

**Social work services in Scotland:  
gathering the views of users and carers**

**Final Report for Audit Scotland  
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**Research Scotland**

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## Executive Summary

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### **About this report**

This research involved discussions with people using social care services and their carers in five local authority areas in Scotland. The discussions explored their experiences of social care services, including accessing care, views on their current service provision, and the extent to which they could influence the services they receive. The research consulted with 165 service users and carers and was carried out during March and April 2016.

### **Accessing and choosing services**

The individuals involved in this research received a wide range of social care services, organised in a wide variety of ways. Experiences of arranging and accessing social care support were therefore very varied.

Many participants, particularly older people, indicated that a crisis situation – such as a fall, accident or illness which involved a hospital admission – resulted in care being put in place. Some felt that their stay in hospital was extended due to the time it took to arrange appropriate care and equipment to enable them to return home.

Participants who had received care and support for a long time often could not remember the process of accessing services. Some individuals who had complex needs from an early age indicated that their route to accessing services was relatively clear. However some, such as foster carers of children with additional support needs, found it harder to access the support they needed. Some participants felt that having an existing relationship with social work services made it easier to access care as needed. A number felt that the situation had to reach crisis point before any information or support was provided.

There were mixed views on the assessment process. Some had a positive experience, perceiving that the assessor was knowledgeable and interested in their care. Others found the process intrusive, and some felt a decision had been made on their care package before the assessment took place. Some participants suggested that the assessment process could be improved by taking more external factors into account, such as background, environment and the views of carers and support staff.

There were mixed views on reassessments. Some service users wanted a reassessment, based on their perception that their health needs had changed, but found this difficult to achieve. Others actively fought against having a reassessment, for fear it would result in a reduced care package.

### **Current service provision**

The participants in this research received a wide range of care and support services. This included support at home; support with daily life; supported accommodation; day care and wider social support services.

Generally, participants with positive experiences of their current service provision highlighted some of the following factors:

- the importance of respectful and flexible carers;
- relationships with carers;
- the ability to influence service delivery through self-directed support; and
- good timekeeping.

However, there were lots of examples of people experiencing services which they were not happy with. Key issues raised by participants included:

- the time allocated to undertake tasks;
- poor timekeeping;
- frequent changes to home care support arrangements;
- lack of flexibility;
- lack of continuity of carers;
- lack of respect for the needs of the individual;
- gaps in skills and training of home care staff; and
- quality of meals.

Several participants in our research indicated that their current level of service provision was not adequate and they wanted to increase their level of support. In some cases, support packages had been reduced and service users were trying to manage with reduced hours.

### **Influencing services**

The type of service provided determined whether service users felt able to influence their service delivery. For example, often where service users had one to one support or had close relationships with staff in sheltered accommodation, they felt confident about influencing the service. Service users with self-directed support generally felt that they had a good level of influence over the service they received.

However, a significant number of service users felt that they had little influence over their social care provision. Some had concerns about speaking up in case the care they received was reduced or changed. Others, particularly older people, didn't want to hurt the feelings of the people providing care. While some had experience of raising issues with care providers and services being adapted accordingly, others found that no steps were taken to rectify issues. Some service users then felt they were not listened to by care providers. Carers were more likely than service users to speak up if they were concerned about any aspects of the service delivery.

### **Impact of services**

Overall, most service users reported that their care impacted positively on their quality of life, including:

- supporting positive social networks;
- building increased confidence;
- encouraging people to try new things;
- developing living and practical skills like cooking, IT, money and travel skills; and

- enabling people to remain in their own homes.

Some, however, felt that their current care package covered only their minimal needs and would like care provision to take into consideration aspects that would contribute to an improved quality of life, such as social activities.

Social care services also impacted on quality of life for carers. Without social care, several carers reported that they would not be able to cope or function. Social care support provided respite for families, helped to keep families together and enabled families to spend more time with their other children. Some carers indicated that without support they would be less healthy, both physically and mentally. A small number indicated that without support they would be unable to sustain employment.

The vast majority of service users and carers said that their circumstances would be considerably worse if social care service provision was not in place. Service users and carers felt that without support, there would be issues such as depression, loneliness, and a general inability to function.

# 1. Introduction

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## About this report

- 1.1 Audit Scotland commissioned us (Research Scotland) in February 2016 to gather views of users and carers on social care services. The research involved discussions with people using social care services and their carers in five local authority areas in Scotland. The research was carried out during March and April 2016.
- 1.2 This research is part of a wider audit of social work services being carried out by Audit Scotland. The audit explores how effectively councils are planning to address the financial and demographic pressures facing social work services.

## Research aims

- 1.3 The research aimed to explore the views of people using social care services, and their carers, to find out:
  - how they have been involved in planning and choosing their services;
  - how they are involved in monitoring and reviewing their services;
  - what choices they are offered about their care;
  - the quality of care they receive;
  - how their care has changed over time to reflect changing needs; and
  - whether they feel they have an influence over the services they receive.
- 1.4 In our consultations with service users and carers, we defined 'social care' as including any of the following:
  - care provided in a day care centre (or similar);
  - home care – help in the service user's home with things like getting up, going out, dressing and cooking;
  - supported accommodation – either through a care home or sheltered housing;
  - housing support – practical help to allow people to stay in their own home; and
  - respite or short term care.

## Research method

- 1.5 Our research focused on five local authority areas, agreed with Audit Scotland. The authorities were selected to ensure a mix of geographies and to include both urban and rural areas. The local authorities included in this research were:
  - East Renfrewshire
  - Glasgow
  - Midlothian

- West Lothian
- Western Isles.

1.6 Our fieldwork targeted the following key groups in each local authority area:

- older people;
- people with physical disabilities or sensory impairments;
- people with learning disabilities;
- young people with disabilities; and
- carers.

1.7 We took a flexible approach to the research, aiming to speak with five to six people in each of these broad groups, in each local authority area. The method used to speak to individuals varied depending on preferences and needs – including either a focus group discussion, a mini group discussion (with just two or three participants), telephone interviews or face to face interviews.

1.8 We completed 33 focus groups (including mini groups) and 12 individual interviews (three telephone and nine face to face). A total of 165 participants were involved in the research.

1.9 We recruited participants through a range of existing organisations in each local authority area, which had relationships with social care service users and carers. We discussed preferred participation methods, communication arrangements and wider support arrangements with each organisation. A total of 28 organisations assisted with recruiting individuals, from across the five local authority areas. Each organisation which assisted us received a donation of £50.

## Profile of participants

1.10 The research involved participants from five local authorities.

Local Authority	Total Participants
Glasgow	61
East Renfrewshire	32
Mid Lothian	23
West Lothian	35
Western Isles	14
<b>Total</b>	<b>165</b>

1.11 The participants included service users with a range of needs, as well as carers.

Participant Type	Total Participants
Carer	37
Young people	37
People with learning disabilities	34
People with physical or sensory impairments	32
Older people	25
<b>Total</b>	<b>165</b>

1.12 Overall, there were slightly more women than men involved in the research. About a third of participants were aged 60 and over, with one fifth being aged 25 or under.

