

Dee CEO of Autism Champions

October 21st 2024



Summary

The Oxfordshire SEND Room Connect event featured Dee from Autism Champions discussing strategies for advocating for children with SEND in education. Dee emphasised the importance of approaching school interactions with "quiet power" and curiosity rather than reacting emotionally.

She highlighted the need for clear communication and setting boundaries. Specific examples included a parent advocating for her son's right to eat alone in a designated room and another parent sharing a successful collaboration with the school to support her child's social needs. Dee also stressed the importance of having a trusted adult at school and using tools like email chains to document communication and ensure accountability.



Questions and Answers

Q: My 12-year-old, who is in secondary school, is on the waiting list for assessments for autism, ADHD, and other neurodivergent conditions (NDC). The school is aware, but he's struggling with friendships, and it's causing him a lot of anxiety. As a parent, I feel like I'm bothering them when I bring it up, especially since it's more of a social/emotional issue rather than an academic one. How can I advocate for him?

A: Let's start by rethinking how you view this. You mentioned it might not seem like a big issue compared to others, but it's clearly important for your child. Schools often wait for a diagnosis before taking action, but you can remind them that under the Equality Act 2010, they are required to make reasonable adjustments based on need, not just diagnosis. You might ask the school: "If my child had an official diagnosis of ADHD and autism, what support would you provide?" This question encourages them to think about what they can do now, rather than waiting.

A good school should be willing to provide support, such as finding a mentor or tutor to connect with your child. They could spend time discussing what's working and what's not and exploring what he thinks would help him feel like he belongs. Including you in this process, or bringing in an advocate, could also be beneficial. This approach doesn't necessarily require extra resources; it's about having an adult who shows interest in your child's well-being. This support can make a big difference, as it helps your child feel heard and may build their confidence in advocating for themselves.

OxPCF with Mental Health Natters

October 4th 2024



Questions and Answers

Q: As a clinician and a parent of a child with special educational needs (SEN), I find it very challenging to advocate for my own child, even though I can do it easily for others. I feel incredibly defensive when it comes to my child, especially when people question his behavior or my parenting. My child has ADHD, and I struggle with rejection-sensitive dysphoria (RSD), which feels even more intense when it's about him. How can I manage my emotions during these situations and advocate more effectively?

A: It's common for parents to feel defensive when their child's behavior or needs are questioned, especially if you feel like you're being judged. This feeling often comes from a sense of powerlessness. When advocating for your child, it's crucial to try to leave emotions at the door because showing strong emotions can sometimes make you feel less in control during conversations with the school.

If it's too difficult to manage your emotions in these situations, consider bringing a trusted person with you—such as a friend, family member, or someone who understands your child's needs. This person can stay calm, help keep the conversation on track, and support you in making sure your concerns are heard.

Another useful approach is "body doubling," where someone simply accompanies you during difficult conversations. Their presence can help keep you focused and grounded. You can also request reasonable adjustments from the school, like providing a written list of points you'd like to discuss during meetings. This way, you can stay organized and ensure that important concerns are addressed.

Lastly, if you need time to process information or respond thoughtfully, don't hesitate to ask for the conversation to be continued over email. This gives you space to respond at your own pace, allowing for more effective communication.



Questions and Answers

Q: I feel like I've become "that parent" because I have two children with autism and ADHD, each with different needs. I'm constantly emailing the school for help or sharing my concerns, and I feel like I'm being seen as annoying or aggressive. I worry that my communication has made me less effective. How can I handle this situation better?

A: Try flipping the situation around. Instead of feeling defensive, approach the school with curiosity. You could say, "I'm aware that I'm frequently reaching out with my concerns, and I want to find a better way to support my children. Can you help me understand how you proactively support autistic and neurodivergent students? What's already in place, and how can we work together so I'm not constantly having to follow up?"

This approach can catch them off guard—in a good way—because it's not confrontational but genuinely curious. It also shifts the focus from complaints to problem-solving.

To be more effective, narrow down your concerns to what's most important. For example, if your priority is making sure your child can arrive at school without being extremely distressed, focus on that first. Simplifying your requests can make it easier for the school to understand and address the key issues.

It's also important to avoid approaching these conversations as battles. While many parents feel justified anger about the support for SEND children, shifting from frustration to a collaborative mindset can change the dynamics. Schools can easily dismiss a parent who is visibly angry, but it's much harder to dismiss a parent who calmly asks, "How do you plan to support my child in this situation?" Small shifts in approach can have a big impact.

