
**Commissioning Social Care Services:
Views of people using social care services and their carers**

Audit Scotland

Final Report September 2011

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1. Introduction and Method

Introduction

- 1.1 Audit Scotland is undertaking an audit of the commissioning of social care services in Scotland. As part of this, we - ODS Consulting – were appointed to gather views from people using social care services and their carers in six local authority areas in Scotland. The research was carried out during August and September 2011.
- 1.2 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.

Method

- 1.3 Our research focused on six 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 were:
- Angus
 - Argyll and Bute
 - East Dunbartonshire
 - Fife
 - Glasgow
 - North Lanarkshire.
- 1.4 These were the same local authority areas that were included in earlier research¹ which gathered the views of private and voluntary sector organisations, which were providing social care services commissioned by local authorities.
- 1.5 As a matter of courtesy, Audit Scotland alerted each of the local authorities in whose area research was being undertaken.

¹ Commissioning Social Care Services: Focus Groups with Social Care Service Providers, ODS Consulting, August 2011

- 1.6 We used a range of different methods to gather the views of service users and carers. This was to:
- make sure that a broad range of service users and carers would be able to take part;
 - take account of the relatively short timescales for undertaking the work; and
 - be responsive to issues around accessibility and communication.
- 1.7 We used three main methods to gather views:
- **A questionnaire survey:** There was a separate questionnaire for service users and carers. The questionnaire could be completed on paper and returned using a prepaid Freepost envelope or online (using Survey Monkey). We made particular efforts to make sure that the questionnaire was accessible. We made sure that the language was straightforward and the questions were clear. We tested the questionnaire with a disability organisation to make sure that it was appropriate. We prepared an Easy Read version of the questionnaire with more visual prompts to help people with learning disabilities to complete the survey. And we offered the opportunity for the questionnaire to be completed through a phone call with a member of our staff team.
 - **Discussion groups:** These generally took place at events where service users were already gathered (although in three cases, an organisation arranged a special event for us to hear the views of service users or carers). This made sure that there were no accessibility or support issues and that the venue was one that the service user or carer knew already and was likely to feel comfortable with. We liaised with the organisation running the event to identify an appropriate time and place for us to run the discussion group. We explained that all the information gathered would be treated with confidence and that no one would be pressurised to take part. We made a donation of £40 to each organisation that assisted us in organising a discussion group to acknowledge the time that they had put into arranging our involvement and as a contribution to the venue costs. The format of the discussion groups varied depending on the nature of the group. In most cases, the format was focus group style with a round table discussion. In a few cases it was more appropriate to hold a series of small group or one-to-one discussions. Discussion groups generally lasted about an hour.
 - **Telephone interviews:** We asked in the questionnaire whether the respondent would be prepared to take part in a telephone interview – or through an email conversation. In addition, organisations were asked to identify people who would be prepared to take part in an interview. We telephoned service users and carers who had indicated that they were prepared to take part to arrange a suitable time for the interview to take place. The telephone interviews generally lasted between 20 and 25

minutes. Those participating in telephone discussions received a £15 voucher to acknowledge their time and involvement.

- 1.8 The questionnaires and the discussion guides for the discussion groups and the telephone interviews were agreed with Audit Scotland in advance. The questionnaire and guides are included as annexes.

Questionnaire survey

- 1.9 The service user questionnaire included questions on the following topics:
- the service (or services) received, and which organisation provided these;
 - their level of involvement in planning and choosing services;
 - their satisfaction with the outcomes from involvement;
 - their level of involvement in monitoring and reviewing services;
 - satisfaction with the choices offered about their care;
 - level of influence they felt over the services that they receive; and
 - the quality of the service.
- 1.10 The carers' survey asked for views on the following:
- their level of involvement in planning the services available to service users;
 - their level of involvement in planning the services available to carers;
 - their level of involvement in monitoring and reviewing services;
 - their satisfaction with the outcomes from involvement;
 - their view on the choices offered to the service user and the quality of the service; and
 - satisfaction with the choices available to carers and the quality of support that they receive.
- 1.11 The questionnaire also allowed us to gather general information about the characteristics of the person involved (such as age; gender; ethnicity and disability).
- 1.12 The initial survey was sent to 212 organisations by email. Many of these organisations had taken part in the research with service providers. Others were drawn from other appropriate databases that we had collated for previous research. The organisations were selected to include those working with the key target groups for this research:
- older people;
 - people with physical disabilities;
 - people with learning disabilities; and
 - people with sensory impairments.
- 1.13 The email contained a link to the online version of both the service users' and carers' surveys. These surveys were also attached to the email so that they

could be responded to electronically, or printed off and posted back directly to us (using Freepost).

1.14 We also indicated that we would provide paper copies, along with Freepost envelopes, to organisations if that was more convenient. Several organisations requested copies of the survey including one carers' forum who offered to mail the survey to 150 people on its mailing list. This organisation was supplied with paper copies, Freepost envelopes and stamps.

1.15 In total, we received 77 service user surveys and 63 carer surveys. It should be noted when interpreting the findings that the majority of surveys were received from people living in North Lanarkshire.

Telephone interview

1.16 We identified potential telephone interviewees in two ways:

- the survey asked those respondents who were willing to take part in a telephone interview to provide their contact details; and
- we asked 62 organisations (drawn from the 212 organisations we asked to support the distribution of the questionnaire survey) whether they could identify any service users who might be prepared to take part in a telephone interview.

1.17 We had thought initially that telephone interviews might have been the preferred method for people giving their views. This was because:

- it may be difficult for people to leave their house (meaning that for some, a discussion group would be inappropriate);
- the subjects discussed will be personal – and some people would be put off participating in an open discussion;
- some people may lack confidence to take part in a wider discussion; and
- some people may only be prepared to allocate a short time to the research.

1.18 However, just six service users and nine carers chose to take part in a telephone interview. Two of the service users and the nine carers who undertook telephone interviews were identified by them returning a questionnaire. We considered how to deal with those people who had been involved twice. At first we thought it may be more appropriate to remove their questionnaire information, to avoid double counting. However, there is useful information from the questionnaire about the demographic characteristics of the individual, which would be lost if we removed this. We have therefore decided on balance (given the relatively small numbers involved) to include the relevant information in both the questionnaire and telephone interview sections.

1.19 The telephone interviews explored in more detail the social care service that was being used; whether the respondent felt involved in the decisions about the care provision; and whether there was a chance to influence the services.

Discussion groups

1.20 The 62 organisations that were invited to assist with identifying potential telephone interviewees also received an invitation to assist with organising discussion groups or face to face interviews with the service users or carers that they worked with.

1.21 Initially, we aimed to conduct at least six discussion groups, of which a maximum of two would be with carers and the rest with service users. There would be at least one group in each of the six local authority areas. However, we increased the number of discussion groups for two reasons:

- the initial discussion groups had smaller numbers attending than we had expected; and
- the number of telephone interviews was considerably smaller than we had initially expected.

1.22 We tailored the general discussion guide for particular target audiences. For example, one discussion took place with older people, some of whom suffered from dementia. We took guidance from the organisation involved about how to amend the discussion guide so that it was as simple and effective as possible.

1.23 In total, 17 discussion groups took place – 13 with service users and four with carers. Table 1.1 indicates the distribution of these.

Table 1.1: Areas, types of groups and number of participants		
Local authority	Type of group	No. of participants
Angus	Older people	9
Argyll and Bute	Carers	5
	Older people	10
East Dunbartonshire	Carers	7
	Older people	21
Fife	Older people	4
Glasgow	Mainly learning disabilities	2
	Mainly learning disabilities	2
	Mainly physical disabilities	5
	Older people	9
	Ethnic minority older people	8
	Older people	7
	Ethnic minority older people	10
	Carers	7
North Lanarkshire	Physical disabilities	5
	Learning disabilities	5
	Carers	8
Totals		124

1.24 It should be noted that many of the service users fell into more than one of the categories we were interested in – for example many of the older people also were physically disabled; had a sensory impairment; or had a learning disability.

Profile of participants

1.25 We discussed at our inception meeting with Audit Scotland the appropriate balance between service users and carers for this research. We agreed that more service users should be involved than carers, and agreed a rough 75%:25% split. Our proposal suggested that up to 120 people would be involved in the telephone interviews and discussion groups. This would equate to around 90 service users and 30 carers taking part in either a discussion group or a telephone interview. We also indicated that the questionnaire survey might bring the total number of service users and carers giving their views to around 200 people.

1.26 In fact, we gathered views from:

- **17 focus group discussions:** 13 of these were with service users and four with carers. They involved 96 service users and 28 carers – a total of 124 people.
- **15 telephone interviews:** six of whom were service users and nine of whom were carers.
- **140 completed questionnaires:** 77 from service users and 63 from carers.

