NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: People's experience using adult social care services
Output: Prioritised quality improvement areas for development.
Date of Quality Standards Advisory Committee meeting: 16 May 2018

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for people's experience using adult social care services. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

People's experience in adult social care services: improving the experience of care and support for people using adult social care services (2018) NICE guideline NG86

Published February 2018. Next review February 2020.

2 Overview

2.1 Focus of quality standard

This quality standard will cover the experience of adults receiving social care. It applies to all settings where care is delivered, including people's own homes, residential care and community settings. Its aim is to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care.

2.2 Definition

The core purpose of adult social care is to help people achieve the outcomes that matter to them in their life. People's experiences of adult social care, and the extent to which they feel supported to live their life as they want to, are therefore of key importance.

2.3 Current service provision

In 2017, just over 650,000 people were receiving adult social care services. Of these 69.8% were in the community support setting and 21% in residential care settings. People were receiving adult social care for the following reasons; physical support (58.8%), learning disabilities support (20.4%), mental health support (11.5%), memory and cognition support (8.2%), social support (2.5%) and sensory support (1.7%).[1]

People in receipt of adult social care services are funded through a variety of methods. In 2014-15 there were approximately 500,000 adults in England whose social care services were paid for through local authority personal budgets[2]. At 31 March 2014, 81% of all people receiving community based services were supported by personal budgets or direct payment. Within this group, 82% of older people were supported by personal budgets and 78% of adults between 18-64 years.[3]

2.4 Management

People receive adult social care services in the community and in residential care from a large number and range of providers that include the private and voluntary sectors. There are wide differences in the size and types of services and care provided. The adult social care sector covers:

- accommodation and personal care provided in residential care homes, nursing homes and specialist colleges (around 16,000 locations)
- personal care provided in the community for more than half a million people, of which the majority is care provided in people's homes through domiciliary care services (around 8,500 services), as well as extra care housing, Shared Lives schemes and supported living services.[4]

The Care Act 2014[5] sets out local authorities' duties in relation to assessing people's needs and their eligibility for publicly funded care and support. Under the Care Act 2014, local authorities must:

- carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care
- focus the assessment on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve

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[1] The Personal Social Services Adult Social Care Survey 2016 - 17, NHS Digital
[2] Personalised Commissioning in Adult Social Care, 2016 National Audit Office
[3] ADASS Personalisation Survey Report 2014, ADASS
[4] State of Care 2016/17 Care Quality Commission
[5] The Care Act 2014, Department of Health and Social Care

- involve the person in the assessment and, where appropriate, their carer or someone else they nominate
- provide access to an independent advocate to support the person's involvement in the assessment if required
- consider other things besides care services that can contribute to the desired outcomes (e.g. preventive services, community support)
- use the new national minimum threshold to judge eligibility for publicly funded care and support.[6]

People's experience of adult social care could be affected by the complex challenges facing social care services. These challenges include:

- rising needs from an ageing population with increasingly complex conditions
- rising costs to providers of adult social care
- restricted public funds to meet those costs and a strain on the resources of those who pay for their own care
- serious challenges in recruiting and retaining good quality staff.

The importance of people's experience of adult social care services is highlighted in Quality Matters which was developed in 2017. Its purpose is to ensure that staff, providers, commissioners and funders, regulators and other national organisations listen to and act on the voice of people using services, their families and carers. It is a shared commitment to high-quality, person-centred adult social care intended to make a difference in care services by working across the sector with people who use these services and their carers.[7]

See appendix 1 for the associated pathway from NICE guideline NG86.

2.5 National outcome frameworks

Table 1 shows the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

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[6] Social Care Institute for Excellence website

[7] Adult Social Care: Quality Matters, 2017 Department of Health and Social Care and the Care Quality Commission

Table 1: Adult social care outcomes framework 2017–18

Domain	Overarching indicators and improvement areas
1 Enhancing quality of life for people with care and support needs	***Overarching measures*** 1A Social care-related quality of life** 1J – Adjusted social care-related quality of life – impact of Adult Social Care Services ***Outcome measures*** **People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs** 1B Proportion of people who use services who have control over their daily life 1C Proportion of people using social care who receive self-directed support, and those receiving direct payments **People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation** 1E Proportion of adults with a learning disability in paid employment** 1F Proportion of adults in contact with secondary mental health services in paid employment** 1G Proportion of adults with a learning disability who live in their own home or with their family* 1H Proportion of adults in contact with secondary mental health services living independently, with or without support* 1I Proportion of people who use services and carers, who reported that they had as much social contact as they would like
3 Ensuring that people have a positive experience of care and support	***Overarching measures*** **People who use social care and their carers are satisfied with their experience of care and support services** 3A Overall satisfaction of people who use services with their care and support *Placeholder 3E Effectiveness of integrated care* ***Outcome measures*** **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D Proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual** This information is contained in the Adult Social Care Survey and used for analysis at the local level.

4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm	***Overarching measure*** 4A Proportion of people who use services who feel safe** ***Outcome measures*** **Everyone enjoys physical safety and feels secure** **People are free from physical and emotional abuse, harassment, neglect and self-harm** **People are protected as far as possible from avoidable harm, disease and injuries** **People are supported to plan ahead and have the freedom to manage risks the way that they wish** 4B Proportion of people who use services who say that those services have made them feel safe and secure
Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

3 Summary of suggestions

3.1 Responses

In total 17 stakeholders and 4 specialist committee members responded to the 2-week engagement exercise 05/03/18 – 19/03/18.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 2 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendices 3 and 4 for information.

Table 2 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Care and support - needs assessment • Timing of assessment • Person-centred assessments	BGS, C&R, GAUK, LCC, PUK, SCM, TLAP
Care and support - planning • Person-centred planning • Personal budgets	BGS, CBF, CD, EJF, HE, LCC, RCGP, RCN, SCMs, TLAP
Care and support - provision • Participation and relationships • Communication and continuity of services • Delivery of care • Protection from abuse	AUK, CBF, EJF, GAUK, HE, PUK, RCN, SCMs
Access and involvement • Access to care • Information on services • Involvement of people using services	AUK, DHSC, GAUK, HE, LCC PUK, RCGP, SCMs

Suggested area for improvement	Stakeholders
Additional areas • Carers • Training • Changes to guideline recommendations • Polypharmacy • Severe learning disabilities and behaviour that challenges • Electronic records • Landscape of services	AUK, BGS, CBF, CD, DHSC, DRUK, GAUK, PUK, RCGP, RCN, SCMs
AUK, Age UK BGS, British Geriatrics Society (Endorsed by Royal College of Physicians) C&R, Care & Repair England CBF, The Challenging Behaviour Foundation CD, Compassion in Dying DHSC, Department of Health & Social Care DRUK, Disability Rights UK EJF, Elcena Jeffers Foundation GAUK, Genetic Alliance UK HE, Healthwatch England LCC, Adult Care-Lincolnshire County Council PUK, Parkinson's UK RCGP, Royal College of General Practitioners RCN, Royal College of Nursing TLAP, Think Local Act Personal SCM, Specialist Committee Member SfC, Skills for Care	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 983 papers were identified for this topic. In addition, 29 papers were suggested by stakeholders at topic engagement and 15 papers internally at project scoping.

Of these papers, 7 have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

4 Suggested improvement areas

4.1 Care and support - needs assessment

4.1.1 Summary of suggestions

Timing of assessment

A stakeholder felt that all older people should undergo comprehensive assessment when starting a complex care package or on arrival in a care home. This should be an assessment that addresses care needs, ability to complete activities of daily living, the requirement for specific environmental adaptations, psychological and medical care needs.

Person-centred assessments

Stakeholders felt that assessments should focus on what matters most to people and draw on people's strengths, needs and ambitions. Using a strengths-based approach to the assessment process, people can be supported to understand their needs, realise what they can do, and how to best use their skills and networks, to achieve their outcomes.

People with rare conditions do not always get an accurate assessment of their needs because the assessor does not have an understanding of the condition. People with Parkinson's disease should have assessments that consider fluctuation and potential changes in future needs.

A stakeholder stated that local authorities should take a holistic view of the person's needs and identify how their needs for care and support impact on family members or others in their support network. Needs assessments often do not consider the impact of the interactions between the needs of multiple affected family members which can underestimate a family's needs.

A stakeholder noted that consideration of a person's housing circumstances and wishes is an integral part of their social care need. Having a good, warm, accessible home plays an important role in supporting the delivery of good social care for people living in their own homes and in supported and specialist housing.

4.1.2 Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 3 to help inform the committee's discussion.

Table 3 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Timing of assessment	No recommendations identified.
Person-centred assessments	**Overarching principles** NICE NG86 Recommendation 1.1.1 **Involving carers, families and friends** NICE NG86 Recommendations 1.1.14 and 1.1.15 **Information** NICE NG86 recommendation 1.2.4 **Needs assessment** NICE NG86 Recommendations 1.3.3, 1.3.4, 1.3.6, and 1.3.7

Overarching principles

NICE NG86 Recommendation 1.1.1

Recognise that each person who uses services is an individual. Use each person's self-defined strengths, preferences, aspirations and needs as the basis on which to provide care and support to live an independent life.

Involving carers, families and friends

NICE NG86 Recommendation 1.1.14

Ask the person at the first point of contact whether and how they would like their carers, family, friends and advocates or other people of their choosing (for example, personal assistants) to be involved in discussions and decisions about their care and support, and follow their wishes. Review this regularly (at least every 6 to 12 months), or when requested.

NICE NG86 Recommendation 1.1.15

If the person would like their carers, family, friends and advocates involved:

- explain the principles of confidentiality, and how these are applied in the best interests of the person
- discuss with the person and their carers, family, friends and advocates what this would mean for them
- share information with carers, family, friends and advocates as agreed.

Information

NICE NG86 recommendation 1.2.4

Local authorities should provide comprehensive information about community resources and support, including voluntary organisations, user-led organisations and disabled people's organisations, and about available housing options.

Needs assessment

NICE NG86 Recommendation 1.3.3

Local authorities must ensure that care and support needs assessment under the Care Act 2014 focuses on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve in their day-to-day life.

NICE NG86 Recommendation 1.3.4

Care and support needs assessment should:

- involve the person and their carers in discussions and decisions about their care and support
- take into account the person's personal history and life story
- take a whole family approach
- take into account the needs of carers
- take into account the person's housing status, and where and who they want to live with
- be aimed at promoting their interests and independence
- be respectful of their dignity
- be transparent in terms of letting people and their families and carers know how, when and why decisions are made
- take into account the potential negative effect of social isolation on people's health and wellbeing.

NICE NG86 Recommendation 1.3.6

Local authorities should ensure that:

- the person is given details of the care and support needs assessment process and timescale at the start

- the person is given details of the nature and purpose of the assessment
- the person can have someone they choose to be present at the assessment
- the assessment uses up-to-date information and documentation about the person
- the person does not have to provide the same information in subsequent assessments.

NICE NG86 Recommendation 1.3.7

If a person who uses services has caring responsibilities, their care and support needs assessment should take account of this. In line with the Care Act 2014, they must also be offered a separate carer's assessment which should identify whether the person they care for is a carer themselves.

4.1.3 Current UK practice

Timing of assessment

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

Person-centred assessments

The ADASS Personalisation Survey Report 2014 survey[8] was completed by 132 councils (87% of all eligible councils) between July and August 2014. The survey invited councils to assess their progress against a number of statements covering 5 themes. One of the themes was ‘improving people’s experience of personalisation’. Councils were asked to RAG rate themselves against achievement:

- green; there has been activity addressing these issues for some time. Plans are comprehensive. Desired outcomes are being or beginning to be achieved
- amber-green; the issues identified are being progressed. There are plans already in place to address them. However, there is some further work to be done to achieve desired outcomes
- red-amber; the issues identified are being progressed, but plans are currently in development or are not complete. There is significant work to be done before outcomes can be achieved
- red; the issues are not currently being progressed. There are no plans in place.

When reporting on assessment processes:

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[8] ADASS Personalisation Survey Report 2014, ADASS

- 95% of responding councils reported green or amber-green status on whether the assessment process recognises and registers the strengths people have
- 90% of councils reported green or amber-green on making the assessment a co-produced document.

When reporting on whether ‘the assessment clearly and unequivocally recognises the role and importance of informal carers’:

- 94% of councils reported green or amber-green status.

4.1.4 Resource impact

No significant resource implications are expected.

4.2 Care and support - planning

4.2.1 Summary of suggestions

Person-centred planning

Stakeholders felt that care and support planning should focus on what matters most to people using services and their carers. They should be involved in their health and lifestyle decisions, and in robust, comprehensive, personalised care and support planning. People receiving adult social care should be empowered to consider and document their end of life care preferences.

A stakeholder noted the importance of people's involvement when planning their reablement and their other care plans. When care and support planning is not centred on the person this can detract from the experience of receiving, or even accepting, care and support.

A stakeholder felt care and support planning is vital to identify the most appropriate way to meet people's needs and empower them to be active in their communities. Sometimes ways of meeting needs relate to service availability and not to the individual outcomes.

A stakeholder felt people receiving adult social care should be offered an allocated coordinator to improve their outcomes.

Older people receiving social care should have a care plan that recognises their individual interests and aspirations and describes how these will be delivered.

Personal budgets

A stakeholder noted that council managed personal budgets should allow genuine choice and control, so that people receiving care and support through council commissioned services have an opportunity to decide which services they receive.

A stakeholder commented that offering a personal budget through direct payments puts people in control of their support. This is fundamental in the Care Act and demonstrates huge benefits, especially when employing personal assistants. A stakeholder highlighted the importance of personal assistants and user-led centres for independent living.

A stakeholder felt that lack of funding will often determine the quality and quantity of care that people receive. Reductions in funding from central and local government come in spite of rising demand, complexity and cost in care provision. Creating long-term sustainable health and social care systems is of ever greater importance with demand for both services continuing to rise. Increased longevity means more people are living for longer with complex, long-term conditions.

4.2.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Person-centred planning	**Care and support plans** NICE NG86 Recommendations 1.3.10 and 1.3.11 **End-of-life support in residential settings** NICE NG86 Recommendation 1.4.18 **Named care coordinator** NICE QS132 Social care for older people with multiple long-term conditions Statement 3 **Designated coordinator** NICE QS101 Learning disabilities: challenging behaviour Statement 3
Personal budgets	**Personal budgets and direct payments** NICE NG86 Recommendations 1.3.18, 1.3.19 and 1.3.20 **Personal assistants** NICE NG86 Recommendations 1.3.23

Care and support plans

<u>NICE NG86 Recommendation 1.3.10</u>

1.3.10 As part of care planning, consider identifying a named coordinator who is competent to:

- act as the first point of contact for any questions or problems
- contribute to the assessment process
- liaise and work with the person, their families, carers and advocates
- liaise and work with all health, social care and housing services involved with the person, including those provided by the voluntary and community sector
- ensure that any referrals needed are made and are actioned.

NICE NG86 Recommendation 1.3.11

Build in flexibility to the care and support plan to accommodate changes to a person's priorities, needs and preferences – for example, by using direct payments (see recommendations 1.3.20 and 1.3.21) and agreeing a rolling 3‑monthly budget so that people can use their money differently each week.

Personal budgets and direct payments

NICE NG86 Recommendation 1.3.18

The local authority must include the person's personal budget in their care and support plan, in line with the Care Act 2014.

NICE NG86 Recommendation 1.3.19

Local authorities should:

- inform people that they have the option to control their own funding to buy different sorts of care and support that meets their needs and chosen outcomes
- provide information, advice and support so that the person can choose which option suits them best
- give people the opportunity to exercise as much control as possible over the way they use any allocated funds to purchase a care package
- inform people of the different options for managing their budget.

NICE NG86 Recommendation 1.3.20

Local authorities should ensure that the direct payment process is:

- transparent about how the level of funding is decided
- straightforward
- accessible to all adults who receive social care and are eligible for local authority funding
- reviewed periodically to make sure that it is meeting the objectives of the care and support plan
- able to meet the legal obligations of the person receiving that direct payment if they employ personal assistants.

Personal assistants

NICE NG86 Recommendation 1.3.23

If people have eligible needs that could be met by employing a personal assistant, the local authority should ensure that this option is discussed with the person and understood by them at the care and support planning stage.

End-of-life support in residential settings

NICE NG86 Recommendation 1.4.18

Managers in residential settings should co-produce a policy on end-of-life care with people who use services and their carers. This should include information about:

- documenting treatment and care preferences at the earliest opportunity (including formal ways of documenting preferences such as Lasting Power of Attorney for health and care decisions, advance statements of wishes and care preferences or advance decisions to refuse treatment)
- a named lead in the residential setting
- training on supporting people and their carers at the end of their lives, tailored to different staff groups and updated regularly
- ongoing support to enable practitioners to support people near the end of their lives, including creative ways of engaging people in discussions (for example, opportunities to discuss end-of-life care with peers).

Named care coordinator

NICE QS132 Social care for older people with multiple long-term conditions Statement 3

Older people with multiple long-term conditions and eligible social care needs have a named care coordinator.

Designated coordinator

NICE QS101 Learning disabilities: challenging behaviour Statement 3

People with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

4.2.3 Current UK practice

Person-centred planning

The Personal Outcomes Evaluation Tool was developed to measure the experiences of people in receipt of personal budgets and personalised care and support. In particular, the tool aims to measure how people experience the planning of their care and support. The 2017 POET report[9] found that:

- 62% of 4,300 respondents felt the information and advice they have to make decisions about their support is good or very good
- 17% rated information and advice about support decisions as poor or very poor
- 72% of respondents said the choice and control they had over their care and support was good or very good
- 80% said their views were fully or mostly included when their support was planned
- 63% said their support made their ability to make everyday decisions better or a lot better.

The personal social services adult social care survey 2016-17[10] received 70,885 responses from people using services:

- 64.7% of respondents said they were either extremely or very satisfied with the care and support they received
- 67.6% of people using services in the community reported they have enough choice over the care and support services they receive
- 6.3% saying they do not want or need choice.

Personal budgets

The POET survey in 2017 reported:

- 51% of respondents said that they could fully or mostly decide how the money in their personal budget was spent

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[9] Personal Outcomes Evaluation Tool (POET) for adults in receipt of social care support - 2017 report, Think Local, Act Personal (TLAP)

[10] The Personal Social Services Adult Social Care Survey 2016 - 17, NHS Digital

- 27%, many of whom were people with learning disabilities, said that they could not decide how the money in their personal budget was spent.

The ADASS Personalisation Survey Report 2014 reported that, at 31 March 2014, 81% of all people receiving community based services were supported by personal budgets or direct payment.

4.2.4 Resource impact

No significant resource implications are expected.

4.3 Care and support - provision

4.3.1 Summary of suggestions

Participation and relationships

A stakeholder felt that helping people to be a part of society should be central to social care delivery. In care homes, residents should be able to access safe outdoor spaces when they want to do so and remain connected to communities.

A stakeholder commented that positive relationships between people using services should be promoted because it is important that people in residential settings remain connected to their community.

Communication and continuity of services

Stakeholders commented that improved communication between health and social care organisations is key to an integrated and joined up system. This includes health and social care, and other partners including the people using services and their families, voluntary and independent sectors. It needs shared records and open communication at all levels and could allow faster access to services, reduced anxiety for workers, increased quality of case monitoring and relapse support.

A stakeholder noted that service users are being asked the same questions repeatedly because previous records are not made available.

Stakeholders felt that continuity in care and support should include ensuring that all practitioners involved with the person's care and support are familiar with how that person likes support to be given and where possible, the same people are supporting the person. If the same staff are not available services should ensure there are good handover arrangements. Continuity of care has a considerable impact on people’s happiness and quality of life, as it can lead to the establishment of positive relationships between care users and staff. Lack of continuity can lead to feelings of isolation, unhappiness and distress.

A stakeholder felt that continuity of care workers is especially important for people with very specific needs and another stakeholder noted the importance of having the same care providers to ensure strict medicines management regimes are met.

Delivery of care

A stakeholder felt services should be timely and deliver what is agreed. The best way to ensure care meets the needs and expectations of users is to fully involve them and their relatives in the assessment and planning process. This means from the outset people using services, where possible, should be given a choice of care provider and be able to select the elements of care that matter most to them.

A stakeholder noted that the timing and speed of response can impact of outcomes for individuals. This is important in effective discharge arrangements, particularly when the aim of intervention is to maximise someone's ability to continue living independently in their own home.

A stakeholder felt 'Quality Matters' should be used to provide a shared commitment to high-quality, person centred adult social care. People's experience of care is integrated across many different health and social care services and is a shared commitment for everyone who uses, works in, and supports adult social care.

Protection from abuse

Stakeholders noted that people with complex needs are at risk of abuse. It is important that robust systems are in place for early identification of abuse, with all areas working effectively, in coordination and communicating effectively to prevent abuse being missed.

4.3.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Participation and relationships	**Promoting positive relationships between people who use services** NICE NG86 Recommendation 1.4.12 **Residential settings** NICE NG86 Recommendation 1.4.15
Communication and continuity of services	**Needs assessment** NICE NG86 Recommendation 1.3.8 **Care and support plans** NICE NG86 Recommendation 1.3.13 **Continuity and consistency** NICE NG86 Recommendations 1.4.7, 1.4.8 and 1.4.10 **Consistent team of home workers** NICE QS123 Home care for older people statement 3
Delivery of care	**Care and support in all settings** NICE NG86 Recommendation 1.4.1

Protection from abuse	**Information** NICE NG86 Recommendation 1.2.1 **Care and support in all settings** NICE NG86 Recommendation 1.4.1

Information

NICE NG86 recommendation 1.2.1

In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including:

- the types of care and support available
- how to access care and support, including eligibility criteria
- how to get financial advice about care and support
- local safeguarding procedures and how to raise safeguarding concerns or make a complaint
- rights and entitlements to assessments and care and support services
- personal budgets and all the options for taking a personal budget – for example, local authority managed, Individual Service Fund or direct payment.

Needs assessment

NICE NG86 Recommendation 1.3.8

Ensure that care and support needs assessment documentation about the person is accurate, up to date and well maintained and clarifies what assessed needs will be met and how.

Care and support plans

NICE NG86 Recommendation 1.3.13

Ensure there is a transparent process for 'matching' care workers to people, taking into account:

- the person's care and support needs and
- the care workers' knowledge, skills and experience and
- if possible and appropriate, both parties' interests and preferences.

Care and support in all settings

NICE NG86 Recommendation 1.4.1

Service providers should foster a culture that enables practitioners to respect people's individual choices and preferences, in all settings where care and support is delivered, by:

- co-producing policies and protocols with people who use services and their carers (see recommendation 1.1.9)
- ensuring that there are open channels of communication between practitioners and people who use services
- using the communication methods that suit the person, in line with the Accessible Information Standard
- supporting people to take managed risks to achieve their goals – for example, taking part in hobbies or sports
- ensuring that there are systems in place for reporting concerns or abuse
- ensuring that practitioners have the time to build relationships with people
- training and supporting practitioners to work in this way, and checking they are doing so.

Continuity and consistency

NICE NG86 Recommendation 1.4.7

Commissioners and managers in all settings should ensure that there is continuity in care and support for people, including:

- ensuring that all practitioners involved with the person's care and support are familiar with how that person likes support to be given
- where possible, the same people are supporting the person
- if the same staff are not available, ensuring there are good handover arrangements
- ensuring that all staff supporting the person have similar levels of skills and competency
- using the same independent advocate where possible.

NICE NG86 Recommendation 1.4.8

Providers and managers in all settings should ensure that:

- people are informed in advance if staff will be changed and
- any changes to care and support – for example, when visits will be made, are negotiated with the person.

NICE NG86 Recommendation 1.4.10

To support collaborative working between services, commissioners and managers should consider putting the following in place:

- a local policy for sharing information relevant to people's care within and between services in line with the Caldicott principles and the Health and Social Care (Safety and Quality) Act 2015
- joined-up policies, processes and systems.

Promoting positive relationships between people who use services

NICE NG86 Recommendation 1.4.12

Service managers and practitioners in day care and residential settings should promote a sense of community and mutual support – for example, by facilitating interactions and building social connections between residents through activities such as social events.

