SUMMARY OF SERIOUS CASE REVIEW USING THE SIGNIFICANT INCIDENT LEARNING PROCESS OF THE CIRCUMSTANCES CONCERNING PY

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1.0 Introduction

PY died on 24 November 2014.In February 2015, PY's case was referred to the Chair of Worcestershire Safeguarding Adults Board (WSAB) for consideration for a Serious Case Review. The Chair of the WSAB made the decision that a Serious Case Review should be undertaken in respect of the circumstances surrounding her death. The aim is to establish whether there are any lessons to be learnt about the way in which local professionals and agencies worked together. Professionals considered whether her untimely death could have been avoided.

PY had been adopted as a young child by parents who had several other adopted children and four children of their own. PY had been known to the learning disability services since 1999 and was cared for by her mother independently until 2011 when the mother's health deteriorated and additional care was provided in order for PY to remain at home.

Her mother died in September 2013 and PY continued to live at home with daily support from members of her family, live-in care, domiciliary care and day care services.

PY had a close relationship with her adoptive mother and her adoptive siblings. Her brother called in every day during his lunch break and sometimes after work. Her sister, who lives some distance away, telephoned three times a day and spoke to the live-in carer as well as PY. Another brother called in at weekends and often brought food.

PY had a diagnosis of severe learning disability, cerebral palsy, spastic tetraplegia, epilepsy, nocturnal tonic clonic seizures, severe skeletal deformity, bilateral knee osteoarthritis, previous staphylococcal scalded skin syndrome, penicillin allergy, tonic clonic seizures, scoliosis, osteoarthritis .She also displayed some low level self-harming and challenging behaviour

Due to her complex needs, PY received a wide range of services from a number of agencies.

Since birth, PY had been registered with a Medical Centre which provided a range of GP services in response to her physical and clinical needs. Care was delivered in her home, via telephone conversations with carers and at the surgery. The GP practice oversaw the support given to her for her cerebral palsy, epilepsy and recurrent infections.

The Community Learning Disability Service (CLDT) is an integrated service consisting of a range of health and social care practitioners, led by a Community Team Manager. PY received assessment, support and regular review from nurses, health care assistants, speech and language therapy, psychiatric and neurological teams.

PY received a service from a Specialist Epilepsy Nurse (SE Nurse) employed by Worcestershire Health and Care Trust who provides specialist support and advice for patients and staff and works closely with the Learning Disability Psychiatrists and the Acute Trust Consultant Neurologist for Learning Disabilities as well as the provision of epilepsy training for Local Authority providers and CLDT Nurses.

In addition, PY attended a day centre managed by Worcestershire County Council five days a

week.

2.0 Examples of good practice

2.1. It is important to recognise and highlight the fact that there were several examples of good practice that were evident in the manner in which professionals engaged with PY and her family.

2.2. The professionals responsible for PY's care provided wide variety of services which enabled her to remain in her own home in accordance with her wishes. They listened to her views and acted to increase the level of home care services to 24 hours a day to enable her to remain in her own home. When PY's mother died, PY was able to remain in her own home due to the level of support which was provided.

2.3. The day centre observed an increase in seizures in PY and appropriately referred her to the Learning Disability Consultant Psychiatrist who then made a referral to the Consultant Neurologist.

2.4. PY received consistent input from a health support worker, the live-in carer and the day care centre. Professionals knew her well and maintained a positive relationship with PY and her family.

2.5. Key documents were shared with the day centre, such as, My Hospital Book, Health Action Plan, guidelines for use of sensory equipment and hydrotherapy, Person Manual Handling Risk Assessment pack and Eating and Drinking Guidelines.

3.0 Summary of learning

3.1 Systems need feedback in order to assess how well they are performing, and to make necessary changes. The outputs of this review are a series of findings, referred to as learning points, about the operation of the multi-agency adult safeguarding system. A set of recommendations for the Worcestershire Safeguarding Adults Board are also included. In this case, the key learning points are as follows:

3.2 PY was a woman with complex needs who needed and received a variety of health and social care services from a range of agencies and professionals. These services were sensitive to her needs and were arranged to enable her to stay in her own home in accordance with her expressed wishes and her best interests.

3.3 However, her untimely death has raised fundamental questions about the effectiveness of the systems that are in place to enable the coordination of services for people with complex needs. In particular, no professional was responsible for the overseeing the full range of services and ensuring that multi-agency plans are implemented and reviewed.

3.4 Providers of general medical services for people with learning disabilities need to ensure that colleagues in social care are made aware of any changes in treatment and medication.

3.5 For people with learning disabilities who also have a diagnosis of epilepsy, the Epilepsy Management Plan should play an essential role in managing the condition, sharing information and providing a link with medication. In PY's case, this did not happen due to a combination of delays in the plan's implementation and the fact that it was not shared with all of the professionals involved in her care.

3.6 It is essential that Epilepsy Management Plans for people with learning disabilities are informed and updated in accordance with changes in prescribed medication and shared with all relevant agencies. In addition, a single Seizure Diary should be completed by all

agencies so as to monitor changes and to share information about factors that trigger a person's seizures.

3.7 All service providers need to be aware of the particular needs of people with learning disabilities with regard to preparing them for, and assisting them with bereavement.

4.0 Recommendations

1. The Worcestershire Safeguarding Adult Board should therefore seek assurance that appropriate arrangements are in place across the partnership to ensure that a named professional undertakes the role of care coordinator with responsibility for the management and review of all elements of care for service users who have complex needs.[1]

2. Reviews of services for people with complex needs should be amalgamated into a single multi-agency review to consider all aspects of their health and social care needs

3. A review protocol should be agreed across the partnership to ensure clarity as to attendance and the provision of reports to reviews of people with complex needs

4. The recording of seizures for by all agencies that provide services for people with epilepsy should be amalgamated into a single Seizure Diary which is appended to the Epilepsy Management Plan

[1] People whose conditions require continuous care and services from a wide range of agencies and professionals are defined as people with complex needs. This group of service users require a single care coordinator to ensure the harmonisation of all aspects of their care management.