



Safeguarding Adults Review

Southend Safeguarding Adults Board (SAB)

"Anne"

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Section One

Why this review was commissioned

- 1.1 The Chair of the Southend-on-Sea Safeguarding Vulnerable Adults Board, Christine Doorly, commissioned a Serious Case Review on 6th October 2014.
- 1.2 The incident that started the referral process for Serious Case Review was the death of “Anne”, an 18-year-old Southend resident, in a Continuing Health Care placement in Essex, on the 20th May 2014. *On 19th May 2014 “Anne”, had an epileptic seizure at 06:00. The seizure lasted 2 minutes and it took “Anne” 15 minutes to recover. Then she was monitored by the night staff during the handover to day staff. “Anne” then went back to bed and went to sleep. When the morning staff went to check on her she was found unconscious in the bed. Emergency services were called and “Anne” was taken to Southend hospital at 09:30am. “Anne” died in the early hours of 20th May.*
- 1.3 In considering what sort of review might take place, the Chair of the Safeguarding Adults Board referred to a section of the Southend, Essex and Thurrock criteria that states

A safeguarding adults board should always undertake a serious case review when:

a vulnerable adult dies (including death by suicide) and abuse or neglect is known or suspected to be a factor in their death. In such circumstances the Safeguarding Adults Board (SAB) should always conduct a review into the involvement of agencies and professionals associated with the vulnerable adult.

The result was a decision to carry out a Serious Case Review.

Section Two Methodology – balancing questions about the case with recommendations for the wider system and future changes

- 2 A Serious Case Review Panel was set up to oversee the Review, with an independent chair, Dr Paul Kingston. Dr Kingston has no professional or other connections to individuals or organisations involved in this review.

2.1 An independent author was also appointed for the Review – Fran Pearson is a qualified social worker and social work manager, registered with the Health and Care Professionals Council. She has also worked as a commissioning manager in the NHS. Since 2007 Fran has been independent chair of both adults’ and children’s safeguarding boards and lead reviewer on safeguarding reviews.

2.2 The panel members were as follows:

Paul Kingston	Independent Chair
Locality Manager	East of England Ambulance Service
Chief Nurse	Southend Clinical Commissioning Group and Continuing Health Care
Director	Residential Provider
Sergeant	Essex Police
Safeguarding Adults Manager	Southend Borough Council Adult Services
Group Manager	Southend Borough Council Children’s Services
Associate Director of Safeguarding	South Essex Partnership Trust
Deputy Head; subsequently Headteacher	Secondary special school
Associate Director of Governance	Southend Hospital
SAB Legal Advisor	
Business Manager	Essex Safeguarding Adults Board

2.3 The panel asked each relevant organisation to carry out an internal review of its practice in working with ‘Anne’. These Individual Management Reviews or ‘IMRs’ are an established part of the Serious Case Review process in Southend-on-Sea, and the analysis and commentary in the IMR has to be signed off by each organisation’s chief executive. **The IMRs are the source material for the section on quality of practice.**

2.4 The Safeguarding Adults Board also regards it as important to hear directly from practitioners as part of the review process. **Learning events with practitioners who knew and worked with “Anne” provide the basis for much of the section *Findings for the Board to consider*.**

2.5 Expert opinion – in January 2015, as the review progressed, panel members decided, based on the complex issues of epilepsy management described in some Individual Management Reviews, that an expert opinion should be commissioned from a neurologist. Dr Lucy Coward of Southend Hospital provided this.

2.6 The views of the family - From the outset, the review panel and authors strongly wanted to involve ‘Anne’'s family. "Anne's" mother and author have been in touch at different stages of the review process. At times it has been overwhelmingly difficult for "Anne's" mother to contribute to the process, but she has done so, and the author and panel want to thank her for this. "Anne's" mother was supported by a professional who she trusted and this was of great help. Between them they wrote comments on the entire report and asked questions. Two factual changes were made to the report as a result. "Anne's" mother also asked questions and commented on other aspects of the report - where she did this, her questions have been addressed in this version of the report. In addition she gave some comments about the finding on mental capacity which was reworded as a result, because "Anne's" mother made a helpful point about some of the language being understandable to professionals but less so for carers, parents and anyone who does not inhabit that professional world.

2.7 Terminology - While the review was under way, the Care Act came into force on 1st April 2015, with the introduction of the term ‘Safeguarding Adults Review’ rather than Serious Case Review. This is the title now given to the review about “Anne”.

