



# State of New Jersey

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## **Innovative Models, Unmet Needs: Expanding Congregate Housing Options for Adults with Intellectual and Developmental Disabilities**

A Housing Conference Organized by the Rowan University Steve Sweeney Center for Public Policy  
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Remarks As Prepared for Delivery

Good morning, everyone. My name is Paul Aronsohn, and I am New Jersey's Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families.

It is really great to be here with all of you for this important, timely conference. I am genuinely grateful for this opportunity.

I say "important" and "timely" for two reasons:

- First, this summer marked the 25<sup>th</sup> anniversary of the US Supreme Court's "Olmstead" decision, which was a watershed moment in the lives of people with disabilities. It was a decision about civil rights and human rights. It was a decision that underscored the fact that people with disabilities matter – what they need matters, what they want matters, what they say matters. And in the context of today's conference, it was a decision that helped put an end to the forced institutionalization of people with disabilities – making it clear that people with disabilities, like all people everywhere, should be able to choose "where" and "how" they live their lives.
- Second, today's conference is important and timely, because despite the tremendous progress made over these past 25 years, many New Jerseyans with disabilities are currently experiencing a very real housing crisis.
  - It is a crisis about availability, affordability, and livability - the need for housing that meets the requirements and preferences of a diverse disability community.

Yes, we certainly have come a long way since the high court's Olmstead decision, but yes, we still have a long way to go.

For my presentation today, I have pulled my remarks from our office's most recent annual report, because in it, we identified housing as one of six of the most persistent, most pressing challenges facing New Jersey's disability community – one of six challenges most often brought to our attention over the past year.

The concerns expressed to us vary.

- For children with complex medical or behavioral needs, the challenge is often availability: Simply stated, there are not enough safe, appropriate community-based residential options for these youth. Many are unable to obtain proper supports at home; yet, there are only a very limited number of "beds" available in State-licensed residences.

- For adults with disabilities, the challenge is often affordability: There are not enough housing options for them in the communities in which they want to live. This is due to high rents, low incomes, and vouchers that are often not aligned with economic reality.
- And for many individuals and families, the challenge is not just quantity, but also quality – finding a place that is livable and appropriate. This is particularly true with respect to State-licensed group homes (for children as well as adults) that are often in disrepair or are unsafe for a variety of reasons.

Granted, here in New Jersey, there are significant resources available that make it possible for many people with disabilities to live well in the community, but clearly, we need to do more.

- We need to make housing information more accessible.
- We need to make housing policies more flexible.
- And we need to be more proactive, more innovative, and more sensitive to the diversity of needs and preferences.

After all, when it comes to housing, one size definitely does not fit all.

So, this is the challenge – to meet the needs and preferences of a large, diverse disability community – including for those with significant medical and/or behavioral needs. But this is also an opportunity – an opportunity to take all of the good work that has been done, all of the good efforts by folks in and out of government, to take it all to the next level.

- Exploring new ways to make community-based living available, affordable, safe, and appropriate – to make it a reality for the many people who need it and deserve it, but who are sometimes shut out of it and forced to go without much needed supports, forced to struggle day-in and day-out, sometimes forced to live in institutions.

So, rather than just talk about “the challenge” this morning, I want to talk also about the opportunity and some of the ideas and suggestions we included in our recently released annual report.

To begin, since access to information is key, our first suggestion is the creation of an online, user-friendly disability-focused housing website that would make it easier for individuals and families to make informed choices about State- licensed residences as well as the opportunity to live in the community in a private, family, or other setting.

- Such a website could include a youth portal about residential treatment options available through the NJ Department of Children and Families – a portal that provides background information about the agencies involved, the regions in which they operate, the types of housing available, and the services and supports offered in their residences (including behavior analysts, nurses, and video monitoring technology).
- Similarly, it could also include an adult portal about residential options available through the NJ Department of Human Services – a portal that provides background information about the agencies involved, the regions in which they operate, the types of housing available, and the services and supports offered in their residences (again, including behavior analysts, nurses, and video monitoring technology).
- The website could include background and contact information about private agencies and organizations that offer a range of accessible and affordable housing options available to people with disabilities throughout the State.
- It could include background and contact information for housing and legal advocacy groups available to people with disabilities and their families.
- It could include information about the range of programs – from housing vouchers to housing loans to utility assistance – that exist and how best to access them.
- And very importantly, it could include a platform for individuals and families to share useful information based on their personal experiences.

Taken together, we are recommending a one-stop, easy-to-use, interactive housing web portal for individuals, families, advocates, providers, developers ... anyone and everyone involved in the disability housing space.

- Again, information is key. Information gives people agency and allows them to make informed decisions.

Next, with respect to housing more generally, we recommend some changes to current policies and practices related to congregate living.

In addition to more medical and behavioral group homes, it is clear that we need to think big and think differently. And we need to act with a compelling sense of urgency.

- **Intentional Communities:** For the past several years, there has been increasing conversation about the need for intentional communities, particularly for those with significant medical and/or behavioral needs. Campuses. Farmsteads. Communities with multiple apartments, shared living arrangements, and more. A four-person group home in a suburban neighborhood is good for some folks, but not for everyone. People with disabilities – like people without disabilities – have different needs, different preferences and deserve different choices and options. We need to more proactively explore intentional communities.
- **Housing Technology:** For the past several years, there has also been an active conversation about the use of video monitoring technology in congregate residences. Led by parent advocates, this conversation has resulted in various pieces of legislation, ongoing policy discussions, and an increase in the use of such technology by residential provider agencies. Indeed, at the end of last year, there were 28 agencies with video monitoring polices approved by the NJ Department of Human Services and an additional 9 agencies waiting for approval.

