



Spotlight issue

Children and young people with additional support needs

The purpose of the spotlight issues series is to highlight themes or topics which have arisen across parental contributions. While these issues are reported across chapters, these short papers highlight key aspects for further reflection.

In our small group chats, and from the Chat national survey, we have heard the views of parents of children and young people with additional support needs (ASN) and disabilities. In our small group chats 33% of parents had a child with ASN. From our 3,676 survey responses 854 parents told us they have a child with ASN/disability (23% of respondents).

Across the Chat parents of children with additional support needs talked about their children. They have told us that children can have particular struggles with friendships and relationships.

Conversations in my home might be different than others in the group. Both boys have got ASD and so a lot of our conversations are about how you create friendships and how you are able to have conversations with peers. One of my sons does have a group, the other doesn't. So, we talk a lot about building relationships, how you take an interest in other people. We have lots of these conversations. We have conversation cards at dinner time, all to help our boys understand how to engage with people. So, this is important learning in our house. The children around them kind of know they are autistic, but I'm not sure they understand the struggles.

(Group chat 28)

Parents can be concerned about their child's vulnerability.

I'd say my youngest has no boundaries. Talks to strangers. No fear. It feels like that puts her in danger. I am quite nervous about any of them going independently to the park to play, and that's what they naturally want to do. We have talked about where safe houses are, you know people they know if they ever need someone. I know we have to let them go to some extent.

(Group chat 12)

You need to keep an eye on the experience your autistic child has of friendships. My son was desperate for a friendship group, then we learned these boys in school only let him hang out so they could make fun of him.

(Group chat 12)

It's tricky, my daughter is a teenager but cognitively is very much younger, with no concept of danger or being vulnerable. She is totally trusting. We do try talking, but she is happy in that place where she trusts everyone. We can't lock her way from the outside world.

(Group chat 14)

He is a very affectionate boy, touchy feely. So, it's about trying to get him to understand that as he is getting a bit older, he can't just go up and touch people, he doesn't seem to get that. With me he'll just put his hand down my top, he's so comfortable with me, but he can't be like that with other people, he doesn't seem to get it. and because he is so sensitive, even if I was to correct him very gently it's like the end of the world.

(Group chat 24)

He is struggling to understand he can't just take his clothes off, say at a friend's house. I suppose he has no sense of embarrassment or shame. He doesn't grasp what his private parts are.

(Group chat 24)

Parents have spoken about their child's understanding and responses to puberty.

We have tried to do some of this since my daughter was young, preparing her long before puberty because we knew that body changes would be difficult. But we didn't know what she would actually be like, like how she would react. There's been dangerous things she's done because she's not liked the feel of something. Like trying to remove body hair with tweezers, trying to fix what she does not feel is right. So, she knew what would happen, but we couldn't prepare her for the emotional response. And she isn't aware of what would be a private thing, so she'll

just tell people that she has her period, or things like the hygiene side, things would just be left on the floor or hidden in her bag. It just catches you out. Just having information that all of this could happen would have been helpful. Information would have prepared us, that things don't present as you'd imagine.

(Group chat 35)

I'd say I have always been aware of the need to think about puberty coming on, or think about things like privacy, but when it happens to him, when he is actually experiencing changes, I know he'll struggle with that.

(Group chat 24)

It's difficult to get this across no matter what way you explain it. My child is non-verbal and had complex needs so you don't necessarily know if they are understanding the information provided.

(Survey response/parent of 9–11-year-old)

My daughter won't tolerate things that are tight, so with her developing and getting into puberty we are struggling with helping her to understand and tolerate wearing a bra. I'm not sure where we are going with this. We did have the period talk when she was younger, we've tried vests, crop tops, but isn't tolerating anything, it's a sensory thing, and not getting that she needs to wear different clothing as she grows. I totally appreciate it's her body, but we've tried a progressive approach and still struggling. It's going to be a long process.

(Group chat 21)

I find this quite difficult. My son has learning disabilities, so I'm not sure I always understand what he understands. We haven't talked about relationships, because I don't think he has that understanding. But what he does know when there are things we need him not to do. So, for example if he wants to masturbate in the bath, we have to say that we don't want to see that, that's something you do in private in your room. When he was younger his hands were always down his trousers, so helping him understand this started then. He will understand that, but it's a regular thing we need to do. But I don't see relationships within his life, that he has that ability, I don't know how we'd approach that with him. With my children who don't have additional support needs, it's much more straightforward, we are led by their questions, and they are learning at school.

(Group chat 14)

Parents have identified the need for understanding and more nuanced approaches to some key concepts like consent and bodily autonomy. There are concerns that mainstream schools may not understand such complexity.

He requires personal care and sometimes we have to wrestle him into clean clothes.

This stresses me as consent is important.

