

Ms. Patti Saylor, RN, MS

Testimony before the Senate Judiciary Subcommittee on the Constitution, Civil Rights, and Human Rights

“Law Enforcement Responses to Disabled Americans: Promising Approaches for Protecting Public Safety Hearing”

**Written Testimony
April 29th, 2014**

I want to thank Chairman Durbin and Ranking Member Cruz for convening today’s hearing on *Law Enforcement Responses to Disabled Americans: Promising Approaches for Protecting Public Safety* before the Senate Judiciary Subcommittee on the Constitution, Civil Rights, and Human Rights. I want to tell you firsthand that today’s hearing will save future lives.

Today, I am here as both a devoted mother and dedicated advocate for people with disabilities. I am the proud mother of three young adult children, Emma, Adam and the late Ethan Saylor. Growing up, I volunteered with Special Olympics Maryland, later earning a degree in Therapeutic Recreation from Shepherd College with an emphasis on working with people with intellectual and developmental disabilities (IDD). Little did I know, in 1987, I would be blessed with the birth of my son, Ethan, who had Down syndrome. Shortly after Ethan was born, I founded F.R.I.E.N.D.S, The Family Resource Information and Education Network for Down syndrome, a parent support network in Frederick, Maryland, now a National Down Syndrome Society (NDSS) affiliate. I later went on to become a registered nurse and earned a Master’s Degree in Special Education from Johns Hopkins University.

I served on the Maryland Developmental Disabilities Council, co-founded The Parent's Place of Western Maryland, and was instrumental in creating inclusive education opportunities for children with Down syndrome in Frederick County. I’ve served on numerous work groups, committees and boards, all in an effort to increase awareness and acceptance of individuals with intellectual and developmental disabilities. I am currently the owner of Health Link LLC, where I provide nursing case management for adults with disabilities who choose to live in their own homes and self-direct their own services with the support of the significant people in their lives. As you can see, I have always been an advocate for people with disabilities.

I want to share more about what brings me here before the Committee today. First, I want the Committee to understand who my son, Ethan, was as a person. Ethan was a 26 year old man. He was a brother and a son, and loved his family dearly. Ethan was the most loving individual, often responding to “I love you” with “I love you more” and leaving us long voicemails that he would sometimes sing to keep us all laughing. He was also strong willed, independent and had a tremendous sense of humor. For example, one time while taking a community college course, Ethan showed up to class with his backpack containing a laptop and a beer because he believed

that's what you did as a college student. Ethan also had his own apartment, and made his own hiring decisions for his support staff and the people he worked with. Ethan's support staff didn't have degrees in Down syndrome or disability, but I often say they had degrees in Ethan because he was a person first and foremost.

Ethan also had a passion for law enforcement. Since he was a young boy, Ethan was fascinated with police officers, people in uniforms, and people with authority. He watched NCIS on a regular basis, had a collection of officer badges and continuously would remind us "I am a good guy". He wanted nothing more than to get a job with our local police department. If Ethan were in the hearing room this morning, he'd want to be right up there sitting with the members of this Committee because that's where all the important people sit.

Today, our family now lives with a void in our hearts as we miss Ethan each day. On January 12th, 2013, our Ethan died in the hands of three, off-duty Frederick County Sheriff Deputies at our local Regal movie theater. Ethan's death was entirely unnecessary. It occurred when three Frederick County Sheriff Deputies sought to remove him from a movie theater for not purchasing a ticket to see the movie Zero Dark Thirty again. Before the Deputies approached Ethan, they were advised by Ethan's support staffer that Ethan had Down syndrome, was sensitive to being touched, and that his mother (me) was on her way to assist. The Deputies ignored the information provided by his support staff and proceeded to manhandle him out of his seat. When he resisted this rough treatment, they forced him into a prone position and handcuffed his hands behind his back with three sets of handcuffs.

While anyone, disability or not, could have been injured or killed in Ethan's situation that evening, our family also remains deeply concerned that Ethan's rights, as an individual with a disability, were violated. The autopsy showed that Ethan's larynx was crushed while being restrained by the officers. The manner in which Ethan was restrained that evening, with his hands behind his back and forced to lie face down on his stomach, has for years been considered excessive due to the chance of positional asphyxia.

Ethan never posed any immediate threat to the safety of the officers or others. The crime at issue was not severe, Ethan was sitting in a movie theater without a ticket and there were far less severe actions the officers could have taken. For example, they could have listened to advice from Ethan's support staffer, and allowed her to deescalate the situation by entering the theater to assist and support Ethan. We also feel there was no consideration, on the part of the Deputies, to the fact that Ethan had Down syndrome – a recognizable disability. We believe that the amount of force that was used on Ethan was not reasonable in light of the severity of the crime, the risk to the officers, the risk to Ethan, and the risk to others in the theater.

