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PUBLIC SERVICES OMBUDSMAN FOR WALES

The investigation of a complaint against Swansea Bay University Health Board

A report by the
Public Services Ombudsman for Wales
Case: 201902686

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Introduction

This report is issued under s.23 of the Public Services Ombudsman (Wales) Act 2019.

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 X and to Mrs X's daughter as Y.

Summary

Mrs X was concerned that inadequate eye care was provided to her daughter ("Y") in light of her known self-injurious behaviour (which included hitting herself on the head and face which were known to cause bruising). As a result, Mrs X was concerned that Y's eye injury was not diagnosed sooner. Y has a diagnosis of Atypical Autism, Learning Disability – mild to moderate and mental health difficulties and was, at the time of the events complained about, living in a specialist residential learning disability unit ("the Unit") run by the Health Board.

The Ombudsman found that while Y received good care in terms of planning and delivery to meet her specialised learning disability needs, there were serious shortcomings in the care Y received in June 2018 relating to her eye management. While staff noted concerns in relation to Y's right eye, which required monitoring, there was no evidence that monitoring took place or that these concerns were escalated to clinical staff. When concerns were raised in September about Y's eye, an urgent review was requested and she was taken to the Emergency Eye Unit at a hospital in the area of another health board where she was diagnosed with total retinal detachment and traumatic cataract of the right eye (a cataract is when the lens inside the eye develops cloudy patches).

While it was possible that Y's retinal detachment occurred in June 2018, the Ombudsman was unable to say with any certainty that earlier referral for ophthalmology advice would have resulted in a different outcome for Y. That said, the failure to monitor Y's eye or refer for specialist advice at that time was a service failure; Y did not receive an appropriate level of eye care which was not in line with the requirement to provide fundamentals of care. This caused Y, a vulnerable young adult, an injustice as she was denied the opportunity of a timely referral and clinical review. It was also a considerable injustice to Mrs X as there will always be an element of doubt about whether the outcome could have been different for Y who ultimately lost sight in her right eye.

The Ombudsman also found that communication with Mrs X about Y's eye condition was inadequate and she was not kept updated. This was a serious communication failing as the news of Y's eye condition came as a shock to Mrs X and caused her alarm and distress which was an injustice to her. The Ombudsman **upheld** Mrs X's complaint.

The Ombudsman cannot determine if the action / inaction of a body within his jurisdiction amounts to a breach of human rights. However, he can comment more broadly on whether the Human Rights Act 1998 is engaged. The Ombudsman recognises that individuals in institutional care settings are amongst the most vulnerable in society and so are amongst the most vulnerable to having their human rights compromised. He found that the failings in Y's care engaged her Article 8 rights (a right to respect for one's private and family life) as the Health Board had not sufficiently demonstrated that it had ensured that the needs of an adult with learning disability, such as Y, were sufficiently respected.

The Health Board agreed to the Ombudsman's **recommendations** that, within **1 month** of the date of his report, it should:

a) Provide Mrs X with a written apology for the failings identified.

The Health Board agreed to the Ombudsman's **recommendations** that, within **3 months** of the date of his report, it should:

b) Refer the report to the Board, and the Health Board's Equalities and Human Rights team to identify:

    i) how consideration of human rights can be further embedded into clinical practice

    ii) relevant human rights training for Registered Nurses on the Unit (and across the Health Board).

c) Arrange for a copy of this report to be shared and discussed at the next Learning Disabilities Service monthly meeting using this case as a learning event to consider:

iii) adopting the SeeAbility (a charity that provides specialist support, accommodation and eye care help for people with learning disabilities, autism and sight loss) functional vision assessment tool as part of a patient's annual review or in an acute or new scenario

iv) arranging training for staff on the Unit from the Health Board's Ophthalmology Department on the importance of identifying and escalating any concerns relating to possible eye injuries

v) a mechanism for ensuring that patients are accessing regular eye tests / eye health checks in line with the National Autistic Society ("NAS") and SeeAbility advice, and the Learning Disability Annual Health Check (part of the 1000 Lives Improvement, the national improvement services for the NHS in Wales) and NICE Pathways "Learning disabilities and behaviour that challenges overview"

vi) arranging training for Registered Nurses on the Unit to take into account relevant advice, such as the NAS and SeeAbility advice, to inform them of the importance of good eye care for learning disabled and autistic patients, especially where those patients' behaviour includes self-injurious behaviour.

