Proponent Testimony for H.B. 465 "Lauren's Law"

Chairwoman Schmidt, Vice Chair Miller, Ranking Member Denson, Honorable members of the Families and Aging Committee.

Thank you for allowing me to testify today in support of House Bill 465 - "Lauren's Law". This law is named after my daughter, Lauren Elizabeth Carter. Lauren is a multiply handicapped individual with significant developmental disabilities. At two months old, and after a few weeks in the hospital, we were told not to expect to take her home. We were given the laundry list of things she would 'never do'. In September of this year, Lauren will turn 37 and, while she may not do things the way everyone else does, she has accomplished a lot of her 'never do' list and she defies predictions on a daily basis. Lauren is non-speaking, blind, g-tube fed, incontinent and has the developmental level of 12 – 18 months. She requires 24/7/365 close supervision and her sleeping pattern could never be described as 'normal'.

As she has grown up, and after she cleared the first few years, <u>the biggest threat to</u> <u>her existence has been the people to whom her care has been entrusted</u>. Three decades ago, Lauren began her ordeal in state sponsored care facilities solely because that is what the system will pay for. The system will pay for someone to be in a care facility but will not provide the same, or similar, resources to the people **most qualified** and **most motivated** to provide quality care to their loved ones.

On May 17th, 1995, Lauren was placed in an Intermediate Care Facility here in Columbus as a resident of Heinzerling Foundation. At the time, she was 7 years old and the distance from our home to Heinzerling was 90 miles with a drive time of an hour and a half one way.

She was placed there because no one cared.

- No one cared that she would not have family nearby,
- No one cared that a facility was inappropriate
- No one cared that she was not a good fit for the operation of Heinzerling as she was the only ambulatory person there at the time.

During this time, Lauren's story was documented by The Columbus Dispatch in a 4-day series called, "Fragile Lives" by Michael Berens.

Heinzerling soon found out that the placement was wrong and that they could not handle her, and she was subsequently moved to a different facility in Middletown, Ohio called Doty House, operated by Abilities First Foundation. While Lauren's life at Heinzerling was questionable, the darkness of **Neglect** and **Abuse** was just beginning with the transfer to Doty House.

Last year, Local 12 Cincinnati reporter David Winter reported that in 2021, the State of Ohio recorded 18,000 Major Unusual Incidents or MUI's. MUI's necessitate an investigation by the county Department of Developmental Disabilities, these incidents are either **substantiated** or **unsubstantiated** and the findings are reported to the Ohio Department of Developmental Disabilities. Some will call for oversight but, what are 18,000 MUI's if not oversight? What we are lacking is repercussions, consequences and accountability.

Here are a few of the MUI's Lauren has endured.

On Wednesday, September 30th, 1998, Lauren, then 11 years old, was pinched by an aide because Lauren pinched her first. During the investigation, it was also noted that a nurse had forced a feeding tube in Lauren's mouth because she was grinding her teeth. She also threatened to put Lauren in a room by herself if she did not behave. The county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but she remained under these conditions because no one cared.

On Friday, December 4th, 1998, Lauren, then 11 years old, escaped from her wheelchair, walked out of the building, down a ramp, across a parking lot, across a church field, across a street, before finally being discovered in the gutter of the street. All the while, she was dressed for indoor activity and was not wearing a coat or shoes. Upon her return and having just proven she did not need a wheelchair; she was nonetheless returned to her wheelchair and an abductor was added in between her legs so that she would not do that again. The police investigated, the county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Thursday, February 25, 1999, Lauren, still 11 years old, was again pinched by a staff member who additionally told her, "I will break your f*****g arms" if she did not cooperate. The county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Tuesday, June 22nd, 1999, Lauren, still 11 years old, was physically and verbally abused by a nurse on staff at Doty House. The nurse shoved a 60-cc syringe in Lauren's mouth as Lauren was grinding her teeth. In addition, the nurse was verbally abusive, called Lauren a 'Devil Baby' and threatened to place Lauren in a closed room by herself. The police investigated, the county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

In December of 2002, Lauren was relocated again to the Fairfield Center in Fairfield, Ohio. This location would later change its name to Takoda Trails following some unpleasant public relations issues and the death of a resident at the hands of another.

