



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

**The Arc of Illinois
Illinois Life Span Program
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Types of assistance we'll cover today

- **Financial Assistance: federal**

- SSI
- SSDI

- **Medical Coverage**

- Medicaid
- Medicare
- Private insurance

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

- What is this PUNS thing anyway?



Expectations for today

My role

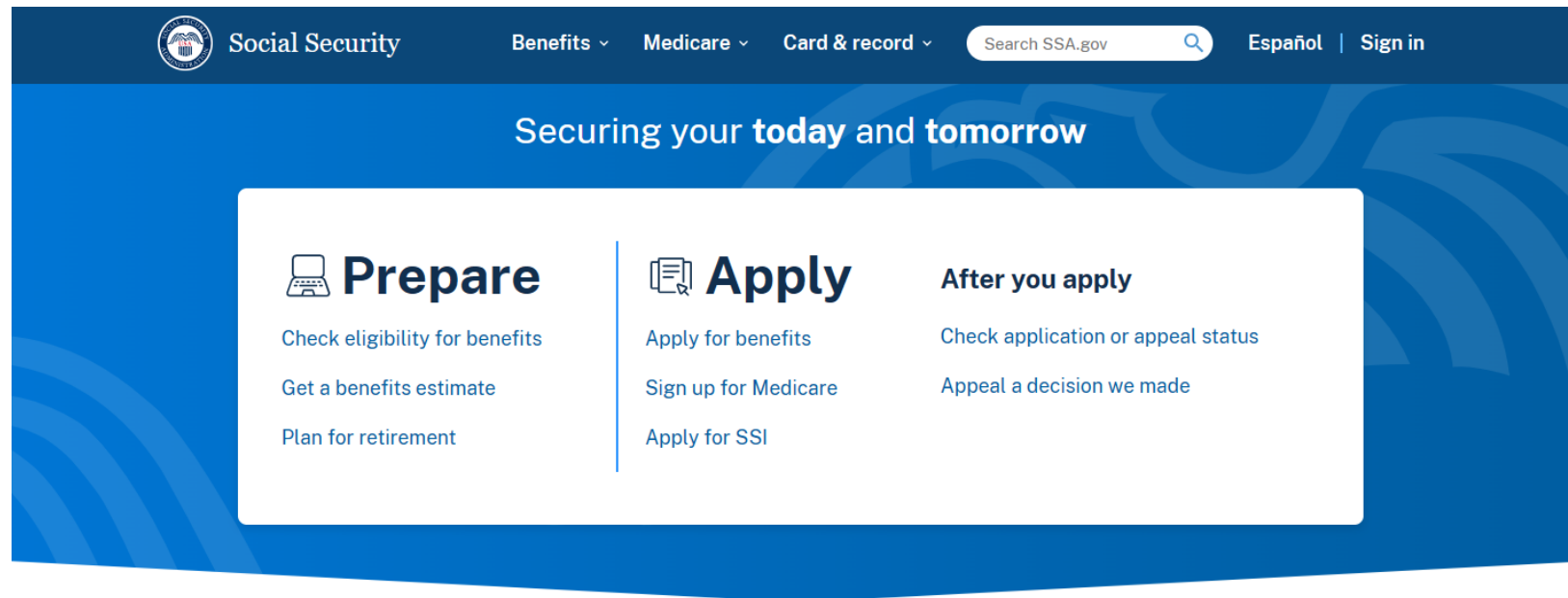
- Define
- Describe
- Direct
- ~~Benefits Counselor~~
- ~~Financial Planner~~
- Fellow parent on this journey

Goals

- Identify federal and state programs that benefit people with disabilities in Illinois
- Describe the eligibility for each
- Describe the difference
- Know where to go for assistance


Social Security Administration

www.ssa.gov



The screenshot shows the homepage of the Social Security Administration website. At the top, there is a dark blue navigation bar with the Social Security logo on the left, followed by the text "Social Security". To the right of the logo are several menu items: "Benefits", "Medicare", and "Card & record", each with a small downward arrow. Further right is a search bar with the placeholder text "Search SSA.gov" and a magnifying glass icon. On the far right of the navigation bar are the links "Español" and "Sign in". Below the navigation bar is a large blue banner with the text "Securing your today and tomorrow" in white. In the center of the banner is a white rectangular box containing three columns of content. The first column is titled "Prepare" with a laptop icon and lists three items: "Check eligibility for benefits", "Get a benefits estimate", and "Plan for retirement". The second column is titled "Apply" with a document icon and lists three items: "Apply for benefits", "Sign up for Medicare", and "Apply for SSI". The third column is titled "After you apply" and lists two items: "Check application or appeal status" and "Appeal a decision we made".

Manage benefits & information



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. Paid monthly.
- 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.
- Two programs: Children’s SSI (up to age 18) and SSI for adults.
- [Understanding SSI - SSI Eligibility \(ssa.gov\)](https://www.ssa.gov/understanding-ssi-ssi-eligibility)



SSI: Supplemental Security Income: Financial Eligibility

- Financial
 - based on household income until the month after the 18th birthday
 - After age 18, parental income is waived.
- Nutshell guidelines: income *and* assets
 - \$2,000 in financial resources (\$3K couple)
 - One home
 - One car
 - [Understanding SSI Resources](#)
 - [Understanding SSI for Children](#)



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. (Earnings under \$1,550/month (\$2,590/mo if blind) in 2024.)
- 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 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 \(ssa.gov\)](#)
- SSI for children under 18yo:
 - [Understanding SSI - SSI for Children \(ssa.gov\)](#)
 - 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 \(ssa.gov\)](#)
 - Income, resources & living arrangements



SSI: Supplemental Security Income

How to apply

- Check eligibility requirements online first:
 - [SSI Eligibility requirements](#)
- Apply online,
 - [Disability Benefits | SSA](#)
 - New link for assistance when applying: [Get Started to Apply for SSI | SSA](#)
 - Apply the month following their 18th birthday
- Or Call National 800 Number:
 - 1-800-772-1213 or local office
 - If necessary, they can schedule an appointment to serve you in person
 - SSA still recommending online & phone contact if possible



SSI: Supplemental Security Income: Helpful links

- [Understanding Supplemental Security Income](#) brochure
- [What You Need To Know About Your Supplemental Security Income \(SSI\) When You Turn 18](#) brochure
- [Links to SSI Spotlights \(ssa.gov\)](#)



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).
- A minor Child/Disabled Adult Child (DAC) can receive SSDI payments *based on their parent’s Social Security earnings* record when a parent:
 - Retires,
 - Starts receiving Disability Benefits themselves (becomes disabled), or
 - Dies.
 - [How You Qualify | Disability Benefits | SSA](#)
- 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 can qualify for...
- Child Disability Benefit (CDB)
 - DAC: Disabled Adult Child (After age 18)
 - Adult with a qualified disability that began before age 22
 - Medical requirements for over 18yo are the same as SSI
 - Unmarried
 - Earnings under \$1,550/month (\$2,590/mo if blind) in 2024



SSDI Social Security Disability Insurance: Beneficiaries

- You can also qualify for SSDI by working and earning credits (previously referred to as “quarters”).
- You can earn up to 4 credits in one year
- 2024 credit is \$1,730
- [How You Earn Credits 2024 \(ssa.gov\)](https://www.ssa.gov)
- ***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 Disability Report](#)



SSDI Social Security Disability Insurance: helpful links

- [Disability Benefits publication](#)
- [Benefits For Children With Disabilities publication](#)
- Disability Starter Kits: helps you get ready for disability interview or online application.
 - [Disability Starter Kits](#) for both children and adults
- SSA website will tell you if you can apply online for these programs



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 must 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.



Illinois Medicaid: All Kids


What children qualify? They must...

- Live in Illinois
- Be under the age of 18 (ends at 19)
- Meet the insurance requirements for All Kids
- Have a family income that meets the All Kids Income Limit. NO asset test.
 - [Healthcare for Kids | HFS \(illinois.gov\)](https://www.illinois.gov/HealthcareforKids)



Illinois Medicaid: All Kids


- All Kids covers children in household with income up to 318% Federal Poverty Level (FPL)
 - Parents/caregivers can get Medicaid coverage with household income up to 138% FPL
 - families should go ahead and apply for their kids even if they are not sure about eligibility
- Financial eligibility calculated using percentages of Federal Poverty Level
 - [NeedyMeds](#) – FPL calculator
 - [Federal Register :: Annual Update of the HHS Poverty Guidelines 2024](#)



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
- [IDHS: Aid to the Aged, Blind, and Disabled \(AABD\) \(state.il.us\)](https://www.idhs.state.il.us)



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


- If eligible, can apply at age 18
 - Apply for SSI first if a new application
- 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”
 - Medical providers can enroll with HFS at any time
- Helps “PUNS pull” process when pulled from the waiting list
- Redeterminations, new card every year



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

Increase to asset limit in 2023! ONLY for AABD category:

- Previously \$2,000 for one person and \$3,000 for a couple
- AABD asset limit is \$17,500 for a single household AND a household of two



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

To apply:

- Apply online
 - [ABE Home Page](#)
- Download application
 - [ABE Application - English](#)
 - [ABE Application - Spanish](#)



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 (2024 annual income of \$20,120/individual, \$27,214/couple) can be covered.
- Federal government reimburses states at a much higher percentage (incentive for states to expand Medicaid coverage under ACA)



Illinois Medicaid: ACA Adults

- To apply
 - Application for Benefits Eligibility (ABE)
 - [ABE Home Page](#)
 - Downloadable written application can be found here:
 - [ABE Application - English](#)
 - [ABE Application - Spanish](#)
 - Family Community Resource Center (FCRC)
 - [IDHS: Office Locator \(state.il.us\)](#)



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 . [Health Benefits for Workers with Disabilities \(HBWD\)](#)
- Workers with countable income up to or less than 350% FPL can 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. [HBWD Premiums](#)



Medicaid: Health Benefits for Workers with Disabilities HBWD

- For more information, please call their hotline at 1-800-226-0768 (TTY 1-866-675-8440)
- [Download application in English](#)
- [Download application in Spanish](#)
- To request an application to be mailed to you, call the hotline above.
- If eligible for HBWD, also eligible for Medicaid Waivers. Stay tuned!

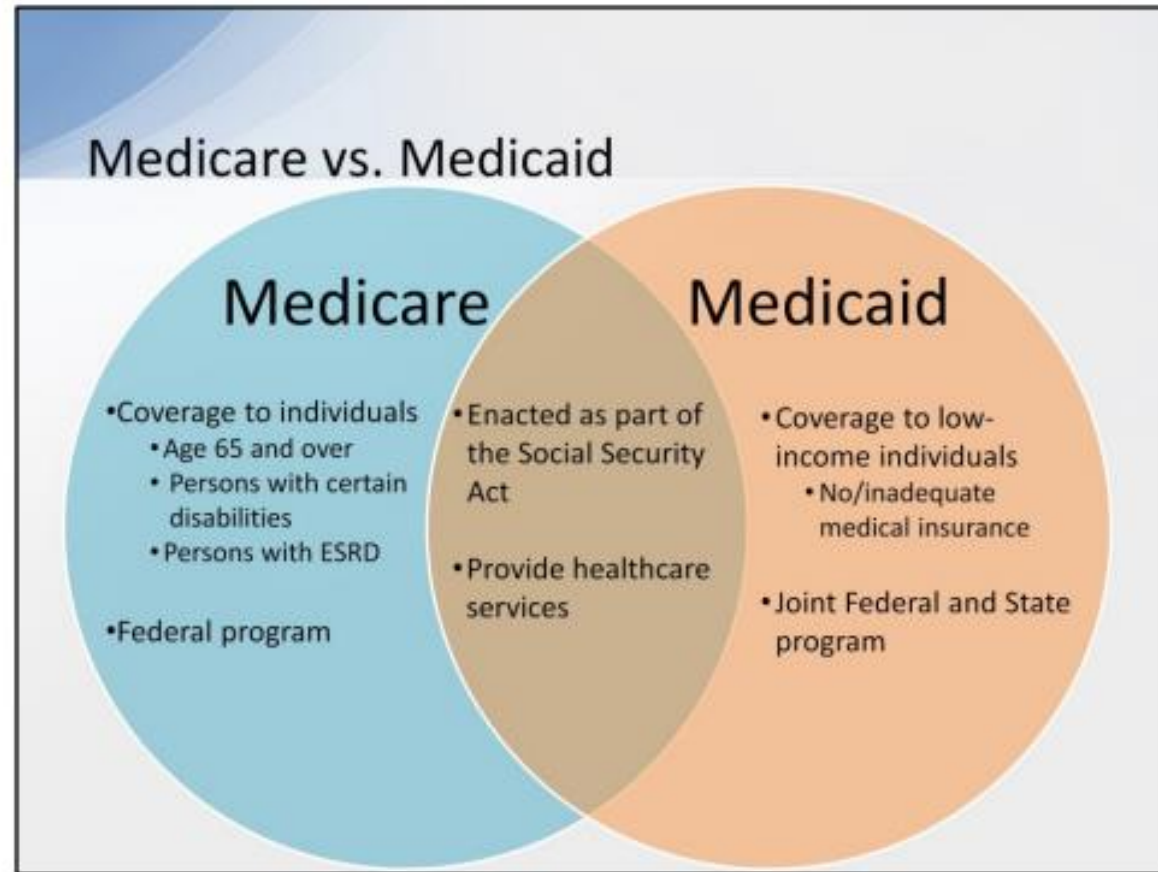


Medical Coverage: Medicare

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) Source for information on this slide and next.

Medical Coverage: Medicare



[Introduction to Medicare \(hhs.gov\)](https://www.hhs.gov/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
- Differences:
 - **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.



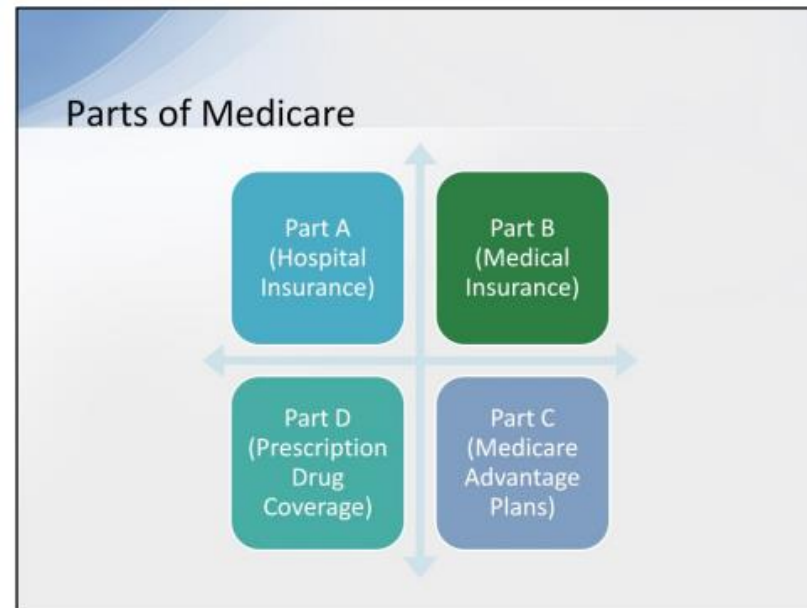
Medical Coverage: Medicare eligibility

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”



[Introduction to Medicare \(hhs.gov\)](https://www.hhs.gov)



Medical Coverage: For more info on Medicare

- Citations for Medicare info
 - [Introduction to Medicare \(hhs.gov\)](https://www.hhs.gov)
- Introduction to Medicare Fact Sheet from Centers for Medicare & Medicaid Services (CMS)
 - [Fact Sheet: Introduction to Medicare \(cms.gov\)](https://www.cms.gov)
- Arc of Illinois Fact Sheet Understanding SSDI and Medicare
 - [Understanding-SSDI-and-Medicare.Sept.-2023.pdf \(illinoislifespan.org\)](https://www.illinoislifespan.org)



Medical Coverage: Private Insurance

Coverage you purchase through

- Your employer,
- Directly from a private insurance company, or through
- Health insurance marketplace
 - 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
 - ABE Illinois 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**
 - Typically larger employers
 - Not required to follow federal ACA mandates
 - Not required to follow individual state mandates
 - Employer contracts with a private insurer to process all claims
 - Employer is covering the costs of medical care
 - Employer determines what is covered
 - Insurer still makes “medical necessity” determination
 - Appeals → US Dept of Labor.
 - Unionized employees → Union Rep



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 usual Medicaid requirements 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](#)
- Illinois has nine HCBS Waivers.



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
- Children and Young Adults with DD Residential Waiver
- 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

- 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 \(state.il.us\)](https://www.idhs.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://www.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



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


- Continued current situation in Illinois
 - *First “children’s pull” in 12 years summer 2022
 - Crisis situations are the exception: at risk of abandonment, neglect, homelessness, extreme danger
 - Get on PUNS ASAP
 - This 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 (or if needing services now)
 - 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)

Persons with Disabilities Waiver

- [Persons with Disabilities | HFS \(illinois.gov\)](https://www.illinois.gov)
 - 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 **Persons with Disabilities Waiver**:
 - Home Based Services
 - 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 Persons with Disabilities 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://www.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”

Waivers we didn't discuss but are available:

- [Medically Fragile/Technology Dependent Children](#)
- [Persons with Brain Injury \(BI\)](#)
- [Persons who are Elderly](#)
- [Persons with HIV or AIDS](#)
- [Supportive Living Program](#)



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 Home Based services through [Persons with Disabilities Home Services Program](#) 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?](#)
- Also available on ABE
 - [Application for Benefits Eligibility \(ABE\)](#)
 - Supplemental Nutrition Assistance Program (SNAP benefits)
 - Person with disability must be 22yo
 - Under age 22: household income considered
 - 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
800-588-7002
- Contact **Illinois Family To Family Health Information Center** for questions involving a deeper dive into health insurance questions, obstacles, etc. for families of children under the age of 22.
[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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