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Subject: 105 CMR 210.000 – Administration of Medications in Schools Testimony Letter

I am writing is support of changes to 105 CMR 210.000 – Administration of Medications in Schools that do **not** prevent students from attending school due to medication needs.I am a mother to an enthusiastic and driven 14-year-old with Cerebral Palsy and Seizure Disorder who **loves** attending her school. My daughter has missed 90 days of school from Sept 2023 – present, including missing school completely from January 9th – April 1st, 2024. The reason she misses so much school is because of the **current** Regulation 105 CMR 210.000 – Administration of Medications in Schools**.** The **current** regulation imposes impossible restrictions for my daughter’s transportation to/from school. My daughter is prescribed Naysilam. Naysilam is an emergency seizure rescue medication that is a controlled substance administered as a nasal spray (parenteral medication). The **current** regulation possesses substantial barriers to her accessing school transportation to/from school because it requires a nurse on the bus in case, she needs the rescue med. The DPH regulation requires a nurse on her transportation to/from school and that it prohibits the delegation of the medication to anyone else. Additionally, the **current** regulation for delegation impacts the ability of a nurse to delegate administration of this medication posing additional barriers (105 CMR 210.004(B)(5), 105 CMR 210.005 (G)(4), 105 CMR 210.005 (G)(6)(6)(2)). Under the **current** regulation for delegation the training required would never be able to be performed because it entails the school nurse be present the first time the emergency rescue medication is administered. My daughter’s seizures are very well controlled where she has one every few years (last seizure was 3½ years ago) and they historically occur at night in her sleep. So, as you can see the current training/delegation guidelines would be an impossible scenario in my daughter’s situation. So, it is even more frustrating for her to be kept from attending school when she has very infrequent seizures. She has missed a significantly greater number of school days in the past 1 ½ year than she has had seizures in her entire life (4 seizures). This is not right! Though I understand safety is important, these regulations prohibit quality of life, prevent education, is discriminatory and denies access to FAPE. My daughter and all of the other students in the same situation deserve to be able to attend school with her peers freely, uninterrupted and to not discriminated against.

Anyone can be trained to administer Naysilam and my daughter’s neurologist has confirmed this as well as the Biopharma company, UCB. There is no medical order necessitating that a nurse delivers this medication.

Our school district had worked diligently to find nurses including using agencies. But with nurse shortages and the low pay rate this has made it incredible difficult to impossible to find nurse as well as retain them. Once they find nurses, most of them are not reliable and they are unable to retain them for beyond short periods of time. In addition, If the nurse is sick or late there is no substitute, and my daughter cannot go to school.

It should also go without saying, that missing this much time from school significantly impacted her ability to make progress, especially for a student who needs repetition to support her learning and progress. My daughter loves school so much that when she finds out she cannot go to school she is distraught for 2-4 hours and has meltdowns, panic attacks and on the verge of hyperventilation. Nurses have been so unreliable that she has anxiety starting the evening before a school day. Worrying if a nurse is going to show up. She’s not relieved until she sees the nurse. There have been several instances where my daughter would be loaded on to the bus, her wheelchair secured and the bus waits for a nurse only for the nurse not to show up and my daughter must get off the bus and come back into the house. The hurt, disappointment, sadness, and anxiety are cruel to put her through. Everyone who knows my daughter knows how much she loves going to school and can see how horribly this affects her. Sabrina loves her school, classmates, and staff so much that she would rather go to school on weekends and school vacations. The anxiety she experiences about whether she will be able to go to school each date is immense. When she cannot go to school it leads to increase anxiety, panic, depression, and tantrums that last hours.

Please understand how the current regulation has so negatively impacted her, her education and her mental well-being while also discriminating against her and preventing FAPE. I am thrilled to see the changes to this regulation and fully support all the changes that support students with emergency rescue medication to be able to access school transportation to be able to access their schools/education as any other student. The need for emergency rescue medication to be delated to un-licensed personnel is vital for my daughter and others to be able to go to school and uninterruptedly. Especially if it is a medication that can be administered by anyone.

An added note not only has this drastically impacted my daughter, but it also negatively impacts myself and my other daughter. It pains us to see her so upset and not to be able to access her education. But also, it negatively impacts my employment and ability to provide for my family. I am a widow who works full time to provide for my family. My job security is drastically impacted by the number of days my daughter misses from school since she cannot stay home by herself. Every working person knows their employer would not tolerate 90 days of work missed especially in a 1 ½ years’ time, even more so a full 3 months at one time.

Please work together to makes these proposed changes to this regulation so that students don’t have to miss school because they have emergency rescue medication. Please make revisions that truly support students being able to get to school and one that the school districts can carry out without barriers. I would also like you to consider exceptions to the regulation that would allow further discussion/agreement when staffing is not attainable. Thank you.