LeDeR Annual Report
Buckinghamshire Place, BOB ICS

For the period 1st April 2022 – 31st March 2023

NHS England and NHS Improvement

Content

Executive Summary

Key Performance Indicators (KPI's):

- All reviews allocated to a reviewer within 2 months of notification
- All reviews are completed within 5 months and two weeks (including Quality Assurance QA) and sent to the Local Area Contact (LAC) for review.
- Numbers are taken from weekly trackers.

Performance:

- 85 reviews contracted for 22/23 with the CSU
- 33 reviews completed for Buckinghamshire. Of these 3 were focussed, 30 Initials.
- There are currently 30 active cases for 2023-24

Learning from reviews

- Evidence of end-of-life plans and advanced care planning were documented, regularly reviewed and communicated to key people involved.
- Documentation to support a person-centered approach where the person with a learning disability was able to expressed their views in a non-verbal or unconventional way, and this was taken into consideration
- Families were largely complimentary of the services their loved ones received
- There is evidence of some excellent multidisciplinary working across acute and community services
- There is a need to improve the quality of annual health checks for learning disability population and health action plans. This includes easy read information for people with learning disability
- Further work is required to seek opportunities to make reasonable adjustments for people with a learning disability to cancer screening.

Key Findings

- Although the uptake in LD Annual Health Checks has increased in the last 2 years, there still remains a mismatch with regards to regular screening and a reticence or lack of information around desensitisation techniques to enable individuals to access screening services confidently.
- Families express concerns about the suitability of LD/Autism placements into care settings due to the shortage of appropriate provision in Buckinghamshire and the range of complexity of care packages.
- The Hospital Passport is not consistently used; however it also does not contain all the relevant information and there still remains a gap in documentation inconsistently shared across systems within the heath sector.
- Evidence seen of good care with all health care teams, including annual health reviews, health action plans, medicines reviews.
- Synergy of care teams in Buckinghamshire is improving with end of life care undertaken at home with Palliative care team and GP input and the care homes' wishes so less people are dying in hospital

Introduction

This is the fifth Annual Report collating learning from the mortality reviews of those living with a learning disability using the learning disability death review (LeDeR) framework. This programme was commissioned and is overseen by NHS England. The review process is a strongly supported partnership activity in Buckinghamshire, with membership from a wide range of organisations. This report presents the findings from the 16 case reviews undertaken in 2022-2023.

Acknowledgements

We would like to acknowledge all those who provided information when requested, especially considering the additional pressures faced during the last year. These include:

- GP surgeries
- NHS Trusts
- Local authority
- Care managers and their staff

Further thanks go to our reviewers for their compassion when completing the reviews, keeping the person at the centre of the process in order to identify learning and share good practice. At the core of LeDeR are the people and their families, our thanks go to the incredible carers, families and friends of those who have died, for sharing their stories, sadness and fond memories.

