Tailoring the Care Certificate: Services for people with a learning disability
The Care Certificate was introduced in 2015 and was developed as a result of the Cavendish Review. The aim was to ensure that all social care and healthcare workers will have a set of knowledge and behaviours that will ensure that they are caring, compassionate and competent in their work.

After five years it was felt that it would support workers completing the Care Certificate if they could contextualise the content of the standards to make them more applicable to specific areas of work within the sector. As a result, the initial four areas of work that have been contextualised are, Learning Disability, Mental Health, Dementia and Lone Working.

These resources are not mandatory and are designed to enhance and support the workbooks. The resources are not stand alone and are recommended for workers who are either new to social care or who are new to this particular area of social care.

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Standard 1: understanding your role

There is a vast network of people and services available to support people with a learning disability and to help promote their independence.

These may include:

- Family and loved ones
- GP
- Learning disability nurse
- Neurologist
- Speech and language therapist
- Social worker
- Physiotherapist
- Occupational therapist
- Advocate
- Housing officer
- Employment teams
- Social groups
- Self-advocacy groups

You will need to be aware of all individual relationships for the person and understand your role within the network to ensure the best outcomes for the individuals you are supporting. The different services, roles and responsibilities may be confusing for the person you are supporting, so part of your role will be helping them to understand these relationships and communicating clearly and professionally with the person and those involved.

Advocacy services are used across all services in social care but learning disability services make particular use of them to help people with learning disabilities ensure their voices are heard.

Example

You are a link worker for Lawrence and are working with him on developing his care and support plan. To ensure Lawrence can fully express his ideas, needs and opinions, you suggest involving an advocacy service, which he agrees to. You meet with him and his advocate regularly over the next few months to identify what is important to him and how he wants to be supported. His advocate is crucial in enabling him to articulate this. Together, you also discuss and agree how he would like his family to be involved in his support and in contributing to his care plan. Through effective partnership working, he now has a care and support plan that he has designed and is in control of.
Many people with a learning disability still experience discrimination. This can be direct or indirect:

- A person wanting to eat in the café however being asked to take their food away to eat
- An activity centre stating in their admission policy that only those in good health can use the facilities
- A hairdresser refusing to book an appointment in the salon for the person you support
- A bus driver refusing access to the transport as the person uses a mobility aid
- A person being told they do not have opportunity to vote as they cannot complete the voting form
- A local college stating a course is not suitable for all people with disabilities

**Activity:**

Are these examples direct or indirect examples of discrimination? Can you think of any other examples of discrimination people may face?

You need to be able to recognise if or when someone you are supporting is discriminated against and know how to challenge discrimination. You will need to remember that the person you are supporting may or may not want you to challenge it, may want to challenge it themselves, and should be offered access to independent advocacy to support them when appropriate.
Case Study: Promoting diversity, equality and inclusion

Joan enjoys eating out and is really interested in food. The service you work in organises regular cooking sessions for people, but Joan never gets involved. You talk to her and to your co-workers about why this is. It transpires that she would like to take part, but that co-workers haven’t been encouraging her to do so because her learning disability means she has limited communication skills and limited mobility. They could be considered to have been unintentionally discriminating against her.

You agree with your co-workers that, if she wants to join in cooking sessions, the activities will be broken down into short, safe manageable tasks in which she can participate and be involved. She gets to touch, feel and smell the different ingredients, along with holding the mixing spoon and gets to taste the food once cooked. You have taken action to actively involve her and promote her independence whilst ensuring she is not discriminated against.

Hate Crime and Hate Incidents:
A hate crime is a criminal offence, such as assault, fraud, or harassment that is considered by the victim, or someone else, to be motivated by:

- Disability
- Race
- Religion
- Transgender identity
- Sexual orientation

People with a learning disability are at particular risk of hate crime and you should be aware of local reporting procedures. You can report Hate Crime through the True Vision website and access support from your local Citizens Advice Bureau.

Mate Crime:
Mate crime occurs when someone, who appears to be a friend, takes advantage of a vulnerable person, for instance by asking for money, expecting to be bought things, or puts pressure on a vulnerable person to do something they don’t want to. People with a learning disability are at particular risk of mate crime. They may not recognise they are a victim or may not feel able to speak up if someone they consider to be a friend is intimidating them.
Understanding the individual is key to providing person-centred care. You'll need to learn about, and understand, what makes the people you support unique, as well as understanding their learning disability and associated symptoms.

