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SPEAKING UP FOR YOU INC protects and defends the human rights of vulnerable people with disability through individual advocacy to address injustices and to make a positive and sustainable difference to their lives.

SUBMISSION

in response to

Productivity Commission 2017,

National Disability Insurance Scheme (NDIS) Costs,

Position Paper, Canberra.

SUFY welcomes the opportunity to comment on the Productivity Commission's Issue Paper on the NDIS Costs.

Speaking Up For You (SUFY) is an individual advocacy organisation that advocates for people with disability who live in the Brisbane and Moreton Region. SUFY promotes, protects and defends the human rights of each person with a disability whom we support in the advocacy relationship.

SUFY strongly supports a viable NDIS and the role it will have in increasing the economic, social and civil participation of people with a disability in Australian society.

SUFY will provide comment on the following issues:

Sustainability of the scheme costs including planning processes, review process, transport allowance housing market readiness advocacy.

There has been ongoing concern expressed by family members and people with a disability about the reported "funding Crisis" and how the NDIS will be funded. This discussion undermines the success of the scheme and brings uncertainty and reluctance for people to fully commit to the scheme. The federal governments proposed welfare cuts on income support to pay for the NDIS increases the likelihood of divisions between people with a disability and other welfare recipients and undermines community support for the NDIS.

The benefits that will come from increased economic and social participation of people with a disability suggest that over the long term the NDIS would pay for its self. According to Mr Della Bosca (Productivity report 2011) new economic modelling forecasts the NDIS will not only make a huge difference to the lives of 460,000 Australians with permanent and significant disability but will repay the taxpayer many times over. Once fully implemented the NDIS has the potential to increase GDP by 22 billion.

The first objective of the NDIS Act 2013 is to give effect to Australian's obligations under the Convention on the Rights of Persons with Disability (CRPD) The CRPD applies human rights specifically to the context of people with a disability and reflects the need for respect for their inherent dignity, individual autonomy (including the freedom to make one's own choices and the independence of the person), the need to be able to participate fully and effectively and be included in society and to be actively involved in decision making processes about policies and programs directly concerning them.

Therefore equally as important as the financial costs associated with the scheme are the broader non-monetary benefits of the scheme. These benefits include increased; community inclusion, dignity, independence; and autonomy for people with a disability

The terms of the review should include the outcomes for people with a disability, measured against human rights framework indicators, including increased community Inclusion, dignity, independence and autonomy and not focus exclusively on financial costs.

The NDIS has choice and control embedded in its philosophical foundations however despite this, people with disability and their family members are reporting problems with the process and methods used to implement the NDIS

One family member received a phone call from a planner who asked her many questions about her disabled daughter but did not tell her that the conversation was part of the planning process. This resulted in confusion and concern and a reluctance for the family member to participate in further telephone conversations. When the family member requested a face to face meeting she was told this was unusual and the planner would have to consult with her manager

Over the phone plans do not facilitate equal access to people's communication needs or allow planners to observe physical cues. The NDIS speaks about participant's ability to exercise choice and control over the quality and scope of supports they receive. Our experience is that the NDIS planner did not create an atmosphere where the person felt in control or empowered but asked for justification as to why the person should remain living on her own and not sharing her supports. A lengthy conversation over the phone is hard to sustain, it is difficult to clarify points or address misunderstandings and little or no rapport is built with the person requiring the support. Given the NDIS is not means tested, families questioned the relevance of the question relating to income and felt it was intrusive and unnecessary. The participant was asked what their annual income was and what was the income of the household?

There is an urgent need for the planning process to be conducted in person with planners as originally intended. Over the phone planning conversations along with the Assessment tools used compromise choice and control.

The National Disability Insurance Scheme can act as a powerful driver of social and cultural reform. For this to occur stakeholders at every level of the system need to be adequately resourced to successfully negotiate the change. Price Waterhouse Cooper (PwC) *Disability expectations: Investing in a better life, a stronger Australia*, 2011 identified four key principles which need to form the foundations of how we approach disability.

These principles are as follows:

- People with a disability have equal rights
- Society has a facilitating role to play in assisting people with a disability to exercise these rights
- People with a disability should have a right in how they access support and
- We should actively pursue inclusion through removing the obstacles to access mainstream supports services and employment

Critical to the success of the NDIS is the assurance that people have access to mainstream services. Without accessible and inclusive transport, employment, education, health services and justice, people will not be able to access all areas of community life. This will result in people relying on disability specialist service thus driving the cost of the NDIS up.

