

The Basics of SSI and Medicaid for Individuals with Intellectual and Developmental Disabilities (IDD)

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To Receive DDD Services at Age 21

- Must be functionally eligible for DDD services <u>and</u> must have Medicaid.*
 - Functional eligibility determined from questionnaire called NJ Comprehensive Assessment Tool (NJ CAT)
- Best way to have Medicaid: Apply for Supplemental Security Income (SSI) at age 18. If receiving SSI will also get Medicaid.
 - In low-income family can apply for SSI as a child.
 - However, some children already have income at age 18 and are not eligible for SSI. There are also other ways to have Medicaid!
- Not required to have legal guardianship to apply for DDD services.
- *There is an exception to the DDD regulation on having Medicaid, which is known as "Non-DAC".



Main Topics to be Covered Include:

- Medicaid Unwinding from the Public Health Emergency
- Planning to apply for SSI
- What happens if the SSI application is turned down?
- ABLE accounts
- If turned down for SSI, can the person with IDD have Medicaid and DDD services?
- What happens if a person with IDD has too much income to qualify for SSI?
- Medicaid managed care and different types of Medicaid



MEDICAID UNWINDING FROM THE PUBLIC HEALTH EMERGENCY



Medicaid "Unwinding" from the Public Health Emergency

☐ Public Health Emergency (PHE) started in March 2020, due to COVID pandemic. ■While the PHE is in effect, no one should lose Medicaid. ☐"Medicaid Unwinding:" When PHE ends, Medicaid will mail redetermination paperwork to everyone who has NJ FamilyCare/Medicaid. ■Medicaid Unwinding should not apply to people with SSI & Medicaid. ☐ If receiving NJ FamilyCare/Medicaid, must respond promptly to Medicaid redetermination paperwork. Failure to respond can result in Medicaid termination!! ■When PHE is scheduled to end, I will announce to my listserv. To sign up: www.mainstreamingmedicalcare.org



Medicaid "Unwinding" (cont.)

What you can do prior to the end of PHE:

- If your type of Medicaid has a maximum amount resources, (e.g., \$2,000) be certain you do not exceed that amount.
- Be sure Medicaid has current mailing address. Call 1-800-701-0710, if need to confirm.
- If notified by Social Security that loved one's current SSI and Medicaid will end, don't delay in submitting necessary paperwork to Medicaid!



Families with NJ FamilyCare/Medicaid

☐ Some families have been covered by NJ FamilyCare/Medicaid for the entire family. Eligibility is because of the family's income, not related to disability. ☐ Be aware that some families now have income above the maximum and are not technically eligible currently. However, families have not received an NJ FamilyCare termination notice due to the PHE. \square When the PHE ends: If the family income is above the threshold, some children with IDD who have NJ FamilyCare will lose coverage when the parents lose coverage. ☐ Whenever parents receive an NJ FamilyCare/Medicaid renewal application, fill it in promptly and return it.



When will the Public Health Emergency (PHE) end?

- The PHE ending date has not been announced.
- The next possible date for PHE to end is mid-April, 2023.
- •There should be announcement 60 days prior to the end of the PHE. We may know in mid-February if it is ending in April or not.



PLANNING TO APPLY FOR SSI



Before Starting the SSI Application

- Before starting the SSI application, it's helpful to set up a folder with:
 - IEPs
 - progress reports and assessments
 - information on child's doctors, including medications and doses
 - part-time jobs (if applicable), including start and end dates and salary;
- Contact the Child Study Team if you need a copy of reports.
- When SSA reviews SSI application they want to know how the disability will affect ability to be self-supporting.



Before Applying for SSI: Resources

- When student is younger than 18, family income is considered. On 18th birthday, family's income is disregarded and only the consumer's income is considered. **Encourage applying for SSI as soon possible after age 18.**
- Before applying for SSI and after receiving SSI: Person with a disability **can't have more than \$2,000** in his/her name, with that person's Social Security number.
- Inform relatives not to leave money in their will to the individual with IDD. They can leave assets in their will to a Special Needs Trust that parents have set up.



Before applying for SSI: Resources (cont.)

- "Spend-down" if amount over \$2,000 is small. Can document for spend-down: summer camp; class trip; therapies not covered by insurance.
- Until the age of adulthood at 18: No spend-down on food, clothing, shelter parent's responsibilities.
- If applicable, consider a Special Needs Trust (SNT). Parents can have life insurance policy with money going to the SNT after their death. **Hire an attorney who specializes in SNT!**



36 Month "Look-Back" on Child's Assets when Applying for SSI

- Child cannot have more than \$2,000 in assets. (money in an ABLE account is an exception.)
- "Assets" includes savings bonds with child's Soc. Sec. number.
- On all financial transfers, there is a 36 month look-back period on the child's assets. This is 36 months before the date the individual filed an application for SSI.
- If the person is already receiving SSI, the 36 month look-back period starts with the date the resources were transferred.



