FASD-CAN
Fetal Alcohol Spectrum Disorder
Care Action Network

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Dear Commissioner

HDC ACT AND CODE REVIEW 2024

Introduction

Fetal Alcohol Spectrum Disorder – Care Action Network (FASD-CAN) Incorporated is a registered charity formed to “unite caregivers, strengthen families, support individuals and educate about foetal alcohol spectrum disorder (FASD) across our communities”. We are the national organisation providing support to caregivers, and we have expanded into secondary roles of providing information on FASD to professionals and caregivers, representing the rights of those with FASD, and providing training and workshops on FASD. Our membership includes FASD individuals, family /whānau of people with FASD, and professionals who support them.

FASD

FASD is a very complex brain and whole of body disorder, characterised by lifelong brain damage. While there are no prevalence data gathered in New Zealand, the Ministry of Health estimates that 3-5% of the population have FASD based on comparable international populations. That makes it more common than Autism, Down’s syndrome, Tourette syndrome, and Cerebral palsy combined. It often results in adverse outcomes such as mental health and addictions, youth crime and involvement in the justice system, lack of employment and very significant caregiver stress. Ironically, the 20% of people with FASD who also have an intellectual disability tend to fare better in life outcomes because their disability is not ‘hidden’ - they are given support, and they may live in a more sheltered environment. For most the disability is largely ‘hidden’ (most are undiagnosed and for many it is not immediately obvious they have a neurodisability). Eighty per cent of those with FASD are not eligible for Disability Support Services, despite all those with FASD having lifelong challenges with everyday activities.

Current situation concerning FASD in Aotearoa

We see the health and disability issues relevant to people with FASD and their whānau in Aotearoa as:

- Lack of adequate funding on an individual, caregiver, family/ whānau and organisational level
- Lack of observance of Human and Disability rights
- Lack of early interventions to mitigate risk of onset of secondary characteristics and symptoms
- Ongoing inequities in resourcing and services for this underestimated and stigmatising neurodisability

- Lack of appropriate (trained) support services and options for people with FASD
- Limited appropriate respite care options

Submission to the HDC's Act and Code Review

General statement

FASD-CAN's concerns primarily relate to the lack of understanding of FASD among the health and disability workforce as a brain-based disability. This can lead to the possibility of abuse of their rights, whether intentional or unintentional, and abuse of their naivety and desire to please others to be liked and accepted. All people with FASD have some degree of executive functioning challenges, making them vulnerable to manipulation and abuse.

Our lived experience is that many people with FASD interacting with health and disability services have their rights ignored or abused. However, without support from caregivers, family and whānau they seldom complain because the complaint process is not easily accessible to them, they do not have faith that anything will be done if they complain, they are afraid complaining may adversely affect their supports, and that they will not be believed because of their neurodisability.

This is the lens we bring to our submission and this is why we particularly support proposed amendments to allow for the support of caregivers, family and whānau or another presentative when a disabled person is interacting with the Health and Disability systems.

Review of the Act

In your review consultation document you posed a number of questions relating to the Act which we now address below. Please note specific submissions on the proposed amendments to the Code are also set out at the end of this document and should be read in conjunction with the questions you have posed.

<u>Topic 1 – Supporting better and equitable complaint resolution</u>

Question 1.1: Did we cover the main issues about supporting better and equitable complaint resolution?

Yes.

Question 1.2: What do you think of our suggestions for supporting better and equitable complaint resolution, and what impacts could they have?
Proposed changes were to:

a. Amend purpose statement
b. Clarify cultural responsiveness
c. Clarify the role of whānau
d. Ensure gender inclusive language
e. Protect against retaliation
f. Clarify provider complaints processes
g. Strengthen the Advocacy Service
h. Improve the language of complaint pathways in the Act

We generally support the proposed changes noting providers often do not advise consumers of their complaints resolution procedures and options. We also strongly support amendments that would give explicit protections from retaliation, and that raise and clarify the role of family/whānau as natural supports in health and disability complaint processes and their ability to make a complaint on behalf of their family member.

