

**East Lothian Community
Care Forum**



Self Directed Support

**A survey about how people who use
health and social care services are using
and managing SDS**



Community Action Research

“We have substantial evidence that this form of research has built the capacity of individuals and communities to evidence the need for and achieve positive change in the services or support provided to their community.

By community led we mean research defined, undertaken, analysed and evidenced by members of the community themselves. It is therefore research of and by the community and not, as is traditional, on and to the community.

The distinction is fundamentally important because in the community led approach it is the community who define and carry out the research to gather evidence and make recommendations for change.”

Acknowledgements

East Lothian Community Care Forum (ELCCF) gratefully acknowledges the opportunity given to ELCCF to carry out this research on behalf of the Integrated Health and Social Care Partnership. Many thanks also to Richard Duffner, a service user volunteer involved in shaping this work.

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Context

East Lothian Community Care forum is the independent voice of service users that, among other duties, acts to provide the local authority with an independent service users' point of view of the services provided.

In February the East Lothian Integrated Health and Social Care Partnership Adult Wellbeing Department asked East Lothian Community Care Forum to carry out a small piece of independent research to find out how people who use services are managing with Self Directed Support. The research was carried out between July and August 2016.

The integration of Health and Social Care services is set out in the Public Bodies (Joint Working) (Scotland) Act 2014¹, in addition to the establishment of a local health and social care partnership as a single management system, the adult health and social care services are managed through a single budget.

The Partnership is in the process of commissioning Care at Home services. This piece of research will inform that process.

Research aim

'SDS in Scotland is part of the mainstream of social care delivery, targeted at empowering people. It is part of creating a healthier nation with stronger and safer communities and is key to achieving a fairer and wealthier Scotland. It puts the principles of independent living into practice and enables people to be active citizens in their communities.'

'Like the social model of disability, it is about reducing or removing the physical, organisational or attitudinal barriers that people may experience in the world around them. It is about flexibility, choice and control and having a decent quality of life. It is ultimately about promoting confidence and wellbeing for those with an assessed need.'

Self Directed Support Scotland

The research aims to show how people are managing self-directed support and how the option they have chosen impacts on the care they receive.

Methodology

The questions were set by East Lothian Council staff involved in commissioning this project. The questions were originally proposed for a 'talking points' interview, inviting service users to participate in an interview situation in order to gather qualitative data. However with the intention of attracting a larger sample, the questions were transferred onto a questionnaire and sent out to all service users at a later stage in the project. This has, to some extent, compromised the qualitative outcome of the evaluation. However the end result stands as a revealing view, and despite the time constraints placed upon ELCCF, the exercise delivers telling insights. East Lothian Council distributed the questionnaires to each service user

¹ http://www.legislation.gov.uk/asp/2014/9/pdfs/asp_20140009_en.pdf

receiving care at home support. Questionnaires were returned to ELCCF for independent analysis. Support to fill out the questionnaire was offered to service users through face to face interviews or over the telephone.

Although it was principally a postal survey the most helpful qualitative data came from 12 responses from family carers of people with a learning disability who made telephone contact.