Residential settings

NICE NG86 Recommendation 1.4.15

Ensure that support in residential care is based on a good understanding of people's needs, including:

- providing practical and emotional support
- accommodating speech and communication needs
- helping people to maintain the personal relationships and friendships that are important to them
- supporting people to take part in activities and social groups that they want to be involved in, both in the residential setting and in the community
- viewing behaviour that challenges as communication

- providing access to community health teams and specialist support.

Consistent team of home workers

NICE QS123 Home care for older people statement 3

Older people using home care services receive care from a consistent team of home care workers who are familiar with their needs.

4.3.3 Current UK practice

Participation and relationships

The POET survey in 2017 reported:

- 81% of people receiving a personal budget rated the quality of their support as good or very good
- 57% said that the support they receive had made enjoying relationships with friends and family better or a lot better.

When asked about the impact support had on them being able to do things in their local area:

- 57.8% of people reported that their support had made a positive difference
- 39% said this aspect of life was not relevant to them and their support.

In the Personal Social Services Adult Social Care Survey 2016-17:

- 45.4% of people using services who responded reported that they had as much social contact as they want with the people they like
- 20% of service users reported not enough or little social contact
- 15.9% reported they had some social contact but not enough
- 5.7% reported they had little social contact with people and feel socially isolated.

Communication and continuity of services

The Care and Support Reform Programme Board undertook a series of Care Act Stocktakes to understand the impact and readiness for implementation of the Care Act. In the 2016 Care Act stocktake[11], which was completed by 151 authorities in England, 93% of councils describe their working arrangements with clinical

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[11] Stocktake 6 2016, The Care and Support Reform Programme Board

commissioning groups as very or generally effective. The majority of councils feel their relationships with the voluntary and private sector are very or generally effective at 85% and 78% respectively.

Fewer councils describe their local arrangements for integration and partnership with primary care providers and NHS acute care providers as effective:

- 52% say relationships are very or generally effective with primary care
- 42% say these are developing but not fully established
- 68% say relationships are very or generally effective with NHS acute care providers
- 30% say these are developing but not fully established.

The ADASS Personalisation Survey Report 2014 survey reported that almost 90% of responding councils reported green or amber-green status on making assessments “a coproduced document which clearly establishes agreements about the responsibilities of different parties”.

The CQC review of home care services in 2013[12] found that some providers were failing to meet standards because people using services had little choice regarding the number of new or unfamiliar care workers who arrived at their home. On many occasions they received no advance notice that they would be visited by someone they didn’t know. A frequently occurring theme throughout the programme was that people wanted the same care workers who know their preferences, needs and level of independence.

No published studies on current practice were highlighted for continuity of care outside the home care setting; this area is based on stakeholder’s knowledge and experience.

Delivery of care

The POET survey in 2017 reported:

- 81% of respondents rated the quality of the support they receive as good or very good
- 74% said the amount of support they receive is also good or very good.

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[12] Not just a number: review of home care services 2013 CQC

Protection from abuse

The POET survey in 2017 reported that over two thirds of respondents felt their support made things better or a lot better when it came to them feeling safe.

In the Personal Social Services Adult Social Care Survey 2016-17, 70.1% of people using services reported that they felt as safe as they want and 86.4% said the care and support they receive helps them feel safe.

The 2016 Care Act stocktake noted that 75% of councils reported an increase in their level of safeguarding activity.

4.3.4 Resource impact

No significant resource implications are expected.

4.4 Access and involvement

4.4.1 Summary of suggestions

Access to care

A stakeholder commented that access to social care support should be based on that person’s specific care and support needs, and not depend on their condition or diagnosis.

A stakeholder felt keeping a record of unmet needs would provide important information towards better funding of social care and noted that local authorities are struggling due to cuts in their budgets.

A stakeholder noted that visiting a doctor or dentist can be difficult for people living in care homes. People who have poor mobility or dementia struggle to get to a practice, and home visits are not always available meaning people who can’t leave their care home do not have access to primary care services.

A stakeholder highlighted the need to identify the epidemiology of the population requiring care, for example where and when they will need care, effective interventions and the costs and benefits.

Information on services

A stakeholder commented that a lack of understanding of what social care is, who it is provided by and how much it costs may lead to delays in people knowing what is available and receiving needs-appropriate support.

Stakeholders felt clear information about how to access social care and needs assessments should be easily available to help people receive support that increases with their growing needs and avoids crisis. One stakeholder highlighted this specifically in relation to people with Parkinson’s disease.

A stakeholder noted that people should be able to access social care services relevant to their needs in a timely, co-ordinated and effective manner. Access to assessment and engagement should be streamlined and less bureaucratic to support those requesting services at a time of crisis. People should be able to access services regardless of background, means or having others to advocate on their behalf.

A stakeholder felt people should be provided with information in the format they prefer in line with the Accessible Information Standard.

Involvement of people using services

A stakeholder highlighted the importance of obtaining feedback from people across residential and community supported living services about the quality of those services and opportunities for service development.

A stakeholder stated that involving people in the design of services means that the services are responsive and purposeful for use them. Recognising people's expertise in co-designing services can be innovative and cost effective.

A stakeholder felt acting on feedback, concerns and compliments is important and highlighted the importance of measuring, collecting and using data more effectively.

Stakeholders felt local authorities should involve people using services in recruitment and training of new staff. Ongoing training or in house training of social workers should be co-produced with people using services.

4.4.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Access to care	**Access to care** NICE NG86 recommendations 1.1.10 and 1.1.11
Information on services	**Information** NICE NG86 recommendations 1.2.1, 1.2.2, 1.2.3 and 1.2.4
Involvement of people using services	**Staff skills and experience** NICE NG86 Recommendation 1.5.3 **Using people's views to improve services** NICE NG86 Recommendations 1.6.7, 1.6.10 and 1.6.11

Access to care

NICE NG86 recommendation 1.1.10

Ensure that everyone with social care needs has access to services based on their needs, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation, and socio-economic status or other aspects of their identity.

NICE NG86 recommendation 1.1.11

Service providers should be aware of the cultural and religious needs of people who use services, and provide care and support that meets these needs. Examples include treatment choices, food choice and preparation, enabling people to dress in accordance with their culture or religion, personal grooming, or changes in timing of services around religious festivals – for example, during Ramadan.

Information

NICE NG86 recommendation 1.2.1

In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including:

- the types of care and support available
- how to access care and support, including eligibility criteria
- how to get financial advice about care and support
- local safeguarding procedures and how to raise safeguarding concerns or make a complaint
- rights and entitlements to assessments and care and support services
- personal budgets and all the options for taking a personal budget – for example, local authority managed, Individual Service Fund or direct payment.

NICE NG86 recommendation 1.2.2

Local authorities should ensure that information about care and support services is widely and publicly promoted – for example, in GP surgeries and community spaces, as well as in specialist services such as homeless health centres.

NICE NG86 recommendation 1.2.3

Local authorities should provide information about the circumstances in which independent advocacy is available, in line with the Accessible Information Standard, and how to access it.

NICE NG86 recommendation 1.2.4

Local authorities should provide comprehensive information about community resources and support, including voluntary organisations, user-led organisations and disabled people's organisations, and about available housing options.

Staff skills and experience

NICE NG86 Recommendation 1.5.3

Service providers should consider involving people who use services and their carers ('experts by experience') in the recruitment and training of staff. For example:

- being on interview panels
- contributing to development and delivery training
- helping to develop job descriptions
- supporting and training others to be experts by experience.

Using people's views to improve services

NICE NG86 Recommendations 1.6.7

Service providers should seek the views of people who use services about the extent to which the things that are important to them are being addressed. This should be done in such a way that the person feels safe to express their views, even if these are critical (for example, a care home resident may not want to give feedback directly to the manager).

NICE NG86 Recommendation 1.6.10

Commissioners and providers should ensure that the results of research with people are used to inform improvements to services.

NICE NG86 Recommendation 1.6.11

Commissioners and service providers should make available the results of research with people who use services, using approaches developed with people who use services. This should include:

- publishing the results
- giving feedback directly to people who took part
- making public how they have responded to people's feedback – for example, by using 'you said, we did' tables or case studies.

4.4.3 Current UK practice

Access to care

In the 2016 Care Act stocktake:

- 52% of councils reported an increase in the number of people requesting an assessment for the first time
- 58% reported an increase in the number of assessments
- 71% reported that, as a result of the Care Act 2014, more people are getting an independent advocate to assist them with their care and support arrangements
- 64% reported an increase in the number of people receiving short term or preventative services.

Information on services

In a 2017/18 survey[13] Deloitte found that 63% of 1071 people surveyed thought that social care was provided by the NHS and 47% thought it was free at the point of need.

In the 2016 Care Act Stocktake, councils overall were confident with their arrangements to provide a comprehensive advice and information service to their whole population. 81% of councils reported that their arrangements for the provision of information and advice are effective, with the remainder developing but not yet fully effective.

In the Personal Social Services Adult Social Care Survey 2015-16[14], responses were received from 73,165 people using services. 53.5% of people reported that it had been very or fairly easy to find information and advice about support, services or benefits. This had decreased slightly from 54.5% in 2014-15. 19.9% reported that it had been fairly or very difficult to find, a slight increase from 19.2% in 2014-15.

The ADASS Personalisation Survey Report 2014 survey included a question on whether councils have an information and advice strategy:

- 8% of councils reported green status
- 38% of councils reported amber-green status
- 12% red status.

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[13] The State of the State 2017/18, Deloitte

[14] The Personal Social Services Adult Social Care Survey 2015-16, NHS Digital

There were wide variations across the regions, with 11% reporting green or amber-green in the North East, compared with 86% in London.

On whether the information and advice provided includes specific elements of information (including what social care is, its relationship to health and health-related care and what care and support services are available):

- 72% of the councils responding reported green or amber-green status
- 26% were red-amber
- 2% were red.

Involvement of people using services

The ADASS Personalisation Survey Report 2014 survey included a question on how far the council takes a wide view of quality assurance and empowers local people to set the framework:

- 25% of responding councils reported green status
- 43% reported amber-green.

The survey also included a question on having a social work training programme for staff in community-based services that takes an asset-based approach to maximising the resilience of individuals and families, with users and carer experts engaged in this training. It found there was significant variation in responses from councils across the country.

4.4.4 Resource impact

No significant resource implications are expected.

4.5 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 16 May 2018.

Carers

Carer identification and support was suggested as an area of quality improvement. This suggestion has not been progressed within this quality standard. A quality standard focussing on carers will be developed following publication of the Carers: provision of support for adult carers guideline which is scheduled for publication in July 2019.

Training

The training of staff was suggested as an area of quality improvement. This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee is therefore asked to consider which components of care and support would be improved by increased training. Training may be referred to in the audience descriptors.

Changes to guideline recommendations

Changing some of the recommendations in NG86 was suggested. This suggestion has not been progressed because changes to guideline recommendations are outside the scope and remit of the quality standards process.

Polypharmacy

Polypharmacy in older people with complex conditions in the community and in care homes was suggested as an area of quality improvement. This suggestion has not been progressed within this quality standard. Quality standards have been developed on medicines optimisation (QS120) and medicines management in care homes (QS85) which include quality statements on medication reviews. In addition a quality standard on medicines management for people receiving social care in the community is in development and expected to publish in June 2018.

Severe learning disabilities and behaviour that challenges

Ensuring the involvement of people with severe learning disabilities and behaviour that challenges using effective communication skills to meet their specific communication needs and working and engaging with families and carers was suggested as an area of quality improvement. This suggestion has not been progressed within this quality standard. A quality standard has been developed on Learning disabilities: challenging behaviour (QS101).

