PUNS, Waiver Services, and Options While Families Wait

The Arc of Illinois
Family Advocate Program
&
Family Support Network

By Ruth Aguilar

Hosted by: District 219

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The Family Advocate program is funded by the Department of Human Services

Meet Ruth

- **Valerie's mom** (Val has IDD)
- Qualified Intellectual Disabilities Professional
- 15+ years of combined experience ID/DD Community
  - Former Individual Service Coordinator ISC
  - Former Self Direction Assistant SDA
- Appointed by Gov. JB Pritzker to the Autism Data Privacy Advisory Group



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Goals for Today

- Understand the role of **The Arc of Illinois** and how we support individuals and their families
- Learn about the **PUNS** process and how it connects individuals to waiver-funded services
- Briefly explore the **services** available upon selection from the PUNS waitlist
- Discover **additional supports** and resources that are available while waiting for a PUNS selection



The Arc of Illinois



Educate

We offer a wide range of programs and trainings to improve care and inspire better tomorrows.

Advocate

We fight for disability rights and equality, raising awareness on life-changing legislation and policies.

Connect

We connect families, self advocates, and care professionals to build an expansive support network.

Part of the Largest National Community-Based Organization

Advocating for and serving people with intellectual and development disabilities and their families throughout the entire life span.

1 of 650 Chapters Nationwide

Advocating on the front lines to ensure that people with IDD and their families have the support and services they need to be fully engaged in their communities.

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Programs of The Arc of Illinois

- *Illinois Life Span*
- *Family to Family Health Information Center*
- *Family Support Network of Illinois*
- *Assistive Technology Program*
- *Ligas Family Advocate Program*
- *Family Transition Project*
- *Training Department*

Plus!
Going Home Coalition,
Operation Welcome Home,
Consumer Stipend,
Public Policy & Advocacy



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Family Advocate Program



- Established as a pilot program in 2014 after the Ligas Consent Decree (2011) to provide consistent information about waiver services and living options statewide (Stanley Ligas)
- Connect families of loved ones with I/DD to similar families seeking funding and services selected from the PUNS
- Share creative ways to utilize waiver funding
- Funded through a grant from the Illinois Department of Human Services
- Work with Independent Service Coordination agencies (ISCs) in getting information about all available options for services to adults and families

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Key Acronyms

CILA: Community Integrated Living Arrangement

DD: Developmental Disabilities

CDS: Community Day Service Programs

PAS: Pre-admission screening

HBS: Home Based Services

ICF-DD: Intermediate Care Facility for individuals with DD

ISC: Independent Service Coordination Agency or Individual Service Coordinator

DHS: Department of Human Services

- DDD: Division of Developmental Disabilities
- DRS: Division of Rehabilitative Services

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For additional acronyms visit:
https://www.dhs.state.il.us/page.aspx?item=65839



Have a family meeting

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Things to Consider

- Who is part of the support system?
  - Do you expect that support system to remain stable and engaged into adulthood?
  - If not, how do you bolster that support?

- What are my preferences?
  - Do I prefer activity, engagement, social time, or do I value more quiet environments?

- How do I make decisions? What support is needed?
- What type of support is needed in daily activities?
- Do I have chronic medical needs that require support into adulthood?
- What are my goals/hopes around employment and independent living for the future?



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Home and Community Based Services Waiver Programs

What is an HCBS Waiver?

A waiver is a program that provides services that allow individuals to remain in their own homes or live in a community setting, instead of in an institution. Illinois has nine HCBS waivers. Each waiver is designed for individuals with similar needs and offers a different set of services.

Who is eligible for a HCBS Waiver?

Individuals must be U.S. citizens or legal aliens and residents of the state of Illinois;

Individuals must meet Medicaid financial eligibility criteria as specified in each waiver;

Individuals must require an institutional level of care as specified in each waiver;

Individuals' service needs must be able to be provided in the waiver at a cost equal to or less than the cost for institutional care; and

