New Zealand Drug Foundation submission:

Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights

Submitted to the Office of the Health and Disability Commissioner on 12 August 2024

The Drug Foundation is a charitable trust. We have been at the forefront of major alcohol and other drug debates for over 30 years, promoting healthy approaches to alcohol and other drugs for all New Zealanders.

Tēnā koutou,

Thank you for the opportunity to provide feedback on the Health and Disability Commissioner's review of the Health and Disability Commissioner Act 1994, and the Code of Health and Disability Services Consumers' Rights.

We welcome the Health and Disability Commissioner's specific focus in this review on the issues affecting people who have 'less of a voice'. People who use drugs often face additional barriers to receiving healthcare, and, may not choose to make a complaint due to fear of additional stigma or even penalties for disclosing drug use. Those who are reliant on certain interventions such as opioid substitution treatment may be even more reluctant to complain for fear of their treatment being compromised. We want to see meaningful engagement with patients who use such services, to understand their concerns.

We have heard first hand that people with lived, and living experience of substance use find it difficult to access healthcare. In the event that their rights have been breached, they find it difficult to make complaints. 'Admitting' past or current drug use can label a person as 'drug-seeking', thereby negatively influencing their care, even if they no longer use drugs. The very fact that drug possession and drug use remain a criminal offence means that fear of disclosing drug use means admission of a crime, which stifles open and honest conversations with health care providers.

We support the modernisation of the Code and the Act to make them inclusive for all genders, ethnicities, and disabilities. We particularly support the efforts to make the complaints process much easier for Māori. We want to encourage further efforts to continually assess and review how the complaints process is working for Māori.

Above all, we want to see a commitment by the HDC to meaningful, continuous dialogue with people with lived experience of substance use, and their whānau.

Nāku noa, nā

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NZ Drug Foundation Te Puna Whakaiti Pāmamae Kai Whakapiri

A. Introduction

1. Overall, we support the intentions and purpose of the HDC's current review. There is no question that making a complaint about health or disability treatment should be as 'fair, simple, speedy and efficient' as possible, with equitable access for all ages, ethnicities, genders, and disabilities.
2. The Drug Foundation's expertise lies in understanding the views and unique situations of people with lived experience of substance use, including those that may experience mild to moderate harm, severe harm, or no harm at all. We advocate for people with both past and current experience of drug use, to have their voices heard in matters directly affecting their care.
3. For the purpose of this submission, we carried out a survey of people with lived experience and their experiences of the healthcare system. Last year, we also hosted a forum with people with lived and living experience of substance use, to talk about their unique perspectives and experiences, including of interacting with the health care system. Some of these views and perspectives are included in our submission.
4. We welcome the HDC's intention to understand the reasons why certain groups may not be making complaints. People with lived experience of drug use can be some of the most vulnerable people who access Aotearoa's health and disability system. We support this review's focus on those who have a harder time making their voices heard, and agree that this may well include those receiving opioid substitution treatment (OST) or residential treatment.
5. The stigma surrounding drug use can create an additional barrier to receiving healthcare, or making a complaint. Disclosing drug use can negatively impact how people are perceived and treated by the health system. If someone is perceived as a 'drug user' first and foremost, health practitioners may not diagnose underlying chronic or acute health conditions (including people with neurodiverse conditions), with detrimental consequences. Disclosing drug use can also mean people are less likely to make a complaint when they feel their rights under the Code have been breached.
6. Additionally, the fear of disclosing illicit activity in the process of making a complaint, or lack of patient choice may all be playing a part in a reluctance to complain if health or disability service provision has not been appropriate. Some may have tried to make a complaint in the past, and not had a satisfactory outcome, leading to reluctance to make a further complaint.
7. We know that Māori people experience disproportionate harm from substance use. Giving practical effect to te Tiriti in the Act, and meaningfully discussing how best to do this with tangata whenua can work towards cementing the full participation of Māori in the complaints process. We strongly believe that Māori clients of the health and disability system should be heard to truly understand their unique experiences.

