



Ligas Family Advocate Program

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Presented by:

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Families Helping Families!

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Human Services*

Programs of The Arc of Illinois

Family Support Network of Illinois

Ligas Family Advocate Program

Illinois Lifespan – Information & Resources

Family to Family Health Information Center

Family Transition Project

Consumer Stipend Program

Assistive Technology Program

Training Department

Goals for today:

- Understand PUNS processes for children
- Learn how to connect with your Independent Service Coordination Agency (ISC)
- Learn about Children Support Waiver
- Describe services and supports provided by the Family Support Network and Ligas Family Advocate Program
- Recognize keys Supports Available
- Begin planning and preparation for service and supports
- Additional Resources



Some 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

Start with Key Questions:

- Who is part of my child's 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 child's preferences? Do they prefer activity, engagement, social time, or do they value more quiet environments?
- How does your child make decisions? What support is needed?
- What type of support is needed in daily activities?
- Does your child have chronic medical needs that will require support into adulthood?
- What are your child's goals/hopes around employment and independent living for the future?

Finding Your Way



Ligas Family Advocate Program

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 HCBS. 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.



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

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

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

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

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



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!

PUNS: What is it?

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

What is PUNS?

PUNS is the state **database** that registers children (2.5 years) and adults who want or need Developmental Disability Waiver services (i.e. Community Integrated Living Arrangements, Home Based Supports, Child Group Homes) funded by the Illinois Department of Human Services/Division of Developmental Disabilities.

As funding is available, individuals are selected from PUNS and invited to apply for DD Waiver services. The PUNS categories, criteria, forms, and instructions for completing the form have recently been revised and now reflect a more streamlined approach to the process. These changes were necessary to reduce confusion, increase transparency, and make the selection process more predictable for individuals with developmental disabilities and their families.

What is a ISC? Gateway to DD Services

INDEPENDENT SERVICE COORDINATION AGENCIES (ISC)

There are 8 Independent Service Coordination (ISC) agencies in the State of Illinois that are contracted with the Division of Developmental Disabilities. They are the doorway or starting point for individuals with developmental disabilities seeking or planning for services.

Who is my Independent Service Coordination agency?

www.dhs.state.il.us – DHS Office Locator – select Developmental Disability Services – enter County of residence (for Cook County also enter zip code)

Eligibility based on Diagnosis

Intellectual Disability: (IQ of 70 and below), evidenced prior to age 18


Developmental Disabilities: are a group of conditions due to an impairment in physical, learning, language, or behavioral areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.

Related Condition:

Cerebral Palsy, Epilepsy, Autism Spectrum disorder, Traumatic Brain Injury or Prader-Willi that is found to be closely related to an Intellectual Disability, having manifested prior to the age of 22

PUNS Categories: Seeking Services

The **Seeking Services** category is for individuals with a developmental disability who currently need or want supports.



Children or Adults enrolling in PUNS can be placed directly into the Seeking Services category, given that they meet the criteria described in the description of Seeking Services above. PUNS selections are only made from the Seeking Services category, as funding is available.

PUNS Categories: Planning

The **Planning for Services** category is for people who do not currently want or need supports but may in the future. It is helpful to know about these situations even though the individual/ family is not anticipating the need for imminent services. The Planning for Services category is for individuals who are not currently seeking services but will be seeking if something happens to the caregiver (e.g. caregiver becomes ill or passes away) or other family circumstances change.

Note: Time spent in the “Planning” category does not move an individual closer to funding. The time on the PUNS list begins being accumulated toward selection only when an individual is in the “Seeking” Category

When should an individual with I/DD place their name on the PUNS list?

Individuals and families are encouraged to place their names on the PUNS lists as soon as possible. As early as 2 ½ years old.

The “wait time” for services does not start until the age of 18

Placing your name on the list as soon as possible, even if well before the age of 18, allows the state to plan for the needs of individuals who will qualify for support in the future

Contact your ISC to be placed on the PUNS list

For the second time in 13 years, individuals were selected for the Children’s Waiver in 2023. They were selected from the **Seeking category**.

Signing Up for PUNS

Individuals who want to be on PUNS should contact the Independent Service Coordination (ISC) agency in their area. You can locate your ISC agency by:

Calling Division of Developmental Disabilities Hotline at 1-888-DD-PLANS and 1-866-376-8446 (TTY) during business hours. When prompted by the recording, type in your ZIP Code and you will be connected with your local ISC agency.

Accessing the [DHS Office Locator](#).

How to Locate your ISC?

IDHS Illinois Department of Human Services
 JB Pritzker, Governor • Grace B. Hou, Secretary

Customers Providers About News Contact

Search 

Office Locator

Due to the Coronavirus situation, IDHS has temporarily closed some Family Community Resource Centers and other offices. For Cash, SNAP & Medical Assistance, please visit ABE.Illinois.gov, call 1-833-2-FIND-HELP (1-833-234-6343), or call your FCRC's [Urgent Call Team](#).

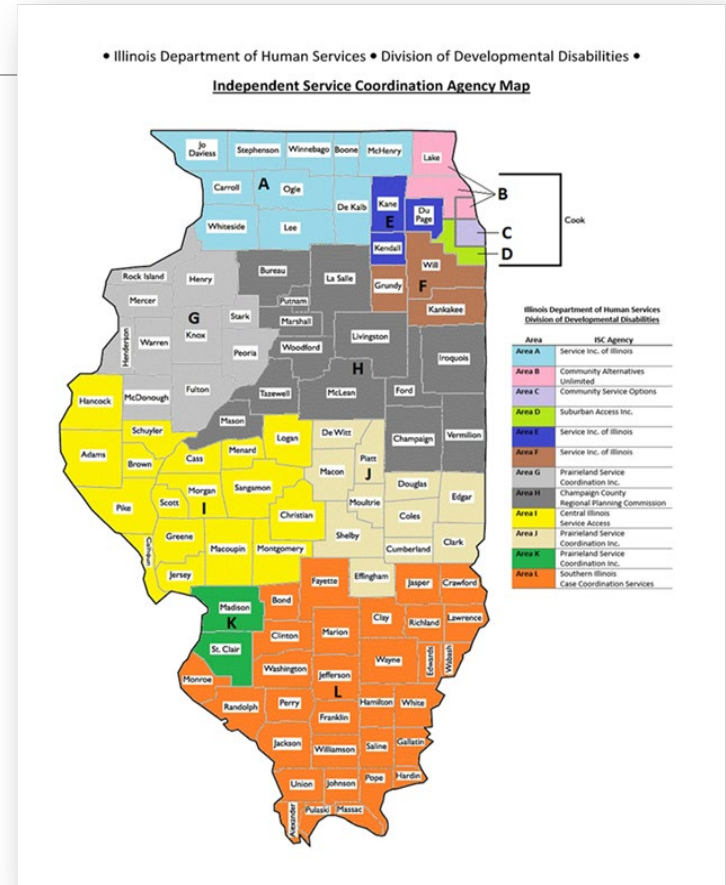
Search for a DHS Office or Service Provider by selecting your county, and, for Cook County, your ZIP Code:

- 1 Select an Office Type:
- 2 Select your County:
- 3

Office Types

- **Administrative Office** - management of DHS services, programs and facilities
- **Child Care Resource & Referral** - information for parents looking for quality child care; and for child care providers
- **Comprehensive Community-Based Youth Services** - provides crisis assistance to youth, 11 to 17 years of age, who have run away from home or have been kicked out of their homes.
- **Developmental Disability Services** - provide information, assessment & referral regarding developmental disabilities.
- **Domestic Violence Victim Services** - provide free and confidential services to help domestic violence victims attain safety and self sufficiency, and to

[https://www.dhs.state.il.us/page.aspx?module=12&officetype=
=&county=](https://www.dhs.state.il.us/page.aspx?module=12&officetype=&county=)



Early
Notification

&

PUNS
Selection

Ensure Medicaid is in place and remains in place

Gather evaluation records from mid-late teen years

Connect with your Independent Service Coordination Agency (ISC)

Become familiar with local Developmental Disability providers

Participate in trainings that are of interest



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Medicaid Home-Based Waiver

Intellectual / Developmental Disabilities

Children's Home Based Services – at a glance

What? Medicaid Waiver

Why? To get services in the community

How? Register on the PUNS database, receive selection letter, begin Pre-Admission Screening to show eligibility*

When? Children & Young Adult are considered between the ages of 3 and 21 (must switch to adult waiver by 22nd birthday)

Who? Anyone with a diagnosis of intellectual and or Developmental Disabilities or related conditions (e.g., Down Syndrome, Cerebral Palsy, Epilepsy, Autism)

*Note: A person holding a PUNS Selection Letter has the option to begin Pre-Admission Screening (PAS) as soon as possible.
Additionally, DHS recently announced that the letters do not have an expiration date.

Benefits

Home Based Services

- **Personal Support Worker (PSW)**

- If individual receiving services is under the age of 18 – parent/legally responsible caregiver is not eligible to be the PSW
 - However, after the age of 18, a parent/guardian can serve as PSW
- Self-Direction Assistance
- Adaptive Equipment
- Assistive Technology
- Home Accessibility Modifications
- Vehicle Modification
- Temporary Assistance
- Behavior Intervention and Treatment
- Training and Counseling Services for Unpaid Caregivers
- Children's Residential Services is NOT included.

Understand key components of Home Based Services

Individual - person receiving waiver funding and support services

Personal Support Worker - person hired by the person/family to provide services and supports. (agency based PSW may be hired too)

Employer of Record - person identified to monitor/manage PSW and keep records of time, training, and services provided

ACES\$ -fiscal agent for the State of Illinois, manages payroll and provides paychecks to PSW

Self Direction Assistance -assists with record keeping and submission of timesheets to ACES\$

Independent Service Coordination –gateway to DD services, assists with difficulties, develops a personal plan, addresses crisis needs, the ISC is your first point of contact for most questions about DD.



Funding

Based on calendar year 2024

It is 2x SSI

- $\$943 \times 2 = \$1,886$ per month

Flexible Spending (Up to 4x SSI in a month)

Annual budget based on 2x SSI per month
(Currently \$22,632)

Two key programs for adults with I/DD in IL

ICF/DD PROGRAM

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

HOME & COMMUNITY BASED MEDICAID WAIVER

Selection from the PUNS waiting list

CILA (Community Integrated Living Arrangement) group homes capped at 8

CILA Licensed by DHS

Paid for with Medicaid waiver funding

Home-Based or CILA options

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

Home Based v CILA

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

Both can be provided in various home environments

CORE DIFFERENCE: Who MANAGES the services?

1. Home-based Supports and Services: Family and Individual manage the services

2. CILA: Developmental Disability Provider Agency manages the services

Home Based Services Program: (funding is fixed =3 times SSI (943.00 in 2024); all services/supports must fit within monthly budget (\$2,829.00)

- Personal Support Worker (PSW)
- Community Day Services program
- SDA -Self-Direction Assistant; 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

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 apt.

How can you use DDD Adult waiver funding once eligible?

Home Based Services Program

Personal Support Workers (including Parent/Guardian)
MUST:

Be at least 18 years old

Can be a parent or guardian for child older than 18

Communicate well with individual and family

Complete all required paperwork accurately

Understand waiver rules on abuse and neglect, human rights, confidentiality, handling of emergencies, and allowable behavior management methods

Show that they can provide services to you safely as written in your Personal Plan

Pass required background checks (*Criminal background, Healthcare Worker Registry, Sex Offender Registry, HFS OIG Sanctions List, and DCFS State Central Registry*)

HBS back-up plan

HOME BASED SUPPORTS: PSW

Monthly FIXED amount:
\$1886 Children

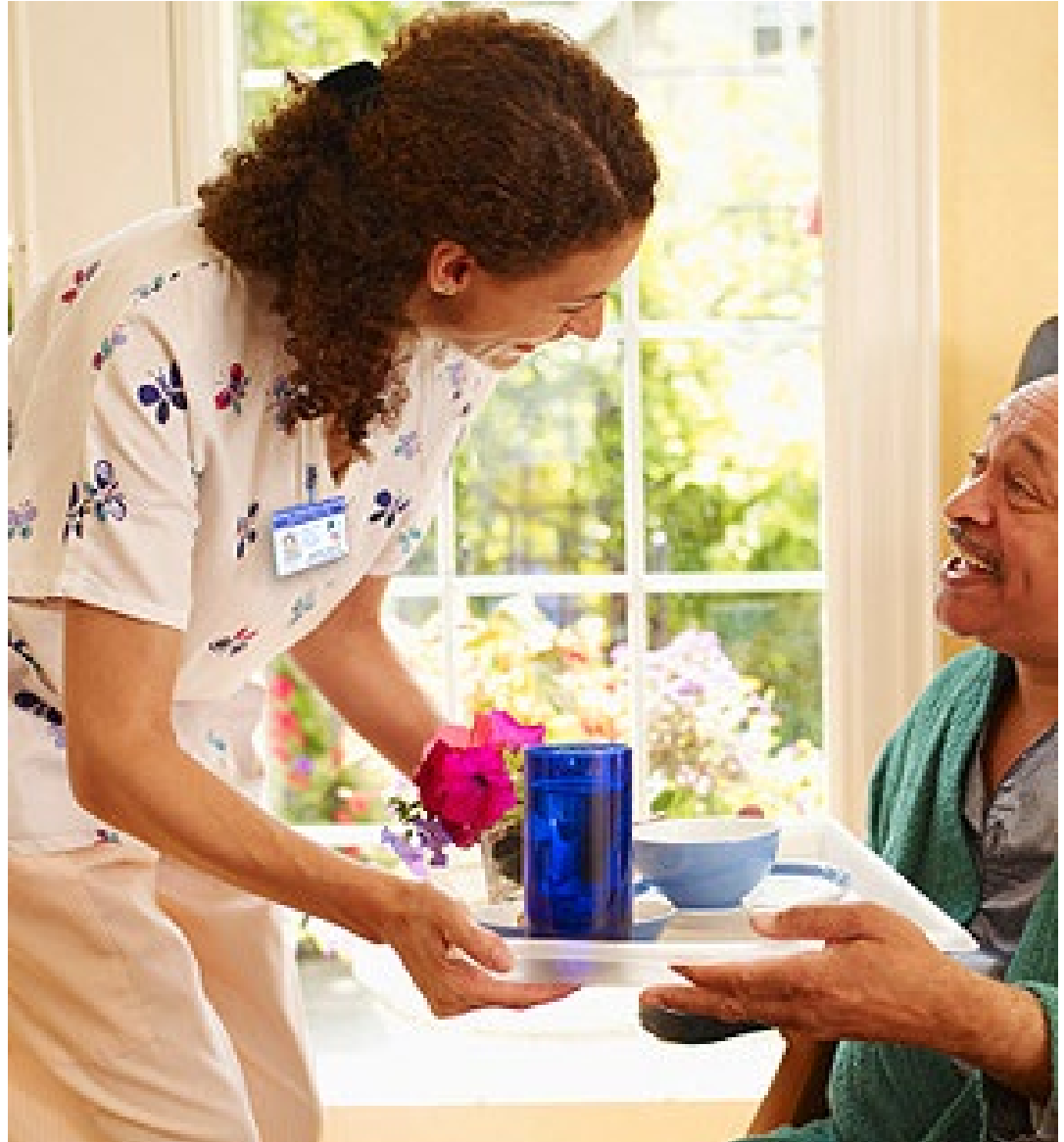
\$2829 Adults

PSW

- Mom/Dad (18 older)
- Friend
- Neighbor
- Adult sibling
- Extended Family member

NOTE: Pass background check

18 years or older



HOME BASED SUPPORTS: PSW New EVV Feature

Please contact Program Director Tasha Whiteside at Aces\$ to get more detailed information on EVV, trainings and EVV forms

Tasha Whiteside

Aces\$ Illinois Program Director

twhiteside@mycil.org

(708) 532-3631

Electronic Visit Verification-Federal mandate that impacts all Medicaid PSWs. This system will electronically verify via CareAttend App (mobile) or IVR (landline) that the PSW has delivered services as they were billed.

Aces\$ Financial Management Services are providing EVV updates and free online trainings

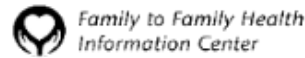
If you would like to view this information please visit their website [ACES\\$ Financial Management Services - Illinois | MyCIL](#)

Where can I use waiver services?



- In the house where I live with my family
- In a house where I live on my own or with a roommate
- In a condo where I live on my own or with a roommate
- In a home with up to 7 other people (group home CILA)
- In supportive housing
- **ONLY** one waiver at a time. (DRS, DDD, DSCC, etc.)

The Family-to-Family Health Information Center (F2FHIC) / Illinois Family Voices



We are part of a national network of F2FHICs, program of The Arc of Illinois and the State Affiliate of Family Voices, a national family-led organization of families and friends of children/youth with disabilities and chronic medical conditions.

Provide information, education and training

Assist families with children up to age 21 with any disability/chronic illness & professionals who serve them with one-to-one support in person, via phone or Zoom

Offer trainings on topics of interest: In 2023 webinars are jointly offered with Illinois Life Span (ILS)

[2022 Monthly F2F Webinars](#)

[2023 Monthly F2F Webinars](#)

Offer an annual Healthcare conference -[2022 Health Care Conference](#)

Present at statewide conferences and as requested

Use our national F2FHIC list serve/Family Voices Affiliate list serve to ask for peer-to-peer connections, request or share information

Common resources offered -federal

Supplemental Security income (SSI)

Social Security Disability Insurance (SSDI)

Medicare Part D Prescription cost help –Extra Help

Supplemental Nutrition Assistance Program (SNAP)

Resources for medically and/or behaviorally complex children/youth

Resources for Families with Medically Complex Children

- [The Circle of Care Guidebook for Caregivers of Children with Rare And/Or Serious Illnesses](#)
- [Kids' Waivers ; Complex Child Magazine ; Medically Fragile Technology Dependent Waiver Family Group on Facebook](#)
- [Medically Fragile Technology Dependent Waiver Website](#) and Email: mftdwaiver@gmail.com

Resources for Families with Behaviorally Complex Children

[Mental Health Resources in Illinois](#)

[Pathways to Success, A New State Program for Medicaid Enrolled Children/Teens Under Age 21 with Complex Behavioral Health Needs](#)

HFS Family Support and Specialized Family Support programs:

<https://www2.illinois.gov/hfs/MedicalProviders/behavioral/Pages/icg.aspx>

CRSA Brochure – [English](#) & [Spanish](#) [CRSA PowerPoint](#)

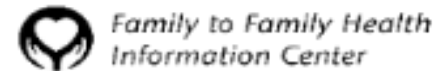


Resources and Grants

- Grant opportunities
- <https://www.illinoislifespan.org/wp-content/uploads/2023/07/Grants-Database-2023-Final.pdf>
- Autism resources
- <https://www.autismheroproject.org/resources>
- Cornerstone Foundation
- <https://www.charlestillman.org/index.aspx>

The Family to Family Health Information Center (F2FHIC)/Illinois Family Voices Affiliate, a program of The Arc of Illinois & the State Affiliate of Family Voices (www.familyvoices.org), a national organization. Our mission is to help families of children up to age 21 with any disability/chronic illness and the professionals who serve them, with resources to enable informed decision making.

- **Susan Agrawal, PhD, Director**
- Family-to-Family Health Information Center at The Arc of Illinois
- (pronouns: she, her, hers)
- **A** 9980 190th Street, Suite C | Mokena, IL 60448
- **T** 815.464.1832 ext 1017 or 866.931.1110
- **C** 779.254.9158 **F** 815.464.5292
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