

Leading my life my way: young disabled people's experiences of using services to live independent lives

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About Scope

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 provide support, information and advice to more than a quarter of a million disabled people and their families every year.

At Scope we know that being able to choose where and how you live has an enormous impact on your quality of life, your sense of independence and your self-esteem. Yet often disabled people struggle to find and afford the support they need to enjoy an independent life. This makes it harder for disabled people to access education and employment, as well as opportunities to develop wider friendships and social lives, or become leaders in their communities. Joined up support is crucial in overcoming these barriers and ensuring independence is achievable for all disabled adults.

The Disability Partnership

This research forms part of the work 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.

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1. Introduction

This report follows on from research we produced last year which showed disabled people aged 18 – 64 were not being supported to live their lives independently due to a poor quality of service provision. 'Leading My Life, My Way' focuses on disabled people aged between 17 and 30 who are about to or are at the point of transition from children's to adult social services, as well as those who have experienced using services for a number of years after transition.

The research presented in this report provides an evidence base that will be of use to social care policy makers. It identifies what works well specifically for young disabled people in accessing services to live independent lives and what areas need development. This will help policy makers to ensure support services provide holistic, joined up support for young disabled people. In doing so, we hope young disabled people's experiences of using support services will be more consistently positive and tailored to their specific requirements. This will help foster a greater confidence in support services and sustain higher aspirations to do what they want in their lives as they enter early adulthood.

2. Key findings

Support services for young disabled people

- Half of respondents (49 percent) believed the services they use support them to live independently, while over a quarter (29 percent) did not believe this.
- Service availability varies across different areas of young disabled people's lives. While adequate support with personal care is widely but not universally accessed, support in areas that help prevent social isolation is less available.
- Where young disabled people do have access to informal and third sector support networks, they are able or expect to get a job that is meaningful. However, support with employment is not meeting the needs and expectations of young disabled people, resulting in disillusionment with employment support services.
- There is no 'one size fits all' approach to supporting young disabled people to live in the home they want to live in. However, a lack of information about accommodation is acting as a barrier to young disabled people living independently.

Care and support plans

- Over a half (53 percent) of our survey respondents said they made all or most decisions in developing their care and support plan. However, one in ten said they did not make any decisions in this.
- Where interview respondents reported a sense of choice and control over their care and support plan, this was often underpinned by informal support from family.
- Over a half of respondents (54 percent) reported that the support they received matched or exceeded their care and support plan, over one in five (22 percent) said their support was generally worse than what was agreed in their plan.
- Interview respondents who attend post-19 Special Educational Needs (SEN) colleges reported confidence they would get the jobs they wanted in the future. However, there was also evidence that it was not always clear how this would happen, indicating they had not yet been included in the employment support process.

Access to advocacy, information and advice

- Survey respondents reported a disparity between the demand and availability of information services, with the most common areas they would like to access for advocacy, advice and information not being the areas currently provided.
- Respondents were generally able to access information services in the format they said they would like to. However, there was a notable disparity between actual use of mobile phone apps (1 percent) and respondents wanting to use this format (20 percent).
- The survey evidenced multiple issues over the quality of information services accessed for support with employment and community involvement.

The impact of the social care system on young disabled people

- Two thirds of respondents (67 percent) have experienced a significant setback in their lives that has prevented them from living independently. Of these people, the vast majority (82 percent) had to wait at least six months for it to be resolved.
- Respondents in their early to mid-twenties are less likely to be satisfied with support services and more likely to experience barriers to accessing the right support to live independently, compared to younger and older age groups.
- Where support cannot be accessed in one area, there is evidence to show it can limit support in other areas, resulting in an overall restriction to living independently.
- Respondents in their early to mid-twenties are having their resilience tested as they attempt to access support services. This has resulted in young disabled people not thinking about how they will live independently in the long term and being more concerned with their immediate future.

3. Methodology

3a. Research design

Research questions

To understand young disabled people's experiences of living independently, we developed hypotheses based on our previous research of disabled people's experiences of social care¹ and a review of existing literature on the subject. These hypotheses in turn formed the basis of our research questions. Our hypotheses focussed on barriers to independent living, the relationship between personal budgets and choice and control, access to advocacy, advice and information about living independently and young disabled people's experiences of services working together in their lives.

Research for this project took a mixed methods approach, using qualitative and quantitative methods. In-depth interviews allow experiential data to be collected because they provide a platform for respondents to talk about their experiences and reflect on how they relate to the questions being asked. We also used a survey to collect quantitative data for this project. While it does not collect in-depth detail of respondents' experiences, it does provide a breadth of scope not possible through qualitative research. This provides a wider context of young disabled people's experiences within which we can frame the more particular understanding provided by the qualitative evidence.

Qualitative approach

This project is focussed on capturing young disabled people's experiences of using services to do the things they want to do with their lives.

Focus groups were organised with participants recruited from post-19 colleges and existing groups of disabled people. This provided an opportunity for the groups to think about the topics for discussion beforehand. For some participants, group discussion was also a more conducive environment to sharing their experiences because this format meant they heard other people's experiences and could reflect on whether or not that was similar to their own experiences. In practice it proved to be an effective method for encouraging participants to think critically about their experiences of living independently.

1. <http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Disabled-people-s-experiences-of-social-care.pdf?ext=.pdf>

We carried out a combination of phone and face to face interviews. Where possible, interviews were conducted in person, but phone interviews were carried out in instances where the former option was not available.

Where respondents had high communication support needs, a support worker or family member was also present to ensure accurate communication between interviewer and interviewee. Where necessary, parts of the interview communicated via a third party have been transcribed in the first person to reflect that person's account.

The data from our interviews was analysed using a 'paving and coding' method. Sections of the transcripts that were relevant to our research questions were highlighted. These sections were used to draw up a list of concepts which were grouped according to themes. For example, 'lack of self-confidence', 'lack of confidence in services', 'confidence in self', 'confidence in services' are all concepts that were grouped under the theme of 'confidence'. The transcripts were then coded according to the concepts and in doing this, it was possible to see how concepts and themes were connected to each other.

Quantitative approach

We developed a questionnaire based on our research questions. This approach ensured the questionnaire remained close to the project's research focus. This also ensured that data collected by the survey could be compared to the data collected in interviews. The survey data provides a context of young disabled people's attitudes to services they use to live independently within which the detailed experiences of interview participants' experiences can be placed.

3b. Sample recruitment

Interviews

Participants were recruited through other third sector organisations, Special Educational Needs (SEN) colleges and by advertising on websites operating in the disability sector. The sampling frame was targeted to ensure a diversity of potential participants in terms of age, gender, location, support need and ethnicity. This also ensured participants were not entirely self-selecting individuals with particularly positive or negative experiences they wanted to share.

We wanted to speak to young disabled people at two particular points in their lives. The first group are people who were going through, or were soon to be going through, transition from children's to adult social care services. The second group are those who had already transitioned and have had experience of using adult services to live independently in early adulthood. The rationale for doing this relates to our hypothesis that experience of using services before and after transition are different and this study provides an opportunity to explore those differences.

Survey

We surveyed 228 people aged 17 – 30 for this project². As with the qualitative research, the rationale for this age range was to provide evidence of people's experience before and during transition as well as that of those people who have already transitioned. Relationships between variables discussed in this report are statistically significant ($p > .05$) unless otherwise stated.

Survey respondents were recruited through free and paid for advertising on Scope's social media channels as well as the Community³ section of the Scope website. Recruitment for the survey was also targeted to ensure the sample was as representative as possible. Potential respondents were targeted according to location, age and support need.

2. The sample size for this project was smaller than that for our 'Disabled people's experiences of social care: findings from the Better Care Survey' report (n=515) due to the smaller population size. The Better Care Survey sampled disabled people aged 18 – 64 while the age parameter for this project is 17 – 30 years old. Not all questions were compulsory, resulting in responses below 228 to individual questions.

3. <https://community.scope.org.uk/>

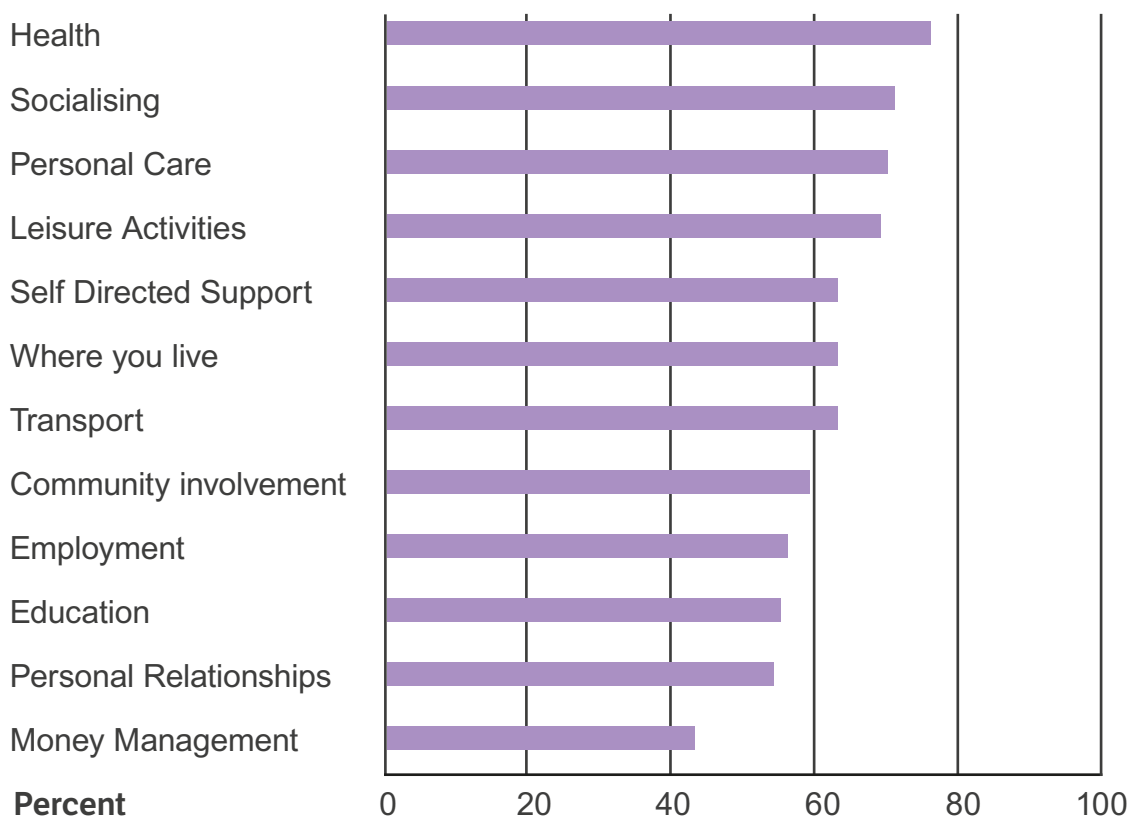
4. What is important for young disabled people?

