

Office of Protection and Advocacy for Persons with Disabilities
Public Hearing Concerning Transition
July 25, 2016

My name is Win Evarts. I live in New Canaan, I'm an advocate for my son Nicholas who has a seizure condition and I/DD, and I'm a board member of Disability Rights CT, a nonprofit organization created to become the successor entity for the activities of the Office of Protection and Advocacy for Persons with Disabilities not transitioned to the Department of Rehabilitation Services.

The transition of CT's protection and advocacy system to an independent entity separate from the documented conflicts of interest and competing mandates that presently hamper establishing, protecting and insuring enforcement of the human, legal and civil rights of people with disabilities in CT is welcome. CT needs a strong protection and advocacy system to improve and sustain the quality of outcomes in the state's many service delivery settings for all its citizens with disabilities. A strong P&A system benefits citizens by being a leading information and referral resource and through multiple activities including individual and class representation, legislative and system advocacy, investigation, monitoring, training and education. These activities are best done in accordance with the prioritized expressed needs of Connecticut citizens with disabilities so that the greatest number of citizens benefit. A strong P&A system is transparently governed by a multi-faceted board of individuals with varying disabilities and others who share a commitment to improving the lives of people with disabilities. The leadership of the successor entity should have demonstrated experience in protection and advocacy for people

with disabilities and strong relationships with other disability organizations to enable effective collaboration. The successor entity's staff need to be strong advocates for the civil rights of people with disabilities and have a solid understanding of the DD Act, the ADA, the Rehabilitation Act, IDEA and other laws protecting the rights of people with disabilities. The successor entity needs to empower and support people with disabilities with knowledge and skills to become advocates for themselves and act to promote and support inclusion of people with disabilities in all aspects of community life.

Connecticut's citizens with disabilities need a successful transition of federally funded services from OPA to a successor entity. Many other states have accomplished successful transitions that assured clients of continuous services using a well-established template. Thank you for the opportunity to speak.



CONNECTICUT
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PROJECT, INC.

TESTIMONY FOR PUBLIC HEARING JULY 25, 2016

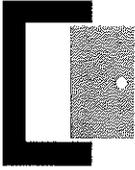
REGARDING CONNECTICUT'S PROTECTION AND ADVOCACY SYSTEM FOR
PERSONS WITH DISABILITIES

My name is Kathleen Flaherty and I am the Executive Director of Connecticut Legal Rights Project, a non-profit law firm which represents low income people with mental health conditions on civil legal matters relating to their treatment, recovery, and civil rights. I also serve on the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Advisory Council, and am a member of the steering committee of the Connecticut Cross-Disability Lifespan Alliance. In addition to being a lawyer, I am also a former client of P&A. The office represented me in filing a Title II ADA complaint against the Connecticut Bar Examining Committee.

Federal law outlines the duties and responsibilities of the agency designated by each state to serve as its protection and advocacy agency with regard to legal representation and other advocacy services. As Connecticut shifts from a state-operated P&A to a nonprofit, it is imperative that the individuals associated with that nonprofit have a full understanding and familiarity with the federal laws under which a protection and advocacy agency must operate. The lawyers and advocates employed by that nonprofit must have an understanding and perspective that reflects an orientation in favor of maximization of legal rights and opportunities for full community inclusion for people living with disabilities. The governor should designate an agency with established connections to all of the various disability communities in Connecticut. Outreach to those communities is required in the priority-setting process, and people with disabilities must have a voice in determining those priorities. You may be familiar with the phrase "Nothing about us without us."

The agency must have the capacity to do the necessary work to protect and advocate for the legal rights of people with disabilities. They should be prepared to operate statewide – and be able to maintain an active presence in facilities that care for people with disabilities. It is only through the ability to monitor conditions in these facilities that adverse conditions can be investigated and a remedy sought to address them.

The agency must have the ability to represent clients in matters regarding education and employment opportunities. Protecting and advocating for clients' legal rights to entitlements, healthcare, and housing will help ensure that Connecticut's disabled residents have access to the services and supports they need to actively participate in our communities.



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July 25, 2016

Testimony of Steven D. Eppler-Epstein, Esq.
Executive Director, Connecticut Legal Services
Regarding Protection & Advocacy for People with Disabilities in Connecticut

Thank you for this opportunity to appear on the subject of the transition of Protection and Advocacy in Connecticut. My name is Steve Eppler-Epstein, and I am the Executive Director of Connecticut Legal Services. We are the largest legal aid program in Connecticut's Legal Aid Network, and we provide services across the state addressing a wide range of legal problems. Our mission is to use the law to protect, benefit and improve the lives of low-income people in our state. As part of that work, we have always represented people with a range of disabilities facing a wide range of legal problems; we have had specific funding and experience working with people with intellectual disability.

We believe that Connecticut would be best served by the designation of a new non-profit Protection and Advocacy agency that is specifically focused on and working with the disability community. Our program is committed to helping serve this community in whatever way would be most effective, and we are committed to continuing our agencies work with the disability community. But for a range of reasons, including both coordination of work and federal administrative compliance, we believe that it is best if a broad legal aid program is not the agency designated as P&A by the Governor. Instead, we believe that the designated Protection and Advocacy agency should be specifically funded and targeted to focus on this work.

We look forward to working closely and collaboratively with the agency that the Governor designates, and to helping with the transition process and future advocacy in any way we can. Thank you for this opportunity to provide input.

July 25, 2016

My name is Sandra Trionfini. I am an attorney in the Waterbury office of Connecticut Legal Services. This testimony is presented in response to Public Act 16-66, requiring Governor Malloy to designate a nonprofit entity to become Connecticut's Protection and Advocacy system.

Since the mid 1980s, Connecticut Legal Services has represented many thousands of people with developmental and intellectual disability throughout Connecticut, including individual clients and the class members of the C.A.R.C. vs. Thorne and Messier vs. Southbury Training School settlement agreements, through contracts with the current OP&A. Since 1990, I have represented many of these individuals within most judicial and administrative forums in the state, including federal and state courts, probate courts and various administrative forums.

As you consider the mission and work of the new OP&A non-profit, I wanted to emphasize the importance of ensuring that those ID/DD individuals continue to have access to advocacy services as part of the new OPA non-profit organization. It is equally important that advocates who are familiar with the special issues presented continue to be active with this work.

ID/DD individuals frequently reside in institutional settings exclusively, for decades. Often, these individuals have aging parents and siblings who require assistance in navigating the systems and structures that their new lives demand. Many of the parents of the individuals are elderly and unable to provide a continuing presence during team processes. Many families live out of state and a significant number of ID/DD individuals are very low-income.

Unique issues faced by ID/DD individuals include accessing community services, integrating into community settings, planning for residential placement closer to families and obtaining appropriate visitation with families and friends. Additionally, ID/DD individuals particularly need access to services

for appropriate end of life considerations, including structuring appropriate guardianships and drafting end of life documents, such as advanced directives.

An example of this involves the recent death of a guardian for an individual who is very high functioning and independent. Advocacy assisted this individual obtain an end to further guardianship, preparation of appropriate advanced directives and end of life planning, including an irrevocable funeral trust and the naming of a health care representative in the event of incapacitation and the opportunity to live in dignity.

Out of state families often need help in representing loved ones through transition processes. Recently, I represented an individual with an aging in state mom and a sibling who resides in California; find a community living arrangement with a private provider agency near to where mom lives. The process included participating in a Request for Proposal solicitation which helped ensure that an appropriate private provider agency develop the residential placement and plan for services. The outcome has been extremely successful and this gentleman is now a member of his new community and happy in his home.

As ID/DD people either remain in institutional placements or become integrated into local communities, it is critically important that they have access to advocacy services to ensure lives with dignity and security. This is particularly true for low-income ID/DD individuals, who are among the most vulnerable populations in Connecticut. Consequently, it is essential that the new OP&A non-profit organization has the ability to ensure that advocacy work is an important part of its mission and that advocates who are familiar with the unique issues and needs of individuals with ID/DD continue with this important work.

Good morning.

My name is John Flanders and I am the Executive Director of the Connecticut Parent Advocacy Center. I am here today because CPAC and the Office for Protection and Advocacy for Persons with Disabilities share a mission, a history, and a legal mandate. CPAC serves as the Parent Training and Information Center (PTI) for the State of Connecticut. Like OPA a PTI is an entity mandated by Federal law to advocate for and support people with disabilities. Because of this shared mission and "DNA" we offer the following testimony

First, I would like to address our shared mission. Together we support families who include children with disabilities in school. This work is vital, and there are already far too people providing this support. Simply put we urge in the strongest possible terms that there be nothing in this process that will result in fewer advocates working for people with disabilities, and in particular for children with disabilities in the state our children cannot afford that.

CPAC's mission is focused on providing support for families that include a child with a disability. As such we are almost exclusively involved with education. In this area both Connecticut State law, and the Federal Law, the Individuals with Disabilities Education Act (IDEA) require that parents be full participants in the team that determines the program that provides their children with special education. Of course that does not always work. Many times families' concerns and input are given short shrift or ignored entirely. Too often their children's needs are unmet. We know because we receive thousands of calls every year from families asking what to do.

The core of our mission is based on the belief that given appropriate training and information that parents can surmount these challenges and be the best advocates for their children. In a given year we provide that support and training between three and four thousand times. Of course it does not work in every case. Every day we talk to mothers and fathers who cannot, despite our efforts, effectively bring their voices into the process. There are many many times when parents simply do not have the means to advocate effectively enough for their children. It may be that the parents' ability to use English is not good enough to advocate effectively, it may be that members of the child's team have set ideas that they will not modify, or it may be a belief that the school lacks the resources to meet that child's needs. Every day we try to direct them to professionals who can join the parents in this process and participate directly in the advocacy. Those resources are already grossly inadequate and already are shrinking. For example as the result of recent budget cuts DDS has been unable to replace its cohort of education counselors to the point where there will be just one for the entire state. OPA is an important resource and if its advocates are also cut the results will do nothing but harm children.

The IDEA provides remedies in situations where parents and their children's schools disagree about the educational program. I'm sure you have all heard stories about "due process" and how difficult it can be for both schools and families. Unfortunately those

remedies rely on an adversarial process, require parents to do most of the work of enforcing their children's rights. There is an old saying that "You can't fight City Hall", but that of course is what the law requires parents to do. That is a tough row to hoe. It was tough for me and I had at least a middle class income, and a law degree. How much harder is it for those with less education, or limited English, or not enough money to afford to hire an advocate or lawyer. OPA serves these people and they simply cannot afford to have that resource taken from them or reduced.

I would like to change tack now because, in addition to our first hand experience with the need for advocacy in the State CPAC also has first hand experience as an independent, no for profit corporation fulfilling a federally mandated role. We are now in our fourth decade being the state's PTI and hope sharing our experience will be helpful in designing the structure to take over OPA.

Unlike OPA, CPAC has never been incorporated in State Government. We have always be an independent entity, run by a Board of Directors, and funded through a combination of Federal Grants, State grants, State contracts and philanthropy. In thinking about our experience two factors seem most compelling to us.

First, the Board of Directors must reflect the population the Office serves. Our enabling legislation requires that a majority of the members of our Board be like the people we serve. That is they must be parents of children under the age of 26 who have a disability. They must share first hand the lives of the parents who receive our training or who call us for help.

The old saw that "there is no substitute for experience" has particular meaning here, and we see it in our work every day. Part of our responsibilities involves participating in a wide range of committees, study groups and task forces who try to improve the services available for students with disabilities. And one of our most important roles in these groups is to ensure that parents get to play a central role in their work. This is not in any way to diminish or discount the role that professionals play. The educators and administrators who also do this work are vital. They bring the scientific professional training that is also integral and no one chooses to make a career working for children with disabilities without truckloads of empathy and concern.

Nonetheless, whenever I bring a mother or father into one of these meetings to describe their experiences the inevitable responses include, "I never really thought about that; I never knew that; and I've never tried it that way."

We are convinced that OPA's new Directors will receive the same benefit from the experience of parents of children with disabilities and from adults who live with those disabilities themselves. We strongly urge that they have the strongest possible role in the governance of OPA.

Similarly, poverty, racial and ethnic differences result in unique challenges. When combined with disability the challenges faced do not just add they reinforce each other

creating little perfect storms of barriers. For that reason we urge you to also ensure the governance of the OPA include a substantial portion of low income and minority participants.

Finally I want to extend an offer. CPAC has spent decades operating as the kind of entity we believe you are trying to create. We want you to be able to use that experience. We want you to see the strengths of our organization and we hope you will be able to learn from and avoid our mistakes. I am offering to work with you in whatever way you think is appropriate, and to offer the support of whomever of CPAC's staff has knowledge and experience that will help. Clearly ensuring that here is an effective OPA is an important reflection of our mission, as well as our hopes for the people of the state.

Thank you.



STATE OF CONNECTICUT

COUNCIL ON DEVELOPMENTAL DISABILITIES



Testimony on the Critical Components of an Office of Protection and Advocacy Submitted by the CT Council on Developmental Disabilities July 25, 2016

My name is Shelagh McClure and I am chair of the CT Council on Developmental Disabilities. Thank you for the opportunity to present our views on the future of the Protection and Advocacy system in Connecticut.

The Office of Protection and Advocacy (OPA) is funded under the federal Developmental Disabilities and Bill of Rights Act of 2000. It is part of the larger DD Network—which includes the Connecticut Council on Developmental Disabilities and the University Center for Excellence in Developmental Disabilities at UConn. As one of the members of that network, we on the DD Council believe we have a distinct perspective on what qualities the reconstituted OPA should possess. And since our federal funding is directly linked to funding for the Protection and Advocacy system, we have a vested interest in seeing a strong OPA in our state that will allow for continued funding from the Administration on Developmental Disabilities to both the OPA and the DD Council.

First and foremost, the entities funded under the DD Act are partners in a network that works with and on behalf of people with disabilities. That foundational principle—that OPA is part of a larger network—must continue to be recognized as a fundamental cornerstone of the OPA as it is reconstituted.

OPA has collaborated with its DD Network partners through the years, as directed by the DD Act. Current collaborative projects cover a broad range of issues important to individuals with disabilities and includes:

- The 2020 Campaign to close the 5 remaining State-operated institutions for individuals with intellectual disabilities. We believe that people with disabilities can live good lives fully integrated the community, while receiving high quality services and supports. This campaign is dedicated to moving the remaining approximately 440 residents by the year 2020 to high-quality, community-based homes. OPA is one of the original 2020 Campaign sponsors.
- OPA staff acts as faculty each year for the Partners in Policymaking leadership training course. Annually, Partners in Policymaking training teaches 25-30 self-advocates or family members of individuals with disabilities various leadership skills to assist them in better achieving their goals and advocating for themselves or their family member. Over the years, we have trained over 300 Partners to be leaders and advocates.

