Oxford University Hospitals
NHS Foundation Trust

Cover Sheet

Trust Board Meeting in Public: Wednesday 9 November 2022

TB2022.092

Title:	**An unplanned admission for a patient with Learning Disability**

Status:	**For Discussion**
History:	**A patient story and perspective is presented at each Trust Board**

Board Lead:	**Chief Nursing Officer**
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Confidential:	**No**
Key Purpose:	**Performance**

Executive Summary

1. The purpose of the paper is to update on the learning from a previous patient story "Charlie's story", to share Frank and Glenys' story and to describe the Trust model for assurance for support for people with learning disability and associated workplan.
2. Update from Charlie's story presented by the Chief Nursing Officer 11th May 2022:
   - The Directorate delivered a staff training programme on 24th August
   - The Spinal pathway for children/ young people was developed
   - The story was translated into easy read
3. Frank and Glenda's story: Frank is 58 and has Down's Syndrome, Autism and Dementia. He was admitted after becoming unwell. Frank's family worked with the clinical teams and Learning Disability Liaison Team during his admission.
4. The Trust submitted the NHSI Learning Disability benchmarks in March 2022 and the results have not yet been published. The key themes for action are
   - Monitoring waiting lists, cancer, inpatient bed days and readmission rates
   - Auditing MCA/ DOLS and restraint specifically for people with learning disability
5. Transition/ moving to adulthood is a 2022/23 Quality Priority. There are 48 transition to adult hood services across the Trust. The Trust is a partner in local ICS transition groups and the Southeast Transition Network. The Trust's transition seminar will be on 21st November.
6. The Trust substantively employs 4.6 WTE nurses for liaison and epilepsy services. The team capacity has been temporarily increased. The Trust also employs 10 Registered Nurses for People with Learning Disability. The identified challenges and risks are the capacity of Learning Disability Liaison Team and the development of a system to increase the 1764 people with learning disability who are flagged and monitoring people with learning disability in their healthcare
7. Both stories highlighted listening to families and the 'bridging' role of both the Trust's learning disability team and the community services.
8. The NHSI Learning Disability improvement standards and the Self Improvement Tool for the assurance model. The Trust wide implementation will be piloted in the Neurosciences Directorate.
9. The Easy Read Friends and Family Test is being implemented across the Trust.
10. Conclusion: This paper gives assurance of the learning following Charlie's story, the impact of the Learning Disability Team's role and the importance of clinical teams working with families to deliver patient centred care described in Frank's story.
11. **Recommendations:** The Trust Board is asked to note the contents of the paper.

Contents

An unplanned admission for a patient with Learning Disability

1. Purpose

1.1. The purpose of the paper is:

- To update the Trust Board on the learning from a previous patient story “Charlie’s story”
- To share Frank and Glenys’ story.
- To describe the Trust model for assurance for support for people with learning disability and associated workplan.

2. Background

2.1. The Chief nursing Officer presented Charlie’s story to Trust Board on 11th May 2022. The story told the experience Charlie and his family as an inpatient on the neurosciences ward. Their experience initially was stressful but with the combined support of Charlie’s Oxford Health community nurse, the Neurosciences matron and the Trust Learning Disability Liaison Team, his further admissions went smoothly. This multiagency and patient and family centred partnership ensured we improved his overall experience.

2.2. Following the presentation of Charlie’s story to Trust Board, we have commenced implementation of a model of assurance which incorporates the NHS I Improvement Standards and the Learning from Learning Disability deaths programme.

3. What we have learned from Charlie’s story.

3.1. A knowledge gap was identified, in response, the Directorate delivered a training programme in August, which brought together the Neurosciences, Safeguarding, Learning Disability and Children’s teams; and focused on communication and working with families.

3.2. Multiagency learning: Charlie’s story was translated into an Easy Read format which was shared with the Oxfordshire Learning Disability and Autism Improvement Board, Oxfordshire Family Support Network, Carers Oxfordshire and My Life My Choice.

3.3. The clinical pathway needed development: The Oxford Spinal Service in collaboration with the Pain Team, and the Learning Disability Team have also now developed and are implementing a pathway for children and young people with complex health issues, including people with a learning disability.

4. Glenys and Frank's story

This is Frank and our family.

Frank is my brother and when we were children we lived with our parents in North Cumbria. Until recently Frank lived in a nursing home. In 2021, Frank moved to Oxfordshire to be near my husband, daughter and me. We are a close family.

