

## September 2024 Update

### 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 on the PUNS.

To get on the PUNS list, one must be likely to 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 ICF/DD). These facilities are not accessed through funding from the Adults with DD Waiver. Individuals with DD do not need to be on the PUNS list to access an Intermediate Care Facility (ICF/DD). In Illinois, there is a wait for Adult 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 differently.

*The Independent Service Coordination Agency (ISC) is the “gateway” to PUNS and funding for services.*

Some of the services funded by the DHS -Division of Disabilities Medicaid Home and Community Based waivers 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 “gateway” to getting on the PUNS and to DD Waiver services. Questions about the individual and his/her needs are part of the PUNS enrollment 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 are in the Seeking Service Category - 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 (if located in Cook County you must include your zip code). DHS Office Locator: [www.dhs.state.il.us/page.aspx?module=12](http://www.dhs.state.il.us/page.aspx?module=12)

## The PUNS list is a wait list

There are 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 total length of time in the Seeking

Services Category after 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](http://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 no longer than 5 years after enrolling.

**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 caregiver'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).
- The person is dissatisfied with the 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.
- The 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 can provide 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](http://www.dhs.state.il.us/page.aspx?item=68933)

It is possible to find out when one is likely to be selected by sending an email with the name of the individual, address, birthdate, and the name of the ISC agency to the following address: [DHS.DDD.PUNS@illinois.gov](mailto: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.

Please remember that PUNS selections only occur from the Seeking Services category; if you need or desire supports, you must be in the Seeking Services category. Those who are enrolled in the Planning category help the Division of Developmental Disabilities plan for future funding needs.

## **Crisis**

Children and adults on the PUNS list experiencing a crisis (homelessness, abuse or neglect) can call their ISC to request consideration of a crisis application for waiver funding. It is important to note that before an individual is evaluated and determined to be in crisis by the ISC they must be placed on the PUNS list.

## **Children and PUNS**

In recent years, the Division of Developmental Disability has occasionally selected children from the PUNS wait-list to apply for in-home supports. 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 a likelihood of developmental disabilities.

## **For more information:**

- Family to Family Health Information Center  
[www.familyvoicesillinois.org](http://www.familyvoicesillinois.org)  
866-931-1110
- Illinois Life Span Program  
[www.illinoislifespan.org](http://www.illinoislifespan.org)  
1-800-588-7002

- The Family Advocates Program  
[www.thearcofil.org/family-advocate-program/](http://www.thearcofil.org/family-advocate-program/)  
708-331-7370
- Family Support Network  
708-331-7370  
[www.thearcofil.org/family-support-network/](http://www.thearcofil.org/family-support-network/)
- The Arc of IL Spanish Helpline - Línea de Información en Español  
708-218-1958