

# The Hidden Costs of Support

Experiences of family carers who support someone with learning disabilities

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## Contents

<b>INTRODUCTION .....</b>	<b>4</b>
<b>WHAT WE DID .....</b>	<b>6</b>
<b>Who took part.....</b>	<b>8</b>
<b>WHAT THEY SAID.....</b>	<b>9</b>
<b>Type of housing.....</b>	<b>9</b>
<b>Role of family carers.....</b>	<b>10</b>
<b>Input of family carers (time and money).....</b>	<b>12</b>
<b>Coordination .....</b>	<b>13</b>
<b>Practical support .....</b>	<b>15</b>
<b>Health.....</b>	<b>18</b>
<b>Community .....</b>	<b>21</b>
<b>Other significant impacts.....</b>	<b>24</b>
<b>Worry about the future .....</b>	<b>26</b>
<b>CONCLUSION.....</b>	<b>27</b>
<b>Next steps.....</b>	<b>29</b>
<b>References .....</b>	<b>29</b>
<b>APPENDIX.....</b>	<b>30</b>



## Introduction

The National Development Team for Inclusion (NDTi) has been working on a crowdfunded research project, exploring the differences between living in Residential Care and Supported Living settings for people with learning disabilities.

The main difference in theory between these two housing models is whether the person's support is provided in-house by the same organisation as the housing provider (Residential Care) or whether housing and support are provided separately (Supported Living). However, little is known about how these different models compare in practice and whether or not people's experiences of support differ according to housing model.

NDTi conducted a consultation exercise with self-advocates and family carers to explore their perspective on different housing options for people with learning disabilities<sup>1</sup>. Family carers told us that the type of housing model was less important than the quality of housing and support that their relative received. They felt that the contribution of family carers is often overlooked and were concerned that people who lack support from their family may be disadvantaged.

Previous research has sought to quantify the quality and costs of different types of housing for people with learning disabilities<sup>2</sup>. However, the contribution of family members is rarely considered, with economic analyses focusing on the cost to providers and services. This is a significant omission because family carers report spending considerable time and money supporting their relative.

If a housing model depends on input from family carers to work well, then this may not be a suitable option for people without family or whose family members aren't able to provide this support. Furthermore, the true cost of a housing and support package may be underestimated due to hidden costs to family members, in terms of time and money.

This survey aimed to explore the role and input of family carers who support their relative, the associated time and costs and how these vary according to the type of housing that their relative lives in.

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<sup>1</sup> [https://www.ndti.org.uk/assets/files/Housing\\_research\\_findings\\_Final.pdf](https://www.ndti.org.uk/assets/files/Housing_research_findings_Final.pdf)

<sup>2</sup> Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., Netten, A., Walsh, P.N., Linehan, C., Hillery, J. & Durkan, J. (1999). *Quality and costs of residential supports for people with learning disabilities: a comparative analysis of quality and costs in village communities, residential campuses and dispersed housing schemes*. Hester Adrian Research Centre, University of Manchester, Manchester.



## Headline Findings

The survey had an enthusiastic response; over 100 people took part indicating that family carers were keen to share their experiences. Many commented that they had not been asked about their contribution in this way before.

It should be noted that the people who responded to the survey were a self-selecting sample and so may not be representative of all family carers. It may be that people who are more involved in their relative's support choose to fill out the survey. The data was also collected before the onset of the COVID-19 pandemic which is likely to have altered family carers' input.

Findings showed considerable input from family carers, of both money and time, in the areas of coordinating support, providing practical support, supporting their relative's health and community involvement. However, there were minimal differences between supported living and residential care and the housing model appeared to have little impact on the amount of support that family carers provided. As expected, family carers whose relative lived at home with them spent significantly more time providing practical support than those whose relative lived outside of the family home.

The extensive comments provided by family carers revealed additional impacts on all areas of their lives, beyond time and money. These included impacts on their health, career and relationships. Respondents were keen to share their experiences of these impacts, which appear worthy of further research.

Family carers who responded to the survey made a clear distinction between their relationship with their family member and the stress of dealing with services. Many said that their relative brought love and joy to their life. However, the stress associated with liaising with, and navigating, services on their behalf was a huge strain.

Many respondents described their families' experiences of "battling" and "fighting" with services on their relative's behalf, in order to get the support that they need. This aspect of supporting their relative was thought to have the biggest effect on their wellbeing, causing fatigue, stress, worry and anger.

These difficulties led to family carers having significant anxiety about the future. Parents in particular were worried about who would look after their relative as they age and become incapable of caring, particularly in the event of their death. As they were overseeing and coordinating their relative's care, there was a fear that support arrangements would fall apart without them.



## What We Did

Questions for the online survey were designed and tested with a family carer. A link for the survey was contained in an introductory email that was distributed via NDTi's network of family carers and via contacts who were formerly members of the National Valuing Families Forum. Respondents were also encouraged to share the survey within their own networks.

We recognise that not everyone may identify with the term 'family carer' and so the survey was open to anyone who provides a significant amount of unpaid support for a person with learning disabilities.

The survey sought to build on the findings of earlier focus groups by exploring the role and input of family carers, to determine how much time and money that family carers typically spend providing support to their relative, and to explore the broader impact on the family carer.

Respondents were asked to estimate how much time and money they had spent providing various forms of support for their relative in the past week (or month). They also had the option to add written comments. Broader impacts (beyond time and money) of providing support were explored in these written comments. Quotes have been lightly edited for clarity.

It is important to note that this data was collected before the onset of the COVID-19 pandemic, and so may not be representative of family carers' input currently.



## Types of Housing

The following definitions of housing types have been used in this survey and report. The abbreviations are used along with colour coding to show which quotes belong to which housing model.

However, we recognise that the housing types are not always clear cut, and there can be considerable variation within and overlap between models.



**Supported Living (SL):** the person owns or rents their home. Accommodation and support are provided separately, so the person is able to change their support provider without affecting their housing, or vice versa.



**Residential Care (RC):** a room in a home where meals, care and support are all provided. These can be private, voluntary sector or local authority run. May include nursing care.



**Living at Home (LAH):** the person lives with their relative(s) in the family home.



**Private / Rented Landlord (PRL):** property rented from a private landlord.



**Other (O):** any type of housing not covered by the above, including home ownership.

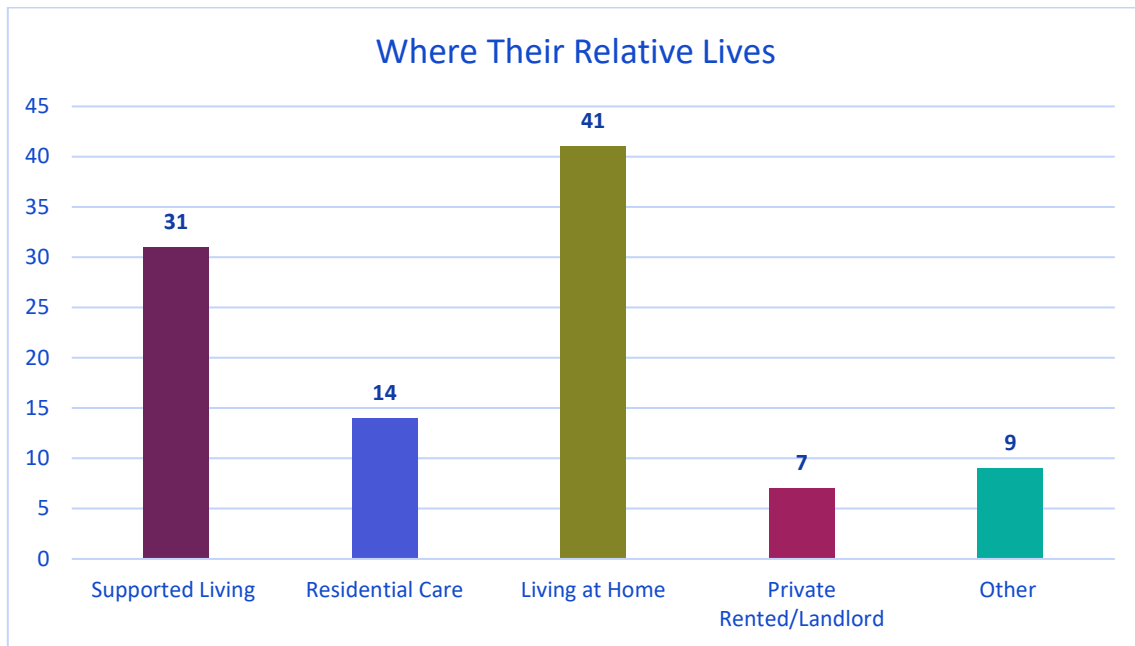
Source: NDTi Housing Choices<sup>3</sup> and NDTi Supported Living – Making the Move<sup>4</sup> reports.

