TO: Disability Care and Support Inquiry
Productivity Commission
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RE: **SUBMISSION TO THE DISABILITY CARE AND SUPPORT INQUIRY – NATURE OF SERVICES AND PAYMENTS**

In the Productivity Commission's *Disability Care and Support Issues Paper* released in May 2010, it states that:

> "The core formal services required for a well functioning disability care and support system are usually grouped into personal care services, respite and accommodation services, community access, community support, income support, employment, transport, aids and appliances, home modification, but also a range of intangible services, such as counselling and mentoring" (p.25).

General comments

It is my understanding that the core specialist disability services listed above are those currently available under the National Disability Agreement (NDA) and Home and Community Care Program (HACC).

Worthy of mention also is that there are other service structures that operate outside the scope of the NDA and HACC, which play a very important role in the everyday lives of adults who have an impaired decision-making capacity, e.g. adults with an intellectual disability. These service structures are the responsibility of the States and Territories and include the Adult Guardian, Public Advocate, Community Visitor Program and Public Trustee (or equivalents). The target group of these services are also high users of specialist disability services under the NDA. The Continence Aids Payment Scheme (CAPS), too, is a core service for many disability groups (e.g. people with spinal cord injuries, spina bifida and cerebral palsy), which operates outside the NDA and HACC.

I have highlighted these examples to emphasise the importance of looking beyond the specialist disability services currently provided under the NDA and HACC when thinking about the "service offer" under the disability care and support scheme.

To this end, I support a different mix of services under the disability care and support scheme to the ones mentioned by the Productivity Commission. I support the inclusion of direct services (not indirect), specialist disability services (not mainstream) and services provided to individuals (not groups) so that persons with disability can engage in the activities, pursuits and processes of everyday life of their choosing.

I also support whole-of-scheme services designed to protect the fundamental human rights and freedoms of people with disability, their families and carers. In my view, this protection should extend to the independent review of disability care and support scheme decisions by the Administrative Appeals Tribunal (AAT), or another appropriate tribunal, to improve the fairness of decisions, accountability and transparency.

Further, I wonder whether disability services that have a direct line of sight to Commonwealth powers laid down in the Australian Constitution should be excluded from the disability care and support scheme owing to potential legislative constraints. Examples that come to mind include government pensions and allowances, Postal Concessions for the Blind (postal) and the National Relay Service (telecommunications).

Unique needs of people with severe or profound disability

From my observation, what differentiates the needs of people with severe or profound disability (the group most likely to qualify for assistance under the scheme) from people with lesser disability and those without disability is their *need for individually planned and coordinated support worker services* to help them engage in the activities, pursuits and processes of everyday life. Hence, my focus on the *actual service* being provided and not the *activity* the person with disability is engaging in. The latter is how many specialist disability services are currently categorised.

I, therefore, do not support the use of service types based on the everyday activities of people with disability as this categorisation only serves to limit what and how much specialist disability support is provided. Most people with severe or profound disability need lifestyle support that covers *all* everyday activities, not just accommodation support or community access. Except for supported accommodation, funding decisions tend to be based on the receipt of one key service type only so as to avoid “double dipping” in a disability support system that struggles to meet the demand for specialist disability services.

Another unique need of people with severe or profound disability is that the person may or may not need *specialist aids and equipment* to support them in their everyday living.

The unique support needs of particular disability groups also warrants special mention. For instance:

- The unique support needs of adults who have an impaired decision-making capacity are supported accommodation, specialist behavioural intervention (where this applies), decision-making services and disability employment support;

- The unique support needs of children with disability pertain to allied health services (e.g. physiotherapy, speech pathologists, occupational therapy, dietician, etc) and aids and equipment (e.g. mobility aids, assistive communication devices);

- The unique support needs of people who are deaf are the National Relay Service, Auslan interpreting services and hearing dogs.

- The unique support needs of people who are blind are print disability services, assistive technology, mobility training and guide dogs.

