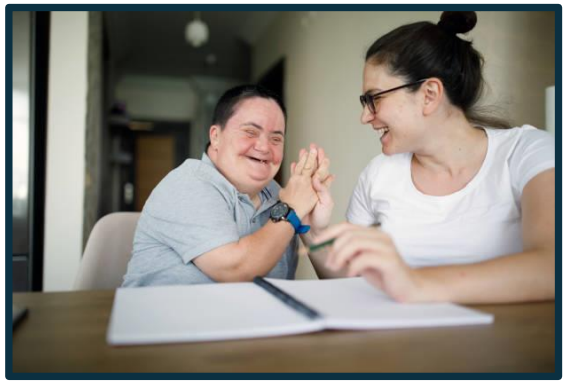

NHS Frimley Integrated Care Board (ICB) LeDeR Annual Report 2023/2024

“Learning from the Lives and Deaths of People with Learning Disabilities and Autism”

For the period 1st April 2023 – 31st March 2024

Contents

NHS Frimley

Acronyms / Abbreviations:

- ICB – Integrated Care board
- ICS – Integrated Care system
- PEG – percutaneous endoscopic gastrostomy, a feeding tube.
- SALT – Speech and Language therapy
- GP – General practitioner
- MDT - Multi-disciplinary team
- RESPECT – Recommended Summary Plan for Emergency Care and Treatment
- DNACPR – Do Not Attempt Cardiopulmonary Resuscitation
- TV – Television
- LD – Learning Disability
- Physio – Physiotherapist
- CT – Computed tomography is a type of scan completed, medical imaging to obtain internal images of the body
- AHC – Annual health checks
- EOLC – End of Life care
- CTPLD – Community Team for people with a Learning Disability
- GP – General Practitioner (Doctor)
- BAME – Black Asian and Minority Ethnic group
- MCA – Mental Capacity Assessment
- DSR – Dynamic Support Register
- CYP – Children and Young People
- PCN – Primary Care network
- NHS – National Health Service
- STOMP – Stopping the Over Medication of Children and young people with a learning disability, autism or both
- STAMP – Supporting Treatment and appropriate medication in Paediatric patients

Executive Summary

- LeDeR is a service improvement programme for people with a learning disability and, more recently, autistic people. It was established in 2017 and is funded by NHS England. ICBs are required to review the deaths of people with a learning disability or who are autistic, with the learning outcomes implemented to improve overall care, reduce health inequalities and prevent further people from an early death.
- In 2023/24 Frimley ICB continued to operate a unified LeDeR programme covering its five places; Slough, the Royal Borough of Windsor & Maidenhead, Bracknell Forest, Surrey Heath, and North-East Hampshire & Farnham. The programme also maintained an interface with region and neighbouring ICB programmes via the monthly Regional Local Area Co-ordinators Group.
- The programme is covered by our Strategy and Policy Framework documents (2023-2026) which reflect our overall aims and ambitions, our governance arrangements, and standard operating processes.
- We revised our quality assurance and sign-off processes to make them more efficient, while retaining a focus on quality. This involved reviewing our Quality Assurance Checklist and expanding the monthly LeDeR Sign-Off Group to ensure a broad level of expertise.
- While the focus has remained on quality, we continue to work on improvement against the national Key Performance Indicator for completion of reviews within 6 months.. There are several factors contributing to this, notably the timeliness of the availability of Structured Judgement Reviews (SJRs) from providers, and reviewer capacity. Agreement was reached to recruit two more reviewers, and these were in post in Quarter 2 2023/24. We continue to work with providers on the flow of SJRs. Work was also progressed with Frimley Health NHS Foundation trust to agree read-only access to their electronic patient record, EPIC, with the aim of enabling more timely access to required information. (This work subsequently came to fruition with access granted in 2024/25.)
- In 2023/24, the Frimley programme received 39 case notifications. Cases are either Initial reviews or Focused. Focused are mandated for cases involving people with a diagnosis of autism (without Learning Disabilities), and for people who belonged to a minority ethnic group. Focused reviews are also triggered where significant issues with care and treatment are identified.
- 24 cases were completed; some of these being cases notified before the start of the financial year. Of these cases, 3 were completed as a focused review. This equates to 13%. The national expectation is that focused reviews should comprise 35% of the total caseload and since the end of 2023/24 performance on this measure has improved; this will be covered in next year's Annual Report.
- Key findings from the programme are summarised on the next slide.

Key Findings to update

Demographics

- **Note on prevalence:** As of April 2023, Frimley ICB had a Learning Disabilities and Autistic People GP Register prevalence of 0.45% of the total population against national average of 0.58%. Work is continuing to ensure that all people who meet the criteria are recorded on GP registers.
- **Gender:** The split of cases notified was 49% male and 51% female. This reflects the overall population split in Frimley ICS.
- **Adults / Children Profile of Notified Cases:** 32 adults and 2 children. Child deaths were reviewed via the Child Death Overview Panel (CDOP) process which feeds back to LeDeR. (Note: From July 2023, national policy changed to exclude child deaths age 4-17 years from the LeDeR notification and review process. Since that change, learning from these cases is identified via the CDOP route rather than LeDeR.)
- **Age:** The average age of adult deaths was 63 years (67 for men, 59 for women); higher than last year which was an average of 58 years. Age range 38-90 years. For comparison, life expectancy for the general population in Frimley ICS is 81 years for men and 84 years for women.
- **Ethnicity:** White ethnicity accounted for 87.2% of deaths; 7.8% of notifications belong to global majority groups within the Frimley population and is a significant reduction from 17.65% in 2022/23, despite a 14.71% increase in notifications.
- **Level of Learning Disability:** Of the completed cases, where recorded, the mix was: 9 mild, 2 mild/moderate, 6 moderate, 0 moderate/severe, 5 severe, 0 profound, 1 severe/autistic, 1 autistic and 0 unknown / unstated. An increase in mild levels and decrease in moderate levels noted from 2022/23.
- **Cause of Death:** Of the completed cases, 25% had the primary cause of death confirmed as respiratory / pneumonia. This is a decrease from 43% in 2022/23. 5 cases related to Aspiration pneumonia and 1 recorded as chest infection. Cancer accounted for 21% of primary causes and cardiac causes were also 21%. Other causes of death varied by category without a consistent identifiable theme. 2 cases (8%) were primary cause of Dementia.
- **COVID-19:** 1 case was referred to having Covid 19 as a secondary cause of death.

Learning (more detail on learning is included in the main report below)

- We identify learning through the analysis of case outcomes from discussions at the Sign off group. These are fed into the LeDeR Steering Group. Learning falls into two broad categories; specific learning outcomes for providers, and thematic learning for the system.
- The Learning into Action Group takes on thematic learning and selects priorities to work on. In 2023/24 the key priorities continued to be, a) Quality auditing of Annual Health Checks, b) Improving cancer screening uptake; c) Improving early detection of deterioration.

Introduction

This is the annual report of the NHS Frimley Integrated Care Board (ICB) LeDeR Programme for 2023/24. It presents information about the lives and deaths of people with learning disabilities and autistic people in the Frimley ICB area notified to and completed by the LeDeR programme from 1st April 2023 to 31st March 2024. Also included are some comparative data and historical learning from previous years.

NHS Frimley ICB delivers the LeDeR programme for the Frimley Integrated Care System (ICS) area, comprising the local areas of Slough, Windsor & Maidenhead, Bracknell Forest, Northeast Hampshire & Farnham, and Surrey Heath. The programme has developed a structure in collaboration with stakeholders for the process of undertaking reviews and putting the learning into action. This report contains information about the types of cases notified to the programme, performance, demographics, equality, learning themes, and actions being taken to improve services and the quality of life for people with learning disabilities and autistic people in Frimley.

Acknowledgements

We would like to thank family members, carers, service providers, reviewers, and ICS colleagues who have contributed to the review of the lives and deaths of people with learning disabilities in Frimley and worked to put service improvements in place. We acknowledge this can be an emotive and lengthy task, therefore truly valuing the collaboration from all. Thank you.