Section Three

Terms of Reference

The panel set seven lines of enquiry for the review to cover:

- I. The effectiveness of the transition process from child services to adult services and whether it was effective in supporting “Anne” and her family
- II. The events leading to the decision to place “Anne” in a residential provision and the commissioning, funding and identification of residential care
- III. The dates of respective agencies’ case management, the effectiveness of that case management and oversight of the residential placements
- IV. “Anne”s’ health condition and whether her health needs were appropriately met
- V. The commissioning of suitable placements for young adults with behavioural issues and/or disabilities and the reasoning behind the placement of a young adult in a registered children’s home
- VI. The Care Plan and the effectiveness of its development, implementation, monitoring, and review. Was the care plan informed by consultation with ‘Anne’ and her family? Was it informed by relevant medical and social needs?
- VII. The effectiveness of how “Anne”s’ health condition was managed by health services, the residential placements, and other relevant services, in the context of her physical and emotional development as a young adult

3.1 The period under review -The panel agreed that the review would cover the period from **1st November 2013 to 20th May 2014**. Contributing agencies were also asked to include any information relevant to the key lines of enquiry listed above or safeguarding of “Anne” dating back to October 2012.

3.2 Parallel processes - There are no other processes outstanding, or that have

been under way during the period of this Safeguarding Adults Review. A Post Mortem examination took place on 27th May 2014 and concluded that “Anne” died of natural causes - 1a Hypoxia Brain Injury; 1b Epilepsy. This report was presented to the Essex Coroner who as a consequence, decided not to hold an inquest.

3.3 What this review is, and what it is not

This review is an attempt to learn from professional practice in the case. The Care Act sets out what the government expects Safeguarding Adults Reviews to do:

SARs should seek to determine what the relevant agencies and individuals involved in the case might have done differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account. Other processes exist for that, including criminal proceedings, disciplinary procedures, employment law and systems of service and professional regulation, such as CQC and the Nursing and Midwifery Council, the Health and Care Professions Council, and the General Medical Council. [para 14.139 of Care and Support Statutory Guidance, issued 23rd October 2014].

Summary of the case

3.4 Family composition: “Anne” her sister; her mother, and at a different address since her early childhood, her father. “Anne” died at Southend hospital in May 2014, at the age of 18.

3.5 “Anne” was a young woman from Southend who, as the result of a difficult birth, had learning disabilities, and from the first weeks of her life, seizures that were usually frequent and caused her fear and difficulties despite continuous efforts by specialists to control them.

3.6 At the time of her death, “Anne” was a resident at a residential children’s home for young people with disabilities. She had been a resident since 1st February 2014, so she was 18 when she came into the children’s home. Leaving home at 18 was something she had apparently expressed a determination to do for some time. The move was preceded by a volatile time at the home she shared with her mother and older sister and ‘Anne’ moved hastily from a regular respite break with one

provider to the placement.

3.7 'Anne' was previously known to the Borough Council's Department for People, initially as a Child in Need by the Children With Disabilities Team, who arranged 10 days per annum respite care. Latterly, 'Anne' had been known to the Transition Team. In January 2014, 'Anne' became the responsibility of the local NHS Clinical Commissioning Group as she became eligible for NHS Continuing Healthcare following a multi-disciplinary team recommendation. 'Anne' was not eligible for adult social care services from the borough council, so the professionals who knew her well in the past were no longer formally involved – although they did offer to advise workers who were new to 'Anne's' arrangements.

3.8 'Anne' was a pupil at a special secondary school for children and young adults with mild to moderate learning disabilities and physical health needs. Before her 18th birthday she had been clear that she wanted to leave school as soon as she was an adult. However in April 2014 she assaulted the headteacher and was excluded. The exclusion was reviewed at least once by the school governing body and remained in place at the time of 'Anne's' death.

3.9 On 19th May two night staff at the placement heard the sounds of what they thought could be 'Anne' having a seizure, and went to her room. They observed 2 or 2.5 minutes further of the seizure before it ended and gave 'Anne' 15 minutes to recover. 'Anne' then went back to bed and went to sleep. When the morning staff went to check on her she was found unconscious in the bed. Emergency services were called and 'Anne' was taken to the local hospital at 09:30am. 'Anne' died in the early hours of 20th May.

3.10 The Social Care Compliance Inspector, East of England (Ofsted) and team conducted a monitoring visit of 20 May 2014. This visit identified a number of significant shortfalls in care practices. None of these shortfalls, from a police perspective, were believed to amount to any criminal offences.

Section Four

What does this case tell us about professional practice?

Key dates: 1st November 2013 to 20 th May 2014	
Early November 2013	'Anne''s 18 th birthday
November 2013	'Anne' tells professionals that she does not want to return home from her regular, planned respite placement
23 rd January	'Anne' is assessed and agreed as eligible for NHS Continuing Healthcare funding. The Community Team for People with Learning Disabilities at the local authority ceases to be involved and case management responsibilities pass to the Commissioning Support Unit where a practitioner is allocated as 'Anne''s case manager
1 st February	'Anne' moves into a placement at a scheme for children, registered with Ofsted
3 rd February	Placement staff register 'Anne' at GP practice no 2
6 th February	Placement staff are unable to wake 'Anne' and call an ambulance. 'Anne' is responsive when paramedics arrive and suggests to placement staff that she had wanted to see if they knew what a seizure looked like. 'Anne' is not taken to hospital
6 th March	'Anne' has an appointment with adolescent transition team at a national hospital after being referred by the specialist hospital for children
8 th March	'Anne' has seizures at the placement and staff call an ambulance – she is taken to the local hospital
18 th March	'Anne', her mother and a worker from the placement attend a final appointment at the specialist children's hospital
7 th April	'Anne' has seizure at the placement, and staff call an ambulance – she is taken to the local hospital and discharged after tests
23 rd April	'Anne' assaults the headteacher at school by punching her. This results in facial injuries for the headteacher, including

