

Disabled people's experiences of social care

**Findings from the Better Care Project
2014-15**

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2015

Scope
About disability

Contents

Executive summary	4
Methodology	9
Part one: How has disabled people’s social care changed since 2010?	11
Changes to hours of support since 2010	16
Flexibility and personalisation	21
Choice and control	25
Part two: What have changes to services meant for outcomes and independence?	30
Support for basic needs and independent living	30
Work and active citizenship	41
Social and community participation	46
Part three: Improving disabled people’s experiences as social care users	52
Direct Payments	53
Relationships with care planners	55
Consistency of staff and joined-up services	56
Assessments and individual contributions	58
Awareness and access to information	59
Advice and advocacy	60
Concluding remarks	63
Appendix 1: Sample	64
Appendix 2: Survey questionnaire	72

Executive summary

Introduction

Scope conducted research into disabled people's experiences as social care users in England as part of a Disability Partnership with the National Autistic Society, Mencap and Sense. This collaboration is part of the Health and Social Care Voluntary Sector Strategic Partnership Programme, funded by the Department of Health, NHS England and Public Health England. While many recent social care research projects have focused on older people's services and experiences as care users, this report shares findings on the views of disabled people aged 18 to 64 who are using social care services in non-residential settings.

With the new Care Act introduced on 1st April 2015 amid ongoing debate around how best to support the role of health and social care services, Scope's research offers new insights into the state of care for working age disabled people at a crucial turning point. Scope hopes this report will provide policymakers and practitioners with new insights from people using services to inform the development of more personalised, outcomes focused social care.

The report paints a detailed picture of disabled people's recent experiences with the social care system, how far services support disabled people to live, work and participate in their communities, and how services can become better at supporting disabled people to live independently in their communities in the future. Research focused on disabled people's experiences with and views of the care planning process. Scope asked disabled people what the impact of assessments and reviews has been on their opportunities to live independently and achieve the outcomes that are important to them. The research also gives new insights which can inform improvements in the delivery of services.

Key findings

- **Just 18% of social care users say services consistently support them to live as independently as possible. 55% say social care never supports their independence.**

Support is central to the way most disabled people define what independence means to them, and how choice and self-determination are achieved. Many disabled social care users see support as necessary in order to achieve the things that are important to them, fulfil their roles as parents, daughters, sons and friends, and be part of social and economic life.

- **27% feel services consistently support their day to day living needs, with 38% saying this never happens.**

Day to day living needs are more likely to be met through support services than needs around independent living. Support to live as independently as possible also appears to

build on support for more basic needs. Social care users whose services always meet their day to day living needs are 11 times more likely to say they are also supported to live as independently as possible, compared to social care users who say their needs are only sometimes or never supported.

- **52% of social care users want more help to be active in their communities, while 30% receive help towards this from social care services.**
- **27% of social care users need more support in their roles as informal carers, compared to 5% who get this help now.**
- **79% of social care users say services are important for enabling them to work, seek work, volunteer and study.**
- **More than half of social care users under 35 want help with working or jobseeking, but only 15% are currently getting support with working and only 13% are getting support with jobseeking.**

Some disabled social care users feel excluded from or not accepted by society. Most social care users want and expect to work, volunteer, be part of their local communities, fulfil caring responsibilities and be active in their society. Some social care users feel constrained in their ability to do this, emphasising the important role of care and support services in enabling active citizenship and independent living.

Disabled social care users emphasise the importance of formal support to complete daily living tasks and live independently, and the value of formal support as an alternative to support from parents, other family and friends. This is particularly important for younger social care users.

- **36% of disabled social care users say support has become worse since 2010. 19% say support has improved.**
- **29% of social care users say their hours of support have been cut, while 24% say their hours have been increased.**
- **83% of those whose hours of support have been cut say they now do not get enough support through their care package.**

Social care users who feel that services have become less effective at supporting them since 2010 are most likely to mention reductions in the hours and scope of their care packages when asked why. Those whose hours of support have been reduced since 2010 are more likely to have negative views of how social care supports them overall, and are more likely to lack support for day to day living needs and for living independently.

Social care users whose hours of support have been increased are more likely to have positive views and experiences, but this relationship is much weaker. Disabled people with positive experiences as social care users are much more likely to emphasise the role of flexible, personalised support and good relationships with planning and support staff as drivers of improvement. Having sufficient hours in your care package may be an important

pre-condition for feeling that services effectively meet needs, but this appears to be a first step towards getting the right support.

- **55% of disabled social care users do not have enough hours in their care package.**

Many more social care users do not have enough hours in their packages than have received a cut in the last five years. These results suggest longer-term, more entrenched unmet support needs amongst social care users. 53% of social care users whose support hours have stayed the same since 2010 do not have enough hours. Some disabled people's care packages have not increased to meet evolving support needs and their conditions and aspirations have changed.

- **Half (51%) of social care users with fluctuating needs say support does not fit in around their changing needs.**

For many social care users, independence is not just about 'what' they do and are supported to do, but also the 'when', 'how' and 'who'. Flexible, personalised services are identified as key to adapting support to changing needs, getting the most out of social care services and feeling in control of your own life. When describing how they feel social care services have become better at supporting them, many disabled people emphasise the role of more flexible support, and the value of this for their independence and quality of life.

- **Half (50%) of social care users feel the services they receive generally or always match what is written in their care plans. A third (32%) of social care users are not getting the standard of care agreed in their care plans.**

For many disabled people, the reliability of formal help is as significant as flexibility in producing services which support people to achieve the outcomes that are important to them. Disabled social care users frequently mention inconsistency in support staff as a key driver for support services not meeting the expectations set out in care plans.

- **28% of disabled social care users have 'complete' or 'a lot' of choice and control in planning their care. 41% have 'very little' or 'none'.**

Choice, self-determination and autonomy are central to the way many disabled social care users define independence, and to the ways people describe achieving and maintaining flexible, personalised services which support independent living.

- **63% of social care users who have choice and control say using a Direct Payment or Personal Budget has helped. 41% of those who do not feel they have choice or control say using a Direct Payment or Personal Budget could help them in the future.**

Many social care users highly value Direct Payments and Personal Budgets. Disabled people told Scope about improvements to their ability to live independently and to have choice and control over the support they use. Some described limitations on the impact of self-directed support as a result of insufficient funding, and the need for additional advice and support to get the most out of services.

- **56% say they need care planners to be more understanding and respectful of what's important to them in order to have choice and control.**

Many disabled people describe the importance of trust and accountability, as well as respect and understanding, in their relationships with care planning staff. Some disabled social care users feel that the care system limits choice and autonomy, because of planning staff maintaining too much control, and because of inflexibility in the system. In some cases, disabled people are so concerned about losing support that they do not feel able to make criticisms of or suggestions about the services they use.

- **Half (49%) of social care users say planning their care with the same people each time would give them more choice and control. 30% of those who have choice and control say that planning care with the same people each time has helped.**

Disabled social care users value consistency in planning staff, while others identify a lack of consistency and join-up within social services as a barrier to having choice and control. Disabled social care users who feel that the different staff involved in their social care work well together describe positive outcomes for their ability to achieve the things that are important to them.

Disabled social care users also emphasise the need for more join-up and better co-ordination between social care and other forms of support. Some people found giving similar information to a number of different agencies, all controlling different forms of support, challenging and time-consuming. Some social care users want more join-up in assessments for support in order to simplify the process, while others see more joined up assessments as a mechanism for improving disabled people's access to the support they need, and creating more personalised and more effective services

- **Half (51%) of social care users who currently lack choice and control say having an advocate at future meetings to plan and review care would help. 12% of those who have choice and control have benefited from this help.**

Some disabled people feel unable to effectively argue their own case at care planning meetings, and describe feeling anxious about assessments and disempowered at meetings. Many disabled people draw on support from a wide range of sources to navigate the care planning process and get the most out of their care and support services. This includes advocacy, legal advice, support from family, friends and charities. Other social care users do not have the advice and support they need to get the most out of their care and support services.

- **A third (33%) of social care users expect services to get worse at supporting them over the course of the next Parliament. Another 10% think they will lose access to support entirely.**

Future expectations of care and support services lag behind past experiences. Fewer social care users expect services to improve (11%) than say things have become better over the last five years (19%). A greater proportion expect their support to get worse or to

be withdrawn (43%) than say that services have actually become worse (36%). This raises further questions around how low expectations of support services might be affecting disabled people's future aspirations and ability to plan for a more independent future through the care planning process.

Report structure

The Methodology section of this report gives information on the design and approach Scope used to conduct this research, how Scope reached disabled social care users and additional information on the analytical approach taken when reporting findings.

Part one explores how disabled people's social care has changed in recent years.

Social care users' views are given on how well services have supported them, and how well they expect services to support them in the future. Three sets of factors are explored as drivers of positive and negative service user experiences:

- Whether and how the number of **hours of support** in people's care packages has changed.
- How far disabled people feel support is **flexible and personalised**.
- How far disabled people feel they have **choice and control** when planning and reviewing care packages.

Part two looks at what changes to disabled people's social care have meant for opportunities to live independently and achieve the outcomes that are important to them. The activities and outcomes social care currently supports disabled people with are compared against those where disabled people have unmet needs and aspirations. Particular attention is paid to how well social care supports disabled people to:

- Work, volunteer, take part in training and study;
- Access and participate in their communities;
- Have meaningful, reciprocal relationships with others.

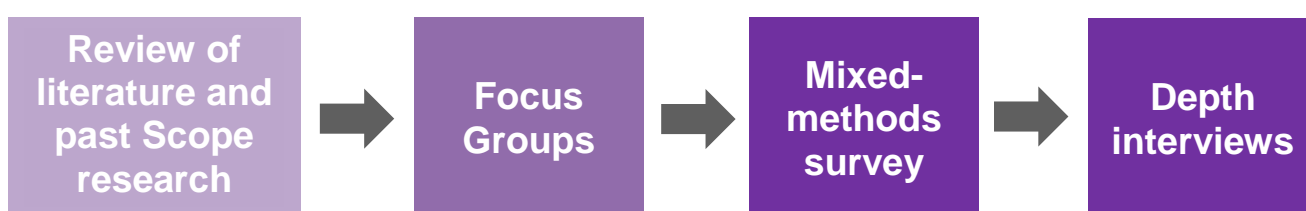
Part three shares insights on how disabled people's experiences as social care users can be improved through the care planning and review process. Disabled people's experiences and views on a range of mechanisms and sources of support are explored, both in terms of what has helped disabled people to have more choice and control and what could improve things in the future.

Only when disabled people are empowered to participate in care planning can services be flexible and responsive to people's individual needs and aspirations. Scope hopes this report will provide policymakers and practitioners with new insights from people using services to inform the development of more personalised, outcomes focused social care.

Methodology

Research design

Scope conducted this research using a multiphase, mixed-methods design. Field work took place between October 2014 and February 2015. Sequential research phases were used to alternate between qualitative and quantitative approaches. This allowed Scope to put disabled people's views at the centre of the research design, informing the development of quantitative research materials using early qualitative findings, and corroborating findings from quantitative activities using further qualitative work with disabled people at the conclusion of the project. The mixed-methods project design permitted thorough triangulation of results, improving the robustness of findings.



First, a review of secondary literature and past Scope research was used to produce research questions and two exploratory focus groups – one with seven disabled social care users living in and around London, and a second group with five young disabled people in North West preparing to make the transition to adult services.

Qualitative findings from focus groups were then analysed concurrently with insights from the literature review to develop a large-scale mixed-methods survey (see Appendix 2). The survey provides both quantitative and qualitative findings from 515 respondents across England.

In the final phase of field work, Scope conducted depth interviews with 15 disabled social care users to gain a more detailed picture of the role of social care in enabling community participation and independent living, particularly for groups who are typically under-represented in social care research: disabled people from black and ethnic minority backgrounds, young disabled people and disabled people identifying as LGBT. Scope used early results from survey analysis to identify areas for further exploration, and to inform the recruitment of interviewees.

Sample recruitment

Research participants came from a wide variety of sources:

- 12 focus group participants were recruited from the networks and services of charities in the Disability Partnership, including Scope and Mencap. Scope worked with Partnership charities and other organisations to produce accessible, inclusive research materials and activities for a range of user groups.

- Our mixed-methods survey was primarily an online survey, with small numbers of surveys completed face to face and by telephone to overcome digital access challenges for some groups of social care users.
- 515 survey respondents were drawn from a range of sources including care users and supporters from Scope's own networks and those of other Disability Partnership charities, Disabled People's Organisations and User Led Organisations, visits to community groups and tenants of specialist housing associations. The assistance of Voluntary Sector Partnership charities in sharing the survey through their networks, and in advising Scope on communications and promotional materials, was invaluable in helping us to achieve relatively representative samples in terms of different impairment types, ethnicities and sexual orientations.
- Scope also used social media promotion on Facebook and Twitter to promote the survey - both free and paid advertising. This may explain the relatively young sample of our mixed-methods survey, with 17% of respondents aged between 18 and 24 and 22% between 25 and 34.
- Scope conducted 7 depth interviews with social care users identified by Sense and NAS, and a further 8 interviews with respondents from our survey. Recruitment concentrated on demographic groups who are typically under-represented in social care research, particularly people with learning disabilities, autism, from black and ethnic minority backgrounds and social care users who identify as LGBT.

Detailed demographic information about the samples for different research phases is available in Appendix 1, at the end of this report.

Analytical approach

In order to develop a full and vivid picture of disabled people's experiences of using social care to live independently, we asked people what they think about the support they use now, how their experiences of support have changed over the last five years, and how they expect the support they use to change over the next five years. Time periods of five years have been chosen for two reasons:

- To provide a medium-term perspective, in which a broad view of the role of support in people's lives and future aspirations can be demonstrated.
- To explore how changes in how social care is funded over the five years following the 2010 Comprehensive Spending Review have affected disabled people's experiences of services, and their opportunities to live independently.

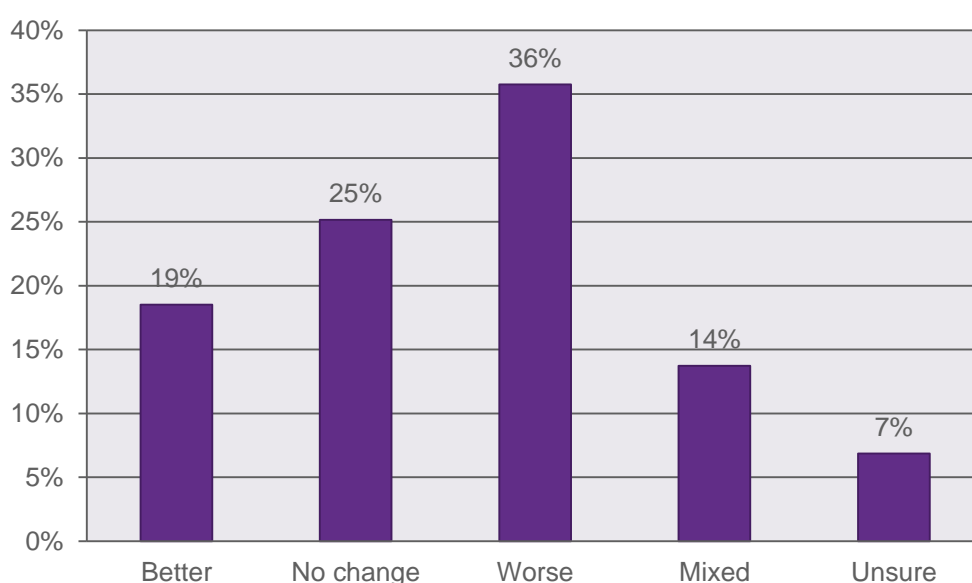
Throughout this report, quantitative findings on differences between groups are discussed only if they are statistically significant (at the 0.05 level).

Part one: How has disabled people's social care changed since 2010?

Change in overall quality of support

Throughout the project, disabled people in our survey, interviews and focus groups described mixed experiences as users of social care services. Respondents to our survey were asked whether the quality of support they receive through social care services has changed over the last five years.¹

Figure 1.1 Change in overall quality of support since 2010



- A quarter of social care users have experienced no change.
- A fifth say services have improved.
- 36% say the services they use have become less effective at supporting them.

For the fifth of survey respondents who say their support has become better, this enables them to achieve more of what is important to them in ways that reinforce independence and self-determination.

“It’s given me self-confidence, focus and a feeling of being proud. I have lots of plans.”

Peter, 21, North West

“Having good social care means that I don’t need to negotiate and compromise on how I want to live. I can be myself, without putting strain on the health and wellbeing of other people.”

Elizabeth, 34, London

¹ Respondents who started using social care and support services after 2010 were asked if the support they receive has changed since they started using services.

“I often look back at what I’ve done since I’ve been in care and when I do I feel really good. My friends and family have noticed a big improvement in me because of what I’ve done. Basically I’ve been encouraged to think of what I want to do and more often than not been given the support to do it, instead of being told I have to do what the council says I have to do.”

Andrew, 37, North West

“My social worker helped me get into supported living and to carry on with it.”

Sally, London

Over a third of disabled social care users told us their care has become less effective at supporting them over time, with implications for people’s ability to live independently. Often, this has happened because of changes to services and the amount of help that is available, or because changes in people’s care needs and life goals have not led to changes in services. For some social care users, a variety of factors have combined to produce a decline in the way services support them.

“Firstly it’s the lack of contact with my social worker and occupational therapist. They never respond when I call them. Secondly it’s the fact that since 2010 I’ve had two thirds of my care package removed because of cuts. Thirdly it’s the fact that I’ve not had a care plan review for over three years.”

Ruth, 41, South East

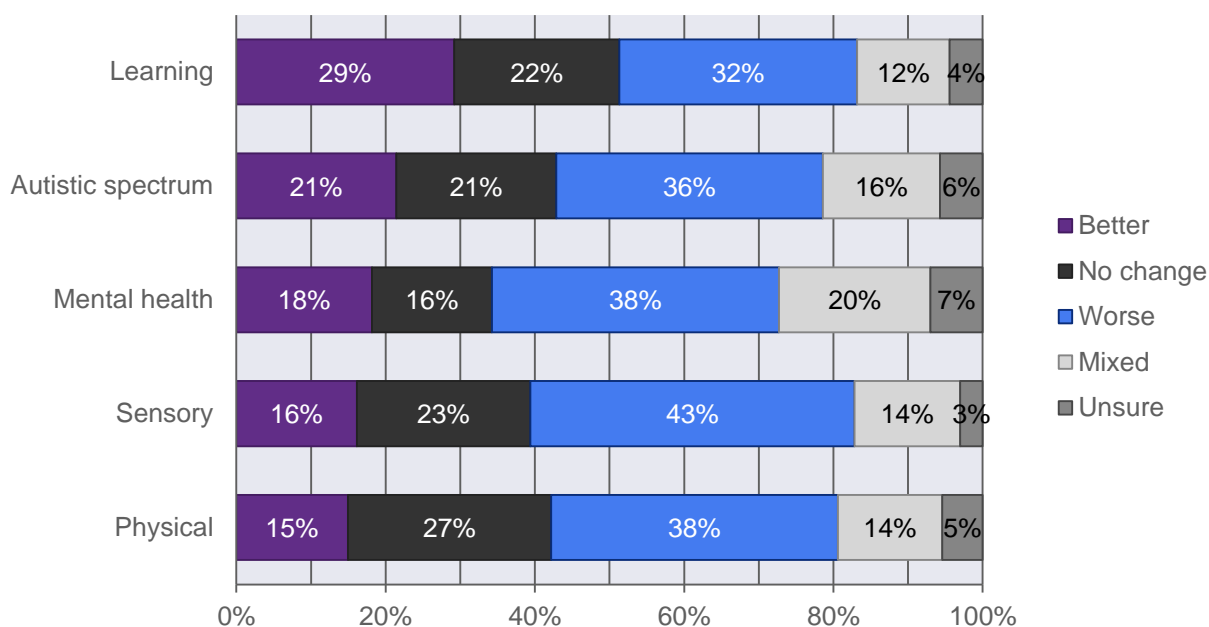
“As a direct result of my support getting worse, much of my independence has been taken away. I rely far more on family, which in turn impacts on their independence.”

James, 47, East of England

“It’s worse because the money doesn’t go as far now as it did when I started.”

Julie, 47, East of England

Figure 1.2 Change in overall quality of support since 2010 by impairment type



55% of survey respondents had more than one impairment type, so there is a large degree of crossover between the above groups in our sample. When splitting by impairment type,

social care users with learning disabilities have the most positive experience of how services have changed over the last five years, with 29% feeling that services have become better at supporting them and 32% saying they have become worse. Social care users with other impairment types had more negative views: only 16% of those with sensory impairment felt services had become better at supporting them, while 43% said things had become worse.

Several survey respondents and interviewees with sensory impairments told us about the particular challenges they face in accessing the support that is right for them, and the importance of this for the overall effectiveness of social care.

“I have been given reduced access to sign language professionals. There is a clear lack of understanding of my deafness.”

Omar, 30

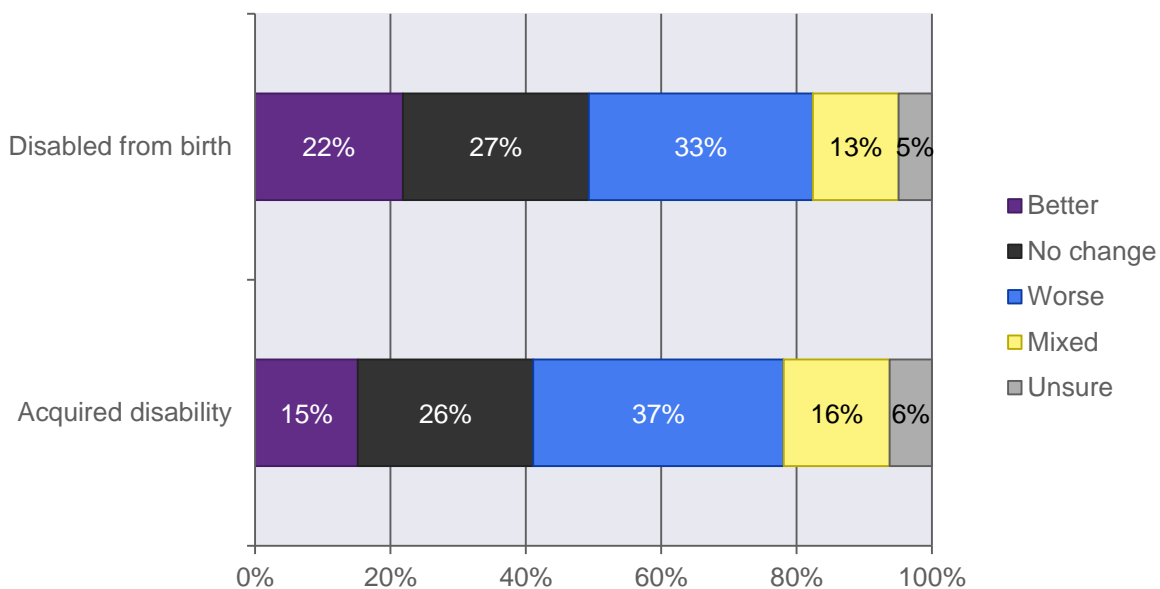
“Now I have specialist providers that understand my disability and can recruit accordingly. Before, I had awful experiences where they recruited whoever. I am deafblind so I need a clear speaker.”