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Questions and Answers

Q: My son is profoundly deaf and uses a cochlear implant. In addition to being deaf, he has special educational needs (SEN) and possibly autism and ADHD. He struggles with social anxiety, has difficulty making friends, and often feels lonely, especially at lunchtime. Last year, the school arranged a play therapist for him, who suggested creating a small group of children who also struggle with friendships. The idea is to give them a space to connect, read together, or discuss games. Could this approach work in other schools as well?

A: Thank you for sharing, Maggie. It's important to help children find their "tribe," especially those with additional needs like being deaf or neurodivergent. A sense of belonging is crucial, and communities like the deaf community can be very supportive. While it's a great idea to create a space where children with similar challenges can connect, we also need to be careful not to isolate them or assume they should automatically become friends just because they share similar struggles.

In large schools, especially secondary schools, it can be overwhelming for students to navigate social dynamics. A small, supportive group can offer a sense of comfort and belonging, but it's important for the school to ensure it's done in a way that respects each child's individuality and needs. It's wonderful that the play therapist is advocating for this in your son's school, and it could be a helpful strategy for other schools to consider as well.

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Questions and Answers

Q: My son travels to a special school that's an hour away, so he uses a taxi. This makes it hard to have quick conversations with the school staff, and emails often go unanswered. I've tried calling and copying multiple people in my emails, but I still don't get responses. How can I improve communication, especially when staff keep changing?

A: It's helpful to have one designated contact person at the school. As a parent, you can request a regular monthly Teams call with this person, so you can have a face-to-face conversation and go through a list of updates and concerns. This can help keep communication consistent, especially if staff changes are frequent.

Since staff turnover is an issue, you could create a personal profile document about yourself, outlining how you prefer to communicate and what you need to best support your child. Include a timeline or list of previous contacts at the school, noting who you've worked with and the dates. This can serve as evidence of the frequent staff changes and prevent you from having to repeat your needs each time someone new joins.

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Questions and Answers

Q: My son is in a mainstream school with an EHCP (Education, Health, and Care Plan), but I'm unsure what the "standard offer" is for SEND (Special Educational Needs and Disabilities) in mainstream settings. He gets 15 hours of support per week, but Section F of his EHCP is poorly written, and we are appealing it. How do I know if he's receiving the right support?

A: There isn't a set "standard offer" for all children with SEND in mainstream schools. Instead, it depends on your child's specific needs as outlined in the EHCP. Oxfordshire does have a general SEND offer, which describes what schools can provide for children with SEND, but your child's support should be individualized.

To ensure your child is getting the right support, focus on two key parts of the EHCP:

- Section B: This should clearly detail your child's needs, describing what challenges they face.
- Section F: This outlines the provision needed to meet those needs. It should match what is described in Section B.

The goal is to make sure that Section F specifies what the school will do to support your child's unique needs. It's not about what other children receive; it's about what your child needs to thrive in their school environment. For more help with understanding the local SEND offer, you can reach out to Oxfordshire Parent Carers Forum.

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Questions and Answers

Q: My autistic son, who has an EHCP and profound sensory needs, struggles to eat around others. His plan specifies that he should have a room to eat alone, but this term, the school allowed other students into his space, causing him to stop eating. I tried emailing the SENCO to address the issue but didn't get a quick resolution. My husband then emailed the headteacher, and the problem was resolved immediately. I don't understand why his approach worked when mine didn't, and what I could have done differently. How should I handle situations like this?

A: It sounds like your husband's direct and straightforward approach made a difference. Often, as women, we try to soften our requests to be considerate of others, which can make our concerns seem less urgent. In situations like this, where your child's needs are clearly outlined in the EHCP, it's important to be firm and direct.

Next time, try stating the need clearly and assertively, for example: "My child must eat alone as specified in his EHCP. This needs to be resolved immediately." You have every right to be firm about your child's needs, especially when they're outlined in legal documents like an EHCP. Sometimes, being clear and direct can be more effective than trying to accommodate everyone's feelings.

