

TRAFFORD SAFEGUARDING ADULTS BOARD

SAFEGUARDING ADULTS REVIEW (SAR)

IN THE CASE OF BILL

FINAL OVERVIEW REPORT

PERIOD UNDER REVIEW

1<sup>ST</sup> SEPTEMBER 2013-26<sup>TH</sup> SEPTEMBER 2014

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## **SECTION 1: INTRODUCTION AND BACKGROUND**

### **1.1 Purpose of the SAR**

This Safeguarding Adults Review (SAR) was established in line with guidance under the Care Act 2014 <sup>1</sup>. The review relates to the death of Bill who died in hospital on 26<sup>th</sup> September 2014. The purpose of the review is to critically examine the care provided to Bill from a range of services during the 12 months before his death in order to determine whether agency practice in caring for Bill met the required standards and what lessons can be learned from practice in this case.

The review panel offer their sincere condolences to Bill's family on their sad loss.

### **1.2 Incident Leading to the SAR**

Bill was aged 54 years and one month when he died in hospital. At post mortem Bill was found to have a piece of bone lodged in his oesophagus which would have caused him discomfort and difficulty in swallowing. This foreign body was not identified in any procedures (e.g. scans and x-rays) undertaken prior to Bill's death.

### **1.3 Background to Bill**

Bill was a single man of White Irish ethnicity, who had been diagnosed with a severe learning disability with associated challenging behaviour and Epilepsy. His clinical records indicate that Bill had long standing behaviour problems dating from early childhood. Bill suffered his first epileptic seizure in 1971 and continued to experience seizures on a frequent basis thereafter.

Bill's communication skills were compromised by his learning difficulties and he was often unable to verbally communicate his needs. Professionals who worked with him established that he was able to understand what was happening when part of a set daily routine or when there was a familiar pattern of questioning. This was however reliant on staff/carers knowing him well to be able to interpret whether he was happy, sad or in pain through his behaviours and verbalisations. For example, if Bill was in pain, professionals reported he would fling his arms out.

He often became agitated when he was fearful, this was particularly apparent in some medical settings for example Bill's GP and hospital staff were aware that he experienced fear of medical procedures which increased his anxiety and volatility in these situations.

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<sup>1</sup> Care Act (2014)

Bill needed full support with most activities involved in daily living. He could dress himself with prompts but relied on carers for most aspects of his personal care. Bill had some difficulties with eating and drinking, he was said to rush his food and drink and was identified as being at risk of coughing / choking if he was not supported to slow down his eating at mealtimes. (As part of his care Bill was supported by the Speech and Language Therapy (SALT) team who made recommendations regarding eating and drinking which were given to his carers).

Bill had lived in supported accommodation for more than 22 years (he first entered care in 1969). During the year under review he lived in supported living accommodation with 3 other adults with learning difficulties. The supported living service was managed by two providers during the period under review. Provider 1 was the provider from September to October 2013 followed by Provider 2 for the remaining period October 2013 to September 2014.

Bill had a supportive family who were keen to be involved in his care and who saw him on a regular basis. Bill was close to his family, they visited him regularly at the supported living service and Bill went home for main holidays and went away on holiday with them once a year. It is documented that he loved going out to the pub, cafes and going walking and had a varied timetable of community activities.

Bill's clinical records indicate that he was known to Trafford Adult Learning Disability services in 1993 when his care was transferred from a local community hospital. At that time, Bill was being reviewed regularly and records indicate that his health had remained relatively stable for a number of years.

All practitioners involved in the review and Bill's family agreed that he lacked mental capacity as defined in the Mental Capacity Act (2005)<sup>2</sup> in certain aspects of his life and that he required support in decision making. During the period under review there are no records of MCA assessments having taken place in relation to any aspect of Bill's life. Best interest meetings were held and family members were involved in most decisions regarding Bill's treatment and care. It should be noted that under the MCA assessment of capacity is situation specific and there is evidence that, on some occasions practical steps were used as directed by the law in order to support Bill's wishes however the recording of these decisions was not always contemporaneous.

In the year under review Bill's general health fluctuated and at times declined significantly. He was admitted to hospital on a number of occasions and at one point in the spring/summer of 2014 he was noted to have lost more than two stones in weight over a period of approximately four months. Investigations were undertaken in hospital to establish whether a malignancy may be the cause of his rapid weight loss; however no malignancy was found.

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<sup>2</sup> Mental Capacity Act (2005)

The panel has found it difficult to build a clear picture of Bill and his daily lived experience from agency records and professional accounts, this is compounded by the family not wishing to participate in the review. The panel spoke to the writers of reports for the review one of whom was Bill's GP. She provided a detailed picture of her interactions with him having known him as a patient for many years. She described Bill as an animated character. He was reported to have had a good sense of humour and interacted well with people despite the fact that he could be agitated when afraid. She observed that Bill responded positively to efforts to understand his needs and to calm situations that he found anxiety provoking.

#### **1.4 Referral for a SAR**

The referral for a SAR was sent to the Trafford Safeguarding Adults Board (TSAB) on 16<sup>th</sup> March 2016. This resulted in a decision to conduct a SAR under the requirements of the Care Act (2014).

The referral for a SAR was made almost 18 months after Bill's death. It was noted by the Coroner at a pre-inquest meeting that this was an unacceptably long period of time and the Coroner requested further information from the Chair of the TSAB as to why there had been such a long delay in a referral being made. The Chair provided a full report to the Coroner detailing the referral process and highlighting missed opportunities to refer the case to the TSAB.

The Chair of the TSAB has requested that this SAR report contains a recommendation to ensure that future serious incidents are given immediate consideration for referral and that all agencies are aware of the requirements to refer and understand the relevant legislation in relation to making a SAR referral (see recommendation 1).

