healthwatch North Tyneside

Carers' Strategy and Carers' Charter

Report on the survey by Healthwatch North Tyneside

February 2015

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For a copy of the appendices go to www.healthwatchnorthtyneside.co.uk or call Healthwatch on 0191 263 5321, email info@heathwatchnorthtyneside.co.uk

Background

The Healthwatch North Tyneside (HWNT) Carers' Survey offered carers the opportunity to have their voices heard on a range of issues related both to the Carers' Strategy (2012-14) and the Carers' Charter. The survey was one of a number of activities aiming to explore the impacts of the 2012-14 Strategy for Carers in their day to day experiences.[1]

The Carers' Strategy (2012-14) aimed to 'raise the profile of carers with a vision to ensure that all carers:

- Feel valued
- Know where to access support
- Are recognised as expert partners in care.

The Carers' Strategy named 10 priority areas, each linked with a list of actions, to achieve this vision. The Carers' Charter was developed as a direct action within Priority 2 (Improved Communication: Raise awareness about the role and the needs of carers).

The Carers' Charter, developed with carers, describes the principles carers should be able to expect from health and social care providers.

Healthwatch North Tyneside Carers' Survey June to December 2014

Respondents commented on their personal needs and their experiences of NHS and social care services, which we have related to the Carers' Strategy and Charter in our recommendations.

Carers' comments are presented in full without changes in relation to the Carers' Charter in the main report and in relation to the Carers' Strategy in Appendix 1. For a copy Appendix 1 go to www.healthwatchnorthtyneside.co.uk or call Healthwatch on 0191 263 5321.

Information gathered in the HWNT survey will be fed back to service providers and commissioners to form part of their overall picture as to whether the Carers' Strategy 2012-14 and its associated actions are achieving the principles expressed in the Carers' Charter.

[1]Additional information on previous activities held to gather carer comments as well as all Carers' Strategy 2012-14, Carers Charter and project documents can be found on www.healthwatchnorthtyneside.co.uk/carers

The Healthwatch North Tyneside Carers' Survey was distributed to carers through a wide range of health and social care providers: statutory, voluntary, community and private organisations around North Tyneside including through the Carers' Champions. It was advertised in the Healthwatch North Tyneside enewsletter and at events, on our website and was available for completion online as well as in hard copy.

About the carers who responded to the survey

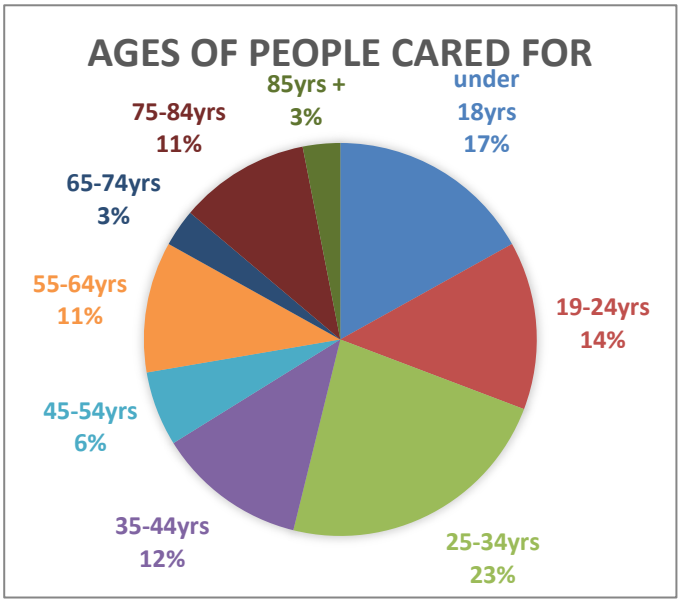
The 70 carer respondents were aged 25 to 84 years and cared for a total of over 86 people: 53 described caring for 1 person, 9 caring for 2 people, and 5 caring for 3+. (3 chose not to specify.) Many respondents were caring for immediate family and many described caring for one or more parents, adult children, younger children or a combination, echoing national trends of a 'sandwich generation' who care for their elders and children simultaneously.

