

# 1           **People's experience in adult social care** 2           **services: improving the experience of care for** 3           **people using adult social care services**

## 4                   **NICE guideline: short version**

5                   **Draft for consultation, August 2017**

6

**This guideline covers** the care and support of adults, including people with learning disabilities, physical disabilities, sensory impairment and mental health or physical conditions. It applies to all settings where care is delivered, including people's own homes, and residential care and community settings. It also takes into account a range of inequalities that people may face, as identified in the equality impact assessment. It does not include health services, including clinical mental health services, or services and support specifically aimed at carers.

### **Who is it for?**

- Practitioners working in adult social care services in all settings
- Care managers and providers (statutory and non-statutory) of adult social care services
- People using services, their families, carers, advocates and the public
- Commissioners of adult social care services.

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the [guideline's page](#) on the NICE website. This includes the guideline committee's discussion and the evidence reviews (in the [full guideline](#)), the scope, and details of the committee and any declarations of interest.

7

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## 1 **Context**

### 2 ***Background***

3 In 2015-16, there were over 800,000 people receiving long-term care and support  
4 (more than 12 months) from adult social care. Services also responded to a further  
5 1.8 million new requests for care and support (including short-term support)  
6 ([Community Care Statistics: Social Services Activity, England - 2015 to 2016](#) Report  
7 NHS Digital). The core purpose of adult care and support is to help people achieve  
8 the outcomes that matter to them in their life. People's experiences of care and  
9 support, and the extent to which they feel supported to live their life as they want to,  
10 are therefore of key importance.

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

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

### 21 ***What is the status of this guidance?***

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

1 ***How does it relate to legal duties and other guidance?***

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

- 4 • [Care Act 2014](#) and associated guidance
- 5 • [Equality Act 2010](#)
- 6 • [Mental Capacity Act 2005](#)
- 7 • [Accessible Information Standard](#)
- 8 • [UN Convention on the Rights of Persons with Disabilities](#).

9 This guideline aims to complement legislation and guidance by providing evidence-  
10 based recommendations about how to improve people’s experiences of care.  
11 Actions already required by law, or recommended in guidance, are not replicated  
12 here unless there was evidence to suggest that these were not happening in  
13 practice, or were of particular importance to people’s experiences of care.

14 ***More information***

**[The following sentence is for post-consultation versions only]** You can also see  
this guideline in the NICE pathway on [\[pathway title\]](#). **[Note: this should link to  
the specific topic pathway, not to the overarching one.]**

To find out what NICE has said on topics related to this guideline, see our web  
page on [adult social services](#).

**[The following sentence is for post-consultation versions only]** See also the  
guideline committee’s discussion and the evidence reviews (in the [full  
guideline](#)), and information about [how the guideline was developed](#), including  
details of the committee.

15

## 1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [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.

### 2 **1.1 Overarching principles**

3 1.1.1 Treat each person who uses services as an individual. Use each person's  
4 needs, strengths, preferences and aspirations as the basis on which to  
5 provide care and support to live an independent life.

6  
7 [This recommendation is adapted from the NICE guideline on [patient](#)  
8 [experience in adult NHS services](#).]

9 1.1.2 Support people to maintain their independence as far as possible. This  
10 means finding out what people want from their life, including participating  
11 in their community, and providing the support and assistance they need to  
12 do so.

13  
14 [This recommendation is adapted from the NICE guideline on [patient](#)  
15 [experience in adult NHS services](#).]

### 16 **Enabling people to make decisions about their care**

17 1.1.3 Respect people's right to make their own decisions, and do not make  
18 assumptions about people's capacity to be in control of their own care (for  
19 example, if the person is severely disabled).

20 1.1.4 Actively involve the person in all key decisions that affect them.

21 1.1.5 If a person lacks the capacity to make a decision, the provisions of the  
22 [Mental Capacity Act 2005](#) must be followed.

1 1.1.6 Provide support to people if they need it to express their views,  
2 preferences and aspirations in relation to their care and support. This  
3 could include:

- 4 • advocacy support
- 5 • an independent interpreter (that is, someone who does not have a  
6 relationship with the person or the services they are using) to enable  
7 people to communicate in a language they can readily converse in,  
8 including sign language
- 9 • communication aids (such as pictures, videos symbols, large print,  
10 Braille)
- 11 • use of evidence-based techniques for communication.

