



## **HAMPSHIRE SAFEGUARDING ADULTS BOARD**

### **SAFEGUARDING ADULTS REVIEW CONCERNING MS B**

#### **OVERVIEW REPORT - DECEMBER 2015**

**INDEPENDENT CHAIR – MARGARET**



**SHEATHER**

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## 1. Introduction

- 1.1. This Overview Report is intended to provide an overview of the deliberations and recommendations of the Safeguarding Adults Review Panel, drawing conclusions from the information and analysis contained in the Individual Management Reviews (IMRs) and other reports commissioned from any relevant parties.
- 1.2. The Safeguarding Adults Review (SAR) was commissioned by the Hampshire Safeguarding Adults Board (HSAB) following the death of Ms B on 12<sup>th</sup> September 2014. The care provider in whose facilities Ms B had lived raised a safeguarding alert with Hampshire Adult Services on 10<sup>th</sup> September because of concerns about what was perceived as Ms B's self-neglecting behaviour and difficulties about achieving an appropriate response to this. They subsequently updated the safeguarding team about Ms B's hospital admission and death
- 1.3. A Safeguarding Adults Strategy Meeting was held on 24<sup>th</sup> October and a Case Conference on 3<sup>rd</sup> December 2014. The Case Conference concluded that the case appeared to meet the threshold for a Safeguarding Adults Review because of concerns about how well systems had worked in this case and how decision making had been led. It was therefore referred to the Safeguarding Adults Board (SAB) Learning and Review sub-group for its consideration, which confirmed that a SAR should be commissioned.
- 1.4. In order to inform the work of the review, IMRs were requested from the following organisations:
  - Southern Health NHS Foundation Trust
  - Portsmouth City Council
  - Portsmouth Hospitals NHS Trust
  - Choice Care
  - Hampshire County Council
  - GP practices
  - South Central Ambulance Service
  - Solent NHS Trust
- 1.5. Ms B was estranged from her family but had identified a longstanding friend, SM, as her next of kin. SM was interviewed by the HSAB Manager at the start of the review and the note of that discussion was considered by the panel alongside the IMRs from the various agencies involved.

## 2. The circumstances that led to a Safeguarding Adults Review being undertaken in this case

- 2.1. Ms B was a 46 year old woman who had a mild learning disability, personality disorder and epilepsy. She was a Portsmouth City Council client who lived in a residential home in Hampshire. She was born on 05/03/68 and died on

12/09/14 at Queen Alexandra Hospital Portsmouth, with the cause of death recorded as (a) heart failure and (b) obesity and depression.

2.2. Under section 44 of the Care Act 2014, the Local Safeguarding Adult Board must arrange a safeguarding adult review when an adult in its area dies as a result of abuse or neglect (whether known or suspected) and there is concern that partner agencies could have worked more effectively to protect the adult. The purpose of a safeguarding adult review is to:

- Determine what might have done differently that could have prevented harm or death.
- Identify lessons and apply these to future cases to prevent similar harm occurring again.
- Review the effectiveness of multi agency safeguarding arrangements and procedures.
- Inform and improve future practice and partnership working.
- Improve practice by acting on learning (developing best practice).
- Highlight any good practice identified.

2.3. In this case Ms B's care and support in the last weeks of her life had involved a complex mix of physical and mental health and care services. Her behaviour had changed significantly and different approaches to respond to this were attempted, but with limited success. Finally her physical health required her admission to hospital and was found to have deteriorated so substantially that little effective treatment was possible. This sequence of events was thought to bring Ms B's case within the requirements of s44 of the Care Act 2014 as it was appropriate to examine more closely how well the partner agencies and systems in place had worked in responding to Ms B's needs.

2.4. Initial preparation work took place in early 2015 and the Core Panel of the review started work in June 2015. An Independent Chair, Margaret Sheather, was appointed to the SAR.

### **3. Terms of Reference**

3.1. The Terms of Reference for the SAR were drafted by the HSAB Chair and Manager and the Independent Chair of the review. They were then considered and amended at the first meeting of the SAR Core Panel and the final version is attached at Appendix 1.

3.2. In addition to the issues of concern arising directly from Ms B's experience, the Terms of Reference seek to address potential similarities with the case of Mr A, who died in 2010. This was the subject of a Serious Case Review completed in 2013.

## **4. Process of the Safeguarding Adult Review**

4.1. The main work of the review was carried out by the Core Panel which met four times to:

- finalise and confirm the Terms of Reference and the reports required from the various agencies to support the review process
- discuss the IMRs received, identify the emerging issues and themes and agree further information needed to enable a full consideration of those issues and themes
- discuss, amend and finalise the Overview Report

4.2. Work on a collated chronology of the activities of all the agencies involved had started as part of the Safeguarding process. This was extended and finalised at the start of the review and provided to IMR authors to inform their work.

4.3. Because of the complex mix of learning disability, physical and mental health and care issues involved in Ms B's case, the SAR panel appointed an independent specialist advisor to support their discussions. This was Dr Mark Scheepers, a consultant psychiatrist with the 2gether Foundation NHS Trust, which is based in Gloucestershire.

4.4. Members of Ms B's family of origin had died when she was a child and her foster father had died 2 years before the period under review. As she had no contact with other family members, they were not involved in the SAR. Her identified Next of Kin, a longstanding friend referred to in this report as SM, was contacted; her comments were included in the Panel's discussions and she was kept informed about the review process.

## **5. Facts of the Individual Case**

5.1. Ms B was a 46 year old woman who had a diagnosis of mild mental impairment and emotionally unstable personality disorder. These features were expressed at times in behaviour that challenges. At the time under review she was one of seven residents at Stokewood Home, part of the residential services for people with learning disabilities and/or mental health needs run by Choice Care. She had moved there in December 2009 from Warby Hospital where she was living on Section 37 of the Mental Health Act 1983 following a conviction for criminal damage and arson. Ms B was subject to a Guardianship Order. On 5<sup>th</sup> September 2014 she moved to St Andrews, a nearby home in the Choice Care group, as a short term measure to try to manage the behaviour she was exhibiting at the time.

5.2. Ms B's early life had been difficult and she had spent time in care and with foster parents. Some members of her own family had died when she was a child and as an adult she had little contact with those remaining. She had

been very upset by the more recent deaths of her foster parents. Ms B was diagnosed with epilepsy at 16 and mild learning disability at 18. From the age of 20 she had several episodes of mental instability including deliberate overdoses and hospital admission for aggressive and challenging behaviour.

- 5.3. In 2003 Ms B was diagnosed with an emotionally unstable personality disorder. The Panel noted that the diagnosis of personality disorder was an unusually late one and that it would have been interesting to know what other possible diagnoses had been considered at the time e.g. Post Traumatic Stress Disorder, adjustment disorder.
- 5.4. Ms B was described as someone who needed a lot of attention and she received 1:1 support in the care home. When she was well and happy she would laugh, listen to music and join in with activities. She felt in control of her life in the home environment. When less well Ms B could be difficult to support, disruptive, reclusive, refusing to attend to her personal care and at times self-harming by cutting herself. She could be destructive of property, would sometimes attack staff when unhappy and had been charged in the past with assault on her carers. Ms B was well supported at Stokewood and staff were committed to caring for her.
- 5.5. A number of professional agencies contributed to Ms B's care and support in addition to the direct care provided by Choice Care, and all were actively involved during the period under review. These were:
  - her regular GP practice and the GP practice local to the second care home she stayed at
  - Southern Health NHS Foundation Trust, primarily through Learning Disability Community Nursing and Ms B's consultant psychiatrist
  - Portsmouth City Council, as the responsible local authority, provided social work/care management support
  - Hampshire County Council was involved in three ways: on 9<sup>th</sup> and 10<sup>th</sup> September as the staff at the second care home sought advice from the Fareham and Gosport Learning Disability Team about expediting a mental health assessment, in the co-ordination of the MHA assessment itself and then in response to a safeguarding referral by the care home after Ms B's death
  - Portsmouth Hospitals NHS Trust, when Ms B was admitted there for investigation of her physical symptoms in early August and then again following her emergency admission on 11<sup>th</sup> September
  - Solent NHS Trust's only involvement was via the LD Liaison Nurse during Ms B's hospitalisation in August 2014, having appropriately transferred their previous wider involvement to Southern Health in 2011.
- 5.6. Ms B was well known to all these agencies, except Hampshire County Council, and they had access to substantial background information about her. During

the rapid changes in Ms B's circumstances during August and September 2014 there was extensive, often daily, sharing of information between different agencies. The issues that emerge from the analysis below relate to how effectively that information was assessed and used during that period.

