



VIDEO TRANSCRIPT

Accessing Medical and Therapeutic Services

Families living with autism spectrum disorder often look for tips on how to handle the many different challenges that may arise. “Real Life Tips for Kids with Autism” is a series of practical videos and resources presented by the experts at Children’s Specialized Hospital.

Nobody’s going to come to you and say “These are the seventy five things you need to do to for your child.” It is a journey that you will go on and your child’s needs will change over time as they become older, as they go from school to aging out of school. Each of those steps in the process, it really is so important that parents make sure that they understand how to find that information and not wait for somebody to give it to them. In the medical model, you think, okay the child will make the diagnosis and then they’ll tell me what to do and then I’ll do what they say and it will be over. It isn’t that easy, it really does require a level of intervention and commitment on the parent’s part to be able to navigate this and really understand how to find all of the different answers.

As much as possible, those feelings of failure and regret and all those things that happen, put them in a box, put a bow on them; they’re not relevant here. What’s relevant is you have a beautiful child who people have spent their entire lives trying to figure how to help live in a world that we could make better together and from my heart I would say to you that you are not on this journey alone and that we are very interested and very committed to making sure that we create a world that is better than it is today.

There’s a whole system in the federal government that is called Early Intervention that every state has access to, that creates the opportunity for children before age three to get in for services. There’s an infrastructure, may be called different things in different states. In New Jersey we call it Special Child Health Service, but there’s an infrastructure where parents can go and say, “I think something is going on, I don’t really know what to do.” Obviously you need to have conversations with your pediatricians, but the truth of the matter is, it’s not a science in reference to being able to say “here’s a blood test let me see what’s going on.” Some of it you as the parent instinctively will know.

As you think about how to access services, as I mentioned in New Jersey we happen to call it Special Child Health Services that you would call, it’s an 800 number and try to navigate this journey that you’re on. It is not income based. You don’t have to be poor, if you will, to be able to access these services. It’s about making sure you find the right services in your community. There’s a range of ways that people pay for those services because there are different payment methods and payment requirements as you get into programs. But the most important thing is starting to figure out how to access them.

If you haven’t accessed them by age three and you need to then think about how to move into that other system, it really is about working with your local school district and every child is entitled to a free and appropriate public education in the United States. It’s a federal law and it is critically important to understand how those processes work and again that Special Child Health Services can help you with that as well as the state has many resources. Every state has many resources to help navigate those journeys and you know many people think, “ Oh well I can’t do that. I’m not...my husband makes too much money or I have a full time job and my husband has a full time job, like we would never be eligible for those programs.” It doesn’t work that way. It really is about making sure you

have access to information and then we figure how to put you in touch with the right way to get them. There's very, very different rules depending on how your health insurance works and what health insurance program you're in. So it's very important to understand those as you begin on this journey. Again, there's sort of an education component and that's different than the medical component.

There are often things that we do in the medical clinical side of the house that will support your child and education, but they are different.

As much as you can develop that partnership, either with a state entity or with your physician or a clinician that your child is working with, that is so important because those relationships will help you navigate that journey. And again there also are many training programs, many of the advocacy organizations offer training programs on how to advocate for your child whether it be with an IEP, with the Individualized Education Program, or within the state system and those are helpful to try and craft a plan, if you will, to make sure you have that life long of attack, if you will, on how to put all those services together.

I think the hardest part for families is sometimes they'll go to a national conference or they'll talk to somebody in another state and they'll hear we have this or we have that, and then it doesn't exist in their own state and they don't know how to reconcile those two things and so I would say it is important to understand that the services are state specific. It doesn't mean you can't advocate for that to happen in your state, but it may not be available as you sit there today. Really having that local information in your own state. Again, use those resources that are available to you - whether they be at the library or your Google searches. Make sure you're asking those state specific information. If your child has a disability, often the state will set up a situation that that child will have a case worker, whether it's in the Department of Children and Families or in the Department of Human Services and just make sure you know that you're on those lists and that you've navigated that. The school system is often an important part of that journey with you until that child turns 21 and then the whole world is different again so it's a process that you will have to go through to make sure that you understand what's available.

It's often hard to listen because you're so focused on trying to succeed and often there are nuances in what people are telling you that will help navigate that differently or better, so "No I can't approve it this way, but maybe I could approve it that way," or "No we couldn't provide those services in school, but maybe you could check your health insurance." And making sure that you've understood what's available and what's possible, understanding that it's different based upon who offers you the insurance, whether it's the employer, or whether it's the government, it's different based on what state you get that insurance in. All of those things are unique so you're going to have to be persistent in that journey and really make sure you ask all those questions and ask them a lot of different ways not because you are trying to get different answers, but because you want to have the full story.

We need to make sure that we keep parents strong through this process so they can help their child be all that they can be and while there are times that I'm sure you are going to be tired please know that it's worth it. Every single day of it is worth it.



Through a partnership with Kohl's Cares, Children's Specialized Hospital is improving access to care for children with special health care needs.



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