A Report by the Deputy Health and Disability Commissioner

(Cases 22HDC03019 and 23HDC01424)

Introduction ... 1
Background ... 2
Complaints and information gathered ... 4
Opinion ... 9
Mr A's complaint ... 10
Mrs B's complaint ... 12
Recommendations ... 15
Follow-up actions ... 15
Appendix A: In-house clinical guidance to Commissioner ... 16
Appendix B: Excerpt from Whaikaha|Ministry of Disabled People's Aotearoa Autism guidelines ... 17

Introduction

1. This report is the opinion of Ms Rose Wall, Deputy Health and Disability Commissioner, and is made in accordance with the power delegated to her by the Commissioner.

2. The report discusses the services provided to Mr A and Mrs B by a disability service and Mr C. The complaints HDC received from these consumers raise concerns about poor organisational processes, a lack of policies and procedures, potential exploitation and treatment of vulnerable consumers, and poor engagement in the complaints process.

3. The following issues were identified for investigation:

- *Whether the disability service complied with relevant professional, legal and ethical standards when it provided Mr A with advocacy support and services from February to November 2022 (inclusive).*

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

- *Whether Mr C complied with relevant professional, legal and ethical standards when he provided Mr A with advocacy support and services from February to November 2022 (inclusive).*
- *Whether the disability service complied with relevant professional, legal and ethical standards when it provided Mrs B with advocacy support and services in May 2023.*
- *Whether Mr C complied with relevant professional, legal and ethical standards when he provided Mrs B with advocacy support and services in May 2023.*

4. The parties directly involved in the investigation were:

Mr A	Consumer
Mrs B	Consumer
Disability services provider	
Mr C	Individual provider

5. In-house clinical guidance was obtained from GP Dr David Maplesden (Appendix A).

Outline of report

6. I will address each complaint, each of the individual issues, and my final decisions in turn.

Background

Disability service and Mr C

7. The disability service[1] was set up in 2019 to help people navigate the mainstream Work and Income New Zealand (WINZ) benefits. Currently the disability service supports mainstream beneficiaries and people with physical and mental illness and neuro-diverse disabilities. The disability service offers disability navigation support with various government agencies and with particular issues such as employment disputes and accident compensation. In addition, the disability service offers individual disability assessments, ongoing disability support, disability information, and disability community presentations. Mr C describes his role as a Senior Disability Service Navigator, and he is the Chairman. Mr C is not a registered health practitioner.[2]

First complaint

8. On 28 November 2022, this Office received a complaint from Mr A[3] about the services provided to him by Mr C and the disability service. Mr A's complaint raised concerns about potentially unethical business practices and overcharges. The complaint is set out in more detail below.

9. On 18 April 2023, Mr C responded to HDC's information request and refuted the complaint. He stated:

[1] A registered charity.
[2] A practitioner who practises in a regulated profession, eg, a doctor, nurse, or psychologist.
[3] Via the Nationwide Health and Disability Advocacy Service.

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> '[T]his complaint has been investigated and resolved by [the disability service] and we now feel it appropriate to say that this matter is ended and that any more issues raised by the former client will not be accepted.'

10. On 21 April 2023, Mr C responded, but he did not respond in full or provide all the documents requested. This Office had requested that Mr C provide the following:

> '[A] **copy** of all policies, procedures and guidelines in place at the relevant time relating to the issues in this complaint, including but not limited to Informed Consent, Complaint Process, and supporting people with disabilities.'

11. Mr C wrote in his response: 'We don't have these policies written yet.'

12. Mr C's response stated that when Mr A signed up, it was clear that he would cause issues. Mr C said that Mr A was a narcissistic autistic and that the disability service could no longer work with him. These derogatory comments raised further concerns about the provider's complaints processes at the time.

Second complaint

13. On 1 June 2023, this Office received a complaint about the disability service and Mr C from Mrs B. The complaint concerned multiple issues related to advocacy support and services provided by the disability service and Mr C. The concerns included potentially unethical business practices, overcharges, a flawed diagnostic process, and the response Mrs B received when she requested her personal health information. This complaint is discussed in more detail below.

14. On 12 June 2023, Mr C responded to HDC's information request. He stated:

> 'We at [the disability service] want our thoughts on file please with relation to this complaint that we have been subjected to by a former client who was exited from our service in May 2023 — this former client has a history of false complaints to government departments and external agencies if they don't get their own way — This complaint [has] been investigated and resolved by [the disability service].'

15. On 12 June 2023, HDC wrote to Mr C requesting a detailed response to Mrs B's complaint, but this was not provided.

Both complaints

16. On 9 August 2023, this Office wrote to Mr C and explained the rights of healthcare consumers. The email stated:

> 'Right 10 of the Code of Health and Disability Services Consumers' Rights (the Code), outlines consumers' right to complain. It is imperative that healthcare providers engage with HDC to resolve consumers' concerns.'

