

*IL Medicaid HCBS Waiver for adults
with I/DD – Know Your Options -
NSSEO*



Families Helping Families!

Programs of The Arc of Illinois

- Illinois Lifespan – Information & Resources
- Family to Family Health Information Center
- Family Support Network of Illinois
- Ligas Family Advocate Program
- Family Transition Project
- Consumer Stipend Program
- Assistive Technology Program
- Training Department

www.thearcofil.org

Illinois Lifespan

- Provides information and resources across the life-span for individuals with intellectual and/or developmental disabilities and their families and friends
- Information and resources include information on advocacy, supports and services for individuals with intellectual and developmental disabilities of all ages, their family members and other stakeholders across the state
- Offers assistance via website and toll-free help line:

Director: Deb Fornoff, www.thearcofil.org/illinoislifespan

illinoislifespan@thearcofil.org

800-588-7002; 815-464-1832 x 1028

Family to Family Health Information Center

Information and resources for families of children under age 22

- The Illinois affiliate of Family Voices of Illinois
- Information offered for families of children and youth with any disability, special needs an/or chronic illness.
- Focus is on healthcare and benefits issues

Faye Manaster, Director –[the arcofil.org/familytofamily](http://thearcofil.org/familytofamily)
815-464-8247 x1029

Toll free: 866-931-1110 (English); 800-588-7002 (Spanish)

Family Support Network

- Offers support to individuals with intellectual and/or developmental disabilities and their families
- Assistance related to individual funding, services and community resources that meet individual needs and are key to independent living
- Individualized assistance
- Problem solving

Shirley Perez, Director
815-464-1832 x1032

The Ligas 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
- 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

Shirley Perez, Director, shirley@thearcofil.org; 815-464-1832 x1032

Mary Dixon, Advocate, mary@thearcofil.org; 815-464-1032 x1017

Megan Mutti, Advocate, megan@thearcofil.org; 815-464-1832 x1022

https://www.youtube.com/watch?v=fwht_cU0pj0

Family Transition Project

Support for individuals and families who want to explore the possibilities of community living for those currently living in large institutions

Katherine, Hamann, Director

815-464-1832 x1019

Consumer Stipend Program

Provides financial assistance so that individuals or their family members can attend a conference of their choice – provided the conference is related to intellectual and developmental disability issues

For questions, please contact Karin at Karin@thearcofil.org
<https://www.thearcofil.org/consumer-involvement-program-consumer-stipend-funds/>

Assistive Technology Program (AT)

- ✓ Funds the purchase of assistive technology for individuals with intellectual and developmental disabilities who have an evaluation from a qualified provider and do not qualify for AT through Medicaid, Medicare or private insurance

Janet Donahue, Director

815-464-1832 x 1012

Training Department

- Training in advocacy
- Offering educational conferences and trainings for self-advocates, family members and professionals

Janet Donahue, Director
815-464-1832 x 1012

Goals for today:

- Share a **basic introduction** to Illinois' Home and Community Based Waiver for Adults with Developmental Disabilities (DD) Medicaid Waiver
- Provide a status update on the Ligas Consent Decree
- Identify services offered within the waiver for adults with DD
- Offer a comparison of the DRS and DDD waivers
- Share examples of creative ways to use waiver funding to enhance independence and live a life like any other with supports

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 designed for individuals with similar needs and offers a different set of services
- For individuals with developmental disabilities, Illinois offers:
 - 1. Children and Young Adults with DD–Support Waiver (DHS-DDD) ages 3-21
 - 2. Children and Young Adults with DD Residential Waiver (DHS-DDD) ages 3-21
 - 3. Adults with Developmental Disabilities (DHS-DDD) age 18 or older

