Manchester Health & Care Commissioning
A partnership between Manchester City Council and NHS Manchester CCG

NHS Manchester Clinical Commissioning Group

Annual Report

Manchester Learning Disabilities Mortality Review (LeDeR) programme

2020

Report written by:

Manchester Health and Care Commissioning on behalf of the Manchester LeDeR Steering Group

Contents

Forward from David Regan and Dr Manisha Kumar

This is the first published annual report describing the LeDeR programme in Manchester.

Any death, irrespective of the circumstances, is a sad event for the families and the carers of the person who has passed away. What this report represents is the work that Manchester Health and Care Commissioning, together with health and care providers, are doing to understand how to help people with learning disabilities live longer lives, with better experiences of health and care services at all stages of their lives, so that they and their families have positive outcomes.

Whilst we are proud of our primary care, community and hospital services in Manchester, particularly this year that has posed the ultimate challenge with COVID-19, there is still much to do to make sure that we reduce the inequalities in health experienced by some communities of people, and to prevent the conditions and diseases that cause premature death, which includes people with learning disabilities as well as their families.

We hope this report conveys the dedication, commitment and care demonstrated by all the commissioners, health and care professionals and voluntary and community sector, working across the service system in Manchester, in partnership with people with learning disabilities and their families.

We wish you all to be safe, supported and have good health.

David Regan

Executive Director of Population Health and Nursing (Manchester Health and Care Commissioning) and Director of Public Health

Dr Manisha Kumar

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Introduction

Manchester Health and Care Commissioning (MHCC) is a single commissioner for health and social care, comprising a partnership between NHS Manchester Clinical Commissioning Group and Manchester City Council.

This is the first report on the Learning Disabilities Mortality Review programme1 (known as LeDeR) and will give an overview of the national LeDeR programme, programme delivery in Manchester, findings from the mortality reviews of Manchester people and the plan for supporting improved outcomes and experiences of people with a Learning Disability.

The LeDeR programme uses the definition of learning disabilities provided in the 2001 White Paper "Valuing People"[2]:

> *"A person with learning disabilities will have:*
>
> - *A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence) and*
> - *a reduced ability to cope independently (impaired social functioning)*
> - *which started before adulthood, with a lasting effect on development."*

Purpose of this report

The Learning Disabilities Mortality Review programme (known as LeDeR) is a unique national programme that aims to impact on the lives of people with learning disabilities in England by driving improvements in the quality of health and social care services delivered to them. It does this by exploring why people with learning disabilities typically die much earlier than people who do not have learning disabilities.

The overall aims of the programme are:

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

[1] http://www.bristol.ac.uk/sps/leder/

[2] http://www.bristol.ac.uk/media-library/sites/sps/leder/leder---briefing-papers/Briefing%20paper%201%20-%20What%20do%20we%20mean%20by%20learning%20disabilities%20V1.2.pdf

- To help reduce premature mortality and health inequalities for people with learning disabilities.

The programme was established in 2015 by NHS England in response to the recommendations of the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD, 2013). CIPOLD found that people with learning disabilities are three times more likely to die from causes of death that could have been avoided with good quality healthcare compared to people in the general population. More recently, analysis of data from the Primary Care Research Database suggested that the all-cause standardised mortality ratio for people with learning disabilities was 3.18, and that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.

The NHS Long Term Plan (published 2019) made a commitment to continued funding for the LeDeR programme to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people. LeDeR is now a permanent and mandated programme supported by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). People with learning disabilities along with their families and carers have been central to the development and delivery the programme. All personal information is protected in accordance with the General Data Protection Regulations.

The programme complements and contributes to the work of other agencies such as Public Health England, academic research studies, National Institute for Health and Care Excellence, the Care Quality Commission inspection programme, Local Government Associations, the Transforming Care Programme, as well as third sector and voluntary agencies.

A key element of the programme is to support local areas to review the deaths of all people with learning disabilities aged 4 years and over using a structured review framework. The University of Bristol provides the technical support for the programme ensuring that all death notifications are allocated to the relevant Clinical Commissioning Group (CCG) Local Area Contact (LAC) via the LeDeR platform. Local reviews are conducted to:

- Identify good practice and what has worked well.
- Identify potential avoidable factors and unwarranted variations in care in order to prevent early and avoidable deaths.
- Make recommendations and create a lessons learned culture to underpin local systems based action plans that directly address the factors that lead to premature deaths as well as improve overall health and social care for people with learning disabilities.

In completing an Initial Review, the reviewer will try to speak to a family member. If there are no family members who can contribute to the review the reviewer will try to talk to someone who knew the person well, which might be a carer or professional. This helps to build a pen picture of the person who has died. The reviewer will also liaise with

professionals who were involved with the person, such as the GP or Social Care providers, and review case notes to look for evidence of good practice or gaps in care.

If the initial review identifies any areas of concern or potential for further learning from a multi-agency review of the death that would contribute to improving practice, the death is subject to a formal panel review involving parties and individuals who were involved in the care of that person.

CCGs are responsible, through their LeDeR Local Area Contact (LAC), for ensuring that their LeDeR reviews are carried out on time and for assuring the quality of those reviews. North of England Commissioning Support Unit (NECS) has been commissioned by NHS England to carry out some reviews on behalf of CCGs to support timely completion. Each CCG area should have in a place a local LeDeR Steering Group comprised of partners from across the health and social care sector which is responsible for developing and overseeing local plans that are aimed at improving the care and treatment of people with learning disabilities.

Deaths of children aged 0 to 17 years are subject to the statutory child death review process. The LeDeR programme is not required to review the deaths of children with learning disabilities in addition to the statutory review process. However, LeDeR reviewers should engage with the child death review process and arrange for the final report from the child death review panel to be shared if appropriate with the LeDeR team in order to collate and evaluate findings.

The University of Bristol analyses and reports on all completed reviews so that common themes, learning and recommendations can be used to inform national policy and practice improvements. The fourth national annual report of the LeDeR programme[3] was published in July 2020 indicates that the majority of people with learning disabilities continue to die before reaching the age of 65. In the general population, 85 per cent of deaths happen at or after the age of 65, but in sharp contrast this is the case for just 37 per cent of people with learning disabilities ([4]previous reports and easy read versions).