<sup>3</sup> [https://www.ndti.org.uk/assets/files/Housing\\_Choices\\_Discussion\\_Paper\\_2.pdf](https://www.ndti.org.uk/assets/files/Housing_Choices_Discussion_Paper_2.pdf)

<sup>4</sup> [https://www.ndti.org.uk/assets/files/Supported\\_Living-Making\\_the\\_Move2C\\_May\\_2010.pdf](https://www.ndti.org.uk/assets/files/Supported_Living-Making_the_Move2C_May_2010.pdf)

## Who Took Part

102 family carers filled out the survey. 77 said they were the parent of someone with learning disabilities, 10 were the sibling, 14 were the child and 3 were related in another way.



The graph above shows which type of housing the respondents' relative lives in. In written comments, respondents shared their reflections on their relative's housing.



## What They Said

### Type of Housing

Many people whose relative lived in a form of supported living felt that this form of support worked well for their relative and improved their quality of life. However, there could be a trade-off with family carers feeling that additional input was required to manage and coordinate support.

*Supporting in this way has hugely improved my relative's life... But the impact on us as parents has been huge... Just wish there was more support for families managing this option. – O*

*My son after many false starts is now in single person supported living with his own team and a wonderful provider who offer support that I previously had to give. – SL*

Some family carers felt that residential care was a safer and more consistent option for their relative than supported living. Others spoke about attitudes to, and negative perceptions of, residential care that they had encountered.

*My son has very complex needs that require the support of a well-coordinated, trained and managed support team within an environment adapted to suit the individual needs of its residents. ... Given the pressures on staffing and funding I have no doubt that my son would be at risk in anything other than a care home where he is currently safe, well cared for by excellent and competent staff working together. – RC*

*Just because she is in residential care, does not mean I do not care or I do not have a lot of input and regular contact, but many professionals think this. – RC*

## Role of Family Carers

Family carers reflected on the difficulty of trying to quantify the support they provide. It can feel transactional to talk about a family relationship in terms of costs and hours. But many family carers felt that there were gaps in services and / or funding packages, which resulted in them fulfilling their relative's unmet needs at their own time and expense. Exploring the additional time and cost expended by family carers is one way to take this into consideration.

*The current model of putting people with learning disabilities into the community is laudable but does not take account of the support they need to manage their lives which is now falling back on - frequently elderly - carers. This does not bode well for the future. – PRL*

Every family is unique and the role that family carers take is unique within them. For example, some people might choose for their family to not be involved in their support. However, there were some themes that came up in the responses, which were as follows:

Family carers who responded to the survey made a clear distinction between their relationship with their family member and the stress of dealing with services. Many said that their relative brought love and joy to their life. However, the stress associated with liaising with, and navigating services, on their behalf could be a huge strain.

*My son is a wonderful person who brings so much pleasure to everyone he comes in contact with... the stress that all of the fighting and battling for him on his behalf has caused a huge negative impact of my own health and wellbeing. – LAH*

*The most stress I experience is not from caring for my son, but from trying to access support we need as a family, and the defensive culture of services. – LAH*

Accessing formal support was frequently described as a “fight” which took a toll on them. Some families had experienced serious failings by services. This meant that they felt unable to trust services and needed to keep monitoring things to make sure that their relative was safe and well.

*We have had to continuously fight to get our son the support he needs...This has caused immense stress and anxiety. We are very concerned about what will happen when we're no longer around. – RC*

*We do what we do because the alternative is not acceptable. Several providers have failed. – O*

In some respects, family carers' involvement in their relative's life was described as simply part and parcel of being a parent (or sibling/ child) with all the ups and downs of family relationships. For example, going out for a meal together could be a way to spend time together as a family, rather than a form of 'support'.

*My wife and I meet up with our relative for a meal in a local restaurant/cafe on average once per week. This is part of our relative's positive behaviour plan but also offers us the opportunity to meet with them in a social/community context that sometimes involves other friends and family. - O*

*I prompt him but because I'm his sister who cares for him the boundaries are often blurred and he interprets my prompting as 'mothering' him or nagging him. I very often have to leave him to his own devices to preserve our relationship. - O*

Other forms of support went beyond usual family relationships and could result in blurred boundaries creating difficulties or conflict with their relative. This was often when family carers were taking on tasks that would typically be done by professionals.

Families also supported their relative in some ways that professionals didn't, for example emotional support. With staff teams changing frequently, family carers may often be the only constant factor. When many different teams are involved in a person's care, family carers can be the ones with their 'finger on the pulse'.

*Families are central to the success of a placement. Professionals should respect and acknowledge this and welcome input of families who save social care and the NHS huge amounts of money. - SL*

*[Services] are maintained by people who are paid salaries and get weekends and holidays to recover from their efforts at work. In contrast, the only people putting the person [first] are doing so in their spare time and/or on benefits. - O*

Despite family carers taking on responsibilities that may fall within a professional remit, they commented how caring was distinct from traditional 'work' that has set hours, a salary and paid time off. They have a relationship with the person they are supporting and therefore cannot switch off from some of these responsibilities, as they felt professionals could.

*It's a life-long job, and not something you can walk away from and leave to others. - RC*

Family carers felt that their contributions were underestimated and unrecognised by professionals. It was felt that professionals were seen as more legitimate than the family carers, despite family carers often providing more support. Family carers felt that their expertise and contributions should be better acknowledged by services.

*I feel side-lined and ignored as a family carer - my daughter had an independent advocate which is important as it seems that role receives more respect. – SL*

