

# Culturally appropriate care guide





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## **About this guide**

The purpose of this guide is to help anyone involved in the care and support of individuals to have a clearer understanding of culturally appropriate care and what that may mean to individuals they support. This may include care and support staff, health professionals, personal assistants (PAs) and family carers.

In this guide, we have focused on supporting people with learning disabilities, autistic people, and people with dementia. We have also considered the experiences of people from ethnic minority backgrounds and people who are LGBT+.

However, cultural identity or heritage can cover a whole range of areas in our lives. **The principles of culturally appropriate care apply to anyone who requires support as we all experience our own culture individually.** Supporting people in a person-centred way and considering all aspects of their lives is important.

This guide is supplemented by a set of training materials and a resource list including easy read resources that may be helpful for anyone, including individuals with a learning disability and/or autistic people and people living with dementia.

A wide range of people and organisations have contributed their time and energy to these resources. We extend our thanks to them within the Acknowledgements section.

A note about terminology. Terminology around race, ethnicity and sexuality evolves continuously. It is important that you learn about preferred terminology used in your organisation and with the individuals you support. It is also important to remain actively conscious of changes.

For the purpose of this document, we have used 'people from ethnic minorities and backgrounds' to refer to all ethnic groups except the white British group. This is in-line with current government guidance (December 2021) on how to write about ethnicity. Ethnic minorities include white minorities, such as Gypsy, Roma and Irish Traveller groups.

We have also used the term LGBT+ to describe Lesbian, Gay, Bi-sexual and Transgender. The 'plus' represents other sexual identities.

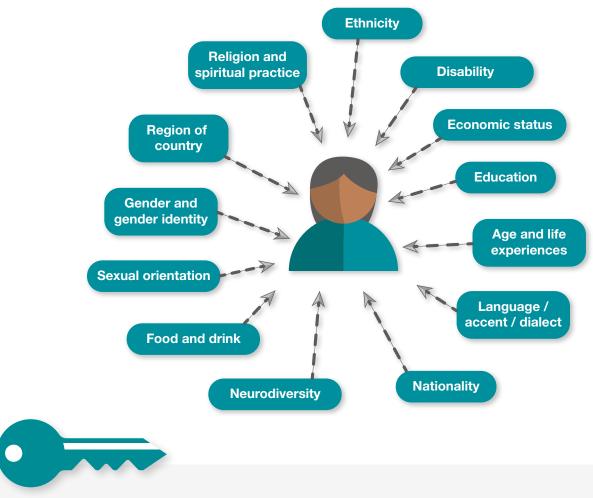
We very much hope the guide and the information resource are effective in supporting you in your role. We welcome your feedback and comments on these products so please feel free to get in touch with Skills for Care staff or contact us via email at marketing@skillsforcare.org.uk

## **Culturally appropriate care**

#### What is culturally appropriate care?

Culturally appropriate care, also called 'culturally competent care' is about being sensitive to people's cultural identity or heritage.

An individual's cultural identity can be based on a wide variety of influences, such as their ethnicity, nationality or religion. However, there are a wide range of influences, and cultural preferences that are expressed in many different ways.



Providers must do everything reasonably practicable to make sure that people who use the service receive person-centred care and treatment that is appropriate, meets their needs and reflects their personal preferences, whatever they might be.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014:

Regulation 9: Person Centred Care

# Culture, mental health and wellbeing

It's important to consider the possible impacts on a person who experiences a lack of culturally appropriate care and support. These may include:

- Low self-esteem
- Lack of self-confidence
- Feeling marginalised (treated as insignificant)
- Having restricted opportunities
- Loss of rights
- Stress and anxiety
- Eating problems / weight loss
- Feeling disempowered
- Depression
- Loneliness
- Sleep problems
- Mental slowing down
- Decline in physical health





I felt lonely. There was no one to talk to. They spoke a different language.

- Indian person with memory vloss, Ethnos research



#### Wellbeing

The Care Act 2014 marked one of the most significant changes to social care law in England for more than 60 years and it has an important focus on promoting wellbeing.

The wellbeing principle makes it clear that a local authority's duty is to ensure that the wellbeing of individuals must be at the centre of all it does.

'Wellbeing' is a broad concept and is described as relating to the following areas in particular:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over their day-to-day life (including over care and support provided and the way they are provided)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal domains
- suitability of the individual's living accommodation
- the individual's contribution to society.

There is no hierarchy in the areas of wellbeing; all are equally important.

There is also no single definition of wellbeing, as how this is interpreted will depend on the individual, their circumstances, and their priorities.

Wellbeing encompasses several areas of life. Therefore, using a holistic approach to ensure a clear understanding of the individual's views is vital to identifying and defining wellbeing in each case.



'A' has Crohn's disease. His previous care provider served him ready-meals from supermarkets. This meant he was missing out on food that he enjoyed and had grown up with.

When the new provider started supporting him, they found he had lost weight and was at risk of malnutrition. The manager checked with his family about his likes and dislikes, and involved the dietitian to see check what food he could have from his own traditions but which wouldn't affect his Crohn's.

They created a menu of safe staple cultural foods with the taste and texture he liked. Staff now cook food with him the way he likes it. His health has improved, his sleep has improved, and negative behaviours have decreased. His mum is grateful, and sad that he had missed out on chapatis and other favourite food for many years.

- Support to Lead, Oldham CQC rating: Good (2021)



#### Older people

The Social Care Institute for Excellence (SCIE) describe mental wellbeing as life satisfaction, optimism, self-esteem, feeling in control, having a purpose and a sense of belonging and support.

Older people, including those living in care homes, often experience depression, loneliness and low levels of satisfaction and wellbeing.

Taking part in meaningful activities, maintaining and developing personal identity, and getting the right help for any health conditions and sensory impairments have been identified as key to improving mental wellbeing.



We just sat there on our own all day; other people were dancing and singing. We had a cup of tea and in the evening they dropped us home. There was no one there we could talk to. There were all English people there.

- Indian carer, Ethnos research



#### People with learning disabilities

Mencap say that there are many reasons why people with a learning disability are more likely to experience poor mental health and outline four types of risk factors:

- Biology and genetics may increase vulnerability to mental health problems
- A higher incidence of negative life events
- Access to fewer resources and coping skills
- The impact of other people's attitudes



P has a learning disability. He liked listening to someone reciting lines from the Koran, and liked to repeat some of the lines. But he was very upset when staff referred to his recitation as 'singing'.

- Support to Lead, Oldham CQC rating: Good (2021)



#### **Autistic people**

The National Autistic Society state that autism is not a mental health problem and that autistic people can have good and bad mental health like anyone else.



