

# Research Report



## Disability Needs Survey

Prepared for: States of Guernsey

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**Prepared for: States of Guernsey**

**Prepared by: BMG Research and the University of Nottingham**

**Date: December 2012**

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Project: 8680

Registered in England No. 2841970

Registered office:

7 Holt Court North  
Heneage Street West  
Aston Science Park  
Birmingham  
B7 4AX  
UK

Tel: +44 (0) 121 3336006

UK VAT Registration No. 580 6606 32

Birmingham Chamber of Commerce Member No. B4626

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# 1 Introduction

## 1.1 Background

When the States of Guernsey decided to develop a Disability and Inclusion Strategy to meet the needs of disabled islanders and the family and friends who support them, one of the first priorities was to ensure that those needs could be accurately identified, understood and prioritised.

There are a range of possible sources of disability information on Guernsey. Public surveys often ask a few generic questions about “health” or “disability”. GPs have records of their patients’ diagnoses. Individual services, set up to meet a particular need, will have a group of people with that need on their books.

However, these information sources can only really tell us about people whose needs have already been identified and are, to a certain extent, being met. By relying on these alone, the people who have already fallen through the cracks would continue to be invisible, and it would be impossible to plan future services in a way that responds effectively to islanders’ needs. Nor would it be possible to gain a good understanding of disability-related issues which are not tackled by services – such as discrimination and unequal access to opportunities.

For this reason, the Social Policy Group (a sub-committee of the States of Guernsey Policy Council) commissioned an island-wide research programme in 2011. This research, which looks at the prevalence of long-term conditions in Guernsey and Alderney, and explores in depth the experiences of disabled islanders and carers, was carried out by BMG Research and the University of Nottingham, in conjunction with the Disability and Inclusion Strategy team, during 2012.

### Long-term Conditions and Disability

The UN Convention on the Rights of Persons with Disabilities gives the following definition:

*“Persons with disabilities **include** those with long-term physical, mental, sensory or intellectual impairments which **in interaction with various barriers** may hinder their full and effective participation in society on an equal basis with others.”*

This means that having a long-term condition is a necessary pre-condition to being disabled, but the presence of exclusionary attitudes or practices is equally important.

The Disability and Inclusion Strategy was created to identify and respond to situations and social conditions which disadvantage or exclude disabled people. It does not have a medical focus – that is, it does not look at people’s conditions or impairments and try to “fix” them.

As such, the primary focus of this research has not been on identifying the full range and detail of long-term physical and mental conditions which islanders have. Rather, it has concentrated on identifying the range of disadvantages, discriminatory practices and practical obstacles which face islanders with long-term conditions when taking part in day-to-day life, education, employment and the life in the wider community.

### Outline of the Research

This research programme has been conducted in two stages:

The **first stage** involved sending a “Health, Wellbeing and Social Inclusion” questionnaire to 1 in 4 households in Guernsey and Alderney. This stage of the research was intended to provide statistical data on the prevalence of different types of long-term condition in the islands. In addition, it has identified the aspects of day-to-day and community life which people with various long-term conditions find particularly challenging.

A key finding from the first stage of the research was that one in five people (21% Guernsey and 19% Alderney) have a disability; that is, have a long-term condition that affects their day-to-day life. This gives an estimate of 13,742 people with a disability on the islands.

It has also enabled us to identify a population of around 4,000 islanders who have a long-term condition, and who have significant difficulty with at least one aspect of day-to-day life or community participation. We believe that this population are the group of islanders most likely to benefit most significantly from the development of Disability and Inclusion policy in Guernsey and in Alderney.

The **second stage** involved face-to-face or telephone interviews with around 300 individuals who identified themselves as disabled: either in the course of the first stage research or in the 2012 Housing Needs Survey conducted by the Guernsey Housing Department. Younger people, and people with more significant communication difficulties, were able to have a parent or carer respond to the interview on their behalf. Altogether, 23% of the interviews were completed by parents and carers on behalf of disabled islanders.

Another 100 interviews were conducted with people who care for or support a disabled person. This was limited to “informal” carers – family and friends – rather than professionals or volunteers. These interviews sought to gather information about the experiences of carers in Guernsey and Alderney.

In both cases, the interviews focused on a number of core areas, including: employment, education, accommodation, equipment, social and health care, financial security, accessibility and social participation.

The data from these interviews cannot be generalised to describe the experience of all disabled islanders and all carers. Rather, it has given an indicative picture of areas where disabled people and those who support them face particular challenges, and helped to focus the Disability and Inclusion Strategy on these areas.

It has also begun to identify some notable differences between various groups of respondents – in particular, differences between the under-24s, the over-67s and the rest of the working age disabled population; and different experiences for people with mental health conditions, communication difficulties and learning- and development-related conditions, compared to the rest of the disabled population.

**How the research will be used**

The data from the Stage 1 research, and the findings and recommendations of Stage 2, have been considered and reflected in the development of the Disability and Inclusion Strategy.

It is hoped that, through the Strategy, a focus on the disability perspective will be incorporated in all future States' policy-making. As such, the data from this research will be made available to other States' Departments and partner organisations to use in planning strategies and services, in order to improve inclusion for disabled people and for carers.

**Additional Acknowledgments**

The Disability and Inclusion Strategy team would like to thank the individual members of the Guernsey Disability Alliance (GDA) who took part in focus groups to shape the questionnaire for Stage 1 of the research, who piloted the Stage 2 survey, and who helped to publicise the research island-wide.

The team would also like to thank all the members of the Disability and Inclusion Strategy Steering Group for their help in planning the research and promoting the survey. Thanks also to the Housing Needs Survey lead at the Housing Department, the Public Health Epidemiologist at the Health & Social Services Department, and members of the Policy & Research Unit for their input on the research.

## 2 Disabled people

### 2.1 Introduction

The core of this report presents the findings obtained from interviews conducted with 271 residents with a disability or long term condition.

A detailed description of the methodology and the resulting profile of respondents by age, gender, and type of condition are shown in Appendices 1 and 2. However, it is important to highlight here that the respondents were self selecting; either as volunteers through the first stage of the study, having provided consent as part of the Housing Needs Survey, or having registered their interest following the publicity of the research. On this basis, these findings provide an indication of the experiences, preferences, and barriers of residents with long term conditions, but these messages cannot be generalised to the whole disabled population of Guernsey and Alderney.

This is in contrast to the first stage where a total of 2,055 households in Guernsey and Alderney, representing 4,894 people, responded to the “Health, Wellbeing and Social Inclusion” survey.

In summary, the following two tables present the profile of the respondents to the first and second stages of the research.

Table 1 shows that there was a higher proportion of respondents interviewed at Stage 2 with communication difficulties, learning, understanding and development difficulties, mobility and dexterity problems, organ problems, and ‘other chronic conditions’.

**Table 1: Profile of the respondents by type of condition in Stage 1 (people with a long-term condition in Guernsey based on valid responses) and Stage 2 of the research**

Condition affects:	Stage 2 respondents (%)	Stage 1 respondents (%)
Mobility and dexterity	73%	56%
Sight and hearing	37%	27%
Communication	29%	16%
Learning, understanding and development	20%	13%
Mental health	24%	30%
Breathing	40%	35%
Organs	59%	46%
“other chronic conditions”	27%	12%
Unweighted base	<b>271</b>	<b>753</b>

Table 2 demonstrates that the age profile of the Stage 2 sample is slightly older than the Stage 1 sample.

**Table 2: Profile of the respondents by age in Stage 1 (people with a long-term condition based on valid responses) and Stage 2 of the research**

Age	Stage 2 respondents (%)	Stage 1 respondents (%)
Under 16	11%	7%
16 to 24	10%	12%
25 to 34		8%
35 to 44	46%	14%
45 to 54		14%
55 to 66		18%
67+	32%	27%
Unweighted base	271	753

## 2.2 Housing

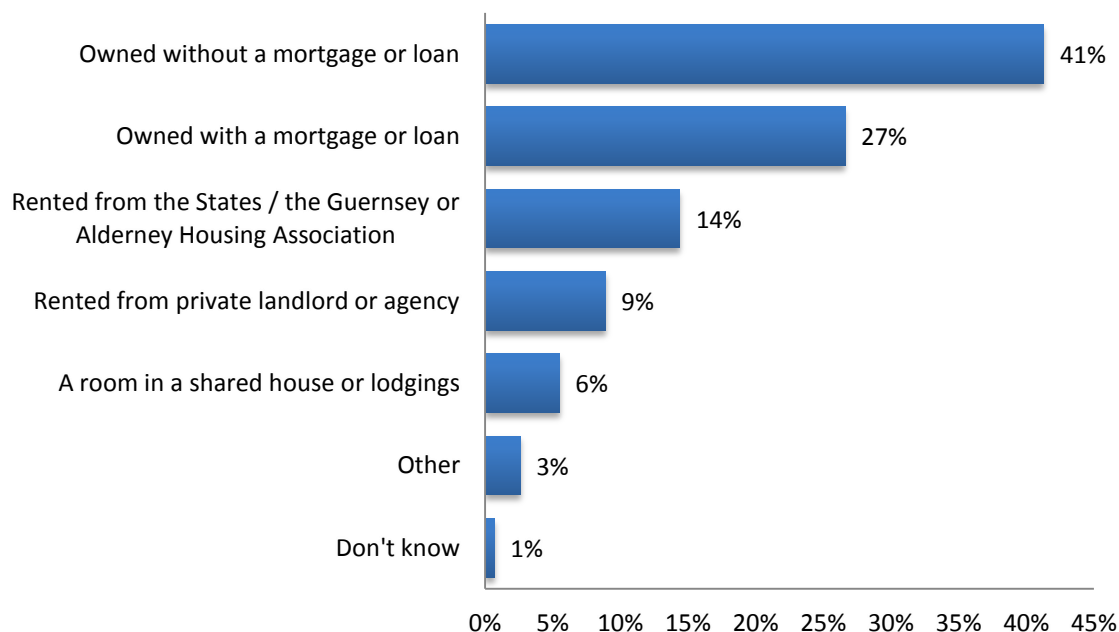
This section looks at the housing needs of people who are living in the community (that is, not in a care home or hospital ward). It looks at:

- Different types of housing.
- Whether housing meets needs – now and in the future.
- Whether disabled people are able to live independently.
- The kind of equipment, aids and adaptations that people need at home.

### 2.2.1 General Overview: Different types of housing

Respondents to the survey come from a range of different housing situations. More than 2 in 3 are owner occupiers of their home (68%); with 41% (112 people) owning their property outright without a mortgage or loan (see Figure 1). 14% (39 people) rent their home from the States and 9% (24 people) rent from a private landlord.

**Figure 1: Which of these best describes your home? (All respondents)**



Unweighted base: 271

The tenure profile varies somewhat from that of Guernsey as a whole. The proportion in social housing (rented from the States/the Guernsey or Alderney Housing Association) is higher in the disability sample than across Guernsey as a whole (14% cf. 8%). However, the opposite is the case for private renters (9% cf. 26%). The proportion of owner occupiers is relatively consistent (68% cf. 62%).

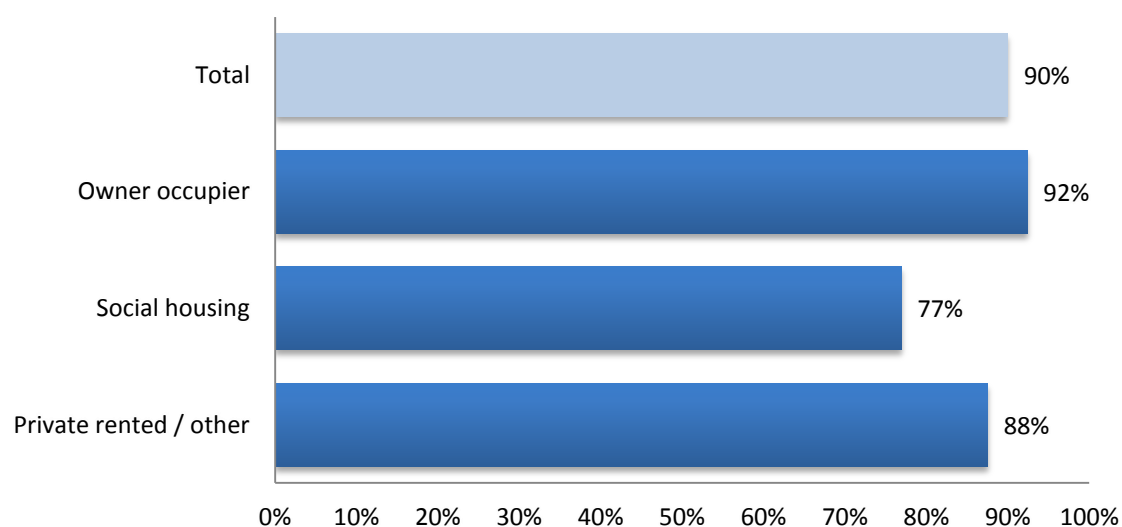
## 2.2.2 Demand for, and use of, housing-related services

### Housing that meets needs – now

Most respondents say their housing meets their current needs (90% overall). However, fewer people who live in social housing feel this way (77% - 30 people). By age, those aged under 16 are by far the most likely to feel their housing does not meet their needs (20% - 6 people), especially compared to people aged 67+ (0%).

People with communication difficulties (20% - 16 people) and learning, understanding and development difficulties (24% - 13 people) are the most likely to feel their housing is not suitable for their needs, compared to people with other types of impairment. Again, this might be due to the fact that this is, overall, a younger cohort of respondents.

**Figure 2: Do you think your housing meets your current needs? (All respondents)**



Unweighted base: 271

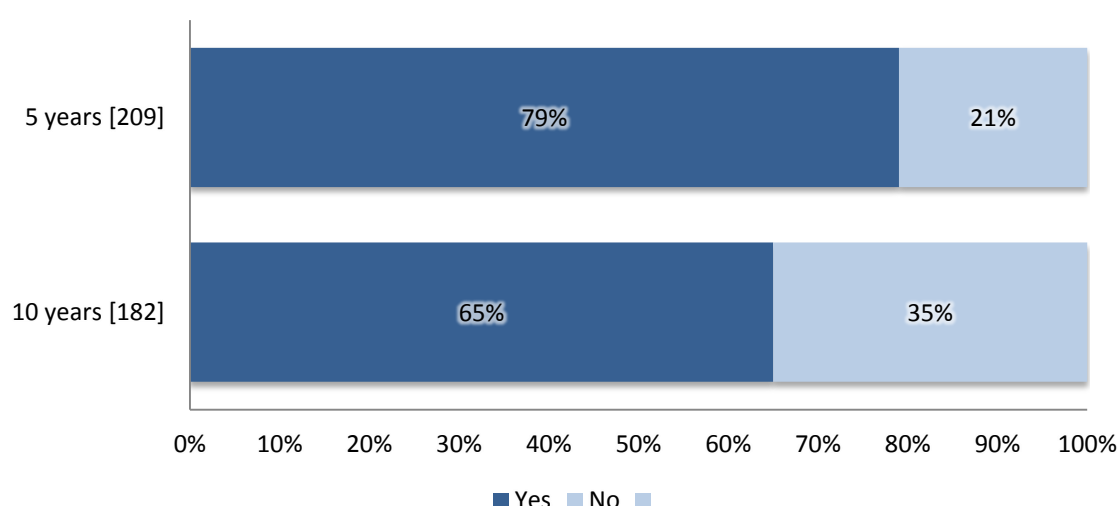
### Housing that meets needs – in the future

Respondents were asked if they thought their accommodation would meet their needs in 5 years time and again in 10 years time. Not all respondents were able to give a valid response (33% 'don't know' whether their housing will meet their needs in 10 years' time), so the valid responses have been used (excluding people who said don't know).

The majority (79%) of respondents say their housing would meet their needs in 5 years time. A lesser proportion (65%) say that it would still meet their needs in 10 years time. 1 in 5 people (21%) definitely feel that their housing will not meet their needs in 5 years time, and this increases to over 1 in 3 people (35%) in 10 years time.

In other words, 63 people in this group of respondents think that their housing will not meet their needs in 10 years' time.

**Figure 3: Will it still meet your needs in...? (All valid responses)**



Unweighted bases in brackets

10 respondents living in social housing and 5 living in private rented accommodation think that their housing will not meet their needs in 5 years time. This amounts to 1 in 4 or 1 in 5 of the respondents living in these types of accommodation. By contrast, 1 in 7 respondents who are owner occupiers think that their housing will not meet their needs in 5 years time – another 28 people.

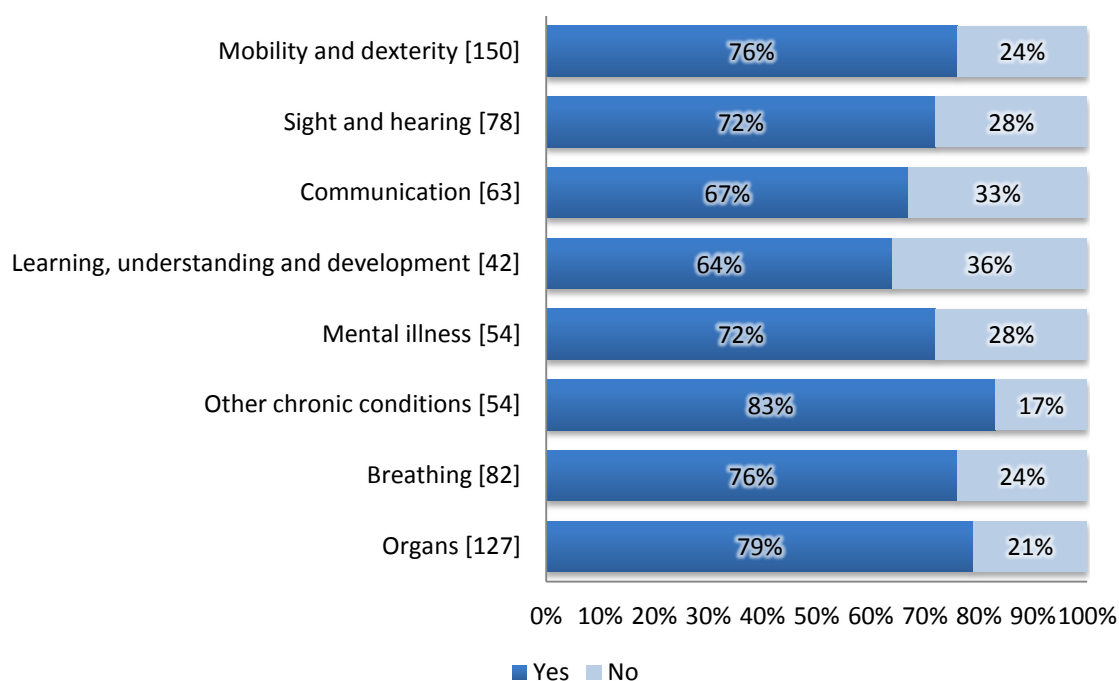
By age, respondents aged under 16 are the most likely to feel that their housing will not meet their needs in 5 years time (30% - 8 people). This may be due to social as much as practical reasons – a number of under-16s will reach adulthood and want to move out of the family home in the next 5 years. 76% (81 people) of respondents aged 35-66, and 90% (47 people) of respondents aged 67+, feel that their housing will meet their future needs. This is perhaps unsurprising given that people aged 67+ are more likely to be owner occupiers. However, despite this optimism, 1 in 3 people over 67 say they would benefit from at least one home adaptation (discussed later in this section).

The following chart (Figure 4) shows the proportion of respondents in different disability groups who feel that their housing will meet their needs in 5 years time,



compared to those who feel that it will not. People with communication difficulties (33% - 21 people) and with learning, understanding and development difficulties (36% - 15 people) are most likely to feel their housing will not be suitable. 1 in 4 people with mobility and dexterity-related conditions (24% - 36 people), who might be more likely to be affected by the physical fabric of their home, say that it will not meet their needs in future. However, these results could be driven more by age than by type of condition – as stated above, the majority of people with communication, learning, understanding and development difficulties are young, and young people are more likely to say their housing will not meet their needs in future. Conversely, more people with mobility and dexterity-related conditions are older, and older people are much more likely to say their housing will meet their future needs.

**Figure 4: Will it still meet your needs in 5 years time? By type of disability (All valid responses)**



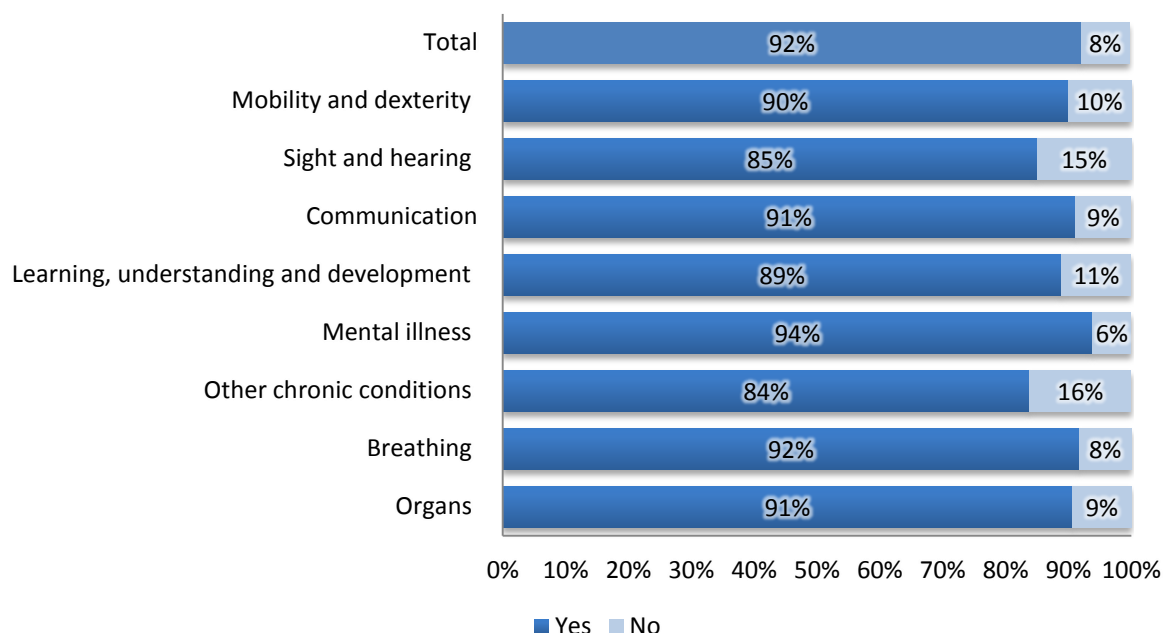
Unweighted bases in brackets

### Accessibility and impact of home environment

Most respondents say they can access all areas of their home (92%), whilst less than 1 in 10 (8% - 21 people) say that they cannot. Figure 5 shows that there are few notable differences among people in different disability groups, although people with sight or hearing issues (15% - 15 people) and people with “other chronic conditions” (16% - 12 people) are more likely to be unable to access areas of their home than other respondents.

In addition to this, respondents with more than one condition are more likely to state they cannot access all areas of their home (9% - 20 people), compared to just one person with one condition.

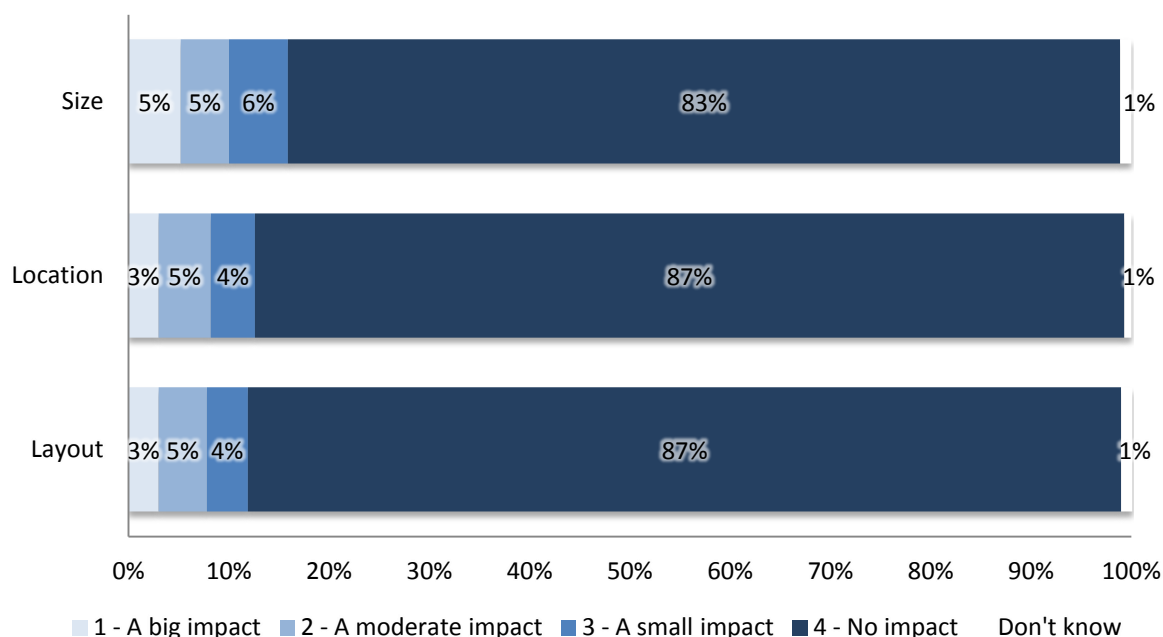
**Figure 5: Can you tell me if you are able to access all areas of your home? By type of disability (All respondents)**



Unweighted base: 271

All respondents were asked to what extent, if at all, the size, location or layout of their home has an impact on their health and well-being. Figure 6 shows that 43 respondents (16%) say the size has an impact, whilst 32 respondents (13%) say that the location does, and 32 respondents (12%) say that the layout has an impact.

**Figure 6: Can you tell me if you think any of the following aspects of your home have a negative impact on your health or wellbeing? (All respondents)**



Unweighted base: 271

12 respondents (31%) in social housing say that the size of their home has an impact on their health and wellbeing; and half of these people say the impact is substantial. By contrast, only 24 people who are owner-occupiers (13%) and 5 private renters (21%) feel that the size of their home has any impact on their health or wellbeing.

Almost 1 in 4 (23%) respondents aged under 16 (7 people) say the size of their home impacts on their health or well-being.

1 in 3 respondents with a learning, understanding and development difficulty (17 people, or 31%) say that the size of their home has an impact on their health and wellbeing, and 13% (7 people) say it has a big impact. 1 in 4 respondents in this disability group live in social housing (24% - 13 people).

There are few notable differences between disability groups, or tenancy types, in terms of the impact that location has on people's health and wellbeing.

A greater proportion of respondents who live in social housing are likely to feel that the layout of their home has an impact on their health and well-being (23% cf. 10% of owner-occupiers). Over 1 in 4 respondents with a mental health condition (17 people, or 26%) say that the layout of their home has an impact on their health and wellbeing.

### **Equipment and Adaptations**

Respondents were asked if they would benefit from any home adaptations (such as stairlifts, adapted bathrooms or wet rooms, or handrails).

1 in 4 respondents (66 people, or 24%) say they would benefit from at least one home adaptation, and this increases to 1 in 3 (27 people - 31%) people aged 67+.

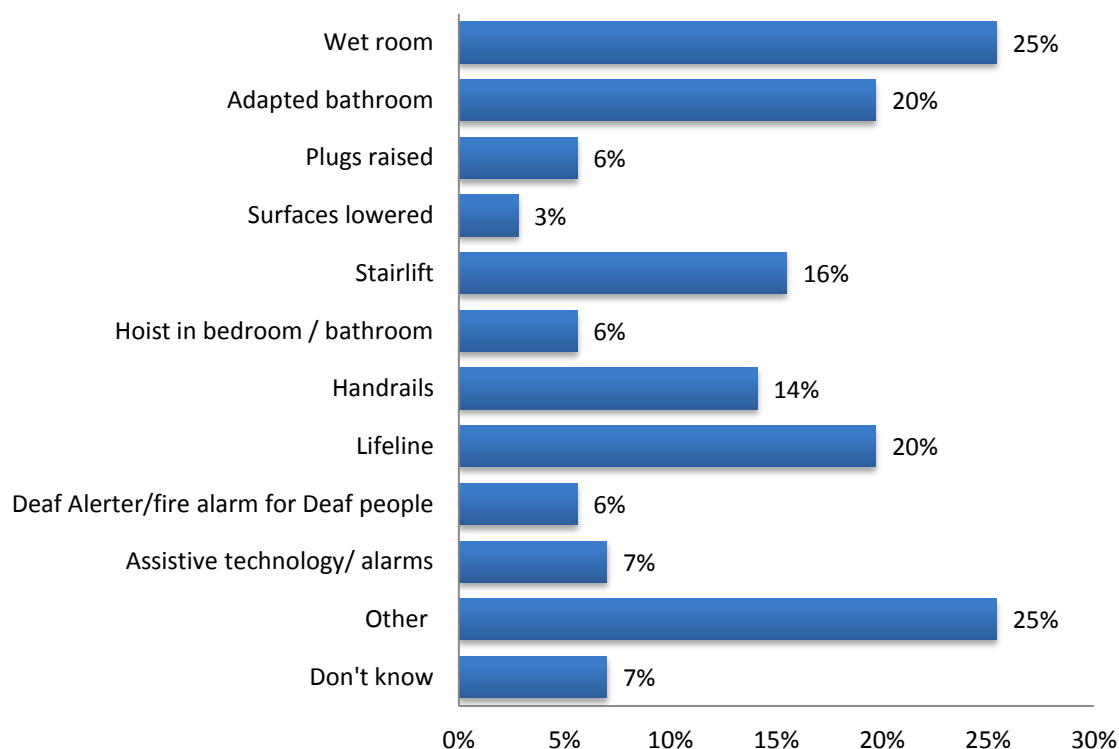
More women than men (29% female cf. 17% male) say they would benefit from at least one home adaptation, which is likely to be due to the fact that there were more women respondents aged 67+. Respondents who live on their own are also proportionately more likely to benefit from adaptations (37% cf. 22% with two and 18% with three or more people in the household), as are those in social housing (15 people, or 38%) and private rented accommodation (10 people, or 42%).

Similar proportions of respondents in every disability group say they would benefit from at least one home adaptation. However, the type of adaptations that people would benefit from varies significantly depending on their disability.

Amongst the respondents who say they would benefit from at least one home adaptation (71 people), 1 in 4 would benefit from a wet room; 1 in 5 an adapted bathroom; and 1 in 5 a Lifeline. 29% of respondents with a mobility or dexterity problem say they would benefit from a wet room (17 people) and 24% say the same about a Lifeline (14 people).

Almost a third (5 people, or 31%) of respondents living in social housing say that they would benefit from an adapted bathroom.

**Figure 7: Thinking about the following types of adaptations (read and/or shown to the respondent), do you think that there is anything you would benefit from, which you don't have at the moment? (All valid responses)**



Unweighted base: 71

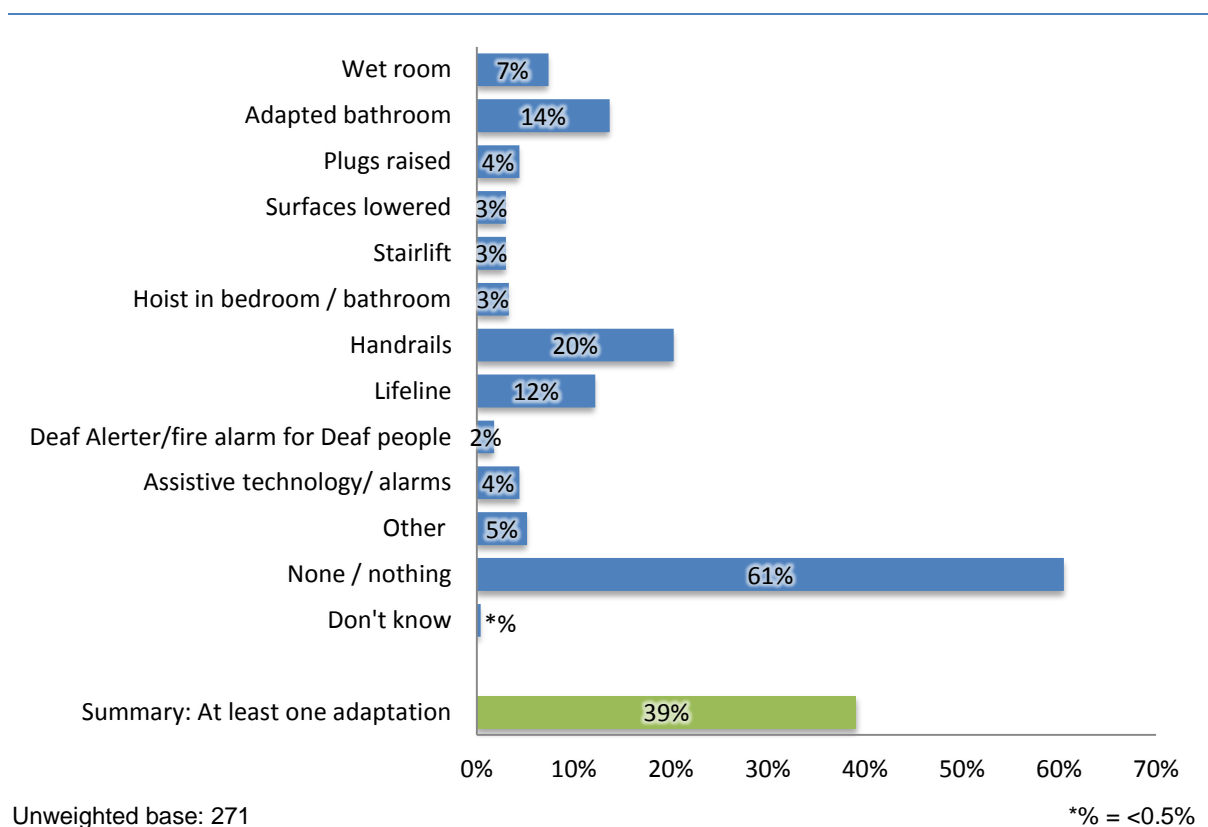
Figure 8 (overleaf) shows the adaptations that respondents currently have to their homes. 3 in 5 respondents do not have any adaptations (164 people, or 61%), whilst the remaining 106 (39%) have one or more. 1 in 5 respondents (55 people, or 20%) have a handrail and 14% (37 people) have an adapted bathroom. 12% (33 people) have a Lifeline.

Older people are more likely to have adaptations to their home (57% aged 67+ (50 people) cf. 32% aged 16-34 (9 people) and 34% aged 35-66 (42 people)), particularly handrails (32% - 28 people) and adapted bathrooms (20% - 18 people). However, as stated above, 1 in 3 people aged 67+ say they would still benefit from home adaptations.

Similarly, while in the previous sub section it was found that respondents in social housing are among the most likely to feel they would benefit from adaptations to their home (39%), they are also the most likely to already have at least one adaptation (21 people, or 54%), particularly handrails (38% - 15 people) and adapted bathrooms (21% - 8 people). This compares to 35% of owner occupiers (64 people) and 25% of private renters (6 people) who currently have at least one adaptation to their home.

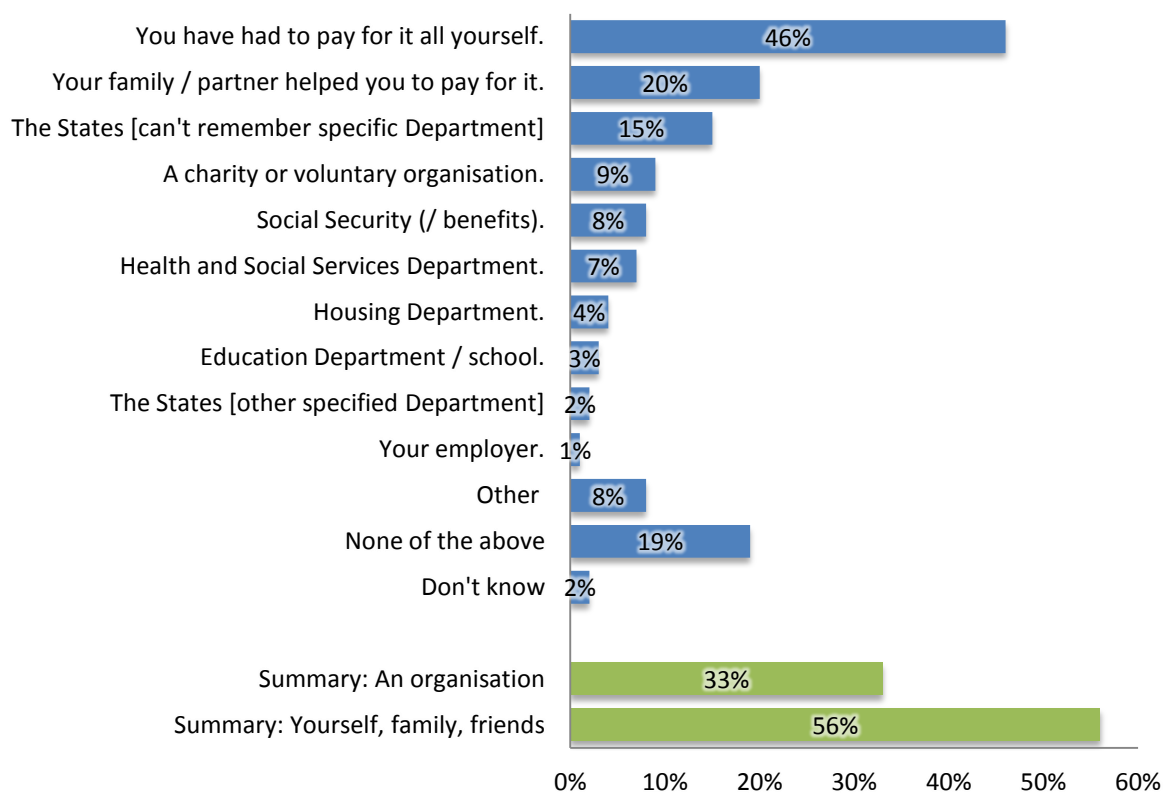
Almost half of respondents with a mobility or dexterity difficulty (94 people, or 47%) currently have a household adaptation, as do 51% with sight or hearing problems (51 people) and 54% with epilepsy (7 people). 3 in 5 people who have had a stroke have at least one adaptation (61% - 11 people), especially handrails (33%), Lifeline (33%) and Deaf Alerter (11%).

**Figure 8: Can you tell me if you have had any of these adaptations to your home? (All respondents)**



Following on from this, those people who have at least one adaptation to their home were asked whether they got any funding to pay for it. Overall, 56% have funded such adaptations themselves (or through family and friends), whilst a third (33%) received funding from an organisation.

**Figure 9: Can you tell me if you have been able to get funding from any of these organisations to help pay for your equipment or adaptations? (All respondents – where have adaptations in the home)**



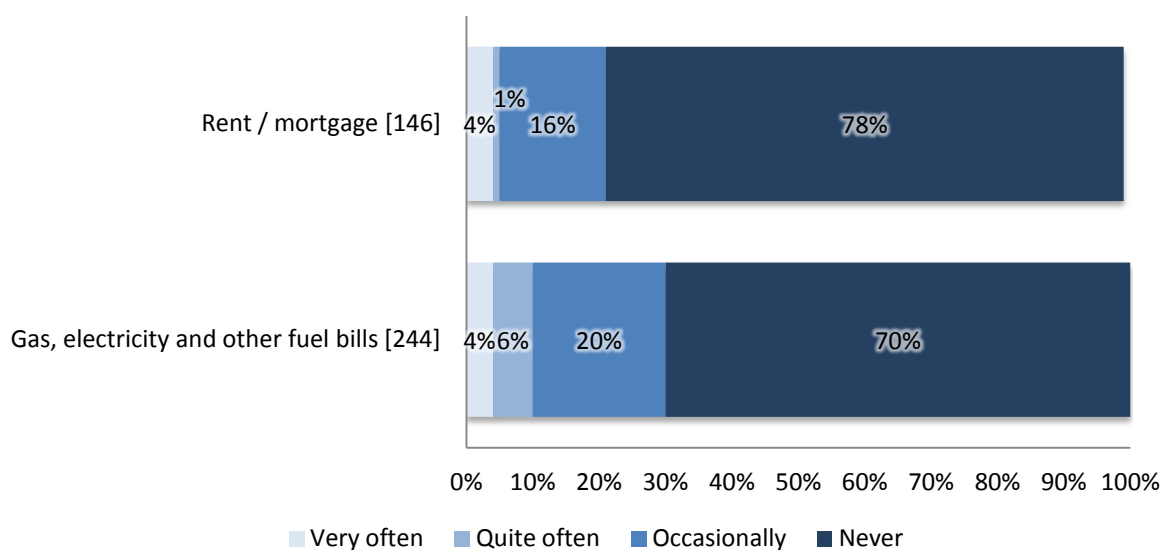
Unweighted base: 106

### The cost of housing

Exploring the financial accessibility of people's housing, the majority of respondents do not find it difficult to meet the costs of their rent / mortgage (78%) or their fuel bills (70%)<sup>1</sup>. Just 5% of respondents (8 people) find it difficult to pay their rent or mortgage very or quite often. This proportion doubles amongst those in social housing (10%), but relates to a very small number of people (3 people). A slightly higher proportion of all respondents find it difficult to meet the costs of their fuel bills very or quite often (10% - 24 people), and this rises again amongst social renters (18% - 6 people), but also amongst private renters (21% - 5 people). 15% of benefits recipients face difficulties paying their fuel bills (19 people), compared to just 4% of non-benefits claimants, as do 17% of people with a household income of less than £10,399 annually (5 people).

<sup>1</sup> The data has been presented based on valid responses, whereby anybody that answered 'don't know' or 'not applicable' has been removed.

**Figure 10: Can you tell me how often your household finds it difficult to meet the costs of the following...? (All valid responses)**



Unweighted bases in brackets

### Living independently

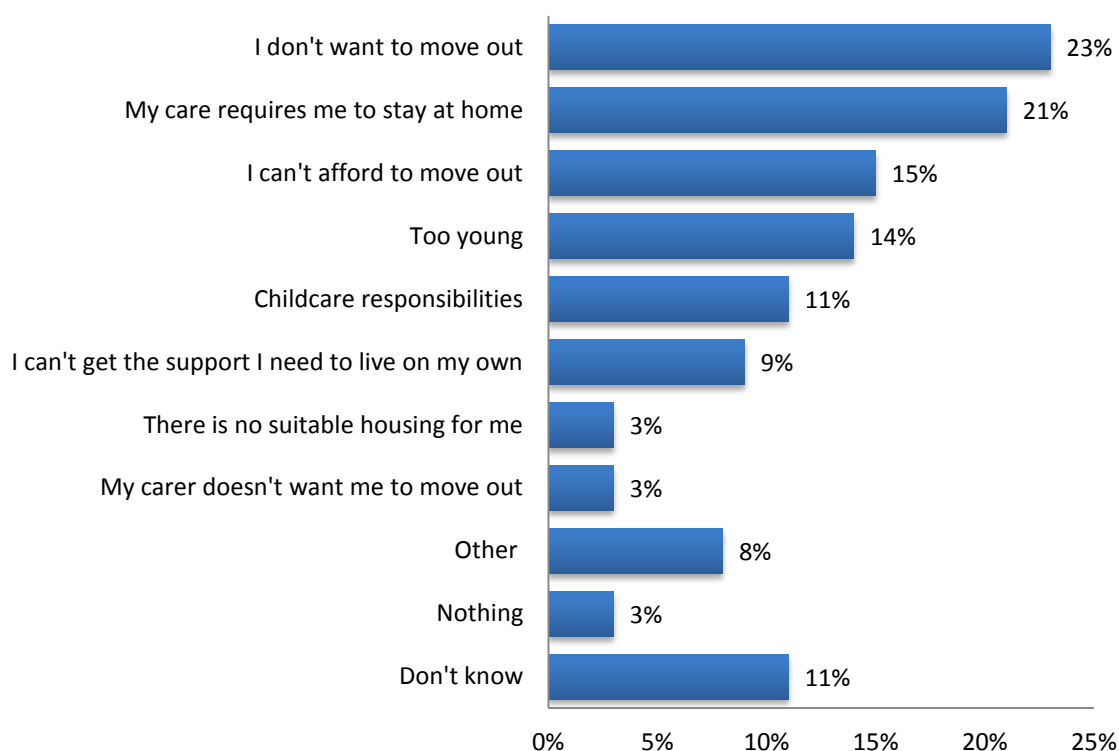
A quarter (24% - 66 people) of respondents aged over 16 report living with family or friends (excluding partners/spouses and children). 64% of respondents aged 16-34 (18 people) fall into this group; as do 31% of respondents in social housing (12 people).

Among some groups of disabled people, as many as 1 in 2 people live with family or friends. This includes people with epilepsy (54% - 7 people); people with learning, understanding or development difficulties (59% - 32 people); and people with communication difficulties (44% - 35 people). This is likely to be connected to the age profile of these respondents, most of whom are in the younger age groups<sup>2</sup>. Respondents with more than one condition are less likely to live with family or friends (23% cf. 30% with one condition – 52 and 13 people).

The 66 respondents that live with friends and family were then asked if there is anything that is stopping them from living on their own. Almost a quarter (23% - 15 people) do not wish to move out, 1 in 5 (14 people, or 21%) say their care requires them to stay at home, and 15% (10 people) cannot afford to move out.

<sup>2</sup> 80% and 73% of those aged under 16 say they have a communication difficulty or a learning, understanding and development difficulty.

**Figure 11: Is there anything that is stopping you from living on your own? (All respondents – where living with family (excluding partner or children) or friends)**



Unweighted base: 66

### 2.2.3 Key issues

An essential component of the States' policy intent to promote independent living for disabled people will be to ensure that Guernsey's current and future housing stock fully meets disabled people's needs. Whilst most respondents say their housing meets their current needs (90%), there are differences by tenure and age with only 77 per cent of people who live in social housing saying that their housing currently meets their needs and 20 per cent of those aged under 16 saying that it does not.

However, future expectations give rise for concern as one in five people (21%) say that their housing will definitely not meet their needs in five years time and over one in three people (35%) that it will definitely not meet their needs in ten years time. Respondents living in social housing (31%) and privately renting (29%) are more likely than owner occupiers (19%) to say that their housing will not meet their needs in five years time. By age, respondents aged under 16 are the most likely to feel that their housing will not meet their needs in five years time (30%). This may be due to many young people wanting to live independently as they enter their 20s, but are uncertain about their accommodation options.

However, there is scope to support independent living for disabled people through providing necessary adaptations to their homes. One in four respondents (24%) say they would benefit from at least one home adaptation, and this increases to one in three (31%) people aged over 67. One in four (25%) say they would benefit from a



wet room; one in five (20%) an adapted bathroom and the same number a Lifeline (a personal emergency alarm). This increases to 29% of people who have mobility or dexterity problem who say they would benefit from a wet room and 24% from a Lifeline. Whilst almost a third (31%) of people living in social housing say that they would benefit from an adapted bathroom.

