



There's more to Healthwatch than health
Social care conference 2015

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On 5 March 2015, the first Healthwatch Newcastle annual conference took place at St James' Park, focussing on social care commissioning and delivery in Newcastle upon Tyne. The event was attended by over 90 delegates from the voluntary and community and statutory sectors and by members of the public.

The three main aims were to:

- Raise awareness that Healthwatch deals with social care for both children and adults
- Hear the views of a wide range of people and organisations about social care in the city
- Help inform the 2015–16 priority setting for Healthwatch Newcastle



The conference was opened by Bev Bookless, the Chair of Healthwatch Newcastle.

Bev informed delegates about the role of Healthwatch and how we perform our work, and also gave a little information about what had been achieved since we began operating in April 2013.

What Healthwatch does

- Makes sure people are informed about changes to social care and health services
- Makes sure people are involved in the design and delivery of services
- Investigates local issues and concerns about services
- Helps people make informed choices about services
- Makes sure organisations fulfil their statutory responsibilities to engage and consult

Healthwatch Newcastle Chief Executive, Steph Edusei, gave some background information about the reasons why social care had been chosen as the conference subject:

- Far less scrutiny of social care services than health care
- Sharp reductions in local authority revenue
- Increasing national attention on social care
- Less focus on social care by Healthwatch Newcastle in the first two years

Healthcare provision in Newcastle is good



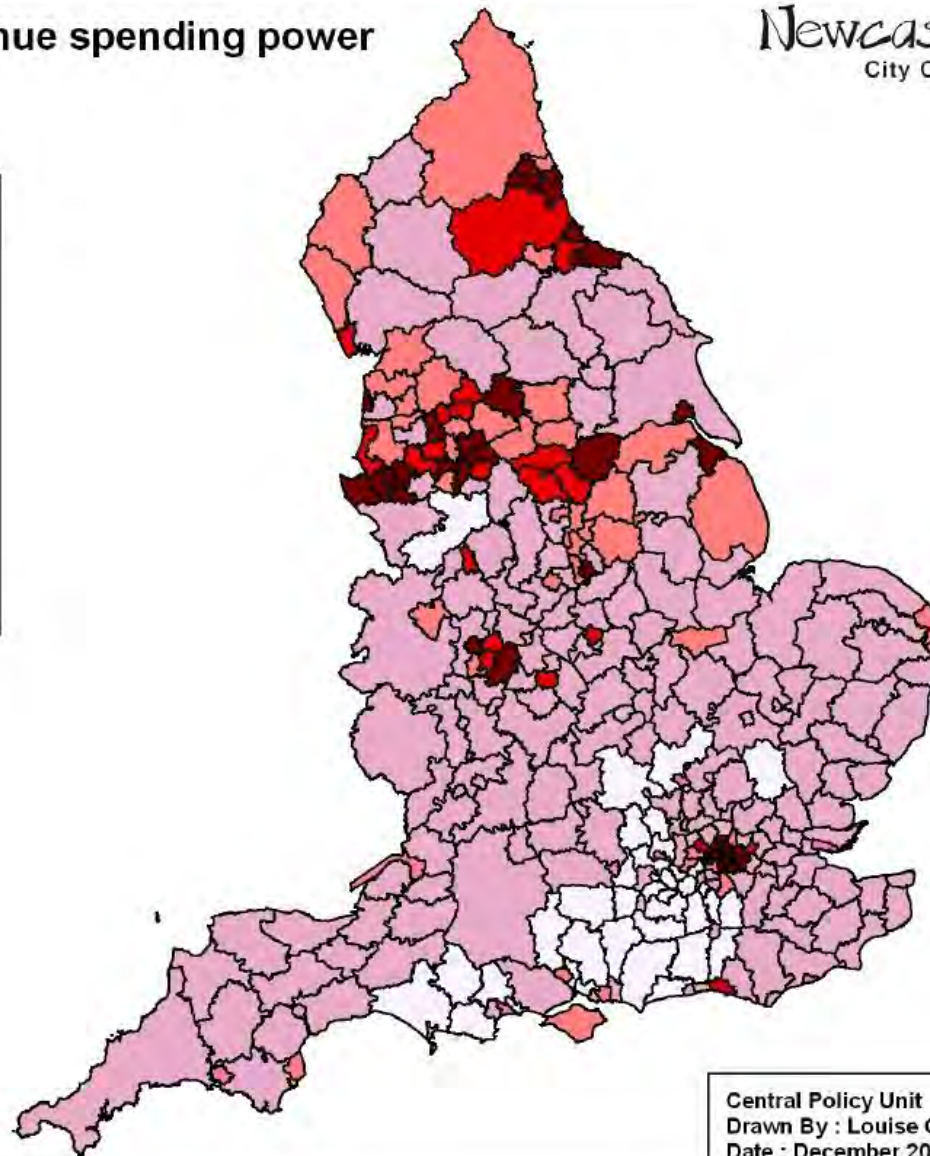
What about social care?