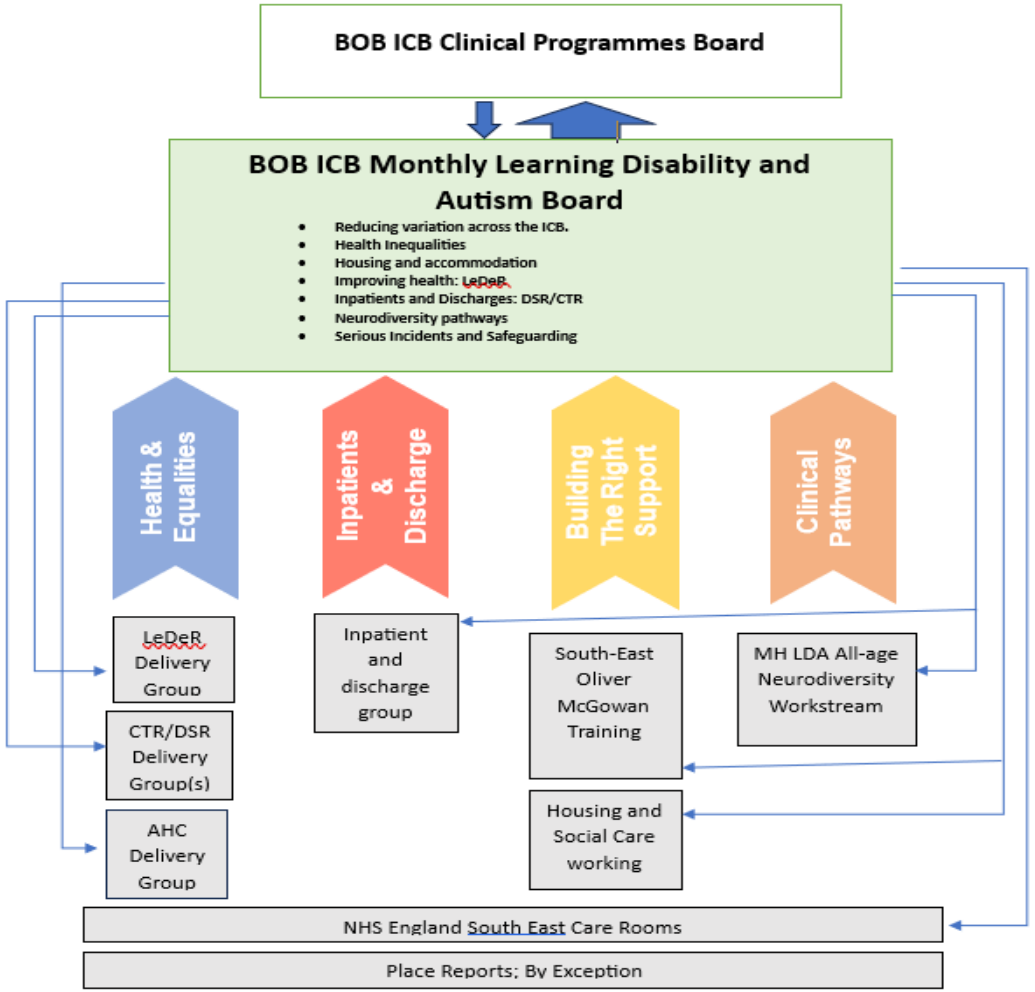
Governance arrangements

- Learning from Deaths in Bucks oversaw historically broader themes and learning from Death related processes

- Staying Healthy Working group oversaw learning and implementation of commissioning intentions from LeDeR

- The Place Quality Forum and formerly CCG Quality and Performance Committee signed off annual reports and actions from LeDeR thematic reviews
- Future proposed governance arrangements are within the next slide

Proposed Future Governance arrangements.



Equality Impact

Public bodies have legal duties to eliminate unlawful discrimination, advance equal opportunities and promote good relations between people. Actively considering the ethnicity of an individual is essential to proactively explore any relationship between mortality and ethnicity.

According to the latest Census in 2021, four in five residents in Buckinghamshire were White (79.9%) which is similar to the England average (81%).

JSNA data for Buckinghamshire indicates 18,600 estimated with a limiting long term illness whose day to day activities are limited a lot (aged 65+) POPPI 2020 estimates Data useful for delivery of healthcare, assessment of progress towards better population health, and the reduction of health inequalities. devising policies to improve access to services, such as adult education and leisure facilities 18,300 estimated to have impaired mobility (aged 18 to 64) PANSI 2020 estimates 19,750 estimated to be unable to manage at least one activity on their own (aged 65+) POPPI 2020 estimates Adults with a learning disability living in stable and appropriate accommodation 76.1% (2020/2021) South East 75.6%; England 78.3%.

Ethnicity

The table shows the ethnicity breakdown of the people whose lives and deaths we reviewed this year.