Community Action Research

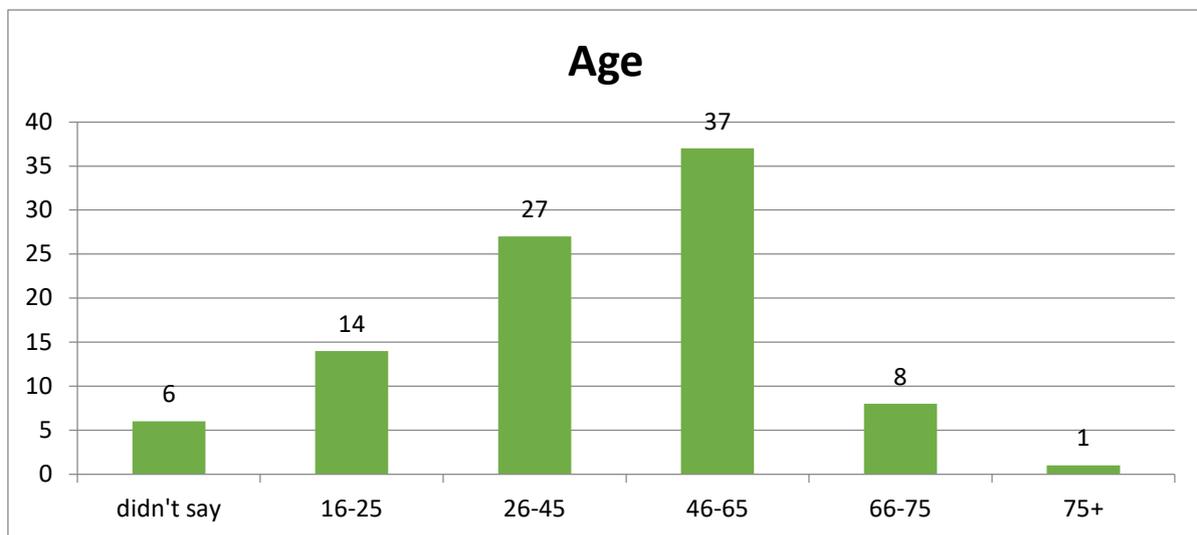
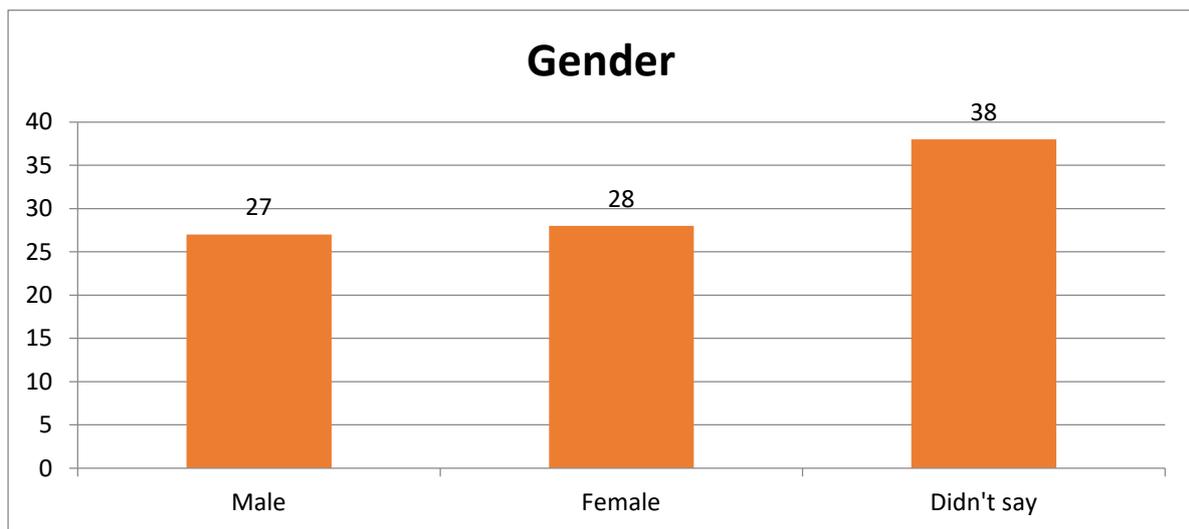
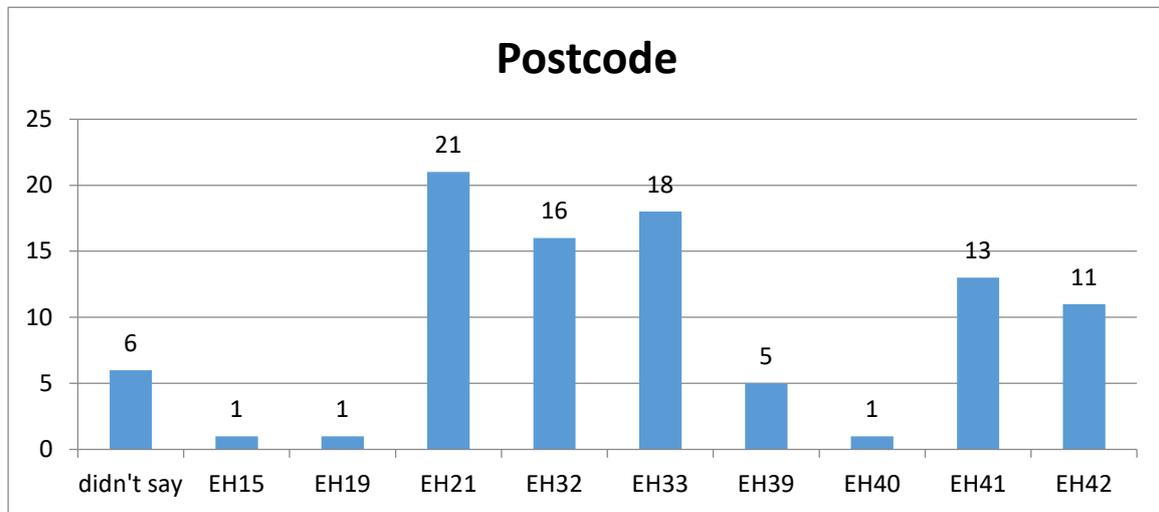
As part of a community action research approach ELCCF volunteers were involved in:

- Collating responses
- Data analysis
- Writing final report.

Approximately 400 questionnaires were sent out. East Lothian Community Care Forum received 100 responses.

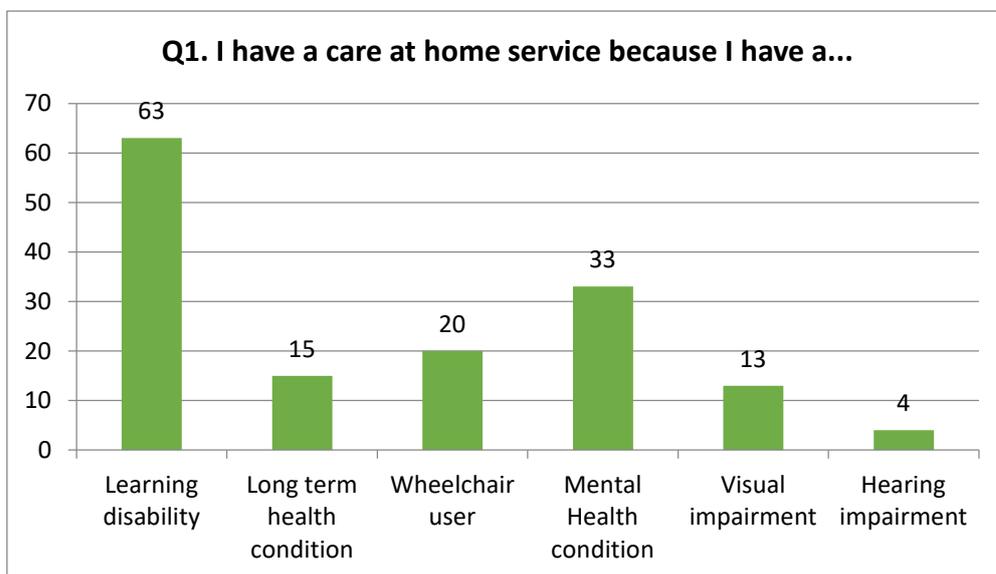
Demographics of Service User Sample

This section describes the characteristics of the service user sample including Geography, Gender and Age.