17. The email noted that 'the Deputy Commissioner is able to formally investigate breaches of Right 10 of the Code' and concluded that if this Office did not receive a response by 23

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August 2023, HDC would 'continue with [its] assessment of [Mrs B's] complaint without [Mr C's] input'.

18. On 27 October 2023, the disability service and Mr C were notified of an investigation in respect of both complaints. HDC asked for a response to Mrs B's complaint and for further information regarding both complaints. Mr C acknowledged receipt of HDC's information request and asked for the password to open the attachment.

19. However, to date, the disability service and Mr C have not responded to this Office's request for further information. Mr C has declined to engage with HDC's processes further.

Complaints and information gathered

Mr A's complaint

Background

20. Mr A has autism[4] and for several years has attended a support group organised by Autism New Zealand. His main income is a benefit from WINZ.

Events leading up to complaint

21. In 2021, Mr C attended an Autism New Zealand session as a support group member. In the session he discussed the disability service and the services he provides for those living with a disability. Mr C told the group that he advocates for and supports people with a disability.

22. Mr A arranged an appointment with Mr C in February 2022 to discuss the services offered by the disability service. During the first appointment, they discussed the terms of the contract agreement, to which Mr A agreed. Mr C explained that he would contact WINZ to review Mr A's benefits and ensure that he was being paid correctly.

23. During the second appointment, Mr A's WINZ benefit payments and a redirection of fees were discussed and agreed upon. Mr A signed a WINZ benefit redirection form. The agreement included that $20 would be redirected weekly from Mr A's WINZ benefit to the disability service's trust account.

24. During the third appointment, Mr C was running late and had forgotten about their meeting. Despite meeting with Mr C for only five minutes that day, Mr A was still charged $80 for the appointment.

25. Mr A became concerned about the length of time it was taking to review his benefit, and he contacted Mr C. During May 2022, Mr C and the disability service sent emails to Mr A's representative,[5] advising that they were working on Mr A's case, and would respond when there had been a response from WINZ.

[4] Autism spectrum disorder.

[5] From a service that promotes and supports consumers into employment.

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26. Mr A felt that Mr C was not taking his concerns seriously and approached WINZ directly. Mr A told HDC that WINZ informed him that it had received a document confirming that Mr C would be acting on Mr A's behalf and for deductions from his benefit to be made directly to the disability service. However, because of the lack of progress,[6] Mr A decided to cancel the WINZ redirection payments at the end of May 2022.

27. With the support of Mr A's representative, a meeting was organised with the disability service on 11 August 2022 in an attempt to discuss and resolve Mr A's concerns.

28. Mr A stated that at the meeting, Mr C was 'defensive in his approach' and would not provide a copy of the redirection form. Mr C also insisted that WINZ was 'lying' about his contact with WINZ. Mr A requested a refund from the disability service, and a confirmation of Mr C being removed from his WINZ file.

29. Mr A did not receive a copy of the signed redirection form, payment details, or the refund he had requested.

30. Mr A is concerned that he never received the agreed service as the benefit review was not completed, and that Mr C took advantage of his vulnerability for 'personal financial gain'. Mr A believes that he is not the only victim of such 'exploitation and manipulation' from the disability service.

31. Mr A stated that this issue has affected his mental health immensely. He feels that because of his disability, he was an easy target to be 'manipulated and exploited' by the service, and now fears that others see him in the same way.

Mr C's response

32. Mr C stated that he has never had any issue with clients wanting copies of the letters they have signed. He said that the disability service holds this information and meeting notes on file, and clients can request this information at any time.[7]

33. Mr C noted that Mr A had read the client engagement letter, the Terms and Conditions, and the itemised invoice documents, and had attended three meetings. Mr C concluded that Mr A had received all the services as per their initial agreement.

34. Mr C told this Office that he made several attempts to contact Mr A to no avail, and that because of this lack of contact, the disability service was ready to discharge him from its service. The disability service discovered that Mr A had been ringing the office on an old phone number, which had changed. Mr C stated:

> '[I]t was clear that the client relationship was broken at this point and we couldn't any longer work with [Mr A] or his Support personnel.
>
> …

[6] Approximately four months.

[7] Previously HDC had asked the disability service/Mr C for a complete copy of Mr A's records, to no avail.

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[N]o outcome was able to be reached with [Mr A] we tried over a meeting held on the 11th August 2022 and we failed to reach any sort of agreement — the only thing that [Mr A] and his support personnel were interested in was getting the $20.00 refunded which we have refused to do as it's not a big deal.'

