S T A T E O F C O N N E C T I C U T
OFFICE OF PROTECTION AND ADVOCACY FOR PERSONS WITH DISABILITIES
60B Weston Street, Hartford, CT 06120-1551
1-800-842-7303 (toll-free CT only) (V/TTY)
(860) 297-4300 (V) - (860) 297-4380 (TTY)
(860) 566-8714 (facsimile)
www.ct.gov/opapd

Testimony of the Office of Protection and Advocacy for Persons with Disabilities
Before the Public Health Committee

March 18, 2015

Submitted by Gretchen Knauff
Assistant Director

Good Afternoon Senator Gerratana and Representative Ritter. We appreciate the opportunity to testify on **Raised Bill 1088, An Act Concerning Services for Individuals with Intellectual Disability** and thank the Committee for raising this very important bill.

As articulated in the Developmental Disability and Bill of Rights Assistance Act "Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self–determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society." For members of the disability community this means, among other things, making choices for yourself; living in a home of your own; a real job for real pay and the opportunity to be a member of a work community; participating and being valued as a member of your community; freedom to worship and be a member of a faith community of your church.

The Office of Protection and Advocacy for Persons with Disabilities (P&A) is a legally based advocacy organization that works to protect the civil and human rights of persons with disabilities in Connecticut. Since the late 1980s, P&A staff and contractors have provided advocacy representation for C.A.R.C. v. Thorne class members as they moved out of Mansfield Training School and into community settings. For the past 12 years, agency staff and contractors have also advocated for residents of Southbury Training School, including residents leaving STS as a result of the Messier v. Southbury Training School consent decree. The following are lessons learned from our advocacy:

- **A plan to eliminate intermediate care facilities (ICF) and move people with intellectual disability out of institutions and into community settings is long overdue and it is the right thing to do**. The Americans with Disabilities Act and the Olmstead decision affirm the right of people with people with intellectual disability to live in the community with appropriate supports and services. Living in the community provides opportunities for choice, freedom and belonging that cannot be found in an institutional environment.

- **It is possible to close institutional environments successfully –** Fourteen (14) states have successfully closed all intermediate care facilities. Connecticut has the ability to be the 15th state. Let's finish what we started more than 20 years ago when Connecticut

successfully closed Mansfield Training School and the class members thrived as members of their communities. Even today, class members continue to live in their communities having benefitted from twenty years of experience that would not have been possible if they had continued to live in the institution. I have attached a brief story about "Rachel" and her life since leaving Mansfield Training School.

- **The plan to close the intermediate care facilities must be developed with an established closure date for the facilities.** In its current form, Raised Bill 1088 does not call for the closure of the facilities by any particular date. The consent decree in C.A.R.C. v. Thorne included a closing date for Mansfield Training School, allowing families to move forward with the process of planning for properly supported placements in community homes. The Messier v. Southbury Training School settlement does not include a closing date and approximately 200 families are in a holding pattern. These families need a closure date to enable them to move forward with planning a move to the community. P&A respectfully requests that the Public Health Committee amend RB 1088 to include a **closure date of June 30, 2020** for all intermediate care facilities in Connecticut.

- **All residents of intermediate care facilities benefit from placement in community settings.** You have probably already heard many of the fears (see Attachment 2) surrounding deinstitutionalization, such as individuals with severe disabilities cannot be served effectively in community settings and that because of the severity of the disability their lives do not change when they move into the community. The reality is that these fears are myths and the reality experienced by this agency is that everyone, regardless of the severity of disability, can move to a community setting. The lives of Mansfield Training School class members were enriched after they left the training school as they became members of their communities, reunited with families, began living in homes of their own, experienced real work and joined faith communities. Southbury Training School residents who moved as a result of the Messier settlement, have also found success in the community. Attachment 3 is a brief story about Nilda, a former Southbury Training School resident who moved to a new home in the community within the past year.

Thank you again for the opportunity to comment on **Raised Bill 1088, An Act Concerning Services for Individuals with Intellectual Disability.** P&A urges the Committee to amend the Bill to add a June 30, 2020 closure date for all intermediate care facilities in Connecticut. Let's make Connecticut the 15th state to close its institutions!

Attachment 1

Rachel (not her real name)

Rachel was born in 1962 in Manchester, Connecticut. She was placed at Mansfield Training School (MTS) at 2 ½ years old. She had very little family contact during her years at MTS. Her behaviors escalated over time and her quality of life suffered as a result. In May 1991, she moved into a community living arrangement in Coventry, Connecticut.

A move into the community opened Rachel's world in amazing ways. She was able to reconnect with family and explore personal preferences in a manner that was inconceivable prior to the move. Rachel let her staff and family know that she enjoyed being well groomed, dressing up, wearing make-up, nail polish, perfume and jewelry. As her personality emerged, she was able to decorate her own room to her taste and display her wardrobe and possessions. Musical preferences were explored and Rachel became an active member of her household and community.

Most importantly, she was reconnected with her family. She presently continues to visit with her mom and brothers once or twice a month, spending most of the holidays with her family. She is now a member of her mother's church and her pastor comes out and visits with her every two weeks. She is a charming individual who is most often happy and smiling, an amazing difference from the behaviorally challenged young woman who moved into her home in 1991.

