200 Lives

Evaluating supported living and residential care for adults with learning disabilities

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#200lives

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Thank you

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Background

In 2020/21 in England, spending on long-term social care for adults with learning disabilities represented 39% of all long-term social care expenditure and 69% of all long-term social care expenditure for adults aged 18-64 years. Of the £5.6 billion spent in 2020/21 on long-term social care for adults with learning disabilities aged 18-64, £1.66 billion (30%) was spent on supported living and £1.74 billion (31%) on residential care (NHS Digital, 2021).

Supported living refers to a housing model where the person owns or rents their home, with accommodation and support being provided separately so that the person can change their support provider without affecting their housing or vice versa. Residential care refers to a room in a home where meals, care and support are all provided. These may be run by private, voluntary sector or local authority organisations (Harflett, Pitts, Greig & Bown, 2017).

In 2020/21 in England, 23% (31,070) of all working age adults with learning disabilities receiving long-term social care support were in supported accommodation and 14% (18,515 people) were in residential care, with considerable geographical variation (NHS Digital, 2021). Furthermore, many of the more than 48,000 adults with learning disabilities receiving long-term social care support, but still living with their families, would prefer to live independently (Mencap, 2012).

Despite the large amounts of public money being spent, we know very little about how good supported living/residential care services are, and how much they really cost. It is 20 years since there was in-depth research about the costs and quality of housing and support for adults with learning disabilities (Emerson et al., 1999); since then, much has changed. Supported living should give people more rights and control over their lives (Harflett et al., 2017) and therefore it has been proposed that this will improve quality of life but there is mixed evidence about better outcomes for people in supported living when compared to those in residential care (Bigby et al, 2017). A systematic review of outcomes for people with learning disabilities in different residential settings indicated benefits of community living but the authors concluded that the variability in results could not be accounted for simply by the model of care and that other factors are influential (Kozma et al., 2009).

Whilst there has been a trend towards supported living, some councils have questioned the value of it and if this is a sustainable trajectory (Rochdale Borough Council, 2017). There is presently an inadequate evidence-base to inform commissioners' decision-making. Bigby et al. (2017) cited work from the UK and US suggesting that supported living is more cost effective than group homes. Earlier research had found no statistically significant differences in costs between supported living schemes, small group homes and larger group homes (Emerson et al, 2001). Whilst the literature is limited, there is research suggesting that higher housing costs for people with learning disabilities are associated with the characteristics of the individuals living in them (Knapp, 2005). A systematic review showed that while supporting people in cluster housing costs less than in dispersed housing this is due to lower levels of staff support and the authors concluded "there is no evidence that clustered housing can deliver the same quality of life as dispersed housing at a lower cost" (p.313 Mansell and Beadle Brown, 2009). There is consensus that further, more robust, research into housing costs is needed to inform policy makers and commissioners (Knapp, 2005; Felce, 2017). An international review of the evidence on the costs and quality of residential services for adults with learning disabilities concluded “More research is required on the factors that drive costs on the one hand and outcomes on the other.” (Page 187, Felce, 2017). Whilst there is a paucity of recent research around housing models, quality and costs we have reviewed relevant literature to inform our outcome measures for the present study.

People in supported living may participate more in local community activities than those in residential homes (Bigby et al, 2017) but many people with learning disabilities have low levels of community participation, irrespective of where they live (Kozma et al., 2009). A study of people living alone with minimal support found that they did not engage much with their community and most of their socialising was with other people with learning disabilities (Bond and Hurst, 2009).

Even where people were living in the community and making use of community places, loneliness was still an issue (Bigby et al., 2017). Previous research has not found a strong association between loneliness and settings, rather it is related to poor relationships with housemates (Kozma et al., 2009). However, incompatibility between residents is more likely in larger settings and those who chose who they could live with were less lonely and happier (Salmon et al., 2019). Those in supported living are generally offered more choice and control over their own lives but some small studies have found that less than half of people with learning disabilities have the opportunity to choose their housemates, even in supported living (Inclusive Research Network, 2010; Salmon et al., 2019).

Despite people in supported living talking about greater self-determination and evidence of higher levels of day-today choices, it seems they still have limited control over their housing situations and support with significant proportions of people not having any choice about moving, where they live, who they live with and who provides their support (Bigby et al., 2017; Salmon et al., 2019). Given the negative effects that social isolation and loneliness can have on wellbeing, physical and mental health and even mortality, this lack of choice can impact on people’s quality of life and health (Public Health England, 2015). There is also very little research looking at the geographical location of their homes and the physical design of the places they live (Salmon et al., 2019).

Money was another area where people were frustrated by their lack of control even in supported living, although budgeting was something that people in supported living with minimal support did struggle with so there may be a need for some help with managing finances (Bond and Hurst, 2009).

Perhaps unsurprisingly, people’s experiences of the support they received is mixed. Whilst many talk about positive and valued relationships with their supporters, others cited examples of supporters being controlling or lazy (Bigby et al., 2017). It is clear that the type of support people get impacts upon their quality of life (Mansell and Beadle-Brown, 2009). Supporters play a key role in facilitating social relationships for people with learning disabilities. Given many people are still lonely and have few close friends irrespective of engaging in community activities, this underlines the importance of staff in supporting people in terms of their social inclusion. Meys et al. (2021) found that staff in supported living set-ups were more likely to focus on helping people to develop and maintain friendships than staff in congregated settings.

Although those in supported living are more likely to have larger social networks and more contact with their family, people still described difficulties with social relationships and feeling lonely (Bigby et al., 2017). As well as living situation, there are other factors that impact on social relations and loneliness, including lack of money, limited access to transport, feeling unsafe in the community and a reliance on others to facilitate outings (Kozma et al., 2009; Meys et al., 2021).

There is some evidence of poorer health outcomes for those in supported living (Bigby et al., 2017) and higher rates of smoking and obesity (Kozma et al., 2009). It has also been suggested that there is the potential for problems with correctly taking medication for those living alone with minimal support (Bond and Hurst, 2009). But in general, there is less of a focus on the relationship between housing models and health outcomes for people with learning disabilities in the existing research literature.

This study was designed to seek the perspective of people with learning disabilities and to include people who did not have capacity to consent to take part in the research to ensure participants with a wide range of support needs. This is important, as we know that those with greater support needs are more likely to have a limited presence in the community and may have poorer outcomes when living in small-scale community-based residences than those with lower support needs (Kozma et al., 2009).

The original aim of this research was to examine the quality and costs of supported living and residential care for 200 adults with learning disabilities aged 18-64 years (see methods for changes as a result of the COVID-19 pandemic).

Research question(s) and objectives

The primary research question addressed by this study were:

How do the quality and costs of services for working age adults with learning disabilities vary between supported living and residential care?

The research addressed the following objectives:

1) To compare the quality and costs of supported living and residential care, the extent to which they are distinct support models in terms of how they operate, the extent to which people's rights are respected and supported, and people's experiences of how they are supported.
2) To understand which factors (e.g., costs, resources, provider organisation, how many people share a home, service practices and cultures, people's needs, the extent to which people's rights are respected and supported) are most strongly associated

with various aspects of people’s quality of life in supported living and residential care.

3) To understand different perspectives (from quantitative indicators, quality checking, qualitative analyses of responses to open-ended questions, and a survey of family members) on the quality of supported living and residential care.

In this report we present information about the supported living and residential care services, how they operate, their costs, and information about the health, wellbeing, exercise of human rights, and lives of adults living in them.

We hope this information can be used by the government, people who commission social care services, organisations who provide housing support for adults with learning disabilities, self-advocacy groups and family groups, and the Care Quality Commission.

Methods

Design

The project is a cross-sectional largely quantitative design, with mixed methods components to allow triangulation across different data sources. Up to four levels of quantitative data were collected:

1. the provider organisation
2. the residential or supported living setting
3. from the individual participant (self-reported and proxy data)
4. a family member (if consent obtained from both participant and family member).

The target sample size for the study was 200 (100 participants from supported living and 100 participants from residential care). This sample size was determined based on findings from the previous Emerson et al. (1999) study, comparing supported living to larger group homes. Using the effect sizes found in the Emerson et al. (1999) study, power calculations suggested that a sample size of 100 per service model would detect at 80% power the differences between the two models in the following indicators, some of which 'favoured' supported living and others which 'favoured' large group homes: average cost, everyday choice-making, physical inactivity and accidents / injuries.

This enables comparison of aspects of supported living and residential care, for example the characteristics of people living in these settings (e.g. support needs, health conditions etc.) and outcomes including choice and control; health and wellbeing; employment; and leisure activities. Qualitative questions and Quality of Life Reviews provide insight into people with learning disabilities' experiences of their housing.

Ethics

As the project concerned people using social care services and sought to include people who may lack capacity to consent to take part, ethical review was sought from the Integrated Research Application System. The project received a favourable ethical opinion from the Social Care Research Ethics Committee (REC reference 20/IEC08/0041).

Recruitment

Potential services were identified through supported living and residential care networks. Information about the project was shared through relevant contacts, such as the National Development Team for Inclusion, the Housing Learning Improvement Network, Rescare and the Association of Directors of Adult Social Services. In addition, 'cold-calling' emails were sent to 64 care providers that managed care homes within reach of researchers for potential face to face visits to collect information (London, the South-West and Greater Manchester). Organisations who were interested in taking part were invited to have a short conversation with the research team. Conversations took place with 31 different provider organisations, of which 16 ultimately took part in the project. Of these:

- 8 organisations put forward only participants from supported living
- 2 organisations put forward only participants from residential care
- 6 providers put forward participants from both supported living and residential care.

Provider organisations were asked to share information about the project with people they support who may be interested in taking part. Eligible participants were people in supported living or residential care who were identified by the provider organisation as having a learning disability, aged 18– 74 years old and who had lived in their current property for at least 6 months. An easy-read information booklet and a YouTube video were provided to share with potential participants. The video can be viewed here.

If people gave informal consent to be contacted about taking part, their details were shared with the research team, who contacted them to arrange an interview and obtain formal consent.

For participants who were thought to lack capacity to consent to taking part in the research process, a ‘personal consultee’ or ‘nominated consultee’ process was followed, in line with Dobson (2008) guidance and the Mental Capacity Act. This involved asking a close family member or member of staff who knows the person well to decide whether they should be involved in the research in line with their best interests. If permission was obtained from a personal or nominated consultee, data related to the participant was gathered via a proxy respondent, a member of staff supporting the individual who knew them well.

Data collection

Information was collected using a combination of participant interviews and questionnaires completed by staff and family members online, via post or over the phone. Quality of Life reviews were completed for a subset of participants. Brief details of the procedures are given below.

Participant Interview – completed via semi-structured interview over video call, phone or face-to-face during a home visit. A small number of interviews were completed by the support provider together with the person and returned via post to the research team.

Interviews were routinely split into two sections of around 60 minutes each, with flexibility to take breaks as and when the participant wanted. There were 200 questions in total with flexibility to skip some items and focus on key questions depending on the person’s level of understanding. Due to COVID-19 home visits were shortened to minimise infection and so a shorter version of the Participant Interview Schedule was used (approx. 100 questions) to maximise the number of people taking part. Participants could have a support person, such as a support worker or family member, with them if they wished. With the participant’s consent, the interviews were audio-recorded. Where interviews took place in-person, infection prevention protocols were followed in line with government and organisational guidelines at the time of the interview.

The interviews consisted of a mixture of closed and open-ended questions in order to gather both quantitative and qualitative data. Topics included participants' views on their home, the impact of the coronavirus pandemic, transport, support needs, money, employment, how they spend their time, social life, safety and health. The *Patient Health Questionnaire* and *Generalised Anxiety Disorder Questionnaire* were included, adapted for people with a learning disability (Breen, 2017), to evaluate depression and anxiety.

The questions were devised by the research team, with some adopted or adapted from the Emerson et al. (1999) study. Members of the project advisory group provided guidance about topics to include in the interview schedule. The research team attended a self-advocacy conference to obtain feedback on a draft version of the interview schedule and consulted 39 people with learning disabilities on the design of the measures and the wording and choice of questions. This feedback was then incorporated in the design of the final versions of the questions. The disability rights-based organisation Changing Our Lives provided feedback on the final version of the interview schedule and assisted with the creation of easy-read prompt cards.

Where participants lacked capacity to answer these questions for themselves, a member of staff who knew them well answered these questions on their behalf using a **Proxy-Participant Questionnaire**.

Proxy Questionnaire: with consent from the participant (where the person had capacity to take part in the research), a member of staff who knew them well (for example, a key worker) completed a questionnaire about the person's life and the support they receive. Questions were adapted from Emerson et al. (1999; 2005), *the Real Tenancy Test* (NDTi, 2015), *Problem Behaviour Checklist* (Tyrer et al., 2016) and the *Client Service Receipt Inventory.* Some questions were devised by the research team such as dietary questions (based on the NHS Eatwell Guide, 2019) and frequency of restrictive interventions (based on CQC mandatory reporting guidance, 2015).

Household Questionnaire: data relating to the participant's home (the residential care or supported living property) were gathered via a questionnaire completed by a representative from the provider organisation (such as the home manager). Questions were adapted from the *Residential Services Setting Questionnaire* (Emerson, Alborz, Felce & Lowe, 1995), *Residential Services Working Practices Scale* (Felce, Lowe & Emerson, 1995), *Group Home Management Interview* (Pratt, Luszcz & Brown, 1979), *Group Home Culture Scale* (Humphreys, Bigby, Iacono & Bould, 2020), *NDTi Housing Typology* (NDTi, 2017), *Architectural Features Scale* (Thompson, Robinson, Graff & Ingenmey, 1990) and the *'Is your practice getting institutionalised?'* survey (Stay Up Late, 2019). Staff completed one questionnaire per household that took part in the project.

Family Carer Questionnaire: where relevant, participants were asked whether they would like their family to participate in a family survey. Where consent was given, the research team sought consent via the support provider to contact the family member. Those who wished to take part completed the survey via post, online questionnaire or over the phone. The survey was comprised of closed and open-ended questions, in order to gather family carers' perspectives on the overall quality of provision, the extent of their own involvement, aspects of the service they valued and aspects they would like to be changed. The survey was based on a previous survey by NDTi (Blood & Cooney, 2020) that sought to estimate the time and money that family carers spend supporting their relatives in supported living or residential care.

Economic Analysis

Details of the economic analysis are presented in the Economic Analysis chapter on page 144.

Quality of Life Reviews were carried out with 14 participants by Changing Our Lives, part of the research team with extensive experience of conducting quality checks. Quality checkers are disabled people who are Experts by Experience and they work in conjunction with a Quality Partner who is an experienced individual with an understanding of both the policy and practice context of the area being reviewed. These reviews acted as quality checks and enabled triangulation of the data collected by the research team, in addition to providing a different perspective on quality from people with lived experience of learning disabilities.

Participants were asked during the consent process whether they would consent to being potentially contacted by the Quality of Life Review team. Purposive sampling was then used to select participants for the Quality of Life Reviews, seeking to ensure that people with a range of ages, ethnic backgrounds and support needs were represented across supported living and residential care.

Reviews were carried out remotely via video call or phone and involved spending time with individuals and 'walking through' their life, getting to know them and asking them a series of questions about their experiences. The Quality of Life review team compiled themes from participants living in supported living and those living in residential care.

Impact of COVID-19 on the project

Preparatory work on the project began in January 2020, including the ethics application and designing the data collection schedules. The UK entered lockdown in March 2020 due to the coronavirus pandemic, with subsequent lockdowns in autumn 2020 and January 2021. This caused immense disruption within the health and social care sector, with increased demand for support coinciding with staff shortages due to staff illness, isolation and caring responsibilities. People with learning disabilities were considered particularly vulnerable in terms of health (Public Health England, 2020) with many people required to shield, and lockdown restrictions having a considerable impact on people's day-to-day routines (Flynn et al., 2021a). Support providers were under extreme pressure to adjust to the restrictions in place whilst continuing to care and support people at a difficult and worrying time. The mandatory vaccine requirement for social care staff further added to staffing pressures, with one provider estimating that their remaining staff had to work 34,500 hours of overtime in September 2021 to keep people safe and supported (Today Programme, 2021). As a result of these pressures, nearly a third of people with learning disabilities report that they were not receiving support services that they were paying for during this time (Flynn et al., 2021b).

These issues had clear ramifications for the project in terms of recruiting participants and data collection. For example:

- The intended research method of conducting home visits with participants was no longer feasible due to restrictions on visiting / travel and concerns about infection risk. The design of the research had to be adapted to focus predominantly on remote data collection methods, such as video calls and phone calls.
- The data collection schedules were revised to reflect the new terrain and the impact of COVID-19 on people's lives. The ethics application also had to be re-written to reflect the move to online data collection, while retaining the option for face-to-face data collection if the situation changed.
- Given the pressure that support providers, people with learning disabilities and their families were under, it was not considered appropriate to advertise the project and generate interest as originally intended and recruitment had to be put on hold.
- Whilst many support providers had expressed interest in taking part in the project, many did not have the staffing capacity to facilitate involvement. This resulted in smaller numbers of participants being put forward per provider than anticipated. Furthermore, some people wished to delay participating until it was possible to meet in person, meaning that they were unable to participate until the latter stage of 2021.
- Whilst many people with learning disabilities became more confident using online technology throughout the pandemic, there remain access issues with the use of online methods (Seale, 2020). For example, people may have been more reliant on staff to facilitate access to the technology. Whilst online data collection is more flexible due to lack of travel, some interviews became quite fragmented, for example frequent rescheduling or people not being available at the scheduled time. This meant additional delays in completing the interviews.
- There were similar challenges in completing the staff questionnaires, which were sent out via post or email; due to staffing shortages staff had limited capacity and research was often not seen as a priority. Despite frequent attempts to chase up missing questionnaires, this resulted in a low response rate with only about 60% of the staff questionnaires returned.

The '200 Lives Project Timeline' provides further detail of the project stages alongside information about the national lockdown restrictions in place at the time.

The following adjustments were made to the initial project design to mitigate the impact of COVID-19 on the project and recruitment difficulties:

- Switching data collection for participant interviews from primarily in-person to primarily remote methods (video call and phone call).
- Increasing the upper limit of participant age from 64 to 74 to allow a wider pool of participants.
- Removing the eligibility criteria that at least 50% of people living together must consent to taking part in the study, as online data collection was deemed to be less intrusive for other non-participating residents than in-person visits. This also increased the pool of participants.
- A 6-month funded extension was granted by NIHR to reflect the time required to amend the ethics application, adjust the methods and allow for an extended recruitment and data collection period. This also allowed for some face-to-face interviews to take place when lockdown restrictions were eased.
- A reduction in the target number of participants from 200 to 100, to reflect issues with staff capacity and recruitment difficulties.

Participant numbers

In total, 107 participants took part in the research (93 participants with capacity to consent and 14 proxy-participants). As data collection was routinely split over several interviews, approximately 215 interviews were carried out, including 20 face-to-face interviews.

Participants with the capacity to consent to take part in the research could, depending on their preference, be interviewed in more than one interview session to complete the participant questions, and there could be a support person present for the interviews. Just over half (57%) of people directly interviewed had a support person with them for at least one research interview, almost always a paid support worker (90% of those with a support person for at least one research interview). For those participants with a support worker present, questions were most commonly answering by the participant alone (56%), by the participant and support person (25%), or by the participant with the support person helping with communication (17%).

200 Lives Project Timeline

Timeline in pink indicates national lockdown restrictions during the COVID-19 pandemic. However, many support providers and care homes maintained their own stricter COVID-19 precautions after official guidance changed so this may not be reflective of all experiences.

Timeline in blue indicates progress on the 200 Lives project.

200 Lives Project Timeline 1 (January 2020-September 2020)

16 March

Work from home order in place

23 March

First UK lockdown announced

May 2020

Easing of lockdown restrictions begins

July 2020

Local lockdown measures in place

January 2020

September 2020

Jan 2020

Work on 200 Lives began, including advisory group.

Feb 2020

Consultation event at Blackpool conference.

March 2020

Conversations with providers on hold as home visits are no longer feasible.

Apr - Aug 2020

Worked on ethics application, adjusted methods and created measures.

Sept 2020

Amended ethics application due to project transfering to MMU.

200 Lives Project Timeline 2 (November 2020 – March 2021)

Nov 2020
Second national lockdown begins.

Dec 2020
Local lockdowns in place.

Jan 2021
Third national lockdown begins.

March 2021
Schools re-open.

November 2020

March 2021

Nov 2020
Ethics application submitted.

Dec 2020
Meeting with ethics committee, ethics amendments & advisory group.

Jan 2021
Favourable ethical opinion received.

Feb 2021
Intensive recruitment of provider organisations.

March 2021
First interviews with supported living participants.

200 Lives Project Timeline 3 (April 2020 – August 2021)

April 2021

Non-essential retail re-opens.

May 2021

Rule of six for indoor gatherings.

July 2021

Most restrictions on social contact lifted.

April 2021 **August 2021**

April 2021

Data collection in progress.

May 2021

Data collection in progress.

June 2021

Advisory group; first interviews with residential care participants; funding extension request submitted.

July 2021

Presented the project at IASSIDD conference; first home visit took place.

Aug 2021

Data collection in progress

200 Lives Project Timeline 4 (September 2021 – January 2022)

Nov 2021

Mandatory vaccinations for social care staff introduced, leading to staff shortages.

September 2021 **January 2022**

Sept 2021

Quality of life reviews completed.

Oct 2021

Received confirmation of funding extension. Final recruitment push.

Nov 2021

Intensive participant interviews and home visits.

Dec 2021

Final participant interviews took place & analysis began.

Jan 2022

Data analysis and report write-up.

Project Findings

Household Information

Information about the housing set-up, staffing, training arrangements and working culture was collected through the Household Questionnaire. One of these was completed per household which participated in the research; for example, if 3 people who lived together took part in the project, only one Household Questionnaire would be completed. These were generally completed by a senior member of support staff such as the house manager.

Household data was available for 11 residential care properties and 23 supported living properties. All of the residential care homes were registered as care homes without nursing. People had their own tenancy at 20 of the 23 supported living properties; 2 were shared ownership and 1 was extra-care housing. Because of the limited numbers of properties and statistical comparisons being conducted, the statistical significance threshold was set at p<0.05 for these comparisons.

As expected by the service model of supported living and residential care, at most supported living properties support and housing were provided by different organisations, whereas they were provided by the same organisation at most residential care properties. This difference was statistically significant (see Table 1). However, there were some instances of support and housing being provided by the same organisation within supported living, and by different organisations within residential care, suggesting that this is not a perfect distinction.

Table 1 also provides information about the organisations managing the housing and support at the properties. The majority of residential care households were managed by for-profit organisations, whilst most supported living properties were managed by Housing Associations with support provided by non-profit organisations. The vast majority of supported living properties were rented from housing associations or registered social landlords, with a small minority being shared ownership or rented from private landlords.

Table 1: Details of the housing set-up

		Supported Living	Residential Care	Test and statistical significance
Are housing and support provided by different organisations?	% Yes	87.0%	18.2%%	**Chi-square=15.412; df=1; p< 0.001**
	% No	13.0%	81.8%	
Who is the housing managed by?	% Social service	0%	9.1%	Not calculated
	% Private (for profit) organisation	4.3%	63.6%	
	% Voluntary (non-profit) organisation	17.4%	18.2%	
	% Housing Association	60.9%	9.1%	
	% Council Housing	8.7%	0%	
	% Own	8.7%	0%	

		Supported Living	Residential Care	Test and statistical significance
Who provides the support in the home?	% Social service % Private (for profit) organisation % Voluntary (non-profit) organisation	0% 9.1% 90.9%	9.1% 63.6% 27.3%	Not calculated
[Supported living only] Does the person rent or own the property?	% Own % Rent % Shared Ownership	4.3% 87.0% 8.7%	NA	Not calculated
[Supported living only] if rented, who is it rented from?	% Housing Association or Registered Social Landlord % Private Landlord	95.0% 5.0%	NA	Not calculated

Table 2 shows the number of long-term places in each household. Residential care households were found to be significantly larger than supported living households in terms of number of residents (on average around 8 residents per residential care property compared to 3 people per supported living property). None of the properties reported any short-term or respite places. There was no statistically significant difference in the number of vacancies between the two service models.

Table 2: Number of places in the setting

		Supported Living	Residential Care	Test and statistical significance
Number of long-term places in the setting	Mean (sd) Range	2.70 (1.72) 1 - 7	8.18 (2.18) 5 - 12	**t=-7.718; df=29, p< 0.001**
Number of vacant long-term places in the setting	Mean (sd) Range	0.10 (0.30) 0 - 1	0.64 (1.03) 0 – 3	t=-1.691; df=29, p= 0.119

Around half of properties in both supported living (50%) and residential care (54.5%) were reported to be exclusively for people with learning disabilities (see Table 3). Where the property also served people with other support needs, these included people with physical disabilities, autistic people and older people. There was no statistically significant difference between the two models in terms of age range of residents.

Respondents were asked to indicate how many people living in the household had a profound or severe learning disability, mild or moderate learning disability and borderline or no learning disability. As this represents the total people living in the household, not all of whom took part in the research, it is important to note that this does not necessarily reflect the participant sample. In participating residential care households, 35% of residents had a profound or severe learning disability, compared to 13.5% of residents in supported living households. 81% of residents in supported living households had a mild or moderate learning disability, compared with 58% of people living in residential care. Few people in households in either setting had a borderline or no learning disability. 28% of residents in residential care households were autistic, compared to 21% of people living in supported living.

There was a statistically significant difference between supported living and residential care, with 82% of residential care settings reporting being specialised for people with a particular support need, compared to 18% of supported living settings. Examples of specialism included epilepsy, autism and mental health difficulties.

Table 3: Which groups of people does the setting serve?

		Supported Living	Residential Care	Test and statistical significance
Which groups of people does the setting serve?	% People with a learning disability only	50.0%	54.5%	Chi-square=0.061; df=1; p= 0.805
	% Other	50.0%	45.5%	
Details of 'other' groups of people served by the setting	% People with learning and physical disabilities	0%	36.4%	Not calculated
	% People with learning disabilities and autism	8.3%	9.1%	
	% Retirement housing for older people	8.3%	0%	
	% People with acquired brain injury	4.2%	0%	
	% People with challenging behaviour	4.2%	0%	
	% General / council housing	25.0%	0%	
Majority age band of people who live in the setting	% 20s	7.1%	0%	Chi-square=4.574; df=5; p= 0.470
	% 30s	28.6%	55.6%	
	% 40s	7.1%	22.2%	
	% 50s	14.3%	11.1%	
	% 60s	35.7%	11.1%	
	% 70s	7.1%	0%	
In this setting how many people have a …	% Profound or severe learning disability?	13.5%	34.9%	Not calculated
	% Moderate or mild learning disability?	80.8%	57.8%	
	% Borderline or no learning disability?	3.8%	1.2%	
In this setting, how many people are autistic?	% Autistic residents	21.2%	27.7%	Not calculated
Is the setting specialised for people with learning disabilities with a particular need?	% Yes	18.2%	81.8%	**Fisher's exact p= 0.001**
	% No	81.8%	18.2%	

		Supported Living	Residential Care	Test and statistical significance
Do people go out to an external day service?	% Yes, everyone	22.7%	0%	Chi-square=2.843; df=2; p= 0.241
	% Yes, some people	18.2%	30.0%	
	% No	59.1%	70.0%	

Table 4 shows information about the building layout of each property. 64% of supported living properties were located in mainstream settings, meaning that housing there is available to anyone whether or not they have care and support needs, compared to 37% of residential care properties. The majority of residential care properties (55%) were located in designated settings, meaning that they were located among mainstream housing with a physical design indicating that the property is for people with care and support needs, compared to 18% of supported living properties. Finally, 18% of supported living properties were located in segregated settings, meaning that housing there is only available to people with care and support needs and is separated by location from mainstream housing and communities, as compared to 9% of residential care properties. There were no statistically significant differences in property location between the two housing models.

In terms of layout of the properties, residential care properties were more likely to feature a separate dining room compared to combined kitchen / dining rooms or combined living / dining rooms in supported living properties. Residential care properties had significantly more bedrooms (an average of 8 per property compared to 3 for supported living), as expected as residential care properties tended to have more people living there. Most residential care properties had a designated bedroom for staff use only (64%), whilst most supported living properties did not (36%); however, this difference was not statistically significant.

Table 4: Building Layout

		Supported Living	Residential Care	Test and statistical significance
Location of the household	% Mainstream	63.6%	36.4%	Chi-square=4.600; df=2; p=0.100
	% Designated	18.2%	54.5%	
	% Segregated	18.2%	9.1%	
Dining room	% Separate	15.0%	45.5%	**Chi-square=7.084; df=2; p=0.029**
	% Combined kitchen/dining room	45.0%	54.5%	
	% Combined living/dining room	40.0%	0%	
Number of living areas	% 1 living area	54.5%	36.4%	t = 0.508, df=31, p= 0.615
	% 2 living areas	27.3%	27.3%	
	% 3 living areas	9.1%	27.3%	
	% 4 living areas	4.5%	0%	
	% More than 4 living areas	4.5%	9.1%	
Number of bedrooms	Mean (sd)	3.14 (2.04)	8.45 (2.30)	**t = 6.793, df=31, p <0.001**
	Range	1 – 9	5 - 13	

		Supported Living	Residential Care	Test and statistical significance
Number of bedrooms for staff use only	% 0 staff bedrooms % 1 staff bedroom	36.4% 63.6%	63.6% 36.4%	Fisher's exact p= 0.163

Table 5 shows aspects of the building design including adaptations and security features. Residential care properties were significantly more likely to have areas that were out of bounds to residents (64%) compared to 22% of supported living properties. No significant differences were reported between the two service models in terms of strengthening of building fabric, furniture and protection of equipment. Residential care properties were significantly more likely to report the use of deadlocks to restrict resident movement. There were no statistically significant differences between the two in terms of distance of the property to the road and size of garden.

Table 5: Building Design

		Supported Living	Residential Care	Test and statistical significance
Are there any areas which are "out of bounds"?	% Yes % No	21.7% 78.3%	63.6% 36.4%	**Fisher's exact p= 0.026**
Is the building fabric visibly strengthened?	% Yes % No	5.6% 94.4%	12.5% 87.5%	Fisher's exact p= 0.529
Is there specially strengthened furniture?	% Yes % No	4.5% 95.5%	11.1% 89.9%	Fisher's exact p= 0.503
Is the fitting of equipment specially adapted (such as protection of TV)?	% Yes % No	4.3% 95.7%	20.0% 80.0%	Fisher's exact p= 0.212
Are there deadlocks etc. to restrict resident movement?	% Yes % No	4.3% 95.7%	44.4% 55.6%	**Fisher's exact p= 0.015**
Does the garden have a secure perimeter and fence?	% Yes % No	55.6% 44.4%	90.9% 9.1%	Fisher's exact p= 0.096
How close is the building to the road?	% Remote from the road % Midway % Facing onto road.	19.0% 47.6% 33.3%	0% 45.5% 54.5%	Chi-square=2.902; df=2; p=0.234

		Supported Living	Residential Care	Test and statistical significance
If there is a garden or grounds, what size are these?	% Campus % Large domestic % Medium domestic % Small domestic	12.5% 12.5% 62.5% 12.5%	0% 45.5% 54.5% 0%	Chi-square=5.550; df=3; p=0.136

Table 6 contains information about the working culture and practice within the household. This measure was created by combining items from the *Residential Services Working Practices Scale* (Felce, Lowe & Emerson, 1995), *Group Home Management Interview* (Pratt, Luszcz & Brown, 1979), *Group Home Culture Scale* (Humphreys, Bigby, Iacono & Bould, 2020) and *'Is your practice getting institutionalised?'* survey (Stay Up Late, 2019). Items were combined to form subscales of rigidity of routines, block treatment, social distance from residents, rules and supporting wellbeing (reverse-scored) with higher scores indicating greater levels of institutional practice. For example, 'are meals always at set times?' was scored as *2 = always at set times, 1 = mostly at set times, 0 = rarely at set times.* These subscales were totalled to create a total score of institutional practice.

Residential care services reported engaging in higher levels of block treatment, with residents being treated as and engaging in activities as a group rather than individually, than supported living services. Otherwise, there were no statistically significant differences between the two models in terms of institutional practice. The range of scores on institutional practice within each service model is notable, with some services reporting very low levels of institutional practice (and some supported living services reporting virtually none) and others reporting fairly high levels. This suggests that there is considerable variation between services in terms of working culture and institutional practice.

Table 6 Routines and Institutionalisation

		Supported Living	Residential Care	Test and statistical significance
Rigidity of routines (higher scores indicate more rigid routines)	Mean (sd) Range	0.91 (0.94) 0 - 3	1.40 (0.97) 0 - 3	t= 1.356; df=29, p= 0.186
Block treatment (higher scores indicate greater block treatment)	Mean (sd) Range	0.75 (0.97) 0 - 3	2.11 (1.54) 1 - 5	**t= 2.493; df=19, p= 0.022**
Social distance from residents (higher scores indicate greater social distance between staff and residents)	Mean (sd) Range	2.73 (2.56) 1 - 10	1.70 (0.95) 1 - 4	t= -1.230; df=27, p= 0.229
Rules (higher scores indicate more rigid rules)	Mean (sd) Range	1.95 (1.28) 0 - 4	1.70 (1.25) 0 - 4	t= -0.509; df=28, p= 0.615

Supporting wellbeing (reverse scored so higher scores indicate poorer support for wellbeing)	Mean (sd) Range	3.94 (1.39) 2 - 7	4.56 (1.33) 3 - 7	t= 1.083; df=23, p= 0.290
Institutional Practice (total score from previous subscales)	Mean (sd) Range	8.67 (4.63) 0 - 17	10.80 (4.16) 6 - 17	t= 1.237; df=29, p= 0.226

Key Findings – Household Data

- Data about the housing set-up was available for 11 residential care properties and 23 supported living properties.
- Housing and support were provided by different organisations at most supported living properties and by the same organisation at most residential care properties, although there were some properties at which this was not the case.
- Residential care households were found to be significantly larger than supported living households in terms of number of residents, with on average 8 residents living in each residential care household compared to 3 people per supported living property.
- Residential care households were significantly more likely to be specialised for people with learning disabilities and a particular support need, such as epilepsy or autism.
- Residential care properties were more likely to have areas that were out of bounds to residents and to report the use of deadlocks to restrict residents' movement.
- In terms of working culture, staff from residential care households reported significantly higher levels of block treatment compared to staff from supported living properties. However, there were few differences in level of institutional practice more broadly across the two service models. A wide range of institutional practice was reported within both models, with some households scoring very low and other scoring very highly.

The People Taking Part in the Project

In total 107 participants in supported living or residential care were recruited into the project. Of these, 93 participants had the capacity to consent to taking part in the project and assent to take part was obtained for a further 14 people without the capacity to consent to take part in the project. Of these 107 people, 77 were living in supported living and 30 were living in residential care.

The 107 participants were recruited from 16 different provider organisations (range 1-19 people per provider organisation).

As well as information collected directly from participants and proxies for participants without the capacity to consent to participate, additional information was available from direct support staff for 64 participants (43 people in supported living; 21 people in residential care).

Where differences between supported living and residential care are described in the text from these datasets, they are all statistically significant differences at p<0.01 (p<0.01 has been set due to the number of comparisons conducted).

Table 7 shows that there were no statistically significant differences between people living in supported living versus residential care in terms of age, gender or ethnicity. People were on average approximately 40 years old, with a wide age range, a majority of people were male, and a large majority of people were white.

Table 7: Age, gender and ethnicity

		Supported Living	Residential Care	Test and statistical significance
Age (years)	Mean (sd) Range	42.8 (12.1) 23 - 70	41.5 (13-2) 19 - 72	t=-0.44; df=96, p=0.658
Gender	% men % women % other	56.0% 44.0% 0.0%	63.3% 33.3% 3.3%	[Men vs Women] Fisher's exact test p=0.506
Ethnicity	% White (all groups) % Asian/Asian British % Black/Black British % Mixed heritage	87.1% 1.4% 8.6% 2.9%	93.3% 0.0% 3.3% 3.3%	Chi-square=1.36; df=3; p=0.715

Table 8 shows that substantial minorities of people in supported living (23%) and residential care (31%) were reported to have had a diagnosis of autism from a professional – slightly higher percentages were obtained from the staff questionnaire. The staff questionnaire also reported that 13% of people in supported living and no-one in residential care had a disagnosis of Down syndrome, 5% of people in supported living and 30% of people in residential care had a diagnosis of Cerebral Palsy, and very few or no people had a diagnosis of Prader Willi Syndrome, Fragile-X Syndrome or Rett's Syndrome. A minority of people in supported living (25%) and residential care (15%) had another diagnosis. There were no statistically significant differences in any of these diagnoses between supported living and residential care.

Table 8: Diagnoses

		Supported Living	Residential Care	Test and statistical significance
Autism diagnosis	% Yes % No % Don't Know	23.0% 62.3% 14.8%	30.8% 65.4% 3.8%	Chi-square=2.36; df=2; p=0.308
Staff Q – autism diagnosis	% Yes % No	27.5% 72.5%	40.0% 60.0%	Fisher's exact p=0.384
Staff Q - Down Syndrome	% Yes % No	12.8% 87.2%	0.0% 100.0%	Fisher's exact p=0.156
Staff Q - Cerebral Palsy	% Yes % No	5.0% 95.0%	30.0% 70.0%	Fisher's exact p=0.030
Staff Q - Prader Willi Syndrome	% Yes % No	0.0% 100.0%	5.0% 95.0%	Fisher's exact p=0.333
Staff Q - Fragile-X Syndrome	% Yes % No	2.5% 97.5%	0.0% 100.0%	Fisher's exact p=1.000
Staff Q - Rett's Syndrome	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Staff Q – other diagnosis	% Yes % No	25.0% 75.0%	15.0% 85.0%	Fisher's exact p=0.513

Table 9 shows that substantial majorities of people in supported living (67%) and residential care (75%) reported having a longstanding illness and/or physical disability. Specific issues reported by 20% or more people in both supported living and residential care were epilepsy (21% supported living; 25% residential care) and issues with mobility (26% supported living; 32% residential care). Specific issues reported by at least 10% of people in both supported living and residential care were physical disability (12% supported living; 29% residential care) and a mental health difficulty (32% supported living; 18% residential care). For substantial numbers of people in supported living (50%) and residential care (32%) additional issues were identified – these issues were very diverse and often multiple, with no single issue emerging as particularly common. There were no statistically significant differences between supported living and residential care.

