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# REPORT TO THE LEGISLATURE

**TO:** Joint Standing Committee on Health and Human Services
**FROM:** Maine Department of Health and Human Services
**DATE:** January 16, 2025
**RE:** Stakeholder Report pursuant to Resolves 2023, Ch. 134, *Resolve, to Establish a Stakeholder Group to Address the Problem of Long Stays for Children and Adolescents in Hospital Emergency Departments*

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The Maine Department of Health and Human Services (DHHS) is submitting this report, pursuant to Resolve 2023, ch. 134, *Resolve, to Establish a Stakeholder Group to Address the Problem of Long Stays for Children and Adolescents in Hospital Emergency Departments*[1]. This resolve requires the Department to convene a stakeholder group to address the challenge of children and adolescents experiencing long stays in hospital emergency departments after they are medically stable and no longer require medical treatment, but appropriate community or residential placements are not available.

Per the Resolve, the Commissioner appointed specific members to the stakeholder group. The standing and guest participants are listed in Appendix A. The appointed stakeholder group was tasked with examining and making recommendations for four focal areas, each of which were dictated in Statute:

1) An appropriate timeline for establishing a secure children's psychiatric residential treatment facility in the State;
2) Strategies to limit the length of stay in hospital emergency departments for children and adolescents who have been medically cleared for discharge;
3) The establishment of an independent children's behavioral health advocate; and
4) A review of hospital assessment and discharge policies.

This report represents recommendations generated by the stakeholder group. It does not reflect the position of the Department of Health and Human Services or Administration, nor does it reflect future proposals of the Department or convey support for specific legislation. The Department will continue to engage with partners and the legislature on specific initiatives as appropriate.

## Stakeholder Engagement & Process

DHHS convened the appointed stakeholder group on a weekly basis over the course of eight weeks, from August 6, 2024, to October 17, 2024, using a hybrid model that offered the opportunity to attend in-person meetings or to join via video conferencing in order to maximize participation

There were consistent themes in the feedback provided by the group. There was unanimity that addressing the problem of children and adolescents experiencing long stays in hospital emergency departments by focusing on singular solutions would be inadequate. Recognizing that any solution

[1] https://legislature.maine.gov/backend/App/services/getDocument.aspx?documentId=105834

to this issue is complex and multifaceted, there was strong advocacy and general consensus for a comprehensive and integrated approach to system of care reform. Therefore, there is need for flexibility in service provision and funding to better meet the unique needs of each child, adolescent and family. Transparent data-driven identification of community-based service needs is necessary to ensure that these services are adequately resourced.

The stakeholder group strived to achieve consensus-based recommendations that aligned with the charge of LD 2009. The stakeholder group made recommendations for the four focal points included in LD 2009. The group was clear that these recommendations should be taken as part of a broader context of systemic recommendations. Additional system of care recommendations reflect the thoughts and diversity of opinions of the stakeholder group.

During the weeks that the stakeholder group met, two subgroups formed, one led by the Maine Hospital Association (MHA) and the other led by the Child and Family Provider Network. Each subgroup shared reports with both DHHS and the larger stakeholder group. The MHA report is included as Appendix C and the Child and Family Provider Network subgroup report is included as Appendix D. Both subgroup reports are included as received. Additionally, Disability Rights Maine provided a letter representing their position on a number of topics, which is included as Appendix E.

**Recommendations**

1. **Strategies to Limit the Length of Stay in Hospital Emergency Departments for Children and Adolescents Who Have Been Medically Cleared for Discharge**

    a. **Stabilizing and Expanding Child and Youth Residential Capacity**
    The stakeholder group had extensive discussion related to the closure of residential beds in CY23-CY24. In order to prevent additional closures and to encourage the reopening of beds, the stakeholder group recommended DHHS outreach providers of residential services, inpatient psychiatric services, and community-based services to understand resource needs and release emergency funds to support intensive staffing levels necessary to serve individuals with acute staffing needs such as 2:1 and 3:1 staffing 24/7. Without the funding to support intensive staffing levels, providers are unable to safely accept children and adolescents or meet their support needs which contributes to long stay emergency department visits.

    b. **Review Opportunities for Flexibilities in Service Delivery Models and Requirements**
    As part of building flexibility into service models that support children and adolescents in the community, it was noted that many residential providers of intellectual and development disability (I/DD) services struggle to meet the Registered Behavior Technician certification requirements resulting in a recommendation for process development to waive this requirement in certain circumstances with DHHS approval.

    c. **Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Obligation**
    Each child, adolescent, and family presents with unique treatment needs. Some of those needs can be readily met within the existing behavioral health treatment structure, however, some cannot. Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) provides a mechanism for funding treatment and support services not otherwise covered. Through

general support, a recommendation was made to ensure that DHHS is meeting its obligation to make available and maximize its use of EPSDT funding per Federal Medicaid law, 42 U.S.C.§ 1396d(r).

d. **Establish Additional Crisis Residential Centers**
There was general support for the recommendation that the Department establish additional crisis residential centers designed to accept referrals from hospital emergency departments. The purpose of these centers would be to provide a more appropriate clinical setting for youth awaiting either an alternative or longer-term placement or in need of shorter-term stabilization better achieved outside of the emergency department.

e. **Expand Community Based Services for the I/DD Population**
There was general support for specific recommendations regarding community-based services for the I/DD population. It was recommended that the Department engage in the development of a comprehensive care system for youth with I/DD that includes the establishment of crisis beds, a strong community and home-based service network, Intermediate Care Facilities for Individuals with Intellectual Disabilities, as well as flexibility for those with multiple needs such as brain injury, mental health, complex medical and neurological needs. It was noted that a range of services for the I/DD population needs to be evaluated and that a comparison of services from the adult system of care might inform the development of a more robust system of care for youth and adolescents with I/DD. The establishment of this system of care would more effectively support those with I/DD to remain in their homes and communities rather than in emergency departments.

f. **Communication on Alternatives to Emergency Departments**
Alternatives to Emergency Department visits were also discussed such as providing education to communities about when, how, and where to access behavioral health crisis services and to ensure that marketing and policies don't reinforce existing stigma about accessing behavioral health crisis services, no matter the setting.