Most of the carers who responded (52) described caring for 5 years or more. No respondents had cared for less than a year. 6 had cared for 1 to 2 years and 8 had cared for 2 to 5 years. One carer identified having cared for the last 50 years.

Most carers taking part in the survey were women - 77% (n51 of n66 who answered this question).

Carers in the survey care for a wide range of ages:

17% (n11) of those cared for are children (18yrs and under);
14% (n9) 19-24yrs;
23% (n15) 25-34yrs;
12% (n8) are aged 35-44;
6% (n4) are aged 45-54yrs;
11% (n7) are aged 55-64yrs;
3% (n2) aged 65-74yr;
11% (n7) 75-84yrs and
3% (n2) aged 85+ years.



Carers identified the main reasons for caring as:

Learning Disabilities or Autism – 38
Physical or mobility disability – 16
Mental Health – 12
Dementia or memory problems – 10
Drug or alcohol dependency – 5
Sensory issues – 4
Age related problems – 3
Long-term or serious illness or condition – 2
Other – 7

Ages of respondents

The majority, 73%, were **aged 45-65.** Within this bracket, respondents were equally from 45 to 54years (n24) and 54 to 65years (n24) age ranges.

In addition:

- 6 respondents were aged 65 to 74 years and 7 were aged 75 to 84yrs.
- Very few carers were aged 25 to 34 years (n3), or 35 to 44years (n2).
- No carers under 25years or over 85 years took part in the survey.

Almost a third of carers faced disabilities themselves

31% (n22) of carers taking part in the survey said they themselves had a disability or long term health condition. Most commonly this was a physical disability or mobility problem (n9), or a long term health condition or serious illness (n9). Other respondents reported age-related problems (n3), mental ill-health (n2) and learning disability or autism (n1).

Where carers responding to the survey live

Over half the respondents (n36) lived in North Shields and Wallsend, 26% (n16) lived in Whitley Bay, and 13% (n8) lived in the North West area of North Tyneside. One carer lived outside of North Tyneside in N63 Northumberland.

Themes from the responses

A number of themes emerged in responses, in particular:

1. The **unpredictable and profound impacts** that caring responsibilities have on the lives of carers and the struggle for their needs to be taken into account.
2. The **battle** carers perceive themselves to be having with statutory services.
3. Significant unmet need for **emotional support**.
4. Significant unmet need for **information and advice**
5. The value of **peer support** and informal networks.
6. **Lack of involvement** in care or service planning

We have expanded on these themes below. Recommendations, linked to priorities in the Carers' Strategy, are made in the following section.

1. Unpredictable impacts

Many carers described the negative impact that their caring role, and their struggle to access information or support, has had on their physical health, mental health, energy levels and ability to cope. Carers described stress, tiredness, exhaustion and, often, a battle to determine what support and what services were available and when, both for the person they cared for and themselves. Many also described the impact that caring responsibilities have on their family as a whole.

- **"Being a carer is the hardest job/role I have ever done. Suddenly you are in the role - no training, or shadowing others, you have to learn and adapt straight away - no one comes to your aid. I spend a lot of time on the phone chasing help and assistance. Nothing happens quickly - frustration and stress is our pay cheque! Disgusting really!" (Q23:10)**

Impacts on family units

- **"As said above the only help we get is from my son psychological nurse. It has put a lot of tension on our family A lot more support for his condition." (Q12: NHS)**
- **"I have a private carer who comes in twice a week. My daughter who lives 65 miles away comes over every week. My wife visits a day centre once a week, all of which I have to pay for (not my daughter). My life is very restricted." (Q14:1 NHS)**
- **"Not a chance I feel supported, just because dad is not aware of the problems his dementia brings, it does not mean there are none and Social**

Services should be trained to be better equipped to deal with the problems dementia brings to the whole family." (Q13:18 Social Care)