Of the deaths notified to the national LeDeR programme in 2019, two-fifths of adults and almost a quarter of children died from pneumonia, an illness which is normally treatable in this country. These figures are very similar to the figures for deaths caused by pneumonia published in the University's two previous annual reports. This report presents findings from 3,195 reviews of deaths of people with learning disabilities notified to the LeDeR programme up to 31st December 2019, with a focus on information about the 2,126 deaths reviewed between 1 January and 31 December 2019.

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[3] http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

[4] http://www.bristol.ac.uk/sps/leder/easy-read-information/annual-reports/

Professor Pauline Heslop, the LeDeR programme lead at the University of Bristol, said: "Pneumonia and aspiration pneumonia remain the most frequently reported causes of death, with little change over the past year. This is concerning as they are causes of death which could be preventable, as well as treatable. Addressing these causes of deaths remains an urgent priority. The disparity between people with learning disabilities and the general population in relation to average age at death, causes of death, and avoidable causes of death remains substantial and urgent action is needed."

It is important that there is an open and transparent exchange of information between health and care services, the people who use these services and their families, and the public. This report is the first step in establishing that communication line.

The timeline for the production of the Annual LeDeR report for Manchester this year has been affected by COVID-19, which has also precluded the full engagement of people with learning disabilities and their families and the Manchester LD Programme Board with the Manchester LD Good Health Group having been recently constituted. However, an easy read version of this report has been produced. Engagement with various groups and Boards regarding this report over the next few months will inform next year's (2021) refresh.

Patient and Public Voice

An integral part of the LeDeR process is to give family members an opportunity to discuss their experiences and any learning they would like to highlight. Family involvement in reviews is desirable, however, time-lags for some outstanding cases has made assuring this difficult. Of the 45 adult reviews completed during this reporting period, family involvement was only achieved in 6 cases. Reasons for family not contributing to the review included no family being involved or contact being inappropriate usually due to their own ill health. In a number of cases the family could not be contacted as contact details were not available and due to time lag between the person's death and the completion of the review, referrers could not be contacted to obtain correct information. More timely completion of the reviews should help to promote better contact with family.

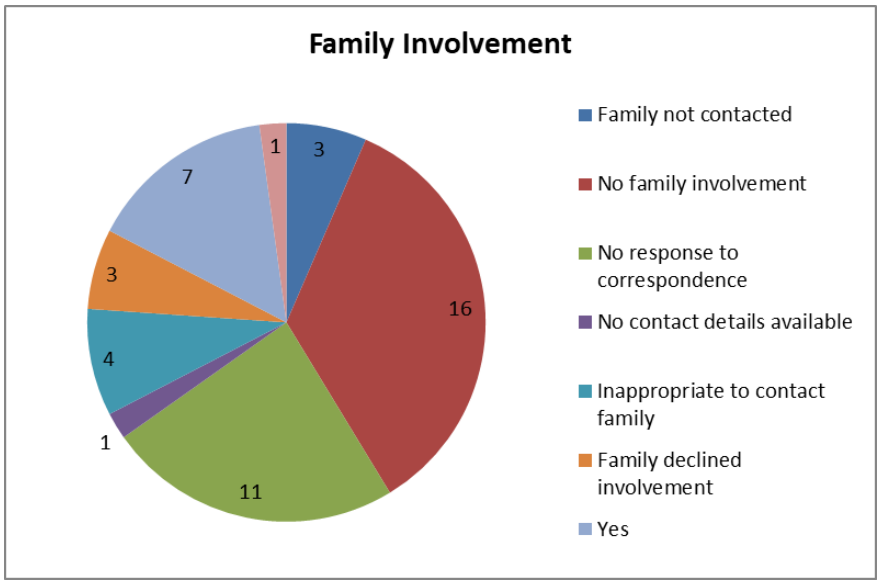


Figure 1 - Family Involvement

As well as trying to involve family members every effort was made to liaise with professionals and carers who knew the person well and were able to help reviewers develop a pen picture of the person and a deeper understanding of their lives.

In future we want to ensure that people from the Learning Disability community and their families are able to actively contribute to and support oversight of the LeDeR programme in Manchester. This will be achieved through the Manchester LeDeR Steering Group and interface with other relevant work programmes including the Manchester LD Programme Board and Manchester LD Good Health Group.

Below are some quotes that have been extracted from pen portraits of people who lived in supported accommodation where family involvement was not prevalent.

> *""The person" loved to look smart having a daily shower choosing her clothes carefully and having matching jewellery and her bangles, her hair had to be combed and look good … Things that made "the person" happy were going out anywhere, shopping for clothes and jewellery and soap, visiting the seaside and the Donkey sanctuary she also loved dogs, she loved to write in her book".*

> *""The person" loved to go out walking and had in the past been on walking holidays with staff. He had a disability car and loved to go out with staff insured to drive him. Often his trips were to the Local Pub for a beer and a pie or cheese on toast. He loved painting and many of his art works are still in the home where he lived until his death".*

Governance arrangements

LeDeR forms part of national deliverables for Transforming Care for People with Learning Disabilities. Four assurance statements related to LeDeR were included within the NHS Operational Planning and Contracting Guidance 2019/2020. These are:

- CCGs are a member of Learning from Deaths (LeDeR) steering group and have a named person with lead responsibility.
- There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.
- CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.
- An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.

In Manchester the MHCC Head of Nursing holds the Primary Local Area Contact (LAC) accountability, leadership and oversight role for LeDeR activity, with the MHCC Lead Nurse as secondary LAC. Together they oversee the assignment, completion and Quality Assurance of reviews as well as collating learning from the reviews to inform system developments.

The Manchester LeDeR Steering Group was established in December 2019 to bring together partners from across the health and care sector to provide a strategic mechanism through which the aspirations of the Learning Disability Mortality Review (LeDeR) programme will be achieved in Manchester. The group, chaired by the MHCC GP Clinical Lead for Learning Disability and Autism, has established Terms of Reference and has agreed a priority plan for 2020-21 based on the learning from the reviews we have undertaken in Manchester.