Cumulative area change in revenue spending power from 2010/11 to 2014/15

Key (£ per head of population)

-  >-£200
-  >-£150 -£200
-  >-£100 to -£150
-  >-£50 to -£100
-  0 to -£50



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Central Policy Unit
Drawn By : Louise Crosby
Date : December 2012



A major part of the conference was devoted to four breakout sessions covering the following areas:

1. Social care from the carer's perspective – led by Rachel Parsons, Newcastle Carers
2. Disabled young people in social care: some key issues - led by David Barker, Percy Hedley Foundation
3. Implications of the Care Act 2014 – led by Liz Greer, ADASS (North East Association of Directors of Social Services)
4. Service user involvement in social care – led by Simon Stevens, an independent disability issues consultant and trainer

1. Social care from the carer's perspective overview

Rachel Parsons, Training and Development Manager at Newcastle Carers, talked about the social care system from the perspective of the carer.

Fazeelat Iqbal also came along to talk about her experience of caring for her daughter.



Rachel gave an overview of some key figures about carers:

- There are 25,810 carers in Newcastle
- 40% of carers are male
- Carers save the UK economy £119 billion a year which is estimated to be more than the total cost of the NHS

Rachel explained the care assessment process in Newcastle, including Personal Budgets, Carer Support Allocation and Carers Assessments, and the changes following the implementation of the Care Act 2014.

In the Newcastle Carers User Survey, 2013–14 the top two concerns raised by carers were:

1. Being listened to by professionals
2. Their [carers] own health

Other issues raised included:

- The value of having specialist adult social care teams and a named social worker
- Having to 'fight your corner' during assessments
- Not being sure what the Carers Support Allocation can be used for
- Need for communication to be clear, consistent and simple
- Transition from children's to adults' services
- Need for personal budgets to include costs to allow a good wage for care workers

Fazeelat Iqbal gave a very personal talk on her experiences of caring for her disabled daughter, who is now a young adult.

During the table discussions, participants raised the following issues in addition to those highlighted in the Newcastle Carers Annual Survey:

How to access and navigate the system

Participants talked about carers often not knowing they are entitled to an assessment and not knowing how to access the system:

“How do I enter the system, what are the rules, who will tell me I need to become a formal carer?”

People not often identifying themselves as a carer was highlighted: they see themselves predominantly as a spouse, parent, son or daughter. Participants talked about the need for a central resource information point including what is available for carers and the need to promote the right under the Care Act 2014 of a carer to request an advocate during assessments and reviews.

Fear of the assessment process

There is a fear among some carers about the assessment process. Some people don't want to admit how bad things have become as there is a fear of being separated from a loved one. Some carers also find it difficult to say “no” and admit they feel unable to do things.

Emotional issues

Many participants highlighted the emotional issues of caring, such as feeling isolated and the distressing aspect of ‘terminal’ caring.

Specific carer groups

Participants highlighted issues for specific groups that are not as well recognised, such as kinship carers, young carers, carers of people who are in residential care and carers of people with drug and alcohol issues. Issues included the need for support – including financial support – self-stigmatisation and flexible working.

Lack of funding

Many participants talked about the negative impact of lack of funding and resources in adult social care.



What will Healthwatch Newcastle do next?

We will record all the comments which will contribute to the evidence base for targeted pieces of social care work.

