

# Consultation results: Community support service consultation



**Date:** January 2016

## Document summary

Results from the consultation on proposed changes to the Learning Disability Community Support Service

## Contents

<b>Background.....</b>	<b>4</b>
Why we are consulting.....	4
What we consulted about.....	4
<b>Consultation process .....</b>	<b>4</b>
How people could take part .....	4
Online survey.....	4
Other forms of feedback .....	5
Responses by method .....	5
Table 1: Responses by method .....	5
<b>Key themes.....</b>	<b>6</b>
Comments .....	6
<b>Summary of consultation responses .....</b>	<b>8</b>
<b>What happens next.....</b>	<b>9</b>
<b>Appendix 1: Survey results.....</b>	<b>10</b>
Chart 1: Do you think we should ask people to pay for the community support service? .....	10
Related comments on whether people should be asked to pay .....	10
Reasons for saying people should be asked to pay .....	10
Reasons for saying people should not be asked to pay .....	11
Reasons for not being sure whether people should be asked to pay .....	13
Chart 2: No one would be asked to pay for the service before April 2016. Is this enough time to enable people to get ready for the change?.....	13
What can we do to help people get ready for the change?.....	14
Chart 3: What do you (or the person you support) use the CSS for? .....	17
Chart 4: Are you happy with the service you get? .....	17
Reasons for feeling happy with the CSS .....	18
Reasons for not feeling happy with the CSS .....	20
Chart 5: Would you stop using the CSS if you had to pay for it? .....	21
Reasons why you would stop using the CSS if you had to pay .....	21
How would paying for the CSS affect your life, or the life of someone you care for?.....	22

Is there anything else you would like to say?.....	24
<b>Appendix 2: Responses via other methods .....</b>	<b>26</b>
Table 2: Responses via other methods .....	26
<b>Appendix 3: Who took part .....</b>	<b>28</b>
Survey responses .....	28
Completing the survey as.....	28
Table 3: Gender.....	28
Transgender .....	28
Table 4: Age .....	28
Table 5: Ethnicity .....	29
Disability .....	29
Table 6: Impairment type .....	29
Table 7: Sexuality .....	30
Religion.....	30
Table 8: Stated religion or belief .....	30
<b>Appendix 4: Consultation information events .....</b>	<b>31</b>
Numbers attending the events .....	31
<b>Appendix 5: Frequently asked questions .....</b>	<b>31</b>

## About this document:

<b>Enquiries:</b> Author: Consultation team Telephone: 01273 481 565 Email: <a href="mailto:ASCLDDPSconsultation@eastsussex.gov.uk">ASCLDDPSconsultation@eastsussex.gov.uk</a>  <b>Download this document</b> From: N/A	<b>Version number:</b> 1 <b>Related information</b>
<b>Accessibility help</b> Zoom in or out by holding down the Control key and turning the mouse wheel. CTRL and click on the table of contents to navigate. Press CTRL and Home key to return to the top of the document Press Alt-left arrow to return to your previous location.	

## Background

We asked for views about our proposals to ask people to pay for the Community Support Service (CSS). People would only pay as much as they could afford.

The CSS helps people to be more independent. The cost for the service is £20 per hour.

### Why we are consulting

Everyone at the Council has been asked to find ways of saving money. People who have other services that are like the CSS have to pay for them. The money people pay for the CSS would be used to help run it.

### What we consulted about

We asked people:

- Do you think we should ask people to pay for the Community Support Service?
- No one would be asked to pay for the service before April 2016. Is this enough time to get ready for the change?
- What can we do to help people get ready for the change?
- What do you (or the person you support) use the Community Support Service for?
- Are you happy with the service you get? Why do you feel this way?
- Would you stop using the Community Support Service if you had to pay for it? If you would stop, why do you feel this way?
- How would paying for the Community Support Service affect your life, or the life of someone you care for?
- Are there any further comments you would like to make?

## Consultation process

The consultation started on 1 October 2015 and closed on 23 December 2015, meaning that it ran for 12 weeks.

### How people could take part

#### Online survey

An online survey was available throughout the consultation period. People could also download a printable version of the survey from the website. We encouraged people to complete the survey as often as they wished, allowing for them to add to or change their views if they learned new information or changed their opinion during the consultation period.

## Other forms of feedback

Those who chose not to complete the survey, but who wished to offer their views, were encouraged to do so by passing on verbal comments to the manager of the service, and written and email feedback.

A series of information events for clients, parents, and carers was held at a variety of locations. The dates and locations of the information events were:

Date	Location
8 October	Conquest Day Centre, St Leonards on Sea
8 October	Bellbrook Centre, Uckfield
9 October	Sovereign Harbour Yacht Club, Eastbourne
9 October	Sovereign Harbour Yacht Club, Eastbourne (Park Lane residents)
21 October	Bellbrook Centre, Uckfield (Field Cottage residents)
23 November	Park Lane Residents Meeting

Following the meetings a list of Frequently Asked Questions was made available via the consultation website (see appendix 5).

Any client who didn't attend a meeting was posted a survey and pre-paid envelope. We also encouraged people to submit comments via members of staff and other supporters.

Where clients were concerned about the changes or the financial implications they were offered the option of talking to a care management worker or having a light-touch financial assessment.

## Responses by method

**Table 1: Responses by method**

Response method	Total responses or attendees
Survey responses	64
Emailed, written or verbal responses	14
Group attendees (see appendix 4 for details)	39
<b>Total</b>	<b>117</b>

## Key themes

It is clear from the consultation that people value the CSS and the service it provides. People particularly value the support it offers around developing life skills and the relationship that clients have with their workers.

Respondents are concerned about whether they would be able to afford the service if they were asked to pay. Some people say they would stop using the service in that case, although a lot of people are unsure about what they would do.

Over half the respondents don't think people should be asked to pay for the CSS. In many cases, this is because they feel that the proposals are unfair, with a few respondents suggesting that savings should be found elsewhere.

A small number of respondents think that people should be asked to pay for the service in light of the need to make savings.

There is also a significant minority who are not sure about the proposal and this reflects a key theme from the consultation: uncertainty. People are unsure about what the proposal would mean for them and want to really understand the financial and personal implications.

The main concerns about the proposal are the financial implications for clients and their families and carers. Many respondents said they do not have much money or are afraid they wouldn't be able to pay for the service. People also said that the proposals would affect their ability to spend their money on other things.

In terms of helping people to prepare for changes to the CSS, the most common suggestion is to provide information and advice on money. This is a reflection of the uncertainty people feel about what the proposals would mean for them personally.

Issues that would need clarification if the proposals went ahead are:

- the cancellation process and whether you would still be charged; and
- whether it would be possible to have group support

## Comments

The following comments made during the consultation highlight some of the key themes.

### Should people be asked to pay for the service?

- "I totally oppose this proposal which will affect people who are vulnerable and often have this service as part of their medical treatment. I am sure the consultation will reveal this is unworkable and unacceptable."
- "The cost seems high which may deter the people who really need it. This may lead to more loneliness and isolation."
- "I [am] on benefits. I have bills to pay. I would worry [whether] I have enough money."
- "Won't really know until I know what the cost will be."
- "If the service is good we should pay for it. But I do worry about how much. If you want something good in life you have to pay for it."

