

## **New Zealand Drug Foundation submission on the health and disability code of expectations for engaging with consumers/whānau.**

Submitted to the Health Quality and Safety Commission via email [consumers@hqsc.govt.nz](mailto:consumers@hqsc.govt.nz) on **31 March 2022**

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.

Our mission is to transform the way Aotearoa New Zealand addresses drug issues. We influence this through our leadership, by supporting communities and inspiring action that promotes wellbeing, is mana enhancing and prevents drug harm.

## Tēnā koe

New Zealand has high rates of alcohol and other drug use. People who use drugs can experience: no harm at all, chronic harm from ongoing use, acute harm from an incident (such as overdose or an accident), problematic use or addiction. The harms can relate to hinengaro, tinana, wairua, whānau, culture, productivity and/or quality of life. They are not limited to mental health impacts, and may be mild, moderate or severe.

For a small group of people, their drug use - whether legal or illegal - causes significant harm. They may experience a range of health issues, some examples include: injury, hospitalisation, dental issues, hepatitis and serious heart and lung disease.

Tragically, the health system often sees people who use drugs in a negative light, as personally deficient, or not worthy of help. As a group they are widely failed by the health system. People who use drugs often miss out on the care they need as a result, whether for drug-related issues or other conditions, from dental care to cancer treatment.

For those who are also poor, disabled, traumatised or otherwise marginalised, the outcomes are even worse.

Māori carry a particularly heavy burden. Māori are significantly more likely to experience substance use issues than other ethnic groups, and more likely to seek help for addictions and not get it. Services that are available are not always fit for purpose or culturally inclusive.

Because of stigma around drug use, even those who use drugs infrequently may feel unable to have honest conversations with healthcare providers, resulting in ongoing unmet health needs (such as undiagnosed hepatitis, for example).

Involving those with lived experience of drug use is proven to improve the relevance and quality of services. Peer involvement is needed throughout the health system to help people who use drugs feel welcome, to make health services fit for purpose and ensure people get adequate care.

We wholeheartedly support the intent of the draft code of expectations. However, it must be made explicit in the code that those with lived experience of drug use should be included in the feedback loop between service providers and those who use those services. Equally, marginalised groups who need, but are not currently accessing available services, should be part of the conversation.

Our submission is structured as follows:

- **PART ONE.** The case for improving how the health system deals with drug use.
- **PART TWO.** How the code can improve the wellbeing of people who use drugs.

Ngā mihi nui,



Sarah Helm  
Executive Director

## **PART ONE – The case for improving how the health system deals with drug use**

### **We have high rates of drug use in New Zealand**

1. The drugs that cause most harm in NZ are alcohol and tobacco. Over 820,000 New Zealand adults drink hazardously.<sup>i</sup>
2. Of the population of New Zealand adults:
  - 79% drank alcohol in the past year.<sup>i</sup>
  - 11% currently smoke tobacco.<sup>i</sup>
  - 15% used cannabis in the past year.<sup>i</sup>
  - 1% used methamphetamine in the past year.<sup>i</sup>

### **Why do people take drugs?**

1. People use alcohol and other drugs for many reasons, including: pleasure and recreation; spiritual discovery; performance enhancement; experimentation; peer pressure; or to self-medicate physical problems, emotional pain or trauma.<sup>ii</sup>

### **Most drug use is not harmful**

2. While it's safest not to use alcohol and other drugs, most people are not harmed much, or at all, by their use. 4 in 5 people who used an illicit drug reported no harmful effects in that year. 7 out of 8 adults who use alcohol report no harmful effects in that year.<sup>iii</sup>
3. The likelihood of harmful use patterns developing depends on a range of social, cultural and genetic factors. Although chemical addiction can play a part, more significant factors contributing to substance use disorders are trauma and abuse, mental health problems, stress, poverty and housing insecurity.

