



Action for More Independence & Dignity in Accommodation

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Advocacy, Self Advocacy, Rights, Accessibility, & Community Living for People with a Disability

NDIS Home and Living Consultation – An Ordinary Life at Home

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Action for More Independence and Dignity in Accommodation (AMIDA) supports people with disability as valued members of our community. AMIDA recognises that people with disability contribute to and develop our community.

AMIDA acknowledges that people with disability have a right to a choice of who they live with and where they live. Further, people with disability have a right to good quality housing which is accessible, affordable and non-institutional. People with disability have a right to live in the community with access to support to participate and have a good quality of life.

AMIDA is an independent advocacy organisation which advocates for good housing for people with disability. We provide advocacy to individuals, with priority given to people with an intellectual disability, and advocate for change in systems which prevent people from achieving good housing.

AMIDA strongly supports **The United Nations Convention on the Rights of Persons with a Disability** and works to assert these rights and community inclusion for people with a disability.

Every disabled person in Australia has different and diverse needs and no two people with disability will have the same wishes and dreams about their home, or where and who they live with, therefore it is extremely important that all living options are flexible and suit the needs of the person with disability not the service provider or the NDIS. People without a disability are able to make these choices about where they live and who they live with. People with disability need to be given the same options available to them so that they can make informed decisions and that may mean that we look at closing Group homes or SDA and providing proper housing choices in the community that meet a person's needs so they have choice and control of their own lives.

These rights are protected under **The Victorian Charter of Human Rights -**

Section 8 Recognition and equality before the law

(1) Every person has the right to recognition as a person before the law.

(2) Every person has the right to enjoy his or her human rights without discrimination.

(3) Every person is equal before the law and is entitled to the equal protection of the law without discrimination and has the right to equal and effective protection against discrimination.

(4) Measures taken for the purpose of assisting or advancing persons or groups of persons disadvantaged because of discrimination do not constitute discrimination.

Section 12 Freedom of movement

Every person lawfully within Victoria has the right to move freely within Victoria and to enter and leave it and has the freedom to choose where to live.

One of the main problems for people with disability is that they are unaware of all of the housing options or funding provided by the NDIS and NDIS planners and Support Coordinators are also not familiar with all of the options so people are often not given choice and control of their decisions, or supported decision making. This is contrary to the changing landscape of the NDIS which is founded on the tenet of 'choice and control'. In this scenario residents of an accommodation service have no one independent of support providers to assist them to even think about what this might mean. Support co-ordinators are often working for the support provider so don't direct them to alternatives, which is a direct conflict of interest. This highlights there is a problem that individuals are not getting the opportunity to seek out accommodation that is best for them.

People living in SDA have not had any choice and control about who they live with or where they live or even in some cases what supports they want. People with intellectual disability (ID) are often looked at by services as the difficult group of disability, and they have a history of being without a voice when major decisions are made about their lives. It is extremely important that more money is provided to allow for the time needed and the expertise required to ensure they are able to make their own decisions. This is often not seen as possible but with the right independent supports and time to develop relationships many more people with ID are able to make their own supported decisions about where and who they live with.

People with cognitive disabilities can and do verbally communicate their experience but sometimes they show what they are feeling via actions. These actions include displaying sadness, depression, anxiety, fear and anger and sometimes acting violently. As human beings and service users they deserve to be listened to when they communicate their unhappiness with home and support received. Disabled people in Australia have the right to be supported and housed appropriately in a way which doesn't make them unhappy and respects their preferences as expressed. When disabled residents of group homes are not listened to the consequences for them and others, they share with can be dire. People who are forced to share group homes are often harmed because service providers and funding bodies do not listen and respond by providing reasonable and necessary housing and supports.

Specialist Disability Accommodation (SDA) and Supported Independent Living (SIL)

AMIDA has had contact with people with disability who have been seeking housing, some people homeless, and have applied for vacancies for apartments or rooms advertised. During the application process when the person has stated they wish to bring their own SIL provider they have then been unsuccessful in their application.

This is extremely concerning to people who are in dire need of housing, during a global pandemic, who cannot secure housing because of their choice of provider of supports.

AMIDA notes a number of organisations have taken over the tenancy process to set up supports in a building and can discriminate over a prospective tenant's choice of SIL provider.

AMIDA asks for more regulation in the market by the NDIA over the organisations guidelines and monitoring of providers.

