

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Advocacy services for adults with health or social care needs

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

1.0 Checking for updates and scope: before scope consultation (to be completed by the Developer and submitted with the draft scope for consultation)

1.1 Is the proposed primary focus of the guideline a population with a specific communication or engagement need, related to disability, age, or other equality consideration?

If so, what is it and what action might be taken by NICE or the developer to meet this need? (For example, adjustments to committee processes, additional forms of consultation.)

The primary focus of the guideline is on a service which will be used by people who are likely to have a specific communication or engagement need. NICE should consider alternative forms of engagement during guideline development and where alternative versions of the guideline should be developed.

1.2 Have any potential equality issues been identified during the check for an update or during development of the draft scope, and, if so, what are they?

- Age

Although advocacy services should be available based on need, there may be a disparity in access based on perception of whether someone could benefit from an advocate, therefore, age may be a factor in whether people are able to access independent advocacy

- Disability

- Disabled people

Disabled people are likely to have significant interactions with health and social care services. The Care and support statutory guidance specifies in which scenarios independent advocacy must be provided. However, it is likely that there are scenarios where independent advocacy would be helpful in enabling people with disabilities to make decisions about their own care. It is also important to ascertain as to whether people who need advocacy are always able to access it.

- People with communication difficulties and/or sensory impairment

Advocacy is a strategy used to maximise choice and control, which makes it important for people with communication difficulties. Sensory impairment and communication difficulties, including profound deafness and age-related sight degeneration and dysphasia, may also develop with or be exacerbated by age. Communication is potentially further hampered if the person's first language is not English.

- People with mental health problems including those subject to the Mental Health Act

People who are detained for treatment under the Mental Health Act may not be considered as subject to the provisions of the Mental Capacity Act or Deprivation of Liberty Safeguards. It is not clear what support to make decisions, some of which may be life-changing, is available to people in secure mental health settings. In most cases, loss of capacity caused by mental illness is temporary, and there may be capacity to take some decisions but not others. People with mental health problems may also have a right to an Independent Mental Health Advocate.

- People with learning disability and with morbidity factors or co-morbidities

Certain conditions such as cerebral palsy, autism and epilepsy, are associated with learning disability because people with these conditions are more likely to have a learning disability. People with learning disabilities are also more likely to develop other health conditions common in older age – such as osteoporosis and diabetes – when they are younger, and services to address these conditions may not provide appropriate support to people who also have learning disabilities to take decisions. People with some categories of learning disability who may lack capacity may be necessarily involved in more complex choices about clinical care than are people in the general population.

- Gender reassignment

Trans people are likely to benefit from independent advocacy. It is important to assess whether trans and intersex people face specific difficulties in accessing these services given the difficulty in accessing gender reassignment services in England.

- Pregnancy and maternity

There is evidence that provision of advocacy to disadvantaged groups can improve health and wellbeing outcomes for mothers and their children. This guideline will need to identify whether there is disparity in access for pregnant women and whether there is an impact from intersectionality (for example, between race and pregnancy)

in availability or access to advocacy services.

- Race

People from Black, Asian and Minority Ethnic communities can face disparity in access and discrimination in health and social care services, and are underrepresented in those accessing advocacy services. The guideline will need to assess how to improve access for these groups, alongside the impact of intersectionality (race and disability, race and sex, race and pregnancy).

- Religion or belief

No specific information has been identified for religion or belief, however, it has been identified that culturally sensitive or appropriate advocacy is a key area for review in the guideline and this is likely to cover religion or belief.

- Sex

Intersex people are likely to have specific health and social care needs and can face discrimination in health and social care services, The guideline will seek to address this in terms of access to advocacy. No further specific information has been identified for sex at this stage. We will seek input from stakeholders for more information on this.

- Sexual orientation

LGBT+ people can face disparity in access and discrimination in health and social care services. The guideline will seek to address this in terms of access to advocacy.

- Socio-economic factors

Socio-economic factors can have an impact on access to health and social care services, including advocacy. The guideline will seek to address this in terms of access to advocacy.

- Other definable characteristics (these are examples):

- Refugees, asylum seekers and migrant workers

Refugees, asylum seekers and migrant workers are likely to have communication needs which might benefit from independent advocacy when accessing health and social care services. These groups also face disparity in access and discrimination in health and social care services. The guideline will seek to address this in terms of access to advocacy.

- looked-after children

Young people in transition to adult services are likely to benefit from independent advocacy. The guideline will seek to address this in terms of access to advocacy services.

- people who are homeless

People who are homeless already face challenges in accessing health and social care services and may have specific needs which could be addressed by independent advocacy.

- prisoners and young offenders

Prisoners and young offenders may have specific needs in accessing health and social care services which could be addressed by independent advocacy

- people with English as an additional language

1.3 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee?

