
ASK THE ARC: YOUR DISABILITY SERVICES QUESTIONS ANSWERED



Staff of The Arc of Illinois

Suzanne Aaron, Susan Agrawal, Annie Bruno, and Tiffany Steinhauser

TODAY'S PRESENTATION

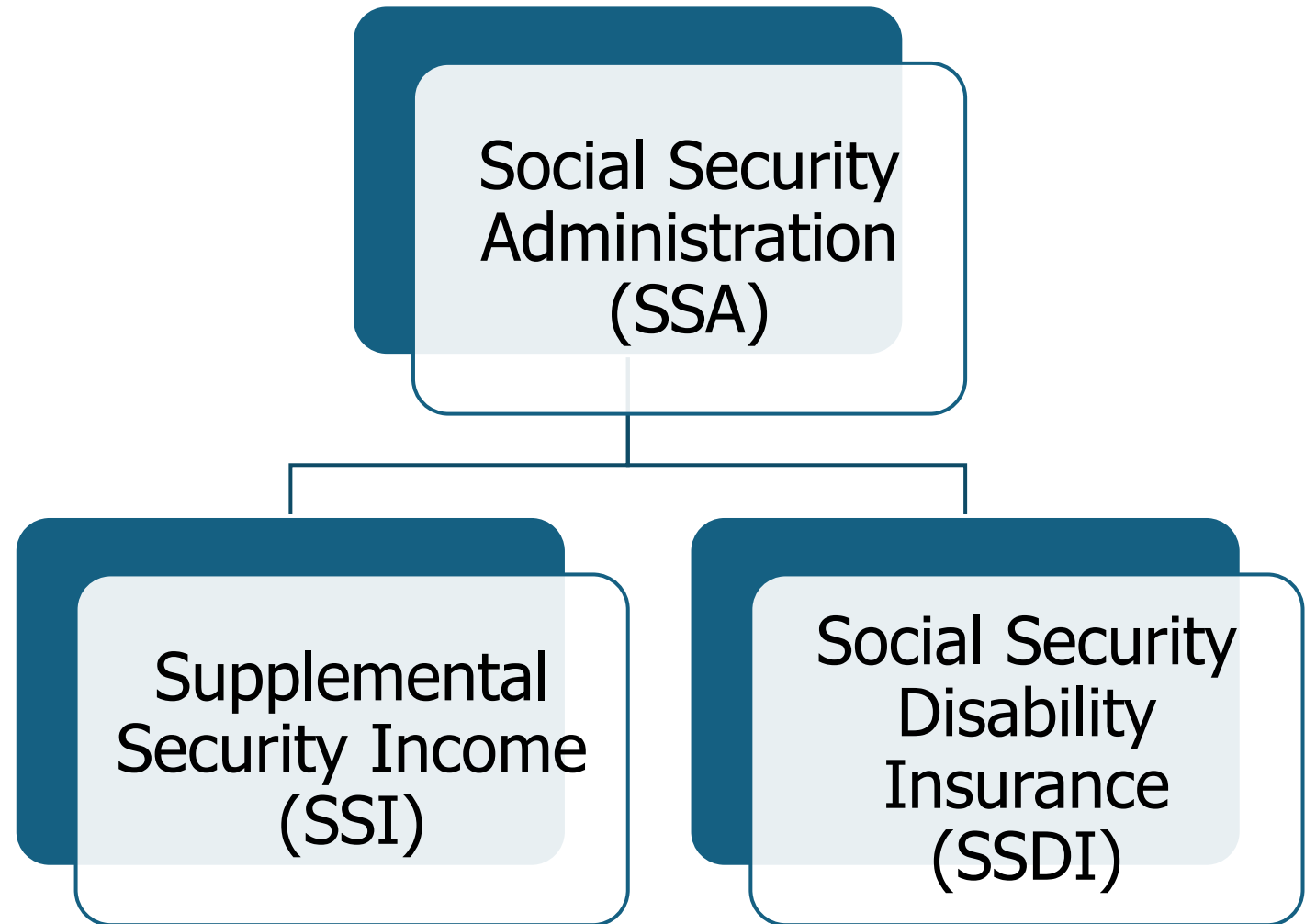
We will answer Frequently Asked Questions on

- Social Security Benefits
- Medicaid, Medicare, and Medicaid Waivers
- The PUNS List and Developmental Disability Waivers
- Special Education and Transition

We will open the floor to answer any additional questions on Illinois benefits and services

SOCIAL SECURITY BENEFITS

SOCIAL SECURITY ACRONYMS



SSI: SUPPLEMENTAL SECURITY INCOME

SSI provides monthly payments to people with disabilities and older adults who have little or no income or resources.

