



Success factors for individualised living arrangements

Knowledge review prepared for Western Australia's Individualised Services by Stillpoint Strategy.

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Chapter 1: The policy context

Introduction

This knowledge review has been prepared to support the Creating Home program developed by Western Australia's Individualised Services (WaiS). The Creating Home program is designed to promote and increase individualised living approaches across Australia by providing capacity-building training to established disability housing providers. The broader aim of the program is to support the National Disability Insurance Scheme (NDIS) to grow the number of individualised living arrangements (ILA) and to improve the market of ILA providers across Australia.

The review is one of several research activities undertaken to support the program and enhance the evidence base regarding effective strategies for delivering financially viable individualised solutions for independent living.

A knowledge review is broader than a literature review and examines the available evidence for ILAs from the published peer-reviewed and grey literature, as well as other information resources such as websites, video and documentary evidence. The purpose of the review is to identify the factors that support successful establishment, maintenance, and sustainability of individualised living arrangements.

This paper does not present an argument for the benefits of individualised living arrangements but begins with the assumption that the policy case to support independent living has already been made. The NDIS's Home and Living Policy, currently in development through a co-design process¹, is just one indication of the growing move away from congregate settings towards more individualised living arrangements in the community.

Broadly, there are four primary types of independent supported living arrangements identified in the literature (National Disability Insurance Scheme, 2021; Thoresen, et al., 2022):

- living alone in one's own home
- living with a host family
- living in one's own home with co-residents
- living with others with whom one is in a friendship or intimate relationship.

People with disabilities are not homogeneous and will have as diverse characteristics as any other segment of the population, so the principle of a person-centred, personalised approach is fundamental to creating a home that suits the individual. Increasingly, the policy environment in Australia and internationally has recognised that arrangements created to meet the particular needs and preferences of the individual bring a number of physical, social, emotional, and economic benefits (Rosken, Crosby, & Fuzesi, 2020; Independent Advisory Council to the NDIS, 2018; Fisher & Purcal, 2010). For many people, the need for support decreases over time as the individual grows in skills and confidence (Cocks & Thoresen, 2017).

There have been few rigorous evaluations of the outcomes of independent living arrangements, and varied measures have been used to measure quality of life and cost-

¹ See <https://www.ndis.gov.au/community/we-listened/home-and-living-consultation-summary-report#next-steps>

effectiveness, limiting comparability of studies (O'Donovan, et al., 2021). This review is based on the existing academic and policy literature as well as the many reports of individuals who have created successful and satisfying independent lives for themselves within their communities. The document summarises the evidence for the factors that contribute to successful ILAs. It does not focus on policy and systems, on the arguments in favour of ILAs, or on the organisations providing support services. Rather, the review summarises what is known about the practical factors that contribute to successful implementation of an independent living arrangement for a person with disability.

The paper is structured as follows:

- Chapter 1 introduces the project, the policy context and methodology
- Chapter 2 presents success factors contributing to effective (that is, satisfactory and sustained) supported living arrangements
- Chapter 3 discusses the implications of these factors for the implementation of independent living arrangements in Australia.

Policy context

According to the Australian Bureau of Statistics (ABS), nearly 20% of people in Australia live with a disability. Of these, just under 6% of people require assistance for one or more core activities (Australian Bureau of Statistics, 2022).

A number of terms and definitions have been used to denote private, non-congregate living arrangements for people with disability, such as 'individual supported living arrangements' (Thoresen, et al., 2022), 'individualized housing' (Oliver, et al., 2022), 'independent living' (European Union Agency for Fundamental Rights, 2018), 'supported living' (Kim & Dymond, 2012), and 'supported housing' (Nelson, et al., 2007). Cocks, et al. (2017) distinguish between 'individual supported living' and 'supported living', suggesting that the latter refers to a person living with no more than two others and with a separation of housing and service provider. In general however, these terms all define an arrangement that may include living alone or with a small number of others who are choosing freely to live together (a maximum of two or three others who are not related to the person with a disability), in a manner similar to people without disability living in the community. A recent definition summarises this concept as "*housing options that are life stage appropriate, where people with disability have choice regarding where and with whom they live, the support they receive and their day to day activities*" (Oliver, 2020, quoted in O'Donovan, et al., 2021).

International de-institutionalisation trends over the past 20 years have supported the move to smaller group homes and, increasingly, to independent living, in order to foster greater choice and control in the lives of people with disability (Oliver, et al., 2022; Fisher & Purcal, 2010). De-institutionalisation has become a normative policy position throughout higher-income countries (Šiška, 2019; European Union Agency for Fundamental Rights, 2018; Independent Advisory Council to the NDIS, 2018; Magee, et al., 2018; Community Living British Columbia, undated). Even so, as JFA Purple Orange (2019) have argued, the original Supported Independent Living (SIL) options put forward by the NDIS tended to make group homes a more attractive option for providers than independent living, due to the structure of funding mechanisms. Over time, the NDIS has increasingly recognised the potential of ILAs, and has recently conducted a national consultation to learn how the

Scheme can improve its support for independent home and living arrangements (National Disability Insurance Scheme, 2021).