d) Arrange for a copy of this report to be shared and discussed with members of the medical and nursing team involved in Y's care using this case as a learning event to highlight the importance of / remind them:

vii) to follow the Nursing and Midwifery Council's Code around providing fundamental of cares to patients' physical healthcare needs, which includes eye care

viii) to remind the team of the importance of being open and transparent with relatives of patients in reporting patients' injuries and serious incidents to their family

ix) to ensure that the clinical practice of monitoring a patient's physical condition is evidence-based and consistent and that concerns are escalated without delay to senior clinical staff for appropriate action.

e) Provide documentary evidence to show that the recommendations have been carried out within the stipulated timescales.

The Complaint

1. Mrs X was concerned that inadequate eye care was provided to her daughter ("Y") in light of her daughter's known self-injurious behaviour (which included hitting herself on the head and face which were known to cause bruising). As a result, Mrs X was concerned that her daughter's eye injury was not diagnosed sooner. The investigation considered the period of care between June and August 2018.

Investigation

2. I obtained comments and copies of relevant documents from Swansea Bay University Health Board ("the First Health Board") and considered those in conjunction with the evidence provided by Mrs X. I also received copies of relevant records relating to Y's eye care at a hospital in the area of another Health Board in Wales ("the Second Health Board"). I sought professional advice from Mr Daniel Alba, a Registered Mental Health Nurse with experience in commissioning and providing mental health, learning disability and autism spectrum disorder services, and Mr Samer Elsherbiny, a Consultant Ophthalmologist, with an interest in managing eye problems of adults with learning difficulties.

3. The Advisers were asked to consider whether, without the benefit of hindsight, the care or treatment had been appropriate in the situation complained about. The Ombudsman determines whether the standard of care was appropriate by making reference to relevant national standards or regulatory, professional or statutory guidance which applied at the time of the events complained about. I have not included every detail investigated in this report, but I am satisfied that nothing of significance has been overlooked.

4. Both Mrs X and the Health Board were given the opportunity to see and comment on a draft of this report before the final version was issued.

Relevant guidance

5. The National Institute for Health and Care Excellence ("NICE") clinical guideline NG11 "Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities whose

behaviour challenges" ("the First NICE Guideline"). This guideline identifies, amongst other things, the need for early identification of behaviour that challenges, including the need for regular risk assessments (for behaviour such as self-injury) and behaviour support plans (to identify proactive and preventative strategies to manage risk to a person who displays challenging behaviour).

6. NICE clinical guideline CG133 "Self-Harm in Over 8s: Long-Term Management" ("the Second NICE Guideline"). This guideline identifies, amongst other things, the need for care plans and risk management plans to address immediate and long-terms risks and to identify strategies aimed at harm reduction.

7. Mental Capacity Act 2005 ("the Act") Code of Practice ("the Code") states that the best interests principle (this is where professionals act in the patient's best interests) applies to any act done, or decision made, on behalf of someone where there is reasonable belief that the person lacks capacity under the Act and covers informal day-to-day decisions and actions.

8. Positive Behavioural Support ("PBS") Competence Framework ("the Framework") produced by the PBS Coalition, a collective of individuals and organisations promoting PBS in the UK. This is a framework for developing and understanding behaviour that challenges and is based on the assessment of the broad social and physical context in which behaviour occurs and is used to construct interventions to enhance quality of life for the service user and their carers.

9. The 1000 Lives Improvement is the national improvement service for the NHS in Wales. The Learning Disability Annual Health Check ("the Health Check") states that people with learning disabilities experience more health inequalities than the general public. The Health Check was introduced in Wales to promote early detection and treatment of health problems in people with learning disabilities. The check includes, amongst other things, vision and communication examinations. The NICE Pathways "Learning disabilities and behaviour that challenges overview" ("the NICE Pathway") states that annual physical healthcare checks should be offered to children, young people and adults with learning disabilities.

