Social care support for carers
Focus Group Report

Venue: Southwark Carers:
3rd Floor Walworth Methodist Church
54 Camberwell Road
London
SE5 0EN

Date of focus group:
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Acknowledgements

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Disclaimer

Please note that this report relates to discussions that took place on the 28th January 2015. Our report is not a representative portrayal of the experiences of all carers, only an account of what was contributed at the time.

Contents

Background

Healthwatch Southwark is a champion for patient and public voice. We want people's voices to count towards improving services. We know that some groups are 'seldom heard' and therefore we aim to engage with these communities in a targeted manner. We want to understand the issues faced by carers in accessing services. We want to find out about their experiences of using services and the challenges they face.

Access to social care support was identified as a priority area for Healthwatch Southwark through public and stakeholder consultation. In June 2014, 'Spotlight on Social Care' Public Forum highlighted some concerns: how information about social care support is given to people, how assessments are carried out (e.g. over the telephone) and whether these assessments are appropriate, and what support is available to those outside of the Fair Access to Care Services (FACS) criteria. We wanted to build on this work as there was consensus that there should to be more understanding around individual needs and choice.

Aim of the focus group

The aim of the focus group was to understand the experiences of carers, particularly the carer's assessment process and, to an extent, their view of the cared-for-person's assessment for a personal budget.

Methodology

The focus group was advertised through Southwark Carers – an organisation that provides support, information and advice to carers across Southwark. At the time of the focus group, they undertook the majority of carers' assessments in the borough. Other services include advocacy, income maximisation, housing support, therapies, counselling, peer support groups, and mentoring.

The session was held over a period of 2.5 hours with 30 minutes for lunch. Before group discussion, each person completed a survey about their carer role.

A total of 12 carers attended, most of whom were adult carers. 2 were parent carers.

Findings

1. Carer's assessment

We wanted to understand what carers knew about the carer's assessment, including how they had found out about it in the first place, and how they had found the application process. We wanted to know what aspects had worked well or if they had any ideas about how things could be improved.

1.1. Finding out about carer's assessments

We found that there was a general lack of awareness and information surrounding carers' assessments. Some said that it had not been easy to find information about the assessment. One person said that he had been a carer for 2-3 years prior to receiving an assessment, despite being in contact with his GP. Another lady said she had been looking after her Mum for around 6 years before she heard of the carer's assessment, and had she not received any information, she would have continued caring in the same way - *"Not sure if it is my fault I have not heard anything about carers' support as I have not attended meetings."*

Those that had support from organisations found the process quite positive - *"well explained", "helpful"* and *"impressive".* It was felt that if you were not associated with an organisation that could help you, getting information about a carer's assessment could be difficult, and you had to rely on your GP or a hospital visit to trigger conversations about this.

Story

X had a carer's assessment with Southwark Carers and it was good. The delay was in finding out about it. X was not aware that he could have an assessment as a carer until he found out from the Staying Well Team well into his second year as a carer. He has since been receiving the one-off direct payment from Southwark Carers and also the 30 hour carer's respite. X suggested that the initial information should be out there at GP surgeries and hospitals so that it is clearer, and so that carers can be assessed and be given support sooner. He said that he saw his GP many times, who never once suggested that he could register as a carer and be referred for a carer's assessment. X said that the impact of assessment has not been huge, but that he got an opportunity to get respite, which he really appreciated.

1.2. Completing the carer's assessment process

When discussing the process of completing the application process for a carer's assessment, it was felt that the information was not very clear – the forms were thought to be confusing and lengthy, and carers would have benefited from help in completing them.

Comments that were made:

- *"I found the form difficult to complete without any support"*
- *"Filled in the form the way I understood but not sure I did it well."*

1.3. Lack of information about support

The eligibility criteria were not felt to be very clear and people found it difficult to explain their situation. One person was told someone would visit their home and explain it to them but this did not happen.

Carers felt that the 'system' needs to have a better understanding of what it is like to be a carer. They said that they need access to information and to know what they are entitled to, otherwise they will never know.

Continuity and relationships were important to the group; seeing *"different people each time"* makes it more confusing as you don't know where to go or who to speak to when you want information and support.

