Redbridge Safeguarding Adults

‘JS’ -

A Discretionary Safeguarding Adults Review (SAR)

Executive Summary

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Case Summary

JS was a 38-year-old male when he sadly passed away. Originally from the South West of England, JS was diagnosed with learning disabilities, Prader Willi Syndrome (PWS), diabetes, and mental health issues. JS died in an acute general hospital in North East London in December 2021.

In the year preceding this, JS went from living in a community setting, to being in acute psychiatric and acute general hospital settings in the South West of England, with numerous readmissions between services in a short space of time. Following these admissions, JS was then moved to a specialist placement in North East London where he lived for less than a month before he was admitted to an acute psychiatric hospital, followed by an admission to an acute general hospital due to rapid deterioration in his physical health.

JS remained here for 6 months, during which time he appeared to make some recovery. JS unfortunately became critically unwell again and sadly passed away in December 2021. The cause of death was septic shock, fungal pneumonia, obesity, fatty liver, and hypertension.

Considerations for future practice

- In regard to service provision for PWS residents, this review identifies two key themes:

    - The number of PWS specific providers, or care providers with experience of supporting residents with PWS, is generally quite a low number.
    - These providers are spread quite far and wide which can often mean service users having to move away from the areas that they grew up in, and from their family and friends.

  Could commissioners at a local level be considering ways to help current learning disabilities/autism providers to be better trained and upskilled in order to be able to support service users diagnosed with PWS?

- In exceptional situations such as this where family are having to travel a significant distance to see service users who are unwell, could there be some support package offered to them which could come out from a carer's strategy? Could organisations pledge support to John's Campaign, or something similar?

- Family were keen to have JS closer to where they were. When JS was in an acute general hospital in London, there were conversations about JS transferring to a hospital closer to family. Could this have been considered at a much earlier point in time?

- There is a need for clarity around who takes the lead on commissioning. There should be guidance (at both a local and a national level) that sets out who should take responsibility so that delays in care are kept to an absolute minimum.

- Meeting organisers need to give due consideration to the necessity of having frequent meetings and the impact that the frequency will have on practitioners in regard to their ability to commit time to meetings as well as what it might mean for them on an emotional level.

- The Prader Willi Syndrome Association (PWSA) to consider establishing an accreditation scheme for PWS specific placements to ensure that the quality of care for residents with PWS is as required, but also to ensure that PWS specific placements feel equipped and supported to care for residents with PWS.

- Redbridge SAB to consider training opportunities for partner organisations to be made more aware of PWS. Given that we know there is a PWS specific provider in Redbridge, it stands to reason that services across Redbridge may support a person with PWS at some point, and it would be pragmatic to ensure that there is some basic awareness of PWS and its associated conditions across the board.

- Ensuring that discharge planning meetings are held with the relevant agencies involved so that patients are discharged safely without the need to be readmitted.

- The introduction of a checklist to prompt commissioners to ensure that all relevant steps have been taken when placing someone out of borough. NHS England have recently produced a document that they are looking to use in the South West region, which could be something used in other areas too.

Identified good practice

- Effective joined up working between lead and host commissioners in trying to find suitable care provision for JS.
- Flexible and creative approaches used to support JS whilst he was in hospital as well as to source support for him for when he was to be discharged.
- The exploration of more than 70 care provisions to see if any were suitable for JS shows a certain determination by professionals to aid discharge from hospital.
- Evidence of liaison with the PWSA around possibly supporting any potential support provider for JS when he would be discharged into the community.
- Evidence of family and carer involvement at most stages of JS' journey within the timeframe under review.
- Use of a variety of methods to contact and involve family at times.
- Family were supported to see JS when he was in hospital.
- There were discharge planning meetings held on a regular basis which family were also invited to attend so they could hear the latest from all professionals.
- Good communication between CCGs (now ICBs) to help find a solution to the situation facing JS. In particular, the co-working around finding placements or beds.
- Even with geographical distance between all parties involved, there was evidence of a real determination to want to work together and to ensure all relevant parties were involved throughout.
- The introduction of a Community Interest Company (CIC), who specialise in supporting people to live well and fulfilling lives, by NHS England showed a desire to want to know more from JS himself and to help the professional network progress their work.
- Involvement at the acute general hospital in London of their own in-house Learning Disabilities and Autism Team to support the different ward settings in how to care for JS. Evidence that they were in regular contact with JS directly where possible and supported wards to make reasonable adjustments when necessary.
- Evidence of the acute psychiatric hospital in London contacting the PWSA for advice and guidance on how to support JS' dietary needs due to his PWS.
- The consideration of JS being repatriated closer to home and where his family are, is a positive step to take in terms of being person-centred and helping to support family/carers to see their loved one.

Recommendations

1	For organisations to review their carers strategies and policies to ensure that there is adequate and appropriate support available to carers who are traveling to see their loved ones who are out of the local authority area.
2	Where practitioners are chairing meetings (professionals' meetings, enquiry planning meetings, discharge planning meetings etc.) they are to consider the necessity of holding these meetings as well as the frequency at which meetings are held. Consideration must be given to how practical it can be to for practitioners to attend frequent meetings.
3	The Redbridge SAB to consider discussing with the PWSA, because of the learning from this review, whether they would commit to driving the agenda for an accreditation scheme for PWS specific placements. This would look at the quality of the care delivered to PWS residents as well as consider if PWS specific placements require any additional support to care for residents with PWS.
4	The Redbridge SAB to consider training opportunities for partner organisations to be made more aware of PWS. Given that we know there is a PWS specific provider in Redbridge, it stands to reason that services across Redbridge may support a person with PWS at some point, and it would be pragmatic to ensure that there is some basic awareness of PWS and its associated conditions across the board.
5	Partner organisations to ensure that discharge planning meetings are held with the relevant agencies involved so that patients are discharged safely without the need to be readmitted
6	The Redbridge SAB to consider the introduction of a checklist to prompt commissioners to ensure that all relevant steps have been taken when placing someone out of local authority area. This could be jointly designed by Adult Social Care and ICB commissioners.