4a. What do young disabled people use services for?

We asked young disabled people whether or not services were important to them in doing the things they want to do in their lives. Over three quarters of respondents to this question said services were important in health and around seven in ten respondents said they were important for socialising, personal care and doing leisure activities.

Respondents reported that services were most important in areas such as employment, education, personal relationships and money management, indicating that support for these areas comes from other sources.

Figure 1.1: Areas in which respondents say using services is important



Number of survey responses are between 97 and 103.

Evidence from our interviews shows that respondents use support to manage their personal care very effectively and in doing so, to live independently in other ways.

“Basically, when I was living away from home I managed my care myself... [it was] a lot to sort out but it was great in other ways. I think it made me realise what was possible in terms of independence in a way that I never really had before.”

Anna, 24, London

There was no evidence from our interviews that young disabled people were not able to access the right level of support for personal care. Our survey evidence shows that a large majority of respondents, four out of five, who want support with personal care get this support. However, a significant proportion (17 percent) of respondents who do want support with personal care do not get this.

This evidence indicates that personal care is an important area for young people for living independently. It is also an area in which most respondents can access support, but it is still an area of unmet need for some young disabled people. Previous research from the Better Care Project found that a third of disabled people aged 18 – 64 felt they did not get the support set out in their care plan and this would impact on their access to support for personal care. In this context, it appears that younger disabled people are more likely to be able to access support in this area, but it should be noted this access is not universal.

However, young disabled people’s experiences of accessing support to prevent loneliness and isolation are more mixed. While our survey indicated young disabled people used services to access this support, our interviews show that respondents rely on sources of support outside of social services to do this.

“[The university] has a group that meets every other week. It’s organised by the disability services. It is for people that may find it harder to make friends at university. And that’s where I’ve met my friends, through that.” Ricky, 26, South East

This indicates that where other sources of support are available, young disabled people are able to do social activities. However, there is also evidence that young disabled people cannot rely on social services to provide that support.

“I think it [support package] covers my blindness and my hearing impairments and the practical things I need to do, but it doesn’t give me enough time to go out and socialise.” Ricky, 26, South East

Young disabled people who were not at university expressed frustration that while they were supported to take part in leisure activities, this was often alone or with a support worker.

“I would like to have more friends and to be that way I wouldn’t always have to go on my own or with staff when I want to go somewhere. I would go with my friends instead.”
Miriam, 20, London

Our interview responses also showed evidence of young disabled people’s reliance on their family for socialising and taking part in leisure activities. One respondent described how he used to spend Saturday nights playing board games with his family. However, as he got older, this stopped and he has not replaced this social activity.

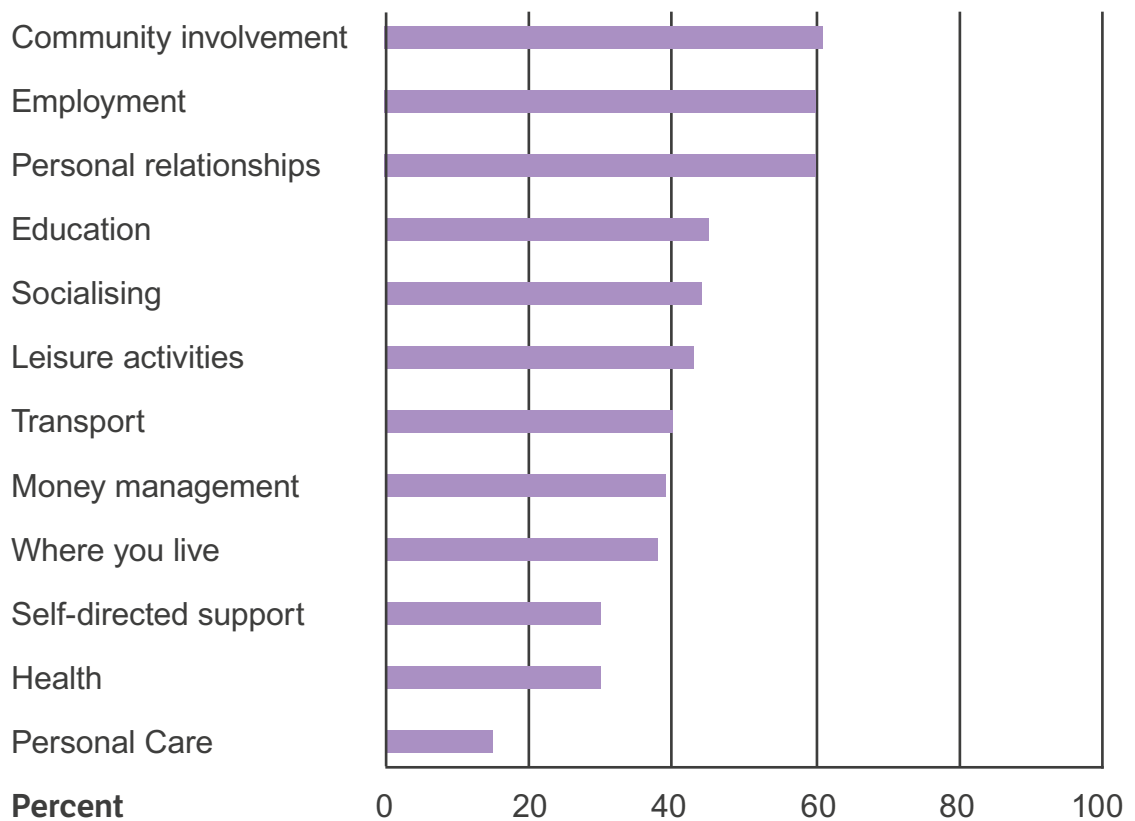
“...we don’t do much on weekends now. My family and I.”
Oliver, 18, London

This indicates that at the point at which disabled people are entering early adulthood, there is a gap in services providing support for meaningful socialising opportunities with people beyond family networks or support workers.

4b. What would young disabled people like to use services for?

In our survey we asked respondents if they used services to support them in different areas of their lives. If they did not, we asked if they would like to. This identified the degree to which services were not meeting the support needs of young disabled people in different areas of their lives.

Figure 1.2: Proportion of respondents who would like support but do not access it in different areas of their life



The figures presented here are the number of respondents who want support in a specific area but don't get it as a proportion of all respondents who want support in that area.

Number of survey responses are between 55 and 118.

This table shows that the most commonly reported areas of unmet need are in community involvement, employment and personal relationships, with around three out of five respondents stating they do not get support in these areas, but would like to.

Employment and employability

Interview respondents reported negative experiences of using Government funded services such as the Work Programme as well as negative attitudes from Job Centre staff.

“They [Work Programme staff] just didn’t seem to have the time to properly talk to the people they were supposed to be helping.”
Becca, 22, East of England

“It’s [the Job Centre] not a particularly nice experience... they’re not particularly friendly and they just try to make you apply for jobs you don’t want to apply for.” Carl, 30, London

These experiences may explain why employment and employability was one of the highest areas of unmet need among young disabled people. Experience of poor quality support to get a job has led to disillusionment with employment support services. As a consequence, young disabled people may be falling out of touch with these support services and therefore not getting the support they need to get a job necessary for living independently.

Our interview research also showed that where respondents did report positive support in this area, it was from third sector organisations or informal support networks such as friends and family. There was also one respondent who is still at college but plans to start her own business in the future and will use her support package to fund carers to support her with this. However, it is anticipated this will be in conjunction with support from friends and family.

“I have carers who will help me with day to day stuff, but mainly my family and family friends who run their own businesses.”
Holly, 19, East of England

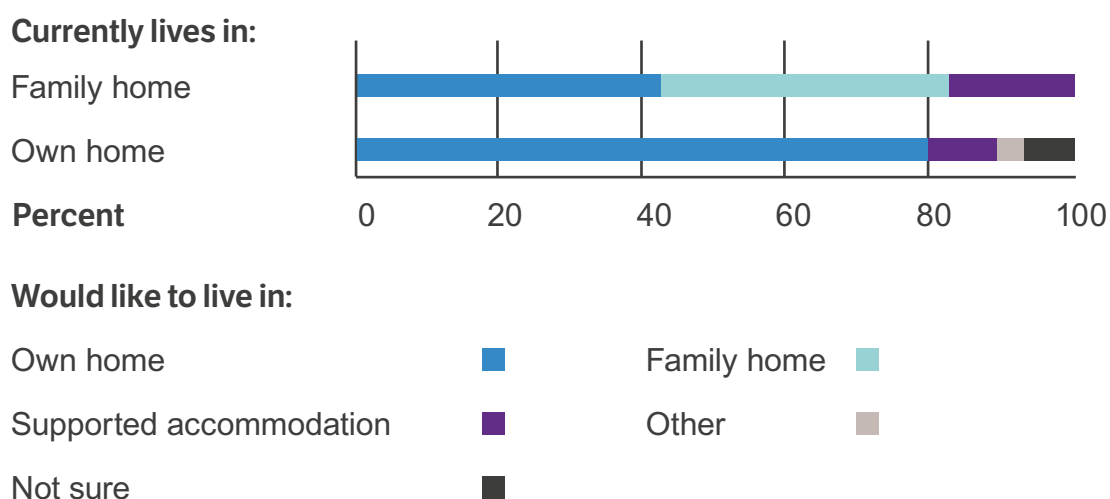
This evidence indicates that where young disabled people do have access to informal and third sector support networks they are able to (or expect to) get a job that is meaningful. However, where these sources of support are not available, young disabled people are trying to negotiate their way through a system that does not account for their support needs.

Where people live

Our survey research found that four in ten (40 percent) of respondents who currently live in their family home would like to continue living at home. A slightly higher proportion (43 percent) of respondents who live in their family home would like to live in their own home. A smaller proportion of respondents currently living at home (18 percent) reported they would like to live in supported accommodation.

Four out of five (80 percent) respondents who currently live in their own home would like to continue living in their own home, while the remaining 20 percent of respondents would like to live in supported accommodation, other accommodation or were not sure.