Cocks & Thoresen (2017:12) note that independent supported living (ISL) is grounded in three assumptions:

- *“all people with the right supports can live in an ISL arrangement*
- *persons with disabilities do not need to live together*
- *people in an ISL arrangement do not have to live alone or independently.”*

There are numerous websites and organisations in Australia and other countries advocating for ILAs, and a growing body of academic and policy research exploring outcomes and success factors (Hole et al 2015). Kim & Dymond noted in 2012 that evidence suggested people in supported living arrangements had better outcomes than those living in group homes, with reference to social inclusion, quality of life, and cost. At the same time, there are still gaps in the evidence base as to what works, particularly for people with high support needs (Thoresen, et al., 2022). Much of the evidence is qualitative and based on small-scale studies or qualitative evidence from individuals' experiences.

Thoresen, et al. (2022) report that the greatest disability service cost is for accommodation support, with \$3.7bn expended in 2016-2017 (through the National Disability Agreement) for just over 39,000 individuals. This is likely to increase as more people seek financial support from the NDIS. Improving the availability of ILAs has the potential to increase individuals' quality of life, capabilities and contribution to the community suggesting that, in the long run, ILAs can be cost-effective for government. A number of studies suggest that many people in ILAs have increased their capabilities over time and as a result have reduced their need for 24-hour support; this may allow government to reallocate support costs in a more tailored and effective manner (Independent Advisory Council to the NDIS, 2018; Fisher & Purcal, 2010).

The Australian Centre for Social Innovation (TACSI) identified three functions of a home:

- *“agency (self-determination*
- *connection (giving and getting)*
- *identity (being and belonging)”* (DeCampo, et al., 2021).

TACSI's report provides a 3-page checklist for a 'good home', beginning with the following question: *“Does your home give you security, agency, control and self-determination?”* (DeCampo, et al., 2021:17). The authors argue that policies, funding mechanisms and markets should incentivise the notion of home as an outcome, in order to improve housing for all people including people with disability, and suggest the use of deliberative and participatory processes that are inclusive and place long-term social and economic benefits before short-term financial gains. These arguments are replicated, in various forms, throughout the literature on de-institutionalisation and independent living.

Methodology

A literature search was undertaken using the following selection criteria:

Table 1: Search criteria

Criterion	Included	Excluded
Publication date	Published since 2010 (except where particularly relevant)	Published before 2010 (except where particularly relevant)
Language	Available in English	Languages other than English
Type of publication	Peer-reviewed articles, government reports, research reports, reports based on lived experience of successful ILA implementation and outcomes	Newspaper articles, opinion pieces
Focus	Implementation of independent supported living arrangements	Other forms of living arrangements, other aspects of living and engaging in community life and work

The literature search included searches of the following web-based resources:

- Social Sciences Database with Full Text (subscription database)
- Research Gate (www.researchgate.net)
- Google Scholar (<https://scholar.google.com.au>)
- Google (for open-access journals)
- WaiS website (<https://waindividualisedservices.org.au>)
- My Home, My Way website (www.myhomemyway.com.au)
- National Disability Insurance Scheme website (www.ndis.gov.au)
- NDIS Independent Advisory Council website (www.ndis-iac.com.au)
- NDIS Data website (www.data.ndis.gov.au).

Guidance was also sought from WaiS as to other relevant publications which may not be in the public domain.

The literature can be roughly divided into several categories:

- **policy:** analyses of Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD), its policy (and other economic or social) implications, and the ways in which governments are responding to the CRPD; analyses of de-institutionalisation and outcomes
- **research:** reports of research into and evaluations of individualised living arrangements, their outcomes and implications
- **implementation:** documented practical examples, advice, 'how-to' tips, and evidence through lived experience of individualised living arrangements

- **advocacy:** arguments for greater implementation of and access to supported independent living options.

More than 115 publications were sourced through the literature search. Of these, 57 have been referenced for this review. Eleven websites were included as resources, primarily for access to videos presenting the lived experiences of people in ILAs.

Several limitations are evident when assessing the literature:

1. There is a lack of rigorous evaluative research providing quantifiable evidence of positive outcomes as a result of independent living arrangements. There are also few standardised measures used, which limits comparability across studies.
2. By and large, the literature does not include many examples or discussion of the experiences of First Nations people with disability, or of individuals from culturally and linguistically diverse backgrounds.
3. There appears to be more research examining independent living for people with intellectual and developmental disability, and comparatively less on physical or psychiatric disabilities. Given the recognised need for living arrangements to be tailored for individuals' needs and preferences, the material presented here may not be applicable for all people with disability.

Many authors acknowledge that the evidence for the effectiveness of ILAs is largely qualitative. At the same time, the extent of this body of evidence gives weight to those factors that are consistently noted as contributing to the success of independent living arrangements. These factors are discussed in the following chapters.

Chapter 2: Success factors for ILA

There are many factors that contribute to the success or failure of personalised housing options, including quality of accommodation, location, transport, funding, availability of support services, and relational support from family and/or friends (O'Donovan, et al., 2021; Nelson, et al., 2007). These factors are double-edged in that, done well, they support successful implementation of independent living and, done badly or in their absence, they create barriers to independent living in the community.