Illinois HCBS waivers continued

- 4. People who are Medically Fragile, Technology Dependent (U of I –DSCC) –under 21 at time of application
- 5. Persons with Disabilities (DHS –DRS) (under age 60 & at risk of nursing home placement)
- 6. Persons with Brain Injury (DHS-DRS) any age + medical services via MCO
- 7. Persons with HIV or AIDS (DHS –DRS) any age + medical services via MCO
- 8. Persons who are Elderly (DoA) -60 and older + medical services via MCO
- 9. Supportive Living (HFS) (ages 22-65 with physical disability or 65 and older)

See: <https://www.dhs.state.il.us/page.aspx?item=56036>

Two 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, paid for by Medicaid

Home & Community Based Medicaid Waiver

Selection from the PUNS waiting list

CILA group homes capped at 8

Licensed by DHS

Paid for with Medicaid waiver funding

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

Some key acronyms:

- CILA: Community Integrated Living Arrangement
- DD: Developmental Disabilities
- DT: Developmental Training (Community Day Programs)
- PAS: Pre-admission screening
- HBS: Home Based Services
- ICF-DD: Intermediate Care Facility for individuals with DD
- ISC: Individual Service Coordination
- DHS: Department of Human Services
 - DDD: Division of Developmental Disabilities
 - DRS: Division of Rehabilitative Services

HCBS for adults with DD are accessed through the PUNS

- PUNS is a database that registers individuals who want or need Developmental Disability Waiver services (i.e. Community Integrated Living Arrangements, Home Based Supports funded by the Illinois Department of Human Services/Division of Developmental Disabilities.
- See: <https://www.dhs.state.il.us/page.aspx?item=41131>

How to get on the PUNS

- Arrange a date for a PUNS interview with your local Independent Service Coordination (ISC) Agency
- See: <https://www.dhs.state.il.us/page.aspx?item=85196>
- The ISC is the “gateway” to PUNS and funding for DD waiver services. Questions about the individual and his/her needs are a part of the PUNS enrollment process.
- How to find your local ISC: contact the DHS Customer Help line: 800-843-6154 or use the DHS Office Locator: <https://www.dhs.state.il.us/page.aspx?module=12> (choose “Developmental Disability Services” as the Office Type along with your county).

PUNS Categories –as of 2018

- **Seeking Services** – For individuals who currently need or desire supports
- **Planning for Services** –for people who do not currently want or need supports but may in the future)

PUNS selections are based on a person’s cumulative length of time in the Seeking Services Category at age 18.

See: <https://www.dhs.state.il.us/page.aspx?item=68933>

“**Crisis**” is not a category of PUNS, but if you are in crisis contact your ISC; see: <https://www.dhs.state.il.us/page.aspx?item=85187>

DHS will give you an [estimate](#) of when you or your loved one will be selected from the PUNS:

EMAIL DHS at:

DHS.DDD.PUNS@Illinois.gov

Include individual's name, Date of birth, service coordination agency, and address



The Ligas Consent Decree

- Ligas v. Eagleson (originally Ligas v. Maram) is a lawsuit filed in 2005 by 9 people with developmental disabilities (plaintiffs) who resided in large private State-funded facilities (ICF-DDs) or who were likely to be placed in such facilities if they did not get community services. A consent decree was approved on June 15, 2011 See:
<https://www.dhs.state.il.us/page.aspx?item=66987>
- * Note: people who are on the PUNS list are class members

Results of the consent decree

- Over 8500 class members have received community services through June, 2019.
- Over a six year period any of the approximately 6000 ICF-DD residents who desired community placement received individualized, independent evaluation and the opportunity to live in the community with appropriate services
- All ICF-DD residents happy with their current placement were not part of the class and were not required to move. The Consent decree requires that resources necessary to meet the needs of those who chose to continue to reside in ICF-DDs are available.
- Over a six year period over 3000 people with developmental disabilities who were living at home without services were given community services
- People in crisis were to be served expeditiously and not count as part of the 3000 people picked for community services. There was no cap on the number of people served through crisis.

What is left with the Consent Decree?

