



Analysis of the West Virginia Intellectual and Developmental Disabilities Waiver Waitlist

December 2019



STATE OF WEST VIRGINIA
DEPARTMENT OF HEALTH AND HUMAN RESOURCES

Bill J. Crouch
Cabinet Secretary

January 15, 2020

The Honorable Jim Justice
Office of the Governor of West Virginia
State Capitol
1900 Kanawha Boulevard, East
Charleston, WV 25305

RE: West Virginia Medicaid
Intellectual/Development Disabilities Waiver
Managed Enrollment List

Dear Governor Justice:

The Home and Community-Based Services (HCBS) Intellectual/Development Disabilities Waiver (IDDW) provides Medicaid funding for home and community-based services to individuals who otherwise would meet the eligibility requirements for higher cost Medicaid-funded institutional care. Due to a number of factors, including the cost of these services, WV has historically had a managed enrollment waitlist.

The Bureau for Medical Services oversees the IDDW programs and services and has provided the attached research for comparison and review in response to your request on December 13, 2019.

We appreciate the opportunity to provide this information and look forward to discussing with you further at your convenience. Please do not hesitate to contact our office with any questions or concerns.

Sincerely,

A handwritten signature in blue ink that reads "Bill J. Crouch".

Bill J. Crouch,
Cabinet Secretary

Attachment(s)

Analysis of the West Virginia Intellectual and Developmental Disabilities Waiver Waitlist December 2019

OVERVIEW

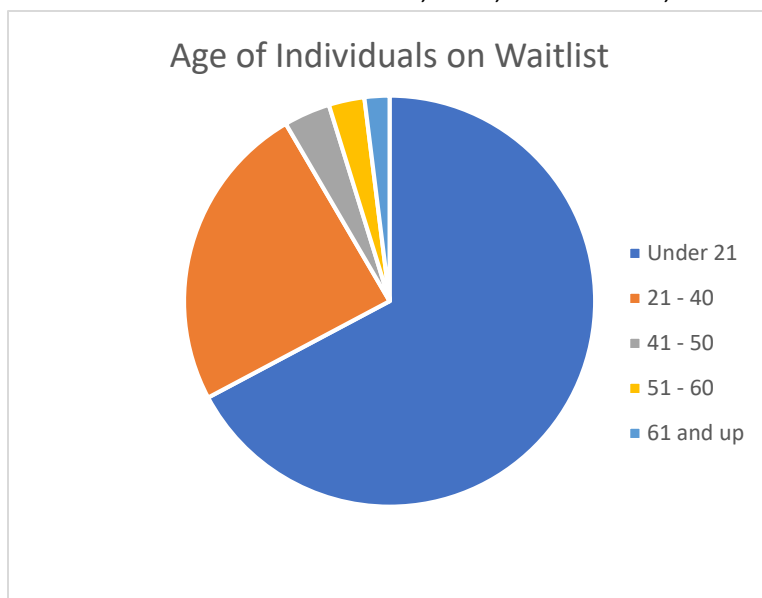
The West Virginia Intellectual/Developmental Disabilities Waiver (WV IDDW) program is a 1915(c) waiver authorized by the federal government through the Centers for Medicare and Medicaid Services (CMS). 1915(c) waiver programs provide home and community-based services and supports to qualifying individuals who meet the eligibility requirements for higher cost Medicaid-funded institutional care. West Virginia’s IDDW program was created in 1987 and has been renewed every 5 years since with CMS.

Forty-four states and the District of Columbia have waivers to provide home- and community-based services to people with intellectual and developmental disabilities (IDD). Some states utilize multiple IDD waivers; Virginia has an IDD waiver that serves very young children and a separate IDD waiver for older children and adults. Each state has developed their waiver program(s) to meet their state’s unique needs, and comparisons of waiver programs across states reflect significant differences in eligibility requirements and the types and amounts of services that are available to program members. West Virginia has a single waiver program to serve both children and adults living in their own homes or in agency operated settings providing 24/7 support and supervision. West Virginia closed its last institution for individuals with IDD, the Colin Anderson Center, in 1992 but many states continue to provide IDD services in state funded institutional settings.

Under the current Medicaid Federal Medical Assistance Percentage (FMAP), 74.94% of the funding for the WV IDDW program is provided by the federal government through CMS. The remaining 25.06% is funded through the West Virginia Department of Health and Human Resources (DHHR). Presently, the WV IDDW program serves 964 children under the age of 18 and 3,867 adults; 82% of adults and all children served by the program live with their families or in certified Specialized Family Care (foster care) homes; 28% of the adults receive services in apartments or small licensed group homes managed by IDDW provider agencies.

