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The investigation of a complaint by Mrs A against Cwm Taf Local Health Board

A report by the Public Services Ombudsman for Wales

Case: 201002624

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Introduction

This report is issued under section16 of the Public Services Ombudsman (Wales) Act 2005.

In accordance with the provisions of the Act, the report has been anonymised so that, as far as possible, any details which might cause individuals to be identified have been amended or omitted. The report therefore refers to the complainant as Mrs A and to her daughter as Sarah. Any employees of the Cwm Taf Local Health Board ("the Health Board"), involved in the events surrounding the complaint, are referred to by their job title.

Summary

Mrs A's daughter, Sarah, was born with severe developmental delay and throughout her life had complex health care needs. Mrs A complained to the Ombudsman about Sarah's treatment and care at the Royal Glamorgan Hospital upon her transition from children's to adult hospital care. Mrs A said that during Sarah's only admission to an adult hospital ward, there were unacceptable delays in administering the appropriate antibiotic medication and that staff were not trained or equipped to meet Sarah's needs because of a lack of co-ordination between services during the transfer of her care. Sadly, Sarah died in hospital on 21 October 2009, aged 20. Mrs A believed that the outcome of her final hospital admission would have been different had Sarah's treatment and care been satisfactory.

The Ombudsman found that arrangements for Sarah's transfer of hospital care were inadequate. There was no evidence either of a clear, co-ordinated transfer process or of an effective hand over of care. The Health Board also failed to plan and deliver services in a way that recognised Sarah's individual needs in accordance with the equalities legislation. Whilst the Ombudsman did not find that the poor transition arrangements contributed to any clinical failing, there was some evidence that the quality of Sarah's care was compromised as a result. The Ombudsman also found that aspects of Sarah's clinical treatment fell below a reasonable standard; the most significant of which were the failure to initiate treatment with intravenous antibiotics within four hours of Sarah's admission to hospital and a further delay of more than 21 hours during which two doses of prescribed oral antibiotics were not given. The Ombudsman was unable to say whether or not the outcome would have been different for Sarah but for those clinical failings. Finally, the investigation identified that there were inadequacies in the Health Board's handling of Mrs A's complaint.

The Ombudsman upheld each element of Mrs A's complaint and made a number of recommendations to the Health Board for further action to address the failings identified. The Health Board agreed to implement the recommendations and to apologise and make a redress payment to Mrs A of £2000 in recognition of the failings in her daughter's care and the resulting uncertainty over the sad outcome.

The complaint

1. With the help of the Community Health Council ("the CHC"), Mrs A complained to me about the treatment and care provided to her daughter, Sarah, during her only admission to an adult hospital ward following her transition[1] from children's to adult health care services. Mrs A was concerned that there were unacceptable delays in administering the appropriate antibiotic medication and that staff were not trained or equipped to meet Sarah's needs because of a lack of co-ordination between services during the transfer of her care. Sadly, Sarah died in hospital on 21 October 2009, aged 20. Mrs A believed that the outcome of this hospital admission would have been different for Sarah had her treatment and care been adequate.

Investigation

2. Comments and copies of relevant documents were obtained from the Health Board and considered in conjunction with the evidence provided by Mrs A. One of my Investigators met with Mrs A at her home to discuss her complaint and later interviewed three members of the Health Board's staff.[2] Independent professional advice was also obtained from Miss Jane Young, a Ward Sister with 25 years nursing experience in a large teaching hospital; Mr Jim Blair, a Consultant Nurse in Learning Disabilities and Dr Devapriya Dev, a Consultant in Respiratory Medicine.

3. A summary of the available standards and guidance considered to be relevant to the complaint is attached at **Appendix 1.**

4. Mrs A, the Health Board and the Welsh Government were given an opportunity to comment on a draft of this report. Their comments have been taken into account in completing the report and finalising its conclusions.

5. Whilst the report does not refer to each and every detail or document considered, I am satisfied that nothing of significance has been overlooked during the investigation.

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[1] The process of arranging transfers of care from children's to adult health care services.

[2] The Assistant Director of Nursing (Legislation and Regulation), the Assistant Director of Nursing (Operations) and the Concerns Investigation Manager.

The background events and evidence

6. This section sets out the main events and the views of both Mrs A and the Health Board.

7. Sarah was born with severe developmental delay and throughout her life had complex health care needs. She was blind and had cerebral palsy which affected all four of her limbs. Sarah's condition was life limiting and although she had reached adulthood, she still had the stature of a child and had developed a number of problems including epilepsy, dislocated hips and curvature of the spine for which she had corrective rods put in place. Sarah had severe difficulties in learning and communicating and was unable to hold or move herself, being dependent upon others for all aspects of her daily care.

8. Sarah was under the care of a Consultant Paediatrician at the Royal Glamorgan Hospital ("the Hospital") and was well known to the clinical and nursing staff on the Children's Ward having being admitted on a number of occasions previously. At the time of the events leading to the complaint, Sarah was19 years old and had been in the process of transition from children's to adult health care services.

9. On **18 May 2008**, a multi-disciplinary team meeting was held by the Health Board to discuss how Sarah was to access appropriate emergency medicine once she had transferred from children's services. It was noted that Sarah was admitted to hospital twice a year on average with dystonia[3] and chest infections. The agreed way forward was for Sarah's GP to arrange direct admission to an appropriate ward with the Bed Management Team who would try to arrange a side room for her. The Adult Nurse said that it would also make sense for Sarah to have a named consultant within adult health services and suggested a Consultant Physician. Mrs A was present at the meeting and the minutes record reassurance given to her "that as an adult any of the wards should be able to manage [Sarah's] needs."

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[3] A movement disorder that causes the muscles to contract and spasm involuntarily.

10. On 25 May, the Consultant Paediatrician wrote a letter to the Consultant Physician to ask if he could take over Sarah's ongoing care locally.

