Sandwell Safeguarding Adults Board

Safeguarding Adult Review (SAR)

Jeff

Overview learning report

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1. Introduction

1.1 This Safeguarding Adult Review (SAR) explores the final months of Jeff's life. It considers the experience for Jeff of moving from his family home to living in a care home and then admission to hospital. The SAR reviews the responses by agencies to his needs.

1.2 Jeff was 75 years of age and had lived in his family home with his brother and his sister, who cared for both Jeff and his brother. Jeff had started to experience some changes in how he functioned, impacting on his gait/mobility and his mood in the late summer of 2019. Dementia screening in January 2020 found 'no significant decline in cognitive function'. When the first 'lockdown' due to the pandemic was enforced in March 2020, the Day Service which Jeff had gone to for all for his adult life closed. Jeff struggled, becoming low in mood, eating less and his mobility deteriorated with him having a number of falls and hospital admissions through the summer. Further to Jeff's sister seeking support from Adult Social Care, in August 2020 Jeff was admitted into a local Care Home. Due to the pandemic restrictions Jeff's sister was only allowed to see him through the window and video call. Jeff's health and wellbeing deteriorated significantly and following admission to hospital Jeff sadly died in November 2020.

1.3 Sandwell Safeguarding Adults Board (SSAB) identified there may be learning regarding how effectively agencies had worked with Jeff during the pandemic.

Context of Safeguarding Adult Reviews

1.4 The Care Act 2014 places a statutory duty on Safeguarding Adults Boards (SAB) to undertake case reviews in certain circumstances as set out below.

Section 44, Safeguarding Adult Reviews:

(i) A SAB must arrange for there to be a review of a case 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:

(a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and

(b) condition 1 or 2 is met.

(ii) Condition 1 is met if:

(a) the adult has died, and

(b) the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

(iii) Condition 2 is met if the adult has not died but the SAB knows or suspects that the adult has experienced serious abuse or neglect.

1.5 The Department of Health's six principles for adult safeguarding should be applied across all safeguarding activity[1] . The principles apply to the Review as follows:

Empowerment:	The Review will seek to understand how the agencies listened to/heard and engaged with Jeff and applied Making Safeguarding Personal. Involving Jeff's family in the Review.
Prevention:	The learning will be used to consider actions for prevention of future harm to others, particularly in relation to holistic, person-centred planning.
Proportionality:	Understanding whether least restrictive and person-centred practice was used; being proportionate in carrying out our Review objectively considering the impact of the pandemic restrictions.
Protection:	The learning will be used to inform ways of working, actions and professional curiosity to protect others from harm.
Partnership:	Partners will seek to understand looking through the lens of person-centred working, how well they worked together and use learning to improve partnership working.
Accountability:	Accountability and transparency within the learning process.

1.6 The SSAB commissioned an independent author, Judi Thorley, to undertake the Review. The author is independent of SSAB and its partner agencies.

1.7 The aspiration of the approach to this SAR is to harness collective 'ownership' for change and improvements which will be embedded for the benefit of the whole Sandwell population.

[1]Making Safeguarding Personal https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/making-safeguarding-personal (accessed October 2021)

2. Jeff

It is important within this Review to introduce Jeff, who he was, what he enjoyed doing in his life, who was important to him and what he meant to his family, friends and staff who supported him. The following introduction has therefore been drafted from listening to his sister, staff who knew him and looking through his life book.

Jeff was a gentleman of 75 years, much loved by his sister and brother whom he lived with as well as his wider family, friends and staff, some of whom had known Jeff for over 30 years. Jeff had a Learning Disability and shared his family childhood home with his sister and brother who also has a Learning Disability. His sister Peggy took over caring responsibilities for Jeff and his brother when their parents passed away.

Jeff is described as larger than life, a bit of a joker who could be stubborn and liked to get to know people well before trusting them. Jeff had gone to Adult Day Services all of his adult life, getting the bus early in the morning and spending the day there. Jeff had built up good, trusted relationships with staff and others at the Day Service, feeling comfortable making his needs and choices very clear both using words and actions, for example staying on the bus when there was a proposed change to a different location.

Jeff liked to look smart, wearing nice clothes and always having a clean-shaven face. He preferred to have a bath as he didn't like the water from the shower on his face. He enjoyed food and prior to 'lockdown' he loved going out in town for meals. He also played ten pin bowling and was pretty good at it.

Jeff had many interests including a love of music, particularly rock 'n' roll, Elvis, and Gerry and the Pacemakers being favourites. Jeff's brother preferred Vera Lynn so Jeff liked to have his own CD player and earphones! Jeff liked to have a newspaper and magazines to look through, enjoying the pictures and hearing from others what was happening. Jeff enjoyed art, feeding the fish at the Day Service, as well as gardening. He also liked to make drinks and be helpful (if he liked you!).

Jeff had a number of health conditions, some of which required regular monitoring and medication: - atrial fibrillation (AF) and benign prostatic hyperplasia (BPH) also known as prostate enlargement (symptoms include frequent urination, trouble starting to urinate, inability to urinate, or loss of bladder control). Jeff was also a large man with a high Body Mass Index (BMI) and increased propensity to heart disease. Jeff also had hypothyroidism.

Jeff had started to experience some changes in how he functioned in 2019 and was referred to the Learning Disability Team for dementia screening. At this stage Jeff's decline is described as changes to his gait/mobility-shuffling, in fact he experienced a bad fall. Also, his mood was low and he became a little short tempered, sometimes agitated with others. The dementia screening showed 'no significant decline in cognitive function'.

Jeff really struggled with the impact of the pandemic; the enforced closure of the day service and not being able to have his usual routine. Depression was mentioned but no intervention planned. Jeff's mobility deteriorated further, and he had a number of falls, being hospitalised on 2 occasions in June and July 2020. Adult Social Care provided mobility aids and a package of care was put in place to support at home after the 2nd admission to hospital. Jeff was also seen by the Frailty Team. Jeff's physical health continued to decline, and he began refusing to go upstairs to bed, sleeping very little. It was recognised that Jeff needed 24-hour care, additional calls were offered but calls

throughout the night were not available. An assessment of Jeff's care and support needs was carried out in mid-July during which Jeff stated that he wanted to stay at home. It was noted that Jeff was not able to acknowledge his care needs or discuss the risks involved to meet his care needs and increased risk of falling. Jeff's sister was exhausted and wanted Jeff to be able to have the care he deserved over 24 hours. Jeff was deemed not to have capacity to understand and therefore best interest decision making was followed and an Independent Mental Capacity Advocate (IMCA) engaged.[2]

Following assessment of his needs by the Senior Lead at a local Care Home, which specialises in care of people with dementia, and a negative Covid-19 test, Jeff was admitted to a Care Home on 3rd August. Due to the restrictions imposed due to Covid-19, contact with his sister was via a video call or through a window. Two weeks following admission Jeff had another fall and was taken to the Emergency Department, returned to the Care Home with antibiotics for cellulitis[3].

Jeff continued to deteriorate over the next 2 months, having increased sore areas to his skin; in his groin area and later his umbilical, refusing support with personal care, often refusing food and not sleeping, putting himself on the floor and not interacting. Care Home liaised with Jeff's sister and community key worker from the day service, encouraging contact via phone and video calls. Jeff's jukebox and fish tank were taken from home and put in his room to help encourage Jeff to go into his bedroom/bed. Care Home contacted the GP on several occasions with consultations over the phone and treatments prescribed. Following a fall on 16.08.2021 Jeff was taken to hospital, he returned to Care Home with a prescription for antibiotics to treat cellulitis. It was noted in A&E records that Jeff had not been sleeping in a bed since admission into the Care Home. The GP arranged for the District Nurses to take blood and dress Jeff's oedematose[4] legs. Jeff had lost 15kg in weight in 2 months. Care Home contacted the Social Worker to request an urgent re-assessment as concerned that the Care Home was not able to meet his needs. A Social Worker commenced the process for alternative accommodation, but the pace of action was impacted by the pandemic restrictions, reduced workforce, etc.

