Learning Disability Mortality Review

Enfield Annual Report

2018 - 2019

Introduction

The Learning Disabilities Mortality Review (LeDeR) programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). It is the first national Programme of its kind in the world.

Its overall aims are:

- To support improvements in the quality of health and social care service delivery for people with learning disabilities.
- To help reduce premature mortality and health inequalities for people with learning disabilities.

The 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 for every person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so. More recently, analysis of data from the Primary Care Research Database suggested that the all-cause standardized mortality ratio for people with learning disabilities was 3.18, and that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.

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 standardized review process. This enables them to identify good practice and what has worked well, as well as where improvements to the provision of care could be made. Recurrent themes and significant issues are identified and addressed at local, regional and national level.

The LeDeR programme began gathering reviews from pilot sites through 2016, and there was an expectation all deaths of people with learning disabilities would be reported from April 2017. Enfield were not part of the pilot programme but did submit 2 reviews in March 2017 as part of the testing phase for the online system. Enfield had been reviewing deaths locally for a number of years.

The LeDeR programme is due for completion in 2020. However, the review programme will continue as part of the NHS 10-year plan.

NHS England have established an Action from Learning Group, to embed the lessons from the mortality reviews.

LeDeR in Enfield

Local Mortality Review Steering Groups are responsible for quality checking reviews before submission to the programme, coordinating actions from reviews and disseminating information from the regional and national groups.

The Enfield LeDeR Steering Group consists of; -

- Head of Integrated Learning Disabilities Service (ILDS)
- Head of Joint Services for Disabled Children
- Designated Nurse for Safeguarding Children, Enfield CCG
- Safeguarding Adults Lead, Barnet Enfield and Haringey Mental Health Trust
- Acute Liaison Nurse Barnet and Chase Farm Hospital
- Acute Liaison Nurse North Middlesex University Hospital
- GP Liaison Nurse, ILDS
- Continuing Healthcare Nurse Assessor, Enfield CCG
- North Central London LeDeR coordinator
- Person Centred Planning Coordinator, ILDS (Local Area Coordinator)
- Named GP for Adults, Enfield CCG

The Local Area Coordinator also attend an NCL steering group, that shares learning across the region and takes a more strategic view.

The National LeDeR Programme process map is currently under review.

A local process is in place and summarised in appendices -

In addition to the Steering Group, Enfield also have a 'Mortality Reviewers Peer Support Group'. This allows reviewers to discuss details of their reviews before taking them to the steering group.

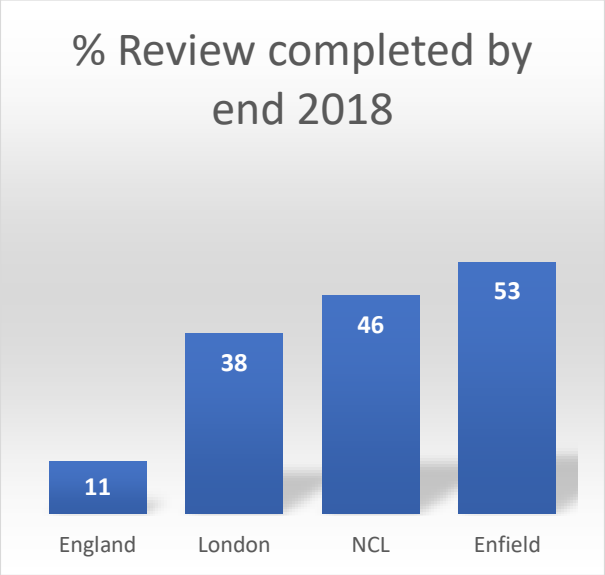
As of the end of April 2019 there were 17 trained and active reviewers in Enfield. 15 were based in ILDS, one in Enfield CCG and one with NCL. Reviewers are trained via an e-learning package hosted on the LeDeR website.

LeDeR reports every calendar year. The report for 2018 was released in May 2019. When comparing figures with LeDeR I will use calendar year 2018. Otherwise I will use the year April 2018 to April 2019.

Some data will also be presented over the whole period of the programme.

