

Productivity Commission - COSTS of NDIS

1. NDIS needs to define more clearly what reasonable and necessary means. This definition needs to be broad enough to encompass the many different needs that disability includes. NDIS planners and others have been advocating that if anyone can purchase the product or service, then participants can't have it funded by NDIS.

There are many products, services and activities available to everyone to enjoy in this country. There are few things that have any restriction on whom may purchase them. The deciding factor for whether it should be considered reasonable or necessary is not even dependent on what your diagnosis is but rather on your need.

Let me use examples to explain.

If I choose to purchase a wheelchair, even though I can walk, I can if I have the money. It's not necessary for me to purchase it though. I don't have a good reason for purchasing a wheelchair at this point in life. It's not reasonable for me to need it.

If I have a business that requires me to keep in touch when I am on the move, I may purchase an iPad to meet that need. It is necessary for me to keep in touch for my business to be sustained. It is reasonable that I purchase the iPad. I could go without it but my business will suffer. Probably the health of myself and my staff would too because of the added stress of not being able to keep in touch. If I didn't have the business, I wouldn't have to buy the iPad. It would not be necessary. I would have no good economic reason for purchasing the iPad.

Funding for NDIS needs to be economically viable so funding from NDIS needs to be economically viable.

NDIS promises no-one will be worse off. It also promises that PWD will have needs met so they can live as independently as possible. So when a person who cannot walk is looking at what meets their needs for being as independent as possible, it will be considering which mobility aids do this best in the most cost effective way. A manual wheelchair may be the cheapest option, financially. It is reasonable and necessary to purchase that. However, there may be extra costs though. They may need to pay someone to push them or they may need to purchase therapy services due to the continual self-propelling needed with this 'economic' option. Also, to meet the PWD need to be as independent as possible, they may need to purchase a motorised wheelchair. There are very good reasons to purchase this costlier product. It is necessary to be able to meet the PWD goals for independent mobility.

It is more reasonable and necessary to purchase this product. While the initial cost may be more, the ongoing cost to DNIS would be greatly reduced. Plus, the PWD will be more independent.

The criteria for defining what constitutes reasonable and necessary is not whether it's something that anyone can buy. It needs this determining question to be asked – "If I didn't have a disability, would I have to buy it?"

PWD on forums testify what has been denied them because the former criteria mentioned above has been used rather than the latter. I will list a few just to show you why the former criteria fails and the latter doesn't.

Toys/manipulatives/games. Anyone can buy them and usually they are purchased for children. However, adults with disabilities such as Autism and intellectual impairments (II) and motor impairments can need these to promote wellbeing physically, emotionally and mentally. Eg. A 59 Intellectually impaired woman relates to dolls and fluffy toys, meeting her need for emotional wellbeing plus dressing them uses fine motor skills that would otherwise waste. She also plays with games such as Connect 4, does jigsaws, plays ball, colours in etc. All things that preschool aged children need to do. These things sustain, along with other life skills she has, the fine and gross motor skills she needs plus they stimulate her mind and meet her emotional needs. When these things are removed from her life, her behaviour and physical and mental health decline severely. She is unable to do basic physical things like walk upstairs. She requires extreme behaviour management. She does not sleep well. So for her these ordinary things that anyone can buy are necessary for her wellbeing. Due to the effects of her disability, she has very good reason to purchase these things. If she did not have II she would not purchase these things for herself. They are necessary for her to purchase ONLY because she does have a disability. Therefore these things should be funded by NDIS.

Consider the business of self-managing NDIS funding. I call this a pseudo-business.

(Centrelink keeps requesting an ABN of me because I am nominee for my sibling and am employer for support staff).

To ensure all daily tasks are done and records kept in the most efficient and effective way, we are setting up electronic management systems to replace paper systems. This streamlines all facets of management – employment business, book keeping, goal achievement, health and wellbeing records for health professionals, etc. Due to the nature of II, my sibling does not have capacity to communicate any of this information, nor to use any tools of communication – words, writing, paper and pen, electronic devices. It is

necessary for formal and informal supports to do this. It is more cost effective, space saving, mobile and efficient to utilise electronic devices, programs and apps to better meet this need for communication between all parties to ensure my sibling's funding is primarily spent assisting goal achievement rather than paying people to run this pseudo-business. Setting up this system also ensures sustainability and longevity of the program beyond current support people should they move on – true independence. Hence my sibling needs to purchase, maintain and upgrade electronic equipment and other office equipment etc. These things are readily available for anyone in the community to purchase. However unless you were running a business, purchasing them would be optional – a personal preference.

If my sibling did not have a disability, purchasing these things may not be a preference. However, because of the disability, there are reasons these things are needed. If my sibling did not have a disability, these things would not be necessary. The goals achieved by and the economic value of these things makes their purchase reasonable and necessary.

NDIS needs to ensure all staff involved in planning and budgeting of funds understand this basis for what is reasonable and necessary. It needs to ensure all people involved in planning and budgeting are exposed to experiences that develop an appreciation and understanding of the things that are reasonable and necessary for a large variety of disabilities. They need to foster an appreciation and acceptance that PWD, their family/advocates/allies and professional team know what is necessary and reasonable because of their lived experience.