Figure 1.3: Where respondents currently live by where they would like to live⁴

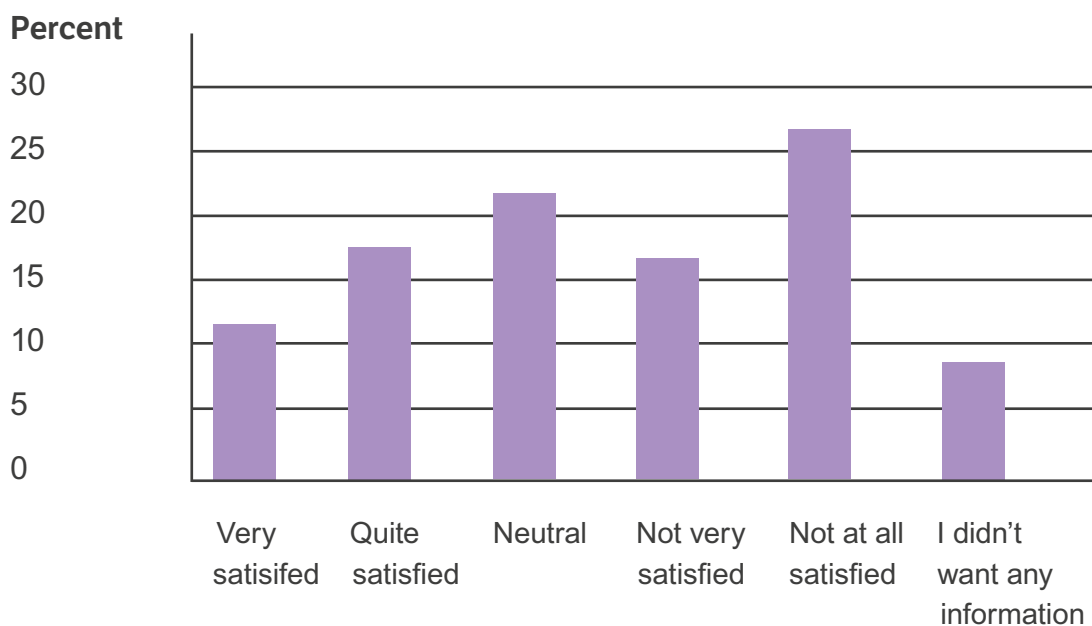


This chart shows data for respondents who currently live in their own home (55 survey responses) or in their family home (40 survey responses). Other categories not presented in this chart are: 'supported accommodation,' 'Extra care' home' and 'other' because the values for these categories were negligible.

A majority of respondents (58 percent) currently living in their family home have aspirations to move out, while a significant minority (43 percent) would like to remain in the family home. Of respondents living in their own home, the vast majority (80 percent) wish to stay there and no one reported that they wanted to move back to their family home. This evidence underpins the idea that independent living may, but does not necessarily mean, living alone. Consequently, young disabled people must be supported to exercise choice and control when accessing services relating to where they live.

Our survey evidence shows that while almost three in ten respondents (29 percent) are 'quite' or 'very satisfied' with accessing information about where they live, more than four in ten respondents (42 percent) are not satisfied, with a quarter of all respondents (26 percent) reporting they are 'not at all satisfied' with accessing this information.

Figure 1.4: Respondents' attitudes to available information options about accommodation



Number of survey responses = 105

The evidence presented in Figures 1.3 and 1.4 indicate that there is no 'one size fits all' approach to supporting young disabled people to live in the home they want to live in. However, respondents do not feel that information services about accommodation are sufficient to meet their aspirations, indicating an information gap that is posing as a barrier to young disabled people living independently.

Interview respondents reported a range of experiences for getting support to live where they want. One respondent spent time in a residential setting and then supported accommodation. Although she preferred the latter because it gave her more freedom and flexibility, supported living still presented challenges such as dealing with noisy neighbours and the respondent did not feel fully supported in dealing with this.

“I think overall the best support I have had is in supported living but that is not with everything that I have needed support.”

Miriam, 20, London

There was a feeling that staff at the supported living service were not trained to deal with behaviour that could be considered challenging and as a consequence, could not support Miriam to resolve her problem with her neighbour. This indicates that even when a person secures the place they want to live, there is an ongoing support requirement to ensure this is a sustainable positive outcome.

When describing infrastructural support such as adaptations to homes being put in place by support services, there is evidence from our interview respondents that this was done early on in their lives.

“When you’re younger it seems to be more of a priority to get things sorted so that you can progress.” Becca, 22, East of England

However, this initial prioritisation of support appears to fall away once a person reaches adulthood and that person can be left not knowing how to access further support in early adulthood.

“But I think, again, as soon as you hit 18 and you’re looking for your own ways to make your flat adapted, it’s a lot harder.” Becca, 22, East of England

This experience indicates that support for adapting homes is more readily available for children and teenagers before they transition to adult social care services. After transition, that support is not necessarily there and young disabled people are not sure how to access support necessary to make their accommodation right for them.

Transport

Interview respondents reported accessibility of public transport as a challenge.

“And people on the buses are so impatient. They’re not patient. I don’t think they know about cerebral palsy or people with difficulties walking. I think they’re not aware.” Zahra, 25, London

Barriers to using public transport to move around relate to attitudes and awareness of disability among transport staff such as bus drivers and station attendants as well as the general public. This barrier may be why many young disabled people would like support on transport.

A number of our interview respondents talked about support they use with public transport and why it is important to them.

William: “You have to get to the bus stop quick. Otherwise it goes.”

Interviewer: “Would you like to take the bus alone?”

William: “No... because you get lost.”

William, 19, South East

“They help me to increase my confidence getting on the bus and also told me to ask the driver to wait until I sat down. I haven’t done that before.” Miriam, 20, London

Without support, public transport systems can be extremely inaccessible for young disabled people to navigate. Our interview evidence shows that young disabled people rely on support to build confidence to get around on public transport and that there are good support services for doing this.

In addition to support with navigating public transport systems, there is also evidence that young disabled people rely on financial support such as subsidised taxis to get around and do the things they want to do with their lives.

“I take the bus more. But when I’m weak and when I’m tired I take the taxis. I’ve got a taxi card... when I’m weak and I need to get to somewhere, I just call the taxi, or when I’m going swimming, I just get the taxi there and get the taxi back.” Zahra, 25, London

However, as shown by Figure 1.2 above, nearly four out of five of our respondents (79 percent) do not feel they are able to access support with transport. This indicates an overall lack of availability for support in an area that young disabled people not only want support with, but is also essential to them having the freedom of movement to do the things they want to do in their lives.

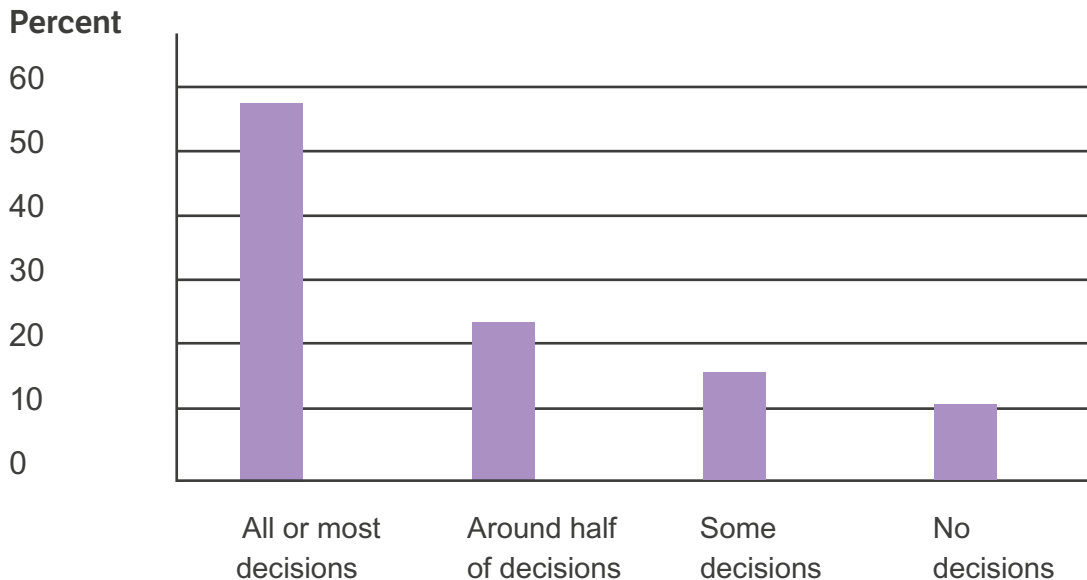
These experiences suggest that young disabled people are being supported with living independently in some ways and with some success. However, this support needs to be ongoing, tailored to that person’s needs and widely available for it to be positive in the long term.

5. Care and support plans

5a. Young disabled people's involvement in developing support plans⁵

Evidence from our survey shows that around half (53 percent) of respondents who answered our question about their involvement in their support plan felt they made all or most of the decisions in developing it. Over a fifth (22 percent) of respondents felt they made around half of the decisions. However, one in four (25 percent) felt they made only some decisions or none at all relating to the development of their care plan.

Figure 2.1: Respondents' involvement in developing their care and support plans



Number of survey responses = 114

This suggests that young disabled people have a range of experiences when it comes to influencing the kind of support they will get. While it is positive that over half of respondents feel they are significantly involved in developing their care plans, there are still one in four respondents who feel they only have some involvement or none at all.

This range of experiences is also reflected in our evidence from the interviews. Interview respondents who attended university showed evidence of using their Disabled Students Allowance (DSA) and local authority funding to control their support very effectively.

5. The question used to identify this in our survey questionnaire refers to respondents making decisions themselves or instructing others to make decisions on their behalf.

“I enjoy being able to employ my own people, it’s nice to have certainty as to who’s coming in and not just random people coming through the door.” Ricky, 26, South East

In this instance, the respondent uses Direct Payments to arrange his support at university and in doing so ensures he is supported by people he knows and has confidence in. It should also be noted that this positive outcome in formal support is nonetheless underpinned by a reliance on informal support networks, in this case a parent.

“I think it’s better that someone who knows me handles my purse strings... because then if anything does go wrong, it’s easy for me to get information on what money I’ve got.” Ricky, 26, South East

There is further evidence of this from another student who employs live in support workers from an agency during term time.