The organisations represented in the LeDeR Steering group include NHS Manchester Clinical Commissioning Group (Nursing, Clinical, Medicines Optimisation, Commissioners, Safeguarding, Quality, Engagement and Communication leads), Manchester University NHS Foundation Trust (Nursing, Governance, Patient Safety and Quality leads), Manchester Local Care Organisation (Nursing, Quality, Service leads), Manchester City Council (Social Care, Safeguarding leads), Greater Manchester Mental Health Foundation Trust (Clinical Governance and Patient Safety leads) and Greater Manchester Health and Social Care Partnership Quality lead.

Representatives from the voluntary and community sector and people with lived experience are currently being scoped to provide input into the Steering group, however these people are also being asked to join other related partnership boards and governance arrangements, so ways are being looked at to ensure that people's time is being used effectively.

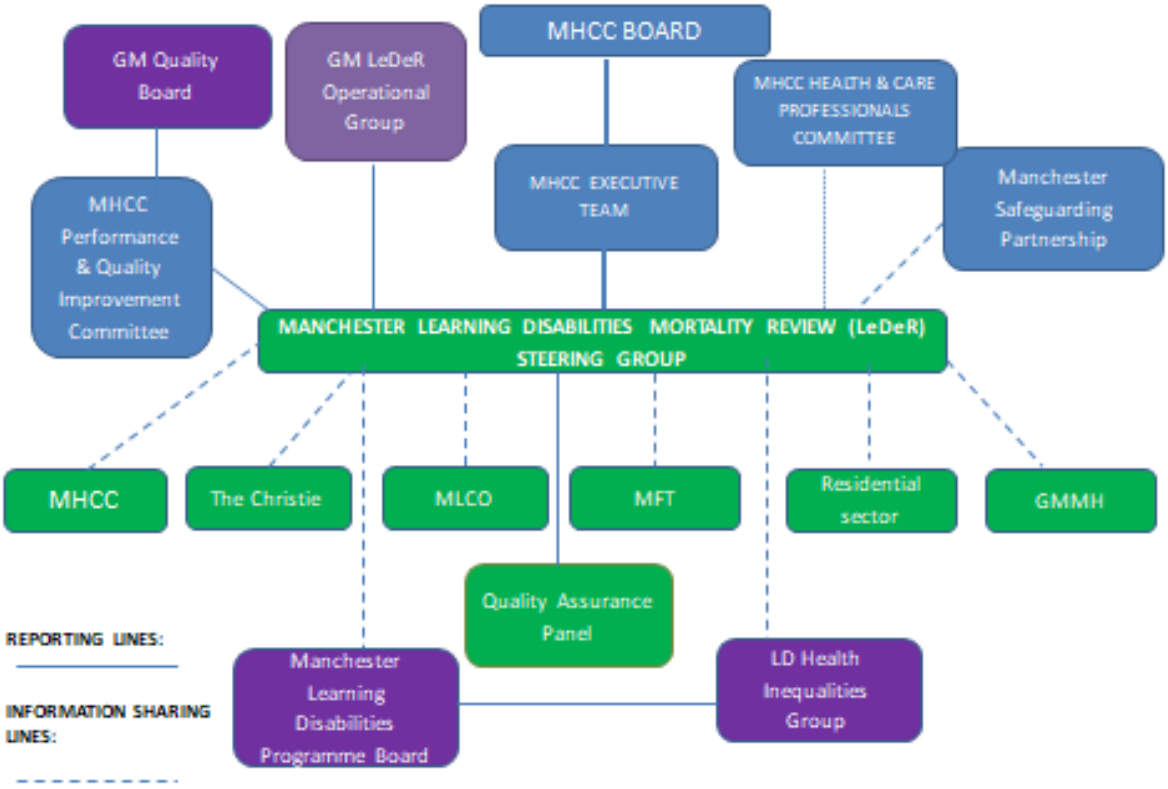
A Quality Assurance Panel (QAP) has been established to support the LACs in assuring the quality of reviews by:

- Initiating professional curiosity in evaluating the circumstances and contributory factors related to the death of the individual
- Utilising a consistent approach in assessing the quality and level of care that the individual experienced leading up to their death
- Identifying patterns and themes related to factors that were causal or contributory to deaths of individuals across the cohort
- Highlighting areas where good or exemplary practice was implemented
- Agreeing cases that meet the LeDeR criteria for Multi-Agency Reviews

The QAP reports into the Manchester LeDeR Steering Group, providing local and national information to support a systemic learning cycle that will enable sustainable improvement.

The below structure describes the reporting and information sharing arrangements of the Manchester LeDeR Steering Group and the relationship between this group and the Greater Manchester system.