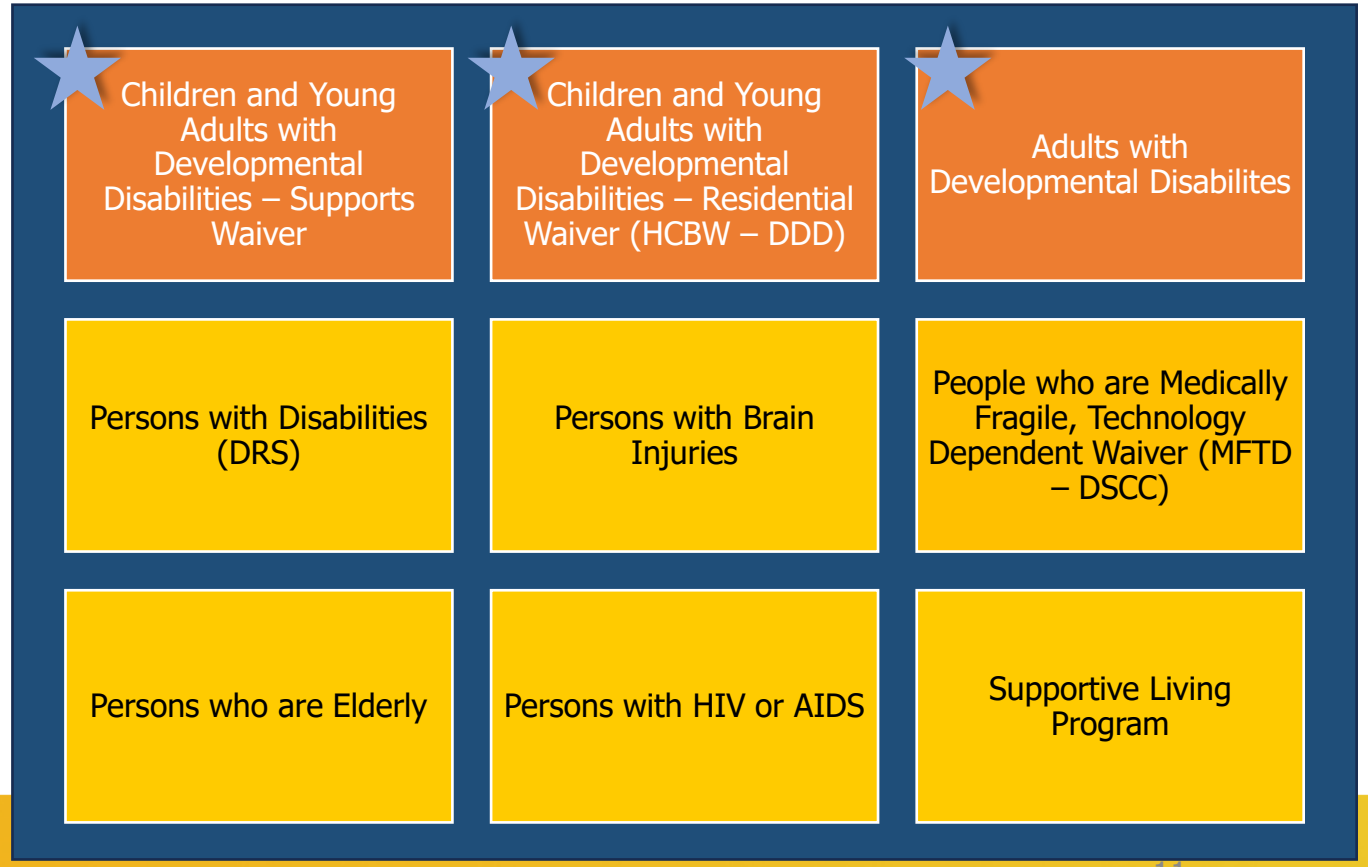
Individuals must meet any other requirements, such as age or diagnosis requirements, specific to the waiver program.

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Illinois Medicaid Waivers

- The state receives approval to operate a waiver from the Federal Center for Medicaid & Medicare Services (CMS). The waiver abides by federal Medicaid regulations (i.e. conflict free case management, Settings Rule).

- 9 waivers
- ★ Utilize the PUNS List
- Home and Community Based Waiver
  - Department of Human Services
    - Division of Developmental Disability



PUNS – What Is It?

- Statewide database that registers children & adults who want or need the Developmental Disability Home and Community Based Waiver

- As funding is available, individuals are selected from the PUNS waitlist and *invited to apply* for waiver services.

- PUNS is not an acronym – it does not prioritize based on urgency of need.



