Hutt Valley District Health Board

A Report by the

Health and Disability Commissioner

(Case 10HDC00396)

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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Executive summary

1. This case relates to the care provided to Ms A in 2009/2010. Ms A, who had an intellectual impairment, lived at home with her parents with the support of a disability support service, which had been contracted by a needs assessment agency.[1] Ms A frequently contacted emergency services declaring that she intended to kill herself because she did not want to continue living with her parents. The disability support service was attempting to find an alternative residence for Ms A.

2. Between 2007 and the time of her death in 2010, Ms A came to the attention of the police and the Hutt Hospital Emergency Department (ED) on numerous occasions for self harming or when she was picked up wandering at night. She had been seen on many occasions by the Hutt Valley District Health Board (HVDHB) Crisis Assessment and Treatment Team (CATT) on referral by the police or ED. On each occasion Ms A was assessed as not having a mental illness and being at low risk of self-harm. Her behaviour was attributed to her intellectual impairment and her desire to find alternative accommodation.

3. Ms A had several previous claims with ACC between 1990 and 2007. In early 2009, Ms A lodged another claim with ACC. The disability support service supported her in making a further ACC claim so that she could receive counselling. As a result of Ms A's previous health history, Ms A's GP prescribed her fluoxetine[2] for depression.

4. In the course of the ACC assessment of Ms A's claim, Ms A was assessed by a clinical psychologist, who declined to provide counselling for Ms A and recommended a referral for counselling for Ms A be made "via the psych services contract" due to the need for specialist intervention. The psychologist recommended that there would be a need to work outside counselling with community agencies, and the GP, to effect referral to the dual diagnosis team[3] (mental health/ID).[4]

5. Later in the year, ACC obtained a psychiatric report which identified that Ms A had several Axis 1 disorders[5], the major diagnosis being Panic Disorder. The psychiatrist noted that Ms A's fluoxetine may need to be increased. The psychiatrist did not agree with previous opinions that the underlying cause of Ms A's erratic behaviour was her intellectual disability. These reports were not provided to HVDHB.

6. Over the next two months, Ms A presented frequently to CATT. On two occasions she self-harmed. The disability support service found her respite care for several days.

7. A few months later, Ms A again came to the attention of CATT and the Police when she reported taking an overdose of medication. She was assessed at ED and

[1] An organisation that assists people with health and/or disability impairment to live in the community by providing a range of support services
[2] Also known as Prozac, this is an SSRI (selective serotonin reuptake inhibitor) anti-depressant.
[3] A specialised team within the mental health service which provides assessment and then advice to the wider mental health service.
[4] Intellectual disabilities.
[5] Common Axis 1 disorders are depression, anxiety, bipolar, autism and eating disorders.

arrangements were made to take her home to her parents, but Ms A left the ED before the arrangements could be finalised.

8. The following day, the police found Ms A wandering. She was assessed by CATT at the police station and cleared for release. Ms A was returned home by the police, but immediately ran away. Sadly, her body was found a short time later.

Decision

9. A number of agencies were involved in Ms A's care, but no one agency took the lead role. Multi-agency involvement and a failure to share information compromised Ms A's care.

10. Ms A's clinical records repeatedly note "no evidence of mental illness". Providers involved in Ms A's care believed her presentations were "learnt behaviours" rather than symptoms of mental distress and viewed her escalating risk behaviours as being purely related to her intellectual disability.

11. HVDHB acknowledged that diagnostic overshadowing was a possible feature in this case which, together with the mental health service's differing levels of expertise in identifying mental health issues in people with an intellectual disability, resulted in the service failing to adequately assess Ms A and appropriately refer her to a dual diagnosis team.

12. HVDHB failed to identify a lead provider, recognise the differing levels of expertise of its staff, provide appropriate dual diagnosis guidance to its CATT staff and thus ensure a referral to another DHB's dual diagnosis consult-liaison team. These failures resulted in Ms A not being provided with services with reasonable care and skill. Therefore HVDHB breached Right 4(1)[6] of the Code of Health and Disability Services Consumers' Rights (the Code).

Outcome

13. HVDHB has acknowledged that it should have been the agency to identify a lead care provider for Ms A, and has provided a written apology to her family.

14. HVDHB has also introduced *Guidelines for the assessment and treatment of Dual Diagnosis – the presence of mental illness and intellectual and/or physical disabilities*, to ensure best practice approaches for HVDHB Mental Health and Addictions staff. Teaching sessions in this topic are planned and a Memorandum of Understanding to strengthen existing work practices and relationship across the DHBs is being developed.

[6] Right 4(1) of the Code states, "Every consumer has the right to have services provided with reasonable care and skill".

Complaint and investigation

15. On 7 April 2010, the Commissioner received a complaint from Mrs B about the services HVDHB provided to her sister Ms A. The following issues were identified for investigation:

- *The appropriateness of the care provided to Ms A by HVDHB over a period of nine months in 2009/2010.*

16. An investigation was commenced on 24 August 2010.

17. The parties directly involved in the investigation were:

Ms A (dec)	Consumer
Mrs B	Complainant
Mr C	Complainant
HVDHB	Provider

Also mentioned in this report:

Ms D	Neuropsychologist/clinical psychologist
Ms F	Disability support service co-ordinator
Ms G	Needs assessment agency co-ordinator
Ms H	DHB2's Regional Service Administrator NASC liaison
Mr I	DHB Community Forensic & Justice Liaison Nurse
Dr J	Consultant psychiatrist
Dr K	DHB2's Central Forensic Mental Health Service consultant psychiatrist
Ms L	Consultant psychologist
Dr M	Clinical psychologist and ACC counsellor
DHB2	A DHB in a main centre

18. Information was reviewed from:

Mr C
Mrs B
HVDHB
A needs assessment agency
Dr E, GP
ACC
A telephone support service
Garry Evans, Wellington Coroner

19. Independent expert advice was obtained from independent psychiatric nurse Ms Bernadètte Paus. Ms Paus' expert advice is attached as **Appendices A and B**.

Information gathered during investigation

Background

20. Ms A suffered brain damage from a brain aneurysm shortly after birth. She had developmental delays, and when she started school it was noted that her abilities were not at the level of her peers. Ms A left school with only basic writing and mathematics skills, and limited reading skills. She was described as having a functional level of an eight to ten year old, no concept of money management and limited reasoning ability. She was assessed as having a mild intellectual impairment. While Ms A was able to make basic choices, she was reliant on other people to make more wide-reaching decisions.

21. Ms A suffered from anxiety when faced with unfamiliar situations and needed support and assistance when making any form of transition. Ms A was able to articulate some understanding of her situation, but when she became frustrated, angry and upset this ability would disappear.

22. Between 1990 and 2007, Ms A made several claims to ACC and, an incident in 2009, led to her making a further claim to ACC for funding for counselling and support.

23. Part of the reason for Ms A's distress was the need to find alternative accommodation. Ms A lived at home with her parents, and did not wish to remain living there. The disability support service[7], was attempting to find an alternative home for her.

24. Ms A's distress presented as self-harming behaviour and overdose attempts, and she was well known to the emergency services – the police and ambulance service. Ms A also frequently contacted telephone counselling services when distressed.

HVDHB mental health service

25. HVDHB provides mental health services for people who have an identifiable or suspected psychiatric disorder that has a significant impact on that person's ability to function, or which is likely to result in long-term impairment. The services provided include acute inpatient care, crisis assessment, community care and treatment.

26. The HVDHB Crisis Assessment and Treatment Team (CATT) provides crisis assessment and short-term follow-up of clients. The team also arranges respite care.

Contact with CATT

27. Ms A was first seen by HVDHB CATT in December 2007, at the request of the police. Ms A had gone to a facility seeking accommodation and, when she refused to leave, the police were called. The police asked CATT to assess Ms A. Ms A denied suicidal ideation, and advised the CATT nurse who was assessing her, that she hated living with her parents. The CATT assessment of Ms A at that time was that she had a "mild intellectual disability", but showed no sign of any mental illness. The nurse

[7] The disability support service is a community-based disability service which provides support to people living in the community. Referrals to the disability support service usually come through a Needs Assessment Service Co-ordination (NASC) agency

noted, "As there were no [mental health] or safety issues she was left [in the care of the] Police for their disposition".

