Bracknell Forest and Windsor & Maidenhead Safeguarding Adults Board

SAFEGUARDING ADULTS REVIEW OF EF

SUMMARY REPORT

This SAR was originally commissioned by Bracknell Forest Safeguarding Adults Partnership Board but was completed and published after the board had joined with Windsor & Maidenhead to form the Bracknell Forest and Windsor & Maidenhead Safeguarding Adults Board. For this reason, you may find references to both boards within this report.

INTRODUCTION

1.1. The purpose of the overview report (of which this is a summary) is to describe the process and outcomes of a Safeguarding Adult Review (SAR) that was carried out into the circumstances around the death of Mr EF who was receiving care, treatment and support from organisations in the Bracknell Forest area prior to his death from natural causes in July 2016.

2. BACKGROUND

2.1. Mr EF

2.1.1. Mr EF was 71 years old when he died in July 2016. He had complex health and care needs including a severe learning disability, severe challenging behaviour and autism. He was able to make simple everyday decisions but had been assessed as lacking mental capacity for decisions on more significant matters.

2.1.2. Mr EF was described as a great character with mischievous, emotional and sensitive qualities. He understood basic words and commands and had limited ways of communicating verbally and using his own sign language. He formed close relationships with the staff looking after him and they were able to communicate with him, able to understand and meet his needs and to empower him to take decisions over daily matters.

2.2. The Safeguarding Adults Review

2.2.1. Although Mr EF's needs appeared to have been well met throughout most of his life, concerns were raised about the way in which services were provided to him and whether organisations could have worked together more effectively towards the end of his life.

2.2.2. The Bracknell Forest Safeguarding Adult Partnership Board (BFSAPB) decided that the criteria requiring a Safeguarding Adult Review set out in the Care Act 2014[1] under Section 44 had been met. Although Mr EF had died of natural causes, the circumstances gave rise to concerns that there may have been failures in the systems that supported him.

2.2.3. The Review was carried out in accordance with the relevant policy and framework *(SAR Protocol)* to identify the lessons learnt from the specific case, and apply them to prevent such circumstances occurring again.

2.2.4. An independent facilitator who had no previous involvement with Mr EF or the organisations providing services to him was commissioned to lead the process and produce the final overview report. The SAR Panel set up to oversee the process chose to apply a modified version of a significant event analysis as the methodology for the review. The Review covered the time period April 2015 until Mr EF's death in July 2016.

2.2.5. The specific lines of inquiry for the review were identified and agreed by the Panel:

i. Facts of the case
ii. Mental capacity
iii. Assessment, diagnosis and interventions
iv. Care setting
v. Inter-agency communication and roles

2.2.6. Mr EF did not have contact with his family, however his sister was notified that the Review had been commissioned and invited to participate. No response was received and therefore it was assumed she wished to have no involvement. Although Mr EF did not have family contact, he formed close relationships involving emotional attachment with his support workers. One of the areas of concern involved whether sufficient credence was given to these relationships in making decisions as he approached the end of his life.

[1] http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

3. CASE SUMMARY

3.1. As part of the Review, each agency involved with Mr EF was asked to produce an Individual Management Report (IMR) and chronology for the period April 2015 to July 2016. The information was then collated and analysed by the independent facilitator and is set out in detail in the full overview report. This is a summary of key events and issues arising.

3.2. Mr EF needed help with every aspect of his daily life, including all personal care. These needs had successfully been met in the same placement for ten years although the nature of the care setting changed from residential care to supported living in 2010. In addition to the 'core' staff (consisting of two staff during the day and one waking night staff) Mr EF shared with the other residents, Mr EF also received 42 hours per week one to one support to manage his behaviours. Mr EF had a particular bond with two of his support workers whom he had known for many years but related to other staff as well. Mr EF's behaviour could be challenging but staff were skilled in managing this and understanding his communication.

3.3. Mr EF became eligible for Continuing Healthcare in March 2010 meaning his package of health and social care was arranged and funded by the NHS outside of hospital.

3.4. Mr EF received a high level of support for his physical health including the administration of sixteen medications and creams. The provider acted on warning signs that his health was deteriorating and contacted health professionals as appropriate with a support worker accompanying him to each medical appointment. He also had access to the same range of general health assessments and interventions as other people of the same age, for example, receiving a flu jab. He had good access to his GP who treated him sensitively and made frequent visits when he was unwell. There is also evidence of very frequent contact and communication between the integrated health and social care team - Community Team for People with Learning Disabilities (CTPLD) – and Mr EF on a wide range of matters regarding his wellbeing.

