Re: The Future Operation of the Courts and Justice Services draft Long-term Insights Briefing for Public Consultation

To: The Ministry of Justice LTIB@justice.govt.nz
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Submitted by: Rare Disorders NZ
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Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract. This submission is in response to the public consultation on the Future Operation of the Courts and Justice Services draft Long-term Insights Briefing.

Rare Disorders NZ

Rare Disorders New Zealand (RDNZ) is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300,000 New Zealanders with rare disorders and the people who care for them. We help those living with rare disorders to navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

Our vision is for New Zealand/Aotearoa to become a country where people and whānau living with a rare disorder experience best possible health and wellbeing. We seek to achieve this by enabling and empowering people with rare disorders to best benefit from services and therapies available in New Zealand, and by championing their collective voice, advocating for provision of world leading evidence based health, disability, education and other services.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand.

RDNZ welcomes the opportunity to provide feedback on the Future Operation of the Courts and Justice Services draft Long-term Insights Briefing.

People living with a rare disorder may or may not identify as disabled, but they often have complex and misunderstood conditions and needs, including accessibility needs. RDNZ appreciates that the draft document recognises that *disabled people are overrepresented in both victim and offender statistics, yet court information, processes and physical spaces still do not sufficiently address their specific needs*. We are pleased to see acknowledgement in the disability and health barriers section that *work will need to continue towards developing more effective and sustainable therapeutic pathways*. RDNZ asks this is expanded on and that there is a commitment to meaningfully integrating Enabling Good Lives principles into this work.

It is pleasing to see recognition that *there is more work to do to put people and families at the centre of the system, so that justice, health, social and education services are coordinated around individual and family needs*. Rare disorders often touch every aspect of a person and their family's life and RDNZ would like to see a more coordinated and whole person approach.

While it is promising to see recognition of the current gaps in the system and to see these areas of work identified in the body of the draft document, it is disappointing it has not made it to the summary or strategic choices.

People with rare disorders and complex disabilities often enter the justice system because timely and coordinated support is unavailable until a crisis occurs. Preventative mental health and behavioural services are limited, leaving families and carers without the help needed to manage challenges early. Carers' own mental health requires recognition and support to prevent burnout, family breakdown, and escalation into justice involvement. Many disabled people struggle to access suitable rehabilitation and treatment services in custody, particularly if they have complex or rare conditions. A comprehensive approach linking education, disability, health, mental health and social supports is essential to ensure early intervention and sustained prevention of both entry and re-entry into the justice system.

RDNZ would like to ensure that, as required by the 2024 Rare Disorders Strategy[i], people and their whānau living with rare disorders are one of the population groups that is being thought about when designing system improvements such as this. In September this year RDNZ worked with Whaikaha to collect feedback from our Support Group Leads on the Draft Disability Strategy. Comments from the Support Group Leads during the discussion on the priority are of Justice are shared overleaf to provide a rare disorder perspective on the justice system.

[1] Ministry of Health. 2024. Te Rautaki o Aotearoa e Pā ana ki ngā Mate Mokorea - Aotearoa New Zealand Rare Disorders Strategy. Wellington: Ministry of Health. Accessible here: http://rare.digitaladvisor.nz/media/pages/file/95/aotearoa-new-zealand-rare-disorders-strategy.pdf

Rare disorder Support Group Leads commentary on the draft New Zealand Disability Strategy priority area of Justice.

Comments from group leads are noted in italics in blue. The actions from the draft Disability Strategy are included to provide context for the discussion.

In the draft New Zealand Disability Strategy there are **7 proposed justice actions** to reach the goal. The Support Group Leads commented on them in turn.

Action 1: Develop and implement a safeguarding framework for disabled people in long-term detention settings (such as prisons and youth justice residences) and Disability Support Services funded residential facilities. The framework will include preventing, reporting, responding, and safely removing disabled people from abusive situations.

- *Regarding to the safeguarding framework and action 1, these systems should be applied not only to residences and DSS facilities, but also when disabled people are under a compulsory treatment act (including hospitalisation under the MHA). As seen in the Abuse in Care Report, both settings open disabled people up to the possibility of abuse, neglect, and violence, and as such safeguarding frameworks/systems should be developed for those in care AND those under treatment acts.*
- *Preventative care, like for carers and consumer.. having people coming in and doing audits to make sure there isn't anything else happening, as there's lots of people who don't know what's wrong, or too scared to say anything. From both ends*

Action 3: Develop a social investment plan for early intervention and support, to reduce the number of disabled children and young people entering the youth justice system.