10. Nursing and Midwifery Council's ("NMC") "The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates" ("the NMC Code"). Amongst other things, the NMC Code sets out the fundamentals of care, which states that Registered Nurses must deliver holistic care to an individual including meeting their physical healthcare needs. Eyecare is a fundamental aspect of physical healthcare.

11. National Autistic Society ("NAS") - Eye care: preparing for an appointment. The NAS says that an "eye test is recommended for all children, and for adults every two years. Autistic people may process visual information differently" ("the NAS advice").

12. SeeAbility (a charity that provides specialist support, accommodation and eye care help for people with learning disabilities, autism and sight loss). Its resource, "Looking after your eyes", says that "Adults with learning disabilities are ten times more likely to have serious sight problems than other people" ("the SeeAbility advice").

13. The Human Rights Act 1998 ("the HRA") incorporated the European Convention of Human Rights ("the Convention") into UK law. Such rights are set out in the Convention through a series of Articles. All public authorities must follow the HRA. It is not the function of the Ombudsman to make definitive findings about whether, or not, a public body has breached an individual's human rights by its actions or inaction. However, he will identify where human rights matters are engaged and comment on a public body's regard for them.

14. Article 8 of the Convention provides a right to respect for one's private and family life. The positive obligation imposed on a public body to respect and promote those rights applies to the way in which health providers exercise their powers and perform their duties. The impact on someone of the failure to provide appropriate medical treatment or care is sufficient to engage Article 8 (and in serious cases to constitute a breach).

15. The Welsh Government has issued statutory guidance on NHS complaints handling. Under the Putting Things Right Guidance ("the PTR Guidance"), Health Bodies are expected to deal with concerns openly and honestly. At the heart of the PTR Guidance is the principle of "investigate once, investigate well".

16. I issued guidance on “Principles of Good Administration and Good Records Management” (“my Guidance”). I expect bodies in my jurisdiction to ensure that when they investigate complaints they do so thoroughly, quickly and impartially (Principle 5 – putting things right). I also expect that bodies learn lessons from complaints to contribute to developing and improving services (Principle 6 – seeking continuous improvement).

The background events

17. This is not intended to be a comprehensive chronology of every medical and nursing input. It outlines key information to assist in reaching conclusions on the complaint. I have limited the background to include information about the management of Y’s eyes as this was Mrs X’s concern and the issue being investigated.

18. Y is 24 years old and has diagnoses of Atypical Autism (presenting with some symptoms of autism), Learning Disability – mild to moderate and mental health difficulties. Her key behaviours include verbal and physical aggression, self-injurious behaviour, non-compliance, property destruction, ritualistic behaviours and socially inappropriate behaviours.

19. Y was admitted to a specialist residential learning disability unit (“the Unit”) run by the Health Board on 6 March 2017. The Unit is designed to meet the needs of people with learning disabilities who have acute mental health or behavioural problems, which cannot be managed within the community service.

20. On 13 June 2018 it was noted that Y had poked her right eye and left a red mark in the corner of her eye and that a body map (a form to document visible marks or injuries on the body) needed to be completed the following day.

21. On 25 June observations of Y’s eyes noted that both pupils were dilated and uneven and to continue to monitor.

22. Staff observed Y’s pupils being unevenly dilated on 27 June. The pupil of the right eye appeared to have a grey shadow. Y said she was able to see through the right eye. Staff were to continue to monitor for any changes.

23. A medical review on 2 July noted facial bruising.

24. On 23 July there was reference to Y pushing a tooth and expressing pain which resulted in a dental visit the following day.

25. On 7 August, Y's body map noted, amongst other things, old bruising to her face.

26. Y's clinical notes referred to a body map being completed on 8 August due to increased swelling and bruising to the right side of Y's face. A medical review on 13 August noted that the swelling was much better.

27. On 10 September, Y's right eye was examined by a Doctor ("the Doctor") due to concerns with the vision in her eye and because Y was unable to see fingers to count. An urgent review was requested.

28. The Doctor discussed her concerns with the Consultant Psychiatrist in Learning Disabilities ("the Consultant") on 11 September. An urgent eye clinic appointment was arranged.

