

Hearsay!

2015

The report

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Executive Summary

Healthwatch Oxfordshire organised 3 local Hearsay! events- in Didcot, Oxford and Banbury- to enable people who use adult social care services to tell Oxfordshire County Council (which pays for these services) what is working well, what is not and to offer suggestions for improving these services.

The main themes that emerged across the 3 events were:

1. *The need for a joined up health and social care system that offers appropriate and adequate information, advice and communication.* People said the different parts of the health and social care system need to improve how they communicate with each other so that patients experience seamless care moving between social care and health care. It was repeatedly suggested that it would help to have a named key worker to guide people through the care system and to have a single, good quality assessment that is regularly reviewed.
2. *The need for a personalised, holistic approach to care with an emphasis on maintaining a person's quality of life.* People said the system was too rigid to respond to their individual needs and often they felt reduced to a symptom rather than being treated as a person. Suggestions for improvement again mentioned the need for a personal key worker, seeing the same GP or care worker, and having good systems to flag up a person's individual characteristics (such as if they are a carer or have dementia) so that the care they receive in any setting takes into account their specific needs.
3. *There is a gap in services for younger people and working age adults* and an urgent need therefore to provide more age-appropriate services, housing, respite care and social activities for them.
4. *It is important to identify carers and their needs and support them adequately.* Many reach crisis point before asking for help. People said GPs should be proactive in identifying carers and giving them information on what support they can get as carers.

When asked what they thought of the event 100% of those who responded said they were glad they had come to the event, felt they had been able to say what they wanted and felt listened to.

This report has been presented to Oxfordshire County Council. The Council will respond with an action plan to improve services at the end of July and another Hearsay! event will be held in early 2016 to report on progress.

Hearsay! 2015: The report

What is Hearsay?

Hearsay! is an event organised for people using adult social care services in Oxfordshire. It has been running since 2010. This is the second year Healthwatch Oxfordshire have been involved in organising Hearsay!

Purpose

The purpose of Hearsay! is to enable local people to tell senior managers at Oxfordshire County Council responsible for adult social care services about what is working well and what is not working so well. People are also encouraged to offer their suggestions on how services could be improved.

Format

For 2015, a new format was adopted, based on suggestions from last year's event. Three smaller, more local events were held in the County- one in the south, in Didcot; one in the city, in Oxford; and one in the north, in Banbury. Each event had the same format- after a brief introduction to the event from Healthwatch Oxfordshire's Chief Executive, Rachel Coney, participants were encouraged to discuss in small groups their thoughts on what is working well in adult social care services and what is not. The discussion at each table was facilitated by a senior manager from Oxfordshire County Council or Oxfordshire Clinical Commissioning Group.

Following these discussions, feedback was sought from each table about the main points raised. Once all the feedback had been gathered, participants were able to vote on which of the issues raised were the most critical for Oxfordshire County Council to address in an action plan to improve services.

Who attended Hearsay?

A total of 47 people attended the 3 events. This included those using adult social care services, their carers, family and friends.

Senior staff from Oxfordshire County Council, responsible for social care in the county- including the Director of Adult Social Care and his two Deputy Directors- attended at least one event each.

Senior staff from the Oxfordshire Clinical Commissioning Group attended each event, including GPs at the Oxford city event.

What did attendees say?

What's working well?

These tended to be specific examples rather than common themes across the 3 events:

- In Didcot, attendees praised the re-ablement service as excellent.
- In Oxford, one attendee praised the care plan his GP wrote for his wife in full consultation with the family.
- Another praised the fact that their surgery had offered them a named person to contact directly when they needed help.
- A care home in Oxford was praised for providing the person with the names of the agency staff who would be attending her, so she knew exactly whom to expect a visit from.
- One attendee in Banbury said direct payments were working well.
- One carer said her carer's grant from her GP was good and enabled her to have a much needed break.
- The day centre in Berinsfield was praised as "fantastic".

What's not working well?