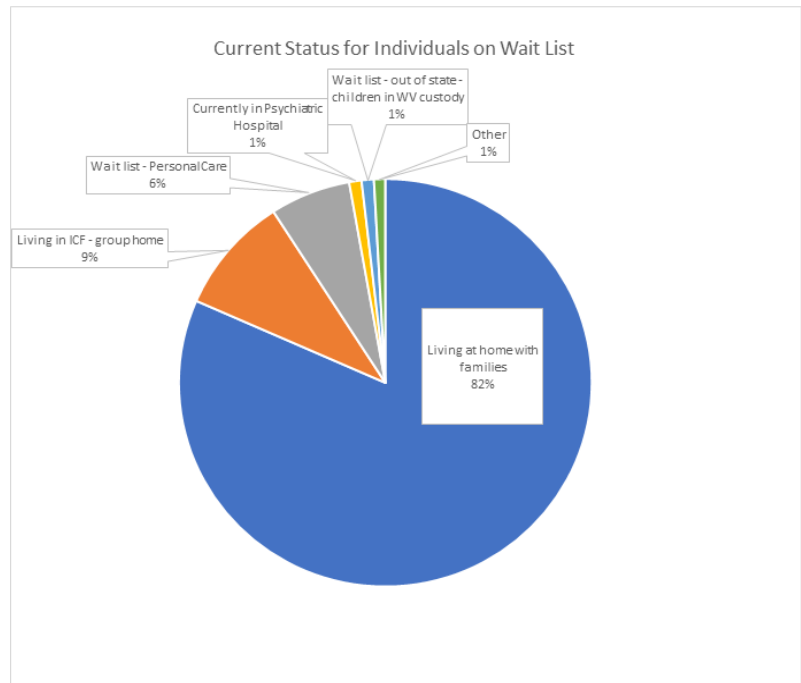
Nearly all states have waitlists for their waiver programs and most have faced legal challenges for failing to provide eligible individuals with needed services within a timely manner, violations of the Americans with Disabilities Act and other laws. As of December 1, 2019, there were 1,068 individuals (718 children and 350 adults) on the wait

list for the WV IDDW program with some being on the waitlist for nearly 5 years.

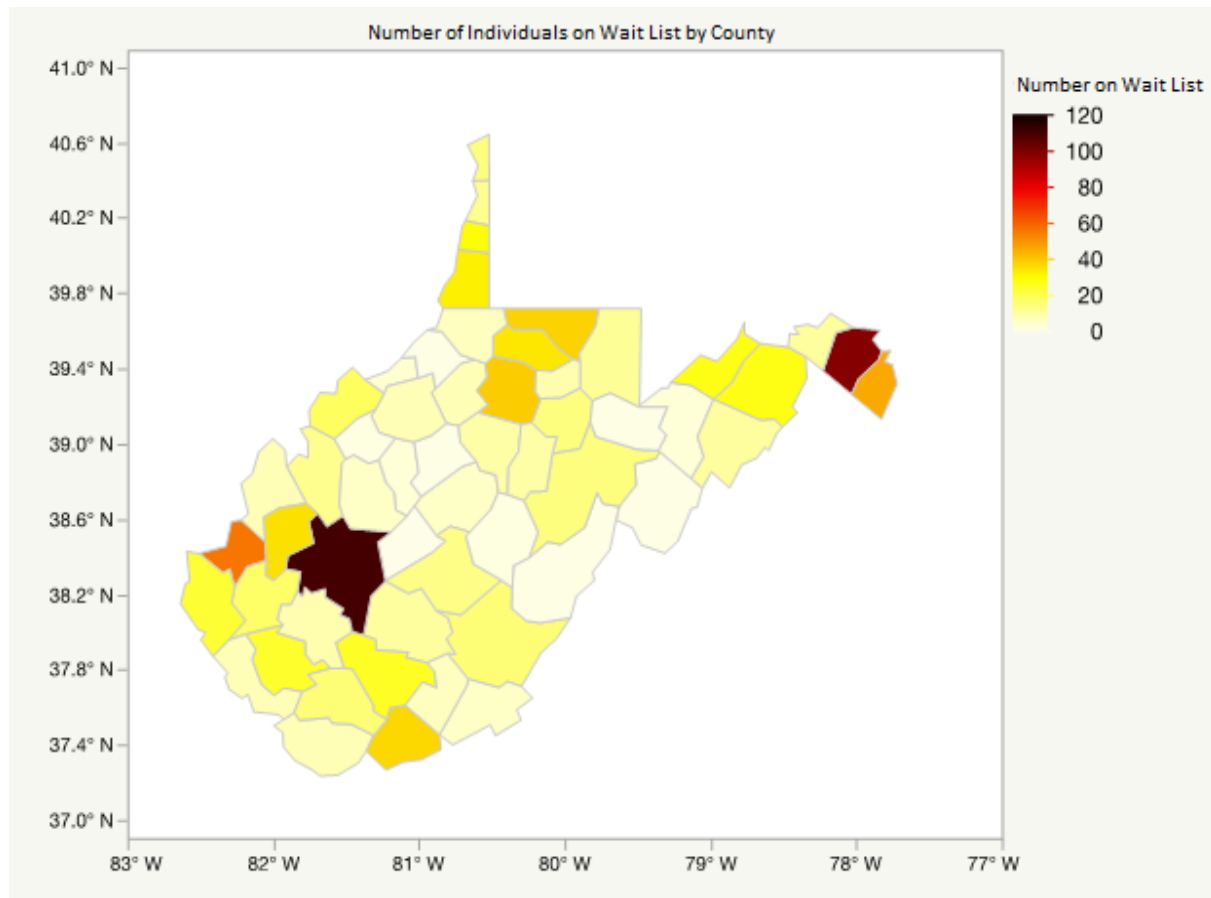


Individuals on the waitlist have completed the application process and have been assessed and determined to meet program eligibility requirements; however, there are no funded “slots” available. For CMS to approve a state’s IDDW application, the state must indicate the maximum number of individuals that will be served through the program based upon available resources including the state’s matching FMAP funds. For state fiscal year 2020, the number of West Virginia’s IDDW slots is 4,896.

Individuals on the WV IDDW waitlist are enrolled after an existing member leaves the program due to death, moving out of state, or because her or she no longer meets eligibility requirements. Approximately 100 individuals exit the WV IDDW program each year, allowing that number to be enrolled from the waitlist. Individuals who have been on the waitlist the longest are the first to receive open slots. It is estimated that at the current rate of slot turnover, those most recently approved for the WV IDDW program will have a ten year wait for access to services. To add slots to the existing waiver, West Virginia must submit an amended application to CMS.



The individuals are evenly distributed statewide with the exception of West Virginia's higher population areas: Charleston/Huntington, Morgantown/Clarksburg, Wheeling, and the Eastern Panhandle.

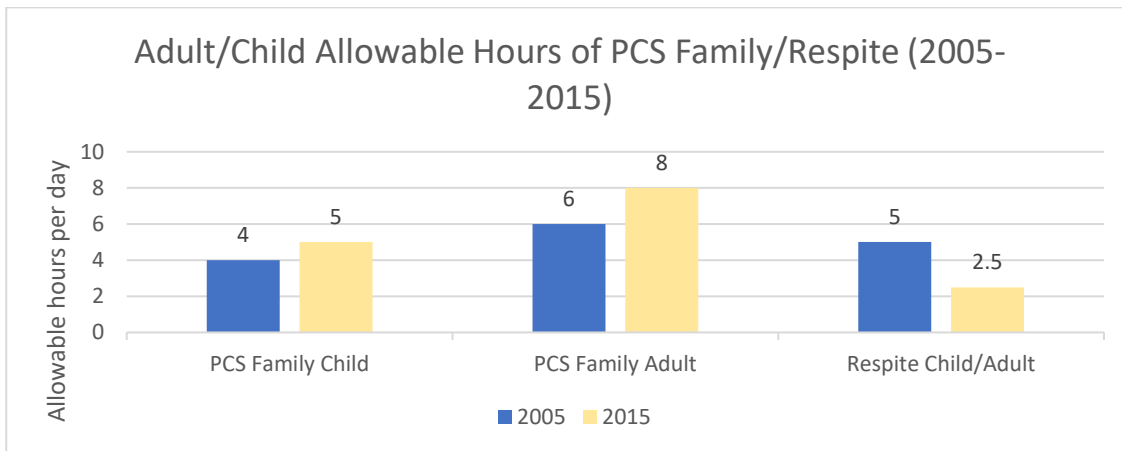


The IDDW program operated within budgetary guidelines until a rate increase in 2011, which also increased limits (“caps”) for family-provided direct care services. The chart below shows increasing IDDW program expenses until 2015 when the program realigned certain direct care services. The 2015 changes resulted in significant cost savings and allowed WV IDDW services to more closely match services offered by surrounding states.



The WV IDDW realignments that most significantly impacted expenditures:

1. Decreasing the average hours per day that a child under the age of 18 can receive for training, monitoring, and supervision in his or her home or local community from 8 hours per day to 5 hours per day.
2. Decreasing the average hours per day that an adult over the age of 18 can receive for training, monitoring, and supervision in his or her home or local community from 12 hours per day to 8 hours per day.
3. Decreasing the average hours per day of respite that both children and adults can receive in their home or local community from 5 hours per day to 2.5 hours per day.
4. Eliminating licensed practical nurse (LPN) billing to administer medications and allowing trained and certified Approved Medication Assistive Personnel (AMAPs) to perform these duties.



Since 2002, CMS has allowed states to offer IDDW program members the option of self-directing their services. Self-direction gives waiver program members or their parents/guardians more control over the services they receive. They are granted *employer authority* which allows them to recruit, hire, train, and supervise their own direct care workers in accordance with applicable laws and program policies. Studies have consistently shown that self-directed workers have less turnover, better understand the individual's needs and preferences, have fewer work-related injuries, and express greater job satisfaction than workers employed by traditional provider agencies.