Ethnicity	White				Mixed/Multiple ethnicity groups				Asian or Asian British				Black or Black British			Other Ethnic Groups		
	British	Irish	Traveller or Gypsy	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed background	Indian	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Chinese	Any other ethnic group	Not stated
No. of reported deaths	14			1						1								
% of all reported deaths	88			6						6								

Deaths of People in our ICS: Buckinghamshire Pen Portraits

***** was a 21-year-old, British Pakistani male with a profound Learning Disability. With other diagnosis' including; Mitochondrial disorder, severe scoliosis, dysphagia and doubly incontinent. All of which were prescribed regular medication to manage these conditions, where appropriate. Last annual Learning Disabilities and medication review was completed by *****'s GP in January 2021. ***** was also under the care of LD Occupational Therapists, LD physiotherapists and the LD community nursing team were initially involved, whilst ***** was transitioning from paediatric services to adults. Continence services were also involved providing ***** incontinence wear. ***** had a high level of need in relation to his physical health and learning disability, requiring support with all aspects of his life to ensure his health, safety and wellbeing. ***** was reliant on others to anticipate and meet his needs throughout the course of the day. Occupational Therapist identified how *****'s family never required or wanted formal carers, with parents providing full-time main care, with a lot of support from external family members. ***** lived within the family home, It is described how ***** had very poor mobility, requiring fully hoisting for transferring and confined to his wheelchair. ***** also thoroughly enjoyed being on the floor, as he was able to move around by pulling himself or rolling. This was one of *****' favourite activities as would play with his 4 younger siblings. Other enjoyments included; partaking in sensory activities such as painting and crafts with his sister and mum, playing with his toys, especially football on the floor and watching children's TV shows on his I-pad. ***** was able to use this and his smart phone, using his finger to scroll and watch different videos. ***** had many family members, who he shrieked with delight when they entered his home to visit him. He was very well loved and cared for and were always taking him to different places in the car, local holidays or visiting family members. ***** was described as a lovely, sociable young man. ***** did not like if things took longer than usual and would usually only co-operate on his terms when it came to things like medical assessments, fittings for his moulded chairs, etc. He required a lot of distraction techniques in such times, which would usually work. He originally attended school until he was 18-years old, however Covid-19 national pandemic resulted in ***** requiring to isolate. During this timeframe, ***** was awaiting day services, however this was also prolonged due to the national lockdown. Whilst at school, reports identify how he most enjoyed the hydrotherapy pool and did lots of work in the standing position at this time. Unfortunately, this did not continue. ***** also began to deteriorate in this timeframe, after acquiring Covid-19 himself, becoming more susceptible to chest infections, which were monthly. ***** was minimally verbal, understanding some spoken words and could sometimes say one-worded sentences. He would shout for attention from his family and was quite resistant to communication aids. He would hold the communication picture book, however his attention was never engaged. ***** could also communicate with some signing, symbols and photographs. Family could identify pain or discomfort by *****'s facial and body language, shouting or moaning out in pain. ***** was 41kg, indicating a BMI of 16.02KG/M2 - indicating underweight. GP medical summary identifies how weight monitoring was in place from January 2021, as this was a 11% weight decrease from previous reading in March 2020. ***** was fully PEG fed with dietician and SALT in place, following aspiration pneumonia and an unsafe swallow following this. ***** doesn't wear glasses and hearing and dental care were also reported stable. ***** did not enjoy getting his teeth brushed, especially when he was unwell, but family usually managed. *****'s parents supported him with all health needs, appointments, welfare and finance.

Pen Portraits continued:

A** was an 88 year old White British lady who was diagnosed with a learning disability in 1933 due to a brain injury that she sustained at birth. The learning disability was categorised as moderate but unfortunately as no next of kin was available to contact for this review it is unclear how this affected her during her life. She had previously lived in supported housing since 2012, she lived in a first floor flat but as she disliked using lifts, she would use the stairs. She enjoyed building positive relationships with her carers and other residents during this time, she liked going to Church at the weekends and her religion was Church of England. A** enjoyed having her nails painted and she would choose the colour, she used to dance and enjoyed knitting. A** did attend a day centre 3 days a week but A** chose that this was too much for her and she then attended once a week. She was diagnosed with Alzheimer's in 2010, over a period of several months February-April 2020 there was a rapid decline in A**'s cognitive functions resulting in her supported living not being able to meet her needs safely. There was a sudden decline in her physical abilities with a further deterioration in March/April 2020 which A** then found it difficult to mobilise without the support of 2 carers because she had had several falls. After a Mental Capacity Assessment and a best interest meeting it was found that A** lacked mental capacity and it would be in her bests interest that she was moved to a dementia care setting with 24/7 specialist care, whilst waiting for a placement she was given 1:1 care for 10 hours per day to maintain her immediate safety. She was at risks of falls and was under the Occupational Therapy team and physiotherapist's, she had a bed that would be lowered to the ground to prevent her falling out, she had a sensor that alerted carers if she was out of her bed for more than 5 minutes. She did become incontinent on a night and wore incontinence pads but managed to use the bathroom throughout the day. She was never referred to the incontinence team at any point in her care. She moved into a nursing home on 20/04/20, her sister died during this time and carers were unsure if she had understood this, she was given an independent advocate from a charity who was present for meetings and decisions. She was noted to have settled into her new housing and was starting to eat better. A** seemed to have issues around food, she was requiring more and more verbal reminders to eat and drink daily, she had been reviewed by dieticians who prescribed shakes to help with her weight but recognised as the Alzheimer's progressed her diet would decline but she should always be encouraged to eat what she could manage. A** became gradually more and more sleepy; she spent more time in bed. Her oral medications were stopped as she was spitting them out more frequently, by early August A** had taken to her bed and was issued medication "just in case", she passed away peacefully in the early morning with a carer with her at her nursing home on 16/08/21.

***** was diagnosed at a very young age with a mild learning disability and attended a school for children with special needs. He lived in High Wycombe all his life, his NOK recalls that there may have been some difficulties during childbirth. ***** had a close relationship with both his parent and did live with them into his early 30's. He was one of 3 children, his older brother emigrated to New Zealand in the 80's and his older sister also emigrated to South Africa in the early 90's. Both *****'s parents decided to also join his oldest sister by emigrating to South Africa in the 90's. ***** kept on touch by making video tapes which he sent to his family overseas. He loved using a video camera and video tapes were sent from his parents. This was how they kept in touch. It was around this time when ***** started to live independently and had a care package, his niece stepped up as NOK and offered support with any issues that arose.

Data Set: Performance

	Notifications No. & %		Completions No. & %		Focussed Reviews	% of all Reviews completed within compliance:
2021/22	23	100%	12	48%	0	48%
2022/23	16	100%	16	100%	1	100%

Local Reviewer Arrangements
Following the COVID pandemic and requirement for front line staff to focus on recovery, Buckinghamshire was faced with a lack of resources. The solution was to engage capacity from the CSU to deal with a rising backlog of cases which commenced in August 2022 and the contract was reviewed on March 2023 and has continued.

In previous years Buckinghamshire had one reviewer to review the LeDeR cases, with a wider pool of people to support discussions with families or carers and to independently review cases. This work for the key reviewer was in addition to their existing Quality management portfolio. Redeployment and prioritising of other work areas as part of COVID recovery led to a backlog of cases.

Delays with receiving provider/local trust information occurs also as the cases go through an internal SJR review first prior to assigning a case to a reviewer. Additionally, if other professionals or services are involved such as safeguarding, police or coroner this can further delay the process.

A plan was put in place for Commissioning Support Unit (CSU) to take over cases from August 2022 with a dedicated pool of reviewers to continue the LeDeR review process.

The local reviewer arrangements changed mid financial year and there was a backlog of 11 cases at the time of handover to the CSU. This was cleared within 3 months and additional to the above figures.

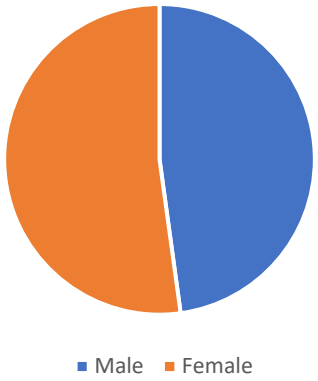
Data Set: Demographics(from local data)

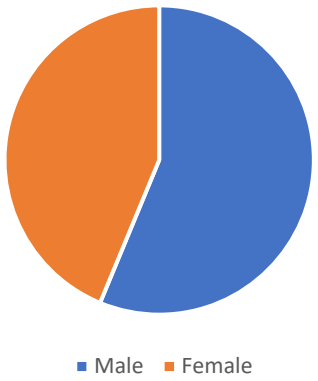
- **Gender**

Cases reported year on year have not shown an significant difference in gender.

