DDAWNY, the Developmental Disabilities Alliance of Western New York is interested in providing input and comment on the Five-Year Consolidated Plans for the County of Erie and the Town of Hamburg and for the ACT Home Consortium including the municipalities of Amherst, Cheektowaga and Tonawanda and the regional Analysis of Impediments to Fair Housing Choice (AI) for all of Erie County, except the City of Buffalo for the period 2015-2019 and the anticipated use of federal CDBG, HOME, ESG and HOPWA funds in 2015 and beyond to address the affordable housing and community development needs identified in the various Consolidated Plans for individuals with intellectual and related developmental disabilities (I/DD).

"A critical consideration in each state is the range of housing options available in the community for individuals with disabilities and whether those options are largely limited to living with other individuals with disabilities, or whether those options include substantial opportunities for individuals with disabilities to live and interact with individuals without disabilities"

Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of Olmstead, June 4, 2013

In particular we wish to comment upon how the Consolidated Plans will address the special needs for housing with supportive services for persons with
I/DD as identified in the various Consolidated Plans' Needs Assessments, and how recent federal guidance in relation to the Americans with Disabilities Act (ADA) and the Olmstead integration mandate by the Departments of Justice, Health and Human Services and Housing and Urban Development has affected current state policy and budgetary decisions by DOB and OPWDD in regard to housing opportunities for this population.

The State and its municipalities face very real challenges in transforming our housing opportunities to meet the housing needs of this population and to do it in a manner compliant with the ADA. These challenges include aging caregivers, a growing school age population, the closure of virtually all residential options of an institutional nature and the fact that funding is not unlimited.

**Aging Care Givers**

In its *Report on the State of the States in Developmental Disabilities 2013: the Great Recession and Its Aftermath*, Broddock, et al, the University of Colorado Coleman Institute for Cognitive Disabilities estimated that 306,376 individuals with Intellectual or Developmental Disabilities reside in the State of New York. 64% or 195,388 reside with a family caregiver. 67,807 or 22% reside in a supervised residential setting and only 14% or 43,181 live alone or with a roommate.

Of the estimated 195,388 individuals living with family caregivers, 39% or 77,173 reside with caregivers who are under the age of 41. At the same time 68,542 individuals (35%) live with family caregivers who are between 41 to 59 years of age. Of great concern are the 49,673 individuals with developmental
As of 2012, an estimated 49,673 Individuals with Intellectual or Developmental Disabilities live with a Family Caregiver aged 60 or Older in New York

disabilities living with caregivers aged 60 or older. These individuals, representing 25% of those living with a family caregiver in New York, are most at risk of homelessness should their family caregivers pass away.

Moreover of the estimated 195,388 individuals with DD being cared for by family caregivers only 27% or approximately 52,630 individuals are currently provided with supports or assistance by the State or provider agencies in the community.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number of Individuals</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Age &lt;41</td>
<td>77,173</td>
<td>39%</td>
</tr>
<tr>
<td>Caregiver Age 41-59</td>
<td>68,542</td>
<td>35%</td>
</tr>
<tr>
<td>Caregiver Age 60+</td>
<td>49,673</td>
<td>26%</td>
</tr>
<tr>
<td><strong>Total: 195,388 Persons</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Students Aging Out

New York and its municipalities also face a growing number of students with disabilities who will soon be aging out of our educational system. Over 1500 students in Western New York are students with disabilities, aged 18 to 21, who will soon be aging out of our school programs 886 of these students reside in
And while SED and OPWDD definitions of who is eligible for DD services differ it is fair to suggest that nearly 400 students with IDD may be aging out of the School system in the next several years.

Of particular concern are those students with disabilities taking the New York State Alternative assessment.

Students eligible for these assessments must have a severe cognitive disability, significant deficits in communication/language, and significant deficits in adaptive behavior. In order to be eligible for the NYSAA, the Committee on Special Education (CSE) for the child must determine that the student requires a
highly specialized education, social, psychological and medical services in order to maximize his or her full potential for useful and meaningful participation in society and for self-fulfillment. The CSE must determine the student requires educational support systems, such as assistive technology, personal care services, or behavioral interventions.

The NYSSAA Secondary ELA is given to students in the fall of the school year they become 17-18 years of age. Students given the NYSSAA in 2011 aged out in June of 2014. SED now indicates an additional 2834 students statewide took the NYSSAA Secondary ELA in the 2013 school year. This includes 159 students in Erie County. The numbers continue to grow and these students are also going to want to live integrated lives in the community.

