

Housing for Adults With Developmental Disabilities

Sue Richards

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Executive Summary

Adults with intellectual and/or developmental disabilities (“Adults with IDD”) are a heterogeneous group of individuals who live with neurological conditions that emerge in childhood. A developmental disability refers to a condition such as autism, cerebral palsy or epilepsy that results in difficulties in three or more life activities such as language, mobility, learning or independent living. An intellectual disability is a significant limitation in intellectual functioning that negatively impacts social and practical skills. Among adults, about 34% meet the criteria for a developmental disability only; 26% meet the criteria for an intellectual disability; and 40% meet both criteria.

In 2000, researchers estimated a population prevalence rate for adults with IDD at nearly 1% of the adult population. Based on this estimate, there are about 7,200 County adults with IDD although it is unclear whether this estimate accounts for dramatic increases in autism since the late nineties. The Council requested this study to better understand the housing challenges that face adults with developmental disabilities and their families.

Community Housing Models for Adults with IDD

The list of seven living arrangements displayed below was developed by a Committee tasked with identifying housing options for adults with autism. The Committee chose these options and the related examples for each because they were found to “maximize choice and independence” and because they furthered community integration. OLO found many parallels between the examples listed below and the efforts of County housing agencies and their nonprofit partners. However, as explained below, OLO also found that some of these options, e.g. farmsteads, do not comply with a federal rule that establishes privacy and community setting characteristics for adults who receive services through a Medicaid Home and Community Based Services (HCBS) waiver.

A Typology of Community Housing Models with Examples

Living Arrangement	Examples
1 Staying in the Family Home	<ul style="list-style-type: none">• A house donated by a family• Elder Cottages Housing Opportunities• Accessory Apartments
2 Living with a (New) Family	<ul style="list-style-type: none">• The LifeSharing Program• The Domiciliary Care Program
3 Renting an Apartment or a Home	<ul style="list-style-type: none">• Rental Units Owned by an LLC• Rental Units Owned by a Nonprofit
4 Purchasing a Residence	<ul style="list-style-type: none">• Ownership by an Individual• Tenants in Common
5 Shared Housing	<ul style="list-style-type: none">• Group Shared Residence• Housing Match Up• A Lodge Model• L’Arche
6 Intentional Communities	<ul style="list-style-type: none">• An Intergenerational Community• Collaboration with a College or University• Farmsteads• Co-housing
7 Licensed Facilities	<ul style="list-style-type: none">• A private licensed facility• A community supported living arrangement

Source: OLO and Pennsylvania Department of Welfare, Bureau of Autism Services, *Housing Options for Adults with Autism Spectrum Disorder*, April 2010.

Housing for Adults Who Are Eligible for Developmental Disability Administration (DDA) Services

OLO found that County adults with IDD who are eligible for Maryland’s Developmental Disability Administration (DDA) services and for a Medicaid Home and Community Based Services (HCBS) waiver have access to community housing options; however, DDA is revising these options and DDA funding shortages limit access to these options.

Federal Community Inclusion Mandates in the State Service System for Adults with IDD

In 1999, the US Supreme Court held in *Olmstead v. L.C.* that the unjustified isolation of two women with behavioral health and intellectual disabilities in a state hospital constituted discrimination based on a disability under the American with Disabilities Act (ADA) and that public entities must make reasonable accommodations to serve individuals in the least restrictive community settings unless doing so would fundamentally alter their services. *Olmstead’s* community integration mandate covers people in institutional settings, such as nursing homes and intermediate care facilities for the intellectually disabled, as well as those at-risk of institutionalization.

The Centers for Medicare and Medicaid Services (“CMS”) is the agency responsible for the federal administration of Medicaid. In 2014, to further states’ compliance with *Olmstead*, CMS issued a rule to further states’ compliance with *Olmstead*. The “settings rule” provisions specify characteristics that qualify a service location as a community setting and provide guidance for providers on individual’s privacy rights, freedom, autonomy and independence. CMS requires states to develop plans to bring the settings of their Medicaid funded providers into compliance.

DDA’s Proposed Revisions to Comply with the CMS Settings Rule

By January 2018, DDA must file an amendment with CMS to renew its Medicaid HCBS waiver. DDA intends to revise its Residential Services to add a new Supported Living service; to expand the Shared Living service; and to create two Community Living Options. DDA proposes to limit the Community Living Options to 4 participants and require participant choice and leases. Stakeholder feedback suggests agreement with DDA’s vision; however, stakeholders suggest DDA consider higher caregiver rents and work to expand housing options.

Comparison of DDA’s Current and Proposed Residential Service Groups

Current Service Name	Proposed Service Name and Setting Options	
n/a	1	Supported Living (New) – Own Home or Roommate
1 Shared Living	2	Shared Living – Own Home or Companion
	3	Shared Living – Host Home
2 Residential Habilitation	4	Community Living - Group Home (Group Home & Alternative Living Units)
	5	Community Living- Enhanced Supervision (Supports)

Source: DDA.

Approximately 40% of County adults with IDD (2,905 adults) are currently eligible for DDA services and most require an institutional level of care. Thirty percent of County adults with IDD (2,165) currently receive in-home or out-of-home support services; and 10% (740 adults) currently receive community coordination services only.

About 12% of County adults (852 adults) currently receive community residential habilitation services from a licensed provider in either a group home (444 adults) or an alternative living unit (408 adults). Group homes are licensed for four to eight people and alternative living units are licensed for up to three people. Medicaid does not cover room and board expenses for these adults; however, if they are categorically eligible for Medicaid, DDA caps the room and board fee that a licensed residential service provider can assess at \$375 per month. DDA policy authorizes residential service providers and Medicaid recipients to use federal programs to subsidize their rents.

About 88% of County adults (2,000 adults) currently receive DDA services in either a family home or their own home (1,325 adults), or receive coordination services (740 adults). These adults all qualify for publicly funded based long term care in a community setting; however, those who are waitlisted for out of home residential services are only prioritized for immediate services funding if they are at risk of homelessness or otherwise in crisis. The DDA waitlist prioritizes future service funding for people with caregivers who are 65 or older.

State and Local Housing Programs for Adults with IDD

OLO's review of housing resources identified several state and local programs and initiatives that provide capital grants, loans and housing vouchers and other rental subsidies. In Montgomery County, OLO's review found the Housing Opportunities Commission, the Department of Health and Human Services and the Department of Housing and Community Affairs work collaboratively with state agencies and numerous nonprofit partners to administer programs that provide housing grants, loans and rental subsidies or homeownership options for low and moderate income households, including people with disabilities.

At the state level, a collaboration of state agencies and other nonprofits known as the Maryland Partnership for Affordable Housing administers a Maryland Bridge Subsidy rental assistance program; a Section 811 Rental Assistance Project; and the Weinberg Apartment program. HOC is partnering with the Maryland Department of Disabilities in the Maryland Money Follows the Person Bridge Subsidy Program. Woodfield Commons is the County's first Section 811 Rental Assistance Project; and, five Weinberg apartment units are occupied in Takoma Park. Many of these programs have extensive waitlists.

Recommended Discussion Questions

Housing for adults with IDD will likely be an ongoing concern for adults, families, residential service providers and County and state officials. OLO suggests the Council use the following questions to structure a discussion with these groups and representatives as future decisions about this issue unfold.

- Question 1: How well do DDA's proposed revisions to the residential service definitions in its Medicaid Home and Community Based Services Community Pathways waiver align with housing choices and preferences of County adults with IDD and their families? If individuals and families share DDA's interest in these models, what County actions and housing resources could best help achieve their expected impacts?
- Question 2: What opportunities and concerns do residential service providers foresee coming out of DDA's proposed revisions to its Residential Service definitions and/or other changes DDA will be making to comply with the CMS settings rule?¹ What County actions and housing resources could best support providers during this transition?
- Question 3: Are there changes to existing County housing programs that could strengthen linkages to adults with IDD and their families to better support their efforts to realize housing stability in the short term and the long term?

¹ This CMS fact sheet has a useful summary. (<https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf>).

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CHAPTER I. INTRODUCTION

In 2006, the newly elected County Executive Leggett tasked a group of 150 residents with identifying the qualities of life in Montgomery County that matter most. Of eight priority objectives, two – “affordable housing in an inclusive community” and “ensuring vital living for all our residents” – hold particular significance for families who have an adult family member with a developmental disability (DD).

The County’s commitment to affordable housing in an inclusive community can be especially challenging for adults with developmental disabilities. A developmental disability is an umbrella term that refers to a group of neurological conditions that affect an individual’s ability to live independently and engage in community activities. Examples of developmental disabilities include autism, cerebral palsy, epilepsy and intellectual disabilities.

Adults with developmental disabilities (“adults with DD”) are a heterogenous group of individuals with diverse and unique interests who require extra supports to live in their homes, work at their jobs and participate in community activities. Some individuals who have an autism spectrum disorder, cerebral palsy or epilepsy will not have an intellectual disability; others may have an intellectual disability with functional limitations due to cognitive impairments (i.e., trouble remembering, learning, concentrating or making decisions about everyday issues) that range from mild to severe; still others may have an intellectual disability with a psychiatric disorder and/or physical impairment. Roughly half of all people with a developmental disability have a cognitive impairment and about ten percent of this subgroup have severe or profound cognitive impairments.

Housing options for adults with developmental disabilities who receive services from state systems have broadened as a result of the effort to move people from living in institutions to living in the community (deinstitutionalization) and a 1999 Supreme Court decision in *Olmstead v. LC*. Living situations such as institutions for the intellectually disabled, nursing facilities and psychiatric institutions gave way to supervised living arrangements in group homes or apartments or homes in the community with supportive staffing provided on-site or on a drop-in basis.

Notwithstanding these changes, most adults with intellectual and/or developmental disabilities (“adults with IDD”)¹ live with family members, including those who receive services from state service systems and those who do not. Whether adults with IDD are eligible for state services or not, individuals and families are likely to face long wait lists for community housing that they can afford.

The Council requested this study to increase its understanding of the housing challenges that face adults with DD and the families that support them. The Council asked OLO to describe the living arrangements for adults with developmental disabilities; to survey programs in other places; to describe housing programs that currently exist to meet these needs, and to offer suggestions about approaches that may be relevant for Montgomery County.

¹ This report uses the terms “adults with developmental disabilities” or “adults with DD” and “adults with intellectual and/or developmental disabilities” or “adults with IDD” interchangeably.

This study has seven chapters in addition to this introduction, organized as follows:

- II. **BACKGROUND** provides information about disability estimates, select federal disability laws including the Developmental Disabilities Assistance and Bill of Rights Act (the DD Act), a review of methods for estimating the developmental disability population, and estimates of County adults with IDD and their living arrangements;
- III. **FAMILY AND COMMUNITY HOUSING MODELS** summarizes a typology of seven community housing approaches that can support adults with DD;
- IV. **STATE AND LOCAL HOUSING PROGRAMS** describes state and local housing programs that provide rental subsidies, homeownership options and funding to develop permanent supportive housing for adults with disabilities;
- V. **HOUSING IN MARYLAND'S DEVELOPMENTAL DISABILITY SERVICE SYSTEM** describes the residential services and housing options available in the state's service system for adults with IDD; and
- VI. **FINDINGS AND RECOMMENDED DISCUSSION ISSUES** offers OLO's findings and recommended next steps.
- VII. **AGENCY COMMENTS** presents information about comments from the County agencies who contributed to this report.

METHODOLOGY AND ACKNOWLEDGEMENTS

OLO staff member Sue Richards conducted this study with much needed support from co-workers Leslie Rubin, Kelli Robinson and Stephanie Bryant. OLO gathered information through document reviews, interviews with County Executive branch staff, Housing and Opportunities Commission staff, Maryland state employees and community members. OLO received a high level of cooperation from everyone involved in this study and appreciates the time and insights of everyone who shared their views.

OLO particularly appreciates the time and contributions of Uma Ahluwalia, Jay Kenney, Kim Mayo, Eldora Taylor, Amanda Harris, Sara Black and Betsey Luecking in the Montgomery County Department of Health and Human Services; of Clarence Snuggs, Jay Greene and Shelia Schmeidel in the Montgomery County Department of Housing and Community Affairs; and of Shauna Sorrells, Fred Swan and Susan Smith at the Housing Opportunities Commission. OLO would also like to thank Patricia Sylvester in the Maryland Department of Disabilities, Judy Pattik in the Developmental Disabilities Administration and Diane Dressler.

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CHAPTER II. BACKGROUND

Adults with IDD require extra supports to live in community housing. This ties Montgomery County's objectives of "affordable housing in an inclusive community" and "vital living for all" not only to protections for persons with disabilities in federal law but also to state systems that fund, deliver and coordinate medical care, long term care and housing services for adults with developmental disabilities. This chapter introduces a conceptual framework for defining "disability," presents an overview of the federal Developmental Disabilities Act and key components of the federal governance structure for people with disabilities, describes efforts to quantify and assess the needs of persons with IDD and presents estimates of County adults with IDD and their living arrangements.

A. An Overview of Disability Models, Terms and Survey Questions

A disability is an impairment due to a physical, mental or psychological condition that causes a difficulty in completing an activity that is part of an individual's daily routine or makes it challenging to engage in community life. This section briefly introduces some of the concepts, terms and definitions used to structure the delivery of services to people with disabilities.

1. Models and Definitions of "Disability"

Researchers often focus on how to define the term "disability." A 2011 academic review in the journal *Health Policy and Planning* describes two models on opposite ends of a spectrum that describe the term (with many hybrid definitions combining aspects of the two):¹

- A **medical model**, which attributes disability to an individual's medical diagnosis, can identify persons with service needs for health and social policy design; and
- A **social model**, which perceives disability as an outcome of a relationship between a person and his or her environment, can be useful for assessing equality of opportunity.

Two World Health Organization (WHO) classifications are widely used to define the term "disability." The first classification, WHO's International Classification of Diseases ("ICD"), includes examples of health conditions that include "diseases, injuries, health disorders, and other health related conditions."² The second classification, WHO's International Classification of Functioning, Disability and Health ("ICF"), "recognizes disability as a dynamic process that involves the interaction of a person's health condition, personal characteristics, the physical environment and the social environment."³ As a

¹ Michael Palmer and David Harley, "Models and measurement in disability: an international review," *Health Policy and Planning* (2011) [hereinafter "Models and measurement in disability"]. At <https://academic.oup.com/heapol/article/27/5/357/749458/Models-and-measurement-in-disability-an-international-review> (Moumen, 2011).

² *A Guide to Disability Statistics*, pages 4-6.

³ Benjamin H. Harris, Gerry Hendershot, and David C. Stapleton, *A Guide to Disability Statistics from the National Health Interview Survey – Disability Supplement*, Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, October 2005, page 4. [hereinafter "*A Guide to Disability Statistics*"]. At <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1206&context=edicollect>.

synthesis of the medical and social models: “the ICF combines a biological understanding of impairment with the social dimensions of disability.”⁴

Per the ICF, a disability is the presence of an impairment, an activity limitation and/or a participation restriction along with the presence of a “health condition.” The ICF terms are defined as follows:

- An **impairment** is “a significant deviation or loss in body function or structure” such as the loss of a limb or the loss of hearing or vision;
- An **activity limitation** is “a difficulty an individual may have in executing activities” such as trouble dressing, bathing, using the telephone or preparing a meal;
- A **participation restriction** is “a problem that an individual may experience in involvement in life situations” such as difficulty participating in the work place due to an issue with the physical work environment; and
- **Disability** is the presence of an impairment, an activity limitation and/or a participation restriction.

These ICF concepts bridge the medical and social models of disability because they allow these four key concepts to be viewed collectively or grouped separately. Specifically,

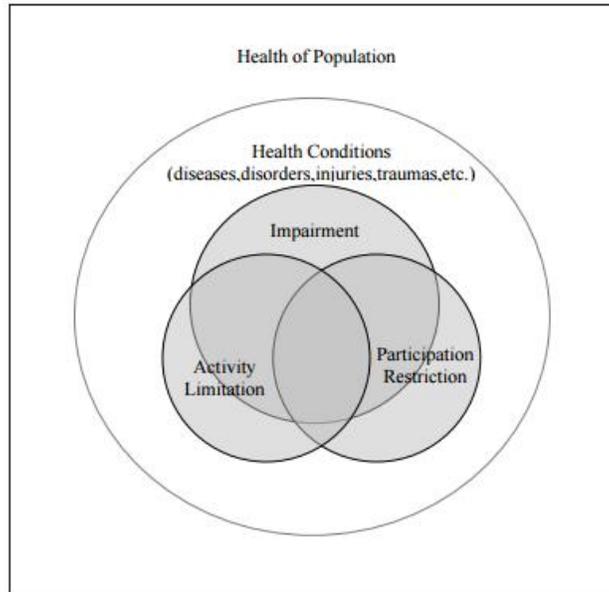
- Viewed together, these concepts define disability broadly as a social pattern that includes any impairment, limitation or restriction. This broad, more inclusive ICF definition of disability aligns with the Americans with Disabilities Act which defines a disability as “a physical or mental impairment that substantially limits one or more of the major life activities, a record of such an impairment or being regarded as having such an impairment.”
- Viewed separately, these four ICF disability concepts permit a two-part disability definition that separates the medical and social models. This view distinguishes between an impairment related to the function or structure of an individual (the first concept) and a functional restriction that limits an individual’s ability to care for themselves or to engage socially (the second and third concepts). In support of this definition, Eggers and Moumen, in a 2011 review of disability variables in the American Housing Survey prepared for HUD, advise it is not only important to distinguish between the impairment and its effects but also to remember that the effects of the impairment depend on the environment or the situational context⁵ For example, in thinking about housing and disability, a living arrangement is an example of a situational context that may influence the effects of an impairment.

The chart on the next page provides a visual illustration of the interrelation of the variables in the ICF model.

⁴ Models and measurement in disability, page 359.

⁵ Frederick J. Eggers and Fouad Moumen, *Disability Variables in the American Housing Survey*, US Department of Housing and Urban Development, Nov. 2011, page 1. [hereinafter “*Disability Variables in the AHS*”].).

Chart 1. Simplified Conceptual Model of Disability Using ICF Concepts⁶



2. Counting Individuals with Disabilities

In 2008, following a design, review and testing period of over ten years, Census Bureau researchers included six questions in the American Community Survey (ACS) that were carefully crafted to collect data about the most important disability characteristics while imposing a minimal burden on the respondents.

The working groups that developed these questions were tasked with measuring disability using a definition of disability that aligned with that found in the Americans with Disability Act (ADA) and meeting the needs of federal agencies for specific information. They adopted a definition of disability as a social process, incorporating concepts from the ICF disability model and another social disability model developed by the Institute of Medicine, a peer institute of the National Academy of Sciences.

The six ACS questions listed below are organized into two groups to highlight the distinction between impairments and an impairment's effect in a particular environment that Eggers emphasized.

The four questions in the first group reflect agreement among working groups over several years that the sensory, cognitive and physical domains were sufficiently representative of all impairments. The two questions in the second group address an individual's functional abilities in two situational contexts – in the home and outside the home. The wording of the first question does not explicitly relate functional difficulties to an impairment whereas the second question does. Population health

⁶ A Guide to Disability Statistics, page 7.

researchers can use these two questions to monitor independent living capabilities or the need for personal assistance or assisted living services.⁷

Table II-1. Questions Related to Disability from the American Community Survey

Impairment questions	
1.	Is this person deaf or does he/she have serious difficulty hearing?
2.	Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
3.	Because of a physical, mental or emotional condition, does this person have serious difficulty concentrating, remembering or making decisions?
4.	Does this person have serious difficulty walking or climbing stairs?
Functioning questions	
1.	Does this person <u>have difficulty</u> dressing or bathing?
2.	Because of a physical, mental or emotional condition, does this person <u>have difficulty</u> doing errands alone such as visiting a doctor's office or shopping?

Source: American Community Survey

Versions of the ACS question set were subsequently adopted as part of the American Housing Survey, the Bureau of Labor Statistic's Current Population Survey and the Census Bureau's Survey of Income and Program Participation.

Table II-2 displays ACS estimates of the number of people with a disability in the County. About 80,000 people or 8% of the County population live with a disability. For most people, the likelihood of living with a disability increases rapidly after age 65: while 16% of 65 to 74 year-olds live with a disability, 45% of individuals 75 and over live with a disability.

Table II-2. ACS Population and Disability Estimates for Montgomery County, 2015

Age Group	Total Population	Any Disability		No Disability	
	#	#	%	#	%
Under 5 years	66,557	440	1%	66,117	99%
5 to 17 years	173,551	6,105	4%	167,446	96%
18 to 34 years	214,504	7,818	4%	206,686	96%
35 to 64 years	423,006	26,130	6%	396,876	94%
65 to 74 years	73,958	11,946	16%	62,012	84%
75 years and over	57,602	25,872	45%	31,730	55%
Total	1,009,178	78,311	7.8%	930,867	92%

Source: American Community Survey 2011-2015 5-Year Estimates, Table S1810.

⁷ Disability Variables in the AHS, p. 24.

B. Key Federal Disability Laws

An array of federal laws establishes the governance structure that protects the civil rights of people with disabilities. For people with developmental disabilities, the Developmental Disabilities Assistance and Bill of Rights Act (“the DD Act”) is important because it provides federal funds to states and public and nonprofit entities for research, advocacy and training programs. The DD Act does not authorize federal funds for direct services; however, its programs are meant to help states and others plan and coordinate services and provide protection and advocacy on behalf of individuals with IDD.

The other laws described below establish civil rights and provide funding for people with disabilities generally. Together, these laws ensure equal opportunities for people with disabilities to participate in society while also establishing a framework to help states coordinate the delivery of services to adults with developmental disabilities.

1. The Developmental Disabilities Assistance and Bill of Rights Act (“the DD Act”)

The Developmental Disabilities Assistance and Bill of Rights Act originated as Title I of the Mental Retardation Facilities Construction Act of 1963 (P.L. 88-164).⁸ This law, which was part of President Kennedy’s initiative to federally fund the construction of community mental health centers, led to many states reducing the population of state institutions, but it did not adequately fund community-based care. As a result, many individuals remained with their families or were left homeless.

DD Act Amendments of 1970. In 1970, Congress passed the Developmental Disabilities Services and Facilities Construction Amendments (P.L. 91-517). This legislation responded to the concerns of families unable to care for their family members at home by promoting the growth of adult community services. It also created “developmental disabilities” as a legal term to describe people who had traditionally been served in state-operated residential institutions and were expected to be served by community-based organizations. Thus, usage of the term “developmental disability” confers a service eligibility status while the term “intellectual disability” refers to a clinical diagnosis.

Some organizations, such as the American Association for Individuals with Intellectual and Developmental Disabilities (AAIDD), have paired the terms “intellectual” and “developmental” disabilities; however, these terms refer to two separate groups of people, with some overlap between the two. As Viriyangkura explains,

There is overlap between the ID and DD populations, but these two populations are not the same. Larson, Lakin, Salmi, Scotte and Webster (2010) presented data indicating that there were many people who qualified for a diagnosis of ID but were not served by the adult service system nor included in the population that is described in the DD Act, and there were many others covered under the DD Act who did not meet criteria for an ID diagnosis. Although a discussion of the reasons why this is the case is beyond the scope of this dissertation, it is relevant to point out that people with ID and people receiving services through state DD agencies are intersecting populations but are not the same population. What the two groups

⁸ This study updates older language and terms for individuals with cognitive difficulties with the term “intellectual disability” except when the language is part of a specific title or reference.

share in common is a need for extra supports that most others in modern society do not need. (Thompson & Wehmeyr, 2008).⁹

The 1970 amendments also authorized federal funds for State planning, services and construction of facilities for individuals with developmental disabilities and required a state plan that designated a planning and advisory council.

DD Act Amendments of 1975 (P.L. 94-103). The 1975 law, the Developmentally Disabled Assistance and Bill of Rights Act, established funding for state protection and advocacy programs to protect the rights of people with developmental disabilities. The law also authorized these programs to pursue legal, administrative and other remedies to ensure the protection of these rights.

DD Act Amendments of 1978 (P.L. 95-602). The 1978 reauthorization of the DD Act expanded the population covered by the Act and replaced a categorical approach to defining the covered population with a functional approach.

DD Act Amendments of 1984 (P.L. 98-527). The 1984 amendments completely reorganized the DD Act. They added a statement of purpose that emphasized help to assure that individuals with developmental disabilities achieved their potential through independence and community integration; and they added employment related activities as a priority service while retaining authorization for social services only on a nonpriority basis. The amendments also authorized services to promote and coordinate activities to prevent developmental disabilities.

