DISABILITY RIGHTS MAINE

ACLU AMERICAN CIVIL LIBERTIES UNION FOUNDATION Maine

GLAD LEGAL ADVOCATES & DEFENDERS

CPR Center for Public Representation

March 29, 2023

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

Re: L.D. 435, *Resolve, to Ensure the Provision of Medically Necessary Behavioral Health Care Services for Children in Their Homes and Communities*

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. Thank you for the opportunity to provide testimony in support of LD 435. We are joined by the following organizations: American Civil Liberties Union of Maine, GLBTQ Legal Advocates & Defenders, and the Center for Public Representation.

Children with behavioral health needs are entitled to receive medically necessary behavioral health services.[1] And to prevent unnecessary institutionalization, these

[1] As a State participating in the Medicaid program, Maine must comply with the EPSDT provisions of the Medicaid Act for all Medicaid-eligible children and youth under the age of 21. The Medicaid Act requires the State to arrange or provide periodic screening to Medicaid-eligible children and youth, in order to identify any behavioral health or other condition early and before those conditions become serious or debilitating. Whenever a screening identifies a healthcare need, it must be followed by a comprehensive assessment or needed diagnostic service, to determine whether and what treatment services are medically necessary. Finally,

services must be offered in their homes and communities.[2] But the State of Maine has, for years, failed to arrange for or provide these services.

As a result, many of these children's symptoms have escalated, leading to hospital emergency room visits, institutional care, and juvenile justice involvement, which, in turn, has resulted in serious, often lifelong consequences. Many of the people Maine has failed are no longer children. And the children this Committee may hear about today, and those the Criminal Justice and Public Safety Committee has been hearing about this session, have likely been denied access to medically necessary and legally required community based behavioral health services for much, if not all, of their lives.

To provide some context, we offer the following timeline:

December 15, 2018 - It has been over four years since the release of the Children's Behavioral Health Services Assessment, which documented significant and longstanding deficiencies within the behavioral health system for children in Maine, and concluded: "Children's behavioral health services are not available immediately (or at all)."[3]

Maine must timely arrange or provide for the treatment and other services necessary to "correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services." 42 U.S.C. § 1396d(r)(5). The scope of the EPSDT obligation is extremely broad, with the State required to provide all Medicaid reimbursable diagnostic and treatment services to eligible children when those services are medically necessary—an obligation not limited to those services that are offered in the State Plan. Crucially, the Medicaid Act and its implementing regulations require that **each service covered by Medicaid must be provided reasonably promptly, and "must be sufficient in amount, duration and scope to reasonably achieve its purpose.**" 42 C.F.R. § 440.230(b). (emphasis added).

[2] The United States Supreme Court has held that Title II of the ADA prohibits the unjustified segregation of people with disabilities. The Court explained: "First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life...Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." *Olmstead v. L.C.*, 527 U.S. 581 (1999).

[3] Maine Department of Health and Human Services, Office of Child and Family Services, "Children's Behavioral Health Services Assessment Final Report", Public Consulting Group, (December 15, 2018). *Available at:* https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/documents/ocfs/cbhs/documents/ME-OCFS-CBHS-Assessment-Final-Report.pdf

March 29, 2019 - Exactly four years ago, this Committee held a public hearing on LD 984 - *Resolve, To Develop Plans to Return to the State Children Housed in Residential Treatment Systems outside of the State*, which required DHHS to "coordinate with families of children who are receiving residential treatment services for behavioral health issues out of state to develop plans to bring the children back to the State." This Committee heard testimony from parents, providers, advocates, and others about the impacts of the failure to provide access to behavioral health services, resulting in the institutionalization of Maine children in facilities hundreds or even thousands of miles from their families and communities. [4] LD 984 was passed and enacted.[5]

February 25, 2020 – More than three years ago, the Maine Juvenile Justice System Assessment found that many "youth are in detention due to a lack of community-based alternatives [and] wait lists for existing programs," and that in the majority of cases "the reason for detention was to 'provide care' for youth." The System Assessment found that "years of under-investment in behavioral health and other services has left the state without adequate programs and services to meet the needs of young people. The system still doesn't work well for many youth and their families, particularly youth with serious behavioral health problems, immigrant youth, African American youth, LGBTQ+ youth, tribal youth, and youth with disabilities."[6]