NDIS funding for transport is not well publicised, inconsistent and makes a mockery of the NDIS as a universal program. This is because South Australia, Victoria, Tasmania and Queensland have removed eligibility to the taxi subsidy programs for new NDIS participants. The reason given by

these State Governments for removal of access to the taxi subsidy scheme is that they will receive transport funding in their plan.

One individual received a letter from the Department of Transport and Main Roads. She was advised to take a letter that they had written to her planning meeting. The letter explained how much she has spent on taxi fares and how much the Taxi Subsidy Scheme had subsidised her travel. They said this letter would act as a starting point for discussions with the NDIS planner. The NDIS Planner disregarded the letter without reading it and said that the Transport Department was wrong. The NDIS Planner did not explain the three levels of transport funding available under the NDIS or how individual's circumstances would warrant a particular level of funding. The planner asked for the person's bank details and said this was so they could pay the mobility allowance into her bank account.

The NDIS was established based on the understanding that the States would contribute to the costs of transport via the existing subsidies. This is consistent in areas such as health and education. The Queensland State Government is now suggesting that they no longer need to provide subsidies for people receiving the NDIS for transport costs.

Because of the different policies between States regarding the taxi subsidies, SUFY recommends that a ***National Transport Subsidy Scheme*** be developed.

For people with a disability to have choice and control about the services they receive and about where and with whom they live they must have safe, secure and affordable housing that meets their needs and which enables inclusion and participation in community life. State governments need to commit to a range of housing initiatives including: increased public housing dwellings that meet the Liveable Housing Designs; offering people a chance to buy their own homes under Shared Equity programs; home modification schemes; and generic social housing programs. These initiatives along with the introduction of the NDIS Specialist Disability Accommodation payments will assist people to find a place to call home.

Mainstream housing, including public housing should be resourced appropriately to ensure people with a disability have housing options that are available to other citizens.

From SUFY's perspective the type of disability that a person has been diagnosed with does not affect supply and demand. Issues relating to the number of people residing in one house, their compatibility, and level of individual support they receive and individual satisfaction all play a part when competing for staff.

People with a disability and family members have shown a preference to hire, train and supervise workers themselves. They have found that training needs to be tailored to the needs of the individual and will actually shy away from employing support workers who may come with qualifications that are not necessary.

They also prefer employing workers on a casual basis as this allows them flexibility to increase or reduce support hours as needed.

Blanket policies such as the ruling in relation to hiring family members, does not provide for choice and control and can result in discriminatory practices. If individuals are managing their own

individual support packages they should be able to make judgements about who they employ including family members.

The decisions regarding the employment of family members should be made on a case by case basis. People who require assistance with the decision making process should have access to a person centred planning process, where the persons allies and supporters accommodate and assist them to understand the implications of the decision

There has been discussion that the employment of family members can adversely affect the dynamics of the relationship and reduce independence for all people with a disability. This statement suggests that disabled people are homogenous in their ability to understand, manage and sustain relationships.

One could argue that Guardianship, where a substituted decision maker is appointed (often a family member), adversely affects the dynamics of the relationship and reduces independence. A Guardian has complete control and authority to make decisions around accommodation, healthcare, provision of services, whom the person has contact with, legal matters and Restrictive practices.

If the NDIS has a mandate to care and protect people with a disability from making what they consider bad choices in regard to the employment of family members maybe it is timely for the introduction of a Supported Decision Making model which allows the individual with a disability to retain the final say in life defining decisions.

Australia's Migration Program ensures that migrants to Australia meet the specific needs of the economy and fill gaps in the labor market where they currently exist. The Family Members as paid Support Workers Policy definition excludes many possible Australians who may be able to fill the gaps in the labor market but are prevented because of their association with the person with a disability.

It is not unusual for a parent (usually a woman) to leave or not take up gainful employment in order to provide care for their disabled family member Lifting the restrictions on NDIA payments to informal carers has been demonstrated in self direction programs in the United States for over 15 years and has contributed to the sustainability of self-directed programs and positively contributed to the GDP. This should be done on a case by case basis, where there is a mix of both formal and informal support provided and hours for family members are limited to a certain number a week.

Despite *The Getting Ready* forums people with a disability are consistently raising their concerns about the NDIS process. The role of independent advocacy should not be underestimated in assisting people through the pre-planning process, understanding what supports and service options that are available to them, what supports are considered reasonable and necessary, feeling confident to ask for a review of their plan if they are not happy and ensuring their plans do not simply replicate their current inadequate supports. Rather than reducing the need for independent advocacy, the processes used in delivering the NDIS have highlighted the need for strong independent relationships and support through advocacy that will ensure that people with disability do exercise choice and control and have their needs met.