NHS
Rotherham
Clinical Commissioning Group

LEARNING DISABILITY MORTALITY REVIEW (LeDeR) PROGRAMME

ANNUAL REPORT

January 1 2020 – March 31 2021

CONTENTS

EXECUTIVE SUMMARY

To date there have been four national annual reports pertaining to the English Learning Disability Mortality Review (LeDeR) programme which commenced in July 2016.

The England wide annual LeDeR reports present information about deaths of those with learning disabilities aged four and over notified to the programme.

LeDeR was established to support local areas to review the deaths of individuals with learning disabilities, identify learning from those deaths and to take forward the learning into local service improvement. The programme is delivered by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHSE&I. It is a joint health and social care project, involving healthcare providers across the health economy, Local Authorities (LAs) and Clinical Commissioning Groups (CCGs).

The LeDeR programme collates and disseminates anonymised information emerging from completed reviews in order that common themes, learning and recommendations can be cascaded and embedded in both policy and local service improvements.

A fundamental aim of LeDeR is to ensure that reviews of deaths lead to reflective learning which underpins health and social care service improvements.

LeDeR reviews are not investigations of care, they aim to promote learning and therefore improve care.

Locally the aim is to maintain the consistently high quality of reviews in Rotherham and to ensure that learning from the reviews is embedded in to practice and service improvement, transforming provision for people with learning disabilities with the ultimate aim of reducing health inequalities.

Across Rotherham since the LeDeR programme started in the summer of 2016 to March 31 2021 there have been 59 deaths notified, all of which have had completed reviews.

There were three deaths of individuals with a learning disability notified to the LeDeR programme between January 1 2020 and March 31 2020: These are included in this annual report as the Rotherham Clinical Commissioning Group (RCCG) 2019 annual report covered the period January 1 to December 31 2019 in line with the 2019 national LeDeR report.

Between April 1 2020 and March 31 2021 there were 14 deaths of people in Rotherham with a learning disability notified to LeDeR.

This annual report will primarily focus on the 17 reviews and subsequent findings from January 1 2020 to March 31 2021.

The 17 reviews indicate that the mean age at death in 2020/’21 in Rotherham was 63 years, with all notified deaths being in respect of adults.

The median (middle) age at death in Rotherham was 68 years for females and 61 for males.

Of the 17 notifications, seven pertained to males and ten to females in comparison to during 2019 when nine deaths pertained to males and five to females.

94% of the LeDeR notifications were people of white British ethnicity.

By far the most frequently reported cause of death in Rotherham was pneumonia which accounted for five deaths, followed by other respiratory causes reported for seven deaths, four of which were Covid-19 positive. The remaining five non respiratory deaths were attributed to old age frailty, sepsis, heart failure, liver abscess and dementia.

Of the four deaths attributed to Covid-19, three were female and all were white British.

KEY FINDINGS

This report's key findings include:

- Within Rotherham 17 deaths were notified to the programme between January 1 2020 and March 31 2021.
- Of these, the majority were female 59 %. This is higher than the national average which is 37%.
- Within Rotherham 94% of adults with learning disabilities whose deaths were notified to the LeDeR programme were white British. This is higher than the national average being 88%.
- Of the 17 individuals, 82% died in hospital compared with 60% nationally.
- The most frequently reported cause of death in Rotherham in both 2019 and 2020/'21 was pneumonia which is consistent with the national findings.
- 94% of reviews concluded that individuals received care that met or exceeded good practice. One review was graded by the reviewer as excellent, 15 were graded as good and one fell short of the expected level of care. Nationally, 63% received care that was graded as meeting or exceeding good practice.
- There is a marked difference between deaths attributed to Covid-19 in the general population compared to people with a learning disability. The Office of National Statistics (ONS) data for the general population of England and Wales reports that 47% of deaths from Covid-19 were in people aged 85 years and older. However, for people with learning disabilities, just 4% of people were aged 85 years and older.

INTRODUCTION

Background

The national Learning Disabilities Mortality Review (LeDeR) programme was established in 2016 following the Confidential Enquiry into the premature Deaths of people with Learning Disabilities (CIPOLD). It was commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England from the University of Bristol. It involved reviewing the deaths of all people with a learning disability to identify potentially avoidable contributory factors. LeDeR focuses on the learning that can be gleaned from reviewing the circumstances in which a person with a learning disability died, and their care and treatment through their life.

Definition of learning disability

The LeDeR programme follows the definition outlined in 2001 by the white paper 'Valuing People' which states that

Learning disability includes the presence of;

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development.