2. Experience of respite care

We wanted to hear about the group's views and experiences of using respite care, as an assessment may identify that carers are entitled to 'a break from their caring role'. This could take different forms, but essentially the cared-for-person would be looked after by someone else, such as a paid carer.

2.1. Relying on social networks

Some of the group had 'back-up' carers, such as another family member, to take over the caring role when a break was needed.

Story

When X has to go away for the night she has to ask her son to look after her husband. But her mind is always at home and because of the husband's circumstances she is worried about leaving her son alone with her husband. She feels she is the only person who can take care of her husband. She is also aware that her son has his own family and life and has to leave his family to look after his Dad.

2.2. Lack of information

The group felt more clarity was needed on how respite care could be used. One person said that some carers received a letter, saying that they were eligible for a one-off 40 hours of respite, but they wanted someone to explain to them how it could be used because they were not sure. They never received this information however, and therefore never used their respite.

Another said they were not aware of being entitled to 40 hours of respite, but then were told it had to be used by a certain date, which was not convenient.

2.3. How respite is used

The group had similar experiences of how they used respite and how they view it - they tend to *"save respite for emergency situations."*

The time given was not enough to do all the things carers needed and wanted to do. A discussion took place about carers' **health and wellbeing**, and how there was not enough time to address these needs. Respite tended to be used for administrative/ caring duties such as shopping, picking up medicine, tidying the house. *"When he goes in to have dialysis, then I have some time but I rush out and do the shopping."*

2.4. Feelings about using respite

Carers shared their feelings of **anxiety and guilt** when they left the cared-for-person alone, when using respite. Comments that were made:

- *"It looks good on paper but you have to leave your loved one with a stranger."*
- *"Staring at a stranger, terrified. A different person comes each time. He hated it."* [carer speaking about her husband who has dementia]
- *"I am always worried if I go out, even for a few hours, unless I am with him"*
- *"Even when you get away, you still think about it a lot. You feel terribly guilty"*

If paid carers came to the home to look after the cared-for-person, this seemed to cause distress because they were unfamiliar and did not know their likes, dislikes, and preferences. Leaving the cared-for-person left the carer feeling upset, anxious and guilty. Having the same paid carers could have relieved some of these emotions.

Story

X looks after her husband who has Alzheimer's. She said one hour of respite can be hardly considered respite because that one hour will be used to do all chores from shopping to 'queuing up' in the pharmacy to get medication for her husband. She said her husband has been in and out of care homes a few times. She tried to use the 30-40 hours of respite but a new carer comes in each time. She thinks there should be some extra money to get the carers in advance, to inform them about what they are expected to do and to allow them to get to know the cared-for-person. X said the carers who come in were total strangers each time and did not speak good English. She said that the fact that the same person would not come to provide respite each time, would only add to the 'bewilderment' of her husband.

2.5. Health and wellbeing of carers

Carers felt it was difficult to get time to themselves and that their lives could feel *“overwhelming”* at times. One said that it was only at night time when everyone was in bed that they could have time alone. Comments that were made:

- *“Feels like we will be in this situation until you aren’t a carer anymore, and we don’t want that”*
- *“We are crashing. I don’t know where to turn. Been in this situation for ages”*
- *“If we feel better, the people we care for feel better”*
- *“I resent it when people ask me to take care of myself. It’s easier said than done”*

Story

X said that she is finding it really difficult to manage her husband’s care and is trying to organise his care with social services. The communication is bad. She has to lift her husband on and off the loo (he is doubly incontinent and totally reliant on her). X resents it when she is told to look after herself. It’s easier said than done. She doesn’t have a moment to herself, and finds all the phone calls and chasing social services tedious, because she worries that her husband will have a fall while she is on the phone. She has to devote all her time and energy to her husband.

3. Personal budgets for the cared-for-person

We wanted to hear about the group’s experiences of personal budgets for the cared-for-person. We explained the term ‘personal budget’ as there was a lack of awareness about what this was, even though some of their cared-for-people had a personal budget.

3.1. Continuity

The carers said that you could be in regular contact with services, but you wouldn’t know who you were speaking to, and then they would send different people to visit you at home. This way, you couldn’t **build a relationship** with the staff.

Some had a good relationship with their Social Worker and felt that this was best when they worked collaboratively with the carer.

Story

A couple of months between assessment and plan being put into place - X did not expect it to be done that quickly. They weren’t aware they were entitled to payments. They didn’t want an external person so they were pleased that the family could care and receive money for this.

3.2. Receiving information

Through these discussions, we learnt that carers found out about personal budgets in different ways.

Through social networks: *They found out about personal budgets and social care support through a friend who told them about it when they were struggling to care for someone. They didn't know that this sort of support was available.*

From a stay in hospital: *They started the process in the hospital – a Social Worker visited, then came to the home to assess needs and what needed to be put in place.*

When an assessment was triggered by a hospital stay, carers found the experience to be *"informative", "helpful", "quick".* They received information they needed and had help completing the forms. The group felt that it shouldn't take a visit to hospital for carers to find out about social care support that is available to them.

The group questioned why GPs do not make this information more available and let carers know what support they could be entitled to. The carers worried that older people may fall through the system - *"what if you live alone?"*

4. Long term plans

We wanted to know what the group's views were of what would happen in the future – for themselves as carers and the cared-for-people. These were the comments made:

- *"Care home - don't want him to go there now"*
- *"I want to look after her for as long as I am alive"*
- *"I feel pressured about a care home"* - one carer said that when her husband was in hospital the staff asked him if he would like to go in a care home. This distressed him and the carer felt she was being forced into making a decision.
- *"You really are on your own. I have no faith in any of it"* – one carer felt there was no time to look at lots of care homes, and she knew of some which were *"appalling"*.

Story

X said that her husband had been in and out of 3 care homes over a short period of time to provide respite for her. She said that the care had been horrendous. They hadn't unpacked his overnight bag including his tooth brush. His teeth had not been brushed. X feels that there is no other alternative for her as she is getting old herself and has poor health.

5. What is the most important thing for you as a carer?

We asked this question to the group. This is what they told us:

- **Carer's health and wellbeing:** to look after yourself, get enough rest, keep in good health
- **Better understanding:** Not being kept waiting during GP appointments - *"I am a carer and I can't leave him alone for too long. I worry all the time"*
- **Better quality care:** Being consulted when decisions are being made for the cared-for-person
- **Shared respite:** Offering activities for carer/family and the cared-for-person together
- **Having a support plan in place** - *"I want to know that if something happens to me, my kids will be ok"*
- **More financial support:** to help get away from it all

Next steps and considerations

The views, experiences and issues arising from this report will feed into Healthwatch Southwark's work plan and activities. This will include our representative roles at Southwark's Clinical Commissioning Group and Southwark Council. On 7 July 2015, a summary paper was presented to Healthy Communities Scrutiny Sub-Committee at Southwark Council. This paper detailed key findings from this focus group, as well as discussions that took place at Healthwatch Southwark's Public Forum in March 2015: "You said, we did!"

Key considerations:

- **Information about support for carers** needs to be more easily available e.g. from the GP, rather than being given this information years down the line.
- **Support when completing the carer's assessment** would be beneficial, as it is perceived as a lengthy and confusing process.
- **More clarity on how to use respite,** as information about this seemed to be variable / not easily understood.
- **Familiarity and consistency are crucial when** paid carers look after the cared-for-person, especially when the carer is not present. There is a need for better systems which ensure that paid carers know the person so they are more at ease.
- **Building relationships with staff** was seen as the best way to work collaboratively with carers.
- **Carers need to be better supported** to look after their own health and wellbeing.
- **Information about personal budgets** needs to be more easily available e.g. from the GP, rather than being given information too late.

Appendix

Information about attendees

Ethnicity (as stated on forms by the carers)	Number
White British	3
British	1
Caribbean	1
African	2
Black	1

Age of carers	Number
40-49	1
50-59	3
60-69	2
70-79	2

Number of years as a carer	Number
0-4	2
5-9	2
10-14	1
15-19	1
20-24	1
25+	1

Carer's relationship to the cared-for-person	Number
Parent of the cared-for person	4
Partner or Spouse to cared-for person	3
Partner and Parent to cared-for people	1

Carers on the Carers Register list	Number
Yes	3
Don't know	5