Figure 2 - Manchester LeDeR Steering Group Governance

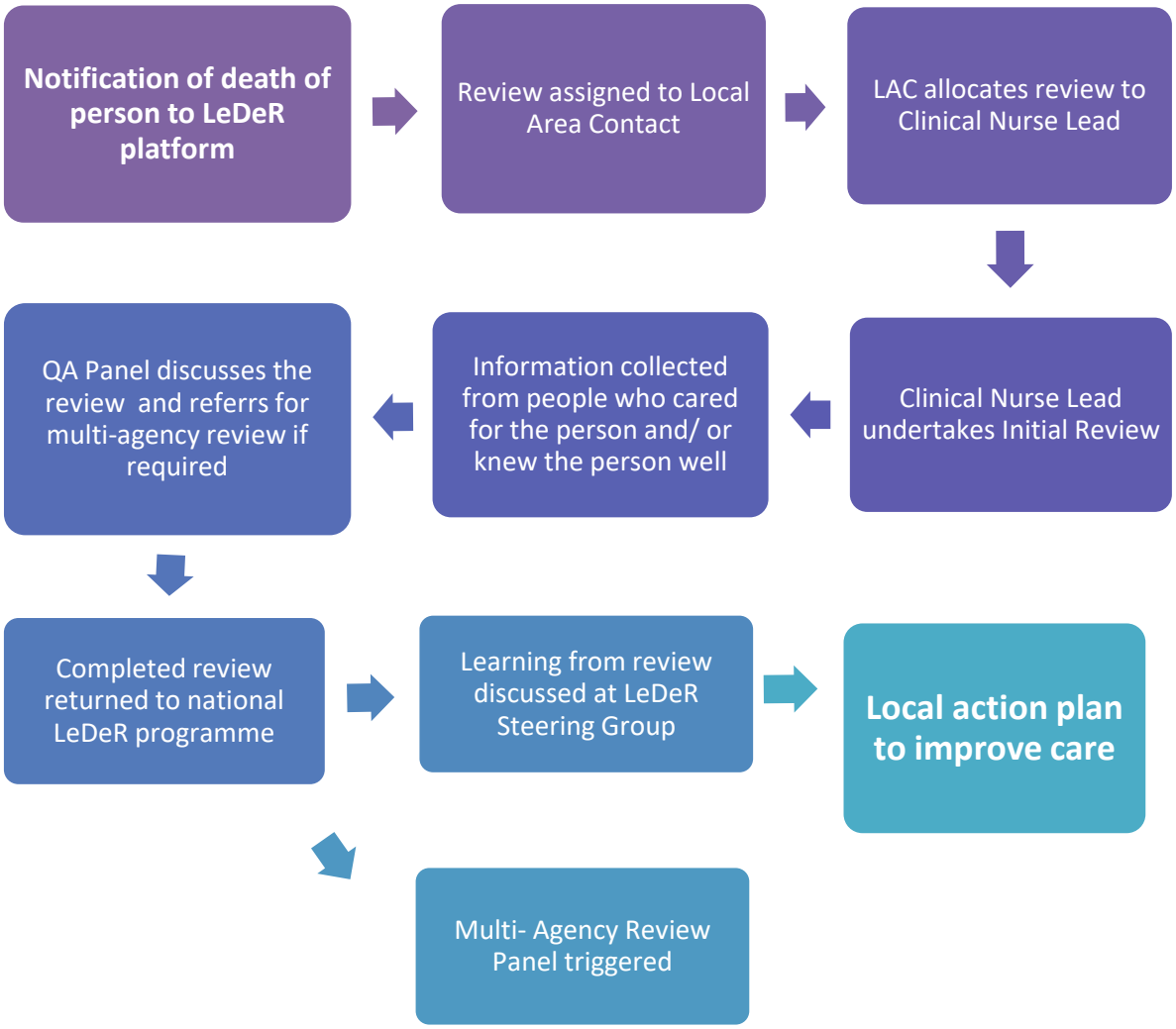


During 2019-2020 the priority for the Manchester LeDeR programme was to ensure that all reviews due were completed by the end of March 2020. (Reviews must be undertaken

within 6 months of notification to the local area contact via the LeDeR platform). Reviews were initially undertaken by community nurses who, due to the responsibilities of their substantive posts were unable to give them the priority required. This was followed by a short term MHCC seconded post which provided a focussed approach to reviews being completed in a timelier manner. Nationally, at this time there were a number of outstanding cases awaiting review. Manchester has focussed resources into expediting these cases within the agreed timelines.

MHCC made the decision to match NHS LeDeR funding in order to establish a dedicated Clinical Nurse Lead for Learning Disabilities to undertake all reviews for Manchester people as well as support quality improvement for the LeDeR programme. This has enabled better, more consistent oversight of reviews and their progress and a quicker response to new cases. As a result, almost all reviews (excepting those subject to ongoing statutory reviews) due by 31st March were completed. We have therefore been able to analyse the findings and collate recommendations to inform our strategic priorities.

Figure 3 - Summary of the LeDeR process in Manchester



In order to embed Multi-Agency Review Panels (MARPs) into the local review process, a local protocol will be established by the Quality Assurance Panel on behalf of the LeDeR Steering Group, that will ensure consistency in triggering MARPs, the process of enquiry utilised and formulations related to quality of care, irrespective of the deceased's history and location of death. This will be developed by end October 2020 as part of Manchester's Implementation Plan going forwards.

Analysis of deaths

The information below includes all deaths of people notified to the Manchester LeDeR programme that are due a review by 31st March 2020 (that is all notifications up to 30 September 2019). In total the deaths of 59 people were notified, 46 of these were adults and 13 were children. The deaths occurred between March 2017 and July 2019.

Place of deaths

42 (71%) people had died in hospital. This is higher than the rate recorded in the national Annual Report which found that 62% of deaths occurred in hospital compared to 46% in the general population. This might indicate that in Manchester some deaths in the community are not being notified to the programme.
Other issues to be considered include unmet healthcare needs, effective advanced care planning and gaps in primary care support for Supported Accommodation and Extra Care facilities.

Causes of death

The national LeDeR annual report listed the following as the most frequently cited causes in part 1 of the death certificates for those aged over 18:

- Pneumonia
- Aspiration Pneumonia
- Sepsis
- Dementia (syndrome)
- Ischaemic heart disease
- Epilepsy

In Manchester the most frequent causes of death for adults were similar:

- Pneumonia
- Cancer
- Aspiration pneumonia
- Sepsis (urosepsis/ bronchosepsis)
- Ischaemic heart disease (of particular concern when considering Manchester's poor outcomes for Cardiovascular disease)

Although epilepsy was only the cause of death for 1 Manchester person it was also recorded as a contributory factor for 3 other people. Similarly, dementia was found to be a contributory factor for 3 Manchester people.

Children

In line with the “Child Death Review: Statutory and Operational Guidance (England)” once the Manchester Child Death Overview Panel (CDOP) is notified of the death of a child aged 4-17 years who has learning disabilities, or is very likely to have learning disabilities but not yet had a formal assessment for this, the information is shared by reporting the death to the LeDeR programme. The Manchester CDOP reports deaths of children to LeDeR via the online referral form and provides core information about the child.

Additional CDOP documentation containing details regarding the circumstances leading to death is submitted to the LeDeR Local Area Contact. Once all investigations have concluded and sufficient information has been collated to ensure the CDOP can undertake a comprehensive review, the Manchester CDOP invites a Manchester LeDeR representative to attend the panel meeting at which the death is reviewed.