Since Rachel's charming personality has emerged, staff respond to her in ways unthinkable when she resided in the institution. They have had jewelry parties at the home, where staff and friends come and share evenings of laughter and shopping. Staff regularly save magazines for Rachel so she can peruse the latest fashions. Mom especially has been made welcome in this environment and is welcomed in her daughter's home. Over the years, mom's regular visits include pizza dinners and movies and, especially, a new found camaraderie with her daughter. Rachel has been included in formal family portraits and is now a present member of her family, for the first time in her life.

Rachel enjoys going to camp each summer and is now able to laugh at jokes and participate in activities with peers. A huge change from the behavioral challenges she faced years ago.

Rachel is a living example of the difference a community placement can make in the life of an individual with severe intellectual disability who is given the chance to be a part of her family and community.

Attachment 2

Deinstitutionalization: Unfinished Business

National Council on Disability Report

October 2012

Excerpt of Myths about Myths and Realities about Deinstitutionalization

Full report can be found at:
http://www.ncd.gov/publications/2012/Sept192012/

Myth 1. Serving "Difficult to Serve" Populations

Statement of Myth

Some institutions must remain open to provide residential and therapeutic services for populations that are the most difficult to serve in the community, including people who are medically fragile, those who are dually diagnosed with ID/DD and mental illness, and those who are involved with the criminal justice system.

Statement of Reality

Eleven states have succeeded in closing all their state institutions and have developed a variety of approaches to provide necessary services and supports in community settings for all populations. These approaches include PCP that integrates ID/DD supports with medical or psychiatric care, crisis teams, short-term stabilization services, and specialized housing.

Myth 2. Severity of Disability

Statement of Myth

People who are currently housed in institutions are more severely disabled than those who live in the community, and no evidence shows that they can be served effectively in the community.

Statement of Reality

More people with extensive support needs are served in the community rather than in institutions, demonstrating that *all* people with ID/DD can be served effectively in the community. While many people in institutions have very significant impairments and will require extensive supports to live in the community, many people with the same level of impairments are already successfully receiving those supports in the community. Many are living with families, with few paid supports.

Myth 3. Cost Comparison by Setting

Statement of Myth

Closing an institution and moving its residents into the community does not save money.

Statement of Reality

The average cost of residential services varies dramatically by type of setting. In 2009, the average annual per capita expenditures were as follows:[i]

- Large state institutions—$196,735
- ICF/DDs (including private institutions and smaller ICF/DD settings)—$138,980
- Home and community-based services—$43,969

On the basis of these figures, it might seem that moving residents from large state institutions to home and community-based services would save more than $150,000 per capita. However, because these figures are average costs calculated across all people residing in each setting, and the average level of need of people in institutions is higher than that of people currently living in the community, the actual savings are somewhat lower and vary significantly by state.

A number of studies show that although community-based services may be more expensive for a small number of people, closing an institution yields cost savings.[ii]

However, there is a risk in framing the deinstitutionalization debate as a cost issue rather than an issue of civil rights and quality of life. Although cost savings can motivate state legislators in the short run, the media may represent the decision as unwillingness to spend funds necessary to care for our most vulnerable citizens.

Myth 4. Funding of Services and Supports

Statement of Myth

The major funding source for services to people with ID/DD are state taxes and local levies. Each state chooses the programs, services, and supports it will make available to people who live in institutions and those who live in the community.

Statement of Reality

Funding for services for people with ID/DD comes from a variety of sources, but Medicaid pays the lion's share. In 2009, Medicaid, with a combination of state and federal dollars, accounted for 76 percent of the $53.2 billion of public expenditures on services for people with ID/DD. The bulk of these expenditures are paid through the ICF/MR program and the HCBS waiver program.[iii] The states' decisions about how to spend funds on Medicaid-eligible people are strongly influenced by Medicaid rules.

Myth 5. Community Capacity and "Waiting Lists"

Statement of Myth

There is no room in the community-based service systems for people who are currently in institutions. Waiting lists are a testament to that reality.

Statement of Reality

People with ID/DD who are leaving institutions are entitled to HCBS waiver program services and supports, which must be made available in the community. The necessary services and supports are identified during discharge planning. Even though almost all states have waiting lists for services, the people who are leaving an institution do not compete with those on the waiting list. Waiver services, including residential supports, can be developed more quickly than institutional care; therefore, once funding is available, services can be quickly put into place.

Myth 6. Benefits of Community Living

Statement of Myth

The lives of people with ID/DD do not change significantly when they leave the institution and move into the community.

Statement of Reality

Life in the community provides the possibility for “freedom, dignity, and a sense of belonging” that is not possible in an institutional setting.[iv]

Myth 7. Institutional Closure and the Impact on the Economy

Statement of Myth

We should keep institutions open to retain good jobs in the small towns and rural areas where many of them are located.

Statement of Reality

People with intellectual and developmental disabilities have a right to live in a setting of their choice; the impact of their choice on the economy of an area that houses an institution is not their responsibility. Moreover, with proper planning, states can mitigate the economic impact of closing institutions.

