LeDeR Annual Report 2022-23

Learning from lives and deaths, people with learning disabilities and autistic people

The learning disability mortality review programme (LeDeR) is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities and autistic people in England.

LeDeR reviews identify any potentially avoidable factors that may have contributed to the person's death and learning and plans of action that individually or in combination, guide necessary changes in health and social care services to reduce premature deaths.

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1. Foreword Sarah Stanley, BLMK ICB Chief Nurse

Welcome to our 2022-23 Annual Report for LeDeR - *Learning from lives and deaths, people with learning disabilities and autistic people.*

I hope this report will provide you with the identified learning and actions we are taking to improve practice and address health inequalities for people with learning disabilities and autistic people. Much progress has been made with the LeDeR programme locally across Bedfordshire, Luton, and Milton Keynes (BLMK) and we have made a key shift from *'how can we implement LeDeR across BLMK?' to 'how can we use LeDeR to improve the lives of people with a learning disability and autistic people?'* The LeDeR programme has identified many examples of good person-centred care and areas of improvement.

During 2022-23 *(1st April 2022 to end of March 2023)* we reviewed 23 deaths of people with a learning disability and identified key learning themes as part of our newly formed Health Inequalities Group. We have continued to work with our system partners to put learning into action on these emerging themes. We are pleased to report that a significant amount of learning has already been embedded and progress made in improving care and reducing inequalities for people with learning disabilities and autistic people. We acknowledge there is still more work to do though in terms of early identification of vulnerabilities, such as age, care settings and pre-existing conditions, including further challenges associated with the key learning themes.

We are pleased to have completed 19 initial and 4 focused reviews this year and shared the learning with our commissioners and system partners who have been fully engaged with the topics and themes identified in our LeDeR reviews through keen discussions. Everyone has been passionately committed to listening, learning, and making real changes across the health and social care system. We are especially proud of the work undertaken collaboratively through our Learning Disability Annual Health Checks Steering Group, Health Facilitation Team, Primary Care, and our GP practices for improving the uptake of people with learning disabilities having an annual health check this year. This is key to ensuring people's long-term health conditions are well managed and detecting health concerns early on.

Moving forward we are confident that LeDeR will continue to help identify learning and system partners are fully committed to continuing this hard work, addressing health inequalities, and supporting service improvement across BLMK for people with learning disabilities and autistic people.

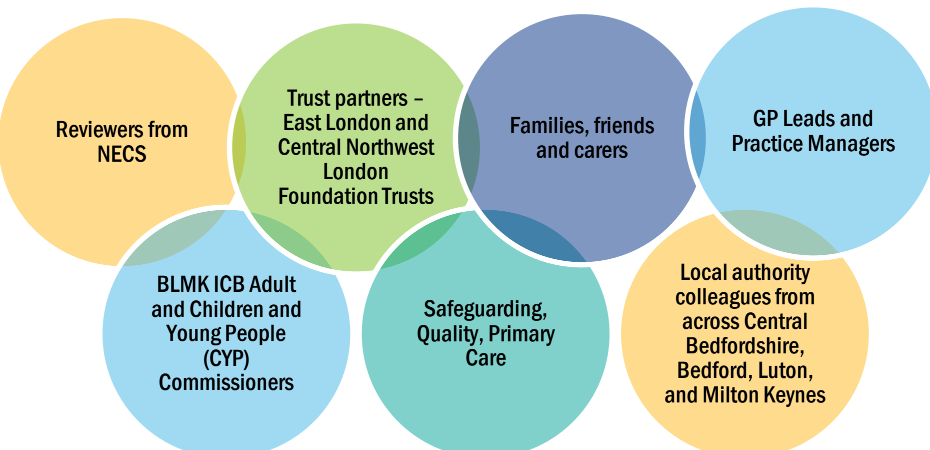
2. Acknowledgements

The strength of implementing LeDeR learning across BLMK is our collaborative approach, working with system partners and stakeholders to making service improvements and preventing people with a learning disability and autistic people from dying early.

We would like to acknowledge our key partners who have been central to implementing the LeDeR work across BLMK. This report reflects the commitment and achievements of these groups and their working relationships, collectively supporting BLMK to reduce health inequalities and implement learning from the LeDeR reviews.

We are particularly appreciative to the family, carers, and friends of people with a learning disability and autistic people for their time and valued contributions to the LeDeR reviews. This has been important and helpful to the review process, enabling us to learn as much as possible about their loved ones, and their experience of services has helped identify learning and influence the improvement of services for other people.

Finally, thank you to all those who have contributed to the development of this annual report and their continued commitment to improving the lives and experience of people with a learning disability and autistic people.



3. Executive Summary

The LeDeR Programme *(Learning from lives and deaths of people with learning disabilities and autistic people)* led by NHS England follows on from the University of Bristol Confidential Enquiry into premature deaths of people with Learning Disability (CIPOLD).

The findings of the CIPOLD 2013 report demonstrated that on average someone with a learning disability lives 20 years less than the general population. In 2019 The NHS England LeDeR report highlighted that the average age of death is 23 years younger than the general population for men with a learning disability and 27 years younger for women. People with learning disabilities in Bedfordshire, Luton, and Milton Keynes (BLMK) population live on average comparable to the national data, however we still have more to do to narrow that gap.

The purpose of the report is to share our findings from LeDeR reviews, to report on the identified learning and the action we are taking to improve practice and address health inequalities for people with learning disabilities and autistic people. Through the BLMK LeDeR Quality Assurance Panel and our Health Inequalities Group, we have been proud to host vibrant meetings where BLMK Integrated Care System (ICS)[1] colleagues and partners have been fully engaged with the topics and themes from our LeDeR reviews. In 2022-23 we carried out 23 LeDeR reviews, 19 were initial and 4 were focused reviews and the learning from these is highlighted in the Key Learning Themes.

We continue to challenge health inequality and strive to improve health outcomes for people with learning disabilities and autistic people with the aim of preventing people from dying prematurely and improving quality of life. We have continued to work with a range of partners to co-produce activities that respond to the learning from reviews, and this is set out in section 9, Local Learning. Our goal is to create a strong culture of person-centred care, working alongside people with lived experience, be vigilant and proactive supporting people with a learning disability and autistic people with their health, care, and well-being.

There are several best practice examples within the report, and they illustrate the progress made across the health and social care system, ensuring reasonable adjustments are considered and that the needs and views of people with a learning disability and autistic people are listened to.

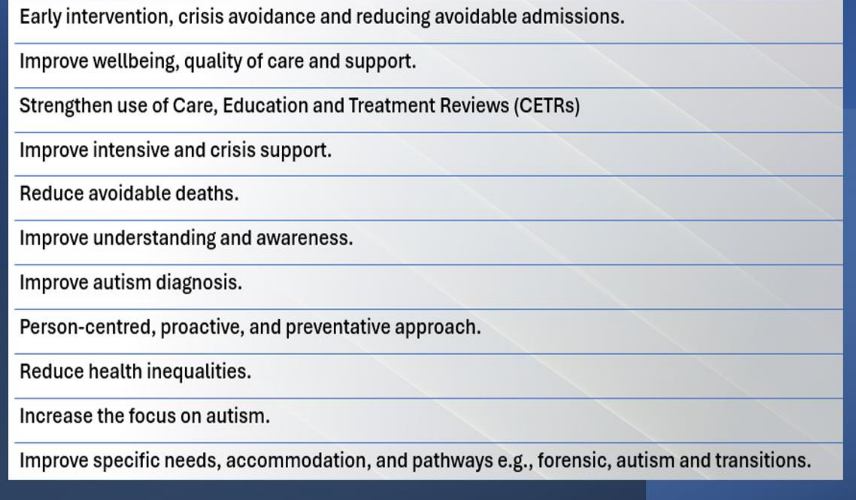
[1] Integrated care systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.

4. Our Achievements in 2022-23

In 2022-23 we have been proud of several achievements in supporting improvements and developing plans to reduce health inequalities for people with a learning disability and autistic people. It is accepted that there is always more work to be done across BLMK and that a system wide approach needs to be taken to realise improvements and embed change.

We are especially proud that among residents receiving an annual health check, 96.7% received a Health Action Plan (an improvement of 11% compared to 2021-22) and more young people, Black, Asian, and ethnic minority communities are also receiving annual health checks.

Our overall aim is to improve access, health and wellbeing outcomes and reduce premature deaths for people with a learning disability and autistic people and we have continued to work closely with our system partners on work programmes that provide improvements highlighted in this table.



Early intervention, crisis avoidance and reducing avoidable admissions.
Improve wellbeing, quality of care and support.
Strengthen use of Care, Education and Treatment Reviews (CETRs)
Improve intensive and crisis support.
Reduce avoidable deaths.
Improve understanding and awareness.
Improve autism diagnosis.
Person-centred, proactive, and preventative approach.
Reduce health inequalities.
Increase the focus on autism.
Improve specific needs, accommodation, and pathways e.g., forensic, autism and transitions.

5. LeDeR Programme in BLMK

Research has shown that on average, people with a learning disability and autistic people die earlier than the general public, and do not receive the same quality of care as people without a learning disability or who are not autistic.

We want to change this. LeDeR reviews deaths to see where we can find areas of learning, opportunities to improve, and examples of good practice. This information is then used to improve services for people with a learning disability and autistic people. To support the LeDeR process within BLMK we have a LeDeR Strategy, aligned to the national LeDeR Policy (2021) providing clear guidance on the process and governance to support the learning from reviewing these cases.

The Learning Disabilities Mortality Review Programme (LeDeR) was established in 2016. It is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people over the age of 4 years with a learning disability are subject to a Learning Disability Mortality Review.

