

State of Connecticut
GENERAL ASSEMBLY



NEEDS OF PERSONS WITH INTELLECTUAL DISABILITY TASK FORCE

MEETING SUMMARY

October 30, 2019

Mr. Weinberg convened the meeting at 1:04pm and welcomed members.

Members present included Mr. Weinberg, Mr. Karan, Ms. Dawn Odour, Ms. Nicole Jean Milo, Mr. Joe Duffy, Ms. Judy Dowd, Mr. Jordan Scheff, Ms. Patricia Fields, and Ms. Cynthia Stramandolini.

Mr. Karan noted that the task force has two purposes, to study the short and long term needs of adults with intellectual disabilities, and to study ways in which services and supports to such adults may be provided. Mr. Karan added that the task force is in the preliminary stages of gathering information that are pertinent to the two purposes and would like to continue discussing other topics and members deem important so that experts in such topics may be invited to present.

Jordan Scheff, Commissioner, Department of Developmental Services (DDS), presented:

Mr. Scheff stated that he will be sharing portions and laying out the canvass of DDS so that the task force is able to decide which areas they need to invest their energy and focus.

Mr. Scheff noted that DDS is responsible for the planning, development and administration of complete, comprehensive and integrated statewide services for persons with intellectual disability and persons medically diagnosed as having Prader-Willi Syndrome. The Department provides services, within available appropriations, through a decentralized system that relies on private provider agencies under contract or enrolled with the department in addition to state operated services. Services include residential services and in-home supports, day services and employment support, family support, respite, case management, and other periodic services such as transportation, interpreter services, and clinical services.

Mr. Scheff added that DDS is funded by the state budget for the Fiscal Years 2020-2021. The DDS portion of the budget includes annualized funding for emergency placements, annualized funding for housing supports and services, and funding for case load growth in the community residential

services account. As of June, 2019, DDS is serving 17, 126 individuals for whom it uses the Connecticut Level of Need Assessment tool in order to assess and identify the funding and services needed by each of them.

Also as of June, 2019, Mr. Scheff stated that there are currently 1, 838 individuals on residential waiting lists. The waiting lists are categorized in three categories and two target groups. Categories include emergency, urgent, and future needs and the target groups are no services and underserved. Of the 1, 838 individuals, 577 of them belong under the emergency and urgent, no services waitlist. 182 individuals belong under the emergency and urgent, underserved waitlist, and 1, 079 belong on the future needs category.

Mr. Scheff also noted that in Fiscal Year 2019, DDS received \$5 million in appropriations for emergency placements. This appropriation was used to create a six bed unit for supporting individuals in crisis called the Step Up Step Down Unit, as well as enhancing and expanding individual support teams focused on providing rapid support to individuals in crisis.

Additional initiatives include the Intellectual Disability Partnership Innovative Employment Outcomes Pilot. This was achieved through Intellectual Disability Partnership, and it focuses on providing support and resources to new businesses that are committed to integrating individuals with intellectual disabilities.

DDS and the Department of Social Services have also proposed amendments to Medicaid Waivers so that they may include options to enhance the independence and quality of life of the individuals served. One of the amendments is to increase the limits on assistive technology, vehicle modifications and environmental modifications so that they may promote community inclusion. The other proposed amendment is to add Remote Supports as a new service. Remote supports allows for real-time, two way communication through an off-site direct service provider that monitors a person's health and safety needs while promoting independent living.

There are multiple legislative committees and Governor's councils that focus on improving the lives of individuals with disabilities. They include: The Medical Assistance Program Oversight Council (MAPOC), Complex Care MAPOC subcommittee, Developmental Disabilities Workgroup, Autism Spectrum Disorder Advisory Council, Behavioral Health Partnership Oversight Council, Long Term Supports and Services Rebalancing Initiatives Steering Committee, Task Force to Increase Employment Opportunities for Persons with Disabilities, Task Force to Study Voluntary Services Program Operated by the Department of Children and Families (DCFVSP), Governor's Task Force on Housing/Supports for Vulnerable Populations, Governor's Council on Women and Girls, and the Governor's Committee on Employment for People with Disabilities.

Adrienne Benjamin, Parent Advocate, presented:

Ms. Benjamin presented a personal story of her daughter's life and the daily challenges of caring for an individual with a disability. She noted that she has been recently become involved with the National Council on Severe Autism which is strictly focused on the unmet needs of individuals with autism. She added that in her perspective, individuals with severe needs, such as her daughter

are left behind. As an example, her daughter may be considered disruptive and destructive in a group home as she has a big personality. She noted that a congregate setting in a community with similar needs as hers would fit her better. A secluded setting would also mean lower vulnerability as she does not have a sense of safety for crossing a road or meeting strangers.

Lauralyn Lewis, Parent Advocate, presented:

Ms. Lewis stated that she is one of the authors of the special act that created the task force. She noted that the purpose of the task force is to focus on two segments of the intellectual disability population. The first segment is the aging population that has more complex needs, such as Alzheimer's, and the second is the population that may not be aging but has severe behavioral needs. Ms. Lewis noted that while the task force's focus is on existing systems within DDS, it must be acknowledged that medical advances have allowed individuals to live longer and this has initiated conversations around residential waiting lists and employment. She added that she is a proponent of independence because her son has down syndrome and is very independent yet acknowledges that what may be a good fit for him today may not remain a good fit tomorrow.

Mr. Weinberg noted that Ms. Lois Nitch is home ill and unable to present at today's meeting.

Mr. Scheff added that while he will reserve Ms. Nitch's story for her to tell, it is a story of challenge and frustration and that in this difficult circumstance, DDS is doing the best they can by her and her loved ones.

Pat Stavola, Parent Advocate, presented:

Ms. Stavola stated that she is the Family Support Coordinator for the North Central Region for the Connecticut Family Support Network. The Network works with individuals with disabilities and their families to find the resources they need to become the best advocates for themselves and their loved ones. She noted that many adults with disabilities are not covered by state agencies such as DDS or Department of Social Services (DSS). Some of the adults not covered may meet the eligibility criteria but because both the public and private systems are difficult to navigate they rely solely on their loved ones. Ms. Stavola added that although she's been working within the disability community for six years, it took her two years to find a suitable independent living situation for her son. She stated that the Network invites speakers to their meetings from state agencies such as DDS, DSS, and the Department of Housing. Additionally, non profit organizations that are not located in Connecticut but have good active programs are also invited to speak on residential services, day services, and employment services. Ms. Stavola noted that the Network is in search of providers in North Central Connecticut that can offer independent living support, whether individually or as a group, to expand skills for individuals with disabilities on transportation, budgeting, in home skills such as cooking and cleaning, and social supports so that individuals can stay engaged in the community.

Mr. Karan thanked the speakers for their presentations and asked members for suggestions on other areas they deem important so that additional speakers may be invited.

Ms. Fields recommended for the task force to contact LiveWell in Southington as an Alzheimer's resource. She stated that LiveWell recently conducted a three-day training on the topic and it may be helpful to hear their perspective.

Mr. Scheff noted that Dr. Lynn McMann, a former employee of DDS, is now employed at LiveWell and offered a connection between Dr. McMann and the task force.

Mr. Karan stated that Dr. McMann is a former student of his and would gladly connect with her and extend an invitation to present to the task force.

Chairpersons Mr. Karan and Mr. Weinberg asked DDS to compile and provide to them a list of providers that offer services for people with severe disability needs so that the task force can identify other potential speakers to invite.

The next task force meeting is scheduled for Wednesday, December 4, 2019 at 1:00 PM.