- OPA has been a partner in support of the Cross Disability Lifespan Alliance, which brings together different disability groups to collaborate on issues of common interest, including legislative issues at the Capitol. We have learned that together, our voices are stronger and more effective.
- The DD Network and other partners are currently working to expand the availability of Customized Employment opportunities for people with disabilities in CT through a customized employment certification initiative.

The transition to a private non-profit OPA must be smooth, with no disruption of services and supports to the individuals currently seeking services through the OPA. Frankly, we believe that the risk of disruption could have been minimized had the decision been made to simply privatize the existing entity, rather than shifting to another non-profit through a selection process. Nonetheless, the DD Council is committed to supporting this smooth transition in whatever way we are able.

It will be critical that the new OPA will be able to fulfill both its "protection" role and its "advocacy" role. As the State budget crisis erodes services for people with disabilities in Connecticut, it will be more important than ever that OPA is adequately staffed and understands its role in the protection of the civil and human rights of people with developmental disabilities, and that it can operate independently from any state agency. It will need legal staff that are skilled in litigation. In addition, the P & A must have resources to advance complex litigation, when necessary, on behalf of those with disabilities in this state. Other essential components include:

1. A strong Board of Directors, with effective, independent and ethical leadership, and consistent with the requirements of the DD Act, well connected to the disability community, and committed to the mission of protecting the civil rights of people with disabilities in Connecticut. The Governing Board must be well supported to fulfill their functions.
2. P & A is a leader in the disability rights movement in the state. As such, their priorities, activities and initiatives must be reflective of the needs of people with disabilities in the Connecticut. Staff must ensure that the agency has adequate resources to protect and advocate for the civil and human rights of people with disabilities in CT, maintain independence from service providing agencies and meet all the federal requirements of a P & A.
3. P n& A must have the ability to maintain a client directed focus, supporting the choices of the individual with a disability and protecting their civil rights. Additionally, this agency must promote public awareness, visibility and access to the program through ease of access, both physical and through social medial, internet and other technology.
4. The P & A must have the ability to be accountable to the people represented by the OPA.

Equally important, OPA must be a strong advocate for those with disabilities—a visible and active presence in the disability community. It must have well-trained staff that can act as a source of information and referral, and that can navigate the complex state and federal regulatory maze. It must have or develop strong ties to state and federal offices and office holders. It must be a trusted voice on disability policy.

We believe that an independent OPA is a better course for Connecticut than its current status as a state agency. Even so, it is important to ensure that it has protection and advocacy for people with disabilities as its primary, if not exclusive focus.

Thank you again for this opportunity. If the Council on Developmental Disabilities can be of further assistance in this transition process, do not hesitate to contact us.

Shelagh McClure, Chair
CT Council on Developmental Disabilities

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My name is Alexandra McGee and I'm president of the CT Council Organizations Serving the Deaf (CCOSD). CCOSD represents 24 different affiliate organizations that are of, for and by the deaf people of CT.

The Office of Protection and Advocacy will be changed from a State agency to non-profit next July, 2017. The CCOSD and deaf community value OPA because they depend on OPA lots for supporting general disability, deaf and deaf/blind. OPA has been very supportive of the deaf community and CCOSD. OPA supported lawsuit some hospitals for interpreters and access to movie theaters with closed captioned. OPA understands about the disability and deaf community.

When a new Director is chosen to for that new non-profit (P & A) want to make sure that a new person must know and be familiar with the deaf community and work cooperatively with us. I feel this is very important that OPA continue their support and advocacy for the deaf community.

Thank you,
Alexandra McGee
CCOSD President
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Public Comment Regarding Connecticut's Protection and Advocacy System for Persons with Disabilities
7/25/2016

Thank you for the opportunity to comment on this matter today. I am Stan Soby, Vice President for Public Policy and External Affairs at Oak Hill, providing supports and services to thousands of Connecticut citizens and their families in over 125 programs across the State.

We firmly believe that there are non-profit advocacy entities that could successfully become the P&A system for Connecticut's citizens with disabilities. We say this based on experience with existing advocacy organizations within the State and in research that indicates all but 4 states and 1 territory currently have an independent P&A system.

Our support of moving in this direction is not a reflection of the work of those at Connecticut's OPA, but a reflection of the national landscape based on Public Law 106-402, the Developmental Disabilities Assistance and Bill Of Rights Act of 2000, and, now, Connecticut PA16-66.

As part of our review of the DD Act, we are lead to ask the question whether the bifurcation of the Protection and Advocacy functions in PA16-66 is, one, best practice and, two, consistent with the language of PL 106-402 at Subtitle C, §143a.2.G., as it relates to the re-location of the Protective function to the Department of Rehabilitation Services (DORS).

We are concerned that the split of functions between two entities unnecessarily introduces the potential for communication gaps that will have an impact on the health, safety and well-being of people with disabilities.

§143a.2.G seems to indicate that, in order to receive the Federal allotment, the P&A system must be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities. While DORS may currently have engagement with a limited number of people with Intellectual or Developmental Disabilities, the number will grow significantly with the implementation of the requirements under the Workforce Innovation and Opportunity Act (WIOA) (PL 113-128). This may pose a conflict.

In response to the specific request for comments from OPM, we would suggest the following would help increase the chances of a successful transition and go-forward.

1. Having a contracted funding amount that would cover the cost of providing the P&A services that the State has deemed necessary.
2. Having the ability (see #1 above) to hire the necessary staff with the appropriate credentials and experience to provide both the Protective and Advocacy services.
3. Having one set of definitions and criteria that apply to the protection of all persons with disabilities, regardless of that disability, whether they receive state-supported services through a particular State Department or not, much as is being proposed by Senator Chris Murphy in his Developmental Disability Improvement Act, that are adopted, in whole, by each State Department.
4. That a uniform electronic incident reporting process be used for more timely reporting and review of incidents, particularly those deemed 'critical', with, again, a uniform definition across State Departments; this, in part, in recognition of the findings of the Office of the Inspector General with respect to the Department of Developmental Services.
5. That this electronic reporting/records system be compliant with federal standards to ensure the records are accessible through the Health Information Exchange to mandated reporters.



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6. That there is clear statutory language for the P&A system to have access to records, including the ability to issue subpoenas, in order to be able to fulfill its mission.
7. That funding is made available to provide an on-line, competency-based abuse and neglect prevention education program free of charge to persons with disabilities, support services providers and mandated reporters, and required for the latter two groups as part of initial or continuing education or training.

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**Testimony regarding
the State Office of Protection and Advocacy for Persons with Disabilities:
Legacy and Next Steps
July 25, 2016**

Undersecretary Foley and other esteemed members of this panel:

My name is Cathy Ludlum. Like many of my colleagues with and without disabilities here today, I need to speak out about the positive impact the State Office of Protection and Advocacy has had through the years. I am sure that many of us will also be making recommendations to preserve as much of the spirit and functionality of P & A as possible when creating its private nonprofit successor.

Being objective about P & A's impending closure will be difficult for me.

In 1986, as a recent college graduate, I wandered into P & A looking for work and opportunity. I found both, and in an abundance I could not have imagined. With no exaggeration, I can trace nearly every good thing that has happened in my life back to this important place. For 24 years I have been living in my own home, hiring 100% of my own support staff, working as a consultant around disability issues, and participating in the vibrant and growing disability community.

While P & A did not make these things happen directly, they came out of a new awareness and connections with people I met through that office. I met some of my closest friends there, and through them met others who have been key to my success.

P & A provided a rich environment where ideas were planted and connections were made. I understand the arguments for and against privatization. The phrase "conflict of interest" has surfaced. It is important to keep in mind, however, that for decades P & A performed its core duties of information, referral, and advocacy effectively and with integrity, in spite of its place within state government.

It also provided a central point for meetings that were the genesis of many important initiatives. Any time the disability community raised a difficult issue, P & A could be counted on to promote the interests of people with disabilities and fledgling advocacy groups.

The closing of P & A (with no legislative hearing and little opportunity until today for input from the disability community that will inevitably be harmed) is a profound loss.

But here ends my eulogy. We must move forward.

(Over, please)

I strongly urge the Office of Policy and Management, the Department of Administrative Services, and others involved in selecting or creating the new protection and advocacy office to incorporate the following:

- The disability community cares deeply about what will happen to the extensive knowledge, structures, and programs P & A has developed and administered throughout the years. Reinventing the wheel is never a good move. Please pack up as much as you can of what P & A has created and bring it with you to the new entity.
- The disability community is relying on you to ensure that our rights are protected. We will be watching closely as you invite proposals, choose a successor, and develop a process for making a smooth transition from one entity to the other. Whether you choose an existing nonprofit or create a new one, the civil rights of people with disabilities must be first on its agenda.
- Proposals should come from people with extensive experience in disability advocacy, who are respected within the disability community, and have focused on civil rights over many years. People who have participated in the national disability rights movement, and especially the National Disability Rights Network, should receive extra points.
- The new organization needs to have a grasp of the diversity within the disability community. People with different disabilities have different experiences and needs. The new agency will need to understand the importance of the cross-disability movement: meeting specific needs while bringing diverse voices together.
- The governing board should include people with disabilities in leadership positions, and it must be diverse in other ways. In addition, however, a majority of its members should be experienced with serving on boards. The board has the responsibility of ensuring the well-being of the organization, and needs people who have these skills.
- The new agency needs to demonstrate its capacity around management issues, such as budgeting, personnel, purchasing, and so on. A new startup without enough qualified leaders and staff will not be equal to the task.
- P & A has many dedicated and capable staff members. They deserve our appreciation, and should not be summarily dismissed. In some other states where protection and advocacy agencies have become private nonprofits, some of the staff from the former state agency were brought into the new entity. Not to do so would deprive the new P & A of critical knowledge. I strongly encourage you to open the way for current staff (if they choose) to join the new entity without loss of salary and state benefits, and with the additional costs being absorbed by the state. I understand the importance of living within a budget, but our rights are worth this investment.

Thank you for the opportunity to speak today. Although I am deeply distressed by the loss of P & A as it has been, I am cautiously hopeful that something of value can arise in its place. This can only happen, however, if protecting and advancing the civil rights of people with disabilities is your *first priority* and that of the private nonprofit you will choose.



**Testimony Regarding
The Office of Protection and Advocacy for Persons with Disabilities
July 25, 2016
By Leslie Simoes, Executive Director, The Arc Connecticut**

Thank you hearing my testimony on the preservation and enhancement of the vital services offered by The Office of Protection and Advocacy for Persons with Disabilities.

My Name is Leslie Simoes and I am the executive director of The Arc Connecticut. The Arc is a 63-year old advocacy organization committed to protecting the basic civil rights of people with intellectual and developmental disabilities and to promoting opportunities for their full inclusion in the life of their communities. We are part of The Arc of the United States. Nationwide there are 675 chapters in 49 states with about 4700 service locations. Across the country we have about 6900 board members, 124,000 staff, more than 46,000 volunteers and collectively we serve more than 1 million people - individuals with intellectual and developmental disabilities or I/DD and their family members.

Here in Connecticut our chapter's total revenue is about \$103 million dollars. There are more than 195 board members, 3,729 staff and more than 1,288 volunteers.

The Office of Protection and Advocacy (OP&A) is funded under the federal Developmental Disabilities and Bill of Rights Act of 2000, the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. It is one of three agencies funded by the act here in CT which include: The Connecticut Council on Developmental Disabilities, The University Center for Excellence in Developmental Disabilities at UConn and The Office of Protection & Advocacy. All three agencies serve an equally important and critical role in supporting the community-based delivery of services to persons with developmental disabilities in creating and enhancing opportunities for independence, productivity, and self-determination.

Under the act, OP&A is specifically charged with the vital role of pursuing legal, administrative, and other appropriate remedies to protect and advocate for the rights of individuals with developmental disabilities.

The OP&A network is the largest provider of legally based advocacy services to people with disabilities in the United States. OP&A's serve individuals with a wide range of disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems.

The Arc believes strongly that the vital role OP&A plays in the lives of people with intellectual and developmental disabilities in Connecticut can actually be strengthened with the transition from state agency to an independent non-profit provided the following occurs:

- OP&A must be adequately staffed and understand its role in the protection of the civil rights of people with developmental disabilities.
- OP&A must have a legal staff that is skilled in litigation. In addition, the agency must have resources to advance complex litigation, when necessary, on behalf of those with disabilities in this state.
- OP&A must be a strong and trusted voice on disability policy. It must have well-trained staff that can act as a source of information and referral, and that can navigate the complex state and federal regulatory maze.

The Office of Policy & Management and the governor's administrative leadership including the Liaison to the Disability Community has an incredible opportunity to support the transition of a vibrant and strong private OP&A system in Connecticut. The Arc is strongly invested in ensuring a successful transition and will assist in any way we can to ensure that happens.

Respectfully submitted on behalf of The Arc Connecticut

Leslie M. Simoes
Executive Director

-----Original Message-----

From: Patti Wilson [<mailto:lifefreepah@gmail.com>]

Sent: Friday, July 29, 2016 4:56 PM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Cc: Lisa Flaherty-Vaughn <lisaflahertyvaughn@gmail.com>; Joseph Ronan <jokerboy985@gmail.com>; Norita Weston <nmweston5@icloud.com>; Colleen LeBlanc <clleblanc07@gmail.com>; Steven Heron <duckyman40@sbcglobal.net>; Sandy Inzinga <SandyInz@comcast.net>; Barbara Cassin <bjcola@comcast.net>; Sandra McGee <patriotlady@cox.net>; Hayles, Colleen <Colleen.Hayles@ct.gov>; Cote, Elizabeth <Elizabeth.Cote@ct.gov>; tbedard40@aol.com; cthandsandvoices@gmail.com

Subject: Public Hearing OPA 07/25/2016 at LOB

David Guttchen
Office of Policy and Management
450 Capitol Avenue
MS#52LTC
Hartford, CT 06106

PUBLIC HEARING OFFICE OF PROTECTION AND ADVOCACY (OPA)

Good Morning. This is Patti Wilson of Newington. I'm an activist for Deaf Grassroots Movement (DGM) of Connecticut (CT). DGM CT was established on April 7, 2016 by following NATIONAL DGM RALLY on May 4th during CT's Legislative's last day of work at that day. We were asked to change a day. Unfortunately we had to follow 45 out of 50 states' National DGM RALLY at our homes' State Capitols - our rally at North Steps in Hartford, CT.

