



**Safeguarding
Adults Board**
LEICESTERSHIRE & RUTLAND

Safeguarding Adult Review 'Nigel'

Independent Reviewer
Allison Sandiford

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1. Brief Summary of Circumstances resulting in the Review

1.1. A core duty of a Safeguarding Adults Board (SAB), under Section 44 of the Care Act 2014, is to review cases in its area where an adult with needs for care and support (whether or not the Local Authority was meeting these needs):

- has died and the death resulted from abuse and neglect, or is alive and the SAB knows or suspects that they have experienced serious abuse or neglect

Importantly Safeguarding Adults Reviews (SARs) are about how agencies worked together to safeguard adults; they are in their nature multi-agency reviews. For a review to be conducted under S44(1) of the Care Act 2014, there must be reasonable cause for concern about how the SAB, its members, or others with relevant functions worked together to safeguard the adult.

1.2. The criteria for this review were met as a male, hereafter known as Nigel, was an adult with needs for care and support, and has sadly died. It was felt that there was learning to be gained regarding agencies working together to protect

2. Safeguarding Adult Review Process

2.1. Methodology

2.1.1. Following agreement that the criteria for a Safeguarding Adult Review had been met, an independent reviewer¹ was appointed.

2.1.2. It was decided that the review ought to be a thematic review which should consider Nigel as an individual but also deliberate the broader issues. The reviewer, whilst ensuring that a streamlined, proportionate approach to reviewing and learning would be taken, sought to engage as many frontline workers and their managers with the review process as possible, to consider why actions and decisions had been taken.

2.1.3. A multi-agency review panel consisting of representation from the agencies involved² was established, and the panel met³ in October 2021 to discuss terms of reference⁴, chronology timelines, the learning event and an expected date of completion.

2.1.4. The panel met on the following dates to monitor the SAR process and discuss learning:

- January 2022
- March 2022

2.1.5. A practitioner learning event was held in January 2022 and was attended by the following agencies/professionals:

¹ Allison Sandiford is an experienced reviewer of children's, adults' and domestic homicide reviews. She has a legal background and has gained safeguarding experience whilst working various roles for Greater Manchester Police.

² Leicestershire and Rutland Clinical Commissioning Group, Leicestershire County Council Adult Social care, Leicestershire Partnership NHS Trust, Learning Disabilities Mortality Review Programme

³ Covid restrictions necessitated that panel meetings and the learning event be virtually attended. As such they convened using Microsoft Teams.

⁴ Appendix 1

- GP and Nurse Practitioner
- Clinical Lead for the LeDeR⁵ Programme
- Leicester City Clinical Commissioning Group
- Adult Social Care
- Leicestershire County Council
- Leicestershire Partnership NHS Trust
- Dietician
- Deputy Head of Nursing of Families, young people, children and learning disabilities (FYPCLD).

*The reviewer met with staff at the Day Care facility separately.

2.1.6. To keep Nigel central to the learning event and to help attendees understand him, the reviewer produced an audio using information provided to the SAR on aspects of his life and personality. This audio is to be used in future learning activities

2.1.7. Feedback from the participants generated positive discussion around areas of practice that could be developed and improved and also highlighted much good practice. This feedback has formed the basis of the recommendations of this report.

2.2. Time Period reviewed

2.2.1. It was agreed that the timeline for the review should predominantly be a year prior to the day that Nigel sadly passed away. However, some safeguarding processes were undertaken prior to this timescale and have been included as they relate to later agency involvement and decisions.

2.3. Parallel Reviews and Processes

2.3.1. The following processes and reviews have been undertaken either prior to, or parallel with the Safeguarding Adult Review commencing:

2.3.1.1. Nigel's death was reported to the Coroner. Her Majesty's Coroner concluded the cause of death to be Covid-19 pneumonia, with cerebral palsy and pressure ulcers being contributory.

2.3.1.2. Nigel has been subject to a Learning Disability Mortality Review. The Learning Disabilities Mortality Review Programme (LeDeR) established in 2016, is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people with learning disability over the age of 4 years, are subject to a Learning Disability Mortality Review. The main purpose of a review is to identify:

- any potentially avoidable factors that may have contributed to the person's death,
- learning and plans of action that individually or in combination, guide necessary changes in health and social care services to reduce premature deaths of people with learning disabilities.

⁵ LeDeR is a service improvement programme for people with a learning disability and autistic people.

2.3.1.3. Leicestershire Partnership NHS Trust have completed a Serious Incident report which has reviewed Nigel's full patient history.

2.3.1.4. The Police Complex Investigation Team commenced an enquiry with partner agencies to determine whether or not criminal offences were evident. The investigation concluded that there was no evidence of a criminal act being committed and the case was filed.

2.3.1.5. Adult Social Care undertook a section 42 enquiry in relation to the concerns raised about Nigel's family *resisting changes in the care plan* and the application of the Mental Capacity Assessment and Best Interests process. The enquiry concluded in August 2021 with the outcome *no further action*.

2.4. Family Engagement

2.4.1. The independent reviewer and the LRSAB would like to offer their condolences to Nigel's family.

2.4.2. Family members of Nigel were notified of this review by the LRSAB and invited to participate. Their decision not to engage is understood and respected.

3. Who was Nigel?

3.1. Nigel has been described as a mischievous gentleman with an infectious sense of humour. He had a love of slapstick comedy and encouraged everyone to be silly. One of his favourite things to do was to make a mess at the Day Centre he attended; he would tip the art and craft materials all over the table to make him, and others, laugh.

3.2. Nigel had a diagnosis of cerebral palsy and severe learning difficulties. He required 24-hour support and lived at home with his parents. Their home was adapted to meet his needs by means of a ceiling track hoist to assist with his transference in the bathroom and there was a stairlift to give him access to the upstairs. Over time Nigel became wheelchair dependent; he could manoeuvre himself around in a manual wheelchair and he had an electric wheelchair which his parents operated when they went out in the community.

3.3. Nigel did not verbally communicate but he could make his feelings known to his parents and to staff at the Day Centre by using his own kind of sign language. He would cough to get a person's attention and he would indicate his needs by pointing to choices.

3.4. Nigel struggled with eating and drinking. He didn't like lumps in his food and mostly had a moist pureed diet but he was able to enjoy some drier foods such as crisps and KitKats. In November 2020 staff at the Day Centre noticed that Nigel was struggling to manage fluid up a straw. Concerned, the manager made a referral which was passed to Speech and Language Therapy.

3.5. In December 2020 Nigel's father contacted the GP practice as a pressure sore that Nigel had on his hip, was getting worse. A referral was made to the District Nursing team but Nigel's parents preferred to manage the sore themselves with the support of the Practice Nurse at the GP surgery and with pressure relieving equipment.

- 3.6. In January 2021, the Day Centre had to close for a week due to a Covid outbreak. Nigel returned to the Day Centre in a poorly state. When he attended two days later, he was crying and refusing to eat. Staff contacted the Speech and Language Team who advised them to contact his parents and 111. Nigel's parents collected him and said that they would take him to the doctors.
- 3.7. The GP surgery arranged for the home visiting service to attend and Nigel was examined by an Emergency Care Practitioner at the home address later that day. Parents were advised to contact the GP or 111 if he didn't improve over the next two days, and to phone 999 if there were any serious changes.
- 3.8. The following day at 18:00 hours, Nigel's father found him unresponsive in his bed.