### **Drugs can cause serious harm to some**

4. For a small group of users, drug use - whether legal or illegal - can cause significant harm. Risks include illness, injury, addiction and even death, with the effects borne by whole communities:
  - Almost 1 in 3 New Zealand adults have a moderate to high risk of experiencing health and other problems from their substance use - mostly tobacco (20% of adults) and alcohol (15% of adults).<sup>iv</sup>

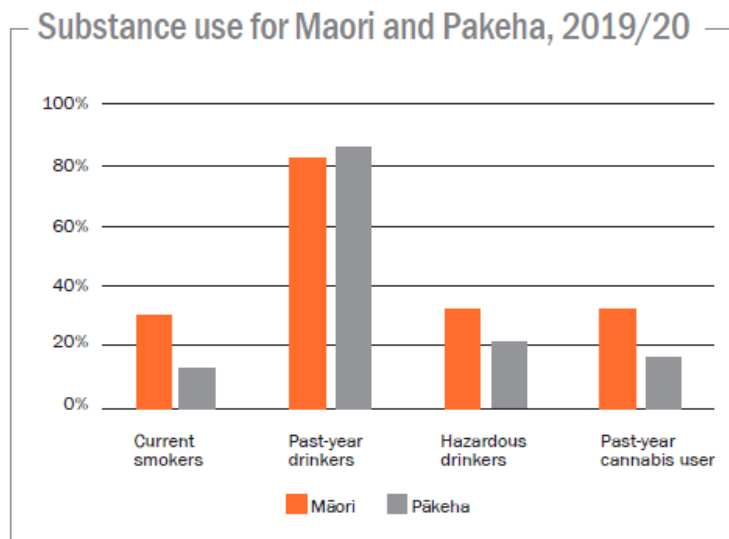
- About 5000 people die each year from smoking and second-hand smoke.<sup>v</sup>
- 1 out of 5 New Zealand adults drink in a way that risks physical or mental harm.<sup>i</sup>

### The most disadvantaged are often the worst affected

5. Māori, Pacific people and people living in areas of socio-economic deprivation are more likely to experience harm from their own alcohol or drug use. Māori, Pacific people, and those living in deprived areas are most likely to want help with their drug use but not receive it.<sup>vi</sup>
6. 60% of community-based offenders have an identified alcohol or other drug problem and 87% of prisoners have experienced an alcohol or other drug problem in their lifetime.<sup>vii</sup>

### Māori have different patterns of drug use and harms to Pākeha

7. Māori continue to disproportionately bear the burden of drug and alcohol harm. Māori are 2.8 times more likely to use tobacco and 2.2 times more likely to use cannabis than non-Māori. The disparity is greater in women for both substances.<sup>i</sup>
8. Māori and non-Māori have similar drinking rates, but Māori are 1.8 times more likely than non-Māori to drink hazardously (in a way that may cause harm).<sup>i</sup>



Source: 2019/20 New Zealand Health Survey

### **There is not enough help available**

9. Around 50,000 New Zealanders receive support to reduce their alcohol or drug use each year,<sup>viii</sup> but estimates suggest that only about a third of those who could benefit from treatment are accessing it.<sup>ix</sup>
10. Services are overextended and underfunded. People often have to wait until their problems have become acute before they can access help.
11. When people seek help but cannot access it, their window of opportunity is missed.

### **The “hard to reach” are consistently failed by the health system**

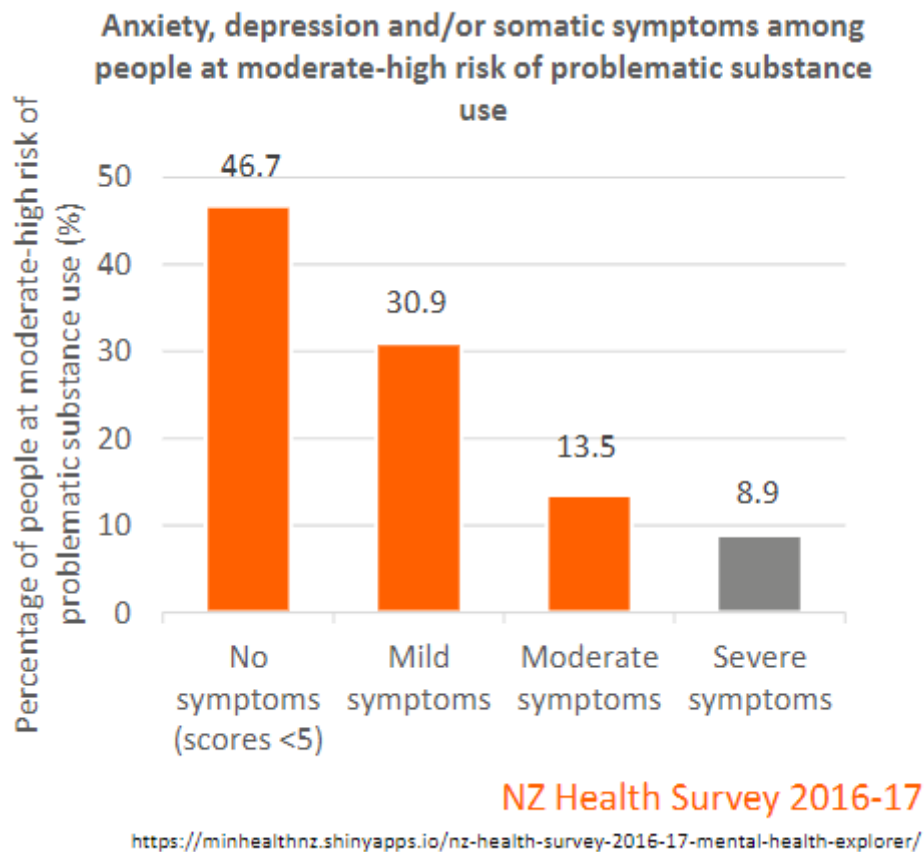
12. There is a small group of people with more severe problematic use or addiction issues who are consistently failed by the health system (and the educational, housing and social welfare systems). This group have generally suffered adversity and trauma, which has led to their current situation. They often suffer from serious co-morbid physical and mental health conditions.
13. This group is often described as “hard to reach”. They have had bad experiences at the hands of the state and are generally distrustful of “the system”. Mainstream services generally don’t work for them. Some of them may be Māori but both their and their whānau’s experience of colonialism may be so severe that they are disconnected from their iwi, hapū or whānau Māori. Even kaupapa Māori services delivered within the iwi-hapū-whānau framework may not be reaching them.
14. We are concerned with the health and wellbeing of this group of people because we acknowledge and respect the inherent dignity of every person. The health and wellbeing of this group also has broader consequences for other people in our society because we are fundamentally all connected. This was demonstrated very clearly in our COVID-19 Delta outbreak where we had to abandon an elimination strategy because COVID had become established in marginalised communities.
15. In our view, the success of any health system changes should be measured by how effective it is at improving the health and wellbeing of this “hard to reach” group.

### **People should be able to access a full range of evidence-based support options for drug and alcohol use at the time they need them.**

16. People face long waiting lists and struggle to access the support they need. There is often little support and information available until someone presents with addiction or is picked up by the criminal justice system. And even then, people continue to face long waiting lists for treatment, despite a welcome increase in funding in the 2019 Budget. The combination of the

growing housing crisis and the economic fallout from Covid will continue to exacerbate this existing need.

17. 1.2 M New Zealanders are estimated to be at moderate-high risk of problematic substance use, according to the NZ Health Survey. Yet nearly half of those will experience no clear symptoms to indicate they may be at risk. When we start the conversation when people are 'struggling' we miss most of the people we are trying to reach.<sup>iii</sup>