B. People with experience of substance use should be specifically acknowledged in the Act and Code

8. We welcome the HDC's acknowledgment that 'addiction' is recognised as a health issue by the Government (as per the National Drug Policy 2015-2020). We support the changes to the Act and Code to adopt the United Nations' definition of disability, meaning 'people who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others'.

9. However, many people who use drugs do not say they experience harm. For those that say they experience harm, the majority do not experience harm which would be considered 'disabling', or 'addictive'. At the same time, their experience of using drugs is highly likely to shape their experience of interacting with any aspect of the health and disability system. Therefore, we want to see the Act and the Code specifically mention people with lived experience of addiction, or with lived experience of substance use as health consumers in their own right. This will be an important part of making the Act and the Code work better for them.

10. Like other health consumers, people with lived experience of substance use will likely identify with several different groups. For example, there is a big overlap between people who are disabled and people who use some drugs. People who report amphetamine use in the past year are 5.14 times more likely to be disabled; for opioid use, they are 3.54 times more likely to be disabled, and for weekly cannabis use, they are 3.79 times more likely to be disabled (Ministry of Health, 2023b). Some people have underlying unmet health needs which may lead them to use drugs, but because of their drug use, their health needs are not investigated properly.
11. We therefore support the HDC acknowledgement that many people hold intersecting identities, and not all people who experience barriers identify with the words 'tāngata whaikaha' or 'disabled people'. We support the HDC's clarification that people with disabling mental health conditions may identify with communities with lived experience of mental distress or harm from substance use, and not the disability community.

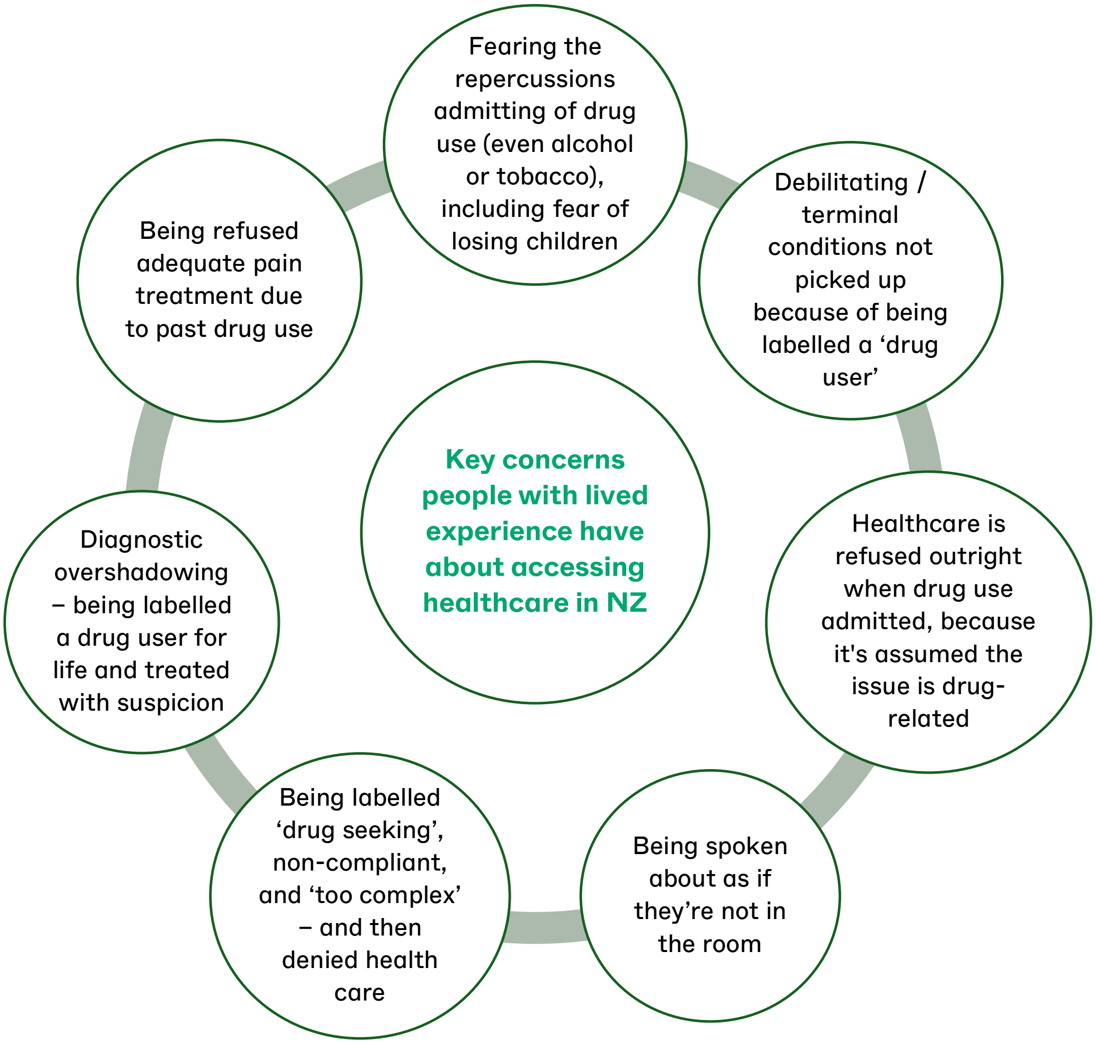
The stigma placed on people with lived experience of substance use gives them less of a voice when accessing healthcare, and can lead to poor health outcomes

