

Section 3. Effective conversations when medication is being considered

This section sets out the elements of an effective conversation when medication is being considered for a child or young person who is autistic or has a learning disability. It is based around a checklist of things that professionals and families should feel comfortable they understand during conversations about medication, in order to make good decisions.

The checklists, like this guide, were co-produced with parents and carers and professionals.

You can download the checklist here, as a list and as an editable version you can type or write answers into.

[CHECKLIST A: What do parents and carers and professionals need to know when considering medication for a child or young person who is autistic or who has a learning disability?](#)

[CHECKLIST A – editable version](#)

When medication is being considered there are five questions professionals and parents and carers should discuss in order to make good decisions. They relate directly to the headings in checklist A.

What are the views and experiences of the child or young person?

Sometimes a child or young person will be able to talk about what their health problem is. But if they use an alternative communication method, for example Makaton or a communication board, or if they communicate primarily using their behaviour, professionals may need additional time and support to understand them. Listening to family members will also be crucial, as they know their children best and will have critical insights.

The ability of the young person to communicate their wants and needs, and the ability of their family and those making prescribing decisions to understand their communication, underpins everything else. The young person, or their family members, may need an advocate to help with this. The professional may need support from a specialist with experience of autism and/or learning disability.

A communication passport is a way of keeping all the information about how a child communicates together in one place. It can help different professionals understand how the child communicates. You can download examples at the end of this section.

Sometimes parents or carers have additional needs themselves which may require support. There might be language or cultural considerations to bear in mind, to make sure parents and carers can access conversations with professionals, understand information, and ensure any support plan works for them and how they live their life.

Who makes decisions?

Exactly how children are involved in decisions depends on their age and if they have the capacity to make the specific decision being considered. Even when children do not have capacity to make their own decision they should be informed about what is happening and the decisions should be explained to them.

Where a child or young person is not able to make a decision themselves, this will be assessed by professionals, in line with the principles in the Mental Capacity Act.

- Capacity – do they have capacity to make the specific decision that needs to be taken to keep them safe?
- Best interests – if not, what decision is in their best interests, and who can we quickly engage who knows them best to help with that decision?
- Least restrictive option for the shortest possible time – if all alternative options have been exhausted, and medication is needed to keep the person safe, what is the least restrictive option we can use, and how do we ensure it is for the shortest possible time?

In most cases parents can make decisions in their child's best interests, but if there are disagreements then the courts will help decide who can make decisions.

You can find out more about assessing capacity in the resources section at the end of this chapter.

Why is medication being considered for this child?

Usually, medication is being considered when a child has been diagnosed with a specific health need. Additional thought needs to be given to this process for autistic children and young people and those with a learning disability, and specialist input might be needed.

This is because:

- Behaviour that might be associated with a mental health need, for example psychosis, might be being caused by something else, such as sensory overload, distress at changes to support, or because of a lack of support. There is evidence that behaviour that challenges is connected to a lack of support to develop essential skills (see **'Essential skills and challenging behaviour case study'**).
- Presentation of health needs, such as anxiety or depression, may look different for some autistic children or children with a learning disability. It can be difficult for non-specialists to distinguish between features of autism and/or learning disability and additional health needs. Parents and carers are likely to have the best sense of how their child presents when they are healthy, compared to when there is a health concern.
- Health professionals who are not specialists in autism or learning disability might not be aware of the full impact of health needs in this group of young people. For example, they might view the significant amount of time an autistic child might be awake in the

night as 'just a phase'. They might underestimate the impact the lack of sleep has on the child's growth and learning, as well as on siblings and parents.

"Sharing information with different teams, especially CAMHS and Learning Disability teams can help. The lack of specialist knowledge of learning disability and autism in mainstream/generic CAMHS can lead to poor diagnosis and prescribing decisions."

What is the wider context of the child's life?

Due to the potential challenges with communication and diagnosis, understanding the wider context of the child or young person's life is crucial when thinking about medication.

Information from assessments of the child's needs across education, health and care, such as an education health and care plan (EHCP), can provide important information about needs and how they are being met. Professionals should consider if the support the child needs is actually in place, or if a lack of support is having an impact on their health. It might be that there are important environmental or other factors that are affecting the child. For example, a change in living arrangements, classroom, or support staff, which could be unsettling.

When a child or young person's situation means they are at risk of an admission to an inpatient unit, they should be placed on a Dynamic Support Register, and have a Care Education and Treatment Review. They may be allocated a Keyworker. It is vital any considerations about medication are included in this process.

Sometimes parents or siblings might have additional support needs, or be impacted by the child or young persons' needs, in ways that require consideration. Seeking input to discussions from other services such as social care, in partnership with the family, might be useful.

Where a child is living away from home, for example in a residential school or college, it is important that all staff involved in the child's care have access to clear and comprehensive information about a child's medication. Teachers and care staff are critical partners, alongside parents and carers and health professionals. Any issues including missed doses, issues with storage, effects and side effects must be recorded and shared with medical professionals involved in the child's care and their parent carer.

"They don't tell you about withdrawal, or dependency, or side effects. And then when you see your child - especially if they're away in a residential place and you don't see them all the time - and you see your child's physical health, and you're not sure what the medication is targeting. The difficulty is how to challenge that professional when the child is not in your care and you know the medication is not working. The problem is not having that voice, and being listening to."

Consider the options for managing this health need, including non-medication and medication options?

In all cases, alternatives to medication should be considered, and medication should never be used instead of an alternative option. Depending on the circumstances of your children this might include positive behaviour support, speech and language therapy, occupational therapy, sensory support, sleep clinic, or other types of community-based support. Some of these approaches work mainly with the child, but many also look at their environment and work with their family and other professionals, to improve the child's quality of life.

Starting from a broad understanding of a child's situation, and connecting with colleagues in other services, enables professionals to explore underlying issues and how the child's needs can best be met. This doesn't mean lots of professionals are directly involved in one big discussion, but rather there is a clear picture shared across professionals, and parents and carers are not left to join up the dots. A child's education, health and care plan (EHCP), and reviews of the plan, might provide a starting point for discussions.

Conversations about options for managing health needs must be informed by the availability of services locally, including how they are accessed and any waiting lists. Some children may be eligible for additional support, for example from the key-working service, to help coordinate their care.

You can find out more about wider options to consider in this video about how Debbie used alternatives to medication to support her daughter Lucy [here](#).

Do parents and carers have the right information to make decisions?

Parents and carers need clear information about the specific health need, the non-medical and medication options for managing it, the evidence for how well those options work, and the implications of those options.

Where medication does need to be considered, it might be that there are several different medication options to treat the identified health need. These should be set out clearly, in writing and easy read versions wherever possible, for the family.

This includes things like what, specifically, the effect or benefit of the medication will be, so that parents and carers can tell if it is working. It also includes information about risks and side effects, and any monitoring requirements. Some medication, like antipsychotics, require monitoring by blood tests. These sorts of requirements must be made clear so they can be part of decision making.

There is less evidence about how well some medication works for children and young people. This is because clinical trials of medication are often done with adults rather than children. Health authorities usually have guidelines setting out where there is strong evidence about using a medication for children, and where evidence is more limited. Talking through the evidence, risks and benefits can be a helpful way of making sure parents and carers and professionals have a shared understanding, and have the right information to make decisions. Further information on this can be found in the resources section below.

This section, and checklist A which sits alongside it, covers conversations where medication is being considered. We discuss the detailed information that parents and carers and professionals need to consider when actually prescribing medication – like dosage, how long it will be taken for, and how it will be monitored and reviewed - in section 4.

Additional consideration: The impact of puberty

Parents, carers and professionals say there are specific considerations around medication for young people who are entering or going through puberty. Two particular issues are commonly raised.

Firstly, puberty can affect hormone levels, which can affect behaviour and mood. Careful discussions with young people and their families, and support for young people to manage some of the changes experienced during puberty, are important at this time. Sleep also changes during this period, and it may take time to adjust to new patterns of sleep.

Secondly, parents and carers talk about the changing caring dynamic as parents cannot use the same techniques, for example picking their children up, as their children become older, taller, heavier and stronger.

Wherever possible, discussions about medication should include anticipating the next stage a child or young person will enter, so that consideration can be given to how their needs and context might change as they grow up.

Essential skills and challenging behaviour case study

Positive Behaviour Support (PBS) is one of many interventions for supporting people who have behaviour that challenges. In recent years researchers have started to consider whether the skills that are often taught as part of a PBS plan, after someone has developed behaviour that challenges, could be monitored and taught to all children who have an intellectual disability as a way of reducing their risk of developing challenging behaviour (and hence their risk of needing medication), and improving their quality of life.