12 1.1.7 Use plain language and communication to encourage and enable people  
13 to be actively involved in their care and support. If technical language or  
14 jargon has to be used, or complicated ideas are being discussed, check  
15 that the person understands what is being said.

## 16 **Access to care**

17 1.1.8 Ensure that everyone with social care needs has access to services  
18 based on their needs, taking account of age, disability, gender  
19 reassignment, marriage and civil partnership, pregnancy and maternity,  
20 race, religion and belief, sex and sexual orientation, and socio-economic  
21 status or other aspects of their identity.

22  
23 [This recommendation is adapted from the NICE guideline on [service user  
24 experience in adult mental health.](#)]

25 1.1.9 Service providers should be aware of the cultural and religious needs of  
26 people who use services, and provide care that meets these needs.  
27 Examples include food choice and preparation, enabling people to dress  
28 in accordance with their culture or religion, personal grooming, or changes  
29 in timing of services around religious festivals, for example, during  
30 Ramadan.

1 1.1.10 Commissioners and service providers should consider seeking advice  
2 from voluntary and community sector organisations with expertise in  
3 equality and diversity issues to ensure that they can deliver services that  
4 are appropriate to the needs and preferences arising from:

- 5 • gender, including transgender
- 6 • sexual orientation and sexuality
- 7 • disability
- 8 • ethnicity
- 9 • religious and cultural practices.

10 1.1.11 Ensure that people who use services and have caring responsibilities  
11 receive support to access social care services, including information about  
12 childcare where appropriate.

13  
14 [This recommendation is adapted from the NICE guideline on [service user](#)  
15 [experience in adult mental health.](#)]

## 16 **Co-production**

17 1.1.12 Local authorities and service providers should work with people who use  
18 adult social care services to co-produce:

- 19 • the information they provide
- 20 • organisational policies and procedures
- 21 • staff training.

## 22 **Involving carers, families and friends**

23 1.1.13 Ask the person at the first point of contact whether and how they would  
24 like their carers, family and friends to be involved in discussions and  
25 decisions about their care and support, and follow their wishes. Review  
26 this regularly (every 6 to 12 months).

27  
28 [This recommendation is adapted from the NICE guideline on [service user](#)  
29 [experience in adult mental health.](#)]

- 1 1.1.14 If the person would like their carers, family and friends involved:
- 2
- 3 • explain the principles of confidentiality, and how these are applied in  
4 the best interests of the person
  - 5 • discuss with the person and their carers, family and friends what this  
6 would mean for them
  - share information with carers, family and friends as agreed.

7 **1.2 *Coordinating care***

8 1.2.1 Local authorities and providers should consider providing people with a  
9 named coordinator who:

- 10
- 11 • acts as the first point of contact for any questions or problems
  - 12 • contributes to the assessment process
  - 13 • liaises and works with all health and social care services involved with  
14 the person, including those provided by the voluntary and community  
15 sector
  - 16 • ensures that any referrals needed are made and are actioned  
appropriately.

17 1.2.2 Support people to make decisions about entering a new care setting or  
18 moving to a different setting. For guidance on transitions between  
19 particular settings, see the NICE guidelines on:

- 20
- 21 • [transition from children's to adults' services for young people using  
22 health or social care services](#)
  - 23 • [transition between inpatient hospital settings and community or care  
24 home settings for adults with social care needs](#)
  - 25 • [transition between inpatient mental health settings and community or  
care home settings.](#)

26 1.2.3 Commissioners and managers should consider putting the following in  
27 place to support collaborative working between services:

- 28
- 29 • a local policy for sharing information relevant to people's care within  
and between services in line with the Caldicott principles



- 1                   • joined-up policies, processes and systems.

2   **1.3        Information**

3   1.3.1       Provide people with information they can easily read and understand in  
4                   line with the [Accessible Information Standard](#).

5   1.3.2       In line with the [Care Act 2014](#), local authorities must provide information  
6                   about care and support services including:

- 7                   • the types of care and support available  
8                   • how to access that care and support  
9                   • how to get financial advice about care and support.

10

11                   Local authorities should also provide information about options  
12                   available for people to control their own funding.

13   1.3.3       Local authorities should ensure that information about care and support  
14                   services (see recommendation 1.3.2) is widely and publicly promoted – for  
15                   example, in GP surgeries.

16   1.3.4       Local authorities should provide information about the circumstances in  
17                   which independent advocacy is available, and how to access it.

