Parliamentary
and Health Service
Ombudsman

Report by the Health Service Ombudsman for England of an investigation into a complaint made by Mr and Mrs M

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Contents

Foreword 2

Introduction 3

Summary 4

Report of an investigation of a complaint about Dr K, South Essex Emergency Doctors Service (SEEDS), NHS South West Essex (the PCT), and Basildon and Thurrock University Hospitals NHS Foundation Trust (the Trust). 10

The complaint 10

Our decision 12

Our jurisdiction and role 13

The basis for our determination of the complaint 14

The investigation 16

The complaint about Dr K 26

The complaint about SEEDS 34

The complaint about the PCT 39

The complaint about the Trust 43

Injustice 62

Conclusions 64

Recommendations 65

Mr and Mrs M's response to our draft report 67

Final remarks 68

Annex A: The specific standards 69

Annex B: The legislative background 72

Annex C: Clinical advice – the GP Adviser 73

Annex D: Clinical advice – the Medical Adviser 74

Annex E: Clinical advice – the Neurologist Adviser 77

Annex F: Report of the Nurse Advisor for Learning Disabilities written on behalf of Basildon & Thurrock University Hospitals NHS Foundation Trust 78

Annex G: The response to Mr and Mrs M's comments, and Mencap's comments, on the draft report 82

Foreword

I am laying this report before Parliament[1] to help others learn from the service failure it describes.

This report is about a young woman with physical and learning disabilities who sadly died in January 2009.

The young woman's parents, complained about a GP, South Essex Emergency Doctors Service, NHS South West Essex (the former primary care trust), and Basildon and Thurrock University Hospitals NHS Foundation Trust. Our investigation found service failure on the part of South Essex Emergency Doctors Service and Basildon and Thurrock University Hospitals NHS Foundation Trust and that this service failure had resulted in unremedied injustice to the young woman and to her parents.

In March 2009 my predecessor, Ann Abraham, and the Local Government Ombudsman, Jerry White, published *Six Lives: the provision of public services to people with learning disabilities*. This brought together six cases that illustrated some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care. This case tells a similarly upsetting story and is a reminder that we continue to see these shocking complaints.

The Department of Health are due to publish their response to our *Six Lives* report shortly. We will continue to publish cases where the NHS has failed to serve people with learning disabilities so that this issue remains the focus of attention and improvement across health and social care.

Dame Julie Mellor, DBE
Health Service Ombudsman

May 2013

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[1] Section 14(4) of the *Health Service Commissioners Act 1993*.

Introduction

This is the report on the investigation into Mr and Mrs M's complaint about Dr K, South Essex Emergency Doctors Service (SEEDS), NHS South West Essex (the PCT), and Basildon and Thurrock University Hospitals NHS Foundation Trust (the Trust). This report contains our findings, conclusions and recommendations with regard to Mr and Mrs M's areas of concern.

This report is preceded by a summary.

Summary

The complaint

1. B (aged 23) had learning disabilities, epilepsy, Russell-Silver syndrome (a form of dwarfism), and severe scoliosis of the spine (abnormal curvature of the spine). She was cared for at home by her parents, Mr and Mrs M.

2. On 21 January 2009 B developed a cough. The next day, Dr K, a GP at the family's local practice (the Practice), visited her at home. He diagnosed acute lower respiratory tract infection and advised her parents to continue giving her antibiotics that had been started the previous day.

3. Overnight Mr and Mrs M became concerned about B's condition, so Mrs M contacted the Practice at approximately 10am on 23 January and requested a further home visit. No one from the Practice visited B on 23 January, but Dr K telephoned the family home at approximately 4pm and spoke to Mr M.

4. Throughout the night B's condition got worse, so at approximately 2.30am on 24 January, Mrs M telephoned the out-of-hours service, SEEDS. She asked for an urgent home visit for B, but the SEEDS doctor declined to visit her. Instead, the SEEDS doctor said that he would send a message to the Practice requesting a home visit the next morning. However, because the next day was a Saturday, the Practice would not be open.

5. At 6.30am on Sunday 25 January Mrs M contacted SEEDS again and a doctor visited B at home. The doctor arranged for B to be taken to the Trust's Basildon Hospital (the Hospital). B remained in the Hospital until 30 January, when she died.

6. Mr and Mrs M complained that Dr K did not diagnose their daughter's condition and that he had refused to make a second home visit on 23 January, so missing a further opportunity to make a diagnosis. Mr and Mrs M complained that when they first contacted SEEDS, the doctor had refused to make a home visit when they asked him to and that, as a result, he had missed an opportunity to diagnose their daughter's condition. Mr and Mrs M also complained about the way the PCT had handled their subsequent complaints about Dr K and the SEEDS doctor.

7. Lastly, Mr and Mrs M complained about the care and treatment provided for their daughter by the Hospital. The matters that concerned them, and which we investigated, were:

   - delays in diagnosing and treating their daughter's condition;
   - the management of their daughter's epilepsy;
   - doctors' communication with them about their daughter's condition; and
   - the absence of a transition plan that they had discussed with the Trust in 2006 to ensure that staff in adult services were aware of their daughter's complex health needs and her family's role in her care.

What we found

Dr K

8. We found that Dr K had taken appropriate action to assess and diagnose B's condition in line with the General Medical Council's *Good Medical Practice* and established good practice. We found that Dr K had taken reasonable decisions about B's care and treatment, based on all relevant

considerations. He considered the history he had obtained from speaking to B's parents and his examination findings, and prescribed appropriately to treat the lower respiratory tract infection that he had diagnosed. We also found that in planning and providing care to B, Dr K had had regard to his obligations to her under disability discrimination law. Therefore, we found no service failure with regard to the care and treatment Dr K provided for B.

SEEDS

9. We found that the first SEEDS doctor Mrs M had spoken to had not taken appropriate action to assess and diagnose B's condition in line with *Good Medical Practice* and established good practice. This meant that he did not have sufficient information to make an informed decision about B's further care and treatment. He did not take reasonable decisions, based on all relevant considerations. Therefore, we found that his care of B fell so far below the applicable standard that this was service failure.

10. Furthermore, we found no evidence that B's rights under disability discrimination law were properly considered by the SEEDS doctor. Therefore, we concluded that in planning and providing care to B, the SEEDS doctor had not had regard to his obligations to her under disability discrimination law. We found that the SEEDS doctor's failings in this respect were so serious as to constitute service failure.

The PCT

11. We found shortcomings in the PCT's handling of Mr and Mrs M's complaint: a misleading statement in its investigation report about advice it had received from the National Clinical Assessment Service; and its failure to investigate the timing of a prescription for antibiotics (which the records said Dr K had written out on 21 January 2009, but which Mr and Mrs M maintained had been written out during Dr K's home visit to their daughter on 22 January).

12. However, we weighed up these shortcomings against the things it did get right. The PCT was '*Being customer focused*' when it took prompt steps to find Mr and Mrs M an alternative GP practice; when it arranged to meet them to ensure that it understood their complaints properly; and when it took steps to liaise with the Trust to ensure that Mr and Mrs M's complaints about B's hospital care were also investigated. In addition, we found that the PCT had 'acted fairly and proportionately' when it commissioned a thorough investigation of Mr and Mrs M's complaints about Dr K and the SEEDS doctor by someone not involved in the events leading to their complaint; and when, at the end of the investigation, it explained what further action it would be taking.

13. Mr and Mrs M complained that the PCT had not found out all the information relevant to their complaints and had not investigated their complaints properly. However, this was a serious complaint and we recognised that it would not have been straightforward for the PCT's staff to investigate. Therefore, taken as a whole, we did not find that the PCT's handling of Mr and Mrs M's complaint fell so far below the applicable standard that it amounted to maladministration.

The Trust

14. We found that there was a prolonged delay before B received the treatment that her condition called for. The Hospital's on-call consultant had acknowledged that it would have been established good practice to treat B's *'severe pneumonia'* with intravenous antibiotics and intravenous fluids, but doctors did not do so. Doctors did not take reasonable decisions, based on all relevant considerations, because they did not consider B's best interests, in line with the *Mental Capacity Act 2005*. Instead, they allowed B to carry on drinking, despite the risk of aspiration (that she might breathe in the fluids), and they tried to give her oral antibiotics, which her records show she was refusing to take. We also found that doctors did not consider transferring B to a high dependency unit, as established good practice says they should have done, and that reviews of her condition by consultants and junior doctors were not as frequent as guidance published by the Royal College of Physicians in 2007 says they should have been. In these regards, we found that B's doctors did not 'get it right' and that their care and treatment of her fell so far below the applicable standard that this was service failure.

15. Although we found a shortcoming (a mistake in writing up a prescription for the drug, midazolam), we were satisfied that doctors' management of B's epilepsy did not fall so far below the applicable standard that it amounted to service failure. This was because a specialist, a consultant neurologist, was involved in the management and treatment of B's epilepsy, in line with guidance issued by the National Institute for Health and Clinical Excellence (NICE) in 2004, and the decisions he made about her anticonvulsant medication were appropriate.

16. B's medical records showed that in some instances doctors did 'get it right' because they were 'customer focused' and dealt with Mr and Mrs M helpfully and sensitively bearing in mind their individual circumstances, and kept them informed about their daughter's condition and treatment in line with *Good Medical Practice*. However, we found that there were other instances, notably a discussion between Mrs M and an on-call consultant on 25 January, where doctors did not carry out their discussions appropriately. While we could not tell from the records how sensitive doctors were in providing information, we had no reason to doubt Mr and Mrs M's account of their conversations with doctors. We found that on these occasions doctors' communication fell so far below the applicable standard that this was service failure.

17. In response to our enquiries, the Trust said that the issue of a paediatric transitional care policy would not have been relevant to the management of B's care at the time of her admission to the Hospital in January 2009, because by then B was already an adult. The Trust argued that as B's condition was chest-based and she was transferred to a chest ward under the care of a chest physician, her care was appropriate, and that the lack of a transition care plan did not have any impact on her.

18. We acknowledged the points the Trust had made, but the fact remained that it had undertaken to put in place a transition care plan for B in 2006, in line with the *National Service Framework for Children, Young People and Maternity Services* published by the Department of Health in 2004, but had not done so. Furthermore, when it met Mr and Mrs M in 2009 it had raised their expectations about a transition

care planning policy but again had failed to keep its promise. The Trust was not 'customer focused' because it did not keep to its commitments and we found that in this regard its actions fell so far below the applicable standard that this was service failure.

19. The Trust had arranged a review of B's care and treatment during her time in the Hospital by its Learning Disabilities Nurse Advisor and it provided us with a copy of her review. This pointed to a number of areas of '*good practice*'. However, the Learning Disabilities Nurse Advisor also identified several '*areas of concern*': a medical registrar's failure to carry out an assessment of B's capacity (in line with the *Mental Capacity Act 2005*) before considering what might be in her best interests; that it was not clear whether doctors had discussed with B's family the possible consequences of Mrs M refusing intravenous medication on her daughter's behalf; and the sister in charge's failure to document what action was taken to resolve Mrs M's complaints about the care B was receiving.

20. In addition, we found nothing to indicate that B's doctors had made it clear to Mr and Mrs M that B was unlikely to improve if she only received oral antibiotics (and oral fluids). Furthermore, we found that her doctors did not have proper regard for B's best interests in the decisions they made about her care and treatment. The on-call consultant who treated B had acknowledged that they did not provide her with the optimum treatment. Therefore, although there were many areas of B's care that were planned and delivered with proper consideration for her rights under disability discrimination law, we found that there were other areas where B's rights were not properly considered. We concluded that in planning and providing care to B in these important areas, the Trust's staff did not have proper regard for their obligations to her under disability discrimination law and we found that their failings in this respect were serious enough to constitute service failure.

Injustice

21. We found that B's rights under disability discrimination law were not properly considered by the SEEDS doctor and the Trust. We found that if they had been, the SEEDS doctor would have visited her and she would have received appropriate treatment more quickly, and once she reached the Hospital, her care and treatment might have been better planned and delivered.

22. We found that when Mrs M contacted SEEDS on 24 January 2009, the SEEDS doctor should have arranged to visit B at home, so that he could adequately assess her condition and arrange treatment where necessary. Because he did not do so, he did not put himself in a position where he could make an informed decision about her further care. Therefore, we found that an opportunity had been missed to get B to hospital as early as possible for treatment and this missed opportunity was the injustice to B that arose in consequence of the service failure we identified.

23. We also found that when B arrived at the Hospital, doctors did not provide her with the treatment that her condition called for. We found that it would have significantly improved B's prospects of surviving her illness: if she had been prevented from eating and drinking; if she had received immediate intravenous antibiotics and active rehydration after admission;

and if advice had been sought from an intensive care doctor and consideration given to a transfer to a high dependency unit. We found that B's doctors had missed any opportunity there might have been – however small – to save her life by providing earlier and more intensive treatment for her. Again, this missed opportunity was the injustice to B that arose in consequence of the service failure we identified.

24. We acknowledged that it was possible B might have recovered from her illness. However, from the evidence we had seen and the advice we had received, we could not say on the balance of probabilities that B would have survived her illness, but for the service failure we had identified. Therefore, we could not say that B's death could have been avoided. Nonetheless, we recognised that Mr and Mrs M would never know whether B would have survived if the SEEDS doctor had visited her at home on 24 January 2009 and referred her to the Hospital, and if doctors at the Hospital had treated her with intravenous antibiotics and fluids sooner and admitted her to a high dependency unit for a higher level of care. We recognised that this uncertainty was likely to be a continuing source of distress for Mr and Mrs M and was an injustice to them that arose from the service failure we had identified.

25. We saw no evidence that the Trust's failure to produce a plan for B's transition from children's to adult services affected the care and treatment she received when she was admitted to the Hospital in January 2009. However, we recognised that the lack of a transition plan and the inappropriate comments doctors made during some of their conversations with B's family would have added to Mr and Mrs M's distress at this difficult time. This was a further injustice to Mr and Mrs M that arose in consequence of the service failure we identified.

Recommendations

SEEDS

26. In recognition of the injustice suffered by Mr and Mrs M, we recommended that SEEDS should write to them with an open and honest acknowledgement of the failings we identified and an apology for the impact these failings had on B and on them. We also asked SEEDS to pay Mr and Mrs M £1,000 by way of financial redress.

27. We were satisfied that the SEEDS doctor had learnt lessons from the failings identified in the partly upheld complaint and that other patients were unlikely to experience the same poor service that B and her parents received. However, we recommended that SEEDS should prepare an action plan that described what it had done and/or planned to do, to ensure that the organisation had learnt lessons from the failings identified in the partly upheld complaint and to avoid a recurrence of these failings.

The Trust

28. In recognition of the injustice suffered by Mr and Mrs M, we recommended that the Trust should write to them with an open and honest acknowledgement of the failings we identified and an apology for the impact these failings had on B and on them. We also asked the Trust to pay Mr and Mrs M £2,000 by way of financial redress.

29. In addition, we recommended that the Trust should prepare an action plan that described what it had done and/or planned to do, to ensure that the organisation and individual doctors had learnt lessons from the failings identified in the partly upheld complaint and to avoid a recurrence of these failings.

30. Lastly, we recommended that the Trust should send Mr and Mrs M a summary of the key actions it had taken to ensure that it had delivered on its commitment to the Department of Health following the recommendation to all NHS organisations in the *Six Lives*[2] overview report.

31. SEEDS and the Trust have agreed to accept our findings and our recommendations.

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[2] *Six Lives* is a joint report published by the Health Service Ombudsman and the Local Government Ombudsman in March 2009. It looked at the services provided for six people with learning disabilities who had died.

Report of an investigation of a complaint about Dr K, South Essex Emergency Doctors Service, NHS South West Essex, and Basildon and Thurrock University Hospitals NHS Foundation Trust.

The complaint

1. Mr and Mrs M's daughter, B (aged 23), had learning disabilities, epilepsy, Russell-Silver syndrome (a form of dwarfism), and severe scoliosis of the spine (abnormal curvature of the spine to one side). She was cared for at home by her parents. Mr and Mrs M complain about the care and treatment she received from Dr K, SEEDS, and the Trust, between 22 and 30 January 2009 when she died.

2. Mr and Mrs M complain that Dr K did not diagnose their daughter's condition and that he refused to make a second home visit on 23 January, missing a further opportunity to make a diagnosis. We have investigated the care and treatment provided by Dr K on 22 and 23 January 2009.

3. Mr and Mrs M complain that, when they first contacted SEEDS on 24 January, the out-of-hours doctor (the SEEDS GP) refused to make a home visit when they asked him to do so. They say that, as a result, he missed an opportunity to diagnose their daughter's condition. We have investigated the care and treatment provided by SEEDS on 24 and 25 January 2009.

4. In addition, Mr and Mrs M complain about the way the PCT handled their complaints about Dr K and the SEEDS GP. They say that the PCT did not find out all the information relevant to their complaints and did not investigate their complaints about Dr K and the SEEDS GP properly. They believe that the investigation conducted by the PCT was a '*cover up*'. We have investigated the way in which the PCT handled Mr and Mrs M's complaints about Dr K and the SEEDS GP.

5. Lastly, Mr and Mrs M complain about the care and treatment provided for their daughter by the Trust's Basildon Hospital (the Hospital) from her admission on 25 January until 30 January 2009. We have investigated the matters that continue to concern them, specifically:

    - the delays in diagnosing and treating their daughter's condition;
    - the management of their daughter's epilepsy while she was in the Hospital;
    - doctors' communication with them about their daughter's condition; and
    - the absence of the transition plan that they had discussed with the Trust in 2006 to ensure that staff in its adult services were aware of their daughter's complex health needs and her family's role in her care.

6. Mr and Mrs M believe that their daughter would still be alive if the serious nature of her condition had been identified sooner by Dr K and the SEEDS GP, and if she had received swifter and better treatment from the Trust. They say that, even if it was too late to save their daughter, it was distressing seeing her treated without care and attention. Mr and Mrs M believe that their daughter was treated less favourably because of her disabilities, including her learning disabilities.

7. By bringing this complaint to us, Mr and Mrs M hope to learn whether their daughter's death could have been avoided. They would also like to receive some assurance that lessons have been learnt, so that what happened to their daughter does not happen again.

Our decision

8. Having considered all the available evidence related to Mr and Mrs M's complaint about Dr K, SEEDS, the PCT, and the Trust, including Mr and Mrs M's recollections and views, and taken account of the clinical advice we have received, we have reached a decision.

9. We find that the care and treatment provided by SEEDS and the Trust fell so far below the applicable standard that this was service failure. We also find that the SEEDS GP and the Trust, in some aspects of B's care and treatment, did not act with regard to disability discrimination law or B's rights as a person with disabilities, and that this was also service failure. We have assessed whether injustice to B and to Mr and Mrs M arose in consequence of the service failure we have identified and concluded that it did. We find that doctors missed any opportunity there might have been – however small – to save B's life by providing earlier and more intensive treatment for her. However, while we acknowledge that it is possible that the outcome for B might have been different, we cannot say that on the balance of probabilities B would have recovered from her illness, but for the service failure we have identified. Therefore, we cannot say that B's death was avoidable. Therefore, we partly uphold the complaints about SEEDS and the Trust.

10. We find no service failure with regard to Dr K's care and treatment of B. Therefore, we do not uphold the complaint about Dr K.

11. We also find no maladministration with regard to the PCT's handling of Mr and Mrs M's complaints about Dr K and the SEEDS GP. Therefore, we do not uphold their complaint about the PCT.

Our jurisdiction and role

12. By virtue of the *Health Service Commissioners Act 1993*, the Ombudsman is empowered to investigate complaints about the NHS in England. In the exercise of our wide discretion we may investigate complaints about NHS organisations such as trusts, family health service providers such as GPs, and independent persons (individuals or organisations) providing a service on behalf of the NHS.

13. In doing so we consider whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the organisation, a failure by the organisation to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the organisation. Service failure or maladministration may arise from action of the organisation itself, a person employed by or acting on behalf of the organisation, or a person to whom the organisation has delegated any functions.

14. When considering complaints about GPs, we may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP themselves, by someone employed by or acting on behalf of the GP, or by a person to whom the GP has delegated any functions.

15. If we find that service failure or maladministration has resulted in an injustice, we will uphold the complaint. If the resulting injustice is unremedied, in line with our Principles for Remedy, we may recommend redress to remedy any injustice we have found.

The basis for our determination of the complaint

16. In general terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, we begin by comparing what actually happened with what should have happened.

17. So, in addition to establishing the facts that are relevant to the complaint, we also need to establish a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those organisations and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.

18. The overall standard has two components: the general standard, which is derived from general principles of good administration and, where applicable, of public law; and the specific standards, which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

19. Having established the overall standard we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the organisation or individual complained about constitutes a departure from the applicable standard.

20. If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

21. The overall standard we have applied to this investigation is set out below.

The general standard – the *Ombudsman's Principles*

22. The Principles of Good Administration, Principles of Good Complaint Handling and Principles for Remedy[3] are broad statements of what public organisations should do to deliver good administration and customer service, and how to respond when things go wrong. The same six key Principles apply to each of the three documents. These six Principles are:

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right, and
- Seeking continuous improvement.

23. Two of the Principles of Good Administration particularly relevant to this complaint are:

- '*Getting it right*' – which includes acting in accordance with the law and with regard to the rights of those concerned; acting in accordance with the public organisation's policy and guidance (published and internal); taking proper account of established good practice; and taking reasonable decisions, based on all relevant considerations.

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[3] The *Ombudsman's Principles* is available at www.ombudsman.org.uk.

- '*Being customer focused*' – which includes keeping to commitments, including any published service standards; and dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.

24. Two of the Principles of Good Complaint Handling particularly relevant to this complaint are:

- '*Being customer focused*' – which includes listening to complainants to understand the complaint and the outcome they are seeking; and responding flexibly, including co-ordinating responses with any other organisations involved in the same complaint, where appropriate.
- '*Acting fairly and proportionately*' – which includes ensuring that complaints are investigated thoroughly and fairly to establish the facts of the case; and ensuring that complaints are reviewed by someone not involved in the events leading to the complaint.

The specific standards

25. The specific standards relevant to this complaint are set out in Annex A of this report.

The investigation

26. We met Mr and Mrs M on 31 March 2011 to discuss the nature of their concerns and the way in which we would investigate the complaint. We confirmed our understanding of the complaint in our letters to them dated 12 and 14 April 2011. We wrote to Dr K, SEEDS, the Trust and the PCT on 25 May 2011 confirming the issues we would investigate.

27. During this investigation we have examined all the relevant documentation. This includes papers provided by Mr and Mrs M, their daughter's medical records and the papers relating to the attempted resolution of the complaint at local level. We have taken account of the comments received from Dr K, SEEDS, the Trust and the PCT, as set out in their correspondence with us.

28. We also obtained advice from three of the Ombudsman's clinical advisers, a GP (the GP Adviser), a consultant general physician (the Medical Adviser) and a neurologist and consultant in neurological rehabilitation (the Neurologist Adviser). The Ombudsman's clinical advisers are specialists in their field and in their roles as advisers to the Ombudsman they are independent of any NHS organisation.

29. In this report we have not referred to all the information examined in the course of the investigation, but we are satisfied that nothing significant to the complaint or our findings has been omitted.