12. The *Voices report: Accompanying report to Kua Tīmata Te Haerenga* by Te Hiringa Mahara – the Mental Health and Wellbeing Commission, describes current and firsthand experiences of people using the mental health and addiction treatment service system. These include lengthy wait times for people in crisis, not knowing which service to use, stigma and discrimination, lack of

suitable options, and difficult access to culturally safe and responsive services for Māori patients and their whānau (Te Hiringa Mahara, 2024b).

13. People who have experienced harm from using substances, especially acute or severe harm, are more likely to need care from the health system. However, due to the barriers described above and below, they often don't get the care they need.

14. In 2023, the Drug Foundation hosted *a Lived and Living Experience Forum: Pae Ora – Our Health*. This brought together people with lived experience of substance use to discuss issues related to seeking healthcare. Some of the key concerns participants discussed are presented below.



15. It is clear that people with lived experience of substance use face unique challenges in accessing healthcare. Whether they currently use drugs or not, stigma can follow them and impact future treatment. Stigma arising from drug

use was described by our *Lived and Living Experience Forum* participants as being ‘systematic’, and a ‘barrier to health care’ and to connection with others. People described feelings of shame and unworthiness which translated into a lack of health care and access to medication. In particular, trans people (especially trans women) and non-binary people felt affected by pronounced stigma.

16. Another group which faces barriers to appropriate health interventions is pregnant people who use drugs. Stigma associated with substance use is amplified during pregnancy. This stigma is commonly associated with the impacts that substances can have on a baby, such as Foetal Alcohol Spectrum Disorder (FASD), and in addition, some substances bring with them stereotypes that people who use them cannot be good parents. Fear of being treated differently or risking criminalisation, or losing custody of their children can mean parents may not access maternity care at all, or may not disclose substance use if they do.
17. We have heard that health care providers who enable open conversations about drug use practices – ‘safe talk’ – are the exception rather than the norm. Facilitating comfortable and non-judgmental conversations about a client’s drug using practices leads to a health care professional learning more about and from their client, building rapport, and supporting them with treatment choices. In turn, clients may internalize this way of communicating and replicate it when talking with others. A health care professional has an opportunity to create a snowball effect of stigma and discrimination reduction by creating a safe space. It is our understanding that such stigma-reduction experiences are atypical; and in fact the opposite is true, whereby repeated interactions with health care professionals compound feelings of shame, leading to poorer health outcomes.

