Worcestershire Safeguarding Adults Board

CASE REVIEW

Overview Report

SUBJECT: Lee Graham

Died 2012, aged 26 years

SILP Lead Reviewer and Report Author: Adrienne Plunkett

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1. Introduction:

1.1. This Lower Level Case Review was commissioned by Worcestershire Safeguarding Adults Board in response to the death of Mr Lee Graham in 2012. The Review has been conducted in accordance with the Worcestershire Safeguarding Adults Board's Lower Level Case Review Protocol. The aim being to establish whether there were any lessons to be learnt about the way in which local professionals and agencies worked together,

1.2. Lee Graham was a young man with a learning disability. At the time of his death he was an inpatient at the Acute Hospital, though had spent many years in residential care. The causes of his death are recorded as respiratory arrest, sleep apnoea and obesity.

2. Framework for Case Review:

2.1. The Worcestershire Safeguarding Adults Board Lower Level Case Review Protocol[1] states there are cases where vulnerable adults or their carers have died, which do not necessarily reach the criteria for a Serious Case Review, but may lead to some inter-agency learning. The WSAB Protocol is based on The Association of Directors of Adult Social Services (2006) guidance [2]on completing case reviews of a serious nature.

3. Introduction to the Significant Learning Incident Process (SILP)

3.1. The SILP methodology reflects on multi-agency work systemically and aims to answer the question why things have happened. Importantly it recognises good practice and strengths that can be built on. The learning model engages frontline staff and their managers in the review of the case, focussing on why those involved acted in a certain way at that time. It is a collaborative and analytical process, which combines written Agency Reports with Learning Events.

3.2. The model is based on the expectation that Case Reviews are conducted in a way that recognises the complex circumstances in which professionals work together and seeks to understand practice from the viewpoint of the individuals and organisations involved at the time.

3.3. The SILP model of review adheres to the principles of:

- Proportionality
- Active engagement of practitioners and managers
- Engagement with families
- Systems methodology
- Learning from good practice

3.4. SILPs are characterised by practitioners, managers and Agency Report Authors coming together for a Learning Event. Agency Reports are shared in advance with the participants and the perspectives of all those involved are discussed and valued. This same group comes together again to consider the draft Overview Report at a Recall Event.

[1] Protocol Case Reviews (lower level), Worcestershire Safeguarding Adults Board.
[2] Vulnerable Adult Serious Case Review Guidance - developing a local protocol, London: Association of Directors of Adult Social Services, 2006.

4. Process for this Case Review:

4.1. The Terms of Reference appear in Appendix 1. This contains the details of the Scoping Period, Agency Reports commissioned and the Specific Areas for consideration. The template for the Agency Reports appears in Appendix 2.

4.2. The Scoping Period for this Case Review is the twelve months prior to Lee Graham's death. Agencies were also asked to provide a brief background of any significant events prior to the Scoping Period. This material would be used primarily to provide the background context and therefore needed to be concise and summarised, highlighting any particular learning points.

4.3. Agency Reports were commissioned from:

- Directorate of Adult Services and Health (DASH)
- Health and Care Trust
- Acute Hospitals Trust
- NHS England (General Practitioner)
- Residential Care Provider

4.4. The SILP Learning Event was held on 23 April 2015 and the Recall Day on 10 June 2015. The Agency Reports were shared with the participants prior to the Learning Event, so that they had a wider understanding of all agencies' involvement. The draft Overview Report was circulated to participants prior to the Recall Day, in order that it could be checked for accuracy and the findings and recommendations fully discussed on the Day. The Overview Report was amended following this discussion.

4.5. The Learning Event was attended by practitioners, managers and Report Authors from DASH, The Health and Care Trust and the Residential Care Provider. The NHS England Author and a GP from the Practice attended. The Acute Trust was represented by the Report Author and the Liaison Learning Disabilities Nurse was present, who had liaised closely with the staff in the Acute Trust who cared for Lee Graham during his admission. The significant gap in attendance was the lack of representation from the Psychiatric and Psychology Services, as Lee Graham had been known to these services over a long period of time, hence their contribution would have been very valuable.

4.6. The Recall Event was attended by representatives from DASH, The Health and Care Trust, the Acute Trust and the Residential Care Provider. The Report Author for the H & CT had tried to gain attendance from the Psychiatry and Psychology Services, but was unable to do so, due to a lack of resources. However, she has given assurance that the learning will be disseminated to these services. Both events were attended by the Designated Nurse for the County.

4.7. It should be recognised that practitioners and managers demonstrated a willingness to participate in the review process and a keenness to learn lessons for practice from the death of Lee Graham. Practitioners openly shared information about their involvements with Lee Graham and his family and were prepared to engage in some challenging discussions. It was apparent that considerable thought had already been given to developments in service provision.

4.8. The Lead Reviewer for this Case Review was Adrienne Plunkett. Ms Plunkett is a trained SILP Lead Reviewer. Donna Ohdedar, Review Consulting, has provided additional scrutiny of the process and Overview Report.

5. Background Information:

5.1. Lee Graham was a white British young person with a diagnosis of severe learning disability, Down's Syndrome and aspects of autistic spectrum disorder, e.g. some obsessional behaviours. He had communication difficulties, but by using a limited vocabulary and Makaton signing he was able to make his needs and choices known to the people who knew him well. Lee Graham was also diagnosed with epilepsy soon after birth, but had had no symptoms for several years. He was short-sighted and required glasses.

5.2. Lee Graham had close relationships with his family; his Mother, Father, Sister and Brother. Sadly Lee Graham's Father died suddenly and unexpectedly in July 2011.

5.3. Lee Graham enjoyed sports; swing ball, basketball, football and swimming. He liked watching DVDs, particularly Only Fools and Horses, and listening to music, including The Black Eyed Peas.

5.4. Lee Graham's experienced extreme anxiety and found change difficult. His behaviour could escalate quickly and become very challenging. Lee Graham could be reluctant to engage in physical activities, often being happier watching. If he did not want to do something it could be very difficult to persuade him otherwise. He had received long term treatment for his anxiety and stress with tranquillisers.

6. Engagement with the family:

6.1. The Designated Nurse for Worcestershire and the Lead Reviewer visited the family in March and met with Lee Graham's Mother, Sister and Brother. The purpose of the Case Review and the SILP model were explained to them. They provided helpful background information regarding Lee Graham.

6.2. The family are concerned that obesity was a key factor in Lee Graham's death and are keen to ascertain whether appropriate steps were taken to address his weight gain in the years before his death. Lee Graham's Mother had raised her concerns with a number of professionals over the years, including the Consultant Psychiatrist, the Community Learning Disability Nurse and the Manager of the Residential Unit.

6.3. In particular, the family wanted the three areas below addressed:

- The GP's role in the management of Lee Graham's weight.
- The quality of Care Planning for Lee Graham.
- Did the staff at the Residential Unit have the requisite training and experience to manage Lee Graham's behaviour? What management oversight was provided?

6.4. Following the Recall Event in June 2015 the Designated Nurse and Lead Reviewer met with the family again in order to share the findings, learning and recommendations from the Case Review.

6.5. The family spoke of feeling reassured that Lee Graham's death had been treated seriously and that a thorough review had been undertaken. His mother expressed sadness that, whilst she was pleased lessons were being learnt, this had only been achieved as a result of Lee Graham's death. His brother was positive about the findings and recommendations and suggested that if a Strategic Plan was developed as a result of the Case Review, that this should be known as Lee's Plan. He felt that this would be tangible evidence that Lee Graham's death was making a difference. **(See Recommendation 1)**

7. History prior to Scoping Period:

7.1. Lee Graham attended a local special school until the age of 13 years, and then he moved to a residential special school where he resided for four years. At the appropriate time an adult residential placement was identified, where Lee Graham moved in 2004. The move led to Lee Graham becoming anxious, stressed and physically aggressive to staff. Following a weekend at home he refused to return and his parents concluded that the placement was not suitable for him. Lee Graham remained at home for a period of time, but his behaviour deteriorated significantly, necessitating hospital admission under Section 3 of the Mental Health Act (1983).