29. Y was taken to the Emergency Eye Unit at a hospital in the area of the Second Health Board ("the Hospital Eye Unit") on 12 September with a diagnosis of likely retinal detachment (when the retina, the light-sensitive tissue lining the back of your eye, separates from the back of your eye and can cause loss of vision which can be partial or total). A referral was made for a further review 2 days later.

30. Y attended the Hospital Eye Unit on 14 September and was seen by a Consultant Ophthalmologist ("the Consultant Ophthalmologist"). The diagnosis was total retinal detachment and hypermature traumatic cataract of the right eye (a cataract is when the lens inside your eye develops cloudy patches; a hypermature cataract is when the lens is pearly white and could have fluid within the capsule). Surgery was not considered to be in Y's best interests. Y no longer had sight in her right eye.

Mrs X's evidence

31. Mrs X said she received a phone call on 12 September 2018 telling her that staff were taking Y to the Hospital Eye Unit for a problem with her eye. She said she had no idea that Y was losing her sight.

32. Mrs X said it was unacceptable that no one considered that Y could lose her sight in the manner she did. She said that Y completely depended on the staff at the Unit to ensure that, if matters got worse, Y was taken to hospital. She said that, unfortunately, Y lost sight in her right eye as a result of hitting her eye and it seemed that Y's eye was in this state for some 6 weeks and no one realised the seriousness of her condition.

33. Mrs X said it was too late to save Y's sight as the injury was old. She said the situation needed urgent treatment to lessen the risk to Y's sight. She said Y was young to lose her sight in the way she did. Mrs X said this was heart breaking and difficult to accept.

34. In commenting on the draft report, Mrs X said that she had found a notebook she kept at the time of the events complained about. She said that, during a visit on 19 August 2018 (a Sunday), she noted that Y's eye was almost closed, her eye was red, and she could not see the white of Y's eye. She said she stood there in front of Y in shock. She left quickly and did not take the opportunity to raise her concerns. She said the notes that follow this entry referred to speaking to the Unit on the following day and being told that Y was having a good day. On the following Wednesday, Mrs X said there was an entry in her notebook noting that Y had significant bruising on her right cheek and that her right eye was inflamed which she noted had gone down by the Friday when she phoned to enquire about Y's eye inflammation.

35. In addition, while the Ophthalmology Adviser said that Y's visual loss was painless (paragraph 60), Mrs X said that people with learning disabilities were able to hide pain and the fact that they did this, did not mean they were not in pain. She added that the Consultant Ophthalmologist at the Hospital Eye Unit said that it was possible that Y was trying to stimulate her eye to help her see better.

36. While the Health Board said that Y's self-injurious behaviour was historical, intense and ongoing since childhood (paragraph 37), Mrs X said that when Y was a child, she was a pupil in a mainstream school. She said Y did not have obvious behavioural problems, although she was very quiet and enjoyed her own company but had many friends. Y's father died when she was 11 years old and she received her diagnosis when she was 12 years old. Her self-injurious behaviour started some years after she moved to a residential school, around the time she was 14 years old.

The Health Board's evidence

Initial response to the investigation

37. The Health Board said that Y's self-injurious behaviour was historical, intense and ongoing since childhood. It confirmed that a Positive Behavioural Support Care Plan ("the PBS" – a plan for providing long-term support to people who may be at risk of developing behaviours that challenge) was in place during her time at the Unit, which was based on Y's historic assessment information and strategies known to be successful in supporting her complex needs. It was updated during her time at the Unit with input from medical and nursing staff and psychologists and included a section on understanding Y's behaviour, the frequency and intensity of it, and the times when each behaviour was likely to occur and what drove such behaviour. The PBS included information on how to address Y's health needs, her likes and dislikes and the best activities, structure and routine for Y.

38. The Health Board said that Y injured herself daily and the PBS relayed this information. The plan noted the triggers for Y's behaviour and how staff should deal with any escalation in behaviour and how to support Y through a crisis. It said Y's key behaviours included verbal and physical aggression, self-injury, non-compliance, property destruction, ritualistic behaviours and socially inappropriate behaviours. In relation to minimising Y's behaviour and risk of injury, the PBS advised of early warning signs, triggers and advice on how to support Y.

