

Thomas

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The **effective investigations** company

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- The teaching hospital
- Thomas's GP's

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Executive summary

Purpose of the investigation

At the time of Thomas's death, his parents had a range of concerns about the care and management of their son throughout his life. They always felt that he did not receive a care package that met his or their needs. Focal points in Thomas's life that caused heightened degrees of concern for his parents were:

- they believed there was a lack of certainty about Thomas's diagnosis of autism (this was in fact diagnosed by his Child and Adolescent Consultant, on 18 November 2010).
- in the period between 2012 and 2013, when Thomas was in his first residential care placement, Norcott House, there were parental concerns about Thomas being abused by staff.
- in the period between 2013 and 2014, during Thomas's two admissions to the assessment and treatment unit, key issues were over medication, that Thomas seemed to deteriorate in this care facility rather than improve, and that he was no longer able to go out or eat the foods he liked. Concerns about ongoing abuse prevailed.
- in the period between July 2014 and February 2015, during Thomas's residence in a care home, Thomas's parents again had concerns about abuse of their son and about his physical health management, specifically relating to the management of his chest infections.

Because Thomas's parents always believed that the death of their son was preventable, and that he could, and should, have had a better life, they canvassed NHS England for an independent review of the circumstances leading to the death of their son and his management in the preceding years. NHS England agreed to conduct an independent investigation and convened a multi-agency meeting on 2 September 2016. The first provider meeting occurred on 8 November 2016. In line with all level three independent investigations, the focus was to identify relevant learning opportunities that could inform improved care and management for the future.

The initial scope of the investigation was not clear, so the independent reviewer met with Thomas's mother and two of his sisters, and extensive terms of reference were agreed, along with a communication strategy. It was made clear to Thomas's mother, at this time, that it may not be possible to deliver on every term of reference as thoroughly as the family wanted because of:

- loss of memory
- the providers of care during Thomas's first admission, under section 2 of the Mental Health Act, and his first residential placement no longer being the providers of those services.

Nevertheless, the lead independent reviewer made an undertaking to meet with the primary agencies who were involved in delivering a service to Thomas during his transition from children's to adult services, and through to his death.

An 'after action review' model was utilised to achieve this, with a small number of one-to-one interviews. This enabled the lead reviewer, and her advisers, to meet

with multi-agency groups 'in the round', and gain a detailed insight into their plans for Thomas and the challenges they experienced in delivering these.

Following a review of each agency chronology, it became clear to the independent team that the phase of Thomas's chronology where there was the greatest opportunity for a different approach, or different action, to have been taken was following his first admission to the assessment and treatment unit (part of the mental health trust) in 2013. 2013 to 2015 was a period in Thomas's life where several issues could have been dealt with differently, leading to the possibility that this might have resulted in a different experience for Thomas, and his family, including a realistic prospect for his survival in February 2015. Therefore, this period has been the primary focus for this review.

Terms of reference

The top-level, focused, key lines of enquiry are as follows.

1. To set out a historical perspective of Thomas's contact with agencies prior to the age of 14, so that the analysis of his management from the age of 14, and his behaviour patterns, are set against the context of his long-term needs.
2. The period of transition from children's into adult services. The intent of this is to review the entirety of Thomas's transition from children's to adult services, and not simply the handover from children's services to adult services. Because of the passage of time, and the significant changes that have occurred in learning disability services, including the Care Act 2014, this section mostly focuses on:
 - the various factors involved in the first Mental Health Act assessment in 2011, when Thomas was 17 years old.
 - Thomas's time at Woodside Hospital and Norcott House.
3. The various issues associated with the mental health trust and their care of Thomas, his transfer to the care home, and the period up to his collapse in February 2015.
4. Thomas's collapse and associated deterioration on 2 February 2015.
5. The allegations of abuse made by Thomas, and his family, on a frequent basis.

The full detail of the terms of reference initially agreed with Thomas's family and NHS England can be found in section 2 of this report.

Incident overview

In the early hours of 2 February 2015, at 5.38am, a 999 call was made by the police, following their response to a 999 call that had been routed to them from Lifeways, a provider of residential services for people with learning disabilities. Thomas, one of their residents, had collapsed and was not breathing. The care home staff commenced basic life support while awaiting assistance.

The ambulance crew arrived at the care home at 5.43am, and transported Thomas to Northern General Hospital at 6.27am, having successfully resuscitated him at the scene. The ambulance crew delivered Thomas into the care of the team at Northern General Hospital at 6.39am, where active treatment of him commenced.

Following immediate assessment and treatment in the emergency department, Thomas was transferred to the intensive care unit, where he was treated and assessed. On 4 February 2015, brainstem tests confirmed that Thomas was 'brainstem' dead, and treatment was withdrawn following conversations with his family. He died at 4.50pm the same day.

The post-mortem report commissioned by Thomas's family, via Irwin Mitchell Solicitors, confirmed the primary causes of Thomas's death as:

- global hypoxic-ischemic encephalopathy
- cardio-respiratory arrest
- chest infection.

This was more detailed than the conclusion formed by the Coroner's histopathologist, who found the primary cause of death to be a chest infection, with the additional contributory factor of Down's syndrome.

An inquest into Thomas's death has not yet been held.

Main findings

Key lines of enquiry 1 and 2, which related to Thomas's transition from children's to adult services and his period of time with Woodleigh Care, were not addressed directly, because of the high risk of little to no return in terms of learning opportunity or service advancement given the passage of time and changes already made within these services. Consequently, only an overview of this period is presented in this report, alongside several observations the author made following her review of information provided by agencies and obtained from conversations with Thomas's family. These observations focus on aspects of this period that Thomas's family consider could have been better for them.

Key line of enquiry 3, which addressed Thomas's experiences from spring 2013 onwards, presented most of learning opportunities. An overview of the findings related to this can be found below.

With specific reference to the mental health trust:

- a more robust and formulaic approach to Thomas's management in 2013 may have impacted positively on his experience and reduced the team's over-reliance on medication as the primary means of managing him.
- there is no evidence that Thomas was abused by any member of staff while he was a patient at the mental health trust. All allegations made by him and/or his family were investigated via the line management arrangements and in line with the requirements of safeguarding vulnerable adults.
- Thomas, and the management of Thomas, was reviewed at least weekly by the medical team and the multidisciplinary team throughout his inpatient episode on the assessment and treatment unit. The management of

Thomas's challenging behaviours dominated these meetings; it is clear from his clinical records and his medication management that the staff paid due regard to Thomas's health needs, attending to issues.

- there are two important factors that could, and should, have been better for Thomas, especially during his first admission:
 - the conduct of a detailed psychological assessment
 - utilisation of the positive behavioural support model.
- the final decision of the Mental Health Act managers was to discharge Thomas from his detention – a decision no professional caring for Thomas agreed with and that the report author and her advisers consider was unsafe.
- making an application to place Thomas under the Court of Protection was unavoidable in this case; the issue about its decision to place Thomas at the care home was not avoidable either, based on the situational context at the time. Under the prevailing circumstances at the time, it is hard to see what else could have been done.
- the circumstance and speed of Thomas's transfer from the mental health trust to the care home, was not optimal and did not allow for a robust discharge planning and handover process between the NHS provider and the care provider; the mental health trust did its reasonable best to support the care home over a four- to six-week transitional period.

With specific reference to Thomas's time at the care home:

- the care home provider comprehensively assessed Thomas's needs before stating their willingness to offer a service to him at their facility.
- the care home provider had made most of their preparations for Thomas, but these were not as complete as they had hoped for owing to the time constraints imposed by the Court of Protection order.
- the clinical commissioning group and the local authority confirmed prior to Thomas's discharge from the assessment and treatment unit that his care package would be funded in full.
- Thomas was registered at a local GP surgery from the commencement of his residency at the care home, and the chronology of Thomas's life at the care home demonstrates regular contact between the care home, the GP surgery and the out-of-hours service.
- the care home provider employed a team of experienced carers to work with and support Thomas and managed to keep usage of agency staff to a minimum.
- because Thomas did not like all staff, the staff rotas were designed to try to respond to this; however, this was not uniformly possible.
- Thomas's medication was managed by the general practice, and via Thomas's psychiatrists; it is indisputable that Thomas's usage of sedative and antipsychotic medication was reduced while he was at the care home.
- there is no doubt that all agencies were committed to facilitating Thomas's return to his home town; the commitment to this was agreed as part of the Court of Protection proceedings, with all parties in attendance agreeing, including Thomas's family. There was however a lack of clarity about the projected timescales for achieving this and the milestones against which progress could be measured. The care home provider had a projected timescale of at least 18 months, which was not uniformly understood.

Regarding key line of enquiry 4, concerning Thomas's management at the Teaching Hospitals NHS Foundation Trust (referred to hereafter as the Teaching Hospital), the report finds that all care and monitoring received by Thomas on and after 2 February 2015 was entirely appropriate; all correct processes were followed and there was no failing in any of his care provision.

The report found that, regarding key line of enquiry 5, all reported safeguarding incidents were investigated and, where proper, reported to the relevant authority. There is also clear evidence throughout that agencies liaised with their relevant safeguarding adults service at the local authority and sought guidance on how best to manage and respond to the repeated allegations of abuse, which were mostly considered unfounded. There were only two instances of confirmed abuse: one in 2013, at the residential care facility; and the other at the end of his residency in the care home, when his mother raised a concern about an apparent carpet burn on her son when he was admitted to the Teaching Hospital. Both instances were robustly investigated by the police, and with the involvement of relevant safeguarding systems and processes. For the wider range of allegations, however, there is some question over the independence of the investigations carried out; it is a finding of this report that, while incidents were properly investigated on an internal level, the level and number of reports should have triggered an external, independent investigation process. This may have provided a more robust level of reassurance to Thomas's family.

Conclusions

The main conclusions of this report are summarised as follows.

- There was a risk that Thomas might get chest infections and possibly pneumonia, possibly secondary to food he may have aspirated.
- The lack of clinical reassessment of Thomas, in the 24 hours after the ambulance crew assessed him on 29 January, was avoidable. Several of his physical observations were outside the normal range of respirations, pulse, and oxygen saturation levels. This should have resulted in either a primary care referral, or a clear instruction to the care home to contact the GP the following morning, so a repeat of his observations was achieved.
- On the balance of probabilities, it is likely that following a GP assessment, Thomas would have been admitted to hospital on 30 January 2015.
- The care home did what was asked of it. It 'observed' Thomas, and where his outward behaviour caused concern, it called for advice, as demonstrated by its contact with NHS 111 on 1 February 2015.

Although it was possible that a cold or chest infection could be life-limiting for Thomas at some point in his life, the author of this report, her advisers and the agencies involved at the time agree that had Thomas been assessed by his GP or any clinical practitioner, and had his observations been reviewed after 29 January 2015, he would have received more assertive treatment and had a chance of recovering from his chest infection.

What has changed since Thomas's death

Several changes have already occurred since Thomas died. It is hoped that these changes will improve the care experience for service users such as Thomas, and their families. It is also hoped that some of these changes will reduce the risk of service users not receiving timely treatment when their physiological health is deteriorating, and there is no decline in their outward behaviour.

The changes already enacted include the following.

- Service users of the learning disability assessment and treatment unit at the mental health trust who require a psychological assessment receive it.
- The Intensive Learning Disability support service no longer retains care coordination responsibility for service users who are placed out of county.
- The Ambulance Service clinicians in the EOC Clinical Hub have access to SystemOne¹, but solely for frequent caller usage to enable care plans to be developed with appropriate teams. As part of a wider piece of work, the Clinical Hub is to gain access to the Shared Care Record, which will enable more information to be available about a patient's past medical history.
- The Ambulance Service has now rolled out the National Early Warning Score (NEWS) assessment, which is mandatory for all medical patients.
- The Ambulance Service is rolling out a patient non-conveyance leaflet, which will allow the ambulance clinician to clearly document the agreed care plan and any actions for the patient or carers to follow.
- The registered care home manager at Thomas's residence in 2014 has, since his death, been instructed by a GP to purchase specific home monitoring equipment for a resident. The GP also provided a simple schedule of upper and lower observation levels for the unskilled carers to refer to. The registered manager reports that this has worked well, and this therefore supports the recommendation that this practice becomes more widespread.

Recommendations

The report recommends the following, based on the evidence and testimony provided.

Recommendation 1

Target audience: The local and regional nursing teams of NHS England North and the commissioners of residential care home placements in the three district councils Thomas resided in

This case underlines the lack of expectation of residential care home staff to be able to deliver a range of physical health observations that individuals in a normal domestic situation either independently, or with the support of family/carers undertake at home. Objectively Thomas may have benefited from having his temperature, respiration rate and pulse checked when he was unwell with chest infections. This could have formed part of his individual support plan and may have enabled a more accurate assessment of Thomas's wellbeing to have been achieved during periods when he was unwell. Furthermore, these basic observations in the

¹ SystemOne is the record keeping system used across primary care services in the NHS.

last week of Thomas's life may have alerted care staff to the fact that Thomas was deteriorating, when this was not obvious from his outward behaviour.

The author of this report appreciates that staff employed by care home providers are not professionally qualified. However, if a basic range of physical health monitoring is within the competency of a normal domestic household, then it seems reasonable that at least this standard is expected as the normal for a residential care facility, where the provider provides a surrogate for the care and support a family might otherwise provide. The local and regional nursing teams of NHS England North and the commissioners of residential care home placements in the three district councils Thomas resided in are asked to raise this issue with the Care Quality Commission to achieve wider exploration of this issue so that uniformity of expectation can be achieved nationally.

Recommendation 2

Target audience: The ambulance service

The ambulance service must achieve reliability and consistency across all its response teams regarding the practice of safety-netting when a decision is made not to transfer an individual to hospital. Safety-netting is where the responding crew make sure that appropriate steps are put in place to assure the ongoing safety of the individual, and to ensure that appropriate and timely clinical follow up happens. In this case that should have occurred the next morning.

As part of the roll-out and use of the 'non-conveyance leaflet', the ambulance service is recommended to audit the success of this intervention within the first six months of roll-out.

Recommendation 3

Target audience: The ambulance service

The ambulance service must satisfy itself that the error of not referring Thomas for primary care follow-up is a one-off incident and does not represent a wider problem across its attending crews, especially regarding residential care facilities. It is recommended that the audit of this issue be presented to the clinical commissioning group along with any remedial action plan, should this be shown to be required.

Recommendation 4

Target audience: The adult safeguarding boards in the three districts Thomas resided in

The adult safeguarding boards in the three districts Thomas resided in need a process that provides evidence-based assurance that concerns about abuse are being appropriately responded to within and across local authority boundaries, including:

- capturing the voice of the service user
- an independent investigation process where clusters of concerns materialise in a single care facility

- more in-depth assessment of the overall approach to care where the volume of concerns being raised indicates this is required.

Furthermore, if there is a history of safeguarding concerns for an adult at risk, and he/she is placed with a new provider in a new authority, a system of reliable handover of information about the history needs to be achieved so that the newly responsible safeguarding team are situationally aware.

Recommendation 5

Target audience: The adult safeguarding boards, clinical commissioning groups and local authorities involved in this case

Thomas's experiences, and those of others highlighted in recent public reports including the Learning Disabilities Mortality Review Annual Report 2017 highlights a need for commissioners to review and reconsider in the current assurance mechanisms used to instil confidence that residential care providers are providing services that are legally compliant; safe, effective and of good quality. Furthermore, that Service Users are free from abuse of any kind.

Thomas's family did not consider that they were provided with any objective assurance of the above during his short adult life.

Devising a workable and sustainable system of assurance may well be challenging, as methods that enable the lived experience of residents to be captured is time consuming. Nevertheless, this cannot be used as a reason for not utilising approaches such as participant and non-participant observer studies². The author suggests this intervention could be used a few times a year, with additional interventions conducted if concerns about quality, safety, compliance or abuse are raised.

Recommendation 6

Target audience: The local and regional nursing teams of NHS England North
The medical and nursing director of the mental health trust involved

A full and validated account of the information provided to and shared by participants at a Mental Health Act review panel must be consistently achieved to avoid critical loss of important information about what was discussed and agreed at the time. This case has highlighted the dangers of not capturing this standard of record.

This and all mental health trusts are asked to consider the following, consider the extent to which they already do this, and if not consider implementing the below as a component of their plan to achieved the stated objective:

- ensure that notes and minutes taken by the hearing managers are scanned and saved alongside the final hearing report and decision made. The lack of

² This can be structured, unstructured, or a combination of both. What is important is the observer work is conducted on a regular basis and not as a 'one off'. The findings must be collated and reviewed over time. Furthermore, families and more able residents could be considered for inclusion as members of an observation team, alongside employees of a provider, and relevant health and social care professionals. Direct observation is a tried and tested quality and safety improvement tool.

retention of comprehensive minutes in this case required the firm of solicitors representing Thomas's father to retrieve those that the involved solicitor had made immediately prior to and during the meeting. These minutes created a different picture of events than the memory recall of the meeting chair.

Recommendation 7

Target audience: The local and regional nursing teams of NHS England North
The medical and nursing director of the mental health trust involved

When a mental health tribunal or managers hearing is convened, those responsible for convening the meeting must achieve a situation where all clinical and non-clinical staff who have a significant involvement in the situation giving rise to the hearing or meeting are asked to provide a written submission, or oral evidence at the hearing. In Thomas's case this did not happen. This resulted in an incomplete picture of the situation and removed the ability of the panel to properly consider its options regarding adjournment. The impact of this lack of situation awareness was stressful for Thomas, his family and all staff involved.

Recommendation 8

Target audience: The District Council, in Thomas's home town, its health partners and residential care providers

A service user's My Support Plan should be just that. This independent process identified that Thomas's My Support Plan was a document created by whichever agency was dominant in Thomas's care at the time. This did not lead to a plan of care that enabled Thomas, or his family, to provide input to the short-, medium- and long-term goals in a way that enabled them to be equal partners in his care planning.

Furthermore, issues such as achieving a long-term residential placement for Thomas in his home town, where he wanted to be, lacked cohesion and clarity. Whilst all agencies were committed to facilitating Thomas's return to his home town, how this was to be achieved and the timeframe for achieving this was not as clear for the family as it should have been. The District Council, in Thomas's home town, its health partners and residential care providers need to determine how the principle of the My Support Plan being truly representative of the needs and aspirations of the service user, can be achieved for individuals in receipt of multi-agency services.

In taking this forward, the District Council in, Thomas' home town, and its partners are also asked to consider how the agreed short-, medium- and long-term goals for an individual can be more concretely formulated within the My Support Plan, so progress with the plan can be accurately assessed and relevant adjustments made where necessary. This would assist in providing the transparency on process and progress that was missing for Thomas.

1 Introduction by the author

Thomas's case is by far the most complex I have undertaken in my professional career as an independent investigator to the NHS. This is partly because of the range of issues about which Thomas's family had concerns, the sheer volume of data Thomas's journey through NHS and care services had generated, and the challenges associated with conducting a historical review where memory has been lost, has faded or is fixed. Nevertheless, I hope that what has been achieved goes some way to ameliorating the sense of injustice Thomas's mother, in particular, felt following the death of her son. I also I hope that the review, and recommendations enable her and her family to feel the effort they made to achieve a review of Thomas's care and management has been worthwhile, even though it has not delivered everything they hoped for.

The information provided by Thomas's family, and that provided by the agencies involved in his care and management, has been used to address each of the agreed terms of reference, as far as it has been possible to do so. These are addressed in turn in the following sections of this report.

However, in brief, there are several issues that particularly struck me about Thomas's case.

The first factor is the complete lack of trust Thomas's family had in statutory services, and their anger at what they consider to have been a raw deal for their son.

The second factor is the deep impression Thomas made on all services with which he came into contact. This was partly because he was funny and engaging, and staff genuinely liked him. It was also because the magnitude and unpredictability of his behaviours were the most challenging staff reported having to deal with.

The third factor is the frustration experienced by Thomas's family, and by agencies, as a result of being unable to develop and sustain consistent and constructive relationships. All agencies, and Thomas's family, report periods of good and constructive working relationships. Thomas's social worker recalls many constructive conversations with his mother, and that there were several times when she assertively advocated for the family's viewpoint regarding Thomas. However, this was not always successful when there were the inevitable range of differing perspectives that emerge in a multi-agency, resource-constrained care environment. All parties also report periods where the relationship was difficult and lacking in unity. This became more notable towards the end of 2013 and then from March 2014, when Thomas was readmitted to the local mental health trust. This was in no small part contributed to by the lack of local residencies that would have been suitable for Thomas, the overall lack of providers with the necessary skills and competencies to be able to offer a workable community support package to Thomas, and the crisis points for Thomas that made achieving a community placement challenging. (See fourth factor.)

The fourth factor is the lack of social care and housing provision for people such as Thomas. There is no legislative requirement for town planners to factor in space for bespoke homes, or buildings, that are designed and constructed to meet the needs

of people with a spectrum of challenging behaviour disorders. This means that when people like Thomas require housing, not only does the right location need to be identified, but a house needs to be found that can be adapted so it can be made safe for the resident and those providing an ongoing package of support and care. A desirable timeline for achieving this is six months under planned conditions. This time, however, might not enable an appropriate package of support to be formulated. A more realistic timeline is 12 months.

The fifth factor is the lack of a transparent, documented, cohesive forward plan for Thomas that was signed up to by all involved agencies and that clearly set out the short-, medium- and long-term goals for him. Such a plan by default needed to:

- belong to Thomas and no single agency
- have target delivery dates clearly identified, accepting that these might need adjusting as the plan progressed, or because of Thomas's changing needs
- go with Thomas wherever he was being cared for.

The central agency in Thomas's case was adult social care. However, they did not 'hold the ring' when it came to care coordination and monitoring the progression of Thomas's plan. The dominant agency tended to be the one Thomas was residing with at any point, and each different agency developed its own 'My Support Plan' for Thomas. Although this seems to be 'normal' practice, the author of this report is not convinced that this approach delivers either optimal coordination or clarity for the family of young people like Thomas.

The sixth factor is the lack of a holistic investigation process following the many allegations of abuse that began to emerge shortly after Thomas's first admission to the local mental health trust through to December 2014. It is clear from documents the report author has reviewed that the allegations made at Norcott House and the concern Thomas's mother raised following her son's admission to the Teaching Hospital were taken very seriously and investigated extensively from a safeguarding perspective, and by the police. However, the majority of allegations were considered to be unsubstantiated. In these cases, there appeared to be an over-reliance on the findings of local management, without any independent check and challenge being instituted.

The author accepts that the volume of allegations made between the early summer of 2013 and December 2014 was challenging for all care providers, and that all were investigated in line with local management arrangements and with safeguarding requirements at the time. However, the inclusion of Thomas in this process, or the consideration of seeking independent oversight, seemed lacking to the report author and peer reviewers. The report author finds the over-reliance on the integrity of each reporting agency incomprehensible given the regularity with which concerns were being raised.

In addition to the points raised above, the initiating confidential inquiry and the Learning Disabilities Mortality Review Programme (2015 to 2018) are of relevance to this NHS England independent process. This is because:

- Thomas died of a treatable condition, and mistakes in his management meant he did not receive the treatment he needed

- his parents consider that neither NHS nor social care professionals listened to them
- his parents consider that without their perpetual contact with the staff at the care home, Thomas would not have been referred to the GP as frequently as he was, and no emergency help would have been sought on 29 January when they considered him to be very unwell (which he was)
- Thomas's parents believe that services consistently did not meet their son's needs – consequently, they consider that he did not enjoy the quality of life he should have done.

Thomas died before the Learning Disabilities Mortality Review Programme commenced in April 2015. However, this report will be shared with the programme lead at Bristol University so that its findings can be included in its analysis.

Further details about these programmes can be found in Appendix A.

2 Introduction from Thomas's Family

With any investigation, it is important to recognise the importance of input from the family. Thomas's family were integral to the decision to undertake the investigation, it would not have occurred without his mother's persistence. Furthermore, his family were pivotal to formulating the scope and boundaries of this investigation, including amendments necessary to these as the process unfolded.

This section of the report provides a brief insight regarding the perspective of Thomas's family. It was challenging to achieve a form of words that properly expressed the family feelings, so almost at the end of the process Thomas's mother, his elder sister and the author of this report met and recorded what it was Thomas's mother and sister wanted to say, and to have included in this report. The below is a distillation of their words. As far as possible the account is verbatim. Structural amendments made to the verbatim account were shared with Thomas's mother and elder sister prior to publication to ensure that the account remained true to what it was they wanted to say.

2.1 From Thomas's mother and elder sister

From his mother

"Thomas was the most beautiful son. In his younger years he was always happy. As his mother, I had a lot of high hopes for him. I wanted him to be independent, or semi-independent at least. Although I adore all my children, Thomas was the centre of my world. He was the first person I thought about in the morning, and when I went to bed, the last person I thought about. Not because I loved him more but because I worried about him more, and the protection instinct never went away. He was just beautiful. He was the most compassionate person that I knew. He was funny, and mischievous. However, from a very early age, you could sense that he was struggling with his environment. Nevertheless, he taught me much about compassion, patience, and love. One cuddle from Thomas and one stroke of the face by his of hands and you felt better immediately".

From his elder sister

"Thomas was an amazing brother. And any family would have been so lucky to have anybody like him. He was just so special. However, I felt that he was seen as a lesser person, but he was more special than anybody that I'd ever come across. The way I and my sisters would like him to be remembered is for the funny, mischievous little man he truly was.

Regarding his care over the years, as a family we all feel he was completely misunderstood. It did not seem that people took the time to get to know him as an individual. His behaviours in his adult life seemed to dominate perspectives about Thomas, and the complexity of his personality was not appreciated. It is in this way that we feel, he was perceived as a lesser person than 'you' and I.