Authors:

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Frimley ICB Overarching Ambitions

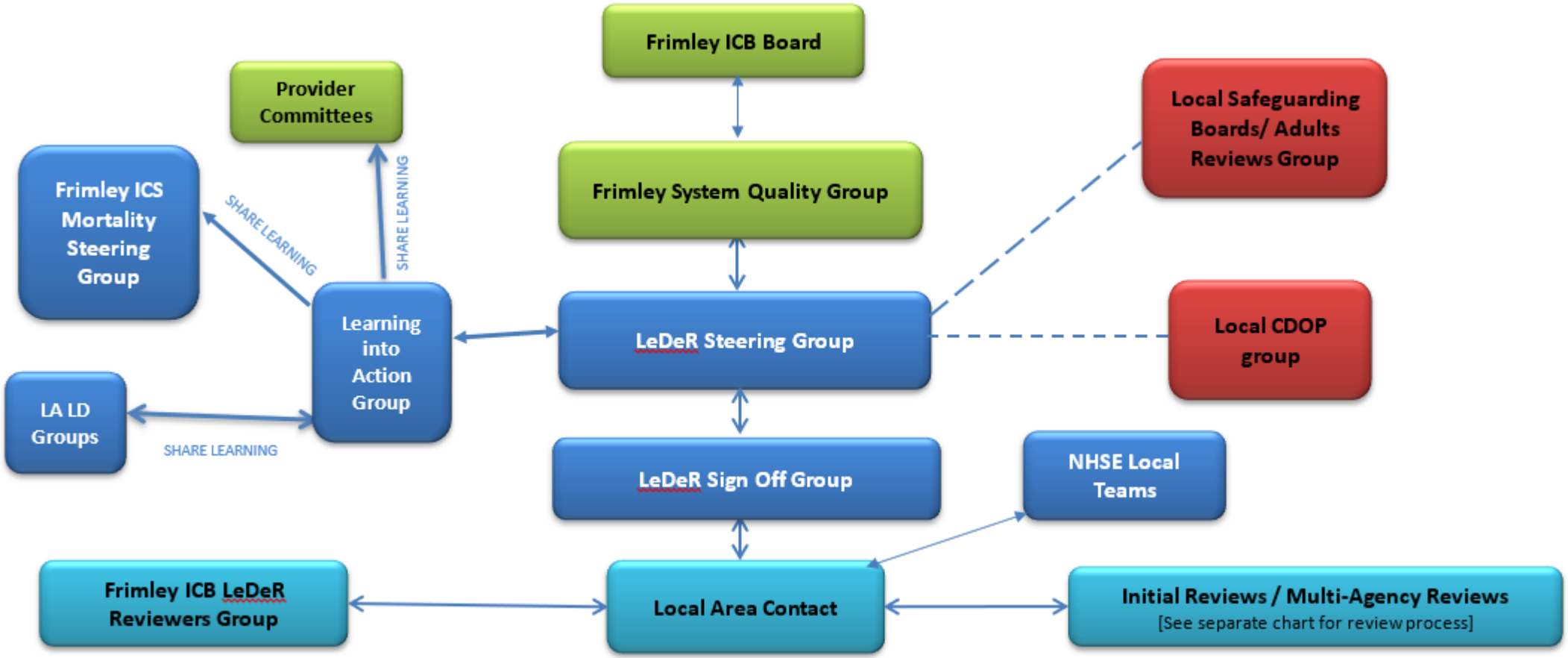
Creating healthier communities with everyone

Frimley ICB Strategic Priorities 2023-2026 - Learning Disability and Autism specific

A new strategy was drafted in which we have identified fourteen areas we need to work on. This is what we will do over the next three years to improve health outcomes for persons with a learning disability and autistic people.

1. We will work to ensure that people with learning disabilities and autistic people have access to the support they require when accessing health services.
2. We will promote a 'Rights Based Approach' in Frimley ICS.
3. We will work to improve the continuity of care when transitioning between primary and secondary care services.
4. We will improve application of the Mental Capacity Act across our partner organisations.
5. We will promote cancer screening.
6. We will work to ensure that people with learning disabilities and autistic people receive the right medication at the right time.
7. We will improve awareness of how to manage good bowel health.
8. We will make better use of Annual Health checks.
9. We will improve the recognition and management of pain.
10. We will ensure consistent access to End-of-Life care in Frimley ICS.
11. We will ensure RESPECT and DNACPR forms are always completed comprehensively.
12. We will actively support and encourage Advance Care Planning.
13. We will meet the health needs of BAME citizens with a learning disability.
14. We will promote system learning.

Governance Structure 2023/24



Our People's Stories

The four following case examples, showing how fulfilled people's lives can be, and the problems that can then arise when they experience deterioration. We have highlighted the good practice and learning identified:

Pen Portrait 1 (ref 16804) LD&A

63-year-old male with Severe Learning disability and autism.

Primary cause of death – Aspiration Pneumonia.

This gentleman had a great sense of humour especially if things had not gone to plan, he would laugh and laugh. He enjoyed going out on trips to the pub for a beer and on holidays.

The deterioration in his physical condition started to affect his ability to function about 20 years before his death. One symptom was that he progressively lost his sight. This did not affect his enjoyment of listening to music and chatting in a group of friends.

He was well known to the speech and language team who had assessed and re assessed his swallowing and put in place plans of care to appropriately deal with his changing abilities. In July 2021 he was admitted to hospital with an aspiration pneumonia. A decision was made in best interest as he lacked capacity to make the decision. The decision making including his brother was to continue with high risk feeding as it was felt that a PEG was not appropriate, and he was discharged back home 2 weeks later.

After only 2 days at home, he was readmitted to the same hospital. During this admission he was seen and assessed by SALT and dieticians, they provide input into the MDT decisions relating to his feeding regime. He remained in hospital being fed via a naso-gastric (NG) tube, unsuccessful attempts were made to find a placement that were able to meet his physical needs including NG feeding and his psychological needs. A PEG was placed allowing for his discharge home to his long-standing care home in December. On discharge he had a number of areas of pressure tissue damage.

He had two further admissions but died at home with the support of his GP, hospice at home team, staff he knew around him and his brother.

Good Practice Identified	- Support from the LD specialist team with best interest discussions re: the need for a PEG feeding tube. The family would like the team to be made aware of this and it to be acknowledged in the review.
Learning Identified	- Acute care staff not identifying that patients with a learning disability need specific communication strategies to ensure that the person has capacity to provide accurate information in response to questions. Staff education and awareness of techniques / tools to support required. - Imperative for Multi-disciplinary teams and the whole system to be aware of delayed transfers of care and consider risks throughout. Delays noted discharging back to his care home on more than one occasion. The MDT needed to be aware of all involved and the impact of decisions made, for e.g. social, psychological.
Acronyms explained	PEG – percutaneous endoscopic gastrostomy, a feeding tube. SALT – Speech and Language therapy GP – General practitioner MDT - Multi-disciplinary team

Our People's Stories continued

Pen Portrait 2 (16739) LD

73-year-old female with moderate learning disability.

Primary cause of death – Spontaneous Gastric bleed.

This lady was known to like baby dolls, puzzles, foot massage, painting her nails, 'teddy dog' and engaged in bean bag games. She would enjoy going into the garden for a picnic, watching TV and listening to music and doing small puzzles.

She was not an early riser and sometimes had bad days – on those days she would have fits of screaming. She would also refuse to stand up on these days and staff had to use aids to move her. When speaking to staff she would vocalise and say "yes" and "no" or be able to tell staff her choice of food. Her brother and his wife live in Cornwall and kept in touch her via video calls. They also visited on occasion.

The LD Physio and Occupational Therapists were working with her to improve her mobility, and she was prescribed regular paracetamol which helped. She was provided with appropriate aids and adaptations. Following a hospital admission, she was moved to respite whilst further changes were made to her home. During this period, she had been unhappy in respite, shouting, screaming and throwing her soft toys around. She would grab at staff in an agitated manner and did not appear happy. Once home, she was much happier, not screaming and was interacting well with staff and with other home residents who came into her flat. She preferred to stay indoors rather than go out.

Sadly, her mobility was slowly worsening, and she needed a wheelchair. Following an increased score on the dementia assessment tool used, a discussion between the LD nurse and the Psychiatrist took place regarding a possible diagnosis of dementia. Further discussion followed with the Home Manager as to reasonable adjustments required for her to have a head CT to aid a formal diagnosis of dementia. Unfortunately, she died before this could be investigated further.

Good Practice Identified	- Care staff recorded as being excellent by the radiographer during an ultrasound.
Learning Identified	- No evidence seen of a test for H.Pylori. This should occur for patients with a gastric bleed. - Staff confusion about the difference between Diabetes insipidus and Diabetes Mellitus, leading to inappropriate tests. Staff education / reminder for the differences for care and treatment.
Acronyms explained	TV – Television LD – Learning Disability Physio – Physiotherapist CT – Computed tomography is a type of scan completed, medical imaging to obtain internal images of the body

Our People's Stories continued

Pen Portrait 3 (ref 21072) LD

59-year-old male with mild learning disability.

Primary cause of death – Acute Left Ventricular failure.