39. The Health Board confirmed that Y's self-injurious behaviour included tapping, slapping and punching her face and head banging. These would occur any time during the day and there did not appear to be any obvious pattern other than when Y became overwhelmed or distressed.

40. The Health Board said that, each time Y displayed self-injurious behaviour, she was checked by both nursing and, if indicated, medical staff, to ensure Y did not require further medical input for any injuries she may have sustained.

41. The Health Board said there was no delay in the diagnosis of Y's eye condition. When nursing staff raised concerns regarding her eye on 10 September 2018, she was reviewed by the Doctor who felt that Y had a cataract in her right eye and required a review by an optician. The findings were also escalated to the Consultant. He was concerned that Y may have sustained a detached retina due to the development of a traumatic cataract.

42. The Health Board said that, before 10 September 2018, there were no clinical indications that Y had sustained a detached retina and there were no signs or concerns regarding Y's right eye and vision. It said that, if staff had been concerned regarding any changes to Y's eye prior to this date, they would have sought an immediate medical review, which was requested as soon as a change in Y's eye became apparent.

43. It confirmed that Y was reviewed at the Hospital Eye Unit on 12 September 2018. She had sustained a total right eye retinal detachment and surgery would be unlikely to restore her eyesight.

44. The Health Board confirmed that yearly eye assessments were recommended for Y.

Further response to investigation

45. After identifying entries in Y's records in June relating to her right eye (paragraphs 20-22), I asked the Health Board what action it had taken to address the reported concerns. It said that the nursing entries in the medical notes during June 2018 documented issues with Y's right eye and the requirement for follow up. This did not happen. It said it was likely that staff continued to review Y's eye regularly and would have documented any

changes with her right eye. However, it said that there was poor documentation regarding this matter from June 2018 onwards. The Health Board said it wished to apologise to Y and Mrs X for the poor documentation and their lack of robustness.

46. The Health Board also apologised that a medical review was not initiated in June 2018 when concerns were raised regarding Y's right eye. It said that Y did not indicate there were any issues with her eye at this time.

47. It said the clinic letter from the Consultant Ophthalmologist following a review on 14 September 2018 noted that Y sustained a detached retina 2 to 4 weeks prior to her review in the Eye Unit and that she had a cataract in her right eye also.

Professional Advice

Mental Health Adviser

48. The Adviser was satisfied that the standard and quality of Y's specialist care at the Unit for her autism, learning disability and mental health problems, including her challenging behaviour, was of a good standard, and in line with national guidelines as were Y's care plans and behavioural support plans, namely:

- The First NICE Guideline - the clinical records showed that staff understood the risks associated with Y's challenging behaviour and how it would escalate quickly and with little warning, and how staff needed to respond to that behaviour.

- The Second NICE Guideline – there was evidence of rigorous risk assessment and comprehensive care planning where Y's areas of risk were regularly assessed and reviewed.

- The Framework – the team clearly recognised and responded to Y's severe and complex behavioural issues and had implemented a robust evidence-based behavioural support plan which was comprehensive, detailed and meaningful by identifying proactive strategies to improve Y's quality of life, addressing her problems and promoting positive behaviour.

- The NMC Code – with the exception that Y's eyecare was not in line with the fundamentals of care.

- The Code – the care was being delivered to Y in line with the best interests principle, including where Y lacked capacity to make decisions in her own interests.

49. The Adviser noted the clinical records provided evidence of continuous recording of events and detailed reports of how staff met Y's daily needs and how they responded to Y's frequently challenging behaviour, including the professional techniques and approaches employed to care for Y and to manage her behaviour.

50. However, the care provided to Y following the documented eye issues was not within the range of acceptable clinical practice. The monitoring of Y's eyes in June 2018 fell short of what was expected of Registered Nurses. He said there was no evidence that staff actively monitored Y's eyes or that they took appropriate action such as escalating these observations to medical staff. This fell short of delivering the fundamentals of care to Y (see paragraph 10). In addition, the Adviser would have expected to see a clear care plan that specifically addressed the risk of injury to Y's eyes considering her ongoing self-injurious behaviour (e.g. slapping her face and thumping her head).