Thomas as he grew up and needed more support and professional care – his mother's memories

"Thomas could be challenging throwing things at things, objects at other objects and taking curtains down because he didn't want them up. This could be difficult

at times, and some of his behaviours made me think he might have a form of autism. But he grew up and overall was doing well. He managed for a certain amount of time in a mainstream school until he got meningitis and then things changed dramatically for him. His anxieties were worse. He was still funny. He was still beautiful. He was still loving. But he was getting distressed more often. And then when he was fourteen there was an incident where we think he was given an overdose of medication. That's when I saw his first psychotic episode. Thomas was distressed by this, and he wasn't fully aware of what he was doing. However, watching him, I felt he had some awareness and tried to control himself. He was breaking things and hitting me but was completely distraught when he realised what he'd done.

Then his teenage years arrived with the expected hormone imbalances. His psychotic events were happening more regularly. But he was still our beautiful Thomas. I felt he was frustrated and his ability to communicate his frustration was limited, this did not help. As a family we struggled to know what to do, to help and support Thomas, in fact we struggled massively. The support we'd had until then seemed to diminish. Thomas's school pulled out. It felt like anybody that was involved with Thomas decided to pull away. This left me feeling abandoned, at a time Thomas's needs were increasing. I could not get Thomas to school, he decided he did not want to wear clothes, and I simply could not persuade him to dress. I came to the point where I couldn't do it on my own anymore. Therefore, Thomas's dad decided to take over. He did a great job, but despite his efforts, Thomas was pulling away from society. He seemed to pull away from the routines that are mundane and normal to most of us, such as hygiene routines. I felt he was not having a good life. He just wanted to watch TV or play computer games or listen to his music. He needed help. I wanted him to have a good quality life. It was at this point we decided to go to Social Services. Thomas was also assessed by a psychiatrist. I remember when Thomas was assessed it was very distressing for him, there were so many people. This must have been around 2011 as it was when Thomas was first detained in hospital. As hard as it was his father and I agreed with the decision, it seemed like the best option for Thomas at that time. It was very hard though watching your son being removed from his home.

First hospital and residential placement:

“Thomas wasn't happy in hospital, but they were trying their best with him. There reached a point where he could move from the hospital environment to a residential setting. The plan was for this to be Thomas's home until everyone thought he could live more independently. However, this did not work out. Thomas was unhappy. He wanted nothing but to be home with his family. Initially he was doing okay but he never saw it as his home. He saw it as a hospital. Sadly, there were allegations of abuse. Thomas' behaviour changed immensely at this time. He'd never been violent or aggressive towards any individual, but he started to behave in this way, and as a family we felt something was very wrong. There were marks and bruises on him. Eventually there were whistle blowers who reported an incident of abuse. The care provider dealt with that, and the bad apples were sacked. I wanted Thomas to stay there as it was his home, and I thought he would settle again with support. However, he clearly did not want to be there. And the provider thought he was deteriorating again and needed

hospitalisation, but not with them. It was tough, as there were not many options and following a brief period of Thomas's dad trying to support Thomas at home, he was admitted to the local NHS mental health facility. We had never wanted this for our son".

Mental Health admissions

First admission

"I didn't think Thomas' life could get any worse, but it did. His behaviours deteriorated beyond anything we recognised as a family while he was in the NHS assessment and treatment unit. To us it seemed that Thomas was protesting loudly about where he was. I felt that I was seeing and reading about a different person than the son I knew. It was heart rending. Some of the described behaviours I've never witnessed. Not at any time right up until the day he died. I am convinced staff did not know how to support him and that he was over-medicated because of this. I felt Thomas was scared. He was frightened. I do not think this was fully appreciated, or appropriately responded to by the professionals. To me he was still my beautiful boy and I felt a strong need to try and protect him. Even so, throughout all the trauma he was experiencing Thomas managed to demonstrate to us, as a family, that he remained the kind, sensitive, compassionate individual we knew."

Thomas had a remarkable strength of character, as his mother I considered "it was outstanding. How he could possibly go through all that trauma and frustration and be taken away from his family and still care and be so concerned about how we were dealing with it. I've never met a more beautiful person ever".

"Everybody agreed that he shouldn't be in the NHS unit, it simply was not the right place for him. We strived to get Thomas out and back home and we succeeded. He went to his dad's, which I think we all knew would not work in the medium or long term. But, we had to pull together as a family and help each other out. That was difficult, and it just didn't work. I believe Thomas' previous trauma had been too much. It is a firm belief of mine that if Thomas had been labelled as distressed instead of challenging, carers and professionals may have gone in with a more sympathetic attitude rather than the approach I feel they had. If you read all the paperwork about Thomas' behaviours, it feels negative. It was tough for the staff, but at the end of the day Thomas needed care, support, comfort and love. I do not believe Thomas was challenging anybody. He was simply the most distressed, scared and vulnerable person I've ever witnessed. Watching him deteriorate, watching his fear and being powerless to do anything to make a difference has been the most painful experience. The desire for him to have a happy life became a dominant force in all my interactions with carers, especially if I felt things were 'not right'".

Second admission

When things did not work out at Thomas's dad's, Thomas was readmitted to the NHS care facility under the Mental Health Act. It was very frustrating. "Everybody had always agreed that Thomas needed to be on his own in his own house with a good care team around him. That was everybody's opinion. But it never materialised. There were promises. There were discussions. But nothing ever moved further forward. It was like he and we were stuck. And then there was a

plan to move him to a different secure unit. It was 150 miles away – that simply could not happen. As his mother I did not believe Thomas would cope with that. Absolutely not. Thomas lived for, and loved seeing his family, that distance would prevent that. We challenged it, there was a Mental Health Act managers hearing and thankfully they discharged Thomas from his detention. This meant he could not be sent away from us. The managers also said Thomas should have a community care package in three days. I was filled with hope and trepidation”. The care package did not materialise.

“I didn't believe the local authority were looking into everything as I wanted it to be looked into. I didn't think they'd thoroughly checked every care provider within the local vicinity. And I still don't believe that to this day.

Events overtook us all and Thomas was sent to a residential care home more than 40 miles from home. It was a carbon copy, building-wise, of [the residence he was abused in]. The staff were untrained as far as I could tell – they couldn't do Makaton, in my opinion, and I saw little effort in this with my son. The furniture wasn't autism-friendly, and the place, it just wasn't suitable. I fought very hard against that and I lost that battle at the Court of Protection”

Final placement

This last residential care home was where my son collapsed in the days before he died. When he first went there “I tried my best to work with the professionals but in a matter of weeks it was worse than I even feared. They were a very young staff including a couple of nice ones, but Thomas was seen as challenging from very early on. The staff did not know Thomas. They knew nothing about the person he was or what he'd been through or who he needed in his life. And then, I felt, it became a battle again - it felt like a battle of wills. All I wanted was for Thomas to be cared for. Not kept like a prince, but to be cared for adequately. To be given safety, hygiene and some love. He didn't get any of that in my opinion. When I voiced my concerns both to the [local authority, CQC, the care home provider, the previous local authority], I was met with hostility. And then came quite serious allegations of abuse from Thomas himself, and which I absolutely believed. He was looking unwell. There were infections. He wasn't being cared for in the sun. He wasn't getting infections treated. He wasn't even, at a GP for a while”. “I felt I had to enquire about and push for everything. Nothing seemed to go as it should, registering with the new GP, Thomas being seen by his new Psychiatrist. Nothing went to plan, and I had to interfere to get things sorted out. It was hard work, and just kept getting worse. Thomas's father felt the same. We were so worried for our son. I felt again, Thomas was scared, and he was ringing me, and other family members up. These are the memories that haunt me. Memories of trying to find out what was happening with my son and being met with hostility. No family, no mother should have those as her last memories of her son's life”.

Thoughts at the end of this review and what needs to change

Attitudes:

Thomas's mother said, "What [Thomas's sister] said about Thomas been seen as a lesser person or as inhuman [I agree with]. For example, when the first proven abuse happened, incidentally, the only proven abuse, nobody ever spoke to Thomas. Nobody ever spoke to us. The court case happened without anything from any of us". That was and remains outrageous. That situation would not happen to you or I. "Treat people with a learning disability as you would treat anyone else", has to become the baseline of how all agencies work.

Listen to the family:

"We did know Thomas. We loved him and wanted to protect him more than anybody. And we were just seen as trouble makers because we wanted to stand up for him. He was not taken seriously when he raised concerns. [People seemed to think he lied]. But Thomas, in our experience, never lied about anything".

Allegations of abuse:

"Every allegation needs to be investigated. It's not good enough that managers and professionals 'in-house' deal with reoccurring incidents. There needs to be a fresh pair of eyes. Somebody needs to come in. Someone needs to speak with the person who is/may be being abused. This did not happen for Thomas. It should have done. Furthermore bringing in independence should not be wait for the 4th, 5th 6th abuse concern, but after two to three concerns are raised, no more."

Advocates:

"Advocates must advocate for the person they represent and properly present the vulnerable persons perspective - rather than what they, the advocate, thinks." Also, family advocates, must be independent of the service delivering the care". We were offered an advocate employed by the NHS facility caring for Thomas! Independence in the advocacy role is vital for all vulnerable adults and their families.

Medication:

"In residential care and in the hospital setting, the use of anti-psychotic drugs for autism needs to change. The first line of defence, in our experience, was drugs. "We don't know what his problem is. We don't know what's wrong with him. But let's throw an anti-psychotic at him." Thomas wasn't mentally ill. He may have been suffering post-traumatic stress at the beginning, definitely towards the end and this needed therapy not drugs."

Better alternatives to hospital admission:

"Somehow to strengthen and improve community care with better qualified care staff, better provision of safe independent living accommodation. Allow families to assist in sourcing something suitable and allow them to be part of the care package, especially during a transitional period". Thomas's case completely underlines the need for this.

Care planning:

“Families must be invited to be involved in developing care plans for the person who requires care in their family. Invite families to the care planning table, allow families to be equal partners in care if they want to be”.

Recommendations emerging from initiatives such as Improving Lives:

“Someone needs to make sure they happen. They were not all implemented for Thomas. This feels unacceptable”.

CCTV:

“As part of care without abuse, could not public areas be covered by CCTV?”

Training for the Police:

“Thomas has had some quite distressing turns so has been taken in an ambulance on occasion, but I've never come across a paramedic who wasn't absolutely amazing. The police on the other hand did not know how to handle someone like Thomas. As a mother of a child with Downs, and Autism, I never, ever want to see someone as vulnerable and as distressed as Thomas to be carted off in the back of a police car in handcuffs and leg restraints. That should not happen. That absolutely should not happen”.

Final words and thoughts

“I simply don't want anybody else to die in the horrible, horrendous way that Thomas did, and I don't want anybody else to have to live like he did either”.

3 Terms of reference

3.1 Key lines of enquiry

The key lines of enquiry were agreed on 20 October, following a half-day meeting with Thomas's mother and two sisters. The detail was agreed so that, throughout the review process, the independent review team could remain mindful of the issues that Thomas's family wished to learn about. The scope was aspirational given the passage of time between Thomas's transition from children to adult services, his untimely death, and the year the review commenced.

What was not fully appreciated by NHS England, or Consequence UK at the time it initially agreed the scope of the review, was the sheer volume of information about Thomas, and the complexity his case posed.

Consequently, a balance was required between trying to meet the needs of Thomas's family, and appropriate expenditure on the review process in consideration of the learning and improvement opportunities. Clarity about the areas the review team needed to focus on was established once it had a comprehensive understanding of Thomas's late teenage and early adult life. This was achieved in February/March 2017, when it became clear that the greatest learning opportunities to be obtained were between March 2013 and the time of Thomas's death in February 2015. The methodology utilised to achieve this clarity is set out in Appendix B

The initial key lines of enquiry were:

1. To set out a historical perspective of Thomas's contact with agencies prior to the age of 14, so that the analysis of his management from the age of 14, and his behaviour patterns, are set against the context of his long-term needs.
2. The period of transition from children into adult services. The intent of this is to review the entirety of Thomas's transition from children to adult services, and not simply the handover from children's services to adult services³. It is considered important that there is an accurate understanding of the planning and provision for his physical, psychological, emotional and daily living needs. The groundwork for this would have commenced from the age of 14 and culminated with the handover from children to adult services. It will have set the foundation for his adult care. Specific reference is made to:
 - a. the process that was followed
 - b. information that was collated by the transition team, and passed on to the first adult service
 - c. qualification/quantification of Thomas's needs
 - d. the support structure for Thomas's mum and dad over this period, and the support during transition.
3. The first Mental Health Act assessment in 2011 when Thomas was 17 years old. The family do not question that this was necessary; they all agree it was

³ At the time these terms of reference were agreed it was not known that Thomas's case was taken by the transitions team, who retained caseload responsibility for Thomas throughout his adult life.

in Thomas's best interests. However, the way it was conducted is still an upsetting memory. Of interest is:

- a. the knowledge and experience of those involved in working with individuals with communication difficulties such as Thomas
 - b. where communication issues are known, is there provision of specialists to work with the individual being assessed (and detained) so that it is less traumatic (what was the situation then, what is it now)?
 - c. how Mental Health Act assessments are managed now for people with learning difficulties, autistic spectrum disorders and Asperger's, where there are recognised communication challenges.
4. Thomas's time at Woodside and Norcott House. Specifically:
- a. To explore why Thomas was placed at Woodside Hospital, and not an NHS facility, during his period of detention under the Mental Health Act.
 - b. Allegation of abuse towards Thomas made by a staff member.
 - c. Continued reports by Thomas to his family of abusive behaviour by staff, and the family's concern they were ignored.
 - d. Requiring Thomas to share his accommodation space with someone else, who was not of his choice, at Norcott House. Was this necessary and/or avoidable? Do people requiring care have any right to choose who they share their day-to-day living space with?
 - e. The entire episode at Norcott House is of concern to Thomas's family. In addition to abuse suffered by Thomas, the family assert that it was only during this episode that Thomas became abusive towards others; the family are aware that he could destroy property, as they have first-hand experience of this, but he didn't usually attack people.
 - f. There was a confirmed allegation and a criminal case proceeded as a consequence. It was at this point that his mother went to the press; she feels that as a consequence her son was asked to leave Norcott House. Was this true? What was the rationale?
 - g. The family do not believe the support provided to Thomas after the confirmed abuse enabled him to process what had happened to him. What additional help was provided to enable him to process this? If none, why not, and what should have been provided to an abuse victim in care, to minimise ongoing psychological impact?
5. The local mental health trust. There are several key issues for Thomas's family, as follows:
- a. Thomas had two admissions to the trust's assessment and treatment unit
 - b. Medication management and sedation – was the range of medication reasonable and necessary?
 - c. Again, allegations of abuse/unkind care were made by Thomas; he was reportedly terrified of one member of staff, and one family member reports witnessing disrespectful behaviour by this person towards Thomas in her presence (mocking him because he could not articulate her name).
 - d. The management of Thomas's physical health, including the:
 - i. assessment of his health needs
 - ii. health action planning
 - iii. management of any periods of physical ill health
 - iv. management of the episode where he contracted pneumonia.

- e. The findings of the Mental Health Act manager's hearings and whether their recommendations were acted on.
- f. The management of psychological trauma following his abuse in Norcott House while at the local mental health trust. What provision was made for Thomas to receive the psychological input required to support him in managing past emotional traumas, and also the trauma of the abuse he had experienced?
- g. The discharge planning for Thomas from the assessment and treatment unit (ATU) to family accommodation, and the handover from ATU to the care home provider when Thomas was admitted to one of their facilities.

(The following points are relevant only to Thomas's last admission to ATU)

- h. Prior to the July 2014 Court of Protection order, in May 2014 Thomas's mother and father exercised their legal right to seek a 'nearest relative' discharge under the Mental Health Act. The motivation for this was their concern that the trust was going to place their son in a secure unit many miles from his home town. Consequently, a Mental Health Tribunal managers' hearing was convened. This concluded that Thomas's continued detention was unlawful, and that the mental health trust had three days to find a suitable and local placement for Thomas. These timescales were unrealistic, and Thomas's mother raised concerns with the solicitor representing Thomas's father about this immediately after the hearing. Therefore, there is a need to:
 - i. explore all perspectives of this episode
 - ii. consider whether the situation could have been managed differently
 - iii. understand how the distress of Thomas's parents was managed (and recognised), and how support was provided to Thomas's parents.
- i. The circumstances leading to the Court of Protection order, and consideration of whether things could have been managed differently, avoiding this situation. In so doing to explore:
 - i. The use of the Mental Health Act and Mental Capacity Act to inform the Court of Protection's decision-making and improve Thomas's life.
 - ii. What facilities were available within Thomas's home town that could have met Thomas's needs, and whether these were considered as options for him
 - iii. What facilities were considered within a 30-mile radius of Thomas's home town (and beyond), and how many were suitable. If there was a provider that could offer the right service for Thomas locally, why was it not utilised?
 - iv. How were funding issues considered? Were there any restrictions on what facilities could be funded, and, if so, did this mean that more local provision was excluded?
 - v. The mental health trust are reported to have told the Court of Protection hearing that if Thomas was not moved, then they would be closing the unit to new admissions. What was the circumstance of this? Was it a reasonable statement to make, and did this unduly

influence the Court of Protection in its decision-making rather than the dominant influence being Thomas's wellbeing and needs?

- j. Consideration of where to place Thomas once the ATU was no longer an option; finding a residential facility for Thomas that was right for him, and acceptable to his family, is recognised as having been a challenge. The family are concerned that sufficient efforts were not taken, and that suitable opportunities within Thomas's home town were not optimised. Specific issues for Thomas's family are:
 - i. The family believe that a suitable healthcare provider had been identified as a potential provider and backed out suddenly. Why?
 - ii. The family had contact with another independently sourced provider, who had constructed a package locally for Thomas that the family supported; it would have taken six months to put in place. Was there no scope for planning a temporary solution while this was done?
 - iii. Why the care home? The family wish to understand why the authorities considered this was the right place for Thomas. They believe much was promised that was not delivered.
6. Thomas's time at the care home is of specific interest because Thomas was a resident at this facility at the time of his collapse, in the days immediately prior to his death. Thomas's family had high expectations of this residential facility and they feel that they, and Thomas, were let down. A key concern is the length of time he resided there, when it was meant to be an interim measure. Specific concerns are:
- a. The handover from the assessment unit to the care home.
 - b. Key elements of Thomas's care package:
 - i. how much was in place before Thomas went to the care home (the state of preparedness for Thomas)?
 - ii. funding considerations and the scope of care package required
 - iii. GP cover and Thomas's needs
 - iv. physical health assessment, planning, and awareness at the care home of Thomas's physical health needs and vulnerabilities
 - v. diet management and choice – use of picture cards
 - vi. skills and experience of staff in working with autistic spectrum disorder patients
 - vii. how did the care home provider ensure that there was always a member of staff on duty who could communicate with Thomas, or at least knew how to communicate effectively with him?
 - viii. staff whom Thomas did not get on with – how was this managed by the care home?
 - ix. use of agency staff unskilled in dealing with autism – how often were agency workers caring for Thomas?
 - x. of the staff employed by the care home provider, what was their skill, knowledge and experience in the field of learning disabilities, autistic spectrum disorders and challenging behaviour, and what specialist training was provided to them (in the context of residential care provision)?

- xi. physical health surveillance, including medication management – how was Thomas’s physical health monitored, and was this reasonable?
 - xii. specifically, the oversight and management of Thomas’s health in the two weeks preceding his death
 - xiii. management of psychological trauma following his abuse in a previous residential care facility – how was Thomas helped to deal with the trauma of abuse?
 - xiv. what was the plan to get him back to his home town prior to his death?
- c. Regarding Thomas’s complaints of abuse:
- i. How were these investigated by the care home provider?
 - ii. To what extent were the complaints explored with Thomas himself, and by whom?
 - iii. How did the care home provider satisfy itself that ‘its staff’ were being wholly truthful, and that Thomas was ‘wholly fabricating’? The family do not believe that Thomas’s complaints were taken seriously, or investigated appropriately, by the care home provider or the relevant safeguarding adults team at the local authority.
- d. The overall decline in Thomas’s behaviours. His mother wanted an MRI, as she felt there was more to his decline than staff thought. It is the understanding of Thomas’s mother that the post-mortem revealed signs of early onset dementia; she wants to know why no one considered early onset dementia.
- e. If there had been a wider range of consideration of organic reasons for Thomas’s deterioration, and this had been diagnosed prior to his death, what difference would it have made to his management?
- f. In the last weeks of Thomas’s life (from the end of January 2015), there was concern about his physical health. It is known that the care home provider contacted:
- i. Thomas’s GP practice
 - ii. The local ambulance service
 - iii. 111
 - iv. Out-of-hours service.
- Was the care provided appropriate?
7. On 2 February 2015, he collapsed and was transported to hospital where he died on 4 February 2015. Because of the unexpected and sudden deterioration in Thomas’s health, the independent process must establish whether:
- a. there was appropriate surveillance and attention given to Thomas’s physical health over this time
 - b. the care home took the right actions, in a timely manner
 - c. those services that the care home approached for assistance and expert advice:
 - i. responded appropriately

- ii. undertook a reasonable assessment of Thomas
- iii. made reasonable treatment decisions.

8. Once Thomas was admitted to hospital, was his care and treatment reasonable and in keeping with the expected care pathway and standards at the time?

3.2 Specific safeguarding relevance

This case is of specific safeguarding relevance. Thomas was known to make a range of allegations towards staff caring for him and his family, which were largely considered to be untrue. However, the fact is he was treated abusively on at least two occasions; his family are concerned that agencies were too quick to discount Thomas's allegations, and that there may have been more occasions than were recognised. Now that Thomas has died, exploring the veracity of this is not possible. However, what can be explored is:

- each agency's response to Thomas's allegations of ill treatment; specifically, how each allegation was captured and explored to come to a determination that the allegation had no substance
- the response of the safeguarding services in the local councils in which he lived
- how the testimony of Thomas was collected following each allegation and who this was obtained by
- how the concerns of Thomas's parents regarding actual/possible abuse of their son were captured, considered and treated.

4 Overview of Thomas's life

This section contains an overview of Thomas's treatment and the major events that affected him. The period 2008 – 2011 is included so the context of his young adult life can be contextualised.

4.1 2008 to 2011

Prior to 2011, Thomas was mainly cared for by his mother, with his father providing additional care in his later teenage years and prior to his first admission to hospital; according to the family GP, both parents did a great job with Thomas.

During his time with each of his parents, Thomas and his parents were supported by the specialist disability team in children's social care. Thomas had an allocated social worker, and his parents were supported in the form of short respite breaks; these, however, were frequently too short in duration to provide meaningful respite. He was also under a consultant in child and adolescent psychiatry, and review meetings were held between this individual and Thomas's social care team.

Thomas also received an extensive range of local resources to enable him to remain at home; these included family-based respite care, residential respite care, community behavioural support and residential behavioural support.

As Thomas got older, his behaviours changed; he became more difficult for his mother to manage on her own. During his mid-teenage years, it became clear that local schools were struggling to meet Thomas's educational needs; formal education completely broke down when he refused to leave his home. Neither his mother nor his father could get him to go to school. Therefore, education provided an alternative agency package; this also broke down due to the risks Thomas posed to staff.

It was the perspective of Thomas's mother that her son required full-time residential care. Thomas's father didn't want this to happen and was willing to take over care responsibilities; this is what happened until Thomas was admitted to an independent hospital, under section 2 of the Mental Health Act, in 2011.

4.2 The Independent Hospital

Thomas was admitted to hospital on 13 June 2011 and transferred to a linked residential care facility on 26 March 2012. On admission, it was acknowledged that, in Thomas's best interests, he would require firm and consistent boundaries, as well as the likely requirement for sedation or tranquilisation to manage his anxiety, and to keep him and others safe. It was accepted by all that admission under the Mental Health Act was the only realistic option.

A care plan was agreed, relating to what was expected of Thomas, his room and family contact. For example, he was expected to be clothed before leaving his room, he was only allowed drinks in his room, and family contact was to be structured and scheduled to predetermined times. The care plan was agreed by everyone, and Thomas's family appeared to have a very good understanding of the proposed boundaries. It was also agreed that it was important to maintain good communication to ensure the care plan was not undermined during times of anxiety.

Overall, Thomas's time in hospital was one of improvement. His challenging behaviour reduced (with the assistance of risperidone), and he improved his socialisation, making community visits with his family. While there was improvement, Thomas's challenging behaviours remained, and he remained unpredictable and a risk to both himself and others. There were also instances where Thomas had hurt himself, with his parents raising concern about how this had come about. These concerns were investigated by the management team, and although there was one allegation of misconduct by a member of staff towards Thomas, which was made by colleagues, there is no evidence to suggest any harm was caused to him during the period between June 2011 and March 2012.

4.3 The Linked Residential Care Facility

Because of the sustained improvements in Thomas, he moved to a residential care facility within the same independent group, on 26 March 2012. The plan was for Thomas to continue improving and to move into his own independent accommodation when he was ready. His residency there did not go as well as hoped. As early as June 2012, Thomas's family were raising concerns about staff's interactions with him; these allegations were investigated by the management and none were substantiated.

In March 2013, there was a concern raised by staff about the actions of two other staff members when attending to Thomas (on 5 March 2013), involving inappropriate handling of Thomas, bending back of his fingers, an alleged kick, inappropriate language used towards Thomas, and inappropriate restraint techniques. Both staff members involved were dismissed, and independent safeguarding authority referrals⁴ were made. Furthermore, one of the staff involved received a suspended jail sentence and 200 hours of community service.

This incident proved to be damaging to Thomas, impacting on his sense of fearfulness, his family's ability to trust care providers and the ability of future providers to build a relationship of trust with Thomas's family; this had a significant and negative impact on the ability of all concerned to communicate constructively around Thomas's needs and best interests.