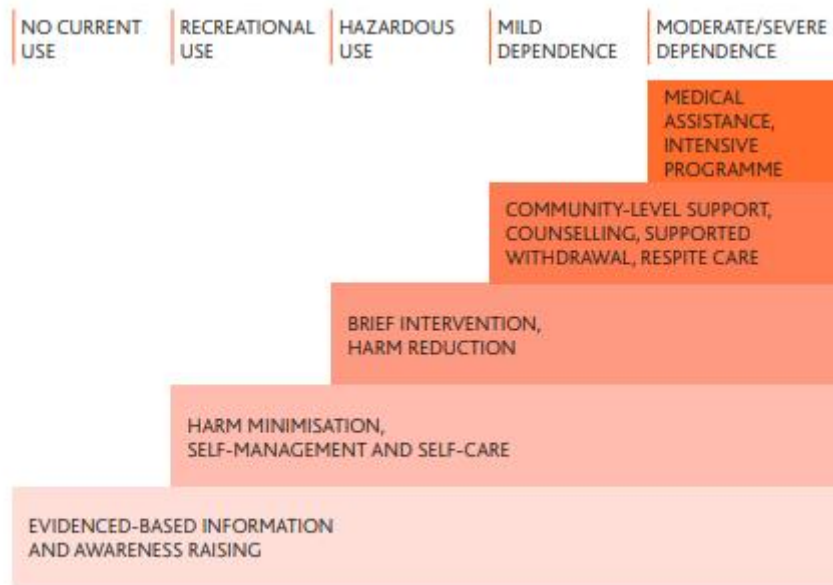
18. Of the 8.9% - or roughly 100,000 people - who experience severe symptoms, only around half receive support each year, meaning that even for people who are struggling, our services fall well short of what is needed.

### **We can make a real impact by targeting all levels of use**

19. As the Mental Health and Addictions Report, *He Ara Oranga*, recommends, we need to focus more on healthy approaches to drugs and alcohol for the whole population, and provide support options well before an individual starts to experience serious problems. This is more effective and more

compassionate – not to mention cheaper - than waiting to be the ambulance at the bottom of the cliff.

20. To support people at all levels of need, we need targeted approaches for each group shown in the diagram below, from those who don't use drugs at all to those who are severely dependent.



Source: National Committee for Addictions Treatment (NCAT). Shaping the Sector.<sup>20</sup>

### The code of expectations can help achieve these goals

21. The code of expectations should require all health and disability services to specifically listen to the voices of people who use drugs, and to people with lived experience of addiction. This will help break down the barriers which prevent people who use drugs getting timely, accessible and appropriate healthcare - not just for drug-related issues, but for any health condition they may be experiencing.

## **PART TWO – Why getting this code right will improve the wellbeing of people who use drugs**

### **Introduction and general comment**

1. The Drug Foundation strongly supports service users and their whānau being directly involved in how all health and disability services are developed, monitored and delivered. The draft code of expectations is welcome, because people who use drugs are not currently included in service development or delivery, and this results in ongoing marginalisation.
2. People who use drugs have demonstrably worse outcomes across the entire health sector. As just one example, people who were accessing AOD services in November 2021 were 30 percent behind other New Zealanders in their vaccination rates. Māori service users were a staggering 42% behind. And for those with substance use issues who *were not able* to access services for whatever reason the rates may well have been significantly worse again (data is not available).
3. This example shows why engagement from those who use drugs is particularly important in developing appropriate and effective services. Involving those with lived experience of drug use, and those who have experienced alcohol and other drug services first-hand, is proven to improve the relevance and quality of services where this is done well.
4. We welcome efforts from HQSC to set out a code of expectations for how those working within the health and disability system will engage with service users and whānau to effectively understand and meet their needs.
5. We note that:
  - a) The inclusion of people who use drugs in service development, monitoring and implementation is barely happening at all in mainstream health and disability services. The result is ongoing marginalisation and services that do not cater to the specific needs of people who use drugs or experience substance dependence issues.
  - b) Engagement with people who use drugs is not even yet happening consistently in the drug treatment and addictions sector itself.

### **The code should specify the need for health and disability services to engage with people who use drugs, people who use or have used AOD services, and their whānau**

6. Tragically, the health system often sees people who use drugs in a negative light, as personally deficient, untrustworthy, or not worthy of help. People who use drugs often miss out on basic healthcare as a result. For those who



are also poor, disabled, traumatised or otherwise marginalised the outcomes are even worse.

7. Involving those with lived experience of drug use, and those who have experienced AOD services first-hand, is proven to improve the relevance and quality of services and make them far more effective and fit for purpose for those who use drugs or experience addiction.
8. One example is an initiative that was implemented under the Te Ara Oranga programme in Northland. Te Ara Oranga is a partnership between police, mental health and addiction services, community groups and iwi service-providers which aims to give methamphetamine-users the opportunity to get therapeutic help rather than receiving a conviction.
9. Under Te Ara Oranga, a screening, brief intervention, and referral process was introduced in the Whangarei Hospital Emergency Department to help people who use methamphetamine receive treatment and other support.<sup>x</sup> The initiative is delivered by a dedicated practitioner with lived experience of methamphetamine use and long-term addiction.
10. An evaluation of Te Ara Oranga showed that the initiative has mellowed and changed emergency doctors' attitudes along with the whole culture around people who come into the emergency department with alcohol and drug issues.<sup>x</sup>
11. Without the participation of a person with lived experience, this would not have been possible.
12. We would like to see involvement of peer support workers and those with lived experience in all emergency departments. Similarly, we would like to see them involved in developing services and approaches in primary care, where they would no doubt have a similarly transformative effect.
13. We recommend the draft code of expectations includes a requirement for service users to intentionally engage with people who use drugs in service design, delivery, monitoring and evaluation. This will help to reduce some of the inequities experienced by people who use drugs throughout the health system.

### **We support the inclusion of the principles from WAI 2575**

14. We strongly support the inclusion in the code of the five overriding principles from the latest decision relating to the WAI 2575 Health Claim to the Waitangi Tribunal.
15. As noted above, due to our history of colonisation, and ongoing social and economic challenges, Māori are significantly more likely to experience substance use issues than other ethnic groups. Māori are also more likely to seek help for addictions and not get it. Services that are available are not always fit for purpose or culturally inclusive. It is therefore particularly

important that Māori who use drugs are empowered through this code to have input into service development and evaluation.

**Not all those who need services currently access them. How can we include them in the conversation?**

16. As noted above, of the 8.9% of New Zealanders – roughly 100,000 people - who are at moderate or severe risk of problematic substance use, and who experience severe mental health symptoms, only around half receive alcohol or other drug support. Some seek out services but are unable to access them, whether due to cost, location, waiting lists or appropriateness of the services offered. Others do not even try to access services, often due to stigma they have experienced in the past, leading to a general distrust of the health system. <sup>xi</sup>
17. Many of these same people are already marginalised and consistently failed by the health system. They may have suffered adversity and trauma, which has led to their current situation. They often suffer from serious co-morbid physical and mental health conditions.
18. It is essential that these people are also involved in developing services and shaping how the health system responds to their experiences - not just those who have been able to access services in the past.
19. The code of expectations touches on this need in the section on equity, which we support. However, we would like to see this expanded on and explained. It should be clear what outreach with less engaged sections of the community might look like, and why it is important.

**The term “consumer” is problematic**

20. The term ‘consumer’ is used in the Code of Health and Disability Services Consumers’ Rights so we understand why it has also been used here.
21. However, we do not support the term, and have received similar feedback from colleagues we have spoken to about it in the AOD sector. The word implies a market-based system and a model of economics that dates from the 1980s. The term fails to connote people’s intrinsic humanity. It does not relate well to the experiences of receiving healthcare - a basic human right - as opposed to a consumer product.
22. Another issue with the word “consumer” is that it implies that the person is a passive recipient of health care rather than someone with agency and an active participant in their own health.
23. Replacing the term ‘consumer’ with ‘service user’ or ‘people who use services’ would be more accurate and give them more agency. We note that

the Ngā paerewa health and disability services standards also prefer that usage and do not use the term 'consumer'.