## **Views on the CSS**

- “I like seeing new people. They have been helping me to learn new things. They help me with appointments and cooking.”
- “I feel that I can cope with things [when] I have my support worker.”
- “[It] encourages independence and confidence, and gives my daughter an opportunity to go out into the community in a normal and enjoyable manner.”

## **How can we help people to prepare?**

- “By giving us as much information as possible and for us to have the opportunity to discuss our own financial situation.”
- “Explain why you have to start charging. Make sure the money is there (they can afford it). Talk them through it. Make sure they understand, or their carer/parent does. Obvious things really.”
- “Give me more time and more information as to how much I may have to contribute.”

## **How would it affect you or someone you care for?**

- “As long as it is affordable, not too much.”
- “Being out of money...would feel stressed.”
- “I can’t answer this question because I don’t know how much I might be asked to pay.”
- “I would have less money to pay for food, accommodation and social activities.”
- “It would restrict what they could afford for pleasure and they might have to give up doing things they once could afford.”

## **Any other comments?**

- “Consultation should be directed to all on the voting register and include the question: “Would you be prepared to pay extra council tax to fund this service?” This very online consultation, analysis and presentation probably costs as much as the service it is trying to cut.”
- “Parent carers like us already save the council a significant amount. As I do all of our daughter’s personal care, to place this extra burden on us is a step too far.”

# Summary of consultation responses

## Survey results

### Number of respondents

**64** people completed a survey (not everyone answered every question)

Three-quarters of those completing the survey (48 out of 64) use the CSS

2 people submitted the survey after the consultation closed

### Should people be asked to pay?

**34** (out of 62 who answered the question) did not think people should be asked to pay

**10** thought they should and **18** were not sure

Those saying no were most likely to object due to the expense (13) or the proposal's lack of fairness (7)

### Is there sufficient time to prepare?

Of 61 answering:

- **21** said yes
- **18** said no
- **22** were not sure

### Ways to help people prepare for change

The most common suggestion – made by **18** respondents – was to provide information or advice on money

The offer of non-specific information, support, or communication was the next most common – suggested by **7** respondents

### Use of the CSS

Over **half** of all respondents used it for:

- learning new skills (**37**);
- doing things in their local area (**35**);
- looking after health (**35**); and
- housing and money (**32**)

### Satisfaction with the CSS, and reasons

**47** (of the 57 who answered) were happy with the CSS and **2** said they were not happy

The most regularly occurring reasons for satisfaction were:

- the help that was offered around life skills (**9** mentions); and
- the client's relationship with workers (**8** mentions)

### Would you stop using the CSS if you had to pay for it?

Of 56 answering:

- **16** said yes
- **17** said no
- **23** were not sure

### Reasons why you would stop using it

The main reason ticked was because they didn't think they could afford it (**17** people)

Others ticked:

- Didn't want to pay for the service (**10**)
- Didn't want a financial assessment (**2**)
- Preferred to use other services (**2**)



### Effect of paying for CSS

The most regularly noted effects were:

- Respondents'/carers' worsening financial situation (**17** mentions); and
- inability to spend money on other things (**9** mentions)

### Other comments

Invited to make any other comments, the majority were negative (**12** of 14 comments) and focused on:

- incorrect public spending priorities (**4**);
- criticisms of the consultation (**2**);
- resistance to paying (**2**) or reluctance to pay by other means (**1**); and
- uncertainty over what non-payment would mean (**1**)

### Other feedback

#### Number of respondents

**39** people attended a consultation information event

**14** other submissions were made through comments at events, by letter, email, phone or through talking to members of staff

#### Should people be asked to pay?

The responses that addressed this element of the consultation said that people shouldn't be asked to pay

The main reason given is that it would be unfair to ask people to pay, although some people just raised the issue of affordability

Many of the responses also raised uncertainties about what the proposal would mean for them and their finances

#### Use of CSS and whether they would continue

A number of the responses talked about the value of the service and how they, or someone they care for, uses the service

Some people said they would stop using the service if they were asked to pay, while others said they would have to look at their options

#### Other issues and queries

Other issues and queries raised included:

- issues with the consultation process and timing;
- the cancellation process and whether you would still be charged; and
- whether it would be possible to have group support

## What happens next

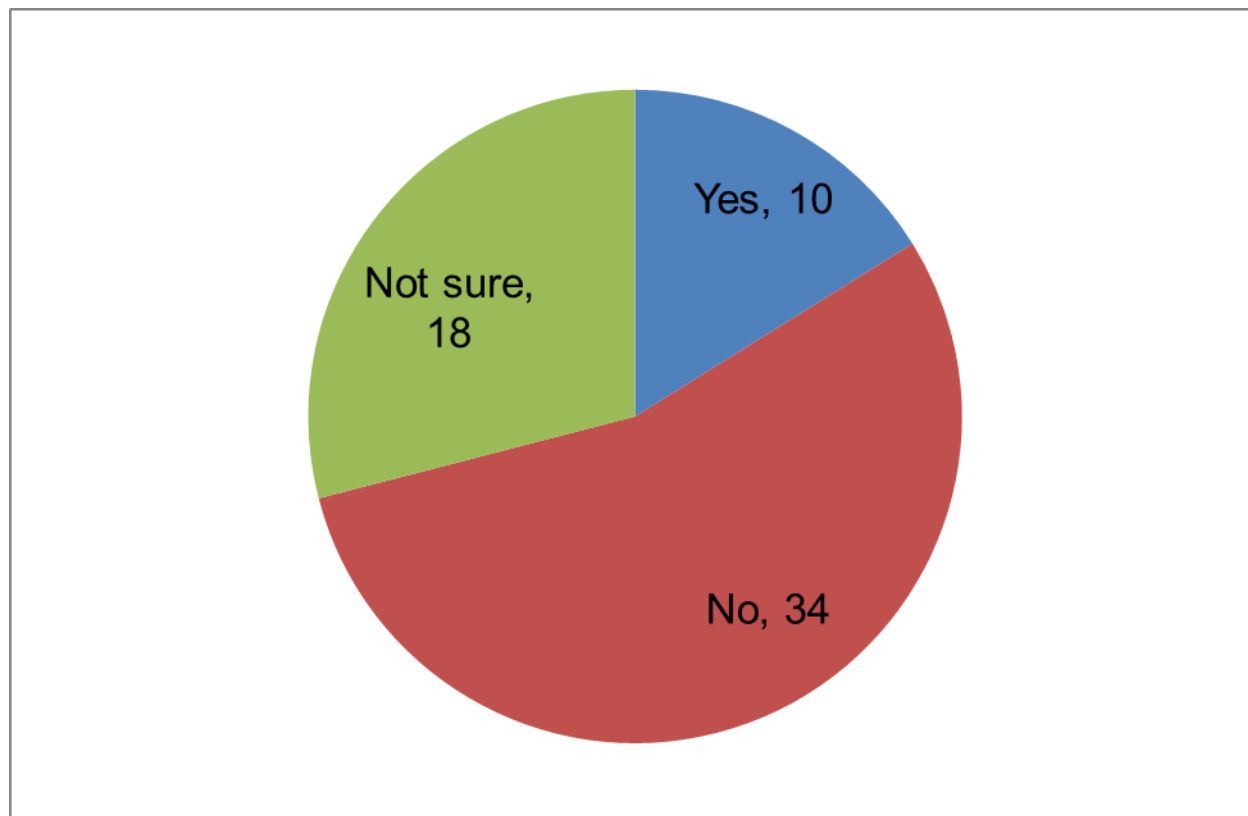
The consultation results will be considered alongside recommendations and an Equality Impact Assessment at the Lead Member meeting on 25 February 2016.