## Input of Family Carers (Time and Money)



### Note



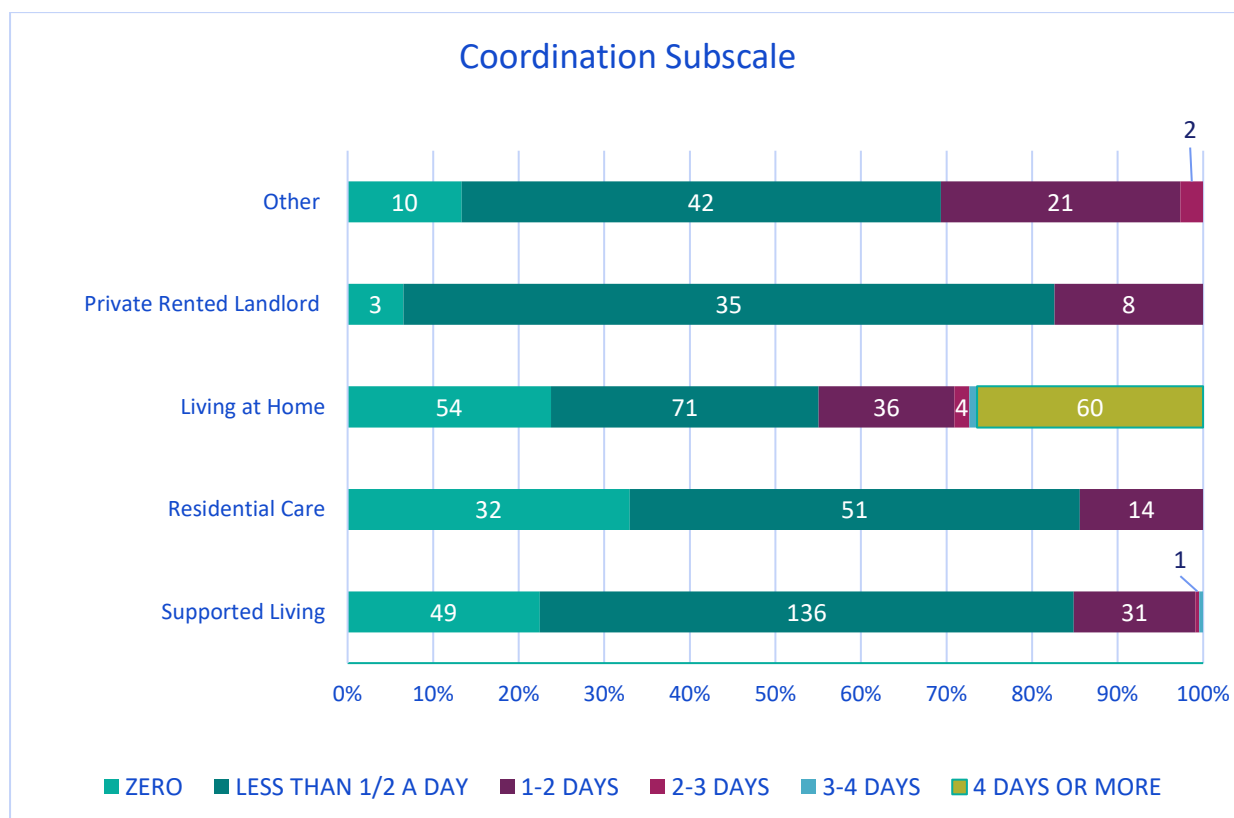
Family carers commented that it was difficult to estimate how much support they provide, particularly when they have been doing so over many years. When we added up responses to calculate the total hours of support provided per week, some respondents had reported totals that were greater than the number of hours in a week. This perhaps reflects the feeling that support provided can be all-consuming and around the clock. It also shows some of the challenges with trying to quantify support and asking people to think back over a long period of time.

We have chosen to present responses grouped together rather than added into a subscale total, because assuming that support is cumulative could be misleading. Different aspects of support might overlap or run alongside each other, rather than being discrete and separate.

Case examples have been presented to show typical responses for each subscale. The totals should be treated as approximations due to the complexity explained above. Further details can be found in the Appendix.

## Coordination

The 'coordination' subscale was made up of 10 items that asked family carers how much time they spend in a typical week coordinating their relative's support. This includes supporting their relative to manage money and benefits, recruit and manage staff and communicate with providers.



The graph shows the responses given, combined into the coordination subscale. The most common answer given by family carers was that they spent less than half a day per week coordinating each aspect of their relative's support. It is important to note that this time refers to each individual item; providing several aspects of support that take half a day each will add up to a considerable amount of time each week.

Statistical analysis showed no significant differences in time spent coordinating support between the different housing models.<sup>5</sup> Further details of the analysis can be found in the Appendix.

<sup>5</sup> This means that differences between the housing models were no greater than what would be expected by chance. For this we use a significance value (p-value) of .05 as recommended in social science research. See Appendix for full details of methodology and analysis.



## Case Examples

Anna\*\*, who supports someone in supported living, estimated spending 4.75 days a week on coordinating her relative's support, mainly communicating with support staff.

Brian\*\*, who supports someone in residential care, estimates spending 2 days a week on coordinating his relative's support.

Carol\*\*, whose relative lives at home, estimates spending 3 days a week on coordinating her relative's support, mainly supporting them to manage their money.

*\*\*identifying information has been changed*

## Written Comments – Coordination

Family carers described coordinating their relative's support in various ways. Their involvement was particularly important when there were concerns about the quality of provision.

*My wife and I are the carers of last resort for our relative. We have a care rota and a cover system but, if both of those fail, one of us has to drop what we are doing and step in to care for our relative. – O*

Family carers described 'pressure points' that require more time and input than usual. One such situation was recruiting and training staff.

*There seems to be a never-ending requirement to feed reviews from DWP ... They are stressful because each one carries the possibility of crashing down the carefully constructed care arrangements for our relative. – O*

*My brother currently lives in accommodation that does not meet his needs, so this requires constant monitoring and action to keep him safe. – SL*

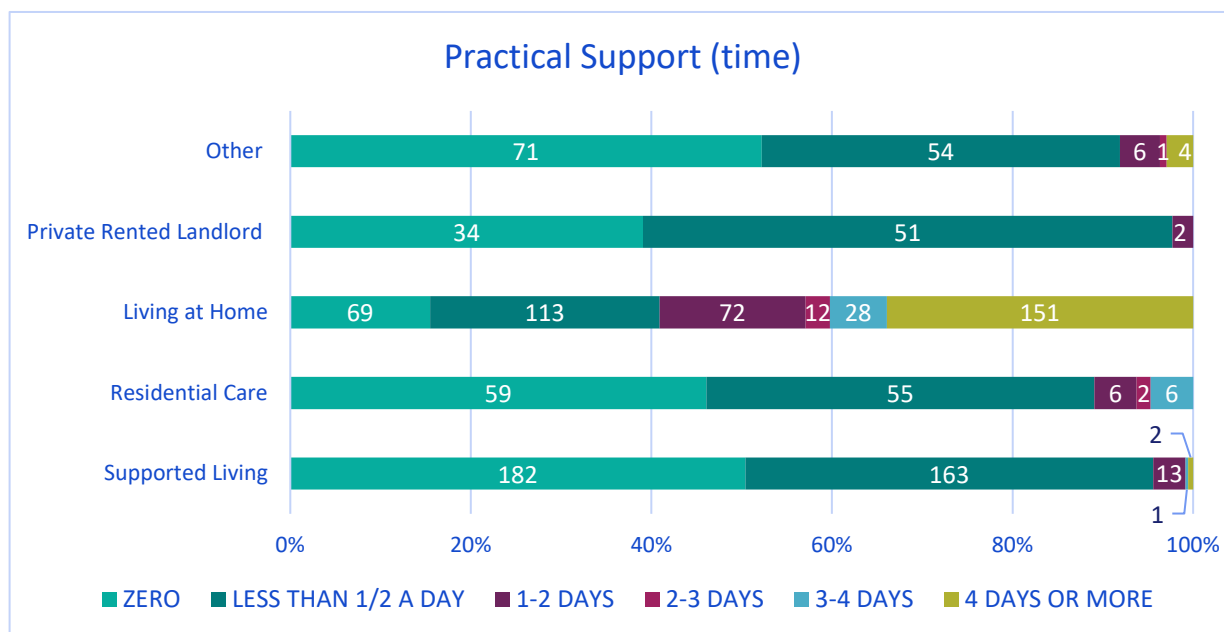
Family carers appeared to be 'filling the gaps' in provision when support and / or housing provision does not fully meet their relative's needs. This can entail time spent supporting the person and money spent subsidising care. They may also step in when something unplanned arises, such as support staff shortages or sickness.

*Impossible to recruit staff in our area, though my son has a personal budget, the support paid for through it does not always materialise... even though I have tried to use care agencies as a self-funder, the cupboard is bare! – SL*

Another pressure point was dealing with benefit reviews and the Department of Work and Pensions. Such reviews were felt to be repetitive, unnecessary and stressful.