5.7. Ms B was a white British woman and there is nothing to suggest that her ethnicity had any bearing on her care and treatment.

## **6. Analysis and Learning Points**

- 6.1. The following sections present the SAR Panel's analysis of the information presented to it through the IMRs and identify the key lessons that the Panel thinks can be learnt from its discussions. Sections 7 – 10 cover the main areas of concern that were identified in the Terms of Reference, including safeguarding issues and learning. Section 11 addresses the similarities with the Mr A Serious Case Review. Section 12 links this report to other recent publications, particularly the findings of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD).<sup>1</sup>
- 6.2. In their discussions the Panel members were conscious that, viewed together and with hindsight, actions or events may seem more obviously demanding of a strong or particular response than was evident at the time. The clearer pattern that is available from our vantage point is necessary for the identification of strengths or gaps in service responses and the learning that can result, but our commentary also seeks to recognise the position of those involved.
- 6.3. All the factual information referred to comes from the chronology, the IMRs, the follow up reports the panel requested from some agencies and the notes of the safeguarding meetings.
- 6.4. The sections below focus on the learning points, but the Panel also wants to acknowledge some examples of good practice that emerged from the events of this case:
  - during Ms B's hospital admission in August there was good support to all parties from the Learning Disability team, and to Ms B from her Stokewood carers
  - there was good work by the Portsmouth City Council social worker in early September in her visits to Ms B, the follow up discussions with the psychiatrist and overall support to the care home staff as their concerns increased
  - the two GP practices worked in close liaison following Ms B's change of care home, with good transfer discussions, and the GP at the second practice briefed him/herself comprehensively about Ms B's background

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<sup>1</sup> The Confidential Inquiry into premature deaths of people with learning disabilities; Norah Fry Research Centre 2013

- Fareham and Gosport LD team, when contacted by the care home, acted promptly, liaised appropriately with other agencies and provided appropriate advice
- the care home staff persisted in raising their concerns and seeking a resolution to Ms B's difficulties

## **7. The recognition and management of Ms B's complex needs**

*The extent of the impact of Ms B's underlying mental health needs and learning disability on the management of her physical health*

- 7.1. Ms B's mild learning disability, emotionally unstable personality disorder and epilepsy presented a complex set of needs to those caring for her. In addition she had been known previously to research health conditions in order to convince health care professionals that she suffered from those conditions, and was reported to have made frequent requests to be visited by a doctor, including insisting at times on being hospitalised (but see also paragraph 7.17 below). This past activity added an additional layer of complexity to the appropriate management of her physical health, as it had been regarded as a behavioural problem rather than being related to genuine physical symptoms and needs. The Panel discussed the impact of this specific issue as well as that of her underlying needs and disability.
- 7.2. Ms B's physical health care during the last few weeks of her life falls into two related phases. The first, in late July and early August, related to her reported shortness of breath and abdominal pain, and included direct contact by Ms B with the 111 NHS helpline on two occasions. She was reviewed by her GP practice three times between 29<sup>th</sup> July and 6<sup>th</sup> August, and on the last occasion was referred to Queen Alexandra Hospital, where she was admitted for tests.
- 7.3. There seems to have been no concern from staff up to this point that Ms B's symptoms were not genuine. During the hospital admission the learning disability liaison team reported to hospital staff that the care home manager had raised concerns with them that some of what Ms B reported may not be the truth, because of her known previous behaviour. However, the hospital's IMR is clear that there is no suggestion in the patient notes that hospital staff thought Ms B was overplaying her symptoms.
- 7.4. The hospital carried out a full assessment and investigation and identified "severely impaired" heart function and pulmonary oedema and her medication was revised to manage the heart condition.
- 7.5. The hospital's findings are clear, but it was difficult to establish what had happened to the patient's copy of the standard discharge letter when Ms B

left hospital.<sup>2</sup> The GP practice received their copy of the letter, but the care home's chronology states that Ms B was discharged from hospital "as they couldn't establish anything wrong with her". It therefore appears that no information was shared with the home about the diagnosed heart impairment and its potential related physical symptoms. Similarly Portsmouth City Council, as the commissioners of her care, understood that QA hospital had said they "couldn't find anything wrong."

- 7.6. There are repeated references both by Choice Care and Southern Health to no problems having been identified, though Choice Care staff accompanied her during her hospital admission, and the diagnosis was therefore not taken into account in responding to her behaviour. Choice Care noted Ms B's medication changes, but this does not seem to have prompted them to enquire about the purpose of the new drugs and any implications they might have for Ms B's care and support.
- 7.7. The discharge from hospital is discussed in more detail in section 8 below, and one of the SAR Panel's key concerns is that the hospital's findings did not appear to have been communicated directly to staff at Choice Care or to other agencies (apart from the GP) responsible for Ms B's care and support. In the Panel's view, the key agencies' lack of awareness of the heart failure diagnosis clearly influenced the management of Ms B's physical health in the following weeks
- 7.8. The second phase of physical health care issues began a few days after Ms B's discharge from hospital as she continued to complain of stomach pain and breathing difficulty. She was not sleeping well, was very noisy at night and starting to lie on the floor rather than in bed. During this phase the view that her actions and requests were a behavioural issue rather than psychiatric or physical became significant. The Consultant Psychiatrist responded to telephone consultations with the care home staff but had a clear view that a visit to Ms B would be likely to exacerbate her behaviour so was not considered an appropriate response.
- 7.9. By the end of August Ms B was still very distressed, refusing her medication, neglecting her personal care and refusing meals, in addition to the other behaviour noted above. There was a meeting between the care home, psychiatrist and social worker on 27<sup>th</sup> at which the psychiatrist continued to suggest that Ms B's presentation was behavioural and that she did not therefore need hospital assessment. There was also discussion about whether Ms B's mental state may have deteriorated as a result of her hospital admission and of the placement in the care home possibly needing to end.

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<sup>2</sup> The hospital's expected standard practice is for the patient's copy of the discharge summary to be placed with the medications.

- 7.10. Over the following week the same pattern of behaviour continued and the care home remained in contact with the GP, Southern Health staff and the Portsmouth City Council care manager. On 3<sup>rd</sup> September the care managers met the psychiatrist to discuss their concerns about Ms B's physical condition and mood and asked him to visit to assess her. He maintained his view about the behavioural origins of the situation, did not feel that a visit would be helpful and suggested respite care for Ms B if her actions were creating too much disturbance in the care home.
- 7.11. Ms B did move to a different care home in the same group, but this only created a brief break in her pattern of behaviour. The care home became increasingly concerned about the deterioration in her attitude and condition. By 9<sup>th</sup> September the Care Manager was recommending a Mental Health Act Assessment, which was discussed with the consultant psychiatrist who advised that the GP should request this. Actions during 10<sup>th</sup> September resulted in the Mental Health Act assessment being carried out at 8pm that evening as the care home felt it could not be left until the following day.
- 7.12. The assessment team, though they had not previously known Ms B, had the relevant knowledge and experience to provide a rounded assessment. The Hampshire IMR makes a number of relevant comments about the process:
- that they considered the interplay between her physical and mental health
  - they drew heavily on the information provided by the care home manager about Ms B's behaviour and history
  - they were informed that the GP had visited the previous day and not considered her physical health to require hospital admission
  - that although the assessment refers to Ms B's requests during the assessment, further discussion with the AMHP indicated that Ms B was unable to communicate meaningfully with the team
- 7.13. The assessment concluded that the criteria for compulsory admission to hospital had not been met for treatment of a mental disorder and that the plan to support her at home was the least restrictive and most sensitive way of providing care and support. The Hampshire IMR also comments that the practitioners involved drew relatively firm conclusions about the causes of her behaviour which, with hindsight, should perhaps have been more tentative.
- 7.14. While not questioning the outcome of the assessment as far as compulsory admission is concerned, the Panel also questioned the emphasis given in the process to the behavioural explanation for Ms B's symptoms. We were also concerned that it appeared she had not been able to communicate effectively with the assessment team. Once compulsory admission had

been ruled out, there does not appear to have been any discussion of alternative responses to her presentation, to support the care home in their concerns about her condition.