After the meeting, we will share the decision with everyone and let people know what is happening next.

## Appendix 1: Survey results

Please note: There may be more themes than comments, as some comments gave rise to more than one theme. All raw comments have been edited to remove personal information.

**Chart 1: Do you think we should ask people to pay for the community support service?**



Note: 2 people did not answer the question.

### Related comments on whether people should be asked to pay

The following three sections show the themes and comments from: 1) Respondents who thought people should be asked to pay for the CSS; 2) Respondents who thought they shouldn't be asked to; and 3) Respondents who weren't sure. In all cases, the themes are shown first and then the raw comments.

#### Reasons for saying people should be asked to pay

The themed reasons for asking people to pay were:

- Can afford it (4 mentions)
- Service is worth it (3)
- Will improve quality of life (1)
- No reason offered (2)

The table below shows people's raw comments.

#### Raw comments

Because I will be able to go out.
Because if there's no more money for the service, then we will lose it and that would be a great shame.
I can contribute more.
If the service is good we should pay for it. But I do worry about how much. If you want something good in life you have to pay for it.
Only if people can afford it.
People should pay but only if they can afford it.
They would value the service.
Those on higher incomes!

### Reasons for saying people should not be asked to pay

The themed reasons for saying people should not be asked to pay were:

- Expense (13 mentions)
- Unfair (7)
- Should fund in other ways (e.g. council tax) (3)
- Service is not worth paying for (1)
- Previous assessment process was not straightforward (1)
- Effect on health and wellbeing (1)
- No reason offered (11)

The table below shows people's raw comments.

Raw comments
Because I can't afford to pay.
Because I don't think it's fair for people with a disability.
Because I'm on benefits.
Because I'm on benefits.
Because some of us don't have paid jobs so we don't get much money...for support.
Because some people can't afford it...that's why I said "No". It would be unfair if someone pays for [the] support service when someone can't pay for [the] service.
Because with all of the cuts people are on the receiving end of, making people pay extra costs for services which could directly affect their health and wellbeing seems very unethical. [Client] currently uses community support services to attend a swimming/hydrotherapy appointment, without which her health could decline further.
Extra time for me to think about.

I am not sure that I would be able to afford the support.
I believe it should be funded by an increase in council tax.
I do not think I could afford [to pay] as I am on benefits.
I don't know why.
I don't think it's fair.
I [am] on benefits. I have bills to pay. I would worry [whether] I have enough money.
I understand about raising costs and cuts, but I have real concerns about asking the most vulnerable people in our society to absorb these cuts. I help young people fill in their PIP forms – most don't understand about budgeting and yet they will have money cut from their slender pot. I actually broke down and cried when I heard about this as I worry tremendously about how my daughter will manage in the future when I am not around, as she probably won't qualify for full support, but will struggle by on a bit of Community Support which she [will] now have to pay more for. She already pays for Daycare support at St. Nicholas Lewes and it all feels like a very slippery slope. All the time I am alive I will absorb this for her, so in a sense it is a tax on me. It makes a bit of [a] mockery of the ESA and DLA that is given to her for essential living costs.
I will not have much money left.
Most people with special needs are on low incomes and can't afford to pay.
Some people's costs are not always...taken into consideration and if they are on benefits this is the income the government excesses [sic] them to need.
The community should support the disabled through the council tax; as I am well under the financial limit it may not affect me directly.
These are some of the most vulnerable adults in our society. We'd be happy to pay a small increase to help these people. This sounds like a PR exercise to sell a decision that has already been made.
Too much has been taken away from...vulnerable people already with the cuts on welfare.
We already pay for it with our taxes.
We do not want to pay for the service as it is getting wasted and we wanted it for other things.
When my daughter was asked to contribute before, the assessment for her income and expenditure was inept...after a long and stressful complaint she was assessed finally accurately with a nil contribution – as will many people with a learning difficulty.
Won't really know until I know what the cost will be.
[First respondent of two]: [No, as] I don't see why we should have to pay towards CSS wages. [Second respondent]: [Yes, as] I don't want to lose the service.

## Reasons for not being sure whether people should be asked to pay

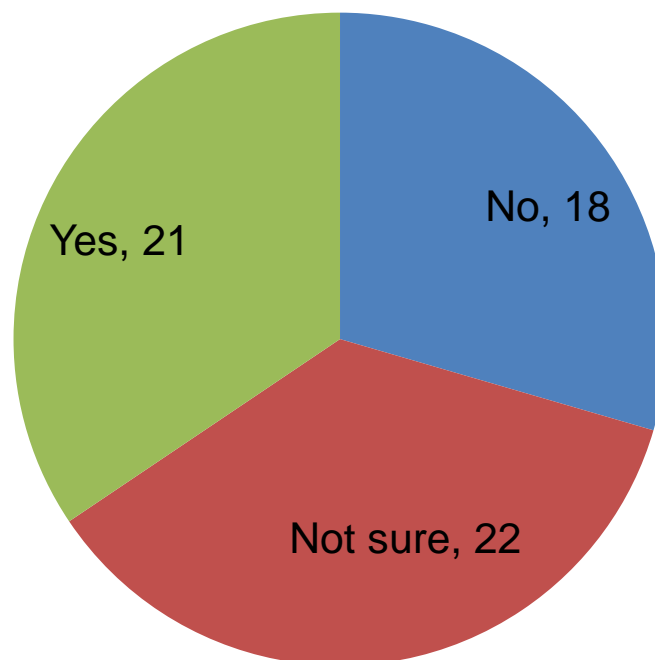
The themed reasons for people who are not sure were:

- Expense (9 mentions)
- Unfair (1)
- No reason offered (1)

The table below shows people's raw comments.

Raw comments
Because I already pay for use of a garage for my collection of books, mags etc.
I would prefer to keep my money.
It does depend on circumstances for the person concerned as each one is different. Rather than lose the service I would say "yes" if it's affordable for that person.
Most people can't really afford it.
Not sure about whether I should pay towards care...not sure if I could afford to?
Some people may not be able to pay and will lose a valuable service.
The cost seems high which may deter the people who really need it. This may lead to more loneliness and isolation.
They might not have much money, in their pockets.
This all depends on how much we would be asked to pay.

**Chart 2: No one would be asked to pay for the service before April 2016. Is this enough time to enable people to get ready for the change?**



*Note: 3 people did not answer the question.*

### What can we do to help people get ready for the change?

In all, 45 respondents answered this question. The themed reasons for helping people to get ready for the change were:

- Provide information/advice on money (18 mentions)
- Offer information/support/communication (non-specific) (7)
- Advise on how changes will operate (4)
- Provide sufficient notice of changes (4)
- Offer psychological support (2)
- Explore other ways of providing the service (2)
- Improve/amend current service (2)
- Don't know/No suggestions offered (11)

The table below shows people's raw comments.

