Medical Officer, Dr C / A Public Hospital

A Report by the

Health and Disability Commissioner

(Case 00HDC12819)



Complaint

[1] Mrs A complained about the services provided to her son, the late Mr B, by Dr C and a public hospital. The specific complaints are that:

- (a) Dr C based her treatment of Mr B on a misdiagnosis of intellectual disability.
- (b) Dr C medicated Mr B unnecessarily and possibly inappropriately.
- (c) Dr C neglected Mr B's need for appropriate care and support.
- (d) Dr C refused to refer Mr B to a specialist in Asperger's Syndrome.

[2] The provisions of the Code of Health and Disability Consumers' Rights that apply to this complaint are:

RIGHT 4

Right to Services of an Appropriate Standard

(1) Every consumer has the right to have services provided with reasonable care and skill.

RIGHT 6

Right to be Fully Informed

- (3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about
 - (c) How to obtain an opinion from another provider; ...

[3] For the reasons that appear in this opinion, I have concluded that there was no breach of the Code by Dr C and the hospital.

Investigation process

[4] The complaint was received on 12 August 1999 and an investigation was commenced on 27 October 1999. On 24 November 1999 the Commissioner advised the parties that, in her opinion, Dr C did not breach the Code of Health and Disability Services Consumers' Rights. Mrs A subsequently requested that the Commissioner reconsider that opinion. The Commissioner agreed to do so and the complaint was reopened on 7 November 2000.

Mrs A	Complainant / Consumer's mother
Mr B	Consumer (deceased)
Dr C	Provider / Medical Officer Special Scale at the hospital
Dr D	Consultant Psychiatrist
Dr E	Consultant Psychiatrist
Dr F	Consumer's general practitioner
Ms G	IHC caregiver
Mr H	Caregiver
Ms I	Staff member at the Polytechnic



Names have been removed to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Ms J	Staff member for the Needs Assessment and Service Coordination agency
Ms K	Psychologist
Ms L	Social Worker at the hospital
Ms M	Staff member at IHC
Ms N	Staff member at IHC

[6] Relevant clinical records were obtained and viewed. Expert advice was obtained from Dr Deborah Antcliff, an independent consultant psychiatrist.

Information gathered during investigation

[7] In early 1994 an educational psychologist advised Mrs A that her son, Mr B, might have Asperger's Syndrome. (Asperger's Syndrome is an autism spectrum disorder characterised by impaired social interactions and restricted interests and behaviours.) Mr B was 14 years old at the time. Mrs A stated:

Until then I had been given numerous and conflicting opinions by various different 'experts' and organisations. Those opinions ranged from 'he is seriously retarded' to 'there is nothing wrong with him'.

[8] On 16 February 1998 Mr B was admitted to the psychiatric ward of the hospital under the care of Dr D, consultant psychiatrist. Following an assessment Dr D wrote in the clinical record:

No history suggestive of mental disorders. Mental state examination is unremarkable. His diagnosis and presentation is consistent with Asperger's. Recent episode now settled. No risks to self or others identified.

[9] Dr D noted, with reference to Axis I of the DSM IV [Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition]:

Asperger's syndrome. Probably normal intelligence.

[10] Under 'Plan' in the clinical notes he recorded:

Diagnosis and management plan discussed. Mother accepting of same. [Mr B] is agreeable. No indication for psychotropic [medication (which includes antianxiety, antidepressant and antipsychotic drugs)]. Refer to psychologist – child/adolescent ? [query] Individual counselling/support ? Family support.

 $Discharge \ back \ to \ GP-offer \ of \ reassessment.$

[11] Mr B was assessed by a social worker on 18 February 1998.



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[12] Social worker notes dated 2 March 1998 recorded:

Home visit. [Mr B] appeared at Accident and Emergency at 11.00am today, and was seen by the Crisis Team. Prior to this, [Mr B] had left one urgent call on my answerphone. I had responded by leaving two messages on their answerphone (by this time they were at A&E). Agrees to visit today. The main problem which presented relates to the fact that [Mr B] and his mother have very little space from each other. Discussed carer relief and agreed to consider [Mr B's] eligibility for this. Also discussed various clubs, organisations, activities which [Mr B] could access. Discussed voluntary work, also discussed Toastmasters International, agreed to find phone numbers for this. [Mr B] is also considering joining a band. Contacted Toastmasters International. Contact number is Message left on answerphone informing him of this. Subsequent message also invites [Mr B] to make an appointment time for carer relief assessment.

[13] Social worker notes dated 5 March 1998 recorded:

Urgent phone call received from [Mrs A] ([Mr B's] mother) today. [Mrs A] and [Mr B] have fallen out, and [Mr B] has decided that he will try to live independently. [Mrs A] would like some help finding supported accommodation for [Mr B]. Discussed short-term options available, however [Mrs A] said she could access these herself without any help. Discussed long-term options. Explained that [Mr B] does not meet our criteria for supported psychiatric accommodation. Agreed that I would liase with Child & Adolescent Services as they may have information pertaining to resources available to [Mr B's] age group. Spoke with [...] at Child & Adolescent Service. [...] stated that a referral for [Mr B] has recently been picked up by a Child & Adolescent Service staff member. [...] will ... get them to ring me.

Liaised with Open Homes – [...]. Discussed [Mr B's] need for long-term support and [...] agreed that [Mrs A] could contact her to discuss their service.

Contacted IHC – was informed that [Ms N] was the right person to speak to, and she would contact me tomorrow.

Contacted CYPS in regard to the possibility that [Mr B] and [Mrs A] may be able to utilise one of their caregivers. [...] (CYPS social worker) informed me that [Mr B] is over the age by which he would be entitled to CYPS support but left a message stating she is happy to discuss this further.

Contacted [...] who had been about to accept the referral for [Mr B], as his mother had been to see them earlier. His psychiatric diagnosis may exclude him from being accepted by them. They stated that they would consider Open Homes or IHC.

Liaison with [Mrs A] and informed her of the progress to date.

[14] On 6 March 1998 the social worker recorded in the clinical notes:

Contacted [Ms N] at IHC, [...] Branch. [Ms N] informed me of two services available to a person with Asperger's syndrome.

- Supported Living this service provides a maximum of 5 hours per week, consisting of a caregiver visiting.
- Contract Board 10-12 days supported living whereby the client lives with a family for that period of time. An additional 2 days contract board is available through another family.

Contacted [Mrs A] and informed her of this service; gave her [Ms N] contact number. Stated I would like to be present if [Mrs A] meets with [Ms N] in [...] to discuss these services, in regard to [Mr B].



Also informed [Mrs A] of the situation with CYPS caregivers. [Mr B] is over the age for that service. [Mrs A] expressed regret that she had not been informed of this service when [Mr B] was entitled to it.

Discussed ... Fellowship and the services available through this. [Mrs A] stated she would not like this to take precedence over his Human Science studies at [a] Polytechnic. We did agree that this could be part of a long-term plan for [Mr B].

[Mrs A] informed me that [Mr B] does have short-term accommodation arranged for the weekend.

[15] Social worker notes on 24 March 1998 recorded:

Home visit. Completed assessment for [Mr B] to apply for carer respite. Also discussed progress to date. Discussed how [Mr B] feels re moving out of home. He feels a little rejected and is having difficulty communicating that at present. Encouraged him to ventilate his feelings in this regard and explained how he is cutting off communication from his mother at present. Discussed Trust Home accommodation. ...

[16] On 6 April 1998 Mr B was assessed by Dr E, consultant psychiatrist at the hospital, after "several days of disruptive behaviour". Dr E recorded in the clinical notes:

17 year old male brought in by Crisis Team for further psychiatric assessment and treatment. He complains of being depressed and of conflicts with his mother 'she wants to control my life'.

[17] Dr E requested a blood workup and "close observation".

[18] Mr B assaulted a staff member on 8 April 1998 and was placed in seclusion. Compulsory treatment under the Mental Health (Compulsory Assessment and Treatment) Act 1992 was initiated.

[19] Dr E saw Mr B on 9 April 1998, in the company of Mrs A. Clinical notes recorded:

Patient seen with mother. She was fully informed re patient's clinical condition. I told her that [Mr B] has been displaying erratic-impulsive behaviour at ward [...]. I told [Mrs A] that a therapeutic trial with carbamazepine [used to treat depressive illness] would be useful. Proscons-side effects of carbamazepine were reviewed with her. I got her permission to start carbamazepine treatment on [Mr B].

Plan: carbamazepine 100mg PO [orally] BD [twice daily] Brain – CT scan EEG Cortisol levels are pending Close observation.

[20] Clinical notes at 3.30pm on 9 April 1998 recorded that Mr B had become physically disruptive after an altercation with another patient and that he was "hitting and kicking walls and throwing himself around". Mr B was placed in seclusion and given an immediate dose of haloperidol (an antipsychotic) 5mgs. He appeared settled at 8.15pm and seclusion was "discontinued". Mr B was advised that if he became disruptive again or exhibited further violent behaviour he would be placed back in seclusion.

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[21] Mr B was reported to be agitated and restless for most of the morning shift on 10 April 1998. Clinical notes at 10.00pm recorded that earlier in the afternoon shift he had been playing with a fan in the smoke room and had received an electrical shock. He then threw the fan out of the window. Mr B was later found "bashing rubbish tin out of his window with backside". He was placed in seclusion at 7.00pm. He was given Melleril (an antipsychotic/anxiolytic) 100mg at 7.25pm "with good effect".

[22] Clinical notes on 11 April 1998 recorded that Mr B was visited by his mother and aunt but requested that they leave after 15 minutes as they were "making him tense". Clinical notes on that day continued:

Talked about the medication – he reported that it makes him a bit calmer – he feels as though his moods are more evened out.

Discussed his erratic behaviours and his lashing out – the fact of adult behaviours = adult repercussions. [Mr B] reported that he is an adult – discussed that he needs to reason out his behaviours – he may wish to hit and hurt but thoughts and actions are separate.

Stated that he was feeling stressed and would like help from staff – PRN meds utilised and staff time given.

Informed of the need to find his nurse and discuss his feelings.

[23] Notes on the morning of 12 April 1998 recorded that Mr B was settled at the start of the duty but became agitated as it went on. He was given clonazepam (a tranquilliser) "with little effect". He became verbally aggressive to patients and staff and "stated he felt like being physically aggressive". Mr B was encouraged to spend time in his room but was finding it difficult. He was given an immediate dose of Melleril.

[24] At the start of the afternoon shift other patients on the ward complained about Mr B's behaviour. He was approached about this and was "belligerent, abusive, swearing at staff". He was asked to stay in his room to "defuse". Mr B was given clonazepam and Melleril and appeared more settled afterwards.

[25] Mr B underwent a medical review on 13 April 1998. Notes recorded:

Patient reviewed this am. Remains mentally unwell with increasing behavioural problems. Insight is nil.

Plan:

- 1. Continue on CTO [compulsory treatment order] via MHA [Mental Health Act] section 13/14.
- 2. Continue current treatment plans.
- 3. Haloperidol 5mg BID [twice daily].
- 4. Cogentin 2mg daily.