Of those people who have at least one adaptation to their home 24 per cent received funding from a public authority. The States could explore whether those people who are owner-occupiers, who say they would benefit from an adaptation, are unable to afford that adaptation. If this is the case then the States' should re-examine its criteria for awarding grants for adaptations. The issue is different for people who live in social housing or who are privately renting. The States' 'landlord' responsibilities for people who are living in social housing should make it easier to meet the need for adaptations whilst the approach in the private rented sector might include a careful mix of incentives and legislation.

Carrying out necessary adaptations will enable disabled people to live in greater safety and comfort and, it can be surmised, would allow them to continue to live in their own home for longer. This would not only contribute to the States' policy aim of promoting independent living and choice but may also be cost effective as it would reduce the number of disabled people who are forced to move into a care home because their own home is unsuitable.

These initiatives will need to be underpinned by legislation requiring 'reasonable adjustments' to be made to Guernsey's current and future housing stock and other public and private buildings (see section 4.2 below). Furthermore, the findings that one in three people (31%) in social housing say that the size of their home has an impact on their health or well-being and 23 per cent who say that its layout has a similar impact (rising to over a quarter of people with a mental health condition), suggest that careful consideration needs to be given to the overall planning and design of Guernsey's housing stock so that all disabled people, including young people wishing to establish a home of their own, can live independently in safety and comfort.

## 2.3 Employment

This section looks at the employment status of people with disabilities or long term conditions, in particular:

- Employment sector and hours worked
- Past employment
- Levels of volunteering
- Access to employment-support services

### 2.3.1 General overview: Employment status

Half of respondents of working age (16-66) with a long term condition are employed (73 people, or 49%), either full time (23%), part time (22%) or self employed (4%). This is in line with the employment rate for disabled people in Great Britain; in 2012 the employment rate for disabled people was 46% compared to 76% for non-disabled people.<sup>3</sup>

There is a larger proportion of respondents in the Stage 2 sample that are unable to work because of their condition (32% - 48 people) compared to Stage 1 (11%).

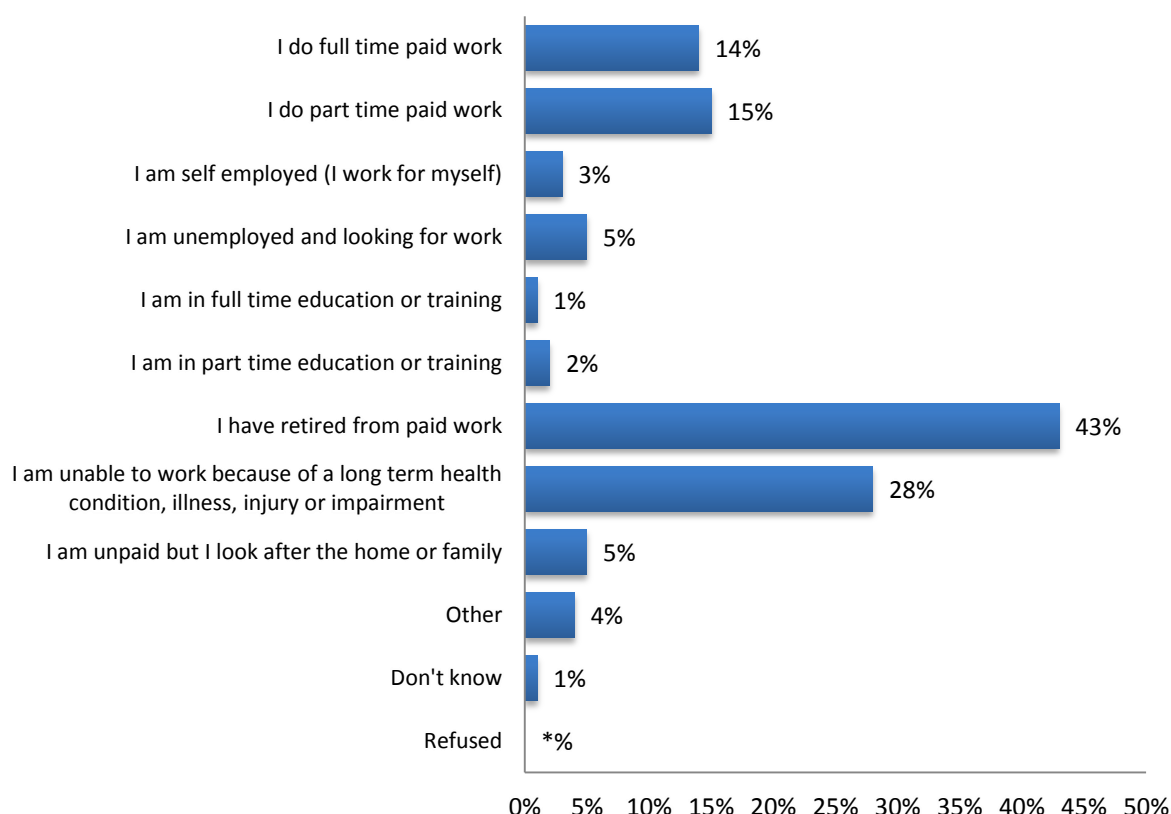
**Table 3: Employment status profile of the Stage 1 and Stage 2 samples, amongst working age respondents only**

Status	Stage 2 respondents %	Stage 1 respondents %
Employed	49%	64%
Unemployed but available for work	9%	4%
Unable to work because of their condition	32%	11%
Unweighted base	153	512

The largest proportion of respondents are retired (103 people, or 43%)<sup>4</sup>. 16% of people aged 16-66 have retired from paid work (24 people) and 19% aged 35-66 (24 people).

<sup>3</sup> Office for Disability Issues (2012) *Disability facts and figures*. Retrieved from <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#imp> on 10<sup>th</sup> December 2012.

<sup>4</sup> The percentages do not add up to 100 because respondents could choose more than one option at this question.

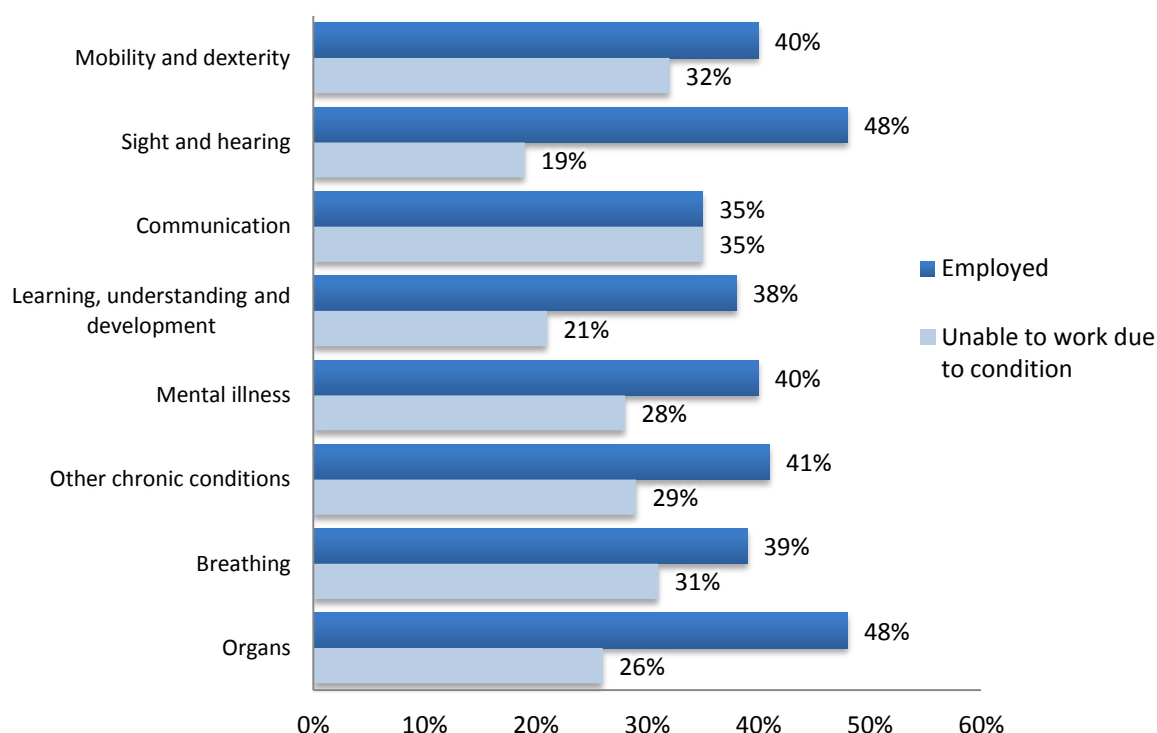
**Figure 12: Employment status (All respondents – where not in full time education)**

Unweighted base: 238

Figure 13 presents the proportion of respondents of working age (16-66) with each type of disability who are employed or unable to work due to their condition. People with communication difficulties are the least likely to be in employment (35% - 16 people), whilst employment levels are higher amongst people with problems with their organs or sight or hearing (both 48% - 42 people and 23 people). People with communication difficulties are also the most likely to not be able to work due to their condition (35% - 19 people), followed by 32% (43 people) of those with mobility or dexterity problems.

People of working age living in social housing are most likely to report not being able to work due to their condition. 30% (12 people) say this is the case, compared to 23% (27 people) of owner occupiers.

**Figure 13: % employed and % unable to work by type of disability (All respondents – where aged 16-66)**



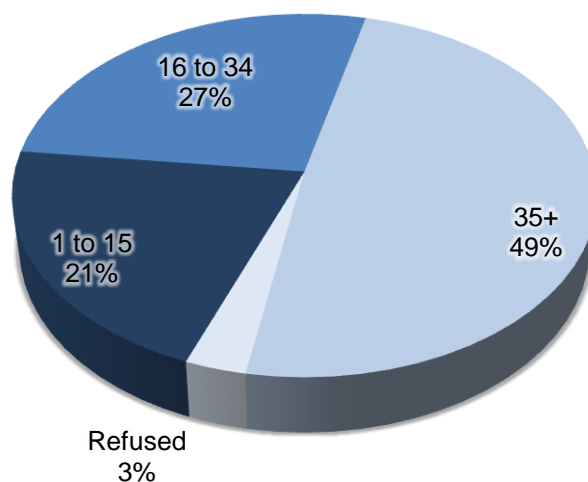
Unweighted bases vary

Amongst the 71 respondents who say they are currently employed, most have only one job (62 people, or 87%) and 8 respondents (11%) have 2 or more jobs. Most of those with 2 or more jobs are women, and women are also more likely to work part time (18% of female respondents cf. 9% male). More than three quarters (77% - 27 people) of all those that work part time are female, compared to 23% male (8 people). 4 respondents with “other chronic conditions” say they have 2 or more jobs, which amounts to 24% of this group.

Half of respondents in employment (34 people, or 49%) work full time hours (35+ per week), whilst 27% (19 people) work between 16 and 34 hours a week (part-time). 1 in 5 (15 people, or 21%) work less than 15 hours per week (Figure 14).

**Figure 14: Can you tell me how many hours of paid work you undertake each week?  
(All respondents – where employed currently)**

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Unweighted base: 71

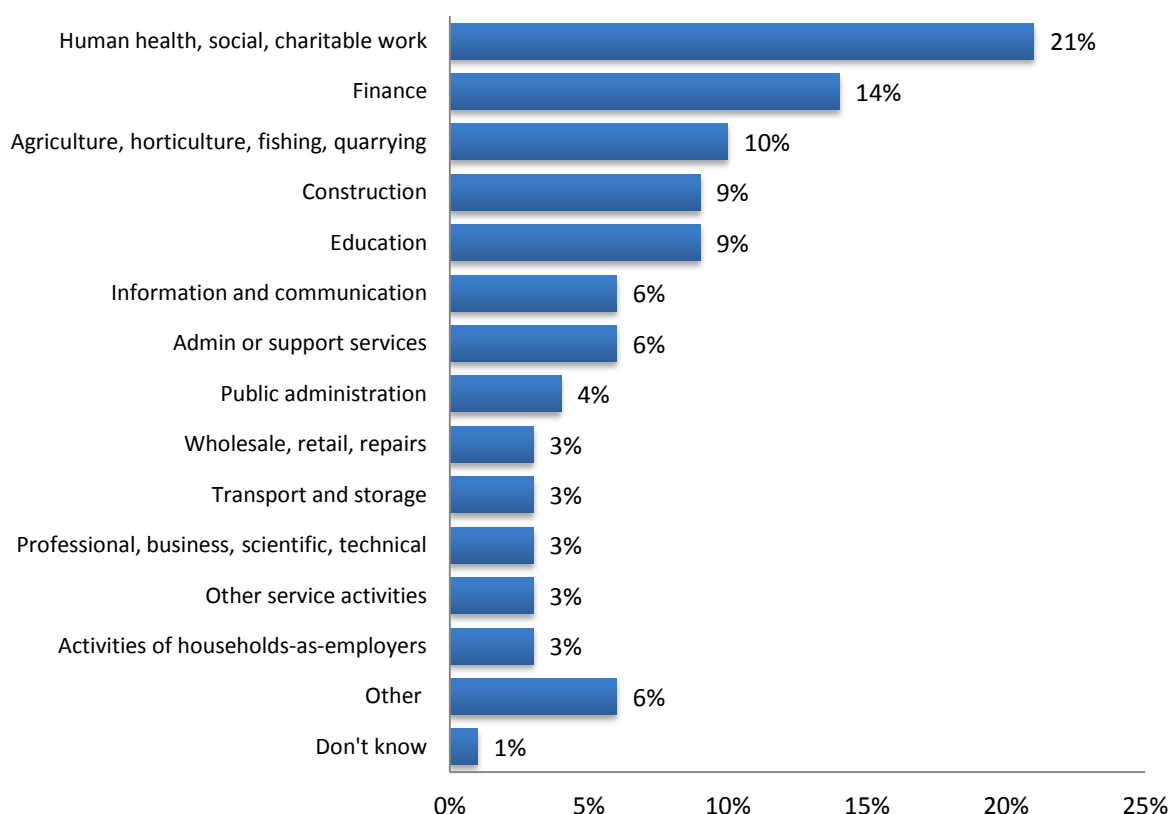
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Respondents are most likely to work in the human health, social, charitable work industry (21% in employment do so). This is far higher than the population as a whole (5%<sup>5</sup>). Only 1 in 7 respondents (14%) work in finance roles (compared to 21% of the population as a whole) and 10% in agriculture, horticulture, fishing or quarrying (compared to 1% of the population as a whole). Given the small sample bases, it is unreliable to explore differences by disability type.

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<sup>5</sup> Guernsey Facts and Figures 2011

**Figure 15: Can you tell me what industry you work in? (All respondents – where employed currently)**

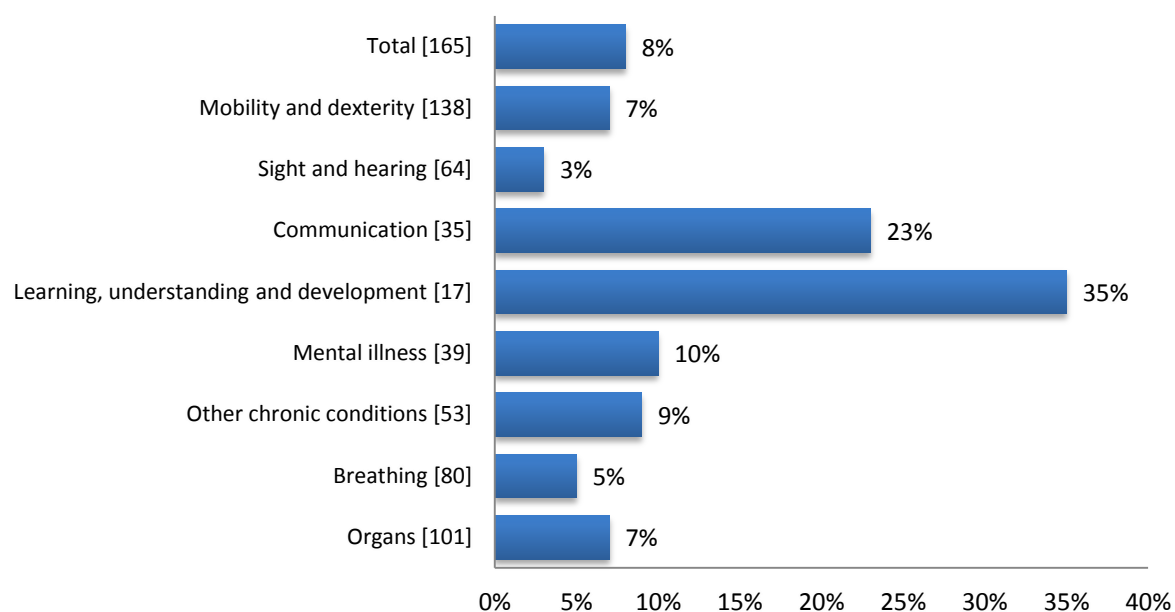


Unweighted base: 70

165 respondents are not currently employed. Only 8% of these people (13 respondents) have never had a paid job or done some kind of paid work. This rises to 16% of respondents living in social housing (4 people) and 13% of respondents who do not have any qualifications (11 people). 10% of those aged 16-66 (8 people) and 6% aged 67+ (5 people) have never had a paid job.

Figure 16 below shows the proportion of respondents with a particular type of condition who have never worked. 38% of working-age respondents with a learning, understanding or development-related condition are in employment. However, of those who are not, 35% (6 people) have never worked. A smaller proportion of respondents with communication difficulties are currently in work (16 people, or 35%); and of the 35 people who are not, 23% (8 people) have never worked.

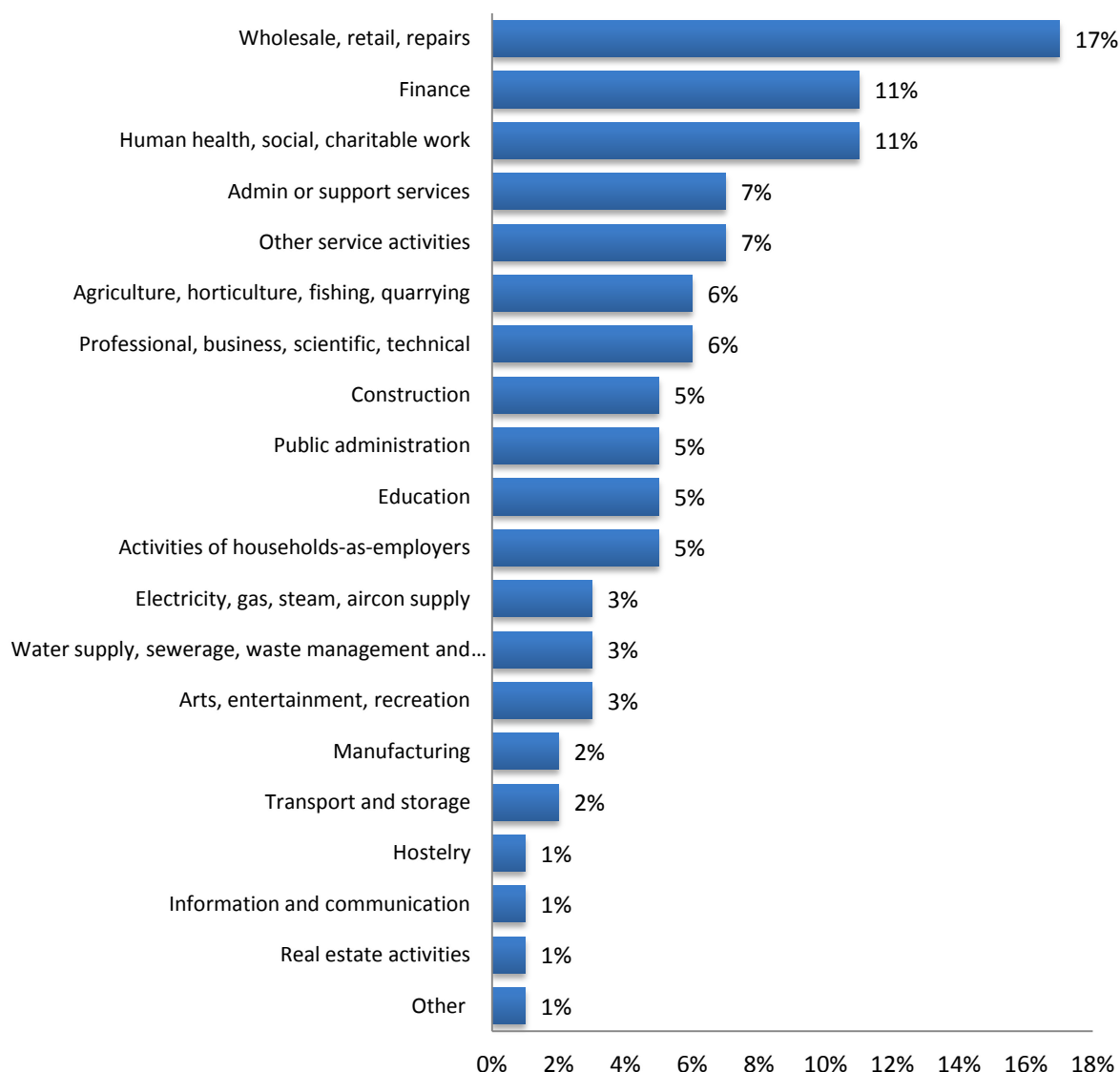
**Figure 16: Have you ever had a paid job, or done some kind of paid work? % no by type of disability (All respondents – where not currently employed)**



Unweighted bases in brackets

Exploring what industries were most commonly worked in amongst those that have previously worked (see Figure 17), these were also human health, social, charitable work (11%) and finance (11%) (mirroring the finding presented in Figure 15). However, the highest proportion (17%) worked in wholesale, retail and repairs, which is an industry worked in by just 3% currently.

**Figure 17: What kind of industry did you work in in your last job? (All respondents – where previously employed)**

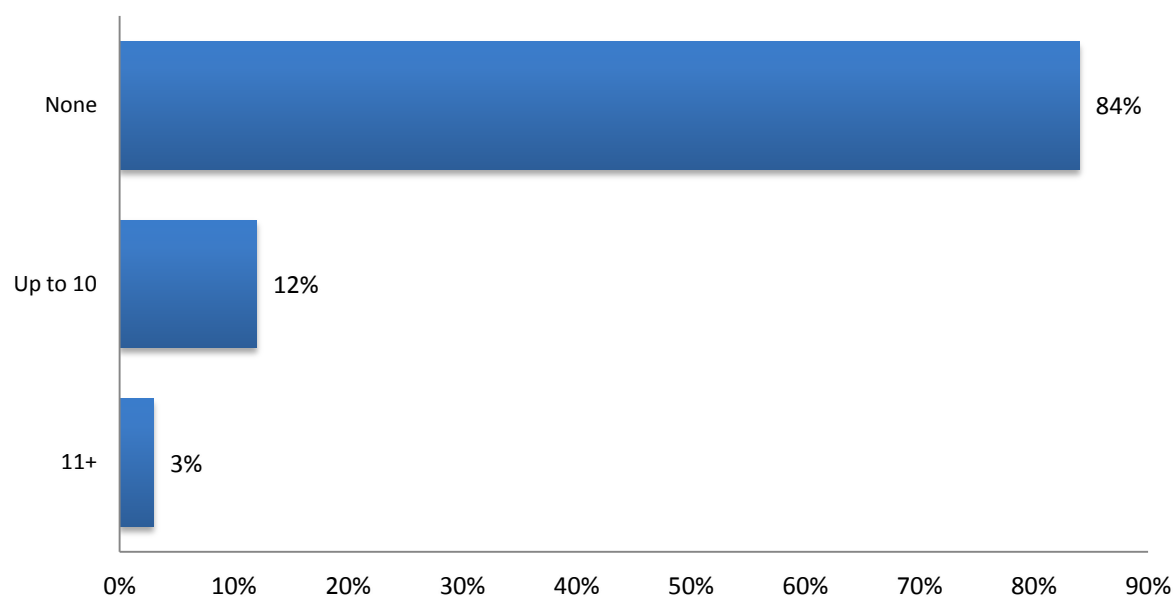


Unweighted base: 151

1 in 6 people not in full time education did at least one hour of volunteering in the past week (15% - 36 people). Figure 18 shows that 12% did between one and 10 hours, whilst 3% did more than 11 hours (7 people). 18% of people aged 16-66 did at least one hour of voluntary work (28 people), compared to 8% aged 67+ (8 people).



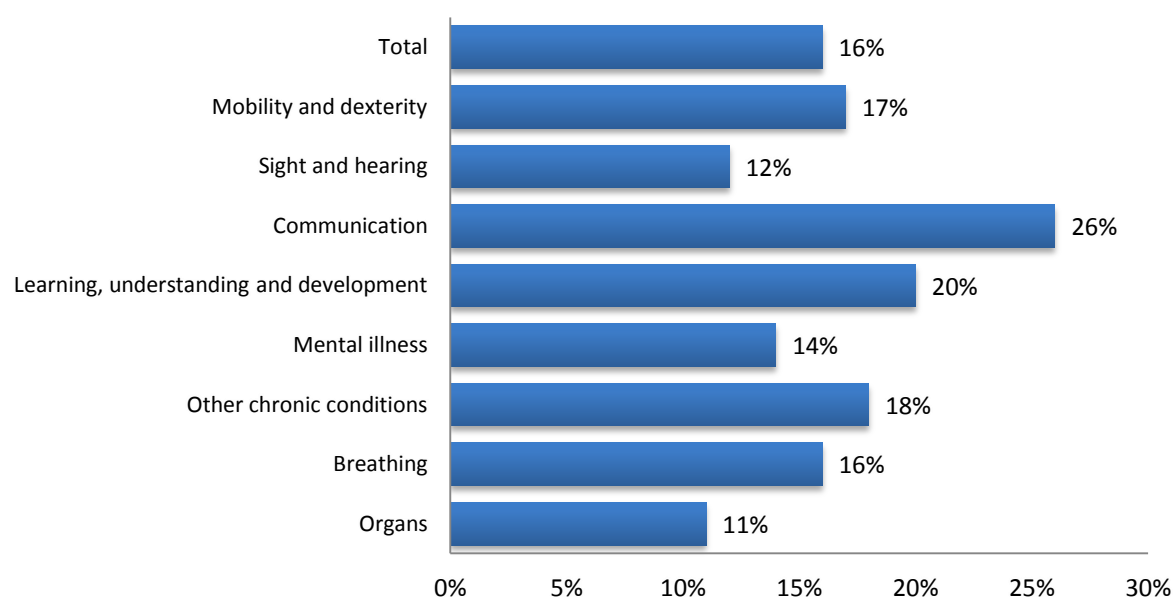
**Figure 18: Can you tell me how many hours of voluntary work did you do in the last week? (All respondents – where not in full time education)**



Unweighted base: 238

A quarter (26% - 13 people) of people with a communication difficulty and 20% with a learning, understanding and development difficulty (6 people) volunteered during the week prior to the interview.

**Figure 19: Can you tell me how many hours of voluntary work did you do in the last week? % at least 1 hour by type of disability (All respondents – where not in full time education)**



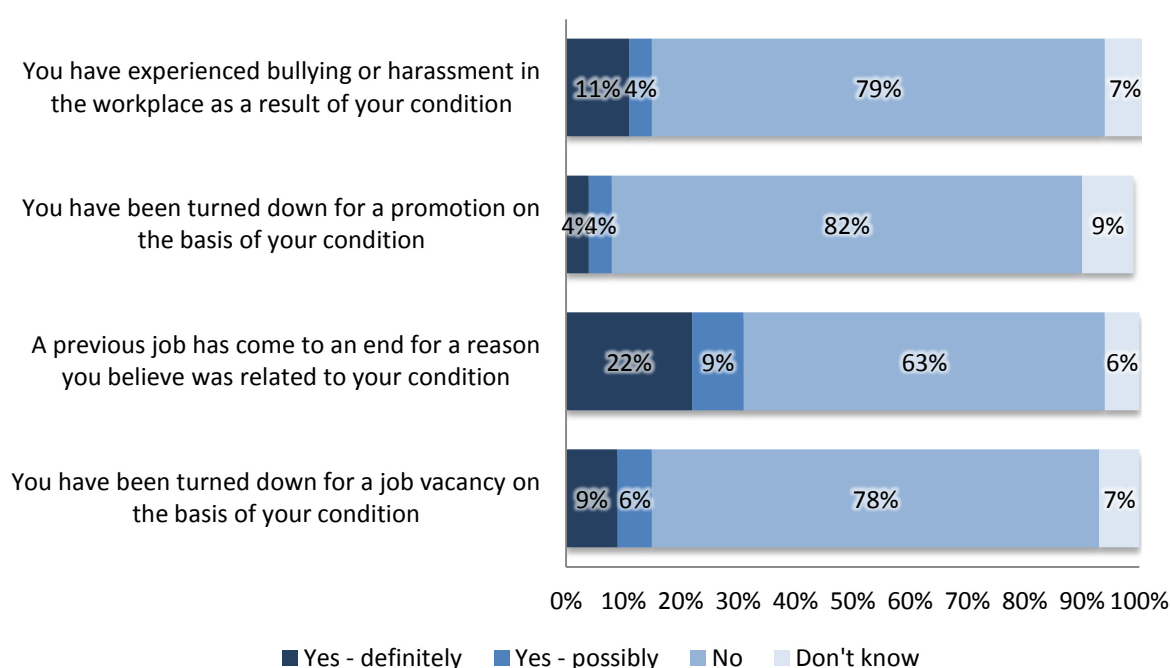
Unweighted bases vary

### 2.3.2 Use of work-related services

Amongst the 228 respondents who currently work, have previously worked, or have done voluntary work in the past week, 14% (33 people) say they have experienced bullying or harassment in the workplace as a result of their condition (Figure 20). A quarter (24% - 17 people) of respondents who are currently employed say this is the case.

Almost a third (31% - 71 people) of people believe their previous job came to an end for a reason related to their condition, with 22% (50 people) definitely believing this was the case. A quarter (25% - 38 people) of those who no longer work believe that they definitely lost a job for this reason.

**Figure 20: Can you tell me if you have experienced any of these? (All respondents – where employed, previously employed or done voluntary work)**



Unweighted base: 228

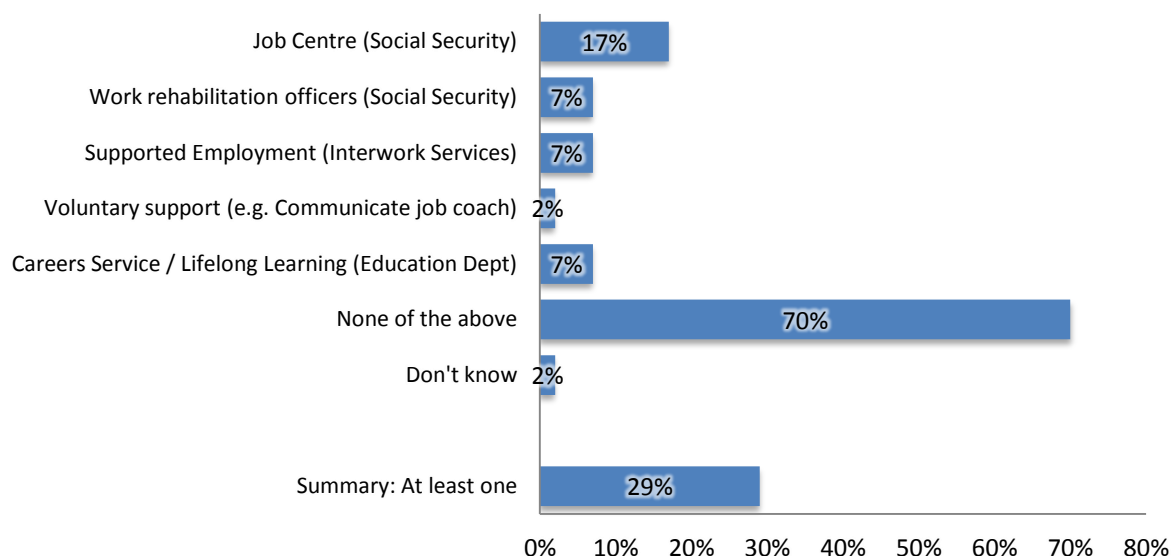
People with conditions relating to communication, learning, understanding and development, and mental health conditions are most likely to have felt discriminated against in the workplace (see Table 4). In particular, half of people with each of these conditions believe their previous job came to an end on the basis of their condition (53% with a mental health condition (30 people), 49% with communication difficulties (23 people), and 48% with learning, understanding and development difficulties (12 people)). 2 in 5 (40%) people with learning, understanding and development difficulties say they have been turned down for a job due to their condition (10 people). This is also the case for 34% of people with a communication difficulty (16 people).

**Table 4: Can you tell me if you have experienced any of these? % yes by type of disability (All respondents – where employed, previously employed or done voluntary work)**

	You have experienced bullying or harassment in the workplace as a result of your condition	You have been turned down for a promotion on the basis of your condition	A previous job has come to an end for a reason you believe was related to your condition	You have been turned down for a job vacancy on the basis of your condition
<b>Total</b>	14%	8%	31%	15%
<b>Mobility and dexterity</b>	15%	9%	33%	14%
<b>Sight and hearing</b>	15%	7%	32%	16%
<b>Communication</b>	28%	<u>21%</u>	<u>49%</u>	<u>34%</u>
<b>Learning, understanding and development</b>	<u>32%</u>	<u>28%</u>	<u>48%</u>	<u>40%</u>
<b>Mental health condition</b>	<u>30%</u>	16%	<u>53%</u>	28%
<b>“Other chronic conditions”</b>	13%	9%	33%	19%
<b>Breathing</b>	15%	9%	35%	16%
<b>Organs</b>	15%	8%	31%	13%

There are a number of work-related services available to people, not only to help them into work, but also to support them during their employment. 1 in 3 (29% - 68 people) of respondents who are not in full time education say they have accessed at least one of these services. The most commonly accessed service is the Job Centre, amongst 17% of respondents (40 people).

**Figure 21: Can you tell me if you have used any of these work-related services? (All respondents – where not in full time education)**

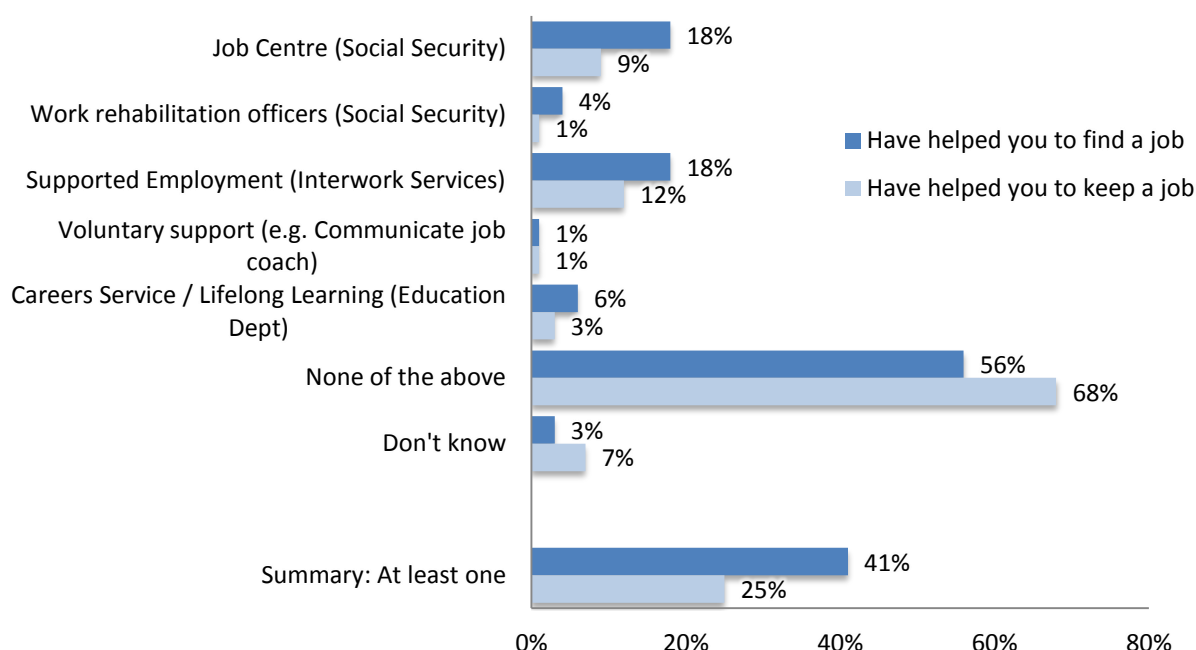


Unweighted base: 238

It is perhaps unsurprising, given the younger age profile, that a higher proportion of respondents with learning, understanding and development difficulties and communication difficulties have accessed at least one of the work-related services (47% and 36% respectively, or 14 and 19 people). Half (52% - 13 people) of all respondents aged 16-34 have accessed the services, as have 44% in social housing and 47% of private renters. Social renters are far more likely to have utilised work rehabilitation officers (21%) and supported employment (15%) than both owner occupiers and private renters (around 5% in all cases).

Following on from this, all users of each service were asked whether it had helped them to find a job or helped them to keep a job (Figure 22). 2 in 5 (41% - 28 people) say at least one of the services helped them to find a job, including 18% who used the Job Centre and 18% who used supported employment (Interwork services). The majority, therefore, did not receive help to find a job via any of the services (56%). Moreover, as shown in Figure 21, 70% of respondents have never used any of these services.

**Figure 22: For each work-related service you have used, do you think any of them...? (All respondents – where used each work-related service)**



Unweighted base: 68

### 2.3.3 Key issues

The States' policy intent is to promote independent living for disabled people and one key aspect of this will be ensuring that those wanting to work receive the support and help they need to facilitate this. Employment can be beneficial for a person's health, it can aid rehabilitation, promote self-confidence and self-esteem, and help improve standards of living. It can also serve to improve the island's economy and its competitiveness. Forty-three per cent of respondents say they have retired, and the employment rate among those who have not is relatively low. However, an unknown proportion of these retirees will have retired 'involuntarily', effectively withdrawn from the labour market because of a perceived lack of support and job opportunities. So, for instance, it may be the case that a proportion of respondents with a mental health condition who report that they are unable to work (43% of all respondents in this group) could do so in the right circumstances. There may be scope to promote independent living through improved employment-related support and help – or through broadening the reach of existing services. This is not to say that all disabled people must seek and take paid work, but that appropriate employment support services can facilitate independent living for a greater number of people.

The island already has a range of employment related services and of those using these services a relatively high proportion (41 per cent) say that they helped them to find a job. Notwithstanding that this is a self-report measure of effectiveness (as opposed to a formal summative evaluation) it appears that current services have a positive effect on moves into paid work. There is, therefore, a good foundation upon which to develop and enhance services. Indeed as discussed below, Guernsey provides a number of employment services that represent best practice.

The range of services that have been found to be helpful in the UK include the following (many of which already appear to be present in Guernsey):

- *Basic skills assessments and action plans.* Assessments have three aims: to assess disabled people's current abilities and personal circumstances; to identify their career goals and aspirations; and determine the training and support that would be required to achieve them. Action plans can help in monitoring progress and provide a check on services provided. Guernsey already has action plans, the 'Return to Work Plan' and the 'Self-Employed Daily Log'. The former may be seen by the individual's doctor and/or (future) employer. However, evidence from the UK is that it is possible that users of the service can be unaware that they have an action plan. Staff need to be transparent about their use and to give clients a copy of any plan. As circumstances can change it is also important that the action plans are regularly reviewed.
- *Advice about vocational direction.* This involves discussions with disabled people about the work they might do, previous work or other experience, the hours they might work, training and qualifications needed and concerns about working. There can also be discussions about specific types of work, notably work trials, supported employment and voluntary work.
- *Advice and help with job search.* Often this involves discussions about where to look for job vacancies, how to complete a job application and CV, and interview preparation. It might also involve accompanying a disabled person to an interview. Guernsey has Work Rehabilitation Officers and Employment Support Officers (provided by the Social Security Department and Interwork Services, respectively) who can provide one-to-one assistance to help disabled people return to employment.
- *Advice and information on the financial implications of moving into work.* This might entail estimating the financial benefits and costs of moving into work or increasing existing hours of work.
- *In-work support.* This is designed to ease a disabled person's transition into employment and address any concerns that might affect their ability to sustain employment. It includes schemes whereby a support worker, personal assistant, or a job coach provided by the public employment service or a mentor, who might be a work colleague, provides workplace based support; assistance with travel costs to and from work; and use of special aids or adaptations in the workplace. Guernsey's Work Rehabilitation Officers and Employment Support Officers can offer disabled employees job coaching to help them learn a job. The island also offers a Gradual Return to Work programme for those in receipt of Incapacity Benefit to help them return to work or begin a new job.
- *Financial incentives paid to disabled people (to encourage moves into employment) and/or to employers (to act as job subsidies).* Payments may be time-limited. Grants may also be available to businesses to fund aids and adaptations to workplaces. Guernsey operates a lump sum Back to Work Bonus for those in receipt of sickness benefits for six or more months who

enter a new job, a discretionary Job Start Expenses scheme to help benefit recipients with exceptional expenses in returning to work and a Recruitment Grant that can be paid to employers who hire long-term Incapacity Benefit recipients.

- *Training and work placements.* Courses tend to be vocational or educational (including basic skills). Guernsey provides Short-Term Training that under some circumstances the Social Security Department will fund and Basic Skills Training (covering IT, reading and numeracy). Whilst training can provide disabled people with useful skills, training courses are not always cost-effective and so the provision of training needs to be kept under review. Work experience opportunities may be unpaid or paid. Guernsey offers benefit recipients an unpaid Work Trail that may last for up to 10 days. In addition, people with a long-term illness may be offered paid work through the Community and Environmental Projects Scheme. International evidence is that these types of scheme are not particularly successful at helping people enter paid work, but they may be undertaken for other reasons: notably maintaining a person's engagement with the labour market.
- *Supported employment (Interwork Services) and therapeutic work.* The Health and Social Services Department runs a supported employment scheme. Therapeutic work as part of some disabled people's treatment plan is also available. For disabled people both of these schemes are potential routes to returning to employment.
- *Voluntary work.* Undertaking voluntary work may aid recovery from an illness or injury and may assist someone who has been out of the labour market for some considerable time to build self-confidence and establish work-related behaviours. However, extended periods of voluntary work may militate against job search and mean that individuals miss paid work opportunities. The use of voluntary work for those wishing to gain employment, therefore, needs to be carefully balanced with job searching. Guernsey allows benefit recipients to undertake voluntary work provided that have their doctor's and Job Centre's approval.

However, these measures, including provided on the island, will be limited in their effectiveness because disabled people face discrimination in the labour market. The survey shows that a third of those who had been in some form of work believed that it ended because of their condition, in some of these cases this will be due to disability discrimination. Moreover, 15 per cent have experienced bullying or harassment in the workplace, eight per cent have been denied promotion and 15 per cent not obtained a job because of their condition.

The potential for independent living through employment will only be possible if disabled people are not discriminated against in the workplace, and this requires a change in employers' attitudes and practices in employing disabled people. This in turn needs to be underwritten by legislation. The case for disability discrimination legislation, which would include employment, is considered further in Chapter 4.

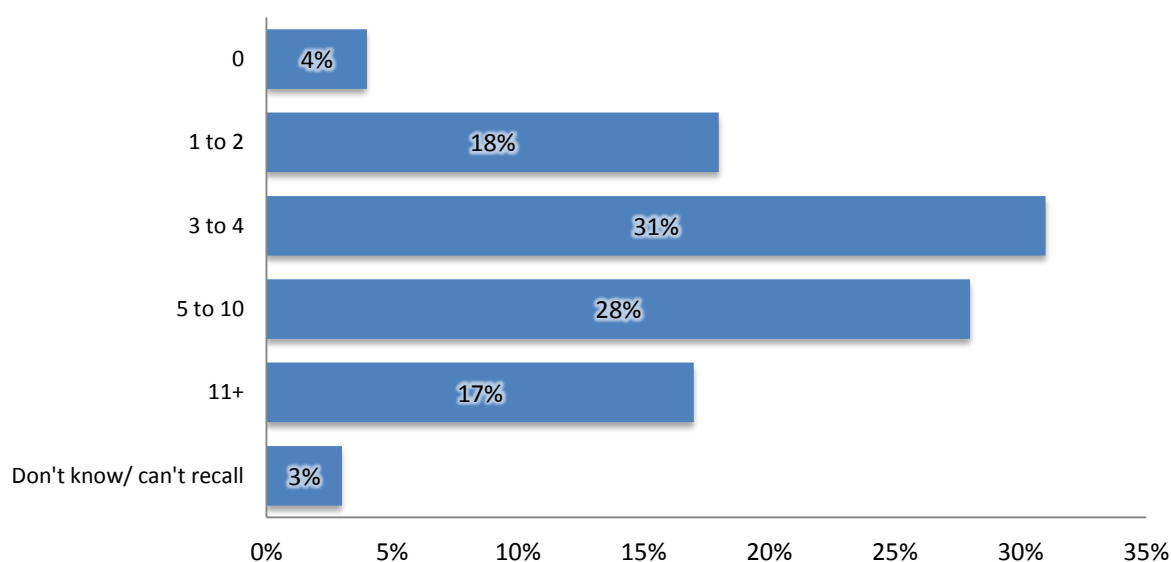
## 2.4 Health and well-being

This section explores people's access to health services, including their GP, specialists, and off-island treatment.

### 2.4.1 Demands for, and use of, services

The large majority of respondents have seen a GP at least once in the past 12 months (253 people, or 93%). Indeed, 45% (122 people) have been 5 or more times and 17% (47 people) 11 or more times. People living in households without a carer are more likely to have seen their GP 5 or more times (47% cf. 38% with a carer). There are marked variations by type of disability, with 58% of people with breathing problems (63 people) and 58% with mental health conditions (38 people) having seen their GP 5 or more times in the past 12 months. A third (32%) of those with mental health conditions have seen their GP 11 or more times over this period (21 people).