In addition to the information in Table 9, the staff questionnaire reported that, of those people in supported living, 80.5% did not experiences seizures, a further 14.6% did not experience seizures because they were controlled by medication, and 4.9% of people experienced seizures less than monthly. Of those people in residential care, 47.4% did not experience seizures, 21.1% did not experience seizures because they were controlled by medication, 15.8% experienced seizures less than monthly, and 15.8% experienced seizures at least monthly. The difference between supported living and residential was not statistically significant at the $p<0.01$ level (chi-square=10.68; df=3; p=0.014).

Table 9: Longstanding illness or disability

		Supported Living	Residential Care	Test and statistical significance
Reported longstanding illness or physical disability	% Yes % No	66.7% 33.3%	75.0% 25.0%	Fisher's exact test p=0.474
Specific longstanding illness or disability				
Physical disability	% Yes % No/NA	12.1% 87.9%	28.6% 71.4%	Fisher's exact test p=0.072
Difficulty seeing	% Yes % No/NA	4.5% 95.5%	14.3% 85.7%	Fisher's exact test p=0.191
Difficulty hearing	% Yes % No/NA	6.1% 93.9%	7.1% 92.9%	Fisher's exact test p=1.000
Difficulty speaking	% Yes % No/NA	7.6% 92.4%	17.9% 82.1%	Fisher's exact test p=0.157
Mental health difficulty	% Yes % No/NA	31.8% 68.2%	17.9% 82.1%	Fisher's exact test p=0.212
Epilepsy	% Yes % No/NA	21.2% 78.8%	25.0% 75.0%	Fisher's exact test p=0.788
Issue with mobility	% Yes % No/NA	25.8% 74.2%	32.1% 67.9%	Fisher's exact test p=0.616
Other	% Yes % No/NA	50.0% 50.0%	32.1% 67.9%	Fisher's exact test p=0.121

Total support needs for each person was calculated as the mean of 11 support needs questions where the question had been scored, with a minimum of 7 out of 11 items scored for the total to be calculated (*1=Can do it on their own; 2=Needs a bit of help; 3=Needs a lot of help; 4=Needs someone to do it for them*). Table 10 shows that people living in residential care had a statistically significantly higher level of support needs than people living in supported living, although the range of support needs is similar across supported living and residential care.

Table 10: Support Required

		Supported Living	Residential Care	Test and statistical significance
Self-reported support needs	Mean (sd) Range	1.82 (0.64) 1.00 – 4.00	2.60 (0.96) 1.27 – 4.00	**t=3.79; df=31.8; p<0.001**
Staff Q – support needs	Mean (sd) Range	1.89 (0.69) 1.09-4.00	2.67 (0.97) 1.00-4.00	**t=3.33; df=30.2; p=0.002**

The extent of behaviour that challenges in the past month for each person was calculated as the mean of 7 questions on the Problem Behaviour Checklist where the question had been scored, with a minimum of 5 out of 7 items scored for the total to be calculated (from *0=Behaviour absent* to *5=Extreme behaviour leading to threat of loss of life or permanent injury or damage*). Table 11 shows that people living in supported living and residential care were reported by staff to have similarly low levels of behaviours that challenge.

Table 11: Behaviours that challenge

		Supported Living	Residential Care	Test and statistical significance
Staff Q – behaviour that challenges	Mean (sd) Range	0.36 (0.53) 0.00-2.00	0.49 (0.51) 0.00-1.57	t=0.94; df=60; p=0.353

Table 12 shows that just over a third of people in supported living (37%) and 13% of people in residential care were in a relationship. A small minority of people in supported living (8%) and no-one in residential care had any children.

Table 12: Relationship status

		Supported Living	Residential Care	Test and statistical significance
Is the person in a relationship?	% Yes % No	37.0% 63.0%	13.3% 86.7%	Fisher's exact test p=0.019
Does the person have any children?	% Yes % No	8.3% 91.7%	0.0% 100%	Fisher's exact test p=0.185

Key Findings – the People Taking Part in the Project

- 107 people took part in the project. 93 people had capacity to consent to taking part in the project and assent to take part was obtained for a further 14 people without the capacity to consent to take part in the project.
- 77 people were living in supported living and 30 were living in residential care.
- The people who took part in the project were aged from 23 – 72 years old, with an average age of 40 years. Most people who took part were male, and a large majority of people were white.
- 23% of people in supported living and 31% of people in residential care were autistic. 13% of people in supported living and no-one in residential care had a diagnosis of Down syndrome, 5% of people in supported living and 30% of people in residential care had a diagnosis of Cerebral Palsy.
- 67% of people in supported living and 75% of people in residential care said that they had a physical disability and / or long-term health condition, such as epilepsy or difficulties with mobility.
- People living in residential care had significantly higher level of support needs than people living in supported living, as reported by staff and people themselves. There were no differences between the two service models in terms of behaviours that challenge.
- About a third of people in supported living and 13% of people in residential care were in a relationship. A small minority of people in supported living (8%) and no-one in residential care had any children.

Housing arrangements

Table 13 shows that according to CQC registration status, 77 people were living in supported living and 30 people were living in residential care. Of the 89 participants with capacity to take part in research answering the question, 87.6% said they were living in the same type of home as the CQC registration.

The vast majority of participants in supported living (84.5%) and over half of participants in residential care (58.3%) knew the organisation running the place they lived in. For those people in supported living the majority rented their home, typically from a council or housing association, although there were a range of arrangements.

According to staff questionnaires, a substantial majority of people in supported living (77%) and residential care (91%) were living in accommodation suitable to their needs.

Wendy's story

Wendy* lives in a supported living bungalow by herself, with 24-hour support from staff. Before this, she lived in a secure unit. She said "it's nice to live [here], its more homely." Wendy loves being able to have a cat. Most of her family live within 10 minutes of her, so she sees them often. She couldn't think of anything that she didn't like or would change about the house (Wendy*, Supported Living).

*(*all names have been changed)*

People with capacity in supported living had on average moved into their home over eight years before (99 months), with people having lived in their current home from 7 months to 29 years. People in residential care had on average moved into their current home just over 10 years before (125 months), with people having lived in their current home from 1 to 22 years. Data from staff questionnaires recorded different mean lengths of time in people's homes (126 months supported living; 90 months residential care) but the ranges were similar. There were no statistically significant differences in the length of time people in supported living and residential care had lived in their current home.

According to staff questionnaires, people in supported living had most commonly moved from their family home (32.6% of people), another supported living dwelling (11.6%) or residential care (9.3%). People in residential home had most commonly moved from their family home (30.0%), another residential care home (30.0%), or supported living (15.0%).

A minority of people in supported living (15%) but over half of people in residential care (52%) did not live close to friends or family, a statistically significant difference across the two service models. According to staff questionnaires, people in supported living lived on average 15 miles from their nearest relative, compared to 30 miles for people in residential care – due to the wide range of distances this was not a statistically significant difference.

According to staff questionnaires, substantial majorities of people in both supported living (84%) and residential care (75%) were living in their ‘home’ local authority area, although 9% of people in supported living and 25% of people in residential care were living out of area (for 7% of people in supported living, the staff member did not know if the person lived in their ‘home’ local authority area or not).

Table 13: Housing arrangements

		Supported Living	Residential Care	
Number of people (according to CQC registration)		77	30	
Does the person know which organisation runs this house	% Yes	84.5%	58.3%	Chi-square=8.73; df=2; p=0.013
	% No	3.6%	8.3%	
	% Don’t know	8.9%	33.3%	
[Supported living, people with capacity only] % Own or rent home	% Own (fully or with mortgage)	1.5%		
	% Shared ownership	1.5%		
	Rent	69.1%		
	Volunteer for provider who provides home rent-free in return	1.5% 4.4%		
	Don’t know	22.1%		
[Supported living, people with capacity only] If renting, who is it rented from (%)	Council or housing association	74.5%		
	Support provider	8.5%		
	Private house managed by housing support provider	2.1%		
	Don’t know	17.0%		
Staff Q – Accommodation suitable for person’s needs	% Yes	76.7%	90.5%	Chi-square=1.79; df=2; p=0.409
	% Somewhat	9.3%	4.8%	
	% No	14.0%	4.8%	
[People with capacity only] Time since person moved into current home (months)	Mean (sd)	98.7 (83.7)	125.1 (80.9)	t=1.21; df=79; p=0.228
	Range	7-348	12-264	
Staff Q – Time since person moved into current home (months)	Mean (sd)	126.1 (89.7)	90.1 (60.2)	t=-1.69; df=44.46; p=0.099
	Range	7-350	12-204	
Does the person live close to friends and family?	% Yes, near friends	27.3%	4.8%	**Chi-square= 13.65 df=3; p=0.003**
	% Yes, near family	27.3%	23.8%	
	% Yes, near both	30.3%	19.0%	
	% No	15.2%	52.4%	

		Supported Living	Residential Care	
Staff Q – how far away in miles is the person from their nearest relative?	Mean (sd)	14.5 (28.7)	29.8 (27.5)	t=-1.85; df=50; p=0.070
	Range	1-150	1-100	
Staff Q – Is the person ordinarily living in another local authority area?	% Yes	9.3%	25.0%	Chi-square=3.88; df=2; p=0.144
	% No	83.7%	75.0%	
	% Don't know	7.0%	0.0%	

Table 14 shows that for people with capacity in supported living, 25% of people were living alone, with the median number of people sharing a house being 3 people and the maximum number of people sharing being 7-10 people. People in residential care most commonly lived in accommodation shared with 7-10 people (48%), with the median being between 7-10 people. There was a statistically significant difference in the number of people participants were living with, with people in supported living sharing with fewer other people than people in residential care.

Among participants with capacity, 10% of people in supported living and 5% of people in residential care were living with their partner, with no statistically significant difference between people in the two types of accommodation.

For a minority of people in supported living (13.9%) and residential care (23.1%) there was at least one person they were unhappy living with; the statistically significant difference between people in the two types of accommodation was largely due to more people in supported living properties living alone and more 'don't know' responses for people in residential care.

Table 14: Number of people in house

		Supported Living	Residential Care	Test and statistical significance
[People with capacity only] Number of people in house (including participant)	% 1 person - live alone	25.0%	4.8%	**Recoded 1-3; 4-6; 7-10; 11+ Chi-square=38.16; df=3; p<0.001**
	% 2 people	19.4%	0.0%	
	% 3 people	22.2%	0.0%	
	% 4 people	19.4%	0.0%	
	% 5 people	5.6%	19.0%	
	% 6 people	4.2%	23.8%	
	% 7-10 people	4.2%	47.6%	
	% 11-20 people	0.0%	4.8%	
	% 21 people or more	0.0%	0.0%	
[People with capacity only] Living with partner	% Yes	9.5%	4.8%	Chi-square=0.3.23; df=2; p=0.199
	% No	36.5%	19.0%	
	% NA	54.0%	76.2%	
Is there anyone you are unhappy living with?	% Yes	13.9%	23.1%	**Chi-square=32.81; df=3; p<0.001**
	% No	55.6%	38.5%	
	% Don't know	0.0%	34.6%	
	% NA	30.6	3.8%	

As Table 15 shows, the vast majority of people in supported living (86%) and residential care (80%) liked living in their current home.

Adam’s story

Adam* moved into this residential home after his father died. He looked around a couple of places and chose this one because it had ‘more room to move around.’ He likes living here and growing vegetables in the garden. He enjoys planning parties together with his housemates. He said that he might like to move in the future, for example if his favourite staff members left, he would want to go with them. He might like to live in a flat with someone else (Adam*, Residential Care).

*(*all names have been changed)*

For most people in supported living (68%) and almost half of people in residential care (46%) their home was the right temperature; homes for most of the remainder of people were the right temperature sometimes (supported living 17%; residential care 32%).

Over half of people in supported living (60%) and half of people in residential care (50%) shared a bathroom. A majority of those sharing a bathroom liked this arrangement (88.5% supported living; 66.7% residential care), and almost everyone with their own bathroom liked this arrangement (95.2% supported living; 100% residential care).

Almost all people in residential care (91%) and over half of people in supported living (57%) shared a kitchen. Whether sharing or having their own kitchen, almost everyone liked their kitchen arrangement.

The vast majority of people in supported living (85%) and everyone in residential care (100%) had a private or shared garden as an outdoor space that they could use.

A majority of people in supported living (63%) and less than half of people in residential care (39%) had to go up steps either to get to their home or their bedroom within their home. People in residential care were statistically significantly more likely to live somewhere where changes had been made to their home because of their health or disability (56%) compared to people in supported living (23%).

Table 15: Aspects of people's homes

		Supported Living	Residential Care	Test and statistical significance
Does the person like living here?	%Yes % OK % No % Don't know	85.5% 7.9% 6.6% 0.0%	80.0% 13.3% 0.0% 6.7%	Chi-square=7.79; df=3; p=0.050
Is the person's home warm enough for them?	% Yes, right temperature % Sometimes % Too cold % Too warm % Don't know	67.6% 16.9% 5.6% 9.9% 0.0%	46.4% 32.1% 7.1% 7.1% 7.1%	Chi-square=8.97; df=4; p=0.062
Does the person share a bathroom with other people?	% Yes % No	59.6% 40.4%	45.8% 54.2%	Fisher's exact p=0.324
Does the person share a kitchen with other people?	% Yes % No	57.3% 32.7%	91.3% 8.7%	Fisher's exact p=0.042
Does the person's home have an outdoor space that they can use?	% Private garden % Shared garden % Balcony % No % Other	64.4% 20.3% 1.7% 8.5% 5.1%	85.2% 14.8% 0.0% 0.0% 0.0%	Chi-square=5.55; df=4; p=0.235
Does the person have to go up steps to get to their home or bedroom?	% Yes % No	62.7% 37.3%	39.3% 60.7%	Fisher's exact test p=0.045
If needed, have any changes been made to where the person lives because of their health or disability?	% Yes % No	22.8% 77.2%	56.0% 44.0%	**Fisher's exact test p=0.005**

Qualitative Findings: What people value about their home

Participants were asked what they particularly liked about their home, and if there was anything that they did not like or would like to change. As noted in the quantitative findings, the vast majority of people said that they liked where they lived. The following aspects were found to be particularly important to people.

Claiming space: making the home your own

Claiming space and actively making spaces within the home their own were important to participants, particularly those who lived with others. This was done in a variety of ways. For example, participants enjoyed being able to paint and decorate their bedroom to their own taste and purchase new furniture. Other people described taking pride in cleaning their home or knowing where things were and ensuring everything was tidied away into the correct places, as one person commented, ***"I like to my home to be, well, spotless."*** – (P1, RC)

The spaces which were claimed extended beyond individual bedrooms into other areas of the home and garden. For example, people valued having their own shed, taking on a role in maintaining and personalising the garden, making use of the garage, or as in the case of the following participant, having a particular spot within the kitchen:

> ***He has his own spots around the house, specifically in the kitchen.***
>
> (P21, proxy response, RC)

These spaces and the ways in which people invested in them and claimed them as their own, enabled people to feel in control over parts of their environment and facilitated a sense of belonging. These spaces also had a role in enabling people to pursue their hobbies or interests with the additional space ensuring there was room for particular activities to take place or equipment to be left out. Additionally, for some participants the claiming of the space was connected to safety. For example, one participant explained how their shed was a place of sanctuary where they could escape difficult housemates, and a proxy-participant respondent described how the control one participant had within their home, by making sure everything was put away properly and in the correct places, helped them to feel secure.

Bethany's story

Bethany* lives in a self-contained flat in a building of flats which together comprise a residential home, with everyone having 2:1 or 1:1 support. She enjoys having her own flat which she was recently able to decorate and re-furbish and she loves having a kitten. She says that staff listen to her which makes her happy unlike her previous home where she didn't think they did. Bethany sometimes struggles with the noise from other housemates and would like to move if she could take her staff team with her (Bethany*, Residential Care).

*(*all names have been changed)*

Day-to-day autonomy

Participants appreciated being in charge over their day-to-day lives, choosing what they did and when they did it. For some people this meant being able to go out when they wanted, either alone or with support, whilst for others this involved watching what they wanted on TV, being able to lounge on their sofa or cook their own food:

Having this control was often connected to freedom as participants, when asked what they liked about their home, stated their 'freedom' or feeling 'freer' as in the following example:

> ***My freedom…. getting out, I don't have to be back at a certain time. I can do what I want… can take charge of my life, got my own front key.*** (P3, SL)

However, when considering how much autonomy people do have over their day-to-day lives, it is important to note that participants often made comparisons to their previous living situations where higher levels of restrictions had been in place. This suggests a lower benchmark for autonomy may have been set. For example, one participant explained he valued his freedom:

> ***"Freedom….I can go out when I want and come in when I want and watch what I want to see without being told what not to watch and stuff and people coming and saying oh no it's my turn to watch it now….I can cook when I want and have it how I want',***

And then went on to describe previous experiences of having to share everything:

> ***"Like when I was in a children's home and foster care and hostel, like with 9 other men so we had to share everything. I had my own bedroom but that was about it."*** (P22, SL)

Whilst a participant who had moved from a long-term hospital into supported living stated, ***"it's much better, more freer, I mean I have been doing more things."*** (P23, SL) Similarly, the participant quoted previously who said they valued doing what they want and having their own front door key also commented, ***"I've got my independence back."*** (P3, SL) after moving from a shared house of 12 people to their own flat.

The autonomy people experienced was also relational, as other people were pulled into their accounts. For example, participants described being treated like an adult, having their decisions respected and staff supporting them to go out when they wanted to:

> ***They accommodate the things I want to do like work. If I need to go out, they allocate me somebody. Say I have been allocated a job they would allocate me a driver.*** (P24, RC)

Therefore, although people felt they had autonomy over day-to-day decisions, the reliance on staff to facilitate this created a sense of precarity, as whilst autonomy could be enabled it could also be denied; something people had often experienced in their previous living situations.

People make a home

Good relationships with other people within their home were important to people in supported living and residential homes alike. For some people the focus was on their housemates, living with friends, celebrating events together and enjoying each other's company, as one participant in supported living stated, ***"It's absolutely brilliant, we have a laugh here…We all get along."*** (P4, SL) and another explained he liked his home because of ***"the people I live with"*** (P25, RC). However, for others, particularly people with higher support needs and people living in residential homes, staff featured heavily. When describing what they liked about their home, participants described staff as being helpful, nice, respectful and supportive as in the following examples:

> ***All the staff where we live are good, they help you through things…I like talking to staff to sit and talk about how I feel.*** (P5, RC)

> ***They are very nice and look after me to the best of their ability and whenever I need anything like shopping fetching for a certain date and so forth, they are very prompt at that.*** (P26, RC)

The prominence of staff within participants' accounts demonstrates the central role staff play; they are not simply on the periphery of the home but a fundamental element of it and central to individual experiences as one person stated, ***"support staff are like a second family."*** (P27, SL)

Echoing the precarity of autonomy discussed previously, there is a sense of precarity attached to people making a home. Participants felt the need to state that staff are helpful, with one participant describing staff as ***"going above and beyond their duties'*** (P26, RC). This suggests that the helpfulness of staff is not something that can be taken for granted. Again, comparisons were made to previous poor experiences reiterating that the decency of staff cannot be assumed as in the following examples, ***"The staff treat you with more respect...I love it, it's a lot better place."*** - (P4, SL) and ***"People listen to me here"*** (P28, RC).

Location, location, location

Freddie’s story

Freddie* lives in a supported living bungalow with two housemates, with his own self-contained area. It is a de-registered residential service. Ideally staff would like to be able to make changes to the building to accommodate his sensory needs; however, trying to get the Housing Association to fix things is difficult and time-consuming. Despite this, staff believe that the current set-up works well for Freddie, as he has made lots of progress in the last few years and no longer takes behavioural medication. Staff attribute this to him being well-supported by a team that knows him well. The location is ideal for him because he is able to go for a walk on the beach every day. Freddie has lived in the area all his life and lots of people stop to say hello to him (Freddie*, Supported Living).

*(*all names have been changed)*

People in both supported living and residential homes valued the location of their home. However, there were similarities and differences between the two groups as to why the location was important. Firstly, people living in both types of accommodation reported appreciating living in quiet locations, ***“I enjoy it, its peaceful and quiet, except sometimes the cows! It’s a nice place to live”*** (P6, SL) with an association made between peace and safety. Secondly, people within both groups valued living close to family or close to the area in which they grew up. This contributed to a sense of belonging and enabled people to feel connected to their local area. For example, one participant discussed how he liked that he lived close to his family even though he was not in regular contact with them, as he bumped into them occasionally in town.

The location held additional importance for people in supported living, as a good location fostered a sense of community and provided easy access to local facilities. This included having good neighbours (something particularly important for participants who had experience of difficulties with their neighbours in their previous home). The shape this took varied between participants, for example one proxy-participant respondent reported the participant liked the neighbours returning their balls when they went over the fence and taking part in street parties, whilst another participant explained how the neighbour sometimes brought round meals for them and a third explained, ***“I enjoy…making sure everyone else is ok like neighbours and friends and stuff”*** (P29, SL).

Being able to access shops and local facilities contributed to participants’ independence and contributed to the freedom some people experienced, particularly when they did not require the support from staff to go out. The location also enabled people to take part in their local community for example by going to church or supporting the local football team as in the following examples:

> ***I think the shops, walking along the canal into town. ASDA obviously… I feel a bit more freedom here.*** (P7, SL)

> ***Good location. Can go on my bike to places and walk places. I go to the church, I go to different churches all the time.*** (P30, SL)

What people don't like about their home

Participants were also asked what they didn't like about their home or if there was anything they would like to be different. Some people said that they liked everything about where they lived. Others discussed aspects of their living situation that were working less well for them, which broadly fell into the following two themes.

People break a home

The centrality of other people to one's enjoyment of home and the underlying precarity of this was reiterated when participants discussed what elements of their home they didn't like or where things could be improved. This appeared to be particularly the case in residential care, reflecting the quantitative finding that people in residential care were more likely to report living with someone that they were unhappy living with. This may also be linked to the fact that people in residential care tended to live with a larger number of people, thereby potentially increasing the chance of not getting along with at least one housemate. Finally, people in residential care were less likely to be involved in choosing who they lived with, which could contribute to subsequent issues of conflict and / or housemates being incompatible.

Participants drew attention to the transient nature of staff and housemates and the negative impact this could have, as the following examples demonstrate:

> ***I don't like people leaving and I don't like change.*** (P8, RC)

> ***It's all gone downhill at the moment [since her friend moved out] every night I just think about what could have happened if she was there.*** (P9, RC)

Participants in both supported living and residential homes reported problems with housemates affecting their enjoyment of their home. This was often related to a perceived mismatch in support needs and the subsequent frustration this could cause as described by the participant below:

> ***Sometimes it gets a little bit hectic because there are ten people doing ten different things at the same time, so everybody wants something all at the same time.... It does get a bit frustrating sometimes...like other people I live with can't talk back to me. They can talk back to me but it takes a while for a conversation so it is like a one-way conversation almost or the ones that you can have a conversation with, they forget what you said so if you are complaining about something to another service user it's like 'shut up I am trying to watch tv' and then two hours later you are telling them to shut up again because I am trying to watch tv. But other than that, I like living here but sometimes I wish I could get away at the same time but at the minute you can't.*** (P24, RC)

Similarly, another participant when discussing what he didn't like about his home stated, ***"sometimes I get on with housemates. Sometimes I don't"*** (P31, RC) with the staff member who was supporting him within the interview explaining he sometimes gets frustrated as ***"[he] is very capable and the people he lives with aren't as capable."***

Alongside differences in support needs, participants drew attention to their housemates' behaviour impinging on their peace and, in some instances, threatening their sense of safety as in the following examples:

> ***Some people just break things.*** (P9, RC)

> ***My house is alright but there are some people I have disagreements with...the lad that I was on about tried to threaten me with a knife.*** (P32, SL)

> ***When it gets noisy with other residents she struggles because we also have a building next to us as well and she does hear lots of banging and stuff.*** (P28, RC – staff member)

However, relationships with housemates were not always static. There were good days and bad days, ***"sometimes it's a bit in between, depends on the day"*** **(P6, SL)** and although difficulties were experienced it was often not enough for the participants to want to change their living situation or move to a different home. For example, participant P32 in the quote above stated ***"my house is alright"*** and participant P24 stated, ***"other than that I like living here."***

Where difficulties were encountered, participants described coping strategies they had in place. For example, participant P24 explained how he would put on his headphones to block out the noise if he had to walk through a communal area. Both P24 and P28 explained how they would not go out on their house minibus if certain other housemates were going due to the noise and behaviour, whilst P31 described going to his shed to escape his housemates shouting at each other as mentioned in 'claiming space'.

Furthermore, there was a sense of acceptance about the situation. Participants were aware it was out of their control and that compromises over their living situation had to be made. This is best summed up by participant P24 who explained:

> ***They can't actually do anything about it as such...I am ok but sometimes I am like 'please do something about this' but then they can't so it is the way it is. Sometimes you have to put up with people you don't like sometimes.*** (P24, RC)

In relation to staff within their home, whilst the quantitative data shows people reported being happy with their support, when discussing this in more detail with participants, there were some aspects of their support which could be improved. However, similar to the situation with housemates above, these incidents were not viewed to be significant enough to affect their overall opinion of their current support.

Examples of dissatisfaction relating to staff and their support included: staff treating the participants' home as a workplace rather than a home, with the participant and their housemates having to stay in the living room when ***"staff have meetings in the kitchen,"*** (P10, RC); a lack of staff impacting on what can be done or when people can go out; and issues with individual staff members rather than the team as a whole, as in the following example:

> ***I just didn't like the way how she was being with me, she was snapping at me and speaking with me out of order and at the end of the day I just don't think that is right as I don't live here to be upset, I live here to be happy.*** (P26, RC)

When prompted by the member of staff supporting them in their interview, one person, who was reluctant to discuss anything they didn't like about their home stated, ***"I asked him nicely, but he said do it yourself he said...he didn't help me. I don't want him anymore"*** (P33, RC).

When it came to a lack of staff impacting on what participants could do, participants again appeared accepting of the situation:

> ***Sometimes it can pop up that there are not enough staff to go out, so I just go back to doing my embroidery, and word searches and watching the quizzes and sport on tele.*** (P32, SL)

Space and place

An additional theme related to physical aspects of the home that people were unhappy with: maintenance of the property, space within their home and, for some people, the location of their home. Whilst issues around accessibility were reported by some people in residential homes (for example, one person commented they were unable to access the laundry room and the kitchen worksurfaces due to the size of their wheelchair and had been waiting a long time for the necessary adaptations to be made), the majority of people reporting on the physical aspects of their home lived in supported living and lived alone or with lower numbers of housemates.

Participants reported being unhappy with the size of their home and desired larger living areas:

> ***The only problem we have with these kinds of flats, with some flats is that they are very small. When it comes to the kitchen you can only fit one person in.*** (P34, SL)

This was an issue which was exacerbated for one participant when staff were also in the home as ***"it can get quite crowded."*** *(*P7, SL)

Issues with accessibility were also reported as desired adaptations (e.g., a built-in seat in the shower, or a wet room) were not in place. Some participants said they struggled not being on the ground floor and, a proxy-participant respondent commented that the house, which was a converted residential home, did not meet the person's sensory needs. The staff member felt it would be easier to resolve these issues if the support provider retained control of the housing as in a registered home.

> ***He needs a specialist environment and trying to get that with the set-up can prove difficult. I think in a registered service it would just be done and it would be perfect for him… there are massive triggers for him everywhere in that house…. The lights are a constant source of triggering his behaviours… So I've been battling with the [housing] providers just to change the lighting to some sort of halogen, low-level inset and it's taken all of that time in order to do that.*** (P13, proxy response, SL)

Additionally, participants reported maintenance issues as repairs were not addressed:

> ***Sometimes I have problems with my hot water and central heating and you have to ring them up and say you are vulnerable and I am vulnerable and I need the heating.*** (P35, SL)

Issues relating to maintenance, alongside the tenancy agreement preventing pets in the house, were often attributed directly to problematic landlords as expressed by the following participant:

> ***Landlord is horrible, he is arrogant, he doesn't come and do any alterations to the house, he puts the rent up.*** (P23, SL)

Lastly, mirroring the importance of location discussed previously, some participants within supported living raised concerns about the location of their home, explaining that they did not always feel safe due to difficult neighbours and/or vandalism and crime as the following two examples demonstrate:

> ***People throw glass. It is a violent place at times and the police come out. The front door was broken, and it took a while to fix, and things keep going wrong. I just want to move to a bungalow with a shed for my bike – I have to bring it upstairs at the moment. We are on a list to move to a bungalow as it is not a good area to live.*** (P30, SL)

> ***I don’t like it because of the area. We have a neighbour the other side, because I have personality disorder, she likes to take the biscuit and take the piss out of people, and I just want out...I don’t like the area as my partner has been mugged so many times. 6 times by the same person.*** (P36, SL)

It is important to note that where issues with the location in relation to neighbours and crime were reported, the participants tended to have less support and therefore did not have a continuous or frequent staff presence within their home. For example, P36 above lived in a block of flats for people with care or support needs and only had a couple of hours support a week, whilst P30, together with his housemate, shared a couple of hours support most days.

Getting help with problems in people’s homes

As Table 16 shows, if there was a problem with the house, such as a leaky roof, a majority of people in supported living (59%) and residential care (68%) would tell their personal assistant or support worker. A minority of people in supported living (compared to no-one in residential care) would contact the housing department (32%) or call the landlord (17%). More people in residential care (37%) than in supported living (5%) wouldn’t ask for help, a statistically significant difference.

Table 16: Sources of help if there is a problem with the person’s house

		Supported Living	Residential Care	Test and statistical significance
Paid help/PA/ Support staff	Yes	58.5%	68.4%	Fisher’s exact
	No/NA	41.5%	31.6%	p=0.573
Friends/family	Yes	5.0%	0.0%	Fisher’s exact
	No/NA	95.0%	100.0%	p=1.000
Social services	Yes	0.0%	0.0%	Not calculated
	No/NA	100.0%	100.0%	
Advocate	Yes	0.0%	0.0%	Not calculated
	No/NA	100.0%	100.0%	
Housing dept/ Local housing authority	Yes	31.7%	0.0%	**Fisher’s exact**
	No/NA	68.3%	100.0%	**p=0.005**
Citizen’s Advice Bureau/ Local advice agency	Yes	0.0%	0.0%	Not calculated
	No/NA	100.0%	100.0%	
Call the landlord	Yes	17.1%	0.0%	Fisher’s exact
	No/NA	82.9%	100.0%	p=0.086
Call the relevant tradesperson	Yes	4.9%	5.6%	Fisher’s exact
	No/NA	95.1%	94.4%	p=1.000

		Supported Living	Residential Care	Test and statistical significance
Wouldn't ask for help/ do anything	Yes No/NA	4.9% 95.1%	36.8% 63.2%	**Fisher's exact p=0.003**
Other	Yes No/NA	9.8% 90.2%	5.3% 94.7%	Fisher's exact p=1.000

Most people living in either supported living (79%) or residential care (59%) would ask for help with house paperwork from support staff/PAs, with a minority of people in supported living (13%) asking for help from friends/family (see Table 17).

Table 17: Sources of help if there is a problem with house paperwork

		Supported Living	Residential Care	Test and statistical significance
Paid help/PA/ Support staff	Yes No/NA	78.9% 21.1%	58.8% 41.2%	Fisher's exact p=0.189
Friends/family	Yes No/NA	13.2% 86.8%	0.0% 100.0%	Fisher's exact p=0.309
Housemates	Yes No/NA	0.0% 100.0%	0.0% 100.0%	Not calculated
Social services	Yes No/NA	2.6% 97.4%	0.0% 100.0%	Fisher's exact p=1.000
Housing dept/ Local housing authority	Yes No/NA	2.6% 97.4%	0.0% 100.0%	Fisher's exact p=1.000
Citizen's Advice Bureau/ Local advice agency	Yes No/NA	0.0% 100.0%	0.0% 100.0%	Not calculated
Call the landlord	Yes No/NA	0.0% 100.0%	0.0% 100.0%	Not calculated
Wouldn't ask for help/ do anything	Yes No/NA	7.9% 92.1%	5.9% 94.1%	Fisher's exact p=1.000
Other	Yes No/NA	2.6% 97.4%	0.0% 100.0%	Fisher's exact p=1.000

As Table 18 shows, for those sharing their home with other people with learning disabilities, people in supported living (43.2%) and residential care (60.0%) would most commonly talk to a support worker/personal assistant if there was a problem with a housemate. Smaller minorities would talk to the person with whom there was a problem (8% supported living; 20% residential care) or friends/family (5% supported living; 11% residential care). Over a third of people in residential care (35%) would not ask for help, compared to no-one in supported living, a statistically significant difference.

Table 18: Who would the person talk to if there is a problem with a housemate (for those sharing a home with another person with learning disabilities)?

		Supported Living	Residential Care	Test and statistical significance
The person there is a problem with	Yes No	8.1% 91.9%	20.0% 80.0%	Fisher's exact p=0.226
Paid help/PA/ Support staff	Yes No	43.2% 56.8%	60.0% 40.0%	Fisher's exact p=0.274
Friends/family	Yes No	5.4% 94.6%	10.5% 89.5%	Fisher's exact p=0.598
Social services	Yes No	0.0% 100.0%	0.0% 100.0%	Not calculated
Advocate	Yes No	0.0% 100.0%	0.0% 100.0%	Not calculated
Housing dept/ Local housing authority	Yes No	0.0% 100.0%	0.0% 100.0%	Not calculated
Citizen's Advice Bureau/ Local advice agency	Yes No	0.0% 100.0%	0.0% 100.0%	Not calculated
Call the landlord	Yes No	0.0% 100.0%	0.0% 100.0%	Not calculated
Wouldn't ask for help/ do anything	Yes No	0.0% 100.0%	35.0% 65.0%	**Fisher's exact** **p<0.001**
Other	Yes No	5.4% 94.6%	25.0% 75.0%	Fisher's exact p=0.045

Key Findings – Housing Arrangements

- Most people in supported living (86%) and residential care (80%) liked living in their current home.
- According to staff responses, most people in supported living (77%) and residential care (91%) were living in accommodation suited to their needs.
- People in residential care were more likely to say that they did not live near to friends or family.
- People in supported living tended to live with fewer people than those in residential care, with a quarter of people in supported living, who had capacity, living alone. The majority of people in residential care lived with 7 or more other people. 10% of people in supported living and 5% of people in residential care lived with their partner.
- People in residential care were more likely to say that they lived with someone they were unhappy living with; however, this is likely due to the fact that more people in supported living lived alone.
- When asked what they liked about where they lived, people particularly valued the ability to make the space their own, for example being able to decorate and having space outside of their bedroom that was 'theirs'. They also valued being in charge of their day-to-day life and being able to choose what they did and when they did it, which gave people a sense of freedom.
- The location of the home was important, particularly to people in supported living. People valued living close to people they know and having easy access to local facilities. This helped to give people a sense of community and independence.
- The people they lived with played a big role in whether someone liked their home or not. For many people, the company of their housemates and staff was one of their favourite things about where they lived. However, it could be difficult when housemates or staff moved on. When people had problems with their housemates or staff, this had a big effect on how they felt about their home.
- Some people were unhappy with some physical aspects of their home, such as the size or location of the property. Sometimes adaptations that people needed had not been made, and some people in supported living had to wait a long time for their landlord to make repairs.

As Table 19 shows, most participants in supported living (66%) and less than half of people in residential care (48%) chose the place they were currently living in. However, fewer people in supported living (37%) and residential care (40%) had looked at anywhere else before moving to their current home.

There were statistically significant differences between supported living and residential care in the extent to which people chose who they lived with. Most people in supported living had chosen who they lived with (46%) or were involved in the process (14%), whereas no-one in residential care had chosen who they lived with (0%) and very few were involved in the process (6%).

30% of people in supported living and 74% of people in residential care reported that someone new had moved in since they started living there, a statistically significant difference. Relatively few people in supported living (14%) or residential care (15%) were involved at least a little in choosing who moved in.

Table 19: Choosing a place to live

		Supported Living	Residential Care	Test and statistical significance
Did the person choose the place where they live?	% Yes	66.2%	47.6%	Chi-square=3.46; df=2; p=0.177
	% No	23.9%	28.6%	
	% Don't know	9.9%	23.8%	
Did the person look at anywhere else before moving here?	% Yes	37.3%	40.0%	Chi-square=0.30; df=2; p=0.858
	% No	43.1%	46.7%	
	% Don't know	19.6%	13.3%	
Did the person choose who they live with?	% Yes	46.0%	0.0%	**Chi-square=20.00; df=4; p<0.001**
	% Was involved in process where possible	14.0%	6.3%	
	% No	26.0%	87.5%	
	% Don't know	4.0%	0.0%	
	% NA	10.0%	6.3%	
Has anyone new moved in since the person started living there?	% Yes	30.4%	73.7%	**Fisher's exact p=0.001**
	% No	69.6%	26.3%	
Did you have any choice about who moved in?	% Yes, fully involved	2.8%	0.0%	**Chi-square=22.00 df=4; p<0.001**
	% A bit, involved a little	11.3%	15.0%	
	% No, no choice	9.9%	55.0%	
	% Don't know	7.0%	5.0%	
	% NA	69.0%	25.0%	

Qualitative Findings: The experience of moving

Participants were asked about the process of moving into their current home, and how they found this experience.

Alex's story

Alex* lives in a flat as part of sheltered housing for older people. She says she didn't really have a choice of where to live, as the local authority said she would be put to the bottom of the list if she didn't accept it. After living in residential care and with her parents for many years, Alex is happy to finally have her own place. However, she wishes she lived with people her own age. Her parents helped her to decorate the flat when she moved in, because it wasn't in a great condition. It can be expensive because her benefits don't cover everything, so she often has to borrow money from her parents (Alex*, Supported Living).

*(*all names have been changed)*

A proactive or reactive move?

This theme captures the explanations people gave for moving into their current home with reasons falling into one of two categories: reactive moves and proactive moves.

