



# North East London LeDeR: The First 100 Cases

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<b>Lead/Author(s)</b>	Beatrice Kivengea/Justin Roper
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## Executive summary

People with learning disabilities are known to die younger than the general population, often from avoidable causes. The Learning Disability Mortality Review (LeDeR) Programme is a world-first: it is the first national programme of its kind aimed at making improvements to the lives of people with a learning disability to reduce the mortality gap.

The LeDeR programme reviews the care (both health and social care) provided to people with a learning disability in the last year(s) / months of their lives. The reviews look at good practice as well as gaps or issues in the care provided. The aim of these reviews are to improve the standard and quality of care for people with learning disabilities. People with learning disabilities, their families and carers have been central to developing and delivering the programme and contributing to the reviews within north east London.

Improvements in the quality of care for people with learning disabilities, improving their health and wellbeing is a major step towards tackling inequalities within health and social care provision.

The north east London (NEL) LeDeR programme covers seven Clinical Commissioning Groups (CCGs):

- Barking & Dagenham
- City & Hackney
- Havering
- Redbridge
- Newham
- Tower Hamlets
- Waltham Forest

NEL is committed to driving change for people with learning disabilities within the region. We will continue to work with our partners and key stakeholders to ensure that the learning from completed LeDeR reviews continues to make a difference to the way services are commissioned and provided. We are also committed to encourage honesty, transparency and sharing of information to obtain maximum benefit from LeDeR cases.

This report provides a review of the first 100 north east London completed reviews, including successes and challenges. This report also provides case studies, as well as recommendations to address identified issues in care. It focuses on the key priorities and areas for development going forward.

The key recommendations from these reviews are:

1. Improve uptake and quality of our annual health checks.
2. Promote health and social case assessments, including Mental Capacity Assessments.
3. Improvements in awareness and knowledge of all staff working with learning disability groups to understand the needs of people with learning disabilities.
4. Improve inter-agency collaboration and communications between professionals and families.

## Introduction

In recent years, the persistence of health inequalities between different population groups has had renewed attention. People with learning disabilities are four times as likely to die of preventable causes compared with the general population. People with learning disabilities have also been highlighted as experiencing markedly poorer health than their non-disabled peers.

The National Guidance on Learning from Deaths, published by the National Quality Board in March 2017, provides a framework for NHS trusts and NHS foundation trusts in England for identifying, reporting, investigating and learning from deaths of people in their care. <sup>1</sup>

The LeDeR programme was established in response to the recommendations of the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD).

CIPOLD reported that avoidable deaths from causes amenable to change by good quality health care were more common in people with intellectual disabilities (37%, 90 of 244) than in the general population of England and Wales (13%).

A more recently analysis of data from the Primary Care Research Database suggested that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.

The LeDeR programme was established to understand the circumstances around these deaths and recommend ways to improve the standard and quality of care for people with learning disabilities. The programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The LeDeR programme contributes to improvements in the quality of health and social care for people with learning disabilities in England by supporting local areas to carry out reviews of deaths of people with learning disabilities (aged 4 years and over) using a standardised review process. This enables health and social care teams to identify good practice, as well as improvements needed to the provision of care. Recurrent themes and significant issues are identified and addressed at a local, regional and national level.

In December 2017, NHS England devolved LeDeR programme to CCGs. Every CCG, local authority and NHS Trust is now responsible for ensuring LeDeR reviews are completed in their area.

## The Purpose of the LeDeR Programme

The main purpose of the LeDeR review of a death of a person with learning disabilities is to:

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<sup>1</sup> NHS England National Guidance on Learning from Deaths: [www.england.nhs.uk/publication/national-guidance-on-learning-from-deaths/](http://www.england.nhs.uk/publication/national-guidance-on-learning-from-deaths/)

- Identify any potentially avoidable factors that may have contributed to the person's death.
- Develop plans of action that, individually or in combination, will guide necessary changes in health and social care services to reduce premature deaths of people with learning disabilities.

Following the pandemic early this year, the NHS England/ Improvement in conjunction with NEL CCGs developed a Learning Disability Covid19 rapid review tool to be used following a death of a person with learning disabilities due to Covid19 or where Covid19 is suspected to have contributed to the cause of death.

Information from these rapid reviews has been gathered and analysed and a summary analysis report is available on page 46, appendix 2.

## **Challenges**

As with any new programme there have been a number of challenges in delivering this across north east London. The most significant challenges to delivering the LeDeR programme have been:

1. CCGs inheriting a large number of deaths for review before being at full capacity, and prior to robust processes being in place locally to review these cases, hence creating a further backlog of cases.
2. A very low proportion of people trained who had completed a review.
3. Trained and willing reviewers lacking the time away from their other duties to be able to complete a LeDeR case.
4. Administrative workload to complete a case.
5. The LeDeR process not being formally mandated.
6. Unclear governance systems for the management of reviews.
7. Lack of clarity with regard to the continuity of the programme.
8. Lack of dedicated resources to support and sustain the programme in the long term, such as funding for independent reviewers.
9. Variable approaches to carrying out reviews and the impact on quality.

In north east London we have been largely successful in overcoming many of these challenges, and we are one of the first Sustainability and Transformation Partnership (STP) areas to complete 100 cases.

The purpose of this report is to highlight the emerging themes from completed cases. This report contains real case studies, but they have been anonymised to protect the identity of individuals and families involved.

## NHS Long Term Plan

The NHS Long Term Plan (LTP) was published in January 2019, and it sets out an ambitious 10-year plan for the NHS to improve the quality of patient care and health outcomes. The aim is to ensure the NHS delivers high quality patient care that is sustainable and cost effective.

The plan sets out a range of aims – making sure everyone gets the best start in life, delivering world class care for major health problems and supporting people to age well. The LTP provides a framework for local systems to develop plans, based on the principles of collaboration and co-design.

Building on work already started, the challenge is for local NHS organisations, in both health and social care, to work with their partners to develop and implement local plans for their local population.

Specific to the learning disability cohort, the LTP seeks to prioritise actions that will help improve services and outcomes for people with learning disabilities, autism or both. The framework has set out five domains in which this would be achieved.

The NHS Long Term Plan focuses on five key areas:

1. Stopping overmedication and improving annual health checks.
2. Awareness training for all staff working with learning disability patients within health and social care settings.
3. Improve community based support by providing more personalised and closer to home care and reduce inpatient admissions.
4. Improve the quality of inpatient care across NHS and independent sector.
5. Reduce waiting times for specialist services.

Source: [www.longtermplan.nhs.uk](http://www.longtermplan.nhs.uk)

The East London Health and Care partnership (ELHCP) is committed to implementing the LTP. Below is a summary of what ELHCP will do to meet the above requirements:

1. Improve uptake and quality of the annual health checks (target is above 75%) and extend this to cover people aged 14+ with a learning disability.
2. Ensure mandatory learning disability awareness training is provided to all staff working with people with learning disabilities and autism.
3. Expand stopping over medication of people with a learning disability, autism or both.
4. Working very closely with care providers or agencies to strengthen collaboration, information sharing and effective communication.
5. Push forward the electronic integration 'digital flag', which will ensure that staff can identify patients known to have learning disabilities or autism and also promote information sharing across all teams.
6. Improve access to community crisis care services to reduce preventable admissions to specialist inpatient services.
7. Extend the keyworker role to cover learning disability, autism or both;
8. Introducing effective ways to reduce wait times for diagnostic assessment.

It is expected that the LTP will go some way to addressing the mortality gap in line with much of the findings of the LeDeR reviews.

## **LeDeR programme statistics: national, London and NEL outlook**

Since the start of the programme in 2016, 6,383 deaths were notified to the LeDeR programme, of which 746 were London and 170 were in the NEL locality.

More than half of NEL notifications (54%), were made by Learning Disability Nurses or therapy staff most commonly working in a Community Learning Disabilities Team or hospital setting. This is over double the national figure of 25%. Most of the children notifications were reported and completed by the Child Death Overview Panel (CDOP) teams.

Below is a summary of key information about the 100 cases whose deaths were notified to the NEL LeDeR programme:

- 56% of the deaths were males and 44% females. This is very close to the national data which indicates 57% for males and 43% for females.
- 98% were single, with a small percentage not recorded or with partners – in line with the national data.
- 53% of NEL notifications were of white ethnic background compared to 90% nationally, and 35% were black ethnic minority compared to 1.8% nationally, while 12% were recorded as 'unknown or other.' This reflects local demographics as north east London is one of the most ethnically diverse areas in the country.
- Approximately 4% had been in an out-of-area placement compared to 9% nationally.
- 10% lived alone with support, in line with national data.

The age range for people with learning disabilities notified to NEL was between 4 and 97 years old. This clearly shows that people with learning disabilities can live as long a life as other groups.

### **Levels of learning disability**

The term 'learning disability' covers a wide spectrum of needs. Relevant to the LeDeR programme, there are four main groups: mild, moderate, severe, and profound with multiple complex health needs. From the 100 completed cases, 27% of these were known to have had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities. These statistics were noted to be consistent with national data. Work is needed to increase the notifications to LeDeR of people with a mild learning disability, as this should be the largest category if all people with a learning disability are reported into the programme.

### **Place of death**

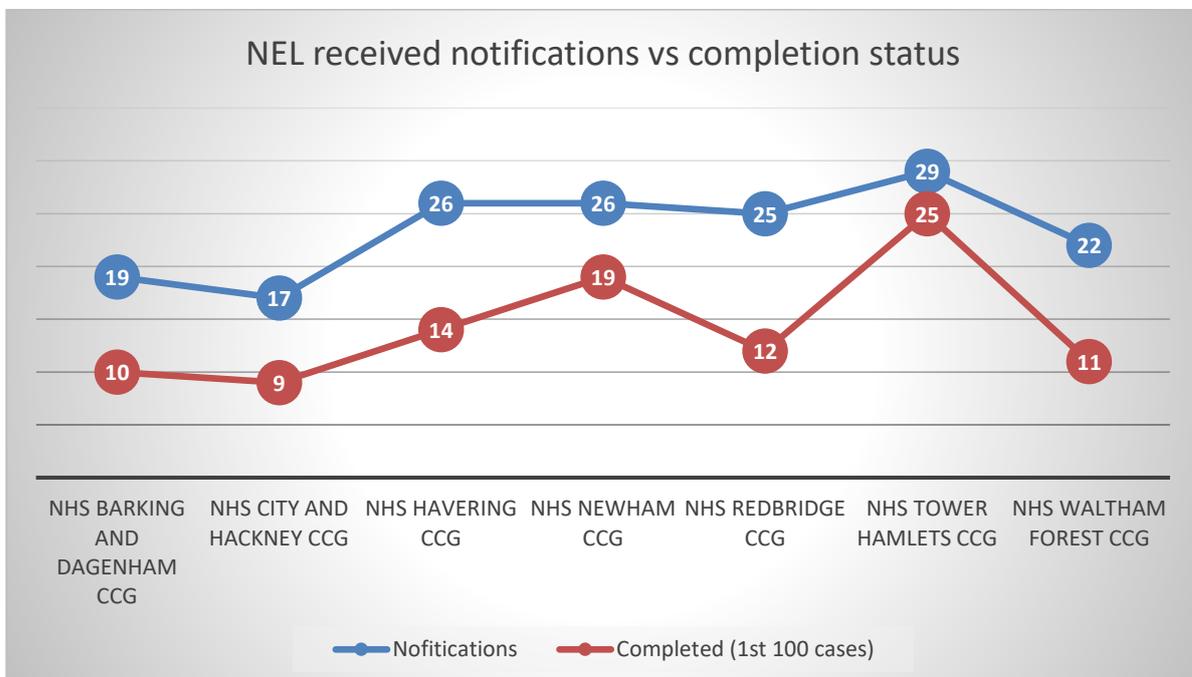
Of the 100 cases, 66% died in hospital (the corresponding proportion for people in the general population is 46%); 22% died at their home; 4% died in a hospice or palliative care unit; 3% died in a residential or nursing home and 2% died in the home of a relative or a friend. The remaining 3% of cases were recorded as unknown.

## NEL - completed LeDeR reviews

By 30 October 2019, the National team had received 6617 cases, 771 of these were London cases and 164 were North East London footprint cases. 100 reviews out of the 164 notifications received had been completed. This means that 61% had been completed and approved by the LeDeR quality assurance process; London and England achieved 53% and 37% respectively.



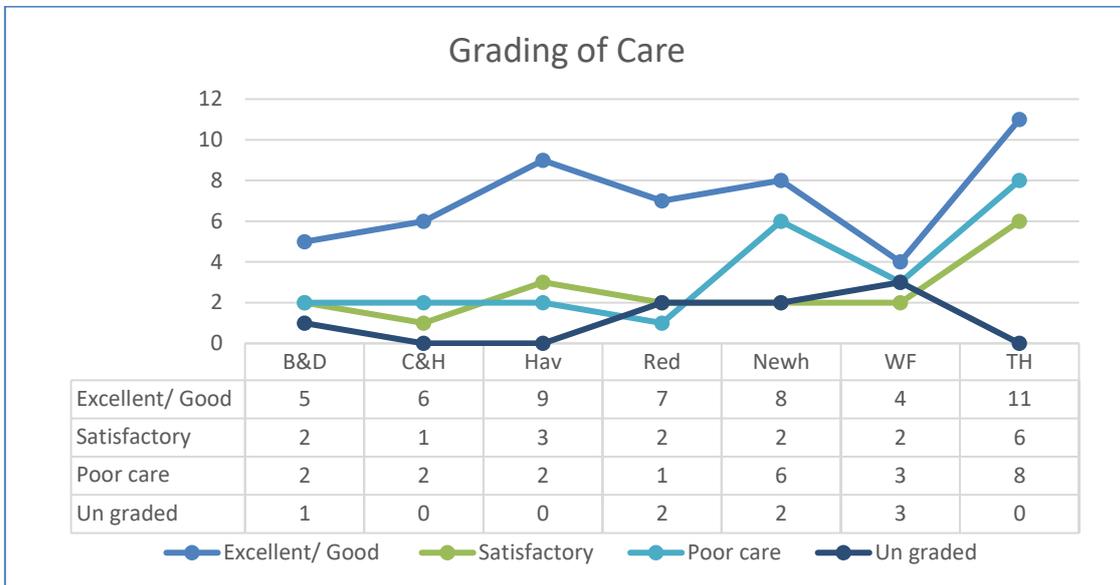
NHS England has set a target for CCGs to complete at least 50% of total notifications received; this means that NEL is performing better than the national target. A report by NHS England in October 2019 demonstrated that NEL is second best in London, and London as a region was ranked best nationally.



