



# BLMK LeDeR Annual Report 2023/24

(from 1<sup>st</sup> April 2023 – 31<sup>st</sup> March 2024)

## Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

**LeDeR is a programme that aims to improve services for people with a learning disability and autistic people**

Our annual report brings together the results from the deaths reported to the BLMK LeDeR Programme and the learning from completed reviews



# Contents

Content	Description	Page
Acknowledgements	Acknowledgement of the contributions from everyone to BLMK LeDeR	3
Glossary	Descriptions of terms used within the Annual Report	4
LeDeR 2023/24 – an overview	An overview from LeDeR 2023/2024	5
Introduction	An introduction to Bedfordshire, Luton and Milton Keynes ICB	6
Purpose of LeDeR	An explanation of the National LeDeR Programme	7
LeDeR in BLMK	Information about the management and workforce for BLMK LeDeR including Governance	8
Achievements and Challenges	The highlights of achievements and challenges from 2023-2024	11
Improving Services	Examples of co-produced activities across all services due to learning from LeDeR	12
LeDeR Notifications	Information about notifications to BLMK LeDeR, deaths and who made a notification to LeDeR	13
About the people who died	Information from notifications to LeDeR; including average age of death, sex at birth, ethnicity, cause of death, place of death, long term health conditions	14
Child Death Reviews	Information from BLMK and highlights of learning from the National Child Mortality Data Base Report 2023	19
LeDeR Reviews	Information about LeDeR Reviews and LeDeR Reviewers	20
BLMK LeDeR Reviews	Information about completed LeDeR Reviews	21
Person at the centre of LeDeR	About Pen Portraits and excerpts from some Pen Portraits	22
Involvement of Families	Information about contributions from families to completed reviews	23
Grading Completed Reviews	The grading of completed reviews based on Quality of Care, Availability and Effectiveness	24
Positive Practice from LeDeR	Examples of Positive Practice, what has worked well	25
Learning into Action - summary	An overview of the collated learning topics from completed reviews	26
BLMK Place Specific Learning Themes	Any learning topics specific to BLMK Places	27
LeDeR Priorities for 2024/25	Our priorities for LeDeR in 2024-2025	28
BLMK Learning Themes - detailed	More information about each of the Learning Topics identified	29
References	Useful information with links	39
Appendices	Appendix 1: National Child Mortality Data Base Report July 2024 – highlights Appendix 2: LeDeR Notifications by BLMK Place Appendix 3: Descriptions of the Grading scores	40

## Acknowledgements

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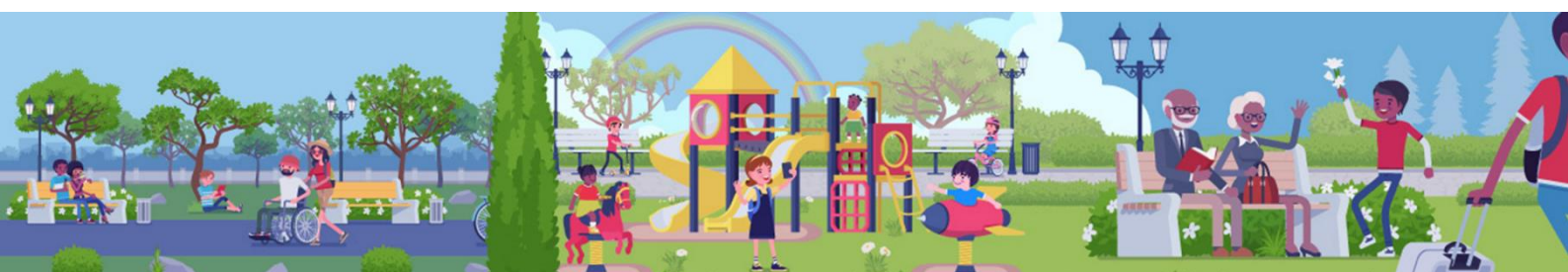
This report reflects and values everyone's commitment to reduce health inequalities and implement learning from the LeDeR reviews and improve services and lives for people with a learning disability and autistic people.

We are thankful to the families, carers, and friends of people for their time and valued contributions to the LeDeR reviews. This allows us to learn as much as possible about their loved ones and their experience of services.

From this, we can help identify learning to influence the improvement of services in the future for other people and reduce health inequalities experienced by people with a learning disability and autistic people.

We would like to acknowledge the following people for their continued support of LeDeR across Bedfordshire, Luton, and Milton Keynes (BLMK) and their hard work and contributions to help us complete the LeDeR reviews, to quality assure the reviews and work in collaboration to put learning into action.

- All families and carers participating in the reviews
- BLMK LeDeR Quality Assurance Panel Members
- All BLMK Primary Care Networks and Practices
- East London Foundation Trust (ELFT)
- Central Northwest London Foundation Trust (CNWL)
- Cambridgeshire Community Services NHS Trust
- Central Bedfordshire Council
- Bedford Borough Council
- Luton Council
- Milton Keynes Council
- Bedford Hospital, Luton and Dunstable Hospital, Milton Keynes University Hospital
- North England Commissioning Services (NECS)
- Positive Support Group (PSG)
- Members of the BLMK Learning Disability and Autism Board
- National LeDeR Team
- NHS East of England Regional Health Inequalities Team



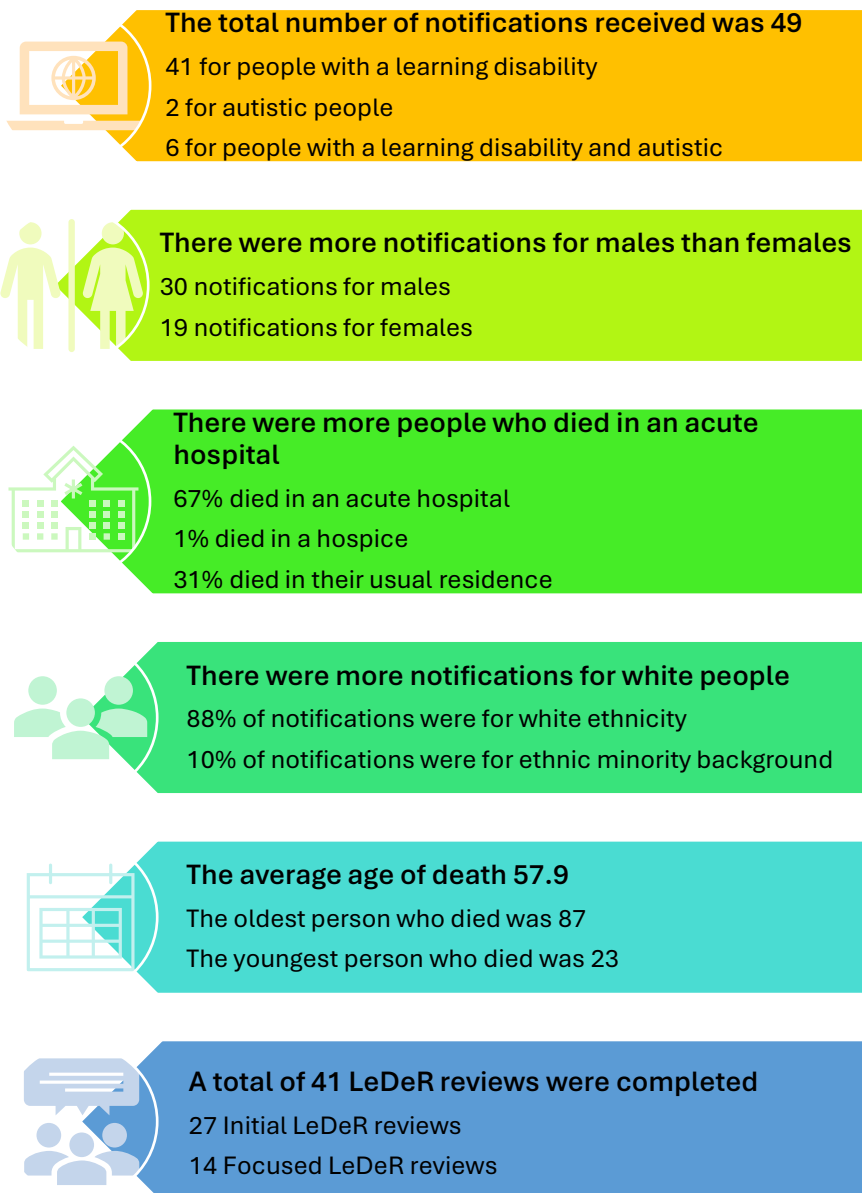
## Glossary

Term	Meaning
Acute Hospital	Acute care hospitals provide short-term care for illness, disease, injury, or surgery, and focus on specialised treatments and services, such as emergency care and critical care units.
Bedfordshire, Luton, and Milton Keynes (BLMK)	BLMK Integrated Care Partnership is an Integrated Care System. This <a href="#">partnership</a> involves organisations working together and includes NHS organisations, local councils, Healthwatch, and voluntary, community and social enterprise organisations.
Child Death Overview Panel (CDOP)	The Child Death Overview Panel reviews the deaths of all children and young people prior to their 18th birthday. The main aim of the CDOP is to prevent future child deaths.
Health Care	Health care focuses on treatment, control and prevention of injury, disease, illness, or disability. There are a range of health care settings including GP services, hospitals, dental services, rehabilitation services.
Health Inequalities	Health inequalities are unjust and avoidable differences in people's health across the population and between specific population groups. These include how long people are likely to live, the health conditions they may experience and the care that is available.
Integrated Care Board (ICB)	An Integrated Care Board is a statutory NHS Organisation responsible for planning the delivery of NHS services to improve the health of the population, including deciding how resources are allocated.
Integrated Care System (ICS)	Integrated Care Systems were legally set up in England in July 2022 and are local partnerships that bring health and care organisations to develop shared plans and joined-up services. They include the NHS, local councils, the voluntary sector, social care providers and other partners with a role in improving local health and wellbeing.
LeDeR	The National Programme Learning from the Lives and Deaths of People with a Learning Disability and Autistic People. LeDeR is a service improvement programme to improve care, reduce health inequalities and prevent early death for people with a learning disability and autistic people.
NHSE	NHSE is shortened from National Health Service England which is the organisation that leads the National Health Service in England.
Service Improvement	The combined efforts of everyone to make changes leading to better outcomes, system performance and workforce development. It involves a systematic and coordinated approach to bring about measurable improvements in health and social care.
Social Care	Social care focuses on providing assistance with activities of daily living, maintaining independence, social interaction, protecting those in vulnerable situations, and accessing a care home or other supported accommodation. Social care is delivered by a range of organisations and professionals, and within families and communities. Social care is funded by people paying for their own care, by local government, or a mixture of the two.