ICF & DC Closures

In the mid 1970s nearly 30,000 individuals with DD resided in 20 state institutions. As a result of the scandal at Willowbrook on Staten Island, New York State shifted the emphasis of care for people with developmental disabilities from institutional care in State-operated developmental centers to not-for-profit operated community residences. Since that time more than 6,200 community homes were developed and 14 institutions have closed, most recently, the West Seneca Developmental Center, the Monroe County Developmental Center and an institution on Staten Island for those with multiple disabilities.

For the past 30 years these community residences have been the primary method used by the state to address the desire of people with developmental disabilities and their families for long-term living arrangements apart from the family home.

The very successful NYS-CARES program, created in 1998 was intended to address the housing needs of the State’s persons with Developmental Disabilities. This unique and innovative program used a combination of State and Federal funds and was intended to develop 7800 community residential beds to add to the State’s existing 36,000 community-based residential beds. The NYS-CARES program was intended to eliminate the waiting list for persons with developmental disabilities desiring placement in out-of-home residential settings.

Unfortunately, the waiting list for housing continues to grow. As of August 2013, OPWDD had
identified 1002 individuals with developmental disabilities in the Western New York region seeking residential opportunities. Of these individuals, 714 reside in Erie County. An analysis of zip codes indicate that 239 of these individuals awaiting housing opportunities reside in the Amherst-Cheektowaga-Tonawanda Consortium, 278 individuals reside in the Rest of Erie County Consortium and 197 reside in the City of Buffalo.

<table>
<thead>
<tr>
<th>Certified DD Residences in Erie County</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Agency</strong></td>
</tr>
<tr>
<td>State of New York</td>
</tr>
<tr>
<td>Aspire</td>
</tr>
<tr>
<td>Autism Services</td>
</tr>
<tr>
<td>Baker Victory Services</td>
</tr>
<tr>
<td>Claddagh Commission, Inc.</td>
</tr>
<tr>
<td>Community Services for DD</td>
</tr>
<tr>
<td>Heritage Centers</td>
</tr>
<tr>
<td>Heritage Christian Services</td>
</tr>
<tr>
<td>Hillside Children's Center</td>
</tr>
<tr>
<td>LDA of WNY</td>
</tr>
<tr>
<td>People, Inc</td>
</tr>
<tr>
<td>Southeast Community Works</td>
</tr>
<tr>
<td>Suburban Adult Services</td>
</tr>
<tr>
<td><strong>Total Erie County</strong></td>
</tr>
</tbody>
</table>

As of January of last year, the 17 counties of the Western Region contained a total of 7626 beds consisting of both IRA and ICF community residences. Of these beds, the state operates 2393 beds and voluntary not for profit agencies operate community residences with a capacity of 5233.

In Western New York there are a total of 3856 community residence beds operated by the State of New York and voluntary not for profit providers. Current Erie County capacity as of last August was 2277.

The recent closure of the West Seneca Developmental Center permitted the transition of its remaining 80 individuals into more integrated settings in the community. As part of a Transformation Agreement with the Federal Government the State also agreed to close the Finger Lakes and Taconic campus-based ICF/IIDs and transitioned the 148 residents of these institutions into community-based residential settings as of December 2013.
The current capacity of these community residences is insufficient to meet the growing needs of this population and continued expansion of community residences using the existing funding models is untenable from both a fiscal and legal point of view.

Since the last planning process for these Consolidated Plans, there has been a sea change in the State's policy with regard to meeting the housing needs of Persons with I/DD.

<table>
<thead>
<tr>
<th>Certified DD Residences in Erie County</th>
</tr>
</thead>
<tbody>
<tr>
<td>August 2013</td>
</tr>
<tr>
<td>HUD Region</td>
</tr>
<tr>
<td>A-C-T Consortium</td>
</tr>
<tr>
<td>Buffalo</td>
</tr>
<tr>
<td>Rest of Erie Consortium</td>
</tr>
<tr>
<td>Total Erie County</td>
</tr>
</tbody>
</table>

In particular, over the past several years, in part because of the state fiscal crisis and in part because of changes in Federal Medicaid policy, the State has eliminated nearly all funding for new single-purpose congregate housing settings for people with developmental disabilities using Federal Medicaid dollars.