28. Ms A came to the attention of CATT on numerous occasions during 2008 when she was picked up by the police when wandering at night. At other times she self harmed and made suicide threats.

29. On 29 August 2008, Ms A was assessed by a psychiatrist at HVDHB after she had swallowed a coin, some alcohol and some of her mother's pills. The psychiatrist recorded that he contacted the needs assessment agency, who informed him that Ms A had been assessed by the Intellectual Disability (ID) Mental Health Service[8] as having no mental illness. The psychiatrist also concluded that Ms A did not have a mental illness.

Psychologist review

30. On 20 September 2008, the needs assessment agency contracted a private neuropsychologist/clinical psychologist, Ms D, to undertake a cognitive assessment of Ms A. Ms D's brief was to evaluate Ms A's cognitive strengths and weaknesses, and to establish the extent of her intellectual impairment. The aim of the assessment was to provide suggestions to assist the disability support service, the agency contracted to support Ms A, in managing her care.

31. Ms D noted that Ms A's intellectual capabilities placed her within the "mild intellectual disability" range, and the primary concern was Ms A's very limited coping skills when she was angry, upset or wanting attention from others. Ms D cautioned that anyone supporting Ms A would need to ensure that she did not misinterpret or have an over-expectation of what was said or implied. The key recommendation was to develop a behavioural management programme with the help of a clinical psychologist with experience in intellectual disability, and to include the police in the implementation of the programme so there would be an agreed joint approach. It is not clear whether this eventuated. In November 2008, the disability support service formulated a Risks and Vulnerability Identification Management Plan for Ms A's carers to follow.

Events in 2009

32. In early 2009, Ms A reported to the disability support service manager about an incident. Ms A was advised to report the incident to the police, a doctor and her parents. She was unable to make a decision about reporting the incident, so she was taken home to decide what she wanted to do. It appears that, after she went home, Ms A told her neighbour about the incident, and the neighbour advised Ms A's father, Mr C. Ms A was examined by a doctor who referred her to the appropriate agency.

33. The disability support service supported Ms A with her ACC claim in order to get ACC funded counselling for the incident.

[8] This assessment report has not been provided to HDC.

34. On 26 Month1, Ms A consulted her GP, Dr E, who considered that she was suffering from depression and prescribed her the antidepressant fluoxetine (Prozac) 20mg.

35. On 28 Month1, clinical psychologist and ACC counsellor, Dr M, assessed Ms A. Dr M recommended that a referral for counselling for Ms A be "via the psych services contract" as the agency, which Ms A's GP had referred her to, had declined to provide Ms A with rehabilitation because of the "complexity of the case". Dr M advised that she was not prepared to provide counselling unless this occurred because, "it will require a specialist intervention and considerable work outside of counselling to keep the boundaries clear between ACC's role and that of other agencies." Dr M noted, "Part of intervention would be to work with community support worker and GP to effect referral to dual diagnosis team[9] (mental health/ID)". Dr M recorded that the community social worker was trying to arrange an advocate for Ms A to assist her to move to supported accommodation. Dr M noted, "Client has ID (intellectual disability) but apparently does not have a Welfare Guardian".[10]

36. Dr M provided her report to ACC. HVDHB advised HDC that the Mental Health and Addiction Service did not receive a copy of Dr M's assessment, so it was unable to give consideration to Dr M's recommendation to refer Ms A to the Dual Diagnosis team. There is also no record of Dr M's report being provided to Ms A's GP or the disability support service.

37. Between Month5 and Month6 2009, Ms A became increasingly distressed. On 2 Month5 2009, Dr E increased Ms A's fluoxetine to 40mg a day.[11]

38. On 8 Month6 2009, Ms A appeared in court over her alleged misuse of a telephone, and her mobile phone was confiscated.

Further contact with HVDHB

39. On the night of 13/14 Month6, Ms A attended ED twice – at 1.30am, when she was brought in by the police with superficial scratches to her wrist, but absconded before she could be assessed – and by the police again at 2.30am when she was found wandering the streets. At the second attendance, Ms A stated that she did not want to be seen by CATT and wished to leave the ED. She refused to accept the advice that she should contact her mother and return home.

40. At 9.42am on 15 Month6 2009, the disability support service co-ordinator Ms F emailed Ms G, the needs assessment agency co-ordinator and Ms H, DHB2's Regional Service Administrator NASC liaison, to update them on Ms A. Ms F stated:

[9] A specialised team within the mental health service which provides assessment and then advice to the wider mental health service team members who provide follow-up care to people with intellectual disabilities. (HVDHB does not have a dual diagnosis team and refers to another DHB's (DHB2) team.)
[10] A person appointed by the Court to look after the care and/or protection of a person with an intellectual disability. The Court specifies the areas the Welfare Guardian has decision-making control over, and how long the Welfare Guardianship will stay in force (usually three years).
[11] Initial dose for persons suffering depression is 20mg orally once daily. The maintenance dose is 20 to 80mg a day in one to two divided doses.

> "I last spoke with a member of the CAT team at 7.45pm last night, at that time [Ms A] was being held at [the] Police station. The CAT team were not willing to assess [Ms A] as they were of the opinion that her behaviour was just that and a direct response to her cell phone being withheld, I expressed being of the same opinion but shared my concerns regarding [Ms A's] vulnerability and her history of walking the streets when in this state.
>
> …
>
> I have been informed this morning that [Ms A] was taken to hospital by ambulance last night at around 11pm, she had [harmed herself]. The hospital would not disclose the specifics of her injuries. [Ms A] left the hospital this morning when they called the police to arrange transport, she has just called the office from a phone box in […] and her support person is on her way to pick her up."

41. Ms F also emailed the HVDHB mental health services stating her concern that Ms A's risk had increased and that Crisis Respite[12] was needed. Ms F noted that she did not think Ms A would remain at home if alternative accommodation was not found for her. Ms F stated, "She has been in great distress and has gone to extreme measures to gather attention to herself."

42. A DHB Community Forensic & Justice Liaison Nurse, Mr I, who was supporting Ms A with her Court appearances, responded to Ms F's email, and agreed with her that referring Ms A to Crisis Respite, "May well help to de-escalate this situation and should be actioned as a matter of urgency i.e. today."

43. Ms F emailed Ms G, Ms H and Mr I again at 11.10am to advise that Ms A's support person, who had been looking for her for an hour, had picked her up after the disability support service received a call to say that Ms A was in a local bakery. However, Ms A jumped out of the support person's car (after she picked her up from the bakery) when it stopped at traffic lights on the motorway. Ms A was last seen heading towards Lower Hutt. Ms F noted, "[Ms A] is in a very distressed state".

44. At 1pm that day, Ms F sent a further email to Ms G, Ms H and Mr I to advise that Ms A had been brought into the disability support service's office by a family member. She was not willing to stay at her parents' home that night. Ms F asked that Ms A be accommodated in respite care that night. She noted, "[Ms A] has her dual diagnosis meeting with ACC in [the city] tomorrow and it is imperative that she be there to proceed with counselling. … She looks very fragile and I am most concerned for her. If anyone else has any idea as to how we could keep her safe tonight I welcome your suggestions."

45. Ms A was provided with crisis respite care for one night. the disability support service sought additional funding to enable her to stay in respite care longer, but the needs

[12] A short-term voluntary residential respite programme (maximum of 7 days) for people aged 5-19 years who experience mental health and/or addiction issues.

assessment agency declined the funding on the grounds that there were other cheaper respite care providers, although those providers had no vacancies.

ACC Psychiatric assessment

46. On 16 Month6 2009, Ms A was assessed by consultant psychiatrist Dr J, for ACC, to ascertain whether her current condition was due to her previous medical history, and to provide clear treatment indications. In her report of 19 Month6, Dr J noted that Ms A had extensive contacts with psychiatric emergency services, and the emphasis on these occasions was on her intellectual disability and a diagnosis of a personality disorder, not on any possible underlying anxiety disorder. Dr J noted that Ms A's intellectual disability was thought to be the cause of her erratic behaviour. Dr J said, "I do not believe this". She stated that Ms A suffered from several Axis I disorders − she had been successfully treated for depression and met some criteria for post traumatic stress disorder, "but the major diagnosis seems to me to be Panic Disorder".

