West Sussex
Safeguarding Adults
Board
Making Safeguarding Personal

West Sussex Safeguarding Adults Board

Safeguarding Adults Review in relation to Clare

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1. Foreword

1.1. The West Sussex Safeguarding Adults Board (referred to as SAB, or the Board) has published this Safeguarding Adults Review (referred to as SAR, or Review) in relation to Clare.

1.2. The Board and the Independent Reviewer wish Clare all the best in her continued recovery in hospital. Clare was invited to contribute to the Review but was too unwell to do this. Instead, Clare's father supported the SAR process by providing information about Clare as a person, details of her life, and a view on the care and support she was offered.

1.3. Clare was born in Littlehampton and did not have any siblings. Clare's father shared that she was a quiet child, with few friends, and was bullied at school. Clare left school at 16, worked occasional cleaning jobs, and lived in supported housing from around the age of 20.

1.4. At the time of this Review and to date, Clare, who is now aged 43, has been detained in a mental health hospital following a significant decline in her mental health, including auditory hallucinations. Prior to her admission voices were telling her that her leg would break if she moved, resulting in Clare remaining seated on her sofa for a period of at least two weeks. During this time, she had been passing urine and faeces where she was sitting, which led to an infection and maggot infestation.

1.5. Following Clare's admission to hospital, a SAR referral was made to our Board. From the information gathered in a prior Safeguarding Adults Enquiry and a Multi-Agency Rapid Review, it was indicated that agencies involved with Clare could have worked more effectively together. There was also a need to consider multi-agency practice, including the coordination of care and consideration of mental health and mental capacity, in the lead up to Clare's admission to hospital. It was agreed that the criteria for a SAR was met, and Independent Reviewer, Clive Simmons, was appointed to lead this Review.

1.6. The purpose of a SAR is to identify how lessons can be learned, and services improved for those who use them, and for their families and carers. This Review looked at the circumstances prior to Clare's admission to hospital and the actions of agencies. Recommendations made will identify lessons to be learned and contribute to service development and improvement. Although agencies have not waited for the outcome of this SAR to consider their own learning, we will ensure that they are fully engaged in taking forward, together, the Review recommendations.

1.7. The Board will monitor progress on the response to recommendations to reduce risks, and to improve practice and services in West Sussex. The Board will also ensure that learning from this Review is widely shared.

Annie Callanan, Independent Chair

2. Introduction

2.1. The Care Act 2014, Section 44, requires that Safeguarding Adults Boards must arrange a Safeguarding Adults Review when certain criteria are met. These are:

- When an adult has died because of abuse or neglect, or has not died but experienced serious abuse or neglect, whether known or suspected, and;
- There is a concern that partner agencies could have worked more effectively to protect the adult.

2.2. From the information gathered in a Safeguarding Adults Enquiry and a Multi-Agency Rapid Review, both coordinated by West Sussex County Council from August 2022, it is indicated that agencies involved with Clare could have worked more effectively together. There is also a need to consider multi-agency practice, including the coordination of care and consideration of mental health and mental capacity, in the lead up to Clare's admission to hospital.

2.3. The West Sussex Safeguarding Adults Board (SAB), Safeguarding Adults Review (SAR) subgroup recommended on 06/10/22 that the criteria to undertake a Safeguarding Adults Review (SAR) was met in respect of Clare. The subgroup acknowledged that agencies were aware of Clare's increasing needs over a period of months, without the development of a clear, multi-agency plan to assess her needs and risks; contributing to Clare's worsening circumstances before she was admitted to hospital. The SAB Independent Chair endorsed the recommendation to progress to a SAR on 29/03/23.

2.4. SARs are required to reflect the six safeguarding adults' principles, as defined in the Care Act. These are empowerment, prevention, proportionality, protection, partnership and accountability.

2.5. The aims of the SAR are to contribute to the improved safety and wellbeing of adults with care and support needs and, if possible, to provide a comfort to Clare and family, and support to professionals.

2.6. There are clear review objectives which have been addressed to achieve these aims. Through a shared commitment to openness and reflective learning, involved agencies have sought to reach an understanding of the facts (what), an analysis and findings (so what), recommendations to improve services and to reduce the risk of repeat circumstances, and a shared action plan to implement these recommendations (now what).

2.7. The review process to meet these aims and objectives has followed a clear path. The Independent Reviewer has chaired an initial panel meeting to agree the review terms of reference; conducted research by critically analysing information provided by involved agencies and by interviewing representatives; presentation of this overview report to the Safeguarding Adults Board for approval and publication; and culminating in action planning.

2.8. The timeframe for the Review is from February 2022, when Clare first began to express concerns about her mobility, to her admission to hospital in July 2022. Contextual information prior to this period is also considered.

2.9. The Independent Reviewer has spoken briefly with Clare by telephone in the initial stages of the Review. She felt that her health was deteriorating and that 'nothing helps' due to the voices. A visit to Clare has not been completed, in view of her mental health condition, although the purpose of the Review has been explained to her. The Reviewer has visited Clare's father, who has contributed very positively to the review learning. He has expressed a wish, separate to this Review, for a focus on addressing Clare's knee pain.

2.10. The Independent Reviewer has met with the following representatives of relevant agencies, either face to face or online, and acknowledges that all contributed positively to the conduct and outcome of the Review. They comprise both professional leads and frontline practitioners:

- Head of Access & Safeguarding; West Sussex County Council (WSCC)
- General Practitioner; Bersted Green Surgery
- Director of Safeguarding & Principal Social Worker; Sussex Partnership NHS Foundation Trust (SPFT)
- Assistant Director, Safeguarding, Planning & Performance; WSCC Adults & Health
- Service Manager, Access & Safeguarding; WSCC Adults
- Head of Service for Mental Health; WSCC
- Team Manager, Mental Health; WSCC
- Senior Social Work Practitioner; WSCC
- Designated Nurse; NHS Sussex, Integrated Care Board (ICB)
- Safeguarding Nurse; NHS Sussex, Integrated Care Board (ICB)
- Specialist Safeguarding Practitioner; South East Coast Ambulance (SECAmb)
- Named Nurse, Adult Safeguarding; Sussex Community Foundation Trust (SCFT)
- Safeguarding Reviews Detective Sergeant; Sussex Police

2.11. The Review is independent of any other process.

3. Circumstances leading to the Review

3.1. Clare is a 43 year old woman who is currently detained in a mental health hospital, following a significant decline in her mental health, which also negatively impacted on her physical health and wellbeing. Prior to hospital admission, she was resident in a supported living scheme in Bognor.

