

Disability Care and Support Productivity Commission

Submission on behalf of Community Lifestyle Accommodation Ltd

Background

Community Lifestyle Accommodation Ltd (CLA) is a not for profit organization registered under the Corporations Act 2001. It is a company limited by guarantee and managed by a board. Our board and membership consists of carers/parents, supporters and people with an intellectual disability. We are committed to providing appropriate housing, combined with individual support, to meet the changing needs of adults with an intellectual disability.

Submission

Our submission is in two parts. Part 1 is our general observations, and Part 2 is our response to specific sections of the draft report. Our responses in this section are based on the needs of people with an intellectual disability.

Part 1

The Draft Report of the Productivity Commission on Disability Care and Support has given families that are caring for someone with a disability cautious hope for the future. It seems that after decades of families crying out for reform the cries have been heard. Currently many caring families are missing out on support and services which are desperately needed for them to enjoy life, as others do in our community. The opening statement of the draft report said it all: -

“The disability support system is inequitable, under funded, fragmented, and inefficient and gives people with disability little choice”

A new approach is definitely needed.

Australia is a wealthy country and as a nation we should provide life long support and services to our most vulnerable citizens and their carers. People with an intellectual and/or physical disability deserve entitlements not charity handouts.

CLA agrees with the recommendations of the Commission, that the Australian and State and Territory Governments form a task force to implement the NDIS and the reporting structure to COAG and Heads of Treasuries meetings. However, this can only commence after all governments agree. Historically this has been shown not to be a quick process and CLA has concerns over this aspect.

CLA supports the financing of the NDIS via general revenue according to a legislated formula. We perceive this as the only solution to ensure guaranteed care and support for eligible people and their families.

Part 2

Draft recommendation 4.3

Proposing to charge an up-front fee is an issue for many and this could be a sticking point. The definition and hence the implementation of this recommendation is unclear. Is the intent to charge people an excess if their family is, or has, contributed significantly to their care? . What happens to a single person who acquires a profound disability in adulthood?

Draft recommendation 4.5

It is stated that the NDIS would cover the provision of specialized accommodation services (net of the standard contribution from a person's income for rent). We have understood this to mean that the person's package would include provision for the monthly costs (i.e. rental). We have been advised that the NDIS will cover capital costs of specialized accommodation and group homes.(for people with a severe/profound disability) The details on how organizations can obtain capital funding to develop this accommodation is not specified and we await advice on this matter.

For other people with a disability who do not require high support the commission is recommending private rental, public housing, support packages and home modifications. Under this recommendation a person with an intellectual disability, living alone, would be extremely vulnerable with a high risk to their personal safety, health and wellbeing. People with a disability in many instances do not have the money to purchase a home.

Many people with an intellectual disability have been placed in boarding houses where they are living in poverty and are vulnerable to exploitation by private boarding house operators and abuse by other residents. They have no one to monitor their medications or medical appointments and are surrounded by co-residents – typically people with serious mental health issues and drug and alcohol abuse. They are also vulnerable to financial, physical and sexual abuse and do not have the skills to manage abusive situations. In fact it is highly likely that they would not recognize the dangers or realize that what is happening is indeed, abuse. They are also likely to assume that any physical relationship is a demonstration of 'love' and/or 'friendship' as many people with an intellectual disability do not understand abstract concepts and find it hard to make friends.

Providing home modifications and support to families are important, but should not be a 'band aid fix' to keep people with disabilities in the family home until the carer dies. It is stated that among the first priorities (e.g. in 2014) in the scheme are the needs of ageing carers, and the people currently housed in aged care facilities. If this is to be achieved it is imperative that funding for capital works for group housing be available prior to 2013 to ensure accommodation is available by 2014. If group housing is not provided in a timely manner, we will have maintained the crisis situation in which we find ourselves now. If consensus between the states, territories and the Commonwealth is not reached, the lack of funding for specialized supported accommodation will exacerbate the desperation of affected families and their needs will once again be unmet.

Government statistics demonstrate the need for appropriate facilities as the Government has acknowledged that the 'baby-boomers' demographic means that in the next twenty years the need for specialized housing for their adult-children with intellectual disabilities will explode, as this group ages and passes away.

A universal design concept that embraces three styles of accommodation reflected in the one residential concept could be considered as a cost effective option for long-term care and support for people with severe/profound intellectual disabilities

Australians with a disability have the right to choose the living option that meets their individual needs and diverse aspirations. Unless adequate support is provided the person with a disability cannot have the Australian dream of a home, quality of life, social inclusion or long-term security to live with their friends in their local community.

Draft Recommendations 5.2 and 5.6

The process of linking families to information and supports and the portability of funded support across states will definitely be of assistance to the health and well-being of families. For many families the sources of information to assist people with an intellectual disability can in many cases be limited to that provided by unpaid carers, caring support groups and medical information. Regional family carer support groups funded by the Federal Government would link families, offer peer support and empower families to take control.