47. Dr J summarised her report stating that the most pressing treatment was Ms A's panic attacks. She noted that Ms A's fluoxetine may need to be increased to enable her to process her thoughts and make more sensible decisions. Dr J also recommended that Ms A have counselling from a clinical psychologist once her panic attacks were under control. She concluded by noting, "Her doctor has asked for a copy of my report, as have the support workers. I am happy about this, as I think that the sooner everyone involved is singing from the same song-sheet, the better for [Ms A]." Dr J's report was provided to GP Dr E and ACC, but not to HVDHB.

Further contacts

48. On 16 Month6 Dr E increased Ms A's fluoxetine to 60mg a day and introduced Metoprolol Tartrate,[13] 100mg a day.

49. On 17/18 Month6, Ms A was twice taken to ED by the police. The first presentation was at 3.15pm. On this occasion Ms A left the department before any arrangements could be made for her care. She was found wandering the streets by the police at 12.03am on 18 Month6. Ms A was threatening to kill herself, so the police returned her to the ED. Ms A was seen by the psychiatric registrar on this occasion, who noted that she could stay in the ED until her parents could be contacted at a "reasonable time" to uplift her. It was planned to contact the needs assessment agency's social worker later that morning regarding ongoing plans for Ms A's management.

Community support

50. On 20 Month6 2009, following a meeting between representatives from the disability support service, HVDHB, CATT and a residential service for people with intellectual impairment, further respite care was arranged for one night.

51. On 27 Month6, Ms G from the needs assessment agency wrote to the disability support service to advise them that, "In spite of all efforts I have been unable to secure a respite or permanent placement for [Ms A] at this time either here in Hutt Valley or in the [wider region]." Ms G noted that the residential service was not able to provide

[13] This is a beta-blocker, often used in the treatment of anxiety

residential care for Ms A for a few months, as they already had a full resident/staff commitment. However, the residential service was willing to work alongside the disability support service to provide some daytime support for Ms A with occasional night-time stays, which would be funded under respite, as a trial with a view to transitioning Ms A to residential care.

52. On 11 Month7 2009, Mr I emailed Ms F to advise her of the outcome of Ms A's court appearances for assault and misuse of a telephone. Ms A had been remanded to appear again on 19 Month9 2010. Mr I stated, "I understand that there has been a very short period of settled behaviour which seems to coincide with [Ms A] having her phone returned to her. … In [Month9] if [Ms A] has been settled & had no further police call outs the police may be willing to revisit this."

53. Community support staff involved in Ms A's care noted that her GP had prescribed fluoxetine for Ms A because the GP considered that she was suffering depression as a result of the incident in early 2009. It was noted that although this medication had helped her to some extent, the concern was that the underlying reasons for Ms A's depression had not been addressed, as she had not had the opportunity for appropriate counselling. An application was made to ACC for funding for counselling.

Further assessments

54. On 15 Month7, ACC requested that a clinical psychologist review Dr J's assessment of Ms A. The psychologist stated:

> "It is clear that this client's depressive experience would also be due to a combination of her poor general coping skills resulting from her intellectual disability as well as her concerns and responses to family tensions that are separate from [Ms A's medical history]. … It would be my opinion that this client's pre-existing intellectual disability continues to be the predominant reason for behavioural and emotional difficulties experienced by this client and would argue that these difficulties are common enough among intellectually disabled individuals that they can be reasonably expected."

55. On 15 Month8 2009, DHB2's Central Forensic Mental Health Service consultant psychiatrist, Dr K, and consultant psychologist, Ms L, assessed Ms A at the request of Mr I. They noted, "The recent emergence of post-traumatic symptomology is understandable in the context of [Ms A's medical] history described…" Dr K and Ms L noted that Ms A had been started on the antidepressant fluoxetine five months earlier by her GP because of concerns that she was depressed. It was noted that Ms A's mood was less negative since this medication was prescribed, but when her symptoms increased in early Month5 2009, the fluoxetine dosage had been increased to 40mg, and a beta-blocker was trialled. The recommendations Dr K and Ms L made "in terms of her mental health" were that:

> "[Ms A] remains under the care of her GP and is reviewed as necessary. Should a second opinion be required, a referral should be made to our team. Regarding medication, [Dr K] advises continuation of fluoxetine at current dose at least until [Ms A] is well established in her new residence and a decision has been made

> about ACC or other therapy, and at least for the next year. … We would recommend developing a management plan outlining [Ms A's] risks and vulnerabilities as well as expectations about how those involved in her care will respond.
>
> Once settled in supported accommodation it may also be helpful to review [Ms A's] need for counselling. Ideally this would focus on containment and coping strategies for any ongoing symptoms and behaviours of concern. This will require a clinician experienced in working with clients with intellectual disability as well [clients who share similar medical history as Ms A]."

56. The report was sent to Dr E and Mr I. HVDHB advised HDC that their Mental Health and Addiction Services were not aware of this report.

CATT contacts

57. On 30 Month8 2009, Ms A presented to CATT stating that she was upset about a telephone call she had made that day to a telephone counselling service in which she had become abusive. Ms A believed that she might be banned from contacting the service and stated that she intended to self harm. The record states that Ms A was "well known" to CATT and her presentation was "behavioural in nature and no diagnosis of any mental illness". She was escorted home to her parents and the situation settled after Ms A received a clarifying text from the telephone counselling service.

58. On 2 Month9 2010, CATT was called to the HVDHB mental health unit to assess Ms A, who had self-presented. Ms A had presented earlier that day to the ED reporting that she had overdosed on her father's medication. Ms A was assessed by the ED and, at discharge, offered the bus fare to go home, which she declined. CATT staff intended to offer to take Ms A home, but she left at 11.20am before these arrangements could be finalised.

59. On 3 Month9 2010, at 1.50pm, CATT was contacted by the police. Ms A had been located by the police. She was wet, muddy and cold, and was taken to the Police Station. The record notes "Upper Hutt [police] insisting on CATT despite CATT advising [Ms A] be returned home".

60. CATT staff spoke to Ms A and noted:

> "Seen @ [the] Police Station. [Ms A] continues to put herself @ risk with self harm type behaviours as a protest because she does not want to be living with old people (her parents). [Ms A] claims to have been promised a place to live but feels let down by ID Services as this is not happening soon enough. Her parents who are her current welfare guardians appear to have no control over her current behaviours.
>
> Apparently [Ms A] has had her cell phone returned to her (after having had it removed due to misuse) and there appears to be a subsequent ↑ in contacts with emergency services and helping agencies ([telephone counselling service]). It

> appears she is using [the telephone counselling service] inappropriately, taking OD father's medications night before last and other contacts with [Police in two areas].
>
> CATT to liaise with [Ms H] Tuesday in an attempt to find out current status re finding secure placement for [Ms A]. [Ms A] will continue to act out meanwhile."

Ms A's death

61. Ms A's sister, Mrs B, advised HDC that when the police dropped Ms A off at home, she ran off. When Ms A had not returned home at 9pm, Mr C contacted the police to report Ms A missing. Mr C thought that this was a serious matter, because he usually heard from one of the emergency services within a few hours of Ms A running away. The police declined to attend.

62. At 8am the next day, Mr C telephoned Mrs B to say that her sister was not home and asked for assistance to look for her. Mrs B and Mr C went to where Ms A had been located by the police the previous day.

63. Sadly, Ms A's body was found at 7pm the following day.

Additional information

Expert Opinion

64. HDC asked independent psychiatric nurse Bernadètte Paus to review the care provided to Ms A and advise whether the appropriate standards had been met. A copy of her preliminary advice is attached as **Appendix A**.