## LeDeR 2023/24 – an overview

Since the implementation of the new LeDeR Policy and new national web platform, BLMK LeDeR Programme has received 106 notifications of deaths. LeDeR National Data Tool

### LeDeR Notifications in 2023/24



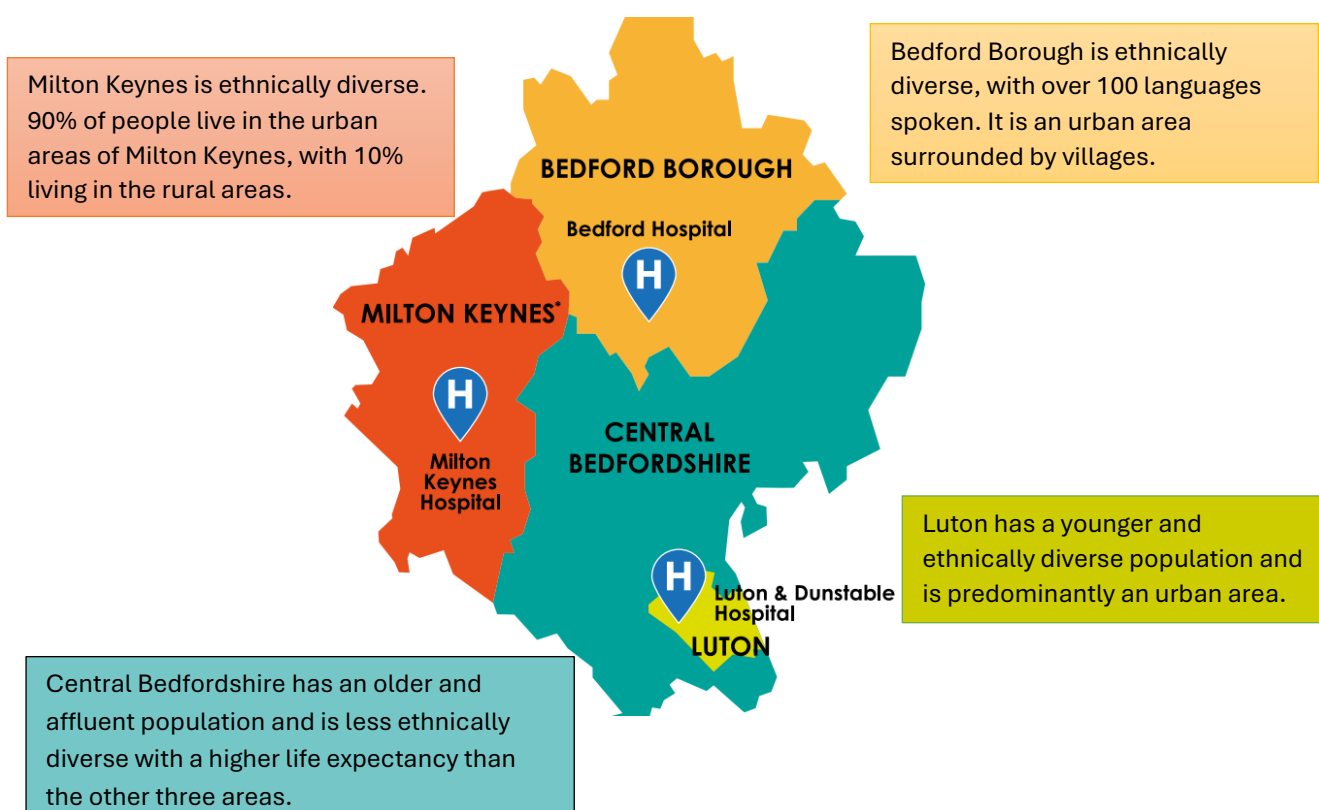
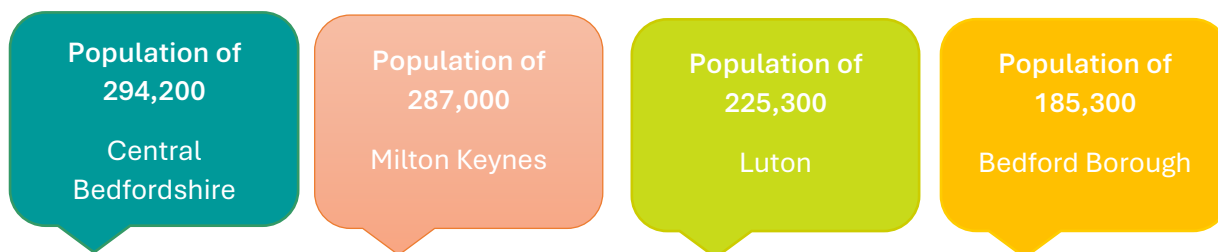
We review every person with a learning disability and every autistic person whose death is reported to LeDeR. The review identifies any cause for concern with their care, any positive practice and where their care could have been improved. People aged 18 years and over are reported to the LeDeR Programme and children 4 -17 years are reviewed as part of the statutory Child Death Overview Process (CDOP).

# Introduction

The Bedfordshire, Luton, and Milton Keynes (BLMK) Integrated Care Board (ICB) brings together health and care organisations across BLMK to collaborate and share responsibility for the health and care of our local population. The ICB is a statutory NHS organisation that decides how to plan and improve people’s health, and deliver high-quality care that is value for money.

The Office of National Statistics (ONS) 2021 reports that BLMK has a population of 991,800.

BLMK ICB provides services in four local areas, these are Bedford Borough, Central Bedfordshire, Luton, and Milton Keynes.



## Purpose of LeDeR

Learning from lives and deaths (LeDeR) is a national service improvement programme (*LeDeR Policy 2021 NHS England*).

Research has consistently shown that people with a learning disability and autistic people die earlier than the general population:

62.9 years is the median age of death for people with a learning disability

55 years is the median age of death for autistic people

82.7 years is the median age for the general population

LeDeR Annual Report NHS England 2022

LeDeR was launched in 2018. At the start of the programme children from age 4 and adults (from age 18) with a learning disability were eligible for a LeDeR review. After the LeDeR Policy was revised in 2021, LeDeR reviews and learning concentrated on reviewing adults with a learning disability and included autistic people. This was to avoid duplicating other national review processes in place such as Child Death Overview Panels (CDOP), which already featured child death reviews.

BLMK LeDeR processes are aligned with other review and investigative processes to share learning.

Reports (also called notification) of the deaths of people with a learning disability or autistic people to the LeDeR programme are not mandatory. However, there is a strong expectation that providers of health and social care services will do so. Notification to LeDeR informs learning and future service improvements, and contributes to reducing health inequalities. Anyone can make a report of death via the National LeDeR website.

LeDeR is a service improvement programme that aims to:

Improve care for people with a learning disability and autistic people

Reduce health inequalities for people with a learning disability and autistic people

Prevent people with a learning disability and autistic people from early deaths

## LeDeR in BLMK

BLMK Integrated Care Board (ICB) is responsible for delivering the LeDeR programme. The programme reports to BLMK ICB Transforming Care Partnership (TCP) Board, chaired by the ICB Deputy Chief Nurse, which has strategic oversight of the reviews and drives the transformation to improve care.

BLMK's LeDeR Programme drives the improvement in the quality of health and social care service delivery for people with a learning disability and autistic people to help reduce premature mortality and health inequalities

BLMK ICS LeDeR Strategy 2022-2025

Our BLMK LeDeR Annual Report for 2023/24 will give you an overview on:

- findings from the LeDeR reviews
- learning from these reviews
- actions that will help to improve services and address health inequalities

BLMK has a strong partnership and collaborative approach that supports the LeDeR process, in line with the national LeDeR Policy 2021.

BLMK recognises the importance of the overall management of the LeDeR programme and employs a workforce with responsibility for different aspects of the programme:

<b>Executive Leads</b>	<ul style="list-style-type: none"> <li>• BLMK ICB Chief Nurse and Deputy Nurse are responsible for the LeDeR programme</li> </ul>
<b>Local Area Contact</b>	<ul style="list-style-type: none"> <li>• Manager of the BLMK LeDeR process ensuring it meets targets and delivers the programme day to day</li> <li>• Oversees the allocation of reviews to LeDeR reviewers, monitors the progress and promotes quality assurance</li> </ul>
<b>LeDeR Facilitator</b>	<ul style="list-style-type: none"> <li>• Shares learning with professionals and reviewing progress</li> <li>• Recurrent themes and significant issues are identified and addressed at a local level, and fed back to the regional NHSE LeDeR team</li> </ul>
<b>LeDeR Administrator</b>	<ul style="list-style-type: none"> <li>• Supports the LeDeR reviewers with review allocations</li> <li>• Updates the review trackers and the national LeDeR platform</li> </ul>

Every person with a learning disability and autistic person whose death is reported to LeDeR will have an initial review of the health and social care they received before their death. We use relevant data and information from each review of the person's life and death to inform the learning.

A focused, in-depth, LeDeR review is completed automatically for people from these groups:

- Black, Asian, or minority ethnic background
- Diagnosis of autism only
- Those under Mental Health or Criminal Justice Restrictions

A review should be focused if:

- there is significant learning for the Integrated Care System (ICS)
- there are concerns about the quality of care, or lack of integrated or coordinated care
- a family member asks
- cause of death is avoidable
- any priorities identified by the ICB, for example, specific clinical area
- health condition, cause of death or circumstances

LeDeR reviews should be completed within six months from the report of the person's death to the ICB LeDeR team. We cannot always complete a LeDeR review in six months due to other processes that we need to wait to be completed, such as a coroner's inquest or other investigations.

LeDeR reviews are not investigations or part of a complaints process, and any serious concerns about the quality of care provided should be raised with the provider of that service directly or with the Care Quality Commission

LeDeR Policy 2021

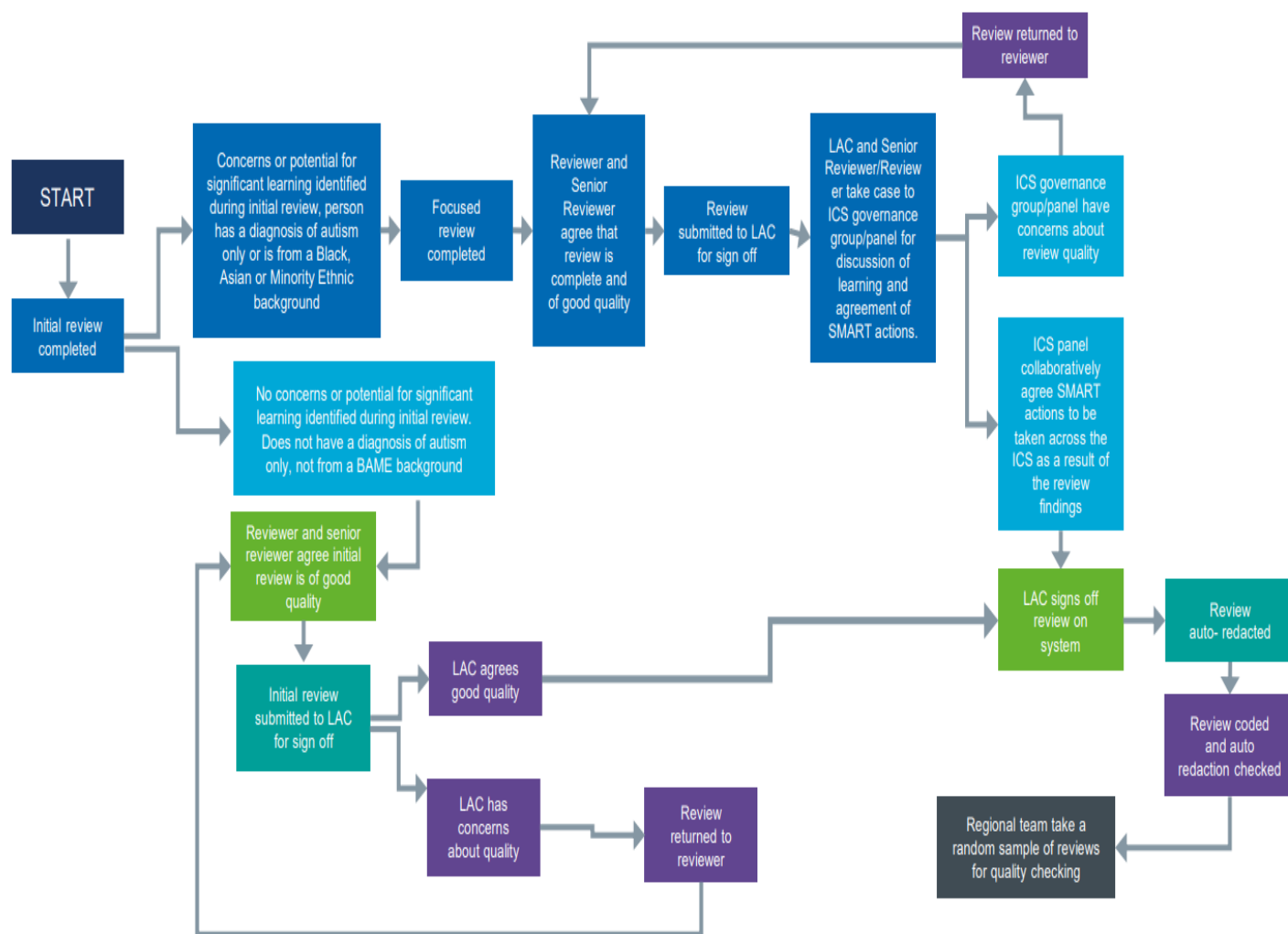
### Quality Assurance Panel

BLMK has a well-established multi-agency LeDeR Quality Assurance Panel with senior representation and clinical experts from across health and social care, including Regional NHS England.