Other activist from Enfield, her name is Lisa Flaherty Vaughn. Representative (REP), She could not be able to come to public hearing. She took a full week leadership seminar at Gallaudet University in Washington, D.C.. She returned home today by train and bus by herself independently. Lisa is President, Deaf Blind (DB) Association of Connecticut (DBAC), and also, BESB Board Member.

Lisa, Joseph Ronan, West Haven, Assistant Rep. and over 75 activists had first rally to fight for our Deaf Equal Rights: Communication Access, Education and Jobs.

We all Deaf, DB, DD (Development Disability) and HOH (Hard of Hearing) use a beautiful visual gestural language, American Sign Language (ASL) everyday.

America's third language in usage of ASL is expanding in U.S. First language is spoken Spanish, and second language is spoken French in America.

Deaf community would not disenfranchise our deaf blind using tactile sign language. Also, with other populations' needs.

In Year 2012, Connecticut Law was passed: Deaf Child's Bill of Rights (DCBR) effective July 1, 2014. Since four years, we did not know how many Deaf, DB, DDD, and HOH children in private and public schools. How we know what Local Education Areas (LEAs) follow students equal rights for their Communication and Language Plans at PPT Meetings. We concern many of them being alone and be deprived their communication access for their current BEST Deaf Education!

We praised OPA for great services. It is important to include Deaf Advocacy at new agency. New director and staff need to take a training, "Understanding Culture through Search DEAFHOOD". Please do not disenfranchised.

Thank You Very Much.

Note: please watch CONN ASL NEWS clicks at <http://americandarn.com/connaslnews/index.html>

From: roselle weiner [<mailto:reallyrosy@gmail.com>]
Sent: Monday, July 25, 2016 4:40 PM
To: Guttchen, David J. <David.Guttchen@ct.gov>
Subject: Opa comments

I was at the session this a.m. re: "NOTICE OF PUBLIC HEARING
AND
REQUEST FOR PUBLIC COMMENT
REGARDING
CONNECTICUT'S PROTECTION AND ADVOCACY SYSTEM
FOR PERSONS WITH DISABILITIES
Public Act 16-66 .

I wish to follow up with written comment. When i moved to CT for 1975/76 school year, i found i could not support myself on \$7,500 teacher salary from ASD [American School for the Deaf]. So i took a part time job as a detailed billing report clerk at Day, Berry, and Howard. I worked 25 hrs more per week but it was at night and weekends. I often found myself alone during these times and there was no visual warning system to alert me nor could i use the voice phone to call for help. So, i got a hearing dog to assist me at those times. The law was clear about it but DBH did not want the dog in their offices. I thought i would have to give up both jobs but people steered me to OPA and after a rather extended period we prevailed on DBH to settle this case in my favor. OPA also advised me how to respond to challenges from ASD.

If not for OPA help, i would not have continued to reside here. Jobs for deaf people are few and far between. Teaching was the love of my life and i was bound and determined to make a go of it. Thank you, OPA, for making me a full class citizen with all the rights and privileges pertaining - - *almost*.

There is still so much more to accomplish in this area. And it is imperative that the transition team be aware of all of the various needs and ways that our rights are curtailed. That is why i wanted to follow up my comments. Thank you again for preparing this forum and for realizing that we need a transitional period and for allowing us to pursue living in my chosen state, CT.

Roselle Weiner
12 vandervere road
West hartford, ct 06117

I am a member of the CT Assn. Of the Deaf and I volunteer on the board of Communication Advocacy Network. I am the retired [2011] librarian and elementals school teacher at ASD.

From: michael lonergan [<mailto:mikelonergan53108@sbcglobal.net>]

Sent: Sunday, July 24, 2016 10:54 AM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Subject:

I am writing in request for public comment regarding the Ct's Protection and Advocacy system for persons with disabilities.

I am not in favor of the privatization of the Ct's Protection and advocacy for two reasons:

1.) As a state employee once had to go to P&A for consultation regarding a personal ADA issue. Because of their state status, advocates there were very helpful in assisting me, more than any other agency.

2.) I also have had the opportunity to recommend P&A advocates to assist people in recovery when working with non state funded agencies when working with disability issues. The advocates state status seemed to help extremely when working with these agencies, it was their state status that gave them the ability to open doors that they may not have been able to with they were private funded.

It's not easy doing advocate work for people with disabilities, let alone counting on grant money and statistics to validate that spending. People with disabilities need flexible and knowledgeable assistance when seeking legal / advocate assistance when facing life quality issues in the community. State funded Protections and Advocacy staff can do that, give them the means to be effective. There are other places in state contracts that can produce the savings that would replace the projected savings from P&A. Look at 1199 over time usage and policies, for example.

Thank you for your time, I hope this information is helpful.

From: hanouvae@comcast.net [<mailto:hanouvae@comcast.net>]

Sent: Sunday, July 24, 2016 11:36 PM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Subject: written comments (OPM)

Parties Involved: City of New Haven, New Haven Police, New Haven Federal Courthouse, Yale Hospital, Atty. John Williams. I am Deaf. On top of that, I also have cataracts, which makes reading difficult for me. In all the incidences involving this situation, all three parties refused to provide a sign language interpreter for me. I requested an interpreter several times, both by gesturing and in writing. The city officers who came originally refused to get an interpreter, then finally brought in a 10-year-old girl to interpret, along with the city office. I asked them to get a qualified interpreter and not use this young girl, who knew very little ASL. When they came to arrest me, they did not provide an interpreter and I did not know why I was being arrested. I had a panic attack and fainted. I was taken to the hospital for heart issues: there, I was handcuffed to the bed rails and could not communicate. The hospital and police officers did not provide an interpreter until 10 hours later and when they did, they limited what she could tell me. they limited the time I could use the interpreter. After I was released, instead of take me home like I thought, the police forced me into a van without any explanation and took me to jail. At this point, I still did not even understand what was going on. At the jail, they did not provide an interpreter and did not tell me why I had been arrested. there was no interpreter. In court, I was provided with a qualified interpreter. However my lawyer also refused to provide an interpreter and force me to use interpreting services provided by Life-Bridges in Bridgeport, which provides free interpreters for the Deaf. He charged me for the time to travel to use the interpreter at this center. All of these incidences are violations of the ADA. The ADA guarantees me the right to effective communication and I did not get this. AS a result, I had to get rid of two vehicles and my boats. On top of that, I now struggle with PTSD and am seeing a counselor. I am also on medication to regulate my heart condition, which was exacerbated by this situation. The ADA also says that covered entities must provide effective communication by a qualified interpreter.

This whole incident was so badly handled. I should have never happened and I should never have suffered though the barbaric, disrespectful treatment caused by the arresting Officers, Being hearing impaired my rights were totally violated. I was entitled to an interpreter, this is by federal

law. To not be able to explain my story of language barrier and make a call to someone was cruel and unforgivable. This is terrifying to think it could happen again to me or to some other deaf person.

Vincent Valanzuolo
182 Norton Street
New Haven, Conn. 06511

(203) 764 2445

From: Lisa Lessard [<mailto:914transparentfaith3@gmail.com>]

Sent: Monday, July 25, 2016 12:03 AM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Subject: **** Department of Rehabilitation Services Interpreting Unit CLOSED. AND Closing of Advocacy for People with Disabilities. STOP these DIRECTIVES... YOU are HURTING the DISABLED within our State.****

JULY 24th 2016: Pass out too all involved in Office Policy and Management Division.

I, being a PARENT, am (Special Educational Advocate and a Disabled Adult) AGAINST THESE FOLLOWING DIRECTIVES, being put FORTH in our State. A.) Through D.)

A.) Department of Rehabilitation Services, D.O.R.S., American Sign Language Unit CLOSED. JULY 15TH 2016.

B.) State Agency, of Advocacy with Disabilities with People with Disabilities.

C.) Taking away from adult children with their Independent Living.

D.) And taken away from services for the blind.

This is taken away from the most vulnerable population individuals in our State.

***** I am HIGHLY AGAINST these DIRECTIVES being put forth. *****

1.) Besides me, being a Special Educational Advocate and also being a Disabled Adult. I am a loving mother, of a special educational student, in transitional schooling, whom is a disabled adult child.

2.) My adult child is profoundly deaf, both ears. And depends on American Sign Language Interpreters through her schooling and her internship jobs. And is a adult child working with the help of Department of Rehabilitation Services Interpreting Unit.

****Since July 15th 2016. My adult child has NOT had American Sign Language Interpreter through her schooling, or at her job internship placements, or in her schooling. My adult child has lots of medical appointments and there was no availability for American Sign Language Interpreters, at those doctor appointments period. ***** Also those doctors do NOT have Marty the computer. My child's hearing aide was broken and getting fixed. Her cochlear implant, was being looked at by a specialist. My daughter, had NO way of understanding what was happening: with in her schooling, job placement, nor doctor appointments.

***** By LAW under Title II of the American with Disability Act, effective communication is suppose too be given too the deaf individual needing an American Sign Language Interpreter.

Under law effective communication is NOT having too write back and forth. **** Example: Who can read a doctor's hand writing ????? Usually a pharmacy has too call the doctors office too interpret the doctors hand writing. And two, whom has that time too have that happen???? Says doctors office for they have a lot of patients they need too see. Writing back and forth takes a lot of time. (doctors exact verbiage)

A parent, is also, NOT under law effective communication. The parent is the parent, and should not be a translator in a situation of any sort !!!!! Plus a parent, is NOT certified NOR registered too make it a legal interpreting situation. That would be: at a doctor's appointment, schooling environment, Emergency Room, Hospital room, Pre Opp for Surgery, Nursing Home situation. Medical anything. In a Court House, Department of Children and Families situation. Crises situation in mental Health Facilities, Juvenile Court situations. Car accidents or Ambulatory Situations. Making a long, American Sign Language story short. Individuals that are deaf have had a HORRIBLE TIME with ASL services, since July 15th 2016.

3.) This explains it the best: Governor Dan Malloy made a Executive decision too close the Department of Rehabilitation Services, American Sign Language Unit.

June 29th 2016 there was a protest in Hartford Connecticut. Deaf community, coming together, with the hearing and speaking community. Showing solidarity towards justice of their communication skills.

Governor Dan Malloy office aide Travis said, "this directive is a done deal, there is nothing you or the deaf community can do about it." "Deal, WE are saving the tax payers State dollars." I asked if there was a plan in place for our deaf community and told, "there is NO PLAN in place, by this office" .

As I researched I found out this directive goes against Title II of the American Disability Act. And is discriminatory towards deaf individuals Civil Rights.

July 15th 2016, D.O.R.S., A.S.L., Unit will no longer be open. And deaf individuals will NOT have registered, certified A.S.L., interpreters. Which translate or can give interpretation skills for this community. Places such as: work places, doctors office's, Emergency Rooms, car accidents, schools with in our State, police stations, or court situations as ALL will be affected. Where a certified and registered Interpreter is needed under laws presently written.

211 information has ONE other A.S.L., agency listed for Services. Which is over burdened already and does not take Emergency anything on the weekends, except hospital situations. So this is not a choice for any deaf person period.

In closing Governor Daniel Malloy, in my opinion, sees deaf individuals as walking dollar signs. And not individuals that need too be able too communicate with the world around them, so can live their lives as we all do.

Deaf community has a workable solution! Stay tuned, for WE can not count on State Government, WE will make a workable solution for all in our deaf community.

SHAME ON THIS GOVERNOR! WE the Deaf community in this State are deaf and proud! Deaf and loud! Shouting for justice.

Everyone, call your Representative and Senators. HELP the DEAF COMMUNITY VOICES BE HEARD!!! Together, WE ALL, can make this difference. Individuals in this State that are Deaf are suffering by the hands of this Governor total Adiministration Directive.

4.). Two days after, I contacted, the Agency of Advocacy with People with Disabilities. TWO DAYS LATER, I found out that agency was next on the Governor's chopping block. This agency helps fight for and with the most vulnerable population, in this State. Fight with the laws at hand under American with Disability Act. Too get equal opportunities within this here State under law.

5.). Independent Living... my child and other children are fighting daily too be all they can be with in our community's. I know, my child, is working harder than hard, so can work and be all she can be. Too be independent and live within our community. As a well formed individual and pay state taxes through a job. Wants too NOT be a burden on anyone and be as Independent as her life skills will allow her too be with in her working environment and housing placement. Which taken money away here, is stunting the growth of any work placement possible. Or making independent living a reality period, too become a dream come true for my or any child in this circumstance.

6.) Services for the Blind. You are taken away services of people whom depend on these services. NOT because a LUXURY but because they can NOT see the world around them. And need too learn how too work around their blindness, with learning tools, so can work with and around the blindness. So they can be all they can be. So they can live and be all they can be.

***** Example: my child vision is 20/400 both eyes, without glasses, that means, she is LEGALLY BLIND.

So my child is deaf, needs ASL Interpreter. Is legally blind without glasses. Working and will graduate high school at age 21, trying too learn all can. So can be as Independent as can be. So can get a job, and pay taxes in this state. *****

+++++. All the above will hinder these factors and put a halt too her becoming all she can be, too get that job and pay taxes in this State. ++++++ How do I know this, for it is ALREADY HAPPENING.

7.). I would ask for Office and Policy and Management too reverse these directives above. And stop seeing the disabled in this State as walking dollar signs. And seeing their daily communication skills as being a luxury. And not way one speaks with the world around them.

8.). I, myself, am a loving and caring mother, of an adult child, whom is a very hard worker. All that has seen her work says, she is a workaholic and strives for the stars and any employer would be lucky too have her in their placement. *** However, you taken her communication skills away, her means of independent living skills away. And making her struggle throughout will make her life I'm possible too succeed in her adult life, period!!!! Or anyone in the same circumstances.