65. Ms Paus noted that prior to 2008, Ms A had a standard home-based community support package which funded community support workers from the disability support service service to have allocated time to support her while she lived at home with her parents. When her behaviour started to escalate in 2009, the disability support service applied for her to be reassessed for a higher level of support hours and in particular for a support package that would allow her to leave home and move into a supported flatting situation. The Needs Assessment agency conducted an assessment and identified that the need for Ms A to find alternative accommodation was a priority.

66. Ms Paus stated that it is well understood that mental health problems can be difficult to recognise and diagnose in people with intellectual disabilities. Ms Paus advised that she considers that Ms A's situation was a case of "diagnostic overshadowing", which is the tendency of clinicians to overlook mental health symptoms in a person with an intellectual disability. They view the presenting behaviours as part of the intellectual disability, rather than a symptom of mental illness, which results in the person with the intellectual disability receiving a level of service below the optimal standards.

HVDHB's response

67. HVDHB was provided with a copy of Ms Paus' preliminary advice and asked to comment.

68. HVDHB advised that it does not have a Dual Diagnosis mental health service, but is able to access the Dual Diagnosis Service through a regional contract with DHB2. Dr M's and Dr J's reports were not made available to HVDHB mental health services. The DHB stated that without these assessment reports the service was unable to implement the recommendations arising from the reports.

69. HVDHB advised that Ms A presented with an intellectual disability component to her presentation. The DHB noted that no comprehensive management plan was developed for Ms A, and that "no evidence of mental illness" can be seen repeatedly in Ms A's file. The DHB stated "The crisis team could have asked more comprehensive questions of Ms A and certainly of her family when she presented in order to inform a specialised impression. At the time, the assessment was not as comprehensive as it could have been".

70. HVDHB acknowledged that the CATT doctor did not see Ms A at any time, nor was she referred to community mental health for consistent follow-up. HVDHB stated, "It is not clear that all of the service staff involved had an understanding of the complexities of intellectual disability as a solitary diagnosis, or as a dual diagnosis". The DHB supported Ms Paus' comment about "diagnostic overshadowing" as being a possible feature in this case, and acknowledged that this phenomenon, alongside differing levels of expertise in identifying mental health issues in someone presenting with an intellectual disability, may have contributed to the presentation of some of Ms A's symptoms being misinterpreted or missed.

71. HVDHB noted that it is apparent that there was multi-agency involvement in Ms A's care and it is difficult to establish which was the lead agency. The various agencies were aware of only parts of her care and no agency had the whole picture. As a result, Ms A's care co-ordination, management planning and care delivery were not linked appropriately, nor adequately explained to her family. It was noted that a placement in a house had been found for Ms A. It was expected that a vacancy would arise later that month, but the unfortunate events that unfolded meant that she never moved into this accommodation.

72. The DHB provided details of the measures that have been taken to improve its service as a result of this case. Those changes are:

- HVDHB Mental Health and Addiction Service is developing a set of guidelines to follow when working with a person with both mental illness and intellectual or physical disabilities, who is presenting with multi-agency involvement. The guidelines will ensure a co-ordinated approach to care delivery, identification of the lead agency, clear lines of communication and articulation of responsibilities, and enable the development of one plan with the client and family.
- A single point of entry service is being implemented (to be known as the Mental Health and Addiction Service Access) to provide a timely and consistent response to those requiring services whilst meeting the client and family cultural needs in assessment and treatment.

- The Access Service aims to have increased integration with the community by employing extra staff specifically to broker internal and external relationships.
- The DHB has a five-year strategic plan for Mental Health and Addiction Services. During the development of the plan, participants are to be asked what is working well and what is not, and what can be done in the short, medium and long term to improve mental health and addiction services in the region. One of the actions is to develop a model that will smooth pathways and ease access of the community to the service, so that staff, clients and families have clear expectations and agreed goals.

Responses to provisional opinion

Mr C

73. In his response to the provisional opinion, Mr C stated that no one from CATT ever came to the house to speak to him and his wife about Ms A. He said that he and his wife looked after her until 2007, knew the most about their daughter and should have been consulted.

74. Mr C said that Ms A was mentally a child in an adult's body. He stated that a lot of the people who looked after Ms A were well meaning, but seemed unaware that she had a "huge amount of mental illness" and, if they had spoken to him and his wife, they would have told them that.

75. Mr C said he believes that Ms A would never have wanted to leave home and would not have been able to cope if she did so. He said he believes that her anxiety about living at home was due to other people telling her that she was an adult and should not be living at home.

Hutt Valley DHB

76. In response to the provisional opinion, HVDHB stated that it accepts that it should have been the agency to identify a lead care provider for Ms A.

77. HVDHB stated:

> "The Crisis Assessment Treatment Team (CATT) has reflected on this case and has developed a Guideline for the assessment and treatment of Dual Diagnosis – the presence of mental illness and intellectual and/or physical disabilities. … These guidelines are intended to serve as a guide to best practice approaches for Hutt Valley DHB Mental Health and Addictions staff.
>
> The staff in the CATT wish to express their sincere condolences to the family of [Ms A] and apologise for their failure to adequately identify and respond to [her] needs.

> A meeting is scheduled during the week commencing 14 May 2012 with the Clinical Leaders of the Regional Dual Diagnosis Team and the Clinical Nurse Manager CATT to finalise dates for the next teaching sessions. They will also establish a Memorandum of Understanding to strengthen existing work practices and relationship across the DHBs."

78. HVDHB provided HDC with apology letters for Ms A's parents and sister. These letters were forwarded on 23 May 2012.

Opinion: Breach – Hutt Valley DHB

Introduction

79. There were a number of agencies involved in the management of Ms A, including the needs assessment agency, the disability support service, HVDHB mental health services and the police. Having considered all of the information provided, including the email correspondence between the various agencies, it appears that considerable efforts went into supporting Ms A and attempting to keep her safe.

80. My independent expert, psychiatric nurse Bernadètte Paus advised that if the behaviour of an intellectually impaired person is deteriorating, as was the situation with Ms A, the expectation would be that the relevant DHB's CATT team would assume the lead role and refer the person to the DHB's community mental health service (CMHS). She considers that the CMHS should then ensure the person receives a comprehensive assessment, most likely from a psychiatrist, and ongoing co-ordination through a case manager. If mental health issues are diagnosed, the assessment may result in a referral to a dual diagnosis team for assessment and recommendation of follow-up care. Thereafter, the dual diagnosis team should co-ordinate the person's care with the CMHS in a joint or collaborative process with the CMHS assuming the ongoing responsibility as the lead team.

81. HVDHB does not have a Dual Diagnosis Team. However, the DHB is able to access this service through a regional contract with DHB2.

Co-ordination of care

82. An important factor in this case was the lack of a single lead agency to co-ordinate Ms A's care. As a result, the care was fragmented and communication between providers was limited.

83. HVDHB accepts that Ms A's care co-ordination, management planning and care delivery were not linked appropriately. The multi-agency involvement and the failure to share information between and within agencies contributed to this situation. As a result, the DHB did not have the full picture and this compromised its ability to provide appropriate care to Ms A.

Failure to assess

84. HVDHB's CATT first had contact with Ms A in December 2007, when she became involved with the Police regarding an alleged trespass. The CATT nurse who assessed her at that time noted that Ms A had a mild intellectual disability, but showed no sign of any mental illness.

85. Throughout 2008, Ms A came to the attention of the Police and CATT on numerous occasions because of her self harming and other risk behaviours. On 29 August 2008, following a further episode of self harm, Ms A was assessed by a HVDHB psychiatrist. The psychiatrist concurred with the Intellectual Disability Mental Health Service's earlier assessment that Ms A did not have a mental illness.

86. In Month6 2009, it became apparent that Ms A's self-harming behaviour was escalating as her distress at having to live with her parents increased. HVDHB acknowledged that Ms A was not seen by the crisis team doctor at this time, nor was she referred to the community mental health team.

87. On 15 Month6 2009, the disability support service Co-ordinator, Ms F, emailed Ms G, the needs assessment agency Senior Service Co-ordinator and Ms H, DHB2's Regional Service Administrator NASC Liaison. Ms F expressed her concern about Ms A's safety and noted that the police had requested that CATT assess Ms A, but this request was declined because a CATT staff member considered "her behaviour was just that".

