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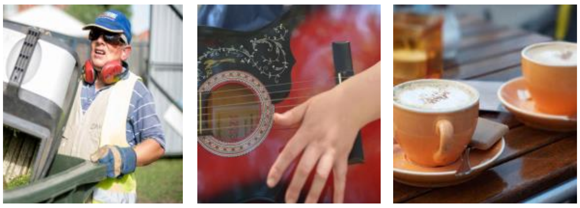

Supporting inclusion of people with cognitive disabilities

‘Not as connected with people as they want to be’ - Optimising outcomes for people with intellectual disabilities in supported living arrangements.

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Executive Summary

Background & Method

Block funded, shared supported accommodation - group homes - have been the dominant service model in Australia since the 1970s. In the UK and Canada particularly, dissatisfaction with the group home model, in terms of outcomes and inflexibility has led to the growth of what is generically known as 'supported living' which separates provision of housing and support and has the potential to deliver more individually tailored support for community living. Little evidence exists about outcomes of supported living or the support arrangements that make it successful. Increased knowledge about the contributing factors to good quality of life outcomes for people who live in supported living arrangements will be important to the National Disability Insurance Agency in making individualised funding decisions, to the disability sector in developing services and necessary practice skills, and to people with intellectual disability and their families in making choices about housing and support options.

The study aimed to develop knowledge about the configuration of support arrangements and social contexts that optimise the success of supported living arrangements and quality of life for service users with intellectual disability. The overarching research question was what factors are necessary to ensure good quality of life outcomes for people with intellectual disability in supported living arrangements.

Mixed methods were used in three distinct sequential phrases: 1) focus groups with people with intellectual disability living in supported living arrangements and staff in services delivering various types of support to people in this type of living arrangement. This phase provided an understanding of the diversity of housing and support arrangements, the experiences and perspectives of service users and support providers, and informed the development of the survey; 2) a face-to-face survey of service users in supported living arrangements provided a snapshot of the types of support and tenancy arrangements, service user characteristics, outcomes and support costs; 3) in-depth case studies with participants selected from the survey respondents explored further factors associated with both good and poor quality of life outcomes.

Summary of Findings

Focus Groups with Service Users

Thirty-four people with intellectual disability in supported living arrangements participated in 7 focus groups. Most were middle-aged, lived in rented social housing, alone or with a co-tenant. Most received a few hours of drop in support with the practical tasks of everyday living. They were secure in the knowledge that back up support would always be available from family or their service provider if they needed it. They used community places and had a mix of strong and weak social ties. Contrary to some overseas studies, most participated in regular structured activities.

Unequivocally people with intellectual disability thought supported living arrangements had enabled a greater sense of independence and control over their lives compared to living with their parents or in a group home. For most people, the freedom to be self-directed, away from others 'dictating' what to do, outweighed the downsides to supported living, which they identified as: having little disposal income, no access to technology at home, limited control over their financial affairs, being lonely, feeling unsafe to go out at night, and difficulties negotiating the quality of their support, social relationships and negative social attitudes.

Focus Groups with Service Providers

Seven staff, who played differing roles in supported living arrangements, from 5 organisations, participated in focus groups or individual interviews. Providers' perspectives about challenges of supported living arrangements mirrored those raised by people with intellectual disability themselves. They gave more attention than service users however to the difficulties of maintaining good health and the negative consequences of social housing that concentrates together people with difficulties negotiating social relationship. They identified different types of support that people with intellectual disability required to thrive in supported living arrangements: practical; emotional; personal development; enabling choice and control; connecting to community groups and building social relationships; connecting to peers; resource raising; managing health and relationships with health professionals; liaison and advocacy with other services; keeping track of things through monitoring, co-ordination and capacity for episodic more intense support; managing tenancy; and backing up informal supporters. From the perspective of service providers, all support whatever its type should be person-centred, flexible, co-ordinated, ethical and respectful of service user choice and control. In their view, policy and funding bodies undervalued co-ordination and monitoring.

The providers suggested that in many instances they and others went beyond their remit, by absorbing the costs of the co-ordination or case management they saw as necessary but were not funded to provide. They provided too some glimpses of the range of skills required by support workers to straddle the breadth of support they might have to provide and manage tensions between enabling, respecting and protecting people who were at times vulnerable to abuse by others or self-neglect.

Service User Survey

The survey was in two parts; a worker who knew each service user well completed the first part, and the second part involved a face-to-face interview with each services user and their worker. Surveys were completed with thirty-one people in supported living arrangements and included many of the same people who had participated in the focus groups. The survey provided more detailed data confirming the broad-brush descriptions gained from the focus groups. On average service users received 4 hours a week of practical support with everyday living, primarily through block-funded outreach or an ISP. A majority participated at least 3 days a week in regular structured activity as a volunteer or supported employee, attended some form of social group and had regular contact with their family. The estimated mean cost of support, including day support was $30,435 ranging from $11,068 to $97,595. Comparison of data about service users in supported living and group homes, drawn from a large longitudinal study, showed that approximately a third of residents in group homes had an ABS score that fell in a similar range to that of people in supported living arrangements. Further analysis using a matched sample of service users in supported living and group homes showed remarkably few differences in the quality of life between people who were receiving these very different types of support.

No-one in supported living arrangements had what might be construed as a ‘good’ quality of life and they were categorised as having either a Mixed-Good or Mixed-Poor quality of life. Overall the data suggested that participants did better in terms of self-determination and emotional well-being than physical well-being, social inclusion, interpersonal relationships or personal development. Indicative factors associated with a better quality of life were younger age, having autism, better health status, strength of family involvement and participation in regular structured activity.

Case Studies

Six cases were selected to represent the diversity of people and their experiences of supported living. A more detailed picture of each person’s life circumstances and support arrangements was gained by talking to them again and interviewing in more depth at least two other people involved in support provision.

The six participants had what we termed a ‘mediocre’ rather than good quality of life. The case studies mirrored the issues raised by both service users and providers vividly illustrating the benefits and challenges of community living for people with intellectual disability. Strikingly, despite their loneliness and absence of close friendships, most service users were satisfied with their living situation and particularly the degree of choice and control they had over their lives. The case studies illuminated the changes in peoples’ lives that might affect support needs, demonstrating the need for flexibility. They gave few further insights into the factors associated with good quality of life in addition to those identified in the survey. The case studies did demonstrate the absence of consistent or sufficiently intensive support to enable people to build and retain a diverse range of social relationships with peers or other community members.

Discussion

These findings are similar to international studies that consistently suggest greater choice and control by service users is the hallmark of supported living. Indeed this theme emerged very strongly from the qualitative data. People with intellectual disability were discerning about good support workers, which they defined as people who listened and had expectations of them. They needed to know who would be coming through the door. Their expertise should be used in appointment processes and they need to be consulted about any staff changes.

Unlike earlier research a majority of service users participated in regular structured activity either in a disability day program, as a volunteer, or supported or paid employee. Our finding that participation in at least 3 days a week of regular structured activity was one of the factors associated with better quality of life suggests that planning for supported living must include and appropriately cost support to enable this type of participation.

A majority of people in supported living arrangements relied on social or public housing and many preferred living alone. Shortage of affordable and social housing poses a major obstacle to expansion of supported living. Our study highlighted the disadvantages of high density social or public housing developments that congregate socially disadvantaged people together and affirms evidence about the advantages of living in an ordinary house dispersed in the community rather than small clustered or segregated settings (Mansell & Beadle-Brown, 2010). Building low density affordable housing in general and dispersed rather than clustered housing specifically targeted for people with disabilities will avoid creation of underlying structures that have potentially negative consequences for people with intellectual disability in supported living.

Our findings were similar in some respects to the only other published Australian study (Stancliffe & Keene, 2000) that compared supported living to group homes; there are few significant differences in the quality of life between matched samples of service users in supported living and groups homes; support costs in group homes are much more expensive, and; there is overlap, in terms of service user level of ability. We concluded that between 30-35% of group home service users fell into the same range of adaptive behaviour score as those in supported living, and could potentially live in supported living options. These were people with mild or moderate rather than more severe levels of disability.

Our findings suggest supported living is a preferable option to group homes for many people, both from the perspective of economics and increased choice and self-direction for people with disabilities. But design of funding schemes and service development must meet the pressing challenge to address support deficits that will improve quality of life outcomes for people in supported living. A detailed reading of this report reveals a catalogue of the problems encountered and issues that require attention. Some stem from the nature of intellectual disability, pointing to the need for more skilled or different kinds of support. But individual difficulties are often compounded, and the need for support increased, as a consequence of negative community attitudes and the failure of services and systems to adequately adjust their processes and ways of doing business to the needs of people with intellectual disability. The Centrelink Centre Pay system caters well for the needs of people with intellectual disability, enabling them to manage payment of utility bills and rent through direct deductions. In contrast, the State Trustees office is often so difficult to do business with that the assistance from a support worker to deal with them is required.

There are particular challenges in supporting people to have good health that will only increase as the current cohort of middle-aged people get older. The undervaluing and lack of funding for co-ordination and case management tasks will become a more pressing problem as the number of people in supported living increase and non-government organisations can no longer absorb these costs. Despite being competent in using mobile phones, iPads and computer programs such as Skype, the majority of participants did not have access to internet or a computer at home and made only rudimentary use of devices. They had little or no access to programs or apps designed to compensate for cognitive disability, particularly low literacy, or to the technical support to set up home internet or mobile devices. Technology has potential to support people with intellectual disability to establish social connections and navigate communities but they are also in danger of further social exclusion as basic information and transactions such as train and bus timetables and medical appointments go online, if steps are not taken to enable their access to technology as a key element of supported living.

The biggest challenges in optimising outcomes in supported living are enabling social inclusion and interpersonal relationships. First, in supporting people with intellectual disability to negotiate often difficult social relationships, and second in providing effective and consistent support to enable people to connect with peers, and the places or activities in communities that are catalysts for friendships. Insufficient people in the study were part of a Key Ring network to undertake any statistical analysis of its impact, but this model warrants further investigation. There were some indications that self-advocacy groups are important places for making friendships. Our findings add further evidence about the urgent need in Australia for demonstration programs to develop and trial person-centred approaches to supporting people with intellectual disabilities to develop and maintain social relationships. Such initiatives are required to identify the key elements of effective support to inform staff practice and service design, as well as those who plan with individual service users and National Disability Insurance Scheme (NDIS) funding schedules.

This study identified factors associated with a better quality of life; being younger age, having autism, better health status, strong family support and participation in regular structured activities. The mediocre quality of life of most participants means a research design, that targets a sample of people with an identifiable very good quality of life will be necessary to identify factors associated with good rather than mediocre outcomes.

Although small scale, this study has added new knowledge to the limited understanding of the supported living arrangements for people with intellectual disability in Australia, and to the wider literature. As well as painting a detailed picture of the life circumstances of people in supported living it has provided more evidence about the benefits of supported living compared to group homes and the overlapping populations of these two types of service. It will potentially inform service design and development of ISPs by illustrating the range of support that may be required, key elements of all support and the practical drop-in support with unlimited back up that works well for service users. We have provided evidence for the importance of participation in regular structured activity to the quality of life of people in supported living and the need to build this into costs and design of ISPs. The study has illustrated the shortcoming of current support arrangements and the challenges that will have to be met if supported living expands in the future, particularly in finding effective strategies to support people to develop friendships and negotiate difficult relationships with others be they utility sales people, neighbours, co-tenants or community members with negative attitudes towards people with disabilities. Our study suggests too the need for continuing work to remove more structural obstacles to a good life in the community for people with intellectual disability, by initiatives to foster more positive community attitudes towards people with disabilities and the growth of dispersed affordable housing.

Recommendations

- In order to identify the key elements of effective support for the development and maintenance of social relationships, demonstration programs should be established to design and trial person-centred approaches for supporting social relationships.
- Promising processes, models and practices for enabling people with intellectual disability in supported living to develop social connections and in particular close friendships should be investigated, including Key Ring model and Self Advocacy groups.
- Individual planning for supported living must include and appropriately costed support to enable regular structured participation in purposeful activities such as paid, supported or voluntary work.
- Ways should be investigated to provide low cost support to enable people with intellectual disabilities in supported living to access basic technology such as internet connections, computers and mobile devices and take advantage of adaptations designed for people with low literacy and cognition.
- Individual planning for people in supported living should take into account their need to access and use technology.
- Individual support planning for people in supported living arrangements should take into account the necessity for support to be person-centred, co-ordinated, and flexible enough to adjust to changes in a person’s life, by providing more intensive episodic support when necessary.
- The potential of people with mild or moderate intellectual disability to live in supported living arrangements, the very significant cost differential between

supported accommodation and supported living arrangements and the minimal differences in quality of life for service users between these two types of support should inform NDIA policies and be considered in individual planning decisions.

- The NDIS or State Governments should develop initiatives to provide information about alternative housing and support options to people with mild or moderate intellectual disability living in group homes and provide support to move into supported living arrangements should they chose to try this option.
- People with intellectual disability should be recognised as ‘experts by experience’ about what constitutes good support and should be involved in processes of staff recruitment.
- Affordable housing should avoid concentrating people with disabilities and other disadvantaged groups together, and development of any housing specifically targeted for people with disabilities should be dispersed rather than clustered to avoid creation of underlying structures that have potentially negative consequences for people with intellectual disability in supported living.
- The responsiveness of the State Trustees Office to people with intellectual disability should be investigated and their business practices in relation to this group, their clients should be reviewed.
- Further research should be undertaken to identify factors associated with good quality of life outcomes in supported living for people with intellectual disability using a design that seeks out people reputed to have good outcomes.

‘Not as Connected With People as They Want To Be’ - Optimising Outcomes for People with Intellectual Disabilities in Supported Living Arrangements

Introduction

Since the 1970’s the adoption of deinstitutionalisation in Australia, has been marked by the gradual closure of institutions and development of supported community living for people with intellectual disability. The dominant service model in all states has been block funded shared supported accommodation (group homes); which combine provision of housing and support, for 4-6 people in ordinary houses with rostered staff support over 24 hours. In Australia approximately 16,433 people with disabilities live in some form of shared supported accommodation and in Victoria almost 5000 people (Australian Institute of Health and Welfare, 2014).

While research shows the overall quality of life for residents in group homes is superior to institutional living, outcomes are variable, particularly on dimensions of engagement, choice, social relationships and inclusion in community activities (Bigby et al, 2012; Kozma et al., 2009). Key determining factors are level of disability, what staff actually ‘do’ to support the people they serve (Mansell & Beadle-Brown, 2012) and effective leadership in implementing and sustaining good practices (Emerson & Hatton, 1996).

Development of Supported Living

In the UK and Canada particularly, dissatisfaction with the group home model, in terms of quality of life outcomes and its inherent inflexibility has led to the growth of what is generically known as ‘supported living’ (Kinsella, 1993). This separates housing from support, and generally means people live alone, with a partner, or share with one or two other people, in accommodation they own or rent, with ‘drop-in’ or full time support tailored to their individual needs (Howe et al.,1998; Stainton et al., 2011). In the US the term ‘semi-independent living’ is used to describe this type of arrangement but, unlike the UK, generally only refers to people who do not require 24 hour support. In Australia, Cocks and Boaden (2011) used ‘personalised residential supports’ to differentiate these newer forms of housing and support from traditional models. Such models of accommodation support, reflect article 19 of the UNCRPD and the right of people to live in the community and to choose where and with whom they live, and Mansell and Beadle-Brown’s (2010) definition of community living as: accommodation located among the rest of the population; that reflects the range of options ordinarily available to the wider population; **e**nables people to choose where, with whom and how they live, and; provides whatever help is required to enable successful participation in the community.

The ‘paradigm shift’ during the last decade that aims to deliver greater person-centred support by replacing block-funded service models by individualised self-directed funding has significantly increased opportunities for supported living options in Australia. Stancliffe’s (2002) analysis of funded accommodation services, for example, points to a rapid increase in drop in or outreach support. Individual support packages (ISPs) in various guises are being rolled out in all jurisdictions and lie at the core of the National Disability Insurance Scheme (NDIS) (2013). These reforms together with the 2012 Federal Government Supported Accommodation Initiative are leading to innovative and more diverse forms of housing and support for people with intellectual disabilities. There is however little data available in Australia about the nature of these options or the people who have taken them up.

Absence of Research on Support Arrangements

There is little evidence about outcomes of supported living, support arrangements that make it successful, or the types of local community where it flourishes (Mansell & Beadle Brown, 2010). Early research in the UK and US that compared supported living to group homes, controlling for individual differences of service users, found supported living to be advantageous on quality of life dimensions of choice, frequency and range of recreational or community based activities, and significantly more cost effective (Howe et al., 1998; Emerson et al., 2001; Stancliffe, 1997; Felce et al., 2008, Perry et al., 2012). On other dimensions, such as vulnerability to exploitation in the local community, frequency of scheduled activities, health and money management, research has found poorer outcomes for people in supported living compared to those in group homes (Felce et al., 2008; Perry et al., 2012; Emerson et al., 2001). The only published Australian study was very small, but had similar findings about advantages of supported living (Stancliffe & Keene, 2000). In contrast, a more recent large Canadian survey found fewer differences between quality of life outcomes for residents in supported living and group homes (Stainton et al. 2011). The only dimension on which supported living excelled was choice and control. This study suggests the absence of appropriate support for residents in supported living may explain the failure to realise advantages found in other studies (Stainton et al, 2011).

Stainton et al.'s conclusion echoes earlier research in group homes about the significance of support arrangements and the quality of support to good resident outcomes. Remarkably, none of the studies of supported living have examined the nature of formal arrangements, either in terms of personal or tenancy/housing support, the availability of informal support, broader community characteristics, or other factors that may facilitate or obstruct successful outcomes. The findings by Emerson et al. (2001) suggest locality may be an important factor. The absence of skilled leadership identified as a factor in the weak implementation of group homes (Beadle- Brown et al., 2012; Clement & Bigby, 2010), may also be important, and this is likely to be exacerbated by the challenges posed by delivering support in more dispersed and individualised settings.

Although there is very little systematic evidence, the Key Ring model suggests supports for service users in a locality to network with each other and the local community are important to successful supported living (Fyffe & Bigby, 2008). The experiences of reference group members suggested that tenancy support is an important factor alongside individual support co-ordination for supported living to be successful, but both access and the cost of social housing may hinder such arrangements. In an evaluation of innovative housing services in Victoria, Fyffe, McCubbery and Bigby (2007) suggested attention to collective as well as individual needs when people share accommodation was important to factor into support arrangements. Stainton et al. (2011) speculated that the strength of informal support from family may be an important factor in enabling good outcomes in supported living.

Significance of Study

The management of self-directed funding and co-ordination of support arrangements are more challenging for people with intellectual disability, particularly those without strong informal support networks, than for people with disabilities without cognitive impairment. If the potential advantages offered by individual support packages and supported living are to be realised by people with intellectual disability, and are to become a real alternative to traditional group homes, then a greater understanding is required about the type of support arrangements and others factors associated with making it work and good quality of life outcomes.

The importance of such an understanding to further the development of supported living is reinforced by the current situation in Victoria, where recent research suggests some residents do not require the high level of support offered in group homes (Mansell, Beadle-

Brown & Bigby, 2013). The dominance of a group home model has meant that it has been perceived as the only option for people who cannot remain in the family home for whatever reason; some service users do not require this level of support and have the potential to live more independently. This study found services users in a sample of 137 people in 34 group homes in Victoria were significantly less disabled than those in comparable English services (Mansell, Beadle-Brown & Bigby, 2013), and included more people with high levels of adaptive behaviour. These service users were engaged in meaningful activity and relationships, albeit slightly limited in variety, but with very little contact or assistance from staff. From a policy perspective, this may represent an inefficient use of resources, particularly given the evidence of benefits in terms of some aspects of quality of life as well as lower costs in supported living (Felce et al., 2008). The development of supported living options, and perhaps also offering these to current group home service users may increase quality of life for people and liberate resources for use elsewhere. Such moves have already occurred in Victoria where approximately 150 service users moved out of group homes to various supported living options between 2002 and 2009 (DHS, 2010). Anecdotally some service users fared very well, whilst in the experience of our research partners, the support for some others has failed to be adequate and some people have eventually returned to group homes. However, there has been no systematic evaluation of the housing options, support arrangements or outcomes for these service users.

Aims and Objectives

The aim of the study was to develop knowledge about the configuration of support arrangements and social contexts that optimise the success of supported living arrangements and quality of life for service users with intellectual disability. This will contribute to the further development of supported living options in Australia. The overarching research question was; what factors are necessary to ensure good quality of life outcomes for people with intellectual disability in supported living arrangements? Specifically,

- What are the quality of life outcomes of people with intellectual disability who receive disability funded support in supported living arrangements, and how do these compare to people living in group homes?
- What individual characteristics are associated with good outcomes for people in supported living?
- What support arrangements are associated with good outcomes of supported living?

- What characterises the informal and formal personal support arrangements, housing or tenancy arrangements, and localities where residents experience good quality of life outcomes, and how do these differ for residents who experience poorer outcomes?
- What is the average cost of housing and support for residents in supported living?
- What factors facilitate and obstruct good outcomes of supported living?

Approach and Overview of Methods

The study used mixed methods and had three distinct sequential phrases: 1) focus groups with people with intellectual disability living in supported living arrangements and staff in services delivering various types of support to people in this type of living arrangement. This phase aimed to understand the diversity of housing and support arrangements, the experiences and perspectives of service users and support providers, and inform the development of the detailed survey conducted in the next phase; 2) a face to face survey of service users in supported living arrangements was used to provide a snapshot of the types of support and tenancy arrangements, service user characteristics, outcomes and support costs; 3) in-depth case studies with participants selected from the survey respondents were used to further explore factors associated with both good and poor quality of life outcomes.

The study was approved by the Human Research Ethics Committee of La Trobe University, and all participants, gave either written or verbal informed consent to participate in the study. To ensure confidentiality this report does not identify the organisations from which people received services and all names of locations, service users and staff have been changed.

The project reference group included 4 service providers, a paid worker from a housing advocacy group for people with intellectual disability, and two people with intellectual disability who were board members of that organisation, one of whom had experience of supported living. The project group met regularly for the first 12 months of the study and members supported recruitment of participants, discussed the findings from the focus groups and assisted with the design of the survey.

The organisation of this report reflects the three phases of the study. The method, findings and a brief discussion of each phase are reported separately, and the final section draws together the common threads of the findings. The appendices contain a detailed set of tables from the survey.

Service User Focus Groups

The focus groups with people with intellectual disability aimed to understand the diversity of their supported living arrangements, explore their perspectives about living in this type of arrangement and identify some of the key issues that affected their quality of life. Together with the knowledge gleaned from the literature the focus groups were also intended to inform the design of the individual survey.

Method

People in supported living arrangements were recruited to participate through invitations and advertisements circulated through self-advocacy groups, social housing and disability support organisations. The Department of Human Services also forwarded a letter inviting participation in the study to people whose client service record suggested they had moved out of a group home in 5 years prior to the study. The criteria for inclusion were that; people had an intellectual disability, were registered as eligible for disability services with the Department of Human Services, were in receipt of some type of disability service, lived either alone or with a maximum of 3 other people who were not parents or siblings, and their housing tenancy was not tied to the receipt of support from the same organisation. Reliance was placed on individual participants identifying themselves as having an intellectual disability and as being in receipt of disability services. Several people attended one of the focus groups who did not identify as having an intellectual disability and their comments were removed from the transcript of that group.

Participants in the focus groups were invited to share their experiences and perspectives on supported living arrangements - what was working well and not so well and how their current arrangements compared to previous living situations. Questions were not invasive and detailed information about individuals’ circumstances was not sought. The groups were co-facilitated by two members of the research team and each lasted between 60-90 minutes

Discussions were recorded and transcribed and the qualitative data analysed using a grounded theory approach (Charmaz, 2014) utilising *Nvivo* as a data management and coding tool. The initial coding schema and emerging categories were discussed among all members of the research team and with the project reference group.

Participants

A total of 34 people who met the eligibility criteria participated in the 7 focus groups that were held in different parts of metropolitan Melbourne and in 2 regional towns. Each group had between 3-8 participants. Table 1 sets out the location, and some socio-demographic data about the participants in each of the groups.

Table 1. Service user focus groups – location and participant numbers

Location	Participants	Male	Female	Average Age (years)
FG 1. Regional – South East	5	2	3	48
FG 2 .Regional -South East	3	1	2	44
FG 3. Inner West Melbourne	3	2	1	55
FG 4. Northern – Melbourne	6	5	1	41
FG 5.Inner South- Melbourne	4	2	2	45
FG 6. Regional – North East	8	3	5	38
FG 7. Outer South - Melbourne	5	2	3	43
Total	34	17	17	42

As Table 2 shows most people either lived on their own or with one other person who was usually an unrelated co-tenant. Five people lived with an intimate partner and one person with their child. The participants ranged in age from 22 to 70 years, and were predominantly middle- aged rather than young adults, with an average age of 42 years.

Findings

Housing Tenure and Support Arrangements

As Table 2 shows the majority of participants rented rather than owned their home, and most lived in some form of subsidised social housing, rented either from the State Department of Housing or a Social Housing Association. Twelve people lived in housing that had been built by a disability service provider and formed part of a small cluster specifically for people with disabilities. Eight of the twelve lived in a cluster of 6 units that had been built on the grounds of a day centre, although were not owned by this organisation. Four people lived in a complex of apartments, each with bedsitting rooms and a shared lounge and kitchen that was owned and built by a disability service organisation. Private rental was the least common form of tenure. Comments from focus group participants about the high cost of private rental and the reluctance of private landlords to rent to people with disabilities may account for the small number of people in this type of tenure. For example one focus group participant spoke about the difficulties she had experienced in getting privately rented accommodation, saying,

> We went through three real estate agents and they never gave us a house, they knocked us back then they [Jane's parents] bought this house that we live in now [FG1].

Table 2. Housing tenure and living situation of service user focus group participants

Focus Group	FG1	FG2	FG3	FG4	FG5	FG6	FG7	Total all groups	
								n	%
Housing Tenure									
Own home	1		2				2	5	16%
Private rental	2	1					1	4	12%
Social housing/ housing commission	2	2	1	6			2	13	37%
Service owned /social housing cluster					4	8		12	35%
Living situation									
Alone	2	3	2	1		3	4	15	44%
Partner				3		1	1	5	16%
Co-tenant	2		1	2	4	4		13	37%
Other family (child)	1							1	3%

Many participants were not clear about the source or limitations on the formal support that they received, and the focus group context meant the specific details of support received by each participant were not ascertained. However, it was clear that the most common form of support was 'outreach' from a worker employed by a disability service provider that was block funded by the Department of Human Services to deliver regular support of low intensity (a few hours a week) for a specific number of people. Participants talked about outreach support as a worker who dropped into their homes at a regular time each week who helped them with things such as, reading letters, paying bills, doing the shopping, some cleaning, menu planning, banking, accompanying them to appointments or going out for coffee. The most common pattern was once a week for one or two hours. Participants also talked about being able to ring the worker or the outreach co-ordinator at other times for advice or support for unexpected situations.