The main purpose of the LeDeR review is to:

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

The national LeDeR Programme, run by NHS[2] England (NHSE), introduced a new national LeDeR policy in April 2021 to build on the programme developed by the University of Bristol. Integrated Care Boards (ICBs) are responsible for delivering the LeDeR programme. The reviews focus on the individual's last year of life and include a pen portrait describing who the person was, their likes and personality, followed by a review of services the person received.

Importantly, the reviews involve family members or staff to ensure that the review answers any queries or concerns they have, and their involvement in writing pen portraits is crucial. The LeDeR guidance states that these are not investigations, but reviews, with the focus on identifying learning and not apportioning blame.

[2] NHS – National Health Service

How LeDeR fits with existing local and national reviews of deaths

There are several different review processes for people who die. For example:

- Child Death Review (CDOP[3]).
- Safeguarding Adults' Review (SAR).
- Review of deaths of people in hospitals.

We will work together with these different processes to try to avoid unnecessary duplication. Reviewers will make it clear to families where and how the LeDeR process links with other reviews or investigations.

Family involvement

Families often know the most about the care received by the person who died. Families will be informed when a review is undertaken, invited to contribute information about the person who died, and offer:

- An opportunity to comment on the draft review.
- A copy of the completed review.

All families are different. Reviewers will talk to them to help them decide how much involvement they want in the LeDeR review. Reviewers will explain how to raise questions or concerns, including those outside of the LeDeR process.

LeDeR Reviews

LeDeR reviewers look to identify best practice by reviewing the person's health and social care records and, where identified, areas where improvements could be made. There is either an **initial review** or a **focused review** both these were introduced into the process with the new LeDeR policy in April 2021. All reviews concerning someone from a Black, Asian or ethnic minority background automatically become focused reviews. In January 2022 NHSE introduced LeDeR reviews for autistic people who do not have a learning disability, and these will also be focused reviews.

LeDeR reviews should be completed within six months from when the BLMK LeDeR team have been notified of the person's death by the national LeDeR team. Sometimes it will not be possible to complete the review in six months because there might be other processes going on such as a coroner's inquest or other investigation. A LeDeR reviewer will wait until all these have been

[3] CDOP - Child Death Overview Panel

completed first. After this, the reviewer uses their judgement to decide if a focused review needs to be undertaken. A focused review will look in more detail at the person's life. The reviewer will also involve more people with different roles where necessary to complete the review.

The reviewer will send the completed review to the BLMK Quality Assurance Panel with the identified areas of learning, good practice, and concern. The panel will decide on actions to take, who will take these actions and the help they need to reduce health inequalities and potentially stop people dying too young.

Governance

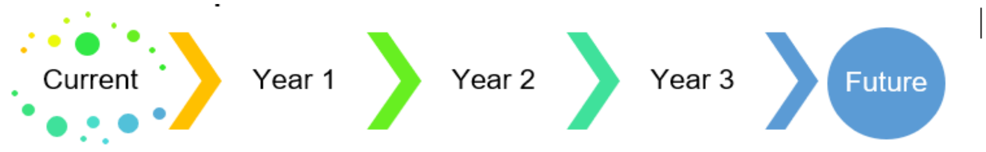
The Executive Leads responsible for the LeDeR programme are the BLMK ICB Chief Nurse and Deputy Chief Nurse. The programme is accountable to the BLMK ICB Transforming Care Partnership (TCP) Board. The TCP Board has met monthly since 2019, including throughout the COVID lockdown periods, overseeing the LeDeR programme.

Representatives attend the TCP Board from the ICS, including the local trust health providers East London Foundation Trust (ELFT) and Central Northwest London Trust (CNWL), the four BLMK local authorities[4] which provide social care, East of England NHSE regional team, commissioners, and clinical leads.

The BLMK TCP Board is chaired by the Deputy Chief Nurse and board members take a strategic level oversight of the reviews of deaths of people with learning disabilities and autistic people and drive transformation to improve care.

The BLMK TCP Board has agreed to develop and oversee the 'roadmap' *(move from current to future)* over the next three years where people with a learning disability and autistic people can be supported to live fulfilling lives within their communities, with access to the right support from the right people at the right time.

The **roadmap** will be set out in the BLMK Learning Disability and Autism Strategy and Delivery Plan with the key programmes and workstreams for people with a learning disability and autistic people, which will focus on specific tasks and timelines.



[4] BLMK local authorities – Bedford Council, Central Bedfordshire Council, Luton and Milton Keynes Council

6. The LeDeR Structure

To strengthen the quality assurance process, we have a LeDeR Quality Assurance Panel that meets monthly to review all initial and focused reviews. It is important to us that we have assurance of the content and the quality of individual reviews.

BLMK Quality Assurance Panel

The BLMK Quality Assurance Panel was first established in July 2019 and membership includes the BLMK Local Area Contact (LAC), acute trust specialist nurses, clinical leads for learning disabilities and autistic people, quality and safeguarding nursing leads, local authority representatives, social care leads, commissioners, East of England NHSE regional LAC and lead for LeDeR, the BLMK LeDeR facilitator and administrator.

The panel reviews all completed cases by our NECS reviewers, who will circulate redacted reviews to the Panel members and present their summary findings, learning and positive practice.

The Panel will ensure all questions have been fully answered, with learning and best practice identified, with appropriate recommendations formulated prior to closing the case on the LeDeR platform. The Panel also identify themes from each review to guide topics for further action.

The LeDeR Team

The Local Area Contact (LAC) is the manager of the BLMK LeDeR process ensuring it meets targets and delivers the programme day to day. The LAC oversees the allocation of cases to trained LeDeR reviewers, monitors the progress and completion of reviews and promotes quality assurance in the closure process of each case.

Our LeDeR administrator supports the LeDeR reviewers with case allocations, following up queries and generally supporting reviewers. The administrator undertakes preparation of papers for the Quality Assurance Panel, updating the review trackers and the national LeDeR platform when reviews are completed as well as recording local learning from each of the reviews.

Our LeDeR Facilitator will ensure that local actions are taken to address the issues identified in reviews. Recurrent themes and significant issues are identified and addressed at a more local level, and this is fed back up to the regional NHSE LeDeR team.

Our LeDeR Reviewers

The LeDeR process is supported by a team of dedicated trained reviewers from North of England Commissioning Support (NECS).

We have been working with NECS for just over two years, when they first supported BLMK ICB with completing a backlog of reviews and during the COVID pandemic when we saw an increase in the number of deaths due to COVID. We commissioned NECS again to support with completing our reviews during 2022-23.

NECS fulfils the LeDeR Policy (2021) requirements for the recommended workforce model, in that they are independent reviewers from BLMK ICB. NECS also employ independent senior reviewers who are available to quality assure the reviews and undertake more complex reviews as well as provide support to the other reviewers.

Our LeDer reviewers have a wealth of background and experience working in health and social care and with people with learning disabilities and autistic people. Many of them are clinical professionals who have worked in hospitals or in the community.

To support reviewers with their first reviews NECS work closely with experienced reviewers and observe our Quality Assurance Panels before presenting cases. Reviewers will act as a point of contact for advice on where to start, how to approach providers and families and how to ensure their review is of good quality. NECS, ensure they provide a safe confidential space to discuss issues and support best practice for new reviewers.

Peer Support Meetings

In addition, NHSE East of England[5]East of England regional team has established Reviewers Support Meetings to offer additional support to our LeDeR reviewers. Meetings are held quarterly, often giving the opportunity to meet other reviewers from across the Region.

These meetings take place face to face and on-line and the aim is to support reviewers with issues and concerns they have around processes or with the reviews they are undertaking and to share their experiences, learning and good practice. These meetings will also update reviewers on information from the national and regional meetings and other LeDeR relevant events.

[5] East of England is comprised of BLMK, Herts & West Essex, Cambridge & Peterborough, Mid & South Essex, Suffolk and Northeast Essex, Norfolk & Waveney

Reviewers are also able to update themselves on any emerging themes or their own individual needs, such as training and support and to have a safe space to raise any concerns or speak to other reviewers as to how they might approach a situation.

The Regional team also holds regular peer support meetings for the LACs across the East of England region. These meetings keep LACs updated with national information on LeDeR, any training or initiatives and changes to the LeDeR programme. They also offer the opportunity to share common issues and concerns arising from the programme as well as sharing good practice, ideas on improving processes and learning into action initiatives.

Learning Disability and Autism Steering Groups

BLMK ICB supports commissioning and service improvement for people with a learning disability and autistic people and works closely with system partners and local authorities across health and social care. There are several key steering groups in place, with representation from health providers in secondary, primary and community care who work with children, young people and adults with learning disabilities and autistic people.

The Learning Disability Annual Health Checks, Reducing Health Inequalities and Learning Disability and Autism Steering Groups are action-oriented groups, which take learning from national and local key themes and trends from LeDeR and implement plans for service improvement and improve quality of care and support.

The LeDeR Learning action group, working closely with our trust partners will:

- Guide the implementation of the programme of local reviews of deaths of people with learning disabilities.
- Receive regular updates from the Local Area Contact (LAC) about the local reviews of deaths of people with learning disabilities.
- Monitor action plans resulting from local reviews of deaths.
- Take appropriate action as a result of information obtained from local reviews of deaths.
- To support the identification of and sharing of best practice in the review process.
- Provide assurance to the Performance and Quality Committee and the ICB TCP Board.
- Provide shared governance for LeDeR and reporting back to their own organisations.