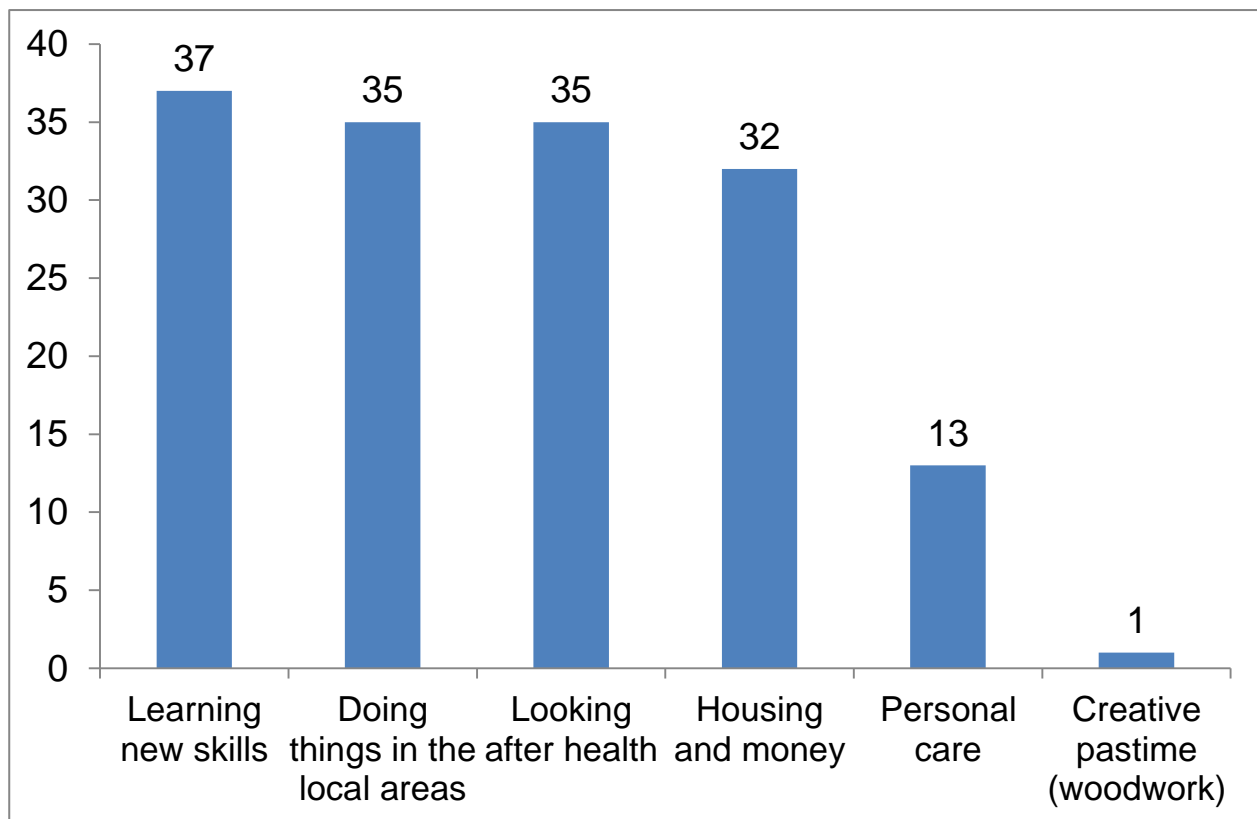
Raw comments
Inform them using as many channels as possible to reinforce the message.
Tell people accurately the criteria you will use for their income and expenditure assessment and what they need to do in readiness to mitigate the impact on their budgets. Also allow for a social life budget. My daughter was allowed £3 per week for her social life in her original income and expenditure budget. Best practice does allow for a contribution towards the household if a service user lives at home. Also for Christmas birthdays and a summer holiday – you all have one don't you.
Negotiate with community organis[ations] who may be providing services that would help meet needs.
Put in place another strategy for helping [client] to maintain good posture.
Better service.
Seeing as the Community Support team are not allowed to handle money for their clients, it would seem like you would need to employ a specialist Money Adviser to go through clients' budgets with them. This is almost ok when their sole income is their benefits, as this is an amount that probably can be calculated publicly, but if it is a case of coming in to tell me what I have to cut back and start examining my spending and income, it is highly insulting and an [invasion of] my privacy.
?
Can't think of anything – whatever needs doing is being done by working out the finances.

Don't know.
Don't know.
Don't know.
Don't know...will need advice from CST.
I do not know.
I don't know.
No chg [sic].
No chq [sic].
Nothing.
Communication.
Give them as much support as they need on an individual basis.
Information.
Information.
Keep informed of any progress.
Talk to them about what they want.
Send round psychological support for all recipients to reduce suicide and potential for self-harm.
This will be such a shock to vulnerable people that one-to-one counselling will be needed to reduce suicide risk.
Give people plenty of notice.
Give them another year to get ready.
You could have at least given out the consultation dates to all members of the public well in advance of the consultations. I found out about this today. The consultations were last week. Reschedule new consultations and do it properly.
By helping them get more money i.e., help with getting job.

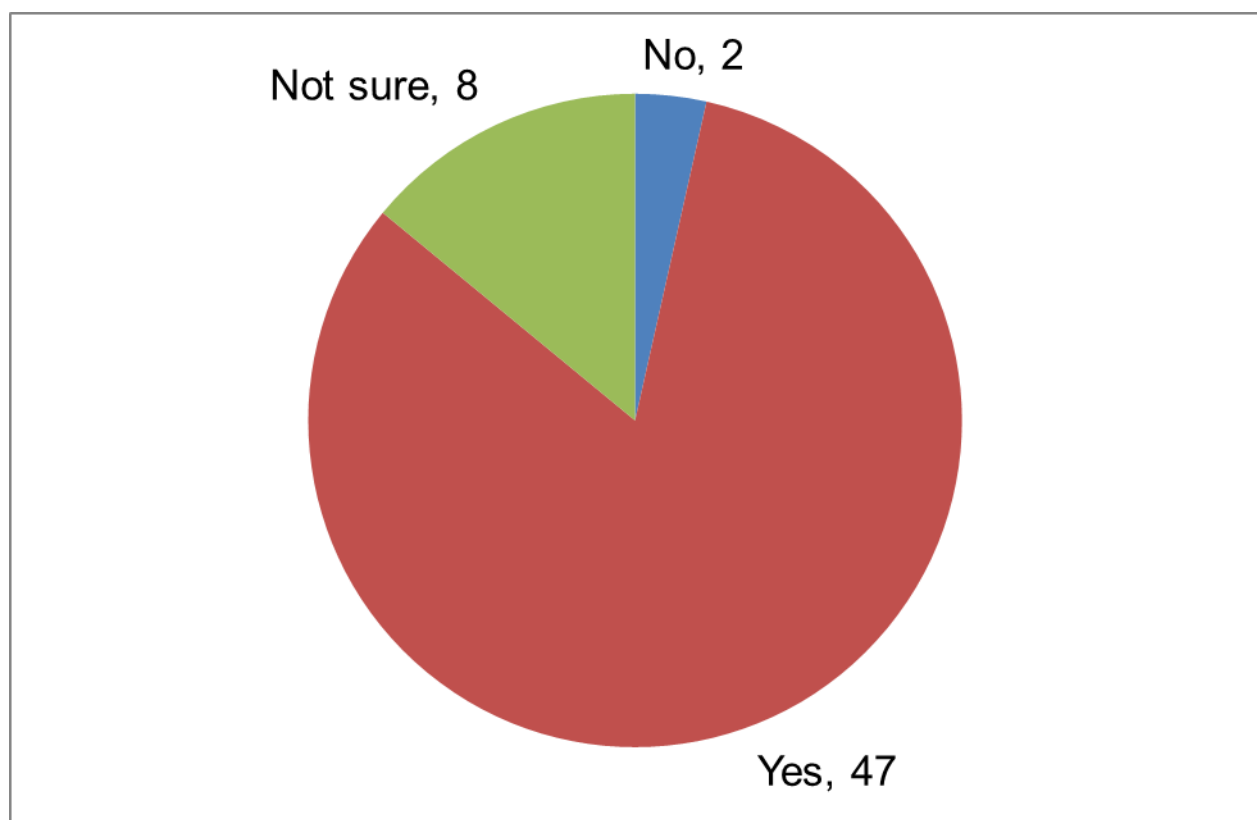
Check finances.
Explain to us how it will work and where the money will go if we have to pay.
Explain why you have to start charging. Make sure the money is there (they can afford it). Talk them through it. Make sure they understand, or their carer/parent does. Obvious things really.
Give me more time and more information as to how much I may have to contribute.
Help people find financial assistance.
Identify those who will face financial hardship.
Look at finance.
More information on how much I pay.
More time and a breakdown of costs.
Personally I would need support so I can find out what extra money I could get to pay for any charges that may be made.
Say whether or not all my support will be stopped.
So that I can spend more money on food.
Tell me how much I am going to have to contribute towards my support.
To say you have to pay for service.
[First respondent of two]: By giving us as much information as possible and for us to have the opportunity to discuss our own financial situation. [Second respondent]: Yes, you could give us some idea how much the service would be.