### **The section on equity needs to be more specific**

24. Statistically, some groups of people are significantly more affected by drug harm than others. They are often the same people who are least able to access appropriate or accessible help.
25. The data shows that drug use prevalence is heavily affected by factors including where you live, your gender, socio-economic status, disability status, and ethnicity. These same factors can also make it harder for people to access appropriate services.
26. As mentioned previously, Māori continue to disproportionately bear the burden of drug and alcohol harm. Māori are 2.8 times more likely to use tobacco, 2.2 times more likely to use cannabis and 1.8 times more likely to use amphetamines (including methamphetamine) than non-Māori. The disparity is greater in women for each substance.
27. Socio-economic status is strongly correlated to type of substance use. Women living in the poorest neighbourhoods are 18 times more likely to use amphetamines (including methamphetamine) than women in the wealthiest neighbourhoods, for example. Similarly, disabled people are nearly three times more likely to use amphetamines than non-disabled people.
28. We know that different ethnicities are at risk from different types of drug harm. As one example, Pacific peoples are around 20% less likely to drink alcohol than the rest of the population. However, those who do drink are significantly more likely to drink hazardously than others.
29. People who are pulled into the criminal justice system are particularly at risk - 87% of prisoners have experienced an alcohol or other drug problem in their lifetime.
30. Achieving equity in healthcare requires taking into account the different socio-economic and other factors that may influence a person's health outcomes and access to treatment, and ensuring the health system is agile enough to respond to those different factors.
31. The equity section of the draft code is extremely high-level and non-specific. We would like it to specify that achieving equity means thinking about gender, ethnicity, sexual orientation, disability, previous experiences of trauma (including from interactions with mainstream services), where a person lives, how wealthy they might be and so on. All of these factors are relevant to in the struggle to access fit-for-purpose services, especially for those who use drugs.

32. We would like to see clearer guidance in this section, along with clear guidelines as to how services should report against equity objectives, to reduce health disparities.

**We have questions about how the code fits with other standards, and how it will be implemented**

33. It is not entirely clear how this code fits with other codes and standards already in use.
34. The code of Health and Disability Services Consumers' Rights<sup>xii</sup> specifies the individual rights a consumer has when they use a health or disability service, such as the right to dignity, the right to be free from discrimination and the right to service of an appropriate standard.
35. The Ngā paerewa health and disability services standards (NZS 8134:2021)<sup>xiii</sup>, were developed as national standards to support the code of rights, and set out how the code should be implemented. The standards (and its predecessors) were developed as a way to benchmark services and to audit DHB-funded services.
36. The standards have been a key driver in the development of 'lived experience' roles in the addiction sector, such as consumer advisors. We would like to see the new code of expectations intentionally build similar roles into mainstream health and disability services.
37. Clauses 2.3.9 – 2.3.14 of the current standards set out guidelines for how service users and their whānau participate in planning, implementation and evaluation of service delivery.
38. There is quite a bit of overlap between these clauses and the HQSC code of expectations. It is not clear which should take precedence, or if the HQSC code is intended to supplement the standards or stand alone.
39. It is also not clear how the code sits alongside the HQSC's Consumer engagement quality and safety marker framework<sup>xiv</sup>, which sets out what partnership and shared leadership with consumers and whānau looks like for service providers.
40. Some clarification around that would be helpful.

**The code could be written in a way that makes it clearer what service providers are specifically required to do.**

41. If the draft code of expectations is intended to supplement or 'flesh out' the national standards, it is essential that they can be easily used as a practical tool. Service providers need to be able to understand clearly how the code is to be applied, and what success looks like.

42. As it stands, the code may not be detailed or specific enough to help service providers understand this, and to ensure that their efforts can be objectively monitored, evaluated and audited against the code.
43. The expectations are aspirational rather than specific, with the passive tense used throughout:
 

“effective outreach to less engaged sections of communities occurs’.

Switching this to a specific requirement for service providers may help, such as “service providers are required to engage those in the community who may benefit from access to their services but are not accessing them. One example is people who use drugs...”
44. It may be that this code will sit above another framework that gives more detail to help service providers understand what is expected of them. However if that is not the case, we recommend that more detail is included about what each expectation means in practise.

**Be clear about monitoring and implementation expectations, to ensure services are held to account**

45. It would also be helpful were the code to explain how performance against the expectations would be monitored and/or enforced, to ensure that services are held to account in terms of taking and acting on feedback to improve services. Aspirational goals mean nothing if they are not followed by implementation.
46. Similarly, it should be clear how ‘consumers’ can make a complaint if the expectations are not upheld (just as when visiting a GP, for example).