Core formal service types

The core formal services that I consider are "required for a well functioning disability care and support system" are:

- Individually planned and coordinated support worker services
- Independent living services and assistive animals
- Supported accommodation
- Decision-making and rights protection services
- Allied health services
- Portability services
- Respite for carers.

Examples of each service category are provided below, along with some additional comments.

1. Individually planned and coordinated support worker services

Individually planned and coordinated support worker services are needed to support people with disability in everyday activities, pursuits and processes. This service type would include:

- in-home support e.g. self-care, meal preparation/”meals on wheels”, health care, domestic assistance, supervision
- out-of-home support e.g. shopping, banking, medical and other appointments
- participation support e.g. life skills & development, vocational education & training, voluntary work, employment (i.e. on-the-job support and work-based personal assistance), social, sports, recreation, and
- transport services.

This service type would also include access to a mobile attendant care service, that is a service that provides a broad range of small action personal care tasks, such as assistance to bed, turning in bed, toileting, giving medication, making cups of tea/coffee, making lunch, etc. The provision of a mobile attendant care service would generally be needed in addition to regular structured disability support provided to the person.

You will notice that, with participation support, I have included on-the-job support and work-based personal assistance only. More specifically, on-the-job support would include supported employment (a job creation labour market program with support worker assistance), on-the-job support in the open labour market and work-based personal assistance.

Disability Employment Services (open employment services) currently provide ongoing case management support to people with disability working in the open labour market. To the best of my knowledge, the predominant focus of this aspect of the service is on monitoring how things are going with the job and offering “moral support”. This does not extend to supporting the person with disability on-the-job in the way that supported employment does. If this is in fact the case, then I would like to see the disability care and support scheme provide this type of support to people with disability in the open labour market.

Further, I am not 100 per cent convinced that the job search assistance function of Disability Employment Services is a good fit with the disability care and support scheme. The reason for this is that, labour market programs that focus on job search assistance are a mainstream service provided to all Australian job seekers. It is not a specialist disability service in that it is not unusual for government-funded mainstream employment service providers to target their services to particular economically disadvantaged groups, such as youth, the mature age, refugees, etc.

I would also like to add that the target group for Disability Employment Services seems to have moved away from people with a severe or profound disability to people with all levels of

disability. A sizeable proportion of this group, then, are unlikely to qualify for assistance under the scheme.

2. Independent living services and assistive animals

This service type would include essential specialist aids and equipment (e.g. mobility aids, incontinence aids), assistive communication devices & services (e.g. assistive technology, Auslan interpreting services), home and workplace modifications and assistive animals (e.g. hearing and guide dogs).

3. Supported accommodation

Under the disability care and support scheme, I would like to see supported accommodation only include the provision of housing in private dwellings (fewer than six people) plus individually planned and coordinated support worker services generally providing 24-hour disability support.

Importantly, this would automatically exclude from the disability care and support scheme supported accommodation that houses six or more people, e.g. institutions, hostels and respite care facilities. These accommodation support services provided under the NDA are clearly inconsistent with the principles, obligations and fundamental human rights and freedoms laid down in the United Nations Convention of the Rights of Persons with Disabilities.

4. Decision-making and rights protection services

Decision-making and rights protection services go hand-in-hand with the provision of supported accommodation. Under this service type, I support the inclusion of, for example, decision-making services and the Community Visitor Program (or equivalent). These disability services are currently provided outside the scope of the NDA and HACC.

Decision-making services are currently provided through the Adult Guardian (or equivalent) and administered by the States and Territories. The Adult Guardian is for adults who have an impaired decision-making capacity and no family, relatives or friends who can act as guardian. The Adult Guardian makes personal and health care decisions in respect of these persons in the areas of, but not limited to, accommodation, education, service provision and medical procedures. Under the disability care and support scheme, I would see decision-making services also covering the use of restrictive practices, such as containment, seclusion and restraint.

