



Sunderland Safeguarding Adults Board
Safeguarding Adults Review
‘Joseph’
Executive Summary

May 2024

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Introduction

- 1.1 Joseph was a 20 year old man with a learning disability, Prader Willi syndrome (PWS), obesity hyperventilation syndrome¹ and type 2 diabetes. Joseph moved to a care home provided by Swanton Care in September 2020. Joseph died following a hospital admission, for genital cellulitis, where he developed infections, then hepatic, cardiovascular, renal, and respiratory failure. He was transitioned to end of life care, after a discussion with his family, and passed away in May 2022.
- 1.2 Following Joseph's death, the Sunderland Safeguarding Adults Board (SSAB) Safeguarding Adult Review Sub-Committee held a scoping exercise regarding the information known in relation to Joseph. The Scoping Panel concluded that the criteria to undertake a Safeguarding Adult Review (SAR), in line with the SSAB SAR Protocol, were met. A recommendation that a SAR be commissioned was taken to the Independent Chair of the SSAB who, after reviewing the information collated by agencies, was in agreement that the criteria for undertaking a SAR was met.

Terms of Refence

- 2.1 A multi-agency panel was established by Sunderland SAB to conduct the review and report progress to the Sunderland SAB. Membership included an Independent Reviewer and representatives from key agencies with involvement.
- 2.2 The purpose of the review was to identify multi-agency learning exploring information under the broad themes of mental capacity (including deprivation of liberty safeguards), advocacy, multi-agency working, communication and information sharing, risk assessment and care planning, organisational factors, the impact of the covid-a19 pandemic and cross-boundary working.

Methodology

- 3.1 Agencies involved with the adult were asked to provide information of significant contacts by preparing an agency chronology and outline report with a focus on the purpose and scope of the review, included a brief analysis of relevant context, issues and events, and an indication of any conclusions reached. Information about action already undertaken, or recommendations for future improvements in systems or practice, was included if appropriate.
- 3.2 Following completion of the agency reports, a Practitioner Learning Event was held with practitioners and managers who were directly involved with Joseph, in order to further explore hypotheses, draw out themes, good practice and key learning from the case including any recommendations for the development or improvement to systems or practice.

¹ Obesity hypoventilation syndrome (OHS) is defined as the combination of obesity (body mass index [BMI] of 30 kg/m² or more), raised arterial or arterialised capillary carbon dioxide (CO₂) level when awake, and breathing abnormalities during sleep, which may consist of obstructive apnoeas and hypopnoeas, or hypoventilation, or a combination of both. [Obesity hypoventilation syndrome | Obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s | Guidance | NICE](#)

Family Involvement

- 4.1 Sunderland SAB wrote to Joseph's parents to inform them that a SAR was being undertaken and invited them to participate through contact with the independent reviewer. A copy of the final report was also shared with the family on conclusion of the review. The family spoke with the independent reviewer, providing feedback on the report and their experiences, and gave agreement for the publication of the Executive Summary.

Background Information and Summary of Events

- 5.1 On becoming an adult Joseph was keen to move out of the family home and live independently. Joseph was eligible for Continuing Healthcare and initially moved to a residential home for older people in Stockton on Tees. The placement was not suitable to meet his needs and manage his behaviour, therefore an emergency temporary placement was found at a care home in Sunderland provided by Swanton Care² to which he moved in September 2020. Joseph was subject to Deprivation of Liberty (DoLS) authorisations throughout his time at Swanton Care.
- 5.2 Joseph's package of care was funded by Tees Valley Clinical Commissioning Group via Continuing Healthcare (CHC).³ The oversight of this package was undertaken by Durham, Darlington and Tees Partnership (DDTP), who employed specialist case managers who had experience in supporting people with complex mental health and learning disabilities to support and manage complex cases in the community, these case managers were employed by Tees Esk and Wear Valleys NHS Trust (TEWV) but worked for DDTP. TEWV learning disability community team also supported Joseph and the care provider but this was in addition to the case management role undertaken by DDTP. In addition to the support offered by case management, Joseph was also subject to annual CHC reviews by the CHC team and the last review was undertaken in February 2022 where Joseph was found to remain eligible.
- 5.3 Joseph weighed 129kg shortly after his admission to Swanton Care, the ideal weight for someone of Joseph's height was 80kg. His weight had increased to 141kg by April 2021, and upon admission to hospital in May 2022 the hospital recorded a weight of 173kg.
- 5.4 In March 2022 Joseph was diagnosed with genital cellulitis, he was admitted to hospital, where he received IV antibiotics, and discharged approximately two weeks later. Joseph attended the emergency department two weeks later and was prescribed oral antibiotics. Two days later he attended the emergency department again, he was admitted and discharged two days later following further antibiotics. A further two days later Joseph was readmitted to hospital where he refused medical interventions and his condition deteriorated and he died around a month after admission.

² The care home provides personal care for up to ten people with learning disabilities or autistic spectrum disorder. The home is rated 'Good' by the Care Quality Commission and was rated as such during the scoping period of this review. The home is one of many provisions provided by Swanton Care.

