

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

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

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?

- **Focus on all adults from age 18 upwards:** The original proposal was that the age range to be considered should be 25+. However, this would exclude young people who may transition into adult services from the age of 18 so the draft scope has been amended to cover adults and young people aged 18+ who are using adult services. Children and young people under 18 years old are excluded from this guideline, not because their views and experiences are not important but in order to keep the guideline focused and the work manageable.
- **Vulnerable groups:** this includes people with learning difficulties, seldom-heard groups, non-English speakers, young people over 18 making the transition to adult services, and people with dementia. The initial indications from the pre-scope search suggest that research on the experience of such groups is limited. Such groups may experience difficulty accessing and using social care provision and their experience is very important. So we should consider how best to involve them in both scoping and development.
- **Overlapping categories:** Many service users may fall into more than one 'population category', in particular those with multiple or complex needs, and

some may also identify as carers. The issue of accessing and using social care provision may be exacerbated because of the complexity of individuals' conditions. The guideline should acknowledge the difficulties caused for individuals from this group.

- **Diversity in population:** People of ethnic minority background, recent migrants and those who do not speak English as their first language are likely to have less access to information and advice, and hence may be disadvantaged when accessing social care services. The guideline should also consider evidence on experiences of people from other minority groups, for example, people from different cultures and religions, as well as LGBT people. Preliminary research as part of pre-scoping work identified that evidence was sparse so the research team will work with the GC to explore alternative forms of data-gathering, as far as possible.
- **Gender:** Some people may prefer that professionals involved in their care are of the same gender. The Health and Social Care Information Centre figures for 2012-13 shows that 60% of service users (of all ages) receiving community-based social care services are female. The guideline should consider evidence on gender issues relevant to service users and carers.
- **People with cognitive impairment including dementia:** People with cognitive impairments such as dementia are often excluded from services and research. The guideline should consider the needs of this group and the difficulties in accessing social care and support.
- **Adults who may lack capacity:** It is important that the guideline considers the particular needs of individuals in this group in respect to communication strategies, quality of services, choice and control, and safeguarding issues. During guideline development it may be necessary to include the views of their carers in relation to these adults experiences, where their ability to speak for themselves is limited.
- **People with communication difficulties, and/or sensory impairment:** This

group may have particular problems in accessing social care services and the guideline should include the need to consider the accessibility of services, and appropriate strategies to support their choice and control. Sensory impairment (e.g. affecting sight or hearing) and communication difficulties may develop with or be exacerbated by age and adults with learning disabilities or people for whom English is not their first language may experience particular problems in this regard.

- **Socio-economic status:** Lower socio-economic status may be associated with poor access to information about care options, or difficulty to pay for alternative care when no adult provision is available, or when individuals do not meet the threshold for adult services. The guideline should acknowledge the potential impact of SES on the experience of care.
- **Location:** The guideline should make clear that inequality of access due to regional variation in provision is acknowledged.
- **People in complex and/or unstable living situations:** This includes people who are homeless, gypsies and others with a traveller lifestyle, or those who have difficult relationships with their family or carers. Individuals identified in this category are potentially more likely to experience difficulty accessing social care provision. The guideline should acknowledge this issue and searches oriented to their personal/social care will be undertaken.
- **Parity of esteem:** Mental health will be treated equally to physical health as it was enshrined in law by the Health and Social Care Act 2012.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

Plans for dealing with these aspects include sensitivity to equality and diversity issues, and search strategies specifically oriented to identify material on these

groups. The Guideline Committee may also make recommendations specifically in relation to particular service users and carers.

It is proposed that service user views about clinical mental health or clinical care services, including inpatient and community psychiatric care, and secondary care is excluded from the scope.

It is also proposed that support for carers, such as respite/short breaks/carers assessments, and their views on that support will be excluded. A separate guideline will cover carer support and experiences in relation to their own support.

The scope includes carer views on the services received by those that they care for and this point is particularly significant for those service users who may not be able to speak for themselves.

Young people's views and experiences in relation to children's services will be excluded. Covering both child and adult experiences would need different approaches, as the legislation, services and processes are different – there is likely to be a significant separate body of evidence in this area.

The scope states that the guideline will cover all settings and services in which adult social care is provided, which could include: provision of equipment; home help and support for independent living; community support and activities; personal budgets; and information, advice and advocacy. To ensure the work is manageable, focused on social care and consistent with other social care guidelines, we propose excluding research that relates primarily to housing support services or transport.