Frank was born in 1964. He has a learning Disability, Down's Syndrome, Autism and developed signs of dementia about two years ago. Our family has always wrapped him in cotton wool, to make sure he was as healthy as possible and nothing traumatic could happen to him. It is important to remember that prior to his stoke he was living independently, living his own life, coming on holiday with us and visiting his family. We had to re-calibrate our expectations after he had his stroke and had sepsis. He is bright and high functioning and can understand the conversations about him.

Frank was very poorly, with a Stroke and Sepsis, just before he moved and now everyday feels like a bonus to us. Frank has had a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) in place for a long time, from when he lived in Cumbria. Frank's Down's Syndrome is visible, but his autism and dementia aren't.

If Frank sees me panicking - he will panic. So, I always need to be mindful to be calm and include him in all the conversations we have about him. He is a sponge for everything and has a large vocabulary, he just doesn't choose to speak. I always make sure that Frank is the centre of everything. I am just his mouthpiece. I want him to have the best shot at everything in life, and when sadly we must face it, a stress free and pain free death.

Frank suddenly became unwell and admission to hospital

On the 16th August, Frank became very unwell, very suddenly. His GP and Nursing Home called 999 and the paramedic crew brought him to the John Radcliffe Emergency Department. The thought of Frank becoming suddenly unwell made me go into panic overdrive. I thought there must be a Learning Disability Liaison Team in the John Radcliffe, as Frank and I had met the learning disability liaison nurse when he was in hospital in Cumbria, so I googled and found the phone number.

Initially, I did not know where in the hospital the paramedics were going to take Frank, and this worried me. The hospital did not know Frank, how unwell he was, and a lot of things could get lost in translation.

Once I had contacted the Learning Disability liaison Team, I felt I had found a safety net. The Learning Disability Team were the continuous thread throughout Frank's admission and treatment.

Frank's GP and the nursing home had given the paramedics lots of notes, but they were lost somewhere during his admission so the fact his hospital passport was on his electronic notes was great, and I had a paper copy which was very helpful.

The ED consultant phoned me as I was driving in. She asked what Frank was like, how he responds to things as she wanted to hear about his back story first hand. The added complexity they had was that they didn't know Frank and didn't know what would help. I was worried about the complexities for him since having two strokes and Sepsis before he moved. I was so relieved when she phoned, and it was fantastic. Our previous experience, from a previous hospital, was that no one phoned, and I felt excluded from his care. The consultant was able to reassure Frank that I was on my way to him – that was lovely.

I was able to go into the Resus area with him and he looked petrified. The team changed his sheets for him and when I came back, he was fast asleep, and I took that as he had calmed down because he knew I was with him. He always needs to know where I am. He is normally OK about having his blood pressure and blood taken except when he is stressed. When I arrived, the team couldn't get blood and he was panicking. He was completely immobile and his SATS were very low. Resus was quiet and lovely. EAU was busier and Frank found that more difficult, he was quieter and more emotional.

The ED team found a pressure relieving mattress for him, that was very kind. Again, this felt like a long time, but it probably wasn't and more that I was so anxious for Frank.

One of the main things I would say when learning to work with the families of people with learning disabilities is understanding the nuanced behaviour of their relative with learning disability. Frank needs a lot of reassurance when he is anxious, and I was worried that people would think he was being difficult. I must be very careful to have conversations about Frank where he can see and hear me. My worry was that he had had another stroke.

It would help me if the ward could phone to say that Frank had moved from EAU. It was a bit of a shock; he had moved to the ward. Very sadly someone opposite to him had passed away and that was upsetting.

The information to best support him didn't seem to be there. They didn't seem to look for the clues how to best help him. I felt I had to repeat myself the whole time which slowed everything down. It was a repetition of the hospital passport on his EPR file.

Eventually it felt like, everyone got on it, and the treatment was to get him back to baseline. We had much more space and so were able to talk in person with staff.

The consultant came to see me and asked me what I thought of the observations. I said you could keep him for ages, and he wouldn't necessarily get any better and

so it would be better for him to be at home as he loves it there. His physical and mental health would deteriorate if he stayed in hospital too long.

It seemed to take ages, because I was worried, the Speech and Language Therapist assessed Frank. They assessed him, his swallowing was OK and that there was no more infection so he could go home. This was reassuring as he does have problems with aspiration. I don't know if this is the case, but it seems that people with Down's Syndrome swallow differently. It was a great result to go home to a place he loves and with people who know him well.

Our Family's thoughts and the future

Everyone was very calm which helped me and Frank. They were also willing to listen and asking what could and should we do, how is Frank normally. It wasn't smooth but then it was a real time process and so sometimes we felt in limbo because the team didn't initially know what was wrong.

It was important for me whilst Frank was in hospital to constantly get across the back story so I could say inside this patient is a man who enjoyed his independent life.

I will update the passport we did for Frank. It is good that it is electronically held as it means it can't go missing.

A shorter synopsis of the hospital passport would be helpful – 'This is why he is being admitted/ Please contact the Learning Disability Team'.

The learning Disability Liaison Team took the weight off me. There was a team who knew what was worrying me and so that Frank would not fall through any cracks. I found that the help from learning disability liaison team in EAU and on the Ward was very helpful. It was like a marker – there is something different about this patient and so in the absence of someone's family the ward team can seek and take on board the advice from the Learning Disability Liaison Team. It's like they are a go between.

There is a Down's Syndrome Act and families are being asked to give evidence for that[1] - I would like to do this.

5. How we support people with learning disability in the Trust

5.1. The Learning Disability Liaison Team employs 3.6 WTE nurses, 2.6 WTE are Registered Nurses, Learning Disability (RNLD) and 1 WTE is a Registered General Nurse (RGN). The Trust also employs 1 WTE specialist epilepsy nurse for people with learning disability. These posts recognise and champion the complexity of healthcare for people with learning disability and act as a 'bridge' between to support people with learning disability, their family, social carers, the Trust multi-disciplinary team and community health services.

[1] The Down Syndrome Act - Downs Syndrome Association (downs-syndrome.org.uk)

5.2. The team has been temporarily increased to include a Healthcare assistant and an administrator, in recognition of the increase in complexity of health needs of people with learning disability accessing our Trust health care services.

5.3. The Trust also employs 10 RNLD in ward based clinical and senior clinical management positions. This has enabled us to extend the knowledge base for supporting people with learning disabilities across the Trust's clinical services.

6. NHS I Learning Disability benchmarks

6.1. The Trust submitted the NHS I Learning Disability benchmarks to NHS Digital in March 2022 and are awaiting publication. The NHS I national Benchmarks 2020 submission published in January 2022 was reviewed to compare the Trust's service with national peers[2].

6.2. The key themes for our action are

- Monitoring waiting lists, cancer, inpatient bed days and readmission rates
- Auditing MCA/ DOLS and restraint specifically for people with learning disability

6.3. We have updated the Trust's Health Inequalities Group, and there is a work stream led by the Information Team and the Learning Disability Liaison Team looking at how we can move this forward.

7. How we work with people with learning disabilities, their families, and carers

7.1. **Working alongside families and carers in clinical care**: Both Charlie and Frank's stories highlight the importance of working with families and listening to their knowledge, expertise, and experience. They both described the importance of coordinated communication across agencies and with families and carers. The Trust's learning disability team and the community learning disability services act as a 'bridge' to facilitate this communication.

7.2. **Carers Policy**: The Trust's Carers policy was ratified in August 2022 and is currently being implemented across the Trust. This includes carers passports, agreement with their relative's clinical team on their involvement with care, support with food, car parking and staying with their relative whilst an inpatient.

[2] Year+3+national+report+appendix+-+FINAL.pdf (oxnet.nhs.uk)

7.3. **Transition/ Moving to adulthood:** This is a Trust Quality Priority for 2022/23 as the move from children to adult services for children and young people with a learning disability has a risk of being complex. There are 48 transition to adult hood services across the Trust. We have achieved

- The Transition tool Ready, Steady, Go, Hello is available for clinicians to use on the Trust's EPR[3]. The uptake of the Ready Steady Go Hello with clinical teams and their patients will be audited as part of the Quality Priority.
- The Trust's Childrens Hospital and the Learning disability Liaison Team have collaborated with colleagues across Berkshire and Oxford Health to develop and implement the children's Healthcare passport[4].
- The Trust has joined the BOB ICS (Buckinghamshire, Oxfordshire, and Berkshire Integrated Care System) Learning Disability/Autism Transition to Adulthood QI project.
- The Trust's Transition seminar will be on the 21st November.

7.4. **Inclusion and Engagement:** The Easy Read Friends developed by NHS England is currently being rolled out for all patients with learning disabilities.

8. Risks and Challenges

8.1. **Workforce** : The workforce requirements and the temporary increase in the Learning Disability Liaison Team was discussed at to the Corporate Performance Review on 15th September and to the Integrated Assurance Committee on 12th October. There is work to ongoing to scope how we can make these posts substantive.

8.2. **Flagging and monitoring/ tracking patients with learning disability in their healthcare**: The information and EPR Team are looking at how we can:

- monitor people with learning disabilities who are on waiting lists, are readmitted to hospital following discharge who those who are on cancer pathways
- develop a coordinated system to add tertiary referrals and children to the flagged and lifetime relationship list on EPR. The Trust currently has 1764 people with learning disability flagged on EPR with a 'lifetime relationship'. This enables the team to track individuals' presentation at ED, inpatient admissions, and outpatient appointments.

[3] Ready Steady Go - TIER Network
[4] Healthcare passport - Children's Services (ouh.nhs.uk)

11. Model of Assurance

11.1. To improve the patient and care experience, the Trust is using the learning disability improvement standards and the Self Improvement Tool for NHS trusts as the assurance model[5][6].

11.2. This model focuses on reducing variations in care and specifically reducing deaths of people with learning disabilities in acute hospital care.

11.3. The standards have been nationally developed by people with learning disabilities and their families, using a quality improvement approach. They measure quality of service and ensure consistency across the NHS in how people with learning disabilities, autism or both are looked after within acute health care.

11.4. There are three standards relating to acute care:

- respecting and protecting rights
- inclusion and engagement
- workforce

11.5. The implementation of the model of assurance is a collaboration between the Assurance Team, the Learning Disability Liaison Team, the Patient Experience Team and the EPR Team. The Divisional Director of Nursing for NOTSSCaN has agreed to the Self Improvement Tool being piloted within the Neurosciences Directorate before rolling out across the Trust.

11.6. A family carer and an individual with a learning disability will be engaged to join the assurance group in phase 2 of the patient safety partners recruitment in April 2023. This also follows the approach used in the NHS England national Learning Disability and Autism Advisory Group[7].

12. Conclusion

12.1. This story has given an update on Charlie's story and introduced Frank and Glenys' story. This paper gives assurance of the learning following Charlie's story, the impact of the Learning Disability Team's role and the importance of clinical teams working with families to deliver patient centred care described in Frank's story.

12.2. The paper also provides assurance of the collaborative engagement and workplan to implement the nationally developed model of assurance for services to support people with learning disabilities in acute healthcare.

[5] NHS England » The learning disability improvement standards for NHS trusts
[6] Reducing_deaths_of_people_with_a_learning_disability_improvement_tool.xlsm (live.com)
[7] Learning disability and autism advisory group - NHS England - Citizen Space

13. **Recommendations**

- The Trust Board is asked to note the contents of the report.

Appendix 1

Objective (SMART)	Date of key milestones / success criteria	Resourcing		Progress	
		Funding agreed (Y/N)	resources available (Y/N)	Risks to delivery	Timescales
Contribute as a system partner to the Oxfordshire LeDeR (learning from Lives and Deaths) programme. The is part of the Vulnerable Adult Mortality Group and a sub group of OSAB.	1. Reporting every death of a person with a learning disability to the LeDeR programme 2. Contributing to the multiagency review and learning. 3. Work with the Trust Clinical Outcomes manager to ensure learning is embedded within the Trust.	N	Y	None	On track
National NHS I Annual Learning Disability Benchmarking programme	1. Year 5 data collection is due to be submitted by 27 January 2023.	N	Y	None	On track
Developing efficient team systems to maximise clinical time.	1. Two workshops held with author of the Molster and Griffiths Nursing model on 24 + 29/06/2022. 2. Next stage is to complete adaptations with the author to adapt the model for acute settings to enable the team to prioritise and focus workload. 3. Complete Affina team journey.	Y	Y	Lack of Team capacity. Temporary increase in staffing capacity will temporarily mitigate.	On track
Training 1. Implement Oliver McGown Training. Developed by HEE. 2. Trial of @At the Elbow' training in the Neurosciences Directorate.	Regional NHSE initial roll out of Tier 1 training into NHS provider trusts who are much more likely to have the online systems and platforms. ICB / place based approach.	N	Y	None	On track

Objective (SMART)	Date of key milestones / success criteria	Resourcing		Progress	
		Funding agreed (Y/N)	resources available (Y/N)	Risks to delivery	Timescales
Review and strengthen Team capacity	1. Temporary increase agreed with CNO 2. Review to strengthen team capacity	N	Y	Temporary Mitigation	. On track
System to update the EPR flag children with learning disability, adults moved to Oxfordshire tertiary referrals, System to monitor and track people with learning disability on waiting lists, cancer and readmission rates.	1. Project has been scoped.	Y	Y	None	. On track
Model of Assurance	1. Tool identified. 2. Self-Assessment pilot with Neurosciences confirmed. 3. Request to report to PSEC agreed.	Y	Y	None	. On track
Audit MCA/ DOLS and restraint	1. Use Trust data already reported and separate out data for people with learning disability.	Y	Y	None	. On track