3.2. Clare has a history of mental health concerns, including auditory hallucinations (voices). From February 2022, she began to express concerns about her mobility, due to long-standing knee pain. She received support from a range of attentive health and social care agencies. Due to voices telling her that her leg

would break if she moved, Clare remained seated on her sofa for a period of at least two weeks in July 2022. She had been passing urine and faeces where she was sitting, leading to an infection and also to maggot infestation from food.

3.3. At the end of July 2022, a Mental Health Act Assessment led to Clare's detention, initially in an acute medical hospital and then in a mental health hospital.

4. Key themes identified for the Review

4.1. As an overriding theme, the Review considers how health and social care agencies can better meet the needs of adults at risk who are self-neglecting due to mental health concerns.

4.2. Examples of attentive, positive practice are also highlighted in the Review report.

4.3. The following specific key themes are identified in the terms of reference and form a thread through the analysis and recommendations within the Review:

- How effective was multi-agency needs and risk assessment, including the coordination of support?
- How effective was the reporting of safeguarding concerns and of threshold decisions?
- How effective was the consideration of mental capacity and active listening to Clare's voice?
- How did resources and environmental factors, such as Covid, impact on care and support?
- How compliant were agencies with legislation, policies, procedures and practice guidance?

5. Pen picture of Clare

5.1. SARs should provide a window into the lived experience of adults at risk.

5.2. Clare was born in Littlehampton and did not have any siblings. From birth, she experienced difficulty with her left foot and knee. In a trampolining accident as a child, her knee was dislocated and Clare believes that it slips out of place from time to time. Her father recalls that she was a quiet child, with few friends, and was bullied at school due to her disability. She left school at the age of 16 and had occasional cleaning jobs, as well as attending a Further Education arts class for a time. Her mother died 12 years ago. More recently, Clare developed a close relationship with a man who it is believed financially abused her, and the Police were involved. Her father feels that the end of the relationship "really did change her" and she lost her sense of optimism. Clare enjoys playing games on her PlayStation and drawing, mainly Anime.

5.3. Clare has lived in supported housing from around the age of 20. On moving to the accommodation she ventured out regularly, but eventually stopped going out altogether due to the voices and her leg pain. Although he has heard about a diagnosis of DiGeorge Syndrome in the year or so prior to hospital admission, Clare's father is not aware that this is a formal diagnosis. Autism and psychotic

episodes were advised as formal diagnoses, although Clare feels that the voices are due to a spiritual possession and not mental illness. Her father states that she was erratic in taking anti-psychotic medication and, although supported by carers, he believes that she had not been taking the medication in the period leading up to hospital admission. He adds that she stopped taking care of herself in the year leading up to hospital admission.

6. Summarised chronology

6.1. Prior to February 2022

6.1.1. It is understood that Clare was born with DiGeorge Syndrome, a genetic condition that causes the under-development of some systems in the body. However, this condition was not diagnosed until very recently. Although her family had concerns about her mental health since her childhood, the first diagnosis was of autism in 2004, which can be associated with the Syndrome. It is also linked to treatment resistant depression, psychosis, and a higher than average risk of infection, mental health concerns and leg pains; all of which have been experienced by Clare. Treatment and care is focussed on symptom management.

6.1.2. The medical records for Clare in 2020 and 2021 reveal that she was experiencing auditory hallucinations, intentional self-harming, psychosis, paranoia and depression. She presented at a Hospital Emergency Department in January 2020, due to experiencing out of body experiences and despair, and she declined Home Treatment Team and crisis resolution support. Clare was detained in hospital under the Mental Health Act from January to May 2020. She was admitted to the Priory Hospital as an informal patient in November 2020, with short-term Sussex Partnership NHS Foundation Trust (SPFT) Crisis Team after-care support and prescribed antipsychotic medication on discharge.

6.1.3. By 2021, Clare was receiving SPFT support through a Community Mental Health Nurse (Lead Practitioner) and a Mental Health Support Worker. She experienced voices compelling her to harm herself and others and did not engage with the Hearing Voices Clinic. Clare did not act on the voices and felt that she had too much to live for; including visits from her father. In March 2021, she attended a Hospital Emergency Department due to the voices and low mood. She requested additional support at home and was discharged with SPFT Crisis Team and Allied Care agency support. Carers assisted Clare with personal care, medication, diet, distraction from the voices and accessing day care (until she stopped attending); visiting for 21 hours per week. In the following few months, she had two informal admissions to Worthing Hospital. On the second of these, she had stopped taking medication for some weeks and was experiencing suicidal thoughts, before resuming medication on discharge. In July and August 2021, Clare presented a couple of times at the GP Practice, due to the voices, and was referred to SPFT for a review of medication.

6.1.4. From August 2021 to January 2022, Clare experienced intermittent low mood and auditory hallucinations, with further hospital admissions. In November 2021, she began expressing that she was experiencing pain in her legs. A GP visited her in December 2021 regarding the leg pains and a

difficulty in rising from her couch, referring her for physiotherapy support. By this time she was contacting the GP Practice approximately once or twice a month regarding her knee and leg pains, as well as the Hospital Emergency Department. The South East Coast Ambulance Service (SECAmb) visited Clare twice in December 2021, due to her hearing voices, and she was conveyed to hospital on one of these occasions, without a record at the GP Practice of receiving a scan or blood tests to diagnose the cause of her knee pain.

6.1.5. Clare rang the NHS 111 line twice in early January 2022, due to suicidal thoughts and weakness in both legs, and was advised to contact SPFT. Later in the same month, she attended the Hospital Emergency Department due to pain in her legs. A letter was forwarded to the GP Practice and there was no record of an x-ray or blood tests. This led to a GP telephone consultation with Clare and an appointment with the First Contact Physiotherapist at Bognor Hospital, which she did not attend. A referral was not made for hospital scans or blood tests related to her knee pain from December 2021 until her hospital admission in late July 2022.