	a fracture. 'Anne' is excluded from school.
24 th April	Placement staff ask for 'Anne''s local hospital neurology appointment to be brought forward to review <i>medication and seizures and out of character behaviour</i>
28 th April	Meeting of school governors results in letter - saying that 'Anne''s fixed term exclusion had been extended until 01.05.14 and that further decisions would be dependent on outcome of a professionals meeting with Social Care. 'Anne' to be home educated by placement staff, and school to send work for her on a regular basis (school IMR)
1 st May	Placement staff offer 1:1 support to school so that 'Anne' can get back into education – school suggest the offer is taken to professionals meeting
1 st May	Placement staff make a referral to an advocacy service
2 nd – 7 th May	Following tonic clonic seizure at the placement, care staff call ambulance and 'Anne' is taken to the local Hospital and admitted
9 th May	Staff meeting at the placement, where a new consultant's revised medication plans are discussed and started. 'Anne''s capacity is also discussed in relation to financial decision-making. The CHC nurse is quoted at the meeting as having advised staff verbally that 'Anne' did not have the capacity to make decisions about her finances and she will put the assessment in writing
11 th and 12 th May	One of 'Anne''s medications – phenytoin – is missed off the list of what staff give her at both 10pm and again at 8am. GP and 'Anne''s mother are advised, GP is left a message but does not return call. This in turn apparently causes a delay in reporting to adult social care, but this ultimately happens too. Staff member(s) given written warning.
15 th May	The CHC nurse emails the placement: 'Anne' has texted her twice saying she is having 'a lot of seizures'. Placement staff reply by email - actually none since the admission on 2 nd May but that a monitor may not be picking up night-time seizures, to be followed up at a hospital appointment
14 th – 17 th May	'Anne' is away from the placement for 2 nights staying at

	her mother's. As advised by the hospital neurologist on her early May admission, 'Anne' is given the last of two week's doses of phenytoin
18 th May	'Anne' has a seizure at 7.30am.
19 th May	'Anne' has a seizure at 6am, staff members assess that it is appropriate for her to go back to bed after 15 minutes, and no medication is given. At 7.45 her daytime worker is on shift and goes into 'Anne's' room. She is not breathing. Cardiopulmonary resuscitation is attempted and ambulance called. After arrival of both First Responder and ambulance, the air ambulance is called and takes 'Anne' to hospital
19 th May	Police arrive at 8.25. Ofsted notified
20 th May	'Anne' dies in the early hours of the morning

This section does not look at every piece of practice that happened during the review period (Nov 2013 to May 2014) rather, at the aspects of practice that are pertinent to the Lines of Enquiry for this review

The effectiveness of the transition process from child services to adult services and whether it was effective in supporting "Anne" and her family

4.1 The later stages of the transition process for 'Anne' was not well managed and there was delay with the essential task of assessing 'Anne' for Continuing Healthcare - with the local authority delaying in referring 'Anne' for this assessment, and the CHC team delaying in their response. At points when these two agencies did push the process forward, it was responsive to 'Anne', involved her, and took her wishes into account. Although both the local authority and the Clinical Commissioning Group identify that the process was not well managed in 2013 as 'Anne' approached her 18th birthday, it is not clear why a process that began more than a year earlier, as per local agreements and national standards, stalled in its later stages.

4.2 A transition protocol of May 2012 sets out the responsibilities of Children's and Adult services for young people in Southend with Disabilities, Learning Difficulties and Long Term Medical Conditions. A social worker from the Community Team for People with Learning Disabilities - CTPLD - became involved in the

transition planning on the 7/2/2012 when “Anne” was 16 and in line with expectations in the Transition Protocol. This makes delays in organising the necessary assessments regarding “Anne”’s eligibility for NHS Continuing Health Care as her 18th birthday drew nearer harder to understand. IMRs from both Adult Social Care and the Clinical Commissioning Group recognise this.

4.3 When ‘Anne’ turned 18, she was living with her mother in Southend, attending special secondary school there, and having planned respite away from home at a local provider. Practitioners appeared sensitive to ‘Anne’ and ensured that she was part of the decision-making - this included the decision to move to a residential provider when the situation at home broke down.

The events leading to the decision to place “Anne” in a residential provision and the commissioning, funding and identification of residential care

4.4 ‘Anne’ moved in an emergency. Practitioners were keen to stress two aspects of this - first of all that in most cases where agencies have to act quickly to support a young person: 'We like to think we can act in a responsive and quick way but will have the chance to put the building blocks in place later – in this case this chance did not happen. Services fragmented and [‘Anne’] died before we had a chance to bring it together, although we must be clear to reflect the good stuff as well as the tragedy... there were many positive things for her – she became independent.' Secondly, practitioners stressed that ‘Anne’ was determined to bring about the changes she wanted in terms of where she lived and whether or not she was in school. Usual agency processes and professional relationships could not always keep up with the pace that these changes required.

