

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

**WHEN YOU ARE GETTING STARTED.**



Early intervention for children with disability

[www.earlyed.com.au](http://www.earlyed.com.au)

## EARLY INTERVENTION MAKES A DIFFERENCE

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### Opportunity and Foundations

"I believe it sets up the foundations for any child with disabilities or special needs for their learning and the stepping stones to enable them to be the best that they can be and support the families and give them the knowledge and strategies to be able to teach their kids all the things that we take for granted in everyday life and learning our skills."

"I have since come to realise that many milestones will not be achieved or severely delayed without consistent practice and focus on weakness through early intervention practices."

### START EARLY

*"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 than we have seen them I wish that I knew that earlier we started early intervention the better."*

*"I think I'd ask for more support when we first started. When I say first started I mean when he was first born, the first 12 months of his life, I think we were still trying to get our heads around ..his multiple diagnosis'. His early intervention wasn't on our radar. Had I known early intervention was something so easy to do, I would have been on top of it. I feel like it's the easiest thing to manage with his whole diagnosis. The earlier you start, the better. I think that's my biggest thing. I wish we had done that."*

### I needed information

"A list of early intervention services & providers with a short summary about what the different service offers (e.g. speech therapy, target age groups etc) Wisdom and perspective – list of books written from a parent's perspective (to show it's not all doom and gloom). There's limited or no studies to show outcomes beyond childhood. I think it's important for new parents to realise this. Doctors are required to provide predictions but everyone is an individual and parent and early intervention does wonders."

"One thing I would initially want to change with early intervention is having more knowledge for the people who don't know anything about it. Because when they come up, you guys give us lots of strategies but we don't know how to do it. So when to start, what to do, we do come up with questions but still there is confusion. They don't know how to put them in their real life. Because sometimes they say this thing works for you but then it doesn't and people get confused. Should I, should I not be doing it. They just lose the track and the thing goes back again."

### Early intervention is important and worthwhile

**"He's just a completely normal child. He's just grown out of the pram. Earlier, I could not leave him because he would just run. There still some issues but we are still working on it. But then still I feel like, Nah, he's quite normal now. I can go out and have my life and still at time enjoying the school holidays. Has worked a lot for me."**

**"I come up with my questions, so these guys just find the right thing, right spot, what to do, when to do. So that helped me a lot."**

### Positive

*"I think the main thing would be to realize how positive the experience of early intervention can be. 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. You have complete control as a parent and you get to focus on your child and you get to focus on what positive things you can do to make sure your child can reach their full potential. One thing I would have really liked to know when I started this journey was just what a positive experience early intervention would be for our family."*

### CHILDREN NEED LOVE AND SUPPORT

"It's difficult you have to sit down and think early intervention is important for some things but at the end of the day what's more important is there's your child your child needs your love more than anything. Your child at the stage needs early intervention to some point but needs your love so much more. I was just sitting there thinking I just need to relax I just need to chill Instead of spending so much time on internet researching, I need to just lie in the hammock with her and have a good cuddle with her and not worry about other stuff."

"Just embrace your child. They are on their journey and it's a special journey and I've often said they are limited editions. My child is limited editions she's one of only 2 in the world. I feel kind of privileged so yeah, but she has taught me a lot as well."

### Advocate

"I think do your research, so look at what early intervention providers are out there and ask questions like what could you do for me, how can I be in control of my child intervention journey, what supports are out there for me and my family. Don't be afraid to ask because there is so much support out there. It is knowing and being an advocate for your child all the time."  
"Keep fighting for your child. You are the best advocate and they are going to need you. And when you get a result it is well worth it. It's a long fight up until school. It's very good."

## The start can be overwhelming

"I was a bit of a daze actually because it was very overwhelming for me personally I don't know how others cope with it. I was just trying to feed her, because I couldn't do what you'd do to a normal child because she choked a bit. Sleeping and all that kind of things were a bit difficult for her. But now I think oh yeah if I had known specifically what they could help with that would have been better for me too."

"I think what would have helped me was getting more information when my baby was discharged. Getting some more information about what he would have needed and what would have helped his development. ...I thought like sometimes he was brought home and that was that. I was brought into no man's land."

"In fact it took 20 months to get a diagnosis for us. So my expectations of finding out what she has when she was born was not realistic and I know that a lot of parents don't get a diagnosis till they're child is 8, 9, 10."