#### **1.5 The SAR Process**

Following TSAB's agreement to conduct a SAR a scoping meeting was held to discuss the terms of reference for the review and to identify agencies that were involved in Bill's care in order to involve them in the review. It was agreed that an Independent Chair/Author with experience of conducting serious case reviews should be sought. A competitive tendering process was initiated and Maureen Noble, an Independent Consultant with extensive experience in safeguarding reviews, was appointed in June 2016.

A panel of senior representatives from key agencies was convened and held its first meeting in early July 2016. A timetable for completion of the review within six months of commencement was agreed and a letter was sent to HM Coroner, Manchester to notify him of the SAR.

The family were notified of the review and were subsequently invited to participate however no response was received to this invitation (see 1.7 below).

The panel met on five occasions and received reports from the following agencies:

AGENCY	ROLE
Provider 1 (FD)	Supported Living Service Provider September 2013 to October 2013
Provider 2 (AFG)	Supported Living Service Provider October 2013 to September 2014
Cheshire and Wirral Partnership (CWP)	Provider of Community Learning Disability Service (Health)
General Practitioner (GP)	Provider of primary care service to Bill
Trafford MBC Learning Disability Service (TCLDT)	Commissioner of Services
University Hospital of South Manchester (UHSM)	Provider of A&E, secondary and acute services.

The final report was presented to an extraordinary meeting of TSAB on 16<sup>th</sup> December 2016.

### **1.6 Other Investigations and Coronial Matters**

Following Bill's death UHSM undertook a serious incident review of the care provided to him. The report from this review was submitted to the Coroner as part of the pre-inquest enquiries and to the SAR panel.

An inquest into Bill's death took place on 23<sup>rd</sup> September 2016. The Coroner recorded a verdict of accidental death.

### **1.7 Involvement of Bill's family in the SAR**

The Head of the Learning Disability Service notified Bill's parents that a SAR was taking place (this decision was taken to ensure that Bill's family received the information via a known source who would be able to mediate on behalf of the panel).

The SAR panel wrote to the family on two occasions following the inquest inviting them to participate in the review. No response was received from the family and the panel considered it inappropriate to contact them again to seek their involvement. This report does not therefore currently contain any comment or views from Bill's family.

The SAR report will be shared with Bill's family prior to publication.

### **1.8 Terms of Reference**

The following terms of reference were set by the SAR panel. Agencies were asked to address each of the terms of reference in compiling their reports to the panel.

1. What action did your agency take to seek and act upon Bill's wishes and feelings in relation to his treatment and/or care needs and how did this influence professional practice?

2. How did your agency communicate (including responding and acting in a timely manner) and share information with other agencies? How effective was this?
3. Did your agency use a personalised plan when providing treatment and/or care to Bill? How effective was this?
4. What involvement did your agency have with Bill's family? How did you seek the views of Bill's family? How did this involvement influence Bill's treatment and/or care?
5. Did your agency send or receive any safeguarding referrals or raise/receive safeguarding concerns in relation to Bill? If so, please provide detail and outcomes
6. How did you follow agency protocols and statutory guidance (including MCA guidance) in relation to Bill's treatment and/or care; please provide information about such protocols and guidance in your responses.

### **1.9 Agency Compliance with the SAR**

Agency compliance with the SAR process was of a good standard however the report provided by Provider 2 lacked detailed information due to inadequate records, changes in staff and difficulty in accessing information from the previous provider.

Each agency has produced an action plan which has been submitted to the SAR panel. A partnership action plan is in preparation the implementation of which will be overseen by the TSAB.

## **SECTION 2: AGENCY INVOLVEMENT DURING THE PERIOD UNDER REVIEW**

### **2.1 Context of services and legislation during the period under review**

The SAR panel feel it is important to provide some context to the configuration of services, relationships between services and changes in legislation during the period under review.

A significant level of change has occurred since Bill's death. The legislation framework has changed with the implementation of The Care Act 2014 into practice. Whilst aspects of the Care Act were not intended for immediate implementation the 'spirit' of the Act should have been evident in the care system and practice should

have been focused on changes in the care system; particularly in relation to underpinning principles such as the principle of individual wellbeing<sup>3</sup>.

A high court ruling in relation to Deprivation of Liberty (DOLs) was made in 2014<sup>4</sup>. This review does not therefore expect that agencies should have anticipated the outcome of this ruling however the issues it raises and addresses were well known amongst agencies at the time of Bill's death, hence reference is made in this report to implementing DOLs guidance.

Bill's admissions to hospital coincided with The Supreme Court Ruling into DOLS legislation (the acid test) which was categorised as 'complete or continuous supervision and control and lack of freedom to leave'. Bill met this criterion during a stay in hospital however UHSM did not implement DOLs guidance. Following this ruling UHSM was able to implement a more robust process for identifying patients requiring DOLS. Since 2014 UHSM has continued to develop resources and support for staff to identify and assess those who meet the requirements for a DOLS authorisation. These improved resources and processes now address the failings that were not identified at the time of Bill's admission.

The records from the Community Learning Disability Service indicate a lack of commissioning input. During the period under review the electronic case recording system was not sufficiently developed to enable information sharing across the various elements within the local authority with information being stored separately on a number of different systems. The overall information system has since changed and from December 2014 the LAS system has been in operation and there are further plans to enhance the sharing of information via an internal recording mechanism referred to as operational safeguarding.

The impact of commissioning and decommissioning supported accommodation provision is noted. The difference in culture and values of different organisations needs to be recognised by commissioners as potentially impacting the quality of service delivery. A recommendation is made to ensure that contracting and commissioning processes that involve changes in organisations and staff do not negatively impact individual care (see recommendation 8).

The council has recently changed the adult safeguarding policy and protocols in order to ensure compliance with The Care Act. This review makes a recommendation regarding training and support for all staff in relation to understanding and implementing Care Act and Mental Capacity Act legislation to ensure that front line staff are equipped to practice in a confident sound manner going forward (see recommendation 3).