Confidentiality and Data Sharing

The National LeDeR programme applied to the national Confidential Advisory Group (CAG) for Section 251 (of the NHS Act 2006) approval for the use of patient identifiable information, in order that reviews can be undertaken regarding the lives and deaths of people with a learning disability.

The programme has been given full approval to process patient identifiable information without consent. Specifically, this provides assurance for health and social care that the LeDeR programme has been scrutinised by the national CAG. The CAG is appointed by the Health Research Authority to provide expert advice on uses of data as set out in the legislation and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved.

The fundamental purpose of the CAG is to protect and promote the interests of patients and the public whilst at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care. More information about Section 251 approval is available at:

www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/

Initial Review

An initial review is completed for all appropriate notifications to LeDeR.

Building on the wider learning from reviewing deaths in NHS Trusts, the LeDeR methodology places the person at the centre of the review. The 'pen portrait' is a strengths based summary of the person's needs, preferences, interests, communication style and community presence.

A chronology is also completed detailing at minimum the last year of the person's life. From the information collated, reviewers are required to draw on this information to formulate recommendations based on issues and learning identified. These SMART recommendations signpost where quality can be improved and good practice shared, as well as the identification of local recurrent themes.

Multi- Agency Review as an integral part of the LeDeR process

The purpose of the multi- agency review is to include the views of a broader range of people and agencies who were involved in supporting the person who died and where it is felt that further learning could be obtained from a more in depth analysis of the circumstances leading up to the person's death.

There are a number of circumstances that would indicate that a multi- agency review is required: These may be identified early in the initial review or may emerge as the review progresses. A multi-agency review is always required when:

- The assessment of the care received by the person is graded at a score of 5 or 6 within the 1-6 rating scale
- Any red flag alerts are indicated in the initial review
- There have been any concerns raised about the care of the person who has died.

ACKNOWLEDGEMENTS

We would like to thank each and every one of the reviewers, their families and care teams. Their unwavering dedication ensured each and every review undertaken was the best it could be for each person and their family. Likewise, without the support of our families, we would not have been able to fully learn from the events their loved ones experienced; ultimately enabling us to positively change services and practice locally.

It is a credit to all of the reviewers that we were consistently able to achieve the target of completing each review within six months of notification.

All historic reviews (pre July 1 2020) were completed and approved four weeks ahead of the national deadline of December 31 2020 as a direct outcome of the consistent contribution of Rotherham LeDeR reviewers.

GOVERNANCE ARRANGEMENTS

The LeDeR programme is part of the national Transforming Care Partnership (TCP) programme and as such local LeDeR performance is reported to NHSE/I through the Sheffield, Rotherham, Doncaster and Bassetlaw TCP Board.

At an RCCG level monthly LeDeR updates are fed into the patient safety and quality assurance meetings which in turn informs the CCG Governing Body.

Rotherham CCG has an established six weekly LeDeR Steering Group at which relevant guidance, annual reports and related publications are discussed and disseminated and learning from completed reviews are presented by reviewers. A quarterly peer review forum is held for reviewers to meet to support each other and share good practice.

Rotherham CCG's second LAC is the Matron in Learning Disabilities and Autism at The Rotherham Foundation Trust (TRFT).

LEARNING DISABILITY DEATHS IN ROTHERHAM NOTIFIED TO THE LeDeR PROGRAMME JANUARY 1 2020 TO MARCH 31 2021

Gender

There has been a significant change in the gender divide in deaths reported in Rotherham to the LeDeR programme: During this reporting period there were more deaths amongst females which is the opposite of the 2019 gender ratio.

	Gender	
	Female	Male
2019	5	9
January 1 2020 to March 31 2020	2	1
April 1 2020 to March 31 2021	8	6

Nationally the 2020 LeDeR reporting of gender

Nationally for people with learning disabilities

- 58% were male
- 42% were female

Three of the four deaths attributed to Covid-19 were females.

Age at death

The mean age at death in Rotherham in 2020/'21 was 63 years which is nine years more than in 2019.

The median age at death in 2020/'21 was 67, which is markedly different to that of 2019 which was 46 years for females and 58 for males.

Nationally in 2018 and 2019 the median age at death was 60, in 2020 it was 61. This increase is for both males and females.

