

Autism and sleep: an interview with Chris Hoyle

1. Can you tell us how you first became interested in autism?

Well, I've actually been interested in autism for over 30 years now, which does sound like a considerable amount of time, and makes me feel quite old. But I studied speech language therapy at university and was very interested in autism back in those days when autism wasn't the big field of interest that it is today. So yeah, very long time ago now.

2. Can you tell us about your current work?

So I trained as a speech and language therapist and started work many years ago in a variety of different locations, including Child Development Unit, special schools, community clinics. But really developed a specialism in working with children and families with autism. I moved to work for The Together Trust, a charity based in Stockport in the northwest of England. And during that time, I was asked if I would go and do some additional training as a sleep practitioner, which I thought was quite an unusual thing to be asked at the time because I'd never even thought about sleep, never come up on the agenda, I'd never asked parents about their child's sleep. And once I done that training and began working with our families, I realised what a colossal problem sleep was for so many of our children and young people. And became really passionate about doing sleep-work with families. I then went on and did a masters degree in my spare time, I did my post-grad research in sleep and autism. I've run a sleep service called The Autism Sleep Clinic for the last 14 years. And as part and parcel of that, we were then asked to apply to run a commissioned service called Sleep Tight Trafford, which we were very successful in doing. And that service has been running since 2016, and that's what I'm here at the conference to speak about.

3. Can you tell us a bit about the causes and impact of sleep problems for autistic children and their families?

Well, sleep problems in our children and young people can have really a devastating impact, not just on the young person, but on the whole of the family. Many of our children can struggle to sleep and can take hours to settle to sleep at bedtime. But that's by no means the end of the story, they can then have problems with night waking, they might be up for several hours in the night, they might not resettle to sleep at all. So they might be up from the early hours of the morning.

Typically, it's all of the above that they struggle with. And this can have a huge impact, on their health and well being, on their attendance at school, on the behaviour, on their ability to learn, stress levels in families tend to be very, very high as well. And sleep problems are often one of the main reasons that parents then access paediatric services to try and get help and support for the sleep problem. So the sleep problems in themselves can have a massive impact, not just on the young person, but on the whole family. And it can take quite a few hours to work out actually what is going on, and each child is very different, and then you do need a personalised approach to sorting out the sleep problems.

4. What factors or processes are involved in creating a personalised sleep plan for an individual?

So what's really important when you're working with our families is taking time to work out what actually is contributing to each child's sleep problems. And it can be quite a lengthy process to go through, it's really important that you gather lots of information 'cause each child you work with is unique and is different. And autism affects each child in a slightly different way. So that's a really important part of the process. And then taking a detailed sleep history, finding out exactly how the child sleeps. If we can, we'll go and look at the child's bedroom because we might be able to offer some specific advice about the child's bedroom sleeping environment as well. And then each child receives a personalised sleep programme, and that is really important that it is tailored for the child's needs. And we also provide personalised package of resources to support each child's sleep programme. So they are really tailored to meet the child's need and that, again is crucial if the child is going to learn to sleep in a better way.

5. How can we tailor support for autistic children and how might this differ from advice to non-autistic children?

I think the main thing with our children is making sure that they really understand the changes that are going to occur. So we use a lot of visual resources to support their new sleep programme, and that is crucial. But also you need to really understand what the child's level of understanding is to make sure that it's tailored at the right level to support their understanding 'cause if the child understands the changes, they're much more likely to be able to follow the new routine that you put in place. And for a successful outcome, would also use things like social stories to help a child's understanding and that, again, is crucial of what you're trying to put in place.

6. Is there any general advice that you can offer to parents of autistic children with sleeping issues?

I think the big piece of advice I'd like to give to all parents out there it is to really seek advice. Sadly, a lot of parents are still told that sleep problems are part and parcel of autism. So we have parents coming to us saying that they've been told that sleep problems are inevitable. But there is always something we can do to make sleep better. So not to give up basically, and to always seek advice and help to put a different sleep programme in place.

7. Are there any plans to extend or replicate your sleep clinic?

I would really hope so. Yes, I mean, we have been approached by several other authorities who are interested in starting sleep services. I certainly think that it would be ideal if every authority in the country address sleep needs for children because it is a growing problem, not just in children with autism, but in the general population as well. So it is something that we do need to look for and address. And ideally, all children should be screened for sleep difficulties when they're on the diagnostic pathway as well, professionals need to start discussing sleep problems with parents from an early age, and helping parents to put new good sleep plans in place.