**Figure 23: Can you tell me how many times you've been to see a GP about your own health and wellbeing, in the past twelve months? (All respondents)**

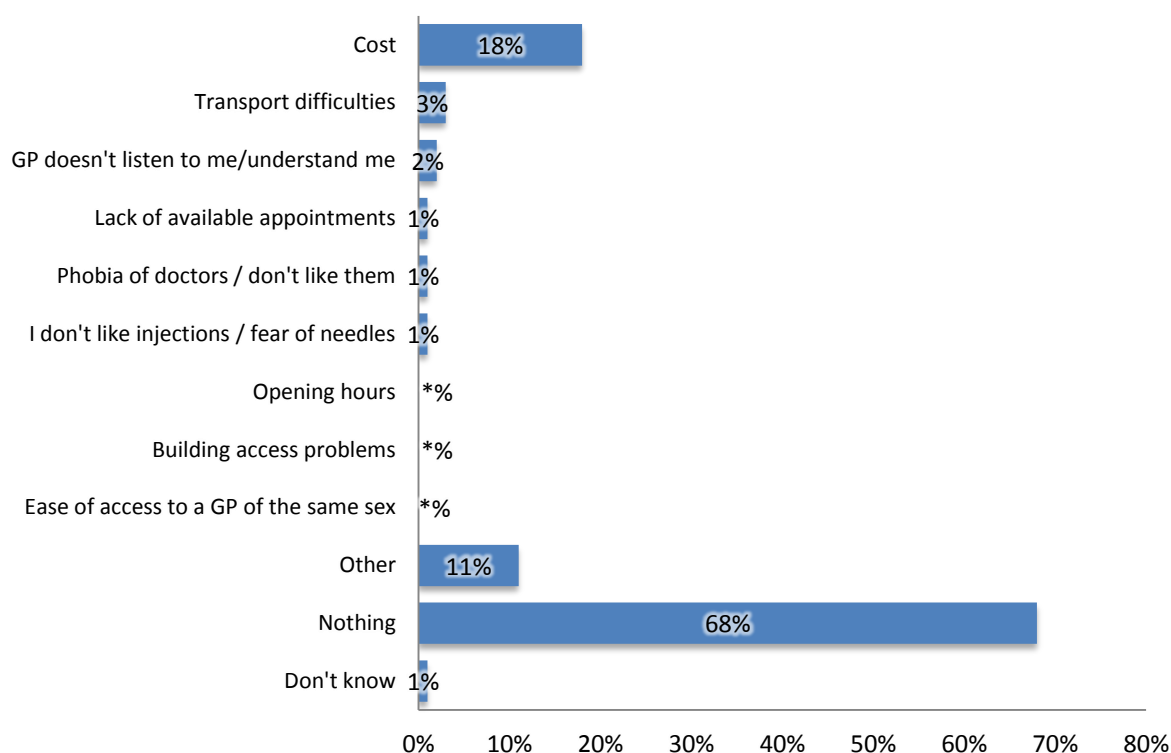


Unweighted base: 271

Cost is the biggest barrier for people when accessing GP services (Figure 24), with charges of in excess of £50 per visit. Whilst the majority of respondents feel nothing puts them off seeing their GP (68%), 18% (49 people) say cost is a barrier. A quarter (26% - 33 people) of respondents aged 35-66 feel the cost of GP services prevents them seeing a doctor, whilst 25% of private renters also feel this way. Despite the greater frequency with which people with a mental health condition visit their GP, cost is a barrier for 28% of this group (18 people).



**Figure 24: Is there anything that puts you off going to see your GP when you need to? (All respondents)**

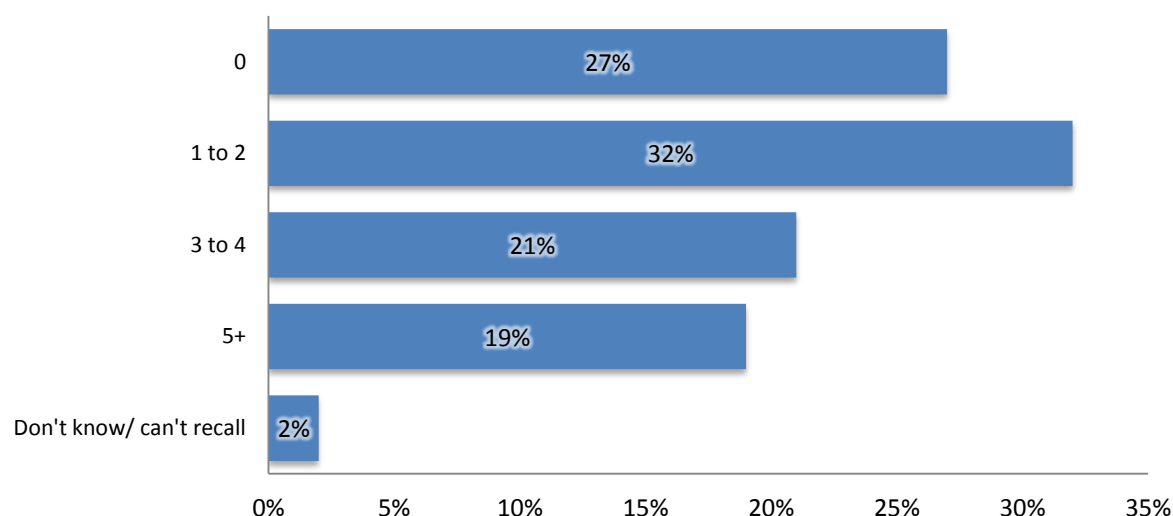


Unweighted base: 271

Almost 3 in 4 respondents (194 people, or 72%) have been to see a specialist about their health and well-being in the past 12 months. 19% (52 people) have been 5 or more times. 93% who are aged under 16 have been to see a specialist (28 people), compared to 69% of those aged 16+. It is important to note here that there are no diagnostic services for adults with autism.

Owner-occupiers are more likely to visit a specialist (75%) as are people with "other chronic conditions" (76% - 56 people).

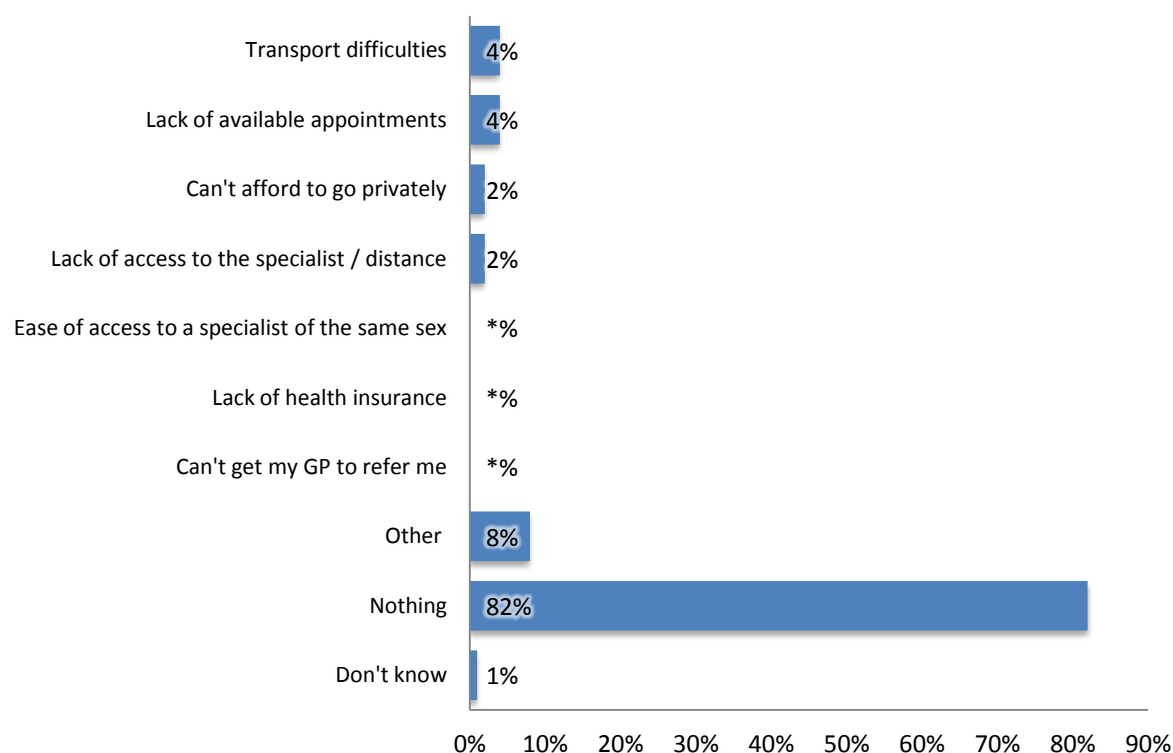
**Figure 25: Can you tell me how many times you've been to see a specialist about your own health and wellbeing, in the past twelve months? (All respondents)**



Unweighted base: 271

82% of people say that there is nothing which would prevent them seeing a specialist, but 17% feel there is at least one barrier. A third (33%) of people with a mental health condition say there is at least one thing which prevents them seeing a specialist, with 11% citing transport difficulties.

**Figure 26: Is there anything that puts you off going to see your GP when you need to? (All respondents)**

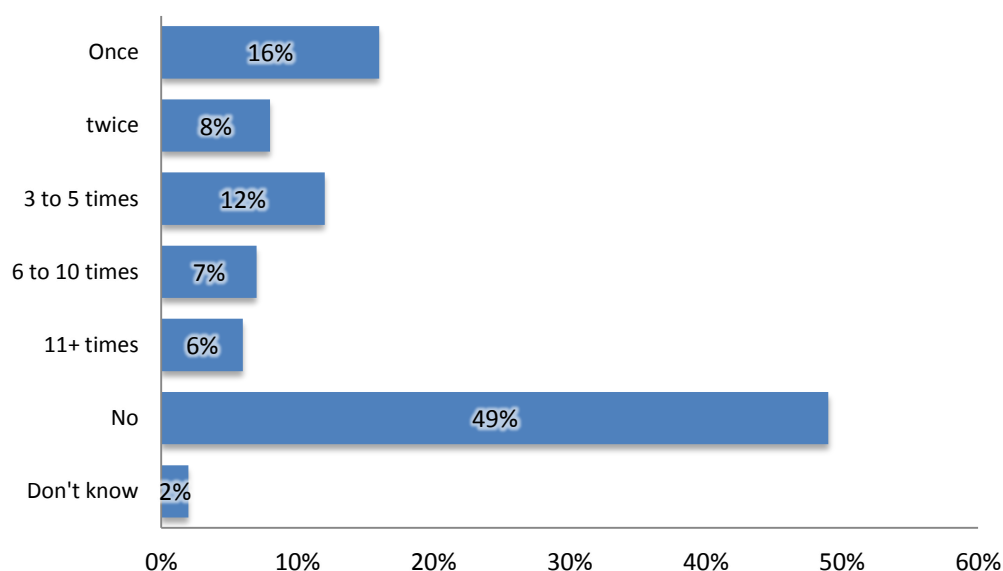


Unweighted base: 271

Half of all respondents have been off-island for a diagnosis, second opinion, operation or other treatment (134 people, or 49%). The rate of off-island treatment increases amongst people with “other chronic conditions” (59% - 44 people) (mirroring the earlier finding regarding these people having seen a specialist most frequently). Higher proportions of respondents with epilepsy (8 people, or 61%) and cancer (11 people, or 65%) have been off-island for treatment.

A third (33%) of respondents have been off-island more than once and 13% (37 people) have done so 6 or more times. The groups more likely to have had off-island treatment 6 or more times include those unable to work due to their condition (21% - 14 people), and people with epilepsy (6 people, or 46%) and cancer (4 people, or 24%).

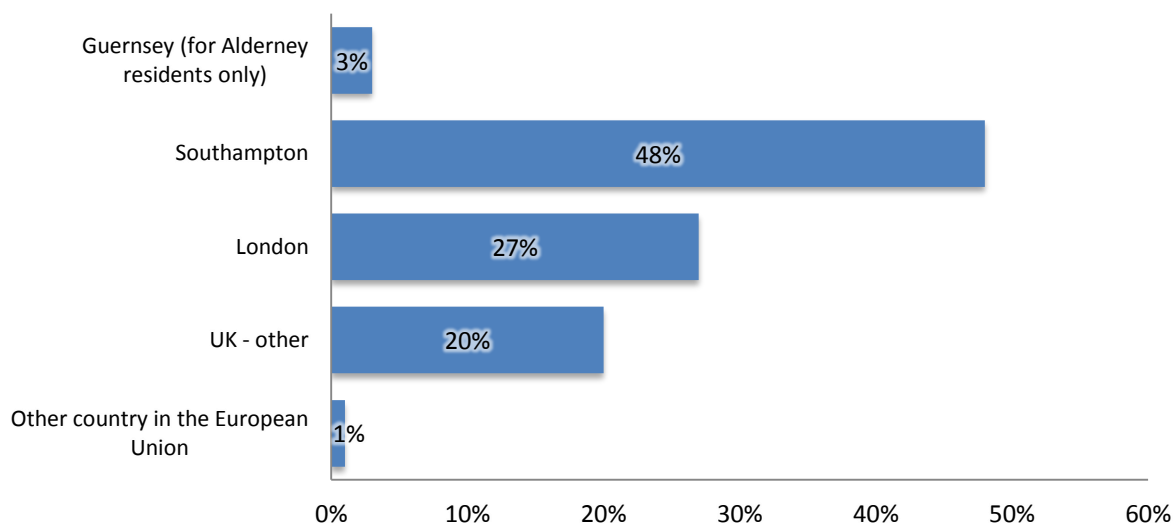
**Figure 27: Can you tell me if you have ever had to go off-island for a diagnosis, second opinion, operation or other treatment? (All respondents)**



Unweighted base: 271

Off-island treatment is most likely to have been in Southampton (48%), followed by London (27%).

**Figure 28: When you last went off-island, where did you go? (All respondents – where been off-island for treatment)**



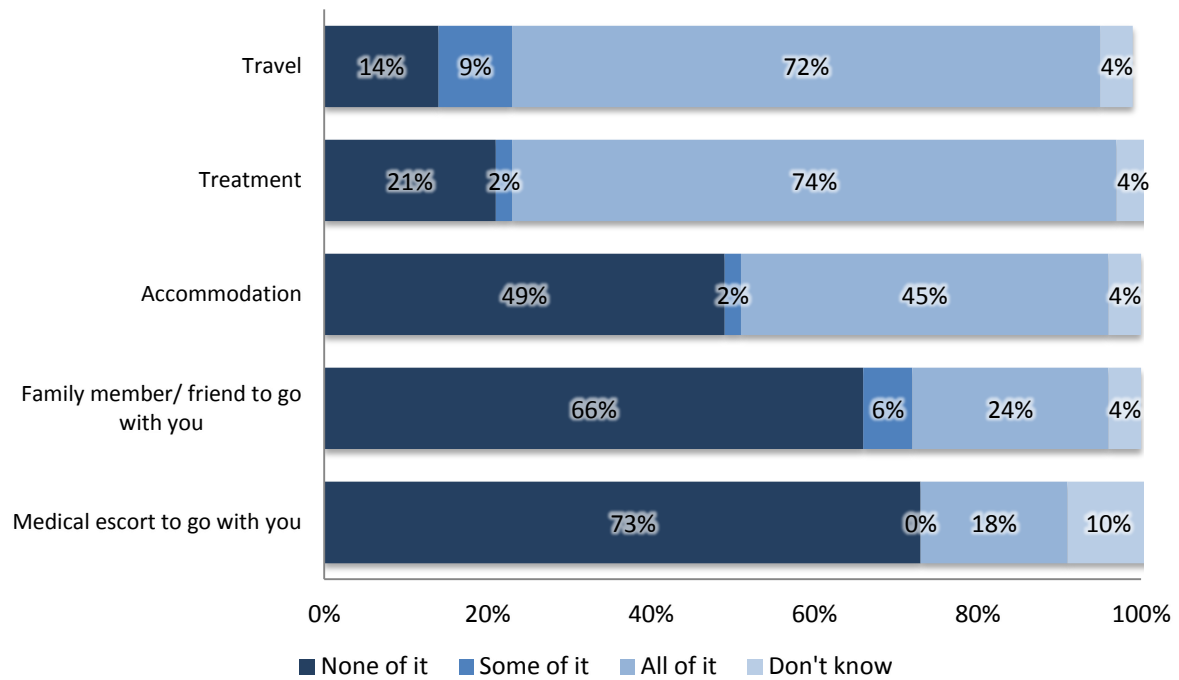
Unweighted base: 137

The majority of respondents who have travelled off-island for treatment stayed for 1 to 2 days (51%), whilst 20% stayed for 11 or more days. A quarter (25%) of those with “other chronic conditions” stayed for 11 or more days.

Following on from this, all respondents who have been off-island were asked whether they got any funding from the States to help them with specific aspects of the trip. Amongst those giving a valid response (removing those that state ‘not applicable’), the large majority received funding for all of the travel (72% - 97 people) and treatment costs (74% - 93 people). 94% of those in social housing received funding for all the travel costs, compared to 68% of owner occupiers. 83% who are unable to work received funding, compared to 70% of those in employment. 4 in 5 people with “other chronic conditions” received funding for travel costs (80% - 35 people).

Funding becomes less common for aspects of off-island treatment such as accommodation (45% all paid for by the States), accompaniment of a family member or friend (24%) and a medical escort to attend (18%). Funding for accompaniment is provided most often for people with learning, understanding and development (42%) and communication (39%) difficulties, which is likely to be due to these being a younger cohort. Just 13% of respondents with breathing problems received any such funding.

**Figure 29: Can you tell me if you got any funding from the States to help you with any of these? (All valid responses – where been off-island for treatment)**



Unweighted bases vary

The variations by type of disability are shown in Table 2.

**Table 5: Can you tell me if you got any funding from the States to help you with any of these? % none of it by type of disability (All valid responses – where been off-island for treatment)**

	Travel	Treatment	Accommodation	Family member/ friend to go with you	Medical escort to go with you
<b>Total</b>	14%	21%	49%	66%	73%
<b>Mobility and dexterity</b>	13%	22%	49%	68%	76%
<b>Sight and hearing</b>	9%	17%	29%	66%	62%
<b>Communication</b>	15%	16%	45%	<b>42%</b>	57%
<b>Learning, understanding and development</b>	17%	20%	50%	<b>38%</b>	50%
<b>Mental health condition</b>	8%	12%	31%	58%	67%
<b>“Other chronic conditions”</b>	9%	19%	48%	67%	81%
<b>Breathing</b>	15%	19%	50%	78%	83%
<b>Organs</b>	14%	18%	49%	71%	77%

Funding for off-island treatment, and more specifically, the receipt of funding for a medical escort or a family member or friend to accompany was discussed at length during a focus group session on Alderney. For further details about the session (including the number of people who attended) see Appendix 2. The key points are:

- Residents of the residential home are not provided with the funding necessary for a nurse or family member to accompany them off-island. However, if they were to go into hospital first then such support would be offered.
- One woman who cares for her husband who requires a monthly injection in Southampton gets no funding to accompany him, which she said becomes very expensive.
- A young woman with visual impairment was not offered accompanied support even though there was no alternative given her condition. Her mother had to fund her own costs to accompany her daughter for treatment.

#### 2.4.2 Key issues

The Social Security Department provides a range of healthcare benefits and assistance towards healthcare costs including Health Benefit, the Medical Expenses Assistance Scheme (MEAS), the Travelling Allowance Grant and the Travelling Expenses Assistance Scheme. The cost of seeing a GP is around £50 per visit. Health Benefit is a grant paid towards the cost of medical consultations with an approved doctor in the surgery, at home, in the Primary Care Centre and A & E at the Princess

Elizabeth Hospital or a consultation with an approved nurse in the surgery. Everyone who normally lives in Guernsey, Alderney, Herm or Jethou and has been registered for the payment of contributions to Guernsey Social Security is covered by the Health Benefit. The benefit is intended to be a part-payment towards the cost of consultations. The remainder of the doctor's bill must be paid either directly by the patient, through their private medical insurance if they have any, or by another States scheme where eligible.

The Medical Expenses Assistance Scheme is a means tested benefit where help towards the cost of primary care and other medical costs is available at the discretion of the Social Security Department. People who are in receipt of Supplementary Benefit may also get help with medical costs.

Despite these schemes and arrangements, respondents report cost as the biggest single barrier to accessing their GP, with 18 per cent of respondents saying that it puts them off seeing their GP when they need to. This rises to 25 per cent of private renters, 26 per cent of people aged 35-66 and 28 per cent (almost one in three) of people with a mental health condition. Furthermore, 17 per cent of respondents said that there is at least one factor that puts them off going to see a specialist. This rises to a third (33%) of people with a mental health condition, with 11 per cent citing transport difficulties. (See discussion in section 2.9.2).

The survey suggests that there may be a relatively high demand for primary care services among people with mental health conditions, as 58% with mental health conditions had seen their GP 5 or more times in the past 12 months. However, a similar proportion of people with breathing problems had also seen their GP 5 or more times in the past 12 months suggesting that the demand from those with mental health conditions for primary care services is unexceptional. Moreover, co-morbidity makes it difficult to say whether demand is high because some people may have had a pre-existing physical condition that has caused them to become depressed, for example.

Medical treatment for island residents is shared between island-based provision (GP and some hospital services) and off-island provision, mainly in Southampton and London for a diagnosis, second opinion, certain operations and treatment that is not available on Guernsey. Almost half (49%) of all people interviewed have been off-island for a diagnosis, second opinion, operation or other treatment. This rose to 59 per cent of people with chronic health conditions, 61 per cent of people with epilepsy and 65 per cent of people with cancer. A third (33%) of people have been off-island more than once and 13 per cent have been off the island for medical treatment six or more times.

The Travelling Allowance Grant (TAG) provides funding and reimbursement of travel expenses for patients visiting Jersey or the UK when medical treatment is not available in Guernsey or Alderney and also for Alderney patients requiring treatment in Guernsey. All residents of Guernsey, Alderney, Herm and Jethou who have been assessed for social security contributions can claim a Travelling Allowance Grant. The children of these residents are also entitled to the grant. To be eligible to claim a Travelling Allowance Grant a person must be seeking treatment or a consultation through the NHS, recommended by an approved doctor, or be seeking private treatment where appropriate treatment is not available in Guernsey or Alderney.

The Travelling Allowance Grant entitles a patient to the cost of travelling from Guernsey or Alderney to the airport nearest to the hospital designated by their GP or specialist. A grant towards Jersey or UK public transport fares taking a patient directly to their designated hospital may also be offered. The Travelling Allowance Grant also covers some costs for an escort if a patient:

- Is under six years old (the Travelling Allowance Grant provides funds for up to two adult escorts to travel with the child);
- Is six years or over and under 18 (the Travelling Allowance Grant provides funds for one adult escort to travel with the patient);
- May need medical attention on the journey (the Travelling Allowance Grant will cover the transport costs of doctors, nurses or members of St. John Ambulance and Rescue Service);
- Who requires a charter flight (they may be accompanied by family or a friend free of charge, so long as there is room on the plane. However, the person accompanying them must pay for their flights home themselves).

For those people who are not covered by the Travelling Allowance Grant, the Travelling Expenses Assistance Scheme (TEAS), which is a non-statutory, means tested benefit may cover the following:

- Travel expenses of a non-medical escort who has been authorised by a doctor;
- Travel expenses to the UK for patients who are visitors to the islands;
- Accommodation costs;
- Other exceptional expenses that would otherwise have to be met by the patient.

All arrangements under the Travelling Expenses Assistance Scheme are agreed on a case by case basis. Special consideration is given to cases involving children.

Almost three-quarters of people who have been off-island for medical treatment had received funding for all of the transport (72%) and treatment costs (74%), while 94 per cent of people in social housing received funding for all the transport costs (compared to 68 per cent of owner occupiers). However, funding for accommodation during off-island treatment is less common, with less than half (45%) paid entirely by the States. The States is even less likely to fund accompaniment by a family member or friend (24%) or a medical escort (18%).

The Alderney focus group gave examples where lack of funding for a nurse or family member to accompany the patient (for example, a husband who needs monthly injections in Southampton or a daughter with visual impairment) put financial pressure on the family.

Clearly the policy intention and the programmes put in place by the States of Guernsey in support of that policy intention is that people with an impairment or a long term health condition who need medical support and treatment should be able to access it. The study has, however, found some gaps between this policy aim and some people's experiences. The main barrier is cost. Cost is a barrier to disabled people being able to access their GP. Some people also reported that they were not able to receive (all) the funding they needed for off-island treatment, in particular for someone to accompany them when having to travel for treatment.



To address these barriers to receiving a timely diagnosis and treatment Guernsey could consider putting the Medical Expenses Assistance Scheme and the Travelling Expenses Assistance Scheme, which at present are at the discretion of the Department, on a statutory rule-based footing and (re)consider the means test and conditions of entitlement so that the medical needs of people with impairments and long term health conditions are fully met. However – especially given the frequency with which some people appear to travel off-island for treatment – the States could examine whether paying in many cases for Guernsey residents to travel to the mainland for a diagnosis, second opinion, certain operations and treatment that are not available on Guernsey is cost effective both in financial terms and in terms of the experience, health and well-being of Guernsey residents, or whether there is an economic, medical and social case for further investment in the island's medical services.

## 2.5 Financial security, income and benefits

This section explores the financial situation of people with long term conditions and the households in which they live. This includes the type and level of income received, whether care and support is paid for, and if so, how much, and the extent to which households find it difficult to meet the costs of a range of day to day expenses.

### 2.5.1 General overview: types and level of income received

All respondents were asked what types of income they have. In summary, 2 in 5 receive at least one benefit (113 people, or 42%), 29% receive an income through employment (79 people) and 41% receive a pension (111 people).

**Table 6: Could you tell me a) what kinds of income you get? And then b) what kinds of income other people in your household get (excluding yourself)? (All respondents)**

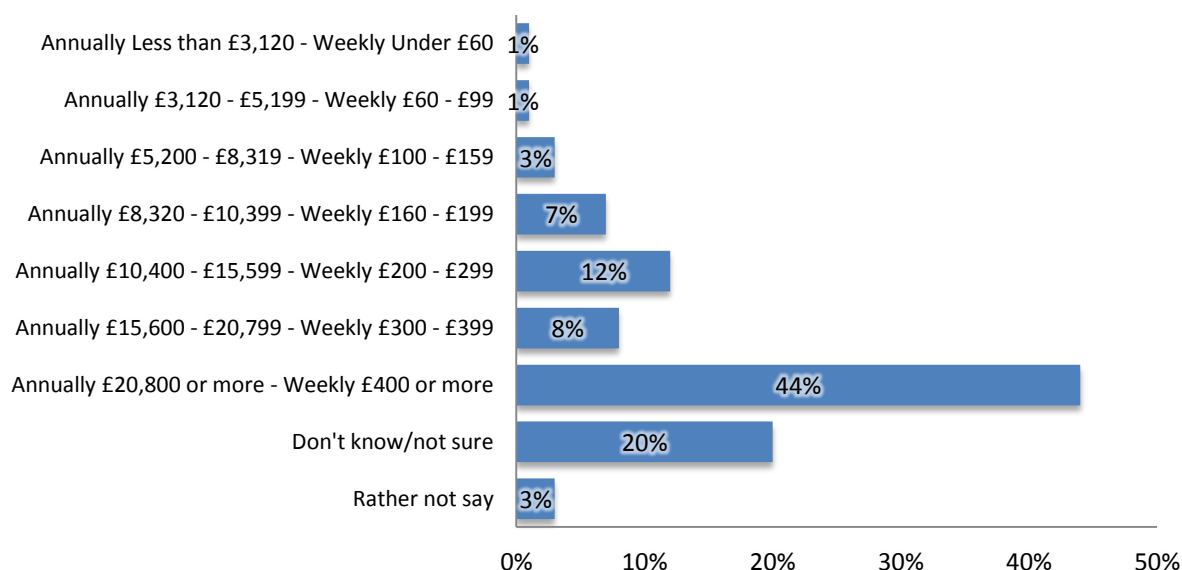
	a) Personal income	b) Household income
Earnings from employment	27%	46%
Earnings from self-employment	3%	10%
Pension from a former employer	17%	24%
State pension	37%	42%
Family Allowance	11%	23%
Unemployment Benefit	2%	4%
Supplementary Benefit	15%	18%
Attendance allowance	7%	11%
Invalid care allowance	4%	7%
Incapacity/invalidity benefit	14%	15%
Other state benefits	7%	7%
Interest from savings etc.	42%	46%
Trust fund	3%	3%
Rent rebate for social housing	5%	8%
Other kinds of regular allowance from outside the household	7%	8%
Other sources	14%	17%
Prefer not to say	8%	35%
<b>Summary: Employment</b>	<b>29%</b>	<b>49%</b>
<b>Summary: Pension</b>	<b>41%</b>	<b>48%</b>
<b>Summary: Benefit</b>	<b>42%</b>	<b>53%</b>
<b>Unweighted base</b>	<b>271</b>	<b>271</b>

There are marked variations:

- Those aged under 16 are most likely to receive an income through attendance allowance (17% cf. 7% overall, or 5 people).
- 23% of those aged 35-66 are in receipt of incapacity / invalidity allowance (29 people) (cf. 14% overall).
- People living in social housing are far more likely to receive Supplementary Benefit (46% (18 people) cf. 5% of owner occupiers (10 people) and 25% of private renters (6 people)), as well as attendance allowance (15% - 6 people), incapacity / invalidity benefit (31% - 12 people) and rent rebate (26% - 10 people).
- There appears to be an age-linked split in the type of benefits accessed by respondents with different types of condition: Attendance allowance is most commonly received by those with communication (15%) and learning, understanding and development (20%) difficulties (i.e. the younger cohort). However, state pension is most commonly received by those with mobility and dexterity (45%), sight and hearing (43%), "other chronic conditions" (47%), and breathing difficulties (51%) (i.e. conditions more common among the older cohort of respondents).

Exploring respondents' household income level after tax, 12% (34 people) say they get less than £10,399 per year. This increases to 17% of people aged 67+ (15 people), 23% in social housing (9 people), and 19% with a communication difficulty (15 people). The largest proportion of respondents have an income of over £20,800 per year (120 people, or 44%), with this increasing to 57% of owner occupiers (104 people).

**Figure 30: Can you tell me how much income your household gets? [You can give this to me as a weekly figure, or as a yearly figure]. I'm talking about the amount of income you have left once you have paid tax. (All respondents)**

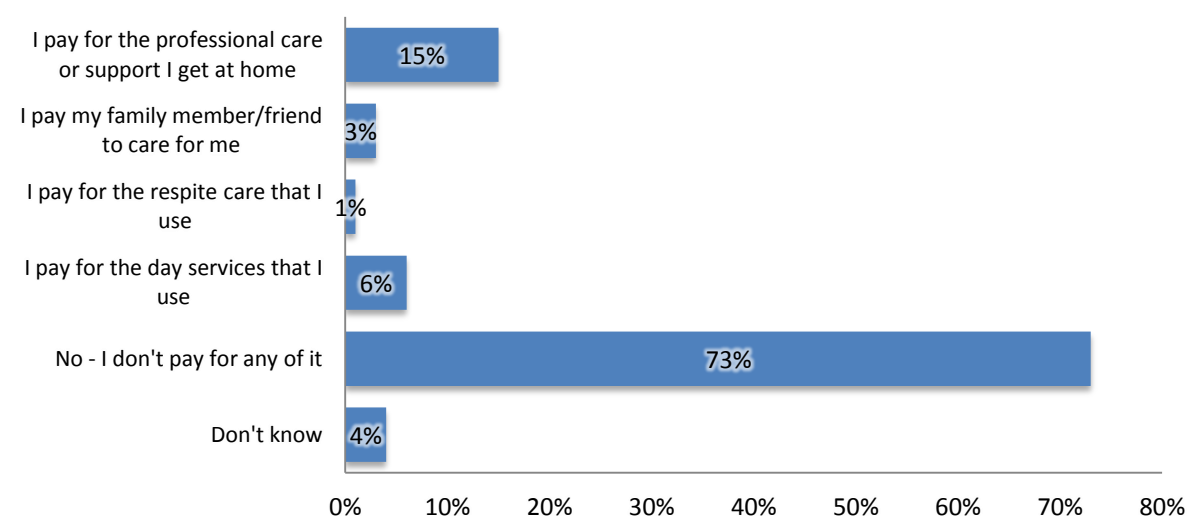


Unweighted base: 271

## 2.5.2 Affording care and support services

Of the 156 respondents who receive care and support, just 23% pay for this support. The majority (73% - 114 people) do not pay for their support and 4% say they don't know. Older people with long term conditions are more likely to pay for their support (30% - 17 people aged 67+), especially the care that they receive in their home (20% - 10 people), as do 29% of people with a learning, understanding and development difficulty (16 people). 9% (4 people) of this latter group pay for the day services that they use.

**Figure 31: Can you tell me if you pay for any of the care or support you receive at the moment? (All valid responses – where receive care and support)**



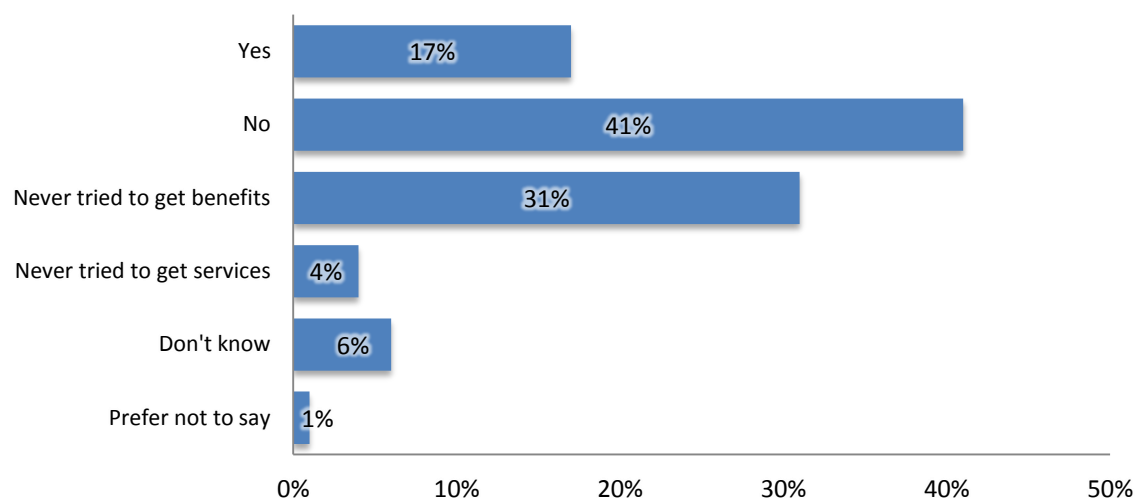
Unweighted base: 156

35 respondents went on to answer how much they spend per week on care and support:

- 39% spend up to £50 per week;
- 18% spend £51 - £100 per week;
- 15% spend over £100 per week.

17% of all respondents (45 people) say that the amount of savings they have has prevented them getting a benefit or other service previously. This is found to be more common amongst those aged under 16 (30% - 9 people) and in social housing (21% - 8 people). Respondents with a learning, understanding or development difficulty are also most likely to have faced problems due to the amount of savings they have (28% - 15 people).

**Figure 32: Can you tell me if the amount of savings you have has ever stopped you getting a benefit or other service? (All respondents)**



Unweighted base: 271

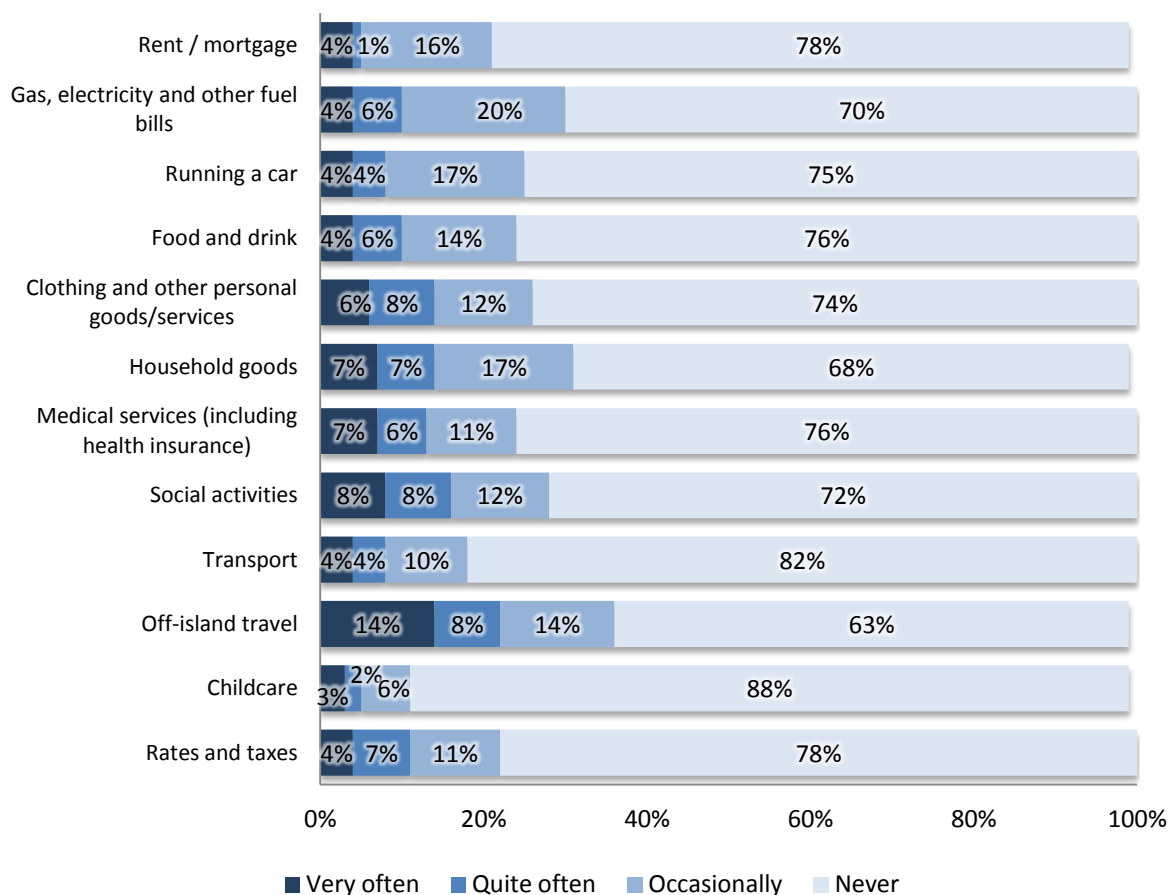
Following on from this, all respondents were asked to rate the extent to which they and their household face difficulties meeting the costs of a range of day to day expenses. Figure 33 presents the data on valid responses. No more than 1 in 10 respondents face difficulties (very or quite often) with meeting the costs of their fuel bills (10%), running a car (8%), food and drink (10%), rates and taxes (11%), and transport (8%). 5% face the same level of difficulty meeting the cost of their rent or mortgage. It is worth highlighting, however, that a higher proportion of respondents have 'occasional' difficulties, especially with fuel bills (20%) and running a car (17%).

The level of difficulty meeting the costs of rent, mortgage and fuel bills was explored in detail in section 2.2.2. In terms of affording food and drink, 28% of respondents in social housing face difficulties, as do 21% of private renters and 19% who are unable to work due to their condition. Respondents with a mental health condition are far more likely than all others to face difficulties very or quite often paying for food and drink (26% - 16 people).

Almost 1 in 6 respondents say they experience problems meeting the cost of social activities (16%), with up to a third (32% - 9 people) of those aged under 16 feeling this way. Respondents in social housing (34%), private renters (28%), and respondents with a mental health condition (38%) are most likely to face problems meeting the cost of social activities.

The same patterns are evident when considering the costs of off-island travel (not necessarily for medical reasons), with as many as 48% of respondents with a mental health condition facing difficulties with this expense (21 people). 40% of respondents with a learning, understanding and development difficulty (14 people) also find it hard to meet the costs of off-island travel.

**Figure 33: Can you tell me how often your household finds it difficult to meet the costs of the following? (All valid responses)**



Unweighted bases vary

### 2.5.3 Key issues

The States of Guernsey's policy intention is that all islanders, including disabled people, should have an adequate income to meet their needs. To this end the States provide a raft of benefits for people including income replacement benefits and benefits specifically designed for disabled people. These benefits are structured around a contributory social insurance scheme to provide financial assistance during old age, bereavement, incapacity, unemployment, maternity and death. This insurance scheme includes two types of sickness and injury benefit: Sickness and Invalidity Benefit; and Industrial Injuries Benefit (comprising of Industrial Injury Benefit, Industrial Disablement Benefit and Industrial Medical Benefit).

In addition to the contributory social insurance scheme there is a non-contributory scheme that provides financial and medical assistance to people unable to safeguard their own welfare or who have insufficient resources for an adequate quality of life; support the wellbeing of children; and provide financial assistance to people with severe disability and their carers. Supplementary Benefit is a means-tested cash benefit intended to bring household income up to the Requirement Rate which is the level which the States believes is sufficient to live on.

While the majority of respondents reported that they could live on their income, some were experiencing difficulties despite the existence of these schemes. For example, up to 10 per cent of people said that they faced difficulties either quite often or very often with paying their rates and taxes (11%), their fuel bills (10%), food and drink (10%), transport (8%), running a car (8%), rent (5%) or mortgage (5%). Over a quarter (26%) of respondents with a mental health condition faced difficulties either very often or quite often paying for food and drink. In addition, 14% of all respondents say they cannot afford to go out and about (see Table 11) and 40% want financial support to access information (Figure 55).

A higher proportion of respondents have 'occasional' financial difficulties, particularly with fuel bills (20%) and running a car (17%). As many as 28% of respondents in social housing face difficulties affording food and drink, as do 21% of private renters and 19% who are unable to work because of their condition.

Almost one in six respondents said that they experienced problems meeting the cost of social activities (16%), which increased to almost a third (32%) of people aged under 16 and 29 per cent under the age of 18. Once again respondents in social housing (34%) and private renters (28%) are most likely to face problems meeting the cost of social activities. Almost four out of ten (38%) respondents with a mental health condition face problems meeting the cost of social activities. This indicates a high level of social exclusion of young disabled people, and people with a mental health condition, which is a worrying finding.

The same patterns are evident when considering the costs of off-island travel, with as many as 48 per cent of respondents with a mental health condition and 40 per cent of respondents with a learning, understanding and development difficulty facing difficulties meeting the expense of leaving the island.

The findings reveal a gap between the policy intention – that Guernsey residents have sufficient income to live in dignity – and the finding that some residents, particularly those with mental health conditions, are facing difficulty with being able to afford to participate in social activities and that as many as 26 per cent of respondents with a mental health condition are struggling even to afford sufficient food and drink.

The explanation for such a high number of respondents struggling to afford basic essentials could relate to the adequacy or to take up of benefits. Take up of benefit entitlement is a major challenge across most social security systems. For example, the European Parliament called on Member States which have a minimum income system to take urgent action to improve the take-up of benefits and monitor levels of non-take-up and its causes, recognising that cases of non-take-up account for between 20-40 per cent of benefits according to the OECD.<sup>6</sup> In Guernsey, some people, particularly those people with mental health condition, learning, understanding and development and communication difficulties may need additional support to access benefits to which they are entitled. This may include targeted publicity to raise awareness of entitlement and support from trained advisors at the Department when making a claim. However, customer representatives in the UK reported that training had not always equipped

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<sup>6</sup> European Parliament (2010) European Parliament resolution of 20 October 2010 on the role of minimum income in combating poverty and promoting an inclusive society in Europe (2010/2039(INI)).

Jobcentre Plus staff to provide the best service to all customers: for instance, it did not fully equip staff to deal effectively with all types of disability issues.<sup>7</sup> Thus the question of appropriate training would need to be given careful thought by the Department.

Adequacy is a major challenge to minimum income schemes. With respect to the EU the European Commission has emphasised that *“in most Member States and for most family types, social assistance alone is not sufficient to lift beneficiaries out of poverty.”* (COM(2008) 639 final)<sup>18</sup>.<sup>8</sup> Assessing the adequacy and effectiveness of minimum income schemes is complex. The definition and measurement of poverty is contested but may be broadly defined as the state of falling beneath *“some minimally decent level of living”*. The States of Guernsey provide means-tested Supplementary Benefit to bring household income up to the ‘Requirement Rate’ which is the level which the States believes is enough to live on. However, in a study of European minimum income schemes Frazer and Marlier (2009) reached *“the clear conclusion ... that the level of minimum income (in many EU countries) falls short and often very far short of an adequate income.”*<sup>9</sup>

To ensure that this is not also the case in Guernsey the States could revisit the basic principles of their minimum income schemes to consider whether the schemes are in practice meeting those principles. This would require defining what is adequate for an islander with an impairment or long term health condition to live in dignity. A significant problem in assessing the adequacy of minimum income schemes may be lack of the necessary data or analysis to determine what is sufficient to combat social exclusion and lead a life that is compatible with human dignity. To address this the States could commission a study of why some people, and in particular some people with mental health conditions, say that they are finding it difficult to take part in social life and in some cases even to feed themselves adequately.

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<sup>7</sup> Stafford, B., Roberts, S. and Duffy, D. (2012) ‘Delivering employment services to vulnerable customers: A case study of the UK’s employment service’, *Social Policy and Society*, Vol. 11, No. 4.

<sup>8</sup> European Commission (2008) ‘Commission Recommendation [2008/867/EC](#) of 3 October 2008 on the active inclusion of people excluded from the labour market [Official Journal L 307 of 18.11.2008].

<sup>9</sup> Frazer, H. and Marlier, E. (2009) ‘Minimum Income Schemes Across EU Member States’, EU Network of National Independent Experts on Social Inclusion. European Commission DG Employment, Social Affairs and Equal Opportunities. Brussels, October 2009.



## 2.6 Personal support

This section explores the personal care and support received by people with long term conditions. It covers a range of different areas, such as:

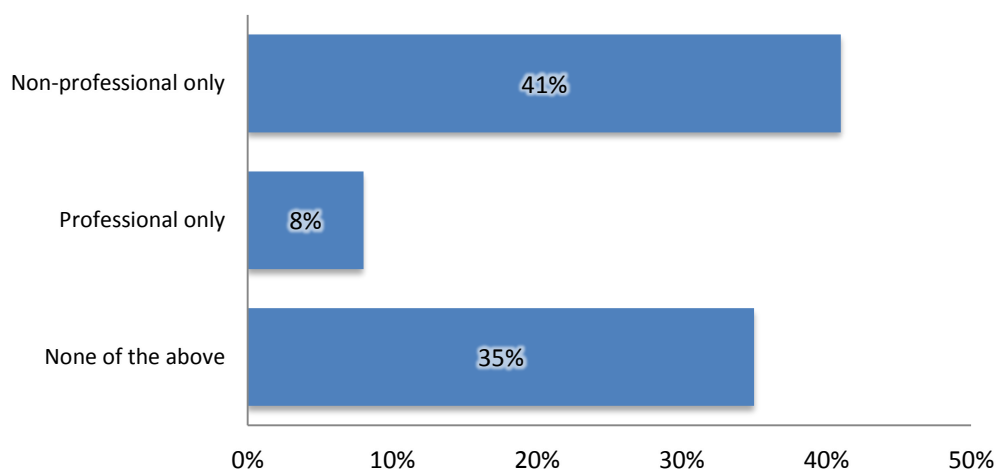
- The level of care provided and by whom
- The type of support provided
- The need for professional support
- Paying for care and support in the future
- Use of equipment and aids
- Use of respite services
- Use of day care services

### 2.6.1 Demands for, and use of, support services

#### Care and support provided

The majority of respondents receive support of some kind (175 people, or 65%). 2 in 5 receive support from a non-professional only (including a family member or friend) (111 people or 41%), while 8% (21 people) receive support only from a professional (including a carer, nurse or social worker).

