

## 'A' for Adjustment

### Session Five - 'A' for Actions

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

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

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

**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.

## A is for Actions – Supplementary Information

<b>Involving family and carers</b>	<p>Involving family and carers is not just the right thing to do, it is highly likely to provide a better outcome for everybody and is enshrined in law. It recognises, respects and values their skills, experience and personalised knowledge about the person they care for.</p> <p>Beth (a young woman with a learning disability) and Robina (a family carer) describe this in their poems:</p> <p><i>I am who I am. I was born to be me. So don't say I can't, cos I can. Just see me, not my disability. (Beth Richards)</i></p> <p><i>....we are the friends and family who Love, support, enable, champion Want equality for - build links for – find out, campaign and question for Enjoy, value, identify with, adapt to include Take pride in, marvel at, celebrate Teach skills, extend, reassure, motivate Listen to, learn from, care about, reflect on Hold knowledge of, hold records on</i></p>
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	<p><i>Want to believe in a good future for Risk-assess, monitor quality, may whistle blow for The person who brought us together with you So we Appreciate you chose this work Warmly welcome your interest, energy, knowledge, insights, skills Expect communication, anticipation of what we need to know, explanation when you cannot say Count on you to support our own rights as carers, including us in decisions when you should Accept we may challenge each other Hope to share trust, confidence, respect Ask you to work with us as allies, partners .... Just as you would if the person who brought us together was your friend or family member (Robina Mallett)</i></p> <p>Both these poems can be found in - Heslop &amp; Hebron (eds.) 2020. Promoting the Health and Well-being of People with Learning Disabilities. Springer.</p> <p>It is important to plan ahead wherever possible with the person and those who know the person best to think about and plan what might be needed; for example when planning a hospital admission you could fill out a Risk, Dependency and Support assessment <a href="https://www.ndti.org.uk/uploads/files/Working_Together_2.pdf">https://www.ndti.org.uk/uploads/files/Working_Together_2.pdf</a></p> <p>Such tools and approach can help to identify and agree what additional support maybe required, and who is best to provide it. Many organisations and services will have specially developed policies and protocols for carers – see if your organisation has a carers policy and / or a carers passport, these identify what support is available for carers such as stop overs, parking, food vouchers etc. See <a href="https://www.gloshospitals.nhs.uk/your-visit/visitors-and-carers/information-carers/">https://www.gloshospitals.nhs.uk/your-visit/visitors-and-carers/information-carers/</a> for some examples if your organisation or service does not have these you could suggest this or help to develop them.</p>
<p><b>Who to involve and where to get support</b></p>	<p>Some organisations or services have staff and roles specifically to support people with learning disabilities, most hospitals now employ Learning Disability Hospital Liaison Nurses (see Z Case Study session 4), Primary Care Liaison Nurses and Community Learning Disability Teams.</p>

	<p>There may be staff who are designated as Learning Disability Champions – these are staff who can provide additional guidance and support to other staff, people and carers; get in touch with them and keep their contact details to hand. Your organisation may have a learning disability patient group or a carer group who can help advise the organisation on how best to support patients with learning disabilities.</p> <p>if your service or organisation does not have these roles or groups you could suggest this or help to develop them; following this learning you may consider becoming a Learning Disability or Autism Champion.</p>
<p><b>Easy read and accessible information</b></p>	<p><i>'Health is everybody's responsibility. Whether you have learning disabilities or not you need information you can understand. This must be accessible. Like everybody else, people with learning disabilities should get information about staying healthy throughout their lives. Like everybody else, people with learning disabilities will want information when they get ill. This is needed before, during and after treatment, whether they go to hospital or not. Like everybody else, if someone with learning disabilities has a health problem the important people in their life will also need information about this. This means people who are paid to support them, their family members and friends. Health is everybody's responsibility.'</i></p> <p>Beth Richards (see reference above)</p> <p>It is a good idea to keep an updated store or library of materials relevant to your area of work; this may be guidance on specific conditions or procedures, it may be more general health advice or even easy to understand maps and directions.</p> <p>NHS England have a website with a section dedicated to information about, and to an extent for, people with learning disabilities. At the time of publication this could be found at: <a href="https://www.england.nhs.uk/learning-disabilities/">https://www.england.nhs.uk/learning-disabilities/</a></p> <p>Public Health England also have a lot of information about people with learning disabilities, search the GOV.UK website as it is not all in the same place. However, putting in 'Public Health England learning disabilities' takes you to a webpage which includes:</p> <ul style="list-style-type: none"> <li>Data on people with learning disabilities (the learning disability profiles and health and care data sets).</li> <li>Summaries of information about specific health inequalities.</li> <li>A link to guidance on reasonable adjustments.</li> <li>A link to a study and report on the use of psychotropic medication.</li> <li>Information on the Autism Self-Assessment framework.</li> </ul>

