DISABILITY RIGHTS MAINE

January 16, 2024

Electronically Submitted

Senator Joseph Baldacci, Chair
Representative Michele Meyer, Chair
Committee on Health and Human Services
Cross Office Building, Room 209
Augusta, Maine 04333

Re: LD 2009 - An Act to Prevent Abandonment of Children and Adults with Disabilities in Hospitals

Dear Senator Baldacci, Representative Meyer, and Members of the Committee on Health and Human Services:

My name is Atlee Reilly and I serve as the Legal Director of Disability Rights Maine, Maine's Protection and Advocacy agency for people with disabilities. DRM provides the following written testimony against *LD 2009 - An Act to Prevent Abandonment of Children and Adults with Disabilities in Hospitals.*[1]

No individual with a disability should spend *any* unnecessary time in an emergency department. As this Committee heard at the hearing on LD 1003 last session, these settings are not therapeutic and are not designed to provide anything beyond immediate stabilization. Allowing people with disabilities to become stuck in these settings is damaging to all involved. But the inability of an individual to leave a hospital after being deemed safe for discharge is a complex problem that requires a comprehensive solution.

[1] As an aside, assuming the needs of children and the needs of adults with disabilities are the same is not a good way to approach policy development because it is reflective of the continued infantilization of adults with disabilities, especially adults with developmental disabilities.

LD 2009 would give plenary power to any one of the hundreds of attending emergency room physicians in Maine to essentially force Maine to take guardianship of an individual who has a parent or private guardian if the parent or private guardian disagrees with the assessment that the individual is safe to be discharged back to their care. We are aware of no other statute that gives a single private actor this kind of power, especially one that appears to circumvent existing legal processes regarding child welfare,[2] child abandonment,[3] and adult guardianship.[4]

Public guardianship is not the panacea that this bill suggests it is. LD 2009 rests on the incorrect presumption that children and adults under guardianship are unable to leave hospitals because they have been "abandoned," and that imposing a requirement that the state intervene and assume "custody" will be a solution. In fact, most often the reason why a person becomes "stuck" in an inappropriate setting such as a hospital is because of a lack of appropriate community-based services, particularly services that support individuals with behavioral health needs.

Moreover, the Probate Code is abundantly clear that the state is a guardian of last resort, and may not be appointed by a court unless there is no suitable private guardian.[5] A law requiring the Department of Health and Human Services to file for guardianship of a minor or an adult without regard of the circumstances of a particular situation, the individual's needs or desires, or the reasons for the inability to discharge, fails to recognize the Department's own protocol in determining such matters, and could lead to a broad overreach of state intervention.

Additional Considerations Regarding LD 2009 and Adults with Disabilities

Adults subject to guardianship unable to discharge from a hospital are very rarely stuck because the guardian has abandoned them. Usually, the guardian is involved in meetings seeking an appropriate placement after discharge. When a case is complex, other individuals are called in, including the Department, the Long-Term Care Ombudsman Program, Disability Rights Maine, or other advocacy organizations. No one's goal is for an adult with a disability to remain in a hospital indefinitely, where they receive no therapeutic services, no community integration, and often cannot physically leave the premises to take a walk or get fresh air. Discharging an individual to the "custody" of the guardian may not be safe, and may not be desirable to the individual. In many cases, adults subject to guardians do not live with their guardians, and are unable to leave a

[2] See generally: Maine Child and Family Services and Child Protection Act, 22 M.R.S. §§ 4001 et. seq.
[3] See: 17-A M.R.S. § 553
[4] 18-C M.R.S. §§ 5-701 et. seq.
[5] 18-C M.R.S. § 5-702.

hospital because they have lost housing due to an unwilling provider accepting them back into their residential setting. The adult may not want to be "taken custody" of by the guardian, or, this may not be feasible for any number of reasons. There has been a longstanding lack of appropriate home- and community-based services that has added to this continuing crisis. As the Department can likely attest, individuals unable to discharge from hospitals are at times already subject to public guardianship without the issue being resolved.

In 2019-2020, a stakeholder group was convened pursuant to LD 1229, Resolve, To Establish the Committee to Study and Develop Recommendations To Address Guardianship Challenges That Delay Patient Discharges from Hospitals. The group consisted of legislators, representatives from OADS, APS, the Long-Term Care Ombudsman Program, Disability Rights Maine, Legal Services for the Elderly, hospitals, judges and registers of probate courts, the Attorney General's Office, and others, and five meetings were convened to discuss this very issue. One of the major topics of discussion in the meetings was an overview of Adult Protective Services protocol for making guardianship determinations for individuals unable to discharge from hospitals. APS was clear that, when they were alerted to such a situation, the protocol was used, and there were times they did conclude that public guardianship was appropriate and necessary to affect discharge. Subsequent to the conclusion of the workgroup, the 130th Legislature passed a bill expanding the circumstances in which someone may obtain emergency guardianship to include delayed discharge from a hospital. DRM, LSE, and DHHS all opposed this bill, in part because they all reasoned that guardianship is not often the barrier to discharge from hospitals, but instead a lack of robust support services. Despite the law going into effect, support services remain lacking, and people remain stuck inappropriately in hospitals. Rather than learning from that experience, LD 2009 doubles-down on the use of guardianship as a means to pave the way for people to leave hospitals.

Additional Considerations Regarding LD 2009 and Children with Disabilities

Our concerns with the current state of the children's behavioral health system have been extensively detailed in testimony already provided to this Committee during the First Session, so we will not repeat those concerns in detail here.[6] In this prior testimony,

[6] DRM testimony on LD 181, *Resolve, Directing the Department of Health and Human Services to Implement Secure Children's Psychiatric Residential Treatment Facility Services*, is available here: http://www.mainelegislature.org/legis/bills/getTestimonyDoc.asp?id=168846; DRM testimony on LD 378, *Resolve, to Eliminate the So-called Fail First Requirement for Children's Residential Services for Certain Individuals Whose Needs Are Unable to Be Met with Home and Community-based Services by Expanding Eligibility for Those Individuals* is available here: http://www.mainelegislature.org/legis/bills/getTestimonyDoc.asp?id=167405; DRM testimony on LD 435 - *Resolve, to Ensure the Provision of Medically Necessary Behavioral Health Care*

which DRM reaffirms today, we have worked to lift up the core findings and conclusions outlined in the 6/22/2022 Letter of Findings from the United States Department of Justice which can be summarized as the obligation to ensure the availability of community-based services for children throughout Maine to prevent unnecessary institutionalization.

Specifically, DOJ found:

> Maine's community-based behavioral health system fails to provide sufficient services. As a result, hundreds of children are unnecessarily segregated in institutions each year, while other children are at serious risk of entering institutions. Children are unable to access behavioral health services in their homes and communities—services that are part of an existing array of programs that the State advertises to families through its Medicaid program (MaineCare), but does not make available in a meaningful or timely manner. This failure is evident in the following ways: first, Maine maintains lengthy waitlists for community-based behavioral health services for children that significantly delay necessary treatment and support. Often forced to wait for hundreds of days to receive services at home, families have no option but to turn to law enforcement and hospitals for help during a mental health crisis, triggering lengthy or repeated institutionalizations. Second, contributing to the waitlists problem, even as Maine approves children and families for community-based services, it fails to sustain a network of providers to meet demand, especially to serve children in rural areas and children with the most significant needs. Third, Maine's crisis services are understaffed and under-resourced. A call to the State's crisis hotline frequently is not answered at all, or families are told that no services are available. Crisis staff may recommend that families take children to hospital emergency rooms or call the police. Fourth, Maine's dearth of Treatment Foster Care providers—a specialized service in which foster parents are trained, supervised, and supported by qualified staff to meet the needs of children in their care who have behavioral health

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Services for Children in Their Homes and Communities is available here: http://www.mainelegislature.org/legis/bills/getTestimonyDoc.asp?id=169548; DRM testimony on LD 1003 - *An Act to Increase Access to Behavioral Health Services for Children and Individuals with Intellectual Disabilities or Autism*, is available: here: https://legislature.maine.gov/backend/app/services/getDocument.aspx?doctype=test&documentId=10016872

needs—subjects young people in the child welfare system to prolonged institutionalization.[7]

The problem of youth stuck in EDs will not abate until these underlying problems are addressed. Providing services to children and families in their homes and communities will help avoid behavioral health crises in the first place. Establishing a robust mobile crisis response system for children that timely addresses the needs of youth and families in crisis will help divert youth from ending up in emergency departments. Establishing no eject no reject principles (as LD 1003 required DHHS develop a plan to do) throughout the behavioral health system for children will help ensure that youth do not become stuck in emergency departments and hospitals. And increasing the availability of therapeutic foster care for youth will provide options when circumstances call for that level of care. This is the work that needs to be done to address the problems LD 2009 seeks to address.

LD 2009 is a band-aid at best; and only then when looked at from the perspective of one party – the hospitals. If enacted, LD 2009 would give immense power to individual attending physicians in emergency departments throughout the state to essentially force changes in the existing legal relationships between parents and children or adults and their guardians. But it would not solve the problem.

In our experience, adults and children generally languish in hospitals not because they have parents or guardians who wish to keep them there, but because of the lack of a network of support services and providers to serve them and keep them safe outside of these institutional settings. An adequate network of support services would not just go far in solving this issue, but would often prevent it from happening in the first place.

Respectfully,

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[7] The June 2022 Letter of Findings from USDOJ is available here: https://www.justice.gov/opa/pr/justicedepartment-finds-maine-violation-ada-over-institutionalization-children-disabilities