Disability Service

A Report by the
Deputy Health and Disability Commissioner

(Case 17HDC00689)

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Contents

Executive summary

1. In 2014, Mr A (21 years old at the time) transitioned from the care of his parents, Mr and Mrs B, to assisted living with a disability service.

2. At this time, the disability service was provided with information that indicated pre-existing vulnerabilities and safety concerns. Despite this information, the disability service told HDC that it did not have a formal risk management plan in place for Mr A.

3. In August 2014, Mr A moved into a home where he received support from the disability service. Mr A was able to come and go from the residence at his discretion. Initially, he transitioned to the home smoothly; however, by early 2015, issues had arisen. The disability service told HDC that Mr A did not take his medication consistently, and that he rang suicide helpline services. The disability service told HDC that staff were concerned that Mr A engaged in lying, manipulating, stealing, and bullying behaviours.

4. In early May 2015, Mr A was involved in two serious incidents, which resulted in him being charged by the Police.

Findings

5. By failing to have in place a risk management plan, the disability service did not provide services to Mr A with reasonable care and skill, and therefore breached Right 4(1) of the Code of Health and Disability Services Consumers' Rights (the Code).[1]

6. Adverse comment was also made about the disability service's documentation.

Recommendations

7. It was recommended that the disability service:

   a) Amend its risk management tool to be in line with expected standards, and provide a copy of the tool to HDC.

   b) Provide a written apology to Mr and Mrs B.

[1] Right 4(1) provides: "Every consumer has the right to have services provided with reasonable care and skill."

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

Complaint and investigation

8. The Commissioner received a complaint from Mr B and Mrs B about the services provided by the disability service to their son, Mr A. The following issue was identified for investigation:

> *Whether the disability service provided Mr A with an appropriate standard of care between 2014 and 2015.*

9. This report is the opinion of Rose Wall, and is made in accordance with the power delegated to her by the Commissioner.

10. The parties directly involved in the investigation were:

Mr A	Consumer
Mr and Mrs B	Complainants
Disability service	Provider

11. Further information was received from:

The District Health Board
The Ministry of Health

12. Independent expert advice was obtained from Mr John Taylor, disability provider, and is included as Appendix A.

Information gathered during investigation

Introduction

13. The disability service delivers both residential based and supported independent living services.

14. Mr A, 21 years old at the time of events, is intellectually and physically disabled.

15. Prior to accessing disability services, Mr A resided with Mr and Mrs B, his parents.

Referral to the disability service

16. In July 2013, Mr A was assessed by a needs assessment and service coordination agency (NASC). The needs assessment document identified that Mr A was known to have:

- An intellectual disability, bipolar disorder, autistic spectrum disorder, Tourette's syndrome, mild seasonal asthma, migraines, seizures, and blackouts that could last up to 12 hours.

- A visual impairment that required high levels of support for safety.
- A history of causing himself and others distress or discomfort. He was also known to have significant behavioural outbursts approximately fortnightly. Sometimes there would be a little trigger, other times not.
- A history of sneaking and hoarding food, smoking, and drinking occasionally.
- The ability to lie and deceive in an accomplished way. He was known to steal money, keys, food, and "odd stuff".

17. The needs assessment document also identified Mr A's family as his key supports.

18. In July 2014, Mr A was referred to the disability service by the NASC on a "supported independent living contract"[1] ("the Contract") for 30 hours of support per week,[2] and staff were provided with a copy of the needs assessment document.

19. A service agreement ("the Agreement") between Mr A and the disability service was signed in July 2014, the aim of which was: "For [Mr A] to be supported to live a full, safe life transitioning to live as independently as possible."

20. Mr and Mrs B were not Mr A's welfare guardians, but they were involved in Mr A's transfer into the disability service's care, and were listed as advocates and emergency contacts. The Agreement states that as advocates, Mr and Mrs B had the authority to assist Mr A with his finances and to be involved with any major decision-making, including any change of residence.