## Don't worry / stress less

"Coming along the journey, going through the steps I would say to someone first starting off, once you make the first contact with an early intervention provider and you have your first meeting. Take a breath, let your shoulders drop and just relax because everything will just start rolling from there. You will have your planning meeting, they'll let you know about services they can offer you, things start rolling you don't need to stress, therapies get booked in, and things just happen. You don't need to stress any further from there."

"We were worried about things that we were not going to need to worry about for years. We were worried about whether she would walk, move out of home one day, whether she would go to school. By the time we left the hospital we had a 10 day old baby, those things were completely down the track. I wish I'd known to just focus on what are the things I could do with my 10 week old, my 4 month old, my 6 month old daughter, to help with her development. It was a lot of energy and a lot of worry that just didn't need to happen. I think part of that was just to focus on my child and not to get too worried about what's happening with other children and what stages they are up to."

## Acceptance helps

"My husband and I often talk that we feel really grateful that we never wasted energy on fighting Georgie's diagnosis and we accepted it very quickly and very quickly became her advocates for getting her every single support, help, and service out there and in the mind frame of this I going to make her the best possible person she can be and get the best outcomes in her life. I would really say don't fight your diagnosis. Accept it and then do everything because your children are a gift. Whoever they are, it's not worth fighting for that."

## Research

"When it came to early interventions services I got some recommendations from the hospital but not a lot so I spent a lot of time researching. And I reached a point where I was getting very anxious because whenever I heard someone say have you tried hydrotherapy? I was like Oh my god I haven't done hydrotherapy I have to do it sort of thing. I reached a point where I was just spending so much time trying to work out what else I can do."

"Doing as much research as possible about how therapy can assist the development of your child and also to prevent and lower the impact of the disability. The earlier you do it, it can sometimes teach your baby some skills to lower the effects of it."

## FOLLOW UP WOULD HELP

***"When I first had Olivia and brought her home, I did get visits from early intervention which kind of went right over my head. I was struggling with a new born with special needs. It's overwhelming having a child anyway let alone having one with special needs. A lot of that I didn't follow up. I think maybe if I had a follow up, if something was put in paper like this is something we could offer you, this is something we could help you with."***

## I need to understand

**"In my experience case workers have a tendency to ask what we want, where, in fact, I do not know what should be needed (I don't know what I don't know)."**

**"I think understanding: have a better understanding of what early intervention is and what an early intervention provider can offer you and will do for you can do for you to help you and your family."**

**"I was not fully appreciative of the benefits of early intervention. If someone had said, with appropriate examples, that the work for kids that is done in terms of early intervention is crucial to them reaching their potential as they grow into childhood."**

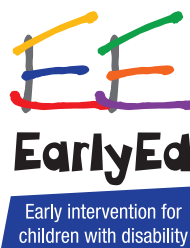
## I JUST DID IT

*I assume they gave me an overview of EI, but I really can't remember what was said. I guess I just started the EI journey and did as I was told! I don't remember doing much research into EI, it was a given to me that this was important if it was offered. I think I would have also contacted DSNSW seeing they had given me an information pack, but I don't remember much of the questions I would have had at that time. I didn't even know there were other EI providers besides Early Ed, I probably didn't find out till a few years later. It is strange, because I trained as an OT (never worked as one), so you would think that I would be doing research and assessing my options. But I don't think I did."*

*"So, I was very lucky to be honest. In terms of, the early days, it was all a bit of a mine field and I didn't really understand what I was supposed to do in each of the therapy sessions."*

## Find professional staff that you like

"We feel very lucky she was able to get the therapies. We were very lucky with the therapist we had. Sometimes, your child may not have a good relationship with the therapists if that is the case then you need to find a new therapist. We see how Rafaela works very well with some therapists and not with others and it makes such a big difference. So we would definitely say that to families, the relationship your child has is extremely important."



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Part of the EarlyEd Families Matter Program.

This resource has been produced by EarlyEd, having been commissioned by ECIA NSW/ACT from grant monies provided by NSW Department of Family and Community Services, Ageing, Disability and Homecare (FACS ADHC) and administered by Early Childhood Intervention Australia (National peak body).

It is part of family-centred project: Babies And Disability - What Families Want Others Families To Know About Early Intervention.

Go to [www.earlyed.com.au](http://www.earlyed.com.au) for more information.