

'A' for Adjustment

Session 3 - 'A' for Approach – Supplementary Information

Guidance, advice and ideas for ensuring a positive, tailored, flexible and effective approach is offered to meet individual needs.

Attitude – A framework / opportunity for staff to explore their thinking about disability, learning disability, discrimination and rights

Adjusted Care – an introduction and overview of the Equality Act and the statutory duties including Reasonable Adjustments

Approach – Guidance, advice and ideas for ensuring a positive, tailored, flexible and effective approach is offered to meet individual needs

Assessment – A review of the common health problems associated with learning disabilities, what to look out for and tools that can help.

Actions – Guidance for staff on what to do and where to get help in response to individual needs and concerns; includes suggestions on how to improve future responses and follow up actions.

The Mental Capacity Act 2005

The Confidential Inquiry into premature deaths of people with a learning disability reported that “professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular regarding assessments of capacity and the processes of making ‘best interest’ decisions”. The Mental Capacity Act (2005) has a very simple framework with five key principles:

1. Assume the person has capacity unless you can prove otherwise.
2. Help people to make their own decision wherever possible.
3. People who have capacity are entitled to make decisions that other people may think are unwise.
4. When making decisions for people who have been assessed as lacking capacity, they must be made using the Best Interests decision making process.
5. Decisions made on behalf of people who cannot make their own decisions should be the least restrictive possible.

The Mental Capacity Act provides a four-stage assessment where people must consider whether the individual for whom the decision needs to be made can:

1. Understand the information
2. Retain this understanding for long enough to –
3. Weigh up the risks and benefits of the decision before –
4. Communicating the decision.

Decision making

Being unable to fulfil any stage of this process can indicate a lack of capacity to make the decision.

<https://www.ouh.nhs.uk/patient-guide/safeguarding/documents/health-workers-guide.pdf>

Decision making

Decision making is the process of choosing one from several options based on experience, values and ethics. This process can be broken down into seven stages:

1. Identification of the decision to be made.
2. Gathering information pertinent to the decision.
3. Identifying possible options.
4. Considering the evidence.
5. Choosing the option.
6. Taking action to implement the chosen option.
7. Review the decision.

Using a staged process like this can help to make informed, considered and deliberate decisions.

Capacity

Capacity

Having mental capacity means being able to make your own decisions. Staff in health and care will often have to assess a person's capacity to make decisions. The first of the key principles of the Mental Capacity Act 2005 is that **we must assume a person has capacity unless we can prove otherwise**, so capacity needs to be assessed every time a decision is needed; any assessment of capacity is date, time and decision specific.

If you need to assess a person's capacity to make a decision, the Mental Capacity Act 2005 requires a two-stage test of capacity:

1. Does the person have an impairment of mind or brain?
 - a. Is this impairment likely to be reversible with treatment?
 - b. Does this impairment mean the person is unable to make the decision for themselves?

If the person does have an impairment of mind or brain, you need to check the second stage of the test of capacity:

2. Can the person fulfill these four requirements?
 - a. **Can the person understand the information given to them?**
 - b. **Can they retain the information?**
 - c. **Can they weigh up the benefits versus risks involved in the decision making?**
 - d. **Can the person communicate what they choose?**

Supported decision making

Best interests decision making

Just because a person is autistic or has a learning disability doesn't automatically mean they can't make their own decisions, but they are likely to need additional support. It is also reasonable for a person with a learning disability or an autistic person to make a decision that other people may think is unwise.

Supported decision-making

Supported decision making under The Mental Capacity Act 2005 means people are helped to have capacity in a way that is meaningful to them, for example using pictures, symbols or audio prompts, involving others, for example family or carers who know the person well, or a British Sign Language interpreter, before any decision that they lack capacity is made.

Supported decision-making is about reducing or removing any barriers that could prevent a person from being able to make a decision for themselves; this is different to shared decision making which is when the person makes a decision in collaboration with others.

Best Interests decision making

Mental Capacity Act Code of Practice requires that the person most closely connected with the specific decision should assess the person's capacity to make that decision.

If the person is assessed as lacking capacity to make a particular decision after all practical steps have been taken without success, the principles of best interests must be followed, involving those who know the person well. The Best Interests decision making process includes:

- Involving the person even if they lack capacity
- Speaking with the people who know the person best e.g. family/ care staff
- Considering the least restrictive option
- Considering what the person may want if they were able to make the decision for themselves

Best interest decisions must be recorded using appropriate documentation, information should include:

- Options relating to the decision.
- Advantages and disadvantages of each option.
- All members of the best interests' decision meeting sign the plan.

Where there is disagreement about what would be in the person's best interests in relation to the decision to be made, and it is not possible to resolve this through discussion, there may need to be an application to the Court of Protection for an independent ruling on the decision.