## **2.2 Key Contacts and Episodes of Practice**

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<sup>4</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/485122/DH\\_Consoolidated\\_Guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/485122/DH_Consoolidated_Guidance.pdf)

During the period under review Bill had numerous contacts with agencies in relation to his day to day care and support needs. This included routine medical appointments and clinical management and specialist treatment and care in relation to specific conditions. Bill's care was provided in the community, primary and secondary care and acute settings.

This report does not provide a detailed record of all contacts with Bill during the period under review. A multi-agency chronology of contacts was compiled to support the review which has been used to identify key or significant points of contact within the 12 months prior to Bill's death. These are set out chronologically below and analysed in section three of this report.

Bill had daily contact with the supported living service and had a one-to-one which was funded for 3.7 hours per day. Bill had a good and supportive relationship with his General Practitioner, whom he saw on a number of occasions during the review period. Bill also had contact with Psychiatric Services, Acute Hospital Services, Speech and Language Therapy Services (where services were appropriately transferred from hospital to community setting), Accident and Emergency Services and the Community Learning Disability Service. A Health Facilitator<sup>5</sup> was assigned to Bill who co-ordinated aspects of his care. Bill was not subject to CPA (Care Programme Approach) at any time during the period under review.

During the period under review Bill was admitted to hospital on four separate occasions. A description and analysis of each presentation and admission is given below.

It should be noted that throughout agency reporting there was reference to 'best interest' protocols being followed in relation to decisions about Bill's care. Best interest decisions relate to situations in which the subject of the decision is deemed unable to make an informed decision for themselves and professionals and/or family members therefore make decisions on their behalf that are deemed to be within the best interests of the subject. Best interest decisions are usually linked to assessment of Mental Capacity under the MCA and it should be noted that there is no evidence of any agency requesting or undertaking a situation specific mental capacity assessment. There was no Lasting Power of Attorney (LPA) on behalf of Bill as his family were closely involved in his care throughout his life.

### **2.3 Contacts and Significant Events during the period under review**

In early September 2013 Provider 1 conducted a choking risk assessment with Bill which identified that he could be at risk at of choking due to the speed of his eating and cramming food. Bill was supported at meal times by staff to eat slower and to have his food cut into smaller manageable pieces. This was documented in an earlier Risk Profile and monitored via a support plan.

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<sup>5</sup> It should be noted that the Health Facilitator was not a designated lead professional for Bill.

At the end of October that year a new provider took over manage of the home where Bill lived.

In early November Bill was seen by his GP as he was experiencing more frequent absence attacks<sup>6</sup> which were taking place around once a week. It was agreed by the GP that Bill would be re-referred to the neurology clinic where he had been seen previously. Two weeks later a letter was sent to expedite his appointment at the neurology clinic which was planned for May 2014. The GP was concerned that this was too long to wait, however there was no further liaison between the GP and the psychiatrist at that time.

There were no significant contacts recorded by agencies in December 2103 or January 2014.

In February 2014 Bill was reviewed by a Consultant Psychiatrist (Learning Difficulties). Following this referral, it was noted by the Speech and Language Therapy service (SALT) that there were issues with eating and drinking. Hospital contacted Bill's GP regarding prescribing for increased seizures and suggested videoing the seizures as Bill would not tolerate investigations. Bill was prescribed a drug to manage increased seizures with a note that this should be monitored and reduced if there were any problems.

That same week Bill underwent an assessment for Dysphagia (the medical term for problems with swallowing) following a referral from Provider 2. It was reported by Provider 2 that Bill had problems with eating and that he had suffered from chest infections as a result. Written and verbal advice was provided to the supported living service on the management of eating and drinking and Bill was placed on a waiting list for support services.

The following month a review officer from the CLDT attended Bill's supported living service to conduct a scheduled review of care. Following this visit the CLDT officer raised a safeguarding alert in which she cited an allegation of neglect by Provider 2 in relation to failure to advise medical professionals of Bill's deteriorating health over the previous 12 months. The officer also cited an allegation of social isolation as a result of poor house management by Provider 2. It has been noted by the Review that provider 2 had been in place for around six months at this time and that there is evidence of Provider 2 supporting Bill to various appointments and engaging in discussions about Bill's weight loss and increased seizures. Provider 2 noted the concerns regarding social isolation and attributed this in some measure to Bill not having one to one support, to the increase in seizures which was resulting in increased tiredness. It had also been noted in a previous review with the Provider that the residents sharing the accommodation were not always compatible and work was ongoing with commissioners to address this issue.

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<sup>6</sup> <http://www.epilepsy.com/learn/types-seizures/absence-seizures>

On the same day a planned review of care was conducted by CWP following notification of a Cause for Concern raised through IAT reporting procedure. The concerns were shared with the CLDT Team Manager (an integrated manager for Adult Social Care (ASC) and adult learning disability health service provided by CWP) who agreed that CWP would visit the supported living service to assess the current concerns to identify any plans that had been put in place to address these.

Two days later a TMBC (ASC) Review officer contacted the senior nurse at Provider 2 for feedback and a manager from Provider 2 had a discussion with the social work senior practitioner about the actions that had been taken so far to address the concerns.

Following this meeting the safeguarding concern was downgraded to level 2 and Provider 2 was asked to investigate and report back. The CLDT manager and CWP manager were notified of this decision and a strategy discussion took place between them. The outcome was for a nurse from Provider 2 to undertake further fact finding and to inform if an investigation was required.

It was recorded by CLDT ASC that no manager from Provider 2 was present for the review of care and that a long-standing member of staff attended the meeting. All managers in Provider 2 were directed at this point that they had to be present at any future meetings.

A number of concerns were identified e.g. Bill's toe nails had not been cut for several months (the member of staff from Provider 2 said that Bill would not allow them to cut his toe nails) which is why this had not been done. A home visit from the chiropodist had been requested and an appointment arranged to complete plan of what support Bill would or would not tolerate.

The reviewing officer concluded that issues in relation to Bill's health had not been sufficiently actioned since the last review of care in March 2013 although Provider 2 disputed this. There were references to Bill's weight and ongoing GP monitoring as his parents had expressed concern that he had lost weight (as referred to earlier Bill had lost more than two stones over a period of 4 months). Provider 2 responded that they had put in place a healthy eating plan which was discussed with a dietician to reduce his weight however no documentation could be found to evidence this.

