Wisdom and Experience Gained

I wish I had…

Wisdom from parents of children who are deaf-blind

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National Consortium on Deaf-Blindness

I wish I had…

taken more time for myself. I wish I had read more novels and magazines, rather than feel guilty about reading materials that were not education-related. I wish I had gone to more parties to balance the education-related conferences.

Sally Prouty
Minnesota

I wish I had learned much earlier to follow Noah's lead, instead of only working on what I was told we should be working on. It was quite a few years before I had learned enough to be comfortable making my own decisions about where Noah was and what his next step should be. If I had followed my own instincts and trusted my knowledge of who he was, he might have made some strides much earlier. Most of all, I wish I had convinced more professionals to look at the WHOLE NOAH, instead of just their piece (e.g., vision, hearing, gross motor, fine motor).

Shelly Voelker
Florida

I wish I had known about non-verbal ways to communicate with my daughter Sara when she was much younger. When Sara was 10, we were introduced to a wonderful educator who specialized in non-verbal communication. Dr. Mary Morse came to Sara's class to talk to the school team about object communication and calendar boxes. It changed our lives for the better. Sara learned that objects represented activities and she loved the power that this knowledge gave her in school and at home. Thanks to Dr. Morse, objects became our words. Then photographs of objects became our vocabulary and Sara's world expanded wonderfully. Frustration for her and the family went way down because she could make choices and requests and they were understood.

Janette Peracchio
Connecticut

I wish I had put more effort into learning sign language. Since my son has a cochlear implant, we spent many years talking to him and having him "learn to listen" rather than signing. Now that he is using sign expressively, we are really behind on knowing all the signs we need to communicate with him.

Jody Wolfe
Illinois

I wish I had known that with all the tears of sadness there would also be tears of joy. Both sets of tears are unimaginable to most other parents. Most parents know certain things will happen as their child grows. In our world of parenthood, we coach, we teach, we model, and we pray. And when a milestone is reached, it is so meaningful and touching. The little joys of finally finding her toes. Her first words. Singing "You are My Sunshine" together. Following me around our home without her walker for the first time when she was 2 1/2, with me on the verge of wondering if it would ever happen. Identifying pictures by sight and using sign language successfully. When those events occur, you could never replace them or ask for more. All of those things that were on a list of things she would never do, now DONE. Tears of joy come and you will never feel more love or be more proud in your lifetime.

Becky Lowell
Texas

I wish I had stood stronger when my son's IEP team wanted to change his communication goals. When his team participated in trainings, we became so enthused by new ideas that sometimes we didn't give the old ideas long enough to work before changing things. Scott has profound mental retardation in addition to being deafblind. I think he needed much longer with an idea before trying something new. For example, we worked hard using sign language as his primary communication system. Then we switched to object cues and touch cues, without giving him adequate time or energy to "get it." We probably ended up confusing him more than assisting him in communicating with us.

Molly Coulter
Alaska

I wish I had...

networked with families and agencies who were subject matter experts in state disability and education laws for deafblind students, so that I could have been better informed on how to navigate the system.

Charmetri Bulluck-Draughn
North Carolina

I wish I had…

the words and eloquence to describe how much better my life is for having my son in it. Sometimes his sensory issues and social delays sadden and frustrate me, but mostly I am blessed and amazed by him. He's a daily lesson in perseverance, a reminder of my personal weaknesses, and living proof that you don't have to be perfect to be God's perfect blessing in someone else's life.

Danielle Pospical
Washington

I wish I had not been so surprised with each new diagnosis and its implications for my son. The most devastating thing to learn is that there is something wrong with your child, but even more devastating is discovering that it should have been found earlier, or handled differently, or that it was completely "missed" by all of the professionals that you entrusted with the care of your child. It is so important to research and to understand your child's diagnosis and its implications yourself because who your child needs to understand them, is you. Professionals can be great supports, but you are your child's best advocate.

Stephanie Jacobs
Missouri

I wish I had lost my fear of not being there. I wish I had forgotten about GUILT, and faced life with more strength and determination. I wish I had done so many other things. And today, I think that everything happened when it had to happen. That everything was a process to help me become who I am today. What happened happened, and now I look to the future and prepare for what it will be. I'm ready!

Monica Quesada
Puerto Rico

I wish I had NOT listened to all of the doctors when Peter was diagnosed! I found I know my child a lot better than any of them ever will. Peter continues to do things that I was told he would NEVER do!! I know he will continue to surprise a lot of doubting folks! I have great faith in him!

Mary McCartney
West Virginia

I wish I had concentrated more on the milestones my son had reached rather than on the ones he had not yet attained.

Dan Wolfe
Illinois

I wish I had received help from the Deaf-Blind Program, from the Hilton-Perkins Program, from the Centro Nacional de Educacion Especial Fernando Centeno Guell in Costa Rica, and especially from the professors, Elizabeth Camacho and Gloria Rodriguez, when my son was born. But it was only when he turned 6 years old that we started working together. They were my map to follow, the light that brightened my path as a mother, a teacher, and a human being.