7.2. Following discharge from hospital in November 2005 Lee Graham moved to the Residential Unit where he remained until his death. This was a small specialist unit with three residents, all with a learning disability and challenging behaviour. The staffing structure included a Home Manager, a Deputy Manager, two Senior Support Workers and seven support staff. All staff were NVQ Level 2 or 3 qualified and received yearly mandatory refresher training. Lee Graham had the same Key Worker from August 2006 until January 2012. Lee Graham was reported to have settled well and the behaviour management strategies employed led to a decrease in incidents of behaviour that was challenging. His family visited regularly throughout his time in the Residential Unit.

7.3. Reviews of the placement and Support Plans in 2009 and 2010 identified Lee Graham's weight gain as a specific issue, stressing the need to encourage his participation in physical activity, to promote a healthy diet and to manage his obsessional behaviour in relation to high calorie foods. The reviews acknowledged the difficulties in achieving this in view of Lee Graham's behaviour that was challenging. It is noted that in 2010 Lee Graham's weight was 16 stone, 101 kgs., (BMI 46).

7.4. Lee Graham was regularly reviewed by the Consultant Psychiatrist, who was in contact with his Mother and her long standing concerns about his weight management are noted by the Consultant Psychiatrist. The GP undertook annual health checks.

7.5. In response to mother's concerns from October 2010 swimming sessions were arranged for Lee Graham at a hydrotherapy pool by the Community Learning Disabilities Nurse. These continued until he became too unwell to participate in the activity in 2012.

8. Scoping Period: Key Practice Episodes:

8.1. March 2011, Annual Review by Community Learning Disabilities Nurse, to July 2011, Review Meeting CLDN1 and Residential Unit Manager:

8.1.1. The Annual Review in respect of Lee Graham's residential placement was undertaken in March 2011 by the Community Learning Disability Nurse (CLDN1), who was the Case Manager at that time. The aim of these Reviews is to ascertain whether there are any

changes in the service user's needs and that the placement continues to meet their needs.

8.1.2. 16 Outcomes were considered relating to physical and mental health, communication and decision making, management of finances, daily living activities, social and leisure activities, relationships. There is reference to the benefits of hydrotherapy for Lee Graham, the need for continuity of staff, and the involvement of Lee Graham's Mother in the management of his finances. It was noted that there were difficulties in reducing Lee Graham's weight as he enjoyed fast foods and refused healthier options. The Residential Unit was offering additional activities, but Lee Graham was declining these and tending to withdraw to his bedroom. No actions were identified from this Review.

8.1.3. In April 2011, as is good practice, the GP undertook an Annual Health Review. The GP held a lead role in the Practice in respect of people with learning disabilities. Since 2009 additional funding has been available to GP Practices in England to routinely undertake annual health checks of people with a learning disability. The aim being to identify unrecognised and potentially treatable health needs and put in place targeted actions to address these, thus helping to address the health inequalities faced by people with a learning disability[3]. A Learning Disability Plan for Lee Graham was in place, which provided the Residential Unit with information as to who to contact in certain circumstances. Lee Graham's obesity was noted: his height was 1.49 mtrs. (4 ft. 10 ins.), weight 107.5 kgs., 16st 13 lbs, BMI 48, and advice was given. The possibility of hypothyroidism being a contributory factor was considered, which would require a blood test to check thyroid function. No further actions were agreed with the Residential Unit and no follow up was planned.

8.1.4. During June and July there were communications between the GP and the Consultant Psychiatrist regarding Lee Graham having a blood test for thyroid stimulating hormone. Such a test was recommended in the GP Guidelines and would indicate whether hormone inactivity was contributing to Lee Graham's weight gain. There was correspondence about the fact that Lee Graham lacked the mental capacity to understand and therefore consent to the test, so this would require a best interests decision. It was agreed to refer Lee Graham to the Community Nursing Team for a program of desensitisation. The referral was made, but was not progressed due to the subsequent death of Lee Graham's father.

8.1.5. In June 2011 the Consultant Psychiatrist reviewed Lee Graham at the Residential Unit. Lee Graham's behaviour was settled, with no significant aggression. The Consultant Psychiatrist had had contact with Lee Graham's Mother, who was concerned about his weight gain (17 stone, 108 kgs., BMI 49.7). The Consultant Psychiatrist discussed this with staff and noted the difficulty in engaging Lee Graham in activities and the tendency to use food to reward good behaviour. The Residential Unit were encouraging a more varied diet and portion control. The Unit advised that Lee Graham went swimming every two weeks, but afterwards was rewarded by a visit to McDonalds for a Happy Meal. Consideration had been given by the Residential Unit to the involvement of a Dietician, but it would be

[3] Health Checks for People with Learning Disabilities: A Systematic Review of Evidence, Learning Disabilities Observatory supported by Department of health,

difficult to get Lee Graham to attend an appointment. No further action was noted in respect of weight management.

8.1.6. There was also discussion of a visit to the family home for Lee Graham, but there was concern that he may interpret this as a placement move, which would distress and unsettle him. Consideration was being given to the use of a muscle relaxant to facilitate a trip of this nature, which would require a Mental Capacity Assessment and best interests decision. The Consultant Psychiatrist was to communicate further with Lee Graham's Mother regarding this.

8.1.7. There was a Review Meeting between the CLDN1 and the Manager of the Residential Unit in July 2011, however, there is no record of the outcome of this.

8.1.8. The Residential Unit completed Support Plans at end of July 2011. These were in respect of: Supporting emotions/behaviours, Supporting (personal and social) relationships, Encouraging in-house activities, Social (community) activities, Diet and eating support needs and Accessing health professionals. In terms of Diet and eating support the short term goal was to 'assist me in choosing my food and helping me to maintain a healthy balance' and the long term goal was to 'promote awareness for me to understand health and non-healthy foods'. The Agency Report Author for the Residential Unit noted that from June 2011 Lee Graham's weight was fluctuating between 16 stone 9 lbs and 17 stone (BMI 49.7), although it was difficult to gain Lee Graham's co-operation to being weighed, so there were challenges in monitoring this.

8.1.9. Lee Graham's family were not involved in formulating and agreeing these plans, as this was not routine practice in the Residential Unit at this time.

8.2. July 2011 – December 2011: Period following Lee Graham's Father's death:

8.2.1. In late July 2011 Lee Graham's Father died suddenly and unexpectedly. This was a great shock for the family and it was their immediate wish that Lee Graham should not be told at that time about his death. Instead he was told that his father was unwell. There were discussions between Lee Graham's Mother, the Residential Unit, Community Learning Disability Nurse and Consultant Psychiatrist regarding how to prepare and tell Lee Graham and advice was sought from the Psychology Service. A Mental Capacity Assessment and best interests decision were not made in respect of whether or not there should be a delay in informing Lee Graham of his Father's death.

8.2.2. Despite Lee Graham not knowing that his Father had died, there was a significant change in his routine, as until then his Father had regularly visited weekly. Lee Graham would also have been aware of the distress of family members. The Consultant Psychiatrist reviewed Lee Graham early in August and noted that although Lee Graham was unaware of his Father's death he was unsettled. Emergency bereavement counselling was activated to help Lee Graham understand the concept of death. His medication was increased, but when reviewed a month later this was causing him to be sleepier, so it was reduced again.

8.2.3. Towards the end of August Lee Graham was informed of his Father's death by his Mother, Sister and Brother. There was a meeting between the Manager of the Residential Unit and the Community Learning Disability Nurse at the end of August. The CLDN1 provided advice about dealing with Lee Graham's bereavement, including provision of a 'bereavement folder'. The Residential Unit were observing a change in Lee Graham's behaviour and he

was becoming even more difficult to engage in activities. The CLDN1 also provided the family with information in dealing with bereavement.

8.2.4. At the beginning of December 2011 the Consultant Psychiatrist undertook a review of Lee Graham. The Consultant had spoken to Lee Graham's Mother prior to the review. She was generally concerned about Lee Graham's welfare. He seemed to be 'in a world of his own' and 'glazed', his eating habits had changed, he was scratching himself and occasionally wetting the bed. The Residential Unit were presenting a very similar picture. Consultant Psychiatrist's view was that it was highly likely that these changes related to Lee Graham's bereavement. At times Lee Graham appeared to understand his Father had died, at other times he talked about his Father being 'poorly'. No actions are recorded from the review.

8.3. December 2011 – April 2012: Period of Lee Graham's health deteriorating:

8.3.1. In mid-December 2011 the GP attended Lee Graham at the Residential Unit, due to concern about 'thick green sputum'. Lee Graham was resistant to being examined by the GP and anti-biotics were prescribed. The GP reviewed Lee Graham a week later. He was brighter, his chest was clear and the cough had settled. No further medication prescribed.

8.3.2. In January 2012 the Consultant Psychiatrist reviewed Lee Graham at the Residential Unit. Some depressive features were noted. Lee Graham was reported to be tearful, his interest in activities fluctuated, he was sleeping more during the day and he was refusing some meals. The self-injury was continuing; scratching and picking at legions. Lee Graham would say that his heart was 'hurting'. There was some discussion about Lee Graham's level of understanding about his Father's death, still talking about him being 'poorly' and it was agreed the Psychology Department would become involved again. Whilst it was recognised that Lee Graham was experiencing emotional distress, it was considered that anti-depressant medication was not indicated.

8.3.3. A meeting took place between Lee Graham's Mother and the Psychologist and plans were made to support the provider in managing Lee Graham's bereavement needs.

8.3.4. CLDN1 ceased involvement with Lee Graham and his family in January 2012 as case responsibility was to transfer from the South CLD Team to the North Team. This was a significant change for the family as CLDN1 had been involved with the family, particularly working with Mother, for some time. The necessary workflow in Frameworki was actioned, but the case was not allocated to a new CLDN for some time and not until Lee Graham became unwell.

8.3.5. The reasons for the delay in allocation were discussed at the Recall Event and it was concluded that this was due to the significant restructuring which was taking place in the CLD Teams at this time. This meant that a large number of cases were transferring between teams and workers and the transfer would have had less priority.

8.3.6. The GP attended the Residential Unit on 23 January 2012. Lee Graham was seen with his Mother and carers. He was chesty, wheezy and sleepy. Anti-biotics were again prescribed for seven days.

8.3.7. At the end of January the Residential Unit completed Support Plans with Lee Graham. These again included: Supporting emotions/behaviours, Encouraging in-house activities, Social (community) activities, Accessing health professionals and Diet and eating support.

In respect of the latter it is noteworthy that there were no changes to the actions to be undertaken, despite the fact that Lee Graham had continued to gain weight and the previous plan had not been effective. There was an additional Support Plan, Supporting me in decision making and choices, the short term goal being for Lee Graham to 'be able to make constructive decisions on my own or with limited control from staff and the longer term goal was for Lee Graham to 'be able to make constructive decisions on his own or with limited control from staff'. Lee Graham's family were not involved in formulating and agreeing these plans, as this was not routine practice in the Residential Unit at this time.

8.3.8. Also in January a Risk Assessment was completed in respect of Lee Graham's weight gain. The action was to be weekly monitoring. However, it was noted at the Learning Event that monitoring Lee Graham's weight was difficult to achieve as he often refused to be weighed. The Residential Unit noted that Lee Graham's approach to food had changed and he appeared to be 'off food'. Some evenings he would refuse a cooked meal, throwing the food away, but he would eat sandwiches. The Manager of the residential Unit considered that Lee Graham's behaviour and demeanour had reverted back to how it had been when he was admitted to the Unit. This was seen as a manifestation of the Lee Graham's grief following his Father's death.

8.3.9. During February 2012 Lee Graham's health deteriorated. He was becoming chestier and generally more poorly. An inhaler was prescribed. It was the shared view of Lee Graham's Mother, the GP and the Residential Unit that it was in Lee Graham's best interests to continue to be treated at home, given the distress and anxiety admission to hospital would cause him, as he may well interpret this as moving home. His Mother visited the Unit on a daily basis.

8.3.10. Early in March there were concerns that Lee Graham had had a fit and admission to the Medical Assessment Unit was agreed. Over the next two days, 5/6 March, there were discussions between Lee Graham's Mother, the GP, Consultant Psychiatrist, CLDN2 and the Residential Unit about how to progress his admission as Lee Graham would resist this. It was agreed that Lee Graham did not have the capacity to agree to hospital admission, but that it was in his best interests to be admitted. Therefore, sedation to facilitate admission by ambulance was agreed. This is fully documented

8.3.11. Lee Graham was admitted to hospital on 6 March 2012. On admission he was 'very poorly' and required emergency intervention to stabilise his condition. His weight was recorded as 121 kgs., (19 stone), BMI 55. Medical records note that 'he stood and walked to the weighing scales'. Lee Graham's family were advised of his condition and they stayed overnight at the hospital. Management of Lee Graham's oxygen levels was very difficult given his distress at use of the oxygen mask. A Mental Capacity Assessment was undertaken and a best interests decision taken in respect of medical intervention. The Liaison Learning Disability Team was involved in supporting and advising the medical staff treating Lee Graham in hospital.

8.3.12. On 13 March the Specialist Registrar in Respiratory Medicine met with the family and advised them of Lee Graham's poor prognosis. Further tests and interventions were difficult due to the distress these caused Lee Graham and his intolerance of oxygen therapy. Lee Graham was considered to be unsuitable for Critical Care and symptom control and palliative care were advised. Following discussion with the family a do not attempt resuscitation order was put in place, which was fully recorded. The DASH Agency Report

Author noted that Lee Graham's weight and physical shape compromised his breathing and limited the treatment options available to the medical staff treating him. Any underlying causes of Lee Graham's health condition could not be identified due to the difficulties of undertaking further tests, including a chest X-ray.

8.3.13. The Plan at this time was to transfer Lee Graham to a placement where he would receive nursing care. NHS Continuing Health Care Funding was agreed from March 2012 and a placement was sought. However, by the end of March Lee Graham's medical condition had deteriorated considerably and he died in hospital on 16 April 2012. The causes of death recorded on his death certificate include respiratory failure, sleep apnoea and obesity.

8.3.14. During Lee Graham's stay in hospital he was supported and cared for by his family and two members of staff from the Residential Unit who were at the hospital for 15 hours each day. In addition, extra nursing staff were supplied to the ward.

9. Post Scoping Period:

9.1. Whilst outside the Scoping Period, it is noted that, following his death, Lee Graham's family lodged a complaint in respect of the care he had received in the Residential Unit, particularly with regard to the management of his weight, given that treatment options on his admission to hospital were limited by his physical condition. An Adult Protection Conference was held and an Independent Complaint commissioned.

9.2. Worcestershire County Council's Care Services Quality Team has worked closely with the Provider to develop and improve practice at the Residential Unit. It is reported that the Unit has been receptive to the advice offered.

10. Thematic Analysis:

10.1. Compliance with Mental Capacity Act

10.1.1. The Mental Capacity Act 2005 came into force in 2007. It applies to everyone involved in the care, treatment and support of people aged 16 or over living in England and Wales who lack the capacity to make all or some decisions for themselves. The Act is underpinned by five key principles: a presumption of capacity, individuals being supported to make their own decisions, the right to make decisions that others may regard as unwise, best Interests and less restrictive option. Under the Mental Capacity Act (MCA) practitioners are required to make an assessment of capacity before carrying out any care or treatment. In order to decide whether an individual has the capacity to make a particular decision two questions must be answered: Is there an impairment of or disturbance in the functioning of a person's mind or brain? If so, is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision? The MCA states that a person is unable to make their own decision if they cannot do one or more of the following: understand information given, retain that information long enough to be able to make the decision, weigh up the information and communicate their decision.

10.1.2. The view of those attending the Learning Event was that Lee Graham lacked the capacity to make many day to day decisions for himself. However, evidence indicates that there was a lack of a consistent approach towards the requirements of the Mental Capacity Act by practitioners working with Lee Graham.

10.1.3. Generally, Mental Capacity Assessments were undertaken and best interests decisions taken in respect of medical interventions, particularly in acute situations, e.g. thyroid stimulating hormone testing, admission to hospital and treatment following admission. There is evidence of good communication between health practitioners, i.e. GP, Community Learning Disability Nurse and Consultant Psychiatrist and with the family regarding MCAs.

10.1.4. However, there are two significant aspects where Mental Capacity Assessments were not undertaken. These were with regard to the management of Lee Graham's weight and diet and the decision to delay telling Lee Graham about his Father's death.

10.1.5. The management of Lee Graham's weight was a long term challenge for the family and practitioners. Support Plans in 2011 and 2012 for Diet and Support Needs outline the short term goal as assisting Lee Graham with choosing foods and helping him to maintain a healthy balance and the long term goal as promoting awareness to understand healthy and non-healthy foods. However, discussions during the review process indicated that Lee Graham did not have the capacity to understand, retain and weigh up the information being provided to him and to make healthy food choices.

10.1.6. A Mental Capacity Assessment would have helped to clarify whether or not Lee Graham did have capacity and if the assessment concluded that he did not this would have led to best interests decisions being made about the type and quantity of food provided to Lee Graham. Further consideration could have also been given to a DOLS (Deprivation of Liberty Safeguards) assessment, as there would be a restriction of a person's freedom, i.e. Lee Graham's freedom to make choices about what he eats. However, it does need to be acknowledged that given Lee Graham's entrenched eating patterns, and his resistance to change, altering his diet significantly would have been very challenging and would have impacted on his behaviour.

10.1.7. Lee Graham's family requested that he was not told immediately about his Father's death and there was then a delay of about a month in doing so, during which time Lee Graham was told that his Father was unwell. Whilst it is acknowledged that this was a very difficult time for the family, who were in shock, grieving and understandably very concerned about how Lee Graham would react to the sad news, many of the participants at the Learning Event were of the view that there should have been a Mental Capacity Assessment and a best interests decision as to whether there should be such a long delay in telling Lee Graham. This meant that there was no opportunity to consider if Lee Graham could be part of his Father's funeral process, e.g. to visit the Church/grave, to send flowers.

10.1.8. At the Learning Event practitioners spoke about the fact that practice and procedures in respect of MCAs, best interests decisions and DOLS was not as developed at the time of the Scoping Period as it is now. This was also the picture regionally and nationally. The framework now in place in Worcestershire enables, and supports, practitioners in working step-by-step through this process and is used routinely. It 'provides a platform to open and structure discussions and decisions' and to record the rationale for a decision. The CLDN1 considered that this framework would have supported him in dealing with the complex issue of when and how to tell Lee Graham about his Father's death.

10.1.9. Also, at the Learning Event there was a discussion about whether there has been a philosophical shift in the approach to working with people with a learning disability. It was

suggested that there was time when the emphasis was to allow people to make their own choices whether or not they had the mental capacity to do so. It is now recognised that when people cannot understand the consequences of the choices they are making it may not be in their best interests for them to make the decision. The framework for mental capacity assessments and best interests decisions are assisting practitioners in making these judgements. **(See Recommendation 2)**

10.2. The Voice of the Service User:

10.2.1. At the Learning and Recall Events the tensions that can develop in balancing the wishes of family members with the rights and needs of an adult service user with a learning disability were explored. It is recognised that Parents can understandably find the shift from holding parental responsibility for their child, and the power to make decisions for them when necessary, to the focus being on mental capacity assessments and best interest decisions challenging.

10.2.2. This was highlighted in the discussion regarding Mother's wish to delay in telling Lee Graham of his Father's death. There was a great deal of sympathy for the family at their sudden loss and an understanding that it would be difficult to immediately face the issue of how best to tell Lee Graham whilst they were still coming to terms with the sudden death themselves. The family would undoubtedly be concerned about the impact of the news on Lee Graham's behaviour and it would be a natural tendency to want to delay this until the family felt more able to deal with Lee Graham's reaction. Lee Graham's mother was keen that his Sister and Brother should also be present when Lee Graham was told.

10.2.3. Whilst participants would want to work very much in partnership with the family, and recognising there is not an easy answer, they were not convinced that this delay was in Lee Graham's best interests. He was clearly emotionally unsettled by the lack of visits from his father. It is apparent that there were discussions with Mother about how best to handle telling Lee Graham of his Father's death and the CDLN1 encouraged her to tell him sooner. However, this was not undertaken or recorded under the MCA Framework.

10.2.4. Whilst Lee Graham would have had difficulty verbalising this, he demonstrated considerable distress at his Father's death. His behaviour and demeanour had changed, he was less active and he spoke of his 'heart hurting'. It was recognised that he was showing some depressive features and a further referral was made to the Psychology Service in respect of bereavement work. It is likely that his emotional state contributed to the deterioration in his physical condition prior to his admission to hospital. He had become less interested in activities and his diet was even more difficult to manage. It appears that agencies were sensitive to Lee Graham's emotional state and his increased vulnerability.

10.2.5. Participants in the Case Review considered that staff at the Residential Unit listened to Lee Graham, who could demonstrate what he did and didn't want/like, and encouraged him to make choices for himself.

10.3. Managing the bereavement of service users:

10.3.1. There was discussion during the review about how to prepare adults with learning a disability for bereavement; of a family member, friend or another resident in a care home. The benefits of raising service users' awareness of death prior to a bereavement were

recognised, also of Residential Units having appropriate resources readily to hand. **(See Recommendation 5)**

10.4. Quality of Care and Support Planning:

10.4.1. During the Scoping Period each service user had an over-arching Needs Summary Care Plan, which was embedded in the contract with the Provider. The Community Learning Disabilities Team, DASH, carried out Annual Reviews of the placement and of the Care and Support Plans which were put together by the Residential Unit. In respect of Lee Graham these Annual Reviews were undertaken by the Care Manager.

10.4.2. The Residential Unit created Lee Graham's Care and Support Plans and it is reported that Support Plans for Lee Graham were completed in January each year and then reviewed by the Manager and Key Worker on a monthly basis. The Lead Reviewer has been provided with copies of the Support Plans completed in July 2011 and January 2012.

10.4.3. During the Scoping Period the Community Learning Disabilities Nurse was the Care Manager and it is the view of the DASH Agency Report Author that the Care Manager did not undertake robust reviews. In particular, there is little evidence of proactive monitoring or challenge in respect of the actions being taken in relation to the healthy eating programme and managing Lee Graham's weight.

10.4.4. It was explained at the Recall Event that CLDN1 had taken on the case to undertake the Continuing Health Care Assessment. However, having completed the assessment, he then assumed the role of Care Manager, of which he did not have experience. At the time there was a significant backlog in the completion of the statutory reviews and 'pressure' to fulfil these statutory responsibilities.

10.4.5. The DASH Agency Report Author notes that there has been a review of the Learning Disability Service, which concluded that 'the role of the Care Manager was blurred with the core functions not being undertaken sufficiently to meet agency requirements, such as care planning and reviewing need and care service quality'. The Service has since been restructured, resulting in greater clarity of responsibilities and clearer distinction between the role of Social Workers and Community Learning Disability Nurses.