30. Mr and Mrs M, Dr K, SEEDS, the PCT and the Trust have had the opportunity to comment on a draft of this report, and their responses have been taken into account in coming to the decision.

Key events

31. B was a patient of the family's local GP practice (the Practice). On Wednesday 21 January 2009 she developed a cough. The next day, Thursday 22 January, Dr K visited her at home. He recorded a temperature of 38.2°C[4] and left lower crepitations.[5] He diagnosed acute lower respiratory tract infection. His note in the patient record about the home visit, timed at 6.14pm, says: '*Acute lower respiratory tract infection – advised to continue re antibiotics started yesterday. Temp 38.2, chest lower crepts*'. His note also included a prescription for two packs of ten paracetamol suppositories to be '*use*[d] *as directed*'.

32. Mr and Mrs M told us that they were concerned that overnight their daughter's condition had deteriorated, so Mrs M visited the Practice at approximately 10am on Friday 23 January. She spoke to the Reception Manager and requested a further home visit. The entry in the Practice's records for this visit request, timed at 10.05am, says: '*Seen by Dr K yest*[erday] – *chest infection* [patient] *now worse with* [shortness of breath] – [Reception Manager] *advised mum if breathing get*[s] *worse to call 999*'.

33. No one from the Practice visited B on 23 January, but at approximately 4pm Dr K telephoned the family home and spoke to Mr M. The note of this conversation in B's records, timed at 4.07pm, says: '*Telephone encounter – with dad – antibiotics started yesterday – still chesty – temp*[erature] *down with paracetamol – requesting chest physio*[therapy] – *will arrange*'.

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[4] A temperature of 38°C or above is usually considered to be a significant fever.

[5] Crepitations or crackles are abnormal respiratory noises, usually heard with a stethoscope.

34. Mr and Mrs M told us that throughout Friday night their daughter's condition got worse, so at 2.24am on Saturday morning (24 January), Mrs M telephoned the out-of-hours service, SEEDS. She spoke to the SEEDS GP. She asked for an urgent home visit for her daughter and for a physiotherapy referral. However, the SEEDS GP declined to visit B and said that he could not arrange a physiotherapy referral because the community physiotherapy team only worked from Monday to Friday. Although Mrs M told him that the Practice did not make home visits on Saturdays, the SEEDS GP said that he would send a message to the Practice requesting a home visit later that morning.

35. At 6.38am on Sunday 25 January, Mrs M telephoned SEEDS again. She spoke to a different doctor, who agreed to visit B at home. The doctor's notes of her examination say '*Pyrexia*[6] *39*[°C] *sweating groaning breathing rapidly chest difficult to examine but wheezing*'. She recorded a diagnosis of aspiration pneumonia[7] and referred B to the Hospital.

36. B was initially admitted to the Hospital's medical assessment unit. She was triaged[8] by a nurse at 10.40am and seen by a junior doctor at 12.20pm. Her temperature was raised at 39°C, her oxygen saturation[9] was reduced at 68 per cent, her heart rate was raised at 142 beats per minute, and her blood pressure was 94/63mmHg.[10] On listening to her chest, the junior doctor heard widespread crackles on both sides. The junior doctor suspected that she was septic[11] and had pneumonia. The junior doctor took blood for testing. The initial plan was to encourage B to drink fluids and give her oral antibiotics in liquid form. A chest X-ray and chest physiotherapy were also to be arranged. The junior doctor noted at the time that B '*will not tolerate intravenous venflon*'.[12]

37. At 2.10pm a nurse noted that B was not happy with her oxygen mask, but that her parents were trying to give her as

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[6] A medical term meaning fever.

[7] Aspiration pneumonia occurs when foreign material (usually food, liquids, vomit or fluids from the mouth) are breathed into the lungs or airways leading to the lungs.

[8] Triage is the process of determining the priority of patients' treatments based on the severity of their condition.

[9] A person's red blood cells carry oxygen through the arteries to the internal organs. Normally, when red blood cells pass through the lungs, 90 to 100 per cent are loaded or 'saturated' with oxygen. However, if a person has lung disease or other types of medical condition, their red blood cells may not be carrying the usual amount of oxygen and their oxygen saturation may be lower than it should be.

[10] The first number is the systolic blood pressure in millimetres of mercury (the highest pressure when a person's heart beats and pushes blood around the body). The second number is the diastolic blood pressure (the lowest pressure when your heart relaxes between beats). Generally, above 140/90mmHg a person has high blood pressure and below 90/60mmHg a person has low blood pressure.

[11] Having sepsis, a potentially life-threatening illness caused by the body's reaction to an infection.

[12] A cannula or flexible tube that is inserted into a vein to deliver fluids or medication.

much oxygen as possible. At the time, Mr and Mrs M told the nurse that their daughter had been drinking well and that they wished '*to hold off on intravenous fluids*'.

38. The junior doctor saw B again at 2.55pm. Her CRP[13] was mildly raised at 32mg/l, but her full blood count,[14] electrolytes[15] and kidney function were normal. The junior doctor noted that the chest X-ray indicated possible reduced volume in the right lung and possible consolidation[16] in the left lung consistent with pneumonia, but that the chest X-ray had been difficult to interpret because of B's scoliosis.

39. Later that afternoon, at 5.25pm, a nurse noted:

> '[Patient] *drinking reasonably well. Has taken oral clonazepam* [and] *lamotrigine*[17] *liquid for mother. Refusing liquid amoxicillin and clarithromycin*[18] *– but parents do not want* [patient] *to have* [intravenous] *access. Chest physio*[therapy] *called – will review shortly.'*

40. Soon afterwards (at 5.30pm), B was seen by the on-call consultant (the On-call Consultant). Her oxygen saturations were 68 per cent on room air, her heart rate was raised at 100 beats per minute, her respiratory rate was raised at 38 breaths per minute, and her blood pressure was unchanged at 94/63mmHg. The On-call Consultant listened to her chest and heard crackles on both sides and wheezes. She diagnosed a severe chest infection. The planned treatment was:

> '[Intravenous] *antibiotics if can cannulate.*[19] *Neb*[uliser]*s.*[20] *Still drinking* [therefore] *encourage oral fluids.'*

41. The On-call Consultant also documented a discussion with Mrs M. Her note says:

> *'For full supportive care but not for resuscitation in the event of a Cardio respiratory arrest.*[21] [B's parents] *are aware she is very ill with a chest infection which is aggravated by her severe chest deformity. They do not want her to be too distressed by intervention – masks, neb*[uliser]*s, etc.'*

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[13] C-reactive protein (CRP) is a protein found in the blood. If a person has inflammation in a part of their body, for example, as a result of an infection, then extra protein is often released from the site of the inflammation and circulates in the blood. Blood tests are commonly used to detect this increase in protein, which are markers for inflammation. CRP is normally less than 10 milligrams per litre.

[14] A blood count is a test that measures the number of cells in a person's blood. It helps doctors diagnose certain conditions such as infections.

[15] Minerals in a person's blood.

[16] In lobar pneumonia, inflammation (irritation, swelling) or infection of the lungs causes fluid to fill a section of the lung, interfering with the uptake of oxygen.

[17] Clonazepam and lamotrigine are drugs that are used to treat epilepsy.

[18] Amoxicillin and clarithromycin are antibiotics.

[19] Insert a cannula.

[20] A nebuliser is a device used to administer medication in the form of a mist inhaled into the lungs.

[21] When a person suffers a sudden failure of the pumping action of the heart and stops breathing.

42. There are no further notes for 25 January, but in a statement she gave during the Trust's investigation into Mr and Mrs M's complaint, the sister in charge of the medical assessment unit said that after local anaesthetic cream had been applied, the medical team succeeded in inserting an intravenous cannula later that evening. She said that she did '*not recall exactly when intravenous access was gained*', but that '*once intravenous access was obtained the method of administration was altered from oral to oral and intravenous routes*'. B's drug charts show that the administration of intravenous antibiotics (amoxicillin and clarithromycin) began at 8pm, and the administration of intravenous fluids began at 9.20pm, on 25 January.

43. At 1pm on 26 January B was reviewed by another doctor during a ward round. She remained unwell and her parents were concerned by her high temperature (39°C). Her oxygen saturations were 78 per cent, despite being given oxygen, and her heart rate remained high at 130 beats per minute. During the review, Mr and Mrs M asked the doctor whether their daughter had aspirated and they explained that B's doctors were '*covering all possible* [lower respiratory tract infections] *including aspiration*'. The doctor explained that their daughter was very hypoxic[22] and that the Patient at Risk Score[23] nurse had been asked to review her. The doctor said that '*ventilation/intubation*[24] *may not be in her best interest*'. The doctor arranged for B to be given 500 millilitres of Gelofusin[25] '*stat*' (at once) intravenously because of her dehydration and hypotension.[26]

44. The Patient at Risk Score nurse reviewed B at 1.15pm. She recommended: four-hourly observations, increasing to one- to two-hourly if B's systolic blood pressure decreased below 100; monitoring of oxygen saturation hourly; the administration of 60 per cent heated humidified oxygen via a face mask with the aim of increasing oxygen saturation to above 90 per cent; two-hourly turning and a turning chart; and physiotherapy. She also recommended that B should be monitored closely '*as patient is in a side room*'.

45. B was transferred to a specialist respiratory ward at approximately 8.30pm on 26 January. Her clinical records show that later that night her oxygen saturation had increased to 93 per cent.

46. On 27 January (10am) the ward manager had a discussion with Mrs M. Her note of the discussion says:

> '*... B has previously had multiple admissions to paediatric services and so I have left a voicemail message with* [the Head of Nursing, Children's Services] *as B's family have had a lot of input from her personally. This is just to be able to learn from other colleagues' experiences of caring for B. I have also contacted* [the learning disabilities liaison nurse] *and left a message on her mobile.*

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[22] Suffering from inadequate oxygenation of the blood.

[23] The Patient at Risk Score is designed to enable health care professionals to recognise 'at risk' patients and to trigger early intervention to help prevent deterioration.

[24] The use of a tube and a machine to help the flow of air into and out of a person's lungs.

[25] Gelofusin is a plasma substitute – that is, a substitute for the fluid portion of the blood.

[26] Abnormally low blood pressure.

'I have obtained paediatric [oxygen] *masks for B's comfort*

- [speech and language therapy] *referral made*

- *will attempt to* [discuss with] [the Chest Consultant]

- *dietician referral made*

'B's mother is so far happy with B's care.'

47. The dietician and learning disabilities liaison nurse visited the ward later that morning, reviewed B and spoke to her mother.

48. At 1.25pm on 27 January a junior doctor reviewed B. During this review B was asleep, but Mrs M told the junior doctor that her daughter was much better than she had been on admission. The junior doctor suspected that B had aspiration and community-acquired pneumonia[27] and considered changing her antibiotics. The junior doctor instructed that hourly observations should continue and because B's scoliosis made it difficult to interpret her chest X-ray, and Mrs M was *'keen for a suitable radiologist to interpret this'*, they planned to review the chest X-ray with the Hospital's radiology department.

49. Later that afternoon, the junior doctor spoke to a consultant neurologist (the Consultant Neurologist) about B's epilepsy. The Consultant Neurologist told the junior doctor that B could safely be given clonazepam drops into her mouth until a speech and language therapy assessment of her swallowing ability had been performed. He said that if the assessment was normal, then her long-term lamotrigine medication could be resumed. The junior doctor also spoke to a more senior doctor (a registrar) about B's rapid heart rate and about changing her antibiotics. The registrar reviewed B himself at 5.20pm.

50. During the afternoon of 27 January B suffered a seizure. A note in her clinical records says:

    'Mum concerned that [her daughter] *isn't getting medication to prevent fits as is* [nil by mouth]. *Reassured* [speech and language therapy assessment] *will be done as soon as possible and* [doctors] *can prescribe another route.* [Mrs M] *happy with this.'*

51. The following morning (9.15am on 28 January) a doctor carried out a review and noted that B had had several seizures during the night and a further seizure that morning. The anticonvulsant drug, lorazepam, was prescribed, to be given '*as needed*' in case of further seizures. In addition, the doctor decided to change B's antibiotics, starting her on Tazocin. The Patient at Risk Score nurse and speech and language therapists also reviewed B.

52. The next day, the Chest Consultant assessed B (9.40am on 29 January). He told Mrs M that B's condition was '*highly likely to be aspiration pneumonia*'. The notes of the assessment also say:

    '[The Chest Consultant] *has gone through her notes for this current admission with* [Mrs M] *explaining the clinical findings and decisions made regarding it at each review and* [Mrs M] *seems okay with decisions.* [Mrs M] *questioned whether it would have been better if* [her daughter] *was made nil by mouth on admission into* [the medical

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[27] Community-acquired pneumonia refers to pneumonia acquired outside of hospital or other healthcare settings.

assessment unit]. *Explained to her if she was alert and no issues were raised about swallowing difficulty at the time and therefore reasonable in the circumstances to have allowed her to eat and drink. She was on the right antibiotics on admission and was made nil by mouth on this ward when her level of consciousness reduced.'*

53. The Chest Consultant's plan was to continue intravenous antibiotics and fluids. B was noted to have been nil by mouth for two days and not to have received any nutrition for four days, so he proposed the insertion of a nasogastric tube[28] for medication and feeding. He also discussed the question of resuscitation in the event that B suffered a cardio-respiratory arrest and agreed to continue the do not resuscitate order that the On-call Consultant had previously talked to Mrs M about on 25 January.

54. Later that day B was visited by the learning disabilities liaison nurse and by the Consultant Neurologist. A nurse also inserted the nasogastric tube.

55. During the Consultant Neurologist's visit, Mrs M expressed concerns about the increasing frequency of her daughter's seizures and the Consultant Neurologist explained that this was most likely the result of her infection. He recommended that all B's anticonvulsant drugs should be resumed and that they should be given to her via her nasogastric tube.

56. A further medical review was conducted at 5.44pm on 29 January. The doctor noted that B remained unresponsive and was *'not a candidate for NIV* [non-invasive ventilation]'.[29] Blood gas tests[30] had been taken and these demonstrated that she had type 2 respiratory failure[31] with carbon dioxide retention.

57. A nutrition nurse specialist saw B at 7pm on 29 January and concluded that she should be reassessed in the morning with a view to starting a slow nasogastric feed. In the notes of her assessment, the nutrition nurse specialist described a discussion she

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[28] A nasogastric tube, or NG tube, carries liquid food, fluids and medicine to the stomach via the nose.

[29] People having difficulty breathing may benefit from using a breathing machine called a ventilator. In 'invasive ventilation' a tube is inserted into the windpipe through the mouth or nose. The person has to be put to sleep in order to tolerate the tube. In 'non-invasive ventilation' a cushioned mask is used (over the nose alone or over the nose and mouth) and connected to the ventilator.

[30] A blood gas test can help determine whether a person has an imbalance of oxygen and carbon dioxide in their blood, or whether their blood is too acidic or too alkaline. The test result may indicate that the person has a respiratory problem, a metabolic (related to the chemical reactions that the body uses to break down food into energy) or a kidney disorder.

[31] In type 2 respiratory failure there is inadequate oxygenation of the blood and higher than normal levels of carbon dioxide.

had had with a doctor. Her note said:

> *'I then discussed prescription for* [intravenous] *midazolam.*[32] *This was prescribed as 10mg* [intravenously]. *This is not a usual medicine to be administered on the ward so I queried the dose with* [the doctor]. *I also* [discussed with] *on-call pharmacist who said that it was ok to give on the ward. I was not happy with this either so further questioned medical staff. As a consequence medical staff realised that the* [intravenous] *midazolam was to be administered buccally.*[33] *Prescription chart changed. Informed* [staff nurse].'

The next day the nutrition nurse specialist noted in the records that she had completed an incident form in respect of this prescribing error.

58. Overnight and into the morning of 30 January, nurses continued to monitor B. At 8.45am the on-call physiotherapist was in attendance when B stopped breathing. Nurses called for a doctor, who confirmed that B had died.

The progress of the complaint

The Practice

59. Mrs M first complained to the Practice in February 2009. She described the events of 21 to 25 January and how her daughter had been given three or four different types of antibiotic after she was admitted to the Hospital. However, she said that '*it was too late*' and she complained that there had been '*total negligence*' in her daughter's care and treatment. She copied her letter to the PCT.

60. The Practice Manager acknowledged Mrs M's letter on 19 February and responded more fully on 27 February. She explained that SEEDS was the Practice's out-of-hours service provider and said that the SEEDS GP had been wrong to suggest that the Practice would make a home visit on Saturday 24 January. She explained the Practice's opening arrangements on Saturdays. The Practice Manager enclosed with her letter comments she had obtained from Dr K about his treatment of B and about his telephone conversation with her father on 23 January.

The PCT

61. The PCT received the second copy of Mrs M's letter on 23 February. The next day Mrs M visited the PCT's offices and met and discussed her complaint with its Director of Quality and Nursing. During the meeting, Mrs M told the Director of Quality and Nursing that '*she never wanted to see* [Dr K] *again*', so staff at the PCT contacted another GP practice about the family registering with them. Mr and Mrs M were subsequently given the contact details of this alternative practice and the contact details of a number of other alternative practices.

62. On 2 March Mrs M met the PCT's Director of Quality and Nursing again. She explained that she was dissatisfied with the response she had now received from the Practice, and the PCT said that it would undertake its own investigation. In the event, the Director of Quality and Nursing met Mr and Mrs M and their Mencap representative on 3 April to find out

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[32] A medication used to treat people who have seizures.

[33] Placed in the mouth to be absorbed through the gums and cheek.

more about their complaint. The issues discussed during this meeting included:

- Mr and Mrs M's request for a further home visit from Dr K on 23 January;
- their request for a home visit from the SEEDS GP on 24 January; and
- B's care once she reached the Hospital.

63. The PCT asked its GP Clinical Lead and its Interim Head of Clinical Standards and Performance to investigate Mrs M's complaints about Dr K and the SEEDS GP, and on 19 August it shared their report with her. The report said that '*Independent advice from the* [National Patient Safety Agency] *National Clinical Assessment Service shows that the rationale for* [Dr K] *not seeing B on Friday 23 January 2009 or arranging for a physio*[therapy] *visit can be considered to be reasonable*'. The report concluded that Dr K's actions had been reasonable, given that he had visited B on 22 January and prescribed antibiotics, and that the advice he had given her parents about physiotherapy had been correct. The GP Clinical Lead and the Interim Head of Clinical Standards and Performance recommended that no action should be taken against Dr K.

64. However, the investigation report concluded that the SEEDS GP's decision not to visit B had been a poor one. The PCT said that, in light of its findings, it had decided to refer the SEEDS GP to the General Medical Council (the GMC) under its Fitness to Practise procedures. In an action plan that accompanied the report, the PCT told Mr and Mrs M about other action it would be taking, including that it would be liaising with the Trust to investigate the issues they had raised about B's care once she reached the Hospital.

65. The PCT's Director of Quality and Nursing and its Interim Head of Clinical Standards and Performance met Mr and Mrs M and their Mencap representative again on 27 August to discuss the investigation's findings. At the end of the meeting, the PCT undertook to meet the Practice *'to review what* [had] *come to light during the investigation*'. It said that this was likely to take four to six weeks and that it would notify Mencap when the meeting had been arranged.

66. However, in November 2009 Mencap contacted the PCT because it had not heard from it. Mencap referred to the meeting on 27 August and said that it had been agreed that the PCT would '*review how it was that key information regarding the family's request for a further visit had not been presented for investigation until a very late stage*'. Mencap also said that it understood that it had been agreed at the meeting '*that the failure of Dr K to present this information, and the fact that he repeatedly stated that the family had not requested a second visit, was a serious issue that needed to be addressed*'.

67. On 27 November the PCT responded. It told Mencap that it had referred the Practice to the GMC. The PCT explained that this was because the Practice had refused to provide the records relating to Mrs M's request for a home visit on 23 January 2009 and because the Practice had made a '*false statement*' about the request for a home visit (that is, that Mrs M had not made a request for a home visit).

The Trust

68. After its meeting with Mr and Mrs M on 3 April, the PCT sent a copy of the notes of the meeting to the Trust. On 12 May the Trust wrote to Mr and Mrs M to explain

why its staff had not been present at the meeting and it confirmed that it had now begun an investigation into the complaints they had raised about their daughter's hospital care. It offered to meet them once this investigation was complete.

69. The Trust subsequently resolved some of Mr and Mrs M's complaints. We have not investigated these. The points Mr and Mrs M raised about the matters we have investigated are:

- that a plan put in place in 2006 to assist in B's transition from children's to adult services had not been available when she arrived at the Hospital;
- that the On-call Consultant had behaved inappropriately and made inappropriate comments about resuscitation;
- that there was a delay in confirming B's condition;
- that the Hospital had not managed B's epilepsy appropriately; and
- that there had been a prescribing error with one of B's anti-epilepsy drugs.

70. On 3 July 2009 the Trust's Chief Executive and other staff met Mr and Mrs M and their Mencap representative to discuss their complaint. Senior staff from the PCT, including the Director of Quality and Nursing, were also present. On 30 July the Trust sent Mr and Mrs M a copy of its draft investigation report.

71. In the report, the Trust responded to Mr and Mrs M's complaints, including the matters that we have investigated (paragraph 69). The Trust said that its Head of Nursing for Medicine and Emergency Care and its Head of Nursing for Children's Services met Mr and Mrs M in the autumn of 2006. It said that they spent time with B's family, understanding her needs and the difficulties they had encountered accessing '*the right kind of care*'. It said that the outcome of the meeting was that Mr and Mrs M were to complete a care plan for B, using a template from the learning disabilities partnership, which could be duplicated in her medical records, as well as being held by her parents. The Trust said that there was also a discussion about identifying a dedicated ward with a dedicated consultant physician for B's care in adult services. However, the Trust said that these plans for her transition from children's to adult services were not completed and it apologised for this. It said that it was the Head of Nursing for Medicine and Emergency Care's intention to arrange for B to have access to a respiratory physician and the respiratory ward, as it was expected that any future illness was likely to be respiratory in nature.

72. The Trust said that the On-call Consultant had asked B's sister to leave the room while she discussed resuscitation with Mr and Mrs M. It said that she felt that it was inappropriate to have a delicate conversation of this nature in front of her sister. It said that the On-call Consultant felt that she was being considerate to B's sister who might have been extremely distressed if resuscitation was discussed in front of her.

73. Responding to Mr and Mrs M's complaint that there had been a delay confirming their daughter's condition, the Trust said that the first doctor, who had examined B within two hours of her arrival in the medical assessment unit, had recorded that she '*probably has a pneumonia*'. It said that he prescribed antibiotics in accordance with his findings and that evidence of this could be found in the medical records.

74. The Trust said that the management of B's epilepsy had been discussed with the Consultant Neurologist by telephone on 27 January 2009. It said that he gave staff advice about B's anticonvulsant medication in light of her being nil by mouth. The Trust said that the Consultant Neurologist had seen B on the ward on 29 January and it explained the drugs she had been given.

