# ‘A’ for Adjustment

## In this section:

- an introduction to ‘A’ for Adjustment;
- the learning resources – a brief overview;
- session one – A for Attitude supplementary information.

‘A’ for Adjustments is a learning resource to support improved access and outcomes for people with a level of disability or impairment that requires services to adjust the way they ordinarily operate. Such adjustments are to enable that person (or groups of people) to receive an equitable level of care and experience which leads to the best possible outcomes for them.

The resource ‘A’ for Adjustments has been developed to meet the requirements of the Equality Act and to reduce the known inequalities that exist in health and care for people with Learning Disabilities and autistic people. This resource is applicable across all age groups as it is important to note that health inequalities start at an early age.

**Premature Mortality**

There is significant evidence that people with learning disabilities are 58 times more likely to die before the age of 50 than that of the general population (Michael, 2008). The Confidential Inquiry into premature deaths of people with learning disabilities (2013) reviewed the deaths of 247 people with learning disabilities. Nearly a quarter (22%) were younger than 50 years when they died, and the median age at death was 64 years; males with learning disabilities dying 13 years younger than males in the general population (65 v 78 years) and females with learning disabilities 20 years younger than females in the general population (63 v 83 years).

Many families and autistic people have raised concerns over early deaths. Research shows that autistic people die on average 16 years earlier than the general population. Autistic people are at increased risk of dying younger from virtually every cause of death. There are specific social, cultural and sensory challenges faced by those with autism which can contribute to premature mortality www.autistica.org.uk

**Quality of Health Care**

The Inquiry demonstrated that this isn’t just a sad statistic but something that can and should be addressed; it provides evidence of factors relating to the provision of care and health services that contribute to health disparities between people with and without learning disabilities. Avoidable deaths from causes amenable to change by good quality health care were more common in people with intellectual disabilities (37%) than in the general population (13%); this means that compared with the general population, 3 times as many people with learning disabilities died in circumstances that good quality healthcare provision would have helped avoid. Problems were identified in advanced care planning, adherence to the Mental Capacity Act, living in inappropriate accommodation, adjusting care as needs changed, and carers not feeling listened to.

**Areas to be addressed**

In response the DHSC has identified actions which have been grouped into 8 key areas:

1. Identifying people with learning disabilities and their need for reasonable adjustments
2. The particular patterns of ill-health of people with learning disabilities
3. The fragmentation of the healthcare provided to people with learning disabilities
4. Deaths amenable to healthcare interventions
5. Adherence to legislation and guidance
6. The imperative to forward plan
7. End of life care
8. Reviewing deaths of people with learning disabilities in the future

This learning will help to improve staff awareness of people with learning disabilities and some of the more common health conditions experienced; perhaps more importantly the learning aims to raise awareness of problems people with learning disabilities, their families and carers experience in getting good quality health care and some of the (often simple) actions that can be taken to reduce these problems or make them less likely to occur.

**Differences for People with Learning Disabilities**

**Common Health problems**

- **Epilepsy** - Up to one third of people with learning disabilities have epilepsy - 20 times greater than that of the general population,
- **Physical disability** - Up to one third will have an associated physical disability (commonly Cerebral Palsy) with health challenges that includes; postural deformities, hip dislocation, chest infections; Dysphagia, gastroesophageal reflux, constipation and incontinence.
- **Mental ill health** - Anxiety disorders, depression and schizophrenia are among the more common mental health problems experienced by people with learning disabilities. Schizophrenia, for example, is three times more common in people with learning disabilities than in the general population
- **Autism and developmental disorders** - 60-70% of people who have an autistic spectrum condition will also have a learning disability. The prevalence of autism increases with greater severity of learning disability. Attention Deficit Hyperactivity Disorder also more common.
- **Cancers** - Gastrointestinal cancers, including those of the oesophagus, stomach and gall bladder, are approximately twice as prevalent in people with learning disabilities, while the prevalence of lung, cervical cancer prostate and breast are much lower than in the general population. Individuals with Down Syndrome are particularly susceptible lymphoblastic leukaemia
- **Coronary heart disease** - is the second highest cause of death of people with a learning disability
- **Dental problems and oral hygiene** - People with learning disabilities are more likely to have tooth decay, loose teeth, untreated oral disease and gum disease than the average member of the general population
- **Diabetes** - the higher rate of diabetes than in the general population which could be due to a greater incidence of obesity, less activity and poorer diet

- **Gastrointestinal problems** - approximately 70% of people with learning disabilities experience gastrointestinal disorders, meaning they are far more prevalent in this patient group compared to the population as a whole
- **Obesity** is far more common in people with learning disabilities, especially women with mild disabilities, than in the general population
- **Respiratory disease** - is the most common cause of death of people with a learning disability
- **Sensory impairments** - approximately 40% per cent of people with learning disabilities have difficulties seeing and a similar proportion has problems hearing
- **Swallowing and eating problems** - difficulties in swallowing are far more common among individuals with learning disabilities than in the general population and are highest among those with profound learning disabilities

