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December 31st, 2016

To: Commissioner Murray, DDS

From: Leslie M. Simoes Position: Executive Director

Organization: The Arc Connecticut

Re: Call for Recommendations, Future of Southbury Training School

The Arc Connecticut is a 63-year old advocacy organization committed to protecting the basic civil rights of people with intellectual and developmental disabilities or I/DD and to promoting opportunities for their full inclusion in the life of their communities. We are part of The Arc of The United States and nationwide there are 675 chapters in 49 states with about 4700 service locations. In Connecticut our organization has 18 chapters delivering direct support and services with total revenue of approximately \$103 million dollars

The Arc was started as a grass roots movement more than sixty years ago by parents of individuals with I/DD who wanted a better life for their sons and daughters. At that time there were virtually no community supports and it was common for doctors to tell parents that the best place for their child was in an institution. Like every parent of any child, they wanted more than an a placement in an institution for their children. Advocating for equal rights and full community inclusion is the foundation of our movement. It is what fueled us in our long battle to close the doors of Mansfield Training school and it is what has fueled us ever since in our battle to close the doors of Southbury Training School and led Arc Connecticut to be a lead plaintiff in Messier VS Southbury Training School.

The Arc Connecticut respectfully submits the following recommendations:

Recommendation 1: Governor Malloy Should Use his Executive Authority and Close Southbury Training School Today

The history of living with a disability in the United States has largely been one of discrimination, segregation and exclusion.

Fortunately, today people with intellectual and/or developmental disabilities (I/DD) have the same basic legal, civil and human rights as other citizens. The U.S. Constitution, federal laws, and federal court decisions have established these rights.

However, despite these tremendous advances lack of political will, fear, poor enforcement of the laws, disregard for binding legal precedent, and societal prejudices keep many people with disabilities stuck in institutions and prevented from being fully included in our society.

Sadly our state, progressive in respecting the lives of so many others, is falling behind in the value it places on the lives of individuals with I/DD and intentionally chooses to segregate individuals with I/DD at Southbury Training School (STS) and the five DDS Regional Centers.

Governor Malloy has an incredible opportunity should he choose to embrace it. By using his executive authority to close Southbury Training School he could join 17 other states in the movement to promote the basic civil rights of individuals with I/DD.

The Arc Connecticut is a named plaintiff and is in active settlement agreement implementation with the state of Connecticut in the Messier VS Southbury Training School. After five years of successful implementation of the Settlement Agreement the facts and data show there are numerous compelling reasons to close Southbury Training School (STS). Two of the most compelling are:

- STS staff made determinations for all individuals living at STS as to the most integrated setting appropriate and the results have been statistically consistent. In the last year staff determined that 294 of the 319 class members can be supported in a community setting. For those 25 individuals whom staff indicated that cannot be supported in the community the primary reason given was life-ending, or life-threatening, illness or disease.
- Since the approval of the Settlement Agreement, over 45 individuals transitioned from STS to community living, *all* class members are happy in their new homes and there have been no instances where a guardian or an individual requested to return to STS from their community home.

It is clear by the success of transitioning STS residents into the communities of their choosing DDS knows what to do. However the only obstacle preventing the final transition of the approximately 480 remaining individuals is political will. We did it 30 years ago with the closure of Mansfield Training School; we can do it again in 2016.

There really is no reason to keep STS open. The Governor needs to use his executive authority and close it today.

Recommendation 2: Do Not Do Another Study

There is a large amount of neutral, non-partisan data both in Connecticut and across the country supporting the closure of publically operated ICF's including data from national trends, CT Legislative Reports, Special Legislative Committee reports and Federal Rulings from the Centers for Medicaid and Medicare.

Initiating another study is not only unnecessary but completely irresponsible and excuse to delay closure. A few of the studies and data include:

- 1990 Results of the CARC VS: Thorne Longitudinal study follows individuals that left Mansfield Training School for 5 years and was intended to find out if the class members in CARC VS: Thorne were actually better off in the community. Page 43 of the report linked above shows that the findings support a compelling inference that the class members were much better off in their new community homes.
- A Special Legislative <u>Southbury Planning Committee Report</u> was released in March 1994 to the then DMR commissioner, calling for the closure of Southbury Training School within five years for many reasons. It was not followed. You can read the report in the link above.
- In 1999 the U.S Supreme Court decided the Olmstead v. L.C. Case and affirmed the constitutional right of individuals with disabilities to live in the community as fully participating members of society. That case, decided under the Americans with Disabilities Act, was about equality, and the principle that people with developmental disabilities have the right to be treated as full citizens, and not to be left to live in segregated settings, outside mainstream of society. Yet Connecticut chose not follow this law and kept operating 5 Regional Centers and Southbury Training School.
- Connecticut's own <u>Legislative Program Review and Investigation Committee</u> did
 a study of this very issue in 2011. The committee recommended that
 Connecticut move away from costly publically operated facilities to a private
 sector service model.

This committee also stated that DDS direct care staff could be redeployed to other capacities in the community and as a gradual transition to private services; DDS staff could provide services to individuals at home who are on the waiting list or by providing respite to families. To date, these recommendations have been ignored.

Yet here we are in Connecticut in 2015, where despite being morally and legally discredited, despite the documented success of Mansfield class member transitions and the 45 individuals successfully transitioning out of STS in the last 5 years, Connecticut policy makers choose to continue to operate Southbury Training School and 5 Regional Centers. And despite these recommendations and numerous others, Connecticut chooses to operate these costly settings and starve the private system of resources and let thousands of families stay on waiting and planning lists until their last caregiver dies. In this fiscal climate it is irresponsible for the state of Connecticut to continue this outdated practice not to mention it is morally and ethically reprehensible.

Recommendation 3: Savings Realized By Closing Southbury Training School Should Stay in the DDS System to Serve More Individuals

DDS has a budget of approximately \$1.1 billion - the second highest budget per capita in the country. Despite this, there is no money in the DDS budget to provide residential supports unless there is an emergency. Even with this second highest budget per capita the private provider system has been starved of resources for over 20 years. Outmoded public policy, unnecessary segregation and expensive publically operated programs remain the barriers to balancing the DDS system of support.

A dear friend of mine said "The justice of a system must be measured by how it treats all of those it was intended to serve". Today there are over 2,000 individuals on the DDS Residential Waiting and Planning Lists and these families waiting for services are being told that they will not receive funding for residential supports unless there is an emergency. An emergency is usually defined as the death or permanent incapacitation of the last caregiver, mostly likely a parent.

This friend also said "A system that denies services to thousands of families while at the same time funding costly institutions that were they opened today would be illegal is not a just system". A system that only concerns itself with those who already have services- and has no funding for those who have no services- is not a just system.

A just system would not permit its individuals with I/DD to languish on a waiting list because of a lack of funding, while it continues to spend disproportionate amounts of money to maintain morally and ethically unjust segregated large institutions.

The JUST move is to close these institutions and expensive publically operated facilities and allow DDS to keep the money it saves by the move to less restrictive, less expensive settings. The savings could then be used to support individuals on the waiting list and be given to the agencies in the private sector supporting these individuals that have been underfunded for over 20 years.

Governor Malloy has the executive power to close Southbury Training School TODAY. He needs to use that power and close it now.

Respectfully submitted by The Arc Connecticut Leslie M. Simoes, Executive Director