J is autistic and loves boat rides from Greenwich to central London. He has been on cruises, and finds them very relaxing.

- Aurora-Nexus, South East London CQC rating: Outstanding (2019)





#### People who are LGBT+

The organisation Mind states that people who identify as LGBT+ are more likely to develop mental health problems, such as low self-esteem, depression, anxiety, self-harm and other mental health problems.

Challenges people face that can affect mental health and wellbeing can include homophobia, stigma, discrimination, rejection and social isolation.



I have had bad experiences with social services and carers, in respect that I was cautioned not to mention I am gay, in case a carer did not approve.

- Harry, 74, London, Stonewall report



#### People from ethnic minorities and backgrounds

The Mental Health Foundation state that challenges such as racism, stigma and inequalities can affect the mental health of people from ethnic minorities and backgrounds.



"Religion is very important to 'A'. We understand how important his religion is to him, so we schedule staff to support him every Friday to go to the Mosque. He is so much more relaxed and in less pain with his Crohn's. He has his frame of Mecca and prayer mat so he can pray at home if he doesn't want to go to the mosque."

- Support to Lead, Oldham CQC rating: Good (2021)



For further information on mental health and wellbeing and easy read guides, please see the culturally appropriate care resource list.

# Culturally appropriate care during the pandemic

In 2021, the Care Quality Commission (CQC) produced information about culturally appropriate care. They identified why culturally appropriate adult social care is more important during the coronavirus (COVID-19) pandemic.

#### During the COVID-19 pandemic, people using services may:

- have less contact with people that understand and affirm their culture for example, family and friends
- have no opportunity for contact with their culture or community outside their home
- spend more time with people who do not share their culture, for example in a care home
- experience more life events that have cultural significance, for example, they may be at the end of their life or lose someone close to them.



'W' recently lost his mum, however his siblings continue with routines and they call and visit regularly. During the pandemic they kept in touch through Zoom. When they celebrate his birthday, he enjoys Caribbean dishes from his favourite restaurant.

- Aurora-Nexus, South East London CQC rating: Outstanding (2019)





During the COVID-19 lockdown I could only access the LGBT+ community through social media.

- Workforce Expert Advisory Group member





A person's care and treatment must be designed to make sure it meets all their needs. There may be times when a person's needs and preferences cannot be met. In these instances, providers must explain the impact of this to them and explore alternatives so that the person can make informed decisions about their care and treatment.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 9: Person Centred Care

## B's story

We support 10 adults with learning disabilities in a small residential care home.

We wanted to find ways for the people we support to stay in contact with their families during lockdown, so that they didn't feel lonely.

'B' is Bengali and a Muslim. We know how important his religion and family traditions are to him. During the COVID-19 lockdown, we wanted 'B' to feel connected to his family, faith and celebrate all the Muslim festivals, without feeling like he is celebrating without his family. We also wanted him to enjoy his traditional foods during these festivals, as well as daily traditional foods.

We have staff here who are Bengali themselves and therefore are better able to cater to 'B's' cultural needs. During lockdown, we supported 'B' to celebrate Eid. Staff cooked up a traditional feast for 'B' and all of us to enjoy. 'B's family sent over clothes which 'B' wore that day.

We wanted to support him maintain contact with his family. We had received an NHS iPad and supported 'B' to Facetime his family throughout lockdown, including during special celebrations, such as Eid.

We noticed how using the iPad to maintain connection with his family made a huge difference to 'B'. From the beginning of lockdown, he had become withdrawn and would choose to sit in his room alone for the most part of the day. Once we had started doing the family video calls, 'B's' mood was better. He was happier and engaged more with the staff.

Once restrictions had eased slightly, we followed infection control guidance to make sure that 'B's' family were able to visit him, and that he was able to visit them. He was even happier when he could visit his mother at home

As 'B' identifies as a Muslim, there are certain dietary restrictions, such as not eating pork. All our staff ensure that there is no pork in any of 'B's' food and that all the food he is given is Halal. He particularly likes rice and curry, therefore there is always a member of staff who can cook a curry for 'B' for either lunch or dinner, which he enjoys very much.

The past couple of years have been tough for everyone. However, we had already known a lot about 'B's' culture, which made it easier to put the traditional festivities together. However, we still had a lot of learning to do about how his family carry out their traditions. We also had to navigate our way around their family's schedules. We achieved this by communicating well with them about visits, in order to avoid disappointment.

Apasen, East London CQC Rating: Good (2019)

### Inclusion and exclusion

Each of us has our own backgrounds, experiences and influences on our lives. These unconsciously contribute to our views, our actions, and the decisions we make. These happen automatically, as our brains make quick judgements and form quick opinions of people and situations. We need to be aware of this, as it can lead to a variety of judgements being made.

They can lead to an **unconscious bias**, which are thoughts or feelings we're not directly aware of, and which influence our judgement.

These can lead us to perceive people positively or negatively. We may think better of someone because we believe they are like us, for example, they may be of the same race, religion or age. Or we may think less of someone because that person is different to us, for example, they might be of a different race, religion or age.

They can also lead to othering. **Othering** refers to where individuals or groups of people see others as being different from them. This can negatively influence how we see each other and how we treat each other. It can lead to a "us versus them" way of thinking. This can lead to negative characteristics being attributed to the other people or group to show how they are different to us.

In addition, they can lead to **stereotyping.** This refers to where we group individuals together and make a judgment about them without knowing them. Some common stereotypes are to do with a person's race, sex, gender, cultural identity, cultural heritage, age and disability. We may make assumptions around a person's needs depending on their characteristics. This means could lead to a person's care being based on false beliefs or assumptions. An example in supporting people with learning disabilities/ autistic people is about age- appropriateness.



A lot of autistic people like 'Thomas the Tank Engine'. This is because they use bright colours, plain language and limited facial expressions.

It's not ok for people to say adults can't watch Thomas the Tank Engine.

- Workforce Expert Advisory Group member



Unconscious bias, othering and stereotyping can lead to people not being treated in the correct way, or not receiving care that meets their needs.

Within the law, people are protected against unfair or unjust treatment, based on their characteristics. Sometimes these can lead to discrimination, where individuals or groups are treated based on their characteristics.



Discrimination refers to where people or groups are treated unfairly or less favourably than other people, based on their characteristics.

#### The Equality Act 2010 and protected characteristics

It is against the law to discriminate against someone because of the following protected characteristics:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation

Anti-discriminatory practice is fundamental to care provision and critical to the protection of people's dignity.

The Equality Act protects those receiving care from being treated unfairly because of any characteristics that are protected under the legislation.

#### **Direct and indirect discrimination**

There are many types of unlawful discrimination, including direct and indirect discrimination.

Direct discrimination can be because of:

- who you are
- who someone thinks you are
- someone you're with.

It's unlawful discrimination if you're treated **differently** and **worse** because of a protected characteristic.

**Direct discrimination** is when you are treated differently and worse that someone else for certain reasons.

**Example:** Not catering for particular religious dietary requirements.

An example of good practice would be:



'K' wanted an active role during Ramadan. Staff were scheduled staff to help support meal preparation at the right time so that she could activity participate in Ramadan.

- Support to Lead, Oldham, CQC rating: Good (2021)



**Example:** not respecting peoples' decisions about who they have relationships with.

Staff need to be aware that their personal views can impact negatively on others:



The carer might have religious views that affect how they support someone who is LGBTQ+ or even just how they support two people who have a learning disability.

- Workforce Expert Advisory Group member



**Indirect discrimination** is when there is a practice, policy or rule which applies to everyone in the same way but has a worse effect on some people than others.

**Example:** A care home providing generic toiletries that may not be suitable for certain skin and hair types.

An example of good practice would be:



Staff make sure that 'A' is supported with the correct creams for his hair. He visits a West Indian barbers every two weeks. The barbers know him well. They get on really well and other customers are from similar backgrounds.

- Aurora-Nexus, South East London, CQC rating: Outstanding (2019)





People using services must not be discriminated against in any way and the provider must take account of protected characteristics, set out in the Equality Act 2010.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 10: Dignity and respect

#### Challenging othering and discrimination

Challenging othering and discrimination can be difficult, however as a care and support staff you may need to help someone speak up about discrimination or speak on their behalf.

#### There are many things we all can do:

- Be aware of intersectionality. This is where all the different factors that make up our culture identities are interconnected, such as gender, caste, sex, race, ethnicity, class, sexuality, religion, disability, weight, physical appearance, and height. These intersecting and overlapping identities can lead to some people being treated less favourably, or more favourably, than others.
- Respect diversity by providing person centred support.
- Treat individuals that you support as unique.
- Work in a non-judgemental way.
- Providing and displaying easy read materials which include information and images that promote inclusion.
- Follow agreed ways of working in your workplace to create an environment that is free from discrimination but feel empowered to challenge practices that may be discriminatory.
- Be confident to challenge, confront and report discriminatory behaviours if you see this is happening in your workplace.
- Reassure the individual involved that they have every right to challenge discrimination and that you will support them.
- Racism and other forms of discrimination towards staff from people using the service can take place. It's important to have an open staff culture so staff can raise this with managers to work out solutions.



Take people as they are, don't judge them on their culture.

- Workforce Expert Advisory Group member



We don't support different cultures just because the law says we must. We support different cultures because it's the right thing to do!

## Case study – a visual representation of culturally appropriate care

Chris is a member of Skills for Care's Workplace Expect Advisory group. Further to a conversation about what "culturally appropriate care" means to each of us, and how we'd like to be treated, Chris created this illustration.

He explains that each jellybean is a unique characteristic that makes someone an individual. Everyone is their own unique mix of characteristic flavours and there's lots of things that are important to each individual. It's important to remember that what we see on the surface of the packet might not always represent the full mix inside.



## Should we match care staff and individuals we support?

You may have considered matching staff with individuals you support on the basis of ethnicity or culture.

For some people, this can be beneficial, but in some instances could be detrimental to the person.

Decisions about culturally matching staff should be made on a case-by-case basis, with careful examination of the needs of the person being supported and the potential staff being matched.

#### Areas to think about

- Ethnicity is complex and cannot be judged on face value. There can be many reasons why people from the same country or religion, for example, may not wish to be matched. Don't assume that people want to be supported by staff with similar characteristics.
- Families may have concerns about stigma and prefer not to be matched from someone from their community.
- Equipping staff with the skills to understand and respond to people's individual cultural needs would help them provide good care to people, regardless of their background.
- Consider other hobbies and interests that staff and clients may have in common, such as art, gardening, shopping, cinema, music.
- Some services make use of skills their staff have that are not strictly part of their job. For example, a member of staff who shares a language with someone using the service could teach their colleagues a few useful phrases. It's important to ask them first if they're happy to do things like this.



In one service, some staff spoke a client's mother language. They taught other staff key phrases that are important to her. These key phrases were recorded in her communication dictionary. Staff use these phrases when she is feeling low. This has led to decreased hospital admissions to due to poor mental health.

- Support to Lead, Oldham, CQC rating: Good (2021)





'A' was very keen to travel to the Caribbean. The team initially supported him and his mum to travel to Disneyland Paris to see how he would cope with a short haul trip. Following a longer trip away, he was supported to travel to the Caribbean by two Caribbean male staff who knew the area well. He loved the trip and attended street parties and hopes to return.

- Aurora-Nexus, South East London, CQC rating: Outstanding (2019)



### Life stories

#### The benefits of life stories

We can learn a lot about someone's background, culture and interests from the individual and their friends and family.

A life story can really help us get to know someone, support meaningful conversations and can help provide personalised care.

#### **Getting started**

- See the Life story section in the resource list to help you get started. <u>Tools for Talking</u> to help think about cultural influences.
- Talk to the person, friends and family to help put together a life story.
- Reminiscence can be used alongside meaningful activities that are sensitive to the persons background and culture.
- Life stories can be in many different forms, such as books, collages, DVDs, memory boxes, apps, personal profiles whatever suits the individual!
- Consider the person's childhood, family and friends, their working life, significant places and events, hobbies/activities, preferences with their appearance, how they like to dress, food, routines and music/TV and general likes and dislikes.

#### Think about...

For someone not originally from the UK it may be helpful to consider the following areas of their earlier lives:

- Be mindful that people who migrated to the UK during the mid-twentieth century may have experienced hostility and racism. Reminiscence work may stir up memories of a difficult period in people's lives.
- Did the person speak another language?
- Where they lived.
- Who they lived with.
- What it looked like.
- Their practices and/or religion.
- Clothing preferences.
- Food and drink they enjoyed.
- Home and work life.



Our care organisation has a strong belief that family members are more important to people's identity and sense of belonging than paid staff. We want staff to support people to build and maintain relationships, even where people haven't seen families for years. Contact can include making calls to family members, sending birthday and Christmas cards. Sometimes it can take several years to build relationships. One man saw his brother for the first time in many years and they were delighted to be reunited.

