

The following story has been adapted from its original form as written by Joni Lloyd. Joni is the mother of two children, one of whom received Birth to 3 early intervention services in New Mexico. This letter is included in a NM Family Infant Toddler Program publication titled "Working Together / Collaborative Consultation: A Family-Responsive Approach to Therapy Service Delivery" by Jacqui Van Horn (1996). Please consider using this story as a discussion tool for professional development purposes with your Birth to 3 or early childhood team.

Joni's Story

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Over the last 6 years since my son moved on from early intervention, I have thought back to those times and wondered how it might have been different. I decided to write a letter to myself as though I was going to embark on this adventure all over again. In writing this letter I will use my past experiences, feelings, and hindsight to share with me as a new mother who is making those decisions and choices and that families are asked to make in the beginning of their early intervention experience. I hope this letter provides insight and is thought provoking to all who read it.

Dear Joni,

I have been thinking quite a bit since you told me that your son was diagnosed with cerebral palsy and that you were considering what to do next. As you know, after my son, Judd was diagnosed with cerebral palsy we decided to begin early intervention services. We wanted to do everything possible for Judd to help him overcome his disability. We really thought that "the more the better" in terms of therapy services for Judd. If once a week was good then two or three times a week would be great!

And yet when I think back, my husband and I both left clues that this may not have been exactly what we wanted and if someone would have picked up on those clues or presented our options to us differently, things would have been very different for our family. We might have chosen different outcomes for Judd and ourselves.

We might not have been interested in enrolling him in the 3 and 4-year-old center-based program primarily for children with special needs. We might have not had to hire an attorney to represent Judd in our fight for him to be able to be fully included in his neighborhood school the year he started kindergarten. I might have felt more powerful and competent as his mother the way I did the year before we knew he had a disability.

So let me share with you some of the things I have learned and questioned these past few years and hopefully you can discover what will be the best choices for your family and son during these early years.

The first time we visited the early intervention agency we were taken on a tour of the facilities and told about the options available to families through their program. I remember seeing a little classroom and saying that I would like Judd to go there when he was old enough because it looked just like a “regular preschool”.

Now I think back and wish someone would have picked up on that clue for me. Had someone said, “Wait a minute, would you like Judd to be in a regular preschool? Because if that is what you want, we can work towards that. We can use that when developing his IFSP and keep that as one of our long-range goals. We can explore the place or places you may like him to go to. Maybe you want Judd to go to the same preschool his sister went to and we can begin to talk to them about that. Maybe you want something totally different than that and we can be flexible and see what happens in the next year”.

All of these ideas and possibilities would have changed the way we would have begun to think about Judd’s and our future. We would have been more hopeful and focused on moving towards our family being included in our community and for Judd to be “one of the gang” like we always wanted and now weren’t sure he would be.

We did choose to begin with intervention in our home 2 times per week. Most of those times were spent not only with the therapist working with Judd, but with me asking questions and voicing my concerns, fears, and hopes with the therapist. This process was the start of a very important relationship in my life. I needed a safe place and a safe person to confide in and this therapist was willing to fill that need for me.

I also began to meet other families. Some of these parents were farther along in their journey than we were and they shared their expertise and knowledge with us. Thinking back on those times now, I feel strongly that the relationships we shared with people in our early intervention program were the most important part of the whole process. The therapy Judd received was excellent, but the confidence, knowledge and support that we received as a family through these relationships liberated us to help Judd in the ways we as a family knew best.

We came up with ways to incorporate the therapist’s ideas and methods into our play routines and everyday activities that we always enjoyed as a family. I now wish that that had been encouraged from the beginning and that I wouldn’t have felt so compelled to do the “homework therapy”. I wish that I hadn’t been so stressed about whether or not Judd could accomplish all the tasks on a developmental evaluation.

I wish I had focused more on what he could do and what he learned. I wish I would have taken time off from therapy during the summer and around holidays. I wish I hadn’t felt so guilty if we missed a session. I wished we had missed more

sessions just so we could have stayed in our pajamas and played on the floor all morning.

I wish we had been reassured that therapy isn't magic, but participating in a family and being a child is magic and that those experiences are what is important. Therapy should help a child and their family to enjoy the things they choose to be involved in and the things that the family feels are important to their child's life, growth, and experiences.

My advice to you now is to value time - time with your baby, time with your family, and time with yourself. Try not to fill every day or every week with early intervention. Allow yourself to just be a mom like you were with your older child. Don't let this experience cloud or dominate the memories that you have of Judd when he was a baby.

Joni, early intervention and therapy is valuable and important for children with disabilities and their families, but don't forget who you were as a family before the diagnosis. Don't forget how capable you were as parents and as a family. Don't forget how you dreamed about Judd's future as well as yours.

Don't forget you still are a family with a rich and unique culture that is all your own. Don't forget you are Judd's mom and that is more important to him now than any other person or program will ever be. Enjoy him and wallow in his babyhood, it passes in a blink of an eye.

All my Love,

Joni