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PUNS Criteria

Diagnosis of Intellectual Disability

- Significantly sub average general intellectual functioning
  - General rule of thumb – Full Scale IQ score of 70 or lower
- Existing concurrently with deficits in adaptive behavior
- Manifested before the age of 18 years

OR

Diagnosis of a Related Condition

(i.e. Autism, Cerebral Palsy, Epilepsy) that results in impairment of general intellectual functioning or adaptive behavior

- Severe, chronic disability
- Manifested before the age of 22
- Likely to continue indefinitely
- Results in substantial functional limitations in three or more of the major life areas: self-care, language, learning, mobility, self-direction, capacity for independent living



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PUNS Categories

Seeking

- Currently want or need services
- PUNS selections are only made from this category, as funding is available (typically once a year).
- Time on the PUNS list begins accumulating toward selection only in this category.

Planning

- Do not currently want or need supports but may in the future.
- For individuals who are not currently seeking services will be needing services if something happens (i.e. caregiver becomes ill).
- Time spent in the 'planning' category does not move an individual closer to funding.

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Emergency / Crisis

- There is a way to be evaluated for crisis and if you meet the criteria, you may be eligible for receiving crisis-based funding. These cases are reviewed meticulously and often involve outside entities like DCFS, police, APS, etc.
- If pursuing CILA placement, ISC agency is allowed to look statewide.
- Individual must be experiencing or at imminent risk of experiencing:
  - abuse (harm done to individual OR aggressive behaviors causing harm to others)
  - homelessness (i.e. living in a shelter)
  - neglect (unable to complete tasks necessary for living)

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Enrolling on PUNS

- When should I enroll my child on PUNS?

  As soon as possible, as early as 2.5 years old

- The 'wait time' for services does not start until the age of 18, only in the Seeking Services category
- Before 18, enrolling on PUNS allows the state to plan for the needs of individuals who will qualify for supports in the future
- Recently, individuals were selected for the Children's waiver; they were in the Seeking Services category. We don't know if another children's selection will happen in the coming years, but you can only be selected for services if you're on the PUNS waitlist and in the Seeking Services category.
- **Contact your ISC agency** – your ISC is your gateway to services; they are the starting point for receiving services through state funding.

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How long will I wait?

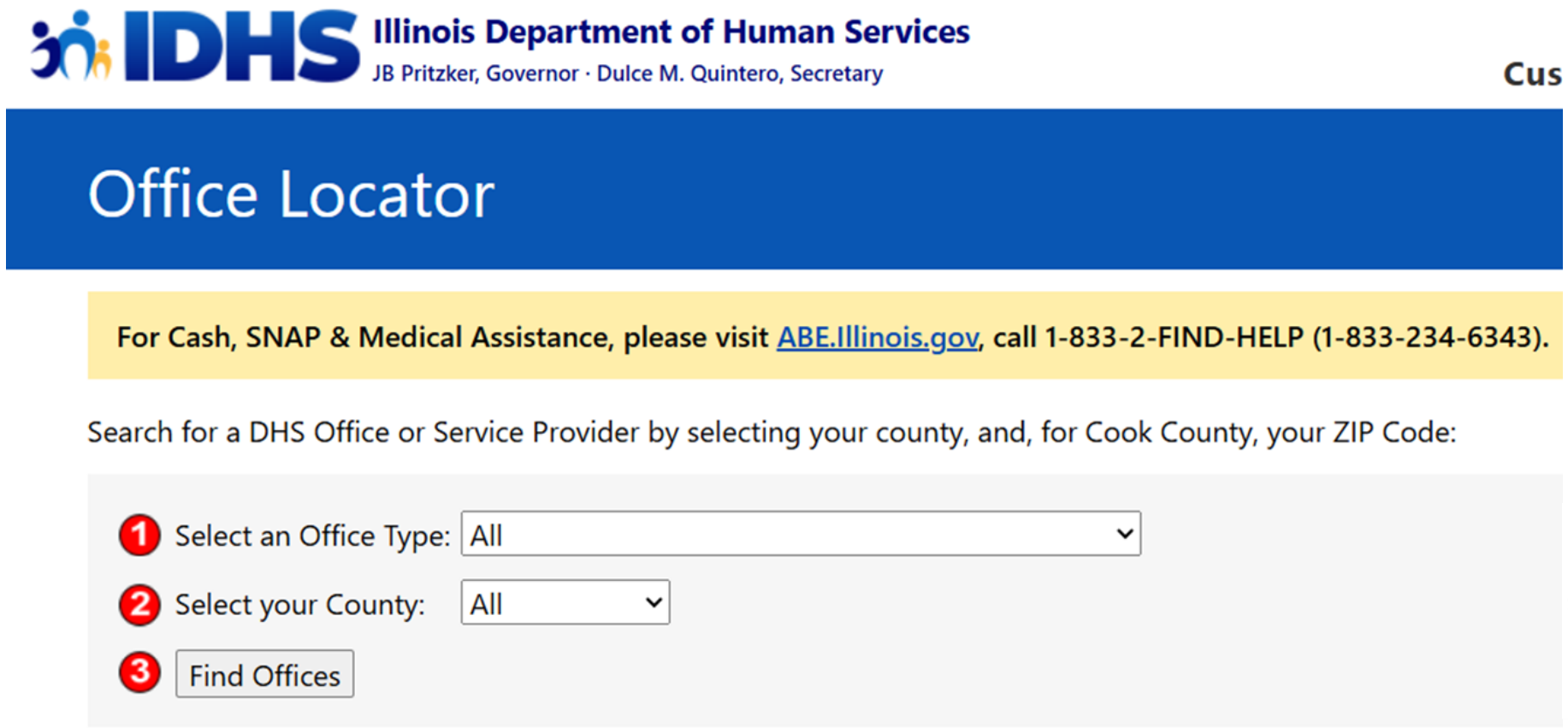
- Children/Adults *must be in the Seeking Services* category to accumulate time towards the PUNS selection.
- Time spent on PUNS, while under the age of 18, *does not count* towards selection.
- Wait time for new individuals on PUNS (age 18 and over) who want or need services is about 5 or more years, on average.
  - We've seen recent improvement on this! Individuals in the most recent selection waited a maximum of 42 months (3.5 years)

