Safeguarding Adults Review

Overview Report "Mr N"

February 2019

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Enfield Safeguarding Adults Board

ENFIELD Council

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1 Introduction and Background

The London Borough of Enfield (LBE) Safeguarding Adults Board has accepted the request for a Safeguarding Adults Review (SAR) to be conducted on the circumstances surrounding the admission and discharge of Mr N, a 32 year old male diagnosed with Learning Disabilities. The SAR Panel agreed the situation met the Care Act Safeguarding criteria for a SAR; specifically the criteria that procedures may have failed and that the case gives rise to serious concerns about the way in which local professionals and/or services work together to safeguard adults at risk.

2 The purpose of the review

- Establish what lessons can be learnt from the circumstances of the case.
- Review the effectiveness of the procedures and processes of the involved agencies.
- Analyse how organisations worked together
- Analyse and expand upon the finding of the various reports.
- Commission a final report that will collate the above and make effective recommendations for change; be that to culture, procedures, process or policy.

2.1 This specific SAR is to consider how organisations, individually and collectively, may have contributed to the serious harm experienced by Mr N in October and November 2015. Secondly, the SAR will consider the response from organisations, individually and collectively, as a result of the significant harm that MR N experienced; this includes but is not limited to LBE Safeguarding Adults Process, London Ambulance Service (LAS) Root Cause Analysis (RCA) and the North Middlesex University Hospital (NMUH) Serious Incident (SI) Procedures. Finally, the SAR will consider based on responses from organisations if there are gaps in the service delivery for adults with learning disabilities which can be identified from this case.

2.2 Individual Management Reports (IMR) will include the following detail and a template will be provided to parties:

2.2.1 Full chronology

2.2.2 Narrative of service involvement a) before Oct 2015 b) Oct 2015-Nov 2015 c) involvement in processes following

2.2.3 Description of the specific services in place to support adults with Learning Disabilities

2.2.4 Any significant factors which impacted on actions or decisions taken (resources, organisational change, staffing)

2.2.5 Evaluation of how service was delivered to Mr N

2.2.6 Pathway for adults with learning disabilities in your service and how you link with partners

2.2.7 Lessons learnt including judgement of organisations service against policy, procedure and practice standards

2.2.8 Recommendations for action

3 Methodology and process information

3.1 Following a review of all available information and a meeting with Mr N's family on the 19th June 2017, the author produced a timeline from the available information for a meeting with all agencies on the 11th July 2017.

3.2 IMRs had been requested from some but not all services. A request for an IMR was made from NHS 111 for an IMR after the meeting in July.

3.3 The GP was requested to ensure that his IMR was undertaken by someone who did not have direct contact with Mr N. The CCG safeguarding lead offered to provide the IMR.

3.4 The IMR from North Middlesex University Hospital (NMUH) was withdrawn at the meeting. The NMUH representatives were new in post and felt that the IMR required input from the learning disabilities team. A new IMR was produced after the meeting.

3.5 Action points following the meeting led the author to meet with London Ambulance Service (LAS) to hear the call recording relating to the transfer to hospital on 2nd November 2015.

3.6 The author visited NMUH on 27th November 2017 to review Mr N's medical records. The accident and emergency records for the 1st and 2nd November were considered along with the inpatient records from the 3rd November onwards.

3.7 An additional time line was produced to reflect information before admission and information relating to what happened after the 3rd November 2015. The purpose of this is to establish a clear narrative which can be agreed by all parties and which enables everyone to understand what happened when.

3.8 The report and timeline are written to be accessible to all audiences with medical terms explained throughout rather than in a glossary.

3.9 A draft thematic report was then presented to the review panel for discussion.

3.10 Follow up discussion in March 2018 led to a request for information from the care provider Edenvale and for the need to gain further information from LBE services.

3.11 The revised IMRs have been considered and included in this report.

3.12 The final draft was submitted to all parties for consideration of factual accuracy.

3.13 NHS 111 felt that there were a number of points of emphasis they wished to clarify. Therefore the report author visited the NHS 111 headquarters on 6th September and a revised draft was produced for their consideration on 7th September.

3.14 A further meeting took place to consider the report and its recommendations on 4th October. Details of correspondence between Mr N's family, his GP and the Enfield Integrated Learning Disabilities Service were supplied at this meeting.

3.15 A final draft was then produced.

4 Background

4.1 Mr N was born in October 1983.

4.2 The electronic GP medical records from the practice where Mr N was registered at the time of the events described here have been reviewed. These do not contain detail of his early life. It was reported in 2004 in a comprehensive assessment that he was born following an emergency caesarean section and required resuscitation.

4.3 He was the first child born to his parents.

4.4 He was born in the UK to a family who came from an EU community country and whose first language is not English. Both of Mr N's parents speak English although his Mother is less confident in formal discussion. Both prefer to speak their first language to fully express themselves clearly.

4.5 He has Down's syndrome. Down's syndrome, also known as trisomy 21, is a genetic condition that typically causes some level of learning disability and certain physical characteristics.

4.6 At the time of Mr N's birth, there was no NHS national screening programme for Down's syndrome. The NHS national screening programme was implemented in 2001. However, other types of prenatal testing were available.

4.7 People with Down's syndrome are more likely than the general population to have hypothyroidism[1]. Mr N has an underactive thyroid and receives medication for this.

4.8 Mr N also has severe learning disabilities. These have been present since early childhood.

4.9 The GP records we have seen commence in 2010.

4.10 The Edenvale (the most recent care support provider) assessment records report that Mr N's family recall that Mr N was verbal and communicative in two languages, that he was able to walk and was essentially developmentally normal. We have been unable to confirm this from contemporary records.

4.11 At around the age of seven he developed epilepsy. The epilepsy was treated with medication which was varied and adjusted at times. The epilepsy has been very difficult to treat.

4.12 The epilepsy had a significant effect on his life as he had frequent auditory induced seizures. The seizures are triggered by noise and his family feel that a quiet environment is more suitable for him.

1 Hypothyroidism is the name given to the condition resulting from an under-active thyroid gland. This means that it is not producing enough thyroid hormone for the body's needs.

