

To whom it may concern,

I present this submission 'in confidence', because I do not wish to make it public because of the position I am advocating and that it may have significant implications both professionally and when I've become a participant of the NDIS scheme. Additionally, I present this submission as a person who has lived with impairment for over half of my life, noting that in the first three years of living with impairment I had little control and very limited choice in my life. Primarily my life was controlled by deficit based legislative, policy, social programs which were developed by professionals who operated within the medical model. The medical model approach led to institutionalised systemic discrimination within specialist disability services and specifically in public goods and services.

What was the Nexus that changed my life from being controlled by professionals to taking self-control and determination of my future supported by professionals who operated from within a strength based or human rights framework of service delivery. However, the major player in my life who enabled my personal and professional aspirations to be realised was my wife. My wife provided my personal care (I have high support needs) for five years prior to me becoming eligible to access personal support, based on my individual needs. Given that I was working at the time of receiving my support and required support services that were not available then nor now at times I need them and in a way that is not intrusive upon the intimacy of my personal relationship with my wife in our bedroom.

I paid my wife for the personal care I required during the night and to get ready for work prior to 7 AM in the morning. My wife also works part-time in her professional capacity. I also employed other workers to carry out other support needs I had during the day and week.

Given the current policy of the NDIS that individuals cannot employ family members would have significant impacts both upon my personal/private and professional life and increase my costs associated with my individual needs being funded by the NDIS.

The impact of having to try to employ a person who would assist me during the night (once or twice to go to the toilet) and to find another worker to commence work at 5 AM and finish at 7 AM results in:

1. My wife and I no longer living in the same room as our private and personal space is being invaded significantly by a support worker. (Ask yourself this question would you like a stranger entering you and your partners bedroom regularly during the night and whilst you are trying to get ready for the day in the morning or ready for the evening?) I believe this proposed practice is placing unnecessary duress on our relationship.
2. When I travel or I have had to recruit workers to start at 5 AM in the morning because my wife has been unavailable, for me to be able to go to work on time and

without unnecessary stress has often proved difficult and resulted in me being late for work and being deeply stressed as I'm trying to conduct myself as a professional and reliable staff member. There is significant anecdotal evidence that people who require workers early in the morning find it difficult to recruit them and retain them. It is not always that workers are unreliable because of a personal trait, things go wrong in their lives as well i.e. a family member being unwell, unreliable vehicle etc.

3. It appears the policy not to employ family members is justified by implying that... 'Employment of family members can adversely affect the dynamics of the relationship and reduce independence for all people with a disability regardless of their circumstances'.

4. I would argue that this policy conflicts with the broad principles of the NDIS: Choice and Control over the services and support they receive.

5. And it conflicts with 'a person-centred model of care and support'.

The current policy as it applies to me as an individual and in the context of my personal relationship with my wife and my family is at great risk of increasing the cost of my individual support needs and service requirements. Additionally, I also believe it is in conflict with article 19 and 22 of the Convention on the Rights of Persons with Disability (CRPD) and also breaches both the Disability Discrimination Act 1992 and the states Anti-discrimination Acts. Thus, placing the NDIA and the Minister for Social Services at risk of being a respondent in a individual or class-action by people with disability who were denied choice and control of the services they receive and who supplies those services.

I clearly understand that the rationale for this policy approach is to protect vulnerable people from exploitation particularly by family members and also doesn't impact upon the ability for family friends to offer informal supports. The policy should be based on an individual in the context of their life, not a blanket policy that is frankly paternalistic and discriminates both directly and indirectly. Clearly there needs to be safeguards for people not to be exploited by any workers irrespective of their relationship to the individual receiving NDIS funding for support. These safeguards should be embedded in the processes that already exists such as the provision of independent advocacy, NDIS case managers, LAC's and the investment into the individuals natural and local community to have agency for the well-being of its members.

Finally, I can clearly state that if it wasn't for my wife's informal and paid support and my broader families and community networks informal and paid support I would not have achieved to date some of my aspirations both professional and personal, I still have many things on my bucket list (professional and personal). I look forward to achieving those through the informal and formal supports I have in my community and to have my personal needs met by the NDIS principles of choice and control, A service that is based upon my individual needs in the context of my family and personal relationships not being interfered or undermined by paternalistic and discriminatory policy.