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To Parliamentary Health Select Committee

Please find attached our submission on the Mental Health Bill 2024

For further enquiries please contact

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Balance Aotearoa

Balance Aotearoa provides high quality mental health and addiction peer support, advocacy, consultancy, and education that enables people to improve their relationships and wellbeing.

Nationally, we work as consultants and advisors on human rights for disabled people and act as an amplification of the voice of people who are experienced or experiencing distress. We represent “persons with psychosocial disability” on the Disabled Persons Organisations’ Coalition, and the Independent Monitoring Mechanism, advising the government and monitoring the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

Our contracts fund us to serve those with significant mental/emotional distress and addiction struggles who live in the community (both urban and rural setting) and those who find themselves in acute psychiatric and forensic inpatient settings. We also employ peer support staff that work within the Hapai Mauri Tangata crisis co-response team working alongside police to respond to mental health call outs. We have an open-door policy and accept anyone who identifies themselves as needing support. We are working towards opening a new crisis café in the next few months to bridge the gap in service provision during weekends, within Whanganui.

Our peer support service kaupapa is summarised as “enabling tāngata whai ora to create and maintain a life worth living”. Balance Aotearoa (formerly known as Balance Whanganui) has operated since the mid 1990's and has its origins in mutual self-help support groups for people experiencing mood disorders. We now focus upon people who experience any form of mental distress and run a range of engaging, holistic recovery focused groups as well as seeing people one-to-one.

We have a strong team of 12 peer support workers. All staff are qualified by experience as we all have lived experience of mental/emotional distress and/or addiction. To guide their practice as peer support workers, all will have participated in a peer support training program that meets the peer support competencies advocated by Te Pou. In addition, all of our team have a Level 4 Mental Health Support qualification or are working towards this.

We have developed a Kaupapa Māori peer support framework with our Kaumatua Kori Hemi from Ratana, guiding us with Mātauranga and Te Ao Māori wisdom and practices when working with people in our community. We also work with the understanding of our community in relation to Te Awa Tupua.

Nō te kawa ora a ‘Tupua te Kawa’ hei taura here nā Te Awa Tupua me ōna tāngata ki te kawa nō tawhito rangi. - The natural law and value system of Te Awa Tupua, which binds the people to the River and the River to the people

Ko te Awa te mātāpuna o te ora - The river is the source of spiritual and physical sustenance, in this we understand that Te Awa Tupua is a spiritual and physical entity that supports and sustains both the life and natural resources within the Whanganui River and the health and well-being of the iwi, hapū, and other communities of the River.

E rere kau mai te Awa nui mai i te Kāhui Maunga ki Tangaroa - The great River flows from the mountains to the sea. Te Awa Tupua is an indivisible and living whole from the mountains to the sea, incorporating the Whanganui River and all of its physical and metaphysical elements.

Ko au te Awa, ko te Awa ko au - I am the River and the River is me. The iwi and hapū of the Whanganui River have an inalienable connection with, and responsibility to, Te Awa Tupua and its health and well-being.

Ngā manga iti, ngā manga nui e honohono kau ana, ka tupu hei Awa Tupua - The small and large streams that flow into one another and form one River. Te Awa Tupua is a singular entity comprised of many elements and communities, working collaboratively for the common purpose of the health and well-being of Te Awa Tupua.

We meet people where they are at and work with them in whatever way they find most helpful. All our work is guided by our tāngata whai ora, as we form intentional peer relationships exploring together ways to wellbeing and empowerment. We steer away from being the experts, and avoid rescuing, correcting and advising, instead we aim to listen and understand, to share our experience as relevant, offer hope and model healthy relationships. Peer support can happen in any environment when people are willing to connect and engage. We are about building healthy communities for ALL people.

Mental health act bill submission

Balance Aotearoa

Introduction:

On behalf of Balance Aotearoa and the voices of tāngata whai ora, we are pleased to submit our response to the Mental Health Bill, which seeks to repeal and replace the Mental Health Act 1992. As an organisation that represents the lived experiences of people with mental distress and addiciton, we are deeply committed to ensuring that any new legislation aligns with the principles of human rights, dignity, and equality for all people.

Our submission draws on the voices of tāngata whai ora, the individuals who experience mental distress and addiction, and incorporates the rights and protections outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). We emphasize that mental health legislation must not only focus on clinical outcomes but also foster an environment of empowerment, inclusion, and self-determination for individuals with mental distress and addiction

We urge the government to take this opportunity to create a system that upholds the rights of tāngata whai ora, ensuring their voices are heard and respected in the decision-making processes that affect their lives. In line with the UNCRPD, we call for a shift towards a mental health framework that prioritizes the autonomy, choices, and well-being of individuals, and that challenges the historical marginalisation of those with mental health conditions.