Key Indicators

Review completion



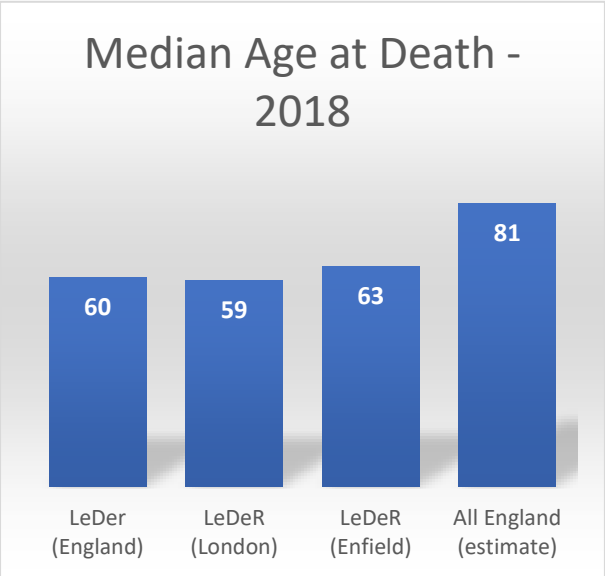
All areas were given a target to complete 50% of reviews by the end of 2018.

NCL, and Enfield particularly, significantly outperformed the national average.

NHS England have developed a backlog project to improve completion, but this will not apply to NCL.

(note – in terms of submission by financial year, 3 reviews were submitted in 2017-18, and 12 reviews were submitted in 2018-19)

Median Age at Death



The Median age at death for the LeDeR Cohort in 2018 was 60. This is a slightly higher health inequality than reported by CIPOLD.

Enfield performed slightly better than England and London in general, but the median age at death was still 18 years younger than the national average.

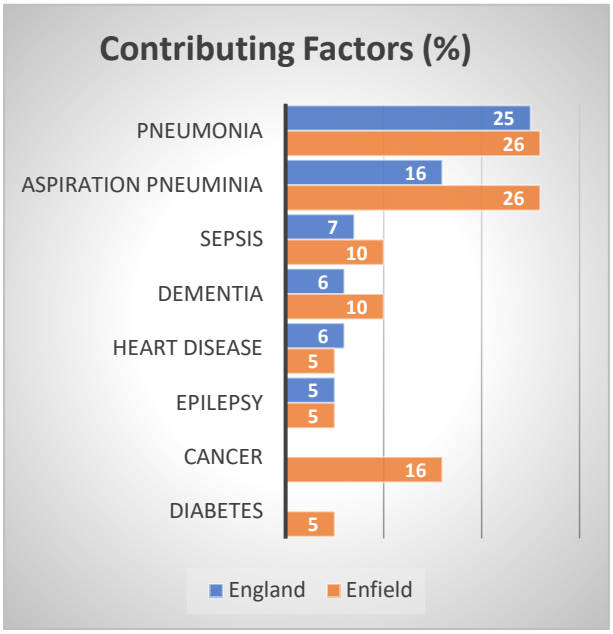
It should be noted that Median Age at Death is strongly influenced by the age demographic of the population, so would not be expected to show a significant trend over the short to medium term.

Numbers of death reported

The estimated number of deaths in London region for 2018 are 419. Enfield reported 19. There is no breakdown by borough available for the year. However, there is data for the period June to Dec 2018, when Enfield reported 9 deaths. This was third highest in the London Region.

As fourth most populous London Borough with the highest number of people known to services in the NCL area, this is to be expected.

Causes of Death



The LeDeR programme has identified some issues with the coding of contributing factors to death on death certificates, for example, 'learning disability' being included on a number of occasions, so results should be treated with caution.

