HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Inadequate support by residential disability service, including medication reminders

Introduction

1. This report discusses the care provided to the late Ms A by Spectrum Care Limited (Spectrum), and the concerns raised by the Coroner in a referral to HDC dated 6 July 2023. As a provider of disability support services, the concerns relate to Spectrum's level of monitoring to ensure that Ms A was medication compliant and physically well. It appears that Ms A had remained in her room unchecked by Spectrum support workers for up to two days after her death, and the post-mortem examination showed that Ms A had not been taking her anticonvulsant medication as prescribed. The cause of her death was noted as 'sudden unexplained death in epilepsy' between Day 1 and Day 3 2021.[1]

Background

2. At the time of events, Ms A, a woman in her early thirties, had been living in supported accommodation provided by Spectrum since 2014. Ms A had been diagnosed with an intellectual disability caused by a traumatic brain injury sustained from a motor vehicle accident when she was two years old. Ms A also had non-insulin-dependent type two diabetes and epilepsy. In addition, Ms A had a long history of threatening and physically aggressive behaviour towards staff and police, and on numerous occasions had presented to mental health services, or the police had been called. Over the years, Spectrum had supported Ms A with anger management, and staff had received training in behaviour support strategies to mitigate Ms A's risks.

Support needs

3. Ms A was very determined to be independent and had strong views around how she lived, who she saw, and who supported her. Ms A shared Spectrum support workers with the person living in the flat next to hers, and she was able to be supported 24/7. However, mostly the support she received was at her own request. Ms A navigated her own way in the community independently and mostly kept the home tidy on her own. Her daily routine consisted of making her own breakfast and lunch, and at 4pm support staff next door would go to her flat and ask if she would like them to cook dinner for her.

Medication

4. Ms A was also determined to be responsible for taking all her oral medications and had requested a week's supply in blister packs, which she kept in her flat. Staff were supposed to remind her daily to take her medication, and if she was in a 'good mood' she would take them. In 2021 there are three recorded instances when Ms A refused to take her medications. Spectrum noted that if Ms A was angry, she would refuse and sometimes throw the medications over the fence or onto the roof, and sometimes she would hide the blister pack so that staff could not check it.

[1] Relevant dates are referred to as Days 1–3 to protect privacy.

Events of Day 1–Day 3

5. On Day 1, staff member B cooked Ms A's dinner after Ms A had been spoken to at 4pm. When staff member B delivered the dinner, music could be heard playing on Ms A's computer. Later that night, Ms A thanked the staff member for the food, and staff member B recalled that music could still be heard from the computer.

6. In the morning of Day 2, staff member B woke up after a sleep-over next door. She recalled noting that the music was still playing on the computer, which made her think that Ms A must be in a good mood, although she did not see Ms A all day. At 3pm, staff member C came on duty, and at 4pm he went to ask Ms A what she would like for dinner. He recalled that music was playing, and Ms A was lying on her bed. Staff member C assumed that Ms A was sleeping and did not want to wake her as this could trigger aggressive behaviour. Ms A was particular about who cooked her meal, and it was not considered unusual for her to refuse staff member C's offer to cook for her when he was on duty. Staff member C continued to hear the music playing in Ms A's flat, but he did not hear from her all evening or during the night.

7. On the morning of Day 3, at approximately 11am, staff member C went to Ms A's flat to check on her and noticed that the music was still playing, and Ms A was lying in the same position as the previous day. Staff member C entered the flat, called Ms A's name, and shook her body, but she remained unresponsive. Staff member C called emergency services, who arrived promptly and confirmed that Ms A had passed away.

Investigation report

8. After Ms A's unexpected death, Spectrum commissioned an independent investigation, which was completed a couple of months later.