[26] Mrs A asked to see Dr E. As a result, a family conference was held between Dr E, Mrs A and Mr B on 14 April 1998. Clinical notes recorded:

[Mrs A] believes medication is helping [Mr B]. He is more settled, calm, co-operative and with less anxiety. CT scan was done today.



[27] Social worker notes dated 14 April 1998 recorded:

Met with [Mr B], [Mrs A] and a friend of [Mrs A's]. Discussed [Mr B's] referral to IHC for contract board. A consensus gained that this the best option; [Mr B] and [Mrs A] rejected the idea of supported psychiatric accommodation. Also assisted [Mr B] and [Mrs A] to complete referral for contract board – agreed to send it to IHC today – marked urgent. Explained that I have also spoken to IHC earlier today regarding the urgency of [Mr B's] need for contract board.

[Mrs A] requested an appointment with me without [Mr B]. Her friend, [...], also attended. Discussed invalid benefit with [Mrs A]. Stated she would assist [Mr B] to complete it and give me the document for the disability allowance. Discussed contract board situation. [Mrs A] is very happy with this. Informed her referral had been posted today and is marked urgent. Discussion of how upset [Mr B] is but also stressed the need for [Mr B] to participate in his own recovery and have a commitment to it. Discussed 'depression' and explained why [Mr B] could be described as having situational difficulties.

[28] On 15 April 1998 Dr C, Medical Officer Special Scale, wrote in the clinical notes:

Remained agitated, erratic behaviour.

Was commenced on haloperidol, and has settled more with this.

[Dr E] met with mother yesterday ? [query] future accommodation/placement. Cover support available for 20 days.

No evidence of depression.

. . .

[29] Dr E saw Mr B on 16 April 1998. Mr B was assessed as:

More co-operative, with less PMA, less erratic behaviour, less anxiety. Taking meds as prescribed, no side effects voiced, no physical complaints.

[30] Dr E discontinued the Clonazepam and started Mr B on lorazepam (an anxiolytic). Carbamazepine was increased. A possible discharge date was noted as 20 April 1998. Mr B was noted to be "ready for discharge" on Friday 17 April 1998. The social worker was contacted regarding accommodation. Weekend accommodation could not be arranged and Dr E agreed that Mr B would remain in the ward over the weekend. Nursing notes recorded:

Discussed respite care with [Mr B]. He thinks he could stay the weekend with friends on a farm at [...], and will phone them in the morning. A.M. nurse will need to check this out with mother and these people and doctor, but [Mr B] is ready for discharge and keen to go.

Pleasant and co-operative, dislikes the ward. Used 1:1 time to discuss living problems/activities i.e. living with mum, tech course he is doing. Feeling tired and sleepy. Medication and effects discussed.

[31] Nursing notes at 10.00pm on 19 April 1998 recorded:

Settled and pleasant about the ward. Not wishing in depth chats. Visited by mother this afternoon which he appeared to enjoy. They are both hoping accommodation will work for [Mr B]. Mood has remained calm and appropriate. Nil displays of anger/outbursts.



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[32] On 20 April 1998 Mr B was noted to be friendly and talkative. His behaviour was described as settled and appropriate. He wanted to be discharged but was aware that accommodation had not been arranged. Social worker notes on 20 April 1998 recorded that an Open Homes caregiver had been arranged for Mr B that evening. However, Dr E decided to delay his discharge until Wednesday night, 22 April 1998. This was to enable nursing staff to assist with his appointment for an EEG at a city on that day. The Open Homes caregiver was duly informed.

[33] Nursing notes subsequently recorded that Mr B's appointment at the city was at 1.45pm on Thursday, 23 April 1998 and could not be changed. Accordingly, he was discharged on 20 April 1998. Notes recorded:

Open Homes rung and this ok - so given script and follow up appt for Wednesday, 6 May at 2.00pm with [Dr C]. Mother will take him to [the city] on Thursday. Discharge.

[34] Social worker notes on 27 April 1998 recorded:

[Mrs A] contacted me, informing me that the Open Homes placement fell through. [Mr B's] caregiver, [...], did not give the tablets required, and he went into spasm. [Mrs A] took him to see [Dr F] [[Mr B's] general practitioner] in [the town] then took him home to live. However, [Mrs A] states that having [Mr B] at home continues to be an unsatisfactory arrangement. Agreed to contact [Ms N] about contract board; have done this and [Ms N] is speaking to the appropriate person at IHC.

Also contacted Open Homes requesting whether [Dr F] is still a caregiver for Open Homes – he is. They are contacting him to ask whether he would consider taking [Mr B] for respite care (he only used 2 days at Open Homes to date). ...

[35] Social worker notes on 1 May 1998 recorded:

Phone call received from [Ms I]. She stated that there have been difficulties with [Mr B] at Polytechnic – he has been extremely sleepy – falling asleep in class and yawning in an exaggerated manner. Agreed to speak to [Mrs A] in regard to his medication. Spoke to [Mrs A] in regard to [Mr B's] medication. She will liaise with [Dr F] in regard to this. Has challenged [Mr P] about whether he is putting on any of his sleepy heaviour; he admits

Has challenged [Mr B] about whether he is putting on any of his sleepy behaviour; he admits that he has exaggerated sometimes. ...

[36] On 6 May 1998 Dr F telephoned Dr C and advised that he had discontinued Mr B's medication the day before due to 'sedation'. It was noted in the clinical record that Dr F was currently Mr B's caregiver "via Open Homes Foundation". Dr C met with Mr B on 6 May 1998, in the company of Mrs A. Mr B admitted experiencing auditory hallucinations and said he had been depressed every day for the last few weeks. Suicidal thoughts were also present "every day". Dr C made a differential diagnosis of depression with psychotic features. She discussed with Mrs A the risks and benefits of recommencing antipsychotic/antidepressant/mood stabilising medication. A decision was taken to recommence Mr B on haloperidol after consultations with Mrs A and Drs F, E and D.

[37] Dr C's clinical notes recorded:

At present do not wish to take this.



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To discuss with [Dr F] re my recommendations and clarify role of specialist. Phoned. Follow up 2/52 [two weeks] with [Dr D]/myself.

Discussed with [Dr E] – recommends recommencement of antipsychotic Haloperidol 5mg nocte [night] and cogentin 2mg mane [morning] and other medication as above.

[38] On 7 May 1998 Dr C discussed Mr B's medication with Dr D who, in view of the side effects Mr B experienced on haloperidol, recommended a change to risperidone.

[39] On 11 May 1998 Mrs A called Mr B's social worker advising that she wanted to discuss changing Mr B from antipsychotic to antidepressant medication. The social worker suggested that Mrs A contact Dr C to discuss this. The social worker also agreed to contact IHC regarding carer relief.

[40] Dr C saw Mr B on 13 May 1998, at Mrs A's request. She agreed to him trialling an antidepressant but emphasised the need for him to continue taking his antipsychotic medication. Mr B's medication was risperidone 2mg twice daily, paroxetine (an antidepressant) 20mg daily, and lorazepam 1mg at night.

[41] Social worker notes on 15 May 1998 recorded that the Needs Assessment and Service Coordination agency was unable to place Mr B immediately "due to the requirements of their own needs assessment". However, Mr B was eligible for a further 14 days of carer relief. The social worker liaised with Dr F and his wife about continuing to care for Mr B under carer relief funding. They were unwilling to do so because they found caring for him "very stressful". Alternative living arrangements were pursued by the social worker.

[42] Social worker notes on that day continued:

Contacted [Dr F] to let him know of the new plan for [Mr B]. He stated they were reluctant to continue caring for [Mr B], said they got the impression from the Polytechnic that it is about to ask him to leave and they could not cope with him being at home all day. ... Thanked [Dr F] for his help and said I will ring to let him know what the new arrangements were.

[43] On 18 May 1998 the social worker visited Mr B and Mrs A at home. The 'carer relief form' was completed. The social worker subsequently sent a report, with "accompanying communication" to the Needs Assessment and Service Coordination agency. She discussed Mr B utilising carer relief with a couple from [another town].

[44] On 22 May 1998 social worker notes recorded:

[Mrs A] contacted me in some distress, stating that [Ms I] is practically asking [Mr B] to leave, at present. I agreed to contact [Ms I] in response to this. [Mrs A] believes [Mr B] is committed to the course and has improved considerably since his medication has changed. Also, agreed to request a meeting of the 4 of us ([Mr B], myself, [Mrs A] and [Ms I]) to discuss his continued participation in the course. Stated I would probably do this on Monday.

[45] The social worker notes on 22 May 1998 also recorded a phone call from the Needs Assessment and Service Coordination agency stating that it required confirmation in writing of Mr B's diagnosis of Asperger's Syndrome. The social worker left a note with



Dr C requesting this confirmation, which would allow Mr B to receive funding from the Needs Assessment and Service Coordination agency.

[46] Social worker notes on 26 May 1998 recorded:

Liaised with [Ms I] and [Mrs A] today. [Mrs A] is very unhappy with the service received from the polytechnic and believes [Mr B] has been disadvantaged as a result. [Ms I] believes every effort has been made to accommodate [Mr B's] disability, and believes [Mrs A] should accept that her son has a disability and cannot keep up with the rest of the class. We have arranged a meeting for Friday at 12.15pm to discuss this difference of opinion.

[47] At the meeting on 29 May 1998 it was agreed that Mr B would choose one topic to continue with on his course and would consider a topic in the vocational course, such as cooking or budgeting. Social worker notes also recorded:

Met with [Mrs A] at her home, at her request, after the meeting. Discussed the implications of [Mr B] coming to terms with the Asperger's Syndrome, and also with his treatment for psychoses. Discussed how his motivation may be affected due to his psychiatric disability, both now and in the future.

[48] Dr C saw Mr B on 3 June 1998. She noted that he had moved to 'permanent placement' with a couple in another town (Mr H and Ms G). Dr C noted that Mr B had no psychotic features, and that there was an improvement with his depressive symptoms, but that there was a need to normalise his sleep pattern. She recommended that he continued with his medication and be reviewed in three weeks' time.

[49] Social worker notes dated 16 June 1998 recorded:

Received phone call from [Ms J], [the Needs Assessment and Service Coordination agency], re Mr B. He has had his Contract Board Residential Placement turned down through IHC, but they are going to reallocate two weeks of carer respite funding indefinitely, until an appropriate residential placement is found. [Ms J] stated that his caregivers ([Mr H] and [Ms G]) have stated they would appreciate some support with motivating Mr B in further activities. Stated I would discuss with our MDT.

Received a phone call from [Mrs A], querying what the story is re [Mr B's] funding. Explained that there are to be reassessments of [Mr B] from a cognitive and psychological point of view. [Mrs A] would like some help for [Ms G], [Mr B's] caregiver. Agreed to make contact.

[50] Dr C's clinical note dated 23 June 1998 recorded:

Discussed with [Ms K] – psychologist (behaviour assessment team) [...] Trust, [in a city] re [Mr B's] psychotic history. Written consent signed from both [Mr B] and his mother. Copy of leaflet re Asperger's Syndrome to give to mother (copy with notes).

