

Transcript

Let's take some time to talk about some of the improved outcomes for people with disabilities over the years and the milestones in disability rights history that led to some really dramatic changes. I'll share with you today my perspective as a professional and also as the mother of a young adult with Down syndrome. I also want to give special thanks to the Joseph P. Kennedy, Jr. Foundation which oversees and supports our Lettercase program. The founder of the Kennedy Foundation was Eunice Kennedy Shriver who was one of the early leaders in the disability rights movement in the US and created Special Olympics.

If you look at the life outcomes for people with genetic conditions over the past 50 years, the change is really dramatic. For example, if a parent in the US found out that their baby was born with Down syndrome in 1960, physicians would often advise them to place their child in an institution. Parents usually told their family and friends that the baby died during childbirth. Back then, families were usually told that the child would only live to about 20. Only 50% of babies with Down syndrome survived past the first year, and parents were also told that children with Down syndrome could not read or write. At that time, this was all true.

In contrast, when parents find out their child is born with Down syndrome today, doctors expect that parent will take the baby home. Families are usually told that the child will probably live a long life to about 60 years. The infant survival rate is over 91%. Parents are also told that children with Down syndrome have a right to attend school and usually learn to read at some level. They are valued members of their communities and have the right work and play like everyone else.

The thing I often point out to genetic counseling students is: did anything change on that 21st chromosome over the past 50 years? And the answer is of course not. These incredible changes were caused by improvements to healthcare and social supports. That is why up-to-date information for expectant parents is so important.

Now when expectant parents have these questions about life outcomes like healthcare, employment, education, and other questions about living with a disability, we really need to understand the laws and supports over the years that have set up the framework for what those outcomes can be. So I'm going to briefly review the disability history timeline, so you can see where these laws have had an impact on those outcomes.

Starting in the 1800's, Institutionalization was common practice for people with disabilities in the US for over 100 years. When institutions were first introduced, they were seen as the more compassionate alternative to poverty and abandonment, but what happened over time is that these institutions became overcrowded, underfunded, understaffed, and the segregation allowed for abuse and neglect. My dad's cousin, Keith, was born with intellectual disabilities in 1960 and lived in one of these institutions in Georgia for over 30 years.

People with intellectual disabilities were almost never seen in public during that era, but after World War 2, some parents in the 1940's and 50's started choosing to raise their children at home even though they had almost no support. They also started parent support organizations

like the Arc to support each other.

Another significant milestone was when President John F. Kennedy created the President's Panel in 1961 to look for solutions to the problems experienced by people with intellectual disabilities. This was the first time a President ever started looking into improving the lives of people with these conditions, and what most people didn't know at the time was that this effort was personal. President Kennedy actually had a sister, Rosemary who had intellectual disabilities.

In the early 1960's, President Kennedy's sister, Eunice Kennedy Shriver, also created Special Olympics to raise public awareness about their competence on the sports field. But her ultimate purpose was bring people with intellectual disabilities out of the shadows.

Another key milestone toward improving healthcare was when President Lyndon Johnson signed the Social Security Amendments of 1965 to provide healthcare to people with disabilities and those who live in poverty through Medicaid. Even now, my son has access to Medicaid as a secondary health insurance because of this law passed over a half a century ago.

Between 1965-1975, Senator Robert F. Kennedy and journalists exposed the rampant abuse and neglect at the institutions where most people with intellectual disabilities still lived. Kennedy called the institution he visited a "snake pit." The institutions were found to be filthy, unsanitary, and medical experiments were performed on the residents without their consent. As these horrible conditions became more widely known, more parents started rejecting that model and saying no I'm going to raise this child at home. This was the movement toward deinstitutionalization in the 1960's and 70's.

In the 1960's and 70's, adults with disabilities also started using their own voices to advocate for better lives through the disability rights movement. Parents who were raising their children at home also started to form condition-specific parent support groups. The National Down Syndrome Congress was formed in the mid 1970's, and the National Down Syndrome Society was created shortly after that. After my son was born with Down syndrome, we were so comforted to be connected right away to the national and local Down syndrome organizations and meet parents who could tell us about the resources we needed.

A key milestone driven by self advocates with disabilities in 1973 was the Rehabilitation Act which said that any entity receiving federal funding could not exclude people with disabilities. Makes sense right? This included after school funding, federal building access, schools, higher education, and public housing. However, people with disabilities like Judy Heumann ended up having to hold a protest in a federal building to finally get the law enacted four years later. If you ever get a chance, the drunk history version of this story is really entertaining and educational.

As parents began raising their children at home, they realized that their kids needed to go to school like everyone else and they started advocating for laws to help their kids. The Individuals with Disabilities Education Act gave children with disabilities the right to attend school in 1975. Before that—1 million children had no access to school, and 3.5 million warehoused. It's hard to believe that just one year before I was born, my son would have had no right to attend a public

school.