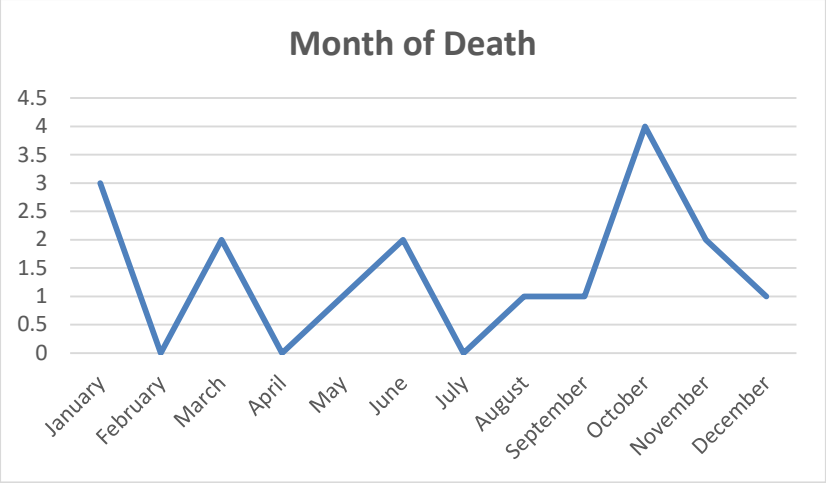
In 2019, the majority of UK deaths in the population as a whole (85%) died at age 65 and over. The corresponding proportion of children and adults with a learning disability for 2018 and 2019 was 38%.

None of the four deaths attributed to Covid-19 were in the 85 years and over age range which is the highest age range at death for the general population. The median age of these four deaths was 70 years.

Month of death

In Rotherham, of the three deaths between January and March 2020, two occurred during March and the other in January.

The majority of deaths between April 2020 and March 2021 were in October, followed by June, November and January (2021) respectively. There were no deaths notified during April, July, February nor March.



Nationally the 2020 LeDeR reporting of month of death

There was a greater proportion of deaths of people with learning disabilities between March 2020 and May 2020.

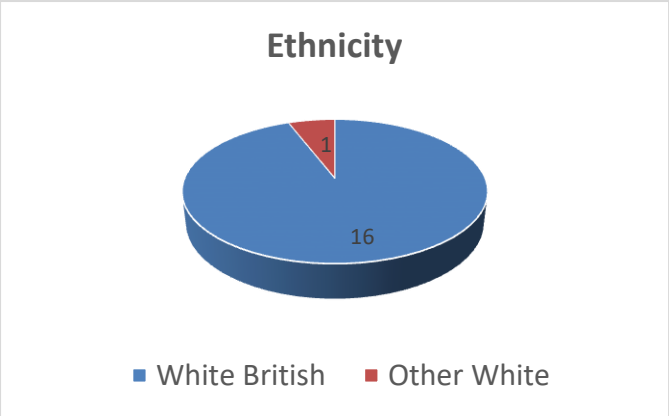
Ethnicity

All bar one of the 17 notified deaths pertained to individuals who were white British.

Similar to 2019, there were no notifications from black and minority ethnic (BAME) communities in Rotherham.

It is likely that this is indicative of underreporting of deaths of people from minority ethnic backgrounds as opposed to a greater proportion of deaths amongst people from a white British ethnicity.

Continued awareness raising of the LeDeR programme and alignment with Medical Examiner's Office reviews will potentially identify learning disability deaths in BAME communities moving forward.

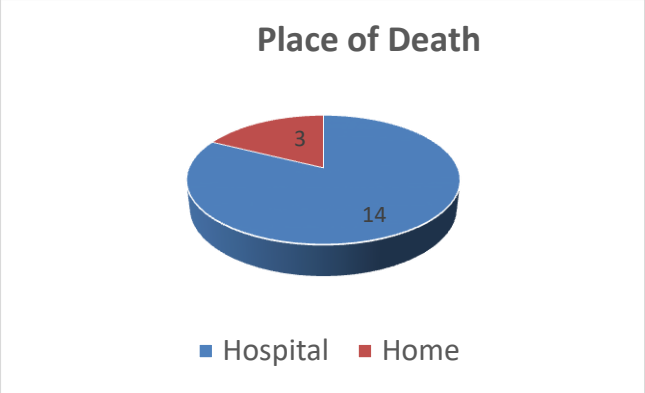


Nationally the 2020 LeDeR reporting of ethnicity

The number of deaths of individuals from different minority ethnic groups is too small to analyse by individual ethnicity. Less than 5% of adults who died were of Asian/Asian British ethnicity (4%) but this was the case for 25% of children in 2020.