Characteristic	Number	Percentage
Female	94	57%
Male	71	43%
Under 25	34	21%
26 to 40	34	21%
41 to 59	44	27%
60 and over	53	32%

1.13 Six participants were from ethnic minority backgrounds. An analysis of these discussions highlighted that their views did not differ significantly from other participants. The quotes from people from ethnic minority backgrounds have been tagged clearly throughout the report.

## 2. Accessing and Choosing Services

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### Introduction

2.1 This section of the report explores people's experiences of finding out about and accessing services, and the level of choice involved in this process.

### Arranging and accessing social care support

2.2 The individuals involved in this research received a wide range of social care services, organised in a wide variety of ways. Experiences of arranging and accessing social care support were therefore very varied.

### *Accessing care in a crisis situation*

2.3 Many participants, particularly older people, indicated that a crisis situation – such as a fall, accident or illness which involved a hospital admission - resulted in care being put in place quickly. Most often participants thought that this care had been organised by hospital staff working jointly with social work services. Often participants indicated that they had limited involvement in organising the care they received, but most were happy with the process. In addition, a small number of disabled people who had experienced injury or disability through a fall or accident indicated that this was their experience, with care being arranged through hospital and social work staff.

2.4 Some people stated that they could not be discharged from hospital until their care package was put in place at home. This resulted in an extended stay in hospital until the arrangements were in place.

“I stayed in hospital for one week longer than necessary to get the care package in place for going home.”

Service user, older person

“I broke my ankle and had to wait for a package of care to be in place which took four weeks, and I had to stay in hospital all that time.”

Service user, young person with physical disabilities

2.5 In these situations, family members often took on the responsibility of working with staff to arrange for support to be put in place, either when older relatives' health was perceived as deteriorating, or when people with disabilities were thought to need more support. However, a number of carers indicated that they were unsure when and how the assessment process took place for support, but assumed that it had happened while the person they cared for was in hospital.

“I had two falls, and was in hospital for four weeks. After that I got the carers. It was my family who organised it.”

Service user, older person

- 2.6 Some participants indicated that even though their support package was organised, they were unable to go home due to delays with fitting equipment and adaptations to their home, to make it suitable for their needs. There was concern that these delays were preventing hospital discharge, and were also significantly impacting on quality of life for those living at home. For example, one carer indicated that her husband was in hospital for four weeks longer than necessary due to delays identifying appropriate support for him to use toileting facilities.

### ***Accessing care from a community setting***

- 2.7 Many participants had accessed care through other routes. Often individuals who had complex needs from an early age indicated that their assessment process and route to accessing services was relatively clear. A small number of carers of children and young people with additional support needs indicated that where needs were complex, there were clear routes through which support could be accessed, involving the NHS, local authority social work and education services and schools. However, for other parents and carers of young people with additional support needs, the route to accessing support was less clear. For example, a number of foster carers with children with additional support needs felt that while initial support with fostering was readily available, it was subsequently very difficult to access care and support for children with additional needs.
- 2.8 Participants who had received care and support for a long time often could not remember the process of accessing services, and their experiences of assessment. The majority of these service users stated they could not remember exactly how long they waited for an initial needs assessment this had taken place a considerable time ago. The general perception was that it had not been a lengthy period of time to wait for their initial assessment.

“I can’t remember how long it took but it was a straightforward process.”

Service user, physical disability

- 2.9 Some had a positive experience and felt they received good support, which was put in place quickly (even if it had not been the full package of care they wanted). Others said they felt communication from social work services was lacking and so had found out about services on their own.

“Communication is not good – social work don’t tell us what we are entitled to, you have to find out from other parents.”

Carer

- 2.10 Some participants believed that having an existing relationship with social work services made it easier to access social care, and that having a named social work contact made the process easier.

“Social work first told me about support.”

Service user, learning disabilities

“Before, I had a social worker and when she discharged me she said that if I needed any more help, I was to contact her. So I did.”

Service user, young person with physical disabilities

2.11 However, many participants across different local authority areas stated that there was no longer a system of providing people with a named social worker. Others indicated that they felt that there was little information available about the assessment process, and that often the situation got to crisis point before any information or support was provided.

“It gets to breaking point before you are listened to.”

Carer

“I think that we should have been offered it [support] sooner, but he wasn’t seeing anyone except the GP. How does the system work? Who would have flagged it up?”

Carer

“I hadn’t realised that I had to ask for a personal assessment, and it was never offered to me.”

Service user, physical disabilities

### **Experiences of the assessment process**

2.12 Many people did not remember their experiences of the assessment process. As outlined above, most of these participants felt that the process had been relatively simple.

2.13 Some service users recalled a positive experience of their assessment, indicating that it was fairly smooth. Often those with a positive experience indicated that the assessor had sufficient knowledge of their condition to make an informed judgement.

“I was a bit nervous at the beginning but there’s nothing they could have done to make the process easier.”

Service user, older person

2.14 Some others who remembered the assessment process felt that they had a negative experience. Most often, this was because participants felt that the process was a ‘tick box’ exercise, and that the assessor was not interested in their care.

“Sometimes people don’t even look at me.”

Service user, older person

“It’s a tick box exercise for the social worker. They are not really discussing my needs; just evidencing that they physically visited.”

Service user, sensory impairment

2.15 In one discussion group, many participants felt strongly that a judgement on their care had been made before the assessment had officially taken place. This was based on the perception that social work services undertake background checks and observation in advance of the assessment.

“They watch you get out the car and how well you can walk before you even get into the assessment. The assessment is made before you’re even in the building.”  
Service user, physical disabilities

2.16 Two other participants reported that they found the assessment process intrusive, and felt uncomfortable with the personal questions they were asked.

“I hated it. They were asking me questions I don’t like; private questions.”  
Service user, learning disabilities

“I felt I was asked questions they should not have asked.”  
Service user, sensory impairment

2.17 Young people had varied experiences of the assessment process. One young participant was very pleased that the assessment process involved them, while another wished they could have been more involved in this process, rather than the assessor dealing with his parents.

“I wish they had listened to me and not my parents at the time. My parents would be most involved, but I wanted my own level of independence.”  
Service user, young person with physical disabilities

2.18 In one group of service users, some participants had experience of living in institutional care settings in the past. These participants had experienced assessment as part of the process of moving from institutional settings into community settings, often as institutions closed down as part of a shift towards community based care. These service users stated that, at the time of this review, they would have liked to have more input into the assessment process; but that it had a successful outcome for them.

“They (social work) didn’t ask me as many questions as I would have liked. I have a voice and I have an opinion. But the assessment did lead to my first independent house.”  
Service user, learning disabilities

“We all sat round a big square table, there was social work and a community nurse and a few other people and I was nervous as sin [interviewer: why?] because I was hoping to get out of the place I was in.”  
Service user, learning disabilities

### ***Improvements to the assessment process***

2.19 Participants made suggestions about improving the assessment process. The most common suggestion related to involving a wider range of views and experiences in the assessment. Many carers and some service users raised

the issue that the assessment process did not take into consideration other factors, such as the service user's background or current environment. Many felt that the views of carers, GPs and support workers should be given more consideration during the assessment process.