Jeff was taken via ambulance to A&E on 26.10.2020 with suspected sepsis, he was very unwell. Jeff was noted to be in an unkempt state with several sore areas including 2 grade 2 pressure areas. An incident was generated about Jeff's pressure areas on the hospital incident reporting system. Family also raised concerns with Adult Social Care about weight loss, non-compliance and sore areas and this was considered under Section 42 Adult Safeguarding enquiry under the Care Act 2014[5], the concern was partially upheld.

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[2]Best interest decisions - Under the Mental Capacity Act 2005, any act done or decision made for or on behalf of an adult assessed as lacking capacity must be done or made in their best interests

[3] Cellulitis is an infection caused by bacteria getting into the deeper layers of your skin, makes your skin painful, hot and swollen and requires treatment with antibiotics. It can be serious if not treated quickly, can spread to other parts of the body, such as, blood, muscles and bones https://www.nhs.uk/conditions/cellulitis/

[4]Oedematose legs- Fluid build-up (oedema): It happens when **the tissues or blood vessels in your legs hold more fluid than they should**. This can happen if you simply spend a long day on your feet or sit for too long. But it may also be a sign that you're overweight or don't get enough exercise, or of more serious medical conditions https://www.nhs.uk/conditions/oedema/

[5] Section 42 of the Care Act 2014 requires that each local authority must make enquiries (or cause others to do so) if it believes an adult is experiencing, or **is at risk of, abuse or neglect**. When an

Jeff was admitted to hospital and treatment commenced. Jeff did not respond to treatment and deteriorated further; Jeff tested positive for Covid-19 on 4.11.2020. Sadly, Jeff passed away on 5.11.2020. Cause of death is documented as 1a) biliary sepsis, 1b) cholecystitis and part 2 frailty and Covid-19. There was no referral to the coroner.

allegation about abuse or neglect has been made, an enquiry is undertaken to find out what, if anything, has happened. https://www.legislation.gov.uk/ukpga/2014/23/section/42/enacted

3. Terms of Reference and methodology

3.1 Terms of Reference

The Review considered the actions and circumstances leading up to Jeff's admission to a local Care Home and final admission to hospital; person-centred actions and decision making by individual agencies, what worked well, not well, any gaps and opportunities which can support agencies to consistently uphold person-centred approaches 'making safeguarding personal'. The Review specifically focused on person-centred decision making and the possible impact that working during a pandemic may have had on Jeff and his family's experience.

The specific areas of focus and questions:

Terms of Reference
1. How did each agency uphold Making Safeguarding Personal, promote person-centred decision making and seek to ensure the voices of both Jeff and his sister, as main carer, were sought and heard in addressing deterioration in health and increase in support needs?
2. How were Jeff's holistic needs considered and planned for, i.e. Physical, Intellectual, Emotional and Social (PIES) • Were the care and support needs of Jeff identified, assessed and responded to appropriately, effectively and in a timely manner so as to prevent further deterioration in condition, plan and implement timely and appropriate support and ultimately promote a person-centred approach and decision making?
3. How was multi-agency working demonstrated throughout and particularly at times of critical decision making • Did the communication between the services/agencies involved with Jeff ensure the effective coordination of service delivery and multi-disciplinary working? • Was there professional curiosity in terms of changed needs, increased contacts/presentations with health and social care, did agencies work together/share information?
4. How and when the Mental Capacity Act (MCA) and Deprivation of Liberty Safeguards (DoLS) were applied and documented? • If and how self-neglect guidance was applied?
5. How the national pandemic impacted on ways of working, person-centred approaches, actions and outcomes? • What if any was the impact on person-centred working, assessment. planning, decision making, communication, co-ordination and review?

3.1.2

Agencies: involved summary of contact/relationship with Jeff	
Sandwell Adult Social Care - Day Services	Provision of Day Services which Jeff attended, continued community support during lockdown. Well established relationships.
Black Country Healthcare Foundation Trust (BCHFT)	Dementia screening. Quarterly reviews with the Learning Disability Clinic.
Sandwell and West Birmingham Clinical Commissioning Group (CCG)	Registered with the same GP surgery for 75 years.
Sandwell Adult Social Care - Duty Social Work	Hospital and community Social Work and Therapy services
Sandwell and West Birmingham Hospitals NHS Trust (SWBHT)	Community and in-patient physical health care services. Clinician, nursing and therapy intervention for and with Jeff as an outpatient, in-patient and in the community
Care Home	Jeff was an inpatient at Care Home from 3.08.2020
West Midlands Ambulance Service (WMAS)	Responded to emergency calls for Jeff both at his home and within the care home

3.2 Methodology

3.2.1.

An appreciative inquiry approach focused on learning from Jeff and his family's experience was used. The SAR also cross referenced to the learning from Hertfordshire MAPCR 'James L'[6] and other similar SARs has been used. This approach has been agreed due to the similarities in the circumstances and outcomes of these 2 individuals' experience and specifically to capture and capitalise on learning already identified, seeking to identify where practice and service fell short and agree actions/interventions to remedy this. The need to appreciate and use learning already available and avoid 'learning anew' has been identified as a key recommendation in the recently published 'Analysis of Safeguarding Adult Reviews', 2020[7]. Specifically 'Independent Authors and SABs are urged to ensure consideration and

[6] James L MAPCR https://www.hertfordshire.gov.uk/media-library/documents/adult-social-services/herts-safeguarding-adults-board/hsab-information-for-professionals/hsab-multi-agency-partnership-case-review-mapcr-james-l.pdf

[7] Analysis of Safeguarding Adult Reviews 2017-2019, Michael Preston Shoot et al 2020. Commissioned by CHIP - the sector-led Care and Health Improvement Programme, co-produced and delivered by the Local Government Association and the Association of Directors of Adult Social

relevant use of existing learning from local, regional and national SARs along with findings and recommendations from other research relevant to the individual and circumstance of the commissioned SAR review'. SSAB is committed to maximise the learning and actions identified from Jeff's and his family's experience. The SSAB wishes to ensure that this will lead to embedded change and improvements. This necessitates consideration of learning already available.

3.2.2.

An appreciative inquiry approach was used to identify further questions for response from each agency's chronology. The chronologies and responses to the questions, along with narrative from Jeff's sister, were used to identify specific areas of focus and inquiry at a reflective learning event with frontline practitioners.

The findings and learning from other SARs and relevant research were used to ask why, how and what in terms of experience, actions/inactions and outcomes, what worked well and not well, what has already been changed/improved and what is the evidence for the impact of these changes/improvements.

3.2.3

While the primary purpose of the Safeguarding Adult Review is to set out how professionals and agencies worked together, including how learning and accountability can be reinforced both in and across agencies and services, it is imperative that the views of the individual/ family and details of their involvement with the SAR are included in this. The Independent Author and SSAB Lead Officer for Protection and Audit met with Jeff's sister to listen to and hear about who Jeff was, her experience as a carer in the months leading up to Jeff's admission to the Care Home and then hospital, and to give the opportunity to hear her reflections and understand the impact both for Jeff's sister and the wider family. Engaging with Jeff's sister to understand expectations helped with the formulation of the Terms of Reference and the learning identified. The independent author and SSAB are extremely grateful to Jeff's sister for her contribution.

Services in England https://www.local.gov.uk/publications/analysis-safeguarding-adult-reviews-april-2017-march-2019

4. Summary of events

4.1 Jeff had started to experience some changes in how he functioned in 2019 and was referred to the Learning Disability (LD) Team for dementia screening. At this stage Jeff's decline is described as changes to his gait/mobility-shuffling, in fact he experienced a bad fall. Also, his mood was low and a little short tempered, becoming agitated with others.

4.2 The Consultant Psychiatrist from the LD Team liaised with Jeff's GP to arrange a CT scan, his sister advised that Jeff would struggle to lie down and be still and would need sedation. Although this was prescribed the CT scan did not happen.

4.3 The Consultant Psychiatrist referred Jeff to a Consultant Psychologist in the LD Team for dementia screening.

4.4 Jeff was discharged by Consultant Psychologist in January 2020 following dementia screening which was documented as showing no significant decline in cognitive function. Jeff remained under the care of the LD Team.