[51] Dr C saw Mr B on 24 June 1998, with Mr H and Ms G. Dr C noted that Mr B was fitting in with his caregivers' lifestyle and was developing routines; he was attending Polytech "okay" and was not as sedated; he denied feeling depressed and had no suicidal ideas; his motivation was gradually improving and his concentration was improved; he denied any auditory hallucinations; he had regular contact with his mother and their



relationship had improved; and he was compliant with medications. Dr C discussed with Mr H and Ms G the prognosis, signs and symptoms of relapse and the importance of compliance with medication. Her plan was for Mr B to continue with his medications and for him to be seen in two months' time.

[52] Social worker notes dated 1 July 1998 recorded:

Appointment with [Mr H] and [Ms G] ([Mr B's] caregivers) in [a town]. Discussed how [Mr B's] placement is going. They reported [Mr B] is fitting in well with the family, and with their children, and has found it easier to fit in at his polytech course since his transition (he is in the same class as [Mr H], but is only doing one paper). They believe that [Mrs A's] expectations of [Mr B] are a little too high. Discussed the meaning of [Mr B's] psychiatric disability. Also discussed how [Mr B] is getting more in touch with his own identity. They had been told [Mr B] liked classical music, when he had confided he hated it; they are aware that [Mrs A] enjoys classical music, and wonder if he had been trying to please [Mrs A].

Discussed possible options for [Mr B]: Aftercare, [Community Trust work placements]. [Ms G] will take [Mr B] to Schizophrenia Fellowship next Friday at 2.00pm, and gradually assist him to utilise this group, before gradually withdrawing.

IHC are hoping to do a lifestyle plan for [Mr B], once [Mr B's] funding is approved. Stated I would be happy to participate in such a plan. [Mr H] and [Ms G] will contact me once a date is fixed. In the meantime, I will not be involved until that time.

[53] Social worker notes on 3 July 1998 recorded that Mrs A had telephoned requesting help arranging payment of the Open Homes bill. She also requested counselling for herself regarding Mr B going into care and to assist her coming to terms with his new diagnosis. Notes continued:

[Mrs A] also queried funding for [Mr B], stated that [the Needs Assessment and Service Coordination agency] were continuing to fund 2 week lots, but I understood that [Mr B] should qualify for IHC funding, according to the cognitive testing. ...

[54] Ms K, a psychologist at a Trust home, was asked to assess Mr B to determine whether he had an intellectual disability and therefore qualified for assistance from IHC. The assessment took place on 15 July 1998. Ms K's report concluded:

[Mr B's] level of general intellectual ability fell into the range of 'mild intellectual disability' and his level of adaptive functioning was significantly below that of his peers. Consequently, [Mr B] has been identified as having an intellectual disability and is therefore able to access the services available to this group.

[55] Mrs A advised:

The assessment report misconstrued information I had given regarding [Mr B's] early development. Further, lack of knowledge of his specific communication skills had resulted in gross inaccuracies. Studies of Asperger's syndrome have established that although there are obvious and characteristic problems with communication, there is no delay in intellectual development. [Mr B] certainly had problems with social interaction and with certain inappropriate behaviours but although he was not an academic, he certainly was not intellectually subnormal, as will be attested by many who knew him.



[56] Ms K advised [note: the questions below were asked of Ms K on behalf of the Commissioner. Her reply to each question is set out following the question.]:

The [...] Trust is based in [a city] and provides a wide range of services for people with intellectual disabilities living within the [...] region. The Behaviour Assessment Team of the [...] Trust provides specialist assessment and support for people with intellectual disabilities. One of the services of the Behaviour Assessment Team is to carry out assessments to determine if an individual has an intellectual disability and therefore if they are eligible for the specialised funding and support services designed for this group.

I have worked in the area of intellectual disability and challenging behaviour for the past seven years. For six of these years I have worked for the Behaviour Assessment Team of the [...] Trust. I obtained my registration as a psychologist specialising in this area four years ago while continuing to work for the Behaviour Assessment Team.

Who referred [Mr B] and on what basis, and what information about [Mr B] accompanied his referral?

[Mr B] was referred to the Behaviour Assessment Team by [Ms J] of [...], the Needs Assessment and Service Coordination agency in [...], on 11 June 1998. This referral was formally made by fax from [Ms J] with a copy of [Mr B's] needs assessment attached (dated 26 May 1998) and a copy of a letter from [Dr C] to [Ms J] (dated 27 May 1998) and a copy of a letter from [Dr C] to [Ms J] (dated 27 May 1998) and a copy of a letter from [Dr C] to [Ms J] (dated 27 May 1998) and a copy of a letter from [Dr C] to [Ms J] (dated 27 May 1998 – please see section below referring to information sourced from [Dr C]).

In telephone contact with [Ms J] I was told that [Mr B] had been referred to the IHC for residential services, which were put in place as an interim measure given that [Mr B] and his mother could no longer continue living together. However, [Mr B's] eligibility to access this service had to be determined before he could be considered for ongoing provision of residential services.

Therefore, [Mr B] was referred to the Behaviour Assessment Team of the [...] Trust to determine if he had an intellectual disability and therefore if he was eligible to access the specialised funding and services available to people with intellectual disabilities. The Behaviour Assessment Team presumed that [Mr B's] mother, [Mrs A], had been consulted about this referral and had permitted the information around [Mr B] to be forwarded as a part of the referral.

The referral was accepted by the Behaviour Assessment Team as it appeared from a historical and adaptive perspective that [Mr B] presented in ways that were consistent with a diagnosis of intellectual disability.

For the purpose of the assessment [Mrs A] was interviewed (21/6/98), [Mr B] was interviewed and assessed using a standardised psychometric test (22/6/98), and [Mr B's] adaptive behaviour functioning was formally assessed with [Mrs A] and again with [Mr H] (IHC contract board provider). I obtained signed consent from both [Mr B] and his mother to access information from [Dr C] and/or [Ms L] of the Mental Health Service at [the hospital].

What information was obtained from [Dr C]?

As outlined above, the referral to the Behaviour Assessment Team was accompanied by a copy of a letter from [Dr C] to [Ms J] (dated 27 May 1998). [Dr C's] letter identified that [Mr B] had



a diagnosis of Asperger Syndrome although he had also experienced a psychotic episode which may have been part of a depressive illness or an early onset of schizophrenia.

Following signed consent from both [Mr B] and his mother, I met with [Dr C] on 22 June 1998 to ask questions about [Mr B's] diagnosis. [Dr C] reviewed the mental health file on [Mr B] as we talked.

From the brief notes I made during this meeting with [Dr C] the key notes were that:

- [Mr B's] initial assessment with Mental Health Services was on 16 February 1998;
- [Mr B] had been given the diagnosis of Asperger Syndrome by a psychologist and paediatrician some five or six years previous (names not recorded);
- [Mr B] had been admitted to the mental health unit at [the hospital] on 6 April 1998 due to concerns over his mood, behaviour and relationship with his mother;
- During his admission [Mr B] was disruptive and agitated, and he had made threats of violence towards himself and others which had led to him being prescribed both regular and PRN [as needed] doses of antipsychotic medications, and he had to be secluded at one point after an altercation with another patient;
- During his admission there was some query over [Mr B's] presentation being caused by behaviour support needs versus actual psychosis;
- After approximately two weeks in the mental health unit [Mr B's] behaviour had settled following further medication changes, and he was described as being more stable and cooperative although he was noted to be bored;
- [Mr B] was discharged on 20 April 1998 as there were no more behaviour or mood problems evident;
- At the time of his first review (6 May 1998) with Mental Health Services after being discharged [Mr B] and his mother had decided to stop the prescribed medications, claiming that he had been over-sedated and was pacing at night. The file notes suggested that the ceasing of medication may have occurred after a conversation with the family's general practitioner. Moreover, [Mrs A] was reported to have controlled the session, she refused to acknowledge [Mr B's] psychosis and the need for medication;
- [Mr B] was reviewed again on 13 May 1998, at which time his medication was Risperidone and Arapax (noted to be the same medication as he was on at the time of my assessment with him one month later) and his mother was thought to be more accepting of his need for medication; and
- [Dr C] expected the true cause of [Mr B's] psychotic episode to become evident over time (ie if it was early schizophrenia then a schizophrenic pattern of behaviour and mood disorder ought to appear as he grew older).

What is your Understanding of Asperger Syndrome?

Due to my experience in the area of intellectual disability I have come into contact with a wide variety of people with Autistic Spectrum Disorders (ie Autism and Asperger Syndrome). One aspect of my registration process was to study the aetiology of many disorders that are found amongst people with intellectual disabilities. In addition, I had participated in a range of formalised training seminars prior to assessing [Mr B], which included: Recognising and Intervening with Adolescents at Risk for Suicide [...], Dual Diagnosis: Mental Illness and intellectual Disability [...], and Autism and Asperger Syndrome [...].

Moreover, I was recognised to have demonstrated a sound working knowledge of the disorder by the Team Leader of the Behaviour Assessment Team of the [...] Trust.



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As highlighted in the background and current situation section of my report, confirmation of [Mr B's] diagnosis of Asperger Syndrome was not part of the referral and so was not investigated as part of this assessment. Given that I was not provided with any firm evidence of this diagnosis for [Mr B], the diagnosis of Asperger Syndrome was taken into consideration but regarded as being speculative.

How you took Asperger's Syndrome into account when testing [Mr B].

The testing procedure engaged in with [Mr B] was that which is recommended in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM IV) for anyone who is suspected to have an intellectual disability. Furthermore, the Wechsler intelligence test that was used with [Mr B] is one of the recommended assessment tools for people with Autism and Asperger Syndrome.

References:

American Psychiatric Association (1994). Diagnostic and Statistical Manual of Mental Disorders (4th Ed.). Washington, D.C: American Psychiatric Press. Ms Iberg, Christopher (1995). Clinical Child Neuropsychiatry. Great Britain: Cambridge University Press.

With specific regard to the testing carried out with [Mr B], on the day that I met him I endeavoured to ensure that he understood and was consenting to the assessment. I met him at the house he was sharing with the care-givers he had been living with for approximately six weeks, and ensured that one of the care-givers was present in the house while I was assessing [Mr B]. I spent time talking with him about his background, family and interests in a bid to encourage him to feel more at ease with my presence and he was also invited to ask me any questions. He was also invited to take breaks during the assessment as he required, which he did to get glasses of water and to go to the toilet.

Although he appeared a little distracted and withdrawn, he appeared to attend to the required tasks to the best of his ability. As noted in my report, [Mr B] was hesitant with questions that he did not know the answer to and appeared anxious at different times during the assessment, particularly during the timed practical tasks. These are not unusual behaviours for a person with an intellectual disability and/or a person with Asperger Syndrome in a situation that they are being formally assessed. [Mr B] was praised for his efforts and told he had done very well on items intermittently throughout the assessment regardless of his actual performance. [Mr B] did not at any point indicate that he wished the assessment to end.

How you took Asperger's Syndrome into account when determining that [Mr B] had an intellectual disability.

According to the DSM IV a diagnosis of Asperger Syndrome cannot be made if there is another diagnosis that can more accurately account for the individual's presentation and subsequent support needs.

