Adult H Review - 6 Step Briefing

The Background

In 2016, the Southampton Local Safeguarding Adults Board (LSAB) considered the case of Adult H, a man with a diagnosis of severe learning disability and autism who sadly died following a short battle with cancer. The case was referred to the Southampton Local Safeguarding Adult Board to identify any learning for the system regarding how Adult H's communication difficulties, diagnosis of learning disability and behaviours, influenced the care he received. A Multi-Agency Partnership Review was commissioned.

Safeguarding Concerns

Adult H needed support in all activities of daily living, requiring support from two carers. He had little insight into his health needs and had severely limited communication skills. Adult H was unable to understand complex information even using adapted information. Adult H was able to understand some very basic information in the context of his familiar routines. He relied on people who knew him well to be able to understand him, and respond to his needs appropriately. Adult H was unable to communicate pain effectively, and demonstrated this through behaviour.

Between July 2015 and September 2015, investigations began into the cause of Adult H's pain and discomfort in swallowing. Referrals were completed to the Community ENT service, and to the Hospital for investigations. During this time, a theme emerged of reliance on the GP to expedite individual referrals to departments for investigation. Overall, Adult H presented to the GP on six occasions between May and October 2015. Presentations included judgements that vomiting and weight loss may be self-induced and "behavioural". During this time, Adult H also presented repeatedly to Accident and Emergency. The elective use of the Emergency Department appeared to be a strategy to overcome issues within the referral pathway. Adult H had previously been seen by Ear Nose and Throat specialists and discharged, with the advice to the GP to make an 'urgent' referral to upper gastro-intestinal surgical team. The GP made this 'urgent' referral, which was graded as routine by the Hospital which the GP was not aware of. At this time the symptoms may have indicated a fast-track referral under Two Week Wait would have been more appropriate.

The Incident

In October 2015, the GP liaised with the Hospital directly for the outcome of the urgent referral. A referral to gastroenterology through the two-week wait process was advised and completed. Miscommunication about Adult H's hospital appointments and poor planning complicated and delayed investigations further. In November 2015 Adult H underwent an operation, a stent was fitted and a biopsy taken. By the time, Adult H had been diagnosed with cancer he had suffered six months of pain and discomfort on swallowing, vomiting, and severe weight-loss. On 17th November 2015, Adult H was diagnosed with oesophageal cancer, which had spread and was terminal. Adult H passed away on 3rd January 2016. The Review Team gave the circumstances of this case their careful consideration and concluded that although the system should have worked better in the diagnosis and coordination of care provided to Adult H, it would not have been possible to prevent the death of Adult H.

The Review

The LSAB considered the case carefully and concluded that did not meet the statutory criteria for a Safeguarding Adult Review. The Board agreed however, that there was significant learning that could be drawn from this case and so a Multi-Agency Review was commissioned. The focus of the review is to move beyond the specifics of this individual case and to identify the underlying issues that are influencing practice and contribute to improving practice within a whole systems approach.

The Findings

FINDING 1: The **Annual Health Check** should be an opportunity for a person with a learning disability to become accustomed to clinical environments and the experience of healthcare and for the GP and their Practice to get to know their patient. It would benefit from greater opportunity for involvement from family members, carer support, and by other agencies including health and social care.

FINDING 2: Underlying causes – 'behavioural' or physical? Great care should be taken in determining the underlying causes of particular behaviours. Medical history and the views of the person, their family, and other professionals can help clinicians understand what is occurring for the individual.

FINDING 3: Multiagency working and coordination of care - The partnership were unable to escalate or navigate around difficulties in communication. There was a general and widespread recognition among participants in the review that the family of Adult H were pivotal in the raising of concerns and acted as a conduit between services.

FINDING 4: End of Life Care pathways and processes - There was a lack of understanding by services who infrequently work with people at the end of their life, of the referral pathways and processes for end of life care.The lack of a shared understanding about a clear pathway for end of life care, and disagreements about referral processes may have caused a delay in Adult H from receiving the right care and support.

FINDING 5: Mental Capacity - Adult H had been assessed to lack capacity to make decisions about his care and treatment. Section 1 of the Mental Capacity Act 2005 (the principles) should have ensured that any decisions made on behalf of Adult H, were made following the 'best interests checklist'.

FINDING 6: Other Learning - There is a need for organisations to support staff to be able to escalate issues in care delivery, or communication. Organisations may need to take responsibility for educating and empowering their staff to feel confident in challenging practice they have concerns about. Recording of outcomes from appointments and meetings, especially in relation to health matters needs to be robust to ensure the accurate transfer and handover of technical information, agreed actions, and who is responsible for completing them.

Useful links for good practice

- GMC guidance on Diagnostic Overshadowing and Unintentional Discrimination
- Free SCIE Mental Capacity Act E Learning including best interests decision-making, and how to support people to make their own decisions
- Learning Disabilities Mortality Review (LeDeR) Programme which includes a repository of case reviews of people who have Learning Disabilities
- NHS Guidance for Annual Health Checks
- 'How do I get a second opinion?' NHS guidance
- NICE (National Institute for Health and Care Excellence) guidance for end of life care for adults
- Preparing to visit a Dr about Psychotropic Medication – a support workers guide
- Southampton LSAB website