- The State agreed that, after six years, it must provide community services to class members at a “reasonable pace” over a three year period. Reasonable pace means:
- The State will serve a minimum of 630 new people from the PUNS list each year
- The State will serve people in crisis expeditiously and without a cap, and the people in crisis will not count towards the 630 new people
- The State will allow moving within the waiver (from CILA to Home-Based and vice-versa) and not count people moving within the waiver towards the 630 minimum
- People in ICF-DDs can become Class Members and get on the PUNS list
- **With this agreed Reasonable Pace Proposal, the goal is that by FY2025, no person 18 or older will wait on the PUNS in the “Seeking Services” category for over 60 months** (i.e. from age 18 to 23 with only a one year gap between the end of the High School Transition Program that ends at age 22 and PUNS selection at age 23). Time on the PUNS in the Planning for Services category does not count toward a PUNS selection.

What happens after the PUNS selection? (an invitation to apply for funding)

Your ISC will assess eligibility for waiver funding (pre-admission screening or PAS)

A person is eligible in one of two ways:

1. Intellectual disability: must have an IQ of 70 or below before age 18

1. Have a related condition (before age 22), likely to continue indefinitely, AND have significant life skill deficits in three or more of the following areas of major life activities:
 - Self care
 - Language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living

How can you use DDD waiver funding once eligible?

- Home-based Services Program: (funding is fixed =3 times SSI) 2020 = \$2349.00/monthly; all services must fit within monthly budget
 - Personal Support Worker (PSW)
 - Community Day Services program
 - SDA -Self-Direction Assistant; optional service (\$46.61/hour for assistance in arranging for, directing & managing PSW services, skills re: recruiting/hiring of PSWs, info on effective communication and problem solving skills)

OR

- CILA –no fixed funding amount
 - Group Home (24/7 care –up to 8 individuals)
 - Host Home (24/7)
 - Intermittent/In home-family CILA (less than 24/7 care daily)
 - House you live in with your family (family CILA)
 - Your own apartment - can be a permanent supportive housing apt.

Home-Based Services Program

Personal Support Workers MUST:

- Be at least 18 years old
- 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*)
- See our webinar on the Home-Based Services Program from July, 2019 at:
<https://www.thearcofil.org/monthly-webinars/>

Services of the DDD waiver

HOME BASED SERVICES PROGRAM –Fixed funding

- Individualized Service and Support Advocacy -ISC
- Supported employment (SEP) –auth. & prior approval
- Community Day Service (CDS) program; temporary intensive staffing in CDS program –auth. & prior approval
- Behavior Counseling (individual & Group)
- Behavior Intervention and Treatment; Psychotherapy
- Adult day care if 60 or older or medically fragile
- 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
- Self-Direction Assistance (SDA)
- Personal Support – Personal Support Worker (PSW)
- Temporary Assistance (if PSW unavailable) –prior auth. & approval
- Nursing; 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

COMMUNITY INTEGRATED LIVING ARRANGEMENT

- Individualized Service and Support Advocacy –ISC
- Residential Habilitation
- Community Day (CDS) program
- Temporary intensive staffing for CDS –auth. & prior approval
- Supported Employment (SEP) –auth. & prior approval
- Adult Day Care (60 and older) –auth. & prior approval
- Other Day Program (formerly sheltered workshop) –auth. & prior approval
- PT/OT/Speech therapy –auth. & prior approval
- Behavioral counseling (individual & group)
- Behavior Intervention and Treatment
- Psychotherapy
- Adaptive Equipment –auth. & prior approval
- Home Accessibility Modifications –auth & prior approval
- Vehicle Modification (as part of the transportation component of the residential rate)

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

For example –SDA services

- Helps individual and family arrange, direct and manage support services in the Home-Based Services (HBS) Program
- Provides education and practical training to help individual and family gain the skills needed to independently manage support services OR an individual can retain an SDA continuously
- Provides education and information to individual and family to ensure they understand their role and responsibilities with HBS
- Must be a Qualified Intellectual Disability Professional (QIDP)
- Must not duplicate the role of the Independent Service Coordination Agency (ISC)
- Current hourly cost to be paid from monthly HBS allotment for an SDA is \$46.61

For example:

Community Day Service Program

- DHS funded programs facilitated by Developmental Disability providers
- Often consist of recreation activities, classes, social activities
- Designed to help with skill development or retention in self-help/adaptive skills, growth in independent living skills, ability to utilize personal choices, and maintain maximum independent living skills

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

What is supportive housing?