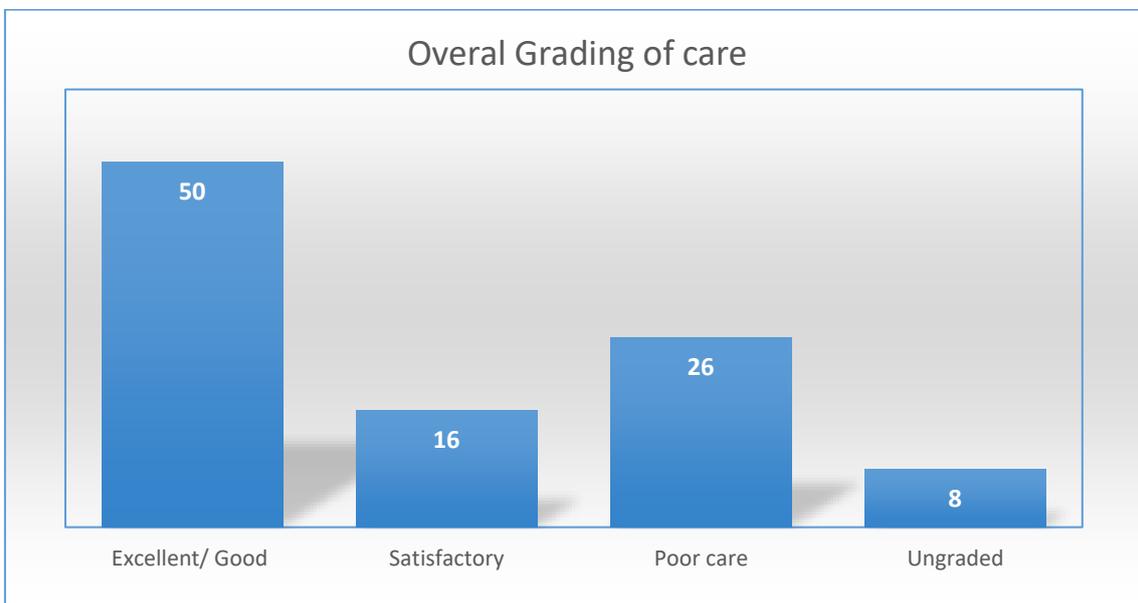
NHS Tower Hamlets was amongst the six pilot sites in London and has received and completed more notifications compared to the rest of the NEL CCGs.

## Grading of care

LeDeR programme uses three broad categories for grading the quality of care provided to people with learning disabilities: poor, satisfactory, and good care. The data collected suggested minimal grading variation across our seven localities as shown below. The ungraded cases were all child reviews, due to the fact that Form C (which is used for completion of children cases) is not compatible with the LeDeR reporting system.



Our findings show that, of the 50% of cases reviewed, people generally received excellent or good care which met or exceeded current best practice.



Comments gathered from completed reviews described good quality care as “...good communication, person-focused, staff providing way above the expected standards, being listened to, valued and individual wishes respected”. Some reviewers documented that the good care provided was within guidelines of good practice and staff did what was expected of them.

Findings showed that 16% of people received satisfactory care; this meant that the care provided was reasonable, but fell short of expected good practice in some areas; however, this did not significantly impact on the person's health and wellbeing.

26% of these completed reviews were graded as poor; the care fell short of expected good practice and the person's health was adversely affected by one or more of the following: delays in diagnosis and care or treatment; gaps in service provision; organisational dysfunction; or neglect. In 6% of cases the care significantly impacted on the person's wellbeing and may have contributed to the cause of death.

## **What does good and poor care look like?**

### **Good care**

George was a 67 year old man with a severe learning disability and complex health needs, and was housebound. George lived in supported living. His GP provided home visits regularly, and he had put in place an admission prevention plan to ensure George does not attend the hospital for issues that could be dealt with in the community.

George was known to the community learning disability teams and was receiving support from an epilepsy nurse, Occupational Therapy and Speech and Language Therapist (SALT) teams. George was deemed to lack capacity, as such, a Mental Capacity Assessment (MCA) was completed and Deprivation of Liberty Safeguards (DoLS) approved and applied.

During George's last admission, he had deteriorated and a decision was reached to refer him for palliative care. A joint discharge meeting was held with all professionals involved with his care. Staff discussed George's care in the community. It was noted that George would want to die at home. A palliative care plan was agreed and put in place.

The professional meeting included George's family, an Independent Mental Capacity Advocate (IMCA), a care home manager and George's main carer, and it was noted that their views were considered. A Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order was explained and signed.

The palliative care team were contacted and all necessary equipment to support George was requested and his flat was prepared for his discharge. The hospital Learning Disability Nurse contacted the SALT regarding his swallowing and advice on current changes in George's health condition. The district nursing team were also contacted and informed of the palliative care plan. His care package was reviewed, and 24 hours care support was put in place.

The palliative care team visited on the day George was discharged. His care plan was discussed with staff who were trained in palliative care and recognising deterioration.

One carer stated, "We felt well empowered and supported to care for George and every time we contacted the palliative nurses, they were available to advise us. The palliative care team were very responsive, kind, supportive and caring."

The family were involved in every decision and they felt that George was treated with respect and dignity. His cousin said, "George had the best care, we could not ask for

any more – the experience was amazing. It was all about George.” George died two weeks later surrounded by his family in his flat.

It was clear George’s care was good, and there was evidence of excellent inter-agency working relationships and good communication across all teams.

For George’s case and others on a palliative care pathway, there were four main areas in which best practice was most evidenced and these were:

- Person-centred care.
- Effective and responsive services.
- Strong and effective inter-agency working / good communication.
- Care coordination.

### **Poor care**

Charlie was 46 and received care as an inpatient on a mental health ward. He was known to have a moderate learning disability. He was known to eat fast, cramming food in his mouth and at risk of choking. He required one-to-one supervision during all meal-times.

Charlie was eating his lunch when he started to choke. Efforts by staff to stop the choking were unsuccessful and a 999 call was made to the London Ambulance Service. Staff also tried to reach a duty doctor via his mobile.

Paramedics attended and emergency resuscitation commenced. Charlie was intubated, ventilated and transported to the nearest A&E department. Charlie was then transferred to the Intensive Care Unit where he later died. Cause of death was recorded as severe diffuse hypoxic brain injury and brain stem death (lack of oxygen in the brain) as a result of choking.

The reviewer identified a number of problems with Charlie’s care. Although Charlie was receiving one-to-one supervision, the staff did not stop him cramming food in his mouth which caused choking. Staff were not trained in cardiopulmonary resuscitation (CPR) and there was no duty medical staff available within the premises. It was also noted that, despite Charlie having a history of poor feeding, there was no evidence that Charlie was risk assessed for choking and no records of a referral to the SALT team for support.

The reviewers’ recommendations about Charlie’s care were that all front line staff be trained on basic life support (CPR); patients at risk of choking be referred to SALT for further assessment and support as required, and one-to-one supervision should be provided to focus on all patient’s needs and risks as documented in their care plans.

### **Safeguarding cases**

According to the charity Mind, safeguarding is about protecting an adult’s right to live in safety, free from abuse and neglect. It is a key part of providing high-quality health and social care. Those most in need of protection include children and young people and vulnerable adults, which include people with learning disabilities.

Some people with a learning disability may not only lack the ability to look after themselves, but may also be at risk because they can't protect themselves from harm, abuse or exploitation, hence the need for risk assessments in accordance with safeguarding policies and guidelines.

The Mental Capacity Act (2005) applies to all people who lack mental capacity in whatever setting, thus offering protection to all vulnerable adults.

Evidence gathered shows that most safeguarding alerts are raised and completed on living patients, however there are exceptional circumstances where a safeguarding response can be triggered on a deceased patient under Section 44. In this circumstance, the case has to demonstrate that the person had unmet care and support needs, experienced or was at risk of abuse or neglect, and was unable to protect themselves.

Six of the cases graded as 'poor care' revealed a number of serious concerns that were deemed to meet safeguarding criteria, and were referred to the Safeguarding Adult Review (SAR) panel. These cases have progressed to safeguarding investigations with the view to learning from them.

Evidence gathered from these cases indicates that social care provision was inadequate or lacking, and that these patients were not enabled to live safely in their own homes. Four of these cases were referred to the London Borough of Newham, whilst the London Borough of City & Hackney and the London Borough of Redbridge received one referral each.

Below are some of the common findings recorded from the six cases:

- Care plans were not reflective of patients' needs and the social care team did not put in place measures to monitor care provision by third party providers.
- In one case the patient was not known to adult social care despite living in the borough all his life.
- No evidence of social care assessments (both patient and carers) despite recorded changes in individual and / or family circumstances.
- No evidence of mental capacity assessments taking place.
- It was noted that some of the cases had safeguarding alerts raised, however it was documented that there was not enough information to progress these investigations.
- Evidence of corroded relationships and mistrust between professionals and families.
- Evidence of inappropriate or lack of reasonable adjustments provided.

### **Common causes of death**

Certification of death provides a permanent legal record of the fact of death, and enables the family to arrange burials and to settle the deceased's estate. The Cause of Death Certificate is set out in two parts:

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

All cases reviewed had both preliminary causes and the exact cause of death recorded on death certificates. 66% of cases reviewed showed that these patients died in hospital and were issued with a medical certificate of cause of death, whilst 28% were referred to the coroner to determine cause of death. The majority of the cases referred to the coroner (22 out of 28 cases) had died in their usual place of residence.

**Below are the common recorded causes of death:**

- Aspiration pneumonia / respiratory problems
- Septicaemia / sepsis
- Pneumonia (hospital or community acquired pneumonia, broncho-pneumonia)
- Cancer
- Heart failure / cardiac arrest
- Epilepsy
- Small bowel obstruction
- Type 2 diabetes / hypothyroidism
- Type 2 respiratory failure
- Constipation
- Pulmonary embolism.

It was noted that in a number of cases part I of the death certificates recorded cause of death as: learning disability, cerebral palsy, Willis syndrome, Nervous system, mental and behavioural disorders, congenital malformations, deformations and chromosomal abnormalities. Our reviewers, some being clinical, recognised that these are conditions that may have contributed to the death, but are not part of the direct sequence leading to death.

Our findings revealed that patients who were found to have poor care or significant gaps in their care provision that contributed to their death died of conditions such as sepsis (septicaemia). Whilst respiratory problems, aspirational pneumonia problems and choking were common in people with swallowing problems and / or severe or profound learning difficulties.

It was also noted that patients who had long hospital stays or had repeated hospital attendances during their last days were at risk of hospital acquired pneumonia. In two reviews, the reviewers noted that the hospital had recorded that these patients were medically well enough for discharge, however the care providers declined to take the patients home, citing increased healthcare needs which the providers felt they were unable to support. These two patients died of hospital acquired pneumonia. A further two patients were noted to have been on a palliative care pathway; however, they attended the emergency department on several occasions during their last days.

**Summary of gaps identified from completed reviews**

At the end of each review the reviewers identified gaps and developed recommendations as indicated. From the 100 completed reviews, there were over 300 findings and learning points identified. Below are some of the main service gaps recorded by our reviewers:

- Inadequate / poor provision of reasonable adjustments.
- Delay in diagnosis and treatment.
- Lack of quality social care assessment for both patients and carers.
- Lack of mental capacity assessments (MCA).
- Lack of / poor coordination of care as evidenced by inappropriate hospital discharges.
- Poor transition planning from children to adult services.
- Lack of staff awareness about the needs of people with learning disabilities.
- Absence of joined-up working between professionals (inter-agency collaboration).
- Poor communication and lack of information sharing.
- Poor quality and uptake of annual health checks and health screening programmes.
- Organisational and system failures, including process and policies for specialist referrals.
- Lack of awareness of the role of specialist community learning disability staff.

### **Common themes recorded across the NEL footprint**

Of the 100 completed reviews, 78 cases identified a total of over 300 learning points. The average was four learning points in each review. Twenty two reviews did not explicitly identify any learning and these were mainly child cases.

The most commonly reported learnings and recommendations were made in relation to the need for:

1. Improved provision of reasonable adjustments, particularly with regards to attending annual health checks.
2. Provision of more information and support for families during end of life care.
3. Improved understanding and application of the Mental Capacity Act and quality of mental capacity assessments.
4. Advanced care planning to support effective transition from children to adult services
5. Improved inter-agency collaboration, including care coordination, information sharing and good communication, particularly for people with complex needs.
6. Improved communication between agencies, professionals and families /carers.
7. More staff training to improve awareness of the needs for people with learning disabilities

The next part of this report will look at these themes in more detail, with findings and recommendations made by our LeDeR reviewers to address these.