35. Mr C concluded:

> '[I]t was clear from the moment [Mr A] signed up with [the disability service] that he was going to cause issues we are aware of others who have experienced what [Mr A] can do if you wrong him and were advised to proceed with extreme caution … [Mr A] is what we term a serious narcissistic autistic who will not ever be able to accept he isn't in the right on most matters.'

36. Mr C stated that Mr A 'abused [the disability service's] office manager who immediately reported the issue to [Mr C]'.

37. In response to the provisional opinion, Mr A questioned the identity of the 'others' referred to in paragraph 35, and why Mr C agreed to work with him if he had been informed to be cautious. In addition, Mr A was 'confused and shocked' about being accused of abusing the office manager, when his only memory of their interaction was asking questions regarding the service.

Further information from Mr A

38. When Mr A was notified that HDC intended to investigate his complaint, he communicated[8] that he did not want to provide further comment. However, he said that he wished 'to let HDC know that he however, trust[s] that HDC will conduct a thorough and fair investigation and in hope that the provider will be held accountable for his doings and ensure that no other person with a disability is exploited in the same way as he was'.

Mrs B's complaint

Background

39. Mrs B stated that she was approached by Mr C after she posted a comment on the New Zealand Autism social media group chat. She said that Mr C claimed that he could help her 'obtain an assessment for Autism'.

40. Mrs B agreed for the disability service/Mr C to help her to obtain an autism assessment. Subsequently, she was sent a questionnaire by Mr C and told that a nurse practitioner would review it, which would take a few days. After 20 days, Mr C informed Mrs B that an official diagnosis of autism had been made. Mrs B provided HDC with a copy of the email from Mr C, which stated:

> 'I had a chat with our nursing advisor last week — and they have had a look at your completed forms and they have told me it's a diagnosis of ASD — Autism Spectrum Disorder around the 85% which is the high functioning end of the Spectrum. I'm sorry

[8] Via the Nationwide Health and Disability Advocacy Service.

its taken this long to give this information we wanted to be 150% Correct before advising.'

41. Mrs B became suspicious that the diagnostic process was flawed,[9] and requested supporting documentation and/or reports, including the name and qualification of the nurse practitioner. Mr C declined to provide her with any of the information Mrs B sought and informed her that a report would cost more and would not be achievable until 2024.

42. Mr C charged $700 for the diagnosis, payment for which was paid by funds redirected from Mrs B's WINZ benefit to the disability service's account. According to Mrs B, WINZ investigated the company and process, and expressed concerns about fraud, given that the process followed for diagnosis was not correct.

43. Mrs B later obtained an autism diagnosis through a registered psychiatrist in private practice.

Mr C's response

44. Mr C stated:

> '[T]his former client has a history of false complaints to government departments and external agencies if they don't get their own way … [W]e aren't actually registered as a Disability Service provider and hold no contracts with particular government departments [and] this complaint has caused additional administrative hours for our staff who have to step away from supporting our clients to tend to a matter that is totally trivial.'

45. In an email to this Office dated 8 August 2023, Mr C stated:

> '[T]his complaint brought by [Mrs B] is not only false and completely untrue but it's a waste of resources by our organisation at all times we tried to assist [Mrs B] professionally and only got back continued disrespectful and unprofessional attitude at no time we were ever rude or unprofessional [Mrs B] didn't contact us when she decided to stop paying fees for the service we provided ... She even went as far as harr[a]ssing our staff when they were on leave and demanding things be done within five minutes of her often frankly unreasonable requests …'

46. Mr C concluded: 'We consider this matter closed and will not [be] reopening any files for [Mrs B] going forward.'

In-house clinical guidance from Dr David Maplesden

47. Dr Maplesden is a vocationally registered general practitioner (GP). He advised that he used the New Zealand guidance[10] as a reference for his clinical advice regarding the diagnosis of autism spectrum disorder (ASD) (autism) in adults.

[9] She had gathered information from other sources regarding 'how to diagnose Autism'.

[10] See Appendix A: Whaikaha | Ministry of Disabled People, NZ Autism Guidelines.

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48. Dr Maplesden stated that preferably, a diagnostic assessment should be undertaken by a multidisciplinary team of healthcare practitioners experienced in autism. In the absence of an assessment team, a healthcare practitioner highly trained and experienced in autism may undertake the diagnostic assessment.

49. Diagnostic assessment of adults should be comprehensive and involve the person concerned in interviews and observation. In addition, standardised ASD assessment interviews and schedules should be used. The intellectual, adaptive, and cognitive skills associated with autism/takiwātanga should be considered seriously and, where possible and appropriate, assessed formally.

50. Usually, diagnosis in the public system involves a GP referral to the adult mental health service with an appropriate outline of mental health history and concerns. In the private sector, the GP may refer the patient to a clinical psychologist with experience in adult ASD, or to a psychiatrist.