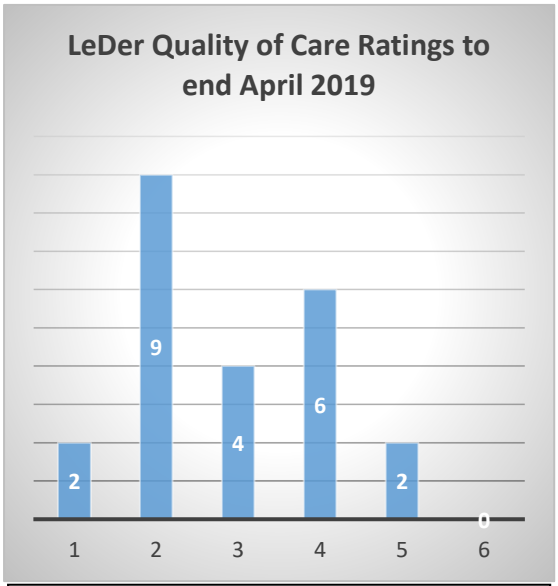
Note there are often multiple contributory factors recorded.

Pneumonia / Aspiration Pneumonia are the primary contributory factors both nationally and locally (although higher in Enfield in this period).

3 people died of cancer in 2018, which is higher than the national rate, but still a small number and we would need more national data to determine if this is significant.

Another 5 people (26%) had 'Cardiac Arrest' as a secondary contributing factor. Most commonly secondary to infection.

Quality of Care



**Note – LeDeR changed the criteria during 2018-19. I have updated rating here to be consistent with new criteria.*

The LeDeR review process includes providing a quality of care rating to each review.

1. This was excellent care (it exceeded expected good practice

2. This was good care (it met expected good practice).

3. This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).

4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.

5. Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.

6. Care fell far short of expected good practice and this contributed to the cause of death.

In 2018 48% of reviews national determined people received care that met or exceeded good practice. Reviews rated 1 or 2 in Enfield were also 48%.

8% of reviews nationally determined people's quality of care fell short of expectations to the extent that it significantly impacted on wellbeing or directly contributed to death. Reviews rated 5 in Enfield also account for 8.6% of reviews. No reviews in Enfield to end of 2018 have been rated 6.

It should be noted that a number of cases have also been subject to Safeguarding and Serious Incident procedures, which delays the LeDeR process. Of the 6 reviews not completed at time of writing, 2 are subject to Safeguarding investigations by the North Middlesex Hospital, 1 was subject to safeguarding investigations by Enfield Council (recently completed and awaiting discussion at steering group), 1 is subject to a safeguarding investigation by Barney Enfield and Haringey Mental Health Trust, and 1 is subject to the Child Death Overview process.

The 2 reviews that identified poor care that could have contributed to the death include one death from sepsis (see below) on one sudden unexpected death in epilepsy. The first was subject to a safeguarding enquiry, and the second subject to a serious incident investigation. The SI identified missed opportunities for the hospital to admit the person after they presented several times at A&E with increased seizure frequency when she became pregnant (see action plan below).

Best practice examples included outstanding support from the community for a young person with terminal cancer, and excellent reasonable adjustments to support someone with terminal cancer in hospital.

Month of Death

LeDeR notes a spike in Pneumonia deaths between October and December 2018. This was not reflected in Enfield, however there was a very significant spike in deaths in between January and March 2018. 10 of the 19 deaths (53%) occurred in this period, and pneumonia was a contributing factor to 7 of the 10 deaths.

Place of death

Nationally 62% of people with Learning Disabilities died in hospital in 2018. In Enfield the figure was 68%.

Action from Learning Groups

The following projects have been identified by the NHS Action from Learning into action group.

Sepsis

The national sepsis group is looking at:

- How people can be helped to spot the signs of sepsis sooner so that they can get treatment quickly.
- How important information about people can be shared with health and care staff.
- How to share what is working across different organisations.

Locally, one of the deaths where the care was rated 5 was a sepsis death. The person had a UTI being treated with anti-biotics and appeared to be responding well. However, they then began to deteriorate rapidly, and an ambulance was called. A Multi-Agency review, in consultation with the attending physician from the A&E department determined that if the staff had been more aware of sepsis, they may have called earlier, and this could have influenced the outcome. The Multi-Agency review was aware of a number of similar reviews across the country, indeed this has been an issue for the NHS regardless of learning disability, which had led to this Action from Learning Project. The Review was clear they did not want this to be seen a criticism of the person's staff team, but a learning point to increase awareness.

Enfield ILDS and Enfield CCG have adopted the 'Stop and Watch' initiative to help supporters identify a rapidly deteriorating patient. Information is available on the MyLife learning Disability pages and hard copies are being distributed by community nurses.

Mental Capacity Act

The national MCA group is looking at how to:

- Tell more people about the Act.
- Help people understand the Act better so they know when and how to use it.
- Help people understand the difficulties that people with a learning disability can face when it comes to the Mental Capacity Act.
- Share what is working across different organisations.

Locally, reviews have found instances where capacity assessments and best interest decision have not been recorded appropriately. No decisions have been determined to be incorrect. Services have been contacted on a case by case basis for feedback as part of the review process.

The local area coordinator has asked to join the learning disabilities working group at the North Middlesex University Hospital to discuss a project to look into this issue.

Constipation

The constipation group is:

- Telling more people that constipation can be prevented and treated, and that it can be a serious condition for people if it goes untreated
- Making some resources for health care professionals and people with a learning disability, their families and carers. These resources have information about spotting the signs of constipation and about having a healthy diet and being active.
- Encouraging people to think and talk about constipation – it can save lives!

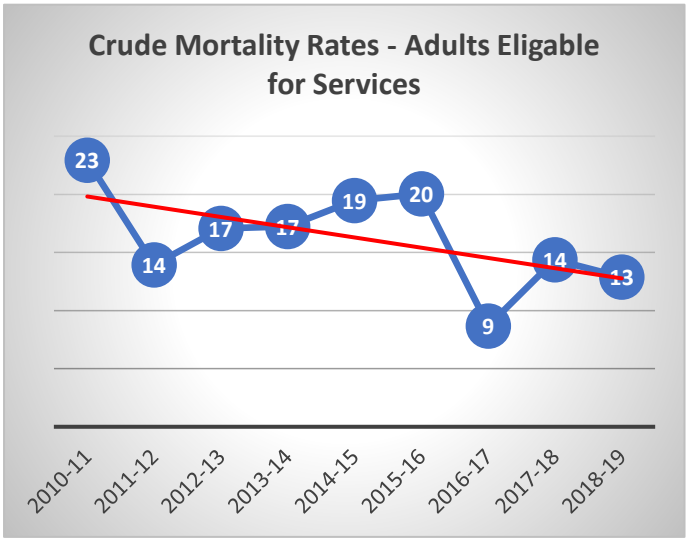
Locally, constipation has not contributed to any deaths. The easy read information on constipation produced by the Action from Learning Group is available on the MyLife Learning Disabilities page and is distributed by Community Nurses as appropriate.

It is also included in the information being circulated as part of the ILDS Nutrition and Exercise Project.

Local Trends

The Enfield End of Life Care Steering group have been monitoring the deaths of adults eligible for services for a number of years now and have sufficient information to establish some significant trends.

Mortality Rate



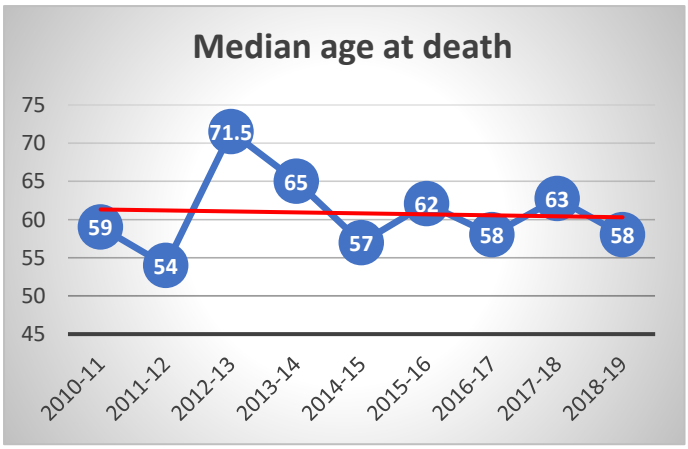
The Mortality Rate has shown a significant drop from 2016-17 onwards, and a trend of approximately 30% reduction since 2010-11.

In 2016-17 the mortality rate for adults with learning disabilities eligible for services was slightly lower than the general population in England.

In 2018-19 this gives a simple mortality ratio of 1.43.

Although LeDeR do not calculate mortality ratios, this is a significant improvement on the CIPOLD figure of 3.18.

