particularly the community learning disability teams, for how they continued to prioritise the programme review work and continued their support to people with a learning disability throughout the pandemic. Also thanks to all those who have participated in our LeDeR events, LeDeR support groups, locality LeDeR forums, online webinars and other events and have helped shape and develop our recommendations.

A special thanks to the NEL Learning Disability and Autism team and local area contacts (LACs), for their guidance and support provided. Finally many thanks to the NEL learning disability and autism clinical leads and the LeDeR reviewer forum for their contribution to this report.

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## Executive summary

This is the second Annual Report for the North East London Learning from Deaths Review (LeDeR) programme. It presents analysis of information about deaths of people with learning disabilities since the start of the programme.

The North East London (NEL) LeDeR programme covers the following 7 Clinical Commissioning Groups (CCGs): NHS Barking and Dagenham CCG, NHS Havering CCG, NHS Redbridge CCG, NHS Tower Hamlets CCG, NHS Newham CCG, NHS Waltham Forest CCG and NHS City and Hackney CCG. At the end of 2020/21 these CCGs merged to become NEL CCG (North East London CCG). As this report is for 2020/21, it continues to refer to the seven (7) separate CCGs.

This report focuses on specific aspects of care provided to people with learning disabilities; highlighting emerging themes, best practice, gaps and areas identified as requiring improvements. Overall performance, North east London achieved 87% completion of reviews, same as London, but above national average of 82%.

People with learning disabilities face more challenges than the general population and this was no exception during the COVID19 pandemic. In March 2020, NEL recorded the first COVID-19 death. Since then more than twice the number of deaths were reported this year compared to the same period in the year before.

Clinical teams across NEL adjusted quickly to new ways of working, provision of advice and assessment; there is no denying however that access to treatment has been impacted by restrictions brought in at national level. This had had a significant effect on people with learning disabilities.

Completed reviews have identified potentially avoidable factors that may have contributed to deaths of people with a learning disability and/or contributed to the person's poor health and wellbeing. Some areas highlighted as requiring improvements are:

- increasing uptake and quality of annual health checks
- provision of personalised reasonable adjustments
- staff awareness on the needs of people with learning disabilities
- more awareness amongst professionals regarding over prescription of antipsychotic medicines
- appropriate application of mental capacity act
- better weight management approaches
- collaborative working and good communication between professionals and families

The NEL LeDeR programme transferred at the beginning of 2020/21, during the pandemic, from being hosted by the Quality and Safety team in WEL CCGs (Newham, Tower Hamlets and Waltham Forest CCGs) and now sits within the NEL learning disability and autism strategic team. We are grateful to the WEL CCG's (now TNW) Quality and Safety team for hosting the LeDeR programme from its inception, and for ensuring that North East London has robust systems in place to enabled the performance of LeDeR programme to be one of the best in London and nationally.

In partnership with local borough commissioners and leads for learning disabilities, plans have been developed to tackle identified health inequalities and to improve the quality of care delivered for people with learning disabilities. The NEL LeDeR programme is committed to working closely with health and social care providers to guide necessary changes in order to reduce premature deaths amongst people with learning disabilities.

## Statement of purpose

The Learning from Deaths Review (LeDeR) programme was established in 2015 following evidence that people with learning disabilities were more likely to die much earlier than their peers. The purpose of reviewing a death of a person with a learning disability is to help identify preventable causes that may have contributed to the person's death and to guide changes in health and social care in order to reduce premature deaths of people with learning disabilities.

The LeDeR programme appreciates the on-going support and contribution of people with learning disabilities, their families/carers, and health and social care partners to all areas of LeDeR review work. The NEL LeDeR programme supports an all-inclusive view looking at the circumstances leading to deaths of people with learning disabilities, and ensures reviews provide reflective learning as well as focusing on embedding learning from reviews into local structures to ensure continuous improvement.

This year (2020-21) has been without a doubt the most challenging year to date due to the Covid-19 pandemic. The rolling out of vaccinations has been highly successful in North East London and across the country, however we acknowledge that there is significant work to be done to fully recover health and care services.

## Challenges and changes to delivery of the LeDeR review programme

The success of the LeDeR programme is built on the efforts of LeDeR reviewers taking part in reviewing process. There has been a shortage of reviewers in North East London to support the reviewing process, which has been further impacted by the demands on clinical staff due to COVID19 pandemic.

In April 2020, working closely with NHS England, NEL LeDeR programme team led in the development and implementation of the COVID19 rapid reviews which were successfully delivered across London and in North East London with the support of Community Learning Disability Teams. This data fed into public health decision making. A specific COVID19 report was previously provided as part of last year's Annual Report.

As a result of COVID19, the LeDeR programme (nationally and locally) received a high number of death notifications building a backlog. In August 2020, NHS England set up a deadline for all reviews that met the backlog criteria to be completed by 31<sup>st</sup> December 2020. Despite COVID19 challenges and fewer LeDeR reviewers, NEL LeDeR programme achieved a completion rate of 87% of all backlog cases.

In 2021/22, NEL will be focusing on planning for delivery of the new *Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy* which was published in March 2021. By 30<sup>th</sup> September the Integrated care systems (ICSs) will have a plan to develop the systems required by the new policy, including:

- Establishing a local governance group or panel, responsible for signing off reviews and agreeing actions
- Expanding the LeDeR programme to include adults with autism
- Delivering focused reviews where required (for BAME patients, adults with autism, or on request by family)
- Creating a larger LeDeR reviewing team, including senior reviewers, reviewers and administrative staff.

It is expected that these systems will ensure that reviewer capacity is in place to continue to deliver all LeDeR reviews within the 6-month timescale. They will also provide the oversight and governance to ensure that action from learning is embedded across NEL.

## Summary findings from completed reviews across North East London

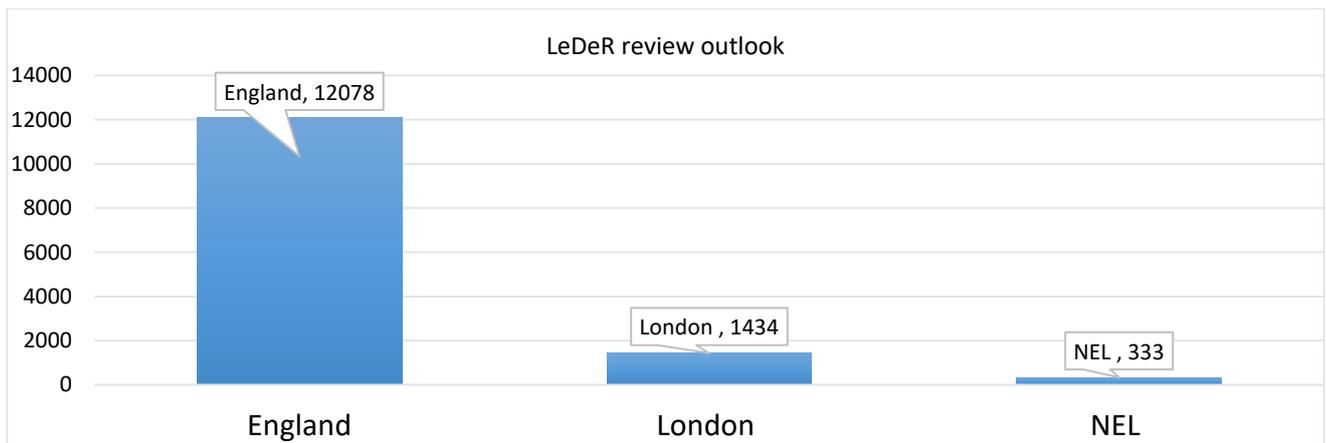
- **Annual Health Checks (AHCs):** over 50% reviews revealed comprehensive annual health checks (AHCs) and health action plans (HAPs) were completed. A few were noted to be of poor quality needing more GP webinars to increase uptake and to improve the quality of AHCs.
- **Care & treatment:** almost all patients had had regular reviews for known health conditions. There were a few success stories on supporting patients stop antipsychotic medicines. Suggestions were made around more social prescribing by GPs; introducing a range of local, non-medical activities, therapies, opportunities and support that can improve people's health and help them live life to the full.
- **Health screening programmes:** uptake for national health screening programmes was noted to be lower than national targets. More awareness of the importance of health screening programmes is needed and GPs encouraged to carry out holistic assessments when seeing patients. Desensitisation and staff training about understanding the needs of people with learning disabilities and liaison with community learning disability services for support were encouraged.
- **Reasonable adjustments:** evidence showed that most services were providing personalised reasonable adjustments. During the COVID-19 period, most patients benefited from GP and community teams' home visits, domiciliary blood test services and virtual consultations. Use of technology to aid service provisions was more evident; more online resources in easy read format to support people with learning disabilities to stay safe.
- **End of Life care and care coordination:** most of the end of life care provision continued with minimal disruption during COVID19 period. There was evidence of good co-ordinated care, MDT meetings and joint decision making. More care staff training was suggested on end of life care to support carers in recognising deterioration and supporting patients participate in advanced care planning when they are able to do so.
- **Hospital discharges:** evidence indicate that there were a few failed hospital discharges and this called for improved discharge planning and a more coordinated approach involving families, carers, social care and the relevant community teams.
- **Communication between professionals and families/carers:** reviews indicated good communication tailored to patients' needs. Acute teams were applauded for their excellent communication and support during the COVID19 period. A few reviews showed poor communication between services and carers' therefore Health and social care teams were encouraged to foster good working relationships and improve communication amongst themselves and carers.
- **Keeping healthy:** there were significant number of referrals to dieticians and weight management services with a few positive outcomes. Reviewers encouraged more personalised approaches and close monitoring and reviewing of the effectiveness of referrals to ensure they deliver outcomes for people with learning disabilities.
- **Social care assessments and reviews:** although there were reviews that showed lack of or delayed mental capacity assessments due to COVID19 restrictions, there were evidence of appropriate social care assessments and reviews aimed to meet patients' changing needs.
- **Staff awareness training:** over 100 carers were trained on RESTORE2" tool to support them in recognising deterioration and appropriate escalation to the relevant teams for timely intervention.

## The LeDeR Programme: National, London and Local outlook

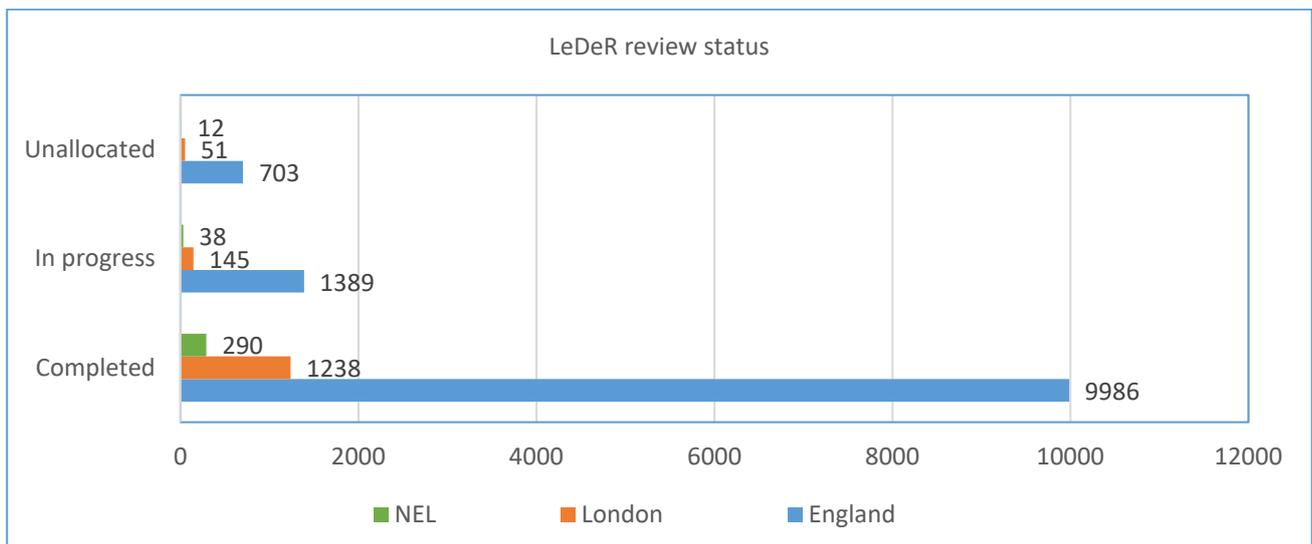
Reviewing the deaths of people known to have had a learning disability helps identify avoidable factors that lead to early deaths, and supports services to improve their quality of care. Providing good quality care to people with learning disabilities and improving their health and wellbeing is a major step forward towards tackling inequalities within health and social care provision.

Clinical Commissioning Groups (CCG), local authority and NHS Trust are expected to ensure LeDeR reviews are completed and changes are put in place to improve services and reduce early deaths for people with learning disabilities.

Since the start of the LeDeR programme in 2017, England has recorded 12078 deaths, 1434 of which were London deaths and 333 were North East London deaths.



North East London (NEL) carried forward 30 reviews from the previous year 2019/20. During this year, a total of 165 notifications required a full LeDeR reviews. As at end of March 2021, 290 (87%) reviews have been completed across North East London, 31 in progress and 12 unallocated.



The LeDeR review performance report as at end of March 2021 shows that 83% (of the 9986) of reviews were completed, while North East London LeDeR programme completed 87%. Unallocated reviews were lowest since the programme began with less than 6% nationally, 4% in London and 3% in North East London.

## Child Deaths

There were 814 deaths of children with a learning disability reported nationally, 116 of these deaths were reported in London and 35 in North East London.



We have requested for information from the National team to try and understand the distribution of child deaths in other London localities as well as nationally and any information about emerging themes and to monitor them going forward.

Child deaths were reviewed under the child death review (CDR) process, which involves collection and analysis of information from known agencies who were involved with the care provision before the child died with a view to identifying any matters of concern affecting the health, safety, or welfare of children, or any wider public health concerns.

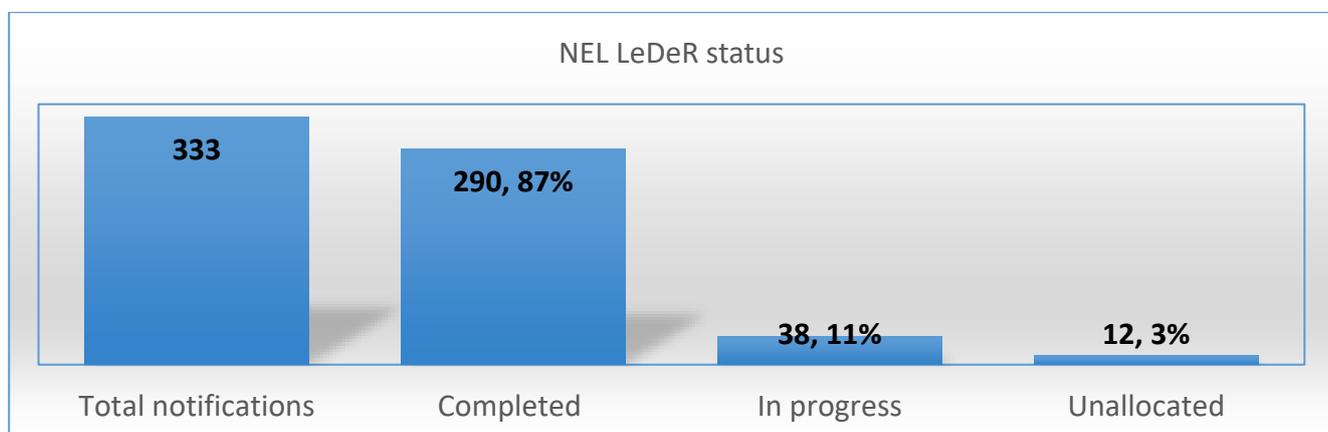
The local CDOP office is expected to invite the LAC or LeDeR reviewer to one or both review meetings. Once the meetings have occurred and the analysis form is completed a copy is uploaded to the LeDeR IT System by the reviewer or LAC or directly by the local CDOP office using a file link. There is no expectation for teams to complete the LeDeR review form on the LeDeR Review System.

## North East London demographic data

This section covers the statistical data collected about the characteristics of all completed reviews since the start of the LeDeR programme. This includes age, gender, ethnicity, type of learning disability, accommodation type, and place of death and grading of care.

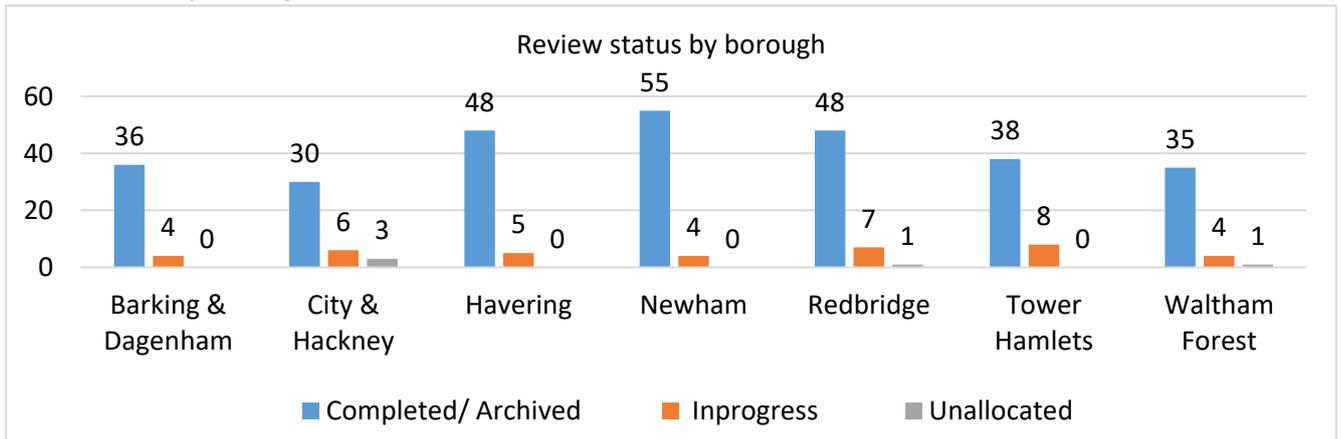
Also covered are the main aspects of care provided to people with learning disabilities which includes annual health checks, weight management, overmedications of antipsychotic medications, provision of reasonable adjustments, cancer screening programmes, mental health and mental health assessments as well as end of life care.

## North East London LeDeR outlook



North East London has received 333 death notifications since 2017. 87% (290) deaths were reviewed and closed by end of March 2021; 38 were in progress and 12 were awaiting allocation once reviewers become available.