Understanding someone’s past is vital in understanding their present and supporting them plan for their future.

**Example**

Jacob lived in a large hospital institution until a few years ago when he moved into support accommodation. Jacob initially became distressed and anxious at mealtimes and the staff team involved found it difficult to support him during these periods.

By talking to those close to Jacob, the staff team established how difficult mealtimes were for him when he lived in the large institution. His food would often be taken by others and wouldn’t be replaced.

The staff team have now been able to support Jacob and agree a person-centred approach to his support at mealtimes. This is having a positive impact and there are less frequent periods where Jacob is distressed and anxious.

Group living environments can make providing person-centred care more challenging as people’s behaviours, preferences and choices impact on everyone in the residence. You should be aware of how changes, people, noise and situations may affect people differently and be on the lookout for subtle, or overt, indications of changes in behaviour and mood as a result of group living.
Identity

Our identity is what makes us unique and is our sense of who we are. It encompasses personality, spirituality, sexuality, values and culture and is built from our beliefs and experiences.

The people you’re supporting may not have fully formed their own personal identity yet. Finding and understanding your identity can take time and experimentation – often, but not always, through adolescence and early adulthood. This can be a confusing, and perhaps scary, time. It’s vital that people with a learning disability are supported to explore and develop their own identity as it’s so closely linked to self-esteem and self-worth. People with a learning disability may be more at risk of losing, or not forming, their identity; perhaps because those around them are trying to protect them, perhaps their need to express themselves in a different way hasn’t been recognised or promoted, or perhaps they want to ‘fit in’ with the people around them.

Activity:

Joe is 20 years old. He lived with his parents until recently when he moved into supported-living accommodation. Soon after he moved in, he started to wear nail varnish and wanted to go shopping for female clothing. His parents are upset and have told staff they don’t want him to do this.

As part of Joe’s support team, what do you do?
Communicating with the person accessing care is an essential part of delivering person-centred care. People with a learning disability may experience barriers when communicating with others. For instance, others may:

- assume the person doesn’t have capacity to communicate
- not understand and react appropriately to the way a person communicates
- use complex language or talk too quickly
- not understand or react appropriately to any cognitive impairment a person may have that inhibits their ability to understand a message.

When communicating with someone with a learning disability, you may need to use additional communication techniques to ensure you both fully understand each other, such as:

- ensuring language is straightforward and use the person’s preferred communication method e.g. Makaton
- checking your understanding of what the person is telling you, and their understanding of what you’re telling them
- asking others close to the person to help you learn to understand them better
- using body language and facial expressions to emphasise what you’re saying or to check your understanding of what someone else is telling you
- being aware of any associated conditions that may further impact the way someone communicates, such as autism or cerebral palsy
- using communication aids.

Various communication aids and technologies are available to support people with a learning disability. The use of these should suit the preferences of the individual accessing care and support. Some examples include:

- signs/symbols
- photographs
- objects of reference
- easy read systems
- Picture Exchange Communication System (PECS)
- photo or word boards
- passports/books
- talking mats
An object of reference is something which signifies to the individual the next step, an activity or a choice. Objects of reference should be relevant to the individual, and different people may use different objects of reference to signify the same activity. For instance, one person’s object of reference for going outside might be their house keys whereas someone else’s reference might be their coat.

Activity:

Jenny has a learning disability and has considerable difficulties communicating verbally. You’re trying to find out what Jenny would like for breakfast.

What barriers might Jenny be experiencing in communicating her preferences? How might you overcome these barriers and support Jenny to communicate her decision?
Standard 7: privacy and dignity

Promoting someone’s privacy, could also include respecting the person’s:

- own personal space and giving them space when they want or need it
- personal information
- right to have personal relationships, including sexual relationships, and supporting them to maintain those relationships.

It is important to recognise that all people are different. Some will seek a lot of privacy and time on their own, whereas others may want more company and to engage with other people.

Because some people with a learning disability also face barriers in communicating their needs, they may not be able to verbally tell you they want privacy. They may not be able to physically remove themselves from a situation, perhaps because of mobility issues or perhaps because of a lack of confidence. You will need to consider how you can recognise when someone needs to leave a situation or their need for privacy and support the person appropriately.