**Chart 3: What do you (or the person you support) use the CSS for?**



**Chart 4: Are you happy with the service you get?**



*Note: 7 people did not answer the question.*

## Reasons for feeling happy with the CSS

The themed reasons for feeling happy with the CSS were:

- Helpful (life skills) (9 mentions)
- Worker relationship (8)
- Enjoyable (7)
- Helpful (non-specific) (6)
- Friendly (4)
- Helpful (personal care) (4)
- Helpful (pastimes) (3)
- Reliable (2)
- Encouragement (2)
- Helpful (emotional) (2)
- Budget advice (2)
- Continuity and regularity (2)
- No elaboration (3)

The table below shows people's raw comments.

Raw comments
Learning money skills. Dietary advice. Support to help sort out benefit problems.
Because [I'm] just happy with one support person once a week.
Because it has helped my son use the bus and his money better. Also he is doing cooking now, which he enjoys.
[It] encourages independence and confidence, and gives my daughter an opportunity to go out into the community in a normal and enjoyable manner.
I am happy with the service and I enjoy it.
My daughter enjoys her day centre, has had the service for 20 years, and would not be able to cope with having her services cut. [I] certainly wouldn't be able to pay extra.
Yes I am happy at my work.
Always friendly [and] helpful, with new ideas for making a more independent living for people with special needs.
Very friendly and helpful team of people who support me.
[Client] is very happy with the service she gets. Her support worker is friendly, helpful,

encouraging and motivating. [Client] looks forward to her swimming as it gives her relief from backache and keeps her supple – [she] has more freedom of movement in the pool.
Very nice.
I like seeing new people. They have been helping me to learn new things. They help me with appointments and cooking.
My daughter is severely autistic with a profound learning difficulty. Autism Sussex centre, [which] she attends, helps her to find coping strategies for her stress. It is a calm, quiet and safe environment enabling her to make significant progress in life skills.
It is helpful and it helps me to remain independent.
They help me live independently.
Without them supporting me, I'd be stuck. They help me with appointments. It would be useful to know who I'd got for support, so I can plan things. Sometimes I can only talk to certain people about certain problems.
Because I get the help I need.
Because when [they] show me something I do it on my own.
Incredibly, they are an amazing bunch, and if I had the money I would happily pay more – but my daughter has already been means-tested for what she can afford to pay.
Yes, because they help me.
You are a good team. Keep up the good work.
Day centres – Southview Close. Conservation. Look after Ashdown Forest.
Because they assist and prompt with my daily personal care and hygiene and support me at the gym.
Because they keep me in check.
Yes.
Fine just the way it is.
Fine just the way it is.
It's very good. They are always there when I need them.
I enjoy my time with my Community Support Worker. It helps me to feel independent and

we get on well together.
I feel that I can cope with things [when] I have my support worker.
I like the people who take me out as they are always happy to take me where I want.
Good key workers. Good service.
I like working with my keyworker.
Members of staff that support me...I get to know them, and get on with them better.
They are wonderful people.

### Reasons for not feeling happy with the CSS

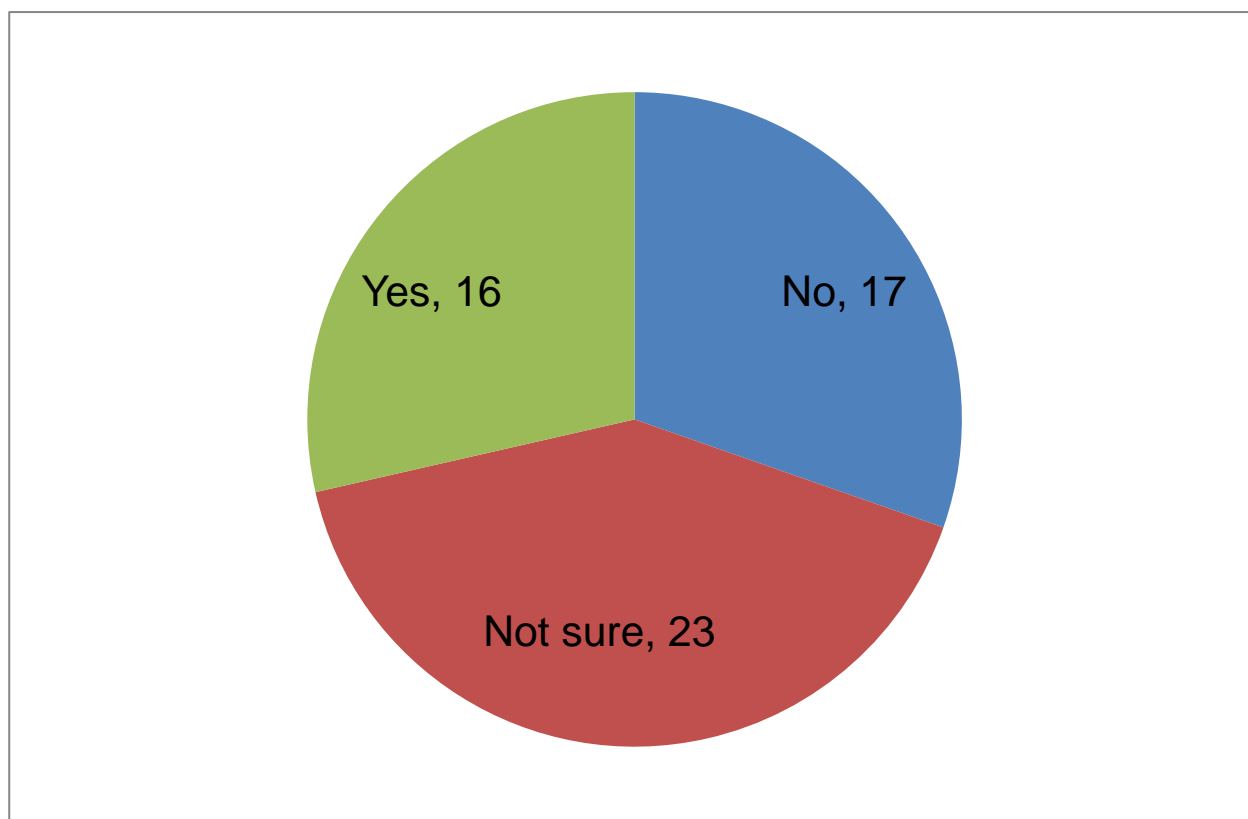
The themed reasons for not feeling happy with the CSS were:

- Restricted quality of life (1 mention)
- Insufficient choice (1)

The table below shows people's raw comments.

