GLOUCESTERSHIRE SAFEGUARDING ADULTS BOARD SAFEGUARDING ADULTS REVIEW REPORT NICK

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Date of Report:

1.Introduction

1.1 The purpose of this report is to describe the process and recommendations of a Safeguarding Adult Review (SAR) carried out into the circumstances around the death of an individual, Nick, who was receiving care, treatment and support for complex health conditions, including learning disabilities, from health and care organisations in Gloucestershire. Nick had complex needs throughout his lifetime and died on 22 January 2018, aged 58, with his death attributed to malnutrition after a period of declining health.

1.2 Nick received a great deal of excellent care during his lifetime and during the final weeks of his life. However, aspects of his care may have fallen short of best practice. Although it may not have altered the eventual outcome for Nick, it is possible that the condition that resulted in his death might have been ascertained at an earlier stage, thus enabling support being provided to Nick, his family and carers.

1.3 The circumstances and background of Nick's death were considered by the Learning Disabilities Mortality Review Programme (LeDeR) which reviews every death of a person with a Learning Disability in England. LeDeR provides a framework for ascertaining the circumstances leading up to death. An experienced and trained practitioner conducts the review, which includes a multi-disciplinary panel discussion before a final report is made. For Nick, the final report highlighted concerns about the care and treatment he received during the last months of his life. These included discrepancies in recording, lack of access to some services in the community, concerns about delays in diagnosis and treatment and an apparent failure to listen to concerns expressed by family and paid carers. Good practice was also noted.

1.4 LeDeR does not consider Safeguarding Adults concerns specifically. However, the multi-disciplinary panel recorded surprise that Nick had 'died at this time from this cause' and a number of 'potentially avoidable contributory factors' were highlighted with respect to care and services. It was considered that, although Nick may have developed a life limiting disorder, the way in which he died of malnutrition may have been avoidable if the cause of his symptoms had been investigated fully sooner. The SAR process allows for many of the wider factors of Nick's health needs and social circumstances to be considered, not least the impact of Nick's gut failure on his resulting malnutrition and the context of the investigations and procedures Nick underwent. For this reason, a referral for a Safeguarding Adults Review was made to the Gloucestershire Safeguarding Adults Board.

1.5 This Safeguarding Adults Review was commissioned by Gloucestershire Safeguarding Adults Board to explore further the areas of concern noted in the Final Report from LeDeR and to identify any learning, which may help avoid such a situation occurring again.

2 Process of Review

2.1 Terms of Reference.

Gloucestershire Safeguarding Adults Board (GSAB) commissioned this SAR. The subject, Nick, lived in Gloucester in supported accommodation; he had a moderate learning disability and Cerebral Palsy. NC lived with his mother for 52 years until she became ill in 2016, when he moved into supported living. Nick's mother died in November 2017 and Nick deteriorated mentally and physically after her death. Nick died of malnutrition on 22nd January 2018. A number of practitioners from several organisations were involved in his care and treatment.

2.2 General:

To establish whether there are lessons to be learnt from the circumstances of the case about the way in which local professionals and agencies work together to safeguard adults at risk.
To review the effectiveness of procedures (both multi-agency and those of individual organisations).
To inform and improve local inter-agency practice.
To improve practice by acting on learning (developing best practice).
To prepare or commission a summary report which brings together and analyses the findings of the various reports from agencies in order to make recommendations for future action.
To connect the learning from previous Safeguarding Adults Reviews (SARs).

2.3 Specific:

To examine how the circumstances leading up to the death of Nick, who died at home on 22nd January 2018, were handled and whether the policies and procedures in place across various agencies during that time were followed.
To consider whether all opportunities to ensure Nick had received appropriate care and support within the overall delivery system were identified up to the time of his death.
To consider if a reassessment of needs should have occurred on discharge from hospital.
To review the effectiveness of multi-agency communications across the agencies involved in his care.
To review the appropriateness and level of care and support he received as his health began to deteriorate, including end of life care.

To review the circumstances surrounding his admission and plan of care whilst in hospital and subsequent discharge and community led care.

To consider whether the views and concerns of family and carers were listened to.

2.4 Principles for a SAR as set out in the Care Act 2014:

- There should be a culture of continuous learning and improvement across the organisations that work together to safeguard adults with care and support needs.
- It should promote the wellbeing and empowerment of adults, identifying opportunities to draw on what works and promote good practice
- The approach taken to reviews should be proportionate according to the scale and level of complexity of the issues being examined
- Reviews of serious cases should be led by individuals who are independent of the case under review and of the organisations whose actions are being reviewed
- Each partner organisation must co-operate in and contribute to the carrying out of the Safeguarding Adult Review. The purpose is to identify the lessons learnt from the specific case and to apply these to future cases to prevent such circumstances occurring again
- Professionals should be involved fully in reviews and invited to contribute their perspectives without fear of being blamed for actions they took in good faith
- Families should be invited to contribute to reviews. They should understand how they are going to be involved and their expectations should be managed appropriately and sensitively.

2.5 Scope. The time period to be covered by the SAR is 22 July 2017 to 22 January 2018, the final six months of Nick’s life.

2.6 Lead Reviewer. An Independent Reviewer was commissioned to lead the process and to write the report. She has the appropriate skills, experience and qualifications to carry out this process and is not employed by any of the organisations involved.

2.7 Organisations involved:

Gloucestershire Hospitals NHS Foundation Trust

Gloucestershire Health and Care NHS Foundation Trust (formerly 2gether NHS Foundation Trust and Gloucestershire Care Services)

Brandon Trust (provider of Brae Walk Supported Living accommodation)

GP

2.8.1 **Methodology.** There is a range of methods for conducting a Safeguarding Adult Review and it is the responsibility of the Board to determine which method suits the case best, ensuring that it is proportionate and appropriate to the situation and makes effective use of resources. For the situation in respect of Nick, LeDeR had provided some of the information required, including a chronology of agency interventions, and a multi-agency meeting had been held on 20 June 2019 to discuss the findings and 'sign off' the report. As all the agencies involved had seen this documentation and either attended or provided written submissions to the Multi-Agency Review, it was appropriate to utilise this documentation.

