

Family Advocate Program

September 15, 2026

Mini Conference Q & A

Rubin Law

I am on the PUNS list. I have a bit of money spread over various accounts (checking, 401K, Roth and a Special Needs trust) should I have to find a financial advisor to help me manage and plan ahead?

If you are on SSI, your maximum assets not in a properly drafted special needs trust is \$2,000. The Roth and 401k count towards that \$2,000. If on SSDI (on your own record or a parent's record) for Social Security your assets are not relevant, however for Medicaid they are. If on traditional AABD Medicaid, the maximum assets not in a properly drafted special needs trust is \$17,500, and the Roth and 401k count. If on HBWD Medicaid the maximum assets not in a properly drafted special needs trust is \$25,000, and the Roth and 401k DO NOT count.

Medicaid

Who can fill out the IL444-2653 form? Does it have to be a QIDP credentialed individual? The 2653 can be filled out by the ISC, SDA, EoR, or any DD Waiver provider.

When it comes to renewing Medicaid, if it's completed a day after the renewal date, can this move you off the list? What List? There is a 90-day grace period to submit the medical redetermination form from the due date.

SANP- Why are you NOT eligible for SNAP if you live with a parent? Is this up to a certain age? We look at SNAP differently. We need to know if everyone buys food, prepares food and eats the food together or not. See SNAP Policies: [IDHS: WAG 25-03-02 \(1\) SNAP \(state.il.us\)](#) [IDHS: WAG 25-](#)

[03-09: Basis of Issuance Table \(1\) \(10-01-22\) \(state.il.us\)](#) [IDHS: WAG 25-03-09: Basis of Issuance Table \(2\) \(10-01-22\) \(state.il.us\)](#) [IDHS: WAG 25-03-09: Basis of Issuance Table \(3\) \(10-01-22\) \(state.il.us\)](#) [IDHS: WAG 25-06-05-a \(1\) Minimum Monthly SNAP Benefit Amount for 1-2 Persons \(state.il.us\)](#)

An individual is on AABD and receives waiver services (CDS and PSW services); Does the state count SSDI as part of his income? He also works a part-time job with income which is about \$1,000. I would want to clarify RSDI vs SSI. SSI is always exempt for medical. For AABD RSDI wouldn't be exempt. It can be exempt for ACA depending on other factors. Under age 22 with a child waiver, income would be exempt.

Any other organizations that help with Medicaid than the ones shown? HFS has Application Agents around the state to assist with the application process. There are also independent Benefit Counselors that can be hired to assist.

My son is 32 years old, was disabled since birth. I am trying to change 1 update, his Medicaid category back to AABD from ACA. It was changed last year in December 2025 and I don't know why. How can this be updated? For a change in a Medicaid medical assistance category, you must go to the FCRC office and request which type of category change you want.

How to change the physical address for Medicaid, but want to keep the mailing address the same? The Report A Change form: IL444-1979 can be filled out and submitted to the FCRC office. If it is for a DD Waiver customer then it can be submitted to the DD Hub.

Can you explain more about the HIPPI program in which Medicaid covers the cost of private insurance for individuals with high medical costs? My adult son receives both SSI/Medicaid, and has Type 1 diabetes, on top of Autism, CP, etc. [IDHS: PM 23-08-01: Health Insurance Premium Payment \(HIPPI\) Program](#) Form to apply is attached.

PUNS/ISC

Why don't the school and hospital records need to be kept until the person passes? I couldn't get many records because the law doesn't support their requiring to keep them. Can this be changed?

Record requirements and the length of time to keep them vary by the entity (DCFS, Schools, Hospitals, etc.). I'm not sure how the timelines could change. It would be up to the entities that license and regulate the programs.

Can an individual receiving HBS funding still apply for home modifications? I thought this was only available under the DRS waiver.

Yes, people in the DD Waiver who receive HBS can apply for home modifications.

Does the ISC need to complete the Discovery and Personal Plan as part of the packet to submit for eligibility?

I have heard this is no longer necessary. We do not need to submit a plan when we are working with DDD to determine eligibility.

If the individual is dropped from the PUNS list and rejected for services, does the Selection letter stay valid so that person can try again later?

The selection letter does not expire.

Can a doctor at a clinic complete required paperwork from the ISC? Or does it need to be a primary care physician?

I'm not sure what paperwork you're referring to. Can you please clarify?

How does an individual change from the Home-based option to the CILA option?

People need to have an increased need. They can then work with their ISC to secure a CILA.

What do ISC's recommend when there are no appropriate services even if the person has waiver funding?

For example, clients cannot function in adult programs. What does that mean that they cannot function in adult programs?

If someone didn't qualify during the PUNS Selection and appealed the decision, yet it was still denied, would they still reconsider since the PAS agency manual was updated?

The manual has been updated but the basic eligibility requirements did not change. You could always contact the ISC to discuss.

If the person pulled from PUNS waitlist had SSI already, would that help with the eligibility? It may help if there are no eligibility documents. Social Security has records indicating when SSI was awarded and why.