This gentleman was kind, loving, cheerful, happy and he lived a very full life. He was an eternal optimist, always saw the glass half full. He happily went through life focussing on the positives and never fretting over things beyond his control or outside his reach. He concentrated on things he cared about: his family, his friends, holidays, sports, parties, family get togethers, and of course his daily newspaper.

Over the years he travelled to most corners of the world. His family photo albums are full of pictures of him laughing and smiling, riding Elephants in Thailand, swimming with dolphins in the US and more.

He began attending a Day Centre, mostly focused on sport. With support from his coach, he went on to participate in numerous national competitions, winning lots of medals.

He made his final move to new accommodation in Farnham where he enjoyed a bit more independence and became increasingly involved in their day service activities. He loved helping in the shop, loading vans and more.

He was a cheerful, loving soul. He had a giant heart, his family loved dearly. Although sudden and unexpected, he passed away peacefully, with dignity, and without pain or suffering. His family just wish he could have stayed a little longer, because they are going to miss him desperately, every day.

Good Practice Identified	- Reasonable adjustments were made by teams at the acute hospital, before, during and after surgery. - Bereaved families were supported with an unexpected death, allowed to stay and say goodbye, taking their time at the care home.
Learning Identified	- Bowel cancer screening invitation was not taken. GP practices to follow up when an invitation is declined or not attended.
Acronyms explained	N/A

Our People's Stories continued

Pen Portrait 4 (ref 23532) LD
50-year-old female with mild learning disability.
Primary cause of death – Alzheimer's disease.

This lady lived at home with her parents. She had two brothers who lived nearby and visited frequently. She attended mainstream school and college. She was bright and worked in M&S for over 20 years. She made videos about LD and once gave a talk to 800 people. She also kept a private diary. She liked to dance, especially modern dance and liked a glass of wine. She took the train and bus by herself to college.

Her mother died in 2021, and her father continued to cook and care for her, along with other family members and her carers. It is not possible to gauge her level of understanding about her mother's death, but she did keep looking at where her mother used to sit. She developed a maternal relationship with one of her carers which gave her some comfort.

Latterly, she greatly enjoyed "Us on a Bus" on a Tuesday afternoon. She preferred to stay close to home and became distressed when attending activities which were out of her usual regime, e.g. going to a day centre. She could show signs of anxiety which those who knew her could recognise – this was thought to be possible doe to the loss of her mother or the pandemic.
In March 2023 she became short of breath and was admitted to hospital. She improved with antibiotics but continued to lose weight. A PEG was discussed but a Best Interest meeting concluded the benefits of a PEG were far outweighed by the risks. It was agreed by all that she would be discharged to the hospice. A syringe driver was set up and anticipatory medication prescribed. She was discharged to the hospice, and she passed away in May 2023.

Good Practice Identified	- No specific examples of good care identified.
Learning Identified	- Carers were not adequately training in moving and handling techniques. This will be fed back to social services. All staff must be safely trained and full risk assessment completed for all patients. - Inconsistent arrival or carers if at all on occasion leaving the elderly father to manage on his own. To be fed back to social services.
Acronyms explained	M&S – Marks and Spencer's retail establishment PEG – percutaneous endoscopic gastrostomy, a feeding tube.

Equality Impact

The public sector Equality Duty, part of the Equality Act (2010), requires public bodies to consider all individuals when delivering services, and that public bodies have due regard to the need to eliminate discrimination and advance equality of opportunity. The LeDeR programme seeks to support and enhance the ICB's fulfilment of this duty by identifying any areas for improvement and translating these into actions to ensure that individuals receive optimal care and treatment with proper consideration of personal circumstances and allowance made for any reasonable adjustments. Reviewers are alert to any indications that an individual's care and treatment may have been adversely affected due to protected characteristics or other factors affecting equality of provision.

Ethnicity

The table shows the ethnicity breakdown of the people we received LeDeR notifications for in 2023/24. The ethnic group headings have been updated in line with the ethnic groups agreed for the 2021 Census.

Frimley ICB received 39 notifications in 2023/24, compared to 34 notifications in 2022/23.

7.8% of these notifications belong to global majority groups within the Frimley population; a significant reduction from 17.65% in 2022/23, despite a 14.71% increase in notifications.

	White					Mixed/Multiple ethnicity groups				Asian or Asian British					Black, Black British, Caribbean or African			Other Ethnic Groups		
Ethnicity	English, Welsh, Scottish, Northern Irish or British	Irish	Gypsy or Irish Traveller	Roma	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed or multiple ethnic background	Indian	Pakistani	Bangladeshi	Chinese	Any other Asian background	Caribbean	African	Any other Black, Black British, or Caribbean background	Arab	Any other ethnic group	Not stated/preferred not to say
No. of reported deaths	34	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	0	1	2
% of all reported deaths	87.2%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0%	0.0%	2.6%	0.0%	0.0%	0.0%	2.6%	0.0%	0.0%	0.0%	2.6%	5.1%

Data Set: Performance

	Notifications No. & %		Completions No. & %		Focused Reviews (including in progress)	% of all Reviews completed within 6 months of notification:
2021/22	41	100%	24	59%	4	62%
2022/23	34	100%	35	103% ↑*	12↑	17%↓
2023/24	39	100%	24	62% ↓	10↓	20%↑

*This includes completion of cases notified in the previous year, so the figure can exceed 100% of the number of cases notified in-year.

Performance Narrative

- The number of cases notified to the ICB in 2023/24 increased by 5, compared to the previous year.
- The number of cases completed in 2023/4 decreased by 41%, compared to 2022/23.
- The number of focused reviews decreased by 17%, compared to the previous year.
- The percentage compliance for reviews completed within 6 months of notification increased by 3% in 2023/24, compared to the previous year.
- Timeliness of completion is a significant risk, resulting in an increased backlog of cases awaiting allocation to a reviewer. Factors affecting performance include limited reviewer capacity, delays in receiving further information and case complexity. Mitigations have been put in place to support improvement with these areas. For example, increasing reviewer capacity and applying for read-only access to the Electronic patient record system, EPIC at FHFT.

Local Reviewer Arrangements

Until September 2023, the programme utilised the skills of four reviewers employed on bank contracts, supported by funding from NHSEI. In September 2023, the team complement grew to six reviewers to promote and support increased productivity. 2023/24 was affected by periods where not all reviewers were available to work on cases.

Reviewers are supported by a monthly supervision group and have access to specialist advice from key people within the ICB, including Safeguarding leads and LD & Autism specialists. They can also access all other members of the LeDeR team as required and often support each other with peer supervision / reflections. Once cases are completed, meetings are held with the LAC to discuss the review. This encourages the provision of one-to-one support and regular contact is maintained. Attendance at our Sign-Off Groups, Steering Groups and Regional Reviewers' Group is also encouraged.

Data Set: Demographics (from local data)

NHS Frimley

Gender

Analysis shows that an equal number of male and female cases were reported in 2023/24.

There were an additional two cases involving people who were male at birth but identified as female. For comparison, the male / female composition of the Frimley ICS general population according to GP registrations is 407,000 male and 405,000 female – roughly a 50/50 split. (These figures do not account for people who identify as non-binary, a subset not currently shown in the available data.)

	2021/22		2022/23*		2023/2024	
	Male	Female	Male	Female	Male	Female
No.	26	15	16	16	19	20
%	63%	37%	50%	50%	49%	51%

*In 2022/23, a further 2 people were male by birth but identified as female.
*In 2023/24, 2 people were male by birth but identified as female, and 1 notification did not state the individual's gender.

Level of Learning Disability (if known)

The information below shows the breakdown of this information for all of the people whose reviews were completed and signed-off in 2023/24, and for whom the level of learning disability had been recorded.

Level of Learning Disability	2021/22	2022/23	2023/24
Mild	7	6	9
Mild – Moderate	1	3	2
Moderate	6	14	6
Moderate – Severe*	1	1	0
Severe	8	6	5
Profound / Multiple	0	2	0
Severe and Autistic	0	0	1
Autistic	0	0	1
Unknown	1	3	0

*Level of learning disability varied between two categories in documentation provided so an in-between classification has been added.