1.27 So the total involvement in the research was 279 people, made up of 179 service users and 100 carers.

1.28 Table 1.2 shows a breakdown of participants by local authority, by type of respondent and by method of response:

Table 1.2: Participants by local authority, type of respondent and method							
	Discussion groups		Telephone		Survey		Total
	Service Users	Carers	Service Users	Carers	Service Users	Carers	
Argyll & Bute	10	5	1	1	0	3	20
Angus	9	0	0	0	10	0	19
East Dunbartonshire	21	7	1	1	7	15	45
Fife	3	1	3	3	5	6	17
Glasgow	48	7	1	1	7	21	79
North Lanarkshire	5	8	0	3	40	7	59
Other authority	-	-	-	-	7	6	12
Not specified	-	-	-	-	1	5	28
Total	96	28	6	9	77	63	279

1.29 As a result of the way that organisations and individuals chose to participate, it should be noted that a large number of the focus group participants were in East Dunbartonshire and Glasgow and a high proportion of the survey respondents came from North Lanarkshire.

Type of care

1.30 In the survey, service users and carers were asked to indicate the type of service they, or the person they care for, receives. Most respondents (39 service users and 36 carers) indicated that the care was in their own home. Table 1.3 indicates the social care services that those responding to the survey received. Respondents were able to give multiple responses – to take account of the fact that some used more than one care service.

Table 1.3: Q: What kind of social care services does the person you care for receive?				
	Service users (n=62)		Carers (n=57)	
Care in a centre	21	34%	16	25%
Care in your own home	39*	63%	36	57%
Living in a care home	2	3%	7	11%
Housing support	18	29%	7	11%
Respite or short term care	9	15%	16	25%

*This may include people living in supported accommodation

1.31 In the discussion groups and telephone interviews with service users and carers we asked them to indicate the type of service they, or the person they care for, received. A number of people received two types of service. Because the discussion groups were organised at venues where people were already meeting, there is a relatively high number of people who received care in a centre, as shown in Table 1.4. In addition, given that it was not possible to give an accurate detailed definition of the different services, there may be some

minor inconsistencies in the way people responded – for example, some people receiving housing support may have described this as care in their own home.

Table 1.4: Q: What kind of social care services does the person you care for receive?				
	Service users (n=102)		Carers (n=37)	
Care in a centre	71	70%	15	41%
Care in your own home	47	46%	14	38%
Living in a care home	0	0	8	22%
Supported accommodation	11	11%	2	5%
Housing support	1	1%	0	0
Respite or short term care	2	2%	2	5%

1.32 The type of care in which service users' views are least represented is living in a care home. Only two service users' views were gathered – although 15 carers of people living in a care home gave their views. It proved difficult to arrange to hold discussion groups in care homes, because it was felt by the care homes that relatives should give agreement. In one case, where an approach to speak to residents in a care home had been agreed, one of the residents died and the funeral was the day planned for our discussion. Naturally, we decided not to proceed in these circumstances.

Service users with access to their own budget

1.33 Twenty-one of the 102 service users that we spoke to in the discussion groups and the telephone interviews had control over some, or all, of the budget for their care. In addition, seven out of the 37 carers were caring for people with control over some, or all, of their budget. This represented about 20% of all those we spoke to. There was a variety of ways that people had control – including Direct Payments (five service users and three carers); Self Directed Support; the Independent Living Fund; and personalisation budgets (which were used in one authority).

Ethnicity

1.34 Additional demographic information was sought through the survey. For example, the participants in this research were asked to indicate their ethnic origin. None of the survey respondents indicated they were from an ethnic minority background.

Table 1.5: Q: Ethnic origin		
	Service Users (n=72)	Carers (n=56)
White Scottish	75%	63%
White UK	25%	37%

1.35 We organised two discussion groups specifically with older ethnic minority people and this allowed us to gather the views of 18 ethnic minority people (10

men and 8 women). None of the telephone interviewees were from an ethnic minority background.

Disability among carers

1.36 In the survey, we asked carers whether they were disabled – and about a fifth (21 per cent) of the carers in our survey had a disability.

Table 1.6: Q: Do you have a disability?	
	Carers (n=61)
Yes	21%
No	79%

1.37 Two of the carers out of the nine (22%) that we spoke to by telephone indicated that they had a disability.

Age and gender

1.38 The survey asked both service users and carers to indicate their age. We have grouped the responses into age bands and the results are shown in the table below. Nearly half (45%) of service users were aged 65 years and over. The majority of carers (65%) were aged between 46 and 64 years old.

Table 1.7: Q: How old are you?		
Age group	Service Users (n=76)	Carers (n=57)
Under 16	0%	0%
16-25	4%	0%
26-45	23%	5%
46-64	29%	65%
65-74	21%	11%
Over 75	24%	19%

1.39 The majority of respondents to the survey were female. Over half (59 per cent) of the service users responding to the survey were female and over three quarters (78 per cent) of the carers were female.

Table 1.8: Q: Are you ?		
Gender	Service Users (n=76)	Carers (n=58)
Male	41%	22%
Female	59%	78%

1.40 We spoke to 66 women (47%) and 73 men (53%) in total through the discussion groups and telephone interviews. We organised one group with older ethnic minority women (8 people) and one with older ethnic minority men (10 people). The people from ethnic minorities that we spoke to all received day care services and a small number received home care services. The points made by people at these groups were very similar to the points made by other older people using day care services. No-one referred to any concerns

about a lack of cultural awareness by the service provider or that the service was not culturally sensitive.

General notes

- 1.41 The following chapters present the findings from the consultations. Verbatim quotes are included to illustrate key points and are tagged as appropriate for context, including the type of care and the local authority area.
- 1.42 Throughout this research different people used different terms to describe their disabilities. We have used the term “learning disability” to describe a range of learning disabilities and learning difficulties, although the individuals involved in this research may not have described themselves as having a “learning disability”.
- 1.43 We have drawn our information from two major sources – the questionnaire **survey** and **discussions** with people (either at discussion groups or telephone interviews). We have gathered the views of both **service users** and **carers** using both these methods. We think that it is important to be clear about the source of the views and whether these are from service users or carers. For this reason, throughout Sections 2 and 3 we have clarified in the margin throughout whether we are reporting on the views of service users or carers – or both. In addition, each time we move from describing the survey findings to the findings from the discussions, we indicate this in the margin. We have used the following symbols:

Service User



Carer



Discussion



Survey



2. Choosing Services

Introduction

2.1 This chapter explores how service users and carers felt about their involvement in choosing the social care services that they receive. It is based on our findings from gathering the views of service users and carers through surveys (by questionnaire) and discussions (through email discussions; telephone discussions; and, mainly, discussion groups). It considers:

- involvement in deciding what care is provided;
- the level of care provided;
- which organisation provides the care; and
- views on information and advice about choosing social care services.

Views on existing services

2.2 Our **survey** of service users found that almost two thirds felt that they definitely received all of the social care services they needed. Another third felt that they mostly received the services they needed. Only a very small proportion felt that they did not get the social care services they needed.



Table 2.1: Q: Just now, do you think you get all of the social care services you need?	
	Service Users (n=74)
Definitely	60%
Mostly	34%
Not really	5%
Not at all	1%

2.3 Our **discussions** also highlighted that most people were broadly happy with the type of support that they received.






2.4 People who received day care support generally felt that this type of support was appropriate and useful. People generally valued the opportunity to get out of the house, and to socialise with others. Some people were initially not keen on the idea of day care, but had grown to like it. For example, one individual was initially “utterly aghast” at the idea of going to a day care centre. However, he was able to visit the centre and staff and participants were encouraging – and now he enjoys attending.





2.5 However, a minority attended day care only because “there was nowhere else to go”. Few were told of any other options, such as other social groups or activities in the area. Indeed, some found it very difficult to find out about the social activities happening locally.



- 2.6 People receiving home care services felt that they wished to remain in their own homes, and that this was the type of support they required. In some cases, carers highlighted that individuals could initially be “too proud for services”, or may not want strangers in their home. However, carers and individuals often negotiated a type of support which met the needs of both. 

- 2.7 Some – particularly a small number of adults with learning disabilities who had lived in institutions – felt that they were discouraged from living independently with the support of home care. Some felt that this was due to the perceptions of support staff. Others felt that family members sometimes doubted their ability to live independently, and could constrain the choices they made. 

“People in institutions think you can’t spend 10 minutes in your own house, but I have shown them”
(Adult with learning disability, home care, Glasgow)

- 2.8 Service users living in supported accommodation generally felt that this was the right option for them. Carers of people in care homes also generally felt that this was the right option now for the person they cared for. However, a minority of carers felt that there was limited choice due to the local authority having a single provider of home care (which they believed did not provide a good service) which led them to make an early decision about the use of a care home. 


“In Glasgow you have a basic choice – (the home care provider) or a care home.”
(Carer of older person, Glasgow)

Deciding what care is provided


- 2.9 The **survey** identified that, although people largely felt that they received the services they needed, fewer felt involved in the decisions about which services they needed. Less than half of both service users and carers felt that they were definitely involved, with around a third feeling that they were mostly involved. Overall, about a fifth of service users and over a quarter of carers felt that they were not really or not at all involved. 