### Performance by borough

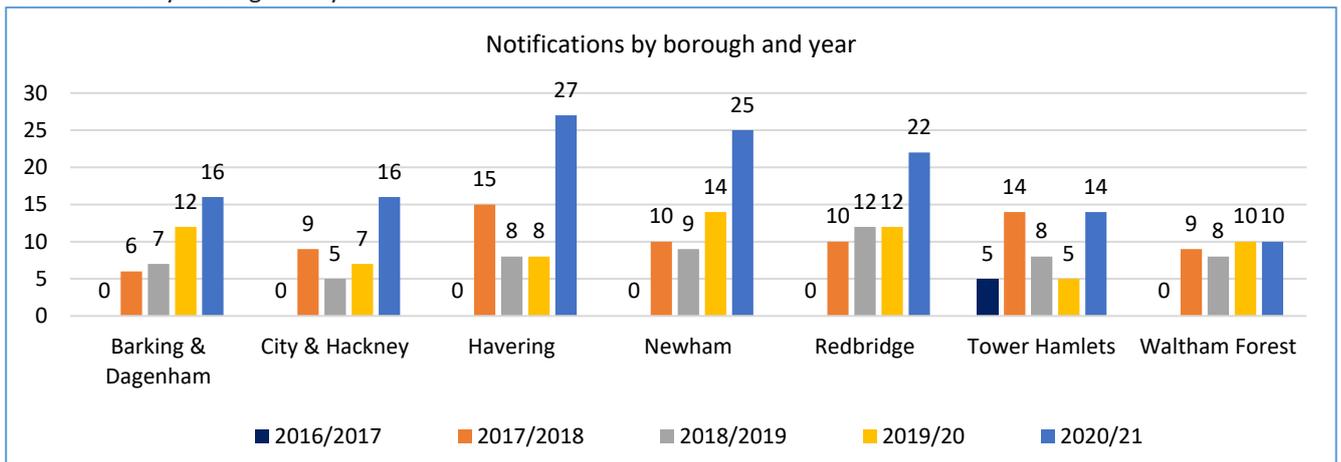


Of the 290 completed reviews, 25 were child deaths aged between 4 to 17 years old, whilst 265 were adults over 18 years old. Below are the borough performances (% of completed reviews):

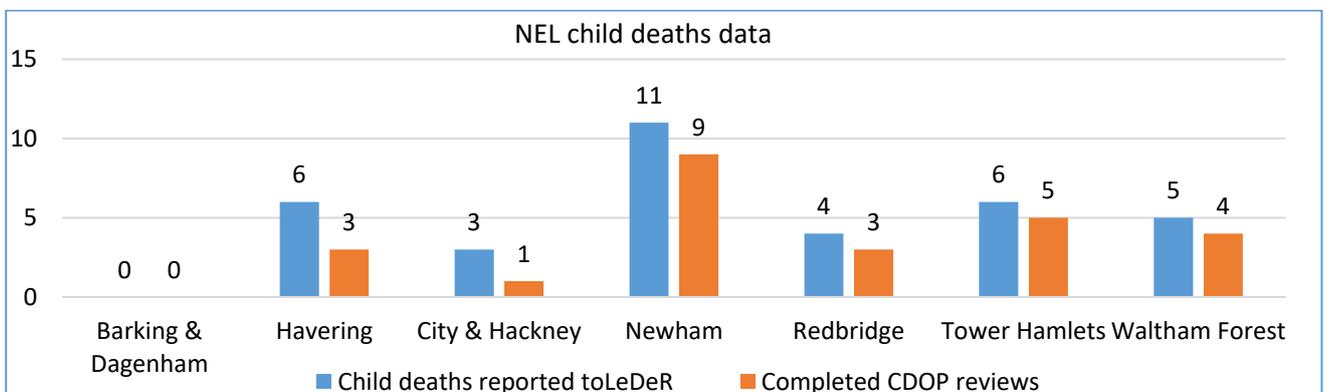
Barking and Dagenham, 88%  
 City and Hackney, 74%  
 Havering, 87%  
 Newham, 86%

Redbridge, 91%  
 Tower Hamlets, 80%  
 Waltham Forest, 90%

### Notifications by borough and year



Whilst Tower Hamlets and Waltham Forest recorded the same number of death notifications during 2020-21 compared to previous years, all other localities recorded a significant increase in the number of death notifications during this current year due to COVID19.



Newham area recorded the highest number of child deaths while Barking & Dagenham had no record of child deaths. As mentioned above more information has been requested to help understand this variation.

## Age at death

The youngest reported death during this year was 5 years old and the oldest was 92 years. The median is 57 years old. This year's data show a very slight change in the age at death, North east London 2019 annual report noted that the youngest death as a 4 years and oldest as 97 years, with a median as 58.

**Gender:** LeDeR data revealed that 123 (42%) reviews were females and 167 (58%) were males compared to last year's annual report 2019 which indicated that 44% females and 56% males. This information seems in line with the national data which indicated that the age-standardised COVID-19 death rate was higher for men than for women with learning disabilities.

## Ethnic Groups

North East London has a very diverse community and the ethnic groups recorded were as below:

- 187 (65%) were of white background, 5 of which were of Gypsy and Travellers communities,
- 68 (23%) Asian - Indian, Pakistani, Bangladeshi or other Asian background
- 29 (10%) Black African and Caribbean, including mixed black
- 6 (2%) were recorded as of other ethnic groups

NEL annual report 2019-20 shows no significant variation in terms of the ethnic groups across the different years.

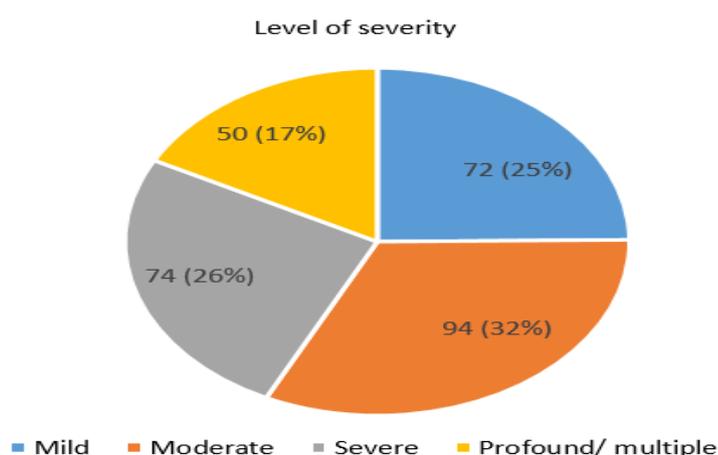
## Level of Learning Disability severity

The Department of Health defines a learning disability as 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood.

Approximate 1.2million of people (951,000 adults and 299,000 children) living in England are known to have a learning disability, 200,000 of these live in London.

Learning disability causes remain largely unknown, however, there are known factors that could lead to a person having a learning disability such as genetics (hereditary), infections, trauma and problems during mother's pregnancy. Some well recognised conditions are cerebral palsy and Prader-Willi syndrome which are associated with having a learning disability.

There are four main categories of learning disability severity: mild, moderate, severe and profound/ multiple learning disability.



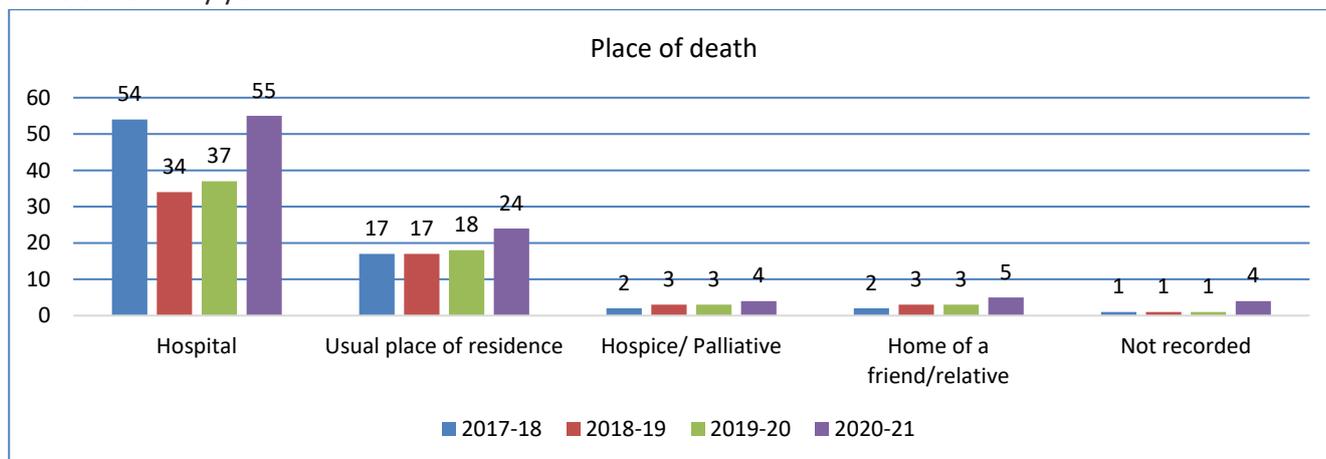
## Place of death

Most patients died in a hospital setting or their usual place of residence and a few were recorded as unknown.

- 180 (62%) died in hospital
- 76 (27%) usual place of residence (own home or residential setting)

- 12 (4%) hospice/Palliative Care unit
- 13 (4%) home of a friend/relative (not usual place of residence)
- 7 (2%) no details of place of death recorded (unknown)

Place of death by year



People prefer dying at home or place of choice. Although LeDeR reviews showed that most people died from hospital settings; evidence show that in 2020-21, more people died in their usual place of residence or own homes or hospice units compared to 2017 when the programme started.

All community deaths were reported to the coroners; the majority had a post-mortem to ascertain the cause of death. For most of the palliative care community deaths, certification was completed by their GPs or on call doctor if reported out of hours. Four (4) reviews were recorded as subject to coroners' inquests.

### Types of accommodation

People with learning disabilities were placed within these five types of accommodations; the majority were in supported living and residential care setting.

- Supported living accommodation – 80 (28%)
- Residential care units 68 (23%)
- Nursing care homes 32 (11%)
- Own homes/living with family- 95 (33%)
- Independent living/ rented accommodation 15 (5%)

All children were recorded as living with family. Over 50% of reviews showed that most of the adults lived in supported accommodation and residential care units.

Changes in accommodation type within the last six (6) months of some of the people's lives were recorded, mainly from supported living or residential units to nursing care due to deterioration and an increase in patient needs.

In three reviews, care settings changed from residential care to supported living even though patient needs never changed. Social care assessments were evident that the patient needs were considered. More support was put in place for patients who moved from residential to supported living to ensure the new settings were suitable and met current needs.

Reviewers' recommended that before any change in care setting is made, patients should be involved in this decision and a thorough health and social care assessment completed to ensure the new placement is suitable and in the person's best interest.

## Pre-existing health conditions

Most patients with a learning disability are known to have other complex physical health complications. Reviewed cases show that over 60% of people with learning disabilities who died had two or more of other physical health conditions. This is thought to be due to a combination of factors more likely to occur in people with a learning disability, including obesity, risks of epilepsy, risk of dysphagia (swallowing problems), mental health issues, difficulties accessing services, and many more. Below is a list of some of the common health conditions recorded from completed reviews.

### A list of common physical health conditions and number of patients affected

Health Condition	Percentage (%)
Skin conditions and prescribed medication	207 (71%)
Impaired mobility	181 (62%)
Respiratory conditions/problems (incl. CoPD/ asthma)	174 (60%)
Falls (risk of falls)	175 (60%)
Epilepsy/seizures	168 (58%)
Constipation/ prescribed laxatives medicines regularly	168 (58%)
Diabetes (Type 1 & Type 11)	164 (56%)
Dental problems	158 (54%)
High blood pressure (hypertension)	150 (52%)
Dysphagia, (aspiration risk)	152(52%)
Iron, Vitamin D and B12 deficiency	142 (49%)
Gastric reflux	110 (38%)
Incontinence	108 (37%)
Obesity	102 (35%)
Mental health needs (Paranoid Schizophrenia, psychotic episodes, depression, bipolar affective disorder/personality disorder, challenging behaviour, anxiety, agitation/irritability behaviour and hallucinations)	99 (34%)
Hyperthyroidism & Hypothyroidism	72 (25%)
Impaired hand use (e.g. unable to move hands to feed self or push away something)	66 (23%)
Renal/ Chronic kidney disease	64 (22%)
Sensory impairment e.g. hearing or visual problems	55 (19%)
Known heart conditions/ Cardiac problems	48 (16%)
Osteoarthritis	41 (14%)
Osteoporosis	38 (13%)
Cancers	38 (13%)
Dementia/ Alzheimer's	24 (8%)
Autism	23 (8%)
Hyperlipidaemia	21 (7%)
Other conditions: Lafora body disease, prader-willis, other chromosomal disorders and associated congenital heart problems	21 (7%)
Downs syndrome	19 (6%)
Cerebral palsy	10 (3%)

## Causes of Death

The Confidential Inquiry into premature deaths of people with a learning disability found that 38% of people with a learning disability died from an avoidable cause, compared to 9% in a comparison population of people without a learning disability.

In approximately 10% (28) of reviews completed concerns had been raised about the circumstances leading to a person's death through serious incidents, safeguarding reviews, complaints and coroners' inquests. Recorded causes of deaths from these reviews were pneumonia, aspiration pneumonia, choking, faecal impaction, sepsis, bronchiectasis, and late stage cancers - conditions which are potentially treatable, if caught in time.

The most common causes of death recorded as recorded in death certificates included:

- COVID-19 (recorded also as COVID-pneumonia, COVID-sepsis, CoV SARs, coronavirus)
- Pneumonia/bronchopneumonia
- Aspiration pneumonia
- Renal failure/renal problems
- Heart/cardiac problems/hypertension
- Respiratory problems/CODP, asthma,
- Multi-organ failure
- Sepsis/urosepsis
- Respiratory failure
- Cancers
- Diabetes
- Frailty

Three (3) were from incidental findings of cancer at late stage. These patients were known to services and had been referred and seen by specialist teams but the actual problems were not picked up on time. They were all diagnosed during their last admission in the hospital.

Two other cases were death from choking. These patients were known to have had fast eating habits or swallowing problems and required 1-1 supervision during meal times and chopped foods, however no updated risk assessments were completed on them. Failings were identified and care graded as poor.

## Main aspects of care delivered for people with learning disabilities

NEL LeDeR report 2019 identified seven recommendations which were also noted to be in line with the NHS long term plan however, due to COVID19 disruption and lockdowns restrictions introduced to limit disease spread, a lot of these planned service improvements were put on hold or little attention has been paid with regards to progressing them.

As a result, most of the recommendations from 2019 may have remained the same however a detailed analysis of how learning from LeDeR reviews has been used to drive quality improvement activity locally has been covered under learning into action section of this report.

This chapter focusses on the findings from the main aspects of care provided to people with learning disabilities and when data is available, how this compares to national data and previous years. As a result of COVID19 there were an increased number of deaths and therefore comparing 2020 data with data from previous years should be treated with caution.

*Please note that LeDeR review data is limited to the last three or four years' of the patient's life. Therefore information will not have been included which was recorded outside of this period*

### Annual Health Checks (AHC)

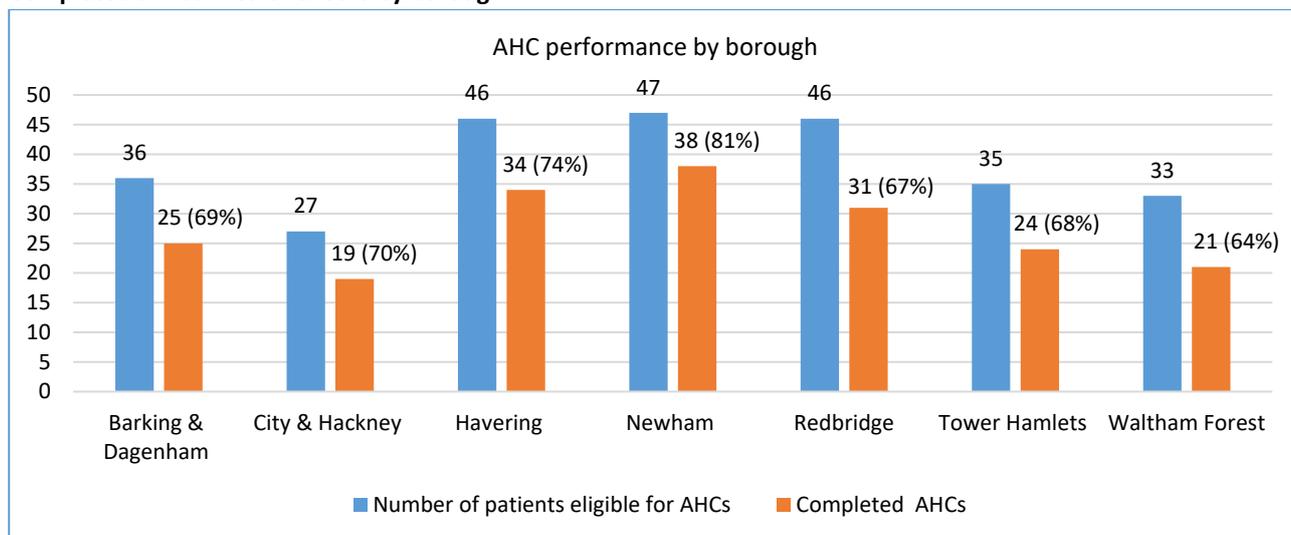
Evidence shows that people with learning disabilities are more likely to experience a greater number of health conditions than the general population. They are also less likely to receive regular health checks or access routine screening.

All people with learning disabilities are entitled to an annual health check. Regular health checks help identify unmet and unrecognised health conditions, leading to early actions to address and treat these health conditions.

270 (out of 290 completed reviews) were eligible for regular annual health checks (aged 14 years and over). 192 (71%) reviews had annual health checks during the last one year of their life. They were all adults aged 22 years and over. In 78 (29%) reviews, reviewers found no evidence of annual health checks in GP records. All reviewed patients had two or more pre-existing health conditions known to their GP.

The graph below show the distribution of these 192 AHCs by borough.

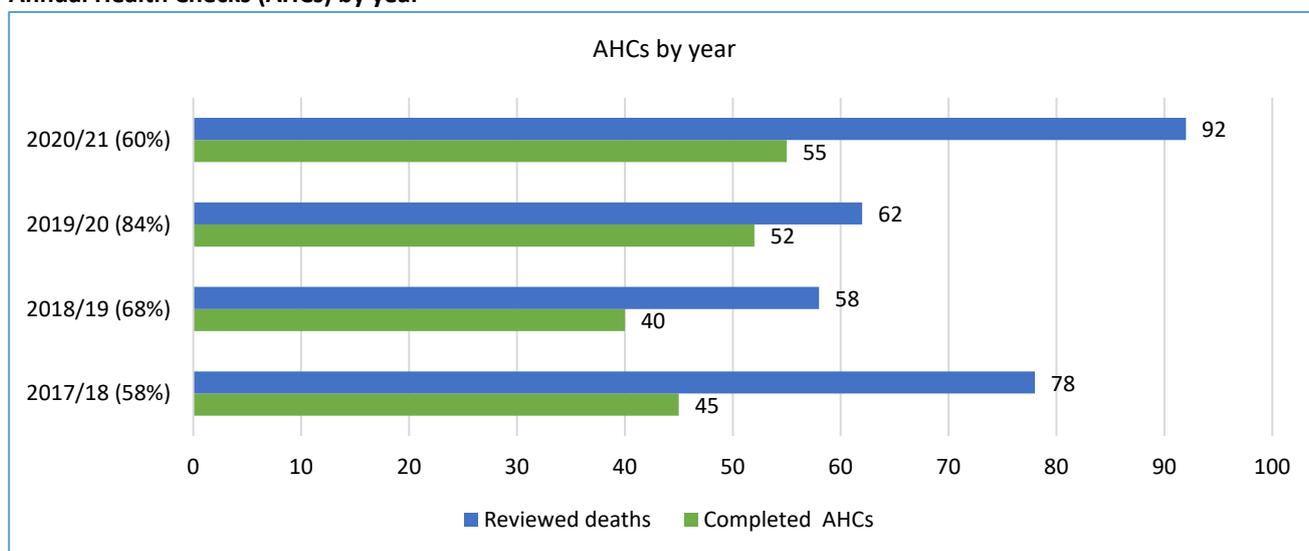
#### Completed annual health checks by borough



People living in Newham were more likely to have AHCs compared to those living in Waltham Forest. An average performance of 70% was recorded across all seven boroughs.