DD Act of 2000 (P.L. 106-402). The DD Act was last reauthorized in 2000. As it stands today, the intent of the DD Act is to help individuals achieve independence, productivity and inclusion in the community. It does this by assuring that “individuals with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under the law.”¹⁰

The DD Act does not fund direct services; instead, it funds an infrastructure of research, training and advocacy organizations and state councils. These entities “are essential in helping states’ Medicaid agencies, developmental disabilities agencies, schools, and other providers to meet the mandates of the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the Olmstead decision through advocacy, research, and training that assures that individuals with significant disabilities are served in the community, rather than in institutional settings.”¹¹

⁹ Yuwadee Viriyangkura, “Understanding The Support Needs Of People With Intellectual and Related Developmental Disabilities Through Cluster Analysis And Factor Analysis of Statewide Data,” (2013). Theses and Dissertations. Paper 75., page 6.

¹⁰ <https://www.aucd.org/template/page.cfm?id=516>. Accessed July 1, 2017

¹¹ <https://www.acf.hhs.gov/sites/default/files/add/DDNetworkPaperFINAL.pdf>

2. The Americans with Disabilities Act of 1990 (ADA)

The ADA is a broad civil rights law that prohibits discrimination on the basis of disability in many domains of community life, including employment (Title I), state and local government activities and programs (Title II), public accommodations and commercial facilities (Title III), telecommunications (Title IV) and miscellaneous items (Title V). The ADA's definition of a person with a disability extends protection to a person who:

- 1) has a physical or mental impairment that substantially limits one or more major life activities; or
- 2) has a history or record of such an impairment; or
- 3) is regarded as having such an impairment.

"Major life activities" means the ability to complete key functions such as self-care, completing manual tasks, walking, seeing, hearing, speaking, learning and working. Determinations about impairments that substantially limit a major life activity are made on an individual, case-by-case basis. Judgment about whether a "substantial limitation" exists is based on how a life activity can be performed by an individual as compared to others in society.

Key provisions in each of the five titles prohibit discrimination on the basis of disability by establishing standards so that people with disabilities receive the same treatment as people without disabilities; so that new building construction is accessible to people with disabilities; and so that reasonable accommodations for people with disabilities are provided unless doing so would create an undue burden or require the fundamental alteration of a program or service.

In 2008, Congress enacted amendments to the ADA ("The ADA Amendments Act of 2008") to address concerns that prior Supreme Court rulings based on the 1990 law had interpreted the ADA's definition of a disability too narrowly. Congress clarified its intent that the definition of "disability" be interpreted in favor of broad coverage of individuals to the maximum extent permitted by law.

3. The Fair Housing Act of 1968 (FHA)

The FHA applies to entities in the housing market, including property owners, property managers, real estate agents, lenders and homeowner and condominium associations. The FHA requires that housing providers must not discriminate on the basis of disability; that they must make reasonable accommodations in their policies and operations so that people with disabilities are afforded equal opportunities to use and enjoy a dwelling unit and a facility's public spaces; and, that they must allow people with disabilities to make reasonable accommodations to their dwelling units and to common use areas. The FHA also specifies design and construction requirements that apply to new buildings with units occupied after March 1991.

4. Sections 503, 504 and 508 of the Rehabilitation Act of 1973

The Rehabilitation Act authorizes funding for disability-related activities including vocational programs and independent living programs. Similar to Title II of the ADA, the key provisions in Section 504 require entities to ensure that their communications with people with disabilities are as effective as their communications with people without disabilities; to make reasonable modifications in policies and operations that deny equal access to people with disabilities unless this results in a fundamental

alteration of a program or service; and, to ensure that people with disabilities are not excluded from programs and services due to inaccessible facilities.

The Rehabilitation Act is important because it significantly expanded the types of organizations that must extend protections for people with disabilities by including entities that receive federal financial assistance from any federal executive department or agency. As a result, its provisions apply to institutions such as hospitals, colleges, public housing authorities and mental health centers.

It is also important because it is the first time that people with disabilities as a group are identified as a separate class, instead of the identification being based on a diagnosis.

5. *Olmstead v. L.C.*

In June 1999, the US Supreme Court held in *Olmstead v. L.C.*¹² that, under the ADA, states could no longer confine people with disabilities in restrictive settings. The case involved two women in Georgia with behavioral health and intellectual disabilities who were confined to a state hospital despite determinations by their physicians' that they could live safely in a community setting.

The Court's decision held that the unjustified isolation of the women constituted discrimination based on a disability both because isolated settings perpetuate beliefs that people with disabilities are incapable of participating in community life and because these settings can severely limit everyday activities.

The Supreme Court ruled that public entities must make reasonable accommodations to comply with the ADA's integration mandate unless doing so would fundamentally alter services. Alternatively, a state could develop a comprehensive plan for placing individuals in less restrictive settings with the goal of integrating individuals with disabilities into mainstream society to the fullest extent possible.

Besides adults with intellectual and developmental disabilities (IDD) living in institutions for the intellectually disabled, *Olmstead's* community integration mandate also covers people in nursing homes as well as elderly individuals and adults with disabilities who currently live in the community and are at-risk of institutionalization. Together, the deinstitutionalization movement and *Olmstead* are re-conceptualizing and replacing long term care settings for adults with IDD and others with individualized housing options.

C. Medicaid Funding and Housing in an Inclusive Community

A 2011 review of the DD Act found that "although the original intent of Congress was that the Administration on Developmental Disabilities would encourage collaboration among agencies that manage key domains in the life of people with developmental disabilities, such collaboration is lacking. Today, federal developmental disability policy is established, primarily by default through the reimbursement mechanisms of the Centers for Medicare and Medicaid Services."¹³

¹² *Olmstead v. L.C.*, 527 U.S. 581 (1999).

¹³ https://www.aucd.org/docs/NCD%20report%20-%20rising_expectations_02-15-11.pdf

Medicaid, which operates as a federal state funding partnership, is the primary source of funding for long term care services and supports for adults with IDD and others but typically does not pay for the housing where care is received in community. Over time, the federal government has instituted a series of rule changes to Medicaid to further de-institutionalization and help states comply with *Olmstead's* community integration mandate. In part, these changes authorize states' access to Medicaid's leveraged financing to fund long term care services to defined groups of people, such as the elderly or adults with IDD, in community instead of institutional settings.

However, since Medicaid rules do not permit reimbursements for room and board payments in community settings, the strategy of providing states Medicaid reimbursement for services in community settings without specifying a source of funds for housing resolves one issue and creates another. Over time, states have developed approaches that specify sources of funds or set payment caps for housing costs; however, states are still developing systematic approaches to sources of funding for newer settings characterized as individualized housing options.

In 2014, the Center for Medicare and Medicaid Services (CMS) issued a new regulation – the “settings rule” – designed to ensure both that long term care service providers abide by principles of self-determination for their clients and that Medicaid clients receive services in integrated settings that encourage community engagement. Because this rule applies to long term care settings for residential services, it has the potential to significantly affect how those who currently rely on Medicaid funds provide residential services in various types of settings. It may also impact families of individuals with IDD and state and local officials who focus on the availability of affordable housing for adults with IDD. See Chapter V for more details about the new CMS rule.

D. Intellectual and Developmental Disabilities Service System Concepts and Estimates

Precise counts of the number of individuals with developmental disabilities are difficult to compile. Congress intended that the DD Act definition of a developmental disability confer service eligibility; however, the task of operationalizing the definition in the DD Act and aligning it with available disability survey data has challenged researchers. This section describes the definition in federal law and presents County population estimates based on two estimating methods.

1. Definitions

The phrase “intellectual and development disabilities” (IDD) refers to a population that experiences a wide variety of lifelong cognitive or physical impairments. These difficulties, which arise and are identified between birth and young adulthood, negatively affect an individual's development and cause significant limitations in intellectual functioning and/or adaptive behaviors.

As noted earlier, Congress established the term “developmental disabilities” in law to refer to a population that receives services from disability service organizations. It encompasses conditions such as autism, down syndrome, epilepsy, Fragile X syndrome and intellectual disabilities. Specifically, the

1990 Developmental Disabilities Assistance and Bill of Rights Act (DD Act) defines a developmental disability (DD) as a:

- [A] severe, chronic disability of an individual that
 - (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (ii) is manifested before the individual attains age 22;
 - (iii) is likely to continue indefinitely; and
 - (iv) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (a) self-care,
 - (b) receptive or expressive language,
 - (c) learning,
 - (d) mobility,
 - (e) self-direction,
 - (f) capacity for independent living and (g) economic self-sufficiency; and
 - (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.¹⁴

Intellectual disabilities (ID) are a subset of developmental disabilities. However, while a developmental disability designates an individual's status as a service system recipient, an intellectual disability is based on a clinical diagnosis. The AAIDD defines an intellectual disability as:

[S]ignificant sub-average intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living social skills, community use, self-direction, health and safety, functional academics, leisure and work with such limitations manifested before age 18.¹⁵

A diagnosis of ID and a determination of DD both occur during the developmental years. Because this phase of the lifespan and the definitional criteria for these disabilities are both fluid concepts, prevalence rates for ID and DD are both higher in childhood and adolescence than adulthood. As

¹⁴ *Developmental Disabilities and Bill of Rights Act* cited in Charles Moseley, Ed.D and K. Charlie Lakin, PhD., *Assessment and Analysis of the Service Needs of Washington, D.C. Residents with Intellectual and Developmental Disabilities - Final Report*, National Association of State Directors of Developmental Disabilities Services, June 1, 2011, page 2.
https://ddc.dc.gov/sites/default/files/dc/sites/ddc/publication/attachments/FinalReportSupportNeedsDCResident_s.pdf. Accessed April 27, 2017

¹⁵ Ibid.

Moseley and Lakin explain:

Because age-related functional skills vary from age group to age group, not all individuals who are identified as having ID and DD in one period of their life will be so identified in another. Most notably in that regard, it has long been recognized that the school years bring the highest rates of identification of students with intellectual and related conditions as the demands of academics in school raise the concerns, trigger the assessments and lead to diagnoses of intellectual disability, multiple handicap, autism and other related conditions that allow the provision of special education. In adulthood, the “active prevalence” of ID and related conditions (i.e., those who are recognized as having the conditions) decreases substantially as the demands of school are replaced by very different demands as well as different sources of opportunity and support for independent living.¹⁶

2. Estimating Methods for Developmental Disability Populations

Individuals with intellectual and/or developmental disabilities (IDD) account for roughly 1% to 2% of the total population; however, no national methodology exists to develop estimates of adults with IDD for service planning purposes. This section presents two sets of estimates based on past research efforts that generated population prevalence rate estimates¹⁷ based on survey data.

a. Boggs and Henney Research Estimate Method (1979)

In 1979, Elizabeth M. Boggs and R. Lee Henney conducted research to produce national- and state-level estimates of children and adults eligible for services under the DD Act.¹⁸ The estimate, for non-institutionalized individuals only, was based on an analysis of the Report of the Survey of Income and Education conducted in 1976 by the U.S. Census Bureau and a definition of major life activities as defined in the DD Act at the time.

In their report, Boggs and Henney noted several limitations of their estimates. They stated that their method probably overestimated prevalence in the older adult age group and overcounted people with sensory or physical handicaps. They took several steps to adjust their estimates to account for these and other limitations.¹⁹ Table II-3 applies the estimates of disability prevalence from Boggs’ and

¹⁶ Ibid, pages 4-5.

¹⁷ A prevalence rate is the occurrence of a defined characteristic in a population group or subgroup. Often, prevalence rate estimates can provide a basis for service level estimates; however, that is not the case for these prevalence estimates due to the plethora of differences in operational definitions, a lack of agreement about the definitions and meaning of commonly used terms and changes in the conceptual models used to frame disability policy discussions over time.

¹⁸ https://mn.gov/mnddc/dd_act/documents/EMC_Institute/83-NFD-EMC.pdf.

¹⁹ For example, they provided estimates for each major life activity by age group but were not able to address the criteria of limitations in three or more areas of activity nor the intent of the DD Act to not count an individual with a severe disability such as deafness or blindness but to count individuals with either a single impairment that created multiple severe limitations or a combination of impairments that created severe limitations; they adjusted

Henney’s research to census estimates of the County population as of July 1, 2014 by age group. This approach yields an estimate of 15,270 to 16,180 individuals with developmental disabilities, including 9,650 adults ages 18 to 64 and 700 seniors.

Table II-3. Estimates of the County Non-Institutionalized Population with Developmental Disabilities – Boggs Method

	Infants Age 0-2	School Age 3-17	Adults Age 18-64	Seniors Age 65+	Subtotal for Estimates	Total FY2015 Population
Total Population	40,400	202,150	647,320	140,570	1,030,480	1,030,480
DD as % of population	3.0	1.87	1.49	0.5	NA	1.57
Number in DD population	1,210	3,780	9,650	700	15,270	16,180
Major Activity		Learning	Work			

Source: OLO based on Annual Estimates of the Resident Population for Selected Age Groups by Sex: April 1, 2010 to July 1, 2015 and Prevalence Rates from Boggs and Henney. Estimates as of July 1, 2014. Census estimates are rounded.

a. Larson Research Estimate Method (2000)

In 2000, Larson et. al. published research based on an analysis of the 1994 National Health Institute Survey – Disability Supplement.²⁰ This research provided multiple sets of population prevalence rate estimates for IDD, including age-and settings-based estimates and estimates for the total population.

Based on Larson’s household prevalence rate estimates and census estimates, there are an estimated 14,460 individuals with IDD in the County living in household settings – including approximately 6,220 adults age 18 and older, 5,130 youth ages six to 17, and 3,110 children. These data are summarized in Table II-4 on the next page.

The household prevalence rates also show that prevalence rates for children (38.4/1,000 children) and youth (31.7/1,000 youth) are much higher than the rate for adults (7.9/1,000 adults). Calculations based on separate rates for different conditions (not shown) indicate that the definition of developmental delay from birth to age 5 adds an estimate of over 2,700 children.

their initial estimates of adults with disabilities to address those who acquired disabilities before age 22; and, they adjusted the estimate for adults with developmental disabilities over 65 to recognize their higher mortality rates.

²⁰Larson, Sheryl A. et al. “MR/DD Data Brief: Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994.1995 HIS-D Introduction,” April 2000. Retrieved September 10, 2016. https://www.researchgate.net/publication/11930914_Prevalence_of_Mental_Retardation_and_Developmental_Disabilities_Estimates_From_the_19941995_National_Health_Interview_Survey_Disability_Supplements.

Table II-4. Estimates of the County Population with Developmental Disabilities – Larson Method

	Birth to 5 Years Old	School Age 6-17	Adults		Subtotals for Age	Total Population
			Age 18-64	Age 65+		
Total Population	80,910	161,680	647,320	140,570	1,030,480	1,030,480
IDD as % of population	3.84	3.17	0.78	0.78	NA	1.49
Number in IDD population in Household Settings	3,110	5,130	5,110	1,110	14,460	NA
# of adults in IDD population in Residential Settings (0.12%)	Not Applicable	Not Applicable	780	170	950	NA
Total IDD Population Estimate	3,110	5,130	5,890	1,280	15,410	15,350

Source: OLO Annual Estimates of the Resident Population for Selected Age Groups by Sex: April 1, 2010 to July 1, 2015 and Prevalence Rates from Larson. Estimates are rounded.

For the non-institutionalized population, Larson found that 48% meet the criteria for a developmental disability only; 24% meet the criteria for an intellectual disability only; and 28% meet the criteria for both. By comparison, among the non-institutionalized adult population, Larson found that 34% meet the criteria for a developmental disability only; 26% meet the criteria for an intellectual disability only; and 40% meet the criteria for both.²¹

Larson’s research also generated prevalence rate estimates for individuals with ID or DD who were living in residential settings such as group homes, nursing homes or psychiatric facilities. According to Moseley and Lakin, individuals with ID accounted for 95.9% of all individuals in these settings and those with DD, but not ID accounted for the remaining 4.1%.

The prevalence rate estimates in Table II-4 show that the additional population from these settings increases the overall adult prevalence rate estimate from 0.78% to 0.90%. When these rates are applied to the adult population estimate, they add 950 individuals in residential settings. This increases the estimate of adults with IDD from 6,220 to 7,170 and the overall estimate from 14,460 to 15,410.

²¹ For more details about the differences between intellectual and developmental disabilities, see Gerry Hendershot, Statistical Analysis Based on the National Health Interview Survey on Disability: A Bibliography and Summary of Findings, April 2005. <http://rtc.umn.edu/docs/NHIS-DBibliography.pdf> Accessed July 2017.

3. Functional Assessment Tools and Levels of Support Intensity

The shift from a medical to a social model of disability was accompanied by a shift from a medical to a functional description of a disability as well. Instead of focusing on biological characteristics, a functional description emphasizes indicators of an individual's performance on tasks required to function successfully in society.

Functional descriptions compare a person's current skills and the skills needed to accomplish a task or goal. This in turn provides the basis for the types and levels of support needed to live independently or whether the types of supports and the frequency of assistance require a 24-hour supervised living arrangement.

This new approach has led developmental disability advocates and state programs to develop functional assessment tools – sets of questions that assess an individual's health conditions and functional needs based on their physical and cognitive abilities. State developmental disability agencies can use functional assessment tools to determine service eligibility only or to determine service eligibility, service planning and service budgets.

No national standards or requirements exist for functional assessment tools. In a 2014 report to Congress, the Medicaid and CHIP Payment and Access Commission (MACPAC) found 124 different functional assessment tools in use for assessment and care planning purposes – including a mix of professional and homegrown tools. MACPAC noted that this variety limits comparisons of service levels and costs among the states' long term services and supports (LTSS) delivery systems.

Maryland's Developmental Disability Administration (DDA) began using the Supports Intensity Scale (SIS), a functional assessment tool used widely throughout the U.S. that provides a standardized measure of the intensity of support needs, in 2010. In contrast to some states that are using SIS to make both eligibility determinations for the Medicaid HCBS comprehensive waiver as well as service plan and budget decisions, DDA's use of SIS is more limited.

The SIS questions cover three areas of potential support needs:

1. The frequency, time and level or type of support an individual needs in each of six different life activity areas;
2. The supports an individual needs for protection and advocacy activities; and
3. An assessment of the types and intensity of supports an individual needs to address medical and behavioral concerns.

With the shift to a functional description of disabilities has come research on how assessment tools can help determine budgetary needs based on the level of supports needed. Yuwadee Viriyangkura, a doctoral student at Illinois State University, completed research in 2013 designed to increase the

knowledge around this issue²² analyzing a dataset of nearly 4,000 individuals in Colorado’s Comprehensive Home and Community Based Waiver Program who had completed SIS assessments. (As explained in Chapter V, states use Medicaid waiver programs to serve individuals who require an institutional level of care in community settings. These individuals are a subset of all adults with IDD.)

Viriyangkura found that people with the most intense support needs in one area (e.g., home living) also had the most intense needs in other areas (e.g., social or employment support needs) and, thus, also the highest support need index scores. The data also showed that this sample of people could be classified into five groups based on the level of supports they required.

Table II-5 summarizes the groups of individuals based on the intensity of their support needs and details about the variation in types of support needs for participants. Viriyangkura cautions that the characteristics are descriptive and are not meant to reflect the supports and services that people should be receiving but can provide information about the most appropriate type of living arrangement and/or level of supervision that an individual needs.

Table II-5. Descriptive Characteristics of People with IDD in Five Support-Intensity Clusters (n=3998)

Group	Characteristics of Individuals	#	%
Support Needs Level 1	People with the lowest intensity of support needs. More likely than others to use individual and supported employment services and to live in the least restrictive community residences. Very few judged to pose a community risk.	320	8%
Support Needs Level 2	Slightly more intense support needs compared to Level 1 but less intense needs than 75% of people with IDD. More likely to work in community jobs (individual and supported employment) than people in other clusters, except for Level 1. Four percent posed a community risk.	680	17%
Support Needs Level 3	People with support needs that measured in the mid-range. Eleven percent posed a community risk – twice the percentage of any other level. Residential living arrangements were more diverse compared to the first two levels and this group had the highest percentage of sheltered employment.	880	22%
Support Needs Level 4	The largest group. Likely to use community services and habilitation services, but few in either supported employment or individual jobs. Living arrangements for this group were diverse.	1,158	29%
Support Needs Level 5	People with the highest intensity of support needs. Far more likely to live in more restrictive housing with multiple housemates (e.g., 20% lived in 8-bed group homes). Individual and supported employment jobs were rare and individuals were the most likely to use community services and habilitation services.	960	24%

Source: OLO and Viriyangkura.

²² <http://ir.library.illinoisstate.edu/cgi/viewcontent.cgi?article=1074&context=etd>.

The AAIDD, which developed and continues to refine the SIS, maintains an online database of more than 100,000 SIS assessments. Research efforts are ongoing to determine how data from these assessments can be used to classify individuals with IDD by the intensity of their support needs.²³

4. Living Arrangement Estimates for County Adults with IDD

The State of the States, a survey of IDD services published annually by researchers at the University of Colorado, provides data about living arrangements for individuals with IDD.²⁴ As shown in Table II-6, in FY2015, nationally 71% of children and adults with IDD lived with their families, 16% lived alone or with a roommate and 13% lived in supervised residential settings.

Compared to the national data, in Maryland, the same percentage of Maryland adults with IDD lived alone or with a roommate (16%); however, a higher percentage of Maryland children and adults lived with families, (74% versus 71%), offset by a lower percentage living in a supervised residential setting (9% versus 13%).

Table II-6. Estimates of Children and Adults with IDD by Living Arrangement

Living arrangement	United States, FY2015		Maryland, FY2015		Montgomery County, FY2015	
	#	%	#	%	#	%
Living with family (children and adults)	3,593,483	71%	70,343	74%	12,084	74%
Living alone or with a roommate	794,164	16%	15,546	16%	2,670	16%
Living in a supervised residential setting	680,851	13%	8,889	9%	1,533	9%
Total	5,068,498	100%	94,778	100%	16,282	100%

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2016. The Montgomery County estimate applies a population prevalence rate of 1.58% to a total population estimate of 1,030,480 and then applies the Maryland living arrangement percentages. Totals do not add due to rounding.

Applying the population prevalence rate and living arrangement percentages for Maryland to the County population estimate yields an estimate of 16,282 adults and children living with developmental disabilities. Of this total, there are an estimated 12,084 children and adults living with their families; 2,670 living alone or with a roommate and 1,533 living in a supervised residential setting.

The previous estimates of County children and adults with IDD in Table II-4 based on Larson’s prevalence rates show there are an estimated 8,240 children under 18 with IDD in County households. If all of these children live with their families, this leaves 3,844 adults who also live with their families (12,084-8,240). Table II-7 displays estimates of living arrangements for County adults with IDD.

²³ Ibid.

²⁴ <http://www.stateofthestates.org/>.

The results in Table II-7 portray the current housing baseline for County adults with IDD before decisions about the new CMS settings rule take effect. The estimates show that each of the three living arrangements provides a significant contribution to the current housing inventory for adults with IDD and suggest the contribution of each is critical to keeping adults with IDD stably housed. Specifically,

- 48% of adults (~3,845) are in housing currently provided by families;
- 33% of adults (~2,670) currently live in their own houses or with a roommate; and
- 19% of adults (~1,530) live in a supervised residential setting.

Table II-7. Estimates of County Adults 18 and Over with IDD by Living Arrangement

Living Arrangement	Estimate of County Adults with IDD	
	#	%
Living with family	3,844	48%
Living alone or with a roommate	2,671	33%
Living in a supervised residential setting	1,533	19%
Total	8,048	100%

Source: OLO based on Larson and Braddock.

Although these estimates provide insight into current housing arrangements for County adults with IDD, their value as a starting point for forecasting future housing demand is limited due to a lack of information about:

- The individualized goals and support needs of adults with IDD and how different housing options might best fit with their plans;
- The plans of County providers who currently offer personal supports and services in supervised residential settings to adjust their business practices to comply with the new CMS settings rule; and
- The anticipated availability and funding stability of both Medicaid HCBS waivers and federal housing subsidies, which are both pre-requisites for many adults with IDD to live independently.

