

Co-presenters: Ashok Roy & Holly Young

The **aim** of this workshop was to explore practical steps that can be taken locally when decisions are being made to start, stop or alter medication for people with learning disability who have behaviour that challenge services with or without autism.

The **objectives** were to:

- Discuss and identify key areas of the system that need to change in order to improve understanding of the roles for stakeholders to make decisions about the use of medication
- Consider how to ensure future expert/stakeholder input to the review of the positive outcomes and negative effects of medication
- To ensure that there is a shared approach to improving the alternative interventions for challenging behaviour (psychotherapy, environmental change, integration into communities) to make it unnecessary to use medication as an option

Outcome

Two key action points around medication were brought to the plenary Action Planning session.

Workshop discussion

Ashok introduced the workshop and the context of over-medication, with Holly presenting results from the STOMP survey of families whose relatives have experience of taking medication.

After this brief introduction, the group was first asked to discuss 'What needs to happen to enable stakeholders to make better decisions about the use of medication?'

- There was much discussion about the importance of multi-disciplinary working, including contributions such as:
 - Other professionals rely on psychiatrists to provide solutions – psychiatrists are in an impossible situation where medication is the only treatment available but cannot resolve the problem.
 - There are beliefs among parents and other professionals that medication is the only option.
 - Professionals outside the prescribing psychiatrist need to provide support so that medication is not the only treatment option available.
 - A service with a joint CB and PBS pathway means that a full multi-disciplinary assessment has to be completed before medication is prescribed. This service has very few people taking medication.
 - Another area does joint psychiatry/psychology assessments.
 - There is a general lack of services such as the above and multi-disciplinary teams.
 - Psychiatrists spoke about prescribing medication to avoid placement breakdown and patients being hospitalised, which could be even worse for

their well-being. There needs to be support from other professionals to make sure this isn't a choice that psychiatrists are faced with.

- Other contributions included:
 - Families should be listened to because they know the person best and may have seen negative reactions to medication in the past. They may be the ones who support their family member when side effects become a problem and who have to coordinate effects to put the appropriate support in place for the person.
 - There is a general lack of accountability for how people are treated.
 - It's important to get the right support in the appropriate setting.
 - Clinicians need to work better with registered managers, who often instigate referrals and can be known to push for medication.
 - There needs to be someone available who can execute the small things that would be helpful in times of crisis, to help prevent people from being prescribed medication.
 - LD nurses are important to be able to link up perspectives, e.g. provider-patient.
 - Psychiatrists face pressure from families who need help and look to them for a solution; they can be difficult to refuse.
 - Psychiatrists need to be more assertive: say no to anyone putting pressure them to prescribe and refuse referrals where there is another more appropriate team/clinician.

After this discussion, the group was asked to consider 'How can everyone work together more effectively to get medication use right for individuals with learning disabilities?'

- There was a discussion about the issues surrounding the initial assessment process:
 - Professionals other than a psychiatrist should assess a person first, so that medication becomes a last resort as other interventions are attempted beforehand.
 - Alternatively, the first assessment could be held jointly between a psychologist and a psychiatrist.
 - However, there are inevitably waiting lists for psychologists, while treatment can be given immediately from a psychiatrist. This could still lead to people receiving medication before other interventions.
 - Families need intermediate support while they are waiting to see a psychologist so that medication isn't the only way of receiving help quickly.
 - People look for simple solutions – perhaps family carers need a simple, generalizable education tool.
- The importance of changing attitudes towards medication was also mentioned:
 - Firstly it needs to be asked whether medication is really necessary, there needs to be a holistic picture of the person and their needs before prescribing.
 - A general starting point should be the attitude that a person does not need medication.
 - Attitudes need to be the first things to change; they come before knowledge and skills.
- Other contributions are included below:

- Even if medication is acceptable to be prescribed during a crisis, there needs to be a clear plan to reduce it as soon as possible afterwards.
- Building blocks for sustainable behaviour support need to be identified and put in place.
- There needs to be investment in prevention.
- There is a need for care managers to be knowledgeable about PBS and support strategies who can pass this knowledge on to support workers and make sure that those support workers are protected and supported themselves.
- There should be NICE guidelines about the use of antipsychotics for challenging behaviour.
- Default prescribing by paediatricians needs to be tackled and paediatricians need to be brought into this planning work.
- There needs to be more information shared between primary and secondary services, nurses could facilitate this as they are at the interface between the two.
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In the final discussion around forming two actions, the following points were raised:

- The need for multi-disciplinary working.
- There is a need for a strong Multi-Disciplinary Team and Intensive Support Team that is holistic and engages with everyone. A key challenge is how to make this a requirement before prescribing medication. Part of this is getting a history to understand the person fully. There was agreement that this is best practice should be happening already.
- Attitudes are based on values and beliefs – difficult to change, but can happen gradually through cultural change in the field.

Actions

Two key priority actions to feed back to the CB-NSG, LD Professional Senate and other stakeholders.

Action	Who	When
Before medication there is always a 'making sense' meeting with all stakeholders which leads to an agreed intervention plan. Make sure a full history is taken from the family and providers before medication is prescribed.	Ashok to draft short statement about this, and present to Medication oversight group to ensure it is included in the key messages for the call to action	Next medication oversight group meeting on November 15
Ensure that existing NICE guidance and RCPsych Practice Guidelines surrounding antipsychotic medication for challenging behaviour is being followed. Audit NICE and RCPsych guidance on medication for people with learning disabilities. Action for the Call to Action Delivery group – template developed and trialled through Care-coordinator	Call to Action Delivery Board to be asked how they are doing this within their work? letter from CB NSG and LD Senate	Will need agreement at Oversight group on November 15