4.5 Jeff was seen in the Learning Disability Clinic on **9th March 2020**, which noted that his mobility had declined since last review and mood 'good'. To be seen in 4 months.

4.6 Jeff started to experience nocturnal enuresis (involuntary urination that happens at night while sleeping) in **February 2020**, visit to GP, advice given.

4.7 Due to the pandemic the nation was put into the first 'lockdown' on **23rd March 2020.** Jeff was not able to go to Day Service which he had done every day for all of his adult life. Family and Day Service staff describe the significant impact that this had on Jeff, 'took it really badly', 'was very unhappy and not himself'.

4.8 Staff from Day Service stayed in contact and provided support to Jeff at home with regular contact, activities to do at home, etc.

4.9 Jeff started to refuse to go to bed, choosing to stay in a chair downstairs. His sister was staying up with him. He also started to eat less and was not interested in activity or helping with chores around the home. Depression was 'mentioned' in the referral for safeguarding adult review and discussion with sister, no treatment initiated. (NB: there was no reference to 'depression' in the chronology or agency responses to questions).

4.10 Jeff's sister contacted Adult Social Care (ASC) in early **June 2020** as she was struggling to support Jeff with his personal care/bathing due to his deteriorated mobility.

4.11 Desktop assessment carried out and bath board and seat delivered to home, unfortunately Jeff's sister states that these aids didn't help. Jeff had been having some falls at home.

4.12 Ambulance called **28th June 2020** due to oedema, abdominal pain and frequent urination. Admitted to hospital, diagnosed and treated for community acquired pneumonia (CAP) as an in-patient, negative for Covid.

4.13 Physiotherapy review whilst in hospital due to history of falls, unwitnessed fall whilst in hospital, noted that falls due to poor balance. Noted not to be using walking aids.

4.14 Capacity assessment completed deemed not able to make decisions.

4.15 **3rd July2020 –** Jeff was discharged home with oral antibiotics to continue and with a package of care which consisted of calls to support with personal care x2 daily

4.16 The Short Term Assessment and Rehabilitation (STAR) service visited Jeff at home on 4th July 2021. The worker was informed of mobility concerns post discharge. Worker observed Jeff negotiating the stairs within the property successfully. Concerns re: night-time disturbances were discussed and advice given to request medication review by GP.

4.17 Social worker from the hospital team visited Jeff at home on 11th July 2021 to carry out an assessment of Jeff's needs, further to sister contacting in early June and 2 follow up calls from Day Service staff. Further to discussion with Jeff and his sister it was agreed that a long-term placement was required as assistance being requested was night-time care which is not provided, increased calls were offered but 24-hour care appeared to be the best option.

4.18 Jeff stated he wanted to stay at home, assessment states that Jeff 'not able to discuss the risks involved and his care needs. Jeff does not acknowledge that he has care needs and is at risk of falls'. Assessment further details that Jeff's sister stated that she is 'at the end of her tether, feels exhausted due to having to stay up with Jeff at night for fear of him falling'. Assessment states that sister requesting 24-hour care however it should be noted that when the independent author and SSAB representative met with her she said that she 'only wanted respite, I just needed some sleep…'. Outcome of assessment was to seek 24-hour care home placement.

4.19 Capacity assessment completed and Jeff deemed not to have capacity, IMCA engaged to follow 'best interest' decision making under the Mental Capacity Act.

4.20 **13th July 2020 –** Ambulance called early morning. Jeff found lying on the bedroom floor in the morning by his sister. Unable to get him off the floor and Jeff had 1 episode of vomiting. Jeff appeared alert but confused, no obvious injuries, unwitnessed fall, query head injury. Assessed and conveyed to hospital for further assessment.

4.21 Seen by Hospital Frailty Team, noted to have delirium due to unresolved community acquired pneumonia, discharged home.

4.22 **14th July 2020 –** Telephone assessment carried out by Clinical Lead at the Care Home, Jeff accepted for admission, subject to funding and negative Covid-19 test.

4.23 **20th July 2020** – Assistant Practitioner (AP) from the Integrated Care Service contacts sister. Following discussion AP contacts ASC to request contact with family re: admission to Care Home.

4.24 Jeff was seen by GP on **24th July 2020** regarding oedema to both lower limbs and eczema, diuretics (sometimes called water pills, help rid your body of salt (sodium) and water) prescribed for oedema and cream for eczema.

4.25 **3rd August 2020 –** Jeff was admitted to a large Care Home registered to provide care to patients living with dementia. Admission was following a negative result for Covid-19. Jeff is noted to have been initially unsettled asking for sister but settled later in the evening. Although a 7-day care plan was drafted and implemented and staff had discussions with Jeff's sister to update plans to meet his needs, Jeff did not have a Person Centred Plan to help staff what was important to and for him etc. Day Service had developed a life book with and for Jeff. Provision was made for Jeff to have some of his favourite things from home, radio, jukebox, fish tank.

4.26 Deprivation of Liberty Safeguards authorised **20th August 2020**

4.27 Due to Covid-19 restrictions, Jeff's sister, other family and friends/staff from Day Service were not able to visit. Contact was maintained via telephone and video calls.

4.28 Out of hours GP contacted on **8th August 2020** due to sore groins, cream prescribed.

4.29 **15th August 2020 –** Ambulance called due to fall and bang to the head. Returned the same day with a prescription for antibiotics for cellulitis.

4.30 Jeff is resistive to staff support, becoming agitated, putting himself on the floor, refusing and resisting contact and personal care, often refusing meals. Staff liaise with Jeff's sister.

4.31 From **8th August to the 26th October 2020** there were numerous contacts with GP from Care Home summary of concerns: -

- J is refusing his meals, eating only a few spoons full some days, other days eating his meals.
- J is getting agitated some days, can shout and is difficult to do personal care for him.
- J is not sleeping at night, sitting upright in his chair most nights and wandering.
- J had a fall and was assessed in A+E treated for cellulitis.

Further creams prescribed for fungal infection to groin, under stomach and umbilicus and medication for sleeping prescribed.

4.32 **5th October 2020** – Care Home contacted Adult Social Care to request an urgent re-assessment of needs as concerned about weight loss and general deterioration and that unable to meet his needs. Social Worker who knew Jeff contacted to advise that an urgent review and alternative placement would be arranged. Video call arranged with sister and community key worker. Sister/family raised concerns with Adult Social Care about Jeff's care and support.

4.33 **On 6th October 2020 –** Jeff's weight loss was discussed with the GP, Jeff had lost 15kg since his admission on 3rd August 2021. GP arranged for District Nurses to take bloods for investigations and to dress oedematous legs.

4.34 Social Worker discussed concerns raised by sister/family about her brother's care with Care Home, happy with responses - no further action.

4.35 **13th October 2020** – District Nurses (DN) visited to take bloods. Noted that DN asked about pressure areas as home staff reported reduced mobility and poor diet, advised by home staff 'skin intact'. DNs visited regularly to dress 'weeping legs', referral made to lymphoedema clinic.

4.36 **22nd October 2020**- GP contacted as umbilicus noted to be sore, red and raised and weeping yellow pus. GP prescribed antibiotics and cream, discussed need to repeat blood test in 4 weeks due to low platelet count (blood cells that help blood to clot).

4.37 **24th October 2020**- Carers contacted Jeff's sister as he was not eating or drinking.

4.38 **26th October 2020 –** 999 call by carers who were concerned that Jeff appears unwell, more lethargic and has a low temperature, infection in umbilicus radiating to groin. Taken to A&E, query sepsis. Jeff was admitted to hospital and treatment commenced for sepsis.

4.39 **28th October 2020** – Safeguarding alert raised and investigation commenced following concerns raised by Jeff's sister regarding possible neglect. The concern was investigated under Section 42 of the Care Act, the outcome was the concern was partially upheld.