NEL annual health check performance as recorded by the commissioning teams were 67% in 2019/20 and 66% in 2020/21; both performances were lower than the national target of 75% uptake of AHC for people with a learning disability.

#### Annual Health Checks (AHCs) by year



The graph above also shows an increase in the number of annual health checks completed since the start of programme in 2017 from 58% to 84% in 2019; due to COVID19, this performance has gone down to 60% in 2020.

Reviewers observed that the quality of completed annual health checks varied from individual to individual. Over half were said to be of good quality standard and provided comprehensive examinations and observations; other were noted to be below the minimum expected standards.

There is evidence of some improvements in the quality of annual health checks during this year 2020-21. Current data shows that 52% of annual health checks were of good quality, an increase of 8% from 44% recorded in 2019-20 financial year.

GPs were recorded as using varied tool kits to undertake annual health checks. Commonly used was the Cardiff health check template while some GPs had developed their own templates.

Evidence showed that in some cases, GPs found it difficult to undertake rigorous physical examinations especially on patients with severe and complex comorbidities - such as neurovascular conditions, Lafora body disease or conditions whose symptoms include stiff joints, difficulty walking, muscle spasms (myoclonus), dementia and those who were wheelchair dependent.

Reviewers noted that some patients had been invited to attend an AHC but did not attend and there was no record to indicate a follow-up from the GP practice to establish why the patient did not attend and offer a further appointment. According to some of the reviews, families and carers were recorded to have said they were busy and did not always have time to attend annual health check appointments. Some said they did not find them helpful. Reviewers recommended more awareness with carers and families to recognise the importance of annual health checks.

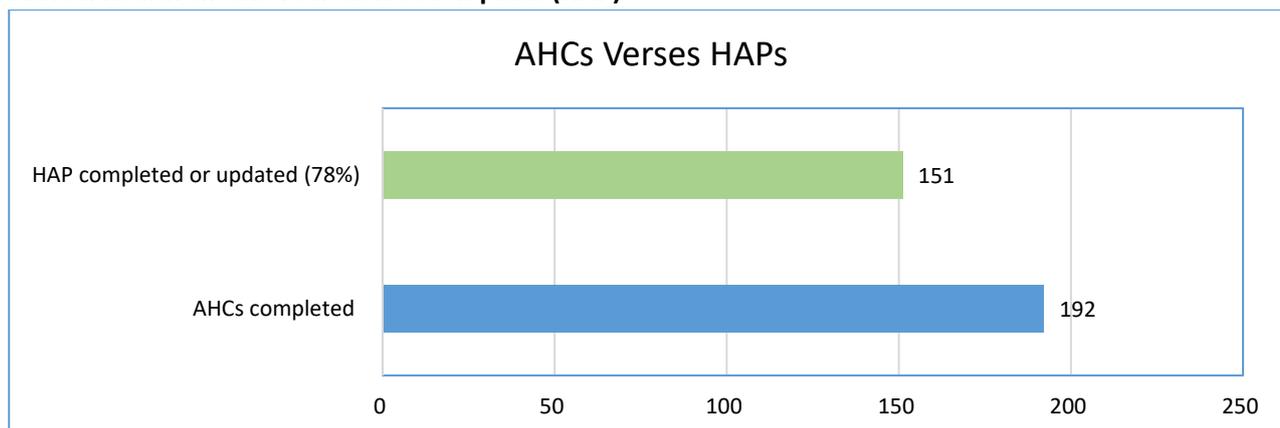
Reviewers recorded that patients who had had a good, comprehensive annual health check were more likely to be referred for further diagnosis and treatment in a timely manner than those that had poor attendance or no checks at all.

Reviews revealed that most GPs were actively reviewing the continuing need for medicines for already known health conditions on an annual basis (such as diabetes, renal, cardiovascular issues, high cholesterol, epilepsy, high blood pressure, dementia amongst others). However, the continuous focus on these already existing conditions was considered to overshadow any new symptoms or new diagnosis. Reviewers recommended that GPs should investigate new symptoms rather than assume they are linked to already existing health condition.

### Health Action Plans

It is expected that at the end of every annual health check, patients should have a health action plan (HAP) summarising what has been discussed and advice provided. Health action plans should set targets to be reviewed before or at the next annual review.

### Annual health checks Vs health action plans (HAP)



Out of 192 reviews that had annual health checks completed, 151 (78%) reviews were recorded as having had health action plans completed or updated. Whilst most records indicated that these action plans were in place or shared, reviewers had no sight of these copies to ascertain the quality of details on them.

There was evidence that where specialist care teams were involved, whether in the hospitals or community teams (psychiatry or psychology), they were actively reviewing the continued need for prescribed medicines regularly.

### Key recommendations on AHC and HAP were made around:

- GPs to follow up missed appointments
- increase uptake of annual health checks to cover 14-22 year olds
- GPs encouraged to consistently use existing best practice toolkits to ensure high quality checks
- health action plans to be completed following every annual health check
- seek support from Community Learning Disability Teams when needed
- patients to be provided with appropriate reasonable adjustments to access services
- more awareness raised with care providers and families to recognise the importance of regular annual health checks as an important element in health protection and timely intervention
- GPs to investigate new symptoms rather than assume they are linked to already existing health conditions

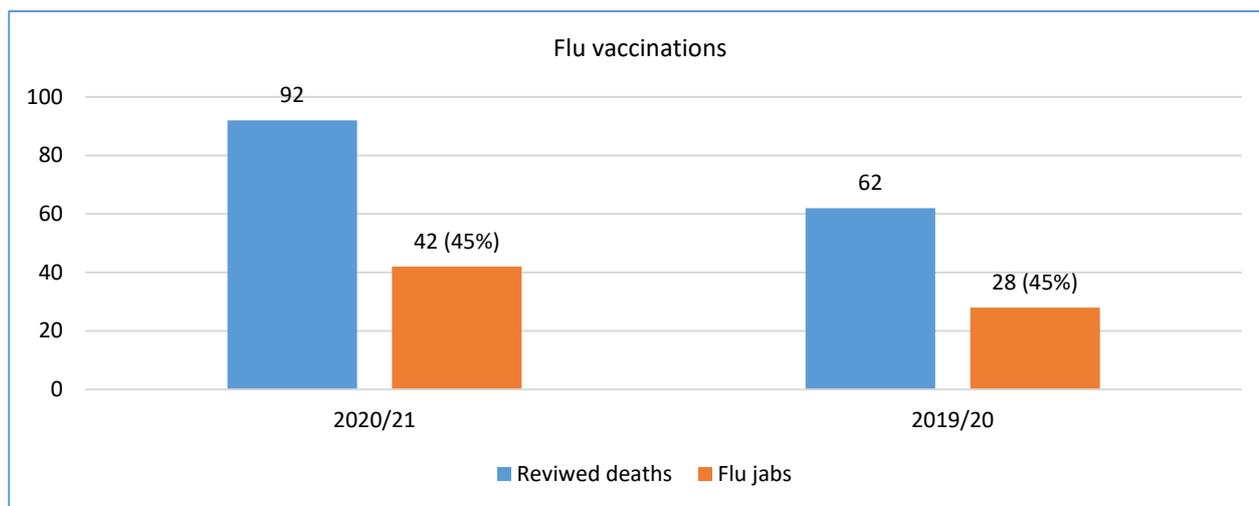
## Health screening programmes

Health screening programmes aim to identify people who are at higher risk of a health problem, so that early treatment can be offered or information given to help them make informed decisions on prevention.

Information gathered from completed child death review analysis form Cs, indicated that all children had had their childhood immunisations up to date. Evidence indicated that nearly half of adults had regular flu vaccinations given.

### Flu vaccinations

The flu vaccine is a safe and effective vaccine. It's offered every year on the NHS to help protect people at risk of flu and its complications. Flu vaccine is offered to everyone aged 65 and over everyone under 65 years of age known to have a medical condition, including children and people with a learning disability, that puts them at risk of flu complications.



It is estimated that 85% of all reviews (154 patients) were eligible for flu jab, however 45% (70) of the completed reviews indicated that they had received a flu jab during the last one year of their life.

According to national statistics, the uptake of flu jabs was recorded as 72.4% in 2019, this means that people with learning disabilities across North East London were less likely to have flu vaccinations compared to general population.

## National cancer screening programmes

Figures on the three main national cancer screening programmes were recorded. These are: cervical screening, breast screening and bowel cancer screening.

### Cervical screening

Cervical screening is offered to all those females aged 25- 64 years and occurs every 3 years up to the age of 49 and every five years up to the age of 64.

123 female reviews were completed, 64 of whom were aged between 25 and 64 years of age and eligible for cervical screening. Only 11 (17%) patients were recorded as having had a cervical screening done.

Evidence showed that most patients were offered screening appointments but families/ carers declined cervical smear test due to the invasive nature of taking the smear sample. In some reviews, families felt that cervical screening was not necessary because these patients were not sexually active.

National performance data as at June 2020 (general population) show:

- London 61.0%,
- England 69.4% a drop from 73% in 2019.

Less than 32% of women with learning disabilities had had cervical cancer screening test, compared to 73% in the general population. This report indicates that women with learning disabilities and autism are almost four times less likely to go for cervical cancer screening tests:

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>

### **Breast screening**

All women aged between 50 and 71 years old should have breast screening offered every three (3) years. Breast screening involves use of an x-ray test (a mammogram test) to spot any cancers (when too small to feel) plus any other abnormalities in a breast.

45 women were eligible for breast cancer screening; 12 (26%) were recorded as having had a mammogram test. This is half the number of women who had received breast screening in 2019/20.

*Breast screening amongst women with learning disabilities is lower compared to the rest of the population. 52% women with a learning disability had received breast screening, compared to 70% of women with no learning disability.*

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities2019>

Recommendations were made around encouraging families and carers to support patients' access to breast screening and self-examinations, using easy read and pictorial information which is readily available. It was recommended that GPs follow up missed appointments with families and carers and ensure appropriate information is provided to families and patients to support them make informed decisions.

### **Bowel screening**

Both men and women aged 60-75 years old should have bowel screening. A home testing kit is sent to a patient's home address every two years to collect a small stool sample to be checked for tiny amounts of blood which could be early signs of cancer.

94 reviews were of patients aged between 60 and 75 years who were eligible for bowel cancer screening. Reviews indicated that 46 (49%) had the bowel screening done.

Bowel screening was noted as the most accessed screening programme compared to cervical and breast screening. This could have been because kits were posted to patients' and no appointment is required. Patients were able to collect samples from home at their own time and carers can flexibly support this to happen.

Some GP records indicated that 'patients had accessed national health screening programmes', but no details of which specific screening programme the GPs were referring to. Reviewers suggested that GPs should keep clear records of cancer screening appointment and record next due date.

*Bowel Performance % (uptake) in general population: London 56.2% while England is 63.8%. 77.8% of people with a learning disability were screened, compared to 83.7% of those without.*

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>.

### **Some of the reasons patients did not access cancer screening programmes were:**

- lack of provision of reasonable adjustments
- poor communication and lack of appropriate information about screening programmes
- staff having little understanding about the needs of people with a learning disability

- anxiety or a lack of confidence for people with a learning disability
- poor working relationships between care providers and health care professionals
- carers/ families not fully involved to support patients
- pain or previous uncomfortable experience
- embarrassment

Reviewers felt that more needs to be done to promote cancer health screening programme, increase uptake and for early intervention and treatment as may be indicated.

### Obesity/Weight management

Evidence shows that people with learning disabilities are more likely to have poor diet and are more likely to be underweight or obese than people in the general population.

Obesity or overweight is when a person carries excess weight or body fat that might affect their health. The body mass index (BMI) is a measure that uses your height and weight to work out if your weight is healthy. There is increasing research evidence that BMI could be a rather poor indicator of percent of body fat and does not capture information on the mass of fat in different body sites especially in persons with poor posture (postural kyphosis) common with persons with learning disability. Therefore, using BMI as a tool and measure, particularly for people with learning disabilities, can be sometimes be misleading.

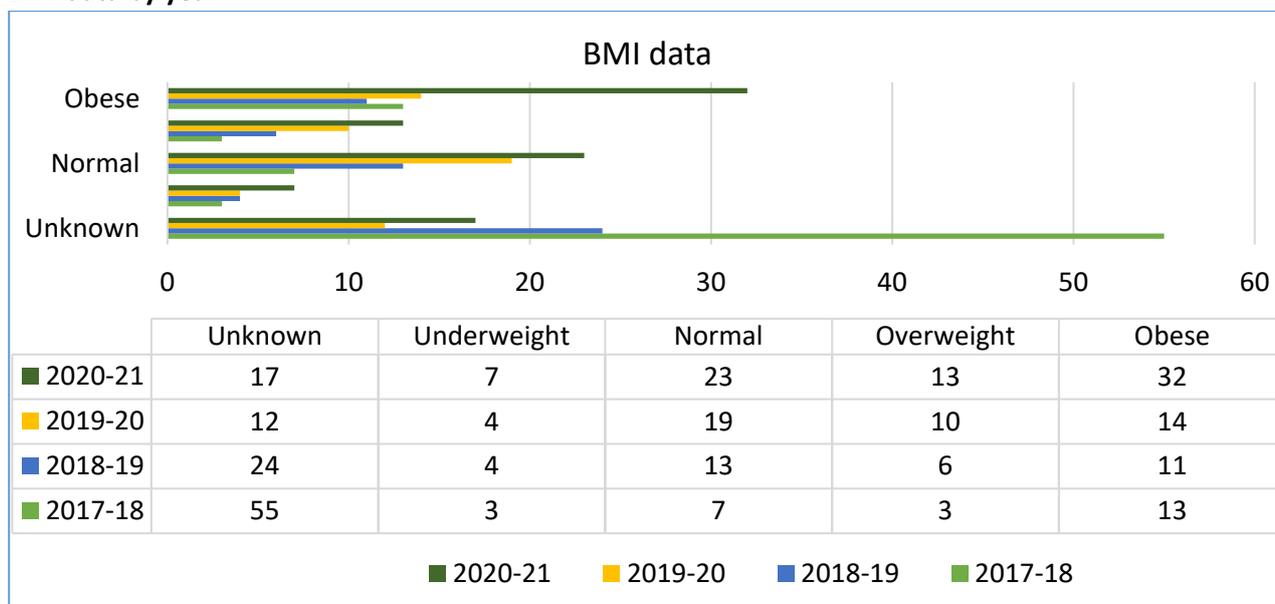
BMI tool is still the most used and acceptable measure of health. A BMI of below 18 means the person is underweight, between 19-24 is normal, over 25 is considered overweight while over 30 is obese. Being underweight (malnourished) or overweight raises the risk of serious health problems, and is known to have a direct impact on the persons' quality of life.

**Below is the analysis of data obtained from completed reviews:**

Categories	<18 BMI	19-24BMI	25-29BMI	> 30 BMI	Unknown
Males	7	37	20	34	60
Females	11	25	12	36	48
<b>Numbers</b>	<b>18</b>	<b>62</b>	<b>32</b>	<b>70</b>	<b>108</b>

182 reviews had recorded BMI readings, most of them taken during annual health checks. 56% (102) were recorded as overweight or obese. This seemed to be in line with the national data (NHS digital Jan.2020) which show that 39.3% of women and 27.8% of men with learning disability were obese, compared with 25.1% of women and 22.7% of men in the comparison general population.

## BMI data by year



During the first year of the LeDeR programme, BMI data was not collected. No data is available on children due to the way reviews are conducted.

Since 2018, there is evidence of a gradual increase in the number of people with a learning disability receiving body mass index (BMI) checks; this has increased from 62% in 2018/19 to 74% in 2020/21.

Reviews results revealed that men were more likely to be overweight and obese than women. The number of patients who were recorded as underweight, overweight as well as obese has gradually increased over the last three years since 2018. However, it is worth noting that in 2020-21 more deaths were reported during this period compared to previous years.

Reviewers found no evidence from records to indicate that attention was being paid on underweight patients. In two reviews, the reviewers recommended awareness amongst care staff and families to recognise health risks and problems associated with being underweight.

Most reviews revealed that patients with a BMI of over 30kgs/m<sup>2</sup> were referred to weight management programmes and provided with advice on balanced diet and regular exercises.

Non-compliance with exercises and healthy diet was recorded as the main reason why most patients were not able to lose weight whilst most of them were said to enjoy their lifestyle. It was not clear from records how most of these exercise class referrals were being monitored.

Reviewers identified that being overweight or obese was a common issue amongst people with a learning disability and this is complicated by poor mobility and/or wheelchair dependency. All overweight and obese patients were noted to have had impaired mobility and/or wheelchair users.

Some GP surgeries and care homes were reported not having weighing scales to help monitor patients' weights, especially those using wheelchairs. Reviewers recommended the use of or access to wheelchair scales to help weigh people in the community.

Findings showed that most exercise referrals were made to 'mainstream community gyms' and it was not clear what support was available for people with learning disabilities from these services.

Suggestions were made around gym services for people with learning disabilities or specific time slots in community gyms with support to encourage participation.

Some patients were referred a nutritionist/dietician, however reviewers had no access to healthy eating plans for comments. Failure to attend a dietitian clinic led to patients being discharged back to their GP. Reviewers suggested that people with learning disabilities should be supported to access dietician services, and missed appointments should be followed up with families and care providers.

There were two successful weight management stories. Overall, families and care staff reported that more needs to be done on weight management.

### **BMI and use of antipsychotic medicines**

45 (44%) of these 102 reviews were known to have been on psychotropic medicines for periods ranging between and 5 and 10 years or more. Research studies by Mencap 2018 indicate that weight gain can be associated with use of psychotropic medicines including antidepressants, mood stabilizers and antipsychotic drugs.

It was suggested that patients with a BMI of over 25 should be regularly reviewed and where appropriate, supported to stop or reduce antipsychotic medicines.

### **Stopping overmedication of people with a learning disability (STOMP)**

STOMP is about helping people to stay well and have a good quality of life by stopping the over use of medicines for people with a learning disability, mainly psychotropic medicines. These are medicines used for psychosis, depression, anxiety, sleep problems, epilepsy and sometimes given to people because their behavior is seen as challenging.