Data Set: Demographics, Age (local data)

All Adults with learning disabilities / autistic notified in 2023-2024:

- There was a total of 39 deaths
- The range of age at death was 38 – 90
- The average age of death was 63 (cf. 64 in 2021/22 and 58 in 2022/23)

Women with learning disabilities / autistic women notified in 2023-2024:

- There was a total of 20 deaths
- The range of age at death was 38 – 90
- The average age of death was 59 (cf. 62 in 2021/22 and 59 in 2022/23)
- Female life expectancy in the general population of Frimley ICS is 84 years

Men with learning disabilities / autistic men notified in 2023-2024*:

- There was a total of 19 deaths
- The range of age at death was 58 - 85
- The average age of death was 67 (cf. 68 in 2021/22 and 60 in 2022/2023)
- Male life expectancy in the general population of Frimley ICS is 81 years

*A further 2 people were male by birth but identified as female. These 2 individuals have only been included in the demographic data for all adults with learning disabilities and/or autism, and not within the gender split data. 1 notification received did not include the gender of the individual, however the review has been completed and gender confirmed; numbers above are inclusive of this update.

*Life expectancy data for the general population has been extracted from the NHS Frimley Equality, Diversity, and Inclusion (EDI) annual report (dated March 2024)

Data Set: Cause of Death for Completed cases.

NHS Frimley

The most common causes of death this year, as with the previous year, were linked to Respiratory conditions – pneumonia / chest infection. This totalled 25% of all completed cases for 2023/24. Cancer and Cardiac issues both totalled 21% of all completed cases. The table below shows the top primary and secondary causes of death for cases completed in 2023/24.

No	Primary Cause of Death (1a)
1	**Respiratory: 6** • Aspirational Pneumonia – 5 cases • Chest Infection -1
2	**Cancer: 5 (1 case of each listed)** • Metastatic Angiosarcoma • Locally advanced and metastatic Carcinoma of the Oesophagus • Carcinoma of the Bladder • Metastatic Ovarian Cancer • Acute Myeloid Leukaemia
3	**Cardiac: 5 (1 case of each listed)** • Pulmonary Embolism • Myocardial Infarction • End stage Heart Failure • Acute left Ventricular failure • Congestive Cardiac failure
4	**Dementia: 2** • Both cases Alzheimer's disease
5	**Other : (1 case of each listed)** • Epilepsy • Sepsis, unknown source • Septic shock with multi organ failure • Hepatic fibrosis and renal transplant rejection • Hanging • Spontaneous gastric bleed

No	Secondary Cause of Death (1b, 1c, 2)
1	**1 case each (1b):** • neurodegenerative diseases of unknown causes • Seizure • Early onset dementia secondary to Down's syndrome • Bilateral lower lobe lobar and bronchopneumonia • hepato-renal failure • Sepsis • Dextrocardia with Congenitally corrected transposition of the great arteries and ventricular septa defect • Coronary Artery disease • Oropharyngeal dysphagia
	1 case each (1c): • Eisenmenger's syndrome secondary to complete atrioventricular septal defect • Gastroenteritis with small bowel ileus
	1 case each (2): • **Covid 19** • **Breast Cancer** • **Nephronophthisis medullary cystic disease** • **Heart failure** • **Frailty, depression** • **Severe right ventricular hypertrophy, cystitis** • **Downs Syndrome** • **Other significant conditions contributing to death: organising pneumonia, pyometra, dementia with LD**

IMPACT – We acknowledge that not all families / carers want to be involved with the LeDeR review process and this is respected. Some examples of feedback from next of kin (NOK) who did participate are given below:

"The next-of-kin (NOK) did not think he was encouraged enough to do things and so lost some ability. He should have been helped more when he lost the use of his fingers and was not given any therapy to try and maintain use. The NOK said there were not enough resources."
(Ref: 18337)

"The family praised the hospital as they almost treated him like a VIP or guest. They were overwhelmed by how kind and tolerant all the staff were, who were said to have gone the extra mile to look after him when he went or his bilateral cataract surgery."
(Ref: 21072)

"As a family we were very happy with the care she received from the care agency and the hospital."
(Ref: 20255)

"A safeguarding concern had previously been raised by his carers following a hospital discharge at midnight. His home was not informed, and he arrived at the doorstep, along with antibiotics in his pocket."
(Ref: 16346)

Learning: Examples of best practice and positive outcomes from the reviews

NHS Frimley

Reasonable Adjustments: GP practice provided spare medications for use as tablets would occasionally be spat out. This is good practice especially for vital medications for conditions such as Epilepsy. The review also mentions that reasonable adjustments were made to accommodate vaccinations and blood tests.

Reasonable Adjustments: Breast clinic and A&E staff made all adjustments required to ensure that she was as distressed as little as possible .

Annual health checks: Annual health checks were completed and attempted to address her general health / lifestyle issues.

Quality of care: The family praised the care received at the care home. The Care home manager went above and beyond staying with her when her family could not be. This made it possible for end-of-life care to be given at her home rather than her being moved to a hospice.

MDT working: Demonstration of holistic care provided by all professionals involved, particularly from the GP practice.

MDT working: Good evidence of a joined-up approach following discharge from hospital between all services, e.g. GP, community health, CTPLD and palliative care.

Cancer screening: The patient did not attend her mammogram in 2019 so easy read information was sent and the matter discussed with her carers. Following that, she had a mammogram in 2020.

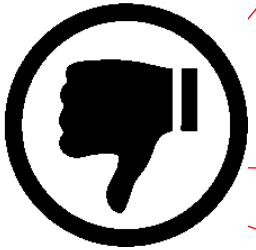
EOLC: He was fully involved with his DNACPR and died where and how he wanted to.

Learning: Examples of specific areas for improvement identified by reviews

Communication with patients: Medical staff would sometimes use complex jargon, especially around cardiac issues, when discussing his condition, which he did not understand. Staff should avoid jargon when explaining complex issues, whether the patient has LD or not, and should use resources such as LD Liaison nurses to comply with this.

Health Passport not in place: These passports can be of great use in enabling hospital staff to understand not only the person's baseline health but also preferences and behaviours. GPs, carers and CTPLDs should ensure all patients with LD have Health Passports.

Reasonable adjustments for clinical procedures: Blood glucose and Cholesterol tests had been declined for monitoring. Staff need to consider a range of options when procedures are problematic and to seek expert advice if necessary.



Communication with family and carers:
Poor communication with family members about care planning and risks. To ensure that the patient's needs are reviewed holistically, we must ensure that families and carers have a voice.

Health Passport not used:
Health Passport available but not used by ward staff. On occasion whilst in hospital, he became upset or agitated which could have been avoided had his passport been read. For example, staff took his glasses off him at night but, as his passport stated, he kept them on at all times and even slept with them, and he was distressed that staff would not allow that. It was also recorded that he could not tolerate spicy food, but a curry was ordered for him.

End of Life Care:
The DNACPR put in place in 2020 was apparently not reviewed when she improved, and there was no evidence of an up-to-date Advance Care Plan or consideration of any anticipatory medications. End of Life arrangements, including DNACPRs, should be reviewed when circumstances change, and appropriate Advance Care Plans should be put in place.

Mental Capacity Assessment: It is not clear that MCA assessments were always carried out when key decisions needed to be made. It must be assumed that a person with LD has capacity until proven otherwise. On-going training and awareness of Mental Capacity Assessment and Best Interest within all provider organisations.

Learning: Examples of thematic areas for improvement identified by reviews

Annual Health Checks: The patient did not have an annual health check in the last year of her life. Learning / Action: To ensure people with LD are actively invited and supported to attend AHCs.

Immunisations: She was not offered an early Shingles or Pneumococcal vaccination. Early vaccinations should be considered for highly vulnerable people.

Delayed Diagnosis: Severe constipation was not investigated / managed effectively at an early stage. Failed endoscopy, lack of follow-up to rebook endoscopy with sedation, and failure to admit under GI surgery for more urgent interventions and investigations.

Quality of Care: Carers were apparently not trained in how to move the patient. Also, the carers at home were not always consistent and sometimes they would not turn up due to staffing shortages, leaving her father to cope alone.

Cancer Screening: The patient had not had cervical screening since 2014 (she did not like it). No evidence of any reasonable adjustments attempted to support her with this screening. Also, bowel screening invitation not responded to. To ensure that reasonable adjustments are explored to support people with LD take up for cancer screening invitations.

Carers Assessments: There was no documentary evidence of a carers assessment. Carers assessments should be routine for people who act as carers.

Listening to Carers: Medical professionals interpreted her screaming and shouting as her not wishing to attend an appointment, whereas this was her normal method of communicating and not necessarily a sign of distress. (This can mean attempts at reasonable adjustments for appointments, screening, immunisations, or other procedures are not fully explored.) Carers should be listened to regarding a patient's behaviours and ways of communicating..