7. About the People - Pen Portraits

In BLMK the Quality Assurance Panel we always start with the reviewer presenting the pen portrait of the person who died, which helps us understand the person's likes and dislikes, their hobbies, what they liked doing, what kind of character and personality they had, and gives us information about their friends and family.

Pen portraits will also give us some indication as to whether the care and treatment they received would have been good enough for our own relatives.

Through the pen portraits we learned there were people who loved going on holidays, especially to the seaside. Some people liked different types of food and trying new dishes, curries and fish and chips were very popular, as well as desserts such as cakes, jelly, and puddings.

There were a few people who enjoyed listening to music and going to concerts or the theatre. It was heartening to know how people enjoyed their lives, whether going to parties or preferring their own company reading books or magazines.

We learned that a few people spent their leisure time watching films and going to the cinema. There were a couple of Harry Potter fans who had been to the Warner Brothers studio. Some people liked being out in the garden or being around animals and visiting the zoo or farms with a few people having their own pets. There were others who enjoyed having their hair and nails done or going shopping and following the latest trends and fashion.

We did realise that family was important for many individuals and being able to attend family occasions. They appreciated the support they received to stay connected with their family and friends. Many people had made strong friendships by attending religious or community events.

We learned a lot from the pen portraits, mostly about how well-loved people were by their family or their carers.

8. Deaths notified to the LeDeR programme

Since the programme began there have been 200 deaths reported to the BLMK LeDeR platform covering the period 1st July 2017 to 31st March 2023.

In June 2021, the LeDeR platform moved from the University of Bristol to NHS England (NHSE). With NHS England now managing the LeDeR platform, and with the introduction of a new national LeDeR Policy, there have been several changes.

The NHSE operating platform for managing reviews went live in July 2021. There were some teething problems as there are with any software changes, but these have largely been resolved through regular dialogue with the regional and national teams, and for 2022-23 we have been able to use the platform more efficiently. The actual review forms have been redesigned to incorporate initial and focused reviews which replaced the multi-agency review (MAR) process. All reviewers had to re-train before they could access the platform and be allocated reviews.

The table below provides a summary of the status of all cases as of 31st March 2023.

Table 1: Summary of deaths notified to LeDeR for BLMK

					In progress							
		All reviews eligible for completion	Unallocated		All reviews in progress		Initial reviews in progress		Focused reviews in progress		All completed reviews	
	No.	No.	No.	% of all reviews	No.	% of all eligible reviews	No.	% of all in progress reviews	No.	% of all in progress reviews	No.	% of all eligible reviews
England total	17149	15316	59	0%	600	4%	395	66%	205	34%	14657	96%
EAST OF ENGLAND COMMISSIONING REGION	1914	1722	2	0%	65	4%	28	43%	37	57%	1655	96%
Bedfordshire, Luton & Milton Keynes	200	180	0	0%	7	4%	4	57%	3	43%	173	96%

The table shows that so far 200 deaths have been notified to BLMK LeDeR dashboard. As of 31st March 2023, the table further breaks down the following data:

- 180 of these reviews were eligible for completion, out of these 173 were completed, that is 96% of all reviews eligible for completion were completed by end of March 2023.
- There were no reviews that were unallocated.
- There were still 7 reviews (4%) in progress, of these 4 were initial reviews and 3 were focused reviews.
- In 2022-23 BLMK completed 23 reviews in total, 19 initial reviews and 4 focused reviews.

The data below is based on the 23 LeDeR notifications received in 2022-23 for those people aged 18 and above. Of the 23 notifications received 4 reviews become a focused review because:

- Further learning was required due to multiple areas of concern.
- The next of kin requested a focused review because the next of kin had concerns about the diagnosis and management of their loved one's treatment.
- One of the notifications was of an Asian background.
- There were concerns about delays to diagnosis and treatment.

Both initial and focused reviews were brought to the Quality Assurance Panel and were graded on quality of care and availability and effectiveness of care **(see Appendix One for Grading of Care)**

In 2021-22 there were more deaths reported than in 2022-23. In 2021-22 there were 34 deaths reported in total, 10 of these were focused reviews and 24 were initial reviews and of the 34 deaths reported, 7 were COVID related deaths.

The table below shows the people who notified us of these deaths:

Table 2: People who notified us of the deaths in 2022-23

People who notified us of the deaths			
	Adult Safeguarding Lead, hospital x 8	Lead Medical Examiner Officer, hospital x 5	Learning Disability Liaison Nurse, hospital x 2
Team Manager of a Social Work team, local authority	Social worker	Adult Safeguarding Nurse Specialist, hospital	Compliance Officer, Support Provider
Specialty Doctor in Palliative Medicine, Hospice	Care Home Manager	Matron for Patient & Family Experience, Hospital	Apprentice Social Worker, Adult Social Care

The table below provides a summary of data of the people who died in 2022-23 **(see Appendix Two for full graphical data and information).**

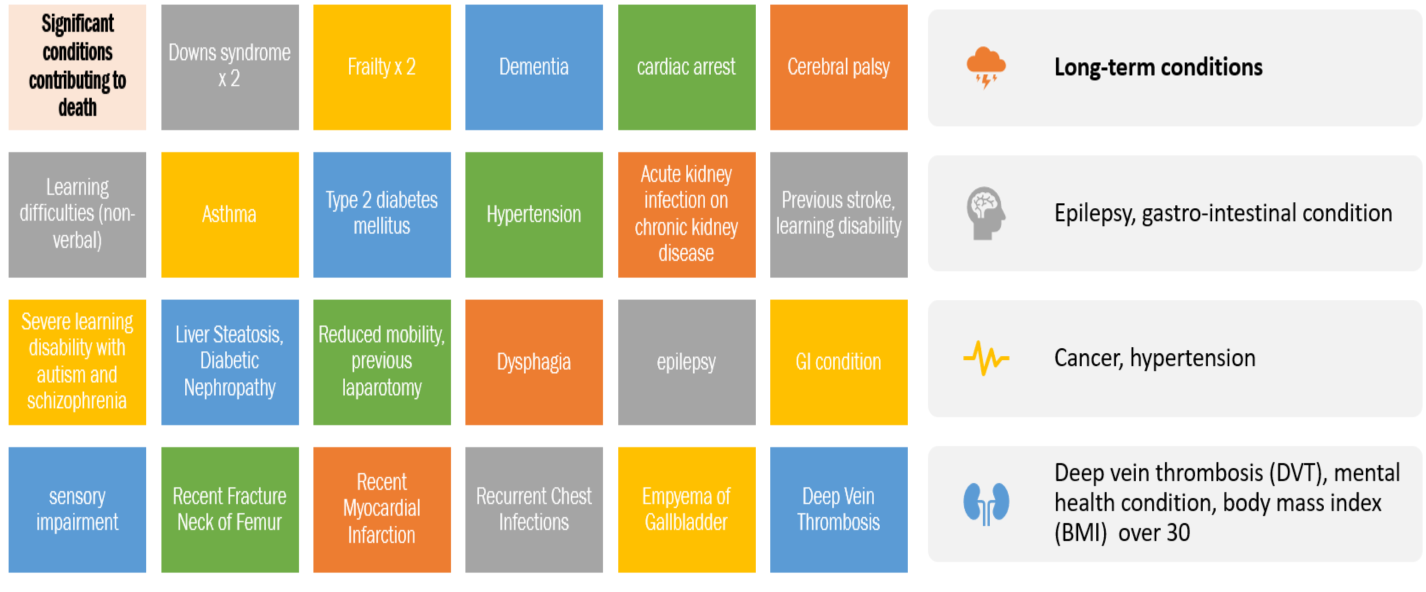
Appendix Two also includes *Additional Data for BLMK* using the NHS England LeDeR Data Tool. This is a new functionality and currently has captured data from January 2023 – end of March 2023. We are confident this data tool will provide more significant data for forthcoming annual reports. For now, we hope you find this helpful.

Table 3: Summary data of the people who died in BLMK in 2022-23

Diagnosis	We had 18 people who died having a learning disability only, 0 people had autism only and 5 people had both a learning disability and autism.
Area	Out of those people who died in 2022-23, there were 8 people who lived in Central Bedfordshire, 6 who lived in Bedford Borough, 4 people who lived in Luton and 5 people who lived in Milton Keynes.
Gender	There were 13 males (57%) who died, and 10 females (43%) who died in 2022-23. This is a slight increase from 2021-22, when there were 53% male and 47% female who had died in BLMK.
Age	The median age of death during 2022-23 was 57 years old. In 2020-2021 the median age of death in BLMK was 56. In 2021-2022 the median age was 58. The average age of death in BLMK between April 1st 2020, and end of March 2023 is 57.
Place	There were 18 people who died in an acute setting (78%), 2 people died at home (9%), 2 people died in a residential/nursing home (9%) and 1 person died in a hospice.
Primary Cause	The primary cause of death was aspiration pneumonia and pneumonia in 2022-23, in comparison to the previous year, 2021-22, when the primary cause of death was COVID pneumonia.
Secondary Cause	The five main secondary causes of death during 2022-23 were cardiac arrest, followed by bowel obstruction, chest infection, Eisenmenger's syndrome, and ascending cholangitis.
Covid	During 2022-23, 9% of deaths were COVID related, a significant reduction compared to the previous year in 2021-22 when 21% of COVID related deaths were recorded.
Ethnicity	During 2022-23 most deaths were 'white British' with 1 noted as 'other white' background,1 preferred not to say and 1 was noted as 'Asian Bangladeshi' background.
Health Checks	19 people had an annual health check within the last year before their death. There were 4 reviews that showed an annual health was not completed – this was either due to be completed or declined.
DNCPR	Out of the 23 reviews completed in 2022-23, there were 16 reviews where there had been a DNACPR in place (70%) which is lower than 2021-2022 (82%) and 2020-2021 (83%).