*‘Every day about 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for. Children and young people are also prescribed them.*

*Whilst these medicines help people stay safe and well, they can cause problems if people take them for too long or take too high a dose or take them for the wrong reason.*

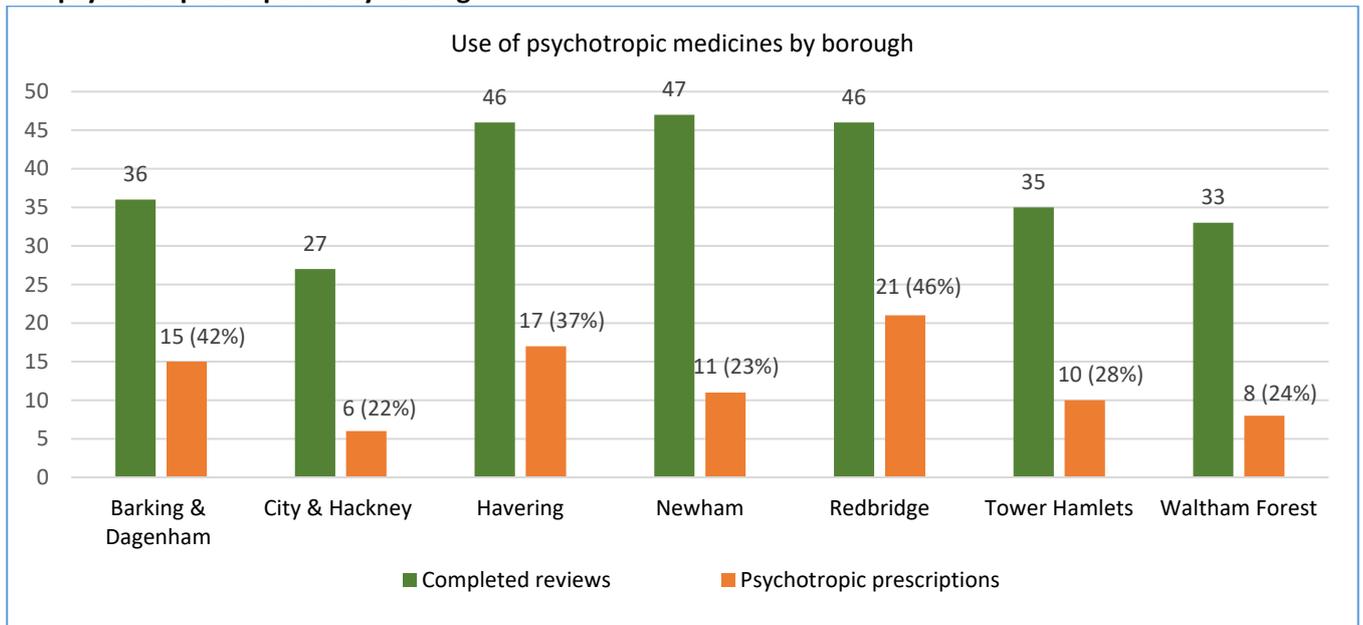
*Some common side effects include: putting on weight, feeling tired or ‘drugged up’ and problems with physical health.*

*Sources: <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>*

Analysis of the 290 completed reviews showed that 99 patients had one or more of the following conditions: epilepsy, psychotic episodes, depression, bipolar affective disorder/personality disorder, challenging behaviour, anxiety, agitation/irritability behaviour and hallucinations.

89% (88 reviews) had had psychotropic medicines prescribed and of these only a small number (11, 11%) were recorded as not being on medication for their challenging behaviours. In some cases, reviewers found no formal diagnosis or reason for these prescriptions.

## Antipsychotic prescriptions by borough

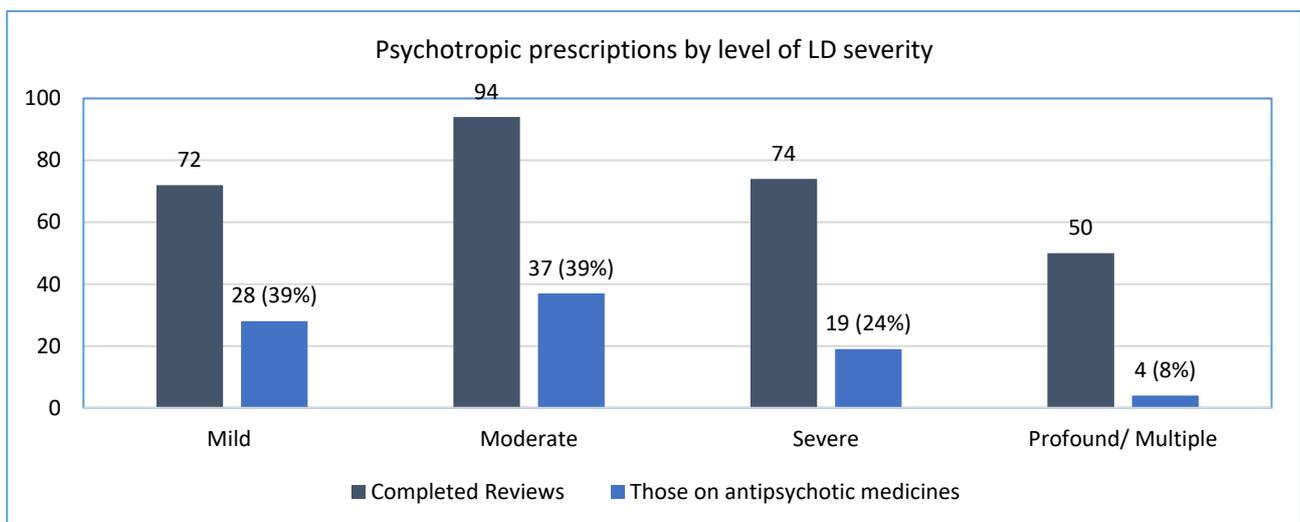


Of the 88 patients prescribed antipsychotic medicines, 21 (46%) were Redbridge patients while 6 lived in City and Hackney. The above data indicate that people with learning disabilities living in Redbridge, Havering and Barking and Dagenham were more likely to be prescribed antipsychotic medicines compared those living in City and Hackney and Newham.

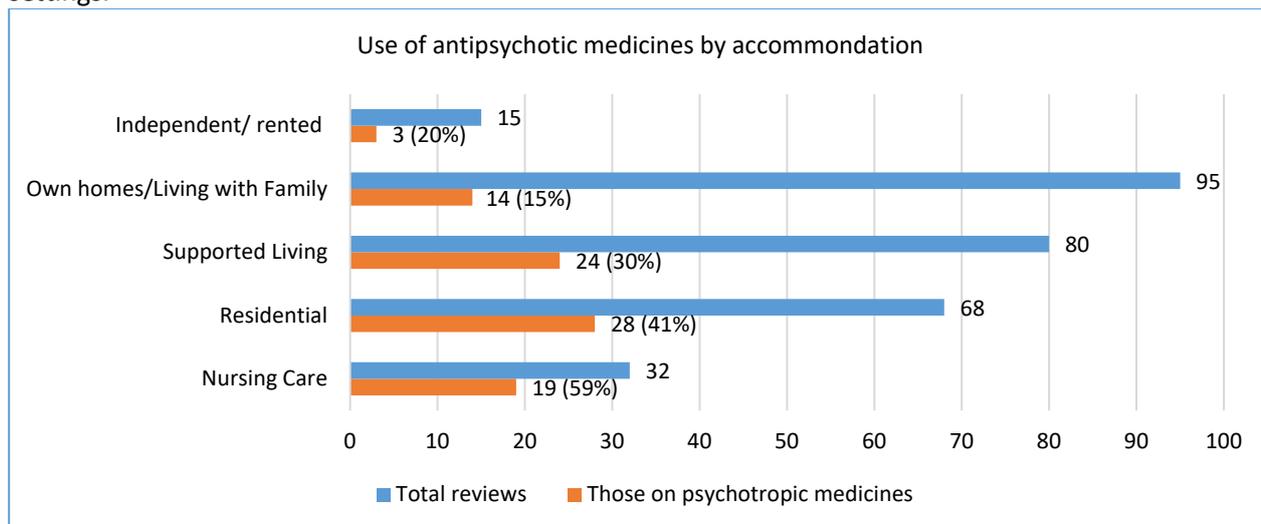
Review results showed that more men were prescribed psychotropic medicines than women - 52 (59%) males were prescribed psychotropic medicines compared to 36 (41%) females. This is in line with the overall male to female ratio which indicate we have a higher number of males diagnosed with a learning disability. Some records (15 reviews) indicated that a number of attempts had been made to withdraw antipsychotic medications, however only four (4) were successful.

More people with mild and moderate learning disabilities were found to suffer from psychotic episodes, depression, bipolar affective disorder/personality disorder, challenging behaviour, anxiety and agitation or irritability behaviour.

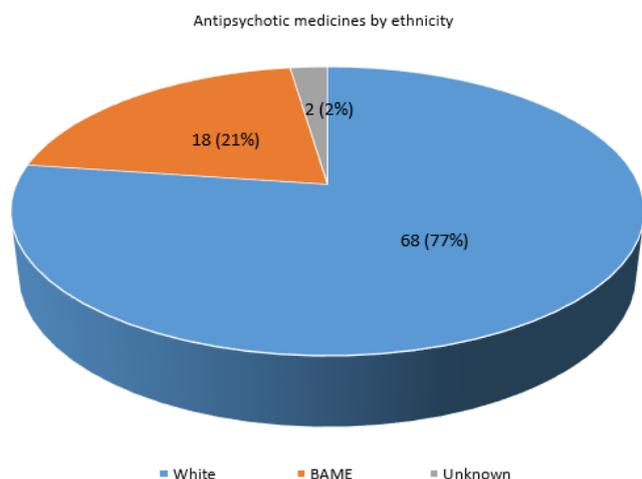
78% of those with mild and moderate learning disability were prescribed psychotropic medicines compared to 22% of those with severe and profound learning disabilities. Below were the findings from completed reviews:



Further analysis showed that patients living in residential, nursing and supported living were more likely to be prescribed psychotropic medicines compared to those living with families and independent accommodation settings.



Of the 88 patients prescribed antipsychotic medicines, 77% (68) were of white background compared to 21% (18) of the BAME ethnic background.



Reviewers recommended more patients to be considered for social prescribing service which is currently provided by GPs to help people with learning disabilities access a range of local, non-medical activities, opportunities and support that can improve their health and help them to live life to the full. It also aims to support individuals to take greater control of their own health. Social prescribing schemes can involve a variety of activities, most of which are provided by voluntary and community sector organisations.

The NHS Long Term Plan commits to embedding social prescribing link workers within every primary care network and NEL Learning Disability and Autism strategy commits to support the implementation of the STOMP pledge.

## Mental Capacity Assessments and Restrictive Legislation

Mental capacity assessments are applied to people aged 16 and over. The aim is to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. MCA covers a wide range of decisions such as day to day decisions on what to wear, personal care, where to shop, to big and serious life-changing decisions like changing homes, major surgery and financial management.

*People who 'may' lack capacity include those with dementia, severe/ profound learning disabilities, mental health illness, suffered stroke or suffered brain injury.*

*But just because a person has one of these health conditions does not necessarily mean they lack the capacity to make a specific decision.*

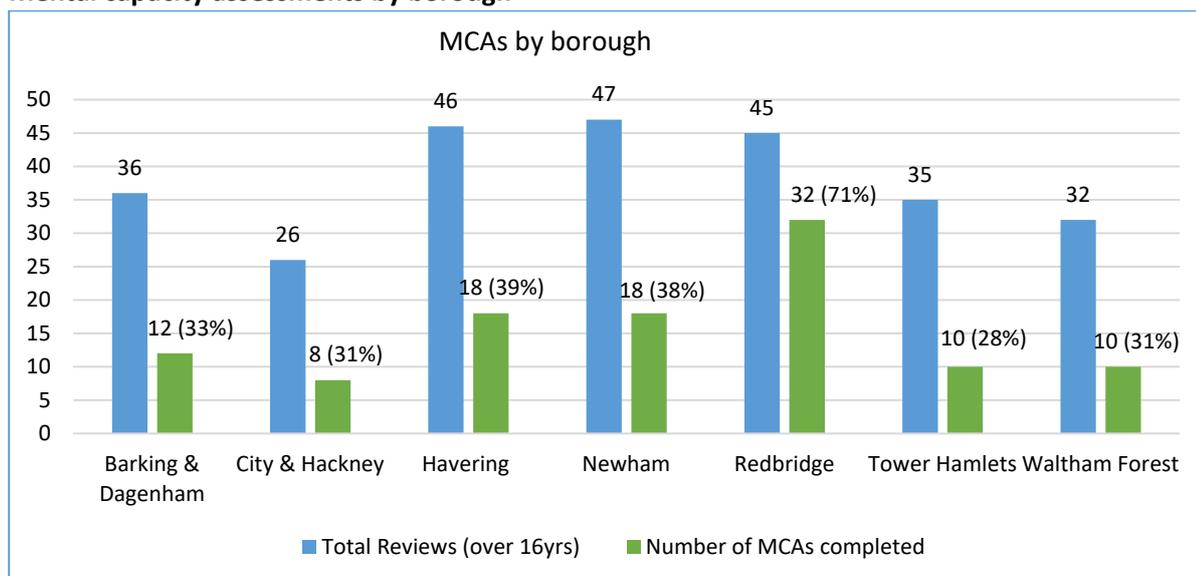
*Someone may lack capacity to make some decisions (for example, to decide on complex financial issues) but still have the capacity to make other decisions (for example, to decide what items to buy at the local shop).*

*MCA helps identify specific areas of support that an individual needs.*

Sources: <https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/>

267 reviews were within this age group and eligible for MCA assessment as may be deemed necessary. 40% of all eligible patients (108), 16 years of age and above, had mental capacity assessments or Deprivation of Liberty safeguards (DoLs) approved. No evidence of mental capacity assessments found in 159 (60%) reviews completed.

### Mental capacity assessments by borough



The above data shows that Redbridge recorded the highest number of mental capacity assessments and/or Deprivation of Liberty safeguards (DoLs) approved. This evidence indicate that people living in Redbridge, Newham and Havering were more likely to have mental capacity assessments or DoLs approved compared to those living in City & Hackney and Waltham Forest.

Overall data showed a decrease in the accumulative percentage from 48% reported in 2019 to 39% in 2020. Reviewers recorded that due to national restrictions put in place because of COVID19, there were delays in getting mental capacity assessments or DoLs completed or renewed in a timelier manner.

This report recognises that there is no clear guidance as to when a person should have mental capacity assessment. The Metal Capacity Act states that:

- assume a person has the capacity to make a decision themselves, unless it's proved otherwise
- wherever possible, help people to make their own decisions
- do not treat a person as lacking the capacity to make a decision just because they make an unwise decision

- treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms
- if you make a decision for someone who does not have capacity, it must be in their best interests

### Deprivation of Liberty Safeguards (DoLS)

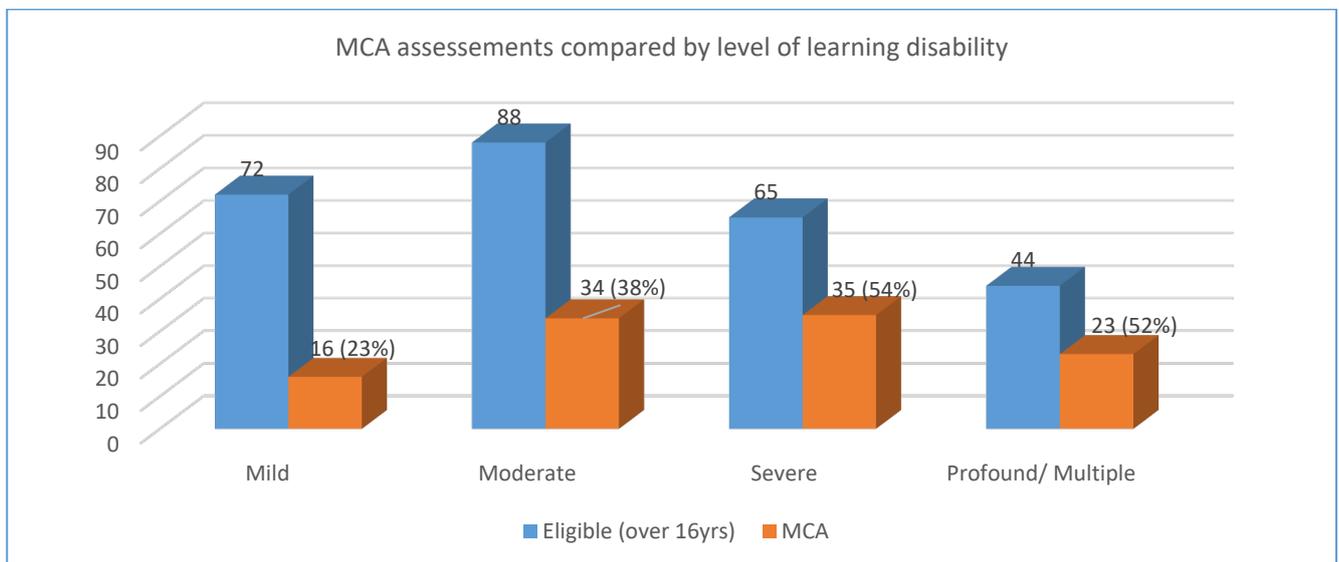
Deprivation of Liberty Safeguards (DoLS) only applies to people who are in a care home or hospital. DoLS are applied for people who are deemed not to have capacity or the ability to consent to their care arrangements; they ensure decisions are made in the person’s best interests.

There was noticeable increase on the number of DOLs referrals from 17% in 2019 to 74% in 2020. 80 reviews out of the 108 (74%), had Deprivation of Liberty safeguards (DoLS) approved. Evidence showed that all those patients who had DoLS in place were either in residential care, nursing care homes or supported living.

During the lockdown period resulting from COVID-19, it is recorded that there were delays in DOLs being renewed in a timely manner. Access to patients was restricted and social services were having to deal with a backlog due to COVID19 restrictions.

### MCA and severity of learning disability

Out of the 108 reviews that had mental capacity assessments- 54% (58 reviews) were known to have had severe and profound, 34 (31%) moderate while 16 (14%) had mild learning disabilities.



People with severe and profound learning disabilities were more likely to have a mental capacity assessments carried out, compared to those with mild learning disabilities.

Most people with mild learning disabilities were assumed to have capacity and less likely to have mental capacity assessments. Reviewers suggested that it is good practice to carry out MCA assessments on all people known to have a learning disability to ascertain the level of support that a person may need.

### Restrictive legislation

Restrictive legislations are statutory rules that limit the rights of a person, like being able to move around freely or stop a person from doing behaviours of concern, such as self-harm or harm to others.

Seven (7) patients had had restrictive legislations in place. Five of them were under Mental Health act sections 49, 43, 42 and 3 for varied reasons. Two (2) reviews were recorded has having had Court of Protection (COP) orders in place due to lack of capacity and their welfare being at risk and decisions had to be made on their behalf. It is not clear how effective these legislations were as this information is not captured in the LeDeR review proforma.

## End of life care

End of life care is also referred to as palliative care or advanced care planning. It involves conversations between people with learning disabilities, their families and carers and those supporting them about their future wishes and priorities for care.