## Findings and recommendations

### 1. Annual health checks

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. It is true to say that it may be difficult for people with a learning disability to know or recognise when they are unwell, to tell someone about it, or communicate symptoms. New symptoms may be overlooked and assumed to be because the person has learning disabilities; this is particularly true in relation to mental health issues.

All people with a learning disability aged 14 years or over are entitled to a full annual health check. Annual health checks for people with learning disabilities have the potential to detect unmet and unrecognised health conditions and lead to targeted actions to address and treat health conditions.

As a minimum the learning disabilities health check should include:

- A full physical and mental health review with referral through the usual practice routes if health problems are identified.
- A check of the accuracy and appropriateness of prescribed medications.
- A discussion of likely reasonable adjustments should secondary care be needed.
- A review of communication needs, including how the person might communicate pain or distress.
- A full physical examination, including weight and blood pressure.
- A short period seeing the person with a learning disability alone to check if anyone is hurting or abusing them or they are suffering any other disability-related hate crime.
- A review of coordination arrangements with secondary care.
- A review of transition arrangements (to adult services) where appropriate.
- Support for the person to manage their own health and make decisions about their health and healthcare, including through providing information in a format they can understand.
- A health action plan completed.

Source: [www.nhs.uk/conditions/learning-disabilities/annual-health-checks](http://www.nhs.uk/conditions/learning-disabilities/annual-health-checks)

Our reviewers reported that 57% of the people reviewed had had their annual health check within a year; 18% had a health check within 2 years; whilst in 7% of adult cases the reviewers found no evidence of an annual health check having taken place at all. It should be noted that this is not necessarily reflective of the total performance across NEL, where 5 of 7 boroughs have routinely met the 75% performance target. However it does suggest that we may need to do more to ensure that our GP learning disability registers are capturing all residents with a learning disability, and/or that we are making sure all those entitled to a health check are being supported to take up this offer if they wish to.

18% of the completed cases were children, 10 of whom were aged 14 years and above, and none had had an annual health check despite the fact that people with learning disabilities in this age group are eligible for an annual health check. These findings indicate that we are not meeting this requirement, and more should be done to ensure annual health checks are made available to this group. Working with transition age young people to access their annual health check will be a priority in the coming year.

Evidence suggests that the quality of these health checks varied; some carried out detailed physical examinations including relevant blood tests and medication reviews, whilst other records showed only blood pressure checks were completed. It was unclear if the records provided to us contained all known details, as we recognise that some GPs complete these forms manually. It is expected that at the end of each annual health check, an action plan is completed. Our review findings show that for 40% of annual health checks completed, an action plan was completed, whilst for others there is no mention if this was completed or not. It is also not clear if these copies were subsequently shared with the patients and their families or carers.

An action plan should summarise patient discussions with the GP and any other relevant information important to the person, their goals and outcomes, including what they want to achieve. Where the person has a personalised care plan in place, it is expected that this action plan would also form part of the Health Action Plan.

It was noted that GPs did not document communication needs for their patients and that most of them had not provided reasonable adjustments, such as: using pictorials (easy read); large print or simpler words to say or ask what is happening; booking longer appointments or putting an appointment at the beginning or end of the day, particularly for people who find it hard to be in a busy waiting room.

In one of the cases, the reviewer noted the following comments from a sister to a person with learning disabilities regarding the provision of reasonable adjustments:

“My parents are not fluent in English. We were never offered an interpreter. I accompanied my parents and my brother to all his appointments.

Our GP was very good, he would explain everything we needed to know about my brother’s condition and how to care for him at home. It was very hard to listen to what was going on about my brother; sometimes I found it very hard to explain to my parents what the doctor was saying.

An interpreter would have made it so much better for the family to communicate with professionals”.

It was evidenced that all people with learning disabilities were accompanied to their appointments by their carers, a family member or partner. Therefore, families and other carers should be involved as a matter of course as partners in the provision of treatment and care unless good reason is given.

GPs and other service providers are expected to ensure that reasonable adjustments are provided to enable and support carers to do this role effectively. This would include the provision of information, but may also involve practical support and service co-ordination.

### **A carer comments about Annual Health Checks (AHC) and reasonable adjustments:**

“The first time, I took Jason for annual health checks, he waited for about an hour. By the time we went into the consultation room, he was anxious, restless and refused examinations. He wanted to go home. I spoke with the practice manager and Jason was offered another appointment late in the evening, last patient.

When we arrived at the surgery, we were informed that the surgery was running 30 minutes late. We went for a short walk and were back on time to see the doctor.

Jason had a longer appointment and I was able to get him to calm down and have a conversation with the GP. The GP was calm and engaging, he wanted to know more about Jason, any changes in his moods, behaviours or any unusual observations that carers may have noted.

The doctor was able to do thorough physical examinations and a medical review and health action plan were completed. Jason did not like needles and the GP referred him for a blood test at the hospital. At the end of the consultation, Jason was given a certificate for his bravery.

A few days later, a GP called Jason with his blood results. Since then, Jason maintained the same GP and he looked forward to seeing his GP.”

From the above case, the GP was able to provide Jason with reasonable adjustments and he was said to enjoy visiting his GP for his annual health check and other illness.

It was also evident from some reviews that some GPs carried out an annual health check when a person visited for another health issue. People with a learning disability do not have to be ill to have a health check or screening.

One carer’s comment: “Giles had his health checks when he visited his GP for another problem”.

Reviewers identified the need for GP practices to recognise the importance of full annual health checks for people with learning disabilities. Full annual health checks help people with a learning disability stay well, and improve their health by spotting problems earlier and helping them get the right care and treatment.

### **Annual health check attendance**

Research findings published by BMJ Open Journal show that people with learning disabilities are more likely to miss their appointments compared to other groups. This was also found from the reviews completed. Our reviewers documented varied explanations for non-attendance or lack of response such as: “did not attend or forgot to attend or no reason, feeling unwell or inpatient at the time in hospital” There was no evidence recorded to indicate that GP practices followed up these cases.

### **Annual health checks non-attendance case study:**

Lisa was 65 years old, known to have moderate learning disabilities and was living in her own flat with the support of carers visiting 15 hours a week.

Lisa was sent a letter asking her to contact the surgery for an annual check appointment – there was no response. Six weeks later, another letter was posted to

Lisa, again asking her to contact her GP for an appointment. Again, there was no response received.

The reviewer found no evidence that any efforts were made to find out why Lisa did not contact her GP to book an appointment.

The GP did not make contact with the community learning disability team, who may have been able to visit and find out what was happening.

Our review findings revealed that Lisa had a new carer who was not reading or checking letters to support Lisa with her appointments.

Our reviewers felt it is good practice that GP practices follow-up the reason(s) for no response or non-attendance to annual health check invites and inform the Community Learning Disabilities Team about patients known to the service and not responding to invitations.

Further comments stated that GPs should work very closely with carers / families to encourage annual health checks and health screening programmes attendance.

### **Taking blood samples**

Many people are afraid of needles, and needles may cause added distress for someone with a learning difficulty. With blood tests, intravenous fluids and medication injections, needles can be hard to avoid in hospital.

Over 90% of our cases showed that people with a learning disability were known to suffer seizures, and blood tests are very important for monitoring the effectiveness and side-effects of some of the medication. This includes anti-epileptic drugs prescribed to people with learning disabilities.

40% of our patients were recorded to have had needle phobia and did not have a blood test as part of their annual health check. Many of these records highlighted “patient has phobia for needles or declined taking bloods.” Further findings show that some GPs referred patients to the hospital for blood tests. Some hospitals have special blood service appointments for people with learning disabilities and those with a phobia of needles.

The Barts Health Learning Disability Nurse in conjunction with colleagues have developed a dedicated weekly phlebotomy clinic that incorporates significant levels of personalisation, reasonable adjustments and repeated appointments for some to support de-sensitisation. This requires a close working relationship with families and carers. It was developed in response to listening to the needs expressed by local carer forums using the NHS England approach ‘Ask, Listen, Do’.

Across NEL, commissioners have been working with providers to look at specialist learning disability blood services (phlebotomy services). The North East London NHS Foundation Trust (NELFT) has established a learning disability phlebotomy service which would help support patients better in the community.

### **Training in Learning Disability Annual Health Checks**

Each year BHR CCGs host an annual training conference in learning disability health checks, which includes training for administrative staff and practice managers in reasonable adjustments. This year the training included a session on LeDeR, focusing on learning from the reviews undertaken so far.

A key consideration for 2020/21 will be how we can expand training in Learning Disability Health Checks and ensure that primary care colleagues benefit from the work that the LeDeR programme is undertaking.

## Recommendations

Systematic studies have found that health checks for people with learning disabilities were the only intervention to significantly increase short-term health promotion and disease prevention activity. Most GPs have signed up to the Enhanced Service Health Check Scheme which requires that they manage a health check register of people with learning disabilities aged 14 years and over who are eligible for an annual health check.

Below are some of our reviewers' recommendations raised about annual health checks and reasonable adjustments:

- People with learning disabilities should have a comprehensive annual health check and health action plans completed.
- Every effort should be made to offer the same doctor of choice for their appointments.
- Consider longer flexible appointment times and ensure less waiting times.
- GP practices should carry out holistic assessments for people with learning disabilities and not just focus on immediate clinical needs, especially during routine appointments.
- Consider home visits, especially for house bound, bed bound and less mobile patients.
- Provide interpretation services / British Sign Language (BSL) for families whose English is not their first language or if they are hard of hearing.
- GP to set up patient alerts that reminds them when patients are due for a medical review or annual health checks.
- De-sensitisation, particularly for patients with significant needle phobia requiring sedation.

## 2. End of life care

People with learning disabilities have the same palliative care needs as the general population and should have access to all the services that people without learning disabilities have. People with learning disabilities may have additional needs due to their disability.

Palliative care helps the patient and family come to terms with illness and dying, and making decisions about their wishes. Palliative care focuses on relieving pain and other troubling symptoms, as well as meeting the person's emotional, spiritual, and practical needs, hence improving the quality of their life during this time. (*Source: Nice guidelines about quality standards.*)

The NHS is committed to improving end of life care for dying people, reducing variation and inequalities in the quality and access to care that people experience. Whilst there has been less documented on end of life care needs specific to people with learning disabilities, in recent years there has been a more pressing need for information and good practice models.

The core principles for delivering end of life care:

- Care is client-centred and integrated.
- Treat individuals with dignity and respect.
- Identify and respect people's preferences.

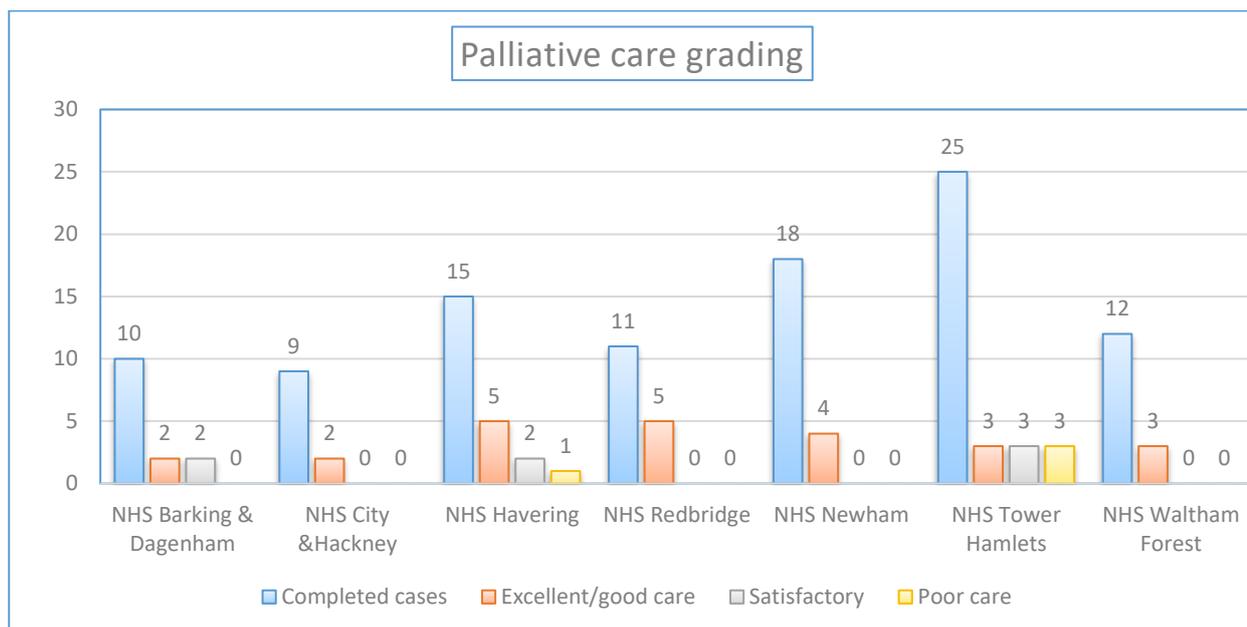
- Provide care after death.

Source: [www.nhs.uk/conditions/end-of-life-care](http://www.nhs.uk/conditions/end-of-life-care)

Studies about profound and multiple learning disabilities by Mencap UK recognise that most people with learning disabilities also have complex medical conditions, making it difficult to access suitable services compared to other groups. Some of the key challenges for people with learning disabilities towards the end of their life are:

- Having more physical and mental health problems.
- Having communication difficulties which make it harder to express their symptoms or may make it harder to express their wishes about their care.
- More likely to be diagnosed with cancer (late stage) which means they have a poorer prognosis.
- Having difficulties accessing healthcare systems due to reduced mobility.