Place of death

14 individuals died in hospital and three died in their usual place of residence. There isn't currently a mechanism to record whether the individual died in their place of choice. Further work to promote advance care planning, including End of Life plans and DNACPR decisions have the potential to go some way to supporting this.



Nationally the 2020 LeDeR reporting of place of death

Nationally for people with learning disabilities 60% died in hospital (compared to 46% of general population).

Jayne was a 65-year-old lady with a mild Learning Disability and several physical difficulties. Jayne was a very independent and strong-willed lady. She was described as having a good sense of humour, being caring and generous. Family were very important to her especially her brothers, nephews and nieces and great nephews and nieces, she loved to spend time with them, talk about them and look at pictures of them.

Jayne had experienced moves to several living environments that had broken down before moving to her final placement where she resided for over eight years, she was very happy there and well-liked by everyone. Family felt that this was the best place she had lived and that she had a good quality of life.

Jayne had not had an Annual Health Check since 2019, though there was reference to an LD health examination documented in her medical notes, this was however merely a conversation with care staff. She had not been offered a smear for a number of years as she had on one occasion declined a smear, in addition to which there was no record of any other age and gender appropriate screening having been offered.

Jayne had been suffering with some swelling and pain in her legs, which were discussed with the GP over the months leading up to her death, a number of different treatments were tried, with only periodic relief.

In December 2020 Jayne became short of breath and an ambulance was called to convey her to Hospital, where unfortunately she died two days later with pneumonia. She had previously had Covid-19 though had tested negative prior to passing away. During the two days hospitalisation Jayne was quite distressed and was not able to tolerate oxygen nor interventions to support her, which resulted in sedation being utilised. During this stay there was some learning identified, for people with learning disabilities and for the general population, particularly in relation to not moving patients from ward to ward during the night, the use of appropriate medication for reducing anxiety and the use and accessibility of the learning disability Hospital Passport.

Severity of learning disability

The severity of learning disability was recorded in all 17 instances and is illustrated in the below table

Severity of learning disability	
Level	n =
Mild	7
Moderate	6
Severe	3
Profound / multiple	1

Nationally the 2020 LeDeR reporting of the severity of learning disability

Nationally for people with learning disabilities the severity was determined as:

- 33% mild
- 35% moderate
- 25% severe
- 7% profound or multiple learning disabilities

Nationally between 2018 and 2020 there has been very little difference amongst adults who died in respect of the level of learning disability. However, nationally there is a greater proportion of deaths of children with profound and multiple learning disabilities than of adults.

Causes of death

The World Health Organisation defines underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence resulting in a fatal injury.

Nationally in 2018 and 2019 the most frequently reported underlying causes of death were in the ICD-10 chapter of disorders of the respiratory system.

The most frequently reported ICD-10 chapters of underlying causes of death within the learning disability population didn't change in 2018 and 2019.

In 2020 the most frequently reported ICD-10 chapter in respect of those with a learning disability was the emergency code for Covid-19.

Locally, between January 1 2020 and March 31 2021 the most frequent cause of death by ICD-10 chapter were diseases of the respiratory system at 47%. Four deaths (23.5%) were attributed to Covid-19.

The remaining five reported causes of death were:

- Old age frailty
- Sepsis
- Heart failure
- Dementia and Down's syndrome
- Liver disease.

Use of antipsychotic medication

STOMP is a national programme to reduce over medication of children, young people and adults with a learning disability, autism or both.

Psychotropic medication is used to treat a range of conditions including bipolar disorder, schizophrenia and psychosis. However, they are also prescribed for people whose behaviour is perceived as challenging and presenting a risk to themselves or others. People with a learning disability, autism or both are more likely to be prescribed these drugs in this way than others.

Remarkably, 47% of the 17 reviews indicated that antipsychotics were prescribed.

Furthermore, psychotropic medicines can cause a number of side effects and have a negative impact on long-term health.

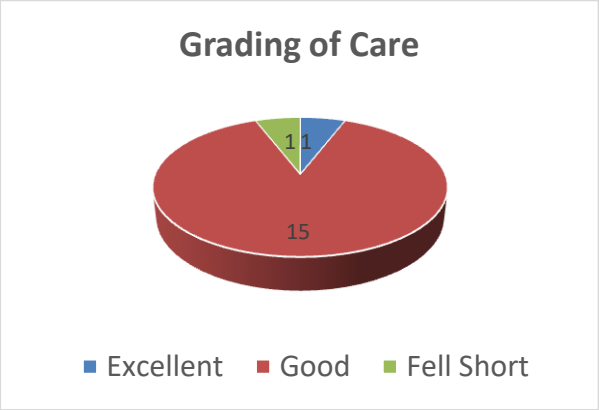
Outcome of review – grading of care

At the end of a review, having considered all the information available to them, reviewers are asked to provide an overall assessment of the care provided to the individual and provide a grade.