We note the NDIS Guidelines state:

Do you need to have the same provider for SDA and your other supports?

No. You can choose the provider you would like for each of your supports.

Your SDA provider must let you change your providers for other supports at any time.

If you want, you could choose a different SDA provider to your other supports like Supported Independent Living (SIL), personal care supports or Support Coordination. That way, you pick the supports and providers that suit you best.

AMIDA has also had reports of Robust SDA properties being built with restrictive practice in the building structure and fittings/fixtures. Restrictive practice is regulated by the Senior Practitioner in Victoria and there are clear guidelines around using the least restrictive means of providing care.

Again AMIDA asks the NDIA to take the actions of SDA providers and building companies into account for regulation and monitoring to ensure the human rights of people with disability are upheld and preserved.

Maintenance and Modifications

Maintenance and modifications for housing is often a difficult issue for people with disability. In our experience since the NDIS started many people with a disability in housing who have needed maintenance or modifications to ensure their housing is accessible and have provided OT reports with the maintenance or modification needs have been clear have faced many hurdles with the NDIS and Office of Housing or Community housing refusing to take responsibility to ensure accessible housing options. This is extremely stressful to the NDIS participant and the supports they need – we have had experience of people in wheelchairs needing to be carried upstairs to enter their home, or crawl up the stair on their own this is not safe and should never happen.

The Productivity Commission Report on the Review of the National Disability Agreement 2019 states "Unclear service boundaries also open the door for strategic behavior as the Australian, State and Territory Governments each have an incentive to use uncertainty about who should

be doing what to cost – shift from mainstream services to the NDIS and vice – versa.” AMIDA has also noticed there is no funding available to community housing providers for modifications. Residents in community housing rely on NDIS funding for modifications. If this is denied they face having to move to an appropriately accessible property. There is a national shortage of affordable and accessible housing stock, which makes this prospect extremely challenging, if not altogether impossible, depending on the modifications needed and the disability the person is living with.

Training

NDIS planners need to have more training about how a person may make choices and how these can be supported. The way planning for NDIS supports needs to be improved so that the person meeting to discuss and recommend the plan is the person who makes the decisions about what the plan includes. Too many times the person with disability spends time with a planner to organize the supports they need and when they receive their plan there are not the supports available within the plan that they need. To review a decision is a difficult process which needs to be streamlined so people have access to support for this. More funding for NDIS appeals workers.

More training for generic services about the needs of people with disability done by people with disabilities. Homeless housing services need to have more training about disability and how to engage with them.

Group Homes and Congregate Living

The current group housing model in Victoria does not offer a good quality of life for many disabled people. Through the work we do at AMIDA we have contact with many people with disability. We regularly receive reports from people who live in group homes that they have no choice about what goes on in the group home they live in. Residents of group homes have reported a lack of control over every day things such as: bedtimes, mealtimes, food choices and when people enter their bedroom (the only private space a person often has, with reports of other residents and staff regularly not knocking and barging in). Let alone have a say on where they live, who they share a house with, the staff who work in the home they live in and the agency that provides the services to the home they live in. It has been reported to AMIDA that violence, abuse, neglect and discrimination is a common occurrence these are both explicit and implicit acts, that affect the resident's health; both physical health and mental wellbeing. People often talk about the fact that they can't even control who comes in the front door. The stories we hear from residents of group homes are stories of the support provided being mainly focused on the group within the home. This work is mainly focused on daily household activities and unfortunately no priority for with little if any individual attention and care taking place.

We have and still hear stories from people who live in group homes who experience some conflict with other residents of the facility. In these instances, mealtimes are still shared, people are forced to eat together (one can only assume for convenience of the support staff) despite the animosity

and fear this leads to. People report being unhappy having been forced to be part of the group and not being given a choice as to where they eat their meal. Residents do not control the environment which can lead to maladaptive behaviours such as, a learned submissiveness as a survival strategy in some people while others may express unhappiness in aggressive ways.

Residents have reported that when key staff leave, the situation in group homes can quickly deteriorate. Staff who do listen and are guided by the preferences of residents are sometimes not supported by colleagues or management in our experience. Staff who report poor treatment of residents and advocate for them are often subtly punished, e.g. with reduced shifts. This results in very good staff being pushed out of the job. Good staff tend to stay together so we see pockets of quality in the sector, but maintaining this quality is a constant challenge. When the resident mix changes or the needs of individual residents' changes, new tensions arise that even the best staff struggle to resolve, and conflicts and neglect of needs can increase.