### NEL: LeDeR palliative care cases



35 of the completed cases were referred for palliative care either in the community or in hospices. Care provided to 24 of these cases was graded as excellent or good; seven were satisfactory and four were rated as poor. Three of the poor care cases were in Tower Hamlets and one was in Havering. It is also recorded that in two of these Tower Hamlets cases, the referrals were completed a few days before the patient died and there are no clear records to indicate that the care changed as a result of this.

We recognise that palliative care can be performed along with the care a patient is receiving from their GP or main consultants. Our review findings indicate that most of these palliative care referrals were completed mainly by the hospital during the last few days or weeks of the person's life. In one case, the GP referred the person to the palliative care team six months before his death and the care for this patient was said to be excellent.

Late recognition of deterioration and poor communication between professionals and with family / carers were highlighted as the most common barriers to good palliative care provision. Carers and families felt that professionals were not listening to them.

Providing the best person-centred care involves a holistic approach to identifying and addressing individual needs and other challenges. Therefore, identification of early end of life warning signs and having a detailed assessment and a care plan put in place to manage pain and other symptoms, are key to improving the quality of life for people with learning disabilities.

### **Hospital discharges**

Many hospitals have a discharge coordinator or planner who helps coordinate the information and care a patient will need after leaving the hospital. NICE guidance from 2017 on discharge planning from emergency and acute hospital teams has emphasised that planning for a patient's discharge from hospital is a key aspect of effective care. It is important that a plan is put in place for when a person with a learning disability is being discharged from hospital. This could include arranging for transport from the hospital, restarting the care package and helping the person settle in once they get home.

When looking at the hospital records we reviewed, it is clear that there are two key things that are likely to change during a hospital stay: a new medication regime from a GP, and an ongoing care plan with social care teams.

Our reviews findings show that more often than not people with learning disabilities are discharged home to families and care homes without an appropriate discharge plan. Carers are then left to find out what has changed and what needs to be done differently.

#### **Inappropriate discharge and failed palliative care**

“Jazz was a 30 year old female with severe learning disabilities who lived with her family all her life. Jazz had had several admissions in the last few months of her life and in her last admission, her mother was not aware that she was dying. She thought Jazz was getting better and that she would be taking her home soon.

It was recorded that Jazz's mother is not proficient in English and was unable to understand terms used by doctors such as 'ceiling of care' - she did not know what this meant. The consultant further said that, Jazz was “going.” Jazz's mother asked “going where?” It was then that the consultant sat the family down and informed them that Jazz had a few days or even hours to live – it was shocking and very distressing for the family.

The family's wish was for Jazz to die at home surrounded by her family, and they requested that she be discharged home.

Jazz was referred to the palliative care team and discharged home without a proper discharge meeting. There is no evidence that the hospital staff contacted the

community team to inform them of Jazz's discharge and the support needed. This left the family unclear if palliative care input would be arranged and, if so, when this would be available to them. 48 hours later Jazz died. No one had visited the family to provide support."

Clearly, the above case study shows evidence of inappropriate discharge, a lack of coordination of the patient's care and a lack of information sharing, as well as poor communication between professionals and carers and families. It was also clear that the family should have been offered interpretation services to help them understand what the care provision entails and to come to terms with the situation in a more timely manner.

### **Successful palliative care**

"My sister, Beryl, was 70-years-old and terminally unwell with cancer. She was known to have a moderate learning disability and complex medical conditions. Several years back she had a mental capacity assessment and was deemed to have no capacity. I was the named next of kin and had power of attorney for her health and wellbeing.

Beryl had been in and out of hospital for six months or so, suffering from chest infections and circulation problems. The GP was very supportive, and he had arranged several home visits. As Beryl's health deteriorated, the GP discussed with the family her wishes and it was noted that she would like to die at home. A referral to palliative care was completed.

After assessing her needs and arranging for the appropriate equipment to be supplied, Beryl was provided 24-hour care and was attended to by highly experienced registered nurses. Working closely with Macmillan Palliative Team, the GP and Community Learning Disabilities Team, we felt this made a real and huge difference to the quality and dignity of care that Beryl needed during the last two months of her life. We received the support we needed at such a difficult time and the staff were kind, helpful and reliable. I don't know what my family would have done without them.

A very big thank you to everyone who was involved in my sister's care."

Whilst we recognise it can be difficult to predict when people are approaching the last 6-12 months of their life, particularly in the case of people with severe learning disabilities, complex physical and medical needs, identifying end of life care needs at an early stage could be beneficial, and can allow more time to plan appropriate support needs effectively with the person and / or the family. (Source: Association of Directors of Adult Social Services (ADASS), Local Government Association (LGA) and NHS England guidance 2015).

One learning disability nurse suggested that: "patients with frequent admissions to hospital and / or showing progressive decline in quality of life should be referred for palliative care assessment."

### **Recommendations**

- The need for strong inter-agency working between professionals and information sharing to help identify deteriorating patients.
- Carers and NHS support staff should be trained to recognise signs of deterioration in a timely manner and how to introduce discussion on planning care at the end of life using a sensitive, supporting and person-centred approach.

- Awareness of advanced care planning with access to adequately skilled staff and accessible resources will help in meeting individuals' wishes, needs and preferences, and ensure support is available during these difficult times.
- More palliative care beds across NEL suited to the needs of people with learning disabilities
- Awareness creation about the role of community learning disability nurses in supporting learning disability patients in the community.
- Early identification of end of life needs in order to support the co-ordination of care.

### 3. Mental Capacity Act (2005) and Deprivation of Liberty Safeguards

The Mental Capacity Act 2005 came into force in 2007. The act aims to empower and protect people who may not be able to make some decisions for themselves. It also enables people to plan ahead in case they are unable to make important decisions for themselves in the future.

The five key principles of the Mental Capacity Act:

1. Every person aged 16 years and over has the right to make his or her own decisions and must be assumed to have capacity unless it is proved otherwise.
2. People must be supported as much as possible to make their own decisions before anyone concludes that they cannot do so.
3. People have the right to make what others might regard as unwise or eccentric decisions.
4. Anything done for, or on behalf of, a person who lacks mental capacity must be done in their best interests.
5. Anything done for, or on behalf of, a person without capacity should be the least restrictive of their basic rights and freedoms.

Source: [www.legislation.gov.uk/ukpga/2005](http://www.legislation.gov.uk/ukpga/2005)

Having mental capacity means that a person is able to make their own decisions. The Mental Capacity Act says that a person is unable to make a particular decision if they cannot do one or more of the following four things:

1. Understand information given to them.
2. Retain that information long enough to be able to make the decision.
3. Weigh up the information available to make the decision.
4. Communicate their decision - this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

We all have problems making decisions from time to time, but the Mental Capacity Act is about more than that. It is specifically designed to cover situations where someone is unable to make a decision because the way their mind or brain works is affected, for instance, by illness or disability, or the effects of drugs or alcohol (sources: [www.nhs.uk/patient-guide/safeguarding/documents/health-workers-guide.pdf](http://www.nhs.uk/patient-guide/safeguarding/documents/health-workers-guide.pdf))

Under the Mental Capacity Act, care providers should ensure decisions about a person's care and treatment are made with their consent. Where a person is assessed as lacking capacity to make a decision, the provider / carer must make a decision in the person's best interests.

Factors to take into consideration when acting in someone's best interest are:

1. Will the person be able to make the decision in future?
2. What are the wishes of the person?
3. What are their beliefs and values?
4. What other factors should be considered?
5. What do other people who know the person well think would be in their best interests?
6. What would be the least restrictive option?

Source: [www.legislation.gov.uk/ukpga/2005/](http://www.legislation.gov.uk/ukpga/2005/)

According to the Mental Capacity Act, Deprivation of Liberty Safeguards (DoLS) should be applied where a person, 18 years old or over, is assessed as lacking capacity to consent to their care arrangements and is therefore likely to be deprived of their liberty. Where care home staff suspect care arrangements could constitute a deprivation of liberty, they must refer the case to their local authority to have it authorised.

Some people with a learning disability may have representatives acting on their behalf or may have set up a Power of Attorney and /or an Independent Mental Capacity Advocate (IMCA).

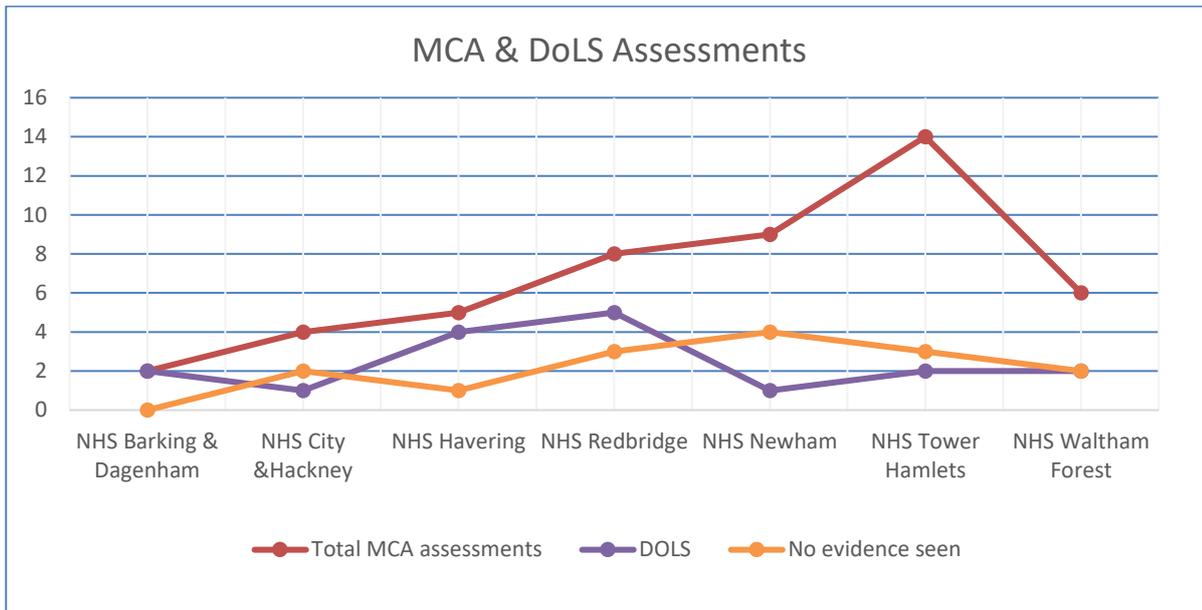
It was noted that in some of our reviews patients had IMCAs acting on their behalf, particularly those with DoLS approved. Evidence gathered revealed that all IMCAs attended or were involved in key decision-making sessions to provide support to the person. In one case there was a delay or lack of representation by an IMCA during a hospital procedure.

### **Mental Capacity Assessments**

Most reviewers agree that all patients known to have had a learning disability should have had a Mental Capacity Assessment (MCA) to determine their capacity to consent and inform care plans for the right support.

Information from our reviews indicates that 48% of the completed reviews had had a MCA completed, 17% of which were DoLS referrals - all the DoLS were approved and acted upon. In 15% of completed cases, the reviewers could not find evidence of a MCA; however, some of the patient records documented that these people were known to lack capacity and care provision was in their best interest.

DoLS assessment records reviewed were noted to be comprehensive in detail, and action plans were completed and put in place. It was also noted that patients with DoLS approved received excellent or good care.



Some patients were recorded as having declined physical examinations, taking bloods, declined social care support or screening programmes even though the needs were indicated. In most of these cases, there was no evidence regarding mental capacity assessments or best interest decision making.

There seemed to be a lack of understanding of roles, responsibilities and competence in discharging the duties placed on professionals under the MCA, and this may have resulted in:

- Delay in diagnosis and treatment of serious medical conditions.
- Delayed, or absent, end of life care planning.
- Non-existent or poor pain management.
- Urgent / proactive treatments not being delivered in line with clinical guidelines and pathways, such as blood tests, x-rays, scans, intravenous therapy and surgical interventions.

#### **Recommendations:**

- All professionals to recognise that it is their responsibility to ensure learning disability patients are assessed to determine whether they are able to make specific decisions about specific things at a specific time- this should be reviewed regularly.
- Care staff should be trained on the Mental Capacity Act to ensure they are able to identify a lack of capacity and refer appropriately for MCAs.
- A person's behaviour should not in itself lead to assumptions about what might be in their best interests. For example – in making an assessment of capacity, the fact that the person in question has a learning difficulty should not in itself lead the person making the assessment to assume that the person with the learning difficulty would lack capacity to decide on issues such as where to live.
- Professionals should act in accordance with MCA practical guidance and the Code of Practice.
- Practitioners should tell people about advocacy services as a potential source of support for decision-making, and ensure families are involved and well informed about key decisions/healthcare plans for their relatives.
- Staff should consider referring patients at risk of losing capacity, as well as those who have fluctuating capacity, to Community Learning Disability Teams for support.

- Professionals should support advance care planning: helping people to plan for their future care and support needs, including medical treatment, and therefore to exercise their personal autonomy as far as possible.

#### **4. Transition from children to adult services**

The Care Act 2014 places a duty on local authorities to conduct transition assessments for children and young people who are likely to need care and support after the age of 18. Preparation for transition from children's to adult health and social care services for young people with special educational needs, disabilities and / or complex health needs should start when the person is 14 years of age.

The Department of Health describes transition as:

“A purposeful, planned process that addresses the medical, psychosocial and educational / vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems.”

The transition from children's to adult health and social care services is recognised as a time when young people are at increased vulnerability. Transition assessments are fundamental in that they provide advice and information about what can be done to meet the person's needs, as well as what they can do to stay well and prevent or delay the development of needs. Hence, it is important that we get it right for young people.

According to the Care Act 2014 and The Social Care Institute of Excellence a parent, carer or the young person, as they approach their 18<sup>th</sup> birthday can ask for a transition assessment. Although transition arrangements are social care-led, this should involve all support areas such as health and social care, mental health, education, financial benefits for the young person, and their family situation, work and housing. Good transition planning should be person-centred with young people and their families being supported to make decisions about their future care.

LeDeR findings demonstrated that out of the 22 children cases completed, four were between the ages of 16, 17 and 18 years and were known to have had severe and profound / multiple learning disabilities. This means that even though they were known to services, their levels of disability clearly indicate barriers to accessing mainstream services available to other young people without learning disabilities.

The two 17-year-old cases had had a referral completed to start the transition process. Records show that in one of the cases transition meetings were postponed due to the person being unwell. The next meeting was planned to take place two weeks prior to his 18<sup>th</sup> birthday. Sadly, he died before the professionals could put a plan together for him.

The reviewer found no record or mention of transition planning in the 16 year old person's records.

#### **Poor transition arrangements**

Jolly was an 18 year old with severe learning disabilities, complex medical conditions and was a wheelchair user. Jolly lived with her family all her life and was supported to attend a special needs school. Her mother was the main carer and during school days Jolly was provided with transport and one-to-one support.

Jolly had input from her GP, epilepsy nurses, community learning disability nurses, a speech and language therapy team, occupational therapists and hospital teams.

Records show that, at the age of 17 years old, a referral was made to adult services. In a meeting attended by the social worker, adult services, Jolly's paediatric consultant and her parents Jolly's care was discussed and it was agreed that this was the right time to start planning for her transition.

Jolly was sharing a bedroom with her parents and they were happy to continue caring for her. It was noted that the family had a spare bedroom that Jolly could use. A referral to the occupational therapy (OT) team was done to assess the premises and advise on the necessary equipment. It was agreed that Jolly needed a special alarm and bedrails. It was also agreed that, once the equipment was supplied, they should start preparing Jolly to move into her own room. Months passed and these items were not delivered.

It was also noted Jolly did not have any care plan in place for further education or support to attend a day care centre. Jolly was spending time at home with her family.

Jolly continued to receive regular home visits from the children services, epilepsy nurses and the SALT team. The epilepsy nurse also discussed 'transition planning' with the family and encouraged her parents to gradually move Jolly into her own room. It was noted that Jolly suffered seizures mainly at night-time and the family was concerned that they had not received the necessary equipment as promised.

Eight weeks prior to Jolly's 18<sup>th</sup> birthday, another meeting took place between the family, Jolly, social worker and a paediatric consultant. Again, the family shared their concerns about moving Jolly into her own room without an alarm and bedrails. However, they were advised that Jolly should be moved out of their bedroom before her 18<sup>th</sup> birthday and they were reassured that the equipment would be supplied soon.

Following this meeting, the parents moved Jolly into her room without the alarm and bedrails. They would regularly visit her room at night to check if she was okay. Jolly had her 18<sup>th</sup> birthday and six months later the family still had not received the required equipment. Most of the children services seemed to stop and there was no communication with the family about where to go for what.

The family contacted the OT team and were told that the original company had no more of the equipment promised, and that they had changed the supplier. The new supplier had promised to deliver these items very soon.

On the day Jolly died she was supported to bed as usual. Her mother woke up to check on her at night and she seemed to be sleeping well. When her mother went in again in the early hours of the morning, Jolly was sleeping in an unusual position. Her mother reached out to re-position her only to discover she was not breathing. Jolly had died. Post-mortem results indicated the cause of death as sudden unexpected death in epilepsy.

From the above case, there were indications of poor communication between professionals and with the family, no plans documented for the patient's education or social activities and, above all, there was a significant delay in supplying the necessary equipment for the patient.

The characteristics of good transition planning include:

- An agreed process for joint strategic planning between children's and adult health and social care services.
- Integrated multi-agency transition plans and pathways which are person-centred.
- Multi-agency transition teams that possess a good skill mix which ensure that adolescent health expertise, professional leadership, key working and supervision and support are available throughout the transition process.
- A clear transition pathway for continued health and social care support.
- Identification of a key worker in adult services.
- Flexible, timely responses to issues that are identified as being problematic, and risk management procedures that include effective follow-up throughout the transition process.
- Early intervention and prevention through an individual health plan.

## **Recommendations**

- Reviewers highlighted that transition for children and young people with learning disabilities and complex medical needs should be an ongoing process rather than a single event, and tailored to suit individual needs.
- Good transition planning and assessments should begin as early as 13 or 14 years of age to ensure that by the time the person is 18 years old there are clear plans in place for the person covering health, social care, education, finance and housing.
- Professionals should foster close working relationships with families and carers and ensure improved communication / information sharing between all teams.
- Patient assessment records should be concise, accurate and include all patient conditions and their management processes.

## **5. Care coordination for people with complex needs**

Care coordination can mean a variety of things, but ultimately it is a patient-centred approach that strives to meet the needs and preferences of individuals, while strengthening the caregiving capabilities of families and service providers. Other characteristics of care coordination include:

- Inter-agency collaboration between all members of a care team, no matter their specialty, role or location.
- Clear communication between all parties involved in a patient's care, including the patient and their caregiver.
- Avoiding unnecessary and / or redundant tests and procedures, which can both improve the care experience and reduce the cost of care.
- Assessing all of a patient's needs – not just their immediate clinical needs.

Effective care coordination requires several things, including good and timely communication between members of a care team, and delivering patient education at the right level, time and place. It also involves creating care plans that treat the patient's medical condition, and that also consider barriers that may prevent them following through on the plan.

### **Inter-agency collaboration**

The results of our reviews were noted to be consistent across adult and child services. Evidence suggests that inter-agency collaboration was poor amongst professionals caring for children and people with complex needs, including those with learning disabilities. There was evidence that professionals were not sharing patient information with their colleagues and other teams. In addition, teams were working from different IT systems and there was no way of viewing other team's records.

Professionals interviewed by our reviewers reported they were so busy that they do not get time to discuss cases with their colleagues. However, they recognised that there were huge benefits of good inter-agency collaboration and communication.

Some of the factors required for positive inter-agency collaboration and communication are:

- Good working relationships, including a commitment from all staff to work together, trust and mutual respect across agencies, and shared understandings.
- Transparent and constant communication between agencies.
- Adequate funding, staffing and time, and the presence of a key worker or care co-ordinator.
- Strong leadership and clear lines of accountability.

There were very few cases (less than 10% of completed cases) where a single comprehensive assessment of the patient and carer was completed. In two of the cases records showed that the GP held regular multidisciplinary team meetings with other professionals, including mental health and social care teams.

### **Good care coordination**

Ben was a 32 year old with severe learning disabilities and complex medical needs. He had input from social care, community learning disability teams, acute and tertiary hospitals, and community mental health teams.

Ben's GP, who was also his care co-ordinator, arranged for a multidisciplinary meeting with all teams involved in Ben's care to discuss his health and social care needs. A care plan was completed and put in place with details of all the teams involved and names of the people to be contacted by carers.

Regular meetings / updates were also put in place to ensure that professionals shared any information about Ben. During these meetings Ben's medication was reviewed, and his care plans were updated to reflect the progressive nature of his condition and his changing needs.

The care manager where Ben lived said: "Care provision for Ben was so easy; carers knew what, how and when to carry out varied tasks and if they had any questions, needed further information, they knew who to contact. They felt supported."

Ben's family said: "Ben's GP was fantastic, he made our life so easy and gave the best to Ben."

The care co-ordinator takes on the role of primary contact with the patient and family, liaising with other care providers to co-ordinate services and providing emotional support for patients and their families through to death. Ideally this role should be filled by a specialist nurse with physical and / or mental health skills.

According to guidance from The Royal College of Nursing Network, a learning disability nurse is a specialist nurse who supports people with a learning disability while they are in hospital and in the community to make sure they get the care they need. It is important that the nurse meets the patient, and their carer if appropriate, as soon as possible after they arrive at hospital or, ideally, before a hospital stay.

The same guidance further states that a learning disability nurse should be able to find out as much as possible about the patient and understand the help that one may need while in hospital or out in the community.

Our LeDeR reviewers recognised variation in job roles across our acute Learning Disability Nursing teams. However they recommended that it is good practice for families and carers to be provided with the contact details for the care co-ordinator and / or Learning Disability Nurse should a crisis occur or they need advice over the phone.

Findings suggest that it is good practice for all patients with complex health needs to have a care co-ordinator. In the cases where evidence of care co-ordination was noted, the care provided was rated as good or excellent.

## **Communication**

Communication is central to providing person-centred care. Reviewers found care was frequently not centred on the individual or tailored to their needs. Issues included care plans not being shared with the person, information not being provided in an accessible format for the person, and a lack of training in communication methods.

When caring for people with learning disabilities, professionals need to adapt the way they communicate so that effective two-way communication can take place. Our reviewers documented that most people with a learning disability prefer face-to-face and one-to-one communication. They are also more comfortable with simple language and large print with less colour, as well as people speaking slowly and clearly, using easy to understand words.

It is important and reassuring that people with learning disabilities are comfortable with the people around them and ensure staff involved with their care know how to communicate with them.

### **Poor communication**

Joy is a 55 year old known to have moderate learning disabilities and bipolar disorder. Joy is literate, but hard of hearing and she lives in her own flat. She has a health passport that shows her preferred communication is by text or letters. She has a mobile phone and a landline.

Joy visited her GP for an urgent prescription and the receptionists informed her that they would contact her as soon as the prescription was ready. Two days later Joy had not heard from the GP, so she asked her carer to find out what happened.

Joy's carer contact the surgery and he was told by the receptionist that a colleague tried calling Joy and left several messages on her phone to let her know that her prescription was ready.

From the above case study, Joy, being hard of hearing, expected her GP to text the message and not leave a message on her telephone. The carer should have checked with Joy about her prescription and assisted her with this in a timelier manner.

All professionals working within learning disability teams should deliver care in line with accessible information standards, which requires that staff find out from carers and families the person's preferred way(s) to communicate and ensure they receive information – for example, through talking, text or in easy read format or braille. They should make a note of the person's preferred choice of communication, ensure this is well documented in their health plan or hospital passport and that other staff involved with this patient know, so that the person can receive information in the right format.

A hospital passport provides important information about a patient with a learning disability, including personal details, the type of medication they are taking, and any pre-existing health conditions. It also contains other useful information, such as their interests, likes, dislikes and preferred method of communication.

In approximately 30% of reviewed cases the patient had a hospital passport. The content of these records varied, some had a lot of information about the person's health conditions, ways to communicate, allergies, likes and dislikes, and all teams involved with the person's care and their contact numbers; others were just names, the person's details and a few lines about their likes and dislikes.

Hospital passports can be very useful for a person with a learning disability when they attend hospital appointments or during admission. As well as giving the hospital staff details about the person's health, hospital passports contain other useful information that can help staff understand the person better and make them feel more comfortable.

Reviewers found that some families and carers experienced a lack of, or poor, communication and were not always treated with kindness, respect and sensitivity. They found that the extent of their engagement also varied and some felt that they are not always listened to.

Our reviewers revealed that some of the common challenges about care coordination include:

- A lack of inter-agency collaboration, poor communication and lack of information sharing.
- A lack of specialised community nurses who will lead on this element.
- A lack of GP engagement due to capacity.
- An inability of the wider health and social care system to prioritise care coordination as 'core businesses'.
- A lack of integrated IT / record keeping systems to share information about patients.

## **Coordinate My Care**

Delivering person-centred quality care means always putting the patient at the heart of their own care. The NHS has introduced an innovative digital platform that enables multidisciplinary care planning for all patients who need urgent care.

Coordinate My Care (CMC) has been developed as part of end of life care planning to give patients an opportunity to create and initiate an urgent care plan where they can express their wishes and preferences for how and where they are treated and cared for. This care plan can be shared electronically with all the healthcare providers working with the patient, ensuring they are referring to one 'single version of the truth' without the need for repetition or any misinterpretation of the patient's situation or needs.

We recognise that most of the time patients are treated and advised by varied healthcare professionals who do not know them. This can lead to a lack of continuity and coordination of care, particularly out-of-hours, leading to the delivery of care sometimes feeling fragmented and less personal for patients and their families / carers.

CMC empowers the multidisciplinary team around the patient to work more effectively together and deliver patients the care they need 24/7. Evidence shows that NHS 111, out-of-hours GPs, and the London Ambulance Service are increasingly viewing these care plans and more needs to be done to encourage all professionals to use this platform.

#### Coordinate My Care Impact:

- More than 46,000 care plans created to date across London.
- 76% of CMC patients have died in their preferred place.
- 19% of patients with a CMC plan die in hospital, compared to 47% nationally.
- CMC is saving the NHS around £2,100 per patient, equating to an annual saving of over £16.8 million in London.

Source: [www.coordinatemycare.co.uk](http://www.coordinatemycare.co.uk)

## Recommendations

- Lack of planning and coordination often came with poor-quality care, and in very few cases reviewers found advanced care planning and good care coordination. It was recorded as good practice that all patients with complex health needs should have a care coordinator to oversee their care and provide liaison with other key health and social care professionals.
- Reviewers felt that professionals should ensure clear communication and share information amongst themselves. Professionals to listen and involve families / carers in decision-making processes, including allowing them to attend consultation sessions unless there is a reason not to.
- The role of community learning disability teams and how this links with other teams was noted to be unclear to many professionals. Reviewers felt more awareness was needed regarding the role of community learning disability teams and for them to be more visible to other professionals, carers and families.
- Reviewers noted that most hospital passports were not adequately completed, particularly for patients living in their own home or in supported living with limited support. Therefore, there is a need for families to be supported to complete and use hospital passports effectively. Well completed hospital passports were found to provide

the necessary information about the patient, facilitating good communication and care provision.

