Senator Cathy Breen, Chair
Representative Drew Gattine, Chair
Committee on Appropriations and Financial Affairs
5 State House Station
Augusta, ME 04333

Dear Senator Breen, Representative Gattine and Members of the Committee;

My name is Kim Moody and I am the executive director of Disability Rights Maine. Thank you very much for taking the time to hear from people with disabilities served by the programs you fund.

Since April, I have been asking each Team at DRM for specific COVID-19 related monthly reports. I received those team reports last Friday and they amount to 28 pages of specific issues and concerns across our agency. I've tried to narrow that down but am sending along to you the following several pages which includes a simple list of both some of the activities we have undertaken to address the ways in which COVID-19 is adversely affecting our clients as well as some of the systemic concerns shared by our teams.

I've included developmental disability, mental health, kids, American's with Disabilities Act team issues and Deaf services. You have the list so I will just talk about a couple of highlights.

Of the 587 new intakes DRM has received since March 16, 2020, 109 of them were specifically COVID-19 related. So while our intakes were slightly down for the first six weeks, nearly 19% of the calls we have received in the past 15 weeks have been complaints related to the effects of the disease.

Thank you for your attention to these vitally important issues.

Sincerely;

Kim Moody
Executive Director

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MAINE'S PROTECTION AND ADVOCACY AGENCY FOR PEOPLE WITH DISABILITIES

DRM Team Updates Specifically Related to the Pandemic
June 2020

Developmental Disabilities Team

1. DRM has received calls that providers are keeping economic stimulus checks and we have provided representation whenever the issue comes up. DRM worked with the Department to resolve this issue on a systemic level. OADS affirmatively issued guidance that people must have control over their own stimulus money.

2. DRM has received numerous cases involving providers restricting visitation, community access, and employment. Our strategy in addressing these issues has been advocating for individualized plans rather than blanket, agency-wide restrictions. Because of this though, our clients are losing independence and other rights. Staff come and go and we even get reports that friends and family of staff visit the settings, but our clients, those for whom these services exist, are often restricted to their rooms.

3. Our clients are often left out of the plan when it comes to making decisions about how to live life under these conditions. The providers that serve them are not including them in these conversations. All of the messaging about planning being person-centered, and talk about self-determination, seems to have been cast aside, and we wonder how we come back from that.

4. DRM conducted a project to contact and survey individuals living in group homes. The sample size was 5% of group homes with 3 or more individuals. We surveyed more than 50 individuals. Approximately a third of people surveyed indicated that their staff was not communicating with them/or not communicating with them enough about COVID-19 or the restrictions placed by the agency. Many of the clients we interviewed had not even heard of the stimulus checks. Other clients want to move but cannot.

5. And many people have felt very isolated in their homes, essentially held prisoners, complaining of being barred access to community activities that the general public can still do (e.g. walks on the beach, take-out food, drive thrus).
6. People are getting stuck in places they want to leave, including hospitals, because of the difficulty in transitioning people.

7. DD clients are at increased risk of being exposed to Covid-19, because so many of our clients live in congregate settings, and in places that are the source of outbreaks. And many have underlying health conditions that put them at greater risk for Covid-related complications. At the same time, our clients are losing independence and other rights because of restrictions related to spreading the disease.

8. Our clients are often left out of the plan when it comes to making decisions about how to live life under these conditions. The providers that serve them do not include them in the conversation. All of the messaging about planning being person-centered, and talk about self-determination, seems to have been been cast aside, and we wonder how we come back from that.

9. Right now, DRM believes we are offered an opportunity to re-envision the way we offer services to people with intellectual and developmental disabilities. The time is right to introduce evidence-based models that transition individuals from receiving day services in facility-based or large congregate group models to receiving services that support individualized engagement in the community.

   The current payment/reimbursement construct incentivizes a lack of choice in activities, community-based options, and schedule. At the same time, the activities in the community continue to be regimented and segregated. Individuals participate in activities that are reserved specifically for individuals with disabilities. The limited meaningful engagement with individuals without disabilities continues to reinforce a false, artificial environment that does not necessarily help individuals with disabilities acclimate to and develop skills for engaging more frequently in typical community settings. At the centers where the community supports are located, during "down time", there are few age-appropriate or scheduled activities focused on helping the participants build skills, pursue individual hobbies, or engage with individuals without disabilities beyond paid staff.