11. On 11 June, the Consultant Physician wrote a letter to the Consultant Paediatrician and explained that patients, such as Sarah, were usually admitted to the Acute Medical Unit ("the AMU") and would be looked after for that episode of care by one of the consultant physician teams. He said that, apart from paediatricians, he was not sure who at the Hospital actually followed up the care of disabled young adults with ongoing complex needs. The letter was copied to the Clinical Director of the Rehabilitation, Intermediate and Community Care Directorate.

12. There is no evidence that Mrs A was ever advised that the Consultant Physician had declined to take over Sarah's care. There is no record of any further consideration by the Health Board as to who should take over responsibility for Sarah's ongoing care. There is also no record that Sarah was discharged from the Consultant Paediatrician's care.

13. Sarah became generally unwell on **16 October 2009**, with increased secretions on her chest. Mrs A suspected that Sarah might have a chest infection and began to treat her with oral antibiotics prescribed by her GP. On the evening of 18 October, Sarah was seen by the out of hours GP who arranged for her to be admitted to the AMU at the Hospital. Mrs A said that the GP informed her that he was admitting Sarah for a chest X-ray and treatment with intravenous ("IV") antibiotics.[4]

14. Upon her admission to the AMU at 8.15 pm, Sarah was examined and blood tests and a chest X-ray were arranged. Sarah was noted to be hypoxic[5] and to have tachycardia.[6] The working diagnosis was of a respiratory tract infection and the plan of treatment discussed with Mrs A

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[4] Antibiotic medications designed to be delivered directly into the bloodstream. They act more quickly than antibiotics taken by mouth because they travel rapidly to the site of an infection, which can be critical in an emergency.

[5] A deficiency in the amount of oxygen reaching the blood tissues.

[6] A fast or irregular heart rate.

was to observe her overnight. Sarah was prescribed a course of oral antibiotics (Amoxicillin 125g) and appears to have been given one dose after midnight, although the entry on the drug chart is unclear.

15. Early on 19 October, Sarah was reviewed during the post-take ward round and it was noted that, because her IV access was difficult, oral antibiotics were being used. The drug chart shows that Sarah's prescription for antibiotics was changed to Amoxicillin 250 mg, three times a day, which was then cancelled. A further prescription for IV Amoxicillin 1g, three times a day was written up and cancelled. A final prescription for liquid Clarithromycin 500mgs, twice a day, and liquid Amoxicillin 500 mg, three times a day, was written up.

16. At 10.20 am, Sarah was also reviewed by a Junior Respiratory Doctor who noted that her condition was stable with no real improvement. Within the treatment plan there is a note indicating that treatment with Clarithromycin/ Amoxicillin should be stopped because there was a risk of interaction with the anti-epileptic medication. A further prescription for antibiotics was written up for liquid Co-amoxiclav 5mls, three times a day.

17. Mrs A said she repeatedly raised concerns that Sarah was not being treated with intravenous antibiotics and that the Junior Respiratory Doctor did not discuss the change to Sarah's treatment plan with her. At interview, Mrs A told my Investigator, that although she repeatedly asked for Sarah to be given intravenous antibiotics, she was advised that this was not the "normal practice". Mrs A said that Sarah was not a "normal" patient and because of this she had hoped that the consultants would work with her when planning Sarah's treatment. She felt that the doctors in adult services were dismissive of her knowledge and experience of Sarah.

18. The Hospital Pharmacist confirmed that the medication request for Co-amoxiclav liquid for Sarah was dispensed by the pharmacy at 3.41 pm and, allowing time for checking, probably would have arrived on the porter's last ward round no later than 5.30 pm.

19. At 4.30 pm however, Sarah was transferred from the AMU to the Respiratory Ward. Mrs A recalled being advised that the antibiotics were not available and that the pharmacy had closed. At bedtime, she was told that the antibiotics had been located in a fridge and recently given to Sarah. From the drug chart, the next dose of antibiotic medicine that Sarah received was before 10.00 pm on 19 October. Although the exact time is not recorded, it was between 21 and 22 hours after the first dose was given.

20. At 00.40 am on 20 October, the Nurse Practitioner was asked to see Sarah because she was in respiratory distress. The Nurse Practitioner recorded that Sarah was to be sat up in a chair. Mrs A said that she asked the Nurse Practitioner not to sit Sarah up because of the rods in her back but that she went ahead and lifted Sarah from underneath her arms which was dangerous.

21. At 2.00 am on 20 October, the Nurse Practitioner reviewed Sarah at which time her oxygen levels had improved but her respiratory rate was still raised. She noted that she would discuss this with the doctor. She reviewed Sarah again at 04.25 am and noted that she had become distressed but had settled when given a Salbutamol nebuliser.[7]

22. Mrs A said throughout that night Sarah's oxygen levels were dropping and she was deteriorating. Although she repeatedly asked for Sarah to be placed on monitors to observe her vital signs, like they used on the Children's Ward, she was refused. At interview, Mrs A explained that the monitors were significant for Sarah because her disabilities and inability to communicate made it difficult to observe that her condition was deteriorating. The records show frequent observations documented in the observations chart and in the clinical notes from 00.40 am on 20 October.

23. Sarah's condition deteriorated acutely on the morning of 20 October. The nursing records show that Mrs A asked for the Nurse to see Sarah at 07.35 am and that the On Call Doctor came straight away. Her oxygen therapy was increased and IV Co-amoxiclav and Paracetamol were given.

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[7] A breathing therapy to improve the air flow into the lungs.

24. Mrs A described the scene on the Respiratory Ward that morning as “bedlam with people running around and not knowing what to do.” Mrs A explained that, upon waking next to Sarah, she noticed that her right eye had drooped and screamed for a nurse to see her. She said that the Nurse casually asked “how does [Sarah] normally look?” and had to be persuaded to call a doctor after telling Mrs A to wait for the doctor’s ward round in half an hour.