All completed reviews are presented to BLMK Quality Assurance Panel to ensure oversight and approval. The role of the panel is to quality check the reviews, identify learning, and agree strategic actions from the LeDeR reviews. This provides us with the appropriate quality assurance for completed reviews within appropriate timescales and system wide health and social care learning and actions to improve services.

Below is a flowchart of the quality process for LeDeR reviews, taken from LeDeR Policy 2021, which starts at the point the ICB has received the notification of a death and has allocated the review to a LeDeR reviewer:

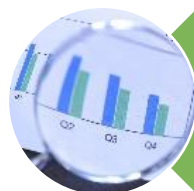
## LeDeR - quality process overview



Our commitment to LeDeR is to build on the strong collaborative approach with our partners and professionals across BLMK who support us to identify how learning can help reduce health inequalities and improve services for people with a learning disability and autistic people.

# Achievements and Challenges in 2023/24

## Our Achievements



**Increased awareness of LeDeR** in BLMK demonstrated by an increase in reported deaths for 2023/24



**Continued success with people having an annual health check** 74% of people with a learning disability had an annual health check during 2023-2024



**Increase in completed focused reviews** gave us more in depth learning and positive practice. We completed 34% focused reviews compared to 17% in 2022 /23



**Pen portrait is at the heart of each LeDeR review**, a description of the person, their personality, what was important to them, their hobbies and interests



**Collaborative and committed Quality Assurance Panel** with health and social care expertise providing collaboration for learning into action



**LeDeR reviewers are experienced, compassionate and committed** presenting good quality, balance, impartial reviews and learning to improve future services

## Our Challenges



**Current climate nationally** - economic, workforce and public health concerns facing all aspects of health and social care



**Transition to a new provider of LeDeR reviewers** from North England Commissioning Service (NECS) to Positive Support Group (PSG)



**Putting learning into action** with limited resources and conflicting priorities, with more resources needed on repeated LeDeR themes to impact change



**Delay in timely completion of reviews** due to change in provider and additional time for transition, as well as quality checking complex focused reviews



**Better comparable data needed** to enable analysis and effectively demonstrate service improvement



**Demonstrating impact in service improvement** from learning into action due to underdeveloped methodologies and limited resources

## Improving Services

Our aim with LeDeR is to improve health outcomes for people with a learning disability and autistic people, to prevent people from dying prematurely and improve their quality of life. We have continued to work with partners to co-produce activities that respond to the learning from reviews. Below is a sample of these co-produced activities:



### Learning Disability Friendly GP Project

- Reviewing Learning Disability registers
- Annual health checks and reduce non-attendance at appointments
- Inclusive Patient Participation Groups



### Learning Disability Annual Health Checks

- Detection of Long Term Conditions
- Comprehensive GP Resource Pack



### Reducing Waiting Lists (Acute Hospitals)

- Reviewing existing pathways to be inclusive
- Admission avoidance
- Collaborative discussions to consider the development of a pathway for sedation



### Breaking Barriers

- Videos to increase uptake for appointments, screening and health checks, including Diabetes, Blood Tests, Weight Management, Cervical Screening



### Diversity and Inclusion

- Engaging with less heard and ethnic communities
- Talking about health and wellbeing to identify people with a learning disability
- Using data to identify population groups and communities



### STOMP (Stop the Overmedication of People with a Learning Disability)

- STOMP Audit in Bedfordshire and Luton
- Working with the Medicines Optimisation Team and Care Homes for medication reviews



### Vaccinations

- Identify reasonable adjustments
- Increasing support to vaccination programmes to access vaccinations
- Health Vaccination Teams working with Primary Care



### Resource Pack for Care Homes and GP Practices

- Includes information about LeDeR and the health conditions experienced by people with a learning disability



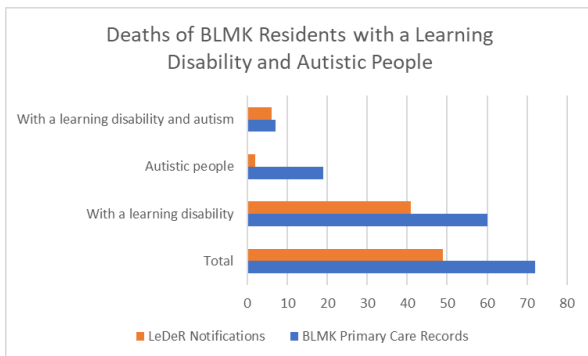
### Oliver McGowan Mandatory Training

- Successful roll-out of the training across BLMK

# LeDeR Notifications

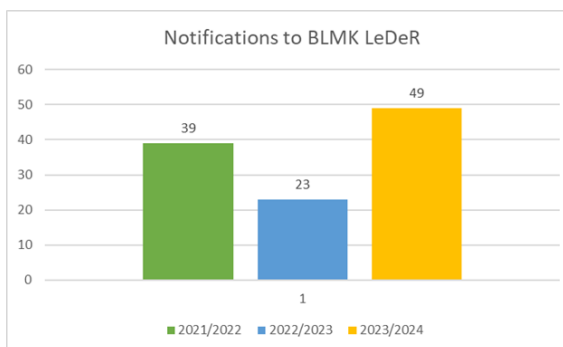
## Deaths of BLMK residents with a learning disability and autistic people

The graph below shows the number of deaths of BLMK residents with a learning disability and autistic people registered on primary care (GP) records compared to those notified to LeDeR.



The graph illustrates a total of 72 people recorded as deceased on the GP records and 49 deaths notified to LeDeR. This means 68% of all deaths were notified to LeDeR.

The graph, right, shows the number of notifications received by BLMK for each year from 2021 -2024.



## The Person who made a notification to LeDeR



The infographic shows who reported to LeDeR. This illustrates that most notifications were received from Learning Disability Liaison Nurses who work in acute hospitals providing support and advice for people with a learning disability and autistic people. This was followed by notifications from Medical Examiners, who provide independent scrutiny of non-coronial deaths. The least notifications were received from GPs. If you would like to know more about the reports in each BLMK place, please see Appendix 2, page 42

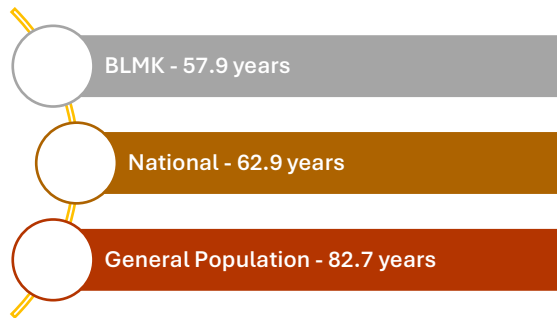
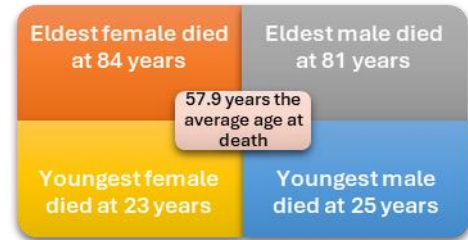
# About the people who died

The notifications we received in 2023/24 told us about the people who died.

One of the aims of LeDeR is to *prevent premature mortality* of people with a learning disability and autistic people. *LeDeR Policy 2021*

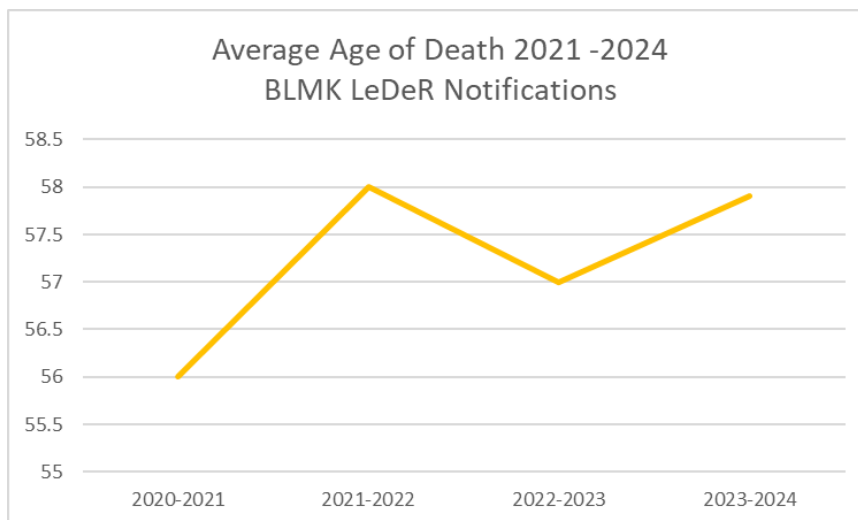
## Average Age of Death

The average age of death of all people notified to BLMK LeDeR in 2023-2024 is **57.9** years.



The average age at death for BLMK residents with a learning disability is below the national average for those with a learning disability, reported by the National LeDeR Annual Report 2022 as 62.9 years, compared to the general population which is 82.7 years.

The graph below shows the average age at death for all completed BLMK LeDeR Reviews from end of March 2020 to end of March 2024:



The graph shows a slight increase in the age of death since 2020.

## Sex at Birth

There were more notifications to LeDeR for males than females.

We had 61% notifications for males and 39% for females, which is comparable to previous years.

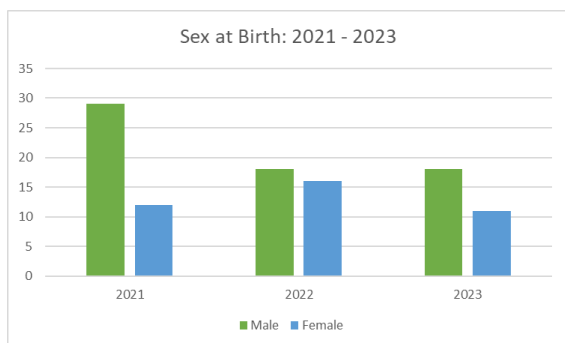
61% of notifications for males



39% of notifications for females

As of March 2024:  
 65% of residents alive, on the Learning Disability Register aged 18+ were males  
 62% of SystmOne recorded deaths aged 18+ were males  
 61% of LeDeR recorded deaths were males  
 Therefore, no gender inequalities were identified in relation to LeDeR reporting

As the graphs below show, since 2021 there have been significantly more deaths reported to LeDeR, and reviews completed, for males than females.



## Ethnicity

Ethnic background of those notified to LeDeR

- 88% white ethnicity
- 6% Asian Indian ethnic background
- 2% Black African Caribbean ethnic background
- 4% unknown

As of March 2024:

- 72.6% of residents, aged 18+, on the Learning Disability or Autism registers were white ethnicity residents
- 85% of SystmOne LeDeR recorded deaths were white ethnicity residents
- Therefore, in BLMK, white residents with a learning disability or autistic were the most likely ethnicity to die, and the most likely ethnicity to be reported to the LeDeR

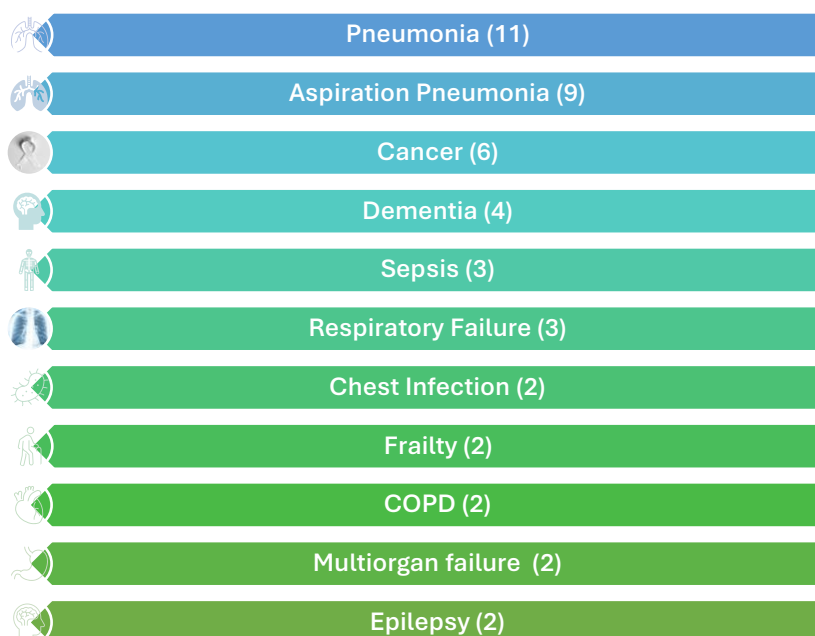
Since 2021 more white people have been notified to BLMK LeDeR and had a completed review, which is similar for all LeDeR notifications in England.