In [Mr B's] case there was evidence that he may not have met some of the DSM IV diagnostic criteria of Asperger Syndrome. Therefore, I was tentative about the accuracy of this diagnosis – as outlined in the first recommendation that I made (4.1 on page 4) regarding on-going regular reviews with Mental Health services "... to clarify if the diagnosis of Asperger Syndrome is appropriate". It is possible that a diagnosis of Autism may have been more appropriate for [Mr B] than Asperger Syndrome. However, the suitability of any such



diagnosis would have required a formal assessment by an appropriately qualified and experienced professional.

I would like to reiterate that the purpose of my assessment was to identify if [Mr B] had an intellectual disability not what had caused it or what other concurrent diagnoses might have been appropriate for him. The assessment that I carried out around [Mr B] demonstrated that he unequivocally met the diagnostic criteria for intellectual disability – regardless of its cause.

[57] Ms K was asked to comment further and advised:

What information [Mrs A] provided during her interview on 21 June 1998.

As you will be aware from my assessment report and my previous letter regarding the investigation, [Mr B] was referred to the Behaviour Assessment Team of the [...] Trust to determine if he had an intellectual disability and therefore if he was eligible to access the specialised funding and services available to people with intellectual disabilities.

According to usual practice when conducting an assessment of this sort, [Mrs A] was contacted to establish that she was willing and able to meet with the writer to discuss [Mr B]. [Mrs A] was subsequently interviewed at her home on Sunday 21 June 1998 (by recollection the appointment was made for the Sunday afternoon as [Mrs A] was due to be out of town for the remainder of the week and neither party wished to delay the assessment).

The purpose of this interview with [Mrs A] was to obtain background information about [Mr B] that might have bearing on a diagnosis of intellectual disability. Consequently, our discussion centred around [Mr B's] birth history, achievement of developmental milestones, social and academic abilities, family life, health issues and any other significant events that may have impacted on his development. We also discussed the events leading up to the assessment (i.e. confirming the need for an assessment of an individual's level of cognitive functioning and the anticipated benefits of this assessment).

[Mrs A] provided an outline of [Mr B's] formative years, family dynamics, school performance, social skills and behaviour, involvement with the Mental Health Service at [the hospital], and his move to residential services following his admission to the Mental Health Unit. The information provided by [Mrs A] was summarised and presented in the 'background and current situation' section of the assessment report. It was also during this interview that [Mrs A] was also asked questions around [Mr B's] adaptive behaviour functioning (see below).

How [Mr B's] adaptive behaviour functioning was formally assessed.

The psychometric testing procedure implemented around [Mr B] was that which is recommended in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM IV) for anyone who is suspected to have an intellectual disability. The DSM IV requires a standardised measure of both the individual's intellectual functioning and adaptive behaviour functioning. The Wechsler Adult Intelligence Scaled – Revised (WAIS-R) was used to measure [Mr B's] intellectual functioning while the Vineland Adaptive Behaviour Scales – Interview Edition (VABS) was used to measure his adaptive behaviour functioning. These are the assessment tools recommended by the DSM IV for diagnosing intellectual disability.

The VABS measures skills required for independent living within the community, identifying how reliable a person is in actually demonstrating these skills in comparison to their peers. The VABS is a standardised questionnaire that focuses on three key areas of functioning:



communication skills (including leisure activities, coping skills and relationships with others) and daily living skills (including domestic and personal care, and community skills). The information collated by the VABS is rated at the time of the administration on the basis of the frequency of the specified skills. The raw scores for each domain (i.e. communication, socialisation, and daily living skills) are calculated, and then converted into standardised scores. The standardised scores are then used to compare the individual's level of adaptive behaviour functioning against that of their peers and to obtain age equivalencies of the individual's level of functioning. It was these calculated age equivalencies that were reported on page 4 of the assessment report.

It is critical for the adaptive behaviour functioning measure to be valid and accurate. Therefore, the VABS must be administered to a person who knows the individual well and who can rate the individual on how reliably they demonstrate the specified skills (i.e. communication, socialisation and daily living skills). In [Mr B's] case it was [Mrs A] who provided the information around his adaptive behaviour functioning. [Mrs A] was interviewed using the standardised format provided by the Vineland Adaptive Behaviour Scales when I met with her on 21 June 1998.

Given that [Mr B] had not lived with his mother for some months, I also administered the VABS with [Mr B's] care-giver (Mr H), who [Mr B] had been living with for approximately two months. This 'doubling up' is fairly common practice when carrying out assessment around people who have had to move out of home as the result of a fractious relationship. The purpose of repeating the VABS is to determine if the individual will be disadvantaged by the responses given by their family.

In [Mr B's] case there was only a slight disparity between the responses of his mother versus those of [Mr H]. In fact, the VABS carried out with [Mr H] measured [Mr B's] adaptive functioning to be lower than that reported by his mother – which may have been a reflection of [Mr B] having only lived with [Mr H] for two months. As a result, the VABS carried out with [Mrs A] was seen to possibly be the more reliable of the two and so was the VABS information incorporated in the assessment report.

DSM IV diagnosis of Asperger Syndrome versus Autism

According to the DSM IV, a diagnosis of Asperger Syndrome cannot be made if there is another diagnosis that can more accurately account for the individual's presentation and subsequent support needs. As identified in my previous letter, on the basis of the information gathered and observations made during my assessment of [Mr B], there was evidence that [Mr B] may not have met some of the DSM IV diagnostic criteria of Asperger Syndrome – hence the suggestion that the diagnosis of Asperger Syndrome may not have been the most accurate diagnosis for him and that Autism may have been more appropriate.

In brief, [Mrs A] identified that [Mr B] was 'different' to his two older siblings from the time of his birth in that he was 'difficult', 'lacked a spark' and was 'unpredictable'. He also demonstrated delays or irregularities in his language development. The concerns around [Mr B] were obviously significant enough to warrant an assessment by a paediatrician around the age of two. [Mr B] was said to have been identified as 'retarded' at this time. He went on to demonstrate a range of social, cognitive and behavioural support needs throughout his childhood and teenage years. While [Mrs A] maintained that [Mr B] demonstrated many indicators of Asperger Syndrome (not detailed during the assessment procedure), [Mr B] was not observed nor reported to have demonstrated any of the typical indicators of this disorder within the two months that he had been living with [Mr H].



The DSM IV diagnostic criteria for Asperger Syndrome stipulates that an individual does not experience a language delay or cognitive impairment, and the disorder is not accounted for by another disorder. [Mr B] clearly demonstrated both language and cognitive impairments from an early age. These two deficits consequently preclude him from being diagnosed with Asperger Syndrome. Furthermore, the estimated age of onset may also be used to support a diagnosis of Asperger Syndrome with the disorder typically evident from the age of three years. However, [Mr B] was 'different' shortly after his birth and at approximately two years of age he was identified as being likely to experience cognitive impairments. Consequently, this information does not support the diagnosis of Asperger Syndrome.

However, these same deficits are included in the diagnostic criteria for Autism - a disorder which is closely linked to, and often overlays with, Asperger Syndrome given that they are both Autistic Spectrum Disorders.

Therefore, it appeared possible that a diagnosis of Autism may have been more appropriate for [Mr B] than Asperger Syndrome although more investigation would have been necessary to determine that he met the remaining diagnostic criteria (i.e. repetitive and stereotyped patterns of behaviour, interests, and activities).

I would like to point out that the verification of either diagnosis (i.e. Asperger syndrome or Autism) would have required a formal assessment by an appropriately qualified and experienced professional. This does not appear to have taken place while [Mr B] was alive and would be difficult to determine in retrospect, particularly given the circumstances. In addition, I would like to reiterate that the purpose of my assessment in June 1998 was to identify if [Mr B] had an intellectual disability not what had caused it or what other concurrent diagnoses might have been appropriate for him.

[58] Dr D saw Mr B at the outpatient clinic on 23 July 1998. Mr B felt "good" on his medications, did not feel too drowsy or sedated, and was happy to remain on them. Dr D recorded under 'Impression' in the clinical notes:

Seems more settled in his behaviour, settled and happier in new environment. ? effect of living in a less stressful environment where expectations are less. He seems to have benefited from antidepressant. No clear evidence of psychotic process.

Dr D recommended that Mr B continue taking his medication, slowly reducing the risperidone if he remained settled with his caregivers.

[59] On 3 August 1998 the Needs Assessment and Service Coordination agency organised a meeting to discuss Mr B's care needs. Ms L, Mr B's social worker, advised that she attended this meeting. Mrs A, Ms J and another staff member from the Needs Assessment and Service Coordination agency, a staff member each from Aftercare and from CCS, and Mr H and Ms G were also in attendance. Ms L advised that the outcome of the meeting was as follows:

Mental Health Needs:

[Mr B] to attend Outpatient appointments with Psychiatrist as required, and take medication as prescribed.

Vocational Needs:



Referral to be made to Aftercare for vocational assessment. [Mr B] and caregivers to arrange with [...].

Personal Needs:

[Mr B] does not require supervision in this area.

Social and Recreational Needs:

[Mr H] will take [Mr B] to the local gym. [Mr B's] need to access community groups and activities to be discussed at family and caregiver meeting with [Mr B] and IHC manager and other community groups. [Mr B] is to attend IHC holiday programme as required.

Accommodation Needs:

[Ms J] will seek funding to support [Mr B's] accommodation need, Contract Board through IHC being the preferred provider.

Caregivers' Needs:

[Ms M] to make referral to IHC Behaviour Support Team re training and ongoing support needs of caregivers.

Mental Health Social Worker to arrange training in area of understanding psychoses for [Mrs A] and IHC staff member, [Ms M]].

Respite Care for caregivers to be every alternate weekend.

Counselling Needs:

[Mr B] is to contact Mental Health Social Worker, [Ms L], if he requires counselling in the future.

Domestic Needs:

[Mr B's] need to learn to budget, use household appliances and learn basic cooking skills to be discussed at family and caregiver meeting with [Mr B] and IHC manager. IHC is to contract caregivers, [Ms G] and [Mr H].

- [60] Ms L advised that she reported the outcome of the meeting to Dr C.
- [61] Dr C's clinical note dated 11 August 1998 recorded:

Phone call from [the staff from], 'Aftercare' re concerns re [Mr B's] ability to do polytech course due to side effects from medication. Advised that this is not seen as major problem and that [Mr B] should be assessed from ability/IQ/motivation/concentration/stress in relation to functioning, rather than 'medication'. Plan: Review [Mr B's] side effects re \downarrow Risperidone if stable.

[62] Social worker notes dated 13 August 1998 recorded:

Liaised with IHC ([Ms M]) in regard to [Mr B]. Stated that the psychosis/depression diagnosis was very uncertain. [Mr B] may have been responding to stress. Discussed the benefits of my attending a case conference, rather than giving specific education sessions, as originally planned. [Ms M] will speak to the caregivers, and to [Mrs A] in regard to same. Discussed this case with [Dr D] at community meeting today.