- **"Alcohol dependence is a varying condition, at times no care is needed, at others it can have dreadful effects on the whole family. It is difficult to make any plans for simple things such as shopping, school open days, daytrips. Holidays, parties and social events are out of the question." (Q14:19 NHS)**

Impacts on work and training

Many carers described further the difficulties they face in caring and working and the impact this has on their health and their ability to continue to work:

- **"Being a carer has impacted negatively upon my ability to continue to work and upon my own mental health." (Q12:2 NHS)**

- **"I have a daughter who has learning difficulties and demanding talking to me many times a day. The mental restraining is ongoing and I would rather they were providing a number to talk to anytime she needed rather than sending her to me. I am 60 years old, still in full time employment and find this sometimes really hard to deal with." (Q12:5 NHS)**

- **"My paid job is seen as unimportant and I am expected to be able to attend multiple hospital appointments without consideration for my work duties. I have a demanding paid job in addition to my caring responsibilities and trying to balance the two is extremely difficult." (Q12:9 NHS)**

2. 'Battling' with services

Some degree of tension may be inevitable in a situation where people depend on the provision of a service where need must be assessed against fixed criteria for that service provision to go ahead. However, the degree to which respondents described experiencing their interaction with statutory services as a conflict seems to be significantly beyond any inevitable level of tension. This is particularly true in light of the principles set out in the Carers' Charter: that carers should be **recognised, valued and involved**.

Carers frequently referred to a sense of being disbelieved, disrespected, 'making themselves unpopular' or 'having to fight' to have their needs listened to. In addition, the ratings they gave about whether the impacts of caring on their lives were taken into account highlighted problems.

Some comments in this area may relate to the period preceding the 2012 - 14 Carers' Strategy, but the sense of a continued struggle was very present in the overall picture presented through the responses and highlights the need for further efforts to listen to and meet carer needs.

- **"My experience with social care has been very traumatic in the past. I have literally had to fight for every bit of help and support that we have ever received." (Q13:2)**

- **"In the last 4 years we have tried to work with the services to get the best. We are the most controlled people in the land." (Q13:13)**

- **"We tend to be treated as numbers and not people and often ignored." (Q14:9)**

- **"We spend an inordinate amount of time 'fighting the system' in one form or other. Our area has some tremendous hospitals for which we are very grateful. But we seem to find new flaws developing and the wholesale and frequent restructuring is becoming chaotic... Practice managers, NHS direct, NHS England CCG's..... we can't keep up with it." (Q14:17)**

- **"I have had to make myself unpopular with the provider to ensure my husband gets the care and therefore the support I need. They know that if they don't I'll be on the phone." (Q15:6 Social Care)**

- **"Sometimes I feel tolerated rather than included in consultations." (Q12:3 NHS)**

- **"I feel valued by the person I care for, other parents, carers, family members and our providers. I do not feel valued by the professionals who should be working for us. We are the employers and customers. No respect shown." (Q12:4)**

- **"I feel in order to receive the support required for my two sons to move forward into Independent supported living, my views have been doubted and I have had to get people who have had hands on experience with my sons to confirm my views." (Q13:7 Social Care)**

Asked about whether the **impact of caring** on their lives was **taken into account** by services, almost **two thirds** of carers disagreed or strongly disagree.

Agree - 11% (NHS) and 15% (Social Care) agreed or strongly agreed that services do take into account the impact of caring on the carer's life.

Disagree - 60% (NHS) and 65% (Social Care) disagreed or strongly disagreed.

Respondents gave slightly more positive responses that their knowledge and expertise about the person they care for is valued, though the proportion who agreed was still less than half and around a third were undecided.

Agree - 41% (n24) of carers using social care services and 43% (n26) of carers using NHS services agree or strongly agree that their knowledge and expertise of the person they care for is valued by these services.

Disagree - 27% (n16) of carers using social care services and 25% (n15) of carers using NHS services disagree or strongly disagree that their knowledge and expertise of the person they care for is valued.