18   1.3.5       Local authorities should consider providing comprehensive information  
19                   about other support groups, including voluntary organisations.

20   **1.4        Care and support needs assessment and care planning**

21   1.4.1       Local authorities must provide independent advocacy to enable people to  
22                   participate in care and support needs assessment and care planning who  
23                   would otherwise have substantial difficulty in doing so, in line with the  
24                   [Care Act 2014](#).

25   1.4.2       People who are supported by an independent advocate during care and  
26                   support needs assessment and care planning should have enough time  
27                   with their advocate:



1 1.4.8 Ensure that care and support needs assessment documentation about the  
2 person is accurate, up to date and well maintained and clarifies what  
3 services will be provided.

4 1.4.9 Tell the person that they may have a copy of any or all of the care and  
5 support needs assessment documentation if they want to.

## 6 **Care and support plans**

7 1.4.10 Build in flexibility to the care and support plan to accommodate changes  
8 to a person's needs and preferences – for example, by using direct  
9 payments (see recommendation 1.4.14) and agreeing a rolling 3-monthly  
10 budget so that people can use their money differently each week.

11 1.4.11 Local authorities and providers should ensure that the person's care and  
12 support plan includes clear information about what involvement from  
13 others (carers, family and friends) they want in their care and support, in  
14 line with the [Care Act 2014](#). (See also recommendation 1.1.13.)

15 1.4.12 Ensure there is a transparent process for 'matching' care workers to  
16 people, taking into account:

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

20  
21 Ensure care workers are able to deliver care in a way that respects the  
22 person's cultural, religious and communication needs.

23  
24 [This recommendation is adapted from the NICE guideline on [home](#)  
25 [care](#).]

26 1.4.13 Care plans should record and address the specific needs of people in  
27 relation to equality and diversity issues.

28  
29 [This recommendation is adapted from the NICE guideline on [dementia](#).]

1 **Personal budgets and direct payments**

2 1.4.14 Local authorities should:

- 3
- 4 • inform people that they have the option to control their own funding to buy different sorts of care **and**
  - 5 • give people the opportunity to exercise as much control as possible
  - 6 over the way they use any allocated funds to purchase a care package.

7 1.4.15 Local authorities should ensure that the direct payment process is:

- 8
- 9 • transparent about how the level of funding is decided
  - 10 • straightforward
  - 11 • accessible to all adult social care users eligible for local authority funding.

12 1.4.16 Local authorities should provide accessible information about direct  
13 payments, and peer support for people to use them. For example, this  
14 could be provided through user-led Centres for Independent Living.

15 1.4.17 Local authorities should ensure that local peer support services are  
16 sufficiently resourced. Their contribution could include:

- 17
- 18 • financial support for local peer support services
  - 19 • providing physical space for people who give peer support to hold meetings with people who use services
  - 20 • helping peer support services with applying for grants for funding.

21 **Personal assistants**

22 1.4.18 If people have eligible needs that could be met by employing a personal  
23 assistant, the local authority should ensure that this option is discussed  
24 with the person and understood by them at the care planning stage.

25 1.4.19 In line with the [Care Act statutory guidance](#), local authorities should inform  
26 people employing personal assistants about where to get support with:

- 27
- recruitment and retention of staff

- 1                   • their role and responsibilities as an employer (for example, payroll and  
2                   background checks).

3 1.4.20   Local authorities should consider the following to deliver support for  
4           people who employ personal assistants:

- 5                   • user-led Centres of Independent Living  
6                   • other peer-support arrangements.

7 1.4.21   In line with the [Care Act 2014](#), local authorities should work with people  
8           who use social care services to develop the market for personal  
9           assistants. For example, this could be done by providing training  
10          opportunities for people who are interested in becoming personal  
11          assistants. Training should be co-produced with people who use services.

## 12 **1.5       *Providing care and support***

13 1.5.1   Service providers, with oversight from the local authority, should build a  
14          culture that enables practitioners to respect people's individual choices  
15          and preferences by:

- 16                   • co-producing policies and protocols with people who use services (see  
17                   recommendation 1.1.12)
- 18                   • ensuring that there are open channels of communication between  
19                   practitioners and people who use services
- 20                   • supporting people to take managed risks to achieve their goals, for  
21                   example, taking part in hobbies or sports that are perceived to be risky
- 22                   • ensuring that there are systems in place for reporting concerns or  
23                   abuse
- 24                   • ensuring that practitioners have the time to build relationships with  
25                   people
- 26                   • training and supporting practitioners to work in this way, and checking  
27                   they are doing so.