10.4.6. The arrangement whereby CLDNs took on the responsibilities of the Care Manager ceased in November 2011, as CLDNs would not necessarily have the training and skills to take on this scrutiny and challenge role. This change enables the CLDNs to focus more on health facilitation, which would have been significant in this case. The Central Reviewing Team undertakes the annual statutory reviews for service users living in stable placements.

10.5. Engagement with family in Care and Support Planning:

10.5.1. The Residential Unit acknowledges that during the Scoping Period families were not proactively engaged in the Care and Support Planning process for the residents. Copies of Support Plans were sent to Lee Graham's parents, but they were not involved in the formulation or review of the Plans. Practice has changed since Lee Graham's death and families are now more fully involved and their views taken into account. Clearly if the family had been involved in the Care Planning Process then their concerns could well have had a greater influence on the plans put in place.

10.5.2. It is acknowledged that there were some communication difficulties between the Manager at the Residential Unit and Lee Graham's Mother, particularly in respect of

weight management and level of physical activity. The Community Learning Disability Nurse was in regular contact with Lee Graham's Mother and, In order to improve communication between the Manager and Mother, he met with them both on a number of occasions. An activity book was initiated, whereby the staff recorded Lee Graham's activities during the week and his Mother was able to read this when she visited. Mother welcomed this as a positive development.

10.5.3. A particular area of difficulty between the Residential Unit and Lee Graham's Mother was the family's pattern of bringing treats, e.g. sweets, crisps, desserts, for Lee Graham each weekend. Staff at the Residential Unit were of the view that given Lee Graham was morbidly obese this did not help with the management of his weight. At the Learning Event the CLDN1 commented that this was a 'maintaining factor' in Lee Graham's eating habits, i.e. it helped to maintain Lee Graham's liking for unhealthy options. However, the family were of the view that this was only once a week and these were not in such quantities as to make a difference. His family bringing treats for Lee Graham appears to be a pattern which had been established over time and he had come to expect this. Given Lee Graham's aversion to change it would have been difficult for Lee Graham's Mother to break this. The CLDN1 tried to promote communication in this respect

10.5.4. At the Recall Event it was recognised that in our society there is a culture of children being rewarded with treats for good behaviour and that for parents with an adult child placed in residential care it is understandable that they would wish to bring treats when they visited. There would also be a reluctance to cease doing so, particularly when there is a strong likelihood that this would provoke challenging behaviour. Breaking a pattern of interaction established over a long period is extremely difficult, both practically and emotionally.

10.5.5. At the Learning and Recall Events there was a discussion about the fact that in some circumstances where the Family's actions were increasing the risk to a service user, consideration would need to be given as to whether this was a safeguarding issue and hence whether safeguarding procedures would need to be triggered. However, the more appropriate course of action would be to work in partnership with the Family.

10.5.6. Lee Graham's Consultant Psychiatrist maintained contact with Mother, so that he was fully aware of her concerns about Lee Graham's wellbeing when he visited Lee Graham at the Residential Unit.

10.5.7. The CLDN1 noted at the Learning Event that, whilst acknowledging there had been some areas of concern and communication difficulties, the Parents were of the view that overall the residential placement did meet Lee Graham's needs. The CLDN1 had discussed the option of a change of placement with Mother, but she recognised that Lee Graham was well settled and that his behaviour was less challenging.

10.6. Management of Lee Graham's weight gain:

10.6.1. The management of Lee Graham's excessive weight was a long-standing concern for his family and practitioners. He was first noted to be developing obesity by the GP shortly before his tenth birthday in 1995. Concerns about his weight gain were being expressed by Mother to the Consultant Psychiatrist from 1999 onwards. In 2002 the Consultant Psychiatrist noted that many 'incidents' in respect of Lee Graham's behaviour were 'food related'.

10.6.2. It is recognised that Lee Graham presented with challenging behaviour, which could become verbally and physically aggressive towards family, residential staff and peers. There is a suggestion in the Agency Reports that a pattern had been established over a many years whereby food was used to manage Lee Graham's challenging behaviour and confrontation/conflict over food was avoided. This had led to engrained eating habits, tending towards unhealthy options. It is also understandable that following Lee Graham's Father's death there may have been a reluctance to upset him.

10.6.3. The GP Agency Report Author noted that the long term use of tranquillisers, which were increased at the time of Lee Graham's Father's death, would have been a contributory factor in his weight gain, as they would have made Lee Graham feel hungry, but less interested in physical activity. They would also have made weight loss more difficult.

10.6.4. When Lee Graham was admitted to the Residential Unit in 2005 his height was 4 feet 10 inches and his weight was 82 kgs., (BMI 37.7). His weight had increased to 113 kgs., (BMI 52) in 2007, but then reduced to 95 kgs., (BMI 43) in 2009, increasing again to 106 kgs., (BMI 48) in July 2011 and to 121 kgs. (BMI 55.7) in March 2012. Therefore from 2007 Lee Graham was severely or morbidly obese, i.e. his weight was a danger to his overall health, and he was at risk of a range of health complications. For Lee Graham, who needed encouragement to participate in physical activities, this would mean that any activity would become increasingly difficult and sleep apnoea may well had led to sleepiness during the day.

10.6.5. The family comment that there was a time before the scoping period in 2009 when an Interim Manager at the home put in place a weight loss plan which included healthy eating and exercise. The family's recollection is that this support resulted in Lee Graham losing weight.

10.6.6. If Lee Graham's weights are correct, then Lee Graham possibly gained 15 kgs., 2 stone 7 ozs, in the nine months before his death, which is a considerable weight gain. At the Recall Event it was noted that there needed to be a degree of caution in respect of Lee Graham's exact weight gain. Close monitoring of weight should be undertaken under the same conditions, e.g. using the same weighing scales, dressed or undressed. In addition, given Lee Graham had respiratory difficulties and his mobility was reduced, it is likely that he had some water retention which would have increased his weight.

10.6.7. When Lee Graham was admitted to Hospital in March 2012, it was noted that his obesity compromised his breathing and limited the treatment options available to medical staff. Obesity is recorded as one of the causes of Lee Graham's death, together with respiratory arrest and sleep apnoea, both of which are complications of obesity. At the Recall Event it was also noted that Lee Graham's behaviour would also have limited the treatment options, e.g. he could not tolerate the oxygen mask and found other interventions distressing.

10.6.8. The Support Plans drawn up by the Residential Unit, in July 2011 and January 2012, included 'Diet and eating support needs' and focused on healthy food choices, fruit and vegetables and portion size. However, it is apparent, given the information above, that these steps were not effective in reducing Lee Graham's weight. There were difficulties for the staff at the Residential Unit in weighing Lee Graham which meant that it was difficult for them to monitor his weight closely. The fact that the Support Plan was unchanged

between July and January would indicate that the fact that Lee Graham was actually gaining weight was not recognised and acted upon.

10.6.9. The Case Manager, DASH, accepted the reassurances of the Residential Unit that Lee Graham was being offered healthy options and portion control was in place. However, there is no evidence that this was scrutinised closely. There was no evidence of a weekly/monthly menu planner and a food diary could have been implemented.

10.6.10. Despite these long-standing concerns there does not appear to have been any multi-agency discussions or co-ordinated action plans to monitor and manage Lee Graham's weight. His weight was not being monitored by any of the doctors involved in his medical care.

10.6.11. The H & CT Agency Report Author notes that 'steps were taken at regular intervals' to address the weight gain. However, it is difficult to identify exactly what these steps were. The CDLN had arranged regular swimming sessions in a local hydrotherapy pool. The Consultant Psychiatrist was aware of the concerns about his obesity and discussed these with the residential staff on the regular visits to see Lee Graham, but there were no actions arising from these discussions.