- 7.15. The following day the care home therefore insisted that the psychiatrist covering for Ms B's usual psychiatrist visit her to assess her situation and advise them about her care. He did so and advised that she should be left for another day or two to see if she improved. The home was not satisfied that this was appropriate, contacted the GP surgery again and pressed for hospital admission for Ms B.
- 7.16. The GP called the South Central Ambulance Services (SCAS) and a hospital admission was booked for four hours later. SCAS phoned the care home to confirm detailed information and when informed that Ms B had been on the floor for three days advised the manager that if she deteriorated any further before the booked ambulance arrived they should call 999 for an immediate response. When the ambulance crew attended as booked Ms B had deteriorated during the previous hour and SCAS took her to Queen Alexandra hospital where she died the following day.
- 7.17. Ms B had several GP visits between 3<sup>rd</sup> and 11<sup>th</sup> September, but by different GPs. A physical assessment was carried out on each visit and the GPs' IMR found evidence that all GPs involved considered physical health issues and the final GP assessment on 10<sup>th</sup> September reported no deterioration in Ms B's physical health.
- 7.18. The SAR Panel concluded that Ms B's underlying mental health needs had a substantial impact on responses to her physical health needs throughout the period under review, but particularly in the second phase of physical health concerns. It appears that her known history of researching and claiming physical illness led to the persistent interpretation of her presentation as a behavioural aspect of her personality disorder rather than arising from actual physical distress or illness.
- 7.19. Given this history, the Panel tried to clarify whether and how Ms B's general care and support plan addressed this issue so that staff caring for her understood how to ensure that genuine health problems were identified and treated. If such a plan was available we would have expected it to be a reference point for decisions in late August and early September. The management of her existing medication might also have been addressed in the care plan: how to support her in managing it and how to respond if she didn't take it
- 7.20. Choice Care clarified that staff were advised to arrange an appointment with the GP whenever Ms B raised a concern about her health, regardless of her known pattern of behaviour, and she often saw one GP who knew her well.

Records also show that staff responded with PRN medication when Ms B reported feeling unwell.

7.21. Choice Care's response also said that Ms B "would often call for an ambulance herself". However, this is not borne out by the report the Panel obtained from SCAS. This showed that since August 2012 there had been five attendances re Ms B. On none of these occasions was the call made by Ms B herself but by the police, fire and rescue service, care home or GP. Two of the five call outs resulted in Ms B being taken to A & E and in the remaining cases she was assessed and treated at the home. The statement about Ms B's own contact was therefore certainly not current in the two years prior to her death. This raised an additional concern for the Panel about the degree to which one aspect of Ms B's presentation had come to dominate responses to her health care.

7.22. The Panel also considered whether Ms B's learning disability affected the response to her physical health and identified three possible impacts:

- Ms B's relatively mild learning disability may have influenced the way in which her capacity to be responsible for decisions about her care was regarded
- Her mild level of disability may also have meant that she was not considered to be entitled to the annual health check. However, her other complex needs and in particular her s117 status would have brought her within its scope. This might have indentified her heart failure symptoms earlier, or at least would have provided clearer background knowledge for the events under review.
- Had she been an older person, professionals may have intervened earlier and more assertively when she was lying on the floor, refusing medication and eating and drinking so erratically

7.23. Overall, in the complex sequence of events during August and September 2014, the IMRs offered no clear evidence about these three possible impacts from Ms B's learning disability. The GPs' IMR found no evidence, despite the challenges to physical assessment presented by her behaviour, that their management of her physical health problems was affected by her learning disability or mental health problems. However, the discussion below of Ms B's capacity to make decisions is also relevant to this point.

### ***Learning points***

7.24. Arrangements for communicating discharge information following a hospital admission for a person receiving care and support need to be strengthened so that all the relevant parties are aware of the outcome of the assessment or treatment. This should usually include a discharge planning meeting and review of the care and support plan. (See also section 8 below)

7.25. Care homes and nursing homes need to put proactive arrangements in place to ensure that they are well-informed about changes to care arising from hospital assessment or treatment.

7.26. It is essential that the care and support plan for a person with complex needs, such as Ms B, includes an effective plan for managing their physical health. The reported history of Ms B's particular behaviours about her physical health came to dominate professional responses to her symptoms in the last weeks of her life and affected the decisions of all the disciplines involved in her care and support.

*How Ms B's own views were taken into account in responding to her, including consideration of her capacity to make decisions about her care and support; the extent to which communication and contact was maintained with Ms B's next of kin*

7.27. Perhaps unusually for this kind of situation, Ms B's views and voice are very audible in the account of her last two months. Her descriptions of her symptoms, her requests and expectations for action, her acceptance or refusal of care and treatment and her views about the move from one care home to another are well-represented in the chronology and IMRs prepared for this review. They are, most of the time, the focal point of all the activity. The main analysis the Panel needed to consider was what response her views elicited from the people responsible for her care and support.

7.28. The panel sought to establish how Ms B's views were taken into account; how she was supported to make informed decisions about her care and support; how she was enabled to understand the consequences of those decisions and at what points the need to assess her mental capacity to take those decisions was identified and acted on. All this was in the context of her care and support arrangements which were that:

- Ms B was living in a care home that provided 24 hour care and support
- she often needed 1:1 care
- she had until recently been supported through the Care Programme Approach
- she was subject to a Guardianship Order

7.29. What we found was an apparent degree of confusion about managing the relationship between Ms B's mental health needs, her learning disability and her capacity to make decisions about her care and support, particularly when those decisions seemed unwise or risky. Also a sense of her being surrounded by concerned people but isolated in trying to get her voice heard effectively.

7.30. There was also a lack of clarity about the potential role of the Mental Capacity Act (MCA) in these kinds of situations. The MCA principles require

that “a person must be assumed to have capacity unless it is established that he lacks capacity”. However, it is also clear from the Guidance to the Act that an assessment of a person’s capacity must be based on their ability to make a specific decision at the time it needs to be made, and not on their ability to make decisions in general.

- 7.31. The IMR from Portsmouth Hospitals Trust makes the clearest statements about the management of Ms B’s capacity as it was handled in the hospital setting. It notes that there was no mention of capacity during her admission in early August but that there was nothing in her presentation then to suggest that she didn’t understand what was happening or was unable to consent to the tests being proposed and carried out. At the time of Ms B’s second admission on 11<sup>th</sup> September there is again no reference to her capacity to consent, but she was clearly too ill to do so at that point.
- 7.32. The Panel did note that, while the decision not to attempt resuscitation (DNAR) at that point may have been the appropriate one, the process for arriving at it is not clear. There was a discussion with SM, Ms B’s next of kin, but it appears to have been more in the nature of informing her of a decision already taken. The MCA would have required an assessment and Best Interests decision about DNAR had this not been pre-empted by the very short time between Ms B’s admission and her death.
- 7.33. There are many references in the chronology and the other IMRs to Ms B being “assumed to have capacity” but these almost all refer to a general ability rather than her capacity in relation to a specific decision. There is one specific statement from Southern Health on 3<sup>rd</sup> September that a mental capacity assessment was completed by the psychiatrist during a telephone contact with a member of staff (at Choice Care) about Ms B’s refusal of medication and that Ms B could “understand information regarding her medication, weigh this in the balance and communicate a choice.” The report recommends that the issue of what are referred to in the report as “long-arm” mental capacity assessments, relying on information provided by a third party should be examined. The SAR Panel endorses this view.
- 7.34. There is very little evidence of any discussions with Ms B about the potential impact on her health and wellbeing of the decisions she was making about her personal care and health. It is therefore not possible to know whether or not she was aware of the risks she was running. The SAR Panel has several concerns about the way in which Ms B’s decisions and her capacity to make them were managed.
- 7.35. The first concern is that there were some specific decisions made about Ms B during the last weeks of her life for which a mental capacity assessment would have been appropriate. One is the move from the first to the second care home, which had a whole range of implications for Ms B’s care and

support. The wider issues about the planning for this move are discussed elsewhere but, given the difficulties that had led to the proposed move, a MCA assessment had the potential to ensure that Ms B was properly supported in the decision making, whether or not she was found to have capacity to make that decision for herself.

7.36. The other key decision was more complex: how to respond to Ms B's requests to be admitted to hospital, her continuing refusal to care for herself or allow others to care for her, and the potential risks to her health that this entailed. Since differences of view existed by then between the various professionals involved with her, a formal assessment of her capacity at that time to make those decisions would almost certainly have served to clarify the issues under discussion, and given independent status to her voice whether expressed directly, or indirectly through an advocate.