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

SSI FINANCIAL ELIGIBILITY

Under 18yo: based on household income

- Understanding SSI - SSI for Children (ssa.gov)

Over 18yo: only individual's income is counted

- Understanding SSI - SSI Resources (ssa.gov)

Under \$2K in assets
(bank accounts,
investments, land,
etc.)

Assets allowed: one
car, one residence,
burial spaces, up to
\$100K in ABLE
account

SSI MEDICAL ELIGIBILITY

Under 18yo: "marked and severe functional limitations"

- In comparison with same age peers, what is child able to do? How much help is needed?

Over 18yo: can you work?

- Work is defined as Substantial Gainful Activity (SGA): 2026: \$1690/mo; \$2830/mo if blind

Disability must have lasted at least 12 months or is expected to last longer than 12 months (or result in end of life)

HOW TO APPLY FOR SSI

Check eligibility
guidelines online
first
Understanding
SSI - SSI
Eligibility
(ssa.gov)

Apply the month
after 18th
birthday

Apply online
Apply for
Supplemental
Security Income
(SSI) | SSA

Or call national
toll-free number
800-772-1213 or
your local office

In-person
appointments
should be
scheduled ahead
of time Make or
change an
appointment | SSA

SSDI: SOCIAL SECURITY DISABILITY INSURANCE, FAMILY BENEFITS, AND RSDI (RETIREMENT, SURVIVOR & DISABILITY INSURANCE)

Family or Survivor Benefits pay benefits to certain family members if parent is “insured”

- Parent must have worked long enough and paid Social Security taxes on their earnings
- 40 credits, in general
- [How You Earn Credits](#)

Child Disability Benefit (previously Disabled Adult Child or DAC) 18yo+

- Receive payments based on their parent’s Social Security earnings record when a parent:
 - Retires
 - Dies
 - Becomes Disabled themselves

Benefits for Children with Disabilities

- [How Does Someone Become Eligible? | Disability Benefits | SSA](#)
- Medical requirements are the same as SSI

BENEFICIARIES: SSDI, FAMILY BENEFITS/RSDI

Under age 18: Family or RSDI

- No disability requirement
- Payments end at age 18 unless...

Turning 18 and disabled?

- Payments can continue with a qualifying disability
- These payments are a Childhood Disability Benefit (CDB)
- Payment based on parent's earnings

Disabled Adult Child (DAC)

- Adult with disability that began before age 22
- Unmarried
- Meets definition of disabled for adults
- Financial eligibility: SGA again

SSDI on own earnings?

- Young adults with disabilities can qualify for SSDI payments off of their own work record
- Example: earn 6 credits before age 24-->SSDI
- [How You Earn Credits](#)

SOCIAL SECURITY APPLICATION DENIED?

Preemptive actions

- Before applying complete online disability reports
- [SSA-3368-BK - Disability Report- Adult](#)
- [Disability Report - Child - SSA-3820-BK](#)
- Provide ALL documentation requested
- Create MySSA.gov account online

If application is denied

- Do not take the first no as the last answer: appeal
- [Appeal a decision we made | SSA](#)
- Watch your U.S. Mail delivery for letters and respond promptly

Policies and publications

- [Links to SSI Spotlights | Supplemental Security Income \(SSI\) | SSA](#)
- [SSA's Policy Information Site - POMS](#)

MEDICAID AND MEDICAID WAIVERS

WHO CAN GET MEDICAID?

Children 0-19

- All Kids: up to 318% of the Poverty Line, regardless of citizenship
- Children of all incomes in some waivers
 - Medically Fragile Technology Dependent Waiver
 - Support Waiver for Children and Young Adults with Developmental Disabilities
 - Residential Waiver for Children and Young Adults with Developmental Disabilities

Adults 18/19+

- **ACA** Category (adults without dependents): \$1835/month or less, no asset limit
- **AABD** Category (adults with disabilities): \$1330/month or less, \$17,500 asset limit
- **HBWD** Category (adults with disabilities who work): \$4655 a month, \$25,000 asset limit

Spenddown

- Allows you to enroll in Medicaid by spending money on medical bills each month
- Especially useful for adults on waivers, since the waiver services cover the spenddown
- Not useful for children in most cases

All Kids Limits (ages 0-19)

Family Size	Annual Income (MAGI)
Family of 2	\$68,808
Family of 3	\$86,868
Family of 4	\$104,940
Family of 5	\$123,000
Family of 6	\$141,060

Yes, you can have private insurance AND Medicaid!