Since Ethan's death, we have been on our own advocacy journey to achieve justice for Ethan, while at the same time ensuring what happened to Ethan never happens to another member of the Down syndrome and disability community ever again. We have heard from advocates and parents all around the world that have been touched by our story, are fearful this may happen

to their son or daughter with a disability, and want to help advocate and ensure that something good comes out of our tragedy.

Right after Ethan's death, we began meeting with the US Department of Justice (DOJ) to share our story and pursue a civil rights investigation. From our understanding, the investigation is underway and we expect a report back from DOJ in the immediate future. Working with the National Down Syndrome Society and National Down Syndrome Congress, we activated the Down syndrome grassroots network to call on Governor Martin O'Malley of Maryland to pursue systemic change at the state level. My daughter and Ethan's little sister, Emma, authored a [change.org petition](#) calling for Governor O'Malley to commence a state investigation into Ethan's death as well as ensure law enforcement, first responders and other public officials all receive the very best training when it comes to their interaction with people with disabilities in the state. Emma's petition, to date, has received over 370,000 signatures, which we delivered directly to Governor O'Malley last September.

In September 2013, a few weeks after our meeting with Governor O'Malley, he issued an [Executive Order](#)¹, due in large part to the circumstances surrounding Ethan's death. The Governor's Executive Order established the [Maryland Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities \(the "Commission"\)](#). The Commission was tasked with (1) recommending statewide policies, guidance, or best practices regarding law enforcement and first responders' responses to situations involving individuals with IDD; and (2) developing a coordinated, collaborative, and comprehensive strategy to ensure enhanced responses to such situations, including consideration of expanding Crisis Intervention Teams and Mobile Crisis Teams for the state of Maryland. We also formed a coalition, Ethan's Law Workgroup, with disability organizations across the state, which is spearheading policy recommendations for the state of Maryland.

We are also proud to partner with The Arc's National Center on Criminal Justice and Disability (NCCJD), a national clearinghouse on criminal justice and disability issues founded by Bureau of Justice Assistance, U.S. Department of Justice with a two-year grant to develop a national center on criminal justice and disability, with a focus on intellectual and developmental disabilities (IDD) and to provide resources, information and referral, training, technical assistance and evaluation for criminal justice and disability professionals and programs.

Our advocacy journey had led us here, before the Senate Judiciary Subcommittee on the Constitution, Civil Rights, and Human Rights. As we continue to advocate for justice for Ethan and systemic change at the federal, state, and local levels of government, I feel we have a real opportunity to ensure what happened to Ethan never happens to anyone with Down syndrome or another disability ever again.

¹Governor O'Malley's Executive Order for the *Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities*; Executive Order dated September 13, 2013

At the federal level, funding is needed to support training of law enforcement when it comes to interacting with individuals with IDD; and we must set standards to ensure that quality and meaningful training is the standard across all law enforcement departments and public sector agencies. At the state level, we have an opportunity to mandate and deploy the Crisis Intervention Team (CIT) model to law enforcement departments across states. We know CIT has a proven record of success, but it has to be mandated and appropriately deployed across law enforcement departments and agencies to make a real difference.

Lastly, I often say that the people and friends at our church didn't have training to work with Ethan, they knew him as a person. When you know someone with a disability and have a relationship with that person, it changes your whole being and perspective. At the local level, we have a real opportunity to build relationships with our local law enforcement and public sector officials, the ones that are on the frontlines serving our communities. We believe that local disability advocacy organizations and providers should build lasting relationships with their local law enforcement and public sector officials. It doesn't take an act of Congress, federal or state mandate, or even money to make you realize that relationships are everything.

In conclusion, we sincerely want to thank members of the Subcommittee, especially Chairman Durbin and Ranking Member Cruz, for their leadership and dedication to all people with disabilities. As I said at the onset, I know that today's hearing will help save future lives and we thank you for that. Rest assured, we are committed to be tireless advocates for our beloved Ethan and all people with Down syndrome and other disabilities; and we will work with members of this Subcommittee to ensure the necessary changes and policies are put in place to ensure what happened to Ethan never happens to another member of this community. We supported Ethan following his dreams and living the life he wanted, a life of love and acceptance. I wake up each day knowing that Ethan's legacy will live on and on through our collective advocacy and shared responsibility for all people with disabilities.