Want to find out when your or your loved one might be selected from PUNS?

Email name and birthday to DHS.DDD.PUNS@illinois.gov
Estimate timeframe will be provided (i.e. Summer 2026)



ISC locator



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Preparing for a PUNS Selection

Pre-Admission Screening (PAS) Process

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Preparing for a PUNS selection

- For selectees aged 18 and over - apply for, and maintain, Medicaid.
  - *Process is different for Children's selections – ISC will guide you.
- Keep school & evaluation records in order and accessible (make copies!).
- Maintain accurate and up-to-date medical records.
- Identify and contact your Independent Service Coordination Agency
- Become familiar with Developmental Disability Provider agencies.
- Be prepared to apply for Medicaid and SSI at adulthood.
  - Transition planning is key! (www.abe.Illinois.gov & www.ssa.gov/applyonline/)
- Consider the need for, and all options around, guardianship.
- Explore supports and services before you need them.



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Document List

Medicaid Card
Social Security Card or Birth Certificate
Medical record that shows diagnosis and age of onset
School records (example: Individualized Education Program)
Psychological Evaluations as available
Psychiatric evaluations for people with Autism ONLY
Annual physical exam & medication list
Guardianship papers or Power of Attorney as applicable

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Psychological Evaluation requirements: https://www.dhs.state.il.us/page.aspx?item=53021

PUNS ⟶ Waiver Services Process

Letter 1

Early Notification

(Anytime, but often December)

- Apply for Medicaid
- Prepare documents for clinical eligibility (IEP, Medical Exam, SS card, ID card, etc.)
- Contact your Independent Service Coordinator (ISC)
- Contact the Arc of Illinois Family Advocate Program
- Research service providers
- Become familiar with the services that will be available upon PUNS selection

Letter 2

PUNS Selection

(6-7 months following Early Notification, usually summertime)

- Your official Invitation to Apply for Services
- Contact your Independent Service Coordinator (ISC), begin Pre-Admissions Screening (PAS)
- If you are currently receiving services & are satisfied, contact your ISC; your selection letter does not expire: https://www.dhs.state.il.us/page.aspx?item=167411
- Have documents ready
- Participate in Discovery Process; ISC develops Person Centered Plan (PCP)
- Decide on services and select providers
- Once finalized, ISC submits packet to DHS for approval

Letter 3

Award Letter

- The state has reviewed your application and approved!
- Services can begin from the effective date on the letter
- Your Independent Service Coordination agency begins monitoring
- 4 quarterly visits & as needed to the home of the individual
- ISC assists with changing/modifying services or providers

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Finding Your Way

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START

Contact ISC to determine eligibility to be on the PUNS waiting list for adult Home and Community Based Services (HCBS) Need help finding your ISC(Independent Coordination Agency? Call DHS at 1-866-337-5267 (TTY: 1-866-376-8446)

Placed on PUNS list to wait for HBCS. You will be categorized as: Planning for services OR Seeking Services(starts at age 18)

Update paperwork yearly with the ISC — doing so will keep you on the PUNS list.

