Learning Report – ‘Lucy’

WSAB
Worcestershire
Safeguarding
Adults Board

What were the circumstances that led to this SAR?

The subject of this case was Lucy (not her real name), who at the time of her death was 19 years of age. She had complex needs from birth including cerebral palsy, severe learning disabilities, visual difficulties and challenges with communication and interaction. She required 24-hour care and support. Her primary carer was her mother with whom she was living permanently at the time of her death. Lucy died at home after being hoisted into the bath. The precise circumstances of her death have yet to be clarified. (Inquest pending).

Lucy had been open to Worcestershire County Council (WCC) children with disabilities team until her 16th birthday when her case was transferred to the WCC young adults’ team. At the age of 19 Lucy was assessed as eligible for NHS continuing healthcare (CHC) funding, and her case was transferred to Worcestershire Health and Care Trust (WHCT) community learning disability team which is a service for adults.

WCC had funded Lucy’s residential placement at a residential school in Hampshire from the age of 11 which Lucy left to return to live at home permanently five months before her death.

What was the nature of the safeguarding concerns?

There is no indication that the commissioners of Lucy’s care gained specific assurance over the support she received in respect of moving and handling whilst being cared for at home on alternate weekends, during school holidays and full time from the point at which Lucy left the residential school.

There was a lack of professional curiosity about how Lucy’s mother was managing to care for Lucy, and her much younger sibling as a single parent who was in full time employment.

Successful transition from children to adult services was compromised by late changes in the plans for Lucy’s future care. Lucy did not transition from the residential school to the residential college as anticipated and efforts to find a shared care placement floundered and the focus shifted to developing a funded plan for Lucy to be cared for at home. Throughout these changes Lucy’s education, health and care (EHC) plan remained unaltered.

The process of determining Lucy’s eligibility for CHC funding took a very long time. The need to assess her eligibility was recognised in September 2014 but her eligibility was not confirmed until April 2016, a period of over eighteen months. Lucy was 17 at the beginning of this period and nearly 19 by the end of it. Even allowing for the complexity of her needs, this was far too long.

The preferred approach to meeting the care and support needs of Lucy when she left residential specialist educational provision was a shared care environment with other younger adults. This proved impossible to achieve. There appear to have been a number of factors which put the shared care approach out of reach particularly a lack of premises which were suitable or capable of being adapted to meet Lucy’s needs and which were within reasonable travelling distance of her mother’s home. As options began to be exhausted the fall-back solution was for Lucy to be cared for largely by family members within the family home.

That it did not prove possible to achieve the preferred approach for Lucy is a cause for concern. It is estimated that more than 55,000 young adults are living with life limiting conditions/complex health and/or complex physical disability needs in the UK and that due to improvements in medical care, the number of these young people surviving into adulthood has increased by 45-50% in the last decade. The challenges involved in finding suitable shared care provision for Lucy was not necessarily an adult safeguarding issue although it could become a safeguarding issue if the options for caring for the increasing number of young adults with extremely complex needs are limited and those young adults find themselves being cared for in unsuitable settings.

The principles of the Mental Capacity Act were only rarely applied by agencies working with Lucy and her family. Lucy’s capacity was assessed only twice after the Act began to apply to her from the age of 16. A key area in which Lucy was let down by not having the Mental Capacity Act applied to her, was in the absence of best interest discussions when key decisions about her future were taken. There is evidence of only one best interest discussion taking place in respect of Lucy. Agencies appeared to continue to relate to Lucy as though her mother retained ‘parental responsibility’ even though this ended when Lucy reached 18 years of age.

Although she was provided with professional support and advice, including a personal health budget ‘broker’, mother has confirmed that she found the complexities of putting a funded care plan in place to address the complex needs of her daughter very challenging and frustrating. In her contribution to this review, mother described the process of securing the CHC funded care package for Lucy as a ‘battle’. Mother went on to argue for training to be provided to the parents of children with very complex needs, particularly to advise them on how to deal with the complexities of transitioning from children to adult services. Mother said that she had not even heard of the Mental Capacity Act until she had the opportunity to read a late draft of the SAR report.

Learning identified	What will help?
Mental Capacity Assessment	It is important not to regard the parents as sole decision makers for decisions for which the young person may lack capacity as milestones are reached such as their sixteenth birthday. Acknowledge that from which point the MCA applies, and their eighteenth birthday, when parental responsibility no longer applies.
Monitoring of out of area placements.	It is important for out of area placements for young people with disabilities to be visited at least twice per year. This will mean that where parents or guardians raise any safeguarding concerns in respect of the placement these are enquired into, and where remedial action is required, checks are made to ensure that action has been taken and safety improved.
Transition planning for children with complex needs.	It is important for transition from children to adult services to begin early. All agencies involved in providing care and support to the young person to be involved, for the education, health and care (EHC) plan to be comprehensive and reflect changes in circumstances and for the parents/carers of the young person to be offered support throughout the transition process.
Seeking assurance about the care provided to adults with complex needs by family carers.	It is important for professionals to satisfy themselves that family carers have the capacity and the support necessary for them to provide safe care to adults with complex needs within the family home.
Hidden' males.	The presence of mother's new partner, in or around Lucy's household, who could have presented a risk to her, went largely unnoticed by professionals. It is necessary for professionals to carry out checks on any new adults who have significant contact with vulnerable children and adults and to clarify who the members of the household are each time a professional visit the family.