51. Dr Maplesden concluded:

> '[A]s noted in the cited guidance, assessment usually included face to face interview, completion of standardised evidence-based psychological tests and questionnaires and gathering of relevant collateral history. The process described by the complainant certainly sounds far removed from accepted practice.'

Responses to provisional opinion

52. Mr A and Mrs B were given the opportunity to respond to relevant parts of the provisional opinion. The disability service and Mr C were given the opportunity to respond to the provisional opinion but chose not to respond.

53. Mr A stated in his response that the purpose in raising this complaint was not to get back money owed or to make issues for the disability service and Mr C, but because he felt that he was not provided with the agreed service. In addition, he considered that the disability service/Mr C took advantage of him due to his disability and that by speaking up it may prevent someone else being treated in the same way.

54. Mrs B stated that the purpose of her complaint was not to receive compensation. Her main purpose was to raise awareness of the disability service's and Mr C's practices in relation to the clientele they market to, the way they deal with clients, their involvement with WINZ redirection of payments and the fact that they were not providing the service Mr C claimed. Mrs B concluded that she would not like anyone else to have to go through what her family was put through as a result of her involvement with the disability service and Mr C.

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Opinion

Introduction

55. I consider that the concerns raised by Mr A and Mrs B are significant. They raise questions about the potential exploitation and disrespectful treatment of vulnerable consumers, and poor engagement in the complaints process. Both complainants have been affected, both financially and emotionally. I am also concerned about the lack of organisational policies and processes in place at the disability service.

56. According to the Code,[11] the Health and Disability Commissioner has a duty to promote and protect the rights of consumers who use health and disability services. Mr A and Mrs B are both consumers with a disability, and they sought the assistance of the disability service.

57. Mr C is the Chairman of the disability service and was the main person involved in providing/facilitating services to Mr A and Mrs B. Mr C describes himself as a Senior Disability Service Navigator. He is responsible for ensuring that the services provided by the disability service comply with any relevant legislation and standards, including the Code. Mr C is also responsible for ensuring that his individual conduct is appropriate.[12]

58. Other than asserting that the complaints by Mr A and Mrs B were false, Mr C and the disability service have provided no information to HDC to support this view. HDC has received copies of email communications that support the versions of events outlined in Mr A's and Mrs B's complaints, and therefore I am inclined to accept the complainants' versions of events despite Mr C's denial.

Jurisdiction

59. Mr C denied that the disability service is a disability services provider, on the basis that it does not hold any formal contracts with either Whaikaha|Ministry of Disabled People, or Health New Zealand|Te Whatu Ora. However, under the Health and Disability Commissioner Act 1994 (the Act) a 'disability services provider' is any person who provides, or holds him- or herself out as providing, disability services. 'Disability services' include services provided to people with disabilities for their care or support or to promote their independence, or services provided for purposes related or incidental to the care or support of people with disabilities, or to the promotion of the independence of such people.

60. The disability service is registered as a charity on the Charities Register and as a charitable trust with the Companies Office. The objects and purposes of the trust are:

> '[To] support those in NZ living with ASD, ADHD, Anxiety; support and advocate for those in NZ living on a mainstream benefit issued by Ministry of Social Development; support and advocate for those in NZ needing a voice on their entitlements to support

[11] The Code of Health and Disability Services Consumers' Rights.

[12] Because of Mr C's and the disability service's non-engagement in HDC's complaint process, we hold no information on whether Mr C is also an employee of the disability service.

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from [sic] other NZ government departments and provide suitable representation to government and other such related official roles; support the work of other community organisations doing work in the area of all disabilities, education, PTSD,[13] FASD;[14] maintain and operate [advocacy services] in accordance with current laws and practices within NZ and provide support to both listed community organisations.'

61. The engagement between the disability service and Mr A and Mrs B can be characterised as provision of advocacy and support services. In the case of Mr A, the purpose was to promote his independence by enabling him to access his entitlements from WINZ. In the case of Mrs B, the disability service undertook to help her 'obtain an assessment for Autism', charged $700 for the assessment, and informed her that an official diagnosis of autism had been made. The disability service was thus a provider of disability services.

62. I have established clearly that the disability service and Mr C held themselves out as providing advocacy and support services to the disability community, and I consider that the disability service and Mr C therefore are disability service providers for the purpose of the Act and Code.[15] Accordingly, I consider that I have jurisdiction to consider the complaints made by Mr A and Mrs B.

Mr A's complaint

Disability service — breach

63. As a disability service provider, the disability service had a duty to provide its vulnerable consumers, including Mr A, with an appropriate standard of service, including complying with the Code.