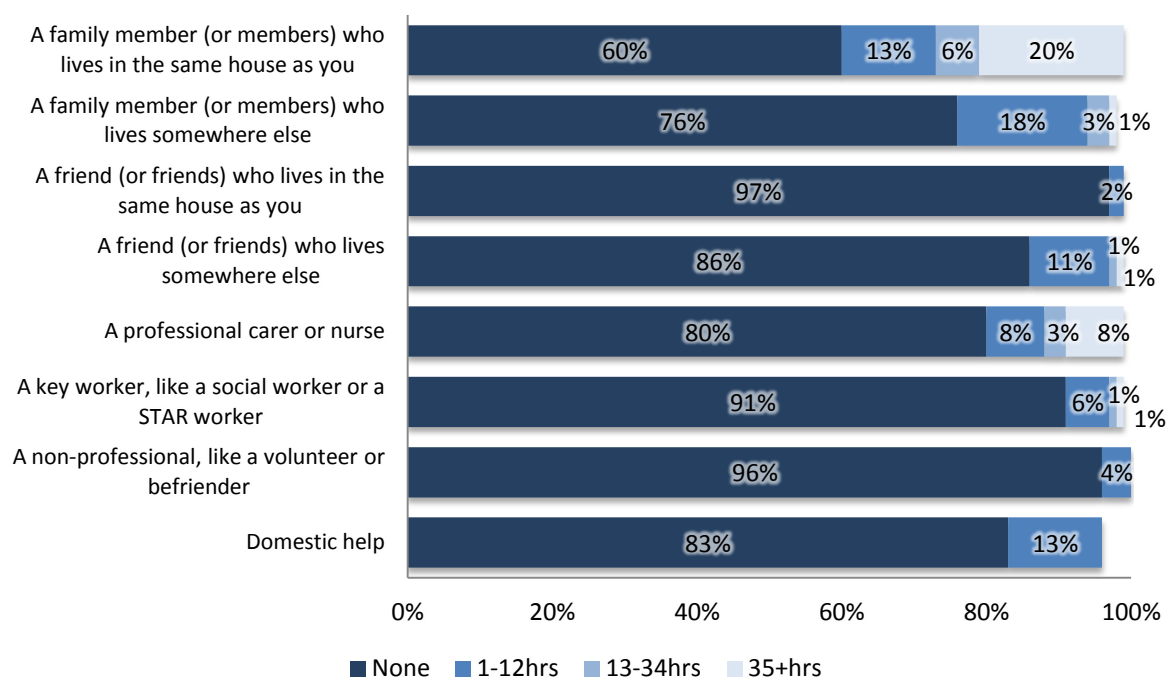
**Figure 34: Can you tell me if any of these people have supported you in the last week? (All respondents)**



Unweighted base: 271

2 in 5 respondents receive support from a family member who lives in the same house as them (39%), with 20% (55 people) receiving 35 or more hours per week of support (see Figure 35). A quarter (23% - 25 people) of respondents who only receive non-professional care receive support from a family member that lives with them. One in five respondents (20% - 53 people) receive some level of support from a carer or nurse, with 8% (23 people) doing so for 35 or more hours per week. Very few respondents (10 people, or 4%) receive support from volunteers.

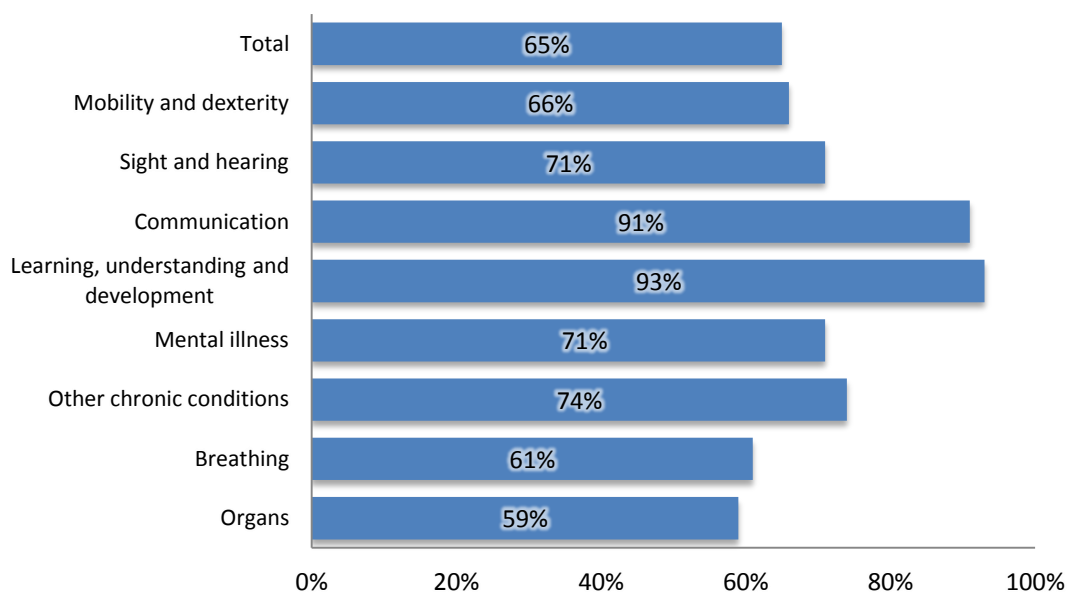
**Figure 35: Can you tell me if any of these people have supported you in the last week, and if so, for how many hours? (All respondents)**



Unweighted base: 271

As many as 91% of respondents with a communication difficulty (72 people) and 93% of respondents with a learning, understanding and development-related condition (50 people) access some kind of support (Figure 36). 63% of those with a learning, understanding or development difficulty receive support from a family member living in the same house as them (34 people), whilst 28% do so from a professional nurse or carer (15 people) and 19% from domestic help (10 people).

**Figure 36: Can you tell me if any of these people have supported you in the last week?  
% yes by type of disability (All respondents)**



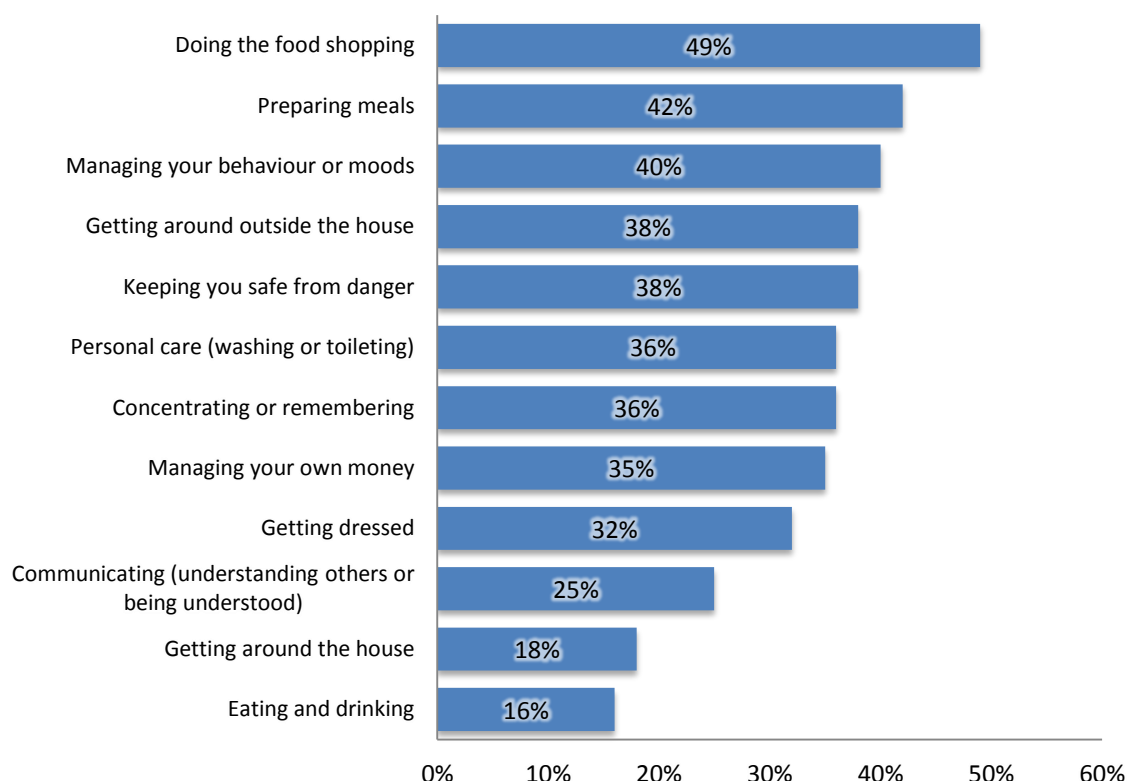
Unweighted base: 271

Figure 37 presents the proportion of respondents who receive care from either a professional or a non-professional that require support for a range of day to day activities. All of these respondents need support with at least one of the activities, but support is more common for doing the food shopping (49% - 76 people), preparing meals (42% - 65 people), and managing behaviour or moods (40% - 61 people). Fewer than 1 in 5 need support getting around the house (18% - 27 people), but this increases to 28% of those with communication and learning, understanding and development difficulties (19 and 13 people respectively). Respondents with these types of disability are also more likely to need support with the following:

- Concentrating or remembering: 58% with communication (39 people) and 64% with learning, understanding and development difficulties (30 people).
- Eating and drinking: 30% and 34% respectively (20 and 16 people).
- Communication: 55% and 60% respectively (37 and 28 people).
- Managing behaviour or moods: 63% and 66% respectively (42 and 31 people).
- Keeping safe from danger: 55% and 62% respectively (37 and 29 people).
- Managing money: 51% and 55% respectively (34 and 26 people).

72% of respondents with a mental health condition (28 people) also require support to manage their behaviour or moods.

**Figure 37: Can you tell me if you need support for any of these activities? From both professional and non-professional carers (All valid responses – where receive care)**

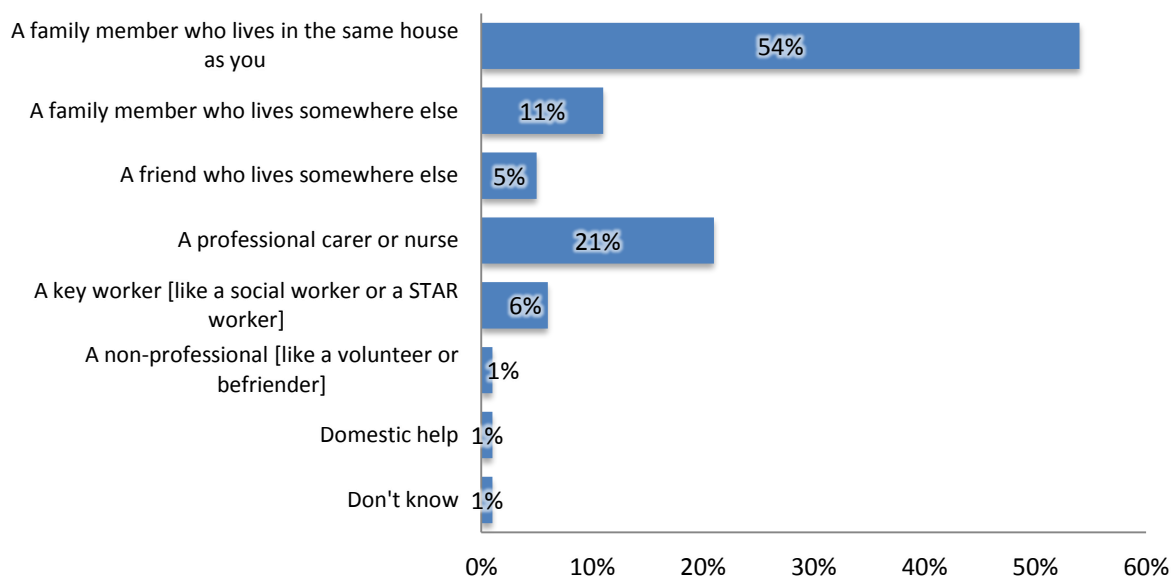


Unweighted base: 154

Figure 38 shows that the majority of respondents who receive care state their main source of care is a family member who lives in the same house as them (54% - 100 people). A further 1 in 5 (21%) regard their main source of support as a carer or nurse and 11% a family member that lives somewhere else. There are interesting variations by type of disability. Although support from a family member living in the same house is the most common form of support for all groupings, a professional carer or nurse is the main source of support for as high as 35% of respondents with “other chronic conditions” (20 people), 24% with mobility or dexterity problems (34 people), and 23% with sight or hearing problems (17 people).

Respondents living in social housing are also more likely to regard a key worker as their main source of support (19% - 7 people), compared to just 3% of owner occupiers (4 people).

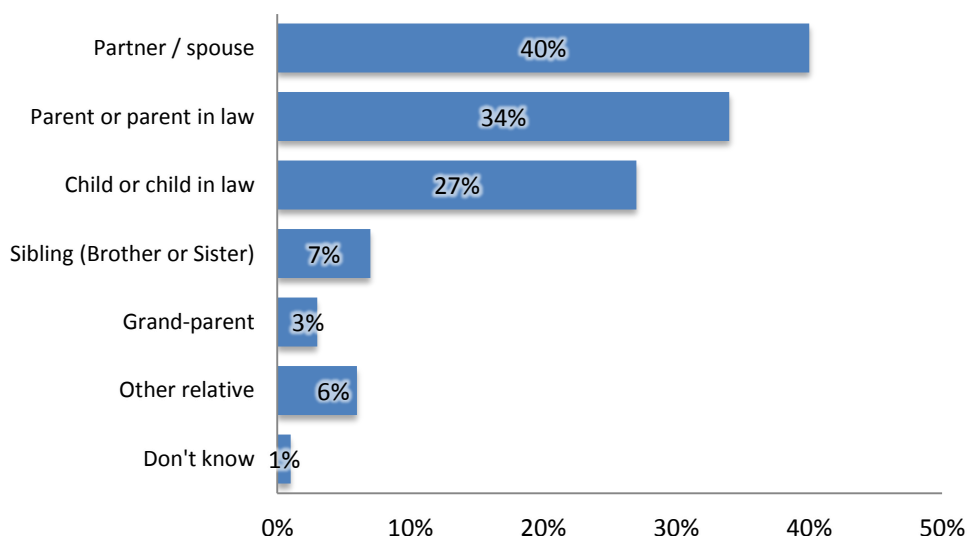
**Figure 38: Can you tell me who you see as your main source of help and support? (All respondents – where receive care)**



Unweighted base: 186

Amongst the 139 respondents who regard a family member living in the same house as them as their main source of support, 2 in 5 (40% - 56 people) are supported by their partner or spouse and 34% (47 people) are supported by their parent or parent in law (Figure 39). A further 1 in 4 (27% - 38 people) receives support from their child or child in law, with 19% (4 people) of those aged 16-34 receiving support from a child or child in law (who is therefore likely to be a young carer).

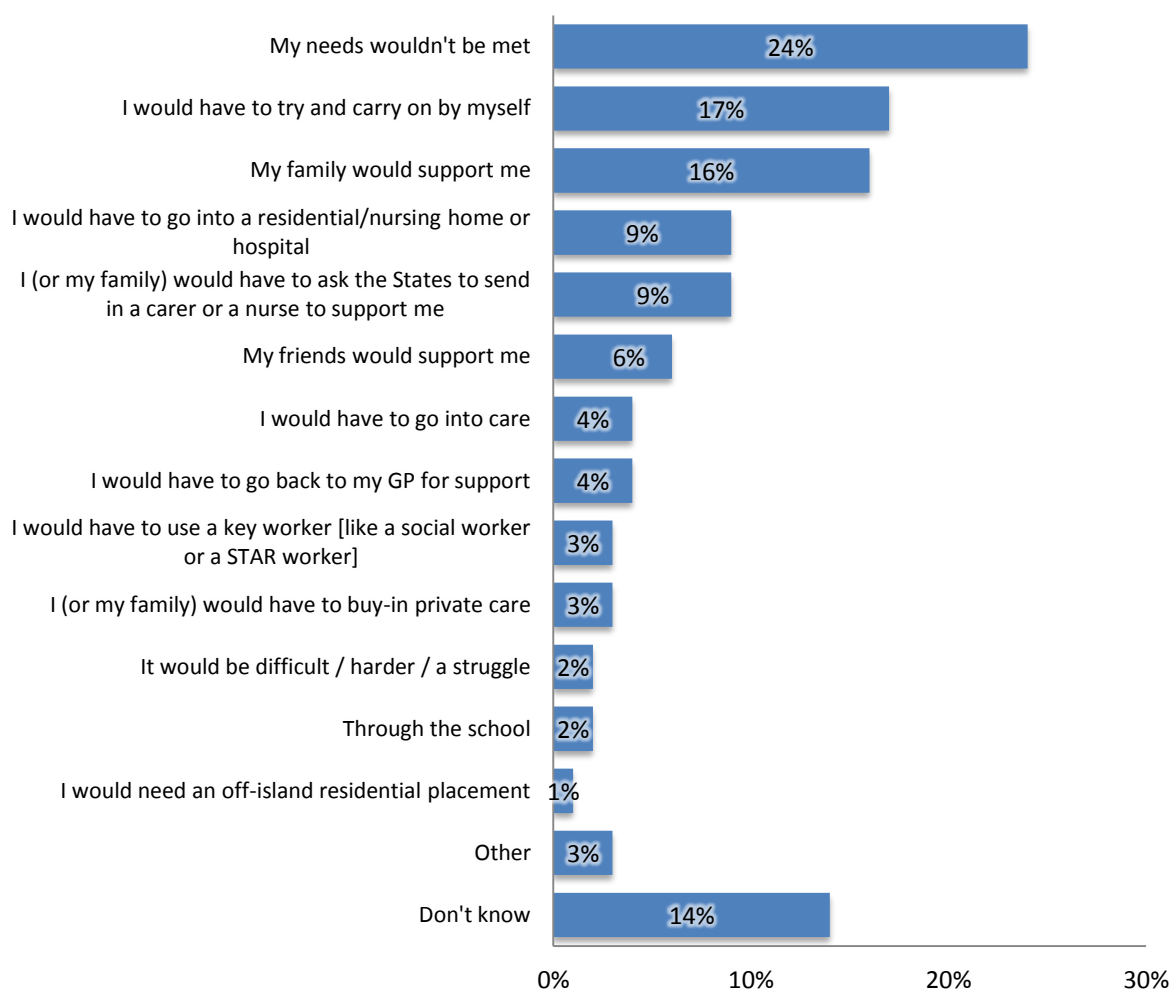
**Figure 39: Can you tell me how you are related to the family member(s) who provides you with care or support? For example, are they your...? (All respondents – where receive care from a family member)**



Unweighted base: 139

A quarter (24% - 44 people) of respondents say their needs would not be met if they did not receive care from their main source of support. It is not known what proportion of these unmet needs would require a response from State funded services, but some call upon services can be expected. In addition, respondents would call upon (in part) State funded service for residential/nursing homes (9% - 17 people), a nurse or carer (9% - 17 people) or a key worker (3% - 6 people). A further 14% (26 people) state they do not know how their needs would be met, and again some might turn to the States for support. Respondents with “other chronic conditions” are most likely to feel their needs would not be met (32% - 18 people), as are 30% of people with a mental health condition (15 people). 9% believe they would have to go into a residential / nursing home, which increases to 21% of people aged 67+ (12 people).

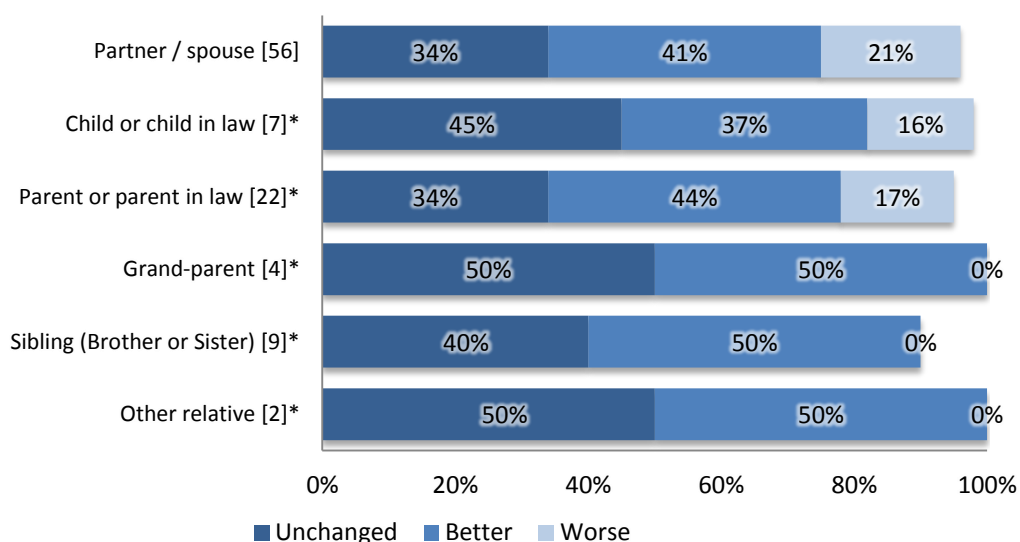
**Figure 40: If you did not receive care or support from this person / these people, how do you think your needs would be met? (All respondents – where receive care)**



Unweighted base: 186

Where respondents receive support from a family member, they were asked whether this has affected their relationship. Where support is provided by a partner or spouse, the largest proportion say their relationship is better as a result of this (41%), whilst 21% say it has become worse (Figure 41). The base sizes are very small where support is provided by a child, a grand-parent, a sibling or another relative.

**Figure 41: Do you think that the care or support this person has provided you with has affected your relationship..? (All respondents – where receive care from each family member)**



Unweighted bases in brackets

\* base size is very low

### Professional support provided

All respondents who receive support from a professional were presented with a comprehensive list of different kinds of professional support services and asked which they use and how often. 1 in 3 (32% - 29 people) people have used a nurse (community or district), with 12% (11 people) doing so every day and a further 9% (8 people) weekly (Table 7). 21% of people with “other chronic conditions” (6 people) receive support from a nurse every day.

Everyday care is shown to be most commonly provided by a carer or senior carer (28% - 25 people), especially amongst those aged 35-67+ (31% - 12 people), and people with “other chronic conditions” (48% - 14 people).

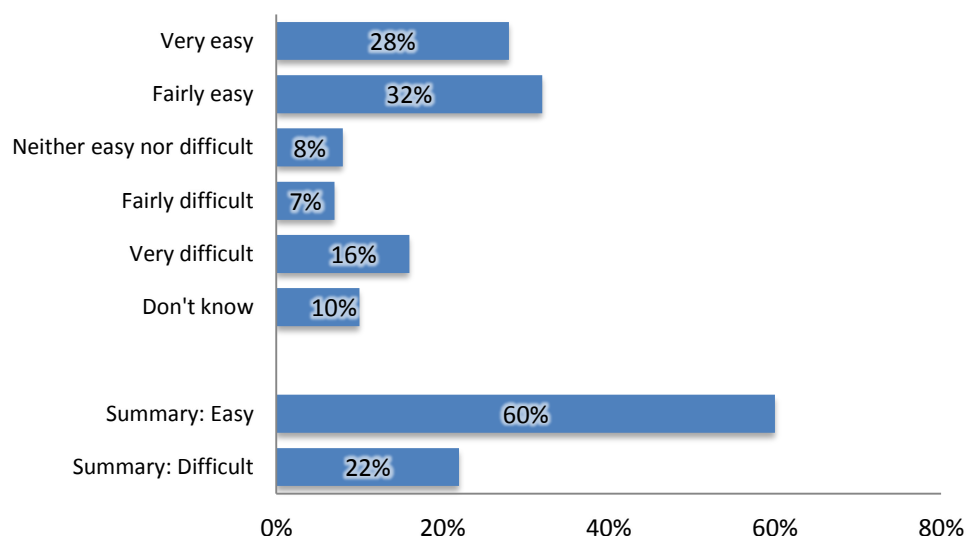
**Table 7: Can you tell me if you use any of these different kinds of professional care and support, and how often...? (Where receive care from a professional)**

	Every day	Weekly	Monthly	Less than monthly	Never	Don't know
<b>Nurse (community or district)</b>	12%	9%	5%	5%	67%	1%
<b>Specialist nurse</b>	4%	5%	1%	8%	74%	7%
<b>A key worker [like a social worker or a STAR worker]</b>	3%	16%	2%	12%	61%	6%
<b>Carer or senior carer</b>	28%	4%	0%	1%	66%	1%
<b>Occupational therapist</b>	1%	3%	2%	7%	80%	6%
<b>Speech and language therapist</b>	0%	1%	2%	4%	88%	4%
<b>Physiotherapist</b>	0%	6%	5%	13%	71%	4%
<b>Educational psychologist (base size = 6)</b>	0%	0%	0%	67%	33%	0%
<b>Health Visitor</b>	0%	0%	0%	1%	92%	7%
<b>Sitting service (during the day)</b>	1%	1%	1%	0%	93%	3%
<b>Sitting service (at night)</b>	2%	3%	0%	0%	91%	3%
<b>Day care</b>	3%	8%	2%	0%	83%	3%
<b>Meals on wheels</b>	0%	5%	0%	0%	90%	4%
<b>Shopping service</b>	0%	3%	0%	2%	90%	4%
<b>Transport service / Voluntary car service</b>	1%	13%	1%	1%	79%	4%
<b>Handyman service</b>	0%	2%	2%	3%	87%	6%
<b>Unweighted base: 90</b>						

3 in 5 people find it easy to access the professional care they receive (60% - 54 people); however, 22% (20 people) find it difficult. There are particular concerns with regards to those with a mental health condition, as 41% (11 people) say it is difficult to access professional support. Likewise, 31% aged 35-66 (12 people), 35% in social housing (6 people), and 33% that receive benefits (18 people) find it difficult.



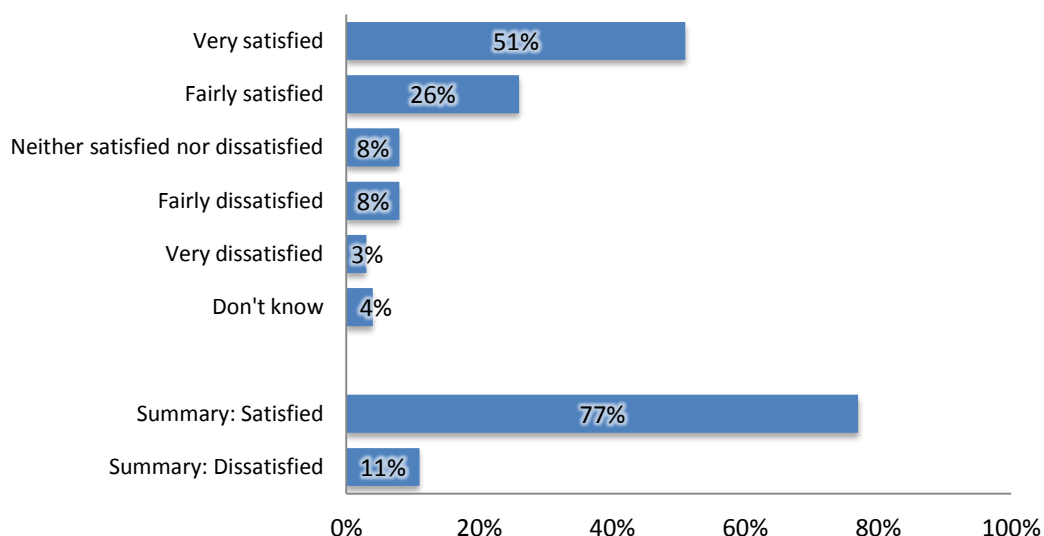
**Figure 42: Can you tell me if you find it easy or difficult to get the professional care and support you need, when you need it? (All respondents – where receive care from a professional)**



Unweighted base: 90

Over three quarters (77% - 69 people) of respondents are satisfied with the professional support they receive, whilst 11% are dissatisfied. Satisfaction is high amongst those aged 67+ (83% - 30 people), but falls to 69% amongst those aged 35-66 (27 people). Owner occupiers are also more likely to be satisfied (77%), which is a likely manifestation of age, whilst this compares to 71% of those in social housing (the private renter sample base was too small to provide a comparison). A quarter (26% - 7 people) of respondents with a mental health condition are dissatisfied with the professional support they receive, which requires further exploration, especially given the earlier finding that this group of people find professional support difficult to access.

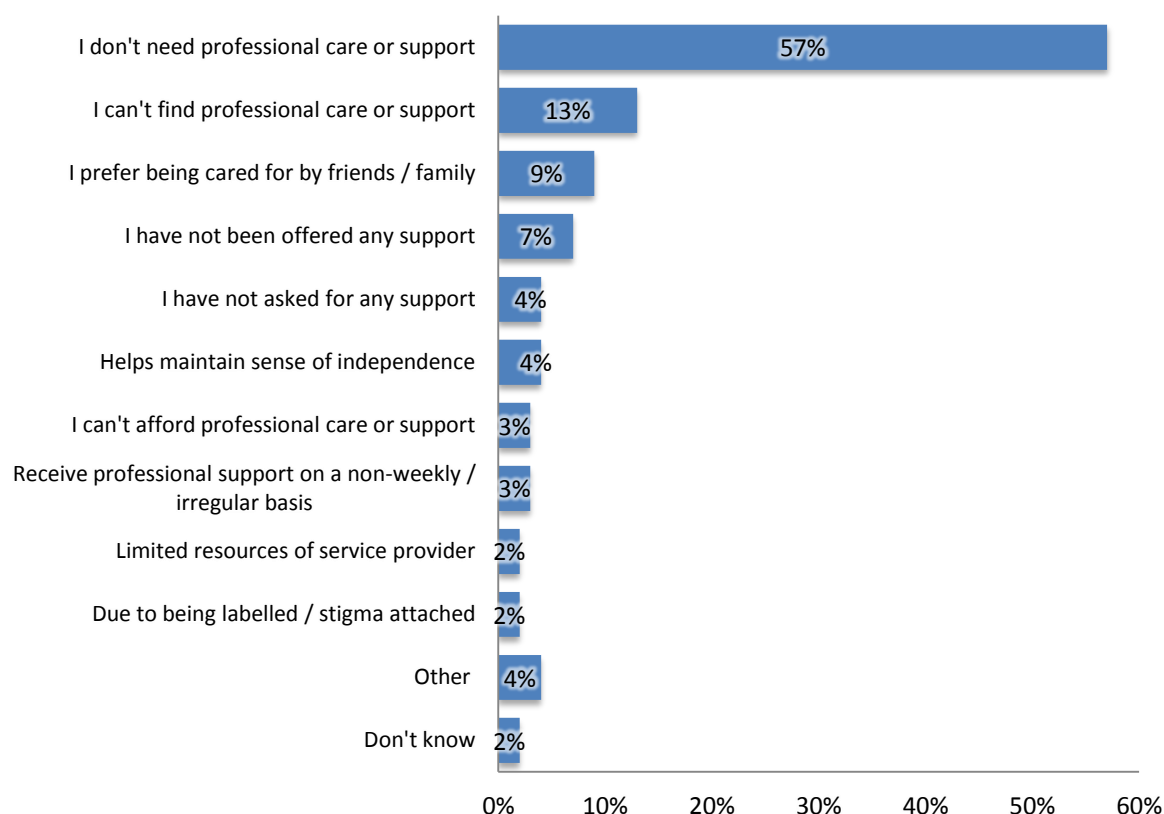
**Figure 43: Can you tell me how satisfied you are, overall, with the professional care and support that you receive? (All respondents – where receive care from a professional)**



Unweighted base: 90

More than half (57% - 68 people) of respondents who do not receive support from professionals, feel they do not need it (Figure 44). However, 13% say they cannot find professional support, with this increasing to 37% (10 people) of those aged under 16 and 27% (9 people) with a learning, understanding and development difficulty. 7% say they have not been offered professional support, and this is higher amongst those with a mental health condition (13% - 4 people) and communication difficulties (12% - 6 people).

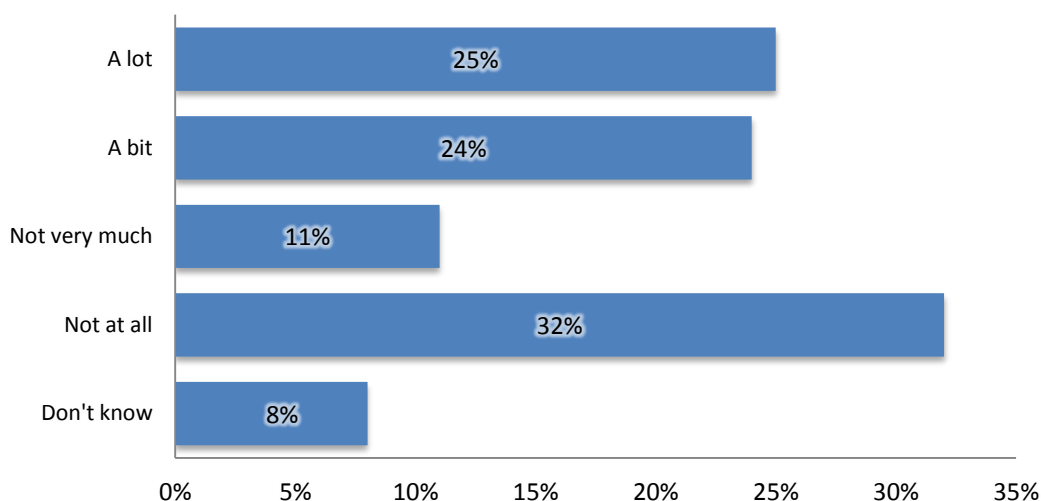
**Figure 44: You've said that you don't receive any support from professionals. Can you tell me why? (All respondents – where receive care but not from a professional)**



Unweighted base: 121

A quarter (25% - 30 people) of respondents who do not receive professional support currently feel such support would be 'a lot' of benefit to them (Figure 45). A further 24% (29 people) feel it would benefit them 'a bit'. Respondents more likely to feel such support would benefit them a lot are aged under 16 (50% - 14 people), who already have a carer in the household (39% - 17 people), have communication difficulties (44% - 22 people), learning, understanding and development difficulties (53% - 18 people), or have a mental health condition (37% - 11 people).

**Figure 45: To what extent do you think you would benefit from getting professional care or support? (All respondents – where receive care but not from a professional)**

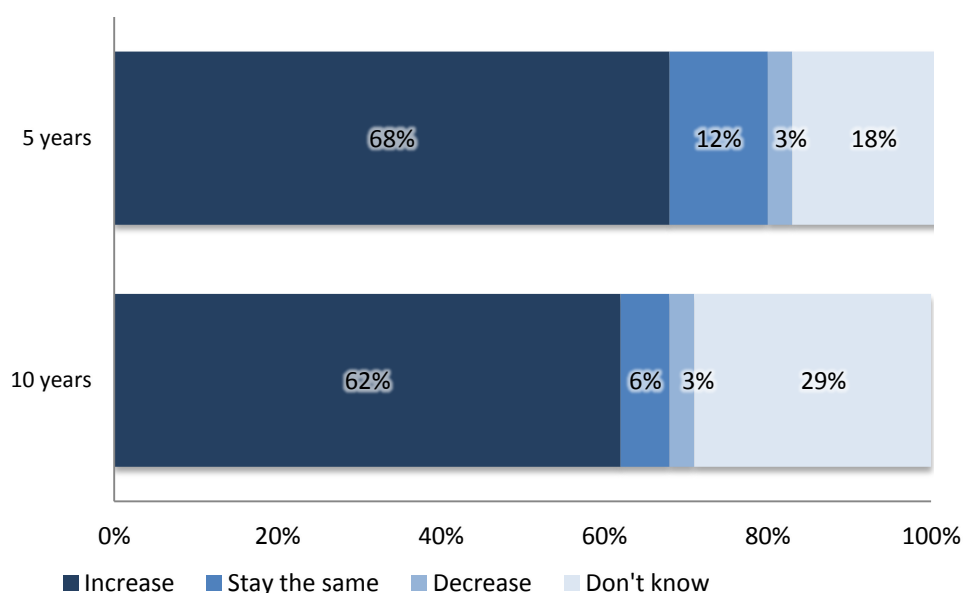


Unweighted base: 121

### Financing care and support in the future

35 respondents interviewed currently pay for the care and support they receive (see Section 2.5.2 for more information). Amongst those providing a valid response (removing anyone that expects not to be using care in the future), the largest majority expect the cost of their care to increase in the next 5 years (68%) and the next 10 years (62%). Just 3% (1 person) expects the cost to decrease over time.

**Figure 46: Can you tell me if you think the amount you are paying for your care and support will increase, decrease or stay the same over the next...? (All valid responses – where pay for care and support)**

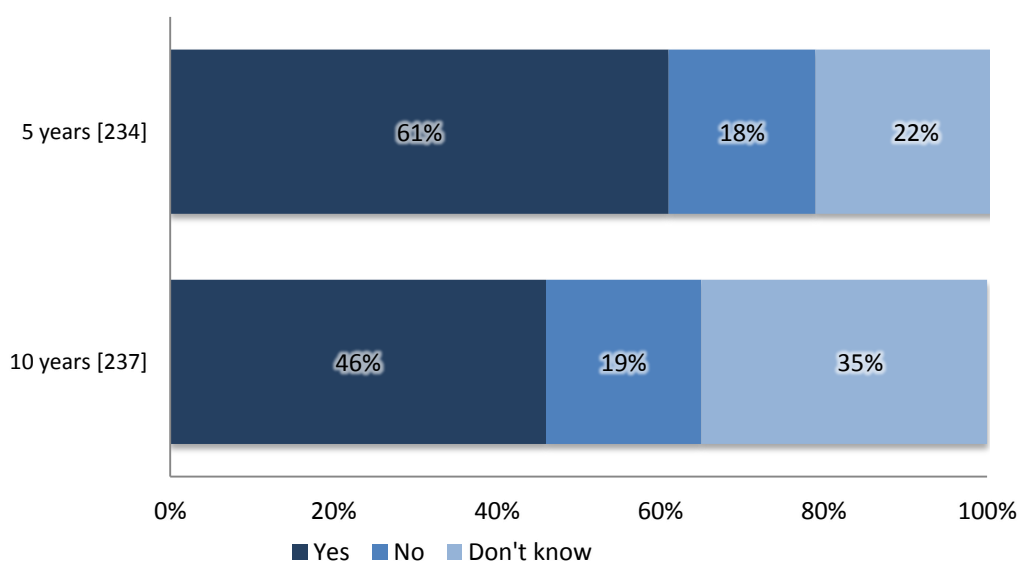


Unweighted base: 34

The cost of support in the future is expected to increase because care will be more expensive (65% - 15 people). A further 30% (7 people) also expect they will need more care in the future.

Although the cost of care and support is expected to rise in the future, most respondents expect to be able to pay for this in the next 5 years (61% - 142 people). 18% (41 people) say they will not be able to afford their care, which increases to 43% of those in social housing (15 people), 35% with a mental health condition (19 people), and 20% that have more than one condition (39 people).

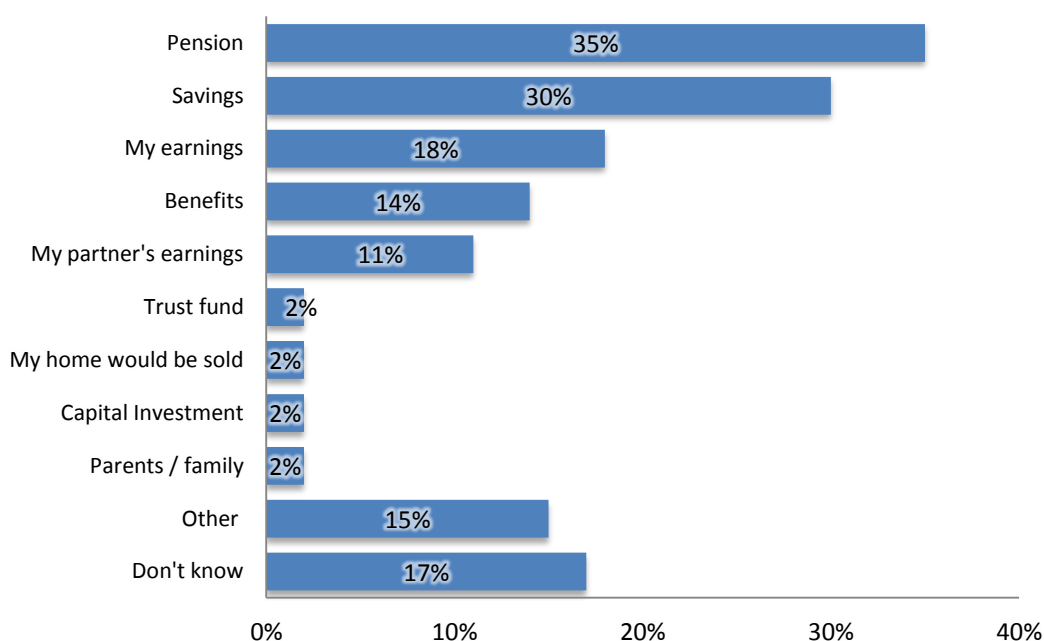
**Figure 47: Do you expect to be able to afford your care and support in the next...? (All valid responses)**



Unweighted bases in brackets

Over a third (35% - 82 people) of respondents expect to pay for their care in the future via their pension, which increases to 60% of those aged 67+ (48 people) (Figure 48). A further 30% plan to use savings (70 people), which is again higher amongst those aged 67+ (49% - 39 people), but also owner occupiers (39% - 62 people). 32% of those with a learning, understanding or development difficulty (15 people) and 30% with a communication difficulty (20 people) do not know how they will pay for their care in the future. A quarter (25%) of those with a mental health condition plan to use their earnings.

**Figure 48: How do you expect to pay for your care in the future? (All respondents – where expect to be paying for care in the next 5 years)**



Unweighted base: 234

### Equipment and aids used in day to day life

As well as support provided by other people, respondents use a range of equipment and aids in their day to day lives. Overall, 86% of respondents (234 people) use some kind of aid, with a walking aid being most commonly used (30%), followed by a bathing / shower aid (22%) and a bed / chair aid (17%) (Table 8). The largest proportion of respondents use medication to help with their moods, behaviour or physical condition (71% - 193 people).

**Table 8: Can you tell me if you use any of these pieces of equipment or aids to help you function in day to day life? (All respondents)**

	%
Walking aid (e.g. wheelchair, walking / zimmer frame, walking stick)	30%
Toileting aid (e.g. bed pans, raised toilet seat, bed pads, incontinence pants)	10%
Dressing / grooming aid (e.g. shoe remover, reacher, shoe horn, zip puller)	5%
Writing aid (e.g. pen/pencil grip, lite touch pen)	5%
Reading aid (e.g. book holder, magnifier)	13%
Computer adaptation (e.g. monitor size, large font keyboard, software)	7%
Bed / chair aid (e.g. adjustable bed, relief pillow/mattress, bed rails)	17%
Eating / drinking aid (e.g. adapted cutlery/utensils, non slip products, ergonomic plates/bowls, trays)	7%
Bathing / shower aid (e.g. non slip products, bath/shower seats, pillow/cushion)	22%
Gripping aids (e.g. reachers, gripping/turning devices)	12%
Hearing aid(s)	8%
Medication to help you manage your moods, behaviour or physical condition.	71%
Vehicle aid (e.g. access ramp, steering wheel adaptation)	6%
Other	8%
None / nothing	14%
Unweighted base: 271	

The large majority of respondents do not feel they would benefit from any of these aids where they don't already use them (71%) (Table 9). However, 6% would benefit from a bed / chair aid, 6% a gripping aid, and 5% a bathing / shower aid. Overall, people aged under 16 are more likely to see equipment or aids as beneficial (37% - 11 people), as do those in social housing (36% - 14 people) and private rented accommodation (38% - 9 people). As with adaptations (shown on Page 13), people that receive non-professional care only are most likely to see equipment / aids as benefit to them (33% - 37 people).

**Table 9: Thinking about that same list of equipment and aids, do you think that there is anything you would benefit from, which you don't use at the moment? (All respondents)**

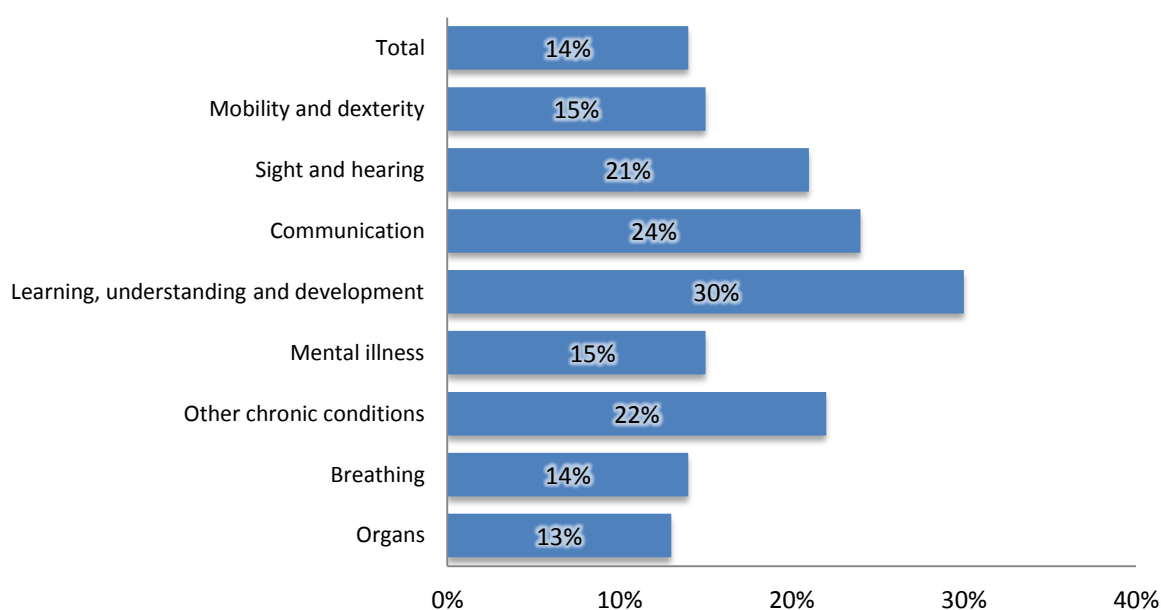
	%
Walking aid (e.g. wheelchair, walking / zimmer frame, walking stick)	4%
Toileting aid (e.g. bed pans, raised toilet seat, bed pads, incontinence pants)	1%
Dressing / grooming aid (e.g. shoe remover, reacher, shoe horn, zip puller)	2%
Writing aid (e.g. pen/pencil grip, lite touch pen)	1%
Reading aid (e.g. book holder, magnifier)	1%
Computer adaptation (e.g. monitor size, large font keyboard, software)	4%
Bed / chair aid (e.g. adjustable bed, relief pillow/mattress, bed rails)	6%
Eating / drinking aid (e.g. adapted cutlery/utensils, non slip products, ergonomic plates/bowls, trays)	1%
Bathing / shower aid (e.g. non slip products, bath/shower seats, pillow/cushion)	5%
Gripping aids (e.g. reachers, gripping/turning devices)	6%
Hearing aid(s)	3%
Medication to help you manage your moods, behaviour or physical condition.	1%
Vehicle aid (e.g. access ramp, steering wheel adaptation)	4%
Other (please specify)	4%
None / nothing	71%
Don't know	3%
Unweighted base: 271	



## Respite care

Some respondents and their carers can access respite care, either as day services or as care-home-based respite. In total, 14% of respondents (37 people) have stayed overnight in a respite care placement. People aged 16-34 are most likely to have used respite care (32% - 9 people), and, as the chart below shows, those with learning, understanding and development difficulties (30% - 16 people). Indeed, people on the 'learning disability register' are entitled to 28 days respite per annum.