4.13 Care for Mr N transferred from children to adult services in 2001. He was initially provided community services at the Formont Day Centre but he ceased attending in 2002 as it was felt by his family that the noisy environment had an adverse reaction on his epilepsy.

4.14 Mr N had support from the Enfield Integrated Learning Disabilities Service (ILDS) this is a multi-professional complex care team, this included occupational therapy, speech and language therapy, reviews by neurologists and psychiatric services.

4.15 Reviews were arranged at Mr N's home rather than at a day centre or hospital. The last review letter is dated 10th June 2014. It noted that ascertaining the seizure history and understanding the burden of caring for Mr N is difficult even when interpreters are used. As is often the case, there are differing views and perspectives between family members and clinicians.

4.16 The records from all sources make clear the evident devotion of Mr N's parents in caring for him. All records also note that they have some unconventional views relating to the management of his medical conditions.

4.17 Mr N has been provided with a package of support to access the community from his own home initially supported by New Directions and from 2014 by Edenvale Care and Support.

4.18 The Edenvale Care and Support risk assessment has been considered as part of this review.

4.19 The package offered 29 hours per week of support. Much of the support related to 2:1 supervision of Mr N. The risk assessment undertaken at the time identified that Mr N was not always alert and required support with all activities of daily living.

4.20 Much of the day to day care fell to Mr N's family with whom he lived.

4.21 We have seen no written evidence to show that they were offered carers assessments from the local authority. The ILDS service report that these were offered but declined.

4.22 Mr N had learning disability reviews with his GP on the 6th June 2014 and 7th January 2015. These revealed that over the year leading up to November 2015, it seemed apparent that Mr N was physically more limited than in the past.

4.23 He no longer verbalised and his mobility was reduced (this was specifically noted in his GP review of January 2015).

4.24 The Edenvale risk assessment supports this view of Mr N's declining physical condition (8th April 2014).

4.25 In addition, his anti-epileptic medication tended to make him drowsy.

4.26 None of the information gathered paints an entirely clear picture of Mr N's ability to communicate or his physical abilities. It appears that the information about Mr N was generally gained from his family and carers and not directly from him.

4.27 We have found no evidence to show any formal assessments under the Mental Capacity Act (MCA). The letter from the consultant psychiatrist dated 10th June 2014 notes that Mr N lacks mental capacity.

4.28 As Mr N was at high risk of aspiration he was assessed by the Speech and Language Therapist (SALT) and video fluoroscopy was undertaken on 8th June 2010. This was normal. Follow up was offered on a symptomatic basis as Mr N's swallow reflex would have been likely to decline over time. He was seen and assessed at home by the dysphagia[2] service. Mr N's parents agreed to re-refer to the service if they had concerns or if there were any changes.

5 Summary of events and findings

5.1 On 27th October 2015, Mr N had an episode of vomiting and his family received advice from the GP. He appeared to improve until the 31st October when further advice was sought from NHS 111 as he was not drinking. The advice provided followed the algorithm for the condition selected. However, the adviser was not fully aware of Mr N's underlying epilepsy and learning difficulties. Consequently there is limited discussion with the clinician to whom the family spoke to establish that Mr N had been able to take critical medication to control his epilepsy on a consistent basis.

5.2 The NHS 111 services is driven by pathways algorithms which prompt questions and indicate the appropriate choice. The call handlers are not able to risk assess cases and if anything indicates a "Red Flag" calls are passed on to a clinician.

5.3 On 1st November 2015 he attended A&E via ambulance after a second NHS 111 call. The ambulance attended promptly. At this attendance Mr N was examined by an emergency doctor and his care was reviewed by a consultant (although the consultant was called away). He was considered to be dehydrated and IV fluids were administered. A chest x-ray was taken which show clear lung fields. An abdominal x-ray showed no obstruction in addition the clinical examination found no serious abnormalities and therefore Mr N was to be discharged home.

5.4 At interview Mr N's family told us that a chest x-ray was not taken on this date (although there is an x-ray film and report for this date.)

5.5 All communication was undertaken with a member of Mr N's family acting as an interpreter.

5.6 There is no record that those treating him considered if this was an appropriate method of communicating with an adult and what capacity Mr N had to consent.

5.7 We are unable to reconcile the accounts of Mr N's family and those of the clinicians involved on the advice provided.

5.8 The process of examination was not satisfactory as far as Mr N's family were concerned. This was exacerbated as they felt that Mr N was too unwell to be discharged and struggled to get him back into their car. The hospital IMR has been unable to confirm how he got back to their car in response to the concerns raised that the family were required to manoeuvre a trolley bed back to their car.

5.9 Additional distress was caused by the accident and emergency discharge letter which was provided to the family and the GP was inaccurate as it stated that he was suffering from asthma.Mr N did not have asthma and the entire discharge letter is inadequate.

2 Dysphagia means difficulty in swallowing.

5.10 Mr N's family requested a home visit from his GP on the 2nd November 2015. This took place. His family were again distressed when the GP asked about the A&E diagnosis of asthma. After examining Mr N, his GP contacted NMUH as he felt admission was indicated. He spoke to the appropriate medical staff and wrote a letter before requesting transport from the London Ambulance Service (LAS).

5.11 The conversation with the LAS was on reflection not entirely functional, as the call handler and the GP did not share the same view of Mr N's condition. The GP believed that his request for transport via ambulance would be prioritized because he was a health care professional who had seen and assessed Mr N. The LAS call handler was establishing not only the need to take Mr N to hospital but did he need the attention of paramedics and treatment before he got to A&E.

5.12 The GP did not appreciate that his request for transport was not prioritized but was treated as any other request for hospital transport, that is according to an LAS view of the condition of the patient.

5.13 Priority is given to patients who need treatment from ambulance staff en route to hospital because, for example, they are not breathing. The view of the GP was that Mr N required rapid transport to hospital.

5.14 The original request for transport was made at 16.01, the family called LAS for updates at 16.53 and again at 18.36. At 19.14 LAS upgraded the call and the ambulance reached Mr N at 19.46.

5.15 The ambulance review recognized that there was a delay in transporting Mr N to hospital but that the call handler had followed an appropriate pathway.

5.16 Mr N arrived at NMUH at 20.16 on the 2nd November 2015. A second chest x-ray showed clear lung fields, vital sign observations were essentially normal with the exception of a raised heart rate which settled.