Summary of Main themes captured from our reviews:

Learning Identified:
Cancer Screening
Annual Health checks (AHC)
Hospital Passport (now Health passport)
End of Life care
Communication

Good practice Identified:
End of Life care
Quality of care
Reasonable Adjustments (RA)
Multi disciplinary working
Cancer screening

Frimley ICB Learning into Action (LiA)

To complement the Frimley ICB Strategic priorities (page 7), the topics below were adopted as the main local priorities for the Learning into Action Group in 2023/24, continued from 2022/23:

1 – Annual Health checks: Evidence suggests that providing health checks to people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses. Ref: Annual health checks and people with learning disabilities - GOV.UK (www.gov.uk). Public Health England's Learning Disabilities Observatory has published a systematic review of evidence concerning the impact of health checks on the health and wellbeing of people with learning disabilities.

2 – Cancer screening: Given that life expectancy for people with a Learning Disability is significantly lower than for the general population, the early detection of life-threatening conditions such as cancer is of vital importance. Ref: Cancer screening: making reasonable adjustments - GOV.UK (www.gov.uk). Some LeDeR cases have found ambiguity around why an individual has not had their screening; an absence of evidence of mental capacity being assessed, relevant best interest decisions documented, or support for individuals and carers to access screening. ICB-level data show lower levels of uptake for people with LD. It is therefore important that we focus on promotion of these checks and support for individuals and carers to access screening, and for clinicians to have the tools to educate and inform people on their importance. This links with the Annual Health Check work described above.

3 – Early Detection of Deterioration: LeDeR cases have shown the importance of swift recognition of deterioration, particularly in community / residential settings where 'soft signs' of deterioration may go unnoticed. The University of Bristol has published a paper on the importance of early detection of deterioration in people with LD – ref: RecognisingDeteriorationLiABulletinFINAL.pdf (bristol.ac.uk).

These three topics are highlighted in yellow in the updates on our strategic aims on the following slides.

Strategic Priority updates 2023 - 2024

No.	Activity / Update	Next steps
1	**We will work to ensure that people with learning disabilities and autistic people have access to the support they require when accessing health services.** **Reasonable Adjustment Digital Flag (RADF) Project:** the aim to create a 'digital flag', or a 'pop up', that appears whenever their healthcare record is opened. This is in line with National roll out which needs to be in progress by April 2024. This flag will state what reasonable adjustments the person has requested, so that they can be implemented at any stage of their patient journey, from booking the appointment, to receiving care, and through to being sharing their experiences afterwards as feedback. Original pilot 2022/23 was in Slough with three care homes, and 28 residents had their RADF template completed (some in their best interest), returned and uploaded to local system. Progress has been made rolling this out across the wider system and with the development of resources, e.g. easy read. This year has been focussing on raising awareness in primary / secondary care services as well as developing resources with people with lived experience. Easy read forms have been shared with local care homes via the ICB's Care Home Forum, and both versions have been shared with local stakeholders via local charities, schools, parent carer forums, and participation groups, e.g., Speak Out and Be Heard. The new patient registration forms now include the question on whether a patient requires reasonable adjustments. Practices and PCNs are also reminded to make every contact count and enquire whether patients require reasonable adjustments. RADF reviews has been added into AHC template on Ardens. This will add some additional questions in a new section on the AHC template, including 'does the person have a RADF?', 'does the person want to change or add a digital flag?', and 'have their reasonable adjustment requests been reviewed?'. RADF forms will not be completed during AHCs though, the request form will be given for completion outside of the AHC. The Learning Disability and Autism team now has a dedicated resources page on the Frimley Health and Care website where patients, parents, carers or other support workers, can access information, the link to the website is: https://frimleyhealthandcare.org.uk/your-health/learning-disability-and-autism/	• Share examples of reasonable adjustments in practice to support implementation across ICS, especially in primary care. • Working with coding teams to capture data across the system.

Strategic Priority updates 2023 – 2024 continued

No.	Activity / update	Next steps
1 cont	• Host RADF forms are available on the Healthier Together platform, place-based SEND Local Offer websites, and other appropriate online platforms across the ICS. The Learning Disability and Autism transformation manager is having introductory meetings with PCNs and using these meetings to promote the Reasonable Adjustments Digital Flag and sharing the reasonable adjustments checklist and guidance that has been compiled. • Consultation with Be Heard (group of adults with learning disabilities) in Bracknell on access to primary care. • LiA presentation on access to primary care (06.06.2023)	
2	**We will promote a 'Rights Based Approach' in Frimley ICS** Across the system a Rights Based Approach has been taken, specifically in projects such as the advocacy and life planning proposals in the LDA Service Development Fund and continued work in the Transforming Care group.	• To be reviewed.
3	**We will work to improve the continuity of care when transitioning between primary and secondary care services.** Hospital passports, now known as **Health passports** are essential in providing vital information between services in managing our patients appropriately, safely and with excellent care. From the Annual Health check audit 2024, it was noted there had been an increase in patients having a passport by 10% from 22/23, but there remained issues with health passports not being shared with GPs for information or input. A Health passport audit was completed with 27 care homes. These all attend the ICB's LD Care Home forum across Frimley ICS. This covers 221 residents. It was reported all residents had a passport in place and 215 of these had been reviewed in the last 12 months.	• Considering digital version. • Potential for a Health passport strategy to be developed. • Working group to progress this priority.

Strategic Priority updates 2023 – 2024 continued

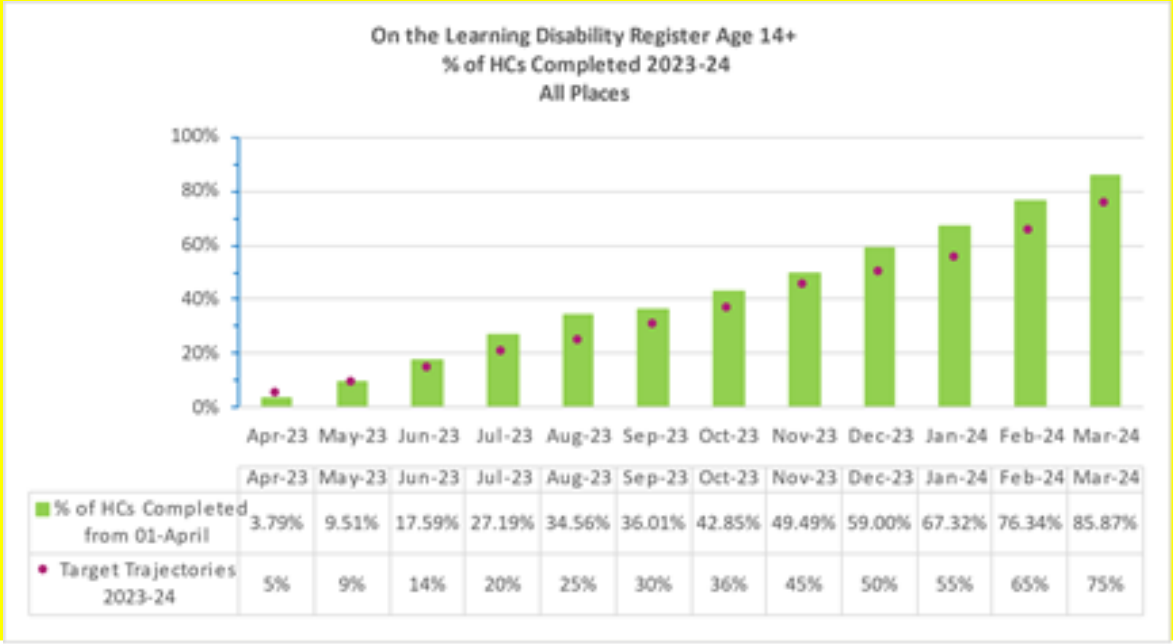
No. 5	Activity / update	Next steps
4	**We will improve application of the Mental Capacity Act across our partner organisations** Across the system understanding of the MCA has been improved through specific resources on the DXS system / LDA resource pack and training as part of the Annual Health Check Quality Audit. From the audit data 23/24, it is indicated MCA was applied and best interest decisions taken where appropriate in 25% of cases. Across the system, all providers continue to deliver training and ensure competency with statutory training requirements. The ICB are providing in level 2&3 Safeguarding training to applicable staff. Directly from the LeDeR programme, promotion continues within all meetings where learning is shared and through the local LeDeR Learning bulletin.	• System works ongoing.
5	**We will promote cancer screening – one of Frimley top three local priorities** ▪ From March 2024, our data shows that uptake remains lower among people with LD: ▪ Bowel screening rates were at 54% for LD uptake and 72% for all population, ▪ Breast screening rates at 42% for LD uptake and 70% for all population and ▪ Cervical screening rates at 30% for LD uptake and 70% for all population. ▪ Frimley Health Foundation trust have provided a focus on screening services working alongside Public health England. This began with reviewing Colonoscopy which led on to all services, including cervical screening. A recovery / action plan has been developed and implemented. ▪ Promotion of Easy read documents has been shared through communications. ▪ Mammography is being reviewed comparing with national resources and communications shared with the system. ▪ AHC audit indicated NHS screening programmes discussed / Easy read information shared applicable for 25% of cases. This has increased from 9% the year before.	• Local working group to be established. • Scoping of current local resources available. • Continual promotion of Easy read documents. • Share and learn – attend national webinars and teaching sessions, e.g. National Cancer screening webinar. • Education / promotional sessions needed for all areas of the system, patients, families, carers, staff.

