

## Section 2 - Parent and carer's views about what works and doesn't work in conversations about medication

Section 1 sets out the elements of effective conversations about medication for autistic children and young people and/or those with a learning disability. In this section, parents and carers set out their own experiences of conversations about medication – both positive and negative - and the impact on their children's lives. These experiences reinforce the importance of the key elements of effective conversations.

The common reasons for ineffective conversations include:

- Lack of trust between families and professionals
- Lack of information
- Medical options are considered in isolation, or as a substitute for services

### Lack of trust between families and professionals

Parents described poor access to health professionals, and insufficient time for discussions, as significant barriers to building the trust needed for an effective conversation. Seeing different professionals, and feeling they had to tell their story again each time, compounded this problem.

*"We had a barrier of even trying to see professionals. We had to wait a long time, even from crisis point."*

*"The paediatrician never replies, there's no CAMHS services. It petrifies me to think, if we can't get NHS support normally, what on earth would we do if she had to go on medication? It worries me because these are quite strong drugs, and we feel left in the lurch. What would the support around medication be when we can't even access basic things?"*

*"Knowing that no matter what I did, I couldn't get a doctor to call me back if something went wrong was a massive problem for me in terms of putting my daughter on medication."*

*"My son was put on medication 2 years ago and there's been no review since."*

Families described a perceived - or real - bias in approach to medication from different individuals or services. They cited blanket approaches from 'we don't use medication here' to automatically prescribing medication without discussion, which undermined trust.

*"One doctor said there's absolutely no point in being on [medication]. Another doctor was giving them out like candy, saying 'yes absolutely, which one would you like to try?' There's a big discrepancy in individual doctors and their attitude to medication... It's uncomfortable as a parent because it doesn't feel like you're getting an educated view. It feels like luck of the draw depending on which doctor you come across in that moment."*

*"I had to fight for the medication, because CAMHS didn't want to prescribe it. The hospital had a policy of taking all children off medication. Anti-psychotics helped save [my daughter's] life."*

Some decisions appeared to be based on assumptions rather than information. This led to families feeling they were not believed when they described their child's health needs.

*"When we got to see a professional, I [experienced] misinterpretation of my child's behaviour, and my parenting was blamed."*

*"My child is different in different circumstances. She masks at school, and it all comes out at home, so it's a battle to get people to understand. It's that thing about not being believed as a parent."*

*"She has demand avoidance, and as that is 'controversial' I felt judged, as though I was making up her problems."*

*"Much less judgement of parents, and more understanding. I think that would go a long way towards good prescribing".*

The positive experiences from parents and carers illustrate what works to build trust. This includes regular contact, honesty, sensitive language, and discussion of the evidence base for medication:

*"Once our medication situation was agreed the paediatrician was actually brilliant... He is my 'go-to person'! He was consistent even around lockdown. I would always get a 6 monthly communication, just to catch up and see how [my son] is doing. I think after [my son] had gone on the medication there was such a big difference they could see that I did know my son. I wasn't asking for some magic pill because someone had told me it existed."*

*"Remote appointments were a real positive for us. We had fortnightly conversations with the team."*

*"The psychiatrist is giving us fortnightly phone calls for follow ups. She is constantly involved. She asks us questions about what we're feeling. She's very honest with us. She'll say 'I don't know if this is going to work, but let's just try it.'"*

*"We have an annual review with the community pharmacist. When it initially started, they said let's try it for 6 weeks, let's keep in touch, and then let's review. And actually, it worked from the very first night, and I thanked him profusely!"*

### **Lack of information**

Where information from parents and carers was dismissed, families reported that it took longer to get their children the right support, and misdiagnosis was common.

*"My son had developmental delay but they kept putting me on parenting programmes. They kept saying 'it's parenting'. But now things are different and I've got my EHCP. And now they're talking about medication, but I just want to see what other options we've got before we put him on anything."*

Parents and carers were also concerned about the lack of information they were given when medication was prescribed. This led to anxiety, and in some cases unsafe practice.

*"It wasn't properly explained, it was just given: 'You need to put him on melatonin'. We didn't know why. They've left us hanging. They just seem to dish it out, no feedback. The only thing they did was double the prescription. It's kind of like 'Have the tablets and go away'."*

*Tablets can be hard to take for any 3-and-a-half-year-old, let alone an autistic one. It's a bit upsetting really, you'd like a bit more feedback from the paediatrician."*

*"There's a massive lack of paper resources to take away and read. For example on fluoxetine, the psychiatrist printed it off for us, brought it over and posted it through the door. That doesn't seem a good use of her time, but it was so valuable for us."*

*"Some of the warnings on the information note are terrifying, like 'May cause sudden suicide', when your child is verging on suicide anyway. I understand they're needed... but as a parent you need some support when you read that. The leaflet as your only support is really unhelpful."*

*"You get limited time in the session with the doctor, so you walk out with what's in the box and what's written on the box. Then you go on Google or Facebook to find out more, and that information isn't necessarily reliable."*

Families reported better experiences when meetings were regular, of sufficient length, and followed up in writing:

*"I've had quite a positive experience with the psychiatrist. I've had 2 or 3 meetings since last year, a good length of time for the discussions. The notes with the letter that's sent afterwards is very detailed, very clear instructions, and I've felt confident that I know exactly what the drug is. I was aware the drug is only for last resort situations, where something happens that is unavoidable."*

### **Medical options are considered in isolation or as a substitute for services**

Parents and carers wanted to be able to discuss the range of treatment options that might support their child; not just medication, and not just wider therapies and support, but both. This requires professionals to take a broad view of the young person's needs, connecting with colleagues from different services to put together the right package of support.

*"It was just putting him on medication, changing the medication, not trying to help us with other situations [or] support him in other ways. It was just 'medication first' for us, and that's not what I wanted. In the end we came off everything... I was worried he'd stopped being [himself]. When we got to CAMHS we talked about his anxieties and what he was feeling, and went about it in a different way."*

*"It would be good to get options. The paediatrician was recently telling me about the neuro-disability nurse and the sleeping team. But I would have loved to have had that information a bit earlier on, so that I'd have known about all the options. I only came to know about them much, much later. But at that point he'd already tried melatonin for about 8 months."*

*"I feel informed as a parent, and I'm confident that health services are doing the right thing, but the missing link is social services. They don't understand it. I was so disappointed when the psychiatrist said 'I can't talk to them, that's beyond my remit.' I felt so let down."*

*"Medication should not be given as a substitute for proper care. Care reviews can identify where gaps in care and support have resulted in the need for medication, and how this could be minimised. From experience, once medication has been prescribed social care see this as 'beyond their remit' and decisions about when to medicate as between health professionals and carers - not acknowledging that the basis for these decisions may begin with access to care and support."*

Where there is a co-ordinated approach across services, families report much better experiences and outcomes:

*"We now get 3 hours respite which we use to give our older son some time. Now that [my son] is happier, we are all happier. His anxiety has gone down, the environment at school is much better, it's a different teacher, sensory needs have gone down. We find he only needs the medication Monday to Friday term time. Some days he won't take his medication because he's like 'Nah, I don't need it.' So we're at a really good point now."  
"If you get the school right and the reasonable adjustments right, then sometimes you don't need to medicate."*

Here are additional resources for further information:

### **Links**

Challenging Behaviour Foundation is a charity that helps families of children and adults with - They have developed a Medication Pathway to support the STOMP campaign with resources and support about psychotropic medication.

<https://medication.challengingbehaviour.org.uk/>

The Challenging Behaviour Foundation medication information leaflet-

<https://www.challengingbehaviour.org.uk/information-and-guidance/health/the-use-of-medication/>