

15 November 2022

The Honourable Ronald Sackville AO QC
Chair - Royal Commission into Violence, Abuse,
Neglect and Exploitation of People with Disability
GPO Box 1422
BRISBANE Qld 4001

Dear Commissioner


On behalf of Life Without Barriers, I present a submission to the Royal Commission. Our submission covers the area of new and innovative housing options that we are developing in partnership with people with disability who use our services.

As stated in the submission, Life Without Barriers is committed to addressing this issue, both within our organisation's activities and as a public policy matter.

We trust that the submission is of use to the Commission's work.

I ask that you please contact Mr Chris Chippendale, Executive Lead Disability Engagement on 0423 025 035 or at chris.chippendale@lwb.org.au for any further information.

Yours sincerely

A handwritten signature in black ink that reads "Claire Robbs".

Claire Robbs
Chief Executive

Submission on housing choices for people with disability for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

This submission describes how new and innovative housing options are being developed by Life Without Barriers (LWB), in partnership with people with disability who use our services. LWB is pleased to provide the submission to highlight the need for such new options and we stress that such options are needed for people with intellectual disability, especially for people with high needs, for whom the traditional group home model has been seen as the most contemporary model. Our submission also highlights the limited role that service providers have had to date in the history of the development of models of supported accommodation and the potential positive role that providers can now have in this area.

Historical models of support, such as the group home, are the product of community sentiment, government policy and funding parameters at particular points in time. Thus, providers like LWB have operated models developed and endorsed by the community and government and have had limited ability to highlight our experiences and the views of people we support in the development of options and models. LWB is optimistic that through the NDIS, and in the Royal Commission's deliberations, we will have the opportunity to provide constructive input in this area.

Our Submission covers the following areas:

- 1. History of housing and support for people with intellectual disability in Australia**
- 2. LWB's current supported accommodation services**
- 3. LWB's Home and Living Project**
- 4. Considerations for the Royal Commission**

1. History of housing and support for people with intellectual disability in Australia¹ ***Institutional model of housing and service provision***

Until the 1980s, most people with disability with moderate to high support needs lived in institutions operated by governments, churches or charities. These institutions were often located in rural areas (such as Stockton and Peat Island in NSW, Ararat in Victoria, and Claremont in WA) and were designed to provide a 'nice' environment for a person's care, but also had the effect of separating people with disability from their communities.

These settings co-located many people with disability and were generally organised around staff and organisational processes and priorities. They delivered support and services under a paternalistic approach. Institutions operated by churches, charities and benevolent authorities were subject to very little regulation, while at the other end of the spectrum, institutions operated by governments were subject to rigid bureaucratic control.

The beginnings of a rights-based approach to service provision

In the 1960s and 70s people with disability and their advocates began to voice concerns about a lack of rights and the failings of the institutional model. The disability rights movement contributed

¹ Refer to attached Appendix "Towards an Inclusive future for people with disability in Australia: Perspectives from history, theory and Policy" Lesley Chenoweth AO and Danielle Stehlik.

to the *Declaration on the Rights of Disabled Persons* on 9 December 1975² and the shift towards a more rights-based approach to service provision.

This was followed by the *Convention on the Rights of the Persons with Disabilities* which was adopted by the United Nations more than 30 years later on 13 December 2006³.

These universal human rights instruments make clear that people with disability have the same rights as everyone else, including the right to have the same choices about:

- living in and being part of local communities
- where they live, and who they live with
- not living in a particular place like a hostel if they do not want to
- access to the same range of services that other people can choose from⁴

Community-based models of disability housing developed in the 1980s and 1990s were designed to replace institutional living arrangements. However, these options were generally still in the form of shared living, just on a much smaller scale.

After deinstitutionalisation, the group home became the standard community-based model. It generally consists of 4-8 people with disability in ordinary homes, either leased or purchased in the general market, or purpose built in clusters by state governments or non-government providers. Under this model, shared 24/7 supports are provided by paid staff.

The shift to the group home model was considered a meaningful improvement compared to the institutional model. The group home model delivered benefits for people with disability in wellbeing, leisure activities, social interaction and greater opportunity to make choices. However, people with disability and their advocates continue to raise concerns that the group home model is far from ideal, and still presents barriers for many people.

Non-government organisations like LWB generally commenced operation in the latter part of the twentieth century and were often started by groups of families who sought non-institutionalised support for family members. Over time, given most of the housing support was designed and funded by governments, the models of support that providers offered largely continued to be restricted to the parameters set by government. In short, this means that the group home model remains the basis for the provision of accommodation.

Supported Independent Living and the NDIS

Under the NDIS, people with disability receive individual funding packages allowing choice and control over their supports, including where and how they live. This may take the form of living in a privately purchased or rented home while receiving in-home supports from a service provider of their choice on an 'as needs basis'. For people with high and complex support needs, this may entail receiving funding for Specialist Disability Accommodation (SDA) that can provide a home that is purpose built to meet their needs.

²United Nations (1975) *Declaration on the Rights of Disabled Persons*, (<https://www.ohchr.org/en/instruments-mechanisms/instruments/declaration-rights-disabled-persons>), accessed on 15 September 2022.

³ United Nations (2022) *Conventions On The Rights of Persons With Disabilities* (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>), accessed on 12 September 2022.

⁴Australian Human Rights Commission (2022), *Human Rights* (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/345108/easy-read-un-convention.pdf), accessed 15 September 2022.

The core benefit of the individualised approach to housing is that it potentially provides a wider range of options, including bespoke homes and living arrangements, (shared or individual), that meet their needs and individual preferences.

However, the potential for greater self-determination is not being fully realised for many people with disability in Australia. Many people continue to live in group homes where they may not feel like they have real control over their home environment.

While many people with disability and their advocates voice strong concerns about the group home model, the evidence is thin and mixed as to whether the supported independent living options currently available present better outcomes for people with disability. There is some evidence that for people with mild to moderate disability, supported independent living provides them with more wellbeing and control over their lives, however the picture is currently unclear for people with high and complex support needs.

Some scholars, such as Professor Christine Bigby⁵ and advocates argue that for people with high and complex needs, the shared living aspect of the group home model is not the main barrier, rather it is the culture and practices within the home that make the difference. In essence Professor Bigby suggests that the group home model may be a positive option that some people with disability may choose.

It is clear that in respect of home and living options, the rights, aspirations, and expectations of many people with disability are yet to be fully realised. We believe that through the NDIS, existing models and approaches need to change so that people with disability are able to determine for themselves where, how and with whom they live. In short, the models now available, with some exceptions such as individualised Living Options (ILO), do not meet contemporary community expectations.

2. LWB's current supported accommodation services

Like similar providers, LWB operates a number of Supported Independent Living (SIL) services – and these are generally group home services. Some residents have lived in these homes for many years. LWB currently operates 440 homes for around 1,400 people across Australia. Around 180 of these homes were transferred to LWB from the NSW and Victorian governments.

These properties often support four or five people and while LWB strives to provide the best service possible, including Active Support⁶. Most of our properties are rented or owned by state governments. Some of the properties may need upgrading or renovation to make them more suitable. Most of the people in these settings are entitled to Specialist Disability Accommodation funding, but if a person we support moves to alternative accommodation that more closely aligns to the life they aspire to, this entitlement will be tested by a new assessment process that is opaque and difficult to navigate. This uncertainty creates a barrier to people feeling confident to change their existing arrangements.

The overwhelming majority of people we support in these services have intellectual disability and many people have complex and high support needs. LWB is also partnering with La Trobe University on a joint Active Support Implementation and Research Project that is aimed at further empowering people in our group homes.

3. LWB's Home and Living Project

⁵ Bigby, C & Bould, E. (2017) *Guide to Group Homes. Evidence about what makes the most difference to the quality of Group Homes*. Centre for Applied Disability Research. Available at www.cadr.org.au

⁶ La Trobe University (2022) *La Trobe University*, (<https://www.latrobe.edu.au/lids/research/effective-disability-services>), accessed 5 October 2022.

In 2020, LWB launched Strategy 2025⁷, our five-year plan to deliver great services, break down systemic barriers and favourably impact the lives of future generations. We recognise that a core element of turning these commitments into action, is trialling new and innovative approaches to co-designing services with the people we support.

Considering the evolution of housing for people with disability outlined above, and in recognition that current models continue to fall short of meeting the needs, aspirations, and rights of many people with disability, LWB has embarked on a new trial to provide contemporary home & living options and choices for people living with disability.

The objective of our new home and living strategy is:

Providing new, contemporary, housing options that facilitate meaningful connections, reflect individual choices, and are financially sustainable.

In doing so, we aim to reinvigorate the current 'Supported Independent Living' model so that it can fulfill the NDIS promise to better meet the choices and rights of people with disability. People with intellectual disability, through their home and living arrangements, need to be able to form valued relationships, have security of housing, access more life choices, and be more fully involved in and contribute to their communities.

This new approach is guided by rights-based principles and places the views and aspirations of people with disability at the centre of how, why, and what we are doing in accommodation. This is in line with the principle 'nothing about us, without us'.

The trial is being undertaken in the context of the NDIS and we recognise that as a provider, we work at the direction of participants. As such, discussions on goals, options and choices occur at the planning stage of the NDIS process. However, at this stage of the development of the NDIS, it is clear that people who have lived in group homes for many years have not had the opportunity to choose new and innovative options.

We recognise that LWB is not an independent advisor and may have a conflict of interest in working with the people we support in choosing 'new LWB options'. We fully appreciate that the people we support can and should have independent advice in their engagement with us. We address this issue in more detail below.

In embarking on this new strategy, and sharing it with the Commission, we hope that it presents a model that could be integrated into the NDIS and adopted across the sector. Further, LWB hopes it may provide a further step in the evolution towards housing for people with disability that upholds their rights, safety, and wellbeing.

Progress towards meeting the objectives of the home and living strategy is driven by a Working Group established from the LWB Board. This group also includes external representatives.

LWB has commenced a consultation process with the 1,400 people in LWB supported independent living services to understand what home and living options would best suit them. The intention is to facilitate supporting them to achieve their housing aspirations so that they can live in fit for purpose homes that meet their needs. New services also need to be staffed in a way that is directed by participants and the service provision must also be financially sustainable.

⁷ Strategy 2025 (2020) *Life Without Barriers*, (<https://www.lwb.org.au/news/life-without-barriers-launches-strategy-2025>), accessed 5 October 2022.

The process is fundamentally aimed at empowering people so that they are not just passive recipients of housing. We recognise that we, as the SIL provider, do not know the best options for people. The people we support are the experts on their own lives and aspirations. LWB's aim is to help clients gain control over their lives and attain the aspiration they choose. We also recognise that change needs to be all inclusive and wide ranging.

Our program is prioritising people that LWB supports who live in private rental stock, which do not provide secure tenancies and which mostly pre-date the NDIS and its SDA provisions. The program also prioritises people in large group homes (usually state government owned properties) and recognises that many people require 'robust'⁸ housing due to their needs. It is generally accepted that at this time, there is a dearth of purpose designed robust housing available for people with disability.

Generally, consultation commences with a preliminary meeting to discuss a participant's existing NDIS plan and how LWB can better support the person with their goals in respect of their home and living arrangements. We have found that many people do not have specific or detailed home and living goals in their plans, but that situation does not preclude involvement in the program.

Engagement is entirely voluntary and involves the person's family and other support people as directed by participants. Informed consent is sought and usually involves the provision of significant information prior to commencing substantive discussions.

The discussions commence about preferred living options from the perspective of individual aspirations, rather than what options are available. Participants may choose who they would like to have accompanying them and often people choose to be accompanied by a support worker and this initial dialogue may involve several short meetings.

The approach we are undertaking asks people to consider:

- who they wish to live with
- where they wish to live
- the design and size of their dwelling
- how they can utilise their SDA eligibility (or likely SDA eligibility if it isn't currently included in a person's plan) to secure a purpose-built property that meets their needs, and
- how they may fully benefit from addressing any conflicts of interest inherent in the management of their housing and support services under the NDIS.

We assist people with disability link with SDA housing providers that are separate from LWB. They may also wish to choose alternative support providers or other options such as Individualised Living Options (ILO) rather than continuing to access LWB services.

At the time of writing (November 2022), LWB has formally engaged with 85 participants. A short summary of their expressed wishes is:

- 70 people indicated that they wish to explore SDA eligibility and new accommodation
- 5 people are exploring other options such as ILOs
- 7 people have requested further information and support to consider their options
- 3 people wish to remain in their current setting

The below case studies show how people can choose to be involved in the program and how the simple process of discussion and information provision can lead to positive outcomes.

⁸ Robust is a design category of the Specialist Disability Accommodation (SDA) [provisions of the NDIS.

Case Study 1 - EH and TA

LWB clients, EH and TA, were given two weeks' notice to leave their rented home after many years. Due to a difficult rental market, LWB staff in conjunction with EH and TA and their families had difficulty in finding appropriate accommodation. Because of the urgency the new house located was considered adequate, but lacked the amenities and design required to best support EH and TA.

It was clear that EH and TA required a long-term option that would better meet their ongoing needs. Because of this, EH and TA were keen to join LWB's Home and Living project, which commenced with discussing their housing goals and aspirations.

As EH and TA are nonverbal and have low comprehension for detailed conversations, the approach to goal setting was extremely flexible. Their supporting team and families assisted with formulating long-term housing goals.

At each step of the process, consent was obtained through the familial guardians. During the client conversations members of LWB staff were present with EH and TA, as their family requested that existing staff assist. Having supported EH and TA over many years, the staff had intimate knowledge of the needs of EH and TA.

With approval from the family, it was decided that EH and TA would pursue Specialist Disability Accommodation funding to best address their long-term needs. The supporting team, family, and Support Coordinator linked EH and TA with an SDA provider that facilitated effective choice and control through the process and final arrangements to build a new home are underway.

