

What parents want other parents to know about early childhood intervention...

ONCE YOU HAVE STARTED.



EarlyEd
Early intervention for
children with disability

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EARLY INTERVENTION MAKES A DIFFERENCE

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CELEBRATE

"The one thing that I really again wish that we had done when we start early intervention was to just stop and celebrate the many successes along the way. When we had our baby we knew that a lot of the early intervention we were going to do was to get her ready for school which was 5 years down the track. There was like this artificial finish line that we were running so hard to get her to. In that time there were so many achievements and milestones, I really wish we just stopped, celebrated each one, taken our time to really appreciate where we got to, then taken another breath and then gotten on to the next thing. So one of the main things would be to really just stop and celebrate all the many successes and achievements you are going to have along the way. Enjoy that and then get onto the next thing. There are so many things you can celebrate along the way with your child, your family, your partner and all these people in EI who are helping you along the way."

"Patience, is another huge huge factor and just being able to recognize those small achievements and celebrate them."

They will do things at their own pace

"I think it's important if they can understand where their child is at and say this is what I want from my child to reach. I have 2 older children and you get these parenting books and your supposed to reach these milestones which my other 2 did so that was fine but I threw out that parenting book when I had Olivia because she was developing at her own pace and her own speed so I wasn't sure like what is she supposed to be doing so things like that I think it would be helpful for them to know ok this is what a child at this stage should be doing, your child is doing at their own speed but we can help them develop when they are ready to get further on."

"They are learning every day. Everything is a slow step. Sometimes, you plateau with their learning but in terms of where they are to in honest we didn't know where they would get to, they are doing great really."

Parents are most important

"This might sound harsh but I think, that you will get a lot of people that want to help you and programs that will be beneficial for you but really you are the only one to drive it yourself so it's important that you very early find out what is the goal what is the end result what is it that you really want. If you find somebody or program that doesn't work enough just be strong enough to say ok, I'll try something else or get a second opinion. Because there is only you that has the ultimate interest in your child's wellbeing and the progress and journey. It's hard I've made mistakes we will make mistakes but never give up. Resilience and determination is very important."

Feel supported

"You have this massive support group at early intervention that are there to help you with whatever you need and you are able to talk to them and if possible start early intervention as early as early as you can."

Ask questions

"It's also about empowering yourself and directing your own goals. Use some of your therapy time to talk to your therapist. I don't think talking to my therapist during the session is a bad thing, I don't want them to spend all of their time, I have at least 15-20 minutes in a session where I am talking to them where my child is at, what we need to do next."

"Don't be afraid to ask for help. Don't be afraid to ask questions. The more questions the better. Don't be afraid to have multiple therapists. They all work together... speech, the OT and the physio. Don't be afraid to connect with other parents, other families within your early intervention group. It's really nice to have that support and share stories because they are going through a lot of the same things that you are going through and what you are feeling. It's nice to know that you are not doing it by yourself."

WRITE THINGS DOWN / MAKE A LIST

"I think one of the things I started doing later but I should have done early on, is when you go to therapy because there is so much information to take on during therapy and then you got the next therapy, you tend to forget. I think I should have spent more time in therapy writing down the action points for myself and less time actually doing therapy with my child because I could do the therapy at home it's just about learning what they are and doing it at home it would have been better use of my time, I tried to just take in and remember everything and my memory is just crap so it wasn't realistic. Now I've got a white board at home where I write her goals for the week. And that way also it's not just my goal."

"I would say make yourself a question list because you will have things pop up. Make yourself a list what you want to ask people whether it's the early intervention people or the doctor. Make yourself a to do list, so, you don't feel overwhelmed of where do I go what do I do. So you have got it written down on paper you can tick it off. Once you have asked your question you can write your answer underneath and you can go back to it. If you sort of think I don't know, that you can check your booklet, yes I asked that and you have your answer in front of you. To me it made things clearer to make a to do list and a question list."

They will be flexible

"We still had amazing support in our playgroup. They were very accommodating to what they could and could not do for Christian. When it came to snack time in playgroup, how can we accommodate him. So it was really good in terms of support, they were willing to adapt to whatever we needed."

