

State of Connecticut
GENERAL ASSEMBLY



NEEDS OF PERSONS WITH INTELLECTUAL DISABILITY TASK FORCE

MEETING SUMMARY

January 8, 2020

Co-chairman of the task force, Mark Weinberg, convened the meeting.

Dawn Odour, Parent of Individual with High Level Needs, presented:

Ms. Odour recounted her personal experience of caring for her son with high level needs, beginning with his adoption to present day, 27 years later. Ms. Odour remarked on her son Ami's life and the way it has impacted hers. Despite being a high-level needs individual, Ami is happy and the best individual Ms. Odour has ever known. She stated that Ami co-teaches with her at the Yale School of Nursing in Operation House Call.

Operation House Call is an initiative that was started by the Arc of Massachusetts to familiarize Advance Practice Registered Nursing (APRN) students at the Yale School of Nursing with the intellectually disabled and medically complex. APRNs are strategically utilized as an alternative to physicians and as such must feel comfortable and knowledgeable when working with the intellectually and developmentally disabled population (IDD). As a result, Operation House Call integrated IDD into their APRN curriculum at Yale.

Ms. Odour stated that the IDD community needs an agency that addresses their needs in a respectful and caring way. While budgetary restraints have always been present, Ms. Odour expressed that there are creative ways an agency can reorganize their staff in order to build an efficient organization in which the State of Connecticut can take pride.

Holly and Wayne Ripley, parents of an individual with intellectual and developmental disabilities, presented:

Mr. and Ms. Ripley remarked on their story of caring for their daughter Elizabeth Ripley. Mr. Ripley stated that in order to receive help in caring for an individual with needs, a parent must let go of that individual and accept that someone else must care for them. As such, Elizabeth had to leave her home because Mr. and Ms. Ripley were unable to care for her. While Elizabeth is now in a private home and well taken care of, Mr. Ripley stated that issues remain. He elaborated that it seems as soon as Elizabeth, and other individuals at the

home, become accustomed to an employee and feel comfortable with them, those employees end up leaving their jobs. This may be due to the age of the employees, which is typically young, and possible underpayment and therefore the employees jump at any other opportunity that may pay them more.

Additionally, Mr. Ripley expressed that the caretakers do not give the patients the opportunity to learn things. He acknowledged that at times it is easier to do something than teach another individual how to do it, but this creates an environment of dependence. Consequently, patients are unable to make independent progress and remain under the impression that everything will be done for them.

Kathleen and Andy Jortner, parent of an individual with intellectual and developmental disability, respectively, presented:

Ms. Jortner noted that Andy has selective mutism and is on the autism spectrum. She also described the wonderful life that Andy has been living as a result of being included in community activities. Ms. Jortner added that she has tried to structure Andy's life so that he is in a large room with many non-disabled peers. Time and time again, this has proven as the best course, not only for Andy, but for many disabled individuals. Although the peers may not be aware of this, they have been Andy's guardian angels throughout his life. Andy has been able to attend school and throughout was always invited at events and parties which made him feel inclusive and part of the community.

Ms. Jortner added that Andy has a job and coworkers that he loves. His coworkers know him and appreciate him. They take the time to teach him new tasks and allow him to do them on his own. This gives Andy a sense of purpose and pride. Although, despite all the support Andy has had, Ms. Jortner expressed her worry that Andy is still vulnerable to manipulation. She added that as a society, we do not see the value in those who take care of our children, our elderly, or our disabled. She emphasized that the caretakers are not paid a livable wage and asked how we can expect them to take care of the IDD community to the best of their abilities considering they are kept below poverty level.

Dawn Lambert, Project Manager, Division of Health Services, Department of Social Services, presented:

Ms. Lambert elaborated on the Department of Social Services (DSS) Community First Choice Program. The program emerged out of the Strategic Rebalancing Plan. It was based on the understanding that actions needed to be taken to build a stronger continuum on the community side so that people would have choices.

Historically, as a result of Medicaid policy, Connecticut has had a stronger focus on institutionalization. Medicaid only provided funds for institutional care, which is considered institutional policy bias, and therefore the State was only able to offer institutional care. Post July 2015, Community First Choice Program became an option under healthcare. It is now considered part of basic healthcare, same as a visit to a primary care provider. An individual must qualify for Medicaid in order to qualify for the program, and any individual eligible for Husky A, C, or Husky D is eligible regardless of age.

Jordan Scheff, Commissioner, Department of Developmental Services, presented:

Mr. Scheff stated that he is here today to provide information on the Department of Developmental Services (DDS) community residential options. Residential options include self-direction, agency based individual home supports, community companion homes, among others.

Self-direction is an approach to service delivery in which an individual and their family have the freedom to develop the support they need to live the life they choose. This allows individuals to design their own support plans, choose the assistance they need, and be the boss of their care by hiring their own staff and controlling their own budget. As of September 2019, over 1,350 individuals are utilizing the self-direction approach.

Agency based individualized home supports allows an agency to provide services and supports to an individual in their own home or their family's home. The supports can assist with improving basic skills, budgeting, shopping, banking and others, and is designed to allow a person to live in their own home or family home. As of September 2019, the Department had over 1,300 individuals utilizing these support services.

Community companion homes are private family homes that provide residence and necessary support services. They offer a nurturing home environment where individuals can share responsibilities, develop relationships, be independent and make their own choices. The homes are licensed by the Department and renewed annually. As of December 2019, there are over 400 licensed companion homes throughout the state.

Individuals or families may wish to pool their resources to create a shared, out of home living arrangement called Continuous Residential Supports (CRS). Each CRS serves three or fewer individuals and can provide 24-hour staff support. The homes are viewed by the Department's Quality and Systems Improvement staff prior to occupancy to ensure standards are met. As of January 2020, Connecticut has over 200 such homes.

Individuals may also utilize shared living. This option offers individuals an opportunity to invite a family member or person with whom they have an existing relation with to live in the individual's home. Living can be developed based upon the individual's specific support needs. Services include support services that assist with acquisition, retention, or improvement of skills related to living in the community. Currently guidelines are being reviewed to increase participation.

Residential services include Community Living Arrangements (CLA) that are operated by DDS regions or private agencies and offer individuals opportunities to live in community housing. CLAs are licensed by DDS and serve six or fewer individuals. Most CLAs are reimbursed through Medicaid. Some are also considered Intermediate Care Facilities for IDD and in addition to being licensed by DDS, they are certified by the Department of Public Health based on federal standards. As of January 2020, Connecticut has over 850 public and private CLAs.

DDS housing initiatives include the Intellectual Disabilities and Autism Spectrum Disorder Housing Program (IDASH). The program is an interagency collaboration to fund the development of mixed use, affordable housing units. Additionally, initiatives include the Housing Innovation Pilot Project with the purpose of establishing and evaluating alternative service models in which individuals who are currently receiving residential services may

move from their existing residential setting, with consent, to a more independent, less restrictive residential setting.

The next task force meeting is scheduled for January 29, 2020 at 1:00 PM in the LOB.