	<p>Guidance for social care staff. The link to the webpage is: <a href="https://fingertips.phe.org.uk/profile/learning-disabilities">https://fingertips.phe.org.uk/profile/learning-disabilities</a></p> <p>The Reasonable Adjustment Guides are for specific service areas and conditions and include links to further resources. Many of the resources are in accessible formats including easy read and film clips, be aware that weblinks within this type of document can sometimes become out of date.</p> <p>The guidance for social care staff includes the Health Charter for social care providers and a number of fact sheets on health issues for people with learning disabilities such as health checks and pain management. The fact sheets also include links to presentations that can be used for further staff training purposes. Some websites are dedicated to providing accessible information for people with learning disabilities. Easy Health is perhaps the best-known example and include a wealth of information in easily searchable categories. See: <a href="http://easyhealth.org.uk/">http://easyhealth.org.uk/</a></p> <p>Picture of Health is another example. See: <a href="http://www.apictureofhealth.southwest.nhs.uk/">http://www.apictureofhealth.southwest.nhs.uk/</a> This is a repository of accessible information collated across the South West of England in 2014.</p> <p>There are also websites dedicated to particular health topic areas. Seeability: <a href="https://www.seeability.org/">https://www.seeability.org/</a> is a good example.</p> <p>If you want accessible information on screening tests for people with learning disabilities who are going to become parents you need to go to: <a href="http://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides">www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides</a></p> <p>There are eight easy read guides which explain the screening tests offered during and after pregnancy including screening for thalassaemia and sickle cell disease.</p> <p>You may well need to personalise the resource for the individual and some websites provide templates you can use for this. For example, NHS Lanarkshire has a number of templates and tools to create personalised letters. See: <a href="http://www.healthlanarkshire.co.uk/letter-templates">http://www.healthlanarkshire.co.uk/letter-templates</a> It is always worth looking at what is out there first, even if it needs adapting, rather than starting from scratch.</p>
<p><b>Sharing information</b></p>	<p>When you have worked with an individual with a learning disability or autism in whatever capacity you will have learnt some valuable information; it is really important to ensure that such information is appropriately shared to help others provide the best possible support and to reduce the number of times people with learning disabilities and their carers have to repeat what they need and how best to work with them.</p>

