



# **How Various States Provide Supports for People with Developmental Disabilities Other than Intellectual Disability and Autism**

**Prepared for:**

Pennsylvania Assistive Technology Foundation (PATF)  
Beyond Diagnosis Project

**Issued:**

July 2025

**Prepared by:**

Rachel Mann, Esq., Consultant  
Pennsylvania Health Law Project (PHLP)

*This report was made possible by support from the Pennsylvania Disability Advocacy Fund, a fund of the Foundation for Enhancing Communities, and by FISA Foundation.*

## **REASON FOR STUDY**

This study was designed to examine how other states' HCBS waivers are serving the population of individuals who have developmental disabilities other than ID and Autism.

Adults in Pennsylvania who have significant developmental disabilities other than Intellectual Disability (ID) or Autism are not receiving Medical Assistance-funded Home and Community Based Services (HCBS) equal to those with the listed disabilities. Examples of other developmental disabilities include, Cerebral Palsy, Spina Bifida, Epilepsy, Muscular Dystrophy, Spinal Muscular Atrophy, ... and the list goes on.

Specific services unavailable to this population include a range of available community living options, appropriate rehabilitative supports, interpreter services (including American Sign Language), housing counseling, and assistance and training to direct their own services. Also, children under age 18 with developmental disabilities other than ID, Autism (or likely to be diagnosed with ID or Autism by age nine), or Medical Complexity (requiring technology and nurses), are not eligible for *any* HCBS waivers in PA – despite the need for services beyond those offered by other programs. These children cannot even get home modifications when necessary to get in and out of their homes.

## **METHOD OF STUDY**

This report pulls information from the Medicaid.gov website which lists and attaches the full HCBS waiver Applications from all the states. These Applications, which are each several hundred pages long, include eligibility rules, service listings and descriptions, service delivery rules, numbers served, administrative and financial information, and other information that the federal government requires from the states to grant approval of the program.

Primary areas of exploration were: How is eligibility for the HCBS waivers defined; what ages are served; and, are certain identified key services included for the full range of persons with DD.

In addition, calls were made to advocates in Pennsylvania (primarily through the Beyond Diagnosis Project) and in select states to confirm that the programs are being generally delivered in accordance with their Applications and to identify any major systemic problems with the functioning of the waivers.

## BACKGROUND

### Developmental Disability

Per the Developmental Disabilities Assistance and Bill of Rights Act of 2000, found at 42 USC 15002 Sec. 102(8):

“Developmental disability” means 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;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency [or for children under age 9, will likely result in these limitations later in life]; 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.

### Medicaid Home and Community-Based Service Waivers

Federal law, through the Center for Medicare and Medicaid Services (CMS) makes HCBS waivers available, at a state’s option, to individuals who, without the services offered by the waiver, would need institutional care. The waiver allows the state to get federal matching funds for services that are not otherwise provided by (or exceed the limitations otherwise imposed by) Medical Assistance.

CMS allows states to include individuals who are determined eligible for one of three levels of care: Hospital, Nursing Facility, or Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID). ICF/IIDs are available to those with intellectual disabilities and those with other “*related conditions*”. (In Pennsylvania we serve those two populations separately, in ICF/IDs and ICF/ORCs).

The state can combine or further limit the population it chooses to serve and can serve individuals with different needs in different waivers. Most states have multiple waivers (as Pennsylvania does). While a person with a developmental disability may be eligible for several types of HCBS waivers, they are only eligible under federal rules if they need a level of care provided in a hospital, nursing facility, or ICF/IID.

## Pennsylvania waivers

Pennsylvania provides Home and Community-Based Services to several discreet populations. Those waivers relevant to this report include:

### **1) Office of Developmental Programs (ODP) waivers –**

- **Consolidated, Community Living, and Person/Family Directed Care waivers** - People of any age with a diagnosis of an intellectual disability or autism, children with a developmental disability under age 9 with a high probability of resulting in an intellectual disability or autism, and children under age 22 with a developmental disability due to a medically complex condition (affecting at least 3 organ systems and requiring medical technology and nurses) are eligible for three HCBS waivers administered by the Office of Developmental Programs (ODP) if they meet an ICF/IID level of need. The three waivers differ primarily in the dollar amount of services they will provide, with the Consolidated Waiver having no individual cost cap.

### **2) Office of Long-Term Living (OLTL) waivers –**

- **OBRA waiver** - Adults (18-59) with a primary developmental disability other than ID or mental illness (i.e., those with “related conditions”), who meet an ICF/IID level of need can be served in the OBRA waiver administered directly by the Office of Long-Term Living (OLTL) unless and until they become eligible for the Community HealthChoices waiver (below). For purposes of the OBRA waiver, “related conditions may include, but are not limited to, cerebral palsy; spina bifida; epilepsy; severe physical disabilities, and autism.” OBRA waiver application at p. 50.
- **Community HealthChoices waiver** - Adults (age 21+) who meet nursing facility clinical eligibility (NFCE) (with or without a developmental disability) can be served by the Community HealthChoices waiver administered by managed care organizations contracted with OLTL.

Pennsylvania adults with developmental disabilities who do not have ID or Autism are only eligible for the HCBS waivers offered by OLTL. The services in the OLTL waivers are not as robust as those in the ODP waivers and service delivery is deficient. As noted above, specific services unavailable to this population include a range of available community living options, appropriate habilitative supports, interpreter services (including American Sign Language), housing counseling, and assistance and training to direct their own services. See Attachment 1 for the list of services in each Pennsylvania waiver.

## Pennsylvania Children

As noted above, children under 18 years of age who have developmental disabilities but do not have ID, Autism, or Medical Complexity requiring the use of medical technology and nurses, are not eligible for any waivers at all. These children cannot get the following services to ensure that they can live with their families rather than in institutions:

- Home modifications, such as widened doorways for wheelchair access and accessible bathrooms, even if they cannot get in and out of their houses without being carried or crawling up and down steps;
- Vehicle modifications that would make it possible for their families to transport them to activities and family events;
- Respite care when their parents are available but exhausted, or need to spend time with other children;
- Certain habilitation services to help them navigate the community;
- “Family medical support assistance”, to help the family access and organize medical services and for nurse oversight of care provided by non-professionals;
- “Life Sharing” services including alternate family homes to enable discharge from hospitals and other institutions. when parents are unable to provide the extraordinary care their children need due, for example, to their own health conditions or disabilities.

## **FINDINGS**

Most other states serve eligible individuals of all ages and types of developmental disabilities equally and provide a wide range of services to them all.

### **States with HCBS Waivers for Individuals with the Full Range of Developmental Disabilities**

Data derived from the Medicaid.gov website shows that most U.S. states – two-thirds - have HCBS waivers that serve all individuals with developmental disabilities who need an ICF/IID level of care including children (at least by age 5). Thus, Pennsylvania is an outlier with respect to its waiver eligibility limitations.