Strategic Priority updates 2023 – 2024 continued

No.	Activity / update	Next steps
6	**We will work to ensure that people with learning disabilities and autistic people receive the right medication at the right time** • Across the system understanding of STOMP/STAMP has been improved through specific resources on DXS / LDA resource pack and promotion of free training. • A STOMP audit was completed 2023/24 (previous STAMP works 2022/23). This was completed with the Medicines Optimisation team. The results were: A total of 23 from 32 individuals (72%) were identified as being over 18 years old, recorded as having a learning disability and/or autism, prescribed a psychotropic medication and living in a care home Out of the 45 medications prescribed the most frequent indications for prescribing were epilepsy (13 medications), challenging behaviour (8), sleeping disorders (3), bipolar disorder (2) and for some the indication was not clear Four different antipsychotics were prescribed to ten different individuals. The audit identified some issues with concomitant prescribing of multiple psychotropics, and in some cases with the use of antipsychotics for challenging behaviours.	• A local LD medicines support service/pathway would ensure that best practice is being followed. • Regular monitoring of treatment response and side effects is crucial. • Local guidance and training on drug monitoring recommended for antipsychotics prescribing should include specific recommendations relating to learning disabilities. • New Mental Health Integrated Community Services roles should work with PCNs/Primary Care to support best practice. • Continued promotion and completion of the Oliver McGowan training on Learning Disability and Autism starkly highlights the risks associated with inappropriate psychotropic medication prescribing.
7	**We will improve awareness of how to manage good bowel health** Bowel health easy reads have been made available through DXS / LDA resource pack and the Primary Care Liaison Nurses in Frimley South offer specific sessions on bowel health for patients, carers and professionals. The ICB has encouraged GPs to notify the Southern Bowel Screening Hub of any eligible patients on their LD registers so that supporting materials can be sent with their screening invitations.	• System works ongoing and to be reviewed. This links with the cancer screening work discussed elsewhere in this report.

Strategic Priority updates 2023 – 2024 continued

No.	Activity / update	Next steps
8	**We will make better use of Annual Health checks (AHC) – one of Frimley top three local priorities** • School audit for review of completion for those aged 14 – 17 years old. As part of this an Annual health check demonstration / awareness session was delivered at Portesbery school. See Appendices for details. • Annual Health Check Quality Audit and training. From NHSE data, out of a regional average of 34.8%, Frimley ICB achieved 42.5% which, puts Frimley in a very good position across the SE region. • LDA gold standard resource pack. • Presentation on reasonable adjustments for Annual Health Checks delivered by NEHF Care Coordinators at LiA meeting 06/06/2023.	• Quality audit to continue. • To reach the 'stretch target' of 85% completion. • The Learning Disability and transformation manager is promoting the importance of AHCs and HAPs as part of discussions with practices and PCNs. This includes ensuring the correct boxes are ticked and SNOMED codes utilised.



	Apr-23	May-23	Jun-23	Jul-23	Aug-23	Sep-23	Oct-23	Nov-23	Dec-23	Jan-24	Feb-24	Mar-24
% of HCs Completed from 01-April	3.79%	9.51%	17.59%	27.19%	34.56%	36.01%	42.85%	49.49%	59.00%	67.32%	76.34%	85.87%
Target Trajectories 2023-24	5%	9%	14%	20%	25%	30%	36%	45%	50%	55%	65%	75%

Strategic Priority updates 2023 – 2024 continued

No.	Activity / update	Next steps
9	**We will improve the recognition and management of pain** Frimley ICS has supported early detection of deterioration with training and education for LD care homes, including use of the Restore2 and Restore Mini tools. A review of pain recognition tools was also undertaken, and further work on this is being scoped.	• Discussion of possible further actions will be included in the Learning Into Action Group agenda.
10	**We will ensure consistent access to End-of-Life care in Frimley ICS** • Respect training has been provided across the system to promote completion. The training discusses the level of detail and clarity required for valuable completion. • The Ardens template also has prompts within the AHC for discussion around End of Life care. • An additional training session regarding Respect and Advanced Care planning was attended by 600 primary care colleagues. This included understanding who should have a respect form, particularly identifying those in the population entitled to ACP and Respect.	• Managing End of Life training sessions, provided in conjunction with Phyllis Tuckwell Hospice are being considered for future training offers. • Respect training continues to be available. • Review these priorities with the Palliative and End of Life care board.
11	**We will ensure RESPECT and DNACPR forms are always completed comprehensively** • Respect training is available on eLFH now for all to access. • Respect Level 3 training is provided by the hospices & the acute trust also provides some. Level one training is a general awareness for all staff, level 2 is for those who might have patients who are at the Palliative End of Life Care stage and they might discuss wishes with them. Level 3 is for those who have undertaken communication skills training and able to be a responsible clinician, discussing the patients wishes including DNACPR and making clinical recommendations.	• As above.
12	**We will actively support and encourage Advance Care Planning** The system are updating the Advance Care Plan (ACP) for adults, which includes reference to children and young people advanced care planning. They are looking to modify their ACP to make it more accessible for autistic people and people with a learning disability as well as hoping to co-ordinate GP training on Advance Care Planning.	• As above. • A toolkit for ACP and LD is being considered for use across the system.

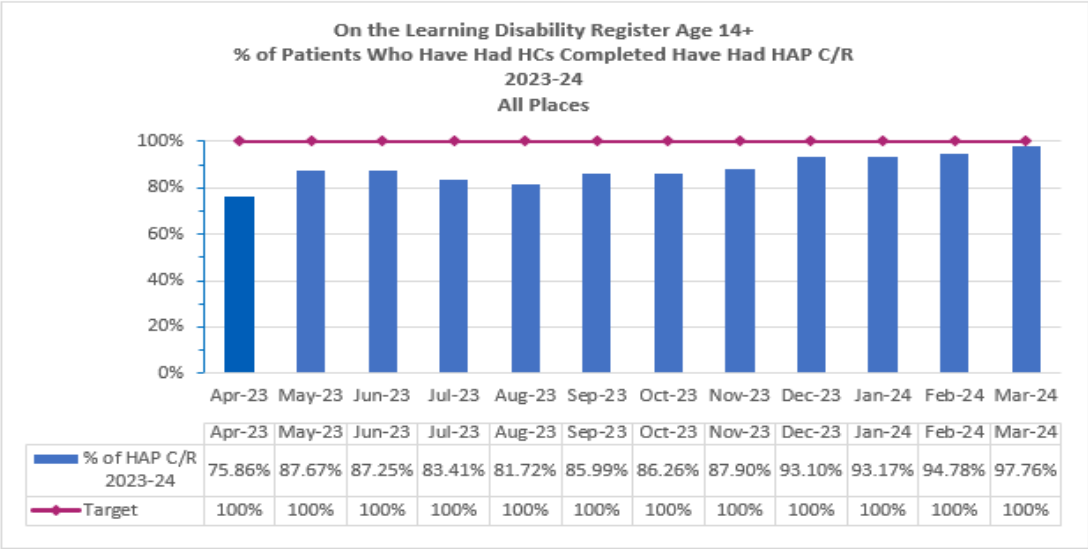
Strategic Priority updates 2023 – 2024 continued

No.	Activity / update	Next steps
13	**We will meet the health needs of BAME citizens with a learning disability** • Initial data gathered in 2022 on BAME citizens with an LD in Frimley South (available on request) • Work in Surrey Heath on the profiles of patients who don't attend their Annual Health Checks and implications for BAME citizens.	• System works ongoing. Awaiting further detail.
14	**We will promote system learning** • 'Learning into Action' is a dynamic group with a wide-reaching agenda and many different types of professionals attending. Cross system learning and working is promoted, and the group has helped enable places to learn from the good work others are doing. • One example of this is that the work with Portesbery School in Surrey is due to be replicated in East Berkshire. • New monthly Learning Disability and Autism Bulletin for professionals across the ICS to share updates, training and good news stories. • Frimley LeDeR Learning bulletin developed quarterly for the ICS. This showcases one headline topic, shares good practice and the learning identified from reviews along with training opportunities locally and nationally. • LeDeR steering group runs quarterly to provide updates on our programme, share developments across the system, highlights good practice / learning identified and provides local and national updates accordingly.	• Learning into Action group to be refreshed and re-established following team changes • Frimley LeDeR Learning bulletin to continue production quarterly and is distributed to all providers within the system, including GPs, BHFT and SABP

Learning into Action updates:

LD Health Action Plans (HAPs) are required to be completed / reviewed during and following an annual health check (AHC). The threshold is100% completion for those who have received an AHC. A gradual increase has been evident over the year and in March 2024, 98% of HAPs were recorded as completed at ICB level. The 2% gap of patients on the LD register not having one in place requires investigation.