Management of complaint

64. Right 10(1) of the Code states that '[e]very consumer has the right to complain about a provider in any form appropriate to the consumer'. Right 10(3) states that '[e]very provider must facilitate the fair, simple, speedy, and efficient resolution of complaints'.

65. On 11 August 2022, Mr A and his support person met with Mr C to try to resolve his concerns. The meeting ended in an impasse, as Mr C stated that he had provided all the services as agreed with Mr A and that the overcharge was 'no big deal'. Mr A stated that during the meeting Mr C was 'defensive in his approach', would not provide a copy of the redirection form, and insisted that WINZ was 'lying' about his contacts with WINZ.

66. The impasse led to Mr A lodging a complaint with HDC.

67. HDC wrote to the disability service and Mr C on multiple occasions, explaining the rights of health and disability services consumers, citing the Code, and asking for further information. The disability service and Mr C refuted the complaint and declined to engage further with Mr A or this Office.

[13] Post-traumatic stress disorder.

[14] Fetal alcohol spectrum disorder.

[15] The Code states that 'provider means a health care provider or disability services provider'.

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68. Despite considering that the complaint was unfounded, I consider it was incumbent on Mr C as a Senior Disability Service Navigator and Chairman of the disability service to engage in the process of resolving Mr A's complaint. This could have included explaining why the benefit review was taking so long and providing the requested information to HDC.

69. I am critical that instead of engaging properly to resolve Mr A's concerns, Mr C chose to use inflammatory language and preconceived judgements to dismiss and minimise the complaint and accuse Mr A of bad behaviour.

70. I note that Mr C stated that the disability service holds documentation and notes on file and that clients can request this information from the disability service at any time, which is in stark contrast to Mr C's actions. Mr A asked for a copy of his signed contract and details regarding payments, which he never received. In addition, this Office has repeatedly asked for further information regarding records on Mr A's file, to no avail.

71. I am concerned that Mr C is unaware of Mr A's right to receive this information, not only under the Health and Disability Commissioner Act 1994 but also under the Privacy Act 2020.

72. Mr A's autism diagnosis was well known to the disability service and Mr C. However, they failed to interact with Mr A adequately and manage his expectations about his complaint. For failing to have a written complaints policy and procedure, and by not engaging in and facilitating the complaint resolution process in a fair, simple, speedy, and efficient manner, I find that the disability service breached Right 10(3) of the Code.

Mr C — breach

Treatment of Mr A

73. Right 1(1) of the Code states that '[e]very consumer has the right to be treated with respect'.

74. Mr C stated that upon 'signing up' with the disability service, Mr A was deemed to be someone 'who was going to cause issues' and to 'proceed with caution', and that Mr A had abused its Office Manager. Mr C did not elaborate or explain where this information came from or give further details. Mr C stated: '[Mr A] is what we term a serious narcissistic autistic who will not ever be able to accept he isn't in the right on most matters.'

75. I am concerned that when Mr C made these comments, he did not consider how disrespectful they were and how they would affect Mr A. When Mr C's response was shared with Mr A, he became very upset and sought support from the Nationwide Advocacy Service.

76. Mr C's response referred to a diagnosis for Mr A. I consider it unacceptable to respond to a complaint with inflammatory comments, preconceived judgements, and assumptions about a person's character, and to use this as an excuse for not continuing to engage in the complaints process.

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77. Mr C knew of Mr A's autism background when Mr A signed up for services with the disability service and, despite this, Mr C used inflammatory language, preconceived judgement, and assumptions, and minimised Mr A's concerns. I consider that Mr C did not treat Mr A with the dignity and respect a vulnerable consumer in Mr A's situation deserves. Therefore, I find that Mr C breached Right 1(1) of the Code.

Mrs B's complaint

Disability service — breach

78. As a disability service provider, the disability service had a duty to provide its vulnerable consumers, including Mrs B, with an appropriate standard of care, including complying with appropriate standards and the Code.

Management of complaint

79. Right 10(3) states that '[e]very provider must facilitate the fair, simple, speedy, and efficient resolution of complaints'.

80. When this Office notified the disability service and Mr C of the complaint from Mrs B, Mr C refuted the complaint and concluded: '[W]e consider this matter closed and will not [be] reopening any files for [Mrs B] going forward.'

81. This Office wrote to the disability service and Mr C on multiple occasions, explaining the rights of healthcare consumers, citing the Code, and asking for further information. The disability service and Mr C declined to engage further with Mrs B or this Office.

82. Despite considering that the complaint was unfounded, it was incumbent on Mr C to engage in the process of resolving Mrs B's complaint.

83. Mr C should have sought to resolve Mrs B's concerns, but instead he was disrespectful toward Mrs B and displayed an unprofessional attitude. Mr C treated Mrs B's request as trivial and a nuisance even though she was entitled to question the diagnostic process and request supporting documents pertaining to her diagnosis.

