



LIVING WITH CHOICE

Community Lifestyle Accommodation LTD

[www.cla-ltd.org](http://www.cla-ltd.org)

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Submission from Community Lifestyle Accommodation LTD (CLA) in response to the current 2019 review of the NDIS Act and the new NDIS Participant Service Guarantee

### Who we are

CLA is a grass roots, community-based organisation on the Mornington Peninsula that has risen to respond to the needs of Carers and their sons and daughters with an intellectual disability.

We are a not for profit entity, a Company Ltd by Guarantee with Deductible Gift Recipient (DGR) status, a dedicated group of parents and skilled volunteers who joined together in Nov 2010 to address the critical need to provide suitable supported accommodation options for our middle-aged sons and daughters before their ageing parents/carers died. After intensive lobbying CLA received some funding from community and service organisations, the majority coming from the State Government Transition Support Program (TSP) to hire a Carer Information Support Advocate who has been working 3 days a week. Our worker is presently run off her feet assisting families with NDIS pre-planning, attending NDIS planning and re-view meeting, assisting participants and families with issues associated with implementing their NDIS package

**The NDIS is a significant and enduring achievement, it has changed the way people with a disability can access support and services to meet their reasonable & necessary needs. At the same time it has highlighted the urgent need to create sufficient & appropriate housing options to meet the urgent needs of older people with severe/profound intellectual disability still living at home with ageing parents/carers. Unfortunately, in the current market, suitable housing options are seldom available for individuals with severe/profound intellectual disability.**

### Transition to the NDIS –Housing Crisis a Major Issue

Older parents/carers initially felt the NDIS would cover housing for their older sons and daughters with severe/profound intellectual disability, especially those people whose names were on the Disability Support Register (DSR) for over 20 years. A promise made when the NDIS was introduced that nobody would be worse off with the introduction of the NDIS” this has not been the case for 94% of people, many with severe/profound intellectual disability who had their name on the DSR, now under NDIS they will not receive a Specialist Disability Accommodation allocation (SDA). This has created a crisis situation for those older people with a disability who will not be part of the 6% of Australians with disability that will qualify for SDA. This is particularly so for those with a severe/profound intellectual disability but who don't have an ambulatory problem. For this cohort the only practical avenue for supported housing is social/affordable housing, which currently has an extremely long waiting list and what is available in many cases does not satisfy the needs of the participant. Additionally, a high percentage of the participants who have an intellectual disability and are aged 40 plus years have lived their whole life with a carer in attendance (either a family member or a carer at their SDS / day activity centre) and hence have become institutionalized. Therefore, accommodation in social housing which is designed for independent living and consequently with low on site support will not provide the necessary safety and environment for this cohort.

The media recently highlighted the number of people being relinquished into State care due to overburdened parents not having a housing option available to place their person in accommodation

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CLA's comments below target the cohort of people who seem to have been forgotten by COAG, Government and NDIA. Older NDIS participant's with severe/profound intellectual disability needing support in all core areas that were on the State Disability Support Register (DSR) prior to the NDIS & now are still living at home with ageing parents. Social housing, private rental or modifying a family home till the parent dies is not the answer. The individual will have a support package but will still have to live at home till the parent dies?

**Constructive Housing Strategy needed now, we acknowledge this review is addressing some of our listed points.**

- **The Productivity Commissions report stated that one of the most disadvantaged groups was the group of people who are now cared for by ageing carers. However, neglect of the housing shortage has meant for many, if not most, individuals still living with ageing carers will need to continue to live at home until housing becomes available**
- Suggestion improve the current framework to give all people with extreme Functional Impairment and high support /complex needs real choice to have a home of their own ASAP
- Clear guidelines & criteria for participants and their families to follow to apply for SDA , and the current delays and process takes too long to confirm eligibility
- These delays and uncertainty are taking a toll on ageing parents, who need to place their person before they die
- Their needs to be a transparent process to determine SDA eligibility and funding allocation
- Planners and support coordinators to be trained in the application of NDIS rules, particularly rule 3.5 criteria (what is reasonable and necessary), as some have little understanding of SDA
- There needs to be a central point of contact (available to participants/parents /carers at the Agency for SDA queries
- Participants told SDA funding cannot be confirmed without a reference to an existing SDA dwelling. (Not always possible )
- Developers require confirmation from participants on availability of SDA for them to confidently build. They need to be able to fill the vacancy
- Participants with severe/profound intellectual disability that need modified housing are being decimated as they are still living at home and not considered homeless!!!
- Consider an additional category to assist older people still living at home with ageing carers to move out of home. This would encourage developers to build innovative housing options as the cost would be less than building for robust or high physical standard.
- Encourage innovative models where SDA funding and Non SDA funded people can live

The DRC, COAG, Ministers and the Agency need to take the lead and deliver SDA housing options to all who meet the criteria. Otherwise we will have lifelong ageing carers dying without ever seeing their loved son or daughter in a home of their own.

