



Center *for* Independence

THROUGH CONDUCTIVE EDUCATION

NAVIGATING DISABILITY BENEFITS AND PLANNING FOR THE FUTURE

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Today we will be discussing...

- SSI and SSDI
- Medicaid Waiver Programs Home Based Services – getting on the list! (PUNS)
- Department of Rehabilitation Services (DRS)
 - Personal Care Assistants
 - College Assistance
 - Employment Services
- Ways to Protect Assets for the Future
 - Special Needs Trusts
 - Illinois Able Accounts
- Guardianship
- Transportation Services
- Supplemental Nutrition Assistance Program (SNAP)

FINANCIAL
ASSISTANCE FOR
CHILDREN AND
ADULTS DISABLED
SINCE
CHILDHOOD:

SSI
SSDI

The U.S. Government provides financial assistance to persons living with disabilities. **Supplemental Security Income (SSI)** and **Social Security Disability Insurance (SSDI)** are two of the most common programs from the Social Security Administration (SSA).

What Is Supplemental Security Income (SSI)? SSI provides minimum basic financial assistance to persons with disabilities (regardless of age) with very limited income and resources. In Illinois, Parental income is taken into consideration when determining eligibility for the child w/ disability.

Parent assets less than \$2,000.00 and significant income limitations.

Monthly Benefit from SSI: \$943.00

Once the child turns 18 – SSA looks to the assets and income of the

Adult with a Disability for SSI eligibility – NOT the parent!

Note: always have a food & shelter agreement with Adult Child with a Disability or monthly benefit will be reduced by up to \$334.44!

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SSI
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What Is Social Security Disability Insurance (SSDI)? SSDI supports individuals who are disabled and have a qualifying work history, either through their own employment or a parent. The SSDI program pays benefits to adults disabled from childhood and whose parents paid into or received Social Security. The SSDI benefit is considered the “child’s” benefit because it is paid on the parent’s Social Security earnings record. No asset limitation.

For the Adults with a Disability to become eligible for this “child” benefit:

- One of his/her parents must be receiving Social Security Retirement or disability benefits
- One of parents must have died and worked long enough under Social Security

OR:

- Adult with Disability has worked and paid into the system for 10 quarters (2.5 years) earning at least \$1,730.00 per quarter. $\$1,740/\$14 = 124$ hours per quarter; 42 hours per month; approx. 12 hours per week.

Average Monthly Benefits from SSDI: Vary \$1,300.00

Benefits: eligible for Medicare after receiving SSDI for 2 years!

Reminder: SSI is only \$943 per month. ☹️

It is Always better to have a work history!

SSI/SSDI Cont...

FOR MORE INFORMATION:

- Disability Evaluation Under Social Security (included Listing of Impairments):

<http://www.socialsecurity.gov/disability/professionals/bluebook/index.htm>

<https://www.ssa.gov/disability/professionals/bluebook/112.00-MentalDisorders-Childhood.htm>

- Disability Letter Guidelines:

<https://www.ssa.gov/disability/professionals/bluebook/evidentiary.htm>

- Social Security administration: <http://www.socialsecurity.gov/disability/>

- To contact your Social Security Administration: 800-772-1213

Can I work and still receive SSI/SSDI?

SSI: To continue to receive SSI, an adult with a disability must:

- To qualify for SSI, you must have limited income and few assets. Social Security requires SSI recipients to have less than \$2,000 in assets, for a single person, and \$3,000 for a couple (not counting money in an [ABLE account](#)).
- The income limit is more complicated. The way Social Security counts income is different than the way we usually think of income. Countable income includes wages or any other kind of money you earn from working, plus money you get from other sources like unemployment, Social Security retirement, or gifts from friends, but also, free food or shelter. In addition, to encourage SSI recipients to work, Social Security excludes part of your income from its calculations.
- Enroll in a Work Incentive Program with SSA – and ALWAYS report your wages to the State of Illinois.

Can I work and still receive SSI/SSDI?

Cont...

SSDI: To continue to receive SSDI, an adult with a disability must:

- have a medically determinable physical or mental impairment that results in the “inability to do any substantial gainful activity” (SGA)

SGA 2024 is \$1,520.00

WORK INCENTIVES

What is a Work Incentive?

- Special rules make it possible for people with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare or Medicaid. Social Security calls these rules "work incentives." Below are the rules that apply under each program.

What is the Ticket to Work Program?

- Social Security's Ticket to Work Program supports career development for Social Security disability beneficiaries aged 18 through 64 who want to work. The Ticket to Work Program is free and voluntary. The Ticket to Work Program helps people with disabilities progress toward financial independence.