After the age of 18, contact DHS by email yearly to see when you may be selected from PUNS DHS.DDD.PUNS@ illinois.gov

Receive **Early Notification Letter from DHS**, you will likely be included in the next PUNS selection and invited to apply for DD waiver services. **Start preparing now.**

Take the time to watch this quick CQL video that describes your living options:

Receive letter from your Arc of Illinois Ligas Family Advocate. Respond by calling the number provided in the letter.

Contact your ISC to begin the planning process for services now. Reach out to DD providers to explore the ways they offer services, learn about their day programs and group homes and visit to see for yourself. Consider how you can live in your own home as independently as you might like. Apply for Medicaid and SSI if you are not already receiving. Medicaid: https://abe.illinois.gov/abe/access SSI: www.ssa.gov

PUNS Selection — You are invited to apply for DD waiver services.

Clinical Eligibility— if not already determined medical and psychological evaluation can be needed to conduct these evaluations - Your ISC will connect you to a provider

Would you like to live in an affordable apartment of your own with support? Your ISC will start the discovery process to learn about your needs for supports and present services available.

You have been found clinically eligible for funding

Begin **Personal Plan Process** (PCP) with ISC. What supports do you want and need? Help at home, job coaching, respite services, transportation, therapy, home adaptations, Community Day programs/classes, help with personal care?

Determine how and where YOU want to receive services

Confused about all of the Acronyms? Contact your Ligas Family Advocate and we will provide you with a list.

Consider the options: Home-Based Services (Support based on your needs in your apartment/ condo/house or family home) OR CILA Services
- Group Home CILA (24/7 support)
- Host Home CILA (24/7 support while living with another family in the community)
-Intermittent CILA OR Family CILA (less than 24 per day support while living in your apartment/condo/house or family home)

Receive award letter for HCBS Waiver funding

BEGIN BUILDING A LIFE YOU LOVE IN THE COMMUNITY

Don't qualify for funding through IL DHS DDD but still need support? The Illinois Life Span Program of The Arc of Illinois can help. Call us at 1-800-588-7002! We would be happy to connect you with useful information including how to find your local DHS Division of Rehabilitation Services office, Center for Independent Living, and other local and statewide resources!

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Support Waiver for **Children and Young Adults** with Developmental Disabilities



- ONLY eligible for Home Based Supports
- In the HBS Program, children ages 3 to 17 and young adults (typically between the ages of 18 and 22) who are enrolled in a Special Education program currently receive HBS funding for services up to $1,934 per month. This funding will increase to $2,088 per month effective January 1, 2026. For individuals in the Children's Support Waiver who choose to use the flexible spending amount, the monthly maximum will be $4,176. The annual maximum is $25,056.

https://www.dhs.state.il.us/page.aspx?item=176484#:~:text=In%20the%20HBS%20Program%2C%20children,increase%20effective%20January%201%2C%202026.

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Adults with Developmental Disabilities

- The Adults with Developmental Disabilities waiver provides services and individualized supports to persons 18 years of age or older with a developmental disability who are at risk of placement in an Intermediate Care Facility for persons with Intellectual or Developmental Disabilities (ICF-I/DD).



- **Home Based Services Program: funding is fixed: 3 times SSI ($994 in 2026) + additional 5% rate increase = all services/supports must fit within monthly budget ($3,132.00)**

  - Personal Support Worker (PSW)
  - Community Day Services program
  - Self-Direction Assistant (SDA); optional service ($54.59)/hour for assistance in arranging for, directing & managing PSW services, skills re: recruiting/hiring of PSWs, info on effective communication and problem-solving skills

- **Community Integrated Living Arrangement (CILA): no fixed funding amount**

  - Group Home (24/7 care –up to 8 individuals)
  - Host Home (24/7)
  - Intermittent/Hourly CILA (less than 24/7 care daily)
  - Your own apartment - can be a permanent supportive housing apartment [27]

How Can You Use DDD Adult Waiver Funding Once Eligible?