CWP allocated a nurse to support Provider 2 with the completion of health actions. Further partnership working was agreed between Provider 2 and the CWP Manager to address future joint working needs and also to look at compatibility issues within some of Provider 2's houses. It is not clear at what point this was completed as this was not entered in the records.

In late March Bill was admitted to hospital, he had become unwell following a seizure and was referred by his GP. After eight days in hospital a discharge planning meeting took place at which Bill was deemed medically fit for discharge. The CWP Health Facilitator requested a risk management plan to be put in place to support Bill

with his mobility and personal care needs; this was to cover a number of areas including eating and drinking (to be reviewed and potentially moved from pureed diet to bite-sized pieces of food), medication, seizure/epilepsy care plan, to address concerns from parents regarding Bill returning to the supported living service and to agree additional support on discharge.

At that time the plan was that Bill would be discharged home at the beginning of April however this discharge did not take place as it was deemed by Provider 2 that they did not, at this time, have robust arrangements in place for Bill's ongoing care needs. Because Bill was at a very high risk of falls (having previously had two falls whilst under supervision by Provider 2) the Physiotherapy service raised concerns with the supported living service regarding poor moving and handling techniques in response to Bill's reduced and variable mobility. Care staff at Provider 2 said they did not accept the Physiotherapy service's advice of restricting mobility on 'bad days' or after a seizure. Community Physiotherapy requested a self-propelling wheelchair for restraint. It is unclear why this was not put in place as there is a difference of opinion regarding responsibility for this decision. The Health Facilitator asked that a risk management plan to support Bill with his care needs and mobility. Provider 2 noted the significant change in Bill's care needs and the need to provide staff training to meet those needs.

The Physiotherapy service documented their concerns and the hospital safeguarding team were informed. The Community Physiotherapy Team and Social Worker were also informed of these concerns. Bill remained in hospital at this time.

A week later a meeting with the family was held to discuss discharge from hospital at which Bill's parents expressed concern that whilst it was important that Bill returned to a familiar environment they still had concerns about the level of care from Provider 2 since the home was taken over. At the meeting the family said that they no longer had regular meetings to discuss care or Bill's level of need. Bill's parents wanted assurance that care staff were advised of epilepsy management and dignity issues. A member of staff at the CLDT agreed to follow up these concerns when Bill was discharged.

A formal decision was agreed with the medical team, SALT and Bill's parents to risk feed Bill with a pureed diet. There was an accepted risk that Bill may still develop aspiration pneumonia despite a modified diet. A discharge plan was put in place that addressed one to one support, eating, drinking and mobility and this was to be reviewed by physiotherapy and SALT. It was agreed that a risk assessment should be in place and that oral anti-biotics be available on discharge. Advice was given that care staff could ring out of hours if they had any concerns. A Best Interest<sup>7</sup> meeting was held which was attended by professionals and by Bill's parents to discuss Bill's discharge. Bill was deemed medically fit for discharge from hospital. Prior to

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<sup>7</sup> <http://www.mind.org.uk/information-support/legal-rights/mental-capacity-act-2005/best-interests/#.WAOuyeArLIU>

discharge on 14<sup>th</sup> April ward staff reported that Bill was experiencing seizures on most days, his mobility was reported as being compromised and it was indicated that a hoist may be required for transfers and environmental adaptations may be required. It was indicated that a Social Worker assessment referral be completed for additional support and that Bill receive support from the community physiotherapist.

Within the next eight days Provider 2 raised concerns regarding Bill's mobility and reported one fall, a GP consultation took place as Provider 2 was concerned that Bill was unable to weight bear and had swelling to his right ankle.

Eleven days after discharge Bill was admitted again to hospital following a fall onto his face. Bill was given a chest X-ray and treated for his injuries. He was discharged from hospital the same day and received a visit from CWP staff the following day. Four days after Bill's discharge a Health action plan was completed by the Provider 2 community nurse.

Following a medication change in early May the emergency GP was contacted by Provider 2 as Bill was said to be not eating or taking medication. Bill was admitted to hospital and diagnosed with left basal pneumonia. Whilst in hospital Bill was agitated and distressed. He was given a chest x-ray a day after admission and no foreign body was observed. It was recorded in CWP notes that Bill was unable to swallow and was aspirating.

The following day TMBC received a cause for concern from CWP regarding lifting and handling of Bill by staff at the supported living service. The supported living service responded that all staff had now received lifting and handling training as they were not normally supporting people who required assistance with mobility.

In June Bill was reviewed by the Consultant Psychiatrist and accompanied by a Manager from the supported living service. Bill was noted to be agitated and excited which could lead to occasional aggression. A drug that can help with anxiety was prescribed and this was to be reviewed in two weeks' time to see if it had been effective. Staff at the supported living service were provided with information about managing side effects of the medication. Use of another drug which can be prescribed to deal with side effects of other medication was discussed however staff felt uncertain about whether this could be appropriately managed by them and the drug was not prescribed. A further review was scheduled for 3 months' time. Two weeks later Bill attended the neurology clinic at a local hospital (not UHSM) and no changes were made to his medication. There was no MCA assessment or best interest meeting recorded in relation to prescribing of medication.

In August Bill attended the acute medicine outpatient's department. A chest x-ray was conducted which showed no radio-opaque foreign body. It was noted that Bill had gained some weight.

During the first week in September Provider 2 recorded that Bill had an upset stomach and it was noted that he had been coughing. It was recorded in Provider 2 notes that on 2<sup>nd</sup> September Bill had gone out and eaten lunch at a local café.

A few days later the supported living service contacted the out of hours GP as Bill was unwell with a cough and cold. A support worker had noted that Bill had refused medication as he was unable to swallow.