Neurodiverse people who use substances can face additional challenges to appropriate diagnosis and treatment

18. Recent research has found that there is a lack of timely diagnosis and appropriate treatment of Attention-Deficit / Hyperactivity Disorder (ADHD), leading to the preventable development of substance use disorder among these people (Boland et al., 2020). ADHD prevalence among illicit stimulant users is as high as 45% (Kaye et al., 2013). For this group of people, their use of illicit substances can prolong or prevent a diagnosis of ADHD due to diagnostic overshadowing[1].

19. We are also aware that in the Canterbury region, people being prescribed with controlled medicines (e.g. ADHD medicine) are sometimes required to sign a

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[1] Diagnostic overshadowing refers to biases in treatment decisions, stemming from clinicians not offering appropriate treatment, delaying treatment, or offering suboptimal treatment because of a belief that the patient will not comply, does not deserve treatment, or will not benefit (Cunningham et al., 2024)

statement before being treated, which includes proactive drug testing. This coercive agreement will mean some people with drug use will stop trying to access healthcare, potentially causing their health to deteriorate. And if a positive drug test is returned, there is a risk of medication being denied, and due to the practice being implemented across the whole region, people may be unable to access another local treatment provider.

20. People with other neurodiverse conditions, such as FASD and prenatal alcohol exposure, are known to have high rates of mental health and substance use problems. It is estimated that up to 5% of people may have FASD, and an estimated 90% of these people will experience mental health challenges across their lifetime (Flannigan et al., 2020).
21. People on the autism spectrum are known to use substances, including alcohol, to self-medicate with to cope with their symptoms (Livingston, 2021). They may be at greater risk of substance use disorders than non-autistic individuals, and may have a harder time accessing healthcare to treat these disorders (Helverschou et al., 2019; Weir et al., 2021).

People with lived experience of substance use may be especially vulnerable and have less of a voice

22. As described above, stigma and feelings of shame can lead to people with lived experience of substance use having less of a voice. We support the HDC's intention to better understand the issues facing tangata whai ora who may have less of a voice, or who are especially vulnerable. An HDC report has found that only a small minority of complaints may be being made about addiction services. For example, only 15 out of 301 mental health and addiction complaints in 2018/19 were about addiction services (Health and Disability Commissioner, 2020). We agree that this needs to be a matter of priority for understanding if there are many people who have complaints but do not feel able to make them, and the reasons why.

23. One reason there are so few complaints about addiction treatment may be that in some remote or rural parts of Aotearoa, there are fewer (or no) choices of substance use treatment service provider compared to other, more populated areas. We know that this can impact people's willingness to make a complaint, due to limited alternative treatment options available should clients want to change providers.

24. Clients of OST services often have less of a voice or may be especially vulnerable. OST clients have reported issues with a power imbalance between themselves and their case managers, feeling that they were distrusted, or that they would be penalised for minor infractions (Allen & Clarke, 2018). The 2020 *Monitoring and Advocacy Report of the Mental Health Commissioner* found examples of OST clients experiencing coercive and disrespectful relationships with their clinicians (Health and Disability Commissioner, 2020).

25. People who access residential treatment services can also be especially vulnerable. We believe they are amongst those who face the most barriers to making a complaint. We want to see the HDC, as well as treatment providers, go above and beyond to ensure that the most vulnerable clients are empowered to know and exercise their rights when it comes to receiving a health or disability service according to the Code.

26. We are also concerned that the recipients of mandated addiction treatment may be among those least likely to complain. In 2022/23, 31 people were detained under the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 (Ministry of Health, 2023a). People detained under the Act may have severe substance addiction, and an impaired decision-making capacity to engage in voluntary or compulsory addiction treatment services. While legal compulsion to receive treatment may be life-preserving, it can also leave some consumers especially vulnerable to their rights being breached under the Code.

People with lived experience of substance use also face additional barriers to making a complaint due to engaging in illegal activity

27. We are also concerned that people who use drugs face additional barriers to making a complaint, because by way of obtaining and using their drugs, they undertake illegal activity.

28. People who use illicit substances should be confident that if they need to make a complaint, that it is explicitly clear that they can express their complaint in confidence. They should also be assured that they will not be referred to the criminal justice system if in the process of making a complaint, they disclose illegal activity such as drug possession or use. Please see our recommendation for additional wording in the Code in paragraphs 52-54.

Ministerial reporting should be expanded to ensure the needs of disabled people, and people who receive mental health treatment are being addressed

29. The Health and Disability Commissioner is currently required under the Act to advise the Minister of Health on any matter relating to the rights of health consumers or disability services consumers (section 14). The Commissioner also reports to the Minister from time to time on the need for, or desirability of, legislative, administrative, or other action to give protection or better protection to the rights of health consumers or disability services consumers (section 15).

30. We support the proposal to add a requirement in the Act for the HDC to report to the Minister for Disability Issues. We want to also see reporting to the Minister for Mental Health added as a requirement in the Act. This would strengthen the HDC’s ability to promote and protect the rights of tāngata whaikaha and people with lived experience of substance use.

C. We support making the complaints process more equitable, accessible, and timely, by engaging with those who have lived experience of substance use

31. We strongly support the recommendations in the *Mental Health and Addiction Service Monitoring report 2024*, which call for greater prioritisation of the voices of lived experience in progressing the development of the mental health and addiction treatment system (Te Hiringa Mahara, 2024a).

32. We encourage the HDC to prioritise listening to people who are, or have been clients of addiction treatment and harm reduction services. We would be encouraged to see the HDC work closely with Te Hiringa Mahara on communicating issues arising from the complaints process which may indicate the need for system monitoring or change.

33. As part of wider work to engage more with people with lived experience, we want to see the formation of forums of people with living or lived experience of substance use at both national and regional or local levels. These forums would proactively provide feedback to health care providers and health care policy. The aim would be to prevent problems happening in the first place, instead of trying to understand how to improve services after complaints have been made.

34. We have heard first hand that people with lived experience of drug use are often dissatisfied with the care they have received. We also understand that treatment providers' own complaint processes are difficult to navigate, or people aren't made aware of how to complain.

35. We have also heard about frustrations with the HDC complaints process. For one of the people we engaged with, this include waiting a year or more for complaint resolution. We also heard that the complainant did not feel their issue was properly understood the first time, so a further complaint needed to be made, with a long wait time for resolution.

36. Participants in the Drug Foundation's *Lived and Living Experience Forum* described how having trained peer advocates that work in health services would be beneficial to help them navigate the health care system, especially after they had been labelled as 'drug-seeking'. They said that peer advocates could help them be informed of their rights and to assist with, for example, challenging diagnostic overshadowing, being placed on restriction notices, and finding out about different treatment options.

37. We believe peer advocates can and already do assist those who want to make a complaint. As such, we strongly support the inclusion of the amendments to Right 10 of the Code to explicitly allow for complaints to be made by support people on behalf of the consumer.

38. Some people do not have access to trained peer advocates as described above. Therefore, we want to see the services provided by the Nationwide Advocacy Service made more visible, to better enable people to make formal complaints. We believe that the Advocacy Service has an important role to play in the rights of people who would benefit from someone helping them navigate the complaints process, including people who may use anonymous health services such as drug checking or needle exchanges. Better awareness of what the Advocacy Service can do for people would make the complaints process more accessible to people who may not feel they are able to make a complaint due to the fact that they are using an anonymous service, or, that they are reliant on the service for life-saving care (eg, OST).

39. We support the HDC's proposal to carry out regular surveys to look for ways to improve people's experience of the complaints process, and to track the impacts of changes following this review of the Act and the Code. We think this should also include the opportunity for people to follow up in depth if they are not satisfied with the outcome of the complaint process, but have not taken this to the Ombudsman, in order to find out why they did not do so.

40. We also support the HDC introducing clinical navigators to help guide people in the complaint process. This could be especially useful for people receiving OST as well as those in residential treatment receiving clinical treatment.

