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Proposed NDIS- comments.

My Comments are based on more than 30 years of working as a senior physiotherapist, with adult acquired brain injured clients and over 5 years with adults with Late Effects of Disability – which covers disabilities acquired at birth and early years of life.

All my comments are in italics and bold type.

Draft Report by Chapters : Overview- tier 3- Access to publicly-funded, individualised supports

“A person getting funded support from the NDIS would have a permanent disability, (or if not permanent, expected to require very costly disability supports) and would meet one of the following conditions:
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- have significant limitations in communication, mobility or self-care (3a in figure 1, and accounting for around 225 000 people)

- have an intellectual disability (3b) (around 50 000 people, not including some people with intellectual disability already covered above)

- be in an early intervention group (3c) (around 80 000 people). This would include two groups of people. One group would be those for whom there was a reasonable potential for cost-effective early therapeutic interventions that would improve their level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). The other would be those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson’s disease, for whom early preparation would enhance their lives. For instance, assisting in retaining bladder control can assist people with worsening Multiple Sclerosis

- have large identifiable benefits from support that would otherwise not be realised (3d). This category takes account of the difficulties of slotting everyone into the specific groups above. The National Disability Insurance Agency would apply this fourth criterion judiciously rather than routinely. It would be constrained by guidelines, and monitored for its effects on scheme costs. If the agency were to use this criterion loosely, it could pose a risk to the overall financial sustainability of the scheme.”

“• have significant limitations in communication, mobility or self-care. “

? who assess this – the report does acknowledge that qualified personal will have a role in assessing . There is no known tool that covers all disabilities- this is acknowledged in the report. .

In WA there are many professionals, PT, OT, SW , psych, SpT, working in the field of rehabilitation in general but very few who have the experience in working with long term disability. GPs are not qualified to make any statement on the rehabilitation needs of individuals- many GP do not understand the impact of physical disabilities and its impact on the day to day functioning of patients.

My Suggestion :
Some tightening up of definitions is required e.g. assessment be made by qualified personal be further qualified by requiring certain criteria.
E.G.
For physical disability – by physiotherapist working with long term disability. There must be short and long term needs projected. Physiotherapist must be able to assess the functional mobility associated with the physical disability and project a short term [5 year] and long term [10]year projection. Based on my experience – those with experience will be comfortable in being able to do a 5 year and 10 year projection.

As suggested in the document , these professionals should not be part of the funding allocation group.

To be cost effective : assessors in the community must take their direction from the statement made by proffessionals, as suggested above.
There needs to be a panel of both consumer rep and professionals, to address disputes that will arise. E.g CAEP clinical advisory group – under DSC in WA- is an effective way of settling difficult or questionable submissions, for very expensive equipment.

Currently, family information about self care and mobility, is accepted and funding allocated accordingly – this is very inaccurate, inefficient system, pts have been put at risk because of this , costing the health system more to try and fill the gaps in services. Family concerns and patient needs must be considered, but should not be the foundation for costing.

"• be in an early intervention group, comprising:
– those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)"

The term reasonable potential for cost effective earl therapeutic intervention – wording is very open and a little misleading-

?define cost effective early therapeutic intervention.

The term ‘Early Intervention’ – can refer to paediatric age group or immediate post hospitalisation for adults. In both cases intensive intervention, that is goal orientated and with defined or projected outcome measures, will be a cost effective outcome. Cost effectiveness can only be judged on review, which must be built in.

Therapeutic intervention - is cost effective , if it prevents onset of complications. In some severe cases this is all that could be possible.

How long is early intervention ? how many months ? how many years?.

The above term is too open and will be defined narrowly by service providers who lack experience.

Early intervention should mean as soon as deterioration is identified – in physical terms , it should be when functional mobility becomes difficult for pt and cares. This can be measured by time taken or inability to manipulate. It should not be when pt is unable to perform a task. The latter is criteria that is currently used. Again professionals should assess this not carers or non professionals.

“Those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)”

The title limits unnecessarily. With genetic testing there are many physical and mental disabilities diagnosed that are not degenerative by nature, but do cause ’degeneration “ in function due to delayed intervention, ineffective therapeutic intervention and poor social care.

Suggestion :
remove the word “degenerative” consider the use of term “ ‘newly diagnosed diseases or disability’ for whom early preparation would enhance their lives “

This will now cover degenerative conditions like MS, MND and late functional deterioration seen in cerebral palsy, spina bifida and polio. The latter groups, have been disadvantaged as they age. In their younger years, their diagnosis, may have left them with a mild physical disability but no functional disability . As they age, they develop functional disability, due to aging effects with a physical disability. This is an old problem only now recognised by those of us working in physical rehabilitation.

“• have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.”

The above is dependent on the opening statement being understood well-definition of who will qualify for the scheme. The above does cover the groups

of pts for whom aging effects is leading to marked functional and physical deterioration, but
the opening statement needs to be stated in the positive.

" Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) -------."

Suggestion : remove the brackets and reword to be more inclusive
" individuals receiving individually tailored , funded supports should be Australian residents, have a disability, 'physical and or mental, that would require on going disability supports'".

Comment on training :

The success of the scheme hinges on appropriate care support staff. Disability training certification is a must. Making this a profession with a structure that allows for advancement /seniority, with a pay structure, that is commensurate to qualifications, will stop the drain from this field.

The current error in the system is assuming that because staff have a certificate, they know how to care for all disabilities.
In house training by some private organisation is not targeted enough. By nature, this has to be generic.
The comment by a consumer suggesting that he preferred a non trained person points to the above problem.

My suggestion :
Targeted Training of carers, by professionals referring pts for carer support, should be mandatory. Private organisations offering carer support, should be required to have key staff trained by professionals , for each client they take on.

Training of professionals, to be able to project the needs of disabled, based on presenting disabilities, is needed throughout Australia. Making sure that professionals assess clients /patients in the appropriate setting should be mandatory, i.e. in the pts own environment and not only in a clinic.

Comment on Governance:

Both suggested schemes is needed. Patients have been disadvantaged for a long time, carers and families have borne the brunt of the workload , with limited support.

IN WA the department looking after clients requiring care , outside the hospitals , is DSC.
I comment on the therapy services only.
This department has cut therapy services down to one of issuing aids and little else- even though, on paper – there should be specialist clinical services.

What is the role of DSC in WA, in this new suggested set up?
Who will review the governance of this new Commission?
My 30 years has seen the one effective govt body, downgrade clinical services and expand administrative services at the expense of pts and families.

Summary
This change to access funding, is much needed. I hope that there is focus on clinical service delivery. Governance is important , if this scheme is to be successful, but over administration will make it a very expensive white elephant..

Thank you for giving me the opportunity to comment.

Yours sincerely
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