3.5. Mr EF, therefore, appears to have been supported to lead a fulfilling and independent life within the constraints of his multiple conditions until his health started to decline over the last few months of his life. This led to increased difficulties for him in mobilising as his health became frailer. He received support from CTPLD with frequent visits including physiotherapist and Occupational Therapist keeping him under constant review and ensuring equipment was in place. However, his gait was described in April 2016 as slow and shuffling with difficulty in turning and frequent falls.

3.6. Mr EF's health deteriorated over the last 14 months of his life requiring an ambulance on 13 occasions with 10 hospital admissions. He was transported to Frimley Park Hospital (FPH) Accident & Emergency ten times. On four of these occasions he was assessed, treated and discharged home. On the other six occasions he was admitted and spent more than 50 days as an inpatient. South Central Ambulance Service (SCAS) also assessed and treated Mr EF at his home on a further 3 occasions.

3.7. SCAS considered three of the thirteen incidents in which they were involved to be potential Safeguarding Adults concerns:

i. Delays in obtaining information about medication out of hours did not lead to a Section 42 Safeguarding Adults Enquiry;

ii. Missed medication also did not lead to formal safeguarding enquiry;

iii. The third incident did however lead to a Safeguarding Adult Enquiry following SCAS concerns that Mr EF was deliberately self-neglecting as a sign of asking for help and that bruises consistent with a human handgrip could be an indication he was being manhandled. Examination in FPH revealed a fractured left rib but the hospital did not raise this as a Safeguarding Adults matter to the local authority. A Safeguarding meeting was held four days later and with the outcome that it was not possible to reach a clear conclusion about whether abuse had occurred. A further meeting arranged for four days later was recorded as a Multi-Disciplinary Team meeting and while it resolved some questions about medication raised at the previous meeting, it did not look at why Mr EF was becoming frailer or provide answers regarding the safeguarding allegations. The Designated Safeguarding Manager therefore

decided that it wasn't possible to reach a conclusion and the Safeguarding Adult outcome was unsubstantiated.

3.8. CTPLD notes show considerable activity in this period in connection with the deterioration in Mr EF's health and his frustration around his inability to so what he wanted to do. He remained in hospital for more than 3 weeks on this occasion.

3.9. Mr EF was finally admitted to hospital again in July 2016 following a fall. He became increasingly unwell and a 'Do Not Attempt Resuscitation' Order was put into place. A request for an Independent Mental Capacity Advocate was made but not in time for one to attend. Provider staff attended the ward to provide familiar faces. Mr EF passed away two days later, peacefully, with someone with him.

4. AREAS OF CONCERN

4.1. Mental Capacity

4.1.1. There was evidence that appropriate assessments recorded Mr EF's lack of mental capacity. The local authority was authorised by the Court of Protection to act as his deputy for property and financial affairs in 2011. However, he could make simple choices e.g. between 2 drinks, and communicated with staff through a mixture of signing, hand gestures and single words.

4.1.2. There were two significant decisions to be made during the review period where Mr EF did not have the capacity to consent:

i. A general anaesthetic required for an eye examination prior to cataract surgery. Mr EF's lack of capacity to consent to the treatment was acknowledged and documented by medical staff. But an Independent Mental Capacity Advocate (who could have supported and represented Mr EF) was not instructed. On reflection, the hospital considers this should have been done. There is a lingering view that the surgery would have taken place anyway as it was in Mr EF's best interests and was successful when viewed retrospectively, however, it should be noted this is not in the spirit of the Mental Capacity Act.

ii. The second decision was the DNAR decision taken just prior to Mr EF's death. This is a record in the patient's notes – a clinical decision made on behalf of a person who lacks mental capacity. There is a lack of consensus about the process and what was discussed with the provider.

4.1.3. The report found the needs, wishes and feelings of Mr EF were not taken into account fully in decisions about his care. Nor were end of life decisions made with appropriate people – his support workers - in absence of his family. An advocate would have provided a voice for Mr EF and ensured his wishes were included in the decisions being made about him but the referral to the IMCA was not made in a timely way and not actioned before Mr EF died.