2. Disabled young people in social care: some key issues overview



David Barker, Director of Business Development and Quality at the Percy Hedley Foundation, spoke about disabled young people in the care system.

David started the session by highlighting key issues for people with disabilities generally, which included:

- Cuts to disability and/or welfare benefits
- Strivers versus shirkers - the language of the welfare debate
- Employment of disabled people - disabled people are still struggling to gain employment
- Increases in disability hate crime

Looking specifically at the key issues for disabled young people, David focused on:

- Choice
- Access to services
- Personalisation
- Outcomes
- Short breaks

Austerity ran as a key theme throughout these issues. Due to the lack of available funding, disabled young people may find that they are entitled to less and choice may be limited. This sparked discussions about the Independent Living Fund, welfare benefits, education and transport.

Independent Living Fund

The Independent Living Fund is closing, meaning there will be a loss of income for some disabled people. Without this income, disabled people might not be able to financially maintain their independence. Delegates discussed whether people would end up moving into residential care for financial reasons.

Changes to disability and welfare benefits

Changes to disability and welfare benefits are disadvantaging disabled people. Disabled people are seeing reductions in the benefits they receive but the job market is not being developed so that disabled people can engage in work.

Education

Some disabled young people on employment support allowance are having to leave accredited courses and being put onto job seekers allowance. These young people have been attending these

courses to improve their employability and therefore this is not helpful. The disabled young person needs to do these courses to progress.

Transport

A disabled young person's choice of school or other services can sometimes be limited by the availability of transport. Some local authorities may pay for transport but limit which services it could take the young disabled person to. Some local authorities have stopped funding transport.

What will Healthwatch Newcastle do next?

Share the content of this breakout session with our young people's group and arrange for them to visit to the Percy Hedley Foundation to allow further exploration of this area.

3. Implications of the Care Act 2014 overview

Liz Greer, Care Act Programme Manager for ADASS, gave an overview of the implications of the Care Act 2014 which came into force on 1 April 2015.



Who is the Care Act 2014 for?

The act relates to adults only but there is new legal duty on councils to carry out 'transition assessments' for children, young carers or child carers before they are 18.

Key principles of the Care Act 2014

- General duty to promote wellbeing
- Supporting people to live as independently as possible for as long as possible
- Prevent, reduce or delay the development of care and support needs
- Outcome focussed care and support planning
- Choice and control over care and support through personalisation, personal budgets and direct payments
- Carers given the same rights as the person they care for

Implications for councils

- A person (now including carers) must only have the 'appearance of need' to qualify for an assessment
- Fair Access to Care Services (FACS) has been abolished in favour of a new national threshold of eligibility for care and support
- The new threshold makes a judgement about whether a person's physical or mental impairment has a significant impact on their wellbeing, meaning they are unable to achieve two or more outcomes described in the Care Act 2014 regulations (one or more outcomes for carers)

- Councils must arrange an independent advocate to facilitate a person's involvement in their assessment or review if no one else is able to provide support; this includes carers assessments
- Information and advice about local care and support services must be provided to everyone; this includes directing people to independent financial advice to help plan for future care costs
- Personal budgets must be provided with an option of direct payment

Implications for carers

- Carers are now on an equal footing to the person they care for
- Carers can request an assessment whether or not the person they care for receives help
- Carers may be eligible for care and support even if the cared for person isn't eligible for or refuses assessments services
- Carers must be provided with a personal budget/direct payment option

During table discussions participants queried what measures were in place to make sure people were aware of the changes and asked if there was a role for local Healthwatch in this process. Participants suggested that more funding could be offered to voluntary sector organisations to offer more general advocacy services.

A suggestion was also made to develop a system to encourage people over the age of 50 to make a plan that included appointing a power of attorney, making a will, and an analytical assessment of providing personal care.



What will Healthwatch Newcastle do next?

Work closely with all key stakeholders over the coming months to monitor the implementation of the Care Act 2014 locally.

4. Service user involvement in social care overview



Simon Stevens, an independent disability consultant and trainer from Coventry, spoke about service user involvement in social care from a national perspective.

Simon is a user of social care services. As social care is a key part in his life, he explained that he believes in investing time in the services he is 'dependent' upon. He felt it was important for him to have his say in social care, both locally and nationally.