Key Programs for Adults With I/DD in IL

Intermediate Care Facility for the Developmentally Disabled (ICF/DD)

Entitlement vs. selected from a waitlist such as the PUNS

A few have wait lists

A few are small at 4 individuals, most are at 9 or higher

Licensed by IDPH (Illinois Department of Public Health), paid for by Medicaid

NOT one of the 9 Medicaid Waivers

Home & Community Based Medicaid Waiver for Adults with Developmental Disability

Medicaid Waiver

Selection from the PUNS waiting list

Home-Based or CILA options

Oversight by Division of DD, Department of Human Services

Services wherever one lives –family home, own home, condo, apartment, affordable housing

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Home Based v CILA

Core Difference: Who Manages the Services?

Home Based
Supports & Services are managed by the family and/or the individual



CILA
Supports & Services are managed by a developmental disability provider agency



Both provide services and supports to individuals with developmental and intellectual disabilities.

Both can be provided in various home environments.

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Services of the DDD waiver

Home Based & CILA

- Community Day Service (CDS) program;
  - temporary intensive staffing in CDS program – auth. & prior approval
- Supported employment (SEP) – auth. & prior approval
- Behavior Counseling (individual & Group)
- Behavior Intervention and Treatment; Psychotherapy
- Adult Day Care (60 and older) – auth & prior approval
- Support Services Team
- PT/OT/Speech Therapy – auth. & prior approval
- Adaptive Equipment – auth. & prior approval
- Assistive Technology – auth. & prior approval
- Home Accessibility & Vehicle Modifications – auth/prior approval
- Nursing

Home Based ONLY

- Self-Direction Assistance (SDA) optional
- Personal Support Worker (PSW)
- Temporary Assistance (if PSW unavailable) – auth. & prior approval
- Emergency Home Response Services; non-medical transportation; training and counseling for unpaid caregivers; out of home respite, adult day care (60 and older) – auth. & prior approval; Other Day Program – auth. & prior approval

Individual Service & Support Advocacy (ISSA) Monitoring
ISC agency – mandated service – no cost to families

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http://www.dhs.state.il.us/page.aspx?item=101181

Resources While You Wait

- Medicaid Waivers in Illinois - https://hfs.illinois.gov/medicalclients/hcbs.html
- Respite - DHS Respite Provider List by County
- Support Groups - IPADD (IL Parents of Adults with Dev. Disabilities), CU Able, CU Autism Network, Down Syndrome Network
- Partners in School Supports - Family Matters, IL Guardianship & Advocacy
- Division of Rehabilitation Services - Home Services
- Autism-specific - TAP UIUC
- Centers for Independent Living – PACE
- Behavior Disorders - Community and Residential Services Authority
- Assistive Technology - Illinois Assistive Technology Program (IATP)
- Siblings - Supporting Illinois Brothers & Sisters (SIBS)
- Parental & Family Counseling
- Social & Recreational - Special Olympics, Best Buddies,

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Department of Rehabilitation Services (DRS) Home Services Program (HSP)

- Personal Assistant (PA)
- Homemaker Services
- Maintenance Home Health
- Electronic Home Response
- Home Delivered Meals
- Adult Day Care
- Assistive Equipment
- Environmental Modification
- Respite Services

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Department of Rehabilitation Services Vocational Rehab (VR)

- 1. What is the Vocational Rehabilitation (VR) Program?

Every state gets money from the federal government to help people with disabilities who want to get or keep a job. The Division of Rehabilitation Services (DRS) uses this money to run the VR program to help people get or keep a job.

- 2. What is a "Person with a Disability?"

This is someone who has a physical or a mental disability that makes it hard for a person to work and the person needs help from DRS to get or keep a job.

- 3. Who Can Qualify for VR Services?

You can qualify if you have a disability and need services from DRS to get or keep a job.

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DRS continued…

What is a Ticket to Work?

If you get Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), you may get a Ticket to Work from Social Security. You should talk to a DRS counselor about why the ticket should be given to DRS.

How Do You Apply?

You need to call a DRS office where someone will help you apply. Your records from doctors, schools, past jobs or other programs will help DRS. When this is done, a counselor will look at all the information to see if you qualify.

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Thank you!

Ruth Aguilar

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Please complete our survey!

This greatly helps the funding for our program.
Scan the QR code below:

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