

Caroline Lahrman - Extended Testimony

This is Henry and Elizabeth Lahrman and I am their mother Caroline. Henry and Elizabeth are 15 years old and were born with profound mental retardation, quadriplegia, and an intractable seizure disorder. It's important to understand that a community setting would greatly reduce Henry and Elizabeth's health and quality of life and could lead to their death. Considering their challenges, Henry and Elizabeth are doing well right now, but that is because of the extraordinary efforts that Heinzerling, their ICF, goes to on a daily basis. I also know how quickly things can spiral down for Henry and Elizabeth, and I know that despite our best efforts, it was not until we placed them at Heinzerling that they stopped constantly crying out of discomfort for their condition, began stabilizing their weight, and got their seizures under better control.

Developmental Disabilities Bill of Rights

Henry and Elizabeth need their family to be their voice in all decisionmaking. Amendments made by the House to the DD Bill of Rights respect this reality by giving individuals with profound needs the ability to have their family members or guardians help them make decisions. I urge the Senate to respect the bonds of family and maintain these amendments to the DD Bill of Rights in the Senate version of the budget.

DODD System Change Since 2005

We are told that Ohio has an institutional bias. But since 2005, **the waiver component of Ohio's Developmental Disabilities System has grown by 175%, nearly \$1 billion.** Over the same period, the number of ICF beds has decreased and funding has grown by a modest 2.6%, as compared to the CPI inflation rate for the 10-year period of 19.6%. Considering that ICFs are operating in the field of health care with costs increasing at 36%, the CPI medical care inflation rate for the 10-year period, it is remarkable that the ICF program has been able to maintain such a high quality of care given a relatively modest growth in funding. Just consider the robust array of services that ICF residents require - licensed nursing; therapy; nutritional, behavioral and psychological support; personal care; community integration - all of that provided by ICFs with only a small growth in funding in an economic sector with a staggering inflation rate. Ohio's ICF providers should be celebrated and held up as a model of how safe, compassionate care can be delivered to our most fragile citizens while respecting the taxpayer's dollar.

Expenditures per Service Model

Service Model	2005	2015	2017
Waivers	\$529,436,901	\$1,454,055,803	\$1,905,867,427
ICFs	\$447,171,597	\$565,551,348	\$570,489,551

Source: Executive Budget & Ohio DODD

Number of Individuals Per Service Model

Service Model	2005	2015	2017
All Waivers	15,363	36,082	42,876
ICFs	5,829	5,598	5,300

Source: Executive Budget & Ohio DODD

IO Waivers vs. ICFs: Number of Individuals Per Service Model

Service Model	2005	2015	% Change
IO Waiver	11,620 (May 2006)	18,900	63%
ICF	5,829	5,598	-4%

Source: Executive Budget, Ohio DODD & State of Ohio Motion for Summary Judgement, Martin v. Taft (for IO Waiver 2006 citation)

IO waivers have increased 63% since 2005 while ICF beds have decreased 4%. Clearly, an institutional bias does not exist in Ohio, nor is the county match system of funding waivers driving people to ICFs.

Protect Health & Safety of ICF Residents

DODD administrative rules create a dangerous living environment for ICF residents with complex needs. Policies in this budget will cause ICFs like Heinzerling to reduce the number of residents per bedroom by building small 6-8 bed settings. The administrative rules in question prohibit this development from occurring on or adjacent to ICF campuses.

ICF residents with complex needs (i.e. profound mental retardation, quadriplegia, tube fed, intractable epileptic seizure disorders and other serious medical conditions), are far too fragile to move into small settings away from the main campus without a licensed nurse 24 hours a day and 24 hour supervision of the personal care staff. Given their inability to communicate, these residents are totally reliant on continuity of care and expert staff to identify health issues before they get out of control. As you can imagine, staffing for this level of care in a small 6-8 bed facility is prohibitively expensive. By building on their campuses, ICFs can maintain appropriate care levels in a cost-effective manner.