Following the assault on Thomas, his father took him to live back at home with him. Thomas was not well at the time, and all parties recognised that he may require a further period of stabilisation in hospital. The then providers of the service at the hospital did not consider it appropriate that he returned there because of the assault incident. Other private providers were considered, but were either unable to admit Thomas, or were considered to be too far from his family. Admission to the mental health facility as the nearest facility was, therefore, explored and encouraged.

Up to the point of the assault, Thomas's time at the residential care facility was a continuation of his time at home and in hospital. His behaviours fluctuated, with a general pattern emerging around visits from or to his family, which he enjoyed and looked forward to. Throughout this time, Thomas's parents kept a close watch on his health and wellbeing, raising concerns as they felt necessary; the management at the residential care facility responded to these concerns promptly and properly.

⁴ <http://www.scie-socialcareonline.org.uk/isa-referral-guidance/r/a11G00000181V9IAI>

After the assault, it was recognised that the residential care facility and its staff had done their best, but it was the wrong environment for Thomas, and he needed a hospital admission. This was first recognised by his consultant psychiatrist, with other agencies in agreement. It took a home-stay visit with his father before Thomas's parents agreed; the assault on Thomas drastically affected their faith in residential and hospital services.

A Mental Health Act assessment was carried out on 9 April 2013 and Thomas was transported to the mental health trust via ambulance without issue.

4.4 The Mental Health Trust – First admission

Thomas was admitted to the assessment and treatment unit (ATU) under section 2 of the Mental Health Act. This was not Thomas's parents' optimal choice; unfortunately, there was no optimal provider in the vicinity.

The assessment and treatment staff recognised early in Thomas's admission that their physical environment was not right for him. The unit is bright and airy but lacks outdoor space, and Thomas needed space. There are a range of relaxation areas within the unit, but, again, Thomas did not like sharing his space; this environment, when full, could be unsettling for him, and likely to exacerbate risk exposure for Thomas and the other residents.

During this stay on the ATU, there were regular Care Programme Approach meetings about Thomas and his needs. Various issues were discussed, including medications, his accusations against staff and his need for assessment from the speech and language team, to assess his dysphagia. He was also seen by his consultant psychiatrist.

Unfortunately, his behaviours deteriorated. He is reported to have been at risk of self-injury, self-neglect, damage to the environment, cramming food in his mouth, inappropriate sexual behaviour, and aggression to staff. There were only occasional days when all or some of these behaviours were absent.

Also, during Thomas's time on the ATU, his family had concerns about his safety, reporting on various occasions that he was being abused; one report alleged that he was being abused at night. These, and Thomas's own allegations, were investigated, and the family was advised and reassured there was no evidence of any abuse; they were also informed of the staffing routine used for Thomas to limit staff exposure.

Although staff appreciated that Thomas's parents were central to an effective and successful care episode, the relationship between the unit and Thomas's parents was not smooth from the moment he arrived. Their anxiety about possible further abuse of their son, and their subsequent distrust of organised care, dominated. When Thomas was admitted, his parents were already of the mindset that the unit was not the right place for their son. Nevertheless, his mother recalls an initial good relationship with the ward manager. However, the escalation in their son's behaviour, the extent to which medication had to be used to try to control those behaviours and his accusations against staff of abuse did nothing to build their confidence.

Throughout Thomas's time on the ATU, community care packages were being sought, as everyone involved felt this would better suit Thomas. Due to his declining behaviours and the risks they posed, no suitable provider could be found, with Grays Healthcare being the last provider to withdraw due to the risks.

At the start of August 2013, Thomas's father applied for a nearest relative discharge of Thomas. A professionals meeting was held at which it was identified that a community care package was unlikely to be able to mitigate the risks associated with Thomas's behaviours, and that he continued to require hospital placement, but the ATU was the wrong environment for him; the plan was for specialist hospitals to be identified that could manage Thomas's behaviours. Thomas's consultant psychiatrist eventually issued a barring order preventing Thomas's discharge.

A Mental Health Act managers' meeting was held about Thomas's continued detention. The result was that he was allowed to return to live with his father (who agreed to section 17 conditions), while maintaining his detained status. This was to be reviewed on a weekly basis and was thought to be the best situation for Thomas, as being in the ATU was leading to deteriorating behaviours.

Although everyone was working towards what they believed to be Thomas's best interests (parents and staff), the work of the occupational therapist who undertook an insightful sensory assessment of Thomas is noteworthy. She provided the only structured, psychologically focused formulation for him prior to 2014.

4.5 Period at home and events leading to second admission to the ATU

On 5 September 2013, following periods of leave that had gone well, Thomas went home with his father. A record made by the occupational therapist four days later indicated that the transition went well and things seemed to be going OK for Thomas and his father at home.

The first five months of Thomas's return went reasonably well. There were challenges and frustrations, some linked to financial support, but, mostly, having Thomas at home was manageable.

From February 2014, the situation began to break down. The trigger was linked to issues with the behaviour of their neighbours, a problem that started in November 2013. Thomas required restraint at home, as he was banging his head and there was a real risk he would badly harm himself; his parents and a police officer were required to perform the restraint. Thomas's social worker also attended and, after assessing the situation, contacted the ATU to determine what medications could be used and whether there was an inpatient bed available; unfortunately, the unit was full.

Thomas continued to bang his head over the next three days, and over the course of the next two weeks he became increasingly more difficult to look after; his parents struggled to cope and called for police assistance on two occasions. A number of meetings were held to discuss how Thomas could be best treated, and various topics were discussed, including Thomas's medication, how to manage his behaviour and the provision of a support package for Thomas to stay in the community.

A Mental Health Act assessment was also discussed and Thomas was assessed on two occasions. The first, on 10 March 2014, concluded that it would not be in Thomas's best interests to be detained. This also took into account Thomas's parents' objection to hospitalisation, and the plan was for Thomas to remain in the care of his father with increased medication.

A multidisciplinary team meeting the following day discussed various issues relating to Thomas, resulting in appropriate medication being prescribed by Thomas's consultant psychiatrist, as well as section 2 papers being completed and left with Thomas's social worker. This course of action was taken as Thomas's parents didn't agree with admitting Thomas to the ATU; however, a Band 8 nurse was tasked with planning for his admission, should it be required.

In the period between assessments, on 12 March 2014, the emergency duty team was contacted by the learning disability support team because of a medical necessity for admission, initiated by Thomas's mother, who was concerned about his laboured breathing. Thomas's consultant psychiatrist believed he should now be in hospital, as provision of medication was not consistent and the process of monitoring his health was failing; this was communicated to Thomas's father. A bed was organised for Thomas in hospital, but Thomas's father did not wish for any further disturbances that night, and Thomas's mother did not want him going into hospital. It was agreed that the team would call Thomas's father the following morning.

Thomas was visited by learning disability professionals for the next two days, to monitor his health, which was accomplished without any problems. Thomas then deteriorated on 14 March 2014 and had to be taken to the local accident and emergency department by his father. He was later discharged. After taking medication, Thomas appeared to settle, and it was agreed that an assessment was not required that evening.

The following day, Thomas was again taken to accident and emergency and a Mental Health Act assessment was undertaken. Application was made under section 2 of the Mental Health Act and Thomas was readmitted to the ATU.

4.6 The Mental Health Trust – Second admission

Thomas was readmitted to the ATU under emergency conditions. Neither his parents nor the unit considered the unit to be the right care environment for him; however, it was the best on offer under the circumstances. The plan was to find somewhere more suitable for him on an 'as soon as possible' basis.

Thomas's behaviours during this period of admission to the ATU differed very little from his previous admission. He still exhibited extreme, challenging and complex behaviours, damaged property, and made allegations against staff. There was the ever-present concern about his risk of choking and aspiration, and there were concerns that the medication combinations being used to calm Thomas were coming close to constituting 'rapid tranquilisation'. Nobody was happy about this situation, but it was required due to the lack of impact other medication had on him.

A new behaviour also emerged: Thomas started making allegations of assault against other residents, which staff thought seemed to be because of unseen stimuli in the corridor.

By this point, the faith Thomas's parents had in the ATU was at rock bottom. Inevitably, this affected their interactions with staff and the credibility they attributed to the information staff provided about various topics associated with Thomas, including assurances about the lack of abuse, safeguarding, medication, nutrition, hydration, dysphagia management and provision of activities for Thomas. It is highly likely that they passed this distrust on, in part at least, to Thomas. This created an impossible situation for everyone.

Thomas's parents continued to raise concerns where appropriate. For example, they were concerned about the side effects of the medication Thomas was taking, and they continued to raise concerns about abuse of Thomas, specifically at a clinical review. Thomas's mother was asked to make a formal complaint, as the allegations had been investigated, with no evidence of abuse being found. The advice of the local safeguarding team was sought, and despite not recommending a referral, they advised that Thomas's mother could make a referral if she wished. She was informed of this by letter, which advised her how to do it.

Psychological input was provided indirectly to Thomas, via the staff, and to his parents. The purpose was to assist staff in understanding Thomas's behaviour from a psychological perspective, and thus make his management more 'psychologically informed'. Support was also provided to staff in the way of mindfulness sessions and formulation sessions, and group supervision was also provided. With Thomas's parents, the aims were to provide emotional support, to improve relationships and communication between them and the staff, and to begin to formulate solutions to Thomas's difficulties. Direct intervention was deemed inappropriate due to the unsettled and uncertain nature of Thomas's placement.

Thomas's medication was continually monitored and adjusted during his admission, and his care coordinator continued to search for a placement. Two possible placements were identified, and funding was also confirmed. Thomas's care coordinator was informed by the deputy director of specialist inpatient services, dental services and clinical administration services that Thomas should be moved to a secure provider, some considerable distance from Thomas's home town, within two days, as they considered the risk Thomas presented to himself, staff and others meant he needed to go as soon as a bed became available.

The care coordinator advised that there had been no inspection of the facilities, as per normal good practice, and that there were concerns about how Thomas's family would take news of the decision. The decision to move Thomas was reiterated and a bed was confirmed to be available from 19 May 2014.

On hearing the decision, Thomas's father exercised his rights as nearest relative under the Mental Health Act and sought a discharge of Thomas from his detention under section 3 of the act. The letter seeking discharge, we believe, stated that he was applying for Thomas to be discharged home with a package of home support until a bespoke community support package could be arranged for him in his own

accommodation. A barring order was issued by Thomas's consultant psychiatrist and the case went to a Mental Health Act managers' hearing on 20 May 2014, where a decision was made to discharge Thomas from his detention.

The mental health trust was given three days to organise a community care package for Thomas. He was to be discharged from his detention under the Mental Health Act on 23 May 2014.

The professionals caring for Thomas, and the solicitor representing Thomas's father, were astounded by the decision. It was their professional belief that Thomas required ongoing care and treatment in hospital, but not in the ATU.

4.7 Events leading up to Thomas's admission to his second residential care home

Thomas was discharged from the Mental Health Act on 23 May 2014 as legally required. He was held on the ATU on a best-interests basis while an appropriate package of support was sourced. Various legal mechanisms were attempted to ensure the safety of everyone on the unit; the Mental Capacity Act, Best Interests, and a least restrictive approach were all used to manage Thomas's challenging behaviours (restraint and medication would still be required until a placement was found).

The main problem the staff encountered was that Thomas lacked the capacity to say where he wanted to live and understand the consequences or implications of this. He wanted to live with his father, but this was not a feasible option. This was exemplified by a series of assessments carried out by the speech and language team, which showed that Thomas could understand his housing options but not his support package requirements; could sort pictures into safe and dangerous and could recognise pictures of his mother's and father's houses; had some understanding of abstract concepts of safe and dangerous but was not able to identify what these might be in different places or the support he required; and had a lack of understanding about court processes.

As Thomas was no longer being treated under the Mental Health Act, and the care team had no powers to maintain him in hospital, an urgent Deprivation of Liberty Safeguards application was made. The application provided a seven-day respite period to enable Thomas to be supported as an inpatient and to prevent him from leaving the unit. The application was subsequently denied, as the independent doctor assessed that Thomas did not meet the threshold for Deprivation of Liberty Safeguards. As a result, Thomas was placed on a section 5(2) of the Mental Health Act for 72 hours.

It was agreed with his mother that an application would be made to the Court of Protection requesting that Thomas remained on the ATU in the short term, while an alternative residence and package of care was achieved. The application was made to the Court of Protection to declare Thomas's proposed care plan in his best interests.

At this time, Thomas's parents requested specialist review of medication, including an ECG⁵ and MRI⁶ to ensure there were no physical health reasons for Thomas's behaviours. A referral for an ECG and MRI was agreed, although a radiographer who had previous experience with Thomas subsequently noted that sedation may be required to carry out the procedure. The need for an MRI was questioned by clinicians, especially the radiologist, who advised that there was a lack of clinical justification for the procedure, as Thomas's CT scan was normal. It was agreed that a second opinion would be sought via referral to a neurologist, and an appointment was arranged.

As the Deprivation of Liberty Safeguards (DoLS) application period was coming to an end and there was no response from the Court of Protection, it was decided at an urgent meeting that all care plans were in Thomas's best interests, and that Thomas should remain on the ward. It was also agreed that Thomas's social worker would request advocacy for IMCA⁷ rather than IMHA⁴. There was also confirmation that the DoLS application had been declined.

The Court of Protection granted an interim order until midnight on 6 June, with a hearing scheduled for 6 June. An order was received on 13 June.

There were various clinical review meetings, held on a weekly basis, at which Thomas, his behaviours and his medication were discussed. It was noted that his behaviours remained unchanged. He was still aggressive to staff and other residents, and he appeared agitated, with safe holds being required on most days. His medication was regularly monitored and even reduced, and placement options were a continual source of discussion. It was also noted that Thomas was receiving music therapy and physiotherapy, both of which were going well.

During his admission to the ATU for the second time, Thomas was allowed to be taken out by his mother. He was taken, with a team member from an independent care provider, with whom Thomas's mother had been liaising, to visit a residential home and a house with a view to a tenancy. They visited McDonald's, and then went to a pub. The outing upset Thomas and police assistance was required to return Thomas to the unit. As a result of this incident, Thomas's 'leave care plan' was suspended until further consideration of the associated risks had been undertaken. His mother later challenged this decision, and she was allowed to resume taking Thomas out, on the assumption she understood and accepted the risks involved. Thomas was subsequently taken out but required prompts and encouragement to return.

Thomas also had an incident where his oxygen saturation levels fell to between 88 and 94%. He was reviewed by the medical team and his mother was informed. Antibiotics were prescribed as a precaution, but the problem resolved itself spontaneously. He was physically examined and found to have no wheeze or

⁵ An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity.

⁶ Magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

⁷ Independent Mental Capacity Advocacy (IMCA) and Independent Mental Health Advocacy (IMHA).

'crepts'⁸; he also had an electroencephalogram (EEG), a test for epilepsy, with normal results reported. It was noted by staff that he was continuing to enjoy foods that were not part of his dysphagia plan, resulting in concern about possible aspiration.

Towards the end of his admission, Thomas was accused of assault by a student nurse, an incident that required the attendance of the police. When being interviewed Thomas made an allegation against staff. This was investigated by the police and no further action was taken on either matter.

On 10 July, a Court of Protection hearing was held. The judge determined that Thomas should be moved from the inpatient unit to a residential care facility 49 miles from his home town. Thomas was noted as being happy about this, cheering and laughing. His mother, however, was not happy about this enforced move⁹.

A Care Programme Approach discharge planning meeting was held at which it was highlighted that there was a very short time frame (three days) to achieve a comprehensive handover of care, and for the new care provider to be ready for Thomas. The plan was for Thomas to travel by ambulance, supported by staff he knew and liked, to the facility, where he would be greeted by his mother and food that he liked would be provided. The new care provider agreed to send pictures to the ATU of the facility and its staff before he arrived. The new care provider had already contacted a private psychology service to provide ongoing psychological support, and an initial psychology appointment was arranged for the week after Thomas's arrival. The psychologist, from the mental health trust, was noted as agreeing she would speak with the new psychologist and update them regarding her assessment of Thomas and his needs.

There were various concerns about the move. Thomas's advocate spoke to Thomas, who seemed pleased with the move, but they questioned whether Thomas had a clear understanding of the situation. Thomas's mother was angry and upset about the decision, feeling that the judge had not been given enough time to assess the situation properly and that there was not enough time to achieve a smooth transition for Thomas. She also thought there was not enough time for him to get to know the new staff.

From the new care provider's perspective, they reported that the team supporting Thomas were all newly recruited and had a range of short-, medium- and long-term experience in working with individuals with learning disability and autism, including challenging behaviour. All received training in Makaton, autism, first aid and safe holds; and had already had many discussions, as a team, about Thomas and how to support him. They said they hoped to work with Thomas's parents as closely as possible to support a positive rapport, and the goal was to get Thomas back to his home town with him having learned skills to be more independent. Four weeks of medication was arranged to go with Thomas to his new home, along with his

⁸ Also referred to as crackles or crepitations. If there is an infection or consolidation in the lungs, these noises are often heard.

⁹ Neither Thomas's mother nor his elder sister drive, so visiting Thomas was not easy for them. Public transport required a combined train and bus journey of between 137 and 164 minutes each way, and this did not include the journey time from Thomas mother's home to her local train station.

specialist equipment such as spoons, a weighted blanket, and newspapers, which he liked to shred.

From a services point of view, psychiatry services were liaising with each other; reports were transferred where applicable and an appointment was booked with the second opinion doctor. Speech and language and psychology services were liaising to ensure handover was achieved, and the new care provider said they would provide support for the neurology appointment in Thomas's home town. Advocacy support was to continue, and Thomas's social worker and CPA coordinator would also continue to visit regularly; initially this was scheduled as weekly for the first four weeks.

Getting an iPad for Thomas was also discussed, to facilitate him FaceTiming his family. Thomas's mother was also supported financially to ensure she could visit Thomas by train or taxi regularly.

4.8 The New Care Home (referred to henceforth as the care home)

4.8.1 July

On 14 July 2014, one of the psychology team had planned to take Thomas's mother to the care home, ready for his arrival. Unfortunately, the transport for Thomas arrived earlier than scheduled, so Thomas arrived first. Thomas's mother was upset. The care home was not ready for Thomas when he arrived; they did not have any food for him, and communication with Thomas was complicated, as not all staff had been Makaton trained. The psychology team spoke with the registered care home manager the day after Thomas moved to share his mother's concerns about this. This conversation revealed that more staff were being trained in Makaton that same week.

Shortly after his arrival, Thomas's behaviour remained the same as on the ATU, but he was able to go to the park and shops accompanied by staff.

As part of the transfer between the mental health trust and the care home, both the occupational therapy and psychology teams transferred their files to the local, community learning disability service and to the care home. They were advised that there were long waiting lists for the community learning disability team.

The speech and language team (from the mental health trust) visited Thomas with the clinical psychologist and noted that the staff were not communicating confidently using Makaton and needed more training. Thomas told them he liked the house and some of the staff. While there, they gave the staff some dysphagia training, concentrating on Thomas's mealtime risks and the need for assessment at every meal, due to his fluctuating risk level. The speech and language team also noted that Thomas responded well to prompts to sit up and slow down. The care home staff reported concerns with Thomas's parents bringing in food that was not part of his dysphagia management plan; this was a prevailing and persistent issue.

Thomas's psychologist and care coordinator visited his father and asked him to observe his son's dietary restrictions, which he agreed to do. It was noted that he did not feel included in the information sharing and planning as he should.

The intensive support team, when they visited, raised concerns about the high levels of 'as needed' medication being used by the care home staff. Because Thomas's new psychiatrist was on annual leave, his previous consultant was asked to attend, which she agreed to do. At her visit, she found Thomas in a good mood, although he was seen eating Doritos, a food not on his recommended list. She discussed the need for a positive behavioural support plan^{10,11}, but the care home didn't have clinical psychology support, only a nurse therapist not trained in Positive Behavioural Support. The issue of psychological support was therefore to be discussed at the next multi-team CPA¹² meeting. Thomas's contact with his parents was also discussed; part of the management plan for the care home was to discuss and agree a routine with his parents.

4.8.2 August

Thomas's previous consultant psychiatrist visited him on two separate occasions. On the first visit, the psychiatrist noted that the care home was making progress, that Thomas had seen his GP three times and that there were still regular incidents but that the staff were coping. Changes to Thomas's medication were made, and during the visit Thomas indicated in sign that he wanted to go home and that he didn't like some of the staff. He was reassured the staff were good people and were helping him get better, so he could go home.

On the second visit, it was noted that there were two days where 'as required' medication wasn't used. This was a marked improvement. It was also noted that there was some concern with breathing difficulties and whether Thomas needed hospitalisation. There is no record of any admission, and the GP Collaborative was contacted twice in August on unrelated matters: whether anxiety medication was affecting his cough, and concerns about 'blank' episodes.

The speech and language report, from the mental health trust, was completed, sent to the team at the care home, uploaded onto the electronic record keeping system in the mental health trust and provided to the speech and language team in the locality in which Thomas was now living. Occupational therapy reports were also provided.

In mid-August the care home made a referral to the local community learning disabilities team. One of this team reviewed the information provided by the previous mental health trust, following which telephone communication occurred with the care home, who confirmed they had all guidelines and were content to continue with these. Around the same time, the mental health trust's clinical psychologist referred Thomas to his now local psychology team for ongoing work.

¹⁰ http://www.bps.org.uk/sites/default/files/documents/challenging_behaviour_-_a_unified_approach.pdf

¹¹ PBS is a way of understanding behaviours that challenge, assessing the broad social and physical context in which the behaviour occurs, and planning and implementing ways of supporting the person which enhance quality of life for both the person themselves and their carers. It's based on the values of recognising each person's individuality and their human rights, a rejection of aversive and restrictive practices, and an acceptance that behaviours which challenge develop to serve an important function for people. <http://www.skillsforcare.org.uk/Topics/Learning-disability/Positive-behavioural-support/Positive-behaviour-support.aspx>

¹² Care Programme Approach (CPA) is a way in which care services are assessed, planned, coordinated and reviewed for someone with complex needs.

There was also a person-centred planning day with a national charity who specialise in working with individuals with learning difficulties. The aim of this day was to work out what would make an ideal home for Thomas to live in, what would make great staff or paid people to help Thomas achieve what he wanted in his life, and what Thomas would do in his day based on his wants and desires. The planning day was pivotal to the plan for Thomas to return home. Unfortunately, this day did not work out as hoped, as the process distressed Thomas and the event had to be terminated¹³.

In the latter part of the month an occupational therapist from the mental health trust attended at the care home to deliver a session to staff about Thomas and occupational therapy. The care home staff reported they thought it would have been useful to receive this at an earlier point in Thomas's placement there.

Thomas made his first allegations against staff at the care home, and Thomas's social worker noted that the registered care home manager was investigating the allegations. The local safeguarding adults team was also informed.

There was an Improving Lives Review^{14, 15} meeting on 19 and 20 August. Thomas had been resident at the care home for approximately six weeks and had the entire top floor of the residence to himself. There was, by this stage, a gentleman residing on the lower floor of the building. The introduction to the report, produced as a result of the review and provided to agencies on 20 September 2014, highlighted that Thomas had a lovely, warm smile; enjoyed listening to music; liked playing football, both in the park and in the large garden; enjoyed the paddling pool in the warm weather; and liked McDonald's, which was his favourite meal. It also stated that he would like to ride a trike and have a drum kit, and that he was visited regularly by his family. The report was largely complimentary about the service Thomas was receiving. The primary area of concern focused on the lack of a specific, robust and structured person-centred plan that took Thomas's needs and wishes into account. It also recommended that a single progressive plan, that would deliver Thomas's return home, needed to be produced by professionals and Thomas's family; it was, however, recognised that this was not feasible at this time.

At the time of this visit there had been no CQC inspection visit, and Thomas is reported as saying "I don't like living here".

An independent social worker also visited the care home towards the end of August and provided mostly positive feedback regarding the way care home staff were approaching Thomas's care and support, including the longer-term planning for his return home.

Two members of the psychology team continued to provide support and input for Thomas's parents. The purpose of one meeting in August was to discuss an autism assessment for Thomas; however, his mother also needed to talk about a range of issues, including the staffing at the care home, their training, and her son's health

¹³ The work with Partners for Inclusion was not concluded and no report was generated.

¹⁴ <https://www.gov.uk/government/publications/improving-lives-the-future-of-work-health-and-disability>

¹⁵ <http://www.challengingbehaviour.org.uk/learning-disability-files/WV---Transforming-Care-2-Years-On.pdf>

needs. The team advised that they would ensure that Thomas's care coordinator was aware of these issues.

4.8.3 September

In a Care Programme Approach meeting in Thomas's home town, it was noted that there had been several days where 'as required' medications were not needed. There were also issues that required resolution: organising a second-opinion psychiatrist, achieving a GP health check, psychology input, formulating a Positive Behavioural Support plan, and sourcing music therapy. Thomas's mother was also unhappy with safeguarding, Thomas's allegations, and the environment of the house. She was also not happy that no residence had yet been identified for Thomas to move back to.

Thomas attended a neurology appointment with his mother and staff from the care home. The care coordinator noted that this didn't go well, with Thomas biting one of the staff who had accompanied him. The conclusion of the appointment was that an MRI was not required based on the symptoms presented (focused on a particular object, vacant expression, unresponsive to verbal communication, agitation and aggression, responding to imaginary people 'Emma and Tom'), reflecting the opinion of the earlier radiologist opinion.

A meeting was held between adult social care; members of the clinical commissioning group, including the clinical lead for personalised commissioning; Thomas's advocate; and his care coordinator. The purpose of the meeting was to discuss the current situation for Thomas and his future.