25. Mrs A said that the Nurse was physically unable to bend down either to carry out Sarah’s observations or to give her an injection and had to stand back and let the On Call Doctor take over. She said the On Call Doctor was also “panicked” and twice left the Respiratory Ward to take advice from staff on the Children’s Ward.

26. At 10.00 am, Sarah was reviewed by the Consultant Respiratory Physician at which time she had a temperature, her oxygen levels were still low and she was fitting. Both the Consultant Respiratory Physician and the Intensive Care Consultant discussed the possibility of further interventions with Mrs A. It was agreed that Sarah would remain on the Respiratory Ward where staff continued to maintain her comfort and to treat her pneumonia. Sarah’s condition did not improve and she passed away at 9.00 am the following morning.

27. At interview, Mrs A said that hospital staff had given her assurances that Sarah’s transition of care would be seamless. They asked her to have confidence and to put her trust in them. Mrs A said that, against her better judgement, she agreed that Sarah could be treated on an adult ward but looking back, she felt that it was the worst decision she had ever made.

28. Subsequently, on **3 February 2010**, Mrs A made a written complaint to the Health Board. Her main complaint was:

> “that certain members of your staff on the adult wards of [the AMU] and [the Respiratory Ward] did not know how to deal with my daughter’s high level of disability and complex needs and to compound this there was no communication between the

> children’s ward and the adult’s ward regarding her on-going needs.”

29. The letter set out various issues including:

- the decision to transfer Sarah’s care from children’s to adult services,
- the failure to treat Sarah in a timely manner with IV antibiotics,
- the various occasions that nurses and doctors failed to consult with her or listen to her views about Sarah, and
- the lack of equipment to meet Sarah’s needs as a small adult, including a face mask, intravenous needles and a hoist for transfers.

30. Mrs A asked to meet with the Health Board to discuss her concerns in more detail and ended her letter with the following,

> “Whilst the outcome may not have been any different, I believe that my beautiful daughter deserved a far better medical service and I hope that by bringing to your attention the problems that we experienced, that it will never happen to another disabled young person again.”

31. On 19 February, the Health Board wrote to advise Mrs A that her complaint had been forwarded to the Head of Nursing for Acute Medicine and Accident and Emergency (“the Head of Nursing”) who would investigate the issues raised and provide a full response within 20 working days. The Respiratory Ward Sister and the Consultant Respiratory Physician provided written comments on the complaint to inform this investigation. In relation to the issue of monitoring, the Respiratory Ward Sister explained that Sarah’s observations were taken throughout the night and that her oxygen therapy was adjusted accordingly. The Consultant Respiratory Physician said that it was “not standard practice” to put a patient on continuous monitoring unless required. He added that at the time of Sarah’s admission, regular observations were adequately performed and the frequency of these observations increased appropriately when she deteriorated.

32. On 23 March, the Health Board wrote to the CHC and offered Mrs A a meeting to discuss her complaint and this took place on 27 April. Present at the meeting from the Health Board were the Head of Nursing, the Senior Nurse and the Consultant Respiratory Physician. On the question of the delay in administering antibiotics to Sarah, the Head of Nursing, having apologised, said that Mrs A should not have been told that Sarah's antibiotics were unavailable and that the pharmacy was closed. She explained that there was an on call pharmacist who could have been contacted. She offered no further explanation on this matter.

33. On the specific issue of treating Sarah with IV antibiotics, the Consultant Respiratory Physician said that her treatment with oral antibiotics to start with, given her initial improvement, was the correct course of action and she was transferred when she deteriorated, which was the appropriate pathway. He further noted:

> " There was no indication when [Sarah] was admitted for her to be on intravenous antibiotics….If [Sarah] had any markers to indicate that she should have been on intravenous antibiotics like low blood pressure, fast heart rate, low conscious level then she would have been."

34. The Head of Nursing agreed to address the nursing issues that Mrs A had raised. In addition, she said that she would investigate further Mrs A's specific concerns about the Nurse and the Nurse Practitioner. The Senior Nurse also agreed to identify paediatric equipment that would benefit patients like Sarah and instruct staff on how to obtain it.

35. The Head of Nursing acknowledged that Sarah's transition to adult services was not as seamless as it should have been and agreed that her nursing care would have been different on a children's ward. The Consultant Respiratory Physician said that the lack of continuity from children's medicine to adult medicine was well documented and that there were some transfers with complications, in particular regarding children with special needs. However, he did not think that treatment by a paediatrician would have changed the outcome for Sarah.

36. At the conclusion of the meeting, Mrs A said that most importantly, the family and carers of adults with complex needs should be listened to by clinicians because they had the most experience in how to look after the people they cared for. The Head of Nursing said that she would take the matter of transition arrangements up with the Divisional Director and, having pursued Sarah's case through official channels, she would provide Mrs A with feedback and an action plan on the agreed way forward.

37. On 28 May, the Head of Nursing provided Mrs A with a copy of the notes of the meeting.

38. On 19 July, the CHC wrote to the Health Board requesting the follow up of a number of matters outstanding from the meeting.

39. On 7 August, Mrs A requested an independent review of her complaint under the NHS Complaints Procedure.

40. On 23 August, the Head of Nursing wrote to the CHC in response to the concerns set out in its letter of 19 July. As part of the response, she detailed the arrangements for ensuring that appropriate paediatric equipment would be available for patients from the point of admission and on to the medical wards. She also enclosed a statement (dated 22 August) from the Nurse Practitioner. This explained that, whilst it was necessary for her to place Sarah in a sitting position in order to aid ventilation, on reflection, she should have asked Mrs A about the best way to move Sarah. She accepted that aspects of her record keeping were very poor and said that she now used the SBAR tool[8] which has added structure to her record keeping and ensured that all relevant details were recorded. Finally, the Head of Nursing said that she wanted to reassure Mrs A that the Nurse who had been unable to take Sarah's observations, was undertaking a customer care course and had completed a piece of reflective practice. She concluded that the Nurse had been seen by the Health Board's Occupational Health Physician and "is swimming."

