Autism Commission Meeting Minutes

February 6, 2019 – 2:00 p.m.–4:00 p.m.

One Ashburton Place, Boston, MA

Present: Secretary Marylou Sudders, Carolyn Kain, Nora Bent for Rep. Christine Barber, Rep. Kimberly Ferguson, Janet George (DDS), Christine Hubbard, Patricia Gentile (NSCC), Josh Greenberg for Kathy Sanders (DMH), Russell Johnston (ESE), Jane Ryder (DDS), Toni Wolf (MRC), Amy Weinstock, Elizabeth Morse(DDS), Chris Supple, Rita Gardner, Jason Albert (EOLWD), Theresa Schirmer, Julia Landau, Michele Brait, Joan Rafferty (DPH), Catherine Canada (DCF), Vinny Strully, Laura Conrad (MassHealth), Dania Jekel and Dan Burke.

**Welcome - Review and Approval of Meeting Minutes from September 27, 2018**

Secretary Sudders called the meeting to order and welcomed the Autism Commission members. Secretary Sudders asked the commission members for a motion to approve the minutes from the meeting December 10, 2018. The minutes were approved unanimously.

**FY20 H1 Budget Proposal Presentation**

Secretary Sudders discussed the proposed budget for EOHHS that included a significant increase in the DDS/DESE program among other increases.

***Highlights***

* Fully funds Turning 22 classes at DDS and smaller disability agencies
* Maintains MRC core services despite reduction in federal funding and federal audit findings
* Chapter 257 funding for human service provider rate review
* Increased rates for chapter 766 schools by $2.2 M
* $4 M increase ($10.5M total funding) for the DDS/DESE program. The program will support approximately 264 new, 760 total youth and their families
* $28.5 M increase to cover changing needs within the existing DDS client base – caused by increasing acuity and aging caretakers
* 4.2 M increase for an additional day of residential and day and wok services due to the leap year

Secretary Sudders discussed the DDS/DESE program and that there has not been an increase to this program in many years. The funding will come from EOHHS and not the Department of Education. There have been conversations that took place during the Autism Commission meetings that brought the need for additional funding to the forefront.

Another highlight is in the MassHealth budget with a significant increase in ABA services for FY20. This is only for individuals 21 and under.

Rita Gardner commented on Chapter 257 rates and adult service providers. There is increasing concern with hiring and attaining workers due to the strong economy and a worker shortage for this type of work. She sees this as a workforce crisis and asked about the RFR to raise the rates for these workers. She is seeing more adult individuals struggling to get adult services, especially individuals with aggressive behaviors. Commissioner Ryder acknowledged that this is a big issue and at a point of crisis. DDS is looking at tangible ways to address hiring and attaining workers. There are discussions on offering better benefits and flexible schedules to help entice the workforce. Providers are still bidding on this work. Secretary Sudders has discussed this issue with Leo Sarkissian from the Arc and they met with the four trade groups (providers) and have strongly suggested the groups find a common voice on this issue and come up with a strategy to address it.

There were discussions on the Healthcare industry and the work they are doing to address the workforce issue. They are creating a pipeline with technical high schools with pathways to healthcare. This could also work for the human service industry.

**Approval of the 2018 Annual Report**

Russell Johnston discussed a consideration for language change in the report under the recommendation for Birth to Three that state “*with specialized consideration for any cultural, linguistic, and/or socio-economic needs of racial, cultural and socioeconomic considerations*”. He asked to change the language to ???

The secretary asked if all were in favor of approving the 2018 Annual Report with the technical change from Russell Johnston. There was a motion to approve by ? , and a second by ? . The 2018 Annual Report was approved unanimously.

**Presentation by Dr. MacDonald, NECC – Infant Sibling Project**

***Symptom Onset and Intervention for Infant Siblings of Children Diagnosed with ASD***

Vinny Strully introduced Dr. MacDonald . This work is being is ongoing and is funded by NECC. The work that is being done is not for a cure but for early detection and intervention.

Dr. MacDonald has 18 babies in this project and is looking to have a total of 60. She will follow the infants for 24 months.

Infant siblings of children diagnosed with ASD have a 19% recurrence risk at 3 years old (Ozonoff et al., 2011). The point at which symptoms emerge is documented in the literature as occurring within 6-12 months. Treatment protocols that have roots in ABA (EIBI; MacDonald et al., 2014) and Infant Start (Rogers et al., 2014) have shown best outcomes. Graupner and Sallows (2017), in a sample of 67 infant siblings, reported symptoms in children under 3 months old. Using weekly developmental assessments and an intervention that combined ABA, developmental models and ESDM, they were able to remediate symptoms in 13 of 14 symptomatic siblings. The purpose of this investigation is to replicate these findings. We hypothesize that if treatment begins at or before 6 months, with a high intensity, outcomes will be better. Siblings will be recruited at birth and be provided weekly screenings focused on identifying symptoms. For those babies who show them, ABA therapy and/or parent coaching will be provided. A group design will be used to compare profiles across groups: symptomatic babies receiving 30 hours of intervention from a trained therapist, symptomatic babies whose parents do not receive parent training. All will receive standardized assessment at 6-month intervals. Results are expected to reveal that earlier age and greater intensity of treatment will result in best outcomes. These findings have implication for service delivery and long term financial obligations.

After the presentation, Commissioner Ryder thanked the Autism Commission members for their participation. With no further business to discuss, the meeting was adjourned.