4.40 Despite treatment/intervention, Jeff continued to deteriorate and became acutely unwell, not responding to treatment. Jeff tested positive for Covid-19. Due to Covid-19, restrictions were in place for visiting, however Jeff's sister was able to visit just before he sadly passed away on **5th November 2020.**

5. Findings, analysis and learning

5.1 Approach to analysis of findings and learning

5.1.1 Further to all agencies submitting chronologies several additional questions were identified for each agency. The chronologies and responses to questions were analysed to identify key timelines and areas for further appreciative inquiry at a learning event with frontline practitioners.

5.1.2 Analysis highlighted 3 specific timelines for consideration:

- Timeline 1: the 6 months from September 2019 to March 2020 when Jeff's health and care needs had started to change, and investigations were carried out regarding possible dementia. Jeff had been referred to and remained under the care of the Community Learning Disability Team;
- Timeline 2: March 2020 to August 2020 during which time Jeff was unable to attend Day Service due to the imposed restrictions due to the pandemic and he started to deteriorate both physically and psychologically and family sought help from Adult Social care;
- Timeline 3: Jeff's admission to a large Care Home in August to November when Jeff passed away in hospital.

5.1.3 At the learning event practitioners were asked to consider what worked well, not well and gaps or missed opportunities along with any good practice under the key headings of Putting People First; Staff and Culture; Systems and Processes; and Partnerships.

5.1.4 These four key areas have been adapted from the National Quality Board (NQB) 'Review of early warning systems in the NHS Acute and Community Services, NQB 2010'[8] and 'Quality in the new health system, NQB 2013'[9]. The Review of early warning systems in the NHS Acute and Community Services was completed by the NQB following the failures at Mid-Staffs Hospital NHS Trust. Whilst the failings and learning were about an NHS provider, the principles and values identified are applicable to all human services. These values and principles were further reiterated in 2013 when the whole health system was changing.

5.1.5 On reviewing the chronologies and responses to agency questions and considering the Terms of Reference, the author recognised that using these 4 key areas would facilitate a holistic review which explored key themes that had emerged from different perspectives, always with the person at the centre in line with 'making safeguarding personal'.

5.1.6 This approach was discussed and agreed to promote open and candid learning, with respectful challenge between frontline practitioners 'holding the mirror up' to support identification of learning that is clearly linked and not siloed, encouraging ownership going forward.

[8] Review of early warning systems in the NHS Acute and Community services, DH National Quality Board 2010
https://www.england.nhs.uk/?s=archived+reports

[9] Quality in the new health system, DH National Quality Board 2013
https://www.england.nhs.uk/?s=archived+reports

5.1.7 The learning and draft recommendations were shared with the Sandwell Learning Disability Advisory Group, which is made up of professionals with expertise in learning disability. Having time to reflect the learning and discuss the draft recommendations with this group gave the opportunity to have 'fresh eyes' consider the learning which enhanced the appreciative inquiry approach, leading to more focused recommendations for embedded improvement.

5.1.8 The findings, analysis and learning are detailed under these 4 key headings.

5.2 Putting People First

5.2.1 Jeff is described as a 'larger than life character' who was a bit of a joker and liked to get to know people before trusting them. Jeff had a stable and familiar home environment which had been his childhood home. Jeff shared his home with his brother and his sister, seeing other family members regularly along with some family friends. Jeff's sister had taken over caring responsibilities for Jeff when his parents passed away. Jeff had built up strong trusting relationships with Day Service staff, some of whom he had known for over 25 years. 'Like many of us Jeff could be stubborn, he'd only make you a cup of tea if he knew you'.

5.2.2 Up until the restrictions of the full lockdown imposed in March 2020, travelling to Day Service every day had been a constant in Jeff's life which it is described that he 'loved'.

5.2.3 Jeff enjoyed routine and familiarity both in his experiences and relationships. The impact of the pandemic meant that all of Jeff's usual routine was completely disrupted. Day Service staff liaised with his sister to maintain consistent contact when allowed, for example taking activities to Jeff at home, going to the shop to get a newspaper/magazine for Jeff to look through. This compassionate, person-centred flexible approach by Day Service staff included advocating on behalf of Jeff and his sister when it became clear that Jeff's declining mobility and mood were impacting on his sister's capacity to continue to support Jeff.

5.2.4 Jeff had a number of interests which were important to him. Day Service staff were able to support Jeff to continue to have access to some of these both at home and within the Care Home.

5.2.5 Jeff had multiple chronic health conditions and received care and monitoring of these from both his GP (one partner had known Jeff since he was a young boy) and specialist hospital-based services. In 2019 Jeff was referred to a Consultant Psychiatrist and local Learning Disability Community Team, prior to this Jeff was not known to the service.

5.2.6 Jeff had been supported by Day Service staff to develop a 'This is me' book which described Jeff and things that were important to him, that he liked to do, etc.

5.2.7 It was good to hear that Jeff had a 'This is me' book, however it is not clear if this was used regularly and in particular if Care Home staff had access to this. At the learning event some agency practitioners said there was information shared about Jeff that they weren't aware of and how helpful it would have been to have known.

5.2.8 Jeff didn't have a Person-Centred Plan (PCP) and Health Action Plan that was known about by each agency/professional involved or became involved.

5.2.9 Jeff and his sister were of a similar age and both had chronic long-term health needs, the prospect of one or the other deteriorating and/or becoming ill, necessitating a change in the caring situation, was predictably unpredictable, yet this had not been discussed with or planned for with Jeff and his sister. Indeed. Jeff had not given the opportunity to say if he wanted to continue living at home

with his sister caring for him, would he like other carers, would he like to live elsewhere and what would that look like.

Comments from the learning event and Learning Disability Advisory Group:
'Managing life transitions and planning for these with the person is essential core work as is contingency planning'
'There's an opportunity to start to plan with older people and carers'

5.2.10 If Jeff had had a PCP it would have focused on him and who was important in his life. There would have been discussion and details as part of the plan which included Jeff's preferences in having his care needs met should he or his sister become ill or be unable to meet his care needs.

5.2.11 No such plan was in place so therefore there were no prior discussions leading to clarity about what is important both to Jeff and for him. In putting people first, listening to and hearing Jeff's voice is essential. It is documented that at the Care Assessment prior to admission to the Care Home, Jeff stated that he wanted to stay at home. Best interest processes were followed as Jeff was assessed as lacking capacity to understand the level of his care needs and make a decision about how best to meet these.

Comments from the learning event and Learning Disability Advisory Group:
'It's a massive jump to go from your own home to residential, what was the contingency planning?'
'…makes you question how plans were developed for Jeff, doesn't seem like there was one lead person co-ordinating'

5.2.12 The Review findings do not dispute that Jeff lacked capacity at the point of assessment in July 2020 about his care needs. However, it is not clear what steps were taken to maximise his involvement, for example, what accessible information was used to support Jeff to understand about his care needs and support him moving into a care home.

5.2.13 Also, the potential impact on Jeff of moving away from his childhood home and his family support into an 80-bedded care home, at a time when he was struggling with his mood and wellbeing due to the Day Service being closed and other restrictions due to the pandemic, was not holistically and adequately planned for, identifying and mitigating identified risks.

5.2.14 As described Jeff did not have a PCP. This meant plans for any changing needs were not in place. There was no detail such as his preferred place of care, and actions to support familiarisation/transition had not been planned for.

5.2.15 As part of the care needs assessment, it is clear that both Jeff and his sister were involved, and their voices/views sought. In considering putting people first, the review learning raises the following questions. To what extent was Jeff supported with his understanding of his circumstances? If not able to live at home what would make Jeff feel happy, safe, and stimulated? What actions would help Jeff in transitioning from home into care? How would the pandemic restrictions impact on both Jeff and his family? What can be done to support continued contact? Was a care package with some respite explored? (this issue will be considered later from the perspective of austerity). Care was at the point of breaking down, did this impact on planning and decisions?

5.2.16 Jeff's sister believed it was the right decision to support Jeff to move into care at the time, she bitterly regrets the decision and is 'wracked with guilt'. The Review has found that intervention/assessment came at crisis point and therefore options and information may not have been fully heard or explored particularly as Jeff was responding very badly to the restrictions of the pandemic and his sister said herself that she was 'at the end of her tether' due to sleep deprivation, physical and mental exhaustion and worry.