Finally, population prevalence rate estimates research based on the 1994 National Health Institute Survey – Disability Supplement data to quantify the prevalence of individuals with IDD does not account for children with autism born in the 1990s who are now aging into adulthood. Given the marked increase in the prevalence of autism diagnoses beginning in the late 1990s, estimates based on these rates may undercount individuals with IDD.²⁵

²⁵ <https://ici.umn.edu/products/prb/213/213.pdf>.

CHAPTER III. FAMILY AND COMMUNITY HOUSING MODELS

Figuring out how to secure affordable, accessible housing that changes across the lifespan is a complex and challenging issue for individuals, families and communities generally. It can be especially so for individuals with IDD and their families because, along with decisions about location and affordability, they must also decide issues about living arrangements, roommates and the arrangement of supports.

As part of this study, the Council asked OLO to provide examples of programs and practices in other places that could be useful for Montgomery County. Typically, research for this task would focus on new approaches or programs implemented elsewhere that look promising. That approach, however, did not work for this particular topic because the needs are extremely broad and diverse; a threshold definition of success is that solutions should embody individual choice; and, understanding an array of solutions that share a common underlying goal matters more than the specifics of a select set of programs.

To respond to the Council's request, this chapter presents a series of excerpts from *Housing Options for Adults with Autism Spectrum Disorder*, ("the Guide").¹ This document, published in April 2010, is the product of a Housing Options Committee appointed in 2008 by the Bureau of Autism Services ("BAS") in Pennsylvania's Department of Public Welfare. The BAS tasked the Housing Options Committee with "identifying and assessing housing options that will meet the varying needs, preferences and abilities of adults living with autism spectrum disorder (ASD) at different points in their life cycle."

To accomplish its task, the Committee articulated a set of guiding principles, developed a set of criteria for selecting housing models and researched a plethora of housing options for individuals with disabilities. As the Guide states, "the long-term goal of the group was to expand the number of viable housing options and models to maximize the choice and independence of adults with autism."

The Guide presents a typology of seven living arrangements and describes 22 examples or models to show ways a particular arrangement could be realized. The Guide is also useful because it tackles the issue of housing from the perspective of a family or a group of families. The County living arrangement estimates in the previous chapter show that nearly half of adults with IDD are stably housed because they live with their families. In OLO's view, this Guide offers a useful framework to structure a conversation with adults and their families about ways to expand their housing options.

This chapter has four sections organized as follows:

- **Part A** presents the philosophy and guiding principles that the Committee used for its work;
- **Part B** explains the seven elements for the creation of a housing option plan;
- **Part C** describes each of the housing settings, followed by brief descriptions of illustrative examples; and
- **Part D** offers observations about some of the examples that have parallels in Montgomery County.

¹ *Housing Options for Adults with Autism Spectrum Disorder*, Pennsylvania Department of Public Welfare, Bureau of Autism Services (April 2010). See http://delco-network.wikispaces.com/file/view/Housing_Options_for_Adults_with_Autism_-_FINAL_-_05-20-10.pdf.

A. Philosophy, Guiding Principles and Section Criteria

The Housing Options Committee identified the guiding principles highlighted in the text box below as a way to establish and articulate expected outcomes for the models it selected. The basis for these principles was the Committee's recognition that individuals with autism have needs and challenges that affect their housing preferences and that these needs change over time.

The Pennsylvania Bureau of Autism Services' Housing Options Committee's Guiding Principles

Foster Community Integration. It is critical that housing models provide opportunities for community integration. The concept of community integration impacts many aspects of housing including scale, design, location and ownership decisions. Given the importance of this concept, the Committee adopted its own working definition of community integration:

Community integration is the opposite of isolation; it provides the opportunity to live in the community and be valued for one's uniqueness and abilities like everyone else. Community integration is a right of all people and encompasses housing, employment, education, leisure/recreation, social roles, peer support, health status, citizenship, self-determination, and religion/spirituality. Community integration should result in community presence and participation of persons with disabilities similar to that of persons without disabilities.

Newly Constructed Units Should Be Adaptable/Visitable. Homes that are adaptable or visitable allow for flexibility in occupancy or visitation by people with physical disabilities or who may develop physical disabilities over time.

Enhance Informed Choice, be Individualized and Personally Fulfilling. Decisions around housing models should be person/family directed and respectful of individual desires and needs. They should also recognize that both needs and desires may change over time and that people may change their homes to meet changing needs. Informed choice can be accomplished through allowing individuals to make their own decisions about the type and location of their housing, with whom they will live, which services they receive and by whom the services are delivered.

Provide Appropriate Housing Alternatives with Measurable Quality of Life Outcomes. It is important for a residential setting to fulfill an individual's unique needs and that there be a sufficient number of housing and service alternatives to address the broad range of people living with autism.

Safe-Guarded for Individual/Family Health and Welfare and Satisfaction. Housing models proposed should maximize the safety, health, and satisfaction of the residents. Models should be consistent with Individual Service Plan goals, designed to minimize reliance upon crisis resources, and help to decrease challenging and inappropriate behaviors.

Be Sustainable. All housing models must have the potential to be sustainable in the long term and have a plan for succession if and when one or more the original residents leave.

Selection Criteria. Given its goal of expanding housing options in order to maximize choice and independence for adults with autism, the Committee wanted to ensure that it was practical in its selection of housing models. The Committee used the criteria highlighted below to guide its selection.

Housing Model Selection Criteria Applied by the PA BAS Housing Options Committee

The housing should be affordable. The Committee endorsed the standard affordability guideline of 30% of income covering housing costs including utilities. In addition, all available public funding sources for housing and services should be leveraged to assure affordability.

Flexible. The housing model should have adequate flexibility to meet the diverse needs of people living with autism and to allow the opportunity for residents to remain in their home as their needs change over time.

Attractive to Individuals Living There. The housing model should be appealing and desirable to the individuals who will be living there.

Utilizes Existing Housing Options. To the extent possible, the housing proposed should build on currently available housing resources. This would allow for more rapid implementation and maximum acceptance by both funding sources and consumers.

Utilizes Available Community Resources. The housing should foster residents' opportunity to participate in community life and make use of its amenities and resources such as shopping, recreation, culture, faith, community, banks, financial institutions, public agencies and other aspects of community life.

Simple, Replicable and Easily Administered. The basic components of the model should be easy to understand and replicable in various types of communities. In addition, the ongoing administration, management and fiscal accountability should require minimal housing expertise.

B. Standard Elements to Accompany the Creation and Development of Housing Options

Development and implementation of a special needs housing model by a family or a group of families is a complicated undertaking. While many nonprofit housing developers may be familiar with the relevant components, a roadmap for those who are new to the arena is useful. The seven elements that the Housing Options Committee identified as fundamental parts of the planning and assessment process are described below.

- 1) **A Housing Plan.** This document identifies the type of housing an individual wants, including location, desired roommates (if any), needed supports to obtain and maintain the home, required implementation steps and a timeline. Plan development can take many shapes and include a variety of participants. The central purpose of a housing plan is to ensure that the adult with IDD or autism is at the center of the process and the plan reflects his or her visions and decisions. The housing choice should be based on the individual having a full and informed understanding of the full range of housing options, with the information presented and delivered in an easily understandable way.

The Committee raised two concerns about housing plans. The Committee noted that the many participants in plan development may not have housing expertise and many people with autism may not have access to formal planning services. Given these concerns, the Committee suggested that families advocate for information about housing options, including the advantages and disadvantages of each in easy to understand formats; housing planning tools

that provide step by step guidance through the process; and access to housing and service planners who can help with the process.

- 2) **A Housing Option Sponsor.** This is the entity that determines the individuals to be served, the model, and people needed to carry out the project. A review of the housing models shows sponsors can include an individual with IDD and family members; a group of family members; a service agency, or a nonprofit housing developer. Sponsors need to have commitment and dedication; time and effort; experience working with individuals with IDD; and, an understanding of available services and supports systems.
- 3) **A Housing Developer or Consultant.** The options proposed by the Committee often are complex and include separate, but interconnected components for funding housing vs. funding needed services. A housing developer or consultant can provide expertise to navigate the process, providing a bridge to housing developers, housing finance agencies, or other resources. Experts can include affordable housing consultants, affordable housing coalitions, and community development organizations.
- 4) **Site Control.** Site control is usually achieved through housing ownership or a lease and the form determines the level of control of the resident. Ownership can include traditional forms such as fee simple ownership, condominium ownership, a housing cooperative, or a limited liability company. An alternative option is a self-directed support corporation (SDSC) formed by an individual with disabilities and his/her family and friends to support the individual in community that can own or rent property and provide services. A long-term lease is an alternative option.
- 5) **Financing.** Financing includes identifying sources of funds to acquire the site or property; funds for building or making repairs; and funds for ongoing operations such as maintenance, repairs, utilities, mortgages, taxes and insurance. The complexity of the financing will depend on the housing model.
- 6) **Management, Operations and Maintenance.** A housing model must have a plan for ongoing management, including responsibilities for rent collections, payments, maintenance and repairs, and ongoing operations. Small properties can be managed by residents or family members while larger properties typically require professional management companies. Some cases can include a mix of the two approaches. Property management not only maintains the value of the property but it also requires residents, families and others to make periodic inspections and monitoring visits.
- 7) **Provision of Services.** A plan for supportive services based on the needs of the resident(s) is a key component of a housing model.

C. A Typology of Housing Arrangements with Examples and Resources

For the purposes of the Guide, a housing setting is a living arrangement that can be defined in terms of one of the many dimensions including the people who are in the household, the type of housing

structure, the number of units in a building or the location of a home. The seven broadly defined arrangements² are:

1. Staying in the Family Home
2. Living with a (New) Family
3. Renting an Apartment
4. Purchasing a Home
5. Shared Housing
6. Intentional Communities; and
7. Licensed Facilities

Arrangement #1. Staying in the Family Home

Under this model, an adult with IDD remains in the family home or in the home of a relative. Advantages include a familiar setting for the individual and potential ease to establish and/or maintain formal or informal support systems. Families can change ownership of the family home to benefit the individual and the Guide advises seeking legal counsel if pursuing this option. Some ownership options to consider include:

- **A Self-Directed Support Corporation.** As noted above, this is a corporation organized by people who know and care about the individual and that is established to help the person obtain supports throughout his or her life, including housing.
- **A Life Estate or Trust.** A life estate allows an individual to remain a tenant for life while putting the property in a trust that allows it to be managed for the individual's use and protected from liens or people who may try to take advantage of the individual.

Staying in a family home requires arrangements for in-home supports and may require funds for property modifications or a shared housing situation to generate revenue to pay for ongoing expenses. Models for staying in a family home include:

1. **A House Donated by the Family.** Under this model, typically an individual's parents or another family member arrange for an individual to continue to live in the family home, including after parents move to another residence or after they die. The Guide recommends consulting with an estate planner to ensure that the transfer does not negatively impact a parent's future needs, such as eligibility for Medicaid if they were to need nursing home care.
2. **Elder Cottages Housing Opportunities (ECHO)** are small, pre-fabricated cottages manufactured by a company in Pennsylvania that can be easily constructed as an accessory building to a family home.
3. **Accessory Apartments.** Accessory apartments are self-contained units attached to a residential house that include a kitchen and bathroom. The Guide notes that this model provides an adult with IDD an independent living unit with easy access to family. Accessory apartments can also provide housing for a caregiver. The Guide also highlights that an individual with a disability

² This study uses "arrangement" instead of "setting" to avoid confusion with the use of the term setting used to mean a location for residential services that is used in the discussion of Medicaid HCBS waivers.

occupying an accessory apartment as a reasonable accommodation can use a housing voucher and only pay 30% towards rent.

Arrangement #2. Living with a (New) Family

Under this arrangement, an adult with IDD lives with a family that is not his or her family of origin, such as a host family or an adult foster care family. These types of programs operate under state licensing regulations. Pennsylvania offers this option through one of its home and community-based services Medicaid waivers for individuals who need more than 50 hours of supervision a week.

This type of arrangement provides affordable, homelike settings; it emphasizes relationships; it makes use of existing housing and can provide housing more quickly than new construction; and it provides more consistency than a group home that is more subject to staff turnover. This type of housing may not be appropriate for individuals with more complex health needs. The Guide emphasizes the importance of providing opportunities for individuals with autism to become acquainted with the host family before finalizing arrangements and exploring the need for training for the host family. The Guide offers two models of this arrangement in Pennsylvania.

1. **The LifeSharing Program.** This program matches families with individuals who need services and pays families a stipend using Medicaid waiver dollars, a portion of an individual's SSI payment, and some limited local funding. The Guide notes that a family with an adult child with autism could become a LifeSharing family for another adult, which would enable their family member to remain at home while providing a source of income. In 2010, 1,400 individuals were living with LifeSharing families in Pennsylvania.
2. **The Domiciliary Care Program.** This program provides a home-like living environment for adults 18 and older who need assistance with daily living activities. A home may have up to three residents. Homes are inspected annually to ensure they meet health and safety standards.

Arrangement #3. Renting an Apartment or a Home

An individual who chooses this approach will rent an apartment or a house, either alone or with others. Several advantages exist in this approach: it enables individuals to live in homes in the community; it gives residents a choice of where to live and of roommates; and, in many cases, it provides a housing solution that is separate from decisions about support services. This separation maintains an individual's choice and control, allowing them to change their support services independently. Market rents in many housing markets, including submarkets in the County, however, often make renting unaffordable.

A variety of rental subsidies exist to help individuals close any gap between a unit's fair market rent and the affordability standard of 30% of an individual's income. As described in Chapter IV, rental subsidies include tenant-based rental assistance, which allow a recipient to shop for and choose a unit that conforms to program quality standards, or project-based rental assistance, which connects the assistance to specific rental units. The Guide offers two Pennsylvania models that illustrate this arrangement.

1. **Rental Units Owned by a Limited Liability Corporation.** Under this model, a group (often parents or family members) forms a limited liability corporation that purchases a unit to be

leased to individuals with disabilities. The LLC is responsible for bills and maintenance and the individuals who rent have the same rights and responsibilities as other tenants. This model provides housing stability and sustainability in the community and it does not affect an individual's eligibility for SSI or Medicaid.

The Guide cites Autism Living and Working, Inc (ALAW), a nonprofit organization that is committed to helping adults with autism secure jobs and live independently in community, as an example. A group of ALAW parents formed two LLCs that each own a house for individuals with autism. ALAW serves as the property and operations manager. A substantial down payment from the LLC makes the homes affordable for the individuals and the occupants have housing choice vouchers that enable them to pay 30% of their income towards rent. Parent volunteers from ALAW manage the homes.

Residents of these houses are enrolled in one of Pennsylvania's Medicaid waivers, which funds the residents' support services. The Guide notes that the support services are provided in accordance with an individualized service plan and can vary from a specified number of hours a week to round-the-clock hours, depending on an individual's needs. The services include community integration, personal assistance and behavioral therapy.

- 2. Rental Units Owned by a Non-Profit Organization.** Under this model, rental homes or condominiums are acquired and renovated by a non-profit organization that operates either as a developer and/or a nonprofit services provider. Property acquisition and development funds typically come from a combination of grants, low interest loans and donations. Funds for ongoing operations come from rent paid by tenants and federal funds distributed by the public housing authority if tenants have housing choice vouchers.

Options for lowering costs include Housing Trust Funds or funds from HUD's HOME program to reduce the initial capital costs, which can reduce the monthly costs that need to be covered by tenant rents. HUD Section 811 funds can also provide development funding and rental subsidies for housing projects for people with disabilities.

As an example, another ALAW project that acquired two houses used a grant from the Pennsylvania Housing Finance Agency for a substantial down payment and obtained a mortgage to finance the remaining project development costs. This provides rental homes for two adults with autism. Similar to the LLC model above, the individuals have HCBS waivers through Medicaid that fund needed services.

ALAW also was awarded HUD Section 811 funding that will enable it to develop and operate four units of subsidized rental housing. The funding will be used to pay for project acquisition and rehabilitation costs and forty-year rental subsidies.

Arrangement #4. Purchasing a Residence

An individual who pursues this arrangement will purchase a property – such as single-family detached houses, condominiums, and townhouses. Individuals can purchase property either alone or with others who may or may not be living with IDD. Individuals can choose different legal structures that can account for individuals choosing to leave the arrangement, such as a corporation with ownership shares or an ownership deed with an agreement that specifies expectations for changing circumstances. Families should consult with experts to determine the best options. Government programs can assist by reducing downpayments and closing costs and by sponsoring programs for first-time homebuyers that reduce borrowing costs.

Advantages of homeownership include locking in long-term control and affordability for an adult with IDD; relying on mainstream financing; and using existing housing stock, which can further community integration. Several considerations related to homeownership include sources of funding for a downpayment and closing costs, obtaining a credit history and developing a plan for the ongoing costs of maintenance, repairs and utilities.

1. **Ownership by an Individual.** The Guide cites as an example an individual living with an intellectual disability, autism and cerebral palsy in a rural community in Pennsylvania who was able to combine a USDA loan with no down payment requirements and a Section 8 award from the local public housing authority's homeownership program to reduce his monthly costs to 30% of his income. The Guide notes that it would be difficult to replicate this model in more expensive housing markets.
2. **Tenants in Common.** Under this model, two or three individuals purchase a home with all of their names on the deed – all having equal ownership of the property. The Guide recommends that purchasers develop an ownership agreement in this circumstance.

The Guide cites as an example Homeworks, a ranch house that was purchased by three adult men with physical disabilities. The men purchased the property as Tenants in Common and entered into an Ownership Agreement that provided six months for an owner to sell their interest to another individual who needed services similar to those in the house. To provide for the sustainability of the house, the men also established a volunteer board with a membership that includes the three owners, a representative from each of their families and professional acquaintances (one with expertise in trusts and one with expertise in services).

The individuals secured purchase funds from the Housing Finance Agency first-time homebuyer program and Medicaid HCBS waivers fund their support services. Family resources from a Special Needs Trust provided a significant down payment to reduce ongoing costs. This arrangement avoided using family contributions for the individuals' ongoing mortgage payments, which would have reduced the individuals' SSI benefit payments. Modifications to the home were paid for with funds from the HCBS waiver and a grant from the Self-Determination Housing Project. The individuals also secured contributions for household goods and other renovations from congregations and corporations.

3. **Limited Equity Cooperative.** A limited equity housing cooperative uses cooperative bylaws to restrict the purchase and sale prices of membership shares in a cooperative to maintain housing

affordability over time. Under this model, shareholders share decisions related to the property. This model provides the benefits of ownership together with the benefits of peer support and shared decision making. Considerations include the legal expertise necessary to establish the cooperative, potential for needed support from family and/or other professionals for decision making and consideration of zoning issues that may arise.

The Guide cites an example of a housing cooperative that was developed for nine adults with serious mental illness. A nonprofit housing organization financed the conversion of a church rectory into a home for residents who had previously lived in group homes. The model provided each resident with their own room in addition to two other rooms with a sitting area and an adjoining bathroom. The house also provided a shared dining and living area and a basement recreation room.

The developer used funds from a Housing Finance program and a mortgage to acquire the property. After the renovation was complete, the developer sold the building to a cooperative and gave each resident a forgivable loan that was used to purchase their membership share. The residents use a major portion of their SSI payments to pay for their room and board and the cooperative receives a monthly supplement from the state Public Welfare agency.

Arrangement #5. Shared Housing

An individual who selects this arrangement will share a home with an unrelated individual(s). Typically, he or she will have a private bedroom while sharing other rooms, such as the kitchen, dining room, living room and other common areas. This arrangement can provide peer support and interdependent relationships; can be more cost effective than an arrangement of individual living units; can make use of existing housing stock; and can be adapted to provide housing for a variety of populations and communities.

Key considerations and issues identified in the Guide are local zoning issues around the definition of “family,” that larger groups may be difficult for some individuals, and that this model is best suited for people who appreciate joint decision making and negotiation. The Guide recommends planning around issues of privacy and personal space and giving careful consideration to resident dynamics.

The Guide presents the following five models to illustrate the various applications of this arrangement.

1. **Group Shared Residence.** Under this model, up to eight unrelated people can share a home or apartment. Residences may be sponsored by nonprofit organizations and members of shared housing typically choose other household members. The members jointly manage the day to day operations of the home and develop rules about issues such as pets and guests. They often buy food and cook and share meals together. Residents pay rents that are used to cover housing operating costs. According to the Guide, if a housing authority includes shared housing as a “special housing type” in its Administrative Plan, this enables residents to use housing choice vouchers.

The Guide cites as an example a nonprofit organization that operates two group shared residences for people with serious mental illness. The nonprofit rents the homes from a private landlord. Residents sign a shared housing contract that establishes household rules and

commits residents to maintain their physical and mental health. Although there are no on-site staff, residents receive case management and participate in a drop-in center. The model helps residents establish a housing record that can serve as a referral for a future living arrangement.

2. **Housing Match Up.** This model connects home providers who are responsible for the operating costs of the house with home seekers who pay rent. A match-up program is often sponsored by a public or private nonprofit organization. The model provides a private room and shared kitchen, dining and other common areas. The Guide cautions that the success of the program depends on compatible matches.

A staff person is responsible for conducting the initial intake and screening and facilitates initial introductions. The Guide strongly recommends trial periods to determine whether the matches are compatible and to understand the effects of behaviors that may not have been identified through the initial screening process. If the public housing authority administrative plan establishes shared housing as a special housing type, a home seeker may use a voucher to reduce their rent.

The Guide notes that this model provides opportunities for inclusion since it can match people with and without autism. It is relatively inexpensive to run because the primary costs relate to the need for a staff person. As an example, the Guide cites the Homeshare Alliance, a program operated by the YWCA. Matches for people with disabilities have been among the hundreds of matches made over the years. A second example is Residential Living Options which is targeted to people with disabilities. This organizations holds meetings to provide opportunities for people to meet socially as a way to identify potential match partners.

3. **A Lodge Model.** According to the Guide, a lodge is a group of four to eight people who share a house and own or are employed in a small business. The types of businesses can include lawn care, printing, transportation services and catering. The purpose of the employment component is to provide an opportunity for vocational and social skill building. This model operates without live-in staff but a lodge coordinator is available to serve as a teacher, coach or group facilitator and there are 24-hour on-call staff for emergencies. The guide cites as an example Fairweather Lodge, which opened its first location in a residential neighborhood.
4. **L'Arche.** L'Arche is an organization that was started in France in 1964. Today, it consists of 130 communities in 30 countries. According to the Guide, "L'Arche enables people with and without disabilities to share their lives in communities of faith and friendship. Community members are transformed through relationships of mutuality, respect, and companionship as they live, work, pray, and play together."³ The community that lives together in a L'Arche house consists of core members, who are people with disabilities, and assistants, who are people who have chosen to share their life with a core member. Core members and assistants make decisions jointly and share responsibility for the house.

The L'Arche community in Erie, Pennsylvania was the first community started in the United States. As of 2010, it operates eight houses and two apartments, with a maximum of four people per house. While the houses were purchased with State funds and operate as licensed group homes, they are guided by the L'Arche philosophy.

³ The Guide, p. 46.

Arrangement #6. Intentional Communities

An individual who selects this arrangement will live with others in a community that is built around a set of shared beliefs. The different sets of beliefs that characterize communities can include a shared commitment to caring for people with disabilities, a shared interest or shared lifestyle. The locations of intentional communities vary among urban, suburban and rural areas. Recognizing the uniqueness of intentional communities, the Guide provided a separate discussion of strengths and considerations for each of the models. The Guide offers four models to illustrate how intentional communities can work in practice.

1. **An Intergenerational Community.** The underlying concept of an intergenerational community is an interest in encouraging and supporting relationships that cross generations. Younger families provide a home for a specific population, such as children adopted out of foster care and seniors receive reduced rent in exchange for acting as volunteers in support of the families. The model gives seniors an opportunity to age in place and young families an opportunity to support seniors. The organizing center for this model is often a specific challenge faced by some residents that the entire community rallies to support.

The strengths of this model are its intergenerational approach and its development of a supportive community. The Committee anticipated that it could provide a community for adults living with autism as a lifesharing model. An issue associated with this model is that the costs to secure and develop a site are considerable given the scale of the model. The Guide cites the example of Hope Meadows, a community established by Generations of Hope, a nonprofit organization that serves children exiting the foster care system. The families at Hope Meadows receive free housing and the seniors pay nominal rent in exchange for volunteering each week. The nonprofit acquired the site and the housing at a nominal cost from the federal government as part of a military base closing.