From our initial engagement, we make the following observations:

- There is a need to constantly address concerns from staff and families. It is important to start with the choices of the person with disability and build processes around this, rather than use the need to 'manage risks' as the starting point.
- We recognise that sometimes it can be difficult for families and support staff to accept their loved one or a person they support taking on risks that they do not agree with.
- Several residents have raised that there is a lack of alternative supported independent accommodation options, such as smaller settings or located in more favourable areas, for people with disability.
- Several respondents stated that current provisions, such as Specialist Disability Accommodation and Supported Independent Living under the NDIS can be difficult to access and may limit choices of the type of accommodation for some people unless people fully understand the details and are able to 'navigate the system'.

Case Study 2 – OS

OS, who has mild intellectual disability, initially accessed LWB supported living due to a history of difficult family relationships and drug use. These factors led to an independent and intelligent person declining in their abilities, resulting in the need for ongoing support. At the time of moving to LWB, OS reported a desire to live without support, with goals of obtaining paid employment, a driver's licence and living independently.

Because of limited options OS needed to move away from family/friends. While this may have been ideal at first to enable psychological and physiological recovery, it eventually became an issue of discontent for OS.

Recently, the LWB Home and Living team discussed potential housing options with OS who enthusiastically welcomed this opportunity. OS had not had that opportunity through the NDIS or elsewhere.

OS provided consent and requested that only their mother attend the 'client conversation'. OS was interested in the Individualised Living Options model due to a desire to live independently (without sharing with others). OS advised they knew their capabilities were stronger than they were currently displaying and wanted to live in an environment where they could grow skills and independence.

Throughout continued conversations, OS indicated a fear of moving too quickly into an ILO model and losing current supports. Instead, with the assistance of the Support Coordinator, an alternative accommodation was identified closer to family and friends. This housing model was a building of units with a shared sleep over, allowing for OS to still receive some regular and on-call supports, but live alone in a private unit.

The new support arrangements are not provided by LWB, with OS changing both housing and support provider. LWB views OS moving to another provider through our Home and Living project as a major success.

Our case studies and experience highlights:

- there is a real need to engage with and listen to people with intellectual disability
- many people who have been long term residents in group homes have not had the opportunity to express their wishes about their housing options
- the starting point to address this issue is simple – it is about providing information and engaging in a conversation
- providers are able to address real and perceived conflicts in this area

4. Considerations for the Royal Commission

There are several considerations we wish to highlight to the Disability Royal Commission:

Why we are undertaking this project

As stated, this process should preferably be undertaken external to the current SIL provider. However, as a SIL provider, LWB has commenced the process due to:

- the NDIS not yet being mature - the system does not currently have the capacity to address this issue in respect of both policy settings and capability in the planning process.
- Consequently, the people LWB (and other providers) support are not able to access contemporary supports based on their true wishes at this time and we believe that this is unfair.
- The people we support in SIL services overwhelmingly have asked us to support them in this process as they value the input from their support staff and our wider organisation.

Managing Conflicts of Interest

The desire and aspiration for independence among our clients is substantial. We recognise that LWB should not be offering people choices that are limited to our organisation only or choices that could be unduly influenced by apparent self interest in maintaining our services. Therefore, we have built a number of safeguards into our processes, including ensuring:

- that the initial engagement with LWB is done by staff separate from the participants' usual support staff
- that all information provided genuinely facilitates external choices engaging with families and advocates, and
- that the process is aligned with participants' NDIS plans ensuring that Support Coordinators are involved.

The need for Information

Given the complexity of the NDIS Home and Living processes, including the SDA provisions, it is evident that participants often need detailed information and support to engage in choosing options. This support must include:

- specialist Support Coordination, that is, with expertise in supporting people with intellectual disability and in respect of home and living options
- supported decision making assistance.

Contributions by Service Providers

As stated, LWB believes that service providers have considerable experience and resources to contribute to addressing this issue. This is supported by the majority of involved in our work. Further, most participants have stated that they would like us to assist them understand options and assist them with managing the process. As a large service provider, we believe we also have an obligation to contribute to improving options for people with disability in ways that are relevant and appropriate.

SDA Challenges

There are significant challenges with the process to obtain eligibility for Specialist Disability Accommodation funding, including:

- unclear eligibility criteria
- unclear criteria for approval at the various levels of SDA eligibility
- inconsistent approvals for people with the same/similar needs. This is especially frustrating for individuals, families, staff and providers that know the participants well and where SIL funding and approvals clearly indicate what level of SDA approval should be given, and
- lengthy timeframes for approvals.

NDIS Complexity and Maturity

The NDIS is the greatest reform in disability services in recent times. The scheme has strengthened as more participants have joined and new providers have entered the market. The way the scheme was introduced, together with its complexity, has impeded the disability community, (including the NDIA/government) from being able to ensure a strong focus on the home and living options that are required for people with intellectual disability with high and complex needs. LWB believes there must be a collaborative response between people with disability and their support networks, government, and providers to address this issue.