- *There needs to be cohesive supports from mental health, DSS, etc etc*
- *What do plans cover? What they need is access to help and support (both the disabled person/child) and family/carers to avoid them even entering the youth justice system. Speaking from experience even getting access for help with a child with an ID is extremely difficult.*
- *Relating to question3. early support at school, education, life skills, social skills*

Action 5: Review, as work programmes allow, the effectiveness of current protections for disabled people in family law, including adoption, guardianship and personal property rights, to identify gaps where strengthened provisions or support are needed.

Any review should also consider supported decision-making and use of plain language in key justice sector legislation and processes. Consideration should be given to reviewing human rights legislation, as work programmes allow.

- The law commission have been reviewing guardianship / PPPR legislation - report due soon. The IDCCR Act allows people with ID to be discriminated against and would not align with the UNCRPD.

Action 7: Develop and implement a plan to make the justice sector workforce more disability competent, including in the use of mana and trauma informed practices. This plan would include increasing recruitment and retention of disabled people and should consider mandatory professional standards.

- *Workforce lacks mandatory disability competence, trauma-informed and supported decision-making training*
- *In terms of educating justice workers, it would be important for this to include education regarding those who have episodic conditions or fluctuating needs. An understanding that appropriate accommodations may differ day-to-day and person-to-person is paramount to fair treatment.*
- *[As an OT caregiver], caregivers do a lot of training around trauma, the effects of traumatic upbringing, family violence, all that sort of stuff, but what I noticed personally is there's not a lot of stuff around disability, like FASD and some things like that, so it would be good to see something that forces OT to do a little bit more work with some of their kids, you know, within their training regime of disabilities.*
- *Disabled people can interact with the justice system as contributors - i.e. jurors or witnesses etc. Courts are not very accommodating and can be exclusionary (many upvotes)*

Support to prevent entry and re-entry into the justice system.

- *We didn't discuss mental health in the health section, but the lack of supports here lead to many behavioural / justice issues (many upvotes).* Response comment: *Specially when they aren't classed as need now, always waiting till its past, preventative measures would be great.* Another response comment: *and family carers mental health*
- *This summary doesn't address that people with complex behaviours as a result of their disability / challenging needs are over-represented in the justice system due to the lack of cohesive supports received. [later noted this is covered in action 3, but not in description of success]*

- *Many people with intellectual/neuro disabilities struggle to access rehab/treatment services in prison*

Disabled rights and complaint systems

- *I can't see anything here that speaks to disabled rights by UNCRPD, or speak to any complaints systems?*
- *Does this include protection for disabled people from the justice system itself which can also abuse them, arrest them for behaviour they can't self manage etc. A young autistic child was arrested here, mistaken for another adult person of police interest, sedated multiple times in the hospital before they were formally identified and they realised it was a child*
- *Little about protecting disabled people from crime in this strategy*

Areas identified as missing from the actions

- *Complex/high needs, intellectual, and non-verbal disabled people again largely absent*
- *Again, no mention of improving assessment and diagnosis for those who are involved with the criminal justice systems*
- *How do we recognise safety of whanau /caregivers here?*
- *Where does restorative justice fit here?*
- *"Surveys show that the rate of divorce in families with a child with disabilities may be as high as 87%." (no accurate data on this, so it would be interesting to run a NZ survey)*
- *In NZ, solo-parents who become the primary carer of a child with very high and complex needs, aren't legally entitled to receive any support from the other parent, once the child turns 16 - not financially, nor in the form of some shared-care with the other parent, for respite breaks. Even though the 16yr old child will receive their own WINZ supported living allowance, the entire responsibility of care is placed on the single primary carer. They are expected to provide 24/7 care on their own, organise all extra support (eg IF paperwork & payments, etc), usually give up their own careers and resort to part-time jobs, lose their kiwisaver perks, their health & wellbeing suffers especially as they age, and often have to subsidise the adult child at times of medical crisis when finances don't stretch. Additional finances and regular monitoring is even necessary when the adult child is moved into a residential setting. It seems unjust and totally inequitable that one parent is permitted to walk away and live free of any responsibility (especially when they have a very lucrative career), when it's their adult child, too.*