During the CDOP meeting, the LeDeR representative may offer advice and expertise about learning disabilities (if appropriate) and ensure that the CDOP provides sufficient core data to support the LeDeR programme. Once the Manchester CDOP has completed the review, documentation is submitted to the LeDeR Local Area Contact. This includes the final Analysis Form which highlights:

- Common contributory factors leading to deaths
- Factors that may have contributed to the vulnerability, ill health or death of the child
- Modifiable factors that may reduce the risk of future child deaths
- Learning points and issues identified in the review
- Recommendations and actions that may inform and support local, regional or national learning

This information is submitted to the LeDeR platform and themes and trends are collated for the city.

Of the children who had died (2019/2020), all had severe learning disabilities as well as life limiting illnesses. During this time, 8 children were notified to LeDeR, their ages ranged between 6 years to 15 years. The summary analysis indicates:

Ethnicity:
Three were White/British, four were BAME and one other whose ethnicity was not specified in the reporting.

Likely causes of death included:
Malignancy

Acute medical or surgical condition
Chronic medical condition
Chromosomal, genetic and congenital anomalies
Perinatal/neonatal event

Positive Practice identified:
Advanced Care Plans with RESPECT document completed.
Personalised End of Life Care
Allocated/Named GP
Bereavement Support from Palliative Care Team
Open access to hospital paediatric care.

Other critical factors to note for adults

A high number of local reviews undertaken for adults found the following clinical features:

- Medication for constipation
- Diabetes
- High BMI – where recorded.
- Dysphagia

Of the 46 adult cases reviewed during the period of 2019/2020, 14 people were found to be prescribed psychotropic medicines. These are medications that affect the brain and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. This number might be higher as some of the earlier reviews undertaken did not include lists of medication. Nationally, the STOMP agenda (Stopping over medication of people with a learning disability, autism or both) was launched in 2016, and acknowledged that prescription of psychotropic medications in adults with learning disabilities was often disproportionate and can lead to physical health problems. There is continuing work locally on the STOMP agenda via the Manchester LD Good Health Group.

Manchester Learning Disabilities Good Health Group

As well as being a key element contributing to the national strategy for Learning Disabilities, LeDeR is a critical element of Manchester's response to the Greater Manchester Learning Disability Strategy (see Appendix), under the priority of "Good Health: Reducing Health Inequalities". Local implementation plans in response to the GM Learning Disability strategy will be performance monitored under the NHSE Improvement and Assurance Framework, including LeDeR.

LeDeR is one of a number of important influences and relationships that will drive this working group as demonstrated by the graphic below:

Figure 4 - Good Health: Manchester Learning Disabilities Health Inequalities Working Group

A number of the other areas in the wheel above are indicated as actions and improvements from local as well as national reviews and are discussed in more detail later in this report. This is not the only group and structure that exists in Manchester to address these health-related issues, but it is a comprehensive representation of some of the critical improvements required.

The Manchester Learning Disabilities Good Health Group is developing a formal health promotion strategy for people with learning disabilities, to address gaps in information and support access to screening in cancer, testing for diabetes, recognising and treatment of constipation and information about reducing obesity. There will also be work with commissioners to better understand the current provision of Speech and Language support in Manchester.

Our action plan

From the reviews undertaken there was evidence of positive practice. However, there were also indications of inconsistencies in care. The key themes found from the reviews are summarised below together with the response/actions that will be taken forward by the Manchester LeDeR Steering Group during 2020/2021:

Mental Capacity Act (MCA)

There were some examples of cases where the MCA had been used appropriately to underpin delivery of care. This included undertaking Best Interest (BI) assessments to support Do Not Attempt Resuscitation (DNAR) decisions). However, there were a number of examples of cases where the use of the MCA and BI decision making was not evident in case notes. Whilst it is recognised that MCA training has been rolled out across services its reviewers frequently recommended this as an action.

Response: The Manchester LeDeR Steering group will ensure staff awareness and appropriate use of the MCA and Best Interest decision making across health and social care providers.

Communications

There were some good examples of communication between different services and also between services and families. In a few cases hospitals had worked well with social care providers to ensure that somebody familiar was with the person at the end of their life. However, there were also a number of examples of cases where communication could have been improved. Social Care providers have reported that hospitals do not always appear to value the knowledge that they have about the person, and their preferences. This means that opportunities for personalised care are missed. Reviews also found that use of hospital passports was patchy.

Response: The Manchester LeDeR Steering group will establish what worked well in cases where there was positive communication and agree across the system to establish that approach as the template.

Reasonable adjustments

In a number of cases reviewers recommended improved training about Learning Disability due to an apparent lack of understanding about the needs of people with Learning Disabilities amongst healthcare staff. This would also help to support communication with families and between providers. Reviewers also noted that in some cases diagnosis of Learning Disability was late and meant that effective care provision was delayed. In one case a referral made by a GP did not include information about the person's disability and therefore access to the service was delayed.

Some of the reviews found minimal evidence of reasonable adjustments having been made as part of healthcare delivery. Healthcare providers are required to make reasonable adjustments for disabled people to make it as easy for them to use health services as it is for people who are not disabled. Although it is likely that reasonable adjustments had been made in a lot of cases recording of these was not evident.

Response: The Manchester LeDeR Steering Group will work with primary, community and hospital providers to ensure that reasonable adjustments for people with learning disabilities is properly understood as a holistic approach.

One review found an excellent example of use of a Learning Disability care plan in a hospital which enabled effective, personalised care planning. However, in another case the use of standardised care plans was noted which meant care was not well tailored to the person's needs.

Response: The Manchester LeDeR Steering Group will work with the Manchester Learning Disabilities Programme Board to ensure that all health and care providers establish an agreed minimum standard of knowledge and awareness of the needs of people with learning disability across all staff cohorts.

End of life care

Reviewers found some excellent examples of care with evidence of personalisation, for example, where people have been admitted to hospital but their wishes to return home being respected with a full package of support so that they can comfortably end their lives in a familiar environment. However, there were some inconsistencies in cases of end of life care and reviewers have recommended more training in end of life care particularly for people with Learning Disabilities.