1 1.5.2 Practitioners working in all settings where care is delivered should take  
2 time to build rapport with the people they support. For example, they  
3 should:

- 4 • talk to them about topics other than the service being provided
- 5 • take an interest in their hobbies or work with them on an individual or  
6 group project, for example, creating memory boards.

7 1.5.3 Practitioners working in all settings where care is delivered should ask the  
8 person using services, their carers, family and friends what name they  
9 prefer to be called, and use their preferred name.

10

11 [This recommendation is adapted from the NICE guideline on [service user](#)  
12 [experience in adult mental health](#).]

13 1.5.4 Practitioners working in all settings where care is delivered should  
14 respond flexibly to the priorities a person might identify each day. For  
15 example, a person might ask a home care worker to spend more time  
16 helping them get dressed and less time on other tasks if they have a  
17 special event to attend.

18 1.5.5 Day care and residential care providers should offer a choice of activities  
19 that are led by the person's needs, preferences and interests, including  
20 activities that motivate them, support them to learn new skills and  
21 increase their level of independence. Recognise that preferences are not  
22 fixed and may change.

### 23 **Continuity and consistency**

24 1.5.6 Service providers in all settings, with oversight by commissioners, should  
25 review staffing numbers and skill mix regularly to ensure that staffing and  
26 skill levels are sufficient.

27 1.5.7 Commissioners and managers in all settings should ensure that there is  
28 continuity in care and support for people, including:



- 1 1.5.12 When designing residential services, providers should ensure that  
2 environments:
- 3 • create space where practitioners and residents can have positive  
4 interactions
  - 5 • are stimulating, while not creating additional challenges for residents,  
6 including those with sensory impairments or dementia (for example, if  
7 the layout is frequently changed)
  - 8 • enable positive risk taking (for example, being able to use outside  
9 spaces)
  - 10 • support residents' autonomy (for example, by adapting kitchen facilities  
11 for people with physical disability).
- 12 1.5.13 Ensure that support in residential care is based on a good understanding  
13 of people's needs, including:
- 14 • providing appropriate practical and emotional support
  - 15 • accommodating speech and communication needs
  - 16 • helping people to maintain the personal relationships and friendships  
17 that are important to them
  - 18 • supporting people to take part in activities that they want to be involved  
19 in, both in the residential setting and in the community
  - 20 • preventing behaviour that challenges.
- 21 1.5.14 Practitioners should support people to participate fully in tasks and  
22 activities by ensuring that:
- 23 • the environment is conducive to their needs
  - 24 • they have access to the equipment they need (for example, hoists or  
25 recliner chairs).
- 26 1.5.15 Managers should ensure that practitioners are trained to support residents  
27 to use any equipment they need.



1 **End of life support in residential settings**

2 1.5.16 Managers in residential settings should co-produce with people who use  
3 services a policy on end of life care including:

- 4
- 5 • a named lead in the residential setting
  - 6 • training on supporting people at the end of their lives, tailored to  
7 different staff groups and updated regularly
  - 8 • ongoing support to enable practitioners to support people near the end  
9 of their lives, including creative ways of engaging people in discussions  
(for example, opportunities to discuss end of life care with peers).

10 1.5.17 Managers in residential settings should consider making available  
11 someone who is independent and not part of the usual staff team to  
12 discuss end of life issues, for people who want to do this.

13 **1.6 Staff skills and experience**

14 1.6.1 Have a transparent and fair recruitment and selection process that:

- 15
- 16 • uses values-based interviews and approaches to identify the personal  
17 attributes and attitudes essential for a caring and compassionate  
workforce **and**
  - 18 • ensures workers have the necessary language, literacy and numeracy  
19 skills to do the job.

20

21 [This recommendation is adapted from the NICE guideline on [home](#)  
22 [care](#).]

23 1.6.2 Local authorities should ensure that people undertaking needs and  
24 eligibility assessments have the knowledge and skills to carry out  
25 assessments as described in recommendations 1.4.3 to 1.4.6.

