NICE Collaborating Centre for Social Care

Service user experience: stakeholder scoping workshop notes (Thursday 29th October)

Break-out group discussions

Six facilitated break-out groups discussed specific aspects of the draft scope. This paper summarises the themes that emerged.

Reviewing the framework

With regards to the layout of the framework, some said that the linear presentation may not best represent service users' experience of social care services, rather; a circular approach which places the individual in the middle was suggested. One group also suggested taking a rights-based approach to care – by focussing on rights and responsibilities – as an additional area to consider alongside the framework, e.g. "empowering citizens".

Groups discussed to what extent the framework was useful in terms of capturing and understanding the important elements of service user experience, as well as highlighting any potential gaps. Comments included:

- What if the service user feels the service is not appropriate for them – it's about agency and autonomy – the starting point should be to look at how you achieve what is actually important to people.

- The collaboration of services (health and social care where relevant) is one of the main factors in how service users experience services – so should be a primary focus of the guideline.

- Need to place a focus on activities that are needed to achieve the good experience – as opposed to a more political approach that creates checklists. KPIs are not always the way to go about assessment.

- What appears to be missing is the barriers to access care and especially what happens before this stage. What is needed in the framework is one or two preliminary steps to identify what even happens before people are assessed for and receive support.

- Choice should be a key theme in the framework – what options do people actually have? Is the appropriate range of care available and accessible?

- Keeping safe while maintaining choice and control should be in the framework.

- Needs to include key terms such as 'dignity' and 'resilience'.

- Needs to include carers and families – the people who help you make your voice heard.

- Service models should not be generic models and should account for change in peoples need over time. Personalisation should be about one person – a care coordinator – to support the user through the pathway.

- Needs to consider how to negotiate the care pathways for people with dementia. Takes a lot of strength and courage to access help.

- Needs to account for planning. For example, there is a lot of stigma about care homes in the media, but residential does not always have to be the last resort. People should be choosing this as a positive option – living in a care home where needs are respected.

- To consider in the framework employment and studying in terms of enabling people to use their skills/be involved in their own care planning.

- To consider in the framework the person's entry into care, as well as accounting for changes throughout their journey.

- To consider in the framework the following interventions: peer support, reablement, stepping up and down care, working with people in crisis, feedback/complaints.

- Transitions and continuity of care should be emphasised.

Title

Overall, groups suggested that the title was too broad and did not define exactly what the guideline intends to do which was to improve people's experiences. Suggested changes to this included:

- Improving adult social care experience of services

- Improving quality of adult social care experience of services

- My experience of adult social care services

Several stakeholders commented that if 'carer experience' is going to be excluded from the title then it will need to be made more explicit in/throughout the scope that we are actually including elements of this.

Population

Groups were generally happy with the populations that were included and excluded. However, while some thought it important to list these, others commented that certain groups were conspicuous by their absence, suggesting either a longer list or no list at all (instead dealing with the populations in the equality impact assessment).

Many emphasised the importance of not overlooking individuals who have not yet gained access to services or are receiving low level social care (i.e. via voluntary-based support). It was thus suggested that people who have not yet received a care assessment should also be included. From this, some of the groups sought clarity in the definition of social care – does it include first contact and assessment, and not just those already in the system?

Other comments included:-

- Not necessary to specify older people in the scope. Older people are most of the population.
- Will this restrict assessment for people transitioning from children to adult services – people who should be using adult services, but are on the cusp?

Equalities

Stakeholders were keen to ensure that the following groups were reflected in the population:

- Mental health
- Learning disabilities
- Sensory impairment
- Hidden disabilities
- Socially isolated
- Those whose package of care comes to an end (those on fixed packages)
- Older people have the worst experiences of social care, despite making up the majority of people in social care
- People with dementia, often denied reablement services
- LGBT are having worse experiences of care. The experience should be as good as anyone else, including during the assessment process
- Those who have communication problems, such as those with speech and language difficulties – as a side population to look at those whose first language is not English

- People with co-morbidities

- Vulnerable heath groups, such as migrants and sex workers

- People with cognitive impairments

- Those with low economic power/resource

- Different geographies/diversity of experience

Settings

Groups thought that it was important to include the below settings:

- Education and the workplace

- Voluntary and community settings

- Home care services (instead of 'people's homes')

- Social care based in primary and secondary health care settings

Activities

Further suggestions to include in this list included:

- 'Lived experience' of service user

- Add 'compassion and engaging in conversation with people' to line 70

- Add 'including the roles of the various care providers' to delivery and coordination of care and support