2.8.2 Further information was obtained through 'conversations' with individuals with key roles in Nicks life during the period under review, with a specific focus on his family and carers. These included NC's brother (ML), the local manager of the Brandon Trust Supported Living Unit in which Nick lived, his GP and the practitioner who carried out the LeDeR review. Gloucestershire Hospitals NHS Foundation Trust also provided a detailed account and analysis of their extensive records. Organisational policies, other SAR reports and research studies were also considered.

2.8.3 The SAR makes use of aspects of 'Learning Together', a validated methodology produced by the Social Care Institute for Excellence and in which the Lead Reviewer is trained and experienced. It focuses on systems and how the different parts of it work together, rather than individual practice. It is not about blame but about learning from experience in order to protect vulnerable people in future. The process is confidential, although the Reviewer reserves the right to raise any issues she believes may result in harm to any individual. Anyone participating will be advised to seek support if they experience any distress at any stage.

2.8.4 It is important to avoid hindsight bias, being wise after the event, as this does not assist the process of understanding the system as it was at the time of the events under review by the people working within it.

2.8.5 Family involvement is essential and expected by the Care Act 2014 if possible. ML was involved closely with his brothers' life and his views are part of this Review. Nick had formed close relationships with his Support Workers in the Brandon Trust over several years. This organisation has participated in this Review and concerns are explored as to whether sufficient credence was given to both family and support workers in making decisions about his care.

2.8.6 The work of the SAR began on 13 January 2020, 2 years after Nick had died, following the Report from LeDeR.

2.8.7 Gloucestershire Safeguarding Adults Board will publish the report and its recommendations in anonymous form once it has been agreed. The report will set out whether there are lessons to be learned about how practitioners and agencies worked together and individually, and how practice will change to improve outcomes for people. This will include identification of practice being shown to have a positive impact for NC and of concerns at practice and organisational levels.

3. Background to Case

3.1 Nick was a white male, aged 58 when he died on 22 January 2018. The eldest of four children, he had a brother, a half-brother and a half-sister. The family lived in, a medium sized village in the Cotswold District of Gloucestershire.

3.2 Nick lived with, and was cared for, by his mother from his birth until he was 52. ML describes his mother as a great advocate for Nick. She was very close to him and sensitive to his needs, being determined that he had opportunities to develop and shine. She supported him to ride and swim, with remarkable success. Nick reached National Standard in Dressage and gained 46 riding certificates. He also liked to swim with the help of swimming aids. ML reflected that Nick was always his mother's priority, but he and his other two siblings accepted this. The family lived in a very supportive village too. His father died on December 29th 1992.

3.3 When Nick's mother was diagnosed with breast cancer, NC moved into supported living accommodation. The family accepted this reluctantly as the right thing to do as no other family member was in a position to provide the level of care he needed. There were some changes in his accommodation over time but during the period of this SAR, Nick lived at Brae Walk, run by the Brandon Trust, in Gloucester.

3.4 Supported Living differs from residential care. Nick had his own tenancy and was assessed by Gloucestershire County Council Social Services for his care and support needs. The Brandon Trust met these through a package of care services commissioned and funded by Social Services and provided by skilled care staff (not registered nurses). Specialist care was provided through the Community Learning Disabilities Team. Nick lived with five other people with similar needs and had the benefit of shared waking night staff and two or three staff on duty during the day to meet all of his personal needs. Contact between Nick and his mother continued with regular telephone calls and frequent visits from his mother. Nick would visit her and his brother occasionally.

3.5 Nick enjoyed his food and would eat everything he was given. He had dysphagia, resulting from cerebral palsy, and was at serious risk of choking so required a specially prepared diet, including thickened fluids, and supervision while eating. He had good input from Speech and Language Therapy and Dietetics.

3.6 There were concerns about weight loss for some time proceeding the SAR period. In May 2017 Nick’s weight was recorded as 40kg with a Body Mass Index (BMI) of 15.2. A person is deemed underweight when their BMI is less than 18.5. The first weight recording in the GP records in the SAR period was made on 9 August 2017 as 38.5kg with a BMI of 14.4. The GP notes the weight loss but states that his diet at Brae Walk was good.

3.7 Nick had a moderate (although described as severe in Hospital Notes) learning disability, hypotension, Microcephaly and Cerebral Palsy. He was not able to verbalise but used Makaton, a communication programme, and his own signs and gestures to communicate. He had a reasonable understanding of information if it was explained slowly and clearly and was said to know his own mind, being quite determined in what he would and would not do. The local manager for the Brandon Trust stated that the support staff working directly with him were able to understand him clearly, as did his mother.

3.8 Nick is described by staff working with him as "a lovely chap, very friendly. He liked the hustle and bustle of being with people". He was friends with the other tenants and was "really happy most of the time", taking pleasure in going on car trips and holidays. He also participated in music sessions, playing the tambourine, and was fond of art. He responded well to pictures and enjoyed spending time with his family. He also liked watching television particularly football and films. ML agrees that Nick was settled and had a very good quality of life with excellent care, prior to becoming ill.

3.8 **Key events in SAR period**. The final six months of Nick’s life were less settled in that he required hospital admissions in response to his deteriorating physical condition. A timeline of medical record entries and events is set out in the Final Report following the Multi-Agency Review conducted by LeDeR so it will not be duplicated here. However, some detailed accounts of key ‘incidents’ are included to enable understanding of circumstances relevant to this SAR.

3.9 On 7 September 2017, Nick was taken to Accident and Emergency after a triage assessment carried out by his GP on the telephone, concerning right hip pain. Nick had an x-ray and was discharged with analgesia and advice.