26 1.6.3 Service providers should consider involving people who use services  
27 ('experts by experience') in the recruitment and training of staff. For  
28 example:

- 29
- being on interview panels



1 **Using people's views to improve services**

2 1.7.2 All research into the views of people using care and support should be co-  
3 produced at all stages, including the research design, how it is carried out,  
4 and any resulting actions (for example, developing or refining quality  
5 indicators or developing monitoring tools).

6 1.7.3 Commissioners and service providers should communicate clearly the  
7 outcome that any exercise to collect people's views is aiming to achieve  
8 and what will be done as a result.

9 1.7.4 Commissioners and service providers should consider using a range of  
10 approaches to gather views and experiences (for example, focus groups,  
11 interviews or observation in addition to surveys), and use evidence from a  
12 range of sources. This could include:

- 13 • the lived experiences of people who use services
- 14 • information from third sector and voluntary organisations that represent  
15 people who use social care services
- 16 • existing sources of information, such as complaints.

17 1.7.5 Local authorities should consider gathering and analysing evidence on  
18 people's experience of services in collaboration with other health and  
19 social care organisations serving the same populations to reduce  
20 duplication and ensure economies of scale.

21 1.7.6 Organisations conducting research should consider from the outset how  
22 to ensure that all groups are able to participate, including people who may  
23 lack capacity. This may involve considering different research methods  
24 (see recommendation 1.7.4) or providing materials in a range of formats.  
25 If the participation or response rate for a particular group is low, take  
26 action to improve it (for example, by sharing a survey with third sector  
27 organisations to recruit participants).

28 1.7.7 Service providers should seek the views of people who use services  
29 about the extent to which the things that are important to them are being  
30 addressed. This should be done in such a way that the person feels safe

1 to express their views, even if these are critical (for example, a care home  
2 resident may not want to give feedback directly to the manager).

3 1.7.8 Anyone who is gathering views should offer an independent advocate to  
4 enable people to give their views and experiences.

5 1.7.9 If a third party or advocate is supporting someone to give their views,  
6 ensure that enough time has been allowed for them to do it.

7 1.7.10 Service providers should consider employing people who use services to  
8 monitor people's experience of health and social care services, including  
9 conducting research. This could be done by:

- 10 • offering training to 'experts by experience' on how to conduct interviews  
11 with people who use services, including supporting them in applying  
12 ethical principles such as informed consent and confidentiality
- 13 • paying them to undertake exit interviews with people who have recently  
14 left a service or moved to another service.

15  
16 [This recommendation is adapted from the NICE guideline on [service](#)  
17 [user experience in adult mental health](#).]

18 1.7.11 Commissioners and providers should ensure that the results of research  
19 with people who use services are used to inform improvements to  
20 services.

21 1.7.12 Commissioners and service providers should make available the results of  
22 research with people who use services, using approaches developed with  
23 people who use services. This should include:

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

1 **Survey research**

2 1.7.13 Consider using existing validated surveys before deciding to develop a  
3 new survey.

4 1.7.14 Local authorities should analyse the characteristics of people who did not  
5 or could not respond to surveys and:

- 6
- 7 • report on any under-represented groups in their published report of the  
8 survey and seek to understand the reasons for this
  - 9 • develop ways to address these gaps in the future, for example, by  
10 considering alternative modes of response, such as a telephone  
11 response line
  - 12 • ensure that information about under-represented groups is fed back to  
13 the survey designers.

13 1.7.15 Local authorities should ensure that people in their organisations who are  
14 responsible for interpreting and implementing survey findings have the  
15 necessary skills and capacity.

16 ***Terms used in this guideline***

17 **Care and support plan**

18 A written plan after a person has had an assessment, setting out what their care and  
19 support needs are, how they will be met (including what they or anyone who cares  
20 for them will do) and what services they will receive. The person should have the  
21 opportunity to be fully involved in their plan and to say what their own priorities are.

22 **Carer**

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

1 **Centre for Independent Living**

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

5 **Communication aid**

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

9 **Commissioner**

10 A person or organisation that plans the services that are needed by the people who  
11 live in the area the organisation covers, and ensures that services are available.  
12 Sometimes the commissioner will pay for services, but not always. The local council  
13 is the commissioner for adult social care. NHS care is commissioned separately by  
14 local clinical commissioning groups. In many areas health and social care  
15 commissioners' work together to make sure that the right services are in place for the  
16 local population.