"The assessments don't take your background or your GP's opinions into consideration – there are a lot of anomalies."

Service user, physical disabilities

"With assessments, how much of the carer's views were taken into account? They don't want the carer there; but it is the carer that bears the brunt."

Carer

2.20 In particular, some hearing impaired participants said the assessment process was complex and some interpreters struggled with the language. These participants felt that it would be very useful to have a support worker present to help convey their needs.

"Having a support worker invited along would improve how it would work and how we share information. That would really help."

Service user, sensory impairment

2.21 Some carers commented that it would be beneficial to have more staff in order to assess all those that need support within a realistic timeframe. And a small number felt that there should be a clearer connection between the assessment and the planning process, focused on outcomes for individuals.

"The assessment process should be streamlined and there should be a lead-coordinator to deliver a clear plan and outcomes for individuals."

Carer

2.22 A small number of participants commented that while the assessment process was positive, the outcome of the assessment was not implemented appropriately. For example, a married couple with physical disabilities stated that while they had a positive experience with the assessment process, this was not followed through as care was put into place. This couple said they felt the social worker listened to what their needs were and recorded this information accurately. Issues arose however when the care company stated they were not able to provide the care at the level or time requested. This couple then felt they had to accept a care package that did not meet their needs.

"Social work came out and asked what we wanted. They did a care plan with the times on it that you say you need, and then the care company say no; they can't do it and they [care company] change it to suit them. They [care company] don't actually ask you what you need."

Service user, physical disabilities

2.23 Another participant was asked to complete a 'self-evaluation' questionnaire which asked about his care needs and his lifestyle. He reported that he received a package that provided his breakfast, lunch and dinner; but had not taken into consideration any of the social or religious needs he identified.

"There was no social time, no religious needs taken into account; but you're not able to challenge it. Why do they ask you, if that's what you're going to get?"  
Service user, physical disabilities

### **Length of wait before services in place**

2.24 In general, service users stated that the waiting time between assessment and having care in place, was not too long. Some service users indicated that they waited a very short time for support. In particular, those with self-directed support generally felt they were able to put together a care package quickly, following the assessment.

"The social work came to my house and went through forms. It didn't take too long to get the care in place; maybe a few weeks."  
Service user, physical disabilities, ethnic minority participant

"My wife sorted out a social work assessment, and it didn't take long before care was in place."  
Service user, physical disabilities

"The social worker was very good and the Self Directed Support package was put together in one month."  
Carer

2.25 However, for some, this perception could be because in the interim period, family and friends provided the care. In general, carers perceived a much longer wait for services to be put in place. For example, some carers reported they had to wait six or seven weeks before some social care services were in place, and this had an adverse effect on the person they cared for. One other example included a wait of 14 weeks to access social care services. In the intermittent period, family members had to take responsibility for providing care.

"When mum came out of hospital the physiotherapy was not in place for seven weeks, which affected her mobility a lot."  
Carer

"When dad was in the hospice, they arranged for his specialist home support. It was supposed to be in place the week he came home, but took 14 weeks. In that time, mum had to do it all."  
Carer

- 2.26 Waiting for adaptations to be made to people's homes tended to take the longest time. There were examples of participants waiting for ramps and wet rooms to replace bathrooms. In some instances, service users chose to pay privately to have these adaptations done more quickly.

"Now, with a lot of things, if you want it you have to buy it. The housing association will help up to a point with adaptations."

Carer

## Reassessments

- 2.27 Some service users had undertaken a reassessment. Views on the need for reassessment were varied. Some service users wanted to have a reassessment, but found it difficult to achieve this, and others fought against having a reassessment in case it resulted in a reduced care package.
- 2.28 Some service users perceived there had been a change in their health, and felt that they should be reassessed for care, in the hope that this would lead to an increased package of care. Many of these service users reported they had encountered difficulties in trying to arrange a reassessment. A number of carers felt that regular reviews would be helpful to ensure that the service user was receiving the right services.

"I find it difficult to get a social work assessment for more hours. I get five hours now, but I feel that my health has got worse. I'm still waiting for social work to do an assessment for more hours."

Service user, learning disabilities

- 2.29 However, some carers and service users had fought against having a reassessment for fear that their current support package would be reduced; or that they would be asked to pay for services they currently accessed for free. Several participants recalled being reassessed when switching to receive self-directed support. All found that their hours were reduced as a result of the reassessment, despite there being no changes in their conditions.
- 2.30 One service user had experienced a reduction in her hours, based on a reassessment, but said that she was not allowed to attend a meeting about the decision.

"I wasn't allowed to attend. There was no transparency. Decisions were made without me, because social work recommended a reduced package, which resulted in a 26% cut to my hours."

Service user, physical disabilities

## Transition from child to adult services

- 2.31 Several service users and carers raised the issue of accessing services during the transition from child to adult services. Some felt that this transition was very smooth, but others noticed differences. For example, one parent carer reported that she noticed a change from when her daughter was first

assessed ten years ago (and received a support package very quickly) to now, when she felt the process was more complicated and that support arrangements had changed.

“Once our daughter started school, the assessment process changed. Last year she had to go through five different assessments.”

Carer

2.32 Other service users felt there were fewer resources available via adult services and that adult services were not as comprehensive. Befriending was one particular area that a number of adults stated they could benefit from, but which were not available through adult services in their area. Some also highlighted that they no longer had one single point of contact for support.

“When I was younger there were a lot more services. There was more befriending and funding. But that changes as soon as you hit 25 years old.”

Service user, physical disabilities, ethnic minority participant

“I found I got more support when I was a child, through Children’s Services, and I had one social worker to deal with everything.”

Service user, learning disabilities

2.33 Others had experience of services being stopped without advance warning as the service user grew older. For example, one carer was told services for her grandchild would stop when he turned 16. This carer believed that this was a result of cuts to funding, and had not been able to find a similar social activity for her grandchild provided by adult services.

“When [grandchild] turned 16 I was told that this Saturday service was going to stop because he would now be under adult services. I had no forewarning, no one from adult services contacted me; I contacted them and they couldn’t offer any support. It’s a funding issue.”

Carer

### 3. Current Services

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#### Introduction

3.1 This section of the report explores how service users and carers felt about the services they currently received. It explores views on the type, level and quality of support provided.

#### Type of support provided

3.2 The participants in this research received a wide range of care and support services. This included support at home, organised through the local authority or through self-directed support; support with daily life – often through a Personal Assistant; supported accommodation; and day care or social support services.