- Common themes that emerged across all 3 events:
 1. **The issue: Navigating the health and social care system is a "minefield" and getting the information, advice and help needed feels like a "huge battle".**
 - Though attendees understood the event was to discuss social care provision, it was striking that at all 3 events the discussion was about both health and social care and the overwhelming request was to offer a much more joined up, coordinated and integrated experience of health and social care.
 - There were repeated pleas to improve communication at all stages of the care journey
 - between GP and patient
 - care home and family
 - between GP and hospitals (when not done well this can mean inadequate hospital notes where a patient's requirements are not stated, or their having dementia is not noted, or this can result in repeated assessments)
 - between hospitals (assessments have had to be repeated because of inadequate communication between hospitals)
 - between GP and carer
 - between consultants
 - between acute and community care
 - between hospital and patient (no one explained to one family the consequences of a particular choice which then prevented the patient from being able to return home and forced her to go to a nursing home much further away than her local residential home)
 - Every time there is a new professional involved there is a new assessment, while on the other hand assessments are often not timely, not reviewed

regularly and often families reach crisis point before they can have an assessment.

Suggestions for improvement: A joined up health and social care system where the different parts communicate well and offer good information and advice:

- Having a named key worker or care navigator to guide people through the complex health and social care system is essential. Support on how to access information on local services and entitlements is needed both for self-funders and those receiving funded provision. This information should be presented in one place- a booklet was suggested- taking into account many people's inability to access the internet as a source of information.
- GP surgeries should play a role in offering information and advice.
- A good quality single assessment rather than multiple assessments, which is regularly reviewed without waiting for families to reach crisis point and which reflect current needs.
- Carers should be helped to identify the support they are eligible to.
- There is a strong need to take a joint approach to sort out transport provision across health and social care.
- The Community Information Network should be promoted more widely, as it does not have a high enough profile and many people do not know about it.

2. The issue: a health and social care system that is not adequately responsive to an individual's needs.

- Many examples of the rigidity of the system were discussed- for e.g. many noted that the carer's assessment form online via survey monkey doesn't allow you to say what you want to say and does not enable you to provide an accurate description of how things really are.
- One person said that since needing care he has lacked the freedom to ever choose his own bed time.
- Another person said they could never be spontaneous and could only do things organised in advance.
- Another example was where the family carer worked part-time, her husband had carers for Parkinson's and Parkinson's dementia and trouble arose if their 9 year old son was ill or has an inset day at school as the care agency staff could not help watch him even when they were in the house, as they were not insured to do so.
- An individual's needs are not adequately anticipated in discharge planning. For example, one person's planned day surgery turned into an 8 day hospital stay because of the lack of appropriate transport even though his transport needs were known beforehand. This happened to the same person twice.
- People are not treated holistically, only as a symptom- their care is divided into silos.

Suggestions for improvement: A person-centred, personalised, holistic approach to care with an emphasis on an individual's quality of life:

- A named key worker should be able to offer information and advice pertinent to the person's current care needs but also to ensure that as their care needs change, the advice and support adapts to reflect this.
- Training for care staff to ensure :
 - A professional manner
 - In-depth knowledge of the Care Act 2014
 - Respect for people's dignity in all care settings
- Continuity of care is crucial- seeing the same GP and agency care staff for example makes a real difference.
- Remember there is an individual at the centre of every intervention- treat the person and their family holistically.
- Discharge planning and anticipating needs is crucial- do not assume family and friends will be able to step in and provide support.
- A good flagging system where each person's medical records and hospital notes should reflect their individual characteristics like whether they are a carer, if they have dementia, or a learning disability etc.

3. The issue: Gaps in age-appropriate services.

- There are not enough services for young people, and working age adults- from 18-60 years, as most services are geared towards older people.
- There are gaps in services for young people with learning disabilities, those with autism, those with complex and multiple needs and families where multiple members need care.
- There are gaps in voluntary sector provision in mental health services for example for those who may not be seeking work but are not elderly.