- **"We have (name of provider), who we often have to contact if the person is not at home when they call to feed him and give his medication. I sometimes give his meds if they cannot. They appreciate my help. I take him shopping, take him to the bank and arrange for his house to be cleaned. I tidy up and put his clothes out for him. I take him out a lot into the country and to his club and the social worker stated in her report that he could not manage without my help." (Q12:10)**

- **"Not had much to do with Health Professionals. We have used generic services since son left education. I feel valued and listened to at our GP surgery and always have done." (Q13:4 NHS)**

A small number of comments made reference to some recent improvement, though many of these also acknowledged continued difficulty:

- **"They are better at listening to me, but still tend to give us what they think we need." (Q13:3 Social Care)**

3. Emotional support and unmet need

In light of the impacts and challenges described above, it is perhaps no surprise that there are still significant unmet needs in terms of the emotional wellbeing and resilience of carers – an essential foundation of being able to fulfil their caring role.

My needs are met: Asked whether their own needs were met by NHS services, 49% (n28) disagreed or strongly disagreed and 18% (n10) agreed. In relation to social care services, 53% (n29) disagreed or strongly disagreed and 16% agreed. In both cases, a significant minority were unsure either way. No respondents strongly agreed.

- **"I am unsure of what I need - but a good chat and a moan as well as some points for help for me because sometimes with he needs of my son and my husband I can feel worn out and overwhelmed." (Q14:10)**

- **"Work has also been affected due to having to return home to deal with falls and blackouts. It is difficult to say what could help as the condition relies on the cooperation of the recipient, but even someone available to talk to would be a huge help." (Q14:19 NHS)**

- **"I have been lucky enough to access psychology for short term support, but not because I was a carer, as this service is available to those who are not caring, but because my caring responsibilities led to anxiety/depression." (Q14:23)**

- **"Never been asked to take carer needs into consideration. Seems low priority and impact underestimated." (Q12 NHS)**

- **"Recently I needed an advocate to attend important meetings but no one was available at short notice. There are advocate for our LD service users but not for us carers." (Q14:8 NHS)**

4. Accessing information and advice

Most respondents described **not having access to information and advice**. 73% (n40) of carers identified lacking information relating to emotional support planning for an emergency 58% (n30) legal matters 54% (n29) and financial support and benefits advice 46% (n26).

65% (n19/29) of carers also felt that **over the past 6 months** they could not get information they needed at the right time.

Carers described a range of issues related to accessing information, not knowing what is available or where to find information as well as the difficulty discussing information about those they care for and being listened and responded to.

- **"A lot more support would be a bonus and a lot more info." (Q15:11 Social Care)**

- **"I have recently placed my wife in respite care for 2 weeks. I made the arrangement. Having completed this survey to the best of my ability and with the little knowledge I have, it would appear that I am completely in the dark as to what help is available and at what cost." (Q20:1)**

- **"Not sure what's currently out there - where do you see a list on offer?" (Q21:12)**

- **"We have to search for the information we need." (Q21:13)**

- **"NO. New items of information keep 'popping out of the woodwork' that would have been useful to know about at an earlier time." (Q21:14)**

- **"NTC's (North Tyneside Council) web site is terrible for finding information. It is much easier to find what you want on Newcastle's web site for example. So it is no good just saying 'oh it's in the public domain on the web site' when the web site is so poor." (Q21:16)**
    - Healthwatch North Tyneside have contacted the council about a number of broken links on the council website related to carers which the council have amended.

- **"I know where to go for it when I need it - information is available, it is the services that are lacking, flexibility and responding to individuals." (Q21:23)**

5. Value of peer support and informal networks

Respondents who had accessed support informally, either meeting with other carers or through voluntary groups, reported these to be very valuable to them.