Janice, 43, East Midlands

“I didn’t have people who are properly trained, and I need people who are trained. Mostly people don’t understand me.”

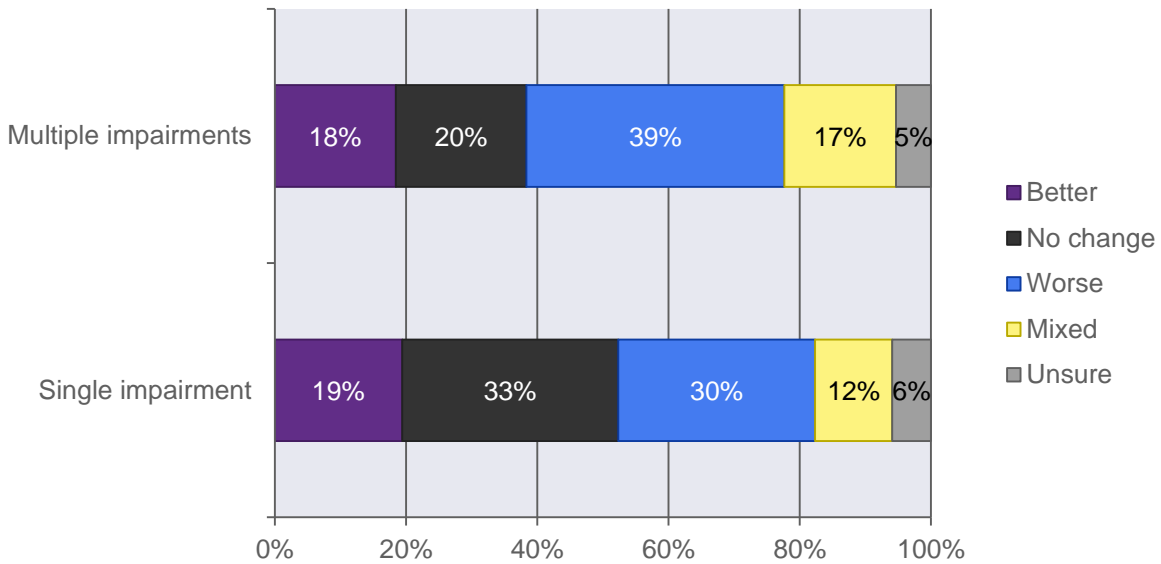
Daniel, 30, London

Figure 1.3 Change in overall quality of support since 2010 by duration of disability



Social care users who have been disabled from birth are generally more satisfied with how services have changed over the last five years compared to those who acquired disability later in life, with a greater proportion feeling that services have improved and a smaller proportion feeling that services have become worse at supporting them.

Figure 1.4 Change in overall quality of support since 2010 by number of impairments

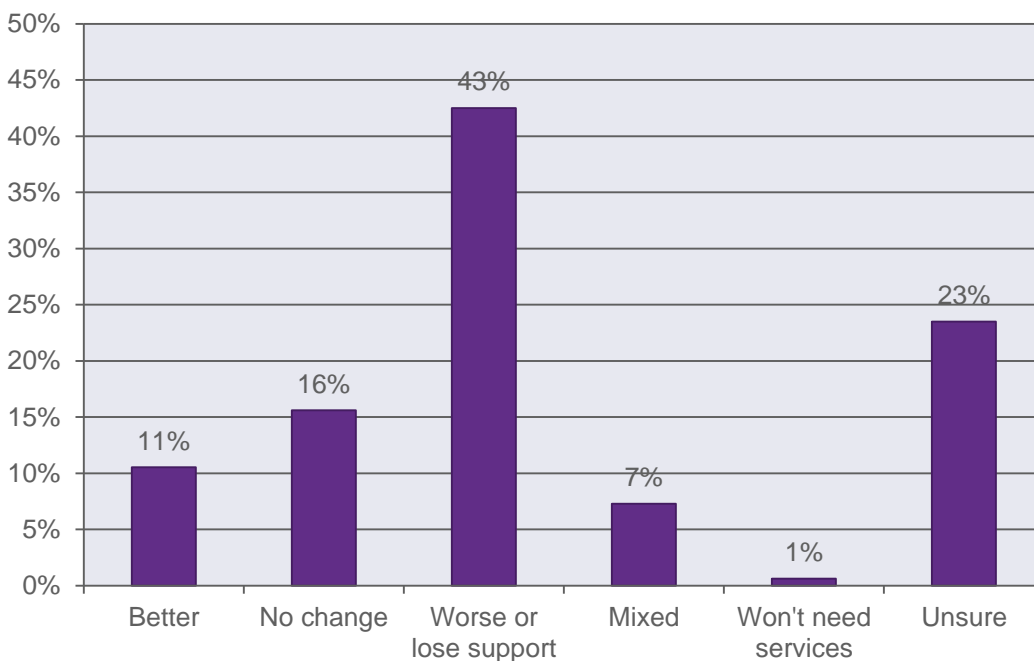


Social care users with multiple impairments and those with one impairment were almost equally likely to feel that services have improved, but a greater proportion of those with multiple impairments (who are likely to have more complex support needs) report that services have become worse at meeting their needs over the last five years.

Expectations of future support

Survey respondents were asked to think about the next five years, and how they feel the services they use will continue to support them over that period.

Figure 1.5 Expectations of change in overall quality of support



- Overall, a third of social care users expect the services they use to get worse over the next five years.
- A further 10% expect to lose access to support services.
- Almost all respondents expect to continue needing services, but only 11% think services will get better at supporting them.

These findings suggest that future expectations of care and support services lag behind past experiences. Fewer social care users expect services to improve (11%) than say things have become better over the last five years (19%). A greater proportion expect their support to get worse or to be withdrawn (43%) than say that services have actually become worse (36%). These results raise further questions around how low expectations of support services might be affecting disabled people's future aspirations and ability to plan for a more independent future through the care planning process.

Explaining trends

Why have some disabled social care users found that services have become more effective at meeting their support needs, while for others services have become less effective? The following sections look at what has driven disabled social care users' recent experiences of services, assessing the significance of:

- Changes to the hours in people's care packages.
- Flexibility and personalisation.
- Choice and control in care planning.

Changes to hours of support since 2010

How have support hours changed?

In an unprompted open text question asking in what ways support services have become less effective, many survey respondents emphasised cuts in the hours of support they can access. This is the most common theme in the responses given to this question.

“There are fewer services and fewer people working in those services, and the budgets of the services still around have been cut so much that, as someone who suffers with depression, I no longer qualify for a lot of them.”

Fiona, 33, East Midlands

In addition to reductions in funding and in the hours of support available, some social care users told us that the support in their care packages or Direct Payments has not changed to meet their increased support needs. In some cases, this has led to a reduction in the scope of activities and outcomes disabled people have formal help with.

“My support hours have been cut by 25%, even though my needs have increased. I do not feel this is truly caring for my needs, as it has made life more difficult for me and my family.”

Laura, 41, East of England

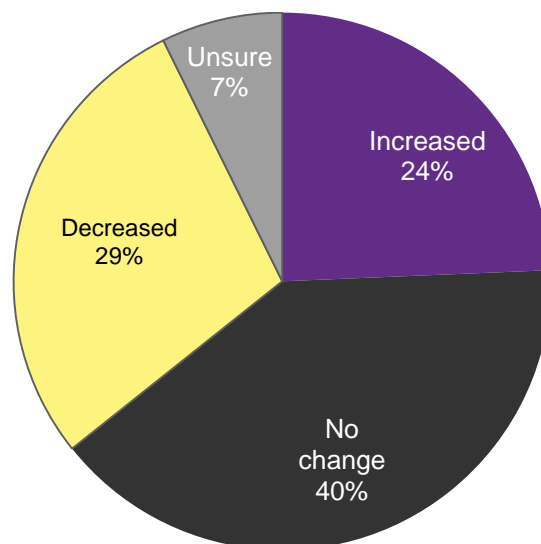
“As my condition has worsened my care has stayed the same, so the hours don't go as far.”

Richard, 52

Figure 1.6 Change in hours of support since 2010²

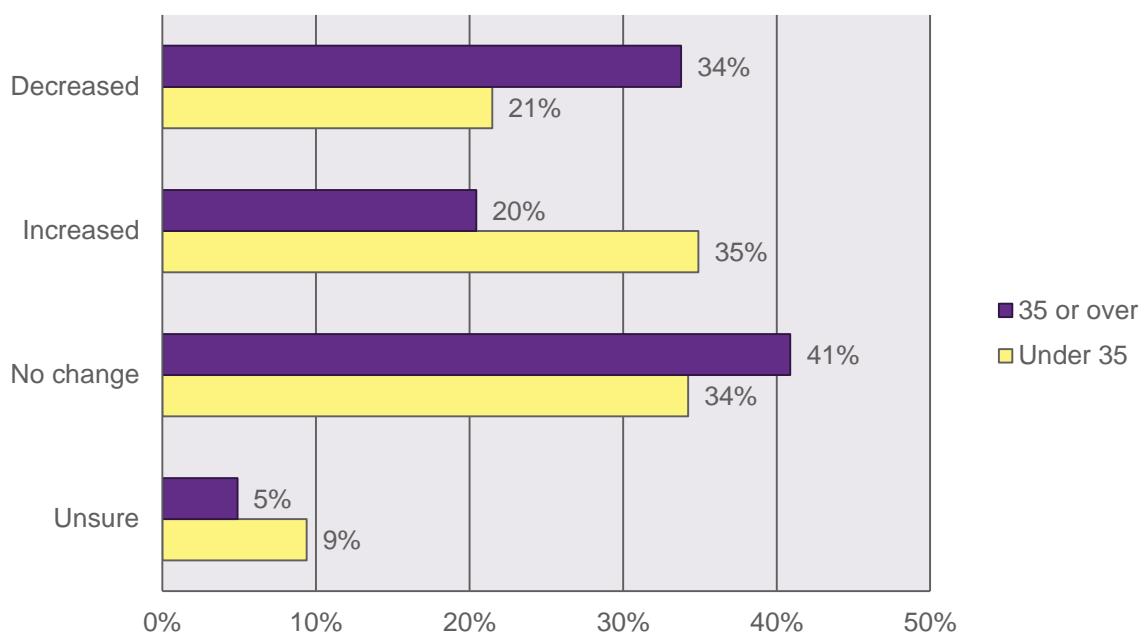
Our survey found that 29% of respondents have experienced reductions in the hours of help they get, with two fifths seeing no change since 2010 and 24% reporting increases in their care packages.

There is no statistically significant difference in these results between respondents using care before 2010 and newer care users.



² Respondents who started using social care and support services after 2010 were asked if the hours of support they received had changed since they started using services.

Figure 1.7 Change in hours of support since 2010 by age



Looking at how care package hours have changed by whether survey respondents are aged under or over 35, results suggest an important difference in the experiences of older and younger social care users. Those over 35 are significantly more likely to report decreases in hours than increases in hours since 2010, while these trends are reversed for younger social care users.

A small proportion (4%) of survey respondents told us they have ‘too many’ hours in their care package. Younger social care users are slightly more likely to feel this way, and to be unsure about whether the hours they get are right for them. These results may reflect demand from disabled social care users for more flexible, personalised services. This theme will be explored in more depth in the following sections.

Several survey respondents used open text responses to say they feel pressured to accept more help than they want, or to accept methods of helping that are not right for them. Some social care users described this as key to living independently and to emotional wellbeing.

“It means getting help for things I ask for help with, but not forcing help onto me for things I've not asked for or do not want.”

Nicola, South East

“It is very important for my mental health. It is important for me to do as much as I can by myself, whilst receiving help only if I need it.”

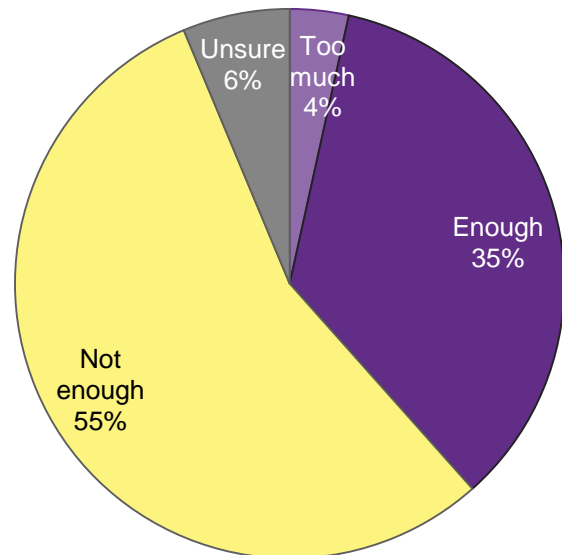
Lucy, 27, Yorkshire and the Humber

Satisfaction with support hours

Figure 1.8 Views of hours of support in care package

When asked how they feel about the hours of support in their care package, 35% say they have enough hours, while 55% say they get fewer hours of support than they need – many more than the 29% who say their hours have been reduced since 2010.

These results suggest longer-term, more entrenched unmet support needs amongst social care users.



“I just get such a small care package, and I’ve been fighting for it and I still can’t get past 8 hours a week. I’m just fed up with constantly trying to get the social worker to see about independent living and being isolated indoors, that I can’t actually have a care package that suits my needs.”

Glynis, East of England

“My hours of support have been cut. I’m under a lot of pressure now to cope on my own.”

Mark, 42, London

“What it means is that I’m getting more and more sores, yeast infections because I can’t wash as regularly as I should be able to. And it’s embarrassing, because I’m incontinent.”

Henry, 54, North West

Figure 1.9 Views of hours of support by change in hours of support since 2010

		Change in hours of support since 2010		
		Increased	No change	Decreased
Views of hours of support	Too much	6.4%	2.6%	3.0%
	Enough	52.3%	44.5%	14.4%
	Not enough	41.3%	52.9%	82.6%

Looking at respondents’ views of the sufficiency of the hours in their care package by whether those hours have changed since 2010, results further demonstrate unmet need in our sample. Unmet need for support hours appears to have been exacerbated by

reductions in services for some social care users. 83% of respondents whose hours have been decreased feel they do not now get enough support.

“I found there was a cutback in social care. To begin with I had enough really, almost enough.”

Jenny, 57, London

59% of those whose hours have increased since 2010 feel they get ‘enough’ or ‘too much’ support, but two fifths still feel their hours do not meet their needs. Over half of those whose hours have not changed since 2010 do not feel they have sufficient hours of support.

In line with these findings, some disabled people whose hours of support have stayed the same told us that the support in their care packages or Direct Payments has not increased to meet evolving support needs as their conditions and aspirations have changed. In some cases, this has led to a reduction in the scope of activities and outcomes disabled people have formal help with.

“My first plan was put in place when I was 19. I am now 22 and the local authority don't accept that my needs have changed, even though my assessment indicates otherwise, and will not support me in building up my support and skills so that I can ultimately move to supported living. I cannot move forward with my life without more support.”

Alex, 22, Yorkshire and the Humber

Figure 1.10 Views of hours of support by actual hours of support in care package

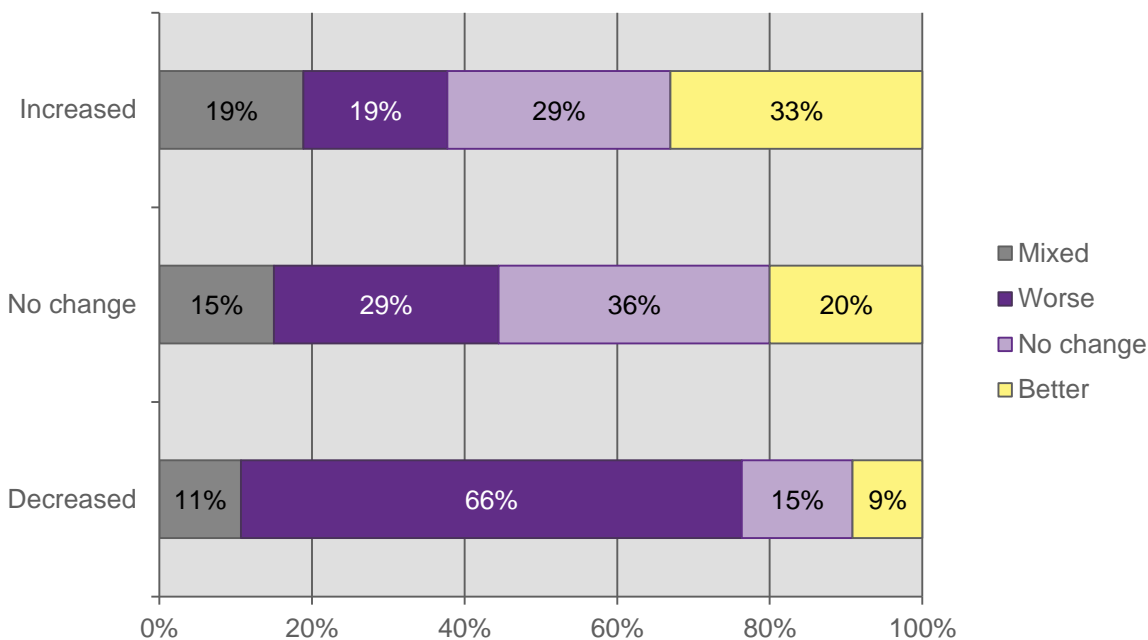
		Actual hours of support in care package					
		36+ hours	26-35 hours	16-25 hours	11-15 hours	5-10 hours	Less than 5 hours
Views of hours of support	Too much	3.5%	6.0%	0.0%	5.3%	3.0%	3.4%
	Enough	48.8%	31.3%	41.3%	43.9%	35.4%	22.4%
	Not enough	47.7%	62.7%	58.7%	50.9%	61.6%	74.1%

Comparing the weekly number of hours in social care users’ care packages against whether people feel those hours meet their needs, a clear relationship emerges only at the extremes. The average (median) number hours in survey respondents’ care packages is 16. Those with more than 35 hours of support each week through their care package are more likely to feel they get enough hours of support, while three quarters (74%) of those with less than five hours of support each week say this does not meet their needs. Otherwise, there appears to be little association between the number of hours of support people get and whether they feel they have enough hours.

What do changes mean for support?

Figure 1.11 Change in hours of support by change in overall quality of support since 2010

While a third of social care users whose hours have been increased feel that their support has improved since 2010, two thirds of those whose hours have been decreased feel their support has become worse. 19% of those with increased hours still feel their services have become worse at supporting them.



In line with evidence from qualitative results, a strong association can be identified between reductions in support hours and negative impressions of how the overall quality and effectiveness of services have changed. Weaker relationships are evident between increases in hours and positive impressions of how support has changed, and between no change having occurred in support hours and negative impressions. While just under a quarter of survey respondents have experienced an increase in their hours of support since 2010, few respondents who said their support has improved mentioned hours of support in explaining this.

As later sections in this report will demonstrate, disabled people with positive experiences as social care users are much more likely to emphasise the role of flexible, personalised support and good relationships with planning and support staff as drivers of improvement. Having sufficient hours in your care package may be an important pre-condition for feeling that services effectively meet needs, but this appears to be a first step towards getting the right support rather than an end point.

Flexibility and personalisation

What is the value of flexible support?

In interviews, a focus group and hundreds of open-text survey responses, disabled social care users strongly emphasised the significance of personalisation, flexibility and choice and control, both for overall experiences as service users and as important enablers for living independently. A system which incentivises these characteristics is key to realising the aims of the Care Act.

“I don’t think one size fits all. I think people need to be assessed on what their personality is. Even with cerebral palsy, you might get two people virtually identical but their needs are going to be totally different. You cannot have a universal care package, professionals have got to study the people they are dealing with and take a holistic approach.”

Steve, 48, London

“They say I can’t have what I need because the local authority or CHC won’t fund it - even when it is a value for money option.”

Alex, 22, Yorkshire and the Humber

“There should be more flexibility month-to-month so that unused hours can be saved for when I am very ill and need a lot more support.”

Claire, 46, East of England

For many social care users, independence is not just about ‘what’ they do and are supported to do, but also the ‘when’, ‘how’ and ‘who’. Flexible, personalised services are identified as key to adapting support to changing needs, getting the most out of social care services and feeling in control of your own life.

“I think the initial interview has to be more in depth: what do you feel comfortable with, what don’t you feel comfortable with. And I think you have to have tight teams, teams that are tied to an area who revisit the same clientele.”

Henry, 54, North West

“To live and enjoy my life to the full. To be able to access activities when I want to, not at set times. To be able to do the things I want to.”

Harriet, 27, North West

“Choosing what time and who helps me with things I can’t do. Not having to constantly justify my choices or feel like live in care home while at home. Being flexible with care arrangements so it doesn’t feel like I’m in jail!”

Elaine, 39, London

“Doing things on my own terms, when, where and however I want. I don’t need to be babysat, I need to live my life.”

Marie, 33

Social care users with fluctuating needs

Figure 1.12 Views on flexibility of care and support services

48% of our survey sample said the number of hours of support they need varies depending on the week, either because of the nature of impairments and health conditions, because of needing to do certain activities some weeks but not others, or because of a combination of these factors.

Of these, around a third say the hours of support they receive changes well according to their varying needs. Half feel this is either not happening or not happening well.

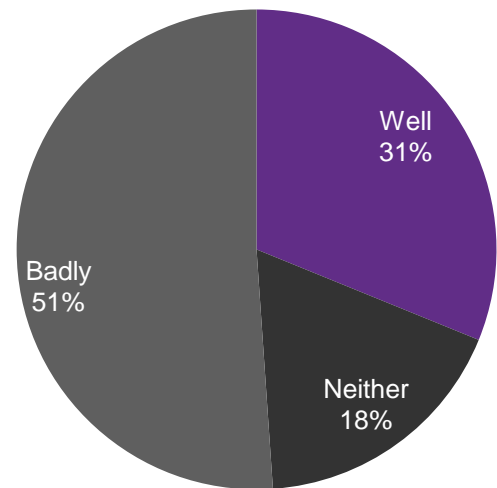
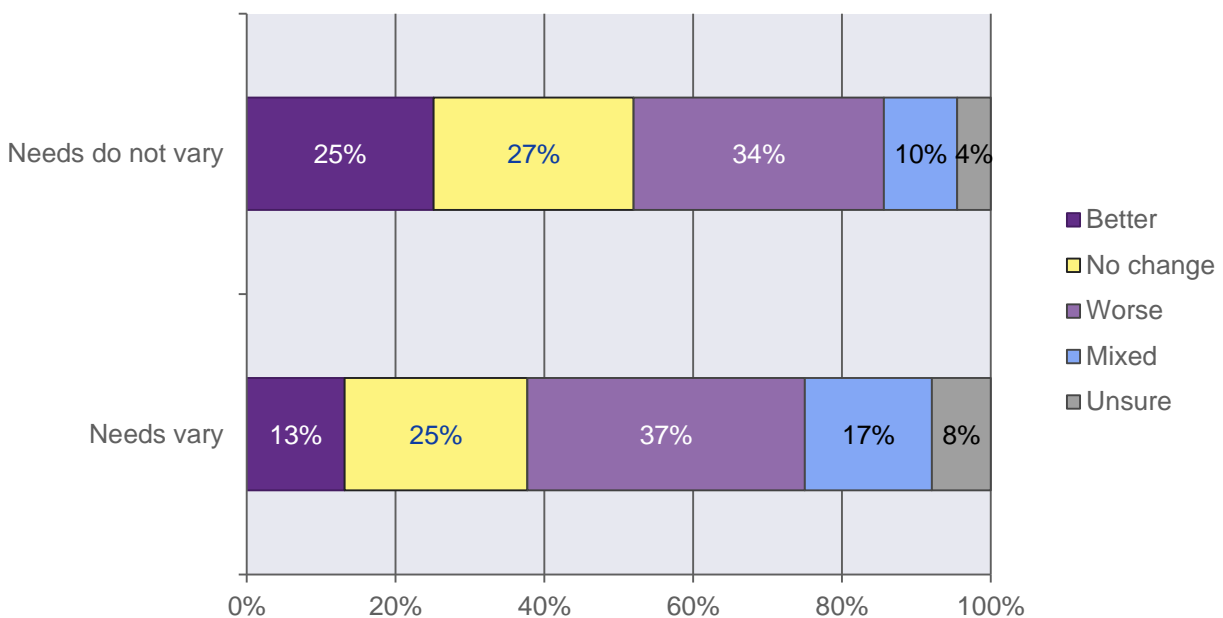


Figure 1.13 Change in overall quality of support by fluctuating needs



Overall, social care users whose support hour needs are the same from week to week were more than twice as likely to report that their support has improved since 2010. Those with fluctuating needs for support hours were more likely to report mixed experiences with services over the last five years, and were slightly more likely to say that services have become worse at supporting them.