Whilst we agree that natural (family??) supports must be considered, the role of unpaid carers must be recognized and their limitations considered. Carers are ageing and are themselves in need of support. This key point must be considered when transitional planning for appropriate suitable supported accommodation for their adult sons and daughters is undertaken.

The Productivity Commission needs to acknowledge the contribution our ageing carers have made to society. Carers cannot be expected to provide 24-hour care for their adult-children in the family home until a health crisis or death. The Government needs to be proactive in providing alternate care and housing, not re-acting when the carer dies. Assessment of carers and their families in a person-centred and family focused framework should not just be desirable, it is essential.

Draft Recommendation 5.4, 5.5, 5.7 and 5.8

We agree with the assessment being carried out by independent assessors.

We agree that the NDIS should reassess peoples' needs for funded support, with a focus on key transition points in their lives.

The Productivity Commission Report has not as yet spelled out clearly what tools, monitoring or implementation will be included in the package. Carers hope that the tools will include attendant care, aids and equipment, home care and home modifications (as required). It is unclear whether there will be a financial cap for each individual or if the individual's needs will be met unconditionally.

Draft recommendation 6.1

CLA supports individualized funding, as it will:

- provide choice to the user and hence more effective service providers
- shift power to the people with a disability and their families
- where the person with a disability is allowed to have the money paid directly into a bank account, support/monitoring needs to be provided to avoid mismanagement or exploitation.

Draft recommendation 6.5

CLA considers that the discounting of the individual's budget by 20% to be unfair if a relative is the support person. If a parent or sibling demonstrates due diligence and appropriate use of funds, the individual should not be financially disadvantaged. The budget cut may discourage an individual from using relatives to provide support.

Draft Recommendation 8.3

We agree that the NDIS should develop and implement a quality framework for Disability Providers. Strict accountability, transparency and best practice are essential. As parents and carers we cannot afford to have more of the same inconsistencies as apply now in our current system.

Establishing an innovation fund that agencies would use for developing and /or trialing novel approaches to disability service provision is an option but needs to be monitored. Our suggestion would be to ask for submissions, then fund the most successful to develop The system—which all could then use.

Draft Recommendation 9.1

CLA would like to see this recommendation not just for Indigenous people, but also extended to small not-for-profit groups that are working towards improving outcomes for people with a disability and their carers. The principal of fostering 'communities that care' to assist families is a partnership that can often achieve the goal of giving people with a disability quality of life and care. Showing leadership in using people's skills in their own local communities can play a major role in fostering social inclusion for all Australians.

Draft Recommendation 17.1

Whilst we understand the reasons for the time line for the NDIS implementation, and the need for prioritization for newly diagnosed people and aged carers, we would stress that the need for services such as respite and specialized accommodation will have reached crisis point by the national roll out. This is because there has been a marked decrease in the numbers of people with a profound disability currently residing in specialist accommodation (e.g. 9.65% in 1981 to 2.5% in 2003). Thus 84% of people with a profound disability still live at home, and the population is ageing. Having middle-aged

people with a disability still living at home with an ageing carer, propped up with a support package is not always the most appropriate solution. As the carer ages and develops health problems, the actual needs of the individual with a disability may not be met as well as in previous years. If an ageing carer is not effectively monitored by family or friends, there can be an ongoing decline in the health and welfare of both carer and son/daughter. There needs to be an interim solution for this urgent need now, otherwise the problem will become insurmountable.

Information Request – Chapter 4

The Mobility Allowance and Child Disability Allowance can be considered as payments for the support of people with a disability and hence could be added to the individual's package. However, the Carer Payment and Carer Supplement are definitely not direct payments for the support of the individual. They are compensation for loss of income and for direct costs the carer has as a result of the caring role. Redirecting these payments to the individual could encourage unpaid carers to reduce their role and hence place further costs on the scheme. Where a carer is unable to participate in the work force due to their role of caring, there should be an added allowance to give financial security to that family.

Draft recommendation 17.4

In the period leading up to the full introduction of the NDIS, the Australian government needs to supplement funding under the NDA to reduce some of the worst rationing of support services.

CLA would like to strongly suggest that the Productivity Commission address:

- the urgent unmet needs of ageing carers to enable them to make accommodation plans for their middle aged sons/daughters before the carers become ill or die. Relief for parents/carers who provide 24/7 care must be a top priority
- the urgent need for respite care options to meet family needs.
- the need for regional support carer networks
- the need for early intervention support when the individual's health needs change
- aids and equipment and home modification
- transport costs for people who have to use taxis
- financial assistance to carers who are unable to work
- recreational opportunities both for the person with a disability and their carer
- employment opportunities for the person with a disability

If the service waiting lists for the above are not addressed first the NDIS will battle to meet the crises and to provide a quality service to all Australians with a disability and their carers into the future.

CLA looks to the Productivity Commission to find a solution to this crisis before 2020.

Australian citizens with a disability and their carers have a right to dignity and equality.