**List of issues** that have been brought up before by many families / advocacy organisations around the NDIS, but for some reason nothing has been done to rectify the issues facing the individual and

their parents/carers. CLA is hoping this review of the NDIS Act & the new NDIS Participant Service Guarantee (Tune report) will force changes to be made to the NDIS process it needs to be simple and user friendly. Clear guidelines, accountability and measured outcomes for the individual. Current Information should be sent to families, medical people and Allied Health Therapists Support Coordinators to understand for people with complex needs it is important to seek advice from medical and Allied Health Therapist involved in the person's life.

Currently the role of Support Coordinators is to advise the participant/carer the details of a service provider who can provide the service required. It is then up to the participant/carer to make the appointment etc. and sign the service agreement. This is onerous and for some a task beyond their skills. The focus should be for the Support Coordinator to do the bulk of the work, not leave it up to participants and their carers.

Support Coordinators to pass on NDIS language for the professionals and therapists to incorporate into their reports to the NDIA

Lack of skilled support staff for participants with high complex support needs

- Importance of a draft NDIS plan for the individual and their carer to view before a decision is made
- Flexible funds in the plan for the individual to use as needed
- Some individuals will need ongoing help with preparing plans and undertaking plan reviews
- LAC's -hit and miss to get a good plan result
- Individuals with complex needs advisable to go straight to a senior planner at a local NDIS office
- LAC's must take notice of carers , they are the experts and have the lived experience
- Longer plans with a backup in case of an emergencies
- Small requests must be able to be changed in a plan without a full review
- Review process takes too long to finalise and sometimes the person runs out of money and their service stop till the new plan is installed
- Urgent on -going support for some families especially ageing parents who are at breaking point , struggling to deal with their own health issues plus supporting several members in the one household.
- Need for case managers for some participants and their families.
- Grandparents caring for an adult with a disability , their partner and their grandchildren
- Some individuals waiting months for decisions on assistive technology items / modify bathrooms etc
- Transport subsidy not adequate for people with severe/profound intellectual disability who cannot go out on their own or use public transport due to their complex needs.
- Supported Housing options for adults still living in the family home with severe/profound intellectual disability and associated disabilities. No options for ageing parents to place them into care before they die. Reasonable and Necessary support needs must be considered for this cohort who have saved the governments billions over a lifetime. Urgent to be addressed immediately. Band –aid fixes not acceptable as the Mornington Peninsula has a high ageing population and as ageing parents die this cohort will be homeless. (Where will they be placed?)

- The lengthy process to apply for a SDA allocation must be simplified & more trained support coordinators who can write a housing report for the person seeking a SDA allocation. People that were on the Disability Support Register for supported accommodation prior to NDIS must be allocated a SDA package as a priority. Their needs were classed as urgent then and some are now in their 50's -60's +. **Surely every person in Australia deserves the right to choose when they leave home, where they live and with whom they live?**
- The process for producing a SIL quotation for people with complex needs entering supported accommodation to have this vital support included in the participants plan is not very transparent. There is not enough information on gaining a SIL package for individuals going into supported accommodation to ensure that an adequate level of care is provided. Real need for support to be provided in their SIL package for dependent resident who may not be able to go out of the house every day from 9am-3pm. It is their home and support should be available on a needs basis. Especially for older people with complex needs. Accessing SIL packages is taking too long to process for the individual, plus if parents choose they should be involved in the process.

While participants have advocates to go guide them through the NDIS process, who is advocating for ageing carers to find homes for their dependents?

**CLA through necessity have had to become a strong voice for our local carer's and also for their sons and daughters. As we all approach this review with hope, we are seeking a strong action plan immediately not just words on paper to assist older people with severe/profound intellectual disability still living at home with ageing parents/carer's ,rightly have a place to call home**

We thank the Government for giving us the opportunity to submit this paper

Yours sincerely

Marie Hell  
Secretary CLA LTD  
Mother to a 47 year old son with Tuberous Sclerosis