- Supportive Housing is affordable rental housing for people with very low incomes and disabilities (or multiple barriers to community living) PLUS the social/health services (including behavioral and physical health) that they want and need to succeed in the community
- Not intended for every population that needs access to affordable housing. The threshold of need for supportive housing is higher than the simple need for affordable housing. <https://www.dhs.state.il.us/page.aspx?item=87600>
- Tenants have leases
- Tenants have funding for supportive services (Intermittent CILA services or Home-Based Support Services)
- Tenant pays a portion of the rent with SSI or SSDI and/or earned income; subsidy covers the rest

Webinar:

<http://attendeegotowebinar.com/recording/631150867397821707> ;

Power Point slides: http://www.thearcofil.org/wp-content/uploads/2020/08/Where-do-I-want-to-live.final_pdf

Differences between the DRS and DDD waivers

DRS Medicaid Waiver

Home Services Program –union membership that offers health care for personal assistants (PA); union sets PA hourly wage

Eligibility: under age 60 with severe disability lasting at least 12 months or life, imminent risk of health facility placement

Services include:

- electronic home-response system
- home-delivered meals; adult day care; assistive equipment; environmental modification; respite, homemaker, **personal assistant/in-home service –PA hours based on determination of need (DON) score; nursing/intermittent, nursing, therapies (PT/OT/Speech); Home Health Aide, Specialized Medical Equipment; Supported Employment**

Specialized Services: 12 week vocational training (blind/visually impaired); employment assistance (deaf/hard of hearing); bilingual staff assistance (Latinx), 2-4 year Illinois state college financial assistance

Note: No Community Day Services programming

DDD Medicaid Waiver

Home-Based Services Program –no healthcare coverage for Personal Support Worker; you set the hourly wage of personal support worker(s)

Eligibility –Intellectual disability prior to age 18 or related condition prior to age 22 with substantial impairment in 3 of 6 areas of major life activities

—**fixed monthly funding at 3 times SSI**

(if support care needs increase must pay from support from fixed monthly amount – **no Determination of Need Score**)

CILA offers residential group home living option

SDA available to assist with personal support worker(s)

Community Day Program is among the services offered;

No financial assistance for 2 -4 year state college

A life with DDD waiver supports

Tony

Age 29

A young
man living
with
autism



Tony, age 29, living with autism, a developmental disability

- Tony and his family preferred for him to stay in his family home, and chose the Home Based Services Program, Tony has \$2349.00/month to plan services and address needs that are documented in his Personal Plan.
- He has three PSWs that are paid at different rates. One is paid \$13.50. The other two are paid \$12.00/hour. The days are consistent. The hours can vary upon Tony's need and PSW's schedule. His PSW's assist him in planning his time, self-care needs, physical fitness, and community involvement. They also provide needed nonmedical transportation.
- Tony attends two different Community Day Program two days each per week. His participation is funded through his Home Based Services Program Waiver funding. He travels to these programs using both municipal and paratransit transportation. He is very active with special recreation programming. His favorite Special Olympics sport is swimming.
- His mother is the "employer of record" and works with ACES\$ to provide payroll services to Tony's PSW's.
- They use a Self-Direction Assistant (SDA) 3 hours per month at a rate of \$46.61 per hour. The SDA assists the family in managing paperwork, reviewing monthly budgets, as well as keeping the family abreast of resources. The SDA is a local community DD provider that the family has used for 5+ years.