6.1.6. The WSCC Working Age Mental Health Service (WAMHS) rang Clare in January 2022 to discuss healthy eating, as carers were concerned about her weight gain. A multi-agency review meeting was held on 13/01/22, involving Clare, her father, a WAMHS Social Worker, SPFT and Allied Care. This led to a revised support plan, including a referral for Occupational Therapy support and discussion of strategies to manage the voices. Later in the month a taster day at a creative arts studio, arranged by WAMHS, was not attended by Clare due mainly to her mobility.

6.1.7. Clare was visited by SECAmb on three occasions in January 2022, due to hearing voices and to her knee pain. On one of these visits, she felt that her knee was dislocated and she declined hospital admission for an examination, as she did not feel that she could move. On the other two occasions she was conveyed to hospital. It was noted that her weight gain, due to a preference for takeaway food, was also impacting on her mobility. The Ambulance Paramedics rang the GP Practice and West Sussex County Council (WSCC) in late January 2022, regarding their concerns about her circumstances, in particular her knee pain. At this time, they presumed mental capacity specific to hospital admission.

6.2. February 2022

6.2.1. A GP Practice Paramedic Practitioner rang Clare three times and visited her four times in February 2022, all concerning her knee pain. On these visits, she was able to weight bear and to flex and extend her knee. Clare was sleeping on the sofa at night, with her legs lowered, and advice was provided on elevating her legs and on a healthy diet. A further appointment with the First Contact Physiotherapist at Bognor Hospital was scheduled, but she did not attend and was discharged from the service. A referral was made to Sussex Community Foundation Trust (SCFT) Community Nursing and medication prescribed, due to foot cellulitis and continued scaling and flaking of the skin on both lower legs.

6.2.2. SCFT Responsive Services Occupational Therapists visited twice in the month. These visits incorporated advice to Clare on elevating her legs and taking exercise. Equipment was ordered, including a recliner chair to assist with elevating her legs. Clare said that she could not exercise due to her leg pains and a referral was made for Physiotherapy support. The therapists noted a concern that she may not have the capacity to make decisions around declining personal care and advice on elevating her legs, without this leading to a decision-specific Mental Capacity Assessment.

6.2.3. The SPFT Support Worker visited Clare in February and was concerned about a deterioration in her mental health. It seems that her emotional wellbeing improved when these visits occurred. Also, telephone contact was maintained by WAMHS with Clare, Allied Care and SPFT, including monitoring diet and encouraging attendance at the creative arts studio.

6.2.4. Clare declined an offer by agency carers to arrange transport to hospital, as she was not elevating her legs or moving, to receive support with personal care, due to her concern that her knee would dislocate.

6.2.5. SECAmb visited Clare on one occasion in February 2022, when she was unable to stand due to her knee pain, providing a dressing to her knee as a placebo treatment, after which she was able to mobilise freely. Clare's capacity to make decisions about hospital admission was presumed.

6.3. March 2022

6.3.1. A Paramedic Practitioner visited Clare in March 2022, prescribing antibiotics and observing a new pressure ulcer to her thigh. At this point the GP Practice had flagged that Clare was housebound, although she was still moving within her flat. Around the same time, Community Nurses visited twice to dress her leg ulcer and pressure ulcers on her thigh and buttock, with support from carers in encouraging her to stand.

6.3.2. A Safeguarding Adults Concern was raised by Allied Care regarding self-neglect on 07/03/22 and was triaged on 10/03/22. WSCC Adult Social Care responded that the threshold for an enquiry was not met and recommended consideration of Tissue Viability Nurse (TVN) support, a Mental Capacity Assessment and either a referral to the Multi-Agency Risk Management (MARM) Panel or the Complex Case Panel. These referrals were not actioned, aside from a request to the GP Practice for a Mental Capacity Assessment, and the reasons were not recorded.

6.3.3. A Social Worker in the WSCC Working Age Mental Health Service (WAMHS) visited Clare, jointly with the SPFT Support Worker, on 10/03/22. Clare was concerned that her knee would become dislocated. The support plan had been implemented in February 2022 and domiciliary care increased, and this was not adjusted or a risk management meeting considered. On 15/03/22, the WAMHS Social Worker emailed the GP Practice to request a Mental Capacity Assessment, as Clare was not following clinical advice. A GP emailed the Social Worker on 31/03/22 to note that SPFT had formally assessed mental capacity in November 2021 and that she had capacity to make health-related decisions. It was further noted that Paramedics and Community Nurses had been visiting and had

not raised any concerns about her mental capacity. The SPFT Support Worker visited on two other occasions during the month, including when Clare's father was present. Clare engaged well and said that she wished to attend the Hearing Voices Clinic.

6.3.4. An SPFT Community Mental Health Nurse (Lead Practitioner) spoke to Clare on the phone towards the end of the month about her suicidal thoughts and referred her for a medication review, joint with a Psychiatrist. Clare expressed that she had been experiencing suicidal thoughts but reiterated that she had too much to live for.

6.3.5. SECAmb visited Clare on one occasion in March 2022, due to her experiencing suicidal thoughts. She remained at home, with advice to talk about her mental health with those supporting her. Clare was presumed to have the capacity to make the decision about remaining at home.

6.4. April 2022

6.4.1. The Proactive Care Team (an administrative team which liaises and makes onward referrals to other health professions) became involved on the basis of two Multi-Disciplinary Team (MDT) meetings in April 2022. These meetings are held monthly at the GP Practice and are attended by the Primary Care Team and other relevant agencies, including occasionally by Social Workers. They continued during the Covid pandemic. It was noted in the initial meeting that Community Nurses were visiting for healing leg ulcer care and that the sacral pressure ulcer had healed. Arising from this meeting, the Proactive Care Team Administrator referred to the Working Age Mental Health Service (WAMHS) for increased domestic support and equipment. At the second meeting, variable compliance with Community Nursing advice was noted, that Clare was not going to bed at night and was not elevating her legs as advised. Some days she was declining assessment and care, but usually the tasks were achieved on the following visit. An increase in personal care support via WAMHS was also awaited. She was no longer assigned to the WSCC Working Age Mental Health Social Worker from this month, although remaining open to the team for review. Proactive Care involvement was pended for a review to be held in three months on 22/07/22, which did not take place as all SCFT teams had discharged Clare by that time; Community Nursing, Responsive Services and Proactive Care.