4. Understanding Nigel's Cerebral Palsy and Other Conditions

- 4.1. Cerebral palsy is a group of neurological disorders that affect motor and development skills. It is caused by damage to, or malformation of, the areas of the brain that control motor function during foetal development⁶. As a direct result of the brain injury or malformation, Nigel suffered impaired motor control and coordination, poor muscle tone, and poor balance and posture.
- 4.2. Nigel had difficulty feeding and suffered dysphagia – difficulty in swallowing food and liquid. In addition, his impaired fine motor skills made it difficult for him to transport some food to his mouth and he relied on a carer and assistive equipment to help him.
- 4.3. The feeding and swallowing problems led to poor nutrition, dehydration and long-term problems of low weight. In 2016 discussions were had regarding him having a percutaneous endoscopic gastrostomy feeding tube but his parents were concerned that he might pull the tube out and the procedure did not go ahead. However the Occupational Therapist and staff at the Day Centre continued to express concerns about his low weight.
- 4.4. Nigel suffered with gastroesophageal reflux disease⁷ which is common among people with cerebral palsy. To alleviate the condition he was prescribed medication, when required, to reduce the production of stomach acid. In addition Nigel often suffered constipation which was managed with prescription and over the counter medication.
- 4.5. It is not unusual for a person who suffers cerebral palsy to have learning disabilities. Nigel is reported to have suffered a severe learning disability. His understanding capabilities affected his capacity to make important decisions about his own health, care and support.
- 4.6. Nigel is reported to have had sensory problems and to have consequently found loud environments difficult. This was managed at the Day Centre by offering him the use of quieter rooms and he would listen to DVDs through earphones which would cancel some external noise.
- 4.7. Co-mitigating conditions that are unconnected to cerebral palsy but often found to coexist with the condition, include Autism and Attention Deficit Hyperactivity Disorder. The Autism spectrum disorder is indicated by social impairments, communication difficulties and

⁶ cerebralspalsyguide.com

⁷ gastroesophageal reflux is a digestive disease in which stomach acid is regurgitated into the oesophagus

repetitive behaviours. It is an umbrella term for a group of brain development disorders. Some documentation provided to this review report that Nigel had a diagnosis of Autism.

5. Thematic Analysis

Professionals at the learning event identified the main concerns regarding Nigel as being: his diet and low weight, how safely he was handled, and the management of his pressure sore. They then considered what support had been available for Nigel and his parents, and deliberated any barriers to putting the support in place.

The Concern	The Support Available	The Barrier
Safe Handling	Equipment could have been provided and/or installed in the home	<ul style="list-style-type: none"> Parents didn't accept the offer of support The MCA was not applied to put support in place that was in Nigel's Best Interest
Low Weight and Dietary Concerns	Dietary advice could have been offered around how to help Nigel eat at home	<ul style="list-style-type: none"> Parents didn't accept the offer of support The MCA was not applied to put support in place that was in Nigel's Best Interest
	Nigel's weight could have been monitored.	<ul style="list-style-type: none"> Suitable scales were not available
	Nigel could have had a feeding Tube	<ul style="list-style-type: none"> Parents didn't accept the offer of support The MCA was not applied to put support in place that was in Nigel's Best Interest
	Equipment could have been provided to help Nigel to eat and drink.	<ul style="list-style-type: none"> Nigel did not have the ability to use the equipment.
Pressure Sore	Nursing Care provided in the Home	<ul style="list-style-type: none"> Parents didn't accept the offer of support The MCA was not applied to put support in place that was in Nigel's Best Interest
	The supply of Pressure Relieving Equipment	<ul style="list-style-type: none"> This was supplied but there was an avoidable delay as the Referral Process was not followed correctly.

This exercise helped to identify key themes and underpinned the following thematic discussions.

5.1. Theme 1: Communication with Nigel

5.1.1. Nigel could not communicate verbally. He did use some sign language but this was not a recognised sign language and was a form of communication between himself and his parents. The review has heard that Nigel was able to demonstrate choices by pointing, and that he had an iPad which had picture symbols of things like feelings, food options and activities - but he didn't like to use this as a tool.

5.1.2. Working with a person who is nonverbal challenges effective person centred communication and professionals at the learning event spoke of further challenge as they were unsure of Nigel's level of understanding. However whilst it may have been problematic or even impossible to determine how much Nigel, with his severe learning disability and communication impairment understood, it is important to emphasise that when professionals are working with nonverbal people, assumptions about their understanding should never be made. Professionals agreed and spoke of the importance of always speaking directly with Nigel and making an effort to include him in conversations about himself.

5.1.3. Although it is clear that some professionals such as those at the Day Centre and those assessing Nigel directly (for example speech and language therapists) were confident in their communication skills with Nigel and were able to use aids such as picture boards, some professionals admitted to a reliance upon Nigel's parents to communicate his wishes and feelings. A professional involved with Nigel explained to the review that they did not consider there to be any issues with parents communicating on Nigel's behalf as they deemed them to understand him and to effectively communicate his wishes.

5.1.4. There is no doubt that Nigel's parents loved him very much and acted in what they always perceived to be in his best interest. But parents asserting their interpretation of Nigel's communication silenced his voice and resulted in some professionals neglecting to communicate with him directly. Instead of accepting parents' voices, a starting point for professionals should have been to ask to see Nigel's communication passport.

5.1.5. A communication passport is a living document that assists a person centred approach by sharing key information about a person who cannot easily speak for themselves. The passport belongs to the individual but family and people who know the person well, help him or her to use it appropriately and to keep it up to date.

5.1.6. Nigel's passport was compiled by staff at the Day Centre, his mother and his speech and language therapist. It explains how he communicates, how he expresses feelings and choices, and what some of his behaviours might indicate.

5.1.7. It is good practice that Nigel had a communication passport but developing and maintaining a person's communication passport is only the beginning. The learning event evidenced that not all professionals knew of communication passports and consequently did not ask to see Nigel's. It is clear that the existence and worth of the communication passport must be widely promoted amongst agencies and professionals outside of the learning disability service.

5.1.8. In 2015 a communication plan for adults with learning disabilities in Leicester, Leicestershire and Rutland entitled Giving Voice to People with Learning Disabilities⁸ was developed. The plan aimed to help everyone make communication for adults with learning disabilities better by using the 5 Good Communication Standards⁹:

5.1.8.1. There will be good information that tells people the best ways to communicate with the person with learning disabilities. This information could be a communication passport or profile.

5.1.8.2. You will help the person with learning disabilities to be involved in making decisions about their care

5.1.8.3. You will be good at supporting the person with learning disabilities with their communication.

5.1.8.4. You will give the person with a learning disability lots of chances to communicate, and lots of experiences to communicate about.

5.1.8.5. You will help the person with learning disabilities to understand and communicate about their health

5.1.9. Learning Disability Partnership Boards were assigned the responsibility to make sure that the plan improved communication for adults with learning disabilities by ensuring that everyone

⁸ A Communication Plan for Leicester, Leicestershire and Rutland (betterlives.org.uk)

⁹ As part of the response to Winterbourne View, 5 Good Communication standards have been agreed nationally. These standards set out the best ways to make communication better for people with learning disabilities

who works with, supports or cares for a person with a learning disability applied the Good Communication Standards to support positive communication.

5.1.10. Upon consideration of this and realisation that other partnership boards were unaware of the project, the review panel has identified that the links between the Partnership Safeguarding Boards and the Learning Disability Partnership Boards would benefit from being strengthened. This would help future projects to achieve their potential by sharing them more widely.

Lesson 1:

Not all professionals were aware of communication passports.

Recommendation 1:

LRSAB to liaise with the Learning Disability Partnership Board to produce a plan to support professionals within partner agencies to communicate with adults with learning disabilities.

5.1.11. Despite the Care Act requiring consideration of advocacy when undertaking assessments, there is no evidence of any formal advocacy ever being considered for Nigel to improve communication. This is an understandable omission as Nigel had both of his parents available to support him as 'an appropriate individual' but a Care Act advocate should have been considered when concerns appeared regarding whether parents were consistently acting in Nigel's best interests

5.1.12. Previous SARs have already alerted Leicestershire County Council to the need to improve professionals' awareness and understanding of advocacy. As a result, advocacy training is included within the thematic priority; Hidden Harm, which is part of Leicestershire and Rutland's Covid recovery plan.

