

## To Whom it May Concern

On many levels, Maine is struggling with how to raise our children in the midst of a pandemic. How will the economy reopen? How can we prevent getting sick? What about childcare? And the all-important question, how will schools reopen?

It appears that children are generally less affected by COVID-19, but there is also the concern about their parents and caregivers, as well as school staff and teachers, especially those in high risk groups. “What is the best way to balance those needs?” has been echoed through the news, social media feeds, and by our national, state and local government leaders. But how does COVID-19 affect the **23% Maine children who have special healthcare conditions?**<sup>1</sup>

COVID-19 is still a very young virus. We don’t know much about how it affects us. However, research is finding that children with underlying health conditions are much more at risk for complications and severe illness from COVID 19 than children without underlying conditions.<sup>2</sup> For example, one study found children with Intellectual or Developmental Disabilities much more likely to have a more severe reaction to COVID-19<sup>3</sup>, while another study showed that COVID-19 may be exacerbated in children with asthma (7.5% <https://www.cdc.gov/nchs/fastats/asthma.htm>) and recommends that these children should be watched carefully.<sup>4</sup>

State-level discussions regarding the reopening of schools have not included representatives of these children with special healthcare needs. As a result, these children’s needs are not being included in reopening plans, putting them at a higher risk level. The recent Maine Department of Education survey did not include questions about disability nor provided an option for families of children with disabilities and/or special health care needs to share their concerns. Even the National American Academy of Pediatrics statement about children and schools included only one statement about children with disabilities. This is extremely disturbing, as children with disabilities are likely to be most negatively impacted by COVID-19. These are some of the same children who receive services and supports that allow them to access their education. These services are often impossible to provide or are less effective remotely and are best provided by qualified professionals. The parents who have access to technology and the energy to try to be their child’s therapist as well as their parent and teacher still fall short, this does not account for families who are unable to provide access or support for many reasons. In both cases their children fall (farther) behind.

Where is the representation of these children in the conversations about community and school openings? Do these children not matter as much as other children?

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<sup>1</sup> Maine Children with Special Healthcare Needs <https://www.maine.gov/dhhs/mecdc/population-health/mch/documents/MAINE-CSHCN-HEALTH.pdf> Accessed on July 14, 2020

<sup>2</sup> Harvard Medical School (July 2, 2020) Coronavirus Outbreak and Kids: <https://www.health.harvard.edu/diseases-and-conditions/coronavirus-outbreak-and-kids> Accessed on July 14, 2020

<sup>3</sup> Turk, Margaret A et. al. (May 24, 2020) Intellectual and Developmental Disability and COVID-19 case – fatality trends <https://www.sciencedirect.com/science/article/pii/S1936657420300674?via%3Dihub> Accessed on July 14, 2020

<sup>4</sup> Barsoum, Zakaria (May 19, 2020) Pediatric Asthma & Coronavirus (COVID-19) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7235436/> Accessed on July 24, 2020

Recently, the Maine Parent Federation asked the Department of Education to join the taskforce to develop Maine's Framework for Returning to Classroom Instruction. A Department representative replied by email on July 8 that the taskforce "included many educational stakeholders with varied perspectives from special services, transportation, curriculum directors, health services, among many others. The draft framework is a work in progress. We are continuing to work with partners across the state and are strongly encouraging local conversations of parents with school leaders as they develop their local community plans." They later encouraged Maine Parent Federation to participate in the survey. The taskforce lacked the parent with disability voice so, we can only assume, that they didn't think about asking questions that will affect 23% of children in Maine.

The Autism Society of Maine, Maine Developmental Disabilities Council, and Maine Parent Federation receive private, state, and federal funds to advocate, in part, with, for, and on behalf of these children and their families. MDDC and MPF receive public funding to serve as representatives of parents, yet they have not even been invited into the discussion.

Students with disabilities need to be represented. If they are not represented in reopening plans, then their needs will not be met. At best, they will not get the education they need to thrive as contributing members of Maine communities. At worst, they will be at higher risk from Covid-19. This is a difficult time for all of us. For families of children with special healthcare needs, it is a particularly scary time.

So, we ask: why are 23% of students, those who are so much more likely to be negatively impacted by this pandemic, not being represented in re-opening decisions?

Thank you for your consideration,

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