D. The Act and the Code need to be more effective for, and responsive to, the needs of Māori

Māori face additional challenges in navigating conventional health services

41. The HDC has acknowledged that Māori engage less with the HDC and the Nationwide Advocacy Service than the HDC would expect, given what they know about the experiences of, and outcomes for, Māori in the health and disability sector. In that respect we want to advocate strongly for proactive measures to understand this better, including engaging with tangata whai ora Māori to listen to their concerns.

42. Māori people experience disproportionately higher rates of use of some substances. In the past year, Māori were 4.01 times more likely to have used opioids, 2.25 times more likely to have used cannabis, and 1.58 times more likely to have used methamphetamine than non-Māori. Māori were also 2.71 times more likely to have used cannabis weekly (Ministry of Health, 2023b). A recent study also found that Māori have a higher proportion of substance use diagnoses than non-Māori (Cunningham et al., 2024).

43. In addition, *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction* found that:

> *Māori participation in conventional services has too often been hindered by the exclusion of whānau, a failed engagement process, offensive practices such as stigmatisation, seclusion, committal, over-reliance on medication, overt racism, and an inability of clinicians to understand Māori world views or te reo Māori.* (Government Inquiry into Mental Health and Addiction, 2018)

44. Māori with either mental health or substance use conditions have been found less likely to report positive experiences in healthcare services than non-Māori. Fewer Māori with these conditions than non-Māori reported being treated with respect and listened to in GP and hospital services. Among people of any ethnicity with a mental health or substance use condition, diagnostic overshadowing is commonly reported. However, Māori are slightly more likely to report this more than non-Māori in GP, emergency department, hospital and pharmacy settings (Cunningham et al., 2024).

To facilitate better outcomes for Māori, a te Ao Māori-based approach is needed

45. We support the HDC's proposals to include tikanga in the Code, and to give practical effect to te Tiriti o Waitangi in the Act. In particular, we support the guidance provided to the HDC by rangatira and Māori leaders in the health and disability sector on the relationship of tikanga to Code rights. We support the HDC's continued engagement with te Tiriti partners to inform decisions on which specific tikanga principles should be explicitly expressed in the Code. Likewise, we support the establishment of the HDC's new Director Māori role on the HDC leadership team.
46. We strongly support the recommendations in *He Ara Oranga* that clients' whānau should be supported to be active participants in their care and treatment. We believe this should include where any complaint or dispute is raised about a person's healthcare or treatment. We look forward to hearing more about how the HDC's hohou te rongo and hui ā-whānau approaches are working to make sure Māori are better able to facilitate the complaints process in a culturally safe way.

E. We support most of the proposed changes to the wording of the Code

47. We support the vast majority of the HDC's proposed deletions and additions to the wording of the Code as written in the consultation document, which have the intention of making the Code better reflect the needs of all health consumers.

Specifically, we support the following proposed changes as we believe they will benefit people with lived experience of substance use:

a. Right 1 regarding clarifying cultural responsiveness
b. Right 1, Right 4, Right 6, Right 7, Right 8, and ‘Definitions’ regarding ensuring gender-inclusive language
c. Right 3, Right 8, Right 10, and ‘Definitions’, regarding clarifying the role of whānau
d. Right 5 and Right 7, regarding strengthening and clarifying the right to support to make decisions
e. Right 10, strengthening references to accessibility; and clarifying the provider complaints processes

48. We especially support the amendments to Right 10 of the Code to explicitly allow for complaints to be made by support people on behalf of the consumer. People with lived experience of substance use may have trusted people in their lives who support them when accessing health care, or if they decide to make a complaint. This provision in the Code could benefit those who feel disenfranchised or unable to navigate the complaints process themselves. We agree with the changes to allow support people to be involved in other ways if they cannot be physically present, as well as for representatives to have their rights under the Code to receive information relevant to a complaint if the consumer chooses.