- **Day care centres** – Most participants who attended day care centres for support were very happy with the provision of care from these centres. Older people in particular commented on the benefits of meeting other people and having company through the day. Disabled people also had positive experiences of day care centres and enjoyed socialising with other disabled people.
- **Home care** – A large number of older and disabled people received home care services, giving them support to stay in their own homes. This includes visits through to continuous care, assistance with activities such as getting in-and-out of bed, showering, meal preparation and administering medication. There were mixed views on the quality of this care, explored further throughout this chapter.
- **Supported accommodation** – We engaged with older participants in supported accommodation, who had access to support 24 hours a day. Also, we met with some people with learning disabilities who received similar support in order to live independently. Both groups of service users were broadly satisfied with the care, which provided an element of independence, while still ensuring support was available when necessary.
- **Personal alarms** – Some older service users had personal alarms, which gave them peace of mind that help would be available in an emergency. In one discussion, the older people felt they had received an excellent service from the company supplying their personal alarms.

“I have a feature that picks up if I get out of bed for too long, in case I’ve fallen in the night. I like to get up and wander about if I can’t sleep, and then there is this booming voice asking if I am ok! It’s first class service.”

Service user, older person

- 3.3 Overall, most comment from participants on experiences of social care related to home care services.

### **Factors influencing experiences of social care**

#### ***Individual carers***

- 3.4 In general, service users felt that a good carer made all the difference to their experience. Participants valued when carers spoke to them respectfully, were flexible to their needs and turned up on time.

“The carer makes the company. If you have bad carers, it makes all the difference.”  
Service user, physical disabilities

“I had a procedure in hospital and I was in and out the same day, but the carer came in to take me to hospital and came back at midnight to take me home. It was above and beyond.”  
Service user, physical disabilities

“I think they do a good job; they couldn’t do any better and we should be grateful to them.”  
Service user, older person

- 3.5 Overall, service users supported by personal assistants or who organised the care themselves generally had more positive experiences.

“I have worked hard to build positive relationships with my PAs. They always work extremely hard to provide good support.”  
Service user, physical disabilities

#### ***Self Directed Support (SDS)***

- 3.6 Some service users chose to employ social care staff themselves through their direct payment budget. These service users tended to have had a positive experience with the support they arranged. This was typically a personal assistant (or team of assistants) who could help with care and support. Overall, those using direct payments were satisfied with their support.

“I receive 37 hours of support and seven sleepovers. I get personal care, support with the running of my flat, to shop and support to be involved in the community. They also enable me to attend university.”  
Service user, physical disabilities

- 3.7 Some service users employed an agency to manage the direct payments on their behalf. This involved the agency being responsible for employing care staff; including paying salaries, working out tax and dealing with holidays and absenteeism. Overall, most service users were happy with this service, preferring to pass the responsibility onto someone else. However, a small number of participants commented that they had found self-directed support difficult to access.

“I didn’t want to do direct payments, I’ll let social work manage that. When you employ staff it’s a whole different ball game. I would rather the care companies do the management.”

Carer

- 3.8 However, a small number of service users perceived they had not received a good service via self-directed support. For example, one young disabled person was charged £16 an hour for a personal assistant, who was paid £8 an hour by the care company. This service user felt the agency took advantage of him and left him able to afford less hours with his personal assistant.

“Because I am paying £16 an hour, it is £99 per visit, so I’m spending all of my allowance on two visits.”

Service user, young person

### **Quality of care**

- 3.9 Discussions around the quality of care, were dominated by views on home care staff. There were common issues identified across all the local authority areas, discussed below.

#### ***Length of time carer spends with service user***

- 3.10 The majority of those in receipt of home care services stated that the carer would be in their home for between 15 and 20 minutes at a time. During this allocated time slot, typical tasks could include being showered or bathed, preparing a meal, and administering medication. Many service users reported that this was not enough time for the home care staff to be able to provide good quality care.

“I had an OT assessment, and social work and they gave me 15 minutes of care. It’s really not enough time. It’s the choice between getting washed or getting dressed.”

Service user, physical disabilities

“I did have [care company], and I got 15 minutes, so I had a choice between having breakfast and them running a bath for me to have on my own once they’d gone, or a shower with no breakfast. Quite often it was only ten minutes. I stopped using them.”

Service user, physical disabilities

“They always seem to be in a hurry to get to the next client.”

Service user, older person

### ***Timekeeping***

- 3.11 Service users discussed their experiences of home care staff arriving either earlier or later than expected. Some participants had experienced home care staff not turning up to appointments at all, leaving the service user with no support. Service users were frustrated at the home care staff’s timekeeping and poor communication.

“Morning call outs, they can be erratic time wise and unstable. They come earlier than they should, and it’s not always the same time.”

Service user, young person

“Sometimes they’re late and sometimes they don’t come at all.”

Service user, learning disabilities

3.12 One service user said that the poor timekeeping of home care staff made her feel as though her life was “controlled” by carers. Others reported feeling stressed, panicky and worried by not knowing when their carer would arrive. One indicated that they had been unable to attend the funeral of a family member due to being unable to change the timing of support.

“Carers are overstretched. They might have three appointments scheduled for 9pm so they might come at 8pm, or 8.30pm instead. Your life is then controlled by carers.”

Service user, physical disabilities

“I mean; how much notice can you give for a funeral?”

Service user, physical disabilities

3.13 Several service users raised the issue of timekeeping in relation to being charged for care which they did not receive. When home carers turned up late, service users found they were still paying for the full appointment time.

“The support was meant to start at 1pm but they didn’t come till 3pm. I went to social work and we added up the hours I was missing out on, and it was like 45 hours over two months. I’m paying, but I’m losing out on hours.”

Service user, learning disabilities.

3.14 In other cases, where home carers were able to complete their tasks in less than the appointment time, service users commented that they should be able to ‘bank’ this time and use it at another date. Instead, they felt they were ‘missing out’ on care that they were paying for.

“The package is not fully tailor-made to our needs. We get 30 minutes, but sometimes they do it in less, like 20 minutes; but you can’t get those 10 minutes back.”

Service user, physical disabilities

3.15 One service user, living in supported accommodation said that it was not uncommon for him to have his time with a carer cut short, if the staff felt there was another service user in the supported accommodation who needed their time more. He said that, because he was quite independent, he was often ‘bumped’ for those who needed more support.

“I have 14 hours a week, but because I’m independent, I’m not a priority for the staff. It’s when people need more support [than me] like those with epilepsy; but I don’t get the hours back.”

Service user, learning disabilities, ethnic minority participant

### ***Frequent changes to home care support***

- 3.16 Service users, particularly those with learning disabilities, spoke of the frequency with which they were told of 'last minute' changes to their home care support schedule. For some, it was the rota for the coming week released too late, or changing allocated time slots without any advanced warning. These service users found this lack of communication unsettling and unprofessional.

"They might phone up on a Friday and change the plans for Saturday."

Service user, learning disabilities

"You don't get your rota till Friday night or Saturday morning about who is coming, and when. It's too late."

Service user, learning disabilities

### ***Flexibility of role (undertaking tasks)***

- 3.17 Most service users felt that the quality of care they received was negatively impacted by the limited flexibility of home care staff in undertaking other household tasks. For example, one older service user had asked for help to rearrange her bed – but was told it was not in the carer's remit.

"Very often I will ask for something to be done, and they say 'sorry, I can't do that' – like I have a mattress topper and sometimes it slips, so I asked her to help me make the bed, and she said no."