*** Think how MANY Disabled LIVES you HAVE IN YOUR HANDS???? And are DESTROYING with these DIRECTIVES from this Governor's office of Governor Dan Malloy Office?????. ***

9.). Only, reason, I am not at this vital important hearing, is I am disabled. In a wheel chair. Not able too walk. After a life changing injury, I accounted, during running in a special election for a seat in the House of Represanatives, with in our State. A foot of major hardware. Where my ankles used too be on one side. Which I unfortunately broke both ankles on one side. And sprained both ankles badly on other side. A bionic foot, which is now perminate, for the rest of my life. And I am trying too learn how too walk again. I have been a special educational advocate for now nineteen years and now living in the disabled world, for the rest of my life. All because, I have a love for my extended family within my city and State. Shame on this State going after this most vulnerable population.

10.). The disabled in this State need help and services too grow and prospure and be all they can be. The deaf in the State are Deaf and Proud. Loud and Proud. Fighting for Justice.

11.). My adult child wants too be there. However, wants too be at work. Wants too keep her responsibilities too her employer. Which is a internship placement but, is reality of what will need too do in the real world. And doing her best too succeed.

12.). Help our disabled community you literally have their lives in your hands. And YOU, will be responsible for ALL: that are HARMED OR HURT, or in some CASES SUFFER HEALTH WISE with these directives being or becoming a reality. Even some shall die for will NOT have the communication skills needed too stay alive at doctors and Emergency situations.

God bless, and God HELP US ALL ... And do the right and ethical stance for all disabled in this State.

Parent, hurting for our disabled in this State.

Thank you. Conneticut Parent and adult child.

From: C Kerwick [mailto:colleen_kerwick@yahoo.com]

Sent: Monday, July 25, 2016 12:33 AM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Cc: Scott Buden <sbuden1@gmail.com>

Subject: Invisible Disabilities

Dear Mr. Guttchen:

I am an attorney at law, duly admitted to practice law before the Federal Courts of the State of Connecticut.

I have a diagnosed disability as a result of being a survivor of coercive control by proxy of my exes abuse of the Family Court. While the Judges of the Superior Court provide me with ADA accommodations, last week Family Relations appeared ill equipped to facilitate my disability and, indeed, triggered it before I had to present in court. Education and training in ADA is needed.

Enclosed please find my contemporaneous sketch of the occurrence and my motion to clarify my ADA accommodations.

I hope this helps!

Colleen

PS: I am willing to volunteer to help your committee, if you need an extra legal mind.

2. On March 18, 2016 Mothers application for accommodations under the Americans with Disabilities Act for PTSD was granted by the Honorable Court (*Kevin Diadamo, Clerk of the Hartford Family Court*).

3. On April 13, 2016 the Honorable Court (*Suarez, J*) denied Fathers motion to modify the order of the Honorable Judge Quinn that he pay for Mothers therapy. It is noteworthy that Father has not paid a nickel to Mothers therapist since the date of that order despite acknowledging receipt of her invoices.

Accommodations under the Americans with Disabilities Act

4. Mother appeared in court on July 20, 2016 on her motion to enter an order regarding specifics of international travel. Mother asked Father’s attorney (Campbell Barrett) if Mother’s ADA Advocate (Philip J Mays LMFT, GAL) could sit with her to accommodate her disability. Campbell Barrett said “no”.

5. Mother entered a room with Ken Savino, Campbell Barrett and Family Relations (Claudia Maxwell). Campbell Barrett started talking about Mother “going on the run” on the day of the “Amber Alert” as a reason to not permit international travel. This was the same courthouse in which Ken

motion, plaintiff injected noise into the proceedings so that the only thing to emerge was the recommendation of a GAL who testified that she spoke to Father and his counsel 18 times and to Mother zero times in the interim as the hearing was strategically continued through January 24, 2014. It appeared that she changed her opinion from joint custody to supervised visitation after Mother testified against GALs before the Task Force on Family Court Reform. Custody was restored after a Trial of the Action specifying the detail of the scam before the Honorable Judge Quinn.

Savino, Campbell Barrett and his protégé Jon Kukucka had reported the “Amber Alert”, which caused Mother to lose custody of her son for eleven (11) months.

6. Mother feared the worst and temporarily lost all faith in the system which allowed this miscarriage of justice to happen. Mother grabbed her papers and stood up to leave the room. Claudia Maxwell pressed the panic button, but when security arrived she said “we are okay” and no intervention was necessary.
7. The incident which triggered Mothers PTSD in advance of the afternoon session before the Honorable Court (*Suarez J*), could have been avoided had Mother moved to clarify her ADA accommodations in advance.

Memorandum of Law

8. Title II of the ADA provides, in relevant part, that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132. Coverage extends to all programs, services, and activities of a state and its agencies, “without any exception.” *Pennsylvania Dep't of Corrections v. Yeskey*, 524 U.S. 206, 209 (1998).

9. The Department of Justice (DOJ) and The Department of Health and

Human Services (HHS) have specifically confirmed that Title II of the ADA and the Rehabilitation Act applies to everything the court does. The DOJ and HHS' regulations must be 'given controlling weight' and their interpretations of those regulations "are entitled to substantial deference." *Blum v. Bacon*, 457 U.S. 132, 141 (1982); *Toyota Motor Manufacturing, Kentucky Inc. v. Williams*, 534 U.S. 184, 195 (2002) *superseded by statute* ADA, § 4, 122 Stat. at 3554.

10. Title II of the ADA abrogates the immunity generally enjoyed by states and their agencies, such as Family Court. *See U.S. v. Georgia*, 546 U.S. 151, 159 (2006); *Garcia v. S.U.N.Y. Health Services Center of Brooklyn*, 280 F.3d 98, 112 (2001); *See Henrietta D. v. Bloomberg*, 331 F.3d 261, 287 (2d Cir. 2003); *Garcia v. S.U.N.Y. Health Services Center of Brooklyn*, 280 F.3d 98, 112 (2001). This court has an obligation to uphold federal law as the sovereign law of the land, ensuring equal protection, including *Hughes v. Rowe et al.* 449 U.S. 5, 101 S. Ct. 173, 66 L. Ed. 2d 163, 49 U.S.L. W. 3346.

WHEREFORE, it is respectfully submitted that, going forward, Mother be accommodated for her Post Traumatic Stress Disorder by not being required to be in the same small Family Relations room as Father and his counsel

without her ADA Advocate or a support person present and/or that Family Relations see Mother and Father separately.

Dated: July 22, 2016

Colleen Kerwick-Savino

CERTIFICATION

This motion was served via electronic mail on Plaintiff' counsel Pullman & Comley on July 23, 2016

Colleen Kerwick-Savino

SUPERIOR COURT OF THE STATE OF CONNECTICUT
COUNTY OF HARTFORD

-----X

KENNETH D. SAVINO
Petitioner

HHD-FA11-4057497S

HON. JUDGE SUAREZ, Presiding

-AGAINST-

COLLEEN KERWICK SAVINO
Respondent

JULY 23, 2016

-----X

After due consideration, the within motion to clarify is:

GRANTED/ DENIED

From: MF Moyer [<mailto:mfmoyer53@gmail.com>]

Sent: Monday, July 25, 2016 11:09 AM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Cc: Sen. McLachlan, Michael <Michael.McLachlan@cga.ct.gov>; Rep. Arconti, David <David.Arconti@cga.ct.gov>; Zavagnin, Amanda <Amanda.Zavagnin@cga.ct.gov>; LUISA SOBOLESKI <lsoboleski@snet.net>

Subject: Public Hearing by OPM on 7/25 at 10:00

To the Office of Policy and Management (OPM),

Thank you for the opportunity to provide input regarding Connecticut's new Protection and Advocacy (P&A) system, as designated by Public Act 16-66.

As a Deaf resident of Connecticut, I feel it's very important that the new P&A system be knowledgeable about the wide variety of issues confronting Deaf and Hard of Hearing individuals and also be able to quickly and successfully advocate for the needs of Deaf and Hard of Hearing, especially after other avenues have been exhausted.

For example, the Interpreting Unit of DORS was recently abolished as a cost-saving measure. However, concerns currently exists among many Deaf and Hard of Hearing people of Connecticut that state money may not actually be saved and also that the quality of interpreters which now must be obtained through non-state agencies may be significantly lowered.

I would like to see the new P&A system as a place where Deaf and Hard of Hearing individuals and organizations can bring these and other valid concerns and as a place providing effective protection and advocacy when concerns can not be resolved.

Thank you again for providing me with this opportunity to express my concerns.

Sincerely,

Mary M. Silvestri
Danbury, CT



CONNECTICUT
LEGAL
RIGHTS
PROJECT, INC.

TESTIMONY FOR PUBLIC HEARING JULY 25, 2016

REGARDING CONNECTICUT'S PROTECTION AND ADVOCACY SYSTEM FOR
PERSONS WITH DISABILITIES

My name is Kathleen Flaherty and I am the Executive Director of Connecticut Legal Rights Project, a non-profit law firm which represents low income people with mental health conditions on civil legal matters relating to their treatment, recovery, and civil rights. I also serve on the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Advisory Council, and am a member of the steering committee of the Connecticut Cross-Disability Lifespan Alliance. In addition to being a lawyer, I am also a former client of P&A. The office represented me in filing a Title II ADA complaint against the Connecticut Bar Examining Committee.

Federal law outlines the duties and responsibilities of the agency designated by each state to serve as its protection and advocacy agency with regard to legal representation and other advocacy services. As Connecticut shifts from a state-operated P&A to a nonprofit, it is imperative that the individuals associated with that nonprofit have a full understanding and familiarity with the federal laws under which a protection and advocacy agency must operate. The lawyers and advocates employed by that nonprofit must have an understanding and perspective that reflects an orientation in favor of maximization of legal rights and opportunities for full community inclusion for people living with disabilities. The governor should designate an agency with established connections to all of the various disability communities in Connecticut. Outreach to those communities is required in the priority-setting process, and people with disabilities must have a voice in determining those priorities. You may be familiar with the phrase "Nothing about us without us."

The agency must have the capacity to do the necessary work to protect and advocate for the legal rights of people with disabilities. They should be prepared to operate statewide – and be able to maintain an active presence in facilities that care for people with disabilities. It is only through the ability to monitor conditions in these facilities that adverse conditions can be investigated and a remedy sought to address them.

The agency must have the ability to represent clients in matters regarding education and employment opportunities. Protecting and advocating for clients' legal rights to entitlements, healthcare, and housing will help ensure that Connecticut's disabled residents have access to the services and supports they need to actively participate in our communities.

July 25, 2016
Re: Public Act 16-66

Susan Skipp MeD,
Certified Forensic Disability Specialist and pending certification of ADA Advocate
via John Jay College of Criminal Justice
Litchfield, Connecticut
2035091585

I a certified teacher with professional certification (more than ten years experience) and, I am a person with disabilities. One of my disabilities and also the most debilitating that affects every aspect of my life was incurred via actions the State of Connecticut Judicial Branch, its employees actors, vendors, suppliers, contractors, etc. I will not discuss much about this issue as it is traumatic, but this legislature needs to be aware of the responsibilities of the Office of Advocacy and Protection, the federal funding obligation that accompanies it, the responsibilities of each actor for the state of Connecticut – including its legislature. Some of the of these obligations are easiest illustrated by me using my own examples. I filed complaints with CHRO and numerous times since 2011 with the Office of Advocacy and Protection. It is a wholly negligent entity for the majority of citizens it should serve. Most of these pages concern laws and responsibilities that must be considered in the state's selection of non-profit organization to replace the Office of Advocacy and Protection.

The non-profit should not be used to create more opacity, keeping the public in the dark about the State's rampant violations and its taxpayers in the dark about the looming financial devastation that will happen because of these rights' violations the state makes daily. One only needs to consider being a student in a classroom and the obligations a school makes. For example, Zero tolerance on bullying isn't because kids commit suicide, it is to enforce the school as a title II entity- same with nearly any State of Connecticut governmental function, it is to cover their liability under 42 USC 12203.

This legislature and the public needs to understand: **It is clear that the same reforms that have occurred in the institution of American Education will undoubtedly take place in the American Legal system. 42 USC 12101-12213 clearly defines this State's obligations.** The emphasis being that reforms not made and mitigations unmade incur incremental harm those victimized by rights violations as well as incremental increases of the liability of state entities. The selected non-profit cannot be used to abdicate the State of Connecticut's unmitigated harm. So rampant are the violations, a small example is in the notice of the hearing concerning PA 16-66:

The Public hearing notice about Pubic Act was released Friday July 22, 2016:

Public Act 16-66 requires Governor Malloy, no later than July 1, 2017, to designate a nonprofit entity to be Connecticut's Protection and Advocacy (P&A) system that will replace the Office of Protection and Advocacy for Persons with Disabilities, which will be abolished by law on July 1, 2017. Public Act 16-66 also requires the Office of Policy and Management (OPM) to issue a Request for Information to solicit information from nonprofit entities as to their capacity to be Connecticut's P&A system.

This notice was released July 22, 2016, yet the last paragraph ends with this:

Please contact the Office of Protection and Advocacy for Persons with Disabilities at least 5 business days before the hearing at (860) 297-4307 if other accommodations (material in large print, assistive listening systems, etc.) are needed. Please refrain from wearing scented products to the hearing."

Perhaps it is the assumption that people with disabilities have visible disabilities. People have invisible disabilities. Does the State only consider invisible disabilities as Schizophrenia according to the judicial branches abysmal training on the interacting with the public under ADA or are people with invisible disabilities are cognitively impaired and not notice a hearing to be held on the 25th was announced on the 22nd- and asked to give five days for to have accommodations? The accommodations offered are only helpful to a small percentage of the population's means for most effective communications. What about people whose disabilities may need other reasonable accommodations to participate and have effective communication? I for one do not have effective communication in this exact process for this exact hearing regarded to above.

How does anyone have access to the hearing date if they do not go on the internet? What effective communication does the State of Connecticut really have in place if it does not even give notice for the people needing accommodations time to ask for them?

Is it standard business practice to give ONLY one full business day for notice of public hearings or is the state of Connecticut substantially altering its business practices for its own protection? Yet when a citizen or litigant makes and reasonable accommodation request, that accommodation (and no cost to the state) is routinely denied to the advantage of the State of Connecticut and the disadvantage of the citizen or litigant?

The OPM is already altering its practices to the harm of the disabled and implies the office has no plans to accommodate, or provide no access to programs, services, public participation for ALL in Government processes. 42 USC§ 12101et al is quite clear.

Second, each entity must have an ADA Coordinator. In short, each entity is responsible for its own evaluation and enforcement. The stickers are meaningless.