Self-directing members also have *budget authority* which gives them more control over how their authorized waiver funds are spent. For example, they can determine their worker's wage rate based upon the amount of service needed, the worker's tenure, and/or performance.

Personal Options, the self-directed option for the WV IDDW program was made available in 2010. Currently, over 1,900 members choose to self-direct some of their waiver services and 2,839 workers are employed by self-directing IDDW members.

PROGRAM ELIGIBILITY

Per CMS requirements, waivers for individuals with an intellectual or developmental disability require that the individuals meet the same level of care standards as individuals living in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID):

1. Diagnosis of Intellectual Disability or a severe Related Condition; and
2. Intellectual Disability or Related Condition must be present prior to the age of 22; and
3. Substantial adaptive deficits in at least 3 of the 6 major life areas:
 - Self-care
 - Self-direction
 - Communication
 - Functional Academics
 - Mobility
 - Capacity for Independent Living
4. Need for an ICF/IID level of care

States define substantial adaptive deficit in a variety of ways. The most common is the use of the standard deviation from the mean which measures the degree that an individual falls from the average range of functioning in the major life areas.

Each of West Virginia's bordering states require at least **2 standard deviations** below the mean for IDDW eligibility. The WV IDDW is more restrictive because it requires **3 standard deviations** below the mean. It is estimated that utilization of a 2 standard deviation methodology would double the number of individuals who would qualify for the WV IDDW program.

Individuals functioning at 2 standard deviations below the mean have delays compared to peers but may live independently or semi-independently. They typically can perform personal self-care with little assistance but are often immature in social skills. Their communication can be concrete, and they may be at risk for being taken advantage of by others. They may be capable of competitive employment but do require support with complex daily living skills and with health care and legal decisions. When compared to their peers, their differences are often not seen until later in childhood. They often do not need 24-hour supervision or assistance.

Individuals functioning at 3 standard deviations below the mean usually show delays from a very young age. Quite often their achievement does not surpass a kindergarten level and independent living is generally not possible. They typically have marked differences from peers in social skills and with communication. Significant support is needed with daily living activities and with self-care. They often require extensive training in order to learn new skills. They are usually unable to make life decisions and require assistance with decision making. Nearly all individuals who function at this level require 24-hour supervision and support.

Below are two profiles of individuals who would not qualify for IDD Waiver services in West Virginia because their communication, capacity, and functional academic skills do not fall 3 standard deviations below the mean. Although these individuals are limited in all areas of their lives, their abilities on a measure of adaptive behavior would likely fall within 2 standard deviations below the mean as opposed to 3 standard deviations, which indicates they would potentially qualify for waiver services in a neighboring state.

PROFILE 1: SAM

Sam is a young adult male with a mild intellectual disability who currently lives alone in a rented, one-bedroom apartment. He is employed at a local restaurant that is within walking distance from his home. He currently works independently but originally was hired through a supportive employment program. He had a job coach for six months that provided him with training and support to complete his simple, repetitive job tasks. During the six months of his employment the job coach gradually provided less support to the individual until he could complete all of his job tasks independently. He walks to and from work regardless of the weather. He does not know how to access public transportation. He takes medication every morning and every night for a minor medical condition. A nurse or staff member certified in administering medication comes to his home to give him his medication. He does not know the name of his medication, the dosage, or the reason he takes the medication. This individual can follow his daily routine (he gets himself up in morning, completes self-care tasks, prepares simple meals, and gets to and from work) independently. He requires staff assistance with grocery shopping, making doctor appointments, getting to and from doctor's appointments, following up with medical recommendations made by treating physicians, paying monthly expenses, managing his money, and making medical decisions. He can make simple purchases with cash but cannot count change so he could be slighted correct change if the store clerk chooses to take advantage of his cognitive limitations. He has a medical power of attorney to assist in making medical decisions but is considered his own guardian. He did not graduate from high school and his academic capabilities are at the fourth-grade level. He enjoys attending church and members of the congregation provide him with transportation to and from church. He has few peers outside of residents of his apartment building who also have an intellectual disability and receive the same level of support from paid staff members. He has a speech impairment which limits his ability to make his wants and needs known to strangers. Individuals who are familiar with him understand most of what he says. When necessary he is able to communicate his wants and needs through gestures.