75. Mr and Mrs M had also expressed concern about the number and frequency of their daughter's seizures while she was in the Hospital. In reply, the Trust said that the Consultant Neurologist had seen their daughter three times in his clinic in 2006 and 2007. It said that in the notes of his consultation in November 2006, he said that B '*might get up to 20 attacks per day and that myoclonic jerks*[34] *were the only manifestation of her epilepsy*'. It said that, as it believed the Consultant Neurologist had told them at the time of their daughter's admission, myoclonic jerks are rarely life-threatening and would not require emergency treatment.

76. The Trust said that the Consultant Neurologist had recommended midazolam buccally once a day for treatment of B's seizures. However, it said that after the nutrition nurse specialist had queried the dose prescribed, it was found that the prescribing doctor (not the Consultant Neurologist) had prescribed the drug to be administered intravenously, which would have concentrated the effect of the dose. It said that there was a delay in administering the midazolam while the dose and route of administration were confirmed.

77. Between October and December 2009 the Trust continued to correspond with Mencap about a number of Mr and Mrs M's complaints, which Mencap said had not been fully addressed. The Trust also met Mrs M again on 30 November. Their discussions were primarily about what the Trust was doing to improve services for people with learning disabilities, rather than about her specific complaints.

78. Dissatisfied, because they did not feel that a number of key points in their complaints had been adequately addressed, Mr and Mrs M complained to us in May 2010. Mencap continues to support Mr and Mrs M in their complaint.

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[34] Myoclonic jerks commonly occur in people with epilepsy, where the electrical activity in the brain becomes disordered, leading to seizures. They are a form of myoclonus, the sudden involuntary jerking of a muscle or group of muscles.

The complaint about Dr K

Responses to our enquiries

79. The Practice uses a computer system called SystmOne. It is supplied by a company called TPP. We contacted TPP to verify the date, time and user name associated with each entry in B's patient record for 22 and 23 January 2009 detailed in the key events section of this report (paragraphs 31 to 33).

80. The information we received from TPP also showed that there were a number of entries in B's patient record for 21 January 2009, which are relevant to the complaint. In the first entry, timed at 4.12pm, one of the Practice receptionists keyed a home visit request. It says:

> *'Mum called in would like a home visit today for daughter. Concerned with chesty cough. Would also like a* [prescription] *for co-amoxicla*[v][35] *as this is the only medication B will take. Note put on duty* [doctor's] *desk.'*

81. Later that evening (at 6.12pm) there is an entry indicating that Dr K ordered a prescription for co-amoxiclav oral suspension for B for a period of seven days.

82. TPP told us that the patient records indicate that at 6.19pm on 21 January the receptionist amended the home visit entry. They said that they could not tell us what amendments were made. They said that it might have been that more text was added or that the name of the doctor assigned to make the home visit had been changed.

83. TPP confirmed that none of the entries had been backdated or otherwise changed in terms of the time or date.

Mr and Mrs M's comments

84. When we met Mr and Mrs M on 31 March 2011 we discussed their complaint about Dr K. We spoke to Mrs M on 15 September and 15 November 2011 to obtain further information about certain aspects of their complaint.

85. Mr and Mrs M said that they lived a short distance from the Practice. They said that another doctor usually saw B but Dr K had seen her a few times. They said that they thought that Dr K should have taken care to find out about their daughter, who was a vulnerable adult. They said he should also have taken more notice of what Mrs M said to him. They said that they knew that B was vulnerable to chest infections and that is why they asked him to visit and arrange physiotherapy for her.

86. Mrs M pointed out to us that Dr K had seen B on 22 January 2009, but there was a note in the GP records showing that antibiotics had been prescribed for her daughter on 21 January (paragraph 81). She described how she had tried to find out more about this, but all the information about the prescription had been destroyed, for example, by the chemist. She said this meant the facts could never be checked and she was disappointed that the PCT had not looked into this properly when they had the opportunity to do so before the records were destroyed.

87. Mr M said that Dr K was a liar. He said Dr K had lied about his daughter's temperature, arranging physiotherapy and the prescription. Mr M said that even though the Practice was close to their home, Dr K still did not come to see his daughter. Mr M said that one of the most distressing things for them was a telephone call from

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[35] Co-amoxiclav is a type of antibiotic.

Dr K one Saturday morning. He said that he believed that Dr K had only telephoned so that he could tell the GMC that he had spoken to them. Mrs M said that this telephone call was to ask the question *'I haven't done anything wrong have I?'*. She said that the call was recorded and passed on to the GMC. She said that they feel this was wrong. She said it was very upsetting.

88. Mrs M said that Dr K had changed the records about the prescription of antibiotics. She said she had told the PCT this and the GMC. Mrs M also said that the Practice had not been willing to give all the relevant information to the PCT for the complaint investigation. She said that they had withheld a letter.

89. When we subsequently spoke to Mrs M on 15 September 2011 we asked her more about the home visit that Dr K made on 22 January 2009. Mrs M said that B had developed a cough on 21 January. She said that the cough was '*not drastically bad*', but by the next morning it sounded unusual. She said that she therefore telephoned the Practice and asked for a home visit later that day. Mrs M said that Dr K visited B at home in the early afternoon on 22 January. She said that he listened to her daughter's chest, but he did not take her temperature. She said that Dr K told her that B had a chest infection in the lower part of her lung and that he would prescribe antibiotics. Mrs M said that she asked Dr K to arrange physiotherapy for B, but he said that this was not necessary. Mrs M said that neither she nor her husband contacted the Practice on 21 January.

90. When we spoke to Mrs M on 15 November 2011 we talked to her about the information we had obtained from TPP. Commenting on the entry in her daughter's patient records for 21 January 2009 (paragraph 80) she said that they were '*complete lies*'. She said that she did not visit or telephone the Practice on 21 January. She said that she telephoned the Practice on 22 January to request the home visit for B.

91. By way of further explanation, Mrs M said that on 20 January 2009 they had taken B to Stanmore Hospital.[36] She said that doctors told them that B's spine had not got any worse. She said that the following day they went out as a family as they were happy about what they had been told. She said that it was after this day out that B began to cough and this was why they were so sure that they did not contact the Practice until 22 January.

92. Mrs M said that the note that said that Dr K had printed a prescription for co-amoxiclav on 21 January (paragraph 81) was wrong. She said that Dr K had written the prescription while sitting in her living room.

Dr K's comments

93. We asked Dr K for his account of his care and treatment of B on 22 and 23 January 2009, and on 7 July 2011 his solicitors (the Solicitors) wrote to us on his behalf.

94. The Solicitors said that Dr K had treated B on a number of occasions prior to the events giving rise to the complaint. They said that B became unwell on 21 January

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[36] The Royal National Orthopaedic Hospital in Stanmore is a specialist orthopaedic hospital. Orthopaedics is the branch of medicine that deals with the prevention or correction of injuries and disorders of the skeletal system and associated muscles, joints, and ligaments.

with a cough that gradually became worse, and on 22 January, Mrs M requested a home visit. They said that Dr K visited B at home on 22 January. The Solicitors said that, on examination, Dr K found that B had a temperature of 38.2°C and crepitations were audible over her left lower lung. They said that Dr K diagnosed an acute lower respiratory tract infection and he prescribed co-amoxiclav, an antibiotic routinely prescribed to treat chest infections, and paracetamol suppositories to bring down her temperature. They said that he also suggested to Mr and Mrs M that physiotherapy would assist in clearing B's chest. The Solicitors said that Dr K envisaged that this therapy would commence after the acute infection had been treated rather than straightaway. They said that Dr K then returned to the Practice and wrote up his note in B's computer records.

95. The Solicitors said that on 23 January, Mrs M attended the Practice and requested a physiotherapy referral and a home visit for B. They said that Mrs M spoke to the Reception Manager. They said that the Reception Manager recorded the visit request in the Practice's SystmOne home visit log, stating that B was reported to be worse, with shortness of breath. However, the Solicitors said that the Reception Manager did not get the impression that the request for a home visit was urgent. They said that, rather, she thought that the main reason that Mrs M attended the Practice was to seek a physiotherapy referral for B. They said that the Reception Manager did not tell Dr K that Mrs M had requested a home visit, because Dr K was not the duty doctor (that is, the doctor allocated to make home visits) that day. The Solicitors gave a copy of the Practice's duty doctor appointments list for 23 January, which they said demonstrated that Dr K was not the duty doctor that day.

96. The Solicitors said that Dr K was therefore unaware of the home visit request for much of his working day on 23 January. They said that at 4.07pm, Dr K accessed B's records in order to telephone B's parents to check on her progress before the weekend. They gave us a printout that they said showed the Practice personnel who had accessed B's records on 23 January and at what time they accessed them. The Solicitors said that it was only on opening the computer records that Dr K became aware that a home visit request had been logged. They said that Dr K proceeded to call B's home as planned and spoke to her father. They said that Dr K was given to understand that Mrs M was not at home at the time of the call.

97. The Solicitors said that Mr M told Dr K that B was still chesty, but her temperature had come down. They said that Mr M confirmed that antibiotics had been started the previous day after Dr K's visit. They said that given that Mr M reported no deterioration in B's condition and, in fact, that there seemed to be an improvement, Dr K did not feel that a further visit was either desired or necessary. They said that Mr M did not repeat the request for a home visit during the telephone call. The Solicitors said that, rather, he asked Dr K to arrange physiotherapy, which Dr K agreed to do. They said that Dr K made a note of the call in B's computer records and he marked the home visit request as completed on the computer system so that the duty doctor would know that a home visit was no longer required. The Solicitors said that after this telephone call, Dr K had no further part in B's care, but he had been saddened to hear of her death in hospital a week later.

98. We also asked Dr K about the entries in B's patient record for 21 January 2009 (paragraphs 80 and 81). In a second letter to us, dated 5 August 2011, the Solicitors said that it was extremely difficult to reconstruct events so long after they had taken place. They said that Dr K had no recollection of the events of 21 January, but in order to attempt to shed light on the sequence of events, the Practice Manager had undertaken an audit of the Practice's computer system. The Solicitors said that the audit had revealed that on 21 January, Dr K accessed B's computer records and then telephoned her home from his surgery. They said that they could not be sure what prompted the call and they speculated on what might have happened. They said that they assumed, but could not state categorically, that B's mother or father explained their concerns and related B's symptoms to Dr K during the telephone call. The Solicitors said that knowing that B was prone to chest infections and also knowing the importance of starting antibiotic therapy as soon as possible to treat chest infections in disabled patients, Dr K issued a prescription for co-amoxiclav, a standard antibiotic for the treatment of chest infections. They said that Dr K then arranged a home visit to B the following day.

99. In response to further questions from us, the Solicitors wrote to us again on 16 April 2012. They gave us a copy of the relevant parts of the audit outlined in paragraph 98, together with information from the Practice's telephone system showing that an outgoing telephone call was made from Dr K's extension to Mr and Mrs M's home telephone number at 6.14pm on 21 January 2009. The information showed that this telephone call lasted for 1 minute and 39 seconds.

100. To clarify the prescriptions that Dr K had issued, the Solicitors explained that Dr K had issued a printed prescription for co-amoxiclav as requested by Mrs M on the evening of 21 January 2009 to be picked up at the Practice's reception. They said that Dr K then hand-wrote a prescription for paracetamol at Mr and Mrs M's home when he made a home visit on 22 January.

The Reception Manager's comments

101. We visited the Practice on 23 August 2011 and met the Reception Manager. We asked her to explain how requests for home visits are dealt with by the Practice and we asked about her conversation with Mrs M on 23 January 2009.

102. The Reception Manager said that usually one of the receptionists will take a request for a home visit over the telephone. She said that the receptionist will take the patient's details and enter a home visit request in SystmOne (the Practice's computer system). She said that most requests for a home visit are received in the morning.

103. The Reception Manager said that each day one doctor, the duty doctor, is tasked with assigning the home visits that have been requested to individual doctors at the Practice. She said that the duty doctor also deals with any queries or telephone calls that arise during the day. However, the Reception Manager said that all the doctors at the Practice can view the list of home visit requests on SystmOne, so some doctors will look at the list and assign themselves to carry out particular home visits. She said that the duty doctor will usually only have to assign those home visits that have not already been picked up by the other doctors in this way. The

Reception Manager said that Dr K was not the duty doctor on 23 January 2009.

104. The Reception Manager said that after morning surgery, the doctors meet in the common room at the Practice to do their paperwork and this is when the duty doctor will assign any outstanding home visit requests. She said that it would depend on how busy morning surgery had been as to when the doctors would meet in the common room, but typically this might be at around 12.30pm, although it could be earlier.

105. When we asked the Reception Manager about the events of the morning of Friday 23 January 2009, she said that Mrs M called at the Practice and asked for her. She said that Mrs M told her that B had a chest infection and that this was getting worse. She said that Mrs M requested a further home visit. She said that Mrs M told her that B was short of breath, so she told her to call an ambulance if B got worse.

106. The Reception Manager said that Mrs M went on to talk about physiotherapy for her daughter. She said that Mrs M seemed more concerned about the physiotherapy than her daughter's shortness of breath. She said that she asked Mrs M how bad B's shortness of breath was and asked '*Do you think she needs an ambulance?*'. The Reception Manager said that she agreed to put B down on the list for a home visit, but said to Mrs M that if B got worse she should call 999. She said that she recorded the advice she gave Mrs M in the '*Comments*' section of the home visit request (paragraph 32). She said that she did not recall Mrs M saying anything to indicate that the home visit was urgent.

107. We asked the Reception Manager whether Mrs M had asked for a specific doctor to make the home visit to her daughter. She said that she could not remember. We also asked whether she had spoken to Dr K about the home visit request. The Reception Manager said that she could not recall speaking to Dr K individually, but she said that she would have spoken to all of the doctors in the common room at the end of the morning surgery.

108. We asked the Reception Manager whether she could tell from the Practice's records at what time the home visit request on 23 January 2009 was allocated to a doctor. She said she could not. She said that all she could say was that Dr K had marked the home visit request '*Finished*' – that is, dealt with – at 4.11pm. She said that she had previously spoken to the Practice Manager about what time the home visit request had been assigned to a doctor and the Practice Manager had told her that it was not possible to obtain this information from the system, having spoken to the system provider (TPP).

Clinical advice

109. The clinical advice we have drawn on in reaching our findings and conclusions is in Annex C to this report.

Our findings

The care and treatment Dr K provided for B

110. Mr and Mrs M complain that Dr K did not diagnose their daughter's condition and that he refused to make a second home visit on 23 January, so missing a further opportunity to make a diagnosis.

111. To decide whether there has been service failure, we refer to the *Ombudsman's Principles* of Good Administration. In order to 'get it right' in his care and treatment of B, Dr K should

have taken account of relevant guidance and established good practice (as set out in this instance in the specific standards outlined in Annex A, paragraphs 10 and 11, and as described by the GP Adviser) and had regard to disability law and B's rights as a disabled person. Dr K should have taken reasonable decisions, based on all relevant considerations. In reaching our findings we have compared what should have happened with what did happen.

112. When we met Mr and Mrs M on 31 March 2011, they said that Dr K had first seen their daughter on 22 January 2009. However, they said that there was a note in their daughter's patient records showing that antibiotics (co-amoxiclav) had been prescribed on 21 January (paragraph 81). Later, when we spoke to Mrs M on the telephone on 15 November 2011, she was clear that she did not visit or telephone the Practice on 21 January. She also said that Dr K had written the prescription for co-amoxiclav sitting in her living room during his home visit on 22 January.

113. However, the information we obtained from TPP and from the Solicitors points to a different sequence of events. It says that Mrs M visited the Practice at approximately 4.12pm on 21 January to request a home visit for her daughter and that Dr K ordered a prescription for co-amoxiclav oral suspension for B later that evening. It says that Dr K wrote out a prescription for paracetamol suppositories on 22 January.

114. We recognise that Mr and Mrs M are convinced that they did not contact the Practice on 21 January, but the computer records we have seen indicate that they did. Furthermore, we have seen nothing to indicate that the Practice's records for 21 January have been changed as Mr and Mrs M suggested they had been when we met them (paragraph 88). Indeed, TPP told us that the records for 21 January had been neither backdated nor otherwise changed in terms of the time or date (paragraph 83).

115. However, what is not in dispute is that Dr K visited B at home the following day. In order to provide good clinical care, *Good Medical Practice* says that doctors must adequately assess a patient's condition, taking account of the history, the patient's views, and where necessary examining the patient. It says that good clinical care should also include providing or arranging advice, investigations or treatment where necessary. So when Dr K visited B at home on 22 January, he should have ensured that he adequately assessed her condition and provided her with appropriate treatment.

116. During his consultation on 22 January, Dr K made a diagnosis of lower respiratory tract infection, based on the history he had taken and his examination findings of a temperature of 38.2°C and left lower crepitations (paragraph 31). He advised B's parents to continue the antibiotic he had prescribed the previous day (co-amoxiclav oral suspension) to treat the chest infection he had diagnosed.

117. The GP Adviser told us that Dr K's diagnosis at this time was reasonable. He said that his diagnosis was based on the history he had taken and an appropriate examination, and that Dr K had prescribed appropriately to treat the condition he had diagnosed. Furthermore, he said that Dr K had prescribed co-amoxiclav suspension, rather than standard amoxicillin, because this type of antibiotic was more likely to work first time.

118. We now turn to the events of 23 January. Mr and Mrs M complain that Dr K failed to make a second home visit that day; a visit that the Practice's records confirm was

requested that morning at approximately 10.05am (paragraph 32).

119. When we spoke to the Reception Manager about Mrs M's request for a further home visit for B on 23 January, she explained the system the Practice uses for allocating home visit requests to individual doctors. However, she could not tell us the precise time the home visit was allocated to a doctor on this occasion, or the name of the doctor at the Practice who had been asked to make the home visit. TPP could not give us this information either. The Solicitors said that, for his part, Dr K only became aware of the request for a home visit when he accessed B's records later that afternoon and that, after speaking to Mr M on the telephone, he did not feel that a further home visit was either wanted or necessary.

120. So, to summarise, while we can be certain that Mrs M requested a further home visit for her daughter early on 23 January 2009, we cannot say when, or to which doctor at the Practice, the request for a home visit was allocated. In addition, we have received conflicting accounts from Mr and Mrs M, the Reception Manager, and Dr K, about the nature and urgency of Mrs M's request, and about what happened that day. We have not been able to reconcile these accounts.

121. However, what we can say, given the advice we have received (Annex C, paragraph 3), is that when Dr K telephoned and spoke to Mr M that afternoon, he was able to adequately assess B's condition in line with *Good Medical Practice*, with the information he obtained from her father and by taking account of her history and his examination findings from his assessment of B the previous day. Furthermore, because Dr K had already assessed B and established a diagnosis of lower respiratory tract infection, the GP Adviser has told us that Dr K was able to take a reasonable decision at this time about whether to visit B at home again.

Disability discrimination rights

122. Mr and Mrs M complain that their daughter was treated less favourably by Dr K because of her disabilities, including her learning disabilities.

123. B was a person with physical and learning disabilities and Dr K was obliged to consider her needs and whether adjustments needed to be made in order to ensure that she had access to health services designed around her individual needs (Annex A, paragraphs 1 to 8). It is clear to us that B's rights under disability discrimination law were engaged here and should have been considered in Dr K's decision making in the planning, and throughout the provision, of her care and treatment.

124. In their letters to us dated 7 July and 5 August 2011 (paragraphs 94 and 98), the Solicitors explained that Dr K had treated B on a number of occasions prior to the events giving rise to Mr and Mrs M's complaint. They said that after Dr K had telephoned Mr and Mrs M's home on 21 January 2009 he issued a prescription for antibiotics, because he knew that B was prone to chest infections and it is important to start antibiotic therapy as soon as possible to treat disabled people who have chest infections. The Solicitors also explained how Dr K had visited B at home on 22 January and how he had planned to telephone Mr and Mrs M on 23 January to check on B's progress before the weekend. We acknowledge that Dr K's account of what happened on 21 and 23 January differs from the account we have received from Mr and Mrs M, but

these comments indicate to us that Dr K did have regard to B's needs as a person with disabilities when he planned and delivered her care.

125. Mr and Mrs M are particularly critical of Dr K for not visiting their daughter again on 23 January. However, as we have explained earlier (paragraph 120), there are conflicting accounts about the nature and urgency of Mrs M's request for a second home visit on 23 January and the advice we have received tells us that it was reasonable for Dr K not to have visited B that day.

Our conclusion about Dr K

126. We recognise that Mr and Mrs M feel strongly about the care and treatment their daughter received from Dr K and that they may feel frustrated that we have not been able to get to the bottom of precisely what happened on 21 and 23 January 2009. However, from the records we have examined, the advice we have received, and the absence of sufficient evidence to the contrary, we find that Dr K took appropriate action to assess and diagnose B's condition, and to provide appropriate treatment, in line with *Good Medical Practice* and established good practice. We find that Dr K took reasonable decisions about B's care and treatment, based on all relevant considerations. He considered the history he had obtained from speaking to her parents, and his examination findings, and prescribed appropriately to treat the lower respiratory infection that he had diagnosed. We also find that in planning and providing care to B, Dr K did have regard to his obligations to her under disability discrimination law. Therefore, we find no service failure with regard to the care and treatment Dr K provided for B.

The complaint about SEEDS

Responses to our enquiries

127. During our investigation SEEDS gave us a transcript of the SEEDS GP's telephone conversation with Mrs M at 2.24am on 24 January 2009 (paragraph 34).

128. The transcript shows that during the conversation, Mrs M explained that B was '*a severely handicapped child with a complete curve on the spine*'. Mrs M asked the SEEDS GP for an urgent home visit for her daughter and for a physiotherapy referral, but her request was declined.

Mr and Mrs M's comments

129. When we met Mr and Mrs M on 31 March 2011, we discussed their complaint about SEEDS.

130. Mr M said that the SEEDS GP is '*disgusting*'. He said he had '*got himself off*' by writing to them with an apology and information about what he had done after their daughter's death. But, Mr M said, he only did this when he found out that there was a recording of the conversation.

131. Mrs M said that she thought the SEEDS GP would have been treated more severely if he had not apologised to them. She said that she is not concerned about the message the SEEDS GP sent to the Practice on the '*autolink system*' for a GP to visit her daughter on Saturday morning. She said that, as far as she is concerned, the key thing is that the SEEDS GP did not come out to see her daughter. She said that the SEEDS GP stressed that he was not aware of the changes that had been made to the Practice's services on Saturdays. She said that he should have been aware. She said that more time was wasted in diagnosing her daughter's illness.

132. Mr and Mrs M said that they had no complaints about the second SEEDS doctor who visited their daughter at home on 25 January 2009 (paragraph 35).

The SEEDS GP's comments

133. In a letter addressed jointly to the manager of SEEDS and the Head of Clinical Standards and Performance at the PCT, dated 20 July 2009, the SEEDS GP said that he had read the transcript (paragraph 127) and the consultation notes he had made at the time of his conversation with Mrs M, and had reflected on both. He said that he was frankly rather ashamed and disgusted at the errors he made at the time.