Completed by Developer: _____

Date _____

Approved by NICE quality assurance lead: _____

Date _____

2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

The consultation process highlighted equality issues which have already been explicitly addressed in the EIA. The first point about how to seek and gain the views of those who lack capacity has been referenced in the EIA in the context of carers articulating the voice of the user where mental capacity may affect communication. This topic area is to be further strengthened through the development of a separate NICE guideline which is currently underway.

Other equalities groups addressed in the consultation are individuals with communication problems caused by issues such as hearing or sight loss, and those who are in the later stages of dementia.

The issues of income inequality and ethnicity were also raised in the consultation. During guideline development we will be particularly mindful of the impact that the latter can have on the risk for specific health conditions or social care needs.

Information, advice and guidance related to eligibility thresholds was also highlighted and is fundamental to enabling service users to make informed care choices.

The Guideline Committee will steer the development of this work to ensure that we have not excluded any of these equalities issues in the process of guideline development.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

One particular point in the consultation that was not addressed in the EIA previously was 'parity of esteem', i.e. valuing mental health equally with physical health. We

have now noted this in the EIA.

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the 'Information for the Public' document recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss;
- British Sign Language videos for a population who are deaf from birth;
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

No, this guideline is about the user experience in adult social care.

Completed by Developer: _____

Date _____

Approved by NICE quality assurance lead: _____

Date _____

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Equality and diversity issues have been considered throughout the development of the guideline. Often, best practice identified for particular groups was considered to represent good practice for all groups, so has contributed to recommendations for all adult social care service users.

More specifically the Guideline Committee have addressed the equality and diversity issues identified in the scope in the follow ways:

Vulnerable groups

At scoping, vulnerable groups were defined as including people with learning difficulties, seldom-heard groups, non-English speakers, young people over 18 making the transition to adult services, and people with dementia.

A specific additional analysis was taken in relation to evidence about the views of and experiences of people with learning disabilities, including autism (see Section 3.4 of the full guideline). This evidence underpinned a number of recommendations, including recommendations about supporting communication (1.1.6), provision of independent advocacy (1.3.4, 1.4.1, 1.4.2, 1.7.8, 1.7.9), building flexibility in to care plans (1.4.10) and offering activities that are led by the person's needs, preferences and interests (1.5.5). These recommendations are based on evidence about people with learning disabilities, but are worded in such a way as to apply to all groups, as the Guideline Committee thought that the practice identified would be appropriate for a range of groups.

With regard to non-English speakers, the review identified a number of studies that included experiences of this group. Recommendation 1.1.6 makes reference to the need to provide independent interpreters to enable people to communicate in a language in which they can readily converse.

Regarding young people in transition to adult services, we did not identify any

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

evidence in relation to this group. The Guideline Committee noted that there is an existing NICE guideline on [Transition from children's to adults' services for young people using health or social care services.](#)

Some evidence was identified in relation to people with dementia. Recommendation 1.1.5 makes reference to the Mental Capacity Act, and recommendation 1.7.6 makes reference to including people who may lack capacity when gathering views and experiences. The recommendations regarding advocacy (1.3.4, 1.4.1, 1.4.2, 1.7.8 and 1.7.9) are also relevant to this group.

Overlapping categories

At scoping, it was identified that many service users may fall into more than one 'population category', in particular those with multiple or complex needs, and some may also be carers. This was considered throughout development, in particular how services work with people who may require a range of support. Recommendations 1.2.1 and 1.2.3 refer to co-ordination between multiple services. Recommendation 1.1.11 and 1.4.7 refer to people who use services and are also carers.

Diversity in population

The Guideline Committee made several recommendations about the need for services to meet the needs of a diverse range of people. The Guideline Committee made a recommendation on equality of access to social care based on need, 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 (1.1.8) and that commissioners should seek advice from representative groups to ensure that they can deliver services that are appropriate to issues of diversity (1.1.10). A recommendation was also made about the need for care plans to record and address the specific needs of people in relation to equality and diversity issues (1.4.13). The focus on personalised approaches to care (recommendations 1.1.1, 1.1.3, 1.1.6) also aims to support delivery of services that

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

can meet diverse needs.

Recommendation 1.4.1 refers to the local authority responsibility to provide an independent advocate to enable people to participate in the assessment and care planning process who would otherwise have difficulty in doing so.