## Causes of Death

The World Health Organisation (WHO) defines the underlying cause of death as the disease or injury that initiated the events directly leading to death.

When someone dies, a doctor who was involved in the person's care completes a medical certificate of cause of death. We obtain the cause of death from the notification to LeDeR and from the information the reviewer obtains during the review process, this means for 5 of the 49 notifications, the cause of death is not known.

Listed below are the ten most common causes of death for people with a LeDeR notification, according to Part 1 of the medical certificate of cause of death. The three most common primary causes of death in 2023/24 were pneumonia, aspiration pneumonia and cancer. In 2022/23, the same three were identified.



Down syndrome was listed as a cause of death on two occasions; this should not be provided as the sole cause of death as Down syndrome itself does not cause death.

There were no deaths where Covid 19 was listed as the cause of death. However, there was one death where prolonged infection due to coronavirus was listed as the primary cause of death and organ failure was the secondary cause of death. In one other death, Covid 19 was listed as the secondary cause of death.

The National LeDeR Annual Report 2022 identified the primary most common cause of death in England was from diseases of the circulatory system, with ischemic heart disease as the leading cause. The second most common cause of death was diseases of the respiratory system, with influenza and pneumonia the leading respiratory causes.

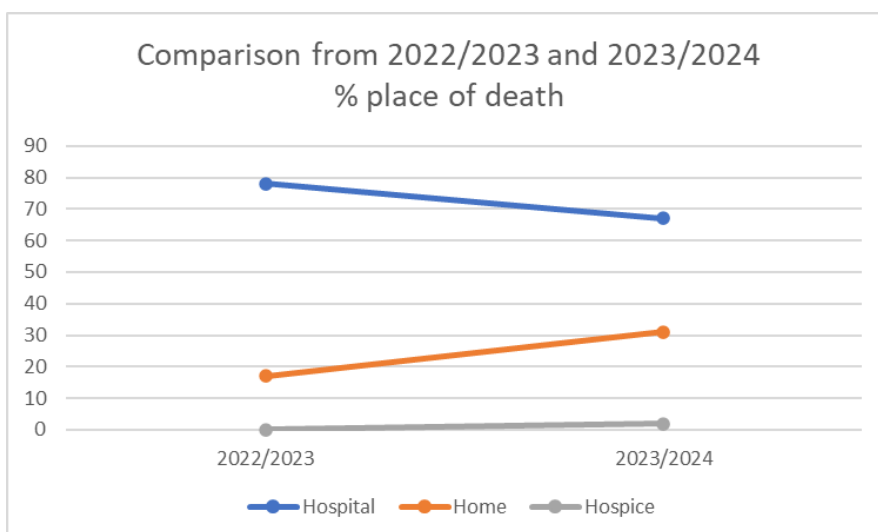
## Place of Death

LeDeR asks about the place of death, where the person died. We are unfortunately unable to make any correlation to people’s wishes or preferences about where they die as this is not referred to within reviews. Sometimes an advanced care plan will record people’s future wishes including the place they wish to die.

In 2018 Macmillan reports that people are dying against their wishes in hospital. In some cases, they might not even be aware that they have a choice about their care in their final days.

*Missed Opportunities Advanced Care Planning Report, Macmillan, May 2018*

The graph below shows a comparison from 2022/2023 and 2023/2024, as a percentage of place of death.



In 2023/24 2% (one person) died in a hospice, 67% (33 people) died in an acute hospital and 31% (15 people) died where they lived.

In 2022/23, 78% of people died in an acute hospital and 17% of people died where they lived.

This demonstrates there has been an 11% reduction of people who died in an acute hospital and an increase of 14% of people who died where they lived. The BLMK LeDeR Strategy 2021 set a target to reduce the number of deaths in an acute hospital to 70%.

Nationally, data during 2018 to 2023 showed that 59% of people with a learning disability died in hospital compared to 45% of the general population.

[www.ons.gov.uk](http://www.ons.gov.uk) Deaths registered in England and Wales 2021

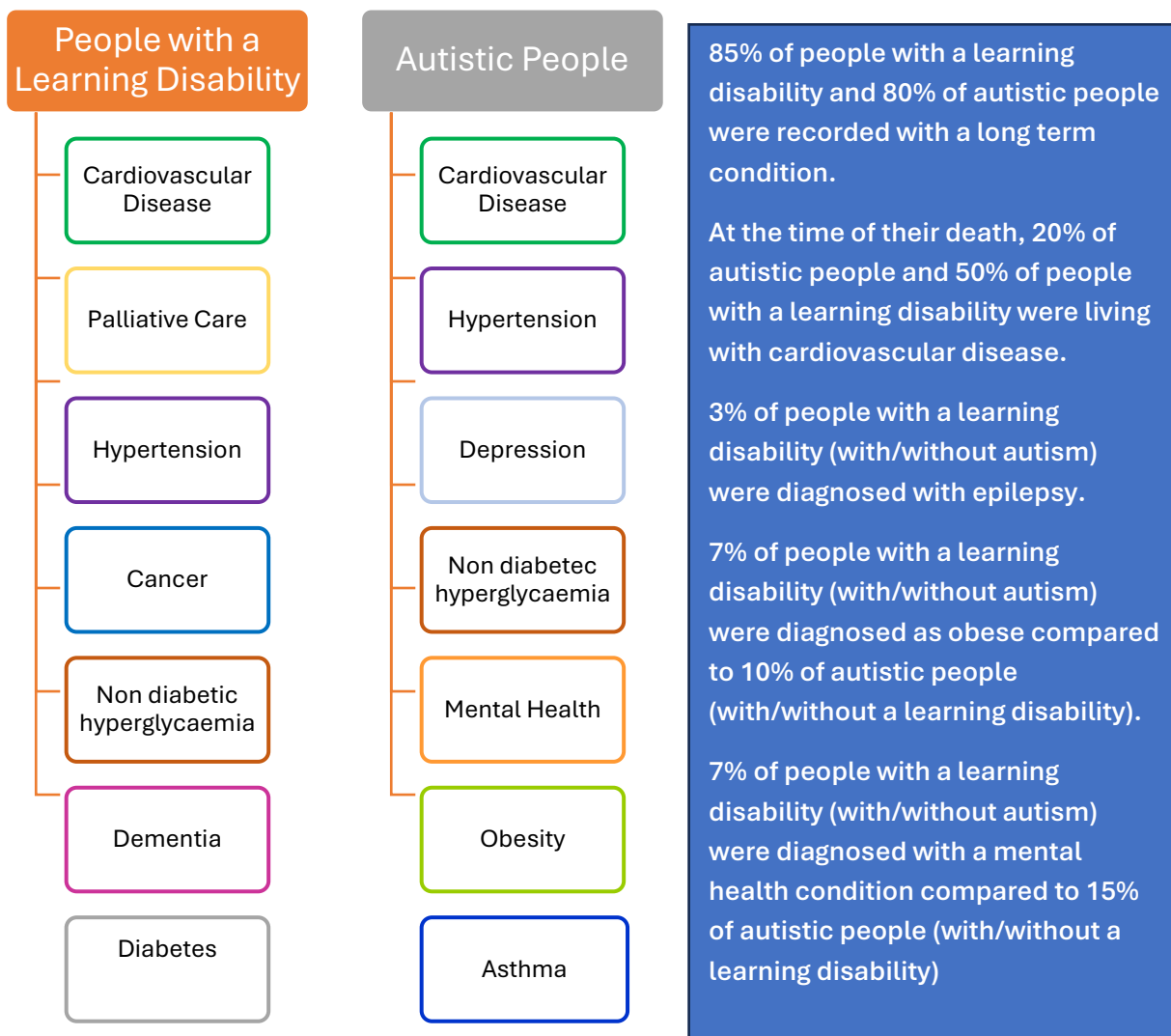
## Long Term Conditions

NHS England describes a long-term condition as:  
**‘those conditions that cannot, at present, be cured and are managed by medication and/or therapies to maintain a good quality of life’**

At the end of March 2024, among living residents in BLMK, 63% of people with a learning disability and 37% of autistic people are recorded as living with a long term condition.

*(BLMK SystemOne Summary Care Record end of March 2024)*

The following is taken from BLMK NHS SystemOne Summary Care Record data for people with a learning disability and autistic people who died during 2023 – 2024 and lists the long term conditions in order of prevalence.



# Child Death Reviews

All child deaths are reviewed as part of the legal Child Death Overview Process (CDOP). Since July 2023, NHS England has removed Child Death Reviews from the LeDeR.

In BLMK there are two Child Death Review Panels. The LeDeR LAC attends the meetings when a child with a learning disability and / or autism is being reviewed. During 2023 – 2024 one child death (with a learning disability or autistic) was reviewed in BLMK. The review identified some learning points:

- delays in 111 responding to parent
- relevant teams did not receive a timely CDOP notification
- keyworker is always allocated to the family following the death of a child
- families receive bereavement information.

This section has some of the learning from The National Child Mortality Database Thematic Report (published July 2024). Please read the full report for all the findings, learning themes and recommendations. The full report can be found at [NCMD | The National Child Mortality Database](#). Appendix 1, page 40, provides further highlights from the report.

## *Learning for children with a learning disability*

Importance of children being on the GP Learning Disability Register and receiving annual health checks

Importance of early and comprehensive advanced care planning - sharing up to date plans with all services

Importance of having a lead Health Care Professional for each child - families feel the need to fulfill this role

Importance of early and robust transition planning for children moving between paediatric and adult services

Challenges for families accessing social care, housing and financial aid - burden of appointments, support, delays, housing provision

Learning from a mother's experience - communication, collection of equipment, support information kept separate from a memory box, open conversations about organ and tissue donation

## *Learning for autistic children*

Challenges experienced by the system for referral and assessment for suspected autism - wait of up to 2 years for assessment

Poor coordination and communication between organisations involved in providing educational, healthcare and children's services

Transition between child and adult health care services - a need for clear referral pathways, transition and support

Importance of suicide prevention education inclusion in relationship/sex/health education

Challenges in diagnosis and treatment of autistic children

## LeDeR Reviews

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### LeDeR Reviewers

We have worked closely with North England Commissioning Service (NECS) for the last three years, who have an expert team of independent reviewers carrying out and completing our LeDeR reviews to present to the Quality Assurance Panel.

BLMK ICS commissions independent LeDeR Reviewers to ensure robust quality reviews.

Following a recent competitive process to choose a reviewer provider, we will be working with Positive Support Group (PSG) from April 2024.

Both NECS and PSG employ senior reviewers to quality assure the reviews and undertake more complex reviews as well as provide support to their reviewers.

LeDeR reviewers have a wealth of experience working in health and social care and with people with a learning disability and autistic people. Our expectation is for reviewers to produce good quality reviews for us to learn from the lives and deaths of people with a learning disability and autistic people.

Working on LeDeR can be emotional and reviewers have support including line management, peer support and supervision. NHS East of England regional team facilitates Reviewers Support Meetings to offer additional support to reviewers. Meetings are held quarterly, allowing peer support for reviewers from across the region.

## BLMK LeDeR Reviews

BLMK LeDeR reviews are completed to a high standard with a holistic perspective of the person's life and death and lead to impartial, reflective learning that supports service improvement.

### LeDeR Reviews in 2023/24

- 41 LeDeR reviews were completed between 1st April 2023 and 31st March 2024
- Of the reviews completed 27 were initial reviews and 14 were focused reviews
- 34% of completed LeDeR reviews were focused reviews. This was close to the NHS England target of 35%



The reason for a focused review was an equal split between Ethnicity and recommended by the reviewer.