	2021/2022	
	Male	Female
No.	11	12
%	48	52

2022/2023	
Male	Female
9	7
56	44





- **Level of Learning Disability**

For every review carried out the level of learning disability for that person is confirmed and recorded as either mild, moderate, severe or profound/multiple. The information below shows the breakdown of this information for all of the people reviews have been completed for in the last year.

Level of Learning Disability	No.
Mild	4
Moderate	6
Severe	2
Profound/Multiple	2
Unknown	2

Data Set: Demographics, Age (local data)

All Adults with learning disabilities who died in 2022-2023:

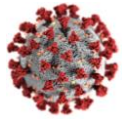
- There was a total of 16 deaths
- The range of age at death was 21 – 88
- The mean average age of death was 64
- The median average age was 63.5

Women with learning disabilities who died in 2022-2023:

- There was a total of 7 deaths
- The range of age at death was 53 – 88
- The mean average age of death was 65
- The median average age was 62
- Female life expectancy in the general population of Buckinghamshire is 00.

Men with learning disabilities who died in 2022-2023:

- There was a total of 9 deaths
- The range of age at death was 21 – 82
- The mean average age of death was 64
- The median average age was 70
- Male life expectancy in the general population of Buckinghamshire is 00.

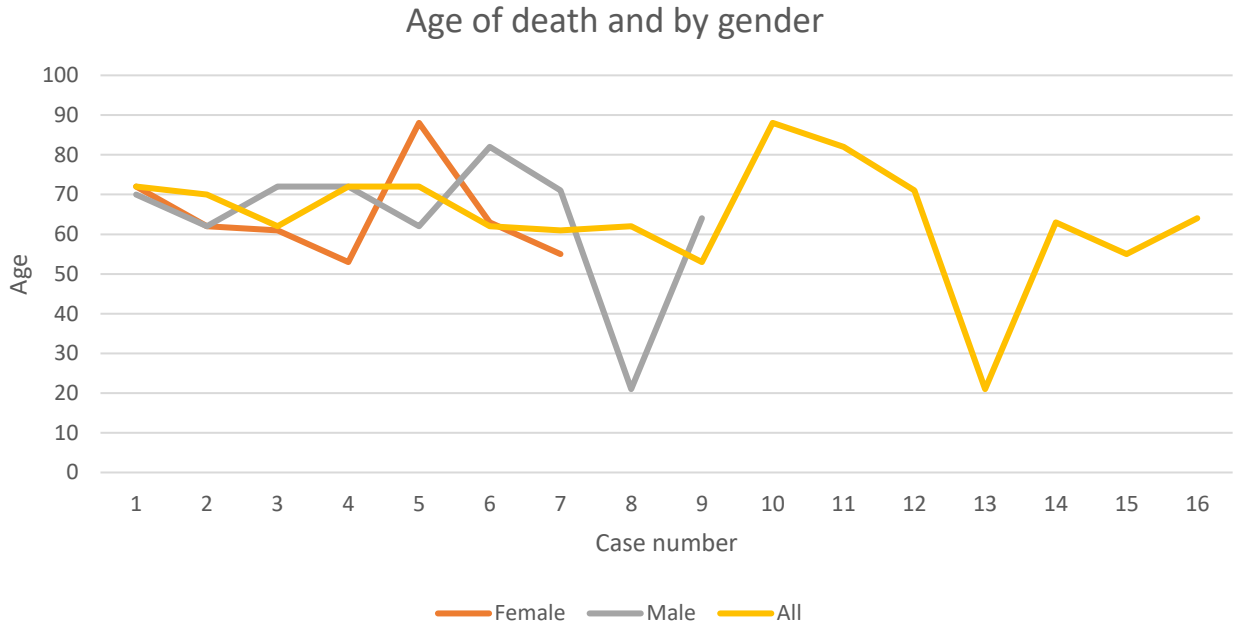


All Adults with learning disabilities who died from confirmed or suspected COVID-19 in 2022-2023:

- There were no deaths from COVID-19 in 2022-2023

Children with learning disabilities who died in2021/2022:

- There were no deaths of children living with a learning disability in 2022-2023



Data Set: Cause of Death.

- **Cause of Death**

The most common cause of death this year was Aspiration pneumonia/Pneumonia
The number of deaths from this was 6 which is 37% of all deaths this year.
The table below shows the top 5 primary and secondary cause of death (where more than one type recorded)

No	Primary Cause of Death	No	Secondary Cause of Death
1	Aspiration Pneumonia	1	Dysphagia
2	Pneumonia	2	LD/Autism
3	Sepsis		
4	End stage dementia		
5	Ischaemic Bowel Disease		

- **DNACPR – Do not attempt cardio-pulmonary resuscitation**

A DNACPR decision is designed to protect people from unnecessary suffering by receiving CPR that they don't want, that won't work or where the harm to them outweighs the benefits

The DNACPR decision-making process should always take account of the benefits, risks and burdens of CPR and consider the individual person's wishes and preferences, the views of the healthcare team and, when appropriate, those close to the person.
Hospital trusts and other providers are legally obliged to have a clear DNACPR policy for staff to follow. It must be accessible so that patients and/or their families are able to understand the decision-making process.

During the first wave of the Covid-19 pandemic, concerns were raised about the potential for "blanket" decisions being made around resuscitation, particularly for more vulnerable populations. As a result, the Care Quality Commission undertook a review of practice across a number of systems, taking into account the understanding and application of the Mental Capacity Act both when it comes to clinical decision making and taking into account the views of individuals.

Buckinghamshire has continued to monitor DNACPR decisions and, to date, still has zero cases.

Action from Learning:
What best practise and positive outcomes have been learned from the reviews

End of life care undertaken at home with Palliative care team and GP input and the care homes wishes so he died at home

SJR identifies xx's final hospital admission was graded as 4 or 5 for his overall care. Family were included and involved with all decisions and discussions, documentation was clear and families wishes were met, being able to sit with xx whilst he remained comfortable before peacefully passing away.

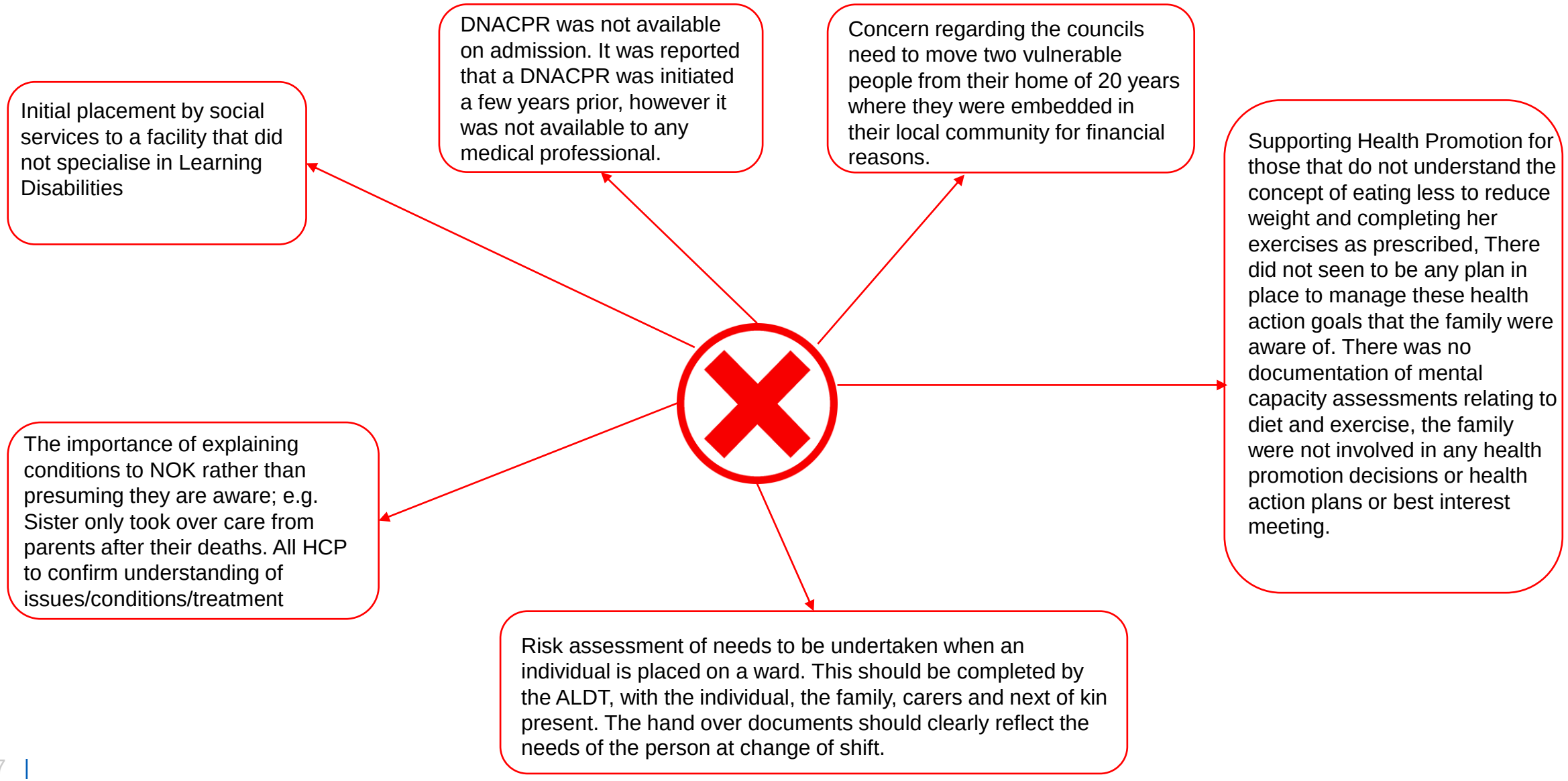
Evidence seen of good care with all health care teams. Annual health reviews, health action plans, medicines reviews. Involvement of correct teams; Acute LD teams, SALT, and evidence of fantastic continuity of care in his first home and good communication with NOK.

IMPACT (some quotes from people/families)

*****'s NOK did want to thank the Learning disability liaison nurse at the hospital who was amazing and did contact her with updates and offered support. The hospital care after the initial issue of not knowing ***** was an inpatient was reported to be "amazing care" His NOK commends the input from the hospital LD team.

The care J received from the staff where he lived was excellent, they really looked after him. He had his own fancy chair and no one would sit in his chair and he was oldest there, so he felt quite important. It was homely, he had friends there. He loved the day trips that they went on after his stroke. The team in the home really helped him to look after his health needs with his GP & annual health check, everything was update to with health care needs, his eye tests and such like. They helped J access all his health appointments.

Action from Learning: What areas for improvement were identified in recommendations from reviews

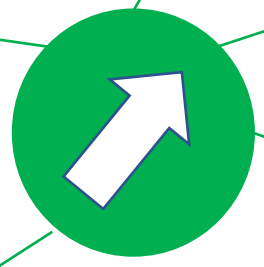


Action from Learning: Local Priorities for delivery in 2023-2024 into 2024/25 based on the learning from reviews locally and nationally

NOK would like to see changes made, so that documentation is shared across systems within the heath sector.

Learning Disability Hospital Passport - identified this is an on-going issue currently due to funding, however is an extremely beneficial document to aid medical professionals, from paramedics, A & E and ward staff to identify any needs when admitted to hospital.

Local Authority review of brokerage procedure to interrogate placement suitability



Seek opportunities to make reasonable adjustments for people with an LD to cancer screening.

Review of use of DNACPR and implementation in care settings