Raw comments
Because I can't go out and I have to use taxis. You used to take me shopping in your car.
I would like to be the boss.

**Chart 5: Would you stop using the CSS if you had to pay for it?**



*Note: 8 people did not answer the question.*

**Reasons why you would stop using the CSS if you had to pay**

The survey gave people a list of options on why they would stop using the service. The reasons why people would stop using the CSS if they had to pay were:

- 17 respondents ticked: I don't think I could afford it
- 10 ticked: I don't want to pay for the service
- 2 ticked: I don't want to have a financial assessment
- 2 ticked: There are other services I'd rather use

People could also tick 'something else' and explain in the box below. The following other reasons/comments were made:

Raw comments
It's a bloody cheek asking people for money when they don't have it.
It's a bloody cheek asking people for money when they don't have it.
Other services I have used [are] cheaper and they take me in their car.
Depends how much.
For what [named person] reviews, I as his carer would carry on doing for [client].
I am happy as it is without messing it up – thank you.
I would like to keep my money in an envelope.
It would need to be seriously considered as other essential and maybe non-essential costs

would need to be cut and it would need serious consideration depending on how much extra was demanded.

### How would paying for the CSS affect your life, or the life of someone you care for?

In all, 54 people commented, with the following themes on how they or someone they care for would be affected:

- Worse off financially (17 mentions)
- Unable to spend money on other things (13)
- Wouldn't/may not have an effect (9)
- Would damage health/wellbeing (5)
- Would restrict travel (3)
- Would damage living arrangements (1)
- Would improve it (1)
- Would/may not use the service (1)
- No elaboration/don't know (8)

Raw comments
I have a lot of other things to pay for. [Wrote "Not Paid."]
I have a lot of other things to pay for. [Wrote "Not Paid."]
?
As long as it is affordable, not too much.
Being out of money...would feel stressed.
Couldn't buy new boots.
CST I can now go to places by myself, I couldn't before.
CST I can now go to places by myself, I couldn't before.
Don't know.
Don't know – stop me doing other things I pay for at the moment.
Don't know until I know [how] much I will have to pay for my support.
Every penny is accounted for. So would mean going without food, gas or electricity. Live in poverty as it is now; can't take [any] more cutbacks.
Finances. I don't know; make me poor.
Hopefully no change.
I can afford to pay.
I can't answer this question because I don't know how much I might be asked to pay.

I don't know.
I don't know.
I don't really know.
I hope that it would focus on positive outcomes rather than maintaining the status quo.
I might have to miss out on other things.
I think I have already covered this. But for my daughter it would mean a lack of skills learning – cooking and travel, training and, as I work f/t, a lack of contact with the outside world, leading to isolation and return to depression and low mood. When put down in black and white, I probably wouldn't stop it for her – so it is a tax on me until I die, then poverty for her.
I will have less money.
I will have less money.
I would have less money.
I would have less money for my day-to-day living.
I would [have] less money to live on.
I would have less money to pay bills and household needs.
I would have less money to pay for food, accommodation and social activities.
I would not be able to do some of the things I do as well as having support because I wouldn't have the money.
I would stick with Eastbourne Community Support Team – ok to get on with and a good bunch of people. If I had to pay it would have to be by direct debit.
I wouldn't have as much money.
I wouldn't mind if the service had to close because of money.
If it was in my budget it would not affect me.
It is not going to affect my life, I am happy to pay for the service.
It means we as a family will have to support him at clubs.
It will leave me less money to live on each month.
It would leave me less money to spend on food, household bills, tv licence.
It would not have much of an effect on my life.
It would restrict what they could afford for pleasure and they might have to give up doing things they once could afford.
It wouldn't [sic].
Leave me with less money.

Less money to spend on me. I pay enough already for rent.
Maybe not use it so much.
Not sure; don't know. It would leave me with less money to spend on shopping bills, clothes, shoes for example.
Paying would take my savings down and make paying bills difficult.
Possibly increase her client contribution.
She wouldn't be able to afford it and as this was a cheaper option for the NHS than regular physiotherapy then this would affect [client's] posture more and give her more pain. If [client] had to pay for this service she wouldn't have enough money to access her day services and clubs.
Some people got upset about it.
The stress of the injustice would be crippling for every community-minded person. We pay for this service for EVERYBODY via our taxes. Stop trying to surreptitiously privatise health and social care.
We already supplement our daughter's income. I am now a pensioner. My husband is close to retirement. We still have a mortgage. I don't think we could keep our daughter at home any longer. She needs 24-hour care and, if not managed well, displays very challenging behaviour.
We are already budgeting our money. We do not need another bill?
Will not be able to go out so much.
It would add more stress on me as I sort out all the bills...It would be quite hard to find the money.

### Is there anything else you would like to say?

A total of 32 comments were made in response to this question. These have been divided into three groups: positive, negative and neutral. The themes within the positive and negative groups are as follows:

Positive general themes (2 comments offered; 2 themes emerged):

- Good service (1 mention)
- Offers opportunities (1)

Negative general themes (12 comments offered; 14 themes emerged):

- Incorrect public spending priorities (4 mentions)
- The consultation is flawed (2)
- Resistant to paying for this service (2)
- Insufficient information received (2)
- Erratic timekeeping/service delivery (2)
- Unwilling to receive this service from another source (1)



- Uncertain over what non-payment would mean (1)

Three comments were classified as neutral, and the remaining 15 comments specified that the respondent did not wish to make any further points.

Raw comments
<b>Positive</b>
I am happy with the service. It is very good.
I like working for the NHS two days: Wednesday and Friday.
<b>Negative</b>
Consultation is meaningless when it is carried out at a safe distance at the other side of the Internet. Every resident should have been consulted personally by letter and asked if they would be prepared to pay for the community support service via an increase in council tax. THAT would be democracy.
Consultation should be directed to all on the voting register and include the question: "Would you be prepared to pay extra council tax to fund this service?" This very online consultation, analysis and presentation probably costs as much as the service it is trying to cut.
People mess me about with the times. Times still change and I'm not told. There was a different time on my rota. When I phone I mostly get Hastings instead of Uckfield..It doesn't help. Not helpful.
Council Tax should be increased to finance community care. The nation gives away money to other countries yet does not wish to support its own needy.
Parent carers like us already save the council a significant amount. As I do all of our daughter's personal care, to place this extra burden on us is a step too far.
The government doesn't prioritise the help needed with social care. They should stop giving aid to other countries and put people in our own country first. There are lots of other ways government could save money, come out of the EU and go after the tax avoiders.
I want more information before I can decide whether or not I can afford or would be willing to pay a contribution towards my support.
I would like more information [name and address added].
It is a shock to pay for something I got for free before.
I live at Park Lane. What would happen to me if I couldn't afford to pay? Would I have to move from Park Lane?
<b>Neutral</b>
I rely on support worker company and....supports.
I would like another cup of tea.
The dangers of burning fires.
<b>Specified they had no other comments</b>
No, don't think so.
[Put a line in the box]

[Put a line through the box]
Don't think so; nothing I can think of.
No.
No.
No.
No.
No.
No.
No.
No.
No.
No.
Nothing else.