Service user, older person

"I used to use [care company] when I came out of hospital, but you ask them to do little things in the house, and they say 'I'm not insured to do that'."

Service user, physical disabilities

"I asked [care company] if they would close the curtains, but they said it was not on the tick list."

Service user, physical disabilities

- 3.18 However, one service user using self-directed support to arrange their own care reported no issues with asking carers to perform additional tasks.

"The private carers are great – they will do any wee jobs that need done, like changing lightbulbs or picking up dog mess."

Service user, physical disabilities

- 3.19 One participant reported that the Personal Assistant that looks after her son is now allowed to use her own car to take him out to day centres or social activities. This parent carer has had to insure the Personal Assistant to drive her own car, so that her son is able to get out of the house.

“I’m happy with the quality of care he is receiving; although the support worker is not allowed to take him out in her car, so I’ve had to insure her to drive my car just so he can get out for the day.”

Carer, ethnic minority participant

### ***Continuity of carers***

3.20 A large number of service users commented that they did not always receive support from the same home care staff members. They felt it was very important to have some continuity with carers in terms of safety and building a rapport, but that this was lacking.

“I don’t like seeing new faces. It’s the reason I looked for a personal assistant.”

Service user, physical disabilities, ethnic minority participant

“When they come to your door you don’t know who they are. When they come to my door I ask them for ID.”

Service user, learning disabilities

### ***Respect and dignity***

3.21 Some service users had experienced home care staff using their mobile phones during their appointment. Service users perceived this as an indication of poor quality care being provided by home care staff.

“It’s the way they treat you sometimes...sometimes they’re on their phone when they’re with you.”

Service user, learning disabilities

“There are people in my house on their phones when they are supposed to be cooking me dinner, so I just went in and did it myself.”

Service user, young person with learning disabilities

3.22 One carer had recently cancelled her contract with a home care service for her husband because she found the carer to be insensitive to her husband’s needs. Her husband had suffered a stroke, brought on by years of excessive smoking. She said the carer was clearly a smoker, which her husband found distressing.

“I was annoyed because my husband’s stroke was brought on because of his heavy smoking, which he had to give up. The carer would come in smelling of cigarettes and coughing, which was very insensitive.”

Carer

### ***Meals***

3.23 A large number of service users and carers were not satisfied with the quality of the meals being prepared for them by home care staff. Service users shared examples of meals being presented to them which were cold or raw.

Service users felt that this was due to the short amount of time home care staff were allocated for each appointment.

“I noticed the carer had only been in for seven minutes, and I wondered how the fishcakes were cooked. I have had to put up a sign saying ‘please make sure that the food is hot’.”

Carer

“She gave me a fish pie and it was cold in the middle. She said she didn’t have time to do it again, so I had to ask her to make me an omelette.”

Service user, older person

### ***Trained home care staff***

3.24 Other service users and carers questioned the skills of some home care staff. For example, some service users needed to be manually lifted, or supported via walking or standing aids. Their experience was that the home care staff did not know how to handle them, or use this equipment safely. In these instances, family members had to step in.

“The girls that came in didn’t know how to use a stand aid, and they couldn’t do manual lifting.”

Service user, physical disabilities

3.25 A small number of participants highlighted that there could be challenges identifying suitably trained staff in remote and rural areas.

“It’s hard to find qualified carers with the right experience (in this area).”

Carer

### **Changes in care over time**

3.26 Service users and carers were asked whether they had noticed any changes in the quality of care they received over time.

3.27 In two local authority areas, home care provision had been subcontracted to a new external supplier. In one local authority, the quality was perceived to have improved via the subcontractor, while in the other, the quality was thought to have declined.

“I feel very lucky to live in [local authority]. The services for disabled people are the best in Scotland compared to other areas. [Local authority] listened to what people wanted, like supported living and individually tailored support plans.”

Carer

“The previous carers supplied by the local authority were much better, but there has been a change to this subcontractor and it has gotten worse.”

Service user, older person

3.28 There were some examples of service users seeing reduced levels of support. For example, in another area, some participants who previously received one to one support on days out had been asked to share this with another client. The affected participants were dissatisfied with this arrangement and felt it was a direct result of a lack of staff, and limited resources.

“They do this to save money, or because there aren’t enough staff members available.”

Service user, learning disabilities

3.29 Another service user was no longer allocated a carer to stay overnight, but had been issued with a buzzer to contact help. This service user felt this change had a negative impact on her care.

“I used to have someone sleep over but that doesn’t happen anymore and I don’t agree with that. I like to have someone over in case I take not well in the night.”

Service user, learning disabilities

3.30 However, there were also examples given of where service users had experienced a reduction in the number of care hours, but were thriving as a result - as this was perceived to have increased their independence.

“I used to get 31 hours of support a week, and five years ago this was cut to 15 hours through personalisation, but I feel brilliant now. I’m doing a lot more for myself and it keeps me independent.”

Service user, learning disabilities

3.31 Some participants with sensory impairments (in one discussion group) discussed a change in the way some services were delivered. They noticed they were now being charged a fee to use BSL supported home care which had once been free to use, and that some services now required a social work referral in order to gain access. As a result, they perceived a decline in the number of people using these services.

“There is a charge now for the service and for some it is expensive and people may not be able to afford it. People have had to withdraw from the service because of being unable to afford it.”

Service user, impairment

3.32 Carers in another local authority area felt there had been a decline in the quality of care. They felt that the quality of care was very much dependent on staff, and there had been significant staff changes in recent times. They perceived this resulted in poorer quality care.

“Staff don’t seem to be as qualified or competent as they used to be.”

Carer

## Level of support

3.33 A significant number of service users and carers stated that they wanted to increase their current levels of social care support.

3.34

“There is not enough time. Three hours is not enough – there is so much to do. It’s very difficult as I am trying to get a house, and three hours is not enough time to help me.”

Service user, learning disabilities

“It is very minimal and only covers my very, very basic needs. I would like more.”

Service user, physical disabilities, ethnic minority participant

3.35 This was particularly apparent where service users had experienced a reduction in their existing support provision but felt this left them with fewer hours of support than they needed.

“I had my support cut a few years ago and lost 14 hours per week. I do miss the flexibility that brought. I have to be extremely organised to fit in all the things I need or want to do. I am aware that due to the cuts, it is unlikely I would get more hours and I am fearful they will try to cut more.”

Service user, physical disabilities

“Before I used to get 22 hours, now it’s 16. I applied for an extra two hours, but I was knocked back – they said it was enough time to have a shower. But its 16 hours over seven days.”

Service user, physical disabilities, ethnic minority participant

3.36 Other service users commented that they would like to increase their levels of support and ask for more hours of care, but they were fearful of their case being reviewed and reassessed, which might lead to even further reductions in support. This issue will be discussed in more detail in the following chapter.

“I would like more, but in the current climate, I’m happy with what I’ve got in case it gets reviewed and gets cut.”

Service user

“I don’t feel like I am in a position to ask for more.”