- Aurora-Nexus, South East London, CQC rating: Outstanding (2019)





'A' is from Jamaica and moved to our service from his parents' home.

We identified things that were important to him, such as food, hair, music, entertainment, and aspirations.

- Aurora-Nexus, South East London, CQC rating: Outstanding (2019)

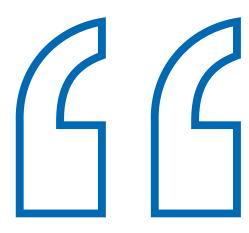




Think about what people used to do with their families or their communities. For example, we used to go to the Goose fair, an annual travelling fair. And I grew up in an area where people worked in the rail industry. Trains are now a hobby of mine.

- Workforce Expert Advisory Group member





# Supporting individuals from ethnic minority groups and backgrounds

The COVID-19 pandemic has had a disproportionate impact on people from ethnic minority groups and backgrounds.

Think Local Act Personal commissioned some specific work as a contribution to addressing this

The aim of their project was to find examples of promising practice that demonstrate what good, personalised care and support looks like for people in ethnically diverse communities.

This included identifying the factors that support high quality care and support, and the barriers that stand in the way. The report outlines key aspects of personalisation.

#### **Think Local Act Personal report**

Personalisation in black, Asian and minority ethnic communities.

- Focusing on the whole person and holistic support; rather than relying on diagnosis or narrow assessments of care needs.
- Flexibility of provision and creative responses; meeting the needs of an individual within the context of their life experience.
- Cultural complexity and competency; attitudes towards illness and disability and challenging stereotypes.
- Building community capacity; drawing on the strengths of the people being supported, their families, and their communities.
- Commitment to support learning and development; creating opportunities for people to learn and develop.

To read the full report and good practice examples, please click here.



There are many Asian communities and sub communities, and each has their own norms, identity, dialects, lifestyle and food. Support teams need to ask the questions to find out what's important to each individual person. This isn't a tick box exercise, and can take several months to build up the correct picture of the person and their family.

- Support to Lead, Oldham, CQC rating: Good (2021)





'A' has CD collection of reggae and RnB music, and uses his iPad to listen to music. He went to 'World music' class and during the pandemic was supported to access online. He likes the Horniman museum where can see items that show the origin of music. He bought a drum and guitar and likes to play these.

- Aurora-Nexus, South East London, CQC rating: Outstanding (2019)



## Black, Asian and Minority Ethnic Communities Advisory Group

In October 2020 Black, Asian and Minority Ethnic Communities Advisory Group, were established to make recommendations to feed into the work of the Social Care Sector COVID-19 Support Taskforce.

#### Their findings included:

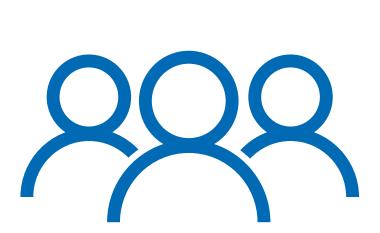
- During the pandemic 'social distancing' caused difficulties within a cultural context; this
  included mourning and grieving in a culturally appropriate manner.
- Information was not translated and what was available was usually online, adding another barrier to access
- There was a lack of services and for multi-generational carers
- Service users and carers could not obtain PPE, including culturally appropriate equipment.
   They also did not know where to seek advice if the person that were caring for contracted COVID-19.
- Participants indicated a strong believe that they experienced differential treatment in social care because of their 'race'. For some, the pandemic 'magnified' existing differences
- Examples included appointments being cancelled without explanation and 'struggling' to have their symptoms taken seriously by professionals.



In our culture we support each other, we visit family, but we were not allowed to do that, that was very difficult...it was isolating and lonely...so difficult.

- Black, Asian and Minority Ethnic Communities Advisory Group member





They identified that good practice occurred where a member of the community, sometimes a faith leader, or an organisation, acted as a 'trusted person' to:

- 'filter' and signpost people to sources of information
- translate guidance and other information
- act as an advocate to breakthrough barriers to access
- support people during bereavement by 'translating' guidance on funerals into cultural practices.



The home is open to people of all religions or no religion. One nun is employed and many older people feel safer and more comfortable with her around. The home feels spiritual, and both residents and staff can go to Mass every Sunday. Mass is in Polish and English. During COVID-19, it was a comfort for people to go to the Catholic chapel on site and have the pictures of the people who died there.

- Antokol, South East London, CQC rating: Good





A Minister, priest or nun spend time with our Polish residents at their end of life, as this is part of their religion and culture. We light a candle, sing, and we accompany every resident in their last days and pray for them. The Priest will give the sacrament of the sick and anoint the person with oil.

- Antokol, South East London, CQC rating: Good



Service users and carers from ethnic minority background and groups involved in the consultation suggested the following action points for the government:

- 'Myth-busting' about the stigma that BAME people are 'super-spreaders'
- Training of health and social care staff about how institutional discrimination within health and care services operate
- Public information campaign explaining to BAME communities the conditions under which they have rights to care and support
- Provision of culturally appropriate services
- Provide priority slots in hospital and GP appointments for older people and carers from BAME communities with specific cultural and religious needs
- A helpline with options for languages that people can access for information about services
- The NHS 'one size fits all' health screening should be adjusted so that where BAME communities experience certain conditions earlier, for example higher rates of high blood pressure and diabetes, they can access screening
- Require hospital and care homes to add vitamin D for BAME residents following regular blood tests.

To read the full report and recommendations, please click here.

## A's story



'A' is Jamaican and a Christian, and lives in a small residential care home with other adults with learning disabilities.

Prior to the pandemic, 'A's' mother would visit every Saturday. She would cook food for 'A's' lunch and dinner, and they would eat together.

Once the pandemic hit, 'A' and her mother had to self-isolate as much as possible. They were both deemed to be clinically vulnerable, and therefore face to face visits had to stop.

To support them to stay connected, we supported 'A' to call her mother every Saturday and on special occasions such as Mother's Day, Christmas and birthdays. 'A' was always very happy after talking to her mum. Her mood would be lifted, particularly as she was missing her mother so much.

'A' would usually have traditional Jamaican food with her mother, therefore we continued this on Saturday's so she wouldn't miss out. During the second lockdown, 'A's' mother would sometimes cook her traditional food, and have it delivered by another family member; 'A' really enjoyed these meals.

These small things made a huge difference in the lives of 'A' and her mother in a time which was tough and lonely for everyone. It was also uplifting for the staff as we felt that we are making the lives of our clients better.