	<p>An emergency application to the Court of Protection can be made if for a court order for a decision in a very serious situation and there's an immediate risk to the person.</p>
<p>Communi- cation</p>	<p>Communication is the exchange of information from one individual to another using methods that both can understand. This may be talking and listening, but also may include reading and writing, facial expressions, pictures, objects, vocalisations and behaviours. It is estimated that 50-90% of people with a learning disability also have difficulties with communication.</p> <p>Communication Tips and short video resources to help Go to https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability for top tips and more information about communicating with a person with a learning disability.</p> <p>This quick guide contains helpful information about how to communicate more effectively with an autistic person https://www.autism.org.uk/about/communication/communicating.aspx</p> <p>Go to this powerful video from the Too Much Information campaign by the National Autistic Society about sensory overload</p> <p>This video by CHANGE people includes helpful tips how better to communicating with people with disabilities https://www.youtube.com/watch?v=wuLAQOHFn2U</p> <p>Five Good Communication Standards</p> <p>The Royal College of Speech and Language Therapists 'Five Good Communication Standards' describes the reasonable adjustments to communication that should be made for people with a learning disability and/or autism (RCSLT, 2013).</p> <p>The document recognises the challenges people may have and gives advice about good communication and what should happen in order to facilitate good communication. It also provides information about where to find resources and a checklist for individuals and organisations to check the standards are being met.</p> <p>The five standards are:</p> <ol style="list-style-type: none"> 1. There is good information that tells people how best to communicate with me. 2. Staff help me to be involved in making decisions about my treatment, care and support. 3. Staff are good at supporting me with my communication. 4. I have lots of chances to communicate. 5. Staff help me to understand and communicate about my health.

Communication tools

Getting Communication Right

Many people (not just people with a learning disability) develop strategies to cover up embarrassment and misunderstanding. This may be acquiescence, nodding or repeating what others have said. It is not uncommon for people with a learning disability or autistic people to learn and repeat phrases or comments without fully understanding what they mean, which can give the impression of a higher level of understanding than they have. Echolalia is a condition in which an individual repeats a word or phrase over and over.

Effective communication not only relies on adequate levels of hearing and vision but also the ability to focus on which movements and sounds are relevant in the sensory information being received. Autistic people are more likely to experience sensory stimuli from the environment in a different way, sometimes having sensitivities to sound, light or touch.

When working with people with a learning disability or autistic people, it is essential to be aware of how we are communicating. Use simple, everyday words which are easier to understand and are usually words that people know. Use concepts that are easier to imagine. The meaning of some phrases may not be obvious, avoid sarcasm or phrases like 'it's raining cats and dogs' as these can be hard to understand.

It is always helpful for a speaker to provide as many clues as possible alongside their speech for a message to be understood. This can be an 'object of reference' such as a toothbrush or tablets.

Communication Tools

Earlier in this training we learnt how important it is to see and understand everyone as an individual – this is an important starting point with communication. Many people with learning disabilities will have a Communication Passport which describes effective communication for them. Some may be familiar with structured visual tools using pictures or symbols, either individual to them (a book of photo's of people, places, preferences etc.) or standardised approaches such as Picture Exchange Communication System (PECS) or 'Talking Mats; some may use simplified hand signing systems such as Makaton or Signalong.'. Technology based communication aids that can be operated using fingertip touch, head or limb movements, or tracking eye gaze to produce speech output from a computer are increasingly common. social stories are also an increasingly common approach which builds a story with pictures and/or objects of reference that features the person experiencing a particular situation such as a medical procedure or test.

It is always worth asking the person and those supporting them if there is anything you can do to improve your communication with them. There are things that will always help such as using short sentences, easy words, allowing time, breaking information down, reducing

Accessible Information Standard (AIS)

background noise and other distractions etc. having an awareness of such issues and working in such a way is sometimes referred to as 'Total Communication'

[The Hospital Communication Book](#) The book contains useful information about why people may have difficulties understanding or communicating. It has useful tips you can use to improve communication, and pages of pictures you can use to help you communicate.

Poster – how to support an autistic person

https://rcni.com/sites/rcni_nspace/files/Autism-poster.pdf

Accessible Information Standard 2016

In 2016, the government introduced the Accessible Information Standard (<https://www.england.nhs.uk/ourwork/accessibleinfo/>). This requires all publicly funded health and social care organisations to adapt their communication to effectively meet the needs of disabled people. Individual's specific needs should be identified and information tailored to make it accessible and understandable for them. Information may need to be produced in an easy read format, recorded onto audio or video, or translated into sign, braille or other languages. With the person's consent this information should be shared with other health and social care agencies to ensure that their preferred method of communication is documented, and appropriate support is consistently offered by everyone involved in their care.

There are lots of tools and aids that you can use to help you such as the The DisDAT tool to identify situations that may distress individuals and indicates when a person may be becoming distressed or in pain.