Service user

## Respite care provision

3.37 A number of carers spoke of the importance of respite care - anything from a few hours at a support group or days away on a short-break. Some carers reported that they struggled to get respite. Two carers said they were not offered any respite as they were perceived to be ‘coping’ by social work services.

“There were no services offered to me. It was like ‘you’re coping, so go away’. I got nothing and I was completely on my own and I felt it.”

“I only recently got a social worker for mum as previously it was thought I was managing fine on my own; but I wanted a social worker because it would help me to access respite.”

Carer

3.38 Carers said that without respite services, the impact on their quality of life would be huge with one referring to respite as a “lifeline” service. This was particularly true where parent carers had other children to consider.

“It feels like another world. We are able to be spontaneous with our other children. It gives us more breathing space and takes the pressure off the family.”

Carer

3.39 Service users had mostly positive experiences of respite in terms of the care itself and the facilities offered. However, there were some examples of respite care being offered in unsuitable locations, such as young disabled people offered a place in care homes for older people.

“I’ve been offered respite, but in an old people’s home. I’m 35 years old.”

Service user, physical disabilities, ethnic minority participant

3.40 In another example, a service user was offered three weeks of respite care, but was allocated a specific three-weeks in which to use it. The timing was not suitable for the service user and therefore she did not use the respite care. She was then told by social work services that because the respite had not been used; it would be removed.

## 4. Influencing Services

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### Introduction

4.1 This chapter explores service users and carers' experiences of influencing the service they receive in terms of the type, method of delivery and level of support.

### Involved in initial decision about care

4.2 Service users were asked whether they were involved in the initial decisions about their care, such as the type of care they received, the amount of care and how it was delivered. Some service users stated that they felt involved in decisions about their care.

"I have three daughters and we all decided that I couldn't cope. We all agreed, but they said 'it's up to you'."

Service user, older person

"I was involved throughout the process with the social work and my contact from [support organisation]."

Service user, physical disabilities

4.3 Other participants said that the social care they received was put in place based on an assessment of their needs and that they were 'told' the type and level of care they were getting.

"It depends on your medical condition. If you've got a memory condition, they'll tell you what you're getting."

Service user, older person

4.4 One participant was told that she would choose the staff on her support team; but in reality she was not involved in selecting all of the staff who worked with her.

"I feel I have good control, but would want a teensy bit more control with choosing my support worker."

Service user, learning disabilities

4.5 There was one example of a carer whose husband's care package was arranged and ready for him coming out of hospital. However, the carer was not informed that this was in place until the day he was to be discharged, when she received a call from social work.

"I don't think I was involved much."

Carer

4.6 Other parent carers had similar experiences and had been told what support was available for their child. One parent carer felt that she was not fully

involved in decisions about her son's care and that there was much room for improvement to ensure that parents and carers could be fully involved in the process.

"They [social work] tell you what you will be offered."

Carer

### **Examples of influencing service delivery**

- 4.7 Discussions focused on whether service users and carers had any influence over the way in which their social care services were delivered. This included aspects of care such as the time care was delivered, and the staff who delivered it.

#### ***Sheltered accommodation***

- 4.8 In two discussion groups, some participants who lived in sheltered accommodation felt strongly that they were involved in decisions about their care. Overall, participants living in sheltered accommodation felt comfortable with the staff and felt they could approach them about any aspect of their care. One participant perceived that staff were more likely to listen to any complaints than managers.

"If I did need anything, I know they would help."

Service user, older person

"We have a service users meeting; the staff listen but the managers don't."

Service user, learning disabilities

#### ***Review of care plan***

- 4.9 Some service users had a care plan which was personalised to their specific care needs. These plans were reviewed on a regular basis, and as such, service users felt that they did have some influence over their care, in that they could change aspects of the plan relatively easily.

"Yes, I've got a care plan. They come out and I just say to them what I need done, so it does meet my needs."

Service user, physical disabilities

"I have a support plan, and I go along with that. We set goals, and I decide the goals, which I like."

Service user, learning disabilities

### **Lead contact**

- 4.10 Those service users assigned a key worker or a lead support worker felt very involved in their own care. Having a dedicated person to speak to about any aspect of their service delivery was said to be very useful.

“Definitely, I feel very involved. If there is a problem, I have a key worker that I can speak to, because loved ones get upset.”

Service user, physical disabilities

“The staff here, they don’t approach you with negativity – you can always speak to someone. They make time for you.”

Service user, physical disabilities

### **Self Directed Support**

- 4.11 Those using direct payments to pay for their own services generally felt able to influence service delivery. However, there was a general acknowledgement among service users and carers that self-directed support required more input and responsibility on the part of the service user or carer, and for some this was too much to consider.

- 4.12 There were examples of those using direct payments having an input into their own care, by interviewing potential staff and having a say on who would work with them.

“I have a say about who is on my team. I got to meet them and do interviews. I did the questions in advance.”

Service user, young person with physical disabilities

### **Limited influence on service delivery**

- 4.13 A significant number of service users perceived that they had no influence over their social care provision. They reported that they were ‘told’ what their care package would include and there had been no opportunities for negotiation.

“What can I decide on? No. I take what I get and I’m thankful for it.”

Service user, older person

“There is no decision about time. The company tells me.”

Service user, older person

“You’re told what you’re getting.”

Service user, physical disabilities

“I’m not involved. The care can change just because someone else decided to take the hours off you.”

Service user, physical disabilities

## Carers views

- 4.14 Several carers were frustrated at attempting to influence the service delivery for the person they cared for. For example, some carers said that they were not fully aware of the social care services their relatives were eligible for, and who could provide these. One carer stated that she did not know how the tasks performed by home care staff during an appointment (such as cooking or cleaning) were agreed, and how they might be changed.

“People don’t know what they can and cannot ask the carers to do; there’s no list of duties.”

Carer

## Confidentiality

- 4.15 A wider issue raised by carers was the issue of confidentiality. Due to doctor-patient confidentiality, some carers found that they were not party to pertinent information about the person they cared for. For example, one participant said that the person she cared for did not allow her to attend any GP appointments with him, which meant that she did not know how best to care for him.

“I have an issue at the moment with my son. He goes to [support organisation] as he’s had issues with depression and suicide, but [support organisation] won’t tell me anything; but I’m his carer.”

Carer

“He does not let me attend any GP appointments with him. I have to look through the cupboards to see what kind of medication he is on.”

Carer

- 4.16 Another carer had experienced difficulty influencing her daughter’s care once her daughter turned 18 and was perceived as able to make decisions for herself. This carer found that the care providers did not seek out, or listen to her view, as the carer. As a result, decisions were made by her daughter, which the carer felt were detrimental to her health.

“I have not been included in discussions or assessments about [daughter’s] care. This is because she is an adult and was deemed to have capacity.”

Carer

- 4.17 Many carers felt strongly that if they were able to share their views at appointments, and at assessment stage, then service providers would be able to make a more accurate assessment which would better influence the service delivery.

## Tailored service

- 4.18 We explored whether service users and carers felt that the social care services they received were tailored to their specific needs. There were mixed views, depending on the type of social care service delivered. For example,

those receiving care through a personal assistant were much more positive that the service met their needs.