10.6.12. The GP identified obesity as an issue in Lee Graham's annual health check in April 2011, but the only action arising from this was to test Lee Graham's thyroid function. Given that the aim of the health check is to identify and treat underlying health conditions and put in place targeted actions, this should have been an opportunity to put in place an Health Action Plan to monitor Lee Graham's weight gain, possibly with the involvement of the Practice's Lead Nurse for People with Learning Disabilities, who could have worked closely with the staff in the Residential Unit. Without being monitored, over the next year Lee Graham's weight increased by approximately 15 kgs. or 2 stone 7 lbs. The CIPOLD Report[4] noted the need for 'proactive use of the annual health check to develop and implement health action plans.' and recommended 'Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.'

10.6.13. It appears that the advice of a Dietician or Specialist was not sought at any stage. It was the view of the staff at the Residential Unit that Lee Graham would not benefit from such input, but a Dietician could have advised the staff in the management of Lee Graham's weight. There is a dietician service in the Health and Care Trust which practitioners may have been able to approach for advice. **(See Recommendation 1)**

10.6.14. The DASH Agency Report Author refers to 'diagnostic overshadowing'. In Mencap's Report, Death by Indifference,[5] diagnostic overshadowing is defined as 'when doctors make dangerous faulty assumptions about people with a learning disability, revealing an overall lack of training and skills in understanding learning disability. They may wrongly believe that a presenting problem is a feature of someone's learning disability and that not much can be done about it. This can often lead to wrong or no diagnosis of a medical condition that needs treatment.' In relation to Lee Graham, this would relate to the fact that people with Down's Syndrome have an increased propensity to weight

[4] Confidential Inquiry into the Premature Deaths of People with Learning Disabilities, University of Bristol, 2013.
[5] Death by Indifference, Following up the Treat me Right! Review, Mencap, 2007

problems leading to obesity, but this should not be seen as an inevitable feature of the condition.

10.6.15. Practitioners at the Learning Event were prepared to reflect on whether 'diagnostic overshadowing' had been a feature of the management of Lee Graham's weight. In particular, whether, was there a sense that Lee Graham's weight was a feature of his learning disability and that not much could be done about it. Certainly there was a lack of proactive management of his weight by agencies. If there had been then the considerable increase in his weight during the Scoping Period would have been identified and acted upon.

10.6.16. The reasons for this lack of a co-ordinated approach to weight management was discussed at the Recall Event. Participants felt that obesity may be seen by practitioners as a secondary health issue, whereas in fact it should be seen as a primary health consideration, which invariably leads to serious medical complications, i.e. respiratory difficulties, asthma, diabetes. In addition, it is possible that, as Lee Graham's obesity was such a long-standing concern, practitioners felt a sense of hopelessness and powerlessness in promoting change and making a difference, particularly as this was complicated by the challenges of managing Lee Graham's behaviour, leading to a lack of a proactive approach. **(See Recommendation 1)**

10.6.17. In response to the death of Lee Graham, one of the GP Link CLD Nurses has reviewed patients with a Learning Disability with BMIs over 30 known to two GP Practices. He found that out of 73 patients there were 27 such patients (1:3), none of whom had a Health Action Plan in place for weight management. Some of these patients had very high BMIs (Over 40), as well as complex health and emotional needs, and required urgent follow up. This raises concern about the effectiveness of the GP Annual Health Reviews and the need for a much more joined up approach. Similar issues were identified in the Learning Disabilities Public Health Observatory's Review undertaken in 2010. [6] **(See Recommendation 3)**

10.7. Contract Monitoring:

10.7.1. Lee Graham was placed in a small specialist residential unit for people with learning disabilities and challenging behaviour. This high-cost placement was jointly funded by Health and Adult Social Care.

10.7.2. The DASH Agency Report Author noted that at the time of the Scoping Period, there was minimal monitoring of the contracts with residential providers and what there was in place tended to be reactive rather than proactive. The Needs Summary Care Plans drawn up at the commencement of a placement were very broad and lacking in any detail, which meant that monitoring the service provided would have proved difficult. Lee Graham's Care Plan noted that he required 24 hour care, 7 days a week, which would be met through placement in a Residential Care Home.

10.7.3. The need for robust contracting, monitoring and reviewing was powerfully highlighted in the review following the Winterbourne View scandal. 'It is a national imperative that there

[6] Health Checks for People with Learning Disabilities: Implications and actions for commissioners, Learning Disabilities Public Health Observatory, 2010

is a fundamental culture change so that those with learning disabilities or autism have exactly the same rights as anyone else to the best possible care and support.'[7]

10.7.4. There have been local developments in respect of commissioning, with increased capacity for contract monitoring. There are now more detailed outcome focussed Care Plans, which specify what the Provider is expected to provide and how a service user's individual needs will be met. In addition more robust arrangements for monitoring the Care Plans are in place, which identify whether the placements are continuing to meet the needs of the service users.

11. Good practice:

- Lee Graham's residential placement was near to his family home, enabling him to maintain close links with significant family members.
- Having experienced earlier disruption, Lee Graham had a long term placement, where his behaviour was managed and became more settled. The stability of the placement meant that he was able to develop relationships with the staff.
- The CLDN1 maintained contact with Lee Graham's family, providing increased support at the time of bereavement. Swimming sessions and the activity diary were arranged by the CLDN1 in response to Mother's concerns about Lee Graham's lack of activity
- The GP Practice's identification of a Lead GP and a Lead Nurse for patients with a learning disability, who undertake the Annual Health Checks.
- Good communication between the primary and secondary health care providers, i.e. GP and Consultant Psychiatrist.
- The Consultant Psychiatrist maintained regular communication with the family, e.g. spoke to Mother prior to visiting Lee Graham at the Residential Unit.
- Good communication between key professionals in respect of Lee Graham's admission to hospital and the need for a mental capacity assessment and best interests decision, which facilitated his admission.
- Excellent communication and documentation, regarding the mental capacity assessments and best interests decisions by the Liaison Learning Disability Team with nursing and medical staff in the Acute Trust. Additional staff provided to support the ward.
- The Residential Unit provided two staff for 15 hours each day to support Lee Graham whilst in hospital.
- The involvement of the Psychology Service to advise in respect of preparing Lee Graham and managing his response to his Father's death, i.e. the provision of tools for working with people with learning disabilities.
- The involvement of the Care Service Quality Team, whose input has led to improvements in practice at the Residential Unit.
- High quality of Worcestershire County Council's MCA training.

[7] Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report, 2012.

12. Key Learning Points:

- The need for a considerably more proactive and co-ordinated multi-agency approach, both at a strategic level and by individual practitioners, to chronic obesity in children and adults with learning disabilities and the importance of guarding against 'diagnostic overshadowing'.
- Need to strengthen practice in respect of Mental Capacity Assessments and best interest decisions, particularly in long term, chronic situations, where a professional judgement is required about when to trigger the process, and to improve the quality of documentation. Need for Providers to ensure that all their staff receive MCA training.
- Contracting arrangements should be more robust. Needs Summary Care Plans needed to be more outcome focussed, so that the progress could have been more closely monitored and reviewed and adjustments made to the plan as necessary.
- Importance of early involvement of the service user and family members in the Care and Support Planning and review processes. Written information could assist the family in understanding the process and their significant role within it.
- The need for GP Annual Health Checks of patients with a learning disability to be more robust, particularly with regard to Health Action Plans. Such Reviews will only be effective and meaningful, i.e. improve outcomes, if plans are put in place to address the health issues identified, especially long-term chronic health needs.
- The potential for further development of the role of the CLDNs, who are now linking with GP Surgeries and can provide expert advice/consultation to other professionals.
- The need for Residential Units to develop knowledge and skills in dealing with the bereavement of service users.

