**Governor’s Commission on Intellectual Disability**

**March 27, 2019 Meeting Minutes**

The Governor’s Commission on Intellectual Disability met on March 27, 2019 at the Executive Office of Health and Human Services.

Present were: James Brett (Chair), Amy Carnevale (phone), Marjorie Cohen, James Cassetta , Aaron Stone, Jo Ann Simons, George Ford, Joanne Jaxtimer, Jane Ryder, Elizabeth Morse, Marianne Meacham and Victor Hernandez.

Chairman Brett called the meeting to order at 4:07pm. On a motion by Joanne Simons and seconded by Joanne Jaxtimer the December 19, 2018 meeting minutes were unanimously approved.

Commissioner Jane Ryder provided an overview of the Department by updating the GCID on:

* The Governor’s FY20 budget was released in January. DDS budget is $2B+, an 8% increase over FY19. Funds the Turning 22 and the DESE/DDS program.
* HWM budget testimonies highlighted the workforce issues facing EHS agencies.

Ms. Simons and Mr. Cassetta brought attention to the prevailing wage challenge and the challenges of expanding DDS services while facing the staff shortages. Ms. Simons also mentioned the staff frustrations directed at management.

Marianne Meacham , DDS General Counsel, reviewed the recent legal issues facing the Department, Photo Consent and Guardianship.

The current photo consent regulations go back to the 1980’s. They require consent for each “release” or use of a photo. DDS has proposed regulatory changes to this rule, as part of its larger proposed amendment to 115 CMR Chapter 5. With expanding social media and an increase in the number of photos taken and shared online the *proposed* Chapter 5 regulations aim to expand the existing consent to provide:

*5.04(2) The right to be protected from private and commercial exploitation including: the right not to be exposed to public view by photograph, film, video, interview, or other means unless prior written consent of the individual or guardian is obtained for ~~each~~ such release; and the right not to be identified publicly by name or address without the prior written consent of the individual or guardian.*

Along with a revised DDS photo consent form, the change will allow individuals or their guardians the option of consenting to the release of a single photo or multiple photos on a specific or multiple media platforms. The written consent will have to be renewed annually (or until withdrawn). DDS will release further guidance on this when the proposed regulations are promulgated.

The use of video monitoring has raised a new issue for the Department. There was recently an incident where the family of an individual in a DDS residence used a “nanny cam” to monitor the care of their loved one. Current DDS regulations are silent on the use of video cameras in DDS funded or licensed homes for safety monitoring or other purposes; regulations do address individuals’ right to privacy. The use of video monitoring thus raises questions about whether, and under what circumstances, individuals or guardians may consent to videotaping in otherwise “private areas.” DDS is in the process of reviewing its practice regarding the use of video within DDS programs. Challenging issues are who would monitor and be a holder of the video, as well as what the criteria for allowing monitoring should be. Another issue pertains to notifying staff that they may be subject to video monitoring. A policy is needed to address these and other issues.

The use of video for purposes beyond safety monitoring, to include “tele-medicine,” and to address staffing shortages, is also being examined.

There was discussion regarding guardianship and “supported decision making” as an alternative to guardianship. There is increased legislative attention on guardianship and some advocates are supporting a bill to create the SDM option for individuals.

With respect to current practice, DDS currently has 10 lawyers who are authorized to file petitions the Probate Court(s) on behalf of the Department for a guardian to be appointed. Parents can and often do initiate this process on their own for their adult children. Advocates feel that this makes it too easy to take away individuals’ rights and have introduced legislation to allow for the option of supported decision making instead of the appointment of a guardian. DDS has met with advocates to discuss the bill and the piloting of supported decision making, and will keep track of this and will report back later.

Due to another engagement many GCID members were attending, the meeting needed to adjourn earlier than scheduled. The next meeting of the GCID is scheduled for June 19, 2019 and this meeting was adjourned at 5:07pm on a motion by Jo Ann Simons and seconded by George Ford.