

insights

How to better advocate for your child on the autism spectrum

by Kate Johnson



When you think about advocacy for a child on the autism spectrum, what springs to mind? Is it the lobbying on the television by interest groups? Is it signing a thought-provoking petition online? Is it a carer trying to push for support at school when life is spiralling out of control for their child? Or is it working with a therapist to try and access a new school/service?

It is all those things and so much more.

If you have a child or adolescent on the autism spectrum, advocacy is something that you may be very experienced in. However, even if you are new to this situation, being able to be effective as an advocate in meetings is essential when supporting your child at school.

Advocacy can be incredibly draining. Depending on the meeting, there may be instances where you hear about every one of your child's challenges while on the inside you are yelling, "But you can't see all the good things!" You may be called in to help make decisions on reduced attendance or to hear the outcome of funding news. At secondary school, the need to communicate with each teacher individually often intensifies as they may not have the same communication system as existed at primary school. This requires additional advocacy efforts.

So, what can you do to advocate well for your child or adolescent in a meeting situation?

- **Understand the purpose of the meeting.** If it is not clear, ask the reason for the meeting at the time it is called. It can be incredibly hard to think logically and recall information when surprised or shocked. Emotions can make us feel so unsure or overwhelmed that we struggle to respond well. By knowing the purpose of a meeting in advance, you can potentially think through some ideas, plan and problem solve in advance.
- **Know your rights.** This is a big one. It is good to be clear, before you enter a meeting, what support you can ask for or what the processes are when a major decision is made. If your adolescent has had their school hours reduced, is there a plan to reintroduce those hours and a timeline for that? Other carers who have had similar experiences may be able to assist by sharing their experiences. The education department in your state will have a document outlining their program for students with disabilities. Download, print and read this thoroughly. If you have therapists supporting your child or teen, you could ask them for advice.

- **Understand your value.** Your voice matters, so don't see yourself as 'just the carer or parent'. You are not 'just' a parent/carer but an important part of your child's village of support. You see the impact of positive strategies and some that need to be assessed. As the carer, you support your child in various environments and can describe approaches that may work well, are supportive and provide for sensory regulation.
- **Be proactive and attend with ideas.** When you know the purpose of a meeting, you can come armed with ideas and strategies to discuss. Is your adolescent's anxiety overwhelming them? Could they benefit from regular sensory or movement breaks using a discrete card so as not to draw unwanted attention? Does the work need to be broken up into sections? Does your child need support to navigate the playground or could the school look at establishing a lunch time club or activity group? Your ideas are valuable and deserve to be heard.
- **Take a support person.** Sometimes, having a support person in a meeting can change the dynamic, especially if there are additional barriers to receiving support. This may be a partner, a supportive friend, an advocate or your therapist – anyone who could add value to the meeting.
- **Take notes.** After the meeting you might need to think about the approach you will take to further advocacy. You may need to engage additional therapy for your child or adolescent. You may need to seek advice and support if you feel something seems a bit 'off' and is not in line with the responses you receive at home. Having notes to refer to at a later stage can help trigger your memory, make follow up calls and track progress.



You may have had an amazing meeting experience, or it could have rocked you to the core. Regardless of how you go in a meeting, it can emotionally drain you. There is something to be said for the therapeutic cry in the car to release emotion. Give yourself space to process and feel it all. Let it out and chat to a supportive and understanding friend. Be kind to yourself!

For more ideas on advocating well for your child, you may like to check out our new resource from Spectrum Journeys called 'The Advocacy Project – a parent's guide to becoming their child's best advocate' and learn from the women who have shared their advocacy lessons and triumphs.



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