O'Donovan and her colleagues (2021) identified five categories of enabling factors for independent living: policy and system, organisational, community and environmental, interpersonal, and individual. This chapter has focussed on the latter three, with an eye on the more practical factors that contribute to success, rather than examining policies and systems or organisational factors. These enabling factors that contribute to success for individuals are presented under five headings and explored in detail below:

- preparation and planning
- housing and accommodation options
- formal and informal support networks
- social participation
- capacity building.

Preparation and planning for an ILA

“My advice would be don't stop believing... there is a mountain in the way, but don't stop [trying to progress].” (person living independently, quoted in O'Connor, et al., 2012)

Success factors:

Careful planning before implementation

'Independence of spirit'

The creation of circles of support or microboards

Within the literature on independent living for people with disability, there is wide agreement that planning and careful implementation are essential foundations when establishing an independent living arrangement. The ISL Manual, 2nd edition (Cocks & Thoresen, 2017) and the Housing Toolkit produced by the Summer Foundation (Winkler et al., 2013) both provide detailed frameworks for planning an independent living arrangement, including identifying how an individual would like to live, what is important to them, indicators of independence, and the attributes to consider in developing an arrangement.

'Well-planned transitions over time' have been noted by Thoresen, et al., (2022) as critical to ensure that a person has the time required to feel comfortable in the new living arrangements. This is supported by Brend (2008) who chronicled the experience of many people moving out of institutional homes in England. Brend noted that sub-optimal outcomes were often the consequence for people who were relocated without consultation to unfamiliar

neighbourhoods where they knew no one, had no natural connections with local services and community groups, and received little follow-up support. O'Donovan, et al. (2021) also suggest that involving the person with disability in the planning and preparation of the transition will enable a more successful transition. Thoresen, et al. (2022) acknowledge that in some instances a group home may be considered as a transitional phase for people who are moving out of larger institutions, in order to assist an individual to acclimatise to the significant change from institutional life into more independent living.

Many parents and families have argued that the move to independent living must be grounded in a focus on the person rather than the disability: on their needs and preferences, and on what is possible, rather than what is not or what may be challenging. For many parents, seeing their child established in an independent living situation has been the fulfillment of a long-held dream, often accomplished without the help of government funding or support mechanisms (Magee, et al., 2018; Rodgers & Rallings, 2016; Community Living British Columbia, undated).

O'Connor, Gilbert, & McGrath (2012) identify '*independence of spirit*' as a prerequisite to the development and maintenance of an independent life. By this, they mean that the individual needs to be highly motivated to achieve his/her goals of independence. In their interviews with 54 people with disability in Ireland, the authors found that exercising choice and control over their own lives was the primary reason for wanting to live independently. The freedom to choose their own home, friends, and activities is considered a vital part of individuals' expressions of their identity. These findings are echoed by Bigby, Bould & Beadle-Brown (2016) in their study of 34 people in Australia who self-identified as having an intellectual disability. Research participants indicated that the benefits of greater self-determination outweighed the frustrations sometimes experienced such as lack of choice for support services, low income, and the general challenges of ordinary life such as not liking one's neighbours.

For many people who have achieved independent living, the establishment of a 'circle of support' or 'microboard' was essential as a means of managing housing arrangements, ensuring sustainable and long-term financial independence, and providing a safeguard to independence through a trusted group of family and friends (Magee, et al., 2018; Cocks & Thoresen, 2017; Arthy, 2017).

A circle of support is just what it sounds like: a group of people who support an individual in their lives, including through building relationships, planning for activities and life goals, and supporting decision-making. It is an informal arrangement founded on relationships and focussed on supporting the individual to live their life to the fullest (COSAM, 2022; Rodgers & Rallings, 2016). Because a circle of support is built on existing family and social networks, each circle will be unique depending on the circumstances and relationships of a particular individual and his/her network (COSAM, undated).

In contrast, microboards provide a legal governance structure through incorporation, and support a person to set and achieve their life goals. They have become more common as people with disability age and parents have sought to create sustainable support arrangements that will provide continuity once the parents are no longer able to provide care (Microboards Australia, 2016).

There are few clear findings regarding funding models to support independent living (O'Donovan, et al., 2021), and there is a dearth of information regarding the funding mechanisms required to support the transition to and establishment of ILAs as opposed to the ongoing maintenance of ILAs through funding for services and accommodation. The one randomised controlled study undertaken by Hoffman, Kehn, & Lipson in 2017 took place in

the US and was inconclusive regarding the use of funding vouchers for rental accommodation (as reported in O'Donovan, et al., 2021).

Other models have included the use of direct payments. In Scotland, a personalised approach has provided four options for funding support: “*direct payments, an individual service fund, services arranged by the local authority, or a mix of these*” (Squire & Richmond, 2017:9).

In Ireland, one organisation established a model of direct payments in which they support individuals with disability to establish a company structure to receive government funding. This funding is then used by the individual to purchase the supports they require. The model places control in the hands of the individual with disability and gives them a legal status as the owner of a company, with corresponding responsibilities. The organisation, Áiseanna Tacaíochta, provides additional assistance through circles of support, staffing and peer support networks (Angelova-Mladenova, 2019). This type of model is likely to reduce the frustration experienced by others, such as reported by Bigby, Bould & Beadle-Brown (2016), who do not have control of their own money.

In all models, placing the individual with disability at the centre of planning and preparation has been identified as the core component of successful implementation. From that first principle, other decisions such as type of housing and service supports will follow.

