Statutory Safeguarding Adults Review (SAR) Report and Findings in respect of an individual to be known as Jenny

This report has been prepared under the statutory requirements of the Care Act 2014 by Internal Reviewer, Eleanor Brazil, Independent Chair of the Bexley Safeguarding Adult Board

Signed off on: 3rd March 2021
Published on: 8th April 2021

1. Introduction

The subject of this review is a white British woman in her early sixties who was assessed as having a mild learning disability and a number of health conditions including epilepsy and dementia. She died a few days after being admitted to a care home after a 17 week stay in hospital. Prior to her death she was known to learning disability and health services.

A Safeguarding Adult Review (SAR) is carried out so that the agencies involved in providing services can learn lessons and improve practice. This SAR follows an earlier review undertaken as part of the national Learning Disability Mortality (death) Review programme.

People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability are dying earlier than they should, many from things which could have been treated or prevented. The learning from deaths of people with a learning disability (LeDeR) programme was set up as a service improvement programme to look at why people are dying and what we can do to change services locally and nationally to improve the health of people with a learning disability and reduce health inequalities. By finding out more about why people died we can understand what needs to be changed to make a difference to people's lives.

In a LeDeR review someone who is trained to carry out reviews, usually someone who is clinical or has a social work background, looks at the person's life and the circumstances that led up to their death and from the information they have make recommendations to the local commissioning system about changes that could be made locally to help improve services for other people with a learning disability locally. They look at the GPs records and social care and hospital records (if relevant) and speak to family members about the person who has died to find out more about them and their life experiences.

In Bexley the findings of the LeDeR are reported to the LeDeR sub-group. In this case the group considered that a further review of the circumstances leading to the death of JH should be undertaken under the Safeguarding Adults Review process to focus on any safeguarding issues and lessons. The purpose of this review is to identify the learning, and to consider the extent to which there are similar or additional themes to those identified in previous reviews.

The aim of this work is to provide information, understanding and insight and importantly, to improve services as a result of that learning.

In view of the LeDeR and the relatively limited range of issues, it was agreed that the SAR should be led by the Independent Chair of the Safeguarding Adult Board, to consider the findings of that review, to identify if there is any additional relevant information and to determine any wider safeguarding lessons.

It was agreed that the SAR would be conducted as learning process, with the information brought together and considered at a number of joint meetings. The final meeting was held in February 2021. This is more than two years since JH died.

2. Criteria for undertaking a SAR

A Local Safeguarding Adults Board must undertake reviews of serious cases in specified circumstances under Section 44 of the Care Act 2014 which sets out the criteria for a Safeguarding Adults Review (SAR). This includes circumstances involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if there is reasonable cause for concern about how the Safeguarding Adults Board, members of it or other persons with relevant functions worked together to safeguard the adult, and the adult has died.

The purpose of the review is primarily to:

(a) identify any lessons to be learnt from the adult's case,
and
(b) apply those lessons to future cases.

3. Information considered

In addition to the LeDeR review, individual management reviews (IMR) and summaries of involvement were received from:

1. Oxleas NHS Foundation Trust – Adult Community Learning Disability Team (CLDT)
2. GP Practices – in Bexley and Greenwich
3. Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital

The SAR review group met in December 2020 and requested that additional information be sought from Greenwich adult social care and from the Greenwich GP.

4. Background

Jenny was a woman in her early sixties, reported to have had mild learning disabilities and suffering from epilepsy since childhood. Little is known about her background, life experiences and personality from the information available to this review. However it is recorded that she was able to function independently for many years.

Prior to moving to Bexley, sometime in 2017 or 2018, she was living in Greenwich.

Jenny had a diagnosis of mild learning disability and other health needs such as epilepsy and eczema, which were well managed with prescribed medication. Prior to moving to live with her boyfriend to Bexley, Jenny was living independently in a one-

bedroom council flat in Greenwich, spending a few days at her boyfriend's house during the week. It is believed she was in a relationship with him for over fifteen years before she died. According to case records the relationship worked well, with both living in separate homes, and meeting up for about 3-4 days in a week.