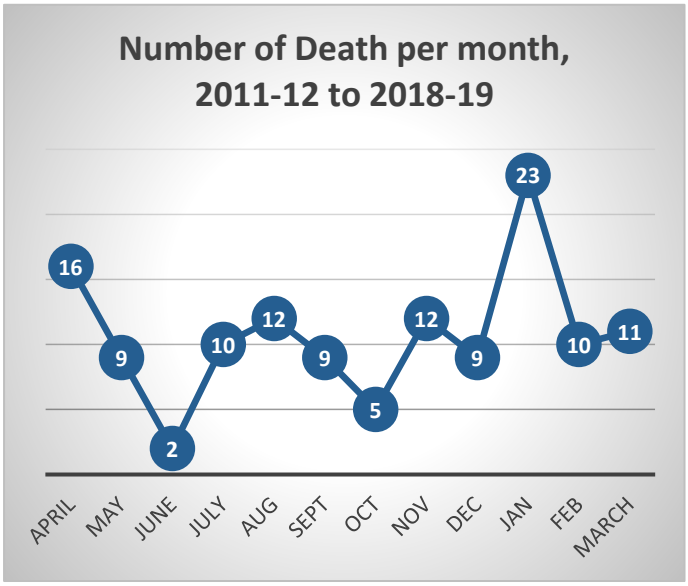
Median Age at Death



There is no significant trend in Median Age over this period.

The Median Age over this whole period is 59, which is consistent with the LeDeR and London figures for 2018.

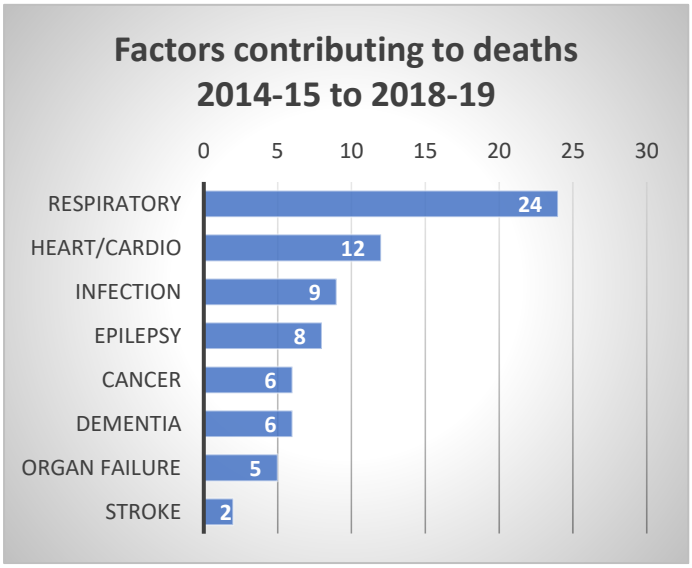
Seasonal Variation



Seasonal variations in Mortality seem much more pronounced amongst people with learning disabilities, with a much higher relative mortality in January.

Over the 9-year period to April 2019, 47% of deaths occurred in the months of January, February, March or April (60 of 128)

Factors Contributing to Death



Respiratory factors have been the dominant contributing factor to deaths over this period.

Heart / cardio factors are second most common factor over the last 4 years. This includes Cardiac Arrest as a secondary factor.

Other Local Learning

- People who died were only half as likely to have had an annual health check than the rest of the population (40% to 80%). Most had long term health conditions and regular contact with health services. It is possible they were not prioritised due to regular input. This has been fed back to the GP liaison Nurse who is working on improving uptake and quality of Annual Health Checks.
- There is a potentially emerging issue around hospital discharge, particularly communication between Acute and Primary health care and Community Services. This is only relevant to 2 reviews in 2018 (one still in progress), but I expect this will become a theme both locally and nationally in future years.

Appendix 1 Enfield LeDeR Steering Group Actions

Below is the Enfield Steering group Action tracker, complete as of end of April 2018.

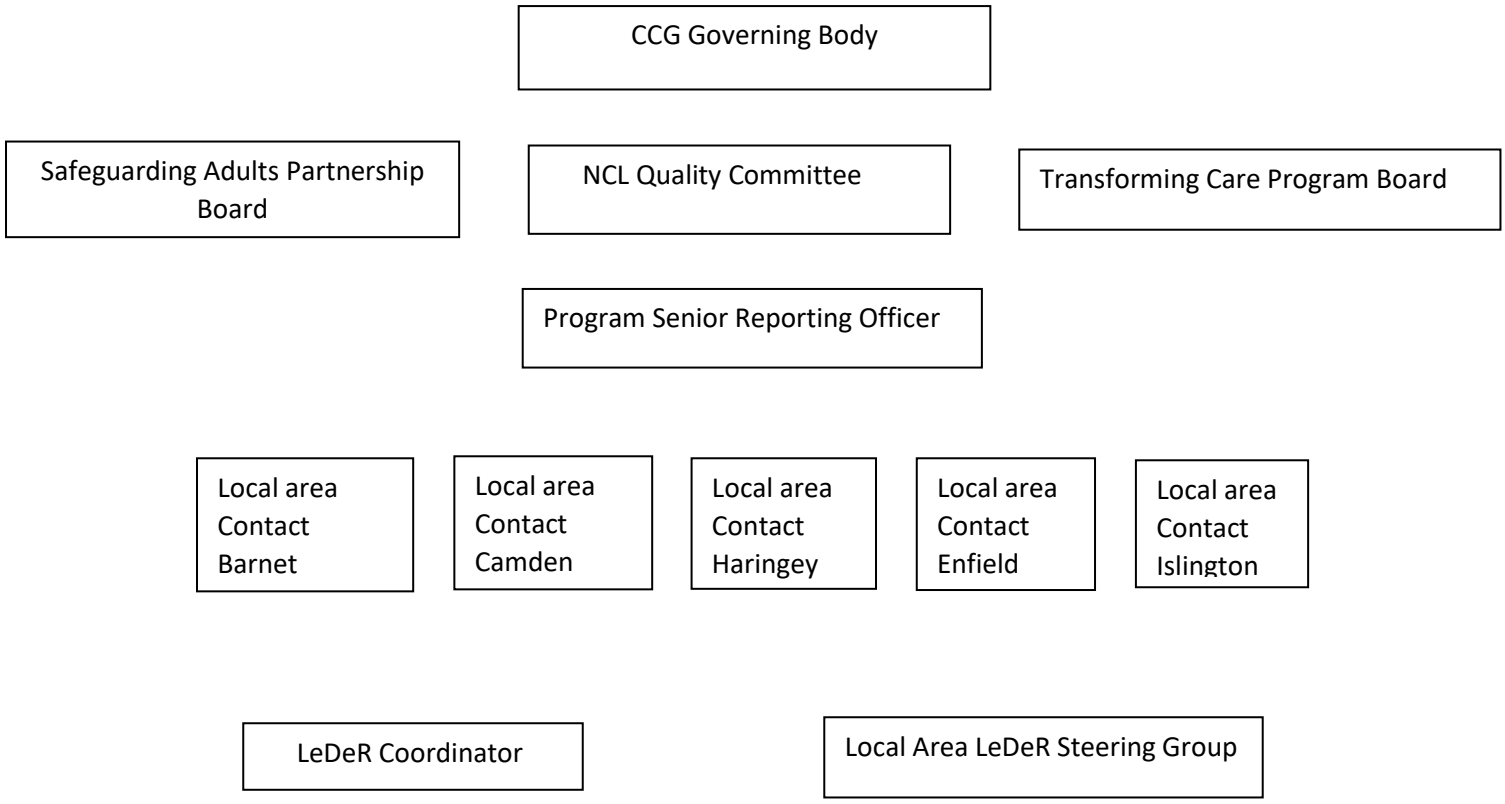
Who	will do what	By When	Outcome
LAC and Community Nursing (ILDS)	Promote these key themes to Health and Care Partners • In what circumstances to identify a Learning Disability • The importance to reasonable adjustments with examples • Consistent application of Mental Capacity Act and Best Interest Decisions	GP Protected Learning Time (Date TBC)	
ILDS GP Liaison Nurse	Improve uptake and quality of annual health checks - including important of continuing Annual Health Checks even when long-term health conditions being managed. Only 19% of people who died in 2017-18 are known to have had a health check.	Ongoing	The GP Liaison Nurse is leading the project locally to improve quality and uptake of annual health checks. This includes raising the issue of people potentially missing from register, or not having annual health checks due to active management of long-term health conditions. This work is ongoing.
Enfield CCG	Improve Care Planning arrangements for (PHB) Direct Payments recipients	Ongoing	Enfield CCG are Leading on project locally to improve quality. There has been a recent change in management, and it is anticipated that this will be picked up by the new team.
LAC	Send short learning piece to BEH to go out with Safeguarding newsletter.	November	
Coronial Service	Consideration should be given regarding the completion of death certificates for children with learning disabilities and the restrictions placed when cause of death is ambiguous	Ongoing	We will continue to report the exact cause of death as recorded on death certificates. Trends on how learning disability is included will be monitored by LeDeR nationally. Niel to write to NHS England to ask about how this is being managed in other areas.

ILDS and NCL	Increase sepsis awareness and the importance of recognising rapid deterioration by promoting the 'Stop and Watch' imitative.	Ongoing	Link on My Life and circulated to all team. Camden CCG also promoting.
NMUH	Develop a pathway for epilepsy in pregnancy to support the current policy.		
ILDS Epilepsy Nurse	Liaise with neurology departments on the use of developing technologies.	Ongoing	
LAC (ILDS)	Write to Barnet Hospital to thank them for the Support offered to TS		**Completed**
LAC (ILDS)	Speak to Community Nurses to ask if they could work with the Smoking Cessation Nurses to make the service more effective for people with Learning Disabilities		Easy read leaflet drafted and posted on the LD page letting smokers with learning disabilities know their options. GP liaison nurse aware and will promote with GP's as necessary. **Completed**
LAC (ILDS)	Request a copy of the consent form for SH's hernia operation be uploaded to LeDeR	15/05/2018	No reply to request, however parents confirmed they signed consent form on SH's behalf. **Completed**
LAC (ILDS)	Write to the Renal Team at the Royal Free Hospital, copying in ALN, thanking them for their support for SH, and including guidance and suggestions on recording future best interest decisions	15/05/2018	**Completed**
LAC (ILDS)	Give positive feedback to IP's carers on behalf of Michelle, specifically on the lovely 95th birthday party they through for Irene, and the way they used the photos to help her flatmates reminisce after she died.		**Completed**

LAC (ILDS)	Request NLH upload (Review ##) medication at time of death, and any examples of best practice they would like to share.	15/05/2018	**Completed**
LAC (ILDS)	Discharge reports to be completed following all clinical contacts, ask managers to remind team members via management meeting	17/07/2018	Add to agenda for management meeting. General reminder that should be acknowledgement, response and discharge for any referrals received. **Completed**
LAC (ILDS)	Invite (service)to next EoLC training and feedback directly to (Manager) in quality of plan for (Review##) (EoLC used inappropriately as a DNAR)	24/07/2018	(Manager) attended training on 24th July 2018. Feedback session with (Manager) and Assistant Manager delivered on 17th July. **Completed**
Designated Paediatrician	Services should make allowances for children with autism who require hospital appointments.	05.06.2018	Review of provision of support for children with challenging behaviour who are unable to make hospital appointments. Secondly, the CDOP consultant has reminded staff within the Trust not to discharge children with complex needs due to non-attendance without establishing an alternative route for assessment. Services should make allowances for children with autism who require hospital appointments. **Completed**
LAC and Community Nursing (ILDS)	Promote these key themes to Health and Care Partners • In what circumstances to identify a Learning Disability • The importance to reasonable adjustments with examples • Consistent application of Mental Capacity Act and Best Interest Decisions	Safeguarding Lead GP Forum (October 2nd)	**Completed**