6.4.2. The SPFT Support Worker visited Clare on three occasions in the month. Clare was finding the voices distressing and was continuing to experience suicidal thoughts but continued to feel that she had too much to live for.

6.4.3. Community Nurses requested GP Practice consideration of a Mental Capacity Assessment, as Clare was not compliant with advice about sleeping in her bed at night and elevating her legs. They were advised to contact the Bedale Centre, where she was assessed later in the month to have capacity to make these decisions. Clare was described as sad, hearing voices, and having occasional thoughts of harming herself, but without a plan or intention to act on these messages. She was not considered to be presenting any new risks and was taking the highest recommended dose of Olanzapine antipsychotic medication.

6.4.4. SECAmb visited Clare on two occasions in April 2022, including when she was hearing voices that were telling her to fall from her balcony and die, but she was still not presenting with suicidal ideation or a plan. Clare said that the voices had been part of her daily life for over two years and that she did not wish to consider hospital admission. She remained at home with worsening care advice and was prompted to ring the Bedale Centre. Her capacity to make the decision about declining hospital admission was presumed.

6.5. May 2022

6.5.1. Agency carers removed a kitchen knife from beside Clare, at a time that she was experiencing suicidal thoughts. They re-referred her to the WSCC Working Age Mental Health Service (WAMHS), due to mental and physical health concerns, including that she was hearing voices and was not standing. A further safeguarding concern regarding a medication error was raised by Allied Care with WSCC on 20/05/22, which was considered to be a non-reportable incident and did not meet the threshold for a safeguarding enquiry. In response, the care management review date was brought forward. A WAMHS Social Worker visited Clare on 26/05/22 and followed up contact with the GP Practice regarding Physiotherapy support and with SPFT regarding the Hearing Voices Clinic. Clare felt that she wished to attend, but could not due to her painful knee. This was followed up by an SPFT Support Worker visit on the following day. Towards the end of the month, carers observed Clare screaming because she felt that the voices were possessing and controlling her and, following sensitive support, she became calm. The carers rang the Bedale Centre to relay this information and Clare's Consultant was updated.

6.5.2. The carers supported Clare in maintaining contact with the Bedale Centre, and she was advised to find distractions from the voices. The Support Worker visited her five times during the month and observed that she had been picking at scabs on her legs to relieve itching. Clare said that she enjoyed visits from her father, but that "the voices take her happiness away." She contacted the Mental Health Team at the Bedale Centre on 16/05/22 and left a message that she thought she needed a nursing home placement. There is no record that this was discussed with her when the Support Worker visited four days later. In late May, SPFT recorded diagnoses as Pervasive Development Disorder (part of the Autism Spectrum), Chronic Fatigue, and Emotionally Unstable Personality Disorder.

6.5.3. A GP Practice Paramedic Practitioner contacted Clare on five occasions in the month, all regarding her knee pain. It was noted that she now had a recliner chair, was seen regularly by Community Nurses, and was also seen by Proactive Care regarding her legs and social issues. Clare received a GP phone call late in the month, and said that her knee was painful and swollen, that she was unable to walk, and that Ibugel was not effective in relieving the pain. Ibuprofen was prescribed and a review was planned for ten days ahead, should her symptoms continue; this did not lead to a medication review.

6.5.4. There was one visit by SECAmb in May 2022, relating to Clare hearing voices and her knee pain. SECAmb wrote to the GP Practice at the end of the month to update that Clare was hearing voices, had an 'anxious knee injury', and that she was treated at home.

6.6. June 2022

6.6.1. A Community Nursing review was held in early June 2022 and, as Clare's wounds had healed and there was no sign of infection, self-care advice was provided to her and the carers. She was discharged from the service.

6.6.2. A further Responsive Services visit by two Occupational Therapists was completed in early June 2022, in relation to her voices and knee pain. A mental health review and full muscular skeletal (MSK) review at Bognor Hospital, including Physiotherapy and a scan of the knee, were planned. Clare was not taking prescribed painkillers and this was not relayed to the GP Practice, SPFT or carers. On the same day, the Proactive Care Coordinator rang the Bedale Centre to request the mental health review, describing Clare as in crisis; to be informed that the centre was involved with Clare, they were aware of her circumstances and can be contacted, including by carers.

6.6.3. In early June, agency carers observed Clare standing in her bedroom and screaming, as she felt that the voices were in her body and had broken her phone. She was encouraged to focus on objects in the room as a distraction. The carers rang the Bedale Centre and were advised that the Lead Practitioner was due to visit the following day. The SPFT Community Mental Health Nurse (Lead Practitioner) and Support Worker visited as planned, completing a medication review, along with a Psychiatrist. Due to Clare's chronic presenting condition and that she was already receiving the maximum dose of antipsychotic medication, there was no change in the prescription. A new referral was made to the Hearing Voices Clinic, with Clare's consent. The Support Worker visited again in mid-June and Clare had 'smashed things' against the wall in her flat in response to the voices. On a further visit towards the end of the month, the Support Worker did not record any concerns.

6.6.4. SECAmb visited Clare on one occasion in June 2022, due to a concern about her mental health. There were no mental capacity concerns and Clare was advised to contact the GP and WAMHS.

6.7. July 2022

6.7.1. A Responsive Services Occupational Therapist visited Clare on 01/07/22 and re-fitted her toilet seat. At this time she was mobilising without equipment and was discharged from the service.

6.7.2. The SPFT Support Worker visited on 12/07/22. Clare was unable to stand and there was a smell of urine in the flat. Carers voiced their concern that she needed care home provision. On 13/07/22, the Community Mental Health Nurse sent a letter to the GP to request blood tests to monitor her physical health and, in particular, her knee pain; and also to check on the Hearing Voices Clinic referral.