The ADA Coordinator is responsible for coordinating the efforts of the government entity to comply with Title II and investigating any complaints that the entity has violated Title II. The name, office address, and telephone number of the ADA Coordinator must be provided to interested persons. **Who is the ADA coordinator responsible for mitigation of my family's harm in UWY FA 10 4022992-s by Six years of violations and damages. The judicial branch has made no attempt to follow and apply the state and federal laws to my son, daughter and me. When will this happen? Right now would be great albeit six years too late.**

I was diagnosed by a judge with “an undiagnosed mental illness” and my children were removed from my custody, and I have not had a means of accessing them OR THE COURT to mitigate this. No jurisdiction existed for the court to remove custody, certainly no jurisdiction existed for a judge to act outside of capacity without any mental health training or licensing to make any diagnoses. This is unlicensed practice of medicine. Please forward Lynda Munro's actions to the state's attorney for prosecution. I have direct knowledge of at least 12 other cases with the same issues.

The State of Connecticut has segregated and isolated my children from me and me from my children. Judicial employees, actors, vendors and suppliers all colluded to violate our rights for unjust financial, political or social enrichment.

Third, I would like to know who is going to be liable for the Office of Advocacy and Protection for the State of Connecticut's negligence to my family?

Who is going to MITIGATE THE HARM AND ENSURE NO FURTHER HARM to my family that is six years ongoing? What enforcement is Connecticut Office of Advocacy and Protection going to use to mitigate its gross negligence in my complaints resulting from UWY FA 104022992-s? **Regulatory references: 28 CFR 35.105-35.107; 35.150(c) and (d).**

II-8.1000 General. Title II requires that public entities take several steps designed to achieve compliance.

If a public entity identifies policies and practices that deny or limit the participation of individuals with disabilities in its programs, activities, and services, when should it make changes? Once a public entity has identified policies and practices that deny or limit the participation of individuals with disabilities in its programs, activities, and services, it should take immediate remedial action to eliminate the impediments to full and equivalent participation. Structural modifications that are required for program accessibility should be made as expeditiously as possible but no later than January 26, 1995. From The

Americans with Disabilities Act Title II Technical Assistance Manual Covering State and Local Government Programs and Services
II-8.0000 ADMINISTRATIVE REQUIREMENTS

When does the Office of Advocacy and Protection, the State of Connecticut and the State of Connecticut Judicial Branch plan to follow this regulation in regard to my family- many others' too, but my son and daughter have been without a mother for five years.

What needs to happen in all state offices is education on effective communication, universal design and non-discriminatory practices that show up in the very announcement of this public hearing.

For an example, I am a teacher. It is my responsibility to identify issues and attempt to differentiate instruction so all have access to education. If a student is having trouble reading- my perception is the child is having trouble reading, I would make a record or my interventions before referring to a specialist. That is the FIRST and MOST stressed: liability for schools which are title II Entities as defined by the Americans with Disabilities Act, Americans with Disabilities Amended Act, ADA/ADAAA2008.



Perhaps a graphic is effective communication for some to understand how badly the State harms its most vulnerable citizens.

Connecticut's branches of Government appear to have a myopic and dismissive attitude towards people with disabilities. For example, if one looks at all of the education reform, from Section 504 of the Rehabilitation act of 1973, IDEA Sheff V O'Neil, PJs Law, Connecticut's own statutes including and not limited to:

CGS §46a- 58(a) prohibition against deprivation of civil rights on the basis of religion, national origin, alienage, color, race, sex, blindness or physical disability

CGS §46a-64 prohibition against discrimination and segregation in places of public accommodations on the basis of race, creed, color, national origin, ancestry, sex, marital status, age, lawful source of income, intellectual disability, mental disability, or physical disability,
CGS §46a-62a Discrimination against families with children prohibited
CGS §46a-69 Discriminatory practices by state agencies prohibited
CGS §46a-71 (as amended by public Act 01-28 non-discrimination in services provided by state agencies on the basis of race, color, creed, sex, marital status, age, national origin, ancestry, intellectual disability, mental disability, learning disability)

CGS §46a-76(a) (as amended by public Act 01-28
Non-discrimination in allocation of state benefits on the basis of race, color, religious creed, sex, marital status, age, national origin, ancestry, intellectual disability, mental disability, learning disability or physical disability
CGS §53-37b deprivation of a person's rights and privileges by force of threat
CGS §46a-68-32 through 46a-68-74 Agency Affirmative Action Plan Regulations
CGS 46a-68j-21-66a-68j43
CGS §46a-68k-1 through 46a-68k-8
GCS §46a-56(d)-1 through 46a-56(d)-7 Contract Compliance regulations
Executive order no 9 Governor William A. O'Neill- Affirmative action compliance mandated a top priority for state agencies
31 CFR –part 51 non-discrimination by revenue sharing recipients

It is clear that the same reforms that occurred in the institution of American Education will undoubtedly take place in the American Legal system. 42 USC 12101-12213 clearly define this State's obligations.

Next the State of Connecticut needs to make this successful in a way accounting the enforcement of both federal and state laws. This is paramount because I really don't think too many people understand the significance of federal funding the state receives and uses if for services in direct opposition to the State of Connecticut's own laws and OVERRIDING FEDERAL laws.

ENFORCEMENT

Concurrently, those required self evaluations **self evaluations** that each agency is to do and really reflect on their practices- what would criteria be for a particular agency to violate ADA/ADAAA2008? What are ways they deny people access, effective communication and participation in the service or program?

A critical, but often overlooked, component of ensuring success is comprehensive and ongoing staff training. What is the judicial branch's self-evaluation concerning my case? It has been in front of The State's Supreme, Appellate and Superior Courts, the Judicial Branch's administration, Elliot Solomon, Sandra Lugos Gines, Martin Libbin, Patrick Carroll, Debra Kulack, etc, the rules committee, tabled for a separate session with an ADA consultant last year- the Judicial Branch cannot claim ignorance, nor can it use that excuse to ignore its damage to my family that is again obligated to mitigate and cause no further harm. Who will take over for the

Office of Advocacy and Protection for that? Lack of rulings in favor of my children and myself are by no means indicators that wrongs didn't happen.

Public entities may have good policies, but if front line staff are not aware of them or do not know how to implement them, problems can arise. It is important that staff -- especially front line staff who routinely interact with the public -- understand the requirements on modifying policies and practices, communicating with and assisting customers, accepting calls placed through the relay system, and identifying alternate ways to provide access to programs and services when necessary to accommodate individuals with a mobility disability. Many local disability organizations, including Centers for Independent Living, conduct ADA trainings in their communities. The Department of Justice can provide information. In my classroom, I am the front line. It is my job to make instruction, content and education accessible to ALL students via UNIVERSAL design. Certainly I have far more students with invisible disabilities than visible ones.

Each branch of government should provide a detailed list of how they have not given access, how they have not made communication effective and have not made programs and services accessible in their self evaluations.

Mission statements should be re-evaluated: here's an IDEA:
http://www.healthiersf.com/ExCELAAfterSchool/Resources/Technical-Assistance/documents/Online_SFUSD_ExCEL_Guide-1.pdf

Short list on a multi volume set:

Judicial Branch, court support services objective function, its way of maximizing a profit base is through violating ADA/ADAAA2008-

Family relations practices have been illegal since January 2009. The Connecticut Family, juvenile and probate Courts and often times criminal too, are also run as if they earn money via rights denial.

If the state of Connecticut were a classroom, and disabled citizens who have reading disabilities come in, The State of Connecticut, its employees, vendors, contractors, suppliers and contractors routinely YELL at the citizens, litigants, clients, etc. for not knowing how "to read." (Or whatever other perceived disability the State Actors ascribe.)

This is evidenced in family court as this legislature is well aware: 42 USC 12203 prohibits intimidation, coercion, interference, and retaliation. The business venture franchised through the judicial branch (association of Family and Consolatory Courts (AFCC) for thirty years is illegal forwards their own programming, is paid to train with their training and leaves out experts. The recent Connecticut's response to Children of Domestic violence was a fail. How many children and adults with PTSD or ongoing complex trauma were on that panel, a common disability resulting from domestic violence? How many experts? Were experts heeded? NO and many forms of DV were not even addressed in fact our own domestic violence redress violates ADA/ADAAA2008. Baby Aaden? How about putting an abuser in a small room with a victim? Violates prohibition of coercion, intimidation, interference and retaliation. However, these are

the very tactics employed to garner federal funding, state funding and citizens' assets regardless of federal protections.

Nearly every agency deriving large amounts of federal funding instead of fulfilling their obligations of making sure that disabled, that includes perceived disabled, do not have the experience of retaliation, interference, coercion, and intimidation. DCF, Family courts and probate courts would cease as a cottage industry- and rightly should.

For helpful services please refer to this link, it applies to the state of Connecticut as a title two entity. Change "student" to "litigant," "citizen," "client" etc. Change "school," school district," "principal," etc. to state of Connecticut employees, actor, suppliers, vendors contractors, including but not limited to attorneys who are vendors in courts, suppliers who are mental health "experts" used in courts, etc.

<http://www.snipsf.org/wp-content/uploads/2011/08/v2010Inclusion-Tool-Kit-Sept-update1.pdf>

The History of the The Office of Advocacy and Protection:

P&A agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities (based on a system of priorities for services). All P&As maintain a presence in facilities that care for people with disabilities, where they monitor, investigate and attempt to remedy adverse conditions. These agencies also devote considerable resources to ensuring full access to inclusive educational programs, financial entitlements, healthcare, accessible housing and productive employment opportunities.

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CAP agencies (many of which are housed within P&A offices) provide information and assistance to individuals seeking or receiving vocational rehabilitation (VR) services under the Rehabilitation Act, including assistance in pursuing administrative, legal and other appropriate remedies.

National Disability Rights Network (NDRN)

(NDRN is the nonprofit, voluntary membership association for the P&A and CAP agencies. Collectively, the network is the largest provider of legally based advocacy services to people

with disabilities in the United States.) Just a suggestion.

There are eight separate P&A programs all described briefly below, in order chronologically based on when they were created.

- PADD (Protection and Advocacy for Individuals with Developmental Disabilities). PADD is the first P&A program, created by the Developmental Disabilities Assistance and Bill of Rights (DD) Act of 1975. P&A agencies are required by the Act to pursue legal, administrative and other appropriate remedies to protect and advocates for the rights of individuals with developmental disabilities under all applicable federal and state laws. The DD Act provided for the governor of each state to designate an agency to be the P&A and to assure that the P&A was, and would remain, independent of any service provider. Most entities designated as P&As are private non-profit organizations created specifically for the purpose of conducting the P&A programs. However, some P&As are part of state government, a few are hybrid quasi-public agencies, and a few P&As reside within civil legal services programs. Subsequent P&A statutes, with a single exception (CAP), provide for the new P&A programs to be housed within the same agency designated by the governors under PADD.
- CAP (Client Assistance Program). CAP was established by the 1984 Amendments to the Rehabilitation (Rehab) Act. Services provided by CAPs include assistance in pursuing administrative, legal and other appropriate remedies to persons receiving or seeking services from state rehabilitation agencies under the Rehab Act. A CAP agency may provide assistance and advocacy with respect to services that are directly related to employment for the client or client applicant. CAP is the only program that does not require the funds to go to the entity designated as the P&A under PADD.
- PAIMI (Protection and Advocacy for Individuals with Mental Illness). The PAIMI Program was established in 1986. The P&As are mandated to protect and advocate for the rights of people with mental illness and investigate reports of abuse and neglect in facilities that care for or treat individuals with mental illness. The Act was subsequently amended to allow P&As also to serve individuals with mental illness who reside in the community.
- PAIR (Protection and Advocacy for Individual Rights). The PAIR program was established by Congress under an amendment to the Rehabilitation Act in 1993. PAIR programs provide for services to persons with disabilities who are not eligible for services under the three previously established P&A programs (PADD, PAIMI, and CAP). With PAIR, the P&As were thus authorized to serve persons with all types of disabilities. Although PAIR is funded at a lower level than PADD and PAIMI, it represents an important component of a comprehensive system to advocate for the rights of all persons with disabilities.
- PAAT (Protection & Advocacy for Assistive Technology). The PAAT program was created in 1994 when Congress expanded the Technology-Related Assistance for

Individuals with Disabilities Act (Tech Act) to include funding for P&As to assist individuals with disabilities in the acquisition, utilization, or maintenance of assistive technology devices or assistive technology services through case management, legal representation and self advocacy training.

- PABSS (Protection & Advocacy for Beneficiaries of Social Security). The PABSS program was established in 1999 when the Ticket to Work and Work Incentive Improvement Act (TWWIIA) was enacted into law. Under this Act, grants to the P&A programs provide advocacy and other services to assist beneficiaries of Social Security secure or regain gainful employment.
- PATBI (Protection & Advocacy for Individuals with Traumatic Brain Injury). The PATBI program was created in 2002 to provide protection and advocacy services to individuals with traumatic brain injury. Although P&As often served such individuals under PAIR, CAP, or PABSS, this grant provides more resources specifically to address the unique needs of this population.
- PAVA (Protection & Advocacy for Voting Accessibility). The PAVA program was established in 2003 as part of the Help America Vote Act of 2002 (HAVA). Under this program, P&As have a mandate to help ensure that individuals with disabilities participate in the electoral process through voter education, training of poll officials, registration drives, and polling place accessibility surveys. P&A agencies may not use PAVA program funds for litigation. There is no such restriction in any of the other P&A programs.

Special Investigatory Authority of P&As

The PADD and PAIMI statutes provide the P&As extraordinary investigative access authority. P&As have:

- Routine access to all individuals with developmental disabilities in facilities providing services.
- Access (within 3 days of request) to all records of individuals with developmental disabilities and other records that are relevant to conducting an investigation
 - When the individual is a client of the P&A and the individual (or a guardian) authorizes such access
 - When the P&A receives a complaint regarding the treatment of an individual or if, as a result of its monitoring activities, there is “probable cause to believe that such individual has been subject to abuse or neglect” and the individual, because of mental or physical condition cannot authorize access and there is no guardian, or the guardian is the state, or a non-state guardian does not respond to the P&A’s offer to assist.
- Immediate access (within 24 hours of request), without consent from another party, to all records in the event of a death, or if the P&A determines there is “probable cause to believe that the health or safety of an individual is in serious and immediate jeopardy.”

A number of state laws give their P&As additional authority for example requiring facilities to report deaths and/or other types of incidents directly to the P&As.