“The concept of care plans seems to me fixed and written in stone. It is not flexible enough to provide for the needs of people with progressive disabilities, and for those who, like me, experience 'flare-ups', where I need more care than I have ever actually received. Sometimes I can manage - other times I just give up on

everything, because I cannot do anything at all. But I have nowhere to go, no-one to help when I need it the most.”

Yasmin, 55, London

What does flexibility mean for support?

When describing how they felt social care services have become better at supporting them, a number of survey respondents emphasised the role of more flexible support, and the value of this for their independence and quality of life. Some mentioned flexibility in the number of hours of support they use from week to week, and in when these support hours can be used.

“I now have a more varied care package to support me and caring for my children.”

Nicole, 37, London

“The hours are not as set, so they are adjustable to my needs.”

James, 29, East of England

“Not having my life run by the clock, and being enabled to come and go and change my mind at the last minute if my requirement changes.”

Sarah, 40, East Midlands

For some, increasing flexibility in the range of activities and outcomes which they get help with has also been key to improving their care user experience since 2010.

“Support services have understood the importance of me feeling that I contribute to the smooth running of the home rather than expecting my partner to do all the house management and so have started to provide shopping escorts and cleaning. They are allowing flexible hours so that when my partner is ill the care agency can provide more hours than normal to cover the extra work needed.”

Rachel, 35, London

While many social care users who have seen the effectiveness of their support improve mention the importance of flexible services, some disabled people who feel their support has become worse since 2010 identify limitations on flexibility as significant. Survey respondents told us about the impact of using support which is not flexible enough in what help is given and how it is delivered. Some survey respondents also mentioned problems with clarity around what money can be spent on and how care services can be used.

“The rules now have taken away the little freedom I had. There are too many rules and no one seems to know the same set.”

Michelle, 27, South West

“I have found that my personal health is better as they help me with personal care and cooking food, and that is making me feel able to do more, but I have found I get no choice to do what I want now. If I want to go out for the day I am not allowed to because there is no flexibility for the care to come later or do tasks that should have been done that day at a later date. I have become a prisoner in my own home.”

Fred, 42, South East

Some disabled people have experienced decreasing hours and flexibility from the care system since 2010. In these cases, reductions in support hours and in the scope of formal

help have interacted with limitations on how support can be used, producing services which are inflexible and which do not enable independence. For some, this has limited their opportunities to live independently, build their skills and achieve their aspirations. Others describe stressful situations in which their health and dignity are not supported. For many disabled social care users facing the effects of cuts, the contrast between previous care packages and the support they now receive is a source of particular concern.

“They will only fund things that directly impact me now – rather than looking to the future and helping to build my skills towards a more independent life. They are totally inflexible. I have to use the same staff for the same hours every week. They refuse to fund things they have previously funded even when they meet eligible needs.”

Alex, 22, Yorkshire and the Humber

“When I had the cut, I lost my resilience. Suddenly it only took a tiny problem for my life to become extremely stressful. I didn't have any leeway for coping with a PA being off sick or similar minor problems. As my illness is made worse by doing too much, my health was frequently in danger.”

Siobhan, 38, South East

“Fewer hours allocated to my care package, limited time for personal care, no time for community access, shopping or appointments. I am more dependent on friends and family than before because there are not enough hours to employ a Personal Assistant or care worker. I feel rushed to complete personal care. At times I have been threatened with being left naked in the shower if I'm not ready. I do not have enough money allocated to pay for extra hours in Direct Payments.”

Kate, 47, East Midlands

It is clear that more care is not the same as better care. Alongside sufficiency in care package hours, disabled people value personalised support services, delivered both flexibly and reliably from the point of view of social care users. The following section will look at one important factor in how this model of support can be achieved: the level of choice and control disabled people have in assessments and meetings to plan the care services they use.

Choice and control

What do choice and control mean to social care users?

Choice, self-determination and autonomy are central to the way many disabled social care users define independence, and to the ways people describe achieving and maintaining flexible, personalised services which support independent living.

“Having choice and control over the support I need to go about my daily life.”

Christina, 54, South East

“Independence isn't doing everything for myself but is being in control of how I live and what I do, whether that's at home or work or out and about. This means a great deal to me because of what I can achieve and the difference it makes to my wellbeing, but also because of the difference it makes to the people I care about.”

Elizabeth, 34, London

For social care users who feel they have choice and control, they describe feeling listened to and respected by care planners.

“I do feel the care planners listen to me as when I plan my care every year, they always take on board what I want and try and let me do it.”

Andrew, 37, North West

“My Care Agency Controller listens to my concerns and takes action. I am very fortunate to have a very well-run care agency.”

Alice, 61, London

Some disabled social care users feel that the care system limits choice and autonomy, because planning staff maintain too much control and because of inflexibility in the system.

“Me having choice and control, not being line managed by a care manager. My wishes being paramount rather than a budget-led department.”

Ciara, 58, London

In some cases, disabled people are so concerned about losing support that they do not feel able to make criticisms of or suggestions about the services they use.

“At one stage my consultant threatened to take my Community Psychiatric Nurse's services away from me and I felt I had to fight to keep her, even though I've got my criticisms of her. At least she is better than nothing.”

Jenny, 57, London

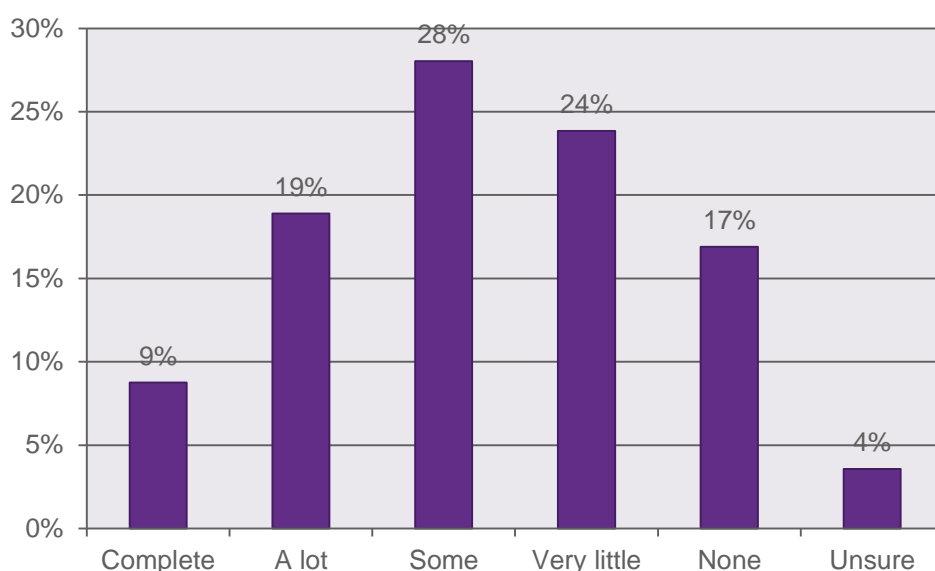
“I'm scared to 'stir them up' in case they suddenly decide to give me fewer Personal Assistant hours.”

Lena, 25, East of England

Choice and control care planning

Figure 1.14 Choice and control in care planning

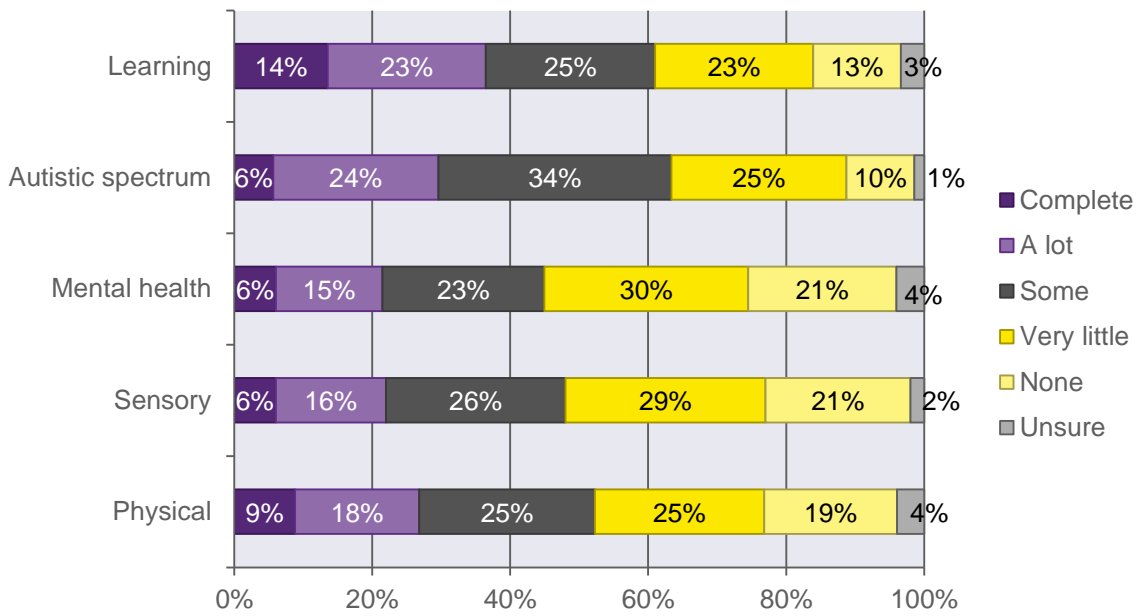
In the Care Act, the care plan is the critical document which influences both the content and delivery of a person's support package. It is therefore essential that disabled people are able to participate as fully as possible in care planning and review processes. The range of experiences with choice and control in the care system is also reflected in quantitative findings from our survey, exploring disabled people's experiences when planning and reviewing support packages.



- Respondents have had mixed experiences of choice and control when planning and reviewing social care and support services.
- 28% of survey respondents have 'complete' or 'a lot of' choice and control.
- 41% have 'very little' or 'none'.

Figure 1.15 Choice and control in care planning by impairment type

55% of survey respondents had more than one impairment type, so there is a large degree of crossover between the above groups in our sample. When splitting by impairment type, social care users with learning disabilities have the most choice and control, with 37% feeling they have 'complete' or 'a lot' of choice and control. Those with mental health conditions and sensory impairments have the least positive assessments of their choice and control in care planning, with around half in each case feeling they have 'very little' or 'no' choice or control, compared to only around a fifth who feel they have 'complete' or 'a lot' of choice and control.

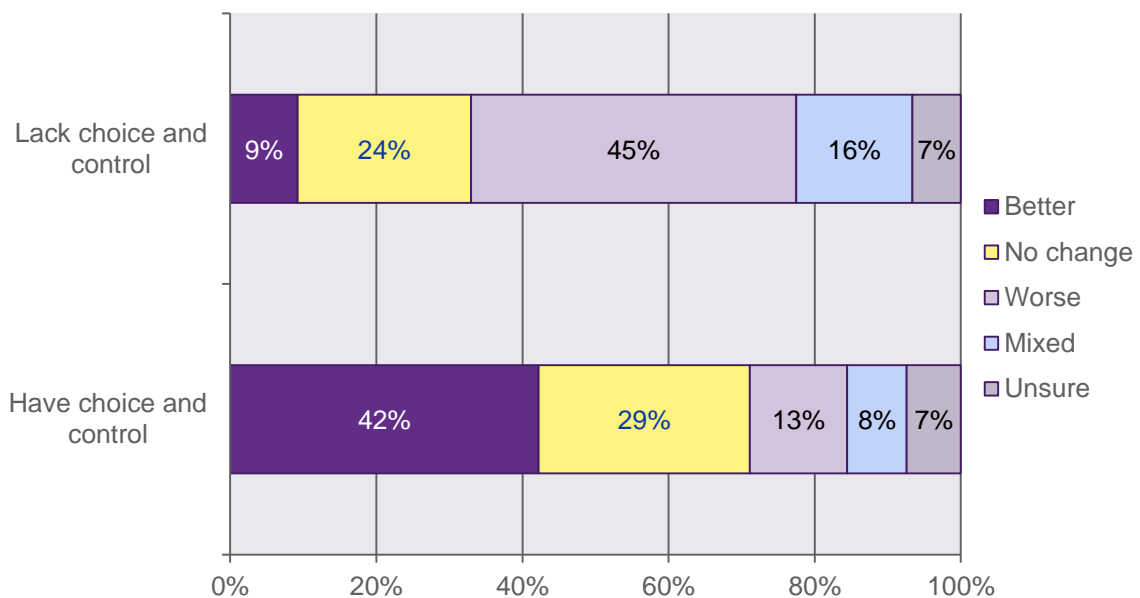


Survey respondents and interviewees with learning disabilities were particularly likely to emphasise the importance of having choice and control at the planning stage and in the way they use support in their daily lives, and to see choice and control as central to their independence and wellbeing.

“I’m much happier. I’m able to live as I choose. There’s less pressure to conform to other people’s views. I feel that I matter as a person and not a burden. I feel that I have as much freedom of choice as anyone else.”
Rochelle, 22

“Support has given me more freedom, more choice. I feel happier and more secure.”
Tom, 27, North West

Figure 1.16 Change in overall quality of support since 2010 by extent of choice and control

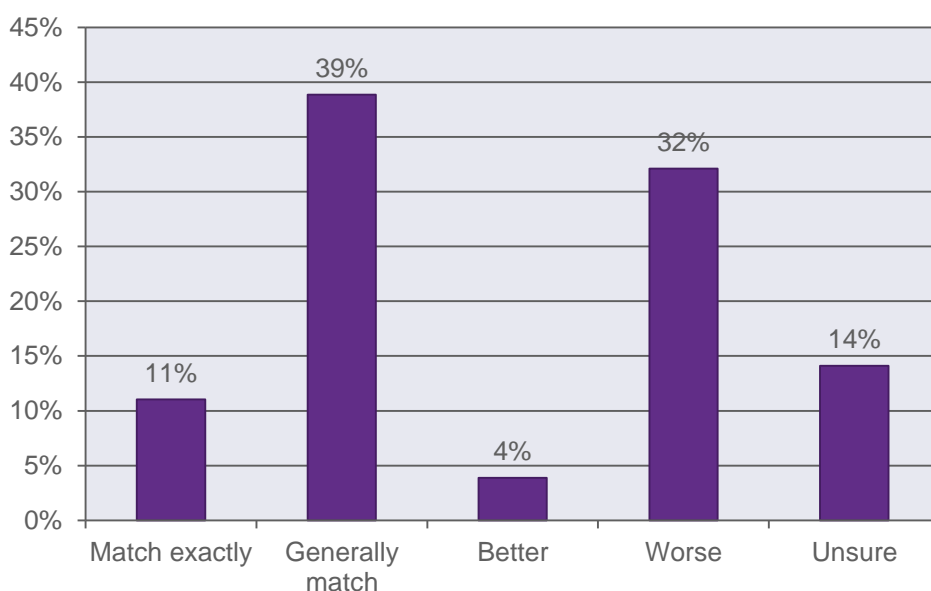


In line with qualitative findings, respondents' experiences of choice and control in meetings to agree care plans have a clear association with social care users' views of how their support has changed over the last five years. 42% of those who report having choice and control in care planning say their services have improved, compared to just 9% of those who report not having choice and control. Instead, 45% of this group say services have become worse over the last five years.

Reliability of support

Figure 1.17 Match between care plans and services received

Survey respondents were asked how far the services they receive match what is written in care plans, thinking about all the information in their plans, including the kinds of support agreed as well as when and how support should be delivered.



- 50% of respondents feel that the services they receive generally or always match what is written in their care plans.
- 32% of respondents feel that they are not getting the standard of support they have agreed with care planners.
- A relatively high proportion of respondents (14%) are unsure about the match between their care plans and the services they actually get.

For the third of respondents who do not feel they are getting the standard of support they have agreed with care planners, this has sometimes impacted on their wellbeing and ability to complete basic personal care and daily living activities.

“My diet is worse as the new PA is even worse at meal-planning than I am. She can't help with checking times or finances, doesn't appear to be able to think of non-physical tasks such as planning / organising and needs constant direction. She's a great help with housework and laundry but doesn't think beyond that despite my care plan stating meal planning, food preparation and checking finances.”

Carole, 50, North West

“Sessions in the care plan are 30 minutes, but actual visits got shorter after the first few weeks, sometimes less than 15 minutes (for a bath!). When the first girl was

introduced, she listened to some pointers and issues, but sometimes people turn up I've never met before who don't seem to have any idea what it says in the plan.”
Frank, 47

Disabled social care users frequently mention inconsistency in support staff as a key driver for support services not meeting the expectations set out in care plans. Staff may not be aware of the contents of care plans, or may simply not know the people they are supporting and what they want from their care. Some disabled people find being supported by inconsistent staff disempowering.

“What’s annoying is that when you don’t end up having the same person all the time you have to explain over again and tell them what you’ve got. Sometimes you don’t want to be reminded all the time of what you’ve got and tell everyone and explain. It is horrible, because you want to be able to do it yourself and it just highlights all the time that you aren’t able to do these things.”
David, London

“To begin with I had not enough continuity. Someone would come, learn the ropes and the next time they were gone and there was a replacement and I would have to go through it all over again.”
Jenny, 57, London

“I am not always well enough to cope with new people all the time. Some of those sent have no idea how to interact with me and make me feel very uncomfortable. I often feel judged. We always do the same things. They have been a great help but I think they could do more to help me attend meetings or courses instead of just going to the same places for coffee and cake.”
Sharon, 55, South West

For many disabled people, the reliability of formal help is as significant as flexibility in producing services which support people to achieve the outcomes that are important to them. In particular, many survey respondents stressed the importance of support consistently happening on time in order to be able to make plans and regular commitments. One interviewee described this as the foundation on which more personalised support can be built.

“I’m not expecting people to understand every form of disability going, or even my disability. I’m expecting them to provide a level of service, generic level of service, not specific, just being there on time, not breaking appointments. The generic, basic stuff. You can build on the other stuff afterwards but it’s just the foundations, there’s a lot of that missing.”
Michael, 41, London

“I have different carers every day who are unfamiliar with my routine. I’m late for appointments and not enough time is allowed.”
Patrick, 36, North West

“I have no set times as to when I receive my care so I cannot make plans to do things in life.”
Stacy, 48, North West

Part two: What have changes to services meant for outcomes and independence?

Support for basic needs and independent living

What does independence mean to social care users?

For the great majority of survey respondents, interviewees and focus group participants in our study, independence is highly valued, and is strongly associated with choice, self-determination, autonomy and maintaining a sense of individuality.

“Being respected for who I am, being treated as an individual and making my own choices.”

Lauren, 52, South East

Support is central to the way most of the disabled people we spoke to define what independence means to them, and how choice and self-determination are achieved.

A nuanced idea of interdependence runs through responses. Many disabled social care users see support as necessary in order to achieve the things that are important to them, fulfil their roles as parents, daughters, sons and friends, and be part of social and economic life.

“Independence means living life in a way that you choose with the support to enable you to achieve what you want to achieve.”

Janice, 43, East Midlands

“Everything. Independence is the ability to do what I can myself and know that there are people I can ask for help who will be there when I need them. It means treating me as a person not an illness, of recognising that the appropriate way of doing a task for Mrs A is not the right way to do the same task for me.”

Rachel, 35, London

“Having ultimate control over my life, including control over the support I need to love my life. It is not being able to do everything myself!”

Jean, 42, London

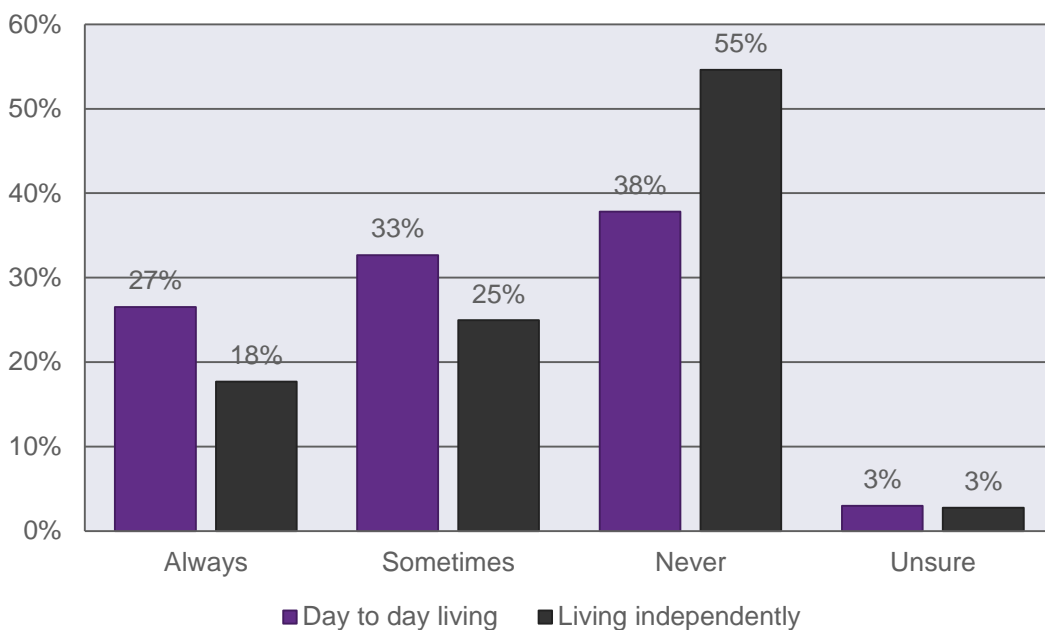
“Being able to choose to do the things I want to do, exactly how, and when. Being a contributing member of society, but most of all being a good mother to my disabled daughter and a good wife to my disabled husband.”

Ellen, 56, East of England

Do services support disabled people to live independently?