In this submission, we outline our key concerns and recommendations for the proposed Mental Health Bill, with a particular focus on enhancing the rights and protections of tāngata whai ora and ensuring that mental health law is reflective of contemporary understanding and practices. We are committed to working collaboratively with all stakeholders to help shape a more just, inclusive, and compassionate mental health system for Aotearoa.

Language:

We would like to see in this document and subsequent documents for “The Treaty” and “The Treaty of Waitangi” and all other reference to be changed to “Te Tiriti o Waitangi”.

Person-centred care:

Our concern is that it has not been well defined in this bill who decides what person-centred care is we have experienced people justify the use of seclusion, restraint and forced treatment as being “person centred” as the person in charge of their care has decided it is what is best for the person’s wellbeing and therefore person-centred. Looking back on our experience majority of us feel that these types of treatment have been unfair and uncalled for and created more harm than good, however the person in charge of our care deemed it essential for our “recovery” and justified their actions as being based on our needs and keeping our needs at the centre of all decisions

What we would like to see is detail on how this will be monitored.

We would like to note that it is our understanding the district inspector for Whanganui only comes to the hospital on request and only works as the district inspector part time so has limited availability. As well, people are not often well advised on who this person is, what their role is or how they can be contacted. We have noted when the district inspector comes into the ward they are not often there for long and there is sometimes an “act” put on by the staff that misrepresents the reality of the situation. As well, the district inspector does not know us and we feel they can be swayed easily when we are unwell and the people in charge of our care misrepresent us.

We would like there to be lived experience roles that cover this monitoring.

To treat people under the Mental Health Act in alignment with the principles of person-centred care and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), it is essential that individuals are empowered to make decisions about their care, whenever possible, and their rights are respected throughout the process. This involves providing accessible information about their treatment options and involving them in discussions regarding their care plans, ensuring they understand their rights and can express preferences. Under the UNCRPD, particularly Article 12, individuals should retain legal capacity, meaning they should be supported in making informed decisions, with appropriate accommodations if needed, rather than being stripped of autonomy. Compulsory treatment should only occur when absolutely necessary, and even then, it must be carried out in a manner that minimizes coercion and promotes the person's dignity. Mental health professionals should work collaboratively with individuals, their families, and advocates to create a care plan that reflects the person’s values, cultural needs, and goals. Ultimately, aligning with the UNCRPD means ensuring that people under the Mental Health Act are treated as equal partners in their own care, preserving their rights, dignity, and agency at all stages.

Supported decision making

We have experienced advanced directives and care plans being used against us, and even having the creation of one being used as a barrier for us being released from hospital care.

We should be able to have a choice whether we want to create one of these or not and not having one should not be used against us or a cause to determine that we do not want to be involved in decisions about us or determine that we are not willing to contribute or make efforts in our wellbeing.

We want the Act to reflect the importance of self determination

There needs to be options for people who are put under the mental health act as to who is involved with decision making, when we are unwell we might not want someone who is legally our next-of-kin or someone who the hospital has assumed has authority when it comes to decisions about us, likewise we have experiences making decisions when we are unwell that have not been what we would have chosen when we are well, it is quite common that we might have experienced becoming very paranoid about people that we usually feel safe around, it is also common that people in our lives have become burnt out with us being unwell. We suggest that there be more than one person as options of people to get involved.

We want to voice that it wouldn’t be unreasonable to request there be funded either independent legal representation or a lived experience advocate offered to us if we are being placed under the Mental Health Act and we suggest that these people are funded independent of Te Whatu Ora.

Care/wellbeing plans and people’s preferences can change, how can we make sure the current one is on the system and that it aligns with our wishes.

Article 12 of the UNCRPD emphasises the right of persons with disabilities to make decisions about their own lives, with the necessary support to do so. Supported decision-making acknowledges that individuals may need assistance in understanding their options or the implications of decisions, but it does not undermine their autonomy. For tāngata whai ora and their whānau, this approach fosters greater empowerment, respect, and dignity, as they are provided with the tools, information, and support to make informed choices about their care. This framework aligns with the UNCRPD's call for a shift away from substituted decision-making and toward practices that enhance the autonomy and legal capacity of people with disabilities, ensuring that they and their whānau are active participants in shaping their mental health outcomes.