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[8] A framework for communication between members of a health care team about a patient's condition: situation, background, assessment, recommendation.

41. On 9 December, the findings of the independent review were communicated to Mrs A and to the Health Board. As well as commenting on the inadequacy of the Health Board's complaint response to date, the Lay Reviewer recommended that Mrs A should be provided with an action plan and a programme of staff training.

42. Mrs A received a follow up letter from the Divisional Nurse on **3 February 2011** setting out changes to the structure of the Hospital's A&E Department and enclosing that department's training needs analysis. In the following weeks, a further exchange of correspondence took place between the Health Board and the CHC as the CHC sought clarification of certain points. On 3 March, Mrs A brought her complaint to me.

Professional advice

What the Nursing Adviser had to say

43. The Nursing Adviser said that, whilst the medical notes did not identify any problem with Sarah's treatment or care due to inappropriate equipment, the Health Board had acknowledged that problems existed. She noted that, through the complaint response, the Health Board had:

- addressed how paediatric equipment should be obtained by nursing staff when required;
- put in place appropriately trained paediatric nurses and an operational policy for the care of children and small adults within an emergency care setting;
- addressed the Nurse Practitioner's poor practice and the Nurse's inappropriate behaviour.

44. The Nursing Adviser said that the reason given by the Health Board for the delay in administering the antibiotic medication did not adequately address the omission. She identified that two doses of antibiotic medication were not given to Sarah. She explained that lack of availability of a drug might, at worst, cause a delay in a single dose. It would not explain a complete omission of two doses. The Nursing Adviser speculated that the repeated prescribing of different antibiotics and dosage during the day may have contributed to the delay but she

could not be certain on this point. This was because the cancelled antibiotics were not timed and dated on the drug chart as they should have been.

45. The Nursing Adviser concluded that, although the Health Board had offered an apology to Mrs A for a delay in administering the antibiotic medication, it had not explained why the antibiotic medication was not administered. It had also not identified a system to prevent this from happening in the future. The Nursing Adviser suggested that further investigation of this issue needed to be undertaken under the Clinical Governance process and a proper action plan developed to prevent a future recurrence.

What the Respiratory Adviser had to say

46. The Respiratory Adviser acknowledged that the issue of transition arrangements for patients like Sarah was a complex and rather contentious problem nationally. From the Health Board's records, he noted that there were problems surrounding "ownership of care" for Sarah and although the matter was escalated to the Clinical Director to deal with, nothing concrete transpired. Consequently, there were delays in instituting oral antibiotics because they were not readily available in syrup form. There may also have been some compromise of service delivery and good clinical practice because staff on the adult ward were not adequately equipped or trained to deal with patients such as Sarah. The Respiratory Adviser commented that, whilst the Health Board had acknowledged shortcomings in its transition arrangements, it needed to provide further evidence of the steps it had taken to remedy those shortcomings.

47. With regard to Mrs A's concerns about the way Sarah's observations were undertaken on 20 October 2009, the Respiratory Adviser said that from 00.40, when Sarah was unwell, appropriate action was documented by the Nurse Practitioner and the observations and management plans were reasonable and adequate.

48. The Respiratory Adviser explained that Sarah was very frail with a hypoplastic[9] left lung and, perhaps, reduced immunity to some extent.

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[9] Under-developed.

She presented at the hospital with a definite right mid and upper zone pneumonia, a fast heart rate, mildly raised CRP[10] (48) and hypoxia of 87% on air.[11] He said that even if her white cell count had been normal, Sarah should have been started with antibiotics immediately on admission and in such a patient, starting with IV antibiotics would be the usual practice. In accordance with British Thoracic Society guidelines,[12] good clinical practice would have been to start IV antibiotics within four hours of presentation to the hospital. Moreover, Sarah should have been started with IV antibiotics because, as the Health Board has acknowledged, she was at high risk of aspiration pneumonia.[13]

49. In addition, the Respiratory Adviser identified a delay of nearly 24 hours before the first dose of oral Co-amoxiclav was given. He noted that the delay in obtaining antibiotics in syrup form would also have been avoided if Sarah had been given IV antibiotics.

50. The Respiratory Adviser said that, although it would have been better if Sarah had been given IV antibiotics in a timely manner, it did not appear to have had an impact on her eventual outcome. He concluded, however, that the delay was unacceptable and was evidence of a serious failure of service.

What the Learning Disabilities Adviser had to say

51. The Learning Disabilities Adviser set out four key requirements to ensure a smooth transition from paediatric services into the world of adult care:

- having a policy in place;
- engagement from adult service in the planning process;
- a personal health care plan for future admission tailored to the young person’s needs; and
- a key worker to take the lead in co-ordinating a young person’s ongoing care.

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[10] C-reactive protein (CRP) is a blood test. Raised levels of CRP in the blood indicate inflammation.

[11] A reduced level of oxygen in the blood. Normal oxygen saturation for a healthy person is between 95-100%.

[12] British Thoracic Society (2009), *Guidelines for the Management of Community Acquired Pneumonia in Adults*

[13] When foreign materials are breathed into the lungs or airway.

52. The Learning Disabilities Adviser said that the Department of Health Guidance on children's hospital services in England (see paragraph 88), provided a useful framework for developing a transitions policy.

53. In terms of best practice, he considered that the health care plan (sometimes referred to as a hospital passport), should be informed and guided by the multi-disciplinary team responsible for the young person's care. In addition to a plan of care, it should contain the contact details of key community and hospital based health care professionals with prior knowledge of a patient's needs. Whilst it was not essential to identify an individual clinician to take the lead in a young person's ongoing care, a named clinician should take on the role of co-ordinating care. He referred to the Royal College of Nursing[14] who also recommended that services should designate a key worker or lead professional to plan the transition and that:

> "There should be shared protocol between children's and adults' services, which is a genuinely shared arrangement, and is properly implemented."