A small number of people received either just an individual support package (ISP) or an ISP as well as block funded outreach support, and some also received HACC services, such as cleaning or home maintenance from their local government. People with ISP's received more intensive support with tasks of daily living such as budgeting, shopping and cooking. Several participants were members of a Key Ring Network that supported them to meet up regularly with other network members who lived in the same area, and provided them with individual advice and referral to other services. Many participants talked about managing the payment of their utility bills and rent through the Centre Pay facility of Centrelink which made direct deductions of a pre-set amount from their fortnightly disability support pension. Some participants also gained regular support through attendance at a disability day program, a self-advocacy group, volunteer and paid part time work. Many participants were in regular contact with family members and talked about support from their parents or siblings to manage finances or day to day living tasks.

Positive Aspects of Supported Living

Sense of security and help being available

Despite their lack of clarity about the source of support, all participants had a strong sense of security - that help would be available should they need it. Everyone named at least one 'go to' person they could contact if they needed help to sort out any difficulties. Many people named both paid workers and family members whom they could readily contact for help. They said for example,

> I've got family around Victoria; they always help me with everything I want. If I do get some problems I just call mum or dad or I could call Donna and Hatty [workers] to discuss things [FG6].

> I do a lot of cooking…I cook a big meal and then put a portion of that into different containers and then freeze them but I do my own clothes shopping. Shoe shopping can be a hassle but my mum helps with that and I guess that's mainly it but if I need help with something it's either mum or Susie or Roger might help out, Roger usually does the maintenance around the unit [FG9].

Sense of freedom to do your own thing and make up your own mind.

All participants talked about the freedom this type of living situation gave them compared to where they had lived in the past. They conveyed a strong sense that they could do their own thing without having to conform to the wishes of a family member or worker -

"you can do what you want", "no-one can order me around" and "you don't have to ask". Participants who had lived with their parents as well as those who had lived in group homes had similar views about the relative freedom of supported living, saying for example,

> I've enjoyed it more than anything..... even living with my mum 'cause my mum was always telling me to do this, do that, you can't do this, you can't wear that, you can't do this, telling me what I can do and what I can't do and things like that, she was always bossing me about [FG2 person previously at home with parents].
>
> I live on my own now and I like it, it's better. Freedom, there's no people dictating to me and telling me what to do, I like it better, I don't want anyone dictating to me. That's what I like about life. I can come and go as I please...you can live and do what you like. See if I want to do something at my place I can…[FG3 person previously in a group home].
>
> You can do what you want, please yourself what you do, be home when you want, you don't have to answer to anyone, you please yourself where you want to go, if you want to go to Melbourne for the day you don't have to ask anyone, if you want to bring someone else, you don't have to ask [FG1, person previously in a group home].

As well as enjoying the freedom to make up one's own mind about what to do, participants spoke about their enjoyment of being independent and doing things for themselves. Rather than resenting having to undertake domestic tasks, they valued being able to do these things for themselves, saying for example,

> I'm pretty good doing everything for myself, I'm pretty independent and get to work and go to Melbourne, do my own shopping, go to the bank on my own, the Trustees put the money in the bank [FG1].
>
> I'm independent and I do everything …Well I do my own shopping; I just do things [FG3].
>
> It's better because...I can pay my bills, have people over for coffee or you know go out with people. Do your own thing, you know, do your own thing as you need it [FG4].

Socially connected – diverse weak and strong ties

All participants talked about their social connections to family, friends or people in their local community. For many their social networks were made up of a diverse mix of people, with whom they had strong or weak ties. Many, but not all people were in regular contact with family members, parents, siblings or nieces and nephews, and a few also had their own children or a partner. Family members were a source of both concrete help and social or emotional support. For example, talking about their connections with family members participants said,

> My oldest nephew is 21 next year and my godson was 20 last year and my nieces and nephews are 18 in October so I see them quite often, they pop round and put stuff together [FG4].
>
> My brother is coming to do some work for me, my sister asked him [FG3].
>
> I ring my brother once a week, I ring my sister at Wangaratta once a week, and my other sister I talk to her every day [FG4].
>
> Elizabeth and I got married in May last year and we both enjoy our work...we enjoy living independently and want to keep doing that…We enjoy being on our own and doing our own thing. We might have workers come in from time to time but we're okay with that [FG4].

Some people talked about the friendships they had with people with whom they worked or having a girlfriend or boyfriend with whom they spent time. Most friendships as in the example below from a participant in FG1 seemed to be with other people who also had intellectual disability.

> I'm good friends with all my work colleagues…They treat me as equal…Sometimes my friend who also works at Safeway come and visit and my other friend he works for the Shire, he comes and visits. [Do they have disabilities?]. Yeah…My boyfriend, he's just fun to hang around with and he really cheers me up when I'm having a down day.

Many participants also talked about being recognised and having brief encounters with neighbours or other people in their immediate locality. They said for example,

> I say good morning when I go to work, say hello…a bloke said g'day to me the other day, I don't know his name [FG1].
>
> I know everybody around me and it's only a court [cul de sac] so there's no problems however if I go away someone is always there to watch my house and keep an eye on

> the place and I've got a lot of friends around the area that always keep an eye on me [FG2].
>
> I talk to the people next door [FG3].
>
> I might talk to a couple of people throughout the day, on the phone, but I know a lot of people but they're not necessarily friends but acquaintances [FG4].

Connections to locality – use of community facilities

Participants were familiar with their local area, and many made use of public and private facilities such as gyms, bowling or social clubs, coffee shops, pubs, and churches. They said for example,

> I prefer to go out and see people, I don't like hanging around the house all the time, I like to be out and go for a walk or have a drink [FG1].
>
> At church…well they are like friends to me, they're really nice and we had a morning tea and really lovely people, really nice [FG3].
>
> I go out to the local café or go and see a live band or something like that, one of the pubs here or something like that [FG6].

Structured regular engagement in purposeful activities

Most participants had a mix of regular structured activities, such as paid or volunteer work, attendance at a disability day program, a self-advocacy or another form of group. These activities gave regular shape to their week, a sense of purpose and were also an avenue for social connections and relationships. Talking about how they spent their time participants said for example,

> Two days a week in a catering crew …I've got my Salvation Army stuff Thursday, bowling Friday and three times a week I do my own self [FG6].
>
> As a casual worker and kitchen hand and cleaner. I'm with the women's group on a Tuesday night if I'm not working. And also I'm involved with our Sunday group…I help a couple of others also on disability so that's about four or five that I help apart from myself on disability as well [FG1].
>
> I work two days a week at the op shop…I go to mosaic classes two times a fortnight [FG5].

> I've got a lot of interests like on the days I don't work, I might go out for walks or do something, do appointments and other things, cook meals, practice my didgeridoo, do stuff on the computer, do lots of other things [FG9].

Difficulties of Supported Living

Although all participants conveyed a definite sense of enthusiasm for their current living situation and the freedom it brought them, they also talked about some of the difficulties of their situation.

Restrictions on opportunities and control

Despite a unanimous sense from participants that they had more choice and control over their lives than in previous living situations, many talked about the restrictions that stemmed from having a low income or not having full control over their financial affairs. All participants relied on disability support pension as their main source of income which meant they had little money for discretionary spending or things such as leisure, clothes or holidays. For example, one participant said about his financial situation,

> Very tight so we don't go out, we don't really do anything, we have to stay home and what little money we do have has to be spent on food 'cause…yeah money is very tight… As for clothes shopping everything I wore I bought them years ago and I just have to keep on wearing the same clothes [FG9].

Very few participants had full control over their own finances, which were managed for them by either a family member or in most cases the State Trustees. They said for example,

> I used to have a card but mum took it away from me and said I can't do it anymore 'cause I buy mostly rubbish for myself. Yeah, I want my bank card back [FG5].

> Do you know how much I get a week, every Tuesday, $130 that's spending money and food money, its $130 every Tuesday, that's my spending money too, that's all they [State Trustees] are giving me [FG1].

Participants who were involved with the State Trustees gave a negative picture of this service, which stemmed from the difficulty of making contact with the Office and the lack of a consistent person to talk with about their affairs. They said for example,

> …different person every time. See it might not be the one person, if I ring up Tuesday there might not be that person on the phone, might be someone different. It's hard to get your administrator [FG1].

> [there is a] contact person at Trustees...but now see there's another number and I can't get them, I get (support worker) to ring them…because I can't get them, I can't ring them up, it's a different, hard number to [FG3].

Several participants also talked about the lack of control they had over how and by whom support was provided. A common concern was not being advised about a change of worker, which meant they might not know which support worker was coming or may not have met them before. For example, one participant talked about the support she and her co-tenant received from a disability support agency using their ISP,

> They help us with the menus, cleaning, cooking, shopping, any appointments and we just lost a really good support worker…there's a bit up and down at the moment, we don't know who is coming and who is not …so it's been really unsettling…Really they need to ring the day before [tell us] who is going to be on and who's not working…I think this organisation is not really good enough because we need to know, my housemate and I need to know who is coming [FG1].

Fears about safety at home and in the community

Many participants talked about incidents where they had been poorly treated or abused by support workers, which for most people seemed to have been in the more distant past, extending back to the time they had lived in institutions or in group homes. Several people however, recalled more recent incidents of abuse by a worker in their own home. One woman said for example,

> But I just don't want this carer…She did something that she, which I didn't like, and I had bruises from it and she digged her nails in really hard and I had bruises [FG1].

A number of people both men and women talked about not being confident or feeling it was unsafe to go out in the evening when it was dark, although no-one gave any examples of adverse events happening whilst being out at night. They said for example,

> I just don't like going out too late, no not places but just going out, if I'm going up the street, if I have to go, if I wanted to see her, she says come up in the night and I said no, I don't know who is hanging about, you don't know who is hanging about [FG3].

> I'm not supposed to go out at night it doesn't feel safe. Even going in a taxi, I will not do that at night [FG1].

> It's dangerous going out at nights [FG9].

Negotiating with co-tenants or troublesome people

Many participants talked about their difficulties negotiating with other people, such as sales people who came to their door, neighbours and co-tenants. In the case of sales people, almost everyone, apart from those who lived in cluster settings, had an example of an encounter with door to door or telephone sales people. Support workers had given participants a range of strategies to deal with sales people from blowing a whistle down the phone to pretending they were only a visitor to the house. Participants said for example,

> Oh I feel sometimes nervous…They are trying to sell things, I just say no we don't want that, no…and then we get these telephone calls…like they want to sell things, if they do that we have a little whistle now, blow the whistle at them [FG3A].

> I had somebody come to the door trying to change the electricity company and I made a fib saying I don't live here, I'm just minding the house. My carer came up with that [FG1].

Although some participants talked positively about their neighbours others had quite difficult relationships, and complained about noise and rudeness. They said for example,

> They have too much drunken parties. I'm here and here's another house. I can hear this woman yelling at her kids [FG1].

> I don't like them, he stole one of the bins of mine and I said you stole one of the bins, you want to put it back into unit one, she said no, she said that's my bin [FG3].

> Well there's a mixture of good and bad neighbours at the flats, bad ones…they stomp on people's ceilings and keep them awake all night…One time I went up there and spoke to him about it, and he threatened to punch me in the face. And then the next day I was watching football…came downstairs, to my front doorstep and abused me on my front doorstep [FG4].

Some participants who had previously lived with a co-tenant talked about the difficulties of sharing and benefits of living alone. They said for example,

> Living by myself, no it wasn't hard but I managed by myself, but sharing with another person is so hard. It's harder… it's not fair for me but I'm going around doing every job in the house [FG3A].

> I prefer living on my own but I don't mind sharing, it depends on who I'm actually sharing with because if you're only sharing, you got to make sure that the other person pays their share of the bills otherwise it is not worth sharing [FG6].

Loneliness and feelings of exclusion

Although many participants had structured and regular activities in community settings and contact with peers and family, they also talked about being lonely, particularly in the evenings. For example, one participant said,

> I look at telly but I'm sick of being by myself in the night, I'd like to go out for a change, like dancing or singing [FG3].

Several others talked about trying and failing to make friends and their feelings of being excluded by the negative attitudes of others towards them. For example, they said,

> I've got a step brother but he doesn't want to see me…make me feel awful because he doesn't really speak to me, he thinks he is better than me…I just feel I want to be wanted. Want people to like me and want to be needed in the world, I just don't want to be with people and friends that don't like me, that's all. I don't ask for much [FG3].

> I don't have many friends because I try to make friends but I used to go to this church …but I had to stop going there because they wouldn't accept me, like coming to their church, I wasn't allowed to sit there.. I was advised not to go back there. I tried everything to go up and say hello to them and get mixed up with them and they just don't want to know me I don't have anyone that doesn't have got disabilities at all…but I try to make friends [FG4].

Poor access to technology at home

Most people who participated had a mobile phone, though not often a smartphone, and knew how to use an iPad and the internet. Many people talked about using the internet and programs such as Skype, Facebook and email at a self-advocacy group, the public library or a day program. Very few participants had access to a computer or the internet in their own home. Cost and an absence of knowledgeable support about setting up systems seemed to account for their poor access to technology at home. For example people said,

> I got one [computer] at mum and dad's…I have one, I don't have the internet. Yeah, I learnt a bit more [using the internet] when I went to self-advocacy group…We got

> Skype now, we can look up Skype…Yeah we've got it at self-advocacy group…we can look up, we can get in contact with people on the computer [FG1].
>
> No I haven't got the internet at home; I think it costs about $100 [FG2].
>
> We used to have a computer but we used to deal with Dodo and each time we were using it, they'll still charge you though, even though it was turned off and we thought that wasn't right so we had it off altogether [FG4].

Discussion Service User Focus Groups

These focus groups portrayed a very mixed picture of supported living for people with intellectual disability. Many participants valued the greater sense of autonomy, independence and freedom from control by others they experienced in this form of living, whilst also describing the limitations of a low income, lack of control over their own finances and being lonely. Like much of the previous research, these focus groups suggested that supported living gives people with intellectual disability a greater sense of choice and control over their own lives than living with parents or in group homes. Their sense of control was experienced in terms of being free from others making decisions about their everyday lives, rather than in relation to their financial affairs. Although participants experienced the restrictions of living on a low income most did not perceive these as interfering with choice and control in the same way that parents or staff might have done in the past – freedom from directly being told what to do by others seemed more important to participant's sense of choice and control, than more indirect restricted choices due to low income or lack of control over money.

Similar to other research, the focus groups suggested that participants did have social connections and participated in a range of community based activities. Unlike other studies, however, many participants were involved in regular structured social activities. It was not always clear who or how these activities had been negotiated but it seemed likely to have been staff at disability day programs, family or outreach staff. These activities created shape to people's lives and facilitated social connections with peers and community members, especially when they took the form of volunteer or paid work. The ongoing role of disability day support services either as a direct service or facilitator of community based volunteering or work should therefore be factored into the type, volume and cost of support.

In terms of tenancy and support for everyday living, most participants lived in subsidised social housing and received regular but low intensity support to manage their household and everyday finances. Basic 'outreach' support of one or two hours a week was supplemented for some people with HACC services or more intensive support with daily living, although only one household of two people talked about more than a twice weekly visit by a support worker. Overall it was clear that participants received much less intensive and frequent paid support than their peers in group homes and many received considerable informal support from family members. Remarkably, given this low level of support, all participants felt secure in the sense that they had someone to turn, to ‘solve problems’ if they needed help, with many naming a support worker as the person who would always be available. Whether such perceptions were real or not is unknowable and may not be relevant, certainly no-one gave any examples of not having their expectations met.

Despite regular activities and connections to local communities, and support with the more practical aspects of everyday living, many participants were lonely, and experienced feelings of being unsafe and socially excluded by community attitudes. Negotiating difficulties with neighbours, co-tenants or salespeople posed problems for some people and few people felt safe going out at night. These issues were raised in all groups and did not seem to be associated with particular localities or housing arrangements. Some people had felt threatened by particular support workers and were unhappy with the management of their finances by State Trustees which particularly in the case of the State Trustees generated the additional task of liaison and advocacy for workers providing regular support.

Poor access to technology at home, such as computers and the internet was an issue identified in the discussions that has not been raised in earlier studies. This is likely to be due to greater contemporary expectations about access and increasing reliance on the internet for payment of bills and basic information about things such as public transport timetables.

Overall these findings suggest that some participants may be under supported particularly in respect to developing and maintaining close friends, managing difficult social situations or managing the quality of their support arrangements. The Key Ring network may be one model of providing support to make friendships with peers in the local neighbourhood that warrants further investigation.

Service Provider Focus Groups

We conducted a focus group and series of interviews with a small number of staff who played differing roles in providing support for people with intellectual disability in supported living. The primary aim was to gain another perspective to inform the design of the face to face survey and to explore from a service provider point of view the type of support that was necessary to ensure a good quality of life and the issues that arose in delivering this.

Method

Participants were recruited through invitations distributed by our research partners and members of the reference group. There was a low response rate and difficulties were experienced in making contact to arrange suitable times for interview or focus group. Service providers were hard to contact and seemed extremely pressed for time. As Table 3 shows the two focus groups and 2 individual interviews included 7 staff from a cross section of organisations. Most of the organisations were block funded to provide specific types of support, for example, advocacy, tenancy or outreach to a minimum number of people. Several organisations also managed ISP's or provided support as part of a person's package. Two of the organisations provided social support using a Key Ring or Neighbourhood Connections model (Fyffe & Bigby, 2008) which was either block funded or purchased as part of an ISP.

Questions were asked about their role in providing support to people with intellectual disability in supported living arrangement, difficulties they encountered in proving support from an organisational point of view, the types of problems the people they supported most encountered, and what in their view were the essential elements of good support for this group of people.

Table 3. Participants in service provider focus groups

Type of Service Provided	Number of Participants
FG 1 Service co-ordinator - including for direct support Manager – tenancy support Paid worker - advocacy service for people with intellectual disability	3
FG 2 Service co-ordinator – including direct support Direct support worker	2
Interview 1 CEO Disability Service Organisation - including delivery of direct support	1
Interview 2 Operations manager Social Housing Association	1
Total	7

Focus groups and interviews lasted for between 60-90 minutes and were conducted by one or in some cases two research team members. They were all digitally recorded and transcribed, and a similar method of analysis was used to that for the service user focus groups.

Findings

Focus group participants represented a range of different service provider perspectives, and although some had a relatively narrow focus on managing or supporting tenancies or advocacy there was considerable overlap in the type of support they provided and their views about the constituents of good support for people with intellectual disability in supported living arrangements. There was a strong consensus about a shortage of both affordable housing and funded support to enable people to live independently in the community rather than segregated and congregated accommodation. This was seen to be the case for a diverse group of people with disabilities some of whom would not qualify for disability support services. The sections below report on the discussions more specifically about people with intellectual disability whom these participants supported.

Multifaceted Support

Participants described the support they gave to people with intellectual disability in supported living arrangements as more varied and complex than it had been described by service users. They contrasted in particular the straightforward types of support they were funded to deliver with the multifaceted support they actually provided. They said for example,

> Strictly speaking we provide housing and tenancy support, community access, participation, social inclusion support and also social support… I guess I also provide a lot of care co-ordination and case management, back up support to those community networkers for the people who are in their Key Rings [FG1].

> Basically we teach independent living skills, we facilitate community access and do general advocacy sort of work …I guess in many ways we're outreach workers and depending on the person sometimes we become de facto case managers…so we have to then look at what services that person has so it might be hooking them into employment, into medical check-ups and things like that, you know where they are living, basically all those types of things that in some ways a case manager may do [FG2].

The various types of support participants described are summarised and illustrated in Table 4, using quotes from participants.

Table 4 Examples of the types of support provided by disability support services

Type of Support	**Examples**
Basic support with tasks of everyday living	…basically we teach independent living skills, we facilitate community access and do general advocacy sort of work [FG2].
Emotional – through difficult periods on a person's life, such as illness, or bereavement	You journey with some people, Harry supports someone who went through breast cancer, I've supported people who've lost family members so you see people at their most vulnerable and you accept them and I think that must strike a chord and of course with them it strikes a bond, you've been with me and then suddenly turn around and say yeah but we're just a paid worker [FG2].
Personal development	I think personally it's watching people grow in whatever way, shape, you know, whether it's learning a skill or developing an intimate relationship, just watching people grow and being part of that process [FG2].
Enabling choice and control	A service user had complained about the support worker telling him what to do because he had suggested the service user could not afford Foxtel - but would be able to if he drank less. The support worker related what his manager had said to the service user, "that's his job, he's got to point out what could happen, it's your choice, totally your choice but that's Pat's job, you don't want to hear it anymore, Pat won't mention it but that's what his job is to point out there are penalties if you do decide to get out of Foxtel". The support worker reflected in this saying, "I think that's the thing, knowing that our role is to provide information and realise they are in control, you can give that information but ultimately it's up to them what to do and if the consequences are significant well getting someone, looking to the guardian or finding an administrator or something needs to be done to support this person [FG2].
Connecting to groups in the community and building relationships with people without disabilities	Helping them try to, if they want, expand [their social network] so I might say, I can't get you a friend however what are your interests and we can link you into a group, recreational and social group who have a similar interest cause that gives you stuff to talk about and we can take it from there so we can actually be involved in, well we might know people who have similar interests and see if they would like to potentially catch up over a cup of coffee [FG2]. A lot of the people we support they do not want their whole lives around living or working with other people with disabilities and they want something that is more generic… but then are those groups or activities, how accommodating are they? Someone I support who is interested in fishing and so finding out, helping them find out where the angling clubs are but then also taking the next step, is there someone that would be able to, not look after him, but be able to help him integrate into that group [FG2]. …try and then assist people work out if they need support to get other places in their community that they don't know where to go to, that's another big one we are seeing now as people are wanting to branch out more and do different things, they don't know how to get there so actually trying to link into services to get them some kind of transport training, travel training support to be able to do that [FG1].
Connecting with peers – sharing information, building relationships and mutual support	…support so the people in those Key Rings are supported to get to know one another because they all live in a close geographical area and make friendships with one another and in a sense they are also supported to become their own peer support friendship network [FG1]. I think when people do start to share their experience then it is a eureka moment if it works, now we've tried that and it works… other people who are also recipients of the same service or know about another service they've used or

	maybe are members of the self-advocacy group and didn't know about this, [for example they might say] did you know there's now these passes you can get for Myki, the access travel pass, I didn't know about that, they don't tell you that do they and it is like where do I get the forms for that …some people are just natural networkers, and other people never hear about it because nobody has thought to include them. I think that's really important, that's what I see as part of the service role is to build those networks and try as much as possible to empower people with information, if you hear about something that's come in that is going to benefit people start to tell them about that too even though it is one extra thing [FG1].
Resource raising	It's like looking for pirate treasure, there is a housing establishment fund that some of the housing services have…it is knowing what service will provide what financial assistance so I may go to one who will say we will offer $250 towards a fridge, another will say we will offer $250 for removalists only, or $300 for removalists only and then get another who will say you've got the option of some rent in advance assistance or white goods assistance, some will be restrictive, some will be a little flexible and offer some various options [FG1]. Well we do a few things, certainly we'll go for bond loans if people are eligible but sometimes they are not. Our service often lends people money so we'll lend them their rent in advance and the removalists costs and organise all that. Then we will have a Centre Pay pay arrangement for them to pay it back over a couple of years often and we'll tend to try, white goods, we've been pretty lucky with whitegoods with DHS, we've been moving people, tended to be able to get them a fridge and washing machine, we've been lucky but the other place to go to are St Vincent de Paul, Salvation Army, because they will assist often with a house set up so we will make applications to them [FG1].
Supporting people to manage their health and relationships with health professionals	…medical and health issues, assisting them to not just go to medical appointments but to understand the medical information they are being given, help with the follow up on how they prepare for that, doing things like blood test scans, x-rays, then following up medical information they receive and in the follow up that too any kind of intervention they might need and that might be around medical or it could be around things like physio or OT supports they might need [FG1].
Locating and referring to other support services	I do a lot of referral to outreach services, for skill development and I do a lot of referrals if people need counselling services, also if people need case management services, all those sorts of referrals [FG1].
Liaison and advocacy with other services involved with the person	…we do a lot of, liaison with State Trustees, we do a huge amount for that because often we find people will just keep getting year after year after year their small amount of money from State Trustees... people have never let them know that there is money in there they might have accumulated that they can spend and there's things they need so we take on assisting them in contacting State Trustees, going out and doing the shopping for things, might be clothing, household goods and items, lots of different things they need, even holidays, all those sorts of things, probably better quality of life is a big aspect of it so we do a lot of it [FG1].
Keeping things on track - case management – ongoing contact involving monitoring, co-ordination with other services, episodic and intensive support as necessary.	…having someone involved in co-ordinating that and ensuring that it is ongoing and you can respond to people's changing needs as they occur, or their changing circumstances.… I think you have to have someone there who is actually involved with the person and knows them well and knows how to assist them and a lot of it might be supporting and working with them. You don't necessarily have to do it for them, but with them, but assist them to make sure that everything is co-ordinated and keeps on going and can be responsive to things they might want to do or want to change or if their needs change further down the track [FG1]

Supporting tenancy	In terms of maintaining their property we will talk to them about, we could talk to services and get them to assist you as well in terms of home help or other services…If someone is in need of support or there's difficulty with a tenancy, it's working out what are the essentials that person needs to maintain their accommodation. Basically it becomes their housing is at risk for whatever reasons so looking at what those reasons are, if it is financial, could be lack of being able to maintain, could be behavioural, had complaints or there's been faults, those kinds of things so it is looking at those, what are the things that are putting this tenancy at risk and then working through [Int2]. Every day is unpredictable, you can get an email or phone call from a tenant who is having issues with neighbours, they are targeting them, giving them a hard time, life is becoming unbearable for them… so it is for me it is a matter of attending to what is happening at the time and ensuring something is flowing with that so you have that outcome rather than festers [FG1].
Back up to informal community support	…a classic example where you work with this woman who has multiple disabilities, physical, sensory, intellectual disabilities and speech impairment as well, she has been left out there on her own for years and years and the neighbours were doing a fantastic job so she would knock, if things would go wrong, the microwave would blow up, she'd locked herself out of the unit a couple of times, she would knock on neighbours doors...The neighbours didn't mind helping her, they were willing to do it, but when we went, so we took her on and worked with her and she's part of the program now, we met with the neighbours, they were so relieved, they said we didn't know what to do, we've had no-one here, we're happy to be the point of contact but we need a backup. There's a limit to what you can expect people to do when they are just left out there on their own so I think this nebulous thing of this being a wonderful community, hang on a minute, let's look at where, where the duty of care lies and it is great to have the community but they need back up too [FG1].