7.37. The Panel's second concern is the lack of consistency between the view of Ms B's capacity and the responses to her requests:

- If it was generally assumed that Ms B did have capacity to make these decisions this view should have been consistently applied i.e. her request to go to hospital should have been given equal weight to her refusal of care and nutrition in the care home
- If she lacked capacity to make the decisions then a formal best interests process should have been carried out
- The discussion on 9<sup>th</sup> September about Ms B seeking hospital admission for the "secondary gains" of care it would bring rather than because of an identifiable physical health need is not really compatible with either position, nor does it seem consistent with her refusal of care and lack of self care, over the preceding two to three weeks

7.38. The final concern of the Panel related to mental capacity issues is that, because Ms B was regarded as having capacity to make decisions about her care, her behaviour in the last weeks of her life was described as "self-neglect". Paragraph 7.18 outlines the arrangements in place for Ms B's care and support, and these identify her as a person who was not considered able safely to take sole responsibility for many aspects of her daily life. While recognising the complex judgements involved in ensuring she was supported to be as independent as possible, the Panel questions whether it is appropriate to talk about "self-neglect" when the person concerned is receiving this high level of care and support. It would have been helpful to have found more reflection in the reports on the judgements made and the point at which it might have been questioned whether self-determination was in Ms B's best interests.

7.39. As it was, by the time of her admission to hospital on 11<sup>th</sup> September Ms B was both very unwell and in a very physically neglected state. This also

links back to the impact, discussed above, of the non-communication of the hospital's diagnosis in early August, since there is constant reference throughout the discussions in late August and early September to there being no physical problem.

- 7.40. The Panel concluded that the two key decision points identified above should both have included consideration of a Mental Capacity Act assessment or, at least, the opportunity for Ms B to be supported by an independent advocate.
- 7.41. The discussion of the Mental Health Act Assessment in paragraphs 7.12-7.14 above has already identified a concern that Ms B's voice was not sufficiently heard in the process. Her ability to communicate effectively at that time is very unclear.
- 7.42. It is relevant to address the extent of communication with SM, Ms B's next of kin at this point as this was another potential source of support for her during this period. As noted in paragraph 4.4 above, Ms B had no contact with her immediate family and her designated next of kin was a longstanding friend who had maintained contact over a number of years. By this time their face to face contact was less frequent as SM had become a foster carer, but they were still in regular phone contact.
- 7.43. SM's information to the Panel was that the first contact she had about Ms B's changed situation was a phone call after Ms B's admission to hospital on 11<sup>th</sup> September. It doesn't appear that Ms B had been in touch with her during the preceding weeks, or that any of the agencies involved had identified that her involvement might have been helpful. SM, when briefed about that Ms B's behaviour at that time, considered it exceptional even in comparison with how she was when in secure accommodation. SM may therefore have provided invaluable information at the time about how out of character that behaviour was, as well as potentially providing support to Ms B and an alternative person to try and understand the reasons for her behaviour.

### ***Learning points***

- 7.44. The requirements of the Mental Capacity Act and the contribution it can make to managing complex situations and ensuring an individual's voice and wishes are effectively communicated need to be much better understood and implemented by all agencies. Among all the other assessments being carried out, this does not seem to have been considered, although this might have been more helpful than a MHA assessment in identifying a way forward and certainly should have been undertaken at the points identified above.

- 7.45. We agree that the appropriateness of “long-arm” assessments (paragraph 7.32) should be re-examined, with a presumption that they are likely to be inappropriate in most cases.
- 7.46. Review and decision-making policies and processes (such as for a move between care settings) need to include prompts to consider:
- MCA assessment to ensure the person concerned is able to contribute appropriately to the discussion and decision making
  - the use of advocacy support, with the person’s consent, whatever their capacity
- 7.47. Greater awareness needs to be maintained about the role of the next of kin and points where their involvement may need at least to be suggested to the person being cared for.

*How effectively the rapid deterioration of Ms B’s health was managed*

- 7.48. The period of rapid deterioration seems to start towards the end of August when the concerns of staff at Choice Care became heightened because Ms B’s behaviours were by then different from those they had experienced previously in caring for her. It was also noted that a community nurse who knew her well considered this pattern of behaviour to be unusual even compared to previous episodes of withdrawal from engagement.
- 7.49. This view informed the care staff’s persistent approaches over the following days to medical, psychiatric and social care agencies for assessment and advice. The SAR Panel looked particularly at what physical signs of illness the care home staff and others were able to identify, given the context that Ms B was wasn’t thought to be physically unwell. We were conscious, though that some symptoms, such as those of heart failure, are not always readily identifiable.
- 7.50. There are a number of records of physical symptoms, other than those of personal hygiene, during this period. They include vomiting, swollen legs and feet, dizziness, limited eating then refusal of food, limited drinking and eventually incontinence. By 10<sup>th</sup> September the risks of Ms B’s pattern of behaviour were considered by the social worker to include risk of tissue breakdown and further physical health deterioration. As noted in paragraph 7.17, the GP examination on the same day did not find her physical health to have deteriorated at that point, but this GP was new to Ms B and had very little prior contact with or about her.
- 7.51. Two different broad attitudes to managing Ms B’s health deterioration are described in the reports:
- a consistent view from psychiatric services that the situation was behavioural and self-neglecting and therefore emphasising the provision of comfort and care in situ

- an increasing view from the care home that stronger intervention of some description and probably physical health care was needed
- 7.52. When the ambulance service arrived on 11<sup>th</sup> September for the booked hospital admission, they found Ms B with reduced consciousness, verbally responsive but incomprehensible. On arrival at hospital, as well as concerns about her blood pressure and breathing, the assessment identified acute kidney injury through dehydration, congestive heart failure, pulmonary oedema and possible sepsis. The view was taken that her mix of conditions and their treatability was such that resuscitation should not be attempted.
- 7.53. Ms B's condition by the time of her admission to hospital explains why the hospital regarded her death as an "expected death" and categorised it as such. However, if it is considered in the wider context of her life outside hospital in the preceding weeks, this would not be an appropriate description.<sup>3</sup> Ms B was only 46 years old and her health conditions had not been considered immediately life-threatening at her hospital assessment only a few weeks earlier. The Panel would therefore have expected each of the organisations involved her care to undertake an internal review as part of their established care governance processes following her death. It would also have been helpful to know more about why the Coroner decided not to take any further action.
- 7.54. The information provided through the IMRs makes it hard to account for the discrepancy between the assessments of Ms B's physical needs on 9<sup>th</sup> and 10<sup>th</sup> September and the very serious condition she was found to be in when admitted to hospital on 11<sup>th</sup>.

### **Learning Points**

- 7.55. The Panel questioned the following aspects of this phase of Ms B's care, which need to be addressed in the actions arising from this report.
- 7.56. It appeared that no one had real confidence in her ability to self-manage, which would suggest that she needed more assertive management, but this was not pursued. Stronger multi-disciplinary discussion and co-ordination, which is discussed in more detail below, may have enabled a clearer, shared view of the appropriate approach to have been arrived at. An MCA assessment may also have helped to clarify the situation.
- 7.57. The care home staff were increasingly concerned about Ms B's physical health but did not seem to feel confident or empowered to take action independently (i.e. take Ms B to hospital themselves or call 999) but persisted in seeking decisions and action from other agencies. It is not clear why they took this approach.

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<sup>3</sup> CIPOLD definition of an unexpected death is "A death which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or predicating the events which led to death"

7.58. As mentioned earlier, the difficulty of breaking away from the dominant description of Ms B's behaviour based on her history, even when new people became involved, e.g. on the Mental Health Act Assessment.

## **8. The overall co-ordination of the care and support provided to Ms B**

8.1. The Panel identified some specific areas in which stronger co-ordination between the various agencies involved with Ms B would potentially have provided greater clarity and consistency in the care and support she was offered in the period under review. These were:

- her discharge from QA Hospital in August 2014
- the formal accountability and decision-making structures around her care
- the management of agency responses to Choice Care's requests for support in managing Ms B's increasing distress and deterioration
- her funeral arrangements

### *The discharge planning process following Ms B's August 2014 hospital admission*

8.2. Ms B's hospital admission in August was a short one but the hospital's IMR reports the identification of "severely impaired cardiac function, which also involved the heart valves". This would appear to have been a new diagnosis. The report also commented that, apart from the medication changes to optimise management of this condition Ms B's care needs were unchanged. This degree of continuity, and the fact that Ms B was returning to a residential care setting may have been the reason why no formal discharge planning discussions took place.

8.3. Such a discussion between the hospital, care staff and Ms B and other relevant people would primarily have ensured that the findings of the hospital investigations were clearly communicated to everyone involved. It would also have provided an opportunity for advice to Ms B and the staff caring for her on the possible impact of the changed medication, discussion of any diet, activity and other lifestyle adjustments that would help to manage the condition. Care home staff would also have been aware that there was to be cardiology outpatient follow-up and the meeting's notes would have provided updating information for all agencies.