Message from [Ms J], [the Needs Assessment and Service Coordination agency] left with [Ms I]. Stated that I would not be providing education sessions on mental health as agreed upon earlier at the case conference. Instead, I would meet with [Ms M] and [Mr B's] caregiver, to participate in a treatment plan for [Mr B]. This was in response to discussion with [Dr D], where he stated the main disability for [Mr B] is his Asperger's Syndrome.

[63] Dr C saw Mr B on 18 August 1998 following a referral by the Crisis Team. Mr B had taken a minor overdose two days earlier, which Dr C attributed to his anxiety and stress about a forthcoming holiday. Dr C believed that it was important to encourage low stress activities for Mr B as a way of avoiding future frustrations and impulsivity. In discussions with Ms G, Mr B's caregiver, and Ms M from the IHC, it was agreed that a Community Trust work placement might provide a more appropriate daily activity than the polytechnic, which Mr B was finding stressful. Dr C recommended that Mr B remain on his medication and discussed her management plan with Dr D, who was in agreement. Dr D advised:

I believe that the medications used in his treatment were necessary and appropriate at the time and found him to be settled when I saw him.

[64] Mrs A advised:

On August 24 [Dr C] concluded "[Mr B's] ongoing problems appear to be secondary to his low IQ (which she stated was 70) and Asperger's syndrome". This, in my opinion, erroneous conclusion (based no doubt on the above psychological assessment) obviously guided her treatment of [Mr B] throughout her dealings with him. This was a serious error which I consider was critical to the eventual outcome. It is a conclusion contradicted by [Dr D] who had noted in his Provisional and Differential Diagnoses on 3 March 1998:

"Asperger's syndrome probably normal intelligence."

[65] Dr C saw Mr B in the outpatient clinic on 29 September 1998. Mrs A told her that Mr B should not be attending daily IHC facility activities and suggested he attend a college. Mr B was unsure what course he should undertake. Dr C discussed the issue of daily activities with both Mr B and his mother. She was aware that Mr B's social worker was exploring options with various facilities. Dr C made a referral to an Activity Programme, which is provided by a local Trust for the benefit of mental health consumers.

[66] Clinical notes recorded:

[Mr B] seen initially alone then with mother [Mrs A] and caregiver [Ms G].

- [Mr B] reports that he is mentally well. Mood-okay, <u>sleep</u> up 1x/night, gets back to sleep ok. <u>Appetite</u> ✓ <u>Weight</u> stable. <u>Concentration</u> ✓ <u>Motivation</u> poor "can't be bothered", "feels bored".
- Reports no problems relationships with [Ms G]/[Mr H] and their family. Has little contact with mother (< once/week) or rest of his family.
- Says would like to see his father in [...].
- Main complaint "bored during the day no activities to do".
- [Mrs A] and [Ms G] joined us and advised that [Mr B] had not been telling "the whole story". [Mrs A] bombarded [Mr B] with questions, instructions eg "tell [Dr C] what you've



been telling me", "what <u>is</u> the problem, [Mr B]?", "I'm fed up listening to you and trying to help you" etc.

- Eventually the main problem identified was lack of daily structure/activities appropriate for [Mr B]. He has apparently tried
 - [Community Trust work placement] for 2-3 days "bored" "walked out".
 - (mum's comments: who wouldn't be bored "putting seeds in packets" he didn't like it, it's not the place for him, he couldn't talk to the people – "analyse what the problem was [Mr B]?")
 - Downtown Centre IHC workshop "wrong place, didn't get along with people, people were different". (Mother again emphasises that [Mr B] doesn't belong with IHC people from her perspective).
- Now considering the option of attending [the college] ? for what course. [Mr B] "I don't know".
- Compliant with medication, with no side effects.

[Mr B] looked physically well – hair washed, well dressed, carrying filofax. Speech – little spontaneous – answers questions appropriately in short sentences. Poor eye contact. No evidence psychosis/depression/anxiety. Poor insight.

Impression: mentally stable. No evidence symptoms psychosis/depression. Asperger's Syndrome.

Plan:

- 1. Long discussion re: daily activities for [Mr B]. ? were [the Community Trust work placement] etc adequately trialled ie only 2-3 days tried. Problems identified by [Mr B] with placements were they <u>HIS</u> problems rather than the 'placement' problems eg difficulty communicating, feeling 'bored'. [Mrs A] believes and aggressively states that [Mr B] doesn't belong in IHC placements. Other options suggested: [...], milking job/paper-round; course or [the college].
- Medications: Paroxetine 20mg daily
 ↓ Risperidone 1.5mg mane and 2mg nocte.
- 3. Follow-up 3/12. If earlier problems aware of contact with crisis team/[Ms L] etc.
- [67] Mrs A advised:

Early in October [Mr B's] IHC caregiver [Ms G] told me that she had telephoned [Dr C] because [Mr B] had spoken of killing himself. Ms G told me she had been wanting her help and advice. [Dr C's] response however had been that she was unable to see [Mr B] and that if there was a crisis [Ms G] should ring the crisis team. [Dr C] said that [Mr B] had seemed well the last time she saw him. The implication was that there wasn't a problem, so she offered neither help nor advice.

By now [Mr B] had been medicated for a considerable time with antipsychotic and antidepressive drugs. I do not believe that his medication or other aspects of his treatment were adequate at this time. [Mr B] was clearly frustrated with the social circumstances he found himself in and this led to severe depression which ultimately prompted him to take the overdose. I acknowledge that Asperger's is a difficult condition to deal with, particularly at the transition to adulthood, but it does appear to be amenable to specialist psychiatric therapy. I therefore asked for a referral to a specialist in Asperger's syndrome when [Dr C] saw [Mr B] on 19 October 1998. She said 'no'. I asked her if she would find the name of a specialist for me. Again she said 'no'.



[68] Dr C last saw Mr B on 19 October 1998 following referral from the Crisis Team for increased aggressive impulsive behaviour, irritability and suicidal thoughts. Dr E reviewed Mr B's care with Dr C. Mr B had no features of depression or psychosis and Dr E advised that a decision was made to admit Mr B to a ward so as "to engage him with the ambulatory Team to increase his daily activities which he felt his carers were unable to do". A conference was held between the Ambulatory Service, which is a type of day hospital service, and Mr B's caregivers. It was suggested that, when Mr B was discharged, he should attend the Ambulatory Service on a daily basis. In discussion with Dr E, Mr B's need for a longer term plan regarding daily activities was discussed, along with the need to involve IHC and his social worker. Mr B's medication was adjusted during his admission. He had no suicidal ideas or feelings of self harm at the time of his discharge.

[69] Dr C's clinical notes dated 19 October 1998 recorded:

Referred by crisis team for assessment re \uparrow suicidal ideas and \uparrow aggressive behaviour.

Initially seen alone, then with caregivers [Ms G] and [Mr H] and mother [Mrs A].

- [Mr B] complains of feeling low in mood for a few days with 'bad thoughts' suicidal ideas. Unable to elaborate.
- Had a few episodes of 'aggressive behaviour' over last few days, unable to identify any 'triggers' or explain his behaviour eg throwing things, tipping over furniture, smashing window with fist at IHC respite care.
- Reports sleep has become \uparrow disturbed, up several times during the night.
- Motivation remains poor, denies any problems with concentration. Feeling 'lifeless'.
- Denies any auditory hallucinations.
- <u>Major stresses</u>: difficulty in finding a daily activity programme for [Mr B], with which he (and his mother) feel comfortable.
- History from caregivers/mother: feeling unable to cope with [Mr B's] ↑ aggressive behaviour, has been ↑ agitated and needing 100% supervision. Follows them around constantly. Had respite care with IHC but [Mr B] smashed a window.
- Compliant with medication, denies any side effects.

<u>MSE</u>: [Mr B] is 18 year old male, with intellectual handicap. He is co-operative at interview. There is poor eye contact. Speech is spontaneous, but with little content – answers me one word answers only. Mood – slightly low and mildly anxious. Affect – reactive on occasions i.e. laughed spontaneously x 2. Reasonable insight. Admitted suicidal ideas but denies any intent.

<u>Impression</u>: 18 year old male with one previous admission – April 1998 ? mood disorder ? psychotic. Long history Asperger's Syndrome and IQ under 70. Has been treated with Paroxetine 20mg and Risperidone 2mg bd with noticeable improvement with mood \downarrow Risperidone 29/9/98.

Over last $4/7 \uparrow depressed \mod, \uparrow$ suicidal ideas and irritability – acting impulsively with aggressive manner e.g. smashed window with no identifying trigger. Main stress: lack of daily structured activity. Carer feels unable to cope with behaviour.

Plan:

1. Option of admission ward [...] vs ambulatory discussed - Carer/[Mr B] both request ADMISSION.



2. Suggest:

Risperidone to 2mg bd.
Paroxetine to 40mg daily
utilise Clonazepam 0.5mg TDS [three times daily] PRN [as needed].

- 3. Plan for admission of 3/7 [three days] with arrangement to D/C [discharge] to ambulatory to attend daily for further assessment.
- 4. Need to look at long term plan re daily activities (involve social worker [Ms L] and IHC).

To discuss with [Dr E], [...] [inpatient MOSS] Mother requesting referral to 'Asperger's Specialist'. Advise see IHC!

[70] Dr C advised:

I discussed increasing antidepressant and antipsychotic medication, on admission, in an attempt to prevent any further relapse. At the end of this assessment, after arranging admission for [Mr B], [Mrs A] requested referral to a specialist in Asperger's Syndrome. I advised her that to my knowledge there was no specialist available in [the region] and that I did not personally know of a specialist dealing with Asperger's Syndrome in New Zealand. I advised that IHC services may have knowledge about specialists visiting New Zealand from overseas, who specialised in the fields of Autism/Aspergers, and advised her to seek information via them. (This is referred to in my written clinical note of 19/10/98.) I also advised that the immediate focus was on admitting [Mr B] to Ward [...] in an acute situation to assess his mental state in view of the possibility of a relapse of depression and psychosis. I discussed the fact that we were not simply dealing with 'Asperger's Syndrome', this was only one factor in a multi-axial diagnosis. I also discussed the fact that [Mr B] would receive a further specialist opinion from [Dr E] during his admission.

I had no further contact with [Mr B], [Mrs A] or his caregivers until his caregivers presented at the mental health reception desk, following his admission to ICU having taken the fatal overdose of medication. I was unavailable at this time, but upon receiving the message asked the receptionist to contact them to offer themselves or [Mrs A] an appointment with myself. They said they no longer required an appointment. ...

[71] Ms G, Mr B's IHC caregiver, in a statement to the Coroner on 7 January 1999, advised:

19 October [Mr B] saw [Dr C]. [Mrs A] was present at the appointment with [Dr C]. [Mrs A] questioned [Dr C's] experience in the field of Asperger and suggested she do some research. [Dr C] said that was not her job. [Mr B] was admitted to ward [...] to increase his medication and give us some time out. ...

[72] Ms G further stated, by letter of 6 December 1999:

On October 19, 1998 I attended an appointment at [the hospital] Mental Health Unit with [Dr C].

[Mr B], [Mr H] and [Mrs A] were present.

The appointment was made after a weekend call out by the crisis team.



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[Mrs A] questioned [Dr C] asking what experience she had with Asperger.