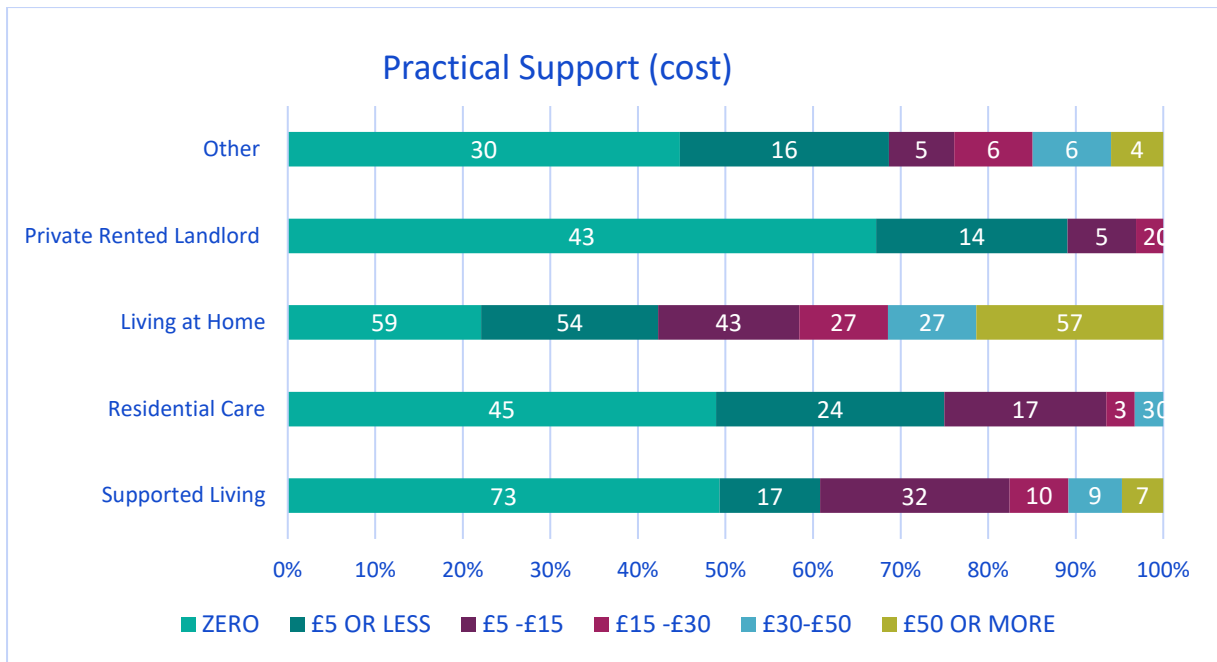
## Practical Support

Family carers were asked about the time spent in a typical week supporting their relative with practical matters. The 'practical support' subscale was made up of 22 items including food and drink, shopping, chores, personal care, home maintenance and repairs, transport and travel, technology and devices.



Statistical analysis showed that the time that family carers spent providing practical support was different according to the housing model. People whose relative lives at home with them reported spending significantly more time supporting them with practical matters than those whose relative lives outside of the family home. There was no significant difference between those whose relative lived in supported living and those whose relative lived in residential care.

Family carers were also asked to estimate the amount of money that they typically spent per week on each aspect of support (for example, buying food). No significant differences were found between different housing models.



### Case Examples

Anna, who supports someone in supported living, estimates spending 4.5 days a week providing practical support, mainly home-making and home maintenance. She estimates spending £202.50 a week, mainly on shopping and home maintenance.

Brian, who supports someone in residential care, estimates spending 3 days a week on providing practical support and spending £22.50 towards food and shopping.

Carol, whose relative lives at home, estimates that the practical support she provides takes up to 7 days a week, mainly buying and preparing food. She estimates spending £225 a week on this, with the biggest expense being food shopping.



## Written Comments – Practical Support

The written comments supported these findings. Paid staff were often the main providers of practical support for people who live outside of the family home. However, family carers still had input into this aspect of support; they described overseeing or supplementing paid support as needed.

*Daily care/support provided by paid carers, but daily input required to ensure things are being addressed. – SL*

Family carers' involvement with household maintenance and upkeep also varied based on the type of housing in which their relative lived. Family carers had little input into the household

*I am responsible for all maintenance and equipment repair within our relative's home. The housing association is responsible for all external aspects of our relative's home. I undertake small items of repair and also supervise any contractors that undertake larger works inside the home. – O*

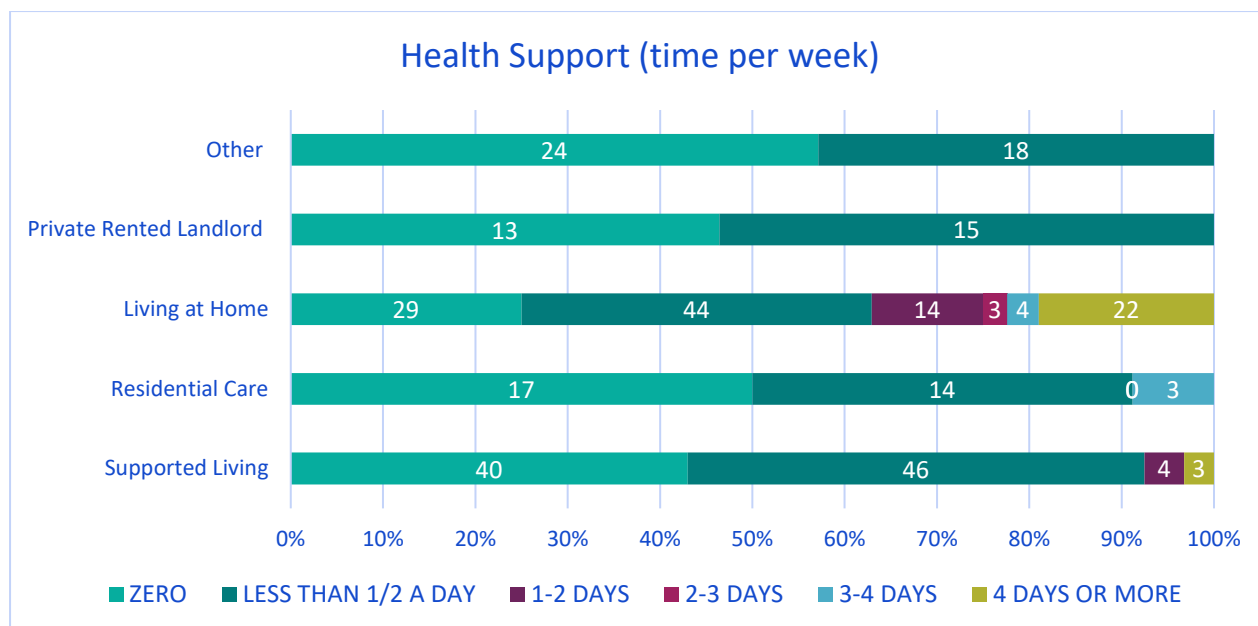
aspects of residential homes. In supported living and rented accommodation, some aspects of maintenance fell under the remit of the landlord, and others were dealt with by the family carer. For those whose relative lived at home, the household maintenance is carried out on behalf of the whole family. Expenses for household maintenance tend to occur in seasonal 'bursts' rather than weekly costs.

When it came to purchasing non-food items, such as clothing, toiletries, support aids and household items, family carers explained that they spent considerable time researching different options in addition to the time taken to actually buy the item. Some items needed frequent replacement due to sensory issues and increased wear and tear.