5.2. Theme 2: Nigel's decisions

5.2.1. When Nigel was a child, his parents had the right to make decisions about his care and upbringing. This is because they had parental responsibility which afforded them legal rights, duties, powers, responsibilities and authority for him and his property. However the power afforded through parental responsibility is never retained over a child when he or she reaches the age of 18 and becomes an adult. Even when, like Nigel they do not have the capacity to make many decisions for himself.

5.2.2. Nigel became an adult in 1992. At this time, the House of Lords had just ruled in *F v West Berkshire*¹⁰ [1991] that if a person 'lacks capacity' and treatment is necessary in their best interests then the doctors could rely on the common law doctrine of necessity. In other words, if doctors considered that a patient lacked capacity to make decisions about an operation, and they believed it was in their best interests, then nobody – including the patient – could sue them for carrying out the operation without consent. Over the years the courts developed a further body of case law adding to, and refining this judgment. Meanwhile The Law Commission recommended that there should be a single comprehensive piece of legislation to make provision for people who lacked mental capacity (like Nigel). The Commission said that the legislation should provide a *coherent statutory scheme to which recourse can be had when any decision (whether personal, medical or financial) needs to be made for a person aged 16 or over who lacks capacity*¹¹. As a result, in 2005 the Mental

¹⁰ *F v West Berkshire HA* [1991] UKHL 1 (17 July 1990) (bailii.org)

¹¹ *Mental Incapacity (Summary of Recommendations)* [1995] EWLC 231 (15 January 1995) (bailii.org)

Capacity Act was introduced. From hereon, this act governed the decision making power of people aged 16 years and above.

- 5.2.3. However multiple examples of Nigel's parents continuing to make decisions on his behalf regarding his care and treatment post this legislation have been provided to this review;
- 5.2.4. Adult social care have documented that there were a number of occasions where parents challenged, appeared to disregard or declined the advice and support of professionals on Nigel's behalf; in 2013 a profiling bed was offered as an alternative to a home constructed wooden bed but declined (the alternative bed was later accepted in 2016). In 2015 mum declined to engage with Occupational Therapy. In 2016 she declined to consider alternatives to a stairlift and advised the social worker she would ask them to leave if they were from health. In 2017 it is case recorded that communication from the Day Centre had stated that *Nigel's anxiety and ongoing behavioural and physical problems cause him to refuse food*, and that he was *malnourished*. However the case notes reflect that mum advised she did not think a dietician appointment was required.
- 5.2.5. Leicestershire Partnership NHS Trust have documented that Nigel's father refused support with Nigel's pressure sore in the home from a Community Nurse, choosing instead to change the dressing himself with support from the GP practice.
- 5.2.6. In these examples Nigel's parents declined support and/or services that Nigel was entitled to, on his behalf, but they did not have the jurisdiction to do this the way they could have when he was under the age of 16. Whilst parents should always have been consulted, other people needed to make some decisions in his best interest and such decisions should have been made using the best interests decision-making process.
- 5.2.7. The importance of other people being involved in best interests decision-making is highlighted when consideration is had to the fact that adult social care case notes state that mum had said in 2019 that she *does not like professionals coming to the house and telling them how to care for their son*. This evidences how parents have a multitude of emotions and conflicting sentiments to contend with when making decisions for their adult children and may not automatically do what is in their child's best interest despite good intention.
- 5.2.8. Because Nigel's parents haven't wished to engage with this review process, the report cannot conclude whether they knew that they no longer had the authority to make all of Nigel's decisions or not, or whether they understood the law governing his decision-making. However professionals have highlighted throughout the course of this review many missed opportunities during consultations and assessments, to provide parents with some understanding of the best interest principle and the Mental Capacity Act.

Lesson 2:

There is no evidence of professionals maximising opportunities to discuss and explain the best interest principle to parents.

- 5.2.9. Feedback from other parents finding themselves faced with the challenges around continued decision-making for their children as they reached adulthood, has evidenced how complicated this area of law is for a parent. The feedback resulted in the NHS England Mental Capacity Act Improvement Programme providing funding to support a workshop for parents and carers of young people from across the East Midlands who had entered adulthood never having the capacity to make their own decisions. The funding also supported the

development of a website myadultstillmychild.co.uk. The website is still available and is a useful *tool aimed to support parents so that they better understand their rights and options in decision making as they continue to love and care for their adult child.*¹²

5.2.10. Mencap have also produced a resource pack for family carers of people with a learning disability that addresses the Mental Capacity Act and practical decision-making; [mental capacity act resource pack 1.pdf \(mencap.org.uk\)](http://mencap.org.uk)

5.2.11. As much support for parents as possible should be signposted by professionals. The transition of their child becoming an adult can be an emotional and stressful time for them and there is a lot for parents to think about. Professionals must take into consideration how a parent might feel when they learn that once their child reaches the age of 16, someone else can become involved in their child's decisions.

5.2.12. Professionals at the learning event were in agreement that parents whose children it is expected will not to have the mental capacity for some or all of their decisions, should be helped to understand how the Mental Capacity Act works and how it will affect them, in advance of their child reaching the age of 16.

Lesson 3:

Professionals allowed parents to continue to make decisions for Nigel instead of consulting the Mental Capacity Act.

Recommendation 2 (to address lessons 2 and 3):

LRSAB should ensure that all professionals have access to training and advice regarding application of the Mental Capacity Act to ensure that best interests decisions are made for adults with Learning Disabilities who continue to be cared for by their parents.

This training should include guidance of how professionals can explain to parents the change in governance as their child gets older.

5.3. Theme 3: The Best Interests Decision-Making Process

5.3.1. The Mental Capacity Act applies to all people who are 16 and over in England and Wales. Whilst the law says that where possible, a person should be helped to make their own decisions, there are people for whom this is not possible. When such a person cannot make their own decisions, other people have to decide what is in their best interest.

5.3.2. Often it is the person's parents who make this best interest decision but sometimes other people must commence the best interest process which will conclude a decision. For example, whilst a parent is able to make everyday decisions such as activities, a medical decision may require a doctor to initiate the best interest process.

5.3.3. The Mental Capacity Act recognises that people with learning disabilities should make the decisions that they are able to and states that judgement about whether a person has the capacity to make their own decision must be taken on a decision-by-decision basis. Nigel was able to make his own decisions about meal choices and activities and to communicate his decision by pointing at pictures. Whilst these decision may seem trivial to some, it was good practice and important to keep him as involved as possible in his own decisions. However, there were many choices he needed to make, such as choices around his healthcare, which he was unable to make and required others to consider a best interest decision on his behalf.

¹² [About Us – MASMC \(myadultstillmychild.co.uk\)](http://myadultstillmychild.co.uk)

- 5.3.4. With regards to the day-to-day decisions that Nigel was unable to make, the most suitable person to assess his best interests would be the person involved with him at the time, possibly his parents or carers at the Day Centre. For medical treatment, the best placed assessor to initiate the best interest process would be the healthcare professional carrying out the treatment.
- 5.3.5. For example in 2016 Nigel was seen by a Nutrition Nurse Specialist for evaluation regarding a feeding tube. There is evidence that the risks and benefits of having the tube fitted were discussed with parents and it is documented that mother was worried that Nigel would pull the tube out. There is nothing on record that indicates whether the surgery was recommended or not, but it is recorded that parents were to go home to consider the operation and were given contact details to relay their decision.
- 5.3.6. From Trust records, there is nothing to indicate that parents made any further contact with any professional to communicate their decision and there is no evidence that it was ever followed up with them by a professional. Professionals mistakenly gave parents the power to make the decision for Nigel. Nigel does not appear to have had a voice in this decision and there is no evidence that a Mental Capacity Assessment was done or that decisions were made in his best interests.
- 5.3.7. If this situation were to arise now, Leicestershire Partnership NHS Trust have assured the review that as per General Medical Council guidance, current practice would see health professionals following the best interests decision process and an accurate record being kept.
- 5.3.8. Similarly this review has been informed of occasions when the Mental Capacity Act process has been started and Nigel has been assessed, but the process has not progressed correctly. For example an Occupational Therapist completed a Mental Capacity Assessment in 2019 in relation to Nigel's ability to understand and consent to the use of a stairlift where his father physically lifted him onto the stairlift.
- 5.3.9. The Occupational Therapist wanted to support Nigel with safe movement around his home but upon assessment it was deemed that Nigel was unable to understand the information he needed to in order to give his consent. And as already noted because, under the law adults have to give their own consent, Nigel's parents could not choose whether to consent or not on his behalf. Instead a professional with knowledge of safe movement should have led the best interest process to decide if a stairlift was in Nigel's best interests.
- 5.3.10. In order to identify how workers/therapist like the Occupational Therapist faced with this process can be supported, the review will now reflect on what is meant by *best interest* and look at the best interests decision process.
- 5.3.11. The 'best interests' principle underpins the Mental Capacity Act. It is set out in chapter 5 of the Code of Practice and states that:

An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

5.3.12. The Code 5.3 states that:

working out a person's best interests is only relevant when that person has been assessed as lacking, or is reasonably believed to lack, capacity to make the decision in question or give consent to an act being done.