In 2015, Jenny was assessed as independent in looking after herself, managing all her care needs. She is reported to have had seizures at night when she was stressed but did not need support to manage this. She managed her finances and home, and travelled everywhere by bus. She was not considered to have substantial difficulties in communication. She had been referred to a Day Centre which she attended twice weekly.

Jenny's partner was thought to be very supportive towards her and they went on holiday together. At some point during 2017 or 2018 she moved from Greenwich to live with him. The records are not clear exactly when this was.

Jenny received health care from both Oxleas NHS Foundation Trust and Lewisham and Greenwich NHS Trust out-patients, as well as from her Greenwich GP. She had been known to Oxleas since 2006 and was reported to have been erratic in attendance at arranged health appointments since that time.

In the seven months prior to her death Jenny's health deteriorated and her care needs increased. Concerns were initially raised in 2017 by the consultant neurologist at Lewisham and Greenwich NHS Trust who wrote to her GP to ask for a referral for dementia and learning disability support. The subsequent involvement of services is summarised below.

In June 2018 she was admitted to hospital. Safeguarding concerns were raised by the London Ambulance Service and Lewisham and Greenwich NHS Trust (Queen Elizabeth Hospital (QEH)) arising prior to her admission regarding neglect but enquiries were not progressed whilst she remained in hospital. On her discharge to a care home in October 2018, a further safeguarding concern was raised by the home, in respect of a category 4 pressure ulcer to the sacrum, and weight loss whilst in hospital. Neither of these safeguarding concerns were looked into.

Sadly Jenny died three days after transfer to the care home.

5. Family involvement

Records show that Jenny had four brothers and two sisters but she was only communicating regularly with one of her brothers as at year 2015. However, when she was in hospital a discharge planning meeting was held and one brother and his wife did attend. Jenny's partner visited her in hospital almost every day. At the meeting the members of Jenny's family nominated her partner as her 'next of kin'. Whilst there is no legal basis to this, it does indicate the importance placed on his role by the family.

Her partner did not wish to contribute to the LeDeR review and neither he nor any other family member have been contacted in relation to this SAR in view of the lack of recent involvement.

6. Summary of known events prior to hospital admission

In the seven months prior to being admitted to QEH, Jenny had several out-patient contacts with different professionals in QEH, arising from referrals from her Greenwich GP, as well as from Oxleas Greenwich Community Learning Disability team. It is difficult to know exactly when she moved to live in Bexley but she remained registered with her Greenwich GP until

June 2018 when her partner took her to register with his Bexley GP in Bexley. She was admitted to hospital on the same day.

The health records suggest different times when she moved, in some saying a year to 18 months before her death. In March 2018 it is recorded that the partner reported that she was then still living alone, although with considerable support from him.

The LeDeR reviewer only had limited access to records held by Greenwich Adult Social Care services. As part of this SAR process, Greenwich Adult Social Care Services have completed a comprehensive IMR. This has greatly added to the knowledge of the involvement of services prior to Jenny's admission to hospital. The information from this IMR and from the health IMRs and the LeDeR review is summarised below.

Until some point in 2016, Jenny attended a day centre two days a week which she enjoyed. She had the opportunity to interact with peers and engage in activities of interest that included Arts, Crafts and Embroidery. Records state that Jenny valued her independence, and she required no additional support to help her at home. She called on her partner, who was a pensioner and former employee of the council for assistance if needed. He provided support with all her medical appointments and correspondence.

During 2016 it was decided to reduce her day centre attendance to one day a week possibly because she was felt to be coping well. Attempts to contact her to undertake support planning failed and she stopped attending the day centre. In December 2016, housing contacted the CLDT to raise a concern that Jenny had no gas supply or heating and seemed confused. However, when contacted, Jenny advised the duty worker that she did not need any other support now that her heating and hot water were working.