9. The report noted that Ms A had been assessed as needing 24/7 support with day-to-day needs, which occurred on a once-a-day basis only, unless Ms A requested additional support or not at all if staff did not want to wake/anger her. It was established that Ms A had not been seen face-to-face by staff for more than one day. Spectrum's new[2] Standard Operating Procedure (SOP) 'Supporting a Person in Supported Accommodation or Respite' states that 'at the very least, it is expected that every person in supported accommodation will be checked at least once per morning, afternoon and evening and their wellbeing confirmed and documented'. Ms A had been prescribed medication for epilepsy and diabetes, to be taken in the morning and evening. Spectrum's SOP 'Medicine Documentation' outlines the following expectations for documentation:

> 'Signing sheets and blister packs of medication are required to be kept in a Medicine Folder in a locked medicine cupboard. Staff are required to sign when medication is administered.'

[2] The SOP was implemented after the event.

10. Spectrum's SOP 'Self-Administration of Medicine Agreement' outlines the conditions for consumers who control their own medication. However, this agreement had not been put in place for Ms A, and the 'Medicine Documentation' SOP was not adhered to.

11. The investigation report stated:

> '[Ms A] operated in a high trust system and she was known to occasionally break that trust. This inevitably put her at risk, and there were insufficient checks and balances in the system to mitigate those risks. [Ms A's] policy of only allowing staff into her space when it suited her was also a risk. While it honoured her independence it also prevented staff from monitoring her welfare and compromised their duty of care.
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> …
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> Staff trusted her to take her medicine but there was no way to check that she had taken it at the right time. When she died, which was probably on the night of [Day1] or in the early morning of [Day 2], it became clear that she had not taken any of her prescribed medication [for the last few days]. This put her at risk and staff had no way of knowing she was at risk.'

Notification of HDC investigation

12. On 11 February 2025 I notified Spectrum of HDC's investigation of this matter. I proposed that HDC find Spectrum in breach of Right 4(4) of the Code of Health and Disability Services Consumers' Rights (the Code)[3] based on the Coroner's findings, Spectrum's investigation report, NASC's Service Authorisation/ICARE documents, and the independent advice received from Mr John Taylor (see Appendix A).

13. On 20 February 2025 Spectrum accepted my proposal to agree to an organisational breach of the Code, as a pragmatic resolution to the complaint.

Response to provisional decision

Spectrum was given the opportunity to respond to the provisional decision and responded that it accepted the proposed recommendations and had no other comments.

Decision

14. Spectrum has a duty of care to ensure that its vulnerable consumers are supported in their daily life adequately, including in taking their medications. Spectrum should be commended for supporting Ms A to live in her own home rather than a group home, thus allowing her much greater independence and service provision alignment with the Enabling Good Lives vision and principles.[4] However, due to Ms A's challenging behaviour and the barriers this caused in terms of minimal staff support and medication reminders, Spectrum failed to mitigate the risks by having in place sufficient checks and balances, as outlined further below.

[3] Right 4(4) states: 'Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.'
[4] https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles

Adequacy of support provided to Ms A, including regular wellbeing checks

15. Regarding Spectrum's planning and placement of checks for Ms A, my independent advisor, Mr Taylor, advised:

> 'When it comes to the appropriate level of planning for this and putting in place adequate checks to ensure [Ms A's] general safety, then it is my view that Spectrum demonstrated a **moderate departure** from the expected standard of care.
>
> The expected standard of care would have envisioned Spectrum to have a much more frequent schedule of checking in, offering support and overseeing her medications.'

16. I accept Mr Taylor's advice and am critical that Spectrum did not actively plan and utilise behaviour support expertise to overcome the barriers created by Ms A, ie, her aggression towards staff members, thus allowing more frequent wellbeing checks to be planned. In addition, I am concerned that the planning did not include alternative ways of ascertaining Ms A's wellbeing, for example by the use of text messages.

17. Regarding Spectrum's frequency of checks and/or face-to-face support of Ms A, Mr Taylor stated:

> '[I]n my view, a once-a-day check-in for someone with "very high support" needs is a **severe departure** from both the expected standard of care and the contract with the NASC.
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> …
>
> Spectrum Care does appear to agree that daily checks on a person supported is well below the expected standard of care as their new SOP … Supporting a Person in Supported Accommodation or Respite states: "However, at the very least, it is expected that every person in supported accommodation will be checked at least once per morning, afternoon and evening and their wellbeing confirmed and documented."'

