

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

KEEPING IT GOING.



EarlyEd

Early intervention for
children with disability

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EARLY INTERVENTION MAKES A DIFFERENCE

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Prioritise

“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.”

FIND A BALANCE

“I wouldn’t stress as much. First year or two years I was really stressed out. Because I was told you have to do speech therapy. Because there’s this whole idea now that the parents are being empowered to do stuff. Which is like yes it’s a good thing but it also has a drawback that you feel guilty if you don’t. So I think there is a balance between doing this stuff doing different exercises but as I said before it’s also important to think like it’s your child, you just need to love them and be there for them, they need to feel loved, not like okay, you have to do this now, you have to do that now. I would just stress less.”

“I think it is important to remind parents once in a while that if it all gets too much, to allow yourself some time (preferably a week if possible) where you are JUST A MUM. To stop feeling guilty for what you are NOT doing, and focus on having FUN with your child. I really feel quite strongly about this and wish someone had told me that it was okay to have a break from it all and pretend you were a normal family.”

“Maintain your humour. Try not to take life too seriously.”

Break things down into steps

“So then you say ok if that can be achieved, he can walk, he can say little words, he can do a puzzle, so then it’s the matter of breaking things down and then working on one little step at a time. That’s how it’s been at school, in a social setting, it’s how it’s been through just using a knife and fork. Everything has to be broken down and at the end of it you do it subconsciously. It’s not something you write down and mark off when you achieve it, that’s just how mark works. I think early intervention has been instrumental, I have become a better parent from going there.”

Regular and at home

“Having all those services at my own place is one thing that I love. I don’t have to go anywhere, they come to my place and do the therapy. They make sure the child’s at his best and they adjust according to child. So, we are just having a lot of fun with them. All their services, everything, I just love it, being around him and around them.”

“There is a big difference being able to go back each week to your therapist and to them seeing how your child is doing. It’s very good.”

YOU ARE A TEAM

“You are a team. Just always remember, therapists do want the best outcome for your child. You are not in competition or anything, they want to help you. They do anything they can to help your child. If for whatever reason you don’t feel like its working, you can talk to other organisations.”

“So in terms of when we first started, I think just having someone there encouraging us and pushing us and telling us what we needed to do, we really needed that. So when we started our physio.. she was really good- she was like why don’t you try this try that. She was there to support us to guide us, she hooked us up with an OT there and working together they helped us build onto what we knew and helped us catch up onto everything that we had missed out. I think that was really helpful just having a cross disciplinary practice where everyone was working together and able to help you all in the one place. It was really helpful for us.”

Challenges

“I would sit and think, yes there are issues and we need to sort them out but you get through it. It’s a bit of a challenge. It’s always going to be a bit of a challenge. You just have to be positive and think of the good things that can happen and have that attitude of being positive and think it’s all going to be fine and we are going sort it out. Then I think that probably really makes a difference as well.”

“You may be tested but difficulties define us, shape us and transform us into a better version of ourselves.”

It’s a long journey

“That it’s a long journey. Things don’t happen as quick as you want them to happen but it is really important that you don’t give up or get don’t down and its okay to get down. And you just know that you are going to have better days. 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. And that will help you feel not so much like you have fallen behind but it will help like the developmental kind of things. I guess mentally it will help you get through everything cause I guess it’s not as hard I guess if you start earlier as you will see the steps a bit quicker.”

Persevere

“I wish that I knew that it was going to be a long journey and for us not to give up hope or get distracted or get down on ourselves. It is a hard journey but it’s not the end of the world. There’s always people there to support you, help you, to ask questions to, it does get easier even though it seems like it doesn’t.”