8.4. As it was, the information about the cardiac diagnosis was not communicated effectively outside the hospital. The discharge summary, sent to the GP, which is handwritten and difficult to read, provides a diagnosis of pulmonary oedema, notes the medication changes and refers to the proposed cardiology outpatient follow up. Beyond this it has only limited information and, while it was logged on to the patient record by an administrative staff member, it is not clear whether the summary was reviewed by a GP when it arrived. As noted earlier, the care home's understanding was that the hospital had not been able to find anything wrong with Ms B.

- 8.5. Because of this gap in communication, routine blood tests to monitor U & E<sup>4</sup> levels were not carried out following Ms B starting on heart medication, as would usually be the case because of the known side effects of Furosemide and Ramipril. None of the IMRs indicate any discussion with Ms B or her carers about the possible side effects of her new medication, advice about management of these effects or the new drugs might interact with her existing medication.
- 8.6. At the time of Ms B's admission to hospital a Learning Disability liaison team was available and they reviewed her care on 6<sup>th</sup> August, the day of her admission. The initial review documented by the LD team notes her Guardianship status and reported Ms B as coping / complying 'ok' with her assessment and treatment. Although Ms B was intermittently non-compliant with care while in hospital, the hospital's IMR finds that her mental health needs and learning disability did not have any real impact on treatment or her physical health condition or basic care as an in-patient.
- 8.7. It was also agreed that a care worker from the home would be present in hospital with Ms B during the day. The team carried out a further review on 8<sup>th</sup> August but no specific action is recorded from this.

### ***Learning Points***

- 8.8. Arrangements for communicating discharge information following a hospital admission for a person receiving care and support need to be strengthened so that all the relevant parties are aware of the outcome of the assessment or treatment. This should usually include a discharge planning meeting and review of the care and support plan and should always include communication of change in condition or treatment. (See also section 7 above) Discharge summaries need to be clear and comprehensive.
- 8.9. Care organisations need to ensure that their staff are as alert to physical health care changes and conditions as to the mental health or learning disability conditions that may be the main focus of care. There need to be good standards, well-monitored for recording physical health issues and acting on concerns.

### ***The formal accountability and decision-making structures around Ms B's care***

- 8.10. Ms B's complex history and needs meant that there were several formal structures involved in her care and support. She was subject to Guardianship under the Mental Health Act<sup>5</sup>, which was provided by

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<sup>4</sup> Urea and Electrolytes test to monitor abnormalities of blood chemistry including kidney failure and dehydration.

<sup>5</sup> The purpose of Guardianship (under the Mental Health Act 1983) is to enable patients to receive care in the community where it cannot be provided without the use of compulsory powers. It provides a framework, as part of the overall care and treatment plan, for working with a patient to achieve as independent a life as

Portsmouth City Council, and which includes the power to decide where Ms B should live and where she should attend for medical treatment.

- 8.11. In addition, her mental health care had been provided through the Care Programme Approach which is intended to ensure that services for someone with mental health problems or a range of related complex needs are assessed, planned and reviewed in a co-ordinated way. There are different accounts of whether the CPA applied in Ms B's case at this stage or not, although her status under S117 of the Mental Health Act would have required this. Southern Health's report states that they apply the criterion of the involvement of two or more clinicians from the team being required as the basis for whether a patient remains on CPA or not. On this basis Ms B would have been discharged when the LD nursing service was no longer involved with her care, but there is no record of a formal discharge.
- 8.12. The report states that Ms B was still technically within CPA at the time of her death, but that this was only because the appropriate administrative processes had not been completed to discharge her. What seems clear from the overall accounts is that the CPA was not being actively applied to Ms B's care and support at this stage. There is no mention of the Care Co-ordinator that would have been in place and no discussions of her care during this period refer to this process.
- 8.13. The Panel's view is that Ms B, as a patient discharged on section 117 aftercare, should have been the subject of CPA and have had an appointed care co-ordinator. This had the potential to provide stronger planning of her care and support including identifying any unmet needs and ways to meet them.
- 8.14. The third structure around Ms B's care and support was general care management, which would have included regular reviews of the care arrangements. This is visible through the involvement of the care manager from the Portsmouth Learning Disability Team, who comes closest to holding a co-ordinating role at this stage of Ms B's care.
- 8.15. These formal accountabilities all offered structures within which the developing crisis in Ms B's care in late August and early September 2014 could have been reviewed and managed in a co-ordinated way that engaged all the relevant parties in discussion. The most obvious opportunity for that was the proposal that she may need to move from the care home where she had been resident for several years. It's not clear why a more formal review and decision-making process, involving Ms B herself, was not used at this point as it had significant potential benefits:

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possible...A guardian is appointed under the Act with limited powers to take decisions on a person's behalf where these decisions are in the patients' best interest.

- sharing views and understanding of a complex situation which was in crisis
- considering the pros and cons of a move as the suggested way of managing the situation
- agreeing the purpose of the proposed move and the intended longer term arrangements
- ensuring Ms B's own views were appropriately represented (see the discussion of capacity above) and her next of kin consulted

### ***Learning points***

8.16. The learning on this point is that formal accountabilities have a positive role to play in managing complex situations, even (or perhaps especially) in fast-moving situations such as Ms B's in 2014. They are intended to be protective of the interests of the person at the centre of their concern and they offer a structure to ensure all views can be heard and all options, and their consequences, considered. A specific review discussion had the potential in this case to create a clearer, shared view of Ms B's presentation and the appropriate responses to it, including contingencies for different developments.

8.17. This is related to the need for an identified lead person to co-ordinate activity and responses in complex cases. They would be responsible for bringing key people together to review the situation and agree a way forward, which might have broken the impasse about the reason for Ms B's behaviour. The Panel recognises the pressures on individual workloads, but good planning and co-ordination can actually save time in reducing the need for multiple individual communications, and in improving clarity.

8.18. The IMR from Southern Health acknowledges that the missed opportunity of implementing the CPA approach denied Ms B the benefits of a multi-agency approach to holistic assessment of her needs and risks. While CPA is not a panacea, the lack of clarity about its use in Ms B's case is a matter of concern. They suggest that a local review of the CPA guidance and its implementation would be appropriate and the Panel would endorse that proposal.

*The support provided to the residential care provider to deliver Ms B's care; responses to requests for support with management of her distress including the availability of out of hours support*

8.19. This issue in some respects follows from the points above, as greater co-ordination and, at key points, more structured decision-making, would have been likely to offer more effective overall support to the residential care provider. The Panel found a picture of the provider managers needing to give information to, and seek advice and decisions from, a range of other agencies, which were not unresponsive to each of the individual contacts

but were not acting within an agreed overall plan. There was no recognised co-ordinating point to ensure that all parties had the same information.

- 8.20. The support to the care provider also takes us back to the first two issues discussed in this analysis: the understanding of the interaction between Ms B's mental and physical health and the management of her capacity to participate in decisions about her care. In both cases, more structured assessment of the situation may have helped the care provider, as well as other agencies, in their responses to Ms B.
- 8.21. Ms B's psychiatrist's consistent position that a visit by him would exacerbate rather than improve her situation was clearly a source of increasing concern and eventually frustration to the care staff. The lack of a forum (such as a review as proposed above) in which this approach could be discussed and negotiated left them feeling unsupported at times, though this was clearly not the intention of the psychiatrist. The care provider's IMR says: *"There is a concern that the level of knowledge that the care provider had of Ms B in terms of recognising that something was wrong was disregarded and the level of support provided was inadequate. The individuals involved in attempts to summon help for Ms B said that they felt as though they were constantly asking for help and explaining the cause of concern but nobody was listening."*
- 8.22. Ms B's social worker did intervene in response to the care provider's concerns. She visited Ms B on 3<sup>rd</sup> September, as described in 7.8 above, and was sufficiently concerned about her general physical and emotional state, and its difference from her usual behaviour, to go and see Ms B's psychiatrist and ask him to make an assessment visit. As already reported, he did not consider this an appropriate response and suggested consideration of respite care as a way of providing some relief for the care home from the impact of Ms B's behaviour.
- 8.23. The social worker was directly involved again on 9<sup>th</sup> September, visiting and taking up her concerns about Ms B's condition with the psychiatrist covering for the regular consultant's leave. This did not result in a general assessment visit by the psychiatrist but led to the proposal that the home should refer Ms B for a formal mental health assessment via the GP.
- 8.24. The panel was struck by the number of occasions when actions were passed on to other people rather than action being taken direct by the person proposing it. This happened both within and between organisations and added to the complexity of the communications from the home's perspective, and their sense that agencies with the power to act were reluctant to do so. The suggestion about referral for a mental health assessment is an example, as it is not clear why the social worker or psychiatrist could not take action direct.

