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Note: The following is a personal submission complied by two parents of children with complex congenital disability, in regards to the NDIS call for submissions. We have drawn on our own experiences and those of other families.

MAIN ISSUE	RECOMMENDED ACTION	ADDITIONAL COMMENTS
• The funding body for disability services is tarred with the welfare brush simply because both services are provided by the one department • The judgement and attitude of some people working in disability services is that of protecting the system from scammers, as it is in welfare, yet we are dealing with disability	• Clearly separate disability and general welfare where possible, especially on a social/attitude level • Be active in offering support • Work to dispel the social myth of shame associated with asking for support	• Combining services spreads resources far too thin (this also applies to disability services being combined with aged services) • There is a strong culture of blame when it comes to congenital disability already, this is only exemplified when it is socially associated with general welfare, and/or the attitude of ‘a cost to society’
• Currently support services (especially those in regional Australia) have to focus far too much on funds rather than support	• A national scheme such as NDIS	• Please note that when it comes to financing and managing the NDIS it is likely changes interstate will become too complicated, as would management through too many sub-agencies. This is especially so considering many people living in rural or regional Australia with complex disability and medical needs travel interstate to receive specialist care.

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• Personal judgment with incomplete or assumed information has no place in support services • Guidelines/policies etc are not always adhered too by some people working in support services • Persons working in support services need a much wider skill base than administration	• Guidelines/policies should always be readily available and staff knowledgeable of them and happy to explain them • Support services need to be transparent and accountable with families about decisions, policies etc • If there is a problem or concerns, they need to be openly discussed and worked out *according to what is best for the family or individual* • Persons working in support services should not be able to deny applications or alter results of applications if there is not clear reason in currently publicly available guidelines or other official documentation, at least not without consultation with the individual /family • Improve on going training and staff support	• For example, we have experienced ‘mocking’ of a main carers limited ability to work full time, and have received comments like ‘everyone has a sob story’ • A carer recently had 2 occasions of unprofessional and unacceptable treatment from the local representative of the statewide funding body, PADP. She was calling to enquire on the progress of an application for funding for her disabled child’s equipment. Her first experience left her sobbing on the kitchen floor after the representative verbally abused the carer for trying to make the representative ‘feel guilty’ and ‘pulling at the heart strings’ in relation to the child’s application. On the carers second encounter, 6 weeks later, she was told the following statement ‘just write a letter, I won’t be here in a month, someone else can deal with you!’ • Representatives in disability services are in a position of power and privilege and their treatment of any carer on any given day can have a massive impact on the lives that carer touches. The representatives have no

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	• Improve staff choice and criteria for hiring staff • Persons working in support services must keep up with current information and should be trained in *at least* basic counseling techniques	idea the mental and emotional stability of the carer and an experience such as the two described above could literally have devastating consequences. • Often these people are a first point of call to a ***very*** vulnerable population
• Disability services are supposed to be delivered on a needs basis. This does not mean that everyone ‘gets a turn’ or receives the same amount and type of support	• If any particular need is assessed as accurate, then that need should be fulfilled (regardless of how much or how little equipment/support that individual/family has or hasn’t already received). For example, a child with complex disability needs a walker no less because he has already been given him a feeding system • The people most in need from our perspective are the following: those with life long disabilities, those with complex disabilities, those with behavioral or sensory/emotional problems that negate participation in mainstream society in a day to day fashion,	• A brief example: Person A has a disability affecting one part of their body or aspect of their lives, yet they receive the same amount of support as Person B who manages multiple/complex disability affecting all areas of their lives • Please also see our ‘I can’ check list tool below as a means to deal with this problem

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	those who also have complex medical needs, those who are unable to care for themselves independently over the age of 18, those who are significantly delayed in development (2+yrs), those with significant disability who in any given year spend more than two months in hospital or unable to participate in their day to day lives, and those who currently fall into neither aged or young care.	
• Applications for service tend to work from the negative ie what is wrong with you or your child?	• Applications for service provision should work from the positive. What an individual CAN do rather than what they can not. • An ***'I can'*** checklist scoring tool	• For example: I/my child/my dependent ***can***: - Walk independently - Dress themselves/myself at an age appropriate level - Feed themselves/myself at an age appropriate level - Access mainstream services without the need for additional contributions from caregiver or individual (in time, money etc) - Access mainstream schooling and/or employment - Toilet at an age appropriate level - Be managed medically/ therapeutically in local area

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		And so on, these questions would need careful consideration in collaboration with all ‘stakeholders’. • There should also be a carers/family component - I can go shopping or complete other daily living activities with my dependent - I can access mainstream services for a break - existing respite services are an option for me - I have family in the local area who provide support - I am of able body and health myself (and so on)
• Support is often left too late and is too limited • A four year old is **not** a baby	• Words like prevention and early intervention need to be revisited and put into action, on the scale of the family unit and quality of life, not only directly at the child/individual affected by disability • Offer support through the NDIS at the onset of disability, not only once someone reaches a certain age or has suffered from a	• Support services appear to define a ‘baby’ as under 5 and therefore not needing of as much support as an adult or older child. In the case of complex and developmental disabilities, many families are near or past breaking point by the time their child is 5. If there are also complex medical issues, in the case of a rare chromosome disorder or similar, they are usually worse in these first years. Families in these situations will be dealing with disability and will have someone they love being completely dependent upon them for 50+ years

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	disability for a certain amount of time. • Effectively communicate that this is support of what is recognised as a very difficult role, not ‘charity’ or general welfare. When it comes to disability, functioning families and individuals save the government (and tax payers) a lot of money in the end	depending on life expectancy. Please don’t leave it till ‘later’ to offer support
• Support services appear hidden	• Services need to be actively and openly offered, some families are barley functioning, let alone in a position to go out and actively seek or ‘fight for’ assistance	• A disabled child or individual and their families/carers should not need to *earn* support
• For some families actual respite (the removal of the *disabled child only*, or the care of the disabled child only in the home) will never be a real option for relief (morally, practically, etc) Perhaps it will only be an option at certain times or under certain circumstances	• Other forms of relief must be made readily available and hold as much value as traditional respite	

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• The emotional health of individuals and families must become more of a priority earlier on in the supporting process	• Support services must, at times, provide for support outside of medical equipment and therapy	

<u>SUPPORT </u>(as defined in the Oxford Dictionary):
verb

- *bear all or part of the weight of; hold up*
- *give assistance to, especially financially*
- *provide with a home and the necessities of life*
- *give approval, comfort, or encouragement to*
- *be actively interested in and concerned for the success of*
- *(as adjective **supporting**) (of an actor or role) of secondary importance to the leading roles in a play or film*
- *suggest the truth of; corroborate*

produce enough food and water for; be capable of sustaining

We sincerely hope this submission brings some new ideas to your forum and creates real change in our world of carers and advocates but most importantly for all people with a disability.

In kindness,

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