**2. An Appropriate Timeline for Establishing a Secure Children's Psychiatric Residential Treatment Facility (PRTF) in the State of Maine**

A majority of the stakeholder group generally agreed that PRTF services are a necessary component of the system of care for children and adolescents; however, stakeholders noted that for a PRTF to be an effective solution it must be considered within the broader system of care. Specifically, in-home and community-based services must be adequately resourced and available in order to prevent long stays in the emergency departments and to ensure that PRTFs don't become long-term placements. There was some agreement amongst participants that PRTF should be recognized as one service within the continuum of care for children and adolescents and as an intensive, more restrictive and costly level of treatment, the group cautioned that it not become a default service. Disability Rights Maine was in opposition to PRTF as reflected in a letter submitted to the Office of Behavioral Health and included in this report as Appendix D.

Two additional points were raised. There was advocacy that PRTFs need to have attached policies that support integrated care for those with dual diagnosis (e.g. behavioral health and developmental needs, behavioral health and medical care needs). Secondly, it was noted that

PRTFs sometimes accept residents from states other than their own and the stakeholder group wanted assurance that PRTFs in Maine prioritize service to Maine residents.

Regarding the timeline to establish the PRTF, the group did not express concerns other than to recommend that PRTF rates through MaineCare be finalized prior to the close of the RFP for capital start-up funding, supported thought Part NNNN of the Budget under P.L. 2023, ch. 643. A project timeline for PRTF is included as Appendix B.

### 3. The Establishment of an Independent Children's Behavioral Health Advocate

The topic of an independent children's behavioral health advocate generated substantial questions and discussion. While there was a lack of overall consensus, it was generally agreed that the group recommend the Legislature form a task force to study the establishment of an Independent Children's Behavioral Health Advocate in order to provide system advocacy for children's behavioral health. Of note, some stakeholders expressed concern about allocating resources toward establishing an advocate when there are more pressing needs to fund in the service delivery system. It was asked that additional consideration be given to concern that an advocate has the potential to replace and not elevate parent voice in their child's care. Therefore, it is imperative that this position is clearly defined. If established, it is recommended that the task force consider the following:

- What is the necessary structure to support children's advocacy such as creating an advocate position within DHHS, establishing a separate Office of Child Advocacy, or expanding resources of existing advocacy agencies to address this work?
- Would the advocate(s) provide system advocacy, individual advocacy or both?
- Would the advocate(s) provide advocacy solely for children's behavioral health or would the scope of practice include child welfare, juvenile justice, and education?
- Should Maine model this work after the existing New England Offices of the Child Advocate?

### 4. Review of Hospital Assessment and Discharge Policies

The stakeholder group explored hospital assessment and discharge policies, both for youth seeking behavioral health support in emergency departments and inpatient hospitalization. There was a recommendation that hospitals providing inpatient psychiatric care consider accepting direct admissions from community-based crisis providers in order to bypass emergency department visits. The group expressed enhanced collaboration between crisis providers (mobile and residential), emergency departments, and inpatient hospitals to support planning for youth in crisis, support to families and better coordination for youth that could have an impact on reducing emergency room visits. Further, the group felt this collaboration would assist with crisis pre-planning to help families avoid the need to seek support in emergency departments altogether.

The hospital systems also noted a challenge related to reimbursement for behavioral health support provided in emergency departments for youth experiencing long stays. Hospital emergency departments are only paid for initial visits and are not reimbursed for days, weeks, or months that youth remain in the emergency department awaiting placement. There was support for improved reimbursement for "Days Awaiting Placement."

## 5. Additional Recommendations

The group noted the potential to refine our referral processes for children's behavioral health services to ensure youth are presented to all potential providers able to meet their needs, given family voice and choice.

The stakeholder group recommended the legislature establish a Select Committee on Youth with Behavioral and I/DD health needs that includes but is not limited to the Health and Human Services Committee.

The stakeholder group recommended that a periodic, scheduled systemic needs assessment, including examining identified service needs with service provider availability regionally, should be conducted, and included a report to the Legislature on recommendations developed resultant of the needs assessment.

There was some discussion of reconsideration for a "no eject, no reject" policy related to children's behavioral health services which is reflected in Appendix D.

Finally, there was a request for the Department to submit additional data reports to the Legislature related to children in the emergency department exceeding 48 hours, residential service denials, youth residing in treatment facilities exceeding one year, number of youth in out-of-state placements and any program closures.

