Richmond and Wandsworth
Safeguarding Adults Board

Safeguarding Adults Review (SAR) in rapid time

‘Issy’

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Authors:

Ruth Lacey - Head of Service Safeguarding Standards, Wandsworth Childrens Services,

Sam Page – Head of Safeguarding St George's University Hospitals NHS Foundation Trust,

Lynn Wild – Head of Professional Standards and Safeguarding, Richmond and Wandsworth Adult social Services

To protect the identities of individuals involved, this report uses randomly selected pseudonyms for the person referred to in this report.

INTRODUCTION

Following the death of Issy and the possible neglect which may have contributed to her death, the Richmond and Wandsworth Safeguarding Adults Board (SAB) agreed on 23 November 2020 to undertake a Safeguarding Adults Review (SAR) using the new 'SAR In-Rapid-Time' methodology recently developed by SCIE. The aim of the SAR was to consider the support which was provided to Issy at the end of her life, to identify if there are any learnings at an organisational or system level.

What is SAR in Rapid Time

A SAR in Rapid Time aims to turn-around learning in a short time frame. The learning produced through a SAR in Rapid Time concerns 'systems findings' which identify social and organisational factors that make it harder or easier for practitioners to do a good job day-to-day, within and between agencies. The process is supported by remote meeting facilities and does require any face-to-face contact.

The final report aims to be as succinct and practical a document as possible. Therefore, details of the methodology and working out process do not form part of the published report.

About this document

This document forms the final output of the SAR in Rapid Time. It provides the systems findings that have been identified through the process of the SAR. Each finding attempts to describe the systems finding barrier or enabler and the problems it creates. It requires thinking beyond Issy's case to wider organisational and cultural factors. These findings are future oriented. They focus on social and organisational factors that will make it harder or easier to help someone in circumstances such as Issy in a timely and effective manner. As such, they are potentially relevant to professional networks more widely.

In order to facilitate the sharing of this wider learning the case specific analysis is not included in this systems findings report. Similarly, an overview of the methodology and process is available separately.

Each systems finding is first described. Then a short number of questions are posed to aid the RWSAB and partners in deciding appropriate responses.

Contact

If you have any questions or queries about the SAR please contact the Richmond and Wandsworth Safeguarding Adult Board:

Name: Ally Smith (SAB Co-ordinator)

Email: SAB@richmondandwandsworth.gov.uk

SUMMARY OF CASE

Issy was 26 years old at the time of her death from a heart attack following sepsis as a result of infected pressure ulcers. She had Congenital Myopathy (CM), which is an extremely rare, inherited disease that affects the muscles. In her case the condition was progressive, severely disabling, and life-limiting. As a consequence of her Congenital Myopathy, she had complex cardiac and respiratory problems. She received specialist support from a Respiratory Unit, which specialises in the treatment of people with neuromuscular conditions. As her condition progressed, Issy become increasingly bedbound, socially isolated and in pain. In March 2020, when COVID pandemic impacted, she was regarded as ‘clinically extremely vulnerable’ and required to ‘shield’, to protect her from infection. This resulted in further isolation.

FINDINGS

Finding 1

“Tunnel Vision” is working to maintain a task focus in pressured work environments which increases the risk of staff inadvertently becoming desensitised to and dehumanising people drawing on health and care services.

System Finding

A range of cognitive biases have been identified by psychologists that affect how we make sense of the world. ‘Tunnel vision’ is one such cognitive bias. It is an understandable response to a pressured environment and is effective at reducing what is in focus and therefore making things appear more manageable. However, it comes with attendant risks associated with not seeing the bigger picture outside of the restricted view that tunnel vision creates. In a safe system, we would expect to see supervision and multi-agency meetings creating opportunities to identify such cognitive biases and review their impact including, any unintended negative consequences.

A troubling feature of this case was the extent to which practitioners working with Issy saw but did not holistically ‘see’ her situation. A large number of people appear to have been desensitised to the neglect of leaving her in a soiled bed and smelling of faeces. The emotional impact of being in a room with a broken hoist, a broken wheel chair and a door too small to let the wheel chair through was not seen. Nor was the reality of being in constant pain, your body expanding , with the example of her sister’s more advanced progression of their shared condition, just along the corridor, taken into account. Professionals who are perfectly sensitive and compassionate in other settings, failed to respond with compassion to Issy’s predicament. Although there was evidence of parts of the wide support system working effectively in partnership, this did not extend to the whole network. There were occasions when important information was not shared and there was no shared understanding of risk. As result, issues such as the safeguarding concern regarding self-neglect became diluted and was not responded to. The impact of COVID-19 simply compounded this situation and left Issy and her family more isolated.

As a consequence, the support Issy received at home was disjointed and characterised by silo working. There were a number of occasions where Issy was on different organisations’ ‘waiting lists’ which meant that access to services was delayed and none of the involved professionals appeared to consider the impact of these delays on Issy’s well-being. There was evidence that

Issy and her family were unaware of how to get Direct Payment statements or how they could use it. They were therefore surprised by the significant surplus which built up and was returned to the Council. The opportunity to explore use of the Direct Payment and to better understand why there was a surplus was never taken and neither did this appear to have been explored with Issy when her care and support plan was reviewed by the social services. None of the involved professionals appeared to be sufficiently professionally assertive or curious regarding Issy's apparent withdrawal from engaging with them or regarding her regular refusal of the available support, despite the risks, particularly to her pressure areas, being clearly understood. Discussions at the professionals workshop revealed individual responsibility for different agencies constrained to discrete tasks, and a readiness to see anything additional as someone else's responsibility and move on from Issy once their own task was completed, or if there was a ready rationale for why it was not feasible.