84. Mrs B stated that she became suspicious that the diagnostic process Mr C had followed was flawed, and she requested the name and qualifications of the assessor (ie, the nurse practitioner) who had provided the diagnosis, as well as supporting documents and the report, as was her right. Mr C declined the information request and stated that a report would cost more and that it would not be achievable until 2024.

85. I am concerned that Mr C is unaware of Mrs B's right to receive this kind of information, not only under the Health and Disability Commissioner Act 1994 but also under the Privacy Act 2020.

86. For failing to have a written complaints policy and procedure, and to engage in and facilitate the complaint resolution process, I find that the disability service breached Right 10(3) of the Code.

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Management of diagnostic process

87. Right 4 of the Code states that '[e]very consumer has the right to services of an appropriate standard'. Right 4(2) states that '[e]very consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards'.

88. Mrs B stated that she was approached by Mr C, who claimed that he could support her to obtain a diagnosis of autism. She was sent a questionnaire and was told that a review would be conducted by a nurse practitioner. When Mr C informed Mrs B that an official diagnosis of autism had been made, she became suspicious that the diagnostic process Mr C had followed was flawed.

89. According to Dr Maplesden's in-house clinical guidance and the NZ Autism Guidance on the Whaikaha|Ministry of Disabled People's website, the formal process of diagnosing autism is much more complex than has been described by Mrs B in her complaint.

90. Diagnosing autism in an adult should include the following:

- The diagnosis should be completed by a multidisciplinary team, or a highly trained healthcare practitioner experienced in autism.
- Diagnostic assessment should be comprehensive and involve the person concerned in an interview and observation.
- Standardised ASD assessment interviews and schedules should be used.
- The intellectual, adaptive, and cognitive skills associated with autism/takiwātanga should be considered seriously and, where possible and appropriate, assessed formally.

91. Because Mr C failed to provide the name and qualification of the nurse practitioner, I am unable to assess whether the individual provider who undertook the review of the questionnaire and subsequently provided a diagnosis is a qualified health professional. I am concerned about the disability service's refusal to provide this information, as it could indicate that the provider in question was not suitably qualified to undertake the assessment.

92. According to Mrs B, the autism diagnosis was based only on a review of a written questionnaire and did not include interviews or observations.

93. Because the disability service and Mr C have not replied formally regarding their diagnostic processes, I question whether standardised ASD questionnaires or schedules were utilised and whether Mrs B's intellectual, adaptive, and cognitive skills were assessed. Based on Mrs B's description of the diagnostic process, it appears that the disability service did not comply with the relevant guidelines.

94. Therefore, I am concerned that Mrs B's diagnosis was made after having reviewed only a questionnaire, which is far from accepted practice and NZ Autism guidelines.

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95. Dr Maplesden concluded: '[T]he [autism diagnosis] process described by the complainant certainly sounds far removed from accepted practice.'

96. Mr C and Mrs B had an agreement that she would be charged $700 for an autism diagnosis and that the cost for this would be deducted from her WINZ benefit.

97. It is concerning that the disability service charged $700 for a diagnosis that does not appear to adhere to any New Zealand guidance standards. Further, after Mrs B was given the diagnosis, she did not receive any document that contained details of the qualifications and name of the person who undertook the assessment, or a summary report or details of the assessment criteria utilised. I consider that the disability service, in its first communication with Mrs B, should have outlined the assessment it was offering, so that Mrs B could make an informed choice about whether she wished to agree to this.

98. As it stands, Mrs B did not pay the agreed fees in full, as she cancelled the deductions. However, she asked to be refunded the amount paid.

99. For failing to provide Mrs B with services of an appropriate standard, namely in accordance with the relevant standards for diagnosing autism, I find that the disability service breached Right 4(2) of the Code.

Mr C — breach

Treatment of Mrs B

100. Right 1(1) of the Code states that '[e]very consumer has the right to be treated with respect'.

101. As a result of Mrs B's request for documentation and subsequent complaint to this Office, Mr C used inflammatory language and preconceived judgements to dismiss and minimise the complaint. He also accused Mrs B of having a history of making false complaints, being disrespectful, and having an unprofessional attitude. Mrs B's potential autism diagnosis was well known to the disability service and Mr C, but they failed to interact with her appropriately and manage her expectations and failed to treat her with the respect she deserved.

102. I am concerned that when Mr C made these comments, he did not consider how disrespectful they were and how they would affect Mrs B. When Mr C's response was shared with Mrs B, she stated: 'I am not surprised about this response from [Mr C].' She said it was the first time she had heard this and that the comments are inaccurate and inappropriate.

