



*Coalition Of Provider Associations*

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Seth Stein, Esq.  
Executive Director &  
General Counsel

**Cerebral Palsy Associations  
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Susan Constantino  
President & CEO

**Developmental Disabilities  
Alliance of WNY**  
Rhonda Frederick  
President

**InterAgency Council of  
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Thomas McAlvanah  
Executive Director

**New York Association of  
Emerging & Multicultural  
Providers, Inc.**  
Yvette Watts  
Executive Director

**TESTIMONY SUBMITTED TO THE  
NEW YORK STATE ASSEMBLY STANDING COMMITTEE ON  
MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES**

**Housing for Individuals with a Mental Illness or  
Developmental Disability**

**Presented by**

Barbara Crosier  
Vice President, Government Relations  
Cerebral Palsy Associations of NYS

JR Drexelius  
Government Affairs Counsel  
Developmental Disabilities Alliance of Western New York

Winifred Schiff  
Associate Executive Director for Legislative Affairs  
The InterAgency Council of DD Agencies

**For the Coalition of Provider Associations**

**December 11, 2017**

***Representing More Than 250 Provider Agencies in New York State***

COPA ♦ 3 Cedar Street Extension, Suite 2 ♦ Cohoes, NY 12047 ♦ 518.436.0467 ♦ info@copanys.org ♦ www.copanys.org

Good morning Committee Chair Gunther and members of the Assembly Standing Committee on Mental Health and Developmental Disabilities. Thank you for your ongoing support of people with Intellectual and Developmental Disabilities (I/DD) and for the opportunity to speak with you today regarding the adequacy of housing opportunities for individuals with developmental disabilities.

We are Barbara Crosier from Cerebral Palsy Associations of New York State (CP of NYS), JR Drexelius of the Developmental Disabilities Alliance of Western New York (DDAWNY), and Wini Schiff of the InterAgency Council of Developmental Disabilities Agencies (IAC). We are here today on behalf of the Coalition of Provider Associations, or COPA.

COPA consists of five associations – The Alliance of Long Island Agencies, Inc. (ALIA), Cerebral Palsy Associations of New York State (CP OF NYS), the Developmental Disabilities Alliance of Western New York (DDAWNY), the InterAgency Council of Developmental Disabilities Agencies, Inc. (IAC), and the New York Association of Emerging and Multicultural Providers (NYAEMP) – because people with disabilities, their families, and the organizations that support them felt the need to unify in their quest to ensure that adequate services are available for those who require them. COPA represents over 250 not-for-profit agencies across New York State that provide supports and services to hundreds of thousands of New Yorkers with intellectual and developmental disabilities (I/DD) and employ more than 75,000 dedicated direct support professionals with combined annual operating budgets of nearly \$5.2 billion.

As New York State seeks to transform the system supporting people with I/DD so that it will be sustainable for future generations, housing is a key and complex component which requires thoughtful planning and investment to ensure that our successful system will include community living options for people with all levels of intellectual and developmental disabilities.

Current waitlists show that as many as 12,000 people are in need of residential services. While we are not suggesting that there are 12,000 people in dire need of placement, there are approximately 2,000 who family experts estimate are in urgent need. \$120 million has been allocated in the last year's budget but this amount must cover all new services, including residential, day and other programs. There was an additional pool of \$15 million in last year's budget allocated for OPWDD affordable housing development. We wholeheartedly support this program and urge you to advocate for increasing it as part of the OPWDD multi-faceted housing solution.

While this allocation is insufficient, there are also bureaucratic delays which routinely impede the use of these funds. Current practice often results in placements that are not ideal for the person in need or those with whom he or she might be placed since they are often made on an emergency basis. Considerations of choice and least restrictive setting become difficult to honor with this approach. Funding, regulatory issues and silos that have been created between agencies prevent creative housing opportunities from being developed and/or implemented. In order to support the rising number of aging New Yorkers with developmental disabilities who

are living longer and need accommodations that all aging people need, new graduates from day and residential school programs who need a variety of supports and services and are increasing in number, with the rising incidence of autism spectrum disorders, with existing resources mostly allowing only those in the most urgent circumstances to obtain out of home housing supports, we need to work together to develop solutions.

We would like to raise three main issues in residential services for people with I/DD that can be addressed to begin to fix the housing dilemma:

- Staff shortages;
- Development, modification and transformation funding shortages; and
- Systemic roadblocks.

Each of these areas would take more time than we have here today but we welcome the opportunity to have these conversations with you to develop sound recommendations to address these issues.