A duty worker spoke with Jenny regarding her non-attendance at the day service. Jenny said she had had an accident and broke her ankle so could not attend, but said she would go to the Christmas Party.

October 2017 to June 2018 (from records)

October 2017 – the Day Service Manager emailed CLDT Duty regarding concerns at Jenny's erratic attendance. Manager advised this had a massive effect on her mental health. Ever since her days were reduced (around a year ago) her attendance had been erratic. Her partner confirmed that she is very confused most days and is very frail. He said that she doesn't want to attend anymore because she feels we don't want her, he passed the phone for her to speak to staff but she was so confused staff couldn't get a clear answer from her. Day service manager suggested Jenny was showing signs of onset of Dementia.

October 2017 - Decision was taken to review Jenny's needs and case was allocated to a new worker in Greenwich CLDT. Between October 2017 and April 2018 several attempts were made to phone Jenny, her partner and on one occasion her brother but all failed to make contact.

Support was being provided by Mencap Welfare Manager to complete the documentation for a long overdue appeal to the DWP Tribunal. She had been wrongly placed in the 'Work Related Activity Group' within her ESA benefit claim.

October 2017- Jenny attended an outpatient appointment with her partner to meet with the Consultant Neurologist. The Consultant was concerned at her condition – her memory was deteriorating, she had suffered weight loss and her gait was unsteady. He wrote to the

Consultant Rheumatologist and requested advice as well as to the GP to query the medication Jenny was taking. He commented that she was vulnerable as she was no longer attending the day centre.

November 2017 - Jenny was referred to the Memory Clinic for a dementia assessment by her GP as she was no longer able to remember her route to the day centre

February 2018 - Telephone contact to arrange appointment with Psychology for assessment due to concerns over her memory. Several unsuccessful attempts to arrange appointments and missed appointment that was arranged.

March 2018 - Jenny attended clinic review by Consultant Haematology. Partner reported Jenny lives alone however he helps with all her activities such as cooking, shopping. Partner also informed the Consultant of Jenny having lost 6kg and having diarrhoea as well as urine incontinence for the last few months. Jenny's partner explained that she was seen at Blackheath Hospital for a colonoscopy and gastroscopy. Arranged for Jenny to have a blood test for B12, folate, ferritin, transferrin saturation, virology, hepatitis B and C, CMV, EBV, VCA, HIV, serum protein electrophoresis and autoimmune screen and chest x-ray. Jenny was booked for bone marrow assessment.

April 2018 - Appointment with Consultant Neurologist missed. The Consultant wrote to the GP concerned that Jenny was a vulnerable patient who has missed an appointment in February 2018 and again this appointment.

April 2018 - Jenny's boyfriend returned telephone call from CLDT saying that Jenny has been unwell and has undergone hospital tests. He stated that Jenny underwent a brain scan two months ago and was informed that she would be too vulnerable to access the community and has a deteriorating front lobal of the brain. He also stated that Jenny had a bone marrow test last week and has a pending blood test next week. He further stated that Jenny's mobility was unsteady, and she had recently experienced falls as well as being urine incontinent. He stated that he has been with Jenny for 15 years, has his own health and COPD issues and is considering moving to a privately rented ground floor property in Bexley as it could benefit them both. Jenny spoke briefly on the phone and stated that she cannot physically attend the day centre at present and did not answer when asked if she would like to be referred again to Oxleas memory clinic. The partner was asked if there is any support that CLDT or Oxleas could assist him and Jenny with. He stated that there isn't at present but would call CLDT in the future if they do require more support.

May 2018 – Telephone call received from GP to CLDT allocated worker who stated that she had concerns about Jenny's current health and wanted to know if allocated worker could visit her at her boyfriend's home. Allocated worker advised that he had spoken to Jenny and partner for consent as he lived out of borough. Allocated worker noted the fact they would have to ask for support as well as Jenny historically not engaging or turning up for appointments, such as the memory clinic.