Risk assessment

21. The disability service told HDC that it did not have a formal risk management plan in place for Mr A. The disability service also told HDC that relevant aspects of Mr A's history were not disclosed to the service.[3] The disability service questions whether it was realistic to develop a comprehensive risk plan and mitigation strategies if critical information about Mr A's mental health history was withheld. It also questions whether a Supported Living Contract provided a strong enough level of support for Mr A.

22. The disability service told HDC:

> "The family were asked if there was any additional or relevant information that was relevant to [Mr A's] support needs. They did not volunteer any additional information

[1] The document states that its aim is to "encourage and support people to think about how they might want to live and how self defined supports can be provided to foster opportunities for people to access their choices".

[2] Mr A received support with shopping, meal preparation, housework, laundry, heating, home safety, finance, and various personal cares.

[3] According to the disability service, prior to Mr A's involvement with them, he had been referred to the Police and to the Mental Health Crisis Team, and had been admitted to hospital for assessment and treatment, and the disability service was not informed of this.

> and in particular [Mr A's] mental health history and assessment detail was not raised by either the family or NASC staff. There was no mention of any behavioural risks by either the family or NASC staff …"

23. Mr and Mrs B told HDC that they believe they provided sufficient information to the disability service, and there was no intention to withhold information. They added that Mr A's life was full of challenges, and they discussed these issues as openly as possible.

24. Since receiving the complaint, the disability service has provided HDC with a draft risk assessment tool. The tool is intended to support staff to get a better understanding of the needs of a person prior to the person accessing support services from the disability service.

Additional plan and assessment

25. The disability service told HDC that staff do not ordinarily complete a written communication plan, but rather work alongside families and natural supports to develop an oral record of intent, which is summarised in an overall plan. The Service Manager for the disability service met with Mr A and his parents to plan support and to conduct a needs assessment.

Response from the Ministry of Health

26. The disability service signed an Outcome Agreement with the Ministry of Health for Community Residential Support — Intellectual Disability. The Ministry of Health told HDC that it is the responsibility of the provider to assess risk and include any actions or strategies in its plans to safeguard a consumer.

Subsequent events

27. In August 2014, Mr A moved into a home where he received support from the disability service. Mr A was able to come and go from the residence at his discretion.

28. Initially, Mr A transitioned to the home smoothly; however, by early 2015, issues had arisen. The disability service told HDC that Mr A did not take his medication consistently, and that he rang suicide helpline services. The disability service said that staff were concerned that Mr A engaged in lying, manipulating, stealing, and bullying behaviours.

29. Mr and Mrs B told HDC that they were not informed when Mr A left the service. However, the disability service told HDC that Mr A contacted the Service Manager on 14 April 2015 and advised that he would not be returning to the home that night, and would be moving out of the home. The disability service stated that the Service Manager contacted Mrs B that night to inform her of the immediate change in Mr A's plan. The disability service has provided details from its mobile data provider showing that a call of approximately 16 minutes took place between the Service Manager's phone and Mr B's phone on 14 April 2015.

30. On 16 April 2015 there is an entry in the Team Meeting Minutes that Mrs B called the house at 3pm. The entry states: "The family has asked us not to give out any money at all even if [Mr A] does return home."

31. On 20 April 2015, a meeting took place between Mr and Mrs B, and representatives from the disability service and the NASC. They discussed Mr A leaving the home, and his future plans.

32. In early May 2015, Mr A was involved in two serious incidents, which resulted in him being charged by the Police.

Documentation

33. The disability service told HDC that staff kept the "legal guardianship status" field on Mr A's service agreement form blank, as they understood that Mr A did not have a legal guardian. The disability service stated that it has since addressed with staff the importance of completing all forms and particularly details relating to legal guardianship.

Responses to provisional opinion

Mr and Mrs B

34. Mr and Mrs B were given an opportunity to comment on the "information gathered" section of the provisional opinion. Where relevant, their responses have been incorporated into the "information gathered" section above.

35. Mr and Mrs B advised that the driving force for making their complaint is to ensure that other vulnerable individuals are provided with the appropriate services when in an assisting living home.

The disability service

36. The disability service was given an opportunity to comment on the provisional opinion. It advised that it accepts the findings and recommendations in the provisional opinion.