Appropriate housing models and accommodation options

“I love this home and I wouldn't give it up for anything.” (person living independently, quoted in Magee, et al., 2018)

Success factors:

- Affordable housing options
- Security of tenure
- Separation of housing and support provision
- Accessibility and ability to modify accommodation

A second principle for successful independent living is that the individual is in control of where they live and has security of tenure (DeCampo, et al., 2021; Small Supports, 2020; Community Living British Columbia, undated).

The term ‘independent living arrangements’ does not refer to a particular model of housing. Rather, ILAs are grounded in an approach to accommodation that is person-centred and tailored to the individual needs and preferences of the person with disability, rather than being determined by the housing provider (Thoresen, et al., 2022). The Australian Centre for Social Innovation (TACSI) also noted the importance of flexible housing options that are adaptable as people’s needs change over the lifespan (DeCampo, et al., 2021).

Gusheh, et al. (2021) note the shortage of accessible housing in Australia, and lament the lack of a mandatory accessibility standard to guide the building of new homes, both private and social (public) housing. There is also a significant shortage of affordable housing in Australia (Bigby et al 2017), leading to disproportionate numbers of people with disabilities

living in social housing, compared to people without disabilities (Thoresen, et al., 2022). Wiesel (2011) points out that when dependent on social housing there can be little option with regard to location and type of accommodation, as allocation can be determined by need rather than preference. Housing options have often been tied to service support options for people with intellectual disability, limiting choice (Wiesel, 2011).

The availability of suitable housing will influence the success and sustainability of an ILA, with a number of authors arguing for an increased supply of available and appropriate housing stock not limited to social housing (Thoresen, et al., 2022; Wiesel, 2011). This does not refer only to accessible accommodation but also to the need for housing options to be safe, offer security of tenure, feel welcoming and comfortable, and be well located with regard to transport and amenities (Magee, et al., 2018). Factors such as inaccessible buildings and poor transport can inhibit sustainable independent living arrangements (O'Connor, Gilbert, & McGrath, 2012).

Nelson, et al. (2007) argue that individual choice of home has an influence on perceptions of quality of life, satisfaction and mental health. In a study of 130 residents with mental illness in supported housing in Ontario, Canada, the authors found that having choice in housing was correlated with greater satisfaction with the quality of housing. Likewise, it was found that having some control of the use of professional support was also correlated with greater adaptation to community living. Overall, Nelson and his colleagues suggest that the quality and type of the accommodation itself can be an empowering factor leading to beneficial mental health outcomes.

The literature is clear that it is critical to separate the provision of housing from the provision of support services (Independent Advisory Council to the NDIS, 2018; Magee, et al., 2018), so that people are able to change support providers if they are unhappy with the service, without having to move home. Bundling services together with housing is a legacy of historic institutional models; instead, policy and funding models need to incentivise providers away from the philosophy of congregate care and services towards person-centred, tailored services (Purple Orange, 2019; Wiesel, 2011).

As noted above, TACSI have identified three functions of a home: agency, connection and identity (DeCampo, et al., 2021). Support services may happen in a home environment but they are not intrinsic to the home itself. Nelson, et al. (2007) suggest that housing systems should be designed to promote individual choice and control, including over the support received. This is beneficial for health outcomes as well as empowering greater independence, providing support for TACSI's notion of agency in being able to control what happens in one's home.

A model which has become popular in the UK, Homeshare, is not specifically about people with disabilities but instead began by pairing older people with younger people for a mutually beneficial home-sharing relationship (Macmillan, et al, 2018). Older people (householders) who want to stay in their home but require practical or social support to do so, can offer spare room in their homes to younger people (homesharers) who live there for a reduced (or no) rent and provide support around the house in kind. These arrangements have been shown to improve wellbeing for older people; reduce isolation; and assist older people to remain in their own home, while providing homesharers with affordable accommodation and intergenerational relationships. This model has also been adapted for people with disability who choose to share their home with other people without disability.

The homesharing model used in Australia by individuals with disability is similar, with the person owning or renting their own home that they then share with housemates who may

pay rent or may assist with domestic and other tasks in return for accommodation (Independent Advisory Council to the NDIS, 2018).

The Independent Advisory Council to the NDIS (IAC) has described homesharing and other models of supported living in their 2018 report, *Pathway to contemporary options of housing and support*. Other models of independent living include ‘Shared Lives’ or host families, in which a person or family opens their home to a person with disability, and ‘KeyRing’ accommodation in which people with disability live near to one another but in their own homes, sharing the assistance of a support person as well as benefiting from a peer support network. All of these models, according to the IAC, have the potential to reduce costs for the NDIS over time, as many people currently receiving 24-hour care in group homes may not actually need this level of support in their own homes. Bigby, Bould, & Beadle-Brown (2017), citing their own and others’ studies, estimated that 30-50% of people with disability currently living in group homes do not need the 24-hour support provided in a congregate setting, and could live in an ILA with appropriate and tailored support.

A critical component of sustainable accommodation is the funding that supports it. Many families have self-funded the purchase of a home for their family member with a disability (Belonging Matters, 2017; Community Living British Columbia, undated), however this is not feasible for everyone. Funding mechanisms need to be sustainable and recognise that early investment in suitable accommodation may reduce longer-term costs through improving health and social outcomes for individuals with disabilities (Thoresen, et al., 2022). There is also evidence that independent living may reduce costs, over time, through reducing the need for support hours as an individual becomes more independent (Squire & Richmond, 2017).