5.17 Mr N was admitted to ward T5 at 03.20 on the 3rd November.

5.18 However, just before midnight on the 3rd November Mr N's condition rapidly became much worse and by the 4th November he was admitted to an intensive therapy unit and was receiving mechanical support with his breathing and was having regular convulsions.

5.19 His diagnosis was of pneumonia.

5.20 Mr N was always at high risk of aspiration pneumonia[3] due to his epilepsy. This was compounded by his physical decline. However it appears from conversations with consultant medical staff, nurses and the Learning Disabilities (LD) liaison nurse and Mr N's mother in the Intensive Treatment Unit (ITU) that her understanding of the risk of aspiration was not as detailed as might have been expected.

5.21 Whilst in ITU, support for Mr N's breathing became more complicated partly due to his epilepsy and problems with achieving effective ventilation. This led to the need for a tracheostomy. His long term nutritional needs were met via a PEG (Percutaneous Endoscopic Gastrostomy) this is a way of introducing food, fluids and medicines directly into the stomach by passing a thin tube through

3 Aspiration pneumonia is a complication of pulmonary aspiration. Pulmonary aspiration is when you inhale food, stomach acid, or saliva into your lungs.

the skin and into the stomach. Both of these procedures were required to treat Mr N's ongoing condition. Mr N's family found it difficult to accept these interventions. There is considerable evidence of staff offering explanations to the family on numerous occasions and there is similar evidence to show that the family found it very hard to accept the treatment offered.

5.22 Prior to this admission Mr N had no hospital passport. This is a system which provides a method of communication between the hospital and the patient. One was introduced for Mr N in December 2015.

5.23 On 21st December 2015 Mr N was transferred to a medical ward and discharged from hospital on 31st August 2016 to a rehabilitation facility.

6 Family view of SAR

6.1 Mr N's family expressed concerns about the care which he had received both before and after the events described here. They expressed dissatisfaction with every service he had contact with but their biggest complaints relate to NMUH. It does not appear from the interviews undertaken and the records reviewed that a position was ever reached where Mr N's family felt content with the healthcare he received.

6.2 The family felt that the SAR review would not help Mr N as it would alter nothing that had already happened. Their desired outcomes were a face to face apology from the first accident and emergency consultant and more physiotherapy for Mr N. They also wished to see him treated more kindly at his present placement where people eat in front of him which they feel is unkind and tactless when he is unable to do so.

7 Themes

7.1 Reasonable adjustments required to meet the needs of people with learning disabilities – services accessed by telephone

7.1.1 Since the introduction of the Equality Act 2010, Services including healthcare are expected to make reasonable adjustments for the requirements of those with learning disabilities (LD).

7.1.2 The NHS 111 and LAS IMRs show, that the reasonable adjustments to services where individuals with a learning disability, who require the support of others to express their needs, are limited.

7.1.3 This is especially notable in the algorithms used by NHS 111 and London Ambulance Service (LAS) to establish risk and to inform action over the telephone.

7.1.4 The added complexity in this case was that communication was via a carer who relayed questions to Mr N's family, for whom English was not a first language.

7.1.5 The NHS 111 service IMR identifies that the adjustment to service for them where a patient has reduced responsiveness is transfer to a clinician. However, if an adult is non verbal the NHS 111 service is very limited in its scope to provide a a service. Establishing that an individual is not as communicative as normal is particularly difficult in these circumstances.

7.1.6 However, unless it is established why the third party is speaking and how well they know the patient it is hard to see how a telephone assessment can be effective.

7.1.7 NHS 111 are able to access interpreting services and did not conclude that this was required in this case.

7.1.8 The LAS IMR identifies that staff have been provided with training in aspects of LD that supports call handlers in selecting the correct pathway.

7.1.9 The LAS algorithms are designed to identify the greatest need and allocate ambulances accordingly. In effect they present a safety net. If the mesh of such a net is too loose then patients can fall through it, if it is too tight then it does not help to differentiate those with immediate need from those who can wait.

7.1.10 A rapid review takes place. The call handler asks: is the patient breathing? This is a simple question which can be easily understood by a non-clinical audience. It can also be easily established.

7.1.11 They also ask is the patient conscious. Assessing level of consciousness in adults for non-clinicians is usually measured by their responsiveness – can they be roused when their name is spoken, can they speak? The algorithms used by LAS do not take account of non-verbal patients and those whose responsiveness is difficult to interpret There are references in the call from the GP as “non-responsive”. There is no prompt to assess how different this was to usual baseline presentation. This is important as it presents a gap in the ability of the service to establish the condition of the patient effectively.

7.1.12 In addition the algorithm does not consider the individual assessment made by an onsite clinician. This fact was not known to the GP at the time of the assessment.

7.1.13 LAS do make clear that they carry out a prioritised assessment before an ambulance is despatched which accords with the severity of the condition of the patient.

7.2 Long term planning – services, perspectives and facing the future

7.2.1 Mr N was seen by adult services and did receive input monitoring his overall health and well-being.

7.2.2 This included an annual review from his usual GP and input from the Integrated Learning Disabilities Service (ILDS).

7.2.3 Contact was maintained with Mr N’s family and the ILDS.

7.2.4 The GP noted that Mr N’s parents were not ready to think of his long term future. Part of their reluctance was noted as having to consider a time when they could not manage him at home. It is unclear if they were offered specific opportunities to explore these feelings and consider options for long term care beyond living at home. Part of the difficulty may have been the ability to communicate easily with an appropriate level of subtlety and sensitivity with Mr N and his parents.

7.2.5 When Mr N's hospital admission led to him being unable to return home the consequent shock was all the greater to the family. Simple adaptations such as a "Hospital passport"[4] were not provided until after his admission on 2nd November 2015.

7.2.6 Special Patient notes could have been added to his record at NHS 111. These would have alerted the NHS 111 service to the fact that Mr N was non verbal and had limited mobility.

7.2.7 Mr N's parents appear to have some perspectives relating to his health and condition which did not accord with those of either health care or care staff. The contemporaneous records show that the family had a different opinion on his ability to mobilize and the risks of him being able to walk unaccompanied. A reduced level of consciousness was noted in medical records but not agreed by Mr N's parents.