6.7.3. SECAmb and Community Nurses visited on 16/07/22. Clare was not moving from the sofa by this date, despite the encouragement of carers, as the voices were saying to her that her left knee would break if she stood up. She was urinating and passing faeces on the couch. Clare refused treatment and hospital admission and the Paramedics presumed capacity to make this decision. They did not relay any action request to SCFT or other agencies.

6.7.4. Allied Care completed an incident report on 17/07/22, stating that Clare cannot use the toilet due to the voices telling her that her left knee would break if she stood up, that she had been sitting in her own urine and faeces for a few days, her breast appeared to be infected from scratching, and the skin on her bottom was red and broken. They managed to support her with hygiene and changing clothes, through encouragement. The SPFT Support Worker visited Clare on 18/07/22 and she said that the voices were getting into her knee, which she was now saying more frequently. Allied Care rang the GP Practice on 19/07/22 regarding Clare's knee, and a Paramedic Practitioner visited her on the same day. Clare presented as orientated and it was noted generally that there were no concerns about her mental capacity. She complained of continuing knee pain and refused a detailed knee examination. The Paramedic Practitioner lightly touched her knee and she asked him to stop, due to the pain. Whilst noting that her knee appeared symmetrical, with no obvious swelling or erythema, he was concerned that she was not moving her leg or knee. He advised that, if not weight-bearing and in pain, she would need to attend hospital for further assessment of her knee. Clare refused hospital admission and was advised, should she change her mind, to request a further home visit; or if there were worsening conditions, to ring for an emergency ambulance.

6.7.5. Allied Care forwarded a further safeguarding concern to WSCC on 19/07/22, relaying that Clare was not moving from the sofa due to the voices, and SECAmb forwarded a report to WSCC on the same date. The Working Age Mental Health Service (WAMHS) emailed SPFT on 21/07/22 to request the involvement of the Assessment and Treatment Service (ATS), due to Clare's presenting condition. It is not clear whether this contact was followed-up.

6.7.6. Carers noted on 23/07/22 that the voices were telling Clare not to move, that the carpet was wet with urine, and there were flies in the room. On the following day, they recorded that there was a strong smell of ammonia and there were broken plates and glass on the floor. SECAmb visited Clare on 24/07/22, after Clare rang to say that she was hearing voices. They were concerned that she was not rising from the sofa and they assessed that she had mental capacity to make a decision about hospital admission (not a formal Mental Capacity Assessment). The Paramedics attending made a referral to WSCC Adult Social Care from the scene and were advised that an urgent visit would be carried out on the following day. They also reported their concerns to the GP Practice.

6.7.7. A WSCC WAMHS Social Worker and the SPFT Support Worker completed a joint visit to Clare on 25/07/22, with her father present. They were advised by the carers that she had not risen from the sofa or accepted help for the previous few days. Clare declined hospital admission and the

involvement of the Mental Health Crisis Resolution & Home Treatment Team (CRHTT). The need for a Mental Health Act Assessment was explained to Clare and was planned. On 26/07/22, a Mental Health Act Assessment was completed, led by a WSCC Approved Mental Health Professional (AMHP), with the two required doctors also present. Clare declined medication and intervention. Detention in a psychiatric hospital was assessed as required, but there were no available hospital beds. The AMHP stated that Clare was presenting with one of the worst declines in physical health that she had seen; that she had been urinating and defecating on the sofa for two weeks and there were flies in the room. It was noted that previously she had been standing and moving around in her flat.

6.7.8. A GP rang Clare on 27/07/22 and she presented as rational and calm, refusing further investigation. The SPFT Community Mental Health Nurse (Lead Practitioner) and Support Worker visited on the following day and provided reassurance to Clare that hospital was the most appropriate place for her to be, and that SPFT would continue to visit her at home whilst admission was arranged.

6.7.9. On 29/07/22, Clare was visited by the Support Worker and a Consultant Psychiatrist on a monitoring basis. SECAmb visited on the same day, noting auditory hallucinations due to her schizophrenia, and that Clare was saying her left leg would break if she moved it. On the same or following day, she was admitted to St Richard’s Hospital, for physical checks prior to psychiatric admission to Meadowfield Hospital. An x-ray of her left knee on 30/07/22 did not uncover any concerns. However, an MRI scan in December 2022, arranged by Clare’s father, revealed that her kneecap was dislocated.

6.8. August 2022

6.8.1. SECAmb submitted a report to WSCC in early August 2022, sharing information about Clare’s circumstances. This led to a WSCC decision later in the month to undertake a safeguarding enquiry.

6.8.2. Clare was detained under the Mental Health Act at Meadowfield Hospital from 20/08/22.

7. Analysis and findings

7.1. Overview

7.1.1. The Independent Reviewer recognises that there were significant examples of positive practice by involved agencies in supporting Clare. Professionals across a range of health and social care agencies visited often and promptly, demonstrating attentive and caring approaches, as well as skilled communication. There was also evidence of regular communication between agencies in raising and responding to concerns.

7.1.2. However, there were missed opportunities over many months for a robust multi-agency risk management meeting to be held, to coordinate a comprehensive, personalised and holistic risk management plan. This

would have enabled fuller consideration of Clare's rapidly deteriorating dual mental and physical health needs and risks, of decision-specific mental capacity, and of her underlying trauma and strengths. All involved agencies could have instigated this process, and a WAMHS multi-agency review meeting, a Proactive Care Multi-disciplinary Team meeting, a joint WSCC and SPFT review visit, and raised safeguarding concerns, were all opportunities to have taken this step.

7.1.3. In the two weeks leading up to hospital admission, a crisis intervention approach and a more timely Mental Health Act Assessment would have been proportionate responses to the rapidly worsening circumstances.

7.2. How effective was multi-agency needs and risk assessment, including coordination of support?

7.2.1. General

7.2.1.1. Whilst Clare was experiencing complex and escalating mental and physical health concerns, it seems evident from the responses received in the review that the supported housing environment and the range of services were appropriate to meet her complex needs.