Rights and complaints

We have experienced the process of making complaints while under the Mental Health Act has historically and currently been fraught with barriers that discourage us from speaking up. Many of us do not trust that we will be heard, based on both past and current experiences where we have been met with disinformation about our rights to complain. We have often been told that complaints are not possible and experienced that raising concerns negatively impacts the care we receive or our chances of being discharged. The complaint process itself is confusing and unclear, and for many, especially those who are already vulnerable, knowing how or where to make a complaint at a service level is not straightforward. Complaining through the Health and Disability Commission (HDC) can feel like an impossible task, with long delays and little tangible outcomes, leaving many of us feeling powerless. These barriers stand in stark contrast to the rights outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 16, which calls for the protection of persons with disabilities from all forms of exploitation, violence, and abuse, and Article 21, which affirms the right to freedom of expression and access to information and article 13 access to justice. Similarly, the Code of Health and Disability Services Consumers' Rights outlines the right to complain and to have complaints taken seriously, yet for tāngata whai ora and their whānau, the reality is far from this ideal. We need a complaint process that is clear, accessible, and trustworthy, where we feel confident that our concerns will be heard, respected, and acted upon without fear of retribution or further mistreatment. It is crucial that mental health services create a system that upholds our rights, promotes transparency, and ensures that our voices are heard and valued in the process of improving care.

Compulsory care criteria

We believe that the criteria for compulsory care under the Mental Health Act is deeply concerning, especially when it comes to decisions about extending care beyond an initial assessment. We believe that any decision to continue compulsory care for more than three days should be made by a panel of individuals, including those who know us and can provide insight into our unique needs and preferences. This aligns with the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 12, which emphasizes the right of individuals with disabilities to make decisions about their own lives, with necessary support, and Article 14, which calls for the prohibition of arbitrary detention. Additionally, the Health and Disability Commission's Code of Rights affirms the right to be treated with dignity and respect, including the right to receive services that are appropriate and provided in a manner that does not cause unnecessary distress.

We also feel that there should be clear guidelines around de-escalation practices to ensure that people are not subjected to coercive tactics. Many of us have experienced being placed in cells under the guise of "de-escalation," which we see as a form of coercion aimed at getting us to agree with decisions that are made for us, in an effort to avoid being locked up. This process is traumatic and undermines our dignity and agency. Assessment and care under the Act should be carried out in a respectful manner, avoiding further distress that could lead to a misinformed decision to continue compulsory treatment.

To safeguard our rights and ensure fairness, we also call for the presence of an independent person during the assessment process—someone whose primary role is to protect the rights of the tāngata whai ora. This independent oversight would provide much-needed reassurance that our voices and well-being are genuinely considered, reducing the risk of decisions being made that do not align with our best interests or rights.

Providing compulsory assessment and care

We agree with everything set out in the "care planning" and "provision of care" sections on page 15 of the briefing notes, as we feel that our voices are accurately represented in these areas. It is essential that tāngata whai ora (people with lived experience of mental health challenges) and whānau are included in all aspects of care planning and decision-making, ensuring that our preferences and needs are central to the process. In alignment with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Articles 12 (right to legal capacity) and 25 (right to health), we assert that the care and treatment process should empower us, not diminish our agency. Our voices must be heard in decisions that affect our care, and this should extend to how funding is allocated to services. We want Te Whatu Ora and Ministry of Health (Manatū Hauora) to ensure transparency and accountability in how resources are directed, particularly in efforts to prevent hospitalization by adequately resourcing community-based mental health services.

Also resourcing needs to reflect the notion that wellbeing is more than taking psychiatric medication, we want talk therapy, EMDR, we want to learn tools, however, medication is available and funded, we can't seem to access anything else.

The recorded care plan should not only reflect our preferences but must also be formally authorized by us, the tāngata whai ora, in a way that ensures our rights are respected. This is in line with the Health and Disability Commissioner's (HDC) Code of Rights, which asserts our right to be involved in decisions about our care, to have our informed consent obtained, and to receive services that are appropriate, respectful, and effective. By having our voices heard in the decision-making process and ensuring we are active participants in shaping our care plans, we are better able to maintain our dignity, autonomy, and well-being throughout the treatment process.

Reducing and eliminating restrictive practices

The Mental Health Bill must clearly define and address the laws around seclusion and eliminate any ambiguity, particularly around the notion of "seclusion areas." Tāngata whai ora and whānau have long expressed concern about the use of seclusion, which often leads to further distress and trauma, rather than fostering recovery. We want the Bill to set a strong, clear legal framework that upholds our right to be treated with dignity, respect, and without coercion, in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Article 14 of the UNCRPD prohibits arbitrary detention and calls for the protection of persons with disabilities from all forms of abuse, including the use of restrictive practices like seclusion.

We also recognize the unique challenges faced by children and young people, who often have limited options for hospitalisation. With only three youth facilities available, children are frequently separated from their whānau and natural supports, which can hinder their recovery. This is a particularly troubling dilemma: when placed in adult wards, they may face seclusion or locked areas, yet being in such environments means they are at least able to see their whānau. This creates a harsh choice between maintaining connection with loved ones or being subjected to restrictive practices.