Have expectations

"It is important to have expectations I still want Olivia to reach her potential I don't know what that is at this point but she has potential to learn and I can see it as she develops. She does it at her own pace, in her own time, but I know there is potential there. Potential for her to learn new skills, she signs, she is starting to say words now. So that's there, so once you get that where you could see where your child is, it's always important to push them a little bit to see how far they could go like you would a normal child. You always want to encourage and support them, same with your child that needs special attention at times."

"Another thing, our Mark certainly tried to get away with murder, and he can because he's so cute. But don't let him get away with it. He can eat as much as we can. There's a thing about people with down syndrome does certain things they don't like. That's rubbish. They can do exactly what we can do. If he doesn't want to walk you'll have to stay home. All the things my daughter can do, he had a go at. On a different level, modified level."

Important to connect with other parents

"That obviously helps too that you have good people around you. But I think it's important you actually grow up and learn to be good networkers when you have a child with a disability. You need to be able to use people to be able to give. Some people walk into your life and walk out of your life. You can't hold on to everybody. Some people will like what you're doing some people won't. We always said from the beginning of an early age, we always said we want you to become a valuable member of the society."

"That's really important for me. Having other parents there who you can relate to, who you can talk to. Because when you talk to ordinary sort of parents a lot of them don't understand. They talk about their kid breaking a leg and what a terrible drama it is. And you sit there thinking like "oh my god they broke a leg wow" But you have to be careful because everything is relative or for them it's a big thing. But if you have other parents who have been through what you have been through, who know what it's like when a child has been at the hospital or ongoing health issues or when there are issues at playground where they are being rejected. It's really important you have that."

Focus

"Focus on one key goal, and then you can have many goals along the way. Every time you meet with your therapist, just remember your key goal and have shared goals with your therapists, they will give you an idea what they think from their experience what your child's next step might be? It can help you to set realistic goals and celebrate all those milestones along the way."

"If you just focus on one key goal while still doing a little bit of the other therapies, it just helps in terms of managing. Don't feel like you can do everything at once. Because as a parent it's really overwhelming in the beginning, just getting your head around everything and learning about your child's needs and that's the most important thing to focus your energy on."

Courses can help

"Group therapies are really good. What would have helped was to be in a group with people on the similar level. It's a lonely journey. We found the playgroups excellent. The special needs playgroups, to be able to meet with other families, chat with the therapists, they were really valuable."

"I have always thrived on other people's experiences and still seek out opportunities to 'network' with other families with a child with a disability. You get great ideas and new perspectives from these meetings and they should definitely be offered from an early stage. The group sessions were an important part of this for me. It is also very strengthening to be able to give advice to other families as you progress through those early years (and come out alive at the end of it!)."

Feelings

"I remember being so angry at times about the need for all these professionals in my life. I would be thinking "They are telling me how to hold my child, they are telling me how to feed my child, they are telling me what to feed my child, they are telling me how to play with my child, they are telling me how to talk to my child... WHY CAN'T THEY JUST LEAVE ME ALONE!!!" I was really struggling with the parent-therapist role that you are given in those early years."

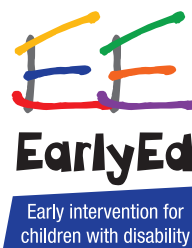
Confidence

"Have confidence in your own knowledge – you know your child better than anyone else. Seek a range of medical opinions to decide a future course of action but trust your instincts."

USE A KEY WORKER APPROACH

"Looking back, I didn't know a lot of the time what I needed. Until someone said we can do this and I'd be like Oh ok, I didn't even think about that. So yeah, always get a good key worker to help you with what direction you want to go. What's important at this stage, do I need to work on this or do I need to work that. Usually you can only work on one thing at a time before you develop that skill properly. Prioritise what's important and what's important for the child. I guess swallow properly to stop from choking rather than say colours and words and things like that. See what's important for them too."

"Look the main thing would be to really do the things that I have said previously which is focus on the here and now, celebrate achievements along the way and I think the other thing would be is to just keep checking in with the therapist about the things that you should be focusing on next. So early intervention is very good at being very family led but if you have a background like me I'm not a teacher, not a doctor, or a nurse, or a psychologist, an OT or a speech therapist or a physio, so my knowledge of child development was very limited and my ability to get across all of that and at the same time bringing up my young family was very difficult."



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