The reviewer recommends a focused review when there is significant learning or there are concerns about the care received.

The inclusion of autistic people was introduced in the LeDeR Policy 2021 and was effective later in the year.



Within BLMK we received two notifications for the death of an autistic person. However, due to the allocation process of reviews these reviews will be completed in 2024/25.

## Person at the centre of LeDeR

The pen portrait describes the person, their character and personality, who they were, what was important to them, their hobbies and interests, people who were important in their life. The pen portrait also explains their preferred method of communication, their health and wellbeing. Also included is an overview of whether their health needs have or have not been met. The pen portrait is also an account of the person's death - how they died and the care they received leading up to that time.

The pen portrait is written about the person, with information gathered from those who knew the person well.

The BLMK Quality Assurance Panel starts with the pen portrait of the person, introducing the person to the Panel and remembering we are talking about a person who lived.



She loved parties and loved Abba, and would always get up and dance if their songs played

He loved football, would watch on TV and sometimes went to live games. He also enjoyed going to the cinema, going out for meals with his family, and playing card games



He liked the sound of water and feel of running water passing through his fingers and enjoyed a sensory garden with water feature. Every year on holiday he loved to play in the pool



He is described as a lovely person who enjoyed bird watching and watching his weathervanes. He had a passion for reading and classical music

He had a wheelchair that was brightly coloured to get about. He had a specialised 'bouncy' sofa



He had good relationships with his peers liked going out in his wheelchair and enjoyed people watching



We frequently heard about the challenges people faced – long term health conditions, frequent hospital appointments. We also understood about the relationships developed in local communities, friendships made with people sharing a home and how important care and support staff were in enabling people to live their life.

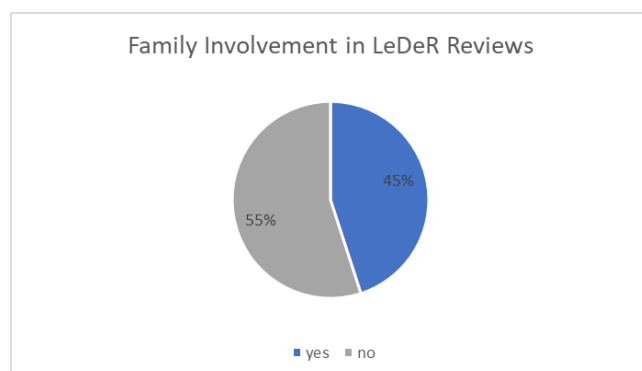
## Involvement of Families

The reviewer contacts families on behalf of BLMK LeDeR Programme and remains the family's contact until the LeDeR Review is completed and quality assured by the Quality Assurance Panel.

The reviewers signpost families to bereavement support if this is considered helpful. A review is still undertaken if a family indicates that they do not wish to participate.

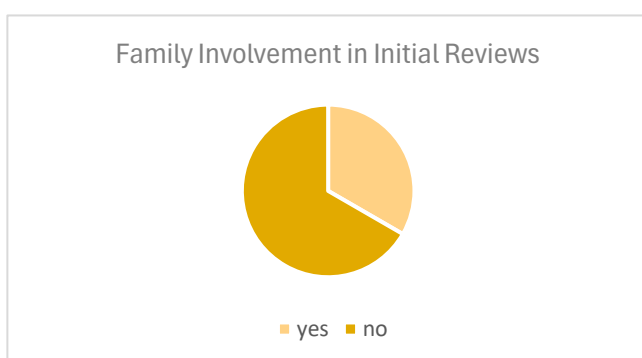
The LeDeR Policy 2021 states:

'as a minimum, families should be informed that the review is taking place, invited to contribute information about the person that has died and offered the opportunity to receive a copy of the completed review'.



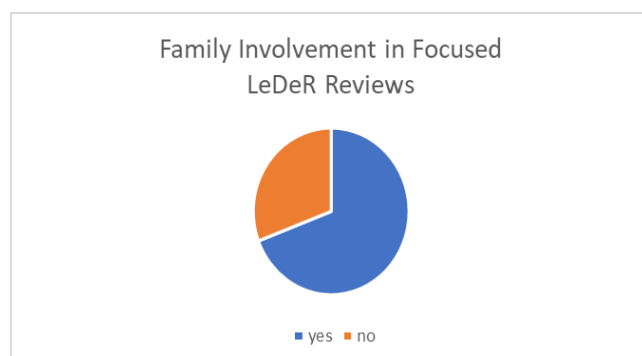
45% of **All Reviews** were completed with contributions from family. Not all families wish to participate, this is for a variety of personal reasons.

Sometimes it was not possible to contact a family member.



33% of **Initial Reviews** were completed with contributions from family.

There was sometimes no response from family or in some situations there was no contact with family.

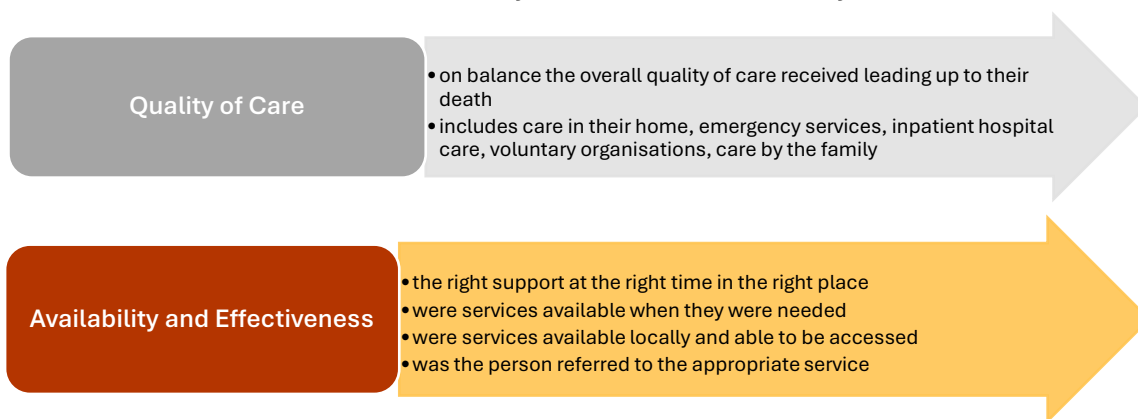


64% of the **Focused Reviews** were completed with contributions from families, mostly siblings.

Some families either declined to contribute or did not respond to any communication.

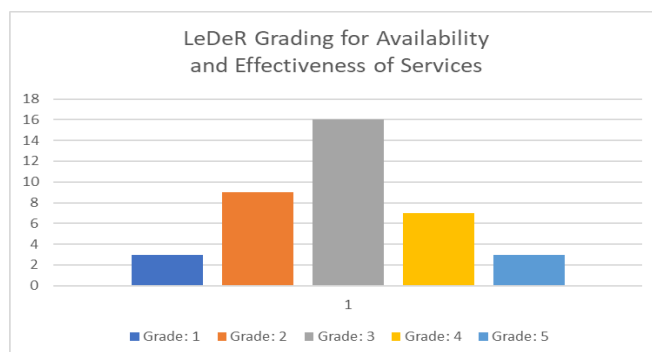
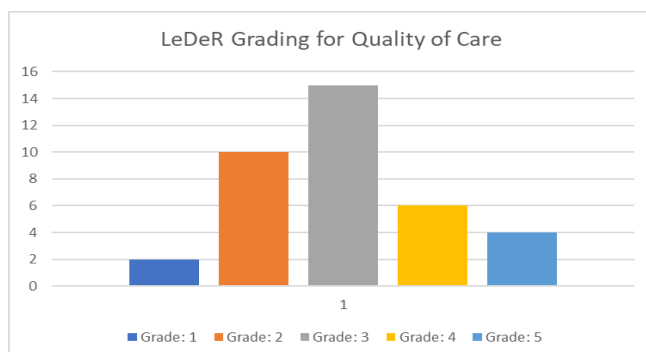
## Grading completed reviews

LeDeR reviews are graded by the Quality Assurance Panel. The Panel grades the completed review presented by the reviewer. The grading is based on two aspects of health and social care services – Quality of Care and Availability and Effectiveness:



BLMK LeDeR Programme currently grades all LeDeR reviews. It is important to acknowledge that the Quality Assurance Panel agrees a grade that is reflective of the collective opinion, from the information presented, on the services received by the person and informs the learning from the review to improve services.

For completed LeDeR reviews, the predominant grade for both Quality of Care and Availability and Effectiveness of Services is grade 3, as shown below:



A Grade 3 is described as:

**Quality of Care:** 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. Please address these issues in your recommendations for service improvement and identify any features of care that current practice could learn from.

**Availability and Effectiveness of Services:** Services fell short of the expected standard, and this did impact on the person's wellbeing but did not contribute to the cause of death.

Please see appendix 3, page 43, for a detailed description of each grade.

## Positive Practice from LeDeR

The LeDeR reviews also capture positive practice, what has worked well during the care and support people received. We share this positive practice across system partners, who take the opportunity to adapt or adopt these standards across their own services.

The following are some of the examples of positive practice that were identified in completed LeDeR reviews.

<p>Excellent end of life care, including a swift transition to hospice care, ensuring her end of life was peaceful</p>	<p>Collaboration between professionals allowed reasonable adjustments to be made to have his annual health check</p>	<p>The palliative care team offered excellent intervention and consideration was made regarding the preferred place of death which was the care home</p>
<p>Despite family living in Australia, the care home made every effort to keep family up-to-date, particularly in relation to the death and also around the arrangements for the funeral, including asking if any personal and wanted items could be sent to Australia</p>	<p>Easy Read Information provided about annual health checks</p>	<p>Evidence of excellent multi-agency intervention in relation to domestic abuse with robust and successful safeguarding which included strong multi agency involvement</p>
<p>A considered and sensitive best interest meeting between the Consultant and family; the family were made to feel their voice counted and was valued</p>	<p>Chlorpromazine was discontinued and positive behaviour strategies put in place to manage distressed behaviour</p>	<p>The intervention provided by her personal assistant was excellent particularly in promoting a healthy lifestyle and in the level of support she was given in hospital at a very difficult and distressing time for her</p>
<p>There was a well-documented final meeting between the ITU consultant and family that indicated a considered and sensitive best interest decision making process, using non-jargonistic language to discuss withdrawal of treatment including ventilation and end of life care and the rationale for this decision. Person was spoken about with compassion and her family was made to feel that their voice counted and valued in contributing to her best interests</p>		<p>The Care Home went to great lengths to support her through the stress of her mother's diagnosis</p>