Applying for SSI – New Process

- To start the SSI application online, use this link:
- SSI Application
- Provide the name, date of birth, and Social Security number of person applying for SSI.
- Mailing address and phone number for person applying for SSI.
- Name, phone number and email address for person doing the application.
- A Social Security representative will schedule an appointment to help with the SSI application. SSA will send an appointment day and time by mail or email, within 7 14 business days. At times, Social Security staff may call to schedule the appointment.



Helpful suggestions when applying for SSI

- Tracey Cahn, Esq. and Risa Rohrberger, Esq. do a great webinar titled: "Potholes on the Road to Getting SSI."
- Very helpful information for families to know when applying for SSI.
- The slides and recording of this webinar are available at www.mainstreamingmedicalcare.org under the "What's New" heading.



Keep a copy of all documents

- Keep a copy of the entire SSI application.
- Keep a copy of all supporting documentation demonstrating that your son/daughter with IDD has a severe disability, (e.g., IEPs, medical reports, hospitalizations).
- It is helpful to have this documentation later, when mom or dad collects Social Security due to retirement or disability (or if parent passes away).

The Arc. of New Jersey

When SSI begins...

- SSI funds should <u>not</u> be deposited in the parent's account!
- A representative payee bank account is an account used by an appointed person or organization to manage the finances of a Social Security beneficiary. Representative payees are chosen by the Social Security Administration to administer the account for a beneficiary.
- SSI checks to be deposited electronically into this new bank account.
- Can't have more than \$2,000 in this bank account!
- If receiving lump sum back payments, have 9 months to spend down. After 9 months, cannot exceed \$2,000 in this account.
- Consider opening an ABLE account, if needed.



Representative Payee Information

- A Guide for Representative Payees
- Frequently Asked Questions (FAQs) for Representative Payees
- (usually a parent or other relative)



SSI and travel outside the U.S.

- Important note: If a person receives SSI and travels out of the U.S. for **30 consecutive days or more**, he/she is not eligible for SSI (or Medicaid) during any month when he/she is outside the U.S.
- An individual who was receiving SSI, and has traveled out of the U.S. for 30 days or longer is not considered by Social Security to be in the U.S. until he/she is in the U.S. for **30 consecutive days** upon returning.



Redeterminations - After Approval for SSI

• After approval for SSI or Medicaid: Must respond in timely way to official requests for re-determinations. SSI and Medicaid can be terminated for failure to respond.

• If moving, be sure Social Security and Medicaid have the new mailing address.



Employment While Receiving SSI

- If person receiving SSI is employed, must report wages monthly to Social Security.
- Substantial Gainful Activity (SGA) \$1,350/mo., gross income (2022).
- If receiving SSI and exceed SGA: Reduction in amount of SSI.
 - However, if receiving SSDI and exceed SGA: Loss of SSDI and required to pay back the "overpayment."



LOOKING AHEAD... WHAT HAPPENS WHEN SON/DAUGHTER HAS SSI AND THEN A PARENT RETIRES, OR BECOMES DISABLED, OR PASSES AWAY?



Section 1634 DAC status

- Changes occur when a person with IDD has SSI and then a parent retires, becomes disabled or passes away.
- Social Security requires new paperwork. Then person with IDD starts to receive Social Security Disability Insurance (SSDI) on the parent's work record.
- Usually, SSI & Medicaid will end in 4 months after SSDI starts. Must apply to the County Board of Social Services with a Request for Information (RFI) Medicaid application.



The DAC Flyer



Disabled Adult Children (§1634 DAC)

§1634 DAC Eligibility Group Requirements*: An individual who was receiving Supplemental Security Income (SSI) benefits and meets the following:

- Is at least 18 years of age;
- Has blindness or a disability which began before the age of 22;
- Has been receiving Supplemental Security Income (SSI) based on blindness or disability; and
- Has lost Supplemental Security Income (SSI) due to the receipt of Social Security benefits on a parent's record due to the retirement, death or disability of a parent.

*A person who meets all of the above criteria may qualify as a Disabled Adult Child under Section 1634 of the Social Security Act (regarding DAC). This designation comes from the Social Security Administration. Eligibility for Medicaid may continue as long as the person is determined blind or disabled. However, if the person receives income from another source or exceeds the resource limits, they may become ineligible for Medicaid coverage.

I lost my SSI benefits and Medicaid coverage when I started receiving Social Security Disabled Adult Child (DAC) benefits. The DAC benefits caused me to be over the SSI income limit. What should I do?