54. The Learning Disabilities Adviser commented on the Health Board's Draft Policy for Children and Young People being Cared for in Adult Environments ("the Draft Policy"). He said that generally the Draft Policy appeared to clearly set out a defined way forward for arranging transitions of hospital care. However, he felt that the Health Board needed to build in greater flexibility around the timing of transfers to meet individual need and that a policy up until the age of 25, rather than 18, would enable the service to be suitably flexible.

What the Health Board had to say

The Assistant Director of Nursing (Legislation and Regulation)

55. The Assistant Director of Nursing (Legislation and Regulation), ("the first ADN") said that whilst there was evidence that the Health Board had undertaken a lot of work to ensure a smooth transition for the

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[14] Royal College of Nursing (2007), *Lost in transition - Moving young people between child and adult health services*

majority of young people, it would be fair to say that it had concentrated on developing its partnership arrangements to ensure that young people's needs were being identified and met, rather than looking at arrangements within the organisation.

56. From a nursing perspective, the issue of transition for community based services had eased with the introduction of the children's community nursing service in 2009. Work had been undertaken with nursing staff on medical wards to identify individuals who would be moving into transition and would require nursing care. There were also clear transition pathways for chronic conditions such as diabetes, epilepsy and asthma and also a group that concentrated on surgical procedures.

57. The identified gap for the organisation was how young people with multiple, complex needs accessed medical services as they moved into transition. Whilst she did not consider that this was a contentious issue she referred to the difficulty in getting individual clinicians to sign up to service delivery.

58. She highlighted the differences in delivery between paediatric hospital services, where clinicians provided more generalist care, and adult medical services that were increasingly arranged around clinical specialities. She said that the main difficulty for the Health Board was that there were very few clinicians within adult medicine able to provide the generic overview that people, like Sarah needed. Anecdotally, having discussed this with her paediatric colleagues, she understood that this was a national problem and not just confined to the Health Board. She also said that professional medical bodies offered differing views to their membership about when and how transfers of care should occur which was not helpful.

59. She highlighted that the Health Board was currently working with primary care providers (such as GPs) on how to develop mechanisms for delivering that generic overview. Work was also being undertaken in conjunction with consultants on how they picked up the care of individuals with complex needs as they go through transition. In order to progress the matter of how best to meet young people's needs, she had

attended two meetings with the Assistant Medical Director to explore the way forward. Mrs A was present at one of these meetings.

60.   When asked to comment on the Health Board's Draft Policy, the first ADN explained that the document had been developed from a safeguarding perspective.[15]   A considered later addition had been to include a section on transition arrangements. She thought that the transition section of the Draft Policy was still under consultation. She also confirmed that there was no procedural guidance on transition arrangements in the pipeline.

61.   On the question of the priority afforded by the Health Board to inpatient transitional care arrangements, she thought that it sat "along with all of the other priorities that we have currently." She referred to the two broad framework documents that the Health Board had to consider when planning and delivering children's services.   She said that the National Service Framework for Children, Young Adults and Maternity Services (see paragraph 85), which is the document that the Health Board has to report on regularly, concentrates on developing multi-agency and multi-disciplinary transition planning. There was no such reporting or monitoring attached to the Universal Standards, which was primarily a benchmarking tool. She conceded that if there had been a specific reporting requirement on inpatient transitional care arrangements, it would have had more of a profile within the organisation. However, it was recognised that it had been an issue for the organisation and the Health Board was trying to address it.

The Assistant Director of Nursing (Operations)

62.   The Assistant Director of Nursing (Operations), ("the second ADN") explained that he had very little involvement with Mrs A's complaint until after the independent review. He had then arranged a meeting with Mrs A in May 2011 because he felt it was important for her to see that the Health Board was putting systems in place to stop what happened to her daughter from happening to anyone else.

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[15] Ensuring that care is provided in a safe environment.

63. Following the meeting with Mrs A, he identified that the Health Board did not have a policy or procedural guidance on inpatient transitional care arrangements in place. He also found that most of the work on transitional care that had been undertaken to date related to arrangements in the community. He later identified that the Health Board was already working on an overarching policy regarding how children were cared for within the organisation which contained a section on transition arrangements broadly setting out roles and responsibilities (see paragraph 89). In order to progress the matter, in late November 2011, he had arranged a meeting with the Assistant Medical Director and the author of the Draft Policy to discuss whether the section on transition was appropriate for young adults, like Sarah, with complex needs.

64. When asked what had happened to the Draft Policy between May 2011 and November 2011, he conceded that there had been delays and that things could have been moved on faster. He said that his progress had been hampered by a number of factors: the Health Board was in a state of flux following re-organisation; people he needed to speak to had left; it was a subject area with which he was unfamiliar and there were changes to his role within the organisation. However, he was confident that it would be easier to facilitate moving the Draft Policy forward now that the Health Board's new management structure was in place. He had taken up his new role alongside the first ADN in November 2011 and their collective knowledge and experience would provide an overview of the whole process within the Health Board. He was not aware of any other activity taking place within the Health Board to address this issue other than the meetings he had arranged to try and move the Draft Policy forward.

65. The second ADN confirmed that the Draft Policy was currently at the consultation phase and that there was no date set for an end to the consultation period. He explained that the process was not as simple as sending out an electronic version to interested parties with a deadline for a response. Agreement and sign up needed to be obtained from a number of interested parties including the individual medical specialties and GPs in the area for whom an enhanced role was envisaged. He did not anticipate that the process would be easy. He re-iterated some of

the first ADN’s comments about the organisational and cultural challenges that needed to be addressed before transition arrangements could be effected. He too thought that it would have been easier to drive the policy forward had the guidance from the Welsh Government on transition arrangements been in the form of a directive. He said that a number of discussions still needed to take place and he speculated that this alone could take up to four months. He recognised that a multi-disciplinary “nuts and bolts” procedure document would eventually need to sit alongside the policy; but he was unable to say when this might occur.