In the early hours of the following day Bill attended the emergency unit at hospital with a diagnosis of bilateral aspiration pneumonia<sup>8</sup>. Bill was treated with antibiotics and chest physiotherapy. Over the next 9 hours Bill was admitted to the Acute Admissions Unit with respiratory distress and later transferred to the intensive care unit due to significant distress. Bill was intubated and ventilated. At this point, there was no consideration given as to whether Bill should be referred for a DOLS (Deprivation of Liberty<sup>9</sup>) assessment.

The following day, after signs of improvement tubes were removed however this caused distress and Bill's swallow was considered to be unsafe and the tubes were reintroduced and a chest X-ray undertaken. This required sedation due to Bill's distress. No foreign body was seen on the X-ray. A plan was agreed in Bill's best interest to keep him intubated. The following day a further chest X-ray was performed and no foreign body was observed.

A CT scan was performed three days later in order to exclude a possible malignancy (a concern that had emerged due to Bill's rapid weight loss). It was noted retrospectively that a foreign body was not recognised on the scan.

Two days later a best interest meeting was held at hospital with Bill's family present. The meeting was held to determine a plan to treat Bill in the short, medium and long term. It was documented that Bill lacked mental capacity to make decisions for himself. Bill's parents, sister and niece were present to represent Bill's interests. The Intensive Care Unit Consultant explained to Bill's family his current diagnosis and the reason for sedating Bill. At this time Bill was on a ventilator<sup>10</sup> and in an induced coma.

All those present at the meeting agreed that Bill's care should focus on symptom relief and comfort. Any therapeutic interventions should only be undertaken with the minimum of distress to Bill. It was agreed that If Bill became very distressed then the use of pain relief and sedation would be in his best interests and that any future treatments should be provided without causing any undue distress to Bill.

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<sup>8</sup> **Aspiration pneumonia** occurs when food, saliva, liquids, or vomit is breathed into the lungs or airways leading to the lungs, instead of being swallowed into the oesophagus and stomach

<sup>9</sup>The **Deprivation of Liberty** Safeguards are an amendment to the Mental Capacity Act 2005. They apply in England and Wales only. The Mental Capacity Act allows restraint and restrictions to be used – but only if they are in a person's best interests

<sup>10</sup> a ventilator is a machine that helps with breathing; a tube is placed in the mouth, nose, or through a small cut in the throat

Seven days later there was an attempt to wean Bill from the ventilator and sedation was stopped. Bill was allowed to wake however it was not possible to remove him from the ventilator. The following day Bill was removed from the ventilator but his condition deteriorated. On 26<sup>th</sup> September Bill sadly died.

A post mortem was undertaken on Bill on 6<sup>th</sup> October 2014. This date lies outside the scope of the SAR however it is relevant to report the findings. A wedge-shaped piece of bone measuring 4cm x 5cm was found obstructing Bill's oesophagus in the upper portion. Bill underwent several radiological investigations during his admissions to hospital none of which identified the object.

It was concluded retrospectively that the likelihood was that Bill had ingested the bone sometime in the two weeks prior to his death and that it would have caused him considerable discomfort particularly when swallowing. Bill spent 15 days in hospital prior to his death and it was deemed highly unlikely that he would have ingested the bone during this period.

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## **SECTION 3 - SUMMARY ANALYSIS OF AGENCY PRACTICE**

### **3.1 Overview**

This section of the report sets out a brief analysis of practice by each agency in line with the key lines of enquiry in the review.

Agencies provided detailed responses to each of the terms of reference and offered critical analysis of agency practice in their individual management reports. This report does not detail all these responses but summarises significant practice from the point of view of what worked well and might be judged to be good practice, to areas where practice was less effective and could be improved upon.

### **3.2 Understanding Bill's wishes and feelings**

#### **3.2.1. Examples of Expected and good practice**

In regard to understanding and acting upon Bill's wishes and feelings it was widely recognised by professionals and family that Bill experienced difficulties in relation to verbal communication and it is apparent that this was taken into account by all agencies involved in the review. Agencies responded in a variety of ways to Bill's verbal and non-verbal communication to try to understand his wishes and feelings and to act upon them.

The review saw a number examples of efforts to respond appropriately. Whilst Bill was in hospital reasonable adjustments were consistently made i.e. providing additional support, sedation for some tests, ensuring that familiar people were with him when tests were being undertaken and familiar staff supporting him at mealtimes.

Bill's GP had built a good relationship with him and looked for non-verbal indicators which became familiar to her. The GP was aware that Bill had a phobia of needles and did not like certain types of examination. He became agitated at times and the GP therefore attempted to structure what was required in consultations according to Bill's known likes and dislikes.

The hospital recorded that Bill was consistent in demonstrating fear and anxiety within the hospital setting. This was witnessed as pushing people away and at times

hitting out, which was interpreted as an expression of refusal by staff. Bill's needle phobia was evident to hospital staff and was well documented in his hospital records. Many clinical decisions around diagnostic tests and treatment were respectful of this and best interest decisions took this into account by choosing a least resistive route to reduce Bill's level of distress. Examples of this include a decision to consider taking a video of seizure activity rather than undertaking Electro Encephalogram (EEG) or blood tests.

CLDT ASC could not determine how Bill's wishes and feelings were addressed from the records they reviewed. There is reference in the records to Bill's mental capacity however there was no background information about mental capacity assessment or best interest decisions.

Provider 1 and Provider 2 demonstrated their understanding and response to Bill's communication difficulties and highlighted how these were accommodated in their respective reports.

### **3.2.2. Areas where practice should be improved**

The review could find no evidence (other than provision of 'reasonable adjustments') to indicate that agencies used communication technologies to assist Bill with communication. It may be that such technologies were explored and found to be inappropriate or ineffective however this is not documented in agency records.

The hospital documented that Bill lacked capacity to consent to care and treatment due to his learning difficulties. There are omissions in the medical records relating to formal capacity assessment although it is documented in the chronology that the best interest process was followed in accordance with The Mental Capacity Act 2005.