Reactive moves were the most common type of move and occurred for people living in both supported living and residential homes. These moves took place in response to an issue with the previous living situation, such as moving in an emergency due to the death of a family member the person was living with, or a sudden decline in mobility within the participant's existing home and support no longer being able to meet their needs. However, not all reactive moves were as a result of an emergency; people in both supported living and residential homes also described moving in response to unhappy or difficult situations such as not getting on with, or being bullied by, their housemates or being unhappy with how they were treated by their support staff:

> ***I used to live in another bungalow for three years. I didn't like it as much. [The support provider] changed and it went downhill… there were staff I didn't get on with there … the other clients put me off there… I wanted to get out of there!***
> (P4, SL)

> ***Every time I needed to go shopping in the other house, they wouldn't take me so I would have to tell my mum I needed shampoo, or I would ask them for a haircut, and they would go, 'no can't have a haircut you have to ask your mum first' that's why I moved in here.*** (P24, RC)

Other reactive reasons given by people who were currently in supported living or had previously been in supported living but were now in a residential home, included moving due to poor living conditions in their privately rented home, ***'we were living down an old area with sewage damp…and I had to move because the ceiling almost came through'*** (P36, SL) or experiencing crime and issues with neighbours. For example, one person moved in response to mate crime in her previous home:

> ***I was getting bullied 24/7. I had my friends coming over and stuff like that and they was asking for a lot of money and food…they were taking the mickey out of me and they were taking all my food out my flat and money as well.*** (P29, SL)

Similarly, another person moved out of his supported living home and was now in a residential home as his home had been taken over by a group of people who were demanding money and using his home to deal drugs.

For some people there were multiple reactive reasons which prompted the move. For example, one participant described being the victim of harassment in their local area, which then had an impact on their mental health resulting in their flat no longer being safe for them:

> ***I had issues with the area due to harassment and abusive comments…we got threatened once, me and my partner, so due to my mental health it wasn't an ideal place.*** (P34, SL)

Proactive moves were less common than reactive moves. These were moves associated with personal progression or development or as the result of pre-empting future issues (i.e., forward planning for the future when health would decline due to age). Examples include developing independence by moving out of the family home following the end of education as one person explained, ***"Before I moved in I used to live at my mum's house…my mum wanted me to be independent"*** (P11, SL) or by moving from a large residential home into a smaller self-contained bungalow on the same site as a stepping stone to living by oneself in the future. There were also examples of moving from a larger residential home into a smaller supported living home with one person commenting, ***"I think it was to try and become more independent"*** (P27, SL) and from shared accommodation to living by oneself and enjoying the benefits this brings, ***"I had been sharing and I wanted to get my own place and you can watch what you want on TV."*** (P35, SL). These examples suggest participants associated living with fewer people, or by oneself, with increased levels of independence.

A bumpy road until settled

Whether the move was for proactive or reactive reasons, planned or in response to an emergency, many people experienced difficulties associated with the move and took a while to feel settled in their new home.

Some people, particularly those who had moved due to an emergency, had to move twice as they moved initially into respite or an interim home before moving into their current home. One person, who moved out of the family home due to a desire for more independence, described a process of 'trial and error' as he moved into a supported living home and quickly realised it wasn't for him before moving into a larger residential home which he preferred.

Participants found moving to be a daunting process and described feeling apprehensive and nervous when they first moved. They reported it took some time to feel settled in their new home, to get used to the staff and other housemates, and to adapt to their new living arrangements, ***"I found it difficult at first. I wouldn't talk much"*** (P12, RC). For some participants this included adapting to differing sensory environments:

> ***After a few weeks I got used to it. It helped because everybody hadn't moved in at that time, so I was able to get used to a few people and then a few more and then it got noisier, and I slowly got used to the level of noise.*** (P24, RC)

Participants experienced a period of adjustment regardless of the reasons behind the move and whether or not they had an existing relationship with their housemates. For example, one person, who was moving from a residential home to a supported living home with two fellow residents, described a range of emotions connected to the move:

> ***All different emotions, excited, nervous, worried.... if it didn't go quite right and that if I wasn't suited to the place?*** (P27, SL)

As noted in the quantitative data, participants in residential care were less likely to have chosen who they live with or have any choice in new housemates who moved in. This may have contributed to feelings of trepidation regarding the move.

Feelings of unease were particularly present when the move was in a response to an emergency and there was a lack of transition visits as one proxy-participant respondent explained:

> ***At the beginning he struggled with the move due to it being so sudden, he protested with not eating food or only eating certain foods, his behaviour was very challenging.*** (P21,proxy response RC)

Furthermore, moving did not occur in a vacuum and some participants faced challenges in other areas of their life which had the potential to make the move harder. These included dealing with the grief of losing a relative, experiencing mental health difficulties, or lacking in self-esteem and confidence. Participants also described parents having concerns about the move, which had the potential to affect their own feelings about the move. Concerns included whether or not the person was ready for the move or if they would be too isolated when moving from shared accommodation to living by themselves.

People in supported living experienced some additional 'bumps in the road'. Some people faced delays due to issues with funding, having to navigate the council housing bidding system and a lack of suitable homes or properties falling through as in the following example:

> ***We had a look round there, but our social worker at the time had a message from them saying they couldn't give us a place there, but they never told us why or anything.*** (P14, SL)

As noted in the quantitative findings, few people had looked around other properties before moving into their current home. This perhaps reflects the lack of options available to them.

Once a property was found, there could still be challenges relating to the condition and the expense of furnishing the property, with one person saying that their home was dirty and smelly when they first moved in.

Smoothing the bumps

Despite experiencing disruption and difficulties when moving, participants drew on examples of good practice which worked well and helped ease the process of moving.

Grace’s story

Grace* lives in a supported living bungalow with 2 other people. She moved here six months ago. In her previous house she had some problems with staff and housemates – “I wanted to get out of there!”. Grace was ‘chuffed’ when she found out that she could move. She had several video calls with her new housemates and staff to meet them before she moved in. She said that the support is much better here – “they respect you” and it’s only a short distance few minutes from her parents’ house. “I have settled down quite well, I love it here.” (Grace*, Supported Living)

*(*all names have been changed)*

Timing was important, for the move to take place at the participant’s pace. This included taking time to get used to the idea of moving, as well as having time to plan the move and ensure transition visits took place. For example, the person who moved from a large residential home into their own bungalow on the same site valued getting used to the idea of moving over several years and being able to make the move when she felt ready rather than when staff first suggested it. Another participant appreciated having time to make numerous transition visits and for these to go at his pace rather than the support providers:

> ***When they moved me in here, they did it slowly, so first of all I had a couple of day visits and then, this is what I requested because I don't do change very well so if something changes and I am not used to something I like to take my sweet time and do it in my own time. So, I asked for a few weeks where I just go for the day and then it turned into a night and then it tuned into two nights and then it turned into three and then I said 'right, now I am used to the staff and everything, now I can move in.*** (P24, SL)

The importance of time is reiterated by a proxy-participant respondent, who explained time was required to build relationships to help the person settle in ***“After work and relationship building he settled into his current house very well.”*** (P21, proxy response, RC)

Friends, family and staff were all important sources of support during the move for both practical and emotional reasons. For example, participants explained they appreciated being able to discuss their options and share the decision-making process with trusted staff and family:

There were different options. I looked at different places and we talked about my mum moving out and I staying with more support. (P25, RC)

So, I spoke to our manager and had a really long conversation with her and decided yes, I would go for it. (P37, RC)

Participants discussed examples of practical support with moving. The presence of familiar people helped them to settle in, for example friends and family visiting them in their home shortly after the move, or someone from their existing support team who they had a good relationship with continuing to work with them in their new home:

We had a tour of our house and chose our bedrooms. But then we did travel training from [old house] lots of times to here, on public transport and walking to here…We had a few staff members from [the old house] come here to help us. (P18, SL)

Whilst participants appreciated knowing their housemates, either through transition visits or existing friendships, this was not enough to allay all worries. However, moving to a home in a familiar location helped ease the process for people in both supported living and residential homes, as participants felt part of the community and valued knowing they had friends and family close by. For example, one participant commented she felt confident she would be OK due to her friends living nearby:

My family were a bit worried about it because they thought I would get very lonely. But at the time I had my partner living up the road and I got very good friend that lives down the road. (P18, SL)

Similarly, another participant was pleased with the proximity to his home town, ***"it's only a couple of miles from my home town so I was looking forward to it"*** (P27, SL) whilst the participant who moved from the main residential home into an on-site bungalow, explained she was worried when a move was first suggested as it might mean moving away from her friends but she felt confident moving into the bungalow as she knew she was able to maintain her social networks.

It is questionable how much true choice participants had over their move, as noted in the quantitative findings few people had looked around anywhere else before moving into their current property. This was further reflected in the qualitative responses, with phrases such as ***“they thought it would be best I moved”*** (P26, RC), ***“I just got put here”*** (P28, RC), and ***“I just got told I was going to live with them”*** (P32, SL) being common. However this did not necessarily corelate with feeling out of control or unhappy with the move, with many people saying that they felt they were able to choose where they lived in both the quantitative and qualitative responses. Participants appreciated small elements of choice and control, for example over the spacing of transition visits described above. Furthermore, confidence was gained from a trust in staff and belief they were acting in their best interests and participants often felt that they did have a choice and were in control of the situation as, ultimately, their wishes to move were respected by the move taking place. It is worth noting that many people were reflecting on moves that had taken place many years previously, so their feelings at the time may have been different.

Jane’s story

Jane* lives in a one-bedroom bungalow in the grounds of a residential home. She has moved here one year ago, to increase her independence, and before this she lived in the main residential home for ten years. Jane likes that she is able to be independent whilst still accessing the support and social activities of the main house when she wants. She is close to her family and moved back in with parents for first three months of lockdown but moved back as she missed her friends. Jane described herself as very active and busy, seeing friends and going to work (Jane*, Residential Care).

*(*all names have been changed)*

Day-to-day Choices

Feeling in control and being able to make decisions about their day-to-day life was an important contributor to people's satisfaction with their home, as noted in the qualitative findings about what people valued about where they live.

Table 20 shows that, in terms of day-to-day choices, a large majority of people in supported living (96%) and residential care (88%) chose when they go to bed. For over half of people in both supported living (58%) and residential care (57%) there were rules about what they could do where they lived; most people were happy with these rules (67% supported living; 59% residential care) although only a minority of people were at least involved a little in making these rules (30% supported living; 24% residential care).

A majority of people in supported living could go anywhere in their own home (with the possible exception of other people's bedrooms where relevant) (61%) compared to a minority of people in residential care (28%), a statistically significant difference. When family visit, most people in both supported housing (68%) and residential care (71%) said (or were reported by a proxy member of staff) that they could be alone with visiting family anywhere in their home. When friends or a partner visit fewer people said (or were reported by a proxy member of staff) that they could be alone with visiting friends or their partner anywhere in their home (58% supported living; 55% residential care). A substantial majority of people in both supported living (79%) and residential care (81%) could be alone as much as they wanted; 15% of people in supported living and 4% of people in residential care were alone too much and would like more company.

Around half of people in both supported living (51%) and residential care (57%) had a key to their bedroom. A big majority of people in supported housing had a key to their front door (88%) compared to a minority of people in residential care (25%), a statistically significant difference. People in supported living were also statistically more likely to know who else had keys to their front door (88% supported living vs 39% residential care).

A majority of people in supported living could get support from staff at home when they wanted it (79%) compared to a minority of people in residential care (31%), a statistically significant difference.

Around one in five people in both supported living (21%) and residential care (20%) had a pet. Of those who did not have a pet, 43% of people in supported living and 23% of people in residential care would like a pet.

In terms of privacy, for almost all people in both supported living (94%) and residential care (82%) no-one came into their home without asking. For almost all people in supported living no-one came into their bedroom without asking (91%) compared to just over half of people in residential care (54%), a statistically significant difference. Almost no-one in supported living had their post opened by someone else without asking (2.6%) compared to almost half of people in residential care (44%), a statistically significant difference. Almost no-one in supported living (5%) or residential care (0%) had someone else looking at their private emails or messages without asking, although it should be noted that this question was judged to be not applicable for 45% of people in supported living and 70% of people in residential care.

Table 20: Choice and privacy in people's homes

		Supported Living	Residential Care	Test and statistical significance
Can the person choose when you go to bed or does someone tell them?	% Can choose % Someone tells them	95.7% 4.3%	88.0% 12.0%	Fisher's exact p=0.336
Does the person have a pet?	% Yes % No	20.8% 79.2%	20.0% 80.0%	Fisher's exact p=1.000
Of those without a pet, would the person like a pet?	% Yes % No % Don't know	43.1% 49.0% 7.8%	23.1% 53.8% 23.1%	Chi-square=3.31; df=2; p=0.191
Are there any rules about what the person can do where they live?	% Yes % No % Don't know	58.1% 31.1% 10.8%	57.1% 25.0% 17.9%	Chi-square=1.05; df=2; p=0.592
Of those with house rules, are they happy with these rules?	% Yes % No % Don't know	66.7% 13.9% 19.4%	58.8% 0.0% 41.2%	Chi-square=4.54; df=2; p=0.103
Of those with house rules, did you help to make these rules?	% Yes, heavily involved % A bit, involved a little % No, not involved at all % Don't know	13.6% 15.9% 47.7% 22.7%	11.8% 11.8% 23.5% 52.9%	Chi-square=5.52; df=3; p=0.137
Can the person get support from staff at home when they want to?	% Yes % Sometimes % No	79.4% 14.7% 5.9%	31.0% 48.3% 20.7%	**Chi-square=20.91; df=2; p<0.001**
Is there anywhere in the house the person is not allowed to go, except for other people's bedrooms?	% Yes % No % Don't know	37.5% 61.1% 1.4%	69.0% 27.6% 3.4%	**Chi-square=9.35; df=2; p=0.009**
Does the person have a key for their bedroom?	% Yes % No % Don't know	50.8% 47.5% 1.7%	57.1% 42.9% 0.0%	Chi-square=0.70; df=2; p=0.703
Does the person have a key for their front door?	% Yes % No % Don't know	88.2% 11.8% 0.0%	25.0% 71.4% 3.6%	**Chi-square=40.24; df=2; p<0.001**
Does the person know who (else) has keys to their front door?	% Yes % No % Don't know	87.5% 11.1% 1.4%	39.3% 25.0% 35.7%	**Chi-square=30.52; df=2; p<0.001**
Does anyone come into the person's home without asking	% Yes % No % Don't know	3.1% 93.8% 3.1%	18.2% 81.8% 0.0%	Chi-square=6.34; df=2; p-0.041

		Supported Living	Residential Care	Test and statistical significance
or when they don't want them to?				
Does anyone come into the person's bedroom without asking or when they don't want them to?	% Yes	9.1%	45.8%	**Fisher's exact p<0.001**
	% No	90.9%	54.2%	
When the person's family come to visit, can they be alone with them or does a member of staff have to be with them?	% Can be alone anywhere	68.3%	70.6%	Chi-square=4.16; df=3; p=0.245
	% Can be alone in specific rooms	0.0%	0.0%	
	% Member of staff required for support	4.9%	17.6%	
	% Member of staff supervises but not required for support	0.0%	0.0%	
	% Don't know	9.8%	0.0%	
	% N/A	17.1%	11.8%	
When your friends and/or partner come to visit, can you be alone with them or does a member of staff have to be with you?	% Can be alone anywhere	57.9%	55.0%	Chi-square=6.73; df=5; p=0.242
	% Can be alone in specific rooms	2.6%	10.0%	
	% Member of staff required for support	5.3%	20.0%	
	% Member of staff supervises but not required for support	7.9%	0.0%	
	% Don't know	2.6%	0.0%	
	% N/A	23.7%	15.0%	
Does anyone ever open the person's post without asking?	% Yes	2.6%	44.4%	**Chi-square=16.67; df=3; p<0.001**
	% No	92.3%	55.6%	
	% Don't know	2.6%	0.0%	
	% N/A	2.6%	0.0%	
Does anyone ever look at the person's private emails or messages without asking?	% Yes	5.0%	0.0%	Chi-square=3.79; df=2; p=0.150
	% No	50.0%	30.0%	
	% Don't know	0.0%	0.0%	
	% N/A	45.0%	70.0%	
Can you be by yourself as much as you want to?	% Can be alone as much as I want	78.5%	80.8%	Chi-square=6.31; df=3; p=0.098
	% Would like to be alone more	4.6%	3.8%	
	% Alone too much – would like more company	15.4%	3.8%	
	% Other	1.5%	11.5%	

Table 21 below shows a statistically significant difference between people in supported living and people in residential care in the use of Deprivation of Liberty Safeguards (DoLS), according to staff. People in supported living were more likely to have never lived under a DoLS than people in residential care (67% supported living; 32% residential care), while people in residential care were more likely to be currently living under a DoLS than people in supported living (13% supported living; 53% residential care). In both supported living (3%) and residential care (6%), very small numbers of people had been the subject of a DoLS application that had not been granted.

Table 21: Deprivation of Liberty Safeguards (DoLS)

		Supported Living	Residential Care	Test and statistical significance
Staff Q: Has the person ever been under DolS in current home?	% Never % DoLS in past but not now % DoLS now % DoLS applied for	67.7% 9.7% 12.9% 9.7%	31.6% 0.0% 52.6% 15.8%	**Chi-square=11.70; df=3; p=0.008**
Staff Q: Has DoLS application been made but not granted?	% Yes % No	3.4% 96.6%	5.6% 94.4%	Fisher's exact p=1.000

The Real Tenancy Test

The Real Tenancy Test (NDTi, 2015) asks 11 questions of supported living arrangements to determine whether people in supported living can fully exercise their housing rights. Although it is designed for supported living arrangements, these questions were also asked of staff in residential care to explore the extent to which there are the differences in people's experience of meaningful housing rights that would be expected from how the two service models should operate.

Table 22 below shows that, in aggregate, people in supported living experienced a statistically significantly greater number of housing rights (9 out of 11) than people in residential care (7 out of 11), although people in both types of service experienced a very wide range of housing rights. Just over a quarter of people in supported housing (27.9%) were reported by staff to experience all 11 Real Tenancy Test housing rights, compared to 4.8% of people in residential care.

In terms of specific housing rights, statistically significant differences between supported living and residential care were largely a feature of the different service models: people being placed in the home because the provider or commissioner needed to fill a vacancy (no-one in supported living vs 26% of people in residential care); areas of the person's home that they cannot access (10% vs 60%); provider equipment (e.g. phone lines, office equipment, files) in the person's home (49% vs 100%); and the landlord/service provider having free access and keys to the person's home (33% vs 90%).

Table 22: The Real Tenancy Test

Staff Q – Real Tenancy Test		Supported Living	Residential Care	
Has the person been moved from their home because of a decision by the support provider or commissioner?	% Yes % No	9.8% 90.2%	10.0% 90.0%	Fisher's exact p=1.000
Has anybody been placed in the home without consultation with existing tenants because the support provider or commissioner needed to fill a vacancy?	% Yes % No	0.0% 100.0%	26.3% 73.7%	**Fisher's exact p=0.003**
Did the person have no other choices when moving into their home?	% Yes % No	24.3% 75.7%	12.5% 87.5%	Fisher's exact p=0.471
Does the person want to move but is not getting support to do so?	% Yes % No	7.1% 92.9%	0.0% 100.0%	Fisher's exact p=0.545
Has a person moved into the house without consultation with the other people who live there already?	% Yes % No	7.1% 92.9%	20.0% 80.0%	Fisher's exact p=0.199
Is there a person in the house that is clearly unhappy living with another person?	% Yes % No	9.8% 90.2%	25.0% 75.0%	Fisher's exact p=0.139
Is the person expected to move if their support needs were to change?	% Yes % No	11.1% 88.9%	26.3% 73.7%	Fisher's exact p=0.249
Is support provided at times prescribed by the support provider rather than the person?	% Yes % No	19.0% 81.0%	52.6% 47.4%	Fisher's exact p=0.014
Is there anywhere in the home that people are restricted from accessing?	% Yes % No	9.5% 90.5%	60.0% 40.0%	**Fisher's exact p<0.001**
Is there equipment such as telephone lines, office equipment and files owned by the housing or support provider in the person's home?	% Yes % No	48.8% 51.2%	100.0% 0.0%	**Fisher's exact p<0.001**
Do the landlord or support provider have free access and hold keys to the person's home?	% Yes % No	33.3% 66.7%	90.0% 10.0%	**Fisher's exact p<0.001**
Total Real Tenancy Test score (higher score=more housing rights)	Mean (sd) Range	9.3 (1.6) 4-11	7.1 (1.8) 5-11	**t=-4.94; df=62; p<0.001**

Moving home in the future

Liam's story

Liam* lives in a residential home with ten other people. He previously lived in a secure unit. "From there moving to here it was a big leap but looking back on my life I've come a hell of a long way... I feel it's bettered my life. I would say that had I not have come here I reckon my life could have been a lot worse." When Liam moved here he met his wife and it was 'love at first sight', they have just celebrated 11 years of marriage. They did explore the possibility of supported living but decided that it 'wasn't for them' as they are happy where they live now. They enjoy the atmosphere of the home and the company of staff and the other residents. They used to go on lots of days out as a couple and it has been hard not being able to do this during COVID (Liam*, Residential Care).

*(*all names have been changed)*

If they wanted to move house, a majority of people in supported living (61%) and residential care (50%) would talk to their support worker/personal assistant. Fewer people said they would talk to friends/family (12% supported living; 13% residential care), social services (6% supported living; 25% residential care), or the housing department (18% supported living; 0% residential care).

Table 23: Sources of help for moving house

If the person wanted to move house, who would they talk to?				
Paid help/PA/ Support staff	Yes	60.6%	50.0%	Fisher's exact
	No/NA	39.4%	50.0%	p=0.700
Friends/family	Yes	12.1%	12.5%	Fisher's exact
	No/NA	87.9%	87.5%	p=1.000
Social services	Yes	6.1%	25.0%	Fisher's exact
	No/NA	93.9%	75.0%	p=0.165
Advocate	Yes	3.0%	0.0%	Fisher's exact
	No/NA	97.0%	100.0%	p=1.000
Housing dept/ Local housing authority	Yes	18.2%	0.0%	Fisher's exact
	No/NA	81.8%	100.0%	p=0.323
Citizen's Advice Bureau/ Local advice agency	Yes	0.0%	0.0%	Not calculated
	No/NA	100.0%	100.0%	
Call the landlord	Yes	3.0%	0.0%	Fisher's exact
	No/NA	97.0%	100.0%	p=1.000
Wouldn't ask for help/ do anything	Yes	0.0%	0.0%	Not calculated
	No/NA	100.0%	100.0%	

Qualitative Findings: Moving home in the future

Participants were asked whether they thought they would move in the future or would like to stay in their current home. Many people had not considered moving, as they felt happy with their current arrangements. Some people did not want to discuss this, perhaps reflecting anxiety that they may be moved against their wishes if they expressed dissatisfaction with their current arrangements. However, some people had thought about moving, either soon or in the future, and their reasons for wanting to move mirrored those noted in the 'Experience of Moving' section (page 49).

Naomi's story

Naomi* lives in an independent living scheme with three other people. The scheme is designed so that people can gain experience living independently with housemates, with the goal of eventually moving into their own flat on-site. Her favourite thing about the house is the staff who she said are 'out of this world.' Naomi gets on with her housemates but her hope is to get her own flat one day. She would 'love to' live by herself one day and have a dog (Naomi*, SL).

*(*all names have been changed)*

Reactive and proactive moves

Similar to the reasons for moving into their current home, participants who had considered moving in the future gave both proactive and reactive reasons for wishing to do so. Reactive reasons tended to echo the themes in what people liked and didn't like about their homes. Proactive reasons meanwhile related to looking ahead to the future and considering how they might be able to develop their independence or progress their relationships.

Participants who had a definite intention to move or were in the early stages of planning to move lived in supported living and wished to move for reactive reasons. There were issues with space, as well as neighbours and local crime and vandalism making participants feel unsafe. These were participants who had minimal support and lived in council housing. However, as explored in the theme 'a bumpy road until settled', moving was not a straightforward process; there were hoops to jump through, multiple factors to take into consideration and barriers in place via the council house bidding systems. For example, one participant stated:

> ***I just want out…I have spoken to [support provider] and they are going to ring up the council to see what the conclusion is going to be… I have to go to the doctors to get more forms.*** (P36, SL)

Another participant explained recent difficulties he had encountered with the bidding system, as he had failed to take into consideration whether his support provider worked in the area where the property he had bid on was located:

> ***I have had my banding demoted a few months ago so I had to re challenge that to get my banding put back to where it is and that's because I didn't have an understanding of the area and if [my support provider] supported the area because if you go out of the area they won't support you.*** (P34, SL)

Alongside this, however, he also explained how he had to consider his mental health when moving, as well as possible racism and if his future property would be too close to his family whom he had a difficult relationship with:

> ***[dad] wants me to move closer you see, and we are like yeah ok we have a property closer to him but it comes down to safeguarding issues as well if something happens it will set off my mental health and sometimes it is not controllable, and I will end up self-harming like I have done in the past so it is a difficult decision.*** (P34, SL)

He had thought of ways to mitigate potential issues in the future as he explained:

> ***We will speak to the neighbourhood officer and just make her aware of the issues and what could possibly happen again, so they are aware of the situation. So, if we said look, we are going to move is there some kind of barrier we could have in place just in case something happens. You know I don't want to be suffering with mental health, depression and anxiety which I already have and have had for years.*** (P34, SL)

Nevertheless, despite trying to anticipate future issues and forward plan, navigating the processes involved in moving was a struggle and he remained concerned about how it would pan out.

Participants in both supported living and residential care discussed having sporadically toyed with the idea of moving. This was usually in response to difficulties encountered with their housemates and a desire to escape particular situations. However, as discussed in the ‘people break a home’ theme, these relationships were not static and there were good days as well as the bad days which, alongside an awareness of the issues moving may cause (discussed in more detail in ‘having to compromise’ below), meant the desire to move was not a continuous one:

> ***I have been thinking about it and then I change my mind and then I been thinking about moving out and then I change my mind again. One day you have a bad day and think 'I'm moving out I am' and the next day you think 'no it's fine you can cope it's fine, carry on with it, it's fine’.*** (P24, RC)

Similarly, one participant described how he had previously used the thought of moving as a coping strategy as he explained he would contact his social worker whenever things were not working well at home:

> ***I used to email them quite a bit or phone up if I was in trouble and say I would like to go, but I’ve not done that for 2 nearly 3 years now.*** (P16, RC)

However, as the issues for the participant above were now resolved he was happy to stay where he was and referred to that period of time as ‘a doolaley moment’:

> ***I had a bit of a doolaley moment but it’s out of the way now. I hit the nail on the head, we are happy where we are now and no I don’t want to move anywhere else… I’ve done really well and I’ve not asked social services to be moved on any more.*** (P16, RC)

Participants who discussed the possibility of moving in the future in relation to progression tended to live in supported living. Reasons for moving included moving in with their partner, ***“My next place would be a downstairs flat with my girlfriend”*** (P23, SL), owning their own home or moving out to live alone or with fewer housemates. For example, one person explained they were, ***“hoping to move into my own place eventually... I would love to live by myself”*** (P17, SL), whilst another stated:

> ***I would like to have my own place whether it be a flat or a house. Whether I organise it with a company and have some support, like a set amount of hours where they come in and do some bits or just check on me to make sure I am ok…I would like to have it where there is literally just one other person, like a friend or something, or my own tenancy by myself.*** (P27, SL)

This again reiterates the point that living alone or with fewer housemates was associated in participants' minds with progression and higher levels of independence.

In addition to the main reasons given above, participants who wished to move either now or in the future also viewed the move as a chance to address some of the accessibility issues they currently faced or an opportunity to choose better housemates. For example, two participants who had discussed moving due to not feeling safe in their immediate area, also both discussed moving into a bungalow to avoid stairs whilst the participant mentioned above who wished to have his own place also mentioned wanting to live with someone 'more on his level':

> ***I would like to live with someone more, without sounding nasty, more on my level...like intellectual level etcetera.*** (SL)

Ali's story

Ali* lives in a ground floor council flat with his partner. They moved here following problems with neighbours in previous flat. Ali likes living with his partner, having nice neighbours and his partner's family nearby. They are trying to move as the flat feels too small but are not sure where to move. They are concerned about being too close to his family whom he has a difficult relationship. They are also worried about being too far from his partner's family and wanting to ensure that they live in a diverse area (Ali*, Supported Living).

*(*all names have been changed)*

Having to compromise

Whilst some people expressed a desire to move, participants were aware how difficult this could be, often based on prior experience from the move into their current home. There was an understanding of the different hoops one would have to jump through and the upheaval it might cause to different areas of one's life as the following participant expressed*:*

> ***It means getting hold of the social workers and then getting hold of this and then changing everything, if I move house I have to change doctors and if I change doctors, I have to change clinics. The thing is I have that much set up that I would need to readjust, it's not practical to move at the minute.*** (P24, RC)

This again highlights the precarity of people's situations, with one change such as moving house potentially disrupting other networks and support systems.

In addition, participants were aware of the limitations of their living situation. For example, one participant who was in residential care expressed a desire to move because of difficulties with her housemates, however she knew if she moved whilst she would escape her housemates, she would also lose her support staff as the member of staff supporting her in the interview explained:

> ***Sometimes she does want to move but because she can't take her keyworkers with her it stops it as she does like us all, but unfortunately she can't take us with her.*** (P28, RC)

There was a sense that participants were having to compromise and weigh up whether moving would be worth it as whilst they may escape one issue they may encounter many more and, as a result, many participants appeared accepting of their situation as the following participant summed up:

> ***It can be a bit tricky at times but it is what it is, you just gotta bear with it. We're not gonna get any better place than living here I'm afraid. The grass isn't always greener on the other side.*** (P16, RC)

Key Findings – Choice, privacy and housing rights

- Most people in supported living and about half of people in residential care said that they chose the place that they currently live in. However less people had looked around anywhere else before moving to their current home.
- People in residential care were significantly less likely to choose who they live with. Most people in supported living had chosen who they lived with (46%) or were involved in the process (14%), whereas no-one in residential care had chosen who they lived with (0%) and very few were involved in the process (6%).
- Some people had moved into their current home for reactive reasons, meaning that they moved in response to an issue with their previous home such as a sudden change in support needs, difficulties with their housemates or the property being in poor condition. For other people, the move was proactive and associated with personal progression, such as moving from a shared home into a self-contained property.
- Many people found the process of moving to be a long and bumpy road, with many obstacles encountered along the way, including a lack of suitable options, issues with funding and interim moves. Lots of people found it daunting to move into their current home and it took them a while to adjust.
- Some things that helped to ease this process were moving at the person’s own pace, time to build relationships with housemates and staff, drawing on emotional support from others and moving to a familiar location.
- In terms of day-to-day choices, there were some differences between supported living and residential care. For example, most people in supported living could go anywhere in their own home (except other people’s homes where relevant) compared to a minority of people in residential care. People in residential care were more likely to say that someone came into their bedroom and opened their post without asking.
- People in supported living were significantly more likely to have their own front door key compared to people in residential care, and to know who else had keys to their front door.
- People in residential care were more likely to be currently living under a Deprivation of Liberty Safeguard compared to people in supported living.
- People in supported living had on average significantly more housing rights as according to the Real Tenancy Test. However there were a wide range of scores on the Real Tenancy Test across both service models, suggesting a wide range of variation in housing rights experienced by participants.
- Most people had not considered moving in the future, as they were happy with their current arrangements. Those that had considered moving gave reasons associated with both reactive (such as not liking the area they live in or not getting on with housemates) and proactive reasons (such as wanting to live alone or with a partner).
- When thinking about moving, people appeared to weigh up whether the upheaval of moving was worth it. They felt that they needed to compromise, and perhaps due to

Support arrangements

In terms of support planning, Table 24 below shows that a substantial majority of people in supported living (72%) and residential care (90%) had a support plan, with a minority of people (22% supported living; 11% residential care) not knowing if they had a support plan or not. Of those with a support plan, a substantial majority of people (79% supported living; 88% residential care) helped to write the plan and for almost everyone the plan was reviewed each year, although less than half of people (48% supported living; 41% residential care) had a copy of their plan. There were no differences between supported living and residential care.

Staff questionnaires (see Table 23) reported that virtually everyone in both supported living and residential care had a support plan reviewed each year, which the person was involved in developing. Staff reported that fewer people (55% supported living; 35% residential care) had a copy of their support plan.

Table 24: Support planning

		Supported Living	Residential Care	Test and statistical significance
Do you have a support plan?	% Yes	71.7%	89.5%	Chi-square=2.71; df=2; p=0.259
	% No	6.5%	0.0%	
	% Don't know	21.7%	10.5%	
Staff Q – does the person have a support plan?	% Yes	97.7%	100.0%	Fisher's exact p=1.000
	% No	2.1%	0.0%	
	% Don't know	0.0%	0.0%	
Of those with a support plan…				
Do you have a copy of your support plan?	% Yes	48.3%	41.2%	Fisher's exact test p=0.762
	% No	51.7%	58.8%	
	% Don't know	0.0%	0.0%	
Staff Q – does the person have a copy of their support plan?	% Yes	54.8%	35.0%	Chi-square=2.90; df=2; p=0.235
	% No	42.9%	65.0%	
	% Don't know	2.4%	0.0%	
Did you help to write the support plan?	% Yes	78.8%	87.5%	Fisher's exact test p=0.689
	% No	21.4%	12.5%	
	% Don't know	0.0%	0.0%	
Staff Q – was the person involved in developing the support plan?	% Yes	97.5%	90.5%	Chi-square=4.41; df=2; p=0.110
	% No	0.0%	9.5%	
	% Don't know	2.5%	0.0%	
Is the support plan reviewed each year?	% Yes	95.5%	100.0%	Fisher's exact test p=1.000
	% No	4.5%	0.0%	
	% Don't know	0.0%	0.0%	
Staff Q – is the support plan	% Yes	92.7%	100.0%	Fisher's exact test p=0.545
	% No	7.3%	0.0%	
	% Don't know	0.0%	0.0%	

reviewed each year?				

Table 25 below shows the average number of one-to-one and shared support hours reported in staff questionnaires. In terms of average one-to-one support hours per person per week, the average for people in supported living was 28 hours per week and for people in residential care 18 hours per week – this was not a statistically significant different between the two service models. In terms of average shared support hours per person per week, people in residential care received statistically significantly more shared support (70 hours per week) than people in supported living (43 hours per week). For both one-to-one and shared support there was very wide variation in the number of support hours different people received.

Table 25: Support hours

		Supported Living	Residential Care	Test and statistical significance
Staff Q: one to one support hours per week	Mean (sd) Range	28.0 (47.9) 0-168	17.7 (16.3) 0-63	t=-1.20; df=52.8; p=0.237
Staff Q: shared support hours per week	Mean (sd) Range	42.7 (56.6) 0-168	69.8 (14.6) 49-105	**t=-2.73; df=49.6; p=0.009**

Staff featured heaving in people’s discussions about what they liked or didn’t like about their homes, illustrating the importance of good quality support and relationships with staff in ensuring that housing arrangements work well.

Sophie’s story

Sophie* lives with her sister in supported living. The support provider recently changed, and staff say that the sisters are much more active and happy since the change. Sophie is involved with church and the local community with good neighbours so has lots of connections beyond paid services. Her mum is very involved in the running of the house and visits regularly. Although the sisters are supported together, staff spoke a lot about their differences and how to respect their individuality when it comes to planning different things e.g., Sophie being supported to do some voluntary work whilst her sister isn’t (Sophie*, Supported Living).

*(*all names have been changed)*

Table 26 shows that about two thirds of people in supported living (69%) and residential care (67%) were very happy with the support they get from staff, and a further 26% of people in supported living and 25% of people in residential care were quite happy with their support. No-one reported being unhappy with their support on the whole. In terms of complaints, 17% of people in supported living and 21% of people in residential care had made a complaint about their support. A further 14% of people in supported living and 26% of people in residential care had complained informally about some aspect of their support. There were no statistically significant differences between the housing models in satisfaction with support or making a formal complaint.

Table 26: People's feelings about their support

		Supported Living	Residential Care	Test and statistical significance
How happy is the person with the support they get?	% Very happy	68.5%	66.7%	Chi-square=0.254; df=2; p=0.881
	% Quite happy	25.8%	25.0%	
	% Not happy	0.0%	0.0%	
	% Don't know	5.5%	8.3%	
Has the person ever wanted to make a formal complaint about the support they get?	% Yes but haven't complained	4.5%	0.0%	Chi-square=2.879; df=4; p=0.615
	% Yes and have complained	16.7%	21.1%	
	% No but someone complained on their behalf	0.0%	0.0%	
	% No but have complained informally	13.6%	26.3%	
	% No	50.0%	42.1%	
	% Don't know	15.2%	10.5%	

Key Findings – Support Arrangements

- Most people in both supported living and residential care had a support plan and were involved in writing it; however few people had a copy of their support plan.
- On average, people in supported living received 28 hours of one-to-one support per week compared to 18 hours for people in residential care.
- People in residential care received significantly more shared support (on average 70 hours per week) compared to people in supported living (on average 40 hours per week).
- Two thirds of people across both service models said that they were very happy with the support they got from staff, with a further quarter being quite happy with their support.

According to staff questionnaires, virtually no-one in either supported living or residential care had experienced any form of restrictive intervention in the past month (see Table 27).

Table 27: Restrictive interventions

Staff Q – restrictive interventions used with the person in the past month		Supported Living	Residential Care	Test and statistical significance
Enhanced observation	% Yes % No	4.8% 95.2%	15.0% 85.0%	Fisher's exact p=0.317
Physical restraint	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Mechanical restraint	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Chemical restraint	% Yes % No	0.0% 100.0%	5.0% 95.0%	Fisher's exact p=0.323
Seclusion	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Segregation	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated

As Table 28 below shows, most people in supported living (85%) and residential care (70%) liked the area they were living in. Over half of people in supported living liked all their neighbours (56%) compared to a minority of people in residential care (17%) who are more likely to not know their neighbours (67% residential care; 24% supported living); these differences between supported living and residential care were statistically significant. Substantial majorities of people in both supported living and residential care felt safe in their home during the day (92% supported living; 84% residential care), felt safe at home at night (91% supported living; 90% residential care), and felt safe in the area where they live (77% supported living; 74% residential care).

