

*Welcome
To The Ligas Family Advocate
Program!*



Families Helping Families!

*The Arc Ligas Family Advocate Program is funded by the Illinois
Department of Human Services*

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

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
www.familytofamily@htearcofil.org; 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

www.thearcofil.org/family support

familysupport@thearcofil.org

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

www.thearcofil.org/ligasfamilyadvocates

ligasfamilyadvocates@thearcofil.org

815-464-1832 x1032

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
thearcofil.org/familytransition
family transition@thearcofil.org
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

Lee Ann McQuen, Director

www.thearcofil.org/stipend

stipend@thearcofil.org

815-464-1832 x 1024

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

www.thearcofil.org/assistivetech

assistivetech@thearcofil.org

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

www.thearcofil.org/training

training@htearcofil.org

815-464-1832 x 1012

Goals for today:

- Share a **basic introduction** to the Adults with DD Medicaid Waiver, both the Home & Community Based Services Program (a program of self-directed services) and provider directed community integrated living arrangements (CILAs)
- Provide a status update on the Ligas Consent Decree
- Identify services offered within the waiver
- 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

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

PUNS Categories

- **Seeking Services** – Individuals selected by length of time on the PUNS list, where the clock for length of time begins calculating either from initial placement (if after the 18th birthday) or from the 18th birthday
- **Planning for Services-** under age 18
- **“Crisis”** is not a category of PUNS, but if you are in crisis (imminent risk of abuse, neglect or homelessness) contact your ISC

August, 2019 PUNS Selection by Age

<https://www.dhs.state.il.us/page.aspx?item=118739>

Age of Applicant	Number Selected	Percent of Total
18-21 years of age	59	5%
22-24 years of age	81	6%
25-29 years of age	525	42%
30-39 years of age	307	25%
40-49 years of age	108	9%
50-59 years of age	46	4%
60+ years of age	123	10%
Totals	1249	100%

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



Ligas Consent Decree Implementation Plan FY2019 Revisions –Reasonable Pace Proposal

- **In May, 2019** the parties agreed on a **goal of 600 individuals in fiscal year 2020 in waiver services, and 630 for the following 4 years as a reasonable pace to address the PUNS waiting list.**
- **In August, 2019 1249 individuals were selected from the PUNS.** Many had received, for the first time, early notification of their 2019 PUNS selection in December of 2018. The Division will continue such early notification of annual PUNS selections to encourage early planning going forward. If responses to PUNS selections are below anticipated targets 6 months after an annual PUNS selection, there will be a second PUNS selection to fill the unused target capacity.
- Among the August 1249 selected (this fiscal year 2020 only) were individuals receiving Home- Based Waiver services who seek CILA placement. By December 31, 2019, the parties will determine the process for moving from Home-Based services to CILA services with reasonable promptness.
- **With this agreed Reasonable Pace Proposal, the goal is that by FY2025, no person will wait on the PUNS 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).
- For those added to the PUNS list prior to their 18th birthday, the 60-month period will begin when the individual turns 18.

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

An Independent Service Coordinator at your Independent Service Coordination (ISC) agency (the agency that got you on the PUNS) will assess eligibility for waiver funding.

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 if eligible?

- Home-based Services Program: (funding is fixed =3 times SSI) 2019 = \$2313.00/monthly; all services must fit within monthly budget
 - Personal Support Worker (PSW)
 - ACCE\$ (Fiscal Intermediary)
 - SDA -Self-Direction Assistant (\$43/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
- 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 (formerly sheltered workshop) – 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)

Summary of PUNS by Selection Detail -

<https://www.dhs.state.il.us/page.aspx?item=117275> (Active, Inactive and Unknown).

- **Total # of individuals on the Active PUNs in both Planning and Seeking Services categories = 19,361:**
 - 12,313 are Planning for Services –under age 18
 - 7,148 are Seeking Services
- **What services are most needed?**
 - Personal Support
 - Transportation
 - Behavioral Supports
- Remember: You may not need the three mentioned above; your person-centered plan developed by your ISC is about YOUR needs and wishes -😊

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, growth in independent living skills, ability to utilize personal choices, and maintain maximum independent living skills

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 28

A young
man living
with
autism



Tony and one of his PSWs



Tony, age 28, 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 \$2313.00/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 \$44.75 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 41, living with Downs Syndrome, a 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 with one staff at a time. All the men are pretty independent, so there are times staff is not in the home while some of the men might be there. 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. There is also no one there between 9 AM and 3 PM during the week. So if a resident is home then, they are by themselves. Everyone has their own bedroom.
- KC works at one of the Day Programs of his CILA provider. He had a community job in the past, and will be looking for another one in the future. His monthly income includes \$60 of the monthly Social Security deposit that his CILA group home provider gets every month, earnings from the 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 NWSRA and Special Olympics, doing many sports, attending many clubs and traveling on short and long trips with them. He recently returned from a trip to Charlotte, NC. Staff drives 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 41, living with Downs Syndrome, a developmental disability

- Zach received Adult Home-Based Waiver Program funding 6 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 Home-based Services Program so in 2019 he has \$2313/monthly to address his needs, some 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 \$43.24/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 6 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 both through NSSRA and NWSRA. 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

- Include the family member who will be receiving services in the decision-making process. Ask them what is important to them. Their priorities may not always match with those of parents.
- Think not only of short-term goals, but also long-term needs.
- As difficult 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:
 - The family member starts learning to use other people to assist them with their daily needs, provide problem-solving advice, etc. It will give them time to develop relationships with those they will need to depend on when the parents/siblings are no longer able to provide that support.
 - It gives the family time to help the family member learn how to advocate for him or herself, when possible.
 - It gives the family time to help the agency and staff understand who your loved one is, their desires, challenges, etc. with input from you as a family member.
 - It gives the family time to help those supporting the family member understand family values.
- Expect that there will be bumps in the road. Appreciate that there are now additional team members 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/

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

Contact Information

- **The Ligas Family Advocate Program:**
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