Not all staff do treat disabled people well in group homes. Some staff do abuse residents, some bully residents, some ignore or neglect people they don't like or find difficult, some treat residents with little respect and some are violent towards disabled people. Ableism is prevalent in the disability sector as it is in society. Sometimes disabled people can speak up and seek justice but often they cannot. Even when they do, they are often not listened to. Even when they have family support and advocacy, they are often not given the response they deserve and have little option but to stay in an abusive group home.

AMIDA has advocated for numerous disabled people experiencing violence, abuse, discrimination and neglect in group homes. The following are a few recent cases examples:

- A new resident moved into a 5 resident group home. The new resident began verbally abusing and harassing other residents in numerous incidents each week. Examples initially included invading privacy by walking in on other residents in the bathroom, swearing, yelling, thumping fists on table and threatening physical assault. Despite protracted advocacy, the response was ineffective from both the initial government service provider and subsequent contracted community service provider. The service provider response focussed on counselling to calm the affected residents, explaining that the abusive resident couldn't help it and discouraging residents from constantly complaining about the issues. Psychological assessments reported the stress of the residents targeted was understandable and increasing. Despite this, only minor increases in support provision occurred. Unsurprisingly, this additional support in the same group setting did not change the level of abuse. Complaints by residents and their families, and consequent meetings at both the house and management level did not result in appropriate action to ensure all individuals were housed and supported adequately and were safe in their own home. For example, it took more than 2 years for the service provider to agree to place a privacy lock on the bathroom door. Over the course of 3 years the abuse escalated to the resident throwing furniture and making an attempt to set fire to the house. The mental health of residents deteriorated, and all residents were ultimately taking medication for mental illness they had not had prior to this resident moving in. Finally, group home support staff were physically attacked, and when they subsequently threatened to resign, the service provider acted to evict the violent resident. As no alternative accommodation was immediately available the resident was sent back to stay with their parents. It is still unclear what will happen in this case and whether the resident will be appropriately housed and supported, returned to the group home or moved to a vacancy in another inappropriate group home. If

a vacancy is left by this resident, it will be filled by the same service provider who allowed abuse to continue for so long. Residents will not have choice and control of who moves into their home.

- In another group home a resident was frequently violently attacked by a co-resident and eventually hospitalised. The family of the disabled person were reluctant to complain and advocate on his behalf. State Government Human Service staff became involved but even with their support 23 unsuccessful applications for alternative accommodation for the victim were made. 18 months later a place was finally made available in a new 1-bedroom specialist disability accommodation house where he is about to move and be safe. No alternate accommodation was sought for the resident who had behaved violently. The vacancy in the house the abused person left will quickly be filled by someone else in urgent need of housing despite it already proving to be an unsafe space. State government funding for staff to assist in these situations ended on June 30th 2020.
- A young woman was sexually assaulted twice in a group home by two different men who were providing her personal care at different times. Despite these matters going through the courts and resulting in prosecution of the perpetrators, the service provider continued to ignore requests, by the family and the AMIDA advocate, for exclusively female staff. Male staff were regularly providing her personal care, including showering. The young woman displayed fear when this happens. Despite it being clear that she did not want to have male workers touch her body, the service provider decided on staffing and continued to provide male workers.

Neglect is a feature of all these examples as even when violence and abuse is reported, **the response**, at all levels of service provider organisations, including government, is minimal, ineffective and does not place the physical safety and emotional wellbeing of disabled people as the first priority. The enormous time it takes to get solutions to problems of abuse exacerbates the problems, further erodes trust, and further silences people. Even where there is a strong desire by service providers to quickly address the abuse, there are several factors that prevent this including lack of alternatives to group housing and lack of support to disabled people to pursue what alternatives there maybe. As a result, service providers tend to try to smooth conflicts over, drag out response times, medicate the unhappy residents and discourage residents' complaint.