2. **Collaboration with a College or University.** Under this model, a nonprofit housing developer develops housing in collaboration with a college community, adults with disabilities and their families. The strengths of this model are the collaboration that occurs among all of the parties, the campus space provided for social and recreational activities and the learning opportunities afforded to students. Considerations include the need to include someone with expertise in Low-Income Housing Tax Credit developments, arranging funding for supports and addressing the difficulty of establishing long-term relationships with students who leave during breaks and after graduation.

The example cited in the Guide is a proposed housing development that is being jointly planned by a university and a housing corporation. The project includes the renovation of a church to provide one and two bedroom units for 19 individuals with disabilities plus the renovation of two adjacent residential properties to house ten students attending the university. The students will serve as buddies, not caregivers. The Guide states the university's efforts to involve the community early in the project were successful in creating community acceptance.

3. **Farmsteads.** This model, which provides both residential and vocational opportunities for adults with disabilities in a rural setting, has been used specifically for adults living with autism. Residents carry out meaningful work that is adapted to their strengths and needs. The

strengths of this model are its track record of success; that adults with autism are fully participating members of the community; that it provides meaningful work; that it provides safe housing that is sustainable over the long term; and, the opportunities afforded by the campus setting. Considerations include potentially high start-up costs; difficulty finding an appropriate site; the need for a source of operating funds beyond the farm revenues; and the high cost to families.

The Guide cites three examples. The first is Bittersweet Farms – a well-known farmstead program in Ohio that has three houses for 20 adults with autism plus a day program for 60 adults. According to the Guide, residents interact with the community through a bell choir, an engine repair shop and a landscaping crew, a tearoom and the sale of their produce. Residents have opportunities to shop and eat in community restaurants to build their social skills.

The second example is Camphill, a farmstead in Pennsylvania that offers a comprehensive, therapeutic way of life for people with disabilities. Camphill, which is based on an international model, offers 11 lifesharing households whose members include 42 individuals with disabilities. The site was donated and the sources of operating funds include residents' SSI payments, contributions from residents' families, rentals of buildings on site and donations and fundraising.

The third example is Safe Haven Farm, a project near Cincinnati, Ohio, developed by a group of parents of young adults with autism who were unable to locate suitable residential and vocational services. They researched other farmstead programs. The farm is expected to provide housing for 24 adults (in two phases) and to provide 24/7 staffing funded through a combination of Medicaid and County funds. The project is expected to have day programs, therapeutic horseback riding and volunteer opportunities for nearby college students as well.

4. **Co-housing.** This model uses a collaborative process to design and establish the community. It is sometimes referred to as an intentional neighborhood. It incorporates a mix of private homes and common areas in an effort to promote social relationships while preserving private spaces. Some co-housing communities offer shared community meals. The strengths of this model are that it offers a safe neighborhood and an opportunity to integrate individuals with disabilities.

Considerations include costs and expertise needed to develop the project and a risk that residents may not engage with individuals with autism. The Guide cites the example of Coho Ecovillage in Corvallis, Oregon, which was developed by an affordable housing developer. One unit is owned by a nonprofit and rented to an individual with physical disabilities. Another four-bedroom unit was purchased by a local provider of residential services to provide housing for three adults and an overnight service person. The housing developer is a Community Housing Development Organization that used several funding sources, including HUD HOME funds and state housing trust funds.

Arrangement #7. Licensed Facilities

An individual who selects this arrangement will access housing if they are determined eligible for residential services through the state agency that provides services for individuals with autism or an IDD. In Pennsylvania, this is the Office of Developmental Programs in the Department of Public Welfare. In

Maryland, this entity is the Developmental Disabilities Administration. The strength of this model is the provision of round-the-clock staffing (if necessary); the availability of experienced staff, and that a comprehensive HCBS waiver funded by Medicaid pays for all supportive service costs. Considerations are that individuals and families have limited input into issues around the management and provision of services and that resource constraints severely limit the availability of waivers.

The Guide describes three service models that are authorized in Pennsylvania – a private licensed facility; an intermediate care facility for the mentally retarded (ICF-MR), and a community supported living arrangement (CSLA). Chapter V describes Maryland’s residential service models.

D. Observations

Parallels exist among the examples in the Guide, current County programs and efforts underway that OLO learned about during the course of this study. For example,

- The examples of rental units owned by a non-profit or limited liability corporation align with County examples such as Housing Unlimited, a County non-profit organization that provides housing for people with serious mental illness.
- The Madison House Autism Foundation is a County nonprofit organization located on a 400-acre farm in Dickerson Maryland that is undertaking a project that will include housing, education, riding and employment opportunities for adults with autism and other IDD.
- The accessory apartment example may merit further investigation given changes to County regulations that allow accessory apartments to be built by right instead of requiring a special exception.
- DDA’s existing service definitions are similar to the descriptions of Pennsylvania’s licensed facilities. In Maryland, community based settings for these services include Alternative Living Units, Group Homes and Adult Foster Care Homes. As explained in Chapter V, DDA is revising to its Community Pathway’s Medicaid Home and Community Based Services (HCBS) waiver to add a new supported living service and to expand its shared living definitions.

CHAPTER IV. STATE AND LOCAL HOUSING PROGRAMS

The State of Maryland and Montgomery County administer several housing programs for people with disabilities, including individuals with IDD. These programs leverage federal, state, county and private funds for housing loans, capital grants, housing development, acquisition and repair, rental subsidies and housing assistance services. Many projects combine multiple sources of funds. In terms of overall funding:

- The sources of federal funds are from Low Income Housing Tax Credits (LIHTC), from HUD Section 811 grants, Section 8 housing voucher, Nonelderly Disabled vouchers, Community Development Block (CDBG) grants, Supplemental Security Income or Social Security Disability Insurance payments, CMS grants and Medicaid HCBS waiver funding.
- The sources of state funds are from the Maryland Department of Health and Mental Hygiene (DHMH) Capital Bond fund, the State Partnership Rental Housing Program and Rental Housing Works.
- The sources of County dollars are primarily from the Montgomery County Housing Initiative Fund which is funded through county recordation taxes with other contributions from HOC's Opportunity Housing Fund which is funded through County Government current revenue dollars; and
- The sources of private funding are from the Weinberg Foundation and other developer proceeds and rent payments that create cross-subsidies that make projects financially viable.

The programs described below offer rental subsidies, capital loans and grants, homeownership opportunities, resident services counseling, permanent supportive housing and housing stabilization and homelessness prevention services.

A. State Administered Programs¹

The State of Maryland currently has two rental assistance programs and a capital loan/grant program for low income people with disabilities that are jointly administered by three state agencies: the Department of Housing and Community Development (DHCD), Maryland Department of Disabilities (MDOD) and the Department of Health and Mental Hygiene. This collaboration of state agencies and other nonprofits is also known as the Maryland Partnership for Affordable Housing.² The rental

¹ OLO's review of state programs focused on state collaborative efforts and program funds targeted to people with disabilities. Besides these efforts, there are other state rental financing programs that provide funding for affordable housing. In addition to the LIHTC program, the state Department of Housing and Community Development also administers 1) a Multi-Family Bond Program to increase the construction and rehabilitation of multi-family housing for low income families; 2) a State Rental Housing Fund with programs that aim to create or rehabilitate rental housing with specific programs for housing rehabilitation, nonprofit sponsors and the elderly; and, 3) the Rental Housing Works program that provides gap financing for projects that use LIHTC, or funding from the Multi-Family Bond State Rental Housing Programs. OLO did not conduct a detailed review of these programs.

² Maryland used federal funds from CMS to establish the Maryland Partnership for Affordable Housing (MPAH), which implements an inter-agency agreement between the Maryland Department of Housing and Community Development, the state Medicaid agency and the Maryland Department of Disabilities.

assistance programs are the Money Follows the Person (MFP) Bridge Subsidy Program and a Section 811 Project Based Rental Assistance Program. The capital grant program is the Weinberg Apartment program. In addition, the Department of Health and Mental Hygiene administers a Capital Bond program and the Department of Housing and Community Development administers a homeownership mortgage program for people with disabilities.

1. The Money Follows the Person (MFP) Bridge Subsidy Program

The Money Follows the Person Bridge program is a state-administered tenant-based rental subsidy program that helps individuals with disabilities move from a “qualifying institution” to independent renting.³ In Maryland, the program is administered as a partnership among the Maryland Department of Disabilities, the Maryland Department of Health and Mental Hygiene, the Department of Housing and Community Development and 12 public housing authorities participating across the state.

Maryland’s Money Follows the Individual Act⁴ (“MFI”), passed in 2003, complements the MFP program by ensuring access to a Medicaid Home and Community Based Services’ (HCBS) waiver for individuals transitioning from institutions to community-based housing if they would otherwise meet Medicaid waiver eligibility criteria. Individuals covered by this law can access HCBS waiver services even if no waiver slots are currently available.

The MFP Bridge Subsidy Program is funded by the Department of Health and Mental Hygiene using Rebalancing funds. This money pays for the state-funded rental assistance. Additional funding comes from federal housing choice vouchers administered through local public housing authorities. The table below summarizes key components of the program.

Table IV-1. Money Follows the Person Bridge Subsidy Program Details

Category	Requirement
Eligibility	Transitioning out of institutional housing 18 years or older Eligible for Medicaid LTSS Recipient of SSI or SSDI Not a sex offender
Household Income	\$19,000 annually or less
Source(s) of Funding	Rebalancing funds, federal housing vouchers
Length of Funding	3 years, then transition to local housing voucher or public housing
Individual’s Responsibility	30% of monthly income to rent and utilities

³ <https://mmcp.dhmfh.maryland.gov/longtermcare/MFP%20BIP/MFP%20Protocols/MFP%20Operational%20Protocol%20202017.pdf>.

⁴ Annotated Code of Maryland, Health General § 15-137.

A Kaiser Family Foundation case study brief found that key components of Maryland’s MFP system include a peer outreach and mentoring system, options counseling and a concerted marketing effort:⁵

- Peer outreach uses individuals with a disability or with LTSS experience to reach out to residents of nursing facilities and other institutions to share their experiences. Individuals are recruited and trained through a peer support contract managed by the Maryland Department of Disabilities.
- Options counseling provides institutional residents with in-depth education about community services and supports, assistance applying for waivers and Medicaid eligibility and support from housing specialists.
- Marketing and outreach materials have included targeted letters, educational articles and training directed to Area Agencies on Aging, Centers for Independent Living, local health departments and advocacy organizations.

Individuals enrolled in the MFP Bridge program also receive services consisting of flexible funds (up to \$700 per program enrollee on a one-time basis) for expenses such as security deposits, rental application fees and other services that Medicaid would not otherwise cover and post transition peer mentoring.

Mathematica Policy Research served as the national evaluation researcher for the MFP program and has issued a series of reports on the MFP Demonstration Program. In its report, *Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2015*, Mathematica identified Maryland as one of seven states with the largest programs, having transitioned 2,428 individuals from institutional to community settings between 2007 and 2015. Of these individuals, approximately 11% were individuals with IDD.

Table IV-2. Individuals Transitioned to Community through Maryland’s MFP Program, 2007-2015

Group	# Transitioned	% of Total
Older Adults	1,138	47%
Persons with Physical Disabilities	956	39%
Persons with Intellectual Disabilities	267	11%
Persons with Other Disabilities	67	3%
Total	2,428	100%

Source: Mathematica Policy Research, *Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2015*

⁵ <http://kff.org/report-section/marylands-money-follows-the-person-demonstration-issue-brief-8581-md/>

As part of its national evaluation, Mathematica reported the types of housing people moved into in the community – homes, apartments, group homes, or assisted-living facilities. Throughout the country, most individuals moved to homes (33%) or apartments (42%), with 14% moving to group homes and 10% moving to assisted-living facilities. Mathematica found similar moving patterns for all groups except for individuals with IDD. Approximately 58% of individuals with IDD moved to group homes.

Mathematica also reported that most states (39 of 44) reported at least one challenge finding housing, with the most common problems being an insufficient supply of affordable housing and an insufficient supply of housing vouchers.⁶

The Montgomery County Housing Opportunities Commission (HOC) is one of 12 public housing authorities (PHAs) statewide partnering with the Maryland Department of Disabilities. After an individual's three-year participation in the MFP Bridge program ends, residents are eligible to receive rent subsidies from HOC's Rent Supplement Program, which is a County Council initiative that provides subsidies for eligible HOC households with incomes between 20% and 40% of area median income. The Rent Supplement Program provides permanent rental subsidies of up to \$600 per month.

According to HOC minutes, in 2016 HOC approved a proposal to set aside 10 units for non-elderly disabled MFP participants. In its consideration of this matter, HOC staff estimated there would be a one-time budget impact of \$10,000 per unit for five units or \$50,000 to retrofit units to address mobility issues for half of the participants who would need retrofits. HOC staff also indicated it expected ongoing property management and maintenance expenses to be covered through HOC's existing arrangements based on the units' HUB locations. Decisions about the location(s) of the ten set aside units are pending.

HOC staff noted that after the three-year MFP subsidy period ends, residents would be eligible to receive a rent subsidy from HOC's Rent Supplement Program, which is a County Council initiative that provides locally funded housing assistance to reduce the rent burden for eligible HOC households with incomes between 20% and 40% of Area Median Income.

2. Section 811 Project Rental Assistance Program

The Section 811 Project Rental Assistance (PRA) program is a state administered project based rental subsidy program that is part of a broader initiative to stimulate and support state-level strategies to increase permanent supportive housing options for extremely low-income individuals with disabilities. It is funded through two Section 811 grants from HUD awarded to the Maryland Department of Housing and Community Development, working under the MPAH umbrella with the Maryland Department of Health and Mental Hygiene and the Maryland Department of Disabilities. The awards, which total \$21 million, are expected to fund subsidies for 300 units.⁷

⁶ <https://www.mathematica-mpr.com/our-publications-and-findings/publications/money-follows-the-person-demonstration-overview-of-state-grantee-progress-january-to-december-2015>.

⁷ <http://dhcd.maryland.gov/HousingDevelopment/Documents/section811/AmendedTSPSection811DHCDApproved.pdf>.

The responsibility of each agency under this program are as follows:

- **The Department of Housing and Community Development**, working with affordable housing developers, is responsible for identifying 300 units in existing or proposed Low Income Housing Tax Credit (LIHTC) developments and other projects that receive federal or state funding. Up to 25% of the units in a selected development can be set aside for the 811 PRA program. DHCD administers rental contracts for the program.
- **The Department of Health and Mental Hygiene**, working with its service providers, identifies the highest need individuals who would benefit from living in community. DHMH is also responsible for administering a responsive system of services and supports.
- The **Maryland Department of Disabilities** manages a statewide referral system for the program and provides outreach, education and technical assistance for the program.

Table IV-3. Section 811 Project Rental Assistance Program Details

Category	Requirement
Eligibility	Have a disability 18-62 years old at time of lease signing Maryland Medicaid recipient SSI- or SSDI-eligible Voluntary access to support services
Income	At or below 30% of AMI in jurisdiction where unit is located
Source(s) of Funding	Federal Section 811 grants (to develop and subsidize rental housing with supporting services for very low-income adults with disabilities)
Length of Funding	5 years
Individual's Responsibility	30% of monthly income to rent and utilities

Individuals must be referred to the program by a “qualifying service system/provider entity,” as determined by DHMH. Those who may submit referrals include:

- Department of Health and Mental Hygiene;
- Mental Health Agency (MHA);
- Developmental Disabilities Administration (DDA);
- Area Agencies on Aging (AoA); and
- Centers for Independent Living (CIL).

MDOD maintains a central registry and waitlist of program applicants and selects participants based on state policy initiatives to reduce the use of institutionalization and unnecessarily restrictive settings and to end homelessness. Maryland has established the following four priority groups:

- Priority Group 1 – Individuals currently living in a nursing home and eligible for Medicaid funded Home and Community Based Services (HCBS);
- Priority Group 2 – Individuals living in community but at risk of institutionalization due to a current housing situation that is substandard or inaccessible;
- Priority Group 3 – Individuals who are Community Pathways waiver participants, Behavioral Health Administration Brain Injury waiver participants, Mental Hygiene Residential Rehabilitation Program participants moving from group homes or alternative living units to independent renting, and people receiving Community Option waivers and living in DHMH assisted living facilities;
- Priority Group 4 - Homeless individuals who are Medicaid eligible as prioritized in the federal Homeless Emergency Assistance and Rapid Transition to Housing Act of 2009

MDOD identifies applicants when units become available. Applicants may refuse a unit without losing their priority status on the waitlist. If an applicant refuses three units, MDOD will review the reasons for refusal and may remove the applicant from the waitlist.

Case managers work with residents to ensure access to units and to increase the likelihood that residents will retain their units through the program. These supports include help acquiring documentation, help with the process to secure reasonable accommodations in the units, transportation assistance, financial assistance for security deposits and/or move-in expenses and help establishing good relationships with property managers.

Program participants contribute 30% of their income for rent and utilities and Section 811 program funds cover the difference for a period of up to five years. Because this is a project-based rental assistance program, the subsidy stays with the unit if a tenant decides to leave. DHMH has set aside \$1 million held in trust by DHCD to fund housing subsidies for up to six months if Section 811 program funding is not renewed at the end of the five-year period.

According to MDOD staff, as of spring 2017, 33 people were housed, two units are complete and in final lease-up, 29 units are almost complete and in initial lease-up, and 12 units are under construction. Another 60 are in underwriting with DHCD. There are 2,456 people on the statewide waitlist, including 368 in Priority Group 1, 49 in Priority Group 2, 344 in Priority Group 3 and 737 in Priority Group 4.

Woodfield Commons in Damascus is the first Section 811 Project Based Rental Assistance project in Montgomery County, with 13 one-bedroom units in the program. Woodfield Commons is a four-story, 84-unit, mixed-income multifamily project developed as a joint venture between Conifer Realty, LLC and the Housing Opportunities Commission. The development uses Low Income Housing Tax Credits and 90% of the units will be restricted to households with incomes at or below 60% of the Area Median Income. In addition, the developer has committed to reserve 15% of the units for people with disabilities.

3. The Affordable Rental Housing Opportunities Initiative for Persons with Disabilities (The Weinberg Apartment Program)

The Weinberg Apartment Program is a joint venture between the Maryland Department of Housing and Community Development, the Maryland Department of Disabilities, and the Maryland Department of Health and Mental Hygiene. Launched in 2011 with grants from The Harry and Jeanette Weinberg Foundation, the program will provide \$2.0 million in capital grants to owners of rental housing developments involved with non-profits as an incentive to designate units for very low-income persons with disabilities.

Projects approved for other DHCD multifamily rental housing financing, including Low Income Housing Tax Credit financing, are eligible for Weinberg capital grants. DHCD works with the Weinberg Foundation to disburse grants and monitor the project for compliance with long-term Weinberg program requirements. Weinberg foundation grants are used to reduce a developer’s debt so the developer can set lower rents. Weinberg apartments typically account for five to ten percent of the units in a project development. The table below summarizes details about the Weinberg Apartment Program.

Table IV-4. Weinberg Apartment Program Details

Category	Requirement
Eligibility	Have a disability and receiving or applying for SSI or SSDI 18-62 years old Not a convicted sex offender Not convicted of possession of methamphetamines on public housing property
Income	10%-30% of area gross median income
Source(s) of Funding	The Harry and Jeanette Weinberg Foundation and DHCD’s Multifamily Rental Housing Program
Individual’s Responsibility	30% of monthly income to rent and utilities

Staff from the Maryland Department of Disabilities report that Weinberg apartments provide housing for people with a range of disabilities, including people transitioning from group homes and a few adults with IDD. In contrast to some other programs, the Weinberg program offers flexibility in choosing people from the waitlist to occupy an apartment to help ensure a successful tenancy. This flexibility also extends to living arrangements. For example, an individual may have a live-in caregiver who is a family member, or those who need significant assistance may have a live-in aide in addition to drop-in services.

As of December 2016, 24 Weinberg Apartments in Dorchester Harford, Montgomery, Princess Anne, and Wicomico Counties are occupied, including five units at Parkview Towers in Takoma Park. Eight additional units are slated for construction. As of Fall 2016, the program had 1,056 people on the statewide waitlist.

4. State Capital Improvement Grants

The Maryland General Assembly provides capital grants to nonprofit organizations for property acquisition and renovation. Nonprofit housing or social service organizations that serve persons with disabilities – including adults with IDD – can receive funding through a legislative initiative capital grant or through the Community Health Facilities Grant program. For both approaches, the source of funds is state General Obligation Bonds and the funds are approved annually as part of the Maryland Consolidated Capital Bond Loan.

- Legislative initiative capital grants are competitive proposals submitted by members of a local delegation and reviewed by the Department of Legislative Services based on guidelines approved by the Governor and the General Assembly.⁸
- The Community Health Facilities Grant program, administered by DHMH, provides capital funds for the acquisition, design, construction, renovation and equipping of facilities to provide mental health, developmental disabilities and substance abuse treatment services – funding up to 75% of the cost of each project. The program helps fund facilities that serve to minimize the institutionalization of mentally ill and developmentally disabled individuals and those with addiction issues.

In the 2017 legislative session, two organizations received legislative capital grants and one received a Community Health Facilities Grant:

- Community Services for Autistic Adults and Children (CSAAC) provides nonprofit educational, residential, vocational and counseling services for individuals with autism. CSAAC received a \$45,000 capital grant to construct a new water tower and sprinkler system at its community school in Brookeville.
- The Madison House Autism Foundation provides nonprofit job training and housing and addresses wellness lifespan needs of adults on the autism spectrum. The Foundation received a \$60,000 capital grant for a Therapeutic Equestrian Center at Madison Fields, a 400-acre farm project that provides jobs for adults on the spectrum and fosters interactions between adults with and without disabilities.
- The Montgomery Housing Partnership (MHP) is a Community Housing Development Organization that develops affordable housing and provides community support services for County families and individuals. MHP received a \$800,000 Community Health Facilities Grant to provide housing for adults with IDD.⁹

⁸ See <http://mgaleg.maryland.gov/pubs-current/current-bond-bill-submission-guidelines.pdf>.

⁹ Montgomery County will allocate \$282,000 of its \$1.9 million federal HOME grant to Community Housing Development Organization Housing Production (\$212,000) and CHDO Operating Assistance (\$70,000) for Montgomery Housing Partnership and Housing Unlimited.

In 2013, the DHMH Capital Bond program awarded HOC and the Jubilee Association of Maryland (Jubilee) a \$835,000 grant to purchase two, three-bedroom single-family houses to house six individuals with developmental disabilities. Jubilee is a nonprofit service provider for individuals with IDD. The DHMH grant covered 75 percent of acquisition and renovation costs to make the two houses handicapped accessible. Montgomery County provided a matching grant for the remaining 25% from the County's Housing Initiative Fund (HIF). When the renovations were complete, HOC provided project-based housing vouchers for the residents.

Other organizations that have received capital funds for housing acquisition and/or renovation projects include The Jewish Foundation for Group Homes and Housing Unlimited, a community housing development organization (CHDO) that provides affordable, supportive housing for individuals with psychiatric disabilities and very low incomes. Housing Unlimited has received four grants since 2008 to purchase 28 scattered site town homes and houses.¹⁰

5. DHCD Group Home Program

The Maryland Department of Housing and Community Development administers the Group Home Program, which provides loans to individuals, limited partnerships, and nonprofit organizations to help construct, acquire, and/or modify housing to serve as group homes or assisted living units for special housing needs. The loans can also be used to refinance existing mortgages. Financing comes from state funds in the Group Home Financing Program and from the Special Housing Opportunities Program's sale of tax-exempt Mortgage Revenue bonds.

Since 2012, the program has funded \$6.2M in loans for 23 properties with 74 total units located throughout the state, including six in Baltimore County, four in Talbot County, three each in Anne Arundel and Prince Georges counties, two each in Frederick and Carroll counties, and one each in Montgomery, Harford and Queen Anne counties.

6. DHCD Homeownership for Individuals with Disabilities Program.

DHCD's Single Family Home unit offers a statewide program that provides mortgages for individuals if a borrower is disabled or if a borrower lives with and is the guardian and primary caregiver for an individual with a disability (regardless of age).

¹⁰ Housing Unlimited provides housing and services that allow adults with mental illness to live independently. Founded almost 15 years ago by parents of adults with mental illness, Housing Unlimited currently houses 68 residents in 13 homes. HIF and federal funding enabled Housing Unlimited to purchase three properties in FY04.