The table below shows the significant and long-term conditions contributing to the deaths from those reviews completed in 2022-23.

Table 4: Significant and long-term conditions contributing to the deaths.



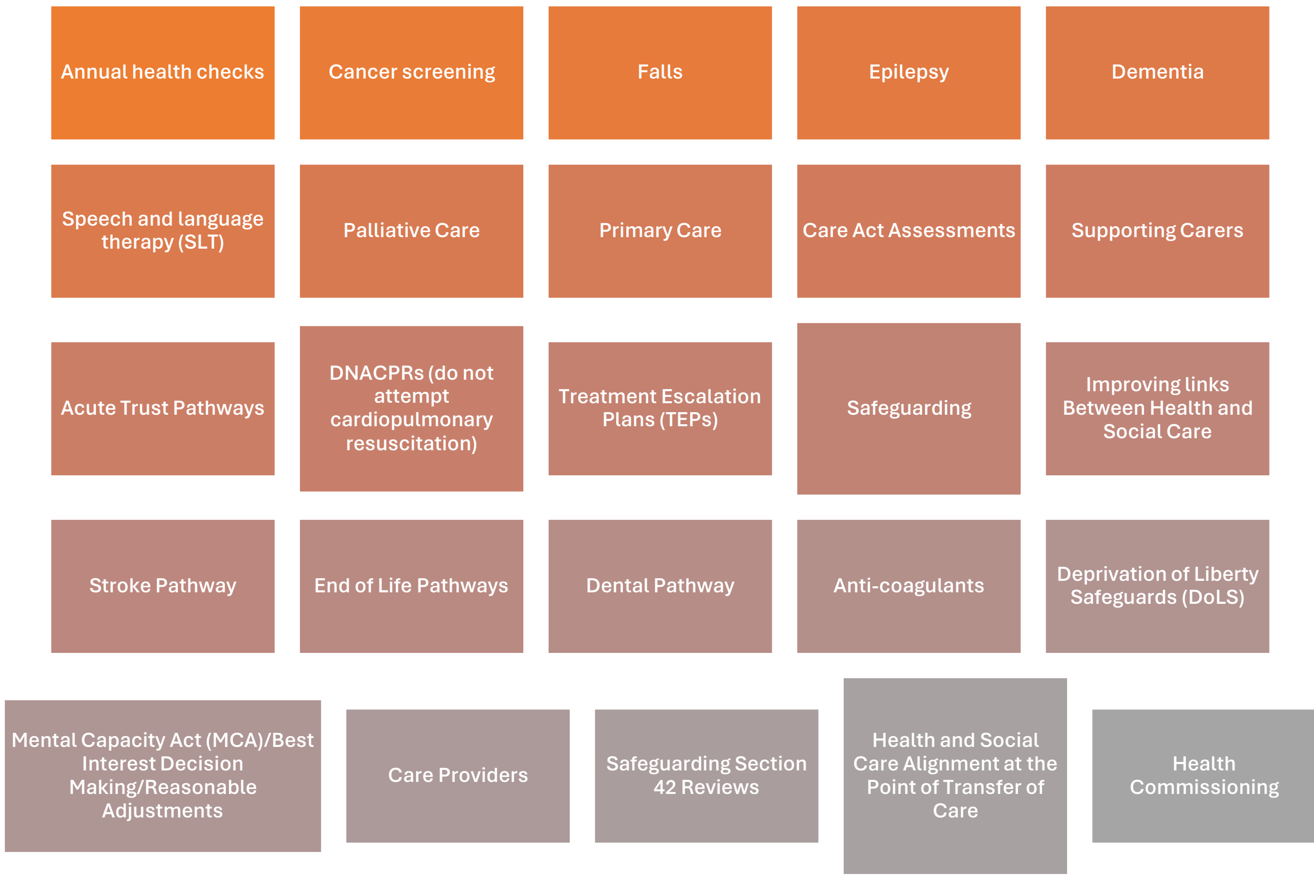
9. Local Learning

Key Learning Themes

The LeDeR reviews carried out in 2022-23 identified several recurring themes for learning, Appendix Three gives a full illustration of the key learning themes.

The table below gives you a summary of the key learning themes from the 2022-23 completed LeDeR reviews.

Table 5: Summary of the Key Learning Themes 2022-23



Ethnicity

Of the 23 notifications received in 2022-23, 22 people were of white ethnicity, 1 did not disclose their ethnicity and only 1 person was of Asian or Asian British background. Although we have had a few more deaths reported from Black, Asian, and other ethnic minority communities in previous years, there continues to be a low number of learning disability deaths reported from these communities. This does not compare with the demographic profile for BLMK, and we believe there may still be under reporting of deaths from these communities.

The table below shows our commitment to ethnic minority communities:

Table 5: Commitment to Ethnic Minority Communities

We have also learned from early indications that there is poor health engagement with annual health checks, screening programmes, health appointments from Black, Asian, and other ethnic minority communities. Our health facilitation teams have started to work with families whose first language is not English, directly supporting, and signposting parents and carers with people with learning disabilities from ethnic communities in accessing health services.

Child death reviews

During 2022-23 there were 7 cases notified to the LeDeR platform, which related to the death of a child with learning disabilities. All the children had profound and / or complex disabilities with multiple co-morbidities. This is an increase from last year when there 5 child deaths reported to LeDeR.

All child deaths are reviewed as part of the statutory Child Death Overview Process (CDOP). The CDOP reviews have a backlog and NHSE has decided to remove CDOP cases from the LeDeR reporting system from 1st July 2023. In BLMK there are two Chid Death Review Panels covering Central Bedfordshire, Bedford and Luton and Milton Keynes. The LeDeR LAC will attend these meetings where a child with learning disability and / or autism is being reviewed.

Involving next of kin in reviews

We have collected data this year on whether next of kin were engaged in the review process and found that 58% of reviews included next of kin. Sometimes these were parents but more usually, due to people's age, they were a brother, sister, niece, or nephew. Where people had previously lived in prolonged stay hospitals or care homes family connections were often lost. Care providers have made special efforts over the years to re-connect people to family, sometimes successfully and sometimes not.

We have also found in reviews where there was no next of kin, that care staff who knew the person well participated in the review. Some care staff have known their residents for twenty, thirty

years or more and have remarkably close relationships. From an overview of completed local reviews during 2022-23, the Quality Assurance Panel has identified several recurring themes. These focus on areas where improvements can be made to improve the health and social care for people with learning disabilities. There is usually more than one theme per review.

Improving uptake of Annual Health Checks

For the first time BLMK achieved the national target of 75% in 2022/23, compared to last year when we achieved 67%. *Source: BLMK SystmOne data*

We are continuing to monitor the rise each month as compared to last year. We are working closely with our GP practices and Health Facilitation Team on identifying those people who have not received a health check since April 2021 or an invitation since April 2022, so that contact for a health check is made.

We are also seeing an improvement in the number of health action plans that are in place following an annual health check, and we learned that 96% of people who had an annual health check in 2022-23 also received a health action plan, compared to 85% in 2021-22.

We have an annual health check steering group that meets every month and task and finish groups that focus on specific areas of work, such as developing the action plan for 2023-24, GP Resource Pack and questionnaires that will help us address barriers for people with learning disabilities receiving an annual health check and also give us indications as to what support we can give to individuals, their families and carers as well as to GP practices.

There are also regular communications in the BLMK Primary Care Bulletin, informing GP practices of performance data, resources, information, and latest news on supporting annual health checks for people with a learning disability.

Areas of Good Practice

The LeDeR reviews not only provide us with learning to improve services, but also areas of good practice, which are important for us to share. The table below highlights some of the areas of good practice that we learned about from the reviews in 2022-23.

Table 6: Areas of Good Practice

Areas of good practice

- Regular support staff continuing to visit the person whilst they were in hospital.
- Best interest decision-making meetings involving family or an IMCA.
- Residential staff providing good care and liaison services with acute learning disability and community nurses
- GPs and practice nurses undertaking home visits and ward visits
- Multi-disciplinary meetings in hospital to review full care of the person, including physical health, cognitive and behavioural needs.
- People with learning disabilities having a clear easy read hospital passport that is fully completed and up to date by residential staff.
- Innovative reasonable adjustments such as meeting a young man in his parents care to take blood.
- Grab sheets with key health and communication information kept on the person's bedroom door for ambulance staff.
- Bereavement support for residents and staff when they lose a friend, they had lived with for 30 years.
- Top up packages for people in residential homes to support changing healthcare needs as people age, ensuring people are not moved unnecessarily from their homes of 25+ years in the last year of their life.

10. Next Steps and Priorities for 2023-24

We hope this report provides the detail of how the LeDeR process has been implemented in BLMK, demonstrating how our governance arrangements support a robust approach to learning from the deaths of people with learning disabilities.

As we have transitioned into an Integrated Care System (ICS) over this past year we have remained passionately committed to continuing to learn because of LeDeR reviews and continuing to drive an innovative work programme that makes changes to improve services and addresses health inequalities experienced by people with learning disabilities and autistic people.

LeDeR reviews provide regular information on the themes and recommendations identified from these reviews and this informs and inspires our programme of work. Some of the agreed priorities identified for health will be progressed as part of the Health Inequalities Group work plan and the Learning Disability and Autism Strategy, reporting to the BLMK TCP Board.