“I just let my parents deal with that because it’s just one less thing to have to worry about.” Katherine, 18, London

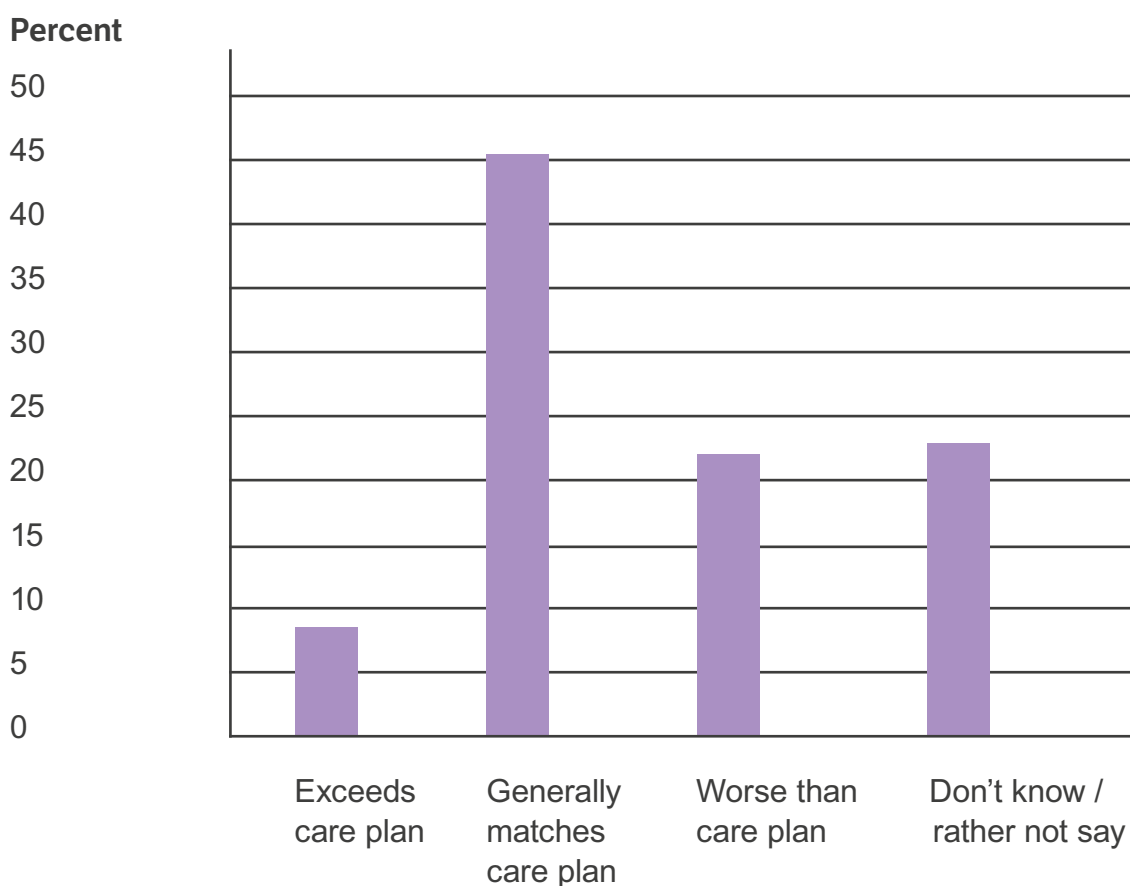
This arrangement is beneficial to the respondent because she can concentrate on doing the things she wants to do in terms of studying and engaging in sports and other activities. However, it again underlines the fact that young disabled people who are successfully doing the things they want to do can only do so where they are getting support from informal support networks.

Our interview research also provided evidence that young disabled people at university can also face challenges to getting the right support to live independently.

“When I was going through the transition process, I was saying ‘look I need all these issues associated with my care plan’ and it was a complete and utter failure. My support was supposed to be implemented 5 – 7 days before I started university, but it wasn’t.” Murphy, 26, North West

This respondent's experience of support not matching what was set out in their plan is also captured by our survey. While over half (54 percent) of respondents said the support they receive at least generally matches or even exceeds their care and support plan, over one in five (22 percent) of respondents said their support was generally worse than what has been agreed in their plan.

Figure 2.2: Respondents' satisfaction with how well their care and support plan matches their support in practice



Number of survey responses = 116

Of the interview respondents who were not at university, there was evidence that young disabled people rely on their families to determine their support plan with social services. Such evidence emerges from interviews with young disabled people who attend post 19 SEN Colleges. Most interview respondents in this group had aspirations to work in sectors such as retail, the theatre and media after they completed college. Some respondents show a firm conviction that they would be able to get a job.

**“Yes, I’m confident. If people say no to me I’m going to say, ‘I’m really sorry but I am working there because it’s my favourite shop!’”
Nicolle, 23, North West**

However, it was also evident from these interviews that the respondents were often unaware of how they were going to secure these jobs. This does not suggest that this support is not there or will not be there in the future, but that these young disabled people have not been included in the employment support process. Where respondents did know where support would come from, once again it was family.

**Interviewer: “Who’s going to help you with [getting a job]?”
Morgan: “I think...I’m not sure. I think it’ll be my Mum.”
Morgan, 19, South East**

There is also evidence from the interview research that parental motivation influences whether or not young disabled people can access support to live independently. This is closely related to reliance on informal support networks but is more proactive in securing the right support for young disabled people. Rather than acting as a ‘safety net’ when support from social care services goes wrong, parental influence is evident where parents are actively advocating for their children to secure the right level of support to live independently, or are supporting them to achieve the outcomes they want in their life. When one respondent was asked if she had pushed for employment support to be included in her care plan, her response was contested by her mother.

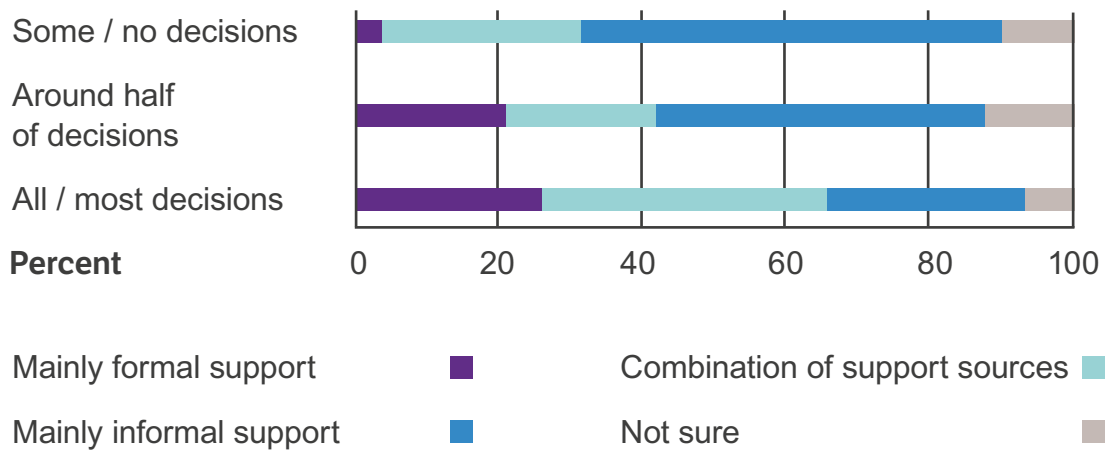
**Miriam: “I don’t think I have really mentioned it.”
Miriam’s mother: “I have, in fact.”
Miriam, 20, London**

“...Because mum told me she wants my name to go in a flat. I think she might do that for me.” Morgan, 19, South East

Furthermore, Miriam’s mother described how she has been advocating for support from the local authority on her daughter’s behalf. Where young disabled people are not involved in developing their support plans, it is often up to families to put pressure on social services to ensure the level and type of support a person wants is taken into account.

There is also evidence to support this in our survey. Of those respondents who reported they make all or most of the decisions relating to their care plan, there was little difference in the proportion of people saying they access information about living independently from formal sources⁵ as from informal sources⁷, just over one in four people. However, of respondents who only make some or no decisions at all, a majority (59 percent) reported they access information about areas related to independent living from informal sources.

Figure 2.3: Care and support plan involvement by type of information source accessed by respondents



Number of survey responses = 113

One possible explanation for this may be that where young disabled people are not involved in developing their care and support plans, they are reliant on family and friends (or possibly their own research) for information about areas of their life such as employment, education, where to live and social opportunities.

Young disabled people’s experiences of influencing their care and support plans are varied. For some, Direct Payments are an opportunity to exercise choice and control over their support. For others, they can be attractive in theory, but hinder choice and control in practice. One possible explanation for the difference in young disabled people’s experiences is the role friends and family play as an informal support network when social services do not ensure a person’s plan reflects what they want to do with their life.

6. ‘Formal’ sources of information include social care professionals, the Government, NHS etc.

7. ‘Informal’ sources of information refer to friends and family, online forums, blog posts etc.

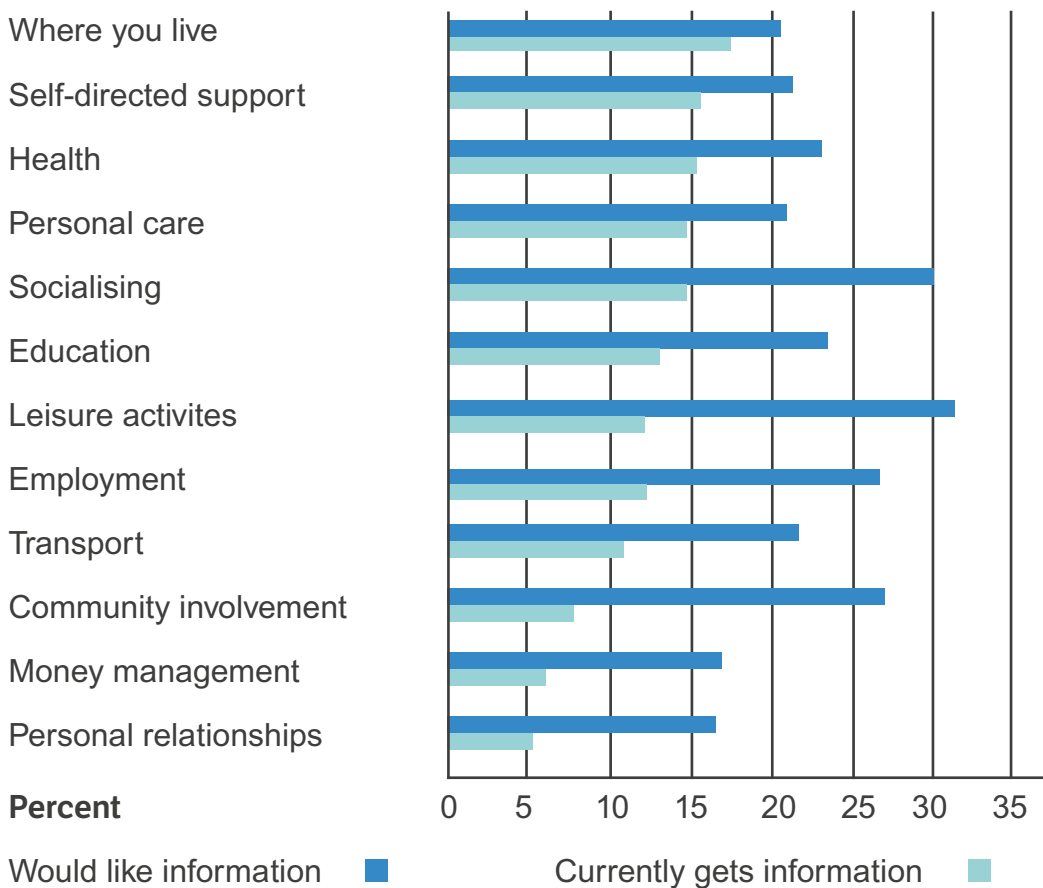
6. Access to advocacy, advice and information

6a. What do types of advocacy, advice and information do young disabled people look for?

In our survey we asked young disabled people about how they accessed advocacy, advice and information about using services to live independently. The most commonly reported areas by respondents were:

- Where they live (18 percent)
- Personal Budgets and Direct Payments (16 percent)
- Health (15 percent)
- Personal care (15 percent)

Figure 3.1: Access to advocacy, advice and information services in each area of respondents' lives



The figures presented in this chart are calculated as proportions of the total number of respondents (228). This question was asked in a way that means it is not possible to distinguish between respondents who answered 'no' and non-responses.

These areas reflect respondents' priorities for accessing support as well as identifying what areas in which advocacy, advice and information are available. However, this differs to what areas young disabled people actually want advocacy, advice and information about.

Respondents to this question most commonly wanted to know about:

- Leisure activities (32 percent)
- Socialising (30 percent)
- Community involvement (27 percent)
- Employment and employability (27 percent)

None of the most popular areas that our respondents want information about match the most common areas that they actually get information about. Figure 3.1 shows there is a particular mismatch in the proportions of respondents who would like to and actually do access information about community involvement, leisure activities and socialising opportunities. This disconnect in these particular areas indicates that advocacy, advice and information services are not set up to support young disabled people to deal with problems associated with isolation and loneliness.

While where they live is not one of the highest reported areas respondents want advocacy, advice and information about, there are still one in five respondents (21 percent) who do want information on this area.

Our interview research shows that the most common area our respondents did not have access to advocacy, advice or information was where they live.

“...probably before I moved away from home I knew even less about what was possible than I do now.” Anna, 24, London

Interviewer: “Did anyone explain any other options about where you could live apart from the flat you’re in now?”

Daniel: “No.”

Daniel, 24, North West

While the interview and survey evidence indicate this is an important area for young disabled people to know more about, it is possible that there are more people who are not aware this is a priority until they are faced with a challenge relating to where they live.

“You don’t know what you need information about until you have an experience that makes you realise what you need.”

Anna, 24, London

This lack of preparation for accessing accommodation was also evident in young disabled people’s experiences of using Direct Payments to pay for support to do things such as go to university.

“...am I going to have the right level of staff to support my needs? How do I explain the rules?’ There are all these issues that were never explained to me as a younger person in that process.”

Murphy, 26, North West

This respondent is speaking in retrospect about when he first started university. It was only at this point that it became clear he had not had access to the advocacy, advice and information necessary to effectively manage the support he had put in place using a Direct Payment. Another respondent was also concerned about information relating to Direct Payments.

“What is happening with direct payments, are people being taken off them? Are people being... you know, what is happening?”

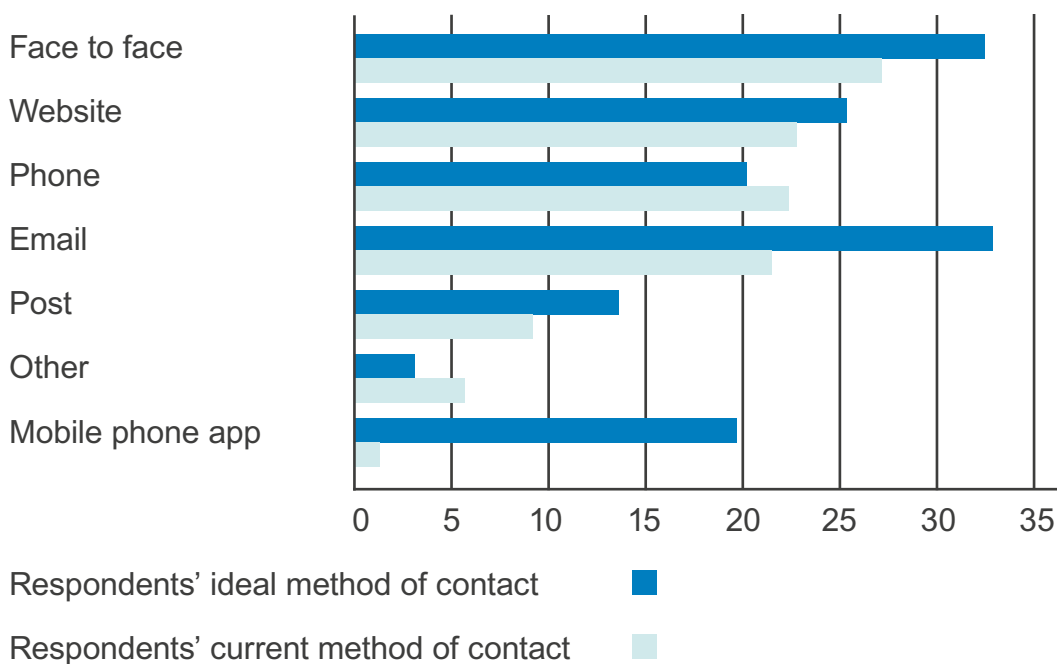
Ricky, 26, South East

In addition to not having the information to manage self-directed support until it is too late, the interview evidence also indicates young disabled people are not confident in whether this method of support will continue for them. As a consequence, young disabled people are presented with another challenge to doing what they want with their lives.

6b. How do disabled people get advocacy, advice and information?

In our survey of young disabled people, we asked respondents in what formats they accessed advocacy, advice and information. The most popular method was face to face contact, with over one in four (27 percent) reporting this. Other popular methods included websites (23 percent), phone (22 percent) and email (22 percent).

Figure 3.2: Respondents' access to advocacy, advice and information by format type



The figures presented in this chart are calculated as proportions of the total number of respondents (228). This question was asked in a way that means it is not possible to distinguish between respondents who answered 'no' and non-responses.

We also asked respondents how they would like to access advocacy, advice and information services. Website, phone and face to face methods of access were again high compared to how respondents actually do access advocacy, advice and information.

However, a greater proportion of respondents report that they want to access advocacy, advice and information via email and mobile phone app than currently do so. This is particularly true of mobile phone apps, where currently 1 percent of respondents report they access this via an app compared to one in five (20 percent) who say they would like to.

Responses to our survey indicate that while young disabled people are happy with accessing advocacy, advice and information via well-established formats such as the internet, phone and in person, there are also newer formats that young disabled want to use but are not necessarily available from providers.

However, with this in mind it is perhaps unexpected that a greater proportion of respondents want to access advocacy, advice and information via email (almost one in three) compared to those who actually do this (over one in five). Email and websites as methods of communicating information rose in tandem so one cannot be considered more established than the other. These findings indicate that there is another reason why there is a reported unmet need for accessing advocacy, advice and information via email.

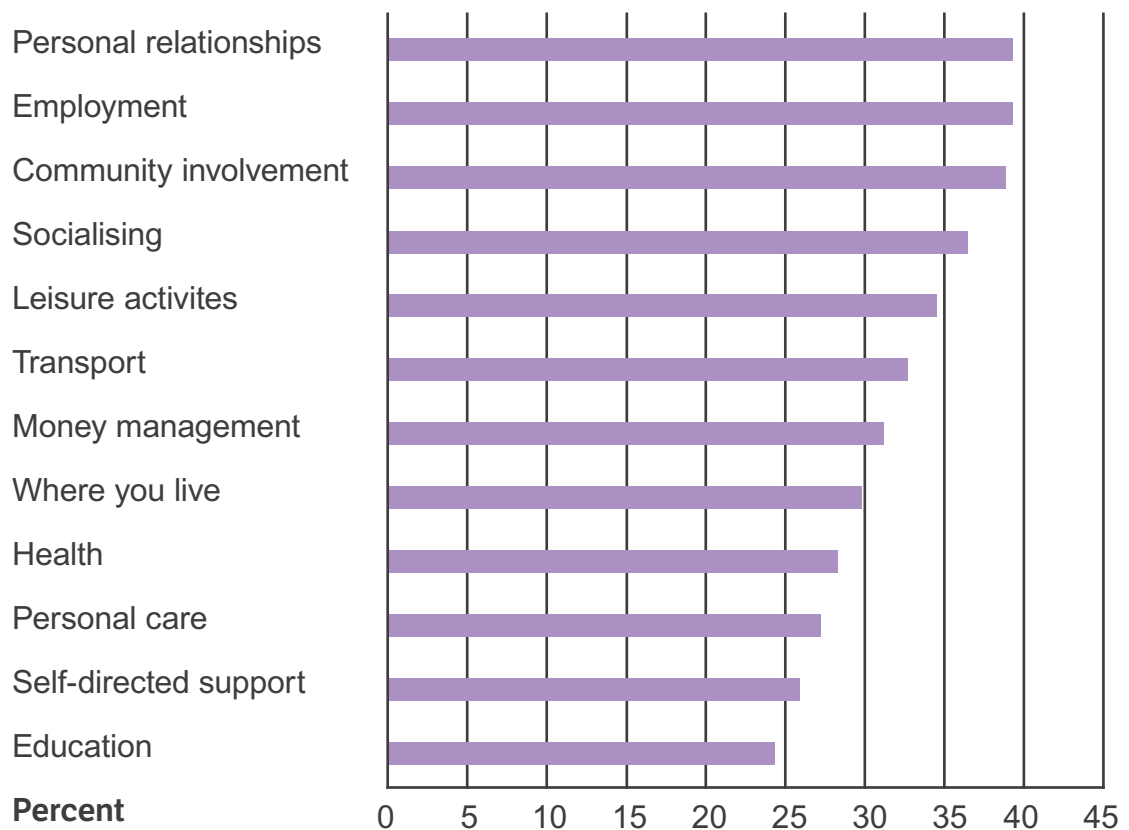
6c. Quality of information services for young disabled people

To determine the quality of information services that young disabled people use for accessing support to live independent lives, we asked questions on three areas:

- Information service accuracy
- Accessibility of information services
- Information about changes to services

We asked respondents whether or not information about different areas of their lives is up to date and accurate. Nearly four in ten respondents said information services were not up to date and accurate in relation to employment and employability (39 percent), personal relationships (39 percent) and community involvement (39 percent).

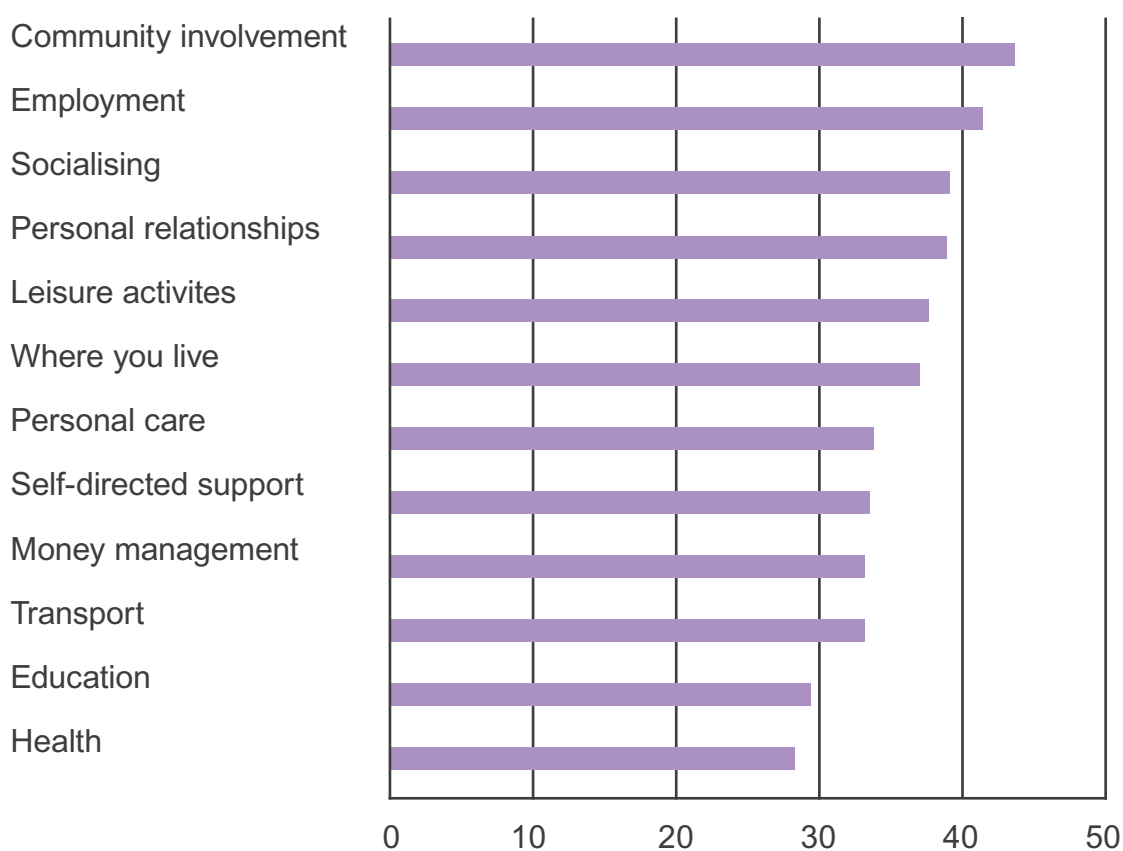
Figure 3.3: Proportion of respondents who do not believe information services are up to date and accurate by area of their life



Number of survey responses are between 109 and 115.

We also asked respondents whether or not information services were accessible for them. Over four in ten respondents did not think information services were available in an accessible format for community involvement (43 percent) and employment and employability (41 percent). Fewer than four in ten respondents reported this statement for socialising (39 percent) and personal relationships (39 percent).

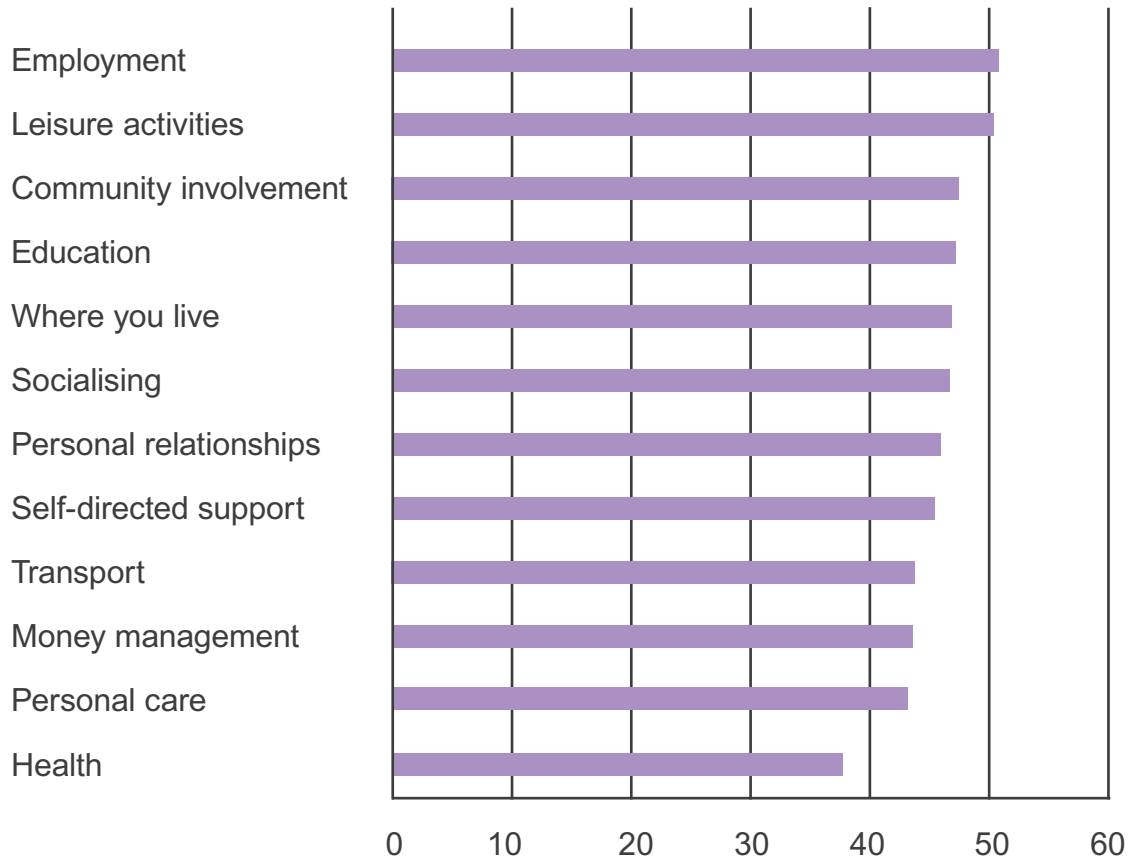
Figure 3.4: Proportion of respondents who believe information services are not accessible by area of their life



Number of survey responses are between 108 and 115.

Finally, we asked respondents to tell us whether or not respondents believe it is easy to find out about changes to services. Around half of respondents said they did not believe it was easy to find out about changes to services in relation to employment and employability (50 percent) and leisure activities (50 percent). Just under half of respondents disagreed with this statement for community involvement (47 percent).

Figure 3.5: Proportion of respondents who believe it is not easy to find out about changes to services by area of their life



Number of survey responses are between 110 and 115.

Results from these three questions indicate there are multiple issues of quality with information services accessed by disabled people who are looking for information about employment and employability and community involvement. The fact that more than one in four respondents told us they want information in these areas indicates that there is not only a need for this information for a significant proportion of our respondents, but that the quality of information that is available has multiple issues of accuracy, accessibility and responsiveness to changing support services.

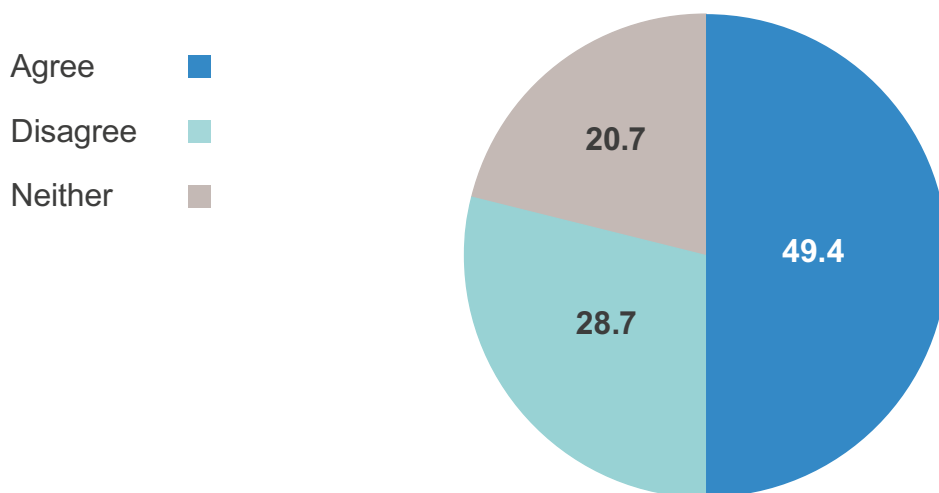
7. The impact of the social care system on young disabled people

7a. Attitudes to living independently in early adulthood

In addition to investigating how young disabled people use services to live independent lives, it is also important to look at the impact that the process of accessing these services has on young disabled people.

Our survey asked respondents to say whether they agree or disagree with the following statement: The services I use at the moment support me to do all the things I want to do in order to live as independently as possible. Around half of our respondents (49 percent) agreed with this statement, while one in five (21 percent) neither agreed nor disagreed and over a quarter (29 percent) disagreed with the statement.

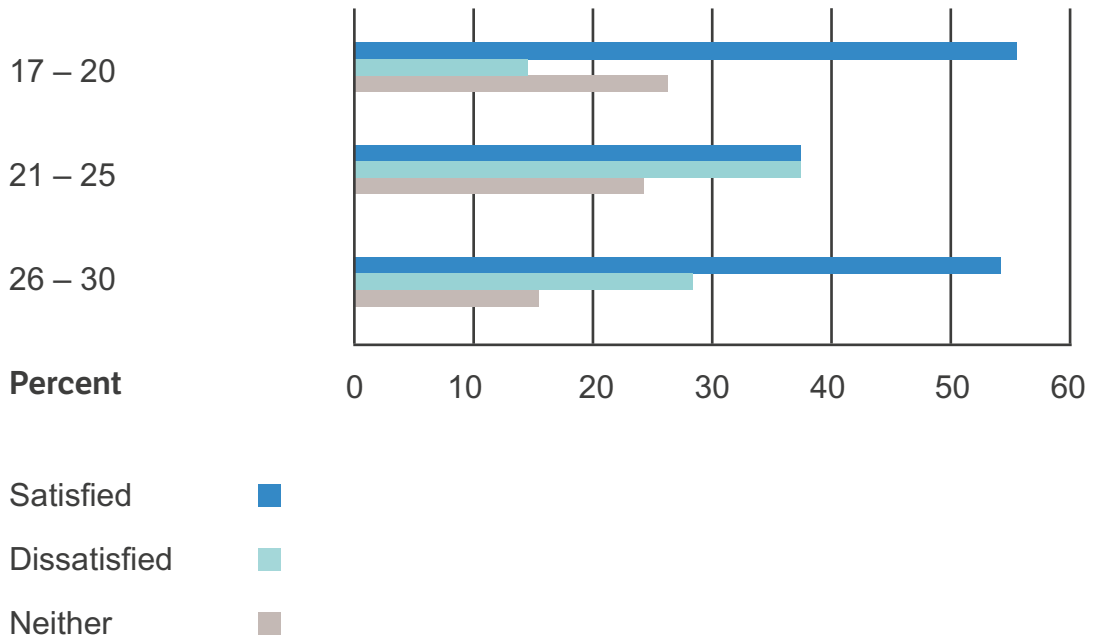
Figure 4.1: Respondents answers when asked if services they use support them to live independent lives



Number of survey responses = 164

That young disabled people believe services are supporting them to live independently is encouraging. However, when these figures are broken down by age, a degree of fluctuation in respondents' attitudes to services is evident.

Figure 4.2: Respondents' satisfaction with services to live independent lives by age⁸



Number of survey responses = 164 (17 – 20 years old = 34, 21 – 25 years old = 53, 26 – 30 years old = 77)

Satisfaction with services is approximately the same for 26 – 30 year olds (55 percent) as it is for 17 – 20 year olds (56 percent). Those aged 21 – 25 years old, however, are significantly less likely to report satisfaction with services (38 percent).

Furthermore, respondents aged 21 – 25 are two and a half times more likely to say they are dissatisfied than the youngest group. This figure is also higher than for those aged 26 – 30 (29 percent). Dissatisfaction among 26 – 30 year old respondents is lower than respondents in their early twenties, but still twice as high as those in the youngest group.

This evidence suggests that as disabled people enter early adulthood, the vast majority are not dissatisfied with services. However, as disabled people access services in their early twenties, they may be facing barriers to living independently that result in higher levels of dissatisfaction with services. One possible explanation for this is that as disabled people reach their mid to late twenties, they are more likely to be using services to do the things they want to, albeit having first gone through a period of poor quality services provision.

8. This relationship is not statistically significant ($p = 0.154$). This means this relationship observed in our sample population of survey respondents cannot be applied to all young disabled people. This may be due to a small sample size for this question ($n = 164$).

7b. Aspirations of younger disabled people

In addition to our survey evidence showing a majority of our respondents are satisfied with the services they use to live independently as they enter early adulthood, our interview research identified high aspiration for what disabled people in this age group wanted to do with their lives.

“I would like to live independently... It would give me more space because I don't want my parents telling me what to do anymore... it would need 24 hour support.” Holly, 19, East of England

“I'd just like to be independent, doing my own things.” Morgan, 19, South East

This evidence from younger respondents shows an appetite for living away from their families and making their own decisions about how they live their lives. However, this was not true of all interview respondents.

“...if I live alone then nobody's with me.” Robby, 20, South East

It should be noted that living independently does not necessarily mean living alone. Some interview respondents also expressed a preference for continuing to live with family in early adulthood. This variety of what independent living means to individuals indicates that a one size fits all approach to support services is not appropriate and must be tailored to the individual if they are to support young disabled people to live independently.

7c. The assessment process

However, evidence from our interview research shows that respondents in their early twenties, and older students looking back to this point in their lives, have had negative experiences of accessing the support necessary to live their lives independently. These experiences include instances of poor quality service provision.

“They [support agency] didn't know what they were doing. They didn't have a clue.” Ricky, 26, South East

There were also instances of respondents not having support to navigate services such as the Job Centre.

**“It’s so stressful. Me and the Job Centre don’t get on!”
Zahra, 25, London**

Where respondents did manage to access employment services, there was evidence that their aspirations for what they want to do with their lives were not being taken into account.

“[I would like] anything based on warehousing or anything like that... they sent me off in retail... just put me on these courses that didn’t really benefit me whatsoever.” Jamie, 22, London

Even where respondents did have access to support services, they were not always personalised to what the individual had identified as necessary for doing the things they want with their lives.

“I wanted a driver, a person who can drive and with my car they need to be over 25. And occasionally they sent me people that either can’t drive because they are too young or people who are scared to drive.” Beckie, 25, East of England

In addition to the quality of support services, respondents were also experiencing cuts to their support packages which meant the things they needed to live independently were no longer available. Research we conducted last year found that support with personal care featured prominently in the care plans of younger disabled people⁹. Similarly, participants in this research project reported their basic needs were being met but resources were not being provided to fund support packages beyond this.

**“I didn’t have enough money in my budget. They cut my costs down an awful lot as well. That’s why I’m living here.”
Daniel, 24, North West**

9. Disabled people’s experiences of social care (2015) HYPERLINK: <http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Disabled-people-s-experiences-of-social-care.pdf?ext=.pdf>

Disabled people are being encouraged to foster high aspirations for doing the things they want to do in their lives in early adulthood and to use services to do this. However, these aspirations are not being borne out in our respondents' experiences. Support services are not meeting expectations of service provision and respondents have experienced significant challenges in using services that pay little consideration to their individual support needs or even what they want to do.

In addition to challenges from support services, our interview respondents also reported negative experiences of the assessment process for getting support. In some instances, this manifested itself as a lack of continuity and poor communication from social workers who were involved in developing care and support plans.

“I had one [social worker] who never came back... I didn't even know them.” Miriam, 20, London

Negative experiences of the assessment process also included attitudes and behaviour from assessors that denied respondents dignity and the acknowledgement that they should be supported to live their lives as they want.

“A social worker said to me once ‘Why can't someone come in and make you a sandwich and then leave?’ I said, ‘Because I'm not a dog. I'm not living my life like that.’” Anna, 24, London

Respondents also reported that assessors would question them in great detail on each part of their care plan, obligating them to prove why they needed each piece of support.

“I was really shocked. How much I had to justify about my care plan... how I had to justify my care plan about why I needed certain things.” Beckie, 25, East of England

“They would question every single aspect of help that you were saying that you needed, which again made me really, really angry that I was having to justify my lifestyle for it to be picked to shreds about how many cups of tea I was drinking a day.”
Anna, 24, London

The cumulative impact of these experiences paints a picture of young disabled people having their lives scrutinised in great detail and being compelled to justify why they need support by the same professionals who decide whether or not they should get that support. Young disabled people have to fight for access to support in a system that can appear stacked against them.

These challenges to accessing the right support to live independently were followed by periods where respondents felt upset and angry at how they were treated.

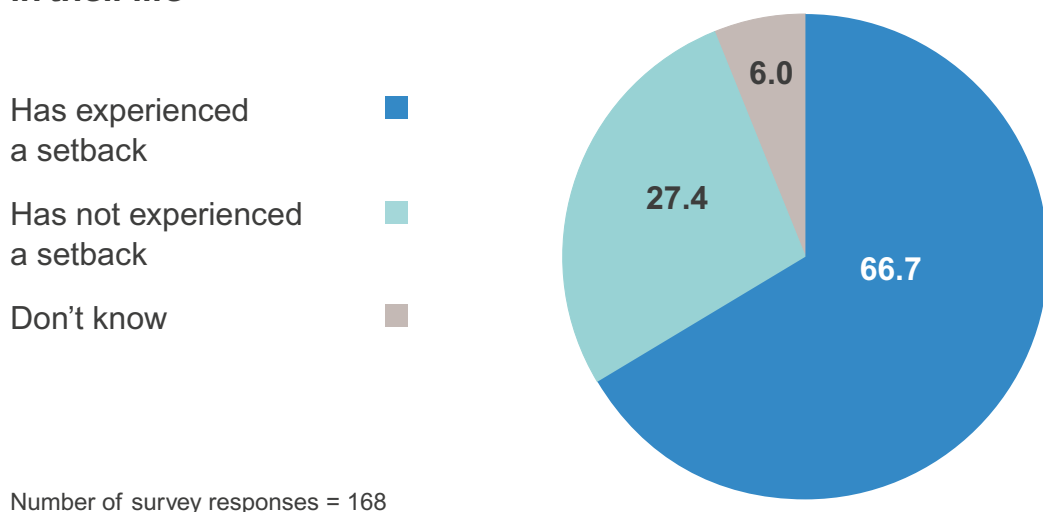
“I walked away from there feeling completely deflated but also just so upset that someone could say that to me.” Anna, 24, London

Young disabled people are growing up to have the same aspirations in early adulthood as young non-disabled people. However, this evidence shows that the system used to assess whether or not they get that support starts from a position of what a person needs rather than what they want. This system of assessment is not conducive to providing support for young disabled people to live independent lives doing the things they want to do.

7d. Impact on young disabled people’s resilience

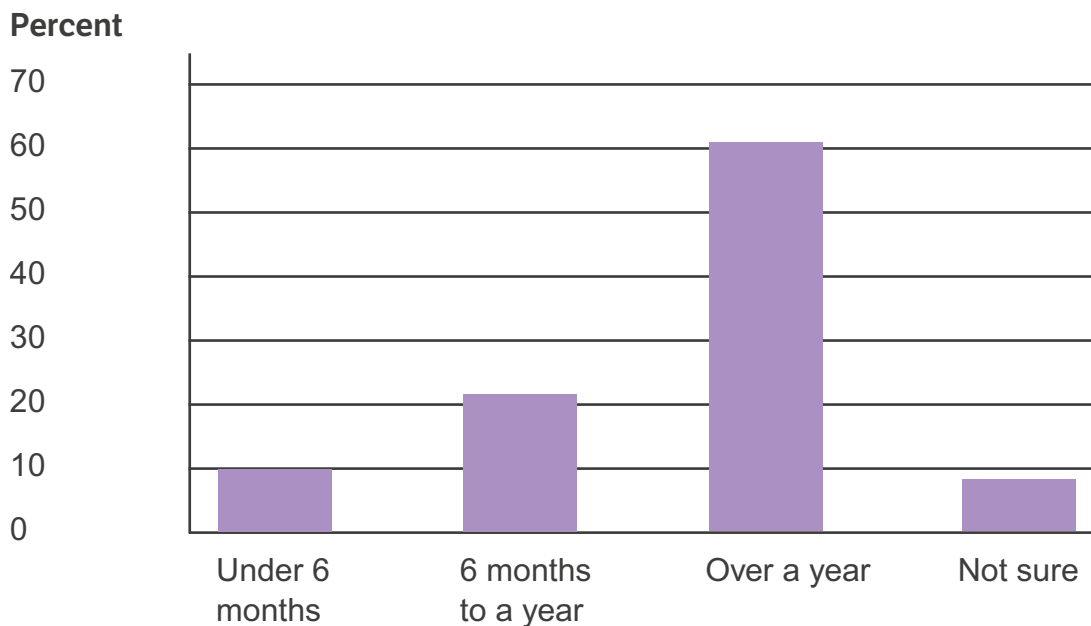
Our survey evidence found that two thirds of our respondents had experienced a significant setback in their life such as losing their job, missing out on a place at college / university or a reduction in their support package.

Figure 4.3: Respondents’ experience of significant setbacks in their life



Furthermore, of the respondents who have experienced a significant setback, only one in ten (10 percent) reported that it was resolved within six months. A further one in five (21 percent) had their problem resolved between six months and a year, while the majority of people in this situation (61 percent) had to wait over a year.

