Submission to the NDIS consultation: Home and Living – An ordinary life at home

Achieve Australia (“Achieve”) welcomes the opportunity to contribute to the development of the NDIA’s Home and Living policy. We note that this policy will inform the way National Disability Insurance Scheme (NDIS or Scheme) participants are supported to pursue their home and living goals. In this submission, we provide our perspective as a service provider with nearly 70 years’ experience in supporting persons with complex intellectual, psychosocial and physical disability. We also reflect our organisation’s passion for social inclusion for people with disability.

Achieve commend the efforts of the National Disability Insurance Agency (NDIA or Agency) to secure feedback from a wide range of stakeholders, including service providers, service professionals, NDIS participants, families of persons with disability and the general community through this consulation process. We agree that there is ample opportunity to provide persons with disability more options and greater flexibility in how to apply funding for housing and supports at home.

# Housing and supports at home matter deeply to achieving inclusion

Achieve agrees that living in the community is the best way for persons with disability to experience social inclusion. Furthermore, we believe social inclusion for people with disability starts at home. Home is where our sense of self and our ambitions for the world we want to live in are continually formed and reinforced. This then extends out into society, where inclusion is influenced by attitudes, relationships, systems, and the physical environment. We want all people with disability to experience inclusion and a sense of belonging.

Persons living with an intellectual or cognitive disability face particular challenges to achieve the NDIA’s vision of ‘an ordinary life at home.’ This is because they need to navigate a complex funding and service ecosystem in order to secure reasonable housing and home supports. For this reason, we agree with the call for creativity and flexibility in designing fit-for-purpose solutions for all persons with disability, including persons with intellectual disability.

# Summary of our concerns

With this context in mind, we point to specific areas where the Consultation Paper fails to grapple with what it will take to deliver on the vision.

* The paper presents a problematic dichotomy between Supported Independent Living (SIL) and Independent Living Options (ILO), with a misleading association between costs and quality outcomes for persons with disability. SIL is positioned as an expensive, legacy model; ILO is presented as the better and cheaper alternative. However, the data on the cost of SIL in the paper does not reflect our experience as a service provider. Further, data on costs is used anecdotally in the Consultation Paper; this cannot allow any reasonable analysis of how well SIL and ILO models help participants achieve better outcomes. In effect, cost is used as an implicit proxy for inefficiency and linked by association with historical approaches to service provision. This characterisation fails to acknowledge the evolution of service delivery and support of improved outcomes for participants.
* There is no recognition that a large number of participants who qualify for SIL have an intellectual disability with high support needs, and that many of these participants have limited or minimal informal support networks. For many of our clients, ILO will never be a realistic model because their families, guardians and advocates lack the level of skill required to secure and manage consistent supports. We are deeply concerned that through this reform the agency will begin to establish a hierarchy of ‘good supports’, where SIL is positioned as a result of a failure to qualify for ILO and less likely to deliver an ‘ordinary life’;
* The push to ILO fails to address the safeguarding and risk questions arising from the enormous asymmetry of power between a person with intellectual disability and an informal carer. We understand that some participants receiving ILO supports are able to establish ‘microboards’ with their families and friends to provide oversight on services. However, there is little in the Consultation Paper to indicate how the ILO model could be rolled out in scale whilst ensuring reasonable standards of service quality. SIL providers have been rightly subject to increased scrutiny to ensure that they are upholding the rights of participants within approved budgets. What systems will be in place to ensure the protection of people within an informal setting in an ILO model? In fact, what measures will be enforced to ensure that ILO supports are being provided at all?
* In contrast, the paper positions group homes as an outdated model and proposes that residential models with five or more participants are inferior. However, some persons with disability may have better outcomes in a five-person home than in a two-person arrangement, particularly if they have complex support needs and limited options for inclusion in the community and beyond. This is in no way a call for a return to large, institutional setttings. Nevertheless, hasty transitions to smaller groupings can reduce social connections; the devastating impact of this on the wellbeing of participants is hardly noted in the Consultation Paper.
* We agree that the process of reimagining ‘an ordinary life at home’ is a complex task that requires conceptualising new ways of being in the world. The paper is virtually silent on how

that reimagining should take place. The SIL/ILO model continues to be funding-centric, rather than focussed on individual aspirations. The Consultation Paper fails to wrestle with the range of supports required to understand both needs and aspiration. The process of imagining a life different from the one I am currently leading is a deeply complex exercise. Settling on limiting possibilities, however, should not be part of the future vision.

Furthermore, we believe that there is a critical need to begin the process of innovating to create new approaches that meet felt and latent needs.