P&As often face resistance to their efforts to investigate abuse and neglect, and numerous cases have been brought by P&As to enforce their access rights. P&As can take a variety of actions in response to findings of abuse and neglect and usually try a combination of steps. They may litigate to enforce constitutional and statutory rights of facility residents individually or as a class action; they may issue public reports describing their findings and recommending corrective action; they may develop cooperative protocols with facilities for monitoring and making improvements; and they may provide technical assistance to facilities and self advocacy training for individuals with disabilities.

Federal Administrators

Each of the P&A programs is separately administered by the federal agencies listed below. The P&As prepare annual performance reports for each of the eight programs and the federal agencies monitor the P&As through these reports and through on-site monitoring visits.

- PADD and PAVA are administered by the Administration on Developmental Disabilities (ADD), located within the Administration for Children Youth and Families (ACYF) at the U.S. Department of Health and Human Services (HHS).
- CAP and PAIR and PAAT are administered by the Rehabilitation Services Administration (RSA), at the U.S. Department of Education (Ed).
- PAIMI is administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), at HHS.
- PABSS is administered by the Social Security Administration.
- PATBI is administered by the Health Resources and Services Administration within HHS.

Enabling Laws:

See appendix

Please be mindful that a non-profit in this context would not have the same status as non-profits in relation to FOIA, financial transactions, this is not possible. The State of Connecticut cannot subvert, delegate or diffuse its responsibility or accountability of the Rights of People with Disabilities to any entity. The State of Connecticut is and has been responsible for its own compliance and negligence thereof, and with in the family, probate and juvenile courts- egregious violations. DCF is as harmful as the judicial branch. The Office of Advocacy and Protection has done neither, and the accountable parties are the administrators of each agency for each branch of government. This is a laundry list of agencies in violation, and the water should not get any murkier: it should be transparent.

Susan Skipp

CONNECTICUT LEGAL RIGHTS PROJECT, INC.

Kirk W. Lowry, Legal Director
P. O. Box 351, Silver Street, Middletown, CT 06457
Telephone (860) 262-5017 • Fax (860) 262-5035
Email: klowry@clrp.org

July 25, 2016

David Guttchen
Office of Policy and Management
450 Capitol Avenue, MS#52LTC
Hartford, CT 06106

Re: Resignation of OPA to Nonprofit Legal Services Organization

Dear Mr. Guttchen

I am the legal director of the Connecticut Legal Rights Project, a statewide legal services organization that represents people with low income and mental health conditions. From 2003 to 2008 I was the legal director of a protection and advocacy organization in Kansas. The nonprofit protection and advocacy agency in Connecticut should meet all the requirements of federal law and the recommendations of the National Disability Rights Network. Moreover, the entity should have an attorney as the executive director with the ability to attract, hire, and retain quality attorneys with litigation experience in civil rights cases. The nonprofit P&A should have a strong proportion of attorneys to paralegals. In my experience, clients want knowledgeable, experienced, loyal, independent, zealous attorneys to represent their cause.

CLRP is willing to help out in any way we can during this transition process.

Yours truly,

s/Kirk W. Lowry
Kirk W. Lowry

July 25, 2016

Mr. David Guttchen, MSW
State of Connecticut Office of Policy and Management
450 Capitol Avenue, MS#52LTC
Hartford, CT 06106

Andrew Bate, MSW
33 Mechanic Street Unit 112
Windsor, Connecticut 06095

Dear Mr. Guttchen:

Thank you for the opportunity to comment on Public Act 16-66, which in pertinent part, abolishes the State of Connecticut Office of Protection and Advocacy for Persons with Disabilities, (P&A) effective July 1, 2017. In the interest of full disclosure, I work for P&A and have done so since 2006. In my opinion, the first characteristic that a nonprofit must have in order to be an effective Protection and Advocacy System agency, is a demonstrated record of systems change efforts within state agencies. For example, if an entity identifies the fact that the state of Connecticut Department of Social Services is not providing accommodations to its clients, the nonprofit entity should have a demonstrated record of pursuing an agreement to provide such accommodations. The Raymond v Rowland settlement intended to do just this. However P&A was not the lead agency in pursuit of that settlement agreement. P&A staff and management knew about individuals not receiving accommodations they needed in order to obtain benefits such as Medicaid, yet P&A did not take the lead role in attempting to change the practices of DSS to better accommodate persons with disabilities. In short, I believe the nonprofit entity should have a demonstrated track record of being the lead change agent with regard to systems change efforts.

This may sound elementary, but the designated nonprofit entity in my opinion, must have a demonstrated history of successful operation in these difficult economic times. First, a common refrain that I often hear at P&A is “We cannot help everybody” and “We do not have the capacity to assist at this time.” While not exclusively the case, this is particularly true in cases involving special education where the cases are all research and staff intensive. In SFY 2015, our own annual report shows that P&A was funded by the state with approximately \$2.3 million dollars. Our Federal allocation was approximately \$1.5 million dollars. The new nonprofit will have to function without any state funding. My understanding is that Gretchen Knauff the P&A Assistant Director, Molly Cole, Director of the Connecticut Developmental Disabilities Council, and Nancy Alisberg, Managing Attorney of P&A have incorporated Connecticut Disability Rights, with the goal of assuming the duties of the existing state agency. While I appreciate the services of all of these individuals to the citizens of the State of Connecticut, all of these individuals have a background primarily in state employment. The nonprofit sector is more competitive than ever, and it will be difficult for a newcomer to navigate this environment.

In all the areas I have mentioned here, the existing legal aid agencies have performed with excellence. They do have to prioritize, but I do believe that they maximize the resources given to them. They do have a fixed capacity for cases but I believe that the threshold for nonprofit entities experienced in providing legal aid is much higher. While Governor Malloy has ultimate authority in designating the new Protection and Advocacy System agency for Connecticut, I

would urge him to consider selecting a group of people that have extensive legal aid and nonprofit experience, or an existing entity that provides these services already. Finally, my understanding is that the Governor will be designating a selection panel to recommend the nonprofit entity that is designated. As a person with a disability, and an individual that has a comprehensive understanding of issues across a variety persons with disabilities, I would like to offer my services.

Thank you for your time and consideration, in the event that anyone has any questions about this testimony, or require more information, I can be reached at 860-967-1959.

Andrew Bate MSW

Public Response To The Office of Policy and Management Regarding Public Act 16-66

presented by Cheryll A Houston, Deputy Director
of the Southwest Regional Mental Health Board

July 26, 2016

Members of the Office of Policy and Management,

My name is Cheryll Houston (resident of Fairfield) and I am writing to you today as the Deputy Director of the Southwest Regional Mental Health Board (SWRMHB). The Regional Mental Health Boards were designed to represent the community's voice: our Catchment Area Councils bring together consumers of mental health and supportive services, their family members, service providers, and appointed representatives of the towns we serve

As a result of Public Act 16-66, the Office of Protection and Advocacy for Persons with Disabilities will be abolished and a non-profit organization will operate the state's protection and advocacy system and client assistance program.

We strongly endorse this decision, believing that people with disabilities in Connecticut need and deserve a strong advocacy system that focuses solely on their best interests.

The CT Office of Protection and Advocacy is currently charged with representing and protecting the rights of

people with intellectual and developmental disabilities, mental illness, physical disabilities and traumatic brain injuries, as well as those in vocational rehabilitation programs.

Under the Office of Protection and Advocacy's current structure, however, the state agency has competing mandates that hamper the protection of the civil, legal and human rights of people with disabilities.

One of the most widely discussed examples of conflict of interest involved the Office of Protection and Advocacy's responsibility to approve requested building exceptions of the handicapped-accessible rule. This is problematic because an agency dedicated to advocating for people with disabilities should not need to weigh the needs of disabled people against the needs of building owners.

As an advocacy organization dedicated to serving people with mental illness, the Southwest Regional Mental Health Board has seen firsthand how vulnerable a population with disabilities is when confronted by individuals and businesses with predatory interests, and we firmly believe that a strong system of protection must be in place to advocate for and protect the needs of people with disabilities.

We also recognize the challenging responsibilities being placed upon this new independent non-profit agency, who must represent the vast audience of people with developmental, mental and physical disabilities. The needs are great and the audience is diverse, but all people are

deserving of protection.

By creating a private, independent non-profit that is solely responsible for protection and advocacy, and faces no conflicting interests or mandates, the state will have a strong agency positioned to truly protect civil, legal and human rights. The Director and members of the agency's Board of Directors should not be solely appointed by the Governor, and the Director should report only to the Board of Directors, not another governmental entity.

We also encourage the recruitment and involvement of consumers, whose experiences and expertise make them a valuable resource to Board and staff.

Currently, forty-five states have moved the responsibilities of the Office of Protection & Advocacy to private non-profit entities to better serve and protect this population in need. We respectfully request that these suggestions be noted as the independent non-profit agency is established in Connecticut. Thank you very much for your consideration.

July 29 2016

Mr. David Guttchen
Office of Policy and Management
450 Capitol Ave.,MS#52LTC
Hartford, CT 06106

RE: Designation of the non-profit P&A entity

Dear Mr. Guttchen:

Thank you for this opportunity to submit comments to the Office of Policy and Management on this most important matter. I am Bruce Garrison, former Program Director with the Office of Protection and Advocacy retired from state service this year after nearly thirty years with this agency. My responsibilities included managing federal grants funding various advocacy programs under my supervision. I reported directly to the agency executive director. I am also a parent of two children with developmental disabilities and experience the challenges they face for their support.

Just prior to my application for retirement, a federal oversight agency issued a report citing the deficiencies of the state run P&A. The complaints of conflict of interest; grant monies not properly spent for intended services; subcontracts with legal services outside the agency; poor performance providing systems change and individual representation were some of the findings in the report presented to you earlier this year. The present executive director has been blamed for these findings despite his brief period of management.

The responsibility for the status of the agency at the time the audit was initiated, falls squarely on the P&A's former executive director and the individuals in management presently transitioning and hoping to be the new entity. The extent individuals were not served by the agency through litigation and individual case advocacy was the direct result of policy and structural decisions made by these individuals over a period of years. The irony is that Connecticut's P&A may again be managed by the same people. Certainly any proposal OPM considers from Disability Rights CT, Inc. ought to look at how these policies are to be reformed for the new entity to be accountable to individuals with disabilities.

A new P&A should offer more than paper compliance with grantors. It should be base on more than serving self interest. It should reflect the priorities of the disability community that the agency is charged to serve. In this regard there has been a record of poor performance.

I write on behalf of individuals with disabilities and their families who have no voice and from a perspective of what my life and passion as an advocate has been all about.

Sincerely,
Bruce Garrison
860-428-9888

Mr.
David Guttchen
Office of Policy and Management
450 Capitol Ave., MS#52LTC
Hartford, CT 06106

Dear Mr. Guttchen,

You might think that The Arc speaks for all with developmental disabilities but that is far from truth

. I am guardian for a brother with a diagnosis of Profound Intellectual and Developmental

Disability. He has resided at Southbury Training School since 1954. I am very happy with the care Paul has received in his home of more than 60 years. I would like Paul to be able to live the remainder of his life at Southbury Training School.

With regard to the replacement of the Office of Protection and Advocacy for Persons with Disabilities I request that the new Protection and Advocacy system includes input from representatives of all disabled people in Connecticut, including representatives of Southbury Training School, the Regional Centers, community facilities and the waiting list.

Thank you for accepting my input as guardian of a person for whom this decision may have a significant impact.

Sincerely,
Elizabeth Wadman Hunt

~~~~~  
Elizabeth Hunt  
14 Cliff Road  
Buzzard  
s Bay, MA 02532

508-759-2479 home  
508-737-1480 cell  
~~~~~

TO: David Guttchen, OPM

FROM: James D. McGaughey

DATE: July 28, 2016

RE: Comments on RFI and selecting a newly designated P&A System for Connecticut

1. Consider the core identities of the entities that may seek to become the designated P&A, and the imagery with which they propose to surround themselves. The name of an organization, its physical location, its affiliations and historical mission (if any), and any symbols it adopts (mottos, logos, etc.) offer important clues about an entity's core identity – who it exists to serve, how it views those people, and what they can expect from it. In the hierarchy of criteria developed to assess proposals, these considerations may seem less important than questions of program capacity, management structure, board composition and the resumes of principals who are responding to a request for information. While those things are, indeed, important, so too is the way an organization presents itself to the world. In part because people with disabilities are still at risk of negative social value judgements, the imagery with which a disability advocacy organization surrounds itself is of particular importance. For instance, it is sometimes tempting for cash-strapped service agencies to locate themselves in remote areas or run down quarters where the cost of rent is low, or to share space with other agencies that provide direct services. While financially expedient, the social imagery associated with such locations tends to transfer to clients and agency employees, lowering expectations and confusing everyone about the entity's core mission and activities, or raising questions about whether it is truly independent. Assurances should be sought that the entity selected for designation is aware of the importance of these issues, and is prepared to attach a high level of priority to them.
2. Look for plans that balance operational flexibility with a steadfast commitment to core advocacy values. The business of operating a state-wide protection and advocacy system is complicated. The "system" must be capable of meeting the continually evolving expectations of multiple federal partners, responding to the ever-shifting needs and priorities presented by state residents with disabilities, and, at the same time, sustaining long-term commitments made to clients and to systems advocacy (reform) efforts – commitments that may consume significant resources and extend over a period of many years. Considerable operational flexibility is required, as specific issues come and go, technologies evolve, statutes, regulations and service systems change. Depending on circumstances, different tools in the P&A tool box (e.g. investigation, litigation, monitoring, policy advocacy) may prove more or less useful. But, operational flexibility must be balanced with the ability to sustain commitments to long term objectives, and to observe certain unchanging principles: ensuring that all aspects of operations are designed to affirmatively confer a deep sense of respect for the people the agency represents, the need to stand independent of potential conflicts of interest, and the need to constantly strive toward a more inclusive world – a world where everyone has a rightful place in the human community. In the RFI, a specific query should be posed about how the responding entities intend to balance these issues.
3. Look for safeguards. Protection and advocacy systems were initially established in response to a series of scandals that had erupted in service systems across the country. Examining the roots of those scandals, Congressional investigators (and the social scientists who helped inform them) recognized that all complex human organizations – even those created with the best of intentions - sometimes fail the people or purposes for which they were created. P&As were

intended to act as an external safeguard against such failures; to provide a place where people who had historically gotten the short end of the stick could turn – an entity that would be capable of investigating, litigating, educating, and otherwise intervening to protect civil and human rights. However, the mere fact that an entity is designated as a state’s official protection and advocacy system does not render it immune from its own potential failures. While the track record of non-profit P&A’s is generally quite good, there have been examples where P&A systems in other states engaged in unacceptable practices, developed compromising relationships, or simply proved to be ineffective. It would be wise, therefore, to look for some built-in safeguards against things going awry in the newly designated P&A. Requiring that the governing board not only meet federal expectations for composition, but that it also include individuals who have previous experience exercising the fiduciary responsibilities inherent in board membership would be one such safeguard. Similarly, requiring a plan for extensive, up-front board training, and for training of new board members as rotation and/or replacement occurs, would help ensure that the governing board remains attuned to its fiduciary responsibilities, that the designated P&A agency remains on track, and that it is continually planning for the future. The RFI should also inquire regarding the responding entities’ plans to submit to periodic independent, external program evaluations. (This will help fill the gap being created by the loss of periodic reviews by State Auditors.) More than financial auditing is required – program practices and compliance issues must also be examined. Planning for such external reviews reflects consciousness of the need to deliberately build safeguards into a designated P&A’s operations. (Assistance in both board training and external evaluations are available through the National Disability Rights Network’s federally subsidized training and technical assistance program.)