**In the AOD services sector, it is essential the code should apply to privately funded services as well as publicly funded ones**

47. It is not clear whether both publicly and privately funded service providers are intended to be covered by the code of expectations.
48. As you will know, in New Zealand, anyone can set themselves up as an additions service provider, without the need to be registered or audited. Service providers which are publicly funded and contracted by DHBs will be regularly audited, and will be contractually obliged to engage with consumers and take feedback into account in service delivery.
49. Privately funded services meanwhile may be run by people who are not registered counsellors or addiction specialists, without oversight or quality control. Service users may be completely unaware that they are paying large amounts of money to be treated by people who may not have qualifications, and within a service that is not required to meet basic codes of expectations. Treatment may be ineffective or even harmful, with no clear

avenue available for service users to make a complaint if something goes wrong.

50. As such, we recommend that this code explicitly cover any individual or service that suggests they are running addiction support, regardless of whether individuals working there are registered, or the service is publicly funded.

## **Final Recommendations**

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1. Be explicit in the code about the need for health and disability services to engage with people who use drugs, people who use or have used AOD services, and their whānau.
2. Ensure that the voices of people who have not been able to access services for whatever reason are also heard, by being more explicit in the code about how this should happen. Be clear what outreach with less engaged sections of the community might look like, and why it is important.
3. Replace the word 'consumer' with 'service user' or 'people who use services'.
4. Make it clearer what is meant by 'equity' in the code, including specific mention of gender, ethnicity, sexual orientation, disability, and experiences of marginalisation, trauma and poverty.
5. To reduce potential confusion for service providers, be clear how the HQSC code of expectations will interact with other guidelines, such as the national standards.
6. Ensure expectations are clear and specific. This may mean either providing more detail in another framework that sits below the code, or putting more specifics in the code itself about what each expectation means in practise.
7. To ensure services providers are held to account under the code, clarify how performance against the expectations would be monitored and/or enforced, and how service users can make a complaint.
8. Ensure the code of expectations covers any individual or service that claims to provide addiction support, regardless of whether the service is publicly funded.

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- <sup>i</sup> Ministry of Health. (2021). Annual Update of Key Results 2020/21: New Zealand Health Survey. Retrieved from <https://minhealthnz.shinyapps.io/nz-health-survey-2020-21-annual-data-explorer/>
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- <sup>iii</sup> Ministry of Health. (2010). *Drug Use in New Zealand: Key Results of the 2007/08 New Zealand Alcohol and Drug Use Survey*. Wellington: Ministry of Health.
- <sup>iv</sup> Ministry of Health (2020). *Mental Health Data Explorer 2016/17: New Zealand Health Survey [Data File]*. Retrieved from <https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-mental-health-explorer/>.
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- <sup>vii</sup> Department of Corrections (2020). *Alcohol and other drug treatment programmes*. Obtained 4 August 2020 under the Official Information Act 1982
- <sup>viii</sup> Ministry of Health (2020). *Alcohol and drug treatment data [data file]*. Obtained 30 July 2020 under the Official Information Act 1982.
- <sup>ix</sup> Health and Disability Commissioner (2020). *Aotearoa New Zealand's mental health services and addiction services: The monitoring and advocacy report of the Mental Health Commissioner*. Mental Health Commissioner's monitoring report (page 103). Auckland: Health and Disability Commissioner.
- <sup>x</sup> Darren Walton (2021). "The Evaluation of Te Ara Oranga: The Path to Wellbeing". Wellington, Crows Nest Research.
- <sup>xi</sup> Ministry of Health (2017). *Mental Health Data Explorer 2016/17: New Zealand Health Survey*. Data retrieved online. Ministry of Health (2017). *Mental Health Data Explorer 2016/17: New Zealand Health Survey*. Data retrieved online.
- <sup>xii</sup> <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>
- <sup>xiii</sup> <https://www.standards.govt.nz/shop/nzs-81342021>
- <sup>xiv</sup> <https://www.hqsc.govt.nz/assets/Our-data/Resources/Consumer-Engagement-QSM-Framework-v3.pdf>