2. NDIS needs to recognise the major shift in the reality of moving from service provider dominated support for PWD to individual, formal and informal support with the view to achieving independence as much as is possible.

NDIS needs to recognise the huge shift in attitudes, opportunities and community support that have to occur and that will be inevitable as NDIS enables PWD to lead a more ordinary life. This change can involve major changes for PWD and their family etc. Transitioning will need time and money to be adequate for the duration of this.

NDIS needs to provide support for family during this time to reduce stress and time that PWD needs to assimilate new routine and people. This needs to be tailored to suit each family and be financial, labour or respite support.

NDIS needs to recognise the need to assist the larger community to provide the level of support and inclusion the changes PWD having choice and control will bring. This will be

through advocating for more training of suitable support staff and professional to provide therapy and assessments.

- a. NDIS needs to ensure there is more encouragement and incentives to attract people to choose supporting individuals as a career. Funding should be available for Certificate 3 in Individual Support regardless of prior education level. Lots of people come from other careers with a very caring attitude and experience but they still need and want to do this training to venture into this field. One of the main problems, particularly in regional areas, is the lack of suitable staff. Support workers from service providers, although trained, often display lack of skill and attitude necessary to assist PWD as best as needed. The OISD course should also be a required just as much as a first aid course.
- b. NDIS needs to promote specialist and therapist career paths to match the increased need and to ensure these are available in regional and rural areas at no extra cost to participants.
- c. NDIS needs to ensure community groups, event organisers, local councils and post-school education facilities are aware of the need for PWD to discover what the community has to offer and to provide what PWD need to actively participate in the meaningful goals PWD have.
- d. NDIS needs to value the role of informal supports and the time it takes for them to assist PWD to become as independent in the community as possible. This requires the NDIS having a better attitude to ensuring informal supports are not disadvantaged while fulfilling their roles, especially financially. Family should be able to be paid for the duration of this set-up/transition time. No one should be worse off. Capacity building needs to fund all training and costs associated with assisting PWD to become as independent as possible especially if they are self managing.
- e. NDIS needs to advocate for more community housing opportunities to enable PWD to live separately from parents and caregivers to enable those people to have productive lives in the community, adding to the economic pool. Housing needs to be integrated not segregated, suit the needs of the PWD and be in an arrangement as others of same age would be. Eg share house for young adults, own house for older adults, individual unit in supported complex for aged persons.

f. Traditional service providers, particularly large organisations, need close monitoring and higher standards of training to ensure entrenched attitudes and practices are removed from this industry.

For too long, service providers have alienated PWD from society creating mini-institutions and distancing them from family and allies. They have had power over the type of care, the funding arrangements, the input level from PWD and families and been in a position of power over the governing bodies due to seemingly meeting unmet needs. They need to learn to be OF SERVICE to PWD and their allies. The minimum standard of training for all people employed in these organisations is the OISD course by Michael Kendrick. NDIS needs to make this part of the requirements for the NDIS registration process for all persons in these service organisations.

g. Support co-ordination needs to continue beyond the first year of plan implementation.

These co-ordinators have established a very good understanding of the PWD they work for and their allies. They can continue to make connections for them and advocate for them better than introducing a new person who knows nothing about the progress of their plan. Continuity makes for sustainability. Transitioning to NDIS requires a lot of time, energy and growth on the part of PWD, their allies and their support co-ordinator. This does not need to be undermined by suddenly introducing a total stranger into the arena. The costs involved with this break in continuity will cost more financially, emotionally and undo the progress made by all concerned especially the PWD. NDIS needs to ensure funding is available for this to continue until the PWD feels they have reached the point of needing only a small amount of support as the local area coordinator will be able to provide.

h. NDIS needs to accept that family is often the best form of support for PWD especially during the transitioning phases of life, when the PWD is unwell or needing extra support for whatever reason.

Family, especially siblings, will know the PWD longer and better than anyone else. Parents and siblings need to be able to lead their own independent, fulfilling lives too. PWD don't wish to be appendages to family members lives. NDIS needs to recognise that family need to replace paid formal support at times in PWD lives. This needs to be valued the same as the paid support it replaces. NDIS needs to fund the time family support PWD just as they would fund any formal support person.

- i. **NDIS needs to promote the establishment of organisations, practices and government policy that provide support for parents, siblings and allies of PWD.** These need to recognise the value of the contribution these people make to the lives of the PWD in their lives. Each of those informal support groups needs to have support from the moment the disability becomes apparent. Parents, siblings, allies all constitute different relationships and different needs. There is no one-size-fits-all approach to supporting each group. I have been a sibling for 55 years. I can now see the effects being a sibling has had on me and my other 4 siblings – emotionally, financially and mentally. Sadly, there has never been any recognition of need for support during our life time. The long term costs of this lack is very evident. The most apparent is the fact that half of the family are not in paid employment due to their own needs for emotional and mental health being unsupported as young siblings. Each different group - parents, siblings and allies, need to have their unique relationships recognised and supported in the best way possible so they can sustain their ordinary role – that of parent, sibling or ally. Only then can the PWD enjoy relationships without the overshadowing of their disability.