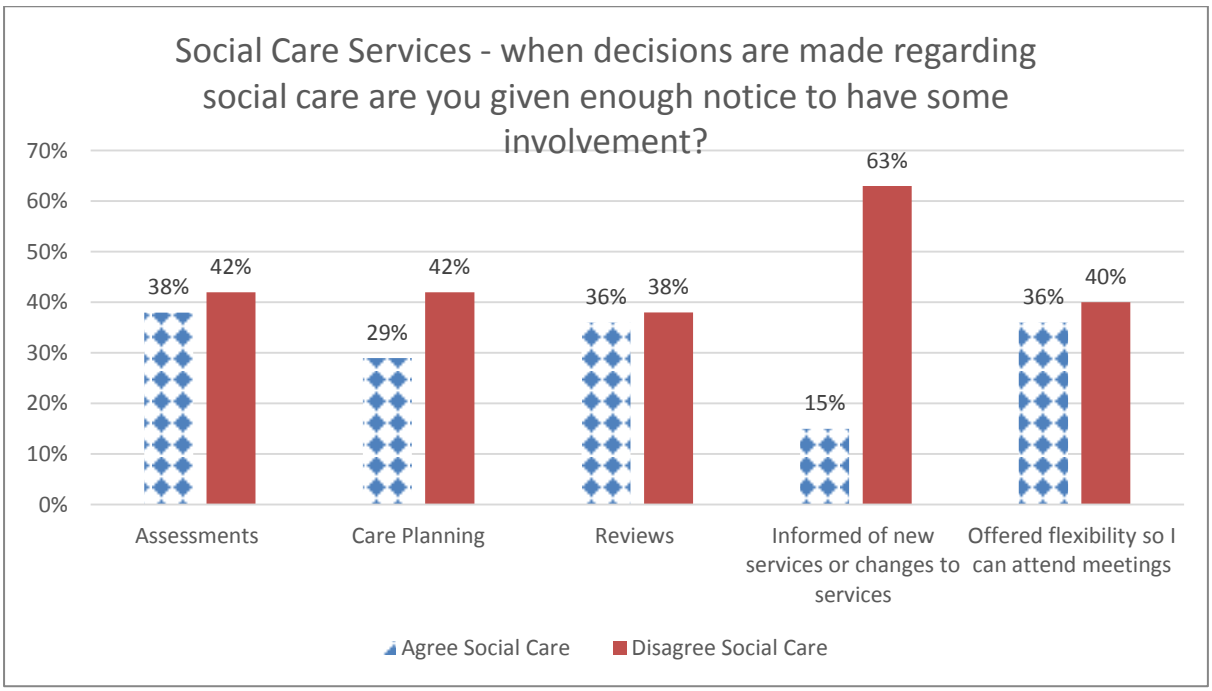
- **"There are some good voluntary services out there that are very helpful and if they can't help they do refer you to someone else." (Q21:25)**
- **"I receive most information from carers support group rather than services." (Q21:27)**
- **"The Carers' Centre has been very helpful and supportive to me." (Q17)**
- **"Carers' Centre is my support." (Q21)**
- **"I get my support from Carers' Centre." (Q21)**
- **"I am unable, most of the time, to leave my wife on her own, which means I am unable to attend any events which I would no doubt find useful. My wife was in a respite care recently and I found the break very beneficial and restful. It is also why I did not receive this survey until 18.8.14 when I attended the Alzheimer's Singing for the Brain at St Columba's Church Hall in North Shields." (Q23:2)**