- 8.25. The shared view about Ms B's capacity to take decisions about her care and support also had a clear impact on the responses the care provider felt able to make to her pattern of behaviour. A formal assessment of her capacity in relation to the key decisions that were made during this period had the potential to clarify the options open to staff responding to her distress and also to involve an advocate.
- 8.26. The care staff at the second home sought and received support from Hampshire County Council staff in the Fareham and Gosport LD duty team on 9<sup>th</sup> and 10<sup>th</sup> September. The staff had contacted the team because of their concerns about the delay in confirming arrangements for the Mental Health Act assessment that had been requested. They were offered appropriate advice both about how to pursue that issue and also about calling 999 if they felt that Ms B could not be safely managed in the home or that health risks such as dehydration were too high and Ms B needed to be seen by a physical health professional.
- 8.27. The care home staff also discussed with the LD team whether this situation should be considered as a safeguarding issue because of Ms B's self-neglect. The team did not accept the case as a safeguarding referral at that point as Ms B's circumstances and presentation did not meet the formal criteria for self neglect (or safeguarding) set out in the Hampshire policy. The Hampshire IMR finds this view to have been entirely understandable as it had been recognised that Ms B's situation was high risk and very concerning, but safeguarding would not necessarily add value to the situation at that point. It appeared that medical attention was required and that this would be the best response to Ms B's needs. The IMR suggests that the use of the CPA to promote a joined up multi-disciplinary approach may have been the most appropriate way to manage the risks in Ms B's case, as discussed elsewhere in this report.
- 8.28. A wide range of care planning documentation was in place to support the staff in caring for Ms B, but this does not seem to have provided a useful reference point as this crisis period unfolded. For example, the guidance to staff about managing Ms B's physical health needs (see paragraph 7.19 et seq) did not help in resolving the impasse that developed about the link between her physical symptoms and mental health needs. They seem to have felt obliged always to reference her previous health-related behaviour to those assessing her, even when their concerns about her physical health were acute.
- 8.29. Out of hours support does not seem to have been a major factor in this sequence of events. The care provider refers only to a "general feeling" that there was no out of hours support available, and other agencies are able to evidence how they did respond when required out of hours. The important

issue was not so much the timing of the support available but the lack of responsiveness the care staff experienced.

### ***Learning points***

8.30. These issues mainly reinforce learning points identified earlier about the need for co-ordination in complex cases in particular, and for clarity about roles and responsibilities between the agencies involved, including who should be taking the lead in an individual case.

8.31. On a more specific point, the panel's view is that the amount of concern from the care staff and others indicated that Ms B's presentation was unusual, compared even to previous difficult episodes. It therefore warranted a visit by the psychiatrist to complete a face to face assessment at an earlier stage in the crisis period, despite his view that there was a risk of it reinforcing the problematic behaviour.

### ***Arrangements made by agencies to ensure a properly dignified funeral for Ms B***

8.32. Ms B had no assets of her own from which the costs of a funeral could be met, nor family that could take on the responsibility, so it was a public health funeral organised by the hospital's Bereavement Officer. There are confusing accounts in the reports about communications between the hospital, the care provider and SM, Ms B's next of kin, about who would take responsibility and what contribution they could make to the arrangements.

8.33. SM felt very strongly that there had been a lack of dignity and respect in the funeral arrangements made for Ms B. She was concerned about the long delay before the funeral was held (two months), the very basic nature of the event which felt to her like a "pauper's funeral" and that it was not permitted to put any kind of marker on the grave. The care providers, for their part, were concerned that Ms B could not be dressed in a favourite outfit and felt they had not been "permitted" sufficient involvement.

8.34. While the nature of the funeral was largely determined by its costs being met from public funds, the long delay was unacceptable. It also appears that communications with those closest to Ms B could have been much better handled so that they understood the limitations of the situation and how they could contribute to the occasion. Direct contact between SM and the care provider might also have been helpful.

### ***Learning points***

8.35. There needs to be clear communication to those close to the deceased about the nature of the arrangements for a public health funeral. Since the time of Ms B's funeral the legal arrangements have changed and it would be the local authority rather than the hospital that would make the arrangements. Some local authorities have very clear and full information

available on their website and this approach needs to be implemented generally.

8.36. Staff making these arrangements need to understand the importance of good communications with all those involved and flexibility wherever possible to enable them to feel involved and to grieve appropriately.

## **9. Communication and sharing of information between the agencies providing care and support for Ms B**

9.1. Many of the issues about communication and information sharing are related to the co-ordination of Ms B's care and have therefore been covered in section 8 above. The particular points that were the focus of this question to the IMR authors were:

- the management of Ms B's move from one residential home to another
- the transfer of care from one GP to another
- information sharing with the residential provider and care team
- the impact of these factors on the quality of care and support provided

9.2. It has already been identified that it would have been appropriate to have a more formal review discussion to plan and manage Ms B's move from one home to another, even for respite as it had implications for her care and support. In the panel's view, the Learning Disability Team should have led this process.

9.3. There seemed to be rapid development between 3<sup>rd</sup> and 5<sup>th</sup> September. On 3<sup>rd</sup> the care provider said they would have to give 28 days' notice on the placement because of Ms B's impact on the other residents and later that day the psychiatrist suggested respite care as a good option to manage this. On 4<sup>th</sup> discussions had moved on to considering the change as potentially breaking the cycle of her behaviour and a proposal from the provider to the Portsmouth City Council social worker for Ms B to move to another of their local homes, which was agreed by the end of the day. Ms B was informed about the move on 5<sup>th</sup> September, responded positively to this and moved the same day.

9.4. As with other aspects of the case, there was a lot of one to one communication between agencies but no evident multi-agency conversation. Even if the pressures of the situation precluded a formal meeting, we would have expected to see more evidence of inter-agency discussion about the pros and cons of the change before the decision was made and of a plan showing the purpose and intended duration of the move and what the longer term arrangements would be. The LD health team were not involved in the discussions about the change of placement at all.

9.5. This links to the communications around the change of GP. The GP practice was not informed of the move from one home to another until after Ms B

had moved, apparently as a result of the GP trying to visit her in the original home. They then initiated the handover to the local practice for the second home.

- 9.6. This may explain the lack of clarity in the reports about why, if this was a respite arrangement, it was necessary to change the GP, particularly at a point where physical health was so prominent in Ms B's care and support arrangements. There is no evidence of a discussion either in the run up to the move or when the GP became aware of the change about whether this was desirable or not, and if not, how to maintain continuity of care.
- 9.7. The IMRs addressed general information sharing across the care teams to different extents. On the positive side, the GPs could evidence extensive contact between them, the care providers and other agencies, and Hampshire County Council found appropriate information sharing had happened both during their brief involvement before Ms B's death and in the safeguarding processes after it. Less positively, Care Choice felt that there was a lack of effective communication between the psychiatrist and GP surgery.
- 9.8. A similar range of findings was reported about the possible impact of communications on the quality of Ms B's care and support. Choice Care confirmed that all the necessary information and documentation had been transferred with Ms B when she moved to the second home so there should have been no impact from that. However the GP report's view was that if they had been informed in advance about Ms B's move between homes then they would have arranged a better handover and the new GP would have had better understanding of Ms B's presenting challenges prior to the deterioration in her physical condition. Southern Health does not think that not using the CPA per se had an adverse impact on quality of care, but that decisions could have been shared better.

### ***Learning Points***

- 9.9. This section largely reinforces learning points identified earlier, but highlights the particular need to ensure that all relevant parties are involved in discussions about a change of care location so as to maximise the continuity of all aspects of care and support.
- 9.10. Discussions of significant changes in care arrangements, such as a move to a different care home, should be clear about the purpose and duration of the change. In this case there seemed to be a focus on the need for respite from Ms B's behaviour for the other residents of her original home more than on the likely impact on her behaviour or other aspects of her care needs. The lack of a more formal decision-making process, and of the records that would have resulted from such a process, made it difficult to establish what was intended.