7.2.8 It is difficult to see from any of the records a shared and consistent view between those offering help and support, in any service, and Mr N's parents. This contributed to lack of a shared vision of Mr N's overall prognosis.

7.2.9 The risk of aspiration pneumonia was high in Mr N's case long before November 2015. Although he had been seen by the dysphagia team and had swallow reflex testing, it does not seem that the family were aware that this remained an ongoing risk which would increase rather than decrease in the future.

7.3 Use of the Mental Capacity Act (MCA)

7.3.1 People with Down's syndrome are all unique individuals and should be acknowledged as a person first and foremost.

7.3.2 Mr N has severe learning disabilities. Down's syndrome was a part of this but not the entire story. People with Down's syndrome have a wide range of abilities.

7.3.3 When the GP for example spoke to LAS of Mr N having Down's syndrome this did not convey the detail of his learning disabilities.

7.3.4 The Mental Capacity Act provides the legal framework for people who need help to make decisions for themselves.

7.3.5 From all of the records we have seen and all of the reports obtained, we have been unable to identify how the MCA was formally applied to Mr N prior to the admission of the 2nd November 2015. From the appearance of the information which we have seen it seems that Mr N's parents made decisions for him as they had done when he was younger.

7.3.6 Use of the provisions of the MCA might have assisted in the conversations with Mr N's family in considering his future options and supported Mr N in decision making processes.

7.3.7 When he was seen in NMUH accident and emergency department on the 1st and 2nd November

4 The aim of the hospital passport is to provide up to date information on patient's with learning disabilities on admission and prevent delay in their assessment and treatment. The document provides staff with important information about the individual patient includes useful contacts with community partners. This 'hospital passport' is the property of the person with learning disabilities and should be kept safe during admission and must be returned to the individual on discharge from hospital.

no consideration is made of his capacity. In addition there is very little consideration of either his or his parents viewpoint on the visit of the 1st November.

7.3.8 The NMUH IMR notes there was "little evidence to support the use of reasonably adjusted pathways for a person with a learning disability who required the support of others to maintain their safety".

7.3.9 It also notes that:

"It is legal requirement in situations where there are concerns that a person may lack capacity to consent, particularly those relating to serious medical treatment, for adherence to the Mental Capacity Act 2005. Research suggests that there is a lack of assessment and/or documentation to support the evidence of the assessment and decision making process and evidence of best interests decision making processes being in place." CIPOLD, 2013[5]

7.4 Professional to professional communication

7.4.1 The IMR process has identified a number of professional to professional communication issues which caused problems and which could easily recur.

7.4.2 The issues fall into three categories:

Inaccurate information sharing

7.4.3 When Mr N was seen in A&E at NMUH on the 1st November the discharge letter which was sent to the GP stated that he was suffering from asthma. This was inaccurate and was not supported by the clinical presentation. The letter lacked any useful clinical detail and consequently did not assist the GP in providing continuity of care. When he asked the family about the trip to A&E with asthma this caused them distress and undermined their confidence in their GP.

Presumption based on previous diagnosis

7.4.4 In describing Mr N as a person with Down's syndrome to both NHS 111 and LAS everyone using that term was correct. However, this diagnosis did not account for his symptoms of illness.

7.4.5 The GP told the LAS call handler when requesting an ambulance that Mr N was "severely affected" by his Down's syndrome such a phrase is open to a wide degree of interpretation.

Shared understanding

7.4.6 In the call to LAS on the 2nd November it is possible to discern a difference between what was said and what was understood.

7.4.7 It was established that Mr N was conscious and breathing. However, his level of consciousness was reduced, his condition was such that he required fairly urgent transfer.

7.4.8 The GP thought he had made clear that the transfer by ambulance was mandated by the patient's condition. To him that meant an ambulance arriving at the property within an hour with a crew capable of physically transporting Mr N on a stretcher.

5 http://www.bristol.ac.uk/cipold/

7.4.9 The call handler thought she had made clear that a patient transport ambulance rather than an emergency ambulance was being arranged.

7.4.10 The GP thought that as he had seen and clinically assessed Mr N and arranged his admission to NMUH that this would feed in to the priority given to the request. This was incorrect. As LAS make clear on their website in a section aimed at health professionals:

"Your call will be triaged similarly to all 999 calls. This triage system exists to match our resources to the nature of the problem. It allows us to identify those calls which are so time-critical that they warrant an emergency vehicle, even if that means diverting an ambulance on the way to another less urgent call. As demand in London for ambulances is usually very high, call triage is a vital way of ensuring that those patients with the most immediate need are dealt with first, ***regardless of who is requesting the ambulance****."* [6]

7.4.11 The GP IMR acknowledges the gap in his understanding of patient transport requests and notes a need to use very precise language when requesting transport.

7.5 Communication and relationships with the family

7.5.1 The IMRs all demonstrate that there was a considerable amount of communication with Mr N's family. However, they all show that it was at points ineffectual.

7.5.2 None of the records we have seen which relate to the long term care of Mr N identify how his point of view is to be heard. His family told us that they preferred to use an interpreter yet none of the reviews or assessments noted this or noted use of translation services. This is particularly relevant as whilst a functional sharing of information might be achieved without an interpreter subtle but important issues such as health beliefs were not picked up.

7.5.3 The conversations with NHS 111 involved either a paid carer or a family member speaking on behalf of Mr N's mother. Many of the meetings involved a family member acting as an interpreter. The situation was initially exacerbated as Mr N's father was not present as he was aboard with a broken leg.

7.5.4 Conversations with the family when Mr N was in ITU were particularly well recorded. The learning disabilities liaison officer was also present for some of the meetings. As previously identified differing health perspectives and opinions along with expectations became apparent. However, no independent interpreter was involved in these meetings.

7.5.5 The review has identified that Mr N's parents had long standing dissatisfaction with all services and this dissatisfaction predates the events of November 2015 and continues. It is unclear if there has ever been any previous attempt to address their dissatisfaction via complaints procedures or any form of reconciliation.

6 http://www.londonambulance.nhs.uk/health_professionals/gp_information/how_the_call_will_be_triaged.aspx

8 Recommendations

8.1 NHS 111 should review the training provided to all staff relating to learning disabilities and non verbal patients and assure itself that it is fit for purpose.