May 2018 - Multi-disciplinary meeting held with South East London Cancer Network Referred as a 2 week wait patient for investigation of macrocytic anaemia and thrombocytopenia first noticed in October 2017. Last MRI showed significant cerebral and cerebellar volume loss. Significant weight loss. Noted that Jenny has limited self-care and is in bed or chair more than half of the waking hours. Management plan: Watchful waiting

May 2018 - Email between the Consultant Neurologist and Greenwich Neuro Rehabilitation team re support for Jenny in the community. Greenwich Neuro Rehabilitation Team were

unable to accept the referral citing Jenny was known to and under the LD services although is not attending appointments. They state having written to the GP to share concerns about this as Jenny does not seem contactable.

7. Events from 4th June 2018

Jenny registered at Lakeside Medial Practice on the 4th June 2018 when she attended for her new patient screening. She was seen by the nurse who noted that she was hypotensive and tachycardic. Her heart rate was 118/min. She was also unable to stand and she had a pressure sore on her sacrum. As a result, an emergency ambulance was called and she was transferred to accident and emergency. Jenny was then admitted to Queen Elizabeth Hospital.

From the Greenwich CLDT IMR:

- 19/06/2018 - Telephone call received from Queen Elizabeth to advise that Jenny was admitted to Ward 3 on 4th June 2018 with reduced mobility, tachycardia and disorientation. Jenny had a weight loss of a stone over a few weeks. Jenny also had bedsores and had pneumonia on admission. Safeguarding concern raised due to the pressure sores. Hospital OT have visited her home and found only a mattress on the floor.

- 20/06/2018 - CLDT Duty Manager - Action for duty officer: To contact next of kin to establish where Jenny is currently living. If Jenny continues to be living in Greenwich, then we are responsible for her care and support and therefore need to ring the hospital.

- 21/06/2018 – Duty officer attempted to follow up with partner; no response.

- 21/06/2018 – Duty officer emailed hospital to ascertain Jenny's current address and who would take lead on the Safeguarding issues.

- 21/06/2018 – Duty worker t/c with Jenny's partner who reported that Jenny has given up the flat in SE18 (address as on framework) and is now living with him in Bexley. He further advised that they are going to be moving to another Bexley address in a few weeks.

- 27/06/2018 – Discussion between allocated worker with CLDT Lead Community Nurse and senior Line Manager regarding Jenny's hospital admission at QEH. Agreed to carry out a joint visit today to assess Jenny's potential care and support needs upon hospital discharge and to establish from Jenny where she considers her home address to be/ where care and support should go- as there is some uncertainty that she is still a Greenwich resident.

A referral was made for an OT assessment in QEH and the records state that Jenny had not moved since her admission to hospital and she would not participate with the assessment for mobility on the ward. She had lost weight while in hospital, and her BMI is recorded to be extremely low at 12. A meeting was held at the hospital on 2/7/2018, attended by one of Jenny's brothers and sister-in-law in addition to her partner. This meeting is described in hospital notes variously as a family meeting, a discharge planning meeting and a Best Interests meeting. It was agreed at the meeting that her partner would be named as her next of kin.

8. Assessments under the Mental Capacity Act 2005 (MCA) and for Continuing Health Care (CHC)

There is no record of any Mental Capacity Assessment under the MCA or associated Best Interest meeting to determine Jenny's capacity to make decisions about her care and treatment throughout the period covered by this report. This should certainly have been considered after she was admitted to hospital. The hospital notes do record discussions with Jenny about her care and there is a note on the hospital file suggesting she had capacity. However, at the meeting on the 2/7/2018, the view was taken that she did not.

Adult social care were involved briefly while Jenny was in hospital and did start a best interest process, to determine if Jenny had the mental capacity to be able to make decisions. However, this assessment was not completed. There is therefore no clear record of a MCA assessment to determine if Jenny had capacity to make an informed decision about plans for her - or an associated Best Interest meeting. The hospital should have ensured that this was completed to establish that she had capacity to agree to her care and treatment as well as any plans for discharge.