The panel has discussed the MCA guidance regarding medication as there was no MCA assessment of Bill's capacity to understand his medication regime and the purpose and consequence of complying with it.

CWP relied heavily on information from care support workers to interpret Bill's behaviour and wishes. Family members were used in making Best interest decisions and were included in discharge planning meetings and care planning meetings.

Consideration of DOLS should take place in line with amendments to the Care Act (2015) in line with the Supreme Court Judgement in 2014.

## **3.3 Communication Between Agencies and Information Sharing**

### **3.3.1. Examples of expected and good practice**

There are examples throughout the review of agencies communicating routine information from practitioner to practitioner and of some inter-agency and multi-agency information systems working effectively.

Practitioners met at best interest meetings and communicated by phone; there were specific meetings held at the supported living service with Bill's family (records of

these meetings taking place appear to be more robust in the early part of the period under review).

Hospital records in relation to Bill's episodes of unscheduled care, investigations and their outcomes are thorough.

### **3.3.2. Areas where practice should be improved**

In entirety information sharing between agencies was inconsistent. Taking into account the inherent problems of multi-agency information recording and management systems the review panel are of the view that care co-ordination and a nominated lead professional with responsibility for sharing information across the agencies would have greatly assisted in information sharing.

The review has seen that systems for recording and sharing information during the period under review (and indeed on an ongoing basis) were limited by agencies having different systems that do not communicate with each other. Work is ongoing in Trafford at a strategic level to address these issues.

There are several examples of inadequate recording in the CLDT ASC system and in Provider 2 (which may be a result of the change-over in October 2013). The review makes a recommendation in relation to information sharing systems, appropriate recording and the role of the lead professional (see recommendation 6).

The report from Provider 2 suggests that recording could be improved. There is some evidence of inconsistent recording rather than contemporaneous notes being made. In response Provider 2 agreed actions to ensure monitoring of foods eaten by Bill.

Communication between key agencies did not necessarily result in timely and appropriate action. The GP was not informed of a care planning meeting in June 2014 nor were they made aware of the safeguarding referrals that took place earlier that year.

CDLT ASC identified from case notes an appropriate level of communication between agencies for specific incidents around the safeguarding alert or the concern for welfare when these had been raised. It was difficult to determine how certain decisions had been made around the level of safeguarding concern due to the absence of recorded information. CDLT ASC also noted that there appeared to be gaps in the recording to demonstrate how monitoring and review of Bill's support package took place in between periods of intervention. (see recommendation 7).

## **3.4 Involving Bill's family in his care**

### **3.4.1. Examples of expected and good practice**

Bill's family were supportive, engaged and involved in his care. All agencies reported the degree to which the family engaged with them. Some services had more contact

with family members than others because of their roles and position in the care system.

There are several examples of Bill's family being consulted in relation to best interest decisions, particularly around decisions taken in relation to Bill's emergency care in hospital.

Staff at CWP did not regularly meet with Bill's family however they did take note of the families wish to be involved and they liaised appropriately with staff at the supported living service. It was acknowledged that Bill's parents were central to decisions based on care and treatment but also that they were vulnerable themselves in having to participate in such a difficult decision as stated above. This prompted inclusion of the wider family to support them when weighing up the benefits and burdens of such difficult options. The family were involved in care plan meetings, MDT meetings on the ward, a pre-discharge planning meeting and in capacity/best interest and end of life meetings.

Provider 1 and Provider 2 involved Bills family in care meetings however the family became concerned about a lack of involvement when Provider 2 took over at the supported living service (see below).

CLDT ASC records show involvement with Bills parents recorded at specific times of intervention during assessments and reviews and discharge planning meetings. There appears to be minimal contact with Bill's family however within the circumstances of Bill living in supported accommodation with care on site, there was no reason for the council to have further input. The general practice of the team would be considered appropriate and in keeping with operating procedures. Through the review meeting which took place on 13<sup>th</sup> March 2014 the service was able to evidence positive outcomes for Bill following the provision of specialist health input, which had been provided in response to concerns expressed by Bill's parents at the meeting.

#### **3.4.2. Areas where practice should be improved**

Bill's family expressed concerns that, following the change in supported living service provider they felt that they were having fewer meetings in relation to Bill's care. There is no record that this concern was acted upon and it does not appear to have been raised again by Bill's family.

CWP clinical staff engagement with Bill's family was limited and as previously highlighted information was not always shared directly with them.

The General Practitioner did not have face to face contact with Bill's family although they have reflected that this is learning for the practice.

Whilst the burden of these decisions was recognised due to their vulnerabilities, there is little evidence of support for them in the decision-making process.

It was good practice to note that Bill's parents had vulnerabilities and that the burden of decision making required support to be provided to them, however there is little or no evidence that Bill's received support from agencies in the context of their role as carers.

### **3.5 Personalised Planning and Care Coordination<sup>11</sup>**

The review received information that demonstrated that personalised plans were in place in relation to aspects of Bill's care and in particular settings, however these plans appeared to be disparate and potentially disjointed thereby not providing a clear single picture of Bill's care needs.

The supported living service providers reported that Bill had a Person-Centered Plan. The plan identified what was important to Bill, what he liked and disliked and what was support looked like for him. This included having a Health Action Plan (HAP) where his health needs were identified and addressed by the involvement of various professionals.

The supported living service providers, CWP and UHSM have demonstrated that a personalised planning approach was used and that there were various plans in place for Bill.

Bill did have a health passport which appears to have been kept up to date but it is unclear how this was used when Bill was admitted to hospital – this may be because of admissions being unplanned and emergency in nature.

#### **3.5.1. Areas of practice that should be improved**

Plans examined by IMR authors noted some issues with record keeping.

There was no record in CDLT ASC to indicate that Bill had a person-centred plan. Records identify that no such documentation was available at an annual review meeting on the 13th March 2014. There was no record of social care assessment or mental capacity assessment documentation to inform person centred planning. It was therefore difficult for the IMR author to identify what action was taken to resolve the absence of the documentation issue. It was also difficult to determine (through the evidence reviewed) how the Social Work team evidenced the way in which they had supported Bill and intervened in a person-centred manner.