³ Tees Valley CCG was dissolved on 30th June 2022 and all CCG's in the north east and north Cumbria became one single organisation - North east and north Cumbria Integrated Care Board (NENC ICB)

Lessons to be learnt

Understanding of PWS

- 6.1 Understanding of PWS and a lack of specialist support and training impacted all areas of Joseph's life, how he was supported and professionals' assessments of him. It meant that his mental capacity was not formally assessed, and he was presumed to have capacity which consequently led to significant weight gain as his dietary intake was unrestricted. This weight gain led to a deterioration in health which was ultimately fatal.
- 6.2 Professionals working with people with PWS need specialist support and training. Ideally people with PWS should receive support from specialist PWS services and in specialist PWS placements, although it is acknowledged that these services may be limited, particularly in the area in which Joseph lived.

Mental capacity assessments

- 6.3 Mental capacity assessments should be undertaken in person wherever possible and this should be the default option. This allows the practitioner to gain a greater consideration of the person's understanding of the relevant information, ability to weigh and use the information, retain the information and communicate the decision. Both Stockton Borough Council and Sunderland City Council confirmed that remote assessments no longer take place.
- 6.4 With regards to PWS, professionals should have a good understanding of the interface between PWS and mental capacity, and have regard to executive capacity to assist in assessing mental capacity.

Deprivation of Liberty Safeguards

- 6.5 The use of equivalent assessments should not be relied upon in the interests of efficiency, particularly where there has been a change in circumstances. When detailing the nature of the deprivation, all aspects of a person's care should be included (such as nutritional intake and diet) and the Guzzardi framework⁴ applied to reflect the nature of the deprivations clearly.

Hospital passports

- 6.6 Hospital passports should be completed as soon as a provider commences their support of a person. Hospital passports should contain information about decision making as it is undoubtable that decisions about care and treatment will need to be made when someone is admitted to hospital. Hospital passports should be shared at the point of admission and when the person moves from one area of the hospital to another to ensure this important information is shared with the relevant professionals. Swanton Care have confirmed that they have changed the hospital admission policy for the organisation, whereby a registered manager needs to check a hospital passport has been taken when a person is admitted to hospital.

Support for and involvement of parents/guardians/informal carers

- 6.7 Parents/guardians/informal carers can often hold invaluable information and knowledge about the person and as such should be consulted with, particularly when

⁴ In *PJ v A Local Health Board and Others* [2015] UKUT 0480 (AAC), Mr Justice Charles relied on the principle in the case of *Guzzardi v Italy* (1980) 3 EHRR stating that "the starting point in assessing whether there has been a deprivation of liberty is "the concrete situation" of the person and the consideration of "a whole range of criteria such as type, duration, effects and manner of implementation of the [restrictive] measure in question."

issues and challenges arise. Parents/guardians/informal carers of people with PWS should also be provided with specialist PWS support and signposted to support agencies.

Action plan and referral tracking

- 6.8 Agencies should have in place mechanisms for recording and tracking agreed actions and referrals to ensure they are completed in a timely manner, and enable follow up and review. This will prevent delays, and failure to complete agreed actions, and will assist in holding others to account.

Commissioning of placements for people with PWS

- 6.9 When commissioning placements for PWS consideration should be given to placements which are PWS and placements with experience of working with people with PWS. Where a person with PWS is placed in a non-specialist placement, commissioners should ensure that the service is adequately prepared and supported and that support is maintained for the duration of the placement. Preparation and support would include specialist PWS training, development of clear care plans and guidelines for managing PWS, regular review of those plans and guidelines, and clear directions for escalation.

Awareness of self-neglect

- 6.10 Professionals across all areas and agencies of the care sector should have a good understanding of self-neglect and how to recognise it. Agencies should recognise the multi-agency approach to self-neglect and be familiar with the local multi-agency self-neglect guidance.

Case management

- 6.11 Where case management responsibilities are devolved to other organisations, the responsible authority should be assured that those functions are delivered as per the relevant guidance and policy.

Recommendations

The following recommendations pertain to two local authority areas; Sunderland and Stockton on Tees, with Stockton on Tees being part of the Teeswide SAB, alongside other Tees Valley local authorities. The learning and recommendations should also be considered and acted upon by the North East and North Cumbria ICB and North East ADASS, as they are a number of system recommendations that are wider than Sunderland and Stockton.

1. Sunderland and Teeswide SABs to seek assurances that agencies who undertake mental capacity assessments have a policy that states that face to face assessments are the default and that any assessments undertaken remotely are supported by a rationale.
2. Sunderland City Council and Stockton-on-Tees Borough Council to ensure the appropriate use of equivalent assessments⁵, ensuring they are not used when there has been a significant change in circumstances or where the previous assessment was undertaken remotely.

⁵ An equivalent assessment is an assessment carried out within the previous 12 months, not necessarily for the purpose of a deprivation of liberty authorisation, that meets all the requirements of a DoLS assessment, is still accurate, and of which the supervisory body has a written copy.