At this time in 2018, the Continuing Health Care (CHC) team were dependant on "trusted assessors" to complete the necessary Decision Support Tool which indicates whether an individual would fit the CHC criteria. The MCA and Best Interest Decision would be completed at ward level when discussing discharge planning and before CHC become involved. The resultant paper work is then requested by CHC and they start to look for a suitable placement. This paperwork is not always forthcoming and there is pressure throughout the system to move patients as soon as medically fit.

The CHC team did not attend hospital at this time due to the role of the "trusted assessors" and therefore would not have been able to complete the MCA and Best Interest Decision. Since then, the pathway has changed and this is now known as Discharge to Assess. The CHC team have had training and undertake appropriate MCA assessments and Best Interest Meetings. Placements are found either by the Local Authority (non-complex needs) and CHC (Complex needs). CHC will then review the individual within 3 months to ascertain the needs and if CHC care is required.

The discharge plan was for her to go into respite care on the 14/7/2018 to care for pressure ulcers and then to move to live with her partner to a new ground floor flat.

Jenny was assessed for CHC, and this was agreed on 9/8/2018. Responsibility for discharge was then with the CHC team. There was a delay in finding a placement for her. Due to the complex nature of the care required several care homes were unable to meet her needs. Jenny also became medically unwell and was not fit for discharge. The discharge to a care home was eventually made on 03/10/2018.

The following is an extract from the LeDeR report:

Information from Continuing Care Assessment while Jenny was in Queen Elizabeth Hospital:-

'Jenny had a diagnosis of dementia and learning disability which negatively impacted on her orientation, ability to make decisions, insight into her care needs and risk awareness. She was disorientated in time but able to recognise key family members especially her partner, ex partner of her sister but not her sister. She was unable to make complex decisions therefore relied on others to make best interest decisions.

Jenny demonstrated episodes of frustration due to being in hospital for which she had to be reassured.

Jenny's cognitive impairment impacted on her ability to communicate her needs but was able to demonstrate non verbal signs of communication but this became less as she became weaker.

Jenny is being nursed in bed for most of the time and co-operates with re-positioning every two hours due to pressure sores. She is either in bed or chair. Had ungradable pressure sore on sacrum.

Accepted for Continuing Health Care 9/8/2018.

Discharged to Maples Care Home on 3/10/2018 with grade 4 pressure sore on sacrum. Air mattress, 2 hourly re-positioning during the day; 4 hourly at night. Tissue Viability Nurse referral was made and wound documentation and photos were taken as part of care planning. Jenny was at nutritional risk and was prescribed supplements and she had fortify food.'

The Care Home should have undertaken an urgent assessment under Deprivation of Liberty guidelines (DOLs) to look at her current plan being appropriate and least restrictive, whilst deprived of her liberty, but sadly Jenny died on 5/10/2018 and this was not done.

8. Summary of safeguarding concerns

Throughout this period the following safeguarding concerns raised:

1. On 5/6/18 By the London Ambulance Service and QEH in respect of neglect, low weight and grade 4 pressure sore on admission to hospital.

2. On 31/7/18 by QEH regarding partner's compliance with following Speech and Language therapy advice when purchasing food items for Jenny that SLT had advised against. The Safeguarding referral also raised concern about inappropriate behaviour by him towards staff.

9. Conclusion

Nationally there has been concern for some years about the number of people with learning disabilities who suffer from poor health, and who die earlier than they should. The LeDeR process was set up to ensure that these issues were considered locally and the lessons from the reviews feed into national learning and action.

In this case the LeDeR review was completed and the chair of the LeDeR sub-group recommended that a SAR be undertaken to focus on any safeguarding issues and additional learning. The reviews concerned a woman in her early sixties who died in 2018.

Additional information from the Greenwich adult social care Individual Management Review was available to the SAR reviewer. This was more detailed than the LeDeR reviewer had access to and added significantly to what was known about this lady's engagement with health and care services prior to her death. It is now over two years since Jenny died.