66. When asked what would happen for patients like Sarah in the meantime, the second ADN said that the Health Board had worked to address the specific issues that Mrs A had raised in her complaint whilst the broader policy issues were being taken forward. He concluded that because the Health Board had begun to develop its procedures in response to individual cases, he would like to think that similar issues would not arise in the future.

The Concerns Investigation Manager

67. The Concerns Investigation Manager (“the Concerns Manager”) explained that she had very little involvement with Mrs A until she requested an independent review of her complaint. In accordance with the Health Board’s procedure at that time, the complaint was referred in the first instance, to a complaint handler within its Corporate Services to investigate and provide a response in conjunction with the relevant directorate. She would have had no involvement with the first stage investigation or any say over the content of the response sent to Mrs A.

68. The Concerns Manager explained that upon receipt of the findings of the independent review in December 2010, she met with the second ADN to consider the Health Board’s response. She said that because work on the transition programme was ongoing, it was felt unnecessary to produce an action plan in response to the Lay Reviewer’s recommendations. She was unable to explain why the directorate had not produced an action plan earlier.

69. The Concerns Manager confirmed that, under the former procedure, the final complaint response would normally be sent to the complainant before any local resolution took place. She added that if an action plan was promised to Mrs A, then one should have been provided. She accepted that the action taken to investigate Mrs A's concerns was not in accordance with the Health Board's procedure at that time. However, since Mrs A's complaint a new NHS complaints procedure had been introduced and the Health Board had taken this as an opportunity to review its internal arrangements. Consequently some of the shortcomings seen in Mrs A's case had been addressed.

Comments on the Draft Report

70. Given the issues that this investigation raised, I felt it appropriate to share a draft of my report with the relevant department of the Welsh Government. In providing feedback, the Welsh Government strongly supported the findings as set out below about relatives and carers not being listening to by healthcare professionals. It too was concerned about the lack of competence in dealing with equality and diversity issues amongst healthcare professional within the acute hospital setting; particularly when treating young disabled patients. I welcome the Welsh Government's endorsement of my findings. However, the Welsh Government also pointed out that there was no equivalent acute adult clinician fulfilling the same role as a paediatrician. In view of this, it expressed concerns about the ability of good transition planning alone to deliver a "seamless" transition from paediatric to adult care. It felt that the focus also needed to be on Health Boards making reasonable adjustments to meet the needs of disabled patients. Acute hospital services should have staff trained in recognising and responding to the needs of all patients, particularly those who face challenges in communication.

Analysis and conclusions

71. The final days of Sarah's life and the events surrounding them continue to be deeply distressing for Mrs A. I offer her and her family my personal condolences through this report. For the Health Board, Sarah's transfer of care presented a difficult challenge due to the complex nature of her continuing health care needs. Although aspects of Sarah's care in the adult hospital setting were good, aspects of her clinical treatment fell

below a reasonable standard and the quality of her care was compromised by the failure to make reasonable adjustments to meet her needs. I will set out my reasons below for drawing these conclusions and the implications that this had for her.

72. The complaint handling in this case was not in accordance with the Welsh Government's guidelines. It is evident that the initial investigation was inadequate which meant that opportunities were missed to identify failings at an early stage. As a consequence, the Health Board was not in a position to satisfactorily answer Mrs A's concerns at the meeting in April 2010. The extent of the delay before Sarah received prescribed antibiotics was not properly identified through the Health Board's investigation, although it was evident in the medical records. This was not acceptable. Subsequently, the Health Board's actions were not communicated to Mrs A in a timely manner and the complaint was allowed to drift over many months without being brought to a conclusion.

73. I am concerned that the focus of the investigation was on highlighting individual failings rather than aiming to identify why things may have gone wrong from an organisational perspective (see paragraph 40). The lack of a robust investigation and an action plan meant that the Health Board failed to grasp in their totality the factors that contributed to a failure of care for a vulnerable person. This hampered the Health Board's ability to learn lessons. In addition, the poor complaint handling served to further compound Mrs A's distress. In April 2010, changes were made to the way in which complaints are handled by the NHS in Wales. There is more emphasis on listening and resolving complaints earlier. I also note that the Health Board said that it has used these changes as an opportunity to address some of the failings that are featured in this complaint.

74. Mrs A complained that Sarah's transfer of emergency hospital care was not "seamless" as it should have been and that Sarah's health care was compromised during her last hospital admission as a consequence. In the light of the Advisers' explanations, I consider that aspects of Sarah's treatment and care fell below a reasonable standard. However, in my view, there was no causal link between the clinical failure to administer IV antibiotics on admission and the transition process. I

cannot be certain that the outcome of this hospital admission would have been different for Sarah had she been given timely treatment with IV antibiotics. We will never know. But whether or not Sarah's death could have been avoided, should not detract from the unacceptable standard of treatment and care that she experienced. The uncertainty that arises from the knowledge that Sarah's treatment was not what it ought to have been represents a clear injustice for Mrs A and I uphold her complaint.

75. Mrs A also questioned the Health Board's decision to transfer Sarah's hospital care to adult services given that her needs remained child-centred. I regard this as a less contentious issue and I note that my Advisers have not questioned the decision to move her. Having made the decision to transfer Sarah, the Health Board should have ensured that the process was properly managed. I accept that transition planning can be difficult, particularly for patients like Sarah who may require input from more than one clinical specialist. However, there were missed opportunities during the transition period to develop practical mechanisms to enable any acute adult clinician to respond promptly and appropriately to Sarah's presenting needs. At the very least, I would have expected to see early involvement from a Learning Disabilities Specialist who could provide advocacy and support and assist in developing an individual health care plan (see paragraph 53). Notwithstanding the poor transition arrangements, I consider that Sarah's care would still have been compromised upon her admission to hospital because health care professionals were not sufficiently sensitive to her needs as a disabled person.

76. Throughout this investigation, I have seen examples organisationally, culturally and at an individual level where there has been a failure to fully appreciate that services for Sarah might need to be planned and delivered in a way that recognised her individual needs (see paragraphs 12, 17, 31, 40). As part of a human rights based approach, a public body must provide services in ways which have regard to the inherent dignity of the individual (see paragraph 93). In my view, not only did the Health Board fail to have sufficient regard for Sarah's dignity, it also failed to adequately fulfil its obligation to make reasonable adjustments to meet her special needs under the equalities legislation in place at the time (see paragraph 82). To that extent, I have

to be critical of the way the Health Board managed the process of her transition and this extends to the lack of engagement at a senior level (see paragraph 12).

77. It also seems to me that the only reason the Health Board has continued to consider this issue at all is in response to Mrs A's ongoing dissatisfaction. Because of the Health Board's somewhat ineffectual response, it is understandable that Mrs A feels that the Health Board has been paying lip service to her concerns. She should not have had to advocate so hard for Sarah and others like her, in order for the Health Board to respond meaningfully to the need for adequate transition arrangements for disabled young people. Therefore, I uphold this aspect of Mrs A's complaint.

78. I note that the Health Board's Draft Policy, which incorporates broad aims on transition, appears to have languished for months and there is no clear timetable for if, or when, it will be implemented. I recognise that this is a complex issue that cuts across clinical specialties and involves multi-agency working and engagement with primary health care services. However, transitions also need to be considered within the broader framework of the Health Board's equality duty. For this to succeed, strong leadership and support will be required at Board level. Until the Health Board rises to the greater challenge of meeting and mainstreaming the needs of disabled patients, I remain concerned that there might be others, like Sarah, whose quality of acute inpatient care is compromised.

79. Finally, I would like to comment on Mrs A's role. The lack of effective transition planning meant that Mrs A was the only person able to provide Sarah with continuity of care after her transfer from children's services. She had been Sarah's main carer and advocate for twenty years and was best placed to give voice to her needs. Yet, Mrs A has repeatedly complained that clinical and nursing staff did not give due consideration to what she had to say. I recently reported on the care of another patient with a learning disability[16] where the family and carer had raised concerns about treatment in hospital that were not recorded or

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[16] Public Services Ombudsman for Wales (September 2011), *The investigation of a complaint by Mrs A and Mr B against Abertawe Bro Morgannwg University Health Board: 201001670*

acted upon. The consequences for this patient and his family were also devastating. It is a troubling and emerging theme of complaints to my Office that carers are reporting that they are marginalised within the health care setting. Their experiences are echoed in the findings of other reports (see paragraphs 90 and 92). The Health Board needs to consider how it can bring the voices of carers and disabled young patients more effectively into the process of planning and delivering services.

Recommendations

80. I recommend that within one month of the date of this report, the Health Board should:

- Provide Mrs A with an apology letter from the Chief Executive for the failings that have been identified in this report.
- Pay to Mrs A the sum of £2,000 in acknowledgement of the poor handling of her complaint, the failings in her daughter's care and the uncertainty over the sad outcome.
- Present my investigation report to the next full meeting of the Board along with a comprehensive action plan based upon the findings and recommendations therein.

Within four months of the date of this report, the Health Board should:

- Investigate the delay in administering the antibiotic medication through the clinical governance framework and put in place systems to prevent a recurrence.
- Produce and keep up to date a register of young people with disabilities and complex health needs receiving support in the community between the ages of 12 years and 18 years and share this information with adult service providers in order to assist with service planning and delivery.
- Ensure that each young person on the register who has reached the age of 14 has in place a comprehensive health transition plan, including plans for hospital care, which is reviewed annually.

- Draw up a comprehensive programme of learning disability awareness training for relevant nursing and clinical staff which must include appropriate recognition of the role of family, carers and advocates in providing information to staff and in helping to make decisions about care.
- Consider ways of working in collaboration with the Learning Disabilities Team to support best practice in patient care and transition planning, including the use of hospital passports, for patients with learning disabilities.
- Ensure that a focused, minuted discussion of the full Board takes place concerning how its hospitals can best guarantee and evidence that it meets the provisions of the Equality Act for patients with learning disabilities.

Within nine months of the date of this report, the Health Board should:

- Put in place an operational transitions policy and procedure for young people with disabilities and complex health care needs moving from children's to adult hospital services (having regard to the advice at paragraph 51).

81. I am pleased to note that in commenting on the draft of this report the Health Board has agreed to implement these recommendations.

Peter Tyndall
Ombudsman 16 March 2012

Appendix 1

Relevant legislation, guidance, policy and research

Equality Law

82. The Disability Discrimination Act 1995 made it unlawful for service providers to treat disabled people less favourably than others for reasons relating to their disability. Section 21 made it unlawful in certain circumstances for service providers to fail to make "reasonable adjustments" to cater for the needs of disabled people.

83. The Disability Discrimination Act 1995 was repealed by the Equality Act with effect from 1 October 2010. It has streamlined and enhanced discrimination legislation generally. The Equality Act 2010 includes similar provisions to the Disability Discrimination Act 1995.

The Welsh Government Guidance

84. The framework for planning and delivering health care for patients up to the age of 18 is contained in two key documents published by the Welsh Government.

85. The National Service Framework for Children, Young Adults and Maternity Services ("the Children's NSF")[17] sets national standards, aimed at improving the quality of care and reducing unacceptable variations in health and social services. The standard on transition for young people is supported by a range of key actions, including the need for every lead health professional to make adequate arrangements for the transfer of young people to adult services, preferably via specific transition clinics involving staff from both paediatric and adult services. Although the expectation of the health service is set by the standards, and the key actions set clear objectives, the practical implementation is largely left to local discretion.