7.2.2. Dual mental and physical health needs

7.2.2.1. **Mental health:** Clare had a diagnosis of DiGeorge Syndrome and her mental and physical health concerns are it seems in part associated with this condition. She experienced distressing auditory hallucinations (voices), intentional self-harm, psychosis, paranoia and depression. Whilst this condition presents from birth, it was not diagnosed until recently and was not commonly known by involved agencies. It is not evident that there has been a clear and consistent diagnosis of Clare's mental health concerns. There was a diagnosis in May 2020 of a Pervasive Development Disorder, Chronic Fatigue and Emotionally Unstable Personality Disorder. In the year preceding the Review timescale, Clare had been detained in hospital under the Mental Health Act and had also been a voluntary inpatient. By 2021, she was receiving regular SPFT support, primarily through a Support Worker and Community Mental Health Nurse (Lead Professional). The experience of voices were a significant presentation in the Review period, telling Clare to take her own life (although she at no point displayed intent or a plan to carry this through) and that her left knee would break if she moved. The focus of intervention was on symptom management, in particular distraction techniques. Clare was referred to a Hearing Voices Clinic, but did not engage with this service, and she was prescribed a high dosage of Olanzapine antipsychotic medication. Whilst there is evidence of attentive and skilled intervention, this was limited in that a holistic care plan and risk management plan had not been developed to address her dual mental and physical health needs. Responsive Services, on visiting in June 2022, discovered that Clare was not taking

medication for pain relief and this was not relayed to the GP Practice, which may have triggered a medication review and further consideration of her mental capacity. However, it is understood that Clare was taking all prescribed medication in July 2022.

7.2.2.2. **Autism:** Clare was diagnosed with autism in 2004, which can also be associated with DiGeorge Syndrome. The Health & Care Act 2022 requires that learning disability and autism training is provided to staff in regulated service provider agencies, commensurate with particular roles. The Reviewer understands that Oliver McGowan mandatory training on learning disability and autism is in the process of being introduced across health and social care agencies within the county.

7.2.2.3. **Mental Health Act Assessment:** A Mental Health Act Assessment was undertaken by a WSCC Approved Mental Health Professional (AMHP) and two doctors in late July 2022. This resulted in Clare's admission, at first in an acute hospital due to her physical health needs and then in a psychiatric hospital. Clare had been sitting on her sofa for at least two weeks, urinating and passing faeces where she sat, as the voices had told her that her knee would break if she moved. As there had not been any significant change in circumstances during that timescale, it would seem to have been appropriate to have considered an assessment at the beginning of this period or earlier. There was also a delay of a few days between the Mental Health Act Assessment and admission to an acute hospital. During this time, an SPFT Consultant Psychiatrist and the Support Worker visited and her condition was monitored. She was admitted to a psychiatric hospital a few weeks later.

7.2.2.4. **Physical health:** Alongside a history of acute mental health concerns, Clare had consistently complained from November 2021 of physical pain in her left knee and from January 2022 of voices telling her that her knee would dislocate if she moved. The GP Practice and Responsive Services regularly reviewed her knee pain and offered physiotherapy appointments in hospital, rather than a full knee examination that would have been a more typical response for a patient exhibiting this consistent complaint. The Ambulance Service also offered to convey Clare to hospital on occasions for an examination of her knee. Clare declined to attend hospital, due to the pain in her knee and the voices telling her that her knee would break if she moved.

7.2.2.5. There was a real sense that agencies considered Clare's knee pain to be a symptom of her acute mental illness, without fully considering and planning for the possibility that a physical injury may be present and that this may be contributing to her auditory hallucinations. Her father feels that services "were convinced that there was nothing terribly wrong with her knee", which led to a reliance on painkillers, when she was in obvious discomfort. She attended hospital in January 2022, which was

an early opportunity to have undertaken a scan of her knee. SECAmb provided a 'placebo' knee dressing in February 2022, which did improve her mobility and this may have had a physical as well as mental health impact and referred to an 'anxious knee injury' in May 2022. A serious recognition that Clare may have been experiencing both a physical injury and voices related to the injury could have led to a proactive, planned medical intervention in hospital. An x-ray was performed when Clare was admitted to hospital in late July 2022, which did not uncover any injury to her left knee. However, her father arranged a private MRI scan in December 2022, which revealed that her left knee was dislocated. Although it has not been established when the dislocation occurred, it is apparent that Clare had been experiencing a knee injury and associated pain for a considerable number of months. Whilst agencies demonstrated concern and Clare had declined hospital admission, there was not a proactive effort to arrange a full examination of her knee from November 2021 until hospital admission in late July 2022. This could have incorporated engagement with Clare and between agencies in planning hospital access arrangements, possibly at a time when she had taken painkillers and her knee pain was less acute.

7.2.2.6. Clare's knee pain and voices telling her that movement would cause her leg to break had led to reduced mobility and self-care over a period of many months, prior to the crisis period in July 2022. By February 2022, she was requiring assistance with walking indoors. In March 2022, the GP Practice flagged that Clare was housebound, which meant that she was either unable to leave the house or very restricted in doing so. She was also sleeping on the sofa at night. Community Nurses had offered consistent advice to Clare on elevating her legs and sleeping in her bed and were concerned that this did not lead to a change. Clare also had a tendency to order takeaway food and during the review period she developed an unhealthy weight gain. Community Nurses offered advice on healthy eating, but there is no indication that a referral to a dietician was considered, which may have been helpful in view of the complexity of her needs. It may have been that her weight exacerbated and disguised her knee injury.

7.2.3. Consistency of support and care needs assessments

7.2.3.1. Clare received attentive support from a wide range of services during the Review period, with communication evident between agencies. These incorporated the Supported Housing Manager and Allied Carers, the GP Practice, SECAmb, SPFT (Support Worker, Community Mental Health Nurse), SCFT (Community Nursing, Proactive Services Occupational Therapy and Physiotherapy, Proactive Care) and WSCC (Working Age Mental Health Service).