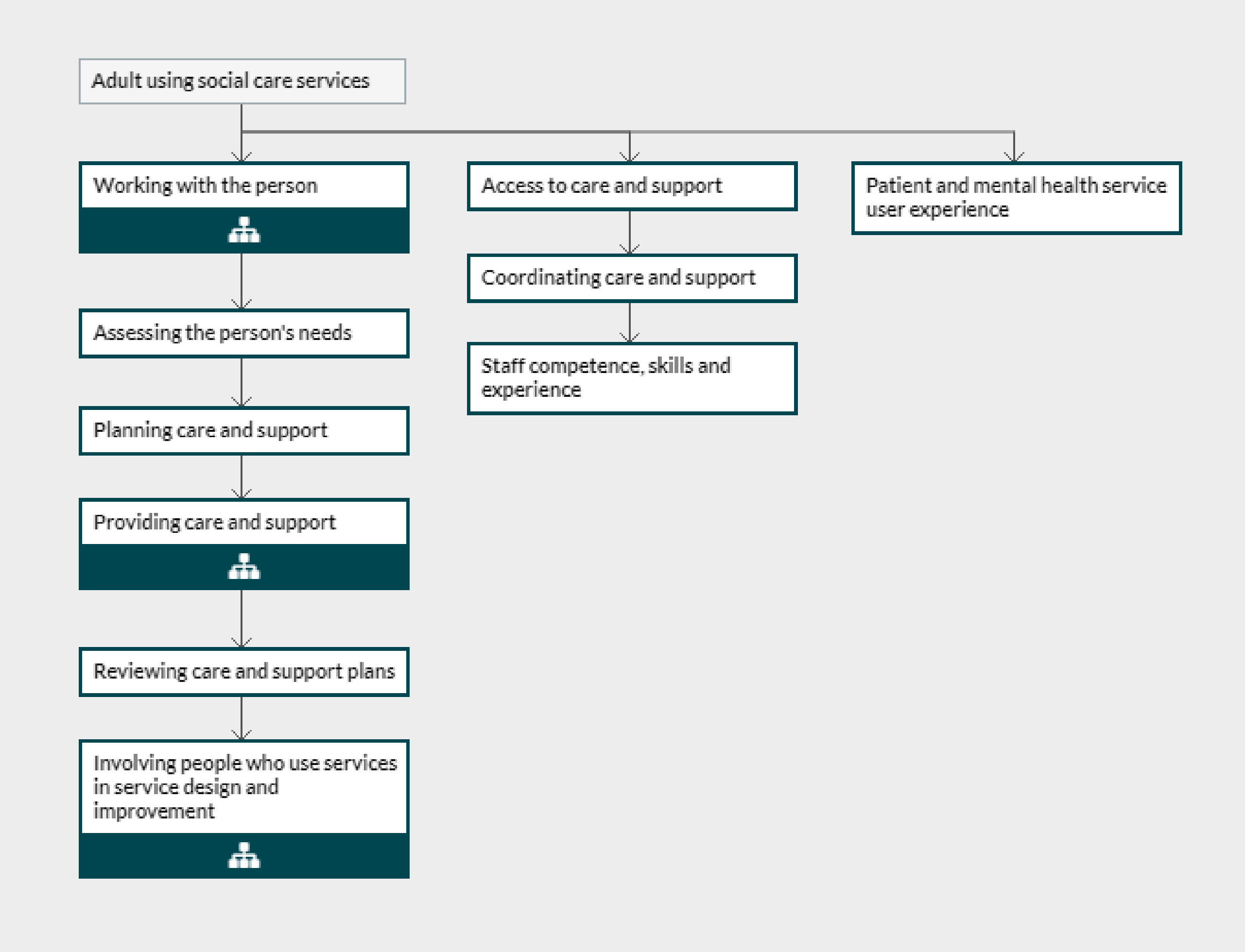
Electronic records

The availability of electronic records to service providers, people using services and carers was suggested as an area for quality improvement. This area is not within the scope of this quality standard.

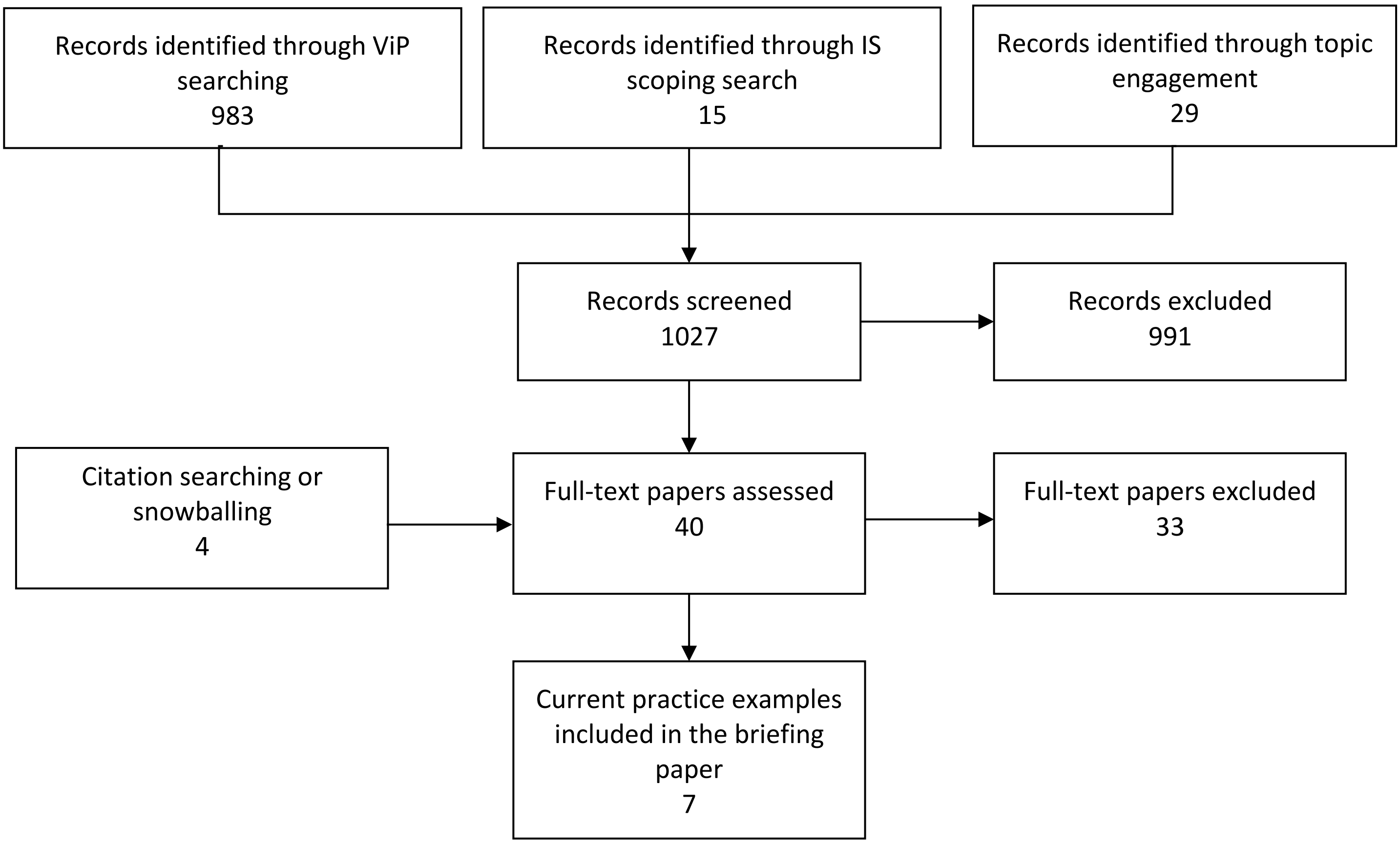
Landscape of adult social care services

Suggestions for areas of improvement relating to the landscape of services included; funding for social care from central and local government, levels of privatisation of social care services, facilitation of the local care provider market, commissioning for better outcomes, better use of joint resources, and market management. These suggestions have not been progressed for inclusion as quality statements. These areas are outside the scope and remit of the quality standards process.

Appendix 1: People's experience in adult social care services overview



Appendix 2: Review flowchart



Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Section 1			
1	British Geriatrics Society (Endorsed by Royal College of Physicians)	All older people should undergo comprehensive assessment at the point of commencement of a complex care package or at arrival in a care home.	This should be a multi-domain assessment that addresses care needs, ability to complete activities of daily living, the requirement for specific environmental adaptations, psychological and medical care needs	This should trigger an individualised management plan which should be co-ordinated by social care/care home and healthcare staff in co-operation	
2	Care & Repair England	Consideration of a person's housing circumstances and wishes as an integral part of their social care need.	Having a good, decent, warm, accessible home plays an important role in supporting the delivery of good social care for people living in the community – in their own homes and in supported and specialist housing. It can enhance the experience of social care for those who use adult social care services. Indeed, housing interventions such as adaptations to the home are an important ingredient in delivering social care services to people in their own homes. Some reference to the role of housing in the quality standard would encourage a greater focus on the delivery of holistic services for people using adult social care services.	Evidence that areas requires improvement include: - Information – the guidance on users experience of social care sets out why information on the options available is key to ensuring people's engagement, providing a positive experience of social care. We think this should include housing options and solutions more clearly. This has not always been the case. A short study undertaken by older people in the NW of England, for example, identified shortcomings in the information and advice available on housing options locally. We know that this is the case in other parts of the country. http://ageactionalliance.org/search-engine-failure-housing-and-care-advice-in-the-north-west/	Many of the chronic health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes. There is an expanding evidence base that considers the impact of housing on health on wellbeing and the value of housing interventions to care and health planning and provision. See NICE evidence at https://www.evidence.nhs.uk/Search?q=housing%20wellbeing (unfiltered) https://www.evidence.nhs.uk/Search?q=housing+impact+on+health+ (unfiltered)

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Assessment – ensuring that, alongside engagement in the assessment process, housing factors are properly considered will mean that people live in the right (warm, safe, secure) environment to provide the foundation for their social care support, health and wellbeing. The guidance on user's experience refers to the Care Act 2014 which also expects that housing factors are a part of an integrated assessment. It also calls for housing options to be considered in the provision of information and advice. This recognises that a consideration of people's housing needs and circumstances is essential to good social care. We would like to suggest that practice in this area could be improved by adding housing to this quality standard. Care planning and provision We would like to see more focus on ensuring that the care plan includes the person's housing circumstances and needs. This means identifying and planning actions that will improve their circumstances - for example home adaptations, home repairs or moving options. It also means ensuring that the support needed to undertake these agreed housing changes can be identified, put in place and monitored	Whilst we would not expect social care practitioners to deal with housing issues, per se, we would argue that housing needs to be considered in any social care assessment and links established with the key agencies locally that can support the development of housing solutions. Social care staff need to know about the common housing issues and who to contact locally to ensure that people's housing circumstances are addressed as far as they impact on a persons' health and wellbeing.
3	Genetic Alliance UK		The Care and Support Statutory Guidance states that: 'Where the assessor does not have the	Patients with rare conditions report difficulties obtaining an accurate assessment of their care and support	This comment is based on our (as yet unpublished) work on social care for patients with rare, genetic

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			necessary knowledge of a particular condition or circumstance, they must consult someone who has relevant expertise. This is to ensure that the assessor can ask the right questions relating to the condition and interpret these appropriately to identify underlying needs.' However this rarely occurs.	needs due to a lack of knowledge about specific rare conditions on the part of the social worker or occupational therapist. This can lead to inadequate or inappropriate care provision.	and undiagnosed conditions. We would be happy to share these with you or discuss them in greater detail.
4	Genetic Alliance UK	Local authorities to take a holistic view of the person's needs and identify how the adult's needs for care and support impact on family members or others in their support network, particularly where those family members also have social care needs.	Families affected by genetic conditions frequently have more than one member of the family with care and support needs.	However, needs assessments rarely consider the impact of the interactions between the needs of multiple affected family members, instead looking at each individual separately. This can lead assessors to underestimate a family's actual needs.	This comment is based on our (as yet unpublished) work on social care for patients with rare, genetic and undiagnosed conditions. We would be happy to share these with you or discuss them in greater detail.
5	Adult Care-Lincolnshire County Council	2Self-care; Strength based approaches and Community assets	The main aim of the Care Act 2014 is to promote people's wellbeing and independence.	Through a strengths-based approach to the assessment process, people can be supported to understand their needs, realise what they can do, and how to best use their skills and networks, to achieve their outcomes. People need linking to local communities, conversations between community commissioners and social work teams and the redevelopment of Neighbourhood teams can support these efforts.	www.thinklocalactpersonal.org.uk Self-care is the fundamental level of health care in all societies and should be seen as a **major public health resource**. http://isfglobal.org/what-is-self-care/

