BRIGHTwater

Brightwater Care Group (Inc.)

SUBMISSION TO THE
SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE
REGARDING INQUIRY INTO THE
FUNDING AND OPERATIONS OF THE CSTDA

This submission is to provide information for the inquiry into the funding and operation of the CSTDA. It has been completed on behalf of Brightwater Care Group (Inc) by the signatories below (p8).

The issues identified below relate to points:-

(b) the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;

and

(c) an examination of the Ageing/Disability interface with respect to Health, Aged Care and other services, including the problems of jurisdictional overlap and inefficiency.

1 Identification of Target Group

It is of concern that a number of systemic issues impact directly on both the clear identification of groups requiring support by the Disability sector and on the ease of identification of individuals belonging within those groups. In addition, the Individual Planning model adopted by the Disability sector prevents advanced planning for specific groups and appears to prevent the development of services for people with similar interests and needs, which cluster around diagnostic groupings.

Adding further complexity is the lack of clarity associated with the word “disability” itself. It is notable that the term “disability” is frequently loosely used to include those who meet the World Health Organisation definition (such as those with Acquired Brain Injury and/or intellectual disabilities and those with health and/or degenerative conditions). This lack of clear definition results in some people falling outside of jurisdictional boundaries erected by all sectors - Health, Mental Health, Disability and Aged.

This lack of clarity of definition results in considerable disadvantages to some. Attention is especially drawn to the following:

(i) *Exclusion or inadequate funding for people with degenerative disability*.

- Although numbers are small, these are people with intensive specialised care needs over a relatively short period of time: for example, approximately 3 years for people with Motor Neurone Disease, 5 or more years for people with Multiple Sclerosis. Characteristically, these specialised care needs are health-related and require regular input from professional staff.
- Some of these people choose to remain in nursing homes to continue to access professional support, in particular those living in rural areas. Alternatively, there is little choice as there is no real other option. One would expect that this group is entitled to additional support to ensure equitable service provision with those who choose to be accommodated in a community living environment.
- For those in this situation who would choose to live in a community living environment, the degenerative nature of their condition means that accurate assessment of current and future care needs, while crucial, is a real challenge. Allowance for professional support is usually not factored into estimated cost of care, and is often calculated only at a care worker rate.

(ii) *Non-inclusion and limited options in the Disability system for young people with dual diagnosis, ie. disabilities, and mental health issues.*

- These young people are not managed well by either the Mental Health or the Disability system. While the Mental Health system may be able to provide a secure environment, it is often challenged by the presenting disability. The Disability system on the other hand is often unable to meet the requirements to manage acute or chronic mental health diagnoses.
- Neither the Mental Health nor the Disability system provides collaborative support across the sectors to address issues where they may have expertise.

(iii) *Restricted direction of Disability accommodation and support funding to people between 50 and 60 years of age.* Such restriction implies that disability and ageing are separate life stages for those with disability, and that disability ends when ageing starts, usually at the age of 50.

- Accommodation options for those between 50 and 60 (and even to 65) are limited despite this group having very different needs to the predominant generation currently occupying Residential Aged Care places who are in their 80s.
- It is questionable whether age should be the main determining factor when assessing eligibility to participate in Disability accommodation funding rounds.

There are three further groups of people whose need to be included in the Disability definition, and therefore to be included in funding and support considerations, is poorly identified. These people are effectively excluded. At most risk are those who already fall within the Health, Mental Health or Aged sectors, even for short-term intervention.

(iv) *Young people in the acute hospital system with high support needs and complex care issues.* The limitations of identifying these individuals may be due to -

- The lack of a systematic method of identifying these people at an early stage in their admission. In addition, there is no clear method for ongoing monitoring of individuals who remain within the hospital system for a number of months.
- Confusing information from outside agencies about the entitlements of these young people and which agency has major responsibility for their ultimate living option.
- The limited accommodation options that are available to these young people, resulting in them being placed low on the priority list for Disability funding.
- Confusion about what is a health issue and what is a disability. For example, where does someone who is 35 with physical complications of severe diabetes fit?

(v) *People under the age of 50 who are receiving Commonwealth care packages in forms other than Nursing Home care.* This is certainly proposed as one eligibility restriction for those with disability in receiving YPINH funding from the current round.

- As this group is not close to chronological old age they are not necessarily like those in the older group and may be equally disadvantaged by the Aged sector.
- HACC services are currently supporting large numbers of young people with disabilities. Funding rules behind HACC and Disability Services mean that the two cannot cross over, restricting access to alternative services for people receiving HACC support.

- When the needs of young people with disabilities in HACC programs change to the point where they require residential care, the system appears to be unresponsive and unable to increase community care to prevent entry into residential accommodation.