For almost one third of people in both supported living (33%) and residential care (32%), someone had been rude or nasty to them because of their learning disability in the past year.

A minority of people in supported living (16%) and residential care (4%) had been the victim of a crime in the past year, with no statistically significant difference between the two service types. Of those of had experienced a crime in the past year, 70% of people had experienced one crime, which was most likely to be abuse/threats or physical assault. Everyone who had been the victim of a crime told someone else about it, who went on to do something as a result.

Table 28 also shows the summary risk management index score, derived from 8 questions in the staff questionnaire (each question, e.g., crossing roads, is scored *1=Does this independently; 2=Facilitated to do this with support; 3=Not permitted to do this*). The number of questions scoring 3 (not permitted) are added to produce a risk management index. In both supported living and residential care relatively few activities were not permitted, with no statistically significant difference between service models at p<0.01.

Finally, Table 28 shows that a minority of people in both supported living (12%) and residential care (19%) had experienced an accident or injury in the home in the last year which required medical attention, and almost no-one (7% supported living; no-one in residential care) had experienced an accident or injury out of the home in the last year which required medical attention.

Table 28: Safety, crime, risk and accidents/injuries

		Supported Living	Residential Care	Test and statistical significance
Does the person like the area they live in?	% Yes % Sometimes yes, sometimes no % No	84.5% 9.9% 5.6%	70.0% 30.0% 0.0%	Chi-square=5.96 df=2; p=0.051
Does the person like their neighbours?	% Yes, like them all % Only like some of them % No, don't like them % Don't know them	56.1% 12.1% 7.6% 24.2%	16.7% 5.6% 11.1% 66.7%	**Chi-square= 13.03 df=3; p=0.005**
Does the person feel safe when they are at home during the day?	% Yes % Sometimes yes, sometimes no % No	92.4% 4.5% 3.0%	84.2% 15.8% 0.0%	Chi-square= 3.33 df=2; p=0.189
Does the person feel safe when they are at home at night?	% Yes % Sometimes yes, sometimes no % No	90.9% 6.1% 3.0%	89.5% 10.5% 0.0%	Chi-square= 1.00 df=2; p=0.608
Does the person feel safe in the area they live?	% Yes % Sometimes yes, sometimes no % No	77.3% 16.7% 6.1%	73.7% 26.3% 0.0%	Chi-square= 1.91 df=2; p=0.386
Have people been rude or nasty to the person because of their learning disability in the past year?	% Yes % No	32.7% 67.3%	31.3% 68.8%	Fisher's exact test p=1.000
Has the person been the victim of a crime in the past year?	% Yes % No	15.5% 84.5%	4.3% 95.7%	Fisher's exact test p=0.268

		Supported Living	Residential Care	Test and statistical significance
Staff Q – risk management index	Mean (sd) Range	0.9 (1.3) 0-5	0.3 (0.7) 0-2	t=2.16; df=62; p=0.034
Staff Q – has the person suffered any accidents or injuries in the home which required medical attention over the last year?	% Yes % No	12.2% 87.8%	19.0% 81.0%	Fisher's exact p=0.472
Staff Q – has the person suffered any accidents or injuries out of the home which required medical attention over the last year?	% Yes % No	7.0% 93.0%	0.0% 100.0%	Fisher's exact p=0.545

Qualitative Findings: Safety

Participants were asked to describe things that help them to feel safe at home or in the local neighbourhood, as well as anything that made them feel unsafe.

Alicia's story

Alicia* lives with her partner in a flat. Her partner supports her to go out, as she has anxiety. They don't feel safe in their home or in the area and want to move because of multiple issues with neighbours and being mugged several times. They moved into their current property following problems in their last house (which was privately rented) due to damp and the landlord stealing their money meant for utility bills (Alicia*, Supported Living).

*(*all names have been changed)*

People create and disrupt safety

In keeping with other themes, interactions with other people were central to participants feeling safe both within and outside the home. Alongside the physical presence of staff, participants associated feeling safe with feeling cared for and looked after by staff and trusting the staff who supported them, Participants also described how much they valued being in a familiar area. As well as feeling connected to the local community (See 'location,

location, location’ theme, page 39), bumping into people they knew when out or knowing friends and family were nearby contributed to their sense of safety as one person stated feeling safe when out depended on **“who I am close to or who I am near”** (P29, SL). Proxy-participant respondents echoed this as one explained:

> ***He’s very well known in the area, so a lot of people say hello to him. He’s lived in the area all of his life, a lot of people know him and will stop and say ‘hi’ and you’re like ‘ooh who’s that’. It’s quite nice, it does feel like a real community and the guys are well respected. I’ve worked in previous places where people have been jeered at or taken the mickey out of and I’ve never experienced that here.*** (P13, proxy response, SL)

When participants were out alone, having a phone on them helped allay their fears as they were able to call friends, family or staff for reassurance or as a precautionary measure to let them know they were on the way home as in the following examples:

> ***Speak to my friends on the phone when I am out and they know what I am like and stuff so they understand what I am going through…they say like calm down, if I can't get hold of my mum or dad.*** (P29, SL)

> ***I’ve got me phone handy if there is anything.*** (P14, SL)

However, whilst other people were sometimes a source of safety, they were also the reason people felt unsafe. Within the home housemates or neighbours were sometimes a threat to safety (as discussed in ‘people break a home’) whilst when out strangers and crowds of people could pose a threat. This was particularly the case for people living in supported living who typically had lower levels of support and often went out alone. Past experiences of being approached by homeless people and experiences of harassment, abuse or crime from strangers, whether encountered personally or observed from a distance, continued to make people feel vulnerable and worried long after the event:

> ***There should be more police in the area... there are dirty people around, asking me for money. It puts me off.*** (P28, RC)

Mainly at night on my way back from work [don't feel safe] because you don't know who is about on the buses. (P22, SL)

Some of the people [in the neighbourhood] aren't very nice…If it's with staff I'm alright but it's when I'm on my own its more difficult… I get picked on by kids and adults. (P12, RC)

I sometimes get asked in town for, people who are begging… Don't like that. (P15, SL)

There was a sense that people had to stay vigilant and judge situations for danger when going out alone and strategies were discussed for keeping safe such as taking a phone (mentioned above), a panic alarm, avoiding certain routes, areas or alleyways or avoiding travelling in the dark and avoiding crowded public transport and potentially anxiety inducing situations:

I don't like the alleyway at the back when it is dark because we have an alleyway, and you don't know who is lurking around or anything when it gets really dark' 'I go out the front way [to avoid the alley]. (P36, SL)

Cos I go past where the houses are and stuff and there's someone following, then I cross over on the other side of the road and if they cross over then I cross over back. (P15, SL)

Furthermore, as participants emphasised the need to keep themselves to themselves there was a sense that participants believed it was their responsibility to stay out of trouble, with harassment just part of life they had to put up with which they did by keeping themselves to themselves:

If people are rude to me now, I just take no notice. They are just pig ignorant. (P23, SL)

I keep myself to myself when I'm out. (P14, SL)

Home as a place of security

Home was frequently identified as a place of safety and familiarity, where people felt comfortable. For some participants this stood in contrast to the outside where people often felt uneasy due to the risks surrounding them and uncertainty about when they may encounter a problem. This is in keeping with the quantitative findings that the vast majority of people felt safe when they were at home, with slightly less people feeling safe in their local area.

Samuel's story

Samuel* lives in a residential home with four other men. He said that he was quite quiet when he first moved in because he hadn't met the other housemates and didn't know what to make of it. Now he 'never shuts up!' Samuel likes watching TV in the lounge and doing gardening. Since COVID, he hasn't been allowed out by himself, which he finds difficult and frustrating. Samuel said that 'some of the people in the neighbourhood aren't very nice' and often pick on him. He said that he spends his time 'doing the normal things that you do in a care home.' He used to do volunteering which he enjoyed, but had to stop doing this during COVID (Samuel*, Residential Care).

*(*all names have been changed)*

Threats outside the home were associated with accessibility issues such as cars and traffic or navigating pavements, as well as other people (see above), with the issues often compounded by difficulties in managing anxiety as shown by the following participant:

> ***When I go out, I have to look around to see who is around and who is following me because I suffer from with anxiety, and I have to look around and if I have heard someone I go 'who is this?'.*** (P36, SL)

In contrast to this, however, home was a familiar and safe place where people knew where things were and what to expect. For example, when discussing safety, one participant who lived in residential care and used a wheelchair stated they felt happy and content:

> ***It is just so clean, tidy and comfortable and…I am living in a lovely atmosphere.*** (P26, RC)

In contrast to this however, they described feeling a bit ***"risky and scared about…crossing roads and going down curbs and ditches and so forth"*** (P26, RC).

Similarly, another participant in residential care explained how he found it reassuring that he knew when he was out, he could come home if he started to feel uncomfortable. A proxy-participant respondent explained that one participant, who lived in supported living, felt safe at home as they were in control of their space and knew where everything was, whereas he felt anxious in previous homes if someone moved his things. As a result of this contrast, particularly for people in residential homes, there was a sense of a boundary existing between the house and the outside world, which needed to be kept secure, for example by being careful about who was let into the house and keeping strangers or 'baddies' away as in the following examples:

Don't let strangers in, we get staff to open the door. (P10, RC)

I feel safe in the house… having CCTV in the carpark keeps us all safe, keeps the baddies away. (P16, RC)

As discussed previously the presence of staff within the home contributed to the sense of security experienced, ***"I feel safe when we're in the house at night… when all the staff are in."*** (P40, RC). This was alongside physical barriers and the use of technology as panic alarm buttons, CCTV or cameras, and intercoms on doors were all listed by participants as items which helped them to feel safe within their home, ***"we have cameras on the property now and a barrier so no one can come up and a fence all the way around."*** (P37, RC)

However, whilst technology and surveillance could be used to increase security, this sometimes tipped into being excessive and restrictive for participants. People, particularly those living in residential homes, spoke about being subject to blanket policies with regards to safety such as not being allowed out by themselves due to Covid:

Before I was going out on the buses, trains, and walks on my own, and now the policy is I can't do those things any more because of COVID. Which I accept, you know… I understand the procedure. (P16, RC)

Another person spoke about staff keeping control of the front door key ***"so that no one escapes" (P12, RC)***. This is further reflected in the findings from the household data that shows that residential care households were more likely to have restrictive elements of building design, such as the use of deadlocks and areas that are 'out of bounds' to residents. Whilst this could be frustrating, participants appeared accepting of the rules in place understanding them to be for their safety.

Key Findings – Restrictive Interventions, Safety and Risk

- According to staff questionnaires, virtually no-one in either supported living or residential care had experienced any form of restrictive intervention in the past month.
- The vast majority of people felt safe at home and most felt safe in the area they live in. People in supported living were more likely to know and like their neighbours than people in residential care.
- About a third of people across both service models said that someone had been rude or nasty to them because of their learning disability in the past year.
- There were no differences between supported living and residential care in terms of accidents in the home, accidents outside of the home and being the victim of a crime in the past year.
- Participants said that other people helped them to feel safe, such as the presence of staff and knowing people in their local area. However, at times other people could make them feel threatened, for example aggressive behaviour from housemates or harassment from strangers.
- People spoke about strategies they used to keep themselves safe, such as taking their phone with them and taking known routes.
- People tended to feel safest when they were at home, as this was a familiar, predictable and comfortable place. They spoke about technology they used to keep the house secure, such as surveillance or panic alarms. However, at times this resulted in restricted freedom for residents, and some people in residential care were subject to blanket policies with regards to safety, such as not being allowed out by themselves.

Money, benefits, personal budgets and hardship

Table 29 shows that most people in supported living (62%) and residential care (58%) said or were reported by proxy staff members to choose how they spend their money, with 29% of people in supported living and 35% of people in residential care sometimes choosing how they spend their money. Small minorities of people in supported living (7%) and residential care (8%) were reported to not choose how they spend their money. Substantial majorities of people in both settings received help looking after their money (82% supported living; 89% residential care). Substantial majorities in supported living (81%) and residential care (91%) were also reported to not need any more help with managing their money. There were no statistically significant differences between supported living and residential care.

Table 29: Choice and help with how the person spends their money

		Supported Living	Residential Care	Test and statistical significance
Does the person choose how they spend their money?	% Yes they choose	61.8%	57.7%	Chi-square=0.602; df=3; p=0.896
	% Sometimes they choose	29.4%	34.6%	
	% No they don't choose	7.4%	7.7%	
	% Don't know	1.5%	0.0%	
Does someone help the person to look after their money?	% Yes	82.1%	88.5%	Fisher's exact p=0.545
	% No	17.9%	11.5%	
Would the person like any (more) help looking after their money?	% Yes	18.8%	9.1%	Fisher's exact p=0.656
	% No	81.3%	90.9%	

For people in supported living who received help looking after their money, most people received this from paid staff (68%), followed by help from their parent(s) (29%), another relative (12%), their partner (5%), social services (10%) or another source of help (10%) (see Table 30). People in residential care who got help with looking after their money all received this from paid staff (100%), followed by their parent(s) (39%), another relative (4%) or another source of help (9%). People in residential care were significantly more likely to receive help from paid staff with their money than people living in supported living.

Table 30: Who helps you to look after your money?

		Supported Living	Residential Care	Test and statistical significance
Parent	% Yes	28.8%	39.1%	Fisher's exact test p=0.432
	% No	71.2%	60.9%	

		Supported Living	Residential Care	Test and statistical significance
Partner	% Yes % No	5.3% 94.7%	0.0% 100.0%	Fisher's exact test p=0.553
Child	% Yes % No	0% 100.0%	0% 100.0%	Not calculated
Other Relative	% Yes % No	11.9% 88.1%	4.3% 95.7%	Fisher's exact test p=0.431
Friend	% Yes % No	0% 100.0%	0% 100.0%	NA
Paid Staff	% Yes % No	67.8% 32.2%	100.0% 0.0%	**Fisher's exact test** **p<0.001**
Social Services	% Yes % No	10.2% 89.8%	0.0% 100.0%	Fisher's exact test p=0.178
Other	% Yes % No	10.2% 89.8%	8.7% 91.3%	Fisher's exact test p=1.000

Table 31 shows that most people in supported living (71%) and residential care (56%) reported having their own bank account. Almost no-one had a joint bank account with their partner. Small minorities of people in supported living (2%) and residential care (12%) had a joint bank account with a family member. A minority of people in supported living (27%) and residential care (15%) had other bank account arrangements, these were varied but included an appointee, family member, or service provider managing the person's money on their behalf – these arrangements were for people with and without the capacity to consent to take part in the research project. There were no statistically significant differences in bank account arrangements between people in supported living and people in residential care.

Table 31: Do you have your own bank account?

		Supported Living	Residential Care	Test and statistical significance
Own bank account	% Yes % No % Don't know	71.2% 24.2% 4.5%	56.0% 40.0% 4.0%	Chi-square=2.21; df=2; p=0.331
Joint account with family	% Yes % No % Don't know	1.5% 93.9% 4.5%	12.0% 84.0% 4.0%	Chi-square=4.74; df=2; p=0.093
Joint account with partner	% Yes % No % Don't know	1.5% 93.9% 4.5%	0.0% 96.0% 4.0%	Chi-square=0.40; df=2; p=0.819
Other	% Yes % No % Don't know	27.3% 68.2% 4.5%	15.4% 80.8% 3.8%	Chi-square=1.53; df=2; p=0.464

As Table 32 below shows, most participants with capacity to take part in the project said that they received benefits (88% supported living; 84% residential care). Most of the rest of participants (10% supported living; 16% residential care) were not sure if they received benefits. According to the staff questionnaire, almost everyone received benefits. Around half of people in supported living (48%) and residential care (53%) said that they received their benefits themselves, with similar percentages reported in staff questionnaires (55% supported living; 48% residential care). Of those that did not receive their benefits themselves, their benefits were most commonly received by their parents or another relative on their behalf (participants with capacity 52.4% supported living; 62.5% residential care; staff questionnaire 41.2% supported living; 80.0% residential care). There were no statistically significant differences between supported living and residential care.

Table 32 also shows that according to staff questionnaires, people most commonly received a Personal Independence Payment (PIP: supported living 76%; residential care), Employment and Support Allowance (ESA: 50% supported living; 79% residential care), and Disability Living Allowance (DLA: 46% supported living; 44% residential care). People in supported living were statistically significantly more likely than people in residential care to receive Housing Benefit (supported living 62%; residential care 0%) and Council Tax Reduction (supported living 50%; residential care 0%). Although not a statistically significant difference, 22% of people in supported living compared to no-one in residential care were on Universal Credit.

Table 32: Benefits

		Supported Living	Residential Care	Test and statistical significance
[People with capacity only] Do you receive any benefits?	% Yes % No % Don't know	87.9% 1.7% 10.3%	84.2% 0.0% 15.8%	Chi-square=0.71; df=2; p=0.700
Staff Q – does the person receive any benefits?	% Yes % No % Don't know	97.7% 0.0% 2.3%	100.0% 0.0% 0.0%	Fisher's exact p=1.000
[People with capacity only] Do you get your benefits yourself?	% Yes % No % Don't know % NA	48.3% 36.2% 12.1% 3.4%	52.6% 42.1% 5.3% 0.0%	Chi-square=1.48; df=3; p=0.687
Staff Q – do people get their benefits themselves?	% Yes % No % Don't know	54.8% 38.1% 7.1%	47.6% 52.4% 0.0%	Chi-square=2.30; df=2; p=0.316
Staff Q – specific benefits received				
Staff Q – Disability Living Allowance	% Yes % No	45.7% 54.3%	44.4% 55.6%	Fisher's exact p=1.000
Staff Q – Personal Independence Payment	% Yes % No	75.8% 24.2%	92.9% 7.1%	Fisher's exact p=0.244

		Supported Living	Residential Care	Test and statistical significance
Staff Q – Universal Credit	% Yes % No	21.9% 78.1%	0.0% 100.0%	Fisher's exact p=0.083
Staff Q – Employment and Support Allowance	% Yes % No	50.0% 50.0%	78.9% 21.4%	Fisher's exact p=0.106
Staff Q – Jobseekers Allowance	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Staff Q – Income Support	% Yes % No	9.4% 90.6%	7.1% 92.9%	Fisher's exact p=1.000
Staff Q – Council Tax Reduction	% Yes % No	50.0% 50.0%	0.0% 100.0%	**Fishers exact p<0.001**
Staff Q – Housing Benefit	% Yes % No	61.8% 38.2%	0.0% 100.0%	**Fisher's exact p<0.001**
Staff Q – Severe Disability Allowance	% Yes % No	9.1% 90.9%	0.0% 100.0%	Fisher's exact p=0.544
Staff Q – Disability Premium	% Yes % No	0.0% 100.0%	7.1% 92.9%	Fisher's exact p=0.304
Staff Q – Enhanced Disability Premium	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Staff Q - Other	% Yes % No	6.3% 93.8%	0.0% 100.0%	Fisher's exact p=1.000

Table 33 shows that a minority of participants with capacity to take part in the project said that they got a personal budget (15% supported living; 23% residential care), although most participants did not know if they were getting a personal budget or not (71% supported living; 77% residential care). In the staff questionnaires, it was also reported that just over a third of people in supported living (37%) and residential care (35%) got a personal budget. Although numbers were small, according to the staff questionnaire people most commonly received a personal budget that was managed by their family (of those getting a personal budget, 47% supported living; 38% residential care).

Table 33: Does the person get a personal budget?

		Supported Living	Residential Care	Test and statistical significance
[People with capacity only] Do you get a personal budget?	% Yes % No % Don't know	14.6% 14.6% 70.7%	23.1% 0.0% 76.9%	Chi-square=2.38; df=2; p=0.305
Staff Q – does the person get a personal budget?	% Yes % No	36.6% 63.4%	34.8% 65.2%	Fisher's exact p=1.000

In terms of other funding issues, according to staff questionnaires no-one received a personal health budget and no-one received a personal wheelchair budget, with a minority of people receiving NHS Continuing Health Care funding (supported living 12.9%; residential care 35.7%; Fisher's exact p=0.111).

As Table 34 shows below, substantial minorities of people in supported living (30%) and residential care (26%) were reported by staff to have to pay a means-tested contribution towards their support, although almost half of staff (supported living 45%; residential care 42%) did not know if this was the case or not.

Table 34: Means-tested contributions

		Supported Living	Residential Care	Test and statistical significance
Staff Q – does the person have to pay a means-tested contribution towards their support?	% Yes % No % Don't know	30.0% 25.0% 45.0%	26.3% 31.6% 42.1%	Chi-square=0.29; df=2; p=0.865

From a list of 12 types of material hardship, a total count of the number of types of material hardship experienced by each participant was calculated. Table 35 shows that people in both supported living and residential care reported generally low levels of material hardship. There were no significant differences in reported material hardship between supported living and residential care.

Table 35: Hardship

		Supported Living	Residential Care	Test and statistical significance
Material Hardship Scale	Mean (sd) Range	1.23 (2.42) 0-12	1.43 (1.96) 0-5	t=-0.403, df=105, p=0.688

Qualitative Findings: Money

Participants were asked how they managed their money and what they thought about this.

Scott's story

Scott* lives in a supported living house with one housemate. They get on really well and like living together. The day service that he attends runs outreach sessions where they go to different places, such as to get ice cream or go trampolining. He also goes on lots of spontaneous days out with staff. Scott's support worker said that social services decided he wasn't allowed to have his own bank card anymore, which has caused huge problems as now the staff have to sign cheques in order to get money out for him. Because more places are becoming cashless due to the pandemic, it feels like he is being left behind. They are trying to fight this decision so that Scott can have more control over his money (Scott*, Supported Living).

*(*all names have been changed)*

The regulation of money: a spectrum of control

Echoing the quantitative findings, most people felt that they had choice over some aspects of their money, but, for most people, ultimate control seemed to rest with someone else. Whilst participants tended to have some control over day-to-day spending money, it was staff or family members who regulated how much money they had access to, for example managing their bank account or receiving their benefits for them. For some participants this was enough to enable them to feel in control of their money. For example, one participant in supported living stated, ***"no one chooses for me"*** (P36, SL) when discussing how her money was managed. However, she then went on to state:

> ***My mum has my other card because I have my money locked up…she has my monthly money saved up from when I was young. She is an appropriate adult for me so if I need anything from it my mum will tell me what things I need.*** (P36, SL)

Reiterating the lack of overall control, participants in both residential homes and supported living referred to having an 'allowance', 'spending money', 'pocket money' or similar. For example, one person commented, ***"every Monday I get pocket money, £5 a day. And I have to sign a voucher for it"*** (P1, RC). As this quote shows, access to money often formed part of a weekly routine, whether that was going to the bank, or being given money by staff on a certain day, ***"each week I take out £40 from the cash point"*** (P31, RC).

For people within residential homes and some people in supported living, access to, and the management of their money, was imbued with bureaucratic processes. Forms had to be signed, receipts kept and checks made:

> ***My money is over at the main house, so I have to go over and get my money and they have a form where they put out how much I have spent or how much I have in my wallet.*** (P37, RC)

This was particularly the case when participants wished to make larger purchases, or when a council appointee was in place as in the following example:

> ***I have to talk to the keyworker first, text her on the phone what I want it for, say I want a pair of trainers, she has to fill out a request form and send it to the people who look after my money and then I have to wait for it to be authorised and then it goes on my bank card.*** (P38, SL)

These processes result in participants lacking privacy in relation to their spending as staff recorded and monitored what was spent:

> ***They have my bank statements, I don't because I don't have a clue how to read them...if there is a problem…the manager comes and tells me 'why have you spent this amount?'....so whenever I spend something what I do is go down the office and say 'look I am going to buy this' or 'I have just brought this can you put it down that I have spent this amount of money' and they log it down so when the statements come through the manager doesn't bother me because they have it written down there, they don't have to come and sit with me for two hours because she wants to know what I spent, where I spent it.*** (P24, RC)

Whilst there was a sense of frustration attached to the time it took to get larger purchases agreed, participants within residential care were largely accepting of the processes in place. However, there were some participants in supported living who were unhappy with how their money was managed when an appointee was in place. Not only were they frustrated at the various hoops that had to be jumped through to access their money, they found the processes infantilising. One person, for example, said they were angry and felt they were being treated like a child, ***"I want to take responsibility for my money. I don't want to be a kid all my life"*** (P23, SL) whilst another described going through so many people to access his money as "*embarrassing*" and "*frustrating*" with it feeling *"like you are having to ask your mum or your brother"* and described being made to feel as if he has no independence:

> ***It takes quite a long time, I do have patience, but how long it takes. I need a break, away from all the interfering. They are acting in their best welfare, it feels like I have no independence, I can't do this and can't do that…maybe they see me as an in-able person not able to cope with looking after my money and not paying my bills…it feels like I have no control over it.*** (P38, SL)

For these participants, the lack of control they had over their money stood in contrast to how independent they were in other areas of their live, for example, P23 was able to drive, whilst P38 had a job and lived alone with minimal support.

Danny's story

Danny* lives in supported living with one other person who he knew previously. He says the best thing about his house is that it is a quiet street and he has good neighbours. Danny would like to have more contact with his family, he also says he does not do a lot and would like to do more things. He doesn't like the landlord as he won't let them make alterations they want. Danny is not happy with the way his money is managed via the council money management team and would like more control over it ('I want to take responsibility for my money. I don't want to be a kid all my life.') (Danny*, Supported Living).

*(*all names have been changed)*

Safeguarding money

The processes in place around the management of people's money, particularly the keeping of money in a safe or money tin in the office or sleep-in room, were often explained in terms of protection or safeguarding. For people in residential homes, the source of the threat to their money was elusive. For example, one participant, when asked why her money was kept in the safe in the office replied, ***"I have nowhere to put it and I rather no money going missing and rather they keep an eye on it"*** (P37, RC). However, it was unclear as to why money might go missing in the first place and whether it was her friends, housemates or staff who could not be trusted or herself.

Participants in supported living however, referenced more tangible threats to their money and described difficulties they had experienced in the past, with some people still suffering the fallout. P38 (in the quote above), despite wanting more control over his money, was aware the appointee was in place to safeguard him from financial abuse which had been an issue in the past:

> ***I guess they are doing it in a safeguarding way so other people don't get hold of it…it has been an issue before and I find it hard to say no to people so to them they think I am getting financially abused.*** (P38, SL)

Nevertheless, he didn't agree with this reason and felt he was ***"being protected too heavily"*** (P38, SL). P38 was not alone in experiencing financial abuse. Another participant stated, ***"my mum can't trust me with the card because I have a neighbour who would take advantage of me"*** (P36, SL) and one person was unable to have his own bank account and had to use his partner's due to the fallout from the financial abuse he had suffered in the past from his family. Alongside this, participants described struggling to budget and look after their money, ***"I do struggle but I am just not very sensible with money, more on taxis than anything."*** (P22, SL) and participants were wary of being scammed or caught out by signing up to payment plans they could not afford:

> ***If I order something from Amazon, I tell my Dad. I like to be safe with my money... Sometimes I check with staff, I show them what I've ordered.*** (P4, SL)

Furthermore, participants described requiring support to challenge unfair bills. Whilst billing errors can occur, it raises the question as to what happens if people don't have support in this area*:*

> ***They help with paperwork and make sure I do things properly because sometimes I rush into things. I rush into these payment plans and things like that. So, I have to make sure that it is an affordable payment plan, I am not paying too much. I just challenged a bill with SSE to do with electric at my old address which I moved from and it was an incorrect bill, so I filed a complaint against them and asked them to relook at the amount they were charging, and they were actually sorry about it and realised they were charging too much and issued a new bill so now I just have £10 a month to clear off £220 where it was nearly £900.*** (P34, SL)

In order to safeguard themselves, participants within supported living who had a greater amount of control over their money, discussed strategies they had in place to both manage their money. This is illustrated in the quote above where the participant ran purchases past staff to ensure she wasn't being scammed, whilst others talked about setting up direct debit payments and partners supporting with budgeting. The quantitative findings show that most people felt that the support they received currently with managing their money was sufficient.

Key Findings – Money, Benefits, Personal Budgets and Hardship

- Most people said or were reported by staff to be able to choose how they spend their money. Most people across both service models received help to look after their money, most commonly from paid staff then the person's parents.
- The qualitative findings reflected this, as most people felt they had choice over some aspects of their money, although ultimate control usually rested with someone else. For example, it was common that someone else would manage their bank account and the person would receive a set amount of spending money per week.
- People spoke about scrutiny that was in place over their spending, for example needing to keep records of their spending and to clear larger purchases with staff. People described the need to protect their money, although it was not always clear where the threat to their money was coming from.
- Around half of people received their benefits themselves. The most common benefits received were (in descending order) Personal Independence Payment, Employment and Support Allowance and Disability Living Allowance. People in supported living were statistically significantly more likely than people in residential care to receive Housing Benefit and Council Tax Reduction, likely due to the differences in the financial set-up of residential care and supported living.
- Most people didn't know whether or not they received a personal budget.
- There were no differences between supported living and residential care in terms of financial hardship, as measured by the Material Hardship Scale.

Table 36 shows that just around a third of people in supported living (34.7%) and residential care (38.1%) had a paid or voluntary job at the time information was collected, although as data collection took place throughout the COVID-19 pandemic further people had their job held over although they weren't formally on furlough (12.5% supported living; 42.9% residential care).

Fourteen people in residential care had a Quality Checker role within their support provider organisation, for which they received a voucher as payment. 82.4% of people within residential care who had a paid job received payment in the form of vouchers, compared to 0% of people in supported living, which was a significant difference, suggesting that this role accounted for the majority of people in residential care who had a job.

Staff questionnaires reported 35% of people in supported living and 19% of people in residential care as having a paid or volunteer job. They said that 9.5% of people in supported living had a paid job compared to 4.8% of people within residential care, and 26.2% of people in supported living had a voluntary job compared to 19.0% of people in residential care. These discrepancies may be due to differences in whether staff considered the Quality Checker roles to be a form of work or not.

Table 36: Paid and volunteering jobs

		Supported Living	Residential Care	Test and statistical significance
Does the person have a paid or volunteer job at the moment?	% Yes % Job being held but not on furlough % No	34.7% 12.5% 52.8%	38.1% 42.9% 19.0%	Chi-square= 13.119 df=4; p=0.011
If they have a job, is the person paid in vouchers for their job?	% Yes % No	0% 100.0%	82.4% 17.6%	**Fisher's exact test p < 0.001**
Staff Q – does the person have a paid or volunteer job?	% Yes % Job being held but not on furlough % No	34.9% 2.3% 62.8%	19.0% 4.8% 76.2%	Chi-square=1.84; df=2; p=0.399

The number of people in paid or voluntary jobs were too small to conduct comparative analyses between people in supported living and people in residential care on the characteristics of these jobs. The people who received payment in the form of vouchers have been removed from the following analyses:

Across supported living and residential care:

- People worked in their volunteer jobs for an average 6.6 hours per week (sd 5.2), ranging from 30 minutes to 18 hours per week.
- 60% of people in volunteer jobs were happy with the hours they worked and 40% wanted more hours.
- A large majority of people (89.7%) were happy with their volunteer job.

- A large majority of people (88.2%) chose their volunteer job.
- People worked in their paid jobs for an average 12.9 hours per week (sd 12.7), ranging from 1 to 37 hours per week (staff questionnaire average 9.3 hours per week, sd=7.6, 1-26 hours per week).
- 66.7% of people in a paid job were happy with the hours they worked, some wanted more hours (16.7%) and 16.7% wanted fewer hours.
- A large majority of people (81.8%) were happy with their paid job.
- Everybody said that they had chosen their paid job (100%).
- Only one person said that they earnt at least minimum wage from their paid job; the other people did not know.

For people not in a paid or volunteer job:

- The most common reasons for the person not having a job were the person's health (40.0% of people), and/or the person not wanting a job (30.0%).
- Just under half of people (48.4%) would like a paid job.
- Under half of people (44.0%) would like a volunteer job.
- 38.5% of people had been offered training to help them work.
- 42.1% of people get help looking for work.

Qualitative Findings: Work and employment

Participants discussed their career aspirations and ideal jobs, and people with paid or voluntary jobs spoke about what they thought about their current role. A number of challenges were described that made it difficult for people to fulfil their career aspirations.

Leon's story

Leon* lives in a two-bedroom supported living flat. He originally moved here with a friend, who later moved out to live with their partner, so Leon decided to stay. This means that he has to pay bedroom tax. Leon receives support a few times a week with cleaning and there are staff on-site if he needs ad-hoc support. Leon has four jobs, two paid and two voluntary roles, and he works one day a week at each. His aspiration is to get a paid role at the organisation he volunteers for, doing advocacy and support (Leon*, Supported Living).

*(*all names have been changed)*

The constraining of opportunities

Participants discussed a number of barriers which prevented them from working or progressing within both voluntary and paid work, with structural issues constraining the availability of opportunities. Firstly, opportunities for work were limited and participants who wanted to work struggled to find suitable roles to apply for. For example, one participant expressed a desire to learn to drive so as to reach jobs in places that were not accessible via public transport. In addition to this, some people felt that being disabled or a lack of the right education or qualifications, prevented them from being able to get a job:

I do want a paid job but probably with my disability I wouldn't be able to get a paid job. (P3, SL)

This is the problem with other jobs, I was looking at one working in a nursery, but I wouldn't have the certificate you would need. (P27, SL)

Paid employment was viewed as out of reach by many and there was a lack of discussion about how it could be made accessible, for example through job carving or reasonable adjustments.

Participants were constrained by the benefits system, as there was a concern about the implications earning money or working more hours would have on their benefits as demonstrated by the following two participants:

The thing we're worried about is losing the benefits if we do too many hours. (P12, RC)

It's to do with my money as I have benefits, but if I do more jobs it would stop my money. (P25, RC)

Such concern was not unfounded, with one participant describing difficulties previously experienced in this area:

I did have a little job about last year or the year before, at a cafe, but I got some money… I forgot to declare that I was working and I got done didn't I? …. I forget to declare it so I'm paying that back. (P14, SL)

Perhaps for this reason, the people who lived in a residential home and reported working, for example in a local café or with the support provider, were paid in vouchers:

I get my money and the money goes to my Dad. It comes in a ticket, a token and my Dad exchanges it in real money for me. (P9, RC)

Low paid work was common, with only half of participants with a paid job saying that they earnt at least the minimum wage.

Participants who were in paid employment also described difficulties which impacted on their ability to sustain the role. For example, one person who was living in supported living and working in a care home, explained how the shift work meant he finished late in the evenings resulting in him having to pay to get a taxi home as he was worried about going on the bus so late. This cost a lot of money and, together with a lack of support in the role, had made the job unsustainable:

> ***I had a job but unfortunately I have had to give it up because it was too far for me to travel, and it was costing me a lot of money, so I had to hand my resignation in. It was just like I wasn't getting the right support. It was a fast pace, and I didn't like the way I got treated and that so...they have been great, but I just wanted a bit more support where I struggle with things. Like I struggle with my writing and money, and I find it quite hard speaking to people, communicate with people, I find that quite hard. I was just thrown in at the deep end...It weren't that far but it was costing me like £15 a time at night because of where we live, it's not dangerous but I don't like it at night sometimes, so it was costing me quite a lot of money from my wages [on taxis].*** (P22, SL)

Ben's story

Ben* lives alone in a flat which he says is 'OK'. His rent is paid by support provider and in return he volunteers with them. Whilst he no longer requires any formal support, Ben is able to access ad-hoc support from the provider when needed. He currently works full-time but is in the process of switching jobs as the hours and commuting distance were too much. He was spending lots of money on taxis to get back from work late at night instead of using the bus (Ben*, Supported Living).

*(*all names have been changed)*

Other participants expressed a desire to progress and be challenged at work, ***"I would like another job, something a bit calmer maybe or a bit more brain-power needed"*** (P7, SL), with one person who was volunteering as a quality checker wanting to capitalise on their experience and work for CQC as an expert by experience but being unable to do so due to so few opportunities. In keeping with the quantitative findings, many people wanted to work more hours at their current job. For example, some participants were unable to work more hours at their voluntary job due to work needing to be shared out amongst all volunteers. Another participant who wished to volunteer, and had been until recently, was unable to continue to do so due to the need to divulge his criminal record which he was uncomfortable doing, ***"it is because I had to divulge my past a bit…I left for a while; said I was ill. That's my excuse."*** (P23, SL)

It's not about the money

Participants who did work, either paid or voluntary, valued the latent benefits working brought. For example, working provided a sense of purpose, with people taking pride in their skills and contributions as in the following examples, ***"They love my company and I always got good skills yeah."*** (P1, RC) *and* ***"I like it as it gets me out and about. It makes me feel important and useful."*** (P25, RC). This was particularly the case for participants who were drawing on their personal experience to help others or address a gap in services. For example, one person was setting up a group to help women who had been abused and another had worked for Transforming Care. For some participants work was a reason to get out of their house and move beyond their immediate environment as well as a means to expand their social networks, to meet and talk with different people, as the following participants who volunteered expressed:

> ***I'm enjoying it actually, cos of mixing with other people….I see customers coming in, chat to them what they want and help them out .*** (P3, SL)

> ***I really love it, it gets me out the house, it gets me to mix with other folks, so I really love it.*** (P26, RC)

The voucher that some people received for their voluntary work was, therefore, viewed as a bonus rather than the motivation for the work:

> ***I love it [quality checking]. It's like a double whammy, I like seeing everyone, meeting the staff there, meeting the residents and seeing how it is run and how they are getting on so that's a bonus and then we get a gift voucher as well so that's what I mean it is kind of like a double whammy.*** (P27, SL)

Similarly, the participant in residential care who was in paid employment focused on the friends she had made through work, rather than the pay. The importance of the latent benefits gained through working is emphasised within the blurring of boundaries surrounding what constitutes work that sometimes occurred. People described day services or social enterprises which required a fee to attend as their place of work as in the following example:

> ***I work in a café every Monday morning…I make a lot of paninis, I've learnt how to make proper coffees with the new coffee machine…I have to pay to work in the café.*** (P6, SL)

Maddy’s story

Maddy* lives in a residential home with five other people. She said ‘it’s a nice home… it’s got a good feeling.’ She does voluntary work at a youth club and also started a social enterprise selling handmade cards. Her dream is to start her own business making candles and jewellery, and she is putting on a stall next year to work towards this (Maddy*, Residential Care).