13. Developments since Scoping Period:

- During 2011/2012 the Community Learning Disability Service was restructured, so that the local authority and health services are now more fully integrated, including physiotherapy, occupational therapy and behaviour specialists. The introduction of the roles of Professional Leads for Nursing (2) and for Social Work (4) have brought about significant improvements in relation to the clarity of roles and responsibilities. The Professional Leads for Nursing are able to promote the learning disability health agenda.
- Community Learning Disability Nurses are now linked with GP Practices. They are able to raise awareness of the needs of people with learning difficulties, provide expert advice and can audit Annual Health Reviews. However, resources limit the scale of this development.
- Primary Care Liaison Nurse (2 days per week) provides training and promotes awareness of the needs of people with learning disabilities in GP Practices (64 Practices). Resources limit the potential for the development of this role.
- The CLDT have set up two group for people where weight management is a difficulty, however, attendance has been an issue.

- GP Practices are identifying a Lead GP and a Lead Nurse for people with a learning disability.
- Development of WSAB's policy and guidance for staff in respect of mental capacity assessments, best interests decisions and deprivation of liberty safeguard (DOLS).
- Strengthening of contracting and contract monitoring process for residential placements for people with learning disabilities. Since 2012 the scope of the Care Services Quality Team has included these providers, previously it had not.
- The Residential Unit has implemented a Weight and Behaviour Action Plan, raised staff awareness of the Mental Capacity Act, best interest decisions and DoLs and promoted the involvement of the resident's family in the Care and Support Planning process. WCC's Care Services Quality Team has supported the Unit in these developments.
- Review of the audit tools used in DASH is being undertaken with view to improving the quality of care planning and review.

14. Conclusion:

14.1. Sadly, Lee Graham died in 2012, aged 26 Years. The causes of his death were recorded as respiratory arrest, sleep apnoea and obesity. Participants in the Case Review reflected on agencies' involvement with Lee Graham and his family and whether Lee Graham's death could have been prevented.

14.2. The discussions concluded that Lee Graham's death at this time could potentially have been prevented, but this would have required considerably earlier and more proactive, co-ordinated, intervention by the agencies working with Lee Graham. It is unlikely that any actions taken during the Scoping Period would have made a difference for Lee Graham.

14.3. Lee Graham had profound disabilities and complex needs, which presented challenges to those caring for him. He had a severe learning disability, Down's Syndrome and aspects of autistic spectrum disorder, with some obsessional behaviour. His behaviour could be challenging and difficult to persuade to do things he did not want to do.

14.4. Concerns about Lee Graham's weight were noted when he was 10 years old and it is evident that his weight management was a long-standing, chronic, problem. Lee Graham enjoyed unhealthy foods and there was a pattern established of food being used to manage his behaviour. Whilst enjoying some activities, he needed encouragement to participate. In order to change this pattern sustained and co-ordinated action needed to have been taken when Lee Graham was much younger.

14.5. There was a lack of co-ordinated, multi-agency, planning to manage Lee Graham's weight. This appears to have been seen as a secondary health issue when in fact it should have been a primary concern for all those involved in Lee Graham's care. It could have been predicted that Lee Graham's obesity would lead to additional, and life-threatening, health problems in the future, e.g. respiratory difficulties, diabetes.

14.6. The Annual Health Check by the GP identified obesity as an issue, but no actions were agreed to address this. The Residential Unit recognised the need to reduce Lee Graham's weight as evidenced in the Support Plans. However, these were not effective and no

challenge or support was offered to the Unit. Contracting and monitoring arrangements were not robust.

14.7. Two factors in the last year of Lee Graham's life appear to have hindered the efforts being taken to reduce his weight and exacerbated the situation; his Father's sudden death and Lee Graham's declining physical health. Lee Graham's grief and depression led to him being less active and more reluctant to engage in physical activities, as well as to a change in his eating patterns. Similarly, his poor health meant that he was less active and slept more during the day.

14.8. Clearly practitioners were concerned for Lee Graham's welfare and his death has had a profound impact on them. Undoubtedly there are lessons to be learnt and consideration is being given to how to work with service users with learning disabilities and weight management difficulties most effectively. Steps are being taken to identify service users who may be at similar health risks, but in doing so the scale and nature of the problem is being identified and this has significant potential resource implications. The optimal way forward must be a co-ordinated, joined up, strategic approach, whereby the resources of all agencies can be maximised. Given the scale of the problem tackling it will probably need to be in incremental steps, initially identifying and working with those who are at the greatest risk.

14.9. It should be recognised that Lee Graham died three years ago and it is apparent that there have been positive developments in systems, policies and practice since then, some of which are identified in Appendix B. However, whilst changes have been made there can be no grounds for complacency.

14.10. The Case Review has identified the following recommendations for Worcestershire Safeguarding Adults Board.

15. Recommendations for WSAB:

1. The development of **'Lee's Plan'**. A multi-agency over-arching strategy to meet the needs of people with a learning disability and chronic (morbid) obesity. (Responsibility of Worcestershire Learning Disability Partnership Board's Health Sub Group?)

2. WSAB's Mental Capacity Act Policy and Practice for staff to be reviewed to ascertain if any amendments are required to include the assessment of mental capacity in chronic, long term, situations.

3. GP Annual Health Checks should have clear Health Action Plans regarding underlying health conditions (For example, should include BMIs over 30). Health Action Plans should detail what is required from each person and agency involved and when it is to be reviewed to determine its effectiveness.

4. Ensure Service Providers are aware of the link CLDN for each GP Practice, through the Domiciliary Care and Provider Forums.

5. WSAB to disseminate widely the learning from the Case Review through a written Briefing for practitioners. The briefing should include a statement on the importance of considering potential bereavement and recognising the needs of the bereaved person as part of the holistic assessment and care plan, and provide information on available resources.

6. WSAB to share the relevant learning from this review with Worcestershire Safeguarding Children Board/WSCB's SCR Sub Group, notably:

- Obesity should be regarded as a primary health condition that should be tackled in childhood.
- A diagnosis of learning disability should not be viewed as an inevitable reason for obesity.

APPENDIX A

Worcestershire Safeguarding Adults Board

CASE REVIEW

TERMS OF REFERENCE & PROJECT PLAN

SUBJECT: Lee Graham

Died 2012, aged 26 years

Version 3: 20.02.2015

1. Introduction:

1.1. This Lower Level Case Review is commissioned by Worcestershire Safeguarding Adults Board in response to the death of Mr Lee Graham in 2012. The review is being conducted in accordance with the Worcestershire Safeguarding Adults Board Lower Level Case Review Protocol. The aim being to establish whether there are any lessons to be learnt about the way in which local professionals and agencies worked together,

1.2. Lee Graham was a young man with a learning disability. At the time of his death he was an inpatient at the Acute Hospital, though had spent many years in residential care. The causes of his death are recorded as respiratory arrest, sleep apnoea and obesity.

2. Good Practice Framework:

The good practice framework used in this Case Review is based on the following:

2.1 The Worcestershire Safeguarding Adults Board Lower Level Case Review Protocol states there are further cases where vulnerable adults or their carers have died, which do not necessarily reach the criteria for a full Serious Case Review but may lead to some inter-agency learning.

2.2 The Association of Directors of Adult Social Services (2006) guidance on completing case reviews of a serious nature identifies three criteria for conducting a serious case review:

A vulnerable adult dies (including death by suicide) and abuse or neglect is known or suspected to be a factor in their death. In such circumstances the SGAB should always conduct a review into the involvement of agencies and professionals associated with the vulnerable adult.

A vulnerable adult has sustained a potentially life-threatening injury through abuse or neglect, serious sexual abuse, or sustained serious and permanent impairment of health or development through abuse or neglect, and the case gives rise to concerns about the way in which local professionals and services work together to safeguard vulnerable adults (See section 5 for commissioning guidance).

