

## **Testimony of Caroline Lahrmann in support of HB 770 Essential Caregivers Act**

Chairman Ginter and Members of the Committee,

My name is Caroline Lahrmann. My husband and I are the parents of three children. Our oldest is 24 and is gainfully employed. Our youngest are twins who turned 21 on November 30th who have profound intellectual and developmental disabilities. As adults, they function at the level of infants and require total care for all of their life needs. They are residents of Heinzerling Community, a highly respected charitable organization in Columbus that is certified by Medicaid as an Intermediate Care Facility for Individuals with Intellectual Disability (ICF). Heinzerling cares for 200 of Ohio's most difficult to care for citizens with intellectual and developmental disabilities. My husband and I are strong advocates of Heinzerling and are deeply grateful for the world class care they provide our children while creating a home-like environment for the residents filled with love, enriching activity, and opportunity.

I am here to testify in support of HB 770, the Essential Caregivers Act that will allow essential caregivers to have access to their loved ones in this time of pandemic to perform care and maintain the social and mental well-being of their loved ones. I urge you to move this legislation forward as it will help remedy the failures in the COVID-19 visitation policies currently in place in Ohio. I am here to tell you that no matter how well-meaning:

1. The visitation policy does not support health and welfare.
2. The visitation policy is cruel.
3. The visitation policy does not respect guardianship law.
4. The visitation policy infringes on the human and civil rights of residents.

### **The Policy Does Not Support Health and Welfare**

The policy to restrict access to individuals in facilities is based on an outmoded and simplistic retail dictionary definition of health - that health is just "the absence of disease or injury." But medical experts have moved beyond this definition to now recognize that health is complete social, mental, and physical well-being.<sup>1</sup> and that health is "a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities."<sup>2</sup>

For someone like my children - that definition of health - that it is a resource, not the objective of living is the most applicable. In the dictionary sense of the word, my children are not healthy people. They have never been and they never will be. But that does not mean they cannot lead full lives to the extent possible and achieve a level of health on a more wholistic level - socially and mentally. And, I am proud to say, that with the help of Heinzerling, they have done so, but the visitation policies in place infringe upon their health. It is not healthy to be restricted from seeing your family and friends. It is not healthy to be unable to go on a walk outside. It is not healthy to not to go to school or work, or for severely intellectually disabled people, a day program. In our desire to achieve the absence of disease during this pandemic, we have created a false standard of well-being for individuals living in residential care facilities.

### **The Policy is Cruel**

Which leads me to my next point. The visitation policy is cruel. To a large degree, the individuals living in residential facilities have no voice. During the pandemic, they are being prevented from engaging in normal life activities, but they cannot protest this fact. Their family members are oftentimes their voice and they are being kept from them. My children are non-verbal. They function as babies. They have no

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<sup>1</sup> World Health Organization definition of health.

<sup>2</sup> "What is good health," Medical News Today, April 19, 2020.

understanding of why they have to see their mom and dad through a plexiglass screen and why their mom who usually showers them with hugs is standing six feet away unable to touch them. Or why they only see us once a week for a half an hour. They typically communicate with us by tugging on our clothes or my son will ram his wheelchair into our legs. They cannot engage in their normal mode of communication behind a screen. But I assure you, even non-verbal people find ways to express their anxiety. As the head of Disability Advocacy Alliance, I have spoken to ICF parents who have told me that their son for the first time is scratching his face because he is so anxious. Or that their son is bored and listless and is losing his capacity to ambulate. This is not health. It is not well-being. The visitation policy in Ohio is inflicting cruel results on the people its ostensibly protects. By keeping out essential caregivers, the family members, these residents are suffering. Are we going to let this continue indefinitely?

As parents of children with profound medical conditions, we go through life knowing that our time with our children may be short. Many individuals like my children are not expected to achieve a long life expectancy. Indeed, we were told at one point that our children would not make it passed childhood. Fortunately, the doctors were wrong, but even so every moment that we have with them is precious. This is especially true for those parents in their 70's and 80's who do not know how much time they personally have left. The state's visitation policy is stealing our loved ones' lives, and stealing the joy that they receive from life, and it is stealing our family moments and the joy we have being together. It is not compassionate and it is not humane to isolate people from those that love them and that they need the most. It is not health.

### **The Policy Tramples on Guardianship Law**

Ohio Revised Code recognizes a guardian as the “person...appointed by the probate court to have the care and management of the person.”<sup>3</sup> Guardians are in a sense an arm of the probate court appointed to ensure the health and safety of our wards. This solemn duty cannot be accomplished if we are not allowed real access to our family members. In normal times, when I visit my children, I come to see them, but I am also checking things out—how well-trained the staff are, the cleanliness, that protocol is being followed. I also look at my children. I look for common injuries that a quadriplegic person experiences. When I engage in their caregiving, changing their diapers, giving them their tube feeds, I am looking and checking that they are physically fine. I do this not because I doubt the dedication and expertise of the Heinzerling staff. I do it because it is my duty and I know no one cares for Henry and Elizabeth they way I do or knows them as well as I know them. It is of great concern that the State of Ohio is preventing guardians throughout the state from performing this crucial role that is expected of them by the probate court.

### **The Policy Infringes on the Human and Civil Rights of Residents**

It doesn't take a constitutional scholar to know that it is not constitutional to restrict lawful citizens who are residents of nursing homes and ICFs from freely coming and going and freely associating with their friends and family. Initially, families were willing to put up with some loss of freedom for their loved ones, but it is now nine months into the restrictions with no end in sight. I feel it is my duty to speak out for the human rights of my children to be able to freely engage in society—to go to school and to be with their family and friends. I believe that the Essential Caregivers Act strikes a balance in this difficult time. It allows the essential caregiver to visit their loved one on a scheduled basis, but it does so by requiring common sense protections to protect the safety of other residents and staff, such as wearing PPE and maintaining distance from other residents and staff.

It is common knowledge that the turnover in nursing homes and ICFs is significant. We also know that employees of facilities are not going home each night to sit alone in a sterile environment only to go to work the next day. It is silly to believe that it is safer for the employees to touch our loved ones than it is

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<sup>3</sup>Definition of “Guardian” as used in Chapters 2101 to 2131 of the Ohio Revised Code.

for a mom or dad or other family member. A person can be hired today at my children's facility and can touch and be with them, but their own mother cannot. This policy does not make sense. Workers are coming into these facilities each day bringing with them all of the contacts they were exposed to in the community the day before. Each employee, then, brings the possibility of exposure to the residents. So visitation restrictions are not the reason my children have been protected from COVID-19. They have been protected because the employees are wearing PPE and practicing other necessary precautions.

I urge this committee to pass the Essential Caregivers Act out of committee. I am grateful for Representative Richardson for sponsoring it. The bill protects the health and safety of the most vulnerable Ohioans by honoring their complete health and well-being and their human and civil rights.

Thank you for your consideration.

Caroline Lahrman  
Mother and Guardian of  
Henry and Elizabeth Lahrman