

**Chairman Kennedy and other Distinguished Members of the HELP Committee:**

**I want to thank you for the opportunity to speak to you today. Though I am not an expert in the technicalities of each section of IDEA, I, like most parents am an expert on the individual strengths and needs of my child and so our family's personal experience with special education is what I will speak to.**

**How do you relate nine years of joy, grief, confusion and success in just a few minutes? I'd like to start off by helping you know my daughter a little. Louisa's favorite things are swimming, horseback riding, and tasting foods - she loves eating spicy or sour things (garlic bread, guacamole and lemon meringue pie are her favorites). She loves to dance with her Daddy and sing with Mom. She has an infectious laugh, is very sociable, and has been described as a "love machine". She has a small verbal vocabulary including "go", "more", "cold", and "Mamama" - my favorite word! Louisa uses a wheelchair for mobility, wears hearing aids and glasses and she receives the majority of her nutrition through a gastrostomy tube. Louisa wears braces on her legs for some activities and uses switch-controlled devices for choice making, entertainment and basic communication, as well as to help out at home with simple chores. Though she often appears non-attentive, don't let her fool you - Louisa is very aware of what occurs around her, and though she needs extra time to respond, she will make her needs, her interest, her frustrations and her amusement known.**

**Every journey has a beginning. Ours started when during a healthy pregnancy I suddenly developed toxemia from causes we will never understand. After a series of prenatal tests determined that Louisa was experiencing fetal distress and fluid in her lungs, Louisa was born by emergency C-Section seven weeks prematurely. During the delivery, Louisa aspirated meconium, which along with immaturity of her lung development resulted in a lack of oxygen and her brain being damaged. Louisa spent her first two months of life on a respirator in the neonatal intensive care units of hospitals in both Des Moines and Omaha, where she was transported by life flight when she was three day old. While at the Medical Center in Omaha she was diagnosed with microcephaly and Cerebral Palsy. We were told that Louisa would likely have problems with gross motor skills, things like walking and dressing herself. Upon her return to the hospital in Des Moines, we began to understand that her life challenges would be more extreme and our family was moving into uncharted territory. Louisa has since been given additional diagnoses of mental retardation, Cortical Visual Impairment, Central Auditory Processing Disorder and being chronically adorable.**

**When Louisa first came home from the hospital at three months old, still on oxygen, we immediately began to seek out information and support for what we knew was going to be an entirely new adventure for our family, hoping to educate ourselves as to Louisa's future needs, exploring all avenues in order to help her achieve the best outcomes and the fullest and most satisfying life possible. One of the first places we looked to was the education system and Iowa's Early Access program.**

**At the age of five months, Louisa began receiving Part C Early Intervention services through the Des Moines School District, at first at home and later in her day care setting. I will never forget the first two women we encountered: Georgia Woodward, an early education teacher, and Jean Linder, an occupational therapist who inspired and supported us throughout the nearly three years we worked with them. Over cups of tea, in our living room, they worked with Louisa, and provided our family with information, strategies and the moral support that helped us move from broken dreams to new hope and understanding.**

Through the Individualized Family Service Plan (IFSP) process they helped us identify our family's and Louisa's strengths and needs and secured the coordinated services and resources we would require. They explained Louisa's rights to a free and appropriate education in the least restrictive environment. This was accomplished in a way that allowed our family to retain our privacy and as much normalcy as possible, not an easy thing when you have therapists, respite care workers, and others involved in your life and in your home. These individuals, like many who have followed, served as the guideposts along our way. One of the most important things they taught me was that we were Louisa's advocates, that we would be required to speak for Louisa and defend her rights to secure the services that she would need in order to reach her fullest potential for a meaningful life. I will be forever indebted to them for their honesty and compassion. I believe that extending the IFSP process through at least age five would be a good thing, as the IFSP family-centered approach to service coordination is invaluable during this time of continued early intervention.

When she was 2 years old, Louisa was registered on the state Deafblind registry. This gave us access to our Deafblind Project staff who provide technical assistance to families and school staff in order to address the unique challenges that children with both vision and hearing impairments face. When Louisa was still a baby, we were provided with strategies for sensory integration, communication by touch cues, and even tips for creating a home environment that encourages her to use and maximize her vision and hearing.

When Louisa was three she attended an inclusive pre-school in a shared program that included both typically developing neighborhood children, other children with disabilities and a Head Start program. She remained in this setting for three years, receiving early childhood education and related services to work on goals identified through the Individual Education Plan (IEP) process.