3.10 On 12 and 26 September, the GP made home visits regarding a chest infection plus vomiting and difficulty eating. He prescribed antibiotics and Nick was much better by the second visit. Further weight loss was noted but no weight recorded.

3.11 Nick was taken to hospital by ambulance on 21 October 2017 with abdominal pain and vomiting. His weight was 36.9kg on admission, a BMI of 13. Investigations took place, including x-ray and CT scan, which showed he had a 'massively dilated stomach and possibly a duodenal stricture'. This required surgery but there was doubt about Nick's mental capacity to consent to this, particularly as there were associated risks. His future care was discussed with his brother, who stated he wanted resuscitation and escalation should the need arise. ML said there had been a similar issue 9-10 years ago. Nick was 'nil by mouth' with intravenous fluids and drugs due to his condition.

3.12 A 'gastro-jejunostomy' was carried out on 24 October by 3 senior surgeons, indicating that the procedure was technically challenging and difficulties were expected. The operation revealed further problems with Nick's stomach. A naso-gastric tube was inserted whilst he was under anesthetic. Following surgery, Nick spent several days in Intensive Care due to low blood pressure and the need for slow re-introduction of food and fluids following bowel surgery. His condition progressed well and the naso-gastric tube was removed. After this, Nick ate a varied pureed diet and dietary supplements under close supervision of a dietician and returned to the main ward on 29 October. However, difficulties continued with his retching and vomiting on eating causing his fluid and food intake to be inadequate. This was due to 'oropharangeal dysphagia', in line with his diagnosis of cerebral palsy, a condition, which may worsen if the individual is unwell. Intravenous fluids were used in addition.

3.13 On 3 November, the consultant surgeon reviewed the situation. Nick was considered 'surgically fit' for discharge, in that the operation had worked, but he was not physically fit enough to leave hospital. The Speech and Language Therapist and multi-disciplinary team explored various types of equipment and food consistency and discharge arrangements were discussed with the Brandon Trust. By 7 November, the team considered his swallowing was back to its 'baseline', pre–admission level. Nick weighed 39.9 kg on discharge, having put on 3 kg during his stay. A risk of pressure sores was noted and pressure areas were checked regularly and dressed as appropriate.

3.14 Nick was discharged on 8 November. Brandon Trust staff expressed concern that they could not manage NC's needs at home safely and that the cause of his swallowing and vomiting had not been investigated fully. A referral to the Community Learning Disability Team was made for physiotherapy on discharge as Nick was not mobilising well. A referral was not made to the Hospital Discharge Team.

3.15 On 14 November 2017, 6 days after discharge, a GP home visit was requested as Nick's abdomen was distended around his laparotomy scar. There were no other symptoms so he was to continue on prescribed medication. A further GP home visit was requested on 23 November 2017 as NC showed signs of a chest infection. He was prescribed antibiotics. His weight was recorded as 27.7kg the same day by the Speech and Language Therapist but the GP did not have access to this information.

3.16 Nick's mother died in November 2017. NC felt the impact of his mothers' death strongly. He was able to communicate his feelings of sadness to his carers. When asked, Brandon Trust staff did not think that his grief affected his appetite or other behavior significantly, although he was clearly suffering.

3.17 On 25 November 2017, a Saturday, Nick was admitted to hospital by the Out of Hours GP Service as he was not eating and staff were very concerned. The hospital records note that he was 'emaciated', with 'chronic decreased food intake' noted. However, NC said he was hungry on arrival at A and E and was given a bowl of porridge, which he ate and did not vomit afterwards. It was considered to be in his best interests for him to go home afterwards as he had no other new symptoms. He was discharged that evening at 21.50 with nutritional supplements. Once home, NC's condition continued to deteriorate, he did not eat for 2 days, and there were further calls to the GP who visited on 28th November. The GP did not receive a Discharge Summary from the Hospital regarding this admission until 6th December. He arranged to visit again on 1 December. Carers became increasingly frustrated at this time and recorded Nick's weight as 27kg, a further loss. The Speech and Language Therapist became increasingly concerned and he asked the Intensive Health Outreach Team (IHOT) to monitor Nick's oral intake whilst awaiting dietetic assessment. He asked the GP to refer for videofluoroscopy urgently. (This is a moving x-ray, which enables diagnosis of dysphagia, swallowing difficulties).

3.18 On 1 December 2017, a GP visited to carry out a review of Nick's condition as planned previously. He suspected a chest infection. He advised the carers to weigh Nick that day and then twice weekly and to inform him if he lost weight again. This was difficult to achieve, as there was no access to sit on scales. On 4 December, it was 32kg (but weighed fully dressed in boots by IHOT). The GP contacted the hospital gastroenterologist about planning an urgent admission for the videofluoroscopy and a naso-gastric tube to maintain Nick's nutrition as he could not eat normally. This is a feeding tube passed through the nose to the stomach. It does not require surgery to place it but it can be uncomfortable and difficult to tolerate. Nick had one inserted under anesthetic during his surgery on 24 October but it was removed as his condition improved.