The dates of respective agencies’ case management, the effectiveness of that case management and oversight of the residential placements

4.5 Among the tools that did not keep up with ‘Anne’'s situation was her Care Plan. The Residential provider IMR says of the Care Plan: *This document does not appear to have been updated once ‘Anne’ left home. It was identified in this document that ‘Anne’ wished to move out when she was 18 years old and that her mother supported this decision. There was nothing on the residential provider's file*

to evidence a discussion between professionals about 'Anne' moving to [the placement] and how [it] had been selected and agreed as a suitable placement for her.

4.6 The contract between the Continuing Healthcare Service and the provider had not been completed and signed prior to 'Anne's' death. The provider told the panel that they develop a support plan for residents very often without the Care Plan from the commissioner. In 'Anne's' case, it was unclear to the panel and indeed to provider, whether the nursing needs assessment for 'Anne' was available to the residential provider.

4.7 During March/April the residential provider's IMR gives an impression of the staff as feeling somewhat isolated in managing some of the issues around 'Anne' – who had only moved in on 1st February. Both the CCG and residential provider's IMRs record that the Continuing Health Care nurse was apologetic for not being in touch during these two months. This reflected the caseloads for the Continuing Care team. However it had the effect of leaving the residential provider staff feeling isolated. There was also an adult learning disabilities team in Health, which was a possible source of support and advice - GP Practice no 2 delayed making a referral onwards to this team, so its potential as a new and appropriate source of support was not explored at any point.

'Anne's' health condition and whether her health needs were appropriately met

4.8 March 2014 saw the handover of care, which had been shared previously, as per the specialist children's hospital's usual arrangements, with the local hospital. The independent neurology review is clear that the documentation from this date onwards relating to inpatient and outpatient activity, 'is very good. Outpatient neurology clinic letters have a clear plan and are copied to all relevant parties involved in ['Anne's] care'. Decisions about adjustments to her medication, especially around the time of her one admission to hospital in 2014 (May 2nd-7th) were appropriate, and 'Anne' was seen the day after discharge in clinic.

4.9 Medication changes though, of the complexity required for a young person with 'Anne's' needs, had implications for 'Anne' and for the rest of the professional network around her. The panel meeting of January 2015, as well as the learning event of June 2015, elicited some striking statements from professionals about the

difficulties that are part of the prescribing system. GP 1 knew 'Anne's mother well, and saw her regularly but did not feel 'in the loop' despite his central role and overview of medication issues. The GP explained to the SAR Panel that adjustments to medication were dealt with between 'Anne's mother, himself and the practice administrator – but there was always a short period following a specialist hospital appointment when adjustments were reliant on 'Anne's mother reporting back on them before written updates arrived from the consultant – 'This is London dealing with London - we were not in the loop'. As it turned out, even when all the management of 'Anne's neurology care was transferred to the local hospital, as opposed to being shared with specialist resources in London, GP systems did not keep up with correspondence. GP2 also gave an account of the difficulties of sifting through the volume of correspondence about patients. 'Anne's health needs and the very complex management of her epilepsy was carried out well by the local hospital, as the expert opinion for this review makes clear.

4.10 While 'Anne' was at school, as noted in both the local hospital and SEPT IMRS, there was close working between the school nurse and the hospital. With the complexity of 'Anne's epilepsy, the understanding and communication between the health professionals who knew her well was not in doubt. The difficulty, as identified by the panel and by practitioners involved in the review was that for other professionals, it is more than complicated - 'you don't know what you don't know' - and for staff in the residential provider setting, without the knowledge of 'Anne' that some of her health network had, complexity could feel daunting. The IMR for the residential provider notes this and speaks positively about the role of staff in ensuring their observations of 'Anne's changing health needs were communicated to health professionals and that her health and medication was reviewed. It was their observations and identification of the changes in 'Anne' that led to them requesting her neurology appointment be brought forward, resulting in her being seen in May 2014 rather than September 2014.