5.3.13. Therefore a capacity assessment must first be undertaken to establish that the person lacks capacity to make the decision. If an assessment has not established lack of capacity you cannot proceed with a best interests decision.

5.3.14. Chapter 5 of the Code of Practice then details what should be taken into account when working out what is in a person's best interests. It sets out some common factors which must always be considered. A community learning disability nurse from Leicestershire Partnership NHS Trust has produced REFLECT as an acronym to help a person recall the aspects.

R	Consider whether the adult can regain capacity
E	Encourage and enable participation of the adult throughout the decision
F	Take into account the adult's past and current feelings about this decision
L	Is life sustaining treatment an issue?
E	Show equal consideration and non-discrimination
C	Consider all relevant circumstances
T	Take the views of others into account

5.3.15. As the table demonstrates, there is a legal obligation for workers considering Nigel's best interests, to engage him in the decision making process as much as possible. And a range of resources have been produced which can help the decision maker to do this. For example, consultation with Nigel's aforementioned communication passport, his health action plan¹³, his hospital passport¹⁴ and his person centred plans¹⁵ would all have helped to inform the decision and keep Nigel central.

5.3.16. There is also a legal obligation to take the views of others into account. Hence, parents would be consulted about the best interests decision, but their choice would not necessarily be agreed with or executed. Also any persons close to Nigel who may have had a view on what they considered would be in his best interests should have been included, for example care staff and health professionals.

5.3.17. No best interest meeting was held, or final decision made, regarding Nigel's stairlift on this occasion. A number of reasons have been identified;

- the complexity of working with Nigel's parents and the risk of them disengaging,
- Nigel's parents seeming at one point to be considering the safe option suggested by the therapist,
- the confidence of the therapist,
- the management support of the therapist and
- a failure to seek legal advice which would have formally guided intervention.

¹³ A health action plan contains information about a person's health and is a plan about what a person needs to maintain good health.

¹⁴ A hospital passport documents essential information about a person should they need to go into hospital.

¹⁵ There are many person centred plans. They can include elements such as personal information, interests, goals, communication methods, medical history, mental health, environmental risks, nutrition and dietary requirements,

5.3.18. It is possible that the use of the Balance Sheet approach would have proved beneficial in this case as it is a transparent and articulate format which demonstrates the consideration of the decision. This method may have given the therapist more confidence in the process and in managing her relationship with the family as its clarity could have helped both professionals and parents to consider the pros and cons of the decision for Nigel.

5.3.19. The Balance Sheet approach was first described by Lord Justice Thorpe in the case of Re A [2000]. And in the wake of this judgment and post implementation of the Mental Capacity Act, the courts frequently refer to adopting the approach when decision-making. This extract depicts the methodology:

“The benefits of the procedure should be entered, and then the disbenefits should be entered. The possible gains and losses should be considered, and the likelihood of them occurring. At the end of this process it should be possible to ‘strike a balance between the sum of the certain and possible gains against the sum of the certain and possible losses. Only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant.’

This makes clear that best interests decisions must be on the basis of weighing up the possible benefits against the possible disadvantages. Medical, emotional, social and welfare benefits and disadvantages should be considered and it is only if the benefits outweigh the disadvantages that the proposed action should be taken.”

5.3.20. The review panel confirmed that whilst some agencies encourage use of a balance sheet style approach, agencies all use different templates. But in an attempt to support practitioners and to offer some structure to the best interest decision-making process, the adult safeguarding board has produced multiple ‘How to’ guides regarding mental capacity in specific situations which can be found on the website¹⁶. And whilst there isn’t a ‘How to consider a best interest decision’ guide, direction is available¹⁷.

5.3.21. There are no full mental capacity assessments in Nigel’s records, but the following three references to best interest decision-making have been found:

03.08.2018	a medical examination was carried out in Nigel’s best interests
02.04.2020	a pressure ulcer care plan identifies that treatment was being carried out in Nigel’s best interests
01.05.2020	a speech and language therapist identified that a swallowing assessment was going to be carried out in Nigel’s best interests.

5.3.22. However, despite the Mental Capacity Act Code of Practice¹⁸ noting that a detailed record should be kept of all best interests decisions, a lack of detail in documentation has resulted in this review being unable to verify; the process followed, who was involved in these decisions and/or whether parents disputed any of these actions.

Lesson 4:

Detailed records must be kept of best interest decisions; this is not only good professional practice but necessary should a decision or decision making process be later challenged or reviewed.

¹⁶ [Local Guidance and Templates – LLR SAB Multi-Agency Policies & Procedures Resource \(llradultsafeguarding.co.uk\)](https://www.llradultsafeguarding.co.uk/)

¹⁷ [7.3 Best Interests – LLR SAB Multi-Agency Policies & Procedures Resource \(llradultsafeguarding.co.uk\)](https://www.llradultsafeguarding.co.uk/)

¹⁸ Mental Capacity Act Code of Practice s.5.15.

The LRSAB has addressed record keeping within their aforementioned [‘best interests’ guidance](#) which notes that records should include:

- How the decision about the person’s best interests was reached;
 - The reasons for reaching the decision;
 - Who was consulted to help decide the best interests;
 - What particular factors were taken into account;
- If written requests from person concerned were not followed, why not;
 - The content and results of any disputes;
- What has been decided in the person’s best interests and reasons for that decision.

5.4. Theme 4: Professionals’ Knowledge of Processes

5.4.1. Whilst the best interests decision making process was not consistently followed, it was good practice that in 2019 the Occupational Therapist escalated her concerns in respect of Nigel’s low weight and his moving and handling, to her manager. This resulted in a safeguarding referral being completed. The safeguarding enquiry was deemed not to meet the threshold but a social worker was allocated as a result.

5.4.2. Unfortunately this practice was not repeated in February 2020 when following another visit to the home address the Occupational Therapist and her manager told Nigel’s mum that consideration may be had to initiating a further safeguarding referral if a safe alternative for the stairlift was not progressed.

5.4.3. Alternative practice could have seen consideration being had immediately as to whether safeguarding thresholds would be met, and the manager making a referral to the safeguarding team as appropriate. However, this course of action was not taken - there is no recorded analysis as to why not, but when asked, the therapist advised that she had felt that she needed someone to support her to take the case forward. She explained that the manager who accompanied her on the home visit to Nigel’s parents had led the visit and she reflected that because at one point, mother appeared to be considering the proposed alternate adaptations, the manager possibly thought things would progress. As such neither a referral or a best interest meeting was arranged.

5.4.4. Better practice would have seen the manager progress a referral to legal services for advice, as the previous manager had done in 2019. However, the manager was a locum manager who was new to the authority and may have not been familiar with the system and agreements. The manager has since left the authority and consequently this review has been unable to ascertain further understanding of events.