## **10. Safeguarding**

- 10.1. While the circumstances of Ms B's death met the criteria for a Safeguarding Adults Review, she had not previously been the subject of safeguarding concerns and there was nothing in the reports received by the Panel to suggest that this had been necessary. The only discussion of safeguarding prior to her death is described in paragraph 8.27 above, based on the analysis in Hampshire County Council's report.
- 10.2. The Panel agreed that the use of the safeguarding process on 9<sup>th</sup> or 10<sup>th</sup> September would not have added value to the responses to Ms B's needs at that point and that a medical response was most appropriate. We also agreed that good risk management is needed in all cases of this kind, whether or not they need a safeguarding response and that there were appropriate options for providing this.
- 10.3. As noted in paragraph 7.38 above, the Panel questioned the appropriateness of referring to self-neglect when the person concerned is receiving the high level of care and support offered to Ms B. We would have expected to find more reflection in the reports on the judgements made and the point at which it might have been questioned whether self-determination was in Ms B's best interests.
- 10.4. Once the safeguarding referral was made after Ms B's death, the appropriate multi-agency arrangements were put in place and resulted in this review.

## **11. Similarities with the case of Mr A**

- 11.1. The review's Terms of Reference include consideration of the similarities between Ms B's case and the findings of the Serious Case Review completed in 2013 about Mr A, a man with learning disabilities who died in 2010. From the executive summary of that review it is possible to see that in both cases:
  - the development of behaviour difficulties led to a change of placement
  - there was no sustained improvement in the new placement
  - carers were frustrated that their concerns were not being taken sufficiently seriously
  - there was significant physical deterioration before the final hospital admission
  - no use was made at key decision points of independent advocacy to support the decision-making process and there were no discussions with the next of kin
  - the principles of the Mental Capacity Act were not well applied and indicated a lack of consistent understanding of its role
- 11.2. The most relevant differences are that:

- in Mr A's case, there were more co-ordinated discussions about the inter-relationship between physical and mental health issues at some points, though this was not consistent
- Mr A was known to have great difficulty with change in his life so the change of placement would have had particular significance for him.

11.3. An Action Plan was developed by the HSAB in response to the fifty five recommendations from the SCR and this was most recently updated in May 2015. It will be useful to cross-reference the HSAB response to this report with that Action Plan as some relevant actions appear to be already underway, while others may have had insufficient impact and need re-visiting in the light of this SAR. Some examples are:

- revision and re-launch of the complex CPA protocol
- the development of a shared protocol for complex learning disability case management
- strengthen communication lines with secondary care in complex cases
- use of risk assessments
- the availability and role of the LD Liaison service
- the decision-making process about placements
- use of advocacy for people with a learning disability
- strengthen clinical leadership for vulnerable adults with complex needs

## **12. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) and other recent publications**

12.1. The CIPOLD was tasked with *“investigating the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. The aim was to review the patterns of care that people received in the period leading up to their deaths, to identify errors or omissions contributing to these deaths, to illustrate evidence of good practice, and to provide improved evidence on avoiding premature death.”*<sup>6</sup> While the Panel has not made a detailed analysis to establish whether Ms B's death at 46 met the Inquiry's definition of “premature”<sup>7</sup>, some of the issues it raises are nevertheless relevant to ensure that appropriate action results from the learning in this case.

12.2. The Inquiry's conclusions and recommendations about developments needed resonate with Ms B's situation:

- improved communications between agencies to reduce the identified fragmentation of care

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<sup>6</sup> CIPOLD Executive Summary

<sup>7</sup> *‘without a specific event that formed part of the “pathway” that led to death, it was probable that the person would have continued to live for at least one more year’*

- a named professional to ensure co-ordination of care, linked to continuing care by specialist healthcare staff rather than short-term or one-off assessments
  - proactive use of the annual health check
  - recognising difficulties in diagnosis or treatment and providing specialist response
  - improved awareness and implementation of the Mental Capacity Act
- 12.3. Two Safeguarding Adults Reviews recently published by Suffolk Safeguarding Adults Board also highlighted related issues in the deaths of a 33 year old man and a 55 year old woman. These include:
- poor communication of specific health conditions when care was transferred to social care/supported living, including hospital discharge information
  - lack of understanding of the MCA
  - lack of multi-disciplinary approach and identified care co-ordinator
  - the respective roles of psychiatry and GP services in ensuring physical health needs are properly understood and addressed
- 12.4. The joint authors of both reviews, Margaret Flynn and Ruth Eley, also compiled a paper on the factors leading to the two individuals' compromised health status, which is published on the Suffolk SAB website alongside the Overview Reports.<sup>8</sup> This may be a useful reference point for the HSAB in considering its actions in response to this report.

### **13. Conclusions**

- 13.1. The Panel's views and concerns are identified throughout the report, but are summarised here. Focussing first on Ms B herself, we were concerned to find so little immediate investigation of the cause of her death at only 46 years old either by the coroner or by the agencies that had been caring for her in the longer term, and which had not been expecting that she might die. She was physically unwell though not, as far as we could establish, considered to be terminally ill. Her death should therefore have been viewed as unusual and prompted an examination of the factors that may have contributed to it so that lessons could be learnt for the future, outside any safeguarding considerations.
- 13.2. We did not identify any single factor that, had a different course been taken, would have led to a different outcome for Ms B. However, we did find a number of missed opportunities to provide better management of Ms B's needs and the response to her becoming acutely unwell that may have influenced the course of events.

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<sup>8</sup> <http://www.suffolkas.org/assets/Safeguarding-Adult-Reviews/Factors-James-and-Amy-For-Website.pdf>

13.3. The Panel concluded that Ms B's underlying mental health needs had a substantial impact on responses to her physical health needs throughout the period under review. A significant element in this was the dominance throughout the period of a behavioural interpretation of her symptoms and requests. Her learning disability also had an impact on the way that her health needs were viewed, particularly as part of her overall complex needs, but also as she became acutely unwell. There were a number of missed opportunities related to this:

- the complexity of Ms B's needs should have entitled her to an annual health check which may have detected her underlying heart condition at an earlier stage
- as a patient discharged on section 117 aftercare, Ms B should have been the subject of CPA and have had an appointed care co-ordinator; this would have provided Ms B with an up to date needs assessment, annual reviews and a framework providing a clear process within which to assess and manage risks around her behaviour
- the lack of a Mental Capacity Act assessment which, formally completed could have provided a more accurate picture of Ms B's ability to make decisions about her care and treatment particularly as she became more unwell; key professionals could have then focused on factual information rather than relying on hearsay and made more consistent responses to her requests for care

13.4. The Panel also concluded that the lack of comprehensive communication about Ms B's heart condition when she was discharged from hospital in August 2014 had a significant impact on her care over the following weeks. The missed opportunities about this were:

- a discharge planning meeting may have established an effective plan for managing her physical health needs, and thereby reduced the influence of her known previous behaviour pattern
- most of the people caring for Ms B were unable to take her heart condition into account in assessing her health needs during the crisis that developed in the following weeks
- in addition, having been placed on Furosemide and Ramipril as a result of her diagnosis, Ms B should have had routine blood tests which would have given her access to appropriate monitoring of her health post-discharge and would have allowed any side effects from her new medication to be detected
- greater involvement of LD liaison nurses may have improved communication during and after the hospital admission

13.5. A further conclusion was that there were weaknesses in processes of assessment, information sharing and decision making. In particular:

- the involvement of an advocate (to which Ms B was legally entitled) would have ensured that her voice was heard and could have provided checks and balances throughout the process
- the greater involvement of Ms B's Next of Kin at an early stage could have provided invaluable information about how out of character Ms B's behaviour was and an alternative person to try and elicit the reasons for that behaviour from Ms B
- the differences in her behaviour that were in any case identified justified an earlier visit by her usual psychiatrist for a face to face assessment
- it would have been preferable for the Mental Health Act assessment that was completed to have been undertaken during working hours so that a GP and psychiatrist familiar with Ms B could have been involved; an assessment out of hours is only usually undertaken when there is an immediate issue of safety
- better recognition of her deteriorating physical health could ultimately have altered the outcome for Ms B or resulted in appropriate end of life care had it been identified

13.6. Finally, it is clear from the cross-references in sections 11 and 12 above that learning from earlier inquiries and reviews is proving hard to embed both locally and nationally.

## **14. Recommendations**

### *Recommendations by the SAR*

- 14.1. In responding to all these recommendations, the HSAB should take into account the actions arising from the review on Mr A and the findings of the CIPOLD and the two SARs referenced in section 12.
- 14.2. Care and Support plans must be clear about how physical health problems are to be monitored and responded to and regularly updated to reflect changing needs.
- 14.3. Arrangements for communicating discharge information following a hospital admission for a person receiving care and support need to be strengthened so that all the relevant parties are aware of the outcome of the assessment or treatment and discharge summaries are clear and comprehensive.
- 14.4. Care organisations need to assure themselves that their staff are as alert to physical health care changes and conditions as to the mental health or learning disability conditions that may be the main focus of care.
- 14.5. Care homes and nursing homes need to put proactive arrangements in place to ensure that they are well-informed about changes to care arising from hospital assessment or treatment.