*'Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences when it comes to the end of life stage.'*

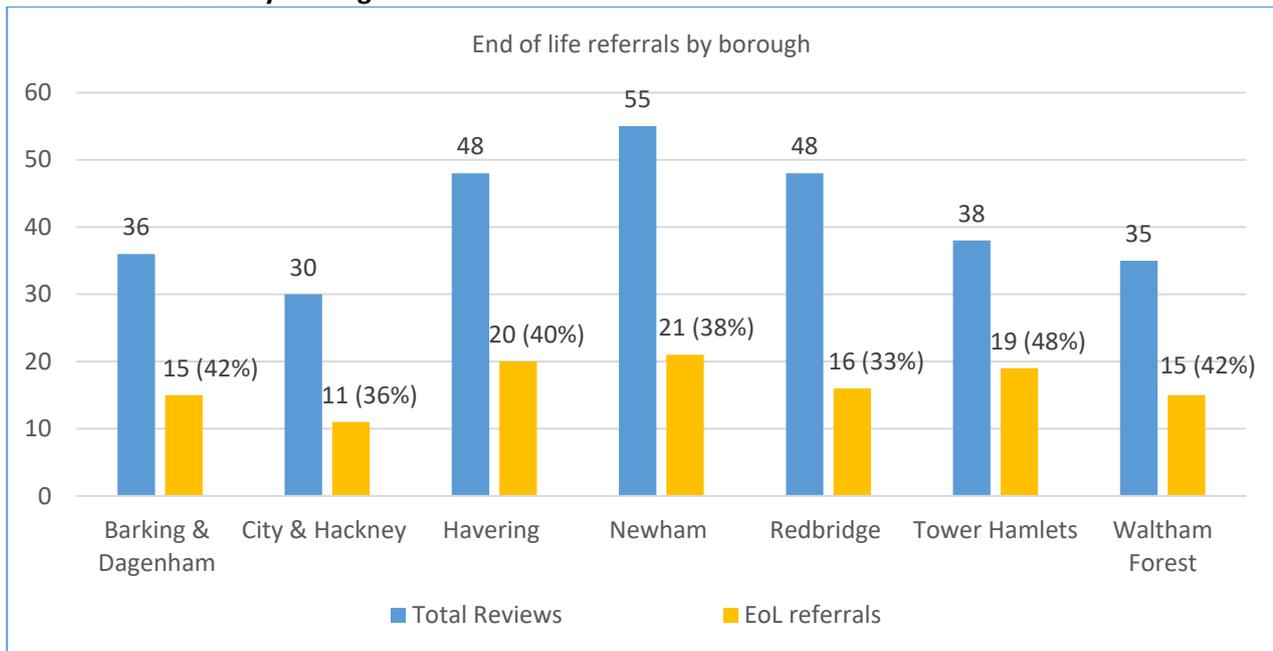
*The aim of advance care planning is to help ensure that people receive care that is consistent with their values, wishes and preferences'*

Source: <https://www.goldstandardsframework.org.uk/advance-care-planning>

117 (40%) reviews showed that patients had end of life plans in place at the time of their death. The end of life period varied between 2 weeks and a day before the person's death. Most of these care plans were decided and put in place at the hospital during the person's last admission.

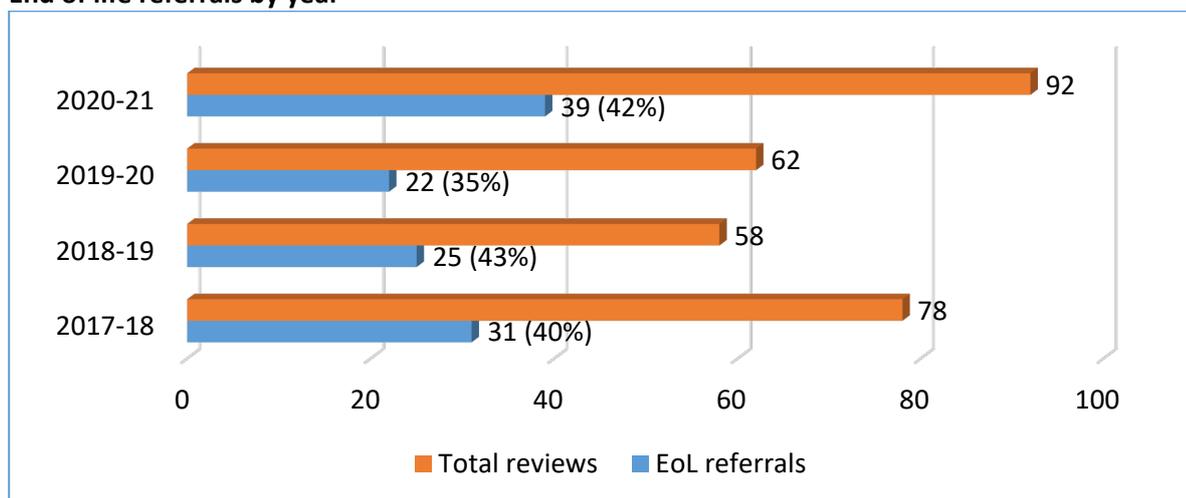
62% (72 of these 117 patients) died in a hospital setting, 32 (27%) in their usual place of residence or own homes and 13 (10%) in a hospice unit. Most of those who died in a palliative care unit and those on a palliative care pathway in the community, were recorded as having had their wishes observed and delivered. There is no data available to indicate whether peoples' wishes were observed in all other settings.

### End of life referrals by borough



From the above results indicate that people with learning disabilities living in Tower Hamlets, Barking and Dagenham, and Waltham Forest were more likely to be referred for end of life care compared to those living in Redbridge and City and Hackney. However, it is worth noting that many of end of life referrals were completed during the patient's last admissions and some may not have had this care pathway started at the time of their death.

### End of life referrals by year



The above review results show a 3% increase in the number of end of life referrals between 2017 and 2018- from 40% to 43%. In 2020 the number of referrals went down to 35% however, there has been an increase in 2020-21 despite COVID19 challenges.

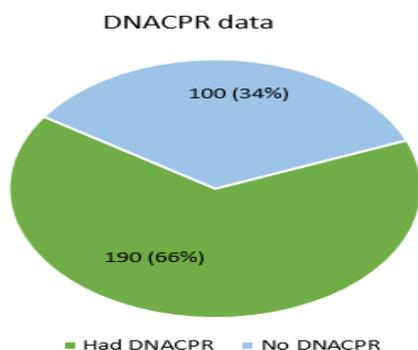
Reviewers recorded that well planned end of life care leads to good quality end of life. In four (4) reviews, patients who had had a palliative care plan in place for longer than a month; the care delivered was graded as excellent or good, and families' feedback was positive.

Training care staff on end of life care, recognising deterioration and making referrals in a timely manner was recommended. Training care staff would empower them to feel more confident in supporting families with advance care planning and enable patients participate/ contribute to their care and wishes at this stage of life.

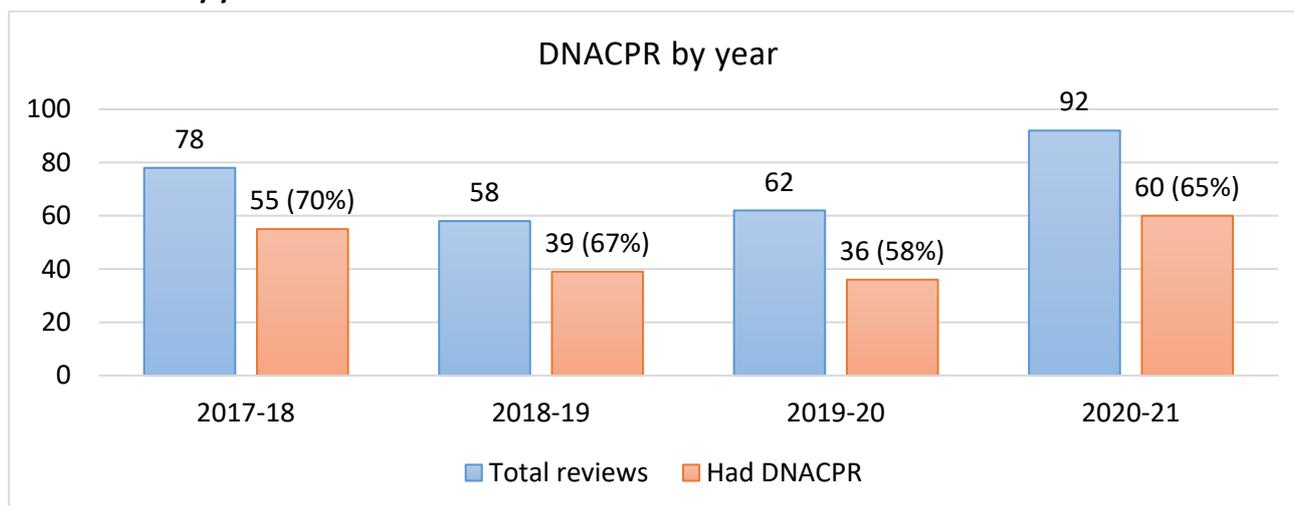
### Do not attempt cardiopulmonary resuscitation (DNACPR)

NICE guidelines state that it is good practice that decisions about do not attempt cardiopulmonary resuscitation (DNACPR) should be clearly communicated to all those involved in the patient's care. It is important that healthcare professionals, patients, families and those close to patients understand that a decision not to attempt cardiopulmonary resuscitation applies only to cardiopulmonary resuscitation (CPR) and not to any other element of care or treatment. A DNACPR decision must not be allowed to compromise high quality delivery of any other aspect of care.

Out of the 290 reviews, 190 (66%) patients had a DNACPR order in place before they died. Most of these were completed in the hospital during the last few days of their life, or shortly before they died. 100 (34%) of these patients did not have a DNACPR order in place; most of these deaths were unexpected from sudden deterioration.



## DNACPR data by year



Some families informed reviewers that they were not involved in DNACPR decisions and for others, the message was not communicated in a manner where they understood the implications of the DNACPR. Reviewers recommended that in a situation where a DNACPR is to be put in place, families should be involved and given the opportunity to ask questions.

Community DNACPRs, which were mainly GP led, were recorded as having had involved families and the care staff involved seemed to understand what needed to be done in the event of a cardiac arrest. The wishes of the patient and the next of kin were followed. Families were allowed to share their views and attend medical appointments if they could. In most cases, families were able to support appropriate care provision and the outcomes were recorded as good or satisfactorily.

Whilst the majority of DNACPR documentations were appropriately completed and correctly followed, some of the DNACPR order forms were noted as inadequate. Some forms had one signature instead of two. Other forms had very little information on them to explain why and how these decisions were reached.

In two reviews, the Acute Learning Disability Liaison Nurse identified that a DNACPR had not been applied appropriately. In one case, the reason given for the DNACPR was learning disability and this was challenged. The clinical staff involved in these decisions withdrew these orders. Recommendations recorded on these reviews encouraged all professionals to challenge inappropriate application of DNACPR orders; learning disability should not be cited as reason for DNACPR or documented as cause of death. The reviewers recognised that while the final DNACPR decision lies with the doctors, it is good practice to discuss with families, other staff and professionals involved in the patient's care.

Acute LD nurses were praised for their relentless efforts to get involved with DNACPR decisions and other key treatment decisions, and for going the extra mile to explain to families what this means as well as providing the necessary support.

Reviewers also documented that mental capacity assessments were not commonly completed to ascertain whether patients had capacity to make DNACPR decisions. Most people with learning disabilities were assumed to lack capacity and in most cases, they addressed their carers or next of kin rather than the patients.

This report recognises that supporting someone who is approaching end of their life can be one of the most challenging work that any social care or health worker face. NEL LeDeR programme will work close with End of life care teams and trained end of life facilitators to support carers and health care professional to have these difficulty and sensitive conversations around DNACPR and end of life plans as important areas to providing high quality and person-centred end of life care.

## Dental Care

Reviewed GP records showed that over half (54%) of all patients had poor oral hygiene and they had been advised to attend regular dental checks. There was evidence that most of the patients with learning disabilities were reluctant to allow regular teeth cleaning contributing to poor oral hygiene. The reviewers found limited evidence that these patients were being referred to specialist dental services due to fear of going to the dentist (dentophobia).

In one review there was evidence of the lack of action taken around the patient's poor oral hygiene. The reviewer stated that "there were missed opportunities by healthcare professionals to refer to specialist dental services or advise family and support staff about the importance of good oral hygiene".

The reviewer recommended that:

- GPs should ensure poor oral hygiene among people with learning disabilities is addressed at every opportunity; community learning disability teams to work closely with GPs; and families and care providers to support patients identified as needing dental care to access this service.
- More awareness is required for families, support workers and care staff about oral hygiene and common diseases and conditions and how this is linked to the health and wellbeing of the patient.

Healthcare professionals to provide patients and carers with information about oral care and how to access dental services in the person's local area including specialist dental services in hospitals.

## Care Coordination

Care coordination in this report refers to bringing together the delivery of a patient's health care from multiple providers and specialists teams especially those with complex long-term conditions. The aim is to work together as a team and improve the health outcomes by ensuring that care from various providers is not delivered in silos, eliminate duplicate tests and procedures and to help save time and reduce costs. In most cases, the GP was the named care coordinator.

The majority of patients recorded as having had care coordinators were mostly those on a continuing health care (CHC) pathway. 42 reviews were recorded as continuing health care funded; over 70% (30) had named care coordinators, most of whom were their GPs, and the outcome of the care provided was graded as good.

The following good practice were evident from these completed reviews:

- easy access to a range of health care services and providers
- good communications and effective care plan transitions between providers
- a focus on the total health care needs of the patient (multiagency decisions)
- clear and simple information that patients can understand

In some cases, reviewers recorded that CHC referrals were completed but there was no evidence of CHC funding being in place. Reviewers recommended that community learning disability services should follow up raised referrals to ensure that patients get access to the services they need.

## Reasonable adjustments

A lack of reasonable adjustments can be a barrier to accessing healthcare settings. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) confirmed that lack of reasonable adjustments could be a contributory factor in a number of avoidable deaths.

Making reasonable adjustments is a statutory duty under the Equality Act 2010. It states that all health and social care providers must make reasonable adjustments to remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether.

Despite challenges due to COVID-19, care services adapted quickly, making reasonable adjustments to ensure equity of access to services and continuity of care. A mix of video and telephone and face to face consultations continued during the pandemic.

Impaired mobility and poor communication were identified as the main areas that were shared across many people with learning disabilities. 25% (72 out of 290) of patients were recorded as wheelchair users and/or homebound particularly toward their end of life. 85% were known to have communication problems.

Reasonable adjustments varies from person to person based on need and can include providing easy-read information, translation and interpretation services, home visits, mobility equipment, and home adaptations to flexible and longer appointment times.

Provision of mobility equipment's, longer appointments and home visits were evident in completed reviews. In some reviews, easy read appointments letters were noted especially in some community services.

### Some exceptional examples of provision of reasonable adjustments from completed reviews:

- a) *One hospital arranged for a pre-admission assessment (for a colonoscopy) to take place from the care home where the patient was used to and comfortable.*
- b) *One patient whose condition was noted to be deteriorating was provided with a special recliner chair which could double up as a bed and a chair.*
- c) *Use of sedation to help undertake some examinations and bloods was evident on some patients who were known to have significant fear of needles.*
- d) *One social care team approved purchase of 'special incontinence pads' as the patient had a reaction to the 'normal supplies'.*
- e) *Another social care team went out of its way to pay for 'a private podiatry service' for a patient who had been on the podiatry waiting list for almost year.*

Whilst this report recognises that a lot has been done, more can be done in the following areas:

- provision of individualised reasonable adjustments
- joint health and social care assessments and regular reviews to identify unmet needs
- provision of translation services for families for who English is not their first language
- provision of patient tailored and/or preferred mode of communications
- provision of suitable and flexible appointments

The report also acknowledges that reasonable adjustments is somewhat hard to measure as each person's needs are different however with the new platform, there is work in progress to try and put in place key information to help capture and monitor future progress on this element.

NEL Learning disability and Autistic programme team has been running GP webinars to encourage GPs to provide personalised reasonable adjustments with the view to improve access to services therefore improved health and social care outcomes for people with learning disabilities.

## Carers' Assessments

A carer's assessment is for anyone aged over 18 years old who is looking after another adult (disabled, ill or elderly) over 18 years old. A carer's assessment provides an opportunity to record the impact caring could have on the person's life and what support or services one may need.

Most families stated that looking after a family member or friend who needs help because of age, illness or disability is a challenge, however this was accepted as their responsibility. Although the LeDeR review form does not provide for gathering specific information about carers assessments, it was evident that some families declined the offer.

Some families feared that a carer's assessment would have an impact on family benefits and/or resulting in the looked-after person being taken into residential care.

*Reviewers acknowledged that without the right information and support, caring can take its toll on family finances, careers, and carer's health and also have a negative impact on others family members and their social life.*

Source: <https://www.carersuk.org/news-and-campaigns/news/carers-assessment-uptake-still-too-low>

Reviewers recognised the vast amount of support and contribution families' put into caring; in eight (8) cases, family members had left work or school to look after their siblings or parent or relative. In some families, siblings were noted to accompany their parents whose English is not first language to act as interpreters in clinical appointments.

Recommendations from these reviews indicated that all carers should be provided with the right information and support to understand the importance of carer's assessments; professionals to work closely together to identify and support carers before they hit a crisis point and more staff awareness about the role of carers.

## Challenges to accessing services

Evidence showed that different groups of people are facing different issues contributing to poor care and subsequent avoidable deaths.

The most recorded barriers to accessing services were: physical disability and poor mobility (including homebound patients) ; lack of provision of reasonable adjustments; poor communication/ language barriers; medical conditions (including mental health issues); isolation; deprivation (poor living and working conditions); in some but few reviews, cultural and religious reasons were mentioned. Long waiting times in some community services, such as speech and language therapy and podiatry services for patients who were not diabetic was also identified as an issue.

## Grading quality of care

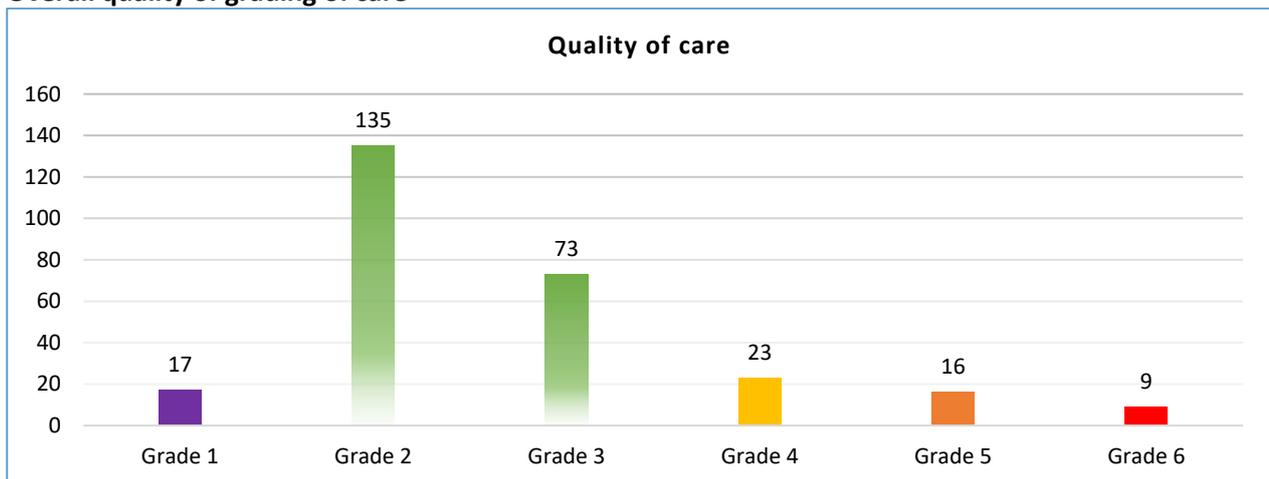
At the end of each review, reviewers were asked to grade the overall quality of care provided and this is based on the following factors:

- Best practice identified during the review process
- Gaps in service provision that might have contributed to the person’s death
- Any issues with organisational systems and processes that may have affected delivery of care including care coordination
- Evidence of abuse or acts of omissions or neglect or safeguarding issues.

The LeDeR review programme uses six categories to grade the quality of care provided. These are: grade 1 and 2, excellent or good (care met expected best practice); grade 3 and 4, satisfactory care (which means care fell short of expected good practice in some areas but this did not impact on the person’s wellbeing) and grade 5 and 6 are poor care. Poor care grades indicate that the care provided ‘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 or contributed to the cause of death’.

