



**North East London
Commissioning Alliance**

LeDeR Programme & Autistic Adults

An alliance of North East London Clinical Commissioning Groups

City and Hackney, Newham, Tower Hamlets, Waltham Forest, Barking and Dagenham, Havering and Redbridge CCGs

Introduction

- LeDeR Programme was established as a result of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD).
- Findings indicated that people with learning disabilities (LD) are four times more likely to die of preventable causes compared with the general population.
- LeDeR programme was set up to understand this and to recommend ways to improve the standard and quality of care for people with learning disabilities.
- Focus was to review all deaths of people with learning disabilities aged 4 years and above.
- In 2017, LeDeR was devolved to the CCGs.
- Until May 2021, the LeDeR programme was hosted by Bristol University when their contract came to an end.
- From January 2022, LeDeR programme has been extended to cover autistic adults

National stats

People with a learning disability

There are 1.5 million people with a learning disability in the UK

- ❖ **351,000 are children aged 0-17**
- ❖ **over 1,130, 000 are adults (England- 951,000 and over 200,000 in London)**

Life expectancy is shorter, they die 20 years younger than those with no learning disabilities.

Approximately half these deaths are due to respiratory related problems which are treatable.

Autistic people

Approximate 1.1% of adults are autistic and the average age of death for autistic people with no learning disability is 16 years younger than the general population.

Health inequalities

- People with learning disabilities and autistic people have greater and complex health needs than the general population.
- They experience higher levels of unrecognised and unmet physical and mental health needs
- They are more likely face multiple barriers accessing health and social care services; including problems with communication, inadequate facilities, rigid procedures (not user friendly) and lack of accessible health promotion information.
- As a result, people with learning disabilities and autistic people are more likely to be admitted to hospital as an emergency case, compared to those with no learning disability and autism.
- ONS 2020, showed that 50% of all admissions for those with learning disabilities are emergencies, compared to 31% of admissions in the general population.

LeDeR successes

Over the last 4 years LeDeR has mainly focused on reviewing deaths for people with learning disabilities aged 4years and over.

NEL achievements:

- Completed over 400 reviews for people with a learning disability
- Achieved 86% performance in completion of reviews
- Prepared two annual reports and a Covid19 review report.
- Provided feedback to care providers and carers/ families
- Two LeDeR conferences in 2019 and 2021 to create awareness of LeDeR programme and its activities
- Participated in Annual Health check webinars and service user engagement events
- Established local action into learning working groups at borough and ELFT/ NELFT levels
- Established good working relationships with all our key partners and stakeholders across NEL, London and nationally.

Service Improvements

- Improved quality of annual health checks and health action plans
- Adoption of a suit of resources to continue delivery of health care services during covid19 (mix of face to face/virtual/telephone options)
- Improved communication between professionals and families/carers
- Use of bespoke reasonable adjustments
- Improved staff awareness of the needs for people with Learning disabilities leading to improved staff efficiencies
- Increased knowledge around Mental Capacity Act and use of best interest decision-making in the delivery of care and treatment.
- Appropriate use and application of DNACPR. Staff are more confident to challenge inappropriate applications.
- Training over 100 carers on recognising deterioration and taking appropriate action aimed to support carers in decision making
- More people being supported to stop overmedication where necessary.

National initiatives as a result of LeDeR

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

Including Autism

From January 2022, LeDeR Programme started reviewing the lives and deaths of autistic adults, 18years and above.

In order to review these deaths, there **must** be a record confirming that the person has had a formal autism diagnosis.



The reason is to help us understand the key health and social care events before their death.

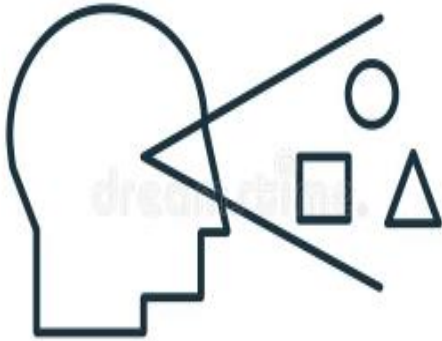
All autistic adults will have both initial and focused review.

Why reviews deaths for autistic adults?



- Approximate 1.1% of adults are autistic in the UK
- Studies indicate that autistic people with no learning disability die 16 years younger than the rest of the general population.
- There is little information known to inform service improvements for autistic people.
- LeDeR reviews will help us collect some data on autistic people to help understand their needs better.

Who is included?



- autistic adults over 18years
- they must have a confirmed diagnosis of autism recorded in their clinical records prior to their death.
- will have initial and focused review

Not included:

- those who self-identify as autistic without a clinical diagnosis from a qualified clinical professionals
- individuals who have been referred for clinical assessments of autism but have died before the actual assessment or before a confirmed diagnosis.

The above are considered as out of scope or not eligible for a LeDeR review.

How to refer for a diagnosis

If you know a patient who may require an autism diagnosis, here are some useful links to accessing diagnostic services across North East London:

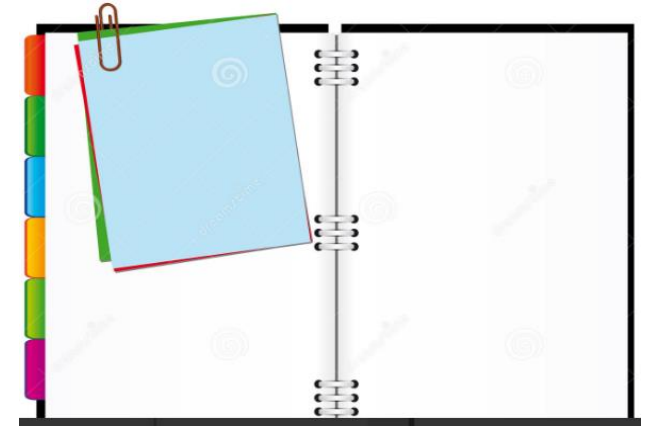
- <https://www.nelft.nhs.uk/services-barking-psychological-services/>
- <https://www.elft.nhs.uk/services/adult-autism-service-tower-hamlets>
- <https://hackney.gov.uk/autism>
- <https://www.nelft.nhs.uk/camhs-autism-spectrum-disorder-asd-resources>
- Newham is in the process of setting up Autism Diagnosis Service which will be operational later this year; in the meantime, GP query ASD and refer to ELFT Assessment and Brief treatment (ABT) for assessment. ABT will provide recommendation for diagnosis (if appropriate). GP can then refer patient to NHS South London and Maudsley (SLAM) Foundation Trust for a formal diagnosis:
<https://www.slam.nhs.uk/national-services/adult-services/>

Other useful links

- <https://mylife.redbridge.gov.uk/redbridge-homepage/categories/health-and-wellbeing/diagnosis-and-assessment/>
- <https://familyserviceshub.havering.gov.uk/kb5/havering/directory/advice.page?id=oAYZvs hukEk>
- <https://www.nhs.uk/conditions/autism/>

Where will a diagnosis be recorded?

- NHS systems: clinical records such as RIO and/or GP records
- Private sector/ clinical practitioners/ assessment records- unless copies were made available to GP prior to their death



If it is reported that an individual had a private diagnosis, the ICS would be expected to ensure that they have seen evidence and that any such private diagnosis is included in the NHS record.

Notifying a death of an autistic person

Families, friends, professionals and other key people can notify us of the death of someone with a known autism condition.

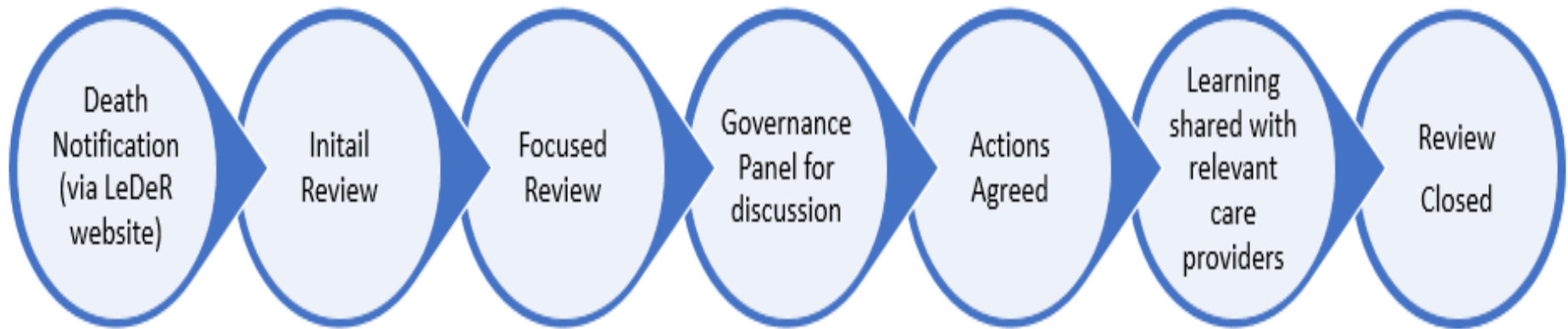
This can be done via LeDeR website: <https://leder.nhs.uk/report>

No referrals by telephone.

The reporter will be asked a number of questions about the person who has died which will provide the LeDeR Team with the information required for the review.

Some of the information include, full details of the person, where the person lived, name of the GP and cause of death if known

LeDeR review process



Governance

- From April 2022, ICSs are responsible for the delivery of the LeDeR programme
- ICS must establish a governance panel made up of representatives of all organisations and service users (voice of people with learning disabilities and autistic people is represented in this governance panel)
- The panel will sign off all autistic adults LeDeR reviews, agree and oversee action plans and agreed improvements.
- Engage with families/carers of autistic adults
- Analyse data from completed review with the view to learning and improving services for autistic adults
- Hold local areas (CCGs) to account for their performance ICS
- ICSs must demonstrate improved health outcomes for people with learning disabilities and autistic adults and reduced avoidable deaths

Expected benefits of including autism

- Better understanding of the needs for autistic persons
- Greater use of appropriate reasonable adjustments in health and social care for autistic people
- Better outcomes for people because of local service improvement projects will be tailored to meet individual needs
- Better working relationships and improved quality of care resulting in better outcomes
- Supports a learning culture through lessons learnt and sharing good practices
- Increased awareness of the main causes of deaths of autistic people, develop ways of preventing and/or minimising these causes
- Training and development opportunities hence improved staff effectiveness and efficiency
- Improve data about the lives and deaths of autistic people
- positive experience for bereaved families of autistic adults
- Supports the delivery of long term plan on reducing health inequalities

Conclusion

- LeDeR is a service improvement programme which involves reviewing information about the health and social care support provided and the circumstances around their deaths
- Engage people with learning disabilities and autism, their families and providers who support autistic people.
- Encourage close working relationships between health , care services, public health, community and voluntary sector will be key to addressing health inequalities , improve outcomes and deliver joint up, efficient services for autistic people.

Commitment:

To continue our efforts to influence and advocate for improved quality of health and social care, reduce health inequalities and prevent avoidable premature deaths for people with a learning disability and autistic adults.

For more information please contact:
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