However, we do not believe the use of the term "autonomy" (as opposed to "independence") materially clarifies the role of whānau in the consumer-provider relationship. In terms of people with FASD, international best practice talks about "respectful interdependence" as the best approach to lessen negative behavioural symptoms, reduce anxiety, maximise success, and support change.

Question 1.3: What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaint processes?

We make no comment.

Topic 2 – Making the Act and the Code effective for, and responsive to, the needs of Māori

Question 2.1: Did we cover the main issues about making the Act and the Code more effective for, and responsive to, the needs of Māori?
Yes.

Question 2.2: What do you think of our suggestions for making the Act and the Code more effective for, and responsive to, the needs of Māori, and what impacts could they have?
Proposed changes were to:
a. Incorporate tikanga into the Code
b. Give practical effect to te Tiriti | the Treaty in the Act.

As a bicultural organisation committed to supporting the views and aspirations of Māori, we commend the Commission for taking the initiative to reflect this in the Review. We believe a start has been made but there is probably more that could be done in the future. However, the use of Māori terms and concepts must be accessible to all people in Aotearoa New Zealander and this will require dual use of both Māori and English in the Act and Code.

Question 2.3: What other changes, both legislative and non-legislative, should we consider for making the Act and the Code more effective for, and responsive to, the needs of Māori?

A mātauranga Māori approach involving manaakitanga (kindness and respect), whanaungatanga (connection), and pono (integrity) should be the standard way of being and doing for all consumers of health and disability services.

Topic 3 – Making the Act and the Code work better for tāngata whaikaha / disabled people

Question 3.1: Did we cover the main issues about making the Act and the Code work better for tāngata whaikaha / disabled people?

Yes.

Question 3.2: What do you think of our suggestions for making the Act and the Code work better for tāngata whaikaha / disabled people, and what impacts could they have?
Proposed changes were to:

a. Strengthen disability functions in the Act
b. Update definitions relating to disability
c. Strengthen references to accessibility

d. Strengthen and clarify the right to support to make decisions
e. Progress consideration of HDC's draft recommendations relating to unconsented research

We generally support the proposed amendments but have made specific comments in relation to the Code.

Question 3.3: What other changes, both legislative and non-legislative, should we consider for making the Act and the Code work better for tāngata whaikaha / disabled people?

We believe the Act could be strengthened by the explicit inclusion of the United Nation's definition of disability as cited in the UNCRPD. This is because its inclusion would make it clear that people with neurodisabilities also meet the definition, and their needs must also be met by the legislation.

We would also like to see the inclusion of a "rights" based approach in the legislation and Code. This includes Human, Disability, Child and Indigenous People's rights as set out in international treaties and Conventions to which we are parties, and the NZ Bill of Rights and the NZ Disability Strategy.

Also explicitly incorporate the social model of disability into legislation and the Code, underpinned by the Enabling Good Lives principles.

Topic 4 – Considering options for a right to appeal HDC decisions

Question 4.1: Did we cover the main issues about considering options for a right of appeal of HDC decisions?
Yes.

Question 4.2: What do you think of our suggestions for considering options for a right of appeal of HDC decisions, and what impacts could they have?
Proposed changes were to:
a. Introduce a statutory requirement for review of HDC decisions
b. Lower the threshold for access to the Human Rights Review Tribunal (HRRT)

We support the proposed changes as fundamental to open and transparent justice.

Question 4.3: What other options for a right of appeal of HDC decisions, both legislative and non-legislative, should we consider?

Less time consuming and onerous processes for people with disability to navigate would be a huge step forward in dispute resolution. People want to be heard and understood, even if a decision does not go their way. If this could be done by the consumer and provider working together to resolve issues of concern before they became a major issue, there would be fewer complaints to the HDC in the first place.

We are aware of the recent HDC report on complaints received in terms of residential disability support services. We would support this information being used to identify common areas of complaint and concern, or providers of concern, so that the HDC could work with them to improve performance across the provider spectrum. To do this would require the HDC to have the legislative ability to intervene when required.