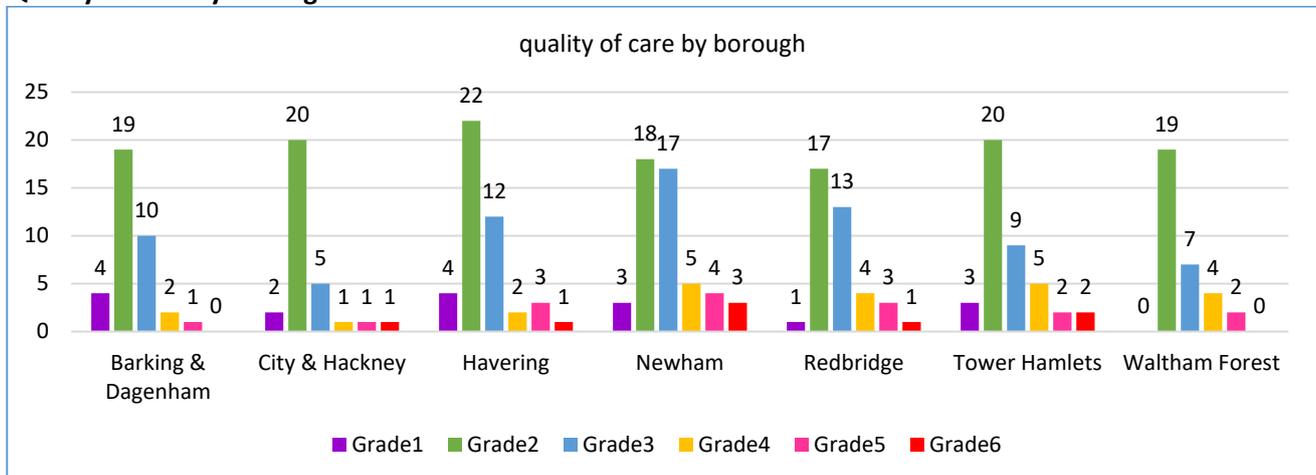
Below is the analysis of grading of care from all completed 273 reviews completed. This figure included all adult cases and 18 child deaths which were completed as part of the child death overview panel (CDOP) process and had had their grading indicated.

### Overall quality of grading of care



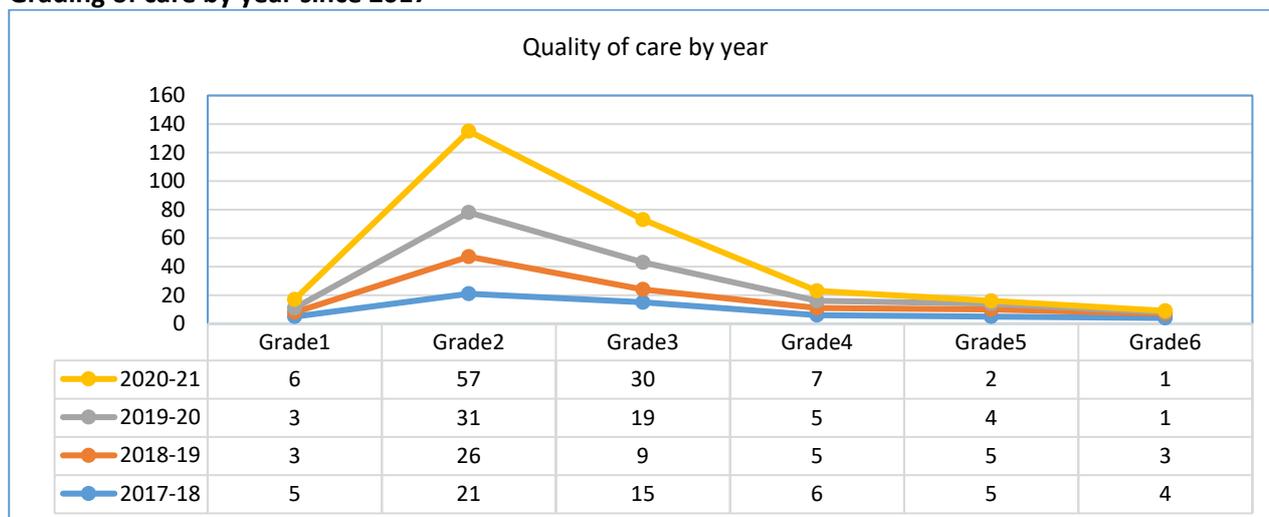
49% (142) of all completed reviews were graded as having received excellent and good care, 33% (96) received satisfactory care while 8% (25) received poor care.

### Quality of care by borough



More people living in City & Hackney and Barking and Dagenham were likely to receive excellent or good quality of care, followed closely by those living in Newham and Tower Hamlets. However, Newham had more reviews graded as poor (grade 5&6) compared to the rest of the six areas.

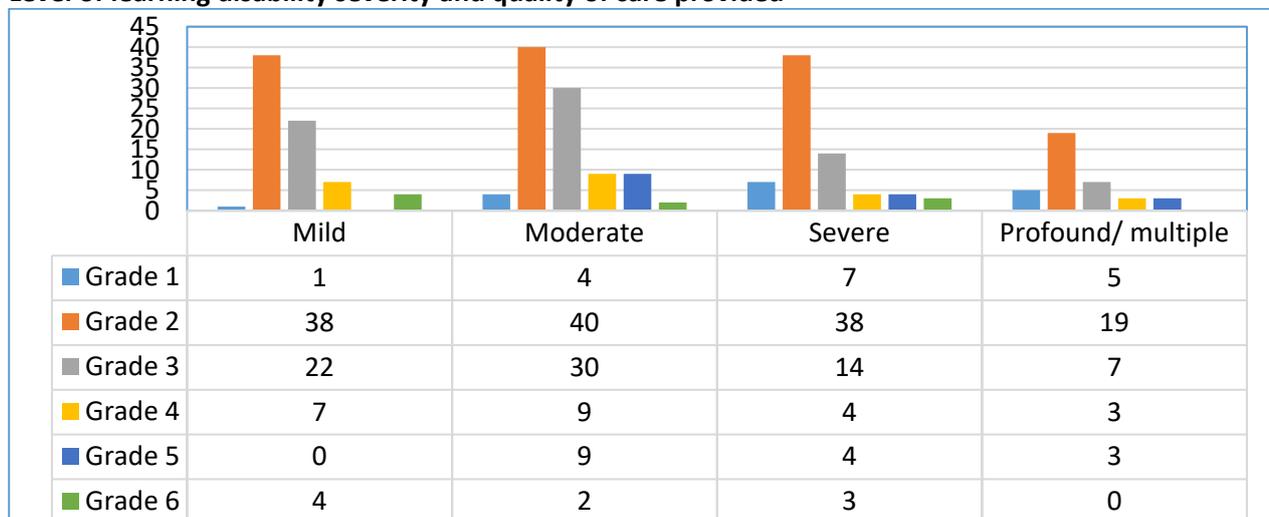
### Grading of care by year since 2017



The above data shows that there was improvement in quality of care provided and this is evidenced by the decrease in the number of poor care cases (grades 5 and 6) from 9 reviews to 3. This translates to a decrease from 16% since the start of the programme in 2017/18 to 3% in 2021

There is notable increase in excellent and good care reviews (grade 1&2) from 25 to 61 reviews; which means an increase from 46% in 2017/18 to 58% on 2020/21.

### Level of learning disability severity and quality of care provided



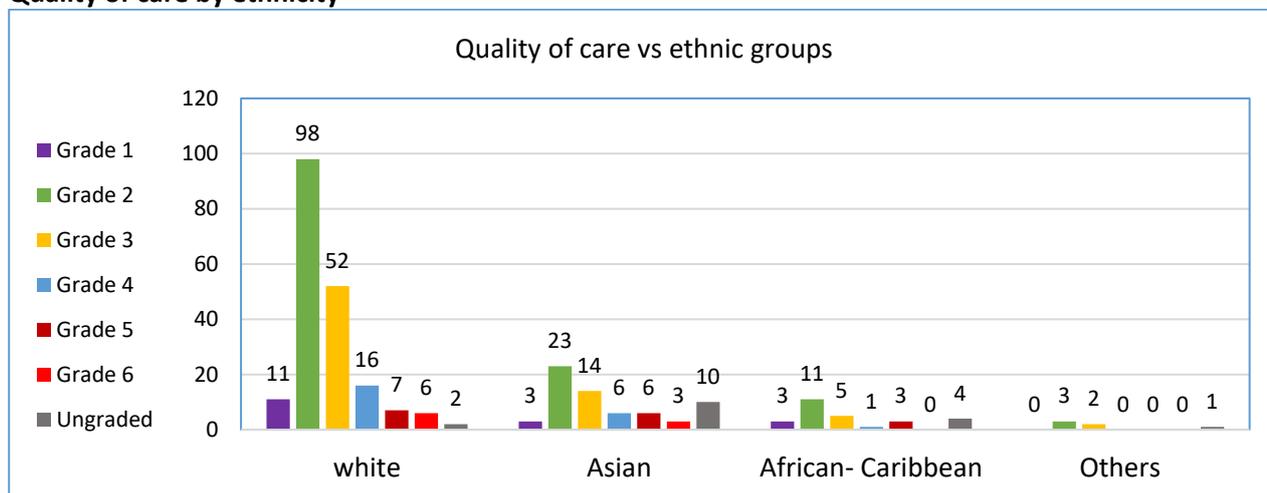
People with mild and moderate learning disabilities were more likely to receive poor care compared to those with profound and multiple learning disabilities.

People with mild learning disabilities were found to be less likely to access community learning disability services. Most of them were said not to meet the criteria to be referred for these services.

## Grading of care and the broad ethnic groups

The 4<sup>th</sup> LeDeR annual report 2019 indicated that people of Black Asian Minority Ethnic (BAME) populations are more likely than others to face barriers in accessing services, less likely to receive specialist services, and more likely to have poor knowledge about those services available to them. The same report acknowledged that the growth of various ethnic communities and linguistic groups, each with its own cultural traits and health profiles, presents a complex challenge to healthcare practitioners and policy makers in terms of achieving equitable access.

### Quality of care by ethnicity



From the above data, people of BAME population groups were more likely to receive poor care (grade 5 and 6) compared to their white peers. This data, shows that 7% (13 out of the 187 reviews of people of white background) received poor care compared to 13% (12 out of the 97) reviews of the BAME background.

This year's findings indicate that there is no significant shift compared to last year's annual report 2019. Current review findings indicate poor patient communication and poor involvement in decision making were recorded in some reviews. Some families whose English was not first language continued to use family members to provide translation services. Most health and social care information was provided in English and it's not clear how much these families were able to understand this information. Similar recommendations were made around:

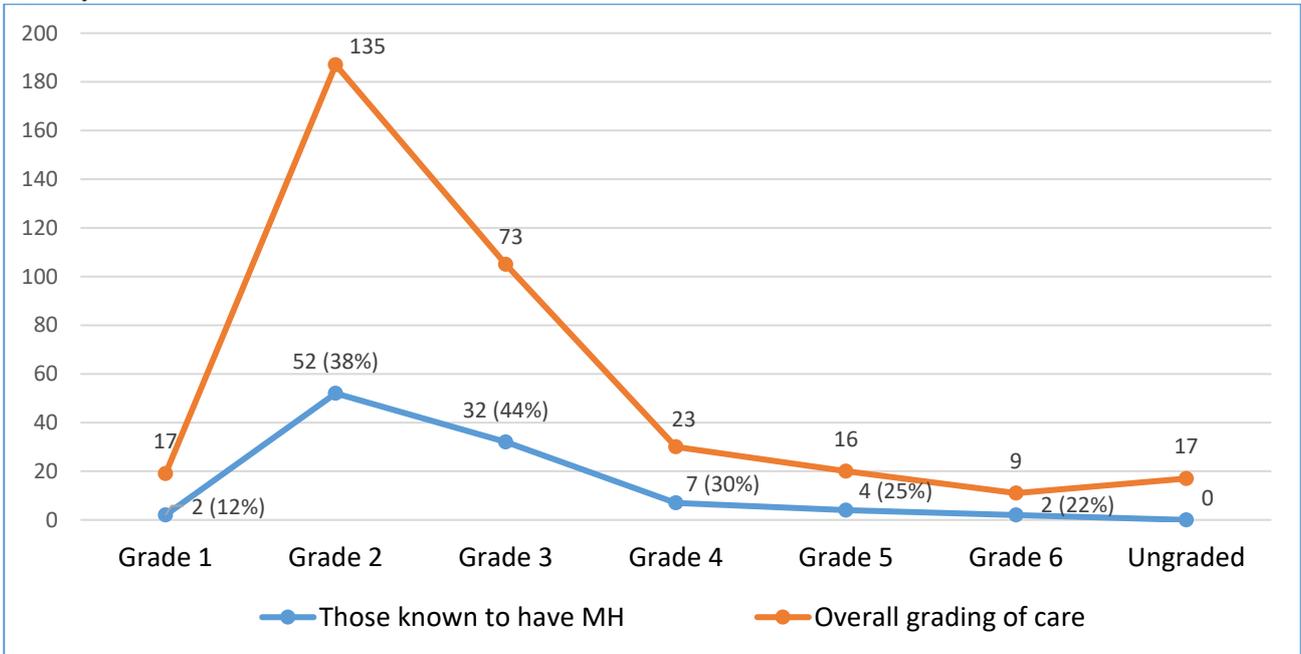
- provision of appropriate information (translation and interpretation services)
- having access to services that are relevant, timely, and sensitive to the person's needs including cultural needs and religious needs
- being able to use the health service with ease, and having confidence that you will be treated with respect

Closing this health gap for people in these population group is now an important priority. The new LeDeR policy has placed emphasis on detailed or focussed reviews on all BAME deaths and having a BAME representative in local LeDeR steering groups to help understand barriers to accessing services facing BAME groups and ensure actions are taken. This role is expected to deliver on the following areas:

- to establish links with local organisations which represent people from BAME communities, especially those with a learning disability and raising the profile of LeDeR within those communities
- to understand the local BAME profile and expected prevalence of people with a learning disability who are from BAME communities in their local area
- to understand and ensure action on local factors relating to people who are from BAME communities and their access to services

The new LeDeR policy will require a focussed review for every BAME death and NEL is committed to ensuring that reviewers are supported to work with families and care providers to ensure focussed reviews capture progress on the above recommendations.

### Quality of care for those with mental health issues

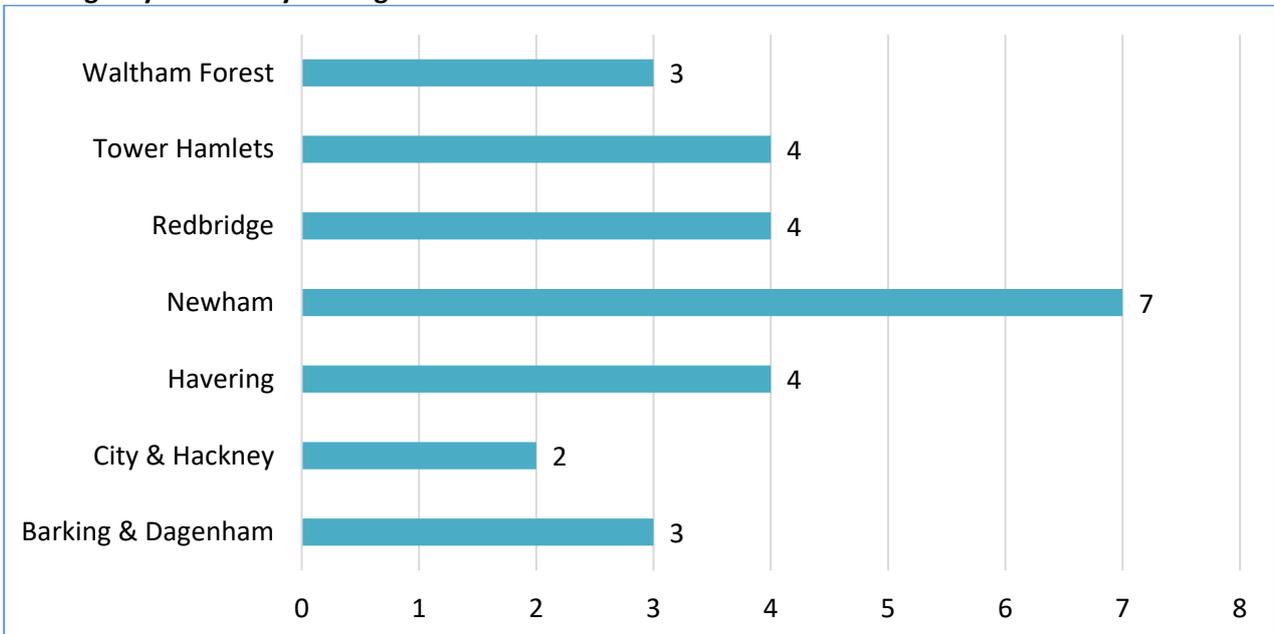


From completed reviews there is an indication that people with mental health issues were less likely to receive high quality care compared to those without. No data is available to indicate how many of the children reviews may have had known mental health issues, most of whom grading of care was not recorded.

### Multiagency reviews (MAR) and safeguarding adult reviews (SAR)

All reviews graded as 5 and 6 indicated that there were concerns or potential issues with the care provided and that a more focussed review (also referred to as multi-agency review) was needed to bring additional learning. 25 reviews were graded as poor; 13 had multi-agency reviews completed and in 12 reviews were referred for further investigation under the adult safeguarding process.

### Multiagency reviews by borough



### Safeguarding adults reviews by borough

Borough	Safeguarding Adults reviews
Barking & Dagenham	1
City& Hackney	1
Havering	2
Redbridge	1
Newham	4
Tower Hamlets	2
Waltham Forest	1

Twelve (12) safeguarding adult reviews (SARs) were completed as a result of LeDeR review referrals. Newham borough had the highest number of SARs. Review findings indicated serious failings with the care provided and this was believed to have had a significantly impact on the persons’ wellbeing and/or had the potential to contribute to the causes of death or contributed to the causes of death.

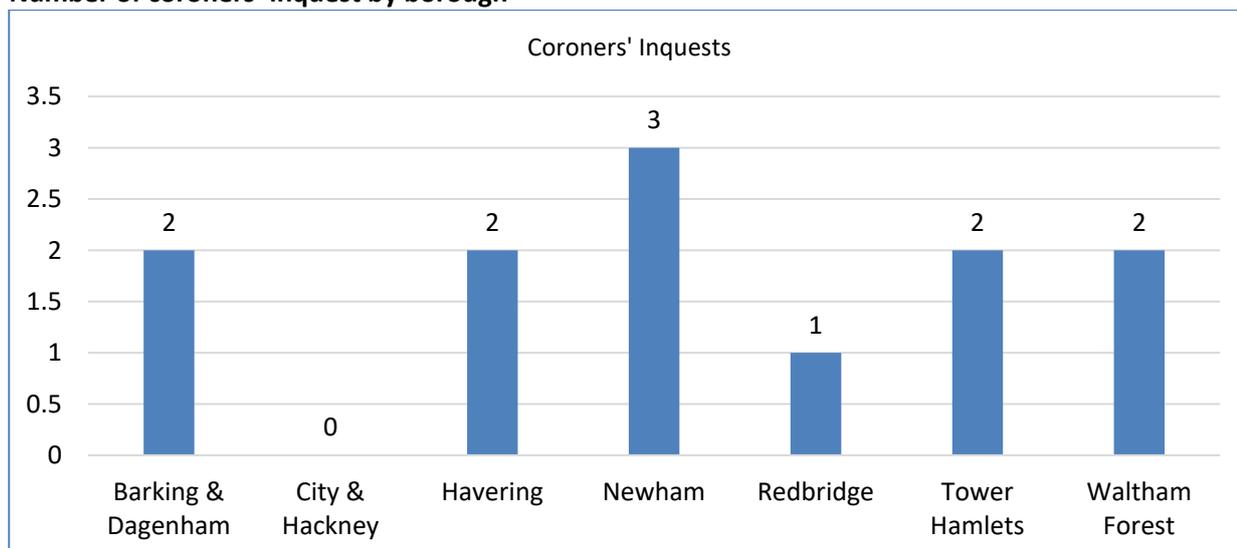
### Coroner’s inquests

All community deaths are referred to the coroners. Where the cause of death is clear and there are no concerns, the GP is authorised to sign a medical certificate which allows families to register the death and proceed with funeral arrangements.