## Appendix 2: Responses via other methods

The table below provides a summary of responses received via other methods.

**Table 2: Responses via other methods**

No.	Method	Who from	Summary
1	Phone call	Carer	They feel that the decision to charge is a done deal. The carer explained about the client's circumstances and the need to continue with swimming as per the GP's instructions.
2	Letter	Parent of client	The letter says this is the wrong area in which to make savings. It explains the positive effect of the CSS for his son – describing it as a 'lifeline'. It queries whether a medical service can be charged for. It says they oppose the proposal which will affect people who are vulnerable and often have this service as part of their medical treatment, concluding by saying that the consultation will reveal the plan is unworkable and unacceptable.
3	Email	Family of resident	The email expressed concern about the proposal and that her family member would not be able to continue living at the residence because of the cost. She said they would want to explore other options if it would mean paying the full cost of the service.
4	Discussion	Family of client	Until there is a financial assessment and he

	with member of staff		knows how much he may have to contribute it is hard to say how he feels.
5	Discussion with member of staff	Client	The client won't make any decisions until he knows what he may have to pay. He is seeking advice as to what to do if he did have to contribute.
6	Discussion with member of staff	Family of client and client	At this point, neither are in favour of paying for the CSS if he was assessed as needing to make a contribution.
7	Discussion with member of staff	Parent of client	Benefits are complicated and he is seeking answers to financial questions about existing and possibly changing benefits claims.
8	Comment	Parent of resident	They said that if we only give six months' notice of the change then that doesn't give people a lot of time to negotiate their way out of a number of other contracts, which might be a year or longer.
9	Email	Parent	The email said that they would make a legal challenge if their daughter is denied services she has been assessed as needing.
10	Letter	Client	They don't think people should be asked to pay for the CSS, as it is not fair. They say they are not going to pay for the service as they are a pensioner and don't have much money left after bills have been paid. They use the CSS to help them read their letters and bills. The letter asks what the Council will do with the money that is saved.
11	Letter	Involvement Matters Team	The group said that people with learning disabilities could have more difficulties if the Council make more changes. They may have to pay for the CSS, but people don't know exactly how much each of them might have to pay. People want to know exactly what it means for them.
12	Survey (wrote responses rather than completing it)	N/A	They don't think people should pay for the service, as it's not fair as people don't have much money. They say they don't want to pay for the service.
13	Email	Parent of client	The email said the client no longer wished to use the CSS because they feel they can't afford the proposed new cost.
14	Comment	N/A	The consultation is taking too long. People are worrying about what is going to happen.

## Appendix 3: Who took part

### Survey responses

#### Completing the survey as...

Three-quarters of those completing the survey (48 out of 64) did so as a user of the CSS. A further 9 completed it as a carer or parent of a client. Another 5 ticked “Other” (of whom 2 added “No”, while the other 3 did not elaborate). One person completed the survey on behalf of an organisation. The remaining respondent did not answer the question.

**Table 3: Gender**

Gender	Respondents	Census
Male	26 (41%)	48%
Female	29 (45%)	52%
Prefer not to say	0 (0%)	N/A
Not answered	9 (14%)	N/A

#### Transgender

No one identified as transgender. Most (51; 80%) said they were not, and 1 (2%) preferred not to say. The remaining 12 (19%) did not answer the question.

**Table 4: Age**

Age	Respondents	Census
under 18	0 (0%)	19.8%
18-24	2 (3%)	7.3%
25-34	8 (13%)	9.6%
35-44	3 (4%)	12.5%
45-54	8 (13%)	14.2%
55-59	7 (11%)	6.3%
60-64	6 (9%)	7.5%
65-74	8 (13%)	11.2%
75-79	2 (3 %)	11.6%
80-84	0 (0%)	
85 plus	0 (0%)	
Not answered	20 (31%)	N/A

**Table 5: Ethnicity**

Ethnicity	Respondents	Census
White British	54 (84%)	98%
White Irish	0 (0%)	
White Gypsy/Roma	0 (0%)	
White Irish Traveller	0 (0%)	
White other	0 (0%)	
Asian or Asian British Indian	0 (0%)	0.6%
Asian or Asian British Pakistani	0 (0%)	
Asian or Asian British Bangladeshi	0 (0%)	
Asian or Asian British other	0 (0%)	
Mixed White and Black Caribbean	1 (2%)	0.5%
Mixed White and Black African	0 (0%)	
Mixed White and Asian	1 (2%)	
Mixed other	1 (2%)	
Chinese	0 (0%)	0.2%
Black or Black British Caribbean	0 (0%)	0.3%
Black or Black British African	0 (0%)	
Black or Black British other	0 (0%)	
Other	0 (0%)	0.3%
Prefer not to say	2 (3%)	N/A
Not answered	5 (8%)	N/A

The “Mixed other” person further self-described as “Cape coloured”.

## Disability

Most (47) survey respondents considered themselves to be disabled, while 8 did not, and 2 preferred not to say. The remaining 7 did not answer the question.

**Table 6: Impairment type**

Impairment type	Respondents
Learning disability	42
Physical impairment	10
Longstanding illness or health condition, such as	4

cancer, HIV, heart disease, diabetes or epilepsy	
Mental health condition	3
Sensory impairment (hearing and sight)	3
Other – comprising:	10

People who ticked 'other' added the following information:

- My nerves/convulsions
- Angina
- Asthma
- Autism (x2)
- Diabetic and have bad legs
- Onset dementia, diagnosed 2013
- Poor eyesight

**Table 7: Sexuality**

Sexuality	Respondents
Bi/Bisexual	0 (0%)
Heterosexual/Straight	45 (70%)
Gay Woman/Lesbian	0 (0%)
Gay Man	0 (0%)
Other ( <i>unspecified</i> )	1 (2%)
Prefer not to say	9 (14%)
Not answered	9 (14%)

## Religion

In all, 29 respondents (45%) considered themselves to have a religion or belief, while 23 (36%) did not; and 4 (6%) preferred not to say. The rest (8; 13%) did not answer the question. The table below shows the breakdown by religion type.

**Table 8: Stated religion or belief**

Religion	Respondents	Census
Christian	25 (39%)	60%
Buddhist	2 (3%)	0.4%
Roman Catholic	2 (3%)	-
Hindu	0 (0%)	0.3%
Jewish	0 (0%)	0.2%

Muslim	0 (0%)	0.8%
Sikh	0 (0%)	0%
Other	0 (0%)	0.7%
No religion	23 (36%)	30%
Religion not stated	4 (6%)	8%
Not answered	8 (13%)	N/A

## Appendix 4: Consultation information events

### Numbers attending the events

Date	Location	Number of people
8 October	Conquest, St Leonards	8
8 October	Bellbrook Centre, Uckfield	11
9 October	Sovereign Harbour, Eastbourne	5
9 October	Sovereign Harbour, Eastbourne (Park Lane residents)	4
21 October	Bellbrook Centre, Uckfield (Field Cottage residents)	4
23 November	Park Lane Residents Meeting	7

## Appendix 5: Frequently asked questions

These questions came up at the consultation information events and were posted on the consultation website.