- Add 'individual and group consultation' following lines 70/71

- Advocacy, peer support and mentoring

- Care reviews

- Financial assessment – personal budgets should be highlighted

- How people access services (including the information, advice and support they receive)

- Improving services/service design

- Integrated teams and multidisciplinary working (these are the foundation to a good experience and set standards)

- It should be asked what a bad experience looks like as you would learn more from this

- Monitoring and evaluation of services

- Prevention and reablement

- Service user feedback/complaints
- Service user involvement in shaping own care, and helping to make services better generally)
- Technology (in the sharing of information and delivery. For example, telehealth Vs telecare, informed choice, capacity, self-help and assessment)
- Transitions between social care services, and health and social care services
- Wellbeing (including involvement in the community)

Several stakeholders noted that medication management in the home by non-clinical staff was a key experience issue – but it may be covered by upcoming guidance. It was also suggested that the recovery agenda in mental health was not clearly covered here.

Approaches and tools to improve experience

One group listed the following existing approaches and tools to improve experience of care which may be useful for reference:

- Macmillan value based standard & behaviours (includes "I" statements" and is being rolled out in hospices now
- Individual Service Funds where local authorities are coproducing them
- Mental Health recovery STAR model
- Enter & View (Healthwatch)
- Peer support
- Peer interaction/input
- Macmillan Quality Mark
- Improving living environment – whether than be the care home or the person's own home

Key issues and questions

Some of the groups expressed their concerns about use of the word 'satisfaction', commenting that this should instead be 'measuring people's experience of services'.

The following questions were also thought to be important for the guideline to address:

- How should assessments be undertaken to ensure that people have the best experience of care right from the beginning?
- What are people's experiences at different stages of their journey?
- What are the aspects of people's experience that cause/improve people's problems?

- What are the characteristics of frontline practitioners that enhance people's experience of care?

- What is the role of digital technologies/telehealth and telecare in SUE?

- What makes people feel like they are maximising their potential?

- What's good about social care, and what's not? What's stopping you from getting there?

Evidence base

Groups suggested a wide call for evidence, comprising both quantitative and qualitative information, including:

- Association of Directors of Adult Social Services (ADASS)

- Advocacy organisations – SAM used by Older People's Advocacy Alliance

- Expert Citizens

- Foundation for People with Learning Disabilities

- Healthwatch

- HSCIC

- Joseph Rowntree

- King's Fund

- Market analysis/statistics and monitoring of delivery

- Mental Health Foundation

- National Voices

- NCPC

- NESTA

- Neurological Alliance

- Out of hours services

- Outcomes based commissioning ensures collection of data

- Public & Patient Voice Partners Forum

- Skills for Care

- Surveys from a range of sources

- Young/Health Foundation

General comments regarding the evidence base were also noted:

- The evidence doesn't always ask the right questions (i.e. judges the outcomes wrongly before any data collection even starts).

- The research methodology being used in social care is not always appropriate.

- Evidence is patchy – potentially talk to Healthwatch England to fill in some gaps.

- Need to get better at person-centred support; there is a need to support the case for resource allocation, as well as time and allocation of resources.

Outcomes

Overall, groups thought that the outcomes were appropriate, and suggested the following should either be included or form part of existing outcomes:

- Ability to gain or re-gain skills

- Empowerment

- Health and wellbeing

- Participation in the community (e.g. attend church, vote)

- Removing 'perceived' from user choice and control

GC composition

Stakeholders agreed with the percentage breakdown being in favour of service users. Groups recommended the following key practitioners:

- Registered manager from an independent provider that mainly provides for local authority contracts and another who mainly provides for private clients

- Care worker

- Social worker

- (Psychologist)

- (Liaison office (e.g. ECLO))

- (Allied health professional)

- (Commissioner of services)

- (General practitioner)

- Someone from the voluntary sector

- Academics

For the service user members, groups suggested:

- Someone buying their own care

- Someone under local authority care

- Someone who can speak for transition group – 18-25

- No single issue people – multi-skilled

- Learning disability users

- Working age people

- Older people

- Carers/people with care needs

- People with neurological/cognitive impairments

Implementation

Causes of poor implementation included:

- Silo working

- Fragmented system

- Commercial interests

- Ageism

General comments and next steps

Groups agreed that the guideline should not be one size fits all, and needs to incorporate:

- Having one trusted person – continuity – care coordinator

- The right language

- Diversity and identity