“Yes, my PA tries to be flexible so I can have the same lifestyle as non-disabled people.”

Service user, physical disabilities

“It is tailored to me. I had 1:1 workers to help with things like finding a job, help with housing applications so it was personalised.”

Service user, learning disabilities

“No; we’re all just a number. If we don’t fit into the system, then that’s just tough.”

Service user, learning disabilities

4.19 Service users and carers reported very varied experiences of influencing the timing of service delivery. Some had positive examples of how the timing of care was changed to meet their needs. However, others had tried to influence timing with little or no impact.

“They used to come at 7.30am and this was inconvenient because mum needed to get ready for work, so we asked to have the time changed to 9am and it was done without a problem.”

Carer

“I mentioned it (erratic timekeeping of home care staff) to [home care organisation] but I was told they were teething problems; but it’s coming up to three months and it’s still the same.”

Service user, young person with physical disabilities

“They don’t listen to my requests. The likes of my timeframe is 7.45am – 8.15am but this week they have been coming at 6am. My daughter contacted them, but they don’t listen, or else they don’t come.”

Service user, older person

### **Able to speak up about social care provision**

4.20 There were mixed views as to whether people felt confident to speak up if they were unhappy about the social care provision they received. Carers were often more likely to speak up, and advocate on behalf of the person they cared for.

#### ***Confident to speak up***

4.21 Some service users said they felt very confident about speaking up if they were dissatisfied with the provision of social care. Some had experience of registering a complaint, and felt it was important to say something if the service was not acceptable.

“I am confident. I am very happy to say anything at [organisation].”

Service user, physical disabilities

“If home care was not good; I would speak up. I’m not a shrinking violet.”  
Service user, older person

“I had a support worker and I didn’t like him, so I complained about him. I didn’t really want to have to, but I needed to do it so I could get a better one.”  
Service user, learning disabilities

4.22 Carers were very likely to speak up if they were not satisfied with the care provided. For example, two carers had contacted their local MSP to complain about the care services they received.

“If I wasn’t there saying no to a lot of things, I think my mum would have gotten a raw deal and she would have had less choice.”  
Carer

4.23 In general, carers felt more confident speaking up if they were supported by specific organisations who provided advocacy and information on what should be expected of social care providers.

“Now that I’m involved in this [carer support organisation] and I know the system, I wouldn’t hesitate to say something.”  
Carer

“Previously we did not feel able to speak up, however, through the support of [carer support organisation] we are more aware of our legal rights and use this to get the support that we need.”  
Carer

4.24 In one instance, a participant who had been a carer for many years said that over time he had learned how to communicate with social care service providers; in effect ‘learning their language’. He now found he was able to deal more effectively with care providers.

“I do have a say, but that is because I have learned to speak their language [social work]. They might say no, but you can apply some pressure.”  
Carer

### ***Not confident to speak up***

4.25 There were also examples of service users who said they would not be confident to speak up if they were unhappy with their care provision. Two service users stated that it was because of their own temperament; they preferred to avoid confrontation.

“I would just accept it. I don’t like confrontation; I just let it happen. When carers come at times that are not suitable, I just accept it rather than complain.”  
Service user, young person with physical disabilities

“I’m not confident to speak up; I just put up with things. I’m a bit shy.”  
Service user, young person with disabilities

4.26 Many of the older people involved in the research indicated that they were less likely to speak up if they thought they might hurt the feelings of the service provider.

“It’s not always cooked right, but I don’t like to say anything. I don’t want to hurt their feelings. They think they’re doing it right.”

Service user, older person

“I say it’s ok because I don’t want to hurt their feelings.”

Service user, older person

### ***Fearful of consequences***

4.27 Several service users said that the reason they would not speak up about the quality of their care, was for fear of losing the support they currently received. Their view was that it was better to ‘put up’ with what they had, than risk losing it completely. This view was held by people of all ages.

“You’ll find most elderly people are a bit afraid. They don’t want to come across as crabbit and they don’t want to lose what they have.”

Service user, older person

“You need to think of what the consequences might be – they might cut your hours.”

Service user, learning disabilities

“It is difficult to say, because I need their help.”

Service user, young person with learning disabilities

4.28 One young service user participating in this research also said that she believed there would be repercussions if she did speak out about issues relating to her care.

“I need to be careful what I say. If I speak out about staff, the rules will change and they’ll get tighter on me, but if I go along with them, they’ll be laid back. If you take it, and bow down to everything they say, then you’re more likely to get a house sooner.”

Service user, learning disabilities

4.29 Another service user said that she believed if you speak up, your file is ‘marked’ and you are registered as a ‘difficult’ person to deal with. This individual was not put off by this; but said that she knew of people who were afraid to complain about their service, for fear of losing out on services.

“You’re supposed to be docile, but if you speak up, then Social Work will mark you down as having an attitude problem. I’m sure my file is marked with a skull and crossbones. But I speak up. I’m not afraid.”

Service user, physical disabilities

## 5. Impact of Services

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### Introduction

5.1 This chapter reports on the difference that social care services have made to service users and carers. Specifically, we explored the impact care and support made to people's quality of life, and to their social networks. The discussions also explored what the circumstances would be if the service user or carer did not have access to social care services.

### Impact on quality of life for service users

5.2 Overall, this research indicated that some service users felt that they had a good, or improved quality of life, and that this was largely down to social care support packages making this possible.

"I think I have a good quality of life; apart from the pain sometimes, I am out every day."

Service user, young person with physical disabilities

"A lot better, I don't get bullied a lot now. I get treated with respect."

Service user, young person with learning disabilities

5.3 Interestingly, however, one service user reported that her quality of life had actually improved since she decided to stop receiving home care support and instead increased the adaptations in her home. She felt that she had not had a positive experience with the home care staff, and this way had improved her quality of life.

"I didn't have a positive experience with [care organisation] and if I can manage on my own with adaptations from the OT then my quality of life is better without them."

Service user, physical disabilities

5.4 However, in one group of service users, participants felt their care package was based around their most basic needs, and did not take into consideration any aspects that would contribute to a better quality of life.

"It's like they think you're happy to be fed and watered. But it's not a life."

Service user, physical disabilities

### *Positive social networks*

5.5 Many service users reported that their social care services supported them to maintain their social networks, to be out in the community, and to live their lives to the full with social trips and holidays.

"I have social networks. I can maintain them because of my support."

Service user, physical disabilities

“I go on holidays with friends and fishing and a pool leagues and domino league.”  
Service user, physical disabilities

5.6 Others found comfort in meeting other like-minded people with whom they shared experiences. Some found this particularly valuable, as they didn't want to worry family members by discussing difficult issues with them but felt that they could do so with peers or support workers.