37. The disability service reported that it is now under new leadership, and has made a number of changes in policy and procedure, including making the Risk Management Plan a compulsory part of the assessment of an individual's support needs.

Opinion: The disability service — breach

Overall standard

38. This case demonstrates the important balance between allowing disabled people the autonomy to make personal choices and ensuring that any identified risks are managed appropriately. The disability service was responsible for many aspects of Mr A's care, and I acknowledge that much of the care provided was considered by my expert advisor, Mr

John Taylor, to be within accepted standards. However, Mr Taylor has identified the disability service's risk management tool as an area of concern, and my report focuses on this.

Risk assessment

39. The disability service was provided with Mr A's needs assessment, which identified that he had an intellectual disability, physical disabilities, mental health issues, and behavioural issues. This information indicated that Mr A was a vulnerable consumer, and that there were inherent risks involved in his care.

40. I am satisfied that the disability service held information that indicated pre-existing vulnerabilities and safety concerns. This represented an opportunity for the disability service to proactively address the risks involved in Mr A's care by having a discussion with Mr and Mrs B about what needed to be done to keep Mr A and those around him safe, and complete a risk management plan.

41. There was no risk management plan in place during Mr A's care. Mr Taylor has advised me that failing to complete a risk management plan amounts to a significant departure from the expected standards and from the Ministry of Health contract. I accept Mr Taylor's advice, and consider that ultimately the failure to complete a risk management plan is the responsibility of the disability service.

42. I am also critical of the disability service for saying that Mr and Mrs B and the NASC did not disclose additional information about Mr A's mental health, and questioning whether it is realistic to develop a comprehensive risk plan and mitigation strategies when information that is critical to such a plan is not shared. As a provider, the disability service had an active responsibility to explore these risks on behalf of Mr A and his family. The needs assessment clearly identifies a number of behavioural risks such as behaviour outbursts, lying, and stealing.

43. By failing to have in place a risk management plan, the disability service did not provide services to Mr A with reasonable care and skill, and therefore breached Right 4(1) of the Code.

Family involvement — other comment

44. Mr Taylor advised that when supporting someone like Mr A, it is critical to the success of that support that all parties work as a team. Mr Taylor stated that the disability service had a practical obligation to appraise Mr and Mrs B, as Mr A's advocates and parents, of significant facets of his support.

45. Mr and Mrs B told HDC that they were not informed when Mr A left the service.

46. The disability service told HDC that Mr A contacted the Service Manager on 14 April 2015 to advise that he would be moving out of the home, and that the Service Manager contacted Mrs B that night to inform her of this immediate change in Mr A's plan.

47. The disability service provided evidence of a telephone call between the Service Manager's phone and Mr B's phone on the night of 14 April 2015 for around 16 minutes. The disability service also provided the Team Meeting Minutes, which include a notation that Mrs B called the house on 16 April 2015 and requested that Mr A not be given money, even if he returned home. This suggests that she was aware that Mr A had left the service.

48. I note the conflicting views of the disability service and Mr and Mrs B. For me to make a finding of fact in favour of one view I must be satisfied that there is sufficient evidence to meet the standard of proof required, namely whether on the balance of probabilities, Mr and Mrs B were informed when Mr A left the service on 14 April 2015. On balance, I am satisfied that this did occur.

49. I am pleased to see that the disability service involved Mr and Mrs B in some of the problem-solving for this issue at a meeting on 20 April 2015. I concur with Mr Taylor's advice that in this instance, the disability service acted within expectations.

Record-keeping — adverse comment

50. Record-keeping is central to ensuring safe and effective care.

51. I note that the disability service did not complete all the forms required when Mr A was transferred to their care. For example, the status of Mr and Mrs B as having legal guardianship was left blank. I am guided by Mr Taylor's advice that this fell short of good practice, and I therefore consider that the disability service's record-keeping was suboptimal.

Recommendations

52. I recommend that the disability service:

a) Amend its risk management tool to be in line with expected standards (as per Mr Taylor's advice), and provide a copy of the tool to HDC within one month of this report being published.

b) Provide a written apology to Mr and Mrs B. The apology is to be sent to HDC within three weeks of the date of this report, for forwarding to the family.