Questions for SAB and partners

- *What can be done to prevent professionals from becoming desensitized to risk where people do not readily engage in support offered?*
- *How common is it for people to experience delays in receiving services such as environmental changes recommended by OT's, wheelchair services and psychotherapies? Are there agreed mechanisms to get these expedited? If so are these mechanisms used?*
- *How common is it for agencies to follow up discussions about complex health and care systems with a written communication to help people to digest the information they have been provided?*
- *How can the SAB enable a common understanding of self-neglect as a form of adult abuse and of how to make a safeguarding referral of these cases?*
- *Does more work need to be done on promoting professional assertiveness and partnership working?*
- *How can the Board get assurance that people's needs continue to be met in the context of health emergencies such as the COVID-19 pandemic?*
- *How much is known about how well hospital discharges are co-ordinated for adults with complex physical disabilities, where the hospital is out of borough and /or a specialist service?*

Finding 2:

Mental Capacity Act training has not achieved a base line understanding of the application of the Mental Capacity Act across agencies and professions.

System Finding

The Mental Capacity Act (2005) (MCA) is underpinned by key principles, the first of which is a ‘presumption of capacity’ which ensures respect for personal autonomy and requires decision on a lack of capacity to be based on evidence, rather than on assumptions associated with factors such as age or disability. The application of the MCA requires the two parts of the capacity ‘test’, i.e. asking:

- whether the person is ‘unable to make a decision for him/herself’ based on an assessment of the person’s ability to understand, weigh up, retain, and communicate her decisions (functional test); and
- whether that inability is because of temporary or permanent ‘impairment of, or a disturbance in, the functioning of, the mind or brain’ (diagnostic test).

Across the partnership there is wide access to training for all professional groups on the application of the MCA. The Board has also received assurance that front line professionals required to apply the MCA in their day to day work, have access to expert advice on working within it. In spite of this, this case raises serious questions about a basic level of understanding about how to apply the MCA principles in practice and assess mental capacity when necessary.

Issy often refused health treatment and care support, for example declining personal care, not wishing to be hoisted, only allowing her mother to change her pad and this infrequently, only accepting psychological support from an agency that was not able to provide this in her home. Her complex and debilitating condition left her in pain, isolated from friends she had previously engaged with, and confined to her bed. Even when her ‘decisions’ resulted in a hospital admission for not eating, practitioners accepted at face value that this was Issy’s right to refuse care and support if she wished to do so. When Issy effectively withdrew from engaging with professionals and left her parents to act as conduits between her and the support being offered, this did not cause any of the professionals to be professionally assertive to speak directly to Issy, to fully explore her mental state and the reasons behind her seemingly unwise decisions. We would have expected questions of pain, depression, and self-neglect to have been explored in relation to the assessment of her capacity to make decisions about refusing care and support. We could also have expected that legal avenues were considered in terms of gaining access to Issy.

Questions for the SAB and partners

- *How often is the lack of a formal diagnosis indicating a disturbance of the mind or brain used as a reason to not explore people’s mental capacity*
- *How well is the impact of depression, pain and fear on decision making capacity understood?*
- *To what extent do practitioners have adequate access to support and supervision with regard to developing a more nuanced understanding of ‘unwise decisions’?*
- *What can the SAB do to support agencies to embed a more holistic understanding of the application of MCA in practice?*
- *Can the Board be assured that agencies are able to deliver a full range of services to people who are effectively ‘housebound’?*

FINDING 3.

Family carers needs and abilities are not fully and holistically explored with the consequence that carers are left feeling unsupported**.**

System Finding

It is not unusual that parents move from the role of parenting children to being family carers for adult children with physical disabilities. This ‘transition’ in role may lead to parent carers being unable to articulate when the caring duties they are expected to carry out are beyond their capabilities.

Issy had a rare congenital condition and received support from a specialist health service with expertise in supporting people with neuromuscular conditions. When Issy was admitted to hospital with complications as a result of not eating and low mood, concerns about the risk of her continuing to self-neglect on returning home were clearly understood by her professional support network. What was less clear to professionals was the extent to which Issy’s parents were able to support her to meet the demands of her care in the community. The hospital staff were sceptical that Issy would comply with necessary care once back home, however there was little appreciation of the fact that the community support which Issy needed required her to be transported to various sites. The difficulties that the family carers experienced in arranging the transport to these meeting was not appreciated or explored with her or her family carers. As a result, non-attendance at appointments was regarded as Issy making a choice rather than recognising the obstacle which travel represented.

Although the multiple worries and pressures within the family system were well articulated at the point of Issy’s discharge from hospital, this was not picked up by any of the agencies, and as a result the needs of her family carers remained unknown and unmet. There was a ready acceptance that Issy’s parent carers were coping, despite evidence to the contrary. During the COVID-19 pandemic, Issy and her parent carers should have been made aware that the Direct Payment could be used flexibly to meet her needs. This was never discussed with her or her parent carers, leaving the family with a sense that they had to wait for approval for the funding they felt they needed.

Questions for SAB and partners

- *What mechanisms are in place to ensure that the needs of family carers are considered holistically?*
- *How effectively are family carers supported to understand and respond to the needs of adult children with complex and progressive conditions?*
- *Does the SAB see the need to explore how family carers are supported to adapt from the roles of parent of a child to carer of an adult with care and support need?*