17 **Co-production**

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

23 **Day care services**

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

1 **Home care**

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

6 **Joint commissioning**

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

11 **Needs assessment**

12 Under the [Care Act 2014](#), local authorities must carry out an assessment of anyone  
13 who appears to require care and support. The assessment should focus on the  
14 person's needs and how they impact on their wellbeing, and the outcomes they want  
15 to achieve.

16 **Peer support**

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

21 **Personal assistant**

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

27 **Personalised care**

28 An approach that puts the person receiving care and support at the centre of the way  
29 care is planned and delivered. It is based around the person and their own needs,

1 preferences and priorities. It treats the person receiving services as an equal partner,  
2 and puts into practice the principle of 'no decision about me without me'.

### 3 **Sensory aids**

4 A sensory aid helps a person when one of their senses is impaired. This may include  
5 hearing aids, eyeglasses, reading devices and telecommunication devices for people  
6 with a hearing impairment.

### 7 **Single, named care coordinator**

8 The person in an organisation who is responsible for coordinating support for the  
9 person and their family if needed, for example, a named social worker.

### 10 **Residential settings**

11 Accommodation where care and support are provided by staff. These settings can  
12 be run by the private sector, voluntary sector or local authority. Residential settings  
13 can include residential care homes and also include supported living.

### 14 **Supported living**

15 An alternative to residential care or living with family that enables adults with  
16 disabilities to live in their own home, with the help they need to be independent. It  
17 allows people to choose where they want to live, who they want to live with, how they  
18 want to be supported, and what happens in their home.

19 For other social care terms, see the Think Local, Act Personal [Care and Support](#)  
20 [Jargon Buster](#).

## 21 **Putting this guideline into practice**

22 **[This section will be finalised after consultation]**

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

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



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

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

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

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

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

- 25 1. **Raise awareness** through routine communication channels, such as email or  
26 newsletters, regular meetings, internal staff briefings and other communications with  
27 all relevant partner organisations. Identify things staff can include in their own  
28 practice straight away.

- 1 **2. Identify a lead** with an interest in the topic to champion the guideline and motivate  
2 others to support its use and make service changes, and to find out any significant  
3 issues locally.
  - 4 **3. Carry out a baseline assessment** against the recommendations to find out  
5 whether there are gaps in current service provision.
  - 6 **4. Think about what data you need to measure improvement** and plan how you  
7 will collect it. You may want to work with other health and social care organisations  
8 and specialist groups to compare current practice with the recommendations. This  
9 may also help identify local issues that will slow or prevent implementation.
  - 10 **5. Develop an action plan**, with the steps needed to put the guideline into practice,  
11 and make sure it is ready as soon as possible. Big, complex changes may take  
12 longer to implement, but some may be quick and easy to do. An action plan will help  
13 in both cases.
  - 14 **6. For very big changes** include milestones and a business case, which will set out  
15 additional costs, savings and possible areas for disinvestment. A small project group  
16 could develop the action plan. The group might include the guideline champion, a  
17 senior organisational sponsor, staff involved in the associated services, finance and  
18 information professionals.
  - 19 **7. Implement the action plan** with oversight from the lead and the project group.  
20 Big projects may also need project management support.
  - 21 **8. Review and monitor** how well the guideline is being implemented through the  
22 project group. Share progress with those involved in making improvements, as well  
23 as relevant boards and local partners.
- 24 NICE provides a comprehensive programme of support and resources to maximise  
25 uptake and use of evidence and guidance. See our [into practice](#) pages for more  
26 information.
- 27 Also see Leng G, Moore V, Abraham S, editors (2014) [Achieving high quality care –](#)  
28 [practical experience from NICE](#). Chichester: Wiley.

## 1 **Recommendations for research**

2 The guideline committee has made the following recommendations for research.

### 3 ***1 Methods and approaches for gathering the experiences of people*** 4 ***who use adult social care services***

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

#### 8 **Why this is important**

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

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

### 25 ***2 Co-producing research into the views and experiences of people*** 26 ***who use services***

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

1 **Why this is important**

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

14 ***3 Identifying barriers and enablers to using the views and***  
15 ***experiences of people who use services to improve services***

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

19 **Why this is important**

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

- 25 • what capacity is needed within organisations to gather data and make use of it,  
26 and whether this is present?  
27 • what factors determine whether the findings of research are implemented in  
28 practice?

1 **4 Use of technology in providing care**

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

4 **Why this is important**

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

17 ISBN: