

10th September 2021

**Submission for the consultation paper “An Ordinary Life at Home”**

To whom it may concern

I write this submission to the **NDIS Home and Living consultation** on behalf of the people and families that Community Living Project (CLP) support.

CLP has worked in close partnership with families since 1984 to build opportunities for a good life for their family member who is living with a disability. We work with one person at a time to craft individualised support in a way that ensures each person (and their family) has as much control as possible over all aspects of their life.

We believe people with disability should belong to and participate in community life. This means their interests are best served when they are supported to grow up in a family, go to their local school, participate in community activities with their peers, as an adult have a home of their own, maintain strong relationships with family and friends, work and participate in community life and have their rights as citizens protected.

People with disability are highly vulnerable to being excluded from ordinary community life. This happens through segregated experiences, which deprive people of opportunities to have the rich range of relationships and experiences that most people take for granted, and congregated activities that stifle opportunities for the individual to be included in everyday life.

Having a stable **home** can open doors to community and growth in capacity and connection. Families and people we support report that NDIS planners and LACs talk about securing a ‘house’ or ‘accommodation’, rather than what it might take to have a home of their own. Only a ‘home’, as it means in the full and richest sense, can offer the comfort and security most people take for granted.

Some people with disability make the move to live in their own home with the assistance of family or friends while others rely on a service or paid support to help them. Organisations and workers play an important role both in what they do to assist a person and also what they don’t do. A particular challenge is creating and maintaining a home when it is also a workplace. CLP has developed a model of Self-directed Support that embraces Family Leadership. This model uses the ‘Seven Steps to self-direction’ developed by Griffith University under the Innovative Workforce Fund (see <http://pearl.staffingoptions.com.au/Article/GetResourceFile/327> ). Self-directed Support builds the capacity and confidence of the person with a disability, their family and their group of workers to engage with and support the natural authority and wisdom of the family. The mission is to create the ‘right relationship’ and working culture between the person, family and agencies to facilitate support for decision making that is acting in the person’s best interest, thus safeguarding the person from harm while building opportunities for a meaningful life.



Specific feedback that CLP families would like to strongly convey regarding home and living options with the current arrangements under the NDIS is outlined below.

- **Options to live in your own home in the community**

- NDIS is not actively supporting individual home ownership (for people who do not have a physical disability). There is discrepancy in that people with an intellectual disability who have bought their own home in the community experience financial disadvantage compared to individuals with a similar level of need who live in SIL funded support. This is in terms of both payment of household utilities (including rates, electricity, water usage, maintenance costs), as well as in terms of funding provided for activities of daily living and community access.
- This discrepancy leads to a sense of only having access to a 'second best choice' of what is possible for the person's vision of home, evidenced by people being required to fit into the narrow NDIS-defined parameter of home, versus holding onto a strong, lifelong commitment of inclusion and creating what the person/family aspire to achieve.
- Support is inconsistent and is experienced as 'dots': pockets of good support may be delivered, but often the support 'dots' are not joined to create an effective flow of good support and therefore a good life. This erratic support means there is a constant need for the person's informal network to fill the gaps to sustain and create a flow of consistent support. For many parents/loved ones this situation leads to a never-ending experience of feeling overwhelmed, exhausted and frightened for the person's future.
- There needs to be a disruption of traditionally held sector views around what a good life actually means and what it takes to achieve it, and for traditional models of support to change in order to really implement changes that the NDIS aspire to.
- Parent feedback re their experience: support to find meaningful options for "home" has been very limited and is difficult to access. Currently accurate, helpful information is difficult to access from NDIS and the sector in general. Other parents are the best source of information.
- There is very limited information available about how to even access *the process* for looking for and achieving a place to call home.
- There is uncertainty regarding how to make decisions around home options and then what to do with these decisions. It is also very hard to 'unravel' the steps that one has taken along the way (eg a change of mind or to make another alternate decision).
- Parents have had to work very hard for their children not to be institutionalised. One mother described her daughter's previous experience in a large accommodation setting as being 'an inmate'.

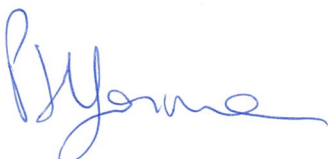
- **Planning process and Goals**

- Goals under the NDIS still seem to be capped within short timeframes. There is a need to think beyond short term, functional goals and plan for a good life.
- Goals in an NDIS plan have a sense of rigidity. As a young adult, changes in one's life are common. The plan needs to accommodate these changes.
- There needs to be much greater flexibility of NDIS plan funds which are currently still rigid.
- Do the planners really listen to how families are articulating the life vision for their son/daughter to work out what the goals are? For a person without disabilities – does one articulate set 'goals' in our life (short term goals and long term goals) to shape how we live our life?

- Many parents are worn out with looking after the son/daughter on a daily or continuous cycle to fully work at the goals. There is often no consideration of this by planners.
  - There is hesitancy on accepting 2-3 year NDIS plans by a young person. While a person and family take up the offer of a longer plan because the planning meeting is regarded as intrusive, when the plan does not enable the person to access the support and services they require, the person/family see the whole planning process and meeting as a total waste of time and emotion.
- **Informal networks in building safe communities**
    - A parent shared that it is a leap of faith to trust that service providers will do the right thing. It is critical to have greater access to someone who can consistently advocate for the person over the long term.
    - A parent shared her vision for her son into the future – there is a transition process for the person in his own home, settling into the local neighbourhood area (so as not to disrupt too much of the person’s lifestyle) and the person mixing with others without disabilities. How do we build and strengthen neighbourhood connection? Often people are keen to connect with others but do not know how to start or be involved.
    - How does a community connect with people who are vulnerable – a parent shared her experience of approaching workers from an accommodation service to ask if the people with disabilities living in the group home house require any neighbourly assistance – she was informed by the staff that there can be no contact with neighbours for privacy reasons.
    - Planning for the future needs to take into consideration that circumstances can change overnight and planning, whilst offering a sense of surety, also needs the flexibility to manage life’s many unknowns and unplanned changes.
  - **ILO development**
    - Families believe the NDIA should take on responsibility to pass on information through training about the different ILO options to families and also to the new ILO support coordinators in the community, to ensure everyone is working in the same way.

“Home” for the people we support is a sanctuary, a place where they feel safe and secure. Their home is a place that they control - control over the things they own and use and the people who come and go. It is a place of personal comfort and a space that family and friends visit. It is the place where people can get to know them best as they can observe and witness for themselves what matters most to that person.

It is imperative that the NDIS demonstrate their understanding and strong deliberation over the support people require to live in their own home... to live a good life.



**Prue Gorman**  
Executive Officer