134. The SEEDS GP said that he was sorry to say that during the telephone conversation it would seem that he latched onto the need for chest physiotherapy to move the sputum[37] and he relied on B's GP's diagnosis as stated by her mother. He said that he still could not understand why on earth he made that decision at the time and why he had that '*tunnel vision*'. He said that reading the transcript now, it was apparent that B probably had '*a nasty chest infection*' and he should have seen her afresh, not relying on anyone else's diagnosis and treatment. He said that he should have stepped back and taken a much broader and new look at the patient. He said that to be able to do this, he should have seen B for himself and therefore should have visited, to be able to make an independent decision. The SEEDS

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[37] Matter coughed up and usually ejected from the mouth, including saliva, foreign material and substances such as mucus and phlegm from the respiratory tract.

GP said that had he done this he was sure that he would have noted other features of '*a nasty chest infection*' and he would have then had to admit B to hospital. He said that he should not necessarily have followed on from her GP's management.

135. The SEEDS GP said that he should also have linked the history of spinal problems to sputum production and possible aspiration in a child with such disabilities. He said that he felt he had failed to latch onto that.

136. The SEEDS GP said that reading the transcript, it was quite clear that B's mother was asking for a visit and that he resisted this. He said that he genuinely did not recall this request. He said that he could only assume that he was so focused on the issue of physiotherapy that this did not register with him.

137. The SEEDS GP said that he was also not at all happy with the write-up he did after the telephone consultation. He said that it was not accurate and it seemed that he had recorded his inaccurate interpretation of the focus of the consultation rather than an objective factual account.

138. The SEEDS GP said that on reflection, he could see that he had made a snap judgment. He said that he felt that this played a detrimental role in leading him to think along a narrow path (the thought that B needed physiotherapy and that physiotherapy could not be given in the middle of the night). He said that he now realised that he should have been more open-minded and more accepting of a wider picture and should have paid more attention to the anxiety of Mrs M. He said that had he done this, he would have made a better clinical decision about B.

139. In his letter, the SEEDS GP went on to describe steps he had taken to produce greater accuracy in writing up the facts after a telephone call and to review his consultation skills. He said that he had approached the appraisal lead[38] for his area and would be approaching the senior trainer at his Deanery[39] to help him improve his consultation skills.

140. In a subsequent letter to Mrs M, dated 6 August 2009, the SEEDS GP said that as far as he was aware, the Practice would open on Saturday 24 January 2009 to deal with patient calls, visits and attendances and would be able to review any urgent faxes and emails that had been sent in. He said that this had been the case until October 2008. However, he said that he had not been informed that the service had substantially changed at that time and that his fax message would not be seen.

141. Again, the SEEDS GP described steps he had taken to address '*the deficiencies in* [his] *consultation skills*'. In addition to the approach to his appraisal lead and Deanery (paragraph 139), he said that he had approached the GP education group (Primary Care Education in South Essex) to help re-educate himself, critically reviewed his most recent consultations, and self-referred himself to the chief executive of SEEDS so that they could '*review* [his] *case through their clinical governance process*'.

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[38] GP appraisal was introduced in England in 2002. It was designed as an educational process with the emphasis on reflection and forward planning with the assistance of a trained peer, known as an appraisal lead.

[39] The East of England Multi-Professional Deanery is a regional centre of excellence whose role is to support the education and development of all clinical professionals.

142. On 1 February 2011 the Medical Protection Society (MPS) wrote to us on the SEEDS GP's behalf. MPS said that in so far as the SEEDS GP's involvement in B's care is concerned, the matter had already been investigated extensively by the PCT and the GMC, resulting in him accepting a warning from the GMC. They said that the SEEDS GP had been greatly affected by B's death and that he is very self-critical of his involvement in her care. They said that as a result of this self-criticism, the SEEDS GP had, of his own initiative, taken remedial action. They said that as a direct result of this case, the SEEDS GP had decided that he will no longer undertake out-of-hours duties.

143. In a second letter to this Office dated 28 July 2011, MPS said that the SEEDS GP could not recall giving consideration to B's learning disabilities. They said that he could not recall being told that she had learning disabilities. They said that his focus was on her chest infection and he was aware that she had significant spinal problems.

The Practice's comments

144. We asked the Practice about its opening arrangements on Saturdays, and on 14 June 2011 they wrote to us.

145. The Practice said that the arrangement had always been, and was at the time of the events in question, that all emergency visits and out-of-hours consultations should be directed to SEEDS. It said that the Practice does not carry out home visits on Saturdays. It said that on Saturdays it is only open between 9am and noon, to see pre-booked appointments in line with its Local Enhanced Service contract with the PCT.

146. The Practice also said that it does not carry out normal administrative work on Saturdays, so the message that the SEEDS GP told Mrs M he would be sending to the Practice (paragraph 34) would not have been read.

Clinical advice

147. The clinical advice we have drawn on in reaching our findings and conclusions is in Annex C of this report.

Our findings

The care and treatment SEEDS provided for B

148. When we met Mr and Mrs M on 31 March 2011 they told us that they had no complaints about the second SEEDS doctor who visited their daughter on 25 January 2009 and referred her to the Hospital. However, Mr and Mrs M complain that when they first contacted SEEDS on 24 January, the SEEDS GP refused to make a home visit when they asked him to.

149. To decide whether there has been service failure, we again refer to the *Ombudsman's Principles* of Good Administration. In order to 'get it right' in his care and treatment of B, the SEEDS GP should have taken account of relevant guidance and established good practice (as set out in this instance in the specific standards outlined in Annex A, paragraphs 10 and 11, and as described by the GP Adviser) and had regard to disability law and B's rights as a disabled person. The SEEDS GP should have taken reasonable decisions, based on all relevant considerations. In reaching our findings we have compared what should have happened with what did happen.

150. When Mrs M telephoned SEEDS in the early hours of 24 January 2009, the SEEDS GP should have known that in order to provide good clinical care, *Good Medical Practice* says that doctors should adequately assess the patient's condition, taking account of the history (including symptoms, and psychological and social factors), the patient's views, and where necessary examining the patient. It says that they should provide or arrange advice, investigations or treatment where necessary. However, in his letter to the manager of SEEDS and the Head of Clinical Standards and Performance at the PCT dated 20 July 2009 (paragraphs 133 to 139), the SEEDS GP admitted that this did not happen. He said that on reading the transcript of the conversation, it was clear to him that B probably had '*a nasty chest infection*' and he should have visited her at home and not relied on her GP's diagnosis and treatment. He said that had he done so, he was sure that he would have noted other features of '*a nasty chest infection*' and he would then have had to admit B to hospital.

151. The GP Adviser told us that the SEEDS GP did not fulfil his obligation to provide good clinical care for B. He said that the SEEDS GP did not adequately assess B's condition, he did not take an adequate history, he did not have the benefit of examining B, and he did not have any idea of the social factors involved in the case. He said that as a home visit had been reasonably requested and was obviously necessary, the SEEDS GP should have arranged to examine and assess B at home, but he did not do so. Instead, the SEEDS GP told Mrs M that he would send a message to the Practice requesting a home visit from one of the GPs later that day.

152. We accept that the SEEDS GP may have believed that the Practice would be open to review his message during the morning of 24 January. However, the transcript of his telephone conversation with Mrs M shows that she told him that the Practice did not make home visits on Saturdays and he ignored her protests. It is also clear to us that if the SEEDS GP thought that a home visit was necessary, then as the GP Adviser has said, he should have carried out a home visit himself.

Disability discrimination rights

153. Mr and Mrs M complain that their daughter was treated less favourably by the SEEDS GP because of her disabilities, including her learning disabilities.

154. As we explained earlier, B was a person with physical and learning disabilities and the SEEDS GP was obliged to consider her needs and whether adjustments needed to be made in order to ensure that she had access to health services designed around her individual needs (Annex A, paragraphs 1 to 8). It is clear to us that B's rights under disability discrimination law were engaged here and should have been considered in the SEEDS GP's decision making in the planning, and throughout the provision, of her care and treatment.

155. In their letter to us dated 28 July 2011 the doctor's representative said that the SEEDS GP could not recall giving consideration to B's learning disabilities. They said that he could not recall being told that B had learning disabilities.

156. We accept that B's learning disabilities were not mentioned during Mrs M's telephone call to SEEDS on 24 January, but Mrs M did tell the SEEDS GP that her daughter was '*a severely handicapped child with a complete curve on the spine*'. Mrs M did

tell the SEEDS GP that her daughter had physical disabilities. Therefore, the SEEDS GP should have considered B's rights under disability discrimination law in his decision making about planning and delivering her care and treatment. However, we have seen nothing to indicate that he did this.

Our conclusions about SEEDS

157. In conclusion, we find that the SEEDS GP did not 'get it right', because he did not take appropriate action to assess and diagnose B's condition in line with *Good Medical Practice* and established good practice. This meant that he did not have sufficient information to make an informed decision about B's further care and treatment. He did not take reasonable decisions, based on all relevant considerations. His care of B fell so far below the applicable standard that this was service failure.

158. Furthermore, we can find no evidence that B's rights under disability discrimination law were properly considered. Therefore, we conclude that in planning and providing care to B, the SEEDS GP did not have regard to his obligations to her under disability discrimination law. We find that the SEEDS GP's failings in this respect were so serious that they constituted service failure.

The complaint about the PCT

Mr and Mrs M's comments

159. When we met Mr and Mrs M on 31 March 2011, we discussed their complaint about the PCT.

160. Mrs M said that the PCT had not done its job properly. It had not found out all the information it could have done. She said that she felt she had to find out the information for the PCT. Mr and Mrs M said that when they went to the meeting at the PCT, they could not understand the person who spoke to them because his English was not good. She said that this was very frustrating. She said that the representative from Mencap also could not understand him.

161. In a later telephone call to us, Mrs M said that she had found out from the personal assistant to the PCT's Director of Quality and Nursing in late 2010 that prescription records are retained for 14 months. She said that Dr K saw her daughter on 22 January 2009 and therefore the prescription records would have been available until probably April 2010. She said that the records would have shown whether Dr K prescribed antibiotics on 21 January, as he claimed, or 22 January as Mr and Mrs M believed. Mrs M said that the GP Clinical Lead and Interim Head of Clinical Standards and Performance who had conducted the PCT's investigation in July 2009 had done so without checking these important records. She said that she believed that the investigation conducted by the GP Clinical Lead and the Interim Head of Clinical Standards and Performance had been a '*cover up*'.

The PCT's comments

162. We asked the PCT to explain what happened after it referred the Practice to the GMC in November 2009 (paragraph 67).

163. In a letter to us dated 3 July 2012, the PCT said that it had encountered difficulties tracking the progress of the complaint, as none of the officers who were originally involved in the investigation were still employed by the PCT. However, it said that from a review of the case files, it understood that the investigation report written by the GP Clinical Lead and the Interim Head of Clinical Standards and Performance (paragraph 63) had been based on information given by the Practice's Clinical Governance Lead in a letter to the PCT dated 24 June 2009. It said that in his letter, the Clinical Governance Lead had said that Mr and Mrs M had not requested a home visit on 23 January 2009.

164. The PCT said that Dr K was not referred to the GMC. However, it said that it did refer the Clinical Governance Lead to the GMC on 11 September 2009 on the grounds that he had potentially misled the PCT during its investigation of Mr and Mrs M's complaint. The PCT said that the GMC subsequently advised it that they would not be taking any further action in response to the PCT's referral, as there was no evidence that the Clinical Governance Lead had misrepresented the information given to him by Dr K and the Practice's Reception Manager when he responded to the complaint.

165. The PCT said that it did consider taking further action against Dr K. However, it said that upon reviewing the response given by Dr K's legal advisers and undertaking an audit of the Practice's computer records for the period in question, it decided that no further action should be taken.

166. The PCT said that in addition to the records audit it had undertaken in June 2009, a further audit of the SystmOne entries for 21 and 22 January 2009 had been undertaken at the request of the GMC in October 2011.

167. In a later telephone call, and an email to us dated 9 July 2012, the PCT said that the case files indicated that there was further communication with Mr and Mrs M, and with Mencap, after it referred the Practice to the GMC in November 2009. The PCT gave us evidence that showed that Mrs M was in email contact with the Interim Head of Clinical Standards and Performance in March 2010 and that the PCT corresponded with Mencap in late 2010. However, the PCT said that the information in the case files was patchy and it could not give us a comprehensive picture of this communication. Furthermore, the PCT said that from looking at the case files it was clear that its Director of Quality and Nursing had kept in close contact with B's family, but that some of this contact had been quite informal and not well documented. The PCT speculated that this was how the family had been told about some of the events after November 2009.

Responses to our enquiries

168. The papers we have examined during the course of our investigation include a letter dated 22 June 2009 from the National Clinical Assessment Service (NCAS), part of the NHS National Patient Safety Agency, to the PCT's Interim Head of Clinical Standards and Performance. In the letter, the NCAS adviser summarises a telephone conversation he had had with the Interim Head of Clinical Standards and Performance on 17 June. The letter says:

> *'I explained that any conclusions as to whether* [Dr K] *made the correct decisions in this case need to be made locally with the PCT taking its own medical advice … It is therefore for your case manager to make any recommendation to the PCT Decision Making Group. I made clear that this is a matter that must be determined locally.'*

Our findings

169. Mr and Mrs M complain that the PCT did not find out all the information relevant to their complaints and did not investigate their complaints about Dr K and the SEEDS GP properly.

170. To decide whether there has been maladministration, we refer to the *Ombudsman's Principles* of Good Complaint Handling (paragraph 24). In order to 'be customer focused', the PCT should have listened to Mr and Mrs M to understand their complaint and the outcome they were seeking. It should have responded flexibly and co-ordinated responses with any other organisations involved. The PCT should have 'acted fairly and proportionately' by ensuring that Mr and Mrs M's complaints about Dr K and the SEEDS GP were investigated thoroughly and fairly to establish the facts of the case, by someone not involved in the events leading to the complaint.

171. The PCT first became aware of Mr and Mrs M's complaint when it received a copy of Mrs M's letter to the Practice on 23 February 2009 and when Mrs M visited its headquarters and met its Director of Quality and Nursing the following day. It was clear at this time that Mrs M did not want to see Dr K again, so the PCT took steps to find the family an alternative GP practice to register with. Over the following weeks the PCT met Mr and Mrs M (on 2 March and 3 April) to ensure that it understood their complaint

and the outcome they were seeking. Because Mr and Mrs M had complained about the care and treatment B had received after she arrived at the Hospital, the PCT sent a copy of the notes of its meeting with them on 3 April to the Trust. When the Trust's Chief Executive met Mr and Mrs M and Mencap on 3 July, senior staff from the PCT, including the Director of Quality and Nursing, were also present.

172. During the meeting on 3 April Mr and Mrs M complained that Dr K failed to make a further home visit to B on 23 January 2009 and that the SEEDS GP failed to make a home visit on 24 January. The PCT arranged for its GP Clinical Lead and its Interim Head of Clinical Standards and Performance to investigate their complaints. Their report (paragraphs 63 and 64) concluded that Dr K's actions had been reasonable, but that the SEEDS GP's decision not to visit B had been a poor one. The PCT explained that, in light of its findings, it had decided to refer the SEEDS GP to the GMC under its Fitness to Practise procedures.

173. Mr and Mrs M believe that the investigation carried out by the Clinical Governance Lead and Interim Head of Clinical Standards and Performance was a '*cover up*'. We do not agree. On the contrary, we consider that the PCT 'acted fairly and proportionately' when it asked the GP Clinical Lead and Interim Head of Clinical Standards and Performance to undertake an independent investigation of Mr and Mrs M's complaint. Nonetheless, there is one aspect of their final report that we consider is misleading. In the report it says that '*Independent advice from the National Clinical Assessment Service shows that the rationale for* [Dr K] *not seeing B on Friday 23 January 2009 or arranging for a physio*[therapy] *visit can be considered to be reasonable*' (paragraph 63). This was a statement repeated when the PCT met Mr and Mrs M on 27 August 2009. However, according to the letter dated 22 June 2009 (paragraph 168), this is not what the NCAS adviser actually told the Interim Head of Clinical Standards and Performance. The advice from the NCAS adviser was that any conclusions as to whether Dr K made the correct decisions in this case needed to be made locally, with the PCT taking its own medical advice.

174. On the other hand, we do not consider that the final conclusions that the GP Clinical Lead and Interim Head of Clinical Standards and Performance came to in their report about Dr K's actions on 23 January 2009, were inappropriate. This is because they found no reason to criticise Dr K's actions and (as we explained earlier in this report) we reached the same conclusion.

175. Mr and Mrs M are also critical (paragraph 161) of the GP Clinical Lead and the Interim Head of Clinical Standards and Performance. They say that they failed to investigate whether Dr K prescribed antibiotics for B on 21 January 2009. They say that the prescription records were retained for 14 months and that the GP Clinical Lead and Interim Head of Clinical Standards and Performance would have had the opportunity to examine them until probably April 2010. We have considered this criticism carefully, but we are unable to reach a firm conclusion. This is because the papers we have examined do not make it clear at what point Mr and Mrs M first raised the events of 21 January, and specifically the timing of the prescription for antibiotics, with the PCT.

176. At the end of the meeting between the PCT and Mr and Mrs M on 3 April 2009, the PCT agreed to investigate their complaint that Dr K had failed to visit B on 23 January. An outcome of the meeting on 27 August 2009 was that the PCT agreed to '*review how it was that key information regarding the family's request for a further visit had not been presented for investigation until a very late stage*' (paragraphs 65 and 66). There is no reference to 21 January 2009 in either set of meeting notes, so we conclude that any query about the timing of the prescription for antibiotics must have been raised by Mr and Mrs M at a later date; possibly during the period after November 2009. The PCT told us that its records for this period are incomplete (paragraph 167).

177. That said, we have explained earlier in this report (paragraph 114) about the difficulty we have encountered establishing what did or did not happen on 21 January 2009. It is likely that even if the PCT had investigated the prescription of antibiotics before April 2010, it would still have been faced with the same conflicting information between Mr and Mrs M's recollection of events and the SystmOne records.

178. In conclusion, we find shortcomings in the PCT's handling of Mr and Mrs M's complaint: the misleading statement in its investigation report about the advice the Interim Head of Clinical Standards and Performance had received from NCAS; and its failure to investigate the timing of the prescription on 21 January 2009. However, we have weighed up these shortcomings against the things it did 'get right'. The PCT was '*Being customer focused*' when it took prompt steps to find Mr and Mrs M an alternative GP practice; when it arranged to meet them to ensure that it understood their complaints properly; and when it took steps to liaise with the Trust to ensure that Mr and Mrs M's complaints about B's hospital care were also investigated. In addition, the PCT 'acted fairly and proportionately' when it commissioned a thorough investigation of Mr and Mrs M's complaints about Dr K and the SEEDS GP by someone not involved in the events leading to their complaint; and when, at the end of the investigation, it explained what further action it would be taking.

179. Mr and Mrs M complain that the PCT did not find out all the information relevant to their complaints and did not investigate their complaint properly. However, this was a serious and complex complaint and we recognise that it would not have been straightforward for the PCT's staff to investigate. Therefore, taken as a whole, we do not find that the PCT's handling of Mr and Mrs M's complaint fell so far below the applicable standard that it amounted to maladministration.

The complaint about the Trust

Mr and Mrs M's comments

180. When we met Mr and Mrs M on 31 March 2011, we discussed their complaint about the Trust. The notes of that meeting, where they refer to the matters we have investigated, are set out below.

181. Mr M said he thought the Hospital treated his daughter '*as a guinea pig*'. He and Mrs M said that their daughter arrived at the Hospital at 7am on Sunday 25 January and was taken straight to the medical assessment unit where she was seen by a junior doctor. At this point they said she was still alert. Mr and Mrs M said that the junior doctor arranged X-rays and told them there was good news because she only had a minor infection. Mrs M said that doctors in the medical assessment unit took a long time to decide where to send her and this meant that she was dealt with by a junior doctor and an on-call consultant physician (the On-call Consultant). She questioned how the junior doctor could make a diagnosis, when more experienced doctors '*did not have a clue*'.

182. Mr and Mrs M said that they feel an opportunity was missed to do a proper assessment. They said that doctors did not take account of the second SEEDS doctor's diagnosis of aspiration pneumonia. They said that this meant B was still eating and drinking when this should have been stopped. They said that doctors at the Hospital did not pick this up. They said that their daughter was not seen by a nutritionist until Thursday 29 January.

183. Mr and Mrs M said that when the On-call Consultant arrived she abruptly asked them who they were. They said that without warning the On-call Consultant said that doctors would not be able to resuscitate B because they would break her ribs. Mrs M said that they felt that the On-call Consultant's manner was appalling for B as well as for them.

184. Mrs M said that at first they were told that their daughter was not seriously ill and then they were told that she was seriously ill. She said doctors did not know what they were doing. She said that she asked to speak to the head of nursing because she had met her before and she asked for B to have physiotherapy.

185. Mr and Mrs M said that their daughter was moved to the respiratory unit the next day (26 January). They said that there they met a locum doctor who said he had only been in the Hospital for six hours and did not know anything about B. They said that they had no faith in this doctor. They said that they also met a registrar who was very matter of fact. They said that they never saw a consultant.

186. Mrs M said that she had asked to see a doctor because B was having seizures. She also said that she asked for her daughter's X-rays to be sent to Stanmore Hospital (a specialist orthopaedic hospital), so that the experts there could interpret them, but this request was refused. She said that B had seen a consultant at Stanmore Hospital the week before she became ill. She said that an X-ray was taken during this visit and there was no sign of infection at that time.

187. Mrs M questioned whether B had been given the correct dose of antibiotics. She said that another GP told her that when a person has a chest infection they should be given 500mg antibiotics and not

250mg. She said that another doctor had commented to her that a very low chest infection is hard to clear and could be an aspiration.

188. Mr and Mrs M said that when they met the Chest Consultant he said that B was dying. Mr M had been upset and the Chest Consultant said they should not be afraid of the word '*dying*'. They said he repeated '*die, die, die*'. They said that the Chest Consultant said that if their daughter lived she could get infections.