3.19 On 4 December, the GP visited at the request of carers regarding Nick's increasing weakness. He contacted the gastro-enterologist who arranged an admission directly into Ward 7A (gastroenterology) on 7th December in order to carry out the videofluoroscopy. However, NC was taken to A and E instead, and then to the Acute Medical Ward much later after Brandon Trust staff had left. IHOT staff visited NC on 8 December on that ward, and found that guidance regarding Nick's high choking risk and subsequent need for supervision when eating and drinking was not being followed on the ward, nor was the equipment advised by Speech and Language Therapy available. IHOT observed him eating a normal meal unsupervised. The Hospital Passport (1), containing the information about this, had been received from Brandon Trust on admission and notes added to it relating to Nick's mood following his mothers' death. NC was moved to Ward 7A after 2 days. He was assessed by Speech and Language Therapy to have a 'severe aspiration' risk (i.e. food and saliva could enter his respiratory system and cause choking) and was to be 'nil by mouth'. He agreed to have a naso-gastric tube but this could not be done immediately due to increased oral secretions, which required medication to dry them up. By 11 December, Nick was clear that he did not want to have a naso-gastric tube inserted and that he wanted to go home and not have treatment. The Learning Disability Liaison Nurse could not be sure if he understood the implications of this decision, i.e. that he would die. She contacted ML, with Nick's permission, and a Best Interest Meeting was arranged. The videoflouroscopy had not yet been done. The option of a 'Percutaneous Endoscopic Gastrostomy tube (PEG), a feeding tube inserted directly into the stomach was raised by the Speech and Language Therapist. Also on 11 December, a CT scan was carried out and compared to one done in October 2016. It showed no malignancy or obstruction in his chest and abdomen but significant oedema in the tissues, a swelling caused by fluid retention.

3.20 The Best Interest Meeting was held on 12 December. The hospital doctor reported that Nick refused to have a naso-gastric tube and wanted to eat normally. The option of a PEG was discussed but the doctor explained that he was too frail to have this surgical procedure. His BMI was 10 and needed to be at least 13. The naso-gastric tube was still an option and the family agreed to this, if Nick was willing. He could also eat, but this carried risks of aspiration and subsequent chest infections. The meeting decision was to try to fit the tube but if not successful, to provide appropriate meals with medication beforehand to reduce the risk of choking and aspiration.

3.21 On 13 December, Nick had a discussion with a Brandon Trust carer and the Learning Disability Liaison Nurse, who explained about the procedure using pictures. Nick agreed to have it, provided he could be sedated and that his carer would be present. The procedure was attempted twice but failed each time due to the tube hitting an obstruction. Nick refused to try again. Subsequent food charts in the notes confirm that Nick was eating at this time, enjoying his food and wanting to get home. On 18 December, his BMI had risen to 10.9 and the aim was stated to insert the PEG when possible as the risks of Nick being able to eat normally were very low.

3.22 On 19 December, the videofluoroscopy was carried out. This revealed numerous serious problems with Nick’s ability to swallow even very tiny quantities effectively without regurgitation or aspiration into the respiratory system. This condition cannot be reversed. Plans for him to return home according to his wishes were then developed with the Palliative Care Team. The Consultant carried out a Mental Capacity assessment and made a Do Not Attempt Cardio-Pulmonary Resuscitation decision. A discussion was held with ML and the GP and there was agreement on community-based care, with antibiotics to be the limit of further medical intervention

3.23 Before discharge on 20 December, a Care Guidance Plan was agreed between the Palliative Care Consultant, Learning Disability Liaison Nurse, GP Nick’s brother and the Brandon Trust staff regarding his ongoing care, particularly choking and ‘ceiling’ of care. A ‘night diary’ was done showing that Nick slept most of the night but needed changing twice due to incontinence. Detailed written information about nutrition was sent to the Brandon Trust. It was planned to try to increase his weight by feeding him orally as far as possible and by using a syringe for fluids. The outcome for Nick was stated as uncertain given his ‘gut failure’. The discharge letter to his GP stated he had ‘pancreatic insufficiency’ and medication prescribed.

3.24 Nick was discharged home on 22 December 2017, after 15 days. The discharge Summary was completed 2 days later and it is not clear when the GP received it.Transport arrived to take him home at 21.40 the previous day but it was ascertained that an agency staff member who did not know Nick was on duty so the discharge was rearranged for the following day. Whilst it was good practice that this situation was identified and addressed, it is of some concern that the discharge was not planned for the daytime when familiar carers were on duty.

3.25 On 2 January 2018, a ‘rapid decline’ in Nick was discussed by a care worker with the Palliative Care Team and Learning Disability Liaison Nurse. His GP attended, noting a chesty cough and low SATs and that he was tearful. The GP requested rapid response input. On 3 January 2018 Nick was taken to A and E but discharged the same day. The GP was not informed that Nick was back home. On 5 January, the Palliative Care consultant visited following a referral from the Brandon Trust. They were keen to avoid unnecessary hospital admissions in Nick’s best interests and to ensure plans were in place to manage his symptoms both at the time and in advance, as Nick was deteriorating. End of life medicines were prescribed ‘just in case’. Equipment was provided in order to manage his basic needs and make him as comfortable as possible. On 10 January, the Palliative Care Consultant noted that there ‘may be a link with hypoxic causation of cerebral palsy having an impact more widely in the body, leading to organ failure at a slightly earlier stage than seen in the wider population’. The pancreatic insufficiency was confirmed. This was said to account for ‘the gradual and cumulative deterioration over recent years’. It is not clear if this could have been identified and treated at an earlier stage.

3.26 Three days before he died, ML explained that Nick wanted to visit his old family home before it was sold following his mothers’ death. This was done. The experience of supporting Nick, taking him in the car and helping with the toilet, distressed ML greatly. He described him as ‘like a skeleton’ or a ‘concentration camp victim’. ML said his brother knew he was dying and hugged him when saying goodbye, which he did not normally do.

3.27 On 22 January 2018, it was clear that Nick was deteriorating fast. He was visited by his family and familiar carers and a friend were with him when he died at 10.30pm.

3.28 On 23 January, the GP discussed Nick's death with the Coroners' Office. It was agreed that the Coroner did not need to be involved further as Nick's death had not been unexpected and a doctor, the Palliative Care Consultant, had treated him during his final illness, although his GP had not seen him since 2 January 2018. The cause of Nick's death as recorded by the Consultant is:

(a) Disease or condition leading directly to death: Malnutrition

(b) Other disease or condition, if any, leading to (a)

Exocrine Pancreatic Insufficiency

(c) Other disease or condition, if any, leading to I(b):

Severe Oropharyngeal Dysphagia

4. Analyses and Reflection

The information gathered will be considered under eight headings, covering the general and specific aims of the SAR set out in the Terms of Reference above. The focus will be on the last six months of Nick's life except where stated.