Simon explained that service user involvement within social care can encompass many things and individuals can decide how involved they want to be. At its simplest level, service user involvement is about service users having a say on the services that directly affect them, by moving from a passive recipient, to an active contributor, to their own support. Other things services users can do include:

- Attending consultation meetings or events
- Sitting on committees
- Teaching local students about their experiences

Simon said that service users and carers should have the opportunity to get involved but it is not a duty. However, if they do choose to get involved, he expressed the importance of service users and carers being:

- Paid for their time, as a recognition of the contribution they make
- Provided with training
- Reimbursed for travel expenses or support costs

Organisations should also think carefully if they are considering recruiting volunteers to represent the service user voice. It is very hard for one person to represent other people so it is important that service users and carers who get involved in wider issues are supported to understand their own viewpoint and how it relates to others.

Other key messages from Simon were:

- Service users and carers should also be considered as experts in their own experiences and be seen as partners and equals with professionals
- Service user involvement has to be meaningful, not a talking shop or a tick box exercise

Discussions

After listening to Simon the group talked about good examples of service user involvement. The examples highlighted were:

- Service users and carers lecturing at universities
- Service user involvement at the Havelock Centre in Hartlepool
- Service user involvement events run by Mental Health Matters where service users help design its services

The group also talked about the issue of representation. It was recognised that recruiting people to represent others is complex and must be managed well to be a success. Recruiting representatives via election was highlighted as a good way forward. Organisations should then ensure the representative understands that:

- They are there to articulate the views of the people they represent
- They may need to articulate views they don't agree with
- They should meet with the people they represent regularly to gather views and also feedback to them about any progress

Gathering views and setting priorities

There were a range of ways for people to give their views at the conference. The breakout sessions were designed to be interactive, although as our evaluation shows we can do more to promote this (see [Conference feedback](#) on page 14).



People were able to cast their votes by using the video booth or tokens.

Everyone was asked to choose from the following areas as priorities for Healthwatch Newcastle for 2015–16:

- Domiciliary (home) care
- Care for people with learning disabilities
- Dementia and older people's care
- Complaints about social care
- Continuing healthcare



Attendees prioritised:

- Dementia and older people's care
- Domiciliary (home) care
- Care for people with learning disabilities



The event closed with an active panel discussion chaired by Bev Bookless, with Guy Pilkington (Chair, NHS Newcastle West Clinical Commissioning Group), Cathy Bull (Assistant Director, Newcastle City Council), Simon Stevens and David Barker participating.

Outcomes from the conference

Our outcomes from the event included:

- Incorporating comments from attendees into our evidence base for targeted pieces of social care work
- Prioritising dementia and older people's care; domiciliary care; and learning disabilities for 2015–16
- Raising awareness of Healthwatch Newcastle and our involvement and interest in social care
- Gaining feedback on priorities for the work of Healthwatch Newcastle during 2015–16



Next steps

We intend to focus on domiciliary home care in the first instance, beginning with desk based research to find out which organisations provides domiciliary home care in Newcastle and what people think of these services. The outcome of this research will define our next steps, which could include focus groups with service users, staff, voluntary and community sector organisations and other key partners.

A similar approach will be taken for the other two priorities chosen by conference delegates: dementia and older people's care, and care for people with learning disabilities.

Conference feedback

The event was declared to have an “excellent programme of speakers and subjects” and the content was described as “stimulating and thought provoking”.