88. Ms F also contacted the HVDHB Community Forensic & Justice Liaison Nurse, Mr I, who was involved in Ms A's management because of her court proceedings, to advise him of her concerns for Ms A. As a result, there were a number of emails between the agencies and Ms A was provided with crisis respite accommodation for that night.

89. On 17 Month6, Ms A was taken to Hutt Hospital ED by the police who found her wandering the streets, but she absconded before being assessed. On 18 Month6 the police again took Ms A to the ED, where she was seen by the psychiatric registrar. Ms A was discharged to the care of her parents, with no further assessment or referral planned.

90. On 20 Month6, there was a meeting between representatives from the disability support service, HVDHB, CATT and the residential service for people with intellectual impairment to discuss Ms A's situation, and further respite care was arranged. However, efforts to arrange permanent residential placement for Ms A were unsuccessful because of a shortage of suitable residential beds.

91. On 15 Month8 2009, Mr I arranged for Ms A to be assessed by DHB2's Central Forensic Mental Health Service's consultant psychiatrist and psychologist. They reported that Ms A's "recent emergence of post-traumatic symptomology" was understandable given her previous medical history, and recommended that a plan to manage her risks and vulnerabilities be developed. Ms A was to remain under the care of her GP, continue on the prescribed antidepressant, and be reviewed as necessary. That report, which signalled that Ms A had developed symptoms of a mental illness,

was given to Mr I and Ms A's GP, Dr E. There is no record of it having been shared with CATT, or with HVDHB's mental health service.

92. Ms A's records indicate that many providers believed her presentations were "learnt behaviours" rather than symptoms of mental distress. It is repeatedly noted that there was "no evidence of mental illness". Ms Paus advised that this "set the scene" for the staff involved in her care to continue to believe that her issues were solely related to her intellectual disability.

93. Ms Paus noted Ms A's previous medical history and said it is not uncommon for people with such a history to suffer anxiety, panic and post traumatic stress disorder symptoms, such as self harming and hysterical over-reaction behaviours. She advised that most people with an intellectual disability have limited coping, interpersonal and communications skills and, if they become mentally unwell and attempt to communicate their distress, their presentation is often viewed as "acting out".

94. Ms Paus considers that Ms A received a sub-optimal level of service because of "diagnostic overshadowing". HVDHB has acknowledged that diagnostic overshadowing was a possible feature in this case. The DHB said that this factor, together with the "differing levels of expertise" of its mental health service staff in identifying mental health issues in people presenting with an intellectual disability, may have contributed to the deficiencies in Ms A's care.

95. In my view, the failure to appropriately assess Ms A as her behaviour escalated meant that the service provided to her by HVDHB was below an appropriate standard.

Summary

96. Ms A was not provided with the level of care she required, because there was a general belief among the persons supporting her that her behaviour was caused by her intellectual impairment and unhappiness at having to live with her parents, rather than any mental health issues.

97. The CATT staff failed to recognise that Ms A required a thorough assessment to determine whether referral to a team skilled in dual diagnosis issues was necessary. A contributing factor was the differing levels of expertise of the CATT staff with regard to mental health issues in people with an intellectual impairment.

98. As a result, Ms A was not reviewed by a CATT doctor when her behaviour escalated and there is no record of any consideration of whether she should be referred to DHB2's dual diagnosis consult-liaison team for assessment and recommendation of follow-up care.

99. In my view, HVDHB's failures to identify a lead provider, recognise and respond to the differing levels of expertise of its staff and thus ensure Ms A was appropriately assessed, resulted in Ms A not being provided with services with reasonable care and skill. Therefore, in my opinion, HVDHB breached Right 4(1) of the Code.

Recommendation

100. I recommend that HVDHB conducts audits on the implementation of the guidelines to follow when working with a person with both mental illness and intellectual disability and the Memorandum of Understanding across the DHBs and reports to HDC on the outcome of the audits by **30 June 2013.**

Follow-up actions

- A copy of the final report will be sent to the Coroner.

- A copy of the final report with details identifying the parties removed, except Hutt Valley DHB and the expert who advised on this case, will be sent to the Ministry of Health Mental Health Directorate and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Appendix A: Independent expert advice – Ms Paus

Bernadètte Paus, Nurse (Practitioner, RCpN; BN; MHSc) provided the following advice:

"Introduction
This report is being provided to the Commissioner following a request for independent expert advice on case number 10/00396 − complaint: against Hutt Valley District Health Board (DHB) […] The advice requested is for a preliminary opinion regarding the standard of care provided to [Ms A] by the Hutt Valley DHB […] to determine the need for further investigation. […]

Event
[In Month9] 2010 Ms A's body was found […]. This occurred after frequent contact with the Hutt Valley DHB's Mental Health Services (MHS) Crisis Assessment and Treatment (CAT) Team and following a period of increasing frequency and severity of self-harming incidents. At the time [Ms A] was also frequently contacting help-lines. She was also receiving support for independent living from the disability support service, a disability community support agency/NGO [non government organisation].

Summary of Relevant/Critical Background Information
[…]

In 2008 [Ms A] was referred to [Ms D] (neuro-psychologist/clinical psychologist) for a cognitive assessment. This evaluation assessed her as having a mild intellectual disability and anxiety related issues. It also found her to have poor adaptive functioning in relation to coping abilities, in particular a low frustration-tolerance threshold with resultant anger management problems.

In [Month1] 2009 [Ms A] was seen by [Dr M] (clinical psychologist, an ACC counsellor who has experience in working with people with intellectual disabilities). It appears that [Dr M] saw [Ms A] as a result of a referral from [an agency] who declined to offer her counselling because of the complexities she presented with. It appears [Ms A] was supported to fill out an ACC […] claims application in the hope of receiving counselling for her previous [medical condition]. By the time [Ms A] saw [Dr M] she had already started having regular contact with the MHS CAT team [Mental Health Services Crisis Assessment & Treatment] and phone help-lines. [Dr M] noted that no one had effected a referral into the MHS's "Dual Diagnosis" team − a specialist consult-liaison team that provides an assessment and advisory service to general mental health clinicians to support people with a dual diagnosis of intellectual disability and psychiatric diagnoses. [Dr M] identified the need to involve this team because of the complexities of the case and also because no one seemed to be acknowledging that there was a mental health component to [Ms A's] presentation. [Dr M's] summary note indicates that she would only be willing to provide psychological intervention if mental health services were involved and in particular the dual diagnosis team because of [Ms A's] complex presentation. I do not have any documentation which shows a referral to the dual diagnosis team or any involvement from them.

ACC requested a further psychiatric assessment to further determine [Ms A's] eligibility for ACC funded counselling. This was completed by [Dr J] (Consultant psychiatrist) in [Month6] 2009. [Dr J] identified definite psychiatric diagnoses and linked these with [Ms A's previous medical condition rather] than her intellectual disability. [Dr J] showed a clear formulation outlining the psychiatric diagnoses (panic disorder, post-traumatic stress disorder and low mood) and also stating that the presentation was not simply related to maladaptive behaviour as a result of her intellectual disability − "Her intellectual disability ..., has been thought to be the main cause of her erratic behaviour. I do not believe this". […] [Dr J] recommended a referral to psychiatric services believing they were the appropriate service to manage [Ms A] given her escalating risky behaviour.

Contact with Psychiatric Services

The first documentation I have pertaining to contact with the MHS CAT team is [in 2007] when [Ms A] had threatened to commit suicide. She had voiced a plan of threatening to "walk and walk until she ran out of breath". This incident occurred subsequent to [Ms A] refusing to leave an […] facility. At the time there were "no mental health issues identified' and she was left at the police station for the police to manage.

Interestingly enough the second documented contact [in early 2008] states that [Ms A] is "well known to the CATT service". So whilst this is the second documented contact that I had in my bundle of documents, the comment gives the impression that there has in fact been a previous contact. On this occasion [Ms A] was detained by police as a result of threats to self harm, again related to not wanting to go back home.