* The paper radically underestimates the level of support the primary stakeholders across the sector (persons with disabilty, the Agency, service providers, families and their carers) need to make home and living supports more straight forward. In our customer engagement research we are repeatedly told that the system is complex, opaque, occasionally bewildering and often exhausting. We strongly recommend investment in capacity building across the board to help participants navigage the service ecosystem. Further, we are aware that similar concerns have been identified within the aged care sector and there is currently a trial underway to look at different models of system navigation. We strongly encourage consideration of whether such an approach would further the objective of ‘empowering consumers’ in the context of the disability services and the myriad of interconnected service systems that people with disability and their supporters have to navigate.
* We suggest that in the absence of capability development and ongoing education, as well as a genuine embracing of innovation to deliver inclusion for all persons with disability, participants cannot meaningfully answer the following questions listed in Appendix D of the Consultation Paper:
  + What information, learning and resources could we create to help you choose your home and living supports?
  + Where would you like to get information to think about where and how you live?
  + Would it be helpful if your informal supports (for example, friends, family and carers) knew more about how and where you want to live?
  + How can we work better with your informal supports to help them know more?

# Bringing Achieve Australia’s recommendations to life

We offer two case studies in this submission to illustrate the concerns we have already voiced, as well as opportunities to build a better NDIS that delivers on the vision of ‘an ordinary life at home.’

# Case study 1: A dangerous journey to finding the right housing and supports

Damian (name changed) is an outgoing and socialable man in his early 40s who enjoys his life sharing a modern apartment with a flatmate. Managing Fragile X Syndrome and intellectual disability has not prevented Damian from enjoying – pre-COVID – his job and an active social life. Prior to transitioning to SIL supports with Achieve Australia in 2017, Damian lived with his mother in the family home in Northern Sydney. He had secured employment services at the AchievAble factory in the Inner West and was a member of the Achieve cleaning crew. While enjoying independence, he also relied on his mother for constant support.

When Damian’s mother decided to sell the family home, she approached Achieve about independent living and accommodation for him as she was unable to live with him in her new home. Damian was supported to move into a one-bedroom community housing unit in Western Sydney with NDIS funding. However, he was only assessed to receive minimal supports.

While Damian was very excited about his new home, the move introduced risk to his life. He had never lived away from his mother before or outside the area he grew up in, and was relocating to a new area of Sydney and with different public transport routes. Due to his social and engaging personality, he would sometimes invite strangers into his home. Sadly, this resulted in several assaults against Damian and the theft of some of his belongings.

People back in his old community understood Damian’s outgoing and friendly personality. In this new environment, he would wander into other people’s units to engage with them, leading to complaints from neighbours, some of whom perceived this behaviour as harrassment. He would often go without eating too, which significantly impacted his health.

Damian has difficulties understanding time. To ensure he was not late for work, he would leave his home in Western Sydney to catch public transport as early as 2am, sometimes arriving at his work in the dark at 4am. This made Damian vulnerable and again he experienced several assaults.

Identifying these risks and the potential for poor life outcomes, Achieve supported Damian to secure the right level of support. Damian told us he wanted, and needed, to live with other people as he can become quite lonely and enjoys the company of others. We introduced him to a potential new flat mate where he could share a two-bedroom SDA apartment in Nortwest Sydney. Damien and the potential flatmate agreed to give it ago. Achieve advocated for Damian to secure SIL and SDA funding to support this move.

Damian has been living with the same flatmate in the same apartment for the past three years. He is thriving in an environment that is suited to his needs and includes:

* Social connections with his flatmate, as well as other residents in the same complex, in a supported environment, because the apartment complex where he lives has a mix of residents and offers greater opportunities for Damian to meet new people and network;
* Continued access to his daily living activities and assistance to manage his time accordingly, and to prompt his daily choices so he is able to maintain his independence while keeping himself safe;
* Access to support 24 x 7 to ensure his wellbeing and safety.

Damian’s story demonstrates the need for careful alignment of the SDA/SIL processes so participants have genuine choice and control over where they live, who they live with, and how they are supported. Damian and his family did not have the experience or information they needed to fully assess the suitability of the housing option they chose. This led to social exclusion for Damian and a lack of psychological and material safety. It also shows why home and living options must be flexible to tailor to the individual needs and aspirations. Furthermore, it highlights the importance of consistent funding, as well as the continued commitment of the community. And that commitment is also based on confidence that appropriate supports are being delivered.

# Case study 2: Transitioning from informal supports similar to ILO to SIL

Brenda (name changed), a woman in her 50s with intellectual disability, shared an apartment in Northern Sydney with a flat mate who had committed to providing informal support overnight.