The Federal Government has indicated the type of segregated single-purpose congregate housing setting relied on by the state for the past 30 years may no longer be appropriate or eligible for Federal Financial Assistance in the delivery of home and community based services under the Medicaid program. There must be a range of options. The options can no longer be living with aging parents and then moving to a supervised IRA. The federal government is requiring states, and by extension local municipalities to develop a range of different housing options all supported by the supports and services necessary for individuals to live in the "most integrated setting" appropriate for their needs.

In March the Centers for Medicare and Medicaid Services finalized it's Home and Community Based Services (HCBS) setting rule. The final rule requires all home and community-based settings to meet certain qualifications in order to be eligible for federal financial contributions to state HCBS waiver programs. In New York ninety-one percent of services provided to individuals with I/DD are provided using Medicaid funds, either pursuant to the State Plan (regular Medicaid) or pursuant to several 1915(c) HCBS waivers.
In order to meet the CMS HCBS setting requirements:

- The setting is integrated in and supports full access to the greater community;
- Is selected by the individual from among setting options
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint
- Optimizes autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

The final rule also includes additional requirements for provider-owned or controlled home and community-based settings. These requirements include:

- The individual has a lease or other legally enforceable agreement providing similar protections
- The individual has privacy in their unit including lockable doors, choice of roommates and freedom to furnish or decorate the unit;
- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.

Any modification to these additional requirements for provider-owned home and community-based residential settings must be supported by a specific assessed need and justified in a person-centered service plan.

Although the HCBS rule as originally proposed presumed a "disability-
specific complex” was not a home and community based setting, the final rule recognized the use of the term would have adverse impacts on affordable housing units and eliminated the term "disability-specific complex” and the final rule adopted the terminology "any other setting that has the effect of discouraging integration of individuals from the broader community"

Thus the key concept is does the housing setting discourage integration? If it does it is not an HCBS setting for purpose of Medicaid funding. Recent CMS guidance regarding settings that have the effect of isolating individuals receiving HCBS from the broader community indicates that settings having the following two characteristics alone might, but will not necessarily, meet the criteria for having the effect of isolating individuals:

- The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability.
- The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provide many services to them

The CMS guidance identifies settings it believes isolate people receiving HCBS from the broader community as having any of the following characteristics:

- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.
- People in settings have limited, if any, interaction with the broader community.
- Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).

The State of New York has conducted analysis of the HCBS settings outlined in the final HCBS regulations and has crosswalked the final regulations with OPWDD’s existing regulations, certification standards, and survey processes/protocols. The State believes based upon this crosswalk that all OPWDD residential settings will comply with the CMS HCBS setting requirements, however the State recognizes that the Federal government further requires compliance to equate with the experience and outcomes of individuals receiving services. The State is also embarked upon a yearlong on-site quality assessment process to establish baseline information from which to determine system compliance with the HCBS rule.
While some individuals with developmental disabilities may well choose to live in the type of setting designed specifically for people with I/DD and with other individuals with I/DD and staff, settings which has been the mainstay of housing development for persons with I/DD over the past 30 years, it is clear Federal policy will no longer support the delivery of services to these individuals using Medicaid dollars in all cases.

In addition, as part of a Transformation Agreement with CMS the State of New York has agreed to certain Special Terms and Conditions in relation to its 1115 Partnership Waiver. Among these terms, the state has agreed to phase out all campus-based and non-campus-based and ICF/DD beds and also agreed to comport with CMS requirements for either "Money Follows the Person" qualified residences or into home and community based settings as outlined in the final rule.

Recently and in accordance with this Transformation Agreement, the state announced its plan to close four additional institutional campuses over the next four years, including OD Heck Developmental Center in Schenectady, the Brooklyn Developmental Center in Brooklyn, the Broome Developmental Center in Binghamton and the Bernard M. Fineson Developmental Center in Queens.

These closures will require the state to find more integrated housing opportunities for over 6700 individuals from institutional placements to more integrated settings in the community. This includes 844 additional individuals, who are currently in state-run campus-based institutions and 659 in state-run and 5213 in voluntary provider-run community-based ICF/IID institutions into more integrated settings in the community.