5.2.17 In terms of Jeff making the transition from his familiar home environment into the Care Home, although it was known that Jeff liked to get to know people before trusting them, no provision was made for Jeff to meet and get to know Care Home staff prior to his admission in August. Notwithstanding the restrictions due to the pandemic, the Review has found that no Person-Centred Planning, bringing those who knew Jeff well together, took place. A care plan and risk assessments were developed for his admission detailing his care needs covering his activities of daily living, but this has been described by practitioners as functional rather than holistic.

5.2.18 It is clear from the Review that the restrictions imposed due to the pandemic impacted greatly on Jeff, with changes to his mood and demeanour described before his admission to the Care Home. There was a missed opportunity to convene a Multi-Disciplinary Team (MDT) meeting with and for Jeff to consider his deteriorating health, both physical and mental, and develop a Person-Centred Plan which acknowledged and described actions to reduce any known risks.

5.2.19 All agencies/practitioners undertook their individual responsibilities and actions following intervention with Jeff and his sister, with some onward referrals happening to address additional identified needs e.g. mobility issues resulting in falls. However, the learning review has highlighted the lack of holistic person-centred working and co-ordination to connect deterioration in physical health, increased attendance or contacts with GP and hospital or mental health/emotional wellbeing to facilitate a holistic plan. Actions were carried out in 'silo', not considering Jeff and the whole of his needs, being curious and making connections to other services/ disciplines.

Comments from the learning event and Learning Disability Advisory Group: *'Would the options have been the same, would Jeff have been treated differently if he was younger?'* *'Where was the dynamic, progressive planning?'*

5.2.20 Having a defined co-ordinated plan which all agencies were sighted on and took ownership for would have reduced the 'silo' working which led to task focused actions as opposed to holistic person-centred working. For example, increased calls with/to the GP, contact to Adult Social Care by Jeff's sister and Day Services, observed and documented deterioration in mobility by the Learning Disability Clinic. Any of these agencies could have triggered an MDT.

5.2.21 Jeff experienced an increased number of falls resulting in attendance and admission to hospital. He had hospital and community assessments from the Falls and Frailty Team resulting in provision of equipment to support mobility at home. A package of care was put in place to support with personal care needs. This is a change in need which was known and addressed. However, the learning event has identified a missed opportunity to come together with Jeff to understand how these changes, along with lockdown restrictions and deterioration with his other health needs, were impacting on his emotional and social wellbeing and proactively plan

with Jeff to maximise his wellbeing and reduce the risks to Jeff of his holistic wellbeing and also the impact of increased care needs on his sister as main carer.

5.2.22 Following admission to the Care Home, Jeff very quickly became non-compliant with his care, refusing personal care, not sleeping and refusing to get into bed (Jeff had started to sleep in a chair whilst still at home, possibly due to repeated falls upstairs), putting himself to the floor, not eating or eating little, declining interaction and wanting to remain in his room. His physical health was impacted with weight loss of 15kg in 2 months and repeated infections. Care Home staff liaised with his sister to refine Jeff's support to meet his needs, contacted health and social care professionals and identified that the Home/service was not best able to meet his needs.

Comments from the learning event and Learning Disability Advisory Group:
'He'd had the same familiar support all of his life, must have been a shock to go into a large home with unfamiliar people…Jeff seemed to object to the arrangements he found he was in any way he could, not eating, sleeping, refusing care…'

1.2.1 The Review found there was insufficient consideration of risks to Jeff from self-neglect. Duty of care relating to these risks had not been sufficiently weighed in respecting his self-determined choices. Jeff's non-compliance was impacting on his skin integrity, with documentation showing that he had a number of prescriptions for skin infections and rashes, losing weight.

1.2.2 A PCP describing Jeff; what is important to and for him; what he likes to do; his usual persona, etc. may have stimulated professional curiosity to consider 'why, what's happening for this gentleman?'

1.2.3 At the learning event, practitioners questioned if Jeff was bereft due to the loss of his relationships, the familiarity of his own space and routine.

Care Home staff comment from the learning:
'We feel he missed his brother and his daily surroundings and mourned their loss, and it seemed the only way he could express his disapproval was by being reclusive and withdrawing from all interactions and interventions.'

1.2.4 Day Service staff including Jeff's keyworker stayed in regular contact with Jeff and his sister throughout lockdown and his admission into a Care Home.

1.2.5 Whilst in the Care Home, Jeff's sister made daily telephone calls to the Care Home and offered advice and guidance to staff. There were only 3 video calls and one 'window' visit facilitated with Jeff's sister.

1.2.6 Regular consultations were made with the GP, one of which resulted in a referral for District Nursing intervention to dress Jeff's legs and take blood for investigations. Due to the pandemic restrictions all of the GP consultations were undertaken over the phone and although Jeff was on the Quality Outcomes Framework (QOF) register as having a learning disability and requiring an annual Learning Disability Annual Health Check[10] these were not offered in 2020 due to

[10] Annual health checks - Clinical evidence shows that Annual Health Checks **can identify undetected health conditions early**, ensure the appropriateness of ongoing treatments and promote health, for example through screening and immunisation. https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/

the pandemic. Although NHS England website advises 'In order to reduce the risk of increased unnecessary deaths in people with a learning disability during the coronavirus outbreak it is essential that annual health checks continue to be carried out'.

1.2.7 Despite the regular contact with the GP, the learning has identified a lack of evidence about escalation of concerns and wider communication.

1.2.8 Reflective learning has highlighted that an alert on the GP system highlighting that Jeff has a Learning Disability and increased risk of health needs may have triggered a review of increased number of contacts and consideration of the nature of the individual consults as a collective/holistically.

5.3 Staff and Culture

5.3.1 The importance of relationships, family, friends, having a feeling of belonging as well as feeling valued and respected is well documented. In Maslow's Hierarchy of Needs, the correlation between having all of our needs met, which includes our social and emotional needs, and the impact on motivation, is explored. [11]

5.3.2 The relationship that Jeff had with the Day Service staff was well established and based on trust. Jeff's keyworker stayed in regular contact with both Jeff and his sister throughout the pandemic and Jeff's admission to the Care Home. They responded flexibly to the situation that was imposed due to the national lockdown. The Review has found evidence of caring and compassionate staff, with some staff going above and beyond their contracted responsibilities.

5.3.3 Maintaining Jeff's relationship with his sister and brother was recognised as essential but the restrictions imposed due to the pandemic meant that Jeff wasn't able to see them on a daily basis as he did every day of his life before his admission into residential care. Jeff used limited vocabulary and could be difficult to understand, therefore this impacted on how he was able to express how he was feeling.

5.3.4 The building of relationships particularly to support a person with their most intimate needs takes time to establish. Jeff was known to struggle with relationships until he knew and trusted people. As Jeff's admission to the Care Home happened firstly at crisis point, i.e. there was no contingency plan which may have supported Jeff to become familiar with staff or understand what moving from his home might feel like and, secondly, during a national pandemic, there was no flexibility built in to give both Jeff and staff time to understand each other and build a relationship.

5.3.5 The Review has found that prior to admission to the Care Home, Jeff's needs were assessed, and his activities of daily living were part of the assessment and plan as were his health needs and medical history. There is provision within the care planning which allows for a settling in period, recognising that the transition into a care home setting can be unsettling for some individuals and impact on their presentation.

[11] 'Maslow's Hierarchy of Needs is used to study how humans intrinsically partake in behavioural motivation. Maslow used the terms "physiological", "safety", "belonging and love", "social needs" or "esteem", and "self-actualization" to describe the pattern through which human motivations generally move'. https://en.wikipedia.org/wiki/Maslow%27s_hierarchy_of_needs Accessed November 2021

5.3.6 Jeff's sister was contacted and his community key worker to assist with planning to meet his needs. There was evidence of person-centred working, with personal items such as a jukebox and fish tank been taken into the home.