The commissioning of suitable placements for young adults with behavioural issues and/or disabilities and the reasoning behind the placement of a young adult in a registered children's home

4.11 When the Panel first met, members were curious and concerned as to why an 18-year-old woman was placed in a children's home. As the review progressed

this became less baffling. The Panel heard about the lack of options for a young person with 'Anne's' needs. She moved in a hurry to the residential provider from a respite placement that she had attended previously. However, managers and staff of the residential provider were all clear that this was an appropriate placement for 'Anne', based on her age and her needs. There was strong representation from staff there, to the IMR author they commissioned, "that the legal definition of an adult (18 years and over) does not fit so clearly within a care situation, as the reality is much more complex with issues of Learning Disability and maturity being relevant factors when considering whether it is appropriate for a group of young people and young adults to live together. 'Anne' was in a home environment with three other residents who were aged 19, 17 and 15 years old. The fourth young adult was living in a self-contained flat that is part of the establishment. The staff gave a consistent view that there was a good fit for 'Anne' in the placement, based on the ages of the other residents and flagged that, in an adult residential care establishment, 'Anne' could have been placed with much older residents. The unanimous view from the residential staff was that this would not have met 'Anne's' needs, as she was a young woman who enjoyed being with teenagers and engaging in teenage activities". This view was not disputed by panel members or other professionals - and there was agreement across all participants in this review about the absence of any alternatives for 'Anne', should the residential placement have broken down.

However, even if other placement options did not exist, there were some aspects of the practice in Anne's case where discussion with family members about the range of options, discussion with other professionals about those options, and review of those options, could have taken place. 'Anne's mother commented that there were in her view two other options that she considered possible for 'Anne'. One was a residential unit outside Southend, where 'Anne' was assessed once. Secondly, 'Anne's mother had hoped that a new development being built locally could be a potential home for 'Anne'. What this highlighted for the Review Panel was the importance of discussion between professionals, service users and family members about placement options. This could include clear and realistic discussion about any new service developments, as for example, there was no guarantee that the new building 'Anne's mother saw, and hoped her daughter might move into, was a service that could safely or appropriately meet her daughter's needs. In the same way, clear discussion between family members and professionals could also clarify the purpose or criteria for any services, such as the one where 'Anne' was assessed for a few days, because the assessment left 'Anne's mother with the impression that

this was potentially a placement where her daughter could be supported longer term, and she questioned whether funding limits stopped this from happening. The Panel member from the NHS, whose organisation funds Continuing Health Care, was absolutely clear that funding limits had not been an issue when 'Anne's urgent move took place, This reinforced the importance of how professionals hold a conversation with family members about available placement options.

The Care Plan and the effectiveness of its development, implementation, monitoring and review. Was the Care Plan informed by consultation with 'Anne' and her family? Was it informed by relevant medical and social needs?

4.12 The lack of a Care Plan was apparent to Managers and practitioners at the residential provider who were trying to make sense of where to go for advice, and how to respond to 'Anne' on several issues because she was over 18. Capacity assessment was a recurrent theme and the source of different approaches by school and residential provider. These differences were one area (of several) that underlined the lack of a current and effective care plan for 'Anne' once she was excluded from school, and living away from home within the funding and case management orbit of Continuing Health Care.

4.13 In the recent past, there had been difference of opinion between the school nurse and local authority social workers around the issue of capacity and what this meant for 'Anne'. The School Nurse informed the Social Worker that 'Anne' did not have the capacity to consent to medication as she was a young girl with a learning disability and a health condition who was thought to be functioning at Level 2 of the National Curriculum which is the level expected of an average seven year old. The SSN1 also raised the concerns that 'Anne's' capacity can fluctuate according to her emotional health and that this could have a direct impact on whether she did or did not take her anti-epileptic medication. The SEPT IMR states "There was clearly a missed opportunity for health and social care to work together to make decisions about 'Anne's' ability to live independently and manage her anti-epileptic medication effectively so that she could reach her full potential at this time".

4.14 With the move to the residential provider, the ending of input from social care and the lack of a care plan, this issue remained unresolved. 'Anne' firstly did not always want to take her medication, and there were also issues with who had control of her finances. As the IMR for the residential provider says: "The staff all stated

that 'Anne' was treated as an adult and they were able to provide examples of how 'Anne' was consulted with and how she contributed to decisions about her care. This included that 'Anne' could choose to opt out of any activities or out of taking her medication. The staff were clear about this and talked about how they would negotiate with 'Anne' in these circumstances but, ultimately, the decision was for her to make as she was deemed to have capacity as an adult".

The effectiveness of how 'Anne's' health condition was managed by health services, the residential placements, and other relevant services, in the context of her physical and emotional development as a young adult

4.14 Professionals told the Panel for this review that 'Anne' was a determined young woman who for some time had had a clear plan to leave home and to take actions that would make this move as likely as possible. There was a mixed picture though as to how responsive some parts of the system were when this situation arose. After her exclusion from school, the residential provider staff took considerable steps to occupy and support 'Anne', but they perceived themselves as being in quite an isolated position - on a "steep learning curve" in terms of this being the first time they had encountered, either organisationally or individually, someone placed through the Continuing Healthcare route. The context of 'Anne's' physical and emotional development as a young adult was well understood by school staff and by the school nurse - once in placement and excluded from school, the residential care staff went to considerable lengths to try and understand this context

4.15 In the period between excluding 'Anne' until the time of her death, the school was trying to get meetings with the adjoining local education authority to plan for her next steps of education - the timing of this created another gap in support for 'Anne' because, as far as her 'new' local education authority was concerned, it was her decision to leave school because she was now 18.