**Figure 49: Have you ever stayed overnight (for one or more days) in a respite care placement on the island? % yes by type of disability (All respondents)**



Unweighted base: 271

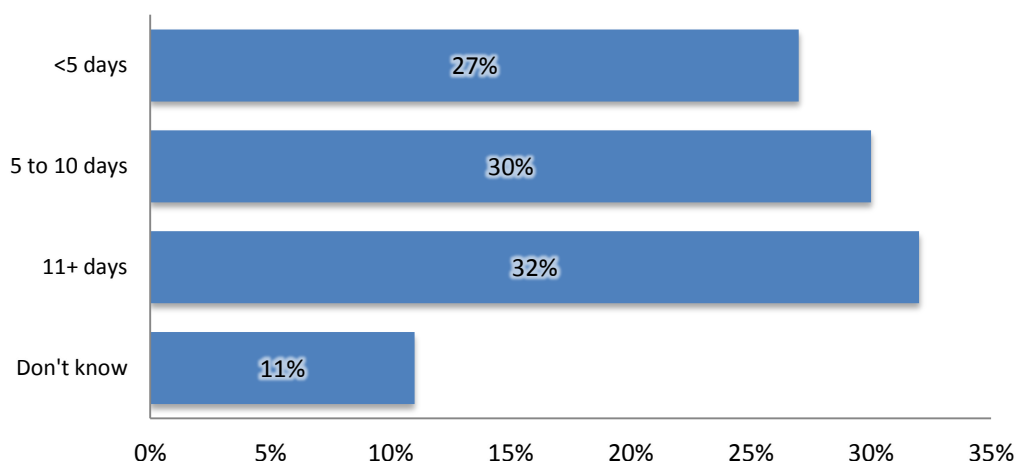
Just 1% of those that have not used respite care have tried but failed to access it.

Amongst users of respite care, a quarter (27% - 10 people) have used it within the last year and 22% between 1 and 4 years ago (8 people). The majority (46% - 17 people) used it more than 4 years ago.

The Croft was used by 30% of respondents (11 people), whilst 32% used a hospital generally (including King Edward VII).

The highest proportion of respondents stayed in respite for 11 or more days (32%), whilst a total of 62% (23 people) did so for more than 5 days.

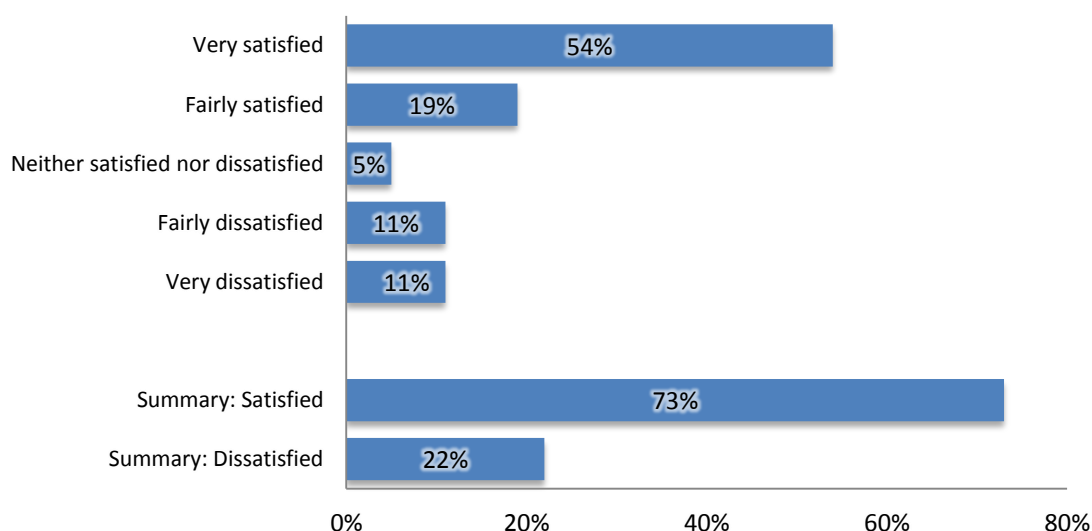
**Figure 50: Can you tell me how long you spent in respite care the last time you used it? (All respondents – where used respite)**



Unweighted base: 37

Nearly three quarters (73% - 27 people) of respondents who have used respite care have been satisfied with the service, with 54% saying they have been very satisfied. Over 1 in 5 (22%, 8 people), however, have been dissatisfied. Perhaps one reason for this is that a third (32% - 12 people) of respondents would have preferred support in the community rather than respite care.

**Figure 51: Can you tell me how satisfied or dissatisfied you have been, overall, with the respite care that you have used? (All respondents – where used respite)**



Unweighted base: 37

The large majority of respondents who have not used respite care say this is because they do not need it (75% - 175 people) (Table 10). However, there are small subsets of the population that didn't know they were able to access respite care (5%), don't know how to access it (4%), and can't get respite care when they need it (1%). 8% of those with communication difficulties and 9% with "other chronic conditions" do not know how to get respite care.

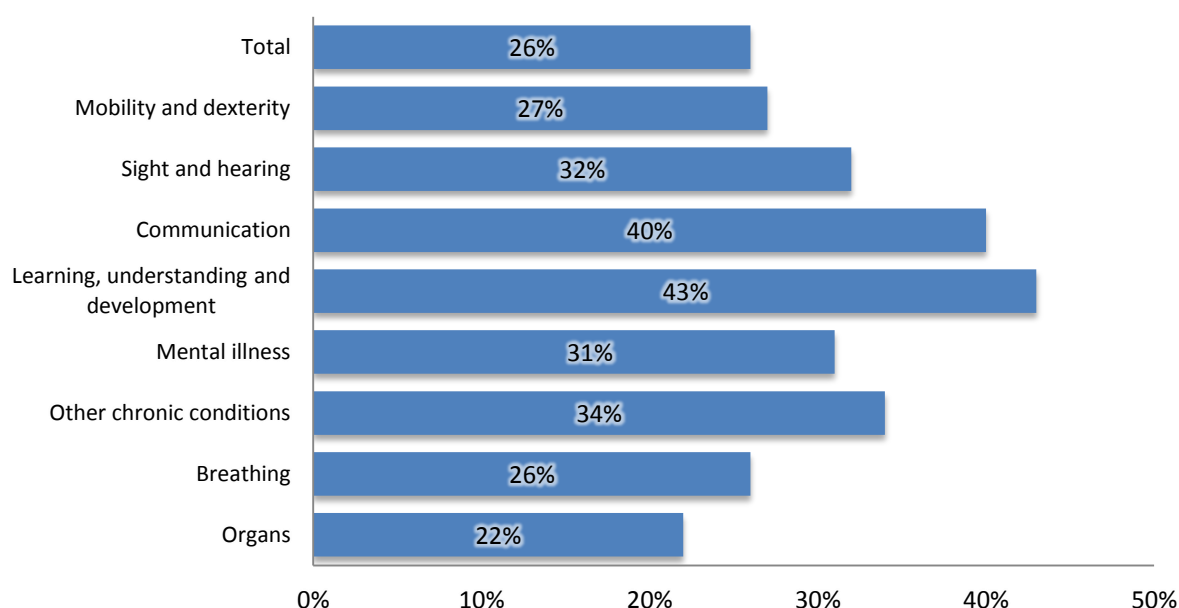
**Table 10: You've said that you have never stayed in respite care. Can you tell me why? (All respondents – where not used respite)**

	%
I don't need respite care	75%
Didn't know I was able to access respite care	5%
I don't know how to get respite care	4%
I just don't want to	3%
I don't know what respite care is	2%
I get support in my own home when my carer needs a break	2%
I can't get the respite care I prefer in Alderney	1%
I can't get respite care when I need it (dates/times)	1%
People with my condition aren't entitled to get respite care	1%
I prefer to be in my own home	1%
It has never been offered me	1%
I have never thought about it	1%
I can't afford respite care	*%
I can't get the respite care I prefer in Guernsey	*%
I'm worried that I wouldn't get to go home if I went into care	*%
Other	15%
Don't know	1%
Unweighted base: 234	

### Day services

A quarter (26% - 61 people) of respondents, who are not in full time education, access day services. These services are accessed more frequently by those aged 67+ (33% - 29 people), women (30% - 44 people), those in social housing (41% - 14 people), and people unable to work due to their condition (43% - 29 people). As can be seen from Figure 52 below, day services are accessed by 43% of people with a learning, understanding and development difficulty (13 people) and 40% with a communication difficulty (21 people).

**Figure 52: Can you tell me if you access day services? (These are groups that meet during the day, or over lunch, for activities/social contact. This is usually with people who are a similar age, or have a similar condition to you) % yes by type of disability (All respondents - where not in full time education)**



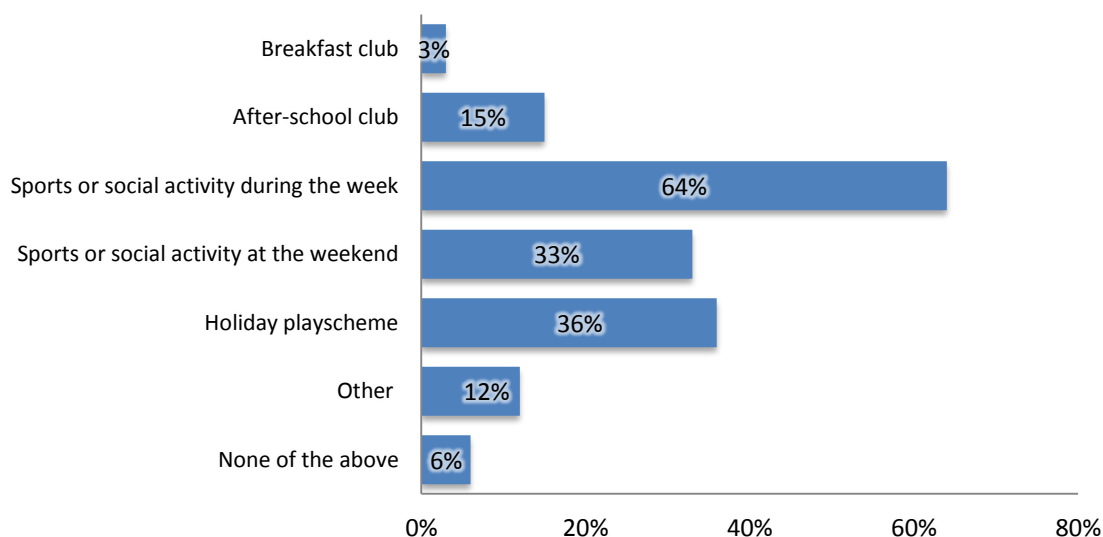
Unweighted base: 238

2 in 5 day service users access it just once per week (39% - 24 people), whilst 28% do so on two days and 32% do so on three or more days.

36% of these respondents attend day services for 1 to 2 hours, 31% for 3 to 4 hours, and 31% for 5 or more hours on any given day.

Amongst the 33 respondents who are still in full time education, 21 (64%) take part in a sports or social activity during the week and 11 (33%) do so at the weekend. 12 (36%) attend a holiday play scheme.

**Figure 53: Can you tell me if you access any of these social / support activities? (All respondents - where in full time education)**



Unweighted base: 33

## 2.6.2 Key issues

To facilitate independent living some disabled people utilise formal care from organisations in the public, voluntary and private sectors and / or informal care from family members and friends. The survey shows that two-thirds (65%) of respondents used some form of formal or informal care during the previous week to the survey. Most (39%) received this care from a family member or friend who lives in the same house as them. Thus a substantial proportion of disabled people rely upon informal carers for personal support and the island benefits greatly from this care because otherwise the States might have to fund formal care provision where individuals in need were unable to privately fund alternative provision. The valuable contribution made by informal carers needs to be acknowledged and celebrated. The key issues affecting informal carers are considered further in the next chapter.

Nonetheless, of those receiving care from a live-in carer, a small number appear to have young carers (minors who are fulfilling a caring role). Young carers are both a difficult group to identify in order to deliver appropriate support and assistance, and are a vulnerable group that requires specialist and particular support because of the nature of the role they perform. Whilst the number affected may be relatively small, policy makers need to ensure that the appropriate support and help is available to young carers.<sup>10</sup>

<sup>10</sup> See Guernsey Press (2009) Young carers could be in the hundreds, *This is Guernsey*, Retrieved from <http://www.thisisguernsey.com/latest/2009/07/04/young-carers-could-be-in-the-hundreds/> on 11<sup>th</sup> December 2012. See also <http://www.youngcarers.net/> for the services that can be provided to young carers.

Less than one in ten respondents (8%) receive formal or professional care. Of those who do, this care is most often delivered by a key worker, nurse or carer / senior carer. Of those receiving some form of formal care, most (77%) are satisfied, although one in ten (11%) are dissatisfied. The survey does not provide data on why most are satisfied and some are dissatisfied and this might warrant further exploration to identify 'good practice'.

There is also some survey evidence of latent demand for formal care. Of those receiving informal care, over half (57%) say they do not need professional care services and a small proportion would not wish to have formal care for a variety of reasons. However, over one in ten (13%) could not find professional care, 7% had not been offered professional care, and 2% said the relevant agency did not have the resources to serve them. Given the reasons listed above for not using professional care services, then of this fifth (19%), a relatively high proportion can be expected to want to access formal care. Moreover, nearly a fifth (18%) of all disabled people claim that they will not be able to pay for their care in five years' time. This suggests that irrespective of any demographic changes – an ageing population is likely to place more demands upon professional services – the existing population of disabled people can be expected to increase its demands upon the States to fund care services.

Some disabled people and their carers do receive benefits (Attendance Allowance/Invalid Care Allowance and Long Term Care Benefit) to help meet care costs. The above findings suggest that the demand for these benefits is likely to increase over time. Accordingly, the States' review of Attendance Allowance and Invalid Care Allowance is timely.

The States could also consider the merits of Personal Budgets. These exist in the UK and other European countries, for example, the Netherlands. In the UK they are known as 'Direct Payments' and 'Individual Budgets'. Direct payments are cash payments made in lieu of social service provision. They can be made to people who have parental responsibility for disabled children, and to carers. In the UK individual budgets build on some of the features of direct payments and aim to provide a more joined-up package of support by including several other income streams in addition to social care services.

The personal care budget (PGB) in the Netherlands is a form of direct payment for disabled people. A disabled person who chooses a personal care budget receives 75 per cent of what their care in kind would cost. They can purchase the type of care they wish including institutional care, social services in their home or use their personal care budget to pay family/ friends who care for them. This is designed to make it easier for disabled people to continue to live at home and in their communities for as long as possible. The Personal Care Budget has proved popular and currently the total national budget is capped and demand exceeds supply.<sup>11</sup>

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<sup>11</sup> Mel Cousins and Associates 'Supports for families with a children with a disability' November 2012.

Policy makers could consider whether a similar scheme could be introduced in Guernsey. There would need to be providers from whom services could be purchased. This could be a family member. In the longer term it can be anticipated that a private market would evolve providing further choice for disabled people and members of their families. The UK experience has generally been positive, but there have been a number of issues, for example, a significant variation in take-up rates between local authorities and concerns about the extent to which users in more rural areas have a choice of provider. There are also concerns that some groups, for instance, elderly people are reluctant to use direct payments. Some disabled people (and their carers) would require support in managing the payments.

The above finding that one in ten could not find a professional care service suggests that the States could consider more widely publicising the professional support available to disabled people.

## 2.7 Accessing information

This section explores where people currently go to find out what services they are entitled to, and how this could be made easier for them. It also looks at the level to which people are unaware of what they are entitled to or where to go for services, drawing on the survey as a whole.

### 2.7.1 Demands for, and use of, services

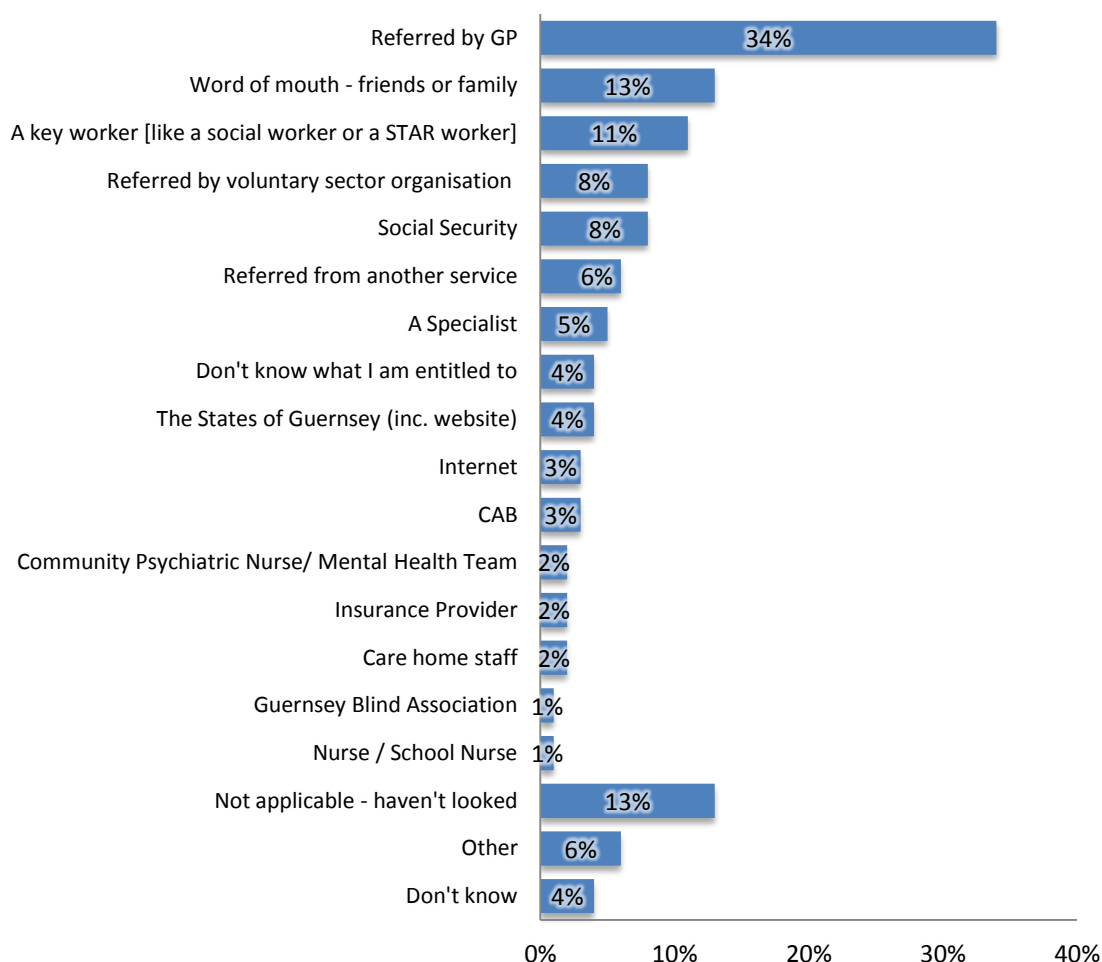
A third of respondents (93 people, or 34%) say they speak to their GP about the services they are entitled to. This is higher amongst owner occupiers (38%) than those in social housing (23%) and private renters (33%), with the latter two much more likely to use a key worker (18% - 7 people and 17% - 4 people cf. 8% owner occupiers – 15 people).

By disability grouping, people with a mental health condition are the most likely to speak to their GP (45%), to a key worker (23%) and to Social Security (11%). They rely much less on word of mouth (3%). Indeed, word of mouth is used most commonly amongst people with a learning, understanding and development difficulty (31% - 17 people), and 40% of those aged under 16 (12 people).

Just 4% say they don't know where they would go or who they would speak to. However, this increases to 20% of men aged 67+ (5 people).



**Figure 54: When you're trying to find out what services you're entitled to, who do you speak to or where do you go? (All respondents)**



Unweighted base: 271

The accessibility of information was a topic raised by attendees at the focus group held in Alderney. The key points are as follows:

- The provision of information is felt by Alderney residents to be inconsistent and outdated. A number of people gave examples of not knowing who to speak to with their queries, with high turnover rates in the Social Services department and no liaison officer on the Island. Staff were found to lack knowledge of the up to date legislation and entitlements of people with disabilities. In one example, the brochures on display in the States' Office were out of date (whilst the new brochures sat in a cabinet having not been put out). It was clear that the focus group discussion session offered Alderney residents a rare opportunity to clarify information with each other as there is so much that is contradictory available.
- There is currently some ad hoc support offered by the Jubilee care home, and it is clear that there are pockets of knowledge amongst residents who have been involved in the system for a long time. Perhaps the clearest message from the session was the need for a dedicated Liaison Officer or Advocacy Worker that

can proactively pull together this knowledge and facilitate working together across the Island. It is clear that there is a desire to work together and a strong community, yet it needs a facilitator to make this happen. Alongside this is the provision of an accessible venue, where networking events can be held.

- Encouragingly, the discussion session demonstrated to residents the benefits of getting together and sharing experiences and knowledge. There was agreement that these could be organised by residents themselves and held regularly.

The majority of respondents feel they would benefit from ways of making it easier for them to access information (Figure 55). 3 in 5 (58%) would find it easier if they had better information about the services that exist and a similar proportion (55%) would find it easier if they knew who services were meant for. Over half (53%) would like services to be more proactive and ask them what they need.

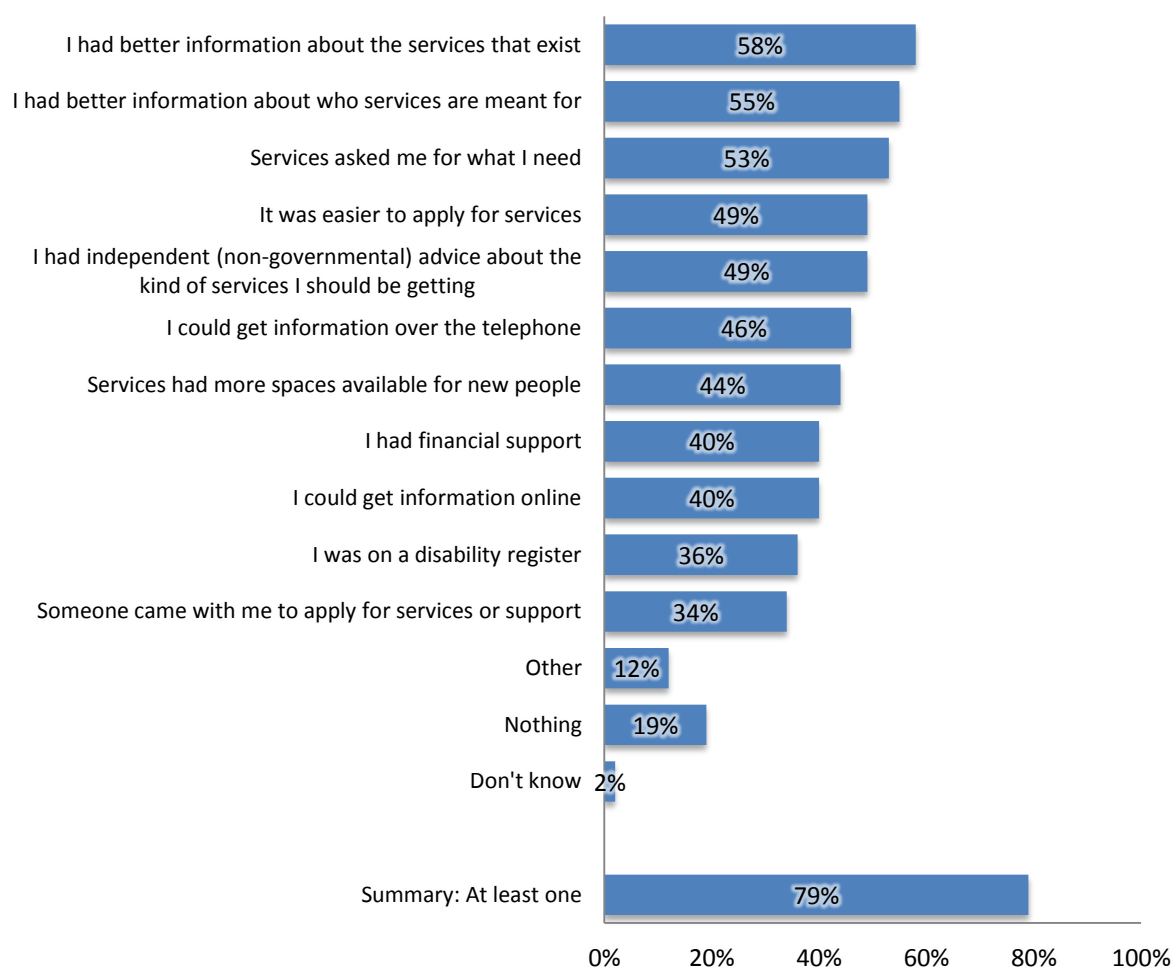
90% of respondents aged under 16 (27 people) would benefit from better access to information and services, compared to 64% aged 67+ (56 people). Exploring this in more detail, 70% of the younger group say it would be easier if services asked them what they needed. Also, 67% state it would be easier for them if services had more spaces available for new people.

Respondents in social housing are more likely to state they would benefit from easier access to services (87% - 34 people), especially if they had support from someone to accompany them to apply for services (51%), and if they had better information about what services exist (72%) and who they are meant for (64%).

Over half (51% - 34 people) of respondents who are unable to work because of their condition would find it easier to access a service if they had financial support and if they had someone to accompany them (40%). 55% of those in employment (39 people) would like to see it made easier to apply for a service.

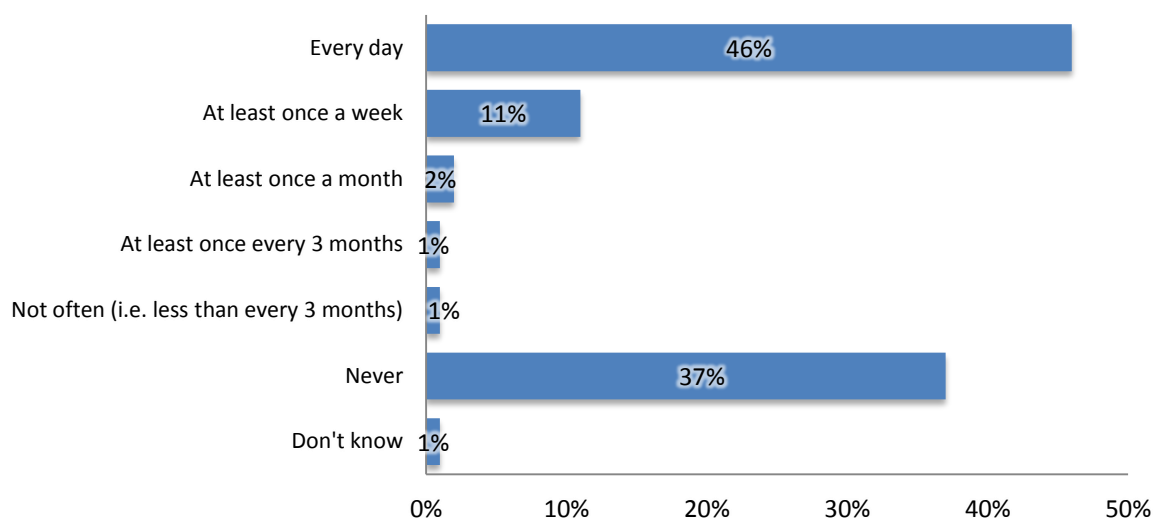
It was found in Figure 54 that respondents with a mental health condition are the most likely to obtain information through official means (i.e. GP, key worker). This group of people are also the most likely to say they would benefit from easier access to information and to services. Indeed, 75% would benefit from better information about what services exist and 72% about what services are meant for certain people. 54% would benefit from more information online and 62% over the telephone. Respondents with a learning, understanding and development difficulty would also commonly benefit from improvements, especially if services asked them what they needed (69%).

**Figure 55: I'm going to give you a list of things that some people say would make it easier for them to access care or support. Do you think that any of these would help you to access care or support? It would be easier for me to get services if... (All respondents)**



Unweighted base: 271

Almost 3 in 5 respondents use the Internet or email at least weekly (154 people, or 57%) (Figure 56). 2 in 5 (100 people, or 37%), however, never use the Internet or email. Variations are driven by the age of the respondent, with 61% of those aged 16-34 using the Internet or email daily, 57% aged 35-66, but just 24% of those aged 67+. Three quarters (76%) of people in employment use the Internet or email at least weekly. Respondents with a mental health condition are the most frequent Internet users (66% at least weekly).

**Figure 56: Can you tell me how often you use the internet or email? (All respondents)**

Unweighted base: 271

### 2.7.2 Key issues

People require timely, easily accessible and accurate information if they are to make informed choices. The survey and qualitative research reveals that there are a number of areas where the provision of information to disabled people could be improved, for example, if there was up-to-date information on the kinds of people who are eligible for different services.

Currently, the main sources visited or spoken to are GPs, friends and family, key workers, and voluntary sector and Social Security staff. The reliance on friends and family and on voluntary sector organisations highlights the key role of community and social networks – that is, the importance of social capital. Such networks tend to be highly trusted by the general public and can be seen as more reliable sources of information than more ‘official’ sources. Accordingly, one way of improving the quality of information available to individuals is for sources of ‘official’ information to ensure that those accessing community and social networking for information receive up-to-date information. This may involve working in partnership with third sector organisations to ensure the timely and effective dissemination of the information to agencies and / or use of community based workers whom disabled people can contact. Interestingly, the focus group on Alderney recommended that a project worker be tasked with this role on the island. There may even be scope for more active involvement of disabled islanders in the co-production of information. In partnership with other stakeholders, disabled people could identify informational needs, co-design how those needs are to be met and be involved in the dissemination of information (for example, using social media).

The survey also shows that there is greater scope for information to be made available digitally:

- 46% said it would help if they could access information over the telephone (Figure 55);
- 44% want to access information online (Figure 55); and
- 63% do use the internet or email (Figure 56)

The younger age profile for those using the internet and email means that the potential for delivering information using web-based technologies will increase in the future. Information providers should ensure that the information they wish to disseminate is available online.

## 2.8 Education

This section explores the experiences and demands of people with long term conditions in full time education. It looks at:

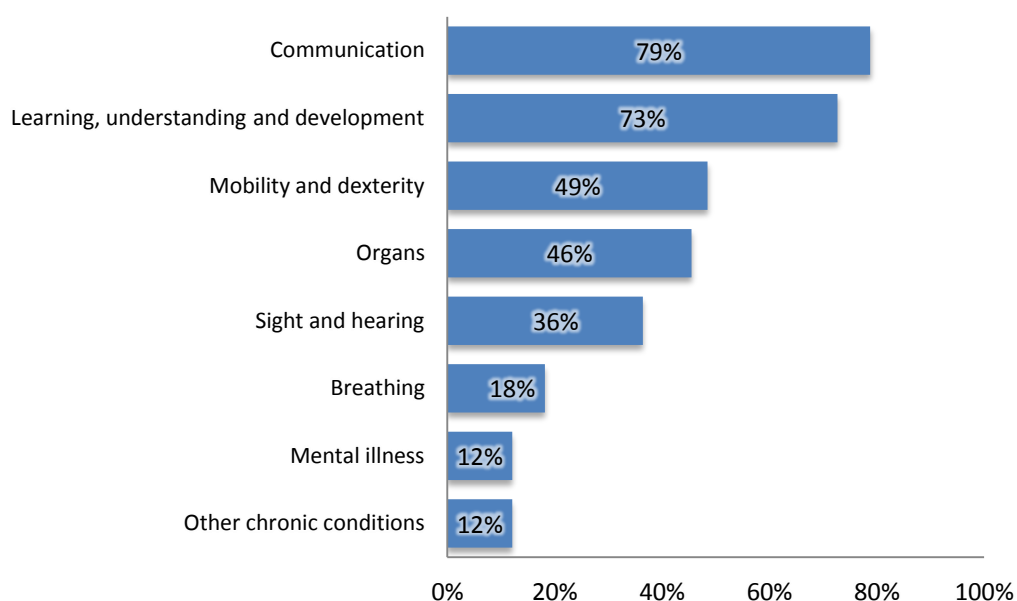
- The school attended, and year
- The level of support or adjustments utilised for exams
- The level of support services accessed and where the greatest demand is for such services

### 2.8.1 Overview: Profile of those in education

33 people in the sample are in full time education, including secondary and further education. All are aged under 18. 91% of these interviews were conducted with the parent or carer of the respondent.

Figure 57 shows that almost 4 in 5 respondents in full time education have a communication difficulty (79%), and 73% have a learning, understanding and development difficulty.

**Figure 57: Proportion of people in full time education with different types of disability (All respondents – in full time education)**



Unweighted base: 33

## 2.8.2 Demands for, and use of, education-related services

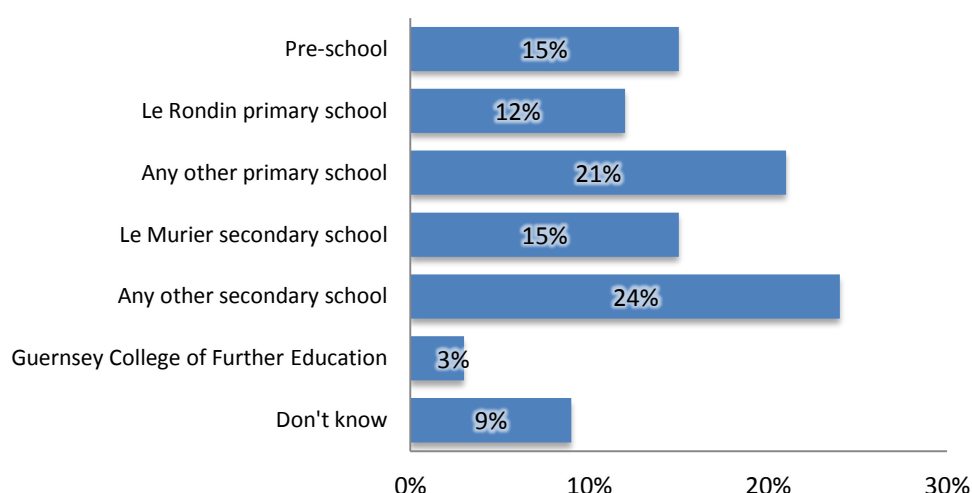
### School attended and year

Figure 58 shows there is a mix of attendance at different schools across Guernsey and Alderney. In summary:

- 5 respondents (15%) are at pre-school;
- 11 respondents (33%) are at primary school, and 4 of these children are at Le Rondin;
- 13 respondents (39%) are at secondary school, and 5 of these young people are at Le Murier;
- 1 respondent (3%) is at the College of Further Education.

All in all, 9 young people (27% of this group of respondents) are at a school for people with Special Educational Needs (Le Murier or Le Rondin).

**Figure 58: Can you tell me what school you go to? (All respondents – in full time education)**



Unweighted base: 33

A third of respondents in full-time education (11 people, or 33%) are in school year 9 or above.

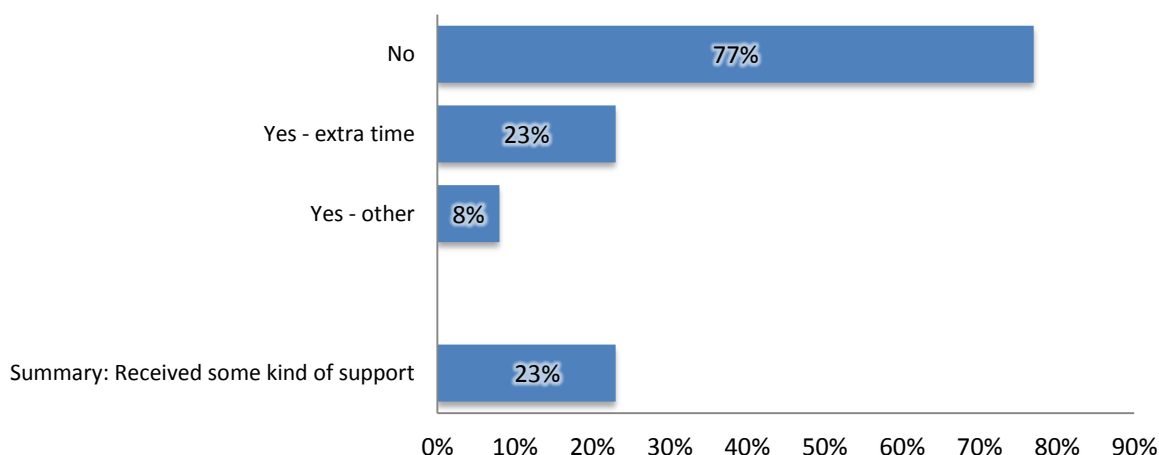
Of those in year 9 or above, over a third (36% - 4 people) took exams during the summer of 2012. 18% (2 people) took their GCSEs.

### Exams and support

Exploring what kind of support people in full time education get when taking exams<sup>12</sup>, a quarter received some kind of support (23% - 3 people). This increases to 27% of those with a communication or a learning, understanding or development difficulty (3 people for each). A quarter (23%) received extra time in their exam (3 people) and 8% some other kind of support (1 person).

<sup>12</sup> This is based on valid responses, removing any respondents that have not taken exams.

**Figure 59: Thinking back to the last exam you took, can you tell me if you had any extra support or adjustments made to make it easier for you to take the exam? If yes, can you tell me what kind? (All valid responses – in full time education)**



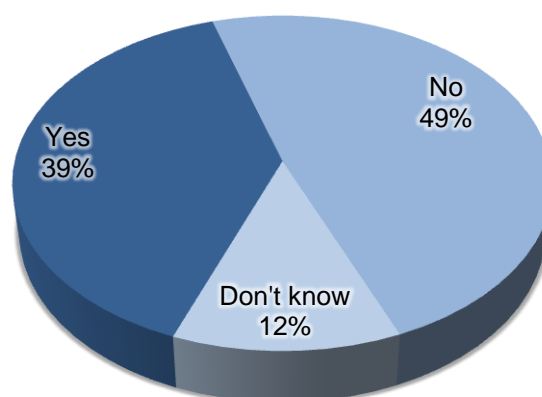
Unweighted base: 13

### Special Educational Needs / Children's Learning Disability Register

2 in 5 respondents have a determination of Special Educational Needs (13 people, or 39%), which is more common amongst girls (42% cf. 36% boys – 8 and 5 people respectively), and those with communication (50% - 13 people) and learning, understanding or development difficulties (54% - 13 people).

67% of respondents on the Learning Disability Register (6 people) have a determination of Special Educational Needs. Conversely, 46% (6 people) of respondents with a determination are also on the Children's Learning Disability Register.

**Figure 60: Can you tell me if you have a determination of Special Educational Needs? (All respondents – in full time education)**

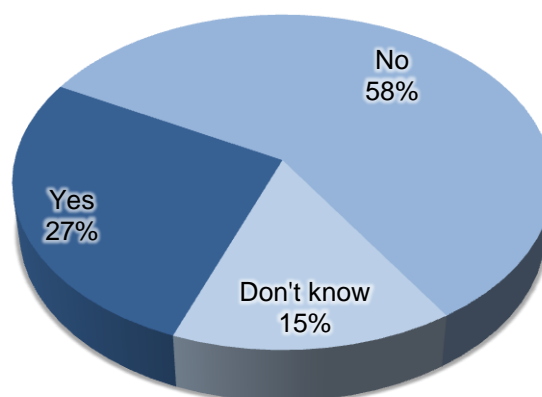


Unweighted base: 33



Over a quarter of respondents (9 people, or 27%) are on the Children's Learning Disability Register. Only 38% of respondents with learning, understanding or development difficulties are actually on the register (9 people). 7 respondents who also have mobility and dexterity issues (44% of this group) are on the register.

**Figure 61: Can you tell me if you are on the Children's Learning Disability Register?  
(All respondents – in full time education)**

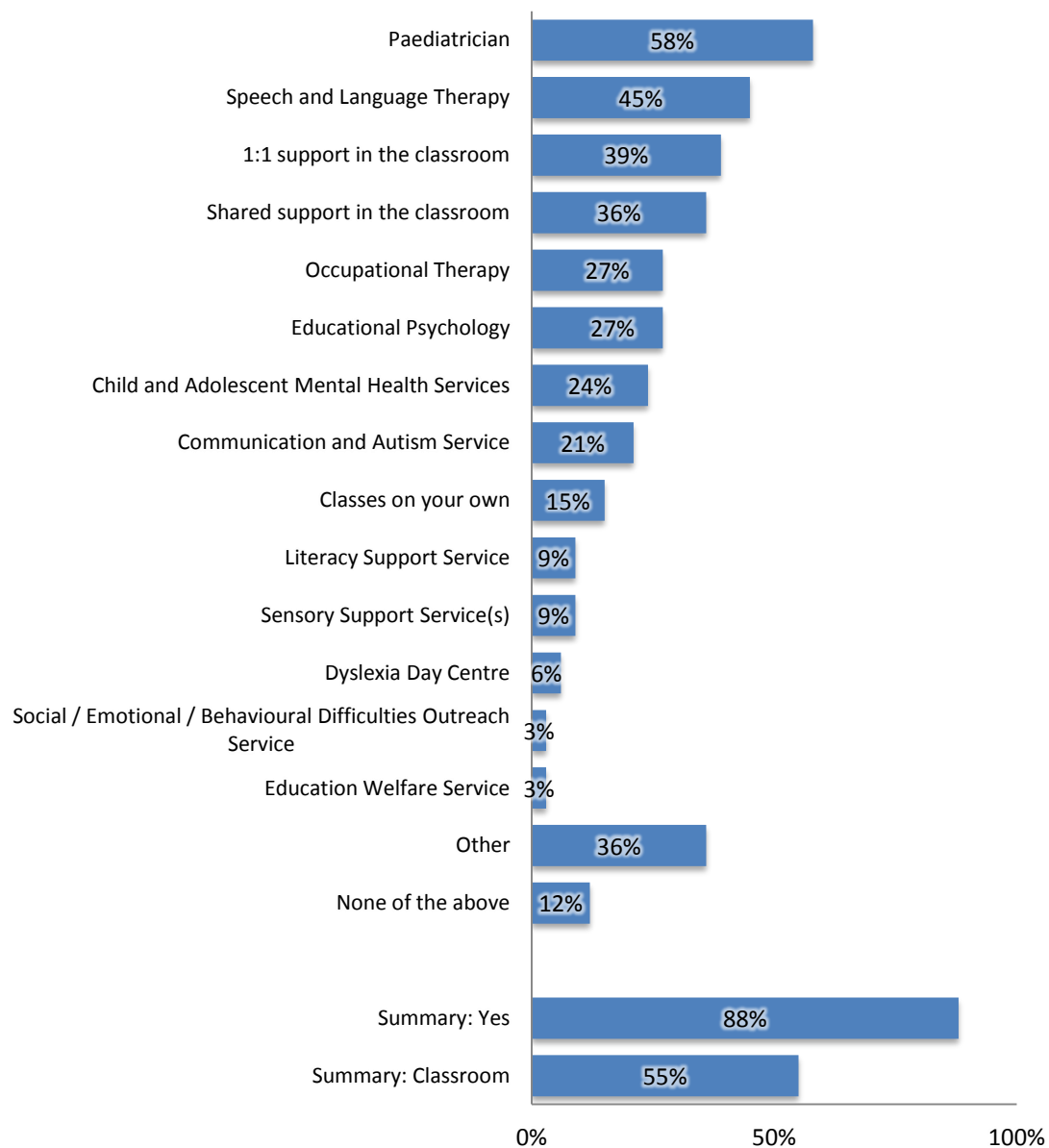


Unweighted base: 33

### Accessing support services

The large majority of respondents utilise at least one form of support service available to them (29 people, or 88%). Interestingly, although more girls have a determination of Special Educational Needs and are on the Children's Disability Register, more boys access a support service (93% cf. 84% girls). Male respondents are more likely to access support in the classroom (43% cf. 32% girls), as well as speech and language therapy (50% cf. 42%). Caution needs to be exercised here, however, due to small sample bases and the likelihood that types of disability will be driving these patterns. Over half (18 people, or 55%) of all respondents in full time education receive support in the classroom.

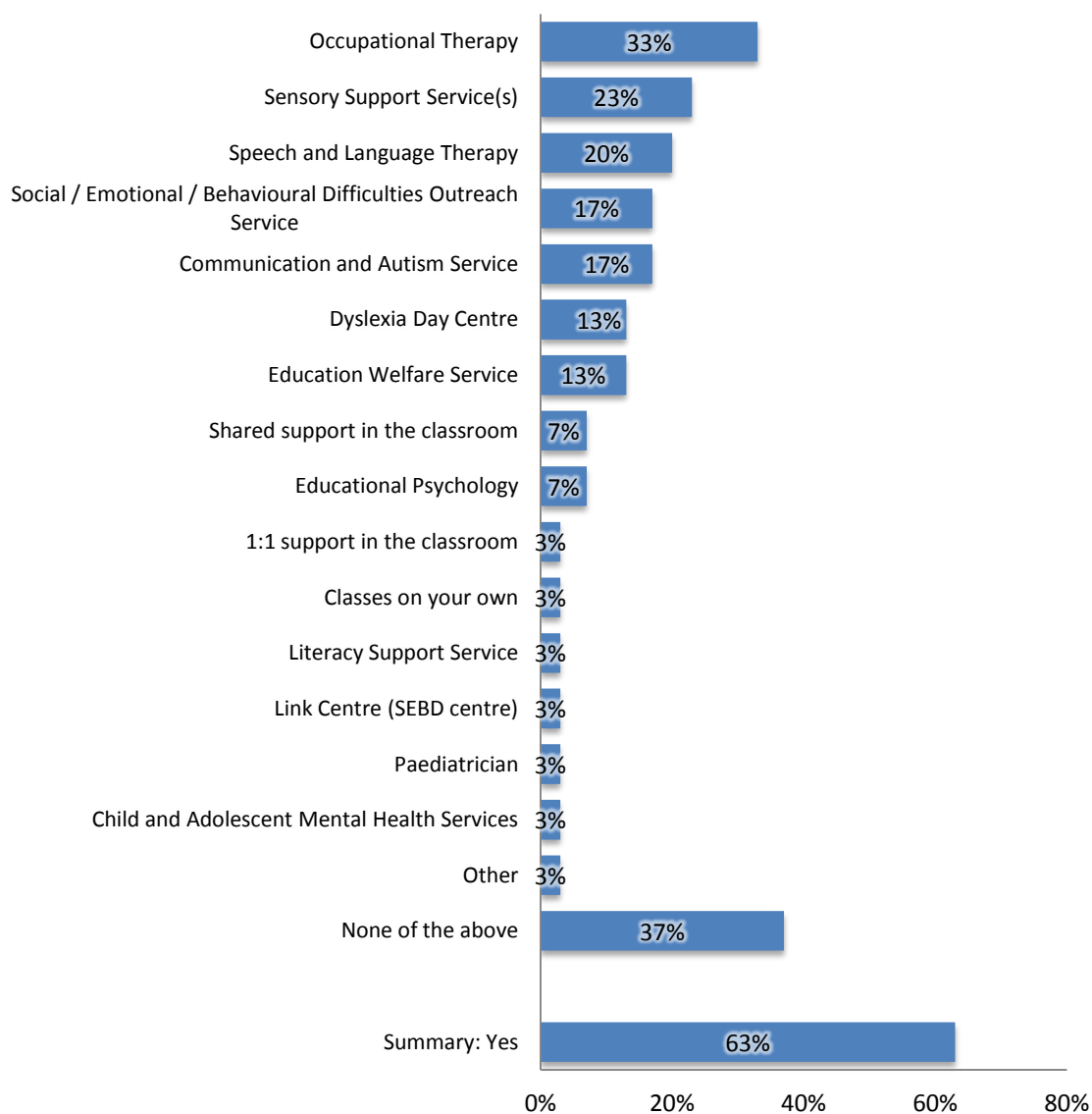
**Figure 62: Can you tell me if you use any of the following support services? (All respondents – in full time education)**



Unweighted base: 33

Figure 63 shows that, overall, 63% of respondents in full-time education say they would benefit from one or more of the education-related services which they have not already used (19 people). 1 in 3 say they would benefit from Occupational Therapy (10 people, or 33%).