It is important to note that not all reviews generate learning, with a significant number of reviews demonstrating good care throughout the life, and end of life, of the individual.

It is reassuring that of the 17 reviews 88% were rated good, 6% were graded as excellent care with the remaining 6% graded as fell short.

There has been a steady increase from 2018-2020 in the proportion of reviewers who felt that a person's care met or exceeded good practice. However, even with this increase in 2020 42% of reviewers felt that the person's care had not met good practice standards.



Nationally the 2020 LeDeR findings for the overall grading of care

From 2018 to 2020 there has been a steady increase in the number of reviewers who perceived that the individual's care met or exceeded good practice, this increased from 48% in 2018 to 58% in 2020.

Whilst the increase is positive, nationally this still means that 42% of reviewers in 2020 perceived that the individual's care had not met good practice. standards

DEATHS FROM COVID-19

In instances when it was perceived that the death may have been Covid-19 related there were additional questions the reviewers were required to explore. These included though were not limited to, whether if appropriate, the individual had received a shielding letter, whether there was adequate access to supplies of PPE for staff and availability of testing.

Nationally, this information was collated as part of a research programme. In November 2020 the University of Bristol published its report into the deaths of 206 people with a learning disability at the beginning of the Covid-19 pandemic. The report highlighted some good practice in relation to the care of people with a learning disability, but it also highlighted concerns about the care that some people received. These findings were summarised in the NHS publication: Learning Disability Mortality Review (LeDeR) programme Action from learning: deaths of people with a learning disability from COVID-19.

Deaths from Covid-19 in the learning disability population in Rotherham were very different than the national and regional findings in so much as nationally the peak month for deaths attributed to Covid-19 was April 2020, when 59% of all deaths were from Covid-19. There were no deaths within the learning disability population of Rotherham during April 2020: Two of the four deaths in Rotherham were in October 2020.

In each region, the number of deaths amongst those with learning disabilities from Covid-19 notified to the LeDeR programme was higher than the number of deaths from Covid-19 in the general population.

Nationally a greater proportion of males than females with a learning disability died from Covid-19 whereas in Rotherham of the four deaths from Covid-19 only one was male.

Consistent with the younger age at death for people with a learning disability, those with learning disabilities who died from Covid-19 were frequently in younger age groups than those in the general population: 4% of those with a learning disability were aged 85 or over, in comparison to 42% in the general population.

The median age of the four Covid-19 deaths in Rotherham was 70 years.

Nationally 21% of people with learning disabilities who died from Covid-19 had Down's syndrome, none of the individuals in Rotherham who died from Covid-19 had Down's syndrome.

In Rotherham 100% of those with a learning disability who died from Covid-19 died in hospital in comparison to 83% nationally.

Lucy was described as a delightful individual to have known. She had learning disabilities, nevertheless had strong opinions and views which she voiced clearly to others. Her character was respected by all and when Lucy spoke, everyone would listen, she was the 'mother' of the house.

Lucy lived in her permanent address for 35 years and made strong connections with other residents and staff members. If there was ever an argument in the home, she would be the one to defuse the situation as she was firm but fair. Lucy had a relationship with another resident of the home, they had been together for many years and had a strong bond, and they enjoyed spending time together. Lucy also had a loving family around her, three nieces and a nephew who she spoke to regularly.

Lucy had a great passion for animals, in which she raised money for charities and involved herself in anything animal related. She was a catholic and was proud of this, having a good sense of belonging to the community.

Every year people with learning disabilities are entitled to an annual health check, in which a health action plan should be completed prior to the appointment, and after the appointment the GP completes their own action plan with the patient to indicate any concerns/areas to follow up. Lucy did not have an action plan in place, which may have enabled Lucy and her carers to better understand more about her health conditions and how best to access support. In the review, it was noted that Lucy had declined a smear many years ago and was never again asked to attend for an appointment; nor was there evidence of a mental capacity assessment completed in this area. This put Lucy at a disadvantage as she did not therefore have the same opportunity as someone else without a learning disability.

