Patient experience
Hello, my name is Joshua and I would like you to listen and let me talk to you. I can help you to learn what is important to me and understand what my priorities are. Ask me about my medicines, but allow me time to process your question and don’t expect a perfect answer. If you can’t communicate with me, find out from the person who looks after me or communicates for me.

I find it difficult if you change the colour or taste of my medicines so I need you to reassure me and work with me to help me understand.

Steps you can take:
- Understand the experience of the person and their carer; their priorities are not necessarily the same as members of their healthcare team
- Ask if the person or their carer have any concerns or questions about their medicines and allow more time for the consultation
- If taking medicines is a problem, explore routes or formulations with the person and/or carer to find a solution that works best for them
- Be consistent in the supply of formulations and flavours as changes to these can cause uncertainty or distress.

Evidence – is the medicine appropriate?
A person with a learning disability may have several long term conditions managed by different clinicians. It is important to regularly review all medicines a person is taking to avoid serious side effects; they should be treated and cared for in the same way as everyone else.

Patient information leaflets need to be in an accessible format and may not be completely relevant if the medicine is being used for an unlicensed indication.

Steps you can take:
- Collate a complete list of all medicines for the person
- Check there is a clear and valid reason for each medicine and that appropriate monitoring and reviews are in place
- Ask the person and their carer about their preferred format of information about their medicines; easy read, pictorial, audio or video versions may be available
- When a medicine is stopped make sure any medicines to manage its side effects are also reviewed
- Find out if there is a local learning disability pharmacist or nurse who you can contact for help and advice.

Safe and effective
A person with a learning disability may have particular problems communicating what their preferences about medicines are, including whether medicines are working for them or causing intolerable side effects. You can have valuable consultations with patients and carers to explore their feelings about taking medicines. Think about the outcomes of treatment that you could ask about.

Steps you can take:
- Discuss individualised treatment goals with the person and their carer
- Provide advice about starting, stopping and switching medicines so this is done as safely as possible
- Ask the person or their carer to request that you are copied into communications about changes to medicines (if they agree)
- Familiarise yourself with the law around the Mental Capacity Act and covert administration and any national or local guidance.

Medicines optimisation as part of routine practice
You have a key role to play to improve outcomes for people with a learning disability; you may see them more frequently than any other health professional so ask them and/or their carer how they are getting on with their treatment and if they have any questions or problems.

Steps you can take:
- Look for opportunities to grow your knowledge and understanding of learning disabled and that of your pharmacy team
- Don’t be afraid to offer help even if you are not certain that you will have all the answers. Patients and carers won’t mind if you need to find out information after the initial consultation, so use the wider team
- Support measures that improve adherence with medicines; these may be simple changes such as the formulation or frequency of administration
- Offer domiciliary MURs to people with a learning disability
- Get involved with local learning disability and carers support groups.
Tariq Chaudry, a seven year old boy with Down's Syndrome, (also known as Down syndrome), comes to your pharmacy with his mum to collect his new prescription for omeprazole 10mg once daily. According to Tariq’s patient medication record (PMR), all his other prescribed medicines are oral liquids, so you decide to invite Tariq and his mum into the consultation room to find out more about the new prescription.

Tariq’s mum explains that the new medicine has been started because Tariq is experiencing regurgitation. You check with them that the list of medicines and formulations on the PMR is correct and you are satisfied that there are no drug interactions with omeprazole. You ask if Tariq is able to swallow tablets or capsules whole and his mum says when they tried this recently Tariq was nearly sick, but he has managed to take tablets dispersed in water in the past. With their permission you contact Tariq’s GP and recommend the prescription is changed to omeprazole dispersible tablets and agree a review date for the prescription. You explain to Tariq and his mum how to disperse the new tablet in water according to the manufacturer’s instructions and provide them with a copy of the Medicines for Children leaflet: Omeprazole for gastro-oesophageal reflux disease (GORD).

Whilst dispensing the prescriptions for a local home for people with a learning disability, you notice that one of the residents, Courtney Harris, has been started on risperidone, as required. You know that there is a much higher rate of prescribing of psychotropic medicines to people with a learning disability compared to the general population, often outside their licensed indication.

You telephone the prescriber to enquire why Courtney has been prescribed risperidone and are told that it is because the staff at the nursing home had reported an increase in Courtney’s challenging behaviour. After a short discussion, the prescriber agrees that this is an inappropriate and unlicensed reason to prescribe risperidone, and decides to cancel the prescription. Together with the prescriber and practice pharmacist you also agree that it would be beneficial to explore any possible physical, medication, environmental or other causes of Courtney’s change in behaviour with Courtney, her family and the wider multidisciplinary team before any further medicines are prescribed.

Where’s the evidence?
- Electronic medicines compendium (eMC) www.medicines.org.uk/emc
- Local learning disability pharmacist and local mental health trust
- Local NHS trust medicines information centre
- NEWT guidelines to administration of medication to patients with swallowing problems www.newtguidelines.com (subscription required)
- NICE www.nice.org.uk
- Pharmaceutical manufacturer – telephone for information about off-licence drug administration.

Where can I learn more about this?
British Institute of Learning Disabilities (BILD) www.bild.org.uk
CPPE learning programmes www.cppe.ac.uk
Foundation for people with learning disabilities www.learningdisabilities.org.uk
Royal College of Psychiatrists www.rcpsych.ac.uk