It needs to be emphasised, however, that the quality of decision-making in the area of supported accommodation is lacking as people in supported accommodation have very little say in where they live, who they live with and how they live their lives. This situation seems to have arisen as a consequence of a practice that assumes that disability service providers and the States and Territories providing the funding make decisions in the best interests of the person with disability.

The *Community Visitor Program* (or equivalent) is also currently administered by the States and Territories and is designed to protect the rights and interests of adults living in designated care facilities, such as institutions, hostels and group homes. Community Visitors are empowered under legislation to make regular unannounced visits to care facilities where they enquire into issues raised by residents or their representatives and resolve complaints on behalf of residents.

5. Allied health services

Allied health services would include, but are not limited to, psychologists, mental health workers, speech pathologists, physiotherapists, dieticians, etc. These services would cover services like early intervention services and behaviour/ specialist intervention currently provided under the NDA and allied health care and carer counselling support currently provided under HACC.

Ideally, allied health services are best provided under Medicare. That said, I am cognisant of the fact that people with disability, their families and carers face barriers accessing these services owing to the out-of-pocket expenses involved and the cap placed on service usage each calendar year.

So, if Medicare was more accommodating of the disability support needs of people with disability, their families and carers, then allied health services would not need to be provided under the disability care and support scheme. To overcome the present issues, I support the issuing of a “disability care and support card” to eligible scheme service users so they can automatically access Medicare allied health services on an assessed needs basis and without any out-of-pocket expenses.

6. Portability services

Portability services are needed to assist people with disability, their families and carers to ensure continuity of

disability support upon moving intra-state and inter-state and when existing service arrangements break down.

At present, continuity of such support is not guaranteed. While each State and Territory has a Portability Coordinator under the NDA, their role seems to be limited to the provision of advice on how to re-apply for the same assistance rather than any genuine active assistance with linking current service users to disability service providers that are able to provide the same type and level of disability support the person received before they moved. Hopefully, this bureaucratic silliness requiring people with disability, their families and carers to re-apply for the same disability support (and join the waiting list) will not be a feature of the disability care and support scheme.

7. Respite for carers

Firstly, I would like to point out that, under existing specialist disability service arrangements, respite care is ad hoc support and is mainly provided as a substitute for much needed regular disability support, namely accommodation support services and community access. I would also like to add that the provision of respite care is first and foremost about giving the carer a break from caring, which may or may not coincide with the wishes of the person with disability.

Under the disability care and support scheme, respite for carers should ideally operate as an emergency service when, for example, the carer is unwell. Hopefully, people with disability will receive the type and level of disability support needed under the scheme so as to minimise carer stress and the need for respite care in its existing form.

Payment for specialist disability services

There is no easy answer to the question of whether or not specialist disability services should be free under the disability care and support scheme. My personal view is that, for the most part, specialist disability services should be provided free, with no payment involved. My reasoning for this is that, most people with disability, their families and carers do not have the capacity to pay for these services. Similarly, people on high incomes would also struggle to pay. I am aware that payment for the receipt of specialist disability services is not currently a feature of the NDA, but is a feature of HACC.

The specialist disability services that people with disability, their families and carers should probably pay for, in the form of a co-payment, would be transport services and “meals on wheels”. There is already a co-payment attached to receiving “meals on wheels” under HACC. I consider that co-payments in

these instances are justified as the costs associated with travel and food are everyday costs for all persons, not just people with disability. The amount of the co-payment should be equivalent to what people would usually pay for the good or service; for example, the cost of travelling from A to B using public transport.

With food services, there are now numerous companies today that deliver ready-made frozen meals. So, for many people accessing “meals on wheels”, they may very well be able to use these mainstream food outlets instead, with some initial assistance. I do, however, recognise that “meals on wheels” has a long history that pre-dates the ready-made frozen meal industry and that it has its supporters, both HACC providers and service users.

(Electronically Signed)

Val Pawagi