Suggestions for improvement: more age-appropriate services including:

More age-appropriate support such as:

- More respite care.
- More housing- extra care housing.
- A greater breadth of services such as social activities on offer for younger and working age adults both from the Council and the voluntary sector. Attendees cited outings that reflect the interests of younger people such as bowling as one example.
- More access to mental health services in general. One attendee mentioned the difficulty in accessing Talking Space.

4. **The issue: There is not enough support for family members who are carers.**
- Carers often reach crisis point before they ask for help. It is important to identify how they can be best supported in their caring role One carer said she had a breakdown before anyone was willing to offer help.
 - Carers often do not know what support they are entitled to and do not know where to get the relevant information.
 - Carers' may themselves be vulnerable and health and social care professionals need to recognise this. An example was given of a care home pressing ahead with discharging an elderly lady into the care of her 85 year old, unwell husband's care.
 - A carer's knowledge of the person they are caring for is often not taken into account in assessments.

Suggestions for improvement: Greater awareness of carers' needs and more support for them:

- GPs' should play a proactive role in identifying carers- there should be a system for GPs to identify carers, track their wellbeing and give them relevant support and information.
- A carer's knowledge of the person they are caring for should be taken into account in assessments.
- Carers' needs should also be taken into account when cancelling and rescheduling their hospital appointments or appointments for those they care for.
- As the needs of the person they care for change, the support offered to carers should also change accordingly.

In addition, there were concerns that arose at the individual events:

In Didcot:

- Anxieties were expressed about the changes to the Independent Living Fund- people need clear information on what the changes are and whether this means a cut to their entitlements.
- Waiting times to access physiotherapy and the gap in the provision between the hospital and the community are lengthy.
- Concerns were expressed about the Wallingford GPs who have lost the contract to the Community Hospital and the detrimental impact on continuity of care.

In Oxford:

- People expressed an urgent need for improved training for care staff both in care homes and agency staff who offer care in the home.
- There were anxieties expressed around the quality of care homes- their poor quality, food, pain management and poor communication to families.

- The cost of care and the link between falling attendance numbers in day centres and cost was discussed. A question was raised if people with low care needs could pay less, if they just wanted to access the day centre for social contact.

In Banbury:

- There is a dearth of disabled housing and a strong need for genuinely accessible housing. Local planners need to take into account the needs of disabled people in housing stock but also in making the entire community accessible- there are not enough dropped kerbs for example.
- People get caught in cross-county boundary issues- falling between Oxfordshire and Northamptonshire or Warwickshire and get passed between the counties. It is a struggle to access appropriate care.
- People who receive care and their family carers are feeling more marginalised, and there is more work to be done on increasing social inclusion.
- There is big issue in accessing information about what direct payments for mental health can be spent on.
- Getting repeat prescriptions for specialist medicines can be difficult. One attendee cited difficulties in getting her GP to prescribe the specialist medication for her child's condition.

Finally, in the discussions people did raise the fact that as Oxfordshire is a rural county, this brings particular challenges in health and social care provision. For those in rural locations often the choice of services and care homes is limited and care can be more costly. There are additional challenges around organising transport and in discharge planning. It was suggested that health and social care commissioners and providers taken these additional barriers into account when commissioning and delivering care.

What did attendees think about the events?

37 out of the 47 people who attended filled in a form telling Healthwatch Oxfordshire what they thought about the event they had attended. 100% said they were glad they came, felt they had been listened to and had been able to say what they wanted to say.

Comments included "Very valuable opportunity to express concerns and receive feedback. Reassuring to hear that action will be taken." "Thank you. It's been great to have people listen and understand our issues."

What happens next?

This report with Healthwatch Oxfordshire's findings has been presented to Oxfordshire County Council. The Council is now working on an action plan on how to address the issues raised and to improve services. This plan to be available at the end of July and will be circulated to all those who attended the events, in addition to being available on Healthwatch Oxfordshire's website. Another Hearsay! event will be held in early 2016 so the County Council can provide an update on the progress it has made since these Hearsay! events.