## Learning into Action – summary

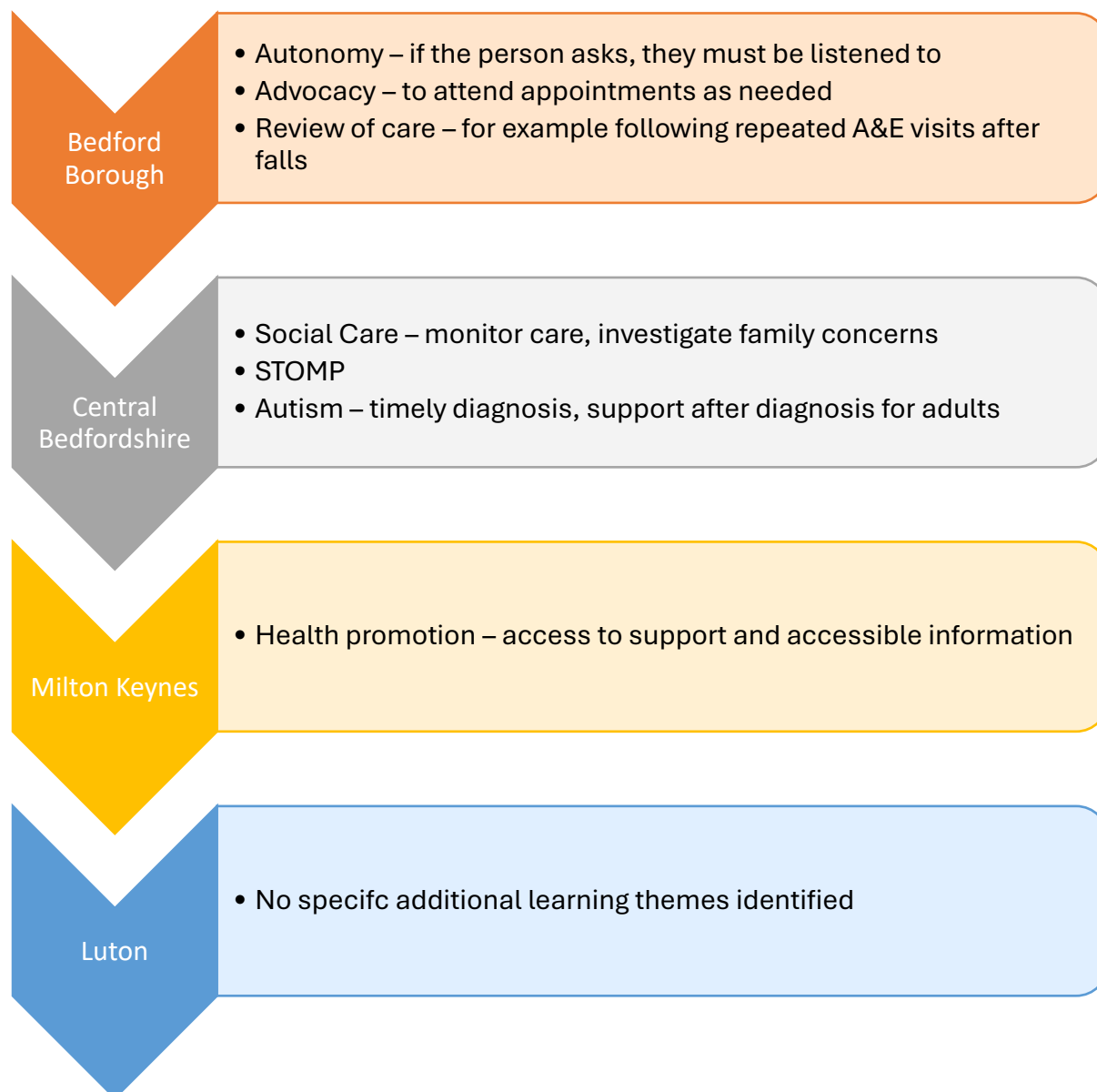
LeDeR reviews provide us with learning to improve BLMK health and social care services and reduce the health inequalities experienced by people with a learning disability and autistic people. We take the issues identified by the reviewer and collate these into themes. If you would like to know more, *please have a look at Learning Themes in more detail on page 29.*

<b>End of Life Care</b>	<ul style="list-style-type: none"> <li>• Timely discussions, recording and sharing</li> <li>• Reasonable Adjustments to care options</li> <li>• Shared Decision Making including accessible information</li> <li>• Best Interests – involving others and recording</li> </ul>
<b>DNACPR</b>	<ul style="list-style-type: none"> <li>• Timely discussions and open honest communications</li> <li>• Recording and sharing</li> <li>• Best Interests – involving others and recording decision</li> </ul>
<b>Advance Care Plans</b>	<ul style="list-style-type: none"> <li>• Triggers for conversations</li> <li>• Planning ahead to talk about</li> <li>• Timely and inclusive</li> <li>• Clarity on terminology</li> <li>• Recording – accessible, up to date, shared and available</li> </ul>
<b>Mental Capacity Act</b>	<ul style="list-style-type: none"> <li>• Understanding and following Principles</li> <li>• Timely referrals for Deprivation of Liberty Safeguards</li> <li>• Recording clearly Mental Capacity Assessments</li> <li>• Recording information for Best Interest Decisions</li> <li>• Use of positive terminology without bias</li> </ul>
<b>Hospital Inpatient</b>	<ul style="list-style-type: none"> <li>• Discharge Planning - timely, detailed plans , sharing</li> <li>• Acute Liaison Team - awareness of role, availability of service</li> <li>• Hospital Passports - raise awareness of purpose, usability and ease of use</li> </ul>
<b>Health Recording by paid Carers</b>	<ul style="list-style-type: none"> <li>• Recording health changes, sharing information, Communication Profiles</li> <li>• Hospital passports - quality of information, up to date</li> <li>• End of Life Care - training and resources, links to Palliative Care Teams</li> <li>• Epilepsy care – training is personalised, Recording</li> <li>• Aspiration - awareness of signs and risks; referral pathways</li> </ul>
<b>Primary Care</b>	<ul style="list-style-type: none"> <li>• Access and Reasonable Adjustments</li> <li>• Recording of information and action specialist recommendations</li> <li>• Annual Health Checks and Health Action Plans</li> <li>• Cancer and Health Screening</li> </ul>
<b>Involving Families</b>	<ul style="list-style-type: none"> <li>• Listening and respecting family’s opinions</li> <li>• Involving families, ask them questions</li> <li>• Information provided to families</li> <li>• Perspective from family and their situation</li> </ul>
<b>Equality Act</b>	<ul style="list-style-type: none"> <li>• Reasonable Adjustments</li> <li>• Best Interest Decisions</li> <li>• Recording any reasons for not following guidance</li> <li>• Accessible Information</li> </ul>

## BLMK Place specific Learning Themes

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In addition to the BLMK Learning Themes, additional Learning Themes were identified for each BLMK Place.



# LeDeR Priorities for 2024/25

BLMK Integrated Care System remains passionately committed to learning from LeDeR reviews. We turn this into action to drive innovative service improvement to reduce mortality and health inequalities, and improve the quality of care experienced by people with a learning disability and autistic people.

The LeDeR reviews provide us with valuable data and information to guide our plans for the coming year. We have recognised priorities that need further consultation and discussion with partners to agree a sustainable service improvement plan.

 <p><b>Diversity and Inclusion</b></p> <ul style="list-style-type: none"> <li>• To strengthen our connections and involvement with people from ethnic minority backgrounds, families and people with lived experiences</li> </ul>	 <p><b>LeDeR Notifications</b></p> <ul style="list-style-type: none"> <li>• To promote the LeDeR Programme to increase notifications to the LeDeR Web Platform of deaths of people from ethnic minority backgrounds and autistic people</li> </ul>	 <p><b>Governance</b></p> <ul style="list-style-type: none"> <li>• To review the multi-agency LeDeR Quality Assurance Panel to provide the best platform for collaborative working, system discussions, identify and evidence learning in action</li> </ul>
 <p><b>Learning in Action</b></p> <ul style="list-style-type: none"> <li>• To facilitate workshops to understand the learning with key partners for each of the emerging themes and identify actions for service improvements</li> </ul>	 <p><b>Share Positive Practice</b></p> <ul style="list-style-type: none"> <li>• A framework for sharing positive practice, as a commitment to 'growing excellence,' to ensure effective channels of communication</li> </ul>	 <p><b>Share Learning</b></p> <ul style="list-style-type: none"> <li>• Engage with partners to drive local conversations about the changes needed to improve the quality of services for people with a learning disability and autistic people</li> </ul>
 <p><b>Pneumonia</b></p> <ul style="list-style-type: none"> <li>• Share learning with partners to agree a service improvement plan</li> <li>• Participate and share information from East of England Regional Health Inequalities Group for Pneumonia</li> </ul>	 <p><b>Annual Health Checks</b></p> <ul style="list-style-type: none"> <li>• To share qualitative learning from LeDeR reviews and annual health checks with Task and Finish Group</li> </ul>	 <p><b>Palliative &amp; End of Life Care</b></p> <ul style="list-style-type: none"> <li>• Partnership working between LeDeR Learning and BLMK Palliative and End of Life Care Transformation Lead</li> </ul>

## BLMK Learning Themes - detailed

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At the end of a review, the reviewer identifies learning issues, concerns, or potential problems.

The learning issues are categorised into one of the following areas:

### Equality and Disability Issues

- examples include reasonable adjustments, communication failings

### All Statutory Duties

- examples include Mental Capacity Act, end of life planning, DNACPR, Statutory Judgement Reviews, statutory investigations

### Quality of Care

- examples include care delivery, practicalities of care procedures, serious incidents, multi-agency investigations, delayed treatment, lack of curiosity

### Care Coordination

- examples include pathway issues, transition, planning of care, referral to specialist teams

### Information Sharing

- examples include family and carers involvement, how knowledge and information was shared, used and documented

### Skills, Knowledge and Competency Issues

- examples include training, carers training, education

The following tables provide further detail about the learning themes identified from completed reviews. Each table contains:

- heading of the learning topic and the national broad theme
- learning from LeDeR reviews – the issues identified by the reviewer
- examples from LeDeR reviews to demonstrate learning required – the experiences of the care received by the person as reported by family, carers, health professionals and from records
- Information about completed LeDeR reviews – data relevant to the learning topic

**Learning Topic: End of Life Care**

**National Broad Theme: Statutory Duties**

**Learning from LeDeR reviews**

- Multidisciplinary Teams to have full discussions about discharge planning.
- End of life care planning is completed with people who have complex health needs and life limiting disease.
- Mental Capacity Act Principles followed for end of life care planning with family included in best interest decisions.
- Hospitals to provide information about bereavement support or Patient Advice Liaison Services.
- Involve Palliative Care Team in considering Anticipatory Medicines via syringe driver when oral medicine cannot be taken consistently.
- Documentation reflects patient care and treatment.

**Examples from LeDeR reviews to demonstrate learning required**

- Lack of clarity led to confusion about level of care. Treatment with invasive blood tests continued, clinical investigations and treatment after a change in presentation.
- Hospital patient record and Treatment Escalation Plan was incomplete, no DNACPR.
- Oral medication for pain relief was missed and no reason was given.
- Family sometimes felt rushed out from hospital following their loved one's death.
- Palliative Care Consultant agreed end of life and the withdrawal of active investigation and treatment, and risk feeding, DNACPR: mother felt things went too fast.
- Unconscious bias may mean family and person were not supported to choose preferred place; care provider felt unable to provide home after cancer diagnosis.
- Care pathways not being clear and conflicting opinions led to limited investigations and unclear prognosis.

**Information about completed LeDeR reviews**

- No autistic people (with or without a learning disability) with a long term condition at the time of their death were recorded on a Palliative Care Register.
- 52% of people with a learning disability (with or without autism) and a long term condition were receiving palliative care at the time of their death.
- 45% of people with a learning disability (with or without autism) were on a Palliative Care Register.
- No autistic people (with or without a learning disability) were on a Palliative Care Register. (SystmOne Summary Care Record data)

A mandatory question for all reviews is 'was the person on end of life care?'



**Learning Topic: DNACPR (Do not attempt Cardiopulmonary Resuscitation)**

**National Broad Theme: Statutory Duty**

**Learning from LeDeR reviews**

- Awareness of timely discussions for DNACPR for all.
- Learning disability or Down syndrome is not a reason for DNACPR.
- Families to be consulted when decisions are made about end of life care and DNACPR.
- Awareness of the use of medical abbreviations and sensitive descriptions of CPR and are not influencing.
- A DNACPR form is completed, and a record made within patient notes to ensure it is clear that a MCA assessment and the best interest decision making process are used to support end of life care.
- GPs to ensure that decisions about DNACPR are documented in the health records.
- Unacceptance of an indefinite, historical DNACPR, without evidence of consideration of current circumstances, best interests and the opinion of family.

**Examples from LeDeR reviews to demonstrate learning required**

- Community and inpatient DNA CPR indicated learning disability or Down syndrome as a rationale.
- There was limited reference to MCA assessment, capacity, and best interest decision making in the hospital patient record.
- Some GP records did not contain a record of the DNACPR and whether it was discussed with the person or family.
- The medical record evidenced resuscitation efforts were not made and this was based on an indefinite DNACPR; this contradicted the GP view that resuscitation was appropriate; the family had no awareness of the indefinite DNACPR and did not have the opportunity to contribute to decision making.
- Unclear communication from the Doctor to family around reasons for a DNACPR.

**Information about completed LeDeR reviews**

- 29 people with a learning disability and autistic people who died had a DNACPR recorded in the history of their GP Records
- 22 people receiving palliative care who died, as recorded in the GP Records, also had a DNACPR recorded.

*SystemOne Summary Care Record data*

A mandatory question for all reviews is: “did the person have a DNACPR recommendation in place at the time of their death?”