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[4] Testimony from the public hearing on LD 984 during the 129th Legislature is available here: http://www.mainelegislature.org/legis/bills/display_ps.asp?ld=984&PID=1456&snum=129&sec3. The ACLU of Maine stated: "Maine's children deserve to live at home and receive services in their communities, and we urge this committee to ensure that they can." DRM's testimony included the following: "The cycle is clear and devastating. Currently, when a young person with mental health issues and/or developmental disabilities qualifies for home and community-based treatment, they spend months, even years, on a waiting list in order to receive the necessary services - or only receive a partial amount of the hours needed. Without appropriate treatment, their behaviors escalate and they are pushed into an unnecessarily high level of care (residential, hospital, emergency room, crisis unit, incarceration)." And the Maine Association of Criminal Defense Lawyers wrote: "A continuum of care and community-based services is what our children need, not more institutions or prisons. Let's fund the programming that helps, not harms, our children. Time is of the essence. Our children are depending on us to do better by them."

[5] 129th Legislature, Resolve 219, Chapter 54 (June 6, 2019), available at: https://legislature.maine.gov/legis/bills/getPDF.asp?paper=HP0739&item=3&snum=129

[6] Center for Children's Law and Policy ("CCLP"), *Maine Juvenile Justice System Assessment Final Report* (Feb. 25, 2020), *available at*

April 7, 2021 – Approximately two years ago, this Committee heard testimony on L.D. 1173 - *Resolve, To Develop a Plan to Treat in Maine Those Children with Behavioral Health Needs Currently Treated Outside the State.* LD 1173 simply would have required DHHS to complete the task it was presented with in 2019: to develop plans to bring children who are receiving residential services outside of the state back home to Maine to receive appropriate services and supports. Again, parents, advocates and providers alike raised the alarm about the failures in the behavioral health system for children and called for action.[7] DHHS testified in opposition to the bill, writing: "Our opposition to this bill is quite simple. (CBHS) division is already hard at work implementing a comprehensive plan to improve behavioral and mental health services available to all Maine children… The development and writing of the plan envisioned by LD 1173 would take time away from the system improvement efforts already underway."[8] As a result, LD 1173 did not pass,[9] even though the number of youth in out of state residential settings had increased since LD 984 was enacted.[10]

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https://irpcdn.multiscreensite.com/de726780/files/uploaded/Maine%20Juvenile%20Justice%20System%20Assessment%20FINAL%20REPORT%202-25-20.pdf

[7] Testimony from the public hearing on LD 1173 during the 130th Legislature is available here: http://www.mainelegislature.org/legis/bills/display_ps.asp?PID=1456&snum=130&paper=&paperId=l&Id=1173# Testimony from Kerri Bickford on behalf of Pathways concluded: "We must act immediately in the interests of the children and families of Maine. They are counting on you. The financial costs of delaying are already piling up. The human costs will be even higher." DRM's testimony concluded: "So, yes, Maine should bring its children home. But in planning to do so, Maine should focus on developing and resourcing appropriate community based and non-institutional services and supports."

[8] Testimony of Todd A. Landry, Ed.D., Director, Office of Child and Family Services, available at: http://www.mainelegislature.org/legis/bills/getTestimonyDoc.asp?id=150526

[9] Ought Not to Pass Pursuant To Joint Rule 310, May 19, 2021 http://www.mainelegislature.org/legis/bills/display_ps.asp?PID=1456&snum=130&paper=&paperId=l&Id=1173#

[10] In March 2019, when this Committee held a hearing on LD 984, there were 73 youth in out of state residential settings. In June 2019, when LD 984 was enacted, there were 75 children in out of state residential settings. And by April 2021, when this Committee held a hearing on LD 1173, that number had increased to 80, (although this was a significant jump from the 68 youth in out of state residential settings in March 2021). Data available at: https://www.maine.gov/dhhs/ocfs/data-reports-initiatives/childrens-behavioral-health

June 22, 2022 – Last summer, the United States Department of Justice (DOJ) issued a letter of findings outlining its determination that Maine unnecessarily segregates children with mental health and/or developmental disabilities in psychiatric hospitals, residential treatment facilities, and at Long Creek Youth Development Center, in violation of the Americans with Disabilities Act (ADA).[11] The DOJ found that Maine children are subjected to unnecessary institutionalization when they 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." And the DOJ found that "Children who are already separated from their families in hospitals and residential treatment facilities struggle to transition back to the community because of the State's waitlists for community-based services."