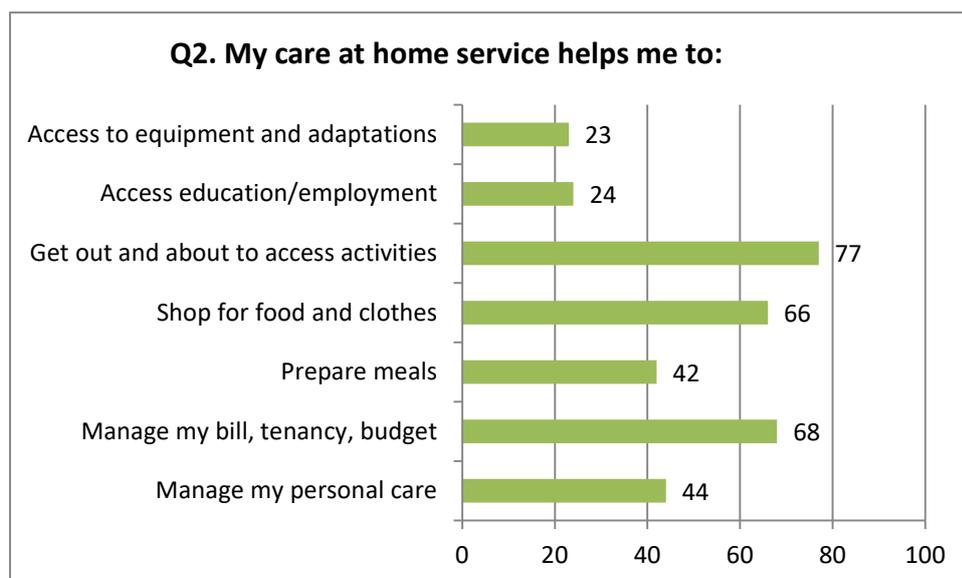
The Data

Q1. Disability



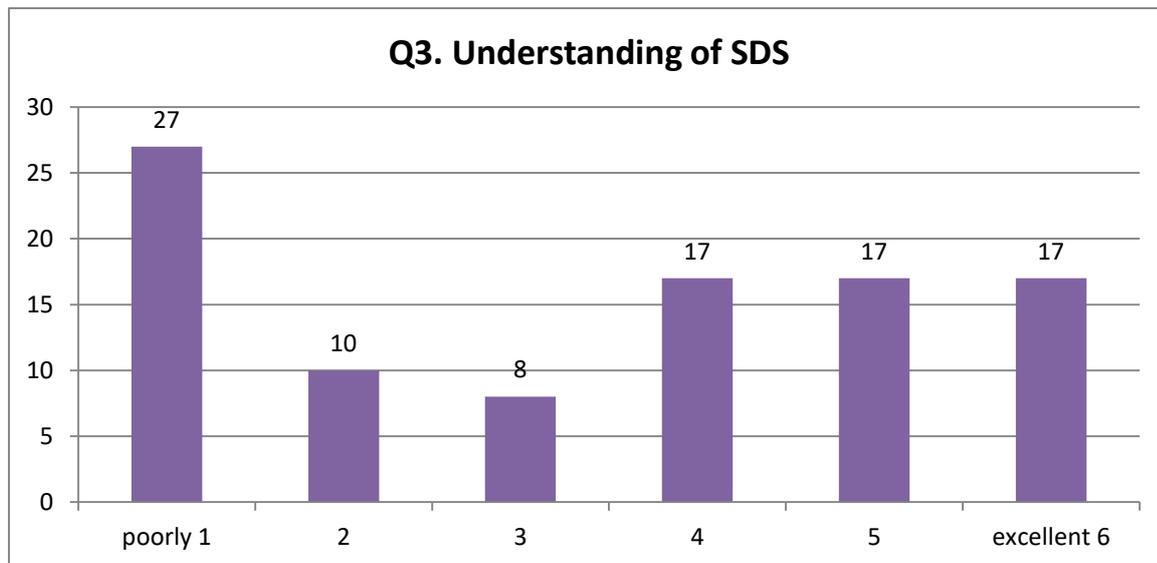
Nearly two thirds of respondents reported having a learning disability – a fifth of whom reported having additional needs. Many of the questionnaires were filled out by support workers who were, in the main, perfunctory with the responses and did not take the opportunity to elaborate on any of the questions. This meant that the statistics from this questionnaire lack the qualitative research we were looking to achieve. The qualitative data (through comments) that was given in the questionnaire came mostly from family carers and/or legal guardians.

Q2. How my care at home service helps me.



Respondents were able to tick multiple options for question 2.

Q3. Understanding of Self Directed Support (SDS)



The statistics in the graph above show that the understanding of SDS is a mixed picture. Many of the respondents who filled out the form did so, on behalf of someone with a learning disability.

- *'This form is completed by a support worker as the service user has little understanding of this'.*
- *'Welfare guardian and social worker make these decisions'.*
- *Because of her disability Miss B only understands so much.*
- *My support worker explained what SDS is.*

Some of the high scores were based on the understanding of SDS that carers/guardian/support workers had. Those who gave lower scores did so borne on the level of understanding their client had.

The picture is also skewed by the fact that many of high scores in question 3 were inconsistent with their corresponding answers to questions 4 and 5. They mostly ticked the East Lothian Council option in question 4 selecting 5a (*I don't really understand how all the options work and just want to stick with what I have always done*). The comments below show that some respondents were unclear about the SDS options and how they work.