CDLT ASC records have not enabled an accurate picture to be gained and there is no evidence that personalised plans were in place.

### **3.6 Safeguarding referrals**

During the period under review three safeguarding referrals were made. The first was in March 2014 following a routine review of care by CWP. The referral alleged abuse by neglect and acts of omission by Provider2. The referral was initially screened at level 3 and then down-graded, with no apparent rationale, to level 2

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<sup>11</sup> Making Safeguarding Personal

with the provider being given the responsibility for addressing the concerns raised. The GP had no record of being notified of this safeguarding referral and retrospectively expressed significant concern regarding lack of notification.

A further safeguarding referral was made at the end of March 2014 by UHSM who alleged abuse by Provider 2 in relation to Bill experiencing a fall on the hospital ward whilst his care assistant had fallen asleep. This referral was dealt with appropriately and in line with procedure.

A final safeguarding concern was raised by CWP in June 2014 following on from telephone call from a care support worker a formal safeguarding referral was made as the support worker had said staff were losing their temper with Bill and the support worker was concerned. The support worker also rang the house manager and raised concerns directly with them. The manager went to the house and reviewed the situation and said there were no issues.

In addition to the safeguarding referrals a number of causes for concern are noted in the records which illustrate discussions between CWP and CLDT ASC managers, however in the majority of cases these concerns do not appear to have been escalated or addressed.

### **3.6.1. Areas where practice should be improved**

The response to the safeguarding referral on 17<sup>th</sup> March was poor. There was no rationale given for downgrading to level 2 and no apparent follow up of the concerns reported.

A number of concerns were identified by CWP staff. Many of these concerns were often seen in isolation and staff did not reflect on these as a whole until 28 May 2014. Issues were not escalated by the clinical team and outcomes of the referrals were never sought by any individual and does not appeared to be have been followed up the team manager when issues and concerns were raised with them.

CWP staff did not report nor did they seek any support or guidance from CWP Adult Safeguarding team. Opportunities were therefore missed to safeguard Bill as allegations were never investigated. The clinical staff stated that at the time they were not clear as they were given differing advice from their team manager and followed local authority processes and not CWP policies.

The area of responding to safeguarding referrals in this review is of significant concern to the panel and, whilst there is some reassurance that practice and processes have improved since the period under review this Review makes a recommendation that the TSAB immediately assures itself of improvements in responding to safeguarding referrals. (see recommendation 1).

The Council (ASC) is the lead agency for safeguarding adults as defined in National guidance and the Local Multi Agency Safeguarding Adults Policy that was in operation. The review identified a number of questions about the progression of individual safeguarding concerns, which made it difficult to determine if the Council

had been effective in its role as lead organisation for safeguarding adults. In addition to this the review could not find the evidence to confirm how the multi partnership had viewed the effectiveness of the Council's safeguarding adult's response, and if any of the partners had raised any concerns about how individual safeguarding concerns had been progressed.

### **3.7 Adherence to guidance and protocols**

Numerous protocols were cited by agencies in their responses to this review. The panel has not viewed individual agency protocols; however, it is apparent that practice is guided by national and local policy and that practice is quality assured against current guidance.

There are notable exceptions to this, particularly in relation to adherence to guidance in relation to assessment under Mental Capacity Act 2005 and a recommendation is made in the regard (see recommendation 2).

CWP noted that on occasion the organisations safeguarding policies were not adhered to.

CDLT ASC could not find sufficient evidence in the records to provide a full response to this question.

## **SECTION 4: WHAT DO WE LEARN FROM THE REVIEW?**

### **4.1. Summary**

As set out in the introduction to this report it is not the purpose of this review to determine the cause of Bill's death and the Coroner has recorded a verdict of accidental death by asphyxiation.

The review found it difficult to establish a clear picture of Bill's daily lived experience. From written records and interviews with practitioners it can be seen that Bill was a man with a profound learning disability who required a range of care which included receiving unscheduled care in medical settings.

It is apparent to the review panel that, although many professionals had contact with Bill, sometimes on a daily basis, Bill's individuality and potential appear to have been obscured in the professional view by his care needs. This is not to suggest that professionals had no aspirations for Bill but it was difficult for the review to see how these aspirations were translated into his daily care.

It has been highlighted earlier in this report that mental capacity decisions are situation specific. The review has noted that recording of mental capacity and best interest decisions was inconsistent in some agencies and in others it was altogether absent, the latter being particularly the case in relation to the CLDT records.<sup>12</sup> The review believes that on the evidence available there is a need to reinforce the guidance regarding best interest meetings and best practice in relation to the involvement of meetings with family members; decision regarding prescribing and administering medication and the recording of MCA assessment and best interest decisions.

### **4.2 Learning Already Implemented**

Due to the delay in a SAR referral there have been some notable changes in practice since Bill's sad death.

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<sup>12</sup> Mental Capacity Act 2005 Code of Practice

As indicated earlier in this report the Care Act 2014, DOLS and the Mental Capacity Act are being embedded into practice. The spirit of Making Safeguarding Personal is embodied within local policy and guidance and the TSAB is undertaking a review of policy and structures to ensure that quality assurance is central to its work.

The Trafford Care Centre initiative is developing and will put in place systems and processes to ensure that a coordinated approach is taken to supporting multi-disciplinary teams.

Individual agencies involved in this review have identified learning in relation to improving awareness of the Mental Capacity Act, DOLS and adherence with safeguarding procedures.

UHSM has implemented a mandatory training programme in relation to learning disability awareness.

### **4.3. Findings**

The review has identified specific and significant learning for each of the agencies involved in providing care to Bill during the period under review.

The panel has identified a number of key themes under which the findings of this review are grouped; these findings lead to eight key recommendations emerging from the review. These recommendations are set out in section 5 of this report.