Many disabled social care users have a clear sense of what living independently means to them, and what they need from support services to achieve this. Looking now at how far disabled social care users are able to meet these aspirations through their support packages, results show how consistently disabled social care users feel services support them to do all the things they need to do as part of their daily routine, and to live as independently as possible.

Figure 2.1 Whether services support day to day living / living as independently as possible



- When asked whether services support day to day living needs, and whether they support living as independently as possible, 27% of our sample feel their care services consistently support them to do all the things in life they need to do.
- 38% feel their needs are never supported.
- 18% feel that services consistently support them to live as independently as possible, while 55% say this never happens.

Interviewees and survey respondents shared their experiences of being able – and not being able – to safely complete basic personal care activities, and what this has meant for their quality of life and wellbeing. Disabled social care users who feel that their services do support their independence some or all of the time described the value of this support, particularly mentioning opportunities to go out, get involved in their communities and feel happier and more confident.

“It’s helped me enjoy a bit of a better quality of life. If I have help with going to swim it improves my mobility and lifts my mood, and help with hobbies also makes me feel better about myself. I’m not so isolated.”

Ellen, 56, East of England

“I am able to be more independent than I was before I was in social care. Now I’m out a lot more including going to an autism centre and doing various activities there. I have done various other things that I wouldn’t have done if I wasn’t in social care, including learning to ski.”

Andrew, 37, North West

“I’m able to go out independently. It’s given me more confidence.”

Emma, 49, South East

55% of disabled social care users feel their care package never supports them to live as independently as possible. Some describe themselves as existing rather than living.

“I am existing. I just survive. I’m lucky if I get two baths a week. I don’t get hot food or drinks Monday to Thursday. I’m lucky if I manage to eat at all. I often don’t get undressed and sleep in my clothes because it’s easier. I sleep on a two seat sofa downstairs so that I will make it to the loo. My house is not wheelchair accessible so I often have to crawl to the loo. This is not a life.”

Jennifer, 44

“It is becoming more and more difficult. I do not bathe every day. I do not eat as well as I should. I am becoming isolated and depressed.”

Henry, 54, North West

Some disabled people who are supported by social care to live in their own homes say they do not get help to get out of the house and lead fulfilling lives.

“I don’t eat, I don’t bathe, I don’t leave the house and therefore don’t socialise or have any opportunity to do so.”

Marie, 33

“I’ve been unnecessarily completely housebound for three years. I’m without medical care, without adequate social care and rotting away in the corner of a dark room. With proper support I could have a full life the way I used to.”

Caroline, 42, South West

“I stay indoors a lot more than when I lived in a residential home.”

Alissa, 54, South West

Survey respondents in all age groups described the importance of formal support to complete daily living tasks and live independently, but younger social care users placed particular emphasis on this point, and on the value of formal support as an alternative to support from parents, other family and friends.

“Independence means not needing anyone else to help me with things except from my carers. It means being able to do what I want to do, when I want to do it. It means not relying on people other than myself and my team.”

Ashley, 19, South West

“Being able to do things like every other 27 year old without having to worry or feel a burden. Having a private life where I don’t have to involve my family and friends if I don’t want to, like going out, going to health appointments. Not feeling trapped.”

Zoe, 27, Yorkshire and the Humber

“Doing things on my own, being able to go out with my friends without my mum being with me.”

Eloise, 18, South East

“Without independence you are no longer a real person, just a burden to your friends and family.”

Kerry, 31, Yorkshire and the Humber

Figure 2.2 Relationship between whether services support day to day living and whether services support living independently

Day to day living	Living as independently as possible			
	Always	Sometimes	Never	Unsure
Always	58.3%	21.2%	18.2%	2.3%%
Sometimes	4.2%	50.9%	44.2%	0.6%
Never	1.0%	5.8%	92.1%	1.0%
Unsure	6.7%	26.7%	20.0%	46.7%

Looking at whether social care users feel they are supported to live as independently as possible by whether those same social care users feel they are supported with day to day living reveals a clear relationship between how these different levels of need are met.

Social care users who say the services they use always meet their day to day living needs are 11 times more likely to say they are also supported to live as independently as possible, compared to social care users who say their needs are only sometimes or never supported.

These results indicate a ‘hierarchy of needs’ operating in disabled people’s social care services. Not only are day to day living needs more likely to be met through support services than needs around independent living; results also suggest that support for independence builds on more basic support.

Basic support is prioritised over support to live as independently as possible both at the system level and at the level of many individual social care users’ experiences, an idea reinforced in stories from survey respondents and interviewees.

“I need for my local council to stop the standard that sees them only pay fully for what is basically glorified babysitting, but expect disabled people to pay for it if we want to actually be independent.”

Cara, 33, East of England

“Needs other than physical care should be given equal priority to ensure a good quality of life.”

Eva, 52, South West

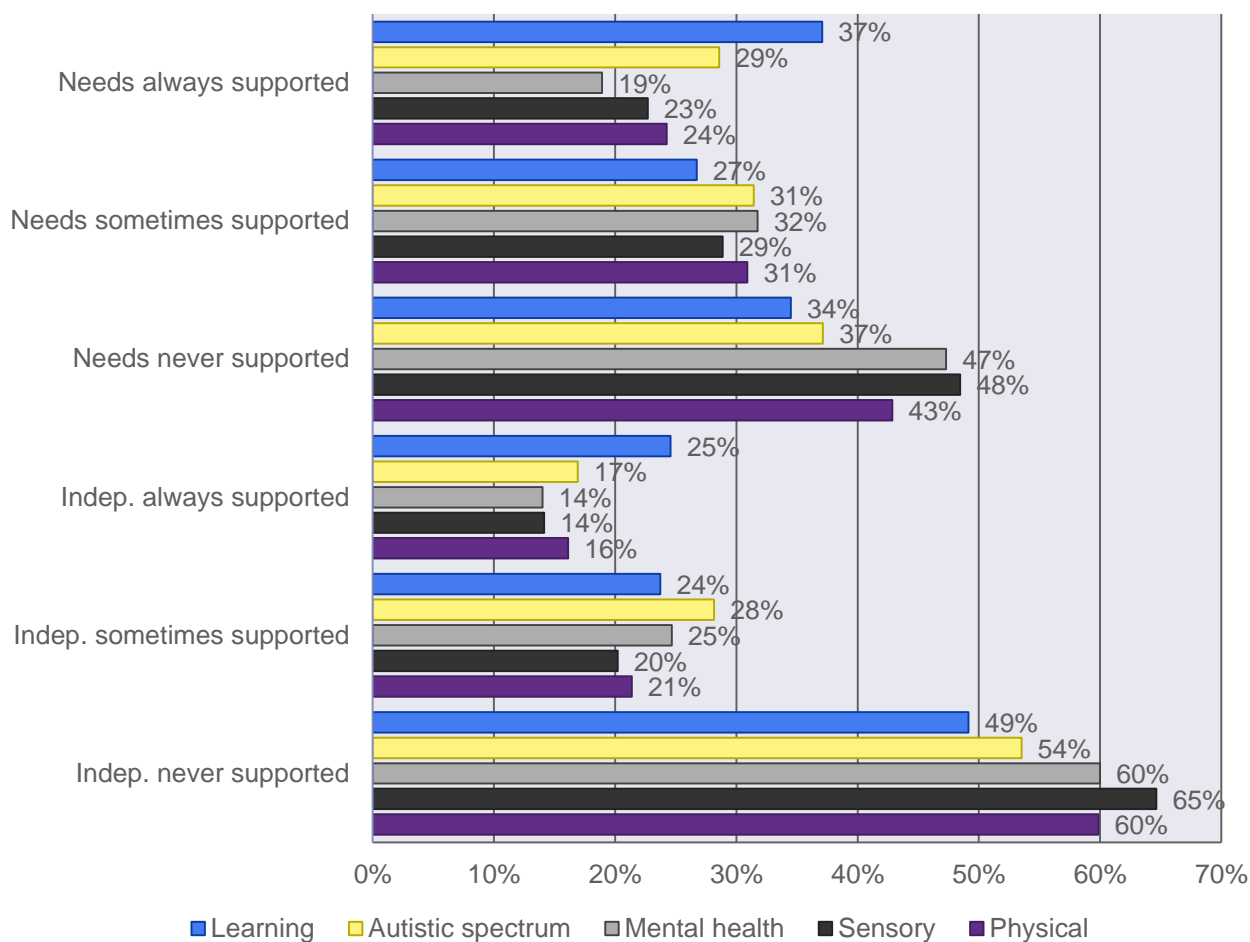
“I need to have quality of life and be able to explore / develop / enjoy my identity, instead of simply existing - being got up, fed, toileted and bathed etc.”

Jonas, 43, East Midlands

“Things like helping me with cleaning my house are not covered that is a very basic need - it makes it hard to ask for more complicated things you know would improve your life but that they don't think are worth the money.”
Jennifer, 26, South East

Figure 2.3 Whether services support day to day living / living as independently as possible by impairment type

55% of survey respondents had more than one impairment type, so there is a large degree of crossover between the groups represented on the graph.



In line with findings elsewhere, the most positive experiences of services was reported by survey respondents with learning disabilities. 37% of social care users with a learning disability feel they are consistently supported to do all the things they need to do to complete their daily routine, and a quarter feel they are consistently supported to live as independently as possible.

The more negative experiences of social care services overall identified by people with sensory impairments and mental health conditions are also reflected here, when looking at more specific outcomes. Just 19% of social care users with mental health conditions and 23% of those with sensory impairments feel their day to day living needs are consistently supported. 14% of social care users with either impairment type say they are always supported to live as independently as possible.

Social care users' priorities for support

Figure 2.4 How far priorities are included in care plans

The idea that social care is more effective at meeting basic needs than it is at enabling independent living is also reflected in survey respondents' assessments of the contents of their care plans. Social care users were asked how far care plans contained the activities, goals and aims important to them.

Views are mixed. 35% of respondents said their care plan contains all or most of their priorities, 31% said some of their priorities are included, and 29% reported that few or none of the things that are important to them are included.

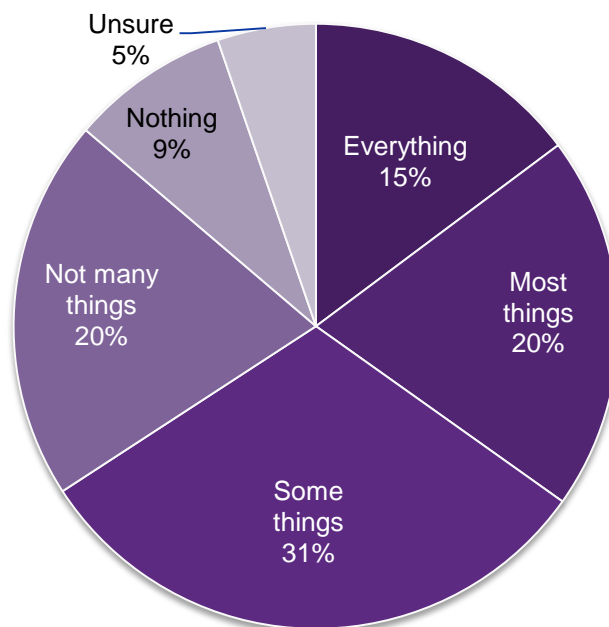


Figure 2.5 Top 10 activities / outcomes social care users get help with

Survey respondents were asked about the role of social care and support services in helping them with a range of 26 activities and outcomes covering different areas of life. These 26 options were developed from focus groups with social care users and young disabled people who are planning to access social care in the future, and from policy priorities identified in the Care Act Statutory Guidance. Using the activities and outcomes identified in these ways, we asked survey respondents:

- what they currently get help with
- what they need support for, but currently aren't being helped with at all or aren't being helped with enough
- whether there are activities or outcomes they would like more or any help with in the future in order to live as independently as possible.

Activities and outcomes where needs are supported	Percentage
1 Maintaining personal hygiene	58.0%
2 Making sure home is clean and liveable	49.0%
3 Being dressed appropriately	47.6%
4 Supporting physical health	47.3%
5 Maintaining healthy diet	41.5%
6 Getting around the home	41.3%
7 Using local services	40.6%
8 Spending time with friends and family	40.2%
9 Using the toilet	38.4%
10 Doing enjoyable things at home	35.1%

The activities and outcomes respondents say they currently get help with reflect an emphasis on supporting day to day living and basic personal care activities over support for active citizenship and independent living outcomes.

Looking at the 10 most commonly selected activities and outcomes, activities that are basic to living feature prominently, with 58% of survey respondents saying they have help to maintain personal hygiene. However, two fifths of survey respondents are also supported to spend time with friends and family, and another two fifths get help to use local services like public transport, the bank or shops.

Survey respondents strongly emphasised the value of support with these activities and outcomes to their lives, and to their ability to engage in activities and outcomes related to living independently in their communities.

“Independence is everything. It means living my life to the fullest extent possible considering my condition. Not being stuck at home and the house becoming a prison. It’s about combatting loneliness.”

Ben, 53, South East

Figure 2.6 Top 10 activities / outcomes where social care users have unmet needs and aspirations

Survey respondents were also asked which activities and outcomes they need more help with to carry out day to day living, and which they would need more help with in order to live as independently as possible. Combining these results allows us to see where unmet needs and aspirations are greatest for disabled social care users.

Activities and outcomes where needs / aspirations are not supported	Percentage
1 Travelling outside local area	60.8%
2 Building new relationships	57.6%
3 Supporting mental health / wellbeing	57.4%
4 Doing enjoyable things locally	54.0%
5 Supporting physical health	53.4%
6 Being involved in community	51.8%
7 Accessing information and advice	50.0%
8 Using local services	49.3%
9 Maintaining healthy diet	48.1%
10 Spending time with friends and family	48.0%

Looking at the most commonly selected outcomes and activities which social care users would like more support with gives a different sense of priorities to the rankings for met needs. Survey respondents identified five outcomes and activities where needs and aspirations are not currently met, which do not also appear in the rankings for currently supported activities. For these options, the proportions of people saying they currently get any support are low, indicating the need for some people’s care plans to include entirely new priorities.

- 58% of social care users say they need more help with building new relationships, compared to 22% who say they currently get this help.
- 61% emphasise more support to travel outside their local area, while 32% said they currently get this kind of help.
- 50% need additional support to access information and advice, compared to 21% of social care users who get help with this.
- 54% need more help to do enjoyable things locally, while 28% have help with this.
- 52% want more help to be active in their communities, while 30% receive help towards this.

Some activities and outcomes related to health and wellbeing, like ‘maintaining a healthy diet’ and ‘supporting physical health’ appear in both groups, suggesting that some social care users need more or better support with more basic care activities, even where these needs may already be recognised in care plans. 57% of survey respondents also told us they need services to be better at supporting their mental health and emotional wellbeing.

In interviews and open-text survey responses, many social care users emphasised the importance of care and support services for maintaining physical and mental health, emotional wellbeing, good nutrition and a generally healthy lifestyle, and described unmet needs in these areas.

“Last year my health deteriorated because of the cuts [to my care package]. I had a severe chest infection and sinus problems due to not being able to go outside enough due to lack of care support. My friendships and relationships have suffered. I have low moods and suffer from isolation and anxiety when my friend cannot take me out.”

Kate, 47, East Midlands

“I am less able to ensure my health is at its best as I'm not eating regular meals because I'm not seeing someone to assist with preparing lunch. I'm not able to get to the toilet during the day so I'm having to wait from 8am sometimes until 10pm.”

Justine, 29, West Midlands

“I don't get cooked meals and as a consequence my health is suffering, especially as I am diabetic. My doctor is not happy with this, but cannot do anything in the face of inflexible rules.”

Charlotte, 49, Yorkshire and the Humber

Some social care users described a lack of join up between the health and social care services they use. This is a particular concern for social care users with mental health conditions, especially where these coincide with physical impairments.

“I think we need to have a National Health and Care Service. It shouldn't just be national health, we need to combine it with a care service so it's free at the point of service.”

Henry, 54, North West

“There seems to be a big mix up in what you can have, and you can't buy NHS services with a social care package. That's out of the question.”

Reagan, London

“I found I need a dietary service and I’ve been getting that on the NHS but the appointments are too far apart, so I wondered if there was some method of getting such a service with appointments closer together. The CPN said that’s not included in social care. Because I thought it was maybe anything that improves your life and wellbeing, and that health matters would come in to it as well. So I find it difficult to define what social care is.”

Jenny, 57, London

Taken together, these findings suggest that disabled social care users need a more holistic care and support service to achieve the outcomes that are important to them. Some social care users also need more or better support with social outcomes and with daily living activities outside the home. ‘Using local services’ and ‘spending time with friends and family’ are amongst the outcomes and activities which social care users are most likely to get support with, and most likely to need further support with.

Older and younger social care users’ priorities for support

Figure 2.7 Top 10 activities / outcomes social care users get help with by age

The table below shows the top 10 activities and outcomes people currently get help with split by whether respondents are aged under or over 35.

Social care users aged 18 to 34		Social care users aged 35 to 64	
Activities and outcomes where needs are supported	Percentage	Activities and outcomes where needs are supported	Percentage
Spending time with friends and family	57.0%	Maintaining personal hygiene	59.6%
Maintaining personal hygiene	52.8%	Making sure home is clean and liveable	52.4%
Supporting physical health	47.2%	Being dressed appropriately	47.6%
Using local services	46.3%	Supporting physical health	46.7%
Being dressed appropriately	45.1%	Maintaining healthy diet	44.4%
Making sure home is clean and liveable	40.1%	Getting around the home	40.0%
Getting around the home	40.1%	Using local services	36.4%
Doing enjoyable things at home	39.7%	Using the toilet	35.6%
Doing enjoyable things locally	38.2%	Supporting mental health / wellbeing	31.3%
Using the toilet	37.3%	Doing enjoyable things at home	30.8%

Eight activities and outcomes are shared between both age groups, suggesting that the needs met through social care services are relatively similar for older and younger service users.

‘Supporting mental health and wellbeing’ and ‘Maintaining healthy diet’ appear in the list of activities and outcomes most commonly supported for social care users aged 35 to 64, but

are not in the list for those aged 18 to 34. 'Spending time with friends and family' is the activity most younger social care users are supported to do, but it does not appear as a top 10 option for older working age social care users. 'Doing enjoyable things locally' also appears in the list for younger social care users but not for those aged 35 to 64.

Social care users aged 18 to 34 are more likely to be getting help with most individual activities and outcomes, and to be getting help with a wider range of activities and outcomes overall. While basic personal care activities still feature prominently in the activities younger disabled social care users are supported with, in some areas more emphasis on social outcomes and on support to do things outside the home is evident.

Figure 2.8 Top 10 activities / outcomes where social care users have unmet needs and aspirations by age

The table below shows the top 10 activities and outcomes where needs and aspirations are unmet, split by whether respondents are aged under or over 35.

Social care users aged 18 to 34		Social care users aged 35 to 64	
Activities and outcomes where needs / aspirations are not supported	Percentage	Activities and outcomes where needs / aspirations are not supported	Percentage
Building new relationships	69.0%	Travelling outside local area	63.1%
Travelling outside local area	65.4%	Supporting mental health / wellbeing	60.4%
Supporting mental health / wellbeing	59.2%	Doing enjoyable things locally	59.6%
Being involved in community	59.0%	Supporting physical health	57.7%
Accessing information and advice	54.7%	Building new relationships	53.7%
Working	53.2%	Using local services	52.5%
Managing money	52.9%	Spending time with friends and family	51.5%
Doing enjoyable things locally	52.9%	Being involved in community	51.2%
Looking for work	51.1%	Accessing information and advice	50.2%
Maintaining healthy diet	50.7%	Making sure home is clean and liveable	49.8%

Both age groups placed emphasis on support with mental health and wellbeing, an outcome which 31.3% of those aged 35 to 64 and 35.2% of those aged 18 to 34 currently get help with. Around 3 in 5 people in each age group need new or additional support with mental health and wellbeing to live as independently as possible, suggesting significant unmet needs and aspirations in this area.

More than half of survey respondents in each age group also identified 'Accessing information and advice' as an area where they needed more support. 50.2% of those aged 35 to 64 and 54.7% of those aged 18 to 34 want more support, compared to 18.5% and 24.5% who currently get some help with accessing information and advice. Further

findings on awareness of and access to information and advice are available on pages 58 to 61 of this report.

“I need more honest information about what is available to me.”

Jaya, 57, North West

Social care users aged 18 to 34 years old put particular emphasis on the need for support to build new relationships and meeting new people, with 69% saying they want help to do this. Around half of younger working age social care users also felt they need help with working, looking for work and managing their money, three outcomes and activities that are not on the list for social care users aged 35 to 64.

“Independence is about being supported to be a part of my community. This is difficult because I am autistic and have extreme sensory difficulties, but I am desperate to have meaningful social contacts and to have a meaningful role or occupation in my community.”

Carrie, 22, London

Younger and older social care users have different priorities for the support which will enable them to carry out their day to day lives and to live as independently as possible. Both groups emphasise the need for support to do things outside the home, achieve social outcomes and be part of their communities. However, social care users aged 18 to 34 are more likely to prioritise outcomes related to active citizenship and social and public life.

Those aged 35 to 64 have a greater focus on better support with activities which are fundamental to daily living, in and outside the home, suggesting that older working age social care users may face particular challenges in using social care services to live as independently as possible.

“I am unable to live I independently. I have a power chair but can't get it out of the house. They are refusing to assist me or sort it because they don't see it as a priority.”

Lola, 62, London

Results for activities and outcomes where social care users' needs and aspirations are unmet differ more by age group than results for activities and outcomes where help is currently given. Younger and older social care users clearly have different aspirations and priorities for how they will use care and support services in the future. The relatively close alignment between the met needs of older and younger social care users suggests that these different aspirations and priorities may not currently be recognised enough in care plans.

Work and active citizenship

What does active citizenship mean to social care users?

When asked what independence means to them, a number of disabled social care users mentioned work, volunteering and other active citizenship outcomes.

“Independence is life! It’s being a member of society and getting paid work.”