Myth 8. Mortality

Statement of Myth

People with ID/DD who live in the community will experience higher mortality than those who receive care in an institutional setting.

Statement of Reality

The mortality rate of people with ID/DD is a function of quality of care and the availability and quality of services and supports, not the setting in which they receive care.

This myth is based on a 1998 study by O’Brian and Zaharia that statistically analyzed the mortality rate of people who were transferred out of institutions in California between 1993 and 1999. Their methodology and findings have been discredited by numerous other researchers, who have found no increase in mortality rates as a result of moving out of institutions.[v]

Myth 9. Olmstead and Choice

Statement of Myth

The Supreme Court ruling in *Olmstead* guarantees people the option to choose, including the right to choose an institution.

Statement of Reality

The *Olmstead* decision was intended to ensure that people with disabilities have the right to treatment in the "most integrated setting appropriate to [their] needs." In most of the recent lower court decisions addressing the issue, the courts generally agreed that the ADA's antidiscrimination position does not provide an actionable right to institutional care.

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[i]. Lakin et al., 2010.

[ii]. Stancliffe et al., 2005.

[iii]. D. Braddock, R. Hemp, M. C. Rizzolo, Haffer, E. S. Tanis, and J. Wu (2011). *The State of the States in Developmental Disabilities (8th edition)* (Denver: University of Colorado, Coleman Institute for Disabilities).

[iv]. Gelser, 2010.

[v]. K. F. O'Brian and E. S. Zaharia (1998). Is it Life Threatening to Live in the Community? Commentary. *Mental Retardation*. October 1998.

A Life in the Community

On a rainy morning, the movie, "Heidi," plays on the television in the living room of a group home. Two women watch. Garlands of orange artificial flowers and autumn-themed figures of straw and cloth decorate the windows and walls. Natural light floods the space, which is open and welcoming and clean. One of the women is Nilda, and this is her new home.

Nilda had been placed at Southbury Training School in 1970, when she was in her early twenties and a doctor advised the placement. Until then, she had lived with family members. Her family, constrained by distance and circumstances, rarely saw her. Also constrained was Nilda's institutionalized life, which lacked privacy, enrichment and choice. Even in 2014, she shared a room with three other women.

In March, 2012, a P&A advocate was assigned to work with Nilda and her family. The goal? To find a placement for Nilda in advance of what the family was told would be Southbury's eventual closing. The parents worried at first: Would she be safe? Would she adjust after spending most of her adulthood in an institution? "This would be a new beginning," the advocate said. "I understood their fears." The advocate spoke their language and shared their culture, enabling her to develop a relationship based on shared identity. (Her relationship with Nilda flourished, too, based not only on the advocate's warmth and cultural affinity, but on Nilda's delight that they were both wearing red nail polish at their first meeting!)

Once the family and Nilda agreed, the advocate shepherded the transitional planning, in the process educating both Southbury and group home staff on the cultural components of some of Nilda's behavior. Previously, for example, Nilda had been labelled physically and verbally aggressive when, in fact, her physicality and the pitch of her voice were often just culturally expressive.

The manager at Nilda's new home says that the adjustment period was remarkably swift and smooth. To ease the transition, Nilda visited the group home several times over the course of six weeks, sharing meals and enjoying overnights. After she moved in, staff members worked to relieve her of some of the habits and anxieties that had been generated by institutionalization. She used to take the jewelry and hair ornaments of others; now that she has her own special items, she no longer takes them from other rooms. She is learning to differentiate between friends and strangers, both in terms of offering affection and taking basic security measures. She is less likely to layer clothes – sometimes six articles at a time – because she has learned that her clothing will no longer disappear. Nilda's family, says the manager, "is flabbergasted at how much the group home will work with them," providing transportation for routine visits and holidays. Nilda, recently met a much younger brother for the very first time.

> **"the adjustment period was remarkably swift and smooth"**

Nilda's bedroom – *hers alone* – has a bed covered in a brightly patterned comforter; it is meticulously made, the result of her own daily effort. Inside the room are decorative items on the wall; a closet; a CD player; a TV; and a bureau filled with clothes and personal items, including the many self-made art pieces that Nilda, left to her own devices, would never recycle, give as gifts, or throw away. On the bed, leaning against the pillows, are two dolls, carefully dressed. The house manager playfully lies on the bed, resting against them; in response, Nilda promptly and with good humor pulls the manager off the bed and adjusts the hat on one of the dolls. Just so.

As part of her day program, Nilda works twice a week at Chili's, rolling silverware in napkins in preparation for tables. Once a week, she volunteers at a nature center, watering the plants. Twice a week, she participates in music appreciation events, singing, dancing and trying out instruments. At home, one of her chores, enthusiastically embraced, is to fold her laundry, which she does every morning. She strings beads into necklaces. She participates in the daily dance parties at the house. She is eager to help staff members with household jobs.

On the TV, a monkey is causing major shenanigans, leaping from a chandelier and irritating the villain in the story. Nilda and her friend dissolve into laughter at the slapstick. Two women, completely attuned to the nuances of human emotion, enjoying a movie at home on a rainy day.