

National Institute for Health and Care Excellence
Social Care Guideline: Supporting Adult Carers
Stakeholder Scoping Workshop Notes
Monday 27th March 2017

Presentations

The group were welcomed to the meeting and informed about the purpose of the day. The Stakeholder Scoping Workshop is an opportunity for stakeholders to review the draft scope and give their input into whether the focus of the scope is appropriate.

The group received presentations about NICE's work, the work of the National Guideline Alliance (NGA) and the work of the public involvement programme. The Chair of the guideline committee also presented the key elements of the draft scope.

Following questions, the stakeholder representatives were then divided into four groups which included a facilitator and a scribe. Each group had a structured discussion around the key issues.

Scope

General comments

Stakeholders noted the following general themes:

- Overarching point on carer's journey/ overall carer's experience
- Important for carers to have a life of their own
- Caring should be a choice, right not to be made to care
- Language:
 - o Using "improving family resilience", instead of "reducing family burden"
 - o Importance of professionals using alternative language "Supporting, providing support for"
 - o Remove "burden" and use "impact" instead (although support for this as outcome)
- There is often a time-lag before people recognised their role as carers
- Distinction between necessary/unnecessary support and the ability to challenge the latter, e.g. when that support might undermine independence
- Closure of local services
- Some local authorities had a carers team
- Implementation issues
- Understanding unwarranted variation, especially in the context of implementing the Care Act
- Emphasize the idea that resources wasted when situations are not managed by the appropriate area.

Stakeholders also discussed the context section.

Why is this guideline needed?

Stakeholders noted the following should be added to this section:

- Impact of caring on carer's health and well-being
- Why this guideline is needed at the particular moment
- Variability in care (for example, differences between rural and urban areas)
- "Worklessness" is another aspect of the economic dimension on top of the value of the caring service provided
- Reference and statistics in relation to hidden carers. They noted that it may take up to 2 years for people to identify themselves as a carer
- Line 25: add "or are aware that they are a carer"

- Caring responsibilities may impact not only on employment, but also other activities
- People do not stop being a carer after transition to care or nursing homes. It would be important to check Carers Act to check if carer status changes
- Importance of contingency planning

They noted the following areas of key legislation:

- Interface with Children’s and Families Act
- “Carers toolkit” (NHS England)
- NICE Dementia Guideline
- “National carers strategy” – DoH to be published soon
- A member of one group mentioned mental health forensic services
- The Carers Trust was also mentioned in relation to changes in care

In addition, the following changes to policy legislation and their potential impact was discussed:

- Changes around End of Life Care and carer elements of EOLC (NICE EOLC guidance of some relevance)
- Brexit and impact on working carers rights in particular
- Care Quality Commission and primary care. It was raised the existence of “Carers registers” but noted these were recognised as good practice but voluntary.

Who is this guideline for?

Stakeholders noted the following groups could also be listed:

- GPs
- Emergency services
- Acute services.
- Pharmacists
- Charities (although this is already included in providers of support & voluntary organisations, it would be good to make it more explicit)
- Employment services/job centres
- Citizens advice services
- Consider sustainability and transformation plans
- Health & wellbeing boards
- Employers of carers (whilst recognising that it wasn’t within the remit to affect employment legislation it was thought it would be useful to show employers what represented good practice (e.g. with regards to carer rights and flexible working))

In addition, they noted the following:

- Providing services currently includes support to carers. Need to add in carers and those who are being cared for. Need to be careful not to exclude the person being cared for entirely from the scope as they will become missed.
- More clarity needed with regards to who’s included in community and voluntary organisations (maybe add hospices?)

Section 3.1 who is the focus? (population)

Groups that will be covered

Stakeholders noted the following groups could be added:

- Modify: “another adult” for “one or more adults”
- Addictions or substance misuse, as this group has particular needs
- Illness

In addition they discussed the following:

- Does not mention both adult & child carers. Whole family approach is missing.
- Adults juggling carrying for another family member and child care.

- Some cases where carer may be supporting adult and child simultaneously (multiple carers)
- A definition of carer is needed, at least a definition for carer for this guideline. This is important because there is a lot of confusion between paid and unpaid carer.
- Many people do not recognise themselves as carers, which in turn makes it difficult for healthcare professionals to identify carers too
- Include pre- and post-bereavement
- Family-system focussed, rather than patient-focussed approach
- Concerns expressed about consistency when transitioning from caring for under 18s to over 18s and also for young carers transitioning to be adult carers
- Check if people who receive carers allowance do qualify as carers (the rationale is that receiving benefits does not mean that someone is a “paid” carer)

Groups that will not be covered

Stakeholders noted the following:

- Concerns about adult carers supporting disabled children being out for the scope.
- It was noted that informal carers may be in receipt of payments, are these excluded from the guideline? They suggested to talk of “paid care workers/professionals”

Equalities

Stakeholders noted the following groups should be added/ modified :

- Carers with children (known as ‘sandwich carers’) typically 45-65, late working age is a growing group. This group has multiple responsibilities
- People caring at a distance should be mentioned as their own specific subgroup.
- Poverty and socially disadvantaged groups
- Gender, as experiences of men and women are different (for example, men are not always regarded as carers; also women are more likely to leave full time employment)
- Geographical (support could be particularly lacking in rural contexts)
- Mental health stigma, made even worse in context of substance abuse
- Military families, serving forces as well as veterans
- Transgender people could be looked at as a separate group, as they have specific needs
- Those who do not accept their role as carer
- Carers who are self-funders
- Working carers
- Change BME to BAME (Black, Asian and Minority Ethnic)

Section 3.2 Settings

Stakeholders noted the following settings could also be included:

- Residential care
- Home or family setting
- Formal and informal community setting
- Acute hospital setting, and ambulance
- Unpaid care – where care is provided to recognise that care is sometimes shared (paid/unpaid)

Section 3.3 Activities, services or aspects of care

Stakeholders discussed and commented on each area in the scope.