We want to ensure more transparency in decision-making regarding our care, with the inclusion of an independent panel to assess the use of restrictive practices. This panel should be empowered to ensure that decisions are made in our best interest, with clear justifications for the use of any form of seclusion. Additionally, we demand access to clear, up-to-date data, including audit reports on the use of seclusion, to ensure that these practices are being used appropriately, if at all. The Health and Disability Commissioner's (HDC) Code of Rights affirms our right to receive services that minimize harm, ensure safety, and respect our rights to be informed, consulted, and involved in decisions about our care. Transparency, accountability, and ongoing monitoring of practices such as seclusion are essential to ensure that our rights are upheld, and that restrictive practices are reduced and eventually eliminated.

Children and young people

Tāngata whai ora and whānau firmly believe that the use of electroconvulsive therapy (ECT) on individuals under 18 years of age should be completely eradicated. We feel that it is deeply harmful to administer ECT to someone whose brain is still developing, and we assert that there should never be a situation where this treatment is considered for children and young people. This aligns with the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 25, which stresses the right to the highest attainable standard of health, and the need for mental health treatment to be safe, effective, and based on the best available evidence. The use of such invasive treatments on developing brains cannot be justified and must be prohibited.

We also advocate for the automatic involvement of a lawyer for children when it is determined that a child must be placed under the Mental Health Act. Young people and their whānau must be fully informed about their rights and have legal representation to ensure their voices are heard and their rights are upheld during the process. This is critical in upholding the Health and Disability Commissioner's (HDC) Code of Rights, which guarantees the right to be informed, the right to give or withhold consent, and the right to have an advocate present when making significant decisions about one's care. Children and young people are vulnerable and deserve the utmost protection, with full legal support to safeguard their well-being and ensure that their treatment is in line with their best interests, human rights, and dignity.

People in the justice system

People in forensic care often face significant challenges, one of the most pressing being the lack of a clear timeline for their treatment and eventual release. Many individuals in forensic care express that they would prefer a prison sentence, as it would provide them with a defined end date, offering a sense of certainty and hope for the future. We want the Mental Health Act to ensure that those in forensic care are given clear, realistic timelines for their care and release. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly Article 14, prohibits arbitrary detention and emphasizes the right to be treated with dignity, respect, and fairness, including the right to be provided with appropriate care and rehabilitation.

Furthermore, we believe that an inpatient unit should not be used as a transitional space from prison to the community. This practice can create a disruptive and challenging environment for individuals who are focused on recovery, as people coming from prison often bring with them behaviours that hinder the therapeutic environment. The Health and Disability Commissioner’s Code of Rights underscores the right to receive appropriate services in a safe and supportive environment, where one’s mental and physical health is prioritized. We also experience concerns about over-medication in forensic care, which can lead to serious physical health issues and early death. We urge the Mental Health Act to include clear provisions to protect our physical health, ensuring that treatment is in line with the UNCRPD’s principles of health and well-being.

Access to hobbies and activities is crucial for recovery and well-being, and we want the Mental Health Act to support our right to engage in these pursuits as part of a holistic care plan. Finally, whānau involvement remains central to our well-being. While we understand that some individuals may have conditions that prevent them from seeing their whānau, or that their whānau may not want to be involved, it is vital that the Mental Health Act reinforces the need for whānau involvement wherever possible. Human rights standards, including those outlined for prisoners in the Nelson Mandela Rules, emphasize the importance of maintaining family connections and support networks during incarceration, and these principles should be applied in forensic care settings as well. Whānau support is key to recovery, and their involvement should be encouraged, respected, and facilitated.

Monitoring, oversight and reporting

We would like to see community mental health services be Audited every two years.

We would like the mental health act reviewed every three years and it to be mandated that tangata whai ora and whanau be involved in the entire process.

Accessible formats

We want to highlight to Manatū Hauora the importance of providing information in alternate formats is fundamental to ensuring dignity and autonomy for individuals, especially in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Article 21 of the UNCRPD emphasizes the right of persons with disabilities to access information in ways that are understandable and accessible, including through formats such as braille, large print, easy-read, or digital media. For tāngata whai ora and individuals with diverse needs, having the ability to read and understand information independently, without relying on others to convey it, is crucial for maintaining their autonomy and making informed decisions about their care. Relying on others to provide information can lead to misinterpretation, bias, or the omission of vital details, potentially infringing on their right to be fully informed. When individuals can access information directly in a format that meets their needs, they are empowered to make decisions based on their own understanding, thus reinforcing their dignity, privacy, and ability to exercise their rights. The Health and Disability Commissioner’s Code of Rights further supports this by asserting the right to receive services that respect an individual’s preferences and ensure they can fully participate in decisions regarding their care. Alternate formats are not just a matter of accessibility but are essential for upholding the fundamental human rights of all individuals, ensuring that no one is left behind due to their disability.

Thank you for the opportunity to input into this important kaupapa. Our members who have contributed to this submission have asked for a response to their thoughts they have expressed.