As Louisa was ready to transition to kindergarten, we visited principals and staff at the three neighborhood schools closest to our home, as well as a separate school for children with disabilities, in order to determine which setting would be most beneficial to her. We decided that Hillis was the place for Louisa. We were most impressed by the welcoming attitude of the Principal, Larry Streyffeler. He didn't flinch when we described Louisa and the services she would require, and let us know that together we would do "whatever it took" to ensure Louisa a positive school experience. Another factor was the physical accessibility of the building, which we realized was an issue we could press had we chosen another school setting, but not having to face that challenge made Hillis an even more attractive choice. Louisa was enrolled in a regular kindergarten classroom. On the last day of school that year, Louisa came home with her first invitation to a birthday party. Such joy! Our Louisa would have friends in her life.

Louisa is now in the third grade where she continues to be included in the general education classroom with friends she has known since kindergarten. Her classroom teacher has the support of a special education teacher who is assigned to the class, as well as two half-time one-on-one associates who assist Louisa with her schoolwork, transfers and personal cares, as well as supporting other students when Louisa is occupied with her classmates or working with her therapists. Louisa has an extensive IEP Team, including her father and I, the principal, her classroom teacher, the special ed. teacher, her associates, as well as her physical therapist, occupational therapist, speech and language pathologist, vision itinerate, a member of the district assistive technology team, a district special education consultant. Other team members have included a school psychologist, the state DB specialist, her Hippotherapy (horseback riding) therapist, a district audiologist, the district special education supervisor, the case manager for her Medicaid Home and Community Based Services Waiver and her Supported Community Living helper (a Waiver provider).

**The IEP process is working for my child. It allows our team to paint the entire picture of Louisa for school programming. It has confirmed to me the importance of partnerships. The older she gets, the more important it is that we build on Louisa's capacities and capabilities and not just those things she cannot master. It is even more important that the players who are involved with painting this portrait are looking at her from several angles. I have been impressed with the teamwork and commitment of the district and school staff that we have worked with. Challenges with multiple disabilities can hide true abilities and talents. Cognitive evaluation of children who are hampered by severe physical and communication impairments is often difficult and we, as parents, have asked that when conclusive evaluations have been impossible Louisa be given the "benefit of the doubt". This has been the foundation of our IEP process.**

**IDEA provides the entitlement of every child to a free and appropriate education in the least restrictive environment. IDEA calls for the continuum of services and access to the general education curriculum. Not all kids will succeed in the same way, or at the same pace, but they all can benefit from the educational experience, gleaned from those things that impact their lives. The original focus of the law was to create access to educational opportunities for students with disabilities. It is also a civil rights law. ALL kids need to experience school and extracurricular activities that promote peer relationships, respect for differences and the pride that comes from accomplishment and extending a helping hand.**

**Louisa loves school and is in turn well loved by her classmates and other students. Her peers take turns being Louisa's helper because everyone wants to be her special friend! Staff have related that Louisa's presence in the classroom has been a motivation for children who had behavioral issues. Being allowed to help Louisa is used as a reward for these kids' good behavior in class. I think that is a wonderful way for Louisa to contribute! Her favorite classes are music, PE and art. She also enjoys "reading" the spelling lists to her peers with the help of a switch-controlled tape recorder. Her friends include her in their play at recess, clamor to sit next to her at lunch and often have wonderful ideas for accommodations in the classroom, so that Louisa will not feel left out of things. For the last two years, Louisa has also attended a half-day summer school program for six weeks in June and July, where her IEP activities are continued.**

**Louisa receives support from her related services staff on either a direct or consultative basis, with most services integrated into the daily class schedule so that she can participate in regular classroom curriculum activities with her peers while working on her own IEP goals. I acknowledge that this can be a challenge sometimes, as we strive to balance Louisa's needs with the needs of other children in the classroom, but I have been overwhelmed with relief and delight when parents of other children have approached me to say that their son or daughter often talks about Louisa and how much their child appreciates and enjoys her. I have several times experienced them thanking me for her being there, as they feel that her presence is a positive thing and has helped their own children be more kind and accepting human beings.**

