# Avivo Submission: An Ordinary Life at Home



# August 2021

Avivo welcomes the opportunity to provide input into ‘An Ordinary Life at Home’ consultation paper. We believe we are well placed, as a long-standing Disability, Aged Care and Mental Health support provider, to highlight what has been working well in relation to individualised living arrangements and what requires attention.

Avivo is a Western Australian, not-for-profit community organisation that has supported people to live in their own home and community for over 50 years.

In the 2020 financial year, we worked with over 3,000 customers, carers and families in the Perth metropolitan area as well as in regional and remote areas as far north as Exmouth and as far east as Merredin.

**Shared Vision of Home & Living**

Avivo is committed to developing a society where people with disability live their lives fully in their own homes and communities. We are fundamentally aligned with the intentions outlined in the paper, having worked for many years with participants and their families to support them to have viable individualised living arrangements.

Participants we work with have individualised living arrangements funded by the NDIA mainly through ILO and SIL. In this response, when we use the term ‘individualised living arrangement’, we are referring to those funded by either of these mechanisms.

It is critical to us, participants and the whole sector to have well developed integrated policies, guidelines, processes and funding methods to support the future of individualised living.

We are committed to working with the NDIA to making the principles outlined in the paper real through effective implementation.

**Operational Guidelines and Funding Caps**

The development of Individualised Living in Western Australia, prior to the NDIA, was based on a partnership between each participant, their family, funders and the support organisation. Arrangements were designed and developed based on person-centred plans and innovative design. A reasonable allocation of funding was known however there was some flexibility with the finally agreed funding.

The current implementation of ILO Operational Guidelines and Price Caps are putting some participants funded under these models at risk. The price capping and pressures from the NDIA to minimize the cost of participants funding is jeopardizing a number of long-term, well-functioning living arrangements.

Since the implementation many participants have experienced the following:

Significant funding reductions, despite the planners being given quotes for support required and evidence to support this

Pressure to consider other living options, including group living models, even when evidence indicates group living may not be suitable or sustainable

Participants not being able to move out of group homes and institutions due to the strict price banding

Greater flexibility is required in the interpretation of the ILO guidelines and price caps, to maximise the potential of individualized living arrangements.

In addition, Avivo are seeing participants who have been funded through a SIL now asked to provide significant evidence that they cannot share their home with other participants and experiencing considerable decreases in funding. The NDIA need to consider that sharing a home is not suitable for all participants and decreases in funding put participants, providers and the health care system at considerable risk. Whilst it is understood by participants, families, and the sector that the Scheme needs to be sustainable this approach is fundamentally limiting participants choice to live an ordinary life.

***Case Study – Tully***

*Tully is a 55-year-old woman with Huntington’s Disease, described by those who know her as kind, knowledgeable, creative, and intelligent. One of Tully’s goals as identified in her NDIS Plan is to live an independent life in her own home with structured supports to enable her safety, comfort, and wellbeing. Tully’s mother and sister, who is also diagnosed with Huntington’s Disease, live close by. Tully’s mother has been a primary support for both Tully and her sister since their symptomatic diagnosis with Huntington’s Disease in 1999 and 2000. This has included direct care, support in the community, support maintaining social connection, dealing with all financial and administrative needs, and working with Tully’s wide range of professionals including direct support, allied health, clinical, and neurological teams.*

*Tully is connected to the Complex Supports Needs team within the NDIS. In 2019 Tully experienced a significant decline in health. This resulted in a SIL being funded for 24/7 rostered care, in Tully’s own home with supports that were tailored to her individual care and support needs. Due to the decline in Tully’s health, she was no longer able to attend community activities as she once could and her ability to maintain informal networks was impacted. Though Tully’s mother had always been her primary carer, she was increasingly finding it more difficult to coordinate the care of both of her daughters and provide direct support to them.*

*In December 2020, the NDIA requested Avivo and Tully explore an Individualised Living Options (ILO) quote. Though Avivo believed that Tully was more suited to SIL supports, an ILO quote was completed in April 2021. This timeframe coincided with the release of the new ILO Operational Guidelines. The quote was supported by a Functional Capacity Assessment, Dysphagia and Communication Care Plan, and Housing Exploration Report, which all reflect Tully’s goal of living independently in her own home and the level of support required by Tully to do this. In addition, the reports highlight that living in her own home, as her disease progresses in paramount to her wellbeing.*

*When Tully was first funded under SIL the funded amount was $748,000. During the exploration of ILO, Tully received several plan extensions, which were all funded at the same amount. At Tully’s last plan review the NDIA planner informed Tully and her mum that a SIL never should have been funded and that her new funded amount would be $260,000, with the view that Tully should explore other more ‘innovative’ options. Tully is now in the late stages of Huntington’s Disease and this reduction in funding is significantly impacting her ability to remain in her own home with her choice of supports, ensuring peace and comfort through her end-of-life journey. Avivo believe that the NDIA needs to fund this reasonable and necessary support to give Tully the choice to remain at home.*

**Partnership Relationship**

Successful Individualised Living Arrangements are designed, developed and sustained through long term partnerships between the participant and many key stakeholders.