Jake, 29

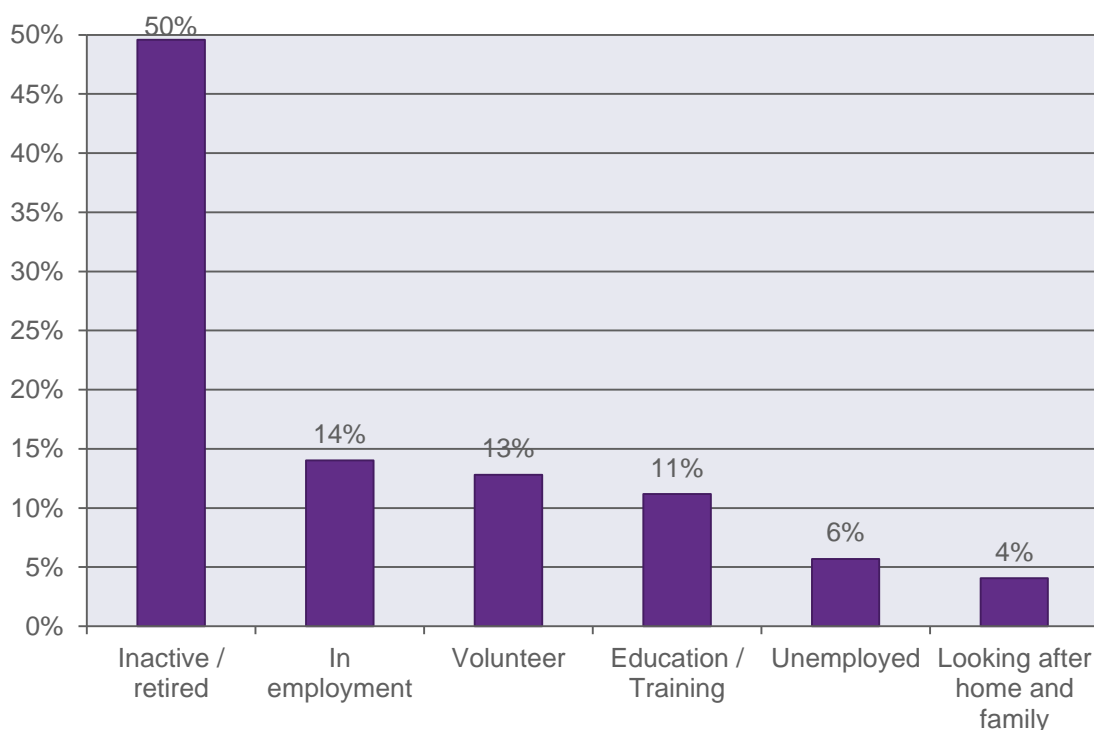
“We base our life on work. If you want to buy a house you need work. If you want to start a family you need work. If you want to go out with friends you need an income, you need work. We base our life on our work and we build our lives from it. When you’re in work it gives you stability. It gives you a meaning, a purpose, a place to go, people to see. It’s so much more than the actual physical work itself.”

Michael, 41, London

“Independence means having choices, going to Preston on my own, working, volunteering, going to football.”

Tom, 27, North West

Figure 2.9 Employment status



*Our survey asked respondents to define their main economic activity. Some respondents told us about additional activities elsewhere in the survey (like volunteering in addition to work or study).

Just under half of respondents are not working or looking for work. 14% of our sample is working, and 4% of these respondents are self-employed. 10% of respondents are

students, driven partly by the relatively young age profile of our sample; 47% of respondents aged 18-24 are studying or are in training for a job. At 28%, this age group also has the lowest rate of economically inactive / retired responses.

Work and volunteering are often seen as important opportunities to participate in society on equal terms with non-disabled people. Work is frequently mentioned alongside other outcomes around social and community participation, inclusion and self-determination.

“Feeling able to do things I enjoy, and those that give life meaning (like working), and having control over my everyday life.”

Dean, 44, North West

“Not being trapped in the house, being able to get to work, see people and socialise. Not putting my little boy at risk. Feeling like a visible and valued person and member of the community.”

Caitlin, 47, South West

Some social care users particularly emphasise the importance of work for earning money and ensuring financial wellbeing.

“Getting a job and being able to keep it. Buying a car so I can get around when I want to.”

Luke, 24, East Midlands

“I would love to do what other people do and earn money in order to go out and do what everyone else does. My sister and brother both have their own homes but I lost mine due to having to fund my own care needs and getting into debt.”

Matt, 42, South East

Some survey respondents and interviewees described feeling pressured to work, or to work more hours than were right for them. Some disabled social care users strongly emphasise the importance of employment that takes account of the additional barriers they face and helps to maintain their health and wellbeing.

“Independence means having choice about what I do from day to day. Being able to do paid work to the extent my disability and health allows.”

Laurence, 47, North West

Independence means I can live my life as I want to, be able to manage all the basic day to day tasks, without so much hassle. It means not being tormented by DWP / ATOS and others, made to feel a failure or a drain if I can't manage paid work.”

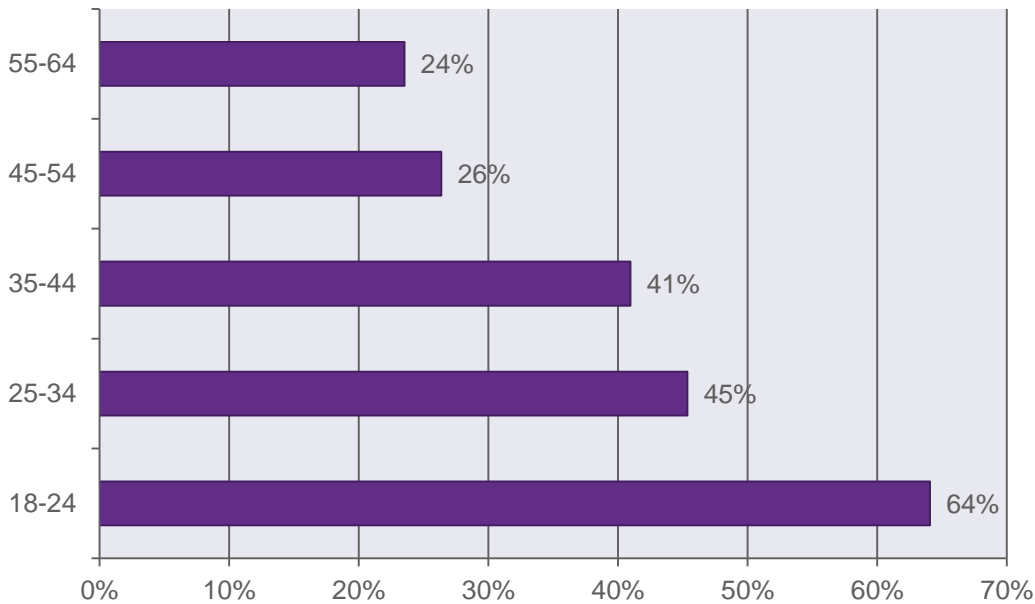
Rosemary, 53, East of England

“I feel very angry, because I worked and I didn't ask to get all these illnesses. I was a bookkeeper and I paid my tax and insurance and I've had to fight for everything. If I was healthy I'd be out there working. I don't particularly like being stuck in four walls, seven days a week.”

Susan, 40s, London

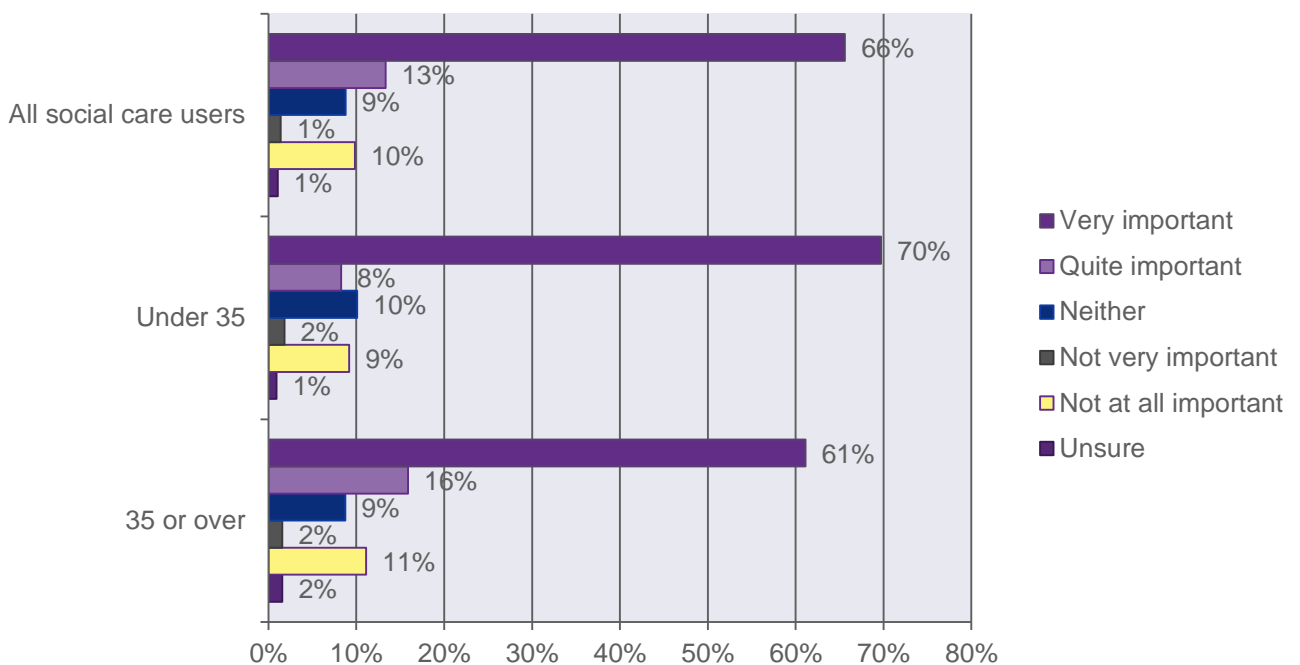
Social care and active citizenship

Figure 2.10 Working, volunteering, training or studying by age



Overall, 40% of respondents are working, volunteering, studying or in training for a job. The percentage of respondents in this group is inversely related to age group, with younger age groups demonstrating higher rates of participation in work, volunteering or learning.

Figure 2.11 Importance of care and support for employment and active citizenship activity by age



Survey respondents were asked how important care and support services are for achieving the things they want to achieve in work, volunteering and learning. Respondents clearly indicated that services are highly important for enabling them to achieve their

employment and active citizenship goals, with 79% of our sample saying services are 'very important' or 'quite important'. There is no statistically significant difference between those in work and those not in work, with those volunteering, jobseeking, studying, training and looking after home and family all indicating an important role for social care in helping with these activities.

Social care users aged 18 to 34 years old are more likely to say that services are 'very important' rather than 'quite important' compared to social care users aged 35 to 64. Otherwise, there are no statistically significant differences between older and younger social care users, with the majority of respondents in all age groups emphasising the central role of support in helping them to achieve their goals. Several social care users described the significance of support for helping them to achieve their goals around work and learning.

"My support is much more flexible now, so I can build it around my job - which I wouldn't even be able to do otherwise. I travel for work, so without help to get around the country I'd be out of a job."

Danielle, 31, London

"I used to just have individual PAs, but now I use some of my budget to pay for a dedicated organisation who are helping me to volunteer and hopefully set up as self-employed cleaner for a couple of hours a week under their supervision. I could end up self-employed under special rules if it works out. My Personal Budget is essential for this and it's not possible without it."

Peter, 21, North West

"Social care means I am ready for college and transport on time."

James, 19, North West

On the other hand, some social care users mentioned losing employment and opportunities to volunteer or study because of support becoming less effective, especially where unmet needs from social care services have coincided with the absence or withdrawal of alternative workplace support.

"I feel much more isolated now. My care was put in place to help me keep a job, and it has done the opposite, causing me to lose my job."

Fred, 42, South East

"I am now more restricted in what I can do which has made me more isolated. To make matters worse, my employer has removed my workplace adaptations and has so far failed to refit them. This has gone on for the past eight months and has worsened my condition still further."

Laura, 41, East of England

"When I have been an employee, I have not received the full amount of support I needed and ended up being sacked or being forced to resign because I was unable to do the job without that support. So, I would need to be sure that I would receive help to stay in work as well as get a job in the first place."

Philip, 50s, North West, self-employed

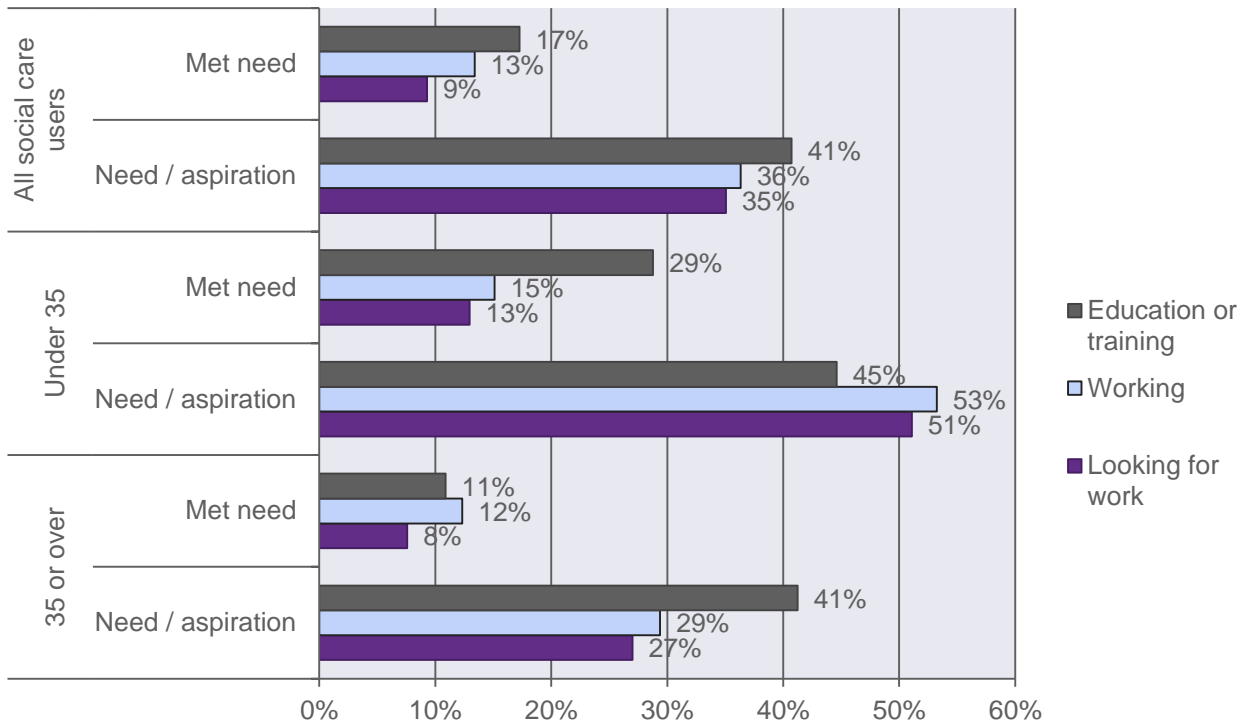
"I couldn't get my care package to honour the fact that for my independence I wanted to do a college course. So I stopped doing my college course because I

didn't think it was fair for my husband to come out at 10pm at night to pick me up when he works long hours, and I couldn't afford a taxi each way."

Glynis, East of England

Figure 2.12 Met need, unmet need and aspirations by age: working, looking for work and education or training

Results show met and unmet need for support to enter employment, stay in and progress in work, and complete education or training.



Social care users under the age of 35 are more likely to be getting help from social care with each of these activities, and are also more likely to report unmet needs and aspirations in these areas compared to older respondents. More than half of social care users aged 18 to 34 want help with working or jobseeking, but only 15% are currently getting support with working and only 13% are getting support with jobseeking. 29% of younger social care users currently use support to help with education or training, while 45% have unmet needs or aspirations around this activity.

Social care users aged 35 to 64 are less likely to get or to want help with work and jobseeking, and are also less likely to get support for study or training. The gap between the aspirations of younger and older working age social care users was larger for working and looking for work than for any other activities or outcomes covered by Scope's survey. However, older working age social care users are almost as likely as younger people to have unmet needs and aspirations around education or training, with 41% of survey respondents reporting this. A far higher proportion of social care users aged 35 to 64 wanted help with learning than wanted help with working or jobseeking.

Social and community participation

What does participation mean to social care users?

In interviews, focus groups and open-text responses in our mixed methods survey, disabled social care users spoke passionately about the importance of being part of their communities and involved in society more broadly, and of having fulfilling relationships with partners, children, other family and friends. These outcomes are identified by many research participants as key to living independent, fulfilled lives on equal terms with non-disabled people.

“Independence means being able to be part of society and having choices which enable me to live a life of equality.”

Neil, 51, East of England

“Freedom, the opportunity to get nearer to reaching my full potential, to joyfully give, receive, help and assist in my relationships with others, to learn and to educate myself, to gain more experiences, to maintain my flat, to maintain my finances, to travel and to have hope, and to remain physically, mentally as healthy as I can.”

Jenny, 57, London

“To be enabled to take part in all aspects of a ‘normal day to day life’ that most people take for granted whether it’s at home or out and about in my local community. To be seen as equal and respected part of the local community.”

Sarah, 40, East Midlands

“To me, social care means providing help to allow people with impairments - mental, physical or emotional - to live in a way that is acceptable to society. This means keeping clean, clothed, fed and playing a part in, and making a positive contribution to, the social life of their community.”

Philip, 50s, North West

Most of the social care users in our study wanted and expected to work, volunteer, be part of their local communities, fulfil caring responsibilities and be active in their society. However, some respondents felt constrained in their ability to do so, emphasising the important role of care and support services in enabling active citizenship and independent living. A number of disabled people shared their experiences of feeling excluded from society.

“Independence means being able to live as I like, making choices I want. Being accepted as a valuable member of society.”

Rochelle, 22

“Independence means living my life day to day without being bullied or hassled.”

Graham, 44

“Independence is about living life to the full and making the most of what I have. Living life and being part of it, not watching life pass by because of a lack of support. That is not living, it is existing.”

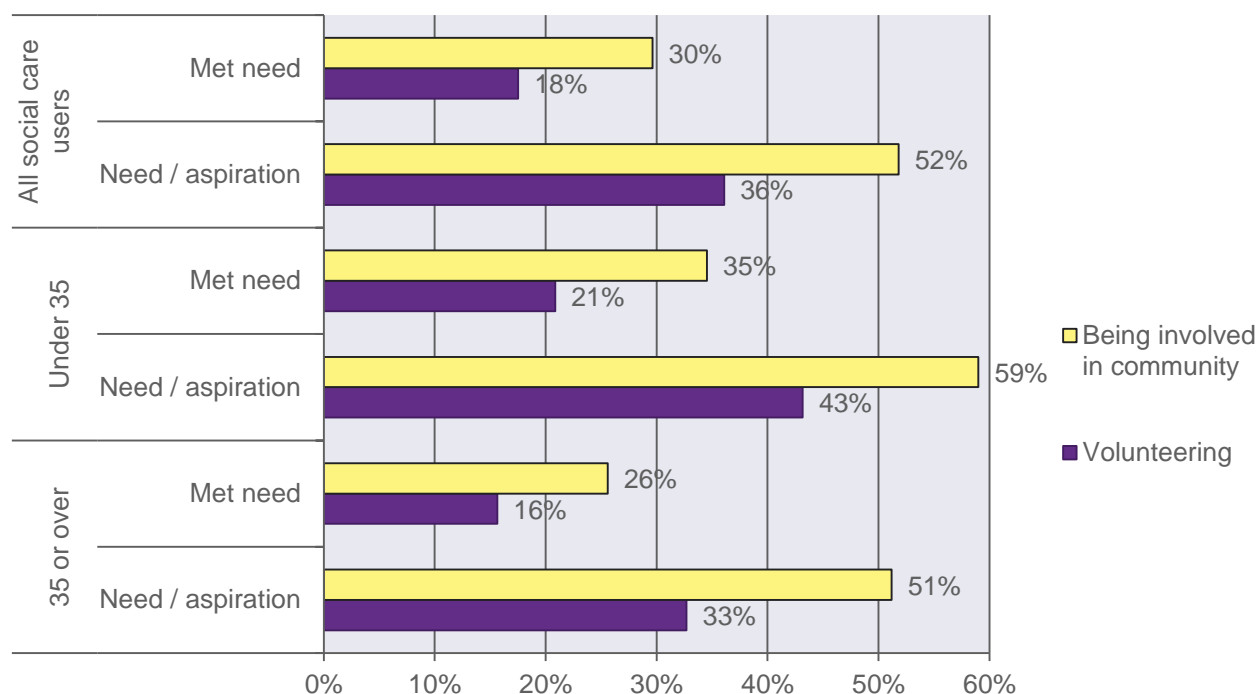
Katy, 43, North West

“It means being able to maintain my dignity and improve my self-esteem. I need more in life than just to be helped to wash and dress and to undress again at the end of a day. I need to have a life outside of the walls of my home and I just don't have that. I may never have total independence in life again but I could have dignity in life if given the right support.”

Stacy, 48, North West

Community participation

Figure 2.13 Met need, unmet need and aspirations by age: volunteering and being involved in community



36% of survey respondents report needing more support to volunteer, and half have unmet needs and aspirations around support to be involved in their communities. Social care users aged 18 to 34 were more likely to be getting help with these activities already, but were also more likely to say they were not currently getting the support they need.

Social care users also emphasised the importance of volunteering and community participation, and of support to do these, in open-text survey responses and interviews.

“With my support worker I could travel more freely and independently, do more and different volunteering and helping, to help children and help in offices. I'd like support through some guiding, orientation and getting to know the place, so I would be able to connect with people.”

Daniel, 30, London

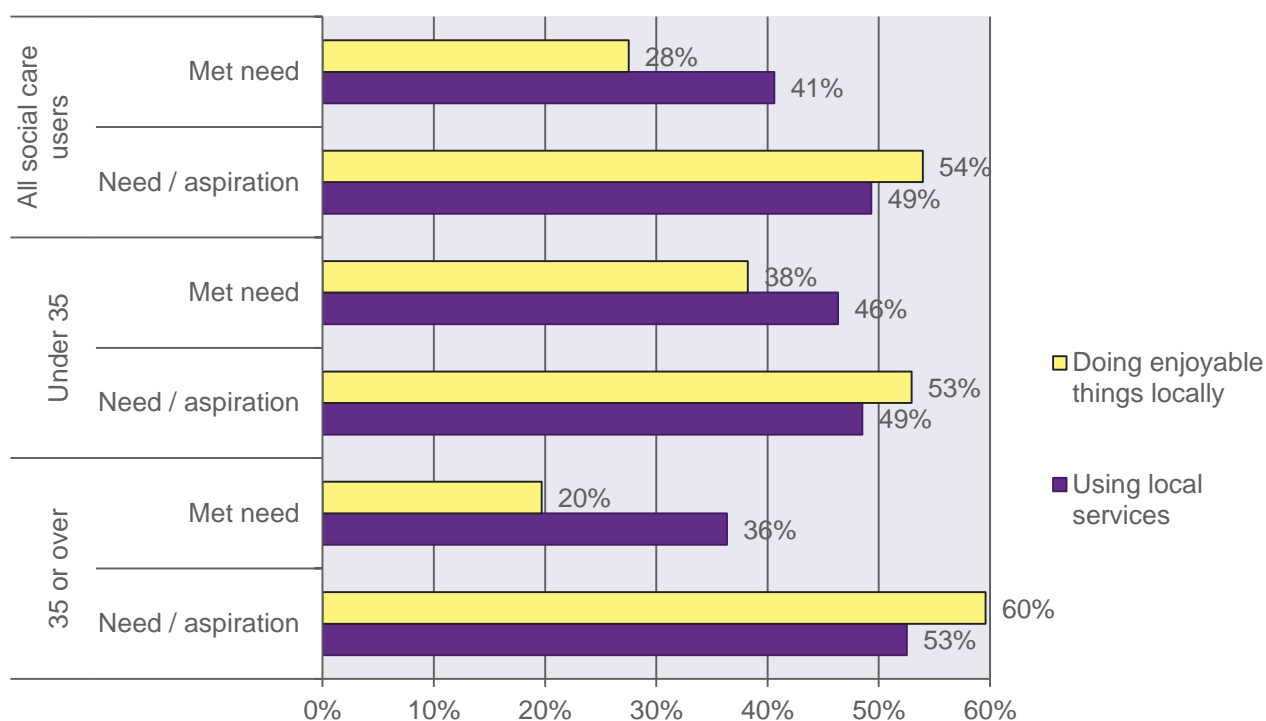
“I would like to join a choir; I love to sing. I would like to feel that although I'm housebound, with a lot of help it is possible for me to get active in my community.”