Following evidence presented by the expert witness in methods of gathering views and experiences for improving care, the Guideline Committee made a recommendation that the survey process should be designed in such a way so as not to systematically exclude particular groups (1.7.6).

Gender

The evidence review did not find studies that were specifically about gendered views and experiences of social care. However, the guideline committee took this issue in to account in developing the recommendations. Recommendation 1.1.8 refers to equality of access to social care based on need, taking account of a range of factors including gender and gender reassignment. Recommendation 1.1.10 refers to seeking advice from voluntary sector organisations about how best to meet needs relating to gender, including transgender.

Adults who may lack capacity

One recommendation refers to the provisions of the Mental Capacity Act 2005 (1.1.5). The Guideline Committee reviewed evidence that that people who lacked capacity can be supported in participating in decisions and made the recommendation that people who mat lack mental capacity should be supported in taking part in the gathering of views that are designed to improve services (1.7.6).

People with communication difficulties, and/or sensory impairment

The Guideline Committee identified people with hearing loss or multiple sensory impairments as a group of interest, and additional analysis was undertaken in relation to this group (see Section 3.5 of the full guideline). The Guideline Committee

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

made a recommendation that cross references the Accessible Information Standard (1.3.1). Recommendation 1.1.6 makes reference to support for communication needs, and recommendation 1.6.7 refers to the importance of having required equipment, including hearing loops. The Guideline Committee reviewed the evidence that the layout and/or design of care homes is a barrier to service use, inhibiting communication. The Guideline Committee made the recommendation that providers of services should ensure that environments support residents' autonomy (1.5.12).

Socioeconomic status

No research evidence was found relating to people's socioeconomic status and the impact this may have on their views and experiences of social care. However the Guideline Committee were aware of the potential impact people's socioeconomic status may have on access to services and made the recommendation that everyone with social care needs has equal access to services based on their needs, taking account of socioeconomic status (1.1.8).

Location

No evidence meeting our criteria was found relating to how a person's location was related to people's views and experiences. The Guideline Committee were mindful of the variation in access to services and made a recommendation that access to services should be based on need (1.1.8).

People in complex and/or unstable living situations:

The evidence review found a small amount of evidence that included people who had been homeless. However the Guideline Committee found that the evidence was not sufficiently robust to make a recommendation. The review did not find other studies that were about the views and experiences of people in other complex or unstable living conditions.

Parity of esteem

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

The Guideline Committee were aware of ensuring that mental health needs and physical health needs were given equal importance in the recommendations.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Disability

The Guideline committee noted that people who are severely disabled may be at risk of having less control and choice over their care. One recommendation suggests that people who provide care should not make assumptions about their capacity to being involved in their own care (1.1.3).

Religion and culture

The Committee reviewed evidence in relation to religion and culture, and made the recommendation that service providers should provide care that meets cultural and religious needs (1.1.9). Recommendation 1.4.12 makes reference to ensuring that care workers are able to deliver care in a way that respects the person's cultural, religious and communication needs. A recommendation was also made about the need for care plans to record and address the specific needs of people in relation to equality and diversity issues (1.4.13).

Sexual orientation and sexuality

A number of studies were identified regarding the experiences of lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) people who use services. The Guideline Committee made a recommendation that there should be equality of access based on a range of characteristics, including sexual orientation (1.1.8). A recommendation was also made about the need for care plans to record and address the specific needs of people in relation to equality and diversity issues

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

(1.4.13).

People receiving care in residential settings

During development, people in residential settings were further identified as a group at risk of poor care. We undertook a specific analysis of evidence in relation to the barriers and facilitators to good experiences of care in residential settings (see Section 3.3 of the full guideline). This resulted in a number of recommendations in relation to how to improve people’s experiences of residential care (1.5.11 to 1.5.17).

People employing personal assistants

During development, people employing personal assistants were also identified as a group requiring particular consideration. A specific analysis was undertaken in relation to evidence on this group, and a number of recommendations developed (1.4.18 to 1.4.21).

3.3 Were the Committee’s considerations of equality issues described in the consultation document, and, if so, where?

Where equalities issues were discussed, they are reported in the Linking Evidence to Recommendations (LETR) tables in the full guideline under ‘Other considerations’.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

The Guideline Committee has sought to ensure that their recommendations do not make access to social care services more difficult. A specific recommendation about equality of access has been made (1.1.8).