## 6. Staff training

A Mencap report published in 2018 suggested that almost a quarter of healthcare professionals have never attended training on how to meet the needs of patients with a learning disability. This lack of training is estimated to contribute to the 1,200 avoidable deaths every year of people with a learning disability.

Mencap professional survey 2018 results showed that:

- 45% of participants believe there is a lack of proper learning disability training.
- 59% felt that lack of training does not receive enough attention from within the NHS.
- 66% would like more training specifically focussed on patients with a learning disability.

Mencap has called for these efforts not to be made in vain by ensuring no health professional can set foot in a hospital without having had training on learning disability.

Lack of awareness amongst staff with regard to the needs of people with learning disabilities was found to be one of the key difficulties in providing high quality care for people with learning disabilities. Most of the home carers or support workers interviewed by our reviewers said they had not had learning disability training and that they believed training would help them understand better the needs of their patients and provide better care.

Our reviewers' recommendations were that it is good practice that all providers put in place an ongoing training and development programme which allows services to find and address any weaknesses, helping staff to be more all-rounded and better skilled at every aspect of their job. Training and development also helps to increase staff confidence within their role.

There are great benefits to staff training and development, such as increased job satisfaction and morale among employees; increased efficiencies in processes and practices; and increased employee motivation, resulting in financial gain; increased capacity to adopt new technologies and methods, as well as increased innovation in strategies and products.

The government has introduced mandatory learning disability training for all staff working with relevant patients and this is due to be piloted in 2020.

## Summary of our recommendations

Most of the learning to date echoes previous reports of deaths of people with learning disabilities, including in the NHS Long Term Plan, and the importance of addressing this cannot be over-estimated.

The most commonly reported learnings and recommendations were made in relation to the need for:

1. Inter-agency collaboration and communication.
2. Awareness of the needs of people with learning disabilities.
3. The understanding and application of the Mental Capacity Act.

As a result of the reviews completed, there have been discussions with providers and commissioners on how to take these findings forward. The ELHCP is working on the NHS LTP implementation strategy, which will address most of these service gaps and improve the quality of life for people with learning disabilities. This would include:

- Improving both the uptake and nature of annual health checks in primary care - the target is above 75%.
- Service providers to clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly review their provision.
- Mental Capacity Assessments to be carried out for all patients deemed to lack capacity or following a decline of services.
- Mandatory learning disability awareness training for all NHS staff caring for people with learning disabilities to be put in place.
- Training for carers, families and staff within supported living and care home. Families / carers to be provided with information about end of life care.
- Strengthening inter-agency collaboration and information sharing, and effective communication between different care providers or agencies and families.
- All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named care coordinator.
- Bereaved relatives and carers must receive an honest and caring response / support from health and social care providers to support their right for meaningful engagement

## Making a difference: LeDeR conference in September 2019

On 12 September 2019 the NEL LeDeR Steering Group held the first-ever LeDeR Learning Conference. This took place at the Great Hall in St Bartholomew's Hospital.



The event was organised in collaboration with The East London Foundation Trust (ELFT), Barts Health NHS Trust, and other partner organisations across east London.

The event had over 120 people attend and it showcased the significant progress NEL has made in completing LeDeR reviews.

### Our key speakers included:

- Jane Milligan – Accountable Officer, North East London Commissioning Alliance.
- Paul Gilluiley – Chief Medical Officer, ELFT.
- Justin Roper – Associate Director Quality for NHS NewhamCCG / NEL LeDeR lead.
- Matthew Richardson – Integrated Learning Disability Commissioner for Tower Hamlets CCG.
- Dr Nicola Payne – Associate Medical Director & London Clinical Champion for LeDeR programme NHS England.
- Dr Sabeena Pheerunggee – GP and Clinical Lead for Learning Disability for NHS Waltham Forest CCG.
- Dr Sanjay Nelson – Clinical Director, ELFT.
- Patricia Handley – Lead Nurse Learning Disabilities, Barts Health.
- Mary Elford – Vice Chair ELFT.

A wide range of healthcare professionals attended the conference, including GPs, carers, community teams, commissioners, safeguarding leads and representatives from NHS England, and the local authorities.

Also featured was an amazing performance by Include Choir, who performed songs such as 'Kind Communication Song, Battle Butterfly, I'm a Believer and Hymn of the Mental Capacity Act'.



The key areas of focus and presentations were informed by our top six themes from our completed LeDeR reviews. These areas are:

- Annual Health Checks for people with a learning disability.
- Caring for those who have difficulties engaging with care-hospital perspective.

- NHS Long Term Plan for people with learning disabilities.
- The revised Liberty Protection Safeguards (LPS) / MCA and Best Interest.
- The role of community services in supporting people with learning disabilities.



Feedback from all those who attended the conference and Twitter followers via #LearningFromLeDeR19 was very positive. 100% of the respondents rated the conference as good, very good or excellent, and 90% found the learning very helpful or extremely helpful. 74% said they would recommend the event to a friend or colleague. MCA and annual health checks were said to be the most interesting presentations, and the performance from the Include Choir was said to be “amazing and uplifting”.

## LeDeR programme – going forward

The Learning from Death guidance emphasises the importance of learning from reviews of the care provided to patients who have died, and that this should form an integral part of a provider’s clinical governance and quality improvement work.

A cross-sector approach to reviewing deaths of people with learning disabilities is underpinned in the Learning from Death guidance, which states that all deaths of people with learning disabilities aged four years and older should be subject to review using LeDeR methodology.

East London Health and Care Partnership (ELHCP) is committed to delivering the NHS Long Term plan for people with learning disabilities across NEL.

Over the past two years, the focus of the LeDeR programme has been clearing the backlog and completing reviews. It is important to move into a more proactive approach to meeting the health needs of people with learning disabilities, which requires targeted action and commitment to improve service delivery where required.

Over the next year or so, NEL LeDeR teams will not only continue with the completion of notifications, but will put more effort into developing SMART action plans and working with commissioners, providers and primary care to put ‘learning into action’ on some of the issues emerging from completed reviews.

### Key priorities and what we are doing to achieve them

Priorities / objectives	Rationale	Actions being taken to address these priorities	Risks / challenges to achievement / mitigating actions
Timely allocation (within two weeks of notification) of cases to reviewers	For all CCGs to grow and maintain a pool of sufficient trained reviewers to enable timely allocation and completion of reviews.	<p>Tower Hamlets and Newham CCGs have a sufficient pool of reviewers and allocations are done within an appropriate period of time.</p> <p>Commissioning for Quality and Innovation (CQUIN) has been put in place with Tower Hamlets and Newham CCGs. This has seen a very positive response to completing reviews.</p> <p>Barking &amp; Dagenham, Havering Redbridge (BHR) CCGs, City &amp; Hackney CCG and Waltham Forest CCG have insufficient reviewer numbers.</p> <p>We will continue working with partners to recruit reviewers.</p>	<p>Shortage of reviewers to take on cases continues to be a challenge.</p> <p>Planned CQUIN discussions with NELFT.</p> <p>Independent reviewers subject to funding.</p> <p><b>Partially achieved - ongoing.</b></p>

Priorities / objectives	Rationale	Actions being taken to address these priorities	Risks / challenges to achievement / mitigating actions
Access to records	The CCGs must ensure reviewers are supported to obtain records in a timely manner.	<p>A Project Officer role is in place and supporting reviewers in accessing records – both health and social care.</p> <p>An email has been sent to all GPs regarding LeDeR approval to share information.</p> <p>Information sharing agreements have been signed with some of our partners: The London Boroughs of Newham and Waltham Forest.</p>	<b>Achieved and ongoing.</b>
Completion of reviews within six months	The Local Area Contact (LAC) is enabled to prioritise the allocation of cases within their job role.	<p>The Project Officer role provides support to LACs with prioritisation and allocation of cases.</p> <p>The LAC role has been defined within new safeguarding adults' role descriptions.</p>	<p>The LAC role needs to be in all relevant job descriptions.</p> <p><b>Achieved and ongoing.</b></p>
	To ensure robust arrangements are in place to support the completion of reviews within six months.	<p>The Project Officer role is in place and working very closely with the LAC to support the allocation of reviews, to facilitate access to health and care records, supports reviewers with admin tasks plus any additional advice and guidance that may be required.</p> <p>The Project Officer role also supports LACs with quality assurance of completed reviews.</p>	<p>The shortage of reviewers continues to be a challenge.</p> <p>We will continue discussions with partners to support the recruitment of reviewers.</p> <p>Planned CQUIN discussions with NELFT and ELFT.</p> <p><b>Partially achieved and ongoing.</b></p>

<b>Priorities / objectives</b>	<b>Rationale</b>	<b>Actions being taken to address these priorities</b>	<b>Risks / challenges to achievement / mitigating actions</b>
Quality assurance of reviews	That completed reviews are sufficiently comprehensive, the cause of death is established and relevant health/social care input is clearly described.	The Project Officer role supports reviewers and LACs to ensure comprehensive completion of the reviews, and that input from all relevant teams is clearly captured.	<b>Achieved and ongoing.</b>
	Ensure a robust system in place to ensure LACs can review completed reviews within two weeks of submission for quality assurance by the reviewer.	The Project Officer role supports LACs with quality assurance of all completed cases. All completed cases are reviewed within two weeks and referred to SAR or for further investigations as deemed appropriate.	<b>Achieved and ongoing.</b>
Family engagement	To ensure information about the LeDeR programme has been communicated to the family and carer organisations, and that they have been offered the opportunity to participate / contribute to reviews.	The Project Officer works with all reviewers to ensure families have the right communication, and have been given the opportunity to participate in LeDeR reviews and comment about the care of their loved ones are received.	LeDeR reviewer training to include family involvement.  <b>Achieved and ongoing.</b>
LeDeR programme's business support function	To ensure the robust and smooth running of the LeDeR programme.	The Project Officer supports all teams with the development and management of the team's business plan, monitoring its progress and reporting risks.	<b>Achieved and ongoing.</b>

Priorities / objectives	Rationale	Actions being taken to address these priorities	Risks / challenges to achievement / mitigating actions
Learning from completed reviews	To ensure there are robust local strategies to support learning from completed reviews, leading to action and service improvements.	<p>The Local Delivery Steering Groups and STP Steering Group have established systems for:</p> <p>(i) Recording and collating recommendations and themes emerging from reviews:</p> <ul style="list-style-type: none"> <li>• TH CCG – has a system in place to track on completion and implementation through the LAC / local LD boards and groups and commissioners.</li> <li>• New CCG / BHR – cases of concern discussed with SAR subgroup (which is multi-agency) and the Safeguarding Health Sub Group which involves primary care and commissioner representation.</li> <li>• WF CCG – has a local steering group, which reviews and approves all cases. The steering group is a multi-agency group representing both health and social care teams.</li> <li>• C&amp;H CCG – has a local steering group, which reviews and discusses all cases. There is annual reporting to the Safeguarding Adults Board and the Planned Care Work stream.</li> </ul> <p>ii) Developing action plans and monitoring progress in response to the themes and recommendations.</p> <p>iii) Embedding learning from reviews into wider health and social care structures and systems with the aim of improving services, hence reducing health inequalities for people with a learning disability.</p> <p>The NEL Learning Disabilities and Autism Board will oversee the imbedding of learning from LeDeR reviews across the STP.</p>	<p><b>Item (i) Partially achieved and ongoing.</b></p> <p><b>Items (ii) &amp; (iii) On-going</b></p>

	<p>Ensure an effective mechanism for communicating learning, actions and quality.</p> <p>Improvements from completed reviews to stakeholders, including employees from providers and families.</p>	<p>The LeDeR Conference (learning event) took place in September 2019.</p> <p>TH CCG – to continue communication learning to its local LD boards and groups and commissioners.</p> <p>All other CCGs to continue to report learning into the Safeguarding Adult Board and Safeguarding Adult Review Group and LD partnership forum.</p>	<p>Future awareness events and training plans are being discussed (subject to funding).</p> <p><b>Partially achieved and ongoing.</b></p>
	<p>Social care and health providers and commissioners are actively engaged in ensuring learning is widely disseminated across organisations.</p>	<p>TH CCG – Integrated services, and the LAC is LD commissioner. The LeDeR process is fed through appropriate channels.</p> <p>Newham &amp; BHR – the LeDeR process is overseen by the Safeguarding Adult Board, which is multi-agency in nature. Key learning is shared with all relevant services.</p> <p>WF CCG and C&amp;H CCG – Steering groups are co-chaired by the Local Area Contacts and CCG.</p>	<p>Promotion is planned once the burden has been reduced and clear processes and dedicated resources are in place.</p> <p><b>Partially achieved and ongoing.</b></p>

## Appreciation

NEL LeDeR leads would like to take this opportunity to say thank you to everyone who has contributed to the LeDeR process, the LeDeR Learning Conference and this subsequent report.

Special thanks to all the families and carers for their assistance and contribution to the LeDeR review process.

The success of the LeDeR programme is built on the efforts of our LeDeR reviewers taking part in this process, the majority of whom are volunteers and undertake reviews alongside their day jobs. We recognise that this is not an easy challenge. I would like to convey our special thanks and appreciation to our LeDeR reviewers, service providers, partner organisations and stakeholder representatives for their support and contribution to the LeDeR review process.

To our Acute Learning Disability nursing teams (at NHS Barts Health, Barking, Havering & Redbridge University Hospital Trust and NHS Homerton University Hospital): thank you for your continued and diligent support to all our learning disability patients and reviewers.

Special thanks to our NEL Steering Group and Local Area Contacts (LAC) for overseeing the successful implementation of the LeDeR programme across NEL:

Eve	McGrath	LAC and Adult safeguarding Lead, BHR CCGs
Jenny	Singleton	LAC and Head of Quality, City & Hackney CCG
Justin	Roper	STP LeDeR Lead, LAC and Associate Director for Quality, Newham CCG
Mark	McLaughlin	LAC and Designated Lead Safeguarding Adults, Waltham Forest CCG
Matthew	Richardson	LAC and Integrated Commissioner, Tower Hamlets CCG
Mohammed	Shofiuzzaman	LAC and Designated Lead Safeguarding Adults, (MCA / DoLs / Prevent Lead), Newham CCG
Beatrice	Kivengea	NEL LeDeR Programme Officer

## Appendix 1: Achieving the requirements of the NHS LTP

### ELHCP Action Plan

Domains	How we will deliver this requirement
Annual health checks	<ul style="list-style-type: none"> <li>We will continue to improve uptake of the existing annual health check in primary care for people aged over 14 years with a learning disability, and make sure that at least 75% of those eligible have a health check each year. We will also work with our GP colleagues to ensure that all annual health checks delivered are of a high quality.</li> </ul>
Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP)	<ul style="list-style-type: none"> <li>We recognise that there is variation across NEL regarding the use of the STOMP-STAMP programmes to stop the overmedication of people with a learning disability, autism or both.</li> <li>We will expand the STOMP-STAMP programmes to stop the overmedication of people with a learning disability, autism or both.</li> <li>Each system will be conducting regular reviews of learning disability and autism prescribing in line with STOMP-STAMP for all psychotropic medication for both adults and children.</li> </ul>
Staff training	<p>Over the next five years:</p> <ul style="list-style-type: none"> <li>The ELHCP expects all primary care colleagues to be trained in learning disability and autism, improving their understanding of the needs of people with learning disabilities and autism.</li> <li>We will work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both.</li> <li>Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems will be expected to make sure all local healthcare providers are making reasonable adjustments to support people with a learning disability or autism.</li> </ul>
'Digital flags'	<ul style="list-style-type: none"> <li>By 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism.</li> <li>The ELHCP will support the rollout of the 'digital flag' together with our IT teams. This will ensure that people receive care around their needs and that services can be personalised around their needs.</li> </ul>
Community based care to reduce preventable admissions	<ul style="list-style-type: none"> <li>We will improve access to community crisis care to reduce preventable admissions to inpatient services.</li> <li>We will explore forensic support and other service models, including new respite and accommodation.</li> <li>In collaboration with our partnering organisations, we will develop specialist community teams for children and young people, and</li> </ul>

	models of care to allow people with a learning disability and autism to stay within community care as opposed to institutional care.
Ensure continuity of care	<ul style="list-style-type: none"> <li>• By 2023/24 we will ensure that children and young people with a learning disability, autism or both will have a designated keyworker to fast track these patients to ensure they are provided with faster diagnostic assessment.</li> <li>• This will be implemented via the development and rollout of a NEL risk register for children with a learning disability, autism or both.</li> <li>• Keyworker support will be provided to children and young people who are inpatients or who are at risk of being admitted to hospital. In addition, we will ensure that it is also extended to the most vulnerable children, including those who face multiple vulnerabilities.</li> </ul>
Implementing personalised care	<ul style="list-style-type: none"> <li>• We will ensure the provision and rollout of personalisation and personal health budgets across NEL.</li> <li>• We will support systems to work towards increasing the uptake of Personal Health Budgets and embedding this requirement within current service specifications and contracts.</li> </ul>
Implementing the national learning disability improvement standard 102	<ul style="list-style-type: none"> <li>• Over the next five years this will be implemented and will apply to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, workforce, specialist care and working more effectively with people and their families.</li> </ul>
Working in partnership across the ELHCP	<ul style="list-style-type: none"> <li>• In line with our STP plans for system based working, the ELHCP is committed to working with all partner organisations, including local authorities, to ensure that packages of care are developed jointly between services and that packages meet the holistic needs of those with a learning disability or autism.</li> </ul>
Meeting NICE guidelines	<ul style="list-style-type: none"> <li>• By 2023/24 we will ensure that all learning disability and autism care across NEL meets the NHS and NICE guidelines.</li> <li>• We will review and look to strengthen the existing Care, Education and Treatment Review and Care and Treatment Review policies, in partnership with people with a learning disability, autism or both, their families and clinicians, to assess their effectiveness in preventing and supporting discharge planning.</li> <li>• We will support systems to implement the 12 point discharge plan through the transforming care programme. This will ensure that patients with lengthy stays are actively being moved towards discharge with plans and processes in place to allow them to receive personalised care.</li> </ul>

## **Appendix 2: Analysis of Covid19 rapid reviews**

### **LeDeR COVID-19 Rapid Reviews Report**

#### **Introduction**

People with learning disabilities have poorer health than their non-disabled peers. Some of these differences are avoidable, and as such represent health inequalities. The LeDeR review programme was established to understand these inequalities and to look at ways to improve the standard and quality of care and reduce avoidable early deaths for people with learning disabilities.

In response to the ongoing coronavirus pandemic, NHS England/ Improvement in conjunction with NEL CCGs developed a Learning Disability Covid19 rapid review tool to be used following a death of a person with learning disabilities due to Covid19 or where Covid19 is suspected to have contributed to the cause of death.

#### **The purpose of the Covid19 rapid reviews**

The purpose of the reviews is to identify any learning or practice that will assist in improving local support, escalating concerns and guide necessary changes in health and social care services in order to reduce further deaths of people with learning disabilities.

NHS England/ Improvement has recognised that these are difficult times and things are having to be prioritised on a clinical and operational basis and the decision to carry out Covid19 rapid reviews need to be made locally.

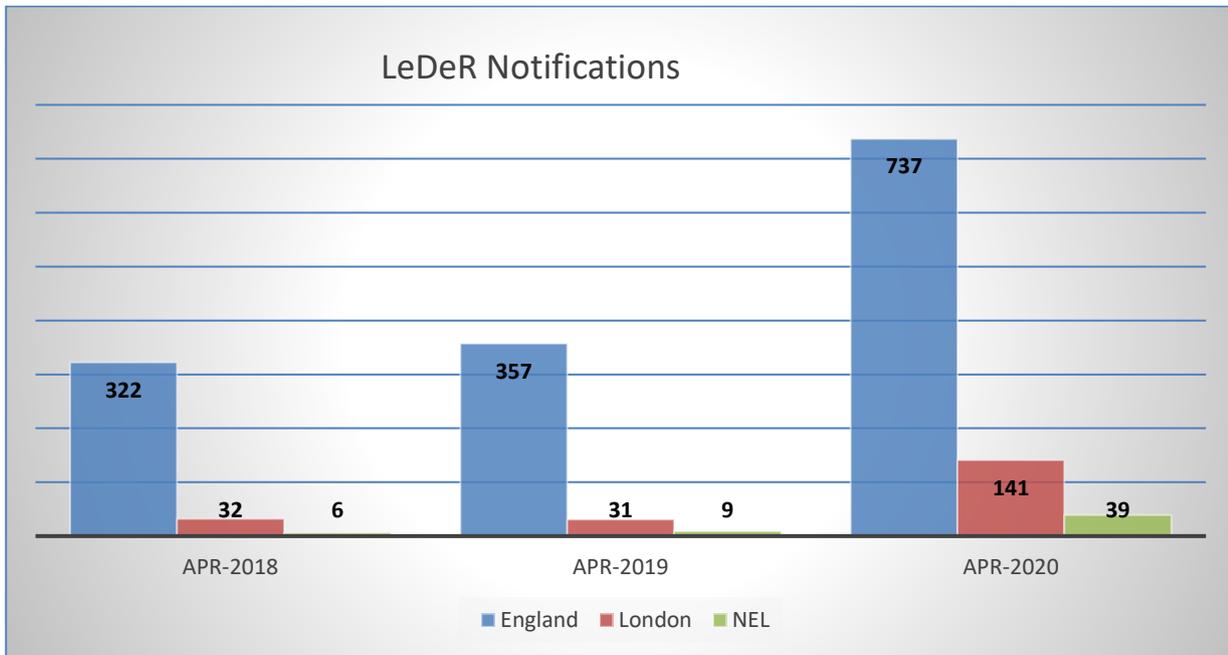
With the support of Community Learning disability teams, health and social care providers, North East London LeDeR Steering Group (consisting of NHS Barking & Dagenham, Havering & Redbridge CCGs, NHS City & Hackney CCG, NHS Newham, NHS Tower Hamlets and NHS Waltham Forest CCG), agreed to participate and carry out Covid19 rapid reviews for both local and regional learning.

The rapid review process does not replace the full LeDeR review.

#### **Death rates during the Covid19 pandemic**

Since the LeDeR review programme was devolved to Clinical Commission Groups (CCGs) in December 2017, we have seen a steady number of death notifications to the LeDeR programme. However from NHS England data in April 2020, the number of notifications increased by more than double compared to the same month in the last two years. This appears to be due to the Covid19 pandemic, even if the deaths may not be specifically identified as caused by Covid19.

#### **LeDeR notifications received in April 2020 compared to April 2019 and 2018**



North East London received 39 notifications in April 2020 compared to 9 and 6 notifications received in April 2019 and 2018 respectively. This is four times more than the usual numbers. In terms of number of deaths in North East London, between the first Covid19 related LeDeR notification on 17 March to 30 April 2020, we have received 46 death notifications. Of these, 36 deaths have been contributed directly to Covid19, however 10 deaths have been contributed to other causes. It appears that some of these deaths may have had Covid19 as a contributing factor but the patients had not been tested; therefore they cannot be categorised as a Covid19 death and as such are not part of the rapid review process cohort. For example we had three patients whose deaths were suspected to have been caused by Covid19, however the coroner's report did not record Covid19 as cause of death. These patients had showed symptoms similar to those of Covid19 but had not been tested and so these cases were not included into the list of rapid reviews.

### NEL rapid reviews analysis

This report covers an analysis of the first 32 completed rapid reviews whose cause of death is linked to Covid19. These patients were tested and confirmed positive for Covid19. The first Covid19 related LeDeR notification was received on 17 March 2020. As at 30 April 2020, we have received 36 Covid19 related notifications. Requests for rapid reviews for all these cases were sent out to the local teams. Thirty two rapid reviews have been completed and returned to LeDeR Local Area Contact (LACs) for approval and subsequently shared with NHS England/ Improvement.

### Below is the analysis of the completed rapid reviews

Location/CCG	Total No. of LeDeR notifications received (CoD- Covid-19 related)	Total No. rapid reviews completed by (30 April 2020)	Total No of LeDeR notifications (17 March– 30 April 2020)
Barking and Dagenham	3	3	6

City & Hackney	5	5	5
Havering	9	9	10
Newham	6	6	7
Redbridge	5	3	9
Tower Hamlets	3	4	4
Waltham Forest	5	2	5
<b>TOTAL</b>	<b>36</b>	<b>32</b>	<b>46</b>

The above completed reviews involved patients who had been tested for Covid19 and the results were positive. Reviewers did note inaccuracies in Covid19 testing. In 10% (2) the patients tested positive on a second (repeat) test. The initial tests were negative.

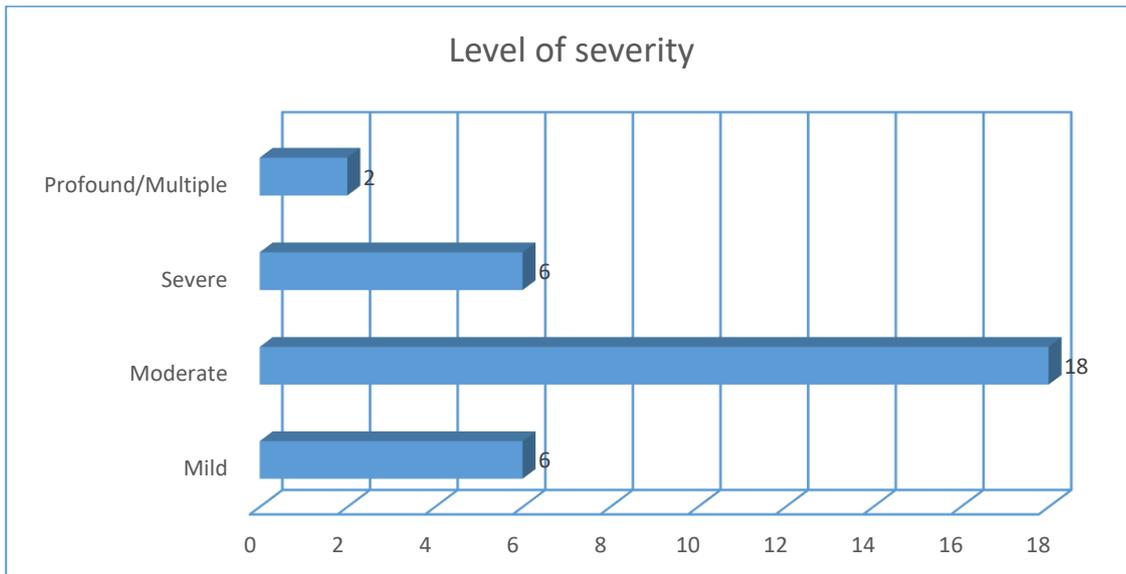
There were three patients whose death was suspected to have been linked to Covid19 however the coroner's report did not record Covid19 as cause of death. These patients had died at home or usual place of residence and referred to the coroners for post mortem. According to their service providers, these patients had showed symptoms similar to those of Covid19. These cases were not included in the list of rapid reviews.

