



**Testimony of Laura Cordes**

**In opposition to LD 2009**

***An Act to Prevent Abandonment of Children and Adults with Disabilities in Hospitals***

**Joint Standing Committee on Health and Human Services**

**January 16, 2024**

Good afternoon, Senator Baldacci, Representative Meyer and esteemed members of the Health and Human Services Committee.

My name is Laura Cordes. I am the Executive Director of the Maine Association for Community Service Providers (MACSP). MACSP is the statewide association of 90 individual, mission driven agencies providing person centered and individualized educational, vocational, residential and community supports, as well as specialized services and care to several thousand of Maine's children and adults who have either intellectual disabilities, autism spectrum disorder, or brain injuries, so that they may live full and meaningful lives in the community.

Thank you for the opportunity to provide testimony on LD 2009 *An Act to Prevent Abandonment of Children and Adults with Disabilities in Hospitals*. I had a conflicting meeting today with the Office of Aging and Disability Services and regret that I could not be in the committee to offer this testimony in person.

LD 2009 requires:

*"...a hospital to discharge a minor or an adult with a disability who is under guardianship to the care of a parent or guardian no later than 48 hours after the attending physician has determined the minor or the adult with disabilities is safe for discharge, and if a parent or guardian does not take custody of the discharged minor or the discharged adult with a disability within that period, the hospital is required to notify child protective services or adult protective services, as appropriate, which must then take custody of the minor or the adult with a disability."*

While LD 2009 reflects a shared and serious concern for the welfare of children and adults with disabilities, we believe the underlying problem that the sponsors wish to address is best solved not by penalizing parents and guardians, but by looking to improve the state's crisis system and specifically the interim support that may be needed before a child or an adult with a disability is discharged from the hospital.

People with intellectual disabilities or autism spectrum disorder who have or develop unique and complicated medical and/or significant behavioral needs deserve access to appropriate and specialized services, including crisis care and individualized supports.

As providers of both case management, residential and community support services to more than 6,000 adults with disabilities, we know that when a medical crisis emerges and a hospitalization is required there are times when a parent, guardian or caregiver is simply not

able to provide the intensive supports that are needed for their adult son and daughter upon discharge. We work closely with families who are desperate for supports within the state's Home and Community Based Service (HCBS) system. Individual placement takes time as each person has their own unique set of needs. While under HCBS there is a right to specific housing and supports; the demand for these specialized services is outpacing available support systems.

Inadequate rates for specialized supports for people with the most complex needs, has led to fewer providers being able to recruit and retain required clinicians and specialists, reflecting the lack of access across the state. If a person with complex needs is receiving services, they may find themselves in an unsafe situation either medically or physically. When this happens there are a myriad of factors that are considered before moving forward with accessing emergency services.

In addition to ensuring that the member who has been discharged from the emergency department has the medical and behavioral supports needed in their home and community, the health and safety needs of family members and/or roommates must be considered. This later factor may necessitate a new placement which requires additional time to secure.

As this committee has heard over the course of several years, the Department itself continues to lack a crisis system that can support individuals who need additional intensive supports when discharged from the hospital before returning to their home in the community. While state-level efforts to provide training via the START model and develop a mobile crisis response are underway, the lack of crisis supports continues to put individuals at risk and parents and guardians and oftentimes, the provider that they have been relying on, in untenable positions.

### **The state has just 8 adult crisis beds and a handful of Emergency Transitional Housing beds.**

We encourage the committee and Department to examine the problem more closely:

- *What data exists for adults with disabilities that documents the problem of long hospitalizations?*
- *What are the reasons that parents or guardians may not be able to take custody of their adult child with a disability within 48 hours?*
- *For individuals with disabilities needing specialized support and placement when discharged from a hospital, what are their specific needs?*
- *How many requests have there been for a crisis bed, or Emergency Transitional Housing? How many have gone unfilled?*
- *How many adults with intellectual disabilities and autism spectrum disorder have been placed out of state? How could we better utilize these resources to ensure that Mainers are supported in state?*

Over the last several years, we have supported legislation that would help ensure that adults with disabilities who have the most complex medical and behavioral needs have the specialized support that would help lead to stabilization, community living and decrease the number of hospitalizations. These bills include:

131st Legislature: [LD 473](#) *Resolve, to Expand the Eligibility for and Increase the Number of Hours of Applied Behavior Analysis Services Authorized by the MaineCare Program*

130th Legislature: [LD 1574](#) *An Act To Ensure Support for Adults with Intellectual Disabilities or Autism*

We welcome your questions and are committed to working with the Department, hospitals and all stakeholders to ensure that people with disabilities have the individualized support that they need and deserve.

Thank you for your consideration.

Respectfully Submitted,

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