The main points from this meeting included the need for psychiatry and psychology input, sourced locally. The psychology provision was also no further progressed; therefore, the commissioners were willing to consider commissioning this on a private basis, and the agreement was for Thomas's care coordinator to liaise with them about it. The adult social care service needed to commence their planning for providing a service to Thomas, in his home town, once he had been assessed by a psychologist and psychiatrist regarding his Positive Behavioural Support. The urgent need for a clinical psychology assessment for Thomas was again underlined.

Also, a planning day with the Improving Lives team was postponed until after the next Court of Protection meeting. The independent psychiatric opinion was discussed, together with the need for clarity about what was required from this. Feedback from Thomas's adult social care team was he had made significant improvements since leaving inpatient services; he required less medication, and he was regularly going out into the community. Finally, Thomas's allegations against staff were raised as a concern and how best to manage these. Concerns about the negativity of Thomas's parents and the possible negative impact this might be having on Thomas and his progress at the care home were also noted in relation to this.

The recommendations arising from the Improving Lives assessment were identified as follows.

- To undertake (or arrange) a detailed functional analysis of Thomas's behaviour. This could then help with bringing an evidence-based structure, as well as supplementing the instinctively creative interventions of the current staff team. This was to follow a positive behavioural support model (achieved).

- For a Communication Passport to be devised following assessment by a Speech and Language Therapist (SALT), capturing both receptive and expressive modes of communication and any supplementary methods used to reinforce communication with Thomas – for instance, integrated use of Makaton and specific/modified signs¹⁶. The risk around swallowing to be assessed and clarified with all professionals and family by SALT.
- A Hospital Passport to be written in an easy and quickly accessible format to help enable/facilitate any future hospital visits.
- Based on clear plans formulated in recommendation 6, move to live near his parents. The county council in Thomas's home town to request housing application.
- For music therapy to be sourced again, commissioned and offered to Thomas (achieved).
- Continue work already commissioned and started with the national charity that concludes with a person-centred service specification being agreed for Thomas. This is to then drive forward the commissioning of services to meet this specification¹⁷.
- A full review of Thomas's antipsychotic medication to be undertaken, and to consider moving away from poly-pharmacy and high use of/dependence upon as required (PRN) medication (achieved).
- For the procedural issues relating to the Court of Protection to be resolved, thus enabling the robust model of care and support that Thomas needs to continue in the most appropriate setting.
- For Thomas's sensory assessment to be fully integrated into his care plan and daily routines.
- An independent advocate to be sourced and provided for Thomas's mother. This needs to be negotiated with her and not chosen for her.

The delivery dates for the above recommendations ranged from October to November 2014, and achievement is as indicated¹⁸.

With regard to Thomas's parents, the psychology service continued to provide support, even though this was not always considered beneficial by Thomas's mother. The service, however, exercised due diligence by continuing to share concerns raised by Thomas's mother with the care home, including Thomas's TV, his sharing

¹⁶ <https://www.makaton.org/aboutMakaton/howMakatonWorks>

¹⁷ This work did not progress with Partners for Inclusion. There were concerns about the style of this group and its appropriateness for Thomas.

¹⁸ The Clinical Commissioning Group in Thomas's home town responded to the Improving Lives report (dated 30 January 2015). It noted that the issue of a person-centred specification for Thomas's support in the community was on hold, but under consideration pending the outcome of the Court of Protection meeting. The clinical commissioning group confirmed that conversations regarding suitable accommodation and support models for Thomas had been taking place. It also noted that in December 2014, Thomas's medication had been reduced, and there was also evidence that the use of PRN medication within the care home had reduced. On the matter of sensory assessment, it was noted that the mental health trust's speech and language communication assessment report, and the eating and drinking assessment report, had been shared with the speech and language team in the locality of Thomas's care home. Furthermore, Thomas had been referred to them for ongoing support. An up-to-date sensory care plan had also been requested from the care home.

staff meals, windows that were not made of safety glass, and staff rotas at the care home.

4.8.4 October

Towards the end of this month Thomas met his new consultant psychiatrist for the first time, and she reduced his medication. Thomas's new music therapist also visited the care home and met with Thomas. The mental health trust also followed up the referral for ongoing psychological input for Thomas.

His new psychiatrist requested an urgent review of Thomas's dysphagia risks, and also requested:

- baseline bloods
- a 'head to toe' by community nursing
- referral to psychology
- a review of Thomas's sensory needs.¹⁹

Thomas's behaviours continued to be noted as an issue, but they were less frequent and less intense. These were all positive progressions for Thomas, but staff noted that sometimes his mood dropped, and this seemed linked to occasions where his future move back home was discussed and it was clear he would not be going to live with his mother or father.

The independently contracted clinical psychologist visited the care home and met with Thomas and the registered care home manager. In subsequent correspondence with the relevant Clinical Commissioning Group, she identified that any interventions for Thomas would need to accommodate physical, cognitive and emotional needs. Thomas's traumatic life events would need to be addressed, and the maladaptive use of restraint would need to be adjusted. The psychologist considered that behaviours exhibited by Thomas that resulted in some form of restraint might be meeting a need in Thomas to be held. She specifically reported that the plan for Thomas would require:

1. "A safe place to live with the appropriate design features. This will be single story (bungalow or flat) with a wet room for hygiene needs (smearing is an issue) and a 'safe-room' to remove the need for restraint. This will be a fully soft-lined sensory room, with music and low coloured lights to make it pleasant, and a half door to maintain communication when Thomas is being held in the room. The Court of Protection will need to sanction the right to lock the door at times of major breakdown in behaviour. This will remove the need for him to be held for long periods and allow for the development of physical contact for positive reasons. He is likely to smear the room, so it must be designed to be robust and easily cleaned. There may still be a need for him to be escorted to the room, but, in time, he will choose to go in to cool off. Other rooms are a bedroom, sitting room, staff sleep-in room and probably an office.
2. Staff appointed for and trained in 'trauma-informed care'. This is support that is offered at the right level of emotional development. Thomas's emotional age is less than 2 (from his behaviour) and he will need to be provided with

¹⁹ On review by the new community learning disabilities team, most of these assessments were not required, as they had already been comprehensively addressed by the previous mental health trust.

constant reliable attachment figures who will meet his needs in an appropriate way, not expecting him to reason as he is not able to, but not giving in to every demand with the consequence of feeding his feelings of omnipotence. This training provides staff with knowledge of early emotional development and attachment issues, with guidance on how to help individuals to develop to the later stages and become, therefore, able to use reason. These staff will need to provide him with meaningful activities appropriate to his age and interests.

3. Staff support for the work. They will need to meet together as a group with an appropriately trained psychologist/psychotherapist to explore the feelings being projected from Thomas and their reaction to this, giving them space to recognise what is happening and decide on what they can do to manage it. Initially this will need to be weekly but will be able to be less frequent as they gain skills and Thomas responds to the intervention.
4. Individual therapy for Thomas. This may have to begin, initially, either side of the safe-room door. There is immense pain behind his distress and addressing it will be likely to lead to breakdown of behaviour in the early stages. He should be able to sit with a trusted therapist within 2 to 3 months. Ideally, he will be seen twice a week. Sessions may be short at first (15-30 minutes) but will progress to an hour.”

4.8.5 November

A professionals' feedback meeting was held, following the legal meeting that had taken place instead of the Court of Protection hearing. The independent social worker submitted a report, written following a visit on 27 August 2014, that was mostly positive about the work the Lifeways team were undertaking with Thomas. It was supportive of their medium- and longer-term perspectives regarding factors that might enable Thomas to make a successful move back home. Thomas's mother's lack of faith in his care package was also highlighted as a possible problem in Thomas's progression. It was also noted at this meeting that Thomas's mother was meeting with the independent psychologist. The local consultant psychiatrist was now identified as Thomas's lead clinician.

At one point in the month, Thomas's father emailed one of the social work team to say that his son needed to come home to live with him, and not in services. This email was forwarded to Thomas's care coordinator. This was not feasible, and to the report author's knowledge was not progressed.

The independent clinical psychologist compiled a more comprehensive report following meetings with Thomas's parents, his advocate and the previous psychologist at the mental health trust. In the report, she made clear that she agreed with the outcome of the earlier autism assessment and that Thomas's age of functioning was approximately two years. It was her opinion that Thomas had experienced a range of trauma at different stages of his life, and each had compounded the effects of the other; it is likely that the initial trauma was something unnoticeable to anyone else, but profound for Thomas, such as being expected to feed himself when he didn't know how. Thomas's responses were primitive:

fight/flight, freeze and 'no' as a word used to fend off things he did not understand. Thomas was able to relax with people he trusted, such as his sister.

She also highlighted that to address the issues within a model of positive behavioural support, all people who might work with Thomas would need a good grounding in early emotional development, would need to be proficient in alternative communication and would have knowledge of autism.

The report suggested that a timetable of positive events for Thomas needed to be agreed and adhered to. Something positive needed to happen every 30 minutes (30 times a day), and only one person was to work with Thomas during each period. The list could comprise daily activities such as cleaning one's teeth, listening to music, going for a walk, playing a game or having a shower. The key point was that the focus should be on giving input to Thomas and asking nothing from him in return; he was also to be praised for every 30-minute period that was incident free. An example of this would be: 'Well done, we have had a good session.' The activities would need to be age appropriate, but recognise that Thomas's behavioural age was less, so the emotional warmth and expectations of success needed to be linked to his emotional developmental stage.

It was also suggested that Thomas required individual therapy; this needed to be provided twice a week, initially in short sessions. For instance, 'books without words' could be purchased that addressed abuse and fear. The independent psychologist highlighted that the therapist for Thomas needed to be carefully chosen. Additionally, a safe room needed to be provided for Thomas, to reduce the need for physical restraint. The psychologist stated that this needed to be "soft-lined and include music and lights to make it a sensory room that [felt] safe". The purpose of the room was to enable Thomas to develop self-regulation. Because it was predictable that a locked door might be required, the Court of Protection would need to sanction it for short-term use only.

The report also recognised Thomas's family's issues and the loss of trust in services.

Finally, the psychologist acknowledged that both Thomas and his father would prefer an arrangement where Thomas's father was in an adjoined flat, or similar. However, the psychologist considered that this may not be in Thomas's best interests, and that living independently of both his parents, but near to them, was better. It was noted that a range of providers would be able to meet Thomas's needs and that all needed to be trained in positive behavioural support.

4.8.6 December

At the beginning of December, Thomas's care coordinator received an email from Thomas's advocate relaying a number of concerns: that Thomas's consultant psychiatrist had cancelled his next appointment and had not rescheduled it until March 2015, that Thomas had developed a new behaviour of biting his own wrists, and that his mother was concerned at the lack of support provided to him during telephone calls.

Thomas's advocate suggested that they ought to have a review meeting before Christmas, and the social care team also contacted Thomas's care coordinator

regarding contingency plans for when Thomas was at his father's over Christmas; she suggested that they undertake a joint visit to Thomas's father.

Thomas's care coordinator made successful contact with the secretary for Thomas's consultant psychiatrist and agreed a telephone consultation, and that the consultant would attend the Care Programme Approach review in early January.

There was a meeting before Christmas, attended by the social care team, Thomas's clinical psychologist, the clinical commissioning group and Thomas's care coordinator. The psychologist believed a home visit for Thomas over Christmas would not be beneficial and he needed to build on his relationships with staff at the care home; she considered it better for Thomas if his family visit the care home at Christmas. It was the task of the care coordinator and Thomas's adult social care team to feed this back to Thomas's parents. Understandably, neither parent was pleased with the news; they thought Thomas was coming home at Christmas. They made it clear that they wanted this information, and their perspective, passed on to all parties of the multidisciplinary and multi-agency team, which was done. Consequently, the multi-professional team liaised with the local police and decided to convene a Best Interests meeting to discuss the issue surrounding Christmas and to formulate a way forward; the result of this was that Thomas's visiting with his family over Christmas was supported.

A detailed support plan was formulated that identified the contact details for the emergency duty team and the residential care home and set out the key hazards considered and the protective measures to contain and/or minimise the consequence of these. Specifically, it addressed travelling by car from the care home to Thomas's father's address, Thomas's understanding that this was a one-off visit home, changeability in Thomas's behaviour while at his father's, Thomas being reluctant to return to the care home, that the house Thomas's dad lived in was different to that Thomas last visited and travelling by car between locations. Each of these points was addressed by a multi-point plan in which Thomas's parents were identified as 'key components'.

The visit went well. There was some upset when Thomas returned, but this was mostly caused by variance in the agreed plan.

Concerns about abuse of Thomas by staff at the care home continued, though none were substantiated. Lifeways liaised with the local adult safeguarding team, and also ensured that his care coordinator was aware.

Thomas was also seen at his GP surgery at the end of December, by a nurse practitioner, because he had loose stools. His observations appeared to be normal and he was advised to have a dry diet and clear fluids for 24-48 hours, then to gradually reintroduce a normal diet. This resolved the episode.

4.8.7 January

Thomas's father contacted adult social care by email. He was 'enraged' about Thomas's care situation and one member of staff in particular. He requested an urgent crisis meeting to discuss safeguarding issues and Thomas's staff team; otherwise, the family would be going to social media. An urgent meeting was

convened. Later, he also advised adult social care that he was taking his son home at weekends and that he did not consider that the safeguarding measures at the care home were working.

Adult social care also received an email from the clinical psychologist, who informed them that she was starting to look at alternative accommodation for Thomas and commencing a training programme for the staff at the care home.

Correspondence received from the care home provider to adult social care also indicated that there were issues between the placement provider and Thomas's family. Thomas's family had reportedly told Thomas that he would be going home every two weeks, but this had not been discussed or agreed. Furthermore, the care home provider considered that weekend visits home for Thomas required more thought before they become a regular event; there was a generalised sense that the clinical psychologist needed to guide the next steps, as it was her expertise that was being relied on.

From a care perspective, in the first week of January the local community learning disability speech and language therapist undertook an initial communication assessment of Thomas. Care home staff asked for further support with functional signs to support him. A further visit was undertaken in the third week of January to continue the communication work. Discussions were also conducted with staff around Thomas's dysphagia management.

In mid-January, a Best Interests meeting was held, at which frustrations on all sides were expressed. It was agreed that the member of staff about whom allegations had been made would no longer work with Thomas, that the clinical psychology report would address some of the issues of concern and that Thomas's family were to be offered their own advocacy support. Contact visits between Thomas and his family were not discussed; this issue was scheduled for another meeting.

The following day, Thomas's care coordinator emailed Thomas's parents to advise that the planned Care Programme Approach meeting that week had been cancelled, as the clinical psychologist could not attend. Thomas's mother was not pleased about this, as she considered that there were several issues that needed resolving on an 'as soon as possible' basis. It also meant that the opportunity for the multi-agency team to meet with the consultant psychiatrist was lost.

In the last week of January, staff attended the first of two whole-day sessions provided by the independent psychologist. The training was entitled 'All Behaviour Has Meaning', and covered behavioural, cognitive, psychodynamic and systems approaches to understanding behaviour. Staff were reported to have engaged well with the material and could relate it well to Thomas, coming up with ideas for how to help him based on an understanding of the meaning of his behaviour.

A newly identified therapist, who had been chosen as the person to deliver individual therapy to Thomas, met with him, and related well to him. The plan was for him to have weekly sessions with her.

At 3.15pm on 29 January, Thomas was seen by an out-of-hours GP, who prescribed him antibiotics for a chest infection. The same day, at 9pm, the care home staff made a call to emergency services because they were concerned about Thomas, as

were his parents. Thomas's parents recall that it was they who prompted staff to make the call. A paramedic crew attended to assess Thomas and determined that transporting him to hospital was not necessary that night.

The next day, the clinical psychologist attended at the care home to undertake the second day of the 'All Behaviour Has Meaning' training. Her report, as previously, stated that staff engaged well with the material and could relate it well to Thomas, coming up with ideas for how to help him based on an understanding of the meaning of his behaviour.

Two days after the 999 call, Thomas and his father went out for a meal. Thomas had a restless night that night, but other than this nothing untoward was noted.

4.8.8 February

Unlike previous sections, this section will detail Thomas's story in the words of others, as doing so captures the events more fully and represents a truer reflection.

The care home notes for 1 February give the impression of a normal day. Thomas called his youngest sister, and Thomas's father was due to call at midday. Thomas was sitting and listening to music. He spoke with his father at 12.20pm and afterwards had bread and an omelette. The record says:

"Thomas has been lively today – Chatting with staff and playing with space hoppers. He watched a movie on TV, ripped newspapers and had a run around. At the end of shift Thomas was sitting in the communal lounge."

The late shift record reports:

"Thomas was sat watching TV on arrival. Then sat chatting to staff. Thomas then sat listening to music. He then started crying saying he needed a doctor for his throat. Staff reassured him that if he took his medicine it will get better. Thomas then started crying wanting to ring mum and dad. Staff sat talking to Thomas and helped him to calm down. He then rang mum at 17.00hrs. He rang his youngest sister after. Thomas then went to his bedroom at 18.00hrs. Said he was going to sleep. Came into the living room at 18.15 sat listening to music on the sofa. Thomas rang his dad at 19:00hrs. He then refused Sunday dinner. Staff {?} a sausage sandwich but he refused. He asked for ice cream. He then refused that. Staff kept prompting Thomas to drink every 10-15 minutes. Staff sat in the living room watching TV with Thomas and was chatting. Thomas's oldest sister phoned him at 20.30hrs. Sat talking to staff. Thomas was sick ... staff cleaned it up, Thomas soiled himself. Staff changed clothes and washed him down. 111 was called said they would ring back in an hour."

The out of hours GP records show that the duty GP did call the care home back within the hour and advised them it was OK to give Thomas his medication.

The night shift record of 1 to 2 February 2015 goes on to say:

“On arrival Thomas was sitting in the lounge watching TV, had a pot noodle for supper at 22:30. [Someone] prompted Thomas to shower, Thomas then went to bed at 22:45. At 23:30 Thomas came to the lounge covered in poo.”

The records show that the support worker took Thomas back to his room to shower. The support worker then changed Thomas’s bed sheets and Thomas went back to bed. The records also show that at 12.30am, Thomas came back to the lounge and required a further shower. This was undertaken by the support worker, who also changed Thomas’s bed sheets. The records indicate that Thomas then went to sleep.

At 2am, Thomas returned to the lounge. He again required a shower having lost control of his bowels. The records report that he refused a shower. Therefore, the support worker washed Thomas in the lounge. Thomas was then noted to have returned to his room, where the support worker showered him. He then went back to sleep.

At 3.30am, Thomas again went to the lounge and refused to go back to bed. The record reports that when the support worker went to Thomas’s room, it needed a complete clean-up, which the support worker did. However, Thomas still refused to return to his room.

There is no further record made. However, the incident form completed on 3 February 2015 by the support worker who was caring for Thomas that night says:

“Thomas was in the upstairs lounge and had soiled his bed sheets, and was covered in poo, I asked Thomas to get a shower, but he wanted to stay in the lounge and asked me for a drink. I then went to the kitchen to get him some water when I came out of the kitchen Thomas grabbed hold of my leg when I leaned down to give him the water Thomas spat out blood and his nose was bleeding too, he then started shaking before going completely limp.

I rolled Thomas onto his front and realised something was seriously wrong with him, I checked his airway and his mouth was clogged up with blood so [I] put him into the recovery position but when I checked his pulse I couldn’t feel anything so I started giving him CPR, when I felt what I thought was a faint pulse I ran downstairs and shouted to my team member to ring 999 and then went back upstairs to continue giving Thomas CPR.”

The support worker involved gave a statement to the police in 2015, which the author of this report has not seen. He was also asked to provide a statement to the Coroner in January 2016, the content of which shows his memory recall was compromised. The exact sequencing of events between 3.30am and 5.30am is therefore unknown.

The paramedic crew report receiving the call to attend at the care home at 5.40am, and they arrived at 5.43am. The initial assessment of Thomas revealed:

“Airway (A): evidence of small amount of blood and vomit in oral cavity
Breathing (B): - absent

Circulation (C): pulseless and when defibrillator was attached to the chest the initial rhythm was asystole (no cardiac output, denoting no electrical activity).”

In response to this, the paramedics initiated treatment. This included the administration of adrenaline (1:10,000 dose). Thomas was also given oxygen and intubated on scene. The crew were joined at 5.51am by several police officers and a clinical supervisor from the regional ambulance service.

Thomas responded to treatment and a palpable pulse was detected; however, this was not maintained for any length of time. Resuscitation therefore continued, and Thomas was removed from the building and transported to the local acute hospital. Although a palpable pulse was confirmed on arrival at hospital, Thomas remained in respiratory arrest.

4.9 Arrival at the Teaching Hospital to time of Thomas’s death

On 2 February 2015 at 6.42am, Thomas arrived in the emergency department after suffering a cardiac arrest in his care home. The paramedics handed over his care and noted that the nature of his arrest was pulseless electrical activity. His observations were: respiratory rate 18²⁰ (mechanical ventilation rate), oxygen saturation 94%, pulse 105, temperature 33.6, Glasgow coma scale 3, and his pupils were fixed. An anaesthetic registrar was in attendance and an electrocardiogram was performed almost immediately.

A short time later, a consultant in intensive care, spoke with Thomas’s family in the emergency department and advised them that Thomas’s situation was grave; his brain had been starved of oxygen for a significant period of time and he was unlikely to recover from this. The emergency department record also identified that Thomas had aspiration pneumonia.²¹

Following the initial assessment in the emergency department, Thomas was transferred to Imaging for a CT²² scan, which confirmed the presence of hypoxic brain injury. He was then transferred to the intensive care unit, where he was given initial stabilisation and a full clinical examination. The management plan was for sedation, ventilation with lung recruitment, therapeutic hypothermia, and inotropes as required. It was identified that his pupils were fixed and dilated at this point; other results showed an abnormal liver function, which was thought to be the result of the prolonged hypoxic period.

The following day, as per protocol, therapeutic hypothermia was stopped. This had been in place for 24 hours and Thomas was allowed to rewarm passively, without the use of heat pads or other aids. Sedation was also stopped. Following this, two intensive care consultants reviewed Thomas and concluded that it was highly likely that he was brainstem dead, but that it was too early to perform the necessary tests to confirm this. It was agreed these would be performed the following day. Over the

²⁰ On the paramedic patient report form it says 13 respirations per minute.

²¹ This was not confirmed on post-mortem. Furthermore, whenever a person is resuscitated it causes aspiration into the lungs, and it would be difficult to determine whether this was present prior to Thomas’s active resuscitation.

²² A computerised tomography (CT) scan uses X-rays and a computer to create detailed images of the inside of the body.

course of the day several discussions took place between the intensive care staff and Thomas's family to explain his condition, the likely diagnosis, and the details and timing of the brainstem death tests.

On 4 February 2015 at 4.50pm Thomas underwent brainstem death tests by two senior intensive care doctors. These tests are, and were, carried out according to strict criteria and following guidelines set out in an official document. Before these tests were conducted both doctors were satisfied that Thomas had a condition that had led to irreversible brain damage. The tests conducted confirmed that Thomas was brainstem dead.

5 Analysis and findings

The purpose of this section is to present the findings of the author and her team. It is structured so that the findings directly relate to the terms of reference that were agreed at the start of the investigation.

5.1 Terms of reference 1-4

It was determined from an early stage in the investigation that addressing these directly was unlikely to provide substantial learning value. The time frame in which the events occurred is sufficiently removed to negate the relevance to any current processes and procedures that apply. However, the author of the report has chosen to address certain aspects from an overview perspective.

5.1.1 Term of reference 1: Thomas's agency contacts prior to age 14

This was not addressed directly.

5.1.2 Term of reference 2: transition from children to adult services

This comprised:

- a. the process that was followed
- b. information that was collated by the transition team, and passed on to the first adult service
- c. qualification/quantification of Thomas's needs
- d. the support structure for Thomas's mum and dad over this period, and the support during transition.

Although this term of reference was not addressed directly, and the family know and understand the rationale for this, there are several comments arising from the period between 2008 and 2011 that the author considers has a bearing on the family's frustration with the involved agencies as time progressed and their levels of fatigue.

With specific regard to part 2.c, the author notes that a key complexity for Thomas, his parents and children's social care services was Thomas's dislike of being away from home and in a new environment. This situation manifested in his teenage years. Unfortunately, his increasing needs meant that the provision of homecare became more difficult to achieve and seemed to exacerbate Thomas's distress, a situation no one considered acceptable.

With specific regard to part 2.d, a key theme for Thomas's mother was the lack of consecutive days of respite care for her son, denying her the ability to take what she considered to be a real break from her son and recharge her batteries.

Although four-weekly weekend respite was provided with an additional annual week's block stay, and additional care during school holidays, until December 2009 this service could not continue thereafter as the respite placement could no longer meet Thomas's needs and his care package was transferred to the Behaviour Evaluation Support Team, which was joint-funded with the Child and Adolescent Mental Health Service.

From this point forwards there was a reduction in the number of consecutive days of respite available. It was the consideration of Thomas's mother that sometimes the number of days offered was too low for her to benefit from. Consequently, she refused this from time to time. It is the experience of the report author that one-nights' respite when caring for a loved one with a chronic condition provides no meaningful respite and therefore fully understands why Thomas's mother refused this.

Now the situation has improved and includes 50:50 or full-time care, which equates to three overnight stays a week, with the young person spending four overnights a week at home. In Thomas's case this level of support would have helped his family but may not have made a difference to the overall stress they experienced. Because Thomas's needs were significant, there is no guarantee that a more extensive respite service would have been available in an appropriate environment for Thomas. Furthermore, it is unlikely that it would have avoided the need for more specialist care provision, as was his situation in 2011.