The incident that triggered this review; could 'Anne's' death have been prevented?

4.16 As referenced earlier in this report, the Care Act Guidance on Safeguarding Adult Reviews states that Safeguarding Adults Reviews "should seek to determine what the relevant agencies and individuals involved in the case might have done

differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again" (Care and Support statutory Guidance:14.139). The events leading up to 'Anne's death involved a single agency - the residential provider - and are analysed extensively in that agency's IMR for this review. The recommendations from that agency reflect the analysis around the event of May. The provider's policies and procedures were not followed by the night staff at this time. The key staff involved no longer work for [the provider]. " it was human error and staff not following policies and procedures on this occasion that resulted in 'Anne' not receiving the care and responses she should have had that morning, rather than the incident reflecting that staff were unable to meet 'Anne's health needs." 'Anne's mother asked, after reading an earlier version of this report, how some of the practices at the scheme could have happened, for example why all staff members were in the handover session rather than keeping a watch on 'Anne'. The agency in fact changed not just what happens at handover, but other practices as well so that the learning from the day of 'Anne's death was very quickly acted upon.

Section Five

Recommendations for each agency (from agencies' own Management Reviews)

The recommendations include a core of actions that are relevant to the Lines of Enquiry for this review, and are captured in the Findings and Recommendations for the Board, and others that are issues noted during the course of the review, but less central to it. All the single agency recommendations can be found in Appendix 1

Section Six

Findings for the Board

These findings are intended to give the Board some areas for consideration in terms of wider safeguarding adults' systems in Southend. They were discussed with practitioners who worked with 'Anne', and then tested out with the panel to see how prevalent these issues might be locally. They are nonetheless quite tentative and for the Board to take a view on.

Finding 1: *Case management arrangements for young people who need solely Continuing Health Care post 18 are currently set up in such a way that professionals who hold the case management responsibility are pulled towards families who are the most vocal, with the consequence that the needs of some young people are less visible.*

Different drivers mean that there is a striking difference between the co-ordination that social care offers to 18-year-olds in transition from children's services, and the approach necessarily taken, due to resources, by the NHS Continuing Health Care service (CHC). Practitioners spoke of the volume of referrals for CHC, because the purpose of the service is to assess eligibility, not to manage cases. Recent changes are intended to improve the service, and the panel received a strong sense of this. However for the distinct group of young people who are eligible only for Continuing Health Care and not for an arrangement at 18 that includes social care, practitioners proposed a backup arrangement with social care that the current system is not flexible enough to allow. This is on the radar of agencies, with a meeting scheduled to look at the Portsmouth model of case management, at different and agreed levels of intensity, for all CHC patients, so that everyone will have some level of case management.

Finding 2

The transitions protocol is comprehensive but the pathways and descriptions of multi-agency planning that it contains are largely based on young adults being reviewed or supported by the local authority's Adult Social Care service, which results in a lack of clear expectations about the transition arrangements for those who are becoming the responsibility of Continuing Health Care only.

Panel members recognised that this is complicated by the different Continuing Health Care criteria for children and adults - something that will be addressed by a new protocol. Panel members also questioned whether the language should be more about changes in commissioning, rather than transition. This would have the effect of recognising that the arrangements of some specialist health partners (including the children's hospital where 'Anne' received her care) override agreed local good practice.

Finding 3

There is clear planning and information-sharing within health agencies about the management of complex epilepsy - but GPs' role as a conduit between specialists and family members or social care providers, is variable as they struggle to manage the volume of correspondence about patients. This means that adjustments to complicated medication plans can be entirely dependent on family carers while updates from specialist doctors are sent and then logged at GP surgeries.

Although the independent neurology review commissioned for this SAR comments that the outpatient neurology clinic letters have a clear plan and are copied to all relevant parties involved in 'Anne's' care - despite the strengths of hospital processes, it could take weeks for a GP to attend to such copied letters. Two big practices do not have SystemOne; and so although the hospital is looking at systems to transfer summaries direct into GP's inboxes by 2020, there remains a potential area of weakness.

Finding 4

Because there is a lack of placement choice for young adults with particular combinations of disability and complex health conditions, some adults in transition are placed in provision that is primarily for children, with a risk that the needs of neither group are met.

Providers and commissioners on the review panel talked about the emerging market of care for young people with disabilities and that consequently professionals have to follow a process of looking for a space and then placing a service user in it - contrary to the way they would like to work. There was some hope that the Care Act may have an impact on this situation, and that local work on quality frameworks across the whole of Essex may also assist. The residential provider reported that when they

opened their children's home, placements were very quickly filled by 14-16 year-olds – and when they reached their late teens, family members were reluctant to move them to new provision where the next youngest person was in fact in their fifties. The lack of placements was described to the review team as stemming in part from difficulties of regulation, and this in turn raised questions about the role of health commissioners in overseeing social landlords who could potentially provide for young people with disabilities.