7.2.3.2. This support was on the whole maintained in the months leading up to Clare's hospital admission in July 2022, during a period of worsening health circumstances. The WAMHS Social Worker was not assigned from April 2022, but the service maintained regular communication and completed home visits in May and July 2022. There was a tendency to focus on maintenance and symptom management, rather than undertaking a more holistic and in-depth care management needs assessment and support plan. This could have incorporated a consideration of Clare's strengths and hopes, such as her repeated comments that she had so much to live for. Also, her request for nursing home care should have been discussed with her, in the context of a wider consideration of her needs, risks and strengths.

7.2.3.3. SCFT Community Nursing support was not provided from June 2022, as Clare's leg and sacral ulcers had healed and it was known that the Proactive Care Team had scheduled a review for the following month. However, she remained at risk of pressure ulcers and a periodic review and contribution to multi-agency risk management were possible options to have maintained contact. In the two weeks prior to hospital admission, there had not been a re-referral to Community Nursing, during a period in which she was at increased risk of skin breakdown. There is, however, a record of Community Nursing visiting in mid-July 2022. The Responsive Services Occupational Therapist and Physiotherapist made further visits to Clare in early June 2022 regarding her knee pain and in early July 2022 to provide equipment.

7.2.4. Multi-agency risk management

7.2.4.1. **Practitioner-level risk management:** As recognised, agencies provided attentive care and communicated with each other, involving some limited joint assessment. However, the assessment and care planning that was undertaken by individual agencies was not sufficiently holistic in considering the interconnected mental and physical health needs and how risk factors were accumulating.

7.2.4.2. Furthermore, involved agencies did not trigger a multi-agency risk management meeting in relation to self-neglect, which would have been beneficial from February 2022 or before; when Clare was housebound and her movement was restricted due to the voices and knee pain. There was, however, a multi-agency review meeting in January 2022, which led mainly to practical support. Clare's father feels that meetings he attended did not lead to effective change and that agencies did not work together effectively. The Proactive Care multi-disciplinary team meeting in April 2022 was a potential opportunity for any involved agency to have triggered a robust risk management process. A multi-agency risk management meeting would have enabled a shared risk assessment and a coordinated risk management plan to address complex circumstances; with possible consideration

of an effective, dual mental and physical health assessment of Clare’s knee pain.

7.2.4.3. The pan-Sussex Self-Neglect Policy provides guidance to all agencies on setting up a multi-agency meeting and, if the risk is not resolved, escalation to the Multi-Agency Risk Management (MARM) forum. An internal meeting was scheduled by SCFT for late July 2022, but this was not timely and did not proceed, as there was no involvement by SCFT agencies by this time. This was a potential opportunity for a wider multi-agency risk management meeting, linked to the risk management procedure.

7.2.5. Multi-Agency Risk Management (MARM) meetings

7.2.5.1. West Sussex Safeguarding Adults Board (WSSAB) has a Multi-Agency Risk Management (MARM) forum to consider risk circumstances at a strategic level, that have not been sufficiently reduced at a practitioner-level.

7.2.5.2. Referral to the forum was a WSCC recommendation in response to a Safeguarding Adults concern in March 2022, but was not followed up and was premature, as a practitioner-led risk management response had not been attempted. The WSSAB MARM criteria requires that all other avenues to address the risk must already have been explored, prior to escalation of the risk concern to this strategic level.

7.2.6. Crisis intervention and trauma-informed approach

7.2.6.1. By June or July 2022, Clare’s worsening conditions were such that a crisis intervention approach would have been proportionate. When the SPFT Support Worker visited on 12/07/22, Clare could not stand, there was a smell of urine, and carers felt that Clare needed admission to a care home. By mid-July 2022, Clare was passing urine and faeces on the sofa. There were flies in the room and also maggots from food debris on Clare’s skin. It seems clear that there should have been consideration of an urgent multi-agency risk management meeting and a Mental Health Act Assessment.

7.3. How effective was the reporting of safeguarding concerns and of threshold decisions?

7.3.1. Escalation of general and safeguarding concerns

7.3.1.1. In the six month period up to hospital admission in late July 2022, SECAmb forwarded reports to WSCC on Clare’s circumstances in January and July 2022, although these were not formal safeguarding referrals. In the same period, Allied carers raised safeguarding concerns with WSCC in March, May and July 2022; on two occasions regarding self-neglect and on one occasion regarding a medication error. The concerns raised

in July 2022 led to a joint WSCC and SPFT visit, Mental Health Act Assessment and hospital admission.

7.3.2. **Safeguarding duty and proportionate response**

7.3.2.1. In March 2022, whilst the safeguarding duty was not considered to have been met, advice was provided to consider a referral to MARM. This demonstrated a consideration of risk management, but the advice was not followed-up and a practitioner-level approach was appropriate at this stage. There is a need for further clarity on the responsibility of all agencies to trigger a risk management meeting, and on when this should constitute a safeguarding concern to be coordinated by WSCC; taking into account both the level of risk and the exhaustion of non-safeguarding risk management intervention, as covered in the WSSAB Safeguarding Adults Thresholds: Guidance for Professionals document.

7.3.2.2. A proportionate safeguarding response in July 2022 would have been to trigger an urgent risk management meeting and a more timely Mental Health Act Assessment.

7.4. How effective was the consideration of mental capacity and active listening to Clare's voice?

7.4.1. **Clare's engagement and mental capacity**

7.4.1.1. A Mental Capacity Assessment had been undertaken in which Clare was not deemed to have capacity to manage her finances. However, it is not clear that a formal Mental Capacity Assessment relating specifically to care and accommodation had been undertaken at any time when there appeared to be sufficient grounds for concern about her decision-making capacity in relation to mobility and personal care; notwithstanding the underlying physical cause.

7.4.1.2. In November 2021 and April 2022, it is understood that Mental Capacity Assessments were completed by SPFT and it was concluded that Clare had the capacity to make health-related decisions; including sleeping on the couch and not elevating her legs. An Occupational Therapist in February 2022, Social Worker in March 2022 and Community Nurse in April 2022 had all raised concerns with the GP Practice that Clare may not have the capacity to make decisions about personal care and clinical advice. A GP in July 2022 noted that there were no concerns regarding Clare's capacity in relation to her worsening conditions. SECAmb consistently recorded that Clare had the capacity to make decisions about hospital admission, although these are not formal assessments within the rigour of Mental Capacity Act requirements. Electronic patient care records held by SECAmb now include information on capacity, as free text to support clinical decisions.

