

PUNS - THE BASICS

From The Arc of Illinois
Family to Family Health Information & Education Center

- ⌚ PUNS stands for Prioritization of Urgency of Need for Services.
- ⌚ PUNS is a list of the people in Illinois with developmental disabilities who need services.
- ⌚ PUNS is for everyone who may need help from the government to pay for developmental disability services now or in the future.
- ⌚ PUNS is the first step toward getting services in Illinois. If you are not on the PUNS list, you are not on the waiting list for services.
- ⌚ To get on PUNS, you need to set up a date to meet with a Pre-Admission Screener. These screeners will ask questions about you and your needs. These questions are part of the PUNS survey. All screeners work for Independent Service Coordination Agencies or ISC's. To get on the PUNS list, you must have a developmental disability. If you don't know if you have a developmental disability, the screener will help you.
- ⌚ To find your ISC, you can call Illinois Life Span at 1-800-588-7002. You can also call DHS at 1-888-DD-PLANS.
- ⌚ When your PUNS survey is done, you are on the list. This doesn't mean that you will get the services you need. It just means that you have made the first step.
- ⌚ Some of the services that people may need are:
 - In-Home Supports
 - Respite Care
 - Job Coaches
 - Group Homes
 - And many others
- ⌚ There is not enough money to give everyone in Illinois the services they need. Right now, many people are working on a fair way to choose who gets services.
- ⌚ Don't forget to update your PUNS form every year. Only people (families) who have completed the PUNS - and keep it updated - have a chance of getting "picked" to receive services.
- ⌚ If you have questions or need help, you can call Illinois Life Span at 1-800-588-7002.
- ⌚ If you want more information about PUNS or Home-Based Services, go to the Family Support Network website at www.familysupportnetwork.org



WHAT IS THE PUNS WAITING LIST?

The PUNS list is a waiting list of children and adults who want to use Medicaid waiver funding for supports and services in the community. The waiver is implemented through the IL DHS Division of Developmental Disabilities (DDD). Individuals who need help from the government to pay for needed DD Waiver services now, or in the future, must register for the PUNS waiting list for both the adult services waiver and the children's waiver services.

Medicaid has a historical institutional bias, which means that a person with intellectual and developmental disabilities (I/DD) is entitled to receive services in an institution, but NOT in the community. Home and community-based services can be capped, and Illinois is allowed to keep the PUNS waiting list for services. This waiting list was so long that the Ligas vs. Hamos lawsuit was filed, and a consent decree was created to increase access to services. Crisis situations, which have a strict definition of homeless, abused or neglected, are addressed outside of the PUNS waiting list.

In 2017, the PUNS categories were changed to "Seeking Services" (for those who want supports now) and "Planning for Services" (for those who do not currently want or need supports but may in the future). PUNS selections are now based on the length of time an individual has spent in the Seeking Services category since the age of 18. (From the Ligas Implementation Plan, 5/3/19)

By FY2025, individuals waiting for services will wait no more than 5 years (60 months on the list). This would mean if a person signed up by 18 for PUNs, they would be pulled when they are 23, 1 year after transition from schools. *Please note that the individual must also be in the "Seeking Services" category. (From the Ligas Implementation Plan, Exhibit A, 5/3/19.)

Facts and Figures

- The PUNS waiting list has 19,474. It can be broken into 6000-7000 people actively seeking adult services, more than 3,000 children waiting for children's waiver services and the remaining more than 9,000 people planning for services.
- According to DHS, 29% of those on PUNS are under 18 years old, 61% are ages 18-39, and 10% are 40 and older.
- 70% of caregivers of those waiting on PUNs are 69 or younger. 30% or 5,917 are 70 or older.
- 65% of those waiting are male and 35% are female.
- Every Illinois State House of Representatives and Senate district have at least 32 and as many as 348 people waiting for services.
- English is the primary language of 18,043 with 1,432 speaking another language as their primary language. We are concerned that there is limited outreach about PUNs to underserved and minority communities.
- Some of the top supports needed by people on PUNs include personal support, transportation, support for employment, and behavioral and speech therapies.