The Ohio Senate has the authority and the duty to protect Ohio's most vulnerable citizens by including an amendment into the budget that would strike DODD administrative rules 5123:2-3-26 (D) (5) and (6). I urge you to allow ICFs to build additional living space on their own campuses in order to meet the proposed residents per room restrictions in ORC 5124.70.

Please make health and safety a priority for our most fragile citizens.

Conclusion

Director Martin rightly stated that the DODD service system was formed with the loving and supremely informed guidance of families and guardians. As a result, Ohio became a place where individuals with intellectual and developmental disabilities could live free from abuse and neglect and the ignorance of their condition that perpetuates such acts.

I leave you with Justice Kennedy's words from his concurring opinion in *Olmstead*. In them, he quotes from the majority opinion. Kennedy writes,

"It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."

Kennedy then quotes from the majority opinion,

*“Justice Ginsburg’s opinion takes account of this background. It is careful, and quite correct, to say that it is not **“the ADA’s mission to drive States to move institutionalized patients into an inappropriate setting...”** (Emphasis added.)*

Kennedy concludes,

*“In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, **States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.**” (Emphasis added.)*

Chairman Oelslager, Vice-Chairman Coley, Ranking Member Skindell and Members of the Finance Committee, I urge you to listen to these wise words and heartfelt warning. Honor the choices of ICF residents which were made with the aid of loving parents and guardians. Please preserve Ohio’s large ICF program so that its vulnerable residents can lead safe and happy lives.

Thank you for the opportunity to testify.

Caroline A. Lahrman
June 11, 2015



Elizabeth and Dad at Heinzerling’s Sensory Park.



Henry hanging out at Heinzerling.

Thursday June 11, 2015

Chairman Scott Oelslager
Senate Finance Committee
1 Capitol Square
Columbus, Ohio 43215

Ranking Member Michael Skindell
Senate Finance Committee
1 Capitol Square
Columbus, Ohio 43215

Vice-Chairman Bill Coley
Senate Finance Committee
1 Capitol Square
Columbus, Ohio 43215

Dear Chairman Oelslager, Vice-Chairman Coley, Ranking Member Skindell and Members of the Senate Finance Committee,

On February 5th, Disability Advocacy Alliance (DAA) began a petition campaign to object to proposals in the Executive Budget which would have financially squeezed Intermediate Care Facilities (ICFs) into significant downsizing and closures and eliminate sheltered workshops and facility-based day programs. DAA reached out to parents and guardians for support of our petition.

In just over five weeks, parents and guardians collected 18,585 signatures which were lodged with the Ohio House Health & Human Services Subcommittee on March 17th. Many individuals continued to collect signatures. Today, we submit an additional 2,710 signatures to the Senate Finance Committee, bringing the grand total lodged with the Ohio Assembly to 21,295 signatures.

This was purely a grassroots movement fueled by love for our children and a spontaneous reaction against policies proposed in the Executive Budget.

These signatures tell three things:

1. Specifically large ICFs are widely supported and needed for the high level of specialized care and community integration they provide.
2. Sheltered workshops and facility-based day programs are widely supported and needed for the valuable products their workers produce and the productive opportunities the programs create.
3. Ohioans overwhelmingly support programs for the developmentally disabled; they want their tax dollars spent responsibly on time-honored programs with proven results.

We respectfully ask you to listen to the voices of everyday Ohioans - the developmentally disabled, their parents, guardians, family members, caregivers and friends. We believe that these individuals - your direct constituents - should determine the course of Ohio's Developmental Disabilities Service System. If we look to Ohioans, we are confident that the health, safety and welfare of our most vulnerable citizens will be protected.

Sincerely,

A handwritten signature in blue ink that reads "Caroline Lahrman". The signature is written in a cursive style and is set against a light yellow rectangular background.

Caroline Lahrman
Disability Advocacy Alliance
Spokesperson