

2007 Legislative Testimony—Shannon Koenig

Good Morning Madame Chairperson. Thank you for giving me the opportunity today to introduce myself and tell you about the importance of the Developmental Disability program and the services they have provided to my son and my family. My name is Shannon Koenig and I am from Helena.

It was almost 5 years ago that my son, Zach, was diagnosed with Autistic Spectrum Disorder. At the time of his diagnosis Zach was two years old. I can honestly say that the last thing I ever expected was to have a child with a developmental disability—that was something that happened to other people. Shock and devastation are the two words that can truly describe what my husband and I were feeling at the time. Fear soon set in as we thought about our son's future and wondered how to help him.

It was Zach's speech therapist who told us we needed to get in touch with an organization here in Helena called Family Outreach. Family Outreach is the contractor who provides the services funded by the Montana's Developmental Disabilities program for this region. We thought we would be able to do everything on our own—we wanted to do everything on our own, but unfortunately as it turns out, because of the Autism diagnosis, our insurance would not cover the therapies that Zach was going to need. Determined to do everything possible to give Zach a chance at a good life, I made the call to Family Outreach.

Because Zach was under the age of 3 and significantly delayed, he was eligible for Early Intervention Services. We were assigned a Family Support Specialist who quite frankly I wanted nothing to do with. We were a family who valued our privacy and all the questions and advice seemed an intrusion at the time.

Looking back now I realize that making that call to Family Outreach was probably the most beneficial thing I have ever done for my son. The Family Support Specialist we were assigned has been more important and valuable to my son and family than any doctor or therapist we have ever seen. She was the one that helped us to fill out the application so that we got on a waiting list for intensive services through the Developmental Disabilities program. In the fall of 2002 we were fortunate enough to be part of a waiting list rollover that was done for children on the waiting list. The services he has been receiving since then have been immeasurably valuable.

Unless you have a child with a developmental disability you can never understand how exhausting the simplest things can be and without the help we got I don't even want to think about where my son and our family would be today. Our Family Support Specialist, Margi, helped me get Zach signed up for the special education preschool and came with me to every one of the meetings to set up his Individual Education Plan and rubbed my back afterwards while I cried in the parking lot. She was able to help us purchase the equipment to make our family room a sensory room that could meet Zach's sensory needs when he is at home. Margi is the one who has found and trained the 8 Habilitation Trainers who have worked with Zach the last 5 years to teach him everything

from daily living skills to educational skills. And every time that Zach has developed a behavior that we don't know how to deal with Margi has come up with an idea to help the situation. The experience, knowledge, and compassion we have got through our relationship with Margi because of the services Zach receives from the state of Montana's DD program have made a huge difference in the lives of every member in our family, not just Zach's.

I would love to tell you that Zach has "recovered" from Autism, but the fact is even though he continues to make progress, it is painstakingly slow. Zach is still very much in need of the services he receives. He has no speech, is very obsessive about some things, has huge sensory needs, and needs to be watched by a responsible adult at all times. Safety is a constant concern. We live in a house with a lock on every door, and every window is braced so he can't squeeze out and run away. For us to go someplace as a family is a major event which doesn't always turn out as we would like because of Zach's Autism. There are normal things that other children love that Zach is terrified of and he can't even tell me why. And, he doesn't have and may never have a single friend because he has no social skills or play skills which could help him communicate with another child.

These are a few of the things that families who have a member with a developmental disability deal with on a daily basis—not just us. I thank God every day that Zach was one of the lucky children who didn't have to spend years on a waiting list to get the services we needed and still need today. Without help I can't imagine what our life would be like. The services that the child and family DD programs are providing don't just affect the disabled child—they have profound effects on every member of the family. Families fall apart when they don't get the support they need. The divorce rate of families with autistic children is 80%. Siblings of developmentally disabled children are often left to fend for themselves as parents are too overwhelmed by the disabled child to worry about the "normal" ones. The respite provided by the DD program is the only time some families—mine included—can go someplace like a restaurant and be a "normal" family.

People have dreams for their children whether they are disabled or not. However parents of developmentally disabled children more often than not are forced to concentrate not on the dreams but the worries for their child's future. In my dreams I would hope that one day Zach would be able to lead a life with very little support. As he gets older the reality of it is this is probably very unlikely. I do believe in miracles and will never give up on my son. However, the realistic part of me worries constantly about his future. Zach will likely need more help that we will be able to give him. He is going to need the support that DD services provide for the rest of his life.

It scares me as I look towards my six year old son's future. I want and need to know that someday when I can't take care of him that he will have a safe place to live. And I want him to have someone who can help find him a job and maybe a hobby he enjoys so life is truly good for him. Really, what I want for him isn't all that different than what I want for my two daughters or anyone wants for their child's future. We all want our children

to be safe and happy. The method of achieving these goals is what will be different for those of us who have developmentally disabled children because our children will always need things we won't be able to provide.

So today I am here to request that you increase funding for the Developmental Disabilities program as much as possible. Although we have been one of the lucky families who got the services Zach needed when he was young, there are too many families with disabled children who aren't as fortunate. Research shows that the services such as those provided by the habilitation trainers give a child a better chance of attaining their full potential. Therefore this is in everyone's best interest. We also need this funding in order to enable the DD program to pay the people who are working with and taking care of our children enough of a wage that they can retain quality employees. Adult Services are another important issue. There are too many adults with developmental disabilities who aren't getting what they need as they spend years on a waiting list. Montana is a wonderful state full of people who have been brought up to help people when they need it, and that is what the DD program is for. The people served by this program can't fight or often even ask for what they need, so it is up to us as parents and communities to make sure that they are given the support they need. Thank you for taking the time to listen to my family's story and all your hard work on this important issue.



Zach Thanks You Too!