Response: The Manchester LeDeR Steering Group will work with primary, community and hospital providers to ensure that end of life care for people with learning disabilities is properly understood and is provided with respect and dignity.

Annual health checks

All people with Learning Disabilities aged 14 and over should be offered an annual health check (AHC) through their General Practice. The AHC aims to establish trust, identify any previously undetected health conditions early, ensure that ongoing treatments are appropriately managed and ensure good continuity of care. Reviewers found that in a number of cases AHCs were not evident within GP records. Completion rates were higher in the more recent reviews reflecting the work undertaken in Primary Care to promote the checks outlined in more detail below. However, there were still some gaps and where AHCs were completed, a Health Action Plan (HAP) was not always evident.

Response: Linking into the Manchester LeDeR Steering Group, the LD Good Health Group will work with GP practices to increase Annual Heath Checks (targets are 67% in 2020/21, rising to 75% in 2021/22) and also ensure that Health Action Plans for people with learning disabilities are also completed, and copies given to people with learning disabilities and their families. This action is also aligned to the identification of people with learning disabilities who should be added to the Learning Disabilities Register to ensure that as many people as possible can utilise all available health improvement opportunities and offers such as Annual Health Checks and Flu vaccinations.

Early Warning Scores/Recognition of Deterioration

In two cases there was evidence in hospital records that observations had not been recorded well or the Early Warning Score that identifies clinical deterioration was not used appropriately and recommendations were made in respect of these. These cases were from the earlier reviews and it is acknowledged that more recently training around recognition of early deterioration and sepsis has been rolled out within hospital settings.

Response: The Manchester LeDeR Steering group will work with hospitals to review effectiveness of training in this setting.

Our priorities 2020/21

The following priorities for the Manchester LeDeR Steering Group have been identified, based on themes and recommendations from local reviews as well as findings, and recommendations from the national LeDeR programme. They form the basis of the Manchester LeDeR Action Plan for 2020/2021:

Mental Capacity Act (MCA): The MCA and associated processes (such as determining the Best Interest for an individual) is a legal requirement underpinned by Human Rights Law. We must ensure that all decisions made in respect of care and treatment of people with Learning Disabilities are made within this legal framework and are in the person's best interests. Gaps in application and recording of the MCA have been a common theme in reviews both locally and nationally. Therefore, we need to strengthen training and audit processes to ensure all health and care professionals have a robust understanding and can apply this properly in their practice.

Personalised Care/ Communication: There needs to be a better understanding of the importance of person-centred care for people with learning disabilities that includes everyone having a communication passport that all professionals in whatever setting refer to regarding that person's needs and wishes.

Understanding and application of Reasonable Adjustments across the health and care system: Wider promotion is required across the health and social care system of the need for reasonable adjustments and how these can be implemented in different settings.

Increase in Annual Heath Checks and Health Action Plans: These need to be linked to ensuring that everyone with learning disabilities who has had an Annual Health Check receives a Health Action Plan that is also made available to the person and their family.

Establish a specific Health Promotion programme that helps people with learning disabilities, and those who care for them to understand early indicators of Cancer and the importance of accessing timely cancer screening.

Increase uptake of Flu vaccine by people with learning disabilities in order to reduce risks of pneumonia, as well as reducing increased risk of contracting the coronavirus infection.

Early recognition of deterioration – this will be linked to the rollout of RESTORE2 training across Manchester homes overseen by the Care Home Strategic Board work projects, Clinical Pathways leads in conjunction with Supporting the Workforce leads.

Our strategic plan 2020/2021

Below is a summary of the progress of the Manchester LeDeR Strategic Plan 2020-2021 against key actions:

Area	Progress
Steering Group	Bi-monthly meetings have been established. These have been temporarily paused between March and June in order to focus on COVID however these have now been stepped back up.
Complete reviews of all outstanding cases due by 31 March 2020	This has been achieved and now working towards the new target of 31st December 2020 for remaining review backlog.
Robust plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of the death	A Clinical Nurse Lead post was established to undertake reviews as well as provide support to the Manchester LeDeR Steering Group Some disruption has occurred due to COVID-19 including access to hospital and GP records. Plans are in place to re-start access.
Process in place to analyse and address the themes and recommendations from completed LeDeR reviews	Quality Assurance Panel (QAP) is well established, themes and recommendations have been analysed. The QAP will implement robust analysis and development of SMART actions for recommendation to the LeDeR Steering Group.
Mental Capacity Act/ Implementation of Best Interest decision-making	Establish access across the system to appropriate MCA training and monitoring of same including Primary Care.

Learning Disability Awareness Training – including personalised care, communication with families/ between health/care providers	Collate information on what has been provided in hospitals and across the community. Evaluate and assess the impact. Support the use of Communication passports through awareness raising. Consider establishment of minimum standard for all health and care staff.
Annual Health Checks	Work has been undertaken to improve uptake of this primary care standard. Ongoing work, adapting to the pressures and increase demand for remote working during the Covid-19 pandemic, is planned to address the completion of Health action plans with a focus on health promotion.
Reasonable adjustments	Reasonable Adjustment Flag to be incorporated on electronic patient records.
Early recognition of deterioration/ sepsis	Continue work on NEWS2 in hospitals and primary care, RESTORE2 will be embedded within care homes and the residential setting.
Further promote Flu immunisation uptake	Develop plan to promote this in collaboration with Manchester Flu Group.
Promote Infection Prevention and Control Training to staff in residential settings for people with learning disabilities	Develop plan to adapt and cascade training that was delivered for Care Homes in May 2020 (also revisit IPC training already delivered to care homes) and expand to all social care settings.

Partner health organisations

Manchester University NHS Foundation (MFT) in accordance with the National Guidance on Learning from Deaths, has a robust mortality review governance, which include specialist clinical review groups, one of which focusses on Learning Disabilities. Manchester Local Care Organisation oversee the NHS community services in Manchester, including the Community Learning Disability Service, and lessons learned form part of hospital mortality reviews, Safeguarding Adult Reviews or serious incident process in primary care.

The MFT Learning Disabilities Steering Group (chaired by MLCO Chief Nurse) which covers Children's and Adult's Health (community and hospitals) is supporting the health actions and deliverables related to learning disabilities across these sites and is firmly linked into the Manchester LeDeR Steering Group and vice versa.

