



# **An Introduction to Benefits: Federal and State Programs Available in Illinois**

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# Types of assistance we'll cover today

- **Financial Assistance**


- SSI
- SSDI

- **Medical Coverage**

- Medicaid
- Medicare
- Private insurance

- **Adult living: Home and Community Based Services or “Medicaid Waivers”**

- What is this PUNS thing anyway?



# Financial Assistance: Defining terms and acronyms!

SSA = Social Security Administration

SSI = Supplemental Security Income

SSDI = Social Security Disability  
Insurance



# SSI: Supplemental Security Income

- As the “income” part of the title indicates, this is money that comes directly to people with disabilities (or their Representative Payee) to meet basic needs of food, clothing & shelter
- Designed to help aged, blind & disabled people who have little/no income
- Paid for/funded by U.S. taxpayers.
- Eligibility determined both financially and medically.
- [Understanding SSI - SSI Eligibility \(ssa.gov\)](https://www.ssa.gov/ssi/eligibility)





# SSI: Supplemental Security Income: Financial Eligibility

- Financial: based on household income until the month after the 18<sup>th</sup> birthday, afterwards individual is considered a “Household of one” and parental income is waived.
- Nutshell guidelines
  - \$2,000 in financial resources (\$3K couple)
  - One home
  - One car
  - More details here: [Understanding SSI - SSI Resources \(ssa.gov\)](https://www.ssa.gov/understanding-ssi-ssi-resources)



# SSI: Supplemental Security Income: Medical Eligibility

- Must meet *Social Security's* definition of “disabled”.
  - If under 18, disability determination based on “marked and severe functional limitations.”
    - What is child able to do, and not do? How much extra help is needed?
  - If over 18, definition changes.
    - The question isn't “Is the person disabled?” or “To what extent is the person disabled?” It is...
    - “Does the disability keep the person from earning a salary to support themselves?” (Can they work?) AKA Substantial Gainful Activity or SGA.
- Has lasted at least 12 months or is expected to last longer than 12 months.
- Can be expected to result in death.



# SSI: Supplemental Security Income: How can it be spent?

- The intention is to provide for life's basic necessities
  - Food
  - Clothing
  - Shelter
- Once those needs are met, balance can be spent on things that will directly help the beneficiary
- Keep good records!



# SSI: Supplemental Security Income: Other information

- [Understanding Supplemental Security Income \(SSI\) -- Home Page \(ssa.gov\)](https://www.ssa.gov/ssi/home)
- SSI for children under 18yo:
  - [Understanding SSI - SSI for Children \(ssa.gov\)](https://www.ssa.gov/ssi/children)
  - recipients who are children: case will be reviewed 2 mo prior to turning 18yo to determine if medical condition meets disability requirements as an adult
- Redeterminations/Continuing Disability Review (CDR):at least once every three years.
  - [Understanding SSI - Continuing Disability Reviews \(ssa.gov\)](https://www.ssa.gov/ssi/cdr)
  - Income, resources & living arrangements





# SSI: Supplemental Security Income

## How to apply

- Check eligibility requirements online first:
  - [Understanding SSI - SSI Eligibility \(ssa.gov\)](https://www.ssa.gov/ssi/eligibility)
- Apply online:
  - [Disability Benefits | SSA](https://www.ssa.gov/disabilitybenefits)
  - Apply the month following their 18<sup>th</sup> birthday
- Call National 800 Number:
  - 1-800-772-1213 or local office
  - If necessary, they can schedule an appointment to serve you in person
  - You must have an appointment to visit an office
  - Masks required, visitor capacity limited



# SSI: Supplemental Security Income: Helpful links

- Publication: Understanding Supplemental Security Income 2021 Edition
  - [Understanding Supplemental Security Income \(SSI\) \(ssa.gov\)](https://www.ssa.gov/pubs/understanding-ssi-2021-edition)
- Publication: What You Need to Know About Your Supplemental Security Income (SSI) When You Turn 18
  - [What You Need To Know About Your Supplemental Security Income \(SSI\) When You Turn 18 \(ssa.gov\)](https://www.ssa.gov/pubs/what-you-need-to-know-about-your-ssi-when-you-turn-18)