According to Hole, Stainton & Rosal (2015), it is not the particular housing model that guarantees success but rather: the quality of relationships in the individual’s life; the intention, planning and support provided to maintain the arrangement; and the larger policy and legislative structures that foster a supportive environment in which the independent living arrangement takes place. This need for supportive community and policy environments has been noted by other authors (Independent Advisory Council to the NDIS, 2018; Magee, et al., 2018; Rodgers & Rallings, 2016). The quality of formal and informal support networks also influence the quality and sustainability of an ILA.

Formal and informal support networks

“I try working out on my own, I try and figure out myself ... if I need a bit of help, I just ring my support worker and the chat helps.” (person living independently, quoted in Magee, et al., (2018)

Success factors:

Trusted relationships with family members, friends and/or support workers (including circles of support and microboards)

Having a leader or coordinator who ensures that the individual’s support needs are met

Strong family support

Control and choice with regard to use of funding

The type and frequency of support provided in ILAs differs widely, with Cocks, et al. (2017) reporting a range from half an hour to 356 hours a week; of the 130 ILAs reviewed by the authors, 45% received less than 10 hours of support a week. Support included both formal support and informal support provided by families. Successful ILAs provide support tailored to the individual's needs, although as Nelson, et al. (2007) have written, service availability does not always meet the preference of the individual.

Trusted relationships provide an element of security for everyone, including those who live with disability (Hole, et al., 2015; O'Connor, Gilbert, & McGrath, 2012). Informal support relationships with family and friends provide vital safety and security mechanisms that can help an individual feel comfortable when moving out of congregate living, knowing that there are people who will look out for them and be available to them (Independent Advisory Council to the NDIS, 2018; Magee, et al., 2018). Circles of support or microboards can be created to support the individual, to ensure safety, comfort, and engagement (Rodgers & Rallings, 2016), providing more formal structures through which family members, friends and support workers ensure an enabling environment for the individual (Rodgers & Rallings, 2016). Whatever the structure of support networks, time and again the evidence confirms that good support is based on authentic and committed relationships.

Bigby, et al., (2016:8) reported that people with disability have a good understanding of what they want in support workers: *"someone who listened, was not controlling, and had high expectations of their capacity to live independently"*. For many people, this may be through enabling an on-call support option as part of the overall structure of support, so that individuals can call upon assistance as they require it, rather than on a scheduled roster basis. As an example, Community Living British Columbia describe an arrangement by which four men living in their own, co-located apartments with a fifth apartment occupied by a live-in support person who is available as needed (Community Living British Columbia, undated). The IAC has pointed out that such arrangements often reduce the need for 24/7 paid support (Independent Advisory Council to the NDIS, 2018).

Having a plan and strategy for managing the formal and informal support required are essential to ensure a smooth transition (O'Donovan, et al., 2021; Wiesel, et al., 2015). O'Donovan, et al. (2021) have identified the importance of staff training so that service providers take a person-centred, strengths-based approach to support. As Šiška (2019:21) has argued, *"empowerment of service users is not merely about changing place of living but also about the attitudes and skills of staff."* O'Donovan and her colleagues further note that family members also may need training to better engage with the person with disability who leaves a congregate setting, to embed a person-centred, independent approach to the new way of life.

In addition to staff and family training, the IAC (2018) have also identified the role of a leader or coordinator who will make sure that the formal support system is meeting the needs of the individual and hold all the (sometimes many) pieces of the support system accountable. This person may or may not be in a paid coordination role.

Thoresen et al (2022) note the challenges in developing and sustaining informal support networks, with many of these dependent on the strength of family ties, while other authors acknowledge that the lack of informal social and support networks contributes to social isolation and loneliness (O'Donovan, et al., 2021; Bigby, Bould & Beadle-Brown 2016). Cocks, et al. (2017) found that quality of life scores tended to be higher for people who required fewer hours of support, and for those who went out more often in the community.

Social participation

"I have lived here all my life... Everyone knows me around town... I stop in for a chat in the community centre and the post office." (person living independently, quoted in O'Connor, Gilbert, & McGrath, 2012)

Success factors:

Mutually beneficial relationships with housemates, friends or neighbours

A 'good match' between people in house-sharing arrangements

Access to 'natural community support', eg the support that develops through relationship and being embedded in a place

Activities that foster the interests and skills of the individual, for instance sport, music or cooking

Structured activities, whether social, educational or through employment

Social inclusion is essential for providing a sense of belonging (DeCampo, et al., 2021; Magee, et al., 2018). One of the primary objectives of independent living arrangements is to facilitate greater engagement with the local community. Many of the stories in the *19 Stories* project first conducted in Australia, and later replicated in Ireland, refer to the value of associating with housemates, neighbours, and the general public (Magee, et al., 2018; Belonging Matters, 2017). O'Donovan et al. (2021) reported that most studies indicate some level of improved community integration following a move to independent living.

Bigby, Bould, & Beadle-Brown (2017) note that among several studies from the UK, Australia and Canada, while outcomes for choice and control were positive, outcomes were lower for safety, social engagement, health, and financial management. The authors conclude that quality of life is comparable to people with disability living in group homes on a range of indicators. This contrasts with findings from other studies, where researchers have found evidence of improvement in health, social, emotional and participation outcomes after transition out of congregate settings into supported independent living accommodation (O'Donovan, et al., 2021). Likewise, Fisher & Purcal (2010) compared qualitative data from six case studies to a prior study by Stancliffe & Keane (2000) relating to four outcome areas: "*social networks (friends and quality family contact); empowerment to make choices and decisions; use of community services (parks, clubs and shops); and participation in domestic tasks*" (p. 534), reporting improvements in all domains.

Hole et al (2015) interviewed 22 people with disability as well as 33 home-share providers and 13 family members in Canada to explore the experiences of people in home-sharing arrangements. They identified creating a '*good match*' between an individual and housemates as the single most essential component of successful home sharing. The authors identified seven factors enabling this relationship, including:

- ensuring that participants' motivations were healthy
- matching providers' skill sets to the needs of the individual
- building strong relational connections
- planning proactively for arrangements and transitions
- ensuring emotional and instrumental supports

- monitoring relational dynamics
- balancing independence and support (Hole, et al., 2015).

The authors identify a further component in successful home sharing as the importance of monitoring and safety, citing concerns expressed by both the home-share providers and the individuals with disability. Like any relationship, sustaining successful living arrangements will depend on ensuring that all parties feel safe and secure in their home life.

Other studies have concluded that the home-share arrangement can provide new opportunities for the individual with disability to make friends and engage with the local community, as they enter into the social network of their housemates (Hole, Stainton, & Rosal, 2015).

Through their interviews with a number of people with disability living independently in Ireland, O'Connor, Gilbert, & McGrath (2012) have identified a number of factors that support social participation and the use of '*natural community supports*', such as family support and encouragement, a secure home, sufficient income, a positive attitude, access to information about local activities and opportunities, and involvement in activities such as work or study, advocacy, or hobbies. Conversely, the lack of these factors (eg friends and supportive relationships, confidence and positivity, access to information) have a compounding effect and can make it difficult for a person to find a place for themselves within the broader community.

For O'Connor and his colleagues (2012), it is clear that many of the participants in the qualitative research valued their independence to the extent that they tried to minimise their use of community supports, while recognising the times and situations in which this support could be most helpful for them. For instance, a person may be able to clean some parts of the house (ie dusting furniture) but need assistance with others (ie washing floors). Or a person might rely on a family member to provide hot meals, but will reciprocate by taking them out for a meal regularly. This ability to provide reciprocal support was considered important by interviewees, as it demonstrated their capability and autonomy and also confirmed that they were not just recipients of help but could also provide help to others in turn.

Having friends and others who can welcome an individual into a community space or activity is also important. The lack of local relationships can also hinder participation in community activities, such as when a friend isn't available or moves out of the area, and can lead to a person withdrawing from social engagement if they don't feel confident or welcome enough to attend on their own (O'Connor, Gilbert, & McGrath, 2012).

Some people have reported difficulty in navigating public social environments such as pubs or concerts; instead, although they may have wished to participate in community events, they have joined peer-support networks of people with disability in which they feel more comfortable and less visible as a person with disability (Magee, et al., 2018; O'Connor, Gilbert, & McGrath, 2012). While this is beneficial as a support mechanism, it points to the need for public venues and social gatherings to be more aware of the need to ensure their environments are welcoming and inclusive.

Other authors also noted the importance of relationships as a natural human support, for people with or without disabilities. Through homesharing or other arrangements in which a person with disability lives with others, the ability to build relationships and expand one's social circle provides many benefits including greater community participation (Thoresen, et al., 2022). Conversely, the lack of these relationships can lead to isolation and the breakdown of an ILA.

Many people with disabilities live in poverty, and poverty itself can be a barrier to social participation (Bjorne, 2020; Magee, et al., 2018). Cocks, et al. (2017) found that just over one-third of people in ILAs were in paid employment, with a further 12% engaged in other types of work including volunteer work, and 26% engaged in community activities or 'alternatives to employment'. The lack of meaningful activities, whether paid or unpaid, can also be a barrier to successful ILAs.

Capacity building

I can look after myself ... and I learned how to cook my meal properly... Sweeping, washing my hair nicely, and brushing my teeth, putting out the garbage—I learned heaps of things ... I don't want to live with my mum any more. (person living independently, quoted in Wiesel, et al., 2015)

Success factors:

Access to learning opportunities and challenges that grow capabilities in daily living

Employment and educational opportunities

Peer-support networks

Training for support workers in person-centred approaches

Use of communication and assistive technology

Capacity building has been identified as an essential component of successful ILAs (Independent Advisory Council to the NDIS, 2018; Magee, et al., 2018; Arthy, 2017). This includes building domestic and self-care skills for the individual who has not previously had to undertake activities of daily living independently, as well as providing support for a person to acclimate to local transport routes, shops and neighbourhood facilities.

Hole, Stainton, & Rosal (2015) report that survey participants in a study of homesharing identified an increase in capabilities of individuals who moved out of group homes into homesharing arrangements. The authors concluded that personal development was an important goal for many of the individuals who moved into homesharing arrangements.

