

Richmond and Wandsworth Safeguarding Adults Board Safeguarding Adults Review – Issy recording script

Issy was 26 years old when she died from a heart attack following sepsis which had resulted from infected pressure ulcers. Issy had an extremely rare, inherited disease that affected her muscles. Issy lived with her parents and Issy's mother was her carer. In Issy's case her inherited disease was progressive, severely disabling, and life-threatening. As her condition progressed, Issy became increasingly bedbound, socially isolated and in pain.

When the COVID pandemic impacted on us all, Issy was regarded as 'clinically extremely vulnerable' and was required to 'shield', to protect her from infection. This meant that Issy was not able to leave her home and resulted in further isolation.

What did the review find?

Practitioners working with Issy did not see her situation holistically and instead they remained task focused. They did not see and understand the impact that Issy's condition and accommodation had on her. Maintaining a task focus in pressured work environments can lead to "Tunnel Vision" in which we inadvertently become desensitised to and dehumanise people who use services and whom we are trying to help.

The review also found that Issy refused care and treatment but professionals did not question her mental capacity to make these decisions. Mental Capacity Act training has not achieved a base line understanding of the application of the Mental Capacity Act across all agencies and professions.

The review found that the needs and abilities of Issy's family carers were not fully and holistically understood. As a result, they were left feeling unsupported.

So, what can we learn?

1. It is important for adults and children's services to have a model for joint working on cases involving young people with complex needs.
2. Parent carers need support and flexibility when their child reaches 18 years old and their role changes from being responsible for a 'child' to supporting an adult. Professionals need to be sensitive to and supportive of parents and the young person and this role change needs to be explored as part of carers assessments and in the context of developing support plans for the young person who relies on their parent carer.
3. Family carers may need practical and advocacy support, particularly when the needs of the person they are caring for are complex.
4. Depression and isolation may impact on people's capacity to make decisions and we need to be professionally confident in distinguishing between unwise decisions and where executive decision-making capacity is impaired.

5. Self-neglect requires a statutory safeguarding response and cases should be progressed even where the chance of us engaging with the person we are trying to support is small.
6. There is a need for simple and accessible information on managing Direct Payments. We need to seek assurance that people with Direct Payments know how to access them, what the balance is and how to seek help when they are confused. We need to fully explore with the person why any surpluses of Direct Payments have accrued, especially if we are thinking about having them repaid to us. And we need to be assured that they understand how to use their allocated funds flexibly to meet their needs.
7. Where people have complex needs there is often a wide range of community support agencies offering support. There is a need for this to be co-ordinated and for there to be a recognised way for sharing information and updating risk assessments.
8. Multiagency hospital discharge meetings offer the opportunity for professionals from acute and community health and social care services to plan the delivery of care with the person and their family carers. These multiagency hospital discharge meetings should be prioritised when discharging young people with complex needs and where there are concerns about how we will engage with them.