ASD: help and support outside your family

This is a transcript of the Raising Children Network video available at http://raisingchildren.net.au/articles/asd_support_video.html. Parents talk about the support they found helpful when caring for their children with autism spectrum disorder (ASD).

**Korrine [mother of two, two with an ASD]:** The fact that I had an online mothers group that I had met when I was about four months pregnant with Bailey, and so we’d all kept in touch, and one thing that was fantastic support, even though there was nobody necessarily in the same situation as me, was the fact that they were someone that I could talk to. I could get online, you know, when Carl was at work, or things had just gotten completely out of control that day. And I could get online, and I could tell somebody what was going on, and I really think that... sort of, that was a massive help to my sanity.

**Tracey [mother of two, one with an ASD]:** I just found that I’ve had to... it sounds bad, but, become a bit more selfish, and realise that, ok, this is the long haul, and I just have to take care of myself and do stuff that um... is good for me. And I like running, so that’s sort of my thing, so when they’re in preschool, you know, mum’s out running.

**Korrine:** Having a group of girlfriends who all had neurotypical kids was brilliant, we get together for nights out and stuff like that, and it kind of allows you to get completely away from the whole thing of autism, which sometimes you need to do, because it engulfs your whole world.

**Laudie [mother of three, one with an ASD]:** From Jonathon’s diagnosis, ah...we were eligible for a case worker, and she was with us pretty much from the time Jonathon was diagnosed. She was a fantastic resource to have, because without her, I wouldn’t have been able to... I wouldn’t have known where to start.

**Elena [mother of three, two with an ASD]:** In my support group, um... I meet a lot of mothers, and a lot of them are newer mothers than me, and it’s really hard to tell someone where to start, and what to do. I can honestly say I did a lot more than I needed to do. So I normally say to them, um... you know, not to do too much at once, because often you don’t know what’s working. It’s ok to try things, if you think something might benefit your child it’s ok to try it. But not to pursue it if you don’t feel like you’re getting any benefit.

**Laudie:** I’ve come to the point now where I look back and I think... I have learnt so much through Jonathon, and I’m ready to help others in their journey through autism. So I joined a program and it’s a volunteer program. And I went to a training session and I learnt so much about talking to families over the phone, who have just had their children diagnosed, and I thought, ‘This is just what I would love to do’ because I didn’t have anyone, really, when Jonathon was diagnosed, and it was a real ordeal at the time. You feel so... lost and alone, so it was just good to be able to pick up that phone and say to someone, I’m here to listen to you.
Korrine: I have three hours of respite a week, but that’s with one person coming to the house, and I can’t leave that one person... even though she’s fantastic... I can’t, I have trouble coping with my two boys on my own. I’m not going to leave somebody else to struggle with the same thing. Especially when it’s not their children.

Jerry [mother of two, one with an ASD]: Daniel ah.. goes to respite service, fortnightly on Saturday, and every vacation. Just like excursion at the school, they go out to the city, zoo or museum, and anywhere. I think it’s quite good for him and I.

Korrine: If you find the right support group, especially of other parents with children with autism, is that most of these families have absolutely amazing stories. And some of them, I have been able to look at my situation, and go, ‘You know what, I’m doing pretty well.’

Tracey: I went to a GP when um.. one of my boys was sick, and we’d just moved into this area. And um... he mentioned a support group, so I then accessed the support group, and I find that really god. Because I find that a lot of the people that I mix with from preschool or whatever, they all have neurotypical children, and they really don’t get it. The only people that can really get you, as far as what your life is like, is the people who are doing it the same.

Korrine: One of the biggest things with having a child with autism is never stop learning, never stop talking to other parents, never stop researching and finding things out, because that’s what will get you ahead, and that’s what will help you, as much as your children.