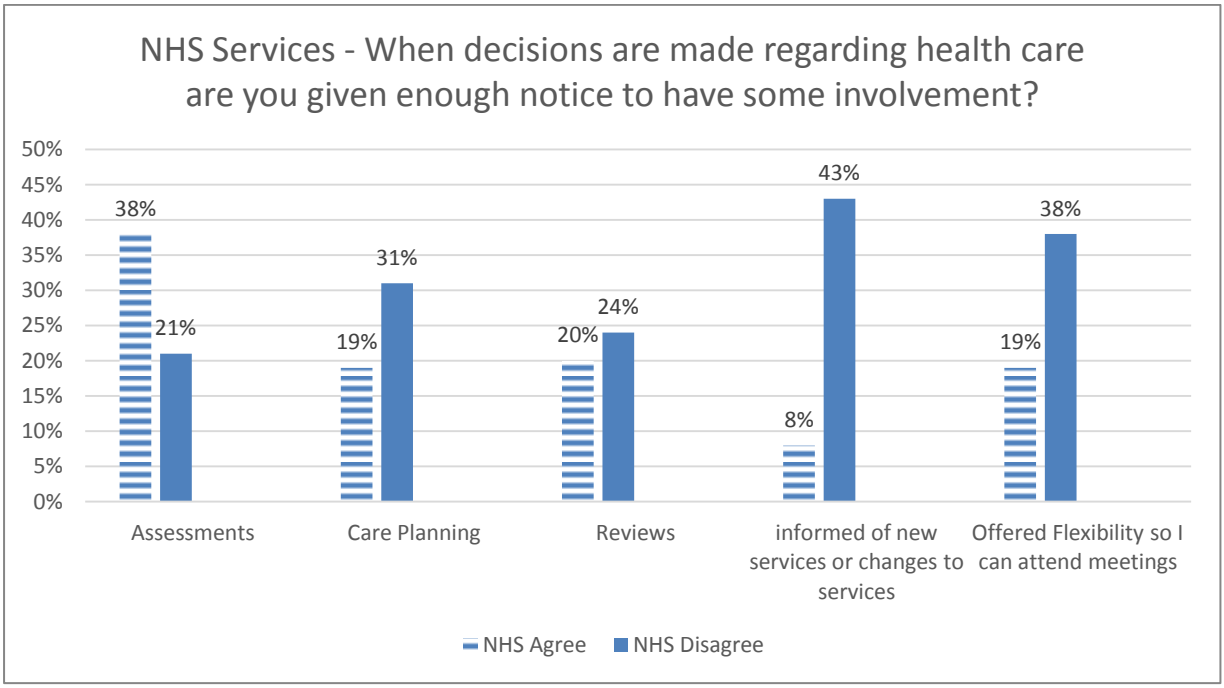
6. Involving Carers

Carer comments show that:

Many carers feel that they have not been informed or kept up to date with changes to services or been given enough notice or flexibility so they can attend meetings.

See charts on next page.





Some carer comments:

- **"As a full time worker it is almost impossible for me to access carers' services as these are, by and large provided during the working day."**

- **"The NHS could not give one jot that I am a carer!! Appointments etc overlap with my caring hours, which I explain to the appointment clerks, yet no flexibility to appointments is provided and no provision is made to provide any form of cover." (Q14: NHS)**

Recommendations

Considering the responses summarised above, we identified three priorities for action:

1. **Clarify what information, support and services** are available to carers, **whether assessed as eligible for service input or not** and what steps **carers** can take to access these, with services **promoting this information more proactively,** including through training for frontline staff.

2. **Promote options for emotional support**, carefully reviewing the places people are likely to look (online and offline) early on in their caring experience.

   This support is desperately needed, but some good options exist already:
   - The **National Carers Direct helpline**, which is free and operates until 9pm (0300 123 1053).
   - **North Tyneside Carers' Centre**, in particular their phone-based support and information service, as well as online and drop-in options.
   - The **Carers' Guide to Health and Wellbeing** produced as an outcome of the 2012-14 strategy could be much more actively promoted.

   Healthwatch North Tyneside commits to helping promote the above in our own signposting and information work.

3. Prioritise the development and implementation of the **Quality Monitoring Tool** referenced in the 2012-14 Strategy incorporating the Carers' Charter and use this to ensure carers needs are being identified, listened to and acted upon, as well as to assess the wider quality of services.

What happens next?

The Carers Strategy review group, which is made up of Council, Carers' Centre and Clinical Commissioning Group (NHS) representatives, have committed to take forward these recommendations (March 2015).

Analysis of carer comments relating to the relevant Carers' Strategy priorities and actions

These three overarching recommendations also come from an analysis of carer comments relating to the relevant Carers' Strategy priorities and actions detailed below.