Poor Acknowledgement of Intangible Forms of Support

As the earlier quotes suggest, often what was funded as direct outreach support to help people to manage tasks of everyday living expanded to include case management tasks such as co-ordination with other service, monitoring, and support with a wide range of other life areas. Participants felt that these more intangible and nebulous types of support were undervalued by funders and in the construction of individualised packages of support. They said for example,

> It seems some of the ISPs are set up and there is an expectation that people will manage those themselves for someone with a cognitive impairment...that is really difficult so things will just fall apart and away and they will have a carer coming but the carer doesn't arrive for, they are asleep and don't answer the door and nobody reports that back to anyone who is managing the package in terms of the quality of care, just these people moving in and out but no-one co-ordinating and communicating the information and I think for some people that is a huge issue [FG1].

> And that's often what they don't want to fund isn't it, they don't fund case management, they will fund care co-ordination, usually they will fund a little bit of that but they don't want to fund that kind of, that support, that overall umbrella kind of thing [FG1].

Participants also made the point very strongly that increasing independence was not always the aim of providing support, which at times was more about maintaining a person's well-being and capacity to rely on services. The participant from the advocacy organisation gave an example of the negative consequences of a short sighted attempt to reduce a person's dependence on services,

> We had a person we were working with, a lot of work had been done to get the district nurse to come every day to ensure he took needed medication and they decided that for his independence it would be better if he moved to his own dosette box and did it himself and within two weeks he was in hospital and never went home again, he went into a nursing home and he could have been still living independently had they kept that going every day [FG1].

Participants from all organisations described having a sense of responsibility to fill the gaps left by poorly constructed schedules of funded support and going beyond what they were funded to do. They saw that their status as non-government organisations, not totally reliant on government funding, gave them the capacity to do this and their mission as creating the imperative to do so. They said for example,

> There are I guess a lot of other supports we provide to people that, we are actually supplying because there's service gaps and no other funding or no other community services to pick them up…we are picking them up because there isn't any other supports that people have to do those things [FG1].

> The innate ability of a not-for-profit to suck it up and get on with it. I guess people have support needs and we know that they are vulnerable and we do what is required, sometimes to our detriment but hopefully not to the detriment of our staff, but we will go beyond and obviously financially beyond [Int1].

Perceptions of Difficulties Encountered by People with Intellectual Disability in Supported Living

In describing what they perceived to be the particular difficulties that people with intellectual disability experienced in supported living arrangements, participants highlighted factors that will require attention if this type of housing and support is to become more common. Some difficulties stemmed from the nature of intellectual disability, pointing to the need for more skilled or different kinds of support. It was also clear that individual difficulties were often compounded by deficits in the system of social housing, and the failure of mainstream social systems to adequately adjust their processes and ways of doing business to the needs of people with intellectual disability.

Managing complex social situations

Participants saw people with intellectual disability as particularly vulnerable to being preyed upon or taken advantage of by unscrupulous others, sometimes family members because of their poor ability to read social situations and negotiate difficult relationships. One participant said,

> One of the biggest disabilities I think people have is dealing with relationships and when you put people together there's going to be problems dealing with relationships and for people that have cognitive impairment or mental illness, intellectual disability it is that much harder to deal with complex social relationships so that's a huge one and often people don't have a lot of support for that side of their lives so someone might be getting a package which is totally and utterly expended on personal care, there's no left overs for anything else and they don't really quite have enough for that but they are determined to hang in there because they don't want to go into a more institutional form of living but it is tight, really tight [FG1].

Individual vulnerability was seen to be compounded by the concentration of people with social problems and often poor social skills in social housing. For example one participant said,

> …they've been perhaps placed into a unit within a block of units where there might already be some social problems in the system, we get so many calls from people who are having problems…because of a threat from other people in their housing block or next door…that feeling of threat which may manifest in terms of verbal abuse on a regular basis but sometimes more than that, we've had people who have had home invasions take place, all sorts of things where people come into their place and have stolen their stuff or taken over their territory… People have waited and waited for some sort of housing and then they find it is not liveable. …It is very difficult for them too often because the other person or people who are providing the threat may also be someone with different social needs that aren't being met so it is a complicated situation…so there's a huge problem out there in terms of not enough

> support for people who have social problems and who all end up living in the same sort of environment and impacting negatively on each other [FG1].

Staying healthy and managing health conditions.

Participants were concerned that people with intellectual disability required significant support to live a healthy lifestyle, and not only to access health professionals but also understand and follow advice given about health conditions. One participant saw this as extending to dental care, diet, and managing things like frozen food or fresh food use by dates. She said,

> They have very poor health outcomes, their diet and nutrition is really poor, their dental hygiene is really poor, they are not getting the regular health checks and sort of health supports that other people get so I think they are really vulnerable in terms of those sorts of issues, they miss out on a lot of things… they have lots of issues around being able to manage food security so they don't understand that if you take something out of the freezer and don't use it all, you can't put it back, they will do that sort of stuff all the time and use past date time food, just really struggle with those sorts of things so there is stuff in the fridge that's been there for months [FG1].

One participant talked about the difficulties he had encountered in trying to support one man with diabetes who had struggled to understand the necessity for a restricted diet and regular injections. This case illustrates some of the fine judgements by workers about whether formal steps need to be taken, such as application for guardianship, to override a person's choice in order to safeguard their well-being,

> I support someone with diabetes and he couldn't specifically see it and get his head around it, we went to international diabetes, and that was an educator and he still couldn't get it…and his condition was deteriorating and very high readings and we made a referral to the RDNS and he is on a daily injection and in the end, after two days, he just said, no I don't want this so it's like what do we do now because he's exercising his choice but the consequence…He saw it as an infringement on his freedom because he has to be home at a certain time every single day so I think that issue, for people who lack an understanding of what their condition means, who may be non-compliant with taking medication for whatever reason…people do have the right to exercise their choice…I suppose dilemma that you are in [FG2].

Being socially isolated

Being socially isolated and particularly without strong or intimate friendships were identified by all service providers as a major problem, reflecting a similar problem identified by service users. The Key Ring support model was seen as one method of helping to build friendships or at least social connections between people who lived in the same locality. Participants said for example,

> We have lots and lots of people who contact us and they are socially isolated, very isolated and things like Key Ring would be ideal. Lots of people I think would benefit from that kind of social networking but it is also problem solving together and often it is about the sharing of experience even within the network [FG1]

> I think, there's a range but I would say predominantly the lack of intimacy and I don't mean sexual, I mean connecting with other people. People say I want more friends, I want a boyfriend, a girlfriend, I want to be married, they are not satisfied with the type of relationships they have, it's just an ongoing thing. They might not be isolated it's just that they don't feel they are as connected as they would like to be, they don't see their family as much as they would like to…an overriding sense that they are not as connected with people as they want to be [FG2].

Access to technology and adjustment of communication to take account of people with intellectual disability.

There was a sense from participants that the potential for improving communication and independence through use of the internet, new technologies, and devices such as iPad was not being realised for the people they worked with. While new technologies held the promise of being adapted and accessible for people with intellectual disability who often have poor literacy skills, through programs such as voice recognition, this was not happening on the ground and people were not even getting the support they needed to set up and use computers and internet connections,

> We've found that people can use the technology in really good ways like Skype, using Skype to make contact so for someone who can't speak over a phone, being able to type…But it only works if somebody else has been able to give you one to one training and set it up and the people at the end who you want to Skype have also been set up [FG1].

> Well my experience, we have a couple of people who can use computers, have to say people love the technology for games, fantastic, and other things…I just think in

> terms of entertainment it provides options for them, they love games and they are easy to use but in terms of actually using the technology to be of assistance in daily living is very difficult, people really don’t have the literacy, they don’t have the technical skills, the money, …and all the stuff you’ve got to get, getting it installed and teaching people how to use it, they are really, very very limited, some people use email as a social contact and that’s fantastic …[but] the email is very complex, it’s really a system that requires a lot of cognitive ability to manage [FG1].

Poor access and inadequate support was seen to be compounded by an increasing reliance on technology for communication, such as mobile phone, web based sources of information or automated phone or ATM systems rather than face to face services, which led one participant to say that she thought people with intellectual disability were,

> really discriminated against, doubly disadvantaged now because there’s so many things [online]… There’s this expectation that you can just access everything on the net and people with a cognitive impairment really struggle with that [FG1].

Participants pointed to a range of difficulties associated with the switch to new technology,

> They [people with intellectual disability] really struggle and I think too you know, people not having landlines, I can see and with a lot of people who don’t because of the cost, but then you wait for 20 minutes on your mobile for Centrelink, how much is that costing and then you use all your credit [FG1].
>
> They change ATMs all the time, go to a different ATM, different set of buttons, different set of commands, really hard stuff and I think that a lot of people have gotten by on that face to face contact but that’s becoming more difficult [FG2].

However they also pointed to ongoing problems with more traditional modes of communication such as letters that took literacy for granted, which continued to mean people with intellectual disability required support to manage transactions with agencies such as Centrelink, and private estate agents. As one participant said,

> I get many tenants who get letters, whether it is from property managers about coming to do an inspection, tenancy review… they just don’t get the message that the person can’t read, doesn’t have that ability to understand the jargon and they don’t read the letter, problems come from that because they just chucked it out, hadn’t read it, don’t understand it [FG1].

> We’ve found that with real estate agents too where they have sent notices under the Act, where they’re supposed to provide a notice which we’ve done, the person can’t read it or access the notice in the letterbox until their support worker comes so they don’t get the notice that someone is coming tomorrow [FG1].

Perceptions of Essential Elements of Good Support for Supported Living

Participants were in agreement on the essential elements that constituted good support for people in supported living - individualised and person-centred, flexible and ongoing with capacity to be of varying intensity, co-ordinated, ethical and respectful of individual choice and control. Table 5 summarises and illustrates these essential elements.

It is notable that two of these elements, flexibility and ongoing capacity to be of varying intensity and co-ordinated were seen by participants as being poorly acknowledged by funders. These five elements of essential support, from the perspective of formal services provide an overarching framework to consider the diverse types of support detailed in Table 4 that services might provide depending on and tailored to each individual’s circumstances. They should not be confused with the conditions necessary to support a good quality of life for people in supported living as they do not take account of key factors such as availability of informal support, social relationships, or involvement in purposeful activities, and as such may be seen perhaps as the necessary but not sufficient conditions that make supported living work.

Table 5. Framework of Perceived essential elements of good support for supported living

Essential Element of Support	**Example**
Individualised and person-centred,	You might have the same issue you want to address but you look at the person and you may have a totally different approach because you have to understand the individual there, how they are going to react, yeah, think I'm always looking at, and certainly people I have supported where it is the same issue but I've handled it, approached it in a different way and I think experience is also part of that training [FG2].
Flexible and ongoing with capacity to be of varying intensity	There is always going to be a need for someone to be there if things go wrong… [FG1] One of the things we try to provide is security and continuity however you also don't want the person to become dependent on a person 'cause it defeats the whole purpose of the program [FG2]. It really depends because even with one person they only might need an hour and a half one week which is the normal program but then needs support with a medical appointment so then you are also taking them to that appointment and help understand and follow up on that so what might be an hour and a half might translate the following week to maybe four hours of support [FG2]. Well I think having that level of continuity for individuals is very important, understanding that organisations may well be the sole holders of a person's history and the responsibility that that holds for an organisation particularly if someone who is highly socially isolated, think we have a moral and ethical responsibility then that probably isn't often discussed. [Int2.
Co-ordinated.	Someone co-ordinating it and keeping track of things….Somebody knows what's going on…Yes that's everything and that someone knows kind of all the different sorts of things this person might request or require and you can co-ordinate it…Well I guess there's the essential things around needing, certainly having to have the housing that is suitable and what the person [FG1].
Ethical and respectful of individual choice and control	Generally it is very individualised so there's certainly some people where that is the case and a few of those people with diabetes and not being able to manage their diabetes without support, there's other people that you're fairly sure that there are some health risks but they just have no desire to be supported. For them it is not a life, a priority. And you have to respect that but be prepared to step in as soon as they request help and you can take the opportunity to be educating them along the way but again there's a whole lot of skills that… I think having a clear mutual understanding around the intent and capacity to do it, to provide support ongoing and to negotiate, that level of honesty with people with intellectual disability and their support networks is imperative. Being reasonable and certainly looking at quality of life and people's desires and goals and how to support those whilst also ensuring that if there is a risk and need that an organisation is prepared to step in at the appropriate time if the person doesn't [Int2].

Discussion Service Provider Focus Groups

Service providers painted a different and more complex picture of the type of support they gave to people in supported living. They focused less on the straightforward practical aspects of support with tasks of everyday living and more on the intangible tasks associated with monitoring and supporting well-being across all life areas, particularly health and relationships, knowing people well and being available to troubleshoot and problem solve with people when they needed it rather than at pre-set times. They illustrated the array of different types of support they provided. Service providers reflected on the benefits of current block funding arrangements that they perceived as enabling flexibility. They lamented the undervaluing by funding bodies of case management and ongoing monitoring with the capacity for varying intensity of support over time to respond to changing needs, which in their view were essential elements of good support. Their issues raise a challenge for designing a fully individualised funding system that has the capacity to factor in varying intensity of support over time to enable quick and preventative responses to issues identified from ongoing monitoring of each individual's well-being.

Participants described themselves as filling the current gap in funding for people in supported living, and being able to do so by existing block funding, cross subsidisation of programs and their access to untied funds derived from other sources. At present services are supporting a relatively small number of people with intellectual disability in supported living, and one of the questions raised is their ongoing capacity to fill gaps and provide unfunded support if the number of people they support increases significantly, as it is likely to do with the roll out of the NDIS.

In their discussions about the ways of providing support, the service providers hinted at the skills required by support workers to work effectively. In particular they described the tensions between enabling service users to exercise choice and control over their lives whilst taking account of their cognitive limitations. This was exemplified particularly in respect of compliance with health care advice and choices about risky lifestyle choices. When and how far to challenge a service user's preference, how strongly to give advice about particular actions and when to adopt a protective mode, by stepping in and seeking involvement of bodies such as the Office of the Public Advocate that might override the rights of the service user to make their own decisions, were all judgements that confronted support workers and their managers. One provider in particular talked about the importance of team work, in sharing knowledge and debating difficult issues, as well as regular practice supervision for front line workers.

Service providers identified similar aspects of supported living where people with intellectual disability particularly struggle to do well to those that service users themselves talked about – social isolation and lack of close friendships, negotiating difficult social relationships and access to technology. They highlighted too, disadvantages and consequent challenges that arise by concentrating affordable housing in particular localities or apartment blocks which creates something akin to ghettoes of people with social problems. In the words of one provider, “there’s a huge problem out there in terms of not enough support for people who have social problems and who all end up living in the same sort of environment and impacting negatively on each other”. Such concentrations increase the support people require to negotiate relationships and building community inclusion, and reinforce the research findings from supported accommodation about the benefits of living in dispersed ordinary housing in the community.

Survey of Service Users

The face-to-face survey of service users aimed to collect quantifiable data about the types of support and tenancy arrangements, individual characteristics, quality of life outcomes and support costs of people with intellectual disability in supported living arrangements. The design was informed by the literature and the focus groups with service users and providers from the first phase of the study. The survey was designed to enable comparison between service users in supported living with an existing dataset about service users in supported accommodation services, as well as to ensure data were collected on all 8 quality of life domains (Schalock et al., 2002).

Method

Participants were recruited through the focus groups, and advertisements circulated through the networks of the partner organisations and wider networks of service providers such as National Disability Services. The criteria for inclusion were the same as for the service user focus groups.

The survey was in two parts, the first part collected data about service user characteristics, community inclusion and formal support arrangements using formal and validated measures (see Appendix 2). It drew on the ‘People we support questionnaire’ used in research on supported accommodation services in the UK and Australia (Mansell et al., 2013). Included in the survey were the short form of the Adaptive Behaviour Scale Part 1 (Hatton et al., 2001), the Aberrant Behaviour Checklist (Aman, Burrow & Wolford, 1995), the Index of Participation in Daily Living (Raynes et al.,1994), and the Choice Making Scale (Conroy & Feinstein, 1986). Open ended questions were included about the type of support, nature of tenancy and living situation of the service user. This part of the survey was completed by a support worker nominated by the service user, as the measures were designed to be completed by a person who knew the service user well. Completed surveys were collected by the researcher when she conducted the face to face interview to complete part 2, which enabled any queries to be dealt with.

The second part of the survey was completed by a face to face interview with the service user and a worker nominated by the service user. It comprised a modified version of the Index of Community Involvement (Raynes et al., 1989), Observed Secondary Health Conditions (Koritsas & Iacono, 2011), The Social Capital Questionnaire (Onyx & Bullen, 2000) and open ended questions about service users' experiences of their living arrangements. All the interviews were conducted by the same member of the research team and lasted between 15 -60 minutes. As well as completing the formal survey instruments at the time, the interviews were recorded and transcribed in full.

Participants

Thirty-one people with intellectual disability living in supported living situations in metropolitan Melbourne and 2 regional locations were included in the survey. Despite following up several other people who received services from other providers there was considerable overlap and thirty survey participants had also participated in the focus groups.

Analysis

The quantitative data was entered into SPSS and analysed using both descriptive and inferential statistics. The quantitative data for each service user were compared to the interview transcript to ensure accuracy. Where necessary it was amended to reflect the qualitative data which was less open to misinterpretation by respondents and reflected the perspective of the service user themselves.

Matched samples

Matched samples were compiled of service users in the current study and service users in supported accommodation, drawing on a dataset from an ongoing study[1]. The samples were matched as closely as possible for age, level of disability (on the short adaptive behaviour scales), physical disability, presence of autism, presence of social impairment and presence of challenging behaviour (score on the ABC). There were no significant differences on any of these attributes for the matched samples (see Appendix 1, Table A9 for details of

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[1] We drew on a data set of supported accommodation service users in three Australian states collected as part of an ongoing study conducted by the research team. Some of this data is published in Mansell et al., 2013 and some is unpublished and was drawn from internal research reports as the study is still in progress.

the matched samples). Compilation of a matched samples enabled comparison between service users in supported living and those in supported accommodation on key measures of quality of life outcome.

Quality of life categorisation

Schalock et al.'s (2002) 8 quality of life domains (QoL) - social inclusion, interpersonal relationships, personal development, physical well-being, emotional well-being, material well-being, self-determination and civil rights, were used as the framework to conceptualise and measure resident outcomes. Items from the survey were extracted and used as indicators for each of the domains; these are set out in Table A1 together with the schema used to rate each item. For each domain, each included survey item was rated as either Good or Poor, and scores were then combined at the domain level into one of three ratings categories, Good, Mixed or Poor.

Based on domain scores an overall category of QoL was calculated. Initially outcomes were categorised into one of 4 groups on the following basis: Good-Mixed (at least 5 of 8 domains good, some mixed, no poor) *n=0*, Mixed-Good (at least 2 domains good, remaining mixed, no poor) *n=14*, Mixed (At least 5 of 8 domains mixed or good, less than 3 domains poor) *n=16*, Poor (No good, at least 5 of 8 domains poor) *n=1*. To ensure sufficient numbers for analysis, the four QoL categories were collapsed, so that each person was categorised into one of two groups; Mixed-Good (*n=14*); Mixed-Poor (*n=17*).

Qualitative data analysis

The qualitative data for each service user were reviewed, and a descriptive narrative of each service users living situation was written. Some of the qualitative data, such as living situation, type of support and services used was categorised so it could be quantified, and described using descriptive statistics.

Presentation of findings

A brief description of the sample and the type of support received is presented in the first part of the findings followed by sections that reflect the research questions; comparison between QoL outcomes for people in supported living and those in supported accommodation services and factors associated with good quality of life outcomes. Detailed tables of findings are included in Appendix 1.

Findings

Description of Service Users

The characteristics of the service users were similar to focus group participants. Predominately they were middle aged, ranging in age from 26-63 years with a mean age of 46 years. As Table 6 shows they were a relatively able group with an average score on the ABS of 239. The lowest score of 166, was higher than the score (151) normally used as an indicator of severe level of disability.

Table 6. Characteristics of sample of service users in supported living arrangements

		Supported Living
	N/n	*31*
Age (years)	M	46
	Range	26-63
Male		42%
Part 1 ABS score	M	239
	Range	166-282
Total score on the ABC	M	12
	Range	0-41
Socially impaired		(n=9) 29%
Physical impairment		(n=9) 29%
Epilepsy		(n=2) 7%
Mental health problems		(n=5) 16%
Visual impairment		(n=2) 7%
Hearing impairment		(n=6) 19%
Autism		(n=3) 10%

The majority of the sample lived alone in some form of social housing rented either from the Department of Housing or a social housing association. They had lived in their current home for 5 years on average with a range of 3 months to 10 years. Participants lived in various locations in metropolitan Melbourne and 2 regional Victorian towns (see Table A2). They all lived on a low income with disability support pension as their main source of income. Although just over a third received additional income no-one had an income of more than the current minimum wage of $33,326.

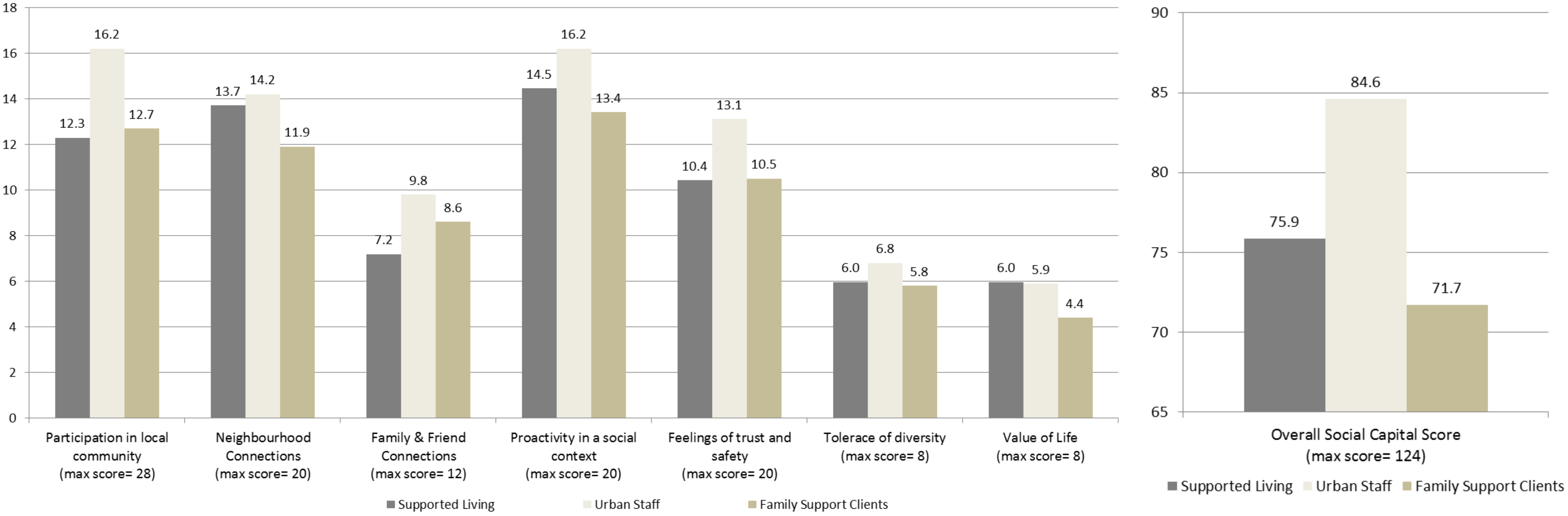
Many participants were involved in regular structured activities or social groups. Over half (87%) attended a disability day program, undertook voluntary work or paid supported employment or a combination of these at least 3 days a week, and 29% did so for 5 days a week. In addition 68% of participants regularly attended a disability specific or mainstream social group, such as a women's group attached to a self-advocacy group or a social group in a community centre, and 29% were members of a self-advocacy group that met fortnightly.

Scores on the Index of Participation in Daily Life, and Index of Community Involvement indicated that participants were very involved in the tasks of everyday living and frequently made use of at least some community facilities (see Tables A3 and A4). Most participants had social contact with family and friends on a regular basis. Over three-quarters of participants had weekly contact with a family member by phone, saw a family member at least monthly and had regular contact with friends outside their home. Most of their friends were people with an intellectual disability but just under half of participants reported having contact with a friend without intellectual disability (see Table A5). Just over half of participants (55%) had someone other than a paid staff person whom they saw as an advocate, which is most cases was a family member.

The mean overall score on the Social Capital Scale was 75.9 with a possible maximum score of 124. As Figure 1 shows, scores were fairly even across all domains with none below the midway point. Figure 1 also compares participants' scores with two groups reported by Onyx and Bullen (2001). These groups are not particularly well matched to the participants in our study -one group was staff in community services and the other parents in receipt of family support services in urban NSW. Nevertheless similar to people with intellectual disability in supported living arrangements parents in receipt of family support services are likely to be living on low incomes, in social housing and regarded as a disadvantaged social group. Visual inspection of the graphs in Figure 1 suggest, on most domains of social capital, people with intellectual disability had scores comparable to family support clients, and lower than community services staff.

Scores on the choice making scale were relatively high with a mean of 76% but a wide range from 44 - 100% (see Table A6). Every participant had one or more health condition with a mean number of 6. Most common health conditions were physical fitness or conditioning problems, vision problems, weight, joint, muscle pain, dental problems, fatigue balance problems/dizziness and mobility (see Table A7).

Figure 1. Social Capital Scale scores, compared to participants' scores with two groups reported by Onyx and Bullen (2001).



Formal Support Arrangements

The pattern of formal support was similar to that described by participants in service user focus groups and included support for tasks of everyday living, allied health care, and participation and social inclusion. All participants received at least weekly and on-call support with problem solving and tasks of everyday living through either block funded outreach or an individual support package. The intensity of this support ranged from 30 minutes to 42 hours a week, with an average of 5.6 hours. However, if the exceptional service user who was experiencing a crisis situation and received 42 hours of support a week is omitted, the average hours of support for the remainder of the sample was 4 hours. Support with everyday living for all participants was delivered by one disability support organisation in their locality, although many people received support from more than one organisation. For example, one participant received Key Ring support from one organisation and support for everyday living funded by an ISP from another agency. Only one person was in receipt of formal case management services. Notably, all but 4 participants were involved in at least 3 days a week of structured activity through a day program, volunteering or supported employment. Table 7 below illustrates the various kinds of support received by participants, and Table A8 provides more details of support for each participant.