7.4.1.3. It is clear that professionals were taking responsibility to consider whether there were grounds to undertake a decision-specific Mental Capacity Assessment. However, it is not clear that the assessments in November 2021 and April 2022 were specifically relevant to personal rather than clinical care. It was notable that Clare did accept support with personal care through Community Nursing encouragement. Also, a WAMHS case record indicates that the responsibility to assess capacity was passed to SPFT, due to possible deterioration in Clare's mental health needs.

7.4.1.4. It does appear that Clare was making decisions that were based on very real experiences of physical pain and mental health trauma. These would seem to have indicated a primary need for a full medical examination (which she may have complied with if planned) and a timely Mental Health Act Assessment.

7.4.2. **Active listening to Clare's voice**

7.4.2.1. It is very evident that professionals from a range of agencies demonstrated empathic and skilled communication and care in very complex and demanding circumstances. However, involved professionals did not exercise sufficient professional curiosity and active listening to better understand Clare's underlying experience of trauma, as well as her strengths and hopes for the future. A more professionally curious approach may have unearthed details on why Clare was hearing particular voices at particular times, including those relating to her knee pain, rather than interpreting what she was saying and potentially developing hypotheses within a medical model perspective. Her father comments that Clare feels agencies do not treat her as an equal.

7.4.2.2. Clare had a close relationship with her father, who might also have provided a source of deeper understanding and perhaps could have supported a risk management plan, such as encouraging Clare's engagement and her attendance at hospital appointments. Clare engaged well with the SPFT Support Worker and was positive about accepting support in March 2022, when her father was present. Also, agency carers spent time with Clare in chatting about music, watching movies and playing games, as a distraction from the voices. They were a further potential source of active listening within a personalised risk management approach.

7.5. **How did resources and environmental factors, such as Covid, impact on care?**

7.5.1. The Reviewer recognises that all service provision is impacted by austerity, that resources are limited, and workload pressures are high. Within this context, a delay in securing a psychiatric hospital bed was a particular concern. This may be attributed to a number of factors; a shortage of psychiatric hospital beds, and of preventative and community

services to enable safe discharge and to avoid admission to hospital. It is acknowledged in this Review that there is a significant national issue concerning the availability of inpatient and community resources.

7.5.2. There were no significant environmental factors in the Review period. The Covid pandemic on the whole predated the main period of worsening conditions for Clare and face-to-face contact was largely maintained by involved agencies throughout.

7.6. How compliant were agencies with legislation, policies, procedures, and practice guidance?

7.6.1. The Care Act requirement of a care needs assessment was fulfilled by WSCC Adult Social Care, in that a comprehensive care package was provided to meet Clare's needs. However, the assessment and care plan was not sufficiently holistic or underpinned by a risk management approach.

7.6.2. A Mental Capacity Assessment should have been undertaken in relation to personal care, in line with the risk judgements of involved professionals. It was not clear that the assessments in November 2021 and April 2022 were specific to personal care concerns, rather than health-related concerns.

7.6.3. A Mental Health Act Assessment was undertaken in July 2022, leading to Clare's detention in a psychiatric hospital, following acute hospital admission. However, it does appear that a more timely assessment was necessary in view of the rapidly worsening conditions.

7.6.4. It is also notable that Clare's mental and physical health concerns are covered by the Equality Act 2010, in terms of reasonable adjustments by services to remove barriers faced due to disability.

7.7. What is the learning from other Safeguarding Adults Reviews concerning self-neglect?

7.7.1. **Thematic Safeguarding Adults Review (Kent & Medway, 2021):** This Review involved relatable circumstances and useful learning. Four adults died at home in 2018 and their circumstances included poor health, isolation, engagement difficulties (not attending GP appointments, not responding to contact and not collecting prescriptions), and a safeguarding referral regarding self-neglect that was not progressed. The recommendations included GP Practices maintaining an up-to-date vulnerable adults list, evidencing arrangements to cover vulnerable adults who do not attend appointments, all agencies raising staff awareness of the self-neglect and hoarding policy, and the SAB developing a multi-agency risk management framework.

8. Recommendations

8.1. **Practitioner-led risk management:** West Sussex Safeguarding Adults Board (WSSAB) to oversee, joint with East Sussex and Brighton & Hove, a review of the pan-Sussex self-neglect risk management procedure; with specific attention to agencies' responsibilities to trigger practitioner-led risk management

meetings, to safeguarding responsibilities, to prioritising attendance, to continued agency involvement in circumstances of significant managed risk, and to exercising professional curiosity. Existing multi-disciplinary team meeting structures should be explored as potential options to enable this approach. It is understood that a pan-Sussex review is currently planned.

8.2. **Training programmes on risk, safeguarding adults, mental capacity and autism:** WSSAB, Learning & Policy subgroup, to oversee compliance with training provision, commensurate with specific roles; covering Risk Management, incorporating professional curiosity and active listening; Safeguarding Adults, incorporating reporting and threshold decisions; Mental Capacity Assessments and Deprivation of Liberty Safeguards (DoLS), incorporating risk-based and decision-specific judgements; and learning disability and autism mandatory training. Also to consider sharing across agencies a learning bulletin that was produced on completion of the Safeguarding Adults Enquiry.

8.3. **Dual mental and physical health needs:** WSCC, SPFT and SCFT to audit a selection of cases involving significant mental and physical health concerns and self-neglect, for assurance of timely diagnosis and robust consideration of dual needs and risks. To culminate in a joint review of existing procedures and good practice initiatives in responding to dual mental and physical care needs, to support multi-agency working.

8.4. **Mental Health Act Assessments:** WSCC to oversee a review by involved agencies of the timeliness of requests for Mental Health Act Assessments in high risk circumstances.

8.5. **Psychiatric hospital admissions:** WSSAB to continue gathering information about, and raising the profile of, health and social care pressures on the ability to admit people to psychiatric hospital beds at the time that they are needed.