51. The fact that staff had noted that Y's pupils were unevenly dilated with the pupil of the right eye appearing to have a grey shadow should have caused alarm. The Adviser said the seriousness of the potential consequences of injury to a person's eye could not be understated. He would have expected all Registered Nurses to recognise the seriousness of injury to a patient's eyes. The Adviser would have expected the Registered Nurses and Medical Practitioners to have made a priority Ophthalmology referral without delay.

52. The Adviser said the NAS and SeeAbility advice recommended regular eye tests. He said this was even more important in light of Y's self-injurious behaviour to her face as the risk of harm / injury to her eyes was increased. He said that Registered Nurses and Medical Practitioners should follow this advice to ensure their patients were able to access regular eye tests / eye health checks. He said this would have been in line

with the NMC Code's fundamentals of care and the recommendations from the NAS and SeeAbility advice. However, Y did not benefit from regular eye tests as recommended. The Adviser was unable to say whether regular eye tests could have prevented or mitigated the problems Y experienced with her eyes.

53. The Adviser noted the Health Board's comments about the poor documentation of Y's eye care in June (paragraph 45). The Adviser said the clinical records did not, in his opinion, indicate that staff deliberately neglected to provide the fundamentals of care to Y, but that staff did not recognise the seriousness of the clinical situation and how Y's self-injurious behaviour presented a continued risk of harm to her eyes. The Adviser believed the failure to properly monitor Y's eyes was not necessarily just an issue of poor, or insufficient, documentation, but was more likely an issue of inadequate monitoring and not taking timely action by referring Y to an ophthalmologist. He said the Health Board assumed that it was likely that staff continued to review Y's eye regularly, but there was no evidence to support this.

54. In summary, the Adviser was critical of the care provided in June on the basis that:

- The eye care Y received was inadequate and not in line with the NMC Code fundamentals of care.

- Despite a clinical concern being identified about Y's eye, the subsequent monitoring of it was ineffectual and timely action was not taken. All Registered Nurses should ensure that the clinical practice of monitoring a patient's physical condition is evidence-based and consistent and that any concerns are communicated to senior clinical staff without delay for appropriate clinical action. This did not happen in Y's case.

- The NAS advice for regular eye tests was not followed.

- Staff did not act in an open and transparent way with Mrs X as they failed to keep her properly informed about Y's eye injury.

Consultant Ophthalmology Adviser

55. The Adviser noted that an incident of poking of the eye was noted in Y's records on 13 June 2018, with observations on 25 June and 27 June noting dilated pupils and the latter entry, a grey shadow on the right eye. He noted that a later medical review on 27 June, by the Consultant, made no reference to Y's pupils or the shadow noted earlier in Y's notes that day. He noted 12 further medical entries between 2 July and 4 September; these made no reference to Y's pupils or the grey shadow on her right eye, but it was unclear if Y was physically seen during these medical reviews, or had her case discussed only.

56. The Adviser said it was possible that Y may have been developing a problem with her vision in June, but that it would be impossible to establish what exactly this was, owing to the difficulty in differentiating Y's challenging behaviour due to her autism from that resulting from her inability to express symptoms of reduced vision. The ability to determine what the problem may have been was further compounded by the fact that there was no record of Y's spectacle prescription for the affected right eye at that time.

57. In terms of the single incident of poking her eye (on 13 June), the Adviser said it could have been one of three things:

1. It contributed to the development of retinal detachment.

2. A behavioural display of worsening vision, which is not uncommon in adults with learning difficulties.

3. Part of Y's well-documented pattern of behaviour.

58. The Adviser said that, for a cataract to develop within hours or days, this typically required a penetrating eye injury. He said the descriptions of the altered shape of the pupil and "grey shadow" were more in keeping with a retinal detachment having occurred with the subsequent chronic inflammation causing the iris of the right pupil (the coloured part the eye) to give the altered pattern compared to the left eye. He said this chronic

inflammation (which is associated with the detached retina), is what led to the development of the cataract to the extent that it started to become visible, initially as a grey shadow that progressed to the dense (hypermature) cataract noted at the Hospital Eye Unit.

