

People's experience in adult social care services: improving the experience of care and support for people using adult social care services

NICE guideline

Published: 20 February 2018

www.nice.org.uk/guidance/ng86

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

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This guideline is the basis of QS182.

Overview

This guideline covers the care and support of adults receiving social care, in their own homes, residential care and community settings. It aims to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care.

Who is it for?

- Practitioners working in adult social care services in all settings
- Service managers and providers of adult social care services
- Commissioners of adult social care services
- People using services (including those who fund their own care) and their families, carers and advocates

Recommendations

People have the right to be involved in discussions and make decisions about their care, as described in [making decisions about your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Overarching principles

- 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.
- 1.1.2 Support people to maintain their independence. This means finding out what people want from their life, and providing the support and assistance they need to do this

Co-production and enabling people to make decisions

- 1.1.3 Respect people's right to make their own decisions, and do not make assumptions about people's capacity to be in control of their own care and support (for example, if the person is severely disabled).
- 1.1.4 Actively involve the person in all decisions that affect them.
- 1.1.5 Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support. Identify and record how the person wishes to communicate and if they have any communication needs (in line with the [Accessible Information Standard](#)). This could include:

- advocacy support
 - an independent interpreter (that is, someone who does not have a relationship with the person or the services they are using) to enable people to communicate in a language they can readily converse in, including sign language
 - a carer, if that is what the person wants
 - communication aids (such as pictures, videos, symbols, large print, Braille, hearing loops)
 - evidence-based techniques for communication
 - additional time to understand and process information
 - environmental conditions that support communication, such as clear lighting, and minimal noise interference.
- 1.1.6 If a person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed.
- 1.1.7 Use plain language and personalise the communication approach to encourage and enable people to be actively involved in their care and support. If technical language or jargon has to be used, or complicated ideas are being discussed, take time to check that the person, or a carer who knows them well, understands what is being said.
- 1.1.8 If a third party or advocate is supporting someone to give their views, ensure that enough time has been allowed for them to do it.
- 1.1.9 Local authorities and service providers should work with people who use adult social care services and their carers as far as possible to co-produce:
- the information they provide
 - organisational policies and procedures
 - staff training.

Access to care

- 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.
- 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.
- 1.1.12 Commissioners and service providers should consider seeking advice from voluntary and community sector organisations such as disabled people's organisations and user-led organisations with expertise in equality and diversity issues to ensure that they can deliver services that meet the needs and preferences arising from:
- gender, including transgender
 - sexual orientation and sexuality
 - disability
 - ethnicity
 - religious and cultural practices.
- 1.1.13 Ensure that people who use services and have caring responsibilities (for another adult or a child) receive support to access social care services, including information about childcare, or respite care

Involving carers, families and friends

- 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.

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.

1.1.16 If a person lacks the capacity to make a decision about whether they wish their carers, family, friends and advocates to be involved, the provisions of the Mental Capacity Act 2005 must be followed.

1.2 Information

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.

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.

- 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.
- 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.

1.3 Care and support needs assessment and care planning

1.3.1 Local authorities must, in line with the [Care Act 2014](#), provide independent advocacy to enable people to participate in:

- [care and support needs assessment](#) **and**
- care planning **and**
- the implementation process and review

where they would otherwise have substantial difficulty in doing so.

1.3.2 People who are supported by an independent advocate during care and support needs assessment and care planning should have enough time with their advocate:

- for preparation before the assessment or care planning session
- to ensure they have understood the outcome afterwards.

Needs assessment

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.

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.

1.3.5 Local authorities should consider the person's preferences in terms of the time, date and location of the care and support needs assessment, and conduct the assessment face-to-face unless the person prefers a different method of assessment.

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.
- 1.3.7 See the [NICE guideline on supporting adult carers](#) for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of people using services who have caring responsibilities.
- 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.
- 1.3.9 Offer the person a copy of any or all of the care and support needs assessment documentation. It should be shared with the person's carer if that is what they want.

Care and support plans

- 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.
- 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.
- 1.3.12 Local authorities and providers should ensure that the person's care and support

plan includes clear information about what involvement from others (carers, family, friends and advocates) they want in their care and support, in line with the [Care Act 2014](#). (See also [recommendation 1.1.14](#).)