# SSDI: Social Security Disability Insurance

- Pays benefits to certain family members if parent is “insured” (worked long enough and paid Social Security taxes on their earnings).
- Minor Child/Disabled Adult Child (DAC) can receive SSDI payments based on their parents Social Security earnings record when a parent:
  - Retires,
  - Starts receiving Disability Benefits themselves (becomes disabled), or
  - Dies.
  - [How You Qualify | Disability Benefits | SSA](#)
- Medical requirements for over 18yo are the same as SSI
- SSI paid for with tax revenue general funds; SSDI paid for by Social Security (FICA) taxes



# SSDI Social Security Disability Insurance: Beneficiaries

- Minor child
  - A child under 18yo can receive SSDI benefits as a dependent regardless of having a disability or not
  - Children receiving SSDI benefits as a minor child may be eligible to continue receiving benefits on parent's record after age 18 \*if\* they have a qualifying disability. Then they are considered a...
- DAC: Disabled Adult Child (After age 18)
  - Adult with a qualified disability that began before age 22
  - Meet definition of disability for adults
  - Unmarried
  - Earnings under \$1,350/month (\$2,260/mo if blind)





# *SSDI Social Security Disability Insurance: Beneficiaries*

- You can also qualify for SSDI by working and earning “quarters”.
- “Quarter of coverage” is a legal term, may also be referred to as Social Security credit.
- Cannot earn more than 4 “Quarters of Coverage” in one year
- 2022 quarter is \$1,510
- [Quarter of Coverage \(ssa.gov\)](https://www.ssa.gov/quarterofcoverage/)
- ***Earn 6 quarters and before age 24 →SSDI!***
- ***SSDI for 24 months → Medicare!***



# SSDI Social Security Disability Insurance: how to apply

- At this time, DAC applications cannot be done online.
- Call 1-800-772-1213 to request an appointment.
- TTY 1-800-325-0778
- To speed up process, complete online Adult Disability report
  - [SSA-3368-BK](#)



# SSDI Social Security Disability Insurance: helpful links

- Disability Benefits publication
  - [Disability Benefits - EN-05-10029 \(ssa.gov\)](#)
- Benefits for Children with Disabilities publication
  - [Benefits For Children With Disabilities \(ssa.gov\)](#)
- Disability Starter Kits: helps you get ready for disability interview or online application.
  - Links for Adult Starter Kits and SSI Child Starter kit and Spanish versions of both are here:
  - [Disability Starter Kits \(ssa.gov\)](#)



# Medical Coverage: Medicaid

- Medicaid is healthcare for low-income Illinoisans
  - Used for medical office visits, hospital stays, therapies & more (stay tuned for Medicaid Waiver discussion)
  - Based on income (“means tested”), household size, immigration status, and state residency
  - Individuals have to fit into a category to qualify.
  - Each category has different eligibility requirements
- Illinois has numerous health coverage options
  - [Medical Programs | HFS \(illinois.gov\)](#)
- Today we’ll cover All Kids, AABD, ACA & HBWD





# Illinois Medicaid: All Kids

- All Kids is Illinois' program for children who need comprehensive, affordable, health insurance, regardless of immigration status or health condition.
- All Kids covers doctor visits, hospital stays, prescription drugs, vision care, dental care, and eyeglasses.
- All Kids covers regular check-ups and immunizations (shots).
- All Kids also covers special services like medical equipment, speech therapy, and physical therapy for children who need them.
- [About All Kids | HFS \(illinois.gov\)](#)



# Illinois Medicaid: All Kids


What children qualify? They must...