Sometimes the person you support may not have a clear understanding of personal privacy or be able to maintain privacy themselves so may need you support with this to not just promote their privacy but their dignity too. This might include:

- supporting the person with their personal care
- recognising their sexual needs
- advising on unsecure clothing
- encouraging the person to keep sensitive documents such as bank statements in a safe place
- discouraging the person from talking about personal information in front of others
- be aware of hidden or masked messages through the words used, for example, asking for their mother may be a desire for affection or comfort.
Dignity and independence

A key part of promoting someone's dignity is enabling the person to make their own choices and to be as independent as possible. To support someone to make their own, informed, choices you could provide up-to-date, accessible, information, and adopt a structured approach to discussion and decision making so that person can make the right choice for them, in an empowering way.

Example

Akio would like to be more independent when using public transport and doesn’t want to always rely on a support worker. The two of you work together to create an independence plan that identifies any associated risks and ways to mitigate them and where and how he needs to gain confidence and understanding. This includes:

- Accessing bus and train timetables
- Learning the best routes to take
- Learning how to purchase tickets
- Knowing who to ask for help
- Knowing how to keep safe when out in the community

You should be aware of how your own personal views or experiences could restrict the choices of the person you are supporting or restrict their ability to actively participate in decision making.

Example

Ava is a residential care worker. She is supporting a group of people to plan and organise a holiday. In a previous job, she organised a holiday to Scarborough which everyone appeared to enjoy. She suggests this would be a good trip and encourages the group to book the same location. Ava thinks what she is doing is right because she believes the people, she is supporting will have a great holiday there. However, she is not encouraging them to share their own ideas, nor is she providing choices so that people can make an informed decision.
Standard 8: fluids and nutrition

You will play a role in supporting the person to choose and prepare balanced meals, but also need to keep in mind that people have the right to make unhealthy choices. In these situations, it’s your role to ensure the person has the information they need to make an informed decision providing they have the capacity to do so.

You could:

■ Help the person you’re supporting plan and cook healthy meals
■ Access information about buying and cooking health food to share with the person, including easy-read information
■ Avoid using food and drinks as ‘rewards’
■ Encourage the person to attend their annual health check
■ Ensure that assistive technology, such as adapted utensils or cooking equipment, is available and in working order

Additional health conditions:
People with a learning disability may have additional health conditions that affects their ability to eat and drink well or increase the level of support they need with regards to their diet.

For instance:
■ Diabetes: This can lead to heart disease or stroke, sore or infected feet, kidney problems, etc.
■ Constipation: The person may feel bloated and have stomach pain. Prolonged constipation can lead to faecal compaction
■ Dysphagia: Coughing or choking on food can lead to chest infections such as aspiration pneumonia

Additional support needs:
People with a learning disability may have additional support needs due to a specific diagnosis and again this may affect their ability to eat and drink well or increase the level of they support they need with regards to their diet.

For instance:
■ Prader-Willi syndrome: This is a genetic condition that can lead to constant hunger and an increased chance of type 2 diabetes
■ Down’s syndrome: This is a genetic condition that can lead to diet related issues such as heart issues, diabetes, food intolerances and constipation
■ Autism: This is a lifelong developmental disability. Many people experience sensory issues which affects sights, smells, texture and tastes. This can lead to the person eating only a limited range of food or others may overeat
**Dysphagia** is a difficulty with swallowing. Signs of dysphagia include coughing or choking when eating, bringing food back up and a ‘gurgling’ wet sounding voice when eating or drinking.

Other specialist workers are likely to be involved in supporting a person with a learning disability maintain or manage their health through fluids and nutrition. You must ensure you adhere to their advice which will be included in the person’s care and support plan, and make other workers aware of changes, risks or issues in line with procedures.

**Communication:**
Some people with a learning difficulty may face barriers in communicating (see Standard 6: communication). In relation to this standard, the person may not be able to express or understand their needs or wants in relation to food and drink, or in relation to their health. See standard 6 for ways you could help overcome this barrier.
People with learning disabilities experience inequalities in accessing health services and treatment, as well as inequalities in accessing jobs, housing and transport. This can all have a negative impact on someone’s wellbeing, quality of life and life expectancy. Working with and supporting a person with a learning disability means you’ll play a key role in reducing inequality and marginalisation and promoting social inclusion.