Table IV-5. Homeownership for Individuals with Disabilities Program Details

Category	Requirement
Eligibility	Borrower has a disability or borrower lives with and is the guardian and primary caregiver for an individual with a disability (regardless of age) First-time homebuyer (exceptions for some veterans or if buying in a Targeted Area ¹¹) Receipt of a Homeownership Counseling Certificate
Maximum Household Income	\$107,000 in Montgomery County
Maximum Property Purchase Price	\$300,000 in Montgomery County
Maximum Underwriting Ratios (some exceptions apply)	30% housing expense-to-income ratio 38% debt-to-income ratio
Interest Rates	2.25% to .25% below the rates offered through the Maryland Mortgage Program Conventional Interest Rate Loan
Mortgage Term	30 years
Disability certificate required from...	Health, mental health, or disability professional

B. Locally Administered Programs

In Montgomery County, the Housing Opportunities Commission (HOC), Department of Health and Human Services (DHHS), and the Department of Housing and Community Affairs (DHCA) work collaboratively with state agencies and numerous nonprofit partners to administer programs that provide housing grants, loans, rental subsidies or homeownership options for low- and moderate-income residents, including people with disabilities.¹² The programs differ in their funding sources, eligibility criteria and populations that they target.

¹¹ <http://mmp.maryland.gov/Pages/Targeted-Areas.aspx>. Some areas of Montgomery County included Targeted Areas.

¹² Examples of other County programs that further the creation of inclusive communities for individuals with disabilities include an annual Developmental Disabilities Supplement payment to support the wages of service providers' direct service workers; a County Design for Life program administered by the Department of Permitting Services that provides partial property tax credits to property owners and home builders for improvements that increase the accessibility, visit-ability and live-ability of residential homes; employment initiatives that include hiring preferences for veterans, veterans with disabilities, persons with disabilities and a non-competitive hiring process for persons with disabilities; and a capital program to resolve access issues to County buildings.

1. General Federal Housing Choice Vouchers (HOC)

Federal housing choice vouchers are rental subsidies funded with federal dollars to help make rental housing more affordable for low- and extremely low-income households. Public Housing Agencies (PHA) (the Housing Opportunities Commission in Montgomery County) administer the vouchers. HOC currently manages an allocation of over 7,400 vouchers for low income households, including households who have individuals with disabilities. The next table summarizes details about the program.

Table IV-6. Federal Housing Choice Vouchers Program Details

Category	Requirement
Eligibility	Families earning below 50% of AMI
Maximum Household Income	\$107,000 in Montgomery County
Maximum Property Purchase Price	\$300,000 in Montgomery County
Maximum Underwriting Ratios (some exceptions apply)	30% housing expense-to-income ratio 38% debt-to-income ratio
Interest Rates	2.25% to .25% below the rates offered through the Maryland Mortgage Program Conventional Interest Rate Loan
Mortgage Term	30 years
Disability certificate required from...	Health, mental health, or disability professional

Federal law requires PHAs to provide 75 percent of vouchers to families at or below 30 percent of AMI (extremely low income (ELI) households).¹³ HOC has an online registration process – HOC Housing Path – that allows individuals to apply for (and get on a waitlist for) its tenant-based and project-based rental subsidies. Opened in July 2015, HOC has received 34,000 online applications. The highest priority areas requested are Silver Spring and Rockville. HOC will provide assistance to applicants who need help with the application process or with subsequent updates. Applications can be filed at public libraries and HOC hub sites throughout the County and HOC is able to set up free email accounts for those who lack computer access.

Types of General Vouchers. Federal vouchers include both tenant-based vouchers and project-based vouchers. While some PHAs only administer one type of voucher, HOC administers both types.

¹³ In 2016, 30 percent of AMI in Montgomery County was \$22,850 annually (\$1,904/month) for a one-person household; \$26,100 annually (\$2,175/month) for a two-person household; and \$29,350 annually (\$2,445/month) for a three-person household.

- **Tenant Based Vouchers.** Tenant-based vouchers allow an individual to rent from any qualified landlord. An individual with a voucher pays no more than 30% to 40% of their income in rent and federal housing choice voucher dollars cover the difference between that amount and the fair market rent. A tenant-based voucher gives a tenant the flexibility to re-locate, within the restrictions of their lease agreement. A portion of HOC's tenant-based vouchers are Mainstream Vouchers that are specifically set aside for individuals with disabilities.
- **Project Based Vouchers.** A project-based voucher is a subsidy that is attached to a particular development. HOC uses its project-based voucher program to contribute to the viability of the housing stock; to increase the supply of affordable housing and location choice for extremely low-income households; to integrate housing and supportive services, including case management; and to promote the coordination and leveraging of resources with nonprofit and public providers who have compatible missions. In 2016, HOC awarded vouchers to The National Center for Children & Families (16 units); Coalition Homes (6 units); and Montgomery Housing Partnership (34 units dispersed across six projects).¹⁴

2. Targeted Funding Programs and Special Purpose Vouchers.

The federal government also funds targeted vouchers for specific groups of people, including persons with disabilities. Programs include Veterans Affairs Supportive Housing Vouchers (VASH); Non-Elderly People with Disabilities Vouchers (or NED Vouchers); and Non-Elderly People with Disabilities Category 2 Vouchers (NED 2 Vouchers). HOC administers over 660 special purpose vouchers targeted to persons with disabilities in addition to its tenant based and project based general vouchers.

3. HOC Resident Services Counseling

HOC's resident services programs provide and coordinate the delivery of services to more than 5,000 residents with a variety of needs. The Disability Services Counseling program provides an additional level of support to help participants with disabilities who live in HOC's subsidized housing access services and resources so that they can live independently successfully. In 2009, HOC estimated that as many as 20% of its residents have disabilities.

The core services provided by HOC staff include information and referrals, short term case management, eviction prevention and crisis intervention. The counselors also provide short term counseling to help residents stay stabilized in housing. These activities can include assistance with navigating HOC procedures and with reasonable accommodation requests. HOC reports that it collaborates extensively with HHS staff and they also consult with other service providers.

¹⁴According to HOC's website, 17 developments receive project-based vouchers with higher maximum income limits. These developments administer their own affordable housing application process and wait lists and are funded through a mix of vouchers and rental subsidies provided through Low Income Housing Tax Credit financing. The maximum income limits for these programs are \$46,750 annually or \$3,896 monthly for a one-person household and \$53,400 annually or \$4,450 monthly for a two-person household.

4. HOC Federal Grants for Permanent Subsidized Supportive Housing Programs

HOC administers three federal grant programs that subsidize supportive housing for homeless individuals. Two programs – Shelter Plus Care and the New Neighbors I and II Programs – serve homeless individuals with disabilities (primarily with serious mental illness) and their families. The third program – the Homeless Assistance Grant – also funds supportive housing. All of these federal grants require County matching funds, which are coordinated through Montgomery County’s Continuum of Care process. (The Continuum of Care Process is a HUD planning process that communities use to coordinate several homelessness assistance grants.)

Shelter Plus care and the New Neighbors I and II Programs. These programs include housing for 64 households. DHHS case managers refer eligible participants to the Mental Health Association (MHA), which provides case management services including assessments. MHA makes the final referrals into the program. HOC staff administer the federal grant, determine client eligibility based on HUD guidelines, coordinate with the County to satisfy the dollar match requirements and collaborate with the Mental Health association. The local match for the federal grant comes from the cost for the Mental Health Association contract and other associated costs.

Federal Homeless Assistance Grant. This federal grant and local matching dollars fund permanent housing and an array of supportive services including intensive case management, referrals for therapeutic and clinical mental health services and assistance with crisis situations. The program, which serves 217 units of permanent housing for households with adults with disabilities, is part of Montgomery County’s Continuum of Care (CoC).

5. HOC Homeownership Programs for HOC Clients

HOC’s Mortgage Finance Division administers two programs that offer homeownership opportunities for HOC residents – the Housing Choice Voucher Homeownership Program and the HOC Homeownership Program. HOC clients that use these programs free up vouchers for other households in need.

The HOC Homeownership Program (“HOC/HOP”) program provides funding for HOC clients to purchase moderately priced dwelling units (MPDUs) in the County. Funding is provided through an HOC Line of Credit and Funds from a County Revolving Fund established to purchase MPDUs. Monies from the resale of an MPDU are repaid to the Revolving Fund.

The Housing Choice Voucher Homeownership Program is an option that public housing authorities may offer so that households with housing choice vouchers may purchase a home. The program includes special terms for participants who are individuals with disabilities. HOC formerly offered this program but it is currently closed. According to HUD data, between 2004 and 2012, this program helped 12 HOC residents purchase units. The next table summarizes details of the program.

Table IV-7. Federal Housing Choice Voucher Homeownership Program Details

Category	Requirement
Minimum Household Income	12 times the prevailing minimum wage
Work and Participation Requirements (waived for elderly and disabled households)	Full-time employment for at least one year before housing assistance begins, complete HOC’s Family Self Sufficiency Program, complete a housing counseling program
Maximum Housing Payment	30% of adjusted household income
Costs covered by Assistance	Mortgage principal and interest, mortgage insurance premium, real estate taxes and homeownership insurance, utilities, routine maintenance, repairs principal and interest on debt that may be needed to finance costs to make the home accessible for a family member with a disability
Maximum Property Purchase Price	\$300,000 in Montgomery County
Length of Financial Assistance	Elderly and disabled households: indefinite Others: 15 years for mortgages 20 years or longer

6. HOC Mortgage Program

This program provides below market rate mortgages to first time Montgomery County homebuyers and includes properties sold through the County’s Moderately Priced Dwelling Unit program. Mortgages are originated through an approved network of lenders. HOC staff is responsible for the underwriting review of each loan that is approved through this network of lenders.

7. Montgomery County’s Housing First Initiative

Montgomery County’s Housing First Initiative is a public-private partnership that implements homeless prevention, housing stabilization, and rapid re-housing programs. Housing First focuses on both homelessness prevention, using rental assistance to stabilize the living situation of vulnerable households and the rapid exit from homelessness through emergency shelter services, shallow rent subsidies and the provision of permanent supportive housing. The work aligns with the Montgomery County Continuum of Care (CoC); the Interagency Commission on Homelessness serves as the CoC governing board. DHHS is the lead for the County’s CoC process and HOC is a CoC member.

Assessment and Eligibility. The Montgomery County CoC uses a coordinated entry system so that families and individuals can access services through multiple access points across the County. The CoC uses two assessment tools depending on whether the household needing services is a family or an individual. Either tool is intended to enable providers to determine a household’s need, vulnerability and housing barriers so that a household is matched to the best available housing option.

For example, the Vulnerability Index-Service Prioritization and Decision Assistance Tool (VI-SPDAT) which is the assessment used for single adult households, collects information about someone’s length

of homelessness, their risks such as whether they have been recently hospitalized or used a crisis service and their socialization and daily functioning including their ability to manage money or care for themselves and their health. The assessment tool is based on self report.

Depending on the results of this assessment, an individual will be matched with the most appropriate and available resources to help resolve their homelessness. The three general levels of assistance are permanent supportive housing; rapid re-housing; or self-resolving. Individuals are prioritized for the housing intervention that best meets their needs based on vulnerability. DHHS' Special Needs staff states that it works closely with Aging and Disability, Maryland DDA, and HOC to connect adults with IDD to the necessary resources. For priority placement into permanent supportive housing programs, the individual and/or referring agency must verify and document disability and length of time homeless.¹⁵

8. County Assistance Programs to Prevent Homelessness

DHHS administers a shallow subsidy rental assistance program for eligible low income seniors, individuals with disabilities and families. Participants must be County residents, have a household income below 50% of AMI, have \$10,000 or less in assets and a rent burden between 25% and 35% of household income based on household size. Households can receive between \$50 and \$200 per month.

HHS administers a second rental assistance program (H-RAP) that provides rent subsidies for individuals with mental illness in licensed care facilities. The program receives referrals from group homes and other licensed providers. To be eligible individuals must receive benefits from a federal or state entitlement program such as Supplemental Security Insurance, Medicaid, Medicare or food stamps.

9. County Permanent Supportive Housing Programs

The County has several programs that provide deep rental subsidies and service coordination to reduce County homelessness through the provision of Permanent Supportive Housing (PSH). Two examples are the Housing Initiative Program administered by DHHS and the Partnership for Permanent Housing 2.¹⁶

PPH uses HOC project-based vouchers to re-locate families from the shelter system into rental housing on the open market. Housing is located throughout the County. In addition, funding from the County HIF creates protection for private landlords by providing guarantees for delayed payments, start-up vacancy loss and non-payment of rent or utilities.

¹⁵ According to HUD a disability is expected to be of long, continuing or of indefinite duration, substantially impedes the individual's ability to live independently, and could be improved by the provision of more suitable housing conditions. The documentations required for disability must be third party and include 1) written verification from a professional licensed by the State to diagnose and treat the disability and certification that the disability is expected to be long-continuing or of indefinite duration and substantially impedes the individual's ability to live independently; (2) Written Verification from SSA; (3) the receipt of a disability check; (4) intake staff recorded observation of a disability that is confirmed and accompanied by evidence above within 45 days/

¹⁶ The original Partnership for Permanent Housing is a public private partnership between the Montgomery County Coalition for the Homeless, the Housing Opportunities Commission and the County Department of Housing and Community Affairs established in 2003. Additional funding that more than doubled the level of effort led to the establishment of PPH2 in 2007.

Both the HIP and PPH2 serve formerly homeless individuals and families previously living in shelters, motels, or other places not meant for human habitation and they target special need populations. They provide the same services using the same eligibility criteria and are both funded through the Housing Initiative Fund and County general fund revenues. Based on its review of program data, DHHS estimates that approximately 5% of the population currently served in the County's permanent supportive housing programs has cognitive deficits including 1% to 2% with developmental disabilities.

Eligibility and Screening. To be eligible for this program, an individual must have a referral from a public or private provider agency, be 18 or older and be a member of a special needs population. Special needs individuals can include those who are elderly and in need of independent housing or assisted living; someone with a developmental disability or a cognitive, sensory or physical disability; a homeless individual or an individual with a chronic substance abuse issue. All referrals are made through the County's Coordinated Entry System and based on vulnerability.

An individual's household income must be at or below 30% of AMI and no more than \$10,000 in assets. A household must have a written lease agreement with a private landlord that complies with County lease regulations as well as a written service agreement with a service coordinator provider that specifies tasks and expectations for the individual. Applications must be signed by both the individual and the provider agency.

Services. DHHS contracts with several service providers including HOC to provide case management services. Providers meet regularly with program participants to ensure clients remain housed and to link clients to other County resources.

10. DHCA Housing Initiative Fund

The Housing Initiative Fund (HIF) is a local housing trust fund that funds housing programs and projects that further County housing policies. A special revenue fund established in County law, HIF funds can pay for predevelopment, acquisition, construction, or rehabilitation costs of affordable residential facilities and for cash rental assistance payments. The main revenue sources for the HIF are property tax revenues, recordation tax proceeds, and investment income.

DHCA awards HIF loans to both public and private entities. These loans are one of several sources of funds that developers and organizations access to develop affordable housing projects. Historically, HIF project loans have expanded the inventory of housing available to adults with (any) disabilities. For example,

- HIF loans were instrumental to the development of Seneca Heights, a service enriched facility that provides 17 units of permanent supportive housing for families and 40 units for individuals. The 2004 project, which was developed through the collaborative efforts of DHCA, HOC, DHHS, the City of Gaithersburg and the Montgomery County Coalition for the Homeless, used HIF loans to acquire and rehabilitate an EconoLodge hotel.

- HIF awarded two loans to Montgomery County Coalition for the Homeless for the purchase of eight units in Silver Spring and ten units in North Bethesda for permanent supportive housing for very-low income individuals with mental disabilities.

11. DHCA's Group Home Rehabilitation Loan Program

This program helps public and nonprofit group home providers fund repairs for group homes that are occupied by low-income, special needs populations. The funds help ensure that group homes are maintained in compliance with County codes. The program is funded with federal Community Development Block Grant (CDBG) dollars. In FY17, the County allocated \$600,000 in CDBG funds to this program and estimated that these funds would pay for repairs to 15 homes. An eligible group home must have been operating for two years and be occupied by elderly or disabled residents with low and moderate incomes.

12. DHCA MPDU Program

The County's Moderately Priced Dwelling Unit law requires DHCA to set aside a percentage of newly constructed MPDUs for acquisition by HOC and nonprofit organizations. Nonprofits have purchased MPDUs to provide housing for special needs populations.

CHAPTER V. HOUSING IN MARYLAND'S DEVELOPMENTAL DISABILITY SERVICE SYSTEM

Adults with IDD and their families who wish to pair publicly-funded, community-based long term care services with the housing resources described in Chapter IV must apply to the state's Developmental Disabilities Administration (DDA) and/or Medicaid for long term care services. DDA's developmental disability services are funded with a mix of state and federal dollars. Thus, multiple federal and state rules determine issues such as service eligibility, the array of services offered, the types and characteristics of service settings and funding sources for room and board payments.

This chapter describes a select set of these rules to help the Council understand some of the variations in support services and funding among the subgroups of adults with IDD. It also describes provisions of the new CMS rule for community settings. It has five parts, organized as follows:

- A. An Introduction to Medicaid**
- B. Maryland's Developmental Disabilities Services System**
- C. Living Arrangements and Long Term Care Settings in an Inclusive Community**
- D. Barriers to Community Integrated Settings for Residents of State Residential Centers**
- E. Sources of Funding for Room and Board Payments for Adults with IDD**

A. An Introduction to Medicaid

Medicaid is a means-tested federal health care program (eligibility is determined by a person's finances) authorized under Title XIX of the Social Security Act (SSA). Medicaid provides medical health care and long-term services and supports (LTSS) to low-income children and adults, the elderly, and individuals with disabilities. Federal law establishes broad program requirements and mandates health coverage and benefits for some populations but leaves choices about other coverage options to individual states. The federal Department of Health and Human Services' (HHS) Center for Medicare and Medicaid Services (CMS) jointly administers and funds the Medicaid program in conjunction with state governments.

Under the funding arrangement for Medicaid, the federal government reimburses states for a percentage of Medicaid program expenditures based on each state's Federal Medical Assistance Payment (FMAP) rate, which is based on a state's wealth. Maryland and seven other wealthy states have a FMAP rate of 50% compared to a FMAP rate of 73% for West Virginia and 76% for Mississippi. Each state makes critical decisions about the criteria that determine Medicaid's coverage scope of services for its residents – leading some to describe Medicaid as a collection of 51 different programs rather than a national program.

Before 1981, the Medicaid program only paid for services if an individual lived in an institution.¹ (And, then and now, the federal government authorized Medicaid to pay for recipients' room and board costs if the recipient lived in an institutional setting.²) In 1981, Medicaid began issuing "waivers" to states to

¹ Institutional settings in the Medicaid program refer places such as nursing facilities, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID), and Institutions for Mental Diseases (IMD).

² See <https://aspe.hhs.gov/report/state-residential-care-and-assisted-living-policy-2004/enabling-medicaid-beneficiaries-pay-room-and-board>.

develop programs that provide Medicaid funding for long term care services (but not funding for room and board expenses) to individuals in their homes or communities.

1. Medicaid Mandatory and Optional Eligibility Categories

Federal rules mandate Medicaid coverage for certain groups, including low-income families, children and pregnant women, adopted children, adults with disabilities and the elderly who receive Supplemental Security Income, certain working individuals with disabilities; and certain low-income Medicare beneficiaries.³ These individuals are categorically eligible for Medicaid and they account for most Medicaid enrollees.

Individuals, including the medically needy, elderly and disabled individuals with incomes above federal minimum standards, and enrollees in HCBS waivers, may be eligible for Medicaid coverage depending on the rules a state adopts to expand coverage. In Maryland, for example, adults with IDD may earn up to 300% of SSI and be financially eligible for the Medicaid Community Pathways Waiver program that provides a comprehensive set of 19 support services. Individuals who qualify through state rules that expand coverage are referred to as “optionally eligible for Medicaid.”

2. Medicaid Mandatory Long Term Services and Supports

Among other services, Medicaid provides “long term services and supports” (LTSS) to individuals who lack the capacity for self-care due to a physical, cognitive or mental disability or condition. “Home and community based services” (HCBS) are a subset of LTSS that are provided in community settings such as private homes, adult day care facilities, assisted living facilities and group homes.

Just as states’ Medicaid plans have mandatory and optional eligibility coverage groups, states’ also have mandatory and optional types of LTSS. For example, in Maryland, home health and personal care are mandatory long term care services that are available to every Medicaid enrollee, while the packages of long term care services provided through Maryland’s nine HCBS waivers are optional and only available to pre-set numbers of beneficiaries.

In addition, in 2005 through the Deficit Reduction Act and in 2010 through the Affordable Care Act, Congress enacted legislation establishing programs to help states improve and extend LTSS to individuals in homes or communities, rather than in institutions. These include:

- **The Balancing Incentive Program (BIP).** This program authorizes incentive grants to states that agreed to increase their share of LTSS spending on HCBS and reduce their spending on LTSS institutional care below 50%. States, in turn, receive an increase in their rates of reimbursement from Medicaid if they met their HCBS spending target increase; and
- **The Community First Choice program.** CFC provides additional funding for states to provide self-directed HCBS services to Medicaid recipients. States can use funding to help move

³ Supplemental Security Income (SSI) is a means-tested federal program that operates as an assistance program of last resort. SSI provides monthly cash assistance to poor working-aged beneficiaries who are blind or disabled and elderly beneficiaries 65 and over with or without disabilities. The monthly federal payment level establishes an assistance floor that is roughly equivalent to 75% of the official federal poverty level.

individuals from institutional living arrangements to community-based arrangements, funding costs such as security deposits, bedding, kitchen supplies and other expenses related to setting up or maintaining an independent living arrangement. Like the BIP, states receiving CFC funds receive an increase in their reimbursement rates from Medicaid. The CFC reimbursement rate is six percentage points higher than a state's usual rate.

As described in Chapter IV, Maryland has used Money Follows the Person (MFP) program resources to fund a state partnership program that encourages the development of community housing for individuals with disabilities. According to Disability Rights Maryland, both Community First Choice and Medicaid Community Personal Assistance Services offer a variety of other in-home support services; and, these services may be especially useful for adults with IDD who are not eligible for the Maryland HCBS Community Pathways waiver services described below.⁴

B. Maryland's Developmental Disabilities Services System and Medicaid Optional LTSS

The Developmental Disabilities Administration (DDA) in the Department of Health and Mental Hygiene (DHMH) manages Maryland's developmental disabilities services system. DDA's mission is to administer a service delivery system for individuals with developmental disabilities and their families that ensures individuals "receive appropriate services oriented to the goal of full integration into the community." DDA's approach is "guided by the principle that individuals with developmental disabilities have the right to direct their lives and services."

DDA accomplishes its mission by providing direct services to individuals with intellectual disabilities in institutions that the DDA operates and by funding a coordinated service delivery system that supports individuals with developmental disabilities in the community. DDA funds its community-based services with a mix of federal and state taxpayer dollars. Individuals must require an institutional level of care and meet other financial eligibility guidelines to be eligible for services funded through a Medicaid HCBS waiver. DDA funds services for individuals who do not meet these requirements with state-only taxpayer dollars.

Over an eight-year period, beginning in 2007, a series of federal and state audits identified significant financial and administrative weaknesses within DDA. A 2013 DDA report "Moving the DDA Forward" described plans to address 17 key challenges across the agency's fiscal, operational, service/delivery and stakeholder communication and engagement responsibilities. A subsequent 2014 report outlined a multi-pronged, multi-year effort to restructure the agency in order to improve service delivery to individuals, stabilize its operations and improve its ability to predict service needs and costs.

Key components of DDA's transformation include:

- A commitment to implement standard assessment tools such as the Supports Intensity Scale and the Health Risk Screening Tool to assess individuals' levels of need;
- A commitment to better align DDA's individual plan processes with person-centered planning best practices and the new HCBS regulations;
- A review of the service definitions in Community Pathway waiver; and
- The development and execution of a rate setting process for DDA funded services.

⁴ Disability Rights Maryland, "Maryland's Developmental Disability Administration (DDA) Medicaid Waiver Administration: A Practical Guide," December 2014.

Because DDA's transformation is ongoing and extensive, many aspects of DDA's service system described below are in a state of flux and will continue to change.