Brolin, et al. (2016) name the '*impossible mission in everyday life*' (that is, the simple but often daunting task of getting through each day) as the primary concern for people with psychiatric disabilities who are living independently. This refers to the challenge of navigating the external world on a daily basis while at the same time managing complex internal mental and emotional challenges. The authors identify the effective response to this mission as '*mastering everyday life*', developing a range of coping strategies to address the inherent challenges that arise each day. Support workers were influential, in this study, in assisting individuals to overcome the impossible mission of living a good life every day and building capacity to live more independently (Brolin, et al 2016).

There is little in the literature regarding the use of assistive technology to assist independent living (O'Donovan, et al., 2021). Lewis and his colleagues (2015) note that while assistive technology is readily available and can be transformative in supporting people with disability, access to information and knowledge about potential supports can be difficult. In other words, in many cases it is not a lack of technology that hinders assistive support, but the lack of facilitative systems to enable individuals to access and choose technologies that will

benefit them. The authors also note that some individuals chose not to have the technology installed in the end because of the challenge of incorporating new technologies into their lives, suggesting the need for adequate implementation support following installation of new technologies (Lewis, et al., 2015).

Likewise, O'Connor, Gilbert, & McGrath (2012) have reported that the use of technology – communication technology as well as assistive technology - has vastly increased the ability of many people to take control of their lives. For instance, many people have been able to shop or do their banking online using a computer or mobile phone rather than having to navigate potentially challenging physical environments. Mobile phone technology has also provided benefits for people who are deaf, through the use of texts and emails which allow instant communication between people without the need for a hearing intermediary.

However, these benefits can also diminish the need to meet people face-to-face which itself can create feelings of isolation, a risk that is also shared by people without disability, particularly people who live alone (Australian Government, 2021). Bigby, et al. (2016) also noted the potential for a lack of technology skills to make it harder for individuals to navigate information sources as more and more information becomes available only through the internet.

The evidence suggests that considerable assistive technologies exist that can enable people to undertake more domestic tasks independently, reducing the need for paid support services and increasing independence and life satisfaction (Lewis, et al., 2015; O'Connor, Gilbert, & McGrath, 2012).

Summary

There is a growing literature examining the effectiveness and outcomes of individualised living arrangements. While much of the evidence is anecdotal, qualitative, and sometimes inconclusive, there are consistent findings that, on balance, people with disability living independently have similar or better outcomes on a range of indicators when compared to people living in group homes. Fisher & Purcal (2010), reviewing the literature, concluded there is evidence of increased independence, social engagement, participation in community and domestic activities, and improved levels of satisfaction.

Brolin, et al. (2016) suggest that people moving out of congregate settings often have lower expectations of what a satisfactory housing arrangement might look like, thus accepting with gratitude conditions that others might find unacceptable. Some less favourable reported outcomes included poorer financial management, although this tended to be outweighed by the benefits of having choice and control over one's life (Bigby, et al., 2016). Indeed, choice and control have been identified as the primary benefits of independent living arrangements (O'Donovan, et al., 2021; Hole, Stainton, & Rosal, 2015; O'Connor, Gilbert, & McGrath, 2012; Community Living British Columbia, undated).

Detailed evidence for cost effectiveness is scarce, although Squire & Richmond (2017) have reported that over a ten-year period in England, the costs of funding independent living reduced for a majority of participants, reportedly due to increased capabilities and reduced need for services. However, the underlying financial data were not provided so it is hard to compare this conclusion to other studies. In general, there is a lack of consistent indicators used across the sector and the ability to compare across studies is limited due to the lack of consistency in measurement tools (O'Donovan, et al., 2021).

Choice and control were also identified as key factors in improved outcomes for people who received direct payments. Outcomes identified included:

- improved levels of support
- increased quality of life
- greater independence and confidence
- improved social relationships
- greater levels of community and economic participation (Angelova-Mladenova, 2019).

In addition, as Nelson, et al. (2007) have argued, perceptions of quality of life were not correlated to the amount of support received by an individual, but on their ability to choose and exercise control over their home environment. It is worth noting that quality of life was examined in a number of studies although not all used a formal quality of life measurement tool (for some examples, see Hole, Stainton, & Rosal, 2015; Nelson, et al., 2007; Cocks, et al., 2017). As more people move into independent living arrangements, it will be beneficial to conduct evaluation studies that measure quality of life and the factors that are most influential in improving life satisfaction.

Table 2 overleaf summarises the success factors that appeared most prominently in this review of the literature. Taken together, these factors provide direction for planning and implementing ILAs. Beyond these, however, the literature argues that a fundamental shift in thinking is required, so that people with disability are able to fully participate in life in the community and are not hidden away in isolation from the world. This has been an ongoing argument for the last few decades, with global advocacy contributing to the closure of large institutions and the movement of people with disability out of large congregate settings into group homes or independent living accommodation (Squire & Richmond, 2017; Brend, 2008). What is also clear, as Dickinson (2017) points out, is that the benefits of living in society do not accrue only to the person released from congregate isolation; people with disability also bring gifts to the community, as many of the *19 Stories* from Australia and Ireland demonstrate.