Brenda also received formal drop-in supports from Achieve during the day and weekends, as well as supports from another provider. The services she received were similar to what is now available in the ILO model; ILO was not available then.

Over time, Brenda’s support needs increased to a point where Achieve was required to provide formal supports covering every hour the co-resident was not obligated to provide support. The flatmate would often go away or be unavailable to provide support despite making an agreed commitment to do so. The relationships at Brenda’s home became quite strained. This situation put pressure on Achieve, because funding did not match the participant’s needs.

Brenda needed to transition to 24 x 7 supports, but finding an appropriate housing option was challenging. She was used to living on her own, but her approved NDIS funding only covered shared supports. A shared arrangement was new for Brenda. After discussions with Brenda’s brothers, the family agreed that the co-resident arrangement was no longer able to meet Brenda’s increased needs and that a SIL share home could be a much better option.

Achieve offered Brenda a vacancy in a home in Northern Sydney, the same area where she had been living. Her family was strongly in favour of this, because that meant she could continue accessing her GP, pharmacist and other services that were already familiar to her. Brenda moved into her new home in 2019; after several months she was joined by another female participant of similar age and support needs in that home. Brenda’s support took a lot of time and effort to ensure that she could adjust to these changes as this was a life changing experience.

During this transition process, Brenda has had some escalated behaviours of concern. This has required additional supports that have not been funded by the NDIS. This has left Achieve to deliver services that cannot be claimed. This demonstrates the need for for greater flexibility in allocating funding so that participants like Brenda can transition to new home and living options successfully.

Brenda’s story shows why capability development should empower participants and their families to interrogate and test possible options against different scenarios. In this case, housing and supports that appeared to meet a person’s needs in a ‘co-residential’ model very similar to ILO fell short when one stakeholder failed to fulfill their obligations. A move to SIL funding was necessary, but that transition required support levels in excess of available funding.

# From practical experiences in case studies to future policy recommendations

The case studies reflect the real lived experience of persons with intellectual disability navigating a very complex system. When Brenda and Damian were supported to consider other options at a pace that suited them, they found the confidence to embrace new opportunities that may have seemed unimaginable to them and their families. It is worth noting that supports at Damian’s apartment complex are shared over a broader group of participants; this also shows how group home funding models can be adapted to other housing models. Their success hinges on ensuring that particpants are able to build relationships and social connections in a way that suits their individual needs.

In both cases, funding levels have changed over time, and the transition to SIL funding has been both recent and necessary. Regardless, this funding has been instrumental in ensuring safety and wellbeing. Both cases also show how participants have marshalled the efforts of providers and family decision-makers to navigate the system to secure appropriate supports and better outcomes while policy and procedural mechanisms from the NDIA were under development. Noting that these are clients in their 40s and 50s, the case studies also bring to life the importance of building service and funding ecosystems that can support their needs as participants grow older. This is highlights the opportunity to develop the NDIS to support ordinary lives at home at any age.

# Achieve Australia’s recommendations for the NDIS Home and Living policy

Based on our experiences supporting people with disability, Achieve recommends that the NDIS Home and Living policy include:

* Recognition of the crirical need for data on transparency on funding, as well as outcomes from disability supports, for stakeholders across the sector;
* Commitment to developing mechanisms to
  + Improve capability for participants and the people supporting them in decision- making to navigate the funding and service ecosystem, so that participants can identify and secure housing and supports models that truly meet their needs;
  + Identify and transition to different service models, including SIL, ILO and new options, as the needs of the individual participant change over time;
  + Ensure that gaps in funded supports are addressed expediently without compromising viability or continuity of service;
* That the NDIA provide greater market stewardship over SDA and other housing options.

Whilst we acknowledge the complexities of providing funded services in a residential environment, we believe that we can work toward better services and funding models to deliver social inclusion for all persons with disability.

Thank you for considering this submission from Achieve Australia.

# About Achieve Australia

Achieve Australia (“Achieve”) is a for-purpose community organisation that has been providing accommodation and services to people with disability since 1952. We champion social inclusion, focusing on the individual needs and lives of the people we work with. Achieve is an NDIS registered provider and delivers expert disability support services around our offices and hubs in the Greater Sydney and the Northern Rivers regions of NSW.

Achieve is firmly of the view that the primary stakeholders for the future Home and Living policy are people with disability. In our submission we do not seek to speak for our clients, rather we offer the perspective of an organisation that supports participants in a range of ways in their daily lives. We have first hand knowledge of how access to housing and NDIS supports has a significant impact on the rights and wellbeing of participants and their ability to live a good life.