LAC (ILDS)	Meet to look at issue of people who have died after PEG insertion (5 in 5 months)	12th November 2018	LAC will summarise finding in annual report. One concrete action was to produce a 'dysphagia information fridge magnet' for families and staff when people with dysphagia are discharged. **Completed**
ILDS End of Life Care Steering Group	Provide Bereavement support training for reviewers	18th February 2019	LAC to discuss with the EoLC Steering Group (and Psychology, head of Psychology). Feedback was that this was in place as part of business as usual and did not need additional monitoring. **Completed.**
LAC (ILDS)	Include carers and service users in Steering Group or Quality Assurance processes.	18th February 2019	LAC will publicise at the February 2019 partnership board, asking if members want to join, and the carers centre of they could publicise. There was no uptake. The group has decided to focus on increasing carer involvement in reviews. **Completed.**

Appendix 2 North Central London LeDeR Governance Structure



Appendix 3 - Enfield Learning Disability Mortality Review Process (Adults)

1. When someone over 17 with a learning disability who is registered with a GP in Enfield dies;

- Inform the EILDS Duty Social Worker (if they were not reporting)
- Duty Social Worker to notify the Learning Disability Mortality Review on line here.
- Duty Social worker to update Care First, and make sure case is on the next CRT agenda.
- Anyone involved in the reporting procedure who has concerns should follow statutory process (safeguarding, serious incident procedures). This can be done at any time during the process.

2. LeDeR will notify the Enfield LAC of the death on the LeDeR system. LAC will allocate a reviewer. Reviewer should be independent and not have worked with the person directly.
If helpful, a 'Buddy Reviewer' who did know the person may be allocated.

3. If a statutory process is taking place, the reviewer will be kept informed as appropriate. Co-operation is important, but statutory processes will take precedence. Typically, a LeDeR review would extract relevant information from the statutory process when it is completed.

4. If the person died in hospital, a hospital mortality review should take place. the Local Reviewer will liaise with the hospital to ensure the processed do not overlap.

5. Once other processes are complete Local Reviewer, in consultation with the LAC, will determine whether an initial or multi-agency review is required (The initial review document is designed to support this decision)

6. The Reviewer will take the initial review to the Mortality Review Steering group.
The steering Group will agree the content of the review and action plan before submission. The Steering Group may ask for more information if they are not satisfied, and the reviewer will return for the next meeting.

7. Local reviewer and LAC will convene a Multi-Agency Review.
Note - If the case has been through a Safeguarding / serious Incident process, this can act as a Multi-Agency review, if no further learning is likely.

8. Local Area Contact to collate learning and share with London Safeguarding Adults Board and Enfield Mortality Review Steering Group.

9. Integrated Learning Disability Service to complete annual End of Life report and submit to Safeguarding Adults Board and Clinical Commissioning Group.

Appendix 4 - Enfield Mortality Review Process (Children)*

When a child (0-17) with a learning disability dies, professional made aware of the death to contact the Enfield SPOC (Tel: 020 8702 5600, Fax: 020 8375 2983, email: beh-tr.enf-pct.ECSCCR@nhs.net.
If there is any doubt whether notification has or has not already been made the professional should always contact the SPOC to confirm

CDOP

A Child Death Notification 'Form A' should be completed and returned securely to the SPOC. If there is any doubt as to whether a Form A is required, the professional should contact the SPOC to confirm

CDOP Coordinator / Designated Doctor will establish which agencies / professionals have been involved with the child and family prior to the child's death

For unexpected deaths the Designated Doctor will decide as to whether a Rapid Response (RR) meeting is required. If a RR Meeting is required professionals involved with the family will be invited to attend.

An Agency Report 'Form B' will be sent to all professionals who have been involved with the child/family for completion

All 'Form Bs' to be securely returned within 3 weeks to the CDOP Coordinator CDOP_GCSx@enfield.gcsx.gov.uk 0208 379 3012

LeDeR

SPOC to report all death of children with Learning Disabilities Aged 4 - 17 to be reported to LeDeR (Children who die under 4 years old who have been determined to have a learning disability may also be reported.) LeDeR will allocate a local reviewer.

LeDeR Reviewer to attend Rapid response meeting if convened.

Quarterly Child Death Overview Panel (LeDeR reviewer to attend relevant portion of meeting)

Safeguarding Children's Board

The LeDeR reviewer will extract relevant information from CDOP to complete Initial Review and take to Mortality Review Steering Group before submitting. Action Plan/Recommendations fed into Safeguarding Children's Board

*process will change 2019/20