We learnt a great deal from the pandemic, we had the chance to experience cultures on a deeper level than previously, and help clients to live their culture and tradition in the absence of their loved ones.

As staff, we learnt that going the extra mile makes a huge difference and that the small details in taking care of clients' cultural and religious needs, and making their families feel involved, even from a distance, makes them feel included, valued and happier.

Apasen, East London CQC Rating: Good (2019)

## Supporting people with dementia

#### Learning disability and dementia

Compared to the rest of the population, people with learning disabilities are at greater risk of developing dementia at a younger age.

One in three people with Down's Syndrome develop dementia in their 50s.

They may experience a more rapid progression of dementia.

They may take longer to receive a diagnosis of dementia due to the communication difficulties they may already have.

## Black, Asian and minority ethnic communities and dementia

In the general UK population, 3 per cent of people with dementia are from black, Asian and ethnic minority communities; around 25,000 people.

This number is expected to double by 2026 with the steepest increase expected in South Asian communities.

Research suggests these communities often face delays in dementia diagnosis and barriers in accessing services.

(Alzheimer's Society)

In 2013, an All-Party Parliamentary Group on Dementia produced a report 'Dementia does not discriminate: The experience of black, Asian and minority ethnic communities'.

The report highlighted that it is likely that dementia is more common among Asian and Black Caribbean communities.

This is because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common among these communities.

The report also highlighted that some support is not appropriate and does not address needs relating to faith or culture.

Families can be reluctant to use some services and try to carry on alone.

## Dementia and diversity - A guide for leaders and managers

In 2016, Skills for Care produced a guide for leaders and managers on dementia and diversity.

#### The guide highlighted:

- There may be a stigma connected with dementia and diagnosis in some cultures/communities.
- Some languages and cultures do not recognise dementia research has found that simple explanations are the best way to manage this.
- People may be more reluctant to access advice and services sensitive communication will be needed.
- Some events may have a significance for some cultures. Examples may include the Holocaust for people of Jewish faith. It's also important to note other events of significance, such as the Windrush scandal for people from Caribbean countries; genocides in many countries; and so on.
- As the dementia progresses, people will regress to a previous time/times in their life. If this was in a different culture, country or language, this is likely to have a profound impact.
- It is particularly important to engage family and friends in finding out as much information as possible. It could also be useful to research the persons culture, country, etc so as to be better informed.



We support a couple where the woman is Polish and has severe dementia but physically well. Her husband is English and 15 years older, mentally well but physically frail. She helps him to walk, and he guides her as she gets confused, so they compensate for each other. He has moved there to be with her to the end. He finds it hard to cope with her dementia and different behaviour, so the team ensure he can spend time with his sons. She often speaks in her mother tongue, which is hard for her husband as he doesn't have a lot of Polish. We have staff who speak Polish and English and we have a Polish speaking GP.

- Antokol, South East London, CQC rating: Good





We used to care for an elderly Catholic priest who had severe dementia. We recognised how his identity as a priest was very important to him so he would concelebrate Mass with the priest. At bed time, he used to go around and give everyone the sign of the cross.

- Antokol, South East London, CQC rating: Good



## Supporting relationships and people who are LGBT+

Many people who receive support are deprived of the opportunity to develop their sexual identity, expression, and relationships, or enjoy family life in the same way as anyone else.

#### Barriers can include:

- Staff lack of knowledge about the law and people's rights
- Staff or family personal, cultural or religious beliefs
- Shared accommodation and lack of privacy

These barriers can increase for someone who is LGBT+

The COVID-19 pandemic has placed further barriers in the way of people finding and maintaining friendships and relationships.

#### Legislation

#### **Human Rights Act 1998**

- Supported by the Mental Capacity Act 2005 and the right to make decisions, people with learning disabilities and autism have the same rights as anyone else under the Human Rights Act 1998, including:
- **Article 8** Right to a private and family life (including decisions about your appearance, your relationships, and your sexual orientation)
- Article 9 Freedom of thought, belief, and religion (the right to choose and change your beliefs, including your beliefs about sexuality, sexual and gender identity, and relationships)
- Article 12 Right to marry and have a family

#### **Mental Capacity Act 2005**

- The Mental Capacity Act is intended to both empower and protect everyone, including people with learning disabilities and/or autism.
- From the age of 18 (or from 16 years in the case of sexual intercourse and medical consent) people with a learning disability and/or autism have the right to make their own decisions.
- This right includes deciding to engage in lawful consensual sexual activity and is only constrained where a person is assessed under the Mental Capacity Act 2005 as lacking the capacity to consent.



I know people who are autistic who are either gay or lesbian and they are well supported. Staff shouldn't be stereotyping people

- Workforce Expert Advisory Group member



#### Promoting sexual safety through empowerment

CQC have produced a report which aims to raise awareness of issues of sexual safety and sexuality in adult social care.

It looks at how people using services are kept safe from sexual incidents, and how they are supported to express their sexuality.

A person-centred approach to care, which considers people's holistic needs, will include an understanding of a person's sexual identity and how they should be supported to appropriately express their sexuality in a way that supports and empowers them and protects them from harm.

The report identifies principles of good practice:

#### **Principles of good practice**

- Leaders should promote a culture of openness that allows people to both discuss issues
  of sexuality and raise issues of sexual safety, as part of a holistic approach to good person-centred care.
- People receiving adult social care are entitled to the same human rights as anyone else, and should be afforded the same dignity, choice, family life, privacy and respect, and should be able to feel safe from sexual harm.
- People who use services should be central to conversations about their needs and choices. Where seen as supportive and agreed to, family members, carers and advocates can also be included.
- Assessments should include information about people's sexuality needs (including current relationships, sexual orientation and understanding of sexual health, where appropriate).
- Care plans should accurately reflect these assessments and note the needs and wishes of people.
- Training should include supporting staff to have informal, everyday conversations about sexuality and sexual safety.
- Recruitment and organisational values should have a human rights focus.
- Providers should work with relevant community groups to give staff and people who use services support and access to information on sexual safety and sexuality.

Read the full report: CQC report – 'Promoting sexual safety through empowerment



Think about places to go. Where people who are LGBTQ+ can go, where they feel safe.

- Workforce Expert Advisory Group member





Staff must respect people's personal preferences, lifestyle and care choices.

People must be supported to maintain relationships that are important to them while they are receiving care and treatment.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 10: Dignity and respect

#### Supporting people who are LGBT+

Age UK have produced a resource pack for professionals on meeting the needs of older lesbian, gay, bisexual and transgender people using health and social care services.