Responses to our enquiries

189. When Mr and Mrs M met the Trust on 3 July 2009, its Head of Nursing, Children's Services, and Head of Nursing, Medicine and Emergency Care, who had met Mrs M in 2006, were present. The notes of the meeting say:

'[The Head of Nursing for Children's Services] *wanted to apologise that B's transition from paediatrics to adult care did not work.* [The Head of Nursing for Medicine and Emergency Care] *also offered her apologies as she was involved in this transition plan, discussed with Mr and Mrs M.*

'[The Head of Nursing for Children's Services] *advised that the East of England* [strategic health authority] *is focussing on transition of patients from children's services to adult care and that she wanted to bring this work to* [the Trust] *to ensure that there is a robust transition process in place.* [She] *said that this would involve two pieces of work – Children's Services getting ready for patient's change and Adult Services ensuring that process is as smooth as possible.* [She] *said that* [Mrs M's] *input on the steering group would help to ensure that the changes work.* [The PCT's Associate Director, Commissioning and Quality] *said that all need to work jointly with social care, education, etc., to ensure that the changes work.* [Mr M] *asked if there was a target date for work and action plans.* [The Head of Nursing for Medicine and Emergency Care] *said that there is no set date as the work is continuous and an ongoing process but as soon as the four bed area is in place Mr and Mrs M will be informed.'*

190. In the subsequent investigation report by Head of Nursing for Medicine and Emergency Care, dated 30 July 2009 (paragraph 70), it said:

'[The Head of Nursing for Medicine and Emergency Care] *and* [Head of Nursing for Children's Services] *met with B's family at their home in the autumn of 2006. This meeting was in response to concerns raised by the family following a poor experience with gynaecological services which was B's first encounter with adult services.* [They] *spent the afternoon with the family understanding her needs and the difficulties that the family* [had encountered] *getting access to the right kind of care. This included out of hospital support. The outcome of the meeting was that the family were to complete a care plan (the template came from the learning disability partnership) for B that could be duplicated within her medical record as well as being held by the family. There was also discussion around identifying a dedicated ward with a dedicated consultant physician for B's care in adult services.*

'These aspects of transition were not completed and for that [the Head of Nursing for Medicine and Emergency Care] *and* [the Head of Nursing for Children's Services] *apologise unreservedly. It was* [the Head of Nursing for Medicine and

Emergency Care's] *intention to arrange for B to have access to a respiratory physician and the respiratory ward as it was expected that because of her scoliosis her presenting conditions were likely to be respiratory in nature.'*

The Trust's comments

191. In a letter to us dated 24 June 2011, the Trust said that a review of B's care and treatment had been undertaken by its Learning Disabilities Nurse Advisor, a post created some time after B's care at the Hospital. The Trust sent us a copy of the review, which has been included in this report at Annex F.

192. The Trust explained in its letter that the original copies of B's healthcare records were not available to the Learning Disabilities Nurse Advisor when she undertook her review, but it said that she did have access to a set of photocopied healthcare records that were in the Trust's complaint file. The Trust said that it was unsure where the original healthcare records were. It said at the time that searches for the original healthcare records were continuing, but it did not anticipate that the loss of the original healthcare records would have impacted significantly on the Learning Disabilities Nurse Advisor's review.

193. In an email dated 2 July 2012 the Trust sent us a number of documents setting out some of the steps it has taken since 2009 to enhance the quality of care for patients with learning disabilities and also the care of children and young people with ongoing chronic health needs moving into adult care. These documents included: the Learning Disabilities Nurse Advisor's job description; specialist assessment forms for adults with learning disabilities and for children and young people; a copy of the Trust's current *Caring for Patients with a Learning Disability Policy*; a blank hospital passport;[40] blank health action plans;[41] and a copy of the Trust's *From Board to Ward Resource pack – Improving health outcomes for people with learning disabilities when they need hospital care*.

194. The Trust said that it appreciated that Mr and Mrs M had raised the issue of the advice they had been given by its Head of Nursing for Medicine and Emergency Care and its Head of Nursing for Children's Services in 2006 about a transition care plan (from children's to adult services) for B. It said that at the time it had been the intention to develop a transition policy. However, it said that this was not the route that the Trust eventually took with regard to individual care planning and that a transition policy was not in place when B was admitted to the Hospital in January 2009.

195. The Trust said that a meeting took place with Mr and Mrs M in July 2009 with its Head of Nursing for Medicine and Emergency Care and its Head of Nursing for Children's Services present. It said that it could only apologise that the

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[40] Hospital passports are filled in by people with learning disabilities and their supporters before or on admission. The aim of the passport is to assist hospital staff so that they can provide better care for the person with learning disabilities, their family and carers.

[41] The health action plan can be used by the person with learning disabilities and their supporters to record information that is important and useful to managing their health and any long-term conditions they may have.

development of the transition policy was not progressed in line with the expectations that were raised at the time of this meeting. It said that both of these key members of staff moved on shortly afterwards to roles in other trusts.

196. The Trust said that while it was aware that some other trusts have gone down the route of developing transition policies, it was not realistic for it to do so without the expertise of a Learning Disability Nurse Advisor or Head of Nursing for Children's Services in post at the time to develop this. However, it said that a transition policy is now nearing completion, which will bring together all the elements of assessment and care that are being practised, as illustrated in the attachments included with its email, in a meaningful and realistic way.

197. The Trust said that it had noted that one of the issues discussed at the July 2009 meeting was the need for B to be referred to the respiratory ward and physician because of her scoliosis, and the likelihood that this would have meant her presenting conditions would be respiratory in nature. The Trust said that the issue of a paediatric transitional care policy would not have been relevant to the management of B's care as she was 23 at the time of her admission. It said that, as in any acutely ill person, the overriding need would have been to assess her specific chronic health needs, as it said the On-call Consultant had explained when we met her. It said that when B was admitted in January 2009 she was transferred to the respiratory ward under the care of first a general physician, and subsequently a chest physician.

198. The Trust said that Mrs M would be aware of the Learning Disabilities Nurse Advisor's role and the work she has been involved in, from her contacts with her, which it believed had continued up to approximately July 2011. It said that it considered that the care of people with learning disabilities, and their carer's experiences, had improved since the appointment of the Learning Disability Nurse Advisor.

The On-call Consultant's comments

199. We met the On-call Consultant to discuss Mr and Mrs M's complaint on 18 August 2011.

200. We began by explaining that we were investigating the care provided for B between her admission to hospital on 25 January 2009 and her death on 30 January. The On-call Consultant confirmed that her involvement had been from the evening of B's admission through to the next day.

201. The On-call Consultant said that when B was admitted she came with a letter from the second SEEDS doctor and she was seen by a senior house officer (SHO[42]). She said that B had a very high temperature and respiratory rate and low blood pressure. She said that the SHO organised a chest X-ray. Because of the deformity of B's chest she said the X-ray was difficult to interpret, but it suggested that there was infection present. She said that it was therefore decided to give intravenous antibiotics. However, the On-call Consultant said that the doctor had difficulty inserting a cannula

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[42] An SHO is a junior doctor.

(a fine tube) into a vein, and had to try a number of times. She said that Mrs M was distressed as she thought this was causing suffering to her daughter and asked for no more attempts to be made to put in an intravenous cannula. She said that the doctor agreed.

202. As B was unable to receive the antibiotics intravenously, the On-call Consultant said that they needed to be given orally. She said that B was awake, and when she was sitting upright, her parents were able to give her fluids and she was not coughing. She said that therefore B was given antibiotics in liquid form.

203. The On-call Consultant said that the clinical findings showed changes on the left side of the chest. She said that because of the anatomy of the lungs it would be expected that if someone had aspirated there would be changes on the right side.

204. The On-call Consultant said that B was also given oxygen, but Mr and Mrs M had to try and hold the oxygen mask on B's face. She said that doctors did the best they could within the limitations of the situation. She said it was difficult to provide optimum care for B with intravenous fluids and antibiotics, as her parents did not wish for further intravenous cannulae to be inserted or for any other invasive interventions. She said that treatment was therefore supportive (oral antibiotics and oral fluids). She said that as it was evening, chest physiotherapy was planned for the next day.

205. The On-call Consultant confirmed that she met Mr and Mrs M only once. She said that she saw B at 5.30pm. She said that, as described, the junior team had had difficulty with B's care. She said that she entered the side room, where B was being nursed, with some other colleagues, but they were called away and left the room. She said that she was therefore left alone with Mr and Mrs M. The On-call Consultant said that she examined B and found her to be very unwell. She said that she wanted to discuss treatment options with her parents and wanted to do this out of the room, away from B, but they did not want to leave their daughter. The On-call Consultant said that Mr and Mrs M also had their other teenage daughter with them and she did not feel it was appropriate to discuss difficult issues in her presence. She said that Mr and Mrs M did not like the fact that she had asked for the other daughter to be taken out of the room. She said that she did not know that their other daughter had learning disabilities.

206. The On-call Consultant said that ideally she would have liked to go to a room where she could sit down with B's relatives, but Mrs M would not allow this and this made the situation more difficult.

207. The On-call Consultant said that Mr M took their other daughter out of the room and she was left with Mrs M. She said at this time it was as if there was a '*sudden wall*' between them. She said that Mrs M was very upset because her daughter was very ill, but she also felt Mrs M was hostile. The On-call Consultant said it was difficult to get Mrs M to a calm level where she was willing to discuss B's treatment. She said that she therefore spent some time discussing B and her background with respect to previous admissions and treatments and what her parents felt about specific interventions. She said that she discussed treatments with Mrs M and talked about specific issues, such as venous access. The On-call Consultant said that she told Mrs M that they wanted to treat B with intravenous antibiotics and fluids

as this was best practice in such a severe pneumonia but would respect Mrs M's wishes about how intensively she wanted them to treat B. She said that Mrs M said that she did not want the doctors to try to get intravenous access. She said that she talked about other treatments, for example, giving oxygen, because B was not tolerating a mask or nasal cannulae.[43] The On-call Consultant said that at this time B was in septic shock. She said that she had a raised temperature, low blood pressure, and was very hypoxic, which indicated respiratory failure. She said that added to this, she had a chest deformity that made it more difficult for her to fight a chest infection.

208. The On-call Consultant said that B's risk of dying was very high with such a severe chest infection. She said that she discussed with Mrs M the options with respect to further intensive treatment. She said she wanted to know what Mrs M would want them to do if B's heart stopped. The On-call Consultant said that she asked Mrs M if she would want them to try and resuscitate B and she explained that if they pressed on her chest this may cause fractured ribs. She said that Mrs M did not want this to happen, she did not want masks, nebulisers or drips but for B to have supportive care. She also said that Mrs M was happy that B should be allowed to drink. The On-call Consultant said that she felt that whereas there had been hostility at the outset, at the end it was calm. They had had a conversation and she knew what Mrs M wanted for her daughter.

209. The On-call Consultant said that after the meeting she felt very tense. She said that Mrs M had implied criticism of everything going on, but she felt that she had tried to incorporate Mrs M's wishes while giving the best care they could. She estimated that the conversation with Mrs M had lasted about half an hour. She said it had taken a long time to '*get through the wall*'.

210. When we met the On-call Consultant we explained that Mr and Mrs M had told us that another doctor had said that B was not very ill and therefore Mrs M had been very shocked and distressed when she discussed things such as whether to resuscitate B. The On-call Consultant said that she did not remember Mrs M saying anything about this at the time. She felt it was unlikely that any doctor would have said this as the SHO had documented the plain facts. She said that, although not in use at the time, the Hospital now use a scoring system that would place B at the highest risk for pneumonia. She said that she cannot be sure what was said, but in A&E people are often scared and doctors try to reassure relatives. However, she said that it was clear that B was very sick. She said that her oxygen saturation was only 68 per cent, which was very low.

211. The On-call Consultant said that in terms of good practice, it was important to know what B's family wanted because it was evening and the night team of doctors needed to be clear about what should be done if B's condition deteriorated. She said that discussing these things was difficult, but needed to be done.

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[43] A nasal cannula is a device that fits into the nostrils and is used to deliver oxygen or additional airflow to patients in need of respiratory help.

212. The On-call Consultant said that she tried to deal with B as best as possible, but felt she was put '*on the back foot*' because of the parents' hostility. She said that she tried to do what was right for B while also taking account of Mrs M's wishes, and also make plans for those looking after B overnight.

The Chest Consultant's comments

213. The Chest Consultant gave us a statement outlining his recollection of B's care and treatment in a letter to the Trust's Head of Nursing dated 15 May 2009.

214. In his letter, the Chest Consultant said that after B had been transferred to a specialist respiratory ward she was reviewed by a locum SHO at 1.30pm on 27 January 2009. He said that the locum SHO spent '*a comfortable amount of time with B*' and made a detailed entry in her notes. He said that the locum SHO's observations were impeccable. He said that there is a note that Mrs M said that B was looking better than at admission. However, he said that on examination the locum SHO found that B was sleepy. The locum SHO also found that she had crackles on both sides and her chest X-ray was difficult to interpret because of the kyphoscoliosis.[44] He said that B was treated for pneumonia.

215. The Chest Consultant said that the locum SHO thought that aspiration was possible in view of B being sleepy. He said that community-acquired pneumonia was the other possibility, because B had come into the Hospital with respiratory symptoms. He said that the locum SHO stopped amoxicillin and added metronidazole and cerfuroxime.[45] He said that the locum SHO also instructed that B should not eat or drink until a speech and language therapy assessment had been completed. He said that he entirely agreed with this. The Chest Consultant said that the locum SHO spoke to the Consultant Neurologist on the telephone and he advised that B could have clonazepam drops buccally until her speech and language therapy assessment. He said that if the speech and language therapy team agreed that she could have medication by mouth, B could have lamotrigine as well. He said that the locum SHO spent most of the afternoon with B.

216. The Chest Consultant said that he and his registrar were in an outpatient clinic on the afternoon of 27 January and at 5pm the locum SHO contacted the registrar. He said that the registrar agreed entirely with the locum SHO's clinical findings and management plan. He said that the registrar also went on to review B again at 5.20pm the same day. He said that the registrar went over B's previous history, clinical examination and results to date and agreed with the management plan. He said that her oxygen saturation at that point was 96 per cent and her blood pressure had also improved. He said that she was not as pyrexial[46] as at admission.

217. The Chest Consultant said that B was reviewed again by his registrar on 28 January at 9.15am. He said that it was noted that she had had seizures during the night. He said that her antibiotic was changed to Tazocin and lorazepam was written in her drug chart, to be given if

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[44] Kyphoscoliosis is the abnormal curvature of the spine both forwards and sideways.

[45] Metronidazole and cerfuroxime are antibiotics.

[46] Feverish.

needed, if she had further seizures. The Chest Consultant said that B was also seen by the Patient at Risk Score team regularly and they agreed that her management plan was adequate and that they could offer little further support.

218. The Chest Consultant said that B was seen by the speech and language therapy team at midday on 28 January and they felt that she was not alert enough to take food and fluid by mouth, so nasogastric tube feeding was suggested. He said that the speech and language therapy team agreed that B should not eat or drink. The Chest Consultant said that although he did not see B on 28 January, she was reviewed by his registrar, who discusses all sick patients with him and with the Patient at Risk Score team.

219. The Chest Consultant said that he saw B on his ward round on 29 January at 9.40am and he spent about two hours with her and her family. He said that he addressed their concerns at that point and explained that her treatment to date was appropriate. He said that he emphasised the fact that when a patient is conscious one can safely feed by mouth, but if a patient's consciousness deteriorates then it would be prudent to withhold oral feeds (food and medication) to prevent continued aspiration. He said that in B's case aspiration was a definite possibility for a number of reasons: her seizures; her kyphoscoliosis; and the fact that she had to be cared for in bed.

220. The Chest Consultant said that B's mother, father (who joined during this discussion) and grandmother were all present with his team and the ward manager when he went through the notes with them explaining the treatment at each point. He said that he explained that it would not be safe to feed B and the plan was to insert a nasogastric tube to give her food and medication. He said that he also explained that B certainly had pneumonia and that doctors were providing treatment for both aspiration and community-acquired pneumonia with the appropriate antibiotics. He said that he explained that pneumonia could worsen in people with normal chests but in patients with physical abnormalities, like B, pneumonia could deteriorate and might even cause death. He said that he discussed resuscitation with her family and agreed that if B deteriorated she was not for resuscitation.

221. The Chest Consultant said that B's mother raised the issue of competence of the doctors and he explained without reservation that he had complete confidence in the assessment and treatment administered to B by both the locum SHO and the registrar. He said that the question of B's chest X-ray being looked at by a radiologist was raised and he told Mr and Mrs M that as a chest physician, he was appropriately trained to read chest X-rays. He said that he reiterated that the possibility of pneumonia, which is treatable, was being dealt with and that X-rays in patients with abnormalities as extensive as B's would be difficult to interpret by chest physicians, radiologists, or specialists. The Chest Consultant said that at this stage the question of getting an opinion from another hospital was not raised by the family and he did not pursue this further because he had clearly explained to her family the unmistakable findings on her chest X-ray.

222. The Chest Consultant said that later that afternoon the Consultant Neurologist saw B. He said that the Consultant Neurologist answered a number of questions from Mr and Mrs M about her treatment

and about the fact that the worsening seizures were probably precipitated by her infections. He said that the Consultant Neurologist made some changes to her medication, which were implemented immediately.

223. The Chest Consultant said that a nasogastric tube was successfully inserted by nurses and B was reviewed again at 5.45pm that evening. He said that it was noted that B continued to be unresponsive and her oxygen saturation had dropped slightly at that point (ranging from 88 per cent to 92 per cent). He said that B was seen by the nutrition team later in the evening and it was decided not to feed her overnight, as her oxygen saturation had fallen. He said that it was decided that the nasogastric tube should only be used for medication. He said that B continued to deteriorate and died on 30 January.

224. To summarise, the Chest Consultant said that B had severe pneumonia causing sepsis.[47] He said that the cause could have been aspiration pneumonia for the reasons he had outlined earlier. He said that she was, nevertheless, treated for aspiration and community-acquired pneumonia. He said that, in his opinion, B's medical treatment throughout her stay in the Hospital was appropriate.

225. The Chest Consultant said that there was a statement made by Mr and Mrs M when they met the PCT on 3 April 2009, which claimed that he had said '*the only thing* [he] *did wrong was not to see B sooner than* [he] *did*'. He said that this was entirely untrue and was likely to have been misconstrued, which he said was understandable as their family was under a lot of stress at the time. He said that during his discussion with B's family he had her notes with him and went through every line with them. He said that he explained to them that even if he had seen B at the time of her admission to the Hospital, it would have made no difference, as he would have treated her in exactly the same fashion as his colleagues had. He said that his comments in this regard have been misunderstood.

The Trust's comments in response to the draft report

226. We shared a draft copy of our report with the Trust on 15 August 2012, and on 19 September it wrote to us with its comments.

227. The Trust said that the transition plan was clearly an issue of high importance to Mr and Mrs M following B's episode of care in 2006. It said that the subject was discussed at the meeting on 3 July 2009 (paragraph 70), where the Associate Director of Commissioning and Quality for the PCT raised the issue of the need to provide co-ordination of care and the transition from children's to adult services. It said that the Associate Director of Commissioning and Quality confirmed the point that there needed to be a joint overall care package and to have one dedicated person to co-ordinate care.

228. The Trust said that the requirement for a single point of expertise was progressed with the Trust's investment in the appointment of the Learning Disabilities Nurse Advisor. It said that it had planned

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[47] NHS Choices describes sepsis as a life-threatening illness caused by the body overreacting to an infection. The body's immune system goes into overdrive, setting off a series of reactions that can lead to widespread inflammation and blood clotting.

that this would be a joint appointment with the PCT, but it had made the decision that this was such a significant role that it needed the person on its premises, available to its learning disability patients and to meet the training needs of its staff. The Trust reiterated its comments set out in paragraph 196 that it had now moved down the route of implementing a transition care policy, which was currently in draft format.

229. The Trust said that whilst it agreed that the transition plan did not progress in the way Mr and Mrs M had anticipated, this was due to priorities highlighted within a number of external and internal reviews. It said that it was unfortunately not possible to give Mr and Mrs M a formal and comprehensive explanation at an earlier point because there was no further contact with them after September 2009. It pointed out that its subsequent correspondence about the complaint had first been with Mencap and then with us.

230. The Trust said that its Learning Disabilities Nurse Advisor had found that it was appropriate for staff to defer to Mrs M with regard to B's best interests and it explained its understanding of the *Mental Capacity Act 2005* (Annex B). The Trust said that it is best practice that if practitioners are faced with a difficult or contentious decision, those closest to the patient are involved in the decision making. It said that this was most relevant with regard to the On-call Consultant's interactions with Mrs M.

231. The Trust said that the On-call Consultant acted at the time in what she felt were B's best interests and also took into account Mrs M's very specific requests with regard to the continuing attempts to insert a cannula. It said that the On-call Consultant explained to Mrs M that antibiotics and fluids were required to treat B, but she was also aware that B was at that point able to take oral fluids. It said that whilst a formal mental capacity assessment was not carried out, there is correspondence within the healthcare records dated 8 November 2006 from the Consultant Neurologist, which identifies that B had severe learning disabilities with no speech and very little comprehension.

232. The Trust said that it felt it was important to review B's episode of care in the context of a patient who was being admitted for acute clinical symptoms with pre-existing and significant health needs and who also had a learning disability. It said it was necessary to prioritise B's clinical care and it was apparent from the healthcare records that throughout B's stay, staff took her needs, and those of Mr and Mrs M and their other daughter, into consideration. It said that B's care in the medical assessment unit progressed in this way and that she was then transferred to the specialist acute respiratory ward, as would be the case for any patient who was admitted with such significant chronic and acute health needs.

233. The Trust said that the On-call Consultant had explained to Mrs M that intravenous antibiotics and fluids would be the optimum treatment for B and that oral medication was unlikely to improve her condition. It said that her family were made aware that B was very ill. It said that their wishes were respected with regard to their feelings about B's best interests and that they did not want her to be distressed by intervention, masks, nebulisers, and so on. The Trust said that B was not noted to be coughing when having her oral fluids and liquid antibiotics which, it pointed out, were signed as having been given.

234. The Trust said that once it was confirmed that B's health was deteriorating, the decision was made to insert an intravenous cannula and Mr and Mrs M were supportive of this. It said that it was therefore of concern to the Trust that its staff's efforts to work alongside Mrs M in providing B with a level of care that was suitable for her needs at this time and was also in line with her wishes, was now being described in terms that its staff did not have proper regard for their obligations to B. The Trust said that the Medical Adviser has suggested that it would have been preferable to have treated B regardless of Mr and Mrs M's wishes. However, it said that having spoken to the On-call Consultant about Mrs M's understanding of the clinical situation and her wishes for B, it felt that this would have caused B's family significantly more distress at that time, and would potentially also have been criticised as an insensitive course of action that was not entirely justified on clinical grounds.

235. Referring to the discussion between Mr and Mrs M and the Chest Consultant (paragraph 188), the Trust said that this was not part of Mr and Mrs M's original complaint and was not therefore answered at the time. However, it said that the Chest Consultant has confirmed that this is something that he would never have said in the way it has been described, especially in such an emotional situation for Mr and Mrs M.

236. The Trust said that the On-call Consultant recalls very clearly her interactions with Mrs M, particularly around the issue of resuscitation, and on further reflection she continues to feel that she handled this sensitively and in consideration of both Mr and Mrs M, their daughter, and B's needs. It said that Mr and Mrs M's recollection of events in this respect are different from those of the healthcare professionals involved in B's care. However, the Trust acknowledged that any consideration of the management of B's care could only draw on the content of the healthcare records with regard to the healthcare professionals involved.

Clinical advice

237. The clinical advice we have drawn on in reaching our findings and conclusions is in Annexes D and E to this report.

Our findings

238. Mr and Mrs M complain about the care and treatment provided for their daughter by the Hospital from her admission on 25 January until 30 January 2009, when she died. The detail of their complaint is set out in paragraph 5.

239. To decide whether there has been service failure, we once more refer to the *Ombudsman's Principles* of Good Administration. In order to 'get it right' in their care and treatment of B, the Trust's staff should have taken account of the relevant guidance and established good practice (as set out in this instance in the specific standards in Annex A, paragraphs 9 to 17, and as described by the Ombudsman's advisers) and had regard to disability law and B's rights as a disabled person. They should have taken reasonable decisions, based on all relevant considerations. In order to be 'customer focused', the Trust's staff should have kept to their commitments and dealt with Mr and Mrs M helpfully, promptly and sensitively, bearing in mind their individual circumstances. In reaching our findings, we have again compared what should have happened with what did happen.