“I find it hard to make eye contact. I find it hard to communicate what I'm saying. But here I see people with similar traits and it's been easier to improve 'cos we share experiences.”  
Service user, young person with learning disabilities

“It is pure support because when you are at home, you put a brave face on for your family because they get upset, but in here they understand us.”  
Service user, physical disabilities

5.7 Many young disabled people involved in this research liked going out with their support workers to undertake activities such as shopping, eating out and going to the cinema. Older people and those with physical disabilities also commented on the benefits of home care support, such as having someone to talk to, and the peace of mind that someone would be coming to check on them. For some, this type of support gave people confidence to go on and try other new things.

“I like the fact that something is in place; somebody to come when I need it. The hours that I get, give me some control over my life so I can decide where I want to go. I've never really had that before.”  
Service user, physical disabilities

“It has given me more confidence so that I might think of volunteering next, the next step to getting back to normal.”  
Service user, physical disabilities

5.8 However, some other service users felt that their health prevented them from maximising their social networks, despite having social care support in place.

“Nothing major because of my seizures; that interferes with my social life.”  
Service user, young person with physical disabilities

5.9 Some older participants were frustrated that their deteriorating health meant that they were no longer independent, and they relied on others to help them maintain social networks.

“I hate not being up and about. I can't do things and I'm not independent. I'm dependent on everybody.”  
Service user, older person

- 5.10 One service user commented that he felt very isolated. He had not found any social activities suitable for him. The opportunities he had identified were restricted to an older age group, and as a result, he felt lonely.

“I am isolated. I tried to find a day club, just somewhere I can play dominoes, but there is nowhere. Unless you are over 60, you can’t get in. I get fed up and it drives me nuts looking at four walls.”

Service user, physical disabilities

### ***Increased confidence***

- 5.11 A number of service users stated that having the social care support in place had increased their own confidence and had maintained a degree of independence.

“I used to be, just kind of living, but now I think I have more confidence.”

Service user, physical disabilities

“It has given me more independence, more confidence.”

Service user, learning disabilities

- 5.12 Two groups of service users from different local authority areas praised their particular support service for empowering them to support themselves.

“It has made me feel more confident and grown up, because we are not treated as disabled, but as a person.”

Service user, young person with physical disabilities

“The difference is that the staff don’t do things for you; they enable you to see what you are capable of.”

Service user, physical disabilities

### ***Living and practical skills***

- 5.13 A number of service users, particularly young people, commented on the practical skills their support assisted them with – including developing cooking skills and healthy eating habits, learning about money, benefits and debt, and developing IT and travel skills. For example, one young service user reported that before his social care support plan was in place, he consumed a lot of take-away meals as he was unable to cook for himself. Now his social care plan includes having his meals prepared and this had a positive impact on his health.

“I was eating a lot of take outs and junk food, but with this (prepared meals), they make sure I eat properly.”

Service user, young person with physical disabilities

## ***Ability to remain at home***

5.14 Social care services allowed many service users to remain in their own homes as an alternative to residential care. This allowed service users to maintain some independence and social life, which they perceived as very important.

“I just think it [having home care support] is keeping me out of residential care. It would horrify me if I had to go into residential care. I want to live independently.”  
Service user, physical disabilities

## ***Impact on carers***

5.15 Social care services also impact on the carer’s quality of life. Without social care, several carers reported that they would not be able to cope, or function with the demands placed on them by the service user’s needs.

“The care package allows me to have a ‘normal life’ and it keeps me healthy. Without the support, I would not be able to function.”  
Carer

“It’s massive. I would probably not have got to this point if not for [support organisation].”  
Carer

5.16 Some service users stated that it was not just their own quality of life which improved through social care services, but also that of their parents or carers. Service users commented that their carers were not as stressed, and the service users no longer felt like a ‘burden’.

“My parent’s health is no longer at risk because of having to care for me. I no longer feel like a burden.”  
Service user, physical disabilities

“My mum is not so stressed and I have more independence.”  
Service user, physical disabilities

5.17 Also having a support package in place meant that carers could relax, knowing that the person they cared for was well looked after. However, some carers mentioned that due to concerns about timekeeping and quality of care, it could be difficult to relax completely.

“The [named service] has an effect on families too. They know I’m safe and it takes the weight and pressure off them.”  
Service user, young person with physical disabilities

## ***Respite for families***

5.18 The provision of social care support helped provide families and carers with some respite from the responsibility of caring for them. It has also helped to keep families together, with some carers indicating that the pressure of caring

without support may have broken the family up. Others indicated that without support they would be less healthy, both physically and mentally.

“It gives my husband a two-hour window of respite.”

Service user, physical disabilities

“Without the respite services we receive, we would not be able to cope and would be very unwell as a result of the strain.”

Carer

5.19 Families with a number of children indicated that respite and care meant that parents could spend more time with other children, doing things which they may not be able to do with children with additional support needs.

“Mum gets a rest then, and she is able to do more things with my younger brother.”

Carer, young person

“It would be harder for mum without the respite. And it would be a lot for the family to deal with.

Service user, young person with learning disabilities

5.20 Many carers indicated that care, support and respite were precious, and were what kept them “sane”. A number also saw real benefits for others within their family. For example, one carer saw a real difference in his dad since support had been available, and his caring role was reduced a little. Another felt that without support, his mum would not have been able to keep her job.

“The most impact is on my dad [a carer]. He would have been depressed and drinking but he’s drinking less and putting on weight, which is good.”

Carer

“It’s definitely had a big impact. My mum keeping her job is probably the biggest.”

Carer

### **Circumstances without social care support**

5.21 The discussions explored what circumstances would be like, if the current levels of social care provision were not available. The vast majority stated that their situations would be far worse without the support in place.

“I think I would probably be dead or in some care home. I think I would have existed not lived.”

Service user, physical disabilities

“If they take [named service] away, I would be forgotten.”

Service user, physical disabilities

“If I didn’t have the support, I think I’d be living as an animal. As it is, I’m hanging by a thread.”

Service user, physical disabilities

5.22 Some service users said that without a care package in place, they would likely experience mental health issues, such as depression.

“Depression would set in big time. Not mixing or having the opportunity to mix with like-minded people.”

Service user, physical disabilities

“It makes a big difference. It keeps me calm and settled. If I didn’t have it, I wouldn’t sleep and it would affect my mental health.”

Service user, learning disabilities, ethnic minority participant

5.23 Older people in particular spoke of the likelihood of experiencing loneliness if their social care services were not available – particularly services that encouraged them to leave the house and meet others.

“Loneliness is a terrible thing.”

Service user, older person

“Coming out here is helpful because I get lonely at home.”

Service user, older person, ethnic minority participant

“Without the service, it would have a dramatic effect on him. He wouldn’t have the routine of doing things. There would be a lot of TV watching.”

Carer

5.24 Some carers of older relatives felt that there was an element of reassurance knowing that home care services, for example, would be checking in on their relatives and be a source of company for them.

“Mum says it’s nice to have somebody to break the monotony of the day – without them it would be a nightmare.”

Carer

5.25 If there were no care packages in place, most service users said that they would have to rely on friends and family to help them. Many carers indicated that without support, there would be significant impacts on their wellbeing and mental health.

“I don’t know where I would be. My mum and dad are dead, so there is no family support, so I would have to rely on friends.”

Service user, learning disabilities