8.2 NHS 111 should consider if the prompts for discussion relating to tolerance of critical mediction in patients who are vomiting are sufficiently robust to offer assurance.

8.3 LAS should consider if their prompts relating to the assessment of non-verbal patients are sufficiently robust.

8.4 LAS should again remind GP's of their approach to allocating transport.

8.5 GP's should consider the proactive use of special patient notes to NHS 111 for non verbal patients, in the same way that patients who are approaching the end of life, to promote effective communication.

8.6 London Borough of Enfield, LAS and NHS 111 should explore with NMUH the most effective way of identifying non verbal clients to their services.

8.7 Use of Hospital Passports should be promoted throughout Enfield and supported by primary care as well as secondary services.

8.8 LBE should develop an approach with Enfield CCG to establish that multi-agency care plans highlight long term considerations which meet the emotional needs of parents who care for their children who are adults with learning disabilities. Specifically pathways for those with Down's syndrome and dementia need to be developed.

8.9 All services mentioned in this report should be prompted to ensure that their services meet the requirements of the Mental Capacity Act and that staff are trained to use these.

8.10 All services should be prompted to ensure that they consider effective use of independent interpreters when discussing complex issues to ensure that there is a complete and accepted understanding for all parties to a discussion.

Background prior to events

Date	Time	Event	Source	Comment
2001		Mr N transfers to adult service and becomes known to LBE ILDS	LBE IMR	
2011		Formal assessment by Speech and Language Therapy service (SALT)	LBE IMR	Communication profile developed which was subject to period review.
06/06/14		LD review	GP IMR	This included a social and physical assessment. A reduced level of consciousness led to a reduction in anti-epileptic medication. Both parents were present at the review. They acknowledged the difficulty they were having in considering long term plans for Mr N especially if they became unable to manage him at home. Physical health plan to deal with issues such as constipation was made.
07/01/15		LD review	GP IMR	This review followed the same pattern as that of the previous year. The same issues were discussed. Both parents were present at the review. In the last year Mr N's parents noted he was communicating less and his mobility had deteriorated. Again difficulty in contemplating long term plans is noted.
12/08/15		Last contact with LBE ILDS prior to admission to hospital	LBE IMR	Additional respite service requested but declined.

Combined Chronology

Date	Time	Event	Source	Comment
Tuesday 27/10/15	Not included in GP letter	Family contact GP surgery as Mr N has vomited. Advised to offer fluids and to attend A&E if the situation worsens.	GP IMR letter Family recall	The advice from the GP practice appears to be appropriate from the description of Mr N's condition. The GP letter does not include any advice on continuing anti-convulsants therapy.
28/10/15-30/10/15				No known contact with health or social care services.
Saturday 31/10/15	17.48-17.59	Phone call to NHS 111 – social carer 1 telephoned for advice as Mr N had started vomiting again *"he was throwing up, vomiting when they give him anything to eat, he has kind of calmed day the last couple of days and today he started again this morning."* The request was for a clinician to come and assess him. The main problem presents as vomiting. Mr N's Down's syndrome was reported. There was some discussion about pain assessment the reply received was *"maybe slight but not a lot, he looks alright"*. Mr N's epilepsy was mentioned and the carer was asked *"is he able to keep down the medications despite the sickness"* and the answer was *"yes"*. Advice about hydration was given which included that he could drink fruit juice. The family were advised that a clinician would call them back.	111 call transcript Family recall	The social carer spoke to the call handler – the call handler who is not a clinician followed the algorithm. Some of the answers provided at the time vary from the family information for example Mr N had not had any medication for several days. The call handler does not enquire why the carer is calling when the family is present. At the time of this call Mr N's father was not in the UK having broken his leg whilst aboard. The advice provided appears to be appropriate and is heard and agreed with the carer.
31/10/15	18.46-19.02	The Nurse called back. The nurse established when the last episode of vomiting occurred (around 16.00), she established that he Mr N had no episodes of diarrhoea and his bowel habit was unchanged. The nurse established that he had epileptic seizures and was told that he had not had any seizures in the last day. She enquired about his level of hydration and general well-being. The carer reports: *"he seems perfectly fine, all we have been giving him is orange juice and water and sipping it the whole way through".* There is further discussion and access is requested to the medical records that would have provided significant information about Mr N's background.	111 call transcript Family recall 111 call recording	The information passed from the call handler to the 111 clinician is not included in the response. Whilst the clinician did gain permission to access the summary care record, this would have enabled her to establish what drugs were prescribed for Mr N there is no absolute clarity abdout anti-epileptic medication and compliance. The nurse was aware that Mr N's mother was in the room. The family responses to the questioning about medication are imprecise. The advice offered is suggests that the problem was thought to be gastroenteritis and this advice is standard throughout the NHS[7]. However the symptoms do not fully align with the advice as Mr N is reported to *Continued on next page.*