- Live in Illinois
- Be under the age of 18
- Meet the insurance requirements for All Kids
  - Children can qualify for All Kids Assist Share and Premium Level 1 even if they have insurance.
  - To qualify for All Kids Premium Level 2, a child must have been uninsured for 3 months, have lost insurance because a job ended, the employer stopped offering insurance, the insurance was COBRA, the premium for the child was more than 5% of the household income, the cost of the family coverage including the child was more than 9.5 % of the household income, the child has special health care needs, or the child lost benefits under another All Kids program or the Health Insurance Marketplace.
- Have a family income that meets the All Kids Income Limit.
  - [How Much Does It Cost? | HFS \(illinois.gov\)](#)



# Illinois Medicaid: All Kids

- **Family Care/All Kids Assist**
  - family income w/in 147% Federal Poverty Level FPL
  - No co-pays or premiums for kids
  - FamilyCare Assist parents have a co-payment
  - [FamilyCare | HFS \(illinois.gov\)](#)
- **All Kids Share**
  - family income over 147%-157% FPL
  - Kids have a co-payment; maximum \$100/year
- **All Kids Premium Level 1**
  - family income over 157%-209% FPL
  - Monthly premiums & co-payments
- **All Kids Premium Level 2**
  - Family income over 209%-318% FPL
  - Monthly premiums & co-payments
- What are the premiums and co-payments?
  - [How Much Does It Cost? | HFS \(illinois.gov\)](#)




# Medicaid: Aid to the Aged, Blind, and Disabled (AABD)

Medical coverage for those who

- Receive Supplemental Security Income (SSI)
  - or are ineligible for SSI due to income or are ineligible for SSI due to expiration of federal time limit on assistance to certain immigrants who have not yet become U.S. citizens.
- Are a U.S. citizen or meet certain requirements for noncitizens
- Live in Illinois
- Are 65 years or older, blind, or disabled
- Apply [Illinois.gov - IL Application for Benefits Eligibility \(ABE\) ABE Home Page](#)





# Medicaid: Aid to the Aged, Blind, and Disabled (AABD)

- If eligible, can apply at age 19
- Can be secondary to private insurance
  - Always payor of last resort
  - Private insurance billed first; balance billed to Medicaid
- Providers need to accept Medicaid
  - “Illinois Public Aid” or “Illinois Medicaid”
- Helps “PUNS pull” process when pulled from the waiting list
- Redeterminations, new card every year
- Illinois gets less money from federal government for AABD, so they prefer for folks to be on...



# Illinois Medicaid: ACA Adults

## ACA Adults

- under the Affordable Care Act (ACA), adults age 19-64 who were not previously eligible for coverage under Medicaid can now receive medical coverage. Individuals with income up to 138 percent of the federal poverty level (monthly income of \$1,506/individual, \$2,028/couple) can be covered.
- Federal government reimburses states at a much higher percentage for these policies (incentive for states to expand Medicaid coverage under ACA)



# Illinois Medicaid: ACA Adults

- To apply:
  - Application for Benefits Eligibility (ABE)
    - [Illinois.gov - IL Application for Benefits Eligibility \(ABE\) ABE Home Page](#)
  - Downloadable written application can be found here:
    - [hfs2378h.pdf \(illinois.gov\)](#)
  - Family Community Resource Center (FCRC)
    - [IDHS: Office Locator \(state.il.us\)](#)
  - [IDHS: Cash, SNAP \(Food Stamps\) & Medical Assistance \(state.il.us\)](#)



# Medicaid: Health Benefits for Workers with Disabilities HBWD

- If you are an individual with a disability, between the ages of 16 and 64 and working, you may qualify for HBWD
- Workers with countable income of up to \$3,404 per month for a single person and \$4,588 per month for a couple may [qualify for the program](#)
- Unlike other Medicaid programs, HBWD allows enrollees to have up to \$25,000 in assets.
- Depending on their income, enrollees pay a [monthly premium](#) based on their income range to receive comprehensive healthcare coverage.