Topic 5 – Minor and Technical Improvements

Question 5.1: What do you think about the issues and suggestions for minor and technical improvements, and what impacts could they have?
Proposed changes were to:

a. Revise the requirements for reviews of the Act and the Code
b. Increase the maximum fine for an offence under the Act from $3,000 to $10,000
c. Give the Director of Proceedings the power to require information
d. Introduce a definition for ‘aggrieved person’
e. Allow for substituted service
f. Provide HDC with grounds to withhold information where appropriate
g. Expand the requirement for written consent for sedation that is equivalent to anaesthetic
h. Clarify the requirement for written consent where there is a high risk of serious adverse consequences
i. Clarify the Code’s definition of teaching and research
j. Respond to advancing technology

We generally support the proposed amendments but please refer to our specific comments in relation to the Code. The fine to a maximum of $10,000 seems too small for the potential effect it can have on the customer, and we would support an increase to a maximum of $50,000 in line with the jurisdiction in other Tribunal settings.

We would like to see the grounds for withholding information kept to a minimum, with a clear requirement for an explanation for withholding information.

We support the requirement for written consent but query why this is not also a requirement for mind altering mental health medication.

Question 5.2: What other minor and technical improvements, both legislative and non-legislative, should we consider?

Consideration of retrospective access to customer information for research purposes needs to be clarified in circumstances where getting informed consent is not viable. It would be beneficial if the HDC issued clear guidelines for Ethics Committees around ethical informed consent processes.

Question 5.3: What are your main concerns about advancing technology and its impacts on the rights of people accessing health and disability services?

The advance of technology and its use in health and disability services is a double-edged sword. For some it may provide freedom and many new opportunities, but for others it poses many risks. Fundamental risks arising from the ever-increasing use of technology relate to breaches of privacy and the right to access and use your data (‘data sovereignty’). In particular, the fast development and use of AI in the absence of law and regulation, is fraught with risk for violation of people’s rights.

Question 5.4: What changes, both legislative and non-legislative, should we consider to respond to advancing technology?

There needs to be explicit law and regulations developed relating to the use of technology in the health and disability system, particularly as it relates to AI.

Review of the Code

You also proposed several changes to the Code which we now address. We consider this in many ways to be the most important document to get right, as it is the most well-known and accessible by people with FASD and their caregivers, family and whānau.

To be effective, the Code needs to be accessible to a wide range of people and delivered in a number of ways that meet the needs of all New Zealanders. For people with FASD, this will vary considerably. Terms like “autonomy” will also need to be either simplified or defined.

Rights 1

1. We fully support the proposed amendment to 1(3)(a).
2. The wording in 1(3)(b) needs more simple clarification as to the meaning of “enable” so there is a clear understanding of what this means.

Rights 2

Right 2(1)

3. We fully support the amendment to Right 2(1)(1) that everybody has the “right to have their mana upheld” while noting as a bicultural document both English and Māori terms should be used.
4. We fully support the proposed amendment to Right 2(1)(2).
5. We fully support the proposed amendment to Right 2(1)(3).

Right 2(3)

6. The proposed change to Right 2(3) is to clarify the role of whānau, as stated in Appendix 2. Definitions of “independence” include “freedom from the control, influence, support, aid, or the like, of others” (Dictionary.com) and “not influenced or controlled by others in matters of opinion, conduct, etc.; thinking or acting for oneself” with a synonym of ‘autonomous’ (Dictionary.com)
7. The definition of “autonomy” is “the ability to make your own decisions about what to do rather than being influenced by someone else or told what to do”. (Collins Dictionary)
8. You appear to have drawn a distinction between the two words despite the title of the Right remaining unchanged.
9. We maintain the change is unnecessary and potentially confusing. The term “independence” is more easily understood than the term “autonomy”.
10. We also do not believe this change will achieve the stated intention of clarifying the role of whānau.
11. Family and whānau are essential natural supports to people with FASD and they have a vital role in advocating for the rights of their family member when they are unable to do so by themselves.