Lucy was predisposed to COVID-19 as she had diabetes, evidence shows that having COVID and diabetes can lead to greater complications. Unfortunately, people with learning disabilities are greatly disadvantaged in respect of the current pandemic. Oftentimes people with a learning disability are unable to articulate feeling differently, being unwell or in pain and are therefore dependent on families and carers to notice observable changes in their presentation and/or demeanour. During the pandemic GP consultations were often undertaken either over the telephone or virtually with a carer rather than with the person with a learning disability which further disadvantaged this population.

IMPROVING HEALTH INEQUALITIES FOR PEOPLE WITH LEARNING DISABILITIES AND AUTISM ACROSS SOUTH YORKSHIRE AND BASSETLAW

Addressing health inequalities faced by people with learning disabilities and autism is a key priority for South Yorkshire and Bassetlaw. We have an established Health Inequalities Steering Group which currently meets six weekly that specifically looks at a collaborative approach, sharing best practice to improve our pathways, provision and more importantly raise awareness.

There are a number of projects across the ICS where we are working to address the health inequalities that our learning disability and autism population are still facing. The latest LeDeR report identifies that people are still dying much earlier than the general population, 22 years younger for males and 27 years younger for females.

The LeDeR ECHO Project

Utilising the ECHO platform, we are rolling out a series of ECHO modules to learning disability and autism care homes, supported living settings and domiciliary care which will increase the knowledge, competency, and confidence of staff. Focussing on the key findings and recommendations from the LeDeR reports including the following which will is phase 1 of the project:

- Constipation
- Epilepsy and seizure control
- Dysphagia/posture
- Sepsis awareness

These sessions will also be available to GP practices, other clinicians and family carers in 2021/22.

ECHO training – Self advocates from Speak Up have attended ECHO training and are now supporting the rollout of the above modules presenting the case studies.

Flyer v7.pdf

SAMI/RESTORE 2 mini tool projects

To compliment the above project, we are also rolling out SAMI Restore 2 mini tool training which is an accredited training programme. The programme offers education and training for care support staff within care settings, supported living, care homes and domiciliary care. Carers are taught to recognise measure and report changes to an individual's health status at an early stage, thus preventing deterioration in that person's health and wellbeing and avoiding preventable deaths in line with the LeDeR programme. The aim of the project is to identify early signs of illness, prevent unnecessary hospital admissions/attendances at UEC (Urgent and Emergency Care), and reduce stress for the cared for person, increase confidence of carers, improve communication with primary care and urgent care services. We will also be providing calibrated equipment including oximeters, blood pressure machines, thermometers and clinical watches. This work will also link in with the national oximeterpPilot.

SAMI - Final FLYER FOR LD V5.pdf

Big Health Days

Speak Up facilitated two Big Health Days prior to the Covid-19 pandemic. Over 200 people with learning disabilities, autism or both attended (the first day was for children and young people and the second day was for adults). As well as working closely with our health action teams - we partnered with SENSE and South Yorkshire Sport so that people had the opportunity to take part

in sport and physical activity. Everyone had the opportunity to take part in 5 workshops on, Cancer Screening, Sexual Health and Dysphagia along with two workshops on physical activity.

Other projects

- SpeakUp self-advocates have co-produced an online accessible newsletter, "Spreading the News". This gives easy read information about Covid-19, lockdown and keeping safe. There have been 19 editions of the newsletter; it has been distributed through the Speak Up website and shared through all communication and engagement Leads across health and social care as well as VCRs and parent carer forums. There are three further co-produced easy reads, "Kick- Out Those Lockdown Blues", offering some ideas on coping with lockdown.

- Speak Up and their advocates carried out Zoom sessions in January 2021 to spread awareness on the "early signs and symptoms of cancer" and the Covid-19 "Grab and Go" sheet. A special edition of the 'Spreading the News' re Cancer Awareness covering five key areas has also been co-produced:

  POSTER Covid 19 Grab and Go sheet an

  Be Cancer Aware.pdf

  The newsletter has been well received and other Integrated Care Systems are asking to use this.

- Linking with local and ICS flu groups to try and increase the uptake of flu vaccinations amongst those with a learning disability and/or autism. Speak Up put together a flu 'Spreading the News' edition in an easy read format which will include all PHE guidance and links to those services to provide support regarding desensitisation.