3. Sunderland City Council and Stockton-on-Tees Borough Council to ensure that best interest assessments, for the purposes of a deprivation of liberty, utilise the Guzzardi principle which details the nature of the deprivations including: type, duration, effect, manner, degree and intensity.
4. NENC ICB, with the support of SSAB partners, to lead the process of ensuring MCA and DoLS information is included in hospital passports. This learning will be shared with NENC ICB Learning Disability Network.
5. Swanton Care to ensure that details about decision making ability is included in all hospital passports, including areas in which a person has been assessed as having and/or lacking capacity and any deprivation of liberty safeguards.
6. Sunderland and Teeswide SAB partner agencies to consider and agree the approach to PWS training for staff in their organisations (this may be targeted to specific individuals or roles, or when the need arises) and to discuss sharing this recommendation regionally.
7. Sunderland and Teeswide SABs to produce a 7 minute briefing on PWS which includes links to relevant resources, including self-neglect, and to share this regionally
8. Sunderland and Teeswide SABs to produce a 7 minute briefing on mental capacity and executive capacity specifically in relation to PWS which includes links to relevant resources.
9. Sunderland SAB to facilitate an independent audit and quality assurance exercise in relation to the recommendations made in SAR Alan and SAR Eva pertaining to mental capacity.
10. Sunderland and Teeswide SABs will seek assurances that learning has been incorporated into agency's training and that a proportion of agency staff attend multi-agency training provided by the SAB.
11. Swanton Care to provide assurances to the Sunderland and Teeswide SABs that there are quality assurance mechanisms in place with regards to the Mental Capacity training that is offered by the service, and its application in practice by individual members of staff.
12. Sunderland and Teeswide SAB partner agencies with responsibility for commissioning accommodation services to share the learning from this review in respect of placing people with PWS into non-specialist services, highlighting the need to give consideration to compatibility, PWS support and guidance for services, and guidance for escalating concerns.
13. Sunderland SAB and Teeswide SAB to explore recommendations made by the London Borough of Redbridge in SAR 'JS' in relation to discussing with the PWS association an accreditation scheme for PWS specific placements.
14. NEAS to issue transfer of care guidance regarding bariatric patients and all agencies to have arrangements in place with NEAS regarding the transfer of care of bariatric patients.

Single agency recommendations

The following agencies made their own recommendations in their Individual Management Reviews.

CNTW

- Safeguarding decision making should be explored in more detail by service leads with the staff member involved in the Initial Response Service triage in June 21 to highlight that, despite the thorough triage that was completed and the good practice that occurred in communicating Joseph's contact and distress to the care team, it would have been considered good practice to have also completed an internal CNTW web based incident form to highlight potential safeguarding concerns Joseph raised during the call.

Swanton Care

- For each review meeting to include "review status quo" as an agenda item.
- To keep a log of MDT meetings in the same way that we complete logs for medical interventions, to will allow effective progress tracking.

North East Ambulance Service

- Reinforce safeguarding roles and responsibilities

North East and North Cumbria Integrated Care Board

- For learning disability to be recorded as an "active problem" on the patients GP electronic medical records when required and includes the use of the correct [SNOMED](#) code (a clinical vocabulary used in an electronic health record helping data to be recorded consistently and accurately).
- All newly registered learning disability patients to be offered a [learning disability annual health check](#) within 12 months of registration and non-attendance is followed up.
- Rapid weight gain in a patient with [Prader- Willi syndrome](#) or a susceptible long term health condition is clearly recorded in the electronic GP consultation notes stating how much the weight gain is and an appropriate management plan including monitoring, reviewing, advice and consideration of referrals to appropriate services included.
- Complications from [Prader- Willi syndrome](#) to be understood by practitioners caring for them. This includes the symptoms, causes, diagnosis, and management.
- To consider commissioning an independent clinical review of Joseph to better define clinical learning.
- NENC ICB, NE ADASS, CNTW and TEWV to evaluate the function and effectiveness of MDTs for people with complex care needs, including leadership, multi-agency oversight responsibilities and consistency of clinical input, care coordination and case management.

- To clarify and agree oversight and case management responsibilities, in addition to a discussion with NE ADASS, ensuring that health and social care assessed needs of individuals truly benefit from a coordinated multiagency approach determined by the need and not the respective funding arrangements.
- To maintain oversight and overview of out of area cases. Including, but not limited to; effective collaboration and communication with all areas (e.g. local authority, case manager, clinical leads, etc.) and should also include the need to understand how a residential placement is coping with complex cases and seeking regular updates and assurances accordingly

South Tyneside and Sunderland NHS Foundation Trust

- The Learning Disability & Autism Team will aim to see inpatients within 24 hours of admission Monday to Friday.
- STSFT ALDAT will amend the Reasonable Adjustments Assessment and implement this assessment into practice. ALDAT will monitor that STSFT acute staff are routinely completing and updating this assessment.