Joy, 44

“I’m quite busy in my local community. I am also very involved with my church. I’m on several committees and boards and I’m monitoring issues at the London Assembly. I was the main carer for my mother up until August this year, so I spent a lot of time with her and seeing to her and her needs and seeing that she was OK.”

Angie, London

Figure 2.14 Met need, unmet need and aspirations by age: accessing local services and recreation



A greater proportion of younger working age social care users said they currently get help to use local services and to do the things they enjoy doing in their communities. Social care users aged 35 to 64 were significantly more likely to report unmet needs and aspirations in these areas, with 53% wanting more help to use local services and 60% wanting more help to do enjoyable things locally. As extracts from interviews and open-text survey responses indicate, many disabled social care users value support with activities and outcomes outside the home, and see this as key to living independently.

“I am more independent because I can go out and get my lunch from the shops and travel to and from my home. I also have more support to find the job I want. I can develop my skills through different activities.”

Kofi, 41, London

“I want to remain living on my own, having choices and options throughout my days. I want to be able to get out into the community, access classes, theatres, shops, meet friends at groups, do crafts in the community, and at home if not well enough to go out anywhere. Independence should mean the same for everyone, within a person’s limitations, and should mean the opportunity to push the boundaries sometimes.”

Paula, 48, East of England

Fulfilling roles and meaningful relationships

When defining independence, many survey respondents described the importance of being able to fulfil care, family and household roles, and of having meaningful relationships with others as parents, partners and friends. Of those who mentioned a specific outcome or area of life important to their independence, having meaningful relationships was the most popular response, jointly with participating in the community.

“Independence helps me to maintain who I am and have some self worth as a parent.”

Nicole, 37, London

“Independence means running my home, working, paying my own bills, socialising and spending time with my family.”

Mary, 39, East of England

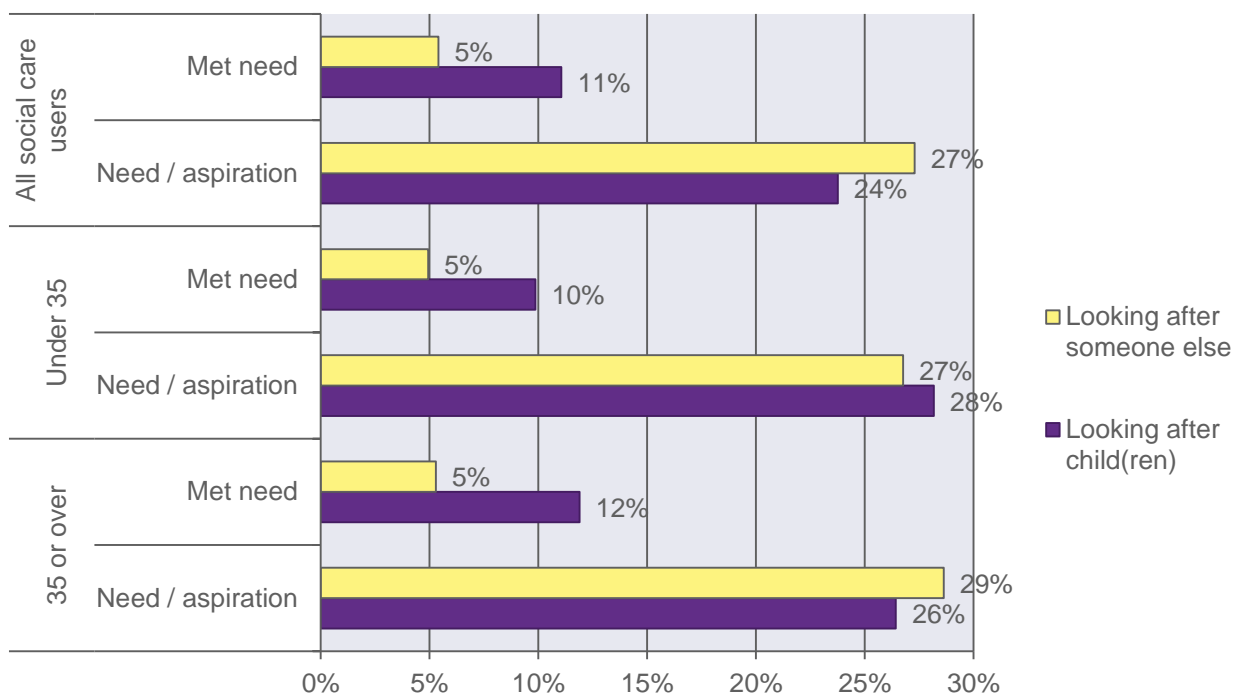
“Independence means everything: happiness, confidence, life, a way to be a proper mum.”

Pauline, 42, South East

“Independence means choosing how I live my life. Being able to get out the house and meet friends and family. Caring for my family.”

Emily, 34, South East

Figure 2.15 Met need, unmet need and aspirations by age: looking after children and caring for others



Survey results reflect disabled people’s needs and aspirations around caring for others, with around a quarter saying they need or would like more support in these areas. However, just 11% currently get help to look after their children, and just 5% are supported

in their roles as carers for other people. There are no statistically significant differences in these results by age.

When describing how their care and support services have improved and what this has meant for this independence, many disabled social care users emphasise the importance of being able to fulfil family and caring roles.

“As my elderly mother's support needs have increased my current PA has been excellent at supporting me to support her.”

Harriet, 54, London

“It's been great. Having the support means I can do things with my PA while my daughter is at school, like wrapping presents and preparing for Christmas. I have been supported as a mother and as a deafblind person in the community to enable me to do what I want and choose to do.”

Janice, 43, East Midlands

As well as enabling them as carers and parents, many disabled people also identify an important role for social care in creating opportunities to have meaningful relationships with partners and friends who currently give (or previously gave) informal help due to insufficient support from formal services.

The importance of fulfilling, reciprocal relationships for living independently was repeatedly emphasised by social care users in focus groups, interviews and survey responses. Many disabled people describe relying on informal support as highly undesirable for this reason.

“Independence means having my husband as a husband and not as a carer filling in the gaps, washing me some days as we run out of hours by the weekend. I want to be a wife not a burden, doing my share of housework, gardening and shopping.”

Victoria, 35, South West

“I think I have to rely too much on friends and neighbours and family, as they all have busy lives so I don't think it's terribly fair on them, and because I always have this fear of getting isolated. Friends are good at listening, but I always feel like I mustn't burden them too much and talk about me and my problems. Whereas if it is a paid person you feel as if – well, they are paid for dealing with burdens.”

Jenny, 57, London

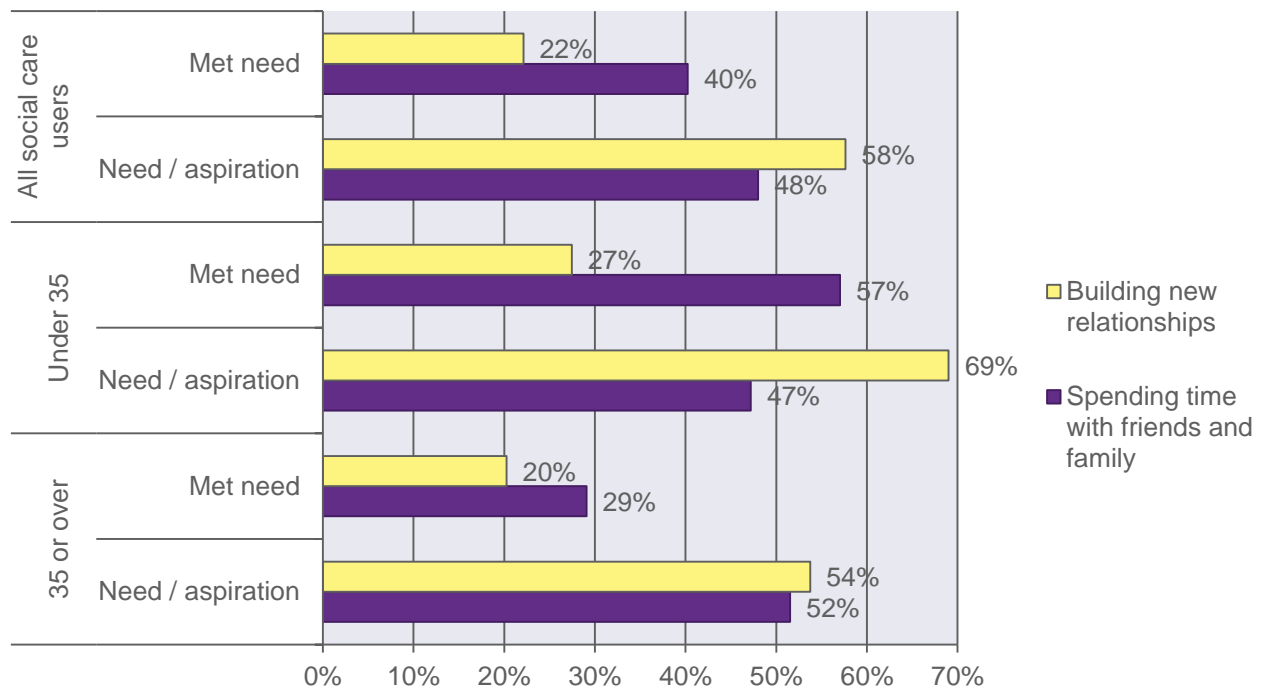
“Having the dignity and freedom of an adult. I don't want my partner to be my carer. I would like them to be my friend and lover.”

Lisa, 46, South West

“The care has saved our relationship as we were close to splitting up at one point due to his inability to cope. It has made my partner feel more supported and makes me feel as if I contribute to the relationship on a practical level, which has improved our mental and relationship health.”

Rachel, 35, London

Figure 2.16 Met need, unmet need and aspirations by age: maintaining and building new relationships



Survey results support qualitative evidence around the significance of meaningful relationships for disabled social care users, with 48% saying they need more support to spend time with friends and family, and 58% saying they need more help to build new relationships.

Splitting results by whether respondents are under or over 35 years old reveals significant differences. Those aged 18 to 34 are much more likely to say they are currently supported by care and support services to build and maintain relationships, but also highlight a high level of unmet need around building new relationships compared to older working age social care users. These findings suggest that support for social inclusion and to have meaningful relationships is important for the majority of social care users, but is a particular priority for younger disabled people.

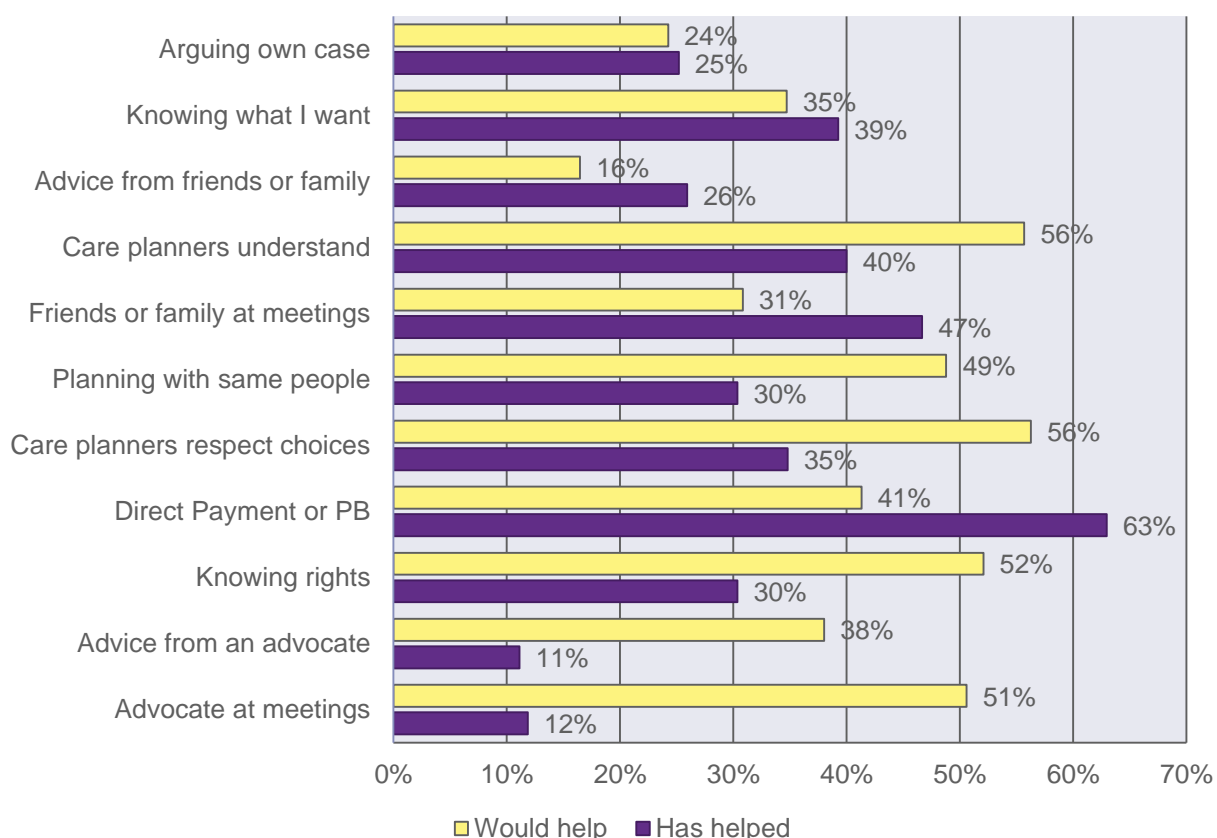
Part three: Improving disabled people's experiences as social care users

In the Care Act, the care plan is the critical document which influences both the content and delivery of a person's support package. It is therefore essential that disabled people are able to participate as fully as possible in care planning and review processes.

Part one of this report shared qualitative and quantitative findings which indicate a high level of significance for choice and control in determining disabled people's experiences with, and outcomes from using, care and support services. Disabled social care users have mixed experiences of choice and control when planning and reviewing their services, with 28% of survey respondents saying they have 'complete' or 'a lot of' choice and control, while 69% say they have only 'some', 'very little' or 'none'.

Social care users who feel they have 'a lot' or 'complete' choice and control in meetings to plan or review their support were asked what had helped this to happen. Those who feel they have only 'some', 'very little' or no choice and control were asked what they thought could help to improve this in the future. Survey respondents made selections from a range of options developed from early qualitative work, and also gave further information in open-text responses.

Figure 3.1 What has helped / would help social care users to have choice and control in care planning



Two enablers which focus on individual agency – ‘arguing my own case at meetings’ and ‘having a clear idea about what I want’ – were selected by similar proportions of those with and without choice and control. Results for the remaining nine options, around access to formal and informal support, show significant differences between the factors which have successfully helped disabled people to have more choice and control, and those identified as future enablers by survey respondents who do not currently have choice or control.

Direct Payments

- 63% of social care users who feel they have choice and control when planning their care say using a Direct Payment or Personal Budget has helped.
- 41% of those who do not feel they have choice or control say using a Direct Payment or Personal Budget could help them in the future.

By far the most important factor which has enabled people to have choice and control when planning their care is using a Direct Payment or Personal Budget. In line with statistical findings, many disabled people shared their experiences of improvements in their support services, their sense of choice and control and their ability to live independently as a result of using Direct Payments or Personal Budgets. Social care users using self-directed support described being able to choose new providers, pay friends and family for care provided, and access the living situation that is right for them.

“I feel I have got more out of using Direct Payments in the past six months than in the previous six years. Since moving into my own place, I have more control and my choices aren't influenced by family or other caregivers.”

Hannah, 26, West Midlands

“The Direct Payment scheme gave me back some level of independence. It helped me in many ways, empowered me to make sure I was receiving good support and gave me some control back to go outside. I feel less trapped indoors and more confident in myself to speak up when something isn't right.”

Kendra, 42, South West

“I changed from agency care to a personal budget, which made a huge difference to my independence. With a personal budget, I am able to use the hours as and when needed. It has changed my life.”

Hillary, 58, South East

While many social care users clearly value Direct Payments and Personal Budgets, some described limitations on their choice and control in care planning as a result of insufficient funding. For some disabled people, payments have increased more slowly than inflation. Others have found that the services and supplies they purchase using Direct Payments and Personal Budgets have become more expensive, or the costs of employing personal assistants have grown, while their payments have remained the same. This has led to a gradual decline in the amount of support available to disabled social care users.

“The amount I have to contribute has gone up although my income hasn't. Also, I've had no increase in Direct Payments in 16 years, and yet tax and NI contributions have increased, and now we are expected to pay for CRB admin and a pension scheme again without any increase.”

Pasca, 47, East of England

“As the years go by, they don’t take into account inflation. So for example if I’m enlisting an agency supplying a reader for let’s say, £8 an hour, in a year or two’s time that can go up to say £10 an hour. The payroll company has already increased its charges for managing the payroll for my personal assistant. Because the money is not increased, over a period ten years I can notice a real reduction.”

John, 50s, London

“I found over the years that I used to receive a Personal Budget, that the money got reduced. Over the years I have been relying more and more on my savings, friends, family and charities for support.”

Jenny, 57, London

Other social care users identified additional support they need in order to be able to use Direct Payments effectively. Some disabled people want more clarity on what they can and can’t use Direct Payments for, while others find the administration necessary to access Direct Payments challenging and burdensome. Additional advice, information and support in these areas could enable more disabled social care users to get the most out of their social care through Direct Payments.

“I am told I am able to use my Direct Payment for something but then later told I’m not. The case workers seem to be clueless. The things that I really need to help me, they are not flexible about. I’m tired of being lied to and do not trust them anymore.”

Warren, 54, East Midlands

“I need better training for my care co-ordinator on how to fill out the paperwork for Direct Payments. I need to not have to reapply for Direct Payments every 6 months when my needs are chronic and ongoing, as this results in enormous delays in direct payments being processed.”

Cathy, East of England

Direct Payments, now used by 153,000 social care users (91,000 of them working age disabled people), have also effectively created thousands of new employers, as social care users recruit, manage and administrate their own support staff.³ Some survey respondents told us about the challenges of managing these new responsibilities, and the need for advice, support and training for social care users and support workers in order for this to be done legally, safely and well.

“With Direct Payments I will get extra help to socialise, but I’m in a catch 22 position. I want to go back to Direct Payments because I need more care, but I’m afraid of getting in to trouble with the paperwork, with wages, with the PAYE. I don’t want that responsibility, but I like the idea.”

Steve, London

“I need someone to offer advice and support to me and my PA, as I got no help with recruitment when my last PA retired, so both my new, young, inexperienced PA and I are floundering. I get Direct Payments from the council but no-one is checking or helping and I don’t feel competent as an employer or as a trainer.”

Carole, 50, North West

³ Health and Social Care Information Centre (December 2014) Community Care Statistics, Social Services Activity, England - 2013-14, Final release

“When directly employing you need support to deal with disciplinary measures - I felt I had to let someone back into my home even when they had tried to be violent towards my husband because I had no support at all. It was awful, I have been stolen from, gas lighted, lied to and ignored.”

Olivia, 32, London

Relationships with care planners

- 56% of those who currently lack choice and control feel that meeting with care planners who understand them and what is important to them, and who respect their choices, would help them to have more choice and control when planning their support.
- Smaller - but still relatively high - proportions of those with choice and control say understanding and respect from care planners has helped them to have choice and control in assessments and reviews.

Social care users who have choice and control in planning their care describe feeling listened to and taken seriously by social workers and other planning staff.

“I feel as though I'm being taken seriously that they are really listening to me and trying to help.”

Veronica, 44, East Midlands

“I have a very kind and sympathetic social worker who listens to me, takes the time to understand and then follows through on what she says she'll do on a timely basis.”

Natalie, 46, North East

For social care users who feel they do not have choice and control, the biggest priority for improving their experience of planning meetings is the attitudes and understanding of care planning staff. Many disabled people say they need more understanding of their lives and needs as individuals.

“What would help is someone listening instead of making wrong assumptions of something they have no idea about.”

Nigel, 63, East of England

“Feeling that care planners have an understanding of my health issues and how these can affect people.”

Kirsty, 60, South East

“There's a lack of understanding my needs, and those of the people who help. There's no back up, for them or me. It's over a year since my last review, and I was left three years without a review previously.”

Rosa, 57, East Midlands

Many disabled people describe the importance of trust and accountability in their relationships with staff – not only with care planners, but also with budget-holders in social services. Several social care users felt the care planning process needs to become more transparent around budgets.

“If there are budgetary constraints that prevent a need being met then this should be explained to the person but the care plan should not have to be re-written solely because of a lack of money. Those aspirations should stay in the care plan to be funded at a later date or to allow the person to seek funding from elsewhere.”

Philip, 50s, North West

“I arrange my care package with my community psychiatric nurse and she isn’t ever able to tell me how much is in the pot of money and what sort of services are available to me. I find it all largely guess work. If I was doing my own budget in a supermarket I would know how much money I have to spend and what is available. So it has surprised me sometimes what’s included in social care and what isn’t.”

Jenny, 57, London

Social care users with the worst experiences of relationships with care planners described poor or no communication from social workers and care coordinators, leading to delays in care reviews.

“I have no contact with professionals who can give me advice or implement change to my support. My care package has not been reviewed for three years. I don’t have a social worker now, or a care coordinator.”

Jake, 29

“I have absolutely no named contact at Social Services. Each assessment has been carried out by a different Social Worker who has then promptly left. No one else will give their name as a contact. At least the money continues to be paid and that just happens to still suit my needs - more or less.”

Lena, 25, East of England

“Presently I am left without care while I'm waiting for the social worker to sort out the finances and arrange the agency to come and make arrangements to come in. This means that everything for me is slower, more difficult and that my day is harder and always more exhausting.”

Eva, 52, South West

Consistency of staff and joined-up services

- 30% of those who have choice and control say that planning care with the same people each time has helped.
- Around half of those who do not have choice and control say that planning care with the same people each time would improve their experience of the care planning process in future.

Reflecting statistical findings, qualitative evidence from interviews and open-text survey responses demonstrates the significance of consistency in planning staff (especially social workers) and of good co-ordination and join-up within social services. Disabled social care users who feel that the different staff involved in their social care work well together describe positive outcomes for their ability to achieve the things that are important to them.

“I am starting to feel like I am getting to know and really like my support worker. She coordinates with my CPN / social worker, and part of her role is to monitor how

I am finding life at the moment, so that my CPN can move quickly to prevent relapse. This has helped me maintain contact with the outside world.”

Catrina, 46, North East

On the other hand, those who do not find their social care to be well co-ordinated and joined up describe feeling stressed and let down by services.

“I have a lot of choice and control with my PAs, but the social services side is very onerous and stressful and I feel I have no control. It would help to have the same person each time, as every year the assessment process feels like a very stressful lottery. It feels like there is the threat of a devastating cut every year.”

Siobhan, 38, South East

“I can't always get hold of my social worker, and I get put with other one that does not know me or anything about me.”