People with a learning disability may experience additional health issues that can impact on their quality of life and life expectancy. These include an increased risk of dementia for people with Down’s Syndrome and an increased risk of developing epilepsy. People with a learning disability are also at risk of ‘diagnostic overshadowing’.

**Diagnostic overshadowing** occurs when symptoms of a new illness or condition are overlooked or aren’t properly investigated because an assumption is made that the symptom is related to a person’s learning disability.

The five main causes of health issues experienced are:

- social risk: health is at risk due to a greater exposure to poverty, poor housing, discrimination, isolation and unemployment
- health risks associated with specific learning disabilities
- communication challenges and a lack of understanding about health issues
- health risks associated with poor diet and lack of exercise
- poor access to health and care services.

Support relating to the health of people with a learning disability is developing. There are current initiatives which include:

- annual health checks through the GP’s practice to help people stay well and detect any signs of ill health at an early stage
- STOMP (stopping over-medication of people with a learning disability) - a health campaign to stop the over-use of psychotropic medication to manage people’s behaviour and enables social care providers to assess their own practices
- the Learning Disabilities Mortality Review (LeDeR) which looks at why people with a learning disability die, to understand how to make improvements to health and care services.

It’s likely that your service will also have health action plans in place for the people you support with learning disabilities. These state what is needed for each individual to remain healthy.
A learning disability is a reduced intellectual ability and as a result may have difficulty with daily living activities. This contributes to the person being more vulnerable to abuse, harm or exploitation because they:

- may be dependent on others to provide care, such as personal care
- may not be able to recognise danger or when they may be at risk
- may not be able to communicate verbally
- may not have the confidence to speak up if they feel something is wrong
- may not be listened too or may not be taken seriously
- may be isolated in their community and their support network
- may be taken advantage of by people who they trust
- may spend time environments such as treatment and assessment units

Your role may therefore involve providing support to reduce the likelihood of abuse or neglect and encouraging the person to speak up if they are being abused, exploited or harmed.

Activity:

You work in a setting for people with learning disabilities. You notice that one of the people you support, Josie, goes out into town with her sister for very short periods of time on a regular basis. She has also frequently become anxious before meeting her sister. One day, you see her and her sister at a cash point and see her withdraw some money and give it to her sister. You think that she looks unhappy doing this and your initial thought is that she might be being financially abused.

Discuss with colleagues and your line manager what you would do next.

Consider:
- How your experiences and opinions might impact your interpretation of the event
- How you can safeguard individuals in the short and long term
- How you would find out more information
- Who you would need to share your concerns with
- What you would need to record and where
- What policy and procedures you need to follow

Provided by Learning Disability England
Organisational abuse:
Best practice, and current policy, dictates that people with a learning disability should be accommodated within the community, however many people still live in different environments such as hospitals or assessment and treatment units. This can make people with a learning disability particularly vulnerable to organisational abuse.

Organisational abuse occurs when an individual’s wellbeing is sacrificed for the smooth running of a service. Inadequate care and systematic poor practice affect the whole organisation and those accessing services. People with a learning disability are potentially more at risk of this kind of abuse because of some/all of the following factors:

■ Large, institutional, residential environments
■ Closed cultures
■ Restrictive shift patterns
■ Inadequate staff training
■ Restrictive practices

Sometimes, workers and organisations will not realise that their practice is restrictive. For instance, there might be restricted visiting hours, activities may stop at a certain time or someone’s mobility aid might be out of reach.

**Closed cultures** can arise wherever people may be less able to self-advocate (speak up for themselves) or are less likely to have their communication needs supported, this can place people more at risk of abuse and human rights breaches.

Whorlton Hall Hospital provided accommodation for people with a learning disability or Autism. In 2019, a BBC investigation exposed systematic abuse of the individuals accommodated there. People living there were mocked, intimidated and restrained by staff. The investigation reinforced how everyone involved in the care of people with a learning disability or autistic people has a role to play in identifying where abuse and human rights breaches may be taking place.
Credits:

This work was made possible through the involvement of the following organisations and people: