

Healthy Communities Scrutiny Sub-Committee

Personalisation: Carer's Focus Group

Feb 2015

What is Southwark Carers?

[Southwark Carer's](#) provides support, information and advice to carers across the Borough. Southwark Carers undertake the majority of Carers Assessments in the borough; these are used to create **support plans** for carers, which can include a **personal budget** towards a holiday or break, **flexi respite hours** to allow the carer up to 30 hours of time per year away from their care role. Other services include advocacy, benefits maximisation, housing support, therapies, counselling, peer support groups and mentoring.

What is Healthwatch Southwark?

[Healthwatch Southwark](#) is the independent consumer champion for patients and the public. We advocate and support local people to get involved in their local health and care services. A key part of our role is the different ways we engage with groups and individuals, and how we use this to influence those responsible to improve services.

One key activity is our community focus group (FG) programme, we hold focus groups every quarter focusing on a particularly topic. We have previously presented our FG findings to this committee from the Latin American Women's Rights Services (LAWRS) and the Southwark Deaf Forum.

In late January 2015, we worked with Southwark Carers to bring together a small group of mainly adult carers to share their experiences, particularly the process of a Carer's assessment and to lesser extent their view of the Cared-For-Person's assessment for a personal budget. Due to the short timescale, this brief will highlight some key issues/findings in relation to personalisation. Detailed FG findings will be available after the March meeting.

Carer's assessment

The whole pathway experience to obtain a carer's assessment from: initial awareness, the process, to its outcome on the carer highlighted a number of key issues, particularly in the context of how 'personalised' services are for carers.

- **The lack of awareness and information surrounding a carer's assessment.** Many said it took years for them to be made aware of a carer's assessment. For some people, this also meant that the role they were currently doing could be part of the personal budget for the cared-for person.
- **The process itself**, i.e. the application, could be very long, confusing and it was **not clear on the eligibility criteria**. Carers mentioned that in the form they did not always know how their responses would be marked against the criteria and would have liked some help in completing the forms.
- **Continuity and relationship building** with local authority officers. Carer's would speak to a 'different person each time' and sometimes did not even know who to contact or where to go.

Carers' assessment outcomes – respite care

Carer's assessments, which had to be reflected in a support plan, related to a 'pot of respite care hours' ('flexi-respite') they could use, and/or a personal budget towards a break or holiday.

When accessing their respite care, many carers stated that it was mainly used to ease their caring duties, and not on their own health and wellbeing, which is the intended use of respite care. They were uncertain on how they could use or access their respite care with many stating they usually '*saved them for emergencies*' or used to carry out household chores or 'carer's admin'. In other situations, upon receiving receipt of respite care, the process dictated that they had to use the respite quickly, and within a certain time period.

Where home carers were brought in to relieve carers, some highlighted this itself was an '*additional stress*', as it would be a 'stranger' coming in and with no preparation time for the home care, they were not familiar with the individual or his or her needs. In some cases, this left the cared-for person bewildered, especially those with cognitive issues, but also create anxiety for carers when they were away.

For example 1 hour respite was not enough because these again were taken up by 'carer's duties, from queuing up at the pharmacy to get medication, food shopping or household chores and not the intended use of respite care. Furthermore, where more hours were provided, travel time was not always considered.

Other issues

- Carer's continuously hear that the **health of a carer** needs to be looked after, however many felt this was 'easier said than done' and that various factors stopped them from being able to concentrate on themselves. This included not being aware they were entitled to an annual health check, or the view that only they knew how to appropriately care for the individual.
- **Emergency care** – Some carers understood the need to plan for emergency care, but sometime these were not carried out by the local authority even after advance notice. Other times, it was not always possible to conform to council processes and timelines to put emergency plans in place, even if they knew about the process which some did not.
- **Hospital discharge** could be a positive trigger for social care to become involved, some experienced very positive experiences of the carers and cared-for-person assessment and the care package put in place. Others experienced extremely negative experiences with little communication between different departments resulting in a repetitive and emotional stressful period.
- Information and how to **access various other services**, around the health and wellbeing of carers and this include the encouragement of **social workers and GPs to signpost** more.
- **Peer support for carers** but also consideration on how they could arrange care for the cared-for-person.
- **Joint respite care breaks** for both carers and cared-for-person, to avoid the anxiety and guilt carers sometimes felt when they were away from the cared-for-person
- **Understanding that being a carer requires precise management skills and 'carer's administration'** and that this is considered by services and staff when arranging appointments (for example not keeping to time or moving times around) but also when in relation to respite care as some carers used the respite care for these reasons.
- Some suggested **training** to be provided on their own health, social care process, legal entitlement etc. to empower them and understand their role.

In summary:

The above issues seem to indicate there is still a long way to go in order to really develop and embed personalised services to carers. This involves a lot of understanding of the role of carers and the daily challenges their face, which others (services, professionals) may not always realise. In the context of a personalised climate, these are some of the key shortcomings raised:

- **Information should be accessible form a variety of sources.** Carer's sighted the GP as a source, but other external bodies. Over the years, we have heard of the growing need of some sort of directory

of support services that is accessible to both GPs, professionals and to the public, instead of reliance on professionals 'historical know-how of services available'

- **Clearer information on the assessment process and accessing respite care and emergency care.** This should be more easily and readily available. Underlying this is the foundation of knowledge that all professionals should have, and being able to potentially provide this at each encounter with carers.
- **More transparency around the eligibility criteria.** Carer's filling in the forms may not know what the 'assessor' is looking for or how to accurately reflect their needs. [*note: this is a different criteria from the FACs and incoming national criteria*]
- **The impact of and how respite care is used means something different** to the Local Authority and to the Carer. Many attendees used this to carry out caring-related duties.
- **Exploration on how respite care can be provided/administered in a more flexible** way to meet the carer's needs. This also includes the process of respite care which can be process-driven.
- **Where home carers are used in respite care, how can we make this personalised** to address carer's concerns, as highlighted above.

Going forward

- Fuller analysis of our questionnaire and focus group findings, to feed into our social care priority: looking at assessment process and what happens to those not eligible, and our sharing of our findings through relevant representative boards.
- Hoping to organise a complementary session focused on children and parent carers social care
- At our next Public Forum on [Thursday 19th March, 4pm – 7pm](#), we will be presenting our Carer's Focus Group findings and discussing these and wider social care issues further.

For further information, please contact us on info@healthwatchsouthwark.co.uk or call 020 7358 7005.