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Questions and Answers

Q: My son has an EHCP that includes various provisions, like OT support for his sensory needs, which has just started. However, there are other areas where he needs help, such as dealing with misunderstandings and frustrations in communication, which he's mentioned before. In his annual review, something called "PEERS" was mentioned as a potential strategy. I'm concerned about the idea of teaching him to behave in a certain way to fit in, rather than giving him tools to understand neurotypical behavior while still allowing him to decide how to use that information. I also feel that the school picks and chooses when to address the provisions in his EHCP. What can I do?

A: Your concern is valid. It's important that your son isn't forced to "mask" or conform in a way that doesn't respect his authentic self. Instead, he should be empowered to understand his own communication style, recognize how it might be interpreted by others, and choose how to apply that knowledge.

When a school delays implementing parts of an EHCP, such as providing support when it's needed, it can be discriminatory. The provisions in the EHCP are meant to be implemented based on your child's needs, not on the school's convenience. If your son needs support with communication now, they should be addressing it now, just as they are providing the OT support. You have the right to insist that the school meet all aspects of the EHCP as specified, rather than delaying or prioritizing certain provisions.

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Questions and Answers

Q: What can I do when a SEND school isn't being flexible around my child's PDA (Pathological Demand Avoidance) needs? The school is out of county, and my child has been attending for over two years with around 50% attendance. They refuse to be flexible.

A: This is a tough situation, especially after two years with no progress and ongoing resistance from the school. It sounds like something needs to change to improve your child's experience and attendance. Here are some suggestions:

- **Get an Advocate:** It's important to have someone to support you and advocate alongside you, not just as a parent. This could be a professional, a representative from SENDIASS (Special Educational Needs and Disability Information, Advice and Support Service), or someone from a local parent carer forum.
- **Look for Small Changes:** Sometimes, after a long struggle, it's easy to miss the potential impact of small adjustments. Ask yourself, "What small change could make a difference?" Even tiny shifts in approach or environment might help.
- **Seek Fresh Perspectives:** It can be helpful to have someone outside of the current situation offer a new perspective. This could be a new staff member at the school, a SEND advisor, or another parent who has been through a similar experience. They might help find a way to "flip things on their head" and come up with new ideas for supporting your child.

The key is not to give up on looking for a different angle or approach, as sometimes even a small adjustment can lead to better outcomes.

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Questions and Answers

Q: My twins have been out of school for four years. They're currently with Dare to Dream but have had four different support workers since January. No specialist school will accept them. What should be the next step?

A: It sounds like your twins need a very tailored and specific approach to their education. Consider looking into EOTAS (Education Otherwise Than At School), which might better suit their unique needs and interests, especially if a traditional school environment isn't working for them. EOTAS allows for more personalized education, focusing on nurturing their interests and strengths. You might find helpful resources and support from SENDIASS, Jules, or relevant EOTAS Facebook groups, which can provide advice and connect you with others who have similar experiences.

Since they've been out of school for a long time and the traditional approach hasn't worked, exploring EOTAS could be a positive next step to provide the support they need.

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Questions and Answers

Q: When should I request an EHCP (Education, Health, and Care Plan) for my autistic child in mainstream education? She receives some SEN support at school, but it seems like she needs more help to reach her potential.

A: If you're already wondering whether your child needs an EHCP, it's likely time to apply for one. You don't need the school to request it—you can apply yourself. You can find a template letter on websites like IPSEA and submit a request for a needs assessment.

It's common to be turned down initially, but don't be discouraged—reapply if necessary. Don't wait for the school to say your child needs more support. If you feel the current support isn't enough, start the process yourself.

It's also helpful to seek support from organizations like SENDIASS, Jules, parent carer forums, and online resources. They can guide you through the process. There are templates and guides available online to help you get started.

Remember, it's better to apply and have the support in place, even if you end up not needing it, than to realize later that you should have applied sooner. While the system may be overwhelmed, that doesn't mean you should stop advocating for your child's needs.

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Questions and Answers

Q: I made significant changes to my child's EHCP due to serious issues, including sexual assault within a specialist setting and grooming at a specialist residential school. Despite this, the local authority (OCC) refused to change any of the provisions or sections, as my child remains at the same setting. They sent a standard letter saying no significant changes are needed. It's incredibly frustrating. What should I do?

A: I understand your frustration—it can feel like you're stuck in a cycle, constantly pushing for changes without seeing progress. It's extremely difficult to watch your child struggle while feeling like the system isn't listening. Keep holding on, though. Sometimes, persistence does lead to change, even if it feels slow. It's important to keep advocating for what your child needs, as challenging as the process may be.