From the AHC audit, 60% of patients were given a copy of the easy read Health action plan. This is an increase from 14% the year before.

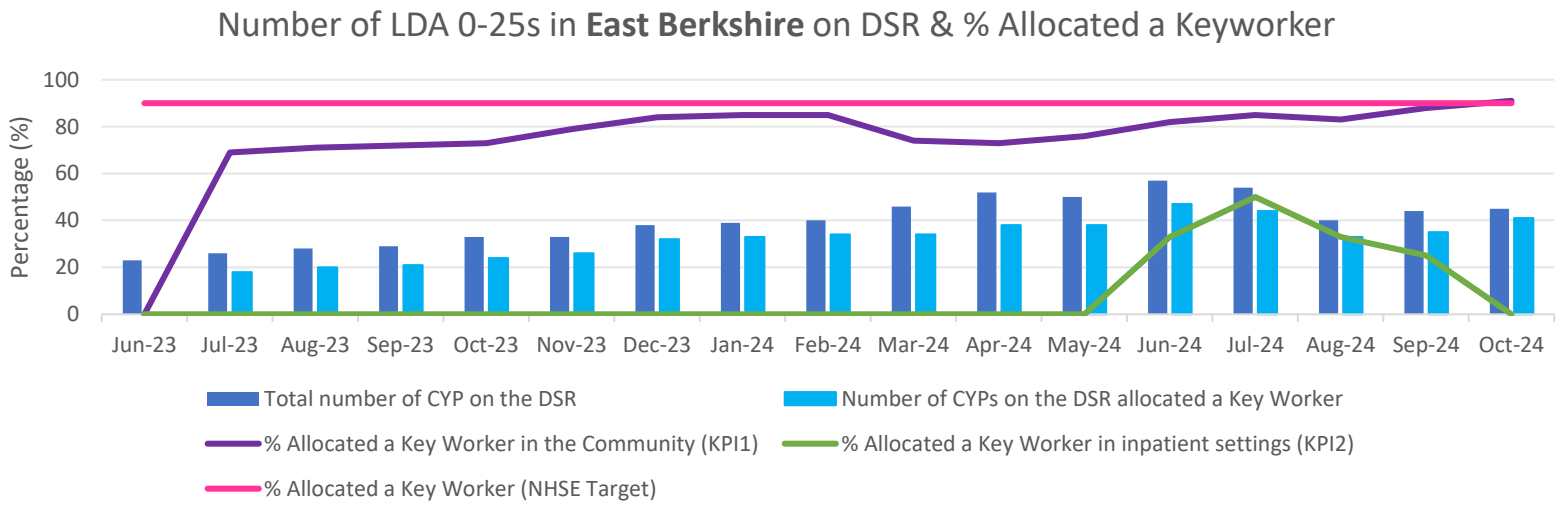


	Apr-23	May-23	Jun-23	Jul-23	Aug-23	Sep-23	Oct-23	Nov-23	Dec-23	Jan-24	Feb-24	Mar-24
% of HAP C/R 2023-24	75.86%	87.67%	87.25%	83.41%	81.72%	85.99%	86.26%	87.90%	93.10%	93.17%	94.78%	97.76%
Target	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Dynamic Support Register (DSR): The ICB LDA team are working on the Dynamic Support Register to make it more meaningful, accessible and inclusive. Once on the DSR, an individual is rated Amber or Red enabling swift access to the Keyworker Service & support provided by Barnardo's. The team have developed a revised DSR referral form which is more user friendly to encourage self-referrals in line with the new national policy on the DSR and Care & Treatment Reviews.

Learning into Action updates continued:

Key Worker Service: When added to the DSR, an individual is referred to a Key worker who then offers advocacy, meaningful rapport and support to the Children and Young People (CYP) & their families. Keyworker service provided by Barnardo's on behalf of Frimley ICB for East Berkshire commissioned from 1st June 2023.
In East Berkshire February 2024, 81% of the Young people on the Dynamic Support Register (DSR) are now allocated a keyworker, against the NHSE target of 90%.
The Key Worker service planned to recruit an additional member of staff earlier than originally anticipated to account for the increased demand using available underspend.



LD Care Homes ICB Support Work:

- Falls awareness and falls management training has been offered to all Care homes across Frimley ICS, including LD homes.
- Restore2 training continues to be offered, and an additional virtual training option provided.
- Virtual Dysphagia Safety and IDDSI (International Dysphagia Diet Standardisation Initiative) sessions have been offered to all homes.

Additional works initiated linked with LeDeR learning:

Promotion of Easy read resources to all clinicians, signposting to the LeDeR Resource bank. This was communicated through all appropriate channels to the Frimley ICS. This also included confirmation that these were linked and available via DXS for ease of use with Primary care.

The Safeguarding team are developing a system wide DNA / was not brought policy and guidelines.

LeDeR Awareness session to be provided to Safeguarding / GP leads within Primary care across the system, to promote the understanding and value of the programme.

The commissioning and provision of Community Equipment pathway is being reviewed within the system, with a particular focus on the assessment, training, provision and maintenance of Suction equipment.

Quarterly Learning Bulletin compiled demonstrating areas of good practice and areas for improvement. This also has a headline topic for further focus and provides links / information regarding any local or national training available. This is disseminated to all partners / providers across the ICS.

To incorporate Lived experience stories into system meetings and learning sessions to promote the impact of good practice and service improvements required.

Service Developments / Improvements in progress:

LeDeR resource bank materials shared with the GP bulletin and DXS links updated.

Promotion of LD week.

Cancer screening webinar and local ICS meetings planned.

Promotion of LeDeR within Primary care.

Promotion of LeDeR within Safeguarding boards / teams.

Sharing the Learning Bulletin with the ICS and all provider services engaged with Frimley population.

Reviewing methods of working for streamlining and improving the quality / sensitivity of the LeDeR programme.

Support directory for Patients with Learning disability, families, carers, professionals and anyone who supports them within Frimley ICS – in discussions to review existing resources.

Additional service review following LeDeR learning:

- Additional LeDeR reviewer capacity following the demands of the programme.
- Resetting of the Learning into Action group following role and team changes.
- Linking with neighbouring ICBs to promote learning and support the provision of Health inequalities Webinars for all clinicians.

The Year ahead – our priorities 2024 / 25

Continue to review the efficiency and effective of the LeDeR programme, e.g. capacity, demand, KPIs and promote collaboration / learning within the Frimley ICS.

Updating and continuing works on the Frimley ICB Strategic Priorities with particular focus on the top three local priorities with one addition:

1) Annual Health checks,
2) Cancer screening,
3) Deteriorating patient, and adding
4) Health passports.

Resetting the Learning into Action group and encourage sharing of good practice and learning throughout the system.

Conclusion

We greatly value the role the LeDeR programme plays in shaping and driving service improvement within our Integrated Care System. Our dedicated LeDeR team strive to reflect individuals' stories, sharing the positive lives led by many and to also identify the learning to support service improvements / reduce health inequalities for our population. This would not be possible without the contribution of all involved from families to provider services whom we acknowledge for their role. Our lived experience volunteer is also invaluable to the team.

There remains more work to be done locally and nationally to address the gap in life expectancy between people with a Learning Disability / autistic people and the general population.

We see recurrent themes in our review findings, and sustained focus is required to achieve positive and meaningful change. And at the same time, we must continue to celebrate the good, as many clinicians and services show dedication with a drive to improve services and care with such passion.

We are considering further ways to disseminate the learning to help provide the evidence to a wider audience and encourage positive changes. The Learning into Action group is being refreshed to support sharing the learning and oversee service improvement workstreams. This will also be the forum for developing new plans for improvement work.

The Strategic priorities will continue to guide the workstreams with a focus on the top three local priorities with the addition of Health Passports. It will also be beneficial to review previous works around respiratory / cardiac service offers, as these continue to be the leading cause of death along with cancer.