4.2. Assessment, Diagnosis and Interventions

4.2.1. It appears that there were no significant shortfalls in the assessment, diagnosis and interventions provided to Mr. EF until his health began to deteriorate from April 2016 onwards. However, from that time, the evidence points to the fact that Mr. EF's health was declining but the assessments did not reflect this or identify that the end of Mr. EF's life was approaching. They were not shared across organisations to provide a coordinated view or assessment of his needs. Some of the risk around him was identified, e.g. mobility, and there were regular monitoring visits from CTPLD. However, risk was not identified fully as evidenced by the increase in involvement from SCAS and the FPH A & E Department in response to calls for assistance for Mr. EF by the Provider. There were several occasions when Mr. EF was very unwell and needed emergency transport to hospital. On at least 6 occasions, he fell and hurt himself badly. The Provider was unable to keep Mr. EF safe during this period with the facilities and staffing they had available.

4.2.2. It is of particular concern that there was no action taken by the funding authority to secure the additional one to one support hours required by the Provider to keep Mr. EF safe between the

original request on 27 April 2016 and his death on 13 July 2016. Concerns were recorded by CHC about the suitability and sustainability of the placement in the longer term as Mr. EF's needs changed.

4.2.3. It is not likely that the above would have prevented the death of Mr. EF but identifying that he was approaching the end of his life would have enabled appropriate care planning and additional services. As greater numbers of people with learning disabilities and co-morbidities live longer in community settings, it is increasingly important for approaching end of life to be recognised. This might be at a younger age and take a different form than is seen in the general population. It might have improved Mr EF's quality of life significantly if he had been provided with support to prevent at least some of the falls and subsequent admissions to hospital, which would have been distressing for him. It might also have met the Care Act criteria for wellbeing more effectively. "Well-being" is a broad concept relating particularly to personal dignity and being treated with respect; physical, mental health and emotional wellbeing; protection from abuse and neglect; control over day-to-day life and domestic and personal issues.

4.3. Care Setting

4.3.1. Mr EF was fortunate in that he was provided with care and support in only three settings since he was nine years old. The shift from residential care to supported living in 2010 created an opportunity for Mr EF to receive personalised care, specifically tailored to his needs. Hi support workers forged an excellent relationship with him over many years, which could not have been easy, and this is to be congratulated.

4.3.2. People with severe learning disabilities are living longer now due to improved medical knowledge. However, there is some evidence that they typically experience age related difficulties at different ages and at a younger age than the general population.[2] This was recognised in part that Mr EF accessed age appropriate health care but more could have been done to identify the signs of his ageing.

4.3.3. During the last seven months of his life, Mr EF had numerous falls resulting in injuries requiring hospital admission and the emergency services being called thirteen times. This is neither a good use of resources nor a good existence for a frail, elderly man reaching the end of his life. It simply was not possible to keep him safe in the existing environment with the agreed level of resources.

4.3.4. Mr EF appeared to feel safe, secure and settled in his care setting and it is likely it would have been the care setting where he would have chosen to live the rest of his life. The provider developed robust and holistic plans taking into account Mr EF's changing needs but these were not acknowledged or acted upon when planning his discharge in April 2016. The assessment indicated the need for additional one to one hours to be agreed from Continuing Healthcare but the process for authorising this was not clear or understood. The report, therefore, concludes that his care needs were not fully identified or granted by the commissioners.

4.4. Inter-Agency Communication and Roles

4.4.1. As reflected in Mr EF's significant health and care needs, communication within and between organisations was very complex. Commitment to working together was demonstrated repeatedly but it was never achieved effectively. There were several missed opportunities to plan Mr EF's care holistically.

4.4.2. There was insufficient recognition of Mr EF's distress while away from home. Although his support workers provided some information to ward staff and stayed with him beyond the hours they were contracted for, during his time in hospital he would have been cared for by strangers. An acute hospital setting may have been appropriate for treating illness but patients with complex care needs are likely to find it difficult. It is also sad that Mr EF's support workers were not aware that his end of life was imminent and that they arrived after he had passed away.

[2] NICE consultation on 'The Care and Support of Older People with Learning Disabilities' 2015

4.4.3. There appears to have been a great deal of communication about Mr EF's needs but insufficient sharing of information. His end of life had not been identified so planning did not happen for that aspect of his needs. His many accidents and injuries suggest overall co-ordination and planning was not adequate and there was confusion regarding who should be a case coordinator across all organisations.