PROFILE 2: JOE

Joe is 29 years old and has lived with his parents his entire life. He attended high school and received a modified diploma upon graduation. Since graduation, most of his time is spent at home or volunteering at the local animal shelter. He receives regular instruction from the staff at the shelter on how to complete his tasks, and he does not require physical or gestural prompting to complete the tasks. Joe's parents often must verbally prompt him to brush his hair, brush his teeth, and straighten his clothing but he is physically capable of completing these tasks. He can read and write at a third-grade level. He can complete simple, single digit addition and subtraction. He is not able to pay bills, make medical appointments, or call a repair service if anything in the home is not operational. He can recognize the numbers on a \$1, \$5, \$10, and \$20 bill. He can communicate his basic wants and needs to those who are familiar with him. His mild speech impairment causes him to have to repeat himself often when speaking to those who do not know him well. He received speech services throughout elementary and middle school. Joe's parents serve as his medical power of attorney as he is unable to make informed medical decisions independently and cannot take prescribed medication on his own. His mother puts his medication in a weekly pill box, and she opens the compartment with the medication he must take each morning and then again, each night. Joe is not able to manage his own funds; therefore, his mother serves as his payee for his Social Security disability benefits. His mother assists him in making small purchases. If there is an item he wants at the store, she makes sure that he has the necessary cash to cover the cost of the purchase and makes sure that he receives the correct change back from the clerk, but she does not participate in the transaction. He does not know how to use a debit or credit card. He does not have any friends outside of family members except for a few people at his church. If he engages in activities with these individuals, it is usually initiated by Joe or his parents. If his parents must go out of town, he does stay at home alone, with a brother or sister checking on him first thing each morning and each evening prior to his bedtime. He can use a telephone to contact his parents, siblings, and neighbors using a binder his mother created with a picture of the individual and his or her phone number written next to the picture. He also knows how to call 911. He knows his address. By practicing with his parents, he is aware of what to do in the event the fire alarm goes off during the night. He is not aware of how to utilize public transportation and depends on his parents to get him places he needs to go.

BUDGET METHODOLOGY

West Virginia is one of several states that uses an individualized budget model to allocate waiver funds to each program member based upon their assessed needs. Once assigned a slot in the IDDW program, a functional assessment is completed with the member and his or her parents, guardians, friends, etc. The results of the assessment are used to determine the member's annual budget. As a result of the class action lawsuit *Michael T. vs. Bowling*, a more transparent and easy-to-understand budget methodology was developed. This methodology has been adjusted twice since July 2018 to accommodate rate increases. The methodology is currently being recalibrated to ensure the budgets align with current service unit caps and usage. DHHR's Bureau for Medical Services is to perform this recalibration at least every other year in accordance with the class action settlement agreement.

Depending on where a member lives and his or her age, the member is assigned a base budget range. There are seven different types of living settings, each with its own budget base:

Base Budget Determined by Living Arrangement Category (Revised 10/1/19)

LIVING ARRANGEMENT CATEGORIES	Low End	High End
YOUTH (below age 18): Living at Home with Family	\$29,643	\$33,081
ADULT: Living at Home with Family	\$38,283	\$44,231
ADULT: Intensively Supported Setting (ISS) Self-Directed	\$82,519	\$94,830
ADULT: Waiver Group Home 4 People	\$79,991	\$87,415
ADULT: Individual Support Setting 3 People	\$106,653	\$112,463
ADULT: Individual Support Setting 2 People	\$127,983	\$133,387
ADULT: Individual Support Setting 1 Person	\$192,637	\$198,933

Once the member receives the standard base budget for his or her age and type of living setting, the budget is increased based on information captured during the member's individual budget assessment. This assessment is commonly conducted in their home setting with the member and the parent or legal guardian. Someone who knows the member well is needed to answer the standardized questions. A structured interview is conducted as well as two standardized assessments, the Adaptive Behavior Assessment System (ABAS) and the Inventory for Client and Agency Planning (ICAP). The entire process takes about 3 hours to complete. Part of the results from the ICAP are utilized to increase the individual's budget to allow purchase of additional services to meet his or her needs. Below is the table that includes the ICAP add-on amounts.

ICAP Increases to Member's Base Budget Range (Original)

Add-Ons	Member Level	ADD
MOTOR SKILLS	Member Level	ADD
If Raw Score = 39-54,	0	\$0
If Raw Score = 33-38,	1	\$1,459
If Raw Score = 27-32,	2	\$2,918
If Raw Score = 15-26,	3	\$4,377
If Raw Score = 1-14,	4	\$5,836
PERSONAL LIVING SKILLS	Member Level	ADD
If Raw Score = 37-63,	0	\$0
If Raw Score = 30-36,	1	\$1,233
If Raw Score = 23-29,	2	\$2,466
If Raw Score = 12-22,	3	\$3,699
If Raw Score = 0-11,	4	\$4,932
EXTERNALIZED PROBLEM BEHAVIOR		ADD
If 1 or more of ICAP E2, E3 or E4 SEVERITY RATING=		
Extremely Serious -or- Very Serious	n/a	\$4,287
Moderately Serious -or- Slightly Serious	n/a	\$2,968
ASOCIAL PROBLEM BEHAVIOR		ADD
If 1 or more of ICAP E6 or E8 SEVERITY RATING=		
Extremely Serious -or- Very Serious	n/a	\$3,840

A letter is sent to the IDWW member prior to his or her annual planning meeting which includes the individualized budget. The member’s team, which consists of the member, their legal representative, staff from all agencies providing services to the member, an advocate if involved, and anyone else the member would like to attend, meets and decides the services which can be purchased within the individualized budget. These services must be documented on a person-centered plan based on the member’s needs and wants. Not all services may be able to be purchased within the assigned budget and other resources may need to be leveraged including natural supports.