4.1.1 Effectiveness of community services. The information shows that the services provided to Nick to meet the daily needs associated with his learning disability and long term conditions were good and enabled him to lead a satisfying life, making the most of his abilities and preferences and providing support where required for his limitations in understanding, lack of speech and physical conditions. The local manager of the Brandon Trust considered that the care services funded for Nick by Gloucester Care Services (Social Care) in a Supported Living environment were appropriate to meet his needs.

4.1.2 The Brandon Trust met NC's needs directly and by liaising with the appropriate source of help and advice when concerns outside of their expertise arose. Key professionals were contacted and attended NC at home, frequently in some cases. This included Speech and Language Therapy, Podiatry, Learning Disability Nursing, Occupational Therapy, Primary Care and, as Nick's health deteriorated, Palliative Care and the Intensive Health Outreach Team. There is evidence of good communication between the agencies in the community and with their input, Nick was able to spend the final month of his life at home in familiar surroundings, supported by people he knew. This was excellent practice and to the credit of everyone involved. Nick's condition was complex and distressing for both him and his carers and family but at least everyone had the satisfaction that he was in the environment he would have chosen.

4.1.3 On each of the two discharges from inpatient care, Brandon Trust staff expressed concerns about their ability to meet Nick's increasing and changing needs at home. This could have put his wellbeing at risk. He was not being discharged to an environment with nursing care and the LeDeR report expresses concern that hospital staff may not have had a good understanding of what Supported Living had in place. Care staff were given advice and guidance and arrangements were made for specialist services, equipment and medication, although some of this took time to arrive.

4.1.4 A referral for reassessment was not made to the Hospital Discharge Team or to the commissioners of his care on either admission. This would have provided the opportunity to ensure that Nick was placed in the most appropriate setting to meet his needs and that his care hours were sufficient. It is evident that Brandon Trust staff made considerable efforts to hold everything together to maintain a good level of care and support for Nick. The local manager told the SAR that the support staff were very pleased to be able to look after him during this period, particularly as they felt they had failed him in their inability to arrange effective help for him previously.

4.2.1 **Effectiveness of Inpatient Care.** Nick was taken to hospital on five occasions during the six months of the SAR period. On three of these, he went to the Accident and Emergency Department but was not admitted. Of the other two, one was unplanned and lasted for thirteen days; the second was planned and lasted fifteen days. In terms of the inpatient stays, it is clear that Nick was very unwell physically and needed to be in an acute hospital setting. He required surgery and specialist care. It may have been possible to avoid the trips to A and E by alternative means.

4.2.2 Other SARs have suggested that acute hospital settings may be particularly difficult for individuals with a learning disability.

> Bracknell Forest and Windsor and Maidenhead Safeguarding Adult Board published a SAR regarding Mr. EF dated 6 November 2017. (2) Mr EF was 71 years old and had complex health and care needs, including a severe learning disability, challenging behaviour and other physical health conditions, including a risk of choking. Like NC, his needs were met effectively within a Supported Living setting until his health started to deteriorate. An ambulance was called on thirteen occasions and Mr EF was admitted to hospital ten times on an emergency unplanned basis. Mr EF found hospital very difficult and his behaviour was challenging on the ward without familiar carers. The SAR

comments that ‘Whilst it appears that all hospital assessments, diagnoses and interventions were timely and necessary, and they were carried out in accordance with the treatment pathways offered to any other patient, this pattern of hospital attendances and admissions would be disruptive and distressing for most people. It is likely to have been even more so for a man aged 71 who has a severe learning disability and autism which would cause him to have limited understanding and ability to adjust to the changes of environment and intrusive medical interventions.’

4.2.3 Nick did not require as many admissions as Mr EF, nor he did he make his level of distress so obvious. However, his carers and brother are clear that Nick was in distress. Not only was his health condition distressing in that he was coughing, vomiting and in pain, he had also recently lost his mother, the most significant person in his life. It seems likely that he would have found the days in A and E and the hospital stays very difficult, being away his home and from familiar people who could understand him. The local manager for the Brandon Trust commented that she was able to understand and communicate with Nick but that his family and the team of front line support workers were far more ‘in tune’ with him and could interpret the nuances of his communication system. With the best will in the world, hospital staff on busy wards cannot replicate this.

4.2.4. Gloucestershire Hospitals NHS Foundation Trust has produced guidelines for staff on the ‘Reasonable Adjustments’ (3)* that should be made for people with disabilities in order to comply with the Equality Act 2010. During the first admission, 21 October – 8 November 2017, the “traffic light’ or ‘hospital passport’ communication aid was in place and a referral made to the Learning Disability Liaison Nurse, who visited Nick on 1 November 2017. This nurse was instrumental in helping NC to understand what was happening. Nick was helped to eat pureed meals as recommended but, despite the need to monitor his food intake closely after surgery, on some days his food charts were not completed fully. Nick received the diagnostic and surgical procedures required to treat his complex bowel condition and staff liaised with his family over consent issues. However, it does appear that Nick was discharged with some significant health factors unresolved giving rise to significant concerns by the Brandon Trust about the safety of his future care. These included the on-going challenge of his ability to consume sufficient food and which led to a further admission one month later.

4.2.5 The second hospital inpatient stay was from 7 December 2017 when the Gastroenterologist planned for NC to be admitted directly to Ward 7A to have a videofluoroscopy. However, this did not go according to plan and Nick was moved three times during his stay, from A and E to the Acute Medical Ward and on to Ward 7A, thus requiring with three sets of staff to implement the Hospital Passport, thus escalating potential risk. When IHOT found him on the day after his admission, he was eating a normal meal, not supervised by staff. This posed a high risk of choking. Feeding equipment appropriate for Nick, as required by the "Reasonable Adjustments' guidance, was not available in hospital until Brandon Trust brought it in.