  Stopping Flu final Oct 20.pdf

- **Health check work -** Prior to Christmas 2020 Speak Up contacted 27 homes in Rotherham (responses from 21) to find out if people had, a hospital passport, Covid-19 "Grab and Go" sheet, had attended their annual health check and had been offered a flu jab. Speak Up were then asked to do the same for Doncaster and Sheffield and to include information about the ECHO training; an online form to capture the information was created. Speak Up have contacted 311 homes. Speak Up also contacted care homes in Barnsley & Bassetlaw to share information about the ECHO training. Findings from the online form will be shared at the South Yorkshire and Bassetlaw Transforming Care Health Inequalities Steering Group.

- **GP Training** – Speak Up have delivered one training session in Doncaster and one in Sheffield, three other dates are booked for Sheffield and one for Rotherham. Speak Up have also been training medical students in Sheffield and have run two training sessions this year to 80 students. Speak Up advocates also ran a session with Sheffield University to health and social care workers to talk about the TCP work and have since been contacted by a dentist who is wanting to create a quality of life scale around oral health.

- **NHSE masterclass** - Experts by Experience at Speak Up helped to run a masterclass for coping with Covid: Supporting people with learning disabilities, autism or both.

- Rotherham has recently become an Exemplar site for Annual Health Checks. This is a positive step locally. Nationally it is recommended that all people with a learning disability receive an annual health check from the age of 14 years upwards on a yearly basis.

PERFORMANCE AGAINST NATIONAL TARGETS

Rotherham LeDeR reviewers consistently undertake high quality reviews which are completed and approved within six months of notification to the programme.

All pre-July 1 2020 reviews were completed and approved four weeks ahead of the December 31 2020 deadline.

FUNDING

The Local Area Contacts (LACs) and reviewers contributing to the LeDeR programme in Rotherham undertake LeDeR work within their substantive roles. There are currently no dedicated LeDeR focussed posts unlike most other CCGs.

Non recurrent monies for 0.4 whole time equivalent Band 7 reviewers were allocated to Rotherham from July to December 2020 to enable completion of the pre-July 1 2020 reviews.

LOCAL PRIORITIES AND THE EVIDENCE BASE THAT SUPPORTS THEM

1. The local LeDeR offer is not reaching BAME communities as there have not been any notifications to the programme: Further initiatives to address this locally need to be a priority.

2. In conjunction with increasing the quantity, and of equal importance, the quality, of annual health checks (AHCs) for those aged 14 and over in Rotherham, there needs to be measurable evidence that AHCs improve health outcomes and that they contribute to reducing premature mortality.

3. RCCG LeDeR Steering Group membership has broadened to include a wider range of stakeholders however this needs to be expanded further to incorporate representation from local advocacy service.

4. As LeDeR is an additional role to reviewer's substantive posts with no dedicated capacity within which to undertake this work, we have not managed to retain all of our reviewers: There are now only three reviewers, all of whom are nurses. Given that there is an average of 14 LeDeR notifications each year, there needs to be ideally a further four reviewers, preferably from other professional backgrounds.

5. Locally there needs to be more emphasis on STOMP, specifically in the context of the review of antipsychotics given the high number of those whose deaths were notified to LeDeR that were prescribed antipsychotics over many years.

6. Regrettably too many individuals with a learning disability were and continue to be inappropriately conveyed to TRFT by paid carers, for example, due to poor management of constipation: Predominantly from supported living environments.

7. Whether appropriately or inappropriately conveyed to TRFT paid carers are often not ensuring that individual's hospital passports are taken with them, which needs to be addressed locally.

8. There was no evidence of utilisation of Covid-19 "Grab and Go" sheets within any of the 17 reviews, which needs to be addressed locally.

9. Similar to 2019, local there needs to be improved application and documentation in respect of MCA/BI.

Areas of improvement

Whilst reviewers identified lots of areas for improvement and further service development the findings from two LeDeR reviews in particular, highlighted several examples of collaborative working across teams and provision of exceptional reasonable adjustments.

Charlotte had a learning disability and Down's syndrome. She was diagnosed with Dementia in 2015, prior to this Charlotte was independent and lived at home with her mum for many years. She loved music, people and travelling the world. Charlotte went on many cruises around the world and very much enjoyed the music of the Irish singer Daniel O'Donnel, having been to many of his concerts. Charlotte was described as loving, fun loving and infectious. She was able to read and write and wrote a life story book before she became ill. Charlotte enjoyed shopping and having a drink, she was very family orientated and had good support around her. She wanted everyone to love, and her sister felt everyone could have learnt from her in this way.