**IDEA ensures that an array of service options are available, based on the unique and individual needs of the child, determined with the input and expertise of the child's parents or guardians. The IEP process ensures that parents have the opportunity to participate as equal partners in decisions being made. An M.O.M. is recognized as equal in expertise to a Ph.D. or M.Ed. when it comes to the determination of appropriate services and placement for our children. I realize that Louisa and our family have been very lucky to have had the overwhelmingly positive experience that we have, and also know that part of that comes from having an understanding of our daughter's rights and our rights and responsibilities as parents.**

**My most important and best-loved job is parenting, but I have been lucky to be able to also work with hundreds of other Iowa families who have children with special needs. My area of expertise is community-based family support services but when I speak to family members who call for information or have questions about special education and IDEA implementation, I often refer them to the staff at Iowa's Parent Training and Information Center and our state Parent-Educator Connection Project for technical assistance. Promoting parent participation and parent-professional partnerships is crucial to the success of our children. When problems occur, we should encourage mediation and resolution of the dispute at the lowest level. Resolution facilitators should be available to all families as a vital component of due process.**

**It is hard to imagine that only a generation ago many children didn't have the opportunity to go to school, were routinely institutionalized or had no options other than "special" schools or segregated classrooms. Many students had disabilities that were not identified or who struggled and failed in a system that was not meeting their unique needs. These children were frequently subjected to cruel taunts and insults, told they were stupid, that they simply needed to try harder. I know this because two of them were my siblings.**

**My brother Hank, eleven months older, and my little sister Audrey, two years younger than me, both had learning disabilities, including dyslexia. In addition, Hank had only partial hearing in one ear and had lost one eye in an accident and so had physical challenges that also affected his learning. When Hank was held back to repeat kindergarten, our parents enrolled him in a parochial school, though we were not catholic, and hired a tutor for extra help. The next year, when he returned to public school, Hank and I were now in the same grade. Because learning came easy to me, it was heartbreaking to watch my brother struggle in class and to hear our peers make fun of him, calling him "dummy" and "Cyclops" and other mean things. I knew he was smart and he was so kind - he was always explaining neat things he had discovered when we took hikes in the park behind our house, he was a wonderful artist and could play the piano by ear as I plodded through my lessons. Audrey fared better because she had less apparent learning problems when young, she was good at "faking it", and was well liked by her teachers and classmates - she was a little cutie pie and fit in socially. She has related to me how terrified she was each day to go to school, afraid that her friends would find out she was "stupid", because she thought that she was.**

**When Hank was thirteen and Audrey ten, my parents enrolled them for three years in a residential school for children with learning disabilities in Florida. This was very expensive, but they had experienced too much frustration and hurt, it was their last resort. My parents, tireless advocates for their own and other children, were founding members of the Iowa Association for Children with Learning Disabilities who participated in hearings like this one, to support creation of an equal educational opportunity for all children. When PL94-142 was passed into law in 1975, it was a time of celebration in our household - but it was a bittersweet victory. It was too late for Hank, and Audrey would graduate one year later, with her high school counselor advising her to consider food service as a career, as that was one of the few things she could succeed at. I am happy to report that after seven years of hard work, with accommodations provided by her community college and universities, my little sister completed her Master's degree in Counseling Psychology and is now a Marriage and Family Therapist, who has spoken at several learning disabilities conferences to provide inspiration and hope to parents whose children who are striving to learn.**

**Hank eventually dropped out of school, had trouble getting or keeping a job and was very depressed. He eventually pulled himself together with the encouragement of a wonderful and supportive wife. He is now a doting grandfather who still takes walks in the woods and shares his**

**knowledge of nature and music and art. I am so proud of him and the man he has become, but feel much heartache knowing that his self-esteem and confidence was destroyed as he was growing up, because his disability was not recognized early, his learning needs were not met, and he was ridiculed and harassed by not only his peers, but his teachers when he was in school. This should never happen to another child.**

**We must be careful when defining the goals of education. I have heard people say that productive, contributing citizens should be the end result of the investment of education dollars. But how do we define productive? Louisa has provided our family with a gift we could never have anticipated - she has helped us and other members of our community grow and become better people through understanding her unique and sometimes hidden gifts and contributions. That is why I am here today, with Louisa as witness that IDEA does work. We must maintain an educational system where truly NO CHILD IS LEFT BEHIND.**

**On behalf of Louisa, Hank, Audrey, my Mom and Dad and every other parent and child with special needs in America, I want to thank you for listening to my family's story, for keeping the faith in our kids and for pursuing excellence in an educational system that serves and includes ALL children.**