Carers' Strategy Priority 1: Earlier identification of carers and provision of quality information

Priority 1 key aims:

- **Improve access to information and advice**
- **Help people to identify themselves as carers**

Priority 1 actions:

1. Develop a 'Golden Question' which will help to identify carers
2. All health and care professionals will commit to asking the 'Golden Question' at first meeting or review when appropriate
3. We review the information that is currently available for carers

Carer comments show that:

- **Information and advice:** Many carers have and continue to experience difficulties in accessing information, knowing what information is available and where and how to get information. Some describe this as affecting their motivation to continue to ask for assistance.

- **Identification as carers:** Some carers describe the difficulties they have faced in not being identified as carers by services and not receiving information, support or assistance. Others describe continuing to be without these and the negative impact that this has on their lives (most notably parent carers of children with ADHD and a carer who cares for a person who refuses services).

Carer comments highlight the need for statutory services to focus more effort on:

- Developing accessible, user friendly systems for all carers to access information whether they are formal or informal carers, assessed as eligible or ineligible for services.

- Offering information in a wide range of ways that are accessible to carers with different needs, for example: supporting access to information through service providers, community services and groups, GP surgeries and activities for people with different needs and situations, for example people with dementia or disabilities.

- Identify carers earlier in their caring journey and guide them to different levels of service pathways.

Carers' Strategy Priority 2: Raise awareness about the role and needs of carers

Priority 2 key aims:

- **Raise awareness about the role and the needs of carers**

Priority 2 actions:

1. Develop a Carers Charter/Set of principles and seek sign up from all partners, include in contracts
4. Organisations ensure all staff receive carer awareness training
5. With immediate effect we will commit to ensuring that we will:
    - include carers' views and opinions in care planning. Carers and families should be recognised as experts and equal partners and should have representation within care planning
    - identify hidden carers and support them to seek assistance.

Carer comments show that:

Priority 2: Action 1: Develop a Carers' Charter, include in contracts: Half of the carers responding to the survey were not aware of the Carers' Charter, of those that were aware of it, 87% think their role as a carer has not improved and many could not see any improvement in service provision as a result of the charter, and many do not feel that their views are listened to or their contribution to society is recognised.

Priority 2: Action 4: Staff training: Many carers feel their views about their needs are not listened to. Carer comments describe 'lip service'.

Priority 2: Action 5: Include carers in planning: Many carers feel they are not given enough notice to be included care planning, or offered flexibility so they can attend meetings.

Priority 2: Action 5: Identify hidden carers: As described above in Priority 1

Carer comments highlight the need for services to strengthen focus on placing carers at the centre of planning and make arrangements to accommodate their different needs to facilitate this, by, for example:

- Developing and strengthening a variety of mechanisms to ensure carers' voices are actively sought, welcomed, heard and responded to including for example online and postal input and feedback for those who cannot attend in person.

- Incorporating the principles in the Carers' Charter within service monitoring and feedback processes.

- Increasing access for all carers to information, advice and signposting at a wide range of venues across the borough so that 'hidden' carers can identify themselves. For example via advertising on plasma screens, posters, information packs, within group activities and word of mouth.

- Incorporate information within advertising that positively represents carer input to society to encourage carers, staff and wider society to take an active part in identifying and acknowledging caring roles.

- Increasing and improving training for frontline staff across relevant services to improve awareness of carers' roles and needs and the services on offer to them.

Carers' Strategy Priority 3: Involvement of carers to influence policy and service development

Priority 3 key aims:

- **Develop mechanisms to give carers a voice**
- **Include carers views in the commissioning of services**

Priority 3 Actions:

Action 2: Contracts will include: obtaining carers views and opinions of the service.

Carer comments show that:

Many carers feel that they have not been informed or kept up to date with changes to services or been given enough notice to take part in service development. Others described not being able to attend meetings due to the weight of their responsibilities and time constraints.

We encourage statutory services to focus efforts on involving carers in processes related to service policy and development by developing:

- A range of mechanisms to ensure carers' voice can be included for example: use IT systems to gather input and feedback from those that find it difficult to attend

- Incorporating feedback systems that feedback to carers and identify how their views are included.