Can I work and still
receive SSI/SSDI?

Ticket to Work Program

- Ticket to Work Program increases opportunities for Social Security disability beneficiaries to obtain employment, vocational rehabilitation (VR) and other support services from public and private providers.
- <https://choosework.ssa.gov/about/work-incentives/>

Resources

Kaylee.Raymond@Illinois.gov

DHS.DRSbenefitPlanning@Illinois.gov



Department of
Rehabilitation

DRS Vocational
Services

What is the purpose of this service?

- Vocational services helps people with disabilities find and keep jobs. The goal is to help customers find quality employment that pays a living wage and offers a chance for advancement.
- DRS staff talk to people about their employment needs and help them find a job or get ready to go to work. They also make sure that people have the supports they need to stay on the job.
- VR counselors help high school students who have disabilities plan for their futures after high school graduation through Transition and STEP programs.
- The Work Incentive Planning and Assistance Program helps people who receive SSDI/SSI benefits understand how working will affect their benefits.
- The Supported Employment Program (SEP) serves eligible people with significant disabilities who want to go to work and need on-going support services to succeed on the job.
- Center for Independence – Working Together Chicago Program

Milestone Contract with DRS

www.WorkingtogetherChicago.org

Can I work
and still
receive
SSI/SSDI?

How
about
Medicaid?

•SSI: If I make too much money can I keep Medicaid?

•Continued Medicaid Eligibility (Section 1619(B))

•What is Medicaid?

•One of the biggest concerns SSI beneficiaries have about going to work is the possibility of losing [Medicaid](#) coverage. Section 1619(b) of the Social Security Act provides some protection for these beneficiaries. To qualify for continuing Medicaid coverage, a person must:

- Have been eligible for an SSI cash payment for at least 1 month;
- Still meet the disability requirement; and
- Still meet all other non-disability SSI requirements; and
- Need Medicaid benefits to continue to work; and
- Have gross earnings that are insufficient to replace SSI, Medicaid and publicly funded attendant care services.

•This means that SSI beneficiaries who have earnings too high for a SSI cash payment may be eligible for Medicaid if they meet the above requirements. SSA uses a threshold amount to measure whether a person's earnings are high enough to replace his/her SSI and Medicaid benefits. This threshold is based on the:

- amount of earnings which would cause SSI cash payments to stop in the person's State; and
- average Medicaid expenses in that State.

•If a SSI beneficiary has gross earnings higher than the threshold amount for his/her State, SSA can figure an individual threshold amount if that person has:

- [Impairment-related work expenses](#); or
- [Blind work expenses](#); or
- [A plan to achieve self-support](#); or
- Personal attendant whose fees are publicly funded; or
- Medical expenses above the average State amount.

2024 1619(b) THRESHOLD AMOUNTS FOR DISABLED SSI BENEFICIARIES In Illinois is \$38,906.00

•<https://www.ssa.gov/disabilityresearch/wi/1619b.htm>

DRS Vocational Services

Cont...

How to apply?

- Use the online [Rehabilitation Services Web Referral](#) to refer yourself or someone else for services.

<https://wr.dhs.illinois.gov/wrpublic/wr/dynamic/referral.jsf>

- Referred by High School Transition Team

Use the [DHS Office Locator](#) and search for Rehabilitation Services to find the nearest local office or call toll-free: (800) 843-6154 (Voice, English or Español) or (800) 447-6404 (TTY).

DRS College Tuition Assistance

Once the child with a disability graduates from high school, they transition to the Department of Rehab Services for Vocational Services. Your child's IEP continues and will now be known as an Individualized Employment Plan.

In addition to employment services, DRS also has the ability to approve **federal Pell Grants for college tuition for people with disabilities.**

Information and Instructions for Students Receiving DHS-DRS Financial Contribution:

<http://www.dhs.state.il.us/onenetlibrary/12/documents/Forms/IL488-2460.pdf>

Home-Based Services – Living in the community

MEDICAID WAIVER PROGRAM-HOME BASED SERVICES:

- 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 waiver is designed for individuals with similar needs and offers a different set of services.
- Illinois Healthcare and Family Service (HFS), the State Medicaid Agency
- A component of the DHS-DRS Home Services Program (HSP)
- **Operating Agency:** Illinois Department of Human Services-Division of Rehabilitation Services (DHS-DRS)

List of Waiver Programs: <https://hfs.illinois.gov/medicalclients/hcbs.html>

Eligible Population:

- Individuals with disabilities who are under age 60 at the time of application and are at risk of placement in a nursing facility
- Individuals 60 years or older, who began services before age 60, may choose to remain in this waiver

Eligibility Criteria:

- U.S. citizen or legal alien
- Resident of the State of Illinois
- Under age 60 at time of application
- Medicaid eligible or enrolled in the Health Benefits for Workers with Disabilities (HBWD) program.
- Medical determination of a diagnosed, severe disability, which is expected last for 12 months or for the duration of life

WHICH WAIVER PROGRAM IS RIGHT FOR YOUR CHILD?