- 14.6. In view of the continuing national evidence about the disadvantage experienced by adults with a learning disability, the HSAB will want to seek assurance that an effective learning disability liaison service is in place across the hospitals that routinely receive Hampshire residents.
- 14.7. Programmes of awareness-raising and training about the Mental Capacity Act need to be in place across all agencies, its role reflected in policy and practice guidance and arrangements made to monitor the Act's implementation in practice
- 14.8. The local CPA framework should be reviewed to ensure consistency with national guidelines
- 14.9. Policy and practice guidance needs to promote the involvement of advocacy services and the role of the next of kin in assessment and decision-making. This should include awareness of guidance about involvement and consultation when a DNAR proposal is considered.
- 14.10. An annual health check should be provided for all people with a learning disability in Hampshire
- 14.11. Arrangements for managing complex cases need to be reviewed to ensure:
  - allocation of a case co-ordinator
  - firm expectations of multi-agency decision-making
  - clear escalation protocols in all agencies for the resolution of conflicts or stuck situations
- 14.12. Responsible councils need to ensure that clear information is available about publicly funded funeral arrangements and that good communication takes place with those closely involved.

*Recommendations by individual agencies*

- 14.13. The individual agencies providing IMRs made a number of recommendations which are shown at Appendix 2.

The SAR Panel commends this report to the HSAB for its consideration and action.

## Terms of Reference for Safeguarding Adult Review re Ms B

This Safeguarding Adults Review (SAR) has been commissioned by Hampshire Safeguarding Adults Board. The Terms of Reference were finalised on 19<sup>th</sup> June 2015. The Individual Management Report MUST address the areas outlined in Section 3 below:

### 1. Ms B

Ms B was a 46 year old lady who had a mild learning disability, personality disorder and epilepsy. She was a Portsmouth City Council client who lived in a residential home in Hampshire. She was born on 05/03/68 and died on 12/09/14 at Queen Alexandra Hospital Portsmouth following septicaemia, heart and organ failure.

### 2. Reason for Review

Under section 44 of the Care Act 2014, the Local Safeguarding Adult Board must arrange a safeguarding adult review when an adult in its area dies as a result of abuse or neglect (whether known or suspected) and there is concern that partner agencies could have worked more effectively to protect the adult. The purpose of a safeguarding adult review is to:

- Determine what might have done differently that could have prevented harm or death.
- Identify lessons and apply these to future cases to prevent similar harm occurring again.
- Review the effectiveness of multi agency safeguarding arrangements and procedures.
- Inform and improve future practice and partnership working.
- Improve practice by acting on learning (developing best practice).
- Highlight any good practice identified.

### 3. Specific Areas of Concern

The specific areas of concern proposed by the HSAB Learning and Review Subgroup are as follows:

3.1. To establish and consider the involvement of agencies with Ms B and to review actions taken by them covering the period 01 August 2014 to 30 November 2014 with particular reference to:

- i) **The recognition and management of Ms B's complex needs.** This should include :
  - (a) the extent to which Ms B's underlying mental health needs and learning disability impacted on the management of her physical health;

- (b) how effectively the rapid deterioration of Ms B's health was managed;
  - (c) how Ms B's own views were taken into account in responding to her over this period, including consideration of her capacity to make decisions about her care and support including her move from one residential setting to another;
  - (d) the extent to which communication and contact was maintained with Ms B's next of kin during the time period stated in paragraph 3.1;
  - (e) the arrangements made by agencies to ensure an appropriately dignified funeral was provided for Ms B.
- ii) **The overall co-ordination of the care and support provided to Ms B.** This should include:
- (a) the discharge planning process following Ms B's August 2014 hospital admission;
  - (b) the support provided to the residential care provider to deliver the care needed by Ms B;
  - (c) the responses of the agencies involved to requests by the residential provider for support with management of Ms B's distress.
  - (d) the availability and responsiveness of out of hours support, particularly psychiatrist cover;
- iii) **Communication and sharing of information between the agencies providing support and care for Ms B.** This should include:
- (a) the management of Ms B's move from one residential home to another;
  - (b) the transfer of care from one GP practice to another;
  - (c) information sharing with the residential provider and care team;
  - (d) the impact of (a) to (c) on the quality of care and support provided.

3.2. To consider the similarities with the Mr A Serious Case Review completed in 2013, and the action plans and impact analysis report completed by the agencies involved in both cases.

## **4. The proposed timescale and methods**

- 4.1 A broadly 'traditional' model will be adopted. The SAR Panel will review the information currently available from provider organisations at its first meeting, and will scope the issues which need to be explored, and request any additional information which is needed. Senior representatives of the provider organisations will be invited to attend the second meeting of the Panel so that emerging issues can be identified and explored. The Panel will consider how practice accorded with the Hampshire Multi Agency Safeguarding Policy and Guidance and national reports such as the Confidential Inquiry into premature deaths of people with a learning disability.
- 4.2 The Panel will aim to produce a report by the end of October 2015 outlining the circumstances, key issues and conclusions of this case in accordance with the HSAB Safeguarding Adult Review Policy and make recommendations to the Hampshire Safeguarding Adult Board. The Chair of the Safeguarding Adult Review will also produce an Executive Summary.
- 4.3 The HSAB Learning and Review Subgroup will produce a multi-agency action plan on behalf of the HSAB in response to the recommendations made and the Quality Assurance Subgroup will monitor its implementation.
- 4.4 Involved agencies will provide HSAB with an 'impact analysis report' upon completion of the actions assigned to them in the multi agency action plan. This would normally be six months after publication of the report into the Safeguarding Adult Review and the accompanying multi agency action plan.
- 4.5 The HSAB Manager will act as the point of contact for the friend known to Ms B and will seek their views prior the start of the review process and will provide updates and feedback on outcomes as required.

## **5. Safeguarding Adult Review Panel Membership**

Margaret Sheather	Chair and Overview Report Author
Sue Lee	HSAB Board Manager
Jo Lappin	Hampshire County Council Adult Services
Angela Dryer	Portsmouth City Council Adult Services
Pauline Dorn	Fareham & Gosport and South Eastern Hampshire CCGs
Tracy Keats	Portsmouth and Isle of Wight CCG
Amanda Kent	Speakeasy Advocacy
MH/LD specialist	Dr Mark Scheepers, <sup>2</sup> Gether NHS Foundation Trust

## **6. Organisations providing care and support for Ms B**

- Portsmouth City Council Adult Services
- Choice Care Group
- Southern Health NHS Foundation Trust
- GPs
- Hampshire County Council Adult Services (Mental Health Act Assessment)
- Hampshire County Council Adult Services Community Team
- Solent NHS Trust
- Portsmouth Hospitals NHS Trust

### Recommendations made by individual agencies in their IMRs

#### Southern Health

- work with Liaison Nurses at the Acute Hospital to agree contact with the CLDT on admission and discharge.
- Exploration of commissioning Southern Health NHS Trust Liaison Nursing posts aligned to Acute Hospitals
- Agree how information can be shared with the advent of new patient record systems in neighbouring trusts. This should include Acute Hospital staff having access to the electronic patient record.
- Exploration through the green light toolkit of appropriate forums for practitioners from Learning Disability and Adult Mental Health services to share and learn from each other
- Consideration given to “self-neglect” within services and when this should trigger multi-professional planning meetings
- Joint safeguarding forums within the locality teams to discuss, share and challenge local safeguarding process and engagement

#### PHT

- Share the case with the discharge planning:
  - request training include updating social care if a requested assessment is no longer required
  - to review criteria for convening a multi-agency/ professional discharge planning meeting and ensure that even if criteria are not met, there may be some circumstances where this could still be beneficial
- Share organisational and multi-agency learning with PHT Safeguarding Leads and others as relevant

#### HCC

- It is recommended that consideration is given within Adult Services to providing staff with guidance on Council responsibilities for funeral arrangements when no alternative arrangements are made
- There is also a multi-agency recommendation in respect of co-ordination of care using the CPA process for people with complex needs

#### CCG on behalf of GP practices

- Identification of a named GP for complex patients
- Regular MDT meetings to include the named GP for complex patients
- Formulation of a multi-disciplinary care plan and risk assessments to include the GP for management of complex patients
- Consideration of when self-neglect should be addressed under the safeguarding adults process