Oxleas had known Jenny since 2006 and their records show that she often did not engage with the service or respond to correspondence, even during the time when she was clearly much more independent and well. In the period leading up to her death from 2015 she did attend some health appointments, but the pattern of missing some appointments and not responding to phone calls continued. Her health deteriorated in the months prior to her death and her care needs greatly increased.

Jenny was well supported by her partner of fifteen years although they lived separately. She moved to live with him at some point between 18 months and 4 months before her admission

to hospital in June 2018, but exactly when is not clear. She remained in hospital until her discharge to a care home in October 2018 but sadly died a few days later.

Greenwich adult social care services retained responsibility for her care until June 2018 as it was not clear whether she had moved to Bexley before that point. She also continued to be open to Oxleas NHS Foundation Trust and to Lewisham and Greenwich NHS Trust out-patient services. However, she was not seen at home in either Greenwich or Bexley and therefore there was no clear picture of how she was coping. The IMR makes a number of recommendations for the Greenwich CLDT relating to the need to undertake home visits and to ascertain where someone is living if it is not clear to ensure appropriate transfer to another local authority.

When the LeDeR review was underway it was thought that Jenny's care and support might have been adversely affected by the move from one local authority to another but this was not the case. There was continuity, but the different agencies did not work together to determine what was really the position. No individual professional went beyond passing on their concerns to another individual or agency. There were a number of times during the period 2016 to 2018 when her key worker from the community learning disability team could have called a multi-agency review to share information and co-ordinate support. This would have been in response to the feedback from the day centre that she was not attending and the view of the centre and other professionals that Jenny's level of confusion was increasing. In the absence of this, not enough was known about the extent of Jenny's needs and what support she might have been prepared to accept. At no point was there any consideration given to offering her partner a Carer's Assessment, or considering whether Jenny had the capacity to make decisions about her care and support.

By the time her partner took her to register with a GP in Bexley her health had deteriorated to the extent that London Ambulance Service and QEH raised safeguarding concerns. These were not progressed while she remained in hospital, nor was a subsequent safeguarding referral that was received while she was in hospital, as it had been decided that those concerns should be looked at as part of the discharge process. In my view they should have been followed up at the time to inform the discharge process.

In the light of these conclusions, I make the following recommendations:

Recommendations

1. In a situation where one or more professionals raises concerns about deteriorating health and increasing care needs, these should be proactively followed up as soon as possible. In this situation a multi-disciplinary review should be called. Any professional can and should ask the CLDT for such a review if they are concerned. If as in this case, there is an allocated key worker from the CLDT they should ensure a review is held if they are aware of concerns raised by other health or care professionals.

2. As part of a review of support needs, every effort should be made to see an individual at home to ascertain how well they are coping. In situations such as these a partner should be offered a Carer's Assessment by adult social care or the CLDT..

3. If safeguarding concerns are raised during hospital admission, enquiries should be progressed and not deferred until the discharge planning process.

4. Whilst the process relating to discharge of patients with complex needs and meeting the criteria for Continuing Health Care has changed since 2018, it is important to ensure that Mental Capacity Act assessments and Best Interest Decisions are completed within the hospital prior to discharge when there is doubt regarding an individual's decision making capacity.

5. All agencies should ensure greater awareness amongst front line staff and managers on when to undertake a MCA assessment, to determine an individual's capacity to agree to their care and support plan, and the follow on Best Interest meeting if required.

6. LeDeR reviews should be progressed in a timely way and wherever possible be completed within 6 months to ensure any learning is acted on. If at any point the LeDeR reviewer considers there were safeguarding issues, then a referral should be made to the SAR sub-group. Where there are difficulties in accessing information requests should be escalated to the SAB.

7. The Bexley Safeguarding Adult Board has established a pressure ulcer task and finish group to consider lessons from a previous SAR. The task group should review the issues raised by this SAR and any additional learning.

Eleanor Brazil

Independent Chair of Bexley Safeguarding Adult Board

March 2021