## Appendix A
## Work Group Participants

**Standing Participants**

- Adam Bloom-Paicopolos, Executive Director – Alliance for Addiction & Mental Health Services
- Adrienne Carmack, MD – Medical Director, Office of Child and Family Services (OCFS)
- Andrew Ehrhard, MD - President of the Maine chapter of American College of Emergency Physicians (ACEP)
- Atlee Reilly – Disability Rights Maine, Managing Attorney
- Carrie Woodcock – Executive Director, Maine Parent Federation
- Cathy Dionne – Executive Director, Autism Society of Maine
- Christine Alberi – OCFS Ombudsman
- Cindy Seekins – Crisis & Counseling, GEAR Parent Network, Director
- David Winslow – Vice President of Financial Policy, Maine Hospital Association
- Dean Bugaj – Associate Director, Children's Behavioral Health Services (CBHS)/Office of Behavioral Health (OBH)
- Debra Poulin – Office of Behavioral Health, Director of Clinical Services
- Hannah Longley – National Alliance on Mental Illness (NAMI) Maine Director of Advocacy and Crisis Interventions
- Jean Haynes - OCFS, Associate Director of Child Welfare
- Jeffrey Austin – Maine Hospital Association, Vice President of Government Affairs and Communications
- Jennifer Thompson – Executive Director of NAMI Maine – Invited and declined invitation.
- Kassandra White - Parent
- Katie Harris – MaineHealth-Chief Government Affairs Officer
- Kevin Beal - Maine Assistant Attorney General
- Lee Wolfrum, DO – MaineHealth – Spring Harbor Hospital Medical Director
- Lisa Harvey-McPherson – Vice President Government Relations, Northern Light Health
- Matt Narel – Regional Director – North American Family Institute - North
- Michael Melia, MD – Northern Light, Chief of Emergency Care, Lead Physician, Emergency Medicine (declined participation)
- Morgan Arbour – Office of Behavioral Health, Executive Assistant
- Nancy Cronin – Executive Director., Maine Developmental Disabilities Council
- Paul Dann – Executive Director of NAFI; President of Maine Child and Family Provider Network
- Sarah Calder – MaineHealth, Senior Government Affairs Director
- Sheena Bunnell – HealthCare Consultant to DHHS, Facilitator
- Suzanne Gagne – Parent
- Michelle Hamel – Care Coordination Manager, Office of MaineCare Services

**Guest Participants:**

- Jamilyn Murphy-Hughes – Northern Light Acadia Hospital – Associate Vice President of Community Services
- Misty Marson – Spurwink Services, Vice President of Residential and Day Treatment Services

- Eric Meyer – Spurwink Services, President and CEO
- Rachel Bouquet – KidsPeace – New England Executive Director
- Alexis Petterson – Community Health and Counseling Services – Crisis Services
- Michelle Hanson – The Opportunity Alliance – Crisis Call line Services
- Rebecca Parsons – Office of MaineCare Services – EPSDT Coordinator

**Appendix B**
**DHHS PRTF Implementation Plan**

| Timeframe | Activity Benchmark | |
|---|---|---|
| **June 2023** | DHHS held a Rate Determination stakeholder meeting on June 15, 2023. The Comment period was active from June 15, 2023, to July 7, 2023. August /September comments were reviewed, and written responses worked on. | ✓ |
| **July – September 2023** | Public comment process closed. DHHS reviewed comments, worked on written responses, consulted with a national PRTF provider on model and rate recommendations. | ✓ |
| **Fall 2023** | DHHS finalizes service model following feedback from local stakeholders and national experts. Draft rate model being reviewed for process consistencies and to see where/if any changes can be made on the draft rate model based on comments from stakeholders. | ✓ |
| **November 2023 – April 2025** | DHHS rule drafting, including senior management internal review | **Ongoing** |
| **August 2024** | DHHS begins drafting RFP/RFA following Part NNNN of the budget, allocating $2 million for capital award supporting development of one or more PRTFs | ✓ |
| **October 2024- February 2025** | DHHS presentation on revised rates. Rates to be finalized following feedback from rate session determination. Publishes result of Rate Determination. | **Ongoing** |
| **November 2024** | DHHS publishes RFP/RFA for capital award developing one or more PRTFs. | ✓ |

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|---|---|---|
| **January 2025** | DHHS presentation on revised rates held January 9th. Public comment period open through January 24th. | ✓ |
| **January 2025 – May 2025** | DHHS to finalize rules, complete internal review and submit to Office of the Attorney General for pre-review of proposed rule drafts; DHHS final revisions to proposed rule drafts; Commissioner review of proposed rule drafts | |
| **April 2025** | DHHS anticipates making an award as a result of Capital RFA/RFP. Contract negotiation to follow post award. | |
| **May-June 2025** | DHHS proposes the Chapters II and III, Section 107, policies. APA public engagement process begins. | |

## Appendix C

**Minority Report Submitted by Maine Hospital Association Subgroup**
**LD 2009 – Resolve Regarding Children Stuck in Hospitals**
**Recommendations**
**October 1, 2024**

1. **Commissioner's Point Person.** DHHS shall employ, within 6 months, a person in the Commissioner's Office who is responsible for facilitating care for youth with behavioral/developmental health needs stuck in hospitals or prior to discharge from a residential treatment facility set to close. This person shall have sufficient decision-making authority to coordinate and solve multifactorial problems impacting children such as kids at risk of being, or actually stuck in, emergency departments and other institutional settings, as well as youth impacted by residential treatment closures. This leader should coordinate among departments to find solutions quickly that will remove stuck kids from deteriorating situations and secure clinically appropriate placement for youth impacted by residential treatment closures.

2. **Restore Services and Prevent Additional Closures.**

   - **Immediate Outreach** to residential, crisis, inpatient psychiatric, and community-based providers who closed beds in 2023-24. To prevent additional closures the Department shall provide immediate funding to support intensive staffing levels for challenging residents and patients and enhanced support to hire appropriate staff to meet the medical needs of residents, and report-back to HHS Committee on the impact of these investments within 90 days.
     - DHHS to immediately enact an emergency funding rule on the upstaffing rate that accurately reflects the costs for residential providers to implement this service at an appropriate staffing level. The goal of this emergency rate is to enable residential providers to increase their capacity to accept higher acuity cases that are currently languishing in hospital emergency departments in need of 2:1 or 3:1 staffing and 24/7 support.
     - In addition to rates, many residential providers experience challenges maintaining staff for all IDD/ASD populations trained in RBT. Lengthy RBT course and exam requirements act as barriers for staff—particularly those from diverse backgrounds for whom English is a second or third language. DHHS shall waive RBT certification, upon application in emergency circumstances to prevent imminent service closures.

   - **DHHS Shall Ensure Its EPSDT Obligation is Met.** Federal Medicaid law, 42 U.S.C.§ 1396d(r), requires state Medicaid programs to provide EPSDT services for members aged 20 or younger that is medically necessary to prevent, diagnose, evaluate correct, ameliorate, or treat a defect, physical or mental illness, or a condition diagnosed by a member's physician, therapist, or other licensed professional whether or not the service

is covered under the State Medicaid Plan. (see 10 CCR 2505-19 § 8.280.4.E.) DHHS will utilize EPSDT Optional Funding, when necessary and appropriate, to prevent the loss of functional skills or mental/physical health. This includes utilizing EPSDT to ameliorate living conditions for children stuck in emergency departments and other situations which would lend to a deterioration of condition.

3. **Crisis Services.**

   - **Crisis Centers.** DHHS shall operate or cause to operate two crisis centers for kids with behavioral health issues stuck in hospitals within 120 days. These centers are places to which hospitals could transfer children who are stuck in the emergency departments. These centers will be designed to better accommodate children temporarily than emergency departments while an appropriate placement is secured.
   - **Youth with DD**. There are no crisis beds for kids with developmental disability (DD). The Department shall develop a plan and operate these beds within 6 months and report-back to HHS Committee on the status of these beds by December 1, 2024.

4. **Exploration of a Continuum of Care Settings Model for Developmental Disability (DD).** The Department shall develop and adopt within 6 months a continuum of care settings model that serves children, with adequate, appropriate, and available care to meet their needs in a variety of settings including the community, PNMI, group level residentials appropriate for youth with DD who also may have medical needs, and when no other setting is appropriate, PRTF or ICF-IID (Intermediate Care Facilities for Individuals with Intellectual Disabilities) group and nursing levels. The continuum of care should include structures to meet the needs of children and youth with any combination of disabilities including developmental, behavioral health, brain injury, substance affected, neurological, and complex medical needs. When higher levels or residential care may be necessary, the Department shall ensure a plan is developed and reviewed regularly to move the youth to the least restrictive environments as soon as appropriate to serve the youth.

5. **Adoption of a Days Awaiting Placement Payment (DAP) for Hospitals.** Hospital emergency departments are only paid for the initial visit and do not receive payment for the subsequent days, weeks, or months (including room and board) that a patient is stuck. DHHS has repeatedly said they are open to providing a Days Awaiting Placement (DAP) Payment. We need both the DAP for 'normal' level of care and a pool of funding for enhanced services where necessary.

6. **Presentation of a Plan to Legislature on June 1**. – The Department shall develop and present a plan that includes a gap analysis that describes all beds/programs added since 2018 and lost since 2018. Plan shall include current information on waitlists, including average and median wait time to access approved services. Plan shall include an update on efforts to reintroduce Maine Wraparound program. Plan shall include an update on efforts to reintroduce Multidimensional Therapeutic Foster Care. Plan shall include update on efforts to bolster existing HCT, ACT, and School-Based services programs. Plan shall also include update on

PRTF, Certified Community Behavioral Health Clinic Medicaid Demonstration project and crisis receiving center(s) for kids.

7. **Statutory Mandated Work Group for Entry-level Workforce.** A work group with diverse stakeholders, including providers, community colleges, Maine College of Health Professions, DOE, DOL, and DHHS, including MaineCare and Licensing, shall meet to develop and implement a comprehensive plan to address the entry-level workforce needs of behavioral health providers and inpatient psychiatric hospitals. The plan shall be presented to the Health and Human Services Committee by January 1, 2026.

8. **LD 118 Data to Be Provided Monthly to Legislature.** Data shall include all children whose ED stay is longer than 48 hours:

    - County;
    - Gender;
    - age breakdown (<10, 10-12, 12>);
    - DD status; and
    - Previous Location (home with biological, home with adopted, home with guardian, group home, hospital, out-of-state, other)

9. **Residential Data to be Provided Monthly to Legislature.**

    DHHS shall report monthly to the Health and Human Services Committee from existing data submitted by residential treatment providers the following information:

    - Number of service denials reported by residential providers by service requested;
    - Number of youth who have been in residential treatment for one year or longer:
        - County,
        - Gender,
        - age breakdown (<10, 10-12, 12>),
        - DD status,
        - Barrier to discharge; and
    - Number of youth in out-of-state facilities, their location, and their length of stay

10. **Closure Notice.** Every time a facility or program for kids with behavioral health and/or DD is closed by a provider, DHHS shall provide to Legislature a 1-page summary (within 2 weeks) including:

    - Operator;
    - Type of facility Summary of other facilities operated by operator;
    - List of similar facilities that remain open;
    - Number of beds closed/slots closed;
    - Number of employees;

- Statement from Operator as to why closing, if any (this is a request DHHS shall make of every operator);
- Summary of DHHS offers of assistance (What did they try to do to prevent closure?); and
- Summary of transition and discharge plans

11. **Select Committee on Kids with Behavioral/DD Health Needs.** Legislature to convene a select committee for the first session like they did on housing, something like: Select Committee on Kids with Behavioral Health Needs or DD with members from HHS, EDU, IFS, JUD and AFA.

12. **Rate Increases / Funding for Community Providers.** To reflect the mounting crisis across the entire children's behavioral health continuum, investment is needed across several services and programs if the system is to improve. Filling one gap within the system, while leaving others unaddressed, will only further exacerbate the upstream and downstream impact of limited-service availability in the home and community on the complexity and severity of unmet needs of children and their families. By January 1, 2025, DHHS shall:

    - **HCT** – Update the 1:1 clinician to BHP ratio to better tie reimbursement to intended program design to increase capacity and adopt an FFS rate component for high acuity cases to enable sustainable funding and staffing to accept more children ready for discharge from residential facilities or emergency departments.
    - ***Assertive Community Treatment (ACT)*** - Maine currently has just one children's ACT team in the entire state, located in Southern Maine. To grow the availability and capacity of this critically needed evidence-based service, DHHS shall offer start-up funding and adjust the MaineCare rate for children's ACT to enable community providers to recruit and establish children's ACT teams in regions across the state.
    - **School-based Services** – Adjust the MaineCare rate for services rendered in schools as community setting services rather than office setting services to increase school-based capacity on the preventative side of the continuum.
    - **TFCO** – Update with provider feedback the reimbursement rate to ensure TFCO can be implemented and delivered across the state.

    After a rate adjustment, DHHS shall report to the Legislature every two years an evaluation of the impact, including an update on waitlists, the number of clients served, programs closed or opened, etc.

**Appendix D**
**Minority Report Submitted by Child and Family Provider Network Subgroup**
**System of Care**

## Introduction

The engagement of all participants in the LD 2009 workgroup has been excellent. The discussion has delved into the details surrounding why children and youth find themselves placed for extended periods of time within hospital emergency rooms. The work of the group also involves an exploration of the steps and timeline necessary for implementing a PRTF's and a child advocates role. Both of which will represent a step toward helping the children's behavioral health system in Maine. There is also a feeling among many group members that the work of the group represents an important opportunity to delve, in a wholistic way, into the overriding needs for Maine's children, youth and families.

To that end several of the group members have asked the question; what needs to be done to truly advance the behavioral and developmental needs of Maine's children and youth and through this how can be best help families to be successful? The document that follows helps to identify the elements necessary for a fully functional System of Care (SoC) and as a group we believe that this information should be included, at a minimum, as a minority report in response to the legislative mandate of LD 2009. Ideally the entire committee would agree to adopt this document as a central part of the report back to the legislature.

## System of Care

As we work to overcome the social, behavioral and mental health challenges that Maine's children, youth and families face, it's critical that we recognize the complexity involved in realizing viable solutions. While there may be similarities in the issues that families face, each family is unique in their way of addressing challenges and in the assets that they bring to support success. Given this we must resist the tendency to pursue a single solution approach. There are no "one size fits all" strategies but rather a true and pressing need to consider the whole array of solutions.

When there are pressing needs it's understandable that our strategy might be to simply address the presenting problem. One might, for example, determine that a PRTF (Psychiatric Residential Treatment Facility) is what is needed when in fact the back up of children needing psychiatric residential services might be the result of a lack of in-home and community-based services when the child's mental health challenge first became apparent. Building a PRTF without considering the entire system of care risks the pursuit of erroneous strategics.

For this reason, it's essential that our problem-solving efforts pursue solutions within a system of care framework. A system of care framework, as defined by Stroul and Friedman, (1986) and Stroul (1996), includes the following:

- "Comprehensive array of services;
- Individualized to each individual child and family;
- Provided in the least restrictive, appropriate setting;

- Coordinated both at the system and service delivery levels;
- Involve families and youth as full partners'; and
- Emphasis on early identification and intervention."

In addition, Maine's Office of Child and Family Services expands on the work of Stroul and Friedman by outlining ten guiding principles which are "essential elements of any successful system of care" (HHS System of Care, 2020). The principles identified below are recognized not only in Maine but across system of care efforts across the country.

1. Family Driven
2. Individualized
3. Strengths based
4. Evidence Informed
5. Youth Guided
6. Culturally and Linguistically Competent
7. Least Restrictive Environment
8. Community Based
9. Accessible and
10. Collaborative

The services that follow represent the component parts to a comprehensive system of care (SoC). System needs are noted and addressing them should be a priority for fully implementing a principle driven system of care.

| Service | Available (Yes/No) | Comments |
|---|---|---|
| **Care Coordination** | No | There is some coordination through case management services, but lacking is comprehensive care coordination using evidenced based practices that fully leverage SoC guiding principles - Family driven, evidence informed, accessible etc. As a part of this the system needs to ensure there are clearly defined roles with clear decision rights and accountability. |
| **Outpatient Services** | Yes | Limited though due to workforce challenges driven by low rates of reimbursement and high productivity standards. Wait lists reported in some cases to be six months in length. |
| **Wrap Around Services** | No (in progress) | High fidelity wrap around services are not currently available, but are in the works… Workforce issues and rates to support the initiative will pose a challenge. |
| **In-Home Services (HCT & ACT)** | Yes | Unfortunately, waitlists are extensive, and the current rate structure has created challenges with the ability to bill for services when cases require greater intensity. There's also a need to address rates of pay for workers, making it hard to attract workforce to these in-home service types. In |

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| | | addition, current funding structure precludes billing for services when member is in another service so hospitalized and individuals in out-of-home placement do not receive services that could help in continuity of care. Need to consider the ability to provide a higher level of care within HCT. |
| **Day Treatment/ Special Purpose Schools** | Yes | There are a number of options for students with special education needs. Consider expanding the availability of these types of services for children and youth that do not have an IEP, but do have behavioral needs that would benefit from special purpose schools. |
| **Partial Hospitalization** | Yes, some | Structured in-person partial hospitalization can help young people to avoid inpatient psychiatric hospitalization. |
| **Mobile Crisis Team** | Yes | While there is some capacity for mobile crisis teams there are challenges to meet the actual demands. Lack of service availability. Need to ensure mobile in person teams. |
| **Diversion Beds/ Crisis Beds** | Yes and No | While there is some availability for crisis beds this option needs to be expanded. In addition, the provision of crisis bed services should be dynamic enough so that they can divert as well as step children/youth down from inpatient psychiatric hospitalization. |
| **Foster Care** | Yes | Rate of reimbursement for foster homes needs to be adjusted. Also, rates need to be adjusted to ensure workforce challenges are addressed. |
| **Therapeutic Foster Care** | Yes | Rates of reimbursement for Therapeutic Foster Parents need to be raised to ensure the availability of foster homes. Rates need to reflect real costs for service operation. |
| **Residential Treatment Services** | Yes | While a number of residential providers exist the total number of residential beds within the state is now less than three hundred and shrinking. Issues related to the rate structure are impacting the ability to pay livable wages for staff, which in turn has resulted in bed reductions across the state. Also, the lack of less restrictive service availability has resulted in young people and children being stuck in out-of-home care. In addition, the increased acuity of youth referred to the program has had an adverse impact on community based residential services. This is seen as being in part related to the breakdown of juvenile justice services. |
| **Shared Living for IDD** | No, not for youth | This option should be implemented to also include a family as well as a professionally staffed approach. |
| **Aftercare Services** | Yes | While a system of aftercare was designed under the State's Family's First Plan, the actual system itself is not functioning as intended. Reimbursement rates for aftercare and the way billing is structured makes it difficult to maintain a workforce. In addition, we need to incentivize parents to help ensure they participate in this |