7 http://www.nhs.uk/conditions/gastroenteritis/Pages/Introduction.aspx

Date	Time	Event	Source	Comment
		The nurse asked if Mr N was able to tolerate his medication and the response was: *"CL – OK and when you give his medication, even if he is vomiting can he still keep the medication down* *CL – well we haven't administered any medicine since he vomited whether cause he doesn't really chew his food we have to administer it to him in yoghurt* *CLN – mmm mmm, OK and does he keep the yoghurt down or do you have to administer it* *CL – yeah, yeah (speaks to some in room) does he keep the yoghurt down, OK so on Tuesday when he went through the same thing* *CLN – mmm mmm* *CL – he did keep it down, so it seems like, any medication we have given to him lately he has been keeping it down, doesn't come back up"* Advice on maintaining hydration was provided and this included offering fruit juice or purchasing rehydration sachets. Advice was offered on attending the GP, calling 111 or A&E. An opportunity to ask anything else was offered; *"she is wondering on Monday if it is possible for her to go to the doctor* *CLN – yeah what I would say to Mum is go to the doctors if the symptoms haven't settled down but over the weekend if he has any new symptoms or if the condition gets worse or changes or if Mum has any other concerns call us back here on 111 because he can be seen by an out of hours doctor if the vomiting doesn't settle down or gets worse, alright"*		*Continued from previous page.* have had no diarrhoea. The pathway does not provide a confirmed condition but offers care advice and treats conditionsas potentially infectious. The advice offered appropriate safety netting[8]. The clinician does not ask why she is speaking to the carer when his mother is there. An interpreter[9] is considered once there is difficulty gathering sufficient information about the patient. The carer gave sufficient information to continue with the assessment and there is communication with Mr N's mother and the carer in English. The GP records may have contained this information. There were no special patient notes on Mr N's NHS 111 record. Family report that he could no longer walk unaided at this point. This detail was not included in the discussion with NHS 111. The Pathways assessment questions are based on the reason for the call. This is the main focus rather than an overall review of Mr N's condition.
01/11/15 Sunday	10.16-10.27	NHS 111 call made by a female family member reporting increased vomiting. The call handler established that Mr N is non-verbal and that he has not tolerated his anti-epileptic medication. He is unable to drink and appears very weak and drowsy.	NHS 111 IMR and call records	The caller makes it clear that the family are concerned and that this is not normal for Mr N. The call handler acknowledges the difficulty in assessing over the telephone and tells the caller that a clinician will call back. There is no mention of Mr N presenting in a "drowsy" state on this call at 10.16. The call advisor confirms that he is awake and conscious. However, misses the fact that he is not behaving as he normally would.

8 Safety netting is a term to describe the approach taken to advise people what to do if their condition worsens.
9 111 have access to language line interpreting services – this was not felt to be necessary in this case.

Date	Time	Event	Source	Comment
01/11/15	10.35-10.41	NHS 111 call back and establish that ambulance is required and arrange despatch of an emergency ambulance via LAS.	NHS 111 IMR and Call records Family recall	Mr N's mother told us that her Brother in Law had called the ambulance. Mr N's father was not present as he was aboard where he had suffered a broken leg. At 10.35am the NHS 111 Clinician spoke to Mr N's aunt which led to NHS 111 arranging an emergency ambulance.
01/11/15	10.39	LAS receive a call via NHS 111 requesting a 999 ambulance to Mr N's home the information received was: *Mr N suffered from epilepsy and Down's syndrome was non-verbal and had been vomiting.*	LAS IMR Family recall	Family report that Mr N was very unwell at this point.
01/11/15	10.59	Ambulance on site: *"On arrival of the ambulance staff it was explained that Mr N and been unwell with vomiting. Mr N had vomited several times a day. It was further explained that Mr N had a history of seizures, the last being approximately 19:00 the previous night and had last vomited at 20:30 also the previous night. Mr N's mother had noticed this morning that he had become unresponsive and lost his mobility.* *"On examination Mr N was not experiencing difficulty in breathing, shortness of breath and had not experienced recent diarrhoea or vomiting. Mr N's level of consciousness was recorded as 15/15[10], it is documented that Mr N was non-verbal and due to this the ambulance staff were unable to fully assess him".*	LAS IMR	Temperature 37.7, pulse 73, BP122/75, respiratory rate 16 and O2 sats 96. Assesed as fully conscious. Last seizure is noted as 19.00 the previous evening and last episode of vomiting 20.30 the previous evening. The report concludes "Patient is non-verbal unable to fully assess patient".
01/11/15	11.40	Left address	LAS IMR	
01/11/15	11.49	Arrived at North Middlesex University Hospital (NMUH) and Mr N was transferred to A&E	LAS IMR LAS patient report form	The LAS patient log is subject to an automated tracking system and this was confirmed by the IMR.
01/11/15	11.04	Patient arrival	NMUH IMR Patient A&E form	This time is presumed incorrect. The A&E form is entered manually and there is no automated tracking system.
01/11/15	12.11	Patient Triaged Respiratory Rate (RR) 18 Oxygen Saturation 98% Pulse Beats per minute (BPM) 81 Blood Pressure (BP) mm/Hg 107/75 GCS 15 Blood sugar 9mmol	NMUH IMR	The IMR notes a triage delay based on the presumption of the earlier arrival time. The levels recorded are all within normal limits. No temperature recording is included in the IMR.

10 This refers to a level on the Glasgow Coma Score – GCS. The Glasgow Coma Scale (GCS) is a reliable, objective method to determine the conscious state of a patient. Three types of response are measured (eye, verbal and motor), and are added together to give an overall score. The lower the score, the lower the patient's conscious state the lowest possible score is 3 (deep coma) and the highest is 15 (fully alert)

Date	Time	Event	Source	Comment
01/11/15	13.45	Respiratory Rate (RR) 12 Oxygen Saturation 94% Pulse Beats per minute (BPM) 85 Blood Pressure (BP) mm/Hg 117/74 Temperature 36.1 degrees Celsius Bloods Taken [The IMR does not state what bloods were taken]	NMUH IMR A&E record	The IMR notes that the patient was non-verbal. It does not reveal if the accompanying family spoke/understood English. Moved to a cubicle.
01/11/15	14.30	Full history taken – 3-4 episodes of vomiting, difficulty sleeping and holding his abdomen. O/E (on examination) chest clear and abdo soft Tongue has moist mucus membranes	NMUH IMR	He was seen by a junior doctor who discussed the case with a consultant who recommended intravenous fluid and X-rays. Family report that this was a female doctor.
01/11/15	Time unknown	Chest and Abdominal X-rays – IMR reports these as normal Blood results for liver function tests, renal tests and full blood count appear normal. Reviewed by a second A&E consultant (male) who noted "moist mucus membranes"	NMUH IMR Family recall	Mr N's family told us at interview that he did not have a chest X-ray on the first visit. However we have established that he did and the X-ray showed clear lung fields. They report that a male doctor listened to his chest. They report that he was asked to examine Mr N's throat but declined to do so. The Safeguarding Adult Review noted: *"Mr N's mother asked the doctors to examine Mr N's throat as it was clearly swollen, however they gave up on the examination because Mr N wouldn't open his mouth."* An abdominal X-ray showed no obstruction.
01/11/15	Time not recorded	Patient was discharged after the IV infusion was completed. The IMR states that safety netting advice was given that is to return if Mr N became more unwell. The IMR states: *The family expressed no concerns about being discharged to their care.*	NMUH IMR Family recall	The family report that no advice was given and they were told that they could leave. The family dispute this and say that they did express concern. The family say that their brother in law acted as an interpreter, the medical record makes no reference to the need for interpreting. Nor is there any consideration of the need to consider the mental capacity act in relation to Mr N's treatment.
01/11/15	Not known	Mr N was discharged.	IMR NMUH Family recall	Mr N was taken to the family's car on a trolley. The IMR states that a wheelchair was unavailable. The family report that a wheelchair was brought but Mr N was too unwell to sit in it. The family report that they spoke to the junior doctor again and asked how could they take him home like this and were told to take him. A member of hospital staff assisted them to take the trolley to the car. The family told us at interview that Mr N's brother and uncle lifted him into the car and the hospital staff member held the trolley.
01/11/15	Time unknown	Hospital discharge summary was produced and sent to the GP Practice.	GP Letter	The discharge summary stated that Mr N was discharged at 17.29 and the diagnosis was asthma. This is not supported by the medical records or the symptoms exhibited. It is incorrect.