Everything we planted in him as a child, the hours and hours, now we are harvesting. We see the fruits of our work in an adult who is independent at home. He cleans the house. He cooks by himself if he doesn't like what I cooked. He cleans the windows, kitchen, and bathrooms, does the laundry, cleans the refrigerator, changes his bedding, looks for and chooses what to wear. Most important, he is a happy person and that makes all of us at home happy.

Ileana Rodriquez de Avalos
New York

I wish I had let other kids lead in playing with Ethan. I was so busy keeping him away from germs, protecting him from possible injuries, and involved in all of his therapies, that I forgot that kids learn and thrive the most through play.

Anna Kegley
Washington

I wish I had…

kept a journal every week, especially about the good things happening in our lives.

Kathy Sheriff
Texas

I wish I had…

taken a family picture at least once a year, no matter how weird or crazy looking we were at the time.

Lisa Rogers
Nevada

I wish I had…

focused more on "teaching" my son social/emotional skills and hadn't worried so much about academics. He is 25 and still has difficulty expressing his frustrations and feelings clearly and without exasperation. I would also have listened less to his teachers and advocated for him more from the start of his life. I am glad we had high expectations for our son because far too often others didn't. When he is happy, nothing stands in his way (literally).

Mary Hancock
Florida

I wish I had spent more time being a mom and enjoying the time with my daughter, Ashley, instead of making every moment a therapy moment. I wish I had praised her more when she put her shirt on by herself, even though it was on backwards, instead of taking it off and making her try it again. The best thing Ashley's pediatrician ever said to me was: "It's okay to be just a mom. Sometimes that is exactly what Ashley needs."

Tracy Jess
Washington

I wish I had a machine that was able to tell us what was happening in our son's thoughts. This would help us communicate with him by having immediate access to what is going on in his mind. This would allow for better two-way communication, as we think he is constantly giving us clues about what he is trying to say. It's just that we are not picking up on the clues. I wonder how much progress we could make in educating our son if we had an inside track into what is on his mind.

Jamey & Amy Vicker
Missouri

I wish I had shared with other families the incredible satisfaction you receive from helping other families of children who are deafblind. After a few years of working with families, I started explaining to them all the benefits of "being there" for another family. The support we get from each other gives us a burst of energy.

Clara Berg
New York

I wish I had known in the beginning that deafblindness didn't mean the end of the world for my child. It is just the beginning of an amazing journey through learning and sharing her story. She teaches us every day that disabilities cannot slow you down. It will be a difficult road, but one with lots of experiences my family would not have had if not for our little miracle. We feel that we are truly blessed.

Teresa Kreeger
Virginia

I wish I had realized the impact on our family of having a child with special needs. Our first child, Hannah, was born with a syndrome that causes deafblindness. We were so focused on her needs that by the time we had our second daughter, Rachel, all I could think about was how the second child would impact Hannah. I thought "God will give us a special child to be there for her." I didn't give much thought to how Hannah's disabilities would impact our younger daughter. We have nurtured both of our children, yet Rachel feels cheated. My husband and I give Rachel a lot of one on one time; but this doesn't make up for the love that she feels she is missing from her big sister. Through the years their relationship has had many challenges. It is evident to me that Rachel, the youngest, is missing out on having a typical sibling relationship. Hannah doesn't show compassion or love towards Rachel. At times I regret not having one more child, which may have balanced out our family. Regardless of these struggles, I love both of my girls with all of my heart and will continue to be there for both of them.

Susan Green
Pennsylvania

I wish I had…

known the importance of holding my child as much as possible in the beginning. Instead of spending so much time trying to understand the diagnosis, I could have been bonding, rocking, playing, and dancing with my son. Touch is so important to these babies. If I could do it again, I wouldn't stop touching him from the moment I met him.

Erin Sefcik
Texas

I wish I had...

let my child take more risks instead of thinking about what could go wrong and bring more problems.

Veronica Tuck
Alabama

I wish I had...

taken more time to explain to my family and friends what was going on with me and my daughter, Sammy. It would have helped both of us to have had more support and understanding with what we were going through.

Patricia Gray
Nevada

I wish I had included my other two children in the everyday life of our youngest son who is deafblind. They deserve to have knowledge about their brother, to learn about how absolutely amazing he is, and the challenges he overcomes everyday. I wish I had empowered them to be more involved in his care from the beginning. Today they feel special because they are able to contribute to his therapy and help him learn to be the best person he can be. The girls get so excited when Michael does something new and they make sure to let me know when he is getting into trouble. We have as close to a normal life as we can now that my older two children are involved.

Caroline Johnson
Kentucky

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For more family stories and to see additional resources and information about children who are deaf-blind, go to www.nationaldb.org.

IDEAs that Work

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