Black, Asian and Minority Ethnic communities

The involvement of people with lived experience and engagement with Black, Asian and Minority Ethnic (BAME) communities to ensure plans and actions are relevant and targeted, is a critical objective of the LeDeR Steering group. We know that BAME communities are disproportionately affected by COVID-19, and that applies to health inequalities in general. Adding the risk of diagnostic overshadowing (described as when a health professional assumes that the behaviour of a person with learning disabilities is part of their disability without exploring other factors such as biological determinants, and risking other co-existing conditions or problems remaining undiagnosed) places people from these communities at even higher risk.

It is important that all professionals involved in a person's healthcare sees the person first and the disability second, so people with lived experience and those from BAME communities can help professionals develop a language and approach that will support accurate diagnosis and timely interventions.

We will be establishing a voluntary and community sector partnership group with a focus on co-production and engagement with people living with a learning disability from BAME communities that will work across the health and care system in Manchester.

Outcomes and achievements related to improving health

Primary care

NHS England and NHS Improvement developed an action plan in response to the National LeDeR 2018 annual report, with the GP annual health check cited as a core component to identify and tackle unmet health needs. Since inclusion of learning disability within the Manchester Primary Care Standards in 2017 (with financial incentives on their completion), there has been a sustained improvement in the uptake rate of the Learning Disability Annual Health check. The 'Primary Care Standard – Learning Disability Audit' report, conducted in September 2019, demonstrated that the uptake of annual health checks for patients with learning disabilities has improved by 14.1% from the period of 2017/18 to 2018/19 to 61.6%, and narrowing the gap to the national uptake rate target of 75%.

This audit also proposed that the quality of annual health checks has improved – with examples of this being wide spread provision of reasonable adjustments such as longer appointments, use of accessible information and flagging of patient's additional needs on electronic records across GP practices in the city.

The LD standard for 2020/21 has been revised to adapt to the evolving requirement for remote consulting. The aspiration is to continue improving the uptake of the Learning Disability Annual Health Check to 75%, and to provide accessible healthcare that meets the

needs of people with learning disability through the provision of reasonable adjustments. At the core, there has been stress on a practical approach to contact all patients on LD register to ensure each person (or carer) understands and is able to safely access healthcare during COVID-19 crisis.

As part of a nationwide scheme, on 1st May 2020 NHS England and NHS Improvement requested that GP Practices, Primary Care Networks (PCNs) and Community Health Providers work to provide a weekly check in for patients identified as a clinical priority, with an emphasis on personalised care in all CQC registered care homes as part of the Framework for Enhanced Health in Care Homes. This is a national service specification (formal launch in October 2020) which requires GPs as part of primary care networks (PCNs) to deliver proactive coordinated care to all care homes residents, including residents with a learning disability, in collaboration with community services and the voluntary sector. The model has 3 principle aims which are to ensure residents receive high-quality personalised care, improve access to services and enable effective use of resources by ensuring the best care and reducing unnecessary hospitalisation.

The Manchester Care Homes Strategic Board Clinical Pathways work project has extended this offer, to include cross checking the homes residents against how many are on the primary care register for LD. This exercise has revealed some discrepancies: of 145 bed capacity for people with learning disabilities in these homes, only 97 are on the primary care register. Thus, there is an opportunity to improve uptake to the LD register and to rectify missing annual health checks. It is recognised that these are interim Covid response arrangements, and they will dovetail into the Framework for Enhanced Health in Care Homes contractual amendment of LD care home delivery which is due to start in October 2020 (part of the Primary Care Network Direct Enhanced Service Specification).

Care homes are aligned to Primary Care Networks and each home is assigned a GP or clinical lead who ensures that the service is being delivered. The service comprises of a weekly MDT and 'home round' and each resident will receive a personalised care and support plan which is developed with the resident and their family and carers, with support from the community learning disability team. Services are 'wrapped around' the individual and their family who are connected to and supported by their local community.

In Manchester, each GP practice has nominated a Learning Disability champion from their clinical team, to promote the use of reasonable adjustments and accessible information within the practice. Manchester CCG has established communication channels with Learning Disability champions to highlight clinical and educational resources and support.

Mental health

The learning from the last National LeDeR annual report has been taken forward via Greater Manchester Mental Health (GMMH) Foundation Trust Mortality Review Group and Trust Physical Health Care group. The Trust Physical Health Care group will be developing care bundles over the next 12 months in relation to some of the key areas that have

resulted in LD deaths, particularly in relation to care of a patient with constipation, diabetes and also respiratory problems such as asthma.

COVID-19

COVID-19 has placed a specific challenge on everyone in all walks of life and every community, but in particular people who are more vulnerable to becoming more ill or dying as a result of the infection. Rapid reviews have been completed for people with learning disabilities who have died during March and April 2020 information from which has been aggregated at both Greater Manchester and North West Region level. The rapid review aim was to compare rates of death in the learning disability population against figures from 2019 in order quickly identify any learning or practise that will improve local support systems or identify escalating concerns. Six deaths were reported in Manchester up to September 2020 where patients had received COVID positive swabs.

The themes identified in the rapid review process highlighted issues related to use of the Mental Capacity Act and initiating timely Best Interest processes, involvement of families in discussing the use of DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation), timely access to testing, Infection prevention and Control procedures in social care settings including access to correct equipment, and lack of equipment and training to carry out basic observations that may have identified worsening conditions such as high temperature and silent hypoxia (person has low oxygen levels but is not observed to be struggling for breath). There is little variation between regions regarding the findings of these reviews.

Actions that address these issues will be taken forward at pace via various plans including the provision of training around Infection Prevention and Control for all social care settings (as above).

Conclusion

This report has aimed to summarise the developments and actions taken by Manchester Health and Care Commissioning working closely with health and care partners in establishing the LeDeR programme in Manchester. As has already been stated there is much more to do to address the factors that contribute to premature mortality of people with learning disabilities in Manchester.

The partners and agencies that have contributed to the work and this report, believe that it is a critical priority to address the health inequalities experienced by people with learning

disabilities and will continue to commit to this programme and its aspirations for the various communities in Manchester.