We will continue to promote the LeDeR programme across our ICS, for example through awareness sessions planned for Primary care, system educational webinars, and presentations at the Mortality Review Group and the System Quality Group. We will continue to dedicate resource to the programme and will constantly strive to ensure that our review work is completed to a high standard, and that it informs improvement work to deliver beneficial outcomes to people with a Learning Disability and autistic people in our communities.

Appendix:

Examples of Learning into Action within Frimley ICS

A review of prescribed psychotropic medicines in adults with Learning Disability (LD), Autism or both within East Berkshire LD care homes

Authors: Tim Langran, Sundus Jawad, James Breeze (NHS Frimley), Orla Macdonald (BHFT)

NHS Frimley

Frimley Health and Care

Introduction

The extent of psychotropic medication use, particularly but not exclusively, antipsychotics and antidepressants in people with learning disabilities and autism has been an area of concern in academic literature for many years. In June 2016, NHS England launched STOMP, a programme to reduce over-prescribing of antipsychotics and antidepressants to people with learning disabilities, autism or both. The programme drew heavily on a Public Health England study documenting the extent of prescribing of psychotropic drugs by GPs.

Aims: To understand the extent of psychotropic medication prescribing in the LD care home population and identify areas for improvement relative to national guideline recommendations. These include trends in the following aspects of the psychotropic drug groups of interest:

- prescribing rate
- prescribing based on indications
- patterns of prescribing

Methods: Searches were run by the Frimley ICB Medicines Optimisation Team (MOT) to identify residents in LD care homes currently prescribed psychotropic medication. The primary care data collected was recorded on the sheet provided by NHSEI.

If gaps in the record were identified, the Berkshire Healthcare NHS FT (BHFT) Specialist Mental Health Pharmacist compared this with information held by BHFT for missing or additional information

Additionally, adults identified with a complex psychotropic medication regimen were passed to the BHFT Mental Health Pharmacist for a specialist medication review.

Results: A total of 23 from 32 individuals were identified as being over 18 years old, recorded as having a learning disability and/or autism, prescribed a psychotropic medication and living in a care home (fig.1).

Out of the 45 medications prescribed the most frequent indications for prescribing were epilepsy (13 medications), challenging behaviour (8), sleeping disorders (3), bipolar disorder (2) and for some the indication was not clear (19) (fig.2). Four different antipsychotics were prescribed to ten different individuals. Five individuals were prescribed an antipsychotic for challenging behaviour/aggression, one for bipolar disorder and four with no clear indication One resident was prescribed as many as 6 psychotropic medicines concomitantly (fig.3).

Regular reviews were being undertaken by both specialist and primary care teams, however, there was a lack of clarity about what monitoring was required as part of those reviews.

From the primary care medical records, only 2 of the 23 individuals (8.70%) were offered non-pharmacological support/psychological therapy services prior to drug initiation.

Discussion and Recommendations: A local LD medicines support service/pathway would ensure that best practice is being followed. Regular monitoring of treatment response and side effects is crucial. This includes documenting progress on treatment targets and conducting appropriate investigations. The indication for prescribing should be clearly documented. There should be more emphasis on non-pharmacological interventions and strategies, offering care staff training and family support, ensuring medications are used as a last resort. Clinical coding of learning disabilities and autism should be checked in all practices and updated during each medication review where appropriate.

Local guidance and training on drug monitoring recommended for antipsychotics prescribing should include specific recommendations relating to learning disabilities. New Mental Health Integrated Community Services roles should work with PCNs/Primary Care to support best practice.

The Oliver McGowan training on Learning Disability and Autism starkly highlights the risks associated with inappropriate psychotropic medication prescribing. This is the government's preferred training package, which all health and social care staff working with LD patients should complete.

References

- Branford D. A study of the prescribing for people with learning disabilities living in the community and in National Health Service care. J. Intellect. Disabil. Res; 38:577–86 (1994).
- NHS England » Stopping over medication of people with a learning disability, autism or both (STOMP)
- Glover G., Williams R., Branford, D., Avery, R., Chauhan, U., Hoghton, M. and Bernard, S. Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Public Health England. (2015).

Portesbery Special School – Annual Health Checks (AHCs)

Dr Oliver Sweeney (GP Clinical Lead) and Pip Catnach (Learning Disability and Autism Development Manager) delivered an Annual Health Check demonstration to students (aged around 12 upwards) at Portesbery School.

AIMS:

- Increase awareness of Annual Health Checks.
- Improve relationships with local schools and young people with learning disabilities.
- De-sensitisation work around doctors / equipment such as stethoscopes.
- Brief healthy lifestyle discussions to improve understanding of health.

How we made reasonable adjustments for the demo

- Created a visual schedule / social story to be given to students in advance (see previous slide).
- Kept it as interactive as possible – less talking, more showing the kit!
- Brought objects of reference to represent aspects of a healthy lifestyle – tennis racket for exercise, teddy bear for sleep, plastic food for diet.
- Used some basic Makaton and the pupils showed us some signs for future demonstrations.

NHS
Frimley

Bracknell Forest ⬢ North East Hampshire ⬢ Royal Borough of Windsor and Maidenhead ⬢ Slough ⬢ Surrey Heath and Farnham

Frimley Health and Care

NHS Frimley

Reasonable adjustments:

Tell us how to help you

If you are supporting someone to fill in this form, please go to page 9.

Reasonable Adjustments

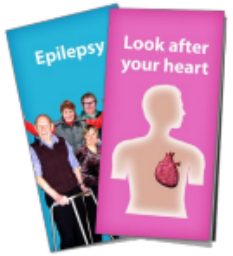
NHS Frimley

Some autistic people and people with a learning disability find it hard to use health services. For example, seeing a GP or going to hospital.

The law says that health services must make changes so everyone can use their services.

These changes are called **reasonable adjustments**.

Some examples of reasonable adjustments are



- having a longer appointment
- getting easy read information
- bringing someone with you to appointments

Use this form to tell us about the changes you need. This helps us to make health services easier for you.

A Reasonable Adjustments Flag can go on your health record. It tells NHS staff about any changes you need.

☐ **yes** - I want a flag on my record

☐ **no** - I do not want a flag on my record

If you ticked **no** you do not need to fill in the rest of this form.

If you ticked **Yes**, please answer the rest of the questions.

We can add information about why you need the changes.

For example:

- autism
- learning disability
- epilepsy
- physical disability

NHS Frimley

Would you like this information to be added?

☐ **yes**

☐ **no**

Your name:

Your date of birth:

Your NHS number:

My reasonable adjustments

Tick the box next to the changes that would help you.

- ☐ longer appointment time
- ☐ appointments at a quiet time of day

- ☐ a quiet place to wait
- ☐ short waiting time

- ☐ help to check in for my appointment

- ☐ ramps, lifts, or wider doors
- ☐ appointments on the ground floor

- ☐ a hoist to move from my wheelchair
- ☐ easy read information

- ☐ large print information
- ☐ information in another language

Which language? ☐

- ☐ a phone call to remind me about my appointment

☐ text message to remind me about my appointment.

☐ support from a carer or family member

☐ see a male member of staff

☐ see a female member of staff

☐ show me the equipment that might be used, before my treatment

☐ time to think and ask questions

☐ a summary of what happened at my appointment, written in a way that I can understand.

I need help with something that is not in this list. Please write what you need in the box:

Please give this form to your GP surgery.

You can:

- print it out and give it in person
- send it by post.
- email it.

We will try hard to make the changes for you. We might not be able to make all of them.

Supporting people to decide

The person I am supporting understands the questions in this form and is able to answer them:

☐ yes

☐ no

If you ticked **no**, talk to other people who know the person well. Agree what is best for the person – we call this **best interests**.

I have spoken to: (names, roles)

Adding a flag to their records is:

☐ in the person's best interests

☐ not in their best interests

Frimley Health and Care

NHS Frimley

Learning Disability Annual Health Check Quality Training

What?

1-hour online training on the ‘gold standard’ annual health checks for people with a Learning Disability in primary care settings.

When?

27th June 2023 2-3pm
Click here to join the meeting

6th July 2023 11.30-12.30
Click here to join the meeting

Alternatively, you can email us for an Outlook invitation to your preferred session

Who?

It is for Frimley ICS staff who carry out or arrange LD annual health checks, including:

- Practice Nurses
- Care Co-ordinators
- Paramedics
- Trainee Nurse Associates
- PCN Pharmacists

Why?

Some key areas for improvement were identified following the Annual Health Check quality audit across Frimley ICS.

To support Primary Care staff to deliver high quality annual health checks to improve health outcomes for people with a Learning Disability.