All but 4 states have HCBS waivers. For purposes of this report, HCBS waivers refer only to those waivers described in section 1915(c) of the Social Security Act. These 4 states use a different type of waiver, called an 1115 Demonstration waiver, to provide community services.<sup>1</sup>

Of the 46 states and the District of Columbia that have HCBS waivers, 37 have at least one waiver that serves *all* individuals (or adults) with developmental disabilities who meet an ICF/IID level of need without regard to diagnosis (although some have narrow definitions of “related conditions”). Most of these states, 34 of the 37, have waivers that (either in a single waiver or in separate waivers) serve

---

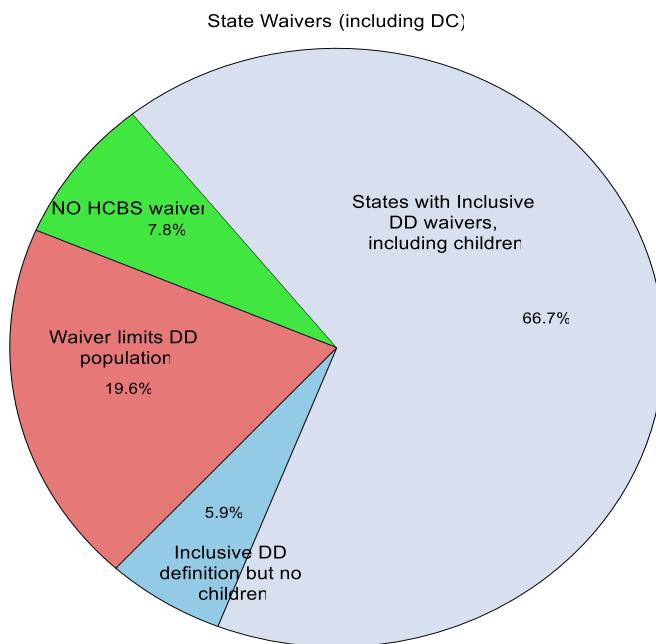
<sup>1</sup> These states are Arizona, New Jersey, Rhode Island, and Vermont.

children with developmental disabilities without regard to diagnosis, at least from age five, and most from birth.<sup>2</sup>

The remaining 10 states<sup>3</sup>, including Pennsylvania, limit the types of developmental disabilities that they serve in their primary DD waivers (usually to Intellectual Disability and/or Autism). Some, like Pennsylvania, have separate discreet waivers that may provide some services to other subcategories of the DD population. In fact, Pennsylvania is one of only a few states with a waiver, the OBRA waiver operated through OLTL, exclusively for adults with developmental disabilities *other than ID* who do not meet a nursing facility level of need. Most states, again like Pennsylvania, have waivers for adults who have a nursing facility level of need, regardless of diagnosis. As described herein, Pennsylvania's OLTL waivers do not provide the same breadth of services that are offered in its waivers for individuals with Intellectual Disabilities and Autism (and medically complex, technology-dependent, children).

Pennsylvania is one of the few states that does not provide any single waiver that serves the full range of individuals (or even adults) with developmental disabilities, and one of the few states that does not serve children with cerebral palsy, muscular dystrophy, epilepsy, etc... (without co-occurring ID, Autism, or severe medical complexity) in any waiver.

Of note: Wisconsin has a single waiver that includes all individuals with disabilities who meet a Nursing Facility, or ICF/IID level of need (a combination of Pennsylvania's ODP and OLTL waivers with no age restrictions).



<sup>2</sup> Idaho and the District of Columbia have no waivers for children, and Connecticut only serves children with Intellectual Disability.

<sup>3</sup> These states are Alabama, Delaware, Iowa, Maine, Massachusetts, Nevada, Oklahoma, Pennsylvania, South Carolina, and Tennessee.

## **Services**

Every state must list in its application for an HCBS waiver the services it will provide and a description of the services including any limitations on the service. States often use different terms for services similar to those in other states, and there is no single nationwide definition of any service.

The following is a general description of how other states provide services to individuals with developmental disabilities who do not have ID or Autism that are unavailable to this population in Pennsylvania. For purposes of this section, “DD waivers” will refer to waivers that serve individuals with developmental disabilities who meet an ICF/IID level of need regardless of specific diagnosis.

### **Family Homes**

At least twelve states, including among others, California, Colorado, Ohio, Wisconsin, and Maryland, have DD waivers that include a service that provides payments to families who provide housing and supports for, and share their lives with, participants who live in the family home or the home of a willing and welcoming family in the community. Such supports generally include assisting the individual to participate in home and community activities. Pennsylvania provides this service to individuals with Intellectual Disability and Autism in its ODP waivers, but not to individuals with other developmental disabilities in its OLTL waivers

### **Supported Independent Living**

At least ten states, including among others, Florida, North Carolina, and Maryland, have support services available to enable individuals to live in homes that they own/rent or control (i.e., are not owned or rented by the service provider) alone or with people they choose. Services range from a few hours a day to live-in care. In some states this may include a family home, merging with other community habilitation services. Pennsylvania provides this service to individuals with Intellectual Disability and Autism in its ODP waivers, but not to individuals with other developmental disabilities in its OLTL waivers

### **Assistance to Participants who Self-Direct Services**

More than sixteen states offer some form of participant direction of services in which the participant can serve as the employer of their attendants. At least seven of those states, including among others, North Carolina, Wisconsin, Maryland, and California have DD waivers that provide substantial support to participants in carrying out their roles as employers. These supports go beyond financial management (e.g., payroll and tax reporting) and service coordination. They include assistance and training in such things as hiring, setting wages, making schedules, and managing staff. Pennsylvania provides this service to individuals with Intellectual Disability and Autism in its ODP waivers, but not to individuals with other developmental disabilities in its OLTL waivers.

### Housing Counseling

At least five states, including North Carolina, Maryland, California, Wisconsin, and Louisiana have DD waivers that provide assistance and training to obtain and maintain independent housing. Areas of assistance and training include: locating housing, choosing housemates, obtaining housing necessities, reviewing leases, communicating with landlords, good tenant behavior, obtaining needed accommodations, etc... Pennsylvania provides this service to individuals with Intellectual Disability and Autism in its ODP waivers, but not to individuals with other developmental disabilities in its OLTL waivers

Of note: North Carolina has a Community Navigator service that includes assistance and training both for participant direction of services and for obtaining and maintaining housing.

### Communication Assistance

At least four states, including California, Ohio, Georgia, and Wisconsin, list a specific communication service that includes interpreters and other communication supports necessary to facilitate and assist persons with hearing, speech, or vision impairment to be able to effectively communicate with service providers, family, friends, co-workers, and the general public. Other states simply say that interpreters will be made available when required for various waiver functions. Pennsylvania provides this service to individuals with Intellectual Disability and Autism in its ODP waivers, but not to individuals with other developmental disabilities in its OLTL waivers.

### Habilitation

Habilitation - that is, training, skill building, and assistance in developing and maximizing independence and community participation is sometimes provided or described as a distinct service, but often is built into a range of other services related to residential support, community participation, and/or employment services. Virtually all the states that have DD waivers include individualized habilitation services as integral parts of their programs, whether designated as such or not. Which services and with what levels of support are needed by a participant is generally determined through an assessment process such as the Supports Intensity Scale (SIS). Pennsylvania provides this service to individuals with Intellectual Disability and Autism in its ODP waivers, but only in a limited way to individuals with other developmental disabilities in its OLTL waivers.

*Attachments 2-6 set out examples of how five states provide services to individuals with developmental disabilities other than Intellectual Disability or Autism including descriptions of select services. While these include some of the services described above, there are a few additional services of interest included. The information is paraphrased from each state's HCBS waiver application as posted by the Center for Medicare and Medicaid on their website. The attachments also include input from advocacy organizations in some states.*

## Summary Chart

Service	PA Waiver Coverage		Other State Coverage (not exhaustive)	Notes
	ODP	OLTL		
Family Homes (Host Home/Life Sharing)	Yes (not PFDS)	No	AK CA CO GA IN LA MD MN NY NC OH WI	Some states limit this service to adults
Supported Independent Living	Yes (not PFDS)	No	CA CO FL GA KY MD MN NC WV WI	Adults  PA OLTL – not a distinct service. Participants can receive other services while living in their own homes, but there is no provider oversight of the living arrangement.
Assistance with Self Directed Services	Yes	No	CA IL MD MN NY NC WI	Colorado provides a training course but not direct assistance
Housing Counseling	Yes	No	CA LA MD NC WI	Additional states provide housing location assistance and/or other pieces of this service
Communication Assistance (Aids/Consultant)	Yes	No	CA GA OH WI	
Habilitation	Yes	Yes (limited)	Most, if not all, states	PA OLTL's "community integration" service is limited in duration and hours/week although exceptions can be made

## **CONCLUSION**

Unlike Pennsylvania, most states make the same HCBS waiver services available to their citizens with non-ID developmental disabilities (i.e., “related conditions”) as they do to those with ID. Most of the states provide HCBS waivers to children with related conditions either in the same waivers or in separate children’s waivers.

While Pennsylvania provides a variety of services to adults with related conditions in waivers administered through its Office of Long-Term Living – certain key services that Pennsylvania offers to individuals with Intellectual Disability (administered by its Office of Developmental Programs) are lacking. Those services, described above, are provided to individuals with related conditions in many other states to varying degrees.

Pennsylvania could add services to its OLTL waivers to better serve this population. For children with related conditions, including those in the custody of the child welfare system, the state could either expand eligibility in OLTL or ODP waivers or create a new waiver within ODP to ensure that they can receive services that will enable them to grow up in families rather than in institutions.

## **Attachment 1 – Pennsylvania Waiver Service Lists**

### **OBRA Waiver**

Provides adult daily living, employment skills development, job coaching (intensive and extended follow-along), personal assistance services, residential habilitation, respite, service coordination, structured day habilitation, behavior therapy, nursing services, occupational therapy, physical therapy, specialized medical equipment and supplies, speech and language therapy, assistive technology, benefits counseling, career assessment, cognitive rehabilitation therapy, community integration, community transition, counseling services, home adaptations, job finding, non-medical transportation, nutritional consultation, personal emergency response system, and vehicle modification services to individuals with developmental disabilities ages 18-59 years who meet an ICF/IID level of care.

### **Community HealthChoices (CHC) Waiver**

Provides adult daily living, employment skills development, job coaching, personal assistance services, residential habilitation, respite, structured day habilitation, counseling services, home health aide, nursing services, occupational therapy, physical therapy, specialized medical equipment and supplies, speech and language therapy, assistive technology, behavior therapy, benefits counseling, career assessment, chore services, cognitive rehabilitation therapy, community integration, community transition services, home adaptations, home delivered meals, job finding, non-medical transportation, nutritional consultation, participant-directed community supports, participant-directed goods and services, personal emergency response system, pest eradication, telecare, and vehicle modification services to individuals ages 65 or older and individuals with physical disabilities ages 21-64 years who meet a nursing facility level of care.

### **Consolidated Waiver**

Provides community participation support, education support services, homemaker/chore, in-home and community support, residential habilitation, respite, supported employment, supports coordination, specialized supplies, therapy services, supports broker services, advanced supported employment, American Sign Language - English interpreter service, assistive technology, behavioral support, benefits counseling, communication specialist, companion, consultative nutritional services, family medical support assistance, family/caregiver training and support, home accessibility adaptations, housing transition and tenancy sustaining services, life sharing, music therapy/art therapy/equine assisted therapy, participant-directed goods and services, remote supports, shift nursing, small group employment, supported living, transportation, and vehicle accessibility adaptation services to individuals with autism ages 0 or older, individuals with developmental disabilities ages 0-21 years, and individuals with intellectual disabilities ages 0 or older who meet an ICF/IID level of care.

## **Community Living Waiver**

Provides community participation support, education support services, homemaker/chore, in-home and community support, life sharing, respite, supported employment, supports coordination, unlicensed residential habilitation, specialized supplies, therapy services, supports broker service, advanced supported employment, American Sign Language – English interpreter service, assistive technology, behavioral support, benefits counseling, communication specialist services, companion, consultative nutritional services, family medical support assistance, family/caregiver training and support, home accessibility adaptations, housing transition and tenancy sustaining service, music therapy/art therapy/equine assisted therapy, participant-directed goods and services, remote supports, shift nursing, small group employment, supported living, transportation, and vehicle accessibility adaptation services to individuals with autism ages 0 or older, individuals with intellectual disabilities ages 0 or older, and individuals with developmental disabilities ages 0 to 21 years who meet an ICF/IID level of care.

## **Person/Family Directed Supports (P/FDS) Waiver**

Provides community participation support, education support services, homemaker/chore, in-home and community support, respite, supported employment, supports coordination, specialized supplies, therapy services, supports broker services, advanced supported employment, American Sign Language – English interpreter service, assistive technology, behavioral support, benefits counseling, communication specialist services, companion, consultative nutritional services, family medical support assistance, family/caregiver training and support, home accessibility adaptations, housing transition and tenancy sustaining service, music therapy/art therapy/equine assisted therapy, participant-directed goods and services, remote supports, shift nursing, small group employment, transportation, and vehicle accessibility adaptation services to individuals with autism ages 0 or older, individuals with developmental disabilities ages 0-21 years, and individuals with intellectual disabilities ages 0 or older who meet an ICF/IID level of care.

## Attachment 2 – North Carolina

North Carolina has one waiver – the **Innovations Waiver** - that serves “individuals with intellectual disabilities or developmental disabilities ages 0 or older who meet an ICF/IID level of care”. In addition, it has three waivers that serve discrete populations who need a hospital or nursing facility level of care.

### **NC Innovations Waiver**

#### **List of services:**

“Provides community navigator, community networking, day supports, residential supports, respite, supported employment, financial support services, assistive technology, benefits counseling, community living and support, community transition, crisis services, home delivered meals, home modifications, individual goods and services, natural supports education, specialized consultation, supported living (periodic), supportive living (transition), supportive living, and vehicle modification services.”

#### **Who's Served:**

The Innovations waiver serves individuals with intellectual disabilities or developmental disabilities ages 0 or older who meet an ICF/IID level of care. North Carolina’s application refers to the federal definition of ICF/IID (and advocates report that “related conditions” is interpreted broadly).

#### **Number Served:**

The Innovations waiver has over 14,000 participants.

#### **Individual Cost Caps:**

The Innovations waiver has an individual cost cap. As of 2024, the individual cost limit was the lesser of \$184,000 or the amount that Medicaid would spend if the individual was institutionalized. Individuals living in their own (not their family) home and receiving Supported Living with 24-hour support can request funds above the cost limit.

#### **Concurrent Waivers:**

The Innovations waiver operates concurrently with 1915(b) waivers including mandatory enrollment in managed care.

## **Services of Interest**

### **1. Community Navigator**

As described in the waiver application, the purpose of Community Navigator Services is to promote self-direction, support the individual in making life choices, assist with a range of tenancy issues, provide advocacy, and identify opportunities to become a part of the community. This service also supports individuals, representatives, and Managing Employers by providing assistance to those that direct their own waiver services. Community Navigators assist and support (rather than direct and manage) the individual throughout the service delivery process.

Examples of specific activities include:

1. Providing initial and intermediate to long-term training as needed on the Individual and Family Directed Supports duties to ensure Employer is competent in the skills to carry out responsibilities of Employer.
2. Providing information/coaching/technical assistance on recruiting, hiring, managing, training, evaluating, and changing support staff, developing schedules, outlining staff duties, determining pay rates, and maintaining required records.
3. Developing an independent housing plan based on the participant's preferences and possible barriers.
4. Assisting with housing search and application processes.
5. Assisting the individual to create and follow a budget and identify resources to cover expenses.
6. Ensuring that living environment is safe and move-in ready.
7. Developing a housing support crisis plan that includes prevention and early intervention services when housing is jeopardized.
8. Assisting with finding and establishing a relationship with a housemate.
9. Providing training on how to be a good tenant.

### **2. Residential Supports – Group Homes or Alternate Family Living**

Residential Supports provides individualized services and supports to enable a person to live successfully in a Group Home or Alternate Family Living setting of their choice. Residential Supports includes the implementation of goals that support the individual to learn new skills, maintain and/or improve existing skills, to assist the person to complete an activity to their level of independence in order to maximize self-sufficiency and increase self-determination. Residential Supports also includes supervision and assistance in activities of daily living when the individual is dependent on others to ensure health and safety and to support individuals in accessing opportunities to have full inclusion in their community. Residential Supports may be provided in an Assisted Family Living setting (AFL). AFL Residential Support sites must be the primary residence of the AFL provider who receives

reimbursement for the cost of care (not for room and board). These sites are licensed or unlicensed in accordance with state rule.

Residential Supports are provided as a tiered support service; levels (1-4) are determined by the Individual Budget Tool (IBT) and other evidence (i.e. medical documentation, etc.) that support members' level of Residential Support needs. North Carolina uses a national assessment instrument called the Support Intensity Scale (SIS) score as one piece of evidence that may be considered when determining the level of Residential Support services.

**3. Supported Living** (and "Supported Living Periodic" (for those needing less than 4 hours per day) and "Supported Living Transition" (for those transitioning to Supported Living)

Supported Living provides a flexible partnership that enables a person/s to live in their own home with support from an agency that provides individualized assistance in a home that is under the control and responsibility of the person/s. The service includes direct assistance as needed with activities of daily living, household chores essential to the health and safety of the individual/s, budget management, attending appointments, and interpersonal and social skills building to enable the individual to live in a home in the community. Training activities, supervision, and assistance may be provided to allow the person to participate in home life or community activities. Other activities include assistance with monitoring health status and physical condition, and assistance with transferring, ambulation and use of special mobility devices.

Persons living in a Supported Living arrangement choose who lives with them - except a person may not live with family members other than a spouse or minor child unless such family members are themselves receiving disability-specific services. There can be no more than three residents including any live-in caregiver. Persons living in a Supported Living arrangement are involved in the selection of direct care staff, participate in the development of roles and responsibilities of staff, and have the right to manage personal funds as specified in the Individual Support Plan.

The provider of Supported Living services cannot own the person/s' home or be affiliated with an owner who would require, as a condition of renting or leasing, the person to move if the Supported Living provider changes.

The Supported Living provider is responsible for providing an individualized level of supports reflecting the person's preferences and determined during the assessment process, including risk assessment, as identified and approved in the Individual Support Plan (ISP). The provider must have 24-hour per day availability, including back-up and relief staff and in the case of emergency or crisis. Supported Living levels 1-3 (from minimal support to 24-hour awake staff) are determined by the Individual Budget Tool and other evidence of support need. The SIS Level is only one piece of evidence that may be considered. Special

Needs Adjustments to the levels are available for temporary circumstances such as illness, gap in roommates, transitions, etc...

#### **4. Community Living and Support**

Community Living and Support, which is the most used service in the waiver, is an individualized or group service that enables the person to live successfully in his/her own home, the home of his/her family or natural supports and be an active member of his/her community. Community Living and Support enables the person to learn new skills, practice and/or improve existing skills and provides supervision and assistance for the person to complete an activity to his/her level of independence. Areas of skill acquisition and/or support may include: interpersonal, independent living, community living, self-care, self-determination, monitoring a health condition, nutrition or physical condition, incidental supervision, daily living skills, and community participation. Community Living and Support also provides technical assistance to unpaid supports who live in the home of the individual to assist the individual to maintain the skills they have learned. Legally responsible relatives can provide this service if the individual has extraordinary needs and the services are necessary to avoid institutional placement.

**Exceptional Needs:** Community Living and Support Exceptional Needs may be used to meet exceptional, short-term situations that require services beyond 12 hours per day. The Individual Support Plan documents the exceptional supports needed based on the SIS® or other assessments that explain the nature of the issue and the expected intervention. A plan to transition the individual to sustainable supports is required. The plan may include the use of assistive technology or home modifications to reduce the amount of the support for behavioral and/or safety issues. Medical, behavioral, and support issues require documentation of when the situation is expected to resolve, evaluations/assessments needed to assist in resolving issues, and other service options explored. - Requests for more than 16 hours daily for more than a 90-day period will only be authorized based on review of a plan that details the transition of the participant from Community Living and Support to other appropriate services.

Community Living and Support can be provided in the home or community. A beneficiary who receives Residential Supports or Supported Living may receive the community component of this service but not the home component. This service is not available at the same time of day as various other waiver and state plan services, including Private Duty Nursing.

**Also of note:** North Carolina's state plan includes up to 16 hours per day of nursing services. Nursing is also a component of the Innovations waiver respite service when needed. However, the waiver will not provide certain services (e.g., Community Living and Supports) at the same time as private duty nursing under the state plan. This likely prevents some individuals from receiving needed services.

### **Input from Advocates**

Advocates raised the following concerns:

1. The individual cost cap prevents some individuals from getting the services they need.
2. There are insufficient nurses and other direct staff available to meet the need.
3. The disallowance of overlap between some state plan services, such as private duty nursing, and some waiver services is a problem.
4. The scope of Community Navigator services is not well known.

## **Attachment 3 – Wisconsin**

Wisconsin has two waivers that serve adults (and one that serves children) with the full range of developmental disabilities, along with individuals who have physical disabilities or are over age 64, who meet a Nursing Facility or ICF/IID level of care. The primary adult waiver is the Family Care waiver. The smaller adult waiver, IRIS (Include, Respect, I Self-Direct), with approximately 27,000 participants, is fully self-directed.

### **Family Care Waiver**

#### **List of services (from Appendix C):**

Adult Day Care Services, Care Management, Daily Living Skills Training, Day Habilitation Services, Prevocational Services, Respite, Supported Employment - Individual Employment Support, Consumer Directed Supports (Self-Directed Supports) Broker, Financial Management Services, Assistive Technology, CIE Exploration, Communication Assistance, Consultative Clinical and Therapeutic Services for Caregivers, Consumer Education and Training, Counseling and Therapeutic Resources, Environmental Accessibility Adaptations (Home Modifications), Health and Wellness, Home Delivered Meals, Housing Counseling, Personal Emergency Response Systems (PERS), Relocation services, Remote Monitoring and Support, Residential Services (1-2 Bed AFH), Residential Services (Other), Self-Directed Personal Care, Skilled Nursing Services RN/LPN, Specialized Medical Equipment and Supplies, Supported Employment - Small Group Employment Support, Supportive Home Care, Training Services for Unpaid Caregivers, Transportation (Specialized Transportation) - Community Transportation, Transportation (Specialized Transportation) - Other Transportation, Vehicle Modifications, Vocational Futures Planning and Support

#### **Who's Served:**

The Family Care waiver serves individuals with intellectual disabilities, developmental disabilities, physical disabilities, or age-related disabilities, ages 18 or older who meet a Nursing Facility or an ICF/IID level of care. Wisconsin refers only to the federal definition of ICF/IID. [Ask advocates?] Wisconsin serves children with the full range of developmental disabilities in a separate waiver.

#### **Number Served:**

The Family Care waiver serves approximately 71,000 participants

#### **Individual Cost Caps:**

The Family Care waiver has no individual cost caps.

**Concurrent Waivers:**

The Family Care waiver operates concurrently with 1915(b) waivers including mandatory enrollment in managed care.

**Services of Interest**

**1. Consumer Directed Supports Broker**

A support broker is an individual who assists a member in planning, securing, and directing self-directed supports (SDS). The direct assistance provided by the support broker depends on the needs of the member and includes assistance, if needed, with recruiting, hiring, training, managing, and scheduling workers.

**2. Housing counseling**

Provides assistance to a member who is looking to acquire and maintain safe, affordable, and accessible housing in the community, where ownership or rental of housing is separate from service provision. The purpose of housing counseling is to promote consumer choice and control, increase access to affordable housing, and promote community inclusion. Housing counseling includes exploring home ownership and rental options and individual and shared housing options, including options where the member lives with their family.

Services may include:

- Assessing the member's preferences regarding type and location of housing, living alone or with others, and other important needs and preferences.
- Assistance with identification of a roommate, if applicable;
- Assistance in establishing credit and meeting obligations of tenancy;
- Assistance with locating and securing available housing;
- Identifying and assisting the member in access to financing, securing supporting documents/records, completing/submitting applications, securing deposits, and locating furnishings;
- Explaining the rights and responsibilities of a tenant with disabilities, including how to file a complaint;
- Supports to assist the member in communicating with the landlord and/or property manager regarding the member's disability (if authorized and appropriate), detailing accommodations needed, and addressing components of emergency procedures involving the landlord and/or property manager; and
- Planning for ongoing management and maintenance of housing.

### **3. Supportive Home Care**

Supportive home care includes the following:

1. Providing support necessary for member safety at home and in the community, including observation or cueing of the member, to ensure that the member safely and appropriately completes activities of daily living and instrumental activities of daily living.
2. Routine housekeeping, shopping, and cleaning activities.
3. Intermittent major household tasks that must be performed seasonally or in response to some natural or other periodic event for reasons of health and safety or the need to assure the member's continued community living (e.g., yard work, snow removal; cleaning of attics and basements; refrigerator/freezer defrosting; cleaning of vehicles, wheelchairs, and other adaptive equipment; and bed bug inspection and extermination).
4. Personal care services including assistance with activities of daily living (ADLs) (e.g., dressing, toileting, etc...) and instrumental activities of daily living (IADLs) (e.g., meal preparation, money management, personal assistance on the job and in non-employment community activities). Personal care may not comprise the entirety of this service. (There is a separate personal care service available.)

This service also covers the cost of community involvement supports. Community involvement supports assist the member with engagement in community-integrated events and activities, through the coverage of associated expenses for support staff to accompany a participant, specifically when a member's attendance is dependent on staff accompaniment. This is limited to the worker's expense only.

A related or unrelated live-in caregiver may provide any or all of the types of supportive home care services.

### **4. Communication Assistance**

Communication Assistance includes devices or services needed to assist members with hearing, speech, communication, or vision impairments. These items or services assist the member to effectively communicate with others, decrease reliance on paid staff, increase personal safety, enhance independence, increase community inclusion, and improve social and emotional well-being.

Communication assistance includes any device, software, or service that addresses these objectives, such as:

- Augmentative and alternative communication systems;
- Hearing or speech amplification devices, aids and assistive devices when not covered under the State Plan;

- Cognitive retraining aids;
- Electronic technology, such as tablets, mobile devices, and related software or mobile/tablet applications, when the use provides communication assistance for the member;
- Training and technical assistance for the member or, where appropriate, legal decision-maker, family members, employers, paid and unpaid caregivers, and other individuals substantially involved in major life functions of the member;
- Evaluation and assessment of communication assistance needs of the member, and;
- The repair, maintenance, and servicing of such systems.

Communication Assistance includes interpreter services, which are provided to members with hearing, speech, or vision impairments and who require interpretation to effectively communicate with people in the community, employees, or others, when not otherwise available or the responsibility of another entity or program.

## Attachment 4 - Ohio

Ohio has 3 waivers that serve individuals of all ages with developmental disabilities who meet an ICF/IID level of need, as well as several waivers that serve individuals with a NF level of need. The largest DD waiver is the Individual Options waiver. The smallest is the Self Empowered Life Funding (SELF) waiver which is fully self-directed.

### **Individual Options Waiver**

#### **List of services (from Medicaid.gov):**

“community respite, habilitation - adult day support, homemaker/personal care, specialized medical equipment and supplies, assistive technology, career planning, community transition service, environmental accessibility adaptations, group employment support, habilitation - vocational habilitation, health care assessment, home delivered meals, homemaker/personal care - daily billing unit, individual employment support, interpreter, money management, non-medical transportation, nutrition, participant-directed homemaker/personal care, remote supports, residential respite, shared living, social work, transportation, waiver nursing delegation, and waiver nursing services.”

#### **Who's Served:**

The Individual Options waiver serves individuals with intellectual disabilities or developmental disabilities ages 0 or older who meet an ICF/IID level of care. Ohio uses a broad definition of “related conditions”.

#### **Number Served:**

The Individual Options waiver serves approximately 30,500 individuals.

#### **Individual Cost Caps:**

The Individual Options waiver has no individual cost caps.

#### **Concurrent Waivers:**

None

## **Services of Interest**

### **1. Money management services**

Money management means services that provide assistance to individuals who need support managing personal and financial affairs. Money Management may also include training to assist the individual in acquisition, retention and/or improvement in money management skills. Money management complements the work of other professionals by facilitating the completion of the day-to-day tasks rather than determining or executing long-term plans.

Examples of supports that may be provided as a component of money management include:

- (a) Bill-paying and preparation of checks for individuals to sign;
- (b) Balancing checkbooks, reconciling bank account statements, and maintaining or organizing bank records;
- (c) Preparing and delivering bank account deposits;
- (d) Assisting an individual with applying for benefits such as Medicaid buy-in for workers with disabilities and other resources as appropriate;
- (e) Assist in maintaining eligibility for monthly benefits such as food stamps;
- (f) Consulting or making referrals for consultation regarding available benefits;
- (g) Making referrals as appropriate for establishment of special needs accounts (e.g., Qualified Income Trusts or Achieving a Better Life Experience Act account);
- (h) Organizing tax documents and other paperwork;
- (i) Negotiating with creditors;
- (j) Deciphering medical insurance papers and verifying proper processing of claims;
- (l) Providing referrals to legal, tax, and investment professionals;
- (m) Notarizing documents;
- (n) Providing assistance associated with money management tasks when an individual relocates (e.g., transferring bank accounts and or updating address with creditors);
- (o) Acting as power of attorney or authorized representative for financial affairs;

### **2. Homemaker/personal care (HPC)**

Homemaker/personal Care services entail the coordinated provision of a variety of services, supports and supervision directed at health and safety and increasing the independence of the individual within his/her home or community. A single person provides the services as part of the natural flow of the day. For example, the provider may prepare a dish and place it in the oven to cook (homemaking), assist the individual

in washing up before a meal and assist him/her to the table (personal care), put the prepared meal on the table (homemaking), and assist the individual in eating (personal care).

Services include:

1. Self-advocacy and self-direction training
2. Daily living skills including assistance and training in accomplishing routine household tasks, meal preparation, personal care, self-administration of medication and other medical supports, proper use of adaptive and assistive devices (including emergency response systems), appliances, home safety, first aid, and communication skills such as using the telephone.
3. Money management services if provided in conjunction with other homemaker or personal care tasks. (Money management is also a stand-alone service)
4. Implementation of recommended follow-up counseling or other therapeutic interventions under the direction of a professional or extension of therapeutic services, which consist of reinforcing physical, occupational, speech and other therapeutic programs.
5. Behavior support strategies includes training and assistance in appropriate expressions of emotions or desires, assertiveness, acquisition of socially appropriate behaviors; or extension of therapeutic services. [note: provider must follow Ohio rules re behavior supports (including prohibited restraints and individual rights) and have documented training in the components of individual's professionally developed behavior support strategy, if any.]
6. Community access services that explore community services available to all people, natural supports available to the individual, and develop methods to access additional services/supports/activities needed by the individual to be integrated in and have full access to the community.
7. Mobility including training or assistance aimed at enhancing movement within the individual's home, mastering the use of adaptive aids and equipment, accessing and using public transportation, independent travel, or other means of providing transportation.

Homemaker/personal care **may be provided to an individual in an acute care hospital** to address the individual's intensive personal care, behavioral support/stabilization, or communication needs when certain conditions are met.

**Note: To the extent that this service is provided in the community, the name is misleading.**

## **SELF Waiver**

### **List of services (from Medicaid.gov):**

“participant-directed homemaker/personal care, residential respite, participant-directed goods and services, participant/family stability assistance, support brokerage, assistive technology, career planning, clinical/therapeutic intervention, community respite, functional behavioral assessment, group employment support, habilitation - adult day support, habilitation - vocational habilitation, health care assessment, home delivered meals, individual employment support, non-medical transportation, remote supports, transportation, and waiver nursing delegation.”

### **Who's Served:**

The SELF waiver serves individuals with intellectual disabilities or developmental disabilities ages 0 or older who meet an ICF/IID level of care. Ohio uses a broad definition of “related conditions”.

### **Number Served:**

The SELF waiver serves approximately 5700 individuals.

### **Individual Cost Caps:**

The SELF waiver has an individual cost cap of \$30,000 for children and \$45,000 for adults.

### **Concurrent Waivers:**

None

## **Service of Interest**

### **Supports Broker**

The SELF waiver is focused on participant direction and provides a service, Supports Broker, that among other things, assists the individual with understanding Employer Authority and Budget Authority, negotiating rates, locating and selecting providers, and keeping the focus of the services and support delivery on the individual and his/her desired outcomes. Per the Waiver Application, “...those enrolled in the program continually communicate with both ODM and DODD about the overwhelmingly positive experiences of enrollment on the SELF waiver and their strong support of self-direction options within the developmental disabilities delivery system.”

## Attachment 5 – California

California has three 1915(c) waivers that serve individuals of all ages who have DD and need at least an ICF/IID level of care, including one huge all-encompassing waiver, one for those who want to self-direct all services, and one limited to those with complex medical or technology needs, as well as an adult waiver for those with a Nursing Facility level of need. The largest waiver is called the Californians with Developmental Disabilities waiver, which I focus on here.

### **Waiver for Californians with Developmental Disabilities**

#### **List of Services (from Appendix C):**

“Behavioral intervention services, community living arrangement services, day service, homemaker, prevocational services, respite care, supported employment, dental services, home health aide, occupational therapy, optometric/optician services, physical therapy, prescription lenses and frames, psychology services, speech/hearing and language services, financial management service, chore services, communication aides, community based adult services, community-based training service, coordinated family supports, environmental accessibility adaptations, family support services, family/consumer training, housing access services, intensive transition services, non-medical transportation, nutritional consultation, participant-directed services, person-centered future planning, personal emergency response systems, self-directed support services, skilled nursing, specialized medical equipment and supplies, transition/set up expenses, vehicle modifications and adaptations services.”

#### **Who's Served:**

The Californians with DD waiver serves individuals with autism, intellectual disabilities, or developmental disabilities ages 0 or older who meet a Hospital, NF, or ICF/IID level of care. Developmental disability includes intellectual disability, cerebral palsy, epilepsy, autism, and other “disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with intellectual disability, but shall not include other handicapping conditions that are solely physical in nature.”

#### **Number Served:**

The Californians with DD waiver serves approximately 179,000 participants

#### **Individual Cost Caps:**

The Californians with DD waiver has no individual cost cap.

#### **Concurrent Waivers:**

None

## **Services of Interest**

### **1. Self Directed Support Services**

This service is available to consumers who have identified an interest in self-directing some or all their services. Assistance provided to participants and/or their families consists of guidance and advisement in ensuring a thorough understanding of responsibilities involved with self-direction of services, to make informed planning decisions about services and supports through the person-centered planning process, development of their initial budget and spending plan, and appropriate practices of hiring, managing, and communicating with staff.

### **2. Housing Access Services**

Housing Access Services include two components:

A) Individual Housing Transition Services.

1. Conducting a tenant screening and housing assessment that identifies the participant's preferences and barriers related to successful tenancy.
2. Developing an individualized housing support plan including identifying when other providers or services, both reimbursed and not reimbursed by Medicaid, may be required to meet the goal.
3. Assisting the individual with the housing search and application process.
4. Assisting the individual with identifying and coordinating resources to cover set-up fees for utilities or service access, and to address conditions in the living environment prior to move-in that may compromise the safety of the consumer including pest eradication and one-time cleaning prior to occupancy.
5. Assisting the individual with details of the move including communicating with the landlord to negotiate a move-in date, reading and understanding the terms of the lease, scheduling set-up of utilities and services, and arranging the move of consumers' belongings.
6. Developing a housing support crisis plan that includes prevention and early intervention services when housing is jeopardized.

B) Individual Housing & Tenancy Sustaining Services -

1. Providing the individual with early identification and intervention for behaviors that may jeopardize housing, such as late rental payment and other lease violations.

2. Providing the individual with education and training on the role, rights and responsibilities of the tenant and landlord.
3. Coaching the individual on developing and maintaining key relationships with landlords/property managers with a goal of fostering successful tenancy.
4. Assisting the individual in resolving disputes with landlords and/or neighbors to reduce risk of eviction or other adverse action.
5. Providing the individual with advocacy and linkage with community resources to prevent eviction when housing is, or may potentially become jeopardized.
6. Assisting the individual with the housing recertification process.
7. Coordinating with the tenant to review, update and modify their housing support and crisis plan on a regular basis to reflect current needs and address existing or recurring housing retention barriers.
8. Providing the individual with continuous training in being a good tenant and lease compliance, including ongoing support with activities related to household management.

### **3. Communication Aides**

Communication Aides are those human services necessary to facilitate and assist persons with hearing, speech, or vision impairment to be able to effectively communicate with service providers, family, friends, co-workers, and the general public. The following are allowable communication aides, as specified in the recipient's plan of care:

1. Facilitators;
2. Interpreters and interpreter services;
3. Translators and translator services; and
4. Evaluation for communication aides and training in the use of communication aides

### **4. Community-based Training**

Community-based training is a participant-directed service that allows recipients the opportunity to customize day services to meet their individualized needs. The service may include opportunities and assistance to: further the development or maintenance of employment and volunteer activities; pursue post-secondary education; and increase recipients' ability to lead integrated and inclusive lives. These services provide assistance with acquisition, retention, or improvement in self-help, socialization, and adaptive skills.

## **5. Participant-Directed Services**

Participant Directed Services are services and activities not otherwise provided through this waiver or through the Medicaid state plan that improve and maintain the participant's opportunities for full inclusion in the community, and enable the development of social skills, independence, and personal relationships. Eligible services or activities must promote active participation in the community, address an identified need in the service plan, be documented in the participant's Individual Program Plan, and purchased from the participant's Individual Budget.

## **6. Family Support Services**

Regularly provided care and supervision of children, for periods of less than 24 hours per day, while the parents/primary non-paid caregiver is out of the home. This service is provided in the recipient's own home or in an approved out of home location to do all of the following:

1. Assist family members in maintaining the recipient at home;
2. Provide appropriate care and supervision to protect the recipient's safety in the absence of family members;
3. Relieve family members from the constantly demanding responsibility of caring for a recipient; and
4. Attend to the recipient's basic self-help needs and other activities of daily living, including interaction, socialization, and continuation of usual daily routines which would ordinarily be performed by family members.

**Family Child Care Home** Family support services may only be provided when the care and supervision needs of a consumer exceed that of a person of the same age without developmental disabilities and when the cost of the service exceeds the cost of providing services to a person of the same age without disabilities.

### **Input From Advocates**

Disability Rights CA noted that the exclusion of physical disabilities is a problem that leads to some individuals not receiving the services they need.

## **Attachment 6 – Maryland**

Maryland has 3 DD waivers (2 for adults and 1 for children) that serve the full range of developmental disabilities - Community Pathways, Community Supports, and Family Supports - and several waivers for individuals who need a Nursing Facility level of care. The main difference between the two adult DD waivers is that Community Pathways, described below, is larger and covers residential services. The children's DD waiver does not cover residential services.

### **Community Pathways**

#### **List of Services:**

Career exploration, community living-group home, day habilitation, live-in caregiver supports, medical day care, personal supports, respite care services, supported employment, support broker services, assistive technology and services, behavioral support services, community development services, community living--enhanced supports, employment discovery and customization, employment services, environmental assessment, environmental modifications, family and peer mentoring supports, family caregiver training and empowerment services, housing support services, individual and family directed goods and services, nursing support services, participant education, training and advocacy supports, remote support services, shared living, supported living, transition services, transportation, and vehicle modification services.

#### **Who's Served:**

The Community Pathways waiver serves individuals with developmental disabilities ages 18 or older who need an ICF/IID level of care. (There is a Family Support waiver for individuals with developmental disabilities age 0-21 who need an ICF/IID level of care.) Maryland uses the federal definition of "related conditions".

#### **Number Served:**

The Community Pathways waiver serves approximately 16,500 participants.

#### **Individual Cost Caps:**

The Community Pathways waiver has no individual cost cap.

#### **Concurrent Waivers:**

None

## **Services of Interest**

### **1. Support Broker Services**

Support Broker services:

1. Assist the participant (or the participant's family or representative, as appropriate) in arranging for, directing, and managing services, including identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services.
2. Provide practical skills training to enable families and participants to independently direct and manage waiver services. Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers and providing information on effective communication and problem-solving.
3. Provide information to ensure that participants understand the rights and responsibilities involved with directing their services.
4. Advise and train on a myriad of issues related to person-centered planning, budgeting, grievance procedures, emergencies, etc...

### **2. Housing Support Services**

Housing Support Services are time-limited supports to help participants to identify and navigate housing opportunities, address, or overcome barriers to housing, and secure and retain their own home.

Housing Support Services include:

1. Reviewing housing programs' rules and requirements and their applicability to the participant;
2. Searching for housing;
3. Assistance with processes for applying for housing and housing assistance programs, and recertification processes;
4. Assessing the living environment to determine it meets accessibility needs, is safe, and ready for move-in;
5. Requesting reasonable accommodations in accordance with the Fair Housing Act
6. Identifying resources for security deposits, moving costs, furnishings, Assistive Technology, Environmental Modifications, utilities, and other one-time costs;

7. Reviewing the lease and other documents, including property rules, prior to signing;
8. Developing, reviewing, and revising a monthly budget, including a rent and utility payment plan;
9. Identifying and addressing housing challenges such as credit and rental history, criminal background, and behaviors;
10. Conducting a tenant screening and housing assessment including collecting information on potential housing barriers and identification of potential housing retention challenges;
11. Developing an individualized housing support plan
12. Education and training on the role, rights and responsibilities of the tenant and landlord; how to be a good tenant; and lease compliance;
13. Coaching to develop and maintain key relationships with landlord/property manager and neighbors;
14. Assistance with bill paying services;
15. Early identification and intervention for behaviors that jeopardize tenancy;
16. Assistance with resolving disputes with landlords and/or neighbors;
17. Advocacy and linkage with community resources to prevent eviction

### **3. Shared Living**

“Shared Living emphasizes the long-term sharing of lives, forming of caring households, and close personal relationships between a participant and the host home. Shared Living facilitates the inclusion of the participant into the daily life and community of the supporter through the sharing of a home and creation of natural opportunities for participation in community life through social connectedness. It is an arrangement in which an individual, couple, or a family in the community share their home and life experiences with a person with a disability. The approach is based on a mutual relationship where both parties agree to share their lives.”

Shared Living services include provision of assistance, support, and guidance for the participant’s development, acquisition, and maintenance of skills necessary to live more independently, and to participate meaningfully in the community. Additional services provided include transportation, delegated nursing tasks, personal care assistance, and

nursing support services. There are three levels of service as determined by assessed need.

#### **4. Supported Living**

Supported Living services enable the participant to: (a) live in a home of their choice located where they want to live; and (b) live with other participants or individuals of their choosing;. Supported Living services are provided in a house or apartment, owned or leased by at least one of the participants or by someone designated by a participant (such as a family member or guardian).

Supported Living services include direct support services for provision of coordination, training, supports, and/or supervision as well as nursing support services. Additional services can include transportation, delegated nursing tasks, and personal care assistance. Supports can be up to 24 hours per day depending on assessed need.

#### **5. Nursing Support Services**

Nursing Support Services provides a registered nurse (RN), licensed in the State of Maryland, to perform Nursing Consultation, Health Case Management, and Delegation services, based on the participant's assessed need. **It does not include direct nursing care.** The RN performs an initial nursing assessment and if needed provides one or more of the following:

1. Nursing Consultation services (for participants with employer authority and whose nursing needs are exempt from state nursing delegation rules) including:
  - a) recommendations to the participant on how to have the participant's health needs met in the community, including accessing health services available in the community and other community resources;
  - b) developing or reviewing of health care protocols, including emergency protocols, for the participant and the participant's uncompensated caregivers for use in training the participant's direct support staff; and
  - c) developing or reviewing of communication systems the participant may need to communicate effectively with: a. The participant's health care providers, direct support staff, and uncompensated caregivers who work to ensure the health of the participant; and b. Resources in the community that may be needed to support the participant's health needs, such as notifying the electrical company if the participant has medical equipment that requires prompt restoration of power in the event of a power outage.

2. Health Case Management services (for participants without employer authority and whose nursing needs are exempt from state delegation rules), including:
  - a) recommendations to the provider and direct support staff on how to have the participant's health needs met in the community, including accessing health services available in the community and other community resources;
  - b) developing a Nursing Care Plan and protocols regarding the participant's specific health needs; and
  - c) providing training to the provider's direct support staff on how to address the participant's specific health needs.
3. Nurse Delegation services (for those participants with or without employer authority, whose nursing needs are delegable under state law) including:
  - a) all of the tasks listed above, plus
  - b) monitoring the direct support staff's performance of delegated nursing tasks, including reviewing applicable documentation that must be maintained in accordance with applicable regulations and standards of nursing care;
  - c) continually monitoring the participant's health by conducting nursing assessments and reviewing health data documented and reported by direct support staff,
  - d) ensuring availability on a 24/7 basis, or providing qualified back-up, to address the participant's health needs as may arise emergently; and
  - e) collaborating with the participant or the provider to develop policies and procedures governing the delegation of nursing tasks in accordance with state law.

### **Input from Advocates**

**Maryland Developmental Disability Council** reported that:

- o Denials of services are increasing and problematic.
- o The waiver will soon be amended to combine the three DD waivers into one (although they don't think that will make residential available to children). The goal is to make it easier for adults whose needs increase to get residential services without having to switch waivers.
- o While they do not have a "communication" service, they do have providers that specialize in serving deaf participants.
- o The DDC found that having too many discreet services, as opposed to fewer but more inclusive services, has made the system much harder to negotiate.

**Disability Rights Maryland** reported that:

- Denials are increasing specifically around Personal Supports Enhanced (2-1 or overnight) due to budget concerns.
- Having too many discreet services, as opposed to fewer but more inclusive services, has made the system much harder to negotiate.
- It is harder to get nursing than it used to be.
- Coordination with Dept. of Health regulations is a problem.