- 78% of completed LeDeR reviews recorded a completed DNACPR.
- 22% of completed LeDeR reviews did not have a DNACPR recorded.



**Learning Topic: Advanced Care Planning**

**National Broad Theme: Information Sharing**

**Learning from LeDeR reviews**

- Advance Care Plans to be considered when significant or recurrent ill health; this may limit the impact of successive admissions and reactive changes to care home provision.
- Advance Care Planning led by Health Care Professionals to record and share preferred priorities for care and place of death.
- Consider a discussion about Advance Care Planning by GP for people with a learning disability and dementia.

**Examples from LeDeR Reviews to demonstrate learning required**

- 5 hospital admissions and 2 changes in providers in the last year, 2 changes of GP, no Advance Care Plan.
- Repeated hospital admissions, frailty and multiple co-morbidities did not trigger conversations about Advance Care Planning.
- An earlier Advance Care Plan should have been considered given the number of hospital admissions with chest infections.
- No evidence of Advance Care Planning.

**Information about completed LeDeR reviews**

- 15% of people with a learning disability (with or without autism) had an Advance Care Plan recorded or declined.
- 5% of autistic people (with or without learning disability) had an Advance Care Plan recorded or declined.
- 58% of people with a learning disability (with or without autism) had a preferred place of death recorded.
- 55% of autistic people (with or without learning disability) had a preferred place of death recorded.

*SystemOne Summary Care Record data*



**Learning Topic: Primary Care**

**National Broad Theme: Quality of Care**

**Learning from LeDeR reviews**

- Poor GP access, face to face appointments and follow-up of non-attendance at referrals.
- GPs should ensure recommendations made by specialists are acted upon.
- System solutions to manage access when obesity prevents access to transport.
- The GP record to show the impact of high BMI and a focus on intervention.
- GP to consider alternative arrangements for invitations to encourage attendance for annual Flu and Pneumonia vaccinations.
- Poor quality annual health check via telephone and no health action plan.
- The GP to provide a comprehensive annual health check with health actions.
- Liaison between GP Practice and Community Learning Disability Facilitators for uptake of annual health check.
- Lack of reasonable adjustments to enable the person to access care and treatment.

**Examples from LeDeR reviews to demonstrate learning required**

- Lack of face-to-face appointments and no record of follow-up or notification to the GP.
- GP did not prescribe meds recommended by neurologist.
- Issues with timely dressing changes in the community; person not considered to be housebound and did not qualify for community nursing.
- Not on the GP learning disability register, did not have an annual health check or health action plan and limited evidence of any reasonable adjustments.
- Health conditions associated with obesity and lifestyle intervention not in the GP record.
- Did not receive flu vaccination and pneumonia vaccine not offered - sent 3 text messages and reminders to book an appointment.
- The annual health check in no way reflected the complexities of health and disability.
- Family asked for a GP visit, medicine was prescribed without being seen or assessed; not seen face to face for an annual health check.

**Information about completed LeDeR reviews**

- 73% of people with a learning disability, who died between April 23 and March 24, had an annual health check in the 12 months prior to their death.
- 74% of all people with a learning disability received an annual health check between April 23 and March 24.

*SystemOne Summary Care Record data*

A mandatory question for all completed reviews is “did the person have an Annual Health Check in the last 12 months before death?”

- 61% of all people with a completed review had an annual health check at some time.
- 10% of all people with a completed review did not have an annual health check recorded at any time.



**Learning Topic: Involving Families**

**National Broad Theme: Information Sharing**

**Learning from LeDeR reviews**

- To ask those who know the person well for information (when the person is in pain).
- To ensure carers are adequately supported and signposted to appropriate services.
- Family to understand how to order from Pharmacists electronically if unable to contact GP, to ensure the person is not without appropriate medicines.
- Social Services to consider how the continuity of care can be improved when a change in service provider.
- Clinical staff to demonstrate professional curiosity to fully understand the concern.
- Social Care to respond to a written complaint made by family regarding the impact upon their family member of loss of day centre provision.
- Funded Care to be monitored and family members' concerns investigated.
- Social Care to provide more support to families on packages of care.

**Examples from LeDeR reviews to demonstrate learning required**

- No one asked her mother about signs of pain when increasing pain medication (to morphine) or included her in the decision.
- Mum struggled to get some prescriptions as she was unable to contact services.
- When the family were trying to arrange for a move to another service, they found the process very difficult, four social workers were allocated over a period of five months.
- Mother felt she was not made aware of options or alternatives.
- Brother felt Mental Health Professionals did not listen to their description of how bad his sister's distress could be, she would say "I'm fine".
- Prior to the Covid pandemic, he attended a day centre 5 days a week, this was described as a massive loss, his mother wrote a complaint, with no response.
- Social Care did not provide enough support to mum with direct payments and mum was told she had to explore appropriately trained carers.

**Information about completed LeDeR reviews**

A mandatory question for all completed LeDeR Reviews is “has there been a conversation with the family/carer about the death?”

- 45% of all completed reviews involved families.
- 64% of focused reviews were completed with contributions from families.



**Learning Topic: Equality Act**

**National Broad Theme: Equality and Disability**

**Learning from LeDeR reviews**

- Reasonable adjustments to allow for an explanation of procedures and why required.
- Lack of reasonable adjustments in Primary Care.
- Identify reasons for non-attendance at Practice appointments or Musculoskeletal Clinic; use of a person-centred approach rather than a blanket approach.
- Refer to Hospital Liaison Team to discuss with family any reasonable adjustments.
- No suitable services to manage weight.
- Reasonable Adjustments to ensure access to appointments including home visits.
- Services to have a flag for complex patients and ensure access to care including prescriptions.
- Reasonable adjustments to enable access care and treatment including home visits.
- To ensure that people are supported to access medical care when requested.

**Examples from LeDeR reviews to demonstrate learning required**

- Text message reminders sent with complex instructions.
- Person discharged from Musculoskeletal Clinic as non-attendance and not rebooked as required; no reasonable adjustments made to process.
- Time in the Emergency Department was stressful, with limited facilities for personal care.
- No reasonable adjustments or specially designed services to meet the individual's needs with weight management.
- Unable to attend health appointments due to health problems and not seen face to face.
- Mum felt let down and services were not clear on her daughter's needs; felt she was treated as an overprotective mother and felt undermined.
- Family asked for a GP visit, medicine prescribed without being seen or assessed; not seen face to face for annual health check.
- The person was not listened to when she requested to see a doctor.

**Information about completed LeDeR reviews**

A question in the focused review is:

Did the person need any reasonable adjustments to engage with Health and Social Care?

Plus, further information is gathered to identify the category and type of reasonable adjustments that were provided for the person.

- Accessible information:
  - communications support
  - requires communications' professional
  - requires specific contact method
  - requires specific information format
- Additional communications support
  - Community language support
- Individual care requirements
- Adjustments to the environment
- Bespoke reasonable adjustments



**Learning Topic: Mental Capacity Act (MCA)**

**National Broad Theme: Statutory Duties**

**Learning from LeDeR reviews**

- Adherence to Mental Capacity Act Principles and best interest decisions in hospital.
- Best interest decisions to be multi-disciplinary and include views of family and those who know the person well.
- All those not free to leave should be assessed for Deprivation of Liberty Safeguards.
- Mental Capacity Assessment to be recorded, outcome clear including any best interest decision and all professionals aware.
- Mental Capacity and best interest decision making to follow a formal process to facilitate joint working for people with complex and progressive conditions.
- The hospitals to consider reasonable adjustments to ensure the person fully understands and retains information provided about their healthcare.
- Professionals to consider involvement of an Independent Mental Capacity Advocate and advocacy when this is indicated.
- To ensure a capacity assessment is undertaken even if the person is accompanied by a parent who is happy to speak on their behalf.

**Examples from LeDeR reviews to demonstrate learning required**

- Face to face appointment declined due to transport and feeling unwell.
- Little evidence of family consulted or an multi disciplinary approach when decisions made.
- No consideration for Deprivation of Liberty Safeguards.
- Limited reference to MCA assessment or best interest decision making.
- The use of MCA and best interest decision making was not applied when her mother wanted a discharge from hospital earlier than planned.
- There was limited evidence of the use of MCA - her Personal Assistant said that information often overwhelmed her, and she had problems processing or retaining information.
- During diagnosis and end of life care, there was no indication of consideration of an Independent Mental Capacity Advocate or advocacy.

**Information about completed LeDeR reviews**

Mental Capacity Act Decisions recorded among 60 people with a learning disability who died between April 2023 – March 2024:

- 1 person recorded with a best interest decision for covert administration of medicine.
- 10 people subject to Deprivation of Liberty Safeguards
- 47 people lack capacity to give consent.  
(SystemOne Summary Care Record data)

Mental Capacity Act decisions recorded among 12 autistic people who died between April 2023 and March 2024:

- 6 people lacked capacity to give consent.
- 3 best interest decisions made on behalf of the person.  
(SystemOne Summary Care Record data)

All mandatory question for all completed reviews is “is there evidence that a MCA assessment was required at the time”



**Learning Topic: Hospital Inpatient**

**National Broad Theme: Quality of Care**

**Learning from LeDeR reviews**

- Nursing staff to recognise behaviour as distress and consider a referral to the Learning Disability Team or Palliative Care.
- To ensure hospital passports are completed with advice on communication.
- Discharge plan following inpatient care to be robust and informative.
- Care Home and Supported Living Providers to ensure support in hospital and Commissioners to provide funding.
- Minimise delay to discharge and timely checks undertaken to ensure fit prior to actual discharge.
- Training for staff in how to communicate with people with a learning disability.
- Inpatient care is not compromised, and the person is treated with equity, dignity, and no prejudicial comments.

**Examples from LeDeR reviews to demonstrate learning required**

- Hospital Passport indicated behaviour change and food refusal when in pain.
- All About Me was incomplete with no evidence of Dementia diagnosis.
- Hospital Discharge Plan to GP was limited to a sentence and wrongly informed GP a best interest decision for long term feeding had not taken place.
- Care Home staff did not provide support to the person in hospital.
- Signs of deterioration at discharge and staff didn't wait for blood test results - readmitted same day with sepsis.
- Discharge delayed for 1:1 funding; developed an infection, began refusing food/drink, not compliant with treatment, led to a significant deterioration.
- Hospital staff unwilling to work with family members to ascertain the best way to communicate, no apparent consideration to any reasonable adjustments.
- Sister concerned about hospital care; not allowing time to support to eat; negative attitudes.

**Information from completed LeDeR reviews**

- 67% of people died in an acute hospital
- Of those who died in hospital:
- 36% died in Bedford Hospital
  - 39% died in Luton and Dunstable Hospital
  - 4% died in Milton Keynes University Hospital



**Learning Topic: Health Recording**

**National Broad Theme: Information Sharing**

**Learning from LeDeR reviews**

- Poor recognition of signs of illness and health deterioration by care staff.
- Care staff to record (when person unable to) bowel movements.
- Training for care staff to ensure accurate information is given to health services to understand urgency.
- Care plans and risk assessments, updated when needs change and following discharge.
- Care providers to ensure that people with a learning disability are supported to access bowel cancer screening.
- Epilepsy training to identify symptoms of seizure, tailored to individuals.
- Care Providers to have systems in place to ensure all staff have up to date epilepsy training in emergency scenarios and administering Rescue Medicine.
- Care Providers to ensure people are referred for Speech and Language Therapy when frequent Chest Infections and Dysphagia.

**Examples from LeDeR Reviews to demonstrate learning required**

- Admitted to hospital with high temperature, shortness of breath and loose stools - no evidence in care records of concern leading up to admission.
- History of constipation and admission to hospital following vomiting and urinary distension; lack of recognition he was constipated.
- Unclear information given by Care Home staff to GP and Emergency services.
- Care Home transfer nursing summary was limited, no end of life care plan; and no evidence Care Provider updated care and support plan after hospital discharge.
- Care Provider did not ensure that the person was supported to complete bowel cancer screening.
- Staff were unable to confidently identify seizures resulting in unclear descriptions and lack of recording; training had been received but insufficient as not tailored to the person.
- Provider had been unable to source any Buccal Midazolam; staff unable to administer rescue medication.
- Several chest infections but did not have Speech and Language Therapy review to identify additional measures to prevent aspiration.