Given this timeline, it is shocking that LD 435 is necessary.

LD 435 would require DHHS to "develop a plan to ensure that medically necessary home based and community-based behavioral health care services for children are available in the scope, intensity and duration necessary to meet the needs of children and their families in each county and region in the State." This simply requires DHHS to do what the law requires, what various experts have been calling for as outlined above; and what it told this Committee it was already doing almost two years ago.

The plan required by LD 435 "must include an assessment of and plan for the needs of children currently in institutional settings within the State and outside the State." One would assume that DHHS has already done this, because how can Maine develop a plan to deliver legally required services and avoid unnecessary institutionalization to meet needs that it has yet to identify? But that appears to be what Maine is trying to do.

And the plan required by LD 435 "must identify clear steps and timelines for implementation and it must identify any additional resources needed to implement the plan." Again, given that DHHS represented to this Committee almost two years ago that it was already "hard at work implementing" such a plan, one would think the detailed plan could simply be presented today. We don't anticipate that will happen.[12]

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[11] The July 2022 Letter of Findings is available here: https://www.justice.gov/opa/pr/justice-department-finds-maine-violation-ada-over-institutionalization-children-disabilities

[12] We understand that DHHS will submit testimony in opposition to this bill today because, in its view, "this work is already happening". And we understand that DHHS will encourage this Committee to focus on implementation. We agree that the successful implementation of a plan

We are hopeful that Maine and the DOJ will work quickly toward a resolution that will finally put Maine on the path to meeting the needs of youth with behavioral health needs in their homes and communities. And we are hopeful that this Committee will do whatever is necessary to encourage DHHS to do just that, while standing ready to provide the resources necessary for the effective implementation of any agreement. If that happens, LD 435 will be, as it should be, unnecessary.

But until that happens, LD 435 remains necessary.[13] We support LD 435.

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to ensure, as LD 435 requires, that "medically necessary home based and community-based behavioral health care services for children are available in the scope, intensity and duration necessary to meet the needs of children and their families in each county and region in the State", must be the goal. But we disagree that such a plan exists. If it did, DHHS would be able to answer foundational questions such as the following:

1) Approximately how many children need [*insert service here, i.e. Hi-Fidelity Wraparound/Intensive Care Coordination, Home and Community Based Treatment, Rehabilitative and Community Support Services/In Home Behavior Therapy, etc.*] in [*insert DHHS service region or county here*]?
2) What is the current capacity for providing [*insert service here*] in [*insert region or county here*], accounting for the anticipated intensity and duration of the service needed?
3) What is the plan to close the gap between [*answer to question 1*] and [*answer to question 2*] and what resources are needed to do so?

[13] Waitlists are an imperfect measure of need for various reasons, including the fact that many families are waiting for case management and may have a hard time getting on the waitlist, and other families may be inappropriately removed from waitlists. And waitlist numbers do not account for the many youth who may be receiving some service (such as "clinician only" HCT) but are not receiving services in the intensity that they need. But imperfect as it is, the most recent publicly available waitlist data illustrates the significant problems with timely access to all of the services for which publicly available data is available. For example, as of December 2022, there were 679 youth waiting for Section 65 HCT services. In Aroostook County, 40 youth were waiting an average of 169 days. In Franklin County, 16 youth were waiting an average of 388 days. In Washington County, 11 youth were waiting an average of 435 days. And there were 300 children waiting for specialized Section 28 services across the state, with 98 youth waiting an average of 330 days in Cumberland County, 29 youth waiting an average of 296 days in Penobscot County, 11 youth waiting an average of 618 days in Hancock County, and 8 youth waiting an average of 362 days in Franklin County. For access to the data, see: https://www.maine.gov/dhhs/ocfs/data-reports-initiatives/childrens-behavioral-health

Sincerely,

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