WHAT MEDICAID WAIVER PROGRAMS ARE AVAILABLE?

Program	Ages	Official Categories	Parent Income & Assets	Waiting List
Medically Fragile Technology Dependent Waiver (MFTD)	0-21 to enter; all ages	Medically Fragile, Technology Dependent	waived	none
Home Services Program (DRS Waivers)	All ages ⁺	Physical Disability, Brain Injury, or HIV/AIDS* (Severe Disability)	counted	none
Support Waiver for Children and Youth with DD	3-22	Intellectual Disability, Developmental Disability, Autism, CP, Epilepsy	waived	Yes, PUNS
Residential Waiver for Children and Youth with DD	3-22	Intellectual Disability, Developmental Disability, Autism, CP, Epilepsy	waived	none
Adults with DD	18+	Intellectual Disability, Developmental Disability, Autism, CP, Epilepsy	not applicable	Yes, PUNS

* Because the Determination of Need looks at Functional Limitations, those without a physical disability, brain injury, or HIV but significant functional limitations may also qualify

+ With some exceptions for those over 60

WHO CAN GET PAID TO CARE FOR THEIR CHILD?

Program	Minors under age 18	Adults over age 18
MFTD Waiver	RN or LPN only CNA possibly coming soon	RN or LPN only CNA for 21+
DSCC Home Care Non-Waiver	RN or LPN only CNA possibly coming soon	RN or LPN only (ages 18-21) CNA possibly coming soon (ages 18-21)
DRS Home Services Program (all waivers)	Unlicensed parents CNA, LPN, or RN	Unlicensed parents CNA, LPN, or RN
Support Waiver for Children and Young Adults with DD	None	Unlicensed parents (ages 18-22)
Adults with Developmental Disabilities	Not applicable	Unlicensed parents

WHAT SERVICES CAN I GET THROUGH MEDICAID WAIVERS?

MFTD Waiver

- Home Nursing (if not through Medicaid)
- Respite
- Home and Vehicle Modifications
- Nurse and Family Training
- Adaptive & Assistive Equipment

Child DD Waiver

- Adaptive & Assistive Equipment
- Behavior Intervention and Treatment
- Home and Vehicle Modifications
- Personal Support
- Self-Direction Assistance

Adult DD Waiver

- Community Day Services
- Residential (Group Home)
- Adaptive & Assistive Equipment
- Behavior Intervention and Treatment
- Home and Vehicle Modifications
- Transportation
- Therapies & Nursing
- Personal Support
- Supported Employment
- Stabilization Services

DRS Home Services Program Waivers

- Individual Provider (Personal Assistance)
- Homemaker
- Adult Day Care
- Home Modifications
- Home Delivered Meals
- Respite
- Nursing, Aide, and Therapies

HOW DO I KEEP MY MEDICAID WHEN I GET SOCIAL SECURITY BENEFITS AFTER A PARENT RETIRES, DIES, OR IS DISABLED?

Two “loopholes” for those who receive too much money because of Social Security Benefits (based off a parent’s work record)

- **DAC OPTION:** Those who previously received SSI benefits qualify for Medicaid under a special state category that does not count the Social Security Family (DAC) Benefit if it is higher than the Medicaid amount
 - [WAG 06-06-01](#): If someone who has lost SSI benefits meets the above criteria, approve medical benefits as an AABD Cash zero grant case.
- **SPENDDOWN OPTION:** The other option for those in waivers -- you will be put in spenddown status, but the cost of waiver services counts toward your spenddown. Since the state knows you will have the same amount of waiver services per month, they fill out a form that states your spenddown will always be met each month.

HOW DO I KEEP MY MEDICAID WHEN I GET SOCIAL SECURITY BENEFITS AFTER A PARENT RETIRES, DIES, OR IS DISABLED?

Example 1

- Jane previously received \$994 a month in SSI.
- Her father recently retired, and she now receives \$1850 a month in DAC benefits based on his work record. This is more than the financial limit for Medicaid.
- Because Jane received SSI first, she qualifies under the state's DAC rule and can keep her Medicaid.

