

Gathering views
Carers Week 2014



Healthwatch Islington

Healthwatch Islington is an independent organisation led by volunteers from the local community. It is part of a national network of Healthwatch organisations that involve people of all ages and from all sections of the community.

Healthwatch Islington gathers local people's views on the health and social care services that they use. We make sure those views are taken into account when decisions are taken on how services will look in the future, and how they can be improved.

During Carers Week, local partners Centre 404 and Islington Carer's Hub (both members of our Steering Group) invited us to host stalls at two of their events and gather the views of carers.

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What we did

We asked carers to talk to us about what makes services harder to use, for them as carers. We asked them to tell us about what things were working well and how services which are more difficult to access could be improved. We gathered their views on a series of Post-It notes and wrote down comments for those who preferred to speak than write.

Over 150 people attended the events and we spoke to 37 people present during that time. Respondents were self-selecting and the views presented represent a snapshot of thoughts on local services.

We liaised with partners at Centre 404 and Islington Carer's Hub to see if our findings echoed the feedback that they get from their service users. They also made sure that we were aware of the work being undertaken to improve services for local carers. The feedback was written up and then we met to discuss the local context, any gaps in provision and relevant recommendations.

Carers gave their views across a range of services and providers. We hope that this information, and that of partner organisations such as Centre 404 and Islington Carer's Hub can be used to inform the local carer's strategy across services.

Where comments were raised that were outside of our remit (for example, relating to the Department of Work and Pensions) these were shared with Centre 404 and Islington Carer's Hub who can use them in their campaign work.

Why we did it

- ▶ The 2011 census tells us that there are 16,311 ‘identified’ carers in the borough with a ‘significant’ caring responsibility (there may be other ‘hidden’ carers who do not identify themselves as a carer). (1)
- ▶ 795 patients were recorded as a carer by their Islington GP practice in March 2011. (2)
- ▶ Islington Council defines a carer as “someone who provides help and support to a partner, child, relative, friend or neighbour who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability.” (3)

Colleagues at Islington Carer’s Hub <http://islingtoncarershub.wordpress.com/> and Centre 404 <http://www.centre404.org.uk/> invited us to be part of the Carers Week Launch event and the Carer’s Well-Being Day event hosted during the week.

We agreed to develop this piece of work in partnership with these organisations and develop recommendations with them.

Overarching themes: What carers need

Access to GP services

This is an issue regularly raised across the community. Carers told us that they value being given sufficient time during appointments and the opportunity to raise more than one issue. Some practices routinely offer double appointments for carers, but this is not consistent across all practices.

Carers at Carers Week told us that they need support from GPs in obtaining referrals on to other services in a timely manner. We note that the Carer's Hub and Centre 404 have been working with GPs to help identify carers. Islington Carer's Hub will continue to work with GP practices and the CCG to help them to identify and support carers.

Some carers also mentioned the importance of flexibility, and for services to be understanding when their caring role means that they cannot attend an appointment.

Recognition that their time has value

Making sure services are efficient, not needing patients to go back several times because services are not set appropriately.

Effective communication

Patients understand that sometimes delays will happen but keep patients and their carers informed so that they know what is going on.

Their records to be read and acted upon

Patient records need to be used effectively so that recorded information is followed up and appropriate support can be provided in a timely way.

What respondents told us

What would improve access to services for carers?

- ▶ Respondents felt that respect for their limited time, and recognition of the impact of caring on carers would help across services. Several respondents also stressed that better communication between services would help.
- ▶ They wanted improved information from GPs and Social Workers about their entitlements. Respondents also called for recognition of their expertise by experience.
- ▶ Respondents mentioned the importance of good training and support for support workers, so that carers know that their loved one is in safe hands and getting the right support.

What works well?

- ▶ There was praise for services with clear, direct pathways, which offered personalised and flexible services, and that gave carers the time they need. Carers also valued services which provided them with information.
- ▶ There was praise for events such as those organised during Carers Week that bring carers together.

What makes access difficult?

When talking about what made services difficult to access, most carers focussed on what makes it difficult for them to access services on behalf of the person that they are caring for, as well as for themselves.

- ▶ Respondents felt that barriers such as language, time constraints and lack of knowledge amongst professionals about specialist conditions made accessing services more difficult for carers and the people they care for (in turn impacting on the carer)
- ▶ There was mention of the impact of their cared for person's condition on their living space as well as the emotional impact.
- ▶ There was a suggestion that more emotional support was needed for carers of people with dementia in the first stages post-diagnosis.
- ▶ Respondents mentioned that obtaining timely GP appointments was also an issue. Respondents also mentioned the complexity of juggling things to get to appointments and the obvious frustration if these are then cancelled or prescriptions are made up incorrectly. It was also mentioned that lost letters or appointments on various sites can further complicate accessing services.
- ▶ One respondent mentioned the need for more respite. Another questioned the quality of some of this respite care.
- ▶ Concerns were raised by carers who care for someone that needs two to one care, that they end up with an inferior service because of the costs involved.
- ▶ The complexity of the Carer's Assessment form was also mentioned by one respondent (we signposted this user to support from the Carer's Hub).

Recommendations

We welcome Islington Carer's Hub's work to encourage GP practices to identify carers. This work includes supporting GP practices to mail out carers information packs to all carers on their lists so they are aware of the support to which they are entitled.

1. For Islington Clinical Commissioning Group (CCG) to encourage practices to offer flexible appointments consistently across practices to meet individual patient and carer needs. This could include double appointments for carers and phone-based/ internet-based consultations, as highlighted in the CCG's Urgent Care Review. We are aware some practices already offer this facility so we request the CCG request all practices to consider similar.
2. For Islington CCG to consider and commission Carer Awareness training, involving carers, for health staff within GP practices but also within the services they commission. The aim would be to enable staff to identify and support carers and recognise the impact of caring on carers' health across providers.
3. For the local health and social services carers commissioners to continue to support opportunities for carers to come together and meet other carers and to explore with the Expert Patient Programme the idea of carer-led conditions-based training programmes for carers based on the Expert Patient Panel model

References

1. Health and Social Care Information Leaflet - Islington Carers Offer, London Borough of Islington, 15th July 2013
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