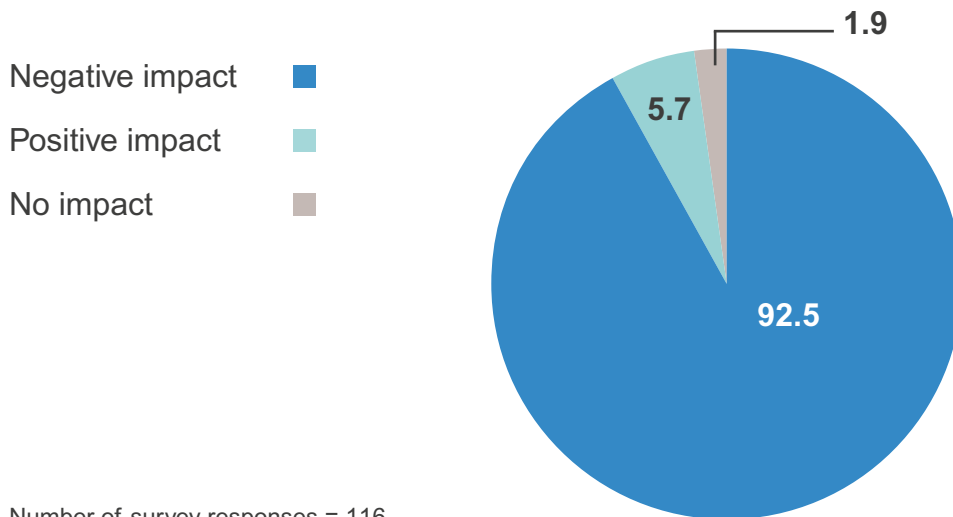
Figure 4.4: Length of time before respondents who experienced a serious setback had their problem resolved



Number of survey responses = 112

Regardless of the time it takes to resolve a setback, of those respondents in this situation, the overwhelming majority (93 percent) reported that it has had a negative impact on their confidence to do the things they need to do to live independently, such as applying for a job or college place, or telling support providers how they want to access their support.

Figure 4.5: Impact of a significant setback on respondents' self-confidence to live independently in the future



Number of survey responses = 116

Analysis of our survey evidence indicates that a majority of respondents have experienced a significant setback in their lives and that for the vast majority these problems took a significant period of time to be resolved. Furthermore, these experiences have had an adverse effect on respondents' confidence to use support services to live independently in the future.

Evidence from our interviews also indicates these experiences have had an impact on young disabled people's resilience and their expectations of the social care system.

“As a disabled person I am locked in my locality because I can't necessarily guarantee that my support package will be transferred.”
Murphy, 26, North West

In the case above, Murphy's concerns about accessing support outside his local authority means that his aspirations for living independently have been tempered and are limited to the local authority area. These fears are not unfounded as our interview research found evidence of services not working well across administrative areas. One respondent who lived in one Health Board area but was funded by another described the challenges he faced trying to get his hearing aid fixed.

“That’s the kind of problem I find in being between two counties. A lot of people say, ‘You don’t officially live here’. That’s a problem.”
Ricky, 26, South East

Where young disabled people cannot access services across different administrative areas, their expectations of doing the things they want to do will be tempered, potentially leading to feelings of disillusionment with the social care system. Young disabled people whose care and support plan is in one administrative area but live in another face an additional barrier to accessing the support they need to live independently. This barrier can discourage young disabled people from thinking beyond their local authority area as well presenting a more practical challenge to sorting out problems with equipment.

The barriers to accessing services to live independently have also had a negative impact on respondents’ well-being.

“I tried to explain as calmly as possible why it [reduction in support] would be detrimental to my well-being.” Beckie, 25, East of England

One respondent noted that living outside of the local authority responsible for their funding meant that they could not access support necessary to deal with depression brought about by their experience at university.

“I was suicidal most days towards the end [of university].”
Anonymous

These experiences of not being able to access services to do the things they want to in terms of education, employment, accommodation and transport as well as around support necessary for mental health and well-being in respondents’ early twenties illustrate the types of barriers faced by young disabled people. These barriers may account for why respondents to our survey in their early twenties were more likely to report feelings of dissatisfaction to services compared to respondents in the younger and older age groups.

Based on evidence from respondents to our interviews, there appears to be a test of resilience among young disabled people as a consequence of their experience of the assessment process and challenges to securing the right level of support to live independent lives.

“They always test your strength a bit and as I’ve got older I’ve got more and more definite and probably less tolerant of people’s questioning.” Anna, 24, London

This evidence indicates that young disabled people are having their resilience strenuously tested by a social care assessment process that is not set up to provide them with support beyond their basic needs. As shown earlier, respondents who could not rely on informal support networks such as family and friends are facing numerous barriers to accessing the right level of support to live their lives independently.

Despite these experiences, the respondents we spoke to in our interviews displayed a degree of stoicism in their attitudes to accessing support in the future.

“I am just trying to stay positive and take one review at a time.” Beckie, 25, East of England

It appears that respondents are positive despite the support available to them rather than because of it.

“I’m not confident, because I know there are changes in the pipeline. But I like to think that... I can maybe exercise some of my muscle over that to stop it happening.” Ricky, 26, South East

Figure 4.2 showed older age groups were more dissatisfied accessing support to live independently in the future than younger age groups. In addition to this, our interview respondents reported a sense of short termism in their care planning as well as a concern about funding for their support packages. These experiences all act as barriers to young disabled people accessing services that will support them to do the things they want to do in their lives.

7e. Young disabled people's outcomes

Interview evidence provided by respondents in their mid to late twenties show that they have succeeded in securing the support they need to live independently in some parts of their lives. One respondent described how he uses the Motability Scheme to pay for an adapted car so he can participate in Boccia tournaments around the country. He had previously been living in his own flat with 24 / 7 support. However, a reduction in his support has meant he now lives with two other people with whom he shares the support.

“I can still do my activities but because there are two other people, sometimes we can't go [out]. You know, if my other housemates have got to go out as well.” Daniel, 24, North West

Daniel is supported to go to Boccia tournaments by his sister, and in the event that she is unable to do this he relies on his paid support to take him. However, as he no longer has one to one support, his ability to do what he wants in his life (to play competitive sport at the highest level) has been compromised by a reduction in the level of support he can access.

Another respondent noted that looking back on how he has accessed support since transitioning to adult services, the support available to him has been limited to what he can access within his local area.

“I would have loved the opportunity to live in different areas etc. and I probably would have done that if I knew that my support is not fixed to a locality.” Murphy, 26, North West

As a consequence Murphy has not lived permanently outside his local authority area and indicates a degree of regret in this because it has limited the experiences he has been able to access as a young person.

“My thinking is, I've got one main move in me, if I'm going to move anywhere I'm going to move somewhere accessible and meets my needs and has my own stamp on it ...creating my own accessible home is a priority for me.” Murphy, 26, North West

He has realised that due to the geographical limitations of his support, if he is to secure support in one area of his life (having his own accessible home), this will need to be at the expense of support in other areas of his life such as living and studying outside his local authority area.

Our interview evidence also indicates that respondents' past experience of accessing support to live independently has resulted in a collapse in confidence of being able to access the right support in the future.

“I quite like my accommodation here at the university and I'd quite like to... I wouldn't mind working here and seeing if I could have an exception to stay in this accommodation.” Ricky, 26, South East

Negative experiences of accessing support in the past before securing the right support has led to a reluctance to go through this again. This indicates a lowering of expectations among respondents that is similar to the geographical limitations outlined above.

The interview evidence outlined above has shown that respondents in their late teens have high aspirations for using services to live independently and are not aware of concrete barriers to doing this. However, as respondents move through their early twenties, these barriers have been evident and have had a significant impact on their well-being and attitudes to using the social care system to access support. Although respondents have eventually succeeded in achieving positive outcomes such as playing competitive sport or going to university using support, there is still evidence that their expectations have been lowered and they have had to make compromises in particular areas of their lives.

8. Concluding remarks

This report has identified what young disabled people consider to be important for them to live independent lives. It has focussed on people at the point they are transitioning to adult services and the aspirations they have in terms of where they live, the types of jobs or education opportunities they want, their social lives and how they expect to achieve these outcomes. This report also investigates the experiences of disabled people in their mid to late twenties in accessing support services necessary to achieve these aims. It reveals barriers to living independently and the extent to which support services have removed these barriers.

In some areas, such as personal care, young disabled people's desire for support has generally been met. However, in other areas such as employment, accommodation and transport support, there is evidence of an unmet need. Our survey and interview research indicates this is due to a lack of personalised support as well as availability of support in these areas.

A majority of our survey respondents reported they had a degree of choice and control over their care and support plans. Our interview respondents showed that this is very successfully achieved where young disabled people administer Personal Budgets themselves. However, this is often underpinned by support from family members, indicating a reliance on informal support networks that are not necessarily available to everyone.

This report also investigates the quality and availability of advocacy, advice and information services for young disabled people. Evidence from our survey indicates a disconnect exists between the areas these services are available to young disabled people and the areas in which young disabled people actually want these services. There were significant minorities of our survey respondents who reported that advocacy, advice and information services were not accurate, accessible or responsive to changing support services.

Experiences of accessing support services to live independent lives have had an impact on young disabled people. As young disabled people enter early adulthood, there is evidence of high aspirations, but a lack of clarity on how they will be supported to achieve what they want to do. Disabled people in their mid to late twenties ultimately secure the outcomes they want in certain areas of their life, but there is evidence that there are negative experiences in their attempts to do this. This can result in a lack of confidence in support services and tempered expectations of the likelihood they will be able to achieve everything they want to in their lives.

Appendices

Appendix 1: Survey sample

Table 1a: Respondents' age

	Number	Percentage
17 – 20	51	22.7
21 – 25	77	34.2
26 – 30	97	43.1

No response to this question: 3

Table 1b: Respondents' gender

	Number	Percentage
Male	42	18.7
Female	174	77.3
Other	7	3.1
Not specified	1	0.4
Rather not say	1	0.4

No response to this question: 3

Table 1c: Age at which respondents acquired impairment(s) / diagnosis

	Number	Percentage
0 – 4	119	56.7
5 – 9	9	4.3
10 – 14	28	13.3
15 – 19	24	11.4
20 – 24	22	10.5
25+	8	3.8

No response to this question: 18

Table 1d: Respondents' impairment(s) and / or condition(s)*

	Number	Percentage
Learning impairment	52	23.1
Mental health condition	66	29.3
Physical impairment	163	72.4
Sensory impairment	45	20.0
Autistic spectrum condition	59	26.2
Not sure	4	1.8
Rather not say	4	1.8
Other	23	10.2

*Total is greater than number of respondents (228) because respondents may record more than one impairment or condition.

No response to this question: 3

Table 1e: Respondents' ethnicity

	Number	Percentage
White English / Welsh / Scottish / Northern Irish / British	95	89.6
White other	4	3.8
Asian or Asian British	3	2.8
Mixed	3	2.8
Rather not say	1	0.9

No response to this question: 122

Table 1f: Respondents' settlement type

	Number	Percentage
Urban	27	25.7
Suburban	40	38.1
Rural	19	18.1
Not sure	19	18.1

No response to this question: 123

Table 1g: Respondents' housing tenure

	Number	Percentage
Own home (bought or rented)	57	53.3
Family home	40	37.4
Supported accommodation	2	1.9
"Extra care" home	4	3.7
Other	4	3.7

No response to this question: 121

Appendix 2: Interview sample

Table 2a: Interview participants' age

	Frequency
17 – 20	10
21 – 25	12
26 – 30	3

Table 2b: Interview participants' gender

	Frequency
Male	12
Female	13

Table 2c: Interview respondents' region

	Frequency
London	7
North West	6
East of England	3
South East	9

Appendix 3: Survey questionnaire

A copy of the questionnaire used for this survey and requests for further analysis of the data are available from the Research Team. Please contact Andy McKeown at research@scope.org.uk.

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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