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| | | part of their child's service delivery. Flexibility as well with other parts of the system would be helpful. For example, having the ability to engage HCT. |
| **Psychiatric Residential Treatment Services (PRTF)** | No | One part of the system of care would be helpful. Can't be developed in a vacuum without addressing other elements needed for a system of care. Without addressing other system related issues, the program will fill up and become a holding tank. The key is to invest in the system upstream as well as add this option. |
| **Young Adult In-Home and Community Services** | No | To include care coordination, housing support, vocational support, in-home counseling. Can be included as a part of the high-fidelity wrap. |
| **Pre-Vocational and Vocational Options** | Limited (Job Corp and Good Will-Hinckley) | Youth transitioning into adulthood would benefit from both vocational and academic tracks to help ensure young people are successful as they move to adulthood. |
| **Young Adult Transitional Residential Services** | Limited (Good Will-Hinckley) | 18–26-year-olds transitional housing services. Provided supportive housing with case management and vocational services. Need to flex out who can be served so as to not depend on medical necessity. |
| **Inpatient Services** | Yes | Need more availability. Youth often meet level of care and there are no beds available. |
| **Skilled Nursing Home Care** | No | As appropriate for young people with IDD that require support with significant and profound medical needs. Should be age-appropriate placement for youth who require this level of care |
| **School Based Services** | Some | This is an area that could help support children and youth with outpatient and behavioral health treatment needs. |
| **Before and After School Care** | No | Families of children experiencing behavioral health needs or who have children are diagnosed with IDD would benefit from supportive services to help maintain their child within their own home and community. |
| **Emergency Room** | Yes | Should only be used in the case of medical emergency |
| **Other…** | | |

The list of services identified within the table above should be viewed as the component parts necessary for successfully operating an effective system of care. When combined with the guiding principles, as identified by the Department, the identified services represent the best path forward to ensuring appropriate levels of care for Maine's children, youth and families.

It's important to note that implementing a system of care in a piecemeal fashion has a detrimental impact on the overall system. For example, creating a new service, such as a PRTF (Psychiatric Residential Treatment Facility), without addressing wage-related issues in the other component parts of the system (e.g., residential care, HCT and outpatient) will have an adverse impact on the stability of existing services by drawing staff to the new service with a better rate structure. As a system each component part is interrelated; for every action there is a reaction. Given this it is critical that moving toward a system of care approach be done with a comprehensive plan and full commitment to meeting the needs of the children, youth and families of Maine.

In addition, to effectively move the system forward, it's essential to recognize the importance of building in an appropriate level of flexibility. Often within system change there are well-meaning and well-intended decisions that result in unforeseen consequences. For example, rigid requirements for serving IDD youth in residential care have resulted in limited treatment options for youth that are considered dually diagnosed. Similarly, the inability to continue HCT services while a child is in placement has adversely impacted the continuity of care. Because of this its critical to build in strategies to address unintended consequences.

And while there are many challenges at hand the good news is that Maine has many of the component parts for an effective system of care. In addition, the number of committed, caring and capable individuals involved are a true foundation for ensuring the success of a system of care. The only thing missing is a full and robust commitment on the part of all stakeholders to ensuring an effective system of care is fully implemented.

**References**

Stroul, B., & Friedman, R. (1986). A system of care for children and youth with severe emotional disturbances (rev. ed.). Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health

Stroul, B. (1996). Introduction: Progress in children's mental health. In B. Stroul (Ed.), Children's mental health. Creating systems of care in a changing society. (pp. xxi-xxxii). Baltimore, MD: Paul H. Brookes Publishing Co., Inc

System of Care, 8/31/2020, Maine DHHS. System of Care | Department of Health and Human Services (maine.gov)

**Author's Note:**

This document (Appendix D) was written by Paul L. Dann, PhD, President and CEO of North American Family Institute and President of the Child and Family Provider Network, with collaboration and input from the following stakeholders: Scott Hayward, State Executive Director, Pathways of Maine, Gary Dugal, President and Executive Director, Good Will-Hinckley, Matt Naral, Regional Director, NFI North, Danielle Loring, LCSW, Executive Director, Morrison Center, Adam Bloom-Paicopolos, Executive Director, Alliance for Addiction and Mental Health Services, Justin Gifford, Executive Director, Becket.