5.3.7 The Review has also highlighted the impact that the pandemic had on both ways of working and staff behaviour. National 'rules' were enforced which we all had to follow. Nationally there was pressure put on central government to consider the impact of restrictions on people with a learning disability and/or autism which led to changes to rules about exercise and key relationships,

5.3.8 At the learning event and focus group with the Learning Disability Advisory Group, staff explored the missed opportunity to work more closely together to ensure person-centred approaches to better understand Jeff, his needs, wishes, what was important to and for him to enable proactive planning both for life transitions and contingency.

5.3.9 The Review found that the pressures of the restrictions and changes to ways of working which saw different priorities agreed and staffing shortages impacted on creative and flexible thinking at the time of Jeff's increased needs and crisis and led to a less person-centred and increased task focused approach.

5.3.10 In addition, the Review has also raised the question about staff awareness and understanding of learning disability, not just within the care home but all staff and disciplines. Did staff know about accessible information, reasonable adjustments?

5.3.11 Jeff's actions of not engaging with staff or other residents, not wanting to be in his room or leave his chair, refusing personal care and not eating can be viewed as self-neglect. Although the GP was contacted and both Jeff's sister and keyworker, the significant weight loss and condition of Jeff's skin evidence a lack of awareness of deterioration and failure to escalate concerns.

5.3.12 The Care Home is registered with CQC to provide both nursing and residential memory care for people living with dementia. Jeff had not been diagnosed with dementia. As a specialist provision for people living with dementia, the staff had additional skills and training relating to dementia care, however their understanding of learning disability and how best to support was limited.

5.3.13 The issue of awareness and understanding about learning disability, diagnostic overshadowing[12] and how best to support Jeff, along with noticing changes, connecting, questioning and communicating with others including triggering a multidisciplinary review, has been identified as a current gap.

5.3.14 This Review found a lack of further questions about Jeff's holistic presentation. There was limited consideration of his symptoms being related to or impacting on his emotional and psychological wellbeing. This was not queried and nor were the different presenting issues connected.

5.3.15 There was a lack of 'professional curiosity' in terms of seeking to ask 'why' and 'what' both prior to admission to and during his admission in the Care Home. Being curious about why Jeff didn't want to engage, have his personal care needs met, was not eating and sleeping. Jeff had dementia screening in 2019 following noticeable changes to his mood, mobility and memory. Although the outcome indicated no significant changes to Jeff's cognition, depression was queried but no intervention commenced.

[12] **Diagnostic overshadowing** occurs when a healthcare professional assumes that a patient's complaint is due to their disability or coexisting mental health condition rather than fully exploring the cause of the patient's symptoms. Often, once a patient has a confirmed diagnosis, there is a tendency to attribute all new behaviours or symptoms to the original diagnosis.
https://en.wikipedia.org/wiki/Diagnostic_overshadowing accessed November 2021

5.3.16 Jeff would 'sit on the toilet all day if allowed, no diarrhoea and just one daily bowel movement, he has lost 15kg in weight since admission 2 months ago'. This discussion took place with the GP with a referral being made to the District Nurses to take blood, following a medical route regarding the weight loss. Physical causation for changes in a person's presentation should always be explored but not in isolation. With hindsight, Jeff was potentially demonstrating his unhappiness, possible confusion and feelings of loss through his actions and things in his control.

5.3.17 The Review found no reference to questions being raised about why Jeff was choosing to stay in the toilet. Why doesn't he want his food? Why is he not sleeping? Why has he lost so much weight? All of these issues were raised with the GP and actions/interventions prescribed and Jeff's sister's and community key worker's advice sought. However, there was no evidence of joined up working, staff being curious and then asking for a multidisciplinary meeting including those who knew Jeff well.

5.3.18 A key question was raised about cultural attitude in terms of Jeff's age and the fact that he had a learning disability. Would decision making and options to support his care needs have been different if he was younger, didn't have a learning disability?

5.3.19 The pandemic ways of working appear to have increased silo working for some staff across all services. Increased difficulty in getting hold of colleagues, contact only via phone or video and increased pressure of workload due to deployment of staff to focus on the pandemic and prioritise work deemed essential affected staff opportunity to reflect and communicate with other colleagues.

5.3.20 Making Safeguarding Personal (MSP) requires staff to put the person at the centre, build a relationship, empower the individual and ensure proportionate responses. MSP also requires balancing duty of care to keep a person safe. Part of this duty is assessing risk with and for a person. The Review has found that identifying deterioration in health and wellbeing, carrying out risk assessment and escalating concerns could have been improved.

5.3.21 Recognising the deteriorating patient, the importance of a Person-Centred Plan, undertaking positive risk assessment, knowing when, how and to whom to escalate are essential skills and awareness for staff to support MSP for each individual. The Review has found that these are areas for improvement.

5.4 Systems and Processes

5.4.1 As described under 'Putting People First', Jeff was 75 years of age with a learning disability and multiple chronic conditions and co-morbidities, yet there was no Person-Centred Plan in place which included contingency and life transition including end of life planning.

5.4.2 There is currently no process in place which requires staff to check if a PCP and/or Hospital passport is in place.

5.4.3 The effect of no plan was urgent crisis assessment and planning during a national pandemic which put additional strain and restrictions on systems and processes. Whilst a pandemic could not have been predicted, crisis, relapse or contingency planning for other circumstances that could impact on Jeff's life and wellbeing could have been risk assessed and planned for.

5.4.4 From September 2019 Jeff had increased contact with existing health professionals, new contacts with others and an increased number of attendances and admissions to hospital during 2020. Any one of these professionals could have called for a multidisciplinary meeting or made enquiries with Adult Social Care

about person-centred planning. As this is not currently built into the process and system of working, professionals work in isolation.

5.4.5 As identified earlier in this report one of the recommendations in the Learning from every Death Review (LeDeR) annual report 2018 is the continued need for guidance on co-ordination and information sharing. The Government response recommended 'establishment of a named care coordinator for all people with learning disabilities with two or more long-term conditions (related to either physical or mental health)'. Jeff did not have a named care co-ordinator, therefore early communication and review did not happen.

5.4.6 An alert about Jeff having a learning disability and possibly needing reasonable adjustments, such as extra time, easy read information and support from a carer, was not in place on any of the electronic systems of the health services that Jeff had regular contact with, e.g. GP, specialist hospital consultants. Sandwell and West Birmingham Hospitals NHS Trust has a flagging system for people with a learning disability which is triggered on admission. Flags are recorded on a Dashboard which is maintained by the Hospital Learning Disability Liaison Nurse.

5.4.7 The Review found that although this flag on admission is in place, a referral was not received by the Learning Disability Liaison Nurse for any of Jeff's admissions which suggests that the flag was not applied.

5.4.8 An alert or flag on all electronic systems about Jeff's learning disability and multiple health conditions could have triggered communication between professionals as well as spotting increased multiple contacts and/or admissions. This could then have led to facilitation of a multidisciplinary meeting for review.

5.4.9 Discharge planning and pre-discharge meetings included multidisciplinary meetings and meetings with Jeff and his sister as main carer, however the Review learning has identified that there is no evidence that multidisciplinary pre-discharge discussions and planning extended to community colleagues.

5.4.10 Jeff was referred to the Sandwell Integrated Care Services (iCares), a community-based service which has 'an approach to managing adults with long-term conditions irrespective of their diagnosis, location or age. It includes a whole range of staff including nurses and therapists providing specialist community interventions which will avoid unnecessary admissions to hospital, help maintain health and wellbeing through care management, improve independence and function with community rehabilitation'.

5.4.11 Jeff had a virtual assessment which is normal practice for the service. The Review learning has identified that if this assessment had of been face to face it is possible that admission into 24-hour care 13 days following virtual assessment may have been different, triggering an urgent admission avoidance visit by an advanced practitioner with the ability to assess, diagnose and treat a range of medical presentations.

5.4.12 Concerns regarding Jeff may have been shared with the urgent response therapy team in iCares. This team have access to emergency step-up beds, packages of care and equipment to keep people safe at home.