When designing and developing Individualised Living Arrangements the following elements are crucial to sustainability:

* Focusing on the participants whole life including lifestyle, wellbeing, cultural identity and security, family and community.
* Genuine partnerships between the participant, their family, their network, and an experienced disability support organisation from the beginning to facilitate the integration of supports that can develop overtime.
* All the parties consciously listening and valuing the participant and their decisions; and seeing who they are and their potential, not just their disability or medical condition.
* Flexibility, for the participant, their family, the provider and the funder to support innovation and design of sustainable arrangements.
* Safeguard and risk planning, that includes the identification of risks that all parties can agree to accept, including the participant, their family, the support provider and the NDIA. Key to this planning is the NDIA’s preparedness to accept the risks and engage in responsive change planning where required.

Current NDIA processes need to change to actively include the support provider as a partner with recognition and back up for the risks involved.

In addition, Individualised Living Arrangements need to be funded to allow for the redesign throughout the plan period where needed, and significant changes in circumstances must evoke a plan review in timely and responsive manner. A factor that may mitigate the impact of change is adequate time for exploration and design, the ability to trial different ILO arrangements and safeguarding and risk planning. These factors should reduce the need for frequent redesign, plan reviews and reduce the risk for all parties.

***Case study- Richard***

*Richard is aged 40, and lives with intellectual, physical and sensory disabilities. He is unable to communicate verbally, and has difficulty expressing his needs and preferences, other than behaviourally. Richard has very few people available to support him in an informal capacity, other than his mother and his long-term disability support workers.*

*Due to the unstable physical and social environment at Richard’s group home, his mother resolved to explore other, more personalised, home and living options that might afford Richard a more stable, relationship-based home life. Her goal was to create a home and care arrangement where Richard could be closer to herself and community, and Richard was able to select workers who would support him to live his best life. Richard was able to build his own home due an inheritance her received from his father*

*Richard’s mother investigated a range of individualised living options (including speaking with other families who had trialled such options) but had concerns about the sustainability of many of these living options. She was also concerned that, given her own age and state of health, any long-term living arrangement for Richard could not be dependent on a high level of continuing input from her, nor require her to step in to make alternative arrangements if the existing arrangement changed or broke down.*

*Whilst in discussions with an established group home provider, the idea of a hybrid accommodation option was explored that included a Homesharer (a person living in the home, rent free in return providing some informal support and companionship) and visiting support workers to provide personal care and other day time supportsThis would be provided by Avivo A safeguard was to build Richard’s home next door to a group home, so in the event of any breakdown in the arrangement Richard could access support from the group home provider.*

*An advertisement for a Homesharer was placed in mid-2020, resulting in only one applicant. The applicant was screened and indicated genuine interest and commitment to the model proposed. However, it soon became apparent that the homesharer was not suitable for the model and was given one months’ notice to vacate.*

*The failure of the Homeshare delayed the process of Richard moving into his own home and also resulted in the Avivo providing 24/7 care.*

*Richard has now lived in his new home for over 8 months. His health and well-being have significantly improved. He sleeps well at night and there has been a considerable decrease in his self-harm behaviours. This is due to him having his own home, a stable team of support workers whom he knows and trusts and the ongoing involvement of his mother. Ironically the group home provider next door is unable to provide on-call night support to Richard due to the high complex needs of the people who live there and cannot be left alone even for the shortest periods.*

*Richard’s mother is very concerned about what will happen when Richard’s plan is reviewed. She is hearing about other participants having their funding decreased and having to provide evidence whey they cannot share their homes and living costs with others. After the failure of the pervious Homeshare arrangement she is unwilling to use this model but with Avivo’s support is exploring other informal supports for Richard to continue to live in his own home. Richard and his mother need to know that NDIA committed to stand by them and has a funding framework to ensure his individual living arrangement is maintained.*

*Richard’s mother has shared with Avivo some of the following considerations around the NDIA’s consultation papers, as it related to the experiences for herself and Richard.*

* *The consultation paper seems to assume that all participants exploring Living Options will have high levels of decision-making capacity*
* *There is little consideration made for people living with more complex disabilities and the support they may require developing appropriate, stable and safe living options*
* *There is not enough consideration for the importance of establishing, monitoring and adjusting arrangements and the timeframes for planning and implementing home and living arrangements for participants with more complex needs.*
* *Inappropriate or failed living arrangements can have catastrophic and enduring consequences for people with more complex support needs and their carers.*
* *The paper fails to explore the cost/benefit analysis for society where these types of innovative models foster caring, cohesive and inclusive societies.*
* *The impact to providers who are currently considering service viability, which will ultimately negatively impact communities and participants*
* *The need for extended planning, safeguarding and back up planning before the commencement of transitions to individualised living, and the flexibility to be responsive to change.*

**Informal Support Networks**

Individualised Living lends itself well to participants who have a good network of informal supports that could include friends, family and connection to community. The presence of informal supports in someone’s life provides them with people they can rely on for friendship, connection to community and guidance.

