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disability.employment@msd.gov.nz

Submission: *Working Matters*: Disability Employment Action Plan

Thank you for the opportunity to comment on the draft plan. Alzheimers NZ¹ has a strong interest in this area as both those with dementia and those who are care partners report significant injustice regarding employment.

Alzheimers NZ

Our organisation has a deep interest in disability. We were established in 1986 and represent people living with dementia at a national level. We raise awareness of dementia, provide information and resources, advocate for high quality services, and promote research on dementia and its impact. We support local Alzheimer's organisations, our members, who provide services at a community level and engage directly with people with dementia and their supporters, family/whānau. We work both nationally and internationally to build a dementia friendly New Zealand - one in which people with dementia and their care partners are empowered, supported and included in society, able to exercise their rights and live as well as possible.

General Comments

We are delighted to see government interest around disability and employment as it is an issue which is important to us. People affected by

¹ Alzheimers NZ uses size 14 font in all public documents to enhance dementia-friendliness.

Alzheimers NZ, Level 4 West Block, Education House, 178-182 Willis Street,
Wellington
PO Box 11 288, Manners Street, Wellington 6142
Phone 04 387 8264 **Website** www.alzheimers.org.nz **Charity registration** CC21026
Alzheimers New Zealand Inc

dementia have stated that they seek to continue to be engaged in roles and activities which are meaningful (see *Dementia Declaration* attached). Although many people affected by dementia no longer have labour force attachments, many do face labour force issues. Around 10% of those with dementia are under 65. Labour force participation is growing rapidly amongst those in older age groups with 14% of people aged 70+ actively engaged – a massive increase from the 4% engaged in 2000. The result is more and more people in the workforce are being affected by dementia.

Alzheimers NZ has a specific interest in three areas related to employment and disability:

1. People with dementia and their ability to access their entitlements under the UN Convention on Rights of Persons with Disabilities (UNCRPD).
2. Care partners whose workforce participation is impacted by their caring responsibilities.
3. The impact of employment issues upon the household/group of people involved, when there is a person with dementia and a care partner together, both of whom have needs.

Therefore, Alzheimers NZ is particularly pleased to see the Action Plan includes:

- People with hidden disabilities (p.7)
- Later in life retraining options which are disability accessible (p.20)
- Job coaching options (p.20)
- Review of eligibility settings and processes or health and disability related benefits (p.22)
- Involving whānau in referral systems (p.22)
- Better recognition of part time and intermittent work etc. (p.22)
- More proactive support for people such as increasing access to and duration of in-work support (p.23)
- Promoting more flexible workplaces (p.29)
- Meaningful ways of measuring success (p.31)

General Improvements to the plan

Include greater reference to the UN Convention

Alzheimers NZ is surprised there is not more mention of the UNCRPD in the Action Plan. It receives a passing reference on page 9. The Plan would be strengthened by actively demonstrating its congruency with the Convention, and disabled people would be well served. It would also solve several problems (see para. below).

Avoid unrealistic ambiguous goals

There is no doubt the writers of the Plan are well-intentioned; however, this sometimes results in fostering unrealistic expectations with unclear meanings. For example – Goal 1 refers to an equal opportunity to access “good work” (p.11). No one has a right to “good work” per se, and ‘good’ work is a vague descriptor.

There is a right not to be discriminated against (UNCRPD 27 (1a)), and a right to ‘just and favourable conditions of work’ (UNCRPD 27 (1b)), which could be used to remedy the vagueness of terms such as “good work”.

A similar problem occurs with Objective 1. The objective that ‘disabled people and people with health conditions “steer their own futures”’ ignores the extent to which everyone’s future is shaped by the context in which we find ourselves. Again, it provides a good example of how the problem could be solved by adhering more closely to the UNCRPD. People do have the “right to gain a living by work which is freely chosen or accepted in a labour market and work environment that is open” (Article 27, Article 1). Such words are clear in meaning and could help solve the problem.

Consider the needs of disabled people in their context

Disabled people do not live in a vacuum. This is very evident in Alzheimers NZ’s work context where the well-being of disabled people is closely connected with the wellbeing of care partners.

Being mindful of this, we are currently working with others in our sector to develop the [Draft New Zealand Dementia Plan 2020 to 2023](#). It includes the

need for de-stigmatisation programmes, age friendly cities, and social support. In other words, it considers the needs of the people in the context they live in.

While we understand *Working Matters* is restricted to those with disabilities, we are surprised that the only place where care is mentioned in the Plan is the section on Pacific peoples. *Working Matters* refers to many other action plans and activities but makes no reference to carers or even *Mahi Aroha*: [the] *Carers' Strategy Action Plan 2019–2023*. This is despite the closely woven interests of disabled people and people who care and the many mentions of whānau in *Employment Matters*. *Mahi Aroha* does make the link and has multiple references to employment issues. It could be helpful to refer to this document in finalising the Action Plan.

Simple improvements

Alzheimers New Zealand notes there are some specific changes which could make for a better Plan. Suggested improvements include the following:

- Tidying up some inaccuracies, e.g. there is no 'right' for anyone to reach their career aspiration(s) (p.7).
- Fixing statements which do not make sense, e.g. "Disabled people and people with health conditions have an equal opportunity to access good work" [*equal with whom?*](p.11).
- Avoiding culturally specific clichés (e.g. replace 'have the reins' with 'be self-determining') (p.15).

Conclusion

Thank you again for the ability to comment on such an important piece of work. Many New Zealanders have been waiting a long time for real improvements in this area, and we look forward to genuine progress. Of course, much of the Plan refers to proposed areas to explore, therefore how effective it is at securing employment rights of people with disabilities depends on its final dimensions and the effectiveness of its implementation.

Nā tō rourou, nā taku rourou, ka ora ai te iwi

With your food basket and my food basket the people will thrive



Dementia Declaration: Our Lives Matter

“We ALL want to be seen, valued, appreciated and loved for who we are.”

As New Zealanders living with dementia, we are citizens whose lives matter. We have the same rights, privileges and obligations as everyone else. Our Declaration sets out what we need to live well.

We live our best possible lives when:



We have control over our lives; we have support to make decisions that are important to us.



We live in knowledgeable communities that include, accept and understand us.



We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable.



We continue to be actively engaged in roles and activities which are meaningful and important to us.



We have the things we need to live well such as housing, privacy, an adequate standard of living, and ways of getting where we need to go.



A circle of support protects our wellbeing, allowing us to maintain strong mutual relationships with our families, whānau, friends, colleagues, and those who are important to us.



We are loved; our presence matters.

“I am still me.”

This Declaration was developed by people living with dementia on Alzheimers New Zealand's Advisory Group.



He Whakapuaki mō te Mate Wareware: He Mea Nui Tō Mātou Noho i Te Ao

“E hiahia ana mātou KATOA kia kitea mai e te tangata kē, kia whakanuia, kia kīa he tangata whai painga, kia arohaina mai mō tō mātou āhua tūturu.”

Hei tāngata nō Aotearoa e noho tahi ana me te mate wareware, he kirirarau mātou, ā, he mea nui tō mātou noho i te ao nei. He rite tonu ō mātou tika, ō mātou whiwhinga, haepapa hoki ki ō ngā tāngata katoa. Tā tō mātou Whakapuaki he whakataki i ngā mea e hiahia ana mātou kia noho pai i te ao nei.

Ka eke mātou ki tō mātou tino teitei ina:



Noho tonu te mana mō mātou ki a mātou anō; kua kaha hoki ngā reo tautoko i ā mātou whakatau mō ngā mea hira ki a mātou.



Noho mātou i ngā hapori mōhio e awhi nei, e whakaae nei, e mārāma pū nei ki a mātou.



Tōkeke tonu te tautoko i a mātou, te tiaki me te whiwhi mōhio tanga i te wā tonu e tika ana, e hāngai ana hoki ki a mātou; e horaina mai ana i roto i te atawhai e te hunga ngākau pūaroa, he tāngata whai pūkenga tōtika, mātauranga tōtika e arotahi ana ki ō mātou hiahia, he pai tō mātou noho tahi me rātou.



Whakauru tonu mātou ki ngā tūranga me ngā mahi whai tikanga, hira hoki ki a mātou.



Tukua ki a mātou tonu ngā mea e hiahia ana mātou ki te noho pai, te tūmataitinga, kia whai moni e pai ai te noho, me ngā āhuatanga kawē i a mātou ki ngā wāhi e hiahia ana mātou ki te haere.



Karapōtingia mātou e tēnei kāhui tautoko, he kāhui e ngāwari tonu ai te noho pipiri ki ō mātou whānau, ki ngā hoa, ki ō mātou hoa mahi, me te hunga e noho nei hei mea nui ki a mātou.



Aroha nuitia mātou; he mea nui tō mātou noho i te ao.

“Ko au tonu ahau.”

He mea tuhituhi tēnei Whakapuaki e te hunga e noho tahi ana me te mate wareware i roto i te Rōpū Tohutohu o Alzheimers New Zealand.