59. The Adviser also said it was possible that, with repeated injury to the right side of the head, especially with the increasing severity of the self-injurious behaviour, that Y may have developed a mild inflammation in the front of the eye. This could have been mild enough not to be detected unless a patient reported symptoms of pain, blurred vision or sensitivity to light. The Adviser said that, untreated, this could contribute to the pupil shape and cataract, irrespective of there being any retinal detachment.

60. The Adviser said there was a delay in diagnosing Y's cataract and retinal detachment. This delay was broadly two-fold:

- Patients with learning difficulties may be unable to verbalise symptoms which was exemplified by Y's tooth pain and wobbly tooth being easily understood and acted upon. Her visual loss was painless, and she may not have noticed it as she was able to maintain her visual behaviour with the vision in the left eye.

- The lack of experience of those caring for her in dealing with eye problems which was evidenced from the documentation of distorted pupil and "grey shadow" in a patient with a history of self-injury. Given the well-documented history of self-injury, the eye symptoms in June should have been reported and they required an eye examination by the medical team. If a medical examination of Y's eyes was impossible due to challenging behaviour, a number of other options would have been available including a domiciliary visit by the optician or, if this was unavailable, a referral to the local hospital eye service should have been arranged.

61. In terms of the impact on Y of the delayed medical review / referral, the Adviser said:

- The delay in diagnosis was weeks to months and that it would be impossible to be any more precise than that.

- It was impossible to know for certain if an earlier referral to the Hospital Eye Unit would have resulted in a different outcome. He said retinal detachment amenable to surgery was not guaranteed to work; surgery has a failure rate and side effects. There would also have been additional challenges in terms of Y's compliance with post-operative instructions.

62. The Adviser said that Y's case illustrated the difficulties encountered when a patient exhibited significantly challenging behaviour demonstrated by the frequency and severity of self-injury in addition to the inability to verbalise symptoms. Whilst eye conditions were generally difficult to manage by non-ophthalmic professional groups due to lack of familiarity (and the NICE Pathway annual health checks do not specify eye checks, although the Health Check does), Y's case uncovered a deficiency of education and training in relation to the relevance of eye signs, as well as the need to pay attention to following through on correctly identified clinical signs to ensure they are communicated well, documented adequately and resolved so that appropriate action was taken. This was especially pertinent given that current data suggested that eye problems affect a significant proportion of adults with special needs. He said one of the difficulties in the absence of clear history of eye symptoms is how to measure vision reliability and that a functional vision assessment tool (such as the one available by SeeAbility) could be used by staff as part of a patient's annual review or in an acute or new scenario.

Analysis and conclusions

63. In reaching my conclusions I have taken account of Mrs X's and the Health Board's submissions, alongside the relevant records. I have also been assisted by the advice and explanations of the Advisers. The advice I have received is clear, which is why I have set it out in some detail above. Whilst I accept the advice in full, the findings below are my own.

64. It is clear from the advice that Y received good care in terms of planning and delivery to meet her specialised needs in relation to her learning disabilities (see paragraphs 48-49). However, there were serious

shortcomings in the care Y received in June 2018 relating to her eye management. Whilst staff noted concerns which required monitoring, there is no evidence that this took place or that these concerns were escalated to clinical staff.

65. Although it is possible that Y's retinal detachment occurred in June, I cannot say with any certainty that an earlier referral for ophthalmology advice would have resulted in a different outcome. Nevertheless, the failure to monitor Y's eye or refer for specialist advice in June was a service failure and furthermore was not in line with the NMC Code requirement to provide fundamentals of care. Therefore, I am clear that Y, a vulnerable young adult, was denied the opportunity of a timely referral and clinical review and this was an injustice.

66. It is also apparent that communication with Mrs X about Y's eye condition was inadequate and the records do not support that the Unit kept her updated. This was a serious communication failure and meant that when Mrs X received a telephone call in September to advise her of the situation with Y's eye, it came as a shock to her and caused her alarm. The failure to inform Mrs X of these concerns caused her distress and was an injustice to her.

67. In addition, the uncertainty about the outcome is a significant injustice to Y who did not receive an appropriate level of eye care. It is also a considerable injustice to Mrs X as there will always be an element of doubt about whether the outcome could have been different for Y who ultimately lost sight in her right eye. I **uphold** the complaint.