4. Consider transition issues. There are many questions that will need to be answered with respect to the transition from State agency to private, non-profit status. I see three big ones:

First, provision must be made for transferring ongoing casework responsibilities (including those involving legal representation), as well as archived material from previous casework that the current agency has a responsibility to maintain. These processes are likely to be fairly labor-intensive, as new client authorizations must be developed and obtained, explanations offered and discussed. Further, there will be a need for considerable storage space or financial resources to enable the transfer of paper records to electronic forms of storage. The newly designated agency should be capable of accepting the on-going case responsibilities as well as any records that the P&A system is required to retain pursuant to both federal and State law.

Second, the experience and knowledge of OPA’s staff represents such a valuable resource that efforts should be made to ensure as many current staff members as possible become employed by the newly designated entity. It would take a number of years for newly hired advocacy staff to acquire a similar level of expertise, during which time there would be a marked reduction in the availability and quality of information and referral services and advocacy representation available to Connecticut residents. In fairness to people who have devoted many years of their lives to the work of OPA, and who have counted on the benefits package available through State employment to assure their family’s security, the State should allow current OPA employees who become employed by the newly designated P&A entity to remain in the pension and health insurance plans that currently cover them, with no additional costs to either the newly designated entity or to those employees. Similarly, salary levels should

remain the same as they currently are, with the State subsidizing the difference between the salary scale established by the newly designated entity and salaries currently being paid.

Lastly, it should be noted that many people with disabilities and their family members have found considerable comfort in just knowing that the current Office of Protection and Advocacy for Persons with Disabilities exists. In an important sense, the agency has been seen as a source of empowerment - a gateway providing access to justice in a world filled with barriers, excuses, abuses and ignorance; a place to turn for wise, experienced counsel. When someone calls P&A, that person does not have to explain his or her whole life story to people who may or may not understand. People calling for help expect, and find, allies. For nearly four decades, this small, programmatically complex agency has meant more to people with disabilities and their families than its size or actual capabilities would suggest. It has represented hope – hope that things will continue to get better, hope that the civil and human rights of people with disabilities will someday be genuinely respected. It would be very important to ensure that the newly designated agency be cognizant of that legacy, and that the State provide the resources necessary to mount a sustained public education campaign to inform all Connecticut residents about the transfer of P&A responsibilities to the new entity, and assurance that it will continue the operations and mission of the existing State agency P&A.

CT COMMUNITY NONPROFIT ALLIANCE



formerly



To: Anne Foley, Under Secretary, Policy Development and Planning Division, Office of Policy and Management
David Guttchen, Director, Connecticut Partnership for Long-Term Care, Office of Policy and Management

From: Julia Wilcox, Senior Public Policy Specialist, CT Community Nonprofit Alliance

Re: Recommendations Regarding Connecticut's Protection and Advocacy System for Persons with Disabilities

Date: July 25, 2016

Thank you for the opportunity to provide recommendations regarding Connecticut's Protection and Advocacy System for Persons with Disabilities. CT Community Nonprofit Alliance (The Alliance) represents more than 550 nonprofit organizations and associations across the state and is the largest advocacy organization representing community nonprofits in Connecticut. Together, our members support more than 500,000 Connecticut residents each year. A substantial number of individuals who receive support through our member organizations and associations, are entitled to - and protected by - essential services provided under the current and proposed system of protection and advocacy.

The Office of Protection and Advocacy (OP&A) for Persons with Disabilities, was established and funded under the federal Developmental Disabilities and Bill of Rights Act of 2000, as an 'independent State agency' created to safeguard and advance the civil and human rights of people with disabilities in Connecticut. Part of a nationwide network of protection and advocacy systems, OP&A operates under both State and federal legislative mandates. Public Act 16-66 requires Governor Malloy, no later than July 1, 2017, to designate a nonprofit entity to function as Connecticut's Protection and Advocacy (P&A) system that will replace the current OP&A (which will be abolished by law on July 1, 2017.) Public Act 16-66 also requires the Office of Policy and Management (OPM) to issue a Request for Information to solicit information from nonprofit entities as to their capacity to be Connecticut's P&A system.

CT Community Nonprofit Alliance (The Alliance) stands in strong support of the forthcoming transition of Connecticut's protection and advocacy services from State Agency to nonprofit provider entity. Our position is based not only upon our knowledge of and confidence in the current network of advocacy organizations and providers, but upon a national precedent for the systems model. Research indicates that all but 4 states and 1 territory currently operate with independent P&A system in place, as opposed to the previously accepted state agency model. With that said, however, while the transition provides an opportunity to build on previous success of the former OP&A, there are a substantial number of challenges and questions to be addressed in order to assure immediate and long-term, sustainable success.

CT Community Nonprofit Alliance respectfully submits the following recommendations and concerns for your consideration:

1. Conflict-free structure: It is essential that the newly established, nonprofit Protection & Advocacy (P&A) entity operate independently from the provider community. Advocacy of this nature must be able to challenge practices and issues within a variety of settings without undue influence or conflicting interest.
2. Inclusion of perspectives of all stakeholders: The current OP&A is one of three agencies originally funded by the federal Developmental Disabilities and Bill of Rights Act of 2000. It is essential that the remaining

agencies: The Connecticut Council on Developmental Disabilities and The University Center for Excellence in Developmental Disabilities at UConn, (and all stakeholders) remain a critical part of the perspective and direction of the new entity. As many have suggested, the long-standing philosophy of ‘Nothing about us without us,’ must be a part of all processes moving forward.

3. Capacity and funding to assure success: The new entity must have the necessary capacity and experience to effectively provide all aspects of services as outlined. Consistent, quality services must be provided on a statewide basis on behalf of individuals with every category of disability. In order for the new entity to secure and maintain the necessary caliber of qualified staff, funding must meet the needs of the actual cost of these services.
4. Potential challenges re: the Abuse & Neglect component transferring to the Department of Rehabilitation Services DORS: It would appear that the bifurcation of the Protection and Advocacy functions (in PA16-66) is a necessary component to a successful transition – and compliance with the language of PL 106-402 at Subtitle C, §143a.2.G., regarding the assignment of Abuse and Neglect to DORS. Concerns have been raised that the split of functions between the new entity and DORS may introduce unnecessary challenges to both efficiency and compliance, in a number of areas including communication, which could potentially have a negative impact upon the individuals served.
5. Consistent and timely provision of casework management: Systems must be in place to prevent the historic back-log of investigations and caseload management. As a part of this process, we recommend that a uniform electronic incident reporting process remain in place to assure more timely and consistent reporting and review of incidents. In addition, these systems must satisfy federal standards and requirements.
6. Ongoing training and communication: We recommend implementation of an on-line, abuse and neglect prevention education program to persons with disabilities, support services providers and mandated reporters – with an established level of requirement for those deemed necessary. We further recommend that the se opportunities are provided without cost to these individuals.

On behalf of the nonprofit provider community, The Alliance urges your continued support of Connecticut’s Protection and Advocacy System for Persons with Disabilities. It is critical to acknowledge that the state’s ability to effectively achieve any of the goals set forth is directly related to the strength and viability of the nonprofit provider network of community services – as well as all collaborative partners and stakeholders.

We look forward to serving as a resource in any way possible, to best achieve the goals of this critically important transition. Please do not hesitate to contact me at any time with any questions or for additional information. Thank you again for your efforts to address these critically important areas of concern and opportunities for improvement.

Julia Wilcox, Senior Public Policy Specialist, CT Community Nonprofit Alliance

JWilcox@ctnonprofitalliance.org 860.525.5080 ext. 1025

From: James Hexter [<mailto:james.l.hexter@gmail.com>]
Sent: Thursday, July 28, 2016 5:22 PM
To: Guttchen, David J. <David.Guttchen@ct.gov>
Subject: Public comment re: Office of Protection and Advocacy for Persons with Disabilities

Dear Mr. Guttchen,

My name is James Hexter, and I am a person with Asperger's syndrome living in North Haven, writing to you today about the future of Connecticut's protection and advocacy (P&A) system for persons with disabilities.

While I have never used the services of the state Office of Protection and Advocacy for Persons with Disabilities (OPA), I do know individuals who work there currently, and I can definitely attest that they are passionate, hard-working people who truly care about the welfare of people with disabilities in Connecticut. Every year these individuals and their co-workers receive thousands of calls from people who need assistance — whether it's with paying their monthly utility bills, avoiding homelessness, fighting discrimination, becoming able to live independently, or investigating abuses and even deaths in our state's many care facilities and group homes. Trying to help people with disabilities in these dire situations can often be very depressing, yet the people at OPA continue to work every day because the work is ultimately necessary and rewarding, and their jobs are too important to leave to anyone else. In particular, OPA has been instrumental in investigating the closure of the Department of Rehabilitation Services' Sign Language Interpreting Services Program, as well as defending the rights of deaf and hard of hearing people in Connecticut who desperately need these affordable services.

Any new P&A system in Connecticut **must** include the people who currently work for OPA. They have knowledge of the ins and outs of our state's services and legal systems, and it is much better for any organization advocating for the rights of persons with disabilities to hire people they know will do an excellent job instead of individuals who may not share the same passion and expertise. Not only will this allow the new P&A to continue to effectively advocate for deaf and hard of hearing individuals in the face of the state's recent layoffs of sign language interpreters, but all people with disabilities in Connecticut can be assured that they will get the same — or even better — quality of services they can get right now through OPA.

I also believe that Disability Rights Connecticut, Inc. is the organization best equipped to successfully implement the new P&A system. I am also acquainted with the individuals in charge of that organization, and I can also vouch for their drive and tenacity to advance the welfare of people with disabilities who live in our state. I cannot think of a better group of people to whom we should entrust the responsibility of running a P&A.

It is my hope that my comments will be taken into consideration as the state continues the process of transitioning to a new P&A system. Thank you very much for taking the time to read this letter, and I wish you the very best.

Sincerely,

James Hexter
(203) 710-8007
james.l.hexter@gmail.com

**Testimony of the National Alliance on Mental Illness (NAMI) Connecticut
In regards to the transition of the functions of the Office of Protection & Advocacy to a
nonprofit entity
July 28, 2016**

Secretary Foley and panelists, my name is Daniela Giordano and I am the Public Policy Director for the National Alliance on Mental Illness (NAMI) Connecticut. NAMI Connecticut is the state affiliate of NAMI, the nation's largest grassroots mental health organization dedicated to building better lives for all those affected by mental health conditions. NAMI Connecticut offers support groups, educational programs, and advocacy for quality of life for individuals and families in the community. I am writing to you today on behalf of NAMI Connecticut to share comments regarding the impending transition of the protection and advocacy functions from the Office of Protection & Advocacy to a private nonprofit entity.

Having heard some compelling testimony at the public hearing on 7/25/16, we would like to stress a few points that were raised plus some additional suggestions.

'Nothing About Us Without Us' is a mantra and guiding principle that needs to be reflected in the new entity, starting with the review team of this transition process, and continuing with the Board of Directors. Considerations should also be made regarding the creation of advisory groups, as they currently exist under the OP&A, including people with lived experience. People with lived experiences, including individuals as well as family members, are great resources invaluable in designing a good process and leading to desirable outcomes for individuals who seek protection and advocacy services. The inclusion and participation of people with lived experience needs to cover all disability groups and communities, across ages and reflect the diversity of Connecticut's communities.

Continuity of access to protection and advocacy services, both during and beyond the transition, is of crucial importance particularly during a time where community services and supports have been cut due to the continued state budget crisis which impacts the access to such services and increases the likelihood for needed advocacy and protection services.

Adequate funding for knowledgeable and able staff will be pertinent to the new entity in fulfilling its function under federal and state statutes, and supporting Connecticut residents to live integrated in communities with access to a variety of needed resources. Staff needs to understand the legal and regulatory requirements on which basis to enforce the protection and advocacy functions as well as the cultural characteristics of the diverse disability communities, and be champions of the individuals and communities this entity will serve.

The structure and processes of the new entity need to be clear about the two-fold advocacy it is called upon to do, on an individual level to respond to violations of laws and regulations and to proactively promote systems change in order to strengthen protections afforded to individuals with disabilities.

This new entity needs to connect with and be part of the already existing network related to advocacy and protection of individuals with disabilities in the state. This will allow it to leverage the existing expertise and work, instead of working in a vacuum or recreating the wheel as sometimes happens when things change or get newly created.

Even though the function of investigating abuse and neglect will stay within the state, i.e. it will move to the Department of Rehabilitation Services (DORS), and will not be part of the scope of the new entity, clear lines of communication of state activities and those of the new nonprofit entity will need to be established in order to collaborate on interrelated issues.

Thank you for your time and attention. Feel free to contact me if you have any questions or require clarifications.

Respectfully, Daniela Giordano publicpolicy@namict.org

From: Betty Brandt [<mailto:brandtbetty@gmail.com>]

Sent: Friday, July 29, 2016 1:58 AM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Subject: Privatization of CT Office of Protection & Advocacy For Persons With Disabilities

The watchword is "Nothing about us without us!"

1) Whatever organization assumes the functions of CT P& A, it must provide positions of influence to people with **lived disability experience.**

2) The organization's lawyers need to be experienced disability rights advocates, & given sufficient funding & resources to do their jobs.