	<p>There are a number of tools in addition to the records ordinarily kept that can help with this. You should look for these when you start to work with somebody with a learning disability or autism and you should return to update them (where possible) and share what you have learnt when you have completed your episode of care. These include:</p> <p><b>Summary Care Records</b>  Summary Care Records (SCR) are an electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care  <a href="https://digital.nhs.uk/services/summary-care-records-scr">https://digital.nhs.uk/services/summary-care-records-scr</a></p> <p><b>Reasonable Adjustment Flag</b>  The Reasonable Adjustment Flag is a national record which indicates that reasonable adjustments are required for an individual and optionally include details of their significant impairments and key adjustments that should be considered  <a href="https://digital.nhs.uk/services/reasonable-adjustment-flag">https://digital.nhs.uk/services/reasonable-adjustment-flag</a></p> <p>It is important to share information following any intervention with others involved in the persons ongoing care and support; this is likely to extend beyond their GP to include specialist services such as Community Learning Disability Teams. You can also check if the person has a Health Action Plan  <a href="https://www.mencap.org.uk/sites/default/files/2016-06/What%20is%20a%20health%20action%20plan%3F.pdf">https://www.mencap.org.uk/sites/default/files/2016-06/What%20is%20a%20health%20action%20plan%3F.pdf</a>  or a Health Passport which may need to be updated.</p>
<p><b>Information for care and support staff</b></p>	<p>It is easy to assume that people providing support to people with learning disabilities are 'health experts'; whilst they are likely to know the person well (although this is not always the case with new or agency staff) and to be able to contribute really helpful information, they in turn will need clear and straightforward guidance at an appropriate level so it can be shared with others involved in supporting the individual.</p> <p>It is important not to make assumptions about what support staff can do, discuss and agree roles for example on admission to hospital, before a procedure or test, when prescribing, making referrals or giving advice etc.</p> <p>It is particularly important to ensure that Discharge Plans take account of the persons living and support arrangements and that any follow up actions including further appointments required are clearly laid out and easy to understand.</p>

<p><b>NHS Improvement Standards</b></p>	<p>NHS Improvement have created a set of standards for services to use to ensure they are providing the best possible care and support for patients with learning disabilities and autistic people. The standards have been developed with a number of outcomes created by people and families — which clearly state what they expect from the NHS.</p> <p>By taking this approach to quality improvement, it places patient and carer experience as the primary objective, as well as recognising the importance of how the NHS listens, learns and responds in order to improve care.</p> <p>The four standards concern:</p> <ul style="list-style-type: none"> <li>▪ respecting and protecting rights</li> <li>▪ inclusion and engagement</li> <li>▪ workforce</li> <li>▪ learning disability services standard (aimed solely at specialist mental health trusts providing care to people with learning disabilities, autism or both)</li> </ul> <p>The standards are intended to help organisations measure quality of service and ensure consistency across the NHS in how we approach and treat people with learning disabilities, autism or both. They are prominent in the learning disability ambitions in the <a href="#">NHS Long Term Plan</a> and included in the NHS standard contract 2019/20.</p> <p>You can check how your service measures up to the Standards and contribute to areas that could be improved  <a href="https://improvement.nhs.uk/resources/learning-disability-improvement-standards-nhs-trusts/">https://improvement.nhs.uk/resources/learning-disability-improvement-standards-nhs-trusts/</a></p>
<p><b>Difficult conversations</b></p>	<p>In your interaction with someone with a learning disability or autism you may have to give bad news or to have a ‘difficult’ conversation. As with other areas covered in this learning resource it is important not to make assumptions and to treat every person as an individual with a unique context. Remember people with learning disabilities or autism have the same rights as anyone else to be fully involved in decisions about their own lives, including in matters of life and death. Your previous learning about Rights, Communication, Capacity and Values will all help you to approach such difficult conversations. Such conversations should be handled with compassion and care, they certainly should not be avoided! The importance of talking about death, dying, end of life care and Do Not Resuscitate has become particularly highlighted during the Coronavirus pandemic  <a href="https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0166-Letter-DNACPR.pdf">https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0166-Letter-DNACPR.pdf</a></p> <p><a href="https://www.hsj.co.uk/mental-health/learning-disabilities-should-never-be-a-reason-for-a-do-not-resuscitate-order/7027489.article">https://www.hsj.co.uk/mental-health/learning-disabilities-should-never-be-a-reason-for-a-do-not-resuscitate-order/7027489.article</a></p>

	<p>Learning Disability England have developed a helpful resource pack around DNACPR <a href="https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/DNACPR-Support-Pack.pdf">https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/DNACPR-Support-Pack.pdf</a></p> <p>The Palliative Care for People with Learning Disabilities is a fantastic resource for support and guidance including end of life planning - <a href="https://www.pcpld.org/links-and-resources/">https://www.pcpld.org/links-and-resources/</a></p>
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## Take Action

### What will be different?

What will you do differently as a result of your learning from A for Adjustment?

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**



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