When people living in the community receive a service in their own home the visiting support worker is usually mindful and respectful that they are in someone's home and that they are there to provide a service to the person. In group homes the support workers are a fixture, not a visitor, and the power relationship shifts to this being a service provision site, rather than someone's home. Disabled people living in group homes don't have choice and control over what happens in their homes including who moves in and who provides support and what support they provide. Staff in group homes make all the decisions in almost all cases and it is common for them to never consult residents and to treat people with a disability as passive recipients of a service designed and managed by others. If residents are consulted about anything it is usually token and limited. Group housing is thought to be cheaper than individual housing with support, but enormous resources and time are spent ineffectively dealing with the problems that inevitably arise due to conflicts and clashes between people. Even if there are some savings in the group housing model, there are inherent problems in the model because people with a disability are harmed and denied their rights to choose and control.

Research into ways of better offering support in group homes has been taking place since the model developed in the 1980's yet violence, abuse, exploitation and neglect continue. Research has in fact shown that the larger the number of staff to residents, the lower the level of resident activity and resident gains were found to occur more when the resident group size was reduced (Felce: 1998:110). It is not possible to prevent violence, abuse, neglect and exploitation in group homes. Community visitors reports over the years continue to document problems in group homes that visitors get to see. If video cameras were in place, though they may infringe the privacy of residents, they may reveal the true extent of the problem of violence, abuse, neglect and discrimination which is likely to be extreme. But they would not prevent the problems inherent in grouping people against their will. Nevertheless, while the model persists, if residents wish to have video cameras in place, monitored by someone other than the service provider, they should have the right to do so. Service providers are unlikely to ever agree to this unless residents are given this right in law.

While disability services continue to operate in this way they risk neglect and abuse occurring and continuing, for which people with disability pay the price. Dominant policy and practice approaches do not consider the prevention and protection of people from harm, focusing primarily on responding to individual instances of maltreatment. Managerial, compliance-based systems may be deflecting attention from recognizing and responding more effectively to abuse and neglect at individual, systemic and structural levels. The current dominant approach fails to develop a culture of prevention and protection for people with intellectual disability. Further, some systemic and structural preconditions are set which make abuse and neglect less likely to be prevented. (Robinson S, Chenowith L. 2011)

AMIDA has advocated for legislated rights of residents living in group homes for many years. Often service providers argued to limit rights. We have heard service providers argue that legal protections should not be extended to group home residents because it is not possible to prevent people being assaulted by other residents and service providers can't be held accountable for this. Many workers in these settings have become desensitised to the harm people with a disability have inflicted on them in these settings. Institutionalisation of workers and residents happens in group settings and although group homes are in general better than the large-scale institutions, they replaced, they have many of the same pitfalls. The group home model is only still in place because of a lack of investment in appropriate alternatives such as individual housing with support for independent living. People contemplating moving out of group homes with their NDIS funding will battle to find accessible, secure and affordable housing. Furthermore, their NDIS funding package will have been set based on a group setting and will be insufficient to cover 24 hours for an individual. They will face a battle to get this increased as the NDIS currently expects most people in Specialist Disability Accommodation to continue to live in group settings. To even know about, let alone seek funding for an individual living option requires enormous advocacy. Most people have no knowledge of an alternative and will

Disabled people in group homes will spend most of their lives sharing their accommodation and they will be profoundly affected by this. The group housing model is expensive to staff and operate with huge amounts of time being consumed by the problems inherent in the model.

Under the NDIS, government subsidies flow to developers of predominantly group homes under the Specialist Disability Accommodation SDA scheme. SDA guidelines require most people to share accommodation. To quote the SDA pricing and payments framework **“Any participant could live independently if unlimited funds were available to support them in their own home. Enabling every NDIS participant to live independently with their required levels of supports would be prohibitively expensive for the NDIS”,** and **“Providing support for participants in a shared living arrangement, where staff and other resources can support more than one participant is often an effective strategy”**. The framework is in place from July 2016 to July 2021. A relevant current AMIDA case which demonstrates the pressure to share is a young woman in a country town who requires a home which accommodates her high physical support needs. Her family are prepared to build an SDA property for her but the NDIA will only allow funding subsidies for the property if it is built to share with at least one other. She does not want to share and would be vulnerable. Also, there is unlikely to be another person in the town requiring the same level of SDA and if they did, may not be a compatible, age, gender, personality etc. The decision to force shared accommodation has been challenged but the case has taken 2 years so far and is still being appealed.

However, independent supported living is successfully occurring for thousands of people with disabilities via the NDIA SDA and SIL funding and it is a form of discrimination to deny this to people living in group homes.