In 2019, The NHS Long Term Plan (LTP)[6] committed to enabling people with a learning disability and autistic people to live happier, healthier, and longer lives. The National Strategy for autistic children, young people, and adults: 2021 to 2026[7] sets out a vision for what the Government wants autistic people and their families' lives to be like in **2026** across six priority areas, and the steps for national and local government.

The NHS England East of England Regional Learning Disabilities and Autism Board also re-affirm their commitment to delivering the NHS Long Term Plan for adults and children and young people with learning disabilities and autism in their Regional Commitments for 2023-24. In response to these Policy commitments BLMK ICB is looking to establish a BLMK Learning Disability and Autism (LDA) Transformation Board to drive further improvements in the health and wellbeing outcomes of people with a learning disability and autistic people.

The LeDeR reviews have provided us with valuable data and information to formulate our work plans for the coming year and beyond and we have already identified several priorities for the forthcoming year 2023-24, set out in the table below:

[6] NHS England » The NHS Long Term Plan
[7] National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk)

Table 7: Priorities for 2023-24

BLMK Learning Disability and Autism Transformation Board from January 2024	Re-instated LeDeR Steering Group from January 2024	Early intervention, crisis avoidance and reducing avoidable admissions	Improve wellbeing, quality of care and support	Strengthen use of Care, Education and Treatment Reviews (CETRs)	Quarterly length of stay and safe and well Quality Assurance Panels from April 2023	Improve intensive and crisis support, autism diagnosis
Person-centred, proactive, and preventative approach	Increase the focus on autism	Improve specific needs, accommodation, and pathways for example forensic, autism and transitions	Focused engagement across BLMK, to learn about barriers faced by people with learning disabilities and autistic people to obtain LDA strategy priorities	Co-produced Learning Disability and Autism Strategy, a 3-year Strategy Implementation and Delivery Plan (2023/24 – 2025/26)	Ongoing engagement with partners and stakeholders on shared work plans, make changes where necessary	Working with Autism Bedfordshire and coproducing videos and resources to help the learning disability and autism community to better understand what to expect during appointments to reduce the fear of the unknown, including signposting to some venues
Type 2 Diabetes (information, GP annual health checks and importance), Tiers 3 and 4 Weight Management, Cancer screening (breast, bowel and cervical)	Autism Diagnostic Assessments	Vaccinations and Blood Tests	Dental Appointments, reasonable adjustments	Improved data extraction and analysis to better understand the long-term conditions of people with learning disability and autistic people	Working closely with learning disability nurses in community across Bedford Borough, Central Bedfordshire and Luton to support with reducing health inequalities and LeDeR	BLMK LDA Forensic Review to clearly quantify the need, outline gaps and requirements

One of our providers, East London Foundation Trust (ELFT) will also be exploring health and social inequalities for people who have a learning disability and autistic people across BLMK, working alongside people, their family, and carers. ELFT will be looking to identify areas of good practice as well as gaps and provide recommendations to the wider system in terms of local solutions as well as inform the BLMK Learning Disability and Autism Strategy going forward. They are also developing a draft LeDeR Policy for the Acute Trusts. Following a literature review, review of local and national drivers, and engagement with local services and service users they have identified 5 key areas of focus:

1. Reduction in readmission rates to acute hospitals.
2. Increase in accessibility and quality of annual health checks, including health action plans.
3. Improve staff understanding of the needs of people with a learning disability and autistic people, with particular focus on acute inpatient and primary care.
4. Improve the outcomes for people with BMI of 25 plus.
5. Improve access to cancer screening services, annual health checks and primary care to people that the system struggles to reach.

11. Glossary of terms

Annual Health Checks	Anyone aged 14 or over who is on their doctor's learning disability register can have a free annual health check once a year.
CDOP	The Child Death Overview Panel is a group of professionals and leaders from Health, Public Health, Police and Children's Social Care who have a statutory responsibility under Working Together to Safeguard Children (2018) and Child Death Review: Statutory and Operational Guidance (2018) to review all deaths of children from birth to the 18th birthday.
CNWL	Central and Northwest London NHS Foundation Trust is an NHS Foundation Trust in England. It provides healthcare in London, Milton Keynes, Surrey and elsewhere.
COVID	Coronavirus disease (COVID-19) is an infectious disease caused by the SARS virus.
NHSE East of England	NHS England East of England is one of seven regional teams that support the commissioning and delivery of high-quality services and directly commission primary care and specialised service.
ELFT	East London Foundation Trust covering Tower Hamlets, Newham, City & Hackney, and Bedfordshire & Luton.
Health Action Plan	As part of the patient's annual health check, GP practices are required to produce a health action plan. A health action plan identifies the patient's health needs, what will happen about them (including what the patient needs to do), who will help and when this will be reviewed.
Health Facilitation	Team of nurses who are specialised in facilitating health care for people with Learning Disabilities.
ICB	An integrated care board (or ICB) is a statutory NHS organisation which is responsible for developing a plan for meeting the health needs of the population.
ICS	A statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area.
LAC	The Local Area Contact for LeDeR Programme.
Local Authorities	Referring to BLMK local authority areas, which include Bedford, Central Bedfordshire, Luton, and Milton Keynes.
MAR	Multi- Agency Review
NHS	National Health Service
NHSE	National Health Service England
System partners	Referring to ICS health and social care partners working together to enable a more joined up, collaborative system.
TCP	Transforming Care Partnership aims to improve the lives of children, young people, and adults with a learning disability and/or autism who display behaviours that challenge.

12. References

- Annual Health Checks dataset (2022-23) *Systmone*
- BLMK LeDeR Strategy (2021)
- BLMK draft Learning Disability and Autism Strategy and Delivery Plan (2023)
- BLMK new Learning Disability and Autism Transformation Board draft
- CIPOLD 2013 University of Bristol Confidential Enquiry
- ELFT Health Inequalities Plan
- King's College London (2021) LeDeR National Report
- LeDeR NHS Policy Learning from Lives and Deaths – People with a learning disability and autistic people (LeDeR 2021)
- LeDeR Trackers for BLMK and NECS – dashboard
- Learning Disability Mortality Review (LeDeR) Programme: Action from Learning https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf
- National LeDeR Report 2019
- NHS England LeDeR Data Tool
- NHS Long Term Plan (2019) https://www.longtermplan.nhs.uk/publication/nhs-longterm-plan/

13. Appendices

Appendix One: Grading of Care

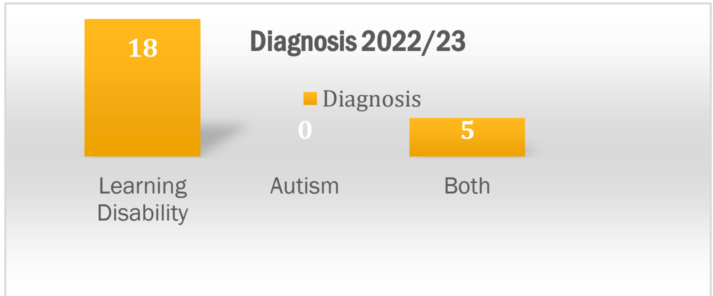
Grading care

Grade	Quality of care	Availability and effectiveness of services
6	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.	Availability and effectiveness of services was excellent and exceeded the expected standard
5	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.	Availability and effectiveness of services was good and met the expected standard
4	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	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.
3	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 fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death.
2	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.	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.
1	Care fell far short of expected good practice and this contributed to the cause of death.	Availability and effectiveness of services fell far short of the expected standard and this contributed to the cause of death.

Appendix Two: Data of the people who died in BLMK in 2022-23

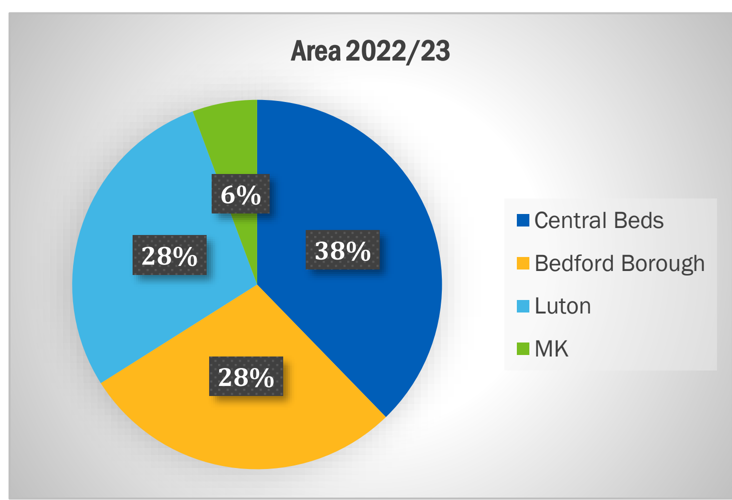
Diagnosis

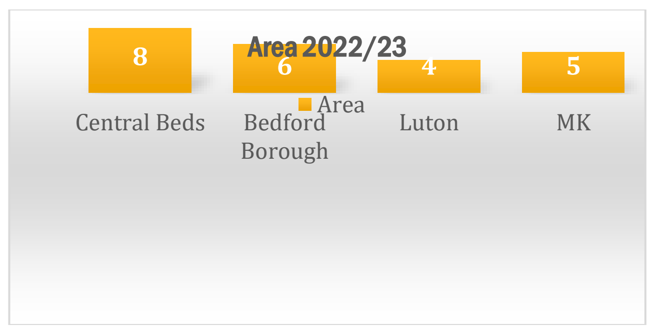
In BLMK we had 18 people who died having a learning disability, 0 people had autism only and 5 people had both.