Parents also realized their children needed better access to healthcare and therapies often not covered by regular health insurance. The Medicaid Waiver program was established in 1981 after President Reagan heard the story of Katie Beckett, a little girl with disabilities and medical needs whose parents wanted to care for her at home instead of putting her in an institution, but they couldn't afford the medical care on their own. President Reagan's administration created the Medicaid waiver to give kids with disabilities access to Medicaid regardless of parent income in cases where staying at home would cost less than or the same as treatment in an institution. This is why our stories matter. Because of the Katie Beckett waiver, my son Andy was able to get speech and physical therapy to help him start speaking in sentences and to ride a bike. The life expectancy for people with Down syndrome has also almost doubled since the 80's thanks to improved healthcare.

In the 1980's, Medicaid also added other waivers to add home and community-based support so that funding started going toward individuals instead of institutions.

The **Baby Doe Amendment** is the name of an amendment to the Child Abuse Law passed in 1984 in the [United States](#). The law requires medical treatment for seriously ill or newborns with disabilities regardless of the wishes of the parents. This case was so shocking to me when I first read about it because it happened in my lifetime during a year I can remember. In the case of Baby Doe, an Indiana baby boy with Down syndrome was born in 1982 with a repairable trachea-esophageal atresia, but his parents were advised by the obstetrician to decline the surgery and let the baby die because the doctor explained that Baby Doe would have a non-existent quality of life because of mental retardation. The hospital objected to this recommendation, but the parents followed the advice of their obstetrician. When the case was brought to Dr. C. Everett Koop who was the US Surgeon General at the time, he was so disturbed by the story that a child was denied basic medical care because of an intellectual disability that he recommended this change to the law. By the time Andy was born in 2000 with an enlarged liver and low platelet count, there was never a question about whether he would receive the medical care he needed or not.

IDEA Part C passed in 1986, and that's when early intervention started so that kids birth to 3 with disabilities could have access to therapy to help meet their developmental milestones. I remember when Andy was born thinking that we would never be able to afford what he needed as 23-year-old parents but that we would sacrifice whatever was needed to help him thrive. It was such a relief when we found out that Early Intervention would be able to provide speech, fine motor, and physical therapy right away. This is how Andy learned to feed himself, take his first steps, and use sign language.

Then, the American with Disabilities Act passed in 1990. The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life—not just publicly funded resources. This includes jobs, schools, transportation, telecommunications, and all public and private places that are open to the general public. To get this law passed, disability rights advocates literally crawled up the stairs of the Capitol to demonstrate their point. It's amazing to me that it wasn't until my freshman year of high school that people with disabilities

had a right to get into any public building where they might want to go. Because of the ADA, Andy can make the type bigger on his iPhone and use voice commands to communicate with friends and get adaptive timing accommodations at work.

In 1999, the Supreme Court Olmstead decision ruled that if people with disabilities could live outside of an institution, they should be given that opportunity. And because of this decision my dad's cousin moved out of the institution in Milledgeville, GA. Now he lives in a group home in a community.

The US Congress unanimously passed the Prenatally and Postnatally Diagnosed Awareness Act in 2008 though it was never funded. There was no requirement as part of this law, but it was supposed to fund 5 million per year for 5 years to establish a clearinghouse of balanced and up-to-date information about genetic conditions. This is still a huge problem in my work because testing and screening have surged forward without the patient and provider education infrastructure to support it.

When the Affordable Care Act became fully functional in 2014, this was also a watershed moment for many people with disabilities because their conditions were by and large considered pre-existing conditions. Before that, we weren't able to purchase a private health insurance policy at all for our son until 2014 when the Affordable Care Act went into effect. Before that, it was tremendously difficult for us when trying to get insurance as small business owners in a state where the Katie Beckett Medicaid waiver wasn't funded sufficiently. We actually ended up moving states where Medicaid was better funded when Andy was 4 years old. And one of the challenges with some of these laws is that they're administered differently in different places. As a medical provider, it's important for you to be aware that the implementation of these laws can vary significantly between different states, so you'll want to find out where families can learn about the resources in your state.

In 2015, Congress passed the ABLE Act that allows families and individuals with disabilities to save more money without losing their public benefits. Before that, people with disabilities and their families couldn't save more than \$2,000 to help them without losing the benefits they need, like Medicaid. This meant that people with disabilities were often stuck in a cycle of poverty, particularly after the death of a parent. But now, we've been able to save over the past few years for Andy's future, and he's been able to save for himself.

All of these historic developments have helped improve the lives of people with disabilities, and they happened because families started raising their children at home, people with disabilities started claiming their own voices, and families and self-advocates started sharing their stories. This is how the outcomes for people with these conditions ended up improving dramatically.