

Autism Commission Meeting Minutes
May 17, 2016
1:30 p.m. – 3:30 p.m.
1 Ashburton Place, Boston, MA

Undersecretary Alice Moore, serving as the designee for Secretary Marylou Sudders, called the meeting to order at 1:35 p.m. and welcomed Commission members.

Minute Approval

Undersecretary Moore asked for a motion to approve the minutes from the April 12, 2016 Commission Meeting. The motion was seconded and passed unanimously.

DESE Presentation and Update

Marty Mitnacht presented on the Department of Elementary and Secondary Education (DESE). Ms. Mitnacht stated that as reflected on the slides, autism is a growing population, and that the different disability categories may include additional students with autism but who have categorized by a different disability by their District.

Chris Supple asked where PDD-NOS falls on the number and percentage of disability categories. Ms. Mitnacht replied that it tends to fall under the development delay category until age 9.

Dania Jekel asked how multiple disabilities are identified. Ms. Mitnacht stated that it is when there is one or more disability that has a primary impact on the student.

Rocio Calvo asked how these numbers, on performance of 10th grades with autism, compared to children that do not have a disability. It was also asked how many students with ASD take the alternate exam. Ms. Mitnacht said that information was not included but that she would provide it.

Julia Landau stated that she was confused regarding the slide on Educational Environment Placement for Students with Autism (slide #7), Ages 3-5, specifically regarding the numbers of services received in inclusive setting vs. substantially separate setting. Carolyn Kain asked if DESE is using the same definition for inclusion for early childhood as it is for other students, amount of time in the general education classroom, as it seems to be more refined here. Ms. Mitnacht agreed that it is very confusing, and that it is what the Federal government came up with. She stated that a substantially separate classroom is where all the students in a classroom have a disability, and there is very little other interaction except in the hallways or perhaps during lunch.

Undersecretary Moore stated that since there is enough confusion and questions regarding the data, that Ms. Mittnacht and Ms. Kain coordinate on receiving questions from the Commission members. Ms. Mittnacht said she would.

Regarding the data on Educational Environment Placement for Students with Autism, Ages 6-21, Janet George suggested that the data may be an under-representation since there are more children with autism where that is not their primary diagnosis, and those children are not being included in the percentages.

Ms. Kain stated that for the students ages 6-21, the students that are substantially separate are receiving zero inclusion services, and asked if that was that how she was using it here for 3-5 year olds. Ms. Mittnacht replied there is some inclusion, but almost none; just sharing the cafeteria and walking in the halls.

Ms. Calvo asked if there is any data to look at by race and ethnicity for inclusion and sub-separate to see if minority students are being placed in substantially separate more often. With regard to date of diagnosis with DD, she stated that her guess was that minority children may get a later diagnosis and she is interested to understand that data. Ms. Mittnacht said they could pull that data, but stated that it would be helpful if the Commission could send her a list of data that they want to see.

Chris Supple stated that with the new regulations implemented on 1/16/16 there are limits on ability to restrain kids, possibly making it more difficult. He suggested looking at data on that. Ms. Mittnacht stated they are treating it as a training issue and will have some reporting available next year.

Cathy Boyle asked about the percentage of children in correctional settings being zero. Ms. Mittnacht said that figure is only counting individuals who have been identified as eligible for special education and have autism as the primary diagnosis. She added that these are not referral cases; they are DYS or Corrections and not from a psych setting or DMH. She continued that DYS seeks reports from the schools, and if those records show special education, DESE would be notified.

Ms. Landau stated Mass Advocates received hotline complaints about substantial numbers of children hospitalized or homebound due to behavioral health issues that the school can't help. Ms. Mittnacht stated their data is updated 3 times per year, and if a child is out for 2 months in a hospital that won't be reported. It does not look at temporary situations. Ms. Landau said all home/hospital situations are not temporary, to which Ms. Mittnacht replied that there are a fair amount of students there most of the time, and some may be out for the whole year. Ms. Landau said that she didn't understand how the percentage could be zero.

Amy Weinstock stated if a child in a correctional setting is not enrolled in school then would they not be in the system for this data, asking if DYS involvement with DESE might also fall off. Ms. Mittnacht replied yes, if a child is not enrolled in a school system those just in DYS are not included.

Regarding the data on Educational Environment Placement, Ms. Kain asked if actual numbers could be provided in addition to the percentages.

Todd Garvin asked how the definition of Autism impacts people who fall under the older definition or people with Asperger's. Ms. Mittnacht replied that their definition does not have the term Asperger's and that they would just fall under the general definition. She added that some children are identified under the general definition of communication, and that it doesn't have to necessarily be "autism." She added that the DSM V definition is not included in DESE's definition, but it is included at DDS.

Regarding the slide that included information on technical assistance from the *Is Special Education the Right Service* document, Ms. Kain stated that it was somewhat of an inclusive list but she did not see behavioral included. Ms. Mittnacht stated that they are in the process of updating the information, and that behavior is something they would consider adding.

Undersecretary Moore asked if they are seeking input on that guidance, which Ms. Mittnacht replied that DESE is waiting for input from schools by the end of the year, which she will then review before releasing it to the public for comment. She added she would notify the Commission when it was out for comment.

Cathy Boyle asked, regarding eligibility, how impact on learning is defined. Ms. Mittnacht replied that it is a combination of academic and non-academic, including the life of the school, adding that there is a need to be well-rounded both academically and socially.

Ms. Landau stated there was an amendment to the special education law in 2004, and that it is important to consider that daily living and functional skills are important to address for children of all ages. Ms. Mittnacht stated that there is individual consideration for all kids, but some may have a stronger focus on when to start to think about how to use those skills, and that generally teens are more focused.

Ms. Kain replied that is a big generalization. Younger kids do have a basic focus on ADLs like toileting, feeding, hygiene, and it continues to be needed for some older children, but the focus should be there throughout their education and not addressed for the first time when they are older students. Ms. Kain said this is impacting individuals' ability to go on to further education, employment, and independent living because they don't have the executive function skills and daily living skills to be independent. She

said that this can also lead to issues of anxiety and depression because they cannot be successful at college, community college or employment.

Ms. Boyle stated that there is a big gap. By the time kids reach 14/puberty and are still refusing to shower, this is going to greatly impact their ability to function when leaving school. Parents are unable to win the battle when children start turning 14, 15, and 16, and the government should establish patterns when kids are small to make it stick.

Ms. Mittnacht replied that theoretically, every kids IEP program should respond to how that kid is presenting. There is no need to say that everything should be taught according to their age, and that transition should be attended to and prioritized, not just academics.

Mr. Garvin asked Ms. Mittnacht to define "incidental learning," to which Ms. Mittnacht gave the example of a child in the back of the classroom who learned by his own experience, perhaps by being bullied. She added it is learning that is not part of a deliberate plan.

Ms. Kain added that it also goes further, citing social skills on the playground as an example that non-ASD children can pick up social skills and cues just by interacting with other children. Children with ASD become isolated because they lack the skills and understanding of how to engage with their peers. For those who cannot gain skills incidentally, by simply being with their peers, there needs to be direct teaching of social skills.

Regarding the Omnibus Law, Ms. Mittnacht and Ms. Landau discussed a survey to gain feedback on opening the endorsement to all general educators, not just special education teachers. Ms. Landau will send the info to Ms. Kain so that everyone can provide their feedback and opinion. Ms. Mittnacht added that once they have developed the guidance on the approval for that, they will begin looking into how to grandfather certain folks in.

General Comments/Discussion

Ms. Jekel pointed out that there are still nearly 50% of students in substantially separate classrooms regardless of inclusion being around for 30-40 years. She asked if Ms. Mittnacht has any analysis on why there is still a 50/50 split.

Ms. Mittnacht stated that she believes it is a combination of large classes, need for personal attention, and protection around the child with disabilities. Many parents think smaller class sizes available in the substantially separate classes are better, and often tend to focus on the near future instead of the long term.

Vinnie Strully added that kids on the spectrum have needs, 30% of which are off the table right away for any inclusion. And while MA has more qualified teachers than most states, the needs are still there for individual and specialized attention.

Ms. Kain stated that the data on placement reflects the system's response to children rather than a reflection of the children themselves, suggesting that inclusion needs to be revisited by a team each year to look at where inclusive opportunities exist for the child, how they can be added as part of their IEP, to start to move children out of substantially separate and into more inclusion. Ms. Kain asked Ms. Mitnacht about the requirement for inclusion, or the least restrictive environment, to occur to the maximum extent appropriate for every student by law, and what was DESE doing to ensure that Districts are complying with that mandate. Ms. Kain asked if this was part of the DESE Program reviews.