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
6	Parkinson's UK	Person centred needs assessments	Parkinson's is an extremely complex condition, with over 40 physical and non-physical symptoms such as pain, depression, dementia, hallucinations, and continence problems. Given the complexity of the condition, it's vital that care assessments follow the requirements set out in the Care Act 2014 to provide assessments in a suitable format, with a consideration of fluctuation as well as potential changes in future needs. This will ensure that people are assessed fairly and get the support they need first time.	Parkinson's UK's 2016 social care survey found that a around a third of Parkinson's Local Advisers – locally based staff that provide advice and signposting to people with Parkinson's disagreed that "assessments in my area have been conducted with a good understanding of Parkinson's" while almost half neither agreed nor disagreed. The advisers' survey gave a mixed picture about whether assessors asked about how a person's condition fluctuates. Around 28% of respondents disagreed and 28% neither agreed nor disagreed. A Parkinson's local adviser explains: *"My local authority has appointed experienced Carer Practitioners to support staff who conduct carer's assessments. They are keen to understand about Parkinson's. The problem comes when Parkinson's is not fully understood and the motor and non-motor symptoms not fully explored or explained. People tend to be very stoical and underplay needs."*	Caring About Parkinson's (2016) available at: https://s3-eu-west-1.amazonaws.com/puk-live-1-d8-ie/2017-09/care_act_experience_report.pdf
7	SCM1	Needs Assessment 1.3.4	The Care and Support Needs Assessment		
8	Think Local Act Personal	Assessments and care and support planning that focus on what matters most to people and are carried out in the form of			

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		conversations, drawing on people's strengths, needs and ambitions.			
		Section 2			
9	British Geriatrics Society (Endorsed by Royal College of Physicians)	Facilitating participation in society should be central to social care delivery.	All older people receiving social care should have a care plan that recognises their individual interests and aspirations and describes how these will be delivered.	In care homes, residents should be able to access safe outdoor spaces when they want to do so	
10	The Challenging Behaviour Foundation	Engaging and working with families	Working and engaging with families and carers is an important consideration in ensuring effective care of people. This is especially important in the care of someone with severe learning disabilities and behaviours that challenge.	'Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs.[15] The National Service Model recognises the importance of involving family carers and other people who know the individual well in their care.[16] Research has shown directly helping families of children and adults with learning disabilities is crucial to ensure the provision of capable and supportive environments for individuals whose behaviours challenge and to ensure a good quality of life for all. Families are diverse – their individual circumstances vary, so understanding each family context is essential to offering appropriate support.	

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[15] Department of Health. (2009). 'Valuing people Now'.

[16] Association of Directors of Adult Social Services, Local Government Association, NHS England. (2015). 'Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition'.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				However, the involvement of families is not always taking place. Findings from the NHSE Building The Right Support evaluation showed that it can be a struggle to involve families. [1] Royal College of Speech and Language Therapists. (2013). Five Good Communication Standards. Accessible at:https://www.rcslt.org/news/docs/good_comm_standards [1] Department of Health. (2009). 'Valuing people Now'. [1] Association of Directors of Adult Social Services, Local Government Association, NHS England. (2015). 'Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition'.	
11	Compassion in Dying	Empowering people within adult social care services to consider and document their future care preferences	1. People place great value on choice and control over decision-making and as we have learned from our service users, planning ahead gives people peace of mind and allows them to live well now. (Compassion in Dying *Plan Well, Die Well*, 2015). 2. 68% of Britons would like more control over decisions about their health (Ipsos Mori, Global Trends – Health, 2017) 3. The NHS is placing greater emphasis on person-centred care. Therefore it is vital that	In 2016, we commissioned the International Longevity Centre to undertake a literature review on the impact of advance care planning which found that the process of thinking about and recording one's treatment and care preferences results in better person-centred care and improved relationships and communication between families and healthcare professionals. Despite these benefits, our experience has shown that there is a lack of awareness among both the general public and health care professionals around the specific ways in which adults can take control of their treatment and care in case	We are not aware of any social care providers or hospitals, hospices, care homes and ambulance trusts which routinely collect the number of patients who have advance care plans which are (or are not) adhered to. However, this report by National Voices provides a useful summary of person-centred care. https://www.nationalvoices.org.uk/sites/default/files/public/publications/person-centred_care_in_2017_-_national_voices.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			specific information on the legal mechanisms available for planning ahead such as Advance Decisions, is widely disseminated.	they lost capacity – i.e. Lasting Powers of Attorney for Health and Welfare (LPA) and Advance Decisions (ADRT) including Advance Statements (AS). For example, we found that while 82% of people say they have strong views about what treatment they would want to refuse and accept at the end of life, only 4% of adults have an Advance Decision or a Lasting Power of Attorney for Health and Welfare (YouGov 2014). Our community outreach work with BAME and LGBT communities highlight the specific barriers they face (My Life, My Decision) when planning ahead in line with their values and priorities. Our CPD-accredited training sessions for healthcare professionals have demonstrated a lack of confidence among healthcare professionals to support people to plan ahead in line with the Mental Capacity Act 2005.	Age UK recently published data highlighting the fact that 1 in 3 people with dementia don't have a care plan which may also be useful. https://www.ageuk.org.uk/latest-news/articles/2018/february/1-in-3-with-dementia-diagnosis-dont-get-nhs-follow-up-support-theyre-supposed-to/?utm_source=National+Voices+Members&utm_campaign=3fe463a673-MU_130717&utm_medium=email&utm_term=0_00458e9137-3fe463a673-225078609
12	Elcena Jeffers Foundation		Individuals involvement in their own Health and life style need now to be in the quality standards.		
13	Healthwatch England	Services that are timely and deliver what is agreed	The best way to ensure care meets the needs and expectations of users is to fully involve them and their relatives in the assessment and planning process. This means from the outset care users, where possible, should be given a choice of care provider and	Healthwatch Hampshire reported that a worrying 75% or respondents to their survey did not feel adequately involved in the selection of their care provider. Healthwatch Staffordshire found that families did have significant influence over the choice of providers but perceived a	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			be able to select which elements of care matter most to them. Some people might want care workers to focus on the basics, like cooking and help dressing, whilst others might wish to use the support to help them continue doing things they used to do outside the home.	lack of flexibility when it came to selecting what times care staff would visit. A number of people reported it felt like care packages were designed to meet the needs of the service provider rather than the service user.	
14	Adult Care- Lincolnshire County Council	1**Use 'Quality Matters'**: to compressively and uniformly provide a shared commitment to high-quality, person centred adult social care. It has been produced to make a difference in care services by working across the sector with people who use these services and their carers.	People's experience of care is not isolated, but integrated across many different health and social care services. To achieve person-centred, high-quality, co-ordinated care we need to recognise and respond to this. This is a shared commitment for everyone who uses, works in, and supports adult social care. It has been co-produced by many different partners coming together, and it will succeed only through continued collaboration.	There is been on-going evidence suggesting that the sector is no co-ordinated in places and that people's experience can be isolated and not integrated when it involves multiple agencies and providers. Quality of service can be variable when it involves so many different services working to different principles. Continuous Improvement is key to service development and developing future models and strategies and people using services and their carers experience is a key component.	'Quality Matters' has been produced with partners across Health and Social Care and the purpose of the document is to bring the adult social care sector together in support of the agreed principles that underpin good quality adult social care. It builds on the partnerships and commitments that we have made before, and sets out clear action plans that support the delivery of priorities improving quality, but does not change the statutory responsibilities or undermine the independence of each organisation. Crucially it highlights that quality is everybody's responsibility. *Ref: Narrative taken from 'Quality Matters' For more information, go to: www.gov.uk/government/publications/adult -social-care-quality-matters*

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
15	Royal College of General Practitioners	5. Interagency collaboration between health and social services with shared records and open communication at all levels	• Faster access to services • Reduced anxiety for workers • Increased quality of case monitoring and relapse support • Ensuring agency demands on a family are not competing or overwhelming • Consistency of message from all involved • Better decision making • Improved ability to provide needed and timely resources • More effective use of limited resources • Development of new policy and practice • Reduction in duplication of service	Literature search from New South Wales Australia www.community.nsw.gov.au/__data/.../researchnotes_interagency_collaboration.pdf	
16	Royal College of Nursing	Improved partnership working between organisations.	Improved communication between organisations is key an integrated and joined up system but this does not just stop at health and social care, other partners have to be valued, respected and involved which includes the service users and their families, voluntary and independent sectors.	There are various models of joint commissioning and integration across the country.	NICE NG86: People's experience in adult social care services: improving the experience of care and support for people using adult social care services (2018)
17	Royal College of Nursing	Offer an allocated coordinator for *all* those in receipt of adult social care	There is evidence to suggest that a named coordinator can improve outcomes for service users	Those who self-fund their care are the people who will be more at risk of abuse or harm as will not receive care reviews/have a point of contact.	NICE NG86: People's experience in adult social care services: improving the experience of care and support for people using adult social care services (2018)
18	Royal College of Nursing	Respect service users as individuals	There is evidence to suggest that involving people in their care and	The framework for enhanced health in care homes (NHS 2016) highlights that	NICE NG86: People's experience in adult social care services:

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		involving them (and family/ friends where agreed) fully in robust, comprehensive, personalised care and support planning	support planning and utilising their expertise improves outcomes.	not all people living in care homes are having their needs properly assessed or addressed.	improving the experience of care and support for people using adult social care services (2018)
19	SCM 1	Personal Assistants 1.3.25	User-led Centres for Independent Living		
20	SCM 2	better integrated assessment between health and social care	Promotes a more resource efficient process and is likely to give a more holistic assessment of individual need	Evidence from service users consistently refers to duplication of assessment processes which can be psychologically distressing and is undermining of professional/ service user relationships	
21	SCM 2	User involvement in the planning of the reablement and other care plans	Research demonstrates that involvement of the service user was a key factor in the success of the reablement episode and all other forms of user contact	A successful reablement episode promotes independence and is likely to reduce cost and demand on other health and social care services	Variety of independent research available
22	SCM 2	speed of response	Both the timing and speed of response can impact of outcomes for individual patients /service users	This important in effective discharge arrangements particularly when the aim of intervention is to maximise someone's ability to continue living independently in their own home	
23	SCM 4		The offering and availability of a personal budget through direct payments as a way of meeting people's needs. Putting people in control of their support is fundamental in the Care Act & through the new NICE guideline and demonstrates huge benefits, especially when employing personal assistants.	The offer and availability of direct payments and the support to manage them differs greatly across local authorities.	

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24	SCM 4		Care / Support planning is vital to identify the most appropriate way to meet peoples needs and empower them to be active in their communities.	Inconsistent practices means that ways of meeting needs relate to service availability and not the individual outcomes.	
25	Think Local Act Personal	**Person-centred assessments/ Care and support planning** How council managed personal budgets can provide for genuine choice and control, so that people receiving the care and support through council commissioned services have a real opportunity to exercise influence of what is provided to them. The person's voice should be central to the process.	Assessments and Care and Support Planning are an essential element of self-directed support. Where they are not centred on the person and focus disproportionately on 'deficits' and on determining eligibility they can detract from the experience of receiving, or even accepting care and support. The quality standard could help to convey and flesh out what good person-centred process looks like and how it can be accomplished.	Evidence from In Control's Personal Outcomes Evaluation survey tool, over a number of years shows that poor processes can have a negative impact on outcomes for individuals and vice versa.	Most recently published report on findings from the Personal Outcomes Evaluation Tool. https://www.thinklocalactpersonal.org.uk/_assets/Resources/TLAP/POETPHB2017.pdf
26	Think Local Act Personal	**Making personal budgets work for all** How council managed personal budgets can provide for genuine choice and control, so that people	The majority of people receiving personal budgets still do so through the mechanism of council managed budgets, and this is particularly the case with older people, who make up the majority of people receiving social care.	There is concern that many people receive a personal budget in name only, and that people all too often continue receiving commissioned services that lack flexibility with uneven quality. The quality standard could set out the key elements and characteristics of good practice that enable for some genuine choice and control, in cases where the person is not	National Audit Office Report, 2016 on Personalised Commissioning in Adult Social Care found significant variation in the way that local authorities were implementing personal budgets https://www.nao.org.uk/report/personalised-commissioning-in-adult-social-care/

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		receiving their care and support through council commissioned services have a real opportunity to exercise influence over their care and support.		directly commissioning the service and relies on the council to do so on their behalf.	
27	Think Local Act Personal	**Co-production with people receiving/needing care and support** The importance and benefits of people receiving care and support, including carers helping to influence the overall planning and delivery of care and support.	Establishing the person's views and those of their carers is an essential underpinning of good quality social care (see 1 above). The views and voice of people receiving care and support can and should also influence how care and support is shaped, planned and delivered. There would be benefit of a quality standard in and around this area.	Whilst there is a general acceptance of the need to involve people with experience of social care at a strategic level, progress is almost certainly mixed. A quality standard covering this area would help promote some of the 'how to'.	Think Local Act Personal National Co-production Advisory Group Co-production Ladder of Participation https://www.thinklocalactpersonal.org.uk/_assets/Resources/Coproduction/LadderOfParticipation.pdf
		Section 3			
28	Age UK	Quality of Care Workforce	The standards should also promote continuity of care as a principle that will improve patient experience.	Continuity of care is a highly valued by people receiving care and especially for those with dementia or reduced mental capacity. Research by the CQC highlighted the importance of continuity of care in domiciliary care services and it is a key recommendation in NICE's home care guidance.	Please see the CQC's *Not Just a Number* report on the importance of continuity of care http://www.cqc.org.uk/sites/default/files/documents/9331-cqc-home_care_report-web_0.pdf Please see NICE's *Home Care Guideline* which provides recommendations on the importance of continuity of care https://www.nice.org.uk/news/feat

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					ure/home-care-guideline-key-recommendations-for-providers Findings from the Age UK social care listening events are yet to be published
29	The Challenging Behaviour Foundation	Safeguarding	People with complex needs are at risk of abuse. It is important that robust systems are in place to prevent and identify abuse of this group, with all areas working effectively, in coordination and communicating effectively to prevent abuse being missed.	There is much evidence demonstrating how people with learning disabilities have a poor experience of safe guarding. Panorama revealed shocking abuse of people with learning disability at Winterbourne View Hospital in 2011. Since then safeguarding has continued to fail people with a learning disability. People with a learning disability are sectioned inappropriately, spending many years in units, experiencing abuse and neglect, including overuse of restrictive practices, not receiving any proper 'assessment or treatment' and not being able to get out and live a fulfilling life, with the right support in their local community. Evidence of this can be found in Mencap and the Challenging Behaviour Foundations 'Out of Sight' report,[17] the report 'Winterbourne View: the Scandal Continues',[18] and the Care Quality Commission and Challenging Behaviour Foundation's 'Three Lives' report.[19] There is wide recognition that people with a learning disability are being	

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[17] Mencap and the Challenging Behaviour Foundation. (2012). 'Out of Sight'.

[18] Mencap and the Challenging Behaviour Foundation. (2014). 'Winterbourne View – the Scandal Continues'

[19] Care Quality Commission and the Challenging Behaviour Foundation. (2014). 'Three Lives'

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				overmedicated in all settings. NHS England launched the Stopping the over medication of people with a learning disability, autism or both (STOMP) programme to help tackle this.[20] There are many examples which highlight the poor experience of safeguarding for people with learning disabilities; the terrible abuse at Mendip House uncovered this year provides a recent example.[21] [1] Mencap and the Challenging Behaviour Foundation. (2012). 'Out of Sight'. [1] Mencap and the Challenging Behaviour Foundation. (2014). 'Winterbourne View – the Scandal Continues' [1] Care Quality Commission and the Challenging Behaviour Foundation. (2014). 'Three Lives' [1] NHS England. (2017). 'Stopping the overmedication of people with a learning disability' [1] Margaret Flynn, Somerset Safeguarding Adults Review Board. (2018). 'Safeguarding Adults Review – Mendip House'	
30	Elcena Jeffers Foundation		Health care and self care should be included in the quality standard.		
31	Genetic Alliance UK	Commissioners and managers in all settings ensure that	Continuity in care and support should include: ensuring that all practitioners involved with the person's care and	People with rare, genetic or undiagnosed conditions frequently have needs which require carers to have additional	This comment is based on our (as yet unpublished) work on social care for patients with rare, genetic

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[20] NHS England. (2017). 'Stopping the overmedication of people with a learning disability'

[21] Margaret Flynn, Somerset Safeguarding Adults Review Board. (2018). 'Safeguarding Adults Review – Mendip House'

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		there is continuity in care and support for people.	support are familiar with how that person likes support to be given; where possible, the same people are supporting the person; if the same staff are not available, ensuring there are good handover arrangements; and, ensuring that all staff supporting the person have similar levels of skills and competency.	knowledge or training. If there is not continuity of care, a substantial amount of time is lost training up each new care worker. This training time reduces the time available to meet that person's social care needs. This frequently means that more care is displaced on to informal carers.	and undiagnosed conditions. We would be happy to share these with you or discuss them in greater detail.
32	Healthwatch England	Service users experience continuity in their care	Continuity of care has a considerable impact on people's happiness and quality of life, as it can lead to the establishment of positive relationships between care users and staff. However, lack of continuity can lead to feelings of isolation, unhappiness and distress.	A number of local Healthwatch have reported concerns around continuity of care, especially with regards to home care. Healthwatch Hampshire found that the times care staff visit can vary between two to three hours from one day to the next. Even though this is often not the individual staff member's fault, this can have a serious impact on the people who rely on these services. Continuity of care staff was also emphasised by both users and their relatives. Feedback from those who had a regular staff member visit them was significantly more positive, with users in particular talking about the importance of building meaningful relationships. Of the 315 care users Healthwatch Newcastle spoke with, continuity of care worker was the number one issue with people stressing the need for 'trust' and 'rapport'.	
33	Parkinson's UK	Continuity of care	It is vital that regular appointments are upheld by the same care providers, to ensure continuity of care and that strict medicines management regimes are met,	Skills for Care estimates that the staff turnover rate of directly employed staff working in the adult social care sector was 27.8% in 2017.	www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/2State-of-the-adult-social-

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			particularly given the complexity of the condition. Parkinson’s UK runs the *Get It On Time* campaign which outlines the importance of people getting their Parkinson’s medication on time, every time in hospitals and care homes. If people with Parkinson's don't get their medication on time, their ability to manage their symptoms may be lost either temporarily or permanently. For example, they may suddenly not be able to move, get out of bed or even walk down a corridor. Such is the importance of medicines timings that if these are not adhered to they can have serious long-term implications for someone with Parkinson’s. A Parkinson’s nurse specialist explains: “*I went to see a lady yesterday…She’d actually she’d come downstairs that morning and she’d forgot to bring her dispersible Madopar with her, which she needs as a rescue dose and she realised this too late and by the time she got back up to the bedroom she was rigid, she was absolutely solid and everything was going off, you know, breakfast and everything and this lady couldn’t do anything, she couldn’t even speak. For myself and the occupational therapist that*	We are also concerned that people with Parkinson’s in social care are not being seen consistently by people who know their condition well, or have a good understanding of Parkinson’s in the first place.	care-sector-and-workforce-2017.pdf • The 2015 Parkinson’s Clinical audit found that less than 50% of those admitted to hospital always got their Parkinson’s medication at the right time. • Please see the Parkinson’s Clinical 2015 audit which highlights findings around the need for people with Parkinson’s to receive better inpatient care. https://www.parkinsons.org.uk/sites/default/files/audit2015_referencereport.pdf Between January 2013 and December 2014 3,320 patient safety incidents were reported via the National Reporting and Learning System involving medicines and people with Parkinson’s in hospitals across England and Wales. This equates to 32 incidents per week, with six causing harm to someone with Parkinson’s. Catherine McKinnell MP, response to commons question 219635, 7 January 2015

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			understood that it wasn't an issue, but for other people around, carers, they really, really struggled with the fact that this person could be faking this, could be putting this on, you know."		
34	Royal College of Nursing	Keep people safe from abuse	Early identification of potential abuse can prevent harm	Safeguarding training is variable across the country. The RCN is leading on the development of an intercollegiate safeguarding guidance for adults, which would be published in the summer.	NICE NG86: People's experience in adult social care services: improving the experience of care and support for people using adult social care services (2018)
35	SCM 1		Promoting positive relationships between people who use services 1.4.12	It is important that people in a residential setting remain connected to communities	
36	SCM 3	Continuity of contact	In todays climate service users are never sure which social worker is going to be working with them when applying for social care		Groups of disabled people I "work" with
37	SCM3	Reliable and obtainable records	Service users are being asked the same questions over and over. Often previous records are not available to whichever social worker picks up the case		Anecdotal evidence
		Section 4			
38	Age UK	Access	The public should be able to access social care services relevant to their needs in a timely, co-ordinated and effective manner. Routes of assessment and engagement access should be streamlined and less bureaucratic to support those requesting services at a time of crisis. There should be access to services regardless of background,	Participants in the listening events groups reported that delays in getting social care needs assessments are putting people in danger. The quality standard should support and consider how to make the process of assessment and engagement more timely and co-ordinated to improve the experience for service users. Participants at the focus groups also spoke of the need for all people to have	Please see Royal London's Freedom of Information request on variation in negotiating care packages with local authorities https://www.royallondon.com/about/media/news/2017/december/foi-replies-reveal-vulnerable-pensioners-at-risk-of-poor-outcome-under-care-home-funding-lottery-royal-london/

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			means or ability to have others advocate on your behalf.	access to high quality care. Research by Royal London found that local authorities will often negotiate packages of support on a case by case basis, with the effect that those with family and carer advocates able negotiate on their behalf are likely to receive more comprehensive provision than those that do not. The Quality Standard should provide guidance on reducing this inconsistency in accessing care support.	Findings from the Age UK social care listening events are yet to be published
39	Age UK	Access to information, advice, advocacy and support	Lack of access to information and advocacy will negatively impact on the experience of social care recipients. Poor public understanding of what is social care, who it is provided by and how much it costs may lead to delays in knowing what is available and in receiving needs-appropriate support.	In recent polling by Ipsos Mori on behalf of Deloitte, nearly two-thirds (63%) of respondents falsely believed that the NHS provides social care services for older people. The same survey also found that 47% of people believe social care services are free at the point of need. These findings are supported by recent listening events undertaken by Age UK. Participants told us that there is little or no information available to people who want to arrange care for older relatives and they were frustrated about the lack of engagement from social care providers and commissioners. Qualitative feedback from councils' suggests access to advocacy is becoming increasingly challenging. "Now only statutory advocacy can be delivered and we are working with our provider to ensure this can continue in the face of rising demand and diminishing resources" (LGA, 2016). For service users navigating a complex system, often at a time of crisis, support provided by independent advocates can be invaluable.	Please see Deloitte's *The State of the State 2017-18* report who commissioned Ipsos Mori to survey the public's understanding on who provides social care and its cost implications. https://www2.deloitte.com/content/dam/Deloitte/uk/Documents/public-sector/deloitte-uk-the-state-of-the-state-report-2017.pdf Please see the Local Government Association's *Stocktake 6 on the Implementation of the Care Act* which reports on increases in the number of carers requesting advice and support and qualitative feedback about availability and capacity of advocacy services. https://www.local.gov.uk/sites/default/files/documents/stocktake-6-report-pdf-43-675.pdf Please see Age UK's *Health and Care of Older People in England*

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				Advocacy will play an increasingly important role in improving the experience of older people without family support as well as those experiencing cognitive decline or lacking capacity. By 2030, the IPPR estimate 230,000 older people with significant care needs will be without family support. The Quality Standard should consider how the provision of information will support a positive experience of the adult social care system. Age UK's analysis of rising levels of demand for services is matched by the LGA's reporting of rising levels of requests for information and advice. The standards should consider the type of information and advice that will be sought by care recipients and carers and how this information is accessed. Information should be clear, concise and support the public to make informed decisions about services they are eligible for and which are appropriate for their needs. Information and advice should be person-centred and support self-care. It should also provide clarity about the cost implications of current and future social care to enable future planning to meet these needs.	*2017* which provides evidence of the rising demand for older adult social care services. https://www.ageuk.org.uk/Documents/EN-GB/For professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true Please see the Institute for Public Policy Research's report *The Generation Strain - Collective Solutions to Care in an Ageing Society* which provides projections on the number of older people without family support https://www.ippr.org/files/publications/pdf/generation-strain_Apr2014.pdf Findings from the Age UK social care listening events are yet to be published
40	Genetic Alliance UK	Access to social care support is based on that individual's specific care and support needs, and is not dependent on the			

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		person's condition or diagnosis			
41	Healthwatch England	Information and advice about care services on offer is simple to find and understand	Giving people access to information about the available services on offer allows them and their families to make the most appropriate decisions for their needs.	A recent review of advice requests received by Healthwatch showed that social care is the most common issue people come to us about. These enquires often come from relatives or friends asking on another person's behalf, especially for older people (65-85 year olds) with Alzheimer's or Dementia. The inconsistency in quality of available information means that people are less able to make informed decisions, which may result in poor or inappropriate care.	In August 2017 Healthwatch England published two briefings looking at people's experiences of adult social care services – *What's it like to live in a care home? Findings from the Healthwatch network* and *Home Care – what people told Healthwatch about their experiences*. These comments are largely based upon findings from these two reports.
42	Healthwatch England	Access to primary care services	Visiting a doctor or dentist can be difficult for people living in care homes.	In some parts of England, such as Derby, people told local Healthwatch that it can be easier to get access to a hairdresser than a dentist if you are a care home resident. People who have poor mobility or dementia struggle to get to a high street practice, and home visits are not always available. This means people who can't leave their care home do not have access to primary care services.	
43	Parkinson's UK	Information about social care and ease of access	The degenerative nature of Parkinson's means that many people with the condition would benefit from the additional support provided by social care. Local authorities in England are obligated under the Care Act 2014 to provide comprehensive information and advice about care and support services in their local area.	Research commissioned by Parkinson's UK has also found that people with the condition are often unaware of social care and how to access it, until they reach crisis point. A person with Parkinson's explains: "*I liken it to a pinball machine that you sort of hit against this or that or, you know, you get your information by happenchance and bumping into people and speaking to people.*"	Tod, Angela Mary et al (2016) *Good-quality social care for people with Parkinson's disease: a qualitative study*, BMJ Open 2016;**6**:2, available at: doi:10.1136/bmjopen-2014-006813 Caring About Parkinson's (2016) available at: https://s3-eu-west-1.amazonaws.com/puk-live-1-d8-

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			Clear information about how to access social care and needs assessments should be easily available to help people with Parkinson's receive support that increases in-step with their growing needs and avoids crisis.	Furthermore, a 2016 social care survey conducted by Parkinson's UK found that 74% of respondents with Parkinson's (180) and 59% of carers (66) were unaware of their local authority's social care information service.	ie/2017-09/care_act_experience_report.pdf
44	Royal College of General Practitioners	1.Epidemiology of the population requiring care i.e. Time, Place, Person, Morbidity, Mortality, Effective interventions, Prevention, Costs, Benefits	Resource Implications	Benchmark, Audit	
45	SCM1	Providing Information 1.1.5	The Accessible Information Standard (AIS) https://www.england.nhs.uk/ourwork/accessibleinfo/		
46	SCM3	Record any unmet needs	Local Authorities are struggling due to cuts in their budgets. Keeping a record of unmet needs would provide first hand information towards better funding of social care		Lack of clarity when requesting FOI around service provision
47	Department of Health & Social Care		Acting on feedback, concerns and compliments		
48	Department of Health & Social Care		Measuring, collecting and using data more effectively		
49	Department of Health & Social Care		Better support and shared focus areas for improvement		

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50	Adult Care- Lincolnshire County Council	Peoples experience of living in residential services *(There is a focus in the NICE Standard in the 'Residentia'l section on End of life and there appears to be a gap in relation to assuring quality*)	To get feedback from more people across residential and community supported living services about the quality of those services and opportunities for service development.	Good quality assessment; review and continued care and support planning is a key area for development across residential services. CQC inspections, local authority and health agencies contract management all identify this across the sector as an area for development, it is frequently linked to a lack of a personalised approach and this is particularly the case for people using these services who have communication difficulties. Key areas to identify are for services to identify and record how people communicate e.g. through physical movements and facial expressions. This can be supported by the use of communication tools so that choices, likes, dislikes and decisions are the persons not assumptions made by others. Carers don't stop being carers because people are no longer at home, we should still encourage and seek their feedback on the services provided. Further development of getting peoples feedback in residential services and their family and carers is required as a key component of quality.	Seldom heard voices *www.healthwatchlincolnshire.co.uk/seldom-heard-voices-reports/* Research evidence from Talking Mats ‘Talking Mats®’ and ref: Joseph Rowntree Foundation Report
51	SCM 1	Staff skills and experience 1.5.3	Involving service users in recruitment and training fosters self worth and well being		
52	SCM 3	Involvement of services users in co-production	The Local Authority should involve service users in the interview process when taking on new staff		From my own experience working on recruitment of social workers

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53	SCM 4		Involving people in the design of services means that services are responsive and purposeful for use them	Recognising peoples expertise in codesigning services can be innovotive and cost effective.	
		Additional area: carers			
54	Parkinson's UK	Support for carers	Friends and family members regularly provide unpaid support for people with Parkinson's, including help with personal care as well as emotional support. Access to timely social care support can both prevent and delay the onset of additional support needs for carers, and enable them to continue their vital role.	Although we welcome requirements in the Care Act to offer assessments to anyone who appears to need support – including carers, it is clear that many carers are not getting the support they need. Research funded by Parkinson's UK found that, based on a sample of 115 carers, mean carer age was 70.7 years, of whom 66.1% were female caring for a median of 16 hours per day. The research also found that over 80% provided help in housework and companionship activities, 63.2% with dressing and 49.1% with feeding. There was a significant relationship between stage of the condition and the level of carer strain.	https://www.tandfonline.com/doi/full/10.1080/13607863.2017.1421612
55	Royal College of General Practitioners	2.Carer identification and support	Statutory services cannot cope alone and the carer is the first line.	Carer experience and support is poorly documented. Key areas for improving resilience of family members who care 1.**Respite care** has demonstrated effectiveness in family care of people with dementia (PWD). 2. Consistent **Sitting & befriending services** uptake by carers of PWD can provide a protective factor against depression. This is significant given that	M Parkinson, S M Carr, R Rushmer, C Abley; Investigating what works to support family carers of people with dementia: a rapid realist review, *Journal of Public Health*, Volume 39, Issue 4, 1 December 2017, Pages e290–e301, https://doi.org/10.1093/pubmed/fdw100

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				depression is a marker for cessation of family care of people with dementia 3.**<u>Carer training, coaching & mentoring</u>** provides additional emotional support, enhance carer empowerment self esteem & provide opportunities to network with other carers develop many useful contacts & gain from peer support/social support. Relevant information & advice supports navigation of the health-care system & signposting of carers 4. **<u>Group Cognitive Behavioural Therapy</u>** (CBT) been shown to exert the broadest impact on carer outcomes, training carers to develop vital cognitive skills including challenging dysfunctional thoughts, positive reframing as well as behavioural skills such as adaptive coping. CBT represents an effective strategy for mediating vulnerability to depression 5. **<u>Mindfulness training</u>** provides strategies for controlling powerful negative thoughts	
56	SCM 2	quality and availability of respite care	User/career evidence suggests this service is vital to maintain the ability of a person to remain in the family home	Supporting carers is fundamental to maintaining family support to individual users in a family setting	
		Additional area: training			
57	Age UK	Quality of Care Workforce	The social care workforce needs to be sufficiently upskilled and trained to allow it to cope with the demands of caring and provide high quality care to service users, particularly for those	Participants at the Age UK listening events told us that they greatly value the contribution from care staff that supports them and their families. However, the groups reported a lack of consistency of	Please see Skills for Care's *The State of the Adult Social Care Sector and Workforce in England* which provides an analysis of the training and qualifications within

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			with complex, long-term physical and mental health conditions. The variable experience of social care service users is a reflection of staff with a fragmented set of skills, values and experience. The Quality Standards should reinforce recommendations for care staff to be engaged in role-appropriate training to improve experience of service users.	care and shared a belief that they lacked sufficient training for their roles. Skills for Care report that more than half (54%) of the care workforce do not hold a relevant adult social care qualification. Participants in the focus group also reported a lack of awareness from care staff about how to communicate with people who have dementia. This is reflected by Skills for Care's analysis that only 39% of care staff are trained in dementia care. Continuity of care is a highly valued by people receiving care and especially for those with dementia or reduced mental capacity. Research by the CQC highlighted the importance of continuity of care in domiciliary care services and it is a key recommendation in NICE's home care guidance.	the care sector http://www.skillsforcare.org.uk/Documents/NMDS-SC-and-intelligence/NMDS-SC/Analysis-pages/State-of-17/State-of-the-adult-social-care-sector-and-workforce-2017.pdf Findings from the Age UK social care listening events are yet to be published
58	British Geriatrics Society (Endorsed by Royal College of Physicians)	Pressure ulceration is an important complication of functional dependency seen frequently in adults who receive social care.		All social care staff should be trained in how to recognise pressure ulceration and should have access to pressure relieving equipment and prompt specialist support if they have concerns about a care recipient	
59	British Geriatrics Society (Endorsed by Royal College of Physicians)	Social care staff have an important role to play in both identifying and preventing malnutrition and dehydration in older	Social care staff should be trained in recommended screening tools to look for malnutrition and dehydration and should be able to access dietetic advice for older people about whom they have concerns	Individualised meal and hydration plans should be available for all adults in receipt of social care.	

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		people with complex conditions.			
60	The Challenging Behaviour Foundation	Specialist skills for the workforce	People with complex needs face a wide range of issues. To meet these needs effectively, staff working with people with complex needs such as those with learning disabilities and behaviours that challenge need to be appropriately skilled.	There is much evidence indicating that the care of people with severe learning disabilities and behaviours that challenge is currently inadequate. Despite the national transforming care programme recognising that people with learning disabilities and behaviours that challenge should be able to get the right support in the community, this is not being provided. Individuals with learning disabilities and behaviour perceived as challenging are likely to: • Live in places or with people they don't like, often a long way from their family home.[22] • Be given too much medication, or inappropriate medication.[23] • Be subjected to restraint.[24] • Be secluded and have their movement restricted.[25] Many people with a learning disability have ended up in an inpatient unit due to a failure to provide or develop the right support and services in the local community. At the end of January 2018 there were 2,465 people with a learning disability in inpatient services.[26] This issue	

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[22] Mansell, J. (2010). 'Raising our sights': services for adults with profound intellectual and multiple disabilities'.

[23] Department of Health. (2015). Government response to No voice unheard, no right ignored'.

[24] Public Health England. (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England'

[25] Care Quality Commission. (2014). Review of learning disability services.

[26] NHS Digital. (2018). Assuring transformation monthly statistics.

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				is a finding of the 2017 National Audit Office report which concluded that there is a lack of a workforce with the right skills to support people with learning disabilities in the community.[27] [1] Mansell, J. (2010). 'Raising our sights': services for adults with profound intellectual and multiple disabilities'. [1] Department of Health. (2015). Government response to No voice unheard, no right ignored'. [1] Public Health England. (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England' [1] Care Quality Commission. (2014). Review of learning disability services. [1] NHS Digital. (2018). Assuring transformation monthly statistics. [1] National Audit Office. (2017). Local support for people with a learning disability.	
61	Compassion in Dying	Training health and care professionals to offer person-centred care that is in line with individuals' goals, preferences and values.	4. People place great value on choice and control over decision-making and as we have learned from our service users, planning ahead gives people peace of mind and allows them to live well now. (Compassion in Dying *Plan Well, Die Well*, 2015).	In 2016, we commissioned the International Longevity Centre to undertake a literature review on the impact of advance care planning which found that the process of thinking about and recording one's treatment and care preferences results in better person-centred care and improved relationships and communication between families and healthcare professionals.	We are not aware of any social care providers or hospitals, hospices, care homes and ambulance trusts which routinely collect the number of patients who have advance care plans which are (or are not) adhered to.

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[27] National Audit Office. (2017). Local support for people with a learning disability.

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			5. 68% of Britons would like more control over decisions about their health (Ipsos Mori, Global Trends – Health, 2017) 6. The NHS is placing greater emphasis on person-centred care. Therefore it is vital that specific information on the legal mechanisms available for planning ahead such as Advance Decisions, is widely disseminated.	Despite these benefits, our experience has shown that there is a lack of awareness among both the general public and health care professionals around the specific ways in which adults can take control of their treatment and care in case they lost capacity – i.e. Lasting Powers of Attorney for Health and Welfare (LPA) and Advance Decisions (ADRT) including Advance Statements (AS). For example, we found that while 82% of people say they have strong views about what treatment they would want to refuse and accept at the end of life, only 4% of adults have an Advance Decision or a Lasting Power of Attorney for Health and Welfare (YouGov 2014). Our community outreach work with BAME and LGBT communities highlight the specific barriers they face (My Life, My Decision) when planning ahead in line with their values and priorities. Our CPD-accredited training sessions for healthcare professionals have demonstrated a lack of confidence among healthcare professionals to support people to plan ahead in line with the Mental Capacity Act 2005.	However, this report by National Voices provides a useful summary of person-centred care. https://www.nationalvoices.org.uk/sites/default/files/public/publications/person-centred_care_in_2017_-_national_voices.pdf Age UK recently published data highlighting the fact that 1 in 3 people with dementia don't have a care plan which may also be useful. https://www.ageuk.org.uk/latest-news/articles/2018/february/1-in-3-with-dementia-diagnosis-dont-get-nhs-follow-up-support-theyre-supposed-to/?utm_source=National+Voices+Members&utm_campaign=3fe463a673-MU_130717&utm_medium=email&utm_term=0_00458e9137-3fe463a673-225078609
62	Royal College of Nursing	Developing the skills and knowledge of the workforce, service user & their	There is evidence to suggest that by developing skills and knowledge service users have better outcomes. People are living longer with multiple co morbidities and are often	There is a variation in the type of and quality of training and education provided to staff working within the independent sector and informal care givers	RCN Guidance: Improving hospital care for older people: a call for action (2014) NICE NG86: People's experience in adult social care services:

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		family/informal carers.	presenting with complex needs necessitating competent care givers, service users and informal carers		improving the experience of care and support for people using adult social care services (2018)
63	SCM 3	On going training or in house training of social workers which should be co produced with service users	In order to approach service users reviews or assessments a first hand knowledge of the social model of disability would be an advantage		Difference of opinions can occur when service users are addressed in terms of their conditions rather than what they want to achieve
64	SCM 4		Staff skills to deliver high quality support in any setting is vital.	There is a huge skills and workforce gap in the care industry that needs addressing.	
		Other additional areas			
65	Disability Rights UK	Changes to guideline recommendations	Under co-production and enabling people to make decisions 1.1.6 I think something needs to be added here because it is too easy to assume that someone lacks capacity to make decisions. I'm not sure whether NICE has produced guidelines here. If it has then they need to be referenced.	This was an issue of concern highlighted in CQC's State of Care report 2016. Specifically "In (care) providers across all sectors, we found variable practice in the implementation of capacity assessments and best interests decision-making. While we have previously highlighted some appropriate practice, we have also found some areas of concern. In particular, many providers made assumptions that individuals lacked capacity without having carried out or documented assessments, or they assessed individuals as lacking capacity without ensuring this was time and decision-specific. For some providers, the 'blanket' approach to capacity assessments suggested to our inspectors that their focus may be more on managing organisational risk than delivering person-centred care. Some providers also made	

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				blanket assumptions that individuals with particular conditions lacked capacity, such as people living with dementia."[1]	
66	Disability Rights UK	Changes to guideline recommendations	1.1.13 re taking into account the caring responsibilities of service users I think it would be helpful to add that support should be provided in a seamless way for the service user whether that support is funded from adults or children's services. Disabled parents often have to deal with conflicts between adult and children's services and who is responsible for what.		
67	Disability Rights UK	Changes to guideline recommendations	1.3.9 about communicating decisions. I think this clause needs strengthening by adding all decisions should be made available in writing. It seems such an obvious thing to do but believe me the calls to us indicate that decisions are often communicated by word of mouth, or over the phone.		
68	Disability Rights UK	Changes to guideline recommendations	1.3 Needs assessment I think something needs to be said about reassessments. People frequently report to us that where a reassessment has taken place which has resulted in a reduction in support decisions take immediate effect which is very upsetting for the service user and, of course, can make life particularly difficult for people employing PAs. There needs to be		

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			an adjustment time of at least 4 weeks.		
69	Disability Rights UK	Changes to guideline recommendations	1.4.13 Residential settings I think there needs to be a bullet point that support and services should be age-appropriate. Younger disabled people find themselves in residential settings that are primarily centred on older people making it difficult for them to access social activities even if they are provided.		
70	British Geriatrics Society (Endorsed by Royal College of Physicians)	Polypharmacy is an important source of morbidity in community-dwelling older people with complex conditions and care home residents	Complex drug regimens can interfere with daily activities and impinge on quality of life.	All older people with complex conditions and care home residents should have regular medication reviews, at least once every six months. Ideally this should be done by a doctor or nurse prescriber in conjunction with a pharmacist and take account of national recommendations on medicine reconciliation.	
71	The Challenging Behaviour Foundation	Understanding and use of effective communication	To ensure the involvement of people with complex needs including those with severe learning disabilities and behaviour that challenge staff need to use appropriate and effective communication skills to be able to meet individual's specific communication needs.	People who have a severe learning disability often do not communicate verbally, but may use other methods of communication, such as signing or using picture systems. Communication methods need to be unique and specific to each individual.[28] This should include consideration to a person's behaviour. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person's needs or wishes are understood.	

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[28] Royal College of Speech and Language Therapists. (2013). Five Good Communication Standards. Accessible at: https://www.rcslt.org/news/docs/good_comm_standards

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72	Royal College of General Practitioners	3.Electronic records available in real time to service provider, carer and "patient"	Cover gaps in service and reduce duplication	Audit, Research and development, Professional development i.e. the clinical governance agenda	
73	Age UK	Funding	Lack of funding will often determine the quality and quantity of care that people receive. Reductions in funding from central and local government come in spite of rising demand, complexity and cost in care provision.	Creating long-term sustainable health and social care systems is of ever greater importance with demand for both services continuing to rise. Increased longevity means more people are living for longer with complex, long-term conditions. Analysis by the Alzheimer's Society indicates that dementia diagnoses are expected to reach 1 million by 2027 and 1.75 million by 2050. The ONS calculate that the numbers of people over the age of 85, who are most likely to have significant care needs, are expected to double over the next 20 years. Funding has not kept pace with increases in demand. Local authority spending on social care fell by 7% in real terms between 2009/10 and 2016/17. As a result, councils have significantly reduced the amount of support available. Tightened eligibility criteria have led to an estimated 25% reduction – more than 400,000 – in the number of older people accessing publicly funded care over that period. At the same time service users report being offered smaller packages of care and are being asked to contribute more in charges – including a growing number of people paying 'top-ups'. The Quality Standard needs to provide clarity about the costs involved in delivering	Please see the Alzheimer's Society report *Dementia UK Update* which provides projections of future dementia diagnoses https://www.alzheimers.org.uk/download/downloads/id/2323/dementia_uk_update.pdf Please see the Office for National Statistics *National Population Projections: 2016-based Statistical Bulletin* which provides projections of the number of people aged 85 and over https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/tablea24principalprojectionenglandpopulationinagegroups Please see The King's Fund, Nuffield Trust and Health Foundation's *Autumn Budget – Joint Statement on Health and Social Care* which provides evidence of reductions in social care funding and tightened eligibility criteria https://www.kingsfund.org.uk/sites/default/files/2017-11/The%20Autumn%20Budget%2

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				high-quality care and transparency for self-funders of care. Carers at the Age UK listening events told us that they feel unsupported and abandoned by the system. Reports of respite centres closing down and a reliance on family members rather than paid care workers which left many relatives feeling so overworked and overwhelmed that their own health suffered as a result. Age UK believe that with rapidly rising levels of unmet need, this strongly suggests that the provision of informal care has not been able to expand significantly to fill the gap left by declining provision of formal care services.	0-%20joint%20statement%20on%20health%20and%20social%20care%2C%20Nov%202017.pdf Please see NHS Digital's Adult Social Care Activity and Finance Report – 2016-17 and Personal Social Services. Expenditure and Unity Cost from 2013-14 to 2015-16 which provides evidence of rising social care client contributions. http://content.digital.nhs.uk/socialcare/collections Please see Age UK's *Health and Care of Older People 2015* which provides evidence of increasing amount of client 'top-ups' for social care services https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Briefing-The_Health_and_Care_of_Older_People_in_England-2015-UPDATED_JAN2016.pdf?dtrk=true Please see Age UK's *Health and Care of Older People 2017* which provides an analysis of how rising provision of informal care to cope with reduced care funding has not been enough to address increasing levels of unmet need. The same report also references Laing and Buisson's 2015 *Care of Older People Market Report*

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					which provides data on increasing use of 'top-ups' to pay for social care services. https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true Findings from the Age UK social care listening events are yet to be published
74	Department of Health & Social Care	Commissioning for better outcomes			
75	Department of Health & Social Care	Improving the profile of adult social care			
76	Royal College of General Practitioners	4.Public/Private ownership with the requirements of profit, dividends in a caring service. Privatisation of these services should be restricted to no more than 10%	Risk of market collapse	Proper terms and conditions for staff, adequate training, career opportunities national standards and regular reports of performance	
77	Genetic Alliance UK	Local authorities fulfil their duty to facilitate the local care provider market, in the sense of using a wide range of approaches to	High-quality, personalised care and support can only be achieved where there are sufficient service providers to meet local need.	Our members report being told that some of their needs cannot be met due to a lack of local services. This suggests many local authorities are either not fulfilling their duty to shape the care market in their local area, or are not successful in their efforts to do so.	This comment is based on our (as yet unpublished) work on social care for patients with rare, genetic and undiagnosed conditions. We would be happy to share these with you or discuss them in greater detail.

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		encourage and shape it, so that it meets the needs of all people in their area who need care and support, whether arranged or funded by the state, by the individual themselves, or in other ways.			
78	SCM 2	Joint commissioning between health and social care	Better use of joint resources,and market management particularly in the commissioning of nursing and specialist residential care home places	Continuing disputes re interpretation of CHC regulations can have a very negative impact on patients/service users both psychologically and financially	
79	Age UK	Variations in quality	Social care service users are subject to significant variation in the quality, provision and capacity of care services. The public have a right to choose high quality care and quality improvement must address the factors that create inequalities and inconsistencies across different care environments.	Participants at Age UKs listening events told us that quality and location are the most important factors when choosing care services. The Care Quality Commission reported on the falling capacity in the nursing home sector, 4000 fewer beds in two years, with wide regional variation in the distribution of these beds. This will impact on the experience of those for which residential nursing care is essential; forced to use services which are sub-standard or far away from their home and support network. The report also noted 'substantial variations in the quality of care that people are receiving – within and between services in the same sector, between different sectors, and geographically'. The effect of this is	Please see The Care Quality Commission's *The State of Health Care and Adult Social Care in England 2016/17* which analyses variations in capacity and quality across the adult social care sector. http://www.cqc.org.uk/sites/default/files/20171123_stateofcare1617_report.pdf Findings from the Age UK social care listening events are yet to be published

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				particularly felt in the transitions between systems, leading people to have poor experiences when they are discharged from, for example, supportive hospital care into poor quality domiciliary care and a lack of integration between the two systems jeopardising their chance of receiving care that is person centred and recovery focused. The report also noted wide variation in the settings where people receive social care, with service users often having little or no choice about where they receive support. Nearly a third of nursing home beds were rated as inadequate or requires improvement, whereas just 17% of domiciliary care services are. Safety is arguably the most important measure the commission assesses services by, yet nearly a quarter (24%) of adult social care services were rated as 'inadequate' or 'requires improvement' for their standard of safety. The safeguarding of social care service users is paramount with providers responsible for ensuring that their clients receive care and treatment and which prevents avoidable risk or harm.	
80	Elcena Jeffers Foundation		That there be a system where even doctors need a doctor of their own if said doctor be come afflicted by ill health. Every One in the United Kingdom needs to buying the National Health Service (NHS) for One Pound (£1.00) as a right in their own		

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			rights this is from Pre-birth to Post-death.		
		No comments			
81	Skills for Care		No formal feedback is being submitted.		