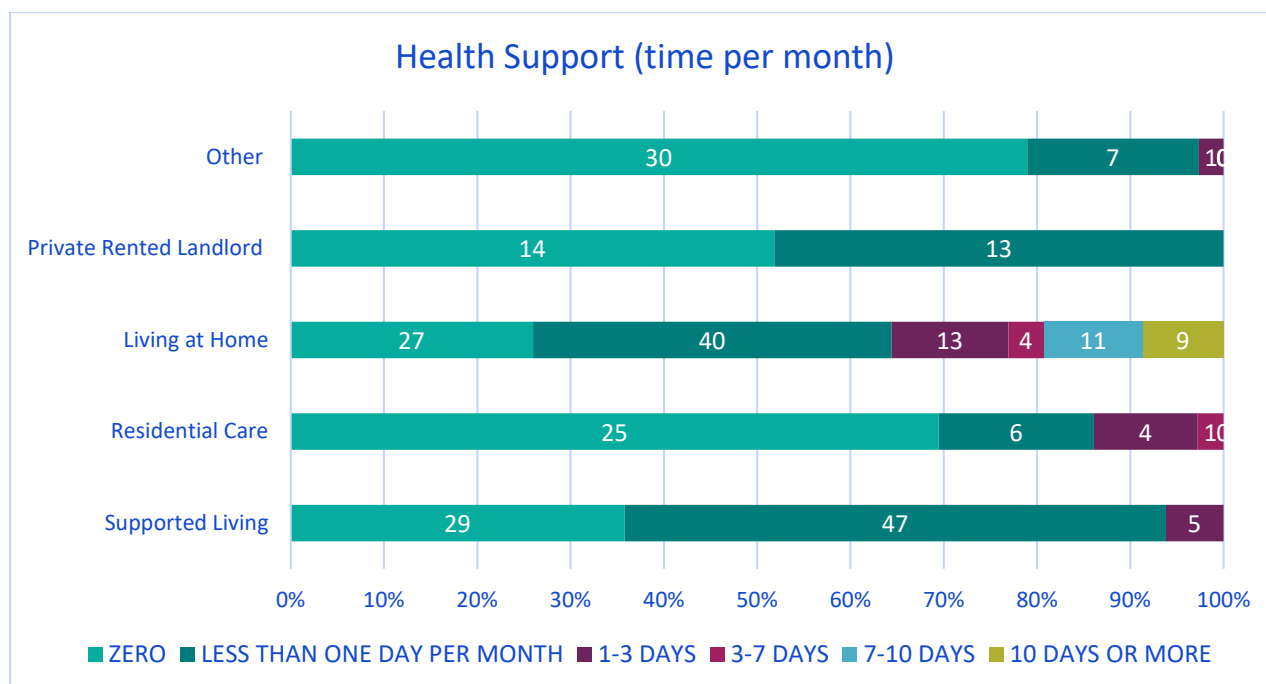
*Online research for appropriate disability-related support aids can take days/hours as/when needed ... plus frequent replacement of clothing, bedding, spectacles and vision aids – can be extremely time-consuming. – SL*

## Health

The 'health' subscale was made up of 7 items. Family carers were asked about the time they spend in a **typical week** supporting their relative with their health, including attending NHS appointments, exercise and healthy eating.

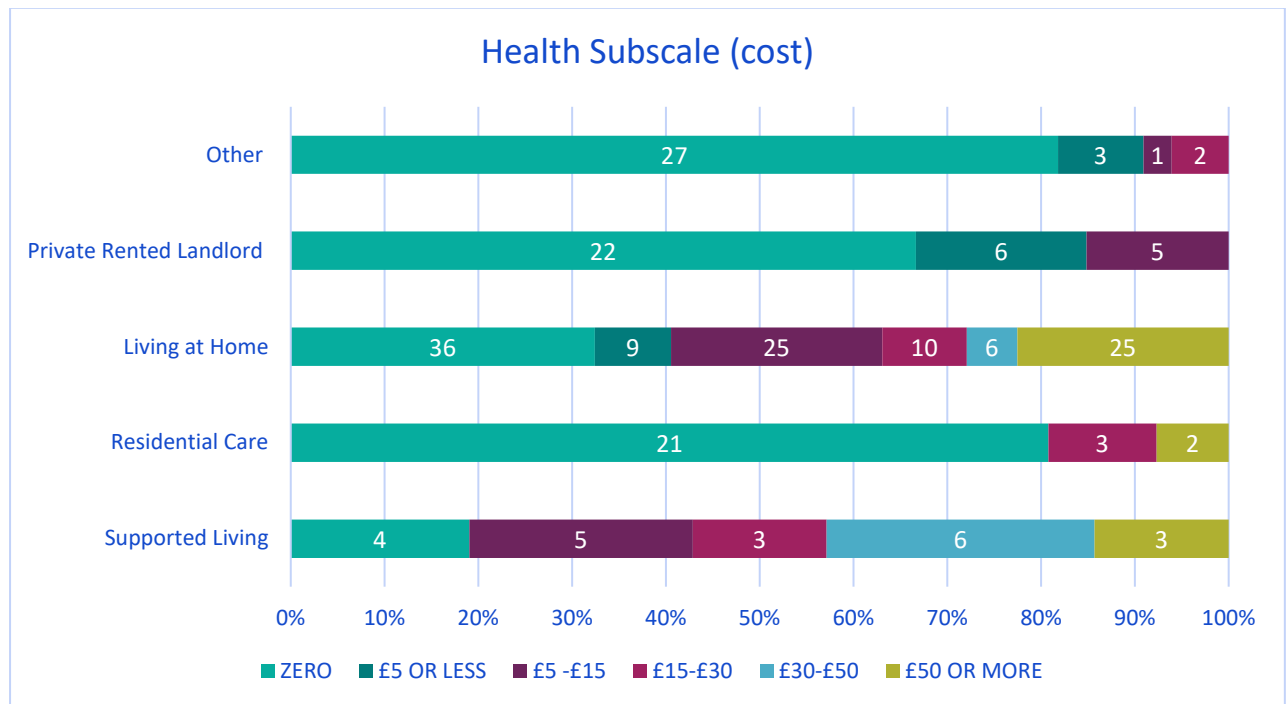


There were also 7 items that asked about the time spent **per month** to access non-NHS appointments (e.g. dentist and optician), psychological support and peer support.



Statistical analysis showed no significant difference for each according to the housing model.

Family carers were also asked about the typical cost to access each form of support. Again, this was not found to differ significantly by housing model.



### Case Examples

Anna, who supports someone in supported living, estimates spending 6 days a month supporting her relative with their health, and spending £224 a month, mainly on private healthcare appointments, sports and specialist activities.

Carol, whose relative lives at home, estimates spending up to 30 days a month supporting her relative with their health, and spending £507 a month towards this, mainly on gym membership and healthy eating.

## Written Comments – Health

Family carers spoke about supporting their relative to attend NHS appointments, for example providing transport or supporting with communication. NHS clinicians should be responsible for ensuring that reasonable adjustments are made to the person's care, but often this fell on the family carer.

*Our relative needs adaptations (particularly to the "standard patient journey") to obtain services from the NHS. Whilst it does not take a large amount of time per week, it takes much more time and effort than it should. – O*

*My brother has many specialist professionals and therapists involved in meeting his needs. Some we access independently because he needs specialist assessments and regular intervention and these are not available via NHS resources. – SL*

Some family carers opted to pay for private or independent services for their relative, when NHS provision was not specialist or frequent enough for their relative's needs.

When it comes to physical and emotional health, there was a sense that family carers provide some things that professionals cannot, for example, consistency and a knowledge of the person's history during medical appointments. Family members also provide emotional support beyond what can be offered by professionals.

*Although my sister lives in supported living I take her to all her medical appointments as I am consistent and other odd staff would take and not know her whole history. – SL*

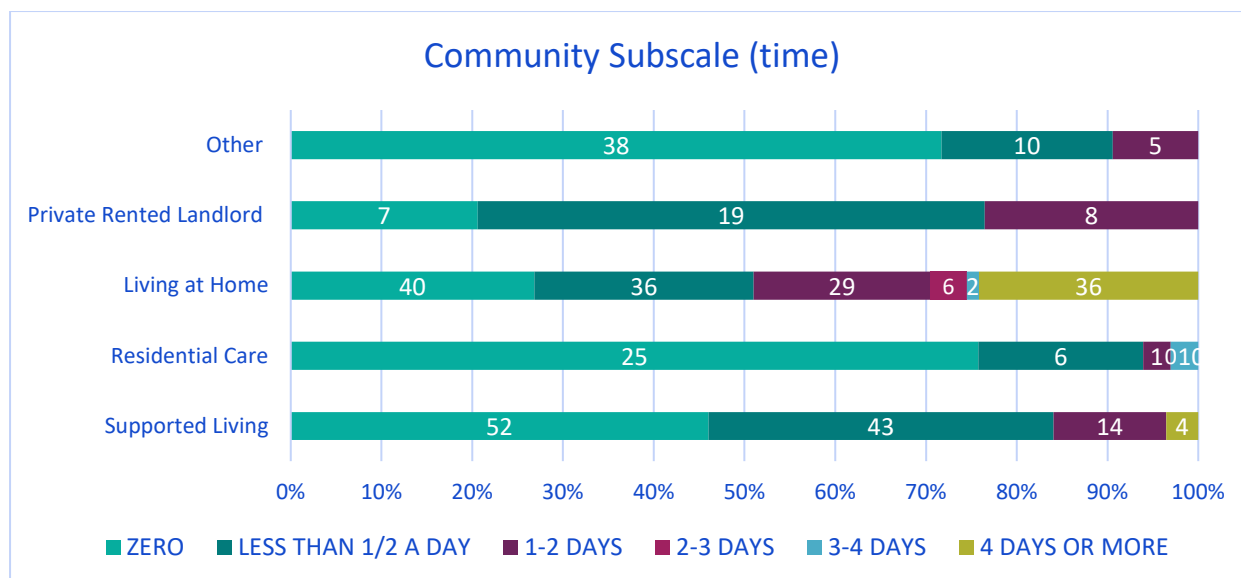
*He needs emotional support from family that will not get from his support worker. – RC*

*She has an advocate from a local organisation, he goes in and listens to her so he can help her....wonderful organisation. He visits every couple of months. – SL*

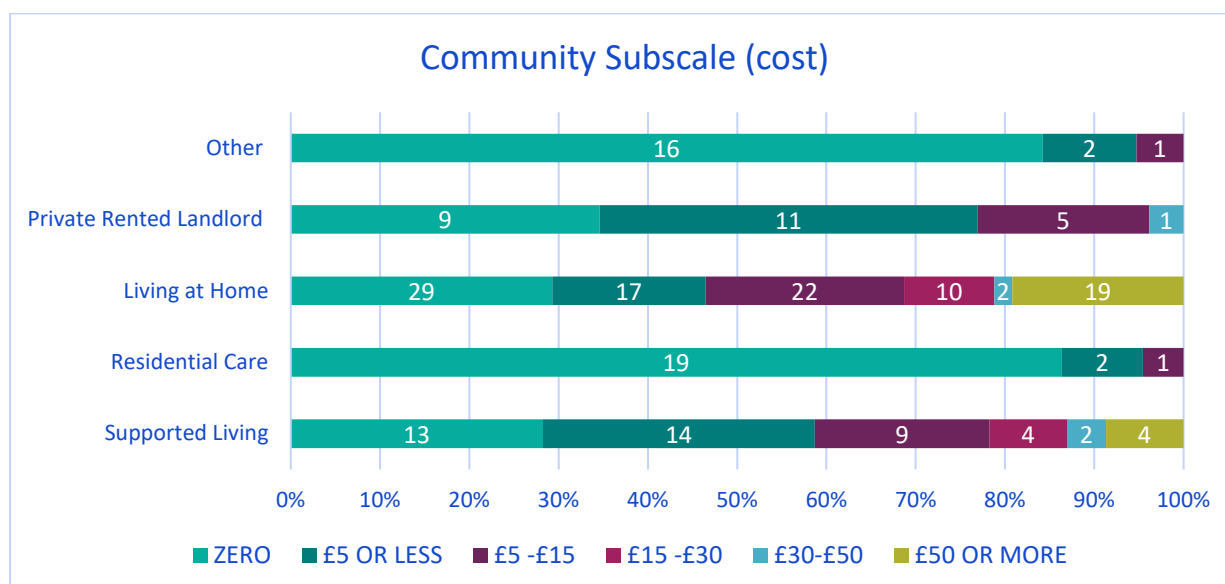
Some family carers discussed non-traditional approaches to health and wellbeing, outside of traditional therapy or mental health support. These included peer support and advocacy groups. There was thought to be a lack of support for some people, for example autistic people.

## Community

The 'community' subscale was made up of 9 items. Family carers were asked about the time that they spend in a typical week supporting their relative with employment, education, social life, leisure, hobbies and culture (such as going to the cinema and concerts).

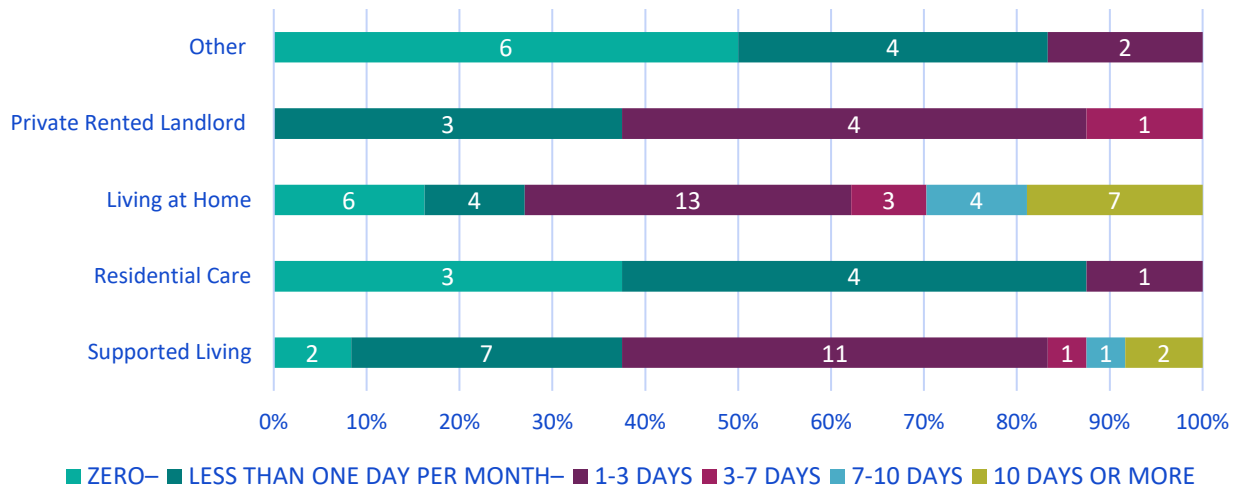


Family carers were also asked about the cost of providing this support (such as paying for transport or tickets). Again, this was not found to differ significantly according to housing model.

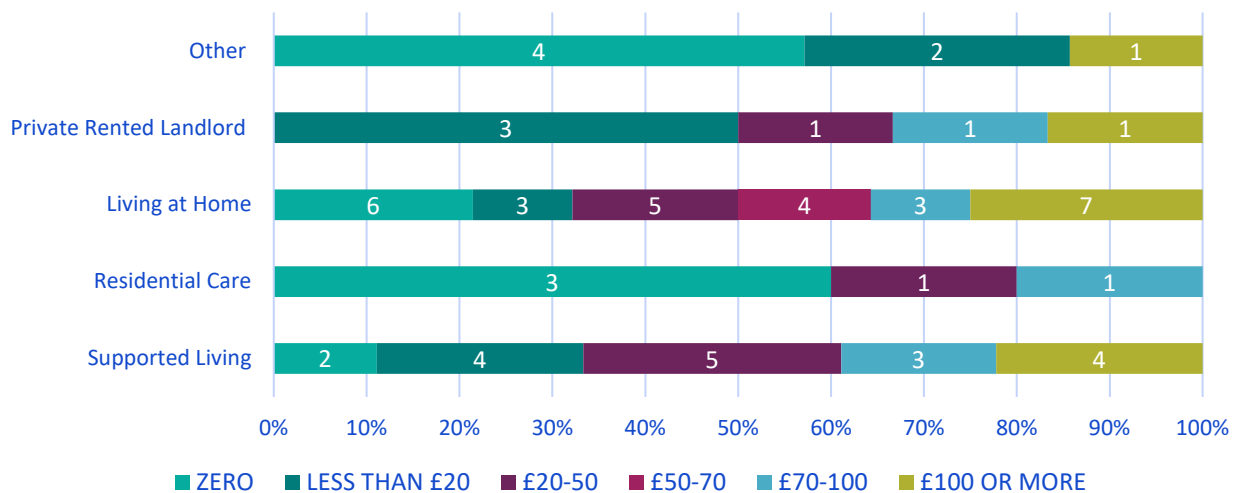


There were also two items asking whether family carers spend time and money supporting their relative with days out and holidays.

### Holidays and Days Out (time)



### Holidays and Days Out (cost)



### Case Examples

Anna, who supports someone in supported living, estimates spending 1.75 days a week supporting her relative with community life and spending £167.50 a week towards this, mainly on education and socialising.

Brian, who supports someone in residential care, estimates spending 0.75 days a week supporting his relative with community life and spending £5 a week towards this.

## Written Comments – Community

Family carers spoke about barriers to their relative accessing activities, work and education. Staff shortages sometimes result in leisure time being spent as a group, rather than individuals being able to pursue their own interests.

One issue was a decrease in opportunities available when their relative left full-time education. Another was changes to funding, meaning that opportunities were no longer free of charge.

Family carers may help to coordinate their relative's social life and hobbies, for example, arranging to meet up with friends and keeping track of their schedule.

*She doesn't do much these days ... She would like to go swimming but can't at the moment due to lack of staff. If it is a group activity she will be taken, but nothing individual is done with her. – SL*

*Some co-ordinating with parents and support workers to enable my daughter to meet up with her friends. working with support worker to make sure that my daughter is taking the lead on their plans. – LAH*

*My husband and I have created projects for our daughter and other people with learning disabilities have joined - we are a charity and get funding from donations. We have done this as we want to do what our daughter likes to do and do not want her in an institution type day centre or project. – LAH*

One person even spoke about setting up activities and social opportunities for their relatives and including other people with learning disabilities, as they weren't satisfied with the options being offered to them.

We were told that, when supporting their relative to do something for the first time, such as trying a new hobby or visiting a new place, there was often an additional upfront time commitment, as family carers may need to research different options extensively to ensure that they are accessible and appropriate.

*Costs of additional support/carers for any short breaks is huge. He needs minimum of 2 carers but his package only funds 9hrs day 1:1 and shared night-time support. All additional costs are borne by him and family. – SL*

When it came to holidays, some people opted to pay for their relative to go away with them. This could be upwards of £1000 per trip. Others said that the cost of additional support to accompany their relative is prohibitive. Some said that their relative would not enjoy a holiday due to the disruption to their routine.

## Other Significant Impacts

In the written comments, family carers told us about additional, indirect impacts of supporting their relative, beyond time and money. Whilst this is not something that we directly measured, family carers were keen to tell us about their experiences. This suggests that there may be other significant impacts (both positive and negative) upon family carers, beyond time and money.

Many respondents described how long-term stress associated with caring and dealing with services had taken a toll on their emotional and physical health. Many family carers said that they felt 'exhausted'. They also had less time to spend on activities that might benefit their health and fitness, for example, exercising.

*Emotional and physical health has suffered - we have aged faster than we otherwise would have. – RC*

*The main physical impact is that I do not have the time to exercise as much as I need. That will have a long-term impact on my health. The main emotional impact is one of unnecessary levels of anxiety and stress. – O*

*Feeling of inadequacy and permanent fatigue. – LAH*

For some, being a part of the learning disability community had brought valued new friendships and peer support. Others found that relationships with family members and friends were affected, often due to the all-encompassing nature of their input, and a lack of time to spend with other people.

*Living a life with learning disability was part of being in a group/community, it didn't matter who you were we were all inclusive together. – SL*

*There seems to be a never-ending requirement to feed reviews from DWP ... They are stressful because each one carries the possibility of crashing down the carefully constructed care arrangements for our relative. – O*



Time spent supporting their relative could also have an impact on family carers' careers, with some needing to work part time, switch to flexible working or retire early. For some respondents, this meant taking jobs with less responsibility, which impacted on their job satisfaction and career progression.

For others being a family carer had opened up new work opportunities, and they chose to work in fields within the learning disability community, which they found rewarding.

*When I became family carer for my brother (20 years ago) I needed flexible working so could only work part-time and often hourly paid contracts. Despite previous management status, my professional standing was lower. – SL*

*I changed from teaching to working with family carers, I have no regrets - it's been hard work but really interesting and usually worthwhile. – PRL*

*I took early retirement at the age of 50 purely as a result of our child's disability. I did pursue a different, much less-well remunerated but very rewarding career in the voluntary sector. – RC*

## Worry About the Future

The most striking emotional impact described by family carers was anxiety about the future. Some worried that appropriate support wouldn't be available for their relative if they needed it, due to austerity and cuts to services.

Many family carers (particularly parents) were worried about who would look after their relative as they age and become less able to provide support. They were particularly concerned about who would step in in the event of their death. As they were overseeing and coordinating their relative's care, there was a fear that support arrangements would fall apart without them. Often this lack of confidence in services was based on tangible issues and failings that the family had experienced in the past.

*My main concern is that there may not be appropriate housing and support for my son near to us, and we will need to continue to care for him at home beyond our ability to manage this well. – LAH.*

*Very worried about what will happen when I die as I have a lot of input into my son's service, albeit not hands on with him. – SL*

*Although our relative does not actually live with us we feel that we are still their main advocates, so we can't relax despite now being well into our seventies. – RC*

*Put simply, without my support and that of my wife our relative's care provision would fall apart. – O*



## Conclusion

The input of family carers, in terms of time and cost, was considerable regardless of the type of housing that their relative lived in. There were minimal differences between housing models, except that those whose relative lives at home reported providing more practical support than others. Regardless, many family carers reported taking on an essential coordination role in their relative's support, even if they do not provide hands-on day-to-day support.

There was a tendency for people whose relatives lived in supported living to report higher time and costs (on the Health and Community subscales) but this was not statistically significant. It may be that the sample size (31 people whose relative lived in supported living) was not large enough to detect these differences, so this survey warrants replication with a larger sample.

One limitation of the survey is that the data was collected before the COVID-19 pandemic, and so the nature of family carers' input may have changed significantly since then. Another is that the study relied upon a self-selecting sample, which means that people who were interested in the survey and who heard about it through their networks were able to take part. It may be that people who are well-connected within the family carer community are more involved in their relative's support, so the sample may not be reflective of all family carers.