The resource highlights why being LGBT continues to be important in terms of person-centred care and support.

This resource was written with older people in mind, however it can be a useful resource when supporting anyone who is LGBT+.

The report highlights that:

- Homosexuality was illegal till 1967 so many people lived in fear of being caught, losing their jobs and even their families.
- Being lesbian, gay, bisexual or trans is about more than your sex life or whether you are in a relationship or not.
- It shapes the way you have experienced life, your interests, likes, dislikes, humour, family, friendships and attitudes. It might also inform the books you read, films you watch and music you enjoy.
- If someone is black, Asian or from another minority ethnic community, they may have a different experience of being older and LGBT and face different challenges because of their culture or faith.
- A positive approach to LGBT service users also offers reassurance to LGBT colleagues who may be anxious about being open about their sexual orientation or gender identity in the workplace. Being a progressive and sensitive service provider is also a step towards being a good employer.

View the resource pack: 'Safe to be me'



I don't want people trying to change me, I know who I am, I know whom I'm attracted to.

I'm out and I'm proud, I've nothing to hide.

- Workforce Expert Advisory Group member





The motto is, the only thing that matters is how you are as a person: background, religion or sexual gender doesn't matter.

- Workforce Expert Advisory Group



#### **LGBT+ terminology**

Terminology evolves continuously so the best advice when working in a person-centered way is to **ask** the person which term they prefer.

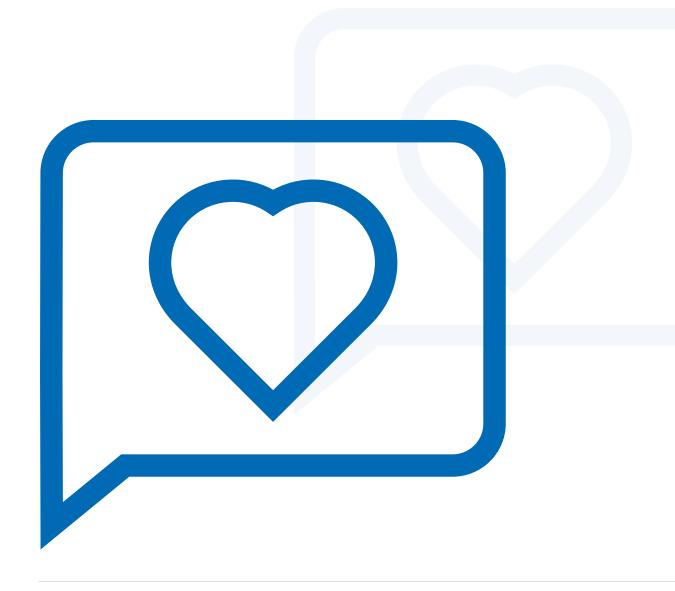
The use of inclusive language must always be considered. The acronym LGBT+ may not be fully understood by some individuals and an easy read guide may be helpful. We have included various guides and easy read information in the resource list.

Here is a quick guide to some terms that may be preferred (non-exhaustive list).

Lesbian	Refers to a woman who has a romantic and/or sexual orientation towards women. Some non-binary people may also identify with this term.
Gay	Refers to a man who has a romantic and/or sexual orientation towards men. Also a generic term for lesbian and gay sexuality - some women define themselves as gay rather than lesbian. Some non-binary people may also identify with this term.
Trans	An umbrella term to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth.  Trans people may describe themselves using one or more of a wide variety of terms, including (but not limited to) transgender, transsexual, gender-queer (GQ), gender-fluid, non-binary, gender-variant, crossdresser, genderless, bi-gender, trans man, trans woman.
Transsexual	This was used in the past as a more medical term (similarly to homosexual) to refer to someone whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth.  This term is still used by some although many people prefer the term trans or transgender.
Non-binary	An umbrella term for people whose gender identity doesn't sit comfortably with 'man' or 'woman'. Non-binary identities are varied and can include people who identify with some aspects of binary identities, while others reject them entirely.
Ві	Bi is an umbrella term used to describe a romantic and/or sexual orientation towards more than one gender.
Hetrosexual/ Straight	Refers to a man who has a romantic and/or sexual orientation towards women or to a woman who has a romantic and/or sexual orientation towards men.
Cisgender	Someone whose gender identity is the same as the sex they were assigned at birth. Non-trans is also used by some people.
Pan	Refers to a person whose romantic and/or sexual attraction towards others is not limited by sex or gender.
Queer	Queer is a term used by those wanting to reject specific labels of romantic orientation, sexual orientation and/or gender identity. It can also be a way of rejecting the perceived norms of the LGBT community (racism, sizeism, ableism etc). Although some LGBT people view the word as a slur, it was reclaimed in the late 80s by the queer community who have embraced it.

	Acronyms
LGBT	Lesbian, Gay, Bisexual, Transgender
LGBTI	Lesbian, Gay, Bisexual, Transgender, Intersex
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning
LGBT+	The + is to be inclusive to everyone that feels part of the LGBTQ+ community but don't feel like they fit into the groups listed in LGBTQ.
FTM	Female to male transsexual person; a trans man.
MTF	Male to female transsexual person; a trans woman.

Source: www.stonewall.org.uk/help-advice



#### Supporting people who are transgender

The Equality and Human Rights Commission produced a guide to explain your rights to equality under the Equality Act 2010. The guide includes the rights of a person who is transgender when accessing health or social care.

#### Equality rights for a person who is transgender

- A healthcare or social care provider which is providing separate services or single-sex services must not exclude a transgender person from the services appropriate to the sex in which the transgender person presents (as opposed to the sex recorded at birth) unless they can objectively justify this.
- Where a transgender person is visually and for all practical purposes indistinguishable from someone of their preferred gender, they should normally be treated according to their acquired gender unless there are strong reasons not to do so.
- Healthcare and social care service providers need to be aware that transgender people may need access to services relating to their birth sex which are otherwise provided only to people of that sex. For example, a transgender man may need access to breast screening or gynaecological services.
- In order to protect the privacy of all users, it is recommended that the service provider should discuss with any transgender service users the best way to enable them to have access to the service.
- A service provider may have a policy about providing its service to transgender users, but this policy must still be applied on a case-by-case basis.
- It is necessary to balance the needs of the transgender person for the service, and the disadvantage to them if they are refused access to it, against the needs of other users, and any disadvantage to them, if the transgender person is allowed access.
- This may require discussion with other service users (maintaining confidentiality for the transgender service user). Care should be taken in each case to avoid a decision based on ignorance or prejudice.

The full guidance can be found on the Equality and Human Rights Commission website here.

#### **Pronouns**

- Using the appropriate pronouns when talking to someone who is transgender works on the basis of respect for the individual.
- Generally the name the person chooses to use indicates their gender preference. So, a transgender person called Steve would be referred to as "he", while another called Rachel would be "she".
- If you are unsure, it's best to ask the person politely how they wish to be known.
- This is especially so if you suspect someone identifies as non-binary, in which case a neutral term like "they" may be more appropriate.

## **His story**



Our service supported a person who is transgender, he liked to be referred to as 'he,' 'him' and 'his'. Every morning he would choose to wear his jeans or a short dress with tights and boots.

As a service, we observed one incident of unconscious bias where a staff member was encouraging him to "put on something warmer" before going into town.

We talked to the staff member, questioning their suggestion about wearing something warmer. They explained that were worried about other people's reactions upsetting the client if he had unwanted attention in the community. The concern was well-intended but was not supporting the client to be who he wanted to be.

He was accepted by other clients without prejudice and was supported to shop for female clothing as he wished. He planned his leaving party and bought a fabulous dress that he enjoyed wearing before leaving our temporary service.

Learning Disability Service, East Sussex County Council

#### **Example from CQC regulatory work and engagement**

Support for a transsexual woman at a supported living provider

M is a transsexual woman with learning needs.

She is not able to go back to her family home and has no contact with her dad and minimal contact with her mum. Her nan is the most involved and supportive member of the family.

She is currently transitioning and was unhappy with the lack of support in her original supported living placement.

M's new supported living provider embraced her choice to dress and act as a woman.

They worked with the specialist sexual health nurse to support her to investigate a surgical and medical intervention to transition to her preferred gender.

This is progressing slowly as her clinic needs to see that M is consistent in her behaviour and decisions. In the meantime, M has grown in confidence and has taken on a job with the local police.

#### Provision of separate or single sex services

There has been debate about the rights of transgender people and there is a range of views as to how society can best balance the needs of different groups.

Much of the debate has focused on access to women-only spaces such as toilets, changing rooms, domestic violence refuges and prisons.

The Equality and Human Rights Commission have produced a guide for service providers (anyone who provides goods, facilities or services to the public) who are looking to establish and operate a separate or single-sex service.

For more information click here:

<u>Separate and single-sex service providers: a guide on the Equality Act sex and gender reassignment provisions | Equality and Human Rights Commission (equality human rights.com)</u>

#### **Support planning**

The Age UK resource pack 'Safe to be me' highlights the importance of considering a person's sexuality when care planning, stating 'A care plan that neglects to include this huge part of a person's individuality is incomplete and is likely to fall short of meeting that person's needs'. They provide the following examples:

- "George would like to have his subscription to Gay Times continued. He enjoys having some of the articles read out to him. He likes going through the 'personal ads' column thinking about who he might like to contact."
- "Rosaria would like to go out to a local gay pub with three of her closest female friends on a monthly basis."
- "Eric still enjoys a sexual relationship with his boyfriend Charles and so when there is a 'Do not disturb' sign on the door, this should be strictly respected."

#### Good practice example

Example from CQC regulatory work and engagement

An older man lived in a care home. He had a photo on his table, which had been taken when he was younger and in the armed forces.

The photo showed another man. His care worker realised it might have some significance and asked him gently about the picture.

Over time the gentleman felt increasingly able to open up and talk about his relationship with the man in the photo.

He had never told his family about it and had kept it a secret for his whole life. Only in the care home was he finally able to talk openly about his sexual orientation, thanks to the relationship and trust built with the care worker.



Assessments of people's care and treatment needs should include all their needs, including health, personal care, emotional, social, cultural, religious and spiritual needs.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 9: Person-centred care

#### Supporting older lesbian, gay and bisexual people

Stonewall have been campaigning as part of a global movement since 1989 and have helped create transformative change in the lives of LGBTQ+ people across communities in the UK.

Stonewall commissioned YouGov to survey a sample of 1,050 heterosexual and 1,036 lesbian, gay and bisexual people over the age of 55 across Britain.

The survey asked about their experiences and expectations of getting older and examined their personal support structures, family connections and living arrangements.

#### The survey showed that lesbian, gay and bisexual people over 55 are:

- more likely to be single
- more likely to live alone
- less likely to have children
- less likely to see biological family members on a regular basis
- more likely to be estranged from their biological family compared to heterosexual people often because their biological family do not approve of their sexual orientation.

#### The Stonewall older people report outlines:

- Care and support staff should never assume a patient's sexual orientation.
- Care and support staff should not discuss their personal views about lesbian, gay and bisexual people or issues.
- Care and support staff should use open questions to encourage service users to be open about their sexual orientation and needs.
- Care and support staff should provide information to patients on opportunities for them to engage with other lesbian, gay and bisexual people socially.

#### Stonewall recommends:

- Care homes should apply the same polices and procedures to same-sex couples wanting to live together in care homes as heterosexual couples.
- Same-sex couples should be allowed private time or allowed to show affection for one another as is the case for heterosexual couples.
- Care homes should develop clear policies on what is acceptable and unacceptable behaviour from patients. Care homes should deal firmly but sensitively with incidents of homophobia from patients.
- Staff should be trained to understand the needs and circumstances of older lesbian, gay and bisexual patients and how to provide them with good quality care.
- Lesbian, gay and bisexual residents should be supported to access opportunities to socialise and meet other lesbian, gay and bisexual people to help them maintain social support networks.
- Care home staff should ensure older lesbian, gay and bisexual people have stipulated who should be given decision making power in the event that they are unable to make decisions about their care for themselves.
- Care homes should make their environments more welcoming by displaying images, posters and materials that reflect lesbian, gay and bisexual people.

## Regional cultures and traditions

#### **Accents and dialects**

The Workforce Expert Advisory Group raised important points about cultural variations in the UK, including different accents, dialects and food preferences.

Each person's accent and dialect can be a source of great pride and an important expression of cultural identity.

Other people can use this information to help work out where we are from and may say things like "Are you a northerner?" or "You sound like you're a southerner".

Even in a small country like England, there's a range of words for the same thing. For example:

What do you call a narrow walkway between two buildings? Alley, alleyway, twitten, ginnel, gennel, snicket, vennel, eight-foot.

What do you call potatoes? Potatoes, spuds, tatties, chips.

What do you call a baby/child? Babby, bairn, nipper, infant, kiddie, tot, pickney.