(vi) *People eligible for Disability support, who are currently in other programs.*

- People within the Brightwater Brain Injury Rehabilitation Service are part of a target group requiring Disability support funding. There is currently no mechanism in place for them to plan to access funds for supported accommodation either within the current system or under the planned YPINH funding round. Those who still require high levels of support (a small minority) are then at risk of entering Residential Aged Care to meet their accommodation needs.
- People who are currently being supported by compensation funding have no mechanism to enter a government-funded system when their funding runs out. This is currently not a planned transition, and people are left in a limbo situation of having run out of funds, and having no application in place for support funding. Often the "quick fix" is to seek an ACAT transfer to Residential Aged Care.
- There are limited options for people with intellectual disabilities living at home, or in Disability-funded Residential Care, whose needs can no longer be met by those environments due to changes in the person or the environment itself. Examples here are:
  - People living with parents who are no longer able to meet their needs due to their own illness or death. Often the "quick fix" for this group is a move to Residential Aged Care because of the slow response time of the Disability system.
  - People living in Residential Aged Care who have changed needs: for example, increased physical care needs due to health changes that can no longer be met in their current environment. Again transfer into the Residential Aged Care system is often the most timely solution.

2 Flexibility Within the System

For those who do enter the Disability system there is an apparent expectation that they, and therefore their needs, will remain static. Planning for future care requirements is not outcome-based with no allowance for life change, improvement in functional capacity or the impact on support needs that temporary changes, such as financial stress, health episodes and even staff movements, can have.

(i) It should be recognised that the original group in the WA YPINH program (a project undertaken in the late 1990s where 95 young people were moved from State-funded nursing homes to supported community accommodation), has changed - not only in their functional ability but also in their capacity to relate to the community and each other. This change is surely not restricted to this specific group, and one would expect that it is replicated to varying degrees by other disability groups who have moved from institutional environments into community-based housing.

Greater flexibility within the system would mean that:

- Some of these people could be relocated to accommodation that -
  - is in another locality because lifestyle changes mean that they would be better served living somewhere else, or
  - offers less support because they have become more independent, or
  - offers more support because they have become more dependent, or
  - has improved compatibility with fellow residents.
- The created vacancies could then be filled by others coming into the system. This may result in some cost savings, eg. someone funded to $90,000 pa moves to a $45,000 pa option, while a new person takes the vacant $90,000 pa position. This would result in two places costing a total of $135,000 pa rather than $180,000 pa.

(ii) Creation of greater flexibility within the Disability system requires examination of more creative accommodation options, both from a physical building point of view and when establishing staffing models.

- Housing design and staffing models should not be seen as mutually exclusive. Creative design can impact on staffing through a number of factors including reduction in manual handling requirements, improved supervision through open plan design and zoning to reduce behavioural impact. (In times of financial limitation, this is a very significant issue for effectiveness and efficiency).

- Variety in housing design, both within a single site and across neighboring localities, will accommodate changes in need without disrupting already established community integration.
- Staffing models that focus not only on care but include a capacity for assessment and review by involved professional staff enables change to be identified and expertly assessed. Flexible accommodation and support options will thus be better utilised. It has been very evident with clients of the original WA YPINH group that changing level of independence is possible, albeit slow, but the system should be flexible enough to respond when they have “outgrown” their home environment.

3 Responsiveness of the System

A system that offers flexibility must also be responsive to change at a pace that suits the needs of the end user.

(i) People's needs do not always change in a gradual way. Sometimes change is sudden, dramatic and requires immediate support.

- Change in a person with disabilities who is already "accommodated" either in individual or group options is often a challenge for agency response, with that agency struggling to provide increased services on the same income. Oftentimes the family has to take up the slack.
- People who suddenly acquire a disability (eg. a head injury, or a physically debilitating disease), have no clear pathway for entering the system. Current vacancy management requirements for the WA YPINH program are time-intensive from an application perspective and answers are a long time coming.

(ii) Families are often challenged by the responsiveness of the Disability system, not so much because of what might be available, but more because of their inability to understand the system and the easiest way to manoeuvre through it.

- While options for accommodation support may be available for people with disabilities, their carers lack clear and consistent information on how to access such support. This often leads to people giving up, or not applying for support they may be entitled to. This issue is often stronger for people with acquired disability who have not had natural entry into the system in childhood.
- The flow-on effect of the lack of responsiveness due to poor information is that this group often enters the Residential Aged Care system where the process is clearer and the information more readily available.

(iii) The current Disability model, Australia-wide, appears to have an emphasis on care giving with less capacity to respond to learning and progress. This, coupled with a quite limited review system, often means that improvement in independent functioning is not responded to in a positive framework. The response, in fact, can appear punitive because it may result in a reduction in funding without a corresponding level of support to upgrade the model of care.

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The authors of this submission have long experience in providing care and services to people with disabilities acquired in adult life due to catastrophic injury, such as brain injury, or seriously debilitating disease, such as Huntingtons Disease, Motor Neurone disease, and other neurodegenerative disease.

These conditions have inherent characteristics -

- of almost inevitable change (either improvement and potential for rehabilitation and re-integration to community living, or deterioration and increasingly high support needs),
- of sudden onset, or unpredictable onset,
- of the need for specialist skills in the care providers. They often begin their "journey" in other service jurisdictions. They are at risk of not being identified as needing, or of being excluded from, Disability services. They are certainly disadvantaged by the inflexibilities and slow response timeframes currently inherent in the Disability Services systems and practices. Should they not be included in Disability, their options for care are extremely limited. Indeed, admission to the Residential Aged Care system is inevitable for many.

The authors have endeavored to describe and explain the situation faced by these people. We have tried to keep a complex issue as simple as possible, and would be happy to provide further information or advice if requested.

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