#### **4.3.1. Finding 1: Lack of Multi-Agency Coordination and Care Management**

Bill's care during the 12 months prior to his death lacked co-ordination and consistency. The review saw no evidence that a dedicated lead professional took responsibility for coordination of care and multi-agency working. Although Bill was resident in the same supported living service (albeit with two different providers it has been difficult for the panel to form a consistent and comprehensive view of Bill's daily life and the responses made by Provider 1 and Provider 2 to Bill's needs.

This is not to say that the care providers did not respond to Bill's needs but that evidence of robust recording, integrated care planning and delivery, consistent and good quality interaction with other professionals and with Bill's family were not evidenced in the reports provided to the SAR by the care provider.

It is the view of the review panel that care-coordination by a lead professional in this case would have strengthened multi-agency working and liaison with Bill's family enabling a clearer and more co-ordinated care response to Bill.

#### **4.3.2 Finding 2: - Mental Capacity and Best Interest Decisions**

Decisions in relation to Bill's mental capacity were not always supported by assessment as required by the Mental Capacity Act.<sup>13</sup>

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<sup>13</sup> <https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>

Bill's death pre-dated refreshed guidance published in 2016 in relation to Mental Capacity Assessment however all professionals working with Bill should have ensured that the guidance in relation to MCA was adhered to.

The review has identified a specific concern in relation to the administration of medicines to Bill without his explicit consent and a recommendation is made in this regard (see recommendation 2).

#### **4.3.3. Finding 3: - Recording and Sharing of Information**

Systems for recording and sharing information were inconsistent and not used to best effect. This is particularly the case in relation to Provider 2 and the CLDT. The panel has seen evidence that improvements have been made in recording systems and makes a recommendation in this regard (see recommendations 2 and 7).

#### **4.3.4. Finding 4: - Responding to Safeguarding Alerts**

Whilst safeguarding alerts and causes for concerns were investigated by commissioners the process lacked rigour and on one occasion relied too heavily on Providers conducting internal investigations.

There was a lack of follow up to evidence that safeguarding referrals were robustly followed up and little evidence that concerns were escalated or addressed. Safeguarding alerts were not shared appropriately and in a timely way with the family or with the General Practitioner. There was a lack of multi-agency focus and shared accountability in managing and following up safeguarding alerts.

#### **4.3.5. Finding 5: Involving Families**

For the most part agencies involved Bill's family appropriately in decisions about Bill's care, although there is no sense in the material viewed of a co-ordinated approach to involving the family (i.e. there is no indication that a lead professional held regular meetings with the family to discuss Bill's ongoing care and day to day needs). The records seen by the review suggest a 'crisis management' approach to family involvement rather than a co-ordinated and integrated way of working.

The review found that agencies took differing approaches to involving the family which led to inconsistencies which would have placed the family in a difficult and stressful position. A single point of contact for families dealing with a range of agencies and supporting a family member with complex needs is crucial to enable the family to make a contribution to care as well as being supported in decision making.

#### **4.3.6. Finding 6: Understanding and acting on the needs of adults with profound learning difficulties**

Efforts and adjustments were made to alleviate Bill's communication difficulties. However, the review has concluded that a more creative approach to overcoming communication difficulties might have been adopted. There is no indication that agencies took a collaborative approach to overcoming communication difficulties or that the use of communication technologies was explored.

## **SECTION 5: RECOMMENDATIONS AND MULTI AGENCY ACTION PLAN**

In line with key learning in this review the panel makes the following recommendations to the TSAB.

### **Recommendation 1**

- (i) TSAB should be assured that the process for making a SAR referrals is clear and timely and that all agencies are aware of the process.
- (ii) TSAB should be immediately assured that the policy and process for making and responding to safeguarding referrals in all partner agencies is in place and that audits are conducted to quality assure the process and outcomes of safeguarding referrals.

### **Recommendation 2**

TSAB should be assured that where issues of capacity are involved agencies are working to the requirements of the Mental Capacity Act and that staff are fully trained, skilled and confident in applying the Act. The Board should seek particular assurance in following areas:

- (i) TSAB should be assured that the legal framework in relation to medication regimes is understood and implemented by all agencies.
- (ii) TSAB should be assured that all agencies involve families and significant others in care planning, reviews and best interest decision meetings.
- (iii) TSAB should be assured that placements are reviewed appropriately

### **Recommendation 3**

TSAB should be assured that all agencies understand their responsibilities in relation to DOLs and that training in awareness raising and applications of DOLs regulations is provided and procedures and policies are adhered to.

### **Recommendation 4**

TSAB should be assured that all agencies strive to implement an aspirational model of care for adults with learning disabilities and that this should be reflected in commissioner specifications.

#### **Recommendation 5**

TSAB should be assured that all agencies are working to the principles of person centred care as set out in the guidance and include 'The Triangle of Care'<sup>14</sup> and 'Making Safeguarding Personal'<sup>15</sup>.

#### **Recommendation 6**

TSAB should be assured that the role of the lead professional is clearly understood and reflected in practice and multi-agency working arrangements.

#### **Recommendation 7**

TSAB should be assured that systems and practice for recording and sharing information are fit for purpose despite barriers inherent in current national systems (i.e. no single national electronic records system).

#### **Recommendation 8**

TSAB should be assured that commissioners have robust arrangements for monitoring, reviewing and acting on information from provider service.

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<sup>14</sup> <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>

<sup>15</sup> [http://www.local.gov.uk/adult-social-care/-/journal\\_content/56/10180/6074789/ARTICLE](http://www.local.gov.uk/adult-social-care/-/journal_content/56/10180/6074789/ARTICLE)

## APPENDIX 1

### Glossary of Terms

CLDT	Community Learning Disabilities Team
CWP	Cheshire and Wirral Partnership
DOLS	Deprivation of Liberty Standards
Dysphagia	A condition that results in difficulty in swallowing
MCA	Mental Capacity Act (2005)
UHSM	University Hospital of South Manchester

APPENDIX 2

(Insert multi agency action plans)

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