In cases where the cause of death is not clear, a post-mortem is requested to formally establish the circumstances surrounding the death. Where the cause of death is linked to ‘natural causes’, the coroner’s office will issue a certificate to the registrar to register the death.

In deaths where the cause of death is still unknown or established as non-natural after the post-mortem, and there is reasonable cause to suggest that the death may have been caused by someone else's actions or negligence, then a coroner's inquest is opened. A total of 12 reviews had coroners’ inquests; in four (4) cases the family had raised concerns.

### Number of coroners’ inquest by borough



Although there results showed relatively the same number of coroners inquests in most boroughs, Newham recorded more inquests while none was recorded under City and Hackney.

## **Staff training**

Delayed recognition of deterioration was identified in last year's annual report as an area impacting on the quality of care provided and recommendation made around staff training on recognising deterioration and understanding the needs of people with learning disabilities.

RESTORE2 is a tool that is designed to support care staff and health care professional to:

- recognise when a person may be deteriorating or at risk of physical deterioration
- act appropriately according to the person's care plan to protect and manage the resident
- complete set of physical observations to inform escalation and conversations with health professionals
- contact the most appropriate health professionals in a timely way to get the right support
- provide a concise escalation history to health professionals to support their professional decision making

It is estimated that over 50 carer staff have been trained on RESTORE2 tool across North east London and the target is to have all care staff trained by 2022. This training has been found to be useful in supporting care staff to carryout basics physical health checks which would have been otherwise hard to do before the training hence improved quality of care provided for people with learning disabilities.

## COVID-19 Pandemic

This section of the report focuses on deaths of people with a learning disability from COVID-19, and the subsequent number of full LeDeR reviews completed.

On 17th March 2020 NEL reported the first COVID-19 death, and since then 84 deaths were reported as caused by COVID-19 or COVID-19 was suspected to have contributed to the cause of death. Most of these death notifications were reported during the months of April, May, and December 2020, and January 2021.

Public health data recognises that some of these deaths would have likely occurred over the duration of the year, however they occurred earlier because of COVID-19. People with learning disabilities were more likely to be disproportionately affected by COVID-19 due to already pre-existing health conditions.

Some of the common listed conditions includes: heart disease, diabetes, lung disease, asthma, dementia, renal problems, obesity, high blood pressure (hypertension), old age and frailty. Reviews revealed that all patients who died of COVID-19 had two or more of these listed health conditions.

In April 2020, in partnership with NHS England/Improvement, NEL CCGs developed a Learning Disability COVID-19 rapid review tool to review deaths due to COVID-19 or where COVID-19 was suspected to have contributed to the cause of death. The purpose was to immediately identify any learning or practice that would assist in improving the local response to Covid-19, escalating concerns and guiding necessary changes in health and social care services in order to reduce further deaths of people with learning disabilities.

An analysis of these COVID19 reviews can be found via this link: <https://northeastlondonccg.nhs.uk/your-health/learning-disabilities-and-autism/>

### COVID-19 deaths by borough

Location	wave 1	Wave 2	End March 2021
Barking & Dagenham	3	8	11
Havering	9	5	14
City & Hackney	5	7	12
Newham	11	3	14
Redbridge	6	7	13
Tower Hamlets	4	7	11
Waltham Forest	5	4	9
<b>Total</b>	<b>43</b>	<b>41</b>	<b>84</b>

135 deaths were reported between April 2020 and March 2021; 90 of them have had a full LeDeR review. 62% (56) reviews recorded COVID-19 as the main or one of the contributing causes of death in the person's death certificate.

The data below focuses on the 56 COVID-19 reviews, which had full LeDeR reviews.

### COVID-19 Demographics

#### Age and gender

The youngest COVID-19 death recorded was 13 years old and the oldest 85 years old. The median was 55 years old.

Data analysis showed that 30 (54%) were males and 26 (46%) were females. Findings revealed that males had a higher mortality rate than females, and the mortality rate increased with age in both sexes. The majority of deaths (70%) were recorded amongst people aged over 50 years and less than 5% in children and young people under 20 years old. This was noted to be in line with the national figures.

## Place of death

82% (46 deaths) occurred in the hospital and 10 (18%) were in their usual place of residence - these were residential, nursing care, supported living or own homes.

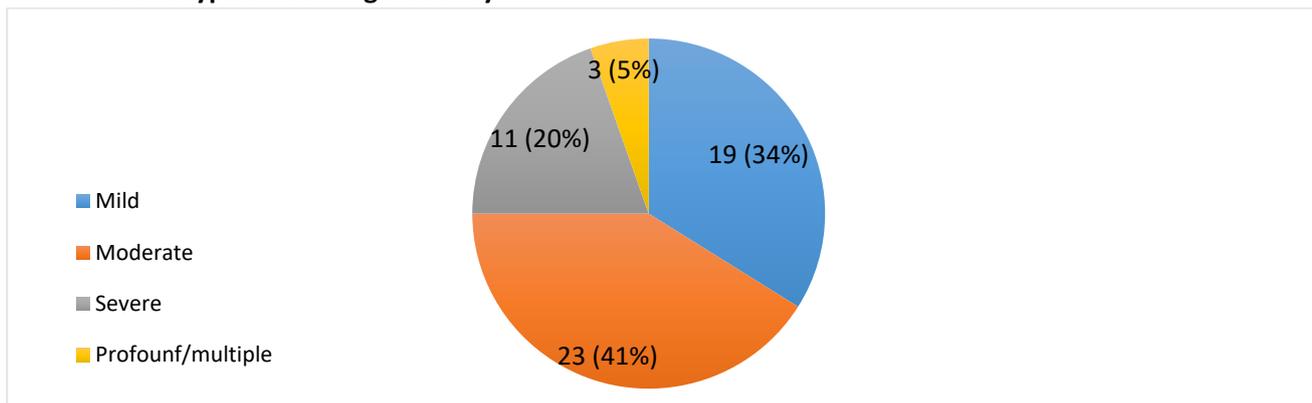
## COVID-19 deaths and BAME groups

The death rates from COVID-19 were higher for White ethnic groups compared to Black and Asian ethnic groups. In every 2 deaths reported of a white ethnic background patient, one had died of COVID-19; while in every 3 deaths amongst BAME groups, one was linked to COVID-19.

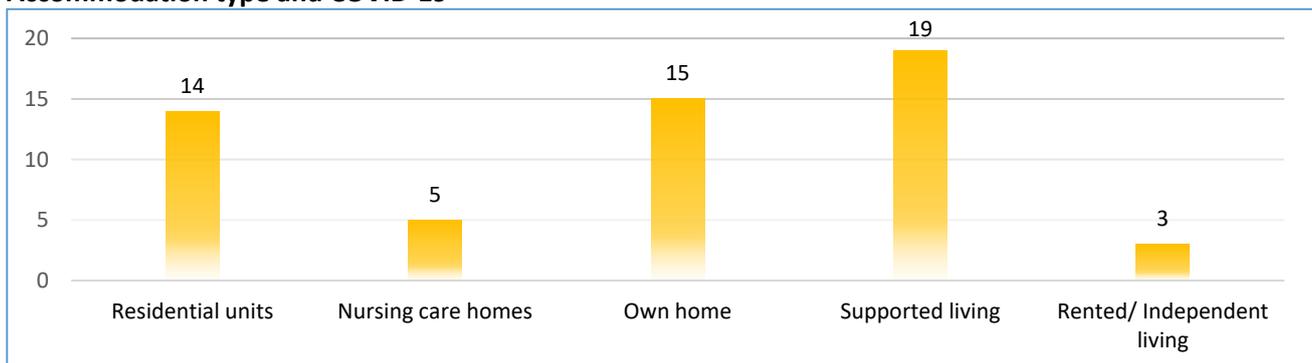
	Total 2020/21 deaths (135)	Covid19 reviews (56)	Percentage % (total no/covid19 deaths)
White	83	41	49%
Asian	25	8	32%
African- Caribbean	15	5	30%
Other	12	2	13%

Patients of Asian ethnic background were found to have had a raised rate of death from COVID-19 compared with those of African-Caribbean ethnic background. Of the 8 deaths reported amongst the Asian communities, 5 were females and 3 males. In deaths amongst the Black African-Caribbean group, 3 were males and 2 were females.

## COVID-19 and type of learning disability



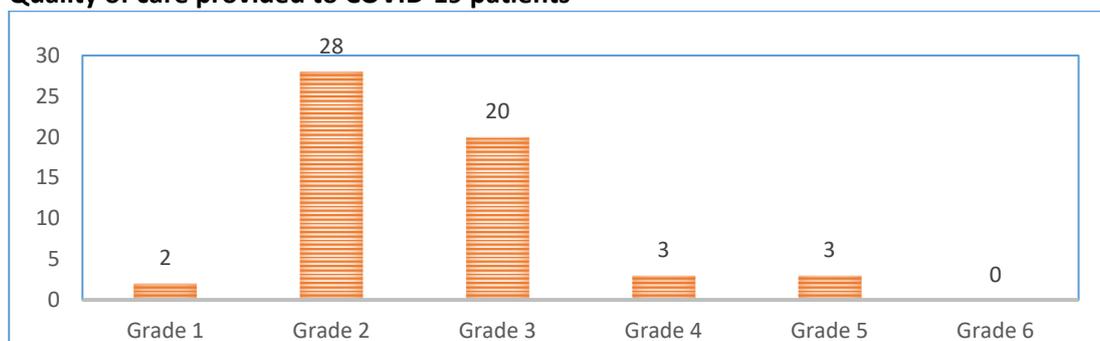
## Accommodation type and COVID-19



The COVID-19 impact on residential settings was very evident. More people with learning disabilities are placed in supported and residential units than in nursing care settings. Review findings showed that supported living units had the highest number of COVID-19 deaths of people with a learning disability, followed by residential units.

38 deaths occurred in people who were living in residential, nursing and supported living settings, while 18 deaths were people living in their own homes and independent or rented accommodation.

## Quality of care provided to COVID-19 patients



Despite the COVID19 pandemic, evidence showed that 54% of care was graded as excellent or good. 41% was graded as satisfactory, while in 5% of cases the care was rated as poor.

## Summary of findings and recommendations from COVID-19 reviews

Mobility impairment and mental health needs were found to be prevalent amongst this group of patients and they were less likely to adhere to COVID-19 guidelines. The need for close regular supervision also meant more contact with staff was necessary despite social distancing rules.

Although COVID-19 symptoms in people with a learning disability were found to be similar and in line with the general population, reviews revealed that these symptoms were not as obvious as in people with learning disabilities. More often than not, these symptoms were more likely to be assumed to relate to their pre-existing conditions rather than a new condition.

Care delivered to patients who were already on palliative care pathway was rated as excellent or good. Evidence showed that clinical staff adjusted appropriately to new ways of working and continued patient care.

During the early stages of the pandemic, the use of hospital passports and/or coordinate my care (CMC) plans were found to help staff to understand patient's needs better in the absence of carers and families.

In some cases, use of DNACPR decisions was found to have been wrongly applied and this was appropriately challenged and improvements put in place. Clear NICE guidance was also developed to support clinical staff on this matter.

Due to COVID19 restrictions, face to face discharge planning meetings did not happen during this period. Reviewers identified the need for more attention to be paid to safe and appropriate hospital discharge planning and to ensure community learning disability teams were involved and/or notified of patients coming out of hospital. In five reviews, people with learning disabilities were unsafely discharged and readmitted less than four days before they died.

Fewer annual health checks were carried out at the beginning of 2020 due to lockdown restrictions and patient concerns about attending GP surgeries in person. Patients were offered both virtual and face to face appointments if they wished in order to receive their check. In some cases, patient and family experience of virtual (telephone or video) consultations was reported as inadequate. The face to face option was found to be more preferable for the majority of people with learning disabilities.

## Lived experiences of patients

This section is about the stories of people who have died. They have families and friends who cherished their lives and whose deaths will never be forgotten by their loved ones. Therefore, we are sharing some of the stories and experiences from completed reviews. This information has been provided by family members or carers who knew the person well. Their details have been anonymised and names changed to further protect their identities.

### Good practice case studies (stories)

#### **JJ died aged 33 from gallbladder cancer and COVID-19**

*“The GP's listened carefully to us, he was honest about areas that were not within his remit of expertise and responded quickly and flexibly by referring us to other services. JJ had regular reviews and bloods tests. GP was responsive to our concerns and provided flexible appointments.*

*As parents, we were involved in every decision, supported and trained to carry out some aspects of care and basic assessments where possible. All decisions and recommendations took into consideration JJ's best interest and we felt our views mattered. We felt safe.”*

- Family comments

#### **CM died aged 35 from aspiration pneumonia and sepsis**

*CM had had several admissions over the 6 months prior to their death. During CM's last hospital admission, the family reported very good experience from all the medical, nursing and allied health professionals.*

*Capacity assessments were carried out and CM was deemed to lack capacity. The family was involved in every stage of decision making on behalf of CM. the LD nurse was very supportive, she provided regular updates.*

*This is what CM's mother told the reviewer: “The hospital learning disability nurse was very good and really helpful when we met her during CM's final stay, we only wish that we had known about her on previous admissions as that would have been very useful. The team was very supportive and communication was very good.”*

#### **HJ died aged 60 from pulmonary oedema and Congestive cardiac failure.**

*HJ's GP was very good. He carried out thorough examinations during appointments. Annual health checks were extensive, including bloods. He did a full body check and would ask many questions about HJ health, behaviours, moods, any changes observed since last appointment. He also did dental checks and always updated HJ's health action plan.*

*HJ had flexi appointment and we could see the GP within a short notice. HJ was referred for stimulating therapy and did really well and enjoyed it, it changed her life. HJ became more active, lively and always looking forward to her therapy session.*

*During her last breast screening appointment, the GPs explained to us (the patient and carer) on how to examine breasts at home. He provided us with an information leaflet with pictorials about how to do this. It was easy to understand and follow. GP advised to report any changes to the surgery. He made it so simple HJ was able to examine herself since then with a prompt.*

- Carer's comments

### **JM died aged 65 from COVID-19 and Bronchopneumonia – Reviewer comments**

*During JM last hospital admission, the learning disability nurse maintained welfare checks and regular contact with JM's family. The LD Nurse explained every medical decision taken. It felt like we were present with JM. Mental capacity assessment was completed and a referral made to IMCA services.*

*JM was discharged with 24 hours care, additional 1:1 day support and 2:1 support in the community thereby ensuring his needs and safety were well taken care of. At the care home where JM lived, a Positive Behaviour Support (PBS) plan and DoLs were in place. His prescription for his 'challenging behaviour' was successfully stopped.*

*JM also had a dietician who worked very closely with the carers and family resulting in positive weight management outcome. It was a team effort, everyone was happy and the care was good.*

### **Poor practice stories**

#### **MM aged 49 died from choking**

*MM was known to have had severe learning disability, PICA, epilepsy and autism. The staff knew him very well, he had lived in the same accommodation unit for over 10 years. He was also known to try eating non-edible things like tea bags, swallowing beads ... He was also known to eat fast putting himself at risk of choking. He required 1-1 supervision while having meals and his food cut into small pieces.*

*MM had a care plan but this was not up to date. He had been seen by a speech and language therapist (SLT) 3 years ago who queried dysphagia but no follow up was done. Care staff were following SLT recommendations, care plans and risk assessments from 3 years ago.*

*On the day of his death, MM choked while having dinner. He was being monitored and his food had been cut up into small pieces. He started to choke and got up from the table and walked towards the room. Staff tried back slaps and abdominal thrusts to dislodge stuck food to no avail; another staff phoned 999 and with support from the emergency team, staff performed first aid and CPR until the paramedics arrived and took over. Sadly, MM died at the hospital.*

#### **JC aged 52 died from Bronchial pneumonia, Bronchiectasis**

*JC was 52 years old and known to have severe learning disability and several chronic conditions including reflux and bronchiectasis. JC was under the care of both respiratory and gastroenterology consultants in the community. She was open to the community nursing team, physiotherapy, and a speech and language therapist.*

*4 years ago, JC had a hospital admission to remove some of her teeth. A good oral clean was done at the time and she was advised on regular visits to the dentist. Reviewers found no evidence that JC ever went to see the dentist. In August 2020 the community LD nurse was concerned about JC's oral health, therefore completed an urgent referral to specialist dental services.*

*JC had lost a significant amount of weight and it was recorded she was experiencing dental pain. The GP increased her pain relief to help manage the pain. It is noted that JC was consistently refusing to open her mouth for oral hygiene purposes and had issues around eating and drinking.*

*During JC's last admission, the admitting doctor recorded that JC was showing signs and symptoms of infection, and possible aspiration pneumonia. JC was started on IV antibiotics during this inpatient stay but was not*

responding. An MDT meeting including community teams, the family and the consultant took place. JC's health was discussed and plans for intervention, which included advanced care planning. JC died four days later.

*Reviewer comments: The diagnosis of bronchiectasis and fibrotic scarring in her lungs, noted in her records, could have been attributed to many years of recurrent infections caused by aspirating bacteria laden saliva as this is known to be a frequent cause of chest infections and more severely, respiratory sepsis in people with learning disabilities who have dysphagia and impaired swallowing.*

*Lack of clarity around a prescription for carbocisteine which should have been explored further by the GP and the respiratory consultant, who wrote several letters to the GP with possibly carbocisteine as one of JC's medications. This medication is considered beneficial and a first line treatment for people with bronchiectasis and tenacious sputum that is difficult to expectorate. It is available in liquid form, so JC would not have had difficulty in swallowing it given her dysphagia and thin fluid diet requirements.*

*Overall, JC lived with family and received good care. She had appropriate input from community services, however there were missed opportunities by healthcare professionals to refer JC to specialist dental services and/or advise family and support care staff about the importance of good oral hygiene.*

*Whilst it not clear if this could have changed the outcome, the reviewer felt that had the GP and the respiratory consultant explored prescribing carbocisteine and JC's oral hygiene been addressed earlier, the outcome could have been different.*

## Learning into action

This section looks at the summary finding and recommendations and how learning from LeDeR reviews is being used to drive quality improvement activity at North east London level.