Follow-up actions

53. A copy of this report with details identifying the parties removed, except the expert who advised on this case, will be sent to the Ministry of Health and the NASC. They will be advised of name of the disability service.

54. A copy of this report with details identifying the parties removed, except the expert who advised on this case, will be placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Appendix A: Independent advice to the Commissioner

The following expert advice was obtained from John Taylor, disability provider:

> "I have been asked by the Deputy Health and Disability Commissioner to provide an opinion on case number C17HDC00689 that relates to the care provided to [Mr A] by [the disability support provider] and [the NASC] between August 2014 and May 2015 leading up to [Mr A] being arrested … I have read and agree to abide by the Commissioner's Guidelines for Independent Advisors.
>
> I have the following qualifications and experience to fulfil this request.
>
> Qualifications: MPhil (Distinction) in Disability Studies, Education and Evaluation; DipPGArts (Distinction) Social Work; BSc (in ethics and science); LTh.
>
> Experience: 30 years of working within the disability sector including the following roles: direct support worker, agency management (over 10 years), agency governance, behaviour specialist (over 10 years), national sector roles such as Chair of NZDSN, National Reference Group for the MoH's New Model, National Leadership Team for Enabling Good Lives, a range of contracted roles and I have helped set up a number of support agencies and disability related businesses.
>
> I have been asked to provide advice to the Deputy Health and Disability Commissioner regarding the adequacy of the care provided to [Mr A] by [the disability service] and [the NASC].
>
> In particular I have been asked to make comment on:
>
> With regard to [the disability service]:
>
> 1. Whether I consider [the disability service] had obligations to advise [Mr and Mrs B] when [Mr A] ceased taking his medication.
> 2. Whether I consider [the disability service] had an obligation to advise [Mr and Mrs B] when [Mr A] left the service.
> 3. The standard of care provided by [the disability service].
> 4. The adequacy of the relevant policies and procedures in place at [the disability service].
> 5. Any other matters that I consider warrant comment.
>
> With regard to [the NASC]:
>
> 1. The adequacy of the needs assessment process for [Mr A].
> 2. The adequacy of the relevant policies and procedures in place regarding needs assessment.
> 3. Any other matters that I consider warrant comment.

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

I have based my opinion on the information listed below:

- The letter of complaint with accompanying documents
- The provider response with accompanying documents
- The [DHB] response
- The Ministry of Health response and accompanying documents.

As I read through the material provided I gained the impression of a young man who comes from a firm and loving family, who left home and wanted to take control of his life. This is common to young people of his age with or without disability and can often cause them to transgress acceptable behavioural and societal codes. It certainly seems to me that [Mr A] was such a young man who had the additional disadvantage of various learning disabilities that further impeded his judgement.

[The Ministry of Health] gave a very good summation of supported living and the difficulties of both allowing people their legal right to self determination and still providing an adequate safety net. The implication is that sometimes, despite best endeavours, things go wrong. In this case, even though not all the support provided to [Mr A] was ideal, it is not clear to me that any single or group of actions could have guaranteed a different outcome.

Did [the disability service] have obligations to advise [Mr and Mrs B] when [Mr A] ceased taking his medication?

When supporting someone like [Mr A], it is critical to the success of that support that all parties work as a team. [Mr A's] parents, [Mr and Mrs B], may not have had a legal right to information[1] but they certainly should have been part of the problem-solving team around this issue. There was no evidence presented that indicated that [Mr A] did not want his parents involved in his support, therefore I consider that [the disability service] did have a practical obligation to apprise [Mr and Mrs B] of significant facets of [Mr A's] support, including issues to do with medication; if for no other reason than to gain their insights into how to manage the situation. In this regard, if [the disability service] did not do this, then I consider [the disability service] fell short of the expected standard to work constructively with the family. (It is not entirely clear to me that they did fail to alert the family to the issue based on what I read.)