1 Identification and assessment of carers (including identification of hidden carers)

- suggested to use formulation, instead of assessment (they group argued assessment is a standard process, whereas formulation takes into account the individual characteristics of the person.);
- it would be important to be more explicit about what we mean by “hidden carers”;
- important to identify carers at admission (for example carer’s passport);

- role of GP in identifying carers;
- acknowledge that assessment is an ongoing process;
- assessment should be understood as a “whole family assessment”, as a carer may be supporting an adult and a child.

2 Information provision and advice needs of carers

- higher importance could be placed on information provision and needs. One group thought information provision could be listed at the top to emphasise this;
- information requirements may vary over “journey”, timely provision of information.

3 Support carers to remain in work, and in education or training.

- rather than emphasis on importance to remain in work, put more emphasis towards advice giving in this area;
- this should be included in the assessment;
- modify to enter and remain in employment;
- consider adding improving employment situation;
- add volunteering as well.

4 Provision of support (practical and emotional), including through the use of:

- carer breaks and respite care
- interventions that support wellbeing and healthy lives
- psychosocial or psychological and non-pharmacological interventions
 - consider moving up in the list;
 - emphasis on the importance of sign posting and information provision, otherwise people will not have access to provision of support carer centres, such as MIND, do provide some information with this;
 - look at provision of support (for those being cared for) to enable carer breaks;
 - look at peer support, carer support groups, carer training, physical training (moving and handling) adaptations in technology/equipment;
 - look at aids and adaptations;
 - importance of having a key contact for carer or a carer coordinator (admiral nurses);
 - crisis management;
 - NHS – offering flexible appointment times, health checks for carers.
 - discuss access to support, as support is not always accessible;
 - more clarity needed about what we meant by carer breaks. Carers do not necessarily need to be away from the person, they need a break from caring responsibilities;
 - activities for the carer and the cared for together or separately;
 - tailored and adapted to people’s needs and wishes (for example HW dementia friendly holidays);
 - split practical and emotional support.

5 Preparing and supporting carers in maintaining healthy family relationships as caring responsibilities change.

- important to make reference to the impact caring can have in the family dynamics;
- consider removing family (in order to include other relationships, such as friends)

6 Supporting carers after care has finished

- important to add when caring is interrupted/ intermittent (for example, a mental health condition can fluctuate, and care is not needed continuously)

7 Training of carers to provide support, including:

- care planning and coordination
- personal care
- distance caring
 - concerns about the use of the word training, as it sounds very formal;

- the use of coaching/ support were considered, however it was noted training is the correct term when talking about tasks;
- they emphasized caring for another person, should be a choice. Therefore “training” should be available to those people who want to do it (but is should not be imposed)
- training needs should be part of the assessment
- distance caring may not be needed here (distance carers will just need to appear somewhere as a group that may need to be thought about, they do not necessarily need to be ruled out specifically here)

In addition, stakeholders considered it important to look at additional areas:

- Different ways of providing care/ support: individual vs relationship approach. For example, in some countries couples are placed together in a caring home; whereas in the UK couples tend to be separated, and the person with care needs is placed in a caring home (“Ageing in place” programme in Australia)
- Use of digital technology to provide care. This can help to provide distance care and to reduce isolation
- Carers’ finances. Maybe this could be covered under information and advice (signposting and providing information are important)
- Access to legal advice
- Planning and provision of support for emergency/crisis
- Support during end of life
- Role of independent advocacy

The group identified some examples of innovative practices in supporting adult carers that could be looked at:

- London Borough of Sutton – Admiral nursing services
- Hereford good practice

Areas that will not be covered

This section had not been completed ahead of the meeting. Stakeholders suggested the following:

- No need to look at benefits advice (as guidance on entitlement is already available)
- No need to make medical recommendations (as NICE guidance is available for particular conditions)

Section 3.6 Main outcomes

Stakeholders noted the following outcomes could also be of interest:

- Financial resilience for carers (are they able to access support to protect their income, juggle work and care?)
- Length of care (prolonging length of being cared for in the community not residential care)
- Physical wellbeing (not only psychological)
- Spiritual, beliefs, and cultural needs

In addition, they noted the following:

- Important to define terms
- Important to use validated tools
- Although this is relating to academia, avoid the use of the term ‘burden’ anywhere in the guideline.
- Use of services surveys
- Consider removing carer competency
- Do not use disruptive behaviour, considering using distress instead

Section 3.5 Key issues and questions

This section was not discussed in detail, as there was more focus on identifying the right areas to be covered. The modifications to the scope areas will lead to modified or additional review questions.

In addition, the following was noted:

- They felt a mixed methods approach, using qualitative and quantitative review questions is useful
- They felt clarity was needed to explain what is meant by effectiveness (in terms of outcomes)
- New question needed to assess how services respond to feed-back;
- They asked whether we were planning to use quality improvement data

Section 3.4 Economic aspects

No comments were made.

Guideline Committee composition

Stakeholders made the following recommendations for the proposed members of the Guideline Committee:

- Commissioners
- Academics
- Social Worker
- Voluntary sector
- Provider/advocacy
- Nursing
- Social worker
- Carers lead
- GP
- Emergency services (Police/ambulance/fire)
- DWP/job Centre +
- Local Government Authority
- E+D