The Coppels



KC, age 42, living with autism, developmental disability

- KC lives in a CILA group home. The family feels he needs support that a CILA group home can provide. The home has 6 adult males. One staff person is there at all times, other than 9 AM to 3 PM during the week. All the men are pretty independent. There are times residents are at home without staff present. For example, if staff is driving one resident, the other men stay home and do not have to travel in the van with the staff. Everyone has their own bedroom.
- KC works at a Senior Residential Facility 3 days a week. The other 2 days, he participates in a Day Program run by the organization that oversees his residential care. His monthly income includes \$60 of the monthly Social Security deposit that his CILA group home provider gets every month, earnings from his community job and Day Program, gifts and support by his parents.
- KC accesses the community regularly on his own. He is near restaurants and shopping. He also is a member of a fitness club along with another resident and their Q.
- Although his DD provider could assist, his parents currently take KC to all doctor appointments.
- Socially, KC is very involved with a local Special Recreation organization and Special Olympics, playing a variety of sports, attending many clubs and traveling on short and long trips with them. Last fall, they went to Charlotte, NC. Staff drive him to most of these programs. If they are not available, then his family drives. He gets together with his girlfriend regularly, with support from either her parents or his.

Zach, age 42, living with autism, developmental disability

- Zach received Adult Home-Based Waiver Program funding 7 years ago at which time he moved into his own townhome. Prior to that, he lived in a Community Living Facility (CLF) for 9 years. Zach and his family self-direct his waiver funding through the Adult Home-based Services Program. In 2020 he has \$2349/monthly to address his needs, which are documented in his Person-Centered Plan.
- The family has an SDA (Self-Directed Plan) for 3.75 hours per month at a rate of \$46.61 hr. through his provider. Zach's dad is the Employer of Record and his mom is his only Personal Support Worker at the present time. Payroll services come from ACES\$.
- As PSW, Zach and his mom go grocery shopping, see medical practitioners, plan and cook meals, purchase clothing and other needed items, & work on additional goals to help him become as independent as possible.
- Zach works as a bagger, first at Dominick's for 13 years and now Jewel for 7 years. He uses Metra to get back and forth to work, using the Ride Free Transit Card. His schedule varies from week to week, so monitoring his income is essential to avoid him becoming ineligible for Medicaid supports and SSDI.
- Zach is active in Special Olympics and Special Recreation programs. When he comes to his parents' home for sports or visits, he frequently uses Pace's paratransit system.
- Socially, Zach has many friends like him who also live in their own places in his town and nearby communities. They access many community services by foot, by bus and train. Zach and his friends are integral parts of their communities.

What One Family Learned as a Result of Receiving Funding –thank you Micki Coppel!

- Include the family member who will be receiving services in the decision-making process. Find out what is important to them. Their priorities may not always match with those of their parents.
- Think not only of short-term goals, but also long-term needs.
- As worrisome as it is to have one's loved one move out of their family home (if that is the choice), there are positives that help make that decision easier:
 - It gives the family member time to develop relationships with those they will have to depend on when the parents/siblings are no longer able to provide that support.
 - It gives the family time to help their loved one learn how to advocate for him or herself, when possible.
 - It gives the family time to provide input as the agency and staff get to know their loved one, their desires, challenges, etc.
 - It gives the family time to help those supporting the family member understand family values.
- There will be bumps in the road. Appreciate that additional team members are now available to navigate those “bumps”.
- Anticipate that the family member will thrive, excel in ways one would never expect and love the new independence gained.
- TAKE A DEEP BREATH AND GET STARTED!

Read core information, apply for Medicaid and SSI at age 18

- Illinois Consumer Handbook for Home-Based Services
 - http://www.dhs.state.il.us/page.aspx?item=101181#a_toc29
- ABE Illinois: Assistance with healthcare, food, cash assistance
 - Abe.Illinois.gov
- Social Security
 - www.ssa.gov/applyonline/

Contact Information

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