Table 2.2: Q: Did you feel involved in deciding which social care services you (or the person you care for) need?

	Service Users (n=72)	Carers (n=62)
Definitely	44%	45%
Mostly	36%	27%
Not really	14%	24%
Not at all	6%	3%

2.10 From the **discussions** we learned that people had heard about the services that they used in a range of different ways:

- through word of mouth from friends and family;
- through an invitation to attend – for day care activities;
- through a referral – from a doctor or social worker;
- through a voluntary or charitable organisation; or
- through a process of assessment for social care services.



2.11 The way in which these systems worked was different in each area, and for each type of service. In some cases, service users felt that support and referrals from doctors and social work were excellent and encouraged people to access services – often day care. In other cases, people found that it was very difficult to get any information or advice on the range of support which may be available. Carers said that in many cases they had to do a lot of research themselves to secure the right support for the people they care for.



“It’s like social work is top secret, I don’t understand what help is around and you have to fight for services. There is no central point.”

(Carer of adult with brain injury, Argyll and Bute)

“The social worker didn’t have a clue about which company to use. And neither did I”

(Adult with physical disability, home care, Glasgow)

“I am not sure about what help you can get. Unless you ask the right questions to the right person, you won’t be told”.

(Carer of older person, East Dunbartonshire)

2.12 Many highlighted that in order to access social care services people often have to contact lots of different people, rather than contacting one central point. Many felt that local organisations – including day care centres and voluntary organisations - were an extremely valuable source of support both for people using services, and their carers. Many felt that the information and advice provided by local organisations helped them to make informed choices about their future.



“They tell you about things and resolve issues. Like problems with home care”.

(Carer of older person, home care and day care, North Lanarkshire)

Choosing the organisation that provides the service

2.13 Our **survey** of service users found that less than half of service users definitely felt involved in deciding which organisation would provide their care, and almost a third felt ‘mostly’ involved. However, almost a third said that they were not really or not at all involved.



Table 2.3: Q: Did you feel involved in deciding which organisation would provide social care services?

	Service Users (n=69)
Definitely	42%
Mostly	29%
Not really	20%
Not at all	9%

- 2.14 Our **discussions** found that some people were closely involved in choosing the organisation(s) that provided their social care services. Those who received direct payments or could control their own social care budgets had the most involvement in this decision. This largely applied to home care services. Individuals could select which organisation they wished to provide services. Many felt that this created a different relationship with staff, as they were clearly the employer and decision maker.



“I wouldn’t join an organisation that wouldn’t do the job. I have had enough of people who said they would support me my way, but then did it their own way”.
(Adult with learning disability, home care, Glasgow)

- 2.15 Service users with control over their budget and which organisation provided their care had often made the choice to change organisation or staff if they were not happy with the service provided. For example:



- One service user was supported by 35 different carers in just five months. This was raised at a review meeting with social work and he decided to move to a new provider.
- One service user felt that the staff providing his home care service were very nice but were not well trained. He was considering changing to a smaller organisation for consistency of staff.

One carer found that the company she contracted to provide home care were expensive, provided a poor quality service and didn’t listen. Working with the person receiving care, they decided to switch to another company who were very good and provided a much better service. This was easy to do under the direct payments system, as money could be used in any way they chose.

- 2.16 For people using home care services without receiving direct payments or a personal budget, the situation was quite different. Many felt that they had no choice in the organisation providing services. Generally the support was organised by the local authority, and individuals were not involved in selecting the organisation providing the service.



- 2.17 Despite not having been offered a choice, some people were satisfied with the support they received. Several people said that they may have been able to look at alternatives – but they hadn't felt the need to explore this.



"I don't feel I have control over what I get . . . but I can't think of any decisions made about me which I was unhappy about"

(Adult with disabilities, home care, Glasgow)

- 2.18 In some cases, people had stopped using home care services which were unsatisfactory, and had chosen instead to receive no support rather than using an inferior service. This was impacting on the level of support required from their carers.



- 2.19 Some found it difficult to tell which organisation the staff visiting their home worked for. This particularly applied to older people getting home care services. In two cases this was related to memory issues, and people said that they knew the name of the organisation was written down somewhere for them. In two other cases, people found it difficult to determine whether it was the local authority or a private company which employed the staff. Most people remembered the names of their individual staff members, rather than the organisation.



- 2.20 People attending day care services generally felt that there was a reasonable degree of choice over which organisation provided their services. This was particularly evident in large urban areas, where there was a high volume of services. A number mentioned that they had attended different centres and felt confident that they could swap to another centre if they did not like the one they attended. Some people attended different centres on different days, to get a range of activities.



- 2.21 People who could get to day care centres themselves had a higher degree of choice. People who relied on transport services to attend day care often felt that they had less choice, as it depended on what transport services were available and the area that they covered.



"If they came and got me five days a week I would be happy to come".

(Older person, day care, Glasgow)

- 2.22 However, a small number of service users felt that the range of day care services available was very limited – with little to no coverage in some areas. This influenced the degree of choice individuals had over which organisation provided services.



- 2.23 Generally people felt that they had a high degree of choice over which supported accommodation or care home provider to use. Most had chosen supported accommodation due to recommendations from family or friends. Generally carers were very involved in choosing care homes. Most felt that they had a high degree of choice, but were not always sure how to go about choosing a suitable home.



Choosing services

One carer found it very difficult to choose a suitable care home for his wife. He found that there was no advice on which care home would be most suitable. They visited one care home which only dealt with one particular condition, but they didn't realise that until they were there. He felt that this was "new territory" for most people and you just have to hope that the home you choose will be suitable. His wife has since had to change care homes, to a more appropriate home.

One carer did a lot of research into the best services for her daughter who has learning disabilities and severe autism. She did not get any help with this. She found the best service was outside her local authority area. Initially the local authority "did not like the price" but a new assessment of her daughter's needs showed that this was the best service for her. She said "they are not thinking about outcomes – just their bottom line".

Deciding the level of care provided

- 2.24 Overall, most service users who took part in the **discussions** were broadly happy with the amount of support that they received.
- 2.25 People receiving day care services appeared broadly very happy with the level of support provided. Most felt that they were able to attend as much as they wanted to, and that they could easily speak to someone if they wanted to attend more often. Often social work or doctors made a suggestion about how often someone should attend, and individuals agreed with this. Often people gave examples of how they had organised to have an extra day if they felt they needed it, or reduced their time at the centre. Decisions were made based on the range of other social opportunities that older people had – including family commitments, volunteering and other activities.
- 2.26 People in supported accommodation and care homes were also broadly happy. Some service users felt that they would prefer to have a 24 hour support warden in their accommodation, rather than emergency cords in the evenings and at weekends. However, they were content with the rest of the support and were not keen to move.



2.27 Some carers felt that support in care homes was understaffed, particularly at transition times during the day and evening. Relatives of residents in one care home had particular concerns about the staffing levels, and had raised this with care home staff. They had been told that the home met the minimum Care Commission (now Social Care and Social Work Inspection Scotland) standards and would not be changing its staffing levels.



2.28 People receiving home care services had very varied views on the level of support received. Some were happy with the involvement they had in this. But many felt that they were not involved in deciding what level of support was required.



“You are just told you will have 10 minutes each day.”
(Adult with physical disability, home care, Glasgow)

2.29 Key issues raised by both service users and carers included:

- Families, friends, neighbours and carers being relied upon to provide support to supplement home care, resulting in major pressures in terms of time and responsibility.
- The amount of time allocated to tasks was often very tight. Many received only 10 minutes of support, which many found was too short to be able to provide the support required.
- The time of day when support is provided is often not based on individual needs.
- Many felt that they had to “push and fight” to get the level of support needed.
- Often support was inflexible and there were certain tasks which staff were not able to undertake.



“[With home care] you get what you are given.”
(Carer of older person, home care and day care, North Lanarkshire)

“There isn’t much you can do in 10 minutes.”
(Older person, day care and home care, Glasgow)

“They were in for half an hour and back out.”
(Adult with physical disabilities, home care, Glasgow)

2.30 Some carers felt that when individuals had negative experiences of home care – with support not being provided as required – this could have a negative long term impact on vulnerable people. Some felt that this could increase caring responsibilities, due to concerns that support would not be provided in a suitable manner or at the correct time. Others highlighted that negative experiences could mean that people stop using services, with no alternative support in place.



- 2.31 Some service users had managed to secure additional support to meet their needs more effectively. Sometimes people were able to influence this through review meetings, or by approaching the council for additional support or an assessment. Others felt that they would like more support, but understood that they had to make choices about how resources were used. For example, one service user would have liked her care worker to come both in the evening and during the day. However, based on the available resources, she has chosen to have support during the day, as this is what she prefers.



- 2.32 Only one service user involved in this research felt that he had too much home care support, and that this was “disenabling” him. This service user had been involved in discussions about the level of support alongside his family. He felt that sometimes people listened to his family more than him, and they had different ideas of what he needed. However, he has managed to express his views and now has slightly less support in place and is happy with this.