There are a wide range of resources available (see resources) such as The MENCAP hospital communication book

<https://www.mencap.org.uk/sites/default/files/2016-06/hospitalcommunicationbook.pdf>

Further evidence is listed by NICE

<https://www.evidence.nhs.uk/search?q=communication+learning+disabilities>

Desensitisation

Desensitisation is a good way of helping people to overcome fears and anxieties. The approach utilises gradual and repeated exposure to a clinical process or environment in order to reduce the established (negative) response. It has been shown to be particularly effective and helpful for people with learning disabilities who are likely to need more time and support to feel comfortable with many clinical procedures or in clinical settings. Desensitisation is a Reasonable Adjustment. A fear of needles and blood tests is common and provides a good example of how desensitisation can help, see:

	<p>https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-reasonable-adjustments-case-studies</p> <p>Desensitisation can be used in any setting or in relation to any procedure that is triggering anxiety such as wearing an oxygen mask, having a tube inserted or going to the dentist, see:</p> <p>https://www.rcn.org.uk/magazines/students/2018/reason-to-smile</p>
<p>NHS Improvement Standards and the LeDeR programme</p>	<p>The involvement of families or carers when a person with a learning disability or autism needs care should not be seen as simply ‘something nice to do’ or even just ‘good practice’. It is essential to achieving the best possible outcomes, avoiding harm and saving resources. If Quality is seen as the combination of effectiveness, efficiency and reducing risk then Quality can only be achieved with the involvement of families and carers – to not do so would be to provide a poor quality service - (see Equality and anti-discriminatory practice)</p> <p>NHS Improvement has developed a set of Standards to assess NHS services’ ability to effectively meet the needs of patients with autism and / or learning disability, the second of which is “Every trust must ensure all people with learning disabilities, autism or both and their families and carers are empowered to be partners in the care they receive”</p> <p>https://improvement.nhs.uk/documents/2926/v1.17_Improvement_Standards_added_note.pdf</p> <p>Guidance such as the Working Together document on hospital care for people with a learning disability https://www.ndti.org.uk/uploads/files/Working_Together_2.pdf provides a structure and guidelines for the involvement of families and carers in achieving the best possible outcomes. Nice has a Quality Standard specifically on the issue, designed to provide the best support for patients whose behaviour can be challenging https://www.nice.org.uk/guidance/qs101/chapter/Quality-statement-5-Involving-families-and-carers</p>

	<p>The Learning Disability Mortality Review - amongst deep concerns about health inequalities and disproportionate numbers of potentially avoidable deaths of people with a learning disability, the government commissioned the Learning Disability Mortality Review (LeDeR) Programme. The findings from LeDeR reinforce just how much more Government, and our health and care system, need to do to give people with learning disabilities the good quality health and social care that they ought to expect as a right. Care that the LeDeR reports demonstrate is all too often denied them. This is simply not good enough.</p> <p>A common theme in the deaths reviewed by the LeDeR programme was the need for better training and awareness of learning disability. The same is true of autism. In responding to the second annual report of the LeDeR programme, the Government set out a series of actions, including a commitment to consult on, and implement, mandatory learning disability and autism training.</p> <p>The involvement of families or carers when a person with a learning disability or autism needs care should not be seen as simply 'something nice to do' or even just 'good practice', it is essential to achieving the best possible outcomes, avoiding harm and saving resources.</p>
<p>Sources of information</p>	<p>Families, carers and indeed people with learning disabilities and or autism are the best sources of information, they just need to be appropriately supported to provide it. However, there a range of sources where further information can be made available:</p> <ul style="list-style-type: none"> • Summary Care Records – all NHS services and increasing numbers of social care settings are able to log on to the NHS Spine, for those staff with the appropriate permissions to view clinical information then it is always worth checking to see if there is information contained in the Summary Care Record (SCR) that can help to understand the person and the support they may need. Increasing numbers of people are giving consent (or by way of a Best Interest Decision) for Additional Information to be added to their Summary Care Record (SCRa) which will provide further information including any Reasonable Adjustments that have been recorded in the GP (primary care) record https://www.england.nhs.uk/learning-disabilities/improving-health/summary-care-records/ • Health Passports – Most areas of the country have a local system that offers people with a learning disability the opportunity to record key information about themselves and their needs in a document often called a Passport, perhaps a Hospital or Health Passport; many use a Traffic Light structure to organise and prioritise the information contained. These documents contain really important information for any staff, so it is always worth asking if a person has one. There is work

being done nationally to provide some consistency in the types of information recorded and the way it is structured see <https://theprsb.org/standards/dcsp/>

- **Reasonable Adjustment Flag** – NHS Digital and NHS England have developed a digital Flag to indicate when a patient has an impairment or disability that may require some Reasonable Adjustments provided by services. The Flag has been built into the NHS Spine to be viewed alongside the Summary Care Record (SCR). This capability has been initially piloted in early 2020 and from there will be integrated into clinical systems, see <https://digital.nhs.uk/services/reasonable-adjustment-flag>

NHS England have produced a video to show the benefits of a Reasonable Adjustment Flag:

<https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

- **GP Registers** – GP Practices hold a register of patients with known learning disabilities as part of the Quality Outcomes Framework (QOF), this register is used to offer Annual Health Checks for patients from the age of 14, included in the Annual Health Check should be the offer of having additional information added to the Summary Care Record (SCRa) and the production of a **Health Action Plan** which identifies areas of known need along with recommended actions. <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme>

Take Action - Approach

What will be different?

What will you do differently as a result of your learning today?

How will you take action?

Who will you involve? Do you require any additional learning or support and where would you go to access this?

By when will you do this?

NHS
Health Education England



This learning resource was commissioned by Health Education England working together with the National Development Team for Inclusion and Skills for Care - August 2020.