- 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.
- 1.3.14 Ensure care workers are able to deliver care and support in a way that respects the person's cultural, religious and communication needs (see [recommendation 1.1.11](#)) .
- 1.3.15 Care and support plans should record and address the specific needs of people in relation to equality and diversity issues.
- 1.3.16 Care and support plans should be regularly reviewed, and include information on how and when these reviews should be carried out.
- 1.3.17 Care and support plans should include contingency planning and what to do in a crisis.

Personal budgets and direct payments

- 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](#).
- 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.

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.

1.3.21 Local authorities should provide accessible information about direct payments, and peer support for people to use them. For example, this could be provided through user-led Centres for Independent Living.

1.3.22 In line with the Care Act statutory guidance, local authorities should support local services that provide peer support. Their contribution could include:

- financial support for local peer support services
- providing physical space for people who give peer support to hold meetings with people who use services
- helping peer support services with applying for grants for funding.

Personal assistants

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.

- 1.3.24 In line with the [Care Act statutory guidance](#), local authorities should ensure that support is available for people employing personal assistants, and that they are told about where to get support with:
- recruitment and retention of staff
 - their role and responsibilities as an employer (for example, payroll, terms and conditions, redundancy and contingency planning).
- 1.3.25 Local authorities should consider the following to deliver support for people who employ personal assistants:
- user-led Centres for Independent Living
 - other peer-support arrangements.
- 1.3.26 In line with the market shaping duty in the [Care Act 2014](#), local authorities should work with people who use social care services and their carers to enable access to personal assistants. For example, this could be done by providing training opportunities for people who are interested in becoming personal assistants.

1.4 Providing care and support

Care and support in all settings

The following recommendations refer to care and support in all settings. For further detail about [home care](#), please see the [NICE guideline on home care for older people](#).

- 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.
- 1.4.2 Practitioners working in all settings where care and support is delivered should ask the person using services, their carers, family, friends and advocates what name they prefer to be called, and use their preferred name.
- 1.4.3 Practitioners working in all settings where care and support is delivered should take time to build rapport with the people they support.
- 1.4.4 Practitioners working in all settings where care and support is delivered should respond flexibly to the priorities a person might identify each day. For example, a person might ask a home care worker to spend more time helping them get dressed and less time on other tasks if they have a special event to attend.
- 1.4.5 Day care and residential care providers should offer a choice of activities that are led by the person's needs, preferences and interests. Encourage people to take part by including activities that motivate them, support them to learn new skills and increase their level of independence. Recognise that preferences are not fixed and may change.

Continuity and consistency

- 1.4.6 Service providers in all settings, with oversight by commissioners, should review

staffing numbers and skill mix regularly to ensure that staffing and skill levels are sufficient.

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.

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.

1.4.9 Support people to make decisions about entering a new care setting or moving to a different setting. For guidance on transitions between particular settings, see the NICE guidelines on:

- [transition from children's to adults' services for young people using health or social care services](#)
- [transition between inpatient hospital settings and community or care home settings for adults with social care needs](#)
- [transition between inpatient mental health settings and community or care home settings](#).

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.

Personal care

- 1.4.11 All practitioners providing personal care should ensure that personal care needs are responded to in a timely, appropriate and dignified manner in line with the person's wishes and their support plan – for example, making sure that people can go to the toilet when and how they want.

Promoting positive relationships between people who use services

- 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

- 1.4.13 Practitioners and managers in residential settings should:
- ensure that the environment allows for people's preferences, self-expression and choice – for example, enabling people to have their own furniture and pictures
 - support people to have control over their own medicines where possible (see the [NICE guideline on managing medicines in care homes](#))
 - deliver care and support in a [personalised](#) and friendly way
 - give people privacy, especially when delivering personal care

- treat people with dignity and respect.

1.4.14 When designing residential services, providers should ensure that environments:

- create space where practitioners and residents can have positive interactions
- are welcoming to visits from family, friends, carers and advocates
- are stimulating, while not creating additional challenges for residents, including those with sensory impairments or dementia (for example, if the layout is frequently changed or there is poor lighting)
- enable positive risk taking (for example, being able to use outside spaces)
- support residents' autonomy (for example, by adapting kitchen facilities for people with physical disability).