Right 2(4)

12. We fully support the proposed amendment to Right 2(4)(3).

Right 2(5)

13. We fully support the proposed amendments to Right 2(5)(1) with the caveat that the consumer should get to identify their “appropriate supports and/or support people ...”, not the clinicians or the service provider.
14. In terms of Right 2(5)(2) you propose no amendment. However, clarification of what the “right to an environment ...” means is essential for joint understanding. And it is more than just “to communicate openly, honestly, and effectively.” It is about maintaining the mana and dignity of the parties as well so that further trauma or harm is avoided.

Right 2(6)

15. We fully support the proposed amendment to Right 2(6)(1)(a).
16. This Right is incredibly important. But it is not just about the right for an explanation of their condition, it is about open transparency when changes are made to their stated condition(s).
17. We have lived experience of a young man with FASD having several diagnoses added to his medical history without any discussion or advice to him of the change. He only found out this had happened when he requested a report from his psychiatrist for an application, and found his main diagnosis of FASD had been

removed from his record and several psychiatric disorders had been added instead, all without his knowledge or an explanation.

18. If consumers have this right to be fully informed, then they must also have the right to photocopy their records.
19. In terms of Right 2(6)(4) the consumer's right is to receive, on request, a written summary of information provided but **in a manner that meets their needs**.

Right 2(7)

20. This suite of Rights is problematic from the perspective of caregivers, families and whānau of people with FASD due to their affected executive functions and dysmaturity, while having the expressive language and physical appearance of their peers. FASD is a "hidden" disability, and very few people with this condition get diagnosed.
21. While we must accept and support the rights of people with FASD to make choices in their lives, this does need to be carefully managed with natural or independent supports, and a longer period of time given for their decision making. People with FASD are often impulsive, easily swayed, do not want to appear stupid when they have not understood what was explained to them, and will just say "yes" to anything to please, and to get out of a room as soon as possible. This is a high-risk area in terms of Health and Disability consumer rights for people with FASD without supported decision-making.
22. We therefore accept the proposed amendments to Rights 2(7)(2), 2(7)(3) and 2(7)(4) while noting our strong concerns above about practice.
23. We support the amendment to Right 2(7)(6)(c).
24. We do not support the proposed change to Right 2(7)(6)(d). Open and transparent information should be provided to satisfy the right to informed consent, and not left to someone else to determine what they consider important for the consumer to know in terms of only "serious" adverse effects.
25. Right 2(7)(6)(c) raises issues relating to mental health medication. The purpose of the proposed amendment is stated as "clarifying the requirement for written consent where there is high risk of serious adverse consequences". The medication used in mental health can have profound effects (both positive and adverse) on the consumer. Therefore Right 2(7)(6)(c) should also apply in these contexts. However, our lived experience is that this does not occur.

Right 2(8)

26. We fully support the proposed amendment to Right 2(8)(1) but seek clarification if this includes via means of virtual technology.

Right 2(10)

27. We fully support the proposed amendment to Right 2(10)(1) to include a representative of the consumer.
28. We also fully support the proposed amendments to new Right 2(10)(5) while noting failure to define a period in 5(e) makes it potentially subject to abuse.
29. We support the amendments to new Right 2(10)(6) but suggest the resolution of the complaint could be done with the consumer and/or their representative where possible and appropriate, and that the expectation of informing the consumer should always be in writing.
30. We support the amendments to new Right 2(10)(7) but again want to ensure that all requirements to "inform" are in writing, and reiterate that failure to define a period in 5(b) makes it potentially subject to abuse.
31. We fully support the proposed amendments to Right 2(10)(8) and 2(10)(9).
32. We support the proposed amendment to Right 2(10)(10) while noting this right must be provided in writing at the beginning of new service delivery, and at any subsequent time, on request.

<u>4. Definitions</u>

33. As submitted in the text above, terms such as "mana" and "autonomy", if they are used, should be defined for clarity.
34. We support the proposed amendment to include "representative" but suggest this should be made in writing wherever possible.

Conclusion

I would be happy to engage with you further about the issues affecting our people with FASD and their caregivers, family and whānau, and can be reached at my email address below.

Yours sincerely

KMilne

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