In extensive written comments, family carers reflected on their role and the complexity of trying to quantify the support that they provide. Some aspects of support are part of any family relationship, whereas others involve more onerous responsibility. Many family carers said that their relationship with their relative brought them joy, but that the long-term stress of dealing with services had taken a toll on them.

Family carers described additional impacts of providing support, beyond time and money. These included long-term impacts on their physical and emotional health, relationships and work. These impacts could be both positive and negative, for example some felt that new career options had opened up to them, whereas others had to limit the number of days they were able to work, which had a knock-on financial impact.

Family carers said that the process of "battling" services had the most significant impact on them. They described how difficult experiences with services and professionals had caused them to lack confidence in services and feel profoundly anxious about the future.

Many worried about what would happen if they became unable to support their relative and feared that their relative's care and support arrangements would collapse without them. This topic has been explored in detail in a report by the Carers Trust<sup>6</sup>.

The findings suggest that family carers find it necessary to fulfil needs and gaps in support that are currently unmet by services. Some are coordinating services to ensure that their relative's basic needs are met. Others are opting to supplement the formal support their relative receives, to ensure that they have a full and happy life. In many cases, family carers believe that the support they provide is essential in holding their relative's support arrangements together. This can require considerable time, expense and emotional energy from family carers. It also has implications for people whose family are not involved in their support, who may be disadvantaged.

Family carers were keen to share their experiences and thoughts with us, suggesting this is a subject that is often overlooked. The findings indicate potential gaps in housing and support packages that need addressing to mitigate costs and impacts on family carers, and to ensure that people without family input are not disadvantaged.



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<sup>6</sup> <https://carers.org/resources/all-resources/105-no-longer-able-to-care>



## Next Steps

This project has helped inform the development of a large-scale research study by NDTi in partnership with Manchester Metropolitan University, London School of Economics and Changing Our Lives. The study, called “200 Lives” will evaluate the quality and costs of supported living and residential care for adults with learning disabilities by speaking to 100 people who live in supported living and 100 people who live in residential care.

The 200 Lives project will continue to explore the input of family carers. We will include a family carers’ survey, that will ask questions about the time spent and cost of providing support, with the aim of identifying hidden costs. Questionnaire scales will be included that measure the impact on family carers’ health, quality of life and careers to explore whether these differ according to the housing model. A detailed economic analysis will be carried out by London School of Economics, and this will include estimated costs reported by family carers.

More information about the project can be found on our website or on twitter [@200Lives](#)

<https://www.ndti.org.uk/projects/evaluating-supported-living-and-residential-care-for-adults-with-learning-d>

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## Appendix

### Methodology

The survey was hosted on Survey Monkey and consisted of 32 questions, of which 8 were demographic questions (the respondent's details and role in relation to their relative). The other questions asked respondents to estimate the amount of time and money they spend in a typical week (or month) supporting their relative. An example question is shown below:

**Please estimate how much time and money you spend in a typical week supporting your relative with their food (and drink). Enter zero or skip if you do not provide this type of support.**

Buying food and drink

Time:

- Zero
- Less than half a day
- 1-2 days
- 2-3 days
- 3-4 days
- 4 days or more

Money:

- Zero
- £5 or less
- £5 - £15
- £15 – 30
- £30 - £50
- £50 or more

Respondents were able to provide further information in written comments, and to skip any questions that they did not want to answer. A copy of the survey is available on request.

## Statistical Analysis

Because the responses are in ranges (e.g. 1-2 days) it is not possible to report an average number of hours / days that family carers spend supporting their relative. In the report, we have chosen instead to show the count of responses grouped into each subscale and the mode, which is the response option that was chosen most often.

To work out whether there was a difference between the amount of support provided by the family carers (in terms of time or money) according to the different housing models, we allocated response options a number from 0-5 and added them together to form subscales. This is an approximation because different aspects of support may run parallel to one another, rather than be cumulative. As noted in the report, some respondents reported totals that exceeded the number of hours in a week. Nonetheless, we felt that this was the best way to approximate the differences with the data available.

Once the subscales had been calculated, we used a one-way ANOVA to explore whether there were significant differences between the different housing models. A p-value of less than .05 indicates a significant difference. As shown in the table below, the subscale of Practical Support (time) was the only one that indicated a significant difference between housing model.

		Df	Sum Sq	Mean Sq	F value	p-value
Coordination	Housing Model	4	63.5	15.88	0.94	0.444
	Residuals	97	1638.5	16.89		
<b>Practical support (time)</b>	<b>Housing Model</b>	<b>4</b>	<b>9794</b>	<b>2448.6</b>	<b>5.881</b>	<b>0.00028</b>
	Residuals	97	40388	416.4		
Practical support (cost)	Housing Model	4	1828	457.1	1.496	0.209
	Residuals	97	29635	305.5		
Community (time)	Housing Model	4	664	165.9	2.138	0.0818
	Residuals	97	7527	77.6		
Community (cost)	Housing Model	4	468	116.98	1.913	0.114
	Residuals	97	5931	61.14		
Health (time per week)	Housing Model	4	236	58.91	1.549	0.194
	Residuals	97	3689	38.03		
Health (time per month)	Housing Model	4	164.8	41.19	1.605	0.179
	Residuals	97	2489.8	25.67		
Health (cost)	Housing Model	4	330	82.62	1.377	0.248
	Residuals	97	5820	60.00		
Holidays (time)	Housing Model	4	32.2	8.068	1.865	0.123
	Residuals	97	419.5	4.325		
Holidays (cost)	Housing Model	4	7.73	1.9324	2.016	0.0982
	Residuals	97	92.98	0.9585		

Post-hoc tests were used to explore this further and find out which housing model involved more support. Tukey’s post-hoc test indicated that the amount of practical support provided by those whose relative lives at home is significantly higher than those whose relative lives in supported living and residential care.

Housing Model	Difference of Means	Lower Confidence Interval	Upper Confidence Interval	Adjusted p-value
LAH-O	15.285366	-4.719827	35.290559	0.2184320
PRL-O	-3.871429	-31.824210	24.081353	0.9952708
RC-O	-6.300000	-30.158428	17.558428	0.9480210
SL-O	-5.203226	-25.831394	15.424943	0.9557627
PRL-LAH	-19.156794	-42.353658	4.040069	0.1551727
<b>RC-LAH</b>	<b>-21.585366</b>	<b>-39.639758</b>	<b>-3.530974</b>	<b>0.0107665</b>
<b>SL-LAH</b>	<b>-20.488592</b>	<b>-33.988881</b>	<b>-6.988303</b>	<b>0.0005210</b>
RC-PRL	-2.428571	-29.020136	24.162993	0.9990690
SL-PRL	-1.331797	-25.068015	22.404421	0.9998648
SL-RC	1.096774	-17.645548	19.839097	0.9998402

A limitation of this data is that it relied on respondents’ self-reports. It can be difficult to estimate and separate out different forms of support. A more accurate method would be to ask family carers to fill out a ‘diary’ in real time recording amount of support provided. However, this may not be practical for family carers, who already have many demands on their time.

## Case Studies

Case studies were created for several families from each housing model, and the responses which were most representative of that model were selected. We used the mid-point of each response category (for example, 1.5 days if the response was 1-2 days) and added them to create an approximate total of time and money spent.

## Qualitative Analysis

The extensive written comments provided by respondents added considerable depth to the answers and reflected on the difficulty in quantifying support. Additional impacts on carers were revealed in these comments, which would not have been captured through numeric data alone. This illustrates the importance of including a qualitative element to such research. In this survey the comments were captured by adding free text boxes below each question where respondents could share their thoughts in their own words.

The written comments were downloaded from Survey Monkey, separated from the quantitative responses and uploaded onto a Word Document. The researcher coded the transcripts and analysed them using framework analysis, to reflect the different domains of support being investigated.