1. Service Eligibility Categories and Differences in the Scope of Services

Maryland law and regulations⁵ consider a person to have a developmental disability if the individual has a "severe, chronic disability":

- Due to a physical and/or mental impairment (other than mental illness only);⁶
- That manifests before age 22;⁷
- That is likely to continue indefinitely;
- That results in an inability to live independently without external support or continuing and regular assistance;⁸ and
- That requires specialized care individually planned and coordinated for an individual.⁹

Based on this definition, DDA makes determinations of service eligibility that classify applicants into two distinct service subgroups:

- DDA classifies an individual as **Supports Only or "SO Eligible"** if s/he meets the first and the third criteria of the definition – having a severe, chronic disability due to a physical and/or mental impairment that is likely to continue indefinitely. These individuals are not eligible for the Community Pathways waiver because they do not require an institutional level of care.

⁵ Maryland law has a functional definition of a "developmental disability," which means the definition is based on the skills an individual needs to function or carry out major life activities, e.g., eating, dressing, paying bills, and how critical the absence of these skills are to a person's health and well-being. States with a categorical definition of a developmental disability require an individual to have a specific clinical diagnosis to be eligible for services.

⁶ A DDA publication, *Advisory Guidelines for Determining Eligibility for DDA Funded Services*, explains the criteria DDA uses to make service eligibility determinations and identifies acceptable sources of testing and supporting documentation. The Guidelines explain that the phrase "a severe, chronic disability" reflects that DDA funding is meant for individuals whose functional impairments are extensive and persistent and they are due to a condition with a neurological basis that impairs the person from performing major life functions. The Guidelines clarify that an intellectual disability qualifies as a developmental disability if it meets the definitional criteria.

⁷ The Guidelines state that information about when a disability first appeared "reflects the fact that severe disabilities, which originate early in a person's life, generally interfere with the acquisition of the most basic skills."

⁸ The Guidelines explain the focus on an applicant's inability to live independently addresses three areas: management of self-care or personal needs; management of a household; and use of community resources. To meet the requirement for external supports, the need should be such that substantial assistance or supervision on at least a weekly basis is needed to complete tasks in these three areas; that the external support is critical to a person's health; and that the external support is related to the neurological condition.

⁹ Maryland Code, Health Gen. Art. § 7-101. The Guidelines explain that individuals who meet these criteria typically have needs that, if not met in the community, would require the level of care needs provided in an institution. The needs are habilitative, not restorative or needed to prevent the loss of functional skills.

People who are “SO Eligible” are eligible for a limited set of Family and Individual Supports Services¹⁰ that are funded with state taxpayer dollars. Funding constraints, however, mean that most people wait before they receive services. (Section 3, below, describes how DDA manages its service wait list.)

- DDA classifies an individual as **Developmental Disability or “DD Eligible”** if s/he meets all five of the definitional criteria. DDA’s Advisory Guidelines state that “a level of care assessment is used to establish (1) the individual’s support needs and (2) need for special, interdisciplinary or generic care, treatment, or other services that are individually planned and coordinated for the individual” and that this assessment complies with the federal rule that a state show that an individual must require an institutional level of care to be eligible for long term care funded with a Medicaid HCBS waiver. DDA’s Advisory Guidelines also state that, under federal waiver rules, an individual must meet the federal definition of a developmental disability in addition to meeting the state definition.¹¹ DD Eligible individuals are eligible for the Community Pathways HCBS waiver because they meet the requirement for an institutional level of care. Service costs are funded with state taxpayer dollars and are eligible for a federal match.

An individual who receives a determination of DD Eligibility has access to a comprehensive set of 19 community support services when funding is available. These services are defined in DDA’s waiver agreement with CMS. Five services relate to an individual’s living arrangement choices and housing options. The first three services provide support in individual’s own home or a family home; the last two provide non-family-based residential support services.

- **Family and Individual Support Services** provide assistance “to enable participation in the community.” These services rely on community resources and use an individual’s existing support network.
- **Personal Supports** (formerly called Community Service Living Arrangements or CSLA) provide hands-on assistance to help or remind recipients to perform tasks and are provided in an individual’s own home, family home, in the community or at work.
- **Live-in caregiver rent** provides money for a personal caregiver who is not related to the recipient of waiver services.
- **Shared Living** is “an arrangement in which an individual, couple or a family in the community share life’s experiences and their home.... It emphasizes the long-term sharing of lives, forming of caring households, and close personal relationships....”

¹⁰ COMAR 10.09.06.01 Definitions, defines Family and Individual Support Services (FISS) to mean:

[A]ssistance provided to an individual to enable participation in the community, which may include, but are not limited to, supports involving: (a) Budgeting; (b) Medication administration; (c) Counseling; (d) Helping an individual to access and complete the individual's education; (e) Participating in recreational and social activities; (f) Accessing community services; (g) Grocery shopping; (h) Behavioral and other services and supports needed by the family of the individual; and (i) Developing relationships.

¹¹ The Advisory Guidelines state “the applicant must have a disability or a condition closely related to an intellectual disability, such as cerebral palsy or epilepsy, which results in substantial functional limitations in three or more of the following areas of major life activity: 1) self-care, 2) understanding and use of language, 3) learning, 4) mobility, 5) self-direction, and 6) capacity for independent living.”

- **Community Residential Habilitation** provides services to help someone learn the skills necessary to be as independent as possible in their personal care and in community life. Services are provided in either group homes (GHs) or alternative living units (ALUs), which are licensed residential services providing ten or more hours of supervision per week for up to three people.

2. Community Service Coordination and Person Centered Planning

Federal and state developmental disability laws intend for state developmental disability systems to help adults with IDD plan and coordinate their services. In Maryland, DDA fulfills these responsibilities through its Coordination of Community Services (CCS) program.¹²

DDA provides these case management services at several points in its service delivery system. Specifically, it funds CCS for:

- People who have applied to DDA for a determination of service eligibility;
- People who have been found eligible for developmental disability services and are waitlisted for services;
- People who are transitioning out of an institution; or
- People who are currently receiving services funded through an HCBS waiver.

CCS responsibilities vary based on the specific needs of each subgroup. For example, during the eligibility determination process, CCS conducts personal interviews and comprehensive assessments and makes eligibility recommendations to DDA. For individuals who are eligible and waitlisted for services, CCS advocates for individuals and provides information on available services.

To comply with federal law and regulation, CCS helps individuals who are receiving services under a HCBS waiver prepare person-centered, individual service plans. These plans state an individual's outcomes and goals and set expectations about how an individual's services are intended to achieve their goals. CCS provides periodic check-ins to assess individuals' well-being, services and any issues that arise. For example, if someone experiences a change in their health status, a service change may be needed. CCS' advocacy can also help determine the level of service funding an individual receives.

3. The Future Needs Registry and DDA's Wait List Service Priority Categories

DDA currently has no funding for services for new participants. DDA maintains two waiting lists of individuals who are either DD or SO eligible. The first list is a Future Needs Registry to track individuals who have been found either DD or SO eligible for service planning purposes. Individuals on this list must keep DDA apprised of current contact information and changes in needs.

The second list is the DDA Waiting list which classifies individuals based on the urgency of their service need. There are two categories for individuals in crisis and a third holding category for tracking individuals who are not expected to need services for at least two years. Although the categories have

¹² In 2013, DDA transitioned to a Targeted Case Management approach for the CCS program. Until then, DHHS provided resource coordination services for everyone who either received or was waitlisted for DDA services. Currently, DHHS provides case management services for 500 adults and children who receive or are waitlisted for DDA services.

time frames associated with them, there is no automatic progression from one category to the next. Exhibit V-1 displays the three service priority groups and the criteria that DDA uses to classify the eligible population waitlisted for services.

Exhibit V-1. Criteria for Priority Service Categories in DDA’s Waitlist

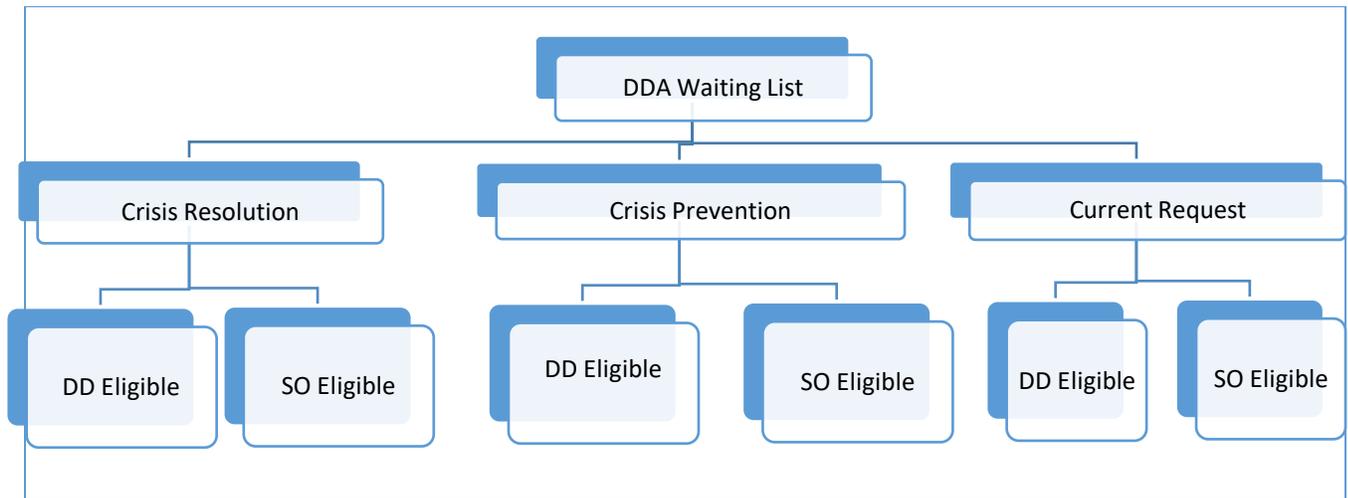
Category	Criteria
Crisis Resolution	<ul style="list-style-type: none"> • Homeless or will be homeless within 30 days; • Victims of abuse or neglect; • At serious risk of causing physical harm to others; • Living with a caregiver who is unable to provide adequate care due to the caregiver’s impaired health.
Crisis Prevention	<ul style="list-style-type: none"> • Is at substantial risk for meeting one or more of the Crisis Resolution criteria within one year; or • Have a caregiver who is 65 years or older.
Current Request	<ul style="list-style-type: none"> • These individuals have a current need for services. They are prioritized for services based on the number of years they have been on the waiting list, with certain exceptions.

Source: DDA and OLO.

The risk of homelessness and the status of a caregiver’s health in the highest priority category (Crisis Resolution) and the existence of a caregiver age 65 or over in the second highest priority category (Crisis Prevention) recognize the significant contribution that families, caregivers and residential support providers make to keep adults with IDD stably housed.

DDA uses information from the eligibility application and interview to make these determinations as well as subsequent information that is provided to update an application. The diagram below shows how an individual’s waitlist classification is based on both their eligibility status, i.e. DD or SO eligible, and their service priority category.

Exhibit V-2. Criteria for Priority Service Categories in DDA’s Waitlist



Source: “DDA Waiting List Initiative – Alcohol Tax Fiscal Year 2012 Memo,” page 2. [hereinafter “FY 2012 Memo”]

Table V-1 compares DDA waitlist data by service eligibility status and service priority category for two periods. The data show:

- The total waitlist population grew by 1,500 names in the six years since May 2011;
- On average, 64% of the total waitlist population in 2011 and 72% in 2017 were eligible for Community Pathways waiver funded services; and
- In both 2011 and 2017, over 80% of waitlisted individuals were in the non-crisis, Current Request category; in 2017, this group accounted for 85% of the waitlist.

Table V-1. DDA Waitlist Data by Service Priority Category and Eligibility Status, 2011 and 2017

Data as of May 2011	Individuals by Eligibility Status				
Service Priority Category ¹³ - Earliest Service Initiation Anticipated ...	Developmental Disability Eligible	Supports Only Eligible	Total	% of category DD Eligible	Category as a % of total wait list
Within 6 months* (Crisis Resolution)	110	8	118	93%	
Within 2 years (Crisis Prevention)	735	369	1,104	67	17
Beyond 2 years (Current Request)	3,233	1,915	5,148	63	81
Total Waitlist	4,078	2,292	6,370	64%	100%
Data as of Feb 2017					
Service Priority Category	Developmental Disability Eligible	Supports Only Eligible	Total	% of category DD Eligible	Category as a % of total wait list
Within 6 months (Crisis Resolution)	62	13	75	83%	1%
Within 2 years (Crisis Prevention)	792	322	1,114	71%	14
Beyond 2 years (Current Request)	4,791	1,881	6,672	72%	85
Total Waitlist	5,645	2,216	7,861	72%	100%

Source: DDA and OLO.

4. Funding Emergencies, Legislative Priorities and Service Priorities in the Budget

Each year, the General Assembly approves DDA’s budget and establishes an annual funding amount for developmental disability services that allocates resources for multiple priorities. These priorities include funding for:

- A budget to continue current services for people already in service that addresses provider service rates and funding for upcoming service change requests;
- Emergency services funding for a mix of time-limited or ongoing services for an immediate health and safety need such as homelessness or loss of a caregiver. People who receive

¹³ Add note about time frames.

emergency service funding include people in the Crisis Resolution category who are known to DDA and others who are not known to DDA;

- The Governor’s Transitioning Youth Initiative which is a program that provides service funding for students who are leaving school. An individual must be DD Eligible to be eligible for this funding. This group may include individuals who applied to DDA and were waitlisted for services in the Current Request category; and
- Services for people in any of the three service priority categories. The General Assembly can use interest earned from the Waiting List Equity Fund for these services; however, state regulations require an 80/20 split between non-emergency and emergency services.¹⁴

5. Developmental Disability Service Models and Service Use Rates

A state developmental disability system organizes delivery of its community based services by broad categories referred to as service groups or models. In Maryland, in addition to the category of community services supports described earlier, an individual’s service plan can include services from one or more of three service categories:

- The **Residential Services Group** provides services that include Alternative Living Units (ALU), Group Homes (GH), Individual Family care (IFC) and Personal Supports (formerly called Community Supported Living Arrangement);¹⁵
- The **Day Services Group** provides services that include day habilitation, supported employment, community learning service and employment discovery and customization; and
- The **Individual Services Group** includes individual and family support services. This service category is also referred to as “Supports.”

Table V-II displays trend data for the number of funded services by service category. Since individuals can be counted in multiple categories, the data provide duplicated service counts. By category, the trend data show a small, steady increase in residential services, with an average of 54 new participants per year; fluctuations in day services and a downward trend in individual support services.

The service utilization rate calculation shows the number of services in a particular group as a percentage of the total service population. A comparison of the service utilization rates for 2012 and 2016 shows little change in the utilization rates for the residential model (26% in both years) and the day model (57% in 2012 and 58% in 2016). There was a slight decline for the Individual model from 39% in 2012 to 35% in 2016.

¹⁴ The Waiting List Equity Fund was established to ensure that funding associated with serving individuals in a State residential center follows them to the community when they are transitioned to a community based care setting, and that any remaining funds are used to provide community based services to individuals on the waiting list. Since DDA has been advised that use of the WLEF is only available for an initial year of placement and not for ongoing services, DDA limits use of the WLEF to place individuals from the waiting list into community supports.

¹⁵ The assignment of Personal Supports to the Residential Model reflects the classification used in the 2011 DLS memo. At other times, Personal Supports are classified as part of the Individual Services Model.

Table V-2. DDA Service Trends – Number of Individuals Served by Service Group, 2012-2016

Services Group	2012	2013	2014	2015	2016	5-year Change	Average Annual Change	Service Utilization Rates by Group	
								2012	2016
Residential	5,990	6,040	6,107	6,209	6,260	270	54	26%	26%
Day	13,246	13,353	13,810	14,138	13,827	581	116	57%	58%
Individual	9,115	8,011	8,259	8,306	8,337	-778	-155	39%	35%
# of Individuals Served	23,359	24,445	25,183	25,315	23,654	295	59	100%	100%

Source: DDA and OLO.

In 2011, a Department of Legislative Services memorandum that developed annualized cost estimates provided data about anticipated service model requests for individuals in the highest priority (Crisis Resolution) service category. This data, displayed in Table V-3, provides insight into the service requests for individuals in Crisis Resolution. For example, it shows 90% of this group had requested residential supports; 89% had requested day supports; 10% had requested individual supports.

Table V-3. Expected Service Requests for Individuals in Crisis Resolution by Service Group, 2011

Services Group	# of requests	Service Utilization Rates by Group
Total Individuals in Crisis Resolution	118	
Residential	106	90%
Day	105	89%
Individual	12	10%

Source: FY 2012 Memo

Comparing the data in Table V-3 to the service use rate data for everyone who is receiving services in Table V-2 shows how the service mix for the crisis resolution subgroup differs from the overall service mix. Specifically, 90% of the crisis resolution group requested residential supports compared to 26% of overall group; and 89% of the crisis resolution group requested day supports compared to 35% of the overall group.

C. Living Arrangements and Long Term Care Settings in an Inclusive Community

The concept of community living for adults with IDD has evolved over time and continues to evolve today. As Larson states,

In the 1970's, community living and participation simply meant, "not living in an institution." Over time the conceptualization of community living has broadened to include an array of lifelong community support alternatives for people with IDD and other disabilities. ... Today, community living and participation are conceptualized as having many critical elements such as: 1) where and with whom a person lives; 2) where a person works and how he or she earns money; 3) what a person does during the day; 4) the quality of relationships developed with

others; 5) what and with whom a person does things of personal interest; 6) an individual's health (physical and emotional); 7) where and with whom they worship; 8) their interest and opportunity to engage in learning and personal growth; and 9) their ability to make informed decisions about their lives (Hewitt, 2014).¹⁶

A state developmental disability system's definitions of the residential and individual services (including the service settings) it offers helps determine the living arrangements and housing choices available to adults with IDD who rely on publicly funded LTSS. And, since Medicaid funds most LTSS, federal rules establish a framework for a state's service definitions.

In January 2014, CMS issued a rule that addresses the characteristics of long term care settings. This rule applies not only to settings for developmental disability residential services, but to settings for developmental disability day services as well as settings for other populations who receive Medicaid waiver HCBS services.¹⁷ This section offers an overview of the new CMS rule; describes the current and proposed living arrangements and residential service settings where adults with IDD receive DDA services; presents information about the State Residential Centers and describes sources of funding for room and board payments.

1. The Center for Medicaid and Medicare Services (CMS) Settings Rule

Since the 1999 Olmstead ruling, the Center for Medicare and Medicaid Services or CMS has implemented a series of programs and rules to help states transform their long term services and supports (or LTSS) and further their compliance with Olmstead. As part of this effort, in January 2014, CMS published a final rule for Home and Community Based Services (HCBS) settings that receive Medicaid funding. The rule took effect March 17, 2014.

Intent and Scope. CMS intends for the rule "to enhance the quality of HCBS, provide additional protections to HCBS program participants, and ensure that individuals receiving services through HCBS programs have full access to the benefits of community living."¹⁸ It applies to both residential and non-residential program settings and providers funded through several Medicaid authorities, including 1915(c) waivers, 1915 (i) State Plans and the Community First Choice programs.

¹⁶ In addition to acknowledging that housing or "where and with whom a person lives" is a critical element of community living, Larson also emphasizes the significance of a well run developmental disability system. She states "Community living and participation for people with IDD is influenced by the availability and competence of those individuals who provide the ongoing support that they require, the design and funding of the service delivery system and state policies regarding the oversight, operation and funding of LTSS." Larson, S.A., Hallas-Muchow, L., Aiken, F., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2016). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, page 7.

¹⁷ According to DHMH's State Transition Plan as of August 2016, the Autism Waiver had 1,009 recipients and 77 providers; the Community Pathways Waiver had 13,854 recipients and 339 providers; the Home and Community Based Options waiver had 4,703 recipients and 1,801 providers; the Medical Day Care Waiver had 4,900 recipients and 179 providers; and the Traumatic Brain Injury Waiver had 74 recipients and 7 providers.

¹⁷ <https://mmcp.dhmdh.maryland.gov/waiverprograms/Final%20Rule%20Plans%20and%20Procedures/FULL%20Transition%20Plan%20Update%209.2.16.pdf> Accessed April 19, 2017.

¹⁸ <https://www.medicare.gov/federal-policy-guidance/downloads/cib-01-10-14.pdf>

Method. The rule establishes a series of characteristics that CMS will use in making its determinations of whether a setting is truly a community setting. In part, the rule requires that services and the settings where they are provided must be:

- 1) in places that are integrated and provide support for full access to the greater community;
- 2) selected by the individual from among options that include non-disability settings;
- 3) identified and documented in a person's plan; and
- 4) based on an individual's needs, preferences and their resources for room and board.

Other provisions that address provider owner or controlled residential settings require legally enforceable agreements and provisions that give individuals the same responsibilities and protections from eviction that other non-disabled individuals have under landlord tenant laws.

Finally, other provisions in the rule:

- 1) Explicitly prohibit certain settings, e.g. nursing facilities or hospitals, that are not home and community based;
- 2) Establish a standard for heightened scrutiny; and
- 3) Allow states to permit certain settings that are already in use to continue as long as they can continue to meet a minimum standard.

CMS has a useful fact sheet that summarizes the key provisions of the HCBS settings rule.¹⁹

Maryland's State Transition Plan Process. Given the breadth of the settings rule impact, CMS established a transition process so that states could "implement the rule in a manner that supports continuity of services for Medicaid participants and minimizes disruptions in service systems."²⁰ States must submit a transition plan for their existing programs and waivers that:

- 1) evaluates the settings in their current waivers and programs for compliance with the new rule;
- 2) identifies those settings that are not in compliance; and
- 3) works with CMS to devise a plan to bring settings into compliance.

Maryland submitted the first draft of its transition plan to CMS in March 2015. In 2016, the Maryland Association of Community Services (MACs), the statewide nonprofit association of over 100 community service providers, sponsored a technical assistance workshop to educate providers on the requirements of the new rule. DDA conducted an initial provider survey; plans to conduct additional surveys based on stakeholder feedback; and expects to begin on-site visits to providers in 2017.

¹⁹ <https://www.medicaid.gov/medicaid/hcbs/downloads/1915i-fact-sheet.pdf>

²⁰ <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-01-10-14.pdf>

Initial Assessment of the Impact. DDA reports that it serves nearly 9,000 individuals who receive some type of residential service, e.g., residential habilitation, shared living or personal supports. This total includes nearly 3,000 people in DDA group homes which serve from four to eight people. DDA has stated that the locations of some of these homes on cul-de-sacs may fall under the federal definition of isolating people from the larger community.²¹

Initially, CMS gave states one year to submit a transition plan and five years to bring settings into compliance. In May 2017, CMS extended the original deadline for complying with the new rule by three years from March 17, 2019 to March 17, 2022.

2. Housing Options in Maryland's Medicaid HCBS Waiver for Adults with IDD

This section describes different community housing model options that exist for individuals with IDD enrolled in Maryland's Medicaid Community Pathways waiver program. The presentation includes an overview of DDA's existing models, followed by information about options DDA is proposing as part of its transformation and its efforts to come into compliance with the CMS settings rule. The presentation of both the existing and proposed models order these options from most restrictive to least restrictive.

a. DDA's Current Individual and Residential Service Definitions

Personal Supports (Previously Community Service Living Arrangement) provides personal support services in a supported living environment. Under this arrangement, a service agency visits a participant's home (typically leased or owned by the participant or a guardian; can include an individual's family home) to provide services. Compared to a specialized living arrangement, this arrangement provides an individual more independence and control over their activities and schedule. Moreover, an individual in supported living who leases or owns their own home can change service providers without disrupting their housing arrangement.

DDA data tabulated in 2014 for the Maryland State Transition Plan shows there are 112 licensed agencies statewide that provide services to 2,681 individuals at 2,502 sites. Almost 90% of the supported living sites (2,358) have one individual; another 117 sites have two individuals; 24 sites have three individuals and three sites have four individuals.

Shared Living. As stated above, under a shared living arrangement an individual with IDD lives with an individual, couple, or family and the people involved mutually agree to share their lives and experiences. An example of shared living is an adult foster care home,²² which is a program that provides a family setting in the community for an aged adult or an adult with disabilities who requires protective oversight, assistance with the activities of daily living, and room and board. DDA data tabulated in 2014 for the Maryland State Transition Plan shows there are 14 licensed providers that provide shared living services to 212 individuals in 170 homes.