If they did fail in this regard, I think that this would be considered a minor departure by our peers as there were a number of things happening at the same time which means it is easy to miss out on useful communication. The bigger issue that is highlighted is that there is a sense of an uneasy relationship between [the disability

[1] Mr B, in his email entitled 'a quick synopsis of [Mr A's] life' commented that they were 'legal guardians'; however this was not indicated in the intake forms when this specific question was asked leaving me assuming that they were not in fact [Mr A's] guardians post 18 years old.

service] and [Mr A's] parents. This would have interfered with communication of issues and should have been resolved earlier.

Did [the disability service] have an obligation to advise [Mr and Mrs B] when [Mr A] left the service?

I consider this is a similar issue to above with the same answer for the same reasons. However it does appear to me that in this instance [the disability service] did include the parents in some of the problem-solving with a meeting held on 20 April 2015 to discuss this particular issue. In this instance I consider [the disability service] acted within expectations.

The standard of care provided by [the disability service].

In general, the standard of care provided by [the disability service] would be within the range expected by their peers. They had good information gathering tools and policies, staff with sufficient training and reasonable supervision. There were a couple of areas where the standard of care fell short of good practice. These are:

- Not all of the forms were completed. For example, the status of [Mr and Mrs B] as having any legal guardianship was left blank. There was no safety plan (noted later) and there was no communication plan with the family.
- [Mr A] was supported within a group situation that appears to be owned by [the disability service]. This is contrary to the intent of supported living and, from what I read, led staff to take a much more authoritative stance with [Mr A] than would be ideal. This came out in a number of the notes such as staff telling [Mr A] to come to [the disability service] for support, [Mr A] being told he could not bring his friends back to his home, and when [Mr A] left the house it was considered absconding. All of these indicate a residential model of support rather than a supported living style of support. This could well have been 'more of the same' for [Mr A] in terms of others telling him what to do.

I doubt that any deficit noted above would have obviously altered the outcome of this situation. As I said in my introduction, [Mr A] appeared to be testing boundaries and creating his own path. Greater family involvement may have assisted or may have aggravated the situation. A more facilitative style of staff support may have helped, but also may not have.

The adequacy of the relevant policies and procedures in place at [the disability service].

I consider [the disability service] had very good incident reporting and, in general, kept good case notes. What was lacking from the information I read was any risk management plan for [Mr A]. Nothing of this sort was presented and neither was it referred to in other documents. If there was no risk management/safeguarding plan this would be a significant departure from both the expected standard and from the Ministry of Health contract.

The adequacy of the needs assessment process for [Mr A].
The needs assessment process appears to be within the range expected and I can see no clear breach of the expected standard. It provided a clear and comprehensive outline of [Mr A's] support needs and the level of support was reasonable given the needs identified.

The adequacy of the relevant policies and procedures in place regarding needs assessment.

The only information I have relating to this question is inferred through secondary documents. Based on that it appears that [the NASC] met its obligations as expected."

The following further expert advice was obtained from Mr Taylor:

"1) Does this response change any of your findings?

Not really. I think my main finding was that [Mr A] wanted to take control of his life away from restriction. This still appears to be the case. One thing to add though is that I note the current CEO of [the disability service] mentioned that the parents and [the NASC] failed to notify [the disability service] of significant issues in [Mr A's] past. Unfortunately this is a common experience for support providers so I agree that this is a systemic issue to deal with. Provision of that extra information to [the disability service] may have materially altered the outcome if [the disability service] and [the NASC] had agreed a different level/ style of support.

I would add that my comment on the lack of a family communication plan relates to this specific situation, where it appeared clear to me there had been contested communication, not as a general rule.

2) Do you have any recommendations, particularly in regard to the risk assessment tool?

I am pleased to see that [the disability service] [has] made this part of their usual practice now. The tool they offer is probably adequate for a residential setting but I would say does not represent best practice for supported living. The most important feature missing is an exploration of the person's vulnerabilities. In supported living one needs to know about things like: financial vulnerability (how they manage money, will they buy anything from whomever turns up at their door, etc), personal safety around others/ strangers, can the person cope in an emergency situation, etc, etc.

3) Do you have any final comments to make?

I think the additional information largely reinforces my view that this was a young man ready to break loose. The information reinforces the contest with the family's view, it adds that [Mr A] was more complex than initially thought and confirms that [the disability service] did a reasonable job albeit not a perfect job."