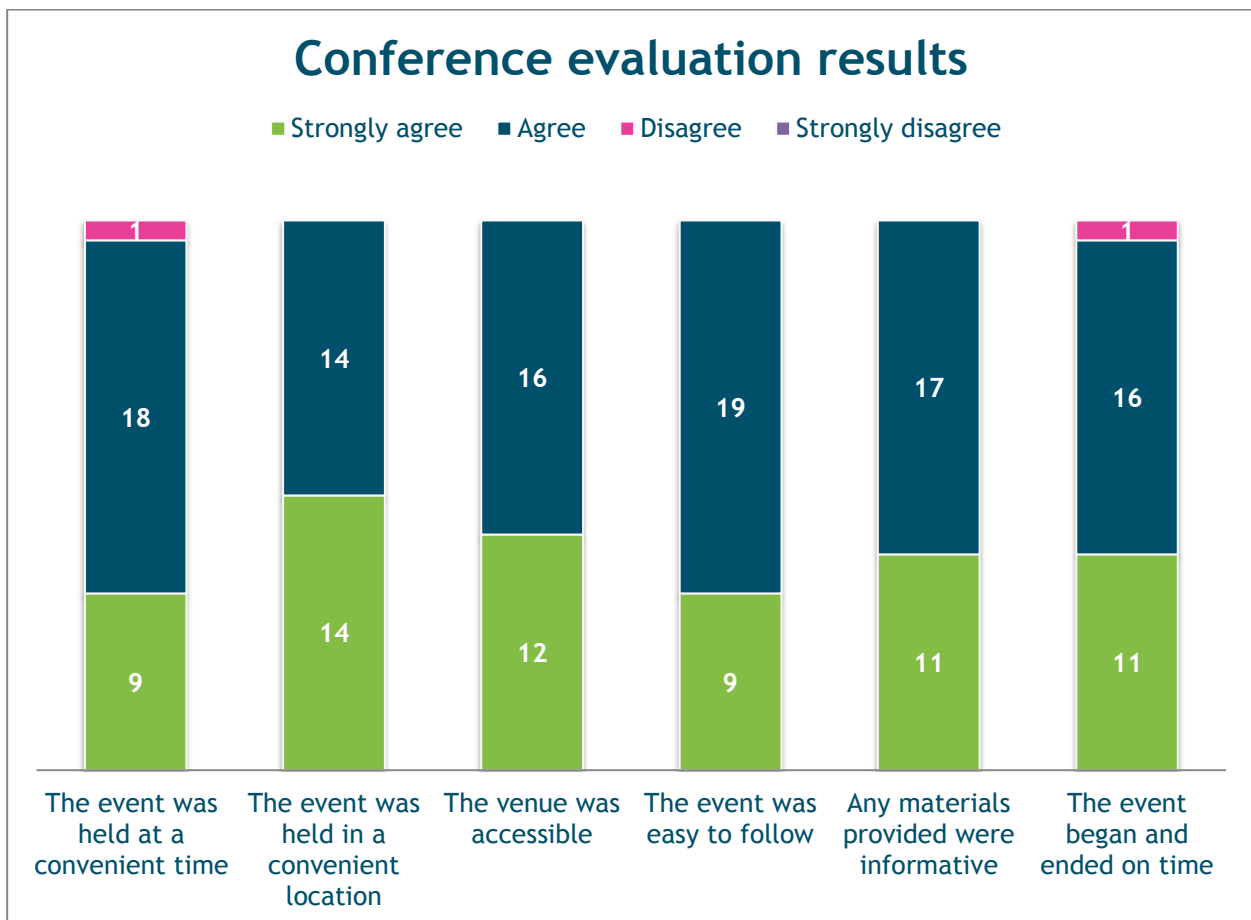
Respondents to the feedback survey said there were “very good speakers and panel” who provided “very realistic answers”. It was not only the speakers and panel that impressed attendees - the Healthwatch Newcastle staff were described as friendly and helpful.

There were positive reactions to the conference being held in a well-known and accessible venue. However, criticisms were made about the internal signage being unclear and the quality of microphones at the venue. St James’ Park staff were helpful in trying to overcome the microphone issues and the unclear internal signage at the venue has been noted for the future.

The evaluation shows that overall the event was held at a convenient time. Nevertheless, it was highlighted that the early time may have been hard for disabled people and carers to attend. Likewise, because the event was held in working hours, a lot of people regrettably missed out on the opportunity to be present.

Some attendees requested a longer conference next time, which would allow more time for workshops and follow-up questions and discussions.

The graph below gives an overall view of the feedback. Overall, the evaluations were positive and will be taken into consideration when planning future events.



Very good
speakers
and panel

Thank you for a
stimulating and
thought-provoking
event

Realistic
answers to
questions
posed

Nice
atmosphere

Possibly smaller
focussed workshop
events on the
issues we voted on

Excellent
programme of
speakers and
subjects



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