Table 7. Support arrangements

Type of Support	n	%
Everyday living		
Outreach – max 2 hours week – regular home, on call, support with problem solving and one other task of daily living	8	26
Individualised support package or more intensive outreach- 3- 8 hours a week, 2-4 visits a week, on call, problem solving and other tasks of daily living	22	71
Individualised support package and case management 42 hours a week, daily visits on call, problem solving and other tasks of daily living	1	3
HACC	9	29
Health related		
Regular allied health such as OT or Physio or health specialist	4	13
Participation and social support		
Employment service job seeking	3	10
Key Ring	10	32
Disability day program such as day service, volunteer or supported employment or combination 5 days week	9	29
Disability day program such as day service, volunteer or supported employment or combination 3 days week	18	58
Regular attendance at social group attendance disability or mainstream	21	68
Self-advocacy group	9	29

Estimated Support Costs

The method of collecting data about support funding and thus costs of providing support that relied on the key worker as the primary informant in the face to face survey was unable to capture a detailed picture of support costs. There were several reasons for this; many respondents were unaware of costs, some of the support they provided was unfunded, and many service users received support from a range of different agencies.

Based on the data about support received which is set out in Tables 7A and 8 we estimated a total weekly and annual cost of support for each participant. This was particularly challenging as we were aware from reference group members that some funding is based on historic or locally negotiated agreements that do not necessarily reflect the current funding schema. For example, one of the organisations involved in the study received a mix of negotiated funding for infrastructure and individualised packages to support a flexible number of people that did not reflect either items or rates in current DHS funding schema.

We used current Victorian Department of Human Services funding rates[2] for outreach support, flexible day support level 3 to estimate cost using the following logic:

- Outreach or ISP support @$42.68 an hour (DHS hourly rate)
- Any type of day support, such as attending a day program, volunteer or supported work @$84.25 a day (DHS flexible day support level 3, calculated from annual rate of $19, 378 based on 46 weeks a year)
- Attendance at social group or self-advocacy group @$42.13 a group (based on cost of 0.5 day of day program support)
- Key Ring support @$113.40 a week (based on local negotiated funding $5,896 a person a year.

For example SU 1 received 2 hrs of outreach support (2x $42.68), regularly attended a social group ($42.13) attended a day program 3 days a week (3x$84.25) attended a self-advocacy group ($42.13) making total estimated weekly support cost of $422.37 ($85.36 + $42.13+ $252.75+$42.13), and an annual cost of $21,963.24.

We did not include HACC, employment or allied health services in the cost estimates as these services are not funded directly by disability services and unit cost figures are not available or too general to be useful.

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[2] (http://www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/plans-and-strategies/key-plans-and-strategies/department-of-human-services-policy-and-funding-plan-2012-2015)

The estimated mean weekly cost of disability support rounded to the nearest dollar was $585, and ranged from a low of $213 a week to high of $1,877. One service user had a significantly higher number of support hours and associated cost than the rest of the sample and as Table 7a shows when this person is omitted from the calculations the estimated weekly cost is $542 an annual figure of $28,196.

Table 7A. Estimate weekly and annual costs of disability support

	Weekly			Annual		
	mean	lowest	highest	mean	lowest	highest
All sample	$585	$213	$1,877	$30, 435	$11,068	$97,595
Sample outlier omitted	$542	$213	$750	$28,196	$11,068	$38,985

Comparison with Supported Accommodation Services

Overlap of supported living and supported accommodation service users

As described in the method section, we used an existing dataset to compare the characteristics and quality of life outcomes of people with intellectual disability using supported accommodation services with those in the current study in supported living. First we compared service users in the two types of living situation on a broad indicator of severity of disability; their score on Part 1 of the Adaptive Behaviour Scale (Hatton et al., 2001). A score of less than 151 is often used to indicate a more severe disability (Mansell et al., 2013). Using this measure, none of the service users in the supported living sample had a severe disability, as they all scored above this cut off with a mean score of 239 and range 166-282.

To ascertain if there was any overlap, on the level of disability, between service users using these two different types of services we looked at the mean and range of ABS scores in each year of the supported accommodation dataset. These are illustrated in Table 8 and suggest that the range of severity of disability among service users in supported accommodation services is wider than those in supported living, but that there is some overlap between the two groups. Looking at the percentage of people in each of the datasets who fell within the same ABS score range and thus whose scores overlapped it can be seen in Table 8 that there was an overlap of between 30 and 35%. This finding suggests that approximately one third of service users receiving support in group homes could potentially live in a supported living arrangements.

Table 8. Percentage of overlap in level of disability of supported living and supported accommodation samples.

	Supported living sample	Supported accommodation samples			
		Year 1	Year 2	Year 3	Year 4
Part 1 ABS score (Range)	239 (166-282)	154 (39-253)	144 (31-277)	139 (22-263)	148 (22-263)
% overlapping		30% (166-253)	35% (166-277)	30% (166-263)	31% (166-263)
% supported accommodation sample below 166 (lowest score of supported living sample)		54%	61%	60%	58%
% supported living group score above the highest score of group home sample		16% (above 253)	4% (above 277)	10% (above 263)	11% (above 263)

Matched samples – comparable outcomes supported accommodation and supported living

As described in the method section, a sample of 29 service users from the supported living project was matched with a sample of people supported accommodation services as close as possible for age, level of disability and 4 other attributes, with no significant differences on any of these (Table A 9). An inspection of the attributes other than those on which they were matched identified 2 significant differences; more people in supported living had a hearing impairment, and more people in supported accommodation had mental health problems (Table A10).

There were very few significant differences on the outcome measures that were available to compare the matched samples, which is indicative of little difference in the quality of life between service users in the two types of accommodation. Comparison on scores on the Index of Participation in Daily Living and the Index of Community Involvement showed no significant differences. Similarly, there were no significant differences in terms of participants' contact with family, friends or whether they had an advocate. As Table 10 shows, the only significant difference was on access to social club, in the direction of those in supported living having more access than those in the group homes.

Table 10. Comparison of indicators of quality of life outcomes for matched samples

		Supported Living	Group Home	*p*
	N/n	29	29	
Score on the Index of Participation in Daily Life	M	74.27%	65.5%	p=0.285
	Range	11.5-100	19.2-100	
Score on the Index of Community involvement	M	53.68	56.60	p=0.662
	Range	18.8-93.8	31.3-100.0	
Score on the Choice Making Scale	M	76.22	69.17	p =0.981
	Range	44-100	2.78-100	
Regular family contact		79%	83%	p=0.664
Contact with friends		76%	83%	p=0.504
Have an advocate		65%	68%	p=0.653
Advocate - Family Member		70%	82%	p=0.201
Family are closely involved in the individual's life, support and decisions		57%	68%	p=0.359
Any type of work (paid or unpaid)		48.3%	52.6%	p=0.768
Attended some form of day programme		41.4%	47.4%	p=0.683
Accesses a social club		44.8%	5.4%	χ^2 8.7 *p*=0.003*

Quality of Life Outcomes in Supported Living Arrangements

As described in the methods section we rated participants as having, Good, Mixed or Poor outcomes on each of the QoL domains (see Table A1), and then rated them across all domains as Mixed-Good or Mixed-Poor (Mixed-Good, at least 2 domains good, remaining mixed, no poor; and Mixed-Poor, at least 5 domains mixed).

As Table 11 shows participants fell fairly evenly across the two groups, with 45% (n=14) categorised Mixed-Good and 55% (n=17) Mixed-Poor, suggesting that overall participants experienced a mixed rather than good quality of life.

Table 11. QoL Outcomes by domain and categorisation of sample

Categorised by QoL outcomes	**Mixed-Good QoL**	**Mixed/Poor QoL**	**All sample**	
QoL Domain	**%**	**%**	**n**	**%**
Emotional well-being				
Good	43	41	13	42
Mixed	57	47	16	52
Poor	0	12	2	6
Interpersonal relations				
Good	0	0	0	0
Mixed	100	94	30	97
Poor	0	6	1	3
Material well-being				
Good	0	0	0	0
Mixed	100	94	30	97
Poor	0	6	1	3
Personal development				
Good	50	0	5	16
Mixed	50	71	19	62
Poor	0	29	7	22
Physical well-being				
Good	7	0	1	3
Mixed	93	41	20	65
Poor	0	59	10	32
Self determination				
Good	43	35	12	39
Mixed	57	59	18	58
Poor	0	6	1	3
Social inclusion				
Good	7	6	2	6
Mixed	93	71	25	81
Poor	0	24	4	13
Rights				
Good	21	6	4	31
Mixed	79	59	21	68
Poor	0	35	6	19

The domains in which a relatively high number of participants were rated Good were Emotional well-being (42%) and Self Determination (39%) but even on these domains more participants were rated as having mixed than good outcomes. Ratings on the domains of physical well-being and personal development were lowest, with 32% of participants rated poor for physical well-being and 22% for personal development. Tables A11-A19 provide details of the rating in each domain.

In order to identify the factors associated with better QoL outcomes, we compared the group categorised as Mixed-Good with the Mixed-Poor group on a range of different individual and contextual dimensions. We found very few statistically significant differences between the two groups. This is likely to be explained by the small sample size but also the degree of similarity between the two groups. As Tables 12, 13 and A16 show, the only significant differences between groups and the factors associated with better outcomes were age, autism, health status, strength of family involvement and participation in structured activities.

Service users who were younger and those with autism were significantly more likely to have a better QoL. Better outcomes were also associated with health status. Service users who had overall a Mixed-Poor QoL had poorer health, and were significantly more likely to have physical fitness and conditioning problems, dental/oral problems, fatigue, joint and muscle pain, contractures, balance problems/dizziness, bladder problems, vision problems, hearing problems, and problems with mobility (see Table A16). Similarly service users with more health conditions, and in particular if those health conditions are rated as significant or chronic were more likely to have Mixed-Poor QoL. Overall participants whose family was closely involved were more likely to have Mixed-Good QoL as well as those who had regular structured activities, such as paid or volunteer work or attendance at a day program for at least three days a week.

Table 12. Individual characteristics of sample living in supported arrangements by QoL outcomes showing significant differences associated with better QoL

		Mixed-Good	Mixed-Poor	*p*
	N/n	14	17	
Age (years)	M	40	50	*Z =2.32* *p=.020**
	Range	24-57	23-63	
Percentage male		57%	29%	p=0.119
Part 1 ABS score	M	241	238	p=0.578
	Range	166-282	184-275	
Total score on the ABC	M	11	12	p=0.952
	Range	0-34	0-41	
Percentage socially impaired		36%	24%	p=0.457
Percentage with a physical impairment		29%	29%	p=0.959
Percent with epilepsy		7%	6%	p=0.887
Percent with mental health problems		14%	18%	p=0.8
Percent with visual impairment		7%	6%	p=0.887
Percent with hearing impairment		7%	29%	p=0.118
Percent with autism		21%	0%	χ^2 4.03 *p*=0.045*

Table 13. Contextual characteristics of sample living in supported arrangements by QoL outcomes showing significant differences associated with better QoL

	Mixed- Good (*n=14)*		Mixed- Poor (*n=17)*		*p*
	N/n	%	N/n	%	
Family are closely involved in the individual's life, support and decisions	11	79	7	44	χ^2 3.77 *p*=0.05*
Any day service, supported voluntary work experience or supported employment or combination) at least 3 days week	14	100	13	77	χ^2 3.78 *p*=0.05*

Discussion Survey of Service Users

The characteristics and living situation of service users surveyed were similar to those of focus group participants, and reflects overlap of participants. They were predominantly middle-aged people living alone in some form of social housing. None had a severe level of disability score on the ABS scale. Those surveyed received similar types of support to focus group participants. Predominantly this was outreach type drop in support with a range of practical tasks for a mean of 4 hours a week and on call back up. In addition most participated in some form of regular structured activity for at least 3 days a week provided directly organised through a disability day program. Most participants were also regular members of some kind of social group and had regular contact with family. Their estimated total weekly cost of disability related support was between $213 and $1877 with a mean of $585. These figures can only be indicative given the uncertain knowledge of respondents about funding levels and local and historic funding arrangement that create inconsistency across organisations. Notably too, the data suggested that none of the participants were funded for case co-ordination or case management, something that the service user focus groups suggested was underfunded and poorly acknowledged but undertaken regardless by service providers on a largely unfunded basis.

Most of those surveyed had a mixed rather than good quality of life. Ratings were particularly low on physical health and personal development and no-one rated good on interpersonal relationships or material well-being domains. Although not completely comparable, the social capital of participants was similar to that of people using family support services. Overall these findings suggest that people in supported living would benefit from greater support, particularly in regard to health, material well-being, personal development and social relationships. .

Participation in regular and structured activities was one of the few factors that distinguished participants with a Mixed-Good QoL from those with Mixed-Poor QoL. A majority worked on a voluntary basis in commercial or non-government enterprises or as supported employees in small scale social enterprises. This finding raises an important question about how and by whom this type of regular participation was facilitated. This was not always clear but in some instances it had been organised and was supported by a disability day program and, in others, through an outreach worker. Several recent Australian studies have demonstrated the skilled support often required to negotiate and support participation in volunteer work or mainstream social groups, and the importance of both monitoring and provision of episodic support when individual or group circumstances change (Bigby et al., 2014; Craig & Bigby, 2014; Shanks, 2012). The association between regular structured participation in activities and quality of life outcomes, indicates that access to facilitative and episodic support to negotiate and sustain participation either through a day program or other form of flexible support provider should be a component of support packages for people in supported living.

Findings from the matched sample comparison (those in supported living with similar characteristics to those in supported accommodation) found very few differences on QoL indicators between the two groups. An unexpected finding from the comparison was the absence of a significant difference on the Choice Making Scale given the strong sense of choice and control expressed by focus group participants and the body of findings from other studies. One likely explanation for this is that staff will have completed the measure for individuals in the supported accommodation datasets and it has been noted in other studies that staff rated measures of choice may sometimes overestimate the actual level of choice (Mansell et al., 2008; Beadle-Brown et al., 2012)

Our findings showed that 30-35% of service users in supported living had a similar level of disability to service users in group homes. These figures support conclusions drawn from other Australian research, by our team (Mansell et al., 2013), and Stancliffe & Keene (2000), that a substantial proportion of service users living in group homes could live in a supported living arrangement.

There are very significant support cost differences between these two types of services. Supported accommodation has an annual cost of at least $80,000 per person, not including day program support of approximately $19,000. In comparison the present study found an average annual cost for supported living, including day support, of $30,435 Although service users in supported living certainly had fewer hours of support than their peers in group homes at less cost, the similarity of QoL on some indicators between the groups may well indicate that neither group receives the type of support necessary to achieve a good quality of life. Nevertheless, the very significant cost differential and minimal differences in QoL for service users between the two service types suggests this disparity and apparent over support of some service users in supported accommodation is something that cannot be ignored in the implementation of the NDIS.

Case Studies

The case studies aimed to describe in more depth, the QoL of people in supported living and identify the factors that contributed to good outcomes and success of these arrangements. Case studies can enable investigation of contextual variables and changes over time that are difficult to capture in survey data.

Method

Six participants from the survey were selected to represent a cross section of characteristics, support arrangements and outcomes; these are shown in Tables 14 and 15. The six case studies included Anna who had the lowest QoL rating (5 domains poor and none good) and participant Max who had one of the highest ratings (3 domains good and none poor).

Consent was sought from participants for a further interview with themselves and with others in their formal and informal support networks. For each person at least two formal supporters were interviewed, but we were unable to arrange interviews with informal network members within the necessary time frame for this last phase of the study. Interviews were open ended and sought detailed information about support and living arrangements and participants experiences of current and past life experiences. *NVivo* was used to facilitate the management and analysis of the data which followed the same approach used with the focus groups, although with some *a priori* analytic codes derived from early stages of the study.

The sections below provide a brief summary of the age, tenancy, support arrangements, social networks and previous living situations of each case study participant, followed by a brief commentary. Their characteristics and ratings on each of the QoL domains are shown on Tables 14 and 15. The first three vignettes are service users who were rated as having Mixed-Poor QoL and the second three are those rated as having Mixed-Good QoL.

Table 14. Quality of life ratings for case study participants

Service User	QoL Group	Emotional well-being	Physical well-being	Material well-being	Interpersonal relationships	Personal development	Self-Determination	Social inclusion	Rights	Domains good	Domain poor
Anna	Mixed -Poor	Mixed	Poor	Poor	Mixed	Poor	Poor	Mixed	Poor	0	5
Sam	Mixed -Poor	Mixed	Mixed	Mixed	Mixed	Poor	Mixed	Mixed	Mixed	0	1
Steven	Mixed -Poor	Mixed	Mixed	Mixed	Mixed	Poor	Mixed	Poor	Poor	0	3
Max	Mixed-Good	Good	Good	Mixed	Mixed	Mixed	Mixed	Mixed	Good	3	0
Helen	Mixed-Good	Mixed	Mixed	Mixed	Mixed	Good	Mixed	Mixed	Mixed	1	0
Wendy	Mixed-Good	Mixed	Mixed	Mixed	Mixed	Good	Good	Mixed	Mixed	2	0

Table 15. Characteristics of case study participants

Service User Code	Location	Gender	Age	ABS	Complex need Mental health	Complex need - physical disability	Complex need - more than three chronic health conditions	Any day programme	Support Basic outreach or more intensive	Advocate not a member of staff
Anna	Inner north	F	56	263	No	Yes	Yes	No	Up to 2 hours week	Yes
Sam	Inner west	M	54	185	Yes	No	No	No	3 – 8 hours a week	Yes
Steven	Outer south	M	23	241	Yes	No	No	No	3 – 8 hours a week	No
Max	Regional southeast	M	50	256	No	No	No	Yes	Up to 2 hours a week	Yes
Helen	Regional northeast	F	31	211	No	Yes	No	Yes	3 – 8 hours a week	Yes
Wendy	Outer south	F	57	215	No	No	No	Yes	3 – 8 hours a week	No

Case Study Vignettes

Anna

Anna is 55 years old, and lived for many of her younger years in an institution for people with intellectual disabilities. She has lived alone in a public housing unit in suburban of Melbourne for 3 years. She is on nodding terms with her neighbours who are mostly elderly people. She has good everyday living skills and manages her own finances, most domestic tasks and gardening at her unit. She has some complex health conditions and is finding it increasingly difficult to walk long distances. She uses a motorised scooter to access the local shops but the difficulties of accessing public transport with her scooter are making it difficult to go further afield.

Anna receives limited practical support and lives on disability support pension. She has an hour a week of outreach support, a HACC funded cleaner once a fortnight for 2 hours, and an annual home maintenance visit to make any necessary repairs to her home. She has a positive relationship with her support worker and the service co-ordinator, Kerry, whom she can ring at any time. She generally rings about 3 times a week, and said, “if I have any problems I usually ring up Kerry”.

Anna has been seeing a psychologist once a fortnight for some time which was arranged through her GP but has nearly reached the allocated number of visits. She is part of a Key Ring network which offers monthly social activities with other members of the network. Her support staff described her support needs as social and emotional. She has a long standing 19 year relationship with an advocate to whom she speaks at a regular time each week for about an hour. The advocate has clear boundaries around this relationship and saw herself as a mentor, supporter, broker, confidante and encourager for Anna, saying that Anna knew that she was not her ‘friend’.

Anna has had a difficult life, experiencing sexual abuse and violence in the institution and from men in the community with whom she has had relationships. She has been married twice and said, of her late husband who died in 2012,

> He was a bit nasty. He was a bit horrible. He used to put me down and stuff like that, but really I should have been lucky. I was lucky to even have him when he was alive because I went out everywhere with him.

She has two children who were removed from her care when they were younger and with whom she now has spasmodic and somewhat exploitative relationships. When they contact her there are often heated arguments, usually about money. As Anna says all her daughter wants is for her to “shout her [pay for] everything”. Giving her children money can mean she has no money to go to the organised activities she is invited to attend. She says however, that her desire to have contact outweighs the fact that dealing with them “makes me feel bad”.

She spends a lot of time with nothing much to do. She does not have any regular structured activity, but occasionally goes on outings organised by a large service provider and intermittently attends the social activities organised through the Key Ring network. She spends some time each day at the local cemetery visiting the grave of her late partner. Support staff were concerned that she is vulnerable in the secluded location of the cemetery given her limited mobility.

Anna misses having someone to go out with and described her life as being “very lonely”. She said for example,

> I try to get out but I can’t go into the Hotel on my own all the time because it’s too lonely…Be nice if I could have a bit of one or two friends. I’m not asking for too many…Just company. Someone to talk to… It’d be nice if I could talk to someone really nice but ones that’s not going to abuse you or controlling.

She has encountered negative attitudes and rejection when she has attempted, without support, to make regular social connections in the community. For example, she briefly attended a local church group but says they rejected her because of her disability and said a local community café discouraged her attendance because they “didn’t like my clothes”.

Her loneliness makes her vulnerable and she is currently in what can only be described as an exploitative sexual relationship with a man she met at a singles club. He visits her once a week but is unwilling to take her out anywhere. She said,

> In one way I’m comfortable with the company but I’m not happy with what he does. He’s not violent. I can talk to him the way I’m talking to you. He’s not violent. He wouldn’t smack into me or--I know he’s using me. He goes with other ladies and all that.

Anna has the practical support she needs to enable her to manage the everyday tasks of community living and has back up with problem solving if necessary. She has secure and subsidised social housing but despite this has little disposal income. In the future she is likely to require more support to manage her health and maintain mobility. But now she needs more support of a different kind to live well. Her unmet support needs are more intangible, around self-esteem and development and social connections. She appears to have unmet needs around emotional support to grieve for her husband, manage the relationship with her children and bring to an end the abusive relationship she is in. Her loneliness and lack of engagement in other activities suggest the need for more intensive support than that offered by the Key Ring network to enable her to have regular involvement in meaningful activities and to form a stronger and more positive network of social relationships. On the other hand Anna likes living in her unit, the "quiet" neighbourhood, and her advocate said Anna feels independent and described her current accommodation as the "best she's ever lived in".

Sam

> Sam is 54 year old, and lives alone in suburban Melbourne. He purchased the unit seven years ago through a government joint ownership scheme, after living in public housing for some years. He likes living alone and having "space", ideally in the future he would like a larger home with "a bit more space".
>
> He has 4 ½ hours of outreach support a week, which was recently reduced from 5 hours. The weekly visit from a support worker follows a similar pattern - they go to a large shopping centre, where together they do Sam's banking, pay bills at the post office, have coffee, go to two different supermarkets and have lunch. Then they return to Sam's unit, unpack the shopping together, the worker reads any mail Sam needs assistance with, and does "a bit of cleaning" in the kitchen. The support worker and the service manager are available by phone but say that Sam rarely calls. Both Sam and his worker were concerned about the recent reduction in support. Sam, because he would like his shopping trip to be at a more leisurely pace, the support worker because she feels he needs more support with domestic tasks. She describes Sam as a "hoarder", saying that his unit is often messy and dirty.
>
> Sam has a good relationship with his support worker who has been the same person for 7 years. "Good support" he says is someone who listens. In the past he has had

"bad ones [who] don't care". He complained to the service about a previous worker who had fallen asleep at his home.

Sam has some mental health problems that are managed by his GP. He manages his own medical appointments and medication, saying that he is "always careful" to make sure he has enough supplies of prescription medication so that he doesn't run out. He regularly phones his GP; for example he recently told her about his new job. He describes her as someone he can "talk to about anything".

Sam was married when he lived in public housing, but now separated. He does not wish to re-marry or have another intimate relationship. He has regular phone contact with his sister, whom he sees "once in a while". The support workers said that Sam's sister is always happy to speak to him on the phone but is not readily available to see Sam in person. He has occasional phone contact with one of his two brothers but is estranged from the other.

Sam receives the Disability Support Pension but until recently worked four days per week for a cleaning company. The company went into receivership and Sam was made redundant along with other employees. He is registered with a disability employment service and has a regular appointment once a fortnight. He does not currently have any regular structured day time occupation but has just begun to do cleaning work at a local bowls club for a couple of hours two days a week. He would like more hours but is enjoying his new job and has made two new 'friends' who he hopes to meet up with outside work in the near future.

He says that he is a little "bored". His only regular social activity is a weekly evening of 10 pin bowling when he participates in a league competition. He has however enjoyed going on regular holidays using a private company.

Sam says that some of his neighbours are friendly and that one lady in particular likes to chat to him. They often talk about "recycling the rubbish and other stuff, anything". There is occasional conflict amongst the fellow residents in Sam's block of units, usually over shared rubbish bins and Sam says that some of the neighbours are "dirty people" but that he "keeps right out" of any disagreements.

Sam says that he is "very happy" with his current living arrangements. He enjoys going to bed and getting up when he chooses, except on days when he goes to work

> and that he can do what he wishes and listen to music in his unit. Sam says that in his current unit he feels independent and does not feel lonely.

Sam has slightly more support than most participants in the study to manage tasks of everyday living but a recent cut by half an hour is seen as having potentially negative consequences to the maintenance of a clean and hygienic living space. He values the time he spends with the support worker who at the moment is the only person who he sees regularly. The loss of his job has put him at risk of social isolation and he may benefit from more intensive support to find more hours of employment or in the interim volunteer work or some form of regular structured activity. He does not have any support with making friendships or regular social activities. Although Sam says he does not feel lonely, he has a very limited network of social support and no strong unpaid relationships other than with his sister.

Steven

> Steven is 22 years old and lives in a block of public housing flats in suburban Melbourne. He has lived there with his girlfriend for 3 years, and before that they lived in temporary housing. Steven thinks the flat is too small for two people and dislikes the neighbourhood, saying that sometimes the neighbours are abusive towards him. He would prefer to live in a larger place nearer to the centre of the city. He shares the costs of food and utilities with his girlfriend whose finances are managed by State Trustees.
>
> Steven's parents are divorced and during his childhood he moved house frequently. He attended a large number of different schools, including special schools all of which he describes in very negative terms, and as places where he was bullied.
>
> The nature of Steven's support had changed in the 6 month period between the survey and the case study interview. He had been in receipt of about 2 hours a week outreach support which was primarily helping him to manage financial difficulties; he had large debts and difficulty paying for rent and food. The support agency arranged for a one-off payment from a charitable organisation to clear the largest of the debts and for all bills to be paid directly through Centrelink's Centre Pay system. The outreach service had also supported Steven to do some cooking classes.
>
> At the time of the second interview outreach support had ceased and his only sources of formal support were from his girlfriend's case manager (from a mental health service) whom they saw irregularly, and a disability employment service. He attends

appointments at the employment service for approximately 1 hour once per fortnight. His worker described the support provided as "helping to build skills for open employment." She works with Steven on job-searching, application writing, interview skills and trying to identify barriers to employment. Steven is doing voluntary work one day per week for 4 hours, arranged by his worker to provide useful experience. He does not enjoy this, seeing it as a waste of time. The placement was originally for two days per week but Steven reduced it to one day because he said that he was "bored" and did not like the company of some of the other volunteers who are all much older than him.