Important Notes

- There are untold number of aging caregivers taking care of their adult children in their own homes without knowledge of PUNs, Medicaid or the waiver.
- No one has been pulled off the children's waiver in 10 years. We estimate that there are more than the stated 3,000 people wanting children's services, but they do not sign up for that list because it has not been pulled recently.
- While waiting for services, individuals can qualify for Medicaid and receive state plan benefits as well as DHS grant funded programs like Respite, the Autism Program and the Arc Life Span, Family Support Network and Family Transition resources.



August 2020 Update PUNS, The Basics

What is PUNS and why is it important?

PUNS is the name for the list of the people in Illinois with developmental disabilities who want or need services, but do not yet have funding. Individuals who need help from the government to pay for needed Division of Developmental Disabilities Waiver services now, or in the future, should register for PUNS.

To get on the PUNS list, one must have a developmental disability (DD). The Independent Service Coordination Agency (ISC) will determine eligibility.

Through Medicaid, a person with DD is entitled to access institutional services (Intermediate Care Facilities), not DD Waiver services. Individuals with DD do not need to be on the PUNS to access an Intermediate Care Facility (ICF/DD). In Illinois, there is a wait for DD Waiver services and one must join the PUNS list unless in crisis (homeless, abused, or neglected). If the consumer is in crisis, speak directly to the ISC. Crisis situations are addressed outside of the PUNS waiting list.

*The
Independent
Service
Coordination
Agency is the
“doorway” to
PUNS and
funding for
services.*

Some of the services funded by the Medicaid waiver programs that may be needed are:

- In-Home Supports
- Job Coaches
- Community Day Services
- Residential Services
- Therapy Services
- And many others

How to get on the PUNS list

To get someone on the PUNS list, a date for a PUNS interview needs to be arranged with the local Independent Service Coordination Agency (ISC). The ISC is the "doorway" to PUNS and funding for DD Waiver services. Questions about the individual and his/her needs are part of the PUNS enrolment process.

The PUNS list is a waiting list for Medicaid waiver funding to pay for services, provided through the IL DHS Division of Developmental Disabilities (DDD).

Don't forget to update the PUNS form every year. Only those who have completed the PUNS - and keep it updated - have a chance to be "selected" to receive services. Watch the U.S. Mail for a letter alerting the consumer that a PUNS annual update is due. If the consumer does not get a letter, call the ISC to schedule an update appointment.

How to find the ISC

To find the ISC for the individual seeking services, call any of The Arc Programs listed on the final page of this document. Contact the DHS Customer Help Line at (800) 843-6154 or go to the Illinois DHS Office Locator and choose "Developmental Disability Services" as the Office Type, along with your county. DHS Office Locator:
<https://www.dhs.state.il.us/page.aspx?module=12>

The PUNS list is a wait list

PUNS is a database, or list, of individuals who want or need Developmental Disability waiver services funded by the Illinois Department of Human Services/Division of Developmental Disabilities. Individuals are selected from the PUNS waiting list and invited to apply for DD Waiver services.

From the Ligas Implementation Plan, 5/3/19. *"Effective August 2017, PUNS categories were revised to "Seeking Services" (for those who want supports now) and "Planning for Services (for those who do not currently want or need supports but may in the future)." Future PUNS selections will be based on the length of time an individual has spent in the Seeking Services category since the age of 18."*

There are now two PUNS categories. The two categories are **Seeking Services**, for people who currently need or desire supports, and **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 since the age of 18. *Note: If you are not in the Seeking Services Category and you are currently in need of supports, you must request that your (Independent Service Coordination (ISC) Agency move you to the Seeking Services category.* www.dhs.state.il.us/page.aspx?item=41131

Thanks to the ongoing Ligas Consent Decree, the Division of Developmental Disabilities plans that by 2025, a person age 18 or older in the Seeking Service Category will be selected from the PUNS in 60 months or 5 years. This means that by 2025, a person in the Seeking Services category at age 18 would receive a PUNS selection at age 23, and by 2025 a person who moves to Seeking Services at age 26 will receive a PUNS selection at age 31, etc. Time on the PUNS in the Planning for Services category does not count toward a PUNS selection.