### **Common recorded causes of death**

As with deaths from other causes, deaths from Covid19 are being registered. All the 36 cases tested positive of Covid19 and recorded as linked to the cause of death. Other common recorded causes of deaths were:

- Respiratory failure
- Pneumonia
- Sepsis
- Multi-organ failure
- Cardiac arrest/ heart failure
- Metastatic Cancers
- Epilepsy
- Bowel obstruction
- Type 2 diabetes

### **Level of Learning Disability severity**



Most Covid19 deaths were recorded with people with moderate learning disabilities.

### Age and Gender

Current data indicates that the youngest patient was 15 years and the oldest 85 years old. 53% (17) of the patients were female and 47% (15) males.

### Accommodation type

Three common types of accommodation were recorded:

- 25% lived in family homes or own home
- 25% in residential care homes
- 50% Supported living

### Pre-existing health conditions

It was noted that all patients had pre-existing health conditions. The main health conditions recorded were:

- |   |                                  |
|---|----------------------------------|
| • Respiratory conditions (COPD, Asthma, recurring chest infections) | • Cancer (lung, prostate, bowel) |
| • Heart conditions  | • Obesity                        |
| • Chronic kidney disease  | • Dementia                       |
| • High cholesterol  | • High blood pressure            |
| • Hypothyroidism  | • Mental health issues           |
| • Diabetes type 2   | • Depression                     |
| • Epilepsy  | • Neurological condition         |

### Covid19 symptoms

Common symptoms recorded were:

- High temperature (fluctuating temperature to some)
- Persistent coughing (others mild cough)

- Cold-like symptoms
- Breathing difficulties (shortness of breath)
- Chest infections
- Others symptoms recorded included general weakness, headaches, body pain, loss of appetite (not eating or drinking), vomiting, loose stool, tiredness, unable to stand and sleeping a lot.

### **End of life care**

19% (6) cases were noted to have been on palliative care pathway (2 from Newham whilst Tower Hamlets, City and Hackney, Barking & Dagenham and Redbridge had one case each).

### **Where the patient died**

93% (30) of the patients died in hospital, while one patient died in a hospital outside of the United Kingdom. 7% (2) died in the usual place of residence, the two were on palliative care pathway and had DNACPR order in place.

### **Access to Community Learning Disability Team (CLDT) prior to admission**

All patients were known to local CLDT teams except for three patients; two had been placed out of borough less than three months at the time of their death. Records show they were known to the CLDT at their original boroughs.

Our review results indicate that 18% (6) of the patients were in contact with the Community Learning Disability Services prior to admission or death, four were end of life pathway and two were receiving continuing healthcare in the community.

### **Length of hospital stay**

Hospital stays varied from a few hours to 38 days. The current data indicates that 66% (21) of the patients were in the hospital between 1 to 7 days. 9% (3) had been inpatients already for over 2 weeks for different health problems and contracted Covid19 whilst in the hospital.

84% (27) were admitted via Accident and Emergency department. 25% (8) were admitted to Intensive Care Unit (ICU) or Intensive Therapy Unit (ITU)

### **Summary of health care support accessed prior to admission**

66 % (21) of patients' families and carers had contacted NHS111 by phone prior to admission. Callers to NHS111 were advised to monitor the situation, 'watch and see', and to use paracetamol to manage fever (high temperature); and to contact 999 for an ambulance if the situation worsens.

18% (6) had contacted their GPs who advised to monitor and call NHS111 for further advice. For all palliative care patients, GPs continued regular contact and reviews via telephone or video links. In one case, the GP carried out a home visit and arranged admission with the hospital.

### **Reasonable adjustments**

78% (25) reviews showed that patients attended A&E with hospital passports, which helped hospital staff understand their patients' needs better.

Acute learning disability nursing teams across the footprint were recorded as very supportive; they were involved in monitoring patients' progress and ensured regular communication with families and staff especially where visiting was not allowed.

In 18% (6) of cases the care managers/support staff/carers were able to provide 1-1 support however, this was noted to have been in the early stages of the pandemic and before the patients tested positive for Covid19.

Review findings show that 13% (4) of patients were cared for within an isolation unit (whilst at the hospital) when the results were reported as positive for Covid19.

Most GPs were able to provide consultations by telephone or through videos links. One patient had a Coordinate My Care (CMC) plan and this was coordinated by the GP.

All palliative care patients had a robust plan in place and were regularly monitored. GPs continued regular reviews (via telephone or video) and the Community Learning Disability Services (CLDS) maintained contact with families by phone. Families/carers were well provided with personal protective equipment (PPE), informed about what to do and who to contact they should need advice or support.

## **Learning**

### **Delayed presentation**

Although there is no clear evidence to suggest early presentation could have made a difference, it is clear from hospital stay records that most patients presented late and seeking hospital assistance early may have been of help to some.

### **Need for improved communication**

16% (5) care home Managers (also known as provider services managers) stated that they were not informed of the Covid19 diagnosis until they received a copy of the patient death notification/certificate.

In one case, the care home manager received mixed messages from the hospital over the diagnosis. Initially they were advised cause of death was bronchopneumonia, then later they were informed that the patient was also suspected to have had Covid19. This was thought to create levels of anxiety, putting staff and other residents at risk.

### **Delayed discharges**

In two of the cases the patients had delayed discharge; they had been in the hospital following successful surgeries and were waiting for an appropriate placement. It is the reviewers' opinion that had they been discharged earlier, there may possibly have been a reduced risk of contracting Covid19.

### **Failed discharges**

There were two instances where patients were discharged and readmitted a day later. The care home managers informed reviewers that they felt that these patients were not well enough to go home and there was no face to face discharge meetings at the hospitals to support appropriate discharge process.

### **Accuracy of results**

Clinical records showed that 9% (3) of patients tested negative on first round of tests; a repeat test performed a few days later and the results were positive. Based on this information, it is possible that symptomatic patients who may have tested negative and no repeat tests were completed, may have been missed out as Covid19 patients based on the first round of tests.

### **Personal Protection Equipment (PPE)**

Evidence from our reviews showed that 75% of our patients lived in residential and supported living accommodation. Speaking with care home managers, it was noted that access to personal protection equipment was a particular problem for supported living providers.

### **Mental Capacity Act/ DoLS and compliance with public health guidelines**

Most reviewers recognised that majority of our learning disability cohort of patients may lack capacity and this could make compliance with public health guidelines and any sudden changes hard to put in place.

In one case, the patient was non-compliant with both public health guidelines and treatment plan and this contributed to his demise. Carers and family members were not allowed to stay with the patient at the hospital which may have caused him anxiety and confusion. Records show that the patient did not have capacity and the reviewer found no evidence of Mental Capacity Assessment (MCA) was completed or Deprivation of Liberty Safeguards (DoLS) applied or approved. The reviewer's opinion was that assessment should be carried on all patients deemed to lack capacity and DoLS approved and where possible involve independent mental capacity advocate (IMCA).

### **DNACPR order**

In the right circumstances, a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order helps ensure a patient's death is dignified and peaceful. All six patients on the palliative care pathway had DNACPR order in place and this was followed appropriately.

In one review, a patient was found unresponsive, had suffered a cardiac arrest, and no cardiac arrest call was put out despite DNACPR not being in place. The DNACPR decision-making process should take account of the benefits, risks and consider the patients and family wishes and preferences.

The same patient's records revealed that there were gaps in monitoring this patient as regularly as was required. The patient deteriorated and the reviewer finds no evidence that this case was escalated appropriately. A further investigation has been started to establish what happened and for lessons to be learned.

## **Good practice**

Our reviewers identified the following good practice:

66% (21) of the patients had hospital passports and these were key in providing vital information about the patient including personal details, how to communicate, type of medication they are taking, any pre-existing health conditions as well as likes and dislikes.

One patient had Coordinate My Care plan (CMC) in place and the GP coordinated his care plan.

Reviews recorded good communication between families/care homes and the hospital staff; most hospitals ensured regular contacts with staff/carers and families particularly where visiting was not allowed.

Acute Learning Disability Nurses were praised for their continued commitment in monitoring patients and supporting families. They co-ordinated patients care with families, ensured that reasonable adjustment were in place, explaining to families the rationale for medical and DNACPR decisions. It should be noted however that the capacity of the liaison nurses is limited and that they often cover more than one site (NEL has one nurse covering the Homerton, one covering Barts and one covering BHRUT). As such it was not always the case that a liaison nurse would be available for support when a patient was admitted. It is therefore recommended that consideration be given to whether the current model is sufficient.

In all six palliative care cases, GPs continued regular reviews (via telephone or video), the CLDTs maintained contact with families by phone. Patients had a robust care plan in place should they become unwell. The families had named contacts, anytime, to discuss any concerns. There was evidence of coordinated care, good communication and information sharing and multidisciplinary team involvement in these cases.

It was noted that one GP carried out a home visit and arranged hospital admission for the patient.

In situations where patients were known or suspected to have had Covid19, they were recorded to have had individual plans in place to manage self-isolation as per Covid19 guidelines. Most patients were compliant with Covid19 management processes. They were provided with private rooms and 1-1 support.

Some care home managers were reported as providing easy read information to help patients understand Covid19 and what was expected of them, although it is not clear how much they understood particularly for those with dementia, severe and profound learning disabilities.

Carers/staff and families provided all of the necessary care/support and information. Staff followed public health guidelines and NHS111 advice, carried out regular monitoring of patients and sought hospital assistance as needed.

## **Summary findings**

All our patients had one or more underlying health conditions such as respiratory conditions (chronic obstructive pulmonary disease (COPD), asthma, and recurring chest infections), heart conditions and chronic kidney disease and at risk of contracting Covid19.

Patients showed varied symptoms which made it difficult to offer accurate predictions of average time to seek further advice or hospital admission. The most common symptoms were temperature and cough.

The most common health care support accessed by patients prior to admission were NHS111 and Accident and Emergency services. Most patients attended the hospital with hospital passports. Excellent care was recorded on all palliative care patients.

The majority of our learning disability patients lived in supported living accommodation.

It was evident that we had more deaths recorded on patients with moderate learning disability compared to mild, severe and profound.

## **Recommendations**

The Covid-19 rapid review analysis has been produced to provide a snapshot of learning so far. 32 of 36 rapid reviews have been undertaken, and we continue to receive LeDeR notifications relating to Covid-19, so the analysis of findings from rapid reviews will continue into 2020/21.

As such, the below recommendations have been compiled based on the rapid reviews completed to date. These may be subject to change and additional recommendations may be made as further work is undertaken. In some cases, recommendations have been made for further information to be collected to further enhance understanding of the circumstances of death.

### **Recommendation 1: Prioritising referrals for Learning Disability Health Checks**

As Learning Disability Health Checks are reintroduced using a blended approach (both virtual and face to face, based on patient choice and clinical risk), those patients with the pre-existing health conditions noted in this report (as well as those with additional risk factors) should be prioritised for an annual health check with their GP.

### **Recommendation 2: Analysis to be undertaken into affected service provision**

75% of patients with a learning disability who were reviewed were living in provider run accommodation, both residential care and supported living. Analysis should be done into which providers were most affected, whether there were any quality concerns at these provisions, whether adequate monitoring was in place and if there was any further support that could have been offered to these services.

### **Recommendation 3: Circulation of accessible information about Covid-19**

Community teams worked hard to ensure that information about Covid-19 was circulated; resources must be made available online to ensure that those who may not be open to community teams are aware of symptoms. Information must also be updated to include Test and Trace and other relevant additions.

**Recommendation 4: Improvements to transfer of care**

Two patients had been placed out of borough at the time of their death and may not have been getting direct input from their local CLDTs. Any out of borough transfers must be referred to the host borough immediately with documented plans in place for interim care if a dispute arises.

**Recommendation 5: Explore the suitability of the NHS111 pathway for patients with a learning disability**

66% of patients' families and carers called NHS111 for advice and support prior to hospital admission. NHS England will be working with NHS111 to ensure that the advice offered regarding Covid-19 for patients with a learning disability is suitable and takes reasonable adjustments into account.

**Recommendation 6: All patients with learning disabilities should have a hospital passport in place**

78% of patients attended A&E with hospital passports, which helped to improve the quality of their care. Community teams, GPs and social care should continue to promote the completion of hospital passports and the recently developed Covid-19 passport for people with a learning disability; this question should be included in the learning disability annual health check.

**Recommendation 7: Improve communication between hospital and care providers**

It is vital that service managers be informed as soon as a resident tests positive for Covid-19, to ensure that all other residents and staff in contact with the service are tested as well. A review will be undertaken with service managers to ascertain if communication improved throughout the pandemic, and an action plan to improve the communication pathway will be developed if needed.

**Recommendation 8: Learning from DNACPRs**

DNACPRs were largely found to be appropriate, but there was one serious incident where procedure was not followed. An investigation will be undertaken into this incident and learning included in the next rapid review update.

**Recommendation 9: Training to be delivered on Covid-19 and the application of the Mental Health Act**

Training in the application of the Mental Health Act in relation to Covid-19 must be undertaken. NELFT colleagues have already worked with 39 Essex Chambers to produce a webinar on this topic.

**Recommendation 10: Further information to be included in rapid reviews**

To support the understanding of risk factors relating to Covid-19, it is recommended that the next rapid review analysis include data relating to ethnicity and Body Mass Index (BMI).