3) PAIMI (the Federal requirement of a distinct component of Protection & Advocacy for Individuals with Mental Illness) needs to be preserved.

4) The emphasis on saving money for the State of CT must not be allowed to result in second-class services for people with disabilities!

Whether economic times are good or bad, the needs of people with disabilities are still there!

Elizabeth Brandt

235 Warde Ter., APT 1 D

Fairfield, CT 06825

-----Original Message-----

From: Anonymous [<mailto:gen7rev@gmail.com>]

Sent: Friday, July 29, 2016 12:41 PM

To: Guttchen, David J. <David.Guttchen@ct.gov>

Subject: Deaf true stories

I am going to share a couple of true stories about deaf people.

There was a time when a young child attended elementary school and this school didn't have an interpreter. A teacher did not have any resources to teach this child therefore, the child was placed in the back corner of a room and worked on puzzles as other pupils continued their education. Just imagine if this child had equal accessibility, he/she could contribute something back to the community, if his/her education and resources hadn't been deprived.

A young couple had to go to a hospital to give birth during a cold, winter storm. On a clear day, the trip would have taken them no more than 20 minutes. Instead it took them at least 2 hours and a lot of cars were abandoned along the way. The young couple met a policeman along the way and used hand gestures to help the couple get through the traffic snarl. After 31 years had gone by, this couple discovered tragic stories that had happened outside the hospital door. They were left in the dark!

One sweet deaf man, who had cerebral palsy since birth, was placed in a mental health institution for over 50 years, before they even realized he was deaf. He never even had any communication during all of those years. A deaf interpreter went to the hospital with him in order to help him understand what was needed to be done prior to having an open heart surgery. The staffs did not want him to misunderstand and be afraid, as he thought he was going to be placed in a mental health institution again, which was not the case.

Finally, a deaf woman who was in her late 30's received a letter. After reading this letter, she was so afraid. She didn't know what to do or who to ask for help so she ended her life. The police found this letter and realized she didn't understand that the letter was simply notifying her that she needs to be present for jury duty. If an advocate was there for her, her life could have been saved.

I want to thank you for taking the time to read these stories. We need a smooth transition (from Office of Protection and Advocate to non-profit agency) with high qualified people who are knowledgeable of our disability/needs in hopes of preventing more tragedies from occurring in the future.

All lives matter.

From: Keith Vinci [<mailto:kvinc53@gmail.com>]
Sent: Friday, July 29, 2016 2:44 PM
To: Guttchen, David J. <David.Guttchen@ct.gov>
Subject: Comments on P&A

As the President of the Connecticut Registry of Interpreters for the Deaf [CRID] I would like to voice my concern with the State transitioning OPA to the private not for profit sector. If the transition of OPA follows the path that the Governor's Office and DORS took in closing the Interpreting Unit of DORS [previously the Commission on the Deaf and Hearing Impaired [CDHI] which was a highly functioning and profitable agency until the State starting fooling with it, and wrongly moved it and housed it in DORS] . The promised smooth transition of the closing of the Interpreting Unit has been an enormous bust; nothing has worked as it was intended and the savings promised the State have already fizzled out [I can elaborate if really interested].

OPA has served the Deaf community admirably. After acquiring an understanding of the uniqueness of Deafness, OPA fought discrimination and disenfranchisement of the Deaf population. With the assistance of OPA and the interpreters of CDHI/DORS, the Connecticut Deaf had a mechanism that allowed their voices to be heard and brought the Deaf into the mainstream of Connecticut society. The dismantling of the Interpreting Unit and the move of OPA is devastating to the Deaf community. Those Deaf fear a return to the isolation and lack of communication access and inclusion that existed prior to CDHI and OPA.

Connecticut was once known as a progressive haven for all citizens, including those with disabilities; a model state for the other 49; not so much any more.

Keith Vinci, CRID President
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Middletown, CT 06457

860-346-7206

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426 STATE STREET
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TELEPHONE (203) 946-4811
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July 29, 2016

By Mail and E-Mail (david.guttchen@ct.gov)

David Guttchen
Office of Policy and Management
450 Capitol Ave., MS#52LTC
Hartford, CT 06106

**Re: Comments Concerning Proposed Independent Office of Protection and
Advocacy for Persons with Disabilities, Pursuant to Public Act 16-66**

Dear Mr. Guttchen:

NHLAA submits these comments to the Office of Policy and Management with respect to the impending creation of an independent Office of Protection and Advocacy ("P and A") apart from state government.

The Protection and Advocacy Systems program ("P and A") was established by Congress in the 1970s to address the severe legal and human rights violations of people in institutions. While those egregious conditions no longer exist, there are still significant infringements on the rights of people with disabilities. They experience abuse and neglect, discrimination in employment and housing, inappropriate educational services, and too frequently must wait years for necessary services and supports.

There are currently 57 P & A programs in the United States and its territories, and each is independent of service-providing agencies within their states. The vast majority also are not part of any state agency and are stand-alone non-profits. Because of recently-enacted legislation, Connecticut's P & A program will now be similarly independent of the potential conflicts inherent in being a state agency.

The P & A program is a critical player advocating for people with disabilities. Connecticut's new P & A program must be structured so as to be able to discharge its sole mission of fostering and protecting the rights of people with disabilities.

First, we urge OPM to listen to the desires of the disability and disability rights communities in Connecticut. While we can't be sure that there will be unanimity on the desired structure for the new P & A office, the community will be best served if it has a

major voice in what that structure looks like. To get started on the right foot, it is critical that the disability rights community be the dominant voice in deciding this. It should also be represented on the team selecting the new entity.

Second, while we do not purport to be the voice of the disability community, we believe that there is agreement on the following principle as well: that the new program be established as a completely separate non-profit entity with a mission dedicated solely to advocacy for people with disabilities. The entity must have the freedom to advocate for services required by state agencies without any perception that upsetting a state agency is problematic. The entity must be free to appoint its own board leadership and, from that leadership, its own executive director and management leadership.

Its mission must be synonymous with that of the national P & A system, i.e., dedication to fostering and protecting the rights of people with disabilities and not as part of a larger non-profit with a different or broader mission. Although the new program will inevitably work closely with other advocates and advocacy agencies, Connecticut's new P & A should not be required report to any other agency or entity in deciding which positions to take or how to advocate. No matter how well meaning such agencies or entities might be, if the new P & A is part of an entity with a broader agenda, its mission could well be subsumed by interference from the larger entity. As a stand-alone non-profit, conflicts of **any** kind can be avoided and the new P & A program can be true to its sole mission.

Third, continuity during this transition is important for P & A's many constituencies. They cannot afford to lose the substantial expertise currently possessed by its many dedicated staff members, or to wait years for such expertise to be rebuilt. Therefore, where possible, current employees of the state agency should be hired by the new independent entity.

Thank you for considering our comments.

Respectfully yours,


Sheldon V. Toubman
Staff Attorney

Testimony for Public Hearing
Public Act 16-66 - to designate a nonprofit entity to be Connecticut's Protection and Advocacy
(P&A) system that will replace the Office of Protection and Advocacy for Persons with Disabilities
Public Health Committee
March 18, 2015

Rosemary Petruzzi
54 Nettleton Hollow Road
Bethlehem, CT 06751

David Guttchen
Office of Policy and Management
450 Capitol Ave., MS#52LTC
Hartford, CT 06106

July 29, 2016

Dear Mr. Guttchen,

My name is Rosemary Petruzzi, and I am the guardian for my Aunt, Mary Lucia Petruzzi, age 71, who currently resides at Southbury Training School (STS).

I am writing to request that the individuals selected to be on the board of the newly designated non-profit Protection and Advocacy Department are unbiased and neutral in their ability to provide choice to all sectors of the spectrum of disability, as it is represented in the citizenry of CT.

We are by law protected by the Olmstead Legislation to have choice.

I have attached the following article, "Olmstead Protects Individual Choice and Recognizes the Need for Higher Levels of Care" By Caroline A. Lahrman, in its entirety, to demonstrate the degree of misinterpretation of the law, as well as the misintentions of the states, and P&A groups around the nation. It is my intention to bring clarity to this issue, and elevate the discussion to that of focusing on the individuals themselves and their needs. That is, and should always be our focus.

I am strongly asking you to consider keeping STS a viable, and restored community for the I/DD citizens of CT, to enjoy for a long, long time. We need to truly take care of our most vulnerable citizens. It is unequivocally our moral obligation.

Thank you for your time and consideration of this matter.

Sincerely,

Rosemary Petruzzi
Niece of Mary Lucia Petruzzi/guardian 3rd gen.
203 266-5752

Olmstead Protects Individual Choice and Recognizes the Need for Higher Levels of Care

By Caroline A. Lahrmann

Individuals with intellectual and developmental disabilities (I/DD) are far too frequently finding life-sustaining services pulled out from under them by agencies charged with the duty to protect them – namely state departments of developmental disabilities and protection and advocacy organizations. They attempt to use the law as a weapon against the community of people with disabilities instead of the tonic it is meant to be.

These agencies tell the public and lawmakers, wrongly, that the Americans with Disabilities Act (ADA) and the U.S. Supreme Court *Olmstead* decision require “de-institutionalization” and “community integration,” regardless of individual need and choice. We are told that “least restrictive environment” in all cases means small community settings, even when many individuals with I/DD cannot be safely served in such settings **and/or** they choose the higher level of care provided in large facilities, such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), facility-based day programs and sheltered workshops.

Don’t be fooled by this deception, and don’t let your elected representatives be fooled either. *Olmstead*’s majority and concurring opinions take great care to stress that “institutions” such as ICFs/IID are a critical part of a range of services that a state must provide to meet the needs of the diverse community of people with mental disabilities. *Olmstead* recognizes that there are individuals who desire and require a higher level of care for whom “institutions” must remain available. *Olmstead* also states that the wishes of individuals are paramount in determining residential placement.

The importance of individual choice, including for some the choice of “institutional care,” is repeated throughout *Olmstead*’s majority opinion as follows:

*“Such action (community placement) is in order when the State’s treatment professionals have determined that community placement is appropriate, **the transfer from institutional care to a less restrictive setting is not opposed by the affected individual**, and the placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities.”*
(Emphasis added.)

“But we recognize, as well, the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand.”

“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”

“As already observed...the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk...Nor is it the ADA’s mission to drive States to move institutionalized patients into an inappropriate setting...”

“For other individuals, no placement outside the institution may ever be appropriate...for these persons, institutional settings are needed and must remain available.”

*“For these reasons stated, we conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, **the affected persons do not oppose such treatment**, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”*
(Emphasis added.)

In his concurring opinion to *Olmstead*, Justice Anthony Kennedy warned against its misinterpretation, specifically pointing to state agencies. Kennedy states in Part I of his concurring opinion, which Justice Stephen Breyer joined, that:

“It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.”

Justice Kennedy then quotes from the majority opinion,

*“Justice Ginsburg’s opinion takes account of this background. It is careful, and quite correct, to say that **it is not “the ADA’s mission to drive States to move institutionalized patients into an inappropriate setting...”**”* (Emphasis added.)

Justice Kennedy concludes,

*“In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, **States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.**”* (Emphasis added.)

Justice Kennedy’s warning has sadly proven prophetic for developmentally disabled citizens around the country who have been forced out of their chosen ICF/IID homes, facility-based day programs and sheltered workshops because of real or perceived threats of litigation, oftentimes from federally-funded protection and advocacy agencies set up to protect our most vulnerable citizens.

Olmstead is not a decision to be feared by individuals seeking specialized services for their unique needs connected to their intellectual and developmental disabilities. Congress demonstrated this fact when it recognized the importance of considering individual choice based on need in ADA (*Olmstead*) enforcement activities in this December 2014 Report language to accompany the Consolidated and Further Continuing Appropriations Act of 2014:

“Deinstitutionalization.-There is a nationwide trend towards deinstitutionalization of patients with intellectual or developmental disabilities in favor of community-based settings. The Department [of Justice] is strongly urged to continue to factor the needs and desires of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Americans with Disabilities Act.” [Conference Report to accompany the Consolidated and Further Continuing Appropriations Act, 2014(for [Commerce, Justice, Science, and Related Agencies](#), p. 17) (December 2014)].

Olmstead embraces options. Its careful and responsible findings respect the diversity inherent in the community of people with mental disabilities and seek to ensure that all people receive safe, appropriate, and individually-driven services.

Caroline A. Lahrman
VOR State Coordinator Ohio
Disability Advocacy Alliance, Co-Founder

July 29, 2016

David Guttchen
Office of Policy and Management

This letter is in response to the request for public comment regarding Public Act 16-66 concerning Connecticut's Protection and Advocacy (P&A) system for persons with disabilities.

After viewing the testimony given at the public hearing held on July 25, 2016, it is apparent that many people have strong opinions and are very passionate about how the privatization of the Connecticut Office of Protection and Advocacy should take place (if at all) and I agree with many of the comments.

It is of utmost importance that the current P&A staff who have done such great work in the past help in making a smooth transition. Continue their Mission Statement. There should be little impact on the P&A clients.

The board, advocacy staff, advisory councils, legal staff, etc. must include individuals with disabilities.

Members of the new P&A should have experience in civil/human rights and advocacy and must be given extensive education and training in the history of and diversity of all disabilities being cognizant of cultural, religious, etc. differences among the state's residents.

My specific comments concern my long term and ongoing guardianship and advocacy for a member of my family who lives in a congregate setting for intellectually/developmentally disabled (I/DD) aging individuals. Many congregate homes, facility based day programs and specialized work settings have been closing. The Department of Justice (DOJ), legislators, state departments of developmental disabilities, and protection and advocacy organizations charged with the duty to protect feel it is their duty to deny individuals this higher level of care and specialized training.

The U.S. Supreme Court *Olmstead* decision (*Olmstead v. L.C.*) recognized the need for individual choice to protect health and safety and the basic civil rights of individuals with I/DD. Justice Ginsburg, in her majority opinion: *"For some individuals, no placement outside the institution may ever be appropriate ... Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing on a case-by-case basis, that setting may be an institution"* - *Olmstead*, at 605

This new non-profit entity, Connecticut's Office of Protection and Advocacy system MUST respect the full meaning of *Olmstead* and support a full continuum of options for individuals with intellectual disabilities.

Respectfully,
Diana G. Mennone
262 Minortown Road
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cc: State Senator Rob Kane
State Representative Eric Berthel