[Dr C] said that she had no expertise in that field to which [Mrs A] suggested she do some research.

[Mrs A] also asked for [Mr B] to be referred to someone who was an expert in Asperger and [Dr C] said no and added she did not know anyone.

When [Mrs A] asked her to ask her colleagues or find someone on the Internet [Dr C] replied "that is not my job".

As a result of this meeting [Mr B] was admitted to ward [...].

[73] Mrs A stated:

Subsequent to the 19 October appointment, [Mr B] asked [Dr C] to admit him because he felt suicidal and knew he didn't want to die. However, he was discharged four days later by [Dr E] who said that [Mr B] didn't belong there. He didn't belong there. However, he did need appropriate care and support.

By now [Mr B] was at crisis point, the seriousness of which was evidenced by the fact that his mood continued to deteriorate and that only days later, on 1 November 1998, he took a fatal overdose.

[74] Mr B attended the ambulatory activity programme on 21 October 1998. Notes recorded:

Out for morning walk, also attending activities. Needed lots of direction. Poor insight in what activities we were doing – encouraged to attend again tomorrow.

[75] On 22 October 1998 it was noted in the clinical records that Mr B was "becoming increasingly bored about the ward". Following a discussion with Dr E it was agreed that Mr B would be discharged that day.

[76] On 28 October 1998 it was agreed that Mr B would attend the ambulatory day programme two mornings a week, starting 30 October for a week, after which time the placement would be reviewed, and other community involvement options for Mr B would be looked at.

[77] Social worker notes dated 28 October 1998 recorded:

Contacted [Ms G] in regard to [Mr B] (returned her call). [Ms G] stated that she was very concerned that [Mr B] was throwing things around the flat. [Ms G] stated that she felt that [Mr B] was used to getting attention from [Mrs A], and he wished to also get it from her. [Ms G] was concerned that [Mr B] did not have enough to do. Agreed to speak to Ambulatory Team in regard to [Mr B] attending there more regularly. Spoke to [...] ... would contact [Ms G], and discuss it. I understand [...] and [Ms G] spoke about this.

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[78] Social worker notes dated 29 October 1998 recorded:

[Ms G] contacted me again, stating that [Mr B]'s behaviour had become unmanageable – that he is constantly throwing things around. She has left their house, so he is not reinforced for this behaviour. Suggested that [Ms G] contact the Crisis Team, if she is concerned about [Mr B], and they will assess him. [Ms G] stated she had already spoken to the Crisis Team earlier that day. Suggested that [Ms G] seek some more support through IHC – perhaps the Behavioural Support Team. [Ms G] stated that she would do this.

[79] Mr B attended the ambulatory day programme on 30 October 1998. Notes recorded:

[Mr B] ... played a game of scrabble with success and participated in several other activities. His concentration was variable. Talked at times about wanting to know what he wants to do but just not knowing. Discussed interests a little. [Mr B] expected to attend on Wednesday.

[80] On 30 October 1998 Mr B's caregivers requested "time out" and he was placed with an alternative IHC board provider for the weekend beginning Friday 31 October 1998. Mr B went to bed at approximately 11.00pm on the evening of 31 October 1998. At some stage that night, or early the next morning, he swallowed a large number of Tegretol tablets, which belonged to someone else, and which were kept in an unlocked kitchen cupboard. He was found collapsed in the street at approximately 8.30am on Sunday 1 November 1998. Mr B was treated at [the hospital] for the overdose. From 3 to 6 November 1998 his condition was one of fluctuating improvement and decline and on 6 November 1998. An autopsy concluded that the cause of death was pulmonary fibrosis and bronchopneumonia.

Independent advice to Commissioner

[81] The following expert advice was obtained from Dr Deborah Antcliff, an independent consultant psychiatrist:

Purpose: I have been asked to provide independent professional advice about whether [Mr B] received an appropriate standard of care from [Dr C] and to answer specific questions regarding his care.

I am a general adult psychiatrist with a special interest in rehabilitation of young adults aged 16-25. Although I am not a specialist in Autistic Spectrum Disorders (which includes Aspergers Disorder) I have had considerable experience of young people in [Mr B's] situation.

I have read all the material provided by the Health and Disability Commissioner but have done no independent research.

The suggestion made by the Psychologist and Paediatrician, when [Mr B] was 14, that he had Aspergers Disorder, was assumed to be correct by the [hospital's] Mental Health Team, despite not being formally substantiated. He had had delayed speech development and was considered 'different' from birth. By two years of age a paediatrician had stated that he could be 'retarded'. This would militate against a diagnosis of Aspergers but there is considerable



debate about whether Aspergers differs in a qualitative or merely quantitative way from Autism. That is why they are referred to as Autistic Spectrum Disorders (ASD).

In the mental health file the recorded observations of his social behaviours and mannerisms were consistent with Aspergers or mild Autism but which it was cannot be definitively clarified now. [Mr B's] mother said he had Aspergers and throughout his file the developmental disorder is clearly identified as the primary issue. The mental health team appear to have been actively integrating this developmental disorder into their assessments of [Mr B's] current presentation and needs.

They did not adopt either an 'illness' or 'intellectual disability' model per se. They were constantly aware of the major stressors that [Mr B] had recently experienced. The separation of his parents and move from the family home combined with the transition from the stability of the school environment into the adult world. They were aware of the impact of all these changes on a person who would have limited coping strategies because of his developmental disorder.

However at every contact [Dr C] was specifically and thoroughly assessing [Mr B] for depression. It was clear she was aware that his was a significant potential problem and she documented this meticulously.

The ASD are usually included in the Intellectual Disability spectrum, whether or not there is significant intellectual disability, because of the pervasive, enduring impairments which make people very vulnerable and in need of specialist support.

The psychometric testing placed [Mr B] at the lowest end of the borderline/normal range on verbal skills and in the mildly impaired range for performance. The adaptive behaviour functioning was evaluated by using information directly from [Mr B's] mother and his current caregiver to confirm the findings. This assessment entitled him to access intellectual disability services.

When [Mr B] presented to the Mental Health services in February 1998 for the first time he had already begun to decompensate and this deterioration continued up to his first admission. The mental health team tried to establish how much of his behaviour was the result of his life changes and how much was potentially caused by an underlying mental illness.

When major decompensation occurs suddenly, it is always a challenge to try to tease out the way the various factors are interacting, because it is a totally new situation for all concerned. The significance of this cannot be underestimated. It is, to all intents and purposes, like starting at the beginning again.

It is likely that [Mr B] was able to maximise his resources and coping while he was at home, with both parents available, the support of the school, where he was known and had extra assistance. There is, though, clear evidence in the various documents that his 'success' was tenuous and conditional. I suggest that a huge contributing factor was the stable environment and encouragement that his mother had been able to provide him. Without this, the level of disability caused by his ASD may have been more obvious.

ASD is variable in its severity and is highly dependent on situational factors. The multiple factors that impacted on [Mr B] at the beginning of 1998 appear to have undermined his ability to cope and this in itself sets off a cascade of secondary consequences, which are almost unavoidable. For instance, his ability to verbalise appears to have deteriorated compared with



the descriptions given in the supporting letters and this would inevitably influence the assessments done. It also reflects what he was capable of doing at that moment in time and that is just as important as what he could do once, because the current situation is what everyone is trying to work with.

The mental health team believed that the major issues for [Mr B] were about finding stable and suitable accommodation after his relationship with his mother became untenable, and finding him occupational activities. From the notes they were committed to exploring every reasonable possibility and they consulted extensively with all the people they thought were relevant. They were aware, and documented, that there was disagreement between the formal assessment of [Mr B's] ability and his mother's evaluation. They tried to accommodate her perspective by including the [...] Polytech tutor in their consultation and by exploring with [Mr B] if there was a course he would like to do at [the college]. He could not identify anything he wanted to do. Significantly, the Tutor stated that [Mr B] could not cope at the Polytech. Nor could I find anything to suggest that the various caregivers thought that he was inappropriately placed in their facilities because he was too intellectually able.

Throughout New Zealand intellectual disability services provide much of the accommodation for people with ASD. They would therefore have been identified as the appropriate provider for [Mr B], particularly after his mother decided not to opt for mental health supported accommodation after his first admission. They have accommodation available for people with severe through to mild intellectual disability and they are regarded as having the best behavioural support services.

I do think that every effort was made to provide appropriate services for [Mr B] and with reasonable care and skill. The entire team was highly professional and they functioned in a collaborative and informative way. The standard of documentation is exemplary.

In response to the specific questions asked of me:

What are the specific standards that apply and were they followed?

There are no specific standards or guidelines for Autistic Spectrum Disorders or Aspergers Disorder because they are so variable and interventions are dependent on individual need. The priorities are for initial diagnosis of ASD and then diagnosis and treatment of concomitant problems, family support, accommodation and occupation. [Dr C] and the team were focused on precisely these issues.

In your opinion, did [Mr B] have a psychiatric illness?

From the notes it does not appear that [Mr B] would meet the diagnostic criteria for a specific psychiatric illness at any stage. However there were clear indications of abnormalities in his mood consistent with a mixed affective state. His Autistic Spectrum Disorder makes diagnosis of a psychiatric disorder more difficult.

Was it necessary for him to be medicated?

There were clear indications for medication. His distress and behaviour during his first admission were sufficient to justify treatment. [Mr B] himself initially identified that the medication was helpful in making him feel more in control and calmer. He was assaultative and aggressive on the ward. These are behaviours that are highly disadvantageous but they are amenable to treatment.



If so, was the medication he received appropriate?

Initially the medication regime was somewhat random but the decision to treat him with Risperidone and Paroxetine was entirely appropriate. Again [Mr B] identified that this combination was effective for him.

Was [Dr C's] diagnosis, on 6 May 1998, of depression with psychotic features reasonable in the circumstances?

[Dr C] was rightly concerned about depression. Although his presentation was not classic she had enough symptoms to justify a diagnosis of depression.

Was it reasonable to recommence [Mr B] on Haloperidol that day?

At about this stage [Mr B] mentioned he had heard voices, which can occur with depression. This would justify the use of Haloperidol, but these symptoms were constantly reviewed and it is clear that the team later did not believe he was hearing voices or was even psychotic. Antipsychotic medications are widely used to minimise aggression and anxiety and are the medications of choice for people who are experiencing agitation resulting from ASD or intellectual disability.

Was it reasonable, on 13 May 1998, for [Dr C] to have agreed to trial [Mr B] on antidepressant medication but to have emphasised the need for him to continue taking antipsychotic medication?

[Dr C] had already canvassed the possibility of introducing antidepressant medication on 6 May but his mother did not want [Mr B] on any medication at that stage. [Dr C] did prescribe it on 13 May in direct response to [Mrs A's] request for her to do so. He was restarted on antipsychotic medication because he deteriorated rapidly when it was stopped.

Was it reasonable, on 3 June 1998, for [Dr C] to recommend that [Mr B] continue with his medication?

The antipsychotic medication appeared to be having a positive effect on [Mr B's] aggressive, agitated behaviours and the addition of the antidepressant also seemed to lift [Mr B's] mood. There would therefore have been no indication to stop it after such a short interval.