5.1.3 Term of reference 3: Thomas's first mental health assessment

This was not addressed directly. The lapse in time was too great, the organisation that received Thomas no longer exists, and the detention was lawful.

5.1.4 Term of reference 4: Thomas's time at the independent hospital and linked residential care facility

With regard to part 4.c, allegations of abuse against staff were not a significant factor of Thomas's time at the independent hospital.

The Operations Director for the hospital undertook an investigation following an escalation in safeguarding incidents at between 18 June and 23 September 2011; a total of 12 safeguarding incidents occurred over this period, all of which were reported to the relevant authority as required. Two related to instances of staff being aggressive towards service users, one of which related to a staff member's treatment of Thomas.

A significant concern raised by Thomas's family related to an allegation by staff from a different care provider, stated to Thomas's sister, that Thomas had required a seven-person restraint during the first week of admission. Thomas did not require restraint during the first week of admission and a seven-person restraint had never been used in the hospital at that time. Thomas's family would not divulge further information or the identity of those making the allegation. Consequently, it was not possible for the hospital to investigate further.

Given the range and frequency of challenging behaviours displayed by Thomas over the nine months he was a patient at the hospital, the number of substantial rather than low-level incidents requiring a dedicated investigation was low. The investigations did not include instances where staff were injured.

The author of this report considers that the investigations conducted were in line with the common standard of practice and with requirements at the time. The hospital management demonstrated a low tolerance of policy non-compliance and

behavioural risk in its staff regarding safeguarding and client vulnerability; it took firm action by dismissing staff who it considered a threat to the good running of its facility and the safety of its staff.

It is considered unlikely that Thomas was mistreated by staff between June 2011 and March 2012.

5.2 Term of reference 5: Thomas's period of care with the Mental Health Trust

5.2.1 Part 5.a: Thomas had two admissions to the trust's assessment and treatment unit about which his family had a range of concerns. These are addressed below.

5.2.2 Part 5.b: Medication management and sedation – was the range of medication reasonable and necessary?

Thomas's family raised a concern that he was over-medicated during his time on the assessment and treatment unit. They showed the author of this report a photograph of him slumped over his food unable to lift his head.

Throughout his first episode of inpatient care, Thomas was treated with a range of medications, including antipsychotic medication, antidepressant medication, everyday pain relief, treatment for *H. pylori*, and antibiotics for a chest infection. A list of Thomas's medication can be found in Appendix C.

Having reviewed the range of medication prescribed for Thomas during his first admission in 2013, the independent consultant in learning disabilities said:

1. The treating team appeared to know that Thomas had a long-standing history of behaviour problems and that he did not respond consistently to medication. The changes of medication, especially antipsychotic medication (risperidone, quetiapine, Clopixol), therefore seem to be very rapid. It is possible that slower increases of dose and use of only one drug at a time would have resulted in fewer side effects. The changes made to his medication and the timescales associated with this did not allow time for staff to ascertain if some of the side effects would have been transient, as they often are. This may have allowed for longer periods of trial of individual medication.
2. Given that many behaviours displayed could have been driven by high arousal and anxiety levels, less toxic drugs such as beta blockers could have been considered.
3. The medication regime does not appear to have been linked to the psychological and behavioural treatments for Thomas in a single jointly agreed treatment plan. Such a plan would have made transparent the treatment objectives, with agreed proactive and reactive strategies as part of a behavioural support plan. This would have been possible at multi-professional formulation meetings. (**Note:** this independent process has identified a deficiency in Thomas's management in this respect.)

4. When the effectiveness of drugs is difficult to establish, a drug-free period may have allowed effective alternative approaches to have been developed and trialled. This would be in the context of a widely held view that medication did not provide significant benefits for him. However, it is accepted that at the time, given Thomas's displayed behaviours and the lack of an alternative management plan, a drug-free period may not have been feasible.

The independent author discussed the management of Thomas with staff involved with him in 2013, including his consultant psychiatrist, the ward manager for the assessment and treatment unit (ATU), the deputy ward manager, and the occupational therapist; their reflections echo the consideration of the independent peers. A significant issue for the team in 2013 was the lack of consistent clinical psychology input for Thomas. This was available in 2014, but all staff consider that a more robust and formulaic approach to Thomas's management in 2013 may have impacted positively on his experience. This might have reduced the team's over-reliance on medication as the primary means of managing him, and medication could have been used alongside psychosocial interventions such as focusing on positive and consistent engagement, sensory factors, physical ill health and environmental issues.

5.2.3 Part 5.c: allegations of abuse/unkind care made by Thomas

There is no evidence that Thomas was abused by any member of staff while he was a patient at the mental health trust. All allegations made by him and/or his family were investigated via the line management arrangements and in line with the requirements of safeguarding vulnerable adults.

Thomas's family recall that he was admitted to the Trust 'in hold'. This concerned them, and they questioned its normalcy. The head of psychological services for the trust advised:

"It may not be normal for patients with learning disabilities, but I suggest that safe holding is best practice for people who are at the time behaving in a challenging and dangerous way. The area is indeed contentious, as the main alternative is involuntary sedation with medication. The norm for people with such presentations would be being brought to hospital by the police or detained in police cells."

It seems that admitting Thomas 'in hold' was the most supportive, and least restrictive, option available for him.

5.2.4 Part 5.d: the management of Thomas's physical health

Thomas, and the management of Thomas, was reviewed at least weekly by the medical team and multidisciplinary team throughout his inpatient episode on the ATU. The management of Thomas's challenging behaviours dominated these meetings. However, it is clear from his clinical records and his medication management that the staff paid due regard to Thomas's health needs, attending to issues such as:

- dysphagia management and choke minimisation
- hay fever

- dental issues
- H. pylori.

Thomas also contracted a lower respiratory tract infection in August 2013. However, he was not diagnosed with pneumonia as his mother remembers. The X-ray report said:

"Patchy consolidation at the right lower zone, but no confluent consolidation or collapse. Normal mediastinal contour. Cardiomegaly with cardiothoracic ratio 0.56. No sign of pulmonary oedema, no destructive bone lesion.

At the time of this infection Thomas was already being prescribed and administered antibiotics of Amoxicillin and Clarithromycin prior to [the] x-ray commenced for H. Pylori. [He was now] Commenced on Augmentin 625mg [three times a day] orally for seven days."

This was partly precautionary and partly because he was also complaining of a toothache.

Notably, on 22 August 2013, assessment by the medical staff revealed no outward sign of chest infection in Thomas, even though he had a consolidated lung.

5.2.5 Part 5.e: the findings of the Mental Health Act managers' hearing in 2014, and whether their 2013 recommendations were acted on

The hearing on 20 May 2014 established that not all recommendations made in 2013 had been acted on. The specific area of omission was the requirement to consult specialists in dual diagnosis. The notes made by the legal representative for Thomas's father recorded that the consultant psychiatrist had not done this because:

"she does not know anyone who specialises in it".

A question was also asked regarding Thomas's assessment by a professional specialising in autism. No one present at the hearing in 2014 could provide a response to this.

The final decision of the Mental Health Act managers was to discharge Thomas from his detention – a decision no professional caring for Thomas agreed with and that the report author and her advisers consider was unsafe.

The situation of convening the meeting was in many respects unavoidable, given the prevailing circumstances. However, the author and her advisers consider there was reasonable opportunity for a different course of action to have been taken by the Mental Health Act managers on 20 May 2014 that would at the very least have enabled a safe discharge decision to have been made. Alternatively, a different course of action may also have resulted in Thomas not being discharged from section 3 of the Mental Health Act.

The key issues influencing what happened at the time were:

- the presentation of the NHS reports to the managers, in terms of making clear why Thomas continued to meet the three legal criteria to justify ongoing care and treatment under the Mental Health Act (1983 amended 2007); neither the reports nor the oral evidence provided at the hearing delivered this clarity
- evidence provided to the hearing. Managers made clear the pressure staff were under to relocate Thomas to a new unit. Staff had also been advised by a senior manager that the urgency of the situation was such that if an appropriate placement was identified, then the service needed to proceed, even if on-site visits with Thomas's family, or the care team, had not occurred. This was understandably, but wrongly, interpreted as also meaning that if the Mental Health Act managers adjourned, then Thomas would be summarily transferred out of the trust the following morning.

Therefore, the Mental Health Act managers considered they had no choice but to conclude the hearing that night, based on the information they had, which did not demonstrate that Thomas met the legal criteria for detention. They were not happy about this at the time and remain dissatisfied about the position the prevailing situation in the trust put them in. At that time, and now, there was no step in the trust's procedures that prompted urgent communication with an executive director of the trust in unusual situations, including a situation where, as in this case, a Mental Health Act managers' panel are inhibited in making what they consider the best decision for a service user because of a prejudicial situation.

Finally, the chair of the panel believed that Thomas's father had confirmed to her that he would be taking Thomas home if he were discharged from his Mental Health Act detention. Thomas's father denies he ever made this commitment. Thomas's advocate supports the recollection of Thomas's father, as does Thomas's mother. The chair of the panel strongly contested the recollection of Thomas's parents. She said she would not have proceeded with the hearing if it had been made plain to her that Thomas had nowhere to be discharged to.

To resolve this issue, the author of this report contacted the firm of solicitors that represented Thomas's father at the hearing. The attendance notes made by the attending solicitor following the decision of the managers to rescind section 3 of the Mental Health Act rendering Thomas no longer detained under the act say:

"[The managers] defer the discharge until Friday (in three days time) at 12 noon for a robust care plan to be put in place locally that Thomas can be treated in locally with family support. ... Following the surprise decision I met with the client, and his former partner, who were very happy but expressed concerns about the timeframe for a care package to be provided. I explained that the local authority had a duty to provide [for Thomas under section 17 and] it is not the case that Thomas will simply be left without accommodation on Friday at noon."

Because the solicitor for Thomas's father is the only individual who maintained contemporaneous notes of the managers' hearing, and because her handwritten notes are also retained with her typed-up record, the author of this report is persuaded that Thomas's father never agreed to take Thomas home if he was discharged from the Mental Health Act.

The notes also revealed that Thomas's mother was not averse to a package of care similar to that which might be available in the secure unit, but simply nearer to home.

5.2.6 Part 5.f: management of psychological trauma, following Thomas's abuse in the residential care facility while he was a patient of the Mental Health Trust

There are two important factors that could, and should, have been better for Thomas, especially during his first admission:

- the conduct of a detailed psychological assessment
- utilisation of the positive behavioural support model, or what is referred to as the 5P or 4P Model in Formulation.

In 2013, there were significant staffing resource issues that prevented continuation of clinical psychology input into the multidisciplinary meetings and a clinical psychology assessment being delivered for Thomas. At the time the risk to community-based clients of not receiving a service was greater than the risk to inpatients who were being supported by a range of professionals, some of whom were able to conduct reasonable levels of assessment and formulation, such as Thomas's occupational therapist. This professional conducted the only structured, psychologically focused formulation for Thomas, while he was a patient, prior to 2014.

The lack of assessment of Thomas was rectified in 2014. A report written in July 2014 makes clear that a model of applied behavioural analysis (the 4Ps approach) was being used and discussed and that this generated ideas about how to work with Thomas.

It is unfortunate that resources in 2013, and the scope of demand on the psychology service, did not allow for this. The head of psychological services is clear that had his service been able to engage in Thomas's case, as it did in 2014, this engagement would have continued when Thomas was discharged to his father's home in September 2013. Accepting the ambivalence of Thomas's family to support any interventions that may have been available to them, in coming to terms with Thomas's pre-admission experiences, it is difficult to argue that timelier, dedicated clinical psychology intervention would not have benefited Thomas.

Thomas's case has highlighted the legitimacy of requesting additional funds to provide necessary assessments and psychological input where the service simply does not have the capacity for this, and where providing it therefore raises risk to other psychology patients to an unacceptable level. It is the author's understanding that now, in 2018, the trust would in similar circumstances make a direct application for additional clinical psychology resources.

The staff working for the mental health trust who were involved with Thomas agree that had they had the requisite knowledge and skills in behavioural analysis, and had they had regular input and support from a clinical psychologist in 2013, Thomas's experience, his parents' experience and their experience would have been much better.

5.2.7 Part 5.g: The discharge planning for Thomas from the ATU and the handover from the ATU to the 2014-2015 Care Home Provider (note this also addresses elements of TOR 7)

The circumstance and speed of Thomas's transfer from the mental health trust to his new residence was not optimal and did not allow for a robust discharge planning and handover process between the NHS provider and the care home provider.

Assurances were given by the care home provider regarding their ability to provide for Thomas's complexities, including his communication, physical health, and dysphagia needs; however, they were not fully able to deliver these at the point of admission. They had, however, embarked on training provision for staff, which was completed within the first six weeks of Thomas's admission. Although staff were trained in Makaton and had reported to the local speech and language therapy service that they understood and could deliver Thomas's dysphagia plan, his local consultant psychiatrist identified that further input with his dysphagia management was required in October 2014. Subsequently the visiting speech and language therapist identified that at no time during her visit on 12 January 2015 did the care team present use sign with Thomas.

It would be easy to be critical; however, Thomas was placed at the new care home by the Court of Protection because it was considered the best option for Thomas, and for the remaining patients in the ATU, at the time. The situation was invidious. It was unpalatable to Thomas's parents, it was going to result in a less than optimal transfer of care simply because there was no time to do the discharge as well as might ordinarily occur. The care home was now in the fast lane as far as achieving a situation of preparedness was concerned. The element that may have made a positive and lasting difference for all involved parties was to have included the local community learning disability service from the start – that is, as soon as the new care home was being considered as a serious contender for service provision for Thomas.

Setting this aside, the chronology extracts set out in Appendix D show that the mental health trust did its reasonable best to support the care home over a four- to six-week transitional period, including on-site attendance by Thomas's previous consultant psychiatrist (because the new consultant to whom Thomas had been referred was not initially available), the clinical psychologist who had assessed Thomas, and one of the occupational therapy team. Although the care home may have benefited from earlier occupational therapy input, this was probably not feasible given the speed of Thomas's transfer to this facility.

5.2.8 Parts 5.i: the circumstances leading to the Court of Protection order, and consideration of whether things could have been managed differently and this situation avoided, and 5.j: consideration of where to place Thomas once the ATU was no longer an option

Making an application to place Thomas under the Court of Protection was unavoidable in this case. The court's decision to place Thomas at Lifeways was most likely not avoidable either, based on the situational context at the time.

Based upon the details found in the chronology extract in Appendix E, and under the prevailing circumstances at the time, it is hard to see what else could have been done. Had adult social care had a more comprehensive portfolio of community providers of complex care packages across the north east and north west, it is possible a more satisfactory solution may have materialised for Thomas and his family. However, it is by no means certain that this could have been achieved in advance of 10 July 2014. In Thomas's case, there is a sense of desperation for all involved parties. The learning that seems to emerge is the need for a comprehensive register of providers of community care packages for individuals such as Thomas, ideally held on a national database that is segregated into regions.

5.3 Term of reference 6: Thomas's time at the care home

5.3.1 Part 6.a: handover from the assessment unit to the care home

This was addressed in section 5.2.6 of this report. In addition to the information set out at 5.2.6, the mental health trust ensured that the care home staff were provided with critical written information about Thomas, including his dysphagia management plan, occupational health assessment and sensory assessment. The content of these documents was comprehensive and would have provided the care home staff with a clear insight as to the optimal approaches to adopt when working with Thomas. An example of the calibre of guidance contained in the sensory report is contained in Appendix F.

5.3.2 Part 6.b.i: how much was in place before Thomas went to the care home (the state of preparedness for Thomas)?

The care home provider had first presented its proposal for supporting Thomas in May 2014, when it became clear that the initial proposal of supported living in one of its bungalows was not feasible. As part of the preparation for Thomas coming to one of its facilities, it promised to:

“work with Thomas's family and full circle of support to identify a property in the Wibsey area for Thomas and offer advice on adaptations required to ensure that it is an appropriate long-term home for Thomas. We will create a unique Support Plan and Behavioural Support Plan, Health Action Plan, Activity Plan, Communication Passport, and undertake comprehensive risk assessments and complete Risk Management Plans that will ensure Thomas receives personalised support and remains safe while developing life skills, achieves desired outcomes, and increased independence.”

The initial proposal was for Thomas to receive two-to-one support from 7am to 10pm, and one-to-one waking night support from 10pm to 7am.

The initial proposal made no undertakings regarding either the skill base of the staff who would be supporting Thomas, or any specialist input, such as psychological support. It did however say:

“we will set up a programme of intensive support to help Thomas to manage his anxieties and behavioural presentation so that Thomas can make a success of supported living”.

Furthermore, the residence recommended for Thomas was to be managed by the company's Challenging Behaviour Expert.

However, no firm decision had been made to place Thomas at this facility in until the Court of Protection order was made. They were however a serious contender for care provision from 22 May 2014. The minutes of a meeting hosted by the district council, in Thomas's home town, on this date say:

"[The care home] – organisation currently provides local respite services in [the local] area. They have proposed the option of a flat on a respite site and have proposed that they can provide wrap around care for [Thomas] whilst longer term options are pursued."

A plan was also made to introduce the care home provider to Thomas's family on 23 May 2014.

Subsequent to this, on 26 June, the care home provider attended the inpatient facility where Thomas was cared for to conduct an assessment of him. Key excerpts from this are set out in Appendix G. This assessment covered areas including communication, health and wellbeing, mental health and wellbeing, self-care, eating and drinking, emotional support and relationships, personal care, and access to community and leisure.

On the basis that the commissioners (health and social care) were satisfied with the care home provider, the company committed to work closely with Thomas and his circle of support to identify, through person-centred processes:

- specific health and support needs
- specific social requirements, and support to access community and leisure activities, educational and work opportunities
- specific health requirements – both mental health and physical health
- allocate a professionally qualified Service Manager, to supervise and support the day-to-day management of the package
- devise with Thomas and other professionals involved in his care a comprehensive Support Plan with associated Risk Assessments as appropriate
- plan and coordinate reviews at six weeks, three months and six months (or as required)
- thereafter, plan and coordinate annual review meetings in conjunction with Care Management and contribute to reviews and provide reports as needed.

The above shows that the care home provider comprehensively assessed Thomas's needs before stating their willingness to offer a service to him at their facility. The assessment was completed 14 days prior to the Court of Protection hearing at which Thomas was ordered to live there. This gave little time for the preparations that were required for the newly brought-together care home team to be completely ready to receive him. This fact must be borne in mind when judging their state of readiness to receive him.

The previous section makes clear that the care home had made preparations for Thomas, but it is equally clear that these were incomplete, including the

preparedness of the facility itself. For example, we understand that the en suite facilities in Thomas's bedroom were not fully functional at the time of admission.

5.3.3 Part 6.b.ii: funding considerations and the scope of care package required

The clinical commissioning group confirmed prior to Thomas's discharge from the ATU that his care package would be funded in full. This included the provision of:

- music therapy, though this took a while to achieve
- independent clinical psychological assessment.

The care package was jointly funded by the clinical commissioning group and the local authority.

The care home provider did engage the services of a nurse who was an accredited cognitive behaviour therapist. However, this individual did not have the breadth or depth of expertise to be able to provide a meaningful package of psychological assessment or support to Thomas. An independent clinical psychologist was sourced and funded by the clinical commissioning group.

Because Thomas was registered with a nearby GP, this also meant he was entitled to the input of the community-based learning disability team, as well as input from the district nurses operating from the GP surgery.

There is no evidence that funding for Thomas's care package was curtailed in any way. On the contrary, when it came to light that the care home provider did not have access to psychological therapy input suitable for Thomas, the clinical commissioning group funded the commissioning of an independent consultant clinical psychologist, to undertake the necessary assessments of Thomas, building on those undertaken within the mental health trust. She also provided specific training for the care home staff to enable them to work successfully with Thomas.

5.3.4 Part 6.b.iii: GP cover and Thomas's needs

Thomas was registered at a local GP surgery from the commencement of his residency at the care home facility. The discharge planning or early admission period for Thomas could have included the GP, alongside other agencies, in a joint-professionals meeting to discuss Thomas's complex needs and to ensure that all involved, and 'at a distance' agencies, who might reasonably be called on to support Thomas were fully appraised of his needs, and the previous experience of those agencies providing support to him through 2013 and 2014. Such a meeting may have reduced some of the initial challenges in obtaining a home-based GP assessment for Thomas. At the time, the complexity of Thomas's needs, and the fact that the optimal place to assess him was at home, was not fully understood at the surgery.

There was regular contact between the care home, the GP surgery and the out-of-hours service during Thomas's time at the care home. Thomas's mother was also keen that Thomas was frequently reviewed, and she initiated this with the care home staff when she considered it necessary.

A record of referrals to the GP and the out of hours service can be found in Appendix H.

5.3.5 Part 6.b.iv: physical health assessment, planning, and awareness of Thomas's physical health needs and vulnerabilities

Based on the assessment information already presented in this report, it is difficult to contemplate care home staff not being aware of Thomas's health needs and vulnerabilities. Alongside their daily records, staff's awareness is underlined by their contacts with the GP surgery; their communications with the speech and language service towards the end of 2014 and in early 2015, alongside their communications with the mental health trust and Thomas's social worker; and the detail set out in Thomas's 'My Support Plan'. It is clear care home staff were mindful of Thomas's dysphagia needs, and the record made by the visiting speech and language professional on 22 January 2015 underlines this:

"Had a long discussion with [carer a] and [carer b] around dysphagia – explained the diet and recommendations put in place by [the mental health trust]. Apart from bread and crisps eating is going ok but Thomas insists on having bread with every meal. Staff struggle with this as they are aware of the risks and best interest decision regarding giving risky food versus challenging behaviour and risk of injury to Thomas and staff. Dysphagia assessment completed on [this] visit and some coughing was observed but overall ok if supported and not left unsupervised. Advised to check mouth is clear before Thomas leaves the table."

One area of practice improvement identified was for the care home staff to ensure instructions included in correspondence from specialist agencies are extracted and included in a service users day to care documents. In Thomas's case although the care home staff proactively communicated with the speech and language team, they did not alert them to the fact that Thomas had been having chest infections. This instruction was a component of the initial correspondence sent from the community learning disabilities service to the care home in August 2014. The then manager of the care home recognises that this should have been captured and acted on. The report author does not believe this omission made a material difference to Thomas's physical care or to the management of his dysphagia. No material changes were made to this when the speech and language team attended in January 2015.

5.3.6 Part 6.b.v: diet management and choice – use of picture cards

This term of reference was too specific; however, discussions around it led to the wider and more useful consideration of Thomas's dysphagia management. The speech and language therapists, from the mental health trust, provided training to five members of the care home team when Thomas first went to live there and impressed upon staff the need for risk assessment at every mealtime. This accommodated Thomas's variable aspiration risk, as well as enabling staff to address Thomas's challenging behaviours if he was not allowed to have a specific food he wanted.

The approach taken by care home staff, in accordance with Thomas's dysphagia plan, was, for the greater part, reasonable. The report author is aware that, from time to time, Thomas was observed by a visiting professional to be allowed 'off dysphagia

plan' food by staff; he was also facilitated in eating 'off dysphagia plan' food by family members. The report author has no criticism of either; food was a core source of enjoyment for Thomas, and it is understandable that, from time to time, the need to maintain stable behaviour and the desire for Thomas's family to bring him a source of enjoyment trumped the more prescribed dietary regime contained within his dysphagia plan.

However, as with Thomas's experiences within the mental health trust, the report author considers that during periods of conflict over Thomas's diet, more consideration could and should have been given to convening a Best Interests meeting between the relevant agencies and Thomas's parents. This would have enabled constructive conversation around foods considered of great risk to Thomas, such as crisps and breaded fried foods, and the consideration of alternatives that Thomas would enjoy, but posed a lesser risk to him.

The author does not suggest that the tensions around safe foods for Thomas would have disappeared altogether, but it may have diminished what was a clear pressure point between family and carers.

5.3.7 Part 6.b.vi: skills and experience of staff in working with autistic spectrum disorder patients

The care home provider reports seeking to recruit staff with a range of qualifications. Furthermore, its staff are required to undertake training towards a qualification once they have commenced employment with the company. However, sometimes staff are recruited without qualifications because they have the right experience for the role. The qualification all support staff are required to attain is an NVQ in Health and Social Care. This qualification covers the whole job of being a support worker, including communication; safeguarding; mental capacity; health and safety; person-centred care; advocacy; promoting mental, social and physical wellbeing; social inclusion; anti-abuse; community access and community presence; human rights; and discrimination. The care home provider reports being satisfied that the staff recruited to work at the care home were competent to look after Thomas and his needs. A summary of the experience of the relevant members of staff is included below.

The home manager had been working in social care since the mid-1990s. He initially worked as a support worker with people with severe learning disabilities and complex needs with challenging behaviour. Then he worked as a senior support worker and manager. The scope of his work experience included individuals with learning disabilities and complex needs, including people with autism, Down's syndrome, phenylketonuria (PKU) and cerebral palsy. The behaviour management approach he used over this period was that advocated by the Crisis Prevention Institute²³. Prior to commencing work with Thomas's care home, the home manager also worked with a nearby council as a person-centred planning coordinator for the whole local authority area, before becoming a manager of an independent provider of residential care for individuals with learning disabilities. During this phase of his career he worked with a wide range of individuals with complex needs. In that

²³ <https://www.crisisprevention.com/>

service, the behaviour management technique used was NAPPI²⁴ (Non-Abusive Psychological and Physical Intervention). During his employment with the providers of Thomas's residential care, the home manager also undertook their own two-day training in the management of actual or potential aggression (MAPA).