(Survey response/parent of 6–8-year-old)

There is an issue when you are teaching your child that their body is their body, that they have choices about what happens to their body, then if your child needs medication and they say no, it's my body. It causes upset. So, it's great that kids learn about their body and their rights, but in primary school it can be an issue if they don't understand between different situations and how these things apply. I think at school they haven't understood how a neurodiverse child might understand some of these messages.

(Group chat 21)

We did decide to always use correct terminology with both boys, about keeping clean. But it's different with them, the oldest who has no additional support needs takes real pride in his appearance and has understood all of this. My youngest with additional support needs means we need to keep talking about this, he needs daily personal care. We always explain, ask for consent, even though he may not really understand this process. And I'm very conscious about how many people do personal care with my son. As a parent I have to automatically give my trust to these people, and that's hard. So, we've used the PANTS campaign with our older child, but the younger doesn't have that cognitive understanding. When you are an ASN parent you have to trust those adults around your child.

(Group chat 14)

Parents have talked about not being prepared or supported to reflect on their child growing up, including consideration of their child's needs as an adult. There are concerns about professional understanding and training.

With my girl I do think about how she will go through the body changes when she hits puberty, but more than that, how would she possibly cope with being pregnant, with having a child, with all the reactions and intolerance she has for so much stuff in terms of sensory experiences. How does a woman with autism cope? I don't know of anything that can help me think that far ahead, it feels like such a hushed-up thing. Like, are health professionals like midwives being taught about neurodiversity?

(Group chat 35)

Parents have expressed concern where there is little or no RSHP learning being offered in their child's special school/ASN unit; or at least if there is, they are not being informed about it.

Even though I know there's a ASN adapted version of the PANTS learning material, the school have never come to us saying anything about that, or saying they are using it. My other child had PANTS in mainstream primary. But no, nothing at all for my child in the special school setting, or at least I haven't heard anything about what they are doing about say body parts or privacy. I could ask, but I wonder how they'd feel about that? Do they assume our children don't need this learning because of cognitive understanding?
(Group chat 14)

I'm just wondering why the school doesn't have these conversations with us more regularly. It's obviously not happening. Is it because of some idea that disabled kids won't have sex? Does that play in to it? You know sexual health and wellbeing is more than just the aspect of having sex. You know, we've spoken about safety, about body parts, about consent. I definitely think that we need to go back to the school about this.

(Group chat 14)

Parents can be concerned about the ways in which mainstream schools facilitate RSHP learning when there are children and young people with ASN in the class.

As a parent of an autistic child, the pace of information is ill thought to enable processing and understanding. In addition, no question should be dismissed as inappropriate, children have different ways to help understand these sensitive subjects.

(Survey response/parent of 9–12-year-old)

We have to acknowledge that the autistic child can behave differently, it's like my son is less mature, still giving me a cuddle at 17, something my other son stopped doing years ago. So how does the sex and relationship education they get in mainstream school help address that? So, like he has reached the age where he might be able to have sex legally, but in terms of understanding and maturity he's not there like a non-neurodiverse kid. And then when he's 18, there will be nothing there to support him.

(Group chat 35)

The thing is they are in mainstream, but the reality is they are not like most of the children. We want them to have friends, but it's a feeling as a parent of constant dread that things will go wrong. I think they did stuff about friendship in the class, but I got no information about it at all, and it certainly hasn't helped my daughter.

It's not tuned in to what she needs.

(Group chat 35)

At 6 years with learning difficulties, our daughter is currently too young to be talking about puberty. In mainstream school this is going to be difficult to address with school.

(Survey response/parent of 6–8-year-old)

I asked the school what they were doing. He came home and I knew he was uncomfortable about something, and when I asked, they said they were doing some learning about bodies and puberty, but they didn't give me detail. I asked if they had some visuals they could use, but they haven't shared anything.

(Group chat 24)

I am happy for my child to cover all of these topics provided it is done by experienced teachers who have an understanding of my son's needs.

(Survey response/parent of 12–18-year-old)

School tells us nothing. I have older children with additional needs. When I asked to be told about any topics coming up involving sex/consent/puberty etc do that I could be sure to have a prior discussion I was told NO it's just part of curriculum. I think this is particularly short sighted particularly as my child had additional support needs! Next, they start blubbering on about parental involvement.

(Survey response/parent of 9–11-year-old)

For me, it isn't a one size fits all topic. But schools don't have the resources to tailor these lessons for each child. It's hard to take into account the neurodiverse children that will be in mainstream schools that learn differently. And they will need tailor made lessons that revolve around them. But basically, there needs to be so much more communication between parent and school, exactly what's being taught. And if we can have the option to exclude our child, based on what we think is right for our child, that's important.

(Group chat 30)

We had been told that the school were delivering the curriculum, but I could tell on the days that it had been done because he came home really dysregulated, I think the classes had been delivered quite awkwardly by the teacher who wasn't comfortable himself with the information. There didn't seem to be a development of a conversation, it felt like this was a case of 'oh we need to get this over and done with'. But for my other son, at his school, it is done with their PSE programme, and they have communicated with us, at least, but not the content.