Lesson 5:

The professional was not appropriately supported to progress safeguarding concerns.

5.4.5. Since this time, the professional has undertaken further training in respect of safeguarding which has given her a clearer understanding of safeguarding thresholds and the confidence to appropriately challenge the decisions of others if she remains concerned about the welfare of another.

5.4.6. Additionally, the team now discuss in 6- weekly supervision sessions if there are any open cases where there are safeguarding concerns and the manager will document the discussions and agreed action plan / time frame on the LAS system. All staff attend relevant Safeguarding training including locum/agency managers as part of their induction

The team can also book in a meeting with the manager in between supervision at any time to discuss any cases of concern. The team ensure that for relevant open cases, there is MDT involvement and maintain communication links with all professionals (e.g. ASC and Health), as this was a learning outcome from the safeguarding meeting. There is also a reflective log which can be used to review and reflect our practice. This is excellent practice and highlights the importance of managers and supervision having regular conversations with staff which encourage the person to ask for training and/or support with an area of their work.

5.4.7. Another example of a referral process not being fully understood is demonstrated when the community nurse visited the home address on the 14th of December 2020 to assess Nigel's pressure ulcer. The nurse assessed that Nigel had an ungradable pressure sore and requested a second opinion from a nursing colleague. Assessment and treatment of the pressure ulcer would have continued with the Community Nursing team with the support of the Tissue Viability Service, but father told the GP Practice that he felt that the Community Nurse had 'shown incompetence' by calling on a colleague for a second opinion. At his request, Community Nurses discharged Nigel from their care and agreed that the Practice Nurse would support parents to dress the wound. The Community Nurse advised the Practice Nurse that an airflow mattress and wheelchair cushion were required to relieve the area of pressure and on the 17th of December the Practice Nurse ordered them from Adult Social Care. However due to this not being the correct procedure they were later ordered by the Trust on the 23rd of December 2020 for next day delivery.

5.4.8. Correct procedure would have seen the Community Nurse ordering the equipment on the day she visited the family via the Community Nursing service. It was good practice that the Practice Nurse had, upon realising that the family were still waiting for the equipment, chased the referral allowing the mistake to be acknowledged and rectified.

5.4.9. In addition to the equipment referral process not being followed, there is further concern in that there is no evidence of anyone having challenged father's decision or explained why it was not, in their professional opinion, in Nigel's best interest to receive GP based care rather than the specialist community nurses care and treatment. As highlighted in the previous sections of this report, parents at this time should have been advised on matters of capacity and best interests, and in the event of them still refusing the support on Nigel's behalf, the concerns should have been escalated. Instead Nigel's rights were overshadowed by his parents' views, opinions and decisions.

5.4.10. Discussions at the learning event brought to light that on occasions professionals were concerned that if they challenged parents about their decisions, Nigel would experience detriment such as him being stopped from attending the Day Centre or further declined access to healthcare.

5.4.11. Such concerns only serve to highlight how staff must be supported to have difficult conversations with service users and their families. A Professional Curiosity resource; Building Confidence in Practice, is currently under consultation and touches on the subject of difficult conversations. When complete it will be available on the internet and the LRSAB will promote its existence.

5.4.12. When conversations don't address a professional's concerns, it is important that they know how to seek safeguarding advice and understand when to follow escalation processes.

- 5.4.13. The safeguarding referral process was explored in depth with the Day Centre. They made a referral to the Learning Disability Referral Management Team in November 2020 when Nigel was struggling to swallow and they had concerns about his general presentation.
- 5.4.14. As a result, on the 25th of November 2020 a member of the Speech and Language Team attended the Day Centre to see Nigel. An urgent assessment was completed and new care plans were put in place. Although following from this, some telephone contacts were had between the Day Centre and the Speech and Language Team, the only other face-to-face contact was on the 8th of December when the member of the team returned to the Day Centre to observe Nigel eating and drinking and to gain feedback on Nigel's use of the Drink-Rite cup¹⁹.
- 5.4.15. The Day Centre has spoken of how worried staff continued to be about Nigel during this period of time. He was refusing to use the Drink-Rite cup and his swallowing was not improving. Accordingly his presentation continued to deteriorate.
- 5.4.16. The Day Centre has said that staff believed that all the medical professionals involved were doing everything they could and although they continued to worry about Nigel's deterioration they believed that nothing more could be done. The Day Centre had been told by Nigel's parents that he was unable to have a feeding tube because of medical reasons, but have said that had they known that it was not a medical decision, and that the GP and nurse was unable to monitor Nigel's weight, then they would have re-referred.

Lesson 6:

The referral process that the Day Centre followed did not provide staff with enough information to ensure that they understood the options available to them if their concerns remained, or Nigel deteriorated post the referral being submitted.

Recommendation 3:

LRSAB to seek assurance that agencies have the processes to provide staff, including commissioned providers, with clear and up to date information of what to do if there are safeguarding concerns for an individual in their care. All staff must have access to information that details safeguarding pathways, explains when and which pathway to follow, and clarifies how to escalate concerns.

5.5. Theme 5: Nigel's Weight/Diet Management

- 5.5.1. Because Nigel would find it difficult to communicate how he felt, whether he was unwell and/or explain any pain, this review has been asked to consider whether diagnostic overshadowing was ever an issue that affected his care and support. Diagnostic overshadowing happens when a health professional, instead of exploring biological factors, mistakenly makes an assumption that the behaviour of a person with learning disabilities is a characteristic of their disability rather than recognising it as a way of expressing pain or distress. Researchers have highlighted that it is particularly pertinent when new behaviours develop or existing ones increase²⁰.
- 5.5.2. Put into other words, the review must ask, did professionals attribute Nigel's behaviours to his learning disability rather than explore the reasons behind them? And did professionals afford him the same diagnostic principles that they would to another patient? The importance of these questions is highlighted when one considers that the Confidential Inquiry

¹⁹ A Drink-Rite Cup is a cup with handles which provides a controlled limited flow of fluid into the mouth

²⁰ Gates B and Barr O. Learning and intellectual disability nursing. Oxford: Oxford University Press, 2009.

into the Premature Deaths of People with a Learning Disability²¹ illustrated that people with learning disabilities have poorer health outcomes.

- 5.5.3. If we consider how a person's relationship with a professional develops in line with their experience of the professional's communication, it has to be recognised that Nigel's difficulties in communicating and being understood must have affected the quality of the relationships he had with some professionals. Especially as not all of the professionals consulted Nigel's communication passport and some relied on his parents to respond and to speak for him. It is therefore reasonable to wonder if such a non-communicative relationship could have resulted in some professionals unwittingly failing to apply the same diagnostic principles that they would to other patients with whom they could easily communicate with.
- 5.5.4. However no information has been provided to this review which would evidence that Nigel's learning disability overshadowed any recognition of him having any physical health problems. To the contrary the review has been provided with multiple examples of healthcare professionals investigating and diagnosing Nigel's health. For example, with regards to his poor nutrition, professionals had formerly considered a feeding tube to support Nigel but the operation had not gone ahead. They also trialled different feeding cups and spoons to try and make feeding easier for Nigel, but these changes distressed him. In addition, following the Day Centre raising concerns, the Speech and Language Team introduced dietary changes to his food at the Day Centre (in the past the addition of nutritional supplements had resulted in Nigel not eating at home so his parents were reluctant to try them again at home). Food fortification was carried out with cheese, butter and cream being added to food and full fat milk used in drinks and shakes.
- 5.5.5. There is also evidence of professionals investigating other medical concerns; for example, examination of Nigel's throat and ears, bloods being taken, and of operations being performed to prevent vomiting,
- 5.5.6. Therefore although Nigel's medical consultations and needs were sometimes overshadowed by his parent's views, wishes and opinions, diagnostic overshadowing does not appear to have been present in his case.
- 5.5.7. The review has heard that Nigel would sometimes refuse to eat and that his parents reported this to be historical. He was place specific regarding where he would eat and consequently he ate hot main meals at the Day Centre and snack type food at home. Professionals were aware of his eating habits, digestive problems and conscious of his low weight.
- 5.5.8. Given all the concerns around Nigel's eating habits and low weight, accurate assessment of his weight and Body Mass Index was essential. He received annual GP health checks but his physical weight was not taken in the GP surgery as they do not have the facility or capacity to weigh patients that are non-weight bearing. Instead, parents would report a weight that they said had been taken at the Day Centre.
- 5.5.9. However, the Day Centre did not have the correct equipment neither and they were of the opinion that the GP was monitoring his weight. Parents did admit to weighing Nigel by standing him on the scales at home and letting go for a short time but there is no record of actual accurate weight.