86. The All Wales Universal Standards for Children and Young People's Specialised Health Care Services[18] ("the Universal Standards")

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[17] Welsh Assembly Government (2005), *National Service Framework for Children, Young People and Maternity Services in Wales*

[18] Welsh Assembly Government (2008), *All Wales Universal Standards for Children and Young People's Specialised Health Care Services*

provide the basis for responsible organisations to plan and deliver co-ordinated networks of specialised health care services. The Universal Standards apply to all children and young people in Wales with particular health care needs. The Universal Standards state that there must be a degree of flexibility around the age of transition to ensure that young people are treated in the most appropriate setting depending on their mental, emotional and physical development. Standard 3, Care of the Child and Family/Patient Experience, requires each responsible organisation to put in place transition pathways "to allow for seamless transition to adult services." There is no set of standards that focuses specifically on delivering care to young people when they are in hospital.

87. The Welsh Government's guidance on handling complaints in the NHS [19] ("the WG Guidance"), advocates that Complaints Managers should consider a range of options to facilitate a local resolution of a complaint. Where a meeting is considered to be appropriate, adequate time should still be allowed for the complaint to be thoroughly and fairly investigated. If the complaint involves clinical matters or named members of staff, the Complaints Manager must involve the doctors or staff members concerned in the process. A full investigation of the issues raised should be completed within four week and where this is not possible, the complainant should be informed of the reason why and when they can expect to received a reply. A complaint facilitated by local resolution will only be concluded once the complainant has indicated that they are happy with the proposed actions. The Chief Executive must respond in writing to all written complaints and the reply should aim to assure the complainant that their concerns have been thoroughly investigated point by point.

The Department of Health Guidance

88. The Department of Health has published standards that apply to all children being treated in NHS hospitals in England[20] ("the Children's Hospital Standards"). The Children's Hospital Standards state that every paediatric general and specialty clinic should have a policy on transition to adult services covering the following: a policy on the timing

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[19] Welsh Assembly Government (April 2003), *Complaints in the NHS: A Guide to handling complaints in Wales*

[20] Department of Health (April 2003), *Getting the right start: National Service Framework for Children - Standard for Hospital Services*

of transfer; a preparation period and education programme; a co-ordinated transfer process; an interested and capable adult clinical service; administrative support and involvement from primary health care and social care.

The Health Board's Draft Policy

89. The Health Board's draft policy for Children and Young People being cared for in Adult Environments ("the Draft Policy"), states the following at part 14:

> "Children and Young People with special/continuing care needs up to the age of 18 years will be directly admitted to the children's wards until a handover of care has taken place.
>
> The Consultant Paediatrician will develop a care plan to be held by the child/family to assist adult services and to fast track access to services at the time of acute admission.
>
> The transition of care from children's to adult services should be supported by the local General Practitioner who will then seek additional help, when needed, from the adult physician. Transition planning should begin as early as possible, and certainly well before the child reaches 18 years.
>
> Paediatricians should ensure full involvement if the General Practitioner in the care of children with complex needs as a key co-ordinator."

Other reports and research

90. Mencap, a campaigning charity for people with learning disabilities, refer in their report, 'Death by Indifference', [21] to institutional discrimination that people with learning disabilities experience. Mencap believes that people with learning disabilities are treated unfairly in all parts of the health care service. The report states that institutional discrimination:

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[21] MENCAP (March 2007), *Death by Indifference*

> "…happens when the people working in a place or organisation
>
> - do not value all people equally
> - do not understand that different people have different needs
> - do not change the way they deliver a service so that it meets different needs…
>
> People who work in the health service often do not understand the needs of people with a learning disability. This means that their needs are not met."

91. In reflecting the experience of people with learning disabilities, the Mencap report highlighted that health care professionals do not listen when their families and carers try to say what is wrong. They commented that:

> "People who care for people with a learning disability know them really well. They notice if the person they care for is acting differently and can see if they are upset or in pain. This is really important if the person with a learning disability cannot talk to the doctor or nurse looking after them."

92. In 2009, the Health Service Ombudsman and Local Government Ombudsman in England issued a report called 'Six Lives: the Provision of Public Services for People with Learning Disabilities'. The report used the experiences of six people to illustrate general problems that were apparent regarding the provision of public services to people with learning disabilities. It referred to the:

> "devastating impact of organisational behaviour which does not adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone. They identify a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care."

93. The British Institute of Learning Disabilities (“BILD”), in their factsheet on the Human Rights Act 1998 (“the HRA”), noted the following:

> “In March 2008 the Joint Committee on Human Rights (the House of Lords and the House of Commons) issued a report: A Life Like Any Other? Human Rights of Adults with Learning Disabilities. This stated that the HRA “provides a legal framework for service providers to abide by and for service users to demand that they are treated with respect for their dignity”. The government response of May 2008 specifically accepted that it is often the most vulnerable members of society, such as people with learning disabilities, who most need the protection and promotion of their rights under the HRA.
>
> It could be argued that by ensuring the human rights of vulnerable people are fully respected, those of all their fellow citizens will be strengthened…
>
> The [HRA] should be used by health and social care professionals as a tool to develop and reinforce a human rights culture and environment. The aim must be to provide services to people with learning disabilities in ways which disregard type or degree of disability, race, ethnicity, religion or other belief, cultural background, gender, or sexual orientation.”

94. The Royal College of Nursing in their ‘Dignity at the heart of everything we do campaign’, [22] offered the following definition of dignity:

> “Dignity is concerned with how people feel, think and behave in relation to the worth of value of themselves and others. To treat someone with dignity is to treat them as a being of worth, in a way that is respectful of them as valued individuals.”

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[22] Royal College of Nursing (2008), *Dignity: at the heart of everything we do*