(Group chat 24)

I am not sure teaching children about 'porn' other than how to avoid encountering it online is appropriate for my daughter as she is autistic and can become traumatised already by what is being taught. It is important to note that autistic teens are usually several years behind their peers in terms of sexual maturity and other than keeping themselves safe, overloading them with porn, stories of abuse etc. is not appropriate until they are at least 15 as it is traumatising and not suited to their processing/mental developmental stage.

(Survey response/parent of 12-18 year old)

Parents have raised concerns about how their child might understand teaching and learning about sex and gender. (The Spotlight Issue: Sex/Gender explores this in more detail).

I feel this type of education lacks transparency. I hear about bits from other parents as they discuss things their children have spoken about. I've already had issues with my son's school to get him the support he needs, I don't feel comfortable demanding to see these lessons. It would be much better if they just openly shared it. It sometimes feels like they keep it a secret on purpose which just concerns me more. I've had to tell him it's ok to be a boy who doesn't like football and sometimes cries after he told me a peer said he was non-binary. I worry a lot about transgender ideology being taught at his school especially since the recent publicity about autistic children being more at risk of struggling at puberty.

(Survey response/parent of 12–18-year-old)

For this parent there would be value in providing opportunities for children and young people who are neurodiverse to learn together.

Why aren't schools bringing neurodivergent children together? To create a space where our children aren't having to navigate the differences all the time. Just a bit of time for them. I get it, we don't want our children to be excluded, but also there are benefits for health and wellbeing and learning to be with peers that are like you.

But supported.

(Group chat 35)

When it comes to RSHP learning in school, the child needs to be present in class to take part. These parents have identified the impact of children being out of school, or out of the class when learning is facilitated.

I have one child in school and one child with high anxiety ASN who does not go to school so has missed out on 3 years' worth of this education.

(Survey response/parent of 12–18-year-old)

Both my boys are neurodiverse, one was severely ill at 15, the other one has been out of school for 3 years, so I don't know what they ever got at school about this stuff. They had little beyond 1st year, so likely no sexual education at school. It's one of the things I need to understand, what would they have got? I don't know what he knows. In the last few years as a family, we've been more concerned with keeping them going. The older one with anxiety, the younger one trying to not go there. I would like to know what they would have got.

(Group chat 35)

My child attends a mainstream setting on a reduced timetable due to LA being unable to provide sufficient support for his additional support needs.

(Survey response/parents of 6–8-year-old)

The school has accepted that my child has ALN and is currently undergoing neuro developmental assessment. Being internally excluded for much of the day and not being taught by a teacher, or indeed having direct teacher input into learning makes for a confused, under-achieving child. How then, will equality be taught in this instance, when it is evident that the child is not receiving parity of education with any other child in that school? How can the child be taught about friendships, relationships, kindness etc. when isolated from peers and with limited chances and places to interact with them?

(Survey response/parent 6–8-year-old)

Reflecting on what RSHP learning must be like if it is to support their child, parents identified the need for clarity and flexibility, with more of a focus on learning that works for the learner.

We know how vulnerable our children are to abuse. Statistics are staggering. Just how much more vulnerable our children are, to predators, but to things like sexting that are part of teenager's lives. There can't be nuance for our children, but then if we make guidance for them too rule bound, they get confused by situations.

(Group chat 24)

Whatever we could access it needs to be quite flexible, so that we can decide, yes, our child is 15 but this animation that looks like it might be for a much younger child would actually work for them.

(Group chat 24)

Whilst parents have been asked to talk and share views and experiences about learning about topics of interest to the Chat it is evident that this learning sits within a bigger picture for families when their child has additional support needs or disability. Parents have talked about feeling that they face struggles with a whole system, this can be overwhelming and that can feel abandoned and left to cope. These bigger issues need to be addressed as we look to deliver support and learning for children with additional support needs and disability.

You feel abandoned on a lot of this, you spend years bringing them up, nobody really helping.

(Group chat 35)

ASN needs must be met before the child is able to learn effectively.

(Survey response/parent of 6–8-year-old)

Our experience is how far behind school is in understanding things like sensory needs, they still come from a behavioural perspective, they wait for things to escalate and then they try to manage behaviour. I'm still trying to understand the language they use, how they work with children on relationships, but what I observe in drop offs and parties is that my son remains quite separate. I understand he has different needs, and the school has put in place certain things, but it feels like he is being othered and being isolated. At the end of the day, we pick him up and he is in a part of the playground near the support worker, reading a book. I'm not sure how good or bad that is because maybe he is just tired and needing to be separate. But if he's never with his peers at the end of the day, is that the balance he needs? I don't trust they are getting the balance right. And if I question these things, they just get defensive. Its constant, trying to navigate this.

(Group chat 24)