- Advertising and information that describes the involvement process:
  - systems carers can use to have their views and needs listened
  - how their views are incorporated
  - how feedback is offered

- Monitoring and reviewing the effectiveness of these mechanisms.

Carers' Strategy Priority 4: Improved carer support and well being

Priority 4 Key aims:

- **Review the effectiveness of support to carers**

Priority 4 Actions:

Action 3: Develop an outcome measure for providers (who do not currently use one) to assess the carer's experience and wellbeing.

Carer comments repeatedly show that most carers feel their health and wellbeing is often not effectively supported by services and many feel they additionally struggle to gain information or support from services, creating increased difficulties affecting their heath and wellbeing and that of their families.

Carers' comments highlight the need for statutory services strengthen their focus on supporting carers with their health and wellbeing by:

- Prioritising development of the Quality Outcome Tool and improve monitoring of carer health, wellbeing and support from first being identified as a carer and their continued health and wellbeing throughout their pathway.

Carers' Strategy Priority 6: Carers have access to emotional support

Priority 6 Key aims:

- **Increase opportunities for carers to access emotional support**

Priority 6 Actions:

1. Develop a Buddy System to support carers
Many carers identified the benefits of having someone to talk to and some described this also as a good way for them to gain additional information.

Carer comments highlight the benefits to carers and statutory services of:

- Ensuring their staff have a full understanding of current opportunities for carers to access emotional support and work to improve these over 2015-16.
- Sharing information about these opportunities with carers

Carers' Strategy Priority 7: Carers are supported to remain healthy

Priority 7 Key aims:

- Explore ways to implement health checks for carers
- Use Commissioning Advisory Boards to review and monitor carer support

Priority 7 Actions:

1. **Implement Carers Health Checks**
2. **Each Commissioning Advisory Board to identify and address the specific needs of carers of the people in their client group.**

As identified earlier, many carers described the impact that their caring role has on their health and wellbeing and on their family as a whole. Some described difficulty in fitting in their health needs, appointments around the needs of those they care for.

Carer comments highlight the benefits to carers and statutory services of:

- Making information about health and opportunities for promoting wellbeing openly accessible for all carers whether formal or informal, in receipt of services or not.
- Reviewing and monitoring carer support related to remaining healthy for newly identified and ongoing carers.

Carer Suggestions:

The survey offered space for carers to comment freely. Some carers offered suggestions that would help to them in their experiences with NHS and Social Care Services:

- **"No -most of the briefings given regarding the new education advice and health plans have been given during the day when I am at work. There are**

some carers who also work and need to keep any holiday entitlements for when the person they are caring for needs to be cared for e.g during school holidays or when they are ill. Providing at least one evening briefing would be hugely beneficial." (Q21: 10)

- "Parent carers need a group organised to discuss their needs, draw conclusions and present a view to the authorities. We have cared for 50 yrs. Nothing changes for the good." (Q23:12)

- "We could do with some root and branch changes to the way that Adult Social Care is run, to be more focused on personalisation and choice, rather than just paying lip-service to it." (Q23:14)

- "Information and signposting to be implemented - a central point of contact – a employee as an adviser we can be up to date with health and social forums to be able to signpost and guide us carers to carry out our role and therefore avoid extra stress. This is the hardest role in my lifetime and I still feel frustrated with the lack of communication in this 14th year of the 21st century. We have no union to go to – or a strong enough voice - we need someone who can pull all the knowledge together and therefore be a paid representative across all services to give us what we need to do the unpaid role. Thank you." (Q15:20)

- "We should have an Advisor ourselves." Q21:24

- "We Carers and the strongest link between our Cared For and the Local Council and Health Authorities and yet we are the weakest in Society simply we are glossed over and yet we still have to look for help. We Carers have always said we need more guidance and communication from these Authorities to assist us in our daily role – all we ask if for backup and the correct equipment to do the Role. Everything seems to take along time and yet in mainstream people get solutions far faster." (Q12:17 NHS & Social Care)

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