Testimony of Kelly Kierstead

In support of Part CC
LD 2214 *An Act to Make Supplemental Appropriations and Allocations from the General Fund and Other Funds for the Expenditures of State Government and to Change Certain Provisions of the Law Necessary to the Proper Operations of State Government for the Fiscal Years Ending June 30, 2024 and June 30, 2025*

Joint Standing Committee on Appropriations and Financial Affairs
February 21, 2024

Good afternoon, Senator Rotundo, Senator Rafferty, Representative Sachs, Representative Brennan and esteemed members of both the Appropriations and Financial Affairs and Education and Cultural Affairs Committees. Thank you for the opportunity to come before you today in support of Part CC of the Governor's supplemental budget which funds the newly designed CDS daily tuition for Special Purpose Preschools.

I am the proud parent of my son, Oliver. We live in Lewiston. This is my third time testifying in relation to Special Purpose Preschools. I came before this committee last year, and I am here again today to ensure that these preschools continue to be paid for the work they do for children during those most important years, ages 3-5, when early intervention is most vital.

THANK YOU for championing my son and so many other children with special needs. The work you did last session to include funding for LD 1309 in the budget, to take the *first step* to ensure that these specialized schools would receive support for *all* of the children that CDS sends their way was amazing. What I see in the budget now in Part CC is the funding for the next step, *implementing* the daily rate that will help these special preschools to stabilize and to be able to start tackling the waitlists that so many families are desperately sitting on.

I was one of those families. Oliver was diagnosed with level three autism the week he turned two. When we got that diagnosis, we were told by every professional, including the CDC, that his brain was growing and early intervention was imperative to him living his best life. We knew that from the moment that we got his diagnosis that this would at times be a difficult path and it was this early intervention that would assist with communication, which in turn affects everything else. I work in this field, and I see firsthand the complications and stress as well as self injurious behavior that can occur when a person cannot communicate basic needs, like whether they are in pain or even thirsty.

Like so many parents of special needs kiddos, we started piecing together services and going on any wait list we could for special purpose preschools. It would take seven months before we got in anywhere, with our journey starting at a private ABA center in South Portland. We were commuting 2.5 hours a day. We were thrilled when we started actual preschool at Essential Learning Solutions in Lisbon when he was 3 in 2021. He flourished. He learned shapes, matching and was even potty training. He is clever, and quickly moved through the stages of PECs. He was talking to us through these pictures, his first words. When we got the news, eight months later in June of 2022, that the preschool was closing due to funding, we were devastated. His teacher shared with us that the funding system was unsustainable.

That August he lost his education including Speech, PT and OT. The early intervention was now on us, trying our best to give him a fraction of the services he lost. That October, we heard from Little Pines, a preschool in Monmouth. We jumped over ten other families on the waitlist simply because we could provide transportation. I want to share that it is a little different with a kid like Ollie. We didn't start off where we were back in August. We started fresh. Potty training, matching shapes. New staff, new routines, new environment.

When you have a child that doesn't speak and cannot express themselves in a traditional way, every new start requires the staff to learn his sounds, his expressions, his actions, and learn who he is. For the first 3 months at any school, I hear "Well, we are still trying to figure Ollie out". And my boy regresses a little each time. But the months went on, and Ollie once again began to blossom. We opted for a second year of preschool as he was eligible. He made some heart connections there, some that still remain, and we got an AAC, a tablet to speak, opening new doors to communication. Less than a year later, we got the call that Little Pines, my son's third school, was closing due to funding. It was, according to the director, not sustainable. I knew that you had included money in the budget to begin intermediate payments while CDS developed the rate for this year. I sent her all the information I could sharing that payment was possibly coming in November. She said they had not heard when they would be paid but they just couldn't wait any longer. The decision had been made. Here we were again, with Ollie losing his friends, his teachers, speech, OT, PT. Given the connections he had made there, what hurt our hearts the most was the lack of closure for our boy. There was no explanation he would understand or the ability to say goodbye. His life changed overnight.

I got a call that week from the Margaret Murphy Center sharing that I had made my way to the top of the waitlist at their special purpose preschool. We had applied in 2020, and again in 2021. Over two years we waited. Had I not had the ability to transport my child, work in another city or bring him to school in another town, we would likely have spent most of that time with no services at all and he would be at square one years behind his peers. Our experience, I believe, is not typical. Ollie was our miracle baby and our only young child. We put all of our energy and focus into him. It seems that the most vulnerable kids have the least opportunity to navigate the system due to their circumstances. Again, we are the lucky ones.

We started at MMC in October. His team is fantastic and they are trying to figure him out like all the schools before. The upheaval of the life of a boy who thrives in the familiar has had notable detrimental effects. Oliver, once almost potty trained at 3, stopped using the bathroom all together at school when he started MMC, requiring trips to the urologist from holding his urine for up to 20 hours. Up a few weeks ago he was drinking just 2 oz a day. His matching goals are closer to 0% than the 40% they were. His daily Self Injurious Behavior has doubled. This is no fault of the school, but I believe, the result of a frustrated child who yet again has to show another group of adults who he is, with no words to do so. Their little lives have enough challenges with so many more ahead.

I'm so thankful for you all and so pleased that Governor Mills and the Department have included funding to implement the daily rate. We can't afford to take a step back. At a time when Maine is out of compliance with the Individuals with Disabilities Education Act and hundreds of families and children are already on waitlists for specialized early education services, I don't want Maine to see another specialized preschool close. I don't want our kids who have found their safe, familiar place in one of Maine's wonderful special purpose preschools, nor the children who have been waiting for a spot, to lose out on the early intervention that gives them their best chance. I don't want us to lose this momentum knowing the difference it will make in the lives and trajectory for children with disabilities.

Please support Part CC in the budget.

Thank you for your time and consideration. I would be happy to answer any questions you may have.

Respectfully Submitted,
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