**Figure 63: Thinking about the same list of services, do you think any of these could help you do better or be happier in education, in addition to the support you already get? (All respondents – that have not used each service)**

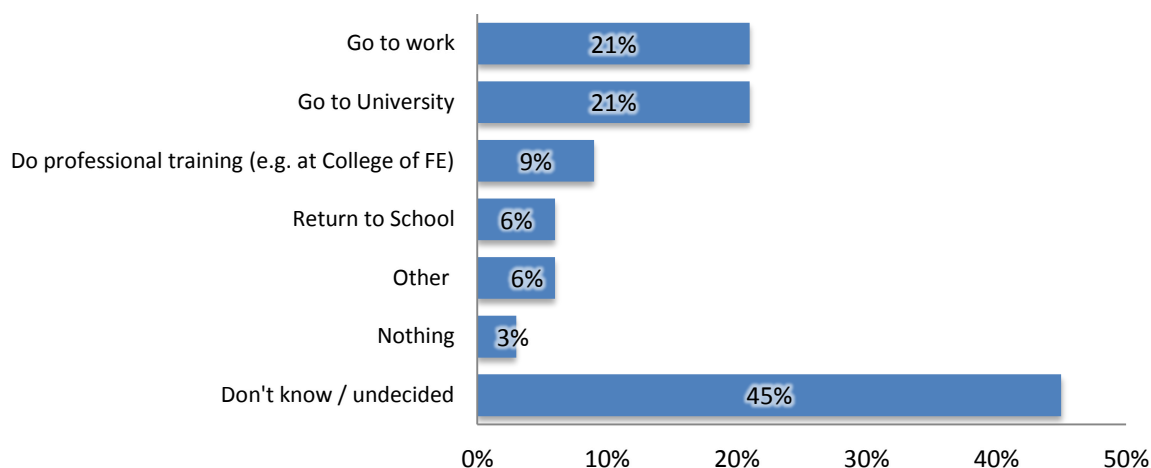


Unweighted base: 30

## Plans for finishing school

1 in 5 respondents in full time education intend to either go into work when they finish school (7 people, or 21%) or go to University (21%). The largest proportion, however, is undecided (45%). A quarter (25%) of people with a learning, understanding or development difficulty intend to go to work (6 people).

**Figure 64: What do you plan to do when you finish school? (All respondents – in full time education)**



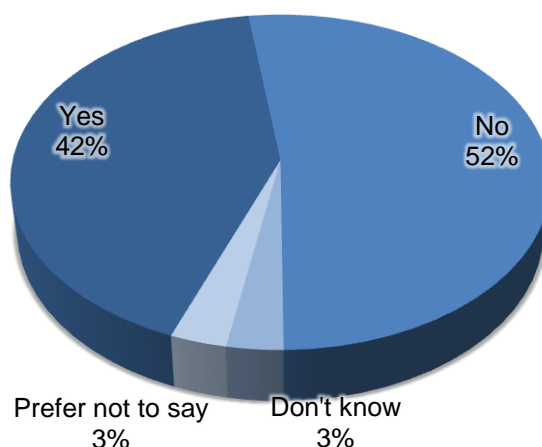
Unweighted base: 33

Only 10 people were aged 14 to 16 in the sample, therefore it is not possible to give a reliable analysis of the kind of support they access to plan for transitions into adulthood.

## Bullying in school

Over 2 in 5 people in full time education have been bullied in school (14 people, or 42%). This is more frequently experienced by boys than girls (64% of young male respondents – 9 boys – and 26% of young female respondents – 5 girls – say they have been bullied). Respondents who have a determination of Special Educational Needs or who are on the Children's Learning Disability Register are less likely to have experienced bullying than other young respondents (38% and 22% of these groups, respectively, say they have been bullied). However, respondents with learning, understanding and development difficulties are more likely to have been bullied on the whole (46% - 11 people).

**Figure 65: Can you tell me if you have ever been bullied in school? (All respondents – in full time education)**



Unweighted base: 33

### 2.8.3 Key issues

The policy aim is to enable disabled people to have the same choices and control over their lives as people without impairments. A key factor in the achievement of this policy aim is equal access to good quality education and appropriate educational support services. The Education Department:

*“recognise[s] that all children and young people are of equal value: they have the same basic emotional, social and education needs regardless of their gender, ethnic origin, ability or disability. [The Department’s] aim is to provide an education system in which every child feels: Healthy and Nurtured; Safe; Achieving and Active; Respected and Responsible; Included.”*<sup>13</sup>

Guernsey provides education for disabled children through a mix of mainstream and special schools and, in off-island placements in a small number of cases where health, education and care needs cannot be met by the provision available in Guernsey. For the majority of children with learning difficulties and special educational needs, education takes place in a mainstream school. This may also include group work or individual support that takes place inside or outside the mainstream classroom. Children with learning difficulties and special educational needs may also attend a special school. The Education Department maintains two special schools for those students who require more specialist provision and a Centre for students with social, emotional and behavioural difficulties.

Le Rondin School and Centre was opened in 2005 and caters for primary age children with a range of special educational needs. Peripatetic education support services who mainly work with pupils in mainstream schools are based at Le Rondin. The Health and Social Services Department's Child Development Centre also operates from Le

<sup>13</sup> <http://www.education.gg/SEN>

Rondin and therapy rooms for occupational therapists, speech therapists and physiotherapists from the Health and Social Services Department are located in the building.

Students of secondary school age with special educational needs attend the Le Murier School which opened in September 2008. The College of Further Education provides Post-16 opportunities although some students may stay at Le Murier until they are 19 years of age.

To be considered for admission to Le Rondin and Le Murier students will have undergone a Formal Assessment which identifies their main area of need as one of the following:

- Moderate Learning Difficulties with Additional Needs
- Severe Learning Difficulties
- Profound and Multiple Learning Difficulties

Students may also have additional need including:

- Communication and interaction difficulties
- Behavioural, emotional and social difficulties
- Sensory, physical and medical difficulties

Twelve per cent of school age respondents are attending Le Rondin primary school and 15 per cent Le Murier secondary school, while 21 per cent attend a mainstream primary school and 24 per cent a mainstream secondary school. 15 per cent attend pre-school.

Of the students who responded almost four in five (26 people, or 79%) in full time education have a communication difficulty and 73 per cent have a learning, understanding and development difficulty (24 people). Two in five have a determination of Special Educational Needs (SEN) (39%).<sup>14</sup> Among the respondents, a SEN determination is more common amongst females (42% cf. 36% males), and those with communication (50%) and learning, understanding or development difficulties (54%). Over a quarter (27%) of respondents in full time education are on the Children's Learning Disability Register.

A large majority of respondents use at least one form of support service available to them (88%). Although, among the respondents, more girls have a determination of Special Educational Needs and are on the Children's Disability Register, more boys access a support service (93% cf. 84% boys). Over half (55%) of all respondents in full time education receive support in the classroom. Again boys are more likely to access support in the classroom (43% cf. 32% girls), as well as speech and language therapy (50% cf. 42%). This is a very complex area but it does suggest that the Education Department and the Health and Social Services Department should together examine

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<sup>14</sup> Children have Special Educational Needs if they have a learning difficulty which calls for special educational provision to be made for them. This comes from the 1987 Amendment to The Education (Guernsey) Law 1970.

whether the resources for diagnosis and support measures are distributed according to need.

The study identifies unmet demand for services. In addition to the support they were already receiving, respondents identified several services that would help them do better or be happier in education, with 36 per cent saying access to occupational therapy would benefit them, 30 per cent saying speech and language therapy, 27 per cent communication and autism service, 21 per cent sensory support service, 15 per cent social emotional behavioural difficulties outreach, 12 per cent dyslexia day centre and six per cent child and adolescent mental health services. The identification of a particular service appears to relate to type of condition. To achieve the policy aim the States should examine the need for and ways to increase the provision of these services in order to improve the educational experience, enjoyment and achievement of children with an impairment and long term health condition in Guernsey's schools.

The States' Education Department makes it clear that it takes any incidents or allegations of bullying, including cyber bullying, very seriously and that it will not tolerate bullying in any of Guernsey's schools, whether physical or verbal. All schools on the island are required to have a policy on bullying, which is usually integrated into their whole-school policy on behaviour. Similarly, the issues underlying bullying, such as pupil self-esteem, relationships, conflict and assertiveness, are addressed within the policies and curriculum advice of the Department and in PSHE and Citizenship work undertaken in schools. The Education Welfare Service supports students who may be suffering problems in connection with bullying.

Nevertheless, more than two in five respondents in full time education said that they have been bullied in school (42%). This increases to 64 per cent of males compared to 26 per cent of females. Bullying is less common amongst students who have a determination of Special Educational Needs (38%) or who are on the Children's Learning Disability Register (22%) but higher amongst those with learning, understanding and development difficulties in general (46%). These figures suggest that the Education Department should examine why the policy intent that all disabled children can feel safe and free of fear in school is not being met fully in all of Guernsey's schools.

Although a proper analysis of people's experiences was beyond the remit of this study, transitions can be difficult for people to make because they involve (complex) decisions and choice. For some children with Special Educational Needs the transition to adulthood, and the associated removal of the support received as a child, can be problematic. A challenge for policy makers is ensuring that this life transition for individuals with a learning difficulty to independent living is supported.<sup>15</sup> Support may be required to cover housing, continuing education/training or employment and other issues.

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<sup>15</sup> Guernsey does have in place guidance on information sharing between children and adult services: see <http://www.gov.gg/CHttpHandler.ashx?id=2359&p=0>.

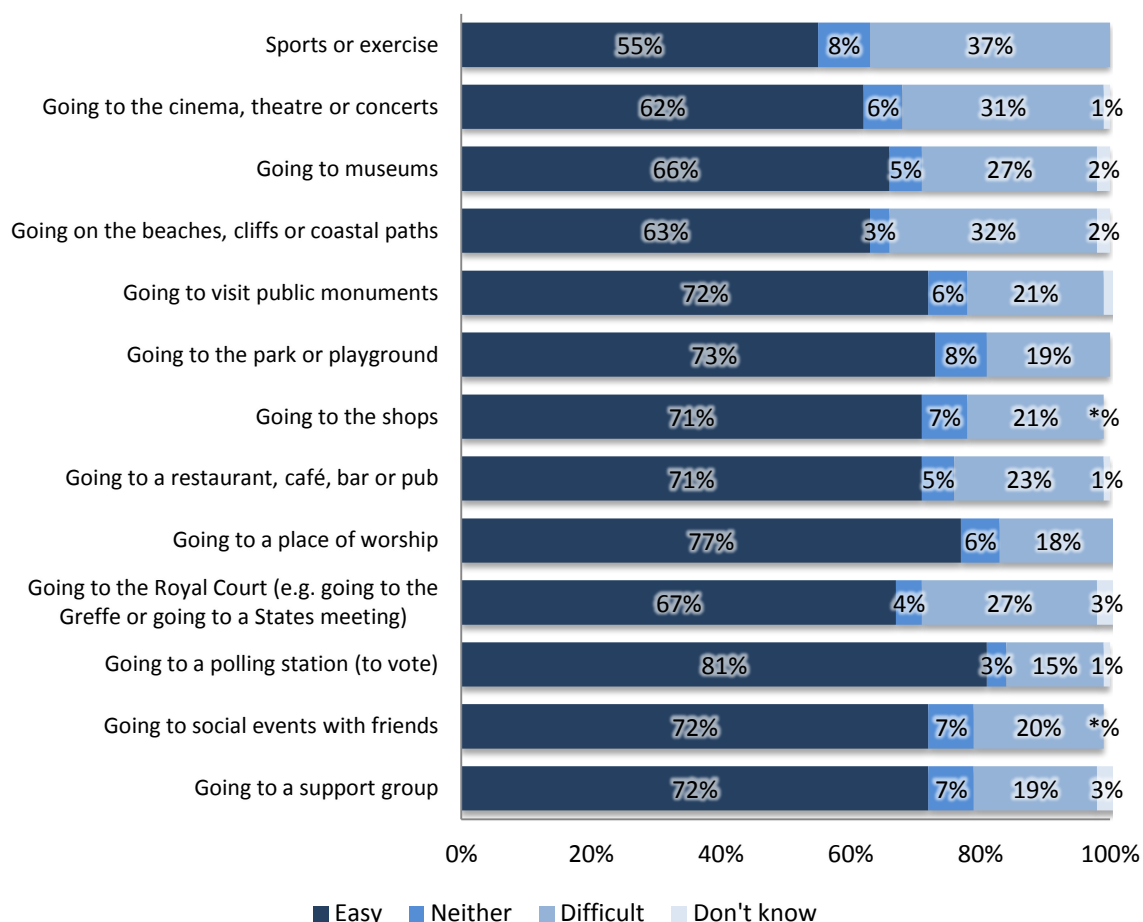
## 2.9 Social life

### 2.9.1 Demand for, use of, and access to services and facilities

All respondents were asked how easy or difficult they find it to access a number of different social and community activities / venues. Almost 2 in 5 find it difficult to access sports or exercise (77 people, or 37%), whilst 32% find it difficult to access beaches, cliffs or coastal paths (73 people), and 31% to go to the cinema, theatre or concerts (62 people). Older respondents are more likely to find it difficult to access sports or exercise (51% - 24 people), as are 50% in social housing (15 people), 55% who are unable to work due to their condition (27 people), and 53% with a learning, understanding or development difficulty (27 people).

1 in 5 find it difficult to go to a park or playground (19%). This increases to a third of those with “other chronic conditions” (33%), 60% with epilepsy, and 31% aged 67+. Similarly, 20% (49 people) find it difficult going to social events with friends, and this is more commonly an issue for those aged under 16 (25% - 7 people), especially boys aged under 16 (46% - 6 people), people in social housing (31%), and 36% with a communication difficulty (25 people).

**Figure 66: Can you tell me how easy or difficult it is for you to access each of these...? (All valid responses)**



Unweighted bases vary



Of the respondents who state they have difficulty accessing at least one of the activities / venues listed in Figure 66, 1 in 5 say it is due to their health or their old age (32 people, or 22%), mobility problems (31 people, or 21%) or the places not being physically accessible (31 people, or 21%). 17% (24 people) say they cannot access suitable transport. 30% of people in employment and 28% with sight or hearing difficulties say they cannot access suitable transport. 14% of respondents say they cannot afford to go out and about, and this increases to 26% of people with a mental health condition, 24% aged 35-66, and 21% in social housing. Almost a third of people with a breathing problem (31%) or a problem with their organs (31%) say their health is a reason for finding access difficult.

**Table 11: What are the main things that can stop you getting out and about? (All respondents – where have difficulty getting out and about)**

	%
<b>My health / old age (excluding mobility)</b>	22%
<b>Mobility problems</b>	21%
<b>The places that I want to visit are not physically accessible</b>	21%
<b>I can't access suitable transport</b>	17%
<b>I can't afford to go out and about, or do hobbies</b>	14%
<b>Support from someone else (accompanied by someone)</b>	9%
<b>The weather</b>	7%
<b>I am afraid / afraid of other people's behaviour</b>	6%
<b>Being in new/strange places affects behaviour</b>	6%
<b>I find it difficult to understand or communicate with other people when I am out and about</b>	5%
<b>Lack of confidence</b>	5%
<b>There are no activities that suit me here</b>	4%
<b>I have no interest in going out and about</b>	3%
<b>I don't know who to contact to get more information [about things I want to do]</b>	3%
<b>There is no (suitable) parking near the places I want to visit</b>	2%
<b>I can't use computers or the internet [to find out about things, or book things]</b>	1%
<b>There are no toilets/changing rooms that I can use</b>	1%
<b>Other</b>	3%
<b>No reason</b>	7%
<b>Don't know</b>	1%
<b>Unweighted base: 145</b>	

The physical accessibility of Alderney was a widespread topic of conversation at the Alderney focus group. The key points were as follows:

- Victoria Street was seen as very problematic, with narrow pavements, a cobbled road surface and no drop kerbs allowing wheelchair access from one side to the other. Although there was an acceptance that there needs to be care taken of the heritage of these streets, it was also felt that only small measures need be taken to address health and safety. This included introducing drop kerbs, making Victoria Street access only for residents, but on the whole a pedestrianised street, and improving the width of one side of the street's pavements. Cars parking on this street are a big issue, especially as they park on the pavements.
- There are insufficient disabled parking bays across the Island. This is particularly the case in Braye Street.
- Whilst the discussion had already focused on the suitability of the Methodist Hall, it was recognised that there is not one venue that meets all of the needs of people with disabilities. For example, where one venue has disabled access, it may not have disabled toilet facilities or a loop. It was strongly recommended that if things were to improve on the Island, then a fully accessible venue is crucial to ensuring all residents can attend discussion groups similar to the one being held for them that day.
- One suggestion from the group was that a number of aluminium access ramps should be available to be rented or hired, as this currently is not offered.

### 2.9.2 Key issues

Promoting social inclusion for disabled people requires that they can easily access social activities in order to fully participate in society. The survey reveals that there are particular facilities and locations that disabled people have difficulties accessing, notably sports or exercise venues, entertainment venues, coastal locations, museums and the Royal Court. Furthermore, a key reason for this difficulty is that the sites are not physically accessible - a fifth (21%) of those experiencing difficulties having a social life claim this (Table 11). Even when respondents identify mobility problems or health as a barrier to accessing services and facilities (Table 8), it is possible that making reasonable adjustments at venues and to street infrastructure would enhance some disabled people's social life. Improving access is an aspect of social exclusion that public policy could tackle through low interest loans, grants and / or legislation. Low interest loans or grants can be used to incentivise owners to improve the physical access of buildings and sites to disabled people. Alternatively, or as a complement to financial incentives, legislation can be used to place a duty on service providers to make reasonable adjustments so that disabled people may access services and goods. The issue of legislative change is discussed further in Chapter 4.

Guernsey does have a Disabled Persons Parking Badge Scheme, disabled bays for parking, a dedicated website (DisabledGo) to provide information to disabled people on the accessibility of sites, 'bleepers' on Puffin signal controlled pedestrian crossings, laws relating to adapted vehicles and 41 buses designed to carry disabled passengers. Nonetheless, some respondents (17%) mention the absence of suitable transport as a reason for problems in accessing social activities. From the survey it is not clear whether this refers to private vehicles and / or public transport, although 2% mention

the lack of suitable car parking near sites. Respondents' concerns might relate to the small number of taxis equipped for wheelchairs or bus routes with buses that are more difficult to use by disabled people. Further research on the nature of these transport issues may be required. In light of this evidence Guernsey could review whether it wished to introduce a Motability Scheme that would enable disabled people to use a government-funded mobility allowance (available to say Attendance Allowance recipients) to lease a new car, scooter or powered wheelchair.

## 2.10 What would have a positive impact

When people were asked to specify in their own words up to three things they feel would make a significant positive difference to their life, a wide range of comments were obtained. These comments have been coded into common themes and presented in Table 12. The largest proportion of people feel support / help would impact their life positively, while financial assistance is mentioned frequently as is a better understanding / public awareness of their condition.

**Table 12: Please can you tell me [up to] three things, which if changed, would make a significant positive difference to your life? (All respondents)**

	1 <sup>st</sup> mention	2 <sup>nd</sup> mention	3 <sup>rd</sup> mention
Support / help (inc. support group, in the house)	11%	10%	10%
Financial assistance	9%	7%	6%
Better disabled access / facilities / issues (inc. funding)	7%	7%	1%
Better understanding / public awareness of my condition	6%	4%	10%
Mobility	5%	2%	0%
Finding Employment	4%	4%	0%
Improved health/overcoming the limitations of disability	3%	2%	1%
Public transport issues / regular service	3%	1%	2%
Information about events / social activities / services / health	2%	3%	4%
Moving to own accommodation	2%	1%	0%
Address mental health issues / better services / strategies	1%	2%	6%
Increase / easier access to respite care	1%	1%	2%
To be given my sight back / improvement to my sight	1%	1%	1%
A bungalow / ground floor living accommodation	1%	1%	0%
Better parking facilities (inc. parking for disabled)	1%	1%	0%
Access to occupational therapy	1%	2%	1%
Provide access to suitable disablement aids/equipment	1%	3%	0%
Improved /advancement in medical science/treatment	1%	1%	2%
Removal of street cobbles from pavements (improving mobility/safety)	1%	1%	0%
Easier/more accessible communication with support services	1%	1%	1%
Stronger disablement discrimination legislation/laws	*%	2%	0%

Better public toilet facilities	1%	0%	1%
Improved medical appointment system/shorter waiting list	1%	1%	0%
Better access to specialised medical facilities/ personal	1%	3%	1%
Having larger /more spacious accommodation	1%	1%	0%
Other	8%	8%	7%
No Comment	31%	39%	50%
Unweighted base	271	186	113

## 2.11 What works well people already

In terms of what people feel is already working well for them, the largest proportion specify the support and care they receive (excluding family), followed by family and friends.

**Table 13: Please can you tell me [up to] three things, which are already working well for you? (All respondents)**

	1 <sup>st</sup> mention	2 <sup>nd</sup> mention	3 <sup>rd</sup> mention
Support I receive / care / medical care / GP / medicines / (excluding family)	26%	15%	16%
Family / Friends	7%	9%	11%
Quality of life (including a good social life)	7%	4%	4%
Getting out and about / mobility / health	4%	2%	3%
I'm working / my job	3%	3%	5%
School / College	3%	2%	1%
My home / accommodation	3%	1%	2%
Being independent / being able to look after myself	3%	1%	1%
My technology / computer / CCTV / phone / TV	1%	2%	1%
Nice environment	1%	2%	4%
Access to public transport system	1%	1%	0%
Having private transport	1%	1%	2%
Hand rail aids	1%	1%	0%
Using sport/ exercise facilities	1%	1%	2%
Other	7%	8%	7%
No Comment	32%	50%	43%
Unweighted base	271	184	92

## 3 Carers

### 3.1 Introduction

This section explores the views of carers, including details of their caring role, employment, financial circumstances, health and well being, and use of respite care.

For the purpose of this survey, we interviewed people who care for a family member, relative or friend. Professional and volunteer carers were not included.

#### Profile of carers

Altogether, 103 carers were interviewed. 81% are aged 16 to 66 and the remaining 19% are aged 67+. The proportion of female carers outnumbers males 3 to 1 (73% cf. 27%). 80% of carers also have a long term condition, most commonly mobility and dexterity issues (53 carers) and organ-related difficulties (56 carers).

**Table 14: Demographic profile of the carer sample (All respondents)**

	%	Sample size
<b>Age</b>		
16 to 66	81%	83
67+	19%	20
<b>Gender</b>		
Male	27%	28
Female	73%	75
<b>Long term condition?</b>		
Yes	80%	82
No	19%	20
<b>Age of person cared for</b>		
Under 16	19%	20
16 to 66	40%	41
67+	41%	42

The largest number of interviews was done with carers of people with communication-related difficulties (31), followed by other chronic conditions (24), mobility and dexterity issues (23), and learning, understanding and development problems (21).

**Table 15: Disability types cared for (All respondents)**

	%	Sample size
<b>Communication</b>	30	31
<b>Other chronic condition(s)</b>	23	24
<b>Mobility and dexterity</b>	22	23
<b>Learning, understanding and development</b>	20	21
<b>Sight and hearing</b>	5	5
<b>Breathing</b>	4	4
<b>Organs</b>	4	4
<b>Mental health condition</b>	3	3
<b>Stroke</b>	3	3
<b>Epilepsy</b>	1	1
	<b>100</b>	<b>103</b>

## 3.2 Caring

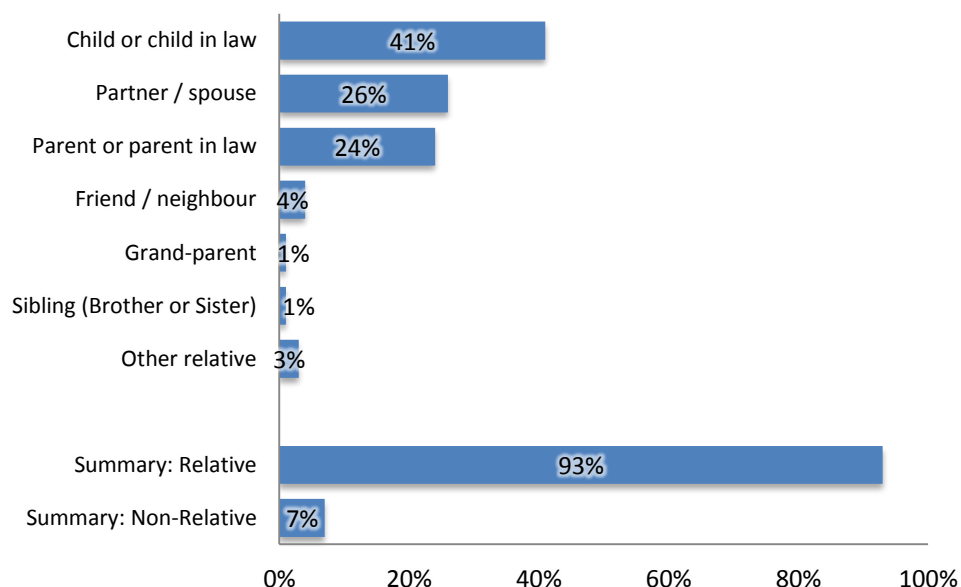
### 3.2.1 General overview: Caring role

The large majority of respondents care for one person (80 people, or 78%), and the remaining one in five (22%) care for two or more people. 33 carers do not live in the same property as the person they care for, and 36% of these (12 people) care for two or more people; compared to 16% who live with the person they care for.

Two in three respondents live in the same property as the person(s) they care for (70 people, or 68%). This rises to 75% of people aged 67+ (15 people), 74% that care for one person, 93% that care for a partner or spouse (23 people), and 86% that care for a child (36 people).

Figure 67 shows that 93% of respondents care for a relative (96 people). Two in five care for a child (42 people, or 41%), a quarter (27 people, or 26%) for a partner or spouse, and 24% (25 people) for a parent. Of those who care for someone who lives separately to them, 18% care for a non-relative.

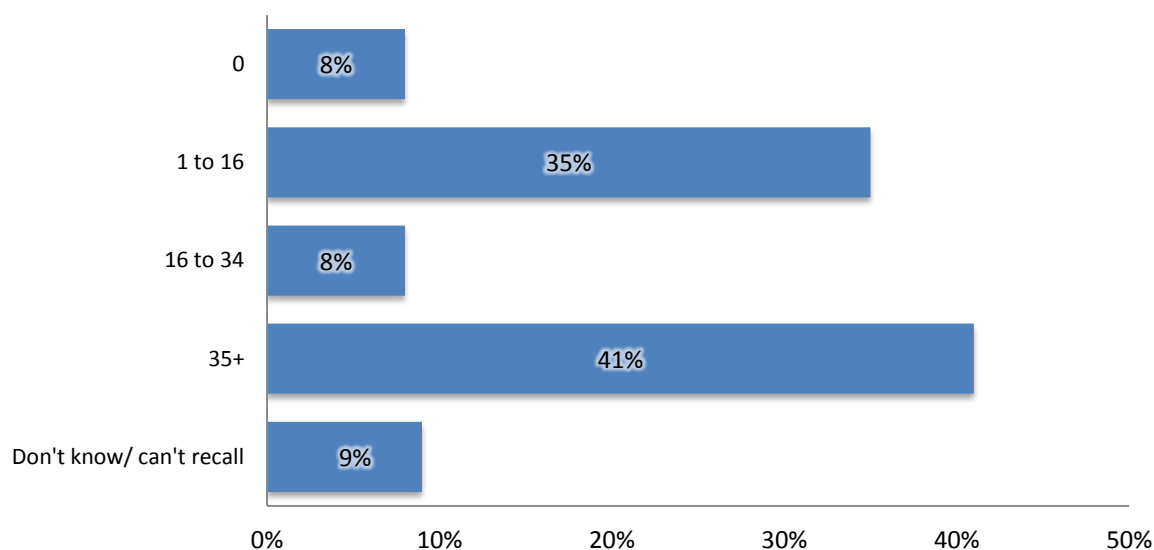
**Figure 67: Can you tell me how you are related to the person you care for? Are they your...? (All respondents)**



Unweighted base: 103

Exploring the extent of care provided, two in five respondents (42 people, or 41%) provide care for 35 or more hours per week. This increases to 50% of respondents aged 67+ (10 people), 41% who themselves have at least one disability (34 people), and 57% that live in the same property as the person they care for. 35% of respondents (36 people) provide between one and 16 hours of care per week. 52% of people who work more than 16 hours per week also provide a caring role of between one and 16 hours (25 people), as do 76% who live in a different property to the person they care for (25 people).

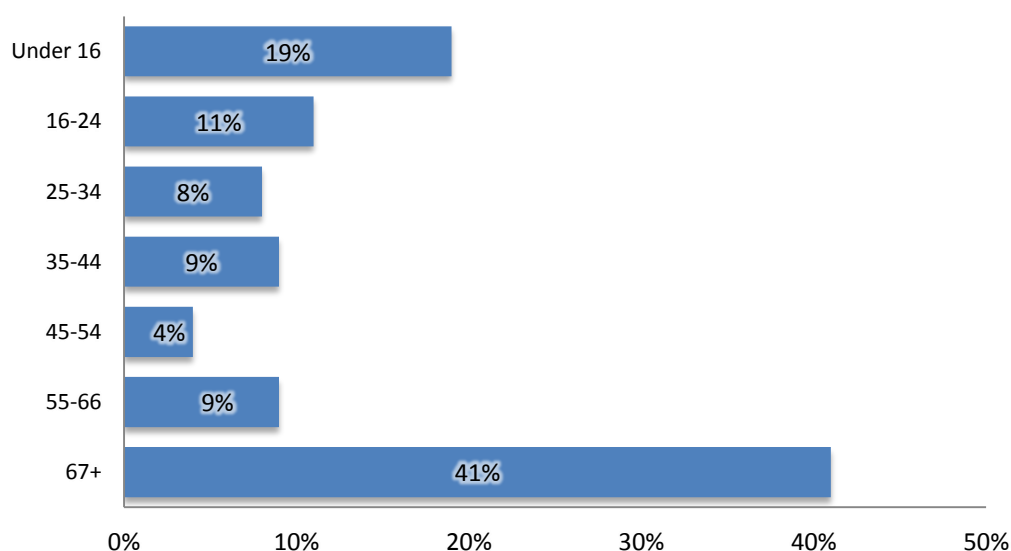
**Figure 68: How many hours did you provide care for this person last week? (All respondents)**



Unweighted base: 103

The largest proportion of respondents (41%, or 42 people) care for someone who is aged 67+ years, whilst one in five care for a child aged under 16 (19%). 50% of those that provide additional care for their child do so for a child aged under 16, and 26% for a young person aged 16-24.

**Figure 69: Can you tell me the age of the person you care for? (All respondents)**



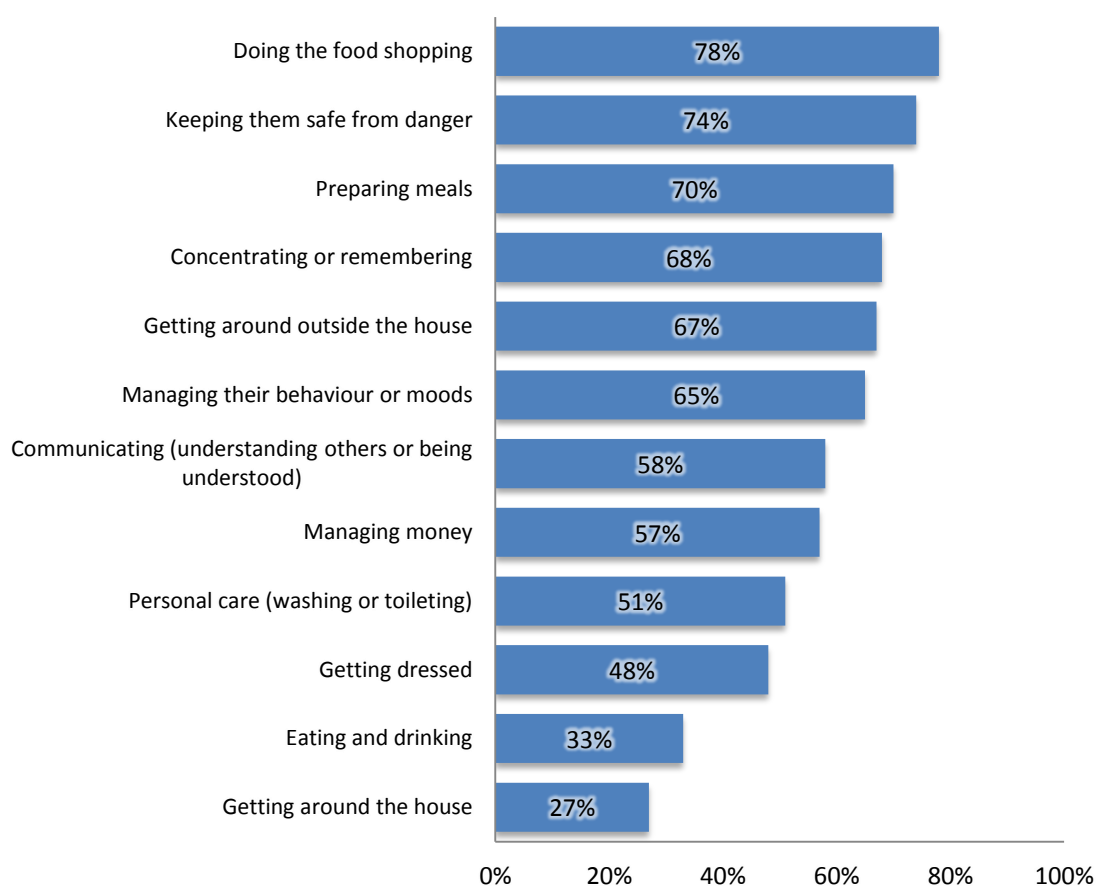
Unweighted base: 103



### 3.2.2 Demands for, and use of, services

Exploring the type of support provided, almost four in five respondents help with the food shopping (78%) and 74% prevent harm. 51% of respondents (53 people) help the person they care for with their personal care (such as washing or toileting). 95% of respondents who care for someone aged under 16, and 75% who care for someone with a learning, understanding or development difficulty, help that person with their personal care.

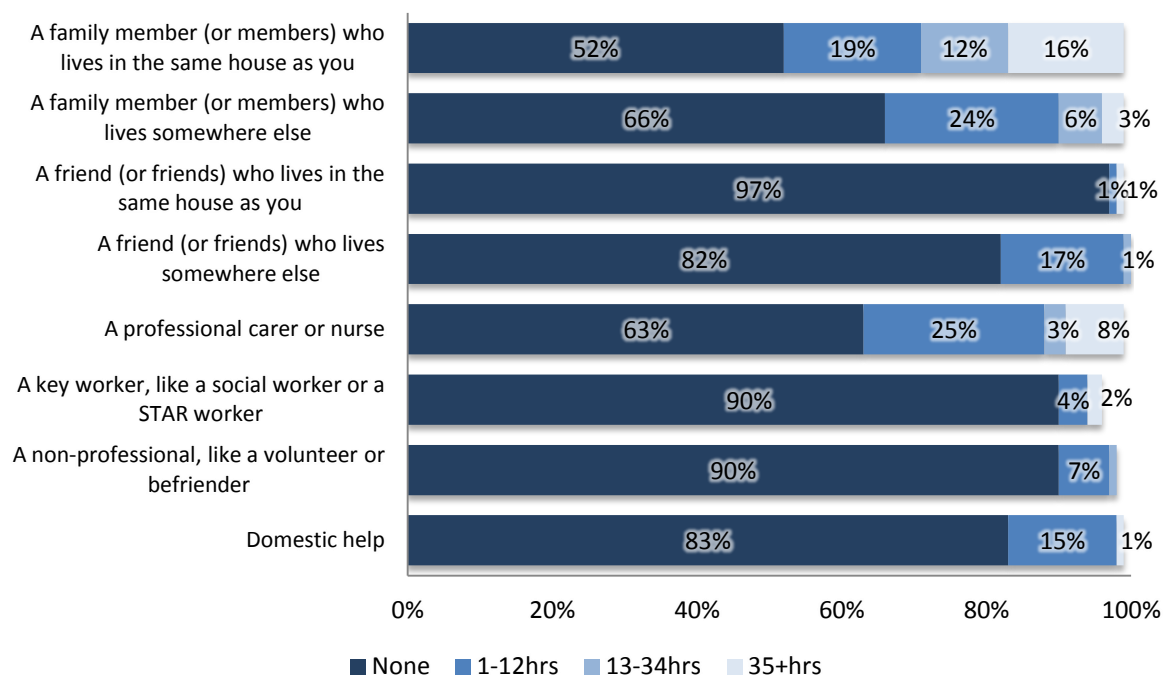
**Figure 70: Can you tell me if you support this person to do any of these? (All valid responses)**



Unweighted bases vary

Respondents report that the person they care for may also receive professional care, and support is alongside that given by friends and relatives. Over one in ten respondents support someone who receives professional care from a nurse for 13+ hours per week (11%); 8% of respondents care for someone who receives such support for 35 or more hours per week. Among people aged over 67, and people with mobility and dexterity-related conditions, the rate of use of professional care appears to be higher: 12% of respondents who care for someone aged 67+ report that they access 35 or more hours of professional care each week, as do 13% of those who care for people who have problems with mobility or dexterity.

**Figure 71: Can you tell me if any of these people, as well as yourself, have supported the person you care for in the last week, and if so, for how many hours? (All respondents)**



Unweighted base: 103

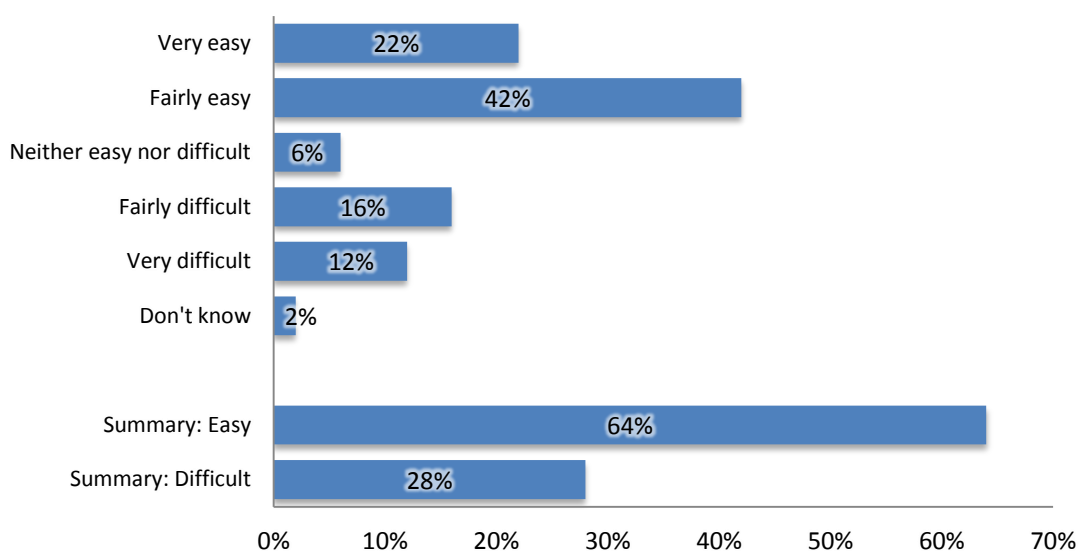
Of the 50 respondents who support someone who also receives professional care, 28% (14 people) say that the person they care for receives additional support from a professional carer or senior carer on a weekly basis, and 34% say that this support is used on at least a monthly basis (Table 16).

**Table 16: Can you tell me if the person you care for uses any of these, and how often?  
(All respondents – where receive care from a professional)**

	At least weekly	At least monthly	At least annually
<b>Nurse (community or district)</b>	12%	20%	24%
<b>Specialist nurse</b>	6%	12%	22%
<b>A key worker [like a social worker or a STAR worker]</b>	8%	16%	36%
<b>Carer or senior carer</b>	28%	34%	34%
<b>Occupational therapist</b>	4%	10%	22%
<b>Speech and language therapist</b>	0%	8%	18%
<b>Physiotherapist</b>	0%	18%	32%
<b>Educational psychologist</b>	0%	0%	50%
<b>Health Visitor</b>	0%	4%	6%
<b>Sitting service (during the day)</b>	10%	14%	14%
<b>Sitting service (at night)</b>	4%	4%	4%
<b>Day care</b>	6%	12%	12%
<b>Meals on wheels</b>	6%	6%	6%
<b>Shopping service</b>	2%	6%	6%
<b>Transport service / Voluntary car service</b>	4%	8%	8%
<b>Handyman service</b>	2%	2%	4%
<b>Unweighted base: 50</b>			

Two in three respondents who support someone who also receives professional care say that it is easy to access such care (64%). This drops, however, to 33% of people who care for a child (6 people) and 48% who also work 16 or more hours per week (10 people). Indeed, 43% of this latter group find it positively difficult to access professional care.

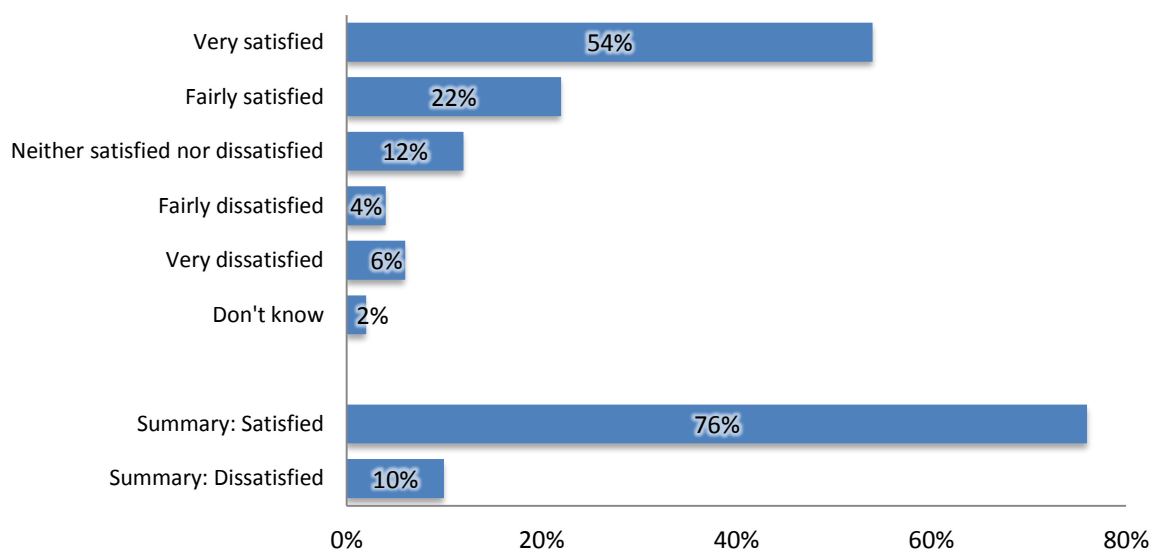
**Figure 72: Can you tell me if the person you care for finds it easy or difficult to get the professional care and support they need, when they need it? (All respondents – where receive care from a professional)**



Unweighted base: 50

The majority of respondents say they are satisfied with the professional care and support that the person they care for receives (76%), whilst 10% are dissatisfied. Mirroring the previous finding, carers who work for 16 or more hours per week are most likely to be dissatisfied with the professional care and support provided (19%), as are those who care for a child (17%).

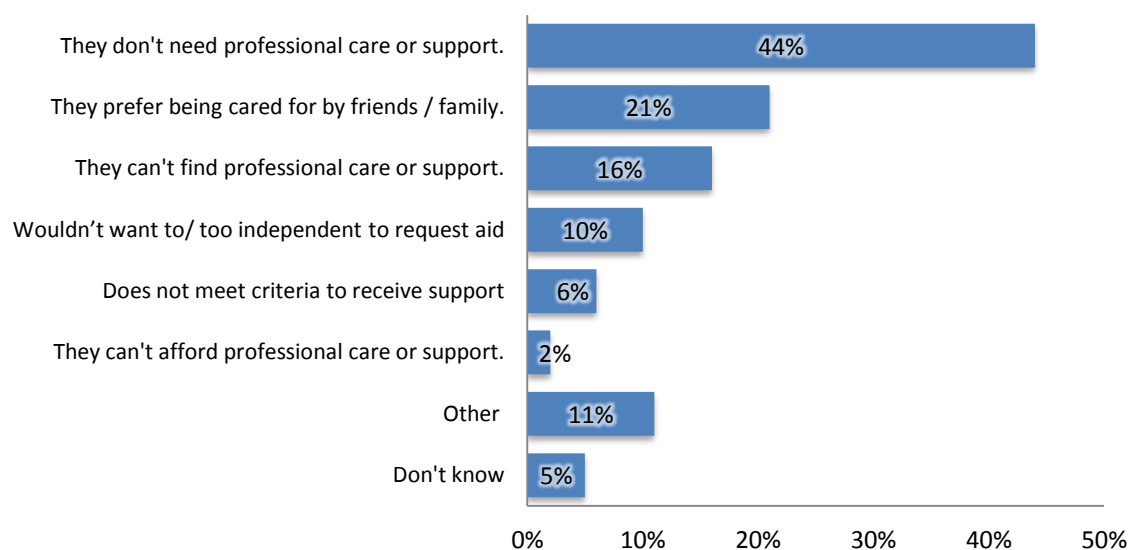
**Figure 73: Can you tell me how satisfied you are, overall, with the professional care and support that they receive? (All respondents – where receive care from a professional)**



Unweighted base: 50

Among respondents who support someone who does not receive care from a professional, 44% (27 people) say this is because the person they care for does not need this type of support. 21% (13 people) say the person they care for prefers to be supported by friends and family than by professionals. 16% of respondents say the person they care for cannot find professional care and support, which is more of an issue for carers in employment (22%), those who care for a child (29%), and those who care for someone with a communication difficulty (29%).

**Figure 74: You say that the person you care for does not receive any support from professionals. Can you tell me why? (All respondents – where do not receive care from a professional)**

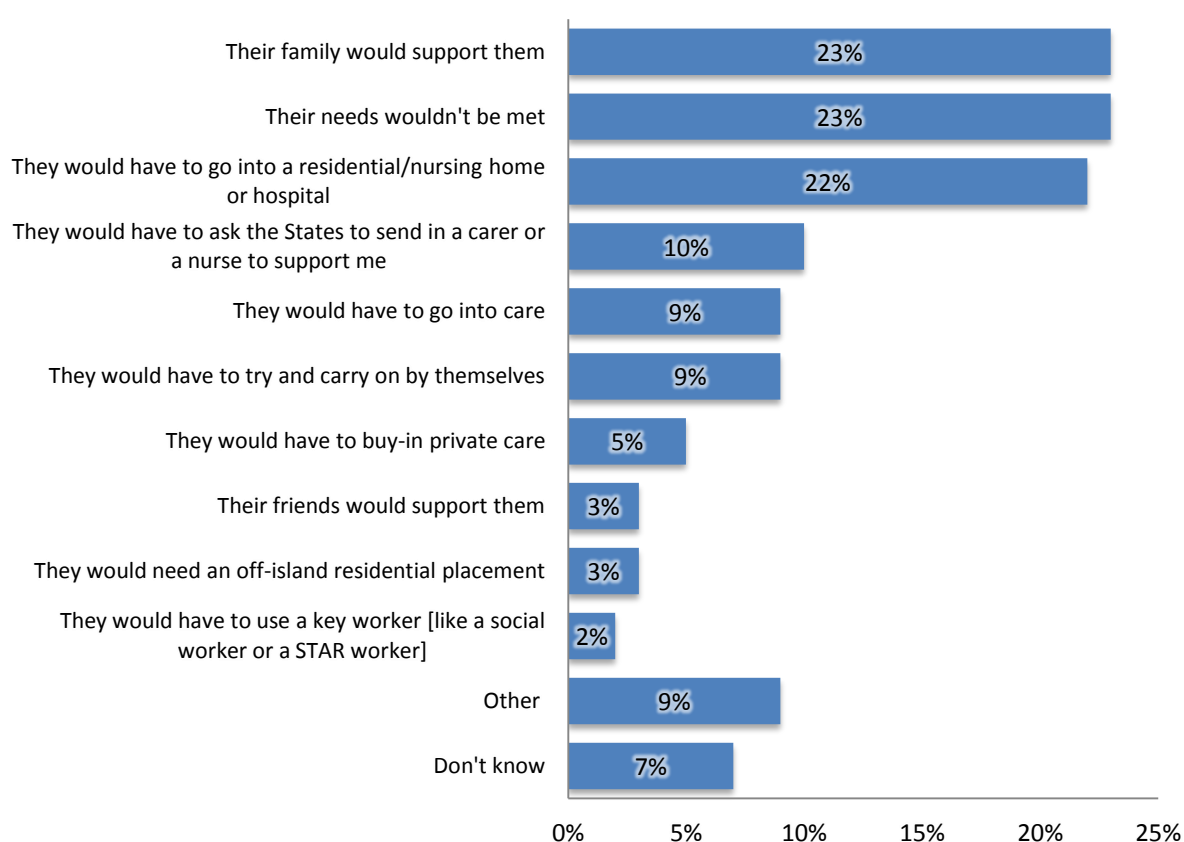


Unweighted base: 62

A quarter (26%) of respondents who provide support to someone that does not receive care from a professional say that such support would benefit the person they care for 'a lot'. Carers in employment are more likely to feel professional support would benefit 'a lot' (32%), as do 46% of people who care for a child, and 57% who care for someone with a communication difficulty.

Almost one in four respondents believe that if they did not provide care to the person they care for, that person's needs would not be met (24 people, or 23%). A further 22% say the person they care for would need to go into a residential / nursing home or hospital.

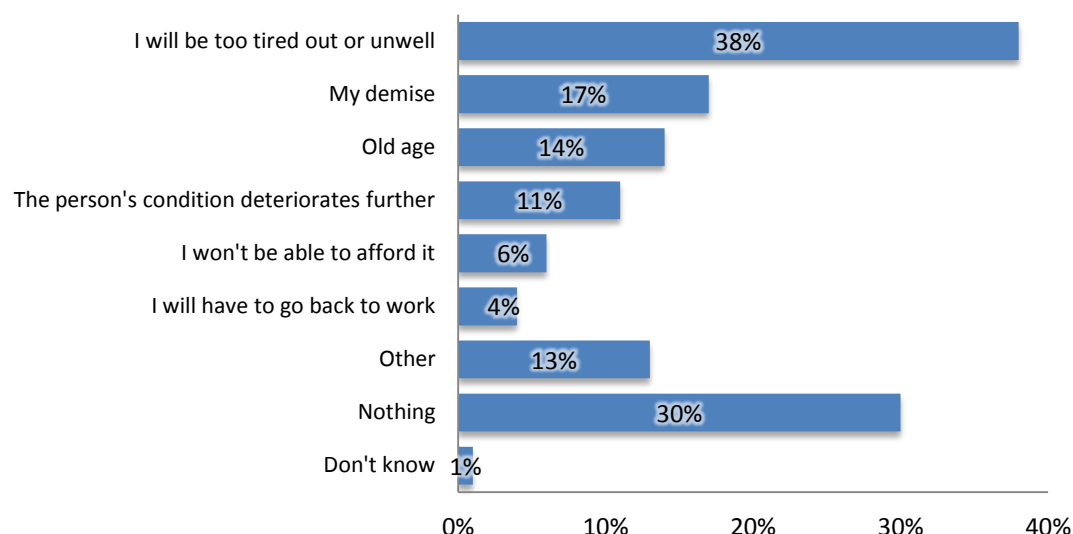
**Figure 75: If you did not provide care for this person, how do you think their needs would be met? (All respondents)**



Unweighted base: 103

All respondents were asked whether there is anything that might stop them providing care and support in the future. Whilst 30% say nothing will stop them, a further 38% (39 people) say they will be too tired or unwell. This increases as a reason amongst those aged 67+ (45% - 9 people), those with a long-term condition themselves (41% - 34 people), and those who care for someone with a learning, understanding or development difficulty (62% - 13 people).

**Figure 76: Is there anything you feel might stop you providing care and support in the future? (All respondents)**



Unweighted base: 103

Among respondents, there are mixed views in terms of the impact that their caring role has had on their relationship with the person they care for. One in three (34%) say that it has had no impact on their relationship, whilst 29% say it has affected their relationship for the better and 33% that it has affected it for the worse.

### 3.2.3 Key issues

The survey of carers confirms the findings, presented in section 2.6, that the informal care provided by family members and friends makes a vital and important contribution to the support and assistance provided to disabled people. – see Figure 75. Most informal care is provided for people aged 67 and over (41%) and for children aged under 16 (19%). Many carers are elderly [19% are over the age of 67] and their ability to provide care long-term may be limited.

Caring can be a demanding responsibility. For 41% of respondents, this means providing care for 35 or more hours per week – and in some instances the carers themselves have long-term health conditions or impairments. Other respondents are in paid work (of more than 16 hours per week) and also provide care of up to 16 hours per week. In addition, the caring role can be the sole responsibility of one person, there being no other family member within the house (52%) or outside the home (66%) who could be called upon.

That family members and friends can have a key caring role should be acknowledged and celebrated by the States. How this might be achieved could be discussed with carers themselves.

Confirming the findings from the survey of disabled people, a minority of respondents say the person they care for is supported by a professional carer, often a nurse or carer/senior carer (see Figure 35 and Table 7). Of those receiving professional support a majority (76%) are said to be satisfied with the support provided.

However, there are two issues that policy makers may wish to consider. First, a quarter of respondents (28%; Figure 72) say that it is difficult for the person they care for to access formal care. Two groups in particular experience problems accessing professional care; those caring for a child aged under 16 years and those working more than 16 hours per week. The survey does not reveal the type of support sought and this would need to be established.

Secondly, a quarter of respondents who care for a person who does not receive professional care state that this would benefit the person they care for 'a lot'. This potential demand for formal care arises partly because the carer has been unable to find professional care (suggesting better publicity and information is required), partly because they or the person they care for does not meet the criteria for support, and partly because they or the person they care for cannot afford to pay for professional support (Figure 74). The last two reasons raise issues about eligibility for formal care, and policy makers could consider the merits and demerits of, say, providing financial assistance so that more informal carers could be professionally supported.

### 3.3 Respite

#### 3.3.1 Demands for, and use of, services

A quarter (25%) of respondents say that the person they care for has stayed overnight (for one or more days) in a respite care placement on the islands. Where the respondent is aged over 67, the person they care for is more likely to use respite care (30% - 6 people), as are children with disabilities (31% - 13 people) and where care is provided for 35 or more hours per week (31% - 13 people).

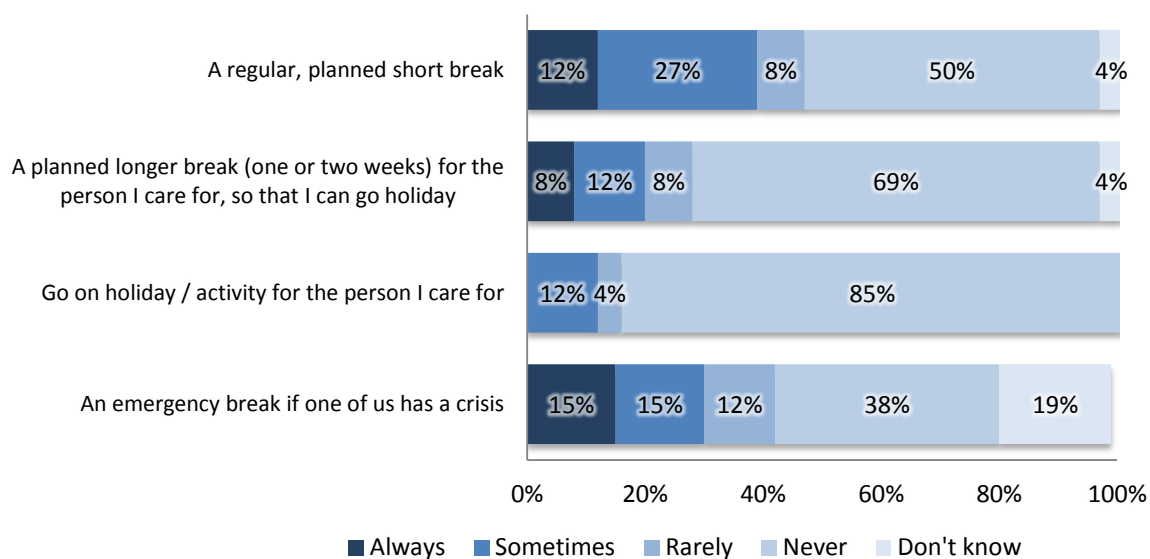
Of the 26 respondents who say the person they care for has used a respite care placement, the largest proportion has used such care within the last year (38%). More than two in five stayed in The Croft (42%) and 23% in a hospital (or King Edward VII). The length of stay varies, with 31% staying for one night, a further 8% for two nights, and 59% for three or more nights. Almost half (47%) stayed for a week or more.

When asked whether the person who used respite care would have preferred support in the community, there are mixed views, with 50% of respondents saying 'no', but 46% saying 'yes'. There are, unfortunately, insufficient numbers of responses to allow this to be explored in more detail.

Respite care can be used in a number of ways and for a number of reasons. Exploring this in more detail, Figure 77 shows that 12% of respondents 'always' use such care as a regular, planned short break. A further 27% 'sometimes' use respite care in this way. 30% say they 'always / sometimes' use respite care in an emergency if either the respondent or the person they care for has a crisis.



**Figure 77: Can you tell me if you and the person you care for are able to use respite care in any of these ways? (All respondents - Where person you care for has used respite)**

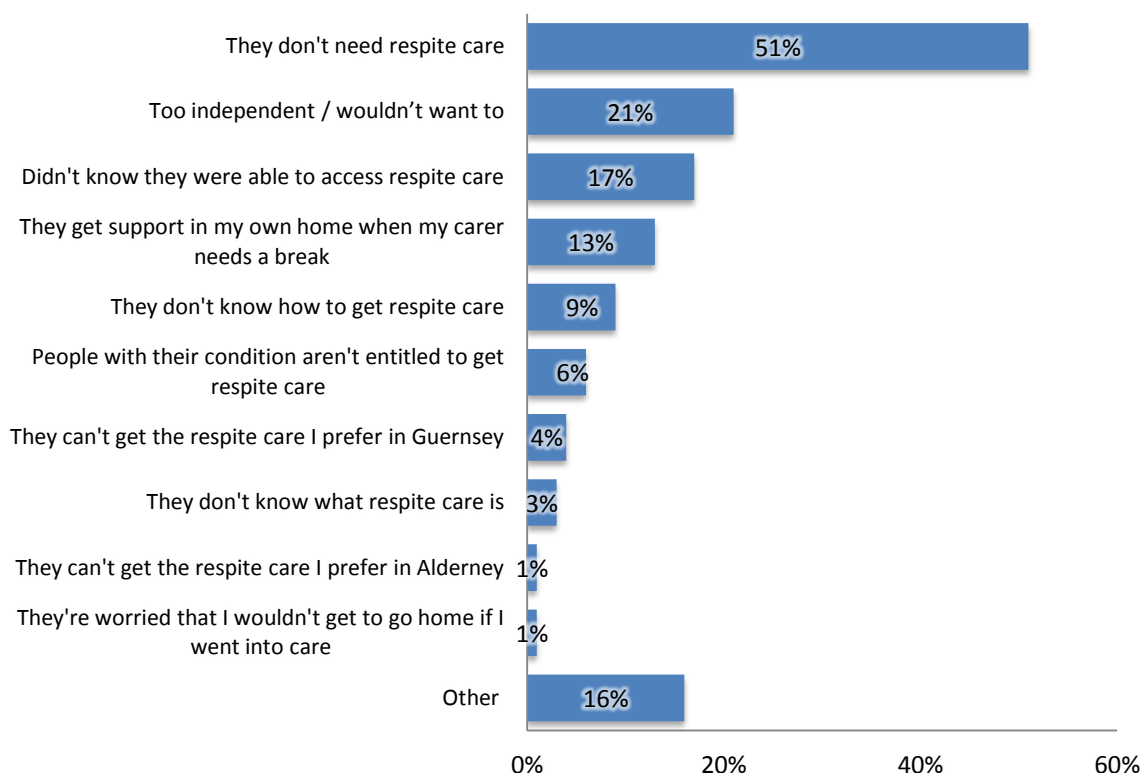


Unweighted base: 26

Among the respondents who care for someone who has never used respite care on the islands, 3% have tried to access respite care but failed (2 people).

The reasons why respite care has never been used are predominantly because the person being cared for does not need it (51% - 39 people) or that they are too independent / would not want it (21% - 16 people) (Figure 78). These reasons are more pronounced where the carer is aged 67+ (64% and 29% respectively). 17% of respondents say they did not know they were able to access respite care, which increases to 28% of people who care for a child and 26% who care for someone with a communication difficulty. 9% say they do not know how to access respite care, which again increases amongst carers of a child (17%) and where the person they care for is aged under 16 (19%).

**Figure 78: You say that the person you care for has never stayed in respite care. Can you tell me why? (All respondents – where not used respite care)**



Unweighted base: 77

17% of respondents who care for someone aged over 18 say that the person they care for accesses day care services. A greater proportion of respondents report that the person they care for uses day care services where care is provided for 35 or more hours per week (27%), and where care is provided to a child (30%) or a parent (28%). Of the 14 carers who say that the person they care for uses day care, 5 use these services one day per week, 4 do so two days per week, and 3 for three days per week. On a typical day where such a service is used, 43% (6 people) spend six hours there, whilst a further 43% (6 people) spend two to three hours there.

### 3.3.2 Key issues

A quarter (25%) of respondents say that the person they care for has stayed overnight, for one or more days, in a respite care placement on the islands. Where the respondent is aged over 67, the person cared for is more likely to use respite care (30%), as are children with disabilities (31%) and where care is provided for 35 or more hours per week. The length of stay varies, with 31 per cent staying for one day while almost half (47% - 12 people) stayed for a week or more. Respite care is used as a regular, planned short break or in an emergency if there is a crisis.

46 per cent of respondents said that the person who had used respite care would have preferred support in the community. Of those who have never used respite care on the

islands 13 per cent of respondents who care for someone aged under 16, or someone with a learning, understanding and development difficulty, have tried to access respite care but failed. Seventeen per cent say they did not know they were able to access respite care. This increases to 26 per cent who care for someone with a communication difficulty and 28 per cent of people who care for a child. Nine per cent of respondents say they do not know how to access respite care, which again increases where the person they care for is aged under 16 (19%).

This raises issues about the level of provision of professional support in the community, availability of respite care and access to available provision including the provision of information and publicity. Opportunities to improve information and awareness on the island are identified and discussed in section 2.7.2 above. The survey shows that information must also be targeted at carers.

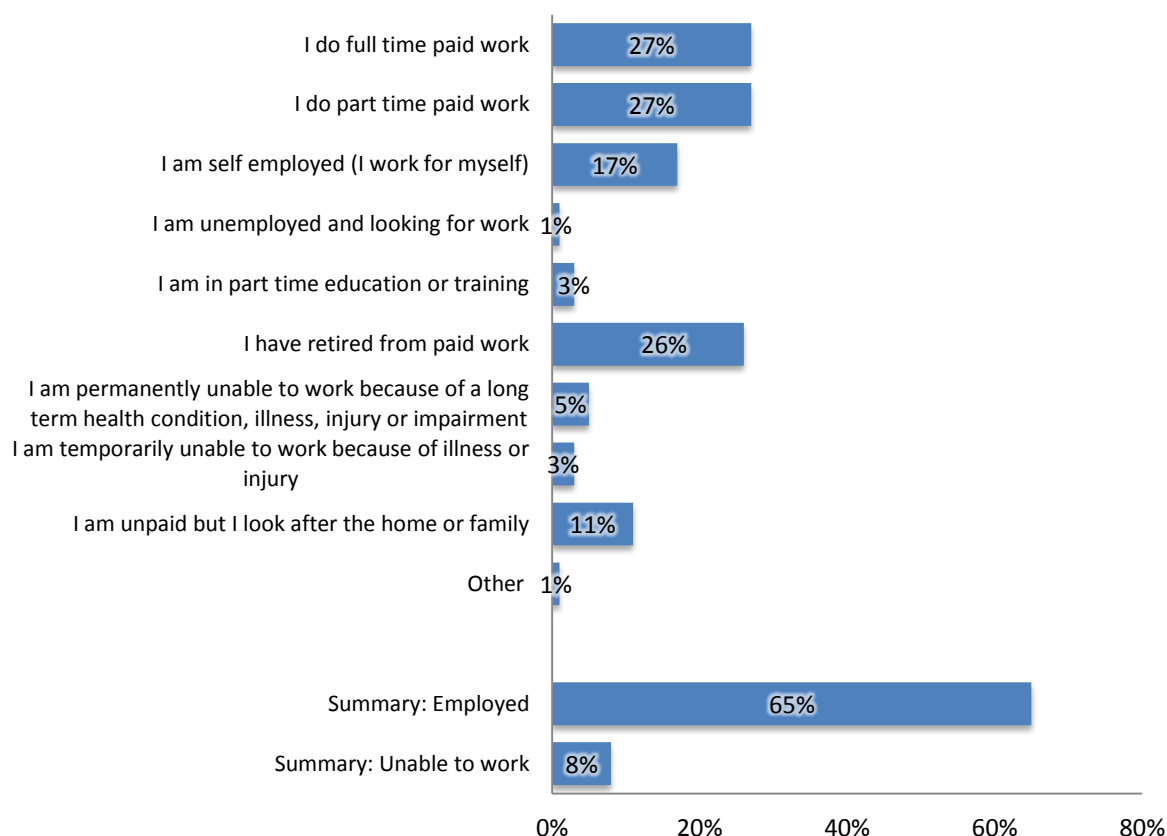
### 3.4 Employment

This section explores the employment status of carers, including the type of work undertaken, the number of hours worked, and the experience of being a carer in employment.

#### 3.4.1 General overview: Employment status

Most respondents are employed as well as being carers (67 people, or 65%), with full time (27%), part time (27%) or self employed (17%) positions. 70% of respondents who provide support for two or more people say they are employed (16 people), as are 76% who care for a child (32 people) and 76% who care for a parent (19 people). 85% of those who care for someone aged under 16 are in employment (17 people), as are 86% who care for someone with a learning, understanding or development difficulty (18 people).

**Figure 79: Can you tell me which ones describe what you were doing in the last week? (All respondents)**



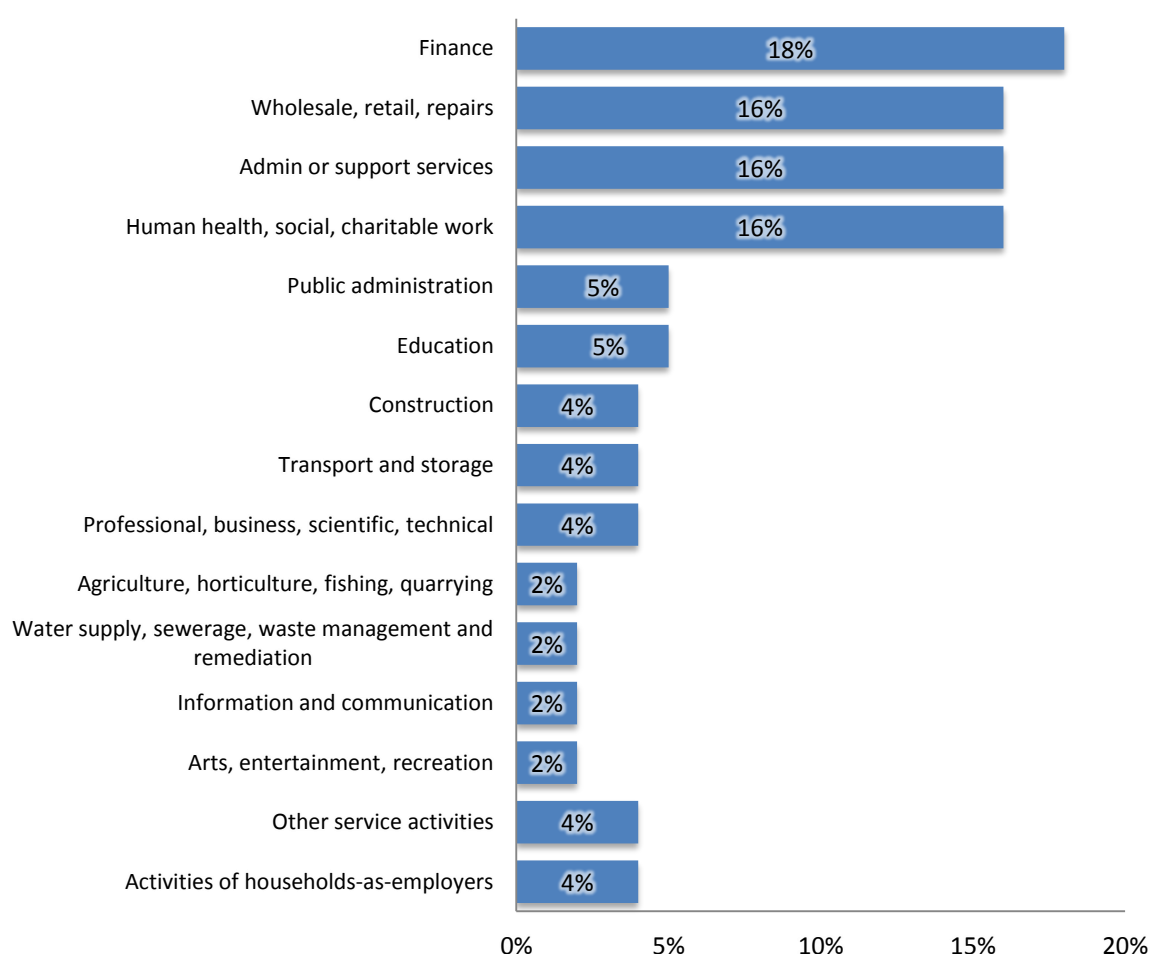
Unweighted base: 103

Of the respondents who are in employment, 89% have one job and 11% have two or more jobs. Male respondents are more likely to have two or more jobs (19%), as are the respondents who provide the fewest hours of care (17% of those who provide 0-12 hours per week – 5 people).

More than four in five respondents (84% - 48 people) work 16 or more hours per week, and 47% work 35 or more hours per week (27 people). Again, males are more likely to work the longest hours (81% work 35+ hours per week), as are those who care for someone aged under 16 (54%) or 67+ (56%). As many as 56% of respondents who provide care for 35 or more hours per week also work for 35 or more hours (10 people). Two in five employed carers (39% - 22 people) have been in their job for ten or more years.

Respondents are most likely to work in finance (18%), wholesale, retail, repairs (16%), admin or support services (16%), or human health, social, charitable work (16%).

**Figure 80: Can you tell me what industry you work in? (All respondents – where in employment)**



Unweighted base: 57

Among respondents who are not currently employed, 96% (44 people) say they have done some kind of paid work in the past. This rate increases to all respondents who now provide 35 or more hours of care per week, and are not in employment. Over two in five of those not in employment previously worked for 35 or more hours per week (43%) and a further 34% worked between 16 and 34 hours. Again, the highest proportion used to work in finance (16%), followed by public administration (14%) and education (11%).

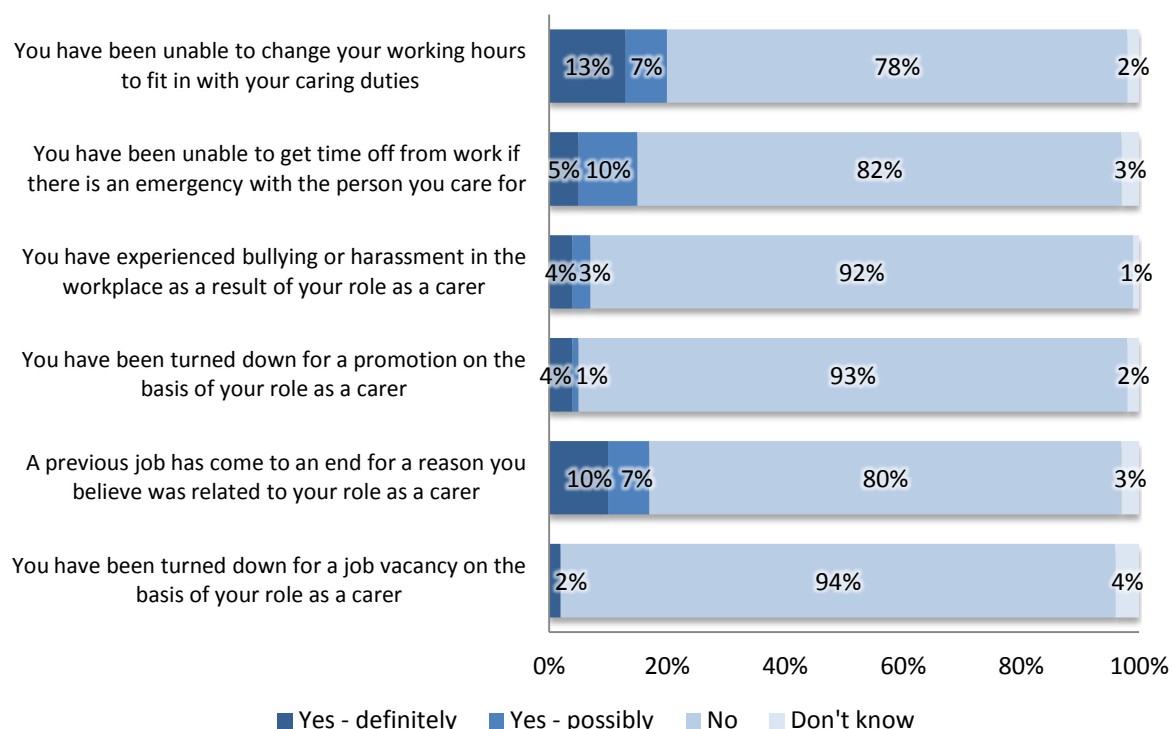
Looking at the rate of voluntary work done, one in five respondents (22% - 23 people) did at least one hour of voluntary work in the week prior to the survey. This rate increases amongst carers aged 16-66 (25%), who are in employment (27%), who care for more than one person (30%), and who care for a child (33%), especially one aged under 16 (40%).

### **3.4.2 Demands for, and use of, services**

All respondents who say they are in employment, have ever been in employment, or have done voluntary work in the past week were asked about a series of statements regarding their experience whilst undertaking this work. The large majority say that they have not experienced any of the situations discussed overleaf. However, 13% say they 'definitely' have been unable to change their working hours to fit in with their caring role. A further 7% say this has 'possibly' happened. A quarter (24%) of those who care for a child say they have had difficulties changing their hours, especially where the child they care for is aged under 16 (35%).

One in six (17%) believe that a previous job came to an end because of their role as a carer; 10% believe this 'definitely' occurred. Again, this rate increases amongst carers of a child aged under 16 (35%).

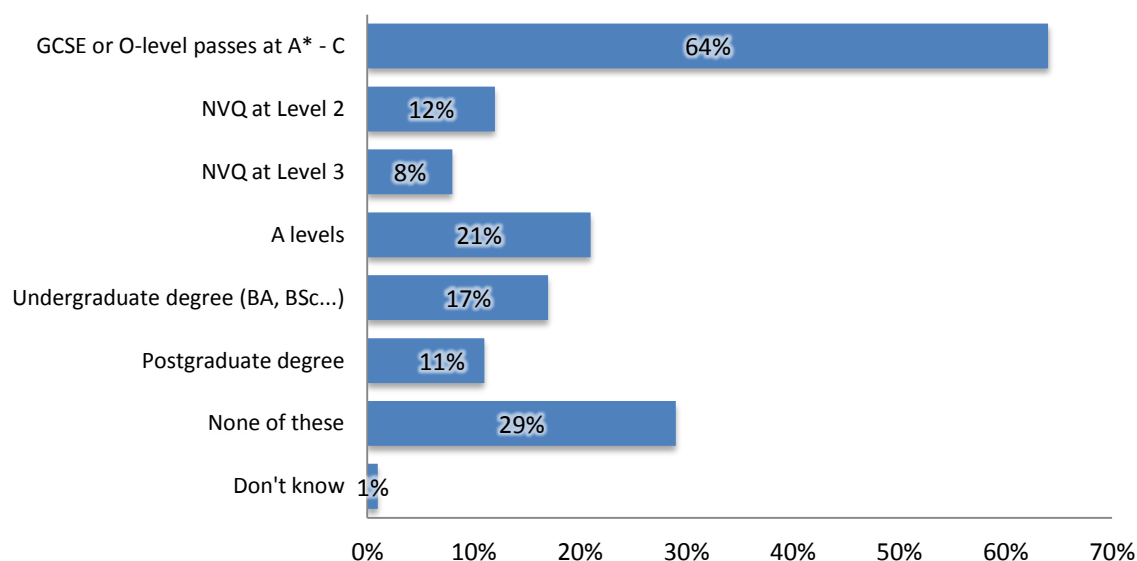
**Figure 81: Can you tell me if you have experienced any of these? (All respondents – where in employment, have been in employment or do voluntary work)**



Unweighted base: 101

Exploring the types of qualifications held by carers, one in six (17%) has an undergraduate degree and 11% a postgraduate degree. Over a third (35%) of people who care for more than one person have an undergraduate degree, as do 29% who care for a child and 30% who care for a child aged under 16.

**Figure 82: Can you tell me if you have any of the following qualifications? (All respondents)**



Unweighted base: 103

### 3.4.3 Key issues

Caring ought to be viewed as a role that is a 'normal' feature of social life, and as such:

*'Caring should not end a carer's career, damage their education, put their ability to acquire skills and training at risk, or force them to give up work.'*  
(Yeandle and Buckner, 2007:v)

As in the UK, most carers in Guernsey (65%) combine caring with paid work. For most (84%) it involves paid work of more than 16 hours per week. Combining both roles is not easy, as Pickard highlights (2004:5 -16)

*'There is a great deal of evidence that carers can experience considerable difficulty in combining caring and employment. Caring can reduce levels of participation through lower hours of work, movement from full-time to part-time work or withdrawal from the labour market altogether. .... The relationship between caring and employment is affected by a number of factors, including the intensity of caring, the nature of employment, the characteristics of the carer and the nature of the relationship with the cared-for person ...'*

Caring is more compatible with part-time work or situations where the worker has some control over their work environment. Caring can reduce earnings and pension rights (partly due to part-time working), and this provides a justification for continued provision of a carer's benefit (Invalid Care Allowance) (see section 3.5.1).

In addition, the overwhelming majority of respondents (96%) say that they have undertaken paid work in the past; and a quarter (22%) have engaged in voluntary work during the past week.

Of those currently or previously in paid work and/or undertaking voluntary work, a significant minority have experienced some form of discrimination in the workplace as a result of their caring role:

- 20% have been unable to adjust working hours to suit their caring responsibilities;
- 17% believe they lost a job because of their caring role;
- 15% have been unable to get time off work in response to an emergency;
- 7% have experienced bullying or harassment due to being a carer;
- 5% have not been promoted because of their caring role; and
- 2% were not recruited because they were carers.

These findings suggest that certain employers' attitudes towards employees who are carers needs to change partly to ensure the social inclusion of carers and who they care for, but also to make their businesses more competitive by recruiting and

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<sup>16</sup> Pickard, L. (2004) *Caring for older people and employment A review of the literature prepared for the Audit Commission*, London: Audit Commission. Retrieved from <http://www.pssru.ac.uk/pdf/dp2015.pdf> on 17th December 2012.



retaining the 'best people' for the job (irrespective of any caring role). A more carer-friendly firm could attract better qualified and motivated applicants.

Yeandle and Buckner (2007:vi-vii) summarise how policy can be taken forward:

*'Protecting carers' right to work, and sustaining them in combining work and care offers the best protection against poverty and financial hardship for carers. The employment, skills and training system needs to play a much more active and explicit role in supporting carers in combining work and care.'*

*Further pensions reform is needed to ensure that carers who take a break from work to care, or who change their working hours or careers, are not penalised in retirement for making the choice to care. Government must take the lead in this and must undertake these reforms as part of a wider review of the way the whole tax, benefits and pensions system works for carers.'*

*Employers and trade unions have a role to play in addressing the design of jobs, creating more opportunities for part-time and reduced hours working at senior levels, and developing appropriate packages of workplace support for working carers.'*

*A new advisory service for SMEs needs to be developed to help smaller organisations give support and advice to carers in their employment, and to explore flexible working solutions which will work to the advantage of their business.'*<sup>17</sup>

Supporting carers in employment should be a relatively high policy priority. As with other areas covered in this chapter, the forthcoming Disability and Inclusion Strategy should view caring as a 'normal' activity and continue to involve carers in the development and delivery of the strategy. To facilitate these changes, providing carers with protection under equalities legislation is proposed (see Chapter 4).

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<sup>17</sup> Yeandle, S. and Buckner, L. (2007) *Carers, Employment and Services: time for a new social contract?*, London: Carers UK. Retrieved from <http://circle.leeds.ac.uk/files/2012/08/carers-uk-report-6.pdf> on 18th December 2012.

### 3.5 Financial security, income and benefits

This section explores the types of income carers receive and the types their household receives more generally. It also looks at the level of income received and the extent to which carers and their household have difficulties meeting the costs of a range of day-to-day expenses.

#### 3.5.1 General overview: types and level of income received

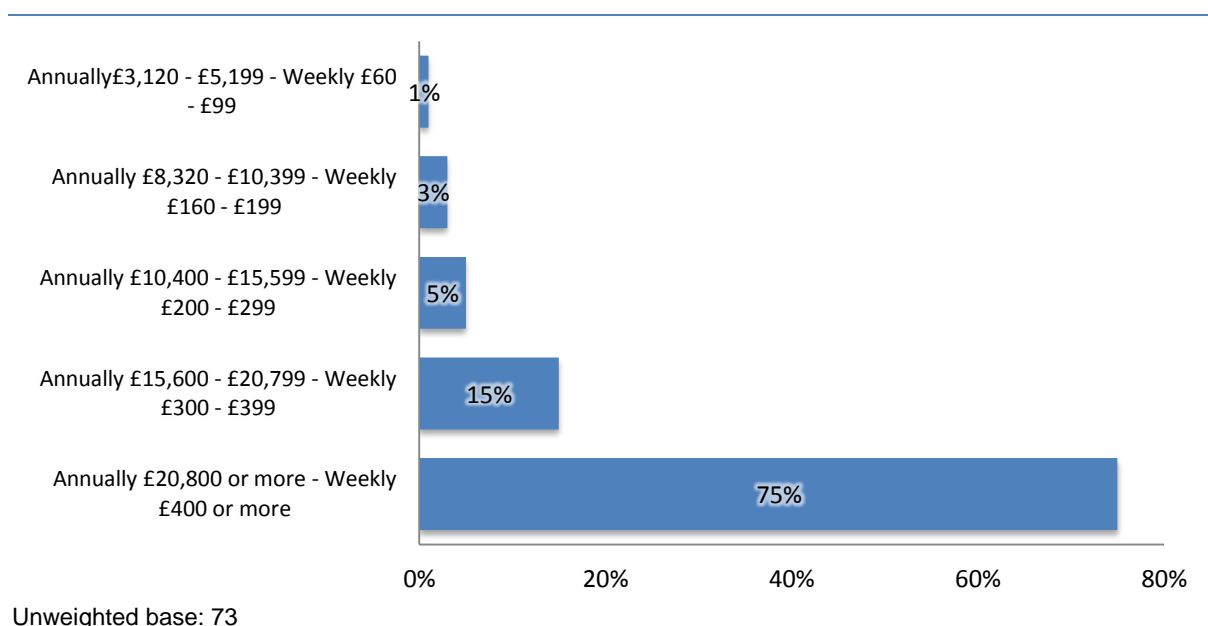
Over half (54%) of respondents receive an income through employment, whilst 40% do so via a pension and 35% via a benefit. Benefits recipients are more likely to be females (41%), those who provide care for 35 or more hours per week (55%), those who care for a child (48%), especially aged under 16 (65%).

**Table 17: Could you tell me a) what kinds of income you get? And then b) what kinds of income other people in your household get (excluding yourself)? (All respondents)**

	Personal income	Household income
Earnings from employment	48%	61%
Earnings from self-employment	8%	19%
Pension from a former employer	22%	31%
State pension	28%	38%
Family Allowance	20%	31%
Unemployment Benefit	0%	1%
Supplementary Benefit	5%	16%
Attendance allowance	7%	28%
Invalid care allowance	18%	23%
Incapacity/invalidity benefit	2%	16%
Other state benefits	1%	3%
Interest from savings etc.	44%	47%
Trust fund	2%	5%
Rent rebate for social housing	9%	9%
Other kinds of regular allowance from outside the household	11%	11%
Other sources	12%	14%
Prefer not to say	6%	13%
Summary: Employment	54%	67%
Summary: Pension	40%	48%
Summary: Benefit	35%	63%
Unweighted base: 103		

In terms of the level of income received, the large majority of households get more than £20,800 a year.

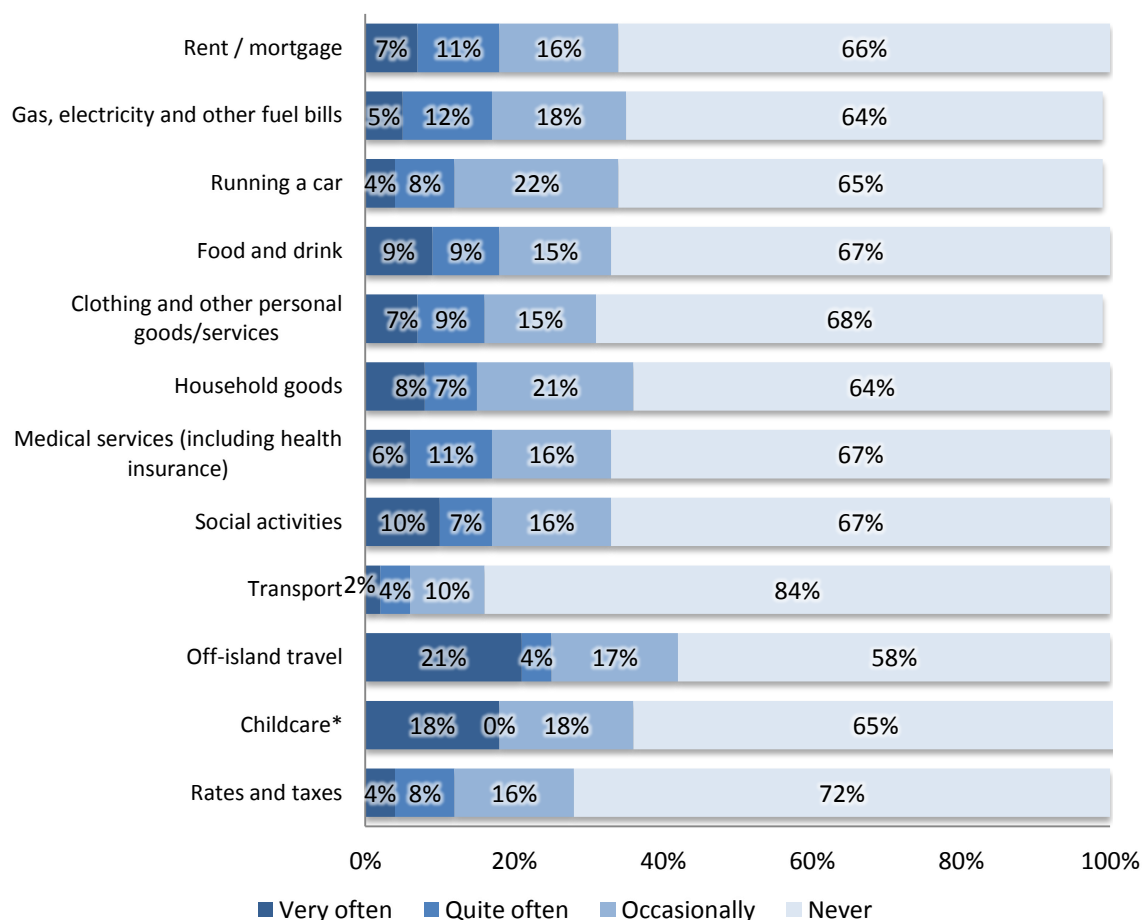
**Figure 83: Can you tell me how much income your household gets? (All valid responses)**



### 3.5.2 Demands for, and use of, services

All respondents were then asked how often, if at all, their household finds it difficult to meet the cost of a range of day-to-day expenses. Figure 84 reveals that one in five respondents find it is 'very often' difficult to cover the cost of off-island travel (21%). 36% of carers of a child, especially aged under 16 (53%) find it difficult very often to meet off-island costs.

**Figure 84: Can you tell me how often your household finds it difficult to meet the costs of each one? (All valid responses)**



Unweighted bases vary

\* small sample base (17)

### 3.5.3 Key issues

Over half (54%) of respondents receive an income through employment, whilst 40 per cent have a pension and 35 per cent another benefit. Benefits recipients are more likely to be women (41%), those who provide care for 35 or more hours per week (55%), those who care for a child (48%), especially one aged under 16 years (65%).

Thirty four per cent said that they are having some sort of difficulty (occasionally to very often) paying their mortgage or rent and 36 per cent are having difficulty paying their gas, electricity and other fuel bills. Furthermore, one in five respondents finds it is often very difficult to cover the cost of off-island travel (21%). This rises to 53 per cent of carers of a child aged under 16.

The issues of adequacy and take up of benefits discussed in section 2.5.3 also apply to carers. Whilst four in five respondents to this Carers' Survey (80%) report that they themselves have an impairment or long term health condition only two per cent are receiving Incapacity Benefit whilst seven per cent are receiving Attendance Allowance. Furthermore, only 18 per cent of respondents are receiving Invalid Care Allowance in

respect of their caring responsibilities. These findings suggest that carers may need additional support, including targeted publicity, to access the benefits to which they may be entitled and confirm that the States' review of Attendance Allowance and Invalid Care Allowance is timely.

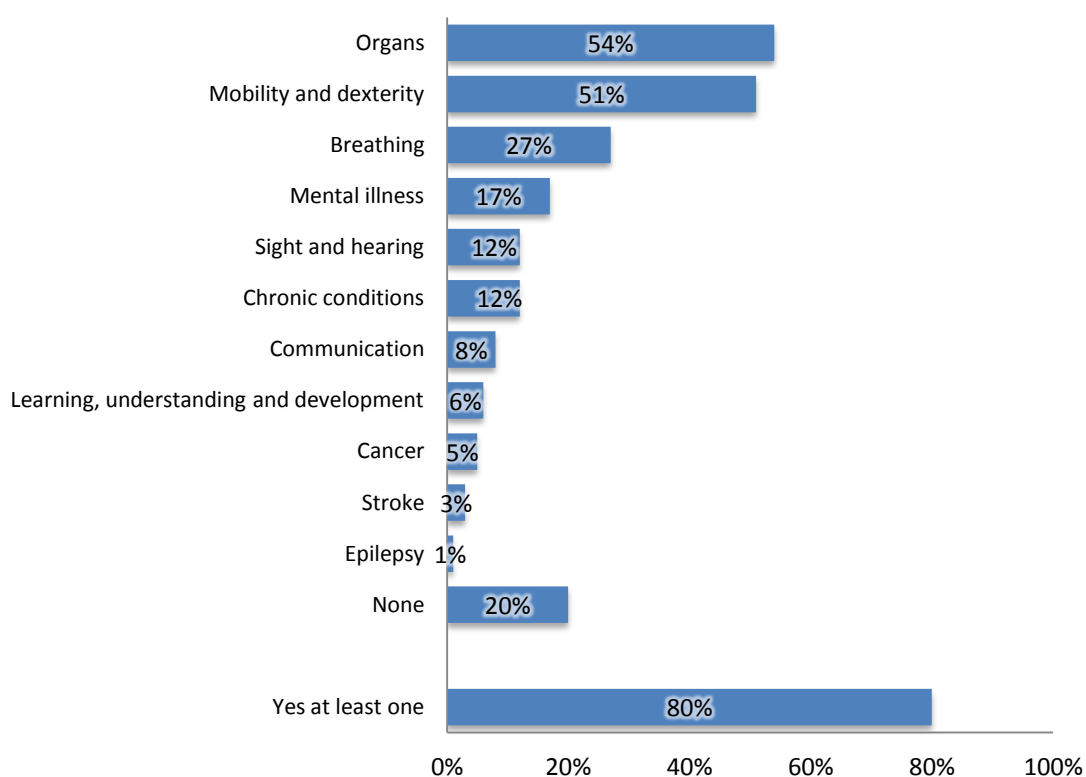
### 3.6 Health and well-being

This section explores the extent to which carers themselves have a disability or long term condition, and what type of condition this relates to. It will also look at the rate of GP attendance and whether there are any barriers to accessing medical services.

#### 3.6.1 General overview: prevalence of long term conditions

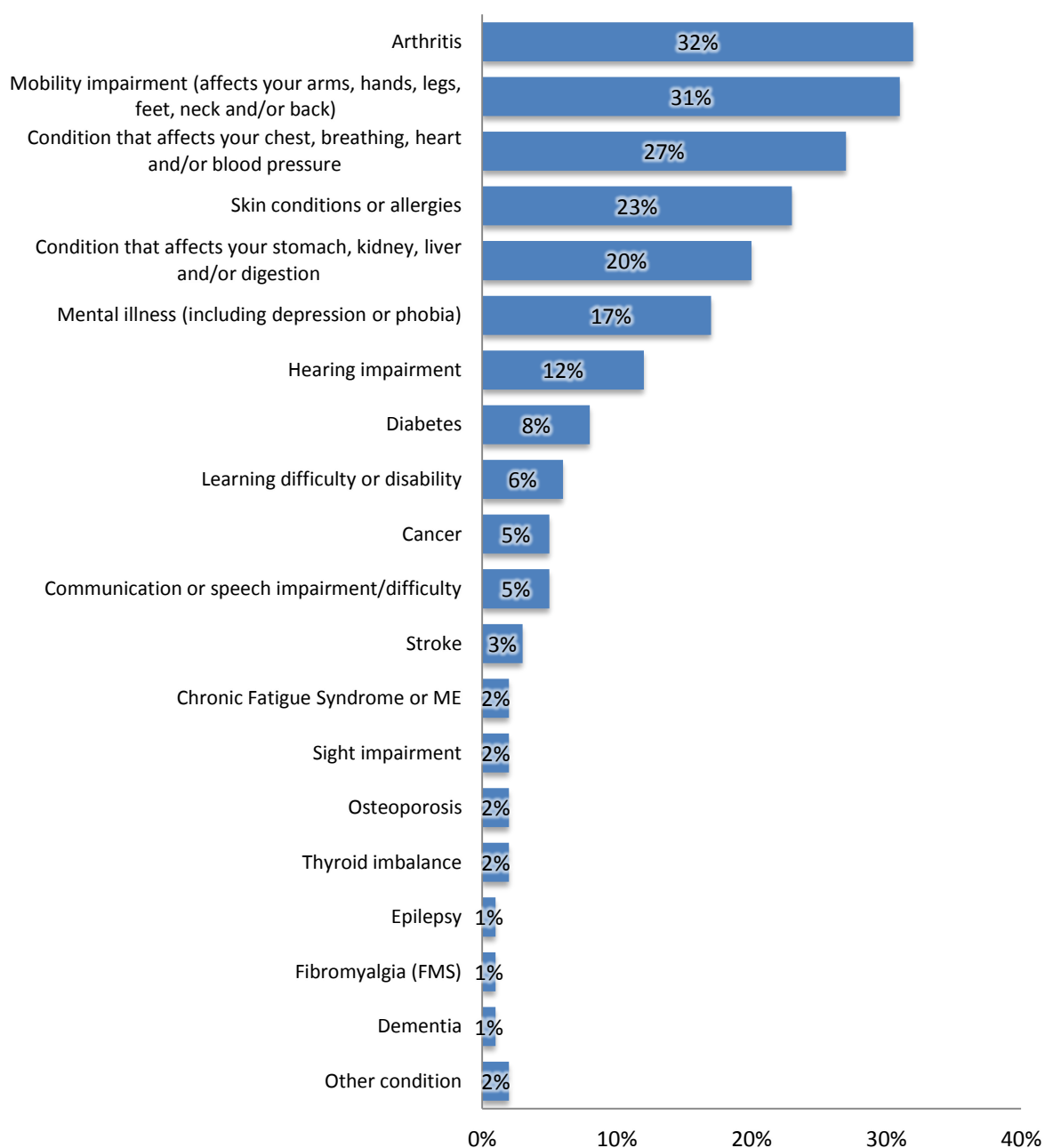
Exploring the extent to which carers have long term conditions themselves, four in five respondents (80%) report having at least one condition. Prevalence is higher amongst those aged 67+ (95%), and those who care for a partner or spouse (89%). Over half (54%) have a condition that affects their organs and 51% their mobility and dexterity.

**Figure 85: Can you tell me whether you have any of the following? By disability grouping (All respondents)**



Unweighted base: 103

Looking in more detail at the types of conditions that carers have, Figure 86 shows that a third (32%) suffer with arthritis and a similar proportion with a mobility impairment more generally (31%). Over a quarter (27%) have a condition related to their chest, breathing, heart or blood pressure and 23% a condition related to their skin or allergies.

**Figure 86: Can you tell me whether you have any of the following? (All respondents)**

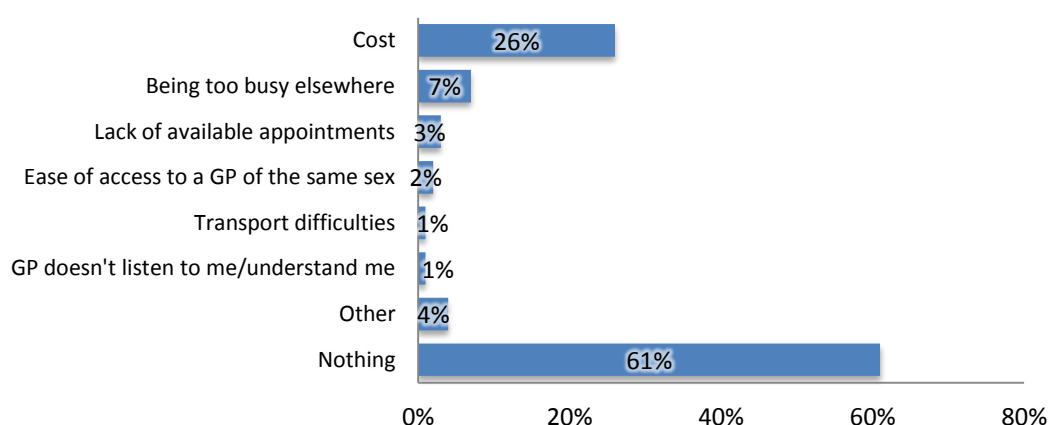
Unweighted base: 103

### 3.6.2 Demands for, and use of, services

More than three in five respondents have been to see a GP about their own health and well being three or more times in the last 12 months (61%), whilst 82% have been at least once. Attendance rates at a GP are higher amongst those aged 67+ (95%), and those with a long-term condition (87%), especially those with a breathing problem (97%).

Whilst the majority of respondents are not put off by anything when they need to see a GP (61%), more than one in four (26%) are put off by the cost, which is more likely to deter carers aged 16-66 (28%), carers in employment (33%), and carers of a child (30%).

**Figure 87: Is there anything that puts you off going to see your GP when you need to? (All respondents)**



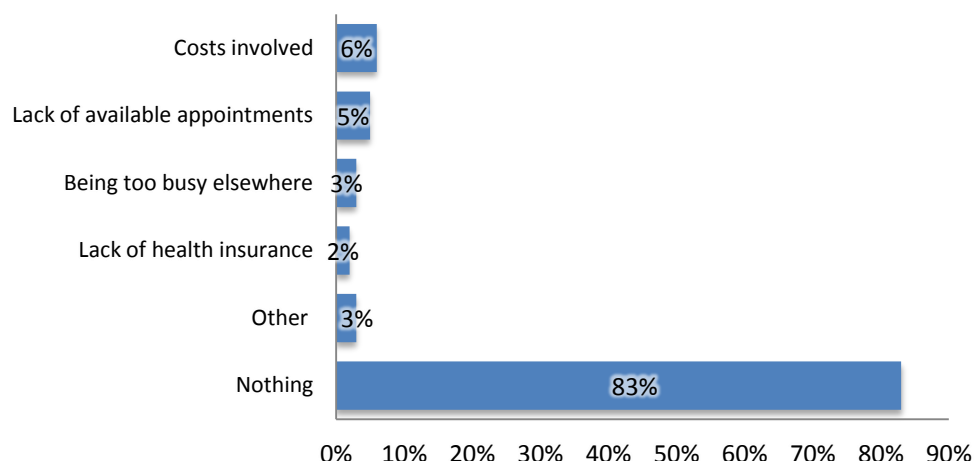
Unweighted base: 103

Over half (53%) of respondents have been to see a specialist about their own health and well being at least once in the last 12 months. 31% have been 1-2 times and 22% three or more times. Females are more likely to have been to see a specialist (57%), as are those with a mobility or dexterity issue (64%), breathing difficulties (65%) and a condition that affects their organs (63%). 69% of people who provide care for more than one person have been to see a specialist regarding their own condition.

The large majority are not put off going to see a specialist for any reason (83%). However cost deters 6% and lack of appointments 5%.



**Figure 88: Is there anything that prevents you from going to see your specialist when you need to? (All respondents)**



Unweighted base: 103

Over half (55%) of respondents support someone who has had to go off-island for treatment, a diagnosis, second opinion, or operation. Over a quarter (27%) care for someone who has had to go off-island three or more times. Four in five (82%) respondents who support someone who has been off-island say that they were able to accompany them. This increases to 91% who care for a child, and all who care for a child aged under 16. Only 9 people say they could not go with the person they cared for during a period of off-island treatment, of whom 3 say this was because they could not afford it and a further 3 say they have other caring commitments.

There is a mixed response when asked who pays for this accompanying travel. Almost half of respondents (48%) say that they pay for themselves, whilst 43% get funding from the States. 62% of carers who work 16+ hours per week say they pay for the travel themselves, as do 64% who care for a partner or spouse and 75% who care for a parent. Carers who support a child are most likely to receive funding from the States (67%).

### 3.6.3 Key issues

Four in five respondents (82%) who support someone who has been off-island say that they were able to accompany them. This increases to 91 per cent who care for a child, and all who care for a child aged under 16. However, whilst 43 per cent got funding from the States almost half (48%) of carers who accompanied someone for a diagnosis, second opinion or treatment say that they paid the costs themselves. Carers who support a child are most likely to receive funding from the States (67%) whilst 62 per cent of carers who work 16+ hours per week say they pay for the travel themselves, as do 64 per cent who care for a partner or spouse and 75 per cent who care for a parent. As reported in section 3.5.2, one in five carers find it is often very difficult to cover the cost of off-island travel (21%). This rises to 53 per cent of carers of a child aged under 16. Furthermore, the Alderney focus group gave examples where lack of funding for a nurse or family member to accompany the patient (for example, a husband who needs monthly injections in Southampton or a daughter with visual impairment) put financial pressure on the family.

These findings confirm the recommendation in 2.4.2 for policy makers to consider whether there is an economic, medical and social case for further investment in the island's medical services and if not whether further support should be given to carers who need to accompany someone with an impairment or long term health condition to the mainland for a diagnosis, second opinion or treatment that is not available in Guernsey.

The finding that four in five respondents (80%) have an impairment or long term health condition with over half (51%) reporting a condition that affects their mobility and dexterity and 17 per cent a mental health condition suggests that many carers need support themselves. The States should review whether sufficient professional care is being provided for disabled people on the island or whether a disproportionate responsibility is falling on family members and other relatives.

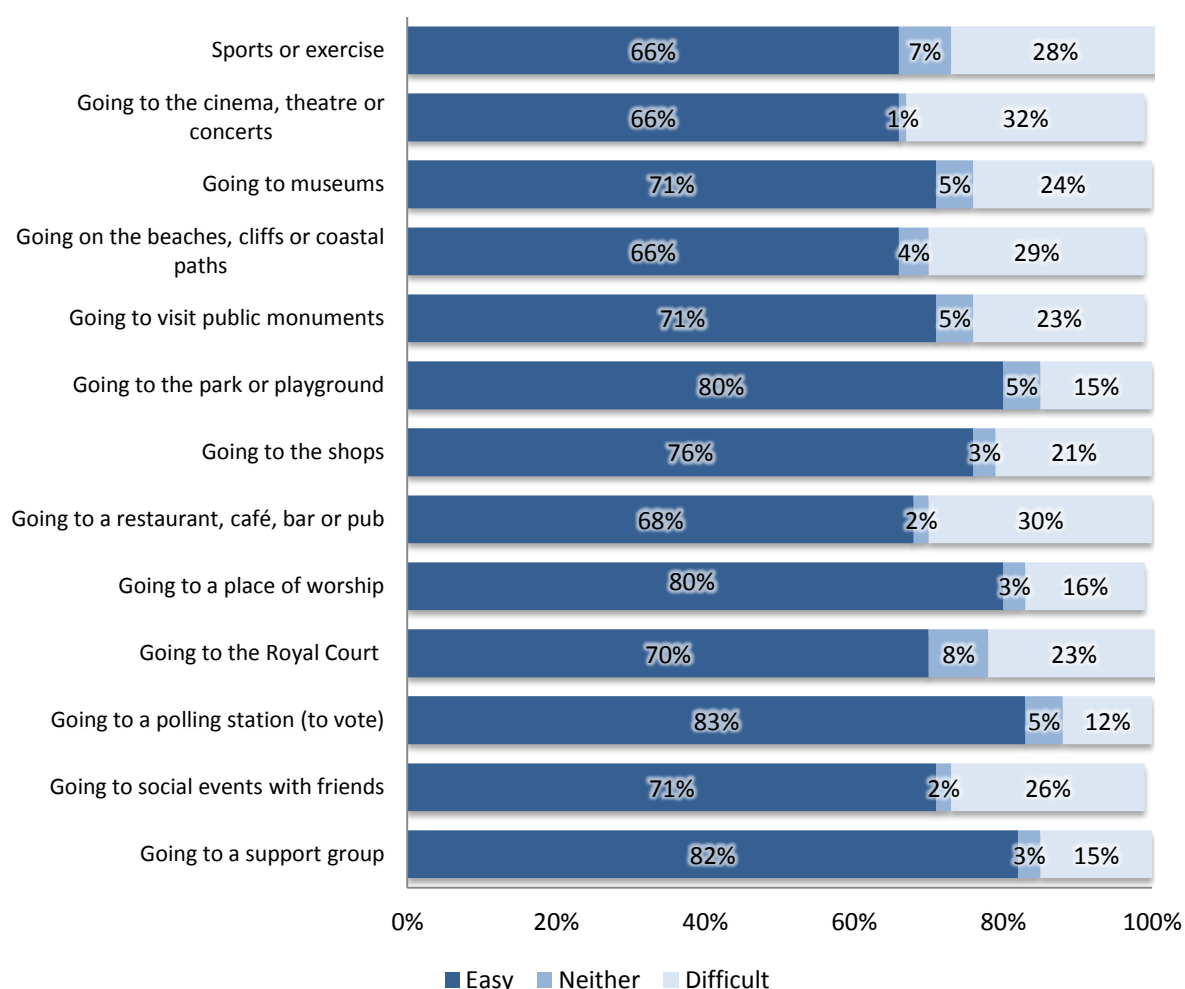
### 3.7 Social life

This section looks at whether carers have any difficulties visiting or accessing social activities or venues.

#### 3.7.1 Demands for, and use of, services

Figure 89 shows that respondents do face difficulties accessing social activities or venues. Whilst the largest proportion find it easy to access such activities, around one in three find it difficult to go to the cinema, theatre or concert (32%), to a restaurant, pub or café (30%), or to the beach, cliff and coastal paths (29%). 26% also find it difficult to do social activities with friends, which is more likely to be an issue for women (29%), carers in employment for 16+ hours per week (33%), carers providing support for 35+ hours per week (47%), and carers of a child aged under 16 (68%). Likewise, women are more likely to find it difficult to go to the cinema, theatre or concerts (34%), as are carers who are employed (39%), those who provide care for 35+ hours per week, and 53% who care for a child.

**Figure 89: Can you tell me how easy or difficult it is for you as a carer to access each of these? (All valid responses)**



Unweighted bases vary

### 3.7.2 Key issues

The policy of social inclusion requires that carers are able to participate fully in social life. Some carers, like disabled people, report that they find it difficult to access some social facilities and activities; although in general the proportion saying this is lower than it is for disabled people (see Figures 66 and 89). The exceptions relate mainly to political participation whereby 8% of carers compared to 4% of disabled people say they have problems accessing the Royal Court and 5% of carers compared to 3% of disabled people find going to a polling station difficult. There is also a slightly higher proportion of carers (4%) than disabled people (3%) saying they have problems accessing coastal locations.

## 3.8 What would have a positive impact

When respondents were asked to specify in their own words up to three things they feel would make a significant positive difference to their life, or the life of the person they care for, a wide range of comments were obtained. These comments have been coded into common themes and presented in Table 18. The largest proportion of people feel support / help would impact their life positively, while financial assistance is mentioned frequently, as was better disabled access / facilities.

**Table 18: Please can you tell me [up to] three things, which if changed, would make a significant positive difference to your life, or the life of the person you care for? (All respondents)**

	1st mention	2nd mention	3rd mention
Financial assistance	16%	10%	9%
Support / help (inc. support group, in the house)	19%	15%	9%
Mobility	1%	1%	0%
Address mental health issues / better services / strategies	0%	1%	0%
Public transport issues / regular service	2%	3%	0%
Better disabled access / facilities / issues (inc. funding)	9%	8%	1%
Finding Employment	1%	3%	0%
Increase / easier access to respite care	8%	6%	9%
To be given my sight back / improvement to my sight	1%	1%	0%
Better understanding / public awareness of my condition	3%	3%	4%
A bungalow / ground floor living accommodation	0%	3%	0%
Information about events / social activities /services/health	3%	3%	4%
Access to occupational therapy	0%	2%	1%
Improved health/overcoming the limitations of disability	4%	3%	6%
Provide access to suitable disablement aids/equipment	5%	1%	1%
Improved /advancement in medical science/treatment	1%	0%	3%
Easier/more accessible communication with support services	1%	1%	1%
Removal of street cobbles from pavements (improving mobility/safety)	0%	1%	0%

Moving to own accommodation	1%	0%	0%
Better access to specialised medical facilities/ personal	3%	5%	4%
Having larger /more spacious accommodation	0%	0%	1%
Other	25%	17%	22%
No Comment	17%	22%	28%
Unweighted base	<b>103</b>	<b>86</b>	<b>67</b>

### 3.9 What works well people already

In terms of what people feel is already working well for them, the largest proportion specify the support and care they receive (excluding family), followed by their quality of life.

**Table 19: Please can you tell me [up to] three things, which are already working well for you? (All respondents)**

	1st mention	2nd mention	3rd mention
Support I receive / care / medical care / GP / medicines / (excluding family)	30%	29%	26%
Being independent / being able to look after myself	0%	3%	0%
Quality of life (including a good social life)	13%	10%	10%
Family / Friends	9%	15%	7%
School / College	9%	2%	0%
I'm working / my job	3%	2%	1%
Getting out and about / mobility / health	2%	0%	0%
My home / accommodation	2%	4%	4%
Access to public transport system	0%	1%	0%
Nice environment	1%	0%	3%
Having private transport	3%	2%	3%
Using sport/ exercise facilities	1%	0%	1%
Access to disability aids	3%	3%	1%
Being in good health	4%	0%	3%
Other	10%	7%	7%
No Comment	14%	21%	37%
Unweighted base	<b>103</b>	<b>89</b>	<b>70</b>

## 4 Conclusion: Legal protections

### 4.1 Introduction

The States of Guernsey is “committed to building an inclusive and caring society and removing barriers to equality, social inclusion and social justice. This means enabling all people to participate fully in education, employment, social life and politics....It means not disabling people by creating a physical environment that excludes them or services which don't meet their individual needs.”<sup>18</sup>

The study has found that whilst the States of Guernsey provides a range of services and support for disabled people, the policy aim to enable disabled people to live independent lives free of discrimination so that they are able to maximise their potential is not yet fully realised.

In particular, the study has found that people with impairments and long term health conditions face discrimination and bullying in Guernsey. Specifically, people with impairments and long term health conditions face discrimination in the labour market, at the workplace, in education and in their access to social facilities, whilst carers may face ‘discrimination by association’ with a disabled person. Disabled employees suffer bullying at work while children suffer bullying at school. This section reviews the evidence of discrimination in the survey and considers legal protections.

### 4.2 Discrimination

**Disability discrimination** is where a disabled person is treated less favorably than a non disabled person on the grounds of their disability. The study has found evidence of discrimination against disabled people in Guernsey. Discrimination can be either direct or indirect. The study has found evidence of both direct and indirect discrimination. Direct discrimination takes place when disability is used as an explicit reason for discriminating. Evidence of direct discrimination has been found with respect to employment practices at work. Section 2.3 shows that a third of those who had been in some form of work believe that their employment ended because of their condition and in some cases this will have been due to disability discrimination. Furthermore, 15 per cent believe that they have not obtained a job and eight per cent have been denied promotion because of an impairment or long term health condition.

Indirect discrimination occurs when regulations and procedures and practices, though not intended to discriminate, nevertheless have the effect of discriminating against certain groups in practice. Indirect discrimination has been found in Guernsey in respect of disabled people’s housing and access to locations and facilities. Section 2.2 found that 23 per cent of people who live in social housing and 20 per cent of people under 16 feel that their housing does not meet their needs. Section 2.9 reveals that there are particular locations and facilities that disabled people have difficulties

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<sup>18</sup> <http://www.gov.gg/disability>

accessing, notably sports or exercise venues, entertainment venues, coastal locations, museums and the Royal Court.

A person subjects a disabled person to harassment where, for a reason which relates to the person's disability, he or she engages in unwanted conduct which has the purpose or effect of:

- violating the disabled person's dignity, or
- creating an intimidating, hostile, degrading, humiliating or offensive environment for him or her.<sup>19</sup>

Bullying is a form of harassment. The survey shows that 15 per cent have experienced bullying or harassment in the workplace. Section 2.8 shows that bullying is also an issue for Guernsey's schools. Whilst the States' Education Department makes it clear that it takes any incidents or allegations of bullying very seriously and will not tolerate bullying in any of Guernsey's schools, whether physical or verbal, more than two in five respondents in full time education said that they have been bullied in school (42%).

Discrimination by association on the grounds of disability occurs if a person discriminates against someone – who may not necessarily be disabled themselves - because they associate with a disabled person. Discrimination by association has been found in Guernsey with respect to carers. Section 3.4.2 shows that carers have experienced discrimination by association because of their role as a carer with respect to being unable to change their working hours to fit with their caring responsibilities, being unable to get time off work in an emergency, being turned down for promotion, losing existing employment, being turned down for a job vacancy and suffering bullying and harassment in the workplace (see Figure 81).

Key findings are that:

- Legislation should underpin the making of reasonable adjustments to Guernsey's current and future housing stock and other public and private buildings.
- Potential for independent living through employment will only be possible if disabled people (and their carers) are not discriminated against in the workplace (or as a result of their caring responsibilities) and this requires a change in employers' attitudes and practices underpinned by legislation.
- As a complement to financial incentives, legislation can be used to place a duty on service providers to make reasonable adjustments so that disabled people may access services (including locations) and goods.

However, at present Guernsey does not have any equalities or anti-discrimination legislation including that for disabled people. There is a Law (the 'Prevention of Discrimination (Enabling Provisions) (Bailiwick of Guernsey) Law, 2004') which

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<sup>19</sup> The Disability Discrimination Act 1995 (Amendment) Regulations 2003 and Equality Act 2010.

empowers the States to introduce anti-discrimination measures, but no provision has yet been made for disability discrimination.<sup>20</sup>

The United Kingdom has ratified the United Nations Convention on the Rights of Persons with Disabilities, but this has not yet been extended to Guernsey. It would seem appropriate for Guernsey to introduce legislation to bring practices on the island in line with the standards of the UN Convention. This would require, at least, introducing robust non-discrimination legislation and legislation to fully protect legal capacity (the latter is discussed in section 4.3 below).

If the States wished to introduce legislation to protect disabled people from discrimination and harassment the Equality Act, which became effective in Great Britain in 2010, could serve as a model. The Equality Act 2010, which consolidates and extends the previous separate equality legislation based on individual protected characteristics, is the culmination of almost 60 years of legislation in Britain to counter discrimination, including discrimination against disabled people. The first legislation to address discrimination against disabled people was the Chronically Sick and Disabled Act which became effective in 1970. The Act required local authorities to register disabled people and publicise services. Discrimination against disabled people was further addressed in subsequent legislation, notably the Disability Discrimination Act 1995 and subsequent amendments. The Disability Discrimination Act (as amended) incorporated principles established in other parts of Britain's anti-discrimination legislation. For example, The Equal Pay Act 1970 and Sex Discrimination Act 1975 had introduced the concept of indirect discrimination and provisions permitting positive discrimination whilst amendments to the Race Relations Act imposed general and specific public sector equality duties.<sup>21</sup> Similar duties were introduced in respect of disability by the Disability Discrimination Act 2005.

The Equality Act 2010 prohibits direct discrimination, indirect discrimination and harassment of disabled people as well as discrimination by association with a disabled person. The Act also places a duty on employers and service providers to make 'reasonable adjustments' where a provision, criterion, practice or physical feature puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled. An employer or service provider must also, where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, take such steps as it is reasonable to provide the auxiliary aid. Furthermore, the Act contains an exception that permits (but does not require) positive action measures, in favour of disabled people, in specific circumstances. Positive action allows an employer to take steps to encourage members of a disadvantage group to apply for jobs. For instance, employers might take steps to ensure that job vacancies are advertised at local disability charities.

The Public Sector Equality Duty of the Equality Act, which came into force in 2011, requires certain specified public bodies and any other organisation when it is carrying

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<sup>20</sup> The only remedy for a person who believes that they have been dismissed because of disability is to bring a case of 'unfair dismissal' to the Employment and Discrimination Tribunal, under the 'Employment Protection (Guernsey) Law, 1998'.

<sup>21</sup> Hepple, B (2010) 'The New Single Equality Act in Britain', *The Equal Rights Review*, Vol. Five.



out a public function to have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities. The Equality Act 2010 (Specific Duties) Regulations 2011 requires public bodies to be transparent about how they are responding to the Equality Duty.

Furthermore, Tribunals are given powers under the Equality Act 2010 to make recommendations which the respondent must implement within a specified time to remove or reduce effects of discrimination on the complainant or “any other person”. The Act extends previous protection which applied only to sex discrimination to all protected categories, including disabled people, making employers liable for harassment of employees by third parties such as customers or clients if he or she fails to take reasonable preventative measures.

Research carried out recently in the UK found that the majority of employers of all types and sizes of organisation express strong support for workplace equality legislation.<sup>22</sup> Indeed, the proportion of respondents reporting that there is a moral reason for their organisation having a policy, or an approach towards equality, exceeds 90 per cent in every category of organisation.<sup>23</sup>

This significant level of engagement in, and expressed support for, equality policies has important implications for strategies to spread equality practices throughout the Guernsey workforce. Findings from the UK study show that British employers are concerned that their establishments are compliant with workplace equality legislation and are also concerned with how their organisation is perceived. This highlights that legislation, combined with the promotion of a social responsibility agenda, may be a valuable tool to influence practice in Guernsey.

### 4.3 Legal capacity

In addition to legislation to combat discrimination, legislation to protect the legal capacity of people with an impairment or long term health condition must be part of a raft of legal protections. These should include (at least) measures to conform to the Convention on the Rights of Persons with Disabilities to ensure that:

- Children with disabilities have the right to express their views freely on all matters affecting them, and that their views are given due weight in accordance with their age and maturity, on an equal basis with other children, and are provided with disability and age-appropriate assistance to realize that right;
- Persons with disabilities have the right to recognition everywhere as persons before the law; enjoy legal capacity on an equal basis with others in all aspects of life; and receive the support they may require in exercising their legal capacity;
- Appropriate and effective safeguards are in place to prevent abuse in accordance with international human rights law and to underpin the exercise of legal capacity;

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<sup>22</sup> Perren, K, Roberts, S. Stafford, B. and Hirsch, D. (2012) *Evaluation of the Implementation of the Equality Act 2010: Report 1 - Organisational Approaches to Equality*. Government Equalities Office, Home Office, London.

<sup>23</sup> Ibid.

- Persons with disabilities enjoy the equal right to own or inherit property, to control their own financial affairs and have equal access to bank loans, mortgages and other forms of financial credit, and are not arbitrarily deprived of their property;
- Persons with disabilities have effective access to justice on an equal basis with others, including through the provision of procedural and age-appropriate accommodations;
- Appropriate training is provided for those working in the field of administration of justice, including police and prison staff;
- Persons with disabilities enjoy the right to liberty and security of person on an equal basis with others; and are not deprived of their liberty unlawfully or arbitrarily, and that the existence of a disability can never justify deprivation of liberty;
- All appropriate measures are taken to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, including encouraging the media and providers of information through the Internet, to make their services accessible to persons with disabilities; and that the use of sign languages is recognised and promoted;
- Discrimination against persons with disabilities is eliminated in all matters relating to marriage, family, parenthood and relationships; and that a child shall not be separated from her or his parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case must a child be separated from its parents on the basis of a disability of either the child or one or both of the parents;
- Persons with disabilities enjoy political rights and the opportunity to exercise them on an equal basis with others.<sup>24</sup>

In this respect it is noted that Guernsey is reforming its mental health legislation and replacing the existing legislation dating from 1939 with new mental health legislation effective from April 2013.<sup>25</sup> It is recommended that Guernsey's policy makers and government lawyers examine the forthcoming legislation to ensure that it complies in all respects to the UN Convention on the Rights of Persons with Disabilities and review this and other current and forthcoming legislation to ensure that, where necessary, it is brought into line with, and keeps pace with, developments in international standards for disabled people including disabled children.

The survey has been highly informative in revealing the prevalence of disability in Guernsey and Alderney; it has also revealed disabled people's and carers' use of existing services and

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<sup>24</sup> Convention on the Rights of Persons with Disabilities.

<sup>25</sup> Order in Council No. XV of 2011 The Mental Health (Bailiwick of Guernsey) Law, 2010.

their wishes for additional support and help. The States are to be congratulated on what has already been achieved; as might be expected there remain outstanding issues and concerns to be addressed, and tackling these can be more effectively attained with appropriate legal protection in place.

## 5 Appendix 1: Profile of the samples

This section shows the demographic profile of the responding sample of 271 people with a disability or long term condition and 103 carers.

### 5.1 Disabled people

The following presents the age, gender, and type of disability profiles of the sample of people with long term conditions. Further information is provided on tenure, employment status, income and benefits status, and household size within the relevant sections in the core of the report.

#### 5.1.1 Age and gender

The age profile of the sample closely matches the age profile of all people with a disability or long term condition across the Bailiwick (as defined through the Stage 1 prevalence survey). One in ten (11%) is aged under 16 (cf. 7% in Stage 1), whilst 57% is aged 16 to 66 (cf. 66% in Stage 1) and 33% is aged 67+ (cf. 27% in Stage 1). There are however, a slightly higher proportion of females in the Stage 2 sample when compared to the Stage 1 sample (62% cf. 55%). It is important to highlight that there is a higher representation of females, especially aged 67+. This has an impact on the patterns found throughout this report by gender, because these can be due in part to age-related variations, and therefore disability-related variations.

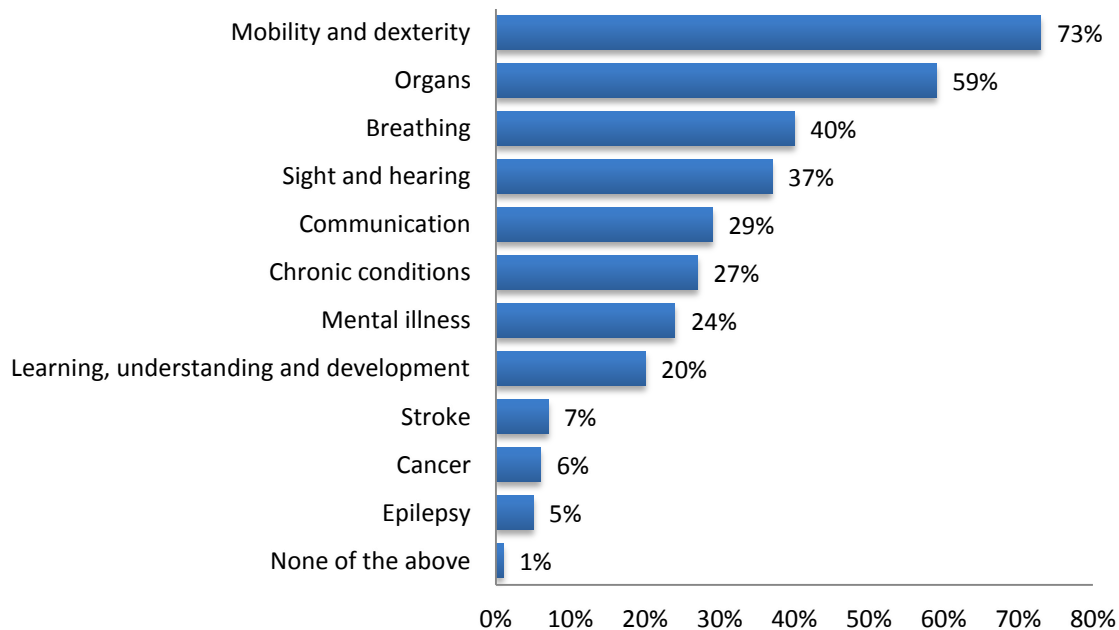
**Table 20: Gender and age profile of the sample (All respondents)**

	%	Sample size
<b>Age</b>		
Under 16	11%	30
16 to 66	57%	153
67+	33%	88
<b>Gender</b>		
Male	38%	103
Female	62%	168
<b>Age and gender</b>		
Male under 16	5%	13
Female under 16	6%	17
Male 16-66	24%	65
Female 16-66	32%	88
Male 67+	9%	25
Female 67+	23%	63

### 5.1.2 Type of disability / condition

The long term condition(s) of all the respondents that took part in Stage 2 have been grouped together into a series of disability types. Figure 90 presents these groups. Almost 3 in 4 (73%) report a condition that affects their mobility or dexterity and 59% their organs. Around 2 in 5 report a condition that affects their sight or hearing (37%) or their breathing (40%).

**Figure 90: Can you tell me whether you have any of the following? Grouped conditions (All respondents)**



Unweighted base: 271

There are marked variations by age, which is important to recognise when engaging with the messages throughout this report. These variations include:

- 80% of those aged under 16 have a communication difficulty and 73% a learning, understanding and development difficulty.
- These conditions are also more prevalent amongst those aged 16-34 (50% communication and 43% learning, understanding and development).
- People aged 35-66 are more likely to have a mental health condition (34%), which mirrors the Stage 1 findings.
- 89% of those aged 67+ have mobility or dexterity difficulties; 67% have a condition that affects their organs; and 47% have a condition that affects their sight and hearing.

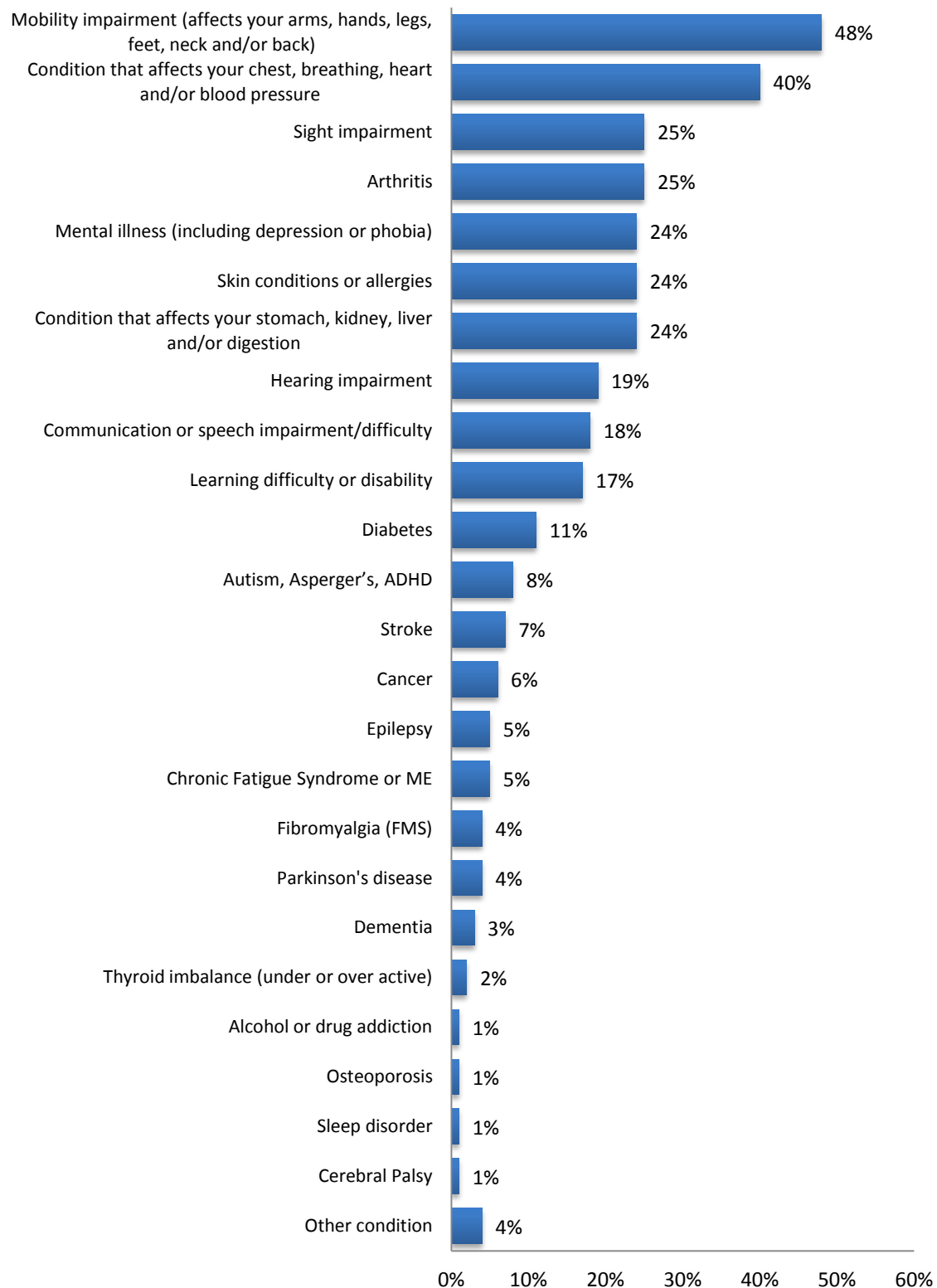
To substantiate the point made on the previous page concerning age, gender and disability type being closely inter-linked, it is noticeable that given the older age profile of females in the sample, they are more likely to have a mobility and dexterity condition (76% cf. 69% male), and sight or hearing difficulties (40% cf. 31% male).

By tenure, people living in social housing are more likely to have a condition that affects their communication (49%), their breathing (54%), and their organs (67%). 46% of private renters have a mental health condition and 42% have sight or hearing difficulties.

1 in 3 people who are unable to work because of their condition have a communication difficulty (34%) and 39% have a mental health condition.

Figure 91 (overleaf) presents the full breakdown of conditions. Almost half (48%) of all people interviewed have a mobility impairment, followed by 40% that have a condition that affects their chest, breathing, heart or blood pressure. 1 in 4 (24%) have a mental health condition.

**Figure 91: Can you tell me whether you have any of the following? All individual conditions (All respondents)**



Unweighted base: 271

## 5.2 Carers

Table 21 presents the age, gender, tenure and household size profiles of the carer sample. Further information regarding employment status and disability status are included within their relevant sections in the core of the report.

The profile is seen to be predominantly females, aged 16 to 66, in multiple occupancy owner occupied households.

**Table 21: Profile of the carer sample (All respondents)**

	%	Sample size
<b>Age</b>		
16 to 66	81%	83
67+	19%	20
<b>Gender</b>		
Male	27%	28
Female	73%	75
<b>Tenure</b>		
Owner occupier	76%	78
Social housing	10%	10
Private rented	9%	9
<b>Number of people in household</b>		
Live on their own	6%	6
2	38%	39
3 or more	56%	58



## 6 Appendix 2: Research design

This section details the methodology used for recruiting, interviewing and analysing the Stage 2 survey, both with people with long term conditions and carers<sup>26</sup> of such. Fieldwork took place between June and September 2012.

### 6.1 Sampling and recruitment

Respondents were recruited via a number of routes to ensure the maximum level of response and the greatest inclusivity for all people across the Islands. These routes are summarised as:

- Via Stage 1: Households with people with a long term condition and/or a carer were invited to provide their details within the Stage 1 questionnaire to volunteer to be interviewed at Stage 2. These households could include multiple people with conditions and/or more than one carer, so care was taken to ensure that all eligible and interested parties were able to take part.
- Via the Housing Needs Survey: The Housing Needs Survey was conducted by the States in 2011, and as part of this research, contact details of households with people with a long term condition and/or a carer were collected (where permission was sought).
- Volunteers through press and media: In the lead up to the Stage 2 fieldwork, the States promoted the survey through the local press and radio, as well as a small-scale poster campaign. As a result of this, volunteers either contacted the States or contacted BMG Research directly to take part in the interviewing.
- Through charities, support groups, organisations: The States and BMG used snowballing techniques to contact a number of disability organisations across the Islands to help with identifying volunteers to take part in the survey. This was particularly useful for recruiting groups of people that were identified part way through the fieldwork period as being under-represented (i.e. younger or older people).

### 6.2 Methodology

A mixed method approach was utilised to ensure that the research was flexible enough to capture the views of all people and was inclusive and unbiased. Interviews were captured predominantly over the telephone; however face to face interviews were conducted where this was a preference and/or where the person's condition required such an approach. These were either done in the person's home, at a support group venue, or accompanied by a support worker of some kind. To further enhance the fieldwork, focus groups or depth interviews were conducted with people in nursing homes and with residents living on Alderney.

In total, 271 interviews were conducted with people with long term conditions / disabilities. 65 of these were done face to face and the remaining 206 done via the

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<sup>26</sup> Carers were defined as someone who provides unpaid or informal care for a family member, relative or friend who has a long term health condition, illness, injury or impairment.

telephone. Where respondents were aged 14 or under, an adult was either requested to be present and their consent provided to interview the child, or the adult answered on the child's behalf. A quarter (23%) of all interviews conducted were answered by someone else as a proxy.

103 interviews were conducted with carers; all of which were done over the telephone.

### 6.3 Qualitative research

To supplement the telephone and face to face interviews, qualitative research was conducted with groups of people that were seen to be under represented during fieldwork. These under-represented groups were older people (specifically 75+) and Alderney residents. In summary, the qualitative research included:

- A focus group with up to 21 people held at the Methodist Church Hall on Alderney.
- In depth interviews conducted with residents at the Summerland Nursing Home.
- A group discussion held at a Guernsey Blind Association event.

### 6.4 Analysis

Given the size of the sample for both the disability and carer results (271 and 103), it has not been possible, at all times, to run meaningful statistical tests looking for significant differences between subgroups of the sample. However, care has been taken to ensure that the results of groups of no lower than 10 people have not been discussed, and that only large variations between sub groups are highlighted.

It is also due to the small sample bases at sub group level that weighting has not been applied to the data. Doing so could over-inflate the representation of small groups within the data.

The term "rebased" means removing some data (normally, data that does not add any information) out of a sample and redoing the calculations as if that data had never been provided. Within this report, this can also be referred to presenting the data as 'valid responses'. For example:

In a sample of 30 people, 12 said they were women, 10 said they were men, and 8 left the question blank. Using that sample,  $(12/30=)$  40% of respondents were women and  $(10/30=)$  33% were men. 27% are unknown.

To **rebase** the data, you would take out the 8 unknowns, and work out the proportion of men and women over a total sample of  $(30-8=)$  22 people. According to the rebased data,  $(12/22=)$  55% of respondents are women and  $(10/22=)$  45% are men.

Figures and tables are used throughout the report to give further detail and clarity to the analysis. Occasional anomalies may appear due to 'rounding' differences (for example, a column of percentages may add up to 99% or 101%, instead of 100%), but these are never more than +/-1%. These tend to occur where respondents have had to give their answer on a scale (e.g. "not at all", "a little" or "a lot"). The following symbols are used throughout this report:

*%	Used when the figure is less than 0.5%
cf.	Means 'confer' (or compare). This is used when two or more figures are compared against each other

## 6.5 Definition of disability groupings

Throughout the report there is mention of 'disability groupings'. These were defined to enable the analysis by disability type to be more meaningful. The definition of these groupings is shown in the table below.

**Table 22: Definition of disability groupings**

Grouping	Definition
<b>Mobility and dexterity</b>	Mobility impairment (affects arms, hands, legs, feet, neck and/or back); condition that affects chest, breathing, heart and/or blood pressure; Arthritis, Parkinson's, Cerebral Palsy.
<b>Sight and hearing</b>	Sight impairment, hearing impairment.
<b>Communication</b>	Autism, Asperger's, ADHD, Learning difficulty or disability, Dementia, communication or speech impairment / difficulty.
<b>Learning, understanding and development</b>	Autism, Asperger's, ADHD, Learning difficulty or disability.
<b>Mental health condition</b>	Mental health condition (including depression or phobia).
<b>"other chronic conditions"</b>	Epilepsy, diabetes, Fibromyalgia (FMS), Chronic Fatigue Syndrome or ME, Dementia, Parkinson's, Osteoporosis, Cerebral Palsy.
<b>Breathing</b>	Condition that affects chest, breathing, heart and/or blood pressure.
<b>Organs</b>	Condition that affects chest, breathing, heart and/or blood pressure, skin conditions or allergies, condition that affects your stomach, kidney, liver and/or digestion.
<b>Epilepsy</b>	Epilepsy
<b>Cancer</b>	Cancer
<b>Stroke</b>	Stroke

## 7 Appendix 3: Acknowledgements

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**Simon Roberts** is an Associate Professor at the International Centre for Public and Social Policy, School of Sociology and Social Policy, University of Nottingham. Before joining the University of Nottingham he was a social and policy researcher at the universities of Brunel and Loughborough. His main research interests include UK, European and international social security, social security and discrimination and disability and discrimination. He is the UK expert and a member of the analytical group on the European Commission's Training and Reporting on European Social Security network.

**Bruce Stafford** is Head of School and Professor of Public Policy at the International Centre for Public and Social Policy, School of Sociology and Social Policy, University of Nottingham. Before joining the School in February 2006, he was a social and policy researcher in local government and at the universities of Birmingham, Loughborough and Salford.

His research interests are focused on policy evaluations and on social security in particular welfare to work, disability issues, and the implementation of policies and delivery of welfare services.



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