²¹ Heslop P., Blair P., Fleming P., et al. Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: Norah Fry Research Centre, 2013.

- 5.5.10. The GP surgery has told this review that there is no other service that they are able to refer to in order to obtain a physical weight for a non-weight bearing patient. Consequently Nigel's weight wasn't ever accurately known or recorded for specialist evaluation. This was discussed extensively at the learning event.
- 5.5.11. Another Safeguarding Adult Review in Leicestershire had also highlighted a problem with access to weighing scales for people in wheelchairs and this has led to weight management being identified as a priority focus for LeDeR. LeDeR have subsequently developed guidance²² which seeks to *create a clear process for accessing specialist weighing facilities in Leicestershire, particularly for non-weight bearing people, and also an approach for onward specialist referrals where concerns are urgent and there are difficulties in obtaining an accurate weight, for example if this would be very distressing for the person.*
- 5.5.12. The document advises that where a person with a learning disability requires specialist weight equipment and there are concerns about his or her weight, guidance should be sought on appropriate weighing venues through multi-agency discussion.
- 5.5.13. The document also states that *If it is difficult to obtain a weight for the person (for example, if weighing a person would cause distress), then there should be a multi-agency meeting with the GP to agree about how onward nutrition specialist referrals will be made based on professional and family concerns.* And consideration should be had to making a referral to the Primary Care Learning Disabilities Team²³. *for specialist guidance and de-sensitisation work where it is difficult to obtain baseline measurements or compliance with treatment/investigations.*
- 5.5.14. The guidance also reiterates that where a professional has been provided with a weight measurement from another agency or family member, the professional should ask questions to establish how accurate the weight measurement might be and record the responses and the given weight, along with a note that it was a third party measurement.

Lesson 7:

Weight management and onward specialist referrals, where weight has been identified as a concern, are a priority.

Work has been undertaken and guidance is being created which identifies procedure for accessing specialist weighing facilities in Leicester, Leicestershire and Rutland and onward referrals.

- 5.5.15. In addition, Leicestershire Partnership Trust in partnership with the Clinical Commissioning Group and Local Authority have been working as a task and finish group to scope where within the organisations, are accessible scales, and the group has been working through options regarding where people who require their weights to be obtained, can access them.
- 5.5.16. Leicestershire Partnership Trust Learning Disability services have purchased sit on scales to be based in Winstanley Drive so that anyone who is open to the learning disability service can now have a baseline weight completed on first assessment, and ongoing if there is a concern in relation to their weight. There is a plan to monitor the scales usage and consider whether there is any requirement for more accessible scales in other localities going forward. The demand for hoisting scales is also being scoped and, if there is a demand, they will be procured.

²² Weights Concerns Guidance for Lancashire

²³ LPT-PCLN@leicspart.nhs.uk

5.5.17. It has also been recognised that there needs to be a wider agreement for individuals who are not open to the specialist community learning disability service within Leicestershire Partnership Trust. It must be agreed how adult social care and Primary Care can access scales. Leicestershire Partnership Trust have advised both Primary Care and the Local Authority that weight clinics across Leicester, Leicestershire and Rutland may need additional commissioning if it is deemed that there is additional need for people with or without a learning disability who need access to accessible weighing equipment.

Recommendation 4:

LRSAB to seek assurance as to how the Weights Concerns Guidance for Health and Social Care Agencies in Leicester, Leicestershire and Rutland is disseminated and made available to professionals, and the board should ensure that a plan is in place to audit the effectiveness of the guidance.

5.6. Theme 6: Coordination of Nigel's Support

5.6.1. In the critical months leading up to Nigel's death he was requiring a range of services delivered by a number of different agencies; alongside his usual health care support he was receiving care for his pressure sores, Occupational Therapy to ensure that he had the correct support aids, Day Centre services, Dietetic Services and Speech and Language Therapy.

5.6.2. Such a range of services can be difficult for families/carers to navigate, and poorly coordinated care and support can result in worse outcomes for people, or crises occurring.

5.6.3. The NICE²⁴ Quality Standard²⁵: Learning Disability: care and support of people growing older, Statement 2²⁶ declares that *People growing older with a learning disability have a named lead practitioner*. This means that commissioners should commission services in which *people growing older with a learning disability have a named lead practitioner*. The named person is allocated responsibility for coordinating and navigating the individual's care and support. This is distinct from the role of an advocate – the local care and support navigator will normally work for the local authority or health service, whereas advocates are independent. Named 'navigators' could be a range of different people from different organisations/ professional backgrounds. They do not have to be clinical but do need to have the right skills to be able to undertake an effective coordinating role for people with a learning disability and to be supported to continue to develop those skills.

5.6.4. This review has been told that there was no lead professional of Nigel's care.

Lesson 8:

Nigel's' care and support was not coordinated by any lead professional.

Recommendation 5:

LRSAB to seek assurance that the NICE Quality Standard: Learning Disability: care and support of people growing older, Statement 2 is being met.

5.6.5. Throughout the course of this review the reviewer has consulted with professionals who worked to support Nigel and has noticed some disparity in what professionals knew and when. For example, the Day Centre thought that Nigel was unable to have a feeding tube

²⁴ National Institute for Health and Care excellence

²⁵ QS187 Published: 24 July 2019

²⁶ [Quality statement 2: Named lead practitioner | Learning disability: care and support of people growing older | Quality standards | NICE](#)

because of medical reasons, and staff at the centre were not informed of the pressure sores until the 4th of January 2021 despite Nigel being in their care five days a week. It appears that other professionals relied upon parents to disclose information to the Day centre.

- 5.6.6. Whilst the line of communication between all professional agencies and private care organisations must be improved, there is clear testimony within this review to support a closer relationship being developed between healthcare professionals and Private Day Centres who are offering significant care to adults, in particular, adults who do not have capacity. Staff at such Day Centres spend a considerable amount of time with a GP's patient and are in a good position to identify and monitor improvement and decline.
- 5.6.7. Had the GP surgery had a relationship with the Day Centre that Nigel attended, it may have been noticed that neither the surgery or the Centre had the facilities to weigh Nigel and monitor his weight accurately. In the absence of this relationship, both parties presumed the other to be supervising his weight.
- 5.6.8. The role of the Learning Disability Primary Care Liaison Nurse has been brought to the review's attention as one that can be utilised to considerably improve communication between a Day Centre and health professionals. The nurses are employed within the Leicestershire Partnership Trust and work with all primary health care services to ensure equitable access for people with a learning disability. Upon discussion it is clear that the Day Centre have only just learned of this role and few professionals from other agencies/organisations are aware that it exists.

Lesson 9:

The role of the Learning Disability Primary Care Liaison Nurse is not widely known amongst professionals within the agencies and organisations who support adults with learning disabilities.