RATES

Average costs of care for ICF/IDD services in state fiscal year 2019 was \$123,252, compared to \$66,000 for an IDWW member services.

There have been periodic rate increases with the most recent occurring in January and October of 2019. The increases targeted the Person-Centered Support (PCS) and Respite services provided by the traditional provider agencies to assist with recruiting and retaining direct care workers.

Service	2010 Rate	2011 Rate	2019 Rate
Person-Centered Support 1:1	\$15.20 per hour	\$20.04 per hour	\$21.80 per hour
Respite	\$15.20 per hour	\$20.04 per hour	\$21.80 per hour

NEIGHBORING STATES

Each of the states that border West Virginia have waiver programs that are comparable to the WV IDWW program. These states (Kentucky, Maryland, Ohio, Pennsylvania, and Virginia) have set individual budget limits and/or service unit caps to control program costs. Like West Virginia, these states allow parents, family members, and legal representatives to be paid workers but with some limitations.

Payments to qualified parents are exempt from federal income tax based upon the Difficulty of Care federal income tax exclusion. Classification as a live-in worker under the Fair Labor Standards Act exempts those workers from overtime wages. In West Virginia, parent workers that qualify for the Difficulty of Care exclusion are exempt from paying federal income tax, but their payments are subject to state income tax.

KENTUCKY

Michelle P. Waiver

Provides adult day health, case management, community access, day training, personal assistance, respite, shared living, supported employment, occupational therapy, physical therapy, speech therapy, community guide, goods and services, natural supports training, transportation, assessment/reassessment, community transition, consultative clinical and therapeutic service, environmental accessibility adaptation services, person centered coaching, positive behavior supports, specialized medical equipment and supplies, vehicle adaptation for individuals with IDD from birth with no maximum age.

Waitlist: 6,970

Supports for Community Living Waiver

Provides conflict-free case management, consultative clinical and therapeutic services, day training, personal assistance, residential support level I, respite, shared living, supported employment, community guide, financial management services, natural supports training, community access, community transition, environmental accessibility adaptation services, goods and services, person centered coach, positive behavior supports, residential support level II, specialized medical equipment and supplies, technology assisted residential, transportation, vehicle adaptations for individuals with IDD from age 3 with no maximum age.

Waitlist: 4,000+

OHIO

Level One Waiver

Provides community respite, habilitation - adult day support, habilitation - vocational, homemaker/personal care, specialized medical equipment and supplies, assistive technology, career planning, environmental accessibility adaptations, group employment support, home delivered meals, individual employment support, informal respite, money management, non-medical transportation, participant-directed homemaker/personal care, remote supports, residential respite, transportation, waiver nursing delegation for individuals with IDD from birth with no maximum age.

Self-Empowered Life Funding Waiver

Allows for a moderate amount of support and is Ohio's first self-directed waiver. Provides 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 inclusion, community respite, functional behavioral assessment, group employment support, habilitation - adult day support, habilitation - vocational habilitation, individual employment support, non-medical transportation, remote supports, transportation, waiver nursing delegation for individuals with IDD from birth with no maximum age.

Individual Options Waiver

For individuals with limited or no natural support and who have a high level of need. Provides 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, 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, waiver nursing for individuals with IDD from birth with no maximum age.

Waitlist: Over 30,000 across the three waivers. In January 2019 every person on Ohio's Waiver Waitlist was moved to a transitional list and began assessment with their county board of developmental disabilities. The purpose of the assessment is to determine the urgency of each individual's need for service and to prioritize the service delivery.

VIRGINIA

Community Living Waiver

Provides group day services, group home residential, individual supported employment, personal assistance services, respite, consumer-directed services facilitation, assistive technology, benefits planning, center-based crisis supports, community coaching, community engagement, community guide, community-based crisis supports, companion services, crisis support services, electronic home-based services, employment and community transportation, environmental modifications, group supported employment, in-home support services, peer mentor supports, personal emergency response system, private duty nursing, shared living, skilled nursing, sponsored residential, supported living, therapeutic consultation, transition services, workplace assistance services for individuals with autism and IDD from birth with no maximum age.

Family and Individual Support Waiver

Provides group day services, in-home support services, individual supported employment, personal assistance services, respite services, services facilitation, assistive technology, benefits planning, center-based crisis supports, community coaching, community engagement, community guide, community-based crisis supports, companion services, crisis support services, electronic home-based supports, employment and community transportation, environmental modifications, group supported employment, individual and family/caregiver training, peer mentor supports, personal emergency response system, private duty nursing, shared living, skilled nursing, supported living residential, therapeutic consultation, transition services, workplace assistance for individuals with autism and IDD from birth with no maximum age.

Building Independence Waiver

Provides group day services, independent living supports, individual supported employment, assistive technology, benefits planning, center-based crisis supports, community coaching, community engagement, community guide, community-based crisis supports, crisis support services, electronic home-based supports, employment and community transportation, environmental modifications, group supported employment, peer mentor supports, personal emergency response system, shared living, transition services for individuals with autism and IDD from birth with no maximum age.

Waitlist: A single statewide waitlist exists for all three Developmental Disability Waivers including the Community Living Waiver. 13,000-strong waitlist for developmental disability waivers. About 3,000 of those on the waitlist are classified as “priority one,” meaning they will need waiver services within a year.

PENNSYLVANIA

Community Living Waiver

Provides community participation support, education support services, homemaker/chore, in-home and community support, life sharing, respite, supported employment, supports coordination, specialized supplies, therapy services, supports broker service, advanced supported employment, assistive technology, behavioral support, benefits counseling, communication specialist services, companion, consultative nutritional services, family/caregiver training and support, home accessibility adaptations, housing transition and tenancy sustaining service, music therapy, art therapy and equine assisted therapy,

participant-directed goods and services, shift nursing, small group employment, supported living, transportation, vehicle accessibility adaptations for individuals with autism and intellectual disabilities from birth with no maximum age, and individuals with developmental disabilities from birth to 8 years of age.

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, assistive technology, behavioral support, benefits counseling, communication specialist, companion, consultative nutritional services, family/caregiver training and support, home accessibility adaptations, housing transition and tenancy sustaining services, life sharing, music therapy, art therapy and equine assisted therapy, shift nursing, small group employment, supported living, transportation, vehicle accessibility adaptations for individuals with autism from birth with no maximum age, individuals with developmental disabilities from birth to 8 years of age, and individuals with intellectual disabilities from birth with no maximum age.

Person/Family Directed Support

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, assistive technology, behavioral support, benefits counseling, communication specialist services, companion, consultative nutritional services, family/caregiver training and support, home accessibility adaptations, housing transition and tenancy sustaining service, music therapy, art therapy and equine assisted therapy, participant-directed goods and services, shift nursing, small group employment, transportation, vehicle accessibility adaptations for individuals with autism from birth with no maximum age, individuals with developmental disabilities from birth to 8 years of age, and individuals with intellectual disabilities from birth with no maximum age.

Waitlist: 9,728 people with developmental disabilities on Pennsylvania's waiting list, but they are primarily adults.

MARYLAND

Family Supports Waiver

Provides personal supports, respite care services, support broker services, assistive technology and services, behavioral support 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, nurse case management and delegation services, nurse consultation, participant education, training and advocacy supports, transportation, vehicle modifications for individuals with developmental disabilities from birth to 21 years of age.

Community Supports Waiver

Provides career exploration, day habilitation, medical day care, personal supports, respite care services, support broker services, assistive technology and services, behavioral support services, community

development services, employment discovery and customization (ending June 30, 2021), employment services (effective December 1, 2019), 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, nurse case management and delegation services, nurse consultation, nurse health case management, participant education, training and advocacy supports, supported employment (ending June 30, 2021), transportation, and vehicle modifications for individuals with developmental disabilities from birth with no maximum age.

Community Pathways

Provides career exploration, community living-group home, day habilitation, live-in caregiver supports, medical day care, personal supports, respite care services, supported employment (ending June 30, 2021), support broker services, assistive technology and services, behavioral support services, community development services, community living-enhanced supports (beginning July 1, 2020), employment discovery and customization (ending June 30, 2021), employment services (effective December 1, 2019), environmental assessment, environmental modifications, family and peer mentoring supports, family caregiver training and empowerment, housing support services, individual and family directed goods and services, nurse case management and delegation, nurse consultation, nurse health case management, participant education, training and advocacy supports, remote support services, shared living, supported living (effective July 1, 2019), transition services, transportation, vehicle modifications for individuals with developmental disabilities from birth with no maximum age.

Waitlist: Currently over 5,000 individuals are on the MD Developmental Disabilities Administration waitlist for IDD services including those available through waiver programs.

Available Waiver Services*	WV	OH	MD	KY	PA	VA
Adaptive & Assistive Equipment		X	X	X	X	X
Assessment/Reassessment				X		
Behavior Support	X		X	X	X	X
Benefits Counseling					X	X
Case Management/ Service Coordination	X			X	X	
Communication Specialist					X	X
Community Learning/Guide Services			X	X	X	X
Crisis Services	X					X
Day Habilitation	X	X	X	X	X	X
Dietary Therapy	X	X			X	
Education Support					X	
Electronic/Remote Monitoring	X	X	X		X	X
Environment Assessment			X			
Environmental Accessibility Adaptation - Home	X	X	X	X	X	X
Environmental Accessibility Adaptation - Vehicle	X		X	X	X	
Family Caregiver Training and Empowerment			X		X	
Family & Peer Mentoring			X	X		X
Goods and Services	X	X	X	X	X	
Home Delivered Meals		X				
Housing Support Services			X			
Interpreter Services		X				
Job Development	X	X	X	X	X	X
Life Sharing Needs Group					X	
Medical Day Care			X			
Money Management		X				
Music, Art and Equine Assisted Therapy					X	
Nursing Delegation		X	X			
Nursing by LPN	X	X			X	X
Nursing by RN	X	X			X	X
Occupational Therapy	X			X	X	
Orientation, Mobility and Vision Support					X	
Participant Education, Training & Advocacy Supports			X			
Person-Centered Support (Personal Care/Homemaker/Companion Services)	X	X	X	X	X	X
Personal Emergency Response System						X
Physical Therapy	X			X	X	
Pre-Vocational Services	X	X	X	X	X	X
Respite	X	X	X	X	X	X
Shared Living		X	X	X		
Speech Therapy	X			X	X	
Support Brokerage			X		X	X
Supported Employment	X	X	X	X	X	X
Transition Services			X	X	X	X
Transportation	X	X	X	X	X	X

**Actual name of service may vary between state waivers*

Comparison of WV Person Centered Support Services (PCS)-Family and Respite Care with Neighboring States

	West Virginia	Kentucky	Maryland	Ohio	Pennsylvania	Virginia
Are parents/legal representatives allowed to be paid workers?	Yes	Yes, if self-directing	Yes, if self-directing	Yes (adults only in IO Waiver)	Yes, adults only	Yes, adults only under limited circumstances
Available units/hrs PCS-Family	Age <18= 5hrs/day based on in/out of school calendar Age ≥18=8 hrs/day	*MPW: 40 hrs/week combined with all services (except Case Mgt and Respite) *SCL: 40 hrs/week	82 hrs/week; though family workers limited to 40 hrs/week per provider	*IO: No set limit *Level 1: Cannot exceed \$5,000/yr for ALL services *SELF: Max for ALL services is \$40K/yr for adults \$25K/yr for children	*PFDS: \$30,000/year limit for ALL services *Consolidated: No upper budget limit	IFDDS: 8 hrs/day ID: 8 hrs/day
Available units/hrs Respite	912 hours/yr or avg of 2.5 hours per day	*MPW - 830 hrs/yr *SCL: 830 hrs/yr	45 days/yr (daily rate); no more than 28 consecutive days/yr	*Community 60 days/yr *Residential - 90 days/yr – *Informal (only available in Level 1) max \$5K/yr for ALL services	*PFDS: 480 units/yr or 30 days/yr \$30,000/year limit for ALL services; 480 units/yr *Consolidated: No upper budget limit	IFDDS: 480 hrs/yr ID: 720 hrs/yr
Additional Information	Average costs program wide are \$66,000 per person; upper budget limit dependent on service limits per age and living arrangement	*2 Waiver programs *Michelle P. Waiver (MPW) *Supports for Community Living (SCL)– does not allow a live-in caregiver to provider more than 40 hrs/week of service; must have intellectual AND developmental disability to qualify	*Community First Choice Waiver	*3 Waiver programs *Individual Options (IO) *Self-Empowered Life Funding (SELF) *Level 1 Waiver offers comparable Respite as available in WV - has a max limit of \$5,000/service year for ALL services	*2 Waiver programs somewhat comparable to WV *Person/Family Directed Support (PFDS) *Consolidated Waiver – no upper budget limit *PA does not generally allow parents/LR to be provider	2 Waiver programs *Individual and Family Disabilities Support (IFDDS) serves age 6 and above *Intellectual Disability (ID) serves below age 6 *Average costs for those <6=\$28,038; for those ≥6=\$65,994

In summary, the services available through the WV IDDW program are similar to services offered in neighboring states and the IDDW waitlist is relatively small compared to other states.

The reason West Virginia has a smaller waitlist is due to the more restrictive eligibility requirement. It has been said West Virginia has the tightest eligibility requirements in the nation, thus ensuring only individuals who require a high level of care are served by this very specialized program. Otherwise, West Virginia would also have a very large waitlist.

Several of West Virginia’s neighboring states have had recent lawsuits over their waitlists. Most states have been required to assess the urgency of each waitlisted individual’s need for services and create a system to prioritize program enrollment for individuals with high-need and those in crisis. In some cases, states have created new programs to provide services to individuals while they remain on the waitlist for waiver services.

State	Number on Wait List(s)
West Virginia	1,068
Kentucky	4,000+
Maryland	5,000+
Ohio	30,000+
Pennsylvania	9,000+
Virginia	13,000+

It is DHHR’s recommendation that the WV IDDW waitlist be cleared as soon as possible. This is an opportune time because the budget methodology is currently being recalibrated and the waiver is in the process of its five-year renewal with CMS.