DISABILITY RIGHTS MAINE

February 11, 2021

Senator Ned Claxton, Chair
Representative Michele Meyer, Chair
Joint Standing Committee on Health and Human Services
Cross Office Building, Room 209
Augusta, Maine 04333

Re: L.D. 118 **An Act to Address Maine's Shortage of Behavioral Health Services for Minors**

Dear Senator Claxton, Representative Meyer, and Members of the Joint Standing Committee on Health and Human Services:

Thank you for providing Disability Rights Maine (DRM) with the opportunity to provide testimony in support of this legislation.

Unfortunately, visits to hospital emergency departments continue to be a reality for many children and families in crisis. DRM works with parents and youth who have been forced to spend days, weeks, and months in an emergency department waiting for appropriate treatment. In part, this is due to Maine's inadequate crisis system. Mobile crisis providers are supposed to respond to a crisis in the child's home, placement, or community.

Unfortunately, when a young person is in crisis, they are often directed to law enforcement and/or their local emergency department. The crisis system was designed for adults, not children, and as a result, crisis providers do not have the expertise needed to meet the unique needs of children and families in crisis. This is one of many issues identified in the 2018 assessment of Maine's Children's Behavioral Health Services by the Public Consulting Group (PCG)[1]. Many of recommendations from the PCG assessment focused on how to improve Maine's crisis system[2] for children and they should be considered in any reform efforts. For example, PCG recommended that the Department of Health and Human

[1] See, e.g., "Children's Behavioral Health Services Assessment Final Report," prepared for the Maine Department of Health and Human Services, Public Consulting Group, December 15, 2018: "Increased Emergency Department Use and Psychiatric Hospitalizations " (beginning on page 31) Available at https://www.maine.gov/dhhs/ocfs/cbhs/documents/ME-OCFS-CBHS-Assessment-Final-Report.pdf.
[2] *Id.* at page 78

Services (DHHS) review the current fee-for-service funding model for crisis providers to determine if this is impacting their ability to adequately staff their programs and respond rapidly to families in crisis, that DHHS develop formalized agreements between crisis providers and hospitals on admission criteria and processes, and that DHHS support crisis providers to receive training on how to safely manage and support children across the spectrum of behavioral health needs.

Until Maine develops more appropriate crisis responses, emergency departments will continue to be used when children could be supported in their communities with appropriate supports. The way Maine currently responds to behavioral health crises is expensive and ineffective. And there is currently no system in place to accurately collect and analyze data for youth who experience extended stays in the emergency department.

This bill requires hospitals to provide data on the number of children with behavioral health needs remaining in hospital emergency departments for "extended stays," including the reason and length of stay, to DHHS. DHHS will then be required to post aggregated data on an annual basis on a publicly accessible website. This information is crucial to understanding the complex dynamics that lead to kids languishing in emergency departments and is consistent with recommendations in the PCG report.

Collecting and analyzing this data is an important first step to understanding the gaps and failures in our current system to support youth and families in crisis and to make long-overdue system improvements.

Attached is a representative sample of cases DRM handled from the past year for youth who've experienced extended emergency department stays.

We would be happy to provide any further information about DRM's work to advocate on behalf and with youth with disabilities and their families who unfortunately find themselves in this situation.

Sincerely,

Katrina Ringrose

Katrina Ringrose
Advocacy Director

Disability Rights Maine
Sample Case Summaries SFY20

DRM Helps Keep Student in Maine after Residential Discharge to ED

The parent of a 15-year-old boy with mental illness contacted DRM after he was abruptly discharged from his residential provider to an emergency department after two weeks. DRM agreed to help the team come up with an appropriate discharge plan that would allow the client to leave the hospital. Through DRM's advocacy, the client was eventually placed at a different and more appropriate residential program. While at the hospital, DRM participated in meetings with the client and parent, hospital staff, case manager, DHHS staff, and with the first residential provider to discuss discharge planning. The team explored discharging the client to a crisis stabilization unit, admission to a different residential program, and a temporary placement at a youth shelter. The client was able to transition to the shelter. DRM continued to work with the team, including through a stay at another emergency department. The team received denials from most in-state residential programs and were talking about the possibility of the client going out of state, something no one wanted. DRM then reached out to another residential provider in Maine and they accepted him.

DRM reaches settlement to protect the rights and improve treatment of a child in a residential program

DRM successfully negotiated an agreement that improved the treatment of a 14-year-old boy with mental illness. Prior to DRM's involvement, the client was in and out of the emergency room and receiving poor-quality care at his residential treatment program. DRM filed a grievance against the residential provider, covering a wide variety of ways in which the provider was violating the client's rights – from safety and respect, to treatment planning, access to the community, restraint and seclusion, and others. After months of negotiation with the provider and their attorneys, the provider agreed to move the client to a different program, which the parent felt would be a better fit for him, as soon as there was an opening. The provider also agreed to provide treatment that complied with the client's rights, and to hire a consultant to work with the team to ensure that the client received the best quality of care. Further, the provider agreed to make their Board Certified Behavior Analysts available to continue working with the client; to include the client and parent in treatment planning; and to invite the parent to join the provider's Parent Advisory Group. The client successfully transitioned to the new program, where he and the parent are generally pleased with his treatment.

DRM assists 15 year old client to leave the emergency room and have improved individualized treatment at residential program

The parent of a 15-year-old girl with mental illness contacted DRM with concerns about the client's treatment at a residential program in Maine, which had resulted in multiple trips and long stays at the emergency department. At the time DRM was contacted, the client was stuck in the emergency department, and had been determined to meet hospital level of care, but no hospital in or out of state would admit her and the residential program would not

support her return. DRM participated in daily calls to advocate for an appropriate plan for her return to the residential program. These advocacy efforts were successful and the client returned to her residential program. Unfortunately, there were several more emergency department admissions before the client was admitted to a hospital in Vermont for treatment. Over the course of eight months, DRM participated in many team meetings to advocate for improved treatment and crisis planning and implementation. DRM provided the parent and client with information about her rights, including the grievance procedure, and was successful in advocating for the completion of a functional behavioral assessment (for both the residential and school programs), development of a positive support plan, and changes to the client's treatment/crisis plan.