# Medicaid: Health Benefits for Workers with Disabilities HBWD

- HBWD [Health Benefits for Workers with Disabilities \(HBWD\) | HFS \(illinois.gov\)](#)
- For more information please call our hotline at 1-800-226-0768 (TTY 1-866-675-8440)
- [download an application](#)
- [request an application](#)

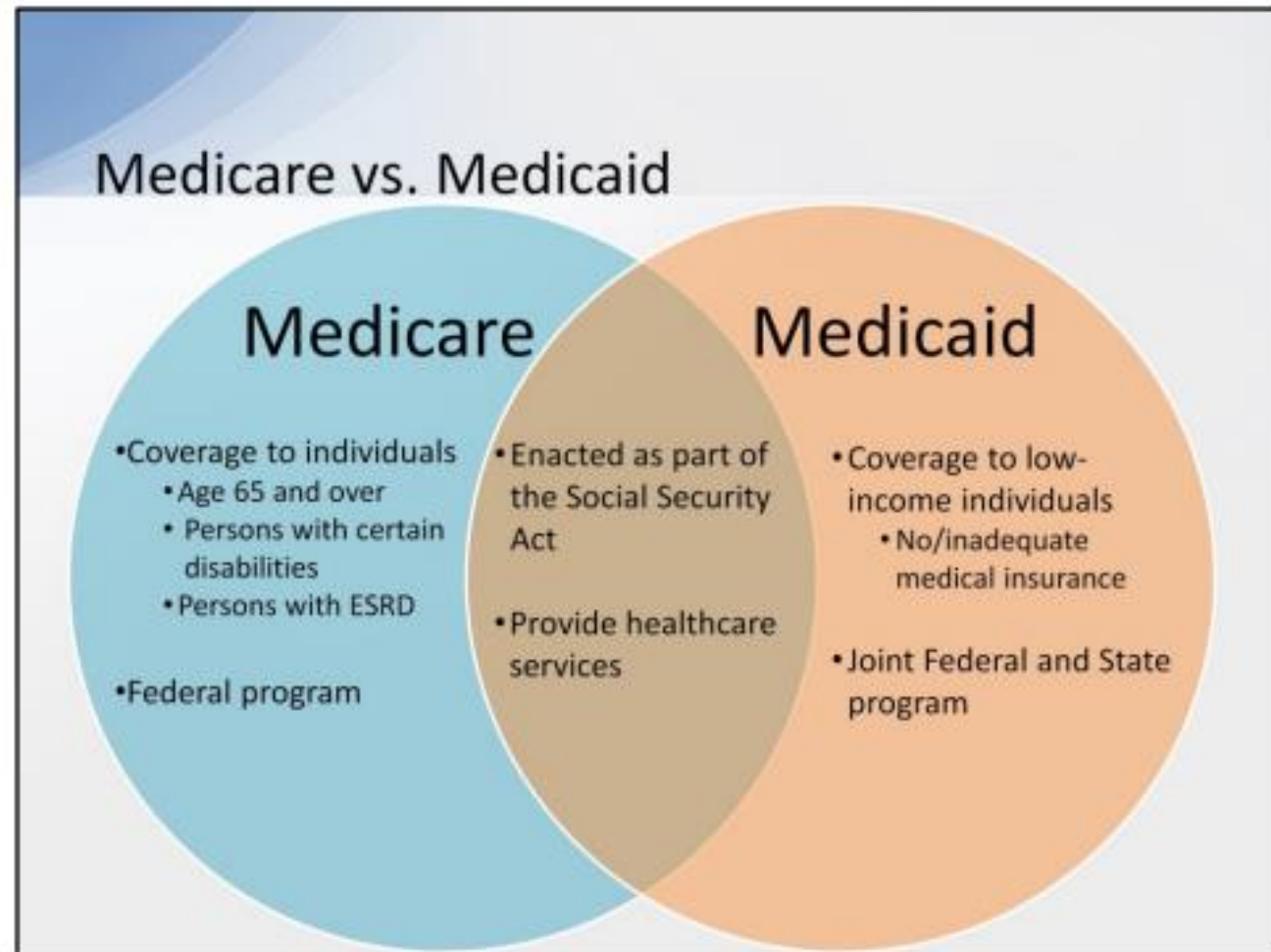


# Medical Coverage: Medicare

For our purposes today:

- Medicare is health coverage for those who have been on SSDI for 24 months (2 years).
- You are eligible for Medicare coverage after 24 months of receiving SSDI benefits, either through being a DAC, working & earning SSDI
- More providers accept Medicare
- [Introduction to Medicare \(hhs.gov\)](https://www.hhs.gov/medicare) Following pictures and info from this link above

# Medical Coverage: Medicare





# Medical Coverage: Medicare

*Medicare vs Medicaid*: how are they different?

- Both provide healthcare services
- Both enacted as part of Social Security Act in 1965
- Medicaid: medical benefits to people with low income, no insurance or inadequate insurance
- Medicare: health insurance for people 65yo+, under 65 w/ disabilities, and all people with End Stage Renal Disease.





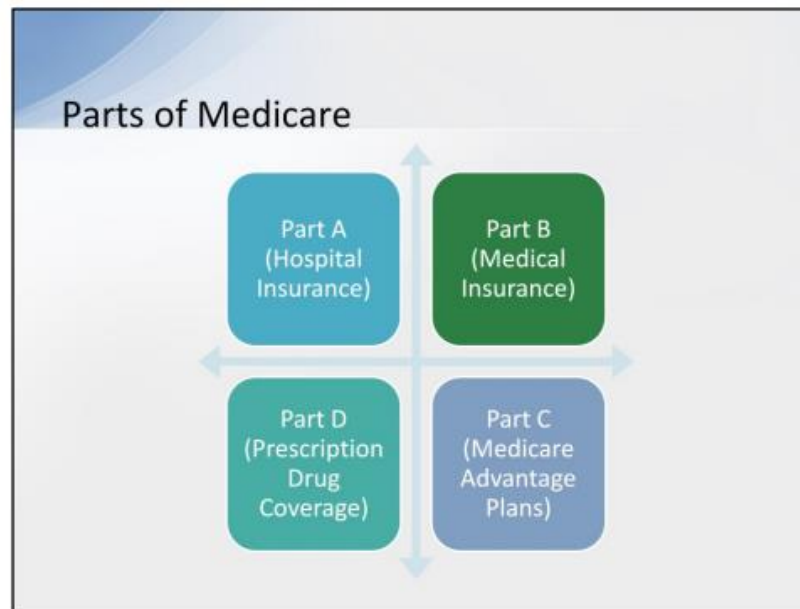
# Medical Coverage: Medicare eligibility

How does a person under 65 with a disability qualify?

- Medical condition that meets Social Security's definition of disability
- Receiving SSDI benefits for 24 months

# Medical Coverage: Parts of Medicare

- Basic Medicare: Part A & Part B.
- Prescription coverage can be added as Part D.
- Part C is optional. “Medicare Advantage Plans”





# Medical Coverage: For more info on Medicare

- Citations for Medicare info
  - [Introduction to Medicare \(hhs.gov\)](https://www.hhs.gov/medicare)
- Introduction to Medicare Fact Sheet from Centers for Medicare & Medicaid Services (CMS)
  - [Fact Sheet: Introduction to Medicare \(cms.gov\)](https://www.cms.gov/medicare/coverage/factsheets)

# Medical Coverage: Private Insurance

Coverage you purchase through

- Your employer,
- Directly from a private insurance company, or through
- Health insurance marketplace
  - [www.Healthcare.gov](http://www.Healthcare.gov)
- If you don't have medical insurance through employer:
  - Purchase directly from private insurance company
  - Purchase on the Marketplace: [www.healthcare.gov](http://www.healthcare.gov)
  - ABE Illinois [Illinois.gov](http://Illinois.gov) - [IL Application for Benefits Eligibility \(ABE\) ABE Home Page](#) (note: not private insurance)





# Medical Coverage: Private Insurance

Two types of policies: Fully funded and Self-funded (ERISA) plans

- Fully-funded
  - These are policies that are regulated by state laws & regulations
  - State mandates cover these policies
  - Individual policies purchased directly from insurer
  - Group policies through employer
  - Insurance companies pay for the costs of medical care



# Medical Coverage: Private Insurance

- Self-funded or ERISA plans
  - Usually larger employers
  - These policies governed by federal laws
  - State mandates do not apply to these
  - Employer contracts with a private insurer to process all claims
    - Employer is covering the costs of medical care
    - Employer therefore has a bit more input on what is covered
    - Insurer still makes “medical necessity” determination



# Medical Coverage: Private insurance take-aways

- “Never take the first no as the last answer.” –Suzanne Aaron ;)
  - If denied coverage for a procedure or therapy, there is always an appeal process.
- Put the customer service number for your insurance company on speed dial.
- Bookmark the Summary of Benefits for your policy.
- Ask if you can be assigned a Case Manager if your family medical situation is complicated

So, what is this PUNS thing anyway?







# Adult living: Home and Community Based Services or “Medicaid Waivers”

## **A VERY *brief* and incomplete history...**

- The way it used to be: individuals with disabilities that had high support needs (therapies, activities of daily living ADLs, supervision, supports, etc) → large group homes or institutions
- But...very \$\$\$ AND very isolating; in some cases abusive, so...
- Home and Community Based Services (HCBS)!
  - A.k.a. Medicaid Waivers
  - “Waive” the requirement to live in a nursing home or institution to receive services



# Adult living: Home and Community Based Services or “Medicaid Waivers”

- Why are they called *Medicaid* waivers?
  - The services that waivers provide are paid for by Medicaid
- “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.”
  - [Home and Community Based Services Waiver Programs | HFS \(illinois.gov\)](#)



# Adult living: Home and Community Based Services or “Medicaid Waivers”

Two different divisions within the Illinois Department of Human Services (DHS) provide waivers to people with Intellectual and Developmental Disabilities (I/DD)

- Division of Developmental Disabilities (DDD)
- Division of Rehabilitation Services (DRS)



# Adult living: Home and Community Based Services or “Medicaid Waivers”

## **Division of Developmental Disabilities**

- Adults with Developmental Disabilities waiver
- Children and Young Adults with DD Support Waiver\* (\*see slide 43)
- Children and Young Adults with DD Residential Waiver\* (\*see slide 43)
- Important: these are not “entitlement” programs, unlike:
  - Intermediate Care Facilities: Developmental Disabilities (ICF-DD)
  - State Operated Developmental Centers (SODCs), a type of ICF-DD
  - No waiting list for the above

ALL have a waiting list. It is called...





# Adult living: Home and Community Based Services or “Medicaid Waivers”

- **PUNS:**

Prioritization of **U**rgency of **N**eeds for **S**ervice

- PUNS is a database that registers people who want/need Developmental Disability Waiver Services, i.e.
  - Community Integrated Living Arrangements (CILAs)
  - Home Based Supports
  - Child Group Homes
- Two categories: Seeking Services and Planning for Services
- [IDHS: Illinois PUNS - Division of Developmental Disabilities \(state.il.us\)](http://state.il.us)



# Adult living: Home and Community Based Services or “Medicaid Waivers”

## Current situation in Illinois:

- Under a federal Consent Decree (Ligas Consent Decree)
  - [IDHS: Ligas Consent Decree Overview \(state.il.us\)](https://state.il.us/idhs/ligas-consent-decree-overview)
  - Lawsuit filed on behalf of adults with DD living in ICF-DDs who wanted to move to live in community OR people living at home who wanted community based services & settings.
  - IL too dependent on institutions
  - Priority for funding went to adults wanting to leave institution and live in their community
- 47<sup>th</sup> in the nation? State of the States report
  - [SOS SABC brief final.pdf \(colemaninstitute.org\)](https://www.colemaninstitute.org/sos-sabe-brief-final.pdf)



# Adult living: Home and Community Based Services or “Medicaid Waivers”

- Continued current situation in Illinois
  - \*No children pulled from waiting list in many years
    - Crisis situations are the exception: at risk of abandonment, neglect, homelessness, extreme danger
  - Still recommended to get on PUNS ASAP
    - Lets legislators & government officials know how many people need services
    - You never know when the situation will change
  - At age 18, move from “Planning” to “Seeking” during annual PUNS review
  - Current policy: no one waits more than 5 years to be pulled from PUNS once in “Seeking” category




# Adult living: Home and Community Based Services or “Medicaid Waivers”

## How to apply for DDD waiver services

- Through your region’s Independent Service Coordination agency
  - [IDHS: Office Locator \(state.il.us\)](https://state.il.us)
  - Office type: enter Developmental Disability Services
  - Select your county
  - Click “Find Offices”
- Meet with a Pre-Admission Screener





# Adult living: Home and Community Based Services or “Medicaid Waivers”

## What services are available?

- In-home supports
- Respite care
- Job Coaches
- Residential Living Arrangements
- Adaptive Equipment
- Etc...



# Adult living: Home and Community Based Services or “Medicaid Waivers”

Remember this?

Two different divisions within the Illinois Department of Human Services (DHS) provide waivers to people with Intellectual and Developmental Disabilities (I/DD)

- Division of Developmental Disabilities (DDD)
- Division of Rehabilitation Services (DRS)



# Adult living: Home and Community Based Services or “Medicaid Waivers”

## Division of Rehabilitation Services (DRS)

### Home Based Services waiver

- [Persons with Disabilities | HFS \(illinois.gov\)](https://www.illinois.gov/IDHS/CommunityEngagement/Pages/Persons-with-Disabilities.aspx)
- Individuals with disabilities under age 60
- Risk of placement in a nursing facility
  - Determined by Determination of Need score (DON)
- Medicaid eligible (there it is again!) or HBWD
- DRS also helps people find jobs, but that’s another discussion!



# Adult living: Home and Community Based Services or “Medicaid Waivers”

- What’s available on the **DRS Home Based Waiver**:
  - Personal Assistant
  - Home Health Aide
  - Homemaker services
  - Adult day care
  - Environmental Accessibility Adaptations
  - Home delivered meals
  - Respite
  - Nursing, etc
- **NO WAITING LIST.**






# Adult living: Home and Community Based Services or “Medicaid Waivers”

## How to apply for DRS Home Based Waiver

- Self-referral
  - [DHS: Rehabilitation Services: Apply Online \(illinois.gov\)](https://www.illinois.gov/dhs/rehabilitation-services/apply-online)
- Through your region’s DRS office
  - [IDHS: Office Locator \(state.il.us\)](https://state.il.us/idhs/office-locator)
  - Office type is Rehabilitation Services
  - Select your county
  - Click Find Offices



# Adult living: Home and Community Based Services or “Medicaid Waivers”

So which is better for my loved one? What’s the difference?

- Totally your call! Each family situation is different
- One difference: DDD waivers offer day programming; DRS does not
- Many people get on DRS Home Based waiver once exiting school services (graduation or Transition services) while waiting to be pulled from PUNS
  - Remember: No waiting list!

# Adult living: Home and Community Based Services or “Medicaid Waivers”



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# Other resources

- ABLE accounts
  - [Why ABLE? | IL ABLE \(illinoisable.com\)](https://illinoisable.com)
- Also available on ABE
  - [Illinois.gov](https://illinois.gov) - IL Application for Benefits Eligibility (ABE) [ABE Home Page](#)
  - Supplemental Nutrition Assistance Program (SNAP benefits)
  - Temporary Assistance for Needy Families (TANF)
  - Medicare Savings Program (MSP)





# Contact information

- Contact the **Illinois Life Span Program** for more information on the topics we covered today.

[www.illinoislifespan.org](http://www.illinoislifespan.org)

800-588-7002

- Contact **Illinois Family To Family Health Information Center** for questions involving a deeper dive into health insurance questions, obstacles, etc.

[Family-to-Family Health Information Center | The Arc of Illinois](#)

815-464-1832, ask for Family to Family





# Thanks for joining us today!

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