This plan includes opportunities for 1048 people to move into person controlled housing by Oct. 1, 2018.
While the state is proposing to reduce total institutional capacity by 6,716, it is only planning to increase certified residential capacity by 5,030 and will rely on non-traditional capacity for an additional 602 beds. The ICF transition plan will result in the net reduction of 1,084 beds statewide for individuals with I/DD.

According to the Federal Government these community settings may include an individual's private home, his or her family's home or a community residence that is home to four or fewer unrelated individuals.

In its agreement with the Federal Government, New York State has also agreed to increase its utilization of supportive housing options, including "non-traditional housing models" such as "Home of Your Own", Family Care, Shared Living, Customized Residential Options and Assets For Independence/Individual Development Accounts (AFI/IDA).

As then OPWDD Commissioner Burke stated in her April 2013 "Road to Reform" report:

"[T]he Olmstead ruling has at its heart the intention that all individuals should receive services in the most integrated/least restrictive setting possible, it is not enough to simply have people served in the community if they continue to be restricted in their engagement in that community. Therefore, OPWDD will also develop new practices to ensure that individuals already living and being supported in community settings are experiencing and engaging in their communities to the fullest extent."

In its recent June 4, 2013 guidance on the role of housing in accomplishing the goals of Olmstead, the Department of Housing and Urban Development stated:

"The Olmstead decision and subsequent voluntary Olmstead planning and implementation, litigation by groups representing individuals with disabilities, and Department of Health and Human Services and Department of Justice enforcement efforts are creating a dramatic shift in the way services are delivered to individuals with disabilities."

HUD goes on to state:

"The integration mandate of the ADA and Olmstead compels states to offer community-based health care services and long-term services and supports for individuals with disabilities who can live successfully in housing with access to those services and supports. In practical terms,
this means the states must find housing that enables them to assist individuals with disabilities to transition out of institution and other segregated settings and into the most integrated settings appropriate to the needs of each individual with a disability. A critical consideration in each state is the range of housing options available in the community for individuals with disabilities and whether those options are largely limited to living with other individuals with disabilities, or whether those options include substantial opportunities for individuals with disabilities to live and interact with individuals without disabilities.

It is clear in reading the current Consolidated Plans the approach to housing for this population relies heavily upon the use of traditional 24-hour care residences in settings which may, but will not necessarily meet the criteria for having the effect of isolating individuals from the broader community. While DDAWNY believes these settings in most cases permit the type broad interaction with the broader community and thus do comport with new Federal rules and guidance, the use of this setting cannot be the sole means to meet the housing needs of this population.

In addition, the State of New York, as a policy matter has dramatically reduced its commitments to develop this form of housing. New York State is prioritizing ongoing development to address its transformational agenda and the transition of residents of all remaining campus and non-campus-based ICF's to community-based settings. The result is only individuals identified as "Priority 1" are expected to reside in a state certified housing setting. These are a limited number of individuals who currently reside in the community and there is a finding by OPWDD of:

- An abusive or neglectful situation constituting imminent risk of harm
- Imminent danger to self
- Imminent danger to others, or
- Homelessness or in imminent danger of becoming homeless

Individuals considered "Priority 2" or "Priority 3" by the state are expected to find uncertified housing in the community and rely upon natural supports to assist in their day to day needs. These individuals are entitled to appropriate supportive and affordable housing options, which generally are currently unavailable in Erie County.

"Priority 2" individuals include those:

- Living with an aging caregiver or where the caregiver is of failing health where no alternative caregiver is available
Housing Policy for People with Developmental Disabilities

• A living situation which presents a significant risk of neglect or abuse
• Mental/physical condition requires care not available in the present situation
• Where the individual presents an increasing risk to self or others
• Where the individual is affected by court or legislative mandate requiring residential placement.

"Priority 3" Include all who present a need but there is no danger to health and safety of the individual or his/her caregiver. Factors considered by OPWDD include:

• Compatibility of the individual with available services
• Compatibility with the other individuals in a shared living arrangement
• Relative need for supports for daily living

DDAWNY believes it is important that housing policy makers here in Erie County rethink and revise housing policy to allow for a substantial increase in the availability of independent housing options for individuals with intellectual and developmental disabilities.

John R Drexelius, Jr.
Government Relations Counsel
DDAWNY
Law Office of John R. Drexelius, Jr.
PO Box 141
Buffalo, NY 14223
716-316-7552
jrdrexelius@gmail.com