Was it reasonable in the circumstances for [Dr C] to have relied upon the psychologist's report, which concluded that [Mr B] had an intellectual disability?

It was entirely reasonable for [Dr C] to have relied on the psychologist's report. Psychometric testing is a specialised area of Psychologist's expertise. The psychologist was experienced in assessments of people with intellectual disabilities and there is no reason to suspect she would have mismanaged the assessment, or not taken into account the communication or performance difficulties involved in the testing. There was nothing to indicate that the findings were an unreasonable assessment of his overall ability at that stage. His mother provided almost all the corroborating information, including his significant early developmental history. The presence of a reader-writer in his School Certificate English exam reflects the level of support he needed to acquire the mark he did.

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Was [Dr C's] subsequent treatment plan appropriate?

The treatment plan appears to be completely reasonable.

Was it reasonable, on 18 August 1998, for [Dr C] to recommend low stress activities for [Mr B] "as a way of avoiding future frustrations and impulsivity"?

[Mr B] had on at least two occasions that were documented complained privately that his mother's expectations were too high and that he was feeling stressed by them. He had also experienced, and not coped with, a series of major stresses in the year. His ASD made him more vulnerable to stress. More failure would have further damaged his self-esteem and could have caused more frustration and irritability. He could not cope at Polytech and was unable to decide on something at [the college]. His motivation had been severely affected but everyone acknowledged how important it was for him to have structured activity in his day. I expect the range of activities available was very limited. While it is totally understandable that his mother would advocate for him to do something that would stimulate and fulfil him, from the notes he does not pick up on any of her suggestions and that would have made it impossible to implement them. When the decision was made for him to go to [a Community Trust work placement] it was because the Polytech were saying he could not cope there. They did not suggest anything more appropriate as an educational institution. It is documented that [Mrs A] was very dissatisfied with their contribution.

Was it reasonable, on 29 September 1998, for [Dr C] to have made a referral to [an] Activity Programme?

[Dr C] could not be expected to have a primary role in sorting out daily activities for patients. She would need to be advised by other members of the multidisciplinary team as to what was available and suitable. This applies equally to [the Community Trust work and the Activity Programme]. She was working closely with the social worker throughout this time.

Was it reasonable, on that date, for [Dr C] to recommend that [Mr B] remain on his medication?

[Mr B] appeared to be having a positive response to his medication. It is standard practice for a person to stay on antidepressants for six months if they have had a good response. Because his ASD was an enduring problem his need for the Risperidone to modify the intensity of his anxiety and distress was also ongoing.

Was [Dr C's] response to [Mrs A's] request for referral to a specialist in Asperger's Syndrome reasonable in the circumstances?

I think the consultant psychiatrist should have considered consulting with either a developmental paediatrician or a child psychiatrist in one of the main centres because ASD is a rare disorder and general adult psychiatrists do not see it often.

This could have been reassuring for [Mrs A] who was clearly trying to ensure that her son was being properly treated and cared for.

The only way [Mr B] could have had an indepth assessment would have been by admission to an adolescent inpatient service in [one] or [the other city] and [the hospital] may or may not have agreed to fund that. Knowing that [Mrs A] was in disagreement with significant aspects



of care I think [Dr C] should have raised this request for a second opinion with her supervisor who should have acted on it.

Are there any other matters you consider relevant in relation to the standard of care provided to [Mr B]?

At the time of the second crisis admission to the mental health unit [Dr C] increased the dose of antidepressant. This reflects her ongoing concern that depression was a significant issue. He was not able to verbalise the depth of his distress and despair which were therefore not fully recognised and that led to his tragic death.

His youth and ASD made his presentation quite atypical but the mental health services appear to have been thorough and careful in their assessments, interventions, consultation, communication and planning. As [Mrs A] was involved in all the major decision making meetings it is very distressing that she experienced that her voice was not adequately heard or attended to. From the notes it is obvious that every effort was made to integrate her perspective although it is also clear that her view on [Mr B's] intellectual ability could not be substantiated at that point in time.

Code of Health and Disability Services Consumers' Rights

[82] The following Rights in the Code of Health and Disability Services Consumers' Rights are applicable to this complaint:

RIGHT 4

Right to Services of an Appropriate Standard

1) Every consumer has the right to have services provided with reasonable care and skill.

RIGHT 6

Right to be Fully Informed

- 3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about
 - (c) How to obtain an opinion from another provider; ...

Opinion: No breach – Dr C

[83] In my opinion Dr C did not breach Right 4(1) or Right 6(3)(c) of the Code.

Right 4(1)

Diagnosis of intellectual disability

[84] Mrs A was concerned that Dr C based her treatment of Mr B on a "misdiagnosis of intellectual disability".

[85] Mr B first presented at the hospital in February 1998 following an episode requiring his admission. He was referred for psychological testing some time later, on 15 July 1998.



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This was "to determine if he had an intellectual disability and therefore if he was eligible to access the specialised funding and services available to people with intellectual disabilities". Ms K, psychologist, determined, after appropriate consultation and testing, that "[Mr B's] level of general intellectual ability fell into the range of 'mild intellectual disability'".

[86] I accept the advice of my independent expert that Dr C was entitled to rely upon the report provided by the psychologist and her further advice that "[t]he [subsequent] treatment plan appears to be completely reasonable." (Refer para 81 above.)

[87] Dr C made reference to Mr B's intellectual functioning only after Ms K had provided her report, indicating that Mr B's general intellectual ability fell into the range of mild intellectual disability. Dr D did not have the report on 16 February 1998 when, on the basis of his initial assessment, he concluded that Mr B was "probably [of] normal intelligence".

[88] In my opinion Dr C's assessment and diagnosis of Mr B was made with reasonable care and skill and did not breach Right 4(1) of the Code.

[89] In commenting on my provisional opinion reaching the above finding, Mrs A expressed the view that "Asperger's was the major contributing factor of [Mr B's] state and that was recognised". Mrs A contends that the finding of intellectual disability was flawed and that it wrongly influenced the medical and social treatment of Mr B. She considers that the complaint against Dr C should be reviewed by an expert who is a specialist in Asperger's syndrome and that a final opinion cannot be reached on her complaint until that is done.

[90] I do not accept Mrs A's contentions. I deal first with the contention that review is required by an Asperger's expert. To resolve the complaint in accordance with the Code I am required to consider whether Dr C met the standard of reasonable care (to which Mr B was entitled under Right 4). The applicable standard of care is assessed by reference to the standard expected of medical staff in Dr C's position. Dr Antcliff, who was consulted as an independent expert, is a "general adult psychiatrist with a special interest in rehabilitation of young adults aged 16–25". Dr Antcliff was appropriately qualified to provide me with expert advice as to whether Dr C's care met the standard of reasonable care properly expected of a medical officer responsible for persons in Mr B's condition.

[91] No review by an expert in Asperger's is required to resolve this complaint. Had such an expert been approached the question that I would have required him or her to answer would have been exactly the same as that posed to Dr Antcliff, namely, whether Dr C met the standard of reasonable care required of persons in Dr C's position. Dr Antcliff has provided me with advice on that matter, and in light of her advice I have concluded there is no need to consult a further expert.

[92] Nor, for reasons that follow, do I agree that Dr C's treatment of Mr B was based on a "misdiagnosis of intellectual disability".



[93] First, it does not appear to me that the findings of the psychological test conducted by [Ms K] in late July can be described as a "misdiagnosis". The conclusion of mild intellectual disability was the outcome of an appropriate test, administered appropriately. Secondly, there is no evidence that the result of that test was relied upon by Dr C in the sense that it was pivotal to Mr B's medical treatment. The intellectual assessment became known to Dr C in August. Mr B's treatment since his first presentation in February had included antipsychotic and antidepressant medication. The opinion of the expert advisor was that it was appropriate that it do so, both before and after the results of the intellectual assessment.

[94] In short, the assessment itself does not appear to have been flawed; Dr C was entitled to rely upon the result reached; and the result reached was not pivotal to Mr B's subsequent medical treatment in any event. That treatment continued, as before, to respond to Mr B's presenting conditions, in light of his responses to medication. In these circumstances I accept the expert opinion that the standard of reasonable care was not breached in relation to Mr B's medication. I do not accept that the treatment was based on a "misdiagnosis" of intellectual disability.

[95] Mrs A, in her comments on my provisional opinion, raised a concern about the reliability of the assessment that was performed by [Ms K]. Ms K had expressed, in her report, doubts over the reported earlier diagnosis of Asperger's. One of Ms K's reasons for doubt was the "diagnosis" of Mr B – by a paediatrician when Mr B was aged two years – as "retarded". (The significance of the point is that, because part of the definition of Asperger's is that there be no other explanation for the subject's symptoms, a diagnosis of "retarded" militates against an Asperger's diagnosis.) Mrs A says that she gave Ms K the information about the diagnosis of "retarded". But she points out that she did so only to demonstrate the wide range of opinions that had been offered over the years in relation to Mr B, and not because it was regarded as an accurate diagnosis. Mrs A says that the paediatrician's examination of Mr B when he was two years old was in fact so brief that his "diagnosis" of Mr B as "retarded" deserved no credence. She is concerned that that statement was then used by Ms K as one of her reasons for doubting the Asperger's diagnosis.

[96] I appreciate Mrs A's concerns. But in my opinion the point has no bearing on the validity of the assessment of Mr B's intellectual ability by the psychologist. As Ms K points out in her report to me, she was not asked to diagnose Asperger's syndrome. That was in any event beyond her expertise. Rather, she administered an intellectual assessment test. It was relevant, however, for me to inquire whether the outcome of that test might have been affected by Mr B's underlying condition. As to that, Ms K comments that the test she administered is one recommended in the Diagnostic and Statistical Manual of Mental Disorders for anyone who is suspected to have an intellectual disability, and that the Weschler intelligence test used with Mr B is one of the recommended assessment tools for people with Autism and Asperger's Syndrome. In other words, such a test would be part of the assessment process for Asperger's, and is for that reason not ruled out by a possible diagnosis of Asperger's. The psychologist further notes the steps taken in the administering of the test so as to ensure Mr B was at ease and able to perform to the best of his abilities.



[97] It follows that I have no evidence that the intellectual assessment was flawed. In any event, I accept the advice of the independent expert that Dr C was entitled to rely upon the result of that test. Further, I do not accept that it is correct to characterise Dr C's treatment of Mr B as based on a "misdiagnosis" of intellectual disability. The treatment of Mr B did not hinge on any such diagnosis. Rather, the result of the intellectual assessment formed (along with the reported diagnosis of Asperger's on an earlier occasion) part of the background information against which Mr B's treatment was being worked out during the period from February to October 1998.

Medication

[98] Mrs A was concerned that Dr C medicated Mr B unnecessarily and possibly inappropriately.

[99] Mr B began receiving medication following his admission to the hospital on 6 April 1998. His behaviour in the days leading up to this admission had been "disruptive" and, while on the ward, he displayed erratic and impulsive behaviour, which included assaulting a staff member. Dr E discussed with Mrs A the need to medicate Mr B and gained her consent to do so. Mr B subsequently admitted that the medication made him "a bit calmer" and felt that his moods were more "evened out". Mrs A noted, on 14 April 1998, that "the medication [was] helping".