Opening hearts and minds to the potential for people with disability to contribute to society is a significant challenge, but is clearly the philosophical underpinning of much of the literature. As Dickinson (2017:3) writes:

“...we also need to work to educate the broader community about disability and to break down the stigma attached to disability. A significant proportion of the population have never met or interacted with an individual with profound disability – in part because of the segregation that has been created through disability policy – and do not know how to act, what to do or what to say. Although there have been some limited improvements in recent years, people with disability are also often absent from our public life and the media in significant ways.”

Table 2: Summary of success factors

Areas of support for ILAs	Success factors
Planning and preparation	<ul style="list-style-type: none"> Careful planning before implementation 'Independence of spirit' The creation of circles of support or microboards
Housing models and accommodation options	<ul style="list-style-type: none"> Affordable housing options Security of tenure Separation of housing and support provision Accessibility and ability to modify accommodation
Formal and informal support networks	<ul style="list-style-type: none"> Trusted relationships with family members, friends and/or support workers (including circles of support and microboards) Having a leader or coordinator who ensures that the individual's support needs are met Strong family support Control and choice with regard to use of funding
Social participation	<ul style="list-style-type: none"> Mutually beneficial relationships with housemates, friends or neighbours A 'good match' between people in house-sharing arrangements Access to 'natural community support', eg the support that develops through relationship and being embedded in a place Activities that foster the interests and skills of the individual, for instance sport, music or cooking Structured activities, whether social, educational or through employment
Capacity building	<ul style="list-style-type: none"> Access to learning opportunities and challenges that grow capabilities in daily living Employment and educational opportunities Peer-support networks Training for support workers in person-centred approaches Use of communication and assistive technology

The next chapter discusses the implications of these findings for the implementation of ILAs in Australia.

Chapter 3: Conclusion

The evidence, in Australia and internationally, demonstrates that people with disability can be supported to live independently in the community, even with high support needs (Magee, et al., 2018; Cocks & Thoresen, 2017; Lehmann, 2017).

It is also clear, in Australia as elsewhere, that an authorising policy environment with legislative and funding structures to support independent living is critical (National Disability Insurance Scheme, 2021; Independent Advisory Council to the NDIS, 2018). In addition to housing and social services, this authorising environment must also include a focus on the built form in order to ensure mainstream public places and services are accessible and welcoming (Magee, et al., 2018). Squire & Richmond (2017) point out that social attitudes regarding disability are as influential as funding and logistical factors in improving life experiences and opportunities for people with disability.

Bjorne (2020), in a philosophical reflection on the legislation supporting disability rights in Sweden, argues that there is a paradox inherent in legislation that seeks to ensure people with disability can live like others in the community, while at the same time requiring that a person with disability is not like others (because they require support through special services accessible only with a diagnosis). She points out that while the policy intention may be for people with disability to *live like others*, the reality – particularly in group homes – has been a tendency for the system to act *as if* the residents are living like others. People who live in group homes with 24-hour staff support are clearly not living like others in the community.

The move to individualised living arrangements offers the opportunity to embed the principle that all people should be able to live as independently as possible, recognising that some people will require more support than others in order to achieve this. Bjorne (2020) argues that the notion that people with disability *live like others* is an illusion, when clearly people with disability experience discrimination, unemployment, segregation, and poverty to a greater extent than people without a disability. She considers such illusions harmful with a tendency to perpetuate the status quo of a life lived differently than those without disability. To get around this, it is not enough to have enabling policy and legislation, but society itself must promote *living with others*, and recognise that the individuals who make up society need to change their responses to, and understanding of, disability and its many manifestations.

This review did not examine the policy and systemic changes required to support ILAs. The NDIS is currently reviewing its own structures to support independent living, and the IAC has argued cogently for policy and system changes. It is clear, however, that policy and system changes are required to create the systemic and structural changes required for people to *live with others* rather than living *as if* they live like others.

The literature confirms that successful implementation of ILAs is dependent upon the commitment and beliefs of people with disability and those who know and support them. There were many stories of family members who were determined that their loved one would achieve a level of independence not supported by the service sector, and made this happen through hard work, passion and commitment of their own resources, often in spite of system and funding barriers. People with disability who have people around them who love them and are dedicated to their well-being are more likely to achieve independent living than those who do not.

For this reason, although the review has focussed on what practical factors support independent living, it is evident that these are only possible where there is a strong personal

network supporting the individual, including people dedicated to the achievement of that goal. Above and beyond any policy or legislative changes, it is the relationships within an individuals' life that will be the best safeguard for successful independent living.

For that reason, changing perceptions and behaviours of people within the community to make people with disability more visible and included is even more important than policy and legislative changes. There is a strong need to create a social fabric that includes people of all abilities, so that people in ILAs are welcomed, are and feel safe, and are empowered to live their best lives. This requires change, not from people with disability, but from others who are willing to share their lives with people with disability, and to make the accommodations necessary to create an inclusive and enabling neighbourhood.

In conclusion, the primary factors that support the successful implementation of ILAs fall into five categories:

- careful planning and preparation
- quality and availability of appropriate housing
- formal and informal support networks
- social participation
- capacity building.

The evidence is clear that ILAs can achieve as good or better outcomes for people with disability, and can benefit their families as well as others in the community or workplace. It also appears clear that for most people independent living is in their best interests to achieve as high a quality of life as possible. Surely this is a goal worth achieving, for everyone.

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