Dear Sir / Madam

I am writing in response to the - NDIS Costs, Productivity Commission Position paper, Overview & Recommendations, June 2017 (Payment of informal carers through NDIA managed plans).

The NDIS aims to offer choice and control to a person receiving disability supports. The person living with the disability is to be at the centre of the system. NDIS aims to ensure that people with disability are given every opportunity to make their own decisions and exercise choice and control. The person chooses the disability supports that best work for them and a plan is established to implement and support this process. However, where the person has an intellectual disability their family must be included in this process. Carers are best placed to understand their own needs and have a unique degree of insight into the person they care for. For most people caring is part of being in a relationship or part of belonging to a family. Those relationships need to be valued, supported and nurtured.
Families provide somewhere for their family member to live, take them to activities, search for suitable services and programs, advocate for change and stand up for their rights. Familial supports play a pivotal role in meeting the needs of people with disabilities. This should be encouraged to continue.

The main difficulty for NDIS seems to lie not in how to work with carers but in working with them at all. A cultural shift within NDIS is required. Professionals must change their attitude towards working with families and carers. Carers ask for professionals to respect their expertise and knowledge. People with disability and their carers must be enabled to make meaningful choices and are provided with information and resources with which to make them, otherwise the notion of 'choice' becomes empty rhetoric and the system will fail to live up to its transformative potential.

It is particularly important to recognise that there are carers who provide supports and services that cannot be provided by formal services or paid support workers. There are benefits to people with disability if there is capacity to employ family members suited to them. For example, family carers will often know the needs and preferences of relatives with disability very well and share an emotional rapport. This particularly the case where the supported person lives in the family home.

Widespread misconceptions about paying family members persist. NDIA references on employment of family members, include statements such as, may reduce the independence of the person with disability and funding a family member to provide supports to a participant can be detrimental to family relationships. These statements lack the necessary empirical reviewed evidence of support.

I would like to bring your attention to; Appendix G: Paying family members - Inquiry report Disability Care.

http://www.pc.gov.au/inquiries/completed/disability-support/report/31-disability-support-appendixg.pdf

Paying family members raises many thorny issues. Despite this, government payment of family members to be carers is an increasingly important aspect of self-directed funding arrangements. It should remain a keystone in any sustainable good disability intervention strategy.

Evaluations of California's In-Home Supportive Services program found family members and friends are simply more reliable than strangers. Another study of the same found that self-directed funding had improved safety, reduced unmet needs and increased people's satisfaction, and that these benefits rose when services were provided by paid family members. In an Australian survey, two of the major concerns about formal support workers expressed by families and friends providing informal care were the trustworthiness and quality of respite and disability services, and the unwillingness of the care recipient to accept another carer or someone else in the home.

The issue of the privacy of other family members who live with the person with a disability is a matter that needs urgent consideration and appropriate recognition.

While there are exceptions, families are usually strongly motivated to support a family member with a disability, and not to exploit them. Where provision of care to a disabled person by a paid family carer does involve exploitation it occurs where there has been a long term unmet need for additional resources at the service site.

Moreover, care from hired relatives may be more efficient than paid formal care, and more flexibly and efficiently directed at the key areas where people need support.

Some families bear all of the costs of disability privately because of the barriers posed by long waiting lists and their concerns about receiving services from formal support workers unknown to them.

Other notable gaps are apparent in respect to poor quality of staff in the disability sector; staff are poorly trained, resourced, lack understanding or sensitivity to disability issues, and, as a result, offer inadequate or poor quality care. In some cases inadequate care extended to violence, abuse and neglect of people with disability. The Four Corners - ABC report, Fighting the System, highlights again the continuing injustice inflicted by the current methodology demanded by a broken disability sector. What is of particular concern is the culture of denial that providers to the disabled engage in to avoid responsibility. While this punishment approach continues services to those with high support needs and their families will continue to deliver unfair and poor outcomes.

These types of approaches include strategies such as exclusion and social isolation, physical injury, violence, abuse and neglect. These approaches often result in a reduction in dignity, reduced access to health services and supports, reduced quality of life, strong negative reactions from others and so forth. These approaches are not consistent with Positive Behaviour Support, which is underpinned by a strong commitment to human rights and a focus on quality of life, citizenship and participation within a family/person-centred approach.

In the Position Paper, attention is bought to employment or payment of family members. Specifically, the NDIA will not fund a family member to provide personal care or community access supports unless all other options to identify a suitable provider have been exhausted.

Features proposed in the Position paper;

- any requirement that paid informal carer not reside at the same location as the participant should be removed. This would be a valuable change.
- The need to exhaust all options to identify suitable providers should be more clearly defined. This is another valuable change.
- It is appropriate for such supports provided by informal carers paid by the NDIS to be reviewed regularly.
- reviewed regularly should be more clearly defined. For example, a review might take place every two to five years depending on individual circumstances and maybe triggered by a family on a needs basis.
- Further consideration needs to be given to the Position papers viewpoint regarding a separate price for the supports provided by informal carers. Paid family members should receive the same work entitlements as any other staff member/employee.

Both provide care and support which can range from supporting someone to go to their local art gallery, to support with banking, shopping and cooking to helping someone with feeding, dressing, or administering medications.

Disability support workers usually hold a Certificate III or IV in Disability. To operate effectively informal carers should be employed as per terms and conditions of employment when successful in their application to the position of community support worker.

It is recognised that informal carers have the necessary qualifications including skills, education, experience needed, personal qualities, educational credentials, professional certifications and therefore should be provided all the benefits other employees in the disability services sector receive.

There are over 2.8 million family and friend carers in Australia providing 36 million hours of care and support every week to a family member or friend because of disability, mental illness, chronic health conditions, frail age and dementia.

In our lifetimes, most of us are likely to either provide care to a family member or friend, or to need care ourselves. The work that unpaid Carers do is essential to the wellbeing of our society and economy.

Carers see themselves as ordinary people who would like the broader community to understand that caring is both rewarding and often challenging. It is important to unpaid Carers that the role is recognised by the community.

Carers support people to live independent lives, to remain in their homes and in their communities. This care is fundamental to family life and our community wellbeing.

Unpaid care is critical to the sustainability of our health and community services systems. It would cost over $57 billion to replace the hours of care provided by unpaid Carers in Australia.

Kind regards,
Elizabeth Wall