

THE STRENGTHS AND LIMITATIONS OF FUNDING IN CREATING A GOOD LIFE.

by Jeremy Ward

Jeremy Ward is a parent whose eldest daughter lived with disability and required support to live in her own home, which she did successfully for over 10 years. His older sister also lived with a significant disability all her life. He has many years of experience in disability advocacy, in the law as it relates to people with disabilities, and in assisting families to plan for the future.



The National Disability Insurance Scheme (NDIS) offers much to be hopeful about. It offers a paradigm shift from a handout or welfare mentality in government support to people with disability, to one of entitlement. It promises people choice and control over the paid supports they receive and how those supports will be provided. It has made disability, and the woeful system currently in place in Australia, front page news.

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Yet, the NDIS will not bring the good life, as a matter of right and entitlement, to every person with disability in Australia. It won't necessarily bring a warm and secure home, loving family and friends, good health, or financial security. It won't bring a meaningful job, happiness, enjoyable recreation activities and the opportunity to travel and take holidays. It won't bring a spiritual element to life, or the capacity to love and be loved.

The NDIS is fundamentally a funding program, and funding, per se, does not create good lives for people on its own. Only people can do that. Funding schemes have many strengths, but also many limitations. At best, they can

provide the framework of paid support to assist people to lead good lives. A good funding scheme will provide flexibility and scope for innovation, and vest meaningful choice and control in individuals and families. At worst, funding schemes perpetuate tired solutions fostered by unimaginative service providers and timid bureaucrats, who seem accepting of people with disability spending their days under the thumb of organisations and systems, supported in activities they don't

like, by people they don't choose.

My family learnt early on that funding could

work well for us if we knew what we wanted: what we wanted the funding for, and how we wanted to use it day to day. In the blunt words of Jean-Paul Sartre, Freedom is what you do with what's been done to you. We learnt to take a “good life stance” in the face of negativity and seek out those who were willing to work with us, ignoring and dismissing those who were not. In our case, this meant that we came to avoid large services and to join with other families seeking the same as us for their family members with disability.

Our mission statement became our guide for what we wanted for our daughter, and what

we wanted funding for. We later came to call it our vision. It was simple and concise – That our daughter would be a valued member of her community.

This vision underpinned all of our decisions about our daughter's

schooling, service provision, moving out of home at 19, meaningful work, and ultimately, around her being supported to live in her own home, regardless of deteriorating health. When we applied for funding, we said we wanted it to help us implement our vision. When we received funding, it was our vision that helped us keep on track, day to day, ensuring we did not waste funding on exercises in time wasting.

To be effective, funding schemes like the NDIS that uphold the importance of choice and control, need to rely on those who receive funding knowing what they want. Individuals and families must do their own work on this. It is their business, family business. It is not the business of governments, funding agencies, services or professionals to tell people what they want or what they need. Many of us benefit from support to do this but ultimately we need to work out fit out ourselves. Similarly, services offering assistance

will need to value and respect people with disability and their families and embrace “working with” rather than

“doing to”. If services fail to walk the talk, people with disability and families will exercise their power to choose and look elsewhere.

To craft the good life, we need to do the hard work on clarifying and sustaining our vision, of what we want, not what others tell us are the limits of what is possible. If we try to choose in a vacuum, not knowing what it is we really want, others will choose for us. They will limit

our choices to the options they offer and they will control how those supports are delivered to suit their needs. Many people need funding,

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but just how much, and for what, are for individuals and their families and supporters to determine, not others. Arbitrary funding “caps” have no place in funding schemes that talk of real choice and control in the hands of people with disability and their families.

This does not mean that there should be a “sky’s the limit” approach. When it is asserted that an individual needs extraordinary levels of funding, something has gone seriously wrong. This is because much of what constitutes the good life cannot be provided or supported through funding. Services which dominate people’s lives with paid support, and squeeze out community, are not supporting those they serve to live the good life. How does funding alone help someone develop meaningful unpaid relationships; to enrich their spiritual life; to love and be loved; to maximize financial security; to have their own home to come home to; to keep them safe? Some people need support to assist them to interact with

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others, and to seek out opportunities in their community, but this does not have to be done always by paid support workers. Indeed, we found very few have the skills and experience to carry out this highly nuanced task. By contrast, members of a support circle, or other personal networks, can approach this with the subtlety and respect that comes only through a loving and committed relationship.

One way to think about where funding might assist in crafting the good life, and where not, is to look at the various aspects of life and ask: where will funding help?

When our daughter first moved into her own home, requiring 24 hour supervision and support, she was assisted by a small amount of government funding and financial contributions from family and friends, which paid for support workers. Her pension, and

The following template is a guide:

Planning Template			
Informal Network	Aspect of Life	Funded \$\$	Unfunded \$\$
	Home		
	Work		
	Relationships and friends		
	Recreation, play, holidays		
	Passions		
	Education		
	Spirituality		
	Healthcare		
	Financial Security		
	Decision-making		
	Safety Planning and security		

The column to the left refers to support that is provided at no financial cost, whether by family, friends, neighbours or others in the community. A member of a local church community who takes a young person with disability to and from church each week, and assists them during and after the church service, is providing valuable informal support.

Funded paid support refers to funding received from government or a local service. In a real choice and control scheme, this will pay for a support worker chosen, trained and supervised by the individual or their family and supporters. Many people require some paid support. The trick is to work out how much is required in a particular individual's circumstances. Unfunded dollars refers to any other financial support, whether the individual's own money (eg, wages or pension to pay rent), or contributions from family and friends.

weekly wages from a job we had created for her, paid for food and rent, while a large group of individuals, including immediate family, spent time with her on a regular basis. She was supported by a combination of funded dollars, unfunded dollars, and informal unpaid support. This was planned and controlled by our family, through a small family governed service which allowed us the freedom to do so.

Using a template like this helps clarify where funding assists the achievement of a goal under a particular aspect of the good life, and where not. There is much that can be done towards planning for the good life for any individual, irrespective of funding. There is much to be done where funding is irrelevant. It is not a critique of funded support to say that funding is limited, merely a statement of reality.

The NDIS and other funding schemes have the potential to make a big difference to those

people with disability who do need significant paid support. Achieving the maximum benefit from such a funding scheme requires much more than completing an application form and submitting to an assessment process. As I have argued above, it requires a clear vision and a detailed plan. It also requires knowledge.

For example, implementing a vision and plan for someone who requires funding and paid support, requires an understanding of:

- the level of paid support actually needed to achieve that vision (this will be learnt by doing, requiring flexibility in funding support through this learning phase)
- how paid support is costed (how far the dollars go, whether from government funding or private contributions; what a particular service charges per hour and whether it is reasonable)
- how to choose (or create) a service that supports the person's vision and plans
- how to build informal supports – consistent with that vision – such as
- a support circle
- planned opportunities to connect (eg, regular meetings for coffee; monthly meals or outings)
- communities of involvement (clubs, interest groups, church congregations)
- flat-mates / house sharing.

People with disability, with their families and supporters, can achieve much of what constitutes the good life if they are clear about their vision and have the support to plan to implement that vision. If the NDIS turns out to be the flexible, coherent, entitlement based funding scheme based on choice and control, which many hope it will be, it may assist individuals and families to achieve their vision and plans for a good life, but it won't

create the good life for them. Only people with disabilities themselves, and their families and supporters, can do that.

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