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.

1.4.16 Practitioners should support people to participate fully in tasks and activities by ensuring that:

- the environment is conducive to their needs
- they have access to the equipment they need (for example, hoists or recliner chairs).

- 1.4.17 Managers should ensure that practitioners are trained to support residents to use any equipment they need.

End-of-life support in residential settings

For more information on end-of-life care, see [NICE's guideline on care of the dying adult](#).

- 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).
- 1.4.19 Managers in residential settings should consider making someone available who is independent and not part of the usual staff team to discuss end-of-life issues, for people who want to do this – for example, from an advocacy organisation.

1.5 Staff skills and experience

- 1.5.1 Have a transparent and fair recruitment and selection process that:
- uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce **and**

- ensures that staff have the necessary language, literacy and numeracy skills to do the job.
- 1.5.2 Local authorities should ensure that people undertaking needs and eligibility assessments have the knowledge and skills to carry out assessments as described in recommendations 1.3.3 to 1.3.9.
- 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.
- 1.5.4 Consider providing opportunities for practitioners to learn from the personal experiences of all people who use services, in all settings where care and support is provided. This could be through:
- forums within residential and day care services
 - audit, planning and evaluation of services
 - practitioners being mentored by people who use services.
- 1.5.5 Service providers should ensure that practitioners are aware of the local arrangements for, and understand the function of, other services that they may need to work with, such as other health and social care service providers and services provided by the voluntary sector.
- 1.5.6 Service providers should provide opportunities for practitioners to take part in interprofessional learning and development.
- 1.5.7 Service providers should ensure that practitioners are able to use any equipment or devices people need – for example, hearing aid loops.

- 1.5.8 Service providers should ensure that practitioners are aware of issues relating to information sharing and confidentiality.

1.6 Involving people in service design and improvement

- 1.6.1 Local authorities must provide opportunities for people who use services to be involved if they want to in strategic decision-making about services, not just their own care and support, in line with the Local Government and Public Involvement in Health Act 2007. This should include involving people in:
- decisions about the way services are commissioned, run and are governed **and**
 - checking that the service is delivering quality care and support.

Using people's views to improve services

- 1.6.2 All research into the views of people using care and support and their carers should be co-produced at all stages, including the research design, how it is carried out, and any resulting actions (for example, developing or refining quality indicators, developing monitoring tools or identifying gaps in services).
- 1.6.3 Commissioners and service providers should communicate clearly the outcome that any exercise to collect people's views is aiming to achieve and what will be done as a result.
- 1.6.4 Commissioners and service providers should consider using a range of approaches to gather views and experiences (for example, focus groups, interviews or observation in addition to surveys), and use evidence from a range of sources. This could include:
- the lived experiences of people who use services
 - information from voluntary organisations that represent people who use

social care services – for example, [Healthwatch](#)

- existing sources of information, such as complaints.

1.6.5 Local authorities should consider gathering and analysing evidence on people's experience of services in collaboration with other health and social care organisations serving the same populations to reduce duplication and ensure economies of scale.

1.6.6 Organisations conducting research should consider from the outset how to ensure that all groups are able to participate, including people who may lack capacity and people with different communication needs. This may involve adapting different research methods (see recommendation 1.6.4) or providing materials in a range of formats. If the participation or response rate for a particular group is low, the organisations should take action to improve it. This could include investigating what specific communication or cultural reasons may account for the low response and adapting materials or response formats to better suit that group.

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).

1.6.8 Organisations or individuals conducting research or seeking feedback from people who use services should ensure that independent advocacy is available and offered when:

- this would help someone to take part **or**
- the person expresses a preference to use advocacy.

1.6.9 Service providers should consider employing people who use services to monitor people's experience of health and social care services, including conducting research. This could be done by:

- offering training to 'experts by experience' on how to conduct interviews with

people who use services, including supporting them in applying ethical principles such as informed consent and confidentiality

- paying them to undertake exit interviews with people who have recently left a service or moved to another service.

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

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.

Survey research

1.6.12 Consider using existing validated surveys before deciding to develop a new survey.

1.6.13 Local authorities should analyse the characteristics of people who did not or could not respond to surveys and:

- report on any under-represented groups in their published report of the survey and seek to understand the reasons for this
- develop ways to address these gaps in the future – for example, by considering alternative modes of response, such as a telephone response line
- ensure that information about under-represented groups is fed back to the survey designers.

- 1.6.14 Local authorities should ensure that people in their organisations who are responsible for interpreting and implementing survey findings have the necessary skills and capacity.

Terms used in this guideline

Care and support needs assessment

Under the [Care Act 2014](#), local authorities must carry out an assessment of anyone who appears to require care and support. The aim of assessment is to understand the person's needs and goals. After carrying out the assessment, the local authority consider whether any of the needs identified are eligible for support.

Care and support plan

A written plan after a person has had an assessment, setting out what their care and support needs are, how they will be met (including what they or anyone who cares for them will do) and what services they will receive.

Carer

A person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or disabled and could not manage without this help. This is distinct from a care worker, who is paid to support people.

Centre for Independent Living

A local organisation run by people with disabilities, that supports disabled people in their area to make choices about how and where they live their lives, with the assistance and support they need to live as independently as possible.

Commissioner

A person or organisation that plans the services that are needed by the people who live in the area the organisation covers, and ensures that services are available. Sometimes the commissioner will pay for services, but not always. The local council is the commissioner

for adult social care. NHS care is commissioned separately by local clinical commissioning groups. In many areas, health and social care commissioners work together to make sure that the right services are in place for the local population.

Communication aid

A communication aid helps a person to communicate more effectively with those around them. This could range from a simple letter board to a more sophisticated piece of electronic equipment.

Co-production

When a person who uses services is involved as an equal partner in designing the support and services they receive. Co-production recognises that people who use social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.

The Think Local Act Personal's 6 principles of co-production are:

- recognising people as assets
- building on people's capabilities
- developing 2-way, reciprocal relationships
- encouraging peer support
- blurring boundaries between delivering and receiving services
- facilitating rather than delivering.

Day care services

Opportunities for people to do things during the day, while living in their own home. These may include social activities, education, or the opportunity to learn new skills. What the local council offers will vary, depending on what a person needs and what is available in that area. People who use services may have to pay something towards the cost.

Home care

Care provided in a person's own home by paid care workers to help them with their daily life. It is also known as domiciliary care. Home care workers are usually employed by an independent agency, and the service may be arranged by the local council or by the person that needs care (or someone acting on their behalf).

Information sharing

Information sharing refers to the sharing of information about people who use services within and between organisations. Personal information can be shared within or between organisations with the person's consent, or if it is believed to be in the public interest. See the [7 golden rules of information sharing](#).

Joint commissioning

When 2 or more organisations in a local area – usually the NHS and local council – work together to plan services to meet the needs of people who live in the area. Together the commissioners plan what kind of services should be available, who should provide them and how they should be paid for.

Named care coordinator

The person in an organisation who is responsible for coordinating support for the person and their family if needed – for example, a named social worker or a nurse. The coordinator role refers to a function and not a post.

Peer support

The practical and emotional help and support that people who have personal experience of a particular health condition or disability can give each other, based on their shared experience. People support each other as equals, one-to-one or in groups, either face-to-face, online or on the telephone.

Person who uses services

A person who receives services from a care and support provider. It is often preferred to

the term 'service user'.

Personal assistant

Someone the person using services chooses to employ to provide the support they need, in the way that suits them best. This may include cooking, cleaning, help with personal care such as washing and dressing, and other things such as getting out and about in the community. A personal assistant can be paid through a direct payment.

Personalised care

An approach that puts the person receiving care and support at the centre of the way care is planned and delivered. It is based around the person and their own needs, preferences and priorities. It treats the person receiving services as an equal partner, and puts into practice the principle of 'no decision about me without me'.

Practitioner

Any worker who provides support to the person and their family and carers. Practitioners include people working in all settings and in different roles – for example, social workers, health professionals and care home staff. Practitioners could also include those with designated roles, such as care coordinators or key workers.

Residential settings

Accommodation where care and support are provided by staff. These settings can be run by the private sector, voluntary sector or local authority. Residential settings can include residential care homes and nursing homes and also include [supported living](#).

Supported living

Accommodation and support that enables adults with disabilities to live in their own home, with the help they need to be independent. It allows people to choose where they want to live, who they want to live with, how they want to be supported, and what happens in their home.

Voluntary sector

Also referred to as 'voluntary and community social enterprise sector' (VCSE). It refers to organisations that are independent of the government and local councils. Their role is to benefit the people they serve, not to make a profit. Social care services are often provided by VCSEs, by arrangement with the council or with the individual. Some are user-led organisations, which means they are run by and for the people the organisation is designed to benefit – for example, disabled people.

The source of some of these definitions is the [Think Local, Act Personal's care and support jargon buster](#). Also see the jargon buster for other social care terms.

Putting this guideline into practice

NICE has produced [tools and resources to help you put this guideline into practice](#).

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Supporting people who use services to maintain their independence is a key requirement for wellbeing and is an achievable expectation, but it will require a significant change in practice for some services.
- Working with people who use social care to ensure that there is a well-developed 'market' for personal assistants (PAs) will lead to better outcomes for people who employ PAs and better use of resources. However, for some authorities this will involve a new focus on market development and a change of practice that will require staff to be re-trained.
- Making sure that people are supported in a residential setting that is appropriate to their needs and building a culture that enables staff to respect people's individual choices and preferences are essential factors in promoting a good quality of life for people who live in a residential setting. Services may find it challenging to implement these changes because they will involve a major rethink in their approach to service delivery.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.
2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.
3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.
4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.
5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.
6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.
7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.
8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See [our into practice pages](#) for more information.

Also see [Leng G, Moore V, Abraham S, editors \(2014\) Achieving high quality care –](#)

practical experience from NICE. Chichester: Wiley.

Recommendations for research

The guideline committee has made the following recommendations for research.

1 Methods and approaches for gathering the experiences of people who use adult social care services

When conducting research for the purposes of service improvement, what research methods are acceptable, appropriate and effective in meaningfully gathering the views and experiences of people who use services?

Why this is important

Current research methods for gathering the views and experiences of people who use services commonly include standardised surveys and measures (for example, patient-reported outcome measures [PROMs]; NHS and social care: public perceptions surveys; The National Adult Social Care User Experience Survey). However, the evidence reviewed for this guideline suggests that measures of this kind may have limitations in terms of how comprehensive and representative these people are who are typically willing and able to respond to these kinds of self-completion postal surveys. This means that some people's views and experiences of social care may not be included in surveys designed to support service improvement. Further research is needed to:

- Determine the extent to which frequently used research methods meaningfully engage people and provide an accurate picture of their views and experiences.
- Develop and test new or innovative methods for gathering views and experiences. This could include narrative methods and the use of technology such as apps. The methods would be compared in relation to how well they were able to provide accurate and detailed information on people's views and experiences of care and support.

2 Co-producing research into the views and

experiences of people who use services

What approaches have been shown to work in supporting the co-production of research for the purposes of service improvement with people who use services?

Why this is important

Co-production is a key concept in the development of public services (Co-production in social care: what it is and how to do it, Social Care Institute for Excellence [SCIE]), and there are many examples in practice that highlight how individuals and communities can positively shape the way that services are designed, commissioned and delivered (Co-production in commissioning, Think Local Act Personal 2015). Co-produced research on the views and experiences of people who use services is a potential means of improving services. Co-producing all stages of the research process with people who use services is an important principle, which may signpost pertinent issues and questions that would have otherwise been neglected. However, there is little published evidence about how to put the principle of co-production into practice in research, although it appears that there may be good practice occurring within the sector.

3 Identifying barriers and enablers to using the views and experiences of people who use services to improve services

What are the barriers and enablers to gathering, synthesising and applying data on the views and experiences of people who use services for the purposes of service improvement?