18. I accept Mr Taylor's advice and am critical that Ms A was not checked sufficiently often, despite having very high support needs.

19. It is concerning that it took such a tragic event for Spectrum to develop and implement a new SOP outlining that wellbeing checks of residential consumers should occur at least thrice daily.

Adequacy of medication support provided to Ms A

20. Mr Taylor advised:

> 'In the case of medication oversight, it is my opinion that this demonstrates a **severe departure** from the expected standard of care. In this case, according to the autopsy, the departure appears to have become a factor in [Ms A's] death.'

21. I accept Mr Taylor's advice and am critical that Spectrum did not adhere to its 'Medicine Documentation' SOP and did not have a 'Self-Administration of Medicine Agreement' in place for Ms A. I am also critical that Spectrum had not planned and developed an

alternative way of reminding Ms A to take her medication. For example, medication reminders could have been placed on her mobile phone to alert her when it was time to take her medication.

Conclusion

22. In my opinion, taking into account the Coroner's findings, Spectrum's investigation report, and Mr Taylor's advice, Spectrum breached Right 4(4) of the Code, which states that every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer. I find that Spectrum did not provide services to Ms A in a manner that minimised harm to her.

23. I note that Spectrum has accepted this finding and has identified service-level failings, as set out in its investigation report.

Recommendations

24. I recommend that Spectrum:

a) Provide a written apology to Ms A's mother and Ms A's whānau for the issues identified in this report. The apology should be provided to HDC, for forwarding to the family, within three weeks of the date of this report.

b) Revise its applicable SOPs to include alternative ways of conducting wellbeing checks of the people in its care, such as utilising emails or text messages (if applicable). I note that my recommendation to use text messages or emails to ascertain a person's wellbeing should not be used instead of face-to-face wellbeing checks. The revised SOPs should be forwarded to HDC within three months of the date of this report, with evidence that these have been communicated to all Spectrum staff members.

c) Revise its applicable SOPs to include alternative medication reminders, such as utilising emails or text messages set up on the consumer's own mobile phone (if applicable). The revised SOPs should be forwarded to HDC within three months of the date of this report, with evidence that these have been communicated to all Spectrum staff members.

d) Reflect on Mr Taylor's advice regarding 'improvements that may help to prevent a similar occurrence in the future' and advise HDC of the changes it will undertake as a result. The reflections and an action plan should be forwarded to HDC within six months of the date of this report.

Follow-up actions

25. A copy of this report with details identifying the parties removed, except the advisor on this case and Spectrum, will be sent to the Ministry of Social Development and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Ms Rose Wall
Deputy Health and Disability Commissioner

Appendix A: Independent clinical advice to Health and Disability Commissioner

The following independent advice was obtained from Mr John Taylor:

'Complaint:	**[Ms A] (dec)/Spectrum**
Our ref:	**C24HDC01596**
Independent advisor:	**Mr John Taylor ONZM**

I have been asked to provide clinical advice to HDC on case number **C24HDC01596**. I have read and agree to follow HDC's Guidelines for Independent Advisors.

I am not aware of any personal or professional conflicts of interest with any of the parties involved in this complaint.

I am aware that my report should use simple and clear language and explain complex or technical medical terms.

Qualifications, training and experience relevant to the area of expertise involved:	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: 37 years of working within the disability sector including the following roles: direct support worker, agency management (over 20 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 operated contracts from MoH, Whaikaha, ACC, Corrections, Oranga Tamariki and MSD.
Documents provided by HDC:	1. Letter of complaint dated 6 July 2023 2. Spectrum's response dated 30 September 2024 3. Combined source documents (including the two documents mentioned above) 4. Additional information provided by Spectrum dated 12/12/24 and 5/2/25

Referral instructions from HDC:	Spectrum 1. *Whether Spectrum provided adequate levels of support to [Ms A], including regular wellbeing checks.* 2. *Whether Spectrum provided adequate levels of support to [Ms A], including regular medication support.* 3. *Any other comments you wish to make relating to the care provided to [Ms A].*

Factual summary of clinical care provided complaint:

Brief summary of clinical events:	This situation was referred to the Health and Disability Commissioner by the Coroner pursuant to section 119 Coroners Act 2006 to consider whether Spectrum care services provided [Ms A] with an appropriate standard of care. (NB: [Ms A] is also known as …, particularly in formal documents such as her NASC assessment and the Coroner's Report. I will keep with the convention set by Spectrum Care and the HDC of referring to her as [Ms A].) The referral came after the unexpected death of [Ms A] who had diagnoses of Traumatic Brain Injury, intellectual disability, epilepsy and non-insulin dependent Type 2 Diabetes and who lived in supported accommodation with Spectrum Care. The circumstances of [Ms A's] passing was that staff had not interacted with her since the evening of [Day 1] and she was later found dead … on the morning of [Day 3]. The formal cause of death was sudden unexpected death in epilepsy and the post-mortem report shows [Ms A] was not taking her anticonvulsant medication. At the time of her death there was no formal monitoring being undertaken by Spectrum Care to ensure [Ms A] was medication compliant.
Question 1: Whether Spectrum provided adequate levels of support to [Ms A], including regular wellbeing checks.	
List any sources of information reviewed other than the documents provided by HDC:	Nil

Advisor's opinion: What was the standard of care/accepted practice at the time of events? Please refer to relevant standards/material.	[Ms A] was supported via a Community Residential Contract and the funding agency, the Needs Assessment and Service Coordination (NASC) agency. [NASC] assessed [Ms A] as having "very high" support needs and anticipated that up to 112 hours per week, an average of 16 hours per day, would be made available for her support. This means that the funder and provider negotiated for [Ms A] to have a high level of oversight. I consider that checking in on a person once a day is well below the expected standard to care for someone with a very high needs support package. Even without that designation, people with an intellectual disability who are supported through a Community Residential contract will almost always require more than this to ensure their overall wellbeing and safety. The mitigating circumstances here are that [Ms A] was apparently quite determined to be as independent as she possibly could be and was unhappy to receive too much support. She also seemed to manage reasonably well with the level of support she received over several years, albeit her family would have liked her to have had more. I suspect from what I have read that it was her challenging response to staff that was the main reason she was left to her own devices so much rather than any habilitative plan. In their response to the HDC, Spectrum Care said: "Based on this assessment, the level of interaction [Ms A] had with staff prior to her passing was deemed appropriate and consistent with the obligations outlined in her Needs Assessment …" However, the Needs Assessment does not specify the level of support agreed to. The Service Authorisation listed the result of that Needs Assessment as "very high needs" so this should have informed Spectrum's practice. In the report commissioned by the CEO the following was noted: "Her support needs were identified as, 'to be supported with dignity and respect with day-to-day needs'". Her staff translated this as, "letting her be herself." (Paragraph 13) Again, quoting from the same report commissioned by the CEO, the authors commented: "[The] policy of only allowing staff into her space when it suited her was also a risk. While it honoured her independence it also prevented staff from monitoring her welfare and compromised their duty of care." (Paragraph 35) Parenthetically, I would congratulate Spectrum for commissioning external people to undertake this review. It

	demonstrates a genuine desire to understand and learn from this situation.
Was there a departure from the standard of care or accepted practice? ● No departure; ● Mild departure; ● Moderate departure; or ● Severe departure.	In the aspect of supporting [Ms A] to live in her own home under a Community Residential Contract, rather than in a group home, Spectrum would be applauded. It certainly offered her much more independence and a much greater opportunity to be in charge of her life. *Spectrum's planning and putting in place checks for [Ms A].* When it comes to the appropriate level of planning for this and putting in place adequate checks to ensure [Ms A's] general safety, then it is my view that Spectrum Care demonstrated a **moderate departure** from the expected standard of care. The expected standard of care would have envisioned Spectrum to have a much more frequent schedule of checking in, offering support and overseeing her medications. *Frequency of checks and/or face to face support.* As I mentioned earlier, in my view, a once a day check-in for someone with "very high support" needs is a **severe departure** from both the expected standard of care and the contract with the NASC. I would add that Spectrum Care does appear to agree that daily checks on a person supported is well below the expected standard of care as their new SOP (Standard Operating Procedure) "Supporting a Person in Supported Accommodation or Respite" states: "However, at the very least, it is expected that every person in supported accommodation will be checked at least once per morning, afternoon and evening and their wellbeing confirmed and documented." If this had been in place at the time then [Ms A] may well have still been alive.
How would the care provided be viewed by your peers? Please reference the views of any peers who were consulted.	The peers I checked with considered this lack of oversight to be significantly (high end of moderate departure) outside of the expected standard of care for the Community Residential contract and insufficient for [Ms A's] safety. At the time of asking I did not have the information that she was classified as "very high" needs. I suspect the peers I consulted would have agreed on a **severe departure** had they been provided with that information.
Please outline any factors that may limit	Nil