[100] I note the advice of my independent expert that:

There were clear indications for medication. His distress and behaviour during his first admission were sufficient to justify treatment.

[101] Mr B's general practitioner discontinued his medication on 5 May 1998, owing to sedation. When Mr B saw Dr C for the first time, on 6 May 1998, she made a diagnosis of depression with psychotic features and recommenced him on haloperidol, which was changed by Dr D to risperidone on 7 May 1998.

[102] My independent expert noted:

At about this stage [Mr B] mentioned he had heard voices, which can occur with depression. This would justify the use of Haloperidol. ...

[103] On 11 May 1998 Mrs A called Mr B's social worker wanting to discuss changing him from antipsychotic to antidepressant medication. She was referred to Dr C, who saw Mr B on 13 May 1998. Dr C agreed to Mr B trialling an antidepressant medication but emphasised the need for him to continue taking his antipsychotic medication. On 3 June 1998 Dr C reviewed Mr B and noted that he had no psychotic features, and his depressive symptoms had improved. She recommended that he continue with his medication. I note the advice of my independent expert:

The antipsychotic medication appeared to be having a positive effect on [Mr B's] aggressive, agitated behaviours and the addition of the antidepressant also seemed to lift [Mr B's] mood. There would therefore have been no indication to stop it after such a short interval.



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[104] Mr B was seen by Dr D, a consultant psychiatrist, on 23 July 1998. Dr D requested that Mr B remain on his medication, slowly reducing the risperidone if he remained settled with his caregivers. When Dr C saw Mr B, on 29 September 1998, she again requested that he remain on his medication, but that the risperidone be reduced. I note the advice of my independent expert:

[Mr B] appeared to be having a positive response to his medication. It is standard practice for a person to stay on antidepressants for six months if they have had a good response. Because his ASD was an enduring problem his need for the Risperidone to modify the intensity of his anxiety and distress was also ongoing.

[105] There is no evidence that Mr B was medicated either unnecessarily or inappropriately. In my opinion Dr C provided clinical services with reasonable care and skill and did not breach Right 4(1) of the Code.

[106] Mrs A made two comments in relation to my provisional findings in relation to medication, as set out in paras 98 to 105. First, that Mr B was "continually prescribed antipsychotics, and it was noted in [Dr C's] notes that I had problems accepting the fact that [Mr B] was psychotic". Secondly, that in October 1998 she had understood that antipsychotics were to be decreased concurrent with an increase in antidepressants, but that she "subsequently found that they had been increased".

[107] As to these comments, I am guided by the advice of the independent expert that the treatment overall was completely reasonable and, specifically, that the antipsychotic risperidone was "entirely appropriate" and that the need for it was ongoing to modify Mr B's anxiety and distress. I note also the expert's advice that "antipsychotic medications are widely used to minimise aggression and anxiety and are the medications of choice for people who are experiencing agitation resulting from *ASD or intellectual disability*" (my emphasis).

[108] I turn to Mrs A's second comment – that she had understood, from Mr B's last appointment with Dr C, that the antipsychotic medication would be decreased. Dr C's notes record: "suggest: [arrow upwards] risperidone to 2 mg bd".

[109] Dr C's written statement said, in relation to the consultation on 19 October 1998:

I discussed increasing antidepressant and antipsychotic medication, on admission in an attempt to prevent any further relapse.

[110] In my opinion, having regard to the advice of the independent expert, this treatment met the standard of reasonable care. From the contemporaneous notes, and Dr C's explanation, it does not seem that there was discussion on 19 October 1998 of the risperidone being decreased. Nor is it clear to me from the information on Mr B's file that it actually *was* increased beyond 2 mg bd – Dr E records that when Mr B was discharged on 22 October 1998 he was to have his medications in a "blister pack (paroxetine 40 mg daily, Risperidone, 2 mg bd)". In any event, the expert's opinion is that the prescribed medication was reasonable throughout.



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Care and support

[111] Mrs A complains that Dr C neglected Mr B's need for appropriate care and support. The concern is that the non-medical aspects of Mr B's care – that is, his accommodation and daily activities – were influenced by the finding of intellectual disability and that this led to inappropriate placements for Mr B. As Mrs A put it in her letter commenting on my provisional opinion, she is "quite certain that his general depression etc was due to lack of appropriate stimulation and that 'low stress activities' such as [the Community Trust work] subsequently exacerbated it".

[112] Mr B's mental health team was focused on ensuring that suitable accommodation was available for him and that he had access to a day activity programme. It is clear that a significant amount of time was devoted to these issues. While there was disagreement between Mrs A and the team about the extent of Mr B's abilities, attempts were made to accommodate her perspective.

[113] I note the advice of my independent expert on this issue:

[Mr B] had on at least two occasions that were documented complained privately that his mother's expectations were too high and that he was feeling stressed by them. He had also experienced, and not coped with, a series of major stresses in the year. His ASD made him more vulnerable to stress. More failure would have further damaged his self-esteem and could have caused more frustration and irritability. He could not cope at Polytech and was unable to decide on something at [the college]. His motivation had been severely affected but everyone acknowledged how important it was for him to have structured activity in his day. I expect the range of activities available was very limited. While it is totally understandable that his mother would advocate for him to do something that would stimulate and fulfil him, from the notes he does not pick up on any of her suggestions and that would have made it impossible to implement them. ...

[114] I am guided by the advice of my independent expert that:

[Dr C] could not be expected to have a primary role in sorting out daily activities for patients. She would need to be advised by other members of the multidisciplinary team as to what was available and suitable. This applies equally to [the Community Trust work and the Activity Programme]. She was working closely with the social worker throughout this time.

[115] I note also that the decision to refer Mr B to IHC for contract board is recorded in the notes to have been made "by consensus" at a meeting with Mr B, Mrs A, a friend of Mrs A's, and a social worker on 14 April 1998. This was before the first meeting with Dr C. (See paragraphs 27 and 28 above).

[116] In her comments on my provisional opinion Mrs A disputes the statement attributed to Ms I of the Polytech on 26 May 1998 that "[Ms I] believes every effort has been made [by the Polytech] to accommodate [Mr B's] disability". In my opinion the accuracy of Ms I's assertion is, for present purposes, a collateral issue. The fact is that it was made, and that was one aspect of the position faced by the team caring for Mr B in 1998. It is not relevant to the complaint against Dr C.



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[117] Mrs A says that she was not told by Dr C of Dr C's belief, recorded in her notes after August 1998, that Mr B had a low IQ and a mild intellectual disability. Mrs A says that this belief was erroneous and that, if she had been told, she would have been able to demonstrate Mr B's ability to Dr C. I have considered this point but do not believe it alters the conclusion I had previously reached. Dr C formed her belief about Mr B's intellectual disability on the basis of the assessment by Ms K. Mrs A was aware of that assessment (though contests its accuracy). The care of Mr B from this point therefore took place against a background in which Ms K's assessment of Mr B was known to both Dr C and Mrs A. I do not accept that it was wrong for Dr C to record the outcome of that assessment in her notes as part of Mr B's background. I do not accept that Mrs A ought to have been advised so that she could have the opportunity to have Mr B "demonstrate his abilities" and refute the assessment. The important fact for present purposes is that there were subsequent disagreements between Mrs A and others over the appropriateness of Mr B's placement and activities. Mrs A's concerns are well documented in the notes. The issue of Mr B's abilities was therefore "in the open" throughout the relevant period and, indeed, it formed the principal cause for contention about Mr B's activities. Attempts were made to offer options for Mr B that corresponded to Mrs A's preferences (such as the college) but in the circumstances it did not appear Mr B was willing. The independent expert has considered these points in her advice that Dr C did not breach the standard of reasonable care.

[118] In my opinion Dr C took appropriate steps to address Mr B's need for care and support and did not breach Right 4(1) of the Code.

Right 6(3)(c)

Second opinion

[119] This complaint emanates from Dr C's consultation with Mr B and Mrs A on 19 October 1998, which was the last one before Mr B's tragic death. Mrs A says that Dr C refused her request for a referral to a specialist in Asperger's Syndrome. She says that Dr C said to her "it was not her job to find out the names of any [Asperger's specialists]". Dr C's account of that aspect of the consultation is that she told Mrs A that, to her knowledge, there was no specialist in [the region] and that she did not personally know of a specialist dealing with Asperger's Syndrome in New Zealand. Dr C says she advised Mrs A to contact IHC as it might have knowledge of overseas specialists visiting New Zealand.

[120] The accounts of all participants in the consultation on 19 October are likely to be correct. Dr C's account is supported by her contemporaneous notes. Mrs A's account is supported by Ms G who was also present. The significant point is that the consultation ended with a request by Mrs A for referral to a specialist. That request was met by Dr C's answer that there was no specialist in [the region], that she knew of no specialist in New Zealand, and that Mrs A should make contact with IHC for suggestions. If Dr C also said it was "not her job to find a specialist", this was said in the context of a simultaneous recommendation that Mrs A could herself approach IHC for advice on locating a specialist.

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[121] In my opinion, no breach of Right 6(3) is established in these circumstances. That provision of the Code entitles a consumer to honest and accurate responses to requests for further opinions. The consultation ended with Dr C having suggested a course of action for Mrs A to take in order to access another provider. Given Dr C's admitted lack of knowledge of an Asperger's expert in [the region] or New Zealand as a whole, that was a reasonable and appropriate course of action. It was honest and accurate, and designed to facilitate rather than hinder the obtaining of another opinion from a specialist. I accept that another approach might have been, as Dr Antcliff observes, for Dr C to undertake to ask her supervisor about the availability of an expert. But I do not think the reasonableness of that possible alternative approach means that the approach actually taken by Dr C on that day was not itself reasonable.

[122] In this regard it is relevant that the consultation was occurring because of a referral of Mr B by the crisis team due to his increased suicidal ideas and aggressive behaviour. At the time Dr C was focused on re-admitting Mr B to the mental health unit "in an acute situation to assess his mental state in view of the possibility of a relapse of depression and psychosis". In an ideal situation I would agree with my expert advisor that Dr C might have taken advice from her supervisor in order to provide the name of an expert. However, I consider that, given the immediate circumstances she faced, Dr C responded to Mrs A's request for a second opinion in a reasonable way.

Opinion: No breach – The Public Hospital

Vicarious liability

[123] Employers are vicariously liable under section 72(2) of the Health and Disability Commissioner Act for ensuring that employees comply with the Code of Rights. Under section 72(5) it is a defence for an employing authority to prove that it took such steps as were reasonably practicable to prevent the employee from doing or omitting to take the action that breached the Code.

[124] As I have concluded that the care provided by Dr C to Mr B was reasonable in the circumstances, no question of vicarious liability on the part of the hospital arises.

Actions

[125] A copy of this opinion will be sent to the Medical Council of New Zealand.

[126] An anonymised copy of this opinion will be sent to the Royal Australian and New Zealand College of Psychiatrists, and placed on the Health and Disability Commissioner website, <u>www.hdc.org.nz</u>, for educational purposes.

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