Steven is estranged from his father and has only occasional contact with his mother by phone. He identified her as someone he would phone if he had a major problem he couldn't solve himself but only as a last resort, saying she "is a terrible person to call" and has offered him little support in the past.

He has six siblings with whom he has occasional phone contact. He has a small number of friends in the local area, describing them as "people I can talk to". He feels that his lack of money sometimes makes it difficult to go out and do the kinds of leisure activities he would like to do with his friends, most of whom are working. He said,

> I used to do karate and go to the gym and do boxing and a bunch of other things, and I was relaxed when I get home because I would then watch some TV and then go to bed. But since I don't have a job I don't do all those hobbies and stuff. I don't relax. I'm stuck here watching crap TV all the time…most of the time I'm just stuck by myself, bored.

He has a long term relationship with his girlfriend but said he felt everything was up to him, he makes all the decisions and provides all the emotional support in the relationship. He said that if he asked his girlfriend to say something positive about him she would "probably say something hurtful". He says that he feels "lonely most of the time".

Steven currently receives the Disability Support Pension. He has had a number of jobs in the last two years; all of these were at fast food outlets or bakeries. These were short-lived and Steven says that he "hates all the food" and would like to work in a

> different kind of workplace. His worker says that Steven has some “issues with reliability” and lost these previous jobs as he was not consistent in his attendance.
>
> Steven expressed frustration with his current situation and the limitations that stem from a low income more than other participants, observing that although he is independent, “I don’t have any money to speak of and I’m stuck here”. He wants to get a paid job as he feels that a lack of money is at the heart of his unhappiness and frustration. His lack of practical outreach support and frustration with the system means he is not getting all the money he is entitled to from Centrelink. He said for example,
>
> > They took it away just recently. I couldn’t fill in the form properly so they said since I didn’t fill in the form they can’t give me rent assistance. [Can you get someone to support you to fill in the form?] It’s only $30.00…Someone could but I just don’t want to go to Centrelink. I don’t want to deal with it. Centrelink’s the enemy. I hate that place...You go in there. They say you have to be there a certain time. You go there and you’ll sit for 40 minutes to get somebody who is trying to rush you as far up as possible and then no help. Well, I’m meeting with them in a couple of days. I’ve got a letter somewhere. I can’t find it. Yeah. And I don’t want to go.
>
> The only positive aspects of Steven’s current living arrangement are his independence from his family home and the close proximity of his flat to the train station. He is despairing of the future saying that when he makes a decision to do something “most of the time something comes and destroys it. There’s always barriers”.

Steven is one of the few participants who clearly needed more practical support with everyday living as well as other forms of support. He has relatively good practical skills but needs support to manage relationships with Centrelink, his neighbours, his girlfriend and family, finding and retaining employment, managing to live on a low income without building up debt. He has little emotional support from family nor close friendships other than his partner, and experiences a strong sense of exclusion from the good things in life. His only regular structured activity is the one day a week of voluntary work that he does not enjoy. His unhappiness and frustration with his life circumstances impact heavily on his emotional well-being and self-esteem.

Max

Max is 60 years old and lives alone in a privately rented unit in a large regional town in Victoria. He has been in this unit for 5 years and previously lived in other rental properties in the town, one of which he shared with a male co-tenant. Max ended that arrangement as he was frustrated by his housemate not “doing his half” of the cleaning and tidying. Max spent much of his childhood and early adult life in an institution for people with intellectual disabilities.

Max is confident in all areas of daily living, shopping, cooking and travelling independently. He has 1 ½ hours of outreach support per week which includes a home visit and phone support as necessary. The support worker reads any correspondence to Max and “just chats” to him about issues of concern. He also has a private cleaner who comes once per fortnight for two hours which he pays for himself. The real estate agent/body corporate at his unit arrange for a gardener to mow the large lawn at the rear of Max’s unit. The service co-ordinator observed that Max had made “amazing progress” towards independence in recent years and requires very little support with any practical tasks. The support worker said Max was phoning quite a lot, “just to talk” about issues concerning a developing relationship with a woman which Max is finding complex and sometimes upsetting and difficult to manage.

Max says that he has “good support” and likes being able to access his support workers by phone whenever he needs to “chat”. He commented that he really likes the fact that his newest support worker is a man because he has a lot of questions and issues to discuss about being in a relationship and feels that it is useful to discuss these with another man. He saw listening as a key aspect of a support workers job, saying, “they’ve got to listen to you. If they don’t listen to you they’re not doing their job properly”.

Max’s finances have been managed by State Trustees since he accumulated some significant debts. His pension and wages are paid directly to State Trustees which pay all his bills and rent and give him a weekly allowance. Max feels that the amount is inadequate but said although he has found the Trustees difficult to deal with, none of his requests to purchase items had been refused and he was recently assisted to buy a stereo under a finance/hire purchase plan.

> Max's mother lives in a nursing home in the same town and he visits her weekly. He has infrequent phone contact with his 5 siblings, 3 of whom live in supported accommodation services in nearby towns and two live in Melbourne. He has a network of friends and acquaintances from his membership of a self-advocacy group. Max has what the service co-ordinator described as an active social life. In football season he attends matches every week, even travelling interstate with a supporters group. He goes to the pub regularly and plays pool with friends. At the time of the interview Max had commenced an intimate relationship with a woman he had known for about 2 months. The issue of sharing money and who paid for household items was a source of anxiety for him. His support worker said this new relationship was the "biggest challenge he has ever faced".
>
> Max is wary of interacting with others in the local neighbourhood. He has experienced a number of incidents in the local community and at work where people have made negative comments about his disability, been verbally abusive towards him and "made fun" of him. He said that he makes a point of not speaking to neighbours saying "it's best to keep to yourself".
>
> Max is employed two days per week at the large supermarket in the town, a job he has held for ten years. For the past five years he has spent between two and three days per week doing voluntary work in the office of the self-advocacy group. However, at the time of the case study interview he was "taking a break" from the group. Max's support service co-ordinator said that she felt that Max was generally very happy and satisfied with his life but at the moment there were some interpersonal issues that were having a negative impact on him. She hoped he would return to the group as she feels that engagement with it has had a huge positive impact on his confidence and skills.
>
> Max feels independent and enjoys living alone, and relishes the fact that he "has the power" over his environment to come and go as he pleases.

Max receives the limited practical support that he needs to manage his daily living. He has regular but limited contact with his mother, but has a strong network of friends and acquaintances around self-advocacy and a football club. He has part time employment and until recently significant involvement in a self-advocacy group. He is experimenting with an intimate relationship and is being supported to work through some of the emotional and practical issues by the outreach support worker and service co-ordinator who know him well. He has experienced negative community attitudes and has little interaction with others in his local area, but uses local shops and the pub with ease. He is however, experiencing some changes that could upset his relatively good quality of life or improve it further.

Helen

Helen is 31 years old and shares a unit with another woman, in a cluster of six units in a regional Victorian town. She has lived here for three years, and prior to that lived with her mother and siblings in a small rural town. Helen has some speech but also uses an iPad communication device.

Helen has an ISP which provides an average of 4 hours individual support a week. She pools some of her hours with other tenants in the unit, getting small amounts of drop in support with cooking most days. She has support for grocery shopping and banking which entails going into town with a group of other service users from the units where she lives. She cleans and tidies her unit independently. She also shares support with other tenants to go out regularly two evenings a week to a local club where she plays pokies and has dinner, and occasionally to special events. She can contact the support worker or their manager when necessary by phone.

She spoke positively about her relationships with support workers, describing her key worker as her “friend” but said she would like to do more tasks for herself and make more decisions. She commented that she didn’t feel listened to by some workers and that she thinks that a good worker would have "hope" for her.

Helen has regular “bust ups” with her co-tenant and gets upset about her lack of interest in cleaning and doesn’t like the way that she teases her about it. Helen is also concerned about her over-interest in cleaning.

One support worker described Helen as missing her family and wanting to have more contact with them. This was not reflected in Helen’s interview where she stated her mother had often been “very angry” with her and done everything for her and that now she was happy to be able to be on her own and to do tasks like cooking by herself.

Helen has a network of acquaintances with whom she participates in social activities who are predominantly other tenants in the units or participants at her day program.

> The service manager commented that she thought Helen always has people around her and that she is “never lonely”.
>
> She attends a day program for 20 hours a week and as part of this undertakes work experience at a local florist, where she trims bunches of flowers and does some general cleaning.
>
> The service manager is proposing that Helen move out of the cluster and into a new house on the other side of town which would be less like living in a disability service. The house would have four residents. It would not include the woman with whom she currently shares and has a difficult relationship with. The manager said that Helen was “very happy and excited” by the prospect of moving into this new house although Helen did not speak about this during her interview.

Helen is well supported with practical aspects of everyday life, though feels she could be better supported to develop skills further and be more independent. She has a difficult relationship with her co-tenant but is very socially connected albeit to a relatively small group of other people with disabilities who live in the block of units or attend a day program. She has regular structured activities at a day centre and one day a week in a florist shop, which she enjoys. She has regular social activities with other people with disabilities in a social club in the town. She likes being more independent from her mother who is still involved in her life. Helen lives a fairly sheltered and segregated life but this seems likely to change if she moves out of the units into a shared house.

Wendy

> Wendy is 57 years old and has lived in the same privately rented flat in suburban Melbourne for 10 years. She lived in a group home for a number of years prior to moving out to a rental flat when she got married. Her husband died several years later and since then she has shared a flat with a close friend and had two unsuccessful attempts at sharing with other people. She says she is happiest living alone.
>
> Wendy manages her own personal care, cooks and cleans her flat and shops independently. She has a small number of ready-cooked meals delivered each week to reduce the amount of cooking she has to do. She has an ISP which gives her 3 hours a week of outreach support. Her support worker described his main role as “teaching independent living skills”, assisting her to maintain contact with her family, by regular phone calls and sending birthday cards and providing emotional support. She

has difficulties with phone calls from telephone marketers, and finds it hard to follow the advice of her support worker to “hang up on them”. She recently signed contracts with marketers from utility companies who had come to her door and was assisted by her support worker and State Trustees to extricate herself from these.

Wendy was positive about her current worker but critical of previous ones who had been “strict” and “controlling”. Her support worker commented that she is often resistant to advice particularly in relation to taking medication or preventative health tests such as mammograms and he tries to provide support in a way that makes her “feel like she’s in control.”

She also gets support from a pastoral care program through a visit once every three weeks from a member of the religious order associated with the disability service. The visits are a chance to chat at home or go out for coffee.

Wendy’s finances are managed by State Trustees who pay bills and give her a weekly allowance for food and transport. If she wishes to make any larger purchases she is supported by her worker to make a request to State Trustees, which he says is “never a problem”. Wendy saves for annual holidays and through a private support company has travelled within Australia and last year to Disneyland in the US.

Wendy doesn’t see her mother very often as she lives some distance away and is not in good health. She has regular phone contact with her but only limited contact with her siblings. She has a friend with whom she has shared several holidays but who unfortunately won’t be able to attend the holiday planned for next year. She does not know her neighbours and says that she does not like their noisy behaviour. She spoke about some negative bullying encounters with strangers in the local community.

Her main social connections are with the people from her 2 days a week volunteer work. The co-ordinator there commented, that “one of the other volunteers on a Wednesday has struck up quite a friendship with her, and will often drive her home and will stay for a cuppa”.

Wendy attends a day programme one day a week at a disability service close to her home which had organised her to work as a volunteer 2 days a week for a large disability provider. She works in a day service for people with moderate to profound intellectual disabilities, supporting people in art classes and with other tasks such as

> serving and clearing up meals and snacks. The co-ordinator said, “she usually gets here at about half past eight in the morning and will stay until about three. It's a good day. It's like a job”. She enjoys this work, which is very close to home meaning she can walk there independently. She has a positive relationship with the staff and is pleased that she has a locker in the staffroom and eats her lunch with the staff rather than the clients.
>
> Wendy would like to move to a different flat in the same area as she is finding the stairs difficult to manage but finding a suitable place at an affordable rent is proving difficult and she is finding this frustrating.

Wendy is well supported to manage practical aspects of everyday life and has some social and emotional support through a pastoral care program. Although she has a limited social network or contact with neighbours, she has regular phone contact with her mother, and several friendships made through her volunteer and shared holidays. She has regular structured activity but few other social or leisure activities. She may have to move in the future if the steps to her flat continue to be a problem and finding affordable private rental may be difficult.

Discussion Case Studies

These six brief case studies give a thumbnail sketch of the life experiences, particularly the absence of close friendships and the loneliness of people with intellectual disability in supported living arrangements. In many ways they serve to illustrate the findings from the survey findings and QoL data.

A thorough qualitative analysis did not discern any clearer pattern of factors associated with better QoL outcomes than those already identified in the survey (younger age, better health, having autism, stronger family support and participation in regular structured activities). This is very likely due to what might be described as the mediocre QoL of participants in this study, and the remarkable absence of anyone with a great QoL – one that could have been rated as very good or even consistently good on all 8 domains.

As the final part of the report will discuss further, this suggests the necessity of a much larger national study to ensure inclusion of people with better outcomes, or a different research design that actively seeks out and investigates the circumstances of people living in supported living arrangements who have reputed excellent outcomes. The section below discusses several issues highlighted by the case studies, but to avoid repetition we leave discussion of essentially similar issues to those raised by the survey to the overall discussion.

Sufficient practical support with tasks of daily living and the security of being able to phone a known support worker or their manager was available to all but one of the case study participants. And again with one exception all participants were relatively satisfied with their living situation, comparing it favourably to earlier periods in their lives when they had lived in more restrictive settings. Despite having low incomes, most talked about enjoying the sense of choice and control over their own lives they had in their current situation; a sentiment loudly echoed in the focus groups. Our findings about the deeply valued choice and control in this type of living arrangement resonates with many earlier studies such as Stainton, et al., 2011 and Stancliffe & Keene, 2000.

The case studies illustrated the fragility of people's lives, and the reflected the issues raised by service providers about the necessity to adapt the intensity and nature of support quickly to take account of change. For example, change to employment, relationships, health, suitability of housing, availability of support and qualities of support workers all evident in the case studies were all likely to impact on peoples' support needs. Anna's funding to see a psychologist was about to run out, Sam had just had his weekly support cut by 30 minutes and lost his 4 day a week job, Steven had recently lost his outreach support, Max was embarking on an intimate relationship and had stopped his long term involvement in a self-advocacy group that had taken up much of his time, both Anna and Wendy were considering moving home.

Case management or co-ordination are key ways to identify and enable rapid and co-ordinated response to changing life circumstances and support needs, that will help to avoid deterioration in people's lifestyle or crisis. The direct support workers and their managers that delivered outreach support or ISPs, knew the people they supported well. They looked out for them in a broad sense, saw them holistically and picked up pressing issues in their lives. In many ways their support reflected defacto case co-ordination and in some instances case management. It is difficult to be certain from our data, but it seems likely that many organisations did provide extensive and varied support that went beyond the parameters of their funding agreements about provision of outreach support. The one type of support identified by the service providers that was largely missing from the support arrangements of case study participants was, 'connecting to groups in the community and building relationships with people without disabilities'. This may account for participants' lack of strong ties to civic society, close friendships and intimate relationships.

Descriptions by participants about their support from outreach workers, clearly resembled the elements identified as essential by the service provider focus groups - individualised and person-centred, flexible and ongoing with capacity to be of varying intensity, co-ordinated and ethical and respectful of choice and control. This had not always been the case however for many participants. They were clear about what for them constituted good support; someone who listened and had expectations of them. They had experienced poor as well as good support in the past and some had been willing to make complaints. This study strongly suggests that people with intellectual disability are discerning about their support and should always be consulted about who their worker will be or changes that might be in the wind.

The case studies gave some insights into broader issues about community attitudes; the negativity of some people, even those for example in church communities or community places, towards people with intellectual disability, and the presence of people willing to prey on others. Issues of technology were largely silent in the case studies, reflective of the absence of internet, smartphones and access to computers and social media, and perhaps too the exclusion of participants from these fast paced new modes of communication.

Summary and Discussion

This mixed method study has examined supported living arrangements of people with intellectual disability from their own perspectives and that of service providers. It has collected qualitative data about experiences and opinions as well as quantifiable data about quality of life and support arrangements. The similar themes evident across data sources affirm the trustworthiness and point to the reliability of this study. This last section briefly summaries the main findings from each data source and in comparing the findings with previous research draws out policy and practice implications.

Summary of Findings

Focus Groups with Service Users

Thirty-four people with intellectual disability in supported living arrangements participated in 7 focus groups. Most were middle-aged, lived in rented social housing, alone or with a co-tenant. Most received a few hours of drop in support with the practical tasks of everyday living. They were secure in the knowledge that back up support would always be available from family or their service provider if they needed it. They used community places and had a mix of strong and weak social ties. Contrary to some overseas studies, most participated in regular structured activities.

Unequivocally people with intellectual disability thought supported living arrangements had enabled a greater sense of independence and control over their lives compared to living with their parents or in a group home. For most people, the freedom to be self-directed, away from others 'dictating' what to do, outweighed the downsides to supported living which they identified as: having little disposal income, no access to technology at home, limited control over their financial affairs, being lonely, feeling unsafe to go out at night, and difficulties negotiating the quality of their support, social relationships and negative social attitudes.

Focus Groups with Service Providers

Seven staff, who played differing roles in supported living arrangements, from 5 organisations, participated in focus groups or individual interviews. Providers' perspectives about challenges of supported living arrangements mirrored those raised by people with intellectual disability themselves. They gave more attention than service users however to the difficulties of maintaining good health and the negative consequences of social housing that concentrates together people with difficulties negotiating social relationships. They identified a range of different types of support that people with intellectual disability might require to thrive in supported living arrangements – practical – emotional- personal development – enabling choice and control – connecting to community groups and building social relationships – connecting to peers – resource raising - managing health and relationships with health professionals – liaison and advocacy with other services – keeping track of things through monitoring, co-ordination and capacity for episodic more intense support –managing tenancy – backing up informal supporters. From the perspective of service providers, all support whatever its type should be – person-centred – flexible – co-ordinated – ethical and respectful of service user choice and control. In their view policy and funding bodies undervalued co-ordination and monitoring. The providers suggested that in many instances they and others went beyond their remit, by absorbing the costs of the co-ordination or case management they saw as necessary but were not funded to provide. They provided too some glimpses of the range of skills required by support workers to straddle the breadth of support they might have to provide and manage tensions between enabling, respecting and protecting people who were at times vulnerable to abuse by others or self-neglect.

Service User Survey

The survey was in two parts; a worker who knew each service user well completed the first part, and the second part involved a face-to-face interview with each services user and their worker. Surveys were completed with thirty-one people in supported living arrangements and included many of the same people who had participated in the focus groups. The survey provided more detailed data that confirmed the broad-brush descriptions of the individual characteristics, circumstances and support arrangements gained from the focus groups. On average service users received 4 hours a week of practical support with everyday living, primarily through block-funded outreach or an ISP. A majority participated at least 3 days a week in regular structured activity as a volunteer or supported employee, attended some form of social group and had regular contact with their family. The estimated mean cost of support, including day support was $30,435 ranging from $11,068 to $97,595. Even at the top of this range, the estimated support costs are likely to be significantly lower than supported accommodation.

Comparison of data about service users in supported living and group homes, drawn from a large longitudinal study, showed that approximately a third of residents in group homes had an ABS score that fell in a similar range to that of people in supported living arrangements. Further analysis using a matched sample of service users in supported living and group homes showed remarkably few differences in the quality of life between people who were receiving these very different types of support.

No-one in supported living arrangements had what might be construed as a ‘good’ quality of life and they were categorised as having either a Mixed-Good or Mixed Poor quality of life. Overall the data suggested that participants did better in terms of self-determination and emotional well-being than physical well-being, social inclusion, interpersonal relationships or personal development. Indicative factors associated with a better quality of life derived from the significant differences between the two QoL groups were younger age, having autism, better health status, strength of family involvement and participation in regular structured activity.

Case Studies

Six cases were selected to represent the diversity of people and their experiences of supported living. A more detailed picture of each person's life circumstances and support arrangements was gained by talking to them again and interviewing in more depth at least two other people involved in support provision.

The six participants had what we termed a 'mediocre rather than good' quality of life. The case studies mirrored the issues raised by both service users and providers vividly illustrated the benefits and challenges of community living for people with intellectual disability. Strikingly, despite their loneliness and absence of close friendships, most service users were satisfied with their living situation and particularly the degree of choice and control they had over their lives. The case studies illuminated the changes in peoples' lives that might affect support needs, demonstrating the importance of flexible support. They gave few further insights into the factors associated with good quality of life in addition to those identified in the survey. The case studies demonstrated the absence of consistent or sufficiently intensive support to enable people to build and retain a diverse range of social relationships with peers or other community members.

Discussion

As already highlighted these findings are similar to UK, USA and Canadian studies (Stainton, et al., 2011; Howe et al., 1998; Emerson et al, 2001; Perry et al., 2013) that consistently suggest greater choice and control by service users is the hallmark of supported living. Indeed this theme emerged very strongly from the qualitative data in our study. People with intellectual disability were discerning about what constituted good support – someone who listened – had expectations of them and needed to know who would be coming through the door. Their expertise needs to be used in appointment processes and they need to be consulted about any staff changes.

This study like others found that people in supported living used local facilities and participated in a range of leisure and community activities. Unlike earlier research however, a majority participated in regular structured activity either in a disability day program, as a volunteer, or supported or paid employee. Although not always clear, this type of participation appeared to have been facilitated by disability day services or drop in support workers. This may be explained by the pattern of attendance at a disability day programs which has been integral to deinstitutionalisation programs in Australia (Bigby, Cooper &

Reid, 2012), being carried over into supported living arrangements, particularly for those people who have moved out of group homes. Notably, however, Stancliffe and Keene (2000), in the only published Australian study with a comparable definition of supported living, did not include the cost of day support in their calculation of support costs. Our finding that participation in at least 3 days a week of regular structured activity was one of the factors associated with better quality of life suggests that planning for supported living must include and appropriately cost support to enable this type of participation.

A majority of people in supported living arrangements in this study relied on social or public housing and many preferred living alone. It adds little to the already well documented shortage of affordable and social housing in Australia that poses a major obstacle to the expansion of supported living. Importantly, it does highlight the disadvantages of high density social or public housing developments that congregate socially disadvantaged people together. The findings reflect too evidence about the advantages of living in an ordinary house dispersed in the community rather than small clustered or segregated settings (Emerson et al., 2001; Mansell & Beadle-Brown, 2010), which was particularly evident in the case study about Helen, and her unnecessarily sheltered and segregated life. Building low density affordable housing which is general and dispersed, rather than clustered housing developments specifically targeted for people with disabilities, will avoid creation of underlying structures that have potentially negative consequences for people with intellectual disability in supported living.

Our finding about the few significant differences between matched samples of service users in supported living and groups homes is very similar to Stancliffe and Keene's (2000) matched sample study. The characteristics of their participants differed slightly from the present study (they were younger had been in their current home for less time and lived in larger households). It is difficult to compare estimated support costs between the two studies, not only because of the differing value of money over time but also inclusion of different items, such as the omission of day support, and use of the house hold rather than individual to calculate unit cost. Nevertheless, both studies found the estimated cost of supported accommodation far exceeded that of supporting living arrangements.

This study like Stancliffe and Keene (2000) identified some overlap in the level of ability of service users in group homes and supported living arrangements. Our design and access to a large data set of group homes service users however, enabled a more finely grained investigation of the similarity between services users. We concluded that between 30-

35% of group home service users fell into the same range of adaptive behaviour score as those in supported living. Given the differing levels of support and cost between the two service types our findings lend support to Stancliffe and Keene's (2000, p. 302) conclusion that "some current residents of group homes in NSW may not need the high levels of staff support they receive, and that they may achieve similar or better outcomes, at lower cost, by living semi-independently".

Given both the similar levels of ability of some service users, and the marginal differences in quality of life outcomes between service types, there can be little doubt that many residents in group homes might do as well in supported living. But while this may be the case there are important further considerations, as Stancliffe and Keene (2000, p.299) warned, "Although outcomes for the two groups were mostly similar, this did not imply that the outcomes were satisfactory. Conceivably, they could have been equally poor". Our study identified real shortcomings in the type of support available to people in supported living arrangements that meant most had a mediocre rather than a good quality of life. Of most concern was their low level of physical well-being, opportunities for personal development, loneliness and absence of close friendships. It is difficult to make comparisons between the quality of life of people with intellectual disability and the general population but those in our study lived close to the poverty line on income support payments with little or no other source of income and had a similar level of social capital to disadvantaged users of family support services (Onyx & Bullen, 2001).

The NDIS is likely to hold possibilities of supported living arrangements for more people currently either in group homes or at home with family. Our findings suggest supported living is a preferable option, both from the perspective of economics and increased choice and self-direction for people with disabilities. But if this is to be the case, design of funding schemes and service development must meet the pressing challenge to address support deficits that will improve quality of life outcomes for people in supported living. A detailed reading of this report reveals a catalogue of the problems encountered and issues that require attention some of which we highlight again here.

Some difficulties encountered by people with intellectual disability pointed to the need for more skilled or different kinds of support. But it was also clear that individual difficulties or the need for support were often compounded by negative community attitudes or the failure of social systems to adequately adjust their processes and ways of doing business to the needs of people with intellectual disability. Parts of Centrelink for example, cater well for the needs of people with intellectual disability, and its Centre Pay system enables people to manage payment of utility bills and rent through direct deductions. In contrast, the State Trustees office was so difficult to do business with that everyone whose affairs they managed needed the assistance from a support worker to deal with them.

There are particular challenges in supporting people to have healthy lifestyles, access health care and manage chronic health conditions. These will grow as the current cohort of middle-aged people get older and experience age related health and physiological changes.

The undervaluing and lack of funding for co-ordination and case management tasks, that are currently absorbed by agencies is a problem that must be confronted. As the number of people in supported living increase, organisations will lose the capacity to flexibly absorb costs of monitoring and co-ordination or adjust to changes in people's lives quickly through intense periods of episodic support unless these aspects of support are built into funding schemes.

The extent and implications of poor access to technology stemmed largely from a normative and relative perspective, rather being a strongly expressed or felt by need issue by service users (Bradshaw, 1972) but are nevertheless important to consider. Despite being competent in using mobile phones, iPads and computer programs such as Skype, the majority of participants did not have access to internet or a computer at home and made only rudimentary use of the possibilities of these devices. They had little or no access to programs or apps designed to compensate for cognitive disability particularly low literacy, or to the technical support to set up home internet or mobile devices. Technology has much potential to support people with intellectual disability to establish social connections and navigate communities but they are also in danger of further social exclusion as basic information and transactions such as train and bus timetables, medical appointments, enquiry services, or ticket booking systems move online if steps are not taken to enable their access to technology as a key element of supported living.