Why this is important

There are several examples of data-gathering processes designed with the purpose of improving services – for example, annual mandatory local authority surveys, audit, and small-scale consultation at the individual organisation level. However, little is known about how the data from these exercises are translated into change and improvement in services, including:

- What capacity is needed within organisations to gather data and make use of it, and

whether this is present?

- What factors determine whether the findings of research are implemented in practice?

4 Use of technology in providing care

What are the views and experiences of people who use adult social care services on assistive technologies?

Why this is important

Assistive technology is one means by which social care services can help people to maintain independence. These technologies include a wide range of devices, ranging from simple, low-cost devices such as pendant alarms, to more intricate home monitoring systems using electronic information and communication technology – for example, integrated systems of sensors, alarms and remote monitoring. Across all population groups, there is a paucity of evidence about how acceptable assistive technology is to people who use services, and the impact of the technology on their satisfaction with services. Issues that could be explored include the extent to which the technology is and can be personalised, anxiety that it may be used to scale back services and reduce human contact, loss of confidentiality where personal information is shared, and ethical questions around privacy and surveillance.

Context

Background

In 2015 to 2016, there were over 800,000 people receiving long-term care and support (more than 12 months) from adult social care. Services also responded to a further 1.8 million new requests for care and support (including short-term support; [NHS Digital Community care statistics: social services activity, England - 2015 to 2016 report](#)). The core purpose of adult care and support is to help people achieve the outcomes that matter to them in their life. People's experiences of care and support, and the extent to which they feel supported to live their life as they want to, are therefore of key importance.

In 2016, 64% of respondents to the annual [personal social services adult social care survey](#) said they were either extremely or very satisfied with the care and support they received. However, only 33% said that they had as much control as they wanted over their daily life; 18% said they had some, but not enough, control and 6% had no control at all.

This guideline is developed in a context of working towards better integration of health and social care, and complements [NICE's guidelines on patient experience in adult NHS services](#) and [service user experience in adult mental health](#). For people who use services, integrated care means joined up, coordinated health and social care that is planned and organised around the needs and preferences of the individual, their carer and family (see [Think Local Act Personal's care and support jargon buster](#)). Relevant to this is the [Care Act 2014](#) that places a statutory duty on local authorities to integrate health and social care and related services where this promotes wellbeing, and prevent, reduce or delay needs.

This guideline covers good practice in the care and support of adults, including people with learning disabilities, physical disabilities, sensory impairment, and mental health or physical conditions. It aims to improve peoples' experiences of care and support services. It is based on evidence about the views of people who use services on what is important to them in their care and support.

What is the status of this guidance?

The application of the recommendations in this guideline is not mandatory. Different types of NICE guidance have a different status within the NHS, public health and social care. Although there is no legal obligation to implement our health and social care guidance, health and social care [practitioners](#) are actively encouraged to follow our recommendations to help them deliver the highest quality care and support. Our recommendations are not intended to replace the professional expertise and judgement of practitioners, as they discuss care and support options with people.

How has it been developed?

The guideline has been developed by a committee of people who use services, and carers and professionals. It has used information from a review of research evidence about people's experiences of care and support, and from expert witnesses. The committee also gave careful consideration to the potential resource impact of the recommendations. The included recommendations are considered to be aspirational but achievable.

How does it relate to legal duties and other guidance?

This guideline does not replace statutory duties and good practice as set out in relevant legislation and guidance, including:

- [Care Act 2014](#) and associated guidance
- [Equality Act 2010](#)
- [Mental Capacity Act 2005](#)
- [Accessible Information Standard](#)
- [UN Convention on the rights of persons with disabilities](#)
- [Human Rights Act 1998](#).

This guideline aims to complement legislation and guidance by providing evidence-based recommendations about how to improve people's experiences of care and support. Actions already required by law, or recommended in guidance, are not replicated here

unless there was evidence to suggest that these were not happening in practice, or were of particular importance to people's experiences.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE topic page on adult's social care](#).

For full details of the evidence and the guideline committee's discussions, see the [full guideline and appendices](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

Update information

Minor changes since publication

September 2020: We have replaced recommendation 1.3.7 with across-reference to the NICE guideline on supporting adult carers. We have incorporated footnotes into the recommendations in line with accessibility requirements.

ISBN: 978-1-4731-2816-3