There is currently not enough alternative housing, especially single bedroom stock. At least 28,000 places are urgently required for disabled people, 12,000 of these new and 16,000 already existing but needing to be redesigned to break down the congregation of group homes.

Currently a tiny amount of new SDA housing is being developed by housing providers: **534 1-2 b/r apartments, 199 2-3 b/r group units, 336 2-3 b/r group houses 440 4-5 b/r group houses and 36 5+ b/r group houses. However, even single bedroom units are being clustered in groups of up to 15 units. A single support provider will be locked in for each cluster with no individual choice for residents.**

Considering the problems that exist with group housing urgent policy change is needed to limit the group size of SDA accommodation and allow for many, many more non share arrangements.

Compared to other OECD countries we have an incredibly low level of public housing which is one viable affordable accessible housing source. But in Victoria, Public housing wait lists are currently around 80,000 people and though the government has committed to building 1000 much more is needed to address the need. **It is relevant to point out that public housing tenants would never be expected to share their tenancy as a matter of policy, despite the long wait lists. Yet people with a disability must share with many others with no choice about who they live with in order to receive essential services.**

Another problem that flows from the lack of housing alternatives is that there is no emergency funding for housing costs. Under the state government disability services, money could be provided to pay for serviced apartments while a long-term housing solution was found. However, the NDIS doesn't pay for housing, so with the full transition to NDIS, there is now no funding for emergency housing.

It is not in the interests of disabled people for the group home model to continue however it will continue for some time even with a huge effort to transition to alternatives. Currently there is very small growth in alternatives but thousands more options must be developed. In the meanwhile, rights to safety must be legislated for and access to advocacy massively increased.

A major barrier is lack of access to advocacy and lack of availability of advocacy. Residents in group homes are often unable to independently contact advocacy services and require support from workers to do this. When they have complaints about the workers or what is happening in the group home, workers are put in a conflict of interest position and this jeopardises a person's access to advocacy. Advocacy services have huge demands placed upon them and require additional funding. Cases can be protracted as service providers drag out matters and respond inadequately. The capacity of advocacy services is such that they cannot provide services to all those requiring it. Most advocacy services in Victoria have closed their waiting lists as they cannot hope to deal with any more cases within reasonable timeframes.

With more resources and rights to enter services, advocacy could outreach to people living in group homes. Advocacy services could also provide residents with rights information and connect them with self-advocacy groups.

Toothless monitoring agencies such as the Quality and Safeguards Commission is another barrier as is the lack of legal rights of residents to protection in group homes and a workable mechanism to exercise these rights.

Self-advocacy groups are very poorly funded yet provide peer support, have experience acting as a group on disability rights issues and provide rights information and skills in self-advocacy. Resourcing for self-advocacy is one off around Australia. Victoria funds a very small number of self-advocacy groups a very small amount of money. They do also fund the Self Advocacy Resource Unit, SARU. AMIDA and SARU were funded to meet with self-advocates with intellectual disability, Acquired Brain Injury and complex communication impairments across Australia and this led to the development of a proposal for the roll out of resourcing units for self-advocacy support specifically for people within these target groups. However, the NDIS Information Linkages and Capacity building funding framework does not allow for this model to be funded and is only short term funding anyway. Despite several applications, no national funding for self-advocacy resourcing has been provided nor has there been any increase to the very small direct funding to self-advocacy groups.

Recommendations to the NDIA from AMIDA

- 1. More education on housing options for staff and service users.**
- 2. Training of NDIA planners, staff and service providers by people with disability.**
- 3. More funding for supported decision making, in particular for people with ID.**
- 4. People living in SDA to have the option to live alone.**
- 5. Reassessment of the Group Home model.**
- 6. Limit the amount of residents to a few people to each congregate living arrangement.**
- 7. Regulation and monitoring by the NDIA over accommodation providers of SDA and SIL.**
- 8. Modification funding by the NDIA essential for all people with mobility needs.**

- 9. Appropriate response to all reports of abuse and neglect by people with disability, especially those living in congregate living.**
- 10. Legislate the right to safety of people with disability in congregate living settings.**
- 11. Much more single bedroom stock of affordable and accessible housing.**
- 12. Funding for emergency housing costs.**
- 13. A genuine commitment to the UN CRPD by the NDIA and incorporation of the feedback from the UN on Australia's UN reporting, into the legislation, regulations and guidelines.**