   There are also very few linkages between community supports and promoting employment. Maine is an "Employment First" state so employment needs to be offered and pursued as a first option but it isn't. There is no financial incentive for providers to move people out of congregate day settings. We can fix these problems through the waivers by changing rate structures, offering providers financial incentives for best

practices, creating new service models and definitions and implementing independent assessments of need.

10. And now, our clients feel pressured into returning to these very day programs that had been closed down due to COVID-19 because providers are reopening and need the business, in order to bill. We are seeing community support programs requiring clients/guardians to sign liability waivers to return to some of these day programs. These waivers would purportedly absolve providers from liability for injury or death to service recipients because of COVID-19, even in cases where the injury is caused by the negligence of the provider. OADS has been unequivocal that this is unacceptable. OADS has instructed public guardians not to sign these waivers and OADS and DRM have advised clients and private guardians not to sign them as well. The AG's office is supposed to be issuing written guidance soon.

    We see the primary issue here as how providers will keep our client's safe, the people for whom these services exist, rather than the other way around.

11. Finally, DRM advocates and attorneys need adequate PPE for our advocates and attorneys so that we can see our clients face-to-face. We are working on that but it is very expensive and hard to come by. We have put in a request to the State of Maine to assist us with acquisition.

Mental Health Team

Riverview/DDPC

12. Our advocates are on-site at Riverview but cannot be in their office at the same time due to the small size of the office. There has been no positive COVID cases on any of the units or in either of the hospitals that have been reported to us or that we are aware of. During these first few months since the outbreak we have been able to conduct advocacy services via telephone at both RPC and DDPC.

    Advocates in both hospitals have been monitoring civil court commitment hearings, attending treatment team meetings and Clinical Review Panel hearings when requested by the client, advocating for individuals around such issues as confidentiality, access to personal property, denial of community treatment, religious freedom, access to rights information as well as information regarding appeal rights, coordination of calls between attorneys and patients, and discharge planning and voting rights.

13. DRM produced a video that is being shown in the private hospitals, explaining what we do and encouraging people to call us. The private hospitals, including Spring Harbor, (we have an advocate embedded in Acadia, funded by Acadia) account for well over 300 of the available beds of the 422 in-patient psychiatric beds in the state, so we are hoping to continue, temporarily, this model.

14. Visitation has been a problem for our clients in hospitals and we advocate for an individualized assessment of each case so that people have access to their families.

Community Advocacy

15. Related to COVID-19, we have been taking numerous cases in which clients are unable to obtain certain services because of the COVID-19 emergency order. Due to these service denials, in conjunction with the Consumer Council System of Maine, we developed a webinar entitled: "Urgent Grievances and Covid 19."

16. DRM obtained the addresses from the Department of all of the Mental Health PNMI providers and sent a flyer informing them that DRM was open during this time. DRM also contacted the CEO/ED's of community mental health agencies and all of the jails, to let them know we were a resource and to inquire about their COVID-19 plans for residences.

17. We continue to see termination of services without Department authorization, most often specifically with regard to medication management. The requirement for the Department's authorization is in provider contracts and comes out of the provisions of the consent decree.

18. Getting the basic needs of people met through the service system right now, is incredibly difficult. People can do Zoom for a medication appointment, but Zoom does not work to help someone get to the grocery store. Also, some service providers are closing or shrinking services and cutting medication management. We have been informed of waitlists for case management.

19. We also worry about the reluctance of the general hospitals to deal with people in crisis while they are feeling the pressure of the pandemic. They already push people to the criminal justice system. We recently had a call from a jail who had a person rejected

from an emergency department at least twice who then ultimately ended up in RPC through the jail system. Being rejected thus by the general hospital will guarantee a longer stay in the state hospital.

Kid's Team

Behavioral health and juvenile justice

20. DRM created a video for use at Spring Harbor for the kids who are there.

21. DRM organized live virtual outreach to all kids at Long Creek, provided information to youth on each unit about DRM and spoke to six youth as a result. Youth generally report no interruption in services including education and are spending time outside.

22. With Adoptive and Foster Families of Maine, DRM provided a webinar to 15 people around access to educational and behavioral health services for youth.

23. DRM participated in the three initial regional community care teams established to support efforts to reduce the use of secure confinement and to try to ensure that the reductions in the population at LCYDC during COVID are enduring.

24. DRM is concerned about the lack of access for kids, to home and community based services. As of June 12th , the kids who are waiting for services include: 414 for HCT, 103 waiting over 180 days; 377 for Section 28 (non-specialized), 111 waiting over 180 days; and 218 waiting for Section 28 (specialized), 112 waiting for over 180 days.
25. It is unclear how many youth receiving services prior to COVID-19 are continuing to receive these services either via telehealth or in-person. We hear from our family partners that families continue to struggle in the absence of these supports.

26. Kids continue to be stuck in EDs during the pandemic, can't easily find solutions because crisis units, residential units, etc, not taking kids due to the pandemic. So kids are in the most dangerous place for longer periods of time given the lack of available options.

27. Even before the pandemic, for hard to serve kids placed out of state, the Department had just reinstated family support for transportation, but due to the pandemic families

are not able to visit their children. Their kids are particularly vulnerable, no accountability or eyes on for kids in far away places.

28. We worry much more about kids being abused or neglected given the lack of outside contacts. Typically schools and other service providers were places that abuse and/or neglect and/or unmet needs were identified.

Education

29. DRM attended the Maine Part B Special Education Advisory Panel meeting in June to participate in the discussion about summer programming and plans for improving access to education in the Fall.

30. Many students with disabilities have not been provided the services and supports they need to access distance learning. A survey of parents showed a lack educational instruction to the majority of our clients. Some students with disabilities cannot benefit from online or remote instruction in any meaningful way.
31. Many students, including many students with disabilities, will have experienced significant regression and many will have new needs due to the significant pandemic related stressors that families across Maine are experiencing.

32. As a result of the above, there will be an increased need for individual and systemic educational advocacy in the 2020-21 school year and beyond. The Legislature has, at your recommendation, funded Maine's only educational advocacy program at DRM since FY 2007 with only a few small cuts so it is now at $126,045 which funds an attorney and part of another. I would ask that, despite the circumstances, you not cut that funding.

33. DRM has issued two initial guidance documents and conducted multiple training events to support families and students in confronting these pandemic related challenges. And DRM will be issuing comprehensive guidance and related self-advocacy materials in August to support students with disabilities and their families. There will be a corresponding training and outreach effort to reach as many families as possible with information about educational rights before the start of the school year.

ADA Team

Voting

34. DRM has worked with SUFU and our Secretary of State's office for many years, to ensure access to voting for Mainers with disabilities. This year, we are very concerned about the lack of access for our clients, to accessible voting. We have received calls from blind individuals who want to vote absentee, but are unable to do so because of a lack of an accessible absentee ballot program in Maine.

35. DRM is developing virtual voting workshops in partnership with allies and constituent groups and voting outreach plans for and with all of our clients, cross disability, including youth, New Mainers and other underrepresented communities.

COVID 19

36. Due to the need, DRM is developing a cross team webinar on Reasonable Accommodations and COVID-19.
37. DRM created a fact sheet on COVID-19 and employment rights and our Deaf Services staff produced an ASL translation of the fact sheet. A DRM attorney Kristin Aiello, was a guest on Maine Calling on June 8 where she discussed ADA/employment rights in the age of COVID-19.

Deaf Services

38. DRM continues to get calls from Deaf adults struggling to navigate remote public services generally – online, self-serve options are English-based and inaccessible. The increased reliance on telehealth services has also caused some problems– doctor's offices are confused about how to schedule and integrate interpreters with video platforms.
39. In June, DRM held three remote Deaf Rights Group (DRG) meetings (good turnout - 10-16 participants at each meeting). DRG meetings are an opportunity for Deaf and Hard of Hearing community members to share their concerns and barriers directly with DRM. Many concerns reported about:

    Deaf access to 'remote' services for agencies and businesses - many rely on in-person services due to communication barriers and lack of internet/phone; struggles with telehealth for Deaf/HH patients; confusion about use and communication barriers related to face masks; and lack of ASL info about voting/elections.

40. DRM is collaborating with DOL, MECDHH, and Maine Hands & Voices to create a resource on face coverings and navigating communication access for Deaf, Hard of Hearing and DeafBlind community members.

41. DeafBlind clients face the steepest access barriers in a 'socially distanced' world. The DB program is adjusting in response, and researching program needs for PPE and modifications. DRM is planning to shift into outreach mode in July, and to renew emphasis on I&R as well.