Area

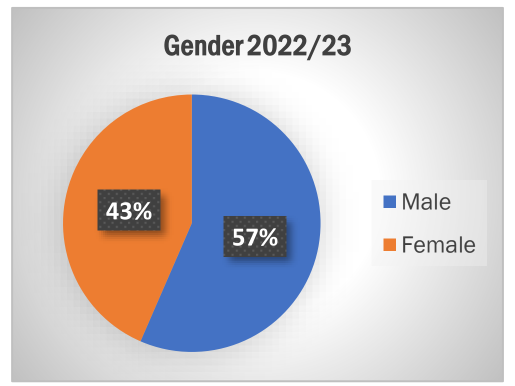
In BLMK of those who died in 2022/23, there were 8 people who lived in Central Bedfordshire, 6 who people lived in Bedford Borough, 4 people who lived in Luton and 5 people who lived in Milton Keynes.





Gender

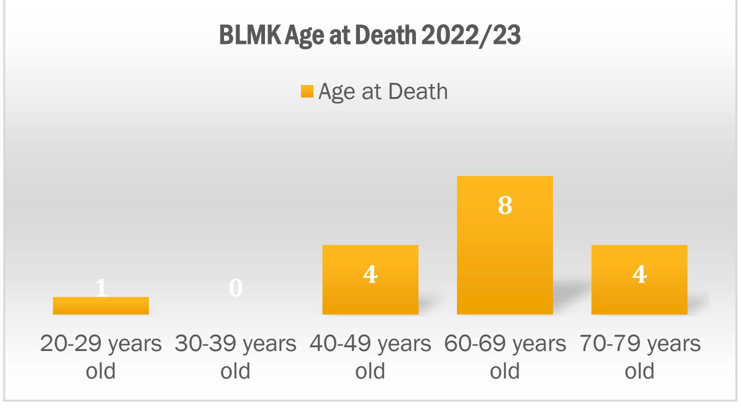
In BLMK there were 13 males (57%) who died, and 10 females (43%) who died in 202/23. This is a slight increase from 2021/22, when there were 53% males and 47% females who had died in BLMK.



This is comparable to the national average, according to King's College data for 2021/2022 where 56% of deaths were male and 44% were female. Nationally, on average, males with a learning disability die 22 years younger than males from the general population, and females 26 years younger than females form the general population.

Age at death

From The King's College London report (2021) the national data on the person's age at death was available for 869 children and 11,915 adults who died and were notified to LeDeR between 2018 and 2021.

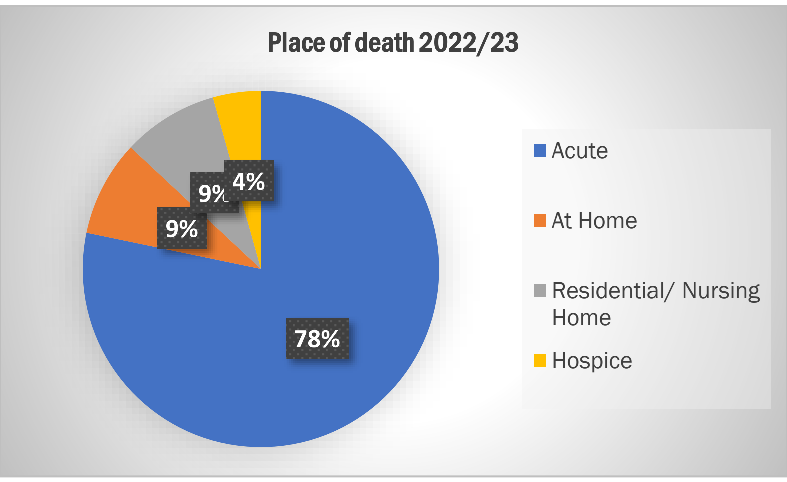


The median age at death for 2021 notifications was 61, which is the same as 2020. The median age at death for males was 61 and 60 for females, based on notifications. The median age at death has increased by 1 year since 2018 and 2019 when it was 60. For children nationally, the median age at death in 2021 was 12, which is an increase of 1 year since 2020.

In BLMK the median age of death during 2022/23 was 57 years old. In 2020-2021 the median age of death in BLMK was 56. In 2021-2022 the median age was 58. The average age of death in BLMK between April 1st 2020 and end of March 2023 is 57.

Place of death

In BLMK during 2022/23 18 people died in an acute setting (78%), 2 people died at home (9%), 2 people died in a residential/nursing home (9%) and 1 person died in a hospice.

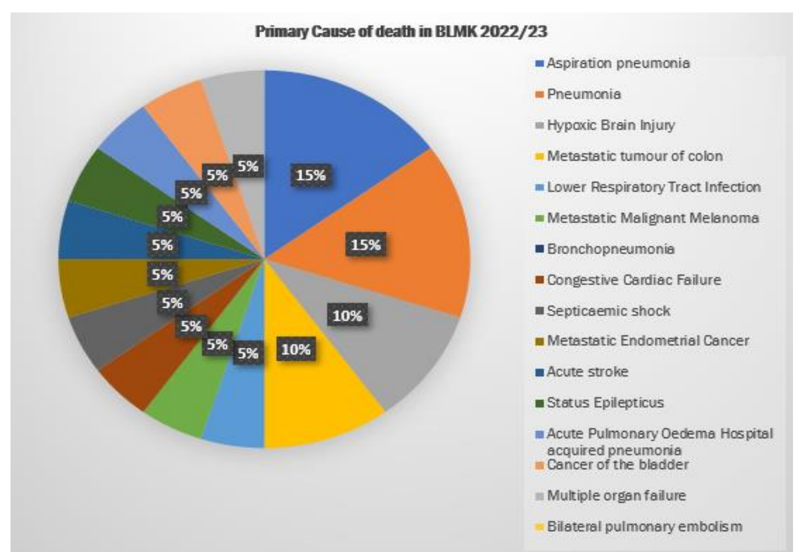


This is a similar pattern to the previous year 2021/22 when it was reported that most people (73%) also died in an acute setting, followed by 18% at home, 6% in a residential/nursing home and 3% in a hospice.

King's College London Data (2021) shows nationally of those whose cause of death was avoidable, 65.5% died in hospital and 29.7% died at their usual residence. For those whose cause of death was not avoidable, 58% died in hospital and 37% died at their usual residence. Place of death remained a significant predictor of avoidable deaths after accounting for other factors.

Primary causes of death

In BLMK the primary cause of death was Aspiration Pneumonia and pneumonia in 2022/23. In comparison to the previous year, 2021/22 the primary cause of death was COVID pneumonia.



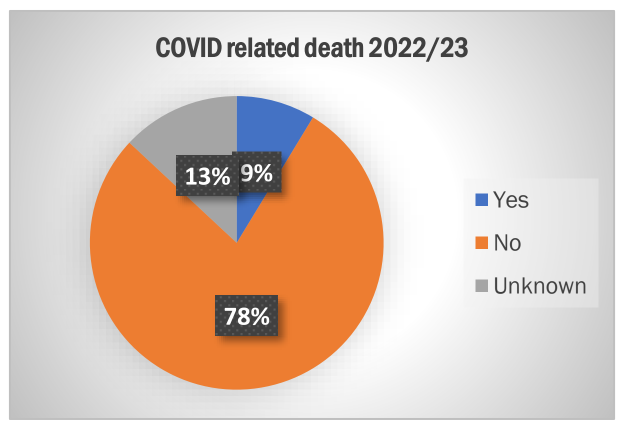
This was also comparable to King's College London's national data (2021) which was also COVID pneumonia in 2021. The King's College London's data (2021) also showed nationally the percentage of respiratory deaths due to pneumonia decreased from 52% in 2018 to 21% in 2021.

Secondary causes of death

The five main secondary causes of death in BLMK during 2022/23 were cardiac arrest, followed by bowel obstruction, cardiac arrest, and chest infection, Eisenmenger's syndrome, and ascending cholangitis. **Other secondary causes** included Covid-19 pneumonitis**,** general debility, Angelman Syndrome, coronary artery disease, small bowel obstruction due to adhesions, Waardenburg syndrome, Hirschsprung disease, recurrent pneumonia, immobility, end stage heart failure.

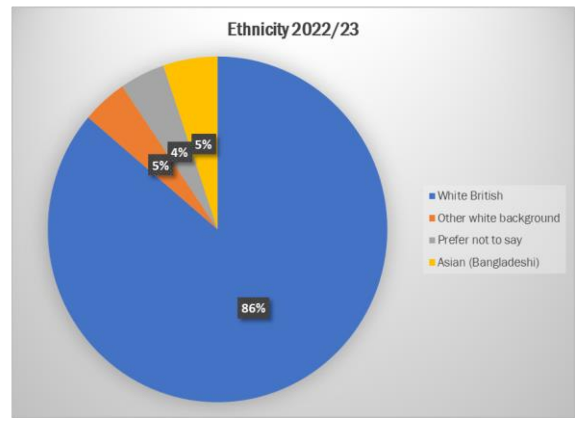
Covid-related deaths

In BLMK during 2022/23, 9% of deaths were COVID related, a significant reduction compared to the previous year 2021/22 when 41% of COVID related deaths were recorded. King's College London's data (2021) showed nationally the rate of excess deaths was more than two times higher for people with a learning disability compared to the general population. COVID was the leading cause of death for people with a learning disability in 2021.