Gloucestershire Hospitals NHS Foundation Trust has clarified that they rarely admit directly to a ward. Their policy is for all patients to go through an Emergency Department or Assessment Unit. It is unrealistic that a bed will be waiting for them, although their GP may have given this expectation. The Trust receives several complaints each year regarding this.

4.2.6 A Best Interests meeting as held on 12 December. ML, and other family members and Brandon Trust staff attended in order to reach a decision on Nick's future medical care. In such circumstances, the Mental Capacity Act 2005 requires a formal meeting to be held. It was particularly important in this case as there were a number of practitioners working with Nick and a consensus had about his treatment not been reached. Representatives from Speech and Language and Dietetics, key practitioners in NC's care, were not present, nor was his GP. Although he had been contacted by the Consultant, ML felt that he was not well prepared for this meeting. It is important for professional staff calling Best Interests Meetings to be aware that most lay people will be unfamiliar with the concepts involved and that they will be under exceptional stress regarding their role in making 'life and death' decisions for a loved one. Written information prior to the meeting may help this.

4.2.7 ML remains angry today at the way in which he thought the hospital treated Nick. He said 'people are scared of people who are not like us' and that Nick was a 'second class citizen'. He thought there was a lack of hospital staff with an understanding of people with learning disabilities, especially people who communicate non-verbally, although he thought the Learning Disability Liaison Nurse was excellent and could 'cut through' some of the problems. Brandon Trust staff agreed with this. ML considered that the hospital wanted to discharge Nick as soon as possible before Christmas (he was discharged on 22 December) irrespective of his condition or need for further investigations. Overall, ML felt that treatment was left too late for his brother so that, in the end, nothing could be done and he was just left to die.

This perception was discussed with hospital staff that considered that they feel they may over-compensate so that they do not appear as discriminating against people with learning disabilities.

4.3.1 **Listening to family and carers.** In the course of the LeDeR review, and reiterated in this SAR, care workers and ML voiced concerns that their anxieties about Nick’s health were not always taken seriously by his GP Practice. They felt they were not listened to. There were visits and calls to the GP Practice when the care staff said they felt that they were "causing a fuss about nothing". ML felt that they had to wait a long time to be seen when seeking medical help. When asked about this, the GP was sympathetic and agreed that Nick’s condition was distressing and extremely difficult to manage, requiring frequent medical attention, and that Brandon Trust staff were’ pulling their hair out’ trying to look after him properly. He did consider that his practice had responded appropriately and the LeDeR timeline does evidence that the practice did respond to concerns and a number of home visits, telephone discussions and blood tests during this period, although several different doctors attended which may have impacted on continuity of care.

4.3.2 At the time of this SAR, 2 years after Nick had died, ML still felt very angry saying that his brother ‘did not need to die the way he did’. When the GP was informed of this, he was surprised as he felt ML had been consulted regarding the treatment plan and was ‘content with what was happening’. ML is a highly articulate and intelligent man. However, it may be difficult to challenge or question a person in a position of authority, especially in the highly emotional circumstances in this case.

4.3.3 The GP reflected that this had been an extremely difficult time for ML, grieving for the recent loss of his mother and facing significant new responsibilities for his brother, whose condition was deteriorating rapidly. He considered that, in retrospect, the family had not been provided with the support they needed. He added that clarification was required about which part of the system took the lead in coordinating care and treatment for a person with complex needs and their families, especially where several teams were involved.

4.3.4 The feeling of not being listened to is subjective. However, given that several people have similar concerns, the Lead Reviewer believes it happened. It is unlikely that any of the staff involved did this on purpose, or even consciously. GP Practices and Acute Hospitals are busy places with staff under pressure to resolve problems quickly and move on to the next one, a system which does not necessarily work with people with special needs and no verbal communication. There is also the possibility of discrimination, or unconscious bias, dismissing the needs of patients with learning disabilities as less important than ‘normal’ people, or ‘second class citizens’ in ML’s words.

4.4.1 **Health monitoring and systems.**

Issues arose which would not have assisted the multi-agency team in monitoring and caring effectively for Nick at home. The first concerns the accurate monitoring of his weight, a key indicator of his deteriorating condition. The LeDeR Report highlights several significant discrepancies in records between agencies. For example, on 23 November 2017, his weight was recorded on the RiO (computer records system of 2gether NHS Foundation Trust, now part of Gloucestershire Health and Care NHS Foundation Trust) as 27.7kg, whereas on the same day it is recorded as 41.27kg in the GP notes. A further example is 1 December 2017, a GP visited and asked for an accurate weight in order to establish whether Nick needed to go into hospital. However, lack of access to appropriate sit–on scales made this difficult due to mobility problems. It was recorded as 36.9kg, with BMI of 13.9. However, on 4 December 2017, it was recorded as 32 kg, BMI 12.1, measured by the Intensive Health Outreach Team when Nick was fully dressed with his boots on.

4.4.2 Different parts of the system would probably not have been aware of the discrepancies at the time. The GP said that he looked for trends in weight gains or loss rather than relying on individual readings but he agreed that it was unhelpful to have so many inaccuracies. Ideally he felt that readings needed to be made from the same scales, standing on a hard surface, to provide an accurate picture over time. He also expressed some frustration with the different computer systems in use across the various teams, which hold key information but which cannot be accessed by everyone involved in a person’s care.

4.4.3 There is some cause for concern about the timeliness and availability of information between different parts of the health system. In particular, the GP did not always receive Discharge Summaries in a timely way, an important communication tool between primary and secondary care.

4.5.1 **Palliative Care**

It was noted during the hospital stay on 20 December 2017 that the outcome for Nick was uncertain. Following the videofluoroscopy, it seems that the full extent of his condition was identified. As neither naso-gastric tube or PEG were viable, feeding Nick appropriately prepared food was the only way for him to obtain nutrition, despite the considerable difficulties caused by his dysphagia. At that point, before discharge, a DNACPR decision was made, indicating the seriousness of Nick’s condition. During this Review, there has been concern raised that this information could have been determined earlier and action taken earlier to install the PEG before he became too frail. Could the videofluoroscopy have been performed during his October hospital admission, for example, when his BMI was above 13? Major feeding problems were evident at that stage although he was discharged without them being resolved.

4.5.2 The Palliative Care Team became involved prior to discharge, putting plans in place for NC to return home on 22 December 2018. The World Health Organisation defines Palliative Care as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. (4) This aim appears to have been fulfilled for Nick and the agencies worked together support him and his carers in his final weeks, enabling him to remain at home with no further hospital admissions.

4.6.1 **End of Life.**

The SAR regarding Mr EF identified that there had been indications that he was approaching the end of his life up to a year prior to his death, although they were not recognised as such at the time. In that area, access to the End of Life Pathway would have enabled appropriate care planning and additional services. It may have been possible to avoid some of the hospital admissions.

4.6.2 As greater numbers of people with learning disabilities and co-morbidities live longer in community settings, it is important for approaching end of life to be recognized and that this might be at a younger age, and take a different form than is seen in the general population. It might have improved Mr EF’s quality of life significantly if he were provided with support to prevent at least some of the admissions to hospital. It might also have met the Care Act 2014 criteria for wellbeing more effectively. "Well-being" is a broad concept relating particularly to personal dignity and being treated with respect; physical, mental health and emotional wellbeing; protection from abuse and neglect; control over day-to-day life and domestic and personal issues. This may also apply to Nick.

4.6.3 Gloucestershire has an End of Life Strategy (5), published in 2016, which describes people are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those in other categories which may be applicable to Nick - general frailty and co-existing conditions that mean they are expected to die within 12 months of existing conditions if they are at risk of dying from a sudden acute crisis in their condition. It recognises that people with additional needs, including learning disability, may require specialist and additional support. “This is sometimes because of an inequality in accessing health services, but may also be because of increased complexities in co-morbidities and communication difficulties’. It states that the ‘Gloucestershire End of Life Board will adopt best practice from other areas who have implemented systems that support those with a learning disability or mental health condition to ensure that they are identified in a timely way and are given the time to talk about death and dying and the opportunity to express their wants and choices in the care they receive at the end of their life’.

4.6.4 It might have been possible to identify at an earlier stage that Nick was approaching the end of his life. This might have enabled Nick, his family and carers to be better prepared in advance and would have facilitated earlier involvement of the Palliative Care Team. It is recognised that determining the approach of end of life is not straightforward. Nick had blood tests and other investigations which indicated poor absorption by his gut, plus weight loss, in April 2017, if not before. The decision about DNACPR was made in hospital following the videofluoroscopy, which identified that his condition could not be reversed. This would not have changed the outcome but it might have provided him with a more settled final few months and less anguish for his family if they had understood the way his health would deteriorate.

4.6.5 Another Gloucestershire SAR, Danny (6), reaches a similar conclusion. ‘It was not recognised in any of the assessments or noted by the hospital that Danny may have been reaching the end of his life. Although his death was unexpected, the deterioration in his health, necrotic toes in particular, could have been identified as signs that he was in the final stages of his life. During this review, an experienced doctor stated that she would not have been surprised if Danny had passed away within a year of these events’.

4.7.1 **Cause of death**. Malnutrition is a medical term but it evokes an emotional reaction. We are shocked that a person died from inadequate nutrition. His GP commented that whilst this definition is accurate, Nick died because his pancreas was not producing the enzymes to enable his body to absorb the nutrients in his food. We do know that he was not receiving adequate nutrition, due to his severe dysphagia. This was the reason both the naso-gastric tube and PEG were considered as methods of providing nutrition directly into his stomach, although neither proved viable options. However, the GP is clear that neither intervention would have prevented his death from this cause ultimately. The Palliative Care Consultant referred to ‘pancreatic insufficiency’ in notes on 10 January 2018 and added that there may be link with ‘cerebral palsy having an impact more widely in the body leading to organ failure at a slightly earlier stage than seen in the wider population’. In other words, his gut failure may have been linked to an existing condition which may cause individuals to become seriously ill or to die at a younger age than someone without the condition.

4.7.2 Following a medical review of health records the Acute Trust have concluded that Nick had died from gut failure; this is not a well-defined medical term, but is explained as an autonomic neuropathy, more common in patients with microcephaly, cerebral palsy or a myopathy. In the last year of his life Nick was losing weight and struggled to eat. The extent of his gut failure was irreversible in this last year for Nick, presenting with a combination of dysphagia (difficulty in swallowing), oesophageal strictures (tightening) and apparent duodenal obstruction.

In general, the reasons for poor gut function and consequent malnutrition are unclear as this is a very difficult and under-explored aspect of medicine. It may be helpful to draw analogies with other organ failures which will ultimately cause death. For example, a person could have a heart attack (myocardial infarction) and live for many more years, but experience a gradual deterioration in heart function until the level of heart failure becomes irreversible and it is no longer medically possible to keep the patient's condition optimised and they come to the end of their life.

4.8.1 **Impact of learning disability on access to health care.** NHS England and NHS Improvement commissioned LeDeR to improve the standard and quality of care for people with a learning disability. Their Third Annual Report, published in May 2019 (7), is based on the review of 1000 individual deaths This states: 'It is of great concern that the latest LeDeR report cites deaths reviewed where there were concerns about the quality of care, and an average age of death that is 23 years younger than the general population for men with a learning disability and 27 years younger for women.

4.8.2 "Nearly half of the deaths reviewed showed that people with learning disabilities received care that met, or exceeded, good practice, but we should expect all people to receive care that meets good practice. The findings suggest we still have a long way to go for people with learning disabilities'.

"One in every 10 reviews completed in 2018 raised concerns about the circumstances leading to death, and 71 adults were reported to have received care that fell so short of good practice that it significantly impacted on their well-being, or directly contributed to their cause of death. This is completely unacceptable. We need to see clear actions being taken to prevent other premature deaths.

"Of particular concern was the identification of diagnostic over-shadowing – or misreading symptoms of illness as being due to a person having learning disabilities, rather than a treatable medical condition. This can be symptomatic of a lack of understanding, or a disregard for people with learning disabilities; an attitude that devalues their lives, makes ill-founded assumptions about their quality of life, and perpetuates health and other inequalities. It is overcoming such societal, discriminatory attitude that is arguably our most significant challenge'.

4.9 Summary The information examined shows that Nick had suffered from several conditions relating to food intake and absorption, probably associated with cerebral palsy, and that these had worsened over several years, accelerating in the last six months of his life. The treatment he received was extensive, including complex bowel surgery. The only evidence to suggest that Nick may have received a lower standard of care than a person without a learning disability was the delay in carrying out the videofluoroscopy, which may have facilitated an earlier decision about alternative feeding methods. However, it may not have prolonged his life significantly and, given what we know about Nick's dislike of feeding tubes, it may have added to his distress and affected his quality of life.

Some of the care provided to Nick was excellent and most of it was good, although aspects of it fell short of good practice, especially the support for Nick's family and carers throughout a very difficult period.

5.1 **Good Practice**

5.2 Brandon Trust care and support of Nick over several years and up to death, working closely with his family.

5.3 The Community Learning Disability Team provided specialist input with a high level of co-ordination and communication with other agencies.

5.3 Palliative Care Team provided specialist services and co-ordination to support Nick remaining in his familiar environment until he died.

5.4 The Acute Learning Disability Liaison Nurse was valuable in providing guidance to colleagues on caring for Nick in hospital and in communicating with NC in ways that he could understand.

5.5 Since this Review was carried out, improvements have been made to the health information systems available for Primary Care and Community Teams. For example, it is now possible for a GP to access information recorded by the Speech and Language Therapy Team, such as weight. This is a great step forward in facilitating integrated care and communication in Practices where this new system is deployed

6.1 **Areas for consideration and Recommendations**. This SAR has also highlighted a number of areas where improvements may be considered. These are shown before each of the corresponding recommendations.

6.2 The delays in carrying out the videofluoroscopy may have resulted in missed opportunities to intervene earlier.

6.2.1 It is recommended that the Board seek assurance that any unconscious bias towards the needs of people with a learning disability is identified and challenged throughout the health and care system.

6.3 Nick’s family and carers considered that staff in Primary and Secondary Care did not always ‘hear’ and respond to concerns and information provided by people who knew Nick very well. This includes use of the Hospital Passport and other tools. Nick could not speak for himself so this was important.

6.3.1 It is recommended that the Board seek assurance from Primary and Secondary Care partners that, where an individual cannot speak for himself, they acknowledge and act on the concerns expressed by the family and carers about his needs, and provide written information where appropriate.

6.4 It may have been possible to identify that Nick was reaching the end of his life at an earlier point, thus enabling other services to support him, his family and his carers.

6.4.1 It is recommended that the Board seek assurance that the Gloucestershire End of Life Board carries out its stated intention to adopt best practice to support those with a learning disability and to ensure that end of life identified in a timely way so that appropriate support can be accessed.

6.5 The Hospital did not always adhere to ‘Reasonable Adjustments ‘ guidance or to specific information provided on NC’s care needs in the hospital passport, especially his diet and eating, thus causing a risk to his health. This was exacerbated by moves from one ward to another. Specialist equipment for feeding and other basic care should be readily available to avoid discrimination.

6.5.1 It is recommended that the Board seek assurance on the necessary processes and care pathway involved in direct admissions for acute episodes of hospital treatment, so that these pathways clearly highlight the need for timely communication and implementation for reasonable adjustments for learning needs and disability.

6.6 When Nick was discharged after each hospital admission, his care needs were not reassessed, which may have resulted in missed opportunities to provide the most appropriate care.

6.6.1 It is recommended that the Board seek assurance on safe and timely hospital discharge, so that assessments are inclusive of Hospital Discharge Team expertise and liaison with care providers and placement commissioners.

6.7 The absence of a single, multi-disciplinary record of information, shared across organisations, made it difficult to form an overview of Nick’s condition and for discrepancies in monitoring information to go undetected.

Clarification on lead roles and responsibilities may be needed for community and primary care staff when managing the care of individuals with very complex needs.

6.7.1 It is recommended that the Board seek assurance that there is clarity about the roles of the Community Learning Disability Team and Primary Care in leading and coordinating the care of people with complex health and care needs. This should include working together to achieve a single approach for recording, managing and sharing patient information that best supports monitoring the health and social care of those with complex care needs.

6.8 It may be helpful to provide written information, including notes on the outcome, to relatives attending Best Interests.

6.8.1 It is recommended that the Board seek assurance that relatives, and other non-professional staff, attending a Best Interests Meeting are prepared well for the meeting, with written information available.

Footnotes

1. Gloucester NHS Health Community; Hospital Passport

2. Bracknell Forest and Windsor and Maidenhead Safeguarding Adult Board SAR EF 6 November 2017.

3. Gloucestershire Hospitals NHS Foundation Trust; Reasonable adjustments Guidance for Staff. May 2016

4. World Health Organisation; Palliative Care Fact Sheet 2020

5. Gloucestershire Clinical Commissioning Group End of Life strategy 2016-2019

6. Gloucestershire Safeguarding Adults Board; SAR Danny

7. Learning Disability Mortality Review Annual Report 2019

Haak, Lenski, Hidecker, Paneth Cerebral Palsy and Ageing: Developmental Medicine and Child Neurology 2009