# Section 1- Why are conversations about medication more complex for autistic children and young people and those with a learning disability?

Each child or young person is unique, and every conversation about medication will be different. But families and professionals point to some common issues that can make these discussions more complex for this group of young people.

## Challenges around communication

Some children or young people might communicate in ways that cannot be clearly understood by others, especially those who do not know them well. It can be difficult for them to find ways to let people know what they are feeling, what they need or want, and when they are in pain. Parents and carers usually have the best insights about how their child communicates, and what their health needs are.
Parents and carers are often managing a lot of competing demands to support their child and sometimes describe feeling a 'power imbalance' with professionals, which can make it hard for them to feel heard in discussions about medication, or to ask questions. Professionals might be managing heavy workloads which can make it hard for them to make the time, and get the specialist support they need, to navigate these communication challenges.

## Challenges around diagnosis

Autistic children and young people and those with a learning disability may not present typical symptoms of physical or mental health needs. This can make diagnosis difficult and may require support from a specialist in autism and/or learning disability. A lack of understanding of learning disability and autism can lead some non-specialist professionals to make assumptions, for example, that signs of anxiety are 'just part of autism'. This is sometimes called 'diagnostic over-shadowing'. This can lead to inappropriate diagnosis, or a lack of diagnosis.
This can work both ways, where sometimes autism and learning disability specialists might lack in depth knowledge of mental health needs. Close joint-working between autism, learning disability and mental health teams - or joint teams - can improve diagnosis and support.
Some children might not yet have a diagnosis of autism. They might have learnt or copied behaviours to try and seem more like their neurotypical peers – sometimes called 'masking' – which can complicate diagnosis. Listening to parents and carers is particularly important in this situation.

*"Social care staff can help to identify mental health needs underlying behaviour concerns and make appropriate referrals. Social care staff should be involved in multidisciplinary teams making decisions about medication."*

*"The most recent social worker said 'Maybe you just need to go on some parenting courses.' Oh what and then he'll miraculously start sleeping after 3 years of medication? I'm happy to*

*go on any courses. But I do find there is a real lack of understanding of autism amongst professionals."*

## Challenges around wider support

Autistic children and young people and those with a learning disability may need additional support to develop key skills like communication, or social and emotional regulation. It can be difficult for parents and carers to get an assessment of their child's needs, and to get the support to meet them. If children can't get the support to learn essential skills - or if the wider support they need is not in place or is changing - that can impact their behaviour.

This can further complicate diagnosis, and can lead to consideration of medication for behaviour which stems from a lack of wider support, rather than from a specific health need. This should not happen, and even in crisis situations every care should be taken to avoid this. Click here for more information about making decisions about medication in crisis situations.

*'We need social care staff involvement in ongoing support and review, as part of regular social care risk assessment and safeguarding practices, as well as initial prescribing. There should be a readiness to intervene with social care support to avoid or minimise the need for medication, rather than see this solely as a health matter.'*

## Worries about psychotropic medication

It can be emotive talking about medication that changes the way a child or young person thinks, feels or behaves – particularly for the young person themselves and their parents and carers. Parents and carers sometimes describe feeling judged when they are seeking support for their child's sleep, behaviour or mood. They also express concerns about whether their child will still 'be themselves' on the medication – while other parents say the medication is what helps their child to 'be themselves'. Sometimes psychotropic medication is used outside of the recognised reasons and while this can be appropriate, it needs careful discussion between professionals and parents and carers.

*"Other parents can be 'against meds'. You worry: are you drugging your child? My niece is diabetic so she has insulin, and no one has a problem with that. But when you say 'I'm thinking of melatonin for my child who doesn't sleep' some people say 'Oh don't do that?!' But why is it different? There's definitely a stigma with psychotropic medication more than any other medication for any other condition."*

*"My daughter was resistant to medication until we found one that worked... Medication felt quite threatening to her."*

## Summary of principles of effective conversations about medication

These challenges can be addressed. This guide aims to help families and professionals to do that together. Good decisions about medication require a partnership between medical professionals and parents and carers, based on clear communication and trust.

The following principles are essential to any good conversation about medication for a child or young person who is autistic or has a learning disability. There is more information on these principles, and checklists to help put them into practice, in the rest of this guide.

**Listen to the young person and their family members – however they communicate.** Health professionals must listen closely when communication might not be straightforward. All children and young people communicate, but this may not be in a way that is easily understood by others. It is crucial to find out how a child lets people know what they need or want, and, for example, when they are in pain. Their family members are likely to know this better than anyone else, so it is important they feel empowered to share this knowledge, and the wider information they have about their child's health and other needs.

**Diagnose the specific health need that medication is being considered for.** While this may sound obvious, parents say professionals do not always address the specific health issue they are concerned about, and instead may see symptoms as a result of their child's autism or learning disability. Professionals must make sure they take the time to understand and diagnose mental and physical health needs when presentation might be atypical or multi-layered. Effective diagnosis of health needs may require specialist autism or learning disability input, for example to help professionals understand what is a result of sensory overload, rather than a mental health condition. Parent carer insights are critical, as they know how their child behaves when they are healthy and when they are not.

**Think about the wider needs of the child and their family, and connect with colleagues to consider non-medication options.** Autistic children and young people and those with a learning disability might be in contact with education, health and care services. Understanding what their wider support needs are, and whether or not that support is in place, is essential to inform any conversation about medication. The non-medication options should always be discussed and carefully considered. This includes support to meet basic needs and to develop key skills, as well as therapeutic options, like speech and language therapy, or talking therapies.

*"My daughter is nine, she has autism, sensory disorder and anxiety. She masks, so she gets no support in school. When she was seven, she tried to end her own life. We're still on waiting lists. I'm concerned she might need medicine before she gets services through the waiting lists."*

**Ensure parents and carers have the information they need to consider non-medical and medication options.** Treatment and support options can be complicated. They can feel overwhelming and, at times, frightening for parents and carers. Consideration of the full range of options – and the benefits, side effects, monitoring requirements and impact on quality of life – need to be set out clearly and in writing wherever possible.

*"Our paediatrician said 'These issues seem to be sensory related' and applied for a grant to get sensory sessions at home with an OT [occupational therapist], to support what happened in school. They wanted to check what we could do before trying medication. They talked us through all of the tools that could help, and the benefits and side effects, including medication, but not just medication. She gave us options and said 'what works best for you?'"*

Here are additional resources for those that want more information:

**Links**

You can find out more about the STAMP campaign on the NHS England website- https://www.england.nhs.uk/learning-disabilities/improving-health/stamp/

Royal College of Psychiatrist's Position Paper on STOMP-STAMP- Provides advice and guidance on how psychiatrists and other relevant healthcare professionals can support the STOMP-STAMP objectives.

**Resources**

Who's Who - A simple list of some of the professionals and teams that maybe involved in conversations about medication.

Jargon Buster- A simple explanation to some of the terms used in this guidance