Disability services and support

This is a transcript of the Raising Children Network video available at http://raisingchildren.net.au/articles/disability_services_support_video.html. Disability experts talk about how to get information about disability services and where to start. They also discuss funding, what makes a good service provider and different types of respite care.

Associate Professor Jan Matthews [Psychologist, Parenting Research Centre]: What makes a good service provider is one that recognises partnership with families, one that acknowledges the family’s own goals as well as the goals of the service, and one that sets out clear expectations for both sides of that partnership: what the service is expected to do but also what the family is expected to do in terms of that service.

Elizabeth McGarry [CEO, Association for Children with a Disability]: We often talk to families about the fact that they’re entitled to have support for their child. So it’s really important not to feel like you’re a burden on society or on the government if you’re seeking support. Your child is entitled to that. So we think it’s really important to feel confident that you have every right to seek out the best support you can find for your child.

Jan: Take some time to think about what type of support is important for them right now. Is it emotional support from family and friends? Is it information or support about the diagnosis, and services they can access straight away? Or is it practical support – someone who can do some shopping for them while they attend appointments; someone who can look after the other children while they concentrate on the child with a disability?

Elizabeth: It’s well recognised that the best support parents can give their child is to stay strong and positive themselves, and to keep their energy levels up. And so looking after yourself is really important. Looking after yourself is one of the best things you can do for your child. It’s not just pampering, it’s not self indulgence at all.

Christine Cameron [Psychologist, Parenting Research Centre]: You might hear about respite services. What they are is a range of services that will take on the care of your child – either for a short time, or a longer time – so that you can do things that it’s difficult for you to do when your child is around.

Elizabeth: There are programs where it’s almost group respite that’s provided, so activities where a group of young people with disability might go together and have an outing. Sometimes they’re available during school holidays as well.

Christine: There are some respite services where the staff or carer will come into your home for just a few hours, or there are others where your child would go and stay either during the day or overnight, or for a number of nights, in a residence.

Kati [Mother of three, one with Down syndrome]: With the respite it’s a good break– not just for myself – it’s a good break for Taylor where it’s just about him, now that he’s got two siblings. And it’s also a good break for the two little boys, and they get some time with me.
Christine: We know that having short breaks that either give you an opportunity to do something you need to do, or give you an opportunity to just take a breath, have a bit of down time – sit and read a book if that’s what you want to do – they’re the things that build your resilience and help you keep going at the times where you need to keep going.

Jan: Support for parents and families can often be sourced online, but parents need to be aware that you need to access trusted sources. Even when there are forums, you need to be really careful about what’s being said on those forums and how you receive that advice. Advice given on forums may not be evidence-based, but it’s something to put into the mix, something to think about, to consider.

Elizabeth: There’s some good information there but it’s not always helpful. I think government websites for children and disability are the best place to start, if you’re looking online. Throughout Australia there’s the national carer counselling service which is a telephone service, and you’re able to ring and speak to qualified people, to talk about how you’re feeling at that time.

Mike [Father of two, one with cerebral palsy]: One thing we found very useful – and once again it was through the physiotherapist – we went to some counselling that was not marriage counselling, but it was counselling about raising a child with a disability, and about some of the realities that you have to face. I think one of the big realities that we had to face, and I think everyone has to face, is that at the end of the day it’s Kennan’s journey that he’s going on. We’ll support him, but he’s the one who has to go through a lot of the pain.

Elizabeth: There are disability specific organisations and groups and it’s always good to make contact with them too because they usually have access to good information that will help you and your child and your family, and so it’s important to go looking for that sort of support. And, paediatricians, social workers, the community health centre, therapists that you might be engaged with, should be able to provide you with the information, or set you on the path to find that information.

The federal government recognises that there are challenges to providing support to children with a disability and so therefore there are allowances that are available through Centrelink. So there’s a carer’s allowance for children called Carer Allowance (Child). And then also if your child has significant disabilities and significant caring needs, there is actually a carer payment for children as well. So it’s important to go to your Centrelink office, or go to the Centrelink website and find out some more about that. At various other times there are other allowances that you can access, so it’s best to go to the Centrelink office or website and find out what’s available to you.