Date	Time	Event	Source	Comment
01/11/15-02/11/15	Overnight	Mr N was taken home by his family.	Family recall	Mr N was carried into the house and spent the night in an easy chair supported by pillows.
02/11/15	Time not stated	Home visit requested from GP.	GP Letter Family recall	GP home visits usually occur between morning and evening surgeries. Mrs I reports that she was not advised of this and expected the GP to arrive earlier than he did.
02/11/15	15.30	GP came and examined Mr N. He found him: *"pyrexial and in a state of unresponsiveness".*	Family recall GP IMR Letter	The GP reports that he spoke to the on call NMUH ED doctor he wrote a letter setting out his concerns which were: increasing lethargy, unable to drink or swallow medication. He notes 3 seizures on the previous day and 2 during the present day. He is pyrexial 37.9 and has a raised pulse 103 – "non-responsive (unlike normal even in the presence of infection)".
02/11/15	16.01	GP Requested *"ambulance for Mr N as he was suffering from dehydration and an infection. It was requested that an ambulance be with Mr N within 1 hour."* The call handler checks details and asks if Mr N is conscious and breathing and he is. The call handler asks *"Does this condition present an immediate threat to his life?"* the reply is *"If this is not properly treated it will be"*. The GP is asked what time response is clinically indicated and replies between an hour and an hour and a half at most. He is then asked if the patient transport ambulance is appropriate the GP replies *"No"* then asks what is meant by patient transport service (PTS) ambulance. He is told what this is and agrees that it will be appropriate.	LAS IMR Call transcript	The GP states that Mr N is "increasingly unwell with a temperature. He is severely affected Down's Syndrome who has a history of seizures and going to be admitted to the North Middlesex Hospital. The medical team have been informed." The discussion between the GP and the call handler is not entirely functional. The GP agrees that Mr N does not need immediate resuscitation but does not appreciate that the consequence of agreeing to PTS means that it could take considerably longer to get Mr N to hospital via the transport service. There is no discussion of how long an ambulance might take and the call ends with "That has all been booked in and arranged within the hour."
02/11/15	16.53	Family rang LAS for an update. The call handler is reported as: *"He told the caller that help may take up to 2 hours. When the caller queried this saying that the doctor had told him it would be 1 hour, the EMD replied that the doctor didn't work for the ambulance service so shouldn't have said that."*	Family recall LAS IMR	The LAS IMR notes that it was reported that Mr N's condition had not changed. The family told me that Mr N was increasingly unwell. The LAS IMR notes that this response showed a lack of empathy and understanding, but the correct procedure was followed.
02/11/15	18.36	A family member called LAS again reporting that Mr N was less responsive.	Family recall LAS IMR	The LAS IMR notes that the wrong procedure was followed in this case as the call handler used the wrong protocol. The protocols exist to help to triage calls and identify the priority for a response. This meant the call got a lower priority than it would otherwise have been given. It is not quite clear from the IMR if the call was upgraded at this time but it was upgraded at 19.14.
02/11/15	19.40	Ambulance despatched.	LAS IMR	

Date	Time	Event	Source	Comment
02/11/15	19.46	Ambulance arrived.	LAS IMR	
02/11/15	19.46-20.10	Mr N was examined by ambulance staff who found: *"Mr N had 4 seizures prior to the ambulance staffs arrival. Mr N was not taking his medication, eating or drinking and his throat was swollen.* *"On examination Mr N's level of consciousness was 10/15; he had low saturations which improved with oxygen therapy. Mr N had good bi lateral air entry and was not experiencing difficulty in breathing or shortness of breath, was not experiencing any pain on palpitation, had no obvious trauma and had good skin colour."*	LAS IMR	This entry is the first note of any new seizures. Mr N's family report that at this stage he had not had any anti-epileptic medication for several days.
02/11/15	20.16	Ambulance arrived at NMUH.	LAS IMR	Handover took place at 20.35.
02/11/15	20.45	Seen for initial assessment Temperature 37.9 celsius which is elevated. A throat examination showed candida (thrush) which made it difficult to see his tonsils. GCS noted as 6/15.	NMUH IMR	The plan was to treat Mr N with anti-fungal drugs for thrush (Nystan), antibiotics (augmentin), Paracetamol to reduce his temperature and relieve pain and intravenous fluid replacement. A chest X-ray was carried out and showed clear lung fields, regular suction was provided and oxygen administered.
02/11/15	20.50	BP 115/55 Pulse 104	NMUH IMR	Elevated heart rate – Tachycardia BP within normal Limits
02/11/15	21.20	BP 110/66 Pulse 116	NMUH IMR	Elevated heart rate – Tachycardia BP within normal Limits
02/11/15	21.50	BP 124/82 Pulse 110	NMUH IMR	Elevated heart rate – Tachycardia BP within normal Limits
02/11/15	22.12	BP 119/77 Pulse 89	NMUH IMR	Normal Heart rate BP within normal Limits
02/11/15	22.30	BP 121/83 Pulse 85	NMUH IMR	Normal Heart rate BP within normal Limits
02/11/15	22.40	BP 112/56 Pulse 85	NMUH IMR	Normal Heart rate BP within normal Limits
02/11/15-03/11/15	*22.41-03.19*	*Mr N was in the A&E department.*		*There is no information in the IMR for this period.*
03/11/15	03.20	Mr N Transferred to ward T5 a medical ward.	NMUH IMR	**The IMR ends at this point.**