In late 2008 there appears to be a progressive escalation in [Ms A's] risky behaviours where she shows a pattern of constantly running away, often placing herself in vulnerable situations, making repeated threats to kill herself, constantly phoning [telephone counselling services]. The police would mostly deal with this and they would often contact the CAT team who would assess "no mental health issues". [Ms A's] self harming behaviours appear to progressively increase in risk with […] but by [Month6] 09 a serious episode of […] − once again after threatening suicide. This incident occurred after her cell phone was confiscated by the police and she was being charged with an offence relating to misuse of a telephone.

By [Month6] 2009 [Ms A's] acting out behaviour appears to have become more serious. Ms F the coordinator from [the disability support service] identifies this risk and on [15 Month6 2009] she urgently contacts members of the MHS by email, updating them on events and expressing her concerns about [Ms A]. She states in the email that she had rung the CAT team the evening before stating her concerns,

"The CAT team were not willing to assess [Ms A] as they were of the opinion that her behaviour was just that and a direct response to her cell phone getting withheld. I expressed being of the same opinion but shared my concern regarding [Ms A's] vulnerability and her history of walking the streets when in this state. [...] I have been informed this morning that [Ms A] was taken to hospital by ambulance last night at around 11pm, she had [harmed herself]. [...]"

Later that day she sends a second email requesting respite for [Ms A], "[Ms A] is not willing to [...] I do not believe that [Ms A] is safe, nor do I think she will remain at home if we do not find an alternative for her. Since 11pm last night she has been in great distress and has gone to extreme measures to gather attention to herself. She looks very fragile and I am most concerned for her".

It appears that after being returned home [Ms A] soon ran away, pulled out her sutures and approached people on the street who rung the CAT team. This appears to have resulted in her placement in crisis respite.

Responding to [Ms F's] email and appearing to be the first MHS clinician to identify the serious level of [Ms A's] risk is the Community Forensic & Justice Liaison Nurse, [Mr I] who had become involved because of the forensic issues. He states in an email in response to [Ms F].

"I am pleased to hear that [Ms A] ended up in respite last night and hope it went ok. I can't emphasise enough my concern in relation to this young lady and the level of risk she is at. Hopefully some form of respite can be continued. She is frustrated with living at home with her aging parents and feels she is not able to talk to them and her problems are not validated resulting in her 'acting out" to gain some attention. This situation has been compounded by the police confiscating her phone as she is now no longer able to contact [a telephone counselling service] as she has done previously and this results in her having to leave the house to gain attention or be listened to. In doing so she is extremely vulnerable wandering around an urban neighbourhood in the dead of night and it appears that following yesterday's incidents the stakes are even higher. I am of the opinion that respite may well help to de-escalate this situation and should be actioned as a matter of urgency i.e. today. I have sent a referral to Mental Health Intellectual Disability team for psychiatric assessment. [...]"

At this point [Ms A] has a few nights in crisis respite, but then returns home. As will be discussed further below her community support hours are increased and plans to move her from home are accelerated. There is another contact with the CAT team on [30 Month8 2009] when [Ms A] self-presented subsequent to being distressed about recent contact with [a telephone counselling service]. She was concerned that she might be banned after being abusive to the [telephone counselling service] team, however, according to the documentation she received a text from [the telephone counselling service] while with the CAT team "which cheered her up" and according to the notes she was taken back home in a relatively settled state. This is the last contact recorded with the CAT team. I do not have any documentation that shows any contact with the MHS over the last few days of [Ms A's] life.

Specialist Dual Diagnosis Mental Health Service

As described above the dual diagnosis service in the Hutt Valley area is a specialised team within the mental health service which provides assessment and then advice to the wider MHS team members who provide follow-up care to people with intellectual disabilities. It is well understood (internationally and nationally) that mental health problems can be difficult to recognise and diagnose in people with intellectual disabilities and that it's important to have clinicians specialised in this field. Dual diagnosis services are specified in our national mental health services specifications

(see service specs in appendix) and should be in place in all DHB mental health services. They have been developed to protect people with an intellectual disability who have a mental health problem from being part of the known national and international statistics of under diagnosis/misdiagnosis/diagnostic overshadowing (which I will describe below) and being inappropriately excluded from psychiatric services.

HVDHB MHS Dual Diagnosis Team Involvement

The first mention of the dual diagnosis mental health service is in August 2008 after [Ms A] had had two presentations to ED and the CAT team in the one day. Firstly she ingested five of her mother's pills for hypertension. Later that day after expressing that she didn't want to go back home she swallowed a coin. The consultant psychiatrist who assessed her as part of the CAT team states in his assessment, "Apparently [Ms A] has been assessed by the ID mental health service and the conclusion is that she does not have any mental illness". I couldn't find any evidence in the file of contact with the dual diagnosis team or any recorded specialist assessment, Neither did I find anything in response to [Mr I's] referral to the dual diagnosis team or a referral sent by [Ms H] from the DHB-based RIDCA service, when he expressed in an email "this is getting quite serious. I have emailed all involved. I have also alerted the […] Mental health Intellectual Disability Team".

Community Service INGO: the disability support service and Needs Assessment Service: [The needs assessment agency]

It appears from the documentation that prior to 2009 [Ms A] had a standard home-based community support package which funded community support workers from [the disability support service] to have allocated time supporting her while she continued to reside in the family home with her parents. This was a home-based support package where the support occurred in the home, but mostly they would take [Ms A] out on community based activities. In 2009 when her behaviours started to escalate the disability support service applied for her to be reassessed for a higher level of support hours and in particular for a support package that would allow her to leave home and move into a supported flatting situation. The Needs Assessment agency conducted an assessment and the need for [Ms A] to leave home was identified as a priority. To help out until a suitable community placement was found her support hours were increased to 25 per week.

Phone Help-lines

According to the documentation [Ms A] had been a long term user of the various help-lines. It appears her use of these increased in the last 6 months of her life, with some of the later contact becoming somewhat abusive towards the help-line staff.

Analysis and Conclusion

This is a sad case and one that appears to involve a common phenomenon where a person with an intellectual disability has received a level of services below optimal standards because of "diagnostic overshadowing". Diagnostic overshadowing is the tendency of clinicians to overlook mental health symptoms in people with an intellectual disability because they attribute the presenting "behaviours" to being part

of having an intellectual disability, rather than a symptom of mental illness. This is not an uncommon problem and is by no means unique to Hutt Valley DHB. An article in the British Medical Journal recently highlighted this problem:

> *"This week a published report by the Joint Committee on Human Rights highlights the widespread denial of fundamental human rights to people with intellectual disabilities by mainstream public service (1). One reason why people with intellectual disabilities receive suboptimal care is diagnostic overshadowing, whereby a presenting symptom of mental illness or physical illness is incorrectly attributed to the person's intellectual disability (2). Although people with intellectual disability have a higher prevalence of mental illness than people with a normal IQ (3), medical professionals are less likely to diagnose psychiatric problems in this group (2). People with intellectual disability are also more likely to have chronic disorders such as epilepsy, cerebral palsy, and genetic syndromes (4, 5). However, their health needs are often unmet (5). Two recent reports by the Disability Rights Commission and MENCAP have highlighted the importance of diagnostic overshadowing in people with intellectual disability in England and Wales (6, 7). They highlight the widespread inequalities encountered.*
>
> BMJ 2008;336:570-571 (15 March)

In my opinion [Dr J's] assessment was thorough and outlined the issues well. I'm not sure if this assessment was available to the HVDHB mental health team. I think it is likely that given [Ms A's] history […] and the way she had been presenting/behaving that she also had some borderline/histrionic personality traits. It's not uncommon to see these disorders and/or symptoms clustered together in people with a history of trauma − anxiety, panic, PTSD symptoms, particularly avoidance of triggers, clustered with self-harming, hysterical over-reactions and behaviours aimed at desperately seeking safety and security.