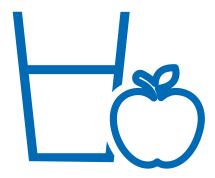
Understand the local accents and dialects of people. This is especially important if people are placed away from their local area or making it more important that people aren't moved away.

- Workforce Expert Advisory Group member



#### Labelling

Labels for people of different regional origins are often used, for example, in the UK, 'Geordie', 'Cockney', 'Jock', 'Taffy', 'Paddy' or 'Scouse' depending on what you sound like when you speak. These terms are seen as offensive to some people, so it's important to be mindful of this.



#### Regional food and drink

Some foods are closely related to certain regions, although may still be eaten and enjoyed in all areas of the country.

We all have our favourite food and some food can be closely related to our background or area we come from.

Food can bring back memories, some good, some bad. The taste, smell and texture of food can bring back memories of not just eating food but also a place or setting, such as school.

Even in a small area like the UK, there is a lot of variation in food.

Cock-a-Leekie	Scottish soup or stew. It combines beef, chicken, leeks, and prunes.
Irish Stew	Irish stew always has a common base of lamb, potatoes, and onion. It could contain any number of other ingredients, depending on the cook.
Yorkshire puddings	Traditionally eaten in Yorkshire as a starter with gravy; the idea was to fill you up before your roast dinner.
Parmo	North Yorkshire/ Teesside- meat covered in breadcrumbs, and deep-fried. Topped with béchamel sauce and melted cheese, served with chips and salad.
Staffordshire oatcake	North Staffordshire- made from oatmeal, flour and yeast to make a batter, which is then fried.
Cornish pasty	Cornwall- pasty with filling of beef, potato, onion and swede, which when cooked together forms a rich gravy.



Where food and/or drink are provided for people who use services, they must have a choice that meets their needs and preferences as far as is reasonably practical.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 9: Person Centred Care

#### Don't make assumptions!

Be mindful not to make assumptions about food someone likes because of where they are from, whether that is regional foods from the UK or from another area of the world. Everyone has different tastes so make every effort to find out what individuals' preferences are.

Involve people as far as possible in shopping for food, meal planning and food preparation. Talk about food likes and dislikes and involve family and friends where necessary.





We support an Irish woman who enjoys potatoes every day.

- Antokol, South East London, CQC rating: Good





Your care plan should include food habits and preferences.

- Workforce Expert Advisory Group member





Our Polish residents prefer to have their main meal in the middle of the day, and a light evening meal. The UK residents prefer it the other way around, so we accommodate that.

- Antokol, South East London, CQC rating: Good



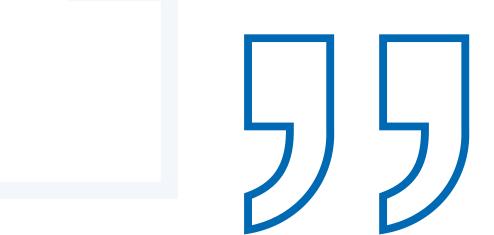


'A' is a black Caribbean woman who enjoys food such as rice and peas, plantain and fried eggs for breakfast, cabbage with sweet pepper and onion steamed together.

On Sundays, she enjoys a roast dinner with everyone else in the house, and it's a nice social occasion.

- Aurora-Nexus, South East London CQC rating: Outstanding (2019)







My son is autistic and the last place he would want to go is a pub. There is an assumption that everyone would want to go to places like that.

- Workforce Expert Advisory Group member





'B' goes to the Caribbean takeaway every Wednesday and has got to know the Jamaican owner.

At home, Caribbean food is also on his menu. He enjoys rice and peas, curried goat, stewed chicken, akee and salt fish with yams or potatoes.

- Aurora-Nexus, South East London, CQC rating: Outstanding (2019)





People should be able to make choices about their diet.

People's religious and cultural needs must be identified in their nutrition and hydration assessment, and these needs must be met. If there are any clinical contraindications or risks posed because of any of these requirements, these should be discussed with the person, to allow them to make informed choices about their requirements.

When a person has specific dietary requirements relating to moral or ethical beliefs, such as vegetarianism, these requirements must be fully considered and met. Every effort should be made to meet people's preferences, including preference about what time meals are served, where they are served and the quantity.

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 14: Meeting nutritional and hydration needs

### Resources



#### **Training Resources**

Three sample training sessions have been designed by ESCC Adult Social Care Training Team, for services that support people with a learning disability and/or autism and dementia. They may also be useful for family carers and personal assistants.

They include session plans, PowerPoints, activities and facilitator notes. You can adapt and build on the content to tailor it to your organisation and the people you support.

Cultural awareness is a wide topic, therefore for the purpose of this framework, we have focused on the following areas:

- Stereotyping
- Supporting individuals from ethnic minorities and backgrounds
- Supporting relationships and people who are LGBT+

You can deliver these as training sessions or print and use them as an information pack and activities along with this framework; it is important that the trainer or facilitator has a good understanding of person-centred approaches.

#### **Resources list**

There are many sources of information online regarding culturally appropriate care, including CQC and government guidance, information, easy read documents and YouTube videos.

We've collated a selection of these in one document, with a brief overview and link, using the following headings:

- General information
- Supporting people from ethnic minority groups and backgrounds
- Sexuality and relationships
- Learning disability / autism
- Older people; Dementia
- Life stories

**Please note:** We are unable to guarantee the accuracy / content of these documents. Also due to the changing nature of terminology and guidance, some information may go out of date. Some documents have been produced for local areas and include support phone numbers; these may only be relevant if you are living in that area, but other information contained in the documents may be helpful.

## **Acknowledgements**

East Sussex County Council (ESCC), Adult Social Care Training Team, funded by Skills for Care, have developed this framework along with sample training sessions and an additional resource list.

Thank you to the Workforce Expert Advisory Group who support Skills for Care, Health Education England and NHS England with workforce development. Their valuable quotations and insight into what culturally appropriate care means to them, have been used throughout this framework.

Skills for Care are also pleased to thank the following organisations who contributed to this guide:

- Learning disability services, ESCC
- Apasen, East London
- Aurora-Nexus, South East London
- Support to Lead, Oldham
- Antokol Care Home, South East London

In this framework, we have also referenced valuable work undertaken by:

- Care Quality Commission
- Think Local Act Personal
- Black, Asian and Minority Ethnic Communities Advisory Group
- Alzheimer's Society
- National Autistic Society
- All-Party Parliamentary Group on Dementia
- Age UK
- Stonewall
- The Equality and Human Rights Commission
- Mencap
- Mind
- Mental Health Foundation
- Social Care Institute for Excellence (SCIE)