49. We have heard about experiences including medical neglect, bullying and ‘gaslighting’ from multiple healthcare providers. One story we heard included a client not feeling that they could make official complaints about these experiences, due to the risk of their care being compromised, as had happened to them upon making previous complaints.

50. We have also heard of a medical professional ceasing treatment of a patient, following the patient making a complaint about their care. The patient described how this happened after they disclosed illicit drug use, and inquired about a prescription for medicinal cannabis.

51. We therefore especially support the proposed changes to Right 10 to include a non-retaliation clause to support people to feel safe to raise concerns and complain. It is important to make it explicit to people that they will not face retaliation simply for making a complaint against a health or disability service. As the HDC has noted, this will be especially important for those who are reliant on care provided to them, including those receiving OST or those in residential

The proposed changes to the Code need to go further, to provide additional protection for people making a complaint

52. The Code also needs to state explicitly that people will not be referred to law enforcement if, while making a complaint, they disclose use or possession of illicit drugs. People with lived experience of drug use should feel confident in exercising their right to make a complaint without fear of legal penalties.

53. We propose additional wording to Right 10, either as part of or in addition to the new proposed clause 9. This should include a directive to providers who have received a complaint not to report, or threaten to report to law enforcement, any illegal activity which is disclosed in the course of making a complaint. This new wording would exclude any reporting that is required by law to prevent harm to the consumer's own or others' health and safety.

54. People should also feel confident that their treatment will not be jeopardised for simply making a complaint about their treatment. We want to see additional protection from retaliation for patients written into the Code whereby, if a patient makes a complaint, this is not sole grounds for a doctor ending the doctor-patient relationship. This is especially important where treatment options may be limited in a particular community or setting.

Considering options for a right to appeal HDC decisions, and minor and technical improvements

55. The proposed changes in Topic 4 and Topic 5 of the consultation document may potentially impact people with lived experience of substance use who make a complaint. However, we have no specific comments. Where the proposals in these two topics may impact people with lived experience, we have covered these issues previously in this submission.

F. Summary of our recommendations

Recommendation 1: the Act and Code should specifically mention people with lived experience of substance use

i. We recommend that the Act and the Code specifically mention people with lived experience of addiction, or with lived experience of harm from substance use as health consumers in their own right.

Recommendation 2: additional Ministerial reporting obligations

ii. We strongly support the proposal to add a requirement in the Act for the HDC to report to the Minister for Disability Issues.

iii. We recommend that reporting to the Minister for Mental Health is also included in the Act.

Recommendation 3: more engagement with clients and those with lived experience

iv. We support more engagement with tangata whaikaha, and specifically people with lived experience of substance use.

v. We recommend the HDC specifically find out more about people with less of a voice, including those receiving OST, those in residential treatment, and those receiving mandated treatment.

vi. We recommend promoting the Nationwide Advocacy Service to broaden access to the complaints process for people with lived experience of substance use.

vii. We support introducing clinical navigators, which could benefit those receiving OST.

Recommendation 4: giving practical effect to te Tiriti o Waitangi, and including tikanga in the Code

viii. We recommend the HDC carries out work to understand why Māori engage less with the HDC and the Nationwide Advocacy Service, including engaging with tangata whai ora Māori with lived experience of substance use.

ix. We recommend more exploration and promotion of the HDC's hohou te rongo and hui ā-whānau approaches, and recommend a report into their effectiveness.

x. We support the HDC's proposals to include tikanga in the Code, and to give practical effect to te Tiriti o Waitangi in the Act.

xi. We support expressly promoting and protecting tikanga within the Commissioner functions, in order to legislate and future-proof the HDC's responsiveness to the needs of Māori.

Recommendation 5: adding a new clause in the Code, directing providers to not report complainants to law enforcement

xii. We propose additional wording to Right 10, to follow the new proposed clause (9), to include a directive to providers who have received a complaint not to report, or threaten to report to law enforcement, any illegal activity which is disclosed in the course of making a complaint.

xiii. We want to see additional wording in the Code which protects against people from being removed from treatment by a particular doctor or service simply because they have made a complaint.

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