If a waiver recipient and their family lives in a rental home or apartment, can they utilize the \$15k for home modifications?

Yes, but the landlord needs to give permission.

When pursuing a crisis for a young adult who is their own guardian due to parent neglect and abuse, why do we get stuck on needing to speak with that parent?

If the individual is an adult, we don't necessarily need to speak to the parents. It would depend on the case.

If a student with ASD has an IQ over 70, can they receive waiver services if they are significantly impacted in 3 or more of the major life areas?

Yes if DDD clinical staff determine that they are clinically eligible.

Is there a link to presenter Patti O'Brien's slides on PUNS?

<https://www.thearcofil.org/fsn-fap-mini-conference-handouts/>

What is the process of requesting missing paperwork:

PCP, Discovery tool and Psych? Call your ISC and request the needed documents.

Does the student need to be over 18 years old for the parent to get paid as a personal support worker?

Yes, 18 years old or older.

SSI/SSDI

Disclaimer: This information is current as of Sept. 15, 2026, but Social Security policy is subject to change. Please visit [SSA.gov](https://www.ssa.gov) for up-to-date information on our programs.

To get survivor benefits does a child have to be receiving SSI between the ages of 18-22?

- No, there is no prior SSI requirement for Survivor's benefits --- please see <https://www.ssa.gov/pubs/EN-05-10084.pdf> for more information.

If a disabled adult earns enough Earned Income credit to get SSDI and Medicare and the parent retires, can that child also receive benefits from the parent as well?

- Maybe. It depends on how much the beneficiary would be due under their SSDI record and parent's record.

Can an undocumented parent that has worked collect benefits for self and DAC?

SSI is limited, how many people in a household can receive?

- We will pay monthly title II and title XVIII benefits to a claimant/beneficiary who is present in the U.S. and who is a U.S. citizen, U.S. national, or lawfully present alien as determined by the Attorney General. Please see <https://secure.ssa.gov/apps10/poms.nsf/lnx/0300204010> *Part B*. for more information.
- Unable to answer the second question, it depends on many factors.

Is there an end age for DAC benefits for SSDI?

- No.

Can a DAC also apply for SSI?

- Yes. But whether the DAC is eligible for SSI benefits depends on many factors, like the DAC's income and resources.

My adult child does not receive the max amount of \$994 in SSI, is that because of my income?

- Maybe. Please refer to notices we send after your SSI appointments (initial claim appointments & post-entitlement appointments) ... they will explain how the SSI payment amount is calculated. The notices also include a summary of what "Income" and "Resources" are being counted.

When I retire, how does this affect my adult child SSI?

- Please call SSA's National 800 # at 1-800-772-1213 to speak to a representative and provide more details.

Is my adult child eligible for my SSI when I pass away?

- No. There are no "Survivor" benefits for SSI.

I cannot create an SSA account for my son. The verification identity does not see him. How can I set this up for him? I am his legal guardian.

- Please call SSA's National 800 # at 1-800-772-1213 to speak to a representative and provide more details.

If a parent applies for retirement benefits at 62, so that child disability becomes eligible for Medicare 24 months later, can they later receive transfer benefits from the other parent when they retire at age 67?

- Unsure what's meant by "transfer benefits" -- please call SSA's National 800 # at 1-800-772-1213 to speak to a representative and provide more details.

My son works and receives SSI. I report his wages every month and I am his representative payee. Can I deposit his paycheck to the representative payee account?

- Please call SSA's National 800 # at 1-800-772-1213 to speak to a representative and provide more details.

My son receives DAC benefits and resides in a CILA and has never worked. Does this affect his SNAP benefits?

- Please see <https://www.ssa.gov/pubs/EN-05-10101.pdf> for more information about SNAP benefits.

My son has been on SSI since he was 18 y/o. He has worked for 4.5 yrs now. When does he qualify for SSDI? My husband and I retired recently.

- Please call SSA's National 800 # at 1-800-772-1213 to speak to a representative and provide more details.
- We can review your son's earnings record and see if he is now insured for SSDI. This information will also be available on his mySocialSecurity account.

Can disabled children claim SS benefits of a parent's record when a parent retires at 62 and transfer to higher increment if the other parent retires at 67?

- Yes.

Can my disabled child begin to take my benefits once I hit 62 even if I do not start to take my benefits yet?

- No.

What happens at REDETERMINATION? Would SSA pull medical records again/ Of the family needs to get a new psychological evaluation on their own?

- Please see <https://www.ssa.gov/ssi/text-redets-ussi.htm> for more information.

Are you required to pay back SSDI if they were told that the person isn't anymore disabled due to working and earnings, but still legally blind?

- Please call SSA's National 800 # at 1-800-772-1213 to speak to a representative and provide more details.

Explain the family cap if my son starts to take DAC and my ex-spouse will be taking my benefits which will be much higher than his own benefits.

- The maximum family benefit is the maximum monthly amount that can be paid on a worker's earnings record. Please see <https://www.ssa.gov/oact/cola/familymax.html> for more information.