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

The Guideline Committee has sought to ensure that the recommendations do not have an adverse impact on people with disabilities, who are a key population for the guideline.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

The Guideline Committee has made a number of recommendations which seek to address equalities issues. These are detailed in Section 3.1 above.

Completed by Developer: _____

Date _____

Approved by NICE quality assurance lead: _____

Date _____

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

The following equality issues were raised during consultation and have been addressed as follows:

Lesbian, Gay, Bisexual, Transsexual, Queer and Intersex (LGBTQ I) community

It was raised during consultation that people from the LGBTQI community may be estranged from their families. The assumption that families are always supportive or should be automatically assumed to be appropriate to be involved in a person's care may therefore disadvantage people from the LGBTQI community. For this reason, we have added advocates to the list of people who may be in the person's supporting network of people that should be involved in their care if that is what they wish (recommendations 1.1.14, 1.1.15, 1.1.16, 1.3.1, 1.3.2, 1.3.10, 1.4.2, 1.4.14).

People who display challenging behaviour

It was raised during consultation that people who display behaviour that is challenging may face additional barriers to good social care. We revised recommendation 1.4.15 that support in residential care is based on a good understanding of people's needs, to read that challenging behaviour should be understood as communication, instead of something that should be prevented, given the experience of people with behaviour that challenges of higher rates of unnecessary restraint and over-medication. We also added to this recommendation that there should be access to community health teams and specialist support.

People with additional communication needs

Stakeholders raised several comments that related to communication needs as a barrier to accessing good care, in particular, in ways to express one's needs and preferences. The Accessible Information Standard is linked to in several recommendations, but it was suggested that every opportunity to follow the standard and make reference to it would be welcomed.

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

- Recommendation 1.1.5 – we added reference to aspects of implementation of the Accessible Information Standard, specifically that people’s communication preferences should be identified and recorded. The recommendation added examples of how to support people to express their views, such as allowing additional time to understand and process information, and to support communication by taking into account environmental conditions that support communication, for example, clear lighting and minimal noise interference.
- Recommendation 1.1.7 has been revised to say that if technical language has to be used then to take time to check that the person or a carer who knows him or her well understands what is being said.
- Recommendation 1.1.8 has been moved from another section to be a standalone recommendation in the general principles that if a person has a third party or advocate supporting them to give their views then they should be allowed time to do this.
- Recommendation 1.4.1 was revised to include using the communication methods that suit the person, in line with the Accessible Information Standard, when providing care and support.
- Recommendation 1.6.6 on conducting research has been revised to say that research should make efforts to include all groups, including people who lack capacity and people with different communication needs. Researchers should investigate reasons for low response rates and make necessary adaptations to response formats to better suit that group.

People who do not speak English

Recommendation 1.1.5 has been revised to include non-English language interpretation as necessary to provision of information, in line with the Accessible Information Standard.

People who are homeless

Consultation comments noted that people who are not in current formal contact with services may be excluded from promotion of such services if they are not widely promoted. Recommendation 1.2.2 has been revised to say that information about care and support, including housing should be publicly promoted, for example, in GP

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

surgeries, but also in community spaces and in specialist services sites, for example, homeless health centres.

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

The Guideline Committee was careful in revising the recommendations to ensure that it would not be more difficult for any groups to access services.

Recommendations 1.1.5, 1.1.7, 1.1.8, 1.4.1, and 1.6.6 make reference to ensuring that practice, particularly communication, takes account of potential barriers to accessing services.

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

The Guideline Committee was careful in revising the recommendations to ensure that the recommendations would not have an adverse impact on people with disabilities. Recommendations have been amended in order to better address barriers to services, in particular 1.1.5, 1.1.7, 1.1.8, 1.4.1, and 1.6.6 on supporting any communication needs.

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

As noted above, several recommendations have been amended in order to better

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

address barriers to services, in particular 1.1.5, 1.1.7, 1.1.8, 1.4.1, and 1.6.6.

4.5 Have the Committee's considerations of equality issues been described in the final guideline document, and, if so, where?

Consideration of equality issues, including response to consultation feedback, is documented in the Linking Evidence to Recommendations tables(Section 3.8.2)

5.0 After Guidance Executive amendments – if applicable (To be completed by appropriate NICE staff member after Guidance Executive)

5.1 Outline amendments agreed by Guidance Executive below, if applicable:

Approved by Developer _____

Date _____

Approved by NICE quality assurance lead _____

Date _____