- **People with severe physical disabilities are eligible to participate in several different programs:**

Home-based Waiver Program People with Physical Disabilities (Managed by DRS)

Eligible on 18th Birthday

No Income Limitation

\$17,000 Asset Limitation

OR:

Developmental Disability Waiver Program (Managed by PAS)

Eligibility based on Prioritization of Urgency of Need

WHICH WAIVER PROGRAM IS RIGHT FOR YOUR CHILD?

Home-based Waiver Program People with Severe Physical Disabilities (Managed by DRS)

Eligible on 18th Birthday – typically no waiting period

Services provided:

- Personal care assistants. (Parents, family members can be personal care assistants)
- PT and OT Services
- Meals
- Electronic monitoring
- For more information on this waiver program visit: <https://www.dhs.state.il.us/page.aspx?item=29738>

OR:

Developmental Disability Waiver Program (Managed by a Preadmission Screening Agency (PAS) or and Independent Service Coordination (ISC Agency)).

These agencies can be contacted through the Developmental Disabilities Helpline at [1-888-DD-PLANS](tel:1-888-DD-PLANS) or at [1-866-376-8446](tel:1-866-376-8446) for TTY.

Eligibility based on Prioritization of Urgency of Need (PUNS)

Some of the services provided:

- In-Home Supports
- Respite Care
- Job Coaches
- Group Homes

WHICH WAIVER
PROGRAM IS RIGHT
FOR YOUR CHILD?

ARC of Illinois Fact Sheet on Medicaid Waiver Programs in Illinois:

<https://www.illinoislifespan.org/wp-content/uploads/2023/09/F2F-Fact-Sheet-Medicaid-Waivers-in-Illinois-for-Children-with-Disabilities.-Sept-2023.pdf>

PUNS – Move up the DD Waiver Wait List!

PUNS – Prioritization of Urgency of Need for Services

- Apply for PUNS NOW
- Puns is for all people with developmental disabilities.
- Puns is for everyone who may need help from the government to pay for developmental disability services now and in the future.
- To get on the PUNS list, one must have a developmental disability (DD). The Independent Service Coordination Agency (ISC) will determine eligibility.
- 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 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.
- 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.

PUNS

Cont...

PUNS Categories:

- Emergency - You need immediate services
- Critical - You will need services within 1 year
- Planning - You will need services in 1 to 5 years

To find your ISC, Independent Service Coordination Agency, 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.

Medicaid Waiver payments not subject to income tax

- Section 1915(c) enables individuals who otherwise would require care in a hospital, nursing facility, or intermediate care facility to receive care in the individual care provider's home. The notice provides that the Service will treat these Medicaid waiver payments as difficulty of care payments excludable from gross income under § 131 of the Internal Revenue Code.
- Parents employed as a Personal Care Assistance for their Adult Child with a Disability are EXEMPT from paying income taxes on wages paid by State of Illinois. (Wages ARE subject to Medicare and SS taxes)

HOW TO SAFEGUARD ASSETS AND BENEFITS

- **Special Needs Trust**
- **Illinois ABLE Account**

If you are considering ways to provide for a loved one with special needs, you have probably discovered the inherent conflict with giving money directly: Any funds you contribute could make this individual ineligible for benefits under the Social Security SSI program, Medicaid, and other forms of public assistance. Your heart may be in the right place, but you could be doing more harm than good when it comes to qualifying for needs-based programs that focus on income and assets.

ABLE ACCOUNTS

Who is eligible?

Any individual who is a U.S. citizen or a legal resident, residing in any state, is eligible to own an IL ABLE Account if:

1. The onset (not necessarily diagnosis) of their disability occurred before the age of 26 (Beginning 2026, the onset of disability age requirement will increase to before age 46)

AND

2. At least one of the following is **true**:

- The individual is currently receiving Social Security Disability Insurance (SSDI)
- The individual is currently receiving, or is entitled to receive, Supplemental Security Income (SSI)
- The individual has identified their condition on the Social Security Administration's List of Compassionate Allowances Conditions, and can certify that the condition produced marked and severe functional limitations prior to age 26 (Beginning 2026, the onset of disability age requirement will increase to before age 46)
- The individual can certify that they are blind, or they have a medically determinable physical or mental impairment that results in marked and severe functional limitations, can be expected to result in death, has lasted, or can be expected to last, for a continuous period of at least 12 months. In this case, the individual has a written diagnosis from a physician.