103. In response to the provisional opinion, Mrs B stated that Mr C's allegations of her making false complaints to government agencies and harassing him, are simply untrue.

104. It is unacceptable for Mr C to use these arguments as an excuse for not providing information or not to engage in the complaints process. Accordingly, by using inflammatory language and preconceived judgements, accusing Mrs B of a bad attitude

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and bad behaviour, minimising her concerns, and disrespecting her, I find that Mr C breached Right 1(1) of the Code.

Recommendations

105. I recommend that the disability service and Mr C provide a written apology to Mr A for their breaches of the Code, including failing to engage appropriately in the complaint resolution process. The apology should be provided to HDC, for forwarding to Mr A,[16] within three weeks of the date of this report.

106. I recommend that the disability service and Mr C provide a written apology to Mrs B for their breaches of the Code, including failing to engage appropriately in the complaints process and providing her with a diagnosis using an inappropriate process. The apology should be provided to HDC, for forwarding to Mrs B, within three weeks of the date of this report.

107. I recommend that the disability service and Mr C develop and implement organisational policies and processes to guide their advocacy and support of people, including but not limited to, management of complaints, redirection of fees, management of client information, support with obtaining diagnoses, and a code of conduct for employees. Any implemented policies and processes should be forwarded to HDC within six months of the date of this report.

108. I recommend that Mr C undertake reflection and learning on the HDC Code. In particular, I recommend that Mr C undertake the learning modules on the Code and complaints management at https://www.hdc.org.nz/education/online-learning/. Reflections should include the specific learning from the two complaints and be provided to HDC within three months of the date of this report.

109. I recommend that Mr C and all employees undertake further training in autism and, in particular, learn about common traits of someone with autism and how to interact appropriately with consumers with autism, using the following guidelines: https://www.whaikaha.govt.nz/about-us/programmes-strategies-andstudies/guidelines/nz-autism-guideline. A reflection on this learning should be provided to HDC within three months of the date of this report.

Follow-up actions

110. A copy of this report with details identifying the parties removed, except the advisor on this case, will be sent to Whaikaha|Ministry of Disabled People, the Ministry of Social Development, Work and Income New Zealand, Charities Services, and the Commerce Commission, and they will be advised of the name of the disability service.

111. A copy of the report with details identifying the parties removed, except the advisor on this case, will be placed on the HDC website (www.hdc.org.nz) for educational purposes.

[16] Via the Nationwide Advocacy Service.

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Appendix A: In-house clinical guidance to Commissioner

Dr David Maplesden provided the following clinical guidance on 26 February 2024:

> 'Autism spectrum disorder (ASD) is complex and NZ guidance includes the following re diagnosis in adults:
>
> 1. Preferably, a multidisciplinary team of health care practitioners experienced in autism should undertake diagnostic assessment of young people and adults suspected of being autistic. In the absence of an assessment team, a health care practitioner trained and highly experienced in autism may undertake diagnostic assessment.
> 2. Diagnostic assessment of young people and adults should be comprehensive and involve the person concerned in interview and observation.
> 3. Standardised ASD assessment interviews and schedules should be used. The intellectual, adaptive, and cognitive skills associated with autism/takiwātanga should be seriously considered and, where possible and appropriate, formally assessed (see Appendix 3.5).
> 4. Health care professionals must have a good understanding of the different forms of expression of autism across developmental stages and the features of common coexisting and alternative conditions.
>
> Diagnosis in the public system would usually involve referral of the patient by the GP to the adult mental health service with an appropriate outline of mental health history and concerns. How the referral is managed will vary between services depending largely on available resources. In private, the GP might refer the patient to a clinical psychologist with experience in adult ASD or to a psychiatrist. As noted in the cited guidance, assessment usually included face to face interview, completion of standardised evidence-based psychological tests and questionnaires and gathering of relevant collateral history. The process described by the complainant certainly sounds far removed from accepted practice.'

The full guidelines are available at:

https://www.whaikaha.govt.nz/about-us/programmes-strategies-and-studies/guidelines/nz-autism-guideline

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Appendix B: Excerpt from Whaikaha|Ministry of Disabled People's Aotearoa Autism guidelines

Part 1: Diagnosis and initial assessment

Overview

Professional concerns about autistic children with less obvious support needs may not develop until children are exposed to the greater social demands of early childhood education or the primary school environment. The Guideline provides key signs for identifying autism in children in separate age bands: 1 to 3 years and 4 to 8 years.

Diagnosis is also important in young people in their teens and adults, although for some of these people diagnosis may only be of academic interest. Others, however, may suffer undue stress, miss out on effective support options and receive inappropriate medical, psychiatric and educational approaches if diagnosis is missed. Telling a person that they have been diagnosed with autism should be undertaken sensitively, giving the person ample time to ask questions, understand what is being said and express concerns. Families, whānau and support people may need to be involved in diagnosis disclosure, especially when a young person is involved.