Doctors' diagnosis and treatment of B's condition

240. Mr and Mrs M say that B was not properly assessed. It seems that they were concerned that B had aspiration pneumonia and should not have been given anything to eat or drink. They are concerned that B was not given the correct antibiotics.

241. When B was admitted to the Hospital on 25 January 2009, her doctors should have assessed her condition and arranged investigations or treatment where necessary, in line with *Good Medical Practice*. B had been very susceptible to chest infections in the past, so the Medical Adviser has told us that aspiration pneumonia, in addition to community-acquired pneumonia, should have been considered as a possible diagnosis because of her severe scoliosis of the spine. In line with established good practice, doctors should have stopped B from eating or drinking until a swallowing assessment had been completed and they should have given her broad-spectrum intravenous antibiotics[48] to treat her infection. However, this did not happen.

242. Following her admission a junior doctor reviewed B and suspected that she was septic and had pneumonia. The junior doctor tried to insert a cannula to allow staff to give B intravenous fluids and intravenous antibiotics, but they failed to do so despite several attempts. Because the junior doctor could not insert the cannula, B's doctors planned to encourage her to drink fluids and to administer oral antibiotics. However, the Medical Adviser told us that if the junior doctor was unable to insert a cannula, a middle-grade doctor, consultant or anaesthetist should have been asked to do so.

243. In trying to insert the cannula the junior doctor caused B distress, so perhaps understandably Mrs M said that she did not want staff to try again. In its letter dated 19 September 2012 (paragraph 233) the Trust said that the On-call Consultant explained to Mrs M that intravenous antibiotics and fluids would be the optimum treatment for B and that she was unlikely to improve if she only received oral medication. The Medical Adviser agrees that B was unlikely to improve if she only received oral fluids and oral antibiotics. However, he pointed out that there is nothing in the records to indicate that anyone, including the On-call Consultant when she met Mrs M, explained to B's parents the importance of inserting a cannula into a vein so that doctors could give B fluids and medication directly into her vein. Indeed, the Trust's Learning Disabilities Nurse Advisor pointed out in her review of B's care and treatment that it was not clear whether doctors had discussed with B's family the possible consequences of Mrs M's resistance to treatments that were essential, but which were causing B discomfort.

244. Because doctors had not inserted a cannula into a vein and Mrs M did not want staff to try again, B was allowed to carry on drinking, even though a possible diagnosis of aspiration pneumonia meant that eating and drinking was not appropriate. Indeed, Mr and Mrs M were encouraged to continue giving B drinks, although the Medical Adviser told us that it was unlikely that adequate hydration would have been achieved with oral fluids. There was also

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[48] Broad-spectrum antibiotics are antibiotics that are effective against a wide range of infectious micro-organisms.

the risk that B might breathe fluid into her lungs. Furthermore, doctors prescribed oral antibiotics for B, rather than the broad-spectrum intravenous antibiotics that she needed; B's clinical records show that she was refusing to take oral antibiotics.

245. In its letter of 19 September 2012, the Trust said that when doctors are faced with difficult or contentious decisions, it is best practice to involve those closest to the patient in the decision making. It said that if it had treated B regardless of Mr and Mrs M's wishes, it would have caused B's family significantly more distress and the Trust might have been criticised as a result. We acknowledge that this was not an easy decision for B's doctors.

246. The *Mental Capacity Act 2005* (Annex B) provides the legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves. It says that a decision made on behalf of a person who lacks capacity must be made in their best interests. In deciding what is in an individual's best interests, the *Mental Capacity Act 2005* says that the person who decides should take into account, if it is practicable and appropriate to consult them, the views of anyone engaged in caring for the person or interested in their welfare. However, the Code of Practice (Annex B, paragraph 2) explains that it is the decision maker's responsibility to work out what would be in the best interest of the person who lacks capacity and that where a decision involves the provision of medical treatment, the doctor or other member of healthcare staff is the decision maker. This means that although it was appropriate for doctors to talk to Mr and Mrs M about what they wanted for their daughter, it was the doctors themselves who were responsible for working out what would be in B's best interests. In this case doctors were faced with Mrs M's natural concerns for the welfare of her daughter. However, it is clear to us that B's doctors did not have proper regard for B's best interests in the decisions they made about her care and treatment, because they decided to abandon their attempts at inserting an intravenous cannula, even though B was unlikely to recover from her illness if she received only oral fluids and oral antibiotics.

247. Indeed, the Medical Adviser told us that during the On-call Consultant's conversation with Mrs M it was agreed that no active treatment would be provided for B. He explained that he had used the word '*active*' because it had been agreed that doctors would not try to insert an intravenous cannula, even though the On-call Consultant has acknowledged that the optimum care for B would have been intravenous antibiotics and intravenous fluids (paragraph 204). Instead, doctors provided what the On-call Consultant described as supportive treatment (oral fluids and oral antibiotics) and allowed B to carry on drinking despite the risk of aspiration. There is no record that they attempted to explain to B's parents the vital importance of inserting a cannula so that fluids and drugs could be given directly into her vein.

248. In the event, B's records show that later in the evening of 25 January the medical team succeeded in inserting an intravenous cannula (paragraph 42). B started receiving intravenous antibiotics at 8pm and intravenous fluids at 9.20pm on 25 January. However, this means that it was more than 9 hours and 10 hours respectively after B's arrival in the Hospital before she received the intravenous antibiotics and fluids that she needed.

249. At approximately 8.30pm on 26 January B was transferred to a specialist respiratory ward, but the Medical Adviser told us that it would have been established good practice to have considered B for a high dependency unit.[49] Transfer to a high dependency unit would have allowed a one-to-one or one-to-two nurse/patient ratio and more frequent and regular monitoring of B's condition, without necessarily causing her distress. The Medical Adviser told us that doctors should have considered transferring B to a high dependency unit when her seizures led to a reduced level of consciousness and impaired respiratory function. However, B's doctors did not do this.

250. The Medical Adviser was also critical of the frequency of B's medical reviews, both by consultants and junior doctors. He pointed out that the Royal College Guidance (Annex A, paragraph 13) recommends that there should be a twice daily consultant-led ward round or review of all patients in acute medical units to support ongoing decision making and to review clinical management plans and results, but B was only reviewed twice by a consultant during her entire time in the Hospital. There was no consultant review between the On-call Consultant's review of B on 25 January and the Chest Consultant's review on 29 January. Furthermore, reviews by junior doctors were infrequent. For example, it was more than 18 hours between the On-call Consultant's review on 25 January and the next medical review on 26 January, and then a further 24 hours before the locum SHO reviewed B on 27 January (paragraph 48).

251. In conclusion, we find that doctors adequately assessed B's condition in line with *Good Medical Practice* and diagnosed her pneumonia without delay. As the Trust explained in its investigation report dated 30 July 2009, the junior doctor who saw B within two hours of her arrival in the Hospital (paragraph 36), suspected that she had pneumonia.

252. However, we find that there was a prolonged delay before B received the treatment that her condition called for. The On-call Consultant has acknowledged that it would have been established good practice to treat B's '*severe pneumonia*' with intravenous antibiotics and intravenous fluids, but doctors did not do so. Doctors did not take reasonable decisions, based on all relevant considerations, because they did not consider B's best interests, in line with the *Mental Capacity Act 2005*. Instead, they allowed B to carry on drinking, despite the risk of aspiration, and they tried to give her oral antibiotics, which her records show she was refusing to take. We also find that doctors did not consider transferring B to a high dependency unit, as established good practice says they should have done, and that reviews of her condition by consultants and junior doctors were not as frequent as the Royal College Guidance says they should have been. In these regards, we find that B's doctors did not 'get it right' and that their care and treatment of her fell so far below the applicable standard that this was service failure.

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[49] A high dependency unit is a unit for patients who require more intensive observation, treatment and nursing care than can be provided on a general ward.

The management of B's epilepsy

253. Mr and Mrs M complain that doctors did not manage their daughter's epilepsy appropriately while she was in the Hospital.

254. The NICE Guidance (Annex A, paragraph 14) says that the management and treatment of epilepsy in a person who has learning disabilities should be undertaken by a specialist, working within a multidisciplinary team. In B's case she had been seen by a specialist, the Consultant Neurologist, during 2006 and 2007. The Consultant Neurologist had diagnosed her with myoclonic epilepsy, for which she was taking anticonvulsant medication.

255. When B was admitted to the Hospital on 25 January 2009, there were no signs of her epilepsy worsening, so her normal anticonvulsant medication was continued. The Neurologist Adviser told us that this was appropriate.

256. However, on 27 January B's general condition deteriorated and this affected her ability to swallow and to take her anticonvulsant medication. Therefore, her treating doctors discontinued her anticonvulsant medication until they had spoken to the Consultant Neurologist (paragraph 49). The Neurologist Adviser told us that this too was an appropriate course of action. In fact, he said that it showed a high level of medical responsibility, because at the time the frequency of B's seizures had not changed.

257. The Consultant Neurologist saw B in person on 29 January (paragraphs 54 and 55). He decided to continue B's anticonvulsant medication without increasing the dosages and he explained to Mrs M that it was likely that the increase in the frequency of B's seizures was being caused by her infection. The Neurologist Adviser told us that the information the Consultant Neurologist gave to Mrs M and the decisions he made about the management of B's epilepsy were appropriate. He said that the Consultant Neurologist had noted that the seizures were short and not severe and that the Consultant Neurologist did not consider them dangerous. Therefore, he said that it was reasonable not to change B's medication and wait for the infection to clear up.

258. The Neurologist Adviser was critical of the error in writing up the prescription for midazolam (paragraph 57), but he pointed out that no midazolam was ever given to B and this mistake was rectified before it could cause her any harm.

259. Therefore, although we have found a shortcoming (the mistake in writing up the prescription for midazolam), we are satisfied that doctors' management of B's epilepsy did not fall so far below the applicable standard that it amounted to service failure. This is because a specialist (the Consultant Neurologist) was involved in the management and treatment of B's epilepsy, in line with the NICE Guidance, and the decisions he made about her anticonvulsant medication were appropriate.

Doctors' communication with Mr and Mrs M

260. Mr and Mrs M complain that at first they were told that their daughter was not seriously ill and then they were told that she was seriously ill. They complain that without warning the On-call Consultant told them that doctors would not be able to resuscitate B because they would break her ribs. They said that when they met the Chest Consultant he said that they should not be afraid of the word '*dying*' and repeated '*die, die, die*'.

261. The GMC's *Good Medical Practice* explains that doctors must be considerate to relatives, carers, partners and others close to the patient, and be sensitive and responsive in providing information and support. So B's doctors should have been responsive to Mr and Mrs M's needs and should have given them, in a sensitive way, the information they wanted and needed about their daughter's condition.

262. In her comments (paragraphs 205 to 209), the On-call Consultant has explained that when she met Mr and Mrs M there were difficult issues that she needed to discuss with them and that she wanted to have this conversation with them in a separate room, away from B and without B's sister being present. However, she explained that Mr and Mrs M did not want to leave B and she was therefore left alone with Mrs M in B's room. The On-call Consultant said that there was '*implied criticism of everything going on*' from Mrs M and that it was '*difficult to get* [Mrs M] *to a calm level where she was willing to discuss B's treatment*'. She said that Mrs M was upset because a junior doctor had tried unsuccessfully to insert a cannula into a vein and had caused B distress. The On-call Consultant described what she did to find out what Mrs M wanted for her daughter.

263. We have no doubt that this was a difficult conversation for all concerned, but as the Medical Adviser has pointed out, the On-call Consultant should not have talked to Mrs M alone. By her own admission this was the one and only time that the On-call Consultant met Mr and Mrs M and she would not have known whether Mr M was happy for his wife to speak for him. Mr M should have been present during any discussions about B's care and treatment, as should another member of the clinical team. As the Medical Adviser said, Mrs M had clearly been upset by the junior doctor's repeated, unsuccessful, attempts to insert a cannula into a vein and it was therefore unlikely that she would be able to give reasonable answers to the On-call Consultant's questions at this time.

264. Furthermore, we have mentioned earlier in our findings that doctors had a responsibility to act in B's best interests, in line with the *Mental Capacity Act 2005*. While it was good practice for the On-call Consultant to find out what care Mrs M wanted for her daughter, there is nothing in the records to indicate that she explained to Mrs M that it was unlikely that B would recover from her illness if she was treated with oral antibiotics and oral fluids alone, and that it would be in B's best interests to try again to insert a cannula into a vein.

265. The On-call Consultant said that during her conversation with Mrs M, she wanted to know what B's parents would want doctors to do if B's heart stopped. This was not an unreasonable question to ask, if it was approached sensitively. However, the Medical Adviser told us that the On-call Consultant's comment that if doctors or nurses pressed on B's chest during an attempt to revive her, this might cause fractured ribs, was inappropriate. He said that likewise it was inappropriate for another doctor to say on 26 January that ventilation or intubation might not be in B's best interests. On the contrary, the Medical Adviser told us that supportive ventilation would have allowed time for the antibiotics B was being given to start working. Furthermore, the Trust's Learning Disabilities Nurse Advisor has pointed out (Annex F) that it would have been good practice to undertake an assessment of B's capacity, in line with the *Mental Capacity Act 2005*, before any decision about her best interests was made.

266. When we met the On-call Consultant we explained that Mr and Mrs M had told us that another doctor had said that B was not very ill and that they had therefore been very shocked and distressed when she talked to them about resuscitation. The On-call Consultant said that she felt it was unlikely that another doctor would have said that B was not very ill, as it was clear that she was very sick. However, she speculated about what can happen in A&E (paragraph 210), where relatives are often scared and doctors will try to reassure them.[50]

267. We cannot tell from B's medical records what Mr and Mrs M were told by a doctor when they first arrived at the Hospital, but we have no reason to disbelieve what they have told us. It was clearly inappropriate for a doctor to tell them that B was not very ill and by doing so, give them false optimism. Likewise, it would clearly have been inappropriate for the Chest Consultant to have said that they should not be afraid of the word '*dying*' and to say to them '*die, die, die*'.

268. In its letter of 19 September 2012 the Trust said that the complaint about the Chest Consultant was not part of Mr and Mrs M's original complaint and that this aspect of the complaint was therefore not answered at the time. However, it said that the Chest Consultant had confirmed that he would never have spoken to relatives in the way described by Mr and Mrs M, especially in such an emotional situation. We take the Chest Consultant's comments to mean that he might have said something to Mr and Mrs M about B dying, but not in the manner they have portrayed. Nonetheless, the fact remains that whatever he did say, Mr and Mrs M found it to be insensitive and inconsiderate.

269. B's medical records show that in some instances doctors did 'get it right' because they were 'customer focused' and dealt with Mr and Mrs M helpfully and sensitively, bearing in mind their individual circumstances, and kept them informed about their daughter's condition and treatment in line with the GMC's *Good Medical Practice*. However, we find that there were other instances, notably the On-call Consultant's discussion with Mrs M on 25 January, where doctors did not carry out their discussions appropriately. While we cannot tell from the records how sensitive doctors were in providing information, we have no reason to doubt Mr and Mrs M's accounts of their conversations with doctors and in particular with the On-call Consultant and the Chest Consultant. We find that on these occasions, doctors' communication fell so far below the applicable standard that this was service failure.

The transition plan

270. Mr and Mrs M are concerned that the transition plan they had discussed with the Trust's staff in 2006 was missing when B was admitted to the Hospital in January 2009. They say that the plan was needed to ensure that staff in adult services understood their daughter's complex health needs and their role in her care.

271. The National Framework (Annex A, paragraph 16) says that all young people should have access to

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[50] Mrs M reiterated in a letter to us dated 9 October 2012 that it was a junior doctor in the medical assessment unit who told them that B only had a minor chest infection (paragraph 181). She said that this was approximately two hours before they met the On-call Consultant.

age-appropriate services that are responsive to their specific needs as they grow into adulthood. It says that the transition to adult services for young people should be planned and co-ordinated around the needs of each young person to maximise health outcomes, life chance opportunities and their ability to live independently. Therefore, as B approached adulthood, the Trust should have talked to her family about her needs and planned for her transition from children's to adult services. This is what the Head of Nursing for Medicine and Emergency Care and the Head of Nursing for Children's Services did in the autumn of 2006.

272. The Head of Nursing for Medicine and Emergency Care and the Head of Nursing for Children's Services met B and her family in 2006 and agreed that her parents would complete a care plan, which could be duplicated within B's medical records, as well as being held by the family. They also talked about identifying a dedicated ward and dedicated consultant physician for B's care in adult services. However, the Head of Nursing for Medicine and Emergency Care acknowledged in the investigation report she prepared for the Trust in July 2009 (paragraph 190) that the plans discussed for B's transition from children's to adult services in 2006 were never completed.

273. When the Trust met Mr and Mrs M in July 2009 to discuss their complaints about their daughter's care and treatment in the Hospital, the Head of Nursing for Medicine and Emergency Care and the Head of Nursing for Children's Services were present and they apologised that B's transition from children's to adult services '*did not work*'. The Head of Nursing for Children's Services explained (paragraph 189) that East of England Strategic Health Authority was undertaking work on the transition of patients from children's to adult services and that she wanted to bring this work to the Trust to ensure that there was a robust transition process in place. The Trust undertook to keep Mr and Mrs M informed about progress in this regard.

274. However, the Trust has now admitted that the development of a transition policy was not progressed in line with the expectations raised with Mr and Mrs M at this time and that it was only in 2012 that a transition policy was nearing completion.

275. In its emails to us (paragraph 197) the Trust commented that the issue of a paediatric transitional care policy would not have been relevant to the management of B's care at the time of her admission to the Hospital in January 2009, because by then she was already an adult. The Trust also argues that as B's condition was chest-based and she was transferred to a chest ward under the care of a chest physician, her care was appropriate, and that the lack of a transition care plan did not have any impact on her.

276. We acknowledge the points the Trust has made, both in its emails and in its subsequent letter to us dated 19 September 2012, but the fact remains that it undertook to put in place a transition care plan for B in 2006, in line with the National Framework, but did not do so. Furthermore, when it met Mr and Mrs M in 2009 it raised their expectations about a transition care planning policy but again failed to keep its promise. The Trust was not 'customer focused' because it did not keep to its commitments and we find that in this regard its actions fell so far below the applicable standard that this was service failure.

Disability discrimination rights

277. Mr and Mrs M complain that their daughter was treated less favourably by the Trust because of her disabilities, including her learning disabilities.

278. As we explained earlier, B was a person with physical and learning disabilities and the Trust was obliged to consider her needs and whether adjustments needed to be made in order to ensure that she had access to health services designed around her individual needs (Annex A, paragraphs 1 to 8). It is clear to us that B's rights under disability discrimination law were engaged here and should have been considered in the Trust's decision making in the planning, and throughout the provision, of her care and treatment.

279. In a letter to us dated 24 June 2011 the Trust said that a review of B's care and treatment during her time in the Hospital had been undertaken by its Learning Disabilities Nurse Advisor and it gave us a copy of her review (Annex F). The review points to a number of areas of '*good practice*': the use of Emlar cream to avoid B experiencing unnecessary pain; the allocation of a side room for Mrs M; that staff recognised that B had additional needs and sought information from her family about those needs; that staff contacted colleagues who had been involved in B's care before she became an adult; that staff contacted B's Learning Disability Community Nurse for advice; that staff obtained equipment from the paediatrics department for B's comfort and support; that one-to-one nursing care was arranged overnight for B to give Mrs M time to rest; and that one to one nursing care was provided at other times to allow B's family some respite.

280. However, the Learning Disabilities Nurse Advisor also identified several '*areas of concern*': the medical registrar's failure to carry out an assessment of B's capacity (in line with the *Mental Capacity Act 2005*) before considering what might be in her best interests; that it was not clear whether doctors had discussed with B's family the possible consequences of Mrs M refusing intravenous medication on her daughter's behalf; and the sister in charge's failure to document what action was taken to resolve Mrs M's complaints about the care B was receiving.

281. We also found nothing to indicate that B's doctors had made it clear to Mr and Mrs M that B was unlikely to improve if she only received oral antibiotics (and oral fluids). Furthermore, we found that her doctors did not have proper regard for B's best interests in the decisions they made about her care and treatment. As the On-call Consultant has acknowledged, they did not provide her with the optimum treatment. Therefore, although there were many areas of B's care which were planned and delivered with proper consideration for her rights under disability discrimination law, we find that there were other areas where her rights were not properly considered. We conclude that in planning and providing care to B in these important areas, the Trust's staff did not have proper regard for their obligations to B under disability discrimination law and we find that their failings in this respect were serious enough to constitute service failure.

Injustice

282. We have concluded that, in planning and providing care for B, the SEEDS GP and the Trust did not have regard to their obligations under disability discrimination law and that this was so serious as to amount to service failure. As we explain in Annex A, paragraph 8, a finding of service failure does not necessarily lead to a finding of injustice. However, in this instance, we find that there was a consequent injustice to B. Her legal rights were not properly considered by the SEEDS GP and the Trust. If they had been, the SEEDS GP would have visited her and she would have received appropriate treatment more quickly. Once B reached the Hospital, her care and treatment might have been better planned and delivered.

283. Mr and Mrs M believe that their daughter would still be alive if the serious nature of her condition had been identified sooner by her GP and by the SEEDS GP, and if she had received swifter and better treatment from the Trust. They say that, even if it was too late to save their daughter, it was distressing to see her treated without care and attention.

284. Once we have decided whether there has been service failure using our usual approach (as set out in paragraph 16) we then go on to decide whether the injustice identified by the complainants (in this case, B's death) arose in consequence of that service failure. In deciding this, we consider the evidence we have seen and the clinical advice we have received and make a decision on the balance of probabilities whether the injustice arose in consequence of the service failure.

285. We find that when Mrs M contacted SEEDS on 24 January 2009, the SEEDS GP should have arranged to visit B at home, so that he could adequately assess her condition and arrange treatment where necessary. Because the SEEDS GP did not do so, he did not put himself in a position where he could make an informed decision about her further care. Furthermore, the SEEDS GP has admitted (paragraph 134) that had he visited B at home he is sure that he would have noted other features of '*a nasty chest infection*' and would then have made arrangements for her to be admitted to hospital (as his colleague did when Mrs M contacted SEEDS again the following day).

286. The GP Adviser told us that if the SEEDS GP had seen and assessed B, and made a decision to admit her to the Hospital, he did not believe that it would have made any difference to the eventual outcome for her, but the SEEDS GP would at least have fulfilled his duty to provide good clinical care for her. That said, it is clear to us that an opportunity was missed to get B to hospital as early as possible for treatment, and this missed opportunity is the injustice to B that arose in consequence of the service failure we have identified.

287. We also find that when B arrived at the Hospital, doctors did not provide her with the treatment that her condition called for. The On-call Consultant has acknowledged that B had '*severe pneumonia*' and should have been treated with intravenous antibiotics and intravenous fluids, but doctors gave her oral fluids and oral antibiotics – which she would not take – instead. Doctors did not act in B's best interests. Furthermore, we find that doctors did not review B as frequently as they should have done or consider transferring her to a high dependency unit for closer and more frequent monitoring. On the contrary, doctors decided that

putting a tube into her throat and connecting her to a breathing machine would not be in B's best interests, even though the Medical Adviser told us that supportive ventilation would have allowed time for the antibiotics B was being given to start working.

288. The Medical Adviser told us that he was unable say what B's chances of surviving her illness might have been. He said that this was because B's physical disabilities, and in particular her severe scoliosis of the spine, would have made her more likely to get chest infections and when she got an infection, would have affected how well she responded to treatment with antibiotics. However, he said that it would have significantly improved B's prospects of surviving her illness if she had been prevented from eating and drinking; if she had received immediate intravenous antibiotics and active rehydration after admission; if advice had been sought from an intensive care doctor; and if consideration had been given to a transfer to a high dependency unit.

289. We acknowledge that it is possible B might have recovered from her illness. However, the evidence we have seen and the advice we have received is not sufficient for us to be able to say on the balance of probabilities that B would have survived her illness, but for the service failure we have identified. Therefore, we cannot say that B's death could have been avoided. What we can say, is that B's doctors missed any opportunity there might have been – however small – to save her life by providing earlier and more intensive treatment for her. Again, this missed opportunity is the injustice to B that arose in consequence of the service failure we have identified.

290. We cannot begin to imagine the distress Mr and Mrs M suffered during the period of B's illness and in particular, when she died, but given the advice we have received, we cannot conclude that B's death was in consequence of service failure by the SEEDS GP or the Trust. However, we recognise that Mr and Mrs M will never know whether B would have survived if the SEEDS GP had visited her at home on 24 January 2009 and referred her to the Hospital, and if doctors at the Hospital had treated her with intravenous antibiotics and fluids sooner and admitted her to a high dependency unit for a higher level of care. This uncertainty is likely to be a continuing source of distress for them and is an injustice to Mr and Mrs M that arose from the service failure we have identified.

291. During our investigation we have seen no evidence that the Trust's failure to produce a plan for B's transition from children's to adult services affected the care and treatment B received when she was admitted to the Hospital in January 2009. However, we recognise that the lack of a transition plan and the inappropriate comments doctors made during some of their conversations with B's family will have added to Mr and Mrs M's distress at this difficult time. This is a further injustice to Mr and Mrs M that arose in consequence of the service failure we have identified.

Conclusions

292. Having studied the available evidence and taken account of the advice from the Ombudsman's clinical advisers, we find that the care and treatment provided by SEEDS and the Trust fell so far below the applicable standard that this was service failure. We also find that the SEEDS GP and the Trust, in some aspects of B's care and treatment, did not act with regard for disability discrimination law or B's rights as a person with disabilities and this was also service failure. We have assessed whether injustice to B and to Mr and Mrs M arose in consequence of the service failure we have identified and concluded that it did. Therefore, we partly uphold the complaints about SEEDS and the Trust. However, we have not found that B's death was avoidable.

293. In relation to Dr K, we find no service failure with regard to his care and treatment of B. Therefore, we do not uphold the complaint about Dr K.

294. We also find no maladministration with regard to the PCT's handling of Mr and Mrs M's complaints about Dr K and the SEEDS GP. Therefore, we do not uphold their complaint about the PCT.

Recommendations

295. We have considered our findings in light of the *Ombudsman's Principles*. Two of the Principles for Remedy particularly relevant to this complaint are:

- '*Putting things right*' – which includes considering fully and seriously all forms of remedy (such as an apology, an explanation, remedial action, or financial compensation).
- '*Seeking continuous improvement*' – which includes using lessons learnt from complaints to ensure that maladministration or poor service is not repeated.

SEEDS

296. In recognition of the injustice suffered by Mr and Mrs M, we recommend that, within one month of the date of this final report, SEEDS should provide them with:

- an open and honest acknowledgement of the failings identified in this report and an apology for the impact these failings had on B and on them (paragraphs 282, 286 and 290); and
- a payment of £1,000 by way of a tangible acknowledgement of the distress that they have suffered.

297. A copy of the apology, and confirmation that payment has been made, should be sent to us.

298. In his letter to the PCT dated 20 July 2009 and his letter to Mr and Mrs M dated 6 August 2009 (paragraphs 133 to 141), the SEEDS GP described the action he had taken to address the deficiencies in his consultation skills and to learn lessons from the failings in his care and treatment of B. The SEEDS GP has accepted a warning from the GMC and his representative has also told us that, as a direct result of this case, he has decided that he will no longer undertake out-of-hours duties. Therefore, we are satisfied that the SEEDS GP has learnt lessons from the failings identified in this partly upheld complaint and that other patients are unlikely to experience the same poor service that B and her parents received.

299. However, we recommend that, within three months of the date of this final report, SEEDS should prepare an action plan that describes what it has done and/or plans to do, including timescales, to ensure that as an organisation it has learnt lessons from the failings identified in this partly upheld complaint (paragraphs 150 to 152, and 156) and to avoid a recurrence of these failings.

300. A copy of the action plan should be sent to Mr and Mrs M, to us, and to the Chief Operating Officer of NHS Basildon and Brentwood Clinical Commissioning Group. SEEDS should ensure that Mr and Mrs M and NHS Basildon and Brentwood Clinical Commissioning Group are updated regularly about the progress against the action plan.

The Trust

301. In recognition of the injustice suffered by Mr and Mrs M, we recommend that, within one month of the date of this final report, the Trust should provide them with:

- an open and honest acknowledgement of the failings identified in this report and an apology for the impact these failings had on B and on them (paragraphs 282, 289, 290 and 291); and
- a payment of £2,000 by way of a tangible acknowledgement of the distress that they have suffered.

302. A copy of the apology, and confirmation that payment has been made, should be sent to us.

303. We also recommend that the Trust should, within three months of the date of this final report, prepare an action plan that:

- describes what the Trust has done and/or plans to do, including timescales, to ensure that the organisation, and individual doctors, have learnt lessons from the failings identified (in paragraphs 252, 269, 276 and 281) in this partly upheld complaint and to avoid a recurrence of these failings.

304. A copy of the action plan should be sent to Mr and Mrs M, to us, to the Chief Operating Officer of NHS Basildon and Brentwood Clinical Commissioning Group, the Care Quality Commission[51] band Monitor.[52] The Trust should ensure that Mr and Mrs M, NHS Basildon and Brentwood Clinical Commissioning Group, the Care Quality Commission and Monitor are updated regularly about progress against the action plan.

305. During our investigation the Trust gave us information about some of the steps it has taken since 2009 to enhance the quality of care for patients with learning disabilities. The Trust also told Mr and Mrs M about some of these steps. However, we note that the Trust's Learning Disabilities Nurse Advisor last spoke to Mr and Mrs M in approximately July 2011. Therefore, we recommend that, within three months of the date of this final report, the Trust should:

- send Mr and Mrs M a summary of the key actions it has taken to ensure that it has delivered on its commitment to the Department of Health, following the recommendation to all NHS organisations in the *Six Lives*[53] overview report.

306. The summary should be copied to us, NHS Basildon and Brentwood Clinical Commissioning Group, the Care Quality Commission and Monitor.

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[51] The Care Quality Commission is the independent regulator of health and social care in England.

[52] Monitor is the independent regulator of NHS foundation trusts.

[53] *Six Lives* is a joint report published by the Health Service Ombudsman and the Local Government Ombudsman in March 2009. It looked at the services provided for six people with learning disabilities who had died.

Mr and Mrs M's response to our draft report

307. In their response to our draft report, Mr and Mrs M told us how the loss of their daughter has affected them and how it will continue to affect them for the rest of their lives. They said that they still feel that their daughter would be alive if each of the doctors she came into contact with had done their job properly.

308. Mr and Mrs M and Mencap raised a number of points and questions in response to our draft report. These points principally related to our findings and conclusions about Dr K, whether B's death was avoidable, and our recommendations for financial remedy. We considered Mr and Mrs M's, and Mencap's, comments very carefully but found no new evidence that would cause us to reconsider our findings and conclusions in this case. We address the key points and questions that Mr and Mrs M and Mencap raised in Annex G to the report.

Final remarks

309. In this report we have set out our investigation, findings, conclusions and decision with regard to the care and treatment B received from Dr K, SEEDS, and the Trust. We have also set out our investigation, findings, conclusions and decision with regard to the PCT's handling of Mr and Mrs M's complaints about Dr K and the SEEDS GP.

310. We hope that Mr and Mrs M will be able to see that their complaints have been thoroughly and impartially investigated and that our conclusions have been drawn from careful consideration of detailed evidence, including the opinion of independent clinical advisers. We also hope that this report will draw what has been a long and complex complaints process to a satisfactory close.

Dame Julie Mellor, DBE
Health Service Ombudsman

May 2013

Annex A: The specific standards

Disability rights

1. Public authorities (and some other organisations with public functions) and service providers were required to comply with the *Disability Discrimination Act 1995* and the *Disability Discrimination Act 2005*, which included the duty to make reasonable adjustments.[54] They should also have had regard to the various statutory codes of practice that have been published to assist in the interpretation of the legislation.

2. Under the *Disability Discrimination Act 2005*, public organisations had a general duty to eliminate discrimination and harassment, to promote equality of opportunity and positive attitudes, to encourage participation in public life, and to take steps to take account of disabled persons' disabilities, even where that involves treating disabled persons more favourably than other persons.

3. In 2006 *The Disability Discrimination Code of Practice (Services, Public Functions, Private Clubs and Premises)* (the Code) came into force. The Code made it clear that a service provider's duty to make reasonable adjustments is owed to disabled people at large and that the duty is '*anticipatory*':

   'Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and make adjustments that may have to be made for them.'

4. Between 1998 and 2001 the Department of Health published a number of documents relevant to people with disabilities, one of which was the White Paper, *Valuing People: a new strategy for learning disability for the 21st Century*. The thrust of these documents was to support the Government's strategy and objectives for achieving improvements in the lives of people with learning disabilities, by helping the NHS meet its duties under the *Disability Discrimination Act 1995*. The intention was that: '*All public services will treat people with learning disabilities as individuals, with respect for their dignity*'. One of the objectives was to:

   'enable people with learning disabilities to access health services designed around individual needs, with fast convenient care delivered to a consistently high standard, and with additional support where necessary.'

5. It is not the Ombudsman's role to adjudicate on matters of disability discrimination law or to determine whether the law has been breached: that is a matter for the courts. The Principles of Good Administration do, however, say that the Principle of '*Getting it right*' includes acting in accordance with the law and with regard for the rights of those concerned, and taking reasonable decisions based on all relevant considerations.

6. If it appears to the Ombudsman that someone's disability rights are engaged in relation to the events complained about, we will expect the public organisation, in accordance with the Principles of Good

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[54] The relevant duties are now set out in the *Equality Act 2010*.

Administration, to have had regard to those rights in the way it has carried out its functions, and to have taken account of those rights as a relevant consideration in its decision making.

7. If the public organisation is unable to demonstrate that it has done so, the Ombudsman will take that fact into account when considering whether there has been maladministration and/or service failure.

8. In cases where the Ombudsman identifies maladministration and/or service failure, it does not necessarily follow that we will also find that injustice has been caused as a result.

National guidance

The General Medical Council

9. The General Medical Council (the GMC – the organisation responsible for the professional regulation of doctors) publishes *Good Medical Practice*, which contains general guidance on how doctors should approach their work. This represents standards that the GMC expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of their work.

10. The guidance relevant to this complaint is contained in *Good Medical Practice* (2006). This says that good clinical care must include:

    '(a) adequately assessing the patient's conditions, taking account of the history (including symptoms, and psychological and social factors), the patient's views, and where necessary examining the patient

    '(b) providing or arranging advice, investigations or treatment where necessary

    '(c) referring a patient to another practitioner, when this is in the patient's best interests.'

11. It also says that doctors must be considerate to relatives, carers, partners and others close to the patient, and be sensitive and responsive in providing information and support.

The Royal College of Physicians

12. In October 2007 the Royal College of Physicians published *Acute medical care – The right person, in the right setting – first time* (the Royal College Guidance). The Royal College Guidance provides detailed recommendations about the remit, configuration and operational policies for acute medical units, like the Hospital's medical assessment unit. It explains that the quality of the first 48 hours of acute medical care is an important determinant of clinical outcomes and that the Royal College of Physicians recognises the need to guarantee the quality of this care and access to this care, 24 hours a day, seven days a week.

13. Under the heading '*Acute medical unit ward rounds, patient review and handover of care*' the Royal College Guidance says:

    'We recommend that the clinical team on the [acute medical unit] *should be consultant led.*

    'We recommend that there should be a twice-daily consultant-led ward round/review of all patients in the [acute medical unit]*, seven days a week, to support ongoing decision making and to review the management plans and results.*

> *'We recommend that there must be time included in the shift patterns for junior medical staff to ensure there is a formal handover of care, akin to that adopted for many years by nursing teams.'*

The National Institute for Health and Clinical Excellence

14. In October 2004 the National Institute for Health and Clinical Excellence (NICE)[55] published its clinical guidance 20 *The epilepsies – The diagnosis and management of the epilepsies in adults and children in primary and secondary care,* together with a quick reference guide (the NICE Guidance). In the quick reference guide, under the heading '*People with learning disabilities*', the NICE Guidance says: '*The management and treatment of epilepsy in a person who has learning disabilities should be undertaken by a specialist, working within a multidisciplinary team*'.

15. It also says: '*For adults, a specialist is defined throughout as a medical practitioner with training and expertise in epilepsy*'.

The Department of Health

16. In October 2004 the Department of Health published *National Service Framework for Children, Young People and Maternity Services* (the National Framework). Under the heading '*Standard 4*' the National Framework says: '*All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood*'. It says:

> *'Transition to adult services for young people is planned and co-ordinated around the needs of each young person to maximize health outcomes, their life chance opportunities and their ability to live independently – this is particularly important for disabled young people or those with long-term or complex conditions.'*

17. Under the heading '*Standard 8*' the National Framework says:

> *'Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives.'*

It also says: '*Multi-agency transition planning takes place to improve support for disabled young people entering adulthood*'.

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[55] In April 2013 the National Institute for Health and Clinical Excellence changed its name to the National Institute for Health and Care Excellence.

Annex B: The legislative background

The *Mental Capacity Act 2005*

1. The *Mental Capacity Act 2005* provides the legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves. Section 1 of the *Mental Capacity Act 2005* sets out a number of principles which apply for the purposes of the *Mental Capacity Act 2005*, including that:

   '(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

   '(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success …

   '(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.'

   Section 4 of the *Mental Capacity Act 2005* makes provision in connection with determining what is in the best interests of a person who lacks capacity to make a particular decision. Section 4(7) requires the person making the determination of what is in a person's best interests to:

   'take into account, if it is practicable and appropriate to consult them, the views of –

   anyone engaged in caring for the person or interested in his welfare … '

2. The statutory *Mental Capacity Act* 2005 Code of Practice was published in April 2007 to provide guidance on how the *Mental Capacity Act 2005* works on a day-to-day basis (the Code of Practice). Under the heading '*What does the Act mean when it talks about best interests?*', the Code of Practice states that:

   'Under the Act, many different people may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for themselves. The person making the decision is referred to … as the "decision maker", and it is the decision maker's responsibility to work out what would be in the best interest of the person who lacks capacity.

   'For most day-to-day decisions, the decision maker will be the carer most directly involved with the person at the time.

   'Where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision maker … '

Annex C: Clinical advice – the GP Adviser

1. The GP Adviser said that when Dr K saw B on 22 January 2009, he made a diagnosis of lower respiratory tract infection (a chest infection) based on her history and his examination findings of a temperature of 38.2°C and left lower crepitations. He said that this was a reasonable diagnosis to have been made.

2. The GP Adviser said that Dr K prescribed an antibiotic co-amoxiclav suspension. He said that co-amoxiclav consists of amoxicillin[56] with the beta-lactamase inhibitor clavulanic acid, which makes it less likely to run into antibiotic resistance.[57] He said that this is a good antibiotic that is more likely to work first time than the standard amoxicillin. So, to summarise, he said that Dr K had made a diagnosis from taking an appropriate history and examination and prescribed appropriately to treat a diagnosis of a chest infection.

3. Referring to *Good Medical Practice* (Annex A, paragraphs 10 and 11) the GP Adviser said that on 23 January 2009 Dr K was able to adequately assess B's condition with the information he obtained from her father during his telephone conversation and by taking into account the history and examination findings from his assessment of B the previous day. He said that in this instance Dr K had already established a diagnosis of lower respiratory tract infection and B was receiving appropriate treatment for this. Therefore, he said that it was not inappropriate for Dr K not to have visited B on this day.

4. Turning to the actions of the SEEDS GP, the GP Adviser reiterated his remarks about *Good Medical Practice* and said that it was clear that the SEEDS GP did not fulfil his obligation to provide good clinical care. He said that the SEEDS GP did not adequately assess the patient's condition, he did not take an adequate history, he did not have the benefit of having examined the patient, and nor did he have any idea of the social factors involved in the case. He said that the SEEDS GP ignored or played down B's mother's views in his telephone conversation with her and did not – when it was obviously necessary and had been reasonably requested – arrange for B to be examined and assessed at home.

5. The GP Adviser said that it was plainly unreasonable that the SEEDS GP did not make a home visit and this was a poor clinical decision. He said that if the SEEDS GP had seen and assessed B and had made the decision to admit her earlier to the Hospital, it would probably not have made a difference to the eventual outcome for B, but the SEEDS GP would at least have fulfilled his duty to provide good clinical care for her.

6. The GP Adviser said that it was also clearly unreasonable that the SEEDS GP proposed sending a message to the Practice to undertake a visit on Saturday 24 January, when Mrs M had told him that the Practice did not carry out home visits on Saturdays. He said that it also begged the question that if the SEEDS GP thought that a visit was necessary, why was it not done at the time – that is, by the SEEDS GP that night.

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[56] Amoxicillin is a penicillin antibiotic used to treat infections.

[57] Antibiotic resistance is a type of drug resistance where a micro-organism is able to survive exposure to an antibiotic.

Annex D: Clinical advice – the Medical Adviser

1. The Medical Adviser said that B was a physically frail adult with a small frame who would have been very susceptible to chest infections, as he understood had occurred in the past. He said that aspiration pneumonia should have been considered on her admission to the Hospital, in addition to community-acquired pneumonia, because of her severe kyphoscoliosis. He said that in line with established good practice, consideration of aspiration pneumonia should have led to B being nil by mouth until a swallowing assessment had been undertaken. He said that it should also have led to her receiving broad-spectrum intravenous antibiotics.

2. However, the Medical Adviser said that although aspiration pneumonia was considered by B's doctors, they did not initially prevent her from eating and drinking. Instead, he said they encouraged her parents to continue giving her oral fluids. In addition, the Medical Adviser said that oral amoxicillin and erythromycin[58] were prescribed, which he said would have been inadequate antibiotic therapy. Furthermore, he pointed out that at 5.25pm on 25 January it is noted (paragraph 39) that B was refusing to take the amoxicillin and clarithromycin syrup that had been prescribed for her.

3. The Medical Adviser said that it is difficult to establish from the conversation between the On-call Consultant and Mrs M at 5.30pm on 25 January how much treatment Mrs M wanted for her daughter. He said that Mrs M declined further attempts at venous access because a junior doctor had failed to insert an intravenous cannula. He said that it is unclear how many attempts the junior doctor made to insert an intravenous cannula, because it is not documented in the records as it should have been. The Medical Adviser said that a middle-grade doctor, consultant or anaesthetist should have been asked to insert an intravenous cannula. However, this did not happen. Instead, he said that after the On-call Consultant's conversation with Mrs M there were no plans for further attempts to insert an intravenous cannula or for intravenous antibiotics to be administered.

4. Indeed, the Medical Adviser said that during the On-call Consultant's conversation with Mrs M, it was agreed that no active treatment would be provided for B. He explained that he had used the word '*active*' because it had been agreed that an intravenous cannula would not be appropriate and B was not made nil by mouth despite the risk of aspiration. He said that it would have been most unlikely for B to have recovered from her illness receiving oral amoxicillin and erythromycin syrup, which by that stage, he pointed out, she had already declined. The Medical Adviser added that it was also unlikely that adequate hydration would be achieved with oral fluids.

5. The Medical Adviser said that the decision not to make B nil by mouth because of the failure to achieve intravenous access was not reasonable. He said that there was nothing in the records to indicate that the fact that B was unlikely to improve with oral antibiotics and oral fluids had been explained to Mrs M by the On-call Consultant. The Medical Adviser said

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[58] An antibiotic used to treat bacterial infections.

that he questioned whether, in failing to administer intravenous antibiotics and fluids, the On-call Consultant and her colleagues had acted in B's best interests (Annex B).

6. As it was, the Medical Adviser said that the medical team succeeded in inserting an intravenous cannula later on 25 January (paragraph 42). He said that B started receiving intravenous antibiotics at 8pm and intravenous fluids at 9.20pm on 25 January. He also pointed out that following a review by a doctor at 1pm on 26 January (paragraph 43), B had to be given 500 millilitres of Gelofusin urgently because of dehydration and low blood pressure.

7. The Medical Adviser said that the On-call Consultant should not have talked to Mrs M alone, particularly as she had not met Mr and Mrs M before. He said that Mr M and another professional witness should have been present. He said that Mrs M was clearly upset by her daughter's illness and the problems with her management thus far, particularly the multiple unsuccessful attempts at intravenous cannulation by a junior doctor. He said that because of her distress she was unlikely to be able to give reasonable answers to the On-call Consultant's questions on her own and without her husband present.

8. The Medical Adviser said that in terms of '*active*' treatment, it would have been established good practice to have considered whether to admit B to the high dependency unit, even if attempts to revive her if her heart stopped, or put a tube into her throat and connect her to a breathing machine, were not to be considered. He said that transfer to the high dependency unit would have allowed a one-to-one or one-to-two nurse to patient ratio and more frequent and regular monitoring of B without necessarily causing more distress.

9. The Medical Adviser said that the On-call Consultant's comment that if doctors or nurses pressed on B's chest this may cause fractured ribs was inappropriate. Likewise, he said that it was inappropriate for another doctor to say on 26 January (paragraph 43) that putting a tube into her throat and connecting her to a breathing machine might not be in B's best interests. He said that if B was to deteriorate this would be because of worsening respiratory function and her heart would only have stopped as a consequence of respiratory failure. He said that supportive ventilation would have allowed time for the antibiotics B was being given to start working. In this regard, he reiterated that a transfer to the high dependency unit should have been considered.

10. The Medical Adviser said that the Royal College Guidance (Annex A, paragraphs 12 and 13) recommends that there should be a twice-daily consultant-led ward round or review of all patients in acute medical units, like the medical assessment unit, seven days a week, to support ongoing decision making and to review management plans and results. However, he said that a consultant had only reviewed B on two occasions while she was in the Hospital, despite her being severely ill with sepsis and pneumonia. He said that there is nothing in the records to indicate that the On-call Consultant reviewed B after her review at 5.30pm on 25 January, presumably because she was not on duty on the medical assessment unit on Monday 26 January. He said that it was unclear which consultant physician was responsible for B on Monday 26 January.