A recent study in London explored this idea explicitly by considering whether certain 'key skills' are risk factors for challenging behaviour. The study defined 'key skills' as those included in a questionnaire called the Essential Eight (E8) which is part of the Essential for Living skills building program developed by McGreevy, Fry and Cornwall (2014). The items in the E8 include skills such as the ability to make a request, the ability to tolerate waiting or removals, transition, sharing and the ability to follow directions. The study occurred at a special school and measured pupil's skills using the E8 and their level of behaviour that challenges using the Behaviour Problem Inventory – short form – schools version.

The findings of the study showed that using the E8 score it was possible to correctly classify whether or not pupils had behaviour that challenges in 83% of cases. In addition, if the pupils in the study had skills that were at the lowest level, they had a 93% chance of having behaviour that challenges, whereas if their skills were at the highest level, they had a 13% chance. The study suggests that the higher a pupil's skill level the less likely they are to have behaviour that challenges. It therefore suggests that monitoring, and teaching, children 'key

skills' may help to prevent the development of behaviour that challenges, and so reduce the possible need for medication.

References:

Armstrong, H., Denne, L.D. and Bailey, T. (2021) The role of key skills as a risk marker for the development of challenging behaviour in children and young people who have an intellectual disability. *International Journal of Positive Behavioural Support*, 11,2, 3-14.

McGreevy, P., Fry, T. and Cornwall, C. (2014) Essential for Living: A Communication, Behavior and Functional Skills Curriculum, Assessment and Professional Practitioner's Handbook. Orlando, FL: Patrick McGreevy.

Considering medication in crisis situations

In most circumstances medication should only be used to treat a specific mental health condition. Non-medical approaches to managing behaviour should always be tried first – particularly attempts to interpret what the behaviour is communicating, and therefore what the young person wants or needs in that moment.

But parents, carers and professionals told us that sometimes a crisis situation develops and a child's behaviour risks hurting themselves or others. Every effort should be made to plan in advance for how a young person will be supported during times when their safety or that of others is at risk. Positive behaviour support, or behaviour plans, can help with this.

When young people are at severe risk of harming themselves or others, and other interventions have not reduced this risk, [NICE Guidance](#) states that medication can be considered to help manage behaviour.

The guidance says professionals must:

- Only offer medication in combination with psychological or other interventions.
- Identify the behaviour causing the severe risk, and agree a way to measure if the medication is effective in reducing the behaviour and therefore the risk.
- Only use a single medication, and start with the lowest possible dose.
- Monitor the effectiveness of the medication and any side effects, and review the use of the medication within 3-4 weeks.
- Stop the medication if it is not having a positive affect within 6 weeks.
- Only prescribe medication for as short a time as possible, and ensure its use is recorded and reviewed.
- Review the medication if there are changes to the child or young person's environment, like staff changes, or to their physical or mental health.

Medication prescribed for use in crisis situations is sometimes described by medical professionals as 'p.r.n.'. This means 'as-needed'. It means that the medication is administered in response to a particular set of circumstances, rather than taken at a regular time each day or week. It is essential that there is a clear understanding between families and professionals about what 'as needed' means for the child experiencing the crisis situation, so there is absolute clarity about when the medication is used and why.

The principles in this guidance around communication, information, non-medical support options, and medication review, become more, not less, important during crisis situations. Actions taken during a crisis intervention should never become 'usual practice'. Medication should never be a long-term plan to address behaviour. More detailed information is in the resources below.

"My son is 18 and was recently prescribed risperidone and it does work for him. It's for emergency use. The difficulty has been with social services. It's become almost a substitute for proper care. 'Oh she's got the medicine now, she can manage' – and that is so wrong...It's been prescribed for my son as a back up, but how it is being used now is for when care isn't available. The only way I'm going to cope when I can't get a care worker is with medication - and that is not ok. It was prescribed for those really unfortunate situations, but it shouldn't be a substitute for proper care."

Resources

[Dignity and Risk](#)- White Lodge All About Me

[Disabled Children's Legal Handbook](#)- Flow Chart

[Mencap Pharmacy Guidance](#) – MENCAP has produced a resource booklet for pharmacists, people with learning disabilities, family members and carers - Section 3 page 21

Links

[Example Communication Passport](#)

[Example Communication Passport](#)

[Decision Making Tool Kit](#)

[Decision Making Guide to Decision Making For Parents](#)

[NICE Guidance](#): Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

[Disabled Children: A Legal Handbook](#) – Decision Making: The Legal Framework