“I probably could be completely independent”
(Young adult with learning disability, home care, Glasgow)

- 2.33 Overall, carers appeared to have a more negative view of the level of home care support provided than service users. Many service users were content with the level provided. However, many carers felt strongly that the person they cared for did not receive enough support and did not have any choice in the matter.



“You are given what people decide you should be given.”
(Carer of young adult, East Dunbartonshire)

“We were told what we could get.”
(Carer of older person, East Dunbartonshire)

Threats to support level

- 2.34 **In discussions** six service users and two carers specifically mentioned that they felt the level of support provided was under threat, due to public sector cuts. In two cases people had already seen their support reduce. There was some suspicion of review meetings and assessments, which some felt were intended to demonstrate that the level of support received could be reduced. Others were worried that the amount of support they received was likely to be reduced in the near future.



“The council is cutting people with learning disabilities off at the moment. They are having to make cutbacks, but they all seem to be for people with learning disabilities. Why not close down a library?”
(Adult with learning disability, home care, Glasgow)

“Going through a financial reassessment has been scary and stressful. We know she could have her support cut”
(Carer of adult with learning disability, North Lanarkshire)

- 2.35 In some cases, service users had experienced reductions in the level of home care provided over time. Many felt that this was related to their needs, and felt that this was reasonable. A small number felt that the cut back was not related to their needs and that it has had a negative impact.



“The Council is a bit strapped. We’ve had to cut my support and the amount of hours of care I receive. It has made things harder. And it is disappointing.”
(Adult with physical disabilities, home care, East Dunbartonshire)

- 2.36 Often carers were being relied upon to provide more support as a result. Some people found it reassuring to have a number they could call in emergencies when support reduced.



Carer involvement in choosing services

- 2.37 **In discussions**, carers tended to have a lot to say about the process of choosing social care services. Some carers felt that they encouraged the person they cared for to access services. Often carers said that this was for the benefit of the person they cared for – to encourage social interaction, to keep people’s minds active and to encourage people to get out of the house. However, some carers felt that often the carer needed the individual to accept support, to reduce pressure and strain on their caring responsibilities. For example:



- Some carers encouraged the person they cared for to go to day care or use respite care, so that they could have a short break from caring.
- Some carers encouraged the person they cared for to access home care support, to allow the carer to work or undertake other responsibilities.
- Some carers worked with the person they cared for to consider moving into a care home, as home care support became unsustainable. By this stage, many carers were visiting the individual three or four times a day, on top of home care support. This type of decision was often very difficult for carers.

“It is hard to look after a parent. It is a hard situation for everyone...You need to find new relationships.”
(Carer of older person, Argyll and Bute)

- 2.38 Many service users felt that their family or carers helped them to communicate and put their own ideas across. However, some felt that their carers encouraged them to make certain decisions about their social care services, which they would not have taken otherwise.



“I would like not to go to the other day care centre, because I don’t like it on a Saturday. But my son makes me go. It suits him for me to be out on a Saturday, because he can’t be there 24 hours a day.”

(Older person, day care, East Dunbartonshire)

- 2.39 Some carers felt that they were not sure how much they should try to influence the decisions the person they cared for made. Carers generally wanted service users to be able to communicate and speak for themselves. However, sometimes carers were concerned that others took what service users said at face value – when people who knew them well felt that this was not what the person actually meant.



“If they say ‘I don’t want that’ to the social worker, then they won’t get the help – even when they need it”

(Carer of older person, home care and day care, North Lanarkshire)

- 2.40 Carers emphasised that the way in which people were involved and asked for their opinion really made a difference. Many felt that it was important that others did not assume that the person being cared for understands the questions being put to them, and can give an informed answer. Sometimes the words people use are not easy for people to understand, and carers emphasised the importance of using simple language.



- 2.41 Some carers were unsure what level of independence they should work towards, and when carers should intervene. Where carers had a formal status – such as Power of Attorney – this was generally easier to understand for all concerned. However, others talked of not being sure about the boundary.



“I don’t want to step on mum’s toes”.

(Carer of older person, care home, Glasgow)

Support for carers

- 2.42 Our survey of carers asked for their views on the choice and control that they have over the services provided for carers. We found that over three quarters of carers were happy with the support available to them.



Table 2.4: Q: Are you happy with the support you receive as a carer?	
	Carers (n=60)
Definitely	37%
Mostly	42%
Not really	13%
Not at all	8%

- 2.43 Two thirds of carers felt mostly or fully involved in deciding what support they received, but a third did not really feel involved in these decisions.



Table 2.5: Q: Did you feel involved in deciding what support is available for carers?	
	Carers (n=61)
Definitely	25%
Mostly	41%
Not really	23%
Not at all	11%

- 2.44 In addition, our survey found that two thirds of carers felt that they had the chance to tell people what they thought of the services available to them, but a third did not.



- 2.45 However, **discussions**, we found that many carers had not been offered support or were not sure what support might be available. Most carers who accessed support relied strongly on voluntary organisations or support groups for their support. Opportunities for carers to come together to share experiences were highly valued by carers. Often carers attended support groups when at crisis point. Many had known about these opportunities for a while, but it often took a major problem for them to take the step to access support.



- 2.46 Carers also valued opportunities to talk about their own feelings and experiences, not only those of the person they cared for. Many felt that there was a bond between carers, as people fully understand exactly what their situation is like.



“[A local carers’ organisation] is great. People will phone on your behalf, and will regularly check how you are.”

(Carer of older person, home care, East Dunbartonshire)

“Everyone helps out, but their energies are based on [the person I care for].”

(Carer of older person, care home, Glasgow)

- 2.47 Several carers also said they received valuable information and advice from services which supported the people they care for.



Overall


- 2.48 Overall, our **survey** found that over a third of service users felt that they had a lot of choice over the social care services they received, and just less than a third felt that they had some. Carers generally felt that service users had slightly less choice, with less than a third thinking the person they cared for had lots of choice about the services they received. 

Table 2.6: Q: Overall, how much choice do you think you (or the person you care for) have about the social care services you receive?

	Service Users (n=68)	Carers (n=62)
Lots	38%	29%
Some	32%	34%
A little	21%	29%
None	9%	8%



- 2.49 Our survey also asked service users how much choice they felt that they should have in relation to their social care services. 

Table 2.7: Q: Overall, how much choice do you think you should have about the social care services you receive?

	Service Users (n=69)
Lots	68%
Some	25%
A little	4%
None	3%

- 2.50 Over two thirds of service users felt that they should have lots of choice, and quarter felt that they should have some. Interestingly, a small proportion – 7% – felt that they should have little or no choice. 

3. Influencing Service Delivery

Introduction

- 3.1 This chapter explores service user and carer views about the extent to which they can influence the way in which social care services are provided. This includes influencing the timing of service delivery, the staff team providing the service, and the quality of service provision.

Opportunities to influence service delivery


- 3.2 Most service users responding to the **survey** were happy with the social care services they received. Overall, 96% were definitely or mostly happy. However, carers were considerably less happy with the services that the person they cared for received. Almost a fifth of carers were not really or not at all happy. 

Table 3.1: Q: Are you happy with the social care services you (or the person you care for) receive?

	Service Users (n=72)	Carers (n=62)
Definitely	60%	37%
Mostly	36%	45%
Not really	4%	13%
Not at all	-	5%



- 3.3 Less than half of all service users felt that they definitely had the chance to tell people what they thought of service provision. Almost a fifth of service users and a quarter of carers felt that they did not get the chance to tell people what they thought. 


Table 3.2: Q: Do you get the chance to tell people what you think of the services you (or the person you care for) receive ?

	Service Users (n=70)	Carers (n=61)
Definitely	47%	36%
Mostly	36%	39%
Not really	10%	15%
Not at all	7%	10%



- 3.4 The survey demonstrated that even when people felt that they had the chance to give feedback, they did not always feel that this was taken into account. Only a quarter of service users and a fifth of carers felt that their views definitely influenced the way services were delivered. Almost a third of service users and half of all carers felt that services did not really change based on their views. 


Table 3.3: Q: Do you feel that services change based on what you say?

	Service Users (n=67)	Carers (n=58)
Definitely	25%	21%
Mostly	45%	28%
Not really	24%	34%
Not at all	6%	17%

3.5 Our **discussions** with service users and carers demonstrated that the extent to which people felt they could influence the way in which services were delivered varied greatly, depending on:



- the organisation providing services;
- the type of service;
- whether they received direct payments (and other forms of self directed support) or not; and
- in some cases, the individuals delivering the service.

Influencing day care services

3.6 People attending day care services overwhelmingly felt that they could influence the activities and services provided at the day care centre itself, if desired. People influenced the types of activities that the day care service provided. For example, in one day care centre a small group of older people asked, over a period of time, for a quiet space away from the music and dominos in the main room. When a new room became available, the manager put some comfortable seats and a table in the room to create this quiet space. Participants were happy that they had been listened to, and felt that this was a “good idea”.



3.7 Broadly, people attending day care were very happy with the services provided. People praised the activities, the social interaction and the support of volunteers at day care centres – which were generally seen as “wonderful”. A number of the day care centres regularly gathered feedback from service users, to influence future service provision.



“They help you with anything – you name it and they’ll help you.”
(Older person, day care, Glasgow)

“This is my second home... We can talk to each other and share with each other.”
(Older person, day care, Glasgow)

3.8 However, there was little evidence of service users being involved in more strategic decisions about delivery of day care services across the local authority area. For example, in one area, the catchment areas for day care centres were in the process of being re-drawn. People attending day care in that area were concerned about the



implications, and whether they would need to go to a different day care centre. However, none of the people involved in this research had been consulted on which area they wished to attend. In another area, cuts to funding had reduced the number of classes and activities on offer. Individuals who took part in this research had not been consulted on these changes.

Influencing supported accommodation and care homes

- 3.9 Older people living in supported accommodation also felt that they had opportunities for feedback and discussion on the service they received. Residents often had had regular weekly meetings with staff to discuss service provision. Most people were very positive about this arrangement, and felt that staff would “help with anything”. However, some felt that nothing changed as a result of these meetings and that they did not have much influence over service provision.



“The warden is great. You just need to mention something and she is there.”
(Older person, supported accommodation and day care, East Dunbartonshire)

- 3.10 Carers of people living in care homes felt that it could often be challenging for residents to communicate their views, due to communication issues, which made it hard for them to influence care directly. Carers often tried to influence care provision in care homes, including:



- quality of care – challenging poor working practices;
- staffing – including staffing levels and continuity of staff team;
- diet and laundry arrangements; and
- activity and entertainment plans.

- 3.11 However, carers were unsure of the influence that they had. For example, one carer mentioned that she had complained about two staff members, and the use of bank staff at the home. The practice of using bank staff had then ceased, and the staff members had “disappeared”. However, she did not get feedback on what had happened and why this change had occurred.



- 3.12 Carers with relatives in one care home felt that while the quality of care was generally good, complaints were often met by the answer that the home met the minimum care standards set by the Care Commission. They felt that these standards should increase. Due to the effort it took to raise issues, carers felt that it was important to “choose your battles”.



“I’m not 100% happy, but I influence the more important things. And nowhere is perfect.”

(Carer of older person, care home, Glasgow)

- 3.13 Carers were also conscious that they did not want to annoy staff at the care home, as this may impact on the quality of service their relative received.



“We are involved to a certain extent. We go part of the way. But our relatives have to live here, so you don’t want to ruffle too many feathers.”

(Carer of older person, care home, Glasgow)

Influencing home care services

- 3.14 People using home care services had very different experiences of the extent to which they were able to influence the services provided. People who received direct payments, had personal budgets or were able to influence how their social care funding was spent generally felt that they had more influence over the services they received.



- 3.15 However, overall where organisations had an ethos of choice and control, service users and carers tended to feel much more involved in decisions about service provision. For example, service users with learning difficulties supported by one organisation commissioned by the local authority strongly felt that they controlled the services they received. Individuals had a good relationship with staff and the organisation’s management team, and had access to advocacy support which helped them to speak up if they wanted to. They also planned exactly how they would use the money that they had been allocated for support, meaning that they could decide how they wanted services to be provided.



- 3.16 Some service users and carers were very happy with the home care services they received, and felt that they could influence service provision.



“She would do anything else if asked.”

(Older person, day care and home care, Angus)

“I feel I have lots of control over [the organisation]. I deal with the carers directly, and organise plans on a monthly basis. I was also involved in interviews for staff.”

(Carer of young adult, East Dunbartonshire)

“Social services were very good, you could flex the time. You can relax if you can have someone at home.”

(Carer of older person, Argyll and Bute)

3.17 However, others felt that they could not influence their home care services. Key issues with home care services included:

- a lack of flexibility in the timing of visits;
- irregularity and lack of consistency in timing;
- a lack of time during visits;
- lack of flexibility of staff and what they do;
- lack of continuity of staff team; and
- rarely being asked for feedback on service provision.



Influencing home care - timing of home care visits

3.18 The issues around timing of home care visits came up numerous times in discussion with both service users and carers. This was a particular issue for services commissioned by or provided by the council – rather than those organised by individuals through self directed support.



3.19 Firstly, there was concern that timings for visits were rigid, and could not be changed. For example, many would have preferred to get up earlier, and go to bed later. However, their daily routine had to fit with the times that home care staff were able to come in to their home.



“At night they come in at 8.40pm, but I would prefer 9pm. In the morning they are sometimes late. I mentioned it to them, and it went well for a wee while. But they are short of male carers”.

(Older person, day care and home care, East Dunbartonshire)

3.20 In some cases, family carers came to be with people later in the evening, so that they could go to bed at a more appropriate time.

“I went to sit with her until 10pm and it was a reasonable time to go to bed.”

(Carer of older person, home care then care home, Glasgow)

3.21 In many cases service users and carers had indicated that they would prefer support at a different time, but had been told this would not be possible. For example, one carer required support for a young adult early in the morning, but was told support was not available before 8am.



“Timing is the main problem. Some times aren’t suitable. It isn’t very flexible.”

(Adult with physical disabilities, home care, Fife)

- 3.22 There was also some concern from both service users and carers about the lack of consistency in the timing of visits. Often timing could be very variable, which impacted on people's ability to plan their day. It was also a particular worry for people who required support at a regular time – for example to take medicine, empty a catheter, get up, go to bed or eat meals. Sometimes people were given quite a wide slot of time when they needed to be in to wait for home care staff to visit.



“The service is not the best you can't depend on them. They come any time from 7.50 to 11.30 in the morning. I have phoned them often to complain, but sometimes people don't turn up.”

(Older person, day care and home care, East Dunbartonshire)

“It was a panic coming here this morning. The bus leaves at 9.45am, and it is hard to get us both ready.”

(Older person, day care and home care, East Dunbartonshire)

- 3.23 This inconsistency caused wider problems. For example one carer felt that a person lost weight because of the times that her meals were arriving, and another individual with dementia got up in the middle of the night because of being put to bed so early.



“She wasn't eating enough. But they brought lunch at 2pm then dinner at 4pm. They wondered why she only wanted a biscuit at teatime.”

(Carer of older person, home care, North Lanarkshire)

- 3.24 Overall, many people using services commissioned or provided by local authorities felt that the services were often timed to fit with staff needs, rather than those of the service user.



“The carer asks to change days based on her own needs, not mine. I get texts asking if she can change the time too.”

(Carer of young adult, East Dunbartonshire)

- 3.25 Some service users and carers felt that home care staff could be inflexible in the support that they provided. In some cases, people said that staff did additional small tasks because they needed done – even though they weren’t supposed to. In other cases people said staff were limited by what they had been told they could do – rather than what the individual required. One service user said his carer refused to do household chores – even though this was on his care plan.
- 3.26 In general, service users were keen to point out that the individual staff members were excellent. But many felt that wider administrative systems meant that staff were not able to provide the quality of care that they should be providing.

Influencing home care - continuity of staff team

- 3.27 There were also concerns from both service users and carers about continuity of staffing for home care services. Again, this was a particular issue within services directly provided or commissioned by the local authority. This was also sometimes (although less often) an issue for people who had chosen their own provider. For many, routine and consistency was important. Some service users were concerned that staff teams changed quickly, and there was little warning of when new staff would be involved.

“Sometimes you are told staff will change. Other times a new person just turns up”
(Adult with physical disability, home care, Fife)

- 3.28 Carers were particularly concerned as they often wanted to make sure that staff were properly trained on the individual’s requirements, and that staff got to know the individual properly. Some carers had concerns that because of changing staff teams, home care staff were not always properly trained to undertake the tasks that were required of them. One carer highlighted that receiving personal care can feel vulnerable – so having lots of different staff working with one individual can be difficult.
- 3.29 While service users and carers highlighted the importance of consistency, most did not feel that this was taken into account.

“You need one company with a core team that understands your needs.”
(Carer of older person, Argyll and Bute)

One carer found that the transition from one council provided service to a council commissioned service resulted in upheaval and lack of continuity. Her husband received an initial period of intensive support when leaving hospital, with this support provided by the council service. After a few weeks, he was transferred to a less intensive service, provided by a different organisation. They feel this resulted in a poorer quality of service and a range of different staff providing the service. Her husband received both home care and day care services. The carer said:

“[The council service] was great – they came in and out at the right time. But now, he (*my husband*) has been out of the hospital for longer and apparently the system changes. We have been changed to [a private council commissioned service]. Now I don’t know who is coming, and they come very late – like at half 10.”

Influencing services through direct payments or self directed support

- 3.30 When people received direct payments or had personalised budgets, there was a strong sense that they were in control. They paid the staff, and many talked of being the boss and the employer. Often this related to home care services.



“I do the telling – in my house, I’m the boss. I’m paying for it, so they can leave the attitude at the door.”

(Older person, home care, Glasgow)

- 3.31 People who received direct payments or personalised budgets mentioned a number of things which made them feel more in control of how services were provided to them:



- Some organisations had an interview stage where people receiving services could interview potential staff, and match up clients with appropriate support staff. People were positive about “getting a choice about who to pick”, although some found this a new and slightly challenging experience.
- Some organisations and individuals who employed staff directly had probation periods for staff, or new staff involved in shadow shifts so that people could see what the staff were like without committing to using them.
- Many talked of regular review meetings, at which they planned how services would be provided – including when and by whom. This was seen as a valuable opportunity to decide the type of support provided, and people said that they felt able to speak up if they wanted to change something.
- Many developed diaries of activities, setting out what people wanted to do each week and what support was required. Others spoke of receiving rotas and other information in advance which helped them be clear about who was coming, when.

- There was a strong sense that people could speak up if something needed to be changed. Individuals who had chosen their own provider spoke of having a good relationship with the manager. This meant they could pick up the phone if they weren't happy, and issues were resolved.
- Some people managed their direct payments on their own, employing staff directly. Others had the support of an organisation. In both cases, people felt that they could change the services provided as they needed.
- For many people who chose their own provider there was a strong sense that they could change the times and activities to suit them. People spoke of using their time flexibly – getting help with chores one day, then going out the next.

“If I was left on my own (to decide how to spend budget) I wouldn't know what to do.”
(Adult with learning difficulty, home care, Glasgow)

“They think I'm a good boss to them. She comes in and says, 'What do you want to do boss?'”
(Adult with learning difficulties, home care, Glasgow)

“It is great. It is in my time, when I need her. Nothing is too much bother.”
(Adult with physical disabilities, home care, Glasgow)

3.32 Overall, this meant that people felt that they were in control of how services were provided. People who received a mixture of home care commissioned directly by their local authority and home care they had chosen themselves (funded by direct payments, a personalised budget or Independent Living Fund) were very clear that the choice, control and flexibility were significantly greater for the services they had chosen themselves. Most people receiving direct payment strongly felt that they could change the staff or organisation providing the service if they needed to.



3.33 This feeling was powerful, and could take time to adjust to for some people. For example, one person at first thought he would get into trouble for changing staff, but has now realised that he really can choose which staff he wants.



“We get the final say and that makes me happy.”
(Adult with learning difficulties, home care, Glasgow)

“We can say what we want (to happen)...within reason.”
(Adult with learning difficulties, home care, Glasgow)

3.34 Some people had been offered direct payments openly, and were encouraged to adopt this approach. Others had to push to receive direct payments – often because they were dissatisfied with existing services. In one area, people said there was a very long waiting list to be considered. One person said it took a year to begin using direct payments, and she needed a lot of support to make the case. The experiences seemed to vary depending on the type of care needs people had, and the approach within the local authority area. Some people knew – for example from experience elsewhere or feedback from others – that this was the way they wanted to organise their social care services. But for others this was a big decision.



3.35 In most cases people had time to think about the transition to organising their own care. However, in one area, one carer said that she had been asked to make the decision about whether to transfer to direct payments within “a couple of days”. Although she felt direct payments would be better and her adult daughter would have more choices, she decided not to go down this route due to concerns about the additional responsibility, time and energy involved.



“It is exhausting being a carer and I didn’t want to be an employer.”

(Carer of young adult, East Dunbartonshire)

3.36 Others had chosen not to move to direct payments due to a perception that they would not be able to fund the same level of care that they currently received. Some people who received direct payments paid an agency or voluntary sector organisation to deliver the service for them.



3.37 Those who had moved from council commissioned or provided services to organising their own care funded by direct payments were generally very positive about the change. Some were initially confused that they could use their money in any way at all – as long as it benefited the person with support needs. However, in time people generally valued this flexibility to organise different levels of care as and when required, at the times that were appropriate to their needs and lifestyle.



“It has made a great difference. I can get out now. The Personal Assistant takes me out.”

(Adult with physical disabilities, home care, Glasgow)

“It is better. I am my own boss. . . . I hire and fire.”

(Adult with physical disabilities, home care and personal support, Glasgow)

Choosing services

A person using social care services talked about her experience of choosing her own support provider. She has a physical disability which means she needs help at home. She used to receive all her support from a service provider the council allocated to her, but she felt this service was inflexible. She now also receives support from a Personal Assistant she employs through an agency (which she pays for from the Independent Living Fund). The process of recruiting a Personal Assistant took time. She had to develop a picture of what she needed and she wanted to then recruit the right person. But she feels the service she gets meets her needs much better. As a result, she hopes to secure direct payments and choose who provides all of her home care herself.

Influencing services through service review

- 3.38 People had had different experiences of how their support had been reviewed. Some people described re-assessments of their care which happened regularly. These might be formal or informal. Regular review meetings were seen as a good chance to influence – and if necessary change – the services people receive.



“They ask me what I think and I have the chance to say if I am happy or not.”
(Adult with physical disabilities, home care, East Dunbartonshire)

“He has a review every so often. If things aren’t going well we can say then.”
(Carer of adult with disabilities, East Dunbartonshire)

- 3.39 Some service users said that home care managers regularly or occasionally talked with them about their care, and asked if they were happy with the level and quality. Others said their care was (or would be) reviewed as part of wider review of people with particular needs in their local authority area. For example, one person had heard that social care in their area was being reviewed for people with physical disabilities in their age group – but didn’t know how that might work.



“Whether it will end up a good thing or a bad thing – I don’t know. It is a bit uncertain.”
(Adult with physical disability, home care, Glasgow)

- 3.40 Several service users talked about the important role that social work services play during periods of change. Some were very positive about their experience of social work. Some felt that changes had been well explained, those involved in the review had asked questions and listened to what they said. But others had very negative experiences. They felt they hadn’t been involved, listened to, or that decisions were being made by people who didn’t really know them.



- 3.42 There was sense that social work had a very powerful role in deciding what changes happen, and what the changes are. One service user summed up these different views:



“Social work makes the big decisions that really affect you. They have lots of power. This is scary. If someone isn’t willing to talk to you it is very difficult. When it is good, they listen, and take in what you are saying. It is easiest when you get to know the person. When you have a good relationship you understand their limits but you can work your way around these. When it is bad they don’t listen. They think they know everything – but that isn’t possible.”

(Adult with physical disabilities, homecare, Glasgow)

Influencing local authority decisions about support

- 3.43 In some cases, service users and carers raised issues with local authorities changing the criteria for deciding who received social care support, and how this was paid for. There were two examples of a lack of consultation on these issues.



In one case, the local authority had been paying for 15 hours a week home care support and respite care for someone who was in his 60s and severely physically disabled. However, they changed their criteria for funding social care. Although the service user was initially told that this would not affect him, when the local authority re-assessed the case it was decided that he no longer qualified for this support as he was under 65. The local authority then said that it would ‘negotiate’ the level they required to pay. The person’s carer said:

“Social work told us we could negotiate how much we could pay. We didn’t know what they meant, and they said, well make us an offer. We said we would be willing to pay a certain amount. Then we got a letter saying we didn’t qualify for any support, and had been assessed as able to pay. We made a formal complaint, and received a letter saying they would reclaim the money for the past 2 years.”

The service user’s carer indicated that there was some consultation on the wider policy decision, but that very few people attend these events. The carer said: “The talk is about having more choice and control, but this has not been the reality in this instance.”

One service user said that their local authority introduced a new way of charging for care services. This meant that service users with more than a certain weekly income would be paying more than they did before. Although the local authority had consulted on the principle of the changes, they did not consult people on the actual rate. Although the local authority had told people this change would be fair, the service user didn’t feel it was.

Supporting service users to influence service provision

- 3.44 Carers and people with support needs were often working hard to strike a balance between making sure the individual can speak up for themselves, and having the carer speak on their behalf. In some cases, service users preferred to speak to their carer who would then speak to the support provider and pass on their views. Some carers also felt that the person they cared for spoke more freely to them, and did not always express their views to the support provider.



“I’m hugely worried about what would happen to people who are on their own – and have nobody to speak up for them.”

(Carer of older person, Argyll and Bute)

- 3.45 However, one young adult who received direct payment felt that sometimes his family tried to make decisions for him. He felt that often his family did make the right decisions, but he would like to be able to say what he thinks. He raised this with the support organisation, and over the past few months he has felt more involved in decisions.



“Sometimes, just dad and mum speak – they think they know best. But I think I know what is best for me.”

(Adult with learning difficulties, home care, Glasgow)

- 3.46 Some of the service users involved in this research had experience of using advocates, to help them to have their voice heard. Everyone with experience of an advocate felt that they helped them to speak out, and to ask the right questions.



“She sorts problems for me. She puts things in a different way so that I can figure it out. She helps with my confidence, because I could be shy.”

(Adult with learning difficulties, home care, Glasgow)

- 3.47 Carers also felt that advocates could help you to step back, and see things from a different perspective. They could help to make sure that carers and service users didn’t miss the important points in a meeting, and understood all of the words and terms used. Some felt that it would also be useful to have clearer “black and white” information about people’s rights, or someone who could provide legal advice on the rights of service users and carers.