Objectives for the 2021/2022 report

The refreshed Manchester LeDeR Programme Annual report for 2021 will include:

- Equality Impact Assessment
- Analysis of prevalence, patterns and themes for learning
- Providers service improvement plans
- Case studies to highlight best practice
- Summary of co-production and engagement activity with people with learning disabilities and their carers around experiences of services and the impact it has had

Appendix

The Greater Manchester Learning Disabilities Strategy and Manchester Learning Disabilities Programme

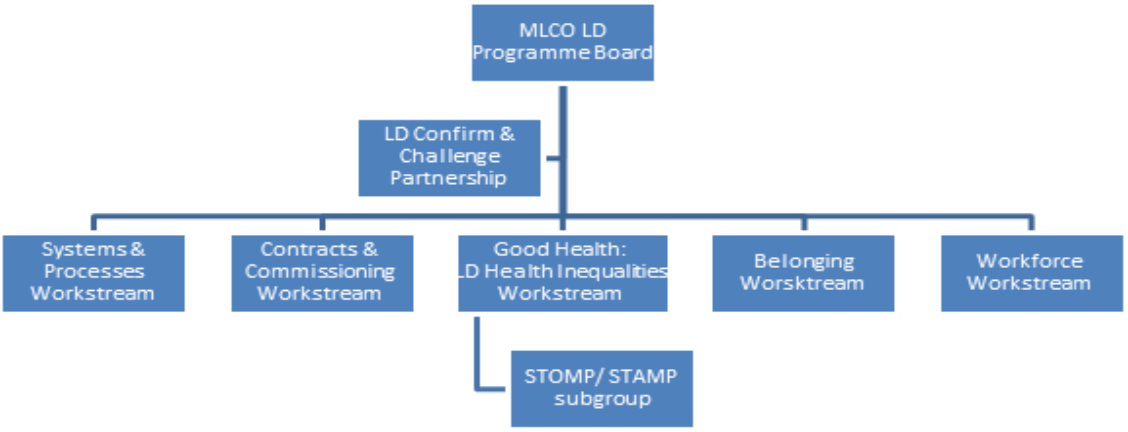
a. The Greater Manchester Learning Disability Strategy (2018) is the plan to make sure people with learning disabilities are valued as equals in Greater Manchester, and to stop the inequalities they are facing in our communities in key areas such as health, housing, employment, education, support, justice and relationships. The delivery of this Strategy is supported and endorsed by Manchester Health and Care Commissioning and Manchester Local Care Organisation (MLCO) and all partner organisations in Manchester. MLCO is responsible for the delivery of the Manchester Learning Disability Strategy on behalf of MHCC and is one of its key programmes of work within MHCC's Operational Plan.

b. The Manchester Learning Disabilities programme will involve the development of multi-year plans to reduce the health and social inequalities experienced by people with learning disabilities. This catalyst programme will support the redesign and transformation of services to deliver a modernised person-centred whole system offer, which facilitates an individual's self-directed aspirations, expectations, preferences and choice. It will transform and reinvest in services which support individuals to connect at a community level and make the most efficient use of the existing workforce by rethinking service models.

c. The vision for the Manchester LD Programme is to ensure that Adults with learning disabilities in the City of Manchester have an equal and ordinary life like everyone else. This is whole system transformation taking the widest view of service delivery and change to incorporate all aspects of needs from the individual's perspective. As such this programme will include the healthcare system, adult social care, communities, providers and people with lived experience. As well as ensuring delivery of the GM Strategies and 10 key priorities, it encompasses the deliverables in the Long-Term Plan, the recent areas of focus in the Phase 3 guidance, and the components of the Transforming Care Programme.

d. The aim is to develop an integrated and single approach to supporting adults with learning disabilities, underpinned by a co-production approach. The programme is taking a systems thinking approach as the core methodology. Whilst there has already been significant progress in many areas, the first phase of this approach is to study the current system in order to fully understand demand, needs and capabilities.

e. The Manchester LD Programme Board is supported by a Manchester Confirm and Challenge LD Partnership, which will ensure all plans are not only scrutinised by People with Learning Disabilities and Lived Experience but as central to their development and implementation. Below are the five key work-streams:



f. Healthcare has been identified as one of the 12 Pillars of independent living with many of the others primarily reflect wider determinants of health, so all have a role to play. A key focus is the reduction in health inequalities by improving access to health services, screening and reasonable adjustments, reduction in the over reliance on specific medications and well as implementing learning from other key programmes of work. To reflect the fundamental need the plan identified Good Health as one of the priority areas the strategy would seek to address across Greater Manchester and it a separate work stream within the Manchester LD Programme with its key functions to:

- To own monitor delivery against the Manchester LD Health Inequalities Action Plan
- To centrally coordinate progress against both the Good Health agenda and to ensure the LD Partnership Board, GM Good Health Working Group and LD Delivery Group is updated of progress
- To support leads and identify routes unblocking of barriers to delivery
- To develop data and intelligence systems related to health inequalities
- To facilitate information sharing across the respective services and partners and serve to develop and enhance system connections
- To ensure the latest national guidance and priorities relating to both COVID 19 and the impact on all groups with protected characteristics are central through all the group's activities and functions

g. STOMP/STAMP Subgroup: Stopping The Over-Medication of children and young People with a learning disability, autism or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP).

Children, young people and adults with a learning disability, autism or both should only be prescribed psychotropic medication when clinically indicated. Psychotropic medication should only be considered for the management of behaviour that challenges when:

- alternatives to psychotropic medication alone (such as Positive Behaviour Support) do not produce positive change within an agreed time, or
- treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour, or
- the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

The STOMP and STAMP subgroup was set up to manage the Manchester programme of reviewing the medication records of all known people in Manchester with a Learning Disability, and to develop plans as to how this will be delivered in partnership with individuals, their families, primary care, community services and Mental health services in Manchester.

Contact and information

For more information related to this report or to find out more about the work of the Manchester LeDeR Steering Group, please send an email addressed to the MHCC Head of Nursing at mhcc.nursingteam@nhs.net.