your assessment of the events.	
Recommendations for improvement that may help to prevent a similar occurrence in future.	Assisting people to live as independently as [Ms A] did is a very appropriate thing to do. It definitely aligns with the Enabling Good Lives vision and principles. To make it work well there needs to be the following processes in place: ● A support agreement that outlines the level and areas of autonomy the person has and the level of intervention the support provider will be expected to have. ● This agreement will ideally involve the person's family, especially in situations such as [Ms A's]. ● This plan will have markers to indicate if it is working or not and a process to review if things are not going well and is the primary vehicle for ensuring that the person has maximum autonomy while still allowing the provider to do their job well. ● There will be a risk and vulnerabilities plan that identifies the ways things might go wrong and the associated support design that mitigates these issues. (Please refer to my brief discussion below on "the dignity of risk.") ● There will be a behaviour support plan that mirrors the above plan. (Refer further comment in the below section) ● There will also be a support plan, and an emergency plan that rehearses potential situations and covers pandemics, earthquakes, fires, etc. (Refer further comment in the below section) ● There will be a regular review of how things are going, preferably monthly and preferably including the family.

Additional Comments

1: Behaviour Support Planning

The two behaviour support plans I read … were disappointing. They were reactive plans giving people advice on what to do when things go wrong. Although this does appear to align with definition of "Behaviour Support" contained with the Tier 2 Service Specifications for Community Residential Care, it is a long way from the expected practice for Positive Behaviour Support (PBS) …

PBS looks to improve the quality of life for individuals with disabilities by understanding and addressing the causes of challenging behaviours. It focuses on promoting positive behaviours through proactive strategies, skill-building, and creating supportive environments, rather than simply reacting to negative behaviours as they arise.

2. Emergency Planning. Spectrum did provide an Emergency plan for [Ms A] but it provided none of the detail of how she was to be kept safe in emergency situations (although this may have been kept elsewhere) and it did not record any attempts to assist [Ms A] to practise her response to various emergencies.
Name: Mr John Taylor
Date of Advice: 5 February 2025

Question 2: Whether Spectrum provided adequate levels of support to [Ms A], including regular medication support.	
List any sources of information reviewed other than the documents provided by HDC:	Nil
Advisor's opinion: What was the standard of care/accepted practice at the time of events? Please refer to relevant standards/material.	The level of oversight of [Ms A's] medication was not at the expected standard and did not match Spectrum Care's own expectation. The expected standard is that people who are supported take their medication, this is recorded and signed off, and any irregularities are both noted and processes amended to prevent future irregularities. For context, medication mistakes would be one of the most frequent errors that turn up in incident reports and for the most part do not prove to be life-threatening for people as a one-off. In this case, [Ms A] was known to be uncompliant with medication and would choose not to take it on some occasions and forget to on others. Missing her meds was clearly not a one-off yet Spectrum Care chose to do nothing to improve this situation. Instead they cite her desire to be autonomous. (This is discussed later in question 3.) The fact that Spectrum Care continued to provide no formal oversight when this non-compliance was known is quite problematic and is certainly a **severe departure** from the expected standard of care even if it was without management knowing (Spectrum Care had a standard operating procedure: "Self-Administration of Medicine Agreement" which sets out the conditions for people who control their own medication. This was not put in place for [Ms A].)

	In addition to this I noticed that the … Safety plan of 30/07/2019 did not look at medication compliance and there was nothing about epilepsy risk or medications risk in the 10/12 2018 Risk Assessment Plan. The latter despite staff knowledge that [Ms A] sometimes refused her medication or even threw it away. It appears that on review post this unfortunate incident Spectrum Care improved their processes and introduced a new SOP "Medicine — Self Administration." This one mentions a Competency test (not provided) and links to the updated "Medicine Self Administration Agreement." The latter agreement does look appropriate.
Was there a departure from the standard of care or accepted practice? ● No departure; ● Mild departure; ● Moderate departure; or ● Severe departure.	In the case of medication oversight, it is my opinion that this demonstrates a **severe departure** from the expected standard of care. In this case, according to the autopsy, the departure appears to have become a factor in [Ms A's] death. People are supported in Community Residential settings because, among other things, they do not or can not always make good decisions without support. So Spectrum Care's narrative that they were ensuring that "Her preferences for independence and autonomy were respected …" ignores their duty to also ensure this is done safely.
How would the care provided be viewed by your peers? Please reference the views of any peers who were consulted.	Spectrum Care's peers would see this as a **severe departure** from the expected standard of care. I suspect Spectrum Care does now too given the changes they made to their Standard Operating Procedures following this event.
Please outline any factors that may limit your assessment of the events.	
Recommendations for improvement that may help to prevent a similar occurrence in future.	Spectrum Care have made improvements to their processes that will hopefully reduce the chances of this situation happening again. Although Spectrum did have a comprehensive list of assessments (57 items) that may relate to any given situation, I could not find a link between the various SOPs staff were expected to work to. This apparent lack of integration of

	performance requirements could mean that important aspects of support are missed. As an example I would point to the new SOP called "Supporting a Person in Supported Accommodation or Respite." There are no links to other expected processes such as support planning, safety planning, etc, nor an overall support model document. This leaves me unclear as to how staff (who in this sector often have poor educational achievement and/or English as a second language) are meant to understand that this new SOP is not all that they need to pay attention to. There could be a whole system that covers off this concern but, if there is, it was not provided.
Name: Mr John Taylor	
Date of Advice: 5 February 2025	
Question 3: Any other comments you wish to make relating to the care provided to [Ms A].	
List any sources of information reviewed other than the documents provided by HDC:	Nil
Advisor's opinion:	Throughout the documents provided by Spectrum Care, there is an ongoing narrative about allowing [Ms A] to have the "dignity of risk." It is reflected in both their internal paperwork and their external investigation. As an example, the executive summary of that external investigation stated: "Root cause analysis suggests that Spectrum Care worked hard to support her strong drive for independence, giving her the dignity of being able to take risks." I want to comment on this because it is a misuse of the concept known as "the dignity of risk." Its use here appears to confuse this concept with what looks to me like a laissez fare approach to support. The "dignity of risk" concept comes out of a time when people with intellectual disability were routinely denied choice and control on the basis that it could lead them into unsafe situations. In reaction to this state of affairs, advocates for choice said: people should be able to live a life similar to other members of their society who are of a similar age. They should

	be able to make choices even if there are some inherent risks to those choices. This notion became known as "the dignity of risk" principle. It is somewhat of a misnomer as it appears to refer to the risk taking as the positive outcome but it is really referring to allowing people to pursue their preferences even if there are risks attached. In operation then, supporters were meant to work with the person to manage those risks such that they did not compromise the person's wellbeing. Spectrum's apparent misunderstanding of this term is also at odds with their Tier 2 Outcome Agreement for Community Residential (August 2023) where dignity of risk is described in section 6.11: "Allowing People the 'dignity of risk' means respecting a Person's autonomy and self-determination to make his or her own choices even if we may disagree. The goal is therefore not to eliminate risk, **but to support the Person with appropriate safeguards, information and strategies to minimise the risk of harm,** so the Person can take positive risks and make choices that are right for them." (Emphasis is mine) To be clear, there is no "dignity" for a person if they are left to face the consequences of risks they could not foresee, manage or understand.
Name: Mr John Taylor	
Date of Advice: 5 February 2025'	