“It is good to have someone helping with meetings, someone who is your ally.”

(Carer of older person, care home, East Dunbartonshire)

4. Summary

Choosing social care services

- 4.1 Overall, most people using social care services felt that they received the services that they needed. In the survey, 94% of service users felt that they 'definitely or mostly' got all the social care services they needed. Most were happy with the type of services received, and the level of support provided.
- 4.2 Although people largely felt that they received the services they needed, fewer (although still a substantial majority) felt involved in the decisions about which services they needed. In the survey 80% of service users felt involved in deciding which social care services they needed.
- 4.3 In discussions, people who received direct payments or could control their own social care budgets told us they felt involved in choosing which organisation provided their services. This often created an ethos of choice and control, with the individual clearly being seen as the employer. This largely applied to home care services.
- 4.4 Many people receiving home care services without being in control of their own budget felt that they did not have any choice in which organisation provided services. While some people were happy with the service anyway, others had stopped using unsatisfactory services and now received no social care support.
- 4.5 People using home care services had varied views on the level of support they received. While some were happy, some felt that the amount of time allocated was not enough, the support was inflexible and they had to "push and fight" to get the level of support needed.
- 4.6 People attending day care services generally felt that there was choice over which organisation provided their service – particularly if living in an area with a high volume of services, and with accessible transport. Most were happy with the level of support provided and felt that they could receive more or less support as required.
- 4.7 People generally felt that they had a high degree of choice over which supported accommodation or care home provider to use. Most were happy with the level of support provided, although there were some concerns about staffing levels.
- 4.8 Many service users and carers felt that social care services were under threat due to public sector cuts. Some had seen their support reduce, and others were concerned that it was likely to reduce in the future.

Influencing service provision

- 4.9 In the survey, most service users were happy with the social care services they received, but less than half felt that they definitely had the chance to tell people what they thought about service provision. Only a quarter felt that what they said definitely influenced how services were provided.
- 4.10 In discussions, people attending day care services told us they felt that they could influence the service if desired – through influencing activities or the use of space within the centre.
- 4.11 People living in supported accommodation felt that they had opportunities for feedback and discussion on the service received, often through regular meetings with staff. Most were positive about this, but some felt that nothing changed as a result.
- 4.12 Carers of people living in care homes felt that it could be difficult to influence the quality of care provided. This was exacerbated by the dependence that their relatives had on the staff in the care home, and difficulties with residents communicating their views directly.
- 4.13 Some people using home care services commissioned or provided by the council felt that they could influence service provision. However, people using home care services that they planned and organised themselves – through having control over their own budget – felt much more involved in decisions about service provision.
- 4.14 Many people using home care services raised particular issues relating to the timing of visits – being inflexible or inconsistent. This impacted on people's quality of life, and people found it hard to influence the timing of visits. Some also raised concerns about inconsistency in staffing arrangements.
- 4.15 People who had organised their own home care services had a strong sense that they were in control. There was evidence of greater feedback, involvement in choosing staff and planning activities well in advance.

Information and advice

- 4.16 In discussions, people indicated that they had accessed services in a wide variety of ways – ranging from an assessment for social care services to hearing about services through word of mouth. Many found it difficult to know about the range of services available, and how to access them.
- 4.17 People who had used advocates were very positive about this experience, feeling that they can help to explain issues simply and help people to ask the right questions.

Carer involvement

- 4.18 Overall, carers were less happy with the social care services the person they cared for received, and felt less involved in decisions about service provision.
- 4.19 Carers had to strike a difficult balance in terms of their influence over social care decisions. Most wanted the person they cared for to have independence, but many felt that without support from their carer service users would not be able to fully express their views.
- 4.20 Most carers felt happy with the support that they received, and most felt involved in decisions about that support. Many carers were relying strongly on support from voluntary organisations or support groups.

Annexes

- 1. Survey for adults who receive social care services**
- 2. Group discussion guide: service users**
- 3. Telephone interview discussion guide: service users**
- 4. Survey for carers of adults who receive social care services**
- 5. Group discussion guide: carers**
- 6. Telephone interview discussion guide: carers**

Annex 1
Survey for adults who receive social care services

Survey for Adults who Receive Social Care Services

Audit Scotland helps to check that public money in Scotland is spent in a fair and sensible way. It wants to find out more about how decisions are taken about social care services.

This is a survey for adults who receive social care services. By this we mean:

- care in a centre – like day care or lunch clubs
- care in your own home – with things like getting up, bathing, dressing and cooking
- living in a care home – a shared home with help on hand when you need it
- practical help to allow you to stay in your own home – like helping you plan or organising a repair
- respite or short term care – support over a short period of time, when you need it most.

We want to gather the views of:

- older people
- people with physical disabilities
- people with learning disabilities
- people with difficulties hearing or seeing

We won't tell anyone who filled in this survey, or what any individual person said. Please fill it in by **9 September**.

If you have any questions please contact Emma Hewitt on freephone 0808 129 2080 or emma.hewitt@odsconsulting.co.uk

About You

1. Who is filling out this survey:

Just me	
Me with help from a friend, family member, carer or support worker	
My friend, family member, carer or support worker on my behalf	

2. How old are you?

3. What is your ethnic origin?

4. Do you have:

	Yes	No
A learning disability?		
A physical impairment?		
Difficulties hearing or seeing?		

5. Are you:

Male	
Female	

6. What council area do you live in?

About Your Social Care Services

7. What kind of social care services do you receive?

	Tick all that apply
Care in a centre Like day care or lunch clubs	
Care in your own home Like helping you get up, bathe and dress	
Living in a care home A shared home with support services	
Housing support Like helping you plan or organising a repair	
Respite or short term care Support for a short time when you need it most	
Other (please tell us more)	

8. Which organisation provides your social care services?

Choosing the Services You Receive

9. Just now, do you think that you get all of the social care support services that you need?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

10. Do you feel involved in deciding which social care services you need?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

11. Did you feel involved in deciding which organisation would provide these social care services?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

Influencing the Way Services Are Delivered

12. Are you happy with the social care services that you receive?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

13. Do you get the chance to tell people what you think of the services you receive?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

14. Do you feel that services change based on what you say?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

Level of Choice

15. Overall, how much choice do you think you have about the social care services you receive?

	Tick one box
Lots ✓✓	
Some ✓	
A little ✗	
None ✗✗	

16. How much choice do you think you should have about the social care services you receive?

	Tick one box
Lots ✓✓	
Some ✓	
A little ✗	
None ✗✗	

17. Do you have any other comments?

--

Stay Involved!

Would you like to take part in a telephone interview to discuss your views in more detail?

	Tick one box
Yes ✓	
No ✗	

Would you like to take part in an email discussion to discuss your views in more detail?

	Tick one box
Yes ✓	
No ✗	

If you want to take part, please tell us your:

Name	
Phone number	
Email address	

**That is the end of our survey.
Thank you very much.**

If you want to speak to someone about this survey, please contact Emma Hewitt on freephone 0808 129 2080 or at

emma.hewitt@odsconsulting.co.uk

Annex 2

Group discussion guide: service users

Group Discussion Guide: Service Users

About This Group

This group will explore your view on the choice and control you have over the social care services you receive. It will last around an hour.

Ground rules – voluntary group, anonymous contribution, feedback

Your views will be part of a report we do for Audit Scotland, which helps to check public money in Scotland is spent in a fair and sensible way. This research focuses on decisions about social care services. Social care services might involve:

- care in a centre
- care at home
- living in a care home
- housing support services
- respite or short term care

Introductions

- Each participant to introduce themselves and tell the group a bit about you, your support needs and the kind of social care support that you receive just now.

Choosing Your Social Care Services

Statement 1: Just now, I receive all of the support and care that I need.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- What works well?
- What are the gaps or problems?
- Are the services of a high quality?

Statement 2: I feel totally involved in decisions about the social care services I receive.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- Were you involved in deciding:
 - which services you would receive?
 - the level or amount of support you receive?
 - which organisation provides the support?
- Did you feel like you had choices about these things?

Statement 3: I feel that people listen to me when I express my views.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- Do you get help to express your views – through an advocate?
- Do your friends, family or carers help you?
- Do people listen to you?

Statement 4: I feel that the services change based on what I need.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- Can you influence the time of day/ week you receive services?
- Do services adapt as your needs change?
- Can you access support for a short time if you need it?

Buzzgroups

In pairs, explore (for 4 or 5 minutes):

- When have you felt very well involved in decisions about the social care services you receive?
- When have you felt very unhappy with the decisions made about the social care services you receive?

Feedback.

The Future

What one thing would make you feel more involved in decisions about the social care services you receive?

Annex 3

Telephone interview discussion guide: service users

Telephone Interview Guide: Service Users

About This Interview

This interview will explore your view on the choice and control you have over the social care services you receive. It will last around 20 minutes. Everything you say will be totally anonymous – we won't tell anyone else what you said.

Your views will be part of a report we do for Audit Scotland, which helps to check public money in Scotland is spent in a fair and sensible way. This research focuses on decisions about social care services.

About You

Name	
Age	
Gender	
Local authority area	
Disability?	
Ethnic origin	

Your Social Care Services

What social care services do you receive just now?

Prompt on different types of:

- care in a centre
- care at home
- living in a care home
- housing support services
- respite or short term care

Which organisation(s) provides these services?

Choosing Which Social Care Services You Receive

Do you feel involved in decisions about:

- which social care services you receive?
- the level of support you receive?
- which organisation provides the support?

Do you feel that you have choices about:

- which social care services you receive?
- the level of support you receive?
- which organisation provides the support?

Do you receive any help to put your views forward?

- through an advocate?
- through family / friends/ carers?

Influencing How Social Care Services Are Delivered

Do you have the chance to influence how the social care services you receive are delivered?

- when you receive services
- which staff support you

- how you use the time available

Do you feel that services are flexible to your own individual needs?

- do the services adapt as your needs change?

Changes to Social Care Services

Have there been any changes to the services you receive over the past few years?

- the organisation providing the service
- the staff
- the type of service received
- the level of service received

Were you involved in discussions about these changes?

- *Prompt on views on this process*

Have these changes made a difference to your life?

- *Prompt on positive/ negative impacts*

Have these changes made a difference to the lives of your friends/ family?

- *Prompt on positive/ negative impacts*

Examples of Good and Poor Practice

When (if at all) have you felt fully involved in the decisions that are made about the social care services you receive?

When (if at all) have you felt very unhappy with the decisions that are made about the social care services you receive?

Improving Practice

What one thing would help you feel more involved in decisions about the social care services that you receive?

Do you have any other comments?

Annex 4

Survey for carers of adults who receive social care services

Survey for Carers of Adults who Receive Social Care Services

Audit Scotland helps to check that public money in Scotland is spent in a fair and sensible way. It wants to find out more about how decisions are taken about social care services.

This is a survey for people (such as family or friends) who care for adults who receive social care services. By social care services we mean:

- care in a centre – like day care or lunch clubs
- care in your own home – with things like getting up, bathing, dressing and cooking
- living in a care home – a shared home with help on hand when you need it
- practical help to allow you to stay in your own home – like helping you plan or organising a repair
- respite or short term care – support over a short period of time, when you need it most.

We want to gather the views of carers of:

- older people
- people with learning disabilities
- people with physical disabilities
- people with difficulties hearing or seeing.

Everything you say will be completely anonymous. Please fill in the survey by **9 September**.

If you have any questions please contact Emma Hewitt on freephone 0808 129 2080 or emma.hewitt@odsconsulting.co.uk

About The Person You Care For

This survey is for people who are carers of friends or family members.

1. Does the person you care for receive support in relation to:

	Tick all that apply
Being older	
Having a learning disability	
Having a physical impairment	
Having difficulty hearing or seeing	
Other (please tell us more)	

2. What kind of social care services does the person you care for receive?

	Tick all that apply
Care in a centre Like day care or lunch clubs	
Care in their own home Like helping them to get up, bathe and dress	
Living in a care home A shared home with support services	
Housing support Like helping them plan or organising a repair	
Respite or short term care Support for a short time when you need it most	
Other (please tell us more)	

3. Which organisation provides these social care services?

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Services for the Person You Care For

4. Do you feel that the person you care for has choices about the social care services they receive?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

5. Do you feel involved in deciding which social care services the person you care for needs?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

6. Are you happy with the social care services that the person you care for receives?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

7. Do you get the chance to tell people what you think of the services the person you care for receives?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

8. Do you think that you should be involved in these kind of decisions and discussions?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

Services for You

9. Do you feel involved in deciding what support is available for carers?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

10. Are you happy with the support that you receive as a carer?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

11. Do you get the chance to tell people what you think of the services available for carers?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

12. Do you feel that services change based on what you say?

	Tick one box
Definitely ✓✓	
Mostly ✓	
Not really ✗	
Not at all ✗✗	

Further Comments and Information about you

13. Do you have any other comments?

14. How old are you?

15. Do you have a disability?

	Tick one box
Yes ✓	
No ✗	

16. What is your ethnic origin?

17. What council area do you live in?

--

18. Are you:

Male	
Female	

Stay Involved!

Would you like to take part in a telephone interview to discuss your views in more detail?

	Tick one box
Yes ✓	
No ✗	

Would you like to take part in an email discussion to discuss your views in more detail?

	Tick one box
Yes ✓	
No ✗	

If you want to take part, please tell us your:

Name	
Phone number	
Email address	

Thank you. Please return this survey in the freepost envelope provided, or send it to:

ODS Ltd, FREEPOST, GLASGOW, G42 8BR.

If you want to speak to someone about this survey, please contact Emma Hewitt on freephone 0808 129 2080 or at

emma.hewitt@odsconsulting.co.uk

Annex 5

Group discussion guide: carers

Group Discussion Guide: Carers

About This Group

This group will explore your views on the social care services that the person you care for receives, and the services you receive as a carer. It will last around an hour.

Ground rules – voluntary group, anonymous contribution, feedback

Your views will be part of a report we do for Audit Scotland, which helps to check public money in Scotland is spent in a fair and sensible way. This research focuses on decisions about social care services. Social care services might involve:

- care in a centre
- care at home
- living in a care home
- housing support services
- respite or short term care

Introductions

- Each participant to introduce themselves and tell the group a bit about the person they care for, their support needs and the kind of social care support that both the individual and their carer receive just now.

Choosing Your Social Care Services

Statement 1: The person I care for has choices about the social care services he or she receives.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- Was there choice about:
 - which services the person you care for receives?
 - the level or amount of support received?
 - which organisation provides the support?

Statement 2: I feel involved in decisions about the social care services the person I care for receives.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- Were **you** involved in deciding:
 - which services the person you care for receives?
 - the level or amount of support received?
 - which organisation provides the support?
- Do you think that you should be involved in these kinds of decisions?

Statement 3: I receive all of the support I need as a carer.

Each participant to show a red, amber or green cards to show if they disagree, are neutral or agree. Hold the card higher up if you feel very strong views!

Prompt on:

- What kind of support do you receive?
- Do you get the chance to tell people what you think about services for carers?
- Did you feel involved in the decisions made about what support you would receive?
- How do you feel about the support you receive as a carer?

Buzzgroups

In pairs, explore (for 4 or 5 minutes):

- When have **you or the person you care for** felt very well involved in decisions about the social care services you receive?
- When have **you or the person you care for** felt very unhappy with the decisions made about the social care services you receive?

Feedback.

The Future

What one thing would make you feel more involved in decisions about the social care services the person you care for receives?

What one thing would make you feel more involved in decisions about the support you receive as a carer?

Annex 6

Telephone interview guide: carers

Telephone Interview Guide: Carers

About This Interview

This interview will explore your views on the social care services that the person you care for receives, and the services that you receive as a carer.

It will last around 20 minutes. Everything you say will be totally anonymous – we won't tell anyone else what you said.

Your views will be part of a report we do for Audit Scotland, which helps to check public money in Scotland is spent in a fair and sensible way. This research focuses on decisions about social care services.

About You

Name	
Local authority area	

Your Social Care Services

What is the main reason that the person you care for has a need for social care services?

What social care services does the person you care for receive just now?

Prompt on different types of:

- care in a centre
- care at home
- living in a care home
- housing support services
- respite or short term care

Which organisation(s) provides these services?

Choice for the Person You Care For

Do you feel that the person you care for has choices about the social care services he/ she receives? *Prompt on:*

- what type and level of support is provided
- which organisation delivers the support
- when services are provided
- which staff provide support

Do you feel that the person you care for receives enough support to be able to put forward his or her views?

Do **you** feel involved in decisions about:

- which social care services the person you care for receives?
- the level of support received?
- which organisation provides the support?

Do you think that you should be involved in these kind of decisions?

- *Prompt on reasons.*

Services and Support for Carers

Do you receive any support as a carer?

Did you feel involved in the decisions made about what support you would receive?

How do you feel about the support you receive?

Do you feel able to influence or change these services to meet your needs?

Do you get the chance to tell people what you think about services for carers?

Changes

Over the past few years, have there been any changes to:

- the services the person you care for receives?
- the services and support that you receive as a carer?

Were you involved in discussions about these changes?

- *Prompt on views on this process*

Have these changes made a difference to your life?

- *Prompt on positive/ negative impacts*

Have these changes made a difference to the person you care for?

- *Prompt on positive/ negative impacts*

Examples of Good and Poor Practice

When (if at all) have you felt fully involved in the decisions that are made about the social care services the person you care for receives?

When (if at all) have you felt very unhappy with the decisions that are made about the social care services the person you care for receives?

Improving Practice

What one thing would help you feel happier about the decisions that are made about the social care services that the person you care for receives?

Do you have any other comments?