Finding 5

The Mental Capacity Act takes as its starting point that, unless it can be shown otherwise, 16 and 17 year olds, as well as over - 18s have the capacity to make their own decisions. This legal framework requires professionals, parents and carers to think about decision-making and rights in such a different way to the approach taken with children under 16 that it can be a challenge for all concerned.

Investment has made into training and support for professionals working with any young person from the age of 16 - most recently in May 2016 with specially commissioned courses for a range of professionals in Southend. The impact of this may be something the Board could consider. The related question which surfaced in 'Anne's case, was how effectively professionals discussed Mental Capacity with her family.

Recommendations to the Board

Recommendation 1

The SAB should ask the Clinical Commissioning Group to report back on the implementation of proposed changes to case management for those adults in Southend who are eligible for Continuing Health Care, and consider raising with the Health and Wellbeing Board any emerging case management gaps for young adults in transition into the service.

Recommendation 2

The SAB should receive an update on, and have the chance to comment on, the draft transition protocol between adults' and children's services, and ask for assurances about the way this is being embedded in the local operating framework so lines of responsibility and co-ordination are clear between health and social care.

Recommendation 3

The SAB should seek updates on work in Southend to enable the sharing of NHS patient information between primary, secondary, specialist care and other health settings - and ask some questions about how this will help not just GPs, but any health professionals with a coordination role for the care of particular service users with complex needs.

Recommendation 4

The SAB should hear back from commissioning colleagues about the impact of the Care Act on placement choice and development for young adults with complex needs.

Recommendation 5

The SAB and the Safeguarding Children Board could sponsor a joint piece of work to understand the different professional cultures around mental capacity and decision-making in services for children and for young adults, with a view to reducing some of the differences in practice that can have a direct and inconsistent impact on young adults with complex needs who are in transition between services.

References

The Care Act *Statutory Guidance* October 2014

Social Care Institute for Excellence *Transition from children's to adult services – early and comprehensive identification* March 2015

Appendix 1:

Single Agency recommendations for improvement or change - this is the full list from each of the Individual Management Reviews

1 East of England Ambulance Service will

- 1.1 Continue to explore ways to send patient non-conveyance information to GPs in order that there is awareness of all attendances and this information forms part of the patient's medical history maintained by the GP.
- 1.2 Expand the uptake of ePCR usage to ensure, where permission is given a SystemOne notification is sent to the GP.
- 1.3 Consider utilizing the Single Point of Contact System to process and pass information. This would require additional funding and impact on the time spent by operational crews on scene.

2 Southend Hospital

Nil recommendations for action on behalf of the Trust

3 Surgery 1

More funding to contract personnel to deal with vulnerable patients individually.

4 Surgery 2

The following issues determined her management could have been improved on.

- 4.1 On receipt of the letter advising reduction of her antiepileptic medication on the 13th of March, the advice was not acted upon with immediacy. Dr A was aware of the request but decided to review the patient in the surgery to discuss the medication change. This was because the recommended regime of the medication reduction was rather complex and was not suitable for dealing with by just altering the repeat prescriptions. However, after she was admitted into A&E with an epileptic fit 3 weeks later, Dr A decided tapering off her medication would have been clinically unadvisable. Whereas this may have been a good decision in retrospect, the patient should have been reviewed earlier.

4.2 There was a delay in referring the patient to the adult learning disability service from the surgery. The letter was received at the surgery on the 11th of April and seen by Dr A sometime on or after the 14th of April. Dr A was aware of the request but had not made the referral by the time the patient died on the 20th of May 2014.

4.3 There could have been better documentation of her medical records

The Surgery has a local safeguarding Adults Policy in place and there is no indication this policy was breached. The administrative procedures in the surgery provided clear audit trail of the management of this patient. However, lessons can be learnt from the issues highlighted above.

5 Southend CCG and Continuing Health Care

5.1 There is an identified need for CHC staff to have more involvement before the placement takes place – better communication between social care and CHC, meet the potential resident, discuss the care needs with them if appropriate and make decisions themselves about the appropriateness of the health and social care package being pl'Anne'd before it is implemented.

5.2 There is an identified need to review CHC staffing, capacity and the prioritisation of assessments so that assessments, involvement and reviews take place at the optimum time and allow more flexibility for moving appointments. Is there a need to review the way that appointments are booked? There is a need for someone to co-ordinate the appointments and diaries?

5.3 There is an identified need for CHC staff to take on more of a case management role so that the CCG can be assured that the care being commissioned meets the person's need, is appropriate and safe.