**Appendix E**

**Letter Submitted by Disability Rights Maine**

November 14, 2024

**SENT BY EMAIL ONLY**
Dean.Bugaj@maine.gov

Dean Bugaj
Associate Director of Children's Behavioral Health Office of Behavioral Health
Maine Department of Health and Human Services

Associate Director Bugaj:
Thank you for the opportunity to review the draft LD 2009 report. While we have general concerns that the report does not capture the breadth of the discussions, the inclusion of the two additional documents in the appendices addresses that to some degree. And we note the absence of any mention of the suggestion that Maine establish no eject no reject principles regarding service delivery to Maine children, as was recommended by the system assessment in 2018 and as we again advocated for in this process. But we write primarily to specifically disagree with the way the PRTF paragraph in the draft report characterizes the discussions and agreements of this group.

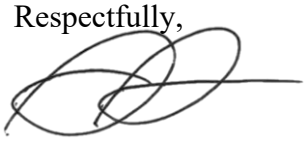
The draft that was circulated contains the following language: *The stakeholder group generally agreed that PRTF services are a necessary component of the system of care for children and adolescents; however, stakeholders noted that for a PRTF to be an effective solution it must be considered within the broader system of care. Specifically, in-home and community-based services must be adequately resourced and available in order to prevent long stays in the emergency departments and to ensure that PRTFs don't become long-term placements. There was agreement amongst participants that PRTF should be recognized as one service within the continuum of care for children and adolescents and as an intensive, more restrictive and costly level of treatment, the group cautioned that it not become a default service.*

DRM has consistently opposed the push to bring a PRTF to Maine, including in detailed testimony delivered to the Committee on Health and Human Services in March 2023, which we attach and incorporate here, where we wrote: "The State of Maine has a legal obligation to our youth to first develop the capacity to serve young people in the community and in their homes, before resorting to building more institutional beds."[1]

During the LD 2009 Workgroup, DRM spoke up on several occasions, consistent with our past positions, to make clear that we did not believe there was an appropriate timeline for a PRTF unless and until Maine first makes community-based services available to children and families in the scope, intensity and duration necessary to meet their needs. And we made clear that any final report needed to reflect DRM's position.[2] So, it is simply not true that there was "agreement amongst participants that PRTF should be recognized as one service within the continuum of care". It is also not accurate to state that there was an agreement that new institutional beds "are a necessary component of the system of care for children and adolescents". Please correct this language and please include this letter as an appendix to the LD 2009 Report.

Finally, thank you for including, in the section regarding the establishment of an Independent Children's Behavioral Health Advocate, the need to consider "expanding resources of existing advocacy agencies to address this work." DRM is Maine's designated Protection and Advocacy Agency for people with disabilities and independent of federal and state government which we believe is a crucial element to effective advocacy. The need for children and their families to access independent advocacy services is clear and critical. But as you know, funding available to DRM to conduct this work was significantly reduced in 2019. Instead of forming another taskforce to study the establishment of an independent behavioral health advocate as recommended in the report, limited resources should be used to adequately fund Maine's already established independent advocacy organization.

Respectfully,



Atlee Reilly
Disability Rights Maine

[1] 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

[2] Our dissenting view was included, to some degree, in the slide deck DHHS prepared for the last LD 2009 workgroup meeting, which stated: "Some stakeholders noted that investments should support the system of care as a whole, and invest in community-based services prior to more intensive residential services to support the broader range of youth seeking behavioral health services." DHHS Slide Deck, Drafts Strategies and Recommendations LD 2009, 10/17/2024. But even this was omitted from the final report.

DISABILITY RIGHTS MAINE

ACLU AMERICAN CIVIL LIBERTIES UNION FOUNDATION Maine

GLAD LEGAL ADVOCATES & DEFENDERS

CPR Center for Public Representation

Maine Developmental Disabilities Council

March 21, 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. 181, *Resolve, Directing the Department of Health and Human Services to Implement Secure Children's Psychiatric Residential Treatment Facility Services*

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

My name is Kim Moody and I serve as the Executive Director of Disability Rights Maine, Maine's Protection and Advocacy agency for people with disabilities.

I am here today to provide testimony in opposition to LD 181. LD 181 instructs the Department of Health and Human Services to "…implement secure children's psychiatric residential treatment facility services in the State". Maine is already institutionalizing children with disabilities unnecessarily due to our failure to provide timely access to home and community-based services that work to keep children in their homes. Efforts should be focused on addressing that failure rather than creating new institutional beds.

**DRM's History on PRTFs**

For many years, DRM has been pushing Maine DHHS to expand access to home and community-based services for Maine families, thereby limiting reliance on more

expensive and damaging institutionalization. The State of Maine has a legal obligation to our youth to first develop the capacity to serve young people in the community and in their homes, before resorting to building more institutional beds. Maine must not rely on bricks and mortar to attempt to meet the unique and individualized needs of our youth. That is not a solution that the State should be proud of, and it's not a solution that is fair to kids, or effective for them in the long run.

Developing congregate, institutional remedies to the problems in our youth behavioral health system reflects backward-looking policy and is an inappropriate and inefficient use of scarce public resources. It also goes against more than 20 years of legal progress made on behalf of people with disabilities of all ages. Youth with serious disabilities – those deemed "at risk of institutionalization" - have a legal right to receive services in the most integrated settings possible, alongside peers with and without disabilities.

**Shared position on PRTFs**

While Disability Rights Maine (DRM) is aware that young people with disabilities are stuck in emergency departments and hospitals and that families are in crisis due to the lack services, we are also aware that the State of Maine still has not developed a community system of care for our kids with disabilities. DRM continues to repeat the same arguments against building more institutional beds. Now, however, we are joined in this effort by diverse and qualified partners who are united around the goal of ensuring that we stop institutionalizing more Maine children due to our state's failure to provide community-based behavioral health services. The following organizations have signed on to this testimony: American Civil Liberties Union of Maine, GLBTQ Legal Advocates & Defenders, the Center for Public Representation, and the Maine Developmental Disabilities Council.