#### **Staff shortages:**

We hope that the first phase of investment in “#bFair2DirectCare” direct support staffing will be sustained and continued in the upcoming budget and that this will begin to address the first issue listed. It cannot be overstated that health and safety is severely compromised by a lack of staffing, leading to inexperienced, unqualified caregivers, burnout and exhaustion and increased incidents which could result in extremely negative consequences. The cost of onboarding a new DSP is estimated at \$4,000 and with vacancy and turnover rates of 12% and 30%, this waste of money is exorbitant. To further illustrate our growing crisis, we have conducted a new vacancy and turnover survey and results will be available shortly. Some providers are faced with such shortages that while they have been able to find and develop new housing opportunities they are unable to staff and open them.

#### **Development, modification & transformation funding shortages:**

While we are grateful for the investment in last year’s budget, which will begin to create a living wage for our direct support professionals who are the backbone of all of our services, we must point out that we have not received a Medicaid Trend Factor in eight years, nor have we received necessary funds to facilitate the transformation of our system of residential supports and services to comply with federal requirements or the changing needs of the people in our care.

Our residential schools have a backlog of “bed blockers,” graduates who are unable to move to adult residential settings due to the housing shortage. Despite identifiable numbers of students each year progressing through our residential schools, we do not have plans in place to ensure these graduates will transition in a timely way each year. This residential capacity problem impacts the schools as well -- there are many children who are placed in out of state schools due to the lack of capacity in New York, with a much higher cost to the State and no federal reimbursement, not to mention the strain on families who are not able to keep their children in

their home State. OPWDD has recognized this problem and has been working with the newly created *Centers of Excellence in the Care and Treatment of Children with Autism Spectrum Disorders and Other Complex Disabilities*, but further investment in the work being done through the Centers requires Legislative support to ensure the cost savings opportunities are realized while also ensuring a better flow of students in and out of this school system. We will be reaching out to you to further discuss this proposal.

We have a growing aging population in New York, both caregivers and those who need support, for whom the current system is not responsive. Many people are aging in residences developed many years ago that can no longer meet their needs without significant capital work or relocation for which OPWDD funding is at best limited or no longer available. We need to provide modifications and/or supports for those who want to age in their homes in a way that fits within individual goals and preferences. ISS funding, which covers the rent for those able to live more independently in non-certified residential settings, is another option which could serve to create additional vacancies in existing certified housing situations but, the rent subsidy caps are too low to reflect market values in many areas of the state. In addition, it often takes three months to an entire year for OPWDD to reimburse providers who are forced to cover the rent for that period of time. While some larger organizations have found ways to subsidize the program, this delay severely limits its success. The \$15 million in OPWDD affordable housing funding made available in the past few budget years has proven to be a successful addition to our housing development initiatives and increasing this allocation is highly advisable. This funding is, however, spoken for even prior to the dollars becoming available and OPWDD providers have had difficulties accessing the larger affordable housing pool under DHCR.

**Systemic roadblocks:**

The Residential Request List (RRL) and Certified Residential Opportunity (CRO) lists are a good attempt at gathering information on need and planning for future residential needs; unfortunately, families and professionals are often unfamiliar with the process for getting on the lists – there is a crucial need for training and information dissemination. 424 new certified opportunities have recently been released, reportedly based on current need. We are certain that there are many more individuals who currently have urgent needs for certified residential opportunities and who would have been on the list if they had access to/knowledge of the CRO system. We are concerned that over-reliance on potentially inaccurate ISPM scores as a way of determining need could be another factor in limiting access to housing. Further, we ask that there be more transparency about the lists/numbers of people seeking residential supports, in general.

We understand that “backfills” are a significant source of certified housing opportunities. When the opportunity available matches the needs of the individual seeking this option then backfilling works! When it doesn’t, frustrating and possibly dangerous situations can result. Many in need of placement are medically frail or have significant behaviors which require enhanced staffing not available in the typical backfill opportunity. Many people with intellectual and developmental disabilities supported by providers also have a mental health diagnosis, yet we often run into barriers that segregate what funds are available for capital development

projects or ongoing supports. When individuals and families choose not to accept a backfill opportunity, usually because it is inappropriate, they are often placed back on the end of the list, increasing their wait-time for needed residential services. Federal rules regarding Home and Community Based Settings Standards and size of the homes are additional complications but federal mandates to honor choice dictate that requests for not sharing bedrooms, living with compatible roommates, etc., should be granted. We need eligibility determinations to be streamlined and creative, cross-agency funding opportunities to be explored.

New York State's commitment to people with disabilities and their families, made after Willowbrook, has carried us this far. We are here today to seek your support for making the changes necessary to provide the appropriate residential opportunities needed when they are needed. This will require both investment and thoughtful changes in procedure. We thank you for this opportunity to offer our comments today. We look forward to continuing to work with you on behalf of people with I/DD in New York State.