5.4 Improved system of record keeping - recording telephone conversations, patient/client interactions, plans for care.

6 Residential Provider

- 6.1 To register with the Care Quality Commission if they are providing residential care to adults

- 6.2 To review and revise their referral process to include a referral form whereby the placing authority signs to confirm that the placement meets the identified needs of the resident, an initial review date is set and agreed, that any review will be brought forward if the residents needs change and where roles and responsibilities are clarified

- 6.3 Directors to ensure the Registered Manager undertakes management oversight and scrutiny of practice for day and night shift workers and that case specific quality assurance findings are recorded on individual case files

- 6.4 The Registered Manager should consider introducing a performance capability initial assessment for Shift Leaders that includes observation of practice to identify evidence that they are confident to, and capable of, leading staff before they lead shifts unsupervised

- 6.5 Directors to review the new placement plans and the new policy of staff signing to show they have read and understood them, to ensure compliance with expectations and review effectiveness of improving communication between shift workers

- 6.6 Night staff to be enabled and expected to work as part of the whole team

- 6.7 Directors should review the new process for administering medication to ensure it is reducing incidents of human error

- 6.8 To review staffing structure to ensure roles and responsibilities are clear and that night staff are enabled and expected to work as part of the overall team

6.9 Practice in working with Adults to be further developed within the team

7 Essex Police

7.1 It is recommended that Police personnel are reminded that where a vulnerable adult is at high risk of immediate serious harm or death, they must immediately consider how to reduce this risk, whilst having regard for the wishes and capacity of the vulnerable adult.

4.4 It is recommended that Police personnel are reminded of the availability of the form SETSAF/1 within the Force Forms database, when to complete it, and the need for its timely submission to the relevant Local Authority and to CRU- PPSOVA.

8 Southend Borough Council Children's and Adults' Services

Some recommendations are relevant to both adult and children services:

8.1 **Children and Adult Transition Workers:** Between the ages of 16 and 17, an assessment of social care needs alongside the completion of an NHS Continuing Healthcare checklist is sent to the appropriate Commissioning Support Unit or Clinical Commissioning Group as appropriate in order for a joint assessment, care plan and determination of eligibility is established for when the individual turns 18. The Care Act 2014 (para 16.79) sets out these steps as outlined by the National Framework (2012);

8.2 **Children's and Adult Commissioners:** For local commissioning arrangements between health and social care to have a greater 'joined up' approach so that the needs of individuals with complex epilepsy and challenging behaviour can be met across several providers;

8.3 **Children's and Adult Services:** A clear transition protocol that mirrors the National Framework for NHS Continuing Healthcare to become embedded in a local operating framework so lines of responsibility and co-ordination are clear between health and social care;

8.4 **Adult Services:** Specialist health and social care practitioners/clinicians are involved in MDT assessments where appropriate to ensure the most accurate and comprehensive portrayal of needs to inform the care plan;

8.5 **Adult Services:** For social care to take part in joint 3 month reviews with health colleagues to ensure long term suitability of placements (especially for those who have gone through the transition process);

8.6 **Adult Services:** Care plans are co-created between health and social care colleagues even when an individual has a 'Primary Health Need' and are eligible for NHS Continuing Healthcare;

8.7 **Adult Services:** To ensure that appropriate health and social care specialists are involved at the MDT assessments meetings to ensure all clinical assessments and evidence inform relevant care plans;

8.8 **Children and Adult Services:** To restart the multi-agency operational and strategic transition group meetings, ensuring that appropriate challenge and scrutiny addresses the key issues from the frontline practitioner group;

8.9 **Children and Adult Services:** To ensure that appropriate and ongoing Mental Capacity Act training is provided for transition workers across children and adult services;

8.10 **Adult Services:** Strategic consideration between the LA and the CCG as to whether integrated health and social care assessment and care management teams would reduce risks and improve outcomes for vulnerable adults who become eligible for NHS Continuing Healthcare.

9 South Essex Partnership Trust

9.1 The implementation of a template for recording the minutes of the Team around the Children meetings will be developed and put on the SystemOne

electronic health records for all Children Services Practitioners in SEPT to access. This will increase the compliance and effectiveness of Children Services Practitioners in SEPT with the internal SEPT guidelines for Team around the Child Meetings issued in March, 2013.

- 9.2 A review of the role and responsibilities of the Specialist School Nursing Service in the assessment of the mental capacity of a young person over the age of 16 in line with the Southend, Essex and Thurrock (SET) Mental Capacity Act 2005 and Deprivation of Liberty Safeguards Procedures. This would identify a clear pathway for the Specialist School Nursing Service regarding the principals of assessing mental capacity for anyone over the age of 16 years and above as well as offering guidance on how to conduct and record the mental capacity act assessment in the electronic health records.
- 9.3 The review would identify the training requirements for the Specialist School Nursing Service to ensure that they have an understanding of the Mental Capacity Act (2005) as it relates to their own responsibilities in the implementation of the assessment of a young person's capacity who has learning disabilities and complex health needs.

10 School

- 10.1 Review the collaborative working and communications with private residential providers
- 10.2 Review the school Exclusion Policy and Procedure: Be more systematic in the presentation of statements to support evidence to Exclusion panels and similar formal hearings.

11 Specialist children's hospital

- 11.1 On Transition the risk of SUDEP (sudden unexpected death in epilepsy) can be included in handover

11.2 advise of risk to young persons can be highlighted and any preventative measures possible be recommended

11.3 Guidance for carers in residential homes on how to care for young persons with epilepsy can be standardised with appropriate training