**Context**

Research and experience demonstrate the folly of relying on institutions to do what only a comprehensive, community-based mental health system can properly do. We should learn lessons from other states instead of repeating their costly errors. For instance, a multi-state demonstration project funded by the Centers for Medicare and Medicaid (CMS) and the Substance Abuse and Mental Health Services Administration (SAMSHA) showed that home and community-based services cost 25% of what it

would have cost to serve those children in PRTFs.[1] Children also showed an increase in behavioral and emotional strengths, including the ability to form interpersonal relationships, develop a positive connection with family members, improve school attendance/perform better at school, and demonstrate self-confidence. At the same time, youth showed reduced suicide attempts and decreased contacts with law enforcement and the juvenile justice system.

Again, it is wrong to spend our scarce resources to build new facilities, in the name of addressing a missing level of care. "Beds" are not the missing level of care in a system that includes approximately 100 inpatient psychiatric beds and nearly 250 residential beds.[2] Currently, there are 1550 children on waiting lists for home and community-based treatment[3], many of them having waited months or even years for services that federal law requires be provided with "reasonable promptness".

At the same time, residential providers have available beds, but are unable to hire staff, so children wait for residential services as well. Presumably, new PRTFs would pay higher wages which would exacerbate the existing workforce shortage within home and community-based services and residential services because workers will be drawn to the higher pay. With fewer staff working in home and community-based services and the existing residential services, it will become even harder to discharge youth from residential facilities and hospitals, and waitlists will grow.

**Department of Justice Agrees**

DRM and our partners are now fully aligned with the United States Department of Justice.

In June of 2022, in response to a complaint filed by DRM, the U.S. Department of Justice found, after investigating Maine's behavioral health system and practice of

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[1] Joint CMS and SAMSHA Informational Bulletin, Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions, May 7, 2013; available at https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf

[2] State of Maine Children's Residential Care Facility (CRCF) Grid, updated 2/8/2023, available at: https://5627605.fs1.hubspotusercontent-na1.net/hubfs/5627605/Client%20Sites/Maine%20ASO/State%20of%20Maine%20Childrens%20Residential%20Care%20Facility%20List%2020230208.pdf

[3] See: Children's Behavioral Health Data Dashboard, https://www.maine.gov/dhhs/ocfs/data-reports-initiatives/childrens-behavioral-health

institutionalizing children, that Maine violates federal law by "failing to provide behavioral health services to children in the most integrated setting appropriate to their needs."[4] 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." This finding from DOJ should not have been a surprise.[5] But it should still serve as a wakeup call.

Most relevant to LD 181, the DOJ expressed specific concern with Maine's plan to create more institutional placements, specifically psychiatric residential treatment facilities (PRTFs), writing: "One of Maine's central priorities for the future is expanding services in institutional settings by creating one or more [PRTFs] for children. Creating or expanding institutional options without timely addressing community-based waitlists suggests that Maine's current plan will do little to decrease its reliance on segregated settings such as residential facilities and psychiatric hospitals, which are more expensive and can exacerbate trauma."[6]

**Addressing the Supposed Need for More Secure Beds**

We've all heard people say that we simply cannot handle some of these kids and therefore Maine needs more secure beds. We believe that there is a specific remedy that will incentivize current providers to serve all kids. We should stop providers from picking and choosing which youth to accept into their programming and/or discharging them when they exhibit behaviors related to the same disabilities that made them eligible for residential placement in the first place. The 2018 Children's Behavioral Health Services Assessment included a recommendation that residential "contracts should specify referral acceptance and denial policies to promote

[4] The letter and press release are available here: https://www.justice.gov/opa/pr/justice-department-finds-maine-violation-ada-over-institutionalization-children-disabilities

[5] It has been over four years since the 2018 Children's Behavioral Health Services Assessment found there were significant problems with access, which concluded: "Children's behavioral health services are not available immediately (or at all)." See: "Children's Behavioral Health Services Assessment Final Report, p. 22 (December 2018). Although the State has endorsed this report and recommendations, this central finding continues to be true.

[6] United States Department of Justice, Maine Letter of Findings, p. 16 (June 22, 2022).

transparency and consistency, and 'no reject, no eject' policies as other states have done." [7]

The 2018 Assessment further advised that these policies be implemented in conjunction with other changes aimed to "strengthen the treatment interventions offered at residential programs" and that rates may need to be revisited at the same time. But while the residential provider rates were raised, and many other changes were implemented, DHHS did ***not*** require no reject, no eject policies as part of the rate increases and reforms.[8] We understand that no eject, no reject requirements will be included in a proposed amendment to LD 1003 - *Resolve, to Increase Access to Behavioral Health Services for Children and Individuals with Intellectual Disabilities or Autism Spectrum Disorders.*

Unfortunately, LD 181 would simply require DHHS to do something it has already been trying to do for a number of years. But passing LD 181 would certainly send the wrong message. Developing more institutional remedies is a choice made by states, a choice to separate more children from their families and communities. LD 181 would further send the message that Maine is prioritizing the creation of more institutional beds before addressing the longstanding and painstakingly documented failures to provide a robust array of community-based services to children with disabilities, services which work.

Maine must turn away from expensive and ineffective institutional solutions and invest in a system that supports children in their homes and communities. For these reasons, we respectfully request that this Committee vote ought not to pass on LD 181. Thank you for your time.

Sincerely,

Kim Moody
Executive Director
Disability Rights Maine

Carol Garvan
Legal Director
American Civil Liberties Union of ME

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[7] Children's Behavioral Health Services Assessment Final Report, p. 74, available at: https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/documents/ocfs/cbhs/documents/ME-OCFS-CBHS-Assessment-Final-Report.pdf.

[8] Taken from our joint testimony in opposition to LD 378, a bill that will make it even easier to institutionalize children, available at: http://www.mainelegislature.org/legis/bills/getTestimonyDoc.asp?id=167405

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