Of the two senior carers who worked with Thomas, one had prior experience of working in residential communities supporting adults with autism, complex needs and severe challenging behaviour. The behaviour management training provided to them was Therapeutic Crisis Intervention (TCI). This individual had also studied for a psychology degree at university and completed a teaching degree, following which she taught at a school for children with autism.

The other senior carer had, in the three and a half years' before joining the team employed to care for Thomas, worked with adults with autism and severe learning disabilities. This experience included care in hospital, in the community, in people's homes and in local services. He was also a qualified paediatric nurse. He had worked with people with challenging behaviour and been trained in breakaway techniques as well as the two-day MAPA course with his new employer.

The remaining ten staff employed by Lifeways to work with Thomas also had substantive experience of working within the field of learning disabilities prior to working with Thomas.

On the basis of the above, and conversations the report author has conducted with the home manager, she is satisfied that the providers of Thomas's residential care gave due regard to the skills and competencies necessary in the team leaders responsible for the service provided to Thomas, and that it ensured that its other care staff had the basic standard of knowledge required for the care they were required to deliver.

5.3.8 Part 6.b.vii: how did the care home provider ensure that there was always a member of staff on duty who could communicate with Thomas, or at least knew how to communicate effectively with him?

The author is aware that communication could be challenging with and for Thomas. That staff caring for Thomas could communicate with Thomas using Makaton was an important issue for his mother. At the point of admission, there was one member of staff who was competent in Makaton. Staff received basic training in Makaton within a week of him becoming a resident. However, when the local SALT team attended to assess the situation in January 2015, they identified that staff were not using sign with Thomas, as they would have expected. When the care home provider was asked about this, they advised that in their experience Thomas was able to communicate in English and staff were able to communicate well with him using the spoken word. This was also their experience of observing Thomas with his family. Staff were knowledgeable about Thomas's vocabulary in Makaton, but this was mostly limited to food, his family and his feelings. The care home provider considers that staff communicated well with Thomas but accepts that visiting professionals may have expected to have seen some usage of sign with Thomas if they were unfamiliar with his ability to communicate effectively in English. The report author accepts the

²⁴ <https://www.nappiuk.com/>

consideration of Lifeways, but also notes the content of the occupational therapy assessment provided to the care home that highlighted the importance of Makaton for Thomas, and the requests for further assistance and support in communicating with Thomas made by the care home staff to the local community learning disabilities team. A plan to address this was made sadly, Thomas had died before this work could be fully implemented.

5.3.9 Part 6.b.viii: staff whom Thomas did not get on with – how was this managed by the care home?

There were 19 support staff at Lifeways, and from time to time it was necessary to utilise the support of agency staff. However, the care home tried to minimise the contact of agency staff with Thomas, preferring instead that agency staff worked with their other resident in the ground floor flat.(See below)

Within the staffing complement, three teams were identified to work with Thomas, but he had no dedicated team so that he could become familiar with all staff. Because Thomas did not like all staff, the staff rotas were designed to try to respond to this; however, this was not uniformly possible. The author appreciates that it is challenging to provide absolute consistency and to accommodate sickness, holiday periods and staff being off-duty. She accepts that the care home did its reasonable best to enable consistency, and that from time to time there will have been situations where staff whom Thomas was not keen on were caring for him.

5.3.10 Part 6.b.ix: use of agency staff unskilled in dealing with autism – how often were agency workers caring for Thomas?

The use of agency staff was limited. Where agency staff were used, the care home provider would tend to use the same regular staff who would have the relevant skills. Between 7 July 2014 and 1 February 2015, agency staff who worked night shifts amounted to 14% of total hours, and agency staff who worked day shifts amounted to less than 10% of total hours. However, where agency staff were used, the care home provider asserts it was rare that they would be placed upstairs with Thomas. Agency staff were almost always allocated to the service users who were based on the ground floor at the care home, and employed staff looked after Thomas.

5.3.11 Part 6.b.x: of the staff employed by the care home provider, what was their skill, knowledge and experience in the field of learning disabilities, autistic spectrum disorders and challenging behaviour, and what specialist training was provided to them (in the context of residential care provision)?

See section 5.3.7.

5.3.12 Part 6.b.xi: physical health surveillance, including medication management – how was Thomas’s physical health monitored, and was this reasonable?

Thomas’s medication was managed by the general practice, and also via Thomas’s psychiatrists. It is indisputable that Thomas’s usage of sedative and antipsychotic medication was reduced while he was at the care home.

With regard to his physical health management, the tables in Appendix H make it clear that Thomas's physical health was reasonably monitored.

5.3.13 Part 6.b.xii: specifically, the oversight and management of Thomas's health in the two weeks preceding his death

This is covered by preceding parts, specifically 6.b.iii, iv and xi.

5.3.14 Part 6.b.xiii: management of psychological trauma following his abuse in Norcott House – how was Thomas helped to deal with the trauma of abuse?

This is covered under part 5.f above.

5.3.15 Part 6.b.xiv: what was the plan to get him back home prior to his death?

This question is one of utmost importance for Thomas's family. There is no doubt that all agencies were committed to facilitating Thomas's return to his home town. However, there was no clear progressive and monitored plan that was formulated and agreed by all agencies to achieve this.

In the material they had provided to commissioners, the care home provider had been clear that they work on the basis of an 18-month residency, to allow sufficient time for settling in, stabilisation and the acquisition of the necessary skills and coping mechanisms for a resident to have the most successful transition into community living. However, there was no consensus among agencies that the author of this report has been able to establish. Furthermore, there was no clear short-, medium- and long-term goal map, with clearly articulated delivery dates (albeit aspirational), to enable the agencies to monitor progress of the plan, including the need for readjustment.

The interventions of the independent clinical psychologist were significant, and in December 2014, adult social care told the report author that because of her work they had a much clearer plan of what Thomas would need in the community and considered that they 'now' could start to plan for this. However, the author did not gain a sense that this was a shared multi-agency perspective.

Although Thomas's parents are unlikely to pass positive commentary about Thomas's placement in the care home, his 'My Support Plan' was comprehensive and completed within three weeks of Thomas arriving at the care home. It comprised 16 individual points that were designed to support Thomas and enable him to move back near to his parents and family, as soon as he was considered stable enough to do so successfully.

5.3.16 Part 6.c.i, ii and iii: regarding Thomas's complaints of abuse

The care home, like other agencies, undertook local management investigations of allegations of abuse. There appear to have been approximately 15-17 allegations made between October and December 2014. In no instance did the internal management review identify features that resulted in the allegations being upheld. However, similarly, as with other providers, the care home has not described to the report author any structured approach that enables them to produce audit data that demonstrates that abuse (either emotional or physical) is not a feature of their residential environments, or how it provides ongoing assurance that 'good' behaviours are consistently displayed by staff across all its facilities. Because this

issue spans more than one component of Thomas's chronology and remains a contemporary issue of concern for care home providers, it is addressed in the recommendations section of this report.

5.3.17 Part 6.d: the overall decline in Thomas's behaviours. His mum wanted an MRI, as she felt there was more to his decline than staff thought. It is the understanding of Thomas's mother that the post-mortem revealed signs of early onset dementia; she wants to know why no one considered early onset dementia.

The issue of the requirement of an MRI scan and the lack of clinical need for this is attended to in earlier sections. Regarding the belief of Thomas's mother that her son had signs of early onset dementia, the report author has seen nothing to support this belief, and neither has any reference to dementia been made in any discussion she had with staff caring for Thomas, including his consultant psychiatrists. The post-mortem following Thomas's death identified no brain abnormalities.

5.3.18 Part 6.e: if there had been a wider range of consideration of organic reasons for Thomas's deterioration, and this had been diagnosed prior to his death, what difference would it have made to his management?

Thomas had a number of clinical tests, including an EEG to test for epilepsy, which he did not have. He was also assessed by a neurologist, who found nothing untoward. As far as the report author can determine, there were no indicators for Thomas to have received a wider range of tests than those that were undertaken. This statement does not diminish his mother's anxiety for her son, and her wish for him to have tests that she hoped might provide an explanation for what she and Thomas's family experienced as a deterioration in Thomas's behaviours. Once Thomas had been assessed in December 2014, there appeared to be some greater clarity that the changes in Thomas's behaviours were considered to be situational and trauma based.

5.4 Terms of reference 7 and 8: the period 2 to 4 February 2015, including Thomas's hospital care

The author's analysis of the information available from the time of Thomas's collapse to the time of his death convinces her that:

- The staff on duty at the care home did their reasonable best to provide CPR to Thomas while they were waiting for paramedic assistance. That they did this is evidenced by the call handler giving advice on what to do, and the observation of the paramedic team on arrival. It is important to remember that the staff are not clinically qualified and can deliver a standard of resuscitation equivalent to any member of the public who has attended a first-aid course.
- The attending crew did a good job in resuscitating Thomas at the scene prior to transporting him to hospital.
- Thomas was attended to immediately on arrival at the local teaching hospital and provided with the treatment he needed, including admission to ITU. He was treated proactively and in line with good practice guidelines of induced hypothermia and passive rewarming, and the timing of the tests on his brainstem was appropriate.

- The teaching hospital was honest with Thomas's family regarding his condition and his low survival chance. He had fixed pupils and a Glasgow coma score of three on arrival at hospital.
- Although the tests undertaken to confirm Thomas's brainstem death were carried out appropriately, and in line with the strict criteria that apply, Thomas's family do not have good memories of when the decision was taken to take Thomas off life support, including ventilation. At that time Thomas was not breathing and was not able to make any respiratory attempts, so the removal of ventilation will not have caused him any distress. It is very hard for families to process this, and the intensive care team understand this.

5.5 Specific safeguarding relevance

It is known that Thomas was abused on one confirmed occasion, at the residential care facility in 2013: one member of staff was convicted of this, and another dismissed from service. Three staff members who were employed by the independent care provider, and who remain working with the current provider of service, are adamant that they took all allegations of assault seriously, liaised with the local safeguarding body, and were unable to find evidence of Thomas being abused, except on this one occasion. Thomas's father, however, remains adamant that support workers employed at the time told him that abuse was occurring. Thomas's mother was also raising concerns and had a safeguarding meeting with the local authority about her son. However, the identity of the staff has not been revealed to the author of this report.

There was also an incident during his residence at the residential care facility, where one of Thomas's sisters raised a concern over an incident of excessive restraint of her brother. This had been reported to her by colleagues working for the same care provider she was employed by at the time. Thomas's care provider asked his sister, on more than one occasion, to reveal her source of information, so that the allegation could be followed up. However, this was not possible, and the issue remained unresolved. The care provider took reasonable steps to understand and explore the concern raised.

The many allegations made by Thomas about staff, and sometimes family members, presented difficulties for all agencies. Although Thomas's parents did not believe the assurances they received from agencies that their son was not being abused, the independent author is satisfied that each organisation investigated all allegations in line with the expected standards in place at the time. This included liaising with the relevant child or adult safeguarding teams appropriately, to seek advice on how best to proceed, and how best to monitor the situation. Thomas's mother was also encouraged to take her concerns to the local safeguarding board.

In addition to investigations undertaken, additional measures were taken to enhance the safeguarding of Thomas. These were not the same in each organisation.

Examples include:

- having a dedicated team of carers for Thomas and trying to ensure that these staff worked with him as far as possible
- maintaining line of sight of Thomas

- rotating staff frequently so no one was exposed to sustained assaultive behaviours for prolonged periods (this was a strategy used by the mental health trust)
- removing staff from Thomas's care team to whom he took a dislike, though because of staffing requirements this was not always possible
- trying to ensure that Thomas's mother was advised of any abrasion or minor injury Thomas sustained and how; this, however, was an area of constant frustration for the family, who often did not feel well informed
- agreeing with Thomas's mother to complete a body map of Thomas each morning and afternoon (any mark, blemish or abrasion would be noted on the body map).

6 What has changed since Thomas's death

Several changes have already occurred since Thomas entered his adult years.

6.1 Children's Services

The district council in which Thomas's parents live, has now commissioned the Affinity Trust²⁵ to develop Positive Behavioural Support plans with up to five children at a time over the next 10 years. This is a significant intervention, and it is anticipated that it will benefit young people like Thomas and enable well-informed packages of care.

6.2 The Independent Care Provider

6.2.1 Visibility of managers

Regarding the systems of work at the time, managers were not as visible in residential areas as they are now, and the organisation had not instituted a system that limited staff's sustained exposure to Thomas's more challenging behaviours. It would now utilise a system of hourly staff rotation when supporting a resident with the range of behaviours and unpredictability that Thomas displayed.

6.2.2 Management of staff stress

Although staff debriefing was available in 2012 and 2013 for those working with challenging clients, there was an over-reliance on the unwavering resilience of the staff to cope with, and rise above, sustained instances of verbal and physical assault.

This would not happen now. The new providers of the residential care facility service have a structured process whereby: "Staff are more closely monitored, our policies and procedures have been updated which are more in-depth – we have in-depth debrief forms, breaks and recuperation time is offered more freely. We complete debriefs after certain incidents, monitoring is in place to ensure all staff support most residents where possible, so they do not get 'burnt out'. Those residents with 'core teams' are large enough to give each other a break. Regular core team meetings are organised with the manager, discussing concerns, stresses and breaks for staff and the resident."

6.3 The Mental Health Trust

6.3.1 Psychological assessment

Service users of the learning disability ATU who require a psychological assessment receive it. When the situation arises that there is insufficient internal provision, the clinical commissioning group is now approached to fund independent provision. The service can show that this has, and does, happen and that assessment has been funded under such circumstances. It is mostly the service's experiences with Thomas that have led to this development.

²⁵ <http://www.affinitytrust.org/>

6.3.2 Service user coordination

The Intensive Learning Disability support service no longer retains care coordination responsibility for service users who are placed out of county. A full discharge care programme meeting now takes place and care coordination is handed to the local learning disability team. The team maintains contact with the service user, his/her family and the newly responsible team by ensuring they are a regular invitee to Care Programme Approach review meetings.

6.3.3 Training in Mental Health Act managers' hearings

The Mental Health Act adviser for the trust, supported by the senior managers for the learning disabilities service, has introduced a training programme for staff in what is required when presenting information to a Mental Health Act managers' hearing. The experiences of Thomas, his parents and the staff within the service have been used to illustrate the possible consequences of being unprepared. The report author understands that this programme has been well received.

6.4 The Ambulance Service

There have been several changes within the ambulance service. These are as follows:

1. The Ambulance Service Emergency Operations Centre has now got access to SystemOne, and the Clinical Hub can access patient records to understand previous patient contact where there is a known concern from a previous medical attendance. A crew will also be able to contact the hub to access SystemOne if they identify features in a patient that lead them to suspect a prevailing health issue or issues. Although routine use of this facility is not expected of attending crews owing to the feasibility of responding to high-volume requests, the fact that it is available means crews can seek further information about a patient if they consider it appropriate based on the field assessment. The use of the newly introduced National Early Warning Score (NEWS) for the ambulance service will influence this.
2. The ambulance service has now rolled out the National Early Warning Score (NEWS) assessment, which is mandatory for all medical patients. This allows clinicians to monitor patients, track deterioration and trigger specific actions at each score. The NEWS was developed by the Royal College of Physicians and is recommended to be used in all patients presenting acutely to hospital and ambulance services. The NEWS assessment is also featured in the NICE recommended Sepsis guidelines, adopted by the ambulance service, and all front-line clinicians have been trained in both the NEWS assessment and the Sepsis Screening Tool.
3. The ambulance service is rolling out a patient non-conveyance leaflet, which will allow the ambulance clinician to clearly document the agreed care plan, and any actions for the patient or carers to follow.

6.5 The Care Home Provider

6.5.1 Service user observations

The registered care home manager at Thomas's care home has, since Thomas's death, been instructed by a GP to purchase specific home monitoring equipment for

a resident. This was a new experience for the home manager. The GP provided a simple checklist of upper and lower observation levels for the unskilled carers to refer to. The instructions are simple: if the BP is less than X, call the GP; if the BP is more than Y, call the GP. The registered care home manager found it worked very well, and stated that he and his staff are, and always have been, willing to do observations under the instruction of the service user's GP when there are clear instructions about what observations to take, what equipment to use, and what the parameters for escalation to the GP are.

7 Conclusions

7.1 Author's conclusions

As indicated at the start of this report, the review of Thomas's care and treatment posed a significant challenge, although the author was keen to meet, as far as possible, the needs of Thomas's family, given the anguish they experienced through most of Thomas's life.

When the review process commenced in November 2016, I was dubious as to whether it would be possible to realise any meaningful learning potential from a case where the emotions of the family, and staff who had cared for Thomas, remained raw. However, this review has revealed opportunities for meaningful learning and system improvement. This is alongside a real sense of the affection staff had for Thomas. I have particular reflections about Thomas's time in the care of the mental health trust and the care home.

The Mental Health Trust

It is clear to me that the ATU staff tried their utmost to provide a service that might meet some of Thomas's needs, despite the environmental limitations. In my professional career, I have never observed staff exhibit such raw emotion about their inability to meet a service user's needs. They aspire to achieve high standards for all service users, and their inability to achieve this for Thomas really affected them. Staff expressed to me a sense of powerlessness to make a tangible and sustained positive difference to Thomas's life, and this has left an indelible imprint on them, with some expressing a sense of failure. The trauma caused by Thomas's assaultive behaviour was also notable. A significant number of staff were injured during their efforts to care for Thomas. Despite this, not one staff member I spoke with had a bad word to say about him; genuine warmth and liking were what was communicated.

Although traumatised by Thomas's experiences, Thomas's family were not the only party traumatised; staff were too, and this cannot be overlooked.

The Care Home

Thomas's family have few positive thoughts about this episode in Thomas's life. However, my review of the care home records revealed an attentiveness to Thomas that his family either did not see or were unable to notice. Although Thomas's family consider that his health deteriorated while he was there, the overall quantitative evidence is that Thomas made progress at the care home. His behaviours settled and his medications were reduced. He went out regularly with his parents, and during Christmas 2014 he went home to his father's house, which went well; it enabled consideration of more regular visits home. This situation could not be imagined when he was resident on the ATU.

In this report I have commented on Thomas's 'My Support Plan'. As a consequence of this independent process, I would like to see a model of 'My Support Plan' that is truly a document for the service user, which follows them through the various agencies they may come into contact with, rather than being a plan that is newly formulated following each change in the dominant care agency, as happened for Thomas. Having immersed myself in Thomas's case, it seems clear that a 'My Support Plan', as well as being the service user's document, needs to be formulated

by the multi-agency community involved with that service user at the various stages of the service user's adult life. Family members also need to be able to contribute to its content and the overall direction of the care journey. In this case, the plan for Thomas's return to his home town was anything but clear, and it seems imperative to me that where a service user is in residential care, but the forward plan is more independent living in the community, then a structured plan for achieving that, with target delivery dates, needs to be agreed by all involved parties. Had this occurred in Thomas's life, I believe it would have made a positive difference for his family and the multi-agency community involved.

Finally

The learning and opportunities for positive change in the care and management of individuals such as Thomas that have arisen from this review have only been possible because of the determination of his family to achieve a review of his care and that the staff working with him demonstrated a willingness to reflect openly, and to accept that some things could and should have been done differently.

Perspectives and opinions I formed as the review process unfolded were shared openly with Thomas's family. Some they agreed with, and some they did not, but open dialogue occurred throughout, which has enabled us, together, to reach a point where the review can be concluded, and the report published. I accept that the process has not met all the needs of Thomas's family, and the review process has not answered all of their questions. I hope that what has been achieved validates the tenacity with which they sought this independent process.

7.2 Main conclusions

The author and review team are satisfied that the agencies involved in the care and management of Thomas set out to provide a good service to him and his family. They are also satisfied that it is unlikely that there was systematic abuse of Thomas during his late teenage and young adult life, while his wellbeing was the responsibility of services.

However, the author and review team consider there were tangible opportunities for Thomas's care experience to have been different between 2012 and 2015, had the following occurred.

- More vigilance when he was at the first residential care facility, and the institution of a system of staff rotation so that no member of staff was looking after Thomas for more than an hour during periods of sustained challenging behaviour and assaults on staff.
- A detailed clinical psychological assessment of Thomas, ideally between 2011 and 2012, but at least in 2013 when he was admitted to the mental health trust.
- The implementation of a biopsychosocial model of care and the formulation of a positive behavioural support plan for Thomas, while he was a patient of the mental health trust in 2013, that delivered a shared and seamless strategy for his management, including short-, medium- and longer-term goals, with agreed reviews that included Thomas's parents.
- The use of Best Interests meetings where Thomas's parents disagreed with recommendations professional staff made in Thomas's best interests. This would have enabled a complete airing of the issues and would have required

his parents to be partners with the responsible agency or agencies in agreeing the plan of care, including measures for risk minimisation and the acceptance of risk where activities pursued posed a recognised risk to their son. The author has no doubt that such meetings may have been tense, but they may have removed the ‘them and us’ situation that became entrenched, particularly around Thomas’s dysphagia management plan. Furthermore, with regard to this specific issue, both parents would have been required to acknowledge that foods they provided for their son increased his risk of aspiration pneumonia, and they would have been required to make clear that they were accepting that risk on their son’s behalf, as he did not have the capacity to accept it for himself.

- There is a realistic possibility that had the Mental Health Act managers’ meeting on 20 May 2014 been adjourned to allow further information to be presented about the package of care being offered by the secure learning disability facility Thomas’s parents objected to, he would not have been discharged from section 3 of the Mental Health Act. This would have resulted in a completely different experience and chronology for Thomas from this point. Whether it would have been a better experience is indeterminable.

Regarding the predictability and preventability of Thomas’s death by hypoxia induced cardiac arrest, secondary to chest infection²⁶, this was not predictable. Thomas was susceptible to chest infections; this was well understood. He was also susceptible to aspirating fluid, and food particles. The care home staff, supported by the speech and language professionals, did what they could to minimise this risk, including the consideration of reasonable risk-taking when withholding a non-recommended food that Thomas wanted might predictably have resulted in a level of challenging behaviour that was riskier than the food he wanted to eat. Lifeways staff can demonstrate they contacted Thomas’s GP about his chest infections and provided the treatment they were instructed to. Furthermore, the information gathered shows they contacted the out-of-hours service or emergency services if they, or Thomas’s parents, were concerned.

Regarding the preventability of Thomas’s death, this is more complex than it might at first seem. Had there been a more robust safety net instituted by the ambulance crew, there was a realistic opportunity that Thomas may have been admitted to hospital by his GP within 24 hours, had his respirations, pulse and oxygen saturation levels remained outside of normal parameters. Because of what subsequently happened, it seems reasonable to presume that Thomas’s observations in these respects remained outside of the normal range. In this circumstance Thomas, on admission to hospital, would have been assessed and an appropriate plan put in place. He would have been monitored using the National Early Warning System. This would have provided staff with the information they needed to act quickly if Thomas deteriorated, and thus given him the opportunity of recovery.

The view of one of the respiratory consultants at the teaching hospital is:

²⁶ The health records mention ‘asphyxiation pneumonia’, but the post-mortem report does not. However, whenever anyone is resuscitated, there will be aspiration in the lungs. The author understands that because of this, it is difficult to say whether Thomas’s chest infection was because of aspirate or not.

“The assessment and observations taken by the GP at 15.15 on 29th January 2017 were not concerning. The observations taken by the ambulance staff at 21.40 are concerning. Although the elevated Heart Rate and Respiration Rate were put down to hyperventilation, they were still raised at 22.00, making this explanation rather less likely. It is unfortunate that the Oxygen saturations were not re-taken at 22.00.

I would have been concerned about this chap and would have thought that he should have been reviewed by a GP the following day.

If his observations had been similar or worse at that time, I suspect that the GP would have admitted him.

In hospital, he would probably have received oxygen (if oxygen saturations still below 94%), had an x-ray and blood tests and may have needed intravenous antibiotics depending on the results of these tests. Staff would have tried to persuade him to allow oxygen and an IV line to be inserted. Sedation is normally avoided at all costs in patients suffering from respiratory failure.”

In the circumstance that Thomas’s observations did not trigger onwards admission to hospital, the care home would have had to rely on their visual observation of Thomas, as they did in 2015. Unfortunately, his outward behaviour was not a good indicator of his physiological wellbeing, especially in someone so young. This is not something an unqualified support worker or a residential care provider would be expected to know.

It is the perspective of the independent team that the most likely scenario is that Thomas’s observations would have remained outside of normal limits and he would have been transferred to hospital on 30 January 2015, with an appropriate treatment plan instituted.

To summarise:

- it was a significant risk that Thomas might get chest infections and possibly pneumonia, possibly secondary to aspiration, most likely from food.
- it was possible that a cold or chest infection could be life-limiting for Thomas at some point.
- the lack of monitoring of Thomas after the ambulance crew assessed him on 29 January was avoidable. Several of his physical observations – respirations, pulse and oxygen saturation levels – were outside of the normal range. This should have resulted in either a primary care referral, or a clear instruction to the care home to contact the GP the following morning, such that a repeat of his observations was achieved.
- on the balance of probabilities, following GP assessment, it is likely that Thomas would have been admitted to hospital on 30 January 2015.
- the residential care home did what was asked of them; they observed Thomas, and where his outward behaviour caused concern they called for advice, as demonstrated by their contact with NHS 111 on 1 February 2015.

Thomas did not receive the clinical assessment he should have done after 29 January. The absence of this removed the opportunity for him to be treated in

hospital if his observations remained outside the normal range, which was likely. Had this omission not occurred, it is possible that, with treatment, Thomas would have recovered from his chest infection.

8 Recommendations

Recommendations

The report recommends the following, based on the evidence and testimony provided.