Example 2

- Eric receives \$1900 a month in Social Security benefits since his father died.
- Because Eric is over the Medicaid financial limit, he has a spenddown of \$660 a month.
- He is enrolled in the Adults with DD Waiver and receives \$3132 in waiver services each month. His caseworker fills out the spenddown form, HFS 2653, that counts his waiver services toward his spenddown each month. He keeps Medicaid.

THE PUNS LIST AND DEVELOPMENTAL DISABILITY WAIVERS

Finding Your Way



Ligas Family
Advocate Program

START

Contact ISC to determine eligibility to be on the PUNS waiting list for adult Home and Community Based Services (HCBS) Need help finding your ISC (Independent Coordination Agency)? Call DHS at 1-866-337-5267 (TTY: 1-866-376-8446)

Placed on PUNS list to wait for HCBS. You will be categorized as: Planning for services OR Seeking Services (starts at age 18)

Update paperwork yearly with the ISC — doing so will keep you on the PUNS list.

After the age of 18, contact DHS by email yearly to see when you may be selected from PUNS DHS.DDD.PUNS@illinois.gov

Receive Early Notification Letter from DHS, you will likely be included in the next PUNS selection and invited to apply for DD waiver services. Start preparing now.



Clinical Eligibility— if not already determined medical and psychological evaluation can be needed to conduct these evaluations - Your ISC will connect you to a provider

PUNS Selection — You are invited to apply for DD waiver services.

Contact your ISC to begin the planning process for services now. Reach out to DD providers to explore the ways they offer services, learn about their day programs and group homes and visit to see for yourself. Consider how you can live in your own home as independently as you might like. Apply for Medicaid and SSI if you are not already receiving. Medicaid: <https://abe.illinois.gov/abe/access> SSI: www.ssa.gov

Receive letter from your Arc of Illinois Ligas Family Advocate. Respond by calling the number provided in the letter.

Take the time to watch this quick CQL video that describes your living options:



Would you like to live in an affordable apartment of your own with support? Your ISC will start the discovery process to learn about your needs for supports and present services available.

You have been found clinically eligible for funding

Begin Personal Plan Process (PCP) with ISC. What supports do you want and need? Help at home, job coaching, respite services, transportation, therapy, home adaptations, Community Day programs/classes, help with personal care?



Determine how and where YOU want to receive services

Confused about all of the Acronyms? Contact your Ligas Family Advocate and we will provide you with a list.

Consider the options: Home-Based Services (Support based on your needs in your apartment/condo/house or family home) OR CILA Services

- Group Home CILA (24/7 support)
- Host Home CILA (24/7 support while living with another family in the community)
- Intermittent CILA OR Family CILA (less than 24 per day support while living in your apartment/condo/house or family home)

Receive award letter for HCBS Waiver funding

BEGIN BUILDING
A LIFE YOU
LOVE IN THE
COMMUNITY

Don't qualify for funding through IL DHS DDD but still need support? The Illinois Life Span Program of The Arc of Illinois can help. Call us at 1-800-588-7002! We would be happy to connect you with useful information including how to find your local DHS Division of Rehabilitation Services office, Center for Independent Living, and other local and statewide resources!

DHS Office Locator

<https://www.dhs.state.il.us/page.aspx?module=12>

CLINICAL ELIGIBILITY REQUIREMENTS

Diagnosis of Intellectual Disability

- Significantly sub average general intellectual functioning
 - General rule of thumb – Full Scale IQ score of 70 or lower
- Existing concurrently with deficits in adaptive behavior
- Manifested before the age of 18 years

AND/OR

Diagnosis of a Related Condition

(i.e. Autism, Cerebral Palsy, Epilepsy) that results in impairment of general intellectual functioning or adaptive behavior

- Severe, chronic disability
- Manifested before the age of 22
- Likely to continue indefinitely
- Results in substantial functional limitations in three or more of the major life areas: self-care, language, learning, mobility, self-direction, capacity for independent living

Current eligibility requirements: <https://www.dhs.state.il.us/page.aspx?item=53021>

The Division of Developmental Disabilities is currently reviewing the process. We are aware that there may be updates to clinical eligibility guidelines in the future. This information is for your awareness and review; no changes or procedural shifts are being implemented at this time.

DRAFT bulletin: <https://www.dhs.state.il.us/page.aspx?item=179071>

EMERGENCY / CRISIS

- There is a way to be evaluated for crisis and if you meet the criteria, you may be eligible for receiving crisis-based funding. These cases are reviewed meticulously and often involve outside entities like DCFS, police, APS, etc.
- If pursuing CILA placement, ISC agency is allowed to look statewide.
- Individual must be experiencing or at imminent risk of experiencing:
 - abuse (harm done to individual OR aggressive behaviors causing harm to others)
 - homelessness (i.e. living in a shelter)
 - neglect (unable to complete tasks necessary for living)



Home Based Services

- Funding is fixed
 - 3 times SSI (\$994 in 2026) + additional 5% rate increase = monthly budget (\$3,132.00)
- “A la Carte”
- All services/supports must fit within monthly budget
- Self-Directed Model: Family/Individual is tasked with managing & coordinating the services
- Most Popular Services:
 - Personal Support Worker (PSW)
 - Community Day Services (CDS)
 - Self Direction Assistance (SDA)

CILA

(Community Integrated Living Arrangement)

- No fixed funding amount
- “All Inclusive”
- Disability Provider Agency is tasked with managing & coordinating the services
- Group Home (24/7 care, up to 8 housemates)
- Host Home (24/7 care, up to 2 housemates)
- Intermittent/Hourly CILA (less than 24/7 care daily)
 - Your own apartment or condo

LONG-TERM SUPPORTS; CAN SWITCH BETWEEN PROGRAMS IF NOT MEETING YOUR NEEDS.

Individual Service & Support Advocacy (ISSA) Monitoring
ISC agency – mandated service – no cost to families

SPECIAL EDUCATION AND TRANSITION

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
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:	• Individualized Education Program (IEP) Family Resource Center on Disabilities • Core Special Education Resources : Resources : What We Do : Family Matters PTIC • https://www.wrightslaw.com/

**Bonus section:
IEP problem-solving!**

Problem	Solution
I do not understand my child's IEP or if my district is following the law, where can I get help?	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 specialed@equipforequality.org
Equip for Equality Helpline	Non-profit with 10 lawyers on staff 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. Smaller amount of callers will get more direct services where E4E will represent parents @ IEP meetings, Mediation, or Due Process. <i>Cases that might qualify:</i> -Least Restrictive Environment -(TDS) parents wanting to keep their kids in transition programs -Denial of Eligibility -Expulsion (A non-example is "the IEP is not robust enough")

Problem	Solution
What if I disagree with a team decision in the IEP?	You have the right to include a statement of dissent, after the IEP. This then becomes a permanent part of your child's IEP. You will type this written statement up and include a request that it be attached directly to the IEP. You will send it to the case manager or the special ed director via email. You should CC the building principal. You need to request this be added to the IEP. 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.
Is there another option before mediation?	State-Sponsored IEP Facilitator: •Trained neutral 3rd Party who is not an employee of the school district •The facilitator is not a member of the IEP team or an advocate of anyone with an IEP •Their job is to promote a dialogue and encourage participation for decision-making but is NOT a decision-maker • 217-782-5589 (you can also find a Facilitator Request Form on ISBE)
How can I file a complaint if my school district is not following IDEA guidelines?	Who to Contact: Contact the ISBE mediation coordinator at the following: (866) 262-6663 (toll-free for parents) or (217) 782-5589. 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. 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. 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
If mediation is not successful, your next option is to file a complaint with ISBE	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. https://www.isbe.net/Pages/Special-Education-Complaint-Investigation-Process.aspx

Problem	Solution
My child's school district will not return my calls, who can I get to listen?	Regional Office of Education Click this link to find your local office: https://apps.isbe.net/ELISAPP/Pages/Public/MessageCenterMap.html
I cannot find a copy of my child's IEP how can I get one?	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.
How long should I keep my child's IEP after they graduate?	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.
I rarely hear from my child's regular education teachers, what can I do?	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.
My child's special education teacher is afraid to speak up about the services my child is/isn't getting, what can I do?	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.

QUESTIONS FROM THE AUDIENCE



OUR CONTACT INFORMATION

Suzanne Aaron

- Suzanne@thearcofil.org
- 800-588-7002

Susan Agrawal

- susan@thearcofil.org
- 779-254-9158

Annie Bruno

- annie@thearcofil.org
- 815-464-1832 x1032

Tiffany Steinhauser

- tiffany@thearcofil.org
- 800-588-7002