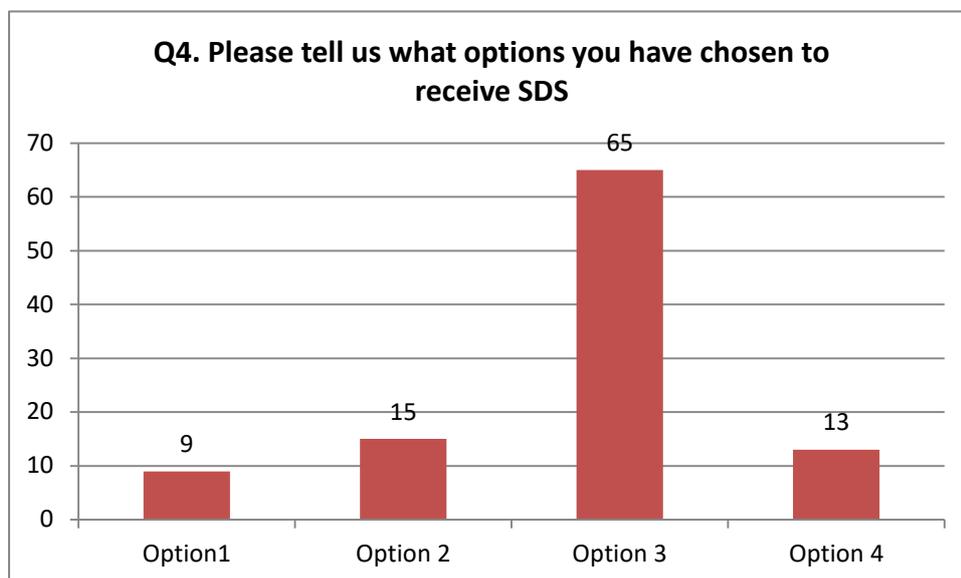
- *As his family carer I don't really understand SDS in terms of the options. I don't understand the rules. We have always kept the status quo because we don't want his hours to be reduced.*
- *As legal guardian my relative has little understanding. I am completing this form on his behalf.*
- *I am filling this out on behalf of my son who has a learning disability. My son's social worker has not explained SDS to me and I didn't know about any of the options.*
- *I am the father and legal guardian. My daughter cannot read or write, so I'm filling in this form as best I can.*
- *I don't get SDS as such. East Lothian Council charges me on a monthly basis and I pay by card.*
- *I don't feel I have full understanding of self-directed support.*
- *I don't understand at all. I don't know about these things. I think I'm being reviewed social worker at the moment because my GP thinks I need more support.*

- *I don't understand what SDS means to be taken as a direct payment. My Carr Gomm care worker has not this form or can advise me on it.*
- *I have just been given this at start of July, was not told this is what I had. Social Worker arranges everything so not aware of what this is about.*
- *I'm filling in this form on behalf of my relative. Their care was not discussed with us. This was 5/6 years ago. We have yet to be reviewed.*
- *I'm filling this in on behalf of my daughter. I have a reasonable understanding. Social work did explain it to me a bit, but I'm still not clear. There seems to be restrictions on what money can be spent where.*
- *Social worker hasn't discussed things with me yet.*

Other comments indicate that family and or legal guardians manage the SDS payments. The statements are neutral and don't show levels of understanding.

- *I leave this to my parents.*
- *If I'm not happy with support I go to the Agency office. If it's a Council issue, I go to the local office at Aldhammer House and can say what I'm not happy about.*
- *I have three people who are my team and work with me daily. I get on with them all and trust them. They are very understanding of my changing needs. They keep me informed of local attractions and shows which I might enjoy going to. Keeping me out and about enjoying my usual hobbies and meeting my friends.*
- *My daughter stays with parents and we are quite happy how things are at the moment*
- *My Mum deals with all things like this as I cannot understand how things work when it gets complicated.*

Q4. Please tell us which option you have chosen to receive SDS.



Option 1: SDS taken as a direct payment (a cash payment).

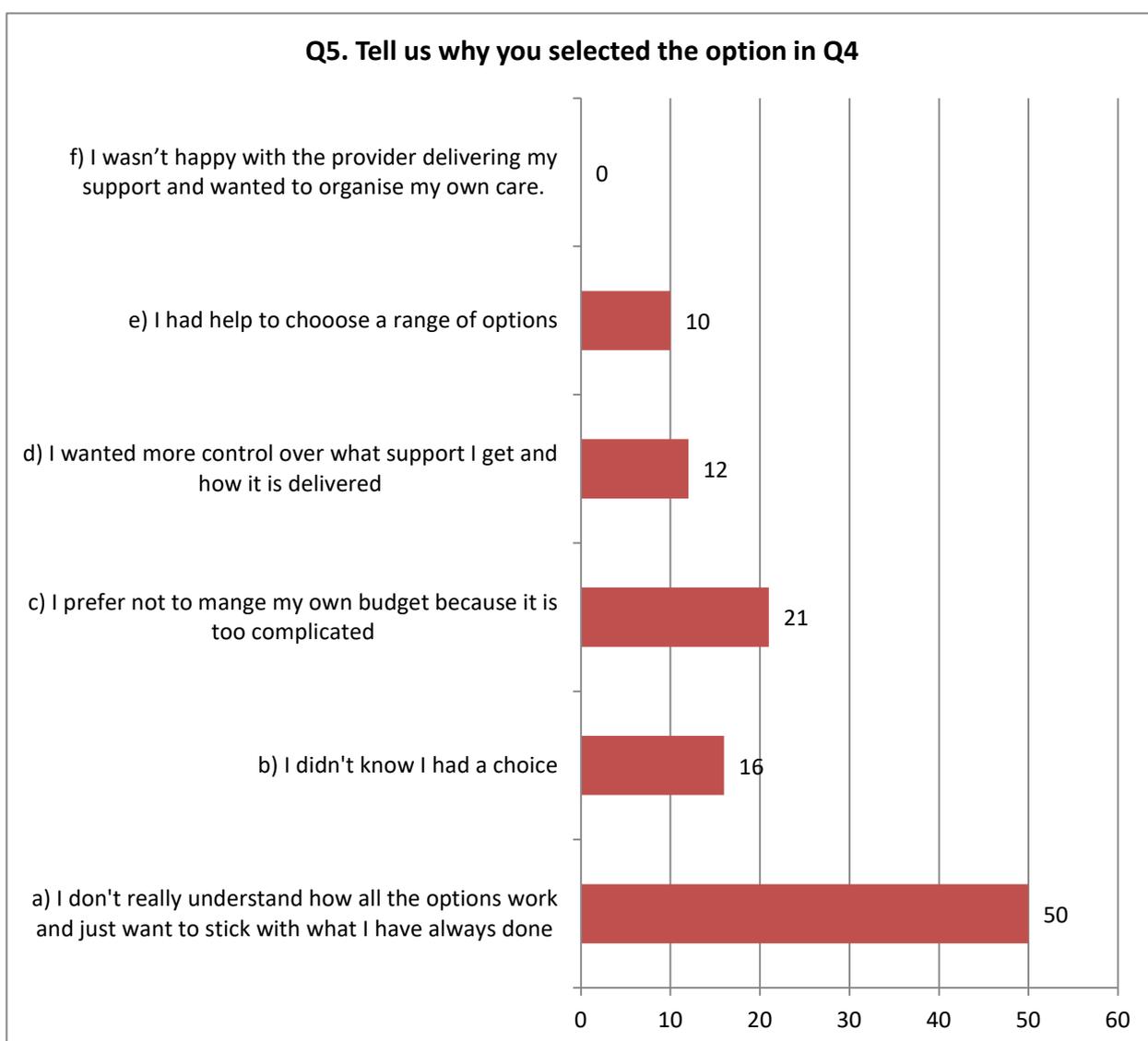
Option 2: You decide and direct how you want to spend your budget but choose not to take responsibility for the financial management.