Paul, 23

“My social worker never gets back to me. The different social workers I've had all tell me different things and I don't have a clue what is ok to use money for anymore. There's constant goalpost moving. They don't understand my illness, including now mental health issues because of all of this.”

Moira, 35, South West

“I have a little boy and there is no shared budget, so children and adult services spend months arguing about funding anything. My mum spends weeks in stressful meetings trying to get support.”

Philippa, 38, North West

Other disabled social care users emphasise the need for more join-up and better co-ordination between social care and other forms of support. Some people found giving similar information to a number of different agencies, all controlling different forms of support, challenging and time-consuming. Some social care users want more join-up in assessments for support in order to simplify the process, while others see service integration as a mechanism for improving disabled people's access to the support they need, and creating more personalised and more effective services.

“I struggle with disability paperwork. In the last year I have had a DLA form, an ESA form, a Social Services assessment, a Social Services plan, I've advertised, interviewed and trained two new PAs, and had two financial assessments (one from Social Services and one from DWP). All this while severely and chronically ill. I also have someone else help me with paying PAs, and tax every month, and six monthly checks on how I'm spending that money. At worst this takes several weeks and leaves me emotionally and physically exhausted. I think the country does need to reduce the burden of assessments on disabled and ill people.”

Siobhan, 38, South East

“Social workers should be, when they are doing assessments, putting you in contact with other people that can help - to get a job and to get more support. Everyone should be working together and collaborating to do that, and that should be just a care package. A care package that looks at everything. Your mental state, your physical state, equipment to get you to work.”

Glynis, East of England

“There must be better communication between Social Services, DWP (especially Access to Work) and the NHS if budgets are going to be pooled to make up one unified direct payment. I think the person's care plan should be the basis for all of these organisations to make their decisions about how much support they will contribute. If this is going to be the case then a lot more help needs to be made available around how to write a care plan properly.”

Philip, 50s, North West

Assessments and individual contributions

Several survey respondents told us that their levels of choice and control are very high in terms of their relationships with care planners and support staff and their understanding of the process, but feel that their ultimate choice and control in planning care and support services is limited by insufficient resources in the system to support independent living.

“I have a lot of choice in how I purchase the hours but I do not have choice and control over the number of hours. My care package was reduced in 2014, so it is now very difficult for me to go out of the house and participate in society, follow interests, see friends and family.”

Sandy, 48, London

“I feel they listen but they have to try and find ways round trying to sort things as they are trying to cut back and give you as little as possible.”

Lilly, 24, East of England

“There is no choice or control, because at the end of the day if the budget isn't there you can't have it.”

Kirsty, 42, West Midlands

Some social care users described how the limitations which budgets place on choice and control affect their financial wellbeing, as individuals are assessed as needing to make larger contributions to funding their own care. Respondents strongly emphasised the need for fairer financial assessments which fully take into account the extra costs of disability.

“It would be better if I didn't have to contribute the £37 a week, which is crippling me financially.”

Joseph, 28

“I have gone into debt as a result of trying to pay for the shortfall in care from my own funds. There is not enough funding in my Direct Payment money. There are not enough hours in my Direct Payment.”

Kate, 47, East Midlands

“I'm supposed to pay contributions towards my support plan, but the council's policy does not take my living arrangements into consideration.”

Priscilla, 45, Yorkshire and the Humber

“My indicative budget is barely sufficient to meet my basic care needs. Then, when charges of 100% of disposable income are made, I have no spare cash to pay for what social care won't cover unless I do some paid employment. Over time that increases my need for social care and the cycle starts again. Social Services also

refuse to take into account the costs associated with work when assessing my charges. The central government guidance states that these costs should be subtracted from my charges but the Council refuses to do this.”

Philip, 50s, North West

Social care users emphasised the importance of income from Disability Living Allowance / Personal Independence Payments for covering a wide range of extra costs. Some disabled people said that using this income to pay for social care is causing them financial difficulty, and feel DLA / PIP should be excluded from financial assessments. Others describe a need for greater clarity about how to define their extra costs, and simpler processes for assessing extra costs and individual financial contributions.

“I was getting the right care, but I knew and they knew that I would only get a small grant towards it. It ended up that I was going to have to pay £75 a week. I haven’t got £75 a week! I’m already paying quite a lot towards my care. It comes out of my DLA but your DLA goes to pay your bills, it goes to live. I’m doing everything I can, but everything costs so much. It’s like a constant battle.”

Henry, 54, North West

“Obviously financial issues are hindering my ability to be more independent too, as all my DLA is needed to pay living costs rather than extra help!”

Stephanie, 38

“DLA should be excluded as income for financial contribution assessments, as it is with the DWP. I need more help with identifying what are classed as disability related expenses for people with mental health problems.”

Cathy, East of England

“Years ago, the charges were worked out more simply. As I was on income support I didn't have to pay for my care. I had to provide financial details but that was it. Now I have to prove that I need DLA and then prove that I've spent it on disability expenses in order not to give this money to Social Services. I have to prove the need twice over! I still don't have to pay, but there is a lot of seemingly unnecessary red tape.”

Siobhan, 38, South East

Awareness and access to information

- 30% of social care users who feel they have choice and control when planning their support say feeling certain about what they are entitled to has helped.
- 52% of those who do not feel they currently have choice and control in care planning say knowing what they are entitled to would help.

Some social care users feel their choice and control in planning is limited by not knowing what they are entitled to. Those who do not feel they are aware of their options say improving this would help them to have more choice and control.

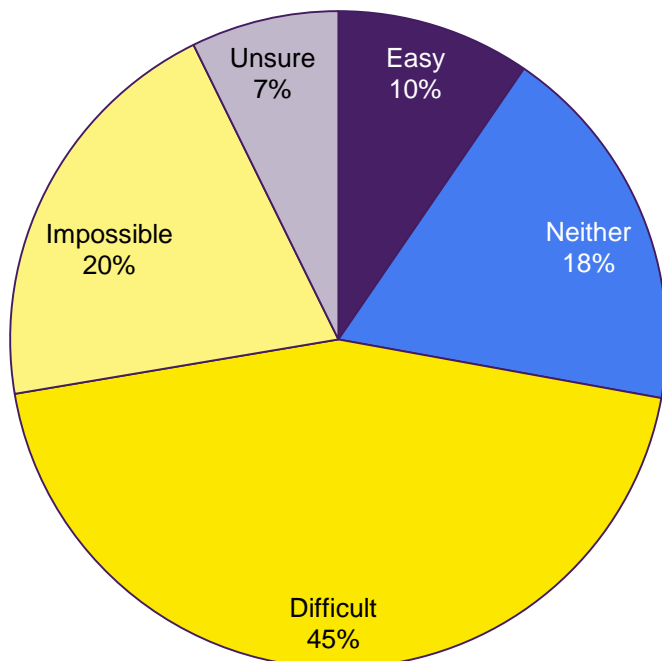
“It would help to be made aware of all the available options out there.”

Peter, 21, North West

“I have heard nothing from social services for two years. When I try to get help with a problem I have no idea who to ask and how. I do not get responses to my

concerns about monitoring, pension changes and possible cuts. This worries me a great deal as it means I have to be more knowledgeable than social services.”
Ciara, 58, London

Figure 3.2 Experiences with accessing information and advice



When asked about their experiences of accessing advice and information about social care and support services, a majority (63%) of social care users report finding this difficult or impossible. Once results for those who do not need advice or information are excluded, this rises to 65%. Just one in ten respondents said information and advice on getting the most out of social care is easy to access.

*2.6% of respondents said they have not needed to get advice or information. These results are not included in this pie chart.

Advice and advocacy

- 47% of those with choice and control say having a friend or family member at meetings with them has helped. A quarter say advice from friends or family has helped.
- Only 11% and 12% respectively have benefited from advice from an advocate and from having an advocate present at meetings.
- Half of social care users who currently lack choice and control say having an advocate at future meetings would help.
- 38% want advice from an advocate before meetings.

Around a quarter of social care users say they have achieved choice and control in the care planning process by arguing their own case, and a quarter of those who do not currently have choice and control feel arguing their own case could improve this in the future. In interviews and open-text survey responses, some disabled social care users emphasised the importance of their own agency and knowledge and accessing the support that is right for them. Often, these people had some professional background in social care.

“I previously worked in the social care sector and have a very good knowledge of self directed support, which is invaluable in accessing good support from social services. Having a regular social worker is also very important.”

Sandra, 46, South East

“I have come from having a 'poor' experience of care manager intervention and feeling I had no choice or control over my care package, to having full choice, understanding and control. I first volunteered and now work for a disability organisation on a project about support plans. I could then write my own support plan with the things that I wanted and that reflected me, not the care manager.”

Jenna

However, many other disabled people say they feel unable to effectively argue their own case at care planning meetings, and describe feeling anxious about assessments and disempowered at meetings.

“I need someone to help me sort things out as I'm not very good at sticking up for myself.”

Shannon, 24, South West

“The care minefield leaves me bewildered and quite honestly terrified and anxious. The more anxious I am, the deeper my depression.”

Ellen, 56, East of England

“I struggle to get my point across at care plan meetings. Often I do not feel that what I say is respected and I will settle for any help I can get rather than argue my case, as I am not a very confident person when it comes to standing up for myself.”

Heidi, 31, North East

Almost half of those who have choice and control in care planning say having family or friends at meetings has helped them to have this. Many disabled people draw on support from a wide range of sources to navigate the care planning process and get the most out of their care and support services. This includes advocacy, legal advice, support from family, friends and charities.

“My family is the main driving force to ensure provision of as much choice and control as is achievable. My family devised my care plan.”

Anonymous

“My family are court appointed deputies for my finance and property and my health and welfare. We take legal advice from legislation and have two solicitors - a public law one and private one and kept informed about changes in law and guidelines. It's constantly a struggle maintaining the budget as professionals try to make cuts. The Challenging Behaviour Foundation are also very helpful.”

James, 19, North West

Other social care users feel they do not have the advice and support they need to get the most out of their care and support services. Several respondents described the need for advocacy services to be more available. Half of those who don't currently have choice and control in planning their care say having an advocate at meetings would help.

“I'd like to be able to go to church. This is in my care plan, but doesn't happen. The same with bathing. I can't use the bath lift without help, but I don't get any and feel unable to ask. It is issues like this that I would like an advocate for as well as I'm dealing with issues where they are just not listening to me.”

Charlotte, 49, Yorkshire and the Humber

“I find what happens is that when I go for help, people are saying ‘well you can do it yourself.’ And when I’ve asked for a social worker people have said ‘you don’t need one, because you can manage yourself.’ But there are times when I’m exhausted, because I take an extraordinary amount of morphine I’m too tired and depressed... And that’s why you need an advocate and a social worker. But I’m not going to get one because they look at me and think, a man who can advocate for himself. But that’s not always the case.”

Henry, 54, North West

“I think advocacy is key. I think it’s so important that people actually have the facilities available to access an advocate and I think that advocate should be independent. I think that that advocate should be free. It should be funded by the government and disabled people should be able to ring up an independent organisation and say ‘I need an advocate. I’m having a needs assessment, I need someone there,’ or for whatever reason, and have that advocate be there for them.”

Reagan, London

Taking together findings indicating challenges with access to information and advice, and unmet need around advice and advocacy both in and out of care planning meetings, social care users’ experiences suggest improved access to advocacy as a mechanism for empowering disabled people to get the most out of their care and support services.

Concluding remarks

This report has summarised some of the main trends in disabled people's recent experiences as social care users. A complex national picture of changes to how care is funded has had a range of effects at the level of individual social care users. Some disabled people using social care services feel supported to take part in work, volunteering, training and study, to access and participate in their communities and have fulfilling, reciprocal relationships with others. At their best, care services empower disabled people to live independently in their communities, with dignity, choice and control over their own lives.

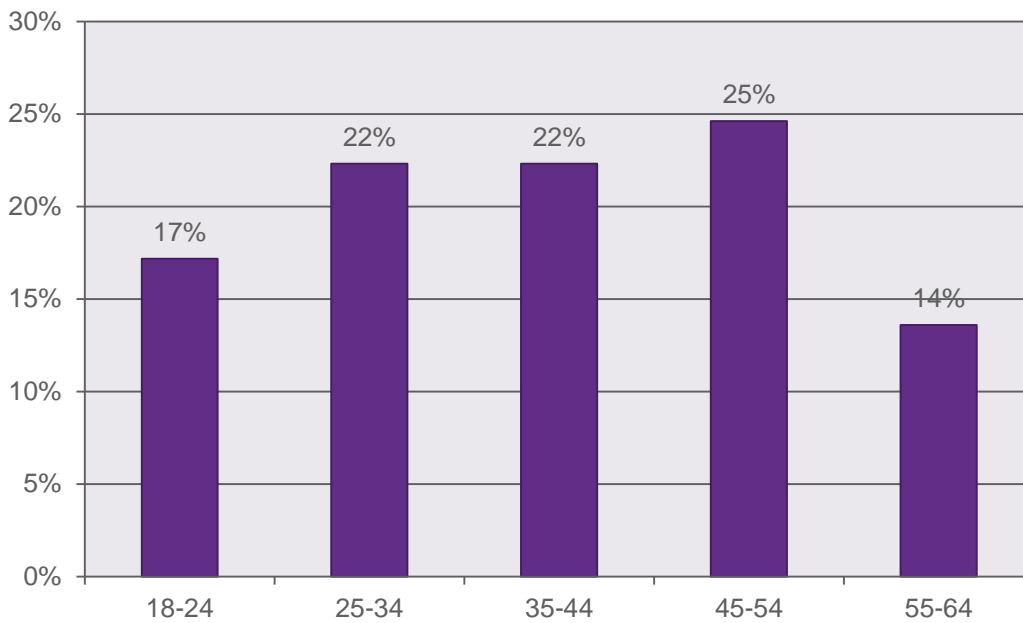
For the majority of disabled social care users, this is an ideal they have yet to reach in their experiences of support services. Many disabled people are not getting the support they need, do not feel the system treats them fairly and feel pessimistic about how services will continue to support them. To get the most out of life, disabled social care users need to have flexible, personalised support which meets both their immediate needs and their aspirations. If the social care system is to empower disabled people to fulfil their potential, it must respond to disabled people as individuals, recognising the real differences in support needs between people of different ages and backgrounds with different priorities and goals in life.

The challenge of how to make social care more personalised, outcomes-focused and better at supporting disabled people to live independently in their communities is shared across the social care system – from ministers developing policy, to commissioners and practitioners and implementing it, through to disabled social care users. Scope hopes this report provides policymakers and practitioners with valuable insights from disabled people to inform the support of the future.

Appendix 1: Sample

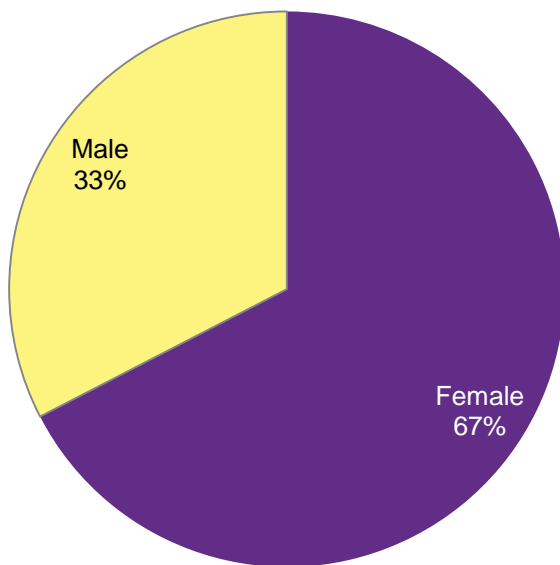
Survey respondents: demographics

Figure 4.1 Current age



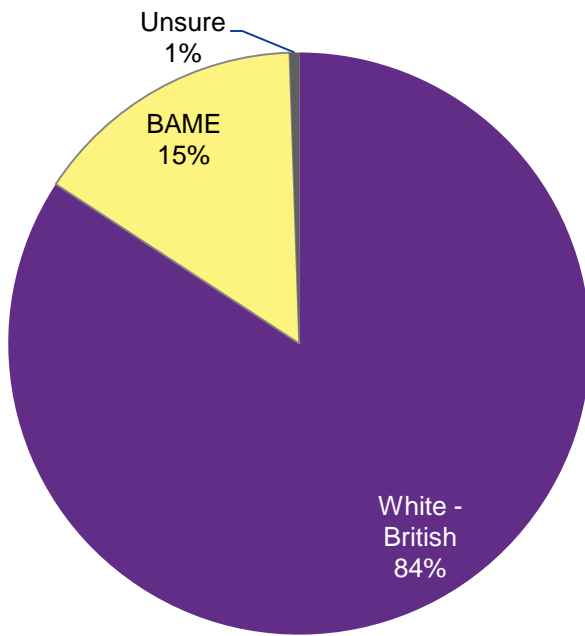
Respondents are distributed relatively evenly across age groups. 39% of our sample is under 35 years old.

Figure 4.2 Sex



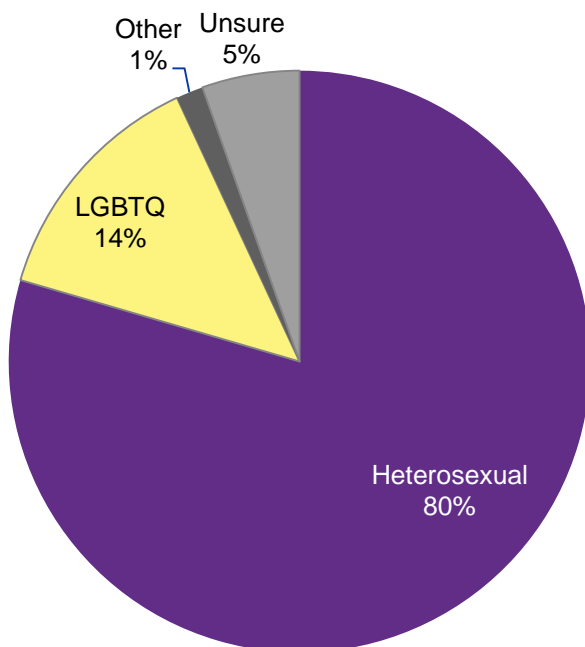
Two thirds of survey respondents are female and one third is male.

Figure 4.3 Ethnicity



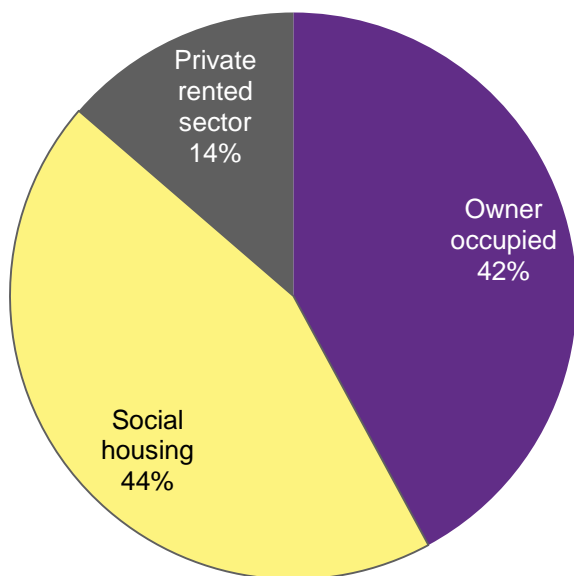
84% of survey respondents identify as White British (including White English, Scottish, Welsh and Northern Irish). 15% of respondents come from black or ethnic minority groups.

Figure 4.4 Sexual orientation



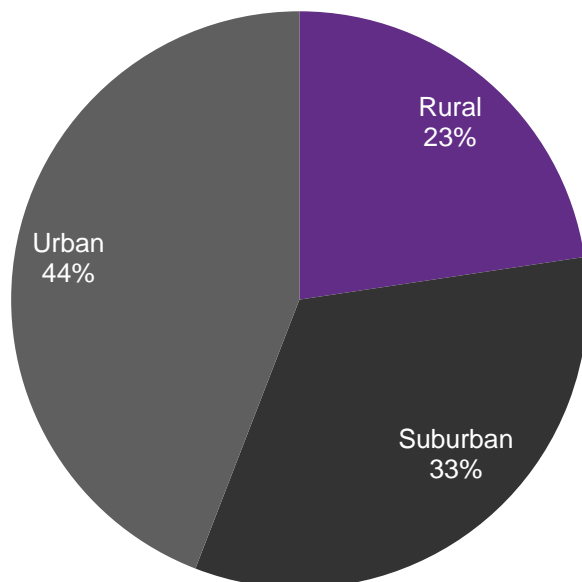
80% of survey respondents identify as heterosexual. 14% identify as LGBT or other.

Figure 4.5 Housing tenure



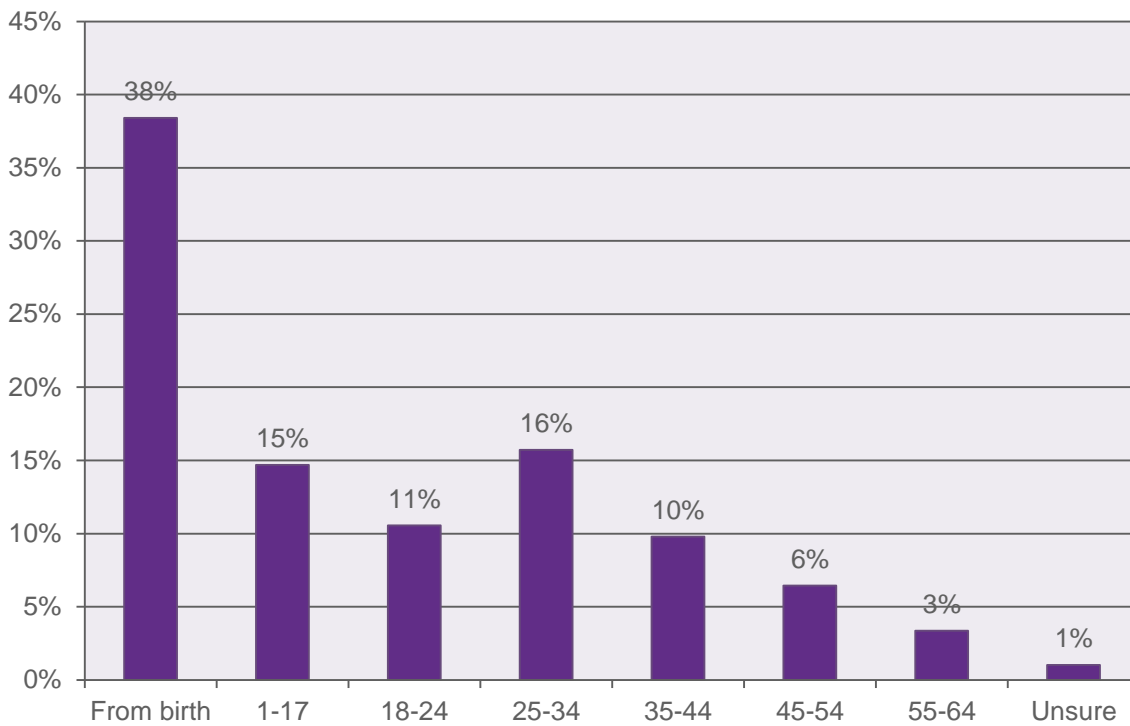
44% of survey respondents live in social housing, with 5% renting supported or assisted living accommodation in this way. 42% of respondents live in owner occupied housing – 19% living in an owner-occupied parental home, and 23% living in owner occupied housing away from their parents. 14% rent from the private sector, reflecting low rates of private renting generally amongst the disabled population.