Recommendation 6:

LRSAB to ensure that the Leicestershire Partnership NHS Trust promote the role of Learning Disability Primary Care Liaison Nurse

5.7. Theme 7: The Stresses of Caring for Nigel

- 5.7.1. Case notes and assessments indicate that both parents were involved in providing care and support to Nigel. Mother supported his morning routine and, as he worked during the day, father provided care and support undertaking the evening routine. Both parents provided support at weekends. Nigel's needs were complex, and it is reasonable to assume that the level of care intervention he required was extensive and continual. As such both parties would have been eligible for a carer's assessment.
- 5.7.2. The Care Act 2014 gives local authorities a responsibility to assess a carer's needs for support, where the carer appears to have needs. The only evidence of a formal carer's assessment being completed with mother was in 2016, which is prior to this review period. In that assessment mother describes the impact of caring on herself and her husband and the involvement of various professionals who provide advice but then do not provide solutions.
- 5.7.3. The review has been unable to establish the frequency that parents were subsequently offered carer's assessments but the Occupational Therapy offered one to mother on the 16th of January 2020 after she had indicated that she was under carer strain. There is no evidence of a formal carer's assessment being offered or carried out with father.

5.7.4. However, given the reported difficulties that parents had engaging with some professionals, it must be recognised that even if they had been offered more, they may not have participated in further carers assessments. It is also debatable whether the use of an independent carers organisation to support or complete carers assessments with them would have helped. But professionals must never predict a carer's response or allow prognostication to affect the type and frequency of support offered to them.

5.7.5. In the absence of parents engaging with this review process, it has not been possible to explore how caring for Nigel affected their emotional health. But professionals at the learning event agreed that those who noticed parents' struggles with accepting assessment and support, should have identified it as a concern and escalated it to be managed effectively.

5.8. Theme 8: The Effects of the Covid Pandemic on Nigel's Care

5.8.1. In December 2019 a coronavirus emerged which was rapidly identified as pandemic. As a result the United Kingdom saw the Prime Minister announcing a national lockdown on the 23rd March 2020.

5.8.2. For people like Nigel with learning disabilities, the Covid pandemic caused a traumatic loss of routine. It was hard for Nigel to understand the loss of activities such as holidays and trips out. It must be acknowledged how Nigel's stress and anxiety would have intensified the demands of his care and although this review is unable to ask his parents for clarification, it undoubtedly must have had an effect on them as his carers.

5.8.3. Professionals worked relentlessly to maintain service and continuity through these uncertain and rapidly changing times but it was unavoidable that things would change for Nigel. Professionals have told this review that one of the biggest challenges arising from the Covid pandemic for them was that it hindered the ability to undertake home visits to Nigel.

5.8.4. Occupational Therapy assessments were undertaken by telephone or by virtual means as service home visits were only completed if essential and following a risk assessment. As a result Nigel was not physically seen by the Occupational Therapist after November 2019.

5.8.5. The Dietetic service was limited from holding clinics and face to face assessments. This meant that a nutritional specialist did not see Nigel at the beginning of January 2021. Instead a telephone consultation was had with parents.

5.8.6. Professionals not attending Nigel at home is reasonable given the pandemic and its associated risks but it is clear that in the absence of face-to-face contact with Nigel, professionals found it harder to monitor his care needs and support. For example, had there been a face-to-face assessment the dietician would have been able to use her experience to assess weight and Body Mass Index.

5.8.7. Despite the pandemic putting the NHS under extreme pressure, the GP remained open and was available to Nigel throughout. It is reassuring that the pandemic had no impact upon the GP practice's ability to arrange an out of hours home visiting service healthcare professional to attend the home address in January 2021 when Nigel was poorly. Similarly it is commendable that the Community Nurse attended to Nigel at home.

- 5.8.8. It is particularly commendable that despite the pandemic, Nigel was still able to have his annual health check in October 2020. A study published in March 2021 led by researchers from the University of Warwick²⁷ and Manchester Metropolitan University spoke to almost 1,000 people across two cohorts. Cohort 1 was made up of people with learning disabilities themselves, while cohort 2 comprised of the family and carers for people with severe learning disabilities who could not respond without assistance. The study found that across cohorts 1 and 2, 60% of people with learning disabilities (who had routinely seen healthcare professionals before the first lockdown) had seen them less or not at all since.
- 5.8.9. 23% of people in cohort 1 and 41% of people in cohort 2 had a medical test or hospital appointment cancelled since the first lockdown. Moreover, 46% (cohort 1) and 48% (cohort 2) of people with learning disabilities who usually have an annual health check, had not had one since the March 2020.
- 5.8.10. Because Nigel would refuse to eat at home, the risk of malnutrition if he didn't attend the Day Centre was great. Therefore Nigel continued to attend the Day Centre 5 days a week during the Covid pandemic. Staff minimised his risk of infection by wearing personal protective equipment, staying 2 metres away from him where possible, supporting him with good hygiene, limiting his interaction with other service users, and remodelling his transport.
- 5.8.11. As other services were not undertaking home visits there was an unavoidable reliance on the Day Centre to communicate any change in need and it is good practice that when staff became concerned for Nigel they referred immediately for support. However, there was an unavoidable closure of the day service in January 2021 due to a Covid outbreak, and hence a period of time when no professional saw Nigel.
- 5.8.12. Data²⁸ released by Mencap in February 2021 demonstrates that every week since the end of November 2020, people with a learning disability have died from Covid disproportionately compared to the general population. This disparity between the proportion of Covid deaths grew dramatically throughout December 2020 and January 2021, around the time that the Day Centre had to close. The data also shows that at this time, the death rate from Covid amongst those with a learning disability rose steeply.
- 5.8.13. In recognition of the effect Covid has had on people with learning disabilities, Leicester, Leicestershire and Rutland learning disabilities team and adult social care have formed a Covid-19 Sub cell²⁹ to provide a coordinated response which will maintain critical services and ensure safe service delivery.
- 5.8.14. One of the processes that have been introduced is a Covid-19 risk register which has now become an established pathway called the dynamic support pathway. In this process organisations RAG (red, amber, green) rate their service users to identify those at greatest risk as result of Covid-19 service changes. Any individual who is identified as being at 'Red' risk' automatically triggers a Multi-Agency Meeting led by the organisation that identified

²⁷ [coronavirus and people with learning disabilities study wave 1 full report v1.0 final.pdf \(warwick.ac.uk\)](#)

²⁸ The data refers to the deaths of people with a learning disability in England that were reported to the Learning Disability Mortality Review – although it is not a requirement for deaths to be reported so many could be missed.

²⁹ The Sub Cell consists of representatives from:

- Leicester City Council
- Leicestershire County Council
- Rutland County Council
- Leicestershire Partnership Trust
- Leicester, Leicestershire and Rutland Clinical Commissioning Group
- Midlands and Lancashire Commissioning Support Unit
- Other relevant partners/stakeholders for specific discussions

the person as being 'Red'. Once the meeting has taken place a residual risk rating is undertaken and where additional support requirements have been identified, partners work together to implement solutions including in-reach visits, increases in care packages, additional staffing, etc., If additional steps do not improve the situation, the individual will be added to the Transforming Care Programme 'Risk of Admission Register'.

5.8.15. The purpose of the cell overall is to:

- Respond as a system to identify those individuals with a learning disability and/or autism, and their families, who are at the greatest risk of being impacted by service closures/changes as a result of Covid-19. This includes people residing outside of Leicester, Leicestershire and Rutland but that the footprint is responsible for.
- Ensure actions are in place to mitigate any adverse impacts of service closures/changes, including: providing support in alternate ways; increasing packages of care; considering creative ways to support people; and using the Risk of Admission Processes³⁰ to prevent mental health hospital admissions.
- Ensure consistent messages are provided to Learning Disability/Autism services providers.
- Understand and address concerns regarding care and support staffing capacity within the independent sector and access to personal protective equipment for community workers.
- Enable the continuation of essential frontline Learning Disability inpatient and community health services

6. Good Practice

There is evidence of much good practice within several agencies who supported Nigel and it is equally important to develop learning from this good practice as it is from any shortcomings:

- 6.1. Professional attendance and engagement at the learning event was excellent
- 6.2. The agency reports returned to the reviewer have been of an exceptional high quality
- 6.3. Nigel had regular annual health checks.
- 6.4. The Occupational Therapist completed a Mental capacity assessment around the stairlift and demonstrated professional curiosity regarding Nigel's weight loss and alerted the GP.
- 6.5. The timing and responsiveness of the Learning Disability Speech and Language Therapist's assessment and advice was in depth, good and timely.
- 6.6. The involvement of the NHS Trust's Tissue Viability Nurses in supporting the GP Practice Nurses despite withdrawal from care by Nigel's father.