WHY USE ABLE ACCOUNT?

IL ABLE Accounts make it possible for people with disabilities and their families to save and invest their money for expenses related to living with a disability.

- **Be in control:** An IL ABLE Account can be opened by an Eligible Individual or Authorized Individual living in any state, at any time. See [Who Can Open an IL ABLE Account](#).
- **Protect federal benefits:** Eligible Individuals can save up to \$100,000 without risking Supplemental Security Income (SSI) benefits. See [IL ABLE & Public Benefits](#).
- **Save and spend tax-free:** Account Owners can save and invest up to \$17,000 a year, and if working, up to \$13,590 more. Earnings and withdrawals on IL ABLE Accounts are tax-free if they are used for a wide range of [Qualified Disability Expenses](#).



SPECIAL NEEDS TRUSTS

Special Needs Trusts allow families to safeguard assets and government benefits. Most Special Needs Trusts are not funded until the death of a parent.

Resources:

ARC of Illinois

<https://www.thearcofil.org/>

GUARDIANSHIP: IS IT APPROPRIATE?

- Family members are not automatically named the legal guardian for their disabled relative.
- In all cases, the court will make a determination as to the need for guardianship and who should serve as guardian.
- A family member may petition the Judge to be named guardian or the disabled person may express a preference as to his guardian. If the disabled person expresses a preference, the Judge will give consideration to the disabled person. However, the Judge appoints whomever will make the best guardian and act in the best interest of the disabled person
- The ARC of Illinois regularly hosts webinars on Guardianship, where participants can learn about adult guardianship, powers of attorney for health, supported decision making, and how to decide which options may be helpful. Participants will also learn how to navigate the court process for adult guardianship.

<https://www.thearcofil.org/event/ils-f2f-lunchtime-webinar-guardianship/>



TYPES OF GUARDIANSHIP CONTINUED

Illinois Guardianship and Advocacy Commission

<https://gac.illinois.gov/>

Other Benefits: PACE Paratransit

- Pace operates accessible fixed route bus systems and also door-to-door transportation services for people with disabilities. However, to qualify for door-to-door services, the person with a disability must live within $\frac{3}{4}$ of a mile of a regularly scheduled PACE bus route.
- Most townships also have transportation services for people with disabilities and seniors through Pace Bus Dial a Ride.
- To learn more about township services: <https://www.pacebus.com/dar>

[HTTPS://WWW.PACEBUS.COM/SITES/DEFAULT/FILES/2021-09/ADA%20COMBO%20ENGLISH%209-3-21.PDF](https://www.pacebus.com/sites/default/files/2021-09/ADA%20COMBO%20ENGLISH%209-3-21.pdf)

[PACEBUS.COM/ADA](https://www.pacebus.com/ada)

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP)

- **Who can receive these services?**
- Most households with low income can get SNAP benefits. The rules are complex, so all of the details are not here. The most important factors which determine the amount of, and eligibility for, SNAP benefits are:
- income and expenses;
- the number of persons who live and eat together
- Use the [SNAP Eligibility Calculator](#) to give an estimate of possible benefits. This is only an estimate.
- Your application must be reviewed by IDHS staff at the Family Community Resource Center. If you apply for benefits and are eligible, you will receive a notice of your eligibility.
- Income
- A household might be eligible to receive **SNAP** benefits if their monthly gross income does not exceed the gross income limits shown below.
- [SNAP Program Income and Benefit Amounts \(English Version\) - DHS 124](#)
- [SNAP Program Income and Benefit Amounts \(Spanish Version\) - DHS 124S](#)
- Households without Disabled or Elderly Persons (age 60 or over) Maximum Monthly Income Allowable

OTHER RESOURCES

The ARC of Illinois

<https://www.thearcofil.org>

Equip for Equality: free legal services to people with disabilities on issues related to their disability. Disability Rights and legal advocacy related to education, employment, independent living, access.

Family Benefit Solutions: helps families obtain government benefits for which they are eligible.
Sherri Schneider, benefithelp@aol.com, 847-279-8506

Kaylee Raymond, DRS Benefits Planning Program. 217-503-5030 kaylee.raymond@illinois.gov or
DHS.DRSbenefitPlanning@Illinois.gov

The Estate Planning Law Group: Special needs trusts, guardianship. 630-871-8691

Life's Plan, Inc.: Trust Management, including Poo 630-628-7189



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