Empower yourself

“So it wasn’t about the 1-hour session being, ok my daughter has to spend as much time in therapy as possible and that is going to give her the best outcome, it was actually I need to go to therapy I need to learn what we are doing in therapy so that I can go home and do it at home. So it’s about what we can take back home. If I had one piece of advice for parents I would say empower yourself, it’s you that needs to teach your child at the end of the day, it’s you that needs to be learning and be active apart of that therapy ask a lot of questions early on, set goals with your therapist and then at home you can incorporate that into your daily life and that way your child is not just getting benefit from that 1 hour a week of OT and PT, but actually they’ll benefit throughout the week. So it’s not a case of does my daughter need 2 sessions of speech therapy a week, actually I can only handle taking in one I get the skills and that week we work on it, so it was just the change of mindset.”

Knowing my rights

“I suppose knowing what my rights and Georgie’s rights were in terms of what could I ask for when I needed more help or was it okay to say back off I don’t need any help. Just knowing what our rights were really would have been more helpful, I think.”

THINK ABOUT INCLUSION

“It’s really important there is inclusion. My daughter for example is very sociable when she goes to playground or shops. Sometimes kids will shy away from her if they don’t know her but when she meets kids she goes to school with and they come say hi how are you, she loves it. And that’s just so important because this friendship sort of issue is such an issue for all kids with disability and if they go to a mainstream school or daycare then they are able to have these friendships, which is really good.”

“There’s many things people with disabilities get away with because we feel sorry for them. And I don’t think we should feel sorry. We shouldn’t feel sorry. I don’t want to be felt sorry for. Its about acceptance, about inclusion.”

Your journey changes

“I think knowing that the journey will change continually, if I had known that it would have been helpful. Sometimes I thought we lived at therapist offices or medical offices and other times life became very normal. My kind of advice for families at the early stages of getting a diagnosis and working out what that means, don’t think every day is going to be the same, or every month or every year. It changes all the time and be okay with that.”

“I don’t know if I know the exact answer there but I think it’s been open to the fact that your journey will change continually. Sometimes you will need a lot of support, sometimes you will be too busy or your child will be consolidating or they’ll be unwell so it’s just knowing and feeling confident to ask the questions and put your hand up.”

Everything doesn’t have to be special

“When you have a child with a disability the medical machine just needs to get underway and there is a lot you can’t control. And often you feel like you have given birth to a disability rather than your beautiful little baby. Early intervention is the opposite of that.”

“What I know now that I didn’t know in the beginning was this whole idea about when your child is disability and special need, you kind of fall into this special sort of trap where everything sort of becomes special. So, your child doesn’t go to swimming lessons anymore, they go to hydrotherapy. There’s all these special sort of words out there. I guess I’m lucky because I have an older daughter so I knew what kind of ‘normal’ was.”

Involve the whole family

“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.”

Keep it fun

“If something doesn’t work you do something else. If that’s not enjoyable for him or us we will find another way and that’s how it is with him. It never stops, you are always teaching him things still teaching him things and you still have to make it fun and enjoyable for all of us. And that’s what they did. Beth was the first contact then the speech therapists, the physiotherapist, then the little group sessions and it was absolutely wonderful, because Mark enjoyed it and I enjoyed it so I could have a chat with the ladies in front.”

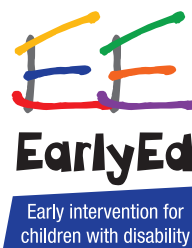
Think about yourself

“And trying to deal with all the emotions as well, like coming to terms with what your child needs that extra support. There’s a lot of energy early on, and just dealing with grief and all the other things associated with being a special needs mum. So just be kind to yourself.”

“I think one of the best things I did and it was a bit by default was that I went and saw a counsellor when mike was 3 months old. She was pretty straight forward and she said to me what to do you want from your child, I was very upset about having this baby with Down Syndrome because I have always been working and ambitious where this child did not fit in. because there is a lot of work and I realized that very early. Not that its bad, but a lot of time has to be spent. She asked why did you have children and I started babbling about how I wanted a baby to love and wanted to have a baby who could love me back. I wanted him to be happy and do a job eventually that he loves. And he’s turned out alright and more. Put it all in perspective, that’s what its all about.”

CHECK IN ON YOUR PARTNER

“Check how your partner is going and invest (time and energy) in your relationship. Tough situations can strengthen your bond.”



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