**Health risks for autistic people**
Multiple studies have found that most autistic adults are at a significantly increased risk of most medical conditions, including cardiovascular disease, diabetes, stroke, circulatory and respiratory conditions

- **Epilepsy** - Between 20% and 40% of autistic people also have epilepsy and this rate increases steadily with age
- **Heart Disease**
- **Mental Illness** - autistic people as at higher risk of mental health problems. Research indicates that 70% of autistic people have one mental health disorder such as anxiety or depression, and 40% have at least two mental health problems.
- **Suicide** - After heart disease, suicide is now the leading cause of early death in adults with autism and no learning disability

**Barriers to Accessing Services**

- People not being identified as having a learning disability and not receiving necessary Reasonable Adjustment
- Staff having little understanding about learning disability
- Failure to recognise that a person with a learning disability is unwell
- Failure to make a correct diagnosis
- Anxiety or a lack of confidence for people with a learning disability
- Lack of joint working from different care providers
- Not enough involvement allowed from carers
- Inadequate aftercare or follow-up care
- A lack of accessible transport links

**So what happens is**

- People with learning disabilities have a higher uptake of medical and dental services, but a lower uptake of surgical specialities, similar overall rates of admission, but shorter stays.

- People with learning disabilities and diabetes have fewer measurements of BMI compared with the general population, those who have strokes had fewer blood pressure checks, and cervical screening and mammography are less likely to be undertaken.

- People with learning disabilities are less likely to be given pain relief, and people with learning disabilities are less likely to receive palliative care (Michael, 2008).

There is irrevocable evidence that people with learning disabilities have higher levels of health need than that of the general population, many of which are unmet. Problems can occur at both an individual and a service level:

- some people with learning disabilities may not seek support from the healthcare system unaided either through lack of recognition, fear, difficulties in managing the process or previous negative experiences
- services can fail to meet individuals needs due to a lack of flexibility, lack of familiarity or confidence, negative assumptions, lack of reasonable adjustment meaning that that healthcare issues can remain undiagnosed or untreated as a consequence.

This learning resource focuses on better understanding of Reasonable Adjustment as a means to address some of these problems; some of the key areas of focus include the role of families and carers, attitudes, knowledge and communication style of health staff as well as issues surrounding the physical environment.

The resource focuses on those at the front line of health care who will come in to contact with people with learning disabilities as part of their everyday work. It offers advice, tips and guidance on how individuals, and the way they work, can make adjustments 'on the ground' and 'in the moment' – we know that health care's greatest asset is staff and it is those people delivering direct care who have the greatest impact on the experience and health outcomes of people with disabilities. Reasonable Adjustments are as much about staff attitude, understanding and approach as they are about ramps, lifts and parking!

## The Learning Resources

The resource **'A' for Adjustments (Learning Disability)** is provided in 5 easy to use packages.

**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.

# Session One - 'A' for Attitude - Supplementary Information

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| **Anti-discriminatory practice**<br><br>**Social and medical models of disability** | In the first session we learnt about discrimination and Equality.<br><br>Anti-discriminatory practice aims to counteract the negative effects of discrimination and to combat discrimination in all its forms. How we see and think about people with a disability is important in determining how we care for them.<br><br>A social model of disability is an important starting point. Rather than a medical model of disability which sees the person with disability as 'having something wrong' that needs to be 'fixed', (probably by somebody else!), the social model sees society and the barriers it places to the aspirations and progress of people with disabilities as being at fault.<br><br>When we base our practice on the social model, we focus on reducing or removing the barriers people with disabilities face. It's not about 'fixing' people – it's about working with them to help them achieve their full potential and experience the same outcomes from services as others.<br><br>See https://rcni.com/hosted-content/rcn/first-steps/anti-discriminatory-practice |
| **Health and care values** | Whether or not we are aware of it, we all live our everyday lives by a set of values that shape how we think and react. Values are beliefs and ideas about how people should behave, which have been formed by our childhoods, families, backgrounds, cultures, religions, educations and relationships.<br><br>Whilst we each have our own values, there are values which are important for working in health and social care. Six values are now recognised as applying to health and social care workers. These are known as 'The 6 Cs':<br><br>**Care**: having someone's best interests at heart and doing what you can to maintain or improve their wellbeing.<br><br>**Compassion**: being able to feel for someone, to understand them and their situation.<br><br>**Competence**: to understand what someone needs and have the knowledge and skills to provide it.<br><br>**Communication**: to listen carefully but also be able to speak and act in a way that the person can understand.<br><br>**Courage**: not to be afraid to try out new things or to say if you are concerned about anything.<br><br>**Commitment**: dedication to providing care and support but also understanding the responsibility you have as a worker |

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| **Person centred working** | We can see how these values support the necessary approach to Reasonable Adjustment and supporting people with a learning disability.<br><br>Each individual should be placed at the centre of their care and support. It must fit the individual, rather than the individual being made to fit existing routines or ways of doing things. This is known as person-centred working. Person-centred values tell you how to work in a person-centred way.<br><br>See https://www.skillsforcare.org.uk/Documents/Learning-and-development/Care-Certificate/Standard-5.pdf |
| **Valuing People** | The Government's strategy for Learning Disability for the 21st Century (Valuing People) set out a clear set of Values to help shape and frame the way people with learning disabilities should be supported. These values are helpful in deciding how to support individuals in our daily work, whatever our role.<br><br>**Rights:** All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary<br><br>**Independence:** While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.<br><br>**Choice**: Everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives.<br><br>**Inclusion**: Inclusion means enabling people with learning disabilities to do ordinary things, make use of mainstream services and be fully included in the local community. |
| **Seeing the whole person, not the disability** | Focus on the person and seeing the whole person, rather than focussing on either the apparent disability or impairment, or the specific symptom presenting in isolation to the whole person will always achieve a better outcome.<br><br>Such an approach will provide the right starting point to understanding the individual, how they are experiencing their current situation and the best way to move forward together. |

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| **Fear and anxiety** | People with a learning disability like much of the population experience increased anxiety in clinical settings and clinical interactions; fears based on past experiences, not knowing what to expect, feeling disempowered, potentially being in pain and uncertain what the future might hold.<br><br>The difference, you may think, is likely to be in the way that people with learning disabilities and autistic people may present that anxiety.<br><br>People's responses in such situations are individual and unique, with some people shutting down and becoming introverted, others becoming completely acquiescent and others again becoming visibly agitated, loud and disruptive – just like any sample of society!<br><br>The real difference, and what often lies at the heart of ensuing difficulties are the way that people with learning disabilities and autistic people are supported and interacted with at such times.<br><br>At the time this learning resource is being developed there is a national research project underway by people with learning disabilities which is asking the question "Are you frightened of people with learning disabilities? Do you trust us? The researchers don't think people with and without learning disabilities are very connected with each other. "We don't know each other well enough, so you might look away from me on the street because you think "he looks different" (https://www.theguardian.com/society/2019/dec/11/i-have-a-question-are-you-scared-of-people-with-learning-disabilities-like-me)<br><br>Previous research by the charity Scope identified that 67 per cent of people feel uncomfortable when talking to a disabled person. A fear of seeming patronising or saying the wrong thing is why most people feel awkward<br><br>Younger people, especially men, are twice as likely as older people to feel awkward around people with disabilities – and one-fifth of 18 to 34-year-olds have actually avoided talking to a person with a disability because they weren't sure how to communicate with them. This is not usually down to prejudice or any real hatred for disabled people, it's more down to not knowing what to do and being worried about saying the wrong thing. |

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| **Negative assumptions and myths** | The importance of values in 'getting it right' for people with learning disabilities and autistic people has been highlighted above. The void created by a lack of such values can often be filled by negative assumptions and stereotypes:<br><br>**People with a learning disability and autistic people deserve pity:**<br><br>It is often the negative attitudes of society and the lack of accessibility within services and the wider community that needs to be changed.<br><br>**People with a learning disability and autistic people cannot lead a productive and a fulfilling life:**<br><br>It can be assumed that people with a learning disability and autistic people cannot have a good "quality of life". The focus is on what the person finds difficult rather than on the person's abilities.<br><br>**Peoples' learning disability is an illness:**<br><br>Disability can be seen as an illness that needs to be fixed, an abnormality to be corrected or cured. People with disabilities are like people without disabilities, they become unwell on occasion or sometimes may be in pain.<br><br>**People with a learning disability are dangerous:**<br><br>Many people assume that anyone with a learning disability or autism is likely to be aggressive or violent. Whilst a very small number of people with a learning disability or autism have developed behaviours that help them avoid situations they find scary or difficult, the focus needs to be on changing the situation and reducing the anxiety<br><br>**People with a learning disability or autism are helpless and dependent.**<br><br>This stereotype tends to mean that people with learning a disability and autistic people are to be pitied as they spend their whole life needing other people's help. It is often assumed that people with a learning disability and autistic people are all in 24 hour care with nurses on hand 24 / 7<br><br>**People with learning disability or autism are to be feared:**<br><br>People with learning disability or autism can be seen as lacking any the moral sense and being a menace to others, to themselves and to their community. |

## Take Action – Attitude
## 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?




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