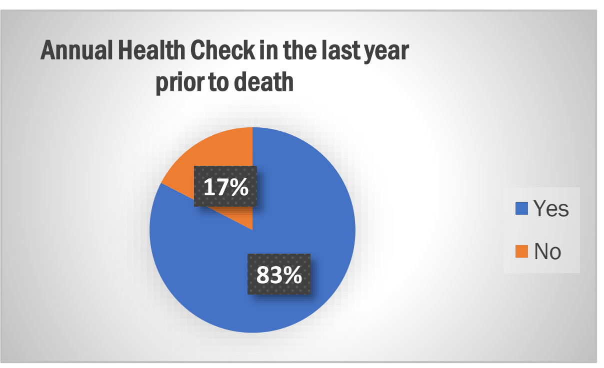
Ethnicity

In BLMK during 2022/23 most deaths were 'white British' with 1 noted as 'other white' background,1 preferred not to say and was noted as 1 'Asian Bangladeshi' background. This is very similar to the previous year 2021/22 and comparable to the King's College London's national data (2021). This national data also showed that people of black, black British, Caribbean or African, mixed ethnic group and Asian or Asian British ethnicity died at a younger age in comparison to those of white ethnicity.



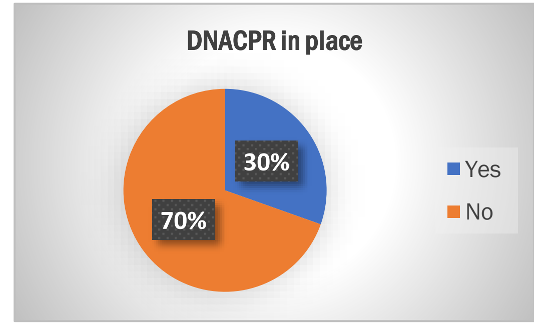
Annual Health Check prior to death

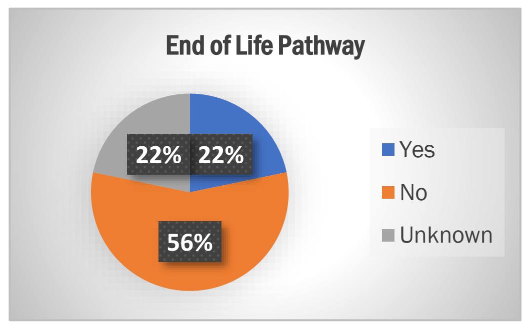
Evidence suggests that providing annual health checks to people with learning disabilities in
primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses. Out of the 23 reviews carried out 19 people had an annual health check within the last year before their death. The 4 reviews that showed an annual health was not completed were either due to be completed or declined.



DNACPR in place

Out of the 23 reviews completed 16 reviews had a DNACPR in place (70%) which is lower than 2021-2022 (82%) and 2020-2021 (83%). The National LeDeR Report (2021) showed that nationally of the 2,662 people that died in 2021 there were 64% who had a DNACPR decision in place at the time of death. This was comparable to 63% in 2018, 63% in 2019 and 64% in 2020.





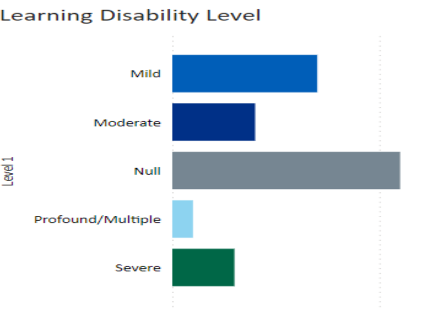
End of life pathway

In 2022-2023 of the 23 reviews 22% of people who died had an end-of-life pathway in place compared to 76% in 2021/22.

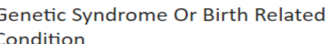
Additional Data for BLMK: Using the NHS England LeDeR Data Tool

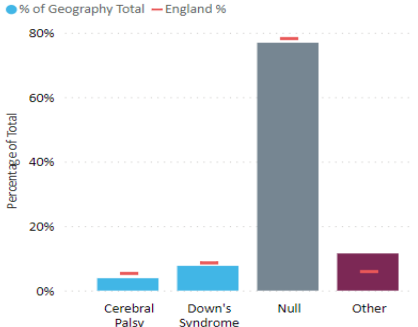
The new LeDeR platform has enabled us to capture further data using the NHS England LeDeR Data Tool. This is a new functionality and currently has captured data from January 2023 – end of March 2023. We are confident this data tool will provide more significant data for forthcoming annual reports. For now, we hope you find this helpful.

Source for all data – NHS England LeDeR Data Tool

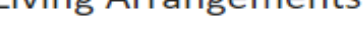


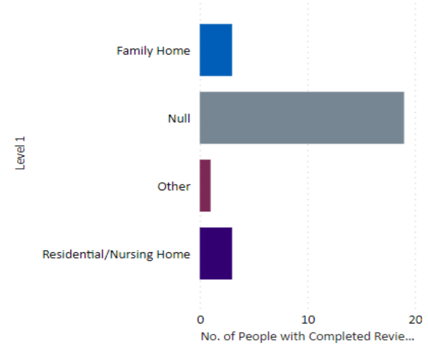
This chart shows the level of learning disability for people for whom LeDeR reviews were completed. The mandatory question "What level of learning disability did the person who died have?" was moved from the focused to the initial review in January 2023. This means that it was not completed for everyone who had a LeDeR review until this time hence the large number of 'null' answers up to this point. Autistic people who did not have a learning disability will also have a null answer to this question.



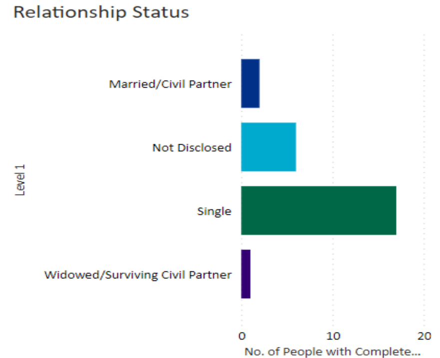


These charts show whether people for whom LeDeR reviews have been completed on the new platform had a genetic syndrome or a birth related condition. The question "Did the person have a genetic condition, syndrome or birth related condition linked to their learning disability?" is a mandatory question in the initial review. This question was moved from the focused review to the initial review in January 2023. The large number of null responses are for people who had an initial review which was completed before this date.

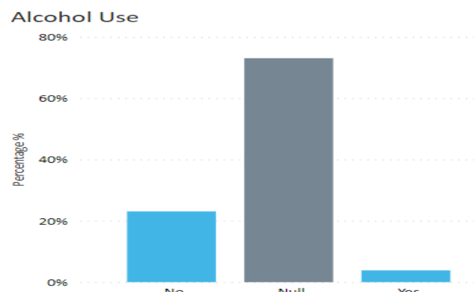




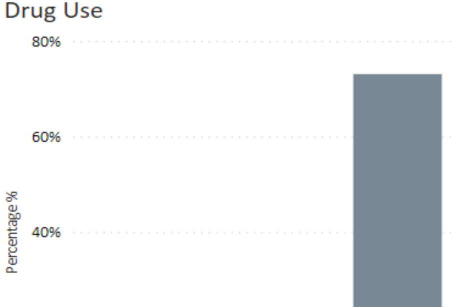
These charts show the living arrangements of people for whom LeDeR reviews were completed on the new platform. The question "what were the person's living arrangements?" is a mandatory question on the focused review. The large number of null responses are for people who had an initial review only.



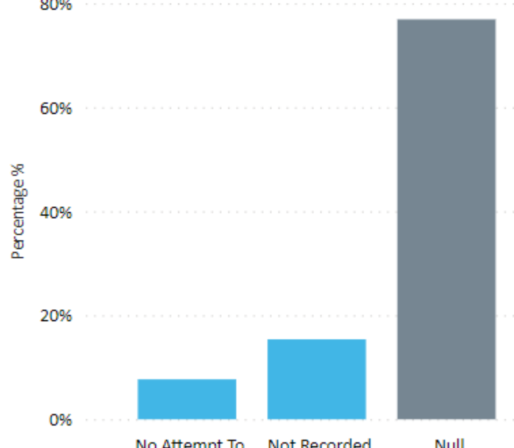
There have been no changes to Relationship Status which combines "Legal marital or registered civil partnership status" and "Did they have a significant relationship, life partner or similar relationship". Current relationship at death that is significant other overrides single and separated.



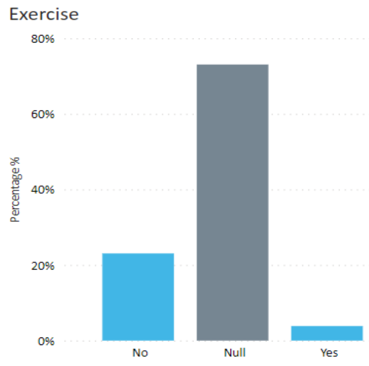
These charts show the alcohol use status of people for whom LeDeR reviews were completed on the new platform. The question "Did the person drink alcohol?" is a mandatory question in the focused review. The large number of null responses are for people who had an initial review only.



This chart shows use of recreational drugs for people for whom LeDeR reviews were completed on the new platform. The data comes from 2 questions "Did the person use cannabis?" and "Did the person use any other recreational drug?" which are non-mandatory questions in the focused review. The large number of null responses are for people who had an initial review only and for people for whom the questions were not answered.



This chart shows use of drug and alcohol services for people for whom LeDeR reviews were completed on the new platform. The question "Was the person accessing drug or alcohol services at the time of their death?" is a mandatory question in the focused review. The large number of responses are for people who had an initial review only.



This chart shows the exercise status of people for whom LeDeR reviews were completed on the new platform. The question "Did the person exercise regularly?" is a question in the focused review. The large number of null responses are for people who had an initial review only.

