

CAP Presentation

Emily Mondschein

I am the Executive Director of GiGi's Playhouse, which is a Down Syndrome Achievement Center that provides free educational, therapeutic, and social supports for individuals with Down syndrome as well as their communities. I have the unique opportunity of working with the largest Down syndrome population in WNY as we are the only place that really offers this type of service.

I am also the mother of two boys, one who has Down syndrome and autism.

Finally, I was an educator and worked within the public school system for 15 years prior to being an executive director, which is where my passion for this work comes from.

As I began researching best practices for the Down syndrome population, I discovered tons of research and data around the general education setting being the most effective setting for students with Down syndrome. People with Down syndrome are visual social learners, and they excel alongside their peers when given the proper supports. However, I discovered a vast discrepancy between what is actually happening in the state of New York and what experts in the field recommend. So, a work group of experts in the field formed to create the first guidance document that exists for this population which is what I am here to share with you today.

Students with Down syndrome have a unique educational profile with a very specific set of strengths and challenges, however, our education systems as well as our service providers and administrators know very little about the educational and developmental profile that exists. We have parents and advocacy groups pushing for these students to be included and districts that really do not know how to do it. Schools are quick to place students with IDD in restrictive settings despite what the research and the law supports because it is easy and it is what has always been done. There are vast discrepancies from district to district, with one excelling on inclusion and the other 10 minutes up the road not even considering it.

I know how hard being a teacher is. When we place one of these complex learners in the general education setting, it is imperative that professional guidance and training is provided to the team working alongside the student. This guidance document delivers practical application for educators and service providers, as well as references to data and research around inclusion. There is also a lengthy resource section that will help in supporting educators. There are no Down syndrome specialists. There are no college courses specializing in Down syndrome. It is no wonder that our schools face such great struggles with including these students within in their rightful setting.

I would like to close by saying, I recently was a part of the NYSED stakeholder engagement seminar on LRE. I was shocked by how poorly our state is doing. I know there is a focus on culturally responsive teaching through NYSED's diversity, equity, and inclusion initiative, which is amazing, but I am wondering what we can do to include the disability population? In a recent report to congress, NYS was found to be the 48th least inclusive state, with only 17% of the IDD population being included in the gen ed setting for 80% or more of the school day. NY state, with its reputation of being inclusive, is really failing our students with disabilities in this aera.

My ask is that NYSED disseminate the “Inclusive Education Guidelines for Students with Down syndrome” on their list serv that educators and administrators subscribe too. The real change isn’t going to start happening until the people at the top start getting these resources into the hands of our school districts across the state. These people will follow the sentiments of NYSED. This is one solid concrete example of how NYSED could endorse inclusion for students with disabilities. And of course, I would be happy to do any work necessary on this, even if NYSED was interested in creating a guidance document specific to NYS. Thank you, on behalf of the disability community, for hearing my testimony today. I look forward to next steps.