One of the fundamental concepts that specialist dual diagnosis clinicians know is that people with an intellectual disability generally always have to some degree limitations in their coping, interpersonal and communication skills. This typically results in a behavioural component to their presentation if they become mentally unwell, where they commonly communicate their distress through their behaviour − typically "acting out" behaviours. What I have read in these documents portrays a picture of a young woman with an intellectual disability and anxiety/panic/PTSD generated symptoms "turning up the volume" on her message of, "I'm not coping, I'm distressed, I can't be here any longer" in order to get people to take her seriously. I don't believe that [Ms A] wanted to die, but neither did she want to stay living at home. She engaged in what could be considered maladaptive ways of signally her message and level of distress, but in the end for many people with an intellectual disability this is the only way they get heard and get their needs met − as much as we as clinicians might not like it. Serious self-harming behaviour is the business of psychiatric services. We know from the research that one of the biggest risks for suicide is self-harming behaviour with recent overseas statistics suggesting that in some 40-60% of successful suicides the person was self-harming prior. Self-harm is something that mental health clinicians

should be concerned about and a history of self-harm that is increasing in frequency and severity warrants a thorough assessment.

It appears that there was a significant decline for [Ms A] […] This would have undoubtedly compounded the dissatisfaction [Ms A] had about living with her parents, making it significantly more distressing by exacerbating the underlying anxiety-trauma related issues. From this point onwards there is a significant increase in contact with the police and MHS.

Psychiatric Services: Hutt Valley DHB
The questions needing to be asked regarding the HVDHB are:

1. Did the dual diagnosis team do a thorough comprehensive assessment of [Ms A]? Did they do an assessment or second review as her risk increased? In the absence of providing any treatment did they provide appropriate recommendations and/or advice to the wider MHS team? From the documents was provided with I could not find any evidence of this.

- [Ms A] was a young woman with an intellectual disability who according to two credible clinicians ([Dr M] and [Dr J]) had psychiatric diagnoses which they believed warranted intervention from the MHS. The dual diagnosis team as the appropriate team to do this.
- When [Ms A] seriously [harmed herself] in [Month6] 2009 she required re-assessment by the dual diagnosis service. It would have been reasonable to expect that following a dual diagnosis assessment and in the absence of them providing follow-up treatment that they would refer [Ms A] to the general community team for monitoring and follow- up from a nurse and psychiatrist. To expect a disability NGO to manage this level of risk and behaviour is unrealistic.
- In the presence of overwhelming subjective distress with insomnia, it would have been reasonable for [Ms A] to have been prescribed a de-arousing medication as a temporary intervention until her accommodation/psychosocial issues were resolved and her distress at a lower level. Whilst prescribing in these circumstances needs to be done cautiously it is not at all uncommon for psychiatrists in this specialist area to prescribe under these circumstances. A low dose of quetiapine, for example, could have been very effective in helping with the insomnia and decreasing [Ms A's] distress as she awaited alternative accommodation. I believe that there was some pharmacotherapy that could have been helpful for [Ms A] during this period, but this would generally only happen as a result of a specialist psychiatrist assessment.
- CATT is an emergency team which doesn't generally have clinicians with dual diagnosis experience in it. Its function is generally to manage immediate crises. As discussed above [Ms A] required some longer-term support from the community team.

2. **Did [Ms A] get the same treatment that someone with a significant anxiety disorder or borderline or histrionic personality would get?**

3. Did [Ms A] get the same treatment in [Month6] 2009 that someone (without an intellectual disability) would get who [self-harmed] as she did, or in [Month8] 2009 did she get the same treatment as someone who had been found […] requiring rescuing?

4. In response to the complaint about [Ms A] being prescribed fluoxetine without follow-up. I understand this was prescribed in [Month6] 2009 but I can't find this in the documentation provided. Despite this, I agree there should have been consultation and medication education provided to the family and/or the disability support service support staff by the prescriber or another delegated clinician, given that [Ms A] had an intellectual disability.

- In regard to this complaint I agree there was a failure to appropriately involve either family/significant others. However, I do not agree that there is any conclusive evidence to show that the fluoxetine increased [Ms A's] suicidal ideation or attributed in any way to her death. In fact the opposite appears to be the case with [Dr J] commenting that it appeared to be having a beneficial effect on her anxiety levels.

Conclusion

- If the HVDHB MHS dual diagnosis team did not conduct a comprehensive specialist assessment of [Ms A] then it is my opinion the care and treatment provided to [Ms A] from the HVDHBs Mental Health Service fell below an acceptable standard of care, particularly from the period of [Month6] 2009 onwards. By this time a full assessment or review assessment was necessary, appropriate and "reasonable".
- If they did conduct an assessment and found no psychiatric diagnosis then this would need to be reviewed and considered in light of [Dr M] and [Dr J's] assessments which both found evidence of psychiatric illness and the need for mental health service involvement.
- The root cause of the problem in this case appears to have been a failure of the dual diagnosis team to either identify psychiatric illness or conduct a thorough specialist assessment and/or to re-assess [Ms A] as her risk increased. This failure then resulted in no referral, advice or guidance to the general community team and in turn no intervention from the community team. In the absence of a full assessment there appears to have been a message communicated to the general team that "there were no mental health issues", This appears to have set the scene for general clinicians believing the issue was non-mental health related and purely disability related and as [Ms A's] risk increased they remained locked into this opinion.

Accepting that there was a failure from the specialist dual diagnosis team does not automatically equate to a conclusion that the service provided to [Ms A] by the HVMHS fell below standards.

(The following section has been deleted as not being relevant to this opinion.)

To conclude, whilst it is my opinion that the dual diagnosis team failed to assess and treat [Ms A] appropriately (medication, appropriate referral), both at the point of referral and as her risk increased and therefore did not provide an adequate level of care, without answering the questions above it cannot be concluded as to whether a thorough specialist assessment would have resulted in treatment/intervention from the MHS that was any different to that provided. Without knowing this we cannot say whether the tragic outcome could have be avoided if the dual diagnosis service had been actively involved as they may have recommended CATT intervention only. The two salient issues here are, we have specialist dual diagnosis services for people with intellectual disabilities as [Ms A] had and by the end of 2009 she had serious self-harming behaviours which are the business of mental health services.

Telephone Help-Lines

According to the HDC referral to me, [Ms A's] sister stated that on [31 Month 8 2009] [Ms A] became upset after contact with the peer support helpline − the disability support service. I'm assuming this is a mistake as the disability support service is the community support agency not a phone-helpline. On assessing the documentation in relation to the help-line involvement I only have documentation from the helpline – [peer support helpline]. The documentation from [the peer support helpline] suggests that there was a difficult phone call with [Ms A] on [1 Month 9 2010] with (one of the [peer support helpline] staff). [Ms A] made another phone call to [the peer support helpline] the following evening and spoke with (another of the [peer support helpline] staff) . She stated that she had been admitted to hospital the previous night as a result of self-harming. I couldn't find documentation in the DHB bundle referring to this admission. Although the phone call on [2 Month9 2010] resulted in a somewhat atypical response in that the staff member contacted [Ms A's] parents letting them know of her whereabouts so they could pick her up. This was done with her permission and in response to her stating that she had no money on her phone to contact her parents. [Ms A] rang back and by this time she was with the police who were about to deliver her back home.

Conclusion:

I consider that the contact that [the peer support helpline] had with [Ms A] is without fault and in no way fell below an acceptable standard given their service specifications. I cannot comment on the service provided by [the telephone counselling service] as I don't have documentation on this.

Community Service/NGO: the disability support service & Needs Assessment Service: [The needs assessment agency]
The process of finding someone a flat or group home always takes time and is generally dependent on a placement in a flat coming up or a community organisation developing a new service. As [Ms A] became more distressed during this critical period in 2009 the service coordinator for the disability support service responded appropriately to her needs as did the Needs Assessment service. Both organisations worked collaboratively and assertively to develop/find a suitable community placement. As outlined above the coordinator from the disability support service identified [Ms A's] risk, informed the right people and tried to get [Ms A] support to manage her increasing risk. There are several emails in the documents (some discussed above) where he outlines his concerns about her increasing risk with evidence of actively liaising with appropriate services, for example, RIDCA (High and Complex Needs Assessment service) and the HVDHB's MHS clinicians. NGOs are very much dependent on getting clinical guidance from MHS clinicians and they are generally not in a position to put in place crisis support for suicidal people − during these times Mental Health Services generally need to intervene and provide support.

