



Ohio House Families and Aging Committee

RE: HB 465
Lauren's Law

Dear Madam Chair:

The Autism Society of Ohio (ASO) is a coalition of the Ohio affiliates of the Autism Society of America and includes the Autism Societies of Central Ohio, Greater Akron, Greater Cleveland, Dayton, Mahoning Valley, and Northwest Ohio. Together, we cover 100% of the state and thousands of individuals and families living with Autism and other developmental disabilities in our communities.

Our mission is ***to create connections, empowering everyone in the Autism community with the resources needed to live fully.***

Thank you for holding hearings on H.B. 465, Lauren's Law. We would like to add our voices to support the spirit of this legislation and to urge the committee to address the many challenges individuals with disabilities and their families are enduring in our state.

Lauren's Law Support

- **Electronic Monitoring:** ASO unequivocally supports the use of cameras in the personal space of individuals living in Intermediate Care Facilities (ICF). The bill is grounded in person-centered decision-making, requiring approval by the resident, guardian, or attorney-in-fact. It also protects a person's privacy by having the camera accessible only to guardians whose role it is to support and ensure that person's safety. It is important that ICFs are held accountable to use the cameras as requested by residents and families.

We would like to add that cameras should be in all congregate settings to protect vulnerable populations and provide safety measures in a non-invasive way. Cameras are everywhere in our society and should be used to ensure the safety of individuals who are not able to protect themselves. We also believe cameras protect both clients and staff, providing a clear and objective understanding of occurrences.

- **New Medicaid Waiver:** The proposal of a family-care waiver to provide Home and Community Based Services (HCBS) can be another option for struggling families who find that living in an ICF or congregate setting is unsafe or unhealthy for their loved one. Families have a right to an alternative method of care when their family member is not being properly cared for. We acknowledge that there should be a

reporting method and strict oversight to ensure the funds are used for the intended purpose.

We must think long-term in Ohio.

While we support Lauren's Law, we also wish to emphasize that cameras are one tool in a broader Ohio "system" that lacks proper housing and appropriately trained staff. Similarly, creating a family waiver is an option that families may utilize, but also does not eliminate the need for a stable care system that does not depend on families. As parents age, the reality is taking care of their adult child forever isn't possible. Siblings and younger family members often have jobs and their own families and may not be able to take on the demands of supporting a person with a disability.

Several legislators during the hearings asked what else needs to be done to improve our current system of ensuring the safety of individuals with Autism/Developmental Disabilities/Intellectual Disability. We would like to share our thoughts.

It's important to reflect on the history of disability in Ohio to understand where we are today. In 1999, the United States Supreme Court in *Olmstead v. L.C.*, held that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act (ADA). In 2019, Disability Rights Ohio won its Class Action Suit to support individuals with disabilities outside of ICFs and into Home and Community Based Services in compliance with the Olmstead Act. However, HCBS is an optional service for states under their Medicaid plan, creating long waitlists and many issues in the system.

In other words, it's the wild-wild-west in Ohio as the "system" is changing while we are living it and it's NOT working. Here are additional suggestions:

- Living safely in the community requires community-based safeguards that do not currently exist.
- There are more than 165,000 active Medicaid providers in Ohio. The standards, background, and training to provide HCBS as a provider are minimal. Just about anyone can open an agency. To protect the safety of the patient, we must expect more expertise from people opening agencies.
- Increase the Medicaid reimbursement rate to provide access to important services. With the current low reimbursement rate, Medicaid is not being accepted by many providers, creating a hardship for individuals to access medical and rehabilitative support.

- Set the bar higher for opening agencies providing HCBS by requiring potential owners/CEOs to have significant (more than one year) experience in leadership, education about disabilities, operations, and management of congregate settings.
- Improve oversight of agencies that are running ICF's and group homes by creating state standards. While the Centers for Medicare & Medicaid Services (CMS) have federal standards of care, this is often not sufficient to protect the well-being of patients. Ohio can improve the quality of care by exceeding the federal requirements to improve the safety and well-being of individuals with disabilities. The Ohio Department of Developmental Disabilities can do this without legislative authority, but so far has not acted.
- Strengthen County Oversight. Along with strengthening the required standards for providers, there must be improved oversight by the County Board of Developmental Disabilities (CBDD). Give County Boards statutory oversight authority with the appropriate funding. This would allow them to carry out oversight of improved standards, including shuttering bad agencies that have multiple violations.
- Similarly, ensure the County Boards have the tools and authority to support families transitioning their loved ones outside of the family home. Currently, guardians are flying blind. Often, they are handed a list of hundreds of agencies to choose from to manage their loved one's home with no criteria or rating system to help with this important decision. That is ridiculous and an impossible task. While I understand why the CBDD's cannot make recommendations, they should have some criteria and ability to assist with quality recommendations that reward the good agencies.
- Develop a rating system that is open to the public with criteria to evaluate agencies (perhaps based on those improved standards). It is easier to find out about a restaurant than it is the providers who are running ICF's and group homes.
- Improve training for Direct Support Professionals: There is minimal training for DSP's and very little incentive for continuing education. Incentivize both the agency and DSP to receive "credits" and dollars for learning how to best support individuals with complex needs.



Thank you for your consideration, if you have any questions, please free to contact Laurie Cramer, Executive Director, Autism Society of Greater Akron, at Laurie@autismakron.org or (330) 940-1441 x3.

Sincerely,
Laurie Cramer
Executive Director
Autism Society of Greater Akron

And the following:

Autism Society of Central Ohio
Autism Society of Greater Cleveland
Autism Society of Dayton
Autism Society of Mahoning Valley
Autism Society of Northwest Ohio