²¹ According to DDA, the effect of the Community Settings Rule is that services provided in facilities, congregate settings, farmsteads and/or services have the effect of isolating individuals from the broader community are considered to have institutional qualities and thus may not be in compliance with the new regulation. To come into compliance, individuals being served in these types of settings may need to be transitioned to more integrated community residences if the setting cannot meet the new standards and fully document compliance with the rule."

²² COMAR § 07.02.17.02(B)(1).

Residential Habilitation – Specialized Living Arrangements. On behalf of DDA, the Maryland Office of Health Care Quality (OHCQ) licenses agencies that provide supervised or supported living settings through the Medicaid waiver for individuals with IDD. Supervised living includes alternative living units²³ (ALU) and group home settings.²⁴

- **Alternative Living Units** are residences that provide services for individuals who require specialized living arrangements due to a developmental disability; that admit no more than three individuals; and provide ten or more hours of supervision per unit per week.
- **Group Homes** are residences that provide services for individuals who require specialized living arrangements because of a developmental disability; that admit between four and eight individuals; and provide ten or more hours of supervision per home, per week.

In specialized living arrangements, the agency provider controls the housing, services, and schedules of residents. ALUs and group home residences include single-family attached or detached houses, apartments, and condominiums located throughout the state.

DDA data tabulated in 2014 for the Maryland’s State Transition Plan shows there are 205 agencies statewide that provide services to nearly 6,070 individuals at roughly 2,100 sites. Just over 3,100 people receive services in an alternative living unit (ALU) and nearly 3,000 individuals (2,961) receive services at 779 group home sites. About 25% of individuals in group homes are in sites with three people or fewer; 50% are in homes with four people and the remaining 25% receive services at sites with 5 or more people.²⁵

b. DDA’s Proposed Residential Service Definitions

DDA’s current waiver is approved through June 2018. By January 2018, DDA must submit a renewal application to CMS. As part of this submission, DDA proposes to restructure its Residential Services to re-align its services with best practices, including an emphasis on person centered planning, and to bring the settings for these services into compliance with the CMS settings rule. As such, as shown in Table V-4, DDA’s proposal:

- Adds a new service definition for Supported Living;
- Expands the Shared Living service into two services to distinguish between a companion service model and a host home model; and
- Creates two new Community Living Services (Group Home and Enhanced Supervision) to replace the current Residential Habilitation services and settings.

²³ COMAR § 10.22.01.01(B)(92).

²⁴ COMAR § 10.09.26.01(B)(910).

²⁵<https://mmcp.dhmf.maryland.gov/waiverprograms/Final%20Rule%20Plans%20and%20Procedures/FULL%20Transition%20Plan%20Update%209.2.16.pdf>. See Appendix 8.

DDA’s proposal envisions a continuum of living arrangement options from Supported Living which is least restrictive to Community Living Enhanced Supervision (Supports) which is the most restrictive:

- The new Supported Living Service would allow up to four individuals to share a residence with up to four roommates in a private home or apartment.
- The Shared Living Companion service envisions a living arrangement where an individual and a companion share a residence in either the individual or the companion’s home whereas the Shared Living – Host Home is similar to the current Shared Living service definition.
- Both the Community Living Services are provider models.

To bring the settings for the Community Living Options into compliance with the CMS settings rule, DDA proposes limiting the size of these settings to four participants. All of the services also include requirements that would address the CMS standards that require participant choice and lease agreements or tenancy rights.

Table V-4. Comparison of DDA’s Current and Proposed Residential Service Groups

Current Service Name		Proposed Service Name	Setting Options
n/a	1	Supported Living (New)	Own Home or Roommate
1 Shared Living	2	Shared Living – Companion	Own Home or Companion
	3	Shared Living – Host Home	
2 Residential Habilitation	4	Community Living – Group Home (GH&ALU)	Provider Licensed
	5	Community Living- Enhanced Supervision (Supports)	Provider Licensed

Source: DDA.

Feedback from Stakeholder Working Groups. DDA established three stakeholder working groups to review its proposed services definitions and provide feedback. Input from the residential work group agrees with the vision to expand the use of supported and shared living. The residential work group suggests to encourage this expansion DDA should expand the limits on caregiver rent; work with the Maryland Department of Housing and Community Development to expand housing; create incentives for services through the rate study that is underway; and, align the vision for these services with existing regulations. The financial work group advises that providers will have fiscal challenges associated with re-positioning the real estate and capital associated with their group homes.

D. Barriers to Community Integrated Settings for Residents of State Residential Centers

Under Medicaid rules, individuals with IDD who meet the criteria for an institutional level of care are entitled to receive care in a State Residential Center operated by DDA. Maryland operates two State Residential Centers. The Holly Center in Salisbury provides services to 57 residents and the Potomac Center in Hagerstown provides services to 45 residents.

Maryland law requires DDA to report annually on written plans of habilitation for these residents. In part these plans address the requirements necessary for an individual to receive services in the most integrated setting and barriers preventing an individual from receiving such services. This section summarizes information from DDA's October 2016 report. Of note:

- DDA has an annual target under Money Follows the Person to transition 20 individuals annually from institutions, which can include State Residential Centers and nursing facilities, to the community where services can be delivered through HCBS. Between March 2014 and March 2015, 29 individuals moved to the community. This total includes 14 from the two State Residential Centers combined and 15 from nursing facilities.
- The treatment professionals and resource coordinators stated that community based residential services were appropriate for 90% (92/102) of the individuals currently at the State Residential Centers and the State Residential Centers were the most appropriate setting for the remaining 10%.

DDA uses three general categories to classify the data it collects about barriers to transitioning:

- **Opposition** includes an individual, family member or guardian who either opposes or disagrees with an individual leaving a State Residential Center to move to an integrated community setting;
- **Court Ordered Placement** refers to an individual who cannot be discharged without court approval; and
- **Community Capacity** means an appropriate provider is not currently available.

DDA compiles data from its review of the written plans to report for each of the three categories and provides additional detail for the first one. According to DDA:

- 65% of the population cited Opposition as a barrier;
- 28% cited Community Capacity; and
- 7% cited Court Ordered Placement.

The detail for the Opposition group shows family members and legal guardians were the entities who most frequently opposed a transfer. Together, family only (27), legal guardian only (16) and family and legal guardian (8) accounted for 51 oppositions or 85% of the group.

E. Sources of Funding for Room and Board Payments for Adults with IDD

The ability of an adult with IDD to live independently in the community (e.g., funding for room and board, support services) depends on several factors, including their current living arrangement, whether they are classified by DDA in a priority service group, and the availability and cost of housing. The cost of housing can be an especially steep barrier to community living for adults with IDD whose main source of income is often SSI.

As stated earlier, SSI income is roughly 75% of the Federal Poverty Level. Moreover, because the SSI program is intended to pay only a minimal level of assistance for food and shelter, SSI rules vary an individual's benefit amount based on whether an adult is alone or married and whether they are a contributing member of their household. For example, the SSI rules reduce an individual's benefit by one-third if he or she lives in a household of another and does not contribute a pro-rata share for food and shelter; however, a living arrangement in a home that a family or adult with IDD owns or a shared living arrangement that includes homeownership can provide long term price stability.

Federal rules prohibit Medicaid from paying room and board costs in a residential care setting.²⁶ Typically, because an individual's SSI payment does not fully cover room and board costs for a community residence such as a group home, other resources are needed to make up the difference. Available resources vary depending on factors such as the type of residence, state rules and an individual's access to other resources.

With federal guidance, states have adopted a range of strategies to address the difference between SSI payments and housing costs to make housing affordable. A 2015 compendium that reviewed states' regulations of residential care settings for older adults and people with physical disabilities identified four general approaches that states use to make these costs affordable to those with limited income. They include:

- Limiting the amount facilities can charge Medicaid clients for room and board to the Federal SSI benefit, minus a small personal needs allowance;
- Providing a state supplement to the SSI payment for people in residential care settings, and limiting the amount these settings can charge to the combined SSI plus state supplement payment;
- Using the 300 percent of SSI standard for HCBS waiver eligibility and setting the maintenance allowance at a level that allows residents to retain sufficient income to pay for room and board; and
- Allowing family supplementation to increase the funds available for room and board, particularly to pay the difference in cost between a shared and private room.²⁷

In the residential care settings for older adults and those with physical disabilities, Maryland caps room and board charges and relies on a State SSI Supplement but does not allow family supplementation.

A 2014 DDA policy transmittal explains the rules for licensed residential service providers in the developmental disability system. The transmittal states the Community Pathways waiver establishes a limitation on room and board charges that authorizes a provider to charge an individual up to \$375 for room and board expenses. The types of costs that can be covered by this payment include housing, food, water, electricity, gas/oil, sewage, trash disposal and local telecommunications. Since Medicaid does not cover these costs, this amount is subtracted from DDA's payments to the provider. DDA states it is not financially liable for any costs not covered by the individual.

²⁶ Title 42 CFR Sec 441.310(a)(2) prohibits the State from making Medicaid payments for room and board except when the participant is receiving institutional respite outside his or her private residence or when the participant requires a live-in caregiver.

²⁷ Mollica, R., Sims-Kastelein, K., and O'Keefe, J. (2007), cited in O'Keefe, J., *Understanding Medicaid Home and Community Services: A Primer*, 2010 Edition, p.138. Accessed

The amount of the fee for adults with IDD who receive services through the Community Pathways waiver depends on how they are eligible for Medicaid. Generally, adults who are categorically eligible for Medicaid because they are SSI recipients pay room and board costs that are capped at \$375. Community Pathway participants who are optionally eligible for Medicaid with incomes up to 300% of SSI pay a higher amount. Room and board costs for individuals not enrolled in the waiver are based on their provider agreement. DDA encourages providers to use the provider agreement to specify the methodology they use for determining room and board charges.

A 2014 DDA policy transmittal states Community Pathway waiver participants may use other federal funds to offset food and housing costs. For example,

- Recipients can use Supplemental Nutrition and Assistance Program benefits to either purchase food in addition to meals that the residential facility providers or assign these benefits to the provider to purchase food for their meals;
- Recipients can use the Housing Choice Voucher Program which provides tenant based rental assistance to subsidize a portion of their rent costs; and
- Residential providers may apply for Section 8, which authorizes payment of rental housing assistance to private landlords, to offset the costs of shelter type expenses.

Finally, for individuals with exceptionally low income or with low income temporarily, DDA will fund with state only dollars the remaining balance of room and board charges.

CHAPTER VI. FINDINGS AND RECOMMENDED DISCUSSION ISSUES

Housing for adults with intellectual and developmental disabilities (IDD) aims to expand options that maximize individuals' choice and independence. It broadly encompasses people who receive care in institutions, the size and setting characteristics of group homes that replaced many of these institutions, and efforts to create more opportunities for shared living and individualized housing options.

The Council requested this OLO study to better understand the living arrangements and housing options that currently exist for individuals with IDD and to identify strategies the Council could pursue to expand these options. This chapter presents OLO's findings and recommended discussion issues. It has five parts organized as follows:

- **Part I** presents findings about definitions of development disabilities, and methods for estimating the County population of adults with IDD;
- **Part II** presents findings about Maryland's developmental disability service system;
- **Part III** presents information about housing for individuals who require an institutional level of care;
- **Part IV** describes housing programs, resources and models for others; and
- **Part V** presents OLO's recommended discussion issues.

PART I BACKGROUND - DEFINITIONS, LAWS, CMS RULES AND ESTIMATES

Finding 1. Adults with intellectual and/or developmental disabilities (IDD) are a heterogeneous group of individuals who live with neurological conditions that emerge in childhood. These conditions create severe limitations in the ability to perform major life activities.

The phrase "intellectual and development disabilities" (IDD) refers to a population that experiences a wide variety of lifelong cognitive or physical impairments. "Developmental disability" refers to conditions due to mental or physical impairments that result in difficulties in life activities such as language, mobility, learning and independent living. "Intellectual disability" refers to individuals who have a significant limitation in their intellectual functioning that negatively impacts social and practical skills. Both types of disabilities arise and are identified between birth and young adulthood.

Adults with developmental disabilities are a heterogenous group of individuals who require extra supports to live in their homes, work at their jobs and participate in community activities. Some individuals who have an autism spectrum disorder, cerebral palsy or epilepsy will not have an intellectual disability; others may have an intellectual disability with functional limitations due to cognitive impairments (i.e., trouble remembering, learning, concentrating or making decisions about everyday issues) that range from mild to severe; still others may have an intellectual disability with a psychiatric disorder and/or physical impairment. Roughly half of all people with a developmental

disability have a cognitive impairment and about ten percent of this subgroup of people have severe or profound cognitive impairments.

Finding 2. An array of federal laws establishes a governance structure that protects the civil rights of people with disabilities. In 1999, the Supreme Court held in *Olmstead v L.C.* that, under the Americans with Disabilities Act, states could no longer confine people with disabilities in restrictive institutional settings.

The federal laws described below impact individuals with IDD. The Developmental Disabilities Assistance and Bill of Rights Act (the DD Act) is described in Finding 3.

The Americans with Disabilities Act (the ADA). The ADA is a broad civil rights law that prohibits discrimination on the basis of disability in many domains of community life, including employment (Title I), state and local government activities and programs (Title II), public accommodations and commercial facilities (Title III), telecommunications (Title IV) and miscellaneous items (Title V). The ADA's definition of a person with a disability extends protection to a person who:

- 1) has a physical or mental impairment that substantially limits one or more major life activities; or
- 2) has a history or record of such an impairment; or
- 3) is regarded as having such an impairment.

“Major life activities” means the ability to complete key functions such as self-care, completing manual tasks, walking, seeing, hearing, speaking, learning and working. Determinations about impairments that substantially limit a major life activity are made on an individual, case-by-case basis. Judgment about whether a “substantial limitation” exists is based on how a life activity can be performed by an individual as compared to others in society.

The Fair Housing Act of 1968 (FHA). The FHA applies to entities in the housing market, including property owners, property managers, real estate agents, lenders and homeowner and condominium associations. The FHA prohibits housing providers from discriminating on the basis of disability and requires that they make reasonable accommodations in their policies and operations so that people with disabilities are afforded equal opportunities to use and enjoy a dwelling unit and a facility's public spaces.

Sections 503, 504 and 508 of the Rehabilitation Act of 1973. The Rehabilitation Act authorizes funding for disability-related activities, including vocational programs and independent living programs. The Rehabilitation Act significantly expanded the types of organizations that must extend protections for people with disabilities by including entities that receive federal financial assistance from any federal executive department or agency. As a result, its provisions apply to institutions such as hospitals, colleges, public housing authorities, and mental health centers.

Olmstead v. L.C. In June 1999, the US Supreme Court held in *Olmstead v. LC*¹ that under the ADA, states could no longer confine people with disabilities in restrictive settings. The Court's decision held that the unjustified isolation of the women in the case constituted discrimination based on a disability both because isolated settings perpetuate beliefs that people with disabilities are incapable of participating in community life and because these settings can severely limit everyday activities. The Court ruled that

¹ *Olmstead v. L.C.*, 527 U.S. 581 (1999).

public entities must make reasonable accommodations to comply with the ADA's integration mandate unless doing so would fundamentally alter services. Alternatively, a state could develop a comprehensive plan for placing individuals in less restrictive settings with the goal of integrating individuals with disabilities into mainstream society to the fullest extent possible.

Besides people with intellectual disabilities living in Intermediate Care Facilities, *Olmstead's* community integration mandate covers elderly individuals and other people in nursing homes and those with disabilities who currently live in the community and who are at risk of institutionalization.

Finding 3. The Developmental Disabilities Assistance and Bill of Rights Act (the DD Act) helps individuals achieve independence, productivity and inclusion in their communities by funding research, advocacy and training organizations and state councils. In turn, these entities help states' Medicaid and developmental disabilities agencies meet federal mandates in the Americans with Disabilities Act, and the *Olmstead* decision.

Congress passed the Developmental Disabilities Services and Facilities Construction Amendments (P.L. 91-517) in 1970 to promote the growth of adult community services so families would be better able to care for their family members at home. This law created "developmental disabilities" as a legal term to describe people who had traditionally been served in state-operated residential institutions and were expected to be served by community-based organizations.

The 1990 Developmental Disabilities Assistance and Bill of Rights Act (DD Act) defines a developmental disability (DD) as a:

- [A] severe, chronic disability of an individual that
 - (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (ii) is manifested before the individual attains age 22;
 - (iii) is likely to continue indefinitely; and
 - (iv) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (a) self-care,
 - (b) receptive or expressive language,
 - (c) learning,
 - (d) mobility,
 - (e) self-direction,
 - (f) capacity for independent living and (g) economic self-sufficiency; and
 - (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of

assistance that are of lifelong or extended duration and are individually planned and coordinated.”²

Last reauthorized in 2000, the intent of the DD Act is to help individuals with developmental disabilities achieve independence, productivity and inclusion in the community. It does this by assuring that “individuals with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under the law.”³

The DD Act does not fund direct services; instead it funds an infrastructure of research, training and advocacy organizations and state councils that help states’ Medicaid agencies and state institutions meet federal disability mandates to serve individuals in the community, rather than institutional settings, when feasible.⁴

Finding 4. Medicaid partners with states to fund long term care services for individuals with IDD in institutional and community settings. The Centers for Medicare and Medicaid Services (CMS), the agency responsible for the federal administration of Medicaid, has issued rules to help states meet *Olmstead’s* community integration mandate. However, because federal rules prohibit using Medicaid funding for room and board payments in community settings, states must establish other strategies to fund shelter expenses.

Medicaid operates as a federal-state funding partnership and it is the primary payer for long term care services provided in institutions or in community residential settings. In institutional settings, such as nursing homes or State Residential Centers that are Intermediate Care Facilities for Individuals with Intellectual Disabilities, Medicaid covers room and board charges; however, in community settings, it does not. Funding authority for Medicaid funding of long term care services in community settings is provided through Medicaid Home and Community Based Services (HCBS) waivers.

CMS has implemented rules to further states’ compliance with *Olmstead’s* community integration mandate that provide states access to Medicaid funds for long term care services for older adults and people with disabilities, including adults with IDD, in community instead of institutional settings. However, because federal rules prohibit Medicaid reimbursements for room and board payments in community settings, states have had to develop other payment strategies for these housing costs.

² *Developmental Disabilities and Bill of Rights Act* cited in Charles Moseley, Ed.D. and K. Charlie Lakin, Ph.D. *Assessment and Analysis of the Service Needs of Washington, D.C. Residents with Intellectual and Developmental Disabilities Final Report*, National Association of State Directors of Developmental Disabilities Services, June 1, 2011, page 2.

<https://ddc.dc.gov/sites/default/files/dc/sites/ddc/publication/attachments/FinalReportSupportNeedsDCResidents.pdf>. Accessed April 27, 2017

³ <https://www.aucd.org/template/page.cfm?id=516>. Accessed July 1, 2017

⁴ <https://www.acf.hhs.gov/sites/default/files/add/DDNetworkPaperFINAL.pdf>.

Finding 5. A Center for Medicare and Medicaid Services regulation issued in 2014 – the “settings rule” – establishes a set of far-reaching provisions to give individuals who receive Home and Community Based Services (HCBS) “full access to the benefits of community living.” The rule affects licensed Medicaid providers of residential services in various types of community settings. States must assess settings of their current providers and establish plans to bring noncompliant settings into compliance.

In 2014, CMS published a final rule for Home and Community Based Services (HCBS) settings that receive Medicaid funding. The “settings rule” is designed to ensure that long term care service providers abide by principles of self-determination for their clients and that Medicaid clients can receive services in integrated settings that encourage community engagement.

The provisions specify characteristics that qualify a service location as a community setting, explicitly excluding settings such as nursing homes or hospitals. Some settings, such as facilities adjacent to a public institution, are “presumed to have institutional qualities” that will subject them to a higher standard of review (“heightened scrutiny”) to comply with the settings rule.

States must evaluate the current settings of HCBS providers and develop transition plans to bring noncompliant providers into compliance. The rule provides guidance for providers on individuals’ privacy rights, freedoms, autonomy, and independence that requires providers to offer individual leases (or agreements that provide similar protections); rights to privacy such as lockable doors; a choice of roommate(s) and freedom to decorate; individually controlled schedules; and physically accessible settings.

This rule applies to long term care settings for residential services and has the potential to significantly affect service providers. In May 2017, CMS extended its original deadline for states’ compliance by three years – from March 17, 2019 to March 17, 2022.

Finding 6. Research estimates of adults with IDD indicate that this group accounts for about 1% of the adult population - with 0.79% of the adult population living in households and 0.12% living in residential settings such as group homes. Research limitations make it difficult to accurately estimate the size of this population for service planning purposes, including housing.

In 2000, researchers published age-based population prevalence rate estimates based on an analysis of the 1994 National Health Institute Survey – Disability Supplement. The combined population prevalence rate for adults living in households (0.79%) and for adults living in residential settings such as group homes (0.12%) was 0.9%.

Based on these rates and a census County population estimate of about 788,000 adults in Montgomery County, this estimating method suggests approximately 7,170 adults with IDD live in Montgomery County, including about 6,220 in household settings and about 950 in group settings.

A review of efforts to develop estimates of the population of children and adults living with IDD show how complex these research efforts are. Some of the factors that make it difficult to generate reliable estimates of service planning populations for adults with IDD, including their living arrangements, include: a lack of a national methodology to develop estimates; a lack of information about adults' individualized goals and support needs and how different housing options might best fit with their plans; and uncertainty about whether estimates based on population prevalence rates published in 2000 account for the marked increase in the prevalence of autism diagnoses that began in the late 1990s.

Finding 7. Researchers have developed functional tools to evaluate the severity of an individual's disabilities and identify required support services. States use these tools for assessments, service planning and budgeting purposes.

States use functional assessment tools to make population-level decisions about eligibility for services, estimate needs for types and amounts of services, and estimate anticipated service costs. These tools assess an individual's health conditions and functional needs based on their physical and cognitive abilities and assess whether an individual poses a community risk that requires higher levels of supervision. There are no national requirements for functional assessment tools and a 2014 report to Congress identified 124 different tools.

The Supports Intensity Scale (SIS) is a widely used functional assessment tool developed by the American Association on Intellectual and Developmental Disabilities (AAIDD) that provides standardized measures of the intensity of support needs for adults. One research study of 4,000 individuals with IDD who required an institutional level of care found that, notwithstanding the importance of person-centered planning, people with IDD can be classified along a continuum of intensity of support needs with five need levels – from the lowest level of supports to the highest. This analysis found more than half (53%) of the people were classified into the two levels with the highest support needs. Specifically,

- People in the lowest need cluster (8%) lived in the least restrictive community residents and more likely to use individual and supported employment.
- People in the second to highest cluster (29%) had diverse living arrangements and were likely to use community and habilitation services, but few had supported employment or jobs.
- People in the highest cluster (24%) were more likely to live in more restrictive housing with multiple housemates and were most likely to use community and habilitation services.

Finding 8. Living with family is the most common living arrangement for people with IDD.

Nationally, 71% of children and adults with IDD lived with their families, 16% lived alone or with a roommate and 13% lived in supervised residential settings. Compared to the national data, more people in Maryland live with their families and fewer people live in supervised residential settings. The County estimates apply the Maryland rates to an estimate of the total population living with IDD.

Table VI-1. Estimates of Children and Adults with IDD by Living Arrangement

Living arrangement	United States, FY2015		Maryland, FY2015		Montgomery County, FY2015	
	#	%	#	%	#	%
Living with family (children and adults)	3,593,483	71%	70,343	74%	12,084	74%
Living alone or with a roommate	794,164	16%	15,546	16%	2,670	16%
Living in a supervised residential setting	680,851	13%	8,889	9%	1,533	9%
Total	5,068,498	100%	94,778	100%	16,282	100%

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2014

PART II THE MARYLAND DEVELOPMENTAL DISABILITY SERVICE SYSTEM

Finding 9. The Developmental Disabilities Administration (DDA) manages Maryland’s services for individuals with developmental disabilities and their families.

The Developmental Disabilities Administration (DDA) in the Department of Health and Mental Hygiene (DHMH) administers a service delivery system for individuals with developmental disabilities and their families that ensures individuals “receive appropriate services oriented to the goal of full integration into the community.” DDA’s approach is “guided by the principle that individuals with developmental disabilities have the right to direct their lives and services.” DDA provides direct services to individuals with intellectual disabilities in institutions that the DDA operates and funds a coordinated service delivery system that supports individuals with developmental disabilities in the community.

Finding 10. In 2017, nearly 22,000 adults aged 18 and over received DDA services statewide, including 2,905 adults in Montgomery County.

Individuals who receive DDA services in Maryland receive services through the Coordination of Community Services (CCS) program only or they receive a larger, comprehensive set of services. DDA contracts with entities to provide these services. CCS helps individuals prepare person-centered, individual service plans that articulate an individual’s outcomes and goals and set expectations about how the services they receive are intended to help achieve these goals. CCS also periodically checks in with individuals about their well-being and services and addresses issues that arise.

DDA serves 2,905 adults in Montgomery County – 740 (25%) receive coordination of community services only (CCS) and 2,165 (75%) receive CCS and additional services. County recipients account for 13% of adults statewide who receive DDA services.

Table VI-2. DDA Estimates of Service Recipients, 2017

# of DDA Adult Consumers who receive:	Montgomery County	Rest of State	Total	% who are County residents
CCS Only	740	5,284	6,024	12%
All Services (Including CCS)	2,165	13,704	15,869	14%
Total # Adults Served	2,905	18,988	21,893	13%

Source: DDA and OLO

Finding 11. DDA determines an individual’s service eligibility based on how an individual meets state definitional criteria for a developmental disability. “Developmental Disability Eligible” (“DD Eligible”) individuals who require an institutional level of care qualify for comprehensive Medicaid HCBS waiver-funded services. “Supports Only Eligible” (“SO Eligible”) individuals who can live independently receive limited state-funded services.

In Maryland, as established in law and regulation, a person is considered to have a developmental disability if the individual has a “severe, chronic disability”:

- Due to a physical and/or mental impairment (other than mental illness only);
- That manifests before age 22;
- That is likely to continue indefinitely;
- That results in an inability to live independently without external support or continuing and regular assistance; and
- That requires specialized care individually planned and coordinated for an individual.

DDA funds its community based services for adults with IDD with a mix of federal and state taxpayer dollars. Individuals must require an institutional level of care and meet other financial eligibility guidelines to be eligible for services funded through a Medicaid HCBS waiver. DDA uses state only taxpayer dollars to fund services for individuals who do not require an institutional level of care and/or for individuals with income above the qualifying amounts for Medicaid or for a Medicaid waiver.

DDA makes determinations of service eligibility that classify applicants into two distinct service subgroups that distinguish those who are eligible for the Medicaid HCBS Community Pathways waiver from those who are not. DDA classifies an individual as Developmental Disability Eligible if s/he meets all five of the state’s definitional criteria for a developmental disability. DDA’s Advisory Guidelines state that under federal rules, an individual must meet the federal definition of a developmental disability in addition to meeting the state definition to receive Medicaid HCBS-waiver-funded services.

People who are “Developmental Disability Eligible” qualify to receive services through a Medicaid Home and Community Based Services waiver. DDA’s Community Pathways waiver offers a set of 19 comprehensive services that are defined in a DDA waiver agreement with CMS.

DDA classifies an individual as “Supports Only Eligible” if s/he meets two of the five criteria in the state’s definition of a developmental disability, i.e., s/he has a severe, chronic disability due to a physical and/or mental impairment and it is likely to continue indefinitely. People who are “SO Eligible” are eligible for a limited set of Family and Individual Supports Services that are funded with state taxpayer dollars. They may receive limited personal and/or employment supports based on where the need is. If they need help at home, they receive personal supports; and, if they need help at the job, they receive employment supports. If they need help in-between, they get individual supports.

Finding 12. DDA’s waitlist prioritizes service funding for people who are at risk of homelessness, whether they need an institutional level of care or not. In February 2017, of 7,861 individuals on DDA’s waitlist, 85% (6,672) were in the lowest prioritized group – those needing funding beyond two years.

DDA’s waitlist for services classifies individuals into three groups. Those in “Crisis Resolution,” including people at risk for homelessness, at risk of causing harm to others or living with a caregiver with impaired health, are prioritized for funding within six months. The second group includes people with a caregiver at least 65 years old and those at risk of being assigned to Crisis Resolution within one year. Individuals with “current requests” are in the lowest priority group. An individual’s funding priority is independent of their eligibility status.

In February 2017, 85% of individuals were prioritized for funding beyond two years; 14% were prioritized for funding within two years and 1% were prioritized for funding within six months. In 2011, 90% of people in the highest priority group were expected to receive out of home residential services.

Table VI-3. Numbers of Individuals on DDA Waitlist by Service Priority Category and Eligibility Status, February, 2017

Service Timing (Priority Category)	Eligibility Status		Total	% of Total Waitlist
	Developmental Disability	Supports Only		
Within 6 months (Crisis Resolution)	62	13	75	1%
Within 2 years (Crisis Prevention)	792	322	1,114	14%
Beyond 2 years (Current Request)	4,791	1,881	6,672	85%
Total	5,645	2,216	7,861	100%

Source: OLO and DLA

PART III HOUSING FOR ADULTS WHO REQUIRE AN INSTITUTIONAL LEVEL OF CARE

Finding 13. Medicaid covers room and board expenses for adults who receive care in an institutional setting. In 2016, treatment professionals said 90% of Maryland residents in a State Residential Center could live in a community setting.

Adults who are categorically eligible for Medicaid and require an institutional level of care are entitled to receive care in an institutional setting. This can be either a State Residential Center or a nursing facility. Medicaid covers room and board expenses for these individuals. In 2016, 105 individuals were in a State Residential Center. Under Maryland law, individuals in an institution who move to a community setting automatically receive long term care services funded through a Medicaid Home and Community Based waiver even when no waiver slots are available.

A 2016 DDA review of written service plans and professional treatment evaluations found that the State Residential Center was the most appropriate setting for 10% of the current population while community based residential services were the most appropriate setting for the remaining 90%. DDA reported the most frequent barriers to transitioning individuals to community settings was the opposition of a family member, legal guardian or an individual (65% of all cases) followed by a lack of an appropriate residential service provider (28%).

Finding 14. DDA administers a Medicaid-funded Home and Community Based waiver for individuals who require an institutional level of care. Personal supports are offered in several places, including an individual's own home or family home. Licensed service providers offer habilitation services in out-of-home settings such as group homes.

An individual enrolled in DDA's HCBS Community Pathways waiver has access to a comprehensive set of 19 community support services that are defined in DDA's waiver agreement with CMS. Those related to housing can be offered in an individual's own home or a family home, or in an out-of-home setting with a host family or with a residential services provider:

- **Community Residential Habilitation** provides services to help someone learn the skills necessary to be as independent as possible in their personal care and in community life. Services are provided in either group homes (GHs) or alternative living units (ALUs), which are licensed residential services providing ten or more hours of supervision per week. Group homes are licensed for four to eight people and ALUS are licensed for up to three people.
- **Family and Individual Support Services** provide assistance "to enable participation in the community." These services rely on community resources and also use an individual's existing support network. They are provided in an individual's own home or their family home.
- **Live-in caregiver rent** provides money for a personal caregiver who is not related to the recipient of waiver services.

- **Personal Supports** (formerly called Community Service Living Arrangements or CSLA) provide hands-on assistance to help or remind recipients to perform tasks and are provided in an individual’s own home, family home, in the community, or at work.
- **Shared Living** is “an arrangement in which an individual, couple or a family in the community share life’s experiences and their home.... It emphasizes the long-term sharing of lives, forming of caring households, and close personal relationships....”

Finding 15. There are nearly 6,100 individuals in Maryland who receive long term care in an out of home community setting funded by the Medicaid HCBS Community Pathways waiver, including 852 in Montgomery County settings.

The Maryland Office of Health Care Quality licenses agencies that provide residential services in specialized living arrangements under the Medicaid HCBS Community Pathways waiver. In specialized living arrangements, the provider controls the housing, services and schedules of the residents. The residences can be single family attached or detached houses, apartments or condominiums.

The data in the table below from 2014 show 6,070 individuals received services in a specialized living arrangement. Of those in group homes, about 25% live with three people or less; 50% with four people, and 25% with five or more people. In Montgomery County, there are 444 people living in 117 group homes and 408 people living in 194 alternative living units.

Table VI-4. 2014 DDA Living Arrangements for Individuals Who Are Medicaid HCBS Waiver Recipients

Type of Living Arrangement	Service Group	Setting	Licensed Size Limits	# of adults served (June 2014)
Supported in own home or family home	Individual	Personal Supports	Not licensed	2,681
Shared in someone else’s home	Residential	Individual Family Care Home	Up to 3 people	212
Specialized	Residential	Alternative Living Unit	Up to 3	3,100
Specialized	Residential	Group Home	4 to 8 people	2,961
TOTALS				8,954

Source: OLO and State Transition Plan and Braddock

Finding 16. DDA caps the fee providers can charge Medicaid waiver recipients and authorizes providers to use Housing Choice Vouchers to subsidize their expenses.

Medicaid does not cover room and board expenses for adults who receive Medicaid funded HCBS in a community setting. Instead, if individuals are categorically eligible for Medicaid, DDA caps the fee a licensed residential service provider can assess for room and board expenses at \$375 per month. The amount can be higher if an individual is optionally eligible for Medicaid or not eligible for Medicaid.

DDA policy authorizes residential service providers and Medicaid Community Pathways recipients to use the Housing Choice Voucher Program and the Section 8 program to subsidize a portion of their rent costs. If an individual has an exceptionally low income, DDA will use state only dollars to fund the remaining balance of room and board charges.

Finding 17. DDA is revising the Residential Service definitions for its Community Pathways waiver because it wants to expand participants' use of Shared Living and Supported Living arrangements and bring providers' settings into compliance with the CMS settings rule. Stakeholders suggest strategies to encourage use of DDA's new services would help.

DDA must file an amendment with CMS to renew its Community Pathways HCBS waiver by January 2018. As part of this task, DDA is revising its current Residential Services definitions. Specifically, DDA's revisions:

- Add a new service definition for Supported Living;
- Expand the current Shared Living service into two services to distinguish between a companion service model and a host home model; and
- Create two new Community Living Services to replace the current Residential Habilitation services and settings.

DDA is also proposing rules to bring the settings for the Community Living Options into compliance with the CMS "settings rule." These changes would limit the size of these settings to four participants each and require participant choice and lease agreements. In August 2015, DDA imposed a moratorium to limit occupancy in those group homes that can accommodate more than four people.

Recent stakeholder feedback agrees with DDA's visions to expand the use of Supported and Shared Living. Stakeholders suggest DDA consider strategies to encourage this expansion that include: setting higher limits on caregiver rents; working with Maryland to expand housing options; using the rate study that is underway to incentivize the use of these services; and aligning the vision for these services with existing regulations.

Finding 18. DDA-licensed residential service providers partner with State and County housing agencies that provide capital grants, loans and housing vouchers or other rental subsidies.

Several state and local programs and initiatives provide capital grants, loans and other funding to DDA providers for property acquisitions and/or renovation projects. At the state level,

- In 2017, two County organizations, Community Services for Autistic Adults and Children and the Madison House Foundation, received capital grants for facility improvements; and the Montgomery Housing Partnership received a Community Facilities Health Grant to provide housing for adults with IDD.
- In 2013, the state Department of Health and Mental Hygiene awarded the Housing Opportunities Commission and the Jubilee Association of Maryland a grant to purchase two three-bedroom single family houses to provide housing for six individuals with IDD. Recipients in other years have included the Jewish Foundation for Group Homes and Housing Unlimited a housing development organization that provides affordable, supportive housing for individuals with psychiatric disabilities and very low incomes.

Licensed providers also use funds from a state group home program administered by the Maryland Department of Housing and Community Development.

In the County, the Housing Opportunities Commission, the Department of Health and Human Services and the Department of Housing and Community Affairs (DHCA) partner with numerous nonprofits to provide grants, loans and rental subsidies.

- HOC provides project based housing vouchers for the residents who occupied the housing acquired as part of the Jubilee partnership. For example, the Partnership for Permanent Housing 2 (PPH2) uses HOC project-based vouchers to re-locate families from the shelter system into rental housing on the open market located throughout the County.
- DHCA administers a Group Home Rehabilitation Loan Program that uses federal Community Development Block Grant funds to ensure group homes are maintained in compliance with County codes.
- DHCA also administers a local housing trust fund (the Housing Initiative Fund or HIF) and makes loans to increase the County's supply of permanent supportive housing. The HIF supported the HOC Jubilee Partnership Program. Previous HIF efforts funded development of Seneca Heights, a facility that provides transitional and permanent supportive housing units, and acquisition of permanent supportive housing units for individuals with mental disabilities in Silver Spring and North Bethesda.

PART IV OTHER HOUSING PROGRAMS, RESOURCES AND MODELS

Finding 19. Maryland has one of the largest Bridge Subsidy Programs nationally to help individuals move from institutional housing to community-based housing. Individuals with IDD are more likely to move to group homes compared to older adults and others who are more likely to move to homes and apartments.

Bridge subsidy programs provide short term, time-limited rent subsidies for people who currently live in an institution and who are eligible for federal housing subsidies such as housing choice vouchers. The short term rent subsidy allows an individual to move sooner than they otherwise would have because it covers rent payments while an individual is waiting to receive a housing voucher.

Mathematica identified Maryland as one of seven states with the largest programs (the Money Follows the Person (MFP) program), having transitioned 2,428 individuals from institutional to community settings between 2007 and 2015. Of these individuals, approximately 11% were individuals with IDD.

Table VI-5. Individuals Transitioned to Community through Maryland’s Money Follows the Person Program, 2007-2015

Group	# Transitioned	% of Total
Older Adults	1,138	47%
Persons with Physical Disabilities	956	39%
Persons with Intellectual Disabilities	267	11%
Persons with Other Disabilities	67	3%
Total	2,428	100%

Source: Mathematica Policy Research, *Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2015*

Throughout the country, most individuals moved to homes (33%) or apartments (42%), with 14% moving to group homes and 10% moving to assisted-living facilities. Mathematica found similar moving patterns for all groups except for individuals with IDD. Approximately 58% of individuals with IDD moved to group homes.

DDA has an annual target to transition 20 individuals annually from institutions. Between March 2015 and March 2016, DDA transitioned 29 individuals into the community, including 14 from the two State Residential Centers and 15 from nursing facilities.

Finding 20. The Housing Opportunity Commission’s Rent Supplement Program provides ongoing rent subsidies for MFP Bridge recipients when state-funded rental assistance ends.

The Montgomery County Housing Opportunities Commission (HOC) is one of 12 public housing authorities (PHAs) statewide partnering with the Maryland Department of Disabilities. After an individual’s three-year participation in the MFP Bridge program ends, residents are eligible to receive

rent subsidies from HOC's Rent Supplement Program, which is a County Council initiative that provides subsidies for eligible HOC households with incomes between 20% and 40% of area median income.

Finding 21. The US Department of Housing and Urban Development (HUD) Section 811 Rental Assistance Project has funds for 300 housing subsidies for people with disabilities who are eligible for Medicaid Home and Community Based Services funding.

The HUD Section 811 Rental Assistance Project, a housing program for people with disabilities who are eligible for Medicaid HCBS funding, is expected to fund 300 units in Maryland. To date, 33 people are housed and 31 people are in lease-up; 12 units are under construction and 60 are in underwriting. The statewide waiting list of 2,456 individuals includes, by priority group: 1) 368 people currently living in institutions and 2) 49 people at risk of institutionalization due to a housing situation.

Finding 22. Woodfield Commons in Damascus is the first Section 811 Rental Assistance Project in Montgomery County. The project, which was developed as a joint venture with the Housing Opportunities Commission, will provide 13 units for people with disabilities.

Woodfield Commons is a four-story 84-unit mixed income multifamily project developed as a joint venture between Conifer Realty, LLC and the Housing Opportunities Commission. The development uses Low Income Housing Tax Credits and 90% of the units will be restricted to households with incomes at or below 60% of the Area Median Income. In addition, the developer has committed to reserve 15% of the units for people with disabilities.

Finding 23. The Weinberg Apartment Program houses nonelderly individuals with disabilities ages 18 to 62 and with household incomes at 15% to 30% of the Area Median Income. To date, of 24 identified units, 14 are occupied, including five in Takoma Park. Over 1,000 people are on a statewide waiting list.

The Weinberg apartment program is a state-administered joint venture for projects approved for other Maryland Department of Housing and Community Development multi-family rental housing financing, including Low Income Housing Tax Credits. It provides capital grants that are used to build housing. In exchange, the developer agrees to low rents and charges no more than 30% of a household's income for rent and utilities.

The program serves people with a range of disabilities including people who are transitioning from group homes and a few adults living with IDD. Eligible households are nonelderly individuals, ages 18 to 62, who receive SSI or SSDI. To date, 24 units have been identified; 14 are occupied, including five in Takoma Park; and, 31 people have benefitted. As of Fall 2016, there were 1,056 people on the statewide waiting list. In contrast to other programs, this program offers flexibility in choosing people from the waitlist to ensure successful tenancies. This flexibility extends to living arrangements such that an individual may have a live-in caregiver who is a family member.

Finding 24. DHHS' homeless prevention programs provide housing stability for adults who are not known or do not receive services from DDA.

Two programs - the Housing Initiative Program -administered by DHHS, and the Partnership for Permanent Housing 2, administered by the Montgomery County Coalition for the Homeless (MCCH), - serve formerly homeless individuals and families previously housed in shelters and motels and they target special need populations. They provide the same services using the same eligibility criteria and are both funded through the Housing Initiative Fund and County general fund revenues. DHHS estimates that approximately 5% of the population currently served in the County's permanent supportive housing programs has cognitive deficits including 1% to 2% with developmental disabilities

Finding 25. A set of seven recommended housing models that maximize choice and independence aligns with DDA's efforts to revise its Residential Services definitions, and with existing County housing programs. Some options conflict with the CMS settings rule. Individual choices should be based on a full understanding of housing options.

A state Housing Options Committee tasked with developing a guide of housing options that would "maximize choice and independence" and meet the needs of individuals with autism across the lifespan recommended a typology of seven broadly defined living arrangements with examples for each. The table below displays a summary of the living arrangements and the examples.

A comparison of these models with DDA's residential services definitions and existing County housing programs and resources shows many of these arrangements exist or are underway in the County. There are concerns that some of the examples, e.g. a farmstead under the "Intentional Communities" arrangement, may conflict with the CMS settings rule. Other examples, e.g., accessory apartments, may offer opportunities for the County to expand its array of housing options.

Table VI-6. A Typology of Community Housing Models with Examples

	Living Arrangement	Examples
1	Staying in the Family Home	<ul style="list-style-type: none"> • A house donated by a family • Elder Cottages Housing Opportunities • Accessory Apartments
2	Living with a (New) Family	<ul style="list-style-type: none"> • The LifeSharing Program • The Domiciliary Care Program
3	Renting an Apartment or a Home	<ul style="list-style-type: none"> • Rental Units Owned by an LLC • Rental Units Owned by a Nonprofit
4	Purchasing a Residence	<ul style="list-style-type: none"> • Ownership by an Individual • Tenants in Common
5	Shared Housing	<ul style="list-style-type: none"> • Group Shared Residence • Housing Match Up • A Lodge Model • L'Arche
6	Intentional Communities	<ul style="list-style-type: none"> • An Intergenerational Community • Collaboration with a College or University • Farmsteads • Co-housing
7	Licensed Facilities	<ul style="list-style-type: none"> • A private licensed facility • A community supported living arrangement

Source: OLO and Pennsylvania Department of Welfare, Bureau of Autism Services, *Housing Options for Adults with Autism Spectrum Disorder*, April 2010.

PART V RECOMMENDED DISCUSSION ISSUES

Adults with developmental disabilities are a heterogenous group of individuals who require extra supports to live in their homes, work at their jobs and participate in community activities. Families, the state's developmental disability service system in partnership with its providers, and state and local housing programs in partnership with their nonprofit partners, work collectively to keep adults with IDD stably housed. Based on population prevalence estimates, there are an estimated 7,200 adults with IDD living in Montgomery County; approximately 850 adults live in group homes or alternative living units.

Housing for adults with IDD is a timely topic and it will likely be an ongoing concern for adults with IDD, County families and the County's residential service providers. OLO suggests the Council use the following questions to structure a discussion with these groups and representatives from DDA as this issue unfolds.

Question 1: How well do DDA's proposed revisions to the residential service definitions in its Medicaid Home and Community Based Services Community Pathways waiver align with the housing choices and preferences of County adults with IDD and their families? If individuals and families share DDA's interest in these models, what County actions and housing resources could best help achieve their expected impacts?

DDA is expected to submit an amendment to the Center for Medicare and Medicaid Services with revisions to the Residential Service definitions in its Community Pathway's HCBS Medicaid waiver by January 2018. DDA's revisions will create a new supported living service that allows individuals to share a residence with up to four roommates and it will expand the shared living service.

The Council may wish to ask adults with IDD and their families for their perspective on these options and the opportunities they would provide. It would also be helpful to hear from DHCA, DHHS and HOC officials about potential issues and opportunities that they see and what resources would be needed to implement the changes.

Question 2: What opportunities and concerns do residential service providers foresee coming out of DDA's proposed revisions to its Residential Service definitions and/or other changes DDA will be making to comply with the CMS settings rule?⁵ What County actions and housing resources could best support providers during this transition?

DDA expects revisions to its service definitions to not only increase the use of Shared Living and Supported Living housing models but also bring residential service providers into compliance with the CMS "settings rule." In addition, DDA is working with its residential service providers on other requirements of the CMS "settings rule."

⁵ This CMS fact sheet has a useful summary. (<https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf>).

The Council may wish to ask DDA officials for a briefing on the CMS settings rule and to hear from County residential service providers about their opportunities and concerns. Given the County resources invested in group homes over the years and the critical role that group homes and alternative living units play in providing community service settings, the Council may also want to ask the County's residential service providers whether there are County actions and/or resources that would be helpful during and after the transition. For example, one provision of the CMS settings rule requires that residents have a lease or similar agreement. It may be useful to hear from DHCA about this issue.

Question 3: Are there changes to existing County housing programs that could strengthen linkages to adults with IDD and their families to better support their efforts to realize housing stability in the short term and the long term?

Housing models that pair publicly-funded services with housing subsidies exist to maximize choice and independence for adults with IDD; however, the availability of new housing models with Medicaid-funded HCBS supports is limited to those adults in crisis.

In Maryland, about 9,000 adults currently live independently in either supported housing (3,000), shared housing (200) or a specialized living arrangement (6,000) and receive services through the state's developmental disability system. About 1,100 people are currently waitlisted for DDA service funding within the next two years because they have an older caregiver and/or are expected to be in crisis and require services funding. When the General Assembly funds people in DDA's highest priority group for services through the annual budget process, approximately 90% receive services in an out-of-home community setting.

DDA currently serves about 2,900 County adults, which means there are about 4,300 adults with IDD who are either not eligible for services, waitlisted for services or unknown to DDA. Adults who are waitlisted for services include both those who are Developmental Disability Eligible and Supports Only Eligible. Some individuals may already live independently in their own homes with paid or unpaid supports; others may be served through County housing programs such as HOC's Residential Services Counseling.

Recommended options for discussion include:

- Asking adults with IDD and their families, service providers, County agencies and DDA to describe possible changes to strengthen service system linkages for housing in the short term and to describe strategies for expanding community housing models that look promising in the long term. For example, one short term housing issue includes the feasibility of planning housing options for transitioning youth or for individuals prioritized for DDA services funding within two years because they have caregivers who are at least 65 years old.

- Asking DDA and the County to address whether the list of County individuals who are waitlisted for service funding within two years could serve as a useful indicator of short-term housing demand and discuss with HOC whether this could also be the basis for an ongoing bridge subsidy rental program.
- Asking DHHS about the value of a summary report about any housing issues families and individuals are experiencing based on the service plans for the families that DHHS serves and for any suggestions to strengthen linkages based on such a review.
- Discussing with adults with IDD and their families what opportunities to expand community housing options and living arrangements look most promising. Depending on the options that emerge, the Council may wish to ask DDA and County officials to weigh in on what changes, if any, would be needed to accommodate these options.

CHAPTER VII. AGENCY COMMENTS

The Office of Legislative Oversight (OLO) circulated a final draft of this report to the Chief Administrative Officer for Montgomery County and to the Housing Opportunities Commission (HOC). OLO appreciates the time taken by County Government representatives and HOC to review the draft report. The written comments from the County Executive and HOC were not available at the printing of this report and will be available in future Council packets.