Conclusion:
I consider that the service provided by the disability support service and the Needs Assessment service was at an acceptable standard. From the documents provided I cannot find any fault with the services provided by these agencies.

Bernadètte Forde-Paus"

Appendix B: Additional expert advice – Ms Paus

"Introduction
This additional report is being provided to the Commissioner following a request for an additional response on case number 10/00396 − complaint: against Hutt Valley District Health Board (DHB), I have been asked to respond to:

1. [Mrs B] ([Ms A's] sister) requested that I read the additional clinical information (emergency team documents) in consideration of my conclusion in the first report.
2. HVDHBs response to the investigation.

Having read the additional information, I do not have anything significant to add to my conclusions in response to [Mrs B's] request. It might be helpful if I corrected the date in bold below from "*the end of 2009*" to "*by the end of 2009 through to her death [in] 2010*". I acknowledge that by reading "*by the end of 2009*" in conjunction with my comments about not having all the clinical case notes, [Mrs B] may think I did not have all the necessary information to provide me with the full picture/series of events leading up to [Ms A's] tragic death, however, I did have access to documentation which had outlined this for me.

> *"To conclude, whilst it is my opinion that the dual diagnosis team failed to assess and treat [Ms A] appropriately (medication, appropriate referral), both at the point of referral and as her risk increased and therefore did not provide an adequate level of care. The two salient issues here are, we have specialist dual diagnosis services for people with intellectual disabilities as [Ms A] had, and by the end of 2009 she had serious self-harming behaviours which are the business of mental health services"*

In my opinion (July 2010) I put forward the view that the dual diagnosis team failed to provide [Ms A] with "*an appropriate level of care*",

> *"The root cause of the problem in this case appears to have been a failure of the dual diagnosis team to either identify psychiatric illness or conduct a thorough specialist assessment and/or to re-assess [Ms A] as her risk increased".*

However, HVDHB's Mental Health Service acknowledge that they did not access the specialist dual diagnosis team, in failing to do this (in combination with an absence of clinicians skilled to work with this client group) I would therefore conclude that the HVDHB's Mental Health Service failed to provide [Ms A] an appropriate service.

However, in drawing this conclusion [Ms A's] death was not easily predictable as she had a history of engaging in self-harming behaviours in order to signal her distress and to convey her message of "I no longer want to live at home, help me", She had shown a pattern of engaging in self-harming behaviour, followed by seeking help and then calming down, usually to a point where she settled back at home for a period of time. So whilst her death **may** have been preventable it was not easily predictable

The HVDHB's Mental Health Service:

- Has acknowledged the failure to utilise the regional specialist dual diagnosis service and is currently developing guidelines, polices and procedures to follow when working with an individual with an intellectual disability who has multiple agency involvement. I am assuming (although it is not actually stated) that this will include involvement from the regional specialist dual diagnosis service.
- Has accepted the likelihood of diagnostic overshadowing being an issue in this case, along with a lack of dual diagnosis skills within the clinical team. They are currently seeking to rectify this problem through training from the regional specialist dual diagnosis team. (The following section has been deleted as not being relevant to this opinion.)
- In acknowledging the failures above there was also acknowledgement that there was a lack of comprehensive assessment and ultimately intervention provided to [Ms A]. As stated above there is a plan to make improvements to the service provided to individuals with an intellectual disability which will improved the care and treatment they receive.
- Acknowledged a lack of family involvement in this case and again they have plans to minimise this occurring in the future with practices that will promote greater family involvement.

In summary it is my opinion that the HVDHB's Mental Health Service appears to have acknowledged their failures and shortcomings in this case and have put appropriate plans in place to rectify the problems inherent in this investigation. I assume there is some process to oversee the implementation of these corrective actions."

[The following section has been deleted as not being relevant to this opinion.]

Further advice

"This information is being provided to the Commissioner following a request for an additional response on the following two questions:

Given that Hutt Valley DHB have stated they did not have a Dual Diagnosis team but could have referred [Ms A] to [DHB2's] team, but did not do so, could you please advise whether you consider the shortcomings you identified in [Ms A's] care were mild, moderate or serious departures from the accepted standard.

- Taking into consideration the national context in terms of dual diagnosis services and their irregular integration within teams (as described in the previous opinion) and whilst not finding it easy to adjudicate a point on the departure scale it would be my opinion that the departure from acceptable standards sat within the moderate range.
- It is also my opinion that the failure was more attributable to a systems (service) failure because it would appear that clinicians within the emergency service had limited clinical skills/training in dealing with people with an intellectual disability and that there wasn't any training to assist them to identify and meet their limitations, nor was there any policy/procedure to

guide them to [DHB2's] dual diagnosis team. It is likely that based on the skills and information they had at the time they thought they were managing [Ms A] in an appropriate way.

Could you also advise who, in your opinion, should have taken the lead in developing a plan for [Ms A's] care?

- The question about who should have been the lead in developing a plan for [Ms A's] care is not entirely straight forward.
- [DHB2's] consult-liaison team (CLT) in this area is a consultation and advisory service, so whilst [Ms A] was awaiting placement in an NGO i.e. she had no community support service currently in place, she should have been receiving support from the DHBs community mental health service given her mental health issues.
- The CLT should have been referred to for assessment which would have resulted in recommendations for treatment and follow-up care from the community mental health team. It is most likely that within these recommendations they would have made further recommendations for the emergency team as to how best manage [Ms A's] crisis presentations to the emergency team.
- So whilst the CLT would have provided the specialist assessment and made recommendations it would have been the responsibility of the community mental health team to take these recommendations and put them into a care management plan – as is standard practice for all patients on their caseloads.
- So in summary it should have been a joint/collaborative process between the dual diagnosis CLT and the mental health services community team that determined [Ms A's] care and treatment, with the community mental health team having the responsibility for being the ongoing clinical lead.
- The community mental health team case-manager would have had the ability to contact the dual diagnosis CLT for advice at any time if they had new or ongoing concerns or needed ongoing advice.
- Although not directly relevant to the question, when [Ms A] moved from home to the NGO the CLT team would have then had another role to play in providing advice and recommendations for her community support plan to the NGO."

Ms Paus provided further advice in response to the following questions:

"What should CAT have done when [Ms A] kept presenting as being a risk to herself? Should they have referred her to her GP so that she could be referred to mental health services or should they have done this themselves. What is the process in these cases?

The CATT team could/should have referred her to the community mental health team which would have ensured thorough assessment, treatment and then coordination. She would have received a comprehensive assessment, most likely from a psychiatrist and then coordination through a case-manager. The case-management role allows for the development of a therapeutic relationship.

Through this the assigned clinician/case-manager would have discovered the […] history/issues and seen that the problem was anxiety/stress related as opposed to challenging behaviour. Part of the case-management role is to support/facilitate the Needs Assessment process which gets people who need long term community (residential, vocational, social etc) support.

It seems that the GP had a role in the management of [Ms A]. Was there any provider that should have been co-ordinating [Ms A's] management? What is the ideal model of service in these circumstances?

If she had been referred to the community team (as outlined above) the case-manager would have had a coordinating function – this would be common and acceptable practice. The ideal situation is to have a Dual Diagnosis team/clinician (intellectual disability and mental health) within the community team who could take on the case-management function. Once [Ms A] was in suitable and supported placement with an NGO it is likely her stress and anxiety would have decreased and then the NGO would take over coordination. You wouldn't expect someone like [Ms A] would require long term involvement from the mental health service. So in answer to your question, coordination of her should have come jointly from the mental health service and the needs assessment service. Because of her presentations with the CATT team and her risk, I would see the responsibility ultimately lying with them in this case.

The GP would be very limited in what s/he could do and this responsibility does not lie with him/her. Their role is to refer people to the appropriate services. In [Ms A's] case this is the mental health team and [the Needs Assessment service]. Too often GPs are left trying to manage complex patients outside of what they are expected to be providing for patients.

Bernadètte Forde-Paus"