Going forward, this important conversation should continue to balance the right to privacy with the right to be safe, and it should continue driving the effort to make video monitoring technology more readily available in State-licensed settings – something that can benefit both residents and staff, particularly when videos are available to help everyone understand “what” happened and “why” in a particular situation. And again, we should also ensure individuals and families are made aware of the agencies that utilize video monitoring equipment, so they can make informed choices when choosing a residence.

Moreover, we should continue to encourage additional conversation and consideration of other technologies that also can help people with disabilities live safe, fulfilling, independent lives – “smart” technologies related to lighting, door locks, window chimes, bed alerts, medication distribution, temperature controls, and more.

- **Out-of-State Residential Placement:** At times, we learn of housing needs that cannot be met by residential options in New Jersey.
  - An individual with severe challenging behavior, who requires a campus setting for their safety and overall well-being.
  - An individual with a complex medical condition, who requires 24/7 supports, but does not want to live in a nursing home, a hospital, or an intermediate care facility.

Although our State has many housing resources for people with disabilities, at present, we cannot meet everyone’s needs, and therefore, when necessary, the State should be more readily willing to consider out-of-state options.

Currently, the NJ Department of Children and Families does occasionally consider and does occasionally place youth in out-of-state locations. The NJ Department of Human Services, however, does not. Hopefully, this will change.

Granted, an out-of-state placement is often not optimal. Not only can it be more challenging for the State to oversee the care provided; whenever possible, it is usually best to keep an individual close to their natural supports, namely their family.

However, sometimes an out-of-state placement is the best, safest choice available. And sometimes, the family is located physically closer to an out-of-state residence than any available in-state options. Moreover, the financial costs are not necessarily greater in out-of-state residences. In fact, Medicaid regulations may make it possible to fund such placements with a mix of State and Federal funds.

We should therefore more proactively explore out-of-state residential placements when appropriate.

In addition to these recommendations, we need to make changes for those for whom congregate living is not the best option – for those who cannot or who choose not to live in group settings, for those who would rather live alone or with family or friends.

Here are just a few ideas:

- **Accessory Dwelling Units:** In his budget address earlier this year, Governor Murphy expressed support for Accessory Dwelling Units (ADU) – standalone or adjacent housing structures developed on the same property as single- or double-family homes. ADUs are often discussed in the context of residential options for grandparents or other family members. Some municipalities allow them. Some do not. Governor Murphy’s proposal would make monies available to encourage their construction.

For New Jersey’s disability community, this could be a big, important step forward, because ADUs provide another important housing option – one that is affordable, accessible, community-based, and can help make it possible for individuals to benefit from the natural supports provided by family and friends. Hopefully, ADUs will become more common and therefore more readily available.

- **Housing Vouchers and Rental Subsidies:** Fortunately, there are multiple housing voucher programs in New Jersey, including the Supportive Housing Connection, which is particularly important for individuals with intellectual or developmental disabilities. Unfortunately, however, the policies regarding their use are sometimes overly restrictive.
  - The vouchers are based on rent standards developed by the U.S. Department of Housing and Urban Affairs, and although they vary either by county or zip code, they often do not reflect the high rents charged in New Jersey. As a result, many individuals/families are unable to live in their community.
  - These housing vouchers also cannot be used to pay rent in family-owned homes. This is unfortunate, because this makes it harder for individuals to live in their communities and makes it harder for their families to provide all-important natural supports. This, in turn, makes it more necessary for some individuals/families to live in State-licensed settings.

We should revisit our approach to both the use of rent standards and the availability of family homes, thereby making community living a reality for more people with disabilities.

- **Environmental & Vehicle Modifications:** At present, the State helps with environmental modifications for both children and adults with disabilities. From fencing and wheelchair ramps on the outside to more accessible bathrooms and living spaces on the inside, the modifications make it possible for individuals to live in the community, often with family and other natural supports.

However, there are limitations, including a prohibition against increasing the overall size of a privately owned house. Although I generally agree with that limitation, I think the policy should be revisited or waived in extenuating circumstances, particularly for those with complex medical and/or behavioral conditions who cannot be properly supported in State-licensed settings. In such situations, the State could enter into an agreement with the homeowner for reimbursement of the funding if/when the house is sold – similar to the Medicaid “estate recovery” policy that requires reimbursement to the government at the time of a person’s death.

Similarly, the policy with respect to vehicle modifications should be revised to allow for the purchase or lease of vehicles in extenuating circumstances - a critically important consideration for many people who want to live in the community, but who need specialized transportation. Here, too, the State could enter into an agreement that would ensure recovery of the funds used for this purpose.

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So, taken all together, here in New Jersey, it is fair to say that we have both big challenges and big opportunities – challenges and opportunities that call on us to be smart and innovative, to be compassionate and thoughtful, and to act fast.

- Without urgently needed reform – without making safe, appropriate housing options more readily available – many people with disabilities, children as well as adults, will continue to face a housing crisis.

And that is why I am grateful for and excited by today’s conference. Rowan University’s Steve Sweeney Center for Public Policy has brought together a good, important mix of stakeholders – Legislative leaders, some of my Murphy Administration colleagues, as well as some of our partners in the advocacy community, the provider community, and most importantly, the family advocacy community.

- From them, you will learn more about the important work already underway as well as the important work that still needs to get done. You will learn more about the challenges as well as the very real opportunities.

And my hope is that today’s conversation will help jumpstart a larger, statewide conversation about the need to think big and to think differently about housing for people with disabilities ... and about the need to act with a real sense of urgency.

Again, thank you for this opportunity, and thank you for being a part of this all-important conversation.

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