5. CONCLUSIONS

5.1. The review process has identified some examples of excellent practice:

- ✓ Mr. EF had access to the range of primary and secondary health services available to the general population of his age.
- ✓ Mr. EF received a good, non-discriminatory service from his GP.
- ✓ Mr. EF's complex health needs were managed without 'diagnostic overshadowing' (i.e. a tendency to attribute all problems to the major diagnosis, i.e. severe learning disabilities)
- ✓ Mr. EF received personalised care in a Supported Living environment, assisted by support workers to gain a good quality of life, despite difficult circumstances at times
- ✓ South Central Ambulance Service raised a concern with the Safeguarding Adult Team regarding unexplained injuries
- ✓ Staff involved carried out their roles professionally and showed interest in, and commitment to, improving Mr. EF's wellbeing.
- ✓ Staff from many organisations and in different roles had tried to work together but were impeded by the inadequacy of systems to support them.

5.2. The following main themes were identified in the report:

i. The requirements of the Mental Capacity Act are not yet fully embedded in practice, including the role of the Independent Mental Capacity Advocate, especially in hospital settings.

ii. In Safeguarding Adults, when an individual lacks capacity and has very frail health conditions, care must be taken to avoid attributing unexplained physical injury to health conditions. In addition, concerns regarding people with injuries and limited communication who are admitted to hospital with unexplained injury should be reported.

iii. Advocacy should be put in place for people with learning disabilities towards the end of life in order to ensure that needs and wishes are fully identified and taken into account when decisions about the future are made. Individuals without capacity have a right to this under both Mental Capacity Act and Care Act 2014.

iv. It is important to recognise the life journey of any individual in assessment, in particular approaching end of life. Health conditions and medications may affect the time at which this occurs in people with complex co-morbidities but recognition of this life stage can enable the individual to receive the most appropriate care.

v. Vital lines of communication were not instigated between all key agencies and this did not enhance a full understanding of the situation by all involved. In turn this did not enhance opportunities to sustain his wellbeing.

vi. Assessment and care planning was not coordinated between organisations and there was no clear process for approach for authorising additional funding for people eligible for Continuing Healthcare. Clear processes for assessment, care planning and authorisation of service provision need to be in place and understood and shared by all staff involved in the care of a person receiving Continuing Healthcare so that needs can be met in a timely way. (This has now been addressed).

vii. Each person with entitlement to Continuing Healthcare who has learning disabilities and other co-morbidities should have an appropriate professional lead or case manager who is able to co-ordinate the convening of multi-agency meetings and planning of services. This may be the professional who has the most direct involvement and access to other service providers working with the individual.

viii. People with learning disabilities may need additional support in hospital. This may be achieved by using support workers with whom the person is familiar on site during the admission to

provide continuity of care and to assure their wellbeing and comfort. Hospital staff need information about the care needs of the person and the proposed discharge environment. Access to a Learning Disability Liaison Nurse has proved invaluable elsewhere.

6. RECOMMENDATIONS

6.1. The final recommendations from the review are

1. Safeguarding Adult Board should receive assurance from Frimley Park Hospital that actions have arisen for the application of the MCA 2005 in relation to consent for treatment and DNAR have been embedded.
2. Safeguarding Adults Board should receive assurance from all agencies that when an individual who has deteriorating health and who experiences an unexplained fall or a significant number of falls in a short period of time that result in injury; the fall incident or incidents will be reported to the local authority in order that any emerging pattern or emerging concern about the reason for the falls can receive an appropriate response.
3. Safeguarding Adults Board should be assured that people with LD who also have deteriorating co-morbidities should have their needs related to approaching end of life included in their assessments and be considered for multi-agency advanced care planning, including advocacy.
4. Safeguarding Adult Board should be assured that key agencies are involved in the assessment and care planning for people with complex health conditions. Key agencies should all be involved in the decision regarding appropriate placement and support in line with multi-agency guidance.
5. Safeguarding Adult Board should be assured that the agency who knows the person the most should be the professional organisation who takes responsibility to call a multi-agency meeting in line with the multi-agency guidance.
6. Safeguarding Adult Board will request that the local authority, CCG and Frimley Park Hospital will explore the possibility of additional support in hospital for people with LD. This may be achieved by using support workers with whom the person is familiar being on site during the admission to provide continuity of care and to assure their well-being and comfort. Decisions should be made on a case by case basis.
7. Safeguarding Adults Board should facilitate a multi-agency learning workshop.