On Friday, October 18th, 2003, Lauren, now 16 years old, received a cut to her hand that required 18 stitches to repair. This incident was not properly reported and was only discovered by the county inspectors as they were investigating a different incident involving a different resident. Quite literally, they found out by accident. Subsequently, the county investigated, the incident **was substantiated**, and the Ohio Department of

Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Wednesday, January 6th, 2010, Lauren, now 22 years old, was again restrained in a wheelchair while at the adult day program of Creative Learning Workshop in Forest Park, Ohio. The county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Thursday, July 21st, 2011, Lauren, now 23 years old, was left on a transport bus at Creative Learning Workshop on one of the hottest days of the year. When she was discovered, after at least 3 hours, she was fully soaked in sweat, had an elevated body temperature, was noted to be in distress and subject to the effects of dehydration. EMS was not called. The police investigated, the county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Tuesday, November 18th, 2014, Lauren, now 27 years old, was found to have a broken clavicle. The origin of the injury is unknown and because there is no video surveillance of the patients, the cause of a broken collarbone remains a mystery. The county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Sunday, August 25th, 2019, Lauren, now 31 years old, was hospitalized with what was deemed to be a bowel obstruction. Lauren had her feeding formula oozing out her surgery site on her belly and up out of her mouth. Upon admission to the emergency room, the staff of the hospital pumped 2 liters of fluid out of the stomach of a young woman who is 4' 7" tall and weighs, typically, around 90 pounds. Upon further discussions, it was determined that stool softeners that were a normal part of Lauren's intake had been discontinued by Takoda Trails. Thankfully, after requiring sedation, Lauren recovered, and the stool softeners again became part of her regular process. The county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Tuesday, November 30th, 2021, Lauren, now 34 years old, sustained a 4" long, 1 ¹/2" wide, cut to her neck. At the time, there was only one employed individual on staff in the building where Lauren resided with approximately 7 other individuals. Lauren could not have done this to herself as she will not hold anything in her hands. The police investigated, the county investigated, the incident **was substantiated**, and the Ohio Department of Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Monday, July 18th, 2022, Lauren, now 34 years old, was left on a transport bus for the second time. This time for a period of 5 hours. The police investigated, the county investigated, the incident **was substantiated**, and the Ohio Department of

Developmental Disabilities received the findings, but again, Lauren remained under these conditions because no one cared.

On Thursday, January 18th, 2024, Lauren, now 36 years old, had access to fall down a flight of stairs in her current group home. Because of 'rights restrictions' it is not possible to secure the door to the basement, thus creating an unnecessary hazard.

From the time she was 7 years old until now, at 36, Lauren has been subjected to **daily neglect and documented abuse**. She's lived a life that could, and should, have been avoided. Accidents can happen but Lauren's life has not been filled with accidents, Lauren's life has been filled with atrocities.

That brings us to today, nearly 3 decades after Lauren was forced into a state sponsored care system that directs resources to provider companies, homes and agencies instead of parents and families.

Thirty years of neglect and abuse. Thirty years of death-defying stories of survival by this one little girl. Thirty years of what can only be described as a "Wrongful Life". **Thirty years of no one caring**.

It's time for this committee to care. It's time for this legislature to care. It's time for the Department of Developmental Disabilities to care. It's time for the Department of Medicaid to care. It's time for the Department of Health to care. It's time for the entire system that exists to care, and it is time to change it.

It's time to pass H.B. 465 "Lauren's Law" and place Families First as the **DEFAULT POSITION** and **FIRST LINE OF DEFENSE** in the care of individuals with Intellectual Developmental Disabilities and to allow for audio/video surveillance in resident's rooms for those who do reside in care facilities.

It's time to end the neglect and abuse heaped on arguably the most vulnerable people in our society, people who are entirely dependent on another human for their daily existence. People who cannot defend themselves and often, cannot speak for themselves.

There will be people who will argue against "Lauren's Law" by saying that "we can't afford to pay parents instead of institutions".

When you read or hear this, the very first thing you should do is find out if the person or organization making the argument is paid, directly or indirectly, by the system in place.

IF THEY ARE, then they are arguing that they, and the system they are a part of, continues to be funded while denying funds to the people **most qualified** and **most motivated** to care for the individuals in question.

The other thing you must do is look at all the people and organizations involved who provide no hands-on care. There is a substantial amount of money devoted to this process that is siphoned off and diverted before ever reaching the most important aspect of the process...caring for the individuals involved.

State level employees County level employees Provider and agency company executives, administrators and supervisors ANYONE not providing hands-on care should be required to justify their continued employment and existence in the care process on an annual basis.

The passage of House Bill 465 – "Lauren's Law" will be a quantum leap forward in changing a decades long problem. In the 1970's, Geraldo Rivera published an expose' on the institutions and asylums in America. People were outraged and asylums were closed. After dealing with Lauren's life for the past 30 years, I can say with confidence, the only things that have truly changed are the architecture, landscaping and paint jobs.

Lauren's story is egregious, but it is not isolated. Over the past 30 years we have witnessed far too much.

It's time to care. It's time to change it. It's time to stop accepting it.

Thank you again for your time and I welcome any questions you may have.