Option 3: East Lothian Council arranges your support for you.

Option 4: a mixture of options 1, 2 & 3.

The statistics in question 3 show that most respondents receive their support through East Lothian Council. In order to understand this statistic further we isolated data from option 3 and matched it with data from Q4 about why they made this choice. Sixty five respondents selected option 3 and 43 cited *'I don't really understand how all the options work and just want to stick with what I have always done'* as their reason. Eight respondents said they didn't know they had a choice, 7 respondents said they preferred not to manage their own budget. Only 5 respondents said they had help to choose a range of options.

Q5. Tell us why you selected the option in question 4.



The graph and comments show that most respondents found the SDS process complicated and preferred to stick with what they have always done. This statistic can be viewed in different ways. For some, staying with the status quo was preferable - if it ain't broke...

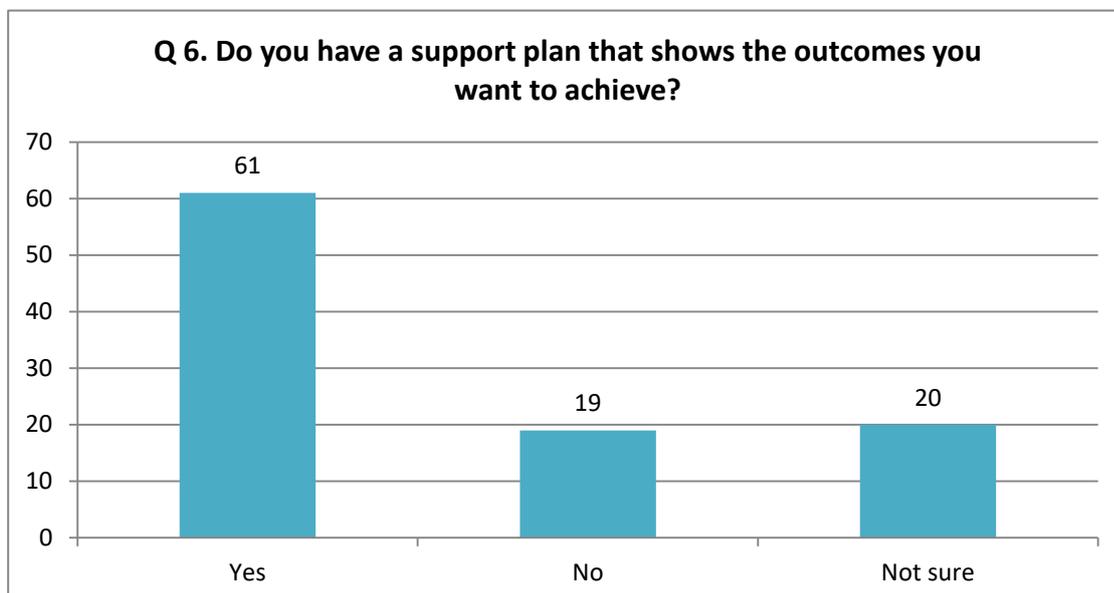
- *I have been with ELCAP for many years now. I like them as they have always encouraged me to speak my mind and know about my rights. For a long time I was involved in things and they listened to my views and opinions.*
- *I know I have rights and if I am not happy with my support, I would go to the office to complain and sort it out.*
- *Ms X is supported at home by support workers employed by ELCAP who support her in her daily living along with her family. A care plan is in place.*
- *I am happy with the support I get from ARK Housing.*

For others comments from Q5 illustrate a clear lack of understanding about the choices available and how they work or feeling stuck within a choice for fear of having service hours cut.

- *I would like her budget to be more flexible to meet choices that work for my daughter. Especially with transport issues. I didn't choose option 1 because my daughter's budget would have been cut and we would not have been able to afford the service she currently has. With direct payments it would have been a shortfall as well as could have been very complicated for me to have arranged a similar service*
- *As far as I know my daughter has not been told what her options are. Her carers have not told me about any visits from East Lothian Council*
- *I don't know it's always been paid for.*
- *I have never heard of the options. I assume East Lothian Council arranges the small amount of care I get now.*
- *I would prefer option 2. Currently his budget is fixed to certain things and the provider offers a range of things that would benefit my son and give him more choice. Options were never explained to me.*
- *My parents deal with respite care but found it quite stressful.*
- *We were happy to stick with what my relative has although we are not entirely happy with the service provider. We didn't realise we could have a mixture of options. This hasn't been explained to us.*

Approx. 10% of respondents said they didn't know they had a choice.

Q6. Do you have a support plan that shows the outcomes you want to achieve?



The comments below illustrate that for those who answered yes to Q5 support plans are in place and helpful in giving collective clarity to service users, their carers commissioners and providers about what care and support has been agreed.

- *Care plan with provider*
- *I agree on goals and outcomes I'll achieve. This is organised and renewed every six months*
- *I get CMS financial management solutions to help with budgeting and monies. They are based in Glenrothes, Fife.*
- *I have a six monthly review of how my support is going and have a personal plan in place*
- *I have been at meetings to discuss this.*
- *I think is outcomes and goals for me in future.*
- *I would remain in my own tenancy with support from Carr-Gomm. Also I would be mentally well and coping with all my routines.*
- *It's all written in my support plan.*
- *My support plan was done through ELCAP who give me support.*
- *Personal support plan with guidelines on finances, weekly budget.*
- *To help with any correspondence.*
- *To support to contact ELVOS.*
- *To support with voluntary work.*
- *We have a really good social worker. But I'm not clear about transport.*
- *It is a support plan done through the home that she is in. Activities are organised by the home*
- *I have support from Carr Gomm which is a national charity. All my key workers are fantastic! They understand my problems with walking, they are patient with that plus I have more confidence and freedom to go out.*
- *It helps us because we are clear about what he gets and the outcomes that support him in his development*

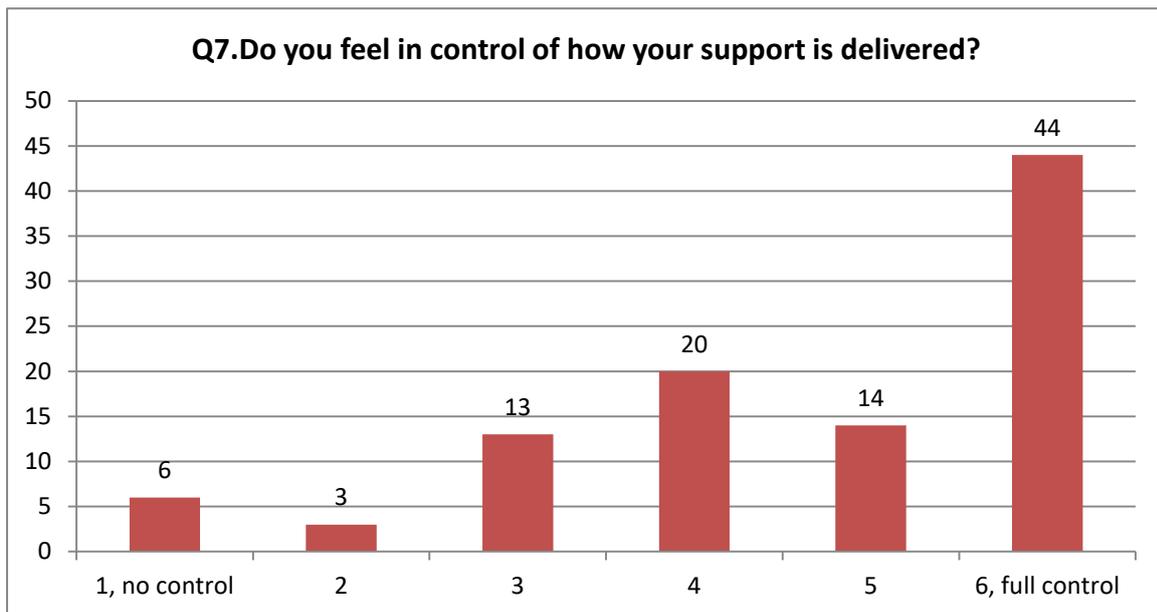
For some who answered yes to having a support plan it was not clear whether the support plan was 'the' official plan that correlates with the allocated budget or the providers' own support plan that is initiated through individual providers for weekly plans and tasks.

- *I have a support plan but not in relation to managing a budget. It is a personal support plan.*
- *My son eventually got a plan. It is arranged by ELC but it is very inflexible. I would prefer option 2 so that my son can opt for different things to do with the provider.*
- *Social work sort all of this as I don't know how things work.*

Over a third of respondents said that they either did not have a support plan or were not sure.

- *I would like a support plan.*
- *I have been housebound for some years now and would like support. Someone has come to help me and I think it is a social worker. I hope I will get a support plan.*
- *I have not been shown a budget or support plan and have never been contacted regards to this.*

Q7. Do you feel in control of how your support is delivered?



Despite many respondents not fully understanding SDS, the statistics show that this did not have an impact on their not feeling in control of how their support is delivered. Most respondents scored 4 and above for this question. The quotes below tell the story:

- *I am happy with my life now I live on my own and have control of most things. I know how to complain to help me be happy.*
- *I did a plan of what my son's life should be and the Thistle have followed that to the T. Previously people coming in for 15 mins to shower was a disaster. It was a dreadful experience. Thistle offer involvement with the family which is a very holistic approach. They stretch my son and introduce him to new things.*
- *Nothing, because my support is fine the way it is.*
- *Various teams involved in how support is delivered, Welfare Guardian, social worker, medical, dietitian but also able to put in some input to daily support*
- *Yes I do.*
- *On the whole yes. In his own tenancy he doesn't need a lot of support as we as a family, do lots of things for him. But our problem is respite. It is not recognised that we need to have a break - it is not taken into account. Also, the Provider tells us that they cannot offer support one month in advance. Why is this? Is there not an expectation that a provider can sort a staffing problem out if they know a month before?*
- *On the whole yes. In his own tenancy he doesn't need a lot of support as we as a family do lots of things for him. But our problem is respite. It is not recognised that we need to have a break - it is not taken into account. Also, the Provider tells us that they cannot offer support one month in advance. Why is this? Is there not an expectation that a provider can sort a staffing problem out if they know a month before?*
- *We are happy with the support*
- *I have control over the private arrangements I have but I don't feel in control of the Council workers who come in to help with my personal care.*
- *NA person has dementia*
- *I feel I'm able to go back to the Council and negotiate changes on behalf of my son if I need to.*

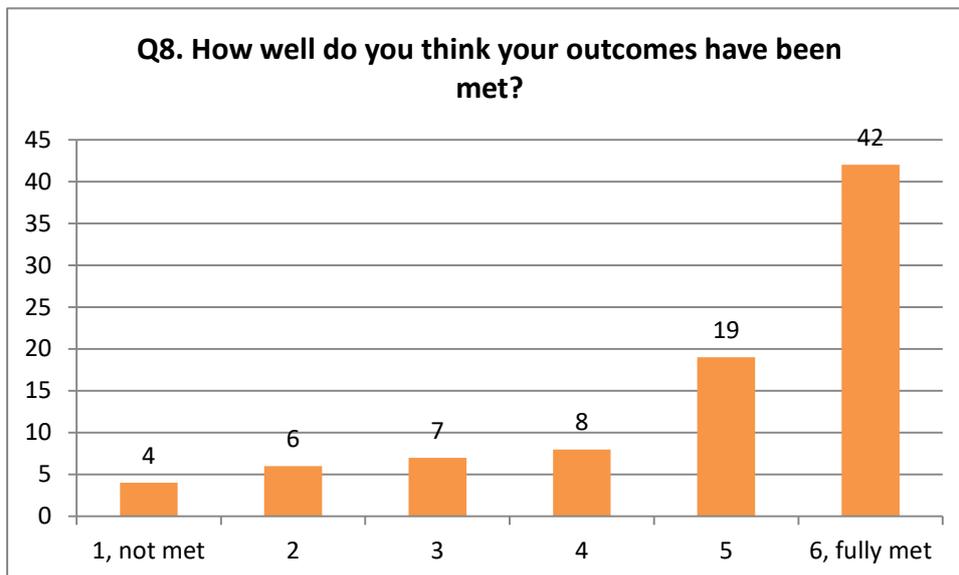
We should also bear in mind that many of the forms were filled out by provider support workers/carers who scored highly on this question on behalf of the person they are supporting. It is therefore difficult to gauge the veracity of the answers.

- Ms x is able to let you know if she is not happy with something, she is supported by support workers 24/7.
- Mr Y is supported at home by support workers employed by ELCAP, along with his family. A care plan is in place.
- Unable to answer this question.

The comments below illustrate where service users and/or their family carers do not feel wholly in control of how their support is provided.

- I try to book my appointments within my support time however this is not always possible if limited appointments are available. I would like to feel more secure and receive support to do these.
- My daughter has not been told about any support from ELC.
- My hours were cut. Doesn't make me happy.
- No, I just take what I have been offered years ago. But now I am being reviewed I hope they will explain all the options that will help me get out of the house a bit.
- The support plan is very rigid and can only do what ELC says it can do on the support plan. How is that going to benefit my son to help him develop when he cannot access a range of activities that the provider offers. I am not disputing the budget but the way it is spent.
- I don't feel in control of the budget. I know where the money is going but I'm not able to follow the budget, which I think would be useful. A quarterly summary of what has been spent would be very helpful. I would like it to be more flexible.
- I would like to be shown my budget, support plan for the services I receive. I would like more personal support and feel that my social worker has not helped enough.

Q8. How well do you think your outcomes have been met?



Similar to question 7 the statistics show that two thirds of respondents scored highly in this question. Caution should be noted as many of the forms were filled out by provider support workers/carers the issue of independence could be called into question. Comments below, mostly left by service users or family carers, bear out the high scores.

- I enjoy what I do with my support as they talk through any issues that arise for me etc.
- I never had discussions with anyone regards this form.
- I'm on the whole happy with the outcomes for my daughters care.

- *My outcomes are written into my support plan and are met by my support staff.*
- *My son is in transition from children's services and it is too soon to say how his current programme is working out.*
- *My staff while ensuring my safety at all times make sure I'm still going to all my usual activities. I am also made aware that I have choices and can choose new activities or not to go if I'm not feeling up to things. Making sure I'm aware of local activities and shows at theatre and local community centres keeping me informed about things I enjoy.*
- *The client has a healthy, happy environment and is able to live life to their full potential. It's thanks to the flexibility of SDS, ELC and Thistle that we were able to negotiate a very good living plan for my brother. I can't praise Thistle enough I don't think another agency would have been able to make such a success*
- *They're being met in every way.*
- *Through work with a number of professionals outcomes are met to as high a standard as possible.*
- *To keep my tenancy and be self-sufficient to live on my own.*
- *provider carer responding on behalf of patient*
- *I'm very pleased with what my son gets for his budget.*

Of the 100 respondents a third either gave low scores or did not answer this question as they reported not having a care plan in place.

- *Not met yet.*
- *Some outcomes are being met but I think I need more support. My GP agrees.*
- *As I just said nothing was ever discussed. I'd like someone to explain what my choices are.*
- *Could do with more respite. My parents deal with all my financial affairs and finding it quite stressful due to red tape and it is all very time consuming.*
- *I do not have a support plan that I know of and I would like one.*
- *I do not feel well informed in regards to what is going on and what my budget is or how anything is paid for.*

Key findings

- **'Self' directed support?** From the qualitative data received mainly from family carers and some service users the evidence shows that in many cases the support falls short of 'self' directed as the name of this approach suggests. A significant majority have their services arranged by East Lothian Council. Question 5 shows that 50% of respondents said *'I don't really understand how all the options work and just want to stick with what I have always done'* and 16% said they didn't know they had a choice. Perhaps more could be done to improve how SDS is introduced at assessment and a checking system be introduced to check for the level of client understanding.
- **Choice.** In Question 5, 66% of respondents said they did not understand how the options work. They wanted to stick with what they have always done or didn't know they had a choice. Although many said that they were happy with the support they or their relative receives, there were additional comments that offered more insight into this question (4). Some did not want to rock the boat in case they ended up with fewer hours; others simply didn't know how the system works and what other choices were available to them. A small number of people raised the issue of flexibility around their budgets. Although people chose to stick with their existing arrangements several family carers reported wanting to see more flexibility around how the budget is used.

It should be recognised that change in itself can be challenging inasmuch as service users and their carers may feel it is too complicated, too much bother, or are afraid of what the change might bring about.

- **Support Plans**
61% of respondents reported having a support plan. Comments highlight that some support plans are done through the provider and others by the Social Worker but the findings are unclear about how many support plans are clearly attached to a budget. Worryingly 39% of respondents either said they did not have a plan or were not sure.
- **In control of how support is delivered**
78% of respondents gave higher scores of 4, 5 and 6 to this question (Q7). We should bear in mind that 72% of forms were filled out by support workers or with the help of support workers which calls into question the independence of the answers. However, the qualitative data we received from this question suggests that people are, in the main, happy with the support that providers are offering and that if any problems arise respondents said they felt confident that they could sort it out with the provider. The less positive comments (mostly from family carers or service users) from this question focus mostly on feeling vulnerable regarding negotiating and understanding budgets and support plans with ELC.
- **How well have outcomes been met?**
Most respondents scored highly to this question. 69% gave higher scores of 4, 5 & 6. Whilst acknowledging the issue of independence, comments showed that having a support plan gave clarity to both service users and their family carers about what

support to expect and to be able to see and contribute to how it is delivered. A third of respondents gave low scores or did not answer this question as they did not have a care plan in place.

Reflections:

Our sample shows that for the majority of the respondents the Council selects and arranges support. This is a fair way from the 'self' directive aspiration of SDS. Statistics show that 66% of respondents who use services and their carers are unclear about SDS and how the options work and are therefore unlikely to choose other options. Added to that is the fear of moving away from the status quo in case that leads to a cut in hours or service.

This indicates that work needs to be done through the assessment process to inform, reassure and encourage more people to check out all the options. Whilst feedback makes it clear that choosing option 1 may be too much to cope with we feel that there should be more support to look at option 2 (to choose your own support while the Council holds the money and arranges the chosen support on your behalf) or option 4 (a mix of options). We recommend a system is introduced to check and document level of understanding at assessment.

We also recommend that clients are given information about advocacy support if they are finding the process difficult to understand and would benefit from additional independent support to help understand the complexities of SDS.

Appendix

Service user Questionnaire

1. I currently have a care at home service because: (please tick)

- a) I have a learning disability
- b) I have a long term health condition such as MS, Parkinson's, Epilepsy
- c) I am a wheelchair user
- d) I have a mental health condition
- e) I am visually impaired
- f) I have a hearing impairment
- g) Other _____

2. My care at home service helps me to: (please tick any that apply)

- a) Manage my personal care
- b) Manage my house/tenancy, paying bills, managing budgets
- c) Prepare meals
- d) Shop for food and clothes
- e) Get out and about to access community activities
- f) Access education and/or employment
- g) Access to equipment and adaptations
- h) Other

3. Please score how well you understand what self-directed support is?

(Please tick) 1 = I don't understand, 6 = I have a good understanding

1, 2, 3, 4, 5, 6

Please say more:

4. Please tell us what option (below) you have chosen to receive your support: (please tick)

Option1: SDS taken as a Direct Payment (a cash payment)

Option2: You decide and direct how you want to spend your budget,
but chose not to take responsibility for the financial management

Option3: East Lothian Council arranges your support for you.

Option4: A mix of options 1, 2 & 3

5. Please tell us why you selected the option in question 4. Below are just some examples, please tick any that fit or add your own reason.

- a) I don't really understand how all the options work and just want to stick with what I have always done.
- b) I didn't know I had a choice.
- c) I prefer not to manage my own budget because it is too complicated.
- d) I wanted more control over what support I get and how it is delivered.
- e) I had help to choose a range of options.
- f) I wasn't happy with the Provider delivering my support and wanted to organise my own care.
- g) Other.

Please comment

6. **Do you have a support plan that shows what outcomes you will achieve with your budget?**
(Please circle.)

Yes / No / Not sure

Please comment:

7. **Do you feel in control of how your support is delivered?**

1= no control, 6 = full control (please tick)

1, 2, 3, 4, 5, 6

8. **If you gave a low score, please tell us what would you give you more control over the Support you receive?**

9. **If your outcomes have been agreed, please score how well you think they have been met?**

1 = Not at all, 6 = Very Well

(Please tick) 1, 2, 3, 4, 5, 6