As the guideline aims to address access to and benefits of advocacy services, it is important to address the equality issues identified. The committee will need to consider each equality strand as well as intersectionality between equality strands when making recommendations. The guideline is likely to have a role to play in attempting to address health inequalities.

Completed by Developer: Nick Staples

Date: 26th November 2020

Approved by NICE quality assurance lead: Kay Nolan

Date: 18th December 2020

2.0 Checking for updates and scope: after consultation (to be completed by the Developer and submitted with the revised scope)

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

- Age

- Older people

One stakeholder highlighted that the majority of those with advocacy needs may be older people and specific consideration of their needs should be considered in the development of the guideline.

- Young people under the age of 18

It was noted by multiple stakeholders that the needs of those under 18 who come into contact with adult services needs to be specifically considered including the range of young people who might be accessing services (for example, looked-after children, young carers, children in health services transitioning to adult services). It was also highlighted that some duties related to advocacy provision e.g. under the Mental Capacity Act and Deprivation of Liberty Safeguards (DoLS) as well as the incoming Liberty Protection Safeguards (LPS) apply to 16 and 17 year olds. In some circumstances, the Care Act applies to young people accessing assessments for transition to adult services as well as young carers. Similarly, Independent Mental Health Advocacy services are available to everyone detained under the Mental Health Act including children and young people.

- All ages

One stakeholder highlighted the importance of ensuring that methods of access and provision are in a range of formats appropriate to people of all ages.

- Disability

- People with non-verbal communication

Two stakeholders suggested that the role of advocacy for people who do not communicate with words needed to be considered specifically and that training people in communicating with people with non-verbal communication was important.

- People in specialist mental health and learning disability and autism inpatient settings

One stakeholder suggested that issues including lack of independence and quality existed in advocacy services for these population groups when delivered by one provider across a range of services and people with different needs. The importance of provision being tailored to the needs of the individual was highlighted which includes provision of local, citizen and peer advocacy as well as self-advocacy. The stakeholder suggested that consideration should be given to who commissions the advocacy service.

- People with a learning disability

One stakeholder noted that given the specific needs of people with a learning disability, the guideline should consider making separate recommendations for this group. Another stakeholder noted that people with severe learning disability and behaviour that challenges are likely to benefit from advocacy services. Another stakeholder highlighted that people with a learning disability are more likely to experience communication difficulties and therefore appropriate support for this group to access advocacy will likely be required.

- Neurological disorders

One stakeholder outlined that people with neurological disorders often do not have their mental health needs met and would benefit from advocacy. The stakeholder also highlighted that people living with Parkinson's disease, Multiple Sclerosis, life-limited genetic conditions such as Huntington's disease or Friedreich's Ataxia, neuro-developmental disorders such as ADHD, ASD, Down's syndrome, Foetal Alcohol Spectrum Disorder (FASD) or those with associated cognitive impairments due to Acquired Brain Injury (ABI) or survivors of brain haemorrhage are all likely to benefit from advocacy.

- People with communication difficulties

One stakeholder noted that people with communication disabilities can be mistaken for lacking mental capacity if their communication needs are not accommodated for. Accommodation of individual needs should be considered in order to determine if advocacy services are required.

- Disabled people

One stakeholder highlighted the importance of ensuring that methods of access and provision are in a range of formats appropriate to disabled people with a variety of impairments.

- Gender reassignment

One stakeholder highlighted that the landscape of practice and policy around shared decision-making and capacity in the context of trans people has undergone some changes since guidelines on decision-making and capacity were published, and advocacy services may be needed to enable equitable access to care.

- Socio-economic factors

One stakeholder identified the importance of taking into account the intersectionality of socio-economic factors alongside other protected characteristics as this often has a detrimental impact on individuals concerned.

- Intersectionality of definable characteristics

One stakeholder highlighted the breadth of the populations that advocacy services work with and the degree of expertise needed, giving an example of dealing with deaf/deafened cohort of service users brings in specialist communication needs and can be further compounded if that person is also from a BAME background.

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

- The population has been clarified to ensure that all those in adult settings (including people under 18 who are accessing an adult service) are included in the guideline.
- A specific point on addressing barriers to accessing advocacy was added to the key themes.
- Mode of delivery of services was added to the key considerations
- Coproduction of services was added to key considerations
- Appropriateness of practice to address equalities was added to key considerations in place of culturally appropriate and culturally sensitive practice to broaden the consideration and ensure full coverage of equalities.

2.3 Have any of the changes made led to a change in the primary focus of the guideline which would require consideration of a specific communication or engagement need, related to disability, age, or other equality consideration?

If so, what is it and what action might be taken by NICE or the developer to meet this need? (For example, adjustments to committee processes, additional forms of consultation)

No – the primary focus has not changed.

Updated by Developer: Nick Staples

Date 04/02/2021

Approved by NICE quality assurance lead: Kay Nolan

Date: 11/03/2021