



Navigating the Maze: Understanding Agencies and Acronyms

The Arc of Illinois Life Span Team

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Information accurate as of 1/23/2026

About The Arc:

Largest National Community-Based Organization

Advocating for and serving people with intellectual and developmental disabilities and their families throughout the entire life span.

650 Chapters Nationwide

Advocating on the front lines to ensure that people with IDD and their families have the support and services they need to be fully engaged in their communities.

Vision and Mission

The Vision:

Happy lives with full participation in the community.

The Mission:

Empowering persons with disabilities to achieve full participation in their community life through informed choices.

Our Advocacy Includes:

Providing key information on legislative and policy issues.

Empowering individuals to stand up for important policies impacting people with ID/DD.

Making information and resources accessible through our programs, webinars, and events.

The Arc of Illinois Life Span Program

Statewide Resources and Information, Focused on Developmental Disability Services and Supports

Illinois Life Span (ILS) is a program of The Arc of Illinois – a statewide advocacy organization committed to empowering people with disabilities to achieve full participation in community life through informed choices.



If you can't find what you need or just want additional help,
please call us at 1-800-588-7002.

All the information you need in one user-friendly location at:
www.illinoislifespan.org



So much to know. So many **acronyms!**



Education

ISBE Illinois State Board of Education

What do they do?

- The State Board consists of nine members who are appointed by the Governor with the consent of the Senate. Board members serve four-year terms, with State Board membership limited to two consecutive terms.
- The board sets educational policies and guidelines for public and private schools, preschool through grade 12, as well as vocational education. It analyzes the aims, needs and requirements of education and recommends legislation to the General Assembly and Governor for the benefit of the more than 2 million school children in Illinois.

Why do I need to know about ISBE?

ISBE oversees education for all students in Illinois. The Special Education Department assures that these programs and services meet state and federal requirements. This involves both compliance and technical assistance functions.

Website

[Illinois State Board of Education](https://www.isbe.net/)

How can I contact ISBE?

- **General inquiries:**
 - **Phone:** (866) 262-6663 or (217) 782-4321.
 - **Email:** support@isbe.net.
 - **Website:** <https://www.isbe.net/>.

IEP	Individualized Education Program
What does this do?	After qualifying for special education services, the IEP documents the goals, objectives and special services (therapies, etc.) for which your child qualifies in order to benefit from their public-school education.
Why do I need to know about this?	If your child qualifies for an IEP, this document guides their education in the public schools and is a legally binding document outlining what your child needs to be successful in school.
Website/resources:	<ul style="list-style-type: none"> • Individualized Education Program (IEP) Family Resource Center on Disabilities • Core Special Education Resources : Resources : What We Do : Family Matters PTIC • Individualized Education Programs (IEPs) - Articles, Law, Regulations, Cases, Frequently Asked Questions about Individualized Education Programs (IEPs) from Wrightslaw

Bonus section: IEP problem-solving!

Problem	Solution
<p>I do not understand my child's IEP or if my district is following the law, where can I get help?</p>	<p>Family Matters Parent Training & Information Center (FMPTIC). Phone: 1-866-436-7842 https://www.fmptic.org/ Equip for Equality Special Education Helpline: 1-866-KIDS-046 (1-866-543-7046) or special@equipforequality.org</p>
<p>Equip for Equality Helpline</p>	<p>Non-profit with 10 lawyers on staff</p> <p>Main purpose: Provide legal advice to parents so they can advocate for their student's IEP or to make a request for an initial evaluation. They also educate on parental rights.</p> <p>Smaller amount of callers will get more direct services where E4E will represent parents @ IEP meetings, Mediation, or Due Process.</p> <p><i>Cases that might qualify:</i></p> <ul style="list-style-type: none"> -Least Restrictive Environment -(TDS) parents wanting to keep their kids in transition programs -Denial of Eligibility -Expulsion <p>(A non-example is "the IEP is not robust enough")</p>

Problem	Solution
<p>What if I disagree with a team decision in the IEP?</p>	<p>ISBE recommends you make a request for an informal meeting with your school. If that meeting does not result in a successful solution, then call a formal IEP meeting. Document everything discussed in the meeting.</p>
<p>How can I file a complaint if my school district is not following IDEA guidelines?</p>	<p>Who to Contact: Contact the ISBE mediation coordinator at the following: (866) 262-6663 (toll-free for parents) or (217) 782-5589.</p> <p>Mediation Request Form: You can find the Mediation Request Form on ISBE's website or request it by calling the ISBE Special Education Division at (217) 782-5589 or (866) 262-6663.</p> <p>How to Submit: Once you have the Mediation Request Form, you can submit it by email, mail, or fax to the ISBE's Special Education Department.</p> <ul style="list-style-type: none"> • Email: statemediation@isbe.net • Mail: Illinois State Board of Education, Special Education Department, 100 North First Street, N-253, Springfield, IL 62777-0001 • Fax: (217) 782-0372
<p>If mediation is not successful, your next option is to file a complaint with ISBE.</p>	<p>A complaint for special education can be filed no more than a year from the initial incident. You will fill out a complaint form detailing information about the alleged violation, including when, where, and why it occurred.</p> <p>https://www.isbe.net/Pages/Special-Education-Complaint-Investigation-Process.aspx</p>

Problem	Solution
<p>My child's school district will not return my calls, who can I get to listen?</p>	<p>Regional Office of Education Click this link to find your local office: https://apps.isbe.net/ELISAPP/Pages/Public/MessageCenterMap.html</p>
<p>I cannot find a copy of my child's IEP how can I get one?</p>	<p>You should contact your child's case manager at school to request a copy or you can call your school district's special education coordinator/director to get a copy.</p>
<p>How long should I keep my child's IEP after they graduate?</p>	<p>Keep the most recent evaluation and IEP <u>FOREVER!</u> Your school is required to keep the IEP records for 60 years (section 4 of the IL School Student Record Act), however, you can't rely on this.</p>
<p>I rarely hear from my child's regular education teachers, what can I do?</p>	<p>Consider requesting an addendum to the IEP that states regular education teachers make bi-monthly or monthly contact(if they are in high school/middle school) or at the elementary level, request weekly or bi-weekly contact. Be flexible in the contact method. In elementary school, another option would be weekly progress reports via planner or other mutually agreeable method.</p>
<p>My child's special education teacher is afraid to speak up about the services my child is/isn't getting, what can I do?</p>	<p>Schedule a phone conference with the teacher, in advance of the IEP meeting, to prepare yourself to advocate for your child's needs and services.</p>



Illinois Services for People with Disabilities



IDHS (or just DHS)	Illinois Department of Human Services
What does this do?	<ul style="list-style-type: none"> • This is the “umbrella” agency under which several departments exist that provide services for Illinois residents. • For our purposes today, we will focus on departments that serve People With Disabilities (PWD – another acronym!)
Why do I need to know about IDHS?	You may get letters from IDHS that explain or approve/deny services from the agencies that serve PWD.
Website:	IDHS: Illinois Department of Human Services



HCBS

Home and Community Based Services Waiver Programs

What does this do?

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.

Why do I need to know about it?

- If a person is at risk of needing institutional level of care, then these programs help them stay in their home and/or community and receive services there instead of in a nursing home or institution.
- If a loved one will need help living independently (bathing, dressing, cooking, feeding, paying bills/managing money, etc.) then these services can provide this support if eligible.

Website:

[Home and Community Based Services Waiver Programs | HFS](#)



DDD

Division of Developmental Disabilities

What does this do?

The DDD oversees and provides services for people in Illinois with Intellectual and Developmental Disabilities (IDD).

Why do I need to know about it?

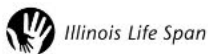
This division oversees three Home and Community Based Services (HCBS) also known as Medicaid Waivers:

- Adults with Developmental Disabilities Waiver
- Children with Developmental Disabilities Support Waiver
- Children with Developmental Disabilities Residential Waiver

DDD also oversees the PUNS database, which is a registry of people who are waiting for any of the above HCBS.

Website:

[IDHS: Developmental Disabilities](#)



ISC

Independent Service Coordination office

What does this do?

ISCs are the point of entry for services from DDD.

Why do I need to know about it?

You must contact your area's ISC to apply for services/be put on the PUNS (see next slide) list if eligible.

Website:

[IDHS: Office Locator](#)

- First drop-down: choose Developmental Disability Services
- Second drop-down: select your county
 - If Cook County, enter your zip code
- Your ISC contact information will be provided
- OR call the Division of Developmental Disabilities Hotline at **1-888-DD-PLANS and 1-866-376-8446 (TTY)**

PUNS

Acronym no longer valid!

What does this do?

PUNS is the database of people who are waiting for HCBS from the DDD in Illinois.

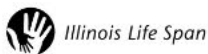
Why do I need to know about it?

- If you have a loved one with IDD that needs or will need help living independently, then the pathway to services from the DDD is to apply through your Independent Service Coordination (ISC!). If eligible, your loved one will be put on the PUNS database.
- Pulls from the PUNS database happen based on time on the list only.

Website:

[IDHS: Signing Up for Services in PUNS](#)

Need help with any of this? Contact our Family Advocate Program!
[Family Advocate Program | The Arc of Illinois](#)



DD Waiver acronyms

CILA	Community Integrated Living Arrangement
I-CILA	Intermittent Community Living Arrangement (typically 15 hours/week of support)
ICF-DD	Intermediate Care Facility for people with Developmental Disabilities
SODC	State Operated Developmental Center
SDA	Self-Directed Assistant – an option under DD waiver
PSW	Personal Support Worker
DSP	Direct Support Professional

DRS

Division of Rehabilitation Services, sometimes “DoRS”

What does this do?

DRS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities.

Why do I need to know about DRS?

DRS provides:

- The Home Services Program [IDHS: Home Services Program \(HSP\)](#)
- Job training and placement through their Vocational Rehabilitation Program [IDHS: Vocational Rehabilitation](#)
- Educational services: [IDHS: Educational Services](#)

Website:

[IDHS: Rehabilitation Services](#)

VR

Vocational Rehabilitation or Voc Rehab

What is this?

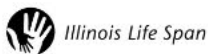
We help people with disabilities find and keep jobs. Our goal is to help our customers find quality employment that pays a living wage and offers a chance for advancement.

Why do I need to know about it?

- They help high school students who have disabilities plan for their futures after high school graduation through our Transition and STEP programs.
- Their 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.

Website:

[IDHS: Vocational Rehabilitation](#)



HSP

Home Services Program

What does this do?

This is DRS' umbrella program that provides HCBS. It helps people with disabilities stay in their own homes and get the services they need.

- Personal Assistant (PA as opposed to PSW under DD)
- Homemaker Services
- Maintenance Home Health (services prescribed by a physician)
- Assistive Equipment
- Environmental Modifications, and more.

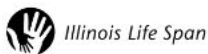
Why do I need to know about this?

- This program has no waiting list (but you still need to meet eligibility)
- May be sufficient to meet the current needs for people with IDD.
- If eligible, you can be on the HSP while waiting to be pulled from PUNS.

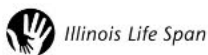
Website:

[IDHS: Home Services Program \(HSP\)](#)

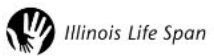
To sign up for either VR or HSP, use the Office Locator [IDHS: Office Locator](#) and choose Rehabilitation Services, or use the Online Rehabilitation Services Web Referral [DHS: Rehabilitation Services: Apply Online](#)



HFS	Illinois Department of Healthcare and Family Services
What does this do?	The Illinois Department of Healthcare and Family Services (HFS) is responsible for providing healthcare coverage for adults and children who qualify for Medicaid, and for providing child support services to help ensure that Illinois children receive financial support from both parents. The agency is organized into two major divisions, Medical Programs and Child Support Services.
Why do I need to know about this?	If your loved one is on Medicaid or will be, this is the agency that oversees this basic and vital resource.
Website:	Illinois Healthcare and Family Services Healthcare and Family Services



Ready for a whole bunch of acronyms?



Programs under HFS & DCFS

[Illinois Healthcare and Family Services](#)

ACA Adults: Affordable Care Act
[Get Covered Illinois](#)

*[IDHS: WAG 25-03-02 \(2\) Medical FPLs](#)
[Cost Changes for Get Covered Illinois Customers](#)

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 (2025 monthly income of \$1,799 individual, \$2,432/couple*) can be covered.

AABD: Aid to Aged Blind and Disabled
[Healthcare and Family Services Medical Benefits | HFS](#)

*[Medicaid Eligibility Income Chart by State \(Updated Feb. 2026\)](#)

Covers seniors, persons who are blind and persons with disabilities with income up to 100 percent of the federal poverty level (FPL) and no more than \$17,500 of non-exempt resources (one person). Federal matching funds are available under Medicaid for these individuals. Also referred to as Healthcare and Family Services Medical Benefits. \$1,304/month effective 4/2025-3/2026*

DCFS: Department of Children and Family Services
[Department of Children and Family Services](#)

Coverage is provided to children whose care is subsidized by DCFS under Title IV-E (Child Welfare) of the Social Security Act as well as children served by DCFS through its subsidized guardianship and adoption assistance programs. (Note: DCFS is not under HFS, but it does provide medical coverage.)

All Kids (not an acronym but important to mention)
[Healthcare for Kids | HFS](#)

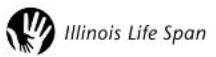
A health insurance program for children living in Illinois who need insurance. Children must be 18 or younger.

HBWD: Health Benefits for Workers with Disabilities
[Health Benefits for Workers with Disabilities \(HBWD\) | HFS](#)

*[Federal Register :: Annual Update of the HHS Poverty Guidelines](#) \$15960/year, \$1330/mo. HBWD 350% FPL = \$4655

The goal of this program is to help people with disabilities work with full Medicaid [healthcare benefits](#). Workers with countable income of up to \$4,655, per month in 2026* for a single person [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 [Premium Costs & Co-Pays | HFS](#) based on their income range to receive comprehensive healthcare coverage

Advocacy organizations



Advocacy

EFE or E4E

Equip for Equality: Illinois' Protection and Advocacy Organization (federally mandated, governor appointed)
[Advancing Civil Rights of People with Disabilities | Equip For Equality](#)

IGAC

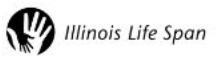
Illinois Guardianship and Advocacy Commission: protects the rights and promotes the welfare of persons with disabilities.
[Illinois Guardianship & Advocacy Commission](#)

PTIC

Parent Training and Information Centers: education on rights and responsibilities under the Individuals with Disabilities Education Act (IDEA)/Special Education.
[Home : Family Matters PTIC](#) Statewide



Federal Programs



SSA

Social Security Administration

What does this do?

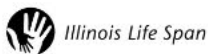
Provides financial protection for our nation's people. They can help you through all life's journeys. [About Social Security | SSA](#)

Why do I need to know about SSA?

Administers [benefits](#) like Retirement, Disability, Survivor, and Family.
Also manages Supplemental Security Income (SSI), enroll people in Medicare, and issue Social Security [numbers and cards](#).

Website:

[The United States Social Security Administration | SSA](#)
ssa.gov



SSI

Supplemental Security Income

What is this?

SSI provides monthly payments to adults and children who have income and resources below specific financial limits, and who meet one of the following criteria:

- They are age 65 or older.
- They are blind.
- They have a medical condition that keeps them from performing substantial gainful activity, which is expected to last one year or result in death

Why do I need to know about this?

Your loved one may qualify for these payments if they meet the eligibility criteria.

Website:

[Supplemental Security Income \(SSI\) | SSA](#)



SSDI

Social Security Disability Insurance

What is this?

Social Security Disability Insurance (SSDI) or “Disability” provides monthly payments to people who have a disability that stops or limits their ability to work.

Why do I need to know about this:

Your loved one may qualify for SSDI if a parent starts receiving Social Security benefits based on their own earnings when they retire, become disabled themselves, or pass away.

If your loved one works, they may qualify for SSDI on their own earnings.

After receiving SSDI benefits for 24 months --> Medicare

Website:

[Disability | SSA](#)



Medicare

Not an acronym!

What is this?

Medicare is health insurance for people 65 or older. You may be eligible to get Medicare earlier if you have a disability, End-Stage Renal Disease (ESRD), or ALS (also called Lou Gehrig's disease).

Why do I need to know about this?

Your loved one may be eligible for Medicare once they have received SSDI benefits for 24 months.

Website:

[Welcome to Medicare | Medicare](#)

The Illinois Life Span team



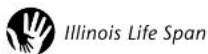
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Questions?



**Illinois Life Span
800-588-7002**

**The Arc of Illinois
815-464-1832
www.thearcofil.org**