Part 1: Learning into Action – how learning from LeDeR reviews is being used to drive quality improvement activity		
Areas of excellent and good practice from completed reviews.	Best practice identified from completed LeDeR reviews	Expected impact/ outcome of this activity
<i>Good quality Annual Health Checks- excellent AHC practice identified</i>	<ul style="list-style-type: none"> <li>– <i>Over 50% reviews showed comprehensive AHCs and HAPs were completed and shared with the relevant team. There was evidence of more coverage with new reviews including full physical examinations, dental care, mental health and bloods</i></li> <li>– <i>In City &amp; Hackney locality, a Darzi Fellow and GP Clinical Lead worked together to develop the Annual Health Check (AHC) template on the GP IT system to make it more meaningful and relevant to people with learning disabilities. Local promotion of AHCs took place through training and presentations at meetings. This saw a 10% increase in those on the LD Register and also the number of completed AHCs. Feedback was that the template was easier to use.</i></li> <li>– <i>In Newham, the CLDT has approved two positions of community Liaison LD nurses to ensure coordination and promotion of high quality annual health checks starting from 14 years.</i></li> <li>– <i>Reviews also showed improved family/ carers engagement during AHC ensuring patient’s comfort and support</i></li> <li>– <i>During the pandemic, more home visits were evident including those who are housebound or known to have had poor mobility issues. Telephone and video AHC appointments were offered to most patients.</i></li> </ul>	<i>Reduced health inequalities, while delivering quality care</i>
<i>Care &amp; treatment</i>	<ul style="list-style-type: none"> <li>– <i>Evidence of regular reviews for all known health conditions.</i></li> <li>– <i>In some reviews, patients were supported to stop use of psychotropic medicines.</i></li> <li>– <i>In one case the allocated dementia care co-ordinator from the community learning disabilities team provided dementia training to the support team of a residential care unit on how to care for people with dementia. Feedback from the staff was very positive.</i></li> </ul>	<i>Timely care and treatment.</i>
<i>Reasonable adjustments - good practices from some of the reviews.</i>	<ul style="list-style-type: none"> <li>– <i>Introduction and implementation of COVID-19 passport during the pandemic</i></li> <li>– <i>Most patients were provided with appropriate mobility equipment suited to their needs</i></li> <li>– <i>Most reviews also showed appropriate home adaptations and provision of ground floor flats were evident from reviews.</i></li> </ul>	<ul style="list-style-type: none"> <li>– <i>Happier healthier lives</i></li> <li>– <i>Easy access to services</i></li> </ul>

	<ul style="list-style-type: none"> <li>– <i>In some cases, good communication was evidenced tailored to patients’ needs, such as easy read appointment or clinic letters, text messages or telephone messages.</i></li> <li>– <i>During the COVID-19 period, most patients benefited from GP and community teams home visits, domiciliary blood test services and telephone consultations. Home visits enabled a holistic assessment including assessment of the home environment that is not possible when seeing patients in a clinic setting.</i></li> <li>– <i>Most GP services provided flexible appointments and access to out of hours GP service especially for those with complex needs and those at risk of sudden deterioration.</i></li> <li>– <i>Easy read information and pictorials were evident particularly within acute settings and in some community services.</i></li> <li>– <i>During the pandemic, City &amp; Hackney has developed online resources and an accessibility toolkit set up with easy read information to support people with learning disabilities to stay safe. This tool also provided advice on health issues and other services. Being an online tool, information can be regularly updated in one place. City and Hackney is looking at using this tool beyond the pandemic, and to share it widely with other teams outside of the LD teams to benefit from it.</i></li> <li>– <i>Some GPs and the acute hospitals were noted to have set up electronic alerts to flag up patients with learning disabilities when due for reviews or admitted at the hospital.</i></li> </ul>	
<p><i>Care coordination: evidence of some good examples of care coordination</i></p>	<ul style="list-style-type: none"> <li>– <i>Most GPs were very involved with their patient's care coordination - liaising with other professionals and ensuring referrals were completed and teams made aware of any changes in a patient’s situation regularly.</i></li> <li>– <i>Excellent practice was identified on the use of multidisciplinary team (MDT) meetings in decision making and good communication between hospital, care homes and community teams.</i></li> <li>– <i>In some cases, there was evidence of improved hospital discharge planning and good coordination of care. For example- there was evidence of comprehensive care plans put together by hospital SALT following admission for aspiration pneumonia, considering risks and benefits of different approaches and following the best interests’ process. These plans were shared with Community SALT for continuity of care after discharge.</i></li> <li>– <i>Patients on continuing health care package were noted to have had good care coordination with a named lead. In two reviews the patients had named consultants to contact if needed.</i></li> <li>– <i>During the pandemic, evidence show that some GPs acted as excellent care coordinators and advocates for patients’ needs and were recorded as thoughtful and responsive in their approach.</i></li> </ul>	<p><i>Care coordination is critical in ensuring smooth transition of care and continuity in delivery of quality care</i></p>

<p><i>Good communication between professionals and families/carers</i></p>	<ul style="list-style-type: none"> <li>– <i>GPs reported using more electronic alerts containing a preferred method of communication with patients</i></li> <li>– <i>Easy to read information and pictorial information was evident particularly within acute hospitals and some community services.</i></li> <li>– <i>Acute teams were praised for excellent communication and relationship with families during the pandemic; including giving regular feedback to family members without being asked.</i></li> </ul>	<p><i>Improved patient experience and making informed decisions.</i></p>
<p><i>Keeping healthy and weight management - evidence of a few positive outcomes of weight management programme.</i></p>	<ul style="list-style-type: none"> <li>– <i>In one patient a mix of diet and exercise classes resulted in a positive weight management outcome. Cookery lessons were offered to promote healthy eating options. The family/carers reported consistency in attendance and the patient was well supported. The patient was said to enjoy cooking his food.</i></li> <li>– <i>A second patient, who was said to have attended several exercise classes without success, was introduced to swimming which he enjoyed and attended twice a week. The results were positive.</i></li> <li>– <i>In City and Hackney, the Five Ways to Wellbeing (5 to Thrive) approach has been rolled out to learning disabilities providers. This included reporting on the outcomes for individuals, such as keeping active and connecting with others.</i></li> </ul>	<p><i>Improved health and wellbeing while preventing long term conditions and ill health.</i></p>
<p><i>End of Life - some reviews indicate good practice in advanced planning and end of life care provision.</i></p>	<ul style="list-style-type: none"> <li>– <i>In most of the end of life care patients, there was evidence of good co-ordinated care which ensured a seamless pathway with minimal disruption. There was evidence of MDT meetings and joint decision making.</i></li> <li>– <i>Some families were provided with information they needed to make informed decisions and they were said to have felt supported. In some cases, MCA assessments were completed and decisions made were in the patient's best interest.</i></li> <li>– <i>In one case, a community physiotherapist visited the patient on the ward to review the effectiveness of a syringe driver to help determine the best place for end of life.</i></li> <li>– <i>Evidence showed that for patient, who were referred on time, end of life care was provided in a dignified and person centred approach.</i></li> </ul>	<p><i>Seamless transition of care, avoiding unnecessary disruptions; supporting the person's wishes and preferences.</i></p>
<p><i>Good social care assessments and reviews</i></p>	<ul style="list-style-type: none"> <li>– <i>Appropriate changes in accommodation setting to meet patients changing health needs was recorded.</i></li> <li>– <i>In some cases, excellent mental capacity assessments and application of the Mental Capacity Act was evident.</i></li> </ul>	<p><i>Personalised care package that met patient's needs.</i></p>
<p><i>Staff awareness training about the needs of people with LD.</i></p>	<ul style="list-style-type: none"> <li>– <i>Across NELFT, 50 care staff have been trained in the RESTORE2 tool to support care staff in recognising deterioration and taking appropriate action. These trained nurses are expected to train all care staff across NELFT on the application of the RESTORE2 tool.</i></li> </ul>	<p><i>Prompt response to deterioration and treatment.</i></p>

Part 2: Learning into Action –Areas requiring improvement and proposed improvement activities		
Poor practices	Proposed service improvement activities at North East London level	Expected impact/ outcome of this activity
Poor quality Annual Health Checks. No evidence of annual health checks for patients aged 14- 19 years old	<p>GP webinars on AHC have been carried out, aimed at:</p> <ul style="list-style-type: none"> <li>– Increasing uptake of annual health checks and to encourage GPs to ensure HAPs are completed and shared with other professionals involved with the patient</li> <li>– Promote use of annual health checks tool kits shared with GPs to guide them on the key areas of coverage during AHC appointments</li> <li>– Provide reasonable adjustments to patients and their carer</li> </ul>	<p>-increase the number of LD patients having access to AHC to cover ages 14 and those with mild learning disabilities.</p> <p>-Early diagnosis and treatment as may be indicated</p>
Care & treatment: dysphagia/ swallowing problems; needle phobia; overshadowing diagnosis;	<ul style="list-style-type: none"> <li>– More appropriate referrals to the SALT team and regular reviews to ensure patients at risk are closely monitored and risk assessments are up to date</li> <li>– More efforts around desensitisation; use of exposure therapy has been recommended which can help patients gradually tolerate needles. CLDT teams to work closely with families and care providers to offer support as required. Excellent practice has been utilised by all boroughs to support the roll out of the COVID-19 vaccine for people with learning disabilities which could be replicated to support access to phlebotomy and other vaccinations.</li> <li>– GPs and healthcare professionals to be supported to reduce diagnostic overshadowing and ensure that all symptoms are thoroughly investigated.</li> <li>– CPR training - all care staff to have regular CPR training or updates to ensure staff are competent if needed to provide CPR.</li> </ul>	<p>-more risk assessments completed and reduced cases of avoidable aspiration pneumonia and choking.</p> <p>-Early intervention and treatment of new conditions</p>
STOMP: overmedication with antipsychotic medicines	<ul style="list-style-type: none"> <li>– Proposed STOMP webinars (online sessions) underway to engage relevant teams with these discussions.</li> <li>– STOMP pathway has been developed to support medication reduction where appropriate and in patients’ best interest; to ensure GPs are aware of pathway and able to refer.</li> <li>– More social prescribing by GPs- introducing a range of local, non-medical activities, therapies, opportunities and support that can improve people’s health and help them live life to the full</li> </ul>	<p>-more STOMP awareness across professionals</p> <p>-more patients supported to stop overmedication of psychotropic medicines, where appropriate.</p>
Lack / absence of reasonable adjustments	<ul style="list-style-type: none"> <li>– Comprehensive health and social care assessment to be completed and ensure appropriate reasonable adjustments are put in place to support patient needs</li> <li>– Ensure there is sufficient provision of interpretation services to families whose English is not first language</li> </ul>	<p>-Evidence of reduced barriers to accessing services and equity in health and social care outcomes.</p>

	<ul style="list-style-type: none"> <li>– <i>Improved communication practices to meet patients’ needs</i></li> <li>– <i>Appropriate appointments (double appointments, flexible) to be provided to all patients with learning disabilities</i></li> <li>– <i>More GPs offering home visits to housebound and poor mobility patients to minimise DNA’s and to ensure continuity and quality of care provided.</i></li> </ul>	
<i>Care coordination: most cases showed absence of care coordination.</i>	<ul style="list-style-type: none"> <li>– <i>More patients with complex health issues having a named lead or care coordinator.</i></li> <li>– <i>More people referred for End of life care; more patients participating in advanced end of life care planning so that their wishes are known in advance.</i></li> <li>– <i>Encourage discussions and closer working relationships between professionals</i></li> <li>– <i>Consistency in care assessments and their implementation - timely assessments and action taken to ensure changing needs are captured and addressed</i></li> </ul>	<ul style="list-style-type: none"> <li>-<i>Evidence of smooth transition of care.</i></li> <li>-<i>Named care coordinator especially for patients with complex needs.</i></li> </ul>
<i>Poor communication: some reviews showed evidence of poor communication between professionals themselves and families/ carers.</i>	<ul style="list-style-type: none"> <li>– <i>Encourage health and social care teams to foster good communications between teams and families.</i></li> <li>– <i>Key decisions to be discussed with families in clear language so that they can understand.</i></li> <li>– <i>Use of hospital passports or coordinate my care plan (CMC) to be encouraged. Carers/ families to ensure patients bring hospital passports when visiting health and social care services. Professionals to ensure these documents are regularly updated.</i></li> <li>– <i>Keeping accurate and fit for purpose patients’ record across all professionals</i></li> </ul>	<ul style="list-style-type: none"> <li>-<i>More meaningful family and carer engagement.</i></li> <li>-<i>Evidence of improved patient and carers’ experience</i></li> </ul>
<i>Obesity and weight management: Most patients referred for exercise classes but showed no improvement in weight loss</i>	<ul style="list-style-type: none"> <li>– <i>More personalised approach in managing patients who are clinically overweight and obese</i></li> <li>– <i>Close monitoring and reviewing of the effectiveness of exercise referrals to ensure they deliver outcomes for people with learning disabilities</i></li> <li>– <i>More social prescribing by GPs- introducing a range of local opportunities including a variety of activities offered by the voluntary sector organisations that can improve people’s health and help them live life to the full</i></li> <li>– <i>Consider development of more flexible options for exercise and healthy eating that include reasonable adjustments, to encourage participation from people with learning disabilities</i></li> <li>– <i>Dieticians to work more closely with GPs to discuss alternative ways of weight management, sharing information on what works and does not work</i></li> <li>– <i>Care staff to be trained on risks of poor nutrition including malnutrition and underweight</i></li> </ul>	<ul style="list-style-type: none"> <li>-<i>Better outcomes from referrals.</i></li> <li>-<i>LD tailored services with support.</i></li> <li>-<i>Improved quality of life and wellbeing.</i></li> </ul>
<i>Poor documentation of DNACPR</i>	<ul style="list-style-type: none"> <li>– <i>DNACPR forms to be completed correctly and implemented appropriately.</i></li> <li>– <i>DNACPR process to be discussed with all those involved with the person’s care and only to be applied as needed.</i></li> <li>– <i>Clinical teams to follow DNACPR NICE guidelines</i></li> <li>– <i>DNACPR training to continue to be provided for frontline professionals</i></li> </ul>	<i>Appropriate application and use of DNACPR as needed</i>

<p><i>Lack of/poor social care assessments and reviews: there was no evidence of regular social care reviews; carers' and MCA in some reviews</i></p>	<ul style="list-style-type: none"> <li>– <i>Improved mental capacity assessments on all learning disability patients deemed to lack capacity</i></li> <li>– <i>Increased use of Independent mental capacity advocates (IMCA) to support patients with key making decisions (such as DNACPR, treatment procedures, finances and personal care), in line with the Mental Capacity Act</i></li> <li>– <i>More regular social care reviews to ensure changing patient needs are captured and acted upon in a timely manner</i></li> <li>– <i>Carers are provided with the right information and support to understand the importance of carers' assessments</i></li> <li>– <i>Professionals to work closely together to identify and support carers before they hit crisis point</i></li> </ul>	<p><i>More evidence of all-inclusive approach in the development of care packages that represent patient's needs</i></p> <ul style="list-style-type: none"> <li>-<i>More social care assessments (MCA and carers) and applications of patient's best interest in all decision making processes.</i></li> </ul>
<p><i>Recognising deterioration / End of life care- Some care staff were noted as not being able to identify deteriorating patients and advanced care planning referrals were delayed.</i></p>	<ul style="list-style-type: none"> <li>– <i>More training on the needs of people with learning disabilities, including end of life training, to be provided to care staff to ensure they are able to recognise deterioration, and provide good quality care and better support to patients' when they get to end of life stage</i></li> <li>– <i>More staff awareness about deaths and supporting carers to have this discussions</i></li> <li>– <i>More discussions with patients, carers and families on advanced care planning for deteriorating patients</i></li> <li>– <i>More end of life information to be made available to patients, care providers and families to help them make informed decisions</i></li> <li>– <i>More awareness about the role of community learning disability teams and how to access them to provide support and ensure people with learning disabilities are able to access services they need</i></li> </ul>	<ul style="list-style-type: none"> <li>-<i>More patients referred to EoL care services in a timely matter and have a comfortable end of life care.</i></li> <li>-<i>improved family/ carer engagement and support</i></li> <li>-<i>better understanding of LD needs</i></li> </ul>
<p><i>Inappropriate Hospital discharges. There was evidence of a number of failed discharges and re-admitted within less than 2 days.</i></p>	<ul style="list-style-type: none"> <li>– <i>Improved discharge planning and a more coordinated approach involving families and carers and relevant community teams</i></li> <li>– <i>Acute LD teams to work closely with CLDT teams and the social care teams on discharge process</i></li> <li>– <i>Discharge information to be clearly explained to patient/families and carers and copies provided to CDLT team and care homes to ensure continuity of care</i></li> <li>– <i>Change of medication to be shared with GPs in a timely manner to ensure carers are able to arrange for prescriptions</i></li> </ul>	<ul style="list-style-type: none"> <li>-<i>Effective and Continuity of care outside the hospital.</i></li> <li>-<i>Family/carer engagement in this process.</i></li> </ul>

## Going Forward

The NEL LeDeR team has carried out a significant number of reviews as part of delivery of the LeDeR programme, and has started to see improvement in practice and the quality of care as part of implementing learning from reviews and the delivery of local SMART action plans. As part of the NEL Learning Disabilities and Autism 3 year strategy, partners will be focusing on continuing to build on these improvements and the recommendations outlined in the 2020/21 Annual Report.

The new *Learning from Lives and Deaths policy* published in March 2021 requires that the LeDeR programme is delivered by the CCGs and local authorities as an integrated care system in order to improve the lives of people with learning disabilities and autism in their boroughs. ICSs are expected to share good practice and embed learning from completed reviews as fully as possible, tailoring the learning to specific roles and teams.

Despite the challenges posed by COVID19, LeDeR review data has identified some improvements have been made since the last annual report 2019-20; however more work is needed to further reduce the health inequalities that we know are experienced by people with a learning disability.

Delivery of the LeDeR review programme and putting learning into action will be supported by the following strategic documents:

- NEL Learning Disability and Autism Delivery Plan 2021-23
- NEL Learning Disability Engagement strategy 2021-23
- New LeDeR policy 2021

The LeDeR programme will continue its efforts to influence and advocate for changes in the following areas:

- to continue GP webinars aimed at achieving an increase in the numbers and quality of annual health checks for people aged over 14 years
- support use of digital alerts by care providers to ensure that people with learning disabilities receive regular checks and reviews and do not miss their appointments
- more awareness amongst professionals with regards to use of psychotropic medications and to stop overmedication of people with a learning disability, where appropriate
- community and social care staff training on recognising deterioration (Restore2 training) to empower them to make timely referrals for further intervention
- to promote quality health and social care assessments to ensure that packages of care are developed jointly between services and that packages of care are personalised around their needs, including provision of appropriate reasonable adjustments
- promote use of effective communications tools, use of hospital passports and Coordinate My Care plans (CMC) to improve staff awareness of the needs of people with a learning disabilities
- better information sharing and close multiagency working relationships
- meaningful family/carer engagements to improve carer/patient experience

Working closely with the NEL Learning Disabilities and Autism Programme team, borough leads, and community teams, the LeDeR Programme will also focus on health specific engagement events/activities as may be informed by local data.

The national LeDeR programme team has led the way on ‘action into learning’ working on key work streams. NEL LeDeR programme will work with local teams to ensure guidance and information from these work streams is disseminated to all relevant local teams.

## Action into learning – National initiatives

The National LeDeR programme has produced and shared extensive guides and information (leaflets) to support health and social care professionals to improve their understanding on some of the conditions that were identified as treatable if picked up early and to support people with learning disabilities and minimise preventable deaths.

These initiatives include:

- Dysphagia and aspirational pneumonia trainings
- Constipation campaigns
- Diabetes management information
- Recognising deterioration (Restore2 and significant7) trainings
- Annual health checks (a GP guide and a check list)
- Application of Mental Capacity and best interests
- An easy guide information on cancer screening
- Epilepsy toolkit which provides information on epilepsy care and key actions to take, with specific guidance for supporting people with a learning disability.
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) guide

## Useful links and resources

Please visit the NEL CCG website for the NEL Learning Disabilities and Autism programme details and resources via this link: <https://northeastlondonccg.nhs.uk/your-health/learning-disabilities-and-autism/>

- The new LeDeR policy 2021
- NEL Learning Disability and Autism Delivery Plan 2021-23
- NEL Learning Disability Engagement strategy 2021-23