Recommendation 1

Target audience: The local and regional nursing teams of NHS England North and the commissioners of residential care home placements in the three district councils Thomas resided in

This case underlines the lack of expectation of residential care home staff to be able to deliver a range of physical health observations that individuals in a normal domestic situation either independently, or with the support of family/carers undertake at home. Objectively Thomas may have benefited from having his temperature, respiration rate and pulse checked when he was unwell with chest infections. This could have formed part of his individual support plan and may have enabled a more accurate assessment of Thomas's wellbeing to have been achieved during periods when he was unwell. Furthermore, these basic observations in the last week of Thomas's life may have alerted care staff to the fact that Thomas was deteriorating, when this was not obvious from his outward behaviour.

The author of this report appreciates that staff employed by care home providers are not professionally qualified. However, if a basic range of physical health monitoring is within the competency of a normal domestic household, then it seems reasonable that at least this standard is expected as the normal for a residential care facility, where the provider provides a surrogate for the care and support a family might otherwise provide. The local and regional nursing teams of NHS England North and the commissioners of residential care home placements in the three district councils Thomas resided in are asked to raise this issue with the Care Quality Commission to achieve wider exploration of this issue so that uniformity of expectation can be achieved nationally.

Recommendation 2

Target audience: The ambulance service

The ambulance service must achieve reliability and consistency across all its response teams regarding the practice of safety-netting when a decision is made not to transfer an individual to hospital. Safety-netting is where the responding crew make sure that appropriate steps are put in place to assure the ongoing safety of the individual, and to ensure that appropriate and timely clinical follow up happens. In this case that should have occurred the next morning.

As part of the roll-out and use of the 'non-conveyance leaflet', the ambulance service is recommended to audit the success of this intervention within the first six months of roll-out.

Recommendation 3

Target audience: The ambulance service

The ambulance service must satisfy itself that the error of not referring Thomas for primary care follow-up is a one-off incident and does not represent a wider problem across its attending crews, especially regarding residential care facilities. It is recommended that the audit of this issue be presented to the clinical commissioning group along with any remedial action plan, should this be shown to be required.

Recommendation 4

Target audience: The adult safeguarding boards in the three districts Thomas resided in

The adult safeguarding boards in the three districts Thomas resided in need a process that provides evidence-based assurance that concerns about abuse are being appropriately responded to within and across local authority boundaries, including:

- capturing the voice of the service user
- an independent investigation process where clusters of concerns materialise in a single care facility
- more in-depth assessment of the overall approach to care where the volume of concerns being raised indicates this is required.

Furthermore, if there is a history of safeguarding concerns for an adult at risk, and he/she is placed with a new provider in a new authority, a system of reliable handover of information about the history needs to be achieved so that the newly responsible safeguarding team are situationally aware.

Recommendation 5

Target audience: The adult safeguarding boards, clinical commissioning groups and local authorities involved in this case

Thomas's experiences, and those of others highlighted in recent public reports including the Learning Disabilities Mortality Review Annual Report 2017 highlights a need for commissioners to review and reconsider in the current assurance mechanisms used to instil confidence that residential care providers are providing services that are legally compliant; safe, effective and of good quality. Furthermore, that Service Users are free from abuse of any kind.

Thomas's family did not consider that they were provided with any objective assurance of the above during his short adult life.

Devising a workable and sustainable system of assurance may well be challenging, as methods that enable the lived experience of residents to be captured is time consuming. Nevertheless, this cannot be used as a reason for not utilising approaches such as participant and non-participant observer studies²⁷. The author

²⁷ This can be structured, unstructured, or a combination of both. What is important is the observer work is conducted on a regular basis and not as a 'one off'. The findings must be collated and reviewed over time.

suggests this intervention could be used a few times a year, with additional interventions conducted if concerns about quality, safety, compliance or abuse are raised.

Recommendation 6

Target audience: The local and regional nursing teams of NHS England North
The medical and nursing director of the mental health trust involved

A full and validated account of the information provided to and shared by participants at a Mental Health Act review panel must be consistently achieved to avoid critical loss of important information about what was discussed and agreed at the time. This case has highlighted the dangers of not capturing this standard of record.

This and all mental health trusts are asked to consider the following, consider the extent to which they already do this, and if not consider implementing the below as a component of their plan to achieved the stated objective:

- ensure that notes and minutes taken by the hearing managers are scanned and saved alongside the final hearing report and decision made. The lack of retention of comprehensive minutes in this case required the firm of solicitors representing Thomas's father to retrieve those that the involved solicitor had made immediately prior to and during the meeting. These minutes created a different picture of events than the memory recall of the meeting chair.

Recommendation 7

Target audience: The local and regional nursing teams of NHS England North
The medical and nursing director of the mental health trust involved

When a mental health tribunal or managers hearing in convened, those responsible for convening the meeting must achieve a situation where all clinical and non-clinical staff who have a significant involvement in the situation giving rise to the hearing or meeting are asked to provide a written submission, or oral evidence at the hearing. In Thomas's case this did not happen. This resulted in an incomplete picture of the situation and removed the ability of the panel to properly consider its options regarding adjournment. The impact of this lack of situation awareness was stressful for Thomas, his family and all staff involved.

Recommendation 8

Target audience: The District Council, in Thomas's home town, its health partners and residential care providers

A service user's My Support Plan should be just that. This independent process identified that Thomas's My Support Plan was a document created by whichever agency was dominant in Thomas's care at the time. This did not lead to a plan of care that enabled Thomas, or his family, to provide input to the short-, medium- and long-term goals in a way that enabled them to be equal partners in his care planning.

Furthermore, families and more able residents could be considered for inclusion as members of an observation team, alongside employees of a provider, and relevant health and social care professionals. Direct observation is a tried and tested quality and safety improvement tool.

Furthermore, issues such as achieving a long-term residential placement for Thomas in his home town, where he wanted to be, lacked cohesion and clarity. Whilst all agencies were committed to facilitating Thomas's return to his home town, how this was to be achieved and the timeframe for achieving this was not as clear for the family as it should have been. The District Council, in Thomas's home town, its health partners and residential care providers need to determine how the principle of the My Support Plan being truly representative of the needs and aspirations of the service user, can be achieved for individuals in receipt of multi-agency services.

In taking this forward, the District Council in, Thomas' home town, and its partners are also asked to consider how the agreed short-, medium- and long-term goals for an individual can be more concretely formulated within the My Support Plan, so progress with the plan can be accurately assessed and relevant adjustments made where necessary. This would assist in providing the transparency on process and progress that was missing for Thomas.

9 Appendix A

9.1 Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

A confidential inquiry into premature deaths of people with learning disabilities was published in 2013²⁸. This report sets out the findings of the confidential review process, which:

“investigated the sequence of events leading to all known deaths of people with disabilities (aged 4 years and older) over a 2-year period in 5 Primary Care Trust (PCT) areas of South West England.”

“[The inquiry reviewed] the deaths of 247 people with learning disabilities over the 2-year period in 2010–2012, approximately 2½ times the number expected. This apparent difference may reflect the under-recognition of people with mild learning disabilities in the community and that two-fifths (42%) had previously lived in local long-stay institutions and then settled nearby. Most (96%) were of white UK ethnicity. The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus, men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.”

“As with the general population, the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%), although both were less prevalent than in the general population (29% and 30% respectively). The final event leading to death was most frequently a respiratory infection in the people with learning disabilities.”

“Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs.”

The inquiry also found that:

“Two in every 5 people whose illness was reported to a doctor experienced problems with having their illness diagnosed. The most frequently reported problem was that the investigations needed to diagnose their illness were not done or posed difficulties. Of note is that in a quarter of cases the concerns of the person with learning disabilities, their family or paid carers were reportedly not taken seriously enough by medical professionals.”

²⁸ Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD).

Problems experienced by people with learning disabilities, and families, in achieving a diagnosis were found to be:

Type of diagnosis problem	% (N69)
Problems with the investigations	41
Died with undiagnosed significant illness	33
Concerns of person, family or paid carers not taken seriously enough	25
Problems with referral to specialist	19
Misdiagnosis	7
Other delays in diagnosis	7
Symptoms/events in hindsight should have been investigated but were not	7
Investigations conducted but no diagnosis of illness	4
Other problems	3

9.2 Learning Disabilities Mortality Review Programme (2015 to 2018)

Following the publication of this confidential inquiry in 2013, a national learning disabilities mortality review programme was set up in 2015. This is a three-year programme:

1. “To support local reviews of deaths of people with learning disabilities throughout England.
2. To undertake a number of other related projects to help us find out how many people with learning disabilities die each year in England and why.”

The ‘Support for local reviews of deaths of people with learning disabilities’ is pertinent to this NHS England commissioned review. Through the Learning Disabilities Mortality Review Programme, all deaths will be reviewed, regardless of the cause of death or place of death, to:

- “Identify potentially avoidable contributory factors to the deaths of people with learning disabilities.
- Identify differences in health and social care delivery across England and ways of improving services to prevent early deaths of people with learning disabilities.
- Develop plans of action to make any necessary changes to health and social care services for people with learning disabilities.”

10 Appendix B – Engagement with Thomas’s family during this independent process

10.1 Initial contact with Thomas’s family

The first face-to-face meeting with Thomas’s mother occurred on 20 October 2016. Thomas’s elder and middle sister also attended this meeting. Contact was successfully made with Thomas’s father in February 2017, and a meeting achieved on 27 February 2017.

10.1.1 Email

It was agreed with Thomas’s family that the best way to keep them updated during the review process was by email. The report author would text Thomas’s father if there was anything specific in these emails that required his attention.

Email updates and communications occurred with Thomas’s family on a monthly, or more than monthly, basis throughout the greater part of the review period. Most of the emails constituted updates for the family about the progress of the review.

10.1.2 Telephone

Telephone communication also occurred with Thomas’s mother, father or elder sister on an as-required basis, and all family members were given the contact details of the report author and advised they could call her at any time.

10.1.3 Meetings

Apart from the initial meeting, the report author and family members meet to review and discuss the draft report in October and December 2017, and with NHS England-North in April 2018. A final meeting occurred between the report author, Thomas’s mother and elder sister on 5 July 2018.

10.1.4 Finalising the report

The time to finalise the report was lengthy for two reasons. Firstly, the initial report consisted of approximately 200 pages and was hard for the family (and others) to digest. It had to be shortened without losing key information or context. Secondly, Thomas’s family wanted him to be described as he was to them, and to share some of their feelings about his care over his short adult life. It was indescribably hard for them to get down in words what it was they wanted to say. This was finally achieved in July 2018.

11 Appendix B - Investigative methods utilised for this independent process

A decision was made at the start of this independent process to employ the principles of the After-Action Review model. This model is based around a process implemented by the military services in the mid 1970's and enabled whole team reflection about:

- What had good well
- Where improvements were required
- Any areas that fell unacceptably below the standards of service delivery or practice required

Because of the number of agencies involved with Thomas, it seemed an approach that would facilitate the multi-professional discussions and reflections necessary for inter-team and cross-team and agency learning to be achieved.

Consequently, on 8 November Consequence UK (CUK) hosted a multi-agency all day meeting to set out the approach, CUK's rationale for utilising this model, and its requirements of each agency. The event was well attended by all agencies.

A key requirement of each agency was to construct an analytical chronology of its care contact with Thomas between the time periods set out in the terms of reference.

This included

- Identifying where it had met the standards required in its agency/professional group
- Where it considered it could have delivered a better service or standard of care, but there were no serious dips in the original service or care provided
- Identifying any areas of care or service provision that had fell so far below the required standards as to constitute a serious breach in service or care standard

All of the direct care staff at the meeting, and their senior managers agreed to this method as the most appropriate in the early phase of the review.

Once each agency had delivered its completed timeline to CUK a series of telephone, and email contact occurred with each agency to achieve the depth of information required to determine the appropriateness of the terms of reference and next steps. The timelines were also shared with the two clinical reviewers for their insights and comments.

Following this a decision was made to host a series of meetings that focused on the terms of reference addressing the care period 2011 – 2015. These meetings ranged from a half-day to a whole day in length, and included frontline practitioners, their immediate line managers, senior managers through to assistant director level in most of the participating agencies.

Thereafter the focus of attention was further crystallised to April 2014 – February 2015.

Additional information was gathered about this period via written correspondence, 1:1 and small group interviews, with the relevant professionals involved. The Coroner's office also provided valuable support by making information, it had already collected, available to CUK.

In addition to the above throughout the process the regular updates provided to the family regarding progress with the review enabled a range of conversations to take place with Thomas's mother and/or his elder sister to test out the family's perspective and emerging information. Although the family recollections did not always match the information gathered from the agencies for the most part CUK was able to negotiate a path through this that has enabled the range of points of view to be respected.

The volume of information gathered during the process was significant, so agencies were asked to engage at an early stage of the information analysis, and to comment and input to this on a term of reference basis. This engagement of the agencies was invaluable as it ensured that the correct interpretation of information and perspectives was achieved.

This process was repeated with Thomas's family, once the report was completed as a readable draft. Thomas's mother and his sisters all engaged with CUK to work through the report in a constructive way, which has also helped shape the final document. It is mostly due to the input of Thomas's family that a decision was made between CUK and the family, and then NHS England-North and CUK, that CUK would produce a condensed report for publication that enabled the key learning points to be presented, whilst protecting Thomas's and his family's right to privacy.

12 Appendix C – Thomas’s medications while under care with the Mental Health Trust

Antipsychotic medication

- Risperidone
- Omeprazole
- Quetiapine
- Clopixol
- Sodium Valproate

Sedative

- Lorazepam
- Promethazine

Antidepressant

- Fluoxetine

Pain relief

- Paracetamol

Hay fever medications

- Promethazine
- Piriton
- Beclomethasone
- Salbutamol inhaler

Antibiotics

- Amoxicillin
- Clarithromycin
- Augmentin
- Treatment for H. pylori
 - i: Omeprazole 20mg BD for 7 days
 - ii: Amoxicillin 1gm BD for 7 days
 - iii: Clairithromycin 500mg BD for 7 days

Discharge medication

- Zopiclone 3.75mg one dose between 8 and 9pm if required
- Gaviscon Advance liquid 10mg TDS
- Petroleum Jelly Topical (QDS) four times/day
- Diprobase Emollient to face morning and nocte
- E45 cream Topical
- Salbutamol inhaler with Volumatic spacer inhaler 2 puffs prn

13 Appendix D – Chronology extract from the discharge planning for Thomas from the ATU and the handover from the ATU to the Care Home Provider in July 2014

The situation for Thomas, his family and the staff working on the ATU was anything other than ideal between May 2014 and the day he moved to the care home.

On 11 July 2014, a Care Programme Approach (CPA) discharge planning meeting was convened. Key points that emerged from this meeting were:

- Thomas was being discharged to the care home on Monday; this provided only three days to achieve a comprehensive handover of care, and the same short period of time for the care home to be 'ready' to receive Thomas.
- How Monday's move needed to look for Thomas – it was planned for his mother to be there to greet him, and for food he liked to eat to be available.
- Transport would be via ambulance, and he was to be supported by staff he knew and liked.
- The care home provider agreed to send pictures of the care home to the ATU, including pictures of Thomas's new home and pictures of the staff so Thomas could see them before he arrived.
- Psychology support: it was acknowledged and agreed that Thomas would need ongoing psychology support when he moved. The care home provider had already contacted a private psychology service to provide this. An initial psychology appointment was arranged for the week after Thomas's arrival. The mental health trust psychologist was noted as agreeing she would speak with the new psychologist and update them regarding her assessment of Thomas and his needs.
- Thomas's perspective: Thomas did not attend the meeting; however, his advocate reported that when he had spoken with Thomas the night before, Thomas seemed pleased with news of his move but may not have had a clear understanding of what this move meant, although he did know he was not returning to life with his mother or father.
- Carers' view: Thomas's mother was very angry and upset about the judge's decision and did not feel the judge had been given enough time to assess the situation properly. She did not feel enough time had been allowed to achieve a smooth transition for Thomas, or for him to get to know the new staff team.
- The care home provider reported that the team identified to support Thomas were all newly recruited and had received training in Makaton, autism, first aid and safe holds. As a team, they had already had many discussions about Thomas and how to support him, and they hoped to work with Thomas's parents as closely as possible to support a positive rapport.
- The goal of Thomas's new care package was to get Thomas back to his home town, with him having learned skills to be more independent.
- Medication: four weeks of medication had been arranged to go with Thomas, as well as his specialist equipment, such as his spoons, a weighted blanket, and a supply of newspapers, which he found relaxing to shred.
- Psychiatric support: the representative from the CCG reported that she was aware that Thomas's current consultant had spoken with the local psychiatry

service and was sending them copies of her reports; there was also an appointment booked with the second opinion doctor on 30 July.

- Speech and language: the psychologist advised that she would be liaising with the care home to ensure handover of both psychology and speech-and-language services.
- Outstanding appointments: The care home said they would provide the support for going to a neurology appointment in Thomas's home town.
- Other matters: Thomas's finances were discussed as he was on S117 funding. There was also discussion around Thomas buying an iPad, so he could FaceTime with his mother, father and sisters. Advocacy support was to continue, and Thomas's social worker and CPA coordinator would also continue to visit very regularly; initially this was scheduled as weekly for the first four weeks.
- Support for family: Thomas's mother was being supported with finances to ensure she could visit her son via train/taxi regularly; this support was to be provided by the care home.

The only issue not discussed was ensuring that the receiving local authority adult social care team were informed that Thomas was coming to the care home. Similarly, there was no provision made for the local community learning disability service to become aware or involved. For someone as complex as Thomas, who had physical health needs as well as complex communication needs, it would have been prudent to have engaged with both local services on an ASAP basis. Under the new Care Act, the requirement for this level of cross-border communication is more stringently articulated. In 2014, it was considered good practice to communicate with local teams when cross-border placements occurred.

The day Thomas was transferred to the care home did not go according to plan. On 14 July 2014, one of the psychology team took Thomas's mother to the care home, ready for his arrival. The plan was she would be there before Thomas. Unfortunately, the transport for Thomas arrived earlier than scheduled, so Thomas was going to arrive there first. This hiccup in the plan introduced several complications:

- Thomas's mother was upset.
- The care home were not wholly ready for Thomas when he arrived and did not have any food for him.
- Communication with Thomas was complicated, as not all staff had been Makaton trained, contrary to the impression given at the CPA discharge planning meeting on 11 July.

The psychology team spoke with the registered care home manager the day after Thomas moved to share his mother's concerns. This conversation revealed that more staff were being trained in Makaton that same week.

The speech and language service did contact the local community disability team; however, this did not occur until 23 July. On the same day, the previous team visited the care home and met with three of the managers and four of Thomas's support team. They observed staff using Makaton but noted that they did not yet do this with confidence. More training was required for the staff. Thomas, however, confidently

communicated with the visiting speech and language professional from using Makaton. He told her that he liked the house and some of the staff.

At this visit, dysphagia training was also provided for five members of the care home staff, focusing on Thomas's mealtime risks and the need for risk assessment every mealtime, as Thomas's dysphagia risk fluctuated. During the time the team were present, they observed Thomas responding to prompts to sit up and slow down when eating. The psychologist who attended also gave the staff an overview of Thomas's needs.

Within 20 days of admission to the care home, the intensive support team from the mental health trust were concerned about the medication being used by care home staff. Because the local consultant psychiatrist was on annual leave, Thomas's previous consultant agreed to visit Thomas until his new consultant could take over. One day later Thomas's care coordinator and the clinical psychologist who had been supporting Thomas and his family visited Thomas's father at his home.

On the same day, the clinical psychologist and consultant psychiatrist went to the care home to see Thomas. Thomas was observed to be in a good mood and greeted them in a friendly manner. He was also eating a bag of Doritos, and coughing; Doritos were not on the recommended food list for Thomas.

During this visit, a discussion took place with the registered care home manager about Thomas's behavioural difficulties and the need for a positive behavioural support plan. It transpired that the care home did not have clinical psychology support, as was initially believed, but had a nurse therapist, who was not trained in positive behavioural support.

The psychologist advised that the next CPA multi-team meeting would need to discuss and agree the need for a positive behavioural support plan in place, as there were restrictive practices in place that could not continue.

A further consultant psychiatric visit was made on 6 August 2014. The record of this says:

"I was informed that they [the care home] are making some progress, but these are early days. GP has been to see [Thomas] 3 times in such a short space of time. There are incidents on regular basis and the staff are able to manage. When seen he was lying in bed half asleep. Was able to converse with me mostly in sign language making the sign of home and saying he wants to go home. He also said that he does not like people in the house. I reiterated that the people there are good people and they are helping him to get better so that he can go to his own home and be visited by his family on daily basis. Changes were made to his medication and faxed to the GP and other professionals by the Medical Secretary."

The following day, 7 August 2014, the speech and language report was completed and sent to the team at the care home, as well as being uploaded onto the RiO system in the mental health trust. The speech and language team local to the care home were also sent a copy of the report.

On 8 August 2014, there was a person-centred planning day with a national charity. The aim of this day was to work out what:

- would make an ideal home for Thomas to live in
- would make great staff or paid people to help Thomas achieve what he wanted in his life
- Thomas would do in his day based on his wants and desires.

The planning day was pivotal to the design and progression of the plan for Thomas to return home. Unfortunately, this day did not work as intended and had to be curtailed owing to Thomas's distress²⁹.

On 14 August, just over one month since Thomas's admission an occupational therapist visited the facility to deliver a session to staff about Thomas and occupational therapy. The staff caring for Thomas reported that it would have been useful to receive this at an earlier point in his placement there.

²⁹ The work with the national charity was not concluded and no report was generated.

14 Appendix E – Chronology extract from the circumstances leading to the Court of Protection order

Thomas was discharged from his detention under the Mental Health Act on 23 May 2014. At this point, there were no powers to hold him in hospital. He could have gone home with either of his parents; this was not a feasible option, and the time frame set out by the Mental Health Act managers following their consideration of Thomas's case on 20 May 2014 was unrealistic. It was a non-deliverable stipulation. Everyone knew this, including Thomas's mother, who raised a concern about the timescales with the legal adviser to Thomas's father on the day of the hearing.

To ensure that Thomas's needs were met, the Mental Capacity Act, Best Interests, and a least restrictive approach were all utilised to ensure the safety of everyone on the unit.

The Mental Capacity Assessment was undertaken by the psychology team. A key issue was Thomas's lack of capacity to say where he wanted to live. His consistent response was with his father. However, he was not able to appreciate the risks associated with this, or the facts leading to the unsuitability of this desire in the immediate short term.

Two Deprivation of Liberty Safeguards applications were also made, but this route was not successful.

Following the refusal of the first application under Deprivation of Liberty Safeguards on 29 May, it was agreed an application would be made to the Court of Protection requesting that Thomas remained on the ATU in the short term, while an alternative residence and package of care was achieved. Because of the delay in receiving confirmation from the Court of Protection, the second application under Deprivation of Liberty Safeguards was made. The Court of Protection order was made by 9 June 2014.

During this time, reasonable efforts were made to source a community package and accommodation for Thomas. However, the realities of the situation then, and now, are that it takes between six and twelve months to source the right package of care and accommodation for someone with complex needs, such as Thomas's. In this case, providers of care packages who initially seemed like possibilities did not pursue the opportunity owing to the risks associated with Thomas. The range of providers locally was low. Knowledge of providers from further afield was not easily sourced (at the time). Similarly, a bungalow was identified by the company, who also agreed to provide the care package for Thomas; however, when the risk assessment was undertaken of the bungalow, it was considered too high risk a building for Thomas without substantial moderation. It was at this juncture that the care home Thomas went to live in was suggested as a viable alternative.

However, the situation in the ATU had reached crisis point by the end of June/early July. The mental health trust was facing staffing challenges as a direct consequence of staff's experiences with Thomas. Other service users were at risk, and senior management were concerned about the ongoing ability of the service to be safely staffed, and to deliver a safe service for all residents. Therefore, in the interests of

safety for all (staff and residents), the trust was clear in its submission to the Court of Protection that the situation of Thomas continuing to reside in the ATU was untenable:

- it was not good for him
- it was posing a risk to other clients
- it posed a risk to staff.

If a more appropriate placement for Thomas could not be found, then it would have to close to all new admissions and transfer existing residents to other specialist learning disability facilities. Thomas would be the only resident on the unit.

Because the care home provider was on the verge of opening a residential facility for people with challenging behaviour and learning disabilities in a nearby town, and its CQC registration was in place, the Court of Protection decided that Thomas should reside there, while something more permanent was sourced for him in his home town. This decision was not welcomed by his family.

15 Appendix F – Core information provided to the care home by the Mental Health Trust

- An updated occupational therapy report dated 4 July 2014. This is a three-page report, the content of which is complex and does not require setting out in this report in order to respect Thomas's privacy.
- A sensory integration report. This highlighted important and useful factors when providing care to Thomas. For example:
 - People need to use deep touch.
 - Personal care routines should not vary between care staff. They should always follow the same pattern.
 - Wrap Thomas in a large bath sheet and rub him vigorously up and down, letting him do this for himself if he wants to. Small towels are not as effective.
 - Maintain awareness that Thomas has problems with knowing and judging the spaces between his body and objects in his environment.
 - "Dressing also needs to be done in the same order each day and try to be just a bit slower but more deliberate in your technique. Say the order out loud as you are about to do it. Thomas dislikes high necks in his clothes and T Shirts."
 - "Don't forget to use Makaton."

"If every staff member follows the same sequence, gives verbal feedback/commentary and uses the same deep deliberate sort of touches then Thomas will not be so reliant on the same familiar staff to cope. Without this strategy and for sensory reasons he will continue to pick and choose and manipulate his behaviour and theirs to ensure his favoured staff work with him."

The report continued in this vein, and the report author found the document illuminating and considers it served as a useful blueprint for working as effectively with Thomas as possible.