However, many people with disability require support to establish these connections if they do not already exist. For Individualised Living to be successful, participants need the opportunity to build and develop a network of informal supports which takes capability, time and flexibility.

All parties need to recognise what is and what is not appropriate for the informal support network to provide. For example, a son being expected to provide personal care for his mother, or a parent providing personal care to their adult child. These examples reflect real life scenarios in which participants are being expected to rely on family or other informal supports to assist them with self-care activities which can place additional stressors on that relationship, adversely affect the quality of those relationships and also negatively impact the dignity of the participant.

**Developing Knowledge and Capability**

Successful Individualised Living is designed with and for each participant using a range of innovative approaches including homesharing, host family support, good neighbours, circles of support and mentoring. These approaches require unique knowledge and skills different from the more traditional models of support. When individualised arrangements are developed by support organisations, planners and families who do not have this specialised expertise and knowledge, participants can be put at risk.

Many WA providers have years of experience in developing, providing and supporting individualised living arrangements. We are committed to supporting the sector to learn and develop, but we need NDIA to make a long-term commitment to a co-designed strategy that supports the development of this capability across all parts of the Sector and provides adequate funding to participants while capability is developed and networks established.

**Commonwealth & State Collaboration**

The design and development of Individualised Living requires specialised knowledge and skills and collaboration between many different parties across government departments and the community. This is particularly the case for participants in different circumstances including moving out of a foster home; moving out of Shared Living (group home): or transitioning from a hospital, health care or a justice facility. Avivo is committed to supporting participants to transition from these situations to ILOs, however, the sector desperately needs the NDIA and State Government departments to work through issues with funding, coordination and support.

**Housing & Tenancy**

The *West Australian Strategy to End Homelessness 2018 - 2028* released by the West Australian Alliance to End Homelessness identified that affordable housing supply is of crucial need, with a coordinated response including community and health sectors recommended to respond to the housing crisis in Western Australia.

Individualised Living approaches such as Host Support, where the host shares their home and lifestyle, can provide the participant with a home. Other approaches depend on participants having access to housing close to family and friends within their community. Housing is a major challenge and needs significant work between the State Government and Federal Governments.

Some Individualised Living arrangements, where people share their homes, require Tenancy Legislation to protect homeowners and housemates when arrangements come to an end. Avivo sought legal advice surrounding a challenging incident in 2020 where after a failed trial period a Homesharer refused to vacate a participant’s home under WA state Covid-19 tenancy legislation. Ultimately, police and the Department of Mines, Industry Regulation and Safety were engaged to evict the individual from the home. This was enormously stressful for the participant’s family and delayed the customer’s right and opportunity to move into their own home.

We understand that this is a mainstream responsibility, however, a collaborative strategy needs to be developed with the State Government to address the housing and tenancy needs of many participants outside of the SDA.

**Payment for support**

Successful Individualised Living arrangements are dependent on Awards and Tax rulings which are the responsibility of numerous Government Departments and Agencies. Current ATO requirements and the SCHADS award constrain the flexibility providers have with how they engage care providers. It is important that the sector work together with government departments to agree appropriate models of support and payment for all parties.

Where a participant is supported in a Host’s home, the host can be paid under three different scenarios, each with its own risks:

Tax-free reimbursement. Providers are currently relying on ATO rulings in relation to foster carers and volunteer respite carers, and some private rulings relating to host arrangements, WA Indivualised Services is working with KPMG to gain a class ruling from the ATO.

Contractor engagement – it can be a fine line between a contractor and employee relationship and the elements that must exist to ensure a host isn’t considered an employee in substance, also serve to separate the host from the support that a provider could give them in an employment relationship, as well as reduce quality and safeguarding oversight.

Employee – The SCHADS award (or any EBA that has passed the BOOT against SCHADS) does not support host support arrangements at all due to the ongoing overtime penalty rates that must be paid. Such a model is entirely financially prohibitive.

We feel it is important that the NDIA is well aware of the risks associated with each scenario, because it impacts the capacity to offer flexible and creative support options, and increases the dependency on formal supports, provided by employees of providers and funded at the appropriate rates.

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