5.4.13 At the learning event, staff described the 'follow up team' which provided support to an individual and family for the first 6 weeks following discharge. This service is no longer in place and staff believed this is due to cost saving. The anecdotal benefits of this service, along with the suggested change to routine assessment by iCares from virtual to face to face for individuals with a learning disability with one or more health conditions, needs further exploration.

5.4.14 Jeff was admitted to a Care Home specialising in the care and support of people with dementia and, whilst staff will have some awareness of learning disability, the

review raises the question re: the appropriateness of the placement as Jeff did not have a diagnosis of dementia.

5.4.15 An important finding identified in the referral, made by the LeDeR reviewer, to the SAB SAR panel is that Jeff had been placed in the Care Home under state detention i.e. following assessment of his capacity Jeff was found to lack capacity and therefore a process of best interests was followed. Jeff was detained using Deprivation of Liberty Safeguards as part of the Mental Capacity Act. As an incapacitated adult, Jeff was required to have a 'Relevant Persons Representative (RPR)[13] 'whose role it is to protect the person's interests and maintain contact throughout the process'. Must be identified Recognising that a person who lacks mental capacity to make some decisions for themselves about treatment and care and has been detained under DoLs may be at risk if that treatment or care is not provided'.

5.4.16 Records confirm that a discussion was held with Jeff's sister about the RPR role, however Jeff's sister does not recognise or recall the term RPR and an explanation of the duties of this role being discussed, she also has no written information about this role.

5.4.17 It is noted by the review that undertaking the duties of the RPR in overseeing care and treatment in line with DoLs was particularly challenging due to the restrictions in place due to the pandemic.

5.4.18 Jeff appeared to be very clearly indicating that he did not want to be living in the Care Home, due to the pandemic contact with his sister and brother was limited to daily phone and just small number of video/window visits following which his sister contacted Social Care to raise concerns.

5.4.19 Jeff was discharged from hospital on 16th August 2020 with a prescription for antibiotics to treat cellulitis and had further prescriptions for antibiotics due to skin infections. The Review has found that follow-up post discharge from hospital and face to face appointments with the GP may have facilitated early/timely review and consideration of Jeff's presentation and interventions.

5.4.20 Escalation – recognising the deteriorating patient. The review heard that as a result of the learning from Jeff's experience the Care Home has, in the last 8 months, introduced the National Early Warning Score[14] which is a nationally developed tool which supports recognition of the deteriorating patient. The Situation Background Assessment and Recommendation (SBAR)[15] escalation and communication tool has also been introduced.

5.4.21 As part of NHS England plan for people with a learning disability and/or autism; Transforming Care'[16]; Building the Right Support, 'all Clinical Commissioning

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[13] Relevant Persons Representative (RPR) It is the role of the RPR to make sure that any conditions of the DoLs are being met and to inform the person of their rights and how to exercise those rights, the role can be undertaken by a family member or friend.

[14] NEWS is a tool developed by the Royal College of Physicians which improves the detection and response to clinical deterioration in adult patients and is a key element of patient safety and improving patient outcomes. https://www.england.nhs.uk/ourwork/clinical-policy/sepsis/nationalearlywarningscore/ Accessed November 2021

[15] 'SBAR can be used very effectively to escalate a clinical problem that requires immediate attention, or to facilitate efficient handover', NHS Institute for Innovation and Improvement 2010 https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/SBAR-Implementation-and-Training-Guide.pdf Accessed November 2021

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[16] **Transforming care** is all about **improving health and care services** so that more people with a learning disability and/or autistic people can live in the community, with the right support, and close to

Groups (CCGs) are required to develop and maintain registers to identify people with a learning disability, autism or both who display, or are at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of admission'. Some areas such as Cheshire and Wirral[17] have extended the register to include those with a learning disability and more than one physical health condition which puts them at risk of admission.

5.4.22 The above is an example of a reasonable adjustment to national policy which ensures a local system to co-ordinate care for an individual like Jeff who has a learning disability and more than one long-term health condition. Having this system in place in Sandwell could be part of an agreed system approach which would secure care co-ordination and encourage more joined up working, reducing silo working to benefit individuals and families.

5.4.23 As referenced, Jeff had an 'All about me' book which details information about Jeff and his likes and dislikes. The Review has found that a more specialised document for people with a learning disability was in the process of development. Progress of this development and the process to embed use of the book across all agencies needs to be reviewed.

5.5 Partnerships

5.5.1 The Review found that there was inconsistent partnership working, with systems not working in a smooth and seamless way. Practitioners recognised that discharge planning could have been better if community colleagues had been involved, if a multiagency plan was in place, if contingency and life transition planning had been in place.

5.5.2 Improved partnership working supported by clear systems and processes could empower all staff from different agencies to think 'holistically' and trigger contingency planning and life transition planning to happen even if it is not within their job role to undertake this.

5.5.3 Seeing and supporting the whole person, thinking about an individual's physical, intellectual, emotional, and social (PIES) needs should be every staff member's and agency's business. Being aware and having the principles of making safeguarding personal at the forefront of thinking would support more person-centred, joined up working. To empower people and families.

5.5.4 This Review has found that the pandemic has had significant impact on ways of working and individual experiences for Jeff and his family and also for staff. At the learning event some improved ways of working were described. For example, using the GP register to identify vulnerable isolated patients which included people with a learning disability and making telephone contact on a weekly basis.

5.5.5 Some actions have already been taken as a result of learning from both Jeff's experience and 'Anne' SAR. For example, the Care Home introduced the National Early Warning Score and SBAR as well as introducing a process to ensure residents can have a named visitor; GP having a 'vulnerable patients' list with weekly contact during COVID-19. These and other actions and good practice

home. This means that fewer people will need to go into hospital for their care NHS England and Improvement. https://www.england.nhs.uk/learning-disabilities/natplan/ Accessed November 2021

[17] Dynamic registers and dynamic systems https://www.england.nhs.uk/learning-disabilities/dynamic-registers-and-dynamic-systems Accessed November 2021

identified from the learning from COVID-19 need to be rolled out across all relevant partner agencies in Sandwell.

6. Conclusions

This review has provided the opportunity to collectively hold the mirror up to reflect and review and identify learning. This includes some gaps or missed opportunities along with areas of good practice, from Jeff and his family's experience and circumstances. The findings identify a missed opportunity to plan with Jeff and those who knew him well for predictable life transitions and challenges. This missed opportunity meant that there was no contingency plan in place to support Jeff to remain at home and/or have a good transition into 24-hour care when his needs changed and his sister as main carer were in crisis. Jeff was 75 years of age with multiple chronic health conditions and his sister, who was his main carer, was a similar age with her own health needs. Better joined up working and person-centred approaches would have ensured proactive planning which detailed both proactive and reactive interventions built on and incorporating what was important to and important for Jeff.

The restrictions imposed due to the pandemic undoubtedly had a great impact on Jeff as he saw his whole life routine altered. Not being able to get out to the Day Service, which he loved or go for meals and play ten pin bowling impacted on his mood and wellbeing. This, along with physical and physiological changes, saw Jeff become more reliant on his sister for care and support for his personal needs. Jeff started to not sleep whilst still living at home, with the result that his sister was completely exhausted. Reaching out for help was a difficult thing for Jeff's sister to do and the outcome of assessment resulting in Jeffs admission to 24-hour care from which he didn't return home has understandably impacted greatly on his sister. The opportunity to embed the principles of making safeguarding personal to better plan together with people and families is a key finding from this Review.

The pandemic also greatly affected staff and ways of working, with sustained and ever-increasing pressures both professional and personal. This Review has found some good practice resulting from changes during and as a result of the pandemic which need to be rolled out widely. No one could have predicted the pandemic but emergencies and changes for individuals, families and services will always happen and should be considered as part of person-centred planning. Having the opportunity to reflect together with partners is a healthy way to continually improve experiences and outcomes. The Review found some areas of good practice with individual staff and agencies going above and beyond expectations and their duty to support Jeff and maintain relationships.

Whilst risk assessment and timely escalation would not necessarily have changed the outcome for Jeff, his experience and that of his sister could have been better, more valuing, respectful and dignified. Better joined up working with a clear plan in place could also have facilitated a more person-centred staff approach and holistic thinking.