Assessment is the process of gathering information about the health, education, and support needs of an autistic person/tangata whaitakiwātanga and their family. This results in an identification of needs and a plan of action to meet these needs.

'Autism/takiwātanga is a developmental condition. Its presentation will vary with age and will vary over time and context in any individual. In Aotearoa New Zealand, there is currently inconsistent and inequitable access to assessment and diagnosis. Young people and adults have no clearly identified pathways for assessment. Multidisciplinary assessment through specialist autism services is recommended for all people seeking an autism assessment. The multidisciplinary team approach leads to more robust diagnosis and assessment, more accurate planning of future services and supports, and reduces repetition and redundancy in the assessment and diagnostic process. Professionals providing assessment and diagnostic services for children, young people and adults with possible autism/takiwātanga also need to fully consider other possible diagnoses (such as the differential diagnosis).

Clinical judgment may be aided by the use of assessment tools, checklists and rating scales. Suggestions for diagnostic tools and the role of cognitive assessment for autism are found in Appendices 5 and 6. However, the applicability of diagnostic and assessment tools to a New Zealand population has not been established and research is required to determine this.'

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Key recommendations for diagnosis and initial assessment
1. Early identification of children on the autism spectrum is essential. Early identification enables early intervention and is likely to lead to a better quality of life. Early identification is achieved by: a. comprehensive developmental surveillance of all children so that variations from typical development are recognised early b. valuing and addressing parental concerns about their child's development c. prompt access to diagnostic services.
2. Te Whatu Ora Health New Zealand should have in place processes that ensure: a. referral pathways for children and adults who may be on the autism spectrum or have developmental challenges are clearly understood by professionals b. services are coordinated within and across sectors c. multidisciplinary, multiagency assessments are provided d. all services are provided in a timely manner.
3. All children suspected of being on the autism spectrum or having other developmental challenges should have an audiology assessment.
4. Preferably, a multidisciplinary team of health care practitioners experienced in autism should undertake diagnostic assessment of young people and adults suspected of being autistic. In the absence of an assessment team, a health care practitioner trained and highly experienced in autism may undertake diagnostic assessment.
5. Diagnostic assessment of young people and adults should be comprehensive and involve the person concerned in interview and observation.
6. Standardised ASD assessment interviews and schedules should be used. The intellectual, adaptive, and cognitive skills associated with autism/takiwātanga should be seriously considered and, where possible and appropriate, formally assessed (*see* Appendix 3.5).
7. Health care professionals must have a good understanding of the different forms of expression of autism across developmental stages and the features of common coexisting and alternative conditions.

3.5 Revision of Guideline recommendations

Good Practice Points	Grade
1.3.5 Diagnosis of ASD in itself may be sufficient. Attempts to delineate ASD from Asperger syndrome may not be valid and are not necessary. *Deleted.* **Rationale:** This Good Practice Point was removed as considered redundant in view of DSM-5 criteria where DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.	✓

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Revised recommendations	Grade
1.2.6 Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing autistic people and take these limitations into account when forming opinions and reporting results. *Unchanged.* **Rationale:** Some diagnostic tools in use are based on DSM-IV[30] criteria, however tools have been developed based on DSM-5[29]. It remains the case that the reliability, validity and appropriateness of assessment tools need to be considered when assessing for ASD.	C
1.2.5 Standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be used. *Changed to:* **1.2.5** Standardised ASD assessment interviews and schedules should be used. **Rationale**: Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV[30] specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.	B B
1.2.7 The assessment of intellectual, adaptive and cognitive skills associated with autism, Asperger syndrome and ASD should be seriously considered and, where possible and appropriate, formally assessed. *Changed to:* **1.2.7** The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed. **Rationale**: The words "assessment of" were removed as redundant in the sentence structure. Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV[21] specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.	B B
6.2 Education and training of local health care professionals in the administration of standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be provided. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established. *Changed to:* Professionals administering standardised ASD assessment tools should be provided with appropriate training. When reporting the results of ASD-specific tests, caution should be exercised as Aotearoa New Zealand norms have not yet been established. **Rationale**: Wording of the first sentence was altered to improve readability and to recognise that not only "local health care professionals" may administer assessment tools. Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV[21] specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.	C C
6.3 Norms should be developed for autism, Asperger syndrome and ASD assessment tools specifically for the New Zealand population. *Changed to:* **6.3** Norms should be developed for ASD assessment tools specifically for the Aotearoa New Zealand population. **Rationale**: Words "autism, Asperger syndrome and" removed. Under DSM-5[29], DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of ASD.	C

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