*(*all names have been changed)*

Key Findings – Jobs and Volunteering

- Around a third of people in supported living and slightly more people in residential care had a paid or voluntary job. Some people had lost their jobs due to the COVID-19 pandemic; for other people, their job was being held for them although they were not on furlough.
- The majority of people in residential care who had a job were Quality Checkers for their provider organisation, for which they received payment in the form of a voucher.
- People in voluntary jobs worked on average just over 6 hours per week, compared to people in paid jobs who worked on average 13 hours per week.
- Only one person said that they earnt at least minimum wage from their paid job; the other people did not know.
- The most common reasons for the person not having a job were the person’s health and/or not wanting a job.
- People discussed a number of structural barriers to finding a job or progressing within their current role. These included a lack of suitable roles to apply for, a lack of opportunities for progression and a lack of reasonable adjustments made to accommodate their disability. People were particularly concerned that their benefits would be sanctioned if they found a paid job or worked too many hours.
- People who worked work valued their roles as they gave a sense of purpose, an opportunity to meet people and learn new skills.

Transport

For many people, having easy access to facilities in their local area was an important consideration when choosing where to live (see 'Location, Location, Location' page 39). Transport options are therefore key in helping people to have a sense of independence and freedom where they live.

Table 37 shows that most people in supported living (55%) and residential care (77%) usually needed someone to go with them if they want to go somewhere; for 20% of people in supported living and 7% of people in residential care this depended on where they were going. For less than half of people in supported living (41%) there was usually someone around to go with them compared to 33% of people in residential care; 21% of people in supported living said that all outings had to be planned in advance, compared to 37% of people in residential care. Statistical tests indicated no significant differences in availability of staff to accompany them between supported living and residential care.

Just over a third of people in supported living (38%) and just over half of people in residential care (54%) had ever had difficulties using public transport.

Table 37: Transport

		Supported Living	Residential Care	Test and statistical significance
When you want to go somewhere, do you usually need someone to go with you?	% Yes	54.7%	76.7%	Chi-square=4.76; df=2; p=0.093
	% No	25.3%	16.7%	
	% Depends on where I am going / how far	20.0%	6.7%	
Is there usually someone around who can help you when you want to go somewhere?	% There is usually someone around who can help	41.2%	33.3%	Chi-square=5.47; df=4; p=0.241
	% Usually have to wait	0.0%	3.7%	
	% Some days there is someone around, some days there isn't	23.5%	22.2%	
	% All outings have to be planned in advance	21.0%	37.0%	
	% Other	13.7%	3.7%	
Do you ever have difficulties using public transport?	% Yes	37.5%	53.8%	Chi-square=3.60; df=3; p=0.308
	% No	55.6%	34.6%	
	% NA (don't use public transport)	5.6%	7.7%	
	% Don't know	1.4%	3.8%	

People in supported living reported using a variety of modes of transport, with the majority walking or travelling by wheelchair / scooter (65%), being driven by someone else (55%) and using a bus or tram (65%); 42% of people in supported living reported using taxis frequently (see Table 38). People in residential care also reported getting around by walking / wheelchair (63%), being driven (47%) and using the bus or tram (47%). In addition, 47% of people in residential care reported travelling in a minibus with people with learning disabilities, compared to 9% of people in supported living. Statistical tests suggested that people living in residential care were significantly more likely to be driven in a minibus compared to people in supported living (Fisher's exact test $p < 0.001$). Other forms of transport mentioned were most commonly Motability vehicles.

Table 38: How does the person usually get to places?

		Supported Living	Residential Care	Test and statistical significance
Walk / wheelchair / mobility scooter	% Yes	64.5%	63.3%	Fisher's exact test p=1.000
	% No	35.5%	36.7%	
Drive myself	% Yes	1.3%	0%	Fisher's exact p=1.000
	% No	98.7%	100.0%	
Driven by family / friends / PA in car	% Yes	55.3%	46.7%	Fisher's exact test p=0.518
	% No	43.7%	53.3%	
In a minibus / car with people with learning disabilities	% Yes	9.2%	46.7%	**Fisher's exact test p < 0.001**
	% No	90.8%	53.3%	
Taxi	% Yes	42.1%	30.0%	Fisher's exact test p = 0.277
	% No	57.9%	70.0%	
Bus / tram	% Yes	64.5%	46.7%	Fisher's exact test p = 0.124
	% No	35.5%	53.3%	
Train	% Yes	32.9%	26.7%	Fisher's exact test p = 0.644
	% No	67.1%	73.3%	
Bike	% Yes	5.3%	3.3%	Fisher's exact test p = 1.000
	% No	94.7%	96.7%	
Other	% Yes	10.7%	20.0%	Fisher's exact test p = 0.217
	% No	89.3%	80.0%	

Key Findings – Transport

- Most people said that they usually needed someone to go with them if they wanted to go somewhere. Staff were not always available to go with them when they wanted to go somewhere.
- The most common modes of transport used by people in supported living were walking / travelling by wheelchair or scooter, using a bus or tram and using a taxi.
- The most common modes of transport used by people in residential care were walking / travelling by wheelchair or scooter, being driven and using a bus or tram. People in residential care were more likely to report travelling in a minibus with people with learning disabilities, compared to people in supported living.

As Table 39 below shows, relatively small minorities of people in supported living (10%) and residential care (14%) were members of a self-advocacy group, although some people who weren't currently members wanted to be (22% supported living; 5% residential care).

Just over three quarters of people in supported living (77%) and residential care (77%) were reported to have someone who helps them speak up. For most people this was a staff member within the person's home or provider organisation (83% supported living; 72% residential care), followed by a family member (40% supported living; 39% residential care), an advocate (19% supported living; 22% residential care) or a social worker (8% supported living; 22% residential care). There were no statistically significant differences between people in supported living and residential care.

Table 39: Self-advocacy and advocacy

		Supported Living	Residential Care	Test and statistical significance
Is the person a member of a self-advocacy group?	% Yes	10.2%	13.6%	Chi-square=5.03; df=3; p=0.170
	% No but would like to be	22.0%	4.5%	
	% No and not interested	50.8%	72.7%	
	% Don't know	16.9%	9.1%	
Does the person have someone who helps them speak up?	% Yes	77.4%	77.3%	Chi-square=0.80; df=2; p=0.670
	% No	19.4%	22.7%	
	% Don't know	3.2%	0.0%	
If so, who helps the person to speak up?				
Family member	% Yes	39.6%	38.9%	Fisher's exact test p=1.000
	% No	60.4%	61.1%	
Friend	% Yes	6.3%	5.6%	Fisher's exact test p=1.000
	% No	93.8%	94.4%	
Staff (within provider / home)	% Yes	83.3%	72.2%	Fisher's exact test p=0.319
	% No	16.7%	27.8%	
Staff (external)	% Yes	2.1%	0.0%	Fisher's exact test p=1.000
	% No	97.9%	100.0%	
Advocate	% Yes	18.8%	22.2%	Fisher's exact test p=0.739
	% No	81.3%	77.8%	
Social worker	% Yes	8.3%	22.2%	Fisher's exact test p=0.199
	% No	91.7%	77.8%	
Other	% Yes	8.3%	16.7%	Fisher's exact test p=0.380
	% No	91.7%	83.3%	

Table 40 shows that almost three quarters of people in supported living (74%) and residential care (74%) were registered to vote. Fewer people (49% supported living; 30% residential care) had voted in the December 2019 general election.

Table 40: Voting

		Supported Living	Residential Care	Test and statistical significance
Is the person registered to vote?	% Yes % No % Don't know	74.2% 18.2% 7.6%	73.9% 21.7% 4.3%	Chi-square=0.38; df=2; p=0.828
Did the person vote in the general election in December 2019?	% Yes % No % Don't know	48.5% 34.8% 16.7%	30.4% 65.2% 4.3%	Chi-square=6.87 df=2; p=0.032

Key Findings – Self-Advocacy, Advocacy and Voting

- Only a few people in supported living (10%) and residential care (14%) were members of a self-advocacy group, although some people who weren't currently members wanted to be (22% supported living; 5% residential care).
- Over three quarters of people said that they had someone who helped them speak up. This was most commonly a staff member within their home or a staff member. 19% of people in supported living and 22% in residential care had an advocate.
- Three quarters of people across both service models were registered to vote, however less than half of people had voted in the last general election.

Table 41 below shows information from staff questionnaires about how often people had been involved in a range of activities indicating different facets of community involvement in the last four weeks. When interpreting the information in this table it is crucial to remember that this information was collected at various stages of the COVID-19 pandemic. Responses were collected over a period of 9 months with various restrictions in place, ranging from partial lockdowns in March 2021 to the majority of legal restrictions on social contact being restricted (see Project Timeline pages 14-17). Furthermore, services may have had their own stricter restrictions in place alongside government guidance, such as operating restrictions on visitors. The impact of staff shortages on the availability of support for various activities should also be considered; People may also have been exercising due caution in where they went and who they met to protect themselves and others.

Table 41 shows that overall staff reported that people in supported living were statistically significantly more likely to experience greater community involvement than people in residential care. Examination of the specific activities in Table 41 shows that there was one statistically significant difference: people in supported living had been out shopping more than people in residential care. For people in supported living, the most common activities were going shopping (average 6.7 times in the last four weeks), going on public transport (5.4 times), and going to a café or restaurant (4.7 times). For people in residential care, the most common activities were trips out with family or friends (3.1 times in the last four weeks), shopping (3.1 times), and going to a café or restaurant (2.7 times).

It is worth noting that overall there were very low levels of community involvement in most of the activities in Table 41 for people in both supporting living and residential care.

Table 41: Index of Community Involvement

Staff Q: Number of times in the last 4 weeks that the person has…		Supported Living	Residential Care	Test and statistical significance
Had guests to stay	Mean (sd) Range	(0.0) 0 - 0	(0.2) 0-1	Mann-Whitney U=420.0; n=63; p=0.157
Had family or friends round for a meal	Mean (sd) Range	0.8 (1.6) 0-8	0.5 (1.0) 0-3	Mann-Whitney U=468.5; n=63; p=0.615
Had been to a social club	Mean (sd) Range	2.1 (3.5) 0-16	(1.3) 0-4	Mann-Whitney U=475; n=63; p=0.707
Been on an overnight stay to family or friends	Mean (sd) Range	0.9 (2.7) 0-16	0.5 (1.1) 0-4	Mann-Whitney U=463; n=64; p=0.815
Had trips out with family or friends	Mean (sd) Range	1.6 (2.2) 0-8	3.1 (3.9) 0-15	Mann-Whitney U=326.5; n=63; 0.080
Been to a café or restaurant	Mean (sd) Range	4.7 (5.1) 0-28	2.7 (2.9) 0-8	Mann-Whitney U=550.5; n=62; p=0.070
Been to a pub or club	Mean (sd) Range	2.3 (3.1) 0-14	1.8 (1.9) 0-6	Mann-Whitney U=395; n=58; p=0.912
Been to a hairdresser	Mean (sd) Range	0.6 (0.8) 0-3	0.9 (0.8) 0-3	Mann-Whitney U=308.5; n=60; p=0.085
Been shopping	Mean (sd) Range	6.7 (4.2) 2-24	3.1 (3.4) 0-12	**Mann-Whitney U=653; n=60; p<0.001**

Staff Q: Number of times in the last 4 weeks that the person has…		Supported Living	Residential Care	Test and statistical significance
Been to a place of religious worship	Mean (sd) Range	0.8 (1.8) 0-8	0.5 (1.3) 0-4	Mann-Whitney U=465; n=63; p=0.630
Been to a sports event	Mean (sd) Range	0.2 (0.8) 0-4	0.5 (0.9) 0-3	Mann-Whitney U=387; n=63; p=0.216
Been to the cinema	Mean (sd) Range	0.5 (1.0) 0-4	(0.6) 0-2	Mann-Whitney U=434; n=63; p=0.894
Been to a concert or play	Mean (sd) Range	(0.4) 0-2	(0.4) 0-2	Mann-Whitney U=460.5; n=63; p=0.544
Been on a public bus, train or tram	Mean (sd) Range	5.4 (11.1) 0-56	1.5 (2.9) 0-10	Mann-Whitney U=494.5; n=62; p=0.278
Been to their bank or post office	Mean (sd) Range	2.1 (2.2) 0-10	(1.6) 0-4	Mann-Whitney U=519.5; n=60; p=0.068
Taken part in a sport	Mean (sd) Range	1.2 (3.0) 0-12	(1.0) 0-4	Mann-Whitney U=446; n=61; p=0.425
Total score for Index of Community Involvement	Mean (sd) Range	31.2 (20.4) 0-84	18.2 (11.2) 1-37	**t=-2.82; df=41; p=0.007**

In the staff questionnaire, staff were asked about the person’s social networks. As Table 42 shows, there were no statistically significant differences between service types in the average number of people in the person’s social network overall (supported living 9.8 people; residential care 8.5 people) or in the average number of people in specific domains of people’s social networks. People in supported living were reported by staff to have the greatest number of people in their family (mean 2.4 people) and formal services (2.4 people) social networks. People in residential care had the greatest number of people in their household (3.3 people) and family (3.1 people) social networks. Within both types of service there was substantial variation in the size of people’s social networks and the average overall size of people’s social networks may be considered to be quite low, although the potential impact of the COVID-19 pandemic on people’s social networks must be borne in mind when interpreting these findings.

Table 42: Social networks

Staff Q: People in the person’s social network		Supported Living	Residential Care	Test and statistical significance
Formal services	Mean (sd) Range	2.4 (2.9) 0-13	1.4 (1.8) 0-5	Mann-Whitney U=297.5; n=48; p=0.165
Household	Mean (sd) Range	1.7 (1.9) 0-8	3.3 (2.5) 0-8	Mann-Whitney U=203.0; n=57; p=0.023
Family	Mean (sd) Range	2.4 (2.1) 0-10	3.1 (2.1) 0-8	Mann-Whitney U=272.0; n=58; p=0.185
Work/day service	Mean (sd) Range	0.9 (1.4) 0-4	(0.4) 0-1	Mann-Whitney U=283.0; n=47; p=0.150
Organisations/clubs	Mean (sd) Range	(2.8) 0-15	(0.6) 0-2	Mann-Whitney U=290.5; n=49; 0.194
Neighbours	Mean (sd) Range	0.8 (1.0) 0-4	(0.3) 0-1	Mann-Whitney U=397.0; n=52; p=0.012

Staff Q: People in the person's social network		Supported Living	Residential Care	Test and statistical significance
Other friends	Mean (sd) Range	1.4 (1.8) 0-7	0.9 (0.8) 0-2	Mann-Whitney U=297.0; n=51; p=0.558
Total number of people in the person's social network	Mean (sd) Range	9.8 (7.0) 1-33	8.5 (5.4) 0-17	t=-0.69; df=56; p=0.496

Most people in supported living (65%) and residential care (77%) were reported to spend their time how they wanted (see Table 43 below). Of the remainder, a minority could do some of the things they liked, it was OK (17% supported living; 18% residential care), and the rest could do some of the things they liked but not enough (supported living 18%; residential care 5%). There was no statistically significant difference between people in supported living and people in residential care.

Table 43: How people spend their time

		Supported Living	Residential Care	Test and statistical significance
When thinking about how the person spends your time, would they say...	% They spend their time how they want	65.2%	77.3%	Chi-square= 2.46; df=2; p=0.293
	% They can do quite a lot of things they like, it's OK	16.7%	18.2%	
	% They can do some of the things they like, but not enough	18.2%	4.5%	
	% They do not do any of the things they like	0.0%	0.0%	

Qualitative Findings: How people spend their time

Participants were asked how they tended to spend their time during the week and at the weekend, and what they liked doing. As with the quantitative data, it is important to remember that various levels of COVID restrictions were in place at the time of speaking to participants. Almost everyone discussed how the pandemic and associated restrictions had disrupted their usual routine and limited what they were able to do.

Will's story

Will* lives in his own flat in a block of supported living flats, managed by two different providers. He likes living by himself and having a spare room for his computer and a football table. Will has a voluntary job and a paid job, and he goes to a drama group. He often goes out by himself in the local area or to visit family. Will's aspiration is for his girlfriend to eventually move into his flat with him; she lives with her family currently. He would also like to teach sign language (Will*, Supported Living).

*(*all names have been changed)*

Creating a structure to the week with what's to hand

Having a routine or structure to their week was important to people:

> ***I like the routine as it was, and if my routine changes one little bit I find that frustrating. I like to know what I am doing and how I am doing it, how I am getting there, when we are getting there...*** (P24, RC)

However, as the quantitative statistics show only around a third of participants had a paid or voluntary job. For those who were volunteering, the work was often sporadic and not on a regular basis. Therefore, in the absence of work or education which can provide a natural rhythm to one's week, people appeared to be trying to create a weekly routine from what else they had to hand. Replicating a typical working week, weekdays were viewed as a time to keep busy whilst weekends were seen as a time of rest, as one participant described weekends were for ***"[Sitting] down and have a rest and that."*** (P31, RC) and another stated, ***"I like the weekend to be quieter than the week."*** (P8, RC) This view was echoed by staff completing the proxy-participant questionnaires whereby one staff member commented, ***"we are currently trying to structure his week more so that the weekends can be used for relaxing"*** (P38, proxy response, RC).

For many participants household tasks thus appeared to have an elevated status. They happened at fixed points in the week as they became incorporated into a weekly routine and seemed to plug a gap left by the absence of other activities. As a result, household tasks featured heavily in participants' accounts of how they spend their time. For example, one person, who had very minimal support, described how they spent their time, ***"washing, laundry, nothing exactly glamorous"*** (P39, SL) whilst other participants, again with minimal support, explained they ***"change bedding on a Friday"*** (P40, SL) or had set days in which they do their food shopping:

> ***Monday or Tuesday I tend to do my food shopping*** (P37, RC)

> ***On Sunday I sit in and watch the tele, the football or do my embroidery and then watch quizzes at night. Same on Saturday I might watch quizzes and that. On Monday, it depends what the weather is like but if it is nice, I might do a bit of shopping or something and the same on Wednesday.*** (P32, SL)

There was, however, a lack of clarity over how much control some participants had over their week and the relationship between the attaching of tasks to particular days and the institutional framework within which they lived. For example, one person stated, ***"I don't***

like Monday. It's one of these days you gotta wake up, do your chores, do your exercise, do all your routines." (P1, RC) with it being unclear whether or not Monday as a day of housework stemmed from her or from her home. Another participant stated, ***"we have an inventory list. What things we're instructed to do for the day."*** – (P5, RC) suggesting these tasks were allocated to them rather than self-directed. Similarly, a participant within supported living stated that ***"at home" they "do daily jobs…cleaning jobs, we take it in turns and have a rota."*** – (P19, SL) again with it being unclear as to whether the rota was put in place by staff or whether it originates from the housemates searching for a fair way to share out the housework.

Louise's story

Louise* lives in a house-share with some friends from school. When they moved in there were some problems with the support organisation, so their families took over running the house as a trust. They have lots of parties and enjoy going on holidays and seeing shows. Louise works in a nursery and loves playing with the children and giving them their lunch. She has competed nationally at swimming. It has been hard not seeing her family during COVID-19, but she sometimes meets up with them outside (Louise*, Supported Living). *(all names have been changed)*

Finding a balance

Whilst having a routine or structure was important, participants also appreciated having room for spontaneous activities and valued bigger trips out, when ***"no two days are the same"*** (P16, RC) and a balance between spending time out of the house and having time at home to relax and enjoy their hobbies. For example, one participant in supported living who was content with how they spent their time described their week as a mixture of both structured and non-structured activities:

> ***I used to do adult education, but I decided not to. I do gardening two days a week and I just spend the rest exploring, going on days out. Been to lots of places recently… I like getting trains and buses.*** (P20, SL)

*S*imilarly, a participant in residential care who was also particularly happy with their week described a week which contained a mixture of work, chores, and social activities, with a balance between time spent out of the house and time at home to watch TV, or chat with friends and family. A third participant, meanwhile, explained how happy they were with not working, despite not quite being retirement age as she found things to do. She was a member of her local church and attended a number of regular groups through the church such as a weekly bible study group and a lunch club in addition to a drama group for people with learning disabilities. She explained her sister had been concerned she would be bored but this wasn't the case:

> ***I think my sister was a bit worried at first that I would get bored doing nothing, but I haven't got bored because you find things to do - go out when you want, stay in when you want. Like today I haven't got dressed!*** (SL)

Whilst the participants drawn on in the above examples had very different weeks to each other, what they had in common was a connection to their local community, a balance between structured activities and spontaneity and ultimately, they felt in control of how they spent their time.

This stands in contrast to many participants, across both supported living and residential homes, who appeared to desire the balance between time at home and time out of the house, but, in the absence of more structured activities or a purpose for leaving the house, described going into town to 'look around' with 'browsing' and 'a bit of shopping' reasons for getting out:

> ***Go get some clothes or something, just look around.*** (P28, RC)

> ***I go out for some fresh air as it does get a bit claustrophobic in here if you are here 24 hours a day…I go out every Tuesday for a breath of fresh air, just down the road and back.*** (P39, SL)

In keeping with this, the quantitative data shows that going to the shops was one of the most frequent things that people did outside of the house.

A lack of money, support, and issues with mobility arose as barriers preventing people from going out and finding the sense of balance that they desired. For example, one of the participants who spent his time going to the café and looking around explained how he used to go to college to do ***"arts and crafts"*** but ***"can't go there no more, it is too expensive for me"*** (P31, RC) whilst another stated, ***"I used to like going to see lots of football matches but I haven't been for a long time. I stopped going before COVID anyway cos it's so expensive"*** – (P14, SL). A staff member supporting one participant in the interview explained how he had recently had his support hours cut, which was going to impact on what he could do:

> ***He recently had his hours shortened he has gone from full 1:1 hours and been deducted about 40 hours which is a substantial amount considering [he] doesn't like to spend any time on his own.*** (P33, RC)

Participants in supported living with minimal support also described the impact of their mental health on what they could do, with anxiety alongside a lack of motivation and confidence often preventing them from going out*:*

> ***I used to go to the hub but I wasn't comfortable around quite a lot of people because there is quite a large group that goes, it is just my anxiety levels and ADHD and stuff.*** (P34, SL)

> ***I used to go to a day centre…[but] my mental health went down and I couldn't do anything else.*** (P29, SL)

Conversely, one participant was aware that his support was pivotal in being able to achieve the balance and life he wanted:

> ***It's good because if I didn't have my support I might decide to just, 'oh I can't be bothered' But with support I can plan days out or whatever I need to do.*** (P6, SL)

Key Findings – How People Spend Their Time

- People in supported living experienced significantly higher levels of community involvement than people in residential care, as indicated by staff responses on the Index of Community Involvement. However, people in both supported living and residential care tended to experience low levels of community involvement in general; this may have been in part due to the COVID-19 pandemic.
- No differences were found in terms of people's social networks as reported by staff across supported living and residential care. The average size of people's social networks was quite small, although COVID-19 may have impacted this.
- Most people felt that they were able to spend their time doing what they liked.
- Many people found it helpful having some sort of structure or routine to their week. As many people did not work, or only worked sporadically, household tasks became more important and often took place on set days.
- People valued having a balance between routine and flexibility, with room for spontaneous days out and activities. A balance of time spent at home and going out was also important.

Table 44 below shows that, according to staff questionnaires, the vast majority of people in supported living (83%) and residential care (95%) had some contact with their family. For people in supported living this was most commonly on a weekly basis (56% of people), followed by seeing family at least a few times a year (25%) or less often (17%). For people in residential care, people most commonly saw their family at least a few times a year (55%), followed by seeing family on a weekly basis (40%) then seeing family once a year or less (5%). For a substantial majority of people in supported living (74%) and residential care (90%) the COVID-19 pandemic had resulted in them seeing their family less often.

Table 44 also shows that most people in supported living (78%) and residential care (62%) had friends they liked to spend time with. People in supported living most commonly saw friends on a weekly basis (57%), followed by seeing friends on a daily basis (23%), at least a few times a year (11%) or less often than this (9%). People in residential care most commonly saw friends at least a few times a year (57%), followed by seeing friends daily (36%) and weekly (7%). These patterns of seeing friends were statistically significantly different across supported living and residential care. Again, the COVID-19 pandemic had resulted in 73% of people in supported living and 56% of people in residential care seeing friends less often.

Table 44: Contact with family and friends (staff questionnaire)

Staff Q – contact with friends and family		Supported Living	Residential Care	Test and statistical significance
Does the person ever see their family/relatives?	% Yes % No	83.3% 16.7%	95.2% 4.8%	Fisher's exact test p=0.250
How often does the person see their family/relatives?	% Every day/ nearly every day	2.8%	0.0%	Chi-square=5.82; df=3; p=0.121
	% Every week/ nearly every week	55.6%	40.0%	
	% At least a few times a year	25.0%	55.0%	
	% Once a year or less	16.7%	5.0%	
Has COVID-19 affected how often they see their family/relatives?	% Yes, see them less % Yes, see them more % No change	73.7% 2.6% 23.7%	89.5% 0.0% 10.5%	Chi-square=2.04; df=2; p=0.361
Does the person have friends they like to spend time with?	% Yes % No	78.0% 22.0%	61.9% 38.1%	Fisher's exact test p=0.232
How often does the person see their friends?	% Every day/ nearly every day	22.9%	35.7%	**Chi-square=16.19; df=3; p=0.001**
	% Every week/ nearly every week	57.1%	7.1%	
	% At least a few times a year	11.4%	57.1%	
	% Once a year or less	8.6%	0.0%	

Staff Q – contact with friends and family		Supported Living	Residential Care	Test and statistical significance
Has COVID-19 affected how often they see their friends?	% Yes, see them less % Yes, see them more % No change	73.0% 0.0% 27.0%	56.3% 0.0% 43.8%	Fisher's exact p=0.337

As Table 45 below shows, by far the most common way for people to keep in touch with family and friends was through phone calls (82% supported living; 73% residential care), followed by Skype/Zoom/Facetime (45% supported living; 48% residential care) and text/Whatsapp messages (23% supported living; 19% residential care). There were no statistically significant differences between people in supported living and people in residential care.

Table 45: Contact with friends and family

How does the person keep in touch with friends and family?		Supported Living	Residential Care	Test and statistical significance
Phone calls	% Yes % No	82.1% 17.9%	72.7% 27.3%	Fisher's exact test p=0.365
Text messages / whatsapp	% Yes % No	23.2% 76.8%	19.0% 81.0%	Fisher's exact test p=0.768
Skype / Zoom / Facetime	% Yes % No	44.6% 55.4%	47.6% 52.4%	Fisher's exact test p=1.000
Email	% Yes % No	7.3% 92.7%	9.5% 90.5%	Fisher's exact test p=0.666
Social media e.g. Facebook	% Yes % No	10.9% 89.1%	14.3% 85.7%	Fisher's exact test p=0.701
Video games	% Yes % No	3.6% 96.4%	0.0% 100.0%	Fisher's exact test p=1.000
Other	% Yes % No	5.5% 94.5%	14.3% 85.7%	Fisher's exact p=0.338

Qualitative Findings: Friends and family

As with how they spent their time, it was clear that the COVID-19 pandemic and associated restrictions had a big impact on whether and how often people were able to see their friends and family. Despite this, people found ways to stay in contact and spoke about relationships in their life that were important to them.

Sarah's story

Sarah* lives in a residential home with five other people. She used to have her own flat with occasional support, however she was finding it difficult to care for herself. Sarah enjoys the company of her housemates but she feels that things have gone 'downhill' since one of her friends moved out - if she could, she would like to move to be closer to her friend. Sarah is good friends with another housemate, but there is one person who she doesn't get on with so well (Sarah*, Residential Care).

*(*all names have been changed)*

Friends: a spectrum of meaning

Participants across both supported living and residential care described a range of relationships when discussing who their friends were. Some participants described close, long-lasting relationships, listing friends by name and describing regular contact. These participants tended to live in supported living as in the following three examples:

> ***Sarah* just lives down the road from me, about 5 minutes, I know her through my drama. She used to be really really shy years ago and she came to a line dancing thing and that is how I first met her…Louise* lives the other end of town and Sam* who lives two mins down the road from me. Sam used to live in the same house as me…Louise goes to my church, and Sam I ring up now and again or she rings me.*** (P35, SL) *(*all names have been changed)*

My friends are Jackie* and Dave*, Karen*, and Simon*…Simon used to live near me and I used to go down there and look after him as he is not well so I used to go down and see them and he used to look after me when I was little and stuff like that and Jackie and Dave I know them through diabetic club - I see them when I can, with lockdown I can't, but Karen and Simon I see quite a lot. Everyday, I come out and see them - just cross the car park and you are there, their bungalow. (P29, SL) *(*all names have been changed)*

The friends I meet up with in Southampton* where I live, we meet up in the centre, go out for meals or go out for a coffee or something… It don't stop there, cos sometimes we get together and travel to Winchester* and Bournemouth*. Bus trips.. (P3, SL) *(*all locations have been changed)*

However, others explained their friends were people they occasionally bumped into in town and said hello to:

I can't always remember their names because they don't see us that often. They are in Bristol* and they might see us in town…but it is only when I am shopping in town…they recognise me and say, 'oh there is the lad I used to do such when his parents were such and such, he's a good lad', oh they speak to us and talk to us and say hello to us. They're nice. (SL)

Other people described their friends as their housemates, ***"kind of friends with everyone in the house"*** (P25, RC), the staff within the home, other people supported by their support provider, their family, or people they saw at groups they attended, but often the friendships did not extend beyond these groups and meeting up with these friends at other times was rare, ***"I see a lot of people at Bingo that speak to us and that"*** (P32, SL). There was a sense that some people were friends by circumstance, and there was little in place to support participants to deepen their friendships, for example by facilitating meetings outside of the groups. For example, one participant spoke about having a boyfriend who she saw at the day centre, but not outside of this, despite wanting to.

There is a friend who is on the other side of town. I meet him a few times…maybe a few times a year...bumping into him. (P31, RC)

They were nevertheless important relationships for participants, and often there was a desire for things to be different. For example, one person commented:

> ***I would like my friends to come round…We had a young lad come round, he goes to a social place called Fusion*, he does the bingo there, so I met him from there.*** (P31, RC)

When asked if he had been to his friend's house, he said he hadn't but *"that would be good"* (*P31, RC).* Another participant meanwhile explained he was trying to take his friendships beyond the group he attended but so far this had failed to materialise:

> ***We arrange to meet up and they seem to be busy, and I say what about another day and it doesn't seem to happen...I have one friend that she does crafting as well. But I have not been able to meet up with her...but except for the friends I see at The Gables* I don't see many friends at the minute, and I am trying to find things to do to make more friends..*** (P27, SL)
>
> *(*all locations have been changed)*

Even sporadic contact was valued by participants and was missed during the pandemic when disrupted schedules made it harder to see these friends.

The importance of belonging

People spoke about the importance of belonging. They valued being part of their local community and many people were proud of their roles within their families, friendship groups or local community. Outside of family, networks such as church, football, and neighbours cropped up as ways in which people felt connected to their community and fostered a sense of belonging. It is worth remembering the quantitative findings (page 99) that people in supported living were more likely to have greater levels of community involvement as reported by staff, be more likely to know their neighbours and be more likely to live near friends and family.

Joe's story

Joe* lives in a supported living house with three other people. He loves living here because of the location, with a view of the football ground, and he can cycle everywhere. Joe is a huge football fan and knows everyone at the football ground. He has started going to the local gym and said 'I love it up there, I know people there' (Joe*, Supported Living).

*(*all names have been changed)*

Participants described church as a source of friendships, emotional and practical support, as well as providing opportunities to volunteer or join in regular social groups, with the role of the church extending far beyond religion. One person commented, ***"My church, its special to me… that church is part of my life."*** (P1, RC) whilst another described the emotional support she got from the church when her partner died and the practical support they offered during COVID:

> ***With COVID I had to stay in as I was one of the ones who had to shield. So church were there, and they did my shopping for me.*** (P35, SL)

Another participant, meanwhile, described the pride and connection she felt when she attended her local remembrance Sunday parade and laid a wreath to remember family members she had lost, and several people described enjoying standing and greeting people into church before the start of services although not necessarily staying for the service.

Amy's story

Amy* lives alone in supported living and has lived here for nearly 20 years. She likes living alone and doesn't feel lonely because she has several friends living by and is involved with her local church, attending various groups/coffee mornings run by the church each week. The church supported her through the death of her partner and also helped her during the pandemic by doing her shopping. Amy doesn't work currently, but has done in the past, and enjoys not working as she can go out when she wants or stay in when she wants. She also attends a drama group twice a week. Amy does most things for herself and only needs a bit of ongoing support from her provider to support with paperwork (Amy*, Supported Living).

Similar to church being more than religion, football was valued for more than the game itself. Supporting a team provided an opportunity to socialise, be it to go to the pub and have a drink with fellow fans when there was a match on or to attend the local club and socialise with people there, for example one person described staying in touch with a member of staff who used to support him as they would both be at the football and stand next to each other to watch the match:

> ***One friend who goes down to the football and used to work here. I meet him down the football quite a lot….he works with the St Johns there...I stand by him.*** (P31, RC)

Whilst another participant would meet his dad at the football ground each week and was proud to be the person who would change the score board at some matches.

Being in a romantic partnership was also important to participants in both residential care and supported living, and again those who were in relationships were proud of their roles which often involved caring for their partner or their partner caring for them. As one participant commented she enjoyed spending time with her boyfriend and “making sure he is ok” (P29, SL) whilst another described how her role was to care for her partner whose support needs were greater than hers. There was a sense of accomplishment attached to overcoming difficulties within or encountered as a result of the relationship as the following quotes demonstrate:

> ***When I moved into this service in 2006 I fell in love at first sight with another service user here… we got engaged … we set the date and got married, it was absolutely brilliant… Marriage isn’t always easy but it’s enjoyable, it has its ups and downs but the good times outweigh the bad times.*** (P16, RC)

> ***As a couple we went to Pride together, holding hands in the parade and everyone is going 'ohhh look at them lot' it’s a different scenario when you are out in public holding hands and you have a disability, and everyone is wondering 'how the heck?' yeah I have had that question before and it's weird.*** (P24, RC)

Conversely, there were participants who were not in a relationship but wished to be, with one person believing a relationship would address the loneliness they felt, “**I haven't really got anyone to talk to when I get home. I haven't got a partner, so I find it quite depressing.”** (P22, SL)

Relationships with family members were varied and whilst some people were in close contact, others spoke of strained relationships and infrequent contact. However, even when relationships were strained or limited, participants spoke of a desire to maintain them and emphasised the times which they did meet up highlighting the importance of being part of a family. For example, one participant spoke about how he would drive to see his cousins as if it was a regular occasion, but it was in fact a rarity. Another described how she was distant from her mum and wished this was different and a third participant who had many difficulties with his family, including a history of abuse, still endeavoured to stay in touch on a regular basis. Where participants felt rejected or left out of their family, they spoke with sadness and hurt and wished it was different:

> ***I get the pictures sent to me of one of my brothers…he got married at the registry office to his civil partner and I wasn't even invited. I only found out it was my Mum's funeral when a friend of the family told me … and that annoyed me as well cos I thought, why didn't they tell me.*** (P14, SL)

> ***I can write a letter and say 'dear Auntie, please tell my cousins that I'm feeling a bit upset because I can't see the two of them, I really would like to see a bit more of them.*** (P9, RC)

Barriers and facilitators of relationships

Friendships, relationships with neighbours and family relationships were, for many participants, difficult to maintain. Participants described being wary of trusting friends due to issues in the past as in the following example:

> ***I've cut down quite lot of friends because of how they have treated me in the past. I am more careful and speaking to more people.*** (P29, SL)

Participants also discussed struggling to maintain relationships with family and friends, particularly following the death of parents where contact with extended family was often lost:

> ***Mainly I speak to my friends, I don't really speak to my family. My mum passed away about 3 years ago and since then I haven't really bothered.*** (P23, SL)

However, location and opportunities to attend structured activities were two factors which facilitated the building and maintenance of relationships. People were often closest to friends who lived locally, allowing them to meet up easily. Likewise, participants considered how close they lived to family as having an impact on their relationship, ***"I used to see my***

sister, she used to pick me up every Wednesday. She moved [away] and I haven't seen her for 4 years." (P6, SL)

Similarly, location was important for participants who did not have close relationships with family members but were still able to feel connected and a sense of belonging to their family as they bumped into each other in town or at the football:

> ***I see them in town mainly…I just bump into them…it feels quite good if I haven't seen them in a long time it is nice to see them again.*** (P31, RC)

The importance of structured activities is evident in the previous two themes as school, college, day centres, social groups, church and football are all places which participants described as contributing to the creation and maintenance of friendships. Where participants wanted more friends, they considered attending structured activities the central means to do this:

> ***I am looking at different fitness things and activities…I am hoping from doing that and going more regularly, making friends through that and hopefully when The Gable* starts properly that as well.*** (P27, SL) *(*all locations have been changed)*

Echoing previous themes, there was a sense of precarity attached to the relationships people had. Living close to friends and family could change if people moved away (as it had for participant P6 quoted above) and friendships were vulnerable to ending if they were not able not extend beyond the setting in which they were made. This was the case for participants who had struggled to stay in touch with their friends during the various COVID related lockdowns or who had not stayed in touch with school friends despite wanting to, ***"I would like to see my school friends more."*** (P17, SL). This suggests people were often reliant on support from staff to help maintain relationships, reiterating the precarity experienced.

Key Findings – Seeing Family & Friends

- People in supported living saw their friends significantly more often than people in residential care. There were no differences between service models in frequency of seeing family members.
- During the COVID-19 pandemic, people across both service models saw their friends and family less often than usual.
- When talking about their friends, people described a range of relationships from long-lasting close friendships to housemates to people that they occasionally bumped into in town. Sometimes people were friends with others through circumstances, for example attending the same day centre, and it was hard to keep up these friendships if someone moved on.
- People were proud of their roles within their families, friendship groups, local communities and / or romantic partnerships. These roles helped them to feel a sense of belonging.
- Many people wanted to broaden their social networks, for example deepening existing friendships, finding a romantic partner or seeing family more often.
- Living close to friends and family helped them to stay in touch; on the other hand, many people found it difficult to maintain connections after loved ones moved away. This meant that relationships were quite precarious and transient at times.

Coronavirus

Table 46 below shows selected indicators relating to the impact of COVID-19. In considering this information it is important to note that data was collected from or about participants for almost a year through the COVID-19 pandemic, with different restrictions, testing and shielding guidance, and different lengths of time since the pandemic started (for further details, see the Project Timeline on pages 14-17).

As Table 46 shows, overall, 16% of people in supported living and 11% of people in residential care had tested positive for COVID-19 at some point. A small minority of people in supported living (4%) and residential care (5%) had self-isolated in the four weeks before information was collected. Substantial minorities of people in supported living (39%) and residential care (39%) had been shielding at some point, with 8% of people in supported living and 11% of people in residential care currently shielding. There were no statistically significant differences between people in supported living and residential care.

Table 46: Coronavirus, self-isolating and shielding

	Supported Living	Residential Care	Test and statistical significance
Yes – tested positive	15.9%	10.7%	Chi-square= 1.27; df=3; p=0.737
Think so but not confirmed	1.4%	0.0%	
No – haven't had COVID	81.2%	85.7%	
Don't know	1.4%	3.6%	
Self-isolated in last 4 weeks			Fisher's exact test p=1.000
Yes	4.0%	5.3%	
No/Don't know	96.0%	94.7%	
Ever shielded			Fisher's exact test p=1.000
Yes	38.8%	38.9%	
No/Don't know	61.2%	61.1%	
Shielding now			Fisher's exact test p=0.652
Yes	8.0%	11.1%	
No/Don't know	92.0%	88.9%	

Key Findings – Coronavirus

- 16% of people in supported living and 11% of people in residential care had tested positive for COVID-19 at some point. There were no statistically significant differences between people in supported living and residential care.
- A small minority of people in supported living (4%) and residential care (5%) had self-isolated in the four weeks before information was collected.
- Around 40% of people across supported living and residential care had been shielding at some point.

Table 47 below shows that, in terms of people's quality of life, a majority of people in both supported living (61%) and residential care (61%) had a quality of life that was mostly good or really great. A small minority had a quality of life that was bad or terrible (5% supported living; 4% residential care), with no difference between supported living and residential care.

People in supported living were statistically more likely than people in residential care to not feel worried or sad at all (56% supported living; 25% residential care) and also to feel very worried or sad (16% supported living; 8% residential care). Just over a fifth (21%) of people in supported living compared to no-one in residential care scored above clinical threshold on the GAD-7 scale for anxiety. In addition, 11% of people in supported living compared to no-one in residential care scored above clinical threshold on the PHQ-9 for depression, although scores on neither of these scales were statistically significantly different across service types. Almost everyone in both supported living (95%) and residential care (96%) had someone they could ask for help when they were feeling down.

Table 47: Quality of life and mental health

		Supported Living	Residential Care	Test and statistical significance
Self-rated quality of life	% Life is really great	25.0%	34.8%	Chi-square= 3.95 df=5; p=0.556
	% Life is mostly good	35.7%	26.1%	
	% Life is OK	33.9%	30.4%	
	% Life is mostly bad	3.6%	4.3%	
	% Life is really terrible	1.8%	0.0%	
	% Don't know	0.0%	4.3%	
How does the person feel in their mind or feelings generally?	% Not worried or sad	55.7%	25.0%	**Chi-square=10.93; df=2; p=0.004**
	% A bit worried or sad	27.9%	66.7%	
	% Very worried or sad	16.4%	8.3%	
Anxiety (GAD-7 total score)	Mean (sd)	4.6 (2.5)	3.3 (2.9)	t=-0.897, df=47, p=0.374
	Range	0 - 17	0-9	
Anxiety (GAD-7 severity classification)	% None	67.6%	66.7%	Chi-square= 5.73 df=3; p=0.126
	% Mild anxiety	11.8%	33.3%	
	% Moderate anxiety	8.8%	0.0%	
	% Severe anxiety	11.8%	0.0%	
Anxiety (GAD-7 score above clinical threshold)	% Below clinical threshold	79.4%	100.0%	Fisher's exact test p=0.058
	% Above clinical threshold	20.6%	0.0%	
Depression (PHQ-9 score)	Mean (sd)	5.1 (5.9)	3.0 (2.8)	t=-1.33, df=48, p=0.191
	Range	0 - 22	0 - 9	
Depression (PHQ-9 classification)	% None	54.3%	80.0%	Chi-square= 3.55 df=3; p=0.315
	% Mild depression	34.3%	20.0%	
	% Moderate depression	2.9%	0.0%	
	% Severe depression	8.6%	0.0%	

		Supported Living	Residential Care	Test and statistical significance
Depression (PHQ-9 score above clinical threshold)	% Below clinical threshold % Above clinical threshold	88.6% 11.4%	100.0% 0.0%	Fisher's exact test p=0.302
Does the person have someone they can ask for help when they are feeling down?	% Yes % No	95.1% 4.9%	96.0% 4.0%	Fisher's exact test p = 1.000

Key Findings – Mental Health and Wellbeing

- About 60% of people across both service models felt that they had a quality of life that was mostly good or really great.
- People in supported living were more likely than people in residential care to say that they felt worried or sad.
- Almost everyone had someone that they could talk to if they were feeling down.

As Table 48 below shows, a substantial majority of people in both supported living (83%) and residential care (88%) rated their own health (or were rated by a proxy staff member) to be good or fairly good, with no statistically significant difference between service types.

Table 48: Self/proxy-rated general health

		Supported Living	Residential Care	Test and statistical significance
Self (or proxy) rated health in the past year	% Good % Fairly good % Not good % Don't know	44.6% 38.5% 15.4% 1.5%	64.0% 24.0% 12.0% 0.0%	Chi-square= 2.98 df=3; p=0.395

Table 49 below presents information from staff questionnaires on people's Body Mass Index (BMI), calculated from staff assessments of the person's height and weight. People in supported living and residential care were similar in their average BMI, with average scores (supported living 27.1; residential care 25.8) falling just within the overweight BMI range (25-29.9). Because BMI information was only available on 36 people in total, information on the percentage of people in different BMI categories were pooled across supported living and residential care: 2.8% were underweight (BMI less than 18.5); 50.0% were a healthy weight (BMI 18.5 – 24.9); 22.2% were overweight (BMI 25 – 29.9); and 25.0% were obese (BMI 30+).

Table 49: Body Mass Index (BMI)

		Supported Living	Residential Care	Test and statistical significance
Staff Q - BMI	Mean (sd) Range	27.1 (6.0) 19.7-42.0	25.8 (6.4) 18.4 – 42.7	t=-0.62; df=34; p=0.541

Table 50 below shows the number of people experiencing a range of specific health conditions in the last 12 months, according to the staff questionnaire. The following health conditions are not included in Table 50 as they were reported to have been experienced by a maximum of one person in total: bronchitis; sciatica, lumbago or recurring backache; piles; varicose veins; angina; heart attack; abnormal heart rhythm; stroke; sepsis.

The only statistically significant difference between service models in a specific health condition was in bowel control, reported by staff for more people in residential care (33%) compared to people in supported living (5%). The average total number of health conditions reported by staff for people with supported living (2.2) and residential care (2.1) was very similar.

For people in supported living, the most common health problems reported by staff were asthma (22%), high blood pressure (20%) and arthritis (17%). For people in residential care, the most common health problems were poor bladder control (38%), poor bowel control (33%) and constipation (33%).

Table 50: Health conditions in the last 12 months

Staff Q – has the person experienced this health condition in the last 12 months		Supported Living	Residential Care	Test and statistical significance
Staff Q - arthritis	% Yes % No	17.1% 82.9%	4.8% 95.2%	Fisher's exact p=0.247
Staff Q - asthma	% Yes % No	22.0% 78.0%	0.0% 100.0%	Fisher's exact p=0.022
Staff Q – recurring stomach trouble / indigestion	% Yes % No	9.8% 90.2%	19.0% 81.0%	Fisher's exact p=0.426
Staff Q - constipation	% Yes % No	12.2% 87.8%	33.3% 66.7%	Fisher's exact p=0.086
Staff Q – poor bladder control	% Yes % No	14.6% 85.4%	38.1% 61.9%	Fisher's exact p=0.054
Staff Q – poor bowel control	% Yes % No	5.0% 95.0%	33.3% 66.7%	**Fisher's exact** **p=0.006**
Staff Q – persistent foot trouble	% Yes % No	12.2% 87.8%	4.8% 95.2%	Fisher's exact p=0.654
Staff Q – persistent trouble with teeth, gums or mouth	% Yes % No	4.9% 95.1%	4.8% 95.2%	Fisher's exact p=1.000
Staff Q - diabetes	% Yes % No	12.2% 87.8%	0.0% 100.0%	Fisher's exact p=0.157
Staff Q – high blood pressure	% Yes % No	19.5% 80.5%	9.5% 90.5%	Fisher's exact p=0.472
Staff Q – heart murmur	% Yes % No	4.9% 95.1%	0.0% 100.0%	Fisher's exact p=0.545
Staff Q – swallowing or choking	% Yes % No	2.4% 97.6%	4.8% 95.2%	Fisher's exact p=1.000
Staff Q – total number of health conditions	Mean (sd) Range	2.17 (1.92) 0-6	2.14 (2.70) 0-10	t=-0.047; df=60; p=0.963

Health: Getting Help

As Table 51 below shows, a majority of people in supported living (77%) and residential care (78%) would go to a support worker for help if they were ill, followed by the doctor (46% supported living; 41% residential care), the hospital (20% supported living; 18% residential care) or another source of help (29% supported living; 18% residential care), including using an alarm or ringing 111. There were no statistically significant differences between people in supported living and residential care.

Table 51: If the person was ill, who would they go to for help

If the person was ill, who would they go to for help?		Supported Living	Residential Care	Test and statistical significance
Doctor	% Yes % No	45.7% 54.3%	41.2% 58.8%	Fisher's exact test p=1.000

If the person was ill, who would they go to for help?		Supported Living	Residential Care	Test and statistical significance
Hospital	% Yes % No	20.0% 80.0%	17.6% 82.4%	Fisher’s exact test p=1.000
Partner	% Yes % No	11.8% 88.2%	0% 100.0%	Fisher’s exact test p = 0.288
Child	% Yes % No	0.0% 100.0%	0.0% 100.0%	Not calculated
Other relative	% Yes % No	20.0% 80.0%	0% 100.0%	Fisher’s exact test p=0.081
Friend	% Yes % No	2.9% 97.1%	0% 100.0%	Fisher’s exact test p = 1.000
Paid help / support worker	% Yes % No	77.1% 22.9%	77.8% 22.2%	Fisher’s exact test p=1.000
Other	% Yes % No	28.6% 71.4%	17.6% 82.4%	Fisher’s exact test p=0.506

Everyone with the capacity to take part in the research said they had a doctor who they could see if they got ill, and staff questionnaires also reported that everyone was registered with a GP. Table 52 shows that a minority of people in supported living saw the same doctor every time (37%) compared to over half of people in residential care (55%), although this was not a statistically significant difference. A substantial majority of people in supported living (74%) and residential care (84%) got on well with their doctor.

Table 52: The GP

		Supported Living	Residential Care	Test and statistical significance
Does the person always see the same doctor at their GP practice?	% Same doctor % Different doctors % Don’t know	36.8% 57.9% 5.3%	55.0% 45.0% 0%	Chi-square= 2.46 df=2; p=0.292
Does the person get on well with their doctor?	% Yes % Some of them % No % Don’t know	74.4% 2.6% 2.6% 20.5%	84.2% 0.0% 5.3% 10.5%	Chi-square= 1.66 df=3; p=0.647

Even though this research was conducted through the COVID-19 pandemic, with attendant changes to how health services communicated with people, Table 53 below shows the most common form of GP consultation in the last year was by going to the GP practice (69% supported living; 41% residential care). Going to hospital (31% supported living; 17% residential care), phone appointments (26% supported living; 36% residential care) and getting a home visit from a doctor (18% supported living; 27% residential care) were also relatively common. There were no statistically significant differences between people in supported living and people in residential care.

Some of these questions were also asked in the staff questionnaire (see Table 54). Staff reported that substantial majorities of people had been to the GP practice in the last year (supported living 83%; residential care 65%). They also reported that people in residential care were statistically significantly more likely than people in supported living to have had a home visit from their doctor (supported living 2%; residential care 40%) and to have had a phone appointment with their doctor (supported living 21%; residential care 65%) in the last year.

Table 53: Contact with health services

Has the person been to the doctor / had a home visit from the doctor in the last year?		Supported Living	Residential Care	Test and statistical significance
Been to practice	% Yes % No	69.1% 30.9%	40.9% 59.1%	Fisher's exact test p=0.037
Been to hospital	% Yes % No	30.9% 69.1%	17.4% 82.6%	Fisher's exact test p=0.272
Home visit from doctor	% Yes % No	17.9% 82.1%	27.3% 72.7%	Fisher's exact test p=0.365
Telephone appointment	% Yes % No	25.5% 74.5%	36.4% 63.6%	Fisher's exact test p=0.406
Other	% Yes % No	9.1% 90.9%	9.1% 90.9%	Fisher's exact test p=1.000

Table 54: Staff questionnaire: Contact with health services

Staff Q – Has the person been to the doctor / had a home visit from the doctor in the last year?		Supported Living	Residential Care	Test and statistical significance
Been to practice	% Yes % No	83.3% 16.7%	65.0% 35.0%	Fisher's exact test p=0.120
Home visit from doctor	% Yes % No	2.4% 97.6%	40.0% 60.0%	**Fisher's exact test p<0.001**
Telephone appointment	% Yes % No	21.4% 78.6%	65.0% 35.0%	**Fisher's exact test p=0.001**

As Table 55 shows, most people with capacity to take part in the research in supported living (77%) and residential care (56%) said they had had an annual health check in the past year. Staff questionnaires reported even higher rates of annual health checks on the past year (79% supported living; 95% residential care). Staff questionnaires also reported that most people in both supported living (74%) and residential care (86%) had had their blood pressure checked in the last year.

Fewer people with capacity to take part in the research had been to the dentist in the past year (54% supported living; 40% residential care), although a substantial majority of people were reported to have regular check-ups with their dentist (79% supported living; 90% residential care). Minorities of people reported getting toothache in the past year (5% supported living; 28% residential care). Staff questionnaires reported a majority of people in supported living (62%) and residential care (76%) seeing a dentist in the past year.

Around half of people with capacity to take part in the research had had an eye test in the past year (46% supported living; 56% residential care), with minorities saying they didn't know when they last had an eye test (16% supported living; 33% residential care). Staff questionnaires reported fewer people in supported living (31%) and residential care (35%) having an eye test in the past year.

Fewer people with capacity to take part in the research had had a hearing test in the past year (23% supported living; 15% residential care), with substantial proportions of people saying they didn't know when they last had a hearing test (44% supported living; 77% residential care). Similar to participant responses, in staff questionnaires 23% of people in supported living and 5% in residential care were reported to have had a heating test, although a majority of staff didn't know if the person had had a hearing test or not (57% supported living; 76% residential care).

Unfortunately, there was information from too few people to conduct analyses of questions on various types of cancer screening.

There were no statistically significant differences between supported living and residential care in this information.

Table 55: Check-ups and dental care

		Supported Living	Residential Care	Test and statistical significance
[People with capacity only] Have you had an annual health check in the past year?	% Yes % No % Don't know	77.4% 27.0% 1.6%	56.0% 32.0% 12.0%	Chi-square= 5.06 df=2; p=0.080
Staff Q – Has the person had an annual health check in the past year?	% Yes % No % Don't know	78.6% 11.9% 9.5%	95.2% 0.0% 4.8%	Chi-square=3.36; df=2; p=0.186
Staff Q – Has the person had their blood pressure measured?	% Yes, in last 12 months % Yes, 1-5 years ago % No, never % Don't know	73.8% 11.9% 2.4% 11.9%	85.7% 9.5% 0.0% 4.8%	Chi-square=1.58; df=3; p=0.665
Has the person had any pain or toothache in the past year?	% Yes % No % Don't know	5.1% 79.5% 15.4%	27.8% 72.2% 0.0%	Chi-square= 8.00 df=2; p=0.018
[People with capacity only] Have you been to the dentist in the past year?	% Yes % No % Don't know	54.4% 45.6% 0.0%	39.9% 55.6% 5.6%	Chi-square=4.10; df=2; p=0.129
Staff Q – When did the person last see a dentist	% Less than 6 months ago	28.6%	38.1%	Chi-square=3.10; df=4; p=0.541

		Supported Living	Residential Care	Test and statistical significance
	% 6 months to 1 year ago % 1-2 years ago % More than 2 years ago % Don’t know	33.3% 16.7% 4.8% 16.7%	38.1% 19.0% 0.0% 4.8%	
Does the person just go to the dentist when their teeth hurt, or do they go for a check-up as well?	% Only when teeth hurt % Regular check-up % Don’t know	14.0% 79.1% 7.0%	5.3% 89.5% 5.3%	Chi-square= 1.12 df=2; p=0.573
[People with capacity only] Do you know when you last had your eyes tested?	% In the last year % 1-2 years ago % 2-3 years ago % 3-4 years ago % Over 4 years ago % Don’t know	45.6% 29.8% 8.89% 0.0% 0.0% 15.8%	55.6% 5.6% 5.6% 0.0% 0.0% 33.3%	Chi-square= 5.92 df=3; p=0.116
Staff Q – when did the person last have their eyes tested?	% In the last year % 1-2 years ago % 2-3 years ago % 3-4 years ago % Over 4 years ago % Don’t know	30.8% 33.3% 5.1% 0.0% 2.6% 28.2%	35.0% 55.0% 0.0% 0.0% 0.0% 10.0%	Chi-square= 5.13; df=4; p=0.275
[People with capacity only] Do you know when you last had your hearing tested?	% In the last year % 1-2 years ago % 2-3 years ago % 3-4 years ago % Over 4 years ago % Don’t know	23.1% 7.7% 5.1% 0.0% 20.5% 43.6%	15.4% 0.0% 0.0% 000% 7.7% 76.9%	Chi-square= 4.95 df=4; p=0.292
Staff Q - when did the person last had their hearing tested?	% In the last year % 1-2 years ago % 2-3 years ago % 3-4 years ago % Over 4 years ago % Don’t know	22.9% 8.6% 8.6% 0.0% 8.6% 57.1%	4.8% 14.3% 4.8% 0.0% 0.0% 76.2%	Chi-square= 4.68; df=4; p=0.322

Medication

Staff were asked to record in detail all the prescribed medications that people were taking. In terms of prescribed medications for regular use, 65% of people in supported living and 43% of people in residential care took no regular prescribed medications (see Table 56). 7% of people in supported living and 24% of people in residential care were taking five or more different prescribed medications, up to a maximum of 10 different medications.

In terms of prescribed medications for use PRN, 14% of people in supported living and 33% of people in residential care had at least one prescribed PRN medication.

In terms of the total number of different prescribed medications (both regular and PRN), a majority of people in supported living (65%) were not on any prescribed medication, compared to less than half (38%) of people in residential care. 12% of people in supported living were prescribed five or more different medications, a common definition of polypharmacy, compared to 38% of people in residential care. There was not a statistically significant difference across service models in terms of total prescribed medications.

Table 56: Number of different prescribed medications

		Supported Living	Residential Care	Test and statistical significance
Staff Q – number of different regularly prescribed medications	% Zero % 1-4 % 5-9 % 10+	65.1% 27.9% 7.0% 0.0%	42.9% 33.1% 19.0% 4.8%	Not calculated
Staff Q – number of PRN prescribed medications	% Zero % 1-4 % 5-9 % 10+	86.0% 14.0% 0.0% 0.0%	66.7% 33.3% 0.0% 0.0%	Not calculated
Staff Q – total number of different prescribed medications	% Zero % 1-4 % 5+ (polypharmacy)	65.1% 23.3% 11.6%	38.1% 23.8% 38.1%	Chi-square=6.70; df=2; p=0.035

Table 57 shows that, according to staff, 15% of people in supported living and 28% of people in residential care were taking laxatives. Fewer people (supported living 10%; residential care 13%) were taking dietary supplements. There were no statistically significant differences between types of service.

Table 57: Laxatives and dietary supplements

		Supported Living	Residential Care	Test and statistical significance
Staff Q – does the person take any laxatives?	% Yes % No	15.0% 85.0%	27.8% 72.1%	Fisher's exact test p=0.290
Staff Q – does the person take any dietary supplements?	% Yes % No	10.0% 90.0%	12.5% 87.5%	Fisher's exact test p=1.000

Healthy Living

As Table 58 below shows, a minority of people in both supported living (17%) and residential care (16%) smoked cigarettes; smaller numbers of people used to smoke (7% supported living; 10% residential care). Staff questionnaires reported slightly fewer people smoking (supporting living 9%; residential care 9%). Small numbers of people with capacity to take part in the research said they vaped at least occasionally (7% supported living; 17% residential care), with staff reported almost no-one vaping.

Three quarters of people in supported living (75%) and residential care (75%) had ever had an alcoholic drink. A small minority of people with capacity to take part in the research said they drank alcohol most days (7% supported living; 6% residential care); a majority of people drank alcohol once a month or less frequently (57% supported living; 63% residential care). Almost everyone who drank alcohol got drunk rarely or never when they drank alcohol (90% supported living; 92% residential care).

Staff reports of the frequency of alcohol use were lower, with a majority of people in supported living (54%) and residential care (63%) reported to drink less often than once every couple of months. Staff considered alcohol use to be a problem for 12% of people in supported living and no-one in residential care.

Around 10% of people with capacity to take part in the research had tried cannabis at some point (9% supported living; 10% residential care). Very few people had ever tried other illegal drugs (6% supported living; 0% residential care). Staff reported that no-one had smoked cannabis and almost no-one had taken any other illegal drugs.

There were no statistically significant differences between supported living and residential care on any of these indicators.

Table 58: Smoking, alcohol and drugs

		Supported Living	Residential Care	Test and statistical significance
[People with capacity only] Do you smoke cigarettes?	% Yes % No % Used to smoke	16.9% 76.3% 6.8%	15.8% 73.7% 10.3%	Chi-square=0.29; df=2; p=0.867
Staff Q – does the person smoke?	% Yes % No % Used to smoke	9.3% 86.0% 4.7%	9.5% 81.0% 9.5%	Chi-square=0.58; df-2; p=0.748
[People with capacity only] Do you vape / use an e-cigarette?	% Never tried it % Tried in the past % Occasionally use % Use everyday	73.3% 20.0% 6.7% 0.0%	75.0% 8.3% 8.3% 8.3%	Chi-square= 4.53; df=3; p=0.210
Staff Q – does the person vape?	% Yes % No	2.6% 97.4%	5.0% 95.0%	Fisher's exact p=1.000
Has the person ever had an alcoholic drink?	% Yes % No % Don't know	75.0% 21.9% 3.1%	75.0% 25.0% 0.0%	Chi-square=0.83; df=2; p=0.662

		Supported Living	Residential Care	Test and statistical significance
[People with capacity only] In the past year, how often did you usually have an alcoholic drink?	% Most days % Once or twice a week % 2 or 3 times a month % Once a month % Once every couple of months % Less often	6.8% 27.3% 9.1% 18.2% 4.5% 34.1%	6.3% 18.8% 12.5% 6.3% 12.5% 43.8%	Chi-square= 3.01 df=5; p=0.699
On the days where the person had an alcoholic drink, how often did they get drunk?	% Every time % Most times % Around half the time % Less than half the time % Rarely % Never	3.2% 0.0% 0.0% 6.5% 19.4% 71.0%	8.3% 0.0% 0.0% 0.0% 16.7% 75.0%	Chi-square= 1.31 df=3; p=0.726
Staff Q - in the past year, how often did the person usually have an alcoholic drink?	% Most days % Once or twice a week % 2 or 3 times a month % Once a month % Once every couple of months % Less often	5.7% 17.1% 8.6% 8.6% 5.7% 54.3%	6.3% 12.5% 0.0% 12.5% 6.3% 62.5%	Chi-square= 3.01 df=5; p=0.699
Staff Q – is the person's alcohol use considered a problem?	% Yes % No	11.9% 88.1%	0.0% 100.0%	Fisher's exact test p=0.309
[People with capacity only] Have you ever tried cannabis, even if only once?	% Yes % No % Don't know	9.4% 87.5% 3.1%	10.0% 90.0% 0%	Chi-square= 0.32 df=2; p=0.852
[People with capacity only] Have you ever tried other drugs?	% Yes % No	6.3% 93.8%	0% 100.0%	Fisher's exact test p=1.000

Table 59 below shows that a majority of people in both supported living and residential care said (or were reported by proxy staff members) to exercise to the point of getting sweaty/out of breath (72% supported living; 59% residential care).

Staff reported that in the last four weeks, people in supported living had done light physical activity on average 15 times, moderate physical activity on average 5 times, and heavy physical activity on average 2 times. Staff reported that people in residential care in the last weeks had done light physical activity on average 18 times, moderate physical activity on average 9 times, and vigorous physical activity on average 4 times. There was very wide variation in both supported living and residential care, with no statistically significant differences between them.

Of those who exercised, on average people in supported living exercised for 166 minutes per week compared to 236 minutes per week for people in residential care, although the range was very wide.

There were no statistically significant differences between supported living and residential care on any of these indicators.

Table 59: Physical activity

		Supported Living	Residential Care	Test and statistical significance
Staff Q - does the person ever do any exercise?	% Yes % No % Don't know	72.2% 26.4% 1.4%	59.3% 40.7% 0.0%	Chi-square= 2.19 df=2; p=0.335
Staff Q – how many times in the last four weeks has the person done light physical activity?	Mean (sd) Range	15.2 (12.3) 0-46	18.0 (22.6) 0-67	t=0.60; df=40; p=0.953
Staff Q – how many times in the last four weeks has the person done moderate physical activity?	Mean (sd) Range	5.0 (8.5) 0-29	8.8 (13.6) 0-34	t=0.72; df=40; p=0.473
Staff Q – how many times in the last four weeks has the person done vigorous physical activity?	Mean (sd) Range	2.3 (6.0) 0-28	3.6 (7.4) 0-20	t=0.55; df=40; p=0.589
Staff Q - for those who do exercise, minutes of exercise per week	Mean (sd) Range	166 (198) 0 - 840	236 (204) 60 – 600	t=-0.893 df=32, p=0.379

Table 60 below shows that a large majority of people in supported living did not require support for eating and drinking, compared to just over half of people in residential care (56%). Relatively few people in supported living required some support for eating and drinking (13%) compared to just over a quarter of people in residential care (28%). A minority of people in residential care (17%) required modified food and fluids to help with swallowing and/or choking difficulties compared to no-one in supported living. There was a statistically significant difference between people in supported living and people in residential care on this question.

The staff questionnaire also asked whether people were likely to be eating and drinking a balanced diet (5 questions) and separately eating or drinking a diet with a high sugar/fat content (3 questions). All questions were scored on a 5-point scale (*1=Not enough; 2=Not* *quite enough; 3=About right; 4=A bit too much; 5=Too much*). Table 60 shows the mean item scores for the balanced diet questions and the high sugar/fat diet questions. For people in supported living and residential care, mean item scores on both sets of questions were at or very close to three (about right), with no statistically significant differences between supported living and residential care. Overall, staff most commonly rated people's diets as very/quite healthy (46% supported living; 67% residential care), with the diets of 32% of people in supported living and 28% of people in residential care rated as neither particularly healthy or unhealthy, and a minority of people's diets rated very/quite unhealthy (22% supported living; 6% residential care).

A minority of people were reported by staff to have a special diet (e.g. vegan) of any kind (10% supported living; 11% residential care). The vast majority of people were reported by staff to typically eat three meals per day (89% supported living and residential care), with the vast majority of people also having some snacks between meals (97% supported living; 89% residential care).

There were no statistically significant differences between people in supported living and residential on questions about diet.

Table 60: Diet

		Supported Living	Residential Care	Test and statistical significance
Staff Q – support with eating and drinking	% Eats & drinks full range, no support needed % Eats and drinks full range, some support needed % Eats & drinks food and fluid modified help swallowing/ choking difficulties	87.2% 12.8% 0.0%	55.5% 27.8% 16.7%	**Chi-square=9.67; df=2; p=0.008**
Staff Q – balanced diet index mean item score	Mean (sd) Range	2.9 (0.4) 1.6-3.6	3.0 (0.2) 2.6-3.5	t=1.32; df=52; p=0.191
Staff Q – high sugar/fat diet index mean item score	Mean (sd) Range	3.3 (0.7) 1.7-5.0	3.1 (0.3) 2.3-3.7	t=-1.34; df=52.3; p=0.185
Staff Q – overall, how healthy is the person's diet?	% Very/quite healthy % Not particularly healthy or unhealthy % Very/quite unhealthy	45.9% 32.4% 21.6%	66.7% 27.8% 5.6%	Chi-square=2.98; df=2; p=0.225
Staff Q – does the person follow any special diet?	% Yes % No	10.3% 89.7%	11.1% 88.9%	Fisher's exact p=1.000
Staff Q – does the person typically eat three meals a day?	% Yes % No	88.6% 11.4%	88.9% 11.1%	Fisher's exact p=1.000

		Supported Living	Residential Care	Test and statistical significance
Staff Q – how often does the person have snacks between meals?	% Never	3.0%	11.1%	Chi-square=3.42; df=3; p=0.332
	% Once a day or less	69.7%	55.6%	
	% A few times a day	21.2%	33.3%	
	% More than one snack between each meal	6.1%	0.0%	

Key Findings – Physical Health

- Most people rated their health to be good or fairly good in the past year.
- People in residential care and supported living had a similar number of health conditions as reported by staff (on average each person had two health conditions). The only significant difference was that people in residential care were more likely to experience poor bowel control.
- Everyone reported being registered with a GP and most people got on well with their GP. There were no significant differences between supported living and residential care in whether the person had seen their GP in the past year; however people living in residential care were more likely to have received a home visit or a phone appointment from their doctor than people in supported living.
- There were no significant differences in frequency of health checks across the two service models.
- 7% of people in supported living and 24% of people in residential care were taking five or more different prescribed medications, up to a maximum of 10 different medications.
- There were no significant differences between people in supported living and residential care in terms of smoking, drinking alcohol, taking drugs and exercise.
- People in residential care were more likely to require some support with eating and drinking that people in supported living. There were no significant differences in terms of healthy eating and general diet.

Factors associated with indicators of health, wellbeing and citizenship

This section explores which personal characteristics, service resources and structures, and service processes are associated with a range of indicators of health, wellbeing and citizenship indicators amongst the people with learning disabilities in the project. Due to the numbers of participants available for specific analyses (particularly as these analyses combine data from the participant, proxy-participant and staff questionnaires) multivariate analyses such as logistic regressions were not possible. Instead, the tables below summarise univariate analyses between selected personal characteristics, service resources/structures and service processes and selected indicators of health, wellbeing and citizenship. All analyses were nonparametric – depending on the nature of the data these analyses were Fisher's exact tests/chi-square, Mann-Whitney U tests, or Spearman's rho correlations. The direction and strength of associations are indicated in the relevant cells of each table, with associations at $p<0.01$ treated as statistically significant.

Factors associated with outcomes – supported living and residential care combined

Tables 61 and 62 below show statistically significant associations for 14 indicators of health, wellbeing and citizenship, combining people living in supported living and residential care and including type of housing support as a potential factor.

In terms of personal characteristics, whether the person had the capacity to take part in the research was associated with indicators of citizenship (having a job, voting, and spending their time how they want), but was not associated with any health or wellbeing indicators.

A person with greater support needs was associated with having a healthier diet, and having less housing rights according to the Real Tenancy Test.

Younger age and having received a diagnosis of being an autistic person from a professional were associated with greater anxiety.

Indicators of general health and mental health were associated with each other but (apart from better general health being associated with better quality of life) not associated with any indicators of healthy lives or citizenship. Challenging behaviour was not associated with any indicator of health, wellbeing or citizenship.

People who had lived in their current place for longer were more likely to report lower levels of depression and spending their time more how they wanted to.

In terms of service resources and structures, whether someone lived in supported living or residential care was only associated with the Real Tenancy Test, as would be expected given the different set-up of supported living and residential care.

Greater size of the person's home (in terms of number of people living there) was associated with lower BMI scores and a healthier diet, people being more likely to spend their time how they wanted, and a lower score on the Real Tenancy Test.

People who had more hours of one-to-one support scored lower on the Real Tenancy Test and were less likely to have voted in the 2019 general election. People who had more hours of shared support also scored lower on the Real Tenancy Test and were more likely to have a healthier diet.

In terms of service processes, the person's place having rules about what they could or couldn't do was associated with the person not being a victim of crime in the past year.

The person having a support plan was associated with them having a more healthy diet, more community involvement and fewer housing rights in terms of the Real Tenancy Test score.

Finally, the person living in a place where a greater number of activities were not permitted at all was associated with fewer housing rights in terms of the Real Tenancy Test score.

Table 61: Factors associated with health and wellbeing indicators: people in supported living and residential care combined

	Better self-proxy rated health	Higher anxiety (GAD7 total)	Higher depression (PHQ9 total)	Higher BMI total	More exercise	Healthy diet	Better self-rated quality of life
Personal characteristics							
Capacity to take part in the research							
Male or female gender				**Female** +			
Greater age			-				
Diagnosis as autistic person		+					
Greater support needs						+	
Greater challenging behaviour							
Higher GAD7 anxiety			++				
Higher PHQ9 depression	-	++					
Better self-proxy rated health							++
Lived in current place for longer			-				
Service resources and structures							
Supported living or residential care							
Number of people in dwelling				--		+	
Number of hours one to one support							
Number of hours shared support						+	
Service processes							
Rules on what the person can do in their house							
Person has a support plan						+	
Risk management – greater number of not permitted activities							

+ / - $p<0.01$; ++ / -- $p<0.001$

Table 62: Factors associated with citizenship indicators: people in supported living and residential care combined

	Higher Real Tenancy Test score	Has paid or voluntary job	Greater community involvement	Bigger size of social network	Voted in 2019 general election	Victim of crime in past year	Spend your time how you want
Personal characteristics							
Capacity to take part in the research		+			++		+
Male or female gender							
Greater age							
Diagnosis as autistic person							
Greater support needs	--						
Greater challenging behaviour							
Higher GAD7 anxiety							
Higher PHQ9 depression							
Better self-proxy rated health							
Lived in current place for longer							+
Service resources and structures							
Supported living or residential care	**Supported living +**						
Number of people in dwelling	--						+
Number of hours one to one support	-				-		
Number of hours shared support	--						
Service processes							
Rules on what the person can do in their house						-	
Person has a support plan	-		+				
Risk management – greater number of not permitted activities	-						

+ / - p<0.01; ++ / -- p<0.001

Quality of Life Reviews

Background and introduction

Overview of the Quality of Life programme

Changing Our Lives are committed to disabled people leading ‘ordinary lives’ and know from experience that where a disabled person has tailored support around them, an accessible home environment and good healthcare, they are able to be active and valued citizens in the community. In this context, Changing Our Lives defines Quality of Life as ‘the degree to which a person lives and enjoys an ordinary life, living in their own home, making their own choices about everyday life, being part of their community, having friendships and relationships, having the opportunity of employment and other opportunities for personal development.’

The underpinning belief of this programme is that if disabled people are supported to lead an ordinary life, they are going to be recognised as equal citizens, not defined or limited by their disability.

A Quality of Life review is a person-centred way of measuring how services enable disabled people to lead an ordinary life.

Quality of Life standards

As each review focuses on an ordinary life, each review is measured against the Quality of Life Standards. The standards were first created in 2002, and over the years have been updated, with the last rewrite commissioned in 2013 by the Department of Health as part of their response to Winterbourne. The current set of standards was launched by the former Care Minister, Norman Lamb in June 2014.

Background to this work

As part of the 200 Lives research team, Changing Our Lives carried out Quality of Life Reviews with 14 people who had taken part in the wider research. Each Quality of Life review is an addition to the data collected through participant interviews and staff questionnaires. The aim was for the Quality of Life Reviews to act as another layer of inquiry and to enable triangulation of the data collected by the research team, as well as providing a different perspective on quality from people with lived experience of learning disabilities.

The review team wrote an individual Quality of Life Review report for each person and this summary chapter outlines themes that emerged from the individual reviews.

Methodology

Coproduction is at the heart of Changing Our Live’s approach and review work is no exception. The review team for this work was made up of three disabled reviewers and two Changing Our Lives officers. Each individual review was undertaken by two members of the team.

The review team initially talked with the person about themselves to get to know them and a bit about their life. This was written into the report under the heading "About Me." The team looked at the following areas of the Quality of Life Standards, to measure how each provider enables disabled people to lead an ordinary life.

- My Home
- Being in Control of my Life
- Having a Full Life
- The Way People Work with Me

Conversations are at the heart of the Quality of Life approach; it is through two-way natural conversations with people that the review team gains the most insight into the individual and their experiences. A set of questions based around the above areas of the Quality of Life standards was developed and used as a basis for conversations with people.

The research team secured the initial consent from individuals they had worked with to take part in a Quality of Life review and forwarded their contact details to Changing Our Lives. The Quality of Life review team then sent out easy read information about the reviews and gained consent from each person before setting up review meetings.

The reviews took place between July and October 2021. All but one of the reviews were carried out virtually due to the pandemic and for this reason they were all planned. The remaining review was carried out via phone calls due to poor internet connection where the person lived. All but one review was completed over at least two conversations with the person which generally lasted between 1.5 – 2.5 hours. One review was completed with just one conversation with the person plus two conversations with the person's support staff and manager.

For seven people, staff were present during conversations. For three people, there was minimal input from staff; for two people staff and the person contributed equally and for the remaining two people staff contributed most of the information as the people they support do not use words to communicate. For one person, a parent was present with the person but made minimal contribution. The review team had follow-up conversations with staff for ten people.

The review team spoke with:

- Eight people who lived in supported living, supported by five different providers.
- Six people who lived in residential care, supported by one provider.

The review team had planned to speak with equal numbers of people in supported living and in residential care. However, COVID-19 related delays in securing involvement from people in residential care within the required timescales meant that an eighth person was included from supported living and only six people from residential care.

Four people in supported living lived alone in their own flat. Three of these people lived in property that was not specifically designated for people with a learning disability. One person lived in a property that is part of a supported living scheme. Four people lived in a shared property.

Two people in residential care had their own self-contained flat with their own front door, which was part of a bigger residential property for people with a learning disability. Four people in residential care lived in a shared property.

People taking part in the Quality of Life Reviews included:

- People from across an age range from their mid-twenties to their mid-fifties.
- One person from a minority ethnic community.
- Seven people who identify as male and seven people who identify as female, including one person who was transgender.
- Two people with the label of profound and multiple learning disabilities.

Findings

My Home

Where I live:

Most people had visited their current home before deciding to live there, although not everyone had looked at other options or had any discussion about the type of property they wanted to live in. In many cases it seemed that people had been informed about a place in a property and had been taken to see it. Two people spoke about having actively planned ahead in terms of where they wanted to live, in that they had talked about options and looked at different places.

One person had had to make a decision about whether to accept a property within 24 hours of viewing it. They had felt under pressure to accept the property because they were aware of the limited availability of alternative suitable property. However, they were not entirely happy with the choice because it is in a block of accommodationfor older people and they are much younger. The person has a goal to move out into something more suitable in the future.

The review team spoke with four people who have physical impairments; one person lived in a fully accessible shared bungalow (residential care), one person lived in a house that is fully accessible downstairs but the person cannot access the upstairs (supported living) - the upstairs rooms are used as storage and as a staff sleepover room. Two of the four people lived in houses that did not fully meet their accessibility needs (one residential care and one supported living).

Who I live with:

Of the eight people who shared their home no-one appeared to have actively chosen the people they lived with, although they all got to meet them before they moved in. One person spoke about meeting prospective new housemates when they visit to look around and having the opportunity to give feedback to managers afterwards about their thoughts and whether they would fit in.

Of the six people who live alone, two people had actively chosen to live alone. For three of the other four people, the decision to live alone seems to have been a more passive process in that:

- Other people inferred what the person might prefer from their knowledge of them
- Properties became vacant and the person was offered the chance to look around.

For the fourth person, family and supporters had used their knowledge of the person to come to a decision for them to live alone.

There were four people who live in residential care where there are pets (either the person's or belonging to the group of people in the home). No-one in supported living had a pet.

My own front door and my own space:

All the people in supported living had their own front door key, but only one person in residential care had independent means of coming and going through the main front door. Generally, people in residential care did not answer the front door to their home or their house phone. Most people in supported living answered their own front door either independently or with support.

Most people across residential care and shared supported living have the option of having their bedroom door (or the door to their self-contained flat) locked, and most people chose to keep their own key and keep their door locked. All of the people the review team spoke to choose where to spend their time when at home.

Three of the homes of people in residential care had offices; these were shared homes. None of the supported living homes had dedicated offices, but some did have staff sleep-over rooms where paperwork was kept.

Being in Control of my Life

Every day decision making:

All of the people reviewed make many or most of their own everyday decisions with support as necessary. However, there were some areas of life where people in shared accommodation make decisions as part of a group rather than having an explicit opportunity to make their own individual choices. For example, most people in shared accommodation (in both residential care and supported living) jointly decide the main meals for the following week, and generally all eat together. Each person said they could choose something else if they didn't feel like what was on the menu for that day. However, as this depends on the person's confidence in speaking up and ability to articulate an alternative choice, there is a possibility that some people are compromising about things that they otherwise would not have to if they were offered a free choice as an individual or if they were living alone.

Another area where people may be compromising rather than acting autonomously is in relation to doing things outside of the home as a group or as an individual. People in shared residential accommodation with higher support needs seemed to go out as part of a group more often than people who live in residential care with less support needs, and those who live alone in both supported living and residential care. This did not seem to be the case in shared supported living, where people went out on their own with support far more frequently. Additionally, there were several examples of people who live in group residential homes saying that staffing levels sometimes affect whether they can go out as and when they wish, and that on occasion they have to wait because there are not enough staff to support them at that time, although they also said that this doesn't happen often.

People living in group residential care homes who need higher levels of paid staff support and people living in supported living with minimal paid staff support appear to have less variety and spontaneity in their lives than people who live in residential care who need low levels of paid staff support or people who live alone in supported living with 24-hour paid staff support. It is notable that one person who receives very low levels of support to live in their own flat in the community said they were currently being supported to explore moving to a supported living scheme because they felt lonely and wanted more emotional support in terms of people to talk to. Another person decided to stay in residential care rather than move into supported living because they perceive they would lose the emotional support that is available 24 hours each day in residential care.

Planning a life and setting personal goals:

There were some good examples of people being supported to pursue very individualised goals, particularly in supported living. Some of the examples include going on holiday to New York with a partner; going to big rugby matches and motorbike racing events; a project to build a shed and patio; getting a different job; and losing a large amount of weight. However, in general, goal planning for most people centred on leisure and one-off experiences, such as going to a festival or on a special holiday and having more fun in life.

There were very few examples of goals set around personal development, for example: contribution to the local community; moving towards work or developing a career; learning a new skill or hobby and striving to improve; actively pursuing personal interests and building up knowledge around them; improving personal competence or skills in a hobby or pastime; or expanding friendships.

Being active in running my own life:

In general, there were more examples of people in supported living being supported to be active participants in running their own life, in particular where the person lives alone. For example, cooking their own meals, arranging their own repairs, getting involved in decorating their home, paying their own bills and answering their own door and phone. In residential care, there were more examples of a hotel model approachto supporting people, so meals being cooked for people by staff, household maintenance being done by paid staff and staff offering activities for people as a group.

Use of vouchers as payment:

All of the people in residential care were Quality Checkers for their provider organisation and receive vouchers for each check they complete. Two people said that they receive vouchers in order to avoid their benefits being affected; this was supported by a manager. One person talked about having another additional job in a local community centre café and receiving vouchers for this work. They were not sure why they were receiving vouchers but their support staff said that they thought it wasrelated to their benefits.

Emerging from lockdown:

In general, the people who were part of this review were behind the curve in returning to a life without COVID restrictions. This seemed to be particularly the case for people living in residential care, some of whom had only just been given the green light to go to places like pubs and cinemas. Further to this, people in residential care were required to wait until managers make decisions about where they can go and what they can do as a group of "residents". For people in supported living, more personalised decisions had been made by the person, or with/for the person(depending on the person's capacity to make those decisions).

Having a Full Life

What people do with their time:

Most people did not attend traditional day services for people with a learning disability. Most people had a small number of things they did regularly on set days (such as to go swimming or the gym) and then decided what to do at other times as they go.

Four people attended a day service before the pandemic where they would travel to a building and do regular pre-planned activities. Three of the four people who attend a day service live in residential care. Three people have already returned to their day service and one person was about to return when their service re-opened. For all four people there seemed to have been very little real discussion about returning that included exploring other potential options, for example, accessing swimming directly or finding alternative volunteering or paid work that is not segregated.

Before the pandemic, two people in supported living attended regular, interest-based groups for people with learning disabilities held during the day that operate as a service (rather than a community-based group). Both people were planning to return to these groups when they re-start. Similarly, although they both expressed very clearly that they wanted to return to these groups, this decision seemed to have happened without a full discussion or support to think about alternative options, such as mainstream groups that offer the same activity.

Most people were part of or attended one or more social and leisure groups that were for disabled people, usually other people with a learning disability, for example, Special Olympics sessions, Riding for the Disabled (RDA) sessions and a dance group. There was just one example of a person attending a mainstream leisure or social group (the person had just recently started going to a yoga classes at their local leisure centre). There were many examples of people using common mainstream leisure facilities such as cinemas, theatres, bowling alleys, parks and nature reserves.

Friendships:

Of the fourteen people reviewed, only three people talked about being in a romantic relationship, two from residential care and one from supported living. Two people lived in the same property as their partner and one person did not. Two people had thought about moving in with their partner, and one of these people had explored it at length with support staff and decided against it, citing their emotional support needs as the main barrier.

There were very few examples of people having non-disabled friends or being supported to make friends outside of the groups they are part of. Only one person talked about having friends in the local community. Some people talked about knowing other people in the community, for example, in a local pub or the local shops, but there did not seem to be any depth to these relationships beyond saying hello and a quick chat when they met. In general, people saw their friends as being the other people they live with if they share their home and the people they see at the groups or day services they go to. However, in general people did not see each other outside of these groups or services. There were very few examples of people keeping in contact with friends throughout the lockdowns.

Similarly, there were very few examples of people knowing and being active in their neighbourhood; this was across supported living and residential care. There were only four examples of a person knowing their neighbours beyond saying hello. One person exchanged birthday and Christmas gifts with a neighbour. Two people in the same house got involved with the neighbourhood fete.

Work:

Six of the people reviewed were in a work-related role within their provider organisation, and their work was recognised by receiving vouchers. There was just one example of a person being in paid work; however, this is an occasional, as and when role. Three people spoke of having paid work in the past: one person finished because of stress, one person stopped working because of the impact on their benefits and the third person was not sure why their work had come to an end. Two people were supported to run a small arts-based social business from their home. However, the sales tend to be limited to family and friends and any income generated used to buy more materials. Only two people talked about planning for paid work in the future.

Some people are in work related roles, either as a volunteer, for example with a local food bank, or in a work related service provision or social enterprise, for example a café run by a service provider that offers work experience. However, only one of these people talked about wanting to use this experience to help them move towards real paid work in the future.

Life in lockdowns:

There were very few examples of people using lockdowns to take up new hobbies or pastimes or to use the break from “life as normal” to make new plans for the future. Generally, people were supported to do home-based pastimes such as board games and crafts, and to adapt their usual interests and hobbies so that they could be done at home, for example, having cinema nights, or doing Zoom exercise classes.

Holidays:

There were some examples of people doing things on holidays that could be further pursued in their everyday lives but haven’t been explored. For example, one person goes on an adventure sports holiday every couple of years but has not done any of the activities such as canoeing and climbing when at home. A couple of people also told us about how much they enjoy night-time entertainment and being out late when they are on holiday but they don’t go out regularly in the evening at home.

The Way People Work with Me

Privacy and respect:

There were some examples, from residential care and supported living, of staff not respecting the privacy of the people they support which was also observed in a couple of the review meetings. For example, support staff letting themselves into someone’s home or room without waiting for a response after knocking, or not knocking at all. Although this may be due to familiarity with the person, or even in agreement with the person, it nevertheless reflects the power imbalance between the person and the supporting staff, and in some cases demonstrates a lack of respect for the person.

Recruitment of staff:

Although there were some examples of people being involved in the recruitment process, this did not happen across the board. Further to this, involvement rarely extended beyond asking some interview questions and giving feedback, for example being part of the decision making process to appoint the best candidate and being part of the probationary period process.

Summary of themes from the Quality of Life reviews

Several themes and issues of note emerged from these reviews. The numbers of people reviewed is small. Therefore, the themes and issues included below describe both some aspects of people’s lives that were mentioned frequently, as well as aspects of people’s lives that are notable because they are not reflective of an ordinary life.

Some points below reflect potential differences across the two models of supported living and residential care, others seem to reflect wider attitudes and values around learning disability which are still too prevalent both within services and across society.

General issues

Supported living, where the person has a high level of staff support, enables a person to live a more varied, spontaneous and personalised life than residential care for a person with similar support needs. To some extent the reverse seems to be true for people in residential care who do not rely on staff support for day to day living. The emotional support available by a 24-hour staff presence in residential care seems to be a perceived benefit that is not available to people with similar needs who live in supported living.

My Home

People had limited choice about where they live and who they live with. People have more control over their home, and the space within it, in supported living. There are issues with the availability of fully accessible homes and the provision of services that make adaptations.

Being in Control of my Life

Everyday choice making is sometimes affected by factors such as, whether a person lives in residential care or supported living, is in shared or single person accommodation and by the level of staff support the person receives.

Approaches to life planning heavily focused on the leisure side of people's lives. Little attention, or none, is given to the areas mentioned above.

People in supported living were more likely to be involved in being active in running their own lives.

Only one person had any kind of paid work.

People in this review are behind the curve in terms of returning to a life with no COVID-19 restrictions, particularly in residential care, and are not involved in decision making around this.

Having a Full Life

Although some people are living very good, happy and full lives, they are not necessarily living ordinary lives. In particular, there were very few examples of people having a spectrum of friendships including with non-disabled people, contributing to the community, being part of mainstream groups and networks, working, or having personal development goals and ambitions.

The Way People Work with Me

Support staff do not always respect the privacy of the people they support.

People are sometimes involved in the recruitment of their support staff but this is often limited to being part of an interview panel and giving some feedback on candidates.

Economic Analysis

The economic analysis was conducted to assess the cost of support for the individuals that were part of the 200 Lives programme from both a societal perspective and a health and social care perspective. The best estimates of nationally representative unit costs were applied to data reported on accommodation type and services used by individuals to estimate annual costs at 2020 prices. Estimated costs of support for each individual in the study were combined and comparisons were made by service category and (separately) by type of accommodation. Regression analysis was conducted to determine which factors were associated with type of accommodation, total costs and health and social care costs.

Methods

Data on the volume of health and social care services used by each participant were collected in the staff survey using an adapted version of the Client Service Receipt Inventory (CSRI). Staff familiar with the individual reported on their frequency of use of health and social care services and other supports. They were also asked if the individual had acquired aids and adaptations which were not provided within their accommodation. Unit cost for services and equipment were drawn primarily from the most recent edition of the PSSRU Unit Cost Report (2020/21) where available. Where unit cost figures were not listed, information was drawn from supplementary sources including general web searches, and where necessary, inflated to 2020 prices. Unit cost data used is listed in Table 72. The costs of aids and adaptations were annuitised over 10 years at a rate of 3.5%.

Accommodation costs were only provided for a small number of respondents – nine from residential care, and 15 from supported living – and reported figures were highly variable (see Table 64). A targeted search was conducted for additional sources of accommodation costs to obtain a reasonable estimate for average accommodation costs to be incorporated into the analysis. We used average costs for residential care and supported housing given in the 2018 Mencap Housing Report (Mencap, 2018) and reported results from the 2019/20 Family Resources Survey (DWP, 2020) for an estimate of the average rent of individuals living independently in private accommodation. These published estimates of accommodation costs were used for each individual in the sample to alleviate uncertainty resulting from the marked variability in accommodation costs reported by survey respondents (which appeared to reflect misinterpretation of the questions and absence of full information available to the staff responding).

We did not include benefit payments in the estimation of total cost of support. From a societal perspective, these are transfer payments, paid in the form of taxes and re-distributed to those in receipt of benefits.

Additional analysis was conducted to assess factors associated with the type of accommodation and annual costs. The independent factors considered in these analyses were chosen on the basis of findings from previous research. They can be broadly categorised as pertaining to the individual's demographic characteristics (age and gender), health, extent of support needs and mental health, and the accommodation type (differentiating residential care from supported housing or independent/private accommodation). The health variables were self-reported general health (good vs fairly good vs not good), whether or not the individual had a long-term illness or physical disability (yes vs no) and whether or not they had been diagnosed as autistic (yes vs no). The extent of support need variables were the number of (i) support needs, (ii) problem behaviours and (iii) health conditions. The mental health indices were scores on the Generalised Anxiety Disorder (GAD-7; Spitzer et al 2006) and Patient Health Questionnaire (PHQ-9; Kroenke et al 2001), the latter an index of depression.

Data were missing for a number of these measures. To maximise the power of the statistical analyses and avoid bias, missing values were imputed. This assumed that the data were missing at random. This means that the distribution of missing and observed values was judged to be similar for subsets of the population defined by other observed variables (such as age and gender) (Rubin, 1987; Bhaskaran and Smeeth, 2014). The method of multiple imputation with chained equations (Van Buuren, 2007) was used. This method uses the partially observed data to derive multiple estimates of each missing value creating multiple copies of the dataset. Ten copies of the dataset were derived using this method. The modelling results combine the estimates derived from each copy, incorporating standard errors associated with the uncertainty resulting from estimation across the multiple datasets.

A logistic regression model was run with accommodation type as the dependent variable, comparing individuals in residential care with those in supported housing or independent accommodation. This model estimated the ratio in odds of living in residential care versus living in supported housing/independently for each independent variable. This analysis was used to help understand if and how participant characteristics varied between settings. Generalised linear regression models (log link and gamma distribution) were run for each of: (i) total costs; (ii) total costs excluding accommodation costs; (iii) health care costs and (iv) social care costs. We ran separate models for health and social care costs as we hypothesised that participants' characteristics would be different for these two groups of services, particularly when viewed in the context of accommodation type. Also, we excluded accommodation type as an independent variable in the model of total costs as the accommodation cost element is directly linked to accommodation type.

To account for the large number of independent variables we wanted to consider in each model relative to the sample size, we determined our final model based on iterative steps. The first step was to run separate models for categories of independent variables - health, extent of support needs and mental health - and retaining the variable with the greatest significance from each of them. The next step was estimating a model with age, gender, accommodation type (except in the total cost model as explained above) and each of the variables added in the first step as independent variables. The final model retained age, gender, accommodation type and those variables from the previous step that were statistically significant (p-value less than 0.05) or approached statistical significance (p-value less than 0.10). Analyses were conducted using STATA version 17.0 (StataCorp, 2021).

Results

Questionnaires were returned from 64 respondents – consisting of 21 in residential care, 29 in supported housing, and 14 in independent living – with varying degrees of completeness. Table 63 shows the extent to which data was available by type of residence.

Table 63 Availability of data across cost type by type of residence – n (row %)

	Sample size	Accomm.	Social care	Health Care	Other services	Aids and adaptations	ANY
Residential care	21	9 (42.9)	6 (28.6)	21 (100)	11 (52.4)	6 (528.6)	21 (100)
Supported housing	29	15 (51.7)	18 (62.1)	27 (93.1)	14 (48.3)	3 (10.3)	29 (100)
Independent living	14	0 (0)	5 (35.7)	12 (85.7)	6 (42.9)	5 (35.7)	12 (92.9)
Total	64	24 (37.5)	29 (45.3)	60 (93.8)	40 (62.5)	27 (42.2)	63 (98.4)

The largest component of cost was that for accommodation. The standard accommodation costs applied were: £1,940 per week for those in residential care, £202 per week for those in supported housing and £97 per week for those living independently. Consequently, total cost for residential care was an order of magnitude higher than that for supported living and those living independently. Residential care users reported total annual costs ranging from £101,430 to £136,760, with a mean of £107,900, which is considerably higher than that for supported living at £16,200, and those living independently at £8,210.

Table 64: Distribution of annual total costs by type of accommodation (£)

	N	Mean	Median	Min; Max
Residential care	21	107,904	103,814	101,036; 136,763
Supported Housing	29	16,204	12,162	10,605; 38,946
Independent	14	8,215	6,249	5,042; 16,843
Total sample	64	44,545	16,187	5,042; 136,763

After accommodation, the largest cost component for the sample as a whole was health care use. Indeed, a high proportion of the sample had used health care (94%). In contrast, only 53% of individuals were reported to have used social care services, although on a *per person* basis, costs for social care were greater (Table 65). Note that we would expect few people drawing on social care among individuals in residential care as this refers to social care provided *in the community* and those in residential care would have some or all of these care needs provided by residential care home staff.

Other services included art therapy, Third Sector Organisation support, drop-in centres, social clubs and sensory suites. The median annual cost among people drawing on these services was £870.

Table 65: Distribution of annual costs by source (£)

	Total sample (n=64)		People drawing on the service		
	Median	Range	N	Median	Range
Health care	731	0 - 14,359	60	845	84 – 14,359
Social care	184	0 – 17,280	34	2,640	184 – 17,280
Other services	0	0 – 18,149	31	869	100 – 18,149
Aids and adaptations	0	0 - 439	14	48	3 - 439
Total - not including accommodation costs	2,357	0 – 35,908	63	2,537	95 – 35,908
Total - including accommodation costs	16,187	5,042 – 136,763	64	16,187	5,042 – 136,763

The logistic regression model of factors associated with living in residential care as compared to living in supported housing or independently is presented in Table 66. The only variable significantly associated with living in residential care was the Support Required Total score (p-value = 0.006). As would be expected, higher required support increased the odds of being in residential care accommodation.

Table 66: Factors associated with living in residential care as compared to living in Supported Housing or independently (n=64)

	Odds ratio	p-value	95% confidence interval	
Age	0.99	0.521	0.95	1.03
Gender				
Female	-			
Male	1.17	0.814	0.31	4.50
Support Required Total score	**1.11**	**0.006**	**1.03**	**1.19**
Constant	0.07	0.049	0.00	0.99

If accommodation costs are excluded from total annual costs, the number of health conditions was significantly associated with these costs (p-value = 0.022). The greater the number of health conditions, the greater are total costs.

Table 67: Factors associated with total costs (excluding accommodation costs) (n=63)

	Coefficient	p-value	95% confidence interval	
Accommodation type				
Supported Housing/Independent	-			
Residential care	0.33	0.374	(-0.40,	1.05)
Age	0.005	0.710	(-0.021,	0.030)
Gender				

	Coefficient	p-value	95% confidence interval	
Female	-			
Male	-0.27	0.485	(-1.01,	0.48)
Number of health conditions	**0.15**	**0.022**	**(0.02,**	**0.28)**
Constant	8.07	0.001	(6.71,	9.44)

As observed in the model of factors associated with accommodation type, the total cost model including accommodation costs found a significant association with the Support Required score only (p-value = 0.001).

Table 68: Factors associated with support costs - including accommodation costs (n=64)

	Coefficient	p-value	95% confidence interval	
Age	-0.006	0.547	(-0.025,	0.013)
Gender				
Female	-			
Male	0.092	0.758	(-0.496,	0.681)
Support Required score	**0.044**	**0.001**	**(0.017,**	**0.070)**
Constant	9.78	0.001	(8.53,	11.03)

The number of health conditions was the only factor significantly associated with health care costs (p-value = 0.001).

Table 69: Factors associated with health care costs; n=60

	Coefficient	p-value	95% confidence interval	
Accommodation type				
Supported Housing/Independent	-			
Residential care	-0.42	0.096	(-0.91,	0.07)
Age	-0.003	0.745	(-0.020,	0.015)
Gender				
Female	-			
Male	-0.14	0.675	(-0.79,	0.51)
Number of health conditions	**0.32**	**0.001**	**(0.220,**	**0.42)**
Constant	7.14	0.001	(6.22,	8.05)

None of the variables considered were statistically significant in the model of social care costs. This may, in part, be due to the relatively small number of individuals for whom social care use was reported.

Table 70: Factors associated with social care costs – excluding accommodation costs (n=34)

	Coefficient	p-value	95% confidence interval	
Accommodation type				
Supported Housing/Independent	-			
Residential care	-0.31	0.418	(-1.06,	0.44)
Age	0.000	0.981	(-0.029,	0.030)
Gender				
Female	-			
Male	-0.17	0.418	(-0.86,	0.52)
Constant	8.64	0.001	(7.18,	10.11)

Personal Independence Payment was the most received benefit received by study participants. The next most received benefits were Employment Support Allowance, Disability Living Allowance and Housing Benefit. The proportion of people receiving Housing Benefit was highest for individuals in supported housing.

Table 71: Benefits received by type of accommodation

Benefits received	Residential care (n=21)	Supported Housing (n=29)	Independent living (n=14)	Total (n=64)
Disability Living Allowance	38.1%	48.3%	14.3%	37.5%
Personal Independence Payment	65.0%	51.9%	78.6%	62.3%
Universal Credit	0%	3.9%	42.9%	11.7%
Employment Support Allowance	55.0%	34.6%	50.0%	45.0%
Jobseekers Allowance	0%	0%	0%	0%
Income Support	5.0%	11.5%	0%	6.7%
Council Tax Reduction	0%	37.0%	42.9%	26.2%
Housing Benefit	0%	57.1%	35.7%	33.9%
Severe Disability Allowance	0%	7.4%	7.1%	4.9%
Disability Premium	5.0%	0%	0%	1.7%
Enhanced Disability Premium	0%	0%	0%	0%

Table 72: Unit costs and data sources

Item	Value	Source	Notes
Health and social care services (CSRI) (per hour)			
Social worker	£46	2020/21 PSSRU Unit Cost Report (p122)	
Care manager	£41	2020/21 PSSRU Unit Cost Report (p127)	
Social services occupational therapist	£47	2020/21 PSSRU Unit Cost Report (p125)	
CCG (case manager)	£55	2020/21 PSSRU Unit Cost Report (p125)	
Respite care overnight stay	£187.29	2020/21 PSSRU Unit Cost Report (p52)	
Support worker / Personal assistant	£25	2020/21 PSSRU Unit Cost Report (p128)	
Home care worker	£32	2020/21 PSSRU Unit Cost Report (p126)	
Inpatient stay	£827	2020/21 PSSRU Unit Cost Report (p83)	
A&E	£188	2020/21 PSSRU Unit Cost Report (p145)	
Outpatient visits (psych)	£137	2020/21 PSSRU Unit Cost Report (p83)	
Outpatient visits (other)	£137	2020/21 PSSRU Unit Cost Report (p83)	
Hospital visits (day)	£840	2020/21 PSSRU Unit Cost Report (p83)	
LD nurse	£44	2020/21 PSSRU Unit Cost Report (p108)	
LD support team	£387	2020/21 PSSRU Unit Cost Report (p57)	
Speech and language therapist	£41	2020/21 PSSRU Unit Cost Report (p104)	
Community occupational therapist	£41	2020/21 PSSRU Unit Cost Report (p104)	
Community physiotherapist	£41	2020/21 PSSRU Unit Cost Report (p104)	
Community psychiatrist	£41	2020/21 PSSRU Unit Cost Report (p104)	
Community psychologist	£65	2020/21 PSSRU Unit Cost Report (p104)	
Community psychiatric nurse	£41	2020/21 PSSRU Unit Cost Report (p104)	
CMHT crisis team visits	£245	2020/21 PSSRU Unit Cost Report (p34)	
Drug and alcohol team visit	£51	2020/21 PSSRU Unit Cost Report (p47)	
GP visits	£33.19	2020/21 PSSRU Unit Cost Report (p111)	

Item	Value	Source	Notes
GP nurse visits	£10.50	2020/21 PSSRU Unit Cost Report (p109)	
Community nurse visits	£11	2020/21 PSSRU Unit Cost Report (p108)	
Dentist visits	£23.8	2020/21 PSSRU Unit Cost Report (p117)	
Optician visits	£30	Web search	
Chiropodist visits	£41	2020/21 PSSRU Unit Cost Report (p104)	
Alternative therapy visits	£50	Web search re acupuncture	
Accommodation			
	-		
Residential care	£1,760 per week	MenCap and Housing LIN Repot April 2018	Applied PSS Pay & Price inflation index
	-		
Supported housing	£183.40 per week	MenCap and Housing LIN Repot April 2018	Applied PSS Pay & Price inflation index
Independent/private rent	£92 per week	Family Resources survey, 2019/20	Applied CPI inflation index
Other costs			
Art therapist	£64	2020/21 PSSRU Unit Cost Report (p67)	
Third sector organisation	£53	2020/21 PSSRU Unit Cost Report (p51)	
Solicitor	£65	NHSemployers.org	
Police	£38.74	London.gov.uk	
Other services			
Day centre	£72	2020/21 PSSRU Unit Cost Report (p50)	
Open employment	-	-	
Sheltered employment	-	-	
Adult education			
Drop-in Centre	£18.10	2020/21 PSSRU Unit Cost Report (p50)	
Social club	£18.10	2020/21 PSSRU Unit Cost Report (p50)	
Sensory suite	£14.35	-	
Recreation therapy	£35	2020/21 PSSRU Unit Cost Report (p104)	

Item	Value	Source	Notes
1-1 staff contact	£25	2020/21 PSSRU Unit Cost Report (p128)	
Adaptations and equipment			
Bath rails	£2.78	https://www.welcomemobility.co.uk/bathroom/grab-rails.html	
Monitor	£80.33	Purchased by study participant	
Pendant alarm	£119	https://www.ageuk.org.uk/products/mobility-and-independence-at-home/personal-alarms/	
Aids and adaptations			
Profiling bed	£700	https://www.medicalsupplies.co.uk/	
Tracking hoist	£750	https://dolphinlifts.co.uk/guide-ceiling-hoists/	
Shower trolley	£2,200	https://www.medicalsupplies.co.uk/	
Shower seat	£30	https://www.medicalsupplies.co.uk/	
Ring doorbell	£90	https://en-uk.ring.com/	
Toilet frame	£35	https://www.welcomemobility.co.uk/bathroom/toilet-frames.html	
Walker	£170	https://activiemobility.co.uk	

Key findings – Economic Analysis

- Total cost for individuals in residential care was an order of magnitude higher than that for supported living and those people living independently due to the high accommodation costs in this sector
- Health care services were used by a high proportion of individuals relative to social care. However, on a per user basis, social care costs were higher than health care costs
- There was a significant positive association between total costs and the number of health conditions
- In a model that excluded accommodation costs, the support required score was the only factor significantly associated with total costs

Family Carer Survey

Participants were asked whether they gave permission for the research team to contact their family to take part in the family survey. The survey consisted of closed and open-ended questions, in order to gather family carers' perspectives on the overall quality of provision, the extent of their own involvement, aspects of the service they valued and aspects they would like to be changed. The survey was based on a previous survey by NDTi (Blood & Cooney, 2020) that sought to estimate the time and money that family carers spend supporting their relatives in supported living or residential care.

Forty-two participants consented to their family being contacted to take part in the survey; the remainder either did not give consent or did not have close family members. The research team made contact with these family members and, where possible, followed up with a reminder email, letter or phone call.

Twenty-four family members in total completed the family survey; 75% of family members who responded had a relative who lived in supported living and 25% had a relative who lived in residential care. Where relevant, statistical tests have been conducted comparing family members of people in supported living and residential care, but it is important to note these tests are statistically underpowered due to the number of family members involved and may not pick up differences that exist.

One respondent was in their thirties (4%), five respondents were in their fifties (21%), ten respondents were in their sixties (42%) and seven respondents were in their seventies or above (29%). One respondent declined to provide their age.

Around half of respondents said they were the mother of the person they support (48%), 16% were the father of the person they support, 24% were the sister of the person they support and one person was a long-term previous foster carer. Two people did not specify their relationship to the person they support.

Around half of respondents said that they do not have a formal role in relation to their relative's financial affairs or welfare (48%). Around a quarter of respondents said that they were a DWP appointee (24%), one person had power of attorney with regards to health and welfare (4%), and two people had power of attorney with regards to financial affairs (8%). Two people (8%) were their relative's property and financial deputy and one person (4%) was their Court of Protection deputy.

Table 73: People who responded to the family carer survey

		Supported Living	Residential Care	Test and statistical significance
Age range	30 – 39 years old	5.9%	0%	Chi-square=4.329; df=3; p = 0.228
	40 – 49 years old	0%	0%	
	50 – 59 years old	17.6%	33.3%	
	60 – 69 years old	35.3%	66.7%	
	70 years old or over	41.2%	0%	
Relationship to the person they support	% Mother	41.2%	83.3%	Chi-square=3.551; df=3; p = 0.314
	% Father	23.5%	0%	
	% Sister	29.4%	16.7%	
	% Other	5.9%	0%	

Supporting their relative to move

The majority of family members (65% in supported living and 83% in residential care) said that they were involved in helping their relative to find and move into their current property. Most of them felt that their involvement in this process was about right, with the exception of two family members whose relative lived in supported living, one who felt they would have liked to be more involved and another who felt that they would have liked to be less involved. Over half of family members said that they received support with this process; this was most commonly from a social worker, with other sources of support including the current housing and / or support provider, friends and family, their GP and the local authority. There were no statistically significant differences between supported living and residential care on any of these questions.

Table 74: Process of supporting their relative to move

		Supported Living	Residential Care	Test and statistical significance
Where did their relative live before moving into their current home?	% Supported living	17.6%	16.7%	Chi-square=4.292; df=5; p = 0.508
	% Residential home	23.5%	16.7%	
	% Residential school or college	17.6%	33.3%	
	% Residential children’s home	0%	16.7%	
	% Family home	35.3%	16.7%	
	% Other	5.9%	0%	
Were they involved in the process of helping their relative to move?	% Yes	64.7%	83.3%	Fisher’s exact p= 0.621
	% No	35.3%	16.7%	
Would they have liked their involvement to be different?	% Would have liked to be more involved	5.9%	0%	Chi-square=0.773; df=2; p = 0.679
	% Involvement was about right	88.2%	100.0%	
	% Would have liked to be less involved	5.9%	0%	

		Supported Living	Residential Care	Test and statistical significance
Did they have support with the moving process?	% Yes	52.9%	66.7%	Fisher's exact p= 0.660
	% No	47.1%	33.3%	
Sources of support with the moving process	Current housing provider	44.4%	25.0%	*Not calculated*
	Previous housing provider	0%	0%	
	Current support provider	11.1%	25.0%	
	Previous support provider	0%	25.0%	
	Family / friends	33.3%	25.0%	
	GP / Doctor	0%	25.0%	
	Local authority	33.3%	0%	
	Social worker	55.6%	75.0%	

Family members were asked how they found the process of helping their relative to find and move into their current home. Experiences ranged from ***'fairly straightforward'*** (SL) to ***'complicated'*** and ***'long-winded'*** (RC) to ***'very difficult'*** (SL).

There seemed to be a polarity in responses, with some families having a good experience of helping their relative to move and others finding the process very difficult and drawn-out process. Interestingly these experiences were spread across both supported living and residential care.

Families who had positive experiences reported feeling well-supported by others, including professionals. The housing and / or support provider played a pivotal role in supporting families through the transition process, as discussed by the family member in the excerpt below:

> ***The professionals whom we worked with to achieve this outcome are a very established Housing Provider, who understand the potential difficulties and challenges their clients may have. We had a dedicated contact who worked with us, listened, supported and helped us to understand the necessary required processes.*** (SL)

It appears that consistency was important, such as having a key contact who the family could liaise with to guide them through the process. The role of the provider organisation started well before their relative had actually moved in and went beyond logistics and practical support.

This was a very emotional time for all the family. We were very lucky to have such good support from the children's residential setting our relative was in and also the setting they have now moved to. Without them the experience would have been very different. (RC)

Other families had minimal involvement in the moving process, which they were generally happy with, as their relative was able to lead the process.

The process did not involve me, it was very much [his] decision and I knew he was happy with the process and proposals which is why I didn't need to be involved. (SL)

Some families experienced challenges in finding a suitable property for their relative. It was important to many families that their relative stayed local, however this depended on the options available in their local area. This could be somewhat of a lottery, with some families struggling to find what they needed nearby. Another challenge was finding housemates who were compatible and well-matched with their relative.

They would offer places that weren't suitable for her needs... Some were big residential care homes for 50+ people out in the middle of nowhere, over an hour's drive from us. She wanted to live in our town to access her normal facilities like swimming club and to see us and go to day centre. (SL)

Some families described very difficult, gruelling and stressful experiences of trying to find a suitable home for their relative. This process took twelve years for one family. Some families felt that they were left to do it all without any support from professionals, for example:

Very hard. No social worker at the time. I did it all. RC)

In several instances, families were faced with sudden closures of their relative's home at the time, meaning that they needed to find a suitable new property with little time and support from services.

The residential school was to close and all of its 'clients' to be re-housed back in the family home! We personally had to look around the country for a suitable home\environment with virtually no help from Authorities. (SL)

These families were left with significant responsibilities whilst at the same time having little power to influence the options available to their relative. Several respondents said that they found professionals from the local authority to be unhelpful and at times, obstructive. This resulted in people being offered housing that was unsuitable due to accessibility or sensory needs, which was frustrating for families.

The social worker was positively obstructive. Stressful. The Council were unhelpful, obstructive and unwilling to actually consider his needs. (RC)

If the social workers actually listened to what we said rather than saying "we don't do that here." The answer to everything was we don't do that here. (SL)

These families found this process to be an uphill battle which took a toll on them. It required endurance and perseverance to push through these barriers and fulfil the goal of independent living for their relative, something that families held to be deeply important.

When asked what would make the process easier, families wanted to feel empowered with more transparency, better information and more involvement of families.

They could explain things better and be more open and honest with financial arrangements. They could include family members in the decisions they are making and not act as if the family members have given up the person moving into them. (SL)

Some respondents gave examples of creative ways in which they had navigated this process. For example, due to being unsatisfied with the options available to their relative, one family had set up their own support organisation. This meant that they were in a better position to support their relative to live the life she wanted.

We started the company to enable our daughter and others to live a life in a community where she could be an active member. Before we developed the company we looked at several places. They were not going to meet her needs. (SL)

Others mentioned the importance of learning from other families who had been through the process. It was helpful to share information with others, for example, practical information about local options, as well as mutual support and solidarity.

A leap of faith

Family members were asked if they had any concerns about their relative moving into their current property. Some described a general sense of trepidation about the change in arrangements. For many people, this was the first time that their relative had moved out of the family home or their first time living alone.

> ***She hadn't lived by herself before. Would it work? We believed that she could be independent, she wanted to be.*** (SL)

Moving was generally seen as a positive step towards independence, which family members desired for their relative. For example, there was excitement about their relative having a new start:

> ***They were looking forward to it, as it was a new house they were all friends from school starting off together.*** (SL)

However, there was understandably some anxiety about the move as it involved change and uncertainty.

> ***Anyone would be worried about whether they are making the best decision?*** (RC)

Family members were worried about how their relative would adjust to the move and whether the right support would be in place. They were unsure whether they could trust the support providers to be responsible for their relatives, and it took a while to build confidence in the support provider.

> ***We were anxious passing over responsibility (in loco parentis) for his care.*** (SL)

> ***Our son being cared for by an unknown [company]... How will he cope with a new care team, handing over our most precious to?*** (SL)

Moving was therefore both scary and exciting, an important step forwards for them and their relative, described as ***"a leap into the unknown"*** (SL).

Views on housing and support

The majority of family members felt that their relative's current home was better than their previous home, with the exception of a small number of people whose relative lived in supported living, who felt that their relative's current home was about the same or a bit worse than their previous home.