16 Appendix G – The Care Homes’ inpatient assessment of Thomas

The care home provider first presented its proposal for supporting Thomas at the care home in May 2014, when it became clear that the initial proposal of supported living in one of its bungalows was not feasible. It promised as part of the preparation for Thomas to come to one of its facilities to:

“work with Thomas’s family and full circle of support to identify a property in the Wibsey area for Thomas and offer advice on adaptations required to ensure that it is an appropriate long-term home for Thomas. We will create a unique Support Plan and Behavioural Support Plan, Health Action Plan, Activity Plan, Communication Passport, and undertake comprehensive risk assessments and complete Risk Management Plans that will ensure Thomas receives personalised support and remains safe while developing life skills, achieves desired outcomes, and increased independence.”

The initial proposal was for Thomas to receive two-to-one support from 7am to 10pm, and one-to-one waking night support from 10pm to 7am.

The initial proposal made no undertakings regarding the skill base of the staff who would be supporting Thomas, or of any specialist input such as psychological support. It did however say:

“we will set up a programme of intensive support to help Thomas to manage his anxieties and behavioural presentation so that Thomas can make a success of supported living”.

Furthermore, the residence recommended for Thomas was to be managed by the company’s Challenging Behaviour Expert.

However, no firm decision had been made to place Thomas at the facility until the Court of Protection order was made. They were however a serious contender for care provision from 22 May 2014. The minutes of a meeting hosted by the district council in Thomas’s home town on this date say:

“[The care home provider] – organisation currently provides local respite services in [the] area. They have proposed the option of a flat on a respite site and have proposed that they can provide wrap around care for [Thomas] whilst longer term options are pursued.”

A plan was also made to introduce the care provider to Thomas’s family on 23 May 2014. Subsequent to this, on 26 June, the care home provider attended the inpatient facility where Thomas was cared for to conduct an assessment of him. Key excerpts from this are set out below.

Communication:

- A core Makaton vocabulary for Thomas would include: hungry, drink, meetings, talking, car, bus, milk, cake, curry, chips, sausages, crisps, chicken,

home, fish, mum, dad, sister, punches, blood, sad, poorly, beer, medicine, takeaways (phone), bread, etc.

- Thomas's understanding of language is better than his speech.
- Listening to music makes him happy. However, music can also have a negative effect, and this will be evident by a change to his rocking, which will become harder, and if he is singing along his voice will become shaky.
- Thomas will always say he wants to return home (meaning his Dad's house) and requires simple and direct communication regarding this, such as "You aren't going home" or "You have a new home now."
- Thomas responds well to non-formal language – "Alright, mate," "Come on, dude," "You're cool." Less is more with Thomas.

Health and wellbeing – Thomas:

- was identified as being short-sighted; a referral to SeeAbility may help to determine how this impacts on his behaviour
- suffers from an underactive thyroid
- is at danger of self-neglect and needs significant prompts and interventions by staff to maintain good standards of hygiene
- has put on weight. He prefers junk food, exercises poorly and also is on prescribed medication, risperidone, which has a common side effect of weight gain. He will need a Healthy Lifestyle plan
- is currently struggling with his eating. He puts a lot of food into his mouth but appears to be forgetting to chew. He is often bent double and his posture is poor for eating safely. He is coughing when eating. He often prefers to eat while sat on the floor. He is on a fork-mashable diet, which he does not like. He has needed first-aid intervention in the form of backslaps to stop him from choking
- has contracted chest infections and pneumonia from inhalation of foods
- can fixate on things such as having a biscuit
- can have problems with both diarrhoea and constipation
- currently has an OT, psychologist and community matron from the intensive support team involved with his care. [The care home] will contact them for further assessment sharing where possible.

Mental health and wellbeing:

- Thomas's moods are currently very changeable and unpredictable. He is described by his clinical psychologist as being often unhappy, puzzled and anxious.
- His mother feels that there is a possibility that he is overmedicated. She would like other potential underlying physical causes to be ruled out.
- Watching violent or aggressive TV can be a trigger for Thomas's challenging behaviour.
- Praise, especially patronising praise, such as 'good boy' or 'well done', are likely to antagonise Thomas.
- Two-to-one staffing and waking night and one other on hand would be suitable staffing. Thomas does not like waking night staff due to the abuse he suffered in the past.
- Thomas benefits from a daily routine where periods of vigorous activity are followed by periods of calm, which are followed by periods of vigorous activity.

Vigorous activity may be playing with a gym ball or football. Thomas needs regular physical activity.

- Thomas has sensory integration issues and gains some benefit from a weighted blanket – a “hugging blanket”, as he calls it. Thomas needs to initiate its use rather than it being imposed on him by staff.
- Thomas talks of imaginary friends (“Emma”) and of what sounds like auditory and visual hallucinations. Risperidone meant that Thomas was less distressed by these “voices”. The clinical psychiatrist described these as becoming “persecutory voices” in an Autism Assessment Report dated 13 February 2014.
- There were differences of opinions about Thomas’s need for routines. Thomas’s family said that his routines enabled them to support Thomas to get things done. The ATU said that Thomas was tolerant of a non-routine-based lifestyle and did not have distinct patterns in which he did things – that is, morning routines, night-time routines, etc.

Self-care:

- Thomas can dress himself when motivated, though he struggles with buttons, zips and fiddly fastenings. He likes loose clothing.
- It is vital to approach Thomas as a quasi-friend and not as a staff member. Use non-formal language such as ‘Pack it in’ rather than ‘Please, stop doing that’ and ‘Come on, dude’ as encouragement.
- It is ingrained in him to be waited on and he will need significant support to develop daily living skills.
- Thomas has some awareness of danger; he knows that a hot stove or hotplate might burn him, for example.

Eating and drinking:

- Thomas uses a special maroon Kapitex spoon to eat. He does not use other cutlery.
- Favourite foods: bread, tuna sandwiches, curry with chapattis, sausage, chips, pasta, roast dinners, samosas, toasties, gravy. He loves tomato ketchup. Unfortunately, burgers, pizza and bread need to be avoided because they don’t mash well. On Sundays he enjoys sausages for breakfast.
- Thomas loves takeaways. Thomas is limited to one takeaway per week; otherwise, he would have one every day. He will choose a variety of different foods from different takeaways. His favourite is Chinese.
- Thomas may try to play staff off against one another to get multiple meals.

Emotional support and relationships:

- Thomas is very close to his family, especially his mum and dad and youngest sister, who lives where she attends university. He also has two other sisters, who both have families. [Consequently] they do not see Thomas as much.
- Thomas sees his nieces and nephews, but he can only be with them for a limited period of time. He can become scared that he’ll hurt them, and this causes him anxiety.
- Thomas remembers the order of everyone’s birthdays and they are special dates to him. He also remembers Halloween, Bonfire Night and Christmas.
- Thomas’s family are his main support network.

- In terms of staff, Thomas tends to respond to younger staff. He doesn't like people who wear uniform. He doesn't like people to be distinguished as "staff". He likes himself and his supporters to be, in a sense, equal.

Personal safety:

- Thomas's mother is unsure as to whether her son recognises abuse and how he would tell others.
- Thomas was the victim of abuse at a previous care home. This was not reported by Thomas. After that occurred, Thomas began to make repeated allegations, much of it unsubstantiated. It is vital that all allegations are treated the same.
- Thomas may make allegations against people which are untrue, potentially malicious or not able to be substantiated. But he has been the victim of abuse in the past. All allegations need to be treated seriously. Staff need to complete incident forms for all allegations. The inpatient unit has had discussions with Safeguarding around the procedures for managing Thomas's allegations. Similar arrangements will be needed elsewhere if need be. A body map should be drawn up if Thomas alleges he has been assaulted.
- All allegations are investigated locally, and findings reported to Safeguarding.
- Having a two-to-one ratio of staff helps protect workers from allegations by Thomas and helps protect Thomas too.
- Thomas will pull things off the walls. The home environment needs to be prepared for him. Things that may need to be managed are TVs, wardrobes, taps, window glass, fire alarm call points, nurse call points, low-level wall-lights, etc.
- Thomas may prefer not to have furniture in his bedroom. Currently, his room only has a bed, a teddy bear and a weighted blanket.

Access to the community and leisure:

- Thomas loves people-watching.
- Thomas enjoys music (Akon, Timbaland, Eminem, Nelly Furtado, Justin Timberlake, Black Eyed Peas, Sinatra, Queen). He listens to music on an MP3 player via headphones.
- Thomas's leisure activities are extremely limited (by his choice) and usually solitary.
- Thomas does not enjoy going out to leisure activities.

Thomas will need support to establish a routine where he leaves the house and develops meaningful pastimes.

17 Appendix H – GP referrals

Referrals to GP, NHS 111, emergency and out-of-hours GP services between 2014 and 2015

Date	Why	Identified by	Communicated to whom	
18 July 2014	Chest infection	Care Home	GP surgery	
<p>Relevant information provided by the care home to GP/NHS 111 or emergency service</p> <p>GP record: New patient to new care home. Spoke to carer, 'snotty and a bit chesty', well in himself. Previous pneumonia. Appointment offered but wanting visit. Not normally housebound but can be aggressive. Long discussion with manager - says would be very difficult to get him up to surgery as he has not yet been assessed for transport etc. Explained this is a deprivation [sic] of his liberties and therefore an adult safeguarding issue - then said would bring him up but telecon half an hr later saying cannot bring him up. Explained will do HV as need to assess the patient but need to discuss things further with managers etc. Explained all visits need to be in by 11.30 am due to resources etc.</p> <p>RESPONSE BY GP PRACTICE: Home visit: Cold like symptoms for past few days. runny nose and cough. Well in himself but mum worried as previous pneumonia. Patient c/o sore throat as main syx. O/e - looks well, temp 37.1. hr 72reg, sats 98%oa. Chest clear. Ears NAD. Throat- unable to see due macroglossia and gagging. Imp: likely viral Plan: 1. Manage symptoms for now with plenty of fluids and [paracetamol] 2. Delayed script given for [penicillin V] as previously very unwell and difficulties with seeing Dr today 3. Advised needs urgent assessment for transport as is otherwise unable to come to surgery. Medication: Phenoxymethylpenicillin 250mg/5ml oral solution - 200 ml - 10ml spoon 4 times/day Drugs not printed - 18 Jul 2014: Phenoxymethylpenicillin 250mg/5ml oral solution Thomas received a subsequent visit from one of the district nurses on 22 July 2014, as he developed a penicillin sensitivity rash to the antibiotics. He was noted to be mostly well and his rash was treated with hydrocortisone cream and his antibiotics changed to Clarithromycin 250mg/5ml oral suspension.</p>				

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
28 July 2014	Cut arm	Care Home	GP surgery	The care home contacted the out-of-hours service over the weekend	Thomas had reacted angrily to a visit he was expecting that did not happen over the weekend. He broke a fire alarm and smashed some glass, cutting his arm in the process. "Has been referred to [a Consultant Psychiatrist] from team [in previous Trust] but don't know when appt is. Meds don't control him when agitated/aggressive- diazepam, haloperidol, lorazepam, promethazine and risperidone. Write to [new Consultant Psychiatrist] to expedite"
28 July 2014 5.35pm	Request for increase in medication	Care Home	GP surgery	Care Home are not managing to contain Thomas's behaviours and request an increase in Haloperidol. This was requested over the weekend via OOH, who passed to regular GP	GP response: "I have expressed my concern re cocktail of meds so for short term script. contact prn. Letter been done to expedite appt as above done by NS. Haldol 2mg/ml oral solution 50 ml - 1.5-2.5mls twice daily ONLY IF NEEDED for severe agitation"
5 August 2014	Scabies		GP surgery	Thomas has a rash on his skin and the carer has seen similar before on a resident	The GP gave phone advice and prescribed Permethrin 5% cream - 60 gram - use as directed
1 September 2014 Approx. 10.30am	Chest infection		Thomas's mother	GP surgery	Thomas's mother was concerned about her son and what she considered to be a chest infection

Date	Why	Identified	Communicated	Relevant information either provided to GP	Response
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		by	to whom	or recorded in the care home record	
1 September 2014, 11.23am	Chest infection	Manager at care home	GP surgery		
<p>Relevant information provided to GP surgery: Manager contacted GP surgery to request home visit. He had contacted the team at care home via his car phone but did not instruct requesting a home visit.</p> <p>Response by GP surgery: One hour later: One of the doctors from the surgery visited Thomas at the care home. She noted he looked well. His oxygen saturation was 98% (i.e. good), pulse 95 and temperature normal. On listening to Thomas's chest there were some upper airway noises. Her impression was possibly a viral infection, possibly bacterial. Because staff had identified a definite change in Thomas's breathing and he had been unwell for three weeks, a further course of antibiotics was to be commenced. The GP did not consider that a chest X-ray was needed as it would not change the clinical management. The GP also noted that Thomas had an eating plan in place and a speech and language assessment (including swallow assessment).</p>					
4 September 2014	Chest infection	Care home	GP surgery	A member of staff called the surgery because she was concerned that Thomas's medication might be contributing to his chest infection, and wanted reassurance about this	A GP has recorded in the record – 'not aware of any link – would need to ask consultant about a change in any of his medications'

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
22 September 2014	Medication management	Care home	GP surgery	Request for more diazepam	The GP checked the psychiatric recommendation, which was for 10 days of diazepam only, and then stop. The GP was curious as to why the care home needed more. It transpired that the care home manager wanted top-up haloperidol for resistant agitation. He reported to the GP surgery that he had used haloperidol this way in the past and it had worked. A top-up amount was agreed.
22 September 2014	Request for home visit		GP surgery	No real reason other than Thomas's mother wanted her son seen by the GP	No acute symptoms and no changes to normal behaviour. Told he had a full neurological assessment the previous week and no concerns. Advised to observe and contact [GP] if new symptoms.
2 October 2014	Rash on chest and stomach		GP surgery	The rash flared up on 1 October, it was itchy and Thomas was scratching at it. It seemed to the care home staff to be the same as the rash he had had a few weeks previously. Now the main rash had gone and remained in groin only.	Home visit by GP who noted: "History: 3/7 hx of rash on neck and groin area. Seen with mother. Examination: scabies neck and groin. itching. not infected. palm sized patch on inner groin bilaterally. 10cm by 4cm patch on back of neck. Diagnosis: scabies Plan: 1. hygiene advice given. 2. Permethrin and Piriton PRN 3. advised if not improving to call GP. Permethrin 5% cream - 60 gram - use as directed Chlorphenamine 2mg/5ml oral solution - 150 ml - 10 mls (4mg [three times a day as required])"

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the lifeways record	Response
13 October 2014	Vacant episodes	Care home and Thomas's mum	GP surgery	Took Thomas to GP surgery	
<p>Seen by GP, we believe with his mother: hypothyroid and vacant episodes for a few seconds or several hours, a few times daily - challenging behaviour over recent months - mum wondering if he needs an 'MRI scan of his whole body' - bowels variable - diarrhoea and constipation.</p> <p>plan - FBC, U&E, TFT, LFT, RBS, Hb a1c, and any others from mental health review check appts.</p> <p>last TSH was abnormal but no further sample apparently.</p> <p>Has psychology and psychiatry input already</p>					
23 October 2014	Cold	Care home	GP surgery	Telephone call to GP surgery reporting: "cough since Monday dry, not unwell in self, no fever, no d&v, no sputum/blood. Says mum feels cough got a bit worse and wanted him checking."	
<p>Response to contact – GP noted: "Sounds viral and advised symptomatic Rx with paracetamol and review if not settling over coming days. Then team leader came on and said cough on and off for few weeks and mum worried. Expressed concern at inconsistent stories and that they need to liaise with mother re what are facts and how they manage their level of concerns and her level of expectation. Noted that on last call on 2/12 someone, [possibly a] carer reported that mother was taking him out for afternoon and that being the case they can bring him to appointment in the morning for review here at surgery re this dry cough."</p>					
24 October 2014	Cold/chesty	Care home	GP surgery	Assessment with the nurse at surgery	

The nurse recorded: “been coughing, sounds chesty but he can’t get anything up, the Dr at the care home listened and said he had a chest infection, otherwise well eating and drinking as normal
 Examination: O/E - temperature normal at 36.5, ears Nil abnormal on examination
 O/E - throat red
 no O/E - exudate on tonsils
 chest, equal air entry, bilateral basal fine creps, no wheeze not in resp distress
 Oxygen saturation at periphery 97 %
 Diagnosis: Chest infection NOS
 Plan: [antibiotics] as px side effects explained, [regular paracetamol] and fluids if any problems return for review, red flags discussed and if any occur to seek medical help
 Clarithromycin 250mg/5ml oral suspension - 140 ml - 2x5ml spoon every 12 hrs”

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
17.1 25 October 2014 1.30pm	Rash on Thomas's face and neck	Care home	NHS 111 who passed the call to the GP Collaborative	The GP spoke to the team leader. The concern was a rash on Thomas's face and neck following antibiotics (clarithromycin) given for a sore throat the day before. He was not short of breath nor was there any itching or dizziness.	
25 October 2014 cont. 9.40pm	Rash on Thomas's face and neck		NHS 111 then GP Collaborative	A GP attended to see him at the care home and the advice given was to stop the antibiotics, give Piriton and if there was no improvement they should either call back or contact the patient's GP.	

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
31 October 2014 3.43pm	Chesty/chest infection	?	GP surgery	Assessment by GP	
<p>GP records note: History as noted above and that Thomas had been run down for a while. Antibiotics had been prescribed a week previously. Sensitivity rash on the Clarithromycin and loose bowels. Now Thomas's ears are also discharging. However, no symptoms elsewhere. Noted not to be his normal self. On chest examination Creps were heard in the mid left zone, good air entry, ear, nose, and throat otherwise NAD. Taking paracetamol. Antibiotics changed to Erythromycin ethyl succinate 250mg/5ml 1 x5ml spoon four times a day.</p>					
30 December 2014	Loose stools and raised temperature	Care home	GP surgery	Seen by a staff nurse at the surgery	
<p>GP records note: History: one-day onset of temp/loose stools Examination: temperature 36.5, ears-nil abnormal detected, throat was red but no visible infection, chest was clear with good air entry. Thomas was noted to be alert and a pleasant young man. He was noted to be eating and drinking normally. Urine was OK, stools were loose.</p> <p>Plan: advised dry diet and clear fluids for 24-48hrs, gradually introducing diet back in.</p>					
2 January 2015 12.39am	Generally unwell	Care home	GP Collaborative		
<p>Care home advised: Thomas had a headache, felt hot and cold and was not himself. He had been given paracetamol at 6.30pm on 1 January. They requested a visit because his parents were worried.</p> <p>GP response: GP asked that Thomas be woken up as it was being assumed that he was ok but no one knew. The carer roused him and he said he had a little headache and felt hot. Advised to give 2 paracetamol. GP called back and Thomas had refused paracetamol as he was feeling a bit better and wanted to go to sleep, the carer was advised to call back or contact Thomas's own GP if his condition worsened.</p>					

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
29 January 2015 1.01pm	Chest infection	Care home	NHS 111		
<p>Information provide to NHS 111 by care home: Carer calling on behalf of learning disability patient. Symptoms of patient - Cold & cough, high temperature - possible rigor paracetamol had been given at 12.30pm.</p> <p>Response: Referred to local GP collaborative service as own GP closed for scheduled protected learning time. Advice provided to care home. Noted that Thomas had just vomited at the end of the call. Message sent to OOH GP at 1.13pm.</p>					
29 January 2015	As above: At 1.05pm the information was passed to the GP Collaborative for prioritisation.				
29 January 2015 2.05pm	Chest infection		Telephone communication between the GP Collaborative and the on-call GP		
<p>Telephone communication: Team leader at care home advised the GP that Thomas's chest has gotten worse and his breathing was quite heavy. He had vomited once. Although he was not eating he was drinking oral fluids all right. He was shaky, shivery, and felt warm/clammy to touch. He had a pneumonia in the past. The patient lives in supported living for people with challenging behaviour. The patient has a past medical history of Downs syndrome and hypothyroidism. His current medications included haloperidol, levothyroxine, loratadine, lorazepam and risperidone. Team leader told GP that the patient has no known drug allergies.</p> <p>The GP established that a home visit was necessary as the patient was not in a fit state to travel. A home visit within 6 hours was offered and agreed upon. The GP also advised the Team Leader to let the GP Collaborative know if Thomas's breathing worsens in the meantime. The consultation ended at 2.15pm.</p>					
29 January 2015 2.54pm to 3.35pm	Chest infection		Home visit by GP		
On arrival at the care home the on-call GP reviewed the notes of the doctor that had visited previously via the Adastra system and the visit					

appeared to be routine. The on-call GP was taken to Thomas's room and there were four carers in the room. One of the carers gave a history that Thomas had been unwell for the three previous days with a chesty cough, fevers, shivers, and a runny nose. Thomas was very cooperative during the examination, although the on-call GP had been advised that he could show violent behaviour. During the examination Thomas was alert and hydrated, he had a pulse of 88 BPM, Resp rate of 10 breaths per minute, 99% oxygen saturation on air and a temperature of 38.3 C. There was good air entry to both lungs with no wheezing, although there were crackles at the left base. Following this, the on-call GP diagnosed a lower respiratory tract infection.

The on-call GP was advised that Thomas was allergic to penicillin so doxycycline monohydrate was prescribed, as per the CCG formulary. The on-call GP advised that Thomas be given two 100mg dispersible tablets immediately, and then one tablet daily for seven days. He did not feel that admission to hospital was necessary as Thomas had a straightforward chest infection and his observations were normal. The GP has reported that he would normally advise patients/carers to seek further advice in 2 or 3 days if there has been no improvement - or sooner if there is deterioration although he cannot recall if this was said at the time due to the time which has elapsed. However, the entry in the notes reflects this: "Treatment: Start antibiotics - review if not settling". Further details were added: "Informational outcome added- Call back if condition worsens or see own GP".

29 January 2015 8.46pm	999 call	Care home	Emergency services	Thomas was reported to be "very distressed, hyperventilating, pain in head and generally anxious"	
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The operations call record also states: At 8.56pm a care home staff member also reported that Thomas had been given antibiotics for "chest pain".
 9pm The response vehicle is waiting for police presence because of Thomas's reportedly 'attacking' a member of staff while the 999 call was in progress.
 9.16pm Police call ambulance control to advise they are not 'on scene'.
 9.35pm The response crew receive a text from the operations centre to say they can now proceed to the scene.
 9.40pm The crew are with the patient.

29 January 2015 9.40pm	The patient record states: "Parents spoke to patient today. Concerns due to patient sounding breathless, had absence today. Parents advised staff to contact 999. On arrival police on scene due to patient challenging behaviour and violence. Patient in room. Staff state his normal self. GP attended today. Given antibiotics for chest infection. Staff report no changes since GP visit. Patient looks well, sounds chesty, respiration rate up although unable to assess due to patient uncooperative. A&E unsuitable for patient. Discussed with patient father, patient to remain at home in 24-hour care. Advised staff to observe patient and recall if required. Unable to record some observations although patient on regularly hourly check. Patient can become stressed and violent in crowded and unfamiliar situations."				
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	Observations at 9.40pm Glasgow Coma Scale: 15 Resp: 20 Pulse: 118 SPO2: 93 Airway clear, Breathing normal		Observations at 10pm Pulse: 121 Resp: 20 BP systolic: 137 BP diastolic: 92 GCS: 15		
Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
30 January 2015 GP record of OOH on 29 January	NA	NA	NA	NA	
Information provided to GP by OOH re home visit: lower tract infection noted. Doxycycline prescribed (this is a broad-spectrum antibiotic used to treat bacterial infections including chest infections and pneumonia and bronchitis).					
1 February 2015 9.32pm	Unwell	Care home	NHS 111		
<p>Information provided by care home: Had not been well in last few days – ‘Just started to vomit now’. The support worker explained that a GP had been to visit the patient on 29 January and had prescribed antibiotics for a chest infection. The support worker wanted medication advice. The patient was due to take 2 x paracetamol and anti-histamine medication and the support worker wanted to know if it was safe to give the medication, as the patient had started vomiting, described as a ‘milky colour’.</p> <p>NHS 111 RESPONSE: The call handler began an assessment using a vomiting pathway and reached an outcome time frame of contact with a primary care service within 24 hours, but the outcome was not given to the support worker in line with NHS 111 procedures. However, the call handler tried to transfer the call to a clinical adviser. All clinicians were busy with other patients and the call was placed on the clinical call back queue. The call handler advised the support worker of the action she had taken and explained that she should receive a call back as soon as possible. The support worker was happy with the information. The call handler gave worsening instructions to the support worker and the call ended. Minor errors were found in the assessment and feedback was given to the call handler concerned. This case was passed to the local GP Collaborative service at 10.08pm.</p>					

Date	Why	Identified by	Communicated to whom	Relevant information either provided to GP or recorded in the care home record	Response
1 February 2015 10.17pm	The on-call GP contacted the care home. The on-call GP record says: "Having confirmed the patients name, date of birth and current address GP asked the carer to clarify what was required. The carer asked for a call back as she wanted to know if it was okay to give Thomas his routine paracetamol and antihistamines, as he had vomited once that evening although he was not feeling sick anymore. GP advised that it was okay to give Thomas his medications, and if he vomited within 30 minutes of taking them she should repeat the medications. GP also advised her to call back if there were any further concerns."				
2 February 2015	Collapse	Care home	Emergency services – 999		
2 February 2015 5.38am	Collapse	Police	Ambulance service	A call is received from the police, who are en route to a male, requesting ambulance attendance. The police state that the home called them thinking they had come through to an ambulance. One of the residents is unconscious (police state unable to get any further information out of them so don't know reasons for him being unconscious), he's not breathing and bleeding from the mouth. The call codes RED1. RED1 requires an emergency response within 8 minutes. The call has been audited and coded correctly.	