### 1) What is the £23,250 threshold, above which a person will have to pay for all care themselves, based on?

Financial assessments are carried out in line with 'The Care and Support (Charging and Assessment of Resources) Regulations 2014'. This legislation states 'In assessing what a person can afford to contribute a local authority must apply the upper and lower capital limits.' The Department of Health sets the upper capital limit annually and this is currently set at £23,250. A person with assets above the upper capital limit is deemed to be able to afford the full cost of their care.

### 2) Various other services are paid for. Why have changes to this service been left until so late in the day?

CSS was originally set up using different funding streams and grants. It was offered as a time-limited service. However, CSS is now core funded (paid from the Council budget). CSS has evolved over time and now provides both ongoing and time-limited services, in

the same way as other Learning Disability (LD) services like Day Services and Respite Services, which are chargeable.

**3) How is the £20.00 cost per hour for Community Support justified when Personal Assistant (PA) services cost around £12 per hour?**

The CSS hourly cost has been calculated by taking into account staffing, service and management costs. We recognise that this rate is higher than the PA; however, the CSS provides a different scope of services from a PA support worker.

**4) This proposal affects no more than 150 people across East Sussex. Is it therefore justified?**

The council has to find savings of £70 to £90 million over the next three years. Services have been asked to review all possible areas where savings could be achieved. Initial calculations indicate that introducing charging could generate up to £50,000 a year which would be put towards the savings target. East Sussex County Council (ESCC) provides a range of support for vulnerable people but is reliant on income from charges to help pay for them.

**5) Are there not large financial implications for ESCC in implementing Financial Assessment?**

The council has a dedicated team who complete Financial Assessments and have the capacity to undertake these as part of their role. Nearly half of the clients who receive CSS have already had a Financial Assessment.

**6) The projection is that this proposal would raise £50,000. Some may see this as low and ask whether it justifies the proposed change?**

If CSS is able to find £50,000 in savings, this would be a significant contribution to the overall savings target for Learning Disability Directly Provided Services. If we are not able to find savings from implementing a charge for services, savings would need to be found elsewhere.

**7) To achieve the £50,000 estimate, this appears to work out as £10 per week per person. So why not just ask for a £10 contribution from everyone?**

ESCC have a "Charging for Care and Support Policy" which outlines government legislation and guidance about how care charges should be determined. The financial assessment looks at how much service the person receives and ensures that people are not charged more than it is reasonably practicable for them to pay; therefore charging rules are applied equally to each individual. This charge will vary, based on the individual's personal circumstances. People will pay either part of the cost, none of the cost or all of the cost of their service.

**8) In Park Lane we were told when the residency began that we had to have CSS. Legally what happens if charging begins?**

Park Lane has two elements of service:

- 1) The night-time support is a core service which is attached to the supported living scheme at Park Lane, and is provided by CSS. Tenants living at Park Lane would need to contribute towards this core service.
- 2) Day-time support hours are provided by the CSS main team. These hours are allocated to individual support needs and do not have to be provided by the CSS.

**9) How often would money be taken?**



ESCC would send invoices every four weeks in arrears.

**10) Would payment be just by direct debit?**

In addition to paying by direct debit there are several other ways clients can pay.

This includes:

- debit card;
- online;
- at the bank;
- at a post office; or
- by standing order.

All the options are shown on the back of your invoice. You may have to pay a charge for making the payment at a bank or post office.

**11) Some day services charge, whether or not the client is in the service. How would the rate be affected if the client were i) on holiday; ii) did not want to attend something; or iii) cancelled something?**

All chargeable services have a cancellations policy. At present the CSS does not have a cancellations policy; therefore this is in development and will be shared with clients and carers if the outcome of the consultation is that charging will be implemented.

The CSS will ask clients to provide notice if they want to cancel a support session. If less than 24 hours' notice is given, the client will still be charged for the support. This is how cancellations work in other charged-for services.

The way clients are charged depends on the amount they are assessed to pay compared with the cost of their care and support. If a person pays a contribution to support, this figure is calculated as an average over 12 months; therefore if a service is cancelled it might not change the amount that you pay.

If the amount you have paid at the end of the year is more than the cost of your care/support, the Financial Assessment team will adjust your contribution and refund the difference.

**12) If support is received as part of a group, how does this affect costing?**

As the CSS has not charged for services before, this question has not arisen previously. As this question has been raised, we will be looking at the charge for support provided as part of a group and will provide further information on this if the decision to charge is taken forward.

**13) I had a Financial Assessment some while ago [2013]. It concluded that I should contribute, but I've seen no money towards the care go out. Does this mean I will need a reassessment?**

If you have not received any other services from ESCC since your financial assessment you would not have been charged, as CSS has remained a free service. Where someone has already been financially assessed we will consider whether we need to carry out another financial assessment visit. In some cases we may be able to review the assessment based on the information we already hold and any information we can gather from the Department for Work and Pensions. If we don't need to visit you again, we will write to inform you how much you are assessed to pay based on the information we hold.

If you did not agree with this amount you could provide any additional information you wish us to consider, or ask us to carry out a full review of your financial assessment.

**14) If a relative pays client contributions towards travel only, does that bypass the need for a Financial Assessment for the client?**

All clients accessing CSS will need to have a financial assessment. Where ESCC provides travel, this is charged at a standard rate and is not subject to a financial assessment. Where travel is normally part of a support provision, for example with a day service, it is charged and this would be included in the financial assessment.

**15) The assessment is completed on current income. This may fluctuate. Do we let Financial Assessment staff know each time this alters?**

If income fluctuates, the financial assessment will be based on an average income. However, if there is any change in financial circumstances, clients will need to let the financial assessment team know, so that the contribution can be reviewed. Financial assessments are automatically reviewed each April in line with benefit changes and the Financial Assessments team will write to clients to let them know how much they have been assessed to pay. If the information used to calculate your contribution is not accurate, clients should send in up-to-date figures so it can be adjusted.

**16) If a financial charge is decided, and relatives decide they cannot afford to pay, can they assess the different kinds of care they could afford?**

Clients and carers can contact the Community Learning Disability Assessment team (CLDT), who will be able to review the client's needs and discuss the alternative support options that might be available. Most alternative services are chargeable.

**17) What can be done to combat possible increase in vulnerability of those clients whose family may decide to fund their care independently?**

ESCC have a statutory obligation to oversee clients' support and safeguarding needs. The CLDT will be involved in any changes to client care provision and will continue to review clients' care provision to ensure clients' needs are being met.

**18) The National Health Service has an interest in these clients. Will the burden pass to it from ASC (e.g. more visits to GPs)?**

Clients may seek support from other services if they choose not to have CSS. Support needs will be overseen by CLDT to ensure clients are aware of all the support resources available to them. CSS is a Social Care service. Clients are able to access the NHS for any health-related needs.

**19) If the desired revenue is not achieved, what happens then?**

We have to find savings from between £70 to £90 million, across the Council over the next three years. Some gaps in funding can be covered by generating more income. If this is not possible, then other means of finding savings will need to be considered.