11. The Medical Adviser added that reviews by junior medical staff were infrequent. For example, he said that it was more than 18 hours between the On-call Consultant's review of B at 5.30pm on Sunday 25 January and the next medical review at 1pm on Monday 26 January. He said that equally there was no evidence of a handover (doctor-to-doctor or consultant-to-consultant) within the medical assessment unit or from the medical assessment unit to the specialist respiratory ward as the Royal College Guidance recommends.

12. The Medical Adviser said that he had noted in the complaint correspondence that the Trust had told Mr and Mrs M that the Chest Consultant undertakes twice-weekly ward rounds and that B had missed the Monday ward round (because she was not transferred to a specialist respiratory ward until approximately 8.30pm on Monday 26 January). The Medical Adviser said that B was a severely ill patient and if the Chest Consultant was too busy attending to other matters, then alternative consultant input should have been arranged for B.

13. The Medical Adviser said that B suffered a number of seizures (paragraphs 50 and 51) partly as a consequence of infection and partly as a consequence of not receiving her oral anti-epilepsy medication. He said that these seizures caused her to become drowsy with reduced levels of consciousness, although the reduced level of consciousness would have been temporary. He said that the seizures also caused impaired respiratory function. Therefore, he said that B's doctors should again have considered transferring her to a high dependency unit at this time.

14. In closing, the Medical Adviser said that he had considered carefully whether the outcome for B might have been different, but he concluded that he could not say what B's chances of surviving her illness might have been. He said that this was because B's physical disabilities, and in particular her severe scoliosis of the spine, would have made her more likely to get chest infections and when she got an infection, would have affected how well she responded to treatment with antibiotics. However, the Medical Adviser said that B's prospects of surviving her illness would have been significantly improved:

- if she had been prevented from eating or drinking and received immediate intravenous antibiotics and active rehydration after admission;
- if advice from an intensive care doctor had been sought and consideration given to a transfer to a high dependency unit;
- if she had received uninterrupted administration of her anticonvulsant medication; and
- if critical care advice had been sought and if consideration had been given to a transfer to the high dependency unit when her seizures led to a reduced level of consciousness and impaired respiratory function.

Annex E: Clinical advice – the Neurologist Adviser

1. The Neurologist Adviser said that B had been seen by the Consultant Neurologist three times as an outpatient during 2006 and 2007. He said that the Consultant Neurologist diagnosed her with myoclonic epilepsy, with up to 20 attacks per day. He said that the Consultant Neurologist noted that the myoclonic jerks were the only manifestation of her epilepsy and that B had been taking long-term anticonvulsant medication (lamotrigine and clonazepam).

2. The Neurologist Adviser said that in line with the NICE Guidance, patients with epilepsy should be treated by a specialist (that is, a neurologist), particularly when the type or frequency of seizures change.

3. The Neurologist Adviser said that following B's admission to the Hospital her long-term anticonvulsant medication was continued as before. He said that this was appropriate, as there were no signs of any worsening of her epilepsy. However, he said that on 27 January 2009 B's general medical state deteriorated and so did her ability to swallow. He said that it was therefore appropriate to discontinue her medication until a neurologist's advice had been sought.

4. The Neurologist Adviser said that on 27 January the Consultant Neurologist was consulted by the treating doctor for advice about B's medication. He said that this was correct and showed a high level of medical responsibility, because at this time there were no recorded signs of B's seizures occurring more frequently. He said that the Consultant Neurologist made recommendations about the form in which her anticonvulsant drugs should be administered (paragraph 49) and that these recommendations were reasonable.

5. The Neurologist Adviser said that the Consultant Neurologist examined B in person on 29 January and spoke to her family, answering their questions. He said that the Consultant Neurologist's explanation that the increased seizure frequency was likely to be caused by the infection was correct. He also said that the Consultant Neurologist's decision to continue with the anticonvulsant medication without increasing their dosages was reasonable. He said that based on the seizure chart and the Consultant Neurologist's entry in the notes, the seizures were short and not severe. He said that as a consultant neurologist, the Consultant Neurologist was capable of judging the severity of the epileptic seizures and he did not consider B's seizures to be dangerous. The Neurologist Adviser said that it was therefore reasonable not to change B's medication and to wait for the infection to clear up. He said that the Consultant Neurologist had, after all, documented in his clinical notes that B previously had seizures up to 20 times per day.

6. Commenting on the doctor's error in writing up the prescription for midazolam to be given intravenously rather than buccally, the Neurologist Adviser said that no midazolam was ever given and that this mistake was rectified before it could cause any harm to B. He said that apart from this mistake with the prescription for midazolam, B's epilepsy was managed appropriately. He said that although B's seizures were occurring more frequently, they were a consequence of her deterioration, rather than a cause of it.

Annex F: Report of the Nurse Advisor for Learning Disabilities written on behalf of Basildon & Thurrock University Hospitals NHS Foundation Trust

RE: [B]

NHS Number: [removed]

Date: 24 June 2011

'This report has been prepared by [the Learning Disabilities Nurse Advisor], *for Basildon & Thurrock University Hospitals NHS Foundation Trust. I have been asked to provide a professional opinion on the care provided to* [B], *from the perspective of reasonable adjustments made to her care pathway. The terms of reference provided by the Parliamentary and Health Service Ombudsmen in their letter of the 25th May 2011 is as follows:*

"Explain what consideration the Trust gave to [B's] *learning disabilities in its care and treatment of her between 25 and 30th January 2009."*

'I am a registered Learning Disability Nurse with 19 yrs of experience across the community and acute healthcare setting. I am not in a position to provide a professional view in relation to either the general nursing or medical care provision, as this is not my field of expertise. I have had contact with [Mrs M] *on occasions, whilst employed at BTUH; however, I was not involved in the care of her daughter. My report is written in an objective and un-bias nature for the Trust and for the purpose of a review being undertaken by the Parliamentary and Health Service Ombudsmen.*

'The report has been prepared using photocopied sections of the healthcare records contained within the complaint file. I have not had access to the original and complete healthcare record, to interview relevant staff, or consider any additional evidence. My professional opinion therefore is restricted to, and only on the basis of what is written within the photocopy of the healthcare record (24pgs in total). I am aware that the original healthcare records could not be located, and therefore I have not had access to the full nursing records for this patient.

'In responding to the Terms of Reference, I have written my report under sub headings to include areas of good practice and areas of concern to ensure that I amplify any considerations given to making reasonable adjustments under the Disability Discrimination Act requirements (which were current at that time).

'Patient Name:[B]
'Date admitted: 25 January 2009
'NHS Number: [removed]

Background

'[B] *was an adult aged 23 yrs. with complex Learning Disability and possibly (?) Russell-Silver syndrome. She had previously been receiving care and treatment from GOSH* [Great Ormond Street Hospital] *and Stanmore and was fully dependent on her parents for all her activities of daily living. Her parents,* [Mr and Mrs M], *were her fulltime carers.*

[B] *was admitted to the Trust at 12.20hrs on the 25 January 2009 accompanied by her parents. The reason for admission was documented by the admitting Senior House*

Officer (SHO) as being a "raised temperature, Cough, Sweating and unwell - not usual self". A differential diagnosis[59] *of sepsis? pneumonia was made. The medical plan prescribed by the SHO was for blood to be taken, provision of antibiotic therapy, increased oral fluids, chest X-ray and physiotherapy.* [B] *sadly died on the 30 January 2009.*

'I am unable to comment on whether an adequate nursing or specialist assessment was undertaken upon admission as this section of the healthcare record is not available to me.

Areas of Good Practice

- *At the time of admission, consideration was given to making reasonable adjustments to* [B]*'s care pathway. The admitting SHO had thought about the use of 'Emlar' cream to avoid unnecessary pain when inserting a cannula and this was applied. This is an area of good practice.*
- [B] *was allocated a side room, to support* [Mrs M] *(her mother) staying overnight to provide care to her daughter. This takes into consideration* [B]*'s need for parental and familiar support in an alien environment. It also gave consideration to the mother' needs, in particular sleeping arrangements, privacy and dignity.*
- *Staff had recognised that* [B] *had additional specialist needs and asked the mother about the "special requirements" that* [B] *had. They also enquired how the ward could "reassure* [B]*'s family" about the quality of care she was being provided with. This demonstrates that staff recognised their own limited knowledge of* [B]*'s complex needs and sought advice from the mother to ensure that there was continuity in the approach to her care needs.*
- *Staff demonstrated good practice by contacting staff in the paediatric department who had previously been involved with* [B]*'s care as a paediatric patient. The rationale for this was to "learn from other colleague's experience of caring for* [B]*". This is a right and just approach to working with colleagues to determine how* [B]*'s specialist needs were best met through the experience of other staff. It also supports the notion of transitional care.*
- *Staff contacted* [B]*'s LD* [Learning Disability] *Community Nurse for advice on appropriate care, which demonstrates effective communication between community and acute Trust staff. It also indicates the staff's commitment to establishing what individual specialist needs* [B] *had and how they could be best met.*
- *Staff arranged for different items of equipment from paediatric department, such as paediatric oxygen mask etc. to be provided purely for the benefit of* [B]*'s comfort and support.*
- *Dedicated 1:1 night staff was arranged despite* [B]*'s mother being present overnight. This was to allow mum to remain with her daughter and provide care during the day, but to ensure she was sufficiently rested and received respite overnight. This again is demonstrable evidence of making reasonable adjustments for* [B] *and supporting the individual needs of the family carers.*

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[59] Differential diagnosis is a systematic method of diagnosing a disorder that lacks unique symptoms or signs.

- *Arrangements were made by ward staff for 1:1 nursing supervision outside of the overnight arrangements to allow the family time away from* [B]*. This would have provided them with respite, whilst being re-assured that* [B] *was being adequately supervised. Staff offered this to the family on many occasions and this was documented in the healthcare record.*

Conclusion on areas of Good Practice:

'In conclusion, in referring back to the terms of reference; it is my opinion that the trust did give comprehensive consideration to [B's] *learning disability in her care and treatment between the 25 January 2009 and 30 January 2009. There is documented evidence within the healthcare record which supports this, and which I have highlighted above. I conclude that during her admission, staff made reasonable adjustments and worked in a creative person centred manner to meet the majority of her specialist needs.*

Areas of practice of concern

- *Discussions were held between the medical registrar and the family on more than one occasion and when requested by the family. The medical register documented in the healthcare record, when discussing her treatment and resuscitative status, that "ventilation/intubation may not* [B]*'s in best interest". A rationale for this was given, on the basis of her hypoxic state and that the Patient at Risk Service would review her care in relation to this. At this point, it would have been best practise for a Mental Capacity Act assessment to be undertaken. There is no documented evidence to suggest that this was considered and/or undertaken from the records available to me.*
- [B]*'s mother refused medication and IV access on her daughter's behalf on more than one occasion. Whilst there was evidence that the provision of fluids was discussed with the family (they wished to attempt oral hydration first) and the appropriate actions taken when this was not achieved, this was not the case with the refusal of medication. Without the benefit of the complete healthcare record, it is not possible to conclude whether or not the potential consequences of omission of medication were considered. This would be particularly pertinent if the medication related to her anticonvulsant therapy.*
- *Within the health care record, it is evident that her mother was on occasions, not satisfied with care* [B] *was receiving. Whilst there are many examples of staff responding to her concerns and communicating effectively with her. There is however, one entry where it is stated that the mothers concerns were "Referred to sister in charge". Disappointingly, there is no corresponding entry from the sister in charge, indicating what action was taken to resolve the concern. I would expect under these circumstances, for the sister in charge to have documented any conversation and reassurance she gave to the family along with any actions taken as a consequence. I could find no evidence of this.*

Conclusion on areas of Concern

'From the healthcare records made available to me, I conclude that there were three areas of concern highlighted above. It is my opinion that staff did not give reasonable "consideration to [B's] *learning disability in its care and treatment between the 25 January 2009 and 30 January 2009" for these particular aspects of her care only.*

Overall Conclusion

‘Reflecting on this case review as a whole, it is my professional opinion that on the balance of probability, there was comprehensive and demonstrable good practice in relation to meeting [B]*’s individual needs. It is evident that consideration was given to the need for reasonable adjustments and this is demonstrated throughout the healthcare record. Whilst the areas of concern indicate that trust policy was not followed in relation to MCA* [Mental Capacity Act] *and documentation, I would suggest that her lack of capacity would have been clear to staff. Staff therefore took the lead from her mother regarding acting in* [B]*’s best interests. It is my opinion, as main carer her mother was well versed with her daughter’s individual and specialist needs and therefore this was a reasonable approach for staff to take.*

‘... RNLD
Learning Disabilities Nurse Advisor

24 June 2011’

Annex G: The response to Mr and Mrs M's comments, and Mencap's comments, on the draft report

1. Mr and Mrs M and Mencap raised a number of issues in a letter dated 9 October 2012 and an email dated 1 November respectively. We deal with the key points below.

The *Report of the Nurse Advisor for Learning Disabilities* (Annex F)

2. Mencap said that it was very unusual for this report to have been requested from a member of the Trust's staff, rather than an independent clinical adviser, and it asked us to commission advice from an appropriate person.

3. We did not request the *Report of the Nurse Advisor for Learning Disabilities*. During our investigation, we asked the Trust what consideration it had given to B's learning disabilities in its care and treatment of her. In response, the Trust commissioned the *Report of the Nurse Advisor for Learning Disabilities* and sent it to us, as paragraph 191 of the report explains.

4. We subsequently decided to include the *Report of the Nurse Advisor for Learning Disabilities* as an annex to our report (Annex F) because it demonstrated that the Trust had looked critically at how staff cared for B and because it had acknowledged that there were a number of things its staff did not get right. However, in considering whether the Trust's staff had proper regard for their obligations to B under disability discrimination law, we did not rely on the *Report of the Nurse Advisor for Learning Disabilities*. We reached our own view, as we did with all the other aspects of Mr and Mrs M's complaint where we took advice.

Dr K

5. Mr and Mrs M said that the decision to visit or not visit B on 23 January 2009 should not have relied solely on how they expressed their request. They said that Dr K should have listened to them because they knew B best, and he should have arranged tests and examinations that could verify the diagnosis. They said that knowing that B had physical and learning disabilities, Dr K should have been more proactive and walked the short distance to see B with his own eyes.

6. In paragraphs 119 to 121 of our report we explain that we were unable to get to the bottom of exactly what happened on 23 January. As Mr and Mrs M have acknowledged, we received conflicting accounts from Dr K, the Reception Manager and from them, about the nature and urgency of the request for a home visit. We were also unable to establish precisely when on 23 January Dr K became aware of the home visit request. However, what we could say was that when Dr K telephoned and spoke to Mr M on the afternoon of 23 January, he was able to adequately assess B's condition with the information he obtained from her father and by taking account of her history and his examination findings from his assessment of her the previous day. We found that he was able to take a reasonable decision about whether to visit B at home again.

7. In their letter, Mr and Mrs M disputed the Solicitors' statement (paragraph 94 of the report) that Dr K had treated B '*on a number of occasions*' prior to her illness in January 2009. However, it is clear from B's patient records that Dr K had seen B at least twice before his visit to her home on 22 January 2009. Also, his comments to us indicated that he did have regard to B's needs as a person with disabilities when he planned and delivered her care, as paragraphs 124 and 125 of the report explain.

8. Mr and Mrs M pointed out in their letter that Dr K's name was on the SystmOne report for 23 January 2009 and they said that this was evidence that the home visit request was allocated to him. As paragraph 108 of the report explains, Dr K accessed B's patient records after he had spoken to Mr M and marked the home visit request '*Finished*', so that the duty doctor would know that the home visit request had been dealt with.

9. In their comments, Mr and Mrs M compared Dr K's decision not to visit B on 23 January to the SEEDS GP's decision not to visit B on 24 January. However, as paragraph 151 of the report explains, we consider that the circumstances here were different, because the SEEDS GP did not adequately assess B's condition, he did not take an adequate history, and he did not have the benefit of having recently examined B.

The Trust said that B was always ill

10. Mr and Mrs M said that they were '*confused at why the doctor and the hospital* [were] *saying that* [B] *was always using these services*'. They said that they felt strongly about this and would like it checked.

11. However, we checked the report and could not see the statement by the doctor and the hospital they were referring to.

Whether B's death was avoidable

12. Mr and Mrs M said that they do not accept that we cannot conclude that B's death was avoidable. They asked us to set out clearly the criteria we use when deciding whether a death was avoidable.

13. To be clearer, we have set out in paragraph 284 of the report how we decide whether the injustice complained about (in this case B's death) arose in consequence of the service failure we have identified.

14. In this case, the Medical Adviser told us (Annex D, paragraph 14) that he could not say what B's chances of surviving her illness might have been. This is because B's physical disabilities, and in particular her severe scoliosis of the spine, would have made her more likely to get chest infections and when she got an infection, would have affected how well she responded to treatment with antibiotics. However, he said that B's prospects of surviving her illness would have been significantly improved: if she had been prevented from eating and drinking; if she had received immediate intravenous antibiotics and active rehydration after admission; if advice from an intensive care doctor had been sought; and if consideration had been given to a transfer to a high dependency unit.

15. Therefore, while we acknowledge that it is possible that the outcome for B might have been different, we cannot say that on the balance of probabilities B would have recovered from her illness, but for the service failure we have identified. Therefore, we cannot say that B's death was avoidable.

16. Mencap said in its email that there was a failure to properly manage B's epilepsy once it was established that she was unable to take her anticonvulsant medication orally and it said that this should be given greater emphasis in deciding if her death was avoidable. However, in his advice in Annex E, the Neurologist Adviser (the expert in this field) concluded that B's epilepsy had been managed appropriately. Indeed, he said that although B's seizures were occurring more frequently, they were a consequence of her deterioration, rather than a cause of it.

The Trust's response to the Ombudsman

17. Mencap pointed out that B's death was the fourth case it is aware of involving the Hospital, and that it is now beginning work with the family of a fifth person who died following an episode of care at the Hospital. Mencap asked us to apply *'strong scrutiny'* to the actions taken by the Hospital.

18. Our role is to investigate complaints that individuals have been treated unfairly or have received poor service from government departments and other public organisations and the NHS in England. The law gives us power to investigate individual complaints and produce a report of our findings that recommends how mistakes can be put right. We expect public organisations to comply promptly and in full with our recommendations for remedy and we will monitor SEEDS's and the Trust's compliance until we are satisfied that our recommendations have been fully implemented.

19. The Health Service Ombudsman is not a regulator and we have no routine inspection powers. If our investigations find significant or repeated mistakes, we share this information with regulators to help them do their job. So, in this instance we will be sending the independent regulators, the Care Quality Commission (CQC) and Monitor, a copy of the report of our investigation into Mr and Mrs M's complaint about the Trust. As paragraphs 303 to 306 of the report explain, we have asked the Trust to send the CQC and Monitor a copy of its action plan and a copy of the summary of the key action points it has taken to ensure that it has delivered on its commitment to the Department of Health, following the recommendation to all NHS organisations in the *Six Lives* overview report.

20. In addition, we have asked the Trust to send a copy of these documents to NHS Basildon and Brentwood Clinical Commissioning Group (the commissioning organisation) and we have asked the Trust to update the CQC, Monitor, and NHS Basildon and Brentwood Clinical Commissioning Group regularly about progress against the action plan.

Financial remedy

21. Mencap said that the payments we had recommended appeared low when compared to payments made to other families Mencap has supported through the complaints process. While Mr and Mrs M had been clear that no amount of money could lessen their distress at the loss of their much loved daughter, they felt that such a low sum devalued the pain and distress that the loss of their daughter has caused. Mencap asked us to explain how we had arrived at our financial remedy and to increase it.

22. Our aim is to restore those affected by service failure or maladministration to the position they would have been in had things not gone wrong. Where that is not possible, we may recommend a financial remedy to recognise that things cannot be put right in that way. Financial remedies in those circumstances cannot be calculated through a mathematical formula and we do not have a 'tariff', instead we try to take account of the particular circumstances of the case and the individual complainant(s).

23. In deciding on the level of a payment, we consider the injustice the person has suffered as a result of the maladministration or service failure we have identified. Any payment we recommend is not compensation for the maladministration or service failure itself but for the injustice suffered. No two cases are exactly the same and the impact of the same type of maladministration or service failure can be very different on individuals depending on their circumstances. Injustice could include: the impact on a person's feelings; the impact on a person's physical or mental health or wellbeing; whether the service failure had a direct or contributory impact on the cause of a person's death; or whether failures in care before death exacerbated the grief suffered by a deceased person's family. So, for example, in cases where we find that a person probably would not have died if things had been handled properly, we may decide that a larger financial remedy is more appropriate than in a case where it is not possible to say the death was avoidable, to recognise the greater distress that their family will have suffered from knowing that their loved one's death could have been avoided. Or we may consider a higher payment is warranted where we can see that a person's family has been caused greater distress from having to witness their loved one suffering pain or receiving inadequate treatment over an extended period of weeks or months. Or we may consider a higher payment is warranted where we can see that the circumstances of someone's death were particularly harrowing for their family – for example, where a family has to live with the knowledge that, without need, their loved one died alone.

24. In arriving at an appropriate level of financial redress, we consider previous recommendations we have made in cases where we judge the injustice to have been similar. To help us do this, we have collected a broad range of information we can refer to. This includes information about a number of cases we have investigated about the care and treatment of people with learning disabilities. It also includes information about a number of other cases where we found that someone's chances of surviving their illness were compromised by failings in their care and treatment or where we found that there was a missed opportunity to provide treatment that may have prevented their death – that is, similar findings about injustice to our findings in this case. That said, no two complaints we investigate are identical and therefore no two complainants will have suffered the same injustice.

25. It is also true to say that in our consideration of injustice in the *Six Lives* complaints, we took care around putting details of the families' injustice into a very public arena. This can be demonstrated by looking at the case of Tom Wakefield, for example, where we simply said that '*there was public service failure by the Council, the PCT, the Partnership Trust and the Acute Trust and that those combined failings resulted in significant unremedied*

*injustice for Tom and his parent*s'. This means that the injustice Mr and Mrs M suffered cannot be compared to the injustice Tom Wakefield's family suffered, because we did not set out the detail of the injustice that Tom and his family had suffered in the *Six Lives* report, as we have done in paragraphs 282 to 291 of this report. However, we have compared the injustice the two families suffered and we think they are different.

26. As we explained earlier, no two cases we look at will be the same and we recognise that no two families will have been affected in the same way, even by broadly similar service failures. In this instance, we carefully considered the individual circumstances of Mr and Mrs M's complaint and the injustice they had suffered (as set out in paragraphs 290 and 291). We were mindful that B's death would have been immensely distressing for them even if the care she had received had been beyond fault. We decided that payments totalling £3,000 (£2,000 from the Trust and £1,000 from SEEDS) represented appropriate financial redress for the additional distress that they suffered as a result of the service failures that we identified.

27. We recognise that no amount of money will lessen the pain Mr and Mrs M feel, and it was certainly not our intention to appear to devalue their pain and distress in any way. However, we are satisfied that the payments we have recommended in the report are appropriate. This is because they are in keeping with the recommendations we have made in other cases where we have found broadly similar injustice.

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