Susan Loring asked what percentages of children are substantially separate and also have co-morbid mental health issues and what ages does that peak. Ms. Mitnacht replied that they do not have that data available, and Undersecretary Moore stated that there will be a list of questions to ask DESE to better understand the data.

Ms. Boyle reiterated Ms. Rocio's point about needing data broken down by race and ethnicity, suggesting children of color may be more strongly represented in substantially separate classrooms, perhaps due to parents not having the wherewithal to advocate. She continued that, in terms of full inclusion, perhaps the physical design of schools could be looked at, as designed could be triggering inability to cope. She added that there is a woman in California having good luck with inclusion with shorter days.

Ms. Mitnacht replied that is on the table for future design and it depends on the responsiveness of the school and teachers.

Ms. Hubbard asked for data at the endpoint, at ages 18 or 21, to see percentages of measurable outcomes like a diploma or certificate. She added there is a big data gap as kids go into adulthood.

Chris Supple asked if there is a way to capture the number of adults by going back in time to see how many adults there are from previous DESE data like they have done in Slide 5, Ms. Mitnacht replied yes but that the system is not that old – only from 2001 and she doesn't consider it reliable date until 2003. She stated that the state level can start to see patterns, though, but added there is a big issue where the state cannot reliably connect the different databases.

Mr. Supple asked about the percentages of kids enrolled with autism, asking why the numbers decreased as the children aged. Ms. Mitnacht stated that the PK group is

ages 3, 4, and 5 so it is a bigger group, but added that autism is still a low incidence disability.

Judith Ursitti asked to see the age of diagnosis as well as when they started receiving services.

Ms. Kain asked if the multiple diagnoses includes ID as well, and therefore captures those eligible for DDS. Ms. Mitnacht replied that it just captures if there are multiple diagnoses, but not which ones, adding they are working on that.

Ms. Kain asked for the race and cultural information to be added to the data. Ms. Jekel asked for primary language as well.

Ms. Calvo stated that there are certain groups for which the school is the main way to get services, especially those whose parents are immigrants and not well-educated.

Subcommittees

Undersecretary Moore asked Ms. Kain to discuss the subcommittees, adding that many have already signed up and encouraging those who would like sign up to get in touch with Ms. Kain. Ms. Kain stated that she has meet individually with just over half of the 35 members and she has additional meetings set up with more Commission members in the coming weeks. Ms. Kain said she had heard from many of the members about which sub-committees they would like to serve on but that she still needed to hear from the remainder.

Ms. Kain read the names of the subcommittees and the members so far. She stated that the adult group could be divided into two different groups: one to discuss the newly eligible and other to focus on the traditional adults who are already in the system. She also suggested splitting the school-aged children into multiple groups: 0 – 3, PK – 14, 14 – 22. She stated she is looking for feedback on that, and also if the Commission has any suggestions on non-members to join the subcommittees.

Ms. Landau raised the question of groups overlapping, for example the adult group will likely also look at housing and employment issues. Ms. Kain said that is something to talk about, that she wanted to do what was most logical but that having more targeted focus on specific issues would be more manageable. Ms. Kain said if sub-committees wanted to consolidate that would be fine but this was an issue where she was asking for input. Ms. Kain said that her goal was to set up meetings for each subcommittee in June where consolidating could be discussed more in length. Ms. Boyle suggested that each group should have a member from another group so there is communication amongst the subcommittees.

Ms. Landau suggested that each committee should look at certain issues that affect all committees, for example non-verbal and barriers to service. Ms. Kain agreed, and asked for specifics to be emailed to her before the next meeting.

Mr. Supple asked that there be two more presentations, one for housing and the other for employment. Undersecretary Moore asked by raise of hands which presentation should take priority, with employment taking precedence. Ms. Kain asked for folks to let her know questions before the presentation so she can ensure that the presenter is inclusive of all the information the members want to know.

There being no further business, upon motion duly made, seconded and approved, Undersecretary Moore adjourned the meeting at 3:25 p.m.