7. Improving Systems and Practice

7.1. Consideration of Other Reviews

7.1.1. One of the recommendations in the Learning Disabilities Mortality Review Programme annual report³¹, published in 2018, highlighted the need for *better understanding and application of the Mental Capacity Act*. Reviewers identified problems with the level of knowledge about

³⁰ [Item 2a - Appx A LCC ROAR process.pdf \(proceduresonline.com\)](#)

³¹ [LeDeR-annual-report-2016-2017-Final-6.pdf \(hqip.org.uk\)](#)

the Mental Capacity Act amongst professionals, as well as concerns about capacity assessments not being undertaken, and best interests processes not being followed. An Mental Capacity Act workstream was established to explore how to support quality improvements and enhance compliance within secondary care for people with a learning disability. The importance of professionals having a high level of knowledge and skill in the Mental Capacity Act and access to specialist advice is highlighted when it is recognised that Nigel did not always have care and treatment which aligned to the best possible outcomes for his health. Had staff felt able to explain the concept of best interest decisions to parents and to apply the concept to his decisions, his physical deterioration may have been averted.

7.2. Developments since the Scoping Period of this Review

Since the scoping period of this review, agencies have already made some important amendments to practice. Some have been included in the body of this report. Other developments include:

7.2.1. Leicestershire Partnership NHS Trust has a robust quality improvement plan in place to improve and address matters relating to pressure ulcer care, Mental Capacity Act knowledge and skill and access to training, specialist advice and guidance relating to cases such as Nigel. Community Nursing Service staff will all have received additional level 3 face to face Mental Capacity Act training as a priority service in 2022. The Trust's safeguarding and Mental Capacity Act policies and procedures have been reviewed and rewritten within the last few months.

7.2.2. Leicestershire Partnership NHS Trust is currently creating a Carer Lead role to establish the governance, training, procedures, assurance framework and to audit compliance with the Care Act (2014), Supporting Adult Carers NICE guideline. In addition the safeguarding team now ensure that advice includes support and advice on carers rights and needs.

7.2.3. Weight Management and Nutrition Guidance is going to be available on the Multi-Agency Policy and Procedures.

7.3. Conclusion

7.3.1. Nigel was a mischievous gentleman with a great sense of humour who lived with cerebral palsy and a severe learning disability. He lived at home with his parents and attended a Day Centre Monday to Friday.

7.3.2. Because Nigel could not communicate verbally he held a communication passport which explained how he expressed his feelings and choices, and what his behaviours might indicate. However, this review has learned that not many professionals outside of the learning disability team and the Day Centre knew that communication passports existed, and consequently did not ask to see it.

7.3.3. This contributed to some professionals allowing Nigel's parents to convey his wishes and feelings on his behalf. This resulted in:

- many professionals not hearing Nigel's voice, and
- parents making decisions on Nigel's behalf.

7.3.4. This was acceptable when Nigel was a child because his parents held parental responsibility but when he got older, Nigel's decision making (post 2005) was governed by the power afforded him through the Mental Capacity Act. Under the act, decisions which Nigel was

deemed to not have the capacity to make, should have been decided using the best interest principle.

7.3.5. This review has identified that professionals did not always consider that the decisions parents made on Nigel's behalf were in his best interest. For example, whilst there is no doubt that parents loved Nigel, the rejection of a community nurse to dress his pressure sores at home denied him specialised care, and the dismissal of a lift in the home, denied him the safest handling.

7.3.6. But, the best interests principle was not followed for Nigel in part, because,

- professionals often lacked the confidence to assert it, and because
- some professionals were deterred from disagreeing with parental decisions for fear that parents would consequently reduce their engagement with services.

7.3.7. Whilst best practice would have seen decisions about Nigel's care being taken under the best interests principle, when professionals became concerned that a parental decision had been made that could put him at risk, a safeguarding concern should have been raised.

7.3.8. Professionals around Nigel were not consistent with safeguarding referral practice and this review has established that this was because many professionals were accepting of the decisions parents made and did not challenge them or explain the Mental Capacity Act. Also some professionals who were concerned, lacked the confidence to challenge the decision of colleagues.

7.3.9. Professionals were all aware that Nigel had long standing issues with eating, digestive problems and they were conscious of his low weight. However, unknowingly Nigel's weight was not being monitored. The GP, who didn't have access to any service able to obtain a physical weight for a non-weight bearing patient, thought that the Day Centre was weighing him, but the Day Centre thought that the GP was. As a result, no professional had an exact weight for Nigel which would have helped to gauge improvement or decline.

7.3.10. The review has uncovered two reasons that contributed to this discrepancy going unnoticed. Firstly, poor multi-agency communication resulted in neither the GP or the Day Centre realising that the other was not measuring weight, and secondly, no single professional was leading Nigel's care. Had a lead practitioner been named, there would have been an individual with responsibility for coordinating and navigating Nigel's care and support and thus the omission may have been realised.

7.3.11. In the absence of a lead practitioner, parents were navigating the services and able to choose which services Nigel accepted and declined. It has become clear that there were some agencies/professionals, that for unknown reasons, parents struggled to engage with but without any overview of the situation, the extent of parents' non engagement and its influence upon the decision-making they were making on behalf of Nigel, was not recognised and was not escalated to be managed effectively.

7.3.12. Unfortunately, Nigel's situation was further complicated by the Covid pandemic. This had an affect on professional practices and resulted in less professionals seeing Nigel in person. It also had a direct effect on Nigel as he was no longer able to do things that he enjoyed such as going out to cafes, or going on holidays with his parents.

7.4. Recommendations

- 7.4.1. LRSAB to liaise with the Learning Disability Partnership Board to produce a plan to support professionals within partner agencies to communicate with adults with learning disabilities.
- 7.4.2. LRSAB should ensure that all professionals have access to training and advice regarding application of the Mental Capacity Act to ensure that best interests decisions are made for adults with Learning Disabilities who continue to be cared for by their parents. This training should include guidance of how professionals can explain to parents the change in governance as their child gets older.
- 7.4.3. LRSAB to seek assurance that agencies have the processes to provide staff, including commissioned providers, with clear and up to date information of what to do if there are safeguarding concerns for an individual in their care. All staff must have access to information that details safeguarding pathways, explains when and which pathway to follow, and clarifies how to escalate concerns.
- 7.4.4. LRSAB to seek assurance as to how the Weights Concerns Guidance for Health and Social Care Agencies in Leicester, Leicestershire and Rutland is disseminated and made available to professionals, and the board should ensure that a plan is in place to audit the effectiveness of the guidance.
- 7.4.5. LRSAB to seek assurance that the NICE Quality Standard: Learning Disability: care and support of people growing older, Statement 2 is being met.
- 7.4.6. LRSAB to ensure that the Leicestershire Partnership NHS Trust promote the role of Learning Disability Primary Care Liaison Nurse

8. Appendix 1

Terms of Reference

- 8.1. How was Nigel's voice heard and how was it determined that decisions about his care were being made in his best interests?
- 8.2. How were Nigel's parents/carers' needs assessed and how were they supported to give safe effective care?
- 8.3. Explore professional responses to any conflict with Nigel's parents/carers regarding his care.
- 8.4. Did professionals allow diagnostic overshadowing to influence their responses to Nigel's significant weight change?
- 8.5. Did all professionals demonstrate 'professional curiosity' and if not, what were the barriers they faced?
- 8.6. How did the Covid pandemic impact Nigel and his family and the support offered to them the support offered to them and wider services available to them?