

Healthy Communities Scrutiny Sub-Committee July 2015

This brief will highlight some key issues/findings in relation to personalisation from a focus group carried out with carers, and in addition, from discussions that have taken place at our public forum events around social care support.

1. Personalisation: Carer's Focus Group

What is Southwark Carers?

[Southwark Carer's](#) provides support, information and advice to carers across Southwark. They undertake the majority of carer 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 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 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.

Key findings

Carer's assessment

The whole pathway experience (initial awareness, process, and outcome) of the carer to obtain a carer assessment highlighted a number of key issues, particularly in the context of how 'personalised' services are:

- **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 is not clear:** We heard that the application process could be very long, confusing, and the eligibility criteria is not clear. Carers said they would have liked some help in completing the forms.
- **Continuity and relationship building with local authority officers:** Carers would speak to a *'different person each time'* and sometimes did not even know who to contact or where to go.

Outcome of carer's assessment - respite care

Some carers assessments, 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 to use the respite within a short and set time period that wasn't always possible.

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, and they were not familiar with the individual or his/her needs and preferences. In some cases, this left the cared-for-person distressed, especially those with cognitive issues, and it also created anxiety for carers when they were away.

An example of this: One hour of respite was not enough because this was taken up by '*carer's duties*' - queuing up at the pharmacy to get medication, food shopping, household chores. This was not the intended use of respite care. On occasions where more hours were provided, travel time was not always considered.

Other issues

- **Health of carers themselves:** Carers felt that were barriers that prevented them looking after their own health and wellbeing needs, feeling that this is '*easier said than done*'. Examples of barriers - lack of information such as knowing about annual health checks, feeling that only they knew how to appropriately care for the individual.
- **Emergency care:** Some carers understood the need to plan for emergency care, but sometimes 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:** Sometimes a positive trigger for social care to be involved. Some had positive experiences of the carers/cared-for-person assessment and the care package put in place. Others had negative experiences with little communication between different departments resulting in a repetitive, emotional and stressful time.
- **Information on services available:** Around the health and wellbeing of carers and suggestion that social workers and GPs signpost more.
- **Peer support for carers:** And consideration of how care can be arranged 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 of what it means to be a carer:** It requires time and management skills and there is '*carer's administration*'. This should be considered by services and staff when arranging appointments (e.g. not keeping to time or moving times around) but also in relation to respite care as some carers used the respite care for these reasons.
- **Training for carers:** 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 for carers. This involves a lot of understanding of the role of carers and the daily challenges they 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 from a variety of sources.** Carer's sighted the GP as a source, but other external bodies should provide information and support. 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/readily available. This is the foundation of knowledge that all professionals should have, and able to provide this at each encounter with carers (if appropriate).
- **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 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 carers' 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.
- HWS to organise a complementary session focused on children and parent carers social care
- Continue discussions about social care support through our public events (see below).

2. Healthwatch Public Forums (All forum reports can be found [here](#))

Our public forums are another way in which we engage with Southwark residents and patients. These take place every quarter. Attendees are Southwark residents, plus representation from the voluntary and community sector, commissioners and providers (who we often invite to speak and hold stalls).

19 March: You Said, We Did!

HWS presented findings from focus group and group discussions took place around this, such as awareness of support, initial contact and the assessment process. Key issues included:

- **Information about social care services should be made easier to access.** Awareness and contact with social care services could take a long time. This could have been improved if information was available through GPs, social workers and better communication and interaction amongst hospital and community services. Some found being in a hospital or part of an organisation easier to access social care services.
- **Experiences varied with assessment.** Hospitals with a face to face social worker sped up the process and planning between health and social care, with information being easier to access.

Signposting and referral happened quickly and they felt more supported. However, once individuals were back in the community, communication and processes took longer.

- Based on their experiences, attendees ranked information as worse because information was rarely available outside of primary care institutions, and both awareness and communication scored average - because they had to seek the professionals themselves, communication was good within institutions, and communication in carers needed to improve across the system.

10 June: Your Care, Your Services: Issues to Solutions!

The forum looked at real-life case studies across the different stage of the social care pathways. Case studies were unpicked in group discussion, and concerns raised:

- With the increase in independently managing personal budgets, it can increase the **vulnerability and safeguarding of people** who could be at risk of abuse, potentially from neighbours and carers or others.
- **Phone assessments are not always appropriate for older people, including triaging.** It cannot show empathy and it may not allow individuals to articulate their needs. This can include downplaying any needs they have or staff missing opportunities to pick up on. **Face- to- Face communication** is seen as a better way of assessing someone's needs rather than over the phone and allows more 'holistic' assessment based on all types of communication (body language etc.) It is a missed opportunity to really understand people's needs rather what is just said.
- **Information and support** has to be independent, useful, and for people to know where to get it. It is particularly important for **those with personal budgets to access** independent support and information to understand what good looks like. Linking patient experience groups with social work outreach could be one way to **widen signposting and information distribution.**
- **Home care quality is varied** including timings and rotas and visits are not always coordinated with wider activity concerning the person. Care staff may not always have the necessary skills.
- **Clear communication** from staff is essential and information at crucial points in the discharge pathway. Personal care needs also need to be considered. Professionals need to take into account family and carers concerns and allow flexibility. Experiences also showed there can be a sharp drop to timely access to care, compared to being in a hospital setting. Frustration and isolation are also factors that decrease patient experience and care.
- **The role of GP** in spotting potential social care needs and acting as a source of information to help get support for the care
- **Carers needs** to be taken into consideration and met. There should be more than one carer to prevent and maintain the carer's health and wellbeing. Being a next of kin and a carer should be clearly defined to avoid assumptions from care coordinator that 'carer support' is enough.
- Advocates identified as key to bettering experiences around information, coordination, support.

In summary...

In summary, many of the issues above highlight that services and processes are not personalised around service users and carers. In many cases, they have had to actively reach out to get the support and information they need. Even then when services are being received, individuals have limited access or know-how of support to address quality issues. This issue can be amplified when managing your personal budget. There needs to be clear expectations and standards so that personal budget holders or users of services are informed, aware and supported to address quality issues.

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