The biggest challenges illustrated by the case studies appear to be around social inclusion and interpersonal relationships. First, in supporting people with intellectual disability to negotiate often difficult social relationships, be they with co-tenants, peers, partners, neighbours, family members, those who prey on vulnerable people or bigoted community members. Second in providing effective and consistent support to enable people to connect with peers, and the places or activities in communities that are catalysts for friendships. This study and our research in Australian groups homes (see for example

Clement & Bigby, 2010; Bigby, Reid & Cooper, 2013) suggests consistent failure particularly in the domain of interpersonal relationships to achieve policy goals of social inclusion. As Reinders, (2002) has suggested, a rights perspective enables people with intellectual disabilities to claim formal status in society as citizens but much more than this is required to facilitate friendships, particularly close ones.

The Key Ring model aims to foster social contact and friendships between peers in the same locality and with community members. One couple surveyed had met through Key Ring, but Anna’s case study points to her need for more intensive support than could be offered by the underfunded Key Ring initiative. The study was not designed to explore in any depth the Key Ring model and the small number of people who used it was insufficient to undertake any statistical analysis of its impact. There was also indication, particularly Max’s case study that self-advocacy groups can be important places for making for friendships, which is reflected in other recent Australian studies (Anderson, 2014; Anderson & Bigby, submitted; Frawley & Bigby, in press).

Our findings add further evidence about the urgent need in Australia to develop and trial person-centred approaches to supporting people with intellectual disabilities to develop and maintain social relationships. Such initiatives are needed to identify the key elements of effective support to inform staff practice and service design, as well as those who plan with individual service users, NDIS funding schedules and service development. Little research evidence exists about the effective models or staff practices for supporting people with intellectual disability to build and maintain social relationships and close friendships. All friends were once strangers, so membership or volunteering in community groups or convivial encounters with strangers are potential pathways (Bigby & Wiesel, 2015; Craig & Bigby in press; Bigby et al., 2014). More deliberate strategies such as matching and formation of circles of support are other models but they lack a strong evidence base about processes used and cost (Fyffe & Raskin, in press; Amado, 2014). What is not clear in any of the research is whether enabling friendships should be built into job design and skills of the outreach workers who provide practical support with everyday living or whether a more dedicated approach with differently skilled workers.

This study aimed to identify support arrangements and other factors that make for a good quality of life for people in supported living arrangements. It did identify some factors associated with a better quality of life; younger age, having autism, better health status, strong family support and participation in regular structured activities. This supports Stainton et al., (2011) speculation about the importance of informal support from family in enabling good outcomes in supported living. Our aims were hampered however, by the mediocre quality of life of most participants. A different research design, that includes a more targeted sample of people with an identifiable very good quality of life will be necessary to identify factors associated with good rather than mediocre outcomes; an approach that has been used in study of house supervisors and group homes (Bigby et al., 2014).

Conclusions

Although small scale, this study has added new knowledge to the limited understanding of the supported living arrangements for people with intellectual disability in Australia, and to the wider literature. As well as painting a detailed picture of the life circumstances of people in supported living it has provided more evidence about its benefits compared to group homes and the overlapping populations of these two service types. It will potentially inform service design and development of ISPs by illustrating the range of support that may be required, key elements of all support and the practical drop in support with unlimited back up that works well for service users. We have provided evidence of the importance of participation in regular structured activity to the quality of life of people in supported living and the need to build this into costs and design of ISPs. The study has illustrated the shortcoming of current support arrangements and the challenges that will have to be met if supported living expands in the future, particularly in finding effective strategies to support people to develop friendships and negotiate difficult relationships with others be they utility sales people, neighbours, co-tenants or community members with negative attitudes towards people with disabilities. Our study suggests too the need for continuing work on broader structural impediments to the quality of life people with intellectual disability, such as negative community attitudes, unresponsive systems such as the State Trustees and the shortage of affordable social housing dispersed throughout the community.

Recommendations

- In order to identify the key elements of effect support for the development and maintenance of social relationships, demonstrations programs should be established to design and trial person-centred approaches for supporting social relationships.
- Promising processes, models and practices for enabling people with intellectual disability in supported living to develop social connections and in particular close

friendships should be investigated, including Key Ring model and Self Advocacy groups.

- Individual planning for supported living must include and appropriately cost support to enable regular structured participation in purposeful activities such as paid, supported or voluntary work.
- Ways should be investigated to provide low cost support to enable people with intellectual disabilities in supported living to access basic technology such as internet connections, computers and mobile devices and take advantage of adaptations designed for people with low literacy and cognition.
- Individual planning for people in supported living should take into account their need to access and use technology.
- The potential of people with mild or moderate intellectual disability to live in supported living arrangement, the very significant cost differential between supported accommodation and supported living arrangements and the minimal differences in quality of life for service users between these two types of support should inform NDIA policies and be considered in individual planning decisions.
- Individual support planning for people in supported living arrangements should take into account the necessity for support to be person-centred, co-ordinated, and flexible enough to adjust to changes in a person's life, by providing more intensive episodic support when necessary.
- The NDIS or State Governments should develop initiatives to provide information about alternative housing and support options to people with mild or moderate intellectual disability living in group homes and provide support to move into supported living arrangements should they chose to try this option.
- People with intellectual disability should be recognised as 'experts by experience' about what constitutes good support and should be involved in processes of staff recruitment.
- Affordable housing should avoid concentrating people with disabilities and other disadvantaged groups together, and development of any housing specifically targeted for people with disabilities should be dispersed rather than clustered to avoid creation of underlying structures that have potentially negative consequences for people with intellectual disability in supported living.

- The responsiveness of the State Trustees Office to people with intellectual disability should be investigated and their business practices in relation to this group, their clients should be reviewed.
- Further research should be undertaken to identify factors associated with good quality of life outcomes in supported living for people with intellectual disability using a design that seeks out people reputed to have good outcomes.

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Appendix 1

Table A1. Quality of life domains, indicators of outcomes and domain scores

Quality of Life Domain	**Survey Questions Used as Indicators**	**Scores** (Good, Mixed or Poor Outcomes)
Emotional Well-being	● Survey Part 2, Social Capital Questionnaire. Q2. Are you satisfied with your life? ○ *Good outcome (Score of 3 or 4) =22* ○ *Poor outcome (Score of 1 or 2) =9* ● Survey Part 1. Q26.1 Possible Problem Behaviour = Total score on the ABC ▪ *Lowest average score in the literature 15.7* ▪ *Poor outcomes (Score 16+) n=11* ▪ *Good outcomes (Score of <16) n=20* ● Survey Part 1. Q26.1 Possible Problem Behaviour ○ *Poor outcome (Stereotypic factor score >2) = 3* ○ *Good outcome (outcome (Stereotypic factor score <=2) =28*	● Good outcomes *(All good)* n=13 ● Mixed outcomes *(Either satisfaction is good OR level of CB = good)* n=16 ● Poor outcomes *(at least satisfaction good and one CB measure poor)* n=2
Interpersonal Relations	● Survey Part 2. Q4. Do you have regular contact with your family? ○ *Poor outcomes (No) n=8* ○ *Good outcomes (Yes) n=23* ● Survey Part 2, Q1. Had friends or family in for a meal OR Had guests to stay OR Been on an overnight stay to family or friends ○ *Poor outcomes (None of the above = yes) n=10* ○ *Good outcomes (At least one of the above = YES) n=21* ● Survey Part 2 Q3b = YES (ever have social contact with the neighbours) AND contact is once a week or more ○ *Poor outcomes (Yes/No & Less than once a week) n=28* ○ *Good outcomes (Yes & Once a week) n=3* ● *Survey Part 2. 2ic. The people I met spoke to me rather than a worker who was with me.* ○ *Poor outcomes (1-3, Not True) n=9* ○ *Good outcomes (4-5, True) n=22* ● *Survey Part 2, Q2h. I experienced negative attitudes or actions from others in the community*	

	○ *Poor outcomes (4-5, True) n=13* ○ *Good outcomes (1-3, Not True) n=28* • Survey Part 2. Q5. Do you have contact with friends? ○ *Poor outcomes (No) n=7* ○ *Good outcomes (Yes) n=24* • *Q6a. Number of friends outside the home* ○ *Poor outcomes (less than two friends outside of the home) n=6* ○ *Good outcomes (2 or more friends outside of the home) n=25* • *Q6b Number of friends without intellectual disabilities* ○ *Poor outcomes (no friends without intellectual disabilities) n=21* ○ *Good outcomes (one or more friend without intellectual disabilities) n=10* • *Survey Part 2 Social Capital Questionnaire. Q17. How many people did you talk to yesterday?* ○ *Poor outcomes = spoke to no one yesterday (score of 1) n=0* ○ *Good outcomes = spoke to at least someone yesterday- a score of 2 or above n=31*	• Good outcomes *(majority of outcomes (6 or more) good and none poor) n*=0 • Mixed *(roughly equal number of good/poor) n*=30 • Poor outcomes *(no more than two good, remainder poor) n*=1
Material Well-being	• *Survey Part 2, Q1. Been to a cinema OR Been to pub OR been to concert/play OR Been on holiday* ○ *Poor outcomes (None of the above = yes) n=8* ○ *Good outcomes (At least one of the above = YES) n=23* • *Q2. I used public transport while out in the community* ○ *Poor outcome (1or 2) n=8* ○ *Good outcome (3,4, or 5) n=23* • *Survey Part 1. Q40. Are they renting their accommodation?* ▪ *Poor outcomes (Yes) n=27* ▪ *Good outcomes (No i.e. they own) n=4* • *Survey Part 1. Q43. What is their current income?* ○ *Poor outcomes (below poverty line - $45,000) n=31* ○ *Good outcomes ($45,000 and above) n=0* • *Survey Part 2. 2id. I handled money (e.g. paying for purchases) during the activity* ○ *Poor outcomes (1-3, Not True) n=4* ○ *Good outcomes (4-5, True) n=27* • *Survey Part 2. Q8. Any full-time or part-time paid employment* ○ *Poor outcomes (no) n=19* ○ *Good outcomes (yes) n=12*	• Good outcomes *(majority of outcomes (5 or more) good and none poor) n*=0 • Mixed *(roughly equal number of good/poor) n*=30 • Poor outcomes *(no more than one good, remainder poor) n*=1

Personal Development	● Survey Part 1. Q28.1 Participation in Daily Life. Index of Personal Development (IPDL_Percent); *Question 28.1 of this section requires you to indicate whether the person does each of the daily tasks on their own, with help or not at all.* ▪ *Mean Total Score=75;* ○ *Poor outcomes (Score of <=75) n=11* ○ *Good outcomes (Score 76>) n=20* ● *Survey Part 2 Q8a.1; Q8a.2; Q8a.3; Q8a.5; Q8a.6; Q8a.8; Q8a.9* ○ *Poor outcomes (If all No) n=9* ○ *Good outcomes (If any Yes) n=22* ● *Survey Part 2. 2ia. I participated in the activity with others rather than simply being present.* ○ *Poor outcomes (1-3, Not True) n=12* ○ *Good outcomes (4-5, True) n=19* ● *Survey Part 2. 2ik. The activity/ies helped me to develop skills in some way.* ○ *Poor Outcomes (1-3, Not True) n=15* ○ *Good Outcomes (4-5, True) n=16* ● *Survey Part 2 Q8 Any employment or other structured day time activities occurring at least once a week (or 5 or more times in a month).* ○ *Poor outcomes =does the person access employment = NO or Yes and Number of attendances <4. n=8* ○ *Good outcomes = yes AND number of attendances 4 or greater. n=23*	● Good outcomes *(majority of outcomes 3 or more) good and none poor) n*=5 ● Mixed *(roughly equal number of good/poor) n*=19 ● Poor outcomes *(no more than one good, remainder poor) n*=7
Physical Well-being	● *Survey Part 2, Social Capital Questionnaire. Q6, Do you feel safe walking down your street after dark?* ○ *Poor outcome (score of 1-3) n=26* ○ *Good outcome (score of 4) n=5* ● *Survey Part 2, Extent of health condition – Overall Health Score* ▪ *Mean Overall Score=12;* ○ *Poor outcomes (Score 13>) n=14* ○ *Good outcomes (Score of <=12) n=17* ● *Survey Part 2, Q7b) Do you have a regular GP? And/or Q7c) Does the District Nurse visit you?* ○ *Poor outcomes (Both No) n=6* ○ *Good outcomes (Either Yes) n=25* ● *Survey Part 2, Extent of health condition Q1. Weight Problems* ○ *Poor outcomes (2-3, Moderate-Chronic) n=13* ○ *Good outcomes (0-1, No problem-Mild) n=18*	● Good outcomes *(majority of outcomes 3 or more) good and none poor) n*=1 ● Mixed *(roughly equal number of good/poor) n*= 20 ● Poor outcomes *(no more than one good, remainder poor) n*=10

Self-Determination	• Survey Part 1. Q28.2 to Q28.7 Choice Making Scale (CMS_percent); *Please indicate whether the service user makes choices in different situations, using the scale provided (no, some of the time, most of the time or yes all of the time).* ▪ *Looking at scores above and below 50 (midpoint of scale);* ○ *Poor outcomes (Score of <=49) n=13* ○ *Good outcomes (Score 49>) n=18* • *Survey Part 2, Social Capital Questionnaire. Q21. If you need information to make a life decision, do you know where to find that information?* ○ *Poor outcome (score of 1 or 2) n=7* ○ *Good outcome (score of 3 or 4) n=24*	• Good outcomes *(both good) n*=12 • Mixed *(one good/one poor) n*=18 • Poor outcomes *(both poor) n*=1
Social Inclusion	• *Survey Part 2, Index of Community Involvement (ICI_percent). Mean Total Score=54;* ○ *Poor outcomes (Score of <=54) n=14* ○ *Good outcomes (Score 55>) n=17* • *Survey Part 2. Q3(a) How many neighbours in the area know you by name or do you know by name* ○ *Poor outcomes (0) n=9* ○ *Good outcomes (1 or more) n=22* • *Survey Part 2. Q3(b) Do you ever have social contact with the neighbours, other than saying hello* ○ *Poor outcomes (No) n=19* ○ *Good outcomes (Yes) n=12* • *Survey Part 2. 2if. I took part in an activity that contributed to the community in some way (e.g. volunteering, looking after someone's garden or pet, helping out someone).* ○ *Poor outcomes (1-3, Not True) n=18* ○ *Good outcomes (4-5, True) n=13* • *Survey Part 2. 2ig. I took part in ordinary activities, not just special activities for people with disabilities.* ○ *Poor outcomes (1-3, Not True) n=17* ○ *Good outcomes (4-5, True) n=14* • Survey Part 2, Q2c. Did you interact with anyone other staff/ or other people with intellectual disability who live in the same house or nearby? ○ *Poor outcomes (No) n=13* ○ *Good outcomes (Yes) n=18* • *Survey Part 2, Social Capital Questionnaire.Q1; Q13; Q14; Q15; Q20;* ○ *Poor outcomes (No more than one of the above questions have a score of 3 or 4) n=8* ○ *Good outcome (If two or more of the above questions have a score of 3 or 4) n=23*	• Good outcomes *(majority of outcomes (6 or more) good and none poor) n*=2 • Mixed *(roughly equal number of good/poor) n*=25 • Poor outcomes *(no more than two good, remainder poor) n*=4

Rights	• *Survey Part 2. 2ib. I was treated with dignity and respect by others in the community.* ○ *Poor outcomes (1-3, Not True) n=17* ○ *Good outcomes (4-5, True) n=14* • Survey Part 2, Q7. Do you have an advocate? ○ *Poor outcomes (No) n=12* ○ *Good outcomes (Yes) n=19* • *Survey Part 2, Social Capital Questionnaire.Q5; Q23; Q24; Q25; Q26;* ○ *Poor outcomes (No more than one of the above questions have a score of 3 or 4) n=16* ○ *Good outcome (If one or more of the above questions have a score of 3 or 4) n=15* • *Survey Part 2. 2ij. I was able to physically access all the facilities visited without any difficulties.* ○ *Poor outcomes (1-3, Not True) n=7* ○ *Good outcomes (4-5, True) n=24*	• Good outcomes *(majority of outcomes 3 or more) good and none poor) n*=4 • Mixed *(roughly equal number of good/poor) n*=21 • Poor outcomes *(no more than one good, remainder poor) n*=6

Table A2. Living arrangements of service users

	n	%
Housing Tenure		
Total in some form of social or public housing	22	71
Private rental	7	22
Own home	1	3
Unclear	1	3
Living situation		
Alone	17	57
Partner	4	13
Co tenant	9	30
Location		
Regional – South East	9	29
Inner West - Melbourne	3	10
Northern – Melbourne	8	26
Regional – North East	6	19
Outer South - Melbourne	5	16
Mean number of years living at their current address	Mean 5.26 Range 0.3-10	

Table A3. Index of Participation in Daily Life

	n	%
Mean percentage score on IPDL (Range)		74.94 (11.5-100.0)
Shopping for food	29	97
Preparing meals	29	94
Setting table	28	93
Serving meals	29	94
Washing up	29	94
Cleaning kitchen	28	90
Cleaning living & dining room	28	90
Cleaning own room	28	90
Cleaning bathroom/toilet	29	94
Shopping for supplies	30	100
Doing own washing	30	97
Doing own ironing	21	72
Looking after garden	17	61

Table A4. Index of Community Involvement

	n	%
Mean Score on ICI		54.10
(Range)		(18.8-93.8)
% who have In the last month:		
Been to hairdressers	22	71
Had family/friends for a meal	14	47
Been out for a meal with family/ friends	21	68
Had guests to stay	10	32
Been on an overnight stay with family/ friends	12	39
Been shopping	31	100
Been to a cinema	11	37
Been to a café	24	77
Been to a pub	15	50
Been to a place of worship	4	13
Been to a sports event	10	32
Been to a social club	18	60
Been to a concert or play	4	13
Been on a bus	22	73
Been to their bank	30	97
% who have In the last month:		
Been on holiday	17	55

Table A5.Contact with family and friends

	n	%
Regular family contact	23	77
Visits from family at least monthly	18	78
Trips out with family at least monthly	13	59
Phone call from family weekly	19	86
Letters from family monthly	5	38
Other family contact monthly	7	64
Contact with friends	24	77
Friends outside of the home		5.28 (2.0-20.0)
How many of these friends also have ID		4.08 (0.0-20.0)
Visits from friends once a month	11	48
Trips out with friends monthly	18	78
Phone calls from friends at least monthly	10	56
Letters or cards from friends monthly	3	33
Other friend contact monthly	4	33
Have visits from some friends without ID	8	42
Have trips out with some friends without ID	10	48
Have phone calls from some friends without ID	7	44
Have Letters or cards from some friends without ID	4	44
Have some other friend contact without ID	3	43
Have a non-staff member as advocate	17	55
Advocate - Family Member	16	51
Advocate - Independent	1	3

Table A6. Choice Making Scale

	n	%
Mean score on CMS		75.87 (44.44-100.00)
What food to buy	19	100
What to eat for main meal	19	100
What to eat and what to leave on plate	18	95
What to have for dessert/snacks	18	95
What to eat when out in cafes etc.	17	89
How room is decorated	19	100
When to be alone	17	94
What personal hygiene products to use	17	94
How hot the house or room is	17	94
What clothes to buy	19	100
What clothes to wear	19	100
What to wear in bed	19	100
When to go to bed on weekdays	19	100
When to go to bed on weekends	19	100
When to get up on weekends	19	100
When to take a nap in evenings and weekends	17	94
When and how often to bathe/shower	19	100
Choice of outings	19	100
What to watch on TV	19	100
When to visit friends	19	100
What to buy or do with personal money	19	100
When and how to take medicines	17	89
How and when to express affection for others	18	95
Whether to engage in minor vices (eg smoking, drinking…)	13	72

Table A7. Health conditions

		n	%
Q1. Weight Problems	**Total (Mild/infrequent-Significant/Chronic)**	**19**	**60**
	No problem	12	39
	Mild/infrequent	6	19
	Moderate/occasional problem	7	23
	Significant/chronic problem	6	19
	Don't Know	0	0
Q2. Physical Fitness and Conditioning problems	**Total (Mild/infrequent-Significant/Chronic)**	**22**	**70**
	No problem	9	29
	Mild/infrequent	4	13
	Moderate/occasional problem	7	23
	Significant/chronic problem	11	35
	Don't Know	0	0
Q3. Dental/Oral Problems and hygiene	**Total (Mild/infrequent-Significant/Chronic)**	**20**	**60**
	No problem	11	35
	Mild/infrequent	4	13
	Moderate/occasional problem	10	32
	Significant/chronic problem	6	19
	Don't Know	0	0
Q4. Respiratory Problems	**Total (Mild/infrequent-Significant/Chronic)**	**6**	**20**
	No problem	25	81
	Mild/infrequent	4	13
	Moderate/occasional problem	0	0
	Significant/chronic problem	2	6
	Don't Know	0	0
Q5. Fatigure	**Total (Mild/infrequent-Significant/Chronic)**	**16**	**50**
	No problem	15	48
	Mild/infrequent	6	19
	Moderate/occasional problem	8	26
	Significant/chronic problem	2	6
	Don't Know	0	0
Q6. Joint and Muscle pain	**Total (Mild/infrequent-Significant/Chronic)**	**20**	**60**
	No problem	10	32
	Mild/infrequent	3	10
	Moderate/occasional problem	3	10
	Significant/chronic problem	14	45
	Don't Know	1	3
Q7. Contractures	**Total (Mild/infrequent-Significant/Chronic)**	**6**	**20**
	No problem	25	81

	Mild/infrequent	2	6
	Moderate/occasional problem	2	6
	Significant/chronic problem	2	6
	Don't Know	0	0
	Total (Mild/infrequent-Significant/Chronic)	**11**	**40**
Q8. Balance Problems/dizziness	No problem	20	65
	Mild/infrequent	7	23
	Moderate/occasional problem	1	3
	Significant/chronic problem	3	10
	Don't Know	0	0
	Total (Mild/infrequent-Significant/Chronic)	**10**	**30**
Q9. Bladder Problems	No problem	21	68
	Mild/infrequent	4	13
	Moderate/occasional problem	2	6
	Significant/chronic problem	4	13
	Don't Know	0	0
	Total (Mild/infrequent-Significant/Chronic)	**1**	**0**
Q10. Pressure Sores	No problem	30	97
	Mild/infrequent	1	3
	Moderate/occasional problem	0	0
	Significant/chronic problem	0	0
	Don't Know	0	0
	Total (Mild/infrequent-Significant/Chronic)	**7**	**20**
Q11. Bowel Problems	No problem	23	77
	Mild/infrequent	5	17
	Moderate/occasional problem	1	3
	Significant/chronic problem	1	3
	Don't Know	0	0
	Total (Mild/infrequent-Significant/Chronic)	**21**	**70**
Q12. Vision Problems	No problem	10	32
	Mild/infrequent	8	26
	Moderate/occasional problem	9	29
	Significant/chronic problem	4	13
	Don't Know	0	0
	Total (Mild/infrequent-Significant/Chronic)	**9**	**30**
Q13. Hearing Problems	No problem	22	71
	Mild/infrequent	3	10
	Moderate/occasional problem	3	10
	Significant/chronic problem	3	10
	Don't Know	0	0
Q14.	**Total (Mild/infrequent-**	**13**	**40**

Problems with mobility	**Significant/Chronic)**		
	No problem	18	58
	Mild/infrequent	3	10
	Moderate/occasional problem	3	10
	Significant/chronic problem	7	23
	Don't Know	0	0
Q15. Seizures	**Total (Mild/infrequent-Significant/Chronic)**	**1**	**0**
	No problem	30	97
	Mild/infrequent	1	3
	Moderate/occasional problem	0	0
	Significant/chronic problem	0	0
	Don't Know	0	0
Sum of Q1 to Q15 (out of 45)			Sum 12/45 Range 1-28
Average score across health conditions			Mean 0.8 Range 0-2
Total with 1 or more health conditions		31	100
Mean number of health conditions (mild to chronic)			Mean 5.9 Range 1-12
Mean number of mild/infrequent problems			Mean 2.0 Range 0-6
Mean number of moderate/occasional problems			Mean 1.8 Range 0-5
Mean number of significant/chronic problems			Mean 2.1 Range 0-7

Table A8. Detailed support arrangements

	Type of Support	**Everyday living**					**Health Related**	**Participation and Social Inclusion**					
		Outreach – max 2 hours week – regular home, on call, support with problem solving and one other task of daily living	Individualised support package or more intensive outreach- 3- 8 hours a week, 2-4 visits a week, on call, problem solving and other tasks of daily living	Individualised support package and case management 42 hours a week, daily visits on call, problem solving and other tasks of daily living	HACC	Estimated weekly hours support daily living	health specific re OT PHISO etc. or other specialist	Employment service job seeking	Key Ring	Disability day program such as day service, volunteer or supported employment or combination 5 days week	Disability day program such as day service, volunteer or supported employment or combination 3 days week	Regular social group attendance disability or mainstream	Self-advocacy group
Service User Code	1	√				2					√	√	√
	3	√				2					√	√	√
	4	√				2					√	√	√
	5		√			4					√	√	√
	6		√			8					√	√	√
	8		√		√	4					√	√	√
	9		√			4		√			√	√	
	10		√		√	8					√	√	
	11		√			8					√	√	
	12	√			√	2			√			√	
	13		√		√	4			√				
	14		√			3	√		√		√		
	15		√		√	8			√		√	√	
	17		√			4		√	√		√	√	
	18	√				2			√		√		
	21		√			6				√			
	22		√			6				√			
	23		√			6				√			

	24		√			6				√		√	
	25		√			6				√		√	
	26		√			6				√			
	28		√			4		√				√	
	29		√			4			√		√		
	31	√			√	0.5	√		√	√		√	
	32		√			2					√		
	33		√		√	8			√		√	√	
	34	√			√	2	√		√	√		√	
	35		√		√	4					√	√	
	36			√		42	√					√	√
	37		√			4				√			√
	38	√				2					√	√	√
	Total	8	22	1	9	173.5	4	3	10	9	18	21	9

Table A9. Characteristics on which the two samples were matched

		Supported Living	Group Home
	N/n	29	29
Age (years)	M	46	42
	Range	24-64	23-65
Percentage male		(*n*=13) 45%	(*n*=16) 55%
Part 1 ABS score	M	242	239
	Range	166-282	210-263
Total score on the ABC	M	12	11
	Range	0-41	0-25
Percentage socially impaired		(*n*=7) 24%	(*n*=10) 35%
Percentage with a physical impairment		(*n*=9) 31%	(*n*=4) 14%

Table A10. Additional characteristics of the matched samples

	Supported Living (*n=29*)		Group Home (*n=29*)		*p*
	N/n	%	*N/n*	%	
Percent with epilepsy	2	7	6	21	p=0.128
Percent with mental health problems	4	14	11	38	χ^2 4.41 *p*=0.036*
Percent with visual impairment	2	7	4	14	p=0.389
Percent with hearing impairment	6	21	1	3	χ^2 4.06 *p*=0.044*
Percent with autism	3	10	1	3	p=0.300
Percent showing more than 5 severe behaviours on ABC	0	0	0	0	p=1.00

Table A11: Percentage positive outcomes for each of the indicators on the QoL Emotional Well-being domain & overall outcome scores

	Mixed-Good (*n=14*)		Mixed-Poor (*n=17*)	
	N/n	%	*N/n*	%
Social Capital Questionnaire - satisfied with life	11	79	11	65
Total score on the ABC (Score of <16)	9	64	11	65
ABC Factor3 Stereotypic Behaviour (<=2)	13	93	15	88
Overall Outcome for Domain				
Percentage Good	6	43	7	41
Percentage Mixed	8	57	8	47
Percentage Poor	0	0	2	12

Table A12. Percentage positive outcomes for each of the indicators on the QoL Interpersonal Relations domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	*N/n*	%
Regular Family Contact	13	93	10	59
Had friends or family in for a meal OR Had guests to stay OR Been on an overnight stay to family or friends	10	71	11	65
Social Contact with neighbours once a week or more	1	7	2	12
The people I met spoke to me rather than a worker who was with me.	5	36	4	24
Did not experience negative attitudes or actions from others in the community	10	71	8	47
Contact with friends	11	79	13	76
Two or more friends outside of the home	11	79	14	82
One or more friend without intellectual disabilities	5	36	5	29
Social Capital Questionnaire - Spoke to at least someone yesterday	14	100	17	100
Overall Outcome for Domain				
Percentage Good	0	0	0	0
Percentage Mixed	14	100	16	94
Percentage Poor	0	0	1	6

Table A13 Percentage positive outcomes for each of the indicators on the QoL Material Well-being domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	*N/n*	%
Been to a cinema OR Been to pub OR been to concert/play OR Been on holiday	12	86	11	65
Used public transport while out in the community	12	86	11	65
Own their home	2	14	2	12
Income $45,000 and above	0	0	0	0
Handled money (e.g. paying for purchases) during the activity	13	93	14	82
Any full-time or part-time paid employment	5	36	7	41
Overall Outcome for Domain				
Percentage Good	0	0	0	0
Percentage Mixed	14	100	16	94
Percentage Poor	0	0	1	6

Table A14 Percentage positive outcomes for each of the indicators on the QoL Personal Development domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	*N/n*	%
Index of Personal Development (Score 76>)	12	86	8	47
Access Full-time paid employment - Open/Closed OR Paid employment – Open OR Paid work experience OR voluntary work experience OR voluntary day activity facility OR Access Social club	13	93	9	53
Participated in the activity with others rather than simply being present.	13	93	6	35
The activity/ies helped me to develop skills in some way	9	64	7	41
Any employment or other structured day time activities occurring at least once a week (or 5 or more times in a month)	13	93	10	59
Overall Outcome for Domain				
Percentage Good	7	50	0	0
Percentage Mixed	7	50	12	71
Percentage Poor	0	0	5	29

Table A15. Percentage positive outcomes for each of the indicators on the QoL Physical well-being domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	*N/n*	%
Social Capital Questionnaire - feel safe walking down street after dark	3	21	2	12
Overall Health Score <=12	13	93	4	24
Have a regular GP? And/or District Nurse visits	11	79	14	82
No problem-Mild Weight Problem	12	86	6	35
Overall Outcome for Domain				
Percentage Good	1	7	0	0
Percentage Mixed	13	93	7	41
Percentage Poor	0	0	10	59

Table A16. Percentage of health conditions rated as mild/infrequent-chronic by QoL category

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*		*p*
	N/n	%	*N/n*	%	
Weight problems	6	43	13	76	p=0.056
Physical fitness and conditioning problems	6	43	16	94	χ^2 9.79 *p*=0.002*
Dental/Oral problems and hygiene	6	43	14	82	χ^2 5.23 *p*=0.022*
Respiratory problems	1	7	5	29	p=0.118
Fatigue	3	21	13	76	χ^2 9.31 *p*=0.002*
Joint and muscle pain	6	46	14	82	χ^2 4.34 *p*=0.037*
Contractures	0	0	6	35	χ^2 6.13 *p*=0.013*
Balance problems/dizziness	2	14	9	53	χ^2 5.01 *p*=0.025*
Bladder problems	2	14	8	47	χ^2 3.77 *p*=0.052*
Pressure sores	0	0	1	6	p=0.356
Bowel problems	2	15	5	29	p=0.368
Vision problems	6	43	15	88	χ^2 7.24 *p*=0.007*
Hearing problems	1	7	8	47	χ^2 5.94 *p*=0.015*
Problems with mobility	2	14	11	65	χ^2 8.02 *p*=0.005*
Seizures	1	7	0	0	p=0.263
Average score across health conditions	.40		1.13		*Z -3.58* *p*=0.001*
Mean number of health conditions (mild to chronic)	3.14		8.12		*Z -3.7* *p*=0.001*
Mean number of mild/infrequent problems	1.36		2.47		*p*=0.1*
Mean number of moderate/occasional problems	1.00		2.47		*Z -2.96* *p*=0.003*
Mean number of significant/chronic problems	.79		3.18		*Z -3.47* *p*=0.001*

Table A17. Percentage positive outcomes for each of the indicators on the QoL Self-Determination domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	*N/n*	%
Choice Making Scale (Score 49>)	9	64	9	53
Social Capital Questionnaire - If you need information to make a life decision, know where to find that information	11	79	13	76
Overall Outcome for Domain				
Percentage Good	6	43	6	35
Percentage Mixed	8	57	10	59
Percentage Poor	0	0	1	6

Table A18. Percentage positive outcomes for each of the indicators on the QoL Social Inclusion domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	N/n	%
Index of Community Involvement (Score 55>)	9	64	8	47
1 or more neighbours in the area know you by name or; you know by name	10	71	12	71
Have social contact with neighbours, other than saying hello	5	36	7	41
Took part in an activity that contributed to the community in some way (e.g. volunteering, looking after someone's garden or pet, helping out someone).	8	57	5	29
Took part in ordinary activities, not just special activities for people with disabilities.	9	64	5	29
Interacted with anyone other than staff/ or other people with intellectual disability who live in the same house or nearby?	10	71	8	47
Social Capital Questionnaire - Two or more of the below questions have a score of 3 or 4; (feel valued by society?; attended a local community event; active member of a local organisation or club; belong in your local community; run into friends and acquaintances when shopping in local area)	12	86	11	65
Overall Outcome for Domain				
Percentage Good	1	7	1	6
Percentage Mixed	13	93	12	71
Percentage Poor	0	0	4	24

Table A19. Percentage positive outcomes for each of the indicators on the QoL Rights domain & overall outcome scores

	Mixed-Good (*n=14)*		Mixed-Poor (*n=17)*	
	N/n	%	N/n	%
Social Capital Questionnaire - treated with dignity and respect by others in the community	9	64	5	29
Have an advocate	10	71	9	53
Social Capital Questionnaire - one or more of the below questions have a score of 3 or 4; (help out a local group as a volunteer; on a management committee or organising committee for any local group or organisation; been part of a local community action group; ever taken part in a local community project or working bee; ever been part of a project to organise a new service in your area)	9	64	6	35
Able to physically access all the facilities visited without any difficulties.	13	93	11	65
Overall Outcome for Domain				
Percentage Good	3	21	1	6
Percentage Mixed	11	79	10	59
Percentage Poor	0	0	6	35

Appendix 2

Survey Part 1

Title: Optimising Outcomes in Supported Living for People with Intellectual Disability

The People We support QuestionnaireUser Needs and Characteristics

Part 1: Support worker questionnaire

……………………………has given signed consent for you to provide information about them and complete this questionnaire.

This questionnaire is the first of a three part survey to gain information about people with intellectual disability who live with support in the community

The first part has been sent to you to be completed prior to a visit by the researcher. During the visit, the second part will be completed during an interview with yourself and ……………………….Following this the third part will be completing during an interview with ……………………………….

This questionnaire will provide information on the needs, skills and characteristics, along with a measure of participation, choice and community involvement of people with an intellectual disability living in supported living situations. There are also some questions on the type of support they have.

Please complete prior to the scheduled visit on…….../………./201.….

Why is this information important?
Because the characteristics of the people living in supported living situations continues to change as people's lives change, it is important to have accurate information about resident characteristics, community inclusion and formal support arrangements to utilise resources effectively.

Are these questionnaires confidential?
These questionnaires are completely confidential and the information gathered will not be used to change resources and/or support individuals receive. Where the information from the questionnaires is included in a report or published paper, it will be done in a general way that preserves the anonymity of the people we support. While some information from this part of the evaluation may also be used to develop a confidential database, which will provide on-going information about the people we support, no names of individual people or services will be used in any report outside of the organisation.

How do I complete the questionnaire?
Please read the information on the following page carefully and then complete the questionnaire. If you require assistance with completing the questionnaire, the researcher will help you at the time of your scheduled meeting.

How long with the questionnaire take to complete?
It should take you no longer than about 30 minutes.

Instructions:

Please note the following general rules:

1. Items that specify “with help” or “with assistance” for completion of the task refer to direct physical assistance.

2. Give credit for an item if verbal prompting or reminding is needed to complete the task, unless the item definitely states “without prompting” or “without reminder”

There are different types of questions in the questionnaire:

The first asks you to tick only the highest level shown by the person concerned. For example

Q7 Eating in public *(Tick highest level)*	
Orders complete meal in restaurants	☐
Orders simple meals like hamburgers or fish and chips	☑
Orders single items e.g. soft drinks, ice cream etc. at a stall or canteen.	☐
Does not order in public eating places	☐

Tick the one statement that best describes the most difficult task /activity the person can usually manage.

The second type of question asks you to read each statement and tick each activity/task the person can usually do. For example

Q17 Other Domestic Activities *(tick all that apply)*	
Washes dishes well	☐
Makes bed neatly	☑
Helps with household tasks when asked	☐
Does household tasks routinely	☑
Can load and use the dishwasher	☐
Can use small electrical kitchen appliances	☑

In question 26, Possible Problem Behaviour, you are asked to rate the person’s behaviour for the last FOUR WEEKS. For each item, decide whether the behaviour is a problem and tick the appropriate box:

None = not a problem at all
Slight = the behaviour is a problem but slight in degree
Mod = the problem is moderately serious
Severe = the problem is severe in degree

When rating this person’s behaviour, please keep the following points in mind:

a) Take relative *frequency* into account for each behaviour. For example, if the person averages more temper outbursts than most other service users you know, it is probably moderately serious or severe even if these occur only once or twice a week. Other behaviours such as “refuses to co-operate”, would probably have to occur more frequently to merit an extreme rating.

b) If you have access to this information, consider the experiences of other care providers. If the person has problems with others but not with you, try to take the whole picture into account.

c) Try to consider whether a given behaviour interferes with the person’s development, functioning, or relationships. For example, body rocking or social withdrawal may not disrupt others, but it most certainly hinders individual development or functioning.

Do not spend too much time on each item – your first reaction is usually the right one.

The People We Support Questionnaire

Resident ID Code ☐☐☐☐☐☐

Date of Birth D D ☐☐ - M M ☐☐ - Y Y ☐☐

Gender Male ☐ ☐ Female

Name of keyworker completing the survey: ....

Date completed D D ☐☐ - M M ☐☐ - Y Y ☐☐

Please tick which box describes the person's ethnic origin/descent:

Is the person from a Culturally and Linguistically Diverse (CALD) background?

Yes ☐ No ☐

<u>If yes</u> please specify: ☐

Does the person wish to be identified as Aboriginal or Torres Strait Islander?

Yes ☐ No ☐

Additional Impairment *(Tick **all** that apply)*

Physical disability	☐	Mental health problems	☐
Hearing Impairment	☐	Autism	☐
Visual Impairment	☐	Epilepsy	☐
Speech impairment	☐	Other (please specify)	☐

Q1 Use of Table Utensils *(Tick highest level)*

- Uses table knife for cutting or spreading ☐
- Feeds self accurately with spoon and fork (or appropriate alternative utensil e.g. chopsticks) ☐
- Feeds self causing considerable spilling with spoon and fork (or appropriate alternative utensil e.g. chopsticks) ☐
- Feeds self with spoon without spilling ☐
- Feeds self with a spoon causing considerable spilling ☐
- Feeds self with fingers ☐
- Does not feed self or must be fed ☐

Q2 Self-Care *(Tick **all** that apply)*

- Lowers appropriate clothing at the toilet without help ☐
- Sits on toilet seat without help ☐
- Uses toilet tissue appropriately ☐
- Flushes toilet after use ☐
- Puts clothes back on without help ☐
- Washes hands without help ☐

Q3 Bathing *(Tick highest level)*

- Prepares and completes bathing independently ☐
- Washes and dries self independently ☐
- Washes and dries with verbal prompting ☐
- Washes and dries self with physical assistance ☐
- Attempts to soap and wash self ☐
- Participates when being washed and dried by others ☐
- Needs total support to be washed and dried ☐

Q4 Dressing *(Tick highest level)*

- Dresses self independently ☐
- Dresses self with verbal prompting only ☐
- Dresses self by pulling or putting on all clothes with verbal prompting and help with fastenings e.g. zips, buttons, velcro. ☐
- Participates in dressing self by pulling or putting on most clothes and fastening them ☐
- Participates when being dressed by extending arms or legs. ☐
- Needs total assistance when dressing ☐

Q5 Shoes *(tick **all** that apply)*

- Puts on shoes correctly without assistance ☐
- Ties shoelaces without assistance ☐
- Unties shoelaces without assistance ☐
- Removes shoes without assistance ☐
- Attaches or detaches Velcro on shoes ☐

Q6 Walking and Running *(Tick **all** that apply)*

- Walks alone ☐
- Walks up and down stairs alone ☐
- Walks down stairs by alternating feet ☐
- Runs without often falling ☐
- Hops, skips or jumps ☐

Q7 Eating in Public ***(Tick highest level)***

Orders complete meal in restaurants ☐

Orders simple meals like hamburgers or fish and chips ☐

Orders single items e.g. soft drinks, ice cream etc. at a stall or canteen. ☐

Does not order in public eating places ☐

Q8 Care of Clothing ***(Tick all that apply)***

Wipes and cleans shoes when needed ☐

Puts clothes in drawer, chest or cupboard ☐

Hangs up clothes without prompting ☐

Calls attention to missing buttons and holes and/or repairs clothing ☐

Q9 Miscellaneous ***(Tick all that apply)***

Has regular control of appetite, eats moderately ☐

Knows postage rates, buys stamps from post office ☐

Looks after personal health e.g. changes out of wet clothing ☐

Deals with simple injuries e.g. cuts and burns ☐

Knows how and where to obtain a doctor's or dentist's help ☐

Knows about benefit services in the community ☐

Knows own address ☐

Q10 Safety at Home ***(Tick highest level)***

Asks whether an unfamiliar object is safe to touch or consume ☐

Is careful about dangers of electrical outlets and sockets ☐

Is careful about danger of hot foods and beverages or hot dishes or pans ☐

Is unaware of possible dangers ☐

Q11 Money Handling ***(Tick highest level)***

Takes care of own money ☐

Calculates change correctly but does not use banking facilities ☐

Add coins of various denominations, up to one dollar ☐

Uses money but does not calculate change correctly ☐

Does not use money ☐

Q12 Purchasing ***(Tick highest level)***

Buys own clothing ☐

Buys own clothing accessories

Makes minor purchases without help (sweets, soft drinks etc.) ☐

Does shopping with minimum support ☐

Does shopping with full support ☐

Does not participate in shopping ☐

Q13 Sentences ***(Tick highest level)***

Sometimes uses complex sentences containing "because", "but" etc. ☐

Asks questions using words such as "why", "how", "what". etc ☐

Speaks in simple sentences ☐

Communicates with sounds or is non-verbal ☐

Q14 Understanding of Spoken Information ***(tick highest level)***

Understands complex information involving a decision e.g. If X do Y, but if not, do Z" ☐

Understands information involving a series of steps, e.g. "First do Z, then do Z". ☐

Answers simple questions such as "What is your name?" or "What are you doing?" ☐

Responds correctly to simple phrases e.g. "Sit down" "stop", "come here" ☐

Is unable to understand even very simple verbal communications ☐

Q15 Numbers ***(Tick highest level)***

Can complete division and multiplication problems ☐

Does simple addition and subtraction ☐

Counts ten or more objects ☐

Rote counts to ten ☐

Counts two objects by saying "one … two" ☐

Discriminates between "one" and "many" or "a lot" ☐

Has no understanding of numbers ☐

Q16 Food Preparation ***(Tick highest level)***

Can use microwave correctly to prepare a meal ☐

Prepares an adequate and complete meal (may use tinned or frozen food) ☐

Mixes and cooks simple food e.g. fries eggs, cooks TV dinners etc. ☐

Prepares simple foods requiring no mixing or cooking e.g. sandwiches, cold cereal, etc.) ☐

Does not prepare food ☐

Q17 Other Domestic Activities ***(tick all that apply)***

Washes dishes well ☐

Makes bed neatly ☐

Helps with household tasks when asked ☐

Does household tasks routinely ☐

Can load and use the dishwasher ☐

Can use small electrical kitchen appliances ☐

Q18 Encouragement & Motivation ***(Tick all that apply)***

If the person is fully reliant on others tick all boxes and go to next question.

Needs constant encouragement to complete task ☐

Has to be made to do things ☐

Does not appear to be interested in setting and achieving goals ☐

Does not appear to be interested in activities ☐

Finishes task last because of wasted time ☐

Is unnecessarily dependent on others for help ☐

Movement is slow and sluggish ☐

Q19 Determination ***(Tick all that apply)***

If the person is fully reliant on others to organise activities tick all boxes and go to next question

Cannot organised activity/task ☐

Becomes easily discouraged ☐

Fails to carry out tasks ☐

Jumps from one activity to another ☐

Requires ongoing encouragement to complete an activity or task. ☐

Q20 Leisure Activities ***(tick highest level)***

Organises own leisure time activities on a fairly complex level, e.g. going fishing, arranging to play snooker etc. ☐

Has an active interest in hobbies, e.g. painting, embroidery, collecting. ☐

Participates in organised leisure activities when arranged for him or her ☐

Engages in simple leisure activities e.g. watching TV, listening to the radio ☐

Does not arrange leisure activities ☐

Q21 General Responsibility ***(tick highest level)***

Very conscientious and assumes much responsibility – always completes activities and/or tasks which have been agreed. ☐

Usually dependable, makes an effort to carry out responsibilities –generally completes activities and/or tasks which have been agreed ☐

Variable, often forgets responsibilities – often does not complete activities and/or tasks which have been agreed. ☐

The person is not currently given responsibility for activities and/or tasks ☐

Q22 Personal Responsibility ***(Tick all that apply)***

Usually maintains control of own emotions, desires etc. ☐

Understands concept of being on time ☐

Seeks and accepts help on instructions ☐

Says (e.g. to staff) if there is a problem ☐

Q23 Consideration of Others ***(Tick all that apply)***

Shows interest in the affairs of others ☐

Takes care of others' belongings ☐

Directs or manages other people's affairs when needed. ☐

Shows consideration of other peoples' feelings ☐

Q24 Awareness of Others ***(tick all that apply)***

Recognises own family ☐

Recognises people other than family ☐

Has information about others, e.g. job, address, relation to self. ☐

Knows names of people close to him or her, e.g. neighbours, co-workers ☐

Knows the names of people not regularly encountered e.g. doctor. ☐

Q25 Social Interaction ***(Tick highest level)***

Thinking about the person's everyday social interaction with peers (not staff, parents or other caregivers) ***tick the ONE statement below*** *that best describes the person's general social interaction.*

Generally does not interact with others – appears distant and unresponsive	☐
Generally does not interact with others but will interact to obtain needs (e.g. to get food or drink)	☐
Responds to and may initiate physical contact such as chasing, tickling, cuddling etc.	☐
Generally does not initiate interactions with others but responds to social, not just physical, contact if others, including peers, make approaches. Joins in passively in social situations. Tries to copy others but with little understanding. Shows some pleasure in passive role.	☐
Makes social approaches actively, but these are usually out of place, naïve, unusual and one sided. The person cannot change their behaviour to match the needs, interests and responses of the other person.	☐
Shy but social contact with well-known people, including peers, is appropriate to individuals support needs.	☐
Social contact with children and adults is appropriate to the individuals support needs. The person looks up with interest and smiles when approached. Responds to ideas and interests of people with similar abilities and contributes to the interaction.	☐

Q26.1 Possible Problem Behaviour

Rate person's behaviour over last month. ***Tick ONE box for each item,*** *rating the behaviour as not a problem, a slight problem, a moderately serious problem, or a severe problem.*

	None	Slight	Mod	severe
Excessively active	☐	☐	☐	☐
Injures self	☐	☐	☐	☐
Lacks energy, slow-moving, inactive	☐	☐	☐	☐
Aggressive to others	☐	☐	☐	☐
Seeks isolation from others	☐	☐	☐	☐
Inappropriately noisy and rough	☐	☐	☐	☐
Meaningless recurring body movements	☐	☐	☐	☐
Screams inappropriately	☐	☐	☐	☐
Talks excessively	☐	☐	☐	☐
Temper tantrums	☐	☐	☐	☐
Stereotyped, repetitive movements	☐	☐	☐	☐
Preoccupied, stares into space	☐	☐	☐	☐

Q26.2 Possible Problem Behaviour

Rate person's behaviour over last month. ***Tick ONE box for each item****, rating the behaviour as not a problem, a slight problem, a moderately serious problem, or a severe problem.*

	None	Slight	Mod	severe
Impulsive (acts without thinking)	☐	☐	☐	☐
Irritable	☐	☐	☐	☐
Restless and unable to sit still	☐	☐	☐	☐
Withdrawn, prefers solitary activities	☐	☐	☐	☐
Odd, bizarre behaviour	☐	☐	☐	☐
Non-compliant, difficult to control	☐	☐	☐	☐
Yells at inappropriate times	☐	☐	☐	☐
Fixed facial expression; does not show emotional reactions.	☐	☐	☐	☐
Disturbs others	☐	☐	☐	☐
Repetitive speech	☐	☐	☐	☐
Does nothing but sit and watches others	☐	☐	☐	☐
Unco-operative	☐	☐	☐	☐
Depressed mood	☐	☐	☐	☐
Resists any physical contact	☐	☐	☐	☐
Moves or rolls head back and forth	☐	☐	☐	☐
Does not attend to instructions	☐	☐	☐	☐
Demands must be met immediately	☐	☐	☐	☐
Isolates self from others	☐	☐	☐	☐
Disrupts group activities	☐	☐	☐	☐
Sits/stands in one position for a long time	☐	☐	☐	☐
Talks loudly to self	☐	☐	☐	☐
Cries over minor things	☐	☐	☐	☐
Repetitive hand, body or head movements.	☐	☐	☐	☐
Mood changes quickly	☐	☐	☐	☐
Unresponsive to structured activities.	☐	☐	☐	☐

Q26.3 Possible Problem Behaviour

*Rate person's behaviour over last month. **Tick ONE box for each item**, rating the behaviour as not a problem, a slight problem, a moderately serious problem, or a severe problem.*

	None	Slight	Mod	severe
Does not stay in seat during structured activities	☐	☐	☐	☐
Will not sit for any length of time	☐	☐	☐	☐
Is difficult to reach or contact	☐	☐	☐	☐
Cries or screams for no apparent reason	☐	☐	☐	☐
Prefers to be alone	☐	☐	☐	☐
Does not try to communicate by gestures	☐	☐	☐	☐
Easily distracted	☐	☐	☐	☐
Waves or shakes hands or feet repeatedly	☐	☐	☐	☐
Repeats a word or phrase over and over	☐	☐	☐	☐
Stamps feet while banging objects	☐	☐	☐	☐
Constantly runs or jumps around the room	☐	☐	☐	☐
Rocks body back and forth	☐	☐	☐	☐
Deliberately hurts self	☐	☐	☐	☐
Does not pay attention when spoken to	☐	☐	☐	☐
Does physical violence to self	☐	☐	☐	☐
Never moves spontaneously	☐	☐	☐	☐
Tends to be excessively active	☐	☐	☐	☐
Responds negatively to affection	☐	☐	☐	☐
Deliberately ignores directions	☐	☐	☐	☐
Has temper outbursts	☐	☐	☐	☐
Shows few social reactions to others.	☐	☐	☐	☐

Q 27.1 Communication
Use of Verbal language ***(tick highest level)***

Verbal ☐
Partially verbal ☐
Minimally verbal ☐
Non-verbal ☐

Q27.2 Main Language **(Tick <u>ONE</u> box only)**

Arabic	☐	Sign Language	☐
Italian	☐	Vietnamese	☐
Cantonese	☐	Spanish	☐
English	☐	Turkish	☐
Greek	☐	Mandarin	☐
Hebrew	☐	Other *(please specify)*	☐
Hindi	☐		

Q27.3 Speaks English **(Tick <u>ONE</u> box only)**

Fluently, like an average native of an English speaking country. ☐
Is able to sustain a conversation in English at a slow pace ☐
Speaks some English, heavily aided by body language ☐
Speaks no English ☐

Q27.4 Understands English **(Tick <u>ONE</u> box only)**

Fluently, like an average native of an English speaking country. ☐
Is able to understand a conversation in English at a slow pace ☐
Understand some English, if spoken slowly, heavily aided by body language ☐
Understands no English ☐

Q27.5 Use of Signs ***(tick highest level)***

Uses 20 + signs ☐
Uses 5 – 20 signs ☐
Uses 1 – 5 signs ☐
Does not use signs to communicate ☐

Please record sign method used: ☐

Q27.6 Use of Symbols ***(tick highest level)***

Uses 20 or more symbols	☐
Uses between 5 and 20 symbols	☐
Uses between 1 and 5 symbols	☐
Does not use symbols to communicate	☐

Please record symbol method used: ☐

Q27.7 Other Means of Communication ***(tick all that apply)***

Objects of reference	☐	Eye contact	☐
Facilitated communication	☐	Gesture	☐
Writing	☐	Point-Eye contact	☐
Reading	☐	Point-gesture	☐
Pictures	☐	Manual aid	☐
Photographs	☐	Type:	
Body Movement	☐	Electronic Aid	☐
Manipulation	☐	Type:	

Q27.8 Prefer Information ***(tick all that apply)***

On tape	☐
On video	☐
Video signed	☐
With pictures	☐
With words	☐
Large print	☐
With symbols	☐

Other

Participation in Daily Life and Choice Making

Question 28.1 of this section requires you to indicate whether the person does each of the daily tasks on their own, with help or not at all.

For questions 28.2 to 28.7 please indicate whether the service user makes choices in different situations, using the scale provided (no, some of the time, most of the time or yes all of the time).

Q28.1 Index of Participation of Domestic Tasks

(Tick ONE box only)

	Yes	with help	no
Shopping for food	☐	☐	☐
Preparing meals	☐	☐	☐
Setting table	☐	☐	☐
Serving meals	☐	☐	☐
Washing up	☐	☐	☐
Cleaning kitchen	☐	☐	☐
Cleaning living and dining room	☐	☐	☐
Cleaning own bedroom	☐	☐	☐
Cleaning bathroom & toilet	☐	☐	☐
Shopping for supplies	☐	☐	☐
Doing own washing	☐	☐	☐
Doing own ironing	☐	☐	☐
Looking after garden	☐	☐	☐

Choice Making Scale

The following questions ask you to consider the extent to which you encourage the resident to make choices in different situations

Q28.2 Food **(Tick ONE box only)**

	No	Some	Most	Yes
What foods to buy	☐	☐	☐	☐
What to eat for main meal	☐	☐	☐	☐
What to eat/leave	☐	☐	☐	☐
What deserts and snacks to eat	☐	☐	☐	☐
Choosing cafes	☐	☐	☐	☐

Q28.3 House, Room **(Tick ONE box only)**

	No	Some	Most	Yes

Decorations to own room	☐	☐	☐	☐
Choosing to be alone	☐	☐	☐	☐
Type of personal hygiene articles	☐	☐	☐	☐
Setting house or room temp	☐	☐	☐	☐

Q28.4 Clothes **(Tick ONE box only)**

	No	Some	Most	Yes
What clothes to buy	☐	☐	☐	☐
What clothes to wear	☐	☐	☐	☐
What to wear in bed	☐	☐	☐	☐

Q28.5 Sleeping and Waking **(Tick ONE box only)**

	No	Some	Most	Yes
When to go to bed on weekdays	☐	☐	☐	☐
When to go to bed on weekends	☐	☐	☐	☐
When to get up on weekends	☐	☐	☐	☐
Naps, evening and weekends	☐	☐	☐	☐
Time & frequency of baths/showers	☐	☐	☐	☐

Q28.6 Recreation **(Tick ONE box only)**

	No	Some	Most	Yes
Choice of outings	☐	☐	☐	☐
What to watch on TV	☐	☐	☐	☐
Visiting friends	☐	☐	☐	☐

Q28.7 Other **(Tick ONE box only)**

	No	Some	Most	Yes
How to spend own money	☐	☐	☐	☐
Taking medicines	☐	☐	☐	☐
How/when to show affection	☐	☐	☐	☐
Use tobacco, alcohol, caffeine	☐	☐	☐	☐

The following questions ask about the type of support that they receive

29. What type of support package does the resident receive?

30. Who manages the support package & does this involve coordination of support?

____

____

31. What is the value of the support package that the resident receives? $______________________

32. What type of support do they have? (Please tick all that apply)

( ) meals planning
( ) cooking
( ) money management
( ) accessing the community
( ) going to medical appointments
( ) meals preparation
( ) shopping
( ) paying bills
( ) problem solving
( ) Coordination/Case Management

( ) Other (please specify) ……………………………………………………………………………………

33. Is there funding for:

( ) flexible community activities
( ) employment service
( ) attending a day program

34. Do they get any other support from another organisation or agency

( ) Yes - From which organisations/agencies? ____

____

( ) No

35. What type of tenancy does the resident have?

36. What is the Postcode of their address? ....postcode

37. How long have they lived at the current address? _________________________years

38. And how long have they lived in the local area? _____________________years

39. Are they living in: (please tick one box only)

[ ] Private house, flat, unit [ ] Public housing [ ] housing commission

[ ] social housing: (please specify the name of the organisation...

[ ] Other (please specify)...

40. Are they renting their accommodation? [ ] Yes [ ] No

41. Who do they live with? (please tick one box only)

[ ] Alone [ ] Partner [ ] Co-residents

[ ] Friend(s) [ ] Other (please specify) ....

42. What is the main source of income for their household? (Please tick one box only)

[ ] Wages or Salary [ ] Pension or benefit

[ ] Other (please specify) ....

42b If you said their main source of income is pension or benefit, do they have any other income?

[ ] Yes: please specify...

[ ] No

43. What is their current income?

[ ] Less than $1000 [ ] $1,001 to $14,999 [ ] $15,000 to $24,999

[ ] $ 25,000 to $34,999 [ ] $ 35,000 to $44,999 [ ] $ 45,000 to $54,999

[ ] $ 55,000 + [ ] don’t know

44. How old were they when they left school? ....years

LA TROBE UNIVERSITY

Survey Part 2

Title: **Optimising Outcomes in Supported Living for People with Intellectual Disability**

Part 2: Joint Questionnaire/Interview
Resident and Key Support Worker

To be completed by the resident and the support worker, with the researcher, at the time of the scheduled meeting. This interview will be audio-recorded and field notes will be taken. Consent has been given previously but it will be re-confirmed at the time of the scheduled meeting.

CONSENT

My name is {***say your name***). I work at Latrobe University and am working on a project about the best way to check how good services are and whether they are helping the people who live in them to have a good life. Today I would like to talk to you about your life here at (***name of home***).

The interview will be in 2 parts: Part 1 is a questionnaire to be completed by you (the resident) and your support worker with the assistance of the researcher; and Part 2 is a recorded face-to-face interview with you and myself (the researcher).

1a) Do you remember signing this form to say that you are happy for me to talk to you today {**show the signed form**}?

Please tick [✓] one box

Yes	☐	**If yes: Go to 1c**
No	☐	**If no: see below**

IF PARTICIPANT DOES NOT REMEMBER SIGNING CONSENT, PLEASE GO THROUGH A NEW CONSENT DOCUMENT WITH THEM AND CHECK THEY UNDERSTAND AND ARE HAPPY TO SIGN. THEN ASK 1b.

1b) Is it still ok to talk to you today and ask you what you think about living here?

Please tick [✓] one box

Yes **Go to 1c**	☐
No **Interviewer to terminate interview**	☐

1c) It would really help me if I can tape our chat today (**point to the recorder**) – this will help me make sure I can listen to you properly today and that I can make good notes about what you say when I go back to the university. Is this ok?

Please tick [✓] one box

Yes **THANK RESPONDENT, PRESS RECORD AND SAY OUT LOUD:** **"**Interview with (**READ SU IDENTIFICATION NUMBER)** on (**SAY DATE**)**"**	☐
No **SAY:** "That's OK; I'll leave the tape recorder off	☐

Resident ID Code: ……………………………………………………………….

Community Involvement

I firstly would like to ask you a few questions about your involvement in the community.

1. ***Within the past month*** have you………………. (interviewer tick either **yes or no below**):		
	Yes	**No**
Been to a hairdressers	☐	☐
Had friends or family in for a meal	☐	☐
Been out for a meal with friends/family	☐	☐
Had guests to stay	☐	☐
Been on an overnight stay to family or friends	☐	☐
Been shopping	☐	☐
Been to a cinema	☐	☐
Been to a café	☐	☐
Been to a pub	☐	☐
Been to a place of worship	☐	☐
Been to a sports event	☐	☐
Been to a social club	☐	☐
Been to a concert or a play	☐	☐
Been on a bus	☐	☐
Been to their bank	☐	☐
And in the past 12 months, have you been		
On a holiday	☐	This ☐

2.

(a) I am going to read some statements, and for each one can you indicate how true each of the statements are thinking about the activities you have participated in the community during past two weeks. On a scale of 1 to 5, with 1 being not at all true, and 5 being completely true/definitely

(Tick ONE box only)

	Thinking about the past 2 weeks					
	n/a	1	2	3	4	5
I participated in the activity with others rather than simply being present.						
I was treated with dignity and respect by others in the community						
The people I met spoke to me rather than a worker who was with me.						
I handled money (e.g. paying for purchases) during the activity						
I only interacted with staff and other people with disabilities						
I took part in an activity that contributed to the community in some way (e.g. volunteering, looking after someone's garden or pet, helping out someone)						
I took part in ordinary activities, not just special activities for people with disabilities						
I experienced negative attitudes or actions from others in the community						

	Thinking about the past 2 weeks					
	n/a	1	2	3	4	5
I used public transport while out in the community						
I was able to physically access all the facilities visited without any difficulties						
The activity/ies helped me to develop skills in some way						

(b) Can you tell me how you were actively involved in the activity/ies listed above:

____

____

(c) Did you interact with anyone other staff/ or other people with intellectual disability who live in the same house or nearby?

☐ YES ☐ No

(ci) If yes, ask…..who did you interact with (e.g. the bus driver, taxi driver, shop keeper...) etc.

____

3.

(a) How many neighbours in the area know you by name or do you know by name (please estimate as best as you can)? **N.B for interviewer: If they live in a clustered setting (e.g. a block of flats which are all for people with disabilities) do not include these people as neighbours and answer question 2d below.**

Interviewer, record the number of neighbours who know the person by name or are known to the person

____

(b) Do you ever have social contact with the neighbours, other than saying hello (e.g. come over for coffee or a bbq or go to the neighbour's house for tea or a party)?

☐ YES ☐ No

<u>If Yes</u>, ask, how often **(interviewer, please <u>tick</u> one box only)**

Less than once a year	☐
Once a year	☐
Up to three times per year	☐
Once a quarter (every three months)	☐
Once a month	☐
More than once a month but less than once a week	☐
Once a week or more	☐

If they live in a clustered setting (e.g. a block of units for people with disabilities) ask….

(c) Do they have contact with people in the other units?

☐ YES ☐ No ☐ N/A

Interviewer, If yes above, ask, how often do you have contact with people in the other units?

(Tick ONE box only)

Less than once a year	☐
Once a year	☐
Up to three times per year	☐
Once a quarter (every three months)	☐
Once a month	☐
More than once a month but less than once a week	☐
Once a week or more	☐

4. Do you have regular contact with your family?

Please tick [☐] one box

Yes (Go to Q 4)	☐
No (Go to Q6)	☐

(a) If yes, ask, who in the family do they see? ____

____

____

(b) If yes at Q4, interviewer, ask, on average how often do they have the following types of contact with family members? Interviewer: Also ask who in the family they have contact from i.e. mum, dad, brother, aunt etc.

Type of contact	**More than once a week**	**Once a week**	**Once a fortnight**	**Once a month**	**Less than once a month**	**Record who in the family?**
Visits from family members						
Trips out with family members						
Phone calls to / from family						
Letters / cards from family						
Other e.g. Overnight stay, facebook/emails (please describe)						

5. Are your family involved in your day to day life and decision making? **Interviewer please tick one box.**

No, there is no family involvement in support or decision making	☐
Family are not actively involved in support or decision making– they leave decision making to service staff etc.	☐
Yes, they are closely involved in the individual's life, support and decisions taken in their best interest	☐

6. Do you have contact with friends?

   ☐ YES ☐ No

   (a) If yes, interviewer ask, How many friends do you have outside of the home (defined as people whom the person meets regularly and who shares activities with the person, who the person might confide in; they would also support one another in some way.

   ☐

   (b) How many of these friends also have a learning/intellectual disability? ______________________

   (c) If yes (at Q6), how often do you have contact with friends?

Type of contact	**More than once a week**	**Once a week**	**Once a fortnight**	**Once a month**	**Less than once a month**	**Record if friends are with or without ID or both**
Visits from friends(s)						
Trips out with friend(s)						
Phone calls to / from friend(s)						
Letters / cards from friend(s)						
Other e.g. Overnight stay, facebook/emails (please describe)						

7. Do you have an advocate?

   ☐ YES ☐ No

   If yes, interviewer ask whether they have….:

A family member as an advocate	☐
A member of staff who acts as an advocate	☐
An independent advocate	☐
Other advocacy arrangements (specify)	☐

8. I am now going to ask about access to employment or regular day services?

Interviewer ask if in the last month they attended the following listed below, if "yes" ask the number of attendances **in the last month**, and the average duration of each attendance. E.g. if they went to day centre 3 days a week for 5 hours then that would be "36" (3 days x 12 weeks) under number of attendances and "5" under average duration of attendance.

	Thinking about the last month				
	Does this person access employment		**If Yes**		
	Yes	**No**	**Number of attendances**	**Average duration of attendance**	**Where**
Full-time paid employment - Open					
Full-time paid employment – Closed e.g. sheltered workshop					
Part-time paid employment – open					
Part-time paid employment – closed e.g. sheltered workshop					
Paid work experience					
Voluntary work experience					
Disability day service					
Voluntary organisation day activity facility					
Social club					
Other (please specify)					

9. I am now going to ask you about health care

a) Who helps you with your health care?

____

____

b) Do you have a regular GP?

☐ YES ☐ No

i) If yes, interviewer, ask how often they see their GP?

Once a month ☐
More than once a month but less than once a week ☐
Once a week or more ☐

c) Does the District Nurse visit you?

☐ YES ☐ No

i) If yes, interviewer, ask how often the district nurse visits them?

Less than once a year	☐
Once a year	☐
Up to three times per year	☐
Once a quarter (every three months)	☐
Once a month	☐
More than once a month but less than once a week	☐
Once a week or more	☐

d) Who helps you manage your medical appointments?

____

____

e) Who helps you manage medication?

____

____

f) Who goes to medical appointments with you and helps you understand what doctors have said?

____

____

g) What are your experiences of medical and hospital appointments?

____

____

____

10. Interviewer, complete the following Health Survey (Section 2) with them:

The following questions are about observed secondary health conditions. You will be asked to report if an observed condition has been a concern for the person with disability during the past year. Observed conditions usually have symptoms that the person with disability, you, friends, family, other staff and/or health care professionals may have observed.

Please refer to this rating scale that appears at the bottom of both pages when indicating the level of the problem.

Extent of health condition

Name of person with disability:

Date: / /

1. Weight problems People with Down syndrome, spina bifida and other developmental disabilities that cause decreased activity have up to 50% risk of becoming obese. Sometimes an individual may not experience the sensation of being full, as is the case with Prader-Willi syndrome. Being underweight may also be a concern, and is sometimes associated with low muscle tone. You may observe low levels of activity or endurance, too much, or too little time spent eating, mobility problems, or ill-fitting clothing.	0	1	2	3	4
2. Physical fitness and conditioning problems Some people with disabilities find they that are not able to do as much as they would like because they are physically unfit. You may observe an individual becoming winded even on a short walk, taking frequent rest breaks, sweating and face reddening after minimal exertion, or avoiding physical activities.	0	1	2	3	4
3. Dental/Oral problems and hygiene People with developmental disabilities are at a greater risk for dental disease and malformations. Teeth may be missing, thinly enamelled, abnormally shaped, or poorly cared for. This could lead to decay, poor fitting bite, toothaches, or progressive tooth loss. You may also observe consistent bad breath or infection. Poor dental hygiene can limit social interactions or eating pleasures.	0	1	2	3	4
4. Respiratory problems These can be the result of poor physical fitness, exposure to environmental irritants, as well as pneumonia, and other respiratory tract infections. Asthma or abnormal breathing structures can cause chronic respiratory problems. Symptoms can include difficulty in breathing; wheezing; excessive, frequent, prolonged coughing; increased phlegm production; increased nasal drainage, or discharge.	0	1	2	3	4
5. Fatigue Fatigue is a tired (though not necessarily sleepy) feeling after minimal exertion. Fatigue is a common problem for individuals with muscular problems. You may observe low motivation levels, slower rates of activity, more breaks, longer sleep periods, or naps.	0	1	2	3	4
6. Joint and Muscle pain This includes pain in specific muscle groups or joints. Individuals who must overuse a particular muscle group or those who must put too much strain on joints are at risk for developing joint and muscle pain. Individuals in wheelchairs with significant spasticity and/or mobility problems are also at risk. You may observe the individual limping, moving with difficulty, complaining to you, or standing up and sitting down with signs of unease.	0	1	2	3	4

Rating scale

0 = No problem
2 = Moderate/occasional problem
4 = Don’t know
1 = Mild/infrequent problem
3 = Significant/chronic problem

If you do not know if the person has a particular condition or you do not know if the person is limited by a particular condition, please circle 4 (4 = Don’t know).

7. Contractures A contracture is a limitation in range of motion caused by shortening of the soft tissue around a joint (e.g., elbow, hip). This occurs when a joint cannot move frequently enough through its range of motion. You may observe deformity, decreased activity, pain, or inability to passively move the joint.	0	1	2	3	4
8. Balance problems/dizziness There is an impaired sense of direction and/or ability to coordinate movement. People may display staggering, clumsiness, or complain of light-headedness following a change in position. This condition can be a sign of medication side effects or inner ear problems.	0	1	2	3	4
9. Bladder problems Persons with poor muscle function or lack of sensation in the area of the bladder are at risk for bladder problems. You may observe evidence of incontinence, leakage, odour, or other associated problems. The individual may complain of a burning sensation during urination or abdominal pain. Blood in, or discoloration of, urine and/or foul smelling urine may also be observed.	0	1	2	3	4
10. Pressure sores These develop as a skin rash or redness and may progress to an infected sore. These are also called skin ulcers or bedsores. Persons who use wheelchairs are at risk for developing pressure sores.	0	1	2	3	4
11. Bowel problems Diarrhoea, constipation, 'accidents', and associated problems are signs of bowel dysfunction. As with bladder problems, persons with impaired muscle function or paralysis in the stomach region are most likely to have bowel problems. Persons who are dependent on others to maintain bowel regularity are also at risk for this condition.	0	1	2	3	4
12. Vision problems Significant loss of ability to see, including blindness. You may observe the individual squinting at printed matter or holding it at a distance, bumping into or tripping over objects, or closing eyes for prolonged periods of time. Individuals who have been prescribed visual aids (eg., glasses), but who are not using them will probably experience limitation as a result of this condition.	0	1	2	3	4
13. Hearing problems The criterion for hearing impairment is 'deafness or difficulty with hearing in general or with hearing particular kinds of sounds'. The individual may not respond to voices or distinct noises, may listen to music or TV at loud volumes, or may talk too loudly or softly given certain situations.	0	1	2	3	4
14. Problems with mobility Many individuals with physical disabilities have difficulty getting around due to loss of strength or muscle control. Individuals with cerebral palsy, spinal cord problems, or central nervous system problems are at risk of problems with mobility.	0	1	2	3	4
15. Seizures Epileptic seizures are common in people with intellectual disability and range from those where the person 'goes blank' (absence), appears in a daydream and does 'funny things' like walking in circles, appearing unaware, or galling down or going still (tonic clonic)	0	1	2	3	4

Rating scale

0 = No problem	2 = Moderate/occasional problem	4 = Don't know
1 = Mild/infrequent problem	3 = Significant/chronic problem	

If you do not know if the person has a particular condition or you do not know if the person is limited by a particular condition, please circle 4 (4 = Don't know).

Social Capital Questionnaire

(Measuring Social Capital in Five Communities in NSW - A Practitioners Guide - P. Bullen & J. Onyx - January 1998)Interviewer, for the following questions ask for **the most appropriate response and circle 1, 2 3 or 4**

1. Do you feel valued by society?

No, not much *Yes, very much*

1 2 3 4

2. Are you satisfied with your life?

No, not really *Yes, very much*

1 2 3 4

3. Have you ever picked up other people's rubbish in a public place?

No, never *Yes, frequently*

1 2 3 4

4. Do you agree that helping others also helps you to have a better life?

No, not really *Yes, very much*

1 2 3 4

5. Do you help out a local group as a volunteer?

No, never *Yes, often (at least once a week)*

1 2 3 4

6. Do you feel safe walking down your street after dark?

No, never *Yes, very much*

1 2 3 4

7. Do you think most people can be trusted?

No, never *Yes, very much*

1 2 3 4

8. If someone's car breaks down outside your house, would you invite them into your home to use the phone?

No, never *Yes, definitely*

1 2 3 4

9. Can you get help from friends when you need it?

No, never *Yes, definitely*

1 2 3 4

10. Does your area have a reputation for being a safe place?

No, not really *Yes, definitely*

1 2 3 4

11. If you needed something would you ask a neighbour for help?

No, never *Yes, definitely*

1 2 3 4

12. Have you visited a neighbour in the past week?

No, not at all *Yes, frequently*

1 2 3 4

13. Have you attended a local community event in the past 6 months (e.g., church fete, school concert, exhibition)?

No, never *Yes, several (at least 3)*

1 2 3 4

14. Are you an active member of a local organisation or club (eg, sport, craft, social club)?

No, never *Yes, very active*

1 2 3 4

15. Do you think you belong in your local community?

No, not really *Yes, definitely*

1 2 3 4

16. In the past week, how many phone conversations have you had with friends?

No, none *Many (at least 6)*

1 2 3 4

17. How many people did you talk to yesterday?

No-one *Many (at least 10)*

1 2 3 4

18. Over the weekend do you have lunch/dinner with other people outside your household?

No, not at all *Yes, nearly always/often*

1 2 3 4

19. Do you go outside your local community to visit your family?

No, never *Yes, nearly always*

1 2 3 4

20. When you go shopping in your local area do you run into friends and acquaintances?

No, never *Yes, nearly always*

1 2 3 4

21. If you need information to make a life decision, do you know where to find that information?

No, not at all *Yes, definitely*

1 2 3 4

22. In the past 6 months, have you done a favour for a sick neighbour?

No, never *Yes, frequently (at least 5 times)*

1 2 3 4

23. Are you on a management committee or organising committee for any local group or organisation?

No, not much *Yes, several (at least 3)*

1 2 3 4

24. In the past 3 years, have you been part of a local community action group?

No, never *Yes, frequently (at least 5 times)*

1 2 3 4

25. In the past 3 years have you ever taken part in a local community project or working bee?

No, never *Yes, often*

1 2 3 4

26. Have you ever been part of a project to organise a new service in your area (eg, youth club, scout hall, land care, Lions, Rotary, Salvation Army)?

No, never *Yes, several times (at least 3)*

1 2 3 4

27. Do you feel free to speak out about things that affect you or your community?

No, never *Yes, definitely*

1 2 3 4

28. If you have a dispute with your neighbours (e.g., over fences or dogs) do you get help to work it out?

No, never *Yes, definitely*

1 2 3 4

29. Does living with people of different cultures make the area better?

No, not really *Yes, definitely*

1 2 3 4

30. Do you enjoy living among people who live differently to you? Interviewer if necessary "by differently" explain by this we mean, people that are noisier than you, play loud music, have parties etc

No, not really *Yes, definitely*

1 2 3 4

31. If a stranger, someone different, moves into your street, would they be accepted by the neighbours?

No, not really *Yes, definitely*

1 2 3 4

<u>Interviewer, only ask the following five questions if they are in paid employment.</u>

32. Do you feel part of the local geographic community where you work?

No, not really *Yes, definitely*
1 2 3 4

33. Are your workmates also your friends?

No, not really *Yes, definitely*
1 2 3 4

34 Do you feel part of a team at work?

No, never *Yes, definitely*
1 2 3 4

35. At work do you take the initiative to do what needs to be done even if no one asks you to?

No, never *Yes, definitely*
1 2 3 4

36. In the past week at work, have you helped a workmate even though it was not in your job description?

No, never *Yes, several times (at least 5)*
1 2 3 4

Survey Part 3

LA TROBE UNIVERSITY

Title: Optimising Outcomes in Supported Living for People with Intellectual Disability

Part 3: Face-to-Face interview

Consent has been obtained from the resident for participation in, and audio-recording of, the interview. The resident has indicated that they understand that they can withdraw, at any time, without explanation. The following questions are the interview guide that has been informed by a literature summary and by focus group interviews.

1. **Can you tell me about where do you live?**
    a. How does it compare to where you lived before
    b. Do you live near family or significant others
    c. Do you have a pet(s)
    d. Do you know your neighbours
    e. How do you get on with your neighbours
2. **Can you tell me about how you get around in the community**
    a. What makes life easy or difficult for you in terms of getting around the community
    b. Do you use public transport, do you have problems with the Myki system, with fines etc.
    c. Who takes you shopping or to appointments or social activities
3. **Do you always feel safe**
    a. Do you ever have problems with people coming to the door or ringing you up to sell you things or get you to sign up to special deals – how do you deal with this
    b. If something happens who do you turn to for help or to ask assistance from
    c. Do you feel safe
    d. Do you go out at night
4. **Who helps you?**
    a. What sort of support do you get, where from, how often
    b. Who do you ask for help
    c. What do you do when something unexpected happens
    d. Are you able to get household repairs done/contact landlord – is it easy or hard
    e. How quickly can you expect things to get fixed or mended
    f. Do you know the names of the people who come into your home to help
    g. Do the same people come to help you or do they change
    h. What do you do if a worker does not arrive
    i. Do you have help with household chores - cleaning and cooking
    j. Who helps you manage medication
    k. Who goes to medical appointments with you or understanding what doctors have said
    l. Does someone else have a key to your house
    m. Who helps to read the mail etc.
    n. Who coordinates all the people who help you and can you contact them

5. **Do you have a say about your money?**
    a. How do you pay the rent and pay for shopping
    b. Do you have to ask someone for money
    c. Do you have a bank access card
    d. Who pays for the big items such as a fridge or TV
    e. Who pays the bills
    f. Do you have enough money to do the things you want to do
    g. Do you ever run out of money
    h. What do you do if you run out of money

6. **How did you get the money or support to move into housing**
    a. Did you get help from family or friends
    b. Did you get help from an organisation

7. **What do you do during the day?**
    a. Do you choose what you do during the day or you program/planned activities
    b. Do you have planned or regular activities?
    c. What activities do you do in your local community e.g. shopping, going to a cafe, going to the bank?
    d. Who goes with you to help you with these activities?
    e. Do you get bored or fed up
    f. Do you have enough to do

8. **Do you feel lonely and who do you talk to?**
    a. Who are your friends?
    b. Do you belong to any clubs or go to the library?
    c. Where do you go to meet up with people?
    d. Does anyone help you to make connections with other people
    e. Do you have friends from work
    f. How often do you have contact with family or friends and what do you do

9. **How do you get information?**
    a. Do you have a mobile phone?
    b. What sort of phone do you have?
    c. Do you have a computer at home?
    d. Do you have access to a computer elsewhere?
    e. Do you have the internet at home?
    f. Do you have access to the internet elsewhere?
    g. Do you use email?
    h. Do you use social media, such as face book or Skype to connect to people?

10. **What are the good things about where you live?**
    a. What do you like about where you are: people, neighbours, place, location, community, location near family, near to shops

11. **Do you have any problems with where you are living?**
    a. Co-residents
    b. Staff
    c. Neighbours
    d. Relationships
    e. Bills
    f. Landlord