Events following SAR timespan

Date	Time	Event	Source	Comment
03/11/15	23.33	Breathing worsens leading to intubation and admission to critical care.	Medical records	A further X-ray was taken and this suggests pneumonia.
04/11/15		Increased frequency of seizures. Continues to be ventilated.	Medical records	Family (Father not present) met with ITU consultant and gave details of previous history indicating that Mr N has 1-2 seizures per day. They were advised about the nature of his illness and treatment. The family indicated that they wished to complain about the number of canulation attempts and the previous discharge diagnosis of asthma.
05/11/15		A different type of ventilation was trialled – CPAP.	Medical records	Consultant met with Mr N's uncle and brother to discuss the possibility of a tracheostomy – the records note that they understood and accepted the plan.
06/11/15		Mr N was reintubated.	Medical records	Further discussion re tracheostomy as Mr N had airway obstruction – the procedure was not urgent and the family were advised that they had time to consider this or other treatment options.
08/11/15		Mr N accidentally extubated himself a different type of ventilation –NIV was introduced.	Medical records	Further update given to family.
09/11/15		NIV continued.	Medical records	Update from a different ITU consultant accompanied by LD liaison officer "From the history and sequence of events it became apparent that he is aspirating on being fed. The mother said he has been coughing when she feeds him and was advised to take him to Barnet hospital for assessment for aspiration". The record then notes *"She felt disappointed that she was not warned about this potential complication before"*. Further discussion of a tracheostomy and PEG feeding tube followed this distressed the family. Mr N at great risk of aspiration pneumonia.
10/11/15		Breathing unaided in the morning.	Medical records	Seizures continued
14/11/15		Reintubated – sepsis.	Medical records	Became unwell again – bacterial pneumonia.
14/11/15		Treated for pneumonia and increased medication due to increased number of seizures.	Medical records	Further discussion of the need for tracheostomy and PEG – this is not accepted by the family. Mr N's mother feels he was well before he came to hospital.
15/11/15		Increased number of seizures.	Medical records	Family advised of Mr N's serious condition and the need for a tracheostomy and PEG.
16/11/15		Meeting with family.	Medical records	Updated on present condition and worsening pneumonia – risks of aspiration discussed.

Date	Time	Event	Source	Comment
17/11/15		Meeting with family	Medical records	Discussion of care with family need for tracheostomy and PEG discussed.
19/11/15		Meeting with family	Medical records	Source of infection at present not entirely clear although multiple tests (including lumbar puncture and body scan) have been undertaken. Presently too unwell for PEG and tracheostomy to be carried out.
22/11/15		Family update	Medical records	Plan to carry out tracheostomy delayed as too unwell.
24/11/15		Family update	Medical records	Plan to carry out tracheostomy tomorrow.
25/11/15		Tracheostomy performed	Medical records	
27/11/15		PICC (peripherally inserted central catheter) inserted to deliver drugs	Medical records	
30/11/15		PEG inserted	Medical records	
01/12/15		Safeguarding alert received	LBE IMR	Concerns raised by family re treatment in NMUH.
02/12/15		Commenced reduction in ventilation	Medical records	
08/12/15		Moved to PCU as improving reduce ventilation	Medical records	
10/12/15		Became pyrexial	Medical records	Antibiotics commenced.
11/12/15		Trachestomy tube changed PICC line removed	Medical records	These are undertaken as precautions as they could be a source of infection.
13/12/15		Antibiotics changed	Medical records	Blood cultures indicated that a different antibiotic would be appropriate.
14/12/15		Reaction to the new antibiotic	Medical records	Swapped to a different antibiotic.
15/12/15		New PICC line	Medical records	
16/12/15		Hospital passport commenced with family	LBE IMR	
17/12/15		Mr N now stable	Medical records	
21/12/15		Moved to medical ward T5	Medical records	Plan to teach family how to use PEG and to mobilise Mr N.
29/02/2016		Best Interest meeting called by the hospital to discuss prognosis for recovery and discharge planning – Consideration for Mr N returning home with support. Attended by Mr N's allocated S/W.	LBE IMR	
16/03/2016		Safeguarding case conference completed.	LBE IMR	

Date	Time	Event	Source	Comment
07/06/2016		Professionals discharge planning meeting held at North Middlesex hospital.	LBE IMR	
21/06/2016		DST meeting held which agreed Mr N was eligible for 100% CHC funding. Possible placements for discharge identified and invited to assess.	LBE IMR	
30/08/2016		ILDS were Informed that Mr N's proposed move to a Neurological Centre (that provides accommodation and treatment for people with complex long-term neurological conditions) had taken place.	LBE IMR	

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The Reviewers

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He has worked as an adviser for the National Clinical Assessment Service. He has also been an Associate Member of the General Medical Council. Previous work has included that of Medical Director roles to several inner city PCT in London. He was a Governing Body member of a London CCG.

He has extensive experience of investigations, clinical assessments and investigations in a range of settings. He has experience across the breadth of the health and care agenda, from service development to delivery at both a strategic and an operational level.

Sheeylar Macey, BA (Hons) MSc RGN RSCN (NMC 82C1590E) is a Partner of Nina Murphy Associates LLP. She is a trained nurse and specialist practitioner in primary care and holds an MSc in primary care development. She has also been a primary care adviser to a Health Authority, a Head of Governance to a Strategic Health Authority and a Clinical Director in primary care organisations.

Sheeylar is fully trained in root cause analysis and has extensive experience of investigations across a variety of settings including custodial care. She is experienced in helping to develop systems and processes to assure good practice in Clinical Governance and has considerable experience of planning and delivering service innovation.

Both Sheeylar and Sadru have authored a large number of reviews including Serious Case Reviews, Independent Management Reviews, Domestic Homicide reviews Death in Custody and Death in Detention reviews and reports for HM Coroner.

Strategic Safeguarding Adults Service
Health, Housing and Adult Social Care

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ENFIELD Council