Appendix Three: Key Learning Themes

Key Themes	Learning
Annual health checks	Improving the quality of annual health checks and the content and communication of health action plans to strengthen the ability to monitoring care. Considering thrombo-prophylaxis for mobility impaired people living with a learning disability.
Cancer screening	Communication between families and carers on 'significant health events' by professionals. Mechanism for best interest decisions when individuals do not want to participate in bowel screening programmes or for participation to be fully supported.
Falls	Service users who experience falls should have a risk assessment undertaken on a regular basis and the impact of mitigating actions in preventing harm should be monitored. Improve education and training for the care provider in relation to falls management. Ensure use and communication of falls risk assessments in provider settings. Ensure that fall prevention strategies are in place and that risk assessments are reviewed following a fall and referrals made to appropriate professionals.
Epilepsy	Regular review for seizure management planning for learning disability patients with epilepsy. Improve education and training for the care provider in epilepsy training. Review the epilepsy pathway and put in place improvements in specialist support in the community setting e.g. community epilepsy service. Improve support for carers of learning disability epilepsy patients.
Dementia Speech and language therapy (SLT)	Ensure appropriate dementia care is available for learning disability service users with dementia. Acute trust to review the PEG decision making pathway and alternatives to PEG insertion. The acute trust to ensure that referrals to community SLT services take place within 48hrs. Timely SLT assessments to take place taking into account cases of rapid deterioration. Care providers to ensure that expertise is available to facilitate remote SLT assessments 5/7. The acute trust to ensure that referrals to community SLT services take place within 48hrs. Timely SLT assessments to take place taking into account cases of rapid deterioration. Care providers to ensure that expertise is available to facilitate remote SLT assessments.
Palliative Care	Raise awareness of palliative care pathway and function of the palliative care hub. Multi-disciplinary Teams (MDT) support in place to promote timely referral to palliative care team. Care providers are aware of palliative care referral pathways. Include social care colleagues in palliative care discussions and planning.
Primary Care	GP home visit and transport to hospital should be arranged for learning disability patients when conditions deteriorate. "Make every contact count" training helps ensure care and support are addressed in a timely manner.
Care Act Assessments	Mechanisms are in place to ensure that all learning disability service users have Care Act assessments carried out by trained assessors with clarification to be sought when safeguarding alerts are raised.

Supporting Carers	Carers to be trained to state a person has a learning disability including level of need. Carers should feel confident to raise issues with GPs e.g. the need for more support. Ensure that cohesive MDT support is in place for carers. Bereavement support should be available for carers and friends within the learning disability community to promote wellbeing. Regular carers assessments should take place in a culturally sensitive way. Risks in relation to carer fatigue should be monitored and recorded. Consideration of advocacy support should be available. A trauma informed care approach should be considered when circumstances arise which make individuals (families) reluctant to access services. Consider how the system can work differently with difficult to engage families.
Acute Trust Pathways	Review more formal arrangements for providing 1:1 support for people with learning disabilities on admission to hospital. Documented sepsis pathway is referenced in medical records. Comprehensive history is taken on admission and training programmes for A&E staff to understand and manage challenging behaviour. Comprehensive medical reviews of the patient's condition takes place during daily ward rounds and treatment plans are in place including access to appropriate diagnostics. Prompt involvement of mental psychology and mental health teams in the acute trust for learning disability patients with a history of mental illness. Comprehensive discharge pathways for people with learning disability including access to rehabilitation. Advocacy support available for patients with a learning disability in the acute trust. Social workers to be informed of hospital discharges.
DNACPRs (do not attempt cardiopulmonary resuscitation)	Process for DNACPRs to be agreed and communicated and implemented across all care settings. Next of kin (NOK) are involved in DNACPR decisions. Relatives understand that treatment interventions continue after DNACPR signed. Ensure DNACPRs are revisited at each admission if they are not indefinite. Acute trusts to review DNACPR orders at an earlier stage when prognosis is poor and learning disability is not cited as a reason for DNACPR.
Treatment Escalation Plans (TEPs)	Treatment escalation plans must be well documented, comprehensive and regularly reviewed.
Safeguarding	Increased awareness for acute staff of the need to raise safeguarding alerts for vulnerable people, particularly when attending A&E. Cases to be referred to the Adult Safeguarding Board under section 44 of the Care Act 2014 when safeguarding concerns identified.
Improving links Between Health and Social Care	Joint care plans to be developed for people with learning disability and mental health needs between health and social care. A clear protocol for delegation of tasks and a mechanism for sharing clinical information between health and social care.
Stroke Pathway	Consider national best practice from the stroke clinical network in managing patients with challenging behaviour who have a cerebrovascular accident (CVA). Mechanism for carers to support clinical decision making relating to emergency interventions following a suspected CVAs. Clear pathway with timeframes to support good use of services when managing life threatening events such as CVAs.
End of Life Pathways	Opportunities are taken to develop advanced care planning e.g. change in care setting or significant changes in care and support needs. Discussions with NOK on plans for admission avoidance, end of life care, ceilings of care and palliative care are in place where necessary in the community setting. Review process for initiation of end-of-life pathways for acutely ill patients with poor prognosis. Support from the palliative care team is in place. Support from NOK/carers as a reasonable adjustment in acute trust settings at end of life. Review the need for palliative care education and training for clinical staff. Once palliative care decisions are made in an acute trust provide appropriate fast track pathways and end of life care in a care home setting where appropriate. Processes are in place to make timely end of life care decisions 24/7. Access to carers and family at the end of life.

Dental Pathway	**Raising awareness by use of existing information, teaching aids and sharing good practice for people with Learning Disabilities and carers for fitting of dentures and oral hygiene.**
Anti-coagulants	**Explore why alternative medication is not considered to prevent blood tests -2 weekly to monitor prothrombin times.**
Deprivation of Liberty Safeguards (DoLS)	**Sustain good practice of processing DoLS applications in a lawful manner. Provide a simple guide for families and carers concerning the implication of DoLS orders that are put in place, including legal implications.**
Mental Capacity Act (MCA)/Best Interest Decision Making/Reasonable Adjustments	**Ensure that when in unfamiliar settings a person with a learning disability has the full range of reasonable adjustments in place including access to those who know them such as family or carers. Ensure MCA assessments and best interest decision making processes are clearly documented in all care settings. Ensure that MCA assessment takes place prior to procedures and best interest decisions are recorded. If unable to undertake the full MCA process, engage in early discussions with NOK and document best interest decisions. Reasonable adjustments provided when examining and taking history from learning disability patients in acute trust settings and ensure that appropriate records are made. Strengthen best interest decision making process to improve families understanding and ensure they feel their views are considered.**
Care Providers	**Care providers understand service user's family tree and preferred contact details. Families are notified when a service user becomes unwell, in line with MCA / best interest decisions. Registered managers to draft protocols, including timeframes. Care provider on-call records/handover should be completed each night and on-call protocols reviewed considering delays in escalating deteriorating condition. Supported living staff to record reason for PRN medication in notes and charts, this should be linked to PRN guidelines. Case notes are detailed, descriptive and record full details of events including times of events. Staff signing notes to ensure that initial and name is printed in capital letters. Appropriate monitoring of temperatures should take place. Hospital passports or equivalent are regularly reviewed and kept up to date. Social worker or GP is informed when learning disability patients decline assessment. Consider how communication with carers from the acute trust can be improved, thereby improving support from carers.**
GP Practices	**GP practices to consider the benefit of having a learning disability lead who could act as a point of contact for the multi-disciplinary team caring for learning disability patients. Clarity around processes for formal LD diagnosis and details of thresholds and referral pathways to access specialist services. Exploring all options to support patients to reduce Body Mass Index (BMI).**
Safeguarding Section 42 Reviews	**Adult safeguarding team should receive assurance on recommendations from the Section 42 Safeguarding Enquiry relating to the care home have been implemented. Evidence that all necessary changes that need to be embedded are obtained through a follow-up assurance visit. Outcomes of safeguarding referrals should be fed back to referrers.**
LeDeR Reviews	**Processes to ensure that care home records are completed, stored and are available for LeDer reviews. Processes to ensure that GPs understand LeDer information requests and can respond appropriately. Ensure that standards of care are reflected in interviews and are adopted across the system.**
Emerging Health Needs	**Care co-ordination and risk stratification models to be implemented when care needs increase. An MDT approach to be used to explore the full range of options to meet care needs. Pathways enable management of complex conditions in the community setting including end of life care with access to acute services for specific interventions only if necessary. MDT approach should be implemented when families make frequent contact with health services in order to determine how to meet new/emerging health needs.**

Health and Social Care Alignment at the Point of Transfer of Care	**When a service user is moved into a residential home from another area, they should be added to a central register of people with LD living in the area, which can be accessed by health and social care.** **Transfer information and care and support plans form Local Authorities must be routinely communicated to all relevant agencies.** **Transferring providers should ensure that comprehensive transfer information is provided to receiving services.** **Health and care providers to be made aware of county boundaries and responsibilities set, including implications for transfer of care.**
Health Commissioning	**Review access to acquired brain injury specialist care.** **Arrangements for continuing health care (CHC) funding to seamlessly follow the patient into a hospital setting to meet specific needs in the community.** **Specialist and complex CHC care provision and contract arrangements should be reviewed to enable skilled carers to follow service users across all care settings.** **Ensure access to PHBs is available.** **Undertake market shaping to develop specialist care to meet complex need out of hospital and in a local setting.** **Provide information to GP practices concerning what community services are available for people with learning disabilities, including thresholds for referral and referral pathways.** **GP records are transferred between GP practices efficiently.**