ISCs will enroll individuals in the Seeking Services category who are in any of these situations:

- Persons whose caregiver is clearly progressing toward being unable to provide care for any number of reasons (age of the caregiver, physical/psychological/health condition of caregiver, health or other situation of the individual). The individual and/or family are coping for now but supports are needed.
- The individual him/herself has a deteriorating situation, which requires formal supports.
- Cases where, although the caregiver and person with developmental disabilities have not been directly affected, a death in the family (especially of a care giver's spouse or other family member who may have assisted in providing care) or other circumstance has affected their situation requiring a need for additional support.
- Situations where the caregiver(s) must work to provide income to pay the rent, etc. If services are not provided, the caregiver(s) would have

to remain at home to provide support, and effectively be unable to continue working.

- Persons who have (or will shortly) graduate from school and will need day supports (i.e., there are no other employment or other day support options available/planned).
- Person is dissatisfied with current setting and would like to have DD residential services.
- Person prefers to live in his/her own home rather than in a funded residential setting but would need supports to do so.
- Person currently lives in out-of-home residential setting that is not funded by the Division of DD and wishes to return to their family home (and family concurs). The family is capable of providing care but would like support to return this person to the home.

ISCs will enroll in the Planning for Services category 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.
- Currently receive funding or services through entities other than DD, and whose eligibility will be terminating primarily due to the age of the individual. This person is not in crisis and does not have a current need or desire for DD services. This might include, but is not limited to, persons who are funded through:
 - Early, Periodic Screening, Diagnosis and Treatment (EPSDT) program
 - Medically Fragile/Technology Dependent Children's Waiver
 - Individual Care Grant supports through the mental health system
 - Illinois State Board of Education or public-school system.
www.dhs.state.il.us/page.aspx?item=68933

From the Independent Service Coordination Manual, posted July 2019. *"PUNS selections for Waiver services will occur as funding is available. Selections will be based on a person's cumulative length of time in the Seeking Services Category after age 18. Selections will not be made from the Planning for Services category. If the individual*

enrolled in PUNS before turning age 18, the length of time begins calculating on the individual's 18th birthday provided that they are in the Seeking service category. In order to move from one category to the other, individuals and/or guardian must notify their ISC. Movement from one category to the other is not automatic."

The waiting time on the PUNS list has been lengthy. It is possible to find out when one is likely to be selected by sending an email with name of the individual, address, birthdate, and the name of the ISC to the following address. DHS.DDD.PUNS@illinois.gov.

Please keep in mind that many factors influence the PUNS list and it changes frequently. There is a possibility that a selection may occur slightly earlier or later than estimated. All estimates of selection and funding availability are subject to appropriation by the Illinois Legislature.

From the Ligas Implementation Plan, Exhibit A, 5/3/19.
"PUNS selections will be tailored such that by the FY2025 selection, no individual will wait on PUNS for over 60 months. For individuals who are added to the PUNS list before their 18th birthday, the 60-month period will begin when the individual turns 18." *Please note that the individual must also be in the "Seeking Services" category.

Children and PUNS

Although very few children have been funded for services except in crisis situations in recent years, there are still Medicaid waiver programs in place for children and youth. Those with current or anticipated future needs are encouraged to complete the PUNS process to get on the PUNS waiting list. A PUNS interview can be requested for children age 2.5 years and older with developmental disabilities.

For more information . . .

If you want more information about PUNS or DD Waiver services, the following Programs of The Arc of Illinois may be helpful:

- Family to Family Health Information Center
www.familyvoicesillinois.org
866-931-1110
- Illinois Life Span Program
www.illinoislifespan.org
1-800-588-7002
- The Ligas Family Advocates Program
www.ligasfamilyadvocateprogram.org
708-331-7370
- Family Support Network
www.familysupportnetwork.org
708-331-7370
- The Arc Spanish Helpline - Línea de Información en Español 708-218-1958

Arc of Illinois staff members are also available to talk about other possible options, programs and services for your family member with a developmental disability.