**Information from completed LeDeR reviews**

- 41% of people lived in a Care Home, Supported Living, Extra Care Community.
- 24% lived with family – usually parents, sometimes a sibling; with or without paid support.
- 22% lived in their own home – often with a partner or spouse, sometimes with paid care.
- 10% of people were living in a Nursing Home.



## References

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LeDeR National Policy April 2021 <https://leder.nhs.uk/resources/leder-policy>

LeDeR Resources [LeDeR - Resources](#)

Making a Notification to LeDeR [Report the death of someone with a learning disability or an autistic person \(leder.nhs.uk\)](#)

BLMK ICB [About Us - BLMK Integrated Care Board \(icb.nhs.uk\)](#)

BLMK Learning Disability and Autism Strategy [Our Strategies - BLMK Integrated Care Board \(icb.nhs.uk\)](#)

# Appendices

## Appendix 1: Summary from National Child Mortality Database Report July 2024

Deaths of children with a learning disability and deaths of autistic children between 1 April 2019 and 31 March 2022 whose death was reviewed by a CDOP before 27 November 2023.

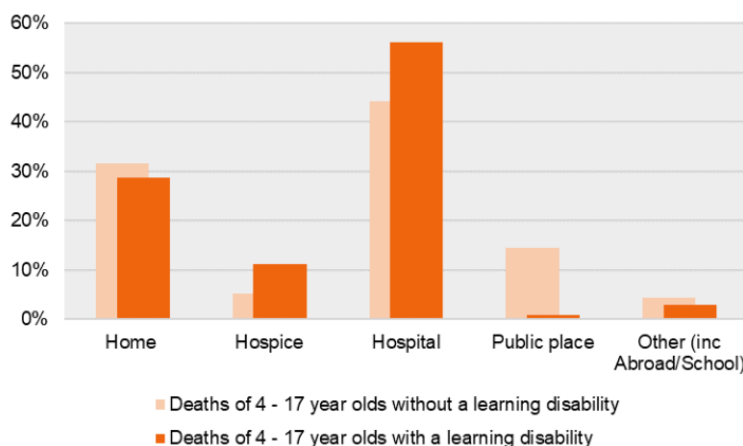
National Child Mortality Database Report July 2024

### Children with a Learning Disability

For the children who died there was a higher proportion of boys compared to girls, 56% boys compared to 44% girls. Of all the children with a learning disability who died, where ethnicity was recorded, 62% were from a white ethnic background, 25% were of Asian or Asian British ethnicity, 7% children were of black or black British ethnicity.

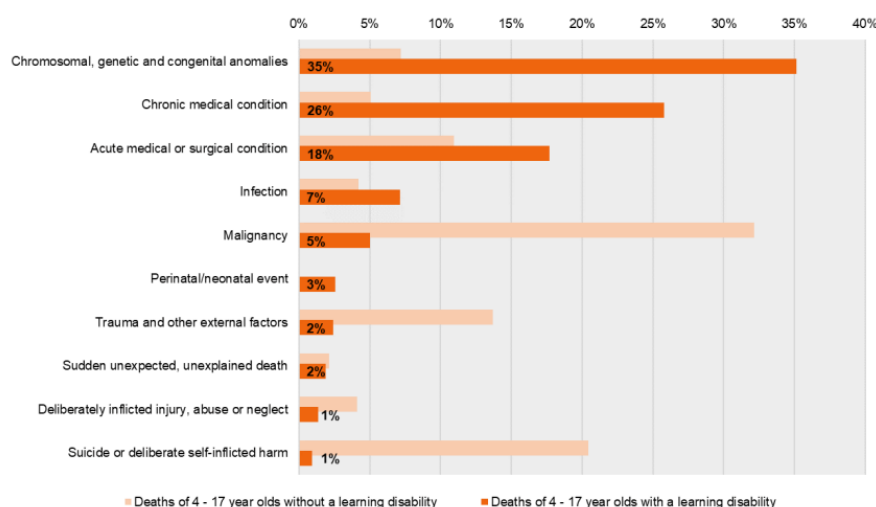
A graph to show the place of death of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022

The most common place of death for children with a learning disability was in hospital. For hospital and hospice, this is higher than for children without a learning disability.



A graph to show the primary cause of death of children aged 4–17 years with and without a learning disability between 1 April 2019 and 31 March 2022

The most common primary category of death for children with a learning disability was chromosomal, genetic and congenital anomalies (35%).



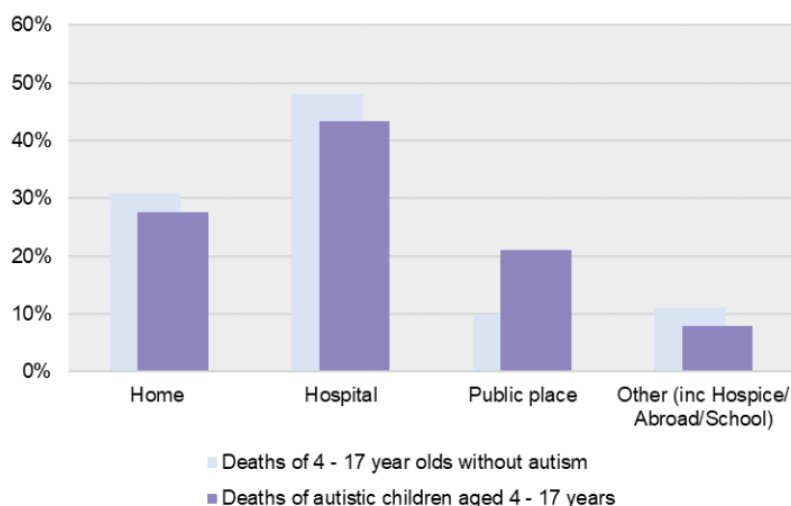
## Autistic Children

For autistic children who died, there were over four times as many boys (81%) as girls (19%). This is reflective of all autistic children where approximately four times as many autistic boys are identified in the population than girls.

Of all the autistic children who died, where ethnicity was known, there were 84% deaths of autistic children from a white ethnic background, and 16% from Asian, black, mixed, or other ethnicities.

A graph to show place of death of autistic children and children without autism aged 4–17 years between 1 April 2019 and 31 March 2022

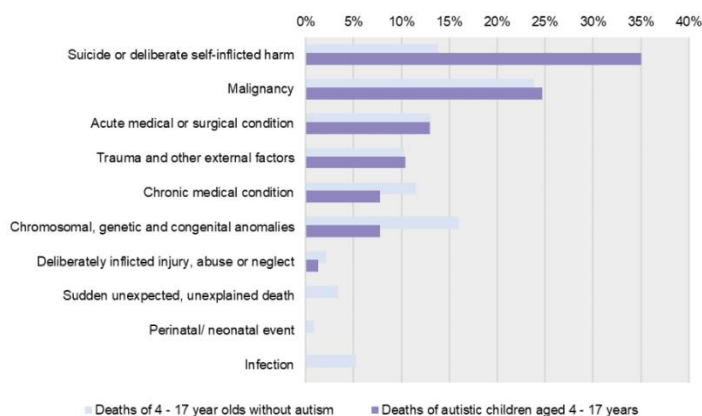
The most common place of death recorded for autistic children was a hospital (43%), followed by deaths at home (28%), deaths in a public place (21%) and deaths in other places (8%) including in a hospice.



## Cause of death

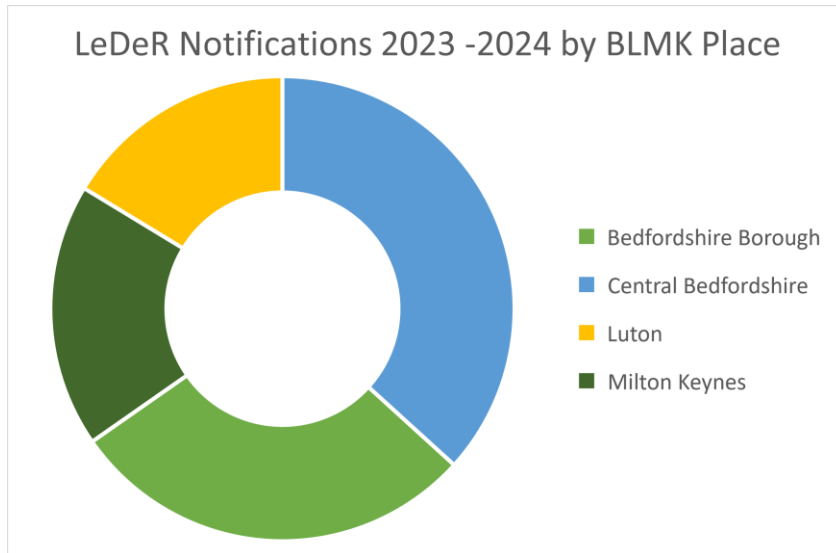
A graph to show the primary category of death of autistic children and children without autism aged 4–17 years between 1 April 2019 and 31 March 2022,

The most common primary category of death for autistic children were categorised by CDOP as dying due to suicide or deliberate self-inflicted harm (35%)

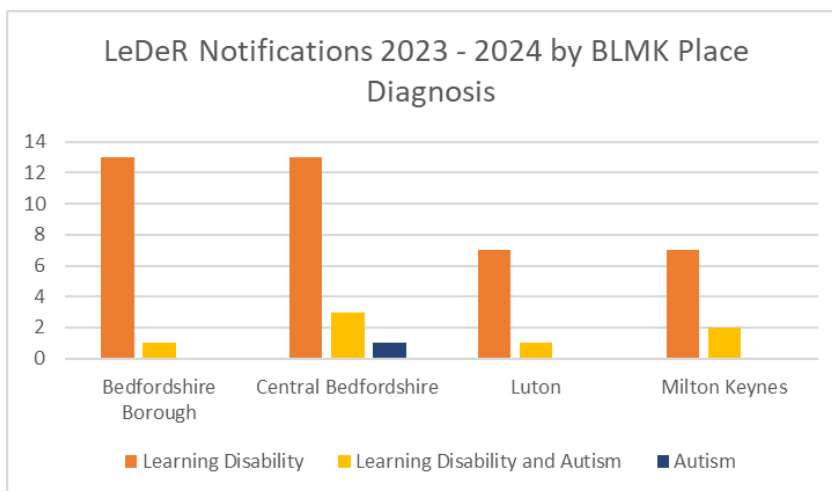


## Appendix 2: LeDeR Notifications by BLMK Place

All reports to BLMK LeDeR Programme are reviewed equally, and it is useful to understand the division of notifications received by BLMK Place.



Most of the work by BLMK ICB is delivered as a partnership by four places: Bedford Borough, Central Bedfordshire, Luton and Milton Keynes.



Most notifications for each BLMK Place are for people with a learning disability.

### Appendix 3: Grading of Completed LeDeR Reviews

Quality of care	Grade for quality of care	Availability and effectiveness of services	Grade for availability and effectiveness of services
This was excellent care (it exceeded expected good practice). Please identify in learning and recommendations what features of care made it excellent and consider how current practice could learn from this.	<b>6</b>	Availability and effectiveness of services was excellent and exceeded the expected standard.	<b>6</b>
This was good care (it met expected good practice). Please identify in the review learning and recommendations any features of care that current practice could learn from.	<b>5</b>	Availability and effectiveness of services was good and met the expected standard.	<b>5</b>
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). Please address these issues in your recommendations for service improvement, and identify in learning and recommendations any features of care that current practice could learn from	<b>4</b>	Availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.	<b>4</b>
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. Please address these issues in your recommendations for service improvement and identify any features of care that current practice could learn from.	<b>3</b>	Availability and effectiveness of services fell short of the expected standard, and this did impact on the person's wellbeing but did not contribute to the cause of death.	<b>3</b>
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.	<b>2</b>	Availability and effectiveness of services fell short of the expected standard, and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	<b>2</b>
Care fell far short of expected good practice and this contributed to the cause of death.	<b>1</b>	Availability and effectiveness of services fell far short of the expected standard, and this contributed to the cause of death.	<b>1</b>