Figure 4.6 Settlement type



44% of respondents live in urban areas, a third in suburban and 23% in rural areas.

Figure 4.7 Age at which became disabled



38% of respondents have been disabled from birth, 15% from childhood and the remaining 46% became disabled in their adult lives.

Figure 4.8 Impairment types

Impairment type	Percentage
Physical impairment	78.3%
Mental health condition	38.5%
Learning disability	30.1%
Sensory impairment	25.5%
Autistic spectrum condition	18.4%
Unsure	1.8%

*Totals add up to more than 100% as participants were able to select more than one impairment type

55% of our sample has more than one impairment type. 12% of respondents have both a physical impairment and a mental health condition, making this is the most common combination of impairment types.

Survey respondents: service user information

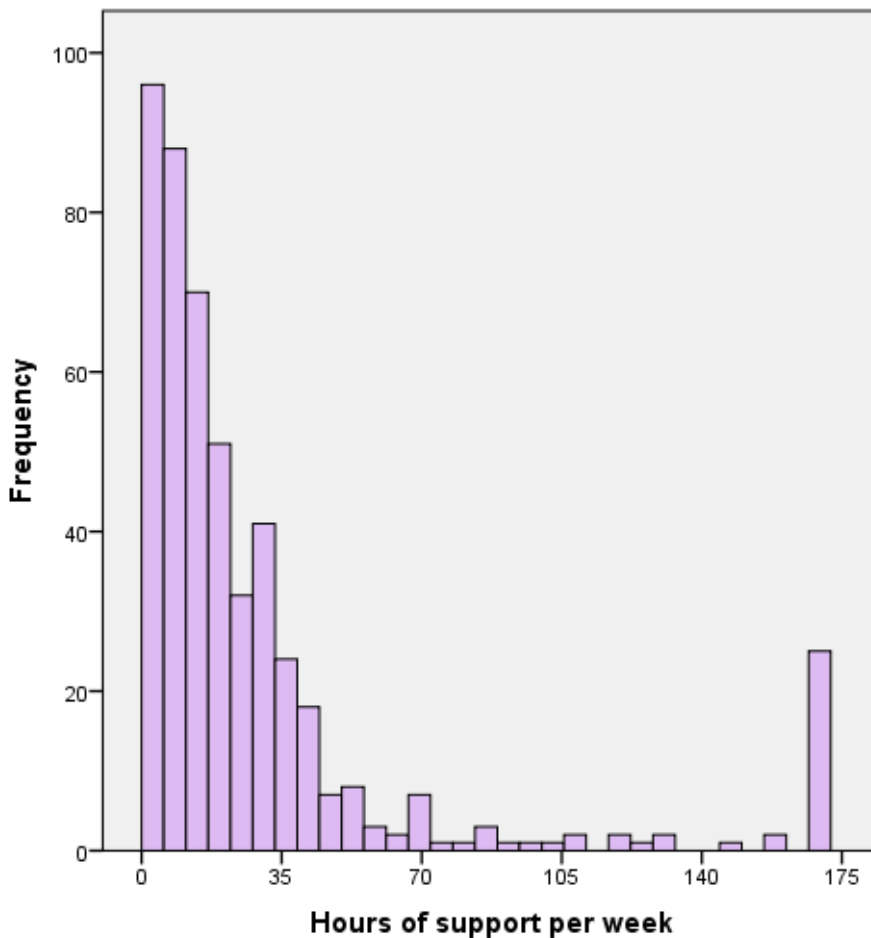
Figure 4.9 Who delivers care and support services

Delivery organisation	Percentage
Private company	59%
Council	31.5%
Voluntary organisation	19.9%
Unsure	2.5%

*Totals add up to more than 100% as participants were able to select more than one type of delivery organisation if applicable

A majority of our sample uses services delivered by private organisations, while almost a third use services delivered by their local authority, and a fifth use voluntary services. 10.8% of respondents use more than one kind of delivery organisation, with most of these respondents using private delivery combined with one of the other types.

Figure 4.10 Hours of support in care package each week



This histogram shows the distribution of hours in respondents' care packages. 50% of respondents have more than 35 hours of support each week. 15% of our sample uses full-

time support, while 14% has 10 hours or less of support each week. Taking the median, the average number hours in respondents' care packages is 16.

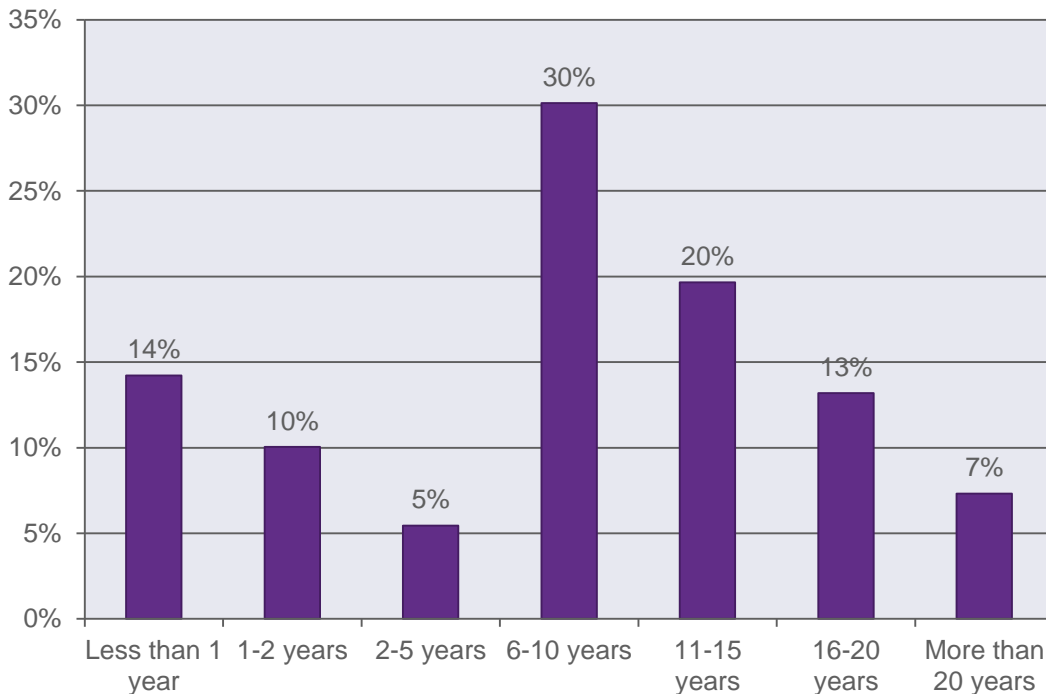
Figure 4.11 How care and support services are funded

Funding source	Percentage
All Council, DP or PB	40%
Individual	39.6%
Family	11.7%
Independent Living Fund	10.4%
Someone else	1.3%
Unsure	6.78%

*Totals add up to more than 100% as participants were able to select more than one funding source if applicable

All survey respondents use funding from their local authority, Direct Payment or Personal Budget to pay for care and support services. Two fifths of our sample use only this money to buy services, while a further two fifths also pay for services using their own income. Around 10% fund services using money from their family, and another 10% using the Independent Living Fund. A small number of respondents are unsure how their support is funded.

Figure 4.12 Time using care and support services



60% of our sample has been using care and support services for 10 years or less. 30% has been using services for five years or less.

Focus group participants: demographics

Scope conducted two exploratory focus groups at the initiation of this research. The first focus group, conducted with disabled social care users living in around London, had seven participants.

Scope recruited from our own service users, and using the networks and services of the Disability Partnership and other charities in the Voluntary Sector Strategic Partnership Programme, including Mind and the Race Equality Foundation. This recruitment was supplemented using the networks of Disabled People's Organisations and User Led Organisations.

Scope is particularly thankful to Mencap, Sense and the National Autistic Society for assisting us with recruiting from their user groups, and for their advice on preparing a focus group which would be accessible and engaging for disabled people with a wide range of impairment types.

The demographics of this group are shown in the table below.

Age	
35-44	2
45-54	3
55-64	2
Sex	
Men	2
Women	5
Ethnicity	
White British	6
Black and ethnic minority	1
Sexual orientation	
LGBT or other	1
Heterosexual	6
Impairment type	
Physical impairment	5
Learning disability	1
Mental health condition	3
Multiple impairment types	2
One impairment type	5
Age at which became disabled	
Disabled from birth	3
Acquired impairment	4

Scope conducted a second focus group with young disabled people at Beaumont, Scope's further education college in North West. The five students we spoke to, aged between 19 and 22, were all preparing to make the transition to adult social services, and preparing for lives as independent adults more broadly. The group included three men and two women.

Interviewees: demographics

Scope conducted 15 depth interviews to provide further explanation for quantitative survey findings, and to explore some of the nuances in different disabled people's experiences as social care users.

Recruitment for interviews concentrated on demographic groups who are typically under-represented in social care research, and especially those under-represented in our survey sample. Scope conducted in-depth interviews with 10 men, 3 people with dual-sensory impairment, three people with learning disability, one asexual person, one transexual man, and four people from black and ethnic minority backgrounds. Scope is particularly thankful to Sense, NAS and Mencap for assisting us with recruiting interviewees and preparing accessible and engaging research materials.

The demographics of this group are shown in the table below.

Age	
18-24	1
25-34	3
35-44	5
45-54	3
55-64	3
Sex	
Men	10
Women	5
Ethnicity	
White British	11
Black and ethnic minority	4
Sexual orientation	
LGBT or other	2
Heterosexual	7
Sexuality not stated	6
Impairment type	
Physical impairment	6
Sensory impairment	5
Learning disability	3
Autistic spectrum	4
Mental health condition	4
Multiple impairment types	6
One impairment type	9
Age at which became disabled	
Disabled from birth	10
Acquired impairment	5

Appendix 2: Survey questionnaire

1. Do you receive social care and support services that are paid for by your local council? This might be support paid for by your council directly, or it might be money you get from your council to buy your own support through a direct payment or personal budget.

- Yes
- No – route away from survey
- Not sure

2. Do you use any other money to pay towards the cost of the care and support services you get through your council, direct payment or personal budget? Please select all that apply.

- No, my council, direct payment or personal budget covers all the cost
- I pay for some of my care and support services
- My family pay for some of my care and support services
- Some one else pays for some of my care and support services
- I use the Independent Living Fund to pay for some of my care and support services
- I pay for some of my care and support services in another way – OPEN TEXT

3. What kind of organisation delivers the care and support services you use? Please select all that apply.

- Private company, like Care UK
- My council provides it directly
- Charity or voluntary organisation, like Scope
- Rather not say
- Not sure
- Other – OPEN TEXT

4. How long have you been using social care and support services for?

- Less than six months
- Six months to one year
- More than one year but less than two years
- Two to five years
- Six to 10 years
- 11 to 15 years
- 16 years to 20 years
- Longer than 20 years
- Not sure
- Rather not say

5. How many hours of support do you have each week through your care package? Please be as accurate as possible. – OPEN TEXT

- Not sure
- Rather not say

6. Thinking about the last five years, what has happened to the number of hours of support you have each week through your care package? If you have been using care and support services for less than five years, please think about your experiences since you started using these services.

- Hours have gone up
- Hours have stayed the same
- Hours have gone down
- Not sure
- Rather not say

7. How do you feel about the hours of support you have each week through your care package?

- I get more hours of support than I need
- I get enough hours of support
- I get fewer hours of support than I need
- Not sure
- Rather not say

8. Do the hours of support that you need each week vary depending on the week? This might be because of changes in the way your impairment or condition affects you, or because the activities and goals you use support to help you with vary.

- No, I need the same number of hours from week to week – go to question 10
- Yes, some weeks I need more hours and some I need less – go to question 9
- Not sure
- Rather not say

9. How well do the hours of support you get vary to fit in with your changing support needs?

- Very well
- Quite well
- Neither well nor badly
- Not very well
- Not at all well
- Not sure
- Rather not say

10. Do you feel that the care and support services you use at the moment support you to do all of the things in life that you need to do, in order to carry out your daily routine?

- Yes
- Sometimes
- No

- Not sure
- Rather not say

11. Do you feel that the care and support services you use at the moment support you to do all of the things in life that you want to do, in order to live as independently as possible?

- Yes
- Sometimes
- No
- Not sure
- Rather not say

12. What is your employment status at the moment? Please select one answer. If more than one option applies, please choose the most important option for you.

- Paid employee – go to question 13
- Self-employed – go to question 13
- Not working, looking for work – skip to question 14
- Not working, not looking for work – skip to question 17
- Volunteer – skip to question 13
- Student – go to question 15
- In training for a job – go to question 15
- Looking after home and family – skip to question 16
- Retired – skip to question 17
- Not sure – skip to question 17
- Rather not say – skip to question 17

13. How important are the social care services you use for helping you to work or volunteer?

- Very important
- Quite important
- Neither important nor unimportant
- Not very important
- Not important
- Not sure
- Rather not say

Continue to question 17

14. How important are the care and support services you use for helping you to look for work?

- Very important
- Quite important
- Neither important nor unimportant
- Not very important
- Not at all important
- Not sure
- Rather not say

Continue to question 17

15. How important are the care and support services you use for helping you to achieve the things you want to achieve in work, volunteering and learning?

- Very important
- Quite important
- Neither important nor unimportant
- Not very important
- Not at all important
- Not sure
- Rather not say

Continue to question 17

16. How important are the care and support services you use for helping you to look after your home and family?

- Very important
- Quite important
- Neither important nor unimportant
- Not very important
- Not at all important
- Not sure
- Rather not say

Continue to question 17

17. The next questions are about the care plan you have agreed with your care manager, social worker or health professional. This should be agreed between you and your care planners when you start using support services. Overall, how far does your care plan contain the activities, goals and aims that are important to you?

My care plan contains...

- Everything that is important to me
- Most of the things that are important to me
- Some of the things that are important to me
- Not very many of the things that are important to me
- None of the things that are important to me
- Not sure
- Rather not say

18. Your care plan should have information about the kinds of support you will get, as well as when and how you will be helped by social care and support services. How far do the care and support services you actually get match what is written in your care plan?

The services I get

- Match what is in my care plan exactly
- Generally match what is in my care plan
- Are generally better than what my care plan says I will get
- Are generally worse than what my care plan says I will get

- Not sure
- Rather not say

19. How far do you feel you have choice and control when planning and reviewing the care and support services you use?

I feel I have

- Complete choice and control – go to question 20
- A lot of choice and control – go to question 20
- Some choice and control – skip to question 21
- Very little choice and control – skip to question 21
- No choice or control – skip to question 21
- Not sure - skip to question 21
- Rather not say – skip to question 21

20. Have any of the following things helped you to have choice and control when planning and reviewing the care and support services you use?

- Using a direct payment, or another type of personal budget
- Advice from friends or family before meetings
- Advice from an advocate before meetings
- Having a friend or family member with me at meetings
- Having an advocate with me at meetings
- Feeling like care planners understand me and what's important to me
- Feeling like care planners respect my choices and what's important to me
- Planning my care with the same people each time
- Having a clear idea about what I want
- Feeling certain about what I am entitled to
- Arguing my own case at meetings
- Something else – OPEN TEXT

21. Do you think any of the following things could help you to have more choice and control when planning and reviewing the care and support services you use?

- Using a direct payment, or another type of personal budget
- Advice from friends or family before meetings
- Advice from an advocate before meetings
- Having a friend or family member with me at meetings
- Having an advocate with me at meetings
- Feeling like care planners understand me and what's important to me
- Feeling like care planners respect my choices and what's important to me
- Planning my care with the same people each time
- Having a clear idea about what I want
- Feeling certain about what I am entitled to
- Arguing my own case at meetings
- Something else – OPEN TEX

22. How far do you feel you are aware of all the support and service options that are available to you as part of your care package?

I feel I am aware of

- All of my options
- Most of my options
- Some of my options
- Very few of my options
- Almost none of my options
- Not sure
- Rather not say

23. What has been your experience of getting advice and information to help you get the most out of the care and support services you use?

I have found it

- Easy to get advice and information
- Neither easy nor difficult to get advice and information
- Difficult to get advice and information
- Impossible to get advice and information
- I have not needed to get advice and information
- Not sure
- Rather not say

24. Thinking about the last five years, which of the following statements best describes your view of how the services you use have supported you? If you have been using care and support services for less than five years, please think about your experiences since you started using these services.

The services I use are

- Better at supporting me now – go to question 25
- No better or worse at supporting me now – skip to question 31
- Worse at supporting me now – skip to question 27
- Better at supporting me in some ways, but worse in other ways – go to question 25
- Not sure – skip to question 31
- Rather not say – skip to question 31

25. In what ways have the services you use got better at supporting you? – OPEN TEXT – go to question 28

26. In what ways have the services you use got worse at supporting you? – OPEN TEXT – go to question 28

27. In what ways have the services you use got better at supporting you and in what ways have they got worse? – OPEN TEXT

28. How has this affected you and your ability to live independently? – OPEN TEXT

29. Thinking about the next five years from now, which of the following statements best

describes your view of how the services you use will continue to support you?

The services I use will get

- Better at supporting me
- No better or worse at supporting me
- Worse at supporting me
- Better at supporting me in some ways, but worse in other ways
- I won't need to continue using care and support services
- I will lose access to care and support services
- Not sure
- Rather not say

32. The next four questions are about the activities and goals that are important to you. We want to know:

A) Which activities and goals do you get help with from care and support services at the moment?

B) Are there activities or goals you need help with from services to carry out your daily routine, but which you are not currently being helped with?

C) Are there activities or goals you would like help with from care and support services in the future in order to live as independently as possible?

For each of the activities and goals listed, please tick the boxes to tell us whether you get help, need it, or want it in the future.

- Seeing or talking to friends and family
- Building new relationships that are important to me
- Looking after my child or children
- Looking after someone else, like a parent
- Supporting my physical health
- Supporting my mental health and state of mind
- Managing and maintaining a healthy diet
- Maintaining personal hygiene
- Using the toilet
- Being dressed appropriately
- Getting around my home and using it safely
- Making sure my home is clean and liveable
- Doing the things I enjoy at home, like listening to music
- Observing my faith or religion
- Connecting with my culture or heritage
- Using local services, like public transport, the bank or shops
- Doing the things I enjoy locally, like exercise or hobbies
- Travelling outside my local area
- Working
- Looking for work
- Volunteering
- Taking part in education or training

- Being involved in my community
- Accessing information and advice
- Using the Internet or other technology
- Managing my money and paying bills

33. Are there any other activities or goals that you get help with from social care and support services at the moment? – OPEN TEXT

34. Are there any other activities or goals that you need help with in order to carry out your daily routine, but which you are not currently being helped with? – OPEN TEXT

35. Are there any other activities or goals that you would like help with in the future in order to live as independently as possible? – OPEN TEXT

36. What does independence mean to you? – OPEN TEXT

37. What kind of home do you live in at the moment? Please select all that apply.

- I own my own home
- My family owns my home
- I rent my home from a private landlord
- I rent my home from my council, a housing association or another social landlord
- I live in a supported living home
- I live in an “extra care” home
- Other
- Not sure
- Rather not say

38. Are you male or female?

- Male
- Female
- Rather not say

39. What is your age in years? – OPEN TEXT

- Rather not say

40. At what age did you become disabled? – OPEN TEXT

- Not sure
- Rather not say

38. How would you describe your impairment(s) or condition(s)? Please select all that apply.

- Learning disability
- Mental health condition
- Physical impairment
- Sensory impairment
- Autism Spectrum Condition

- Other impairment(s) or condition(s)
- Not sure
- Rather not say

39. If you would like to tell us more about your impairment(s) or condition(s) and how they affect your life, please use the box below. – OPEN TEXT

40. How would you describe your sexuality or sexual orientation?

- Heterosexual
- Gay or lesbian
- Bisexual
- Queer or other
- Not sure
- Rather not say

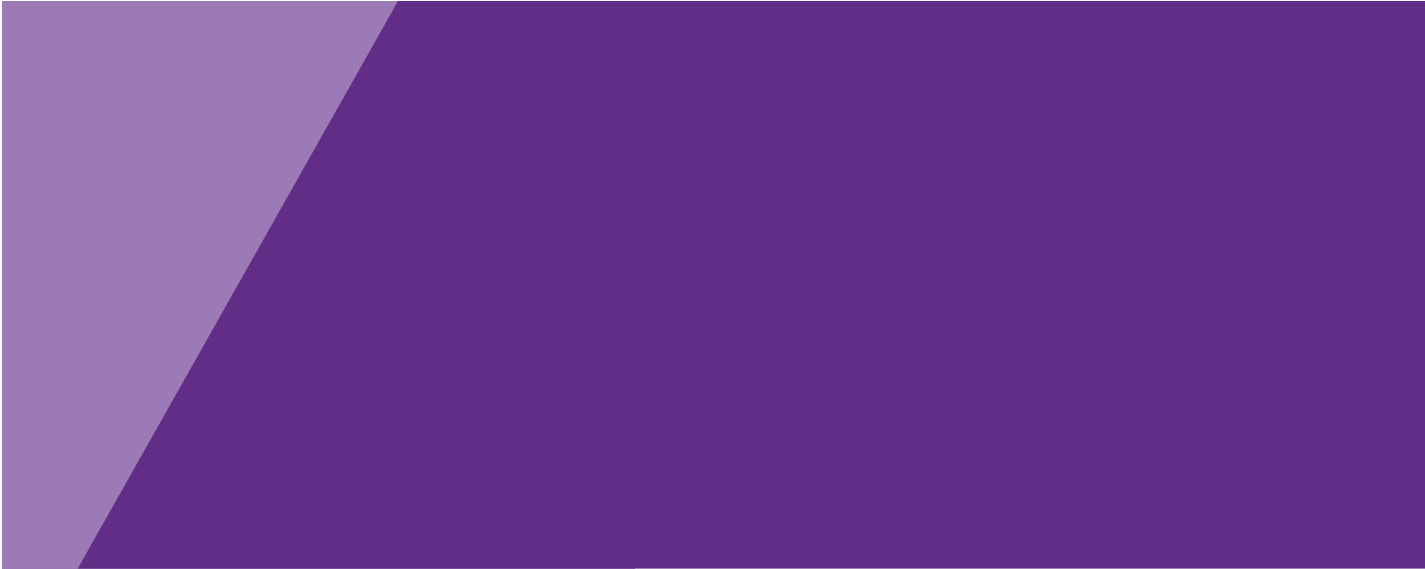
41. How would you describe your ethnicity?

- White - English / Welsh / Scottish / Northern Irish / British
- White – Other
- Asian or Asian British
- Black or Black British
- Arab or Arab British
- Mixed
- Any other ethnic group (please specify)
- Not sure
- Rather not say

42. What kind of area do you live in?

- Urban
- Suburban
- Rural
- Not sure
- Rather not say

43. Please tell us the first part of your postcode (such as DS1) or the town you live in (such as Darlington).



Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

We'll provide support, information and advice through our services when disabled people and their families need us. And we'll raise awareness of the issues that matter. We'll keep influencing change across society until this country is great for everyone.

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Scope
About disability