Table 75 shows family members' satisfaction with different elements of their relative's housing and support arrangements. There were no statistically significant differences between supported living and residential care in terms of overall satisfaction. The only statistically significant difference was that people whose relative lived in supported living tended to be more satisfied with how near their relative lived to them than people whose relative lived in residential care.

Table 75: Satisfaction with their relative's current home

		Supported Living	Residential Care	Test and statistical significance
How good is their current home in relation to their previous home?	% Much better % Quite a bit better % A bit better % About the same % A bit worse	58.8% 11.8% 0% 17.6% 5.9%	66.7% 16.7% 16.7% 0% 0%	Chi-square=4.725; df=5; p = 0.450
Satisfaction with their relative's current support and housing arrangements (total) ***Lower scores indicate better satisfaction***	Mean (sd) Range	22.7 (17.0) 14 - 61	22.6 (13.6) 14 - 49	t= -0.011; df=19, p= 0.991
Satisfaction with how near their relative lives to them	% Very satisfied % Mostly satisfied % Somewhat satisfied % Neutral % Somewhat dissatisfied % Very dissatisfied	88.2% 5.9% 5.9% 0% 0% 0%	33.3% 16.7% 33.3% 0% 16.7% 0%	**Chi-square= 7.797; df=3; p = 0.050**
Satisfaction with how homely the property is	% Very satisfied % Mostly satisfied % Somewhat satisfied % Neutral % Somewhat dissatisfied % Very dissatisfied	64.7% 29.4% 0% 5.9% 0% 0%	66.7% 16.7% 16.7% 0% 0% 0%	Chi-square= 3.465; df=3; p = 0.325
Satisfaction with how well the physical environment suits their relative's needs	% Very satisfied % Mostly satisfied % Somewhat satisfied % Neutral % Somewhat dissatisfied % Very dissatisfied	58.8% 29.4% 5.9% 0% 5.9% 0%	100.0% 0% 0% 0% 0% 0%	Chi-square= 3.551; df=3; p = 0.314

		Supported Living	Residential Care	Test and statistical significance
Satisfaction with how frequently they have contact with their relative	% Very satisfied	70.6%	83.3%	Chi-square= 1.238; df=4; p = 0.872
	% Mostly satisfied	11.8%	16.7%	
	% Somewhat satisfied	5.9%	0%	
	% Neutral	5.9%	0%	
	% Somewhat dissatisfied	5.9%	0%	
	% Very dissatisfied	0%	0%	
Satisfaction with how involved they are in decisions about their relative's support	% Very satisfied	52.9%	66.7%	Chi-square= 1.896; df=4; p = 0.755
	% Mostly satisfied	23.5%	16.7%	
	% Somewhat satisfied	5.9%	16.7%	
	% Neutral	5.9%	0%	
	% Somewhat dissatisfied	0%	0%	
	% Mostly dissatisfied	11.8%	0%	
	% Very dissatisfied	0%	0%	
Satisfaction with how much they are kept informed	% Very satisfied	41.2%	66.7%	Chi-square= 2.884; df=5; p = 0.718
	% Mostly satisfied	23.5%	33.3%	
	% Somewhat satisfied	17.6%	0%	
	% Neutral			
	% Somewhat	5.9%	0%	
	dissatisfied	0%	0%	
	% Mostly dissatisfied			
	% Very dissatisfied	0%	0%	
		5.9%	0%	
Satisfaction with how well their relative is treated with dignity and respect	% Very satisfied	76.5%	83.3%	Chi-square= 0.382; df=2; p = 0.826
	% Mostly satisfied	17.6%	16.7%	
	% Somewhat satisfied	5.9%	0%	
	% Neutral	0%	0%	
	% Somewhat dissatisfied	0%	0%	
	% Mostly dissatisfied	0%	0%	
	% Very dissatisfied	0%	0%	
Satisfaction with how happy their relative is	% Very satisfied	64.7%	83.3%	Chi-square= 5.172; df=3; p = 0.160
	% Mostly satisfied	29.4%	0%	
	% Somewhat satisfied	5.9%	0%	
	% Neutral	0%	0%	
	% Somewhat dissatisfied	0%	16.7%	
	% Mostly dissatisfied	0%	0%	
	% Very dissatisfied	0%	0%	
Satisfaction with the extent of choice available to their relative	% Very satisfied	52.9%	83.3%	Chi-square= 6.330; df=4; p = 0.176
	% Mostly satisfied	35.3%	0%	
	% Somewhat satisfied	0%	16.7%	
	% Neutral	5.9%	0%	
	% Somewhat dissatisfied	5.9%	0%	
	% Mostly dissatisfied	0%	0%	
	% Very dissatisfied	0%	0%	

		Supported Living	Residential Care	Test and statistical significance
Satisfaction with the emotional support available to their relative	% Very satisfied	70.6%	66.7%	Chi-square= 3.292; df=3; p = 0.349
	% Mostly satisfied	23.5%	16.7%	
	% Somewhat satisfied	4.3%	16.7%	
	% Neutral	4.3%	0%	
	% Somewhat dissatisfied	0%	0%	
	% Mostly dissatisfied	0%	0%	
	% Very dissatisfied	0%	0%	
Satisfaction with how your relative spends their time	% Very satisfied	58.8%	50.0%	Chi-square= 3.425; df=4; p = 0.489
	% Mostly satisfied	23.5%	16.7%	
	% Somewhat satisfied	11.8%	16.7%	
	% Neutral	0%	0%	
	% Somewhat dissatisfied	0%	16.7%	
	% Mostly dissatisfied	0%	0%	
	% Very dissatisfied	5.9%	0%	
Satisfaction with efforts made to maintain contact with other family members and friends (if applicable)	% Very satisfied	52.9%	66.7%	Chi-square= 4.316; df=5; p = 0.505
	% Mostly satisfied	29.4%	16.7%	
	% Somewhat satisfied	0%	0%	
	% Neutral	5.9%	0%	
	% Somewhat dissatisfied	5.9%	0%	
	% Mostly dissatisfied	0%	16.7%	
	% Very dissatisfied	5.9%	0%	
Satisfaction with support their relative receives to have an active and / or healthy life	% Very satisfied	82.4%	66.7%	Chi-square= 1.679; df=3; p = 0.642
	% Mostly satisfied	5.9%	16.7%	
	% Somewhat satisfied	0%	0%	
	% Neutral	5.9%	16.7%	
	% Somewhat dissatisfied	0%	0%	
	% Mostly dissatisfied	0%	0%	
	% Very dissatisfied	5.9%	0%	
Satisfaction with the extent to which their relative gets on with the people they live with (if applicable)	% Very satisfied	66.7%	50.0%	Chi-square= 4.792; df=4; p = 0.309
	% Mostly satisfied	13.3%	33.3%	
	% Somewhat satisfied	13.3%	0%	
	% Neutral	6.7%	0%	
	% Somewhat dissatisfied	0%	0%	
	% Mostly dissatisfied	0%	16.7%	
	% Very dissatisfied	0%	0%	

What they value about where their relative lives

When asked about what they liked about their relative's current home, family members' opinions mirrored those given in the participant responses (page 36). These aspects were broadly similar across supported living and residential care.

With regards to the home itself, family members liked properties that were a good size, with enough space for their relative. It was important that the home was well-kept and had a homely feel. Family members valued properties that were in safe and quiet neighbourhoods, with convenient access to local facilities such as shops and leisure facilities. Many said that they liked the fact that the home was near to them so they could visit their relative easily.

A large well-kept home in an up-market area with little crime. Large garden and nice walks from the door-step. A convenience shop nearby. Within walking distance to town centre... near to the rest of his family. (SL)

That he lives on a large self-contained site. Activities are available both on and off site. Peaceful, rural setting, plenty of opportunities. (RC)

Like the participant responses, people such as housemates and staff played a central role in family members' views about the house.

He lives with people he has known since school and considers them his 2nd family. (SL)

It was important to families that their relative got on well with the people they lived with and had plenty of opportunities for social interaction. The quality of support from staff was also frequently mentioned as a factor influencing how good the house was, particularly during the COVID-19 pandemic when people were more reliant on staff as social engagements were limited.

Family members particularly valued the opportunities that the housing provided for their relative, enabling them to be independent and have an active and full life. These included access to activities and being part of the local community.

I like the fact that our relative is treated as an individual and that their disability is not seen as an obstacle to them participating in any activities they choose. (RC)

The guys who live in the house have individual support and are not treated as a group of five to go to everything together. They are supported to have activities in the local community and don't only go activities run for disabled people. (SL)

It was important that people were treated as individuals and that their own choices and aspirations were respected.

> ***Since our relative moved into their own home, alongside a direct payment and supporting personal health budget, this combined professional and family support has achieved for our relative to 'live their own life' 'their choices'.*** (SL)

Ultimately, family members felt the set-up was working well if their relative was happy there.

What they would like to improve about where their relative lives

As with the participant responses, whilst people could make a home they could also break it (page 44). Within the family responses, this focused particularly on staff with several family members discussing improvements they would like to see regarding their relative's support arrangements. For example, one family member was unhappy with the inconsistency of staff who supported their relative:

> ***Knowing who the staff are and get involved with staff changes. I don't know who they are - names change every 5 minutes.*** (SL)

Another family member said they would like better communication from the team manager.

> ***I would like to see the manager of the residence being more involved with the family and being more accessible.*** (RC)

Similar to the participant theme of 'space and place' (page 44) family members discussed aspects of the building design that they would like to see improved, for example adding an en-suite or improving accessibility. As noted in the participant responses, some supported living properties were in a poor condition and one family described a problem with the landlord not addressing breakages and repairs:

> ***Upkeep of the building is awful, car park is dirty, outside lights don't work and aren't replaced. Social landlord doesn't do her job properly and check that things are working. Daughter can't stand the flickering lights. Landlord don't fix things in a timely way - don't ring you back.*** (SL)

Another family member would prefer if their relative lived closer to them, reiterating the importance of location:

> ***I would like my relative to be able to move closer to home and family*** (RC)

The support they provide to their relative

Family members were asked about how they balance supporting their relative with other aspects of their life, such as work, looking after themselves and their social life, as shown in Table 76. Some of these questions were taken from the Adult Social Care User Survey (2020). Again, there were no statistically significant differences on any of these domains between people whose relative lived in supported living or residential care.

Around half of family members rated their general health as good or very good in the past year. The majority of family members felt that they were able to look after themselves well enough and to spend some time doing things they value and enjoy.

The vast majority of respondents had not experienced any financial difficulties in the past year. 23.5% of people whose relative lived in supported living and 33.4% whose relative lived in residential care were in full-time or part-time paid employment. Of these, all of them felt either well-supported by their employer, or that they did not require support from their employer with regards to combining paid work with supporting their relative.

29.4% of people whose relative lived in supported living felt that their relative's support arrangements work well without their input; no one whose relative lived in residential care endorsed this option. 100% of people whose relative lived in residential care and 52.9% of people whose relative lived in supported living felt that they keep an eye on their relative's support arrangements, but generally things work well without their input. A minority of people whose relative lived in supported living felt that they needed to coordinate their relative's support arrangements in order for them to work (11.8%), or that their relative's support arrangements would fall apart without their input (5.9%).

Table 76: Balancing caring with other aspects of life

		Supported Living	Residential Care	Test and statistical significance
General health in the past year	% Very good	23.5%	16.7%	Chi-square= 1.707; df=4; p = 0.789
	% Good	41.2%	33.3%	
	% Fair	11.8%	33.3%	
	% Bad	17.6%	16.7%	
	% Very bad	5.9%	0%	
Looking after themselves	% I look after myself	80.0%	100%	Chi-square= 1.176; df=2; p = 0.555
	% I can't look after myself well enough	6.7%	0%	
	% I feel I am neglecting myself	13.3%	0%	

		Supported Living	Residential Care	Test and statistical significance
Self-rated quality of life	% So good it could not be better	5.9%	0%	Chi-square= 0.608; df=3; p = 0.894
	% Very good	41.2%	33.3%	
	% Good	23.5%	33.3%	
	% Alright	29.4%	33.3%	
	% Bad	0%	0%	
	% Very bad	0%	0%	
	% So bad it could not be worse	0%	0%	
Spending time doing things they value	% I'm able to spend my time doing things I value or enjoy	68.8%	33.3%	Fisher's exact p= 0.178
	% I do some of the things I value or enjoy with my time, but not enough	31.3%	66.7%	
	% I don't do anything I value or enjoy with my time	0%	0%	
Social life	% I have as much social contact as I want with people I like	70.6%	40.0%	Chi-square= 3.697; df=2; p = 0.157
	% I have some social contact with people but not enough	17.6%	60.0%	
	% I have little social contact with people and feel socially isolated	11.8%	0%	
Control over their daily life	% I have as much control over my daily life as I want	76.5%	50.0%	Chi-square= 3.011; df=2; p = 0.222
	% I have some control over my daily life but not enough	17.6%	16.7%	
	% I have no control over my daily life	5.9%	33.3%	
Support and encouragement from others	% Enough encouragement and support	80.0%	60.0%	Chi-square= 1.867; df=2; p = 0.393
	% Some encouragement and support	13.3%	40.0%	
	% No encouragement and support	6.7%	0%	
Experience of financial difficulties	% No financial difficulties	94.1%	83.3%	Fisher's exact p= 0.462
	% Financial difficulties to some extent	5.9%	16.7%	
	% A lot of financial difficulties	0%	0%	
Current employment status	% Retired	47.1%	50.0%	Chi-square= 5.202; df=6; p = 0.518
	% Employed full-time	17.6%	16.7%	
	% Employed part-time	5.9%	16.7%	
	% Self-employed full-time	0%	0%	
	% Self-employed part-time	11.8%	0%	

		Supported Living	Residential Care	Test and statistical significance
	% Not in paid work	5.9%	0%	
	% Doing voluntary work	11.8%	0%	
	% Other	0%	16.7%	
Has the support they provide impacted on work?	Opened up new work opportunities	11.8%	16.7%	
	Changed career	0%	0%	
	Reduced hours at work	11.8%	16.7%	
	Reduced responsibility at work	0%	0%	
	Unable to work due to caring responsibilities	5.9%	0%	
	Retired early	17.6%	0%	
	Became self-employed	11.8%	0%	
Combining paid work and support they provide	% Feel supported by employer	33.3%	50.0%	Fisher's exact p= 1.000
	% Don't feel supported by employer	0%	0%	
	% Don't require support from employer	66.7%	50.0%	
Their input in relation to their relative's support arrangements	% Support arrangements work well without their input	29.4%	0%	Chi-square= 4.329; df=3; p = 0.228
	% Keep an eye on support arrangements, but generally work well	52.9%	100.0%	
	% Need to coordinate support arrangements in order for them to work	11.8%	0%	
	% Support arrangements would fall apart without their input	5.9%	0%	

Being part of a team

With regards to their role and involvement in their relative's support, the majority of families who responded to the survey felt that things generally worked well without their input, or with them keeping an eye on things.

In arrangements that worked well, family members described feeling as though they are part of a team supporting their relative. This included families, social services, support providers and the person themselves.

> ***I feel my brother is well looked after and I am part of a good team providing his care*** (RC)

In the following quote, a family member discusses how they remain involved in their relative's life, but they trust the support provider to handle everyday issues that arise. This arrangement seems to work well for them.

> ***We are very fortunate that our son is supported by an excellent company. We are fully involved in [his] life but [org] take care of all day to day issues and we have complete confidence in their support for [him].*** (SL)

This is echoed in the following quote in which the family member appreciates being involved in decisions but equally values the views of professionals who work with their relative.

> ***We have been very lucky to have our family member living full time in a very caring and dynamic environment. We have an exceptionally good relationship with the provider and we work well together as a team. I am still involved in all major decisions and value the opinion of the carers and key workers involved in the family member's care.*** (RC)

Some families had opted to take a more central role by either setting up their own provider organisation or becoming a trustee of their relative's support. They felt that the additional time this involved was worth it because their relative received better quality support, as follows:

> ***I am involved with the support as I am a Trustee of the independent living trust. This means more time than if a care provider was used but it is better as the support provided is very much better.*** (SL)

The importance of listening to and valuing families' input was emphasised throughout the responses:

> ***'Family' input should not be underestimated, it is as important, valid and necessary as professional input is.*** (SL)

This is further emphasised in accounts where arrangements were not working well and families felt side-lined and ignored; in some cases, feeling abandoned by services and left to sort things out themselves.

> ***People over-estimate her abilities so she doesn't always get the support she needs...The worst part for me is it's a constant battle, it always has been and it always will be and it doesn't need to be that way....when Valuing People was done, money put aside to support carers. All of those things have been taken away. Family carers get used and they abuse our good nature.*** (SL)

The above quote shows the impact of austerity on families, with support for family carers being stripped away and some families left feeling precarious and vulnerable.

Key Findings – Family Perspectives

- Twenty-four family members completed the family survey; six whose relative lived in residential care and eighteen whose relative lived in supported living.
- Most of them said they had been involved in the process of helping their relative to find and move into their current home, and most felt that their level of involvement in this process was about right. Sources of support with the moving process included social workers, housing and / or support providers and friends and family.
- Some families found the process of finding their relative's current property to be straightforward and felt well-supported by professionals, such as social workers. Housing and support providers played an importance role in supporting families through the transition, even before the person had moved into their home.
- Other families had very difficult experiences of finding somewhere suitable for their relative, due to a lack of suitable options, being left with little support from professionals and finding the authorities to be unhelpful and at times, obstructive.
- To improve this process, families would like to be empowered with more information, transparency and opportunities to exchange experiences with other local families.
- Most family members who responded to the survey felt that their relative's current home was better than their previous home. There was no statistically significant difference in overall satisfaction between supported living and residential care. However, people whose relative lived in supported living were significantly more satisfied with how near their relative lives to them, compared to people whose relative lived in residential care.
- Families valued properties that were a good size, well-kept and homely, in safe locations with easy access to local facilities. It was important to many that their relative stayed living locally to them. Relationships with housemates and staff were also important, as well as opportunities that the housing set-up provided their relative to live the life they wanted.
- Communication with and consistency of staff was thought to be something that could be improved. Other respondents would like changes to be made to their relative's property, such as making it more accessible or adding an en-suite.
- 29.4% of people whose relative lived in supported living felt that their relative's support arrangements work well without their input. 100% of people whose relative lived in residential care and 52.9% of people whose relative lived in supported living felt that they keep an eye on their relative's support arrangements, but generally things work well without their input.
- In arrangements that worked well, family members described feeling as though they were part of a team supporting their relative. Whilst the extent of their input was different for each family, this generally mean remaining involved in decisions whilst having confidence in the support provider to handle everyday issues.

Summary & Conclusions

Main messages

Taking the project's findings together, there are a number of main messages for commissioners, service providers, housing providers, regulators and policy-makers to consider. People with learning disabilities, self-advocacy groups and families will hopefully also find these main messages useful in providing evidence to underpin the support people want.

Before going through these main messages, it is important to note the project's limitations and the impact of the COVID-19 project on the pandemic.

Limitations and the impact of COVID-19

The COVID-19 pandemic has had an impact on this project in several ways, which places some limitations on how the project's findings can be interpreted. Most obviously, the project recruited 107 participants (77 people in supported living and 30 people in residential care) rather than the 200 participants planned, as supported living and residential care services were operating under extreme pressure throughout the duration of the project. These reduced numbers have limited some of the analyses we planned to do and has also meant less statistical power for comparisons between supported living and residential care. The necessary change of data collection approaches from face-to-face to largely remote methods resulted in more flexibility in interviews with participants, but fewer opportunities to directly encourage highly pressured staff to provide complete data, particularly in terms of data for costing purposes. This has resulted in more limited costing information being available than anticipated.

The reduced number of participants also meant that the project included a smaller number of places where people lived and provider organisations than originally anticipated. Although 31 provider organisations expressed an active interest in participating in the project, 16 provider organisations were eventually involved, with COVID-19-related pressures being cited by interested but non-participating providers. The sample of services and service providers evaluated in this project cannot be considered to be representative, but we believe they do offer a detailed insight into how supported living and residential care services operate and the lives of people with learning disabilities drawing on these services.

The final impact of COVID-19 on this project is that the people taking part were likely to have been living with more internally and externally imposed restrictions on social activities and freedom of movement than before the pandemic. While we only collected a very small amount of information during periods of lockdown, public health protection measures, measures taken by staff and service providers, and people's sense of civic responsibility may all mean that measures of people's social lives, particularly away from where people lived, are not as extensive as they may have been before the pandemic. There were also substantial numbers of people in both supported living and residential care who had been shielding at some point in the pandemic, although smaller numbers of people were shielding at the time we collected information. The extent to which life (including social care supports) will return to pre-pandemic levels is also unclear for people with learning disabilities in the UK (Flynn et al., early view).

Message 1

Commissioners, service providers and regulators need to ensure that the restricted lives people in supported living and residential care have experienced during the pandemic do not become the long-term norm, and that there are opportunities for people to consider afresh how they want to be supported.

Who is being supported?

There were no differences in the age, gender or ethnicity of people in this project living in supported living and residential care, with a wide range of ages (18 to 72 years), a majority of men, and approximately 90% of people being white. There are no national data available for comparison purposes to evaluate how similar or different people in this project were to the population of adults with learning disabilities in England living in supported living or residential care.

On average, people in residential care had greater support needs than people in supported living, although there were people with the full range of support needs living in both settings. There were no overall differences between people in supported living and residential care in a range of diagnoses, longstanding impairments, or behaviours that are a challenge to others. People in residential care were reported to be more likely to have bowel control issues and to need support with eating and drinking than people in supported living. Over a quarter of people described themselves, or were reported by staff to have been assessed by a professional, as being autistic. Just under a quarter of people had a diagnosis of epilepsy, and over a quarter of people had an issue with mobility.

Although there were some differences as outlined above, it is important to note that both supported living and residential care supported people with a wide range of needs. This is a similar pattern to that reported by Emerson et al. (1999) in supported living compared to group homes in England in 1997 and 1998.

Message 2

Both supported living and residential care services can support people with a wide range of needs for support. Commissioners cannot assume that a particular support model is required to support a person with particular needs. Equally, commissioners need to ensure that, whatever the service model, people with greater health and support needs have the specific support in place to keep people healthy and well.

The characteristics and operation of supported living and residential care services

There were both similarities and differences in the characteristics and operation of supported living and residential care services. On average, residential care homes had more people living in them (8 people) than supported living homes (3 people). Housing and support were provided by the same organisation in all residential care homes but by different organisations in most (but not all) supported living properties, despite this being a defining feature of the Supported Living model. Residential care properties were more likely to be specialised for people with learning disabilities with a particular need, and to have adaptations made to the property, while a quarter of people in supported living were in unadapted ex local authority housing. People had lived in their current home for an average of around 10 years (longer than the average 5 years reported by Emerson et al., 1999), with no differences between supported living and residential care, although the range in the length of time people had lived in their current home in both types of housing was large (from 7 months to almost 30 years).

Residential care homes were more likely to include areas out of bounds to people living in them, and to use deadlocks within the home to restrict people's access to certain areas or rooms, with other physical indicators of 'homeliness' similar between supported living and residential care properties. Physical indicators of homeliness were little different than those reported in Emerson et al. (1999). People in residential care homes were also less likely to have their own front door key and more likely to have people coming into their bedroom without asking than people in supported living. People in residential care homes were also much more likely to be under a DoLS than people in supported living, although services across the board rarely prohibited any activities.

On average, people in residential care were more likely to experience block treatment (for example everyone in the home going out together rather than individually) than people in supported living (a similar pattern to that reported by Emerson et al., 1999), although it is important to remember that some people in supported living lived alone or with their partner. In other aspects of 'institutional' life (for example having to conform to rigid routines or social distance between people with learning disabilities and support staff) there were no differences between supported living and residential care, although there was wide variation in institutional practices within both supported living and residential care.

There are some clear structural and operational differences between residential care and supported living, with the increased size of residential care homes associated with restrictions in access to areas of people's homes and greater block treatment of people living in residential care homes, although variations in the physical homeliness and the extent of institutional routines were evident within supported living and residential care services.

Message 3

Commissioners and regulators need to directly contract and/or proactively monitor both supported living and residential care for physical aspects of properties, institutional routines, and issues of access and privacy within the person's home, to ensure that people feel their house is indeed their home.

Message 4

The housing stock used for supported living needs to be fully accessible and adapted for people with a range of support needs, both in terms of adaptations within the property and in accessibility to the property from outside. Housing with the capacity to adapt to people's changing needs across the lifecourse is also crucial in enabling people to stay in their home (if they wish to) and reduce the need for unplanned reactive house moves (DHSC, 2021).

Housing rights

Supported living services did not all embody the Real Tenancy Test standards (NDTi, 2015) in terms of people's housing rights, with only just over a quarter of people in supported living experiencing all 11 components of the Real Tenancy Test. It is worth noting that although the Real Tenancy Test standards are not designed for people in residential care, people in residential care recorded on average 7 out of 11 components, compared to an average of 9 for people in supported living.

Message 5

Commissioners and regulators should adopt or develop an equivalent to the Real Tenancy Test standards in contracting, monitoring and regulating supported living services. Service providers can also use these or equivalent standards, as can people with learning disabilities and (where relevant) families when considering a house move. A parallel set of standards concerning housing rights should also be developed for residential care services.

How people feel about where they live

The vast majority of people in both supported living and residential care said they liked where they lived, with people often making comparisons to where they lived before moving to their current home when evaluating where they lived now. People valued being able to make their home their own, for example in decorating their home or finding spaces in shared areas that were ‘theirs’. People also valued having day-to-day autonomy over their lives, and feeling a sense of home gave people a sense of freedom and being respected as an adult. For most people home was a place of safety and familiarity, although security measures to establish a boundary between the person’s home and the outside could sometimes feel restrictive.

Most people in supported living said they had chosen their current home although fewer people had looked at anywhere else before moving. Almost half of people in supported living chose who they lived with, although relatively few people were involved in choosing new people who moved into their home after them. About half of people in residential care said they had chosen their current home, although no-one in residential care had chosen who they lived with.

Message 6

For service providers, ensuring that people have spaces of their own (in both personal and shared areas), arranging as they wish them to, is essential, which will include financial support for furniture and decoration on a regular basis.

Message 7

Security measures for people’s homes should be proportionate, with the scale and nature of these measures decided by those people living in the property.

Moving house

Most people experienced a bumpy road when it came to moving house. Many hurdles arose to a smooth house move, including a lack of options of places to move to, funding issues, disruptive interim moves rather than a move to a desired destination, and COVID-19-related disruptions. These were issues both for reactive house moves (in response to problems in the person’s current living situation) and proactive house moves (towards a person’s life goals). A change of home was a major life event for people, and allowing people to take time to make the change, people moving to areas they were familiar with, people choosing and spending time with future housemates incrementally, and continuity of support throughout the process, were all important in smoothing the road.

When people were considering potential future house moves, both reactive and proactive reasons for moving were mentioned, although many people felt a sense of needing to compromise given the difficulties involved in moving house.

Message 8

For commissioners, service providers and housing providers, maximising the opportunities for people to engage proactively in a house move, with the process smoothed and supported at the person's pace and with them in control of the process, is a high priority.

Message 9

It is vital that commissioners, service providers and housing providers respect the right of people with learning disabilities to a meaningful lifecourse through adulthood, rather than assuming a perpetual present for people. This means respecting and facilitating people to develop their aspirations and wishes for the future, including moving home when people want to get their own place, live with a partner, become more independent, or move away from housemates they dislike.

Place

Most people in both supported living and residential care liked the area they lived in and felt safe both in their home and in their local area. People in supported living were more likely to know and like their neighbours compared to people in residential care. People spoke about various strategies to keep themselves safe when they were out, such as taking known routes, being out with other people, and keeping their phone on them, with a general sense of vigilance for potential danger.

Around a third of people in both supported living and residential care said that someone had been rude or nasty to them because of their disability in the past year, with fewer people experiencing a crime (largely abuse/threats or physical assault). A minority of people in both supported living and residential care experienced an injury/accident at home requiring medical attention, with almost no-one experiencing this out of the home – fewer people experiencing accidents/injuries than reported by Emerson et al. (1999).

People living in residential care overall lived a life that revolved more around their home than their immediate neighbourhood, supported by costings data regarding use of other social care supports. In supported living services, people's experiences of both their home and their immediate neighbourhood varied widely and had a huge impact on people's lives. People really valued living in homes of good quality and in friendly neighbourhoods with easy access to local amenities and transport (family members agreed with these priorities). In contrast, poor quality housing in neighbourhoods that felt threatening could lead to isolated and restricted lives. These are functions of broader social policy issues related to austerity and the availability of housing, rather than functions of supported living or residential care approaches to supporting people.

Message 10

The location of supported living housing stock and residential care homes, and what their neighbourhoods afford for people living there, need to be prime considerations for commissioners and providers.

Social connections

People in residential care lived further away from family and friends than people in supported living, although many people in both supported living and residential care saw their family every week. Average distances from family (15 miles for people in supported living; 30 miles for people in residential care) were similar to those reported by Emerson et al. (1999). Families generally kept an eye on how things were going with the service for their relative, although families were more varied in how much they were involved with supported living services. Most people in both supported living and residential care had friends they liked to spend time with, with people in supported living more likely to see friends regularly than people in residential care. Sometimes people's friendships with others were a function of people sharing a house or meeting regularly at a day service, with few opportunities to cultivate and deepen these friendships outside of services rendering them quite fragile if people's circumstances changed.

Overall, people's social networks in both supported living and residential care were relatively small, although potentially larger than those reported by Emerson et al. (1999). Other people (both housemates with learning disabilities and support staff) could make a home, in terms of fun, companionship and emotional support, or could break a home in terms of conflicts and people disliking each other, which could have a major impact on people's sense of home.

It is also important to remember that 37% of people in supported living and 13% of people in residential care were in a relationship.

Message 11

The location of a property in terms of closeness and ease of meeting up with family and friends outside of the person's home is crucial to people's wellbeing.

Message 12

Service providers need to facilitate ways for people to develop and maintain enduring friendships with people outside of services.

Message 13

People in relationships who want to live together should be supported to do so, in the type of arrangement they want to live in.

How people spend their time, including paid employment

Although the COVID-19 pandemic is likely to have been a factor in this, for people in both supported living and residential care how most people spent their time revolved largely around domestic tasks, going to the shops and using public transport to create a structure for the week, while also allowing time for spontaneity and time to relax. People in residential care homes were more likely to travel by shared minibus with housemates than people in supported living. Many people wanted opportunities for progression and self-improvement in a whole range of areas of their lives, although these opportunities were limited and often reliant on support staff.

There was very little focus on employment, with people citing the complications of the benefits system as a barrier to a paid job and people in residential care being paid in vouchers. Whether in voluntary or paid work, average hours per week were low (less than 10 hours per week). Both rates of employment and average hours worked were little different to those reported by Emerson et al. (1999). People with a job particularly valued the sense of purpose that came with their job, as well as a sense of pride in their skills and contributions and connections with fellow workers.

Message 14

Effective support for people to get into fulfilling paid employment that allows people to develop their skills and change with their aspirations requires reform of the benefits system, commissioner action (for example in commissioning effective and proactive supported employment schemes), service provider encouragement and housing in locations that allow safe travel to and from work, as well as engagement with local employers.

Money

The vast majority of people in both supported living and residential care were reported by staff to be receiving benefits, most commonly PIP, ESA and DLA. People in supported living were more likely to receive housing benefit and council tax reduction. Levels of material hardship were low.

While most people in both supported living and residential care reported being able to choose how they spent their money, it was clear that for most people this choice was restricted to limited aspects of their money, with ultimate control usually resting with the person's service, staff, or in some cases a family member. People in residential care were generally accepting of this safeguarding of their money by the service. For people in supported living the picture was more mixed – people were more likely to understand risks from scammers or financial exploitation by other people, and some people would seek out support when they needed it (for example with larger purchases), while for others the degree of financial control exerted by others was seen as infantilising.

Message 15

Greater training and support for people to manage their own money is required, to enable people to make informed decisions about their financial arrangements.

Service costs

Including accommodation costs, service costs were on average much higher for residential care than for supported living (whether support housing or independent living). Greater support needs were associated with living in residential care and with higher total support costs (including accommodation costs); people having a greater number of health conditions was associated with higher support costs excluding accommodation costs. While the vast majority of people for whom costings information was available were using health services, fewer were using social care services outside the person's home, other services outside the home, or had aids and adaptations.

Disability Living Allowance and/or Personal Independence Payment benefits were almost universal across both supported living and residential care. Except for people living in more independent forms of supported living, universal credit was very rare. Around half of people in both supported living and residential care were receiving Employment Support Allowance, with few people receiving income support and no-one receiving Jobseekers Allowance. Housing Benefit and Council Tax Reduction were received exclusively by people in supported living, but by less than half of people living in supported living.

Message 16

Commissioners should not use service model or total service cost as a proxy for making decisions about appropriate and safe support for people with greater health and support needs. More individualised information and monitoring is needed to ensure that people are getting the amount and nature of support they need to live lives that are both safe and fulfilling.

Health and wellbeing

Most people in both supported living and residential care said that their life was at least mostly good, with very few people saying life was bad or terrible. Compared to people in residential care, people in supported living were more likely to be not worried or sad, or very worried or sad, indicating the divergent experience of people in supported living. No-one in residential care reported themselves to be above clinical thresholds on measures of anxiety or depression, compared to 21% and 11% of people in supported living, although these differences were not statistically significant. Almost everyone said they had someone they could talk to if they were feeling down.

In terms of physical health, almost half of people with BMI data were overweight or obese, similar rates to those reported by Emerson et al. (1999). For people in supported living, the most common health problems reported by staff were asthma (22%), high blood pressure (20%) and arthritis (17%). For people in residential care, the most common health problems were poor bladder control (38%), poor bowel control (33%) and constipation (33%).

The vast majority of people in both supported living and residential care had had regular contact with their GP, even during the COVID-19 pandemic, with people in residential care more likely to have had home visits or phone appointments rather than visiting the GP practice. A substantial majority of people had had an annual health check in the last year, but less than half of people had seen a dentist, had an eye test or had a hearing test in the last year. Compared to Emerson et al. (1999), more people had had an annual health check and had their blood pressure measured, similar numbers had had an eye test and fewer people had had a hearing test.

According to a common definition of polypharmacy (McMahon et al., 2021) – 5 or more different prescribed medications – 12% of people in supported living and 38% of people in residential care were experiencing polypharmacy. 15% of people in supported living and 28% of people in residential care were regularly taking laxatives, a similar level in residential care to that reported in other research (Robertson et al., 2018).

Less than 10% of people in supported living or residential care smoked (lower levels for those in supported living compared to Emerson et al., 1999) and even fewer vaped. A majority of people were reported by staff to very infrequently or never drink alcohol, similar to Emerson et al. (1999), although a small minority of people in supported living were considered to have a problem with alcohol. A majority of people in both supported living and residential care were reported to do some form of physical exercise, although this was largely light exercise. People in residential care were more likely to require support with eating and drinking, although overall there were few differences in staff reports of people having a healthy diet.

Message 17

Routine health assessment and access to primary care is common; priorities are for regular dentistry, hearing tests and eye tests.

Message 18

Commissioners, regulators and service providers need to continue to focus on supporting people's long-term health in terms of diet, physical exercise and managing obesity. The Office for Health Improvement and Disparities has a crucial role to play in reasonably adjusting general population public health approaches to effectively include people with learning disabilities in supported living and residential care.

Citizenship

Relatively few people in supported living or residential care were members of a self-advocacy group or had an advocate; most people said a staff member or family member helped them to speak up. Almost three-quarters of people in both supported living and residential care were registered to vote, although less than half of people had voted in the December 2019 general election.

Message 19

Service providers have a crucial role to play in supporting people to exercise their citizenship rights and responsibilities, including initiatives such as Promote The Vote (James et al., 2021).

Commissioning for individuals

While there are some predictable overall differences between supported living and residential care, there is wide variation in both the characteristics and costs of these services, the characteristics of people being supported, and in people's experiences of them, particularly for supported living. Residential care offers a group living experience with a pattern of advantages and disadvantages very similar to that reported by Emerson et al. (1999). Perhaps differently to Emerson et al. (1999), in this study people in supported living can have very divergent experiences, from housing and support that is closely connected to neighbourhoods, amenities, friends and family and fosters a sense of freedom and belonging, to housing that is not suitable for people's requirements in neighbourhoods seen as potentially threatening.

Commissioning strategies solely based on 'service model' will not guarantee a particular type of experience or support, let alone housing and support that is aligned with what individuals want. It is also evident that commissioners and service providers need to commission on 'place', which is challenging in current housing circumstances but is vital if people are to flourish and become active citizens in their local communities. 'Place' is essential to many domains of people's lives that have been shown in this project to continue to be unnecessarily limited and constrained, such as paid work, active social lives, physical activity and people being fully part of their neighbourhoods and communities.

Commissioners also need to develop commissioning methods that allow and encourage people with learning disabilities to develop and grow over the lifecourse, which includes maintaining routinely accessible housing that can adapt to people's changing needs over time but also places a much greater emphasis on supporting people to consider, plan for, and choosing to move house where people wish to for proactive reasons.

Message 20

An individualised, place-based commissioning approach that moves with people with learning disabilities over time is a profound challenge to existing commissioning approaches, but is required for people with learning disabilities living in both supported living and residential care.

Strategic direction

While this project indicates signs of a more mature housing and support market for people with learning disabilities compared to that reported by Emerson et al. (1999) over 20 years ago, the overall picture in terms of people's experiences of support seems to be fairly similar. Paid employment is still rare and people's lives are still constrained in many important respects, both in aspects of daily autonomy such as managing money and in bigger life decisions like where people live and who they live with. Residential care and supported housing services in particular are also not an island – as with all of us place (and our feelings of belonging and safety within them), transport and economic factors are crucial to people's health, wellbeing and how people live their lives.

Message 21

The last overarching national strategy for people with learning disabilities in England was Valuing People Now, a three-year strategy published in 2009 (Department of Health, 2009). A comprehensive national strategy is urgently required to bring together these elements of people's lives and supports to provide clear, evidence-based direction for people with learning disabilities, family members, service providers and commissioners.

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