68. Although I have not specifically investigated the Health Board's handling of Mrs X's complaint, it is appropriate for me to comment on it in the context of my findings. The Health Board's investigation failed to identify that Y's eye care in June 2018 fell far below the standard expected from healthcare professionals. It told Mrs X (and my office initially) that, up until 10 September, staff had not been concerned about Y's eyesight. This was clearly not the case. I am pleased the Health Board acknowledged the failings identified in my report when I raised concerns with it about the June entries in Y's records. However, had the Health Board investigated Mrs X's

complaint in accordance with the principles of the PTR Guidance and my Guidance (paragraphs 15 & 16), it would have identified the shortcomings in Y's eye care and would have been able to take action to learn lessons from her care much sooner.

69. Whilst it is not for me to determine whether there was a breach of Y's human rights, and as it is uncertain if the outcome would have been different had she been referred immediately, it is important I comment on it in this case. It is recognised that individuals who are in institutional care settings are amongst the most vulnerable in our society and are amongst the most vulnerable to having their human rights compromised. It follows that there is an extra level of responsibility on public bodies to ensure that policies and practices respond appropriately to the needs of the vulnerable (both corporately and by individuals).

70. The failing in this case, in my view, engages Y's Article 8 rights. The Health Board has not sufficiently demonstrated that it ensured the needs of an adult with a learning disability, such as Y who was unable to effectively articulate her vision problems, were sufficiently respected. Had this been properly considered at the time, Y would have been referred in a timelier way. I ask that the Health Board reflects on what happened in Y's case to avoid a repetition with other vulnerable people in its healthcare settings and take forward my recommendations.

71. Finally, Y's learning difficulties were such that she was completely dependent on those who cared for her to ensure that she received a good standard of care and intervention. Her vulnerability should have placed a greater onus on staff to satisfy themselves that the symptoms she displayed were investigated further. It is in this context that I am issuing this report as a public interest report because there are wider lessons for all bodies within my jurisdiction who care for vulnerable adults with learning difficulties to learn from this case. They are amongst the most vulnerable in our society and it is arguable that public bodies should be more vigilant to ensure their needs are met, especially when their vulnerability may make it more difficult for them to articulate or express concerns.

Recommendations

72. I **recommend** that, within **1 month** of the date of this report, the Health Board:

a) Provides Mrs X with a written apology for the failings this investigation has identified.

73. I further recommend that, within **3 months** of the date of this report, the Health Board:

b) Refers the report to the Board, and the Health Board's Equalities and Human Rights team to identify:

i) how consideration of human rights can be further embedded into clinical practice

ii) relevant human rights training for Registered Nurses on the Unit (and across the Health Board).

c) Arranges for a copy of this report to be shared and discussed at the next Learning Disabilities Service monthly meeting using this case as a learning event to consider:

iii) adopting the SeeAbility functional vision assessment tool as part of a patient's annual review or in an acute or new scenario

iv) arranging training for staff on the Unit from the Health Board's Ophthalmology Department on the importance of identifying and escalating any concerns relating to possible eye injuries

v) a mechanism for ensuring that patients are accessing regular eye tests / eye health checks in line with the NAS and SeeAbility advice and the Health Check and NICE Pathway

vi) arranging training for Registered Nurses on the Unit to take into account relevant advice, such as the NAS and SeeAbility advice, to inform them of the importance of good eye care for learning disabled and autistic patients, especially where those patients' behaviour includes self-injurious behaviour.

d) Arranges for a copy of this report to be shared and discussed with members of the medical and nursing team involved in Y's care using this case as a learning event to highlight the importance of / remind them:

vii) to follow the NMC Code around providing fundamental of cares to patients' physical healthcare needs, which includes eye care

viii) to remind the team of the importance of being open and transparent with relatives of patients in reporting patients' injuries and serious incidents to their family

ix) to ensure that the clinical practice of monitoring a patient's physical condition is evidence-based and consistent and that concerns are escalated without delay to senior clinical staff for appropriate action.

e) Provides documentary evidence to show that the recommendations have been carried out within the stipulated timescales.

74. I am pleased to note that in commenting on the draft of this report **Swansea Bay University Health Board** has agreed to implement these recommendations.

Nick Bennett 17 September 2020
Ombudsman

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