Jeff lived with a number of complex physical health needs, and his mood and mobility had started to change during 2019, then the pandemic hit in March 2020 and the restrictions impacted on Jeff greatly. There was no named care co-ordinator identified for Jeff and

therefore there was no clear plan in place which was known and understood by all who knew Jeff and no multidisciplinary meeting facilitated which could have seen contingency planning put in place early in Jeff's experience.

Finally, there was a lack of 'professional curiosity' following Jeff's admission to the Care Home which saw his non-compliance, refusal of personal care, refusing food, not sleeping and multiple infections being addressed reactively as they arose and not questioned in relation to holistic, emotional wellbeing. Failing to be curious, asking why, or what or how, impacted on the quality of care Jeff experienced in the last few months of his life and therefore on his quality of life. Knowledge, skills and awareness about learning disability, physical health conditions and recognising the deteriorating patient have also been identified as contributing factors to Jeff's poor experience in the last 2 months of his life. This lack of curiosity, person-centred thinking and planning along with the restrictions imposed by the pandemic resulted in a very poor experience for Jeff in his last few months of life.

This review has identified a small number of recommendations, some of which are reflected in other SARs; 'James - Hertfordshire SAB' and 'Anne - Sandwell SAB'. Essentially the learning is not new and the onus is on the partners and Safeguarding Adults Board to work together to embed real change.

7 Recommendations

The Safeguarding Adults Board should seek urgent assurance that Jeff's brother does now have a Person-Centred Plan in place which includes contingency and end of life preferences/planning

1. **Formal assessment and review processes for Person-Centred Planning (PCP), life transition and contingency planning: Adult Social Care should take the lead on working in partnership with other relevant stakeholders to:**
    - Review processes and procedures to ensure that assessments under the Care Act 2014 are person-centred and completed using Independent Advocates where appropriate and that these are reviewed at least annually
    - Provide assurance that all assessments are holistic and involve health and other partner agencies and those who know the person well
    - Review and seek assurance of implementation of life transition and contingency planning that details what is 'important to and important for' a person with a learning disability
    - Incorporate clear and explicit processes for End-of-Life decisions/planning and positive risk assessment and planning
    - Review the process for Person-Centred Planning (PCP) which should be aspirational for the individual, development of a PCP which is followed by the MDT
    - Provide assurance that all care and support is reviewed at least annually and always following a change in need
    - Ensure that the process allows for a carer or any partner agency to request/ trigger a review

    **It has been suggested that life transition planning is initially rolled out for older carers who will be caring for older adults with learning disability and therefore at higher risk of ill health and needs change. The current Sandwell older carers data set to be used*

2. **Joint working across health and social care to agree the detail expected to be recorded within 'alerts or flags' on all electronic systems**
    - Clarity of understanding of 'alerts or flags' on systems for additional needs/reasonable adjustments
    - Consider functionality which highlights increased contacts to any service and allows for information sharing for any adult who may be deemed at risk.
    - Review policy/policies for information sharing to ensure that there is sufficient detail to instruct and empower all frontline staff of circumstances to and method for information sharing for an adult who may be deemed to be at risk
    - The review should include 'permissions' within electronic systems and protocols to enable information sharing between different electronic systems

3. **Recognition of carers needs and carers voice**
    - SAB policy and procedures subgroup to seek assurance of application of the policy for carers' assessments

- Adult Social Care and the CCG to seek assurance as part of safeguarding assurance process that all providers proactively offer and/or refer carers for assessments and include carers needs as part of review assessments
- Utilise the Sandwell older carers as a sounding board to test out how the process for carers needs and voice currently works and what could improve this, linking findings to recommendation 1

4. **Joint working across health and social care to develop a process for care co-ordination and communication for any adult at risk with two or more long-term conditions (related to either physical or mental health). This should include a Dynamic Risk Register. The process should ensure that:**

- All involved are clear about their own and others' roles and responsibilities
- There are clear and explicit communication mechanisms
- All involved are clear of what circumstances should trigger calling a Multi-Disciplinary Team (MDT) and their accountability for this
- There are clear and explicit escalation processes including to and with whom
- Expectations and actions relating to Admission and Discharge to in-patient and residential facilities are clearly defined
- The locally held Dynamic Risk Register is reviewed and protocol agreed to include adults with two or more long term conditions who are at risk of admission
- Include a check within the process that requires professionals at each patient contact to check if life transition and contingency plans are in place/have been or require review

5. **Conduct a scoping exercise of Easy Read information available relating to life transitions, end of life and decision making across health and social care:**
    - The Learning Disability Advisory Group to lead a piece of work with all partners including people with a learning disability and family carers, to scope easy read information currently available relating to all life transitions, end of life planning and contingency planning for adults with a learning disability
    - Make sure there is easy-to-read information available to help people make decisions about their care and support and that staff know about their responsibilities when a person is making decisions
    - Review information currently available for relatives about 'Relevant Persons Representation' (RPR) initiated for an adult who lacks capacity and detained under DoLS legislation
    - Work with people with a learning disability and families to review what is available, identify any gaps and develop an agreed approach to having 'difficult' conversations.

6. **Carry out a service review to look at redesign of Adult Social Care provision which follows the life span - all age disability team:**
    - Review current service structure to ensure that the right people with the right skills and expertise relating to learning disability and other disabilities are capitalised on across the life span

- Develop protocols which support and empower staff to follow the principles of 'Making Safeguarding Personal'
- Use 'Working Together', The Care Act' and learning from this and other SARs to clarify expectations of practitioners relating to 'Making Safeguarding Personal', PCP, life transition and contingency planning
- Review current understanding of and working practice relating to process for 'Best Interest' decision making under the Mental Capacity Act and Deprivation of Liberty Safeguards - link this action to recommendation 1, 3 and 4 to agree mechanism to embed consistent approach to empowering decision making and the RPR role.

7. **SAB to seek assurance from each relevant agency that good practice and learning actions have been embedded into practice:**
    - Bring staff together to talk about working practice and cultural changes to embed 'Making Safeguarding Personal', promote independence, rights, choice and control and making reasonable adjustments
    - Seek assurance that recommendations and learning from both Jeff's experience and 'Anne' SAR have been implemented across Sandwell.
    - Clinical Commissioning Group to work with GP membership and Local Medical Council to review approaches to 'alerts' and 'flags' on electronic systems about learning disability in line with recommendation 2 and consider how the good practice identified in 'Anne' SAR of contacting patients on the vulnerable patients' list on a weekly basis during COVID-19 can be continued and incorporated into all practices
    - Seek assurance that learning from the section 42 enquiry and this Review have been implemented by the Care Home
    - Seek assurance that actions implemented at the Care Home relating to NEWS, SBAR and protocols for named visitors have been rolled out across all independent providers
    - Review arrangements for supervision to facilitate the opportunity for health and social care staff to review actions and consider implications of individual needs on system working and communication

As part of the Review the author had the opportunity to have a focus group with the Sandwell Learning Disability Advisory Group to discuss the Review findings and draft recommendations. This opportunity to have 'fresh eyes' use their expertise to further scrutinise the learning and recommendations was incredibly helpful. If the opportunity to liaise with 'subject matter experts' is not routinely utilised the Independent Author would strongly recommend that the SAB consider incorporating engagement with subject matter experts routinely as part of SARs.

About the Independent Author

Independent author

Judi Thorley was commissioned to undertake this Review and act as Independent Author. Judi is both a Registered Learning Disability and Registered General Adult Nurse with over 35 years' experience working within the NHS. Judi has worked in a range of services in leadership and clinician roles within Learning Disability, Acute Services, Education and Commissioning. Judi's previous roles include Strategic Regional Lead for learning disability health and safeguarding adults and from 2013 until 2018 Chief Nurse and Director of Quality and Safeguarding within 2 Clinical Commissioning Groups.

Since 2018 Judi has continued in a part-time role within the NHS and has carried out a range of independent consultancy work encompassing service reviews in community and hospital services, review of arrangements for adult safeguarding, SARs and development and delivery of leadership development programmes.