Serious abuse takes place in an institution or when multiple abusers are involved, the same principles of review apply. Such reviews are, however, likely to be more complex, on a larger scale, and may require more time. Terms of reference need to be carefully constructed to explore the issues relevant to each specific case. ADASS (2006) p3.

3. Methodology:

3.1. This Case Review will be conducted using the Significant Incident Learning Process (SILP) methodology, which reflects on multi-agency work systemically and aims to answer the question why things happened. Importantly it recognises good practice and strengths that can be built on, as well as things that need to be done differently to encourage improvements. The SILP learning model engages frontline practitioners and their managers in the review of the case, focussing on why those involved acted in a certain way at that time. It is a collaborative and analytical process which combines written Agency Reports with Learning Events.

3.2. This model is based on the expectation that Case Reviews are conducted in a way that recognises the complex circumstances in which professionals work together and seeks to

understand practice from the viewpoint of the individuals and organisations involved at the time, rather than using hindsight.

3.3. The SILP model of review adheres to the principles of;

- Proportionality
- Learning from good practice
- Active engagement of practitioners
- Engagement with families
- Systems methodology

4. Scope of Case Review:

4.1. Subject Lee Graham: Date of Birth: 20.09.1985

Date of Death: 16.04.2012

4.2. Timeframe: 12 months prior to the date of Lee Graham's death

4.3. In addition agencies are asked to provide a brief background of any significant events and safeguarding issues in respect of this adult. This could include a significant event that falls outside the timeframe if agencies consider that it would add value and learning to the review.

5. Agency Reports:

5.1. Agency Reports will be requested from:

- Worcestershire Health and Care NHS Trust
- Worcestershire Acute Hospitals NHS Trust
- NHS England (GP)
- Worcestershire County Council's Directorate of Adult Services and Health (DASH):
- Pathways Care Group Ltd

5.3. Agencies are requested to use the attached Report Template.

6. Areas for consideration:

6.1. Generic Analysis

- Critically analyse and evaluate the events that occurred, the decisions made and the actions taken or not. Were there missed opportunities or episodes when there was sufficient information to have taken a different course? Were assessments conducted effectively and appropriate conclusions drawn?
- Where judgements were made, or actions taken, which indicate that practice or management could be improved, try to get an understanding not only of what happened, but why.
- Review the effectiveness of policies and procedures (both single and multi-agency)

- From an inter-agency perspective, were processes and communication effective?
- Did services operate in silos rather than being "joined up" with each other?
- Were professionals proactive in escalating concerns and providing effective challenge when appropriate?
- What supervision and management oversight was provided during the period of the Case Review? Were these in accordance with the agency's policy and procedures?
- Is there any evidence that Safeguarding Adults training supported the practitioners in this case or is training identified as lacking in a particular area?
- Identify examples of good practice, both single and multi-agency.

6.2. Specific Analysis

- Was there compliance with the Mental Capacity Act 2005?
- What assessments were made of Lee Graham's needs, and actions taken to address these, particularly in the last twelve months of his life?
- What was the quality of Care and Support Planning, particularly with regard to health promotion, e.g. weight management, nutrition and exercise? Was this informed by assessments?
- What guidance/protocols were in place in the residential unit for the management of excessive weight gain and were these adhered to?
- Was it identified that the steps being taken to address Lee Graham's weight gain were not being effective and, if so, what action was taken? Was expert advice sought from specialist health practitioners at any stage?
- How effectively was the family engaged in the Care and Support Planning process? Was there a sense of partnership working with the family? How were any concerns which were raised by the family handled?
- As the commissioners, how effectively did the local authority fulfil its function of reviewing and quality assuring Lee Graham's residential placement?
- Does the way Lee Graham was responded to highlight any gaps or deficits in service provision?

7. Engagement with the family

A key element of SILP is engagement with family members, in order that their views can be sought and integrated into the Review and the learning. WSAB has already informed the family that this Case Review is being undertaken.

Further contact will be made to invite them to participate in the form of a home visit, interview, correspondence or telephone conversation prior to the Learning Event. Their contribution will be woven into the text of the Case Review Overview Report and they will be given feedback at the end of the process.

8. Timetable for Case Review:

Scoping Meeting	29 January 2015
Letters to Agencies	9 February 2015
Agency Report Authors' Briefing	24 February 2015
Engagement with family	March 2015
Agency Reports submitted to WSAB	9 April 2015
Agency Reports quality assured	9 – 16 April 2015
Agency Reports distributed to participants of Learning Event	16 April 2015
Learning Event	23 April 2015
First draft of Overview Report to WSAB	22 May 2015
Recall Event	10 June 2015
Second draft of Overview Report to WSAB	17 June 2015
Presentation to WASB Sub Group	24 June 2015

Version 3: 20.02.2015

Appendix B

Key Single Agency Recommendations:

Directorate of Adult Services and Health (DASH):

- Through audits of case files, ensure the needs identified in service user assessments are reflected in their care and support plans, with clear outcomes that can be monitored and reviewed. To be incorporated in the current review of the case file audit process in order to further improve care and support plans and to develop robust systems for review.
- The council should routinely monitor and review the quality of service provider care and support plans to ensure that they are appropriate to the needs identified in service user assessments and outlined in statutory care and support plans.
- As part of WCC's quality assurance process, the council should routinely audit the level of training on safeguarding, mental capacity and DoLS for all staff working in service provision commissioned by WCC.
- Ensure that social workers and officers undertaking statutory activities on behalf of WCC are aware of the systems for alerting the organisation to concerns relating to the quality of service provision commissioned by WCC.
- Outline in policy the quality standards and good practice for care and support planning in residential and nursing care settings – this should be an extension to the principles and practice outlined in the existing Personal Support Planning policy applied specifically to residential and nursing care settings.
- Examine the level of awareness of organisational/institutional abuse across community social work teams in order to identify the specific training needs relating to this particular form of abuse

NHS England (GP):

- Identify a learning disabilities dietician for the area. (**NB**: NHSE has commented that Dieticians are part of secondary care, so are not commissioned by that organisation. Also, the aim is for people with learning difficulties to have equal access to mainstream services, rather than having separate, and different, provision.)

Clinical Commissioning Groups:

- Practices which are signed up to the Directed Enhanced Service for the Learning Disabilities Health Check Scheme are strongly recommended to offer all patients over 14 years with learning disabilities, who are on the Practice Register, an Annual Health Check , which will include producing a Health Action Plan.
- As part of the Health Check all learning disability patents should have a physical examination and a discussion of any chronic illness and health promotion needs and these should form part of the Health Action Plan for each person.

Worcestershire Health and Care Trust:

- To consider assessment of mental capacity in all areas where specific decisions are required that may impact on the person, in order that a 'best interest' decision is always made for a person who does not have mental capacity.

- Specific tools to measure the mental and physical health and well-being of people with learning disabilities in the Review process, is indicated in recognition of the report from the Department of Health. Health Inequalities and People with Learning Disabilities in the UK (2010)
- Specific tools relevant to the needs of people with learning disabilities should be accessed and used in the Review Process and the option to upload the information to framework facilitated.
- As commissioners of a service it would be advisable and advantageous to provide written guidance to Providers of the specific expectations of the service and in order to measure achievements and outcomes in order to comply with clinical governance requirements.
- Where people with learning disabilities have specific needs, i.e. incontinence, dementia, eating problems, epilepsy etc. and management is not deemed to be effective, consultation with specialist services is indicated and referrals to specialists considered and made accordingly and routinely in response to recommendations in the Valuing People now Strategy (Department of Health 2009)
- If a service is to be commissioned from a Provider the commissioners should specify the expectations required by the Provider in order to meet the needs of the person for whom the service has been commissioned. Therefore completion of an initial care-plan, by the practitioner as a reference point is indicated, with any subsequent changes documented accordingly.

Appendix C

References:

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