Following her dementia diagnosis, Charlotte's health gradually deteriorated over the years for which she received support from many health professionals, particularly towards the end of her life. Reasonable adjustments were made for Charlotte which included home visits from practitioners as opposed to her having to attend the GP surgery/clinics and towards the end of her life, 24 hour care was available should Charlotte or her family require this. She was also provided with aids/adaptations for support which included a battery powered wheelchair so she could go out on walks with her family. Charlotte's family highlighted how supportive and responsive her care team were and they felt that they were well supported by professionals when caring for Charlotte. The LeDeR review highlighted how there is a lack of understanding about Down's syndrome and Dementia and also learning disabilities and Dementia per se. During the review Charlotte's sister raised concerns around diagnostic overshadowing and a lack of understanding that an individual's presenting behaviours may be due to Dementia and not the person's learning disability. Charlotte's family fed back the need for professionals to develop better understanding around this through training sessions.

Terry was a Rotherham resident all of his life. Living in the family home with his Mum, Dad and 4 siblings.
He lived in the family home, following his siblings leaving the nest to pastures new. Sadly, his father passed away and in around 2000 Terry's Mum's health also started to falter. Mum was no longer able to care for Terry and her decision was to give Terry a new home in a supported living environment, within the Rotherham area he knew and loved.

Terry had a great relationship with the care team who provided him support. He continued to have regular visits from his siblings and his Mum continued to visit until she was 93 years old.

Terry was a very sociable and likeable gentleman, with lots of friends. He enjoyed line dancing in a local village hall. This went from line dancing to in his later years and somewhat compromised health to chair dancing. Canoeing was another of Terry's much loved activities, his instructor even taught him to perform a canoe roll, which he loved! Again, on the aquatic theme, Terry also enjoyed swimming.

For Terry's 60th birthday his supported home hosted him a James Bond themed birthday! He had around 40 of his friends and family to celebrate, all in suitably themed dress for the occasion.

He attended a day centre in the Rotherham area for many years, where he had many friends. He enjoyed the social activities that were offered to him and was very saddened at the closure of this service. Terry found this very upsetting and he was unable to keep those friendship links he had formed there.

Sadly, in the last three to four years of Terry's life, his health did begin to deteriorate. He was experiencing during this time, fairly frequent chest infections which required antibiotic therapy to treat. These chest infections tuned into episodes of pneumonia, which Terry found it harder to bounce back to health from. Terry had great engagement from the community learning disability services, including nursing, speech and language therapy and physiotherapy.

Though there is evidence for Terry of referrals to respiratory services and good use of the mental capacity act including his beloved family in all decisions when he needed support, there is little evidence of appropriate health and age appropriate screening being offered to Terry.

In the final two years of his life, his mobility and physical health had both deteriorated. He was struggling to mobilise as he had previously done. Sadly, this deterioration led to him being moved out of his beloved supported living home, as they were finding it difficult to meet his health needs. He moved into a care environment with clinical staff available to support him. Sadly, whilst in the community Terry contracted Covid19 and was admitted to a local hospital with Covid pneumonia. During this time, he had engagement from both the hospital learning disability teams and community teams to ensure reasonable adjustments were made to his care pathway.

Sadly, this was Terry's last admission to hospital where he passed away.

LeDeR POLICY

The national LeDeR policy, learning from life and death reviews of people with a learning disability and autistic people was published on March 23 2021 which will determine the delivery of LeDeR in the future.

https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf

CONCLUSION

The local LeDeR offer in Rotherham is a robust model which would be further enhanced by reviewers from backgrounds other than nursing, ie allied health professionals and/or social care.

The national LeDeR policy and the proposed ICS approach to LeDeR locally will without doubt further embed LeDeR across South Yorkshire.

APPENDIX 1 - GLOSSARY

AHCs	Annual Health Checks
BAME	Black, Asian and Minority Ethnic
CCG	Clinical Commissioning Group
CDOP	Child Death Overview Panel
DH	Department of Health
DoLS	**Deprivation of Liberty Safeguards**
GB	Governing Body
HQIP	Healthcare Quality Improvement Partnership
ICS	Integrated Care System
LA	Local Authority
LAC	Local Area Contact
LeDeR	Learning Disability Mortality Review
MAR	Multi- Agency Review
MCA	Mental Capacity Act
NHSE&I	NHS England & NHS Improvement
RMBC	Rotherham Metropolitan Borough Council
TCP	Transforming Care Partnership
TRFT	The Rotherham NHS Foundation Trust