You or your guardian should have received a letter from the Social Security Administration (SSA) verifying that you may continue to be eligible for Medicaid coverage under the §1634 DAC eligibility group. If you did not receive or no longer have this letter, call the Social Security Administration at 1-800-772-1213, Monday through Friday between 7 am and 7 pm, to request a Benefit Award letter verifying Social Security benefits as a Disabled Adult Child or Disabled Dependent Child who received SSI in the past.





The DAC Flyer



Obtaining Medicaid after Losing SSI Benefits

For individuals ENROLLED in the Division of Developmental Disabilities (DDD)
Supports Program or Community Care Program:

DDD will send you or your guardian the NJ FamilyCare Aged, Blind, and Disabled Programs Request for Information (RFI) Packet in a blue envelope, including instructions about where to send the completed form. It is important to complete this RFI Packet as soon as possible and return it as instructed. After your packet is reviewed (this can take up to 90 days), you or your guardian will receive a Final Determination letter.

For individuals NOT ENROLLED in the DDD Supports Program or Community Care Program:

Your local County Board of Social Services will send you the NJ FamilyCare Aged, Blind, and Disabled Programs Request for Information (RFI) Packet in a blue envelope. It is important to complete this RFI Packet as soon as possible and return it to the County Board of Social Services. After your packet is reviewed (this can take up to 90 days), you or your guardian will receive a Final Determination letter.

If you do not receive the RFI Packet soon after you are notified about your Medicaid being terminated, contact your County Board of Social Services to request it: www.nj.gov/humanservices/njsnap/home/cbss.shtml



If you have questions, or if you have difficulty obtaining Medicaid for an individual who may be eligible for §1634 DAC status, please contact your support coordinator or send an email to DDD's Medicaid Eligibility Help Desk: DDD.MediEligHelpdesk@dhs.nj.gov



WHAT HAPPENS IF THE SSI APPLICATION IS TURNED DOWN?



What Happens if a Person Applies for SSI and is Turned Down?

- Family is advised to appeal in timely manner. Easiest way to appeal:
 - www.socialsecurity.gov/disability/appeal
- Possible reasons for denial of SSI:
 - Assets above \$2,000
 - Special Needs Trust not done correctly
 - Medical documentation not sufficient to justify a severe disability, per SSA requirements.



Individuals With High Functioning Autism who Apply for SSI

- SSI is intended for persons with a severe disability.
- In doing the SSI application, parents should include <u>all</u> of their child's diagnoses, if applicable. For example: autism, seizure disorder, depression, OCD, etc. with medical documentation of the diagnoses.
- Persons with high functioning autism (i.e., Aspergers), may be turned down for SSI. They can apply, but they should be prepared to be turned down and appeal.



If Turned Down for SSI...

- Parents may want to contact attorney to represent the son/daughter at a hearing with administrative law judge.
- If attorney accepts the case, there should not be a fee. After the attorney wins the case, the fee is a % of the lump sum back payment from Social Security.
- The Arc of New Jersey has names of attorneys who specialize in this type of representation.



ABLE ACCOUNTS



Achieving a Better Life Experience (ABLE) Act of 2014

- Persons with disabilities can deposit up to \$16,000/year in an ABLE tax-exempt savings account.
- Eligibility: Must be receiving SSI or SSDI; Age of onset of disability must be before age 26, **OR**
- With medical documentation, can deposit money into ABLE account (up to max. of \$16,000/yr) as spend-down *before* applying for SSI.
- ABLE accounts won't affect continuing financial eligibility for SSI, Medicaid and other public benefits.



ABLE Accounts (cont.)

- ABLE accounts are available in NJ and in other states. https://savewithable.com/nj/home.html
- The **ABLE National Resource Center website**www.ablenrc.org, has state-specific information. Great website; webinars; state-by-state comparisons.
- Important: Upon the death of the beneficiary, the state in which he/she lived may file a claim for all or a portion of the funds in the ABLE account to recoup costs paid by the state while the beneficiary was receiving services through the state Medicaid program.



What to do if Parents Opened a 529 Account for Child With IDD?

- Eligible educational institution: any college, university, vocational school, or post-secondary educational institution.
- Be sure the account owner is a parent or grandparent, not the person with IDD. The student should be the designated beneficiary
- When applying for SSI as long as account owner is not the individual with IDD, a 529 account is <u>not</u> counted as asset when SSI applicant is 18 or older.



What to do if Parents Opened a 529 Account For Child With IDD? (Cont.)

- If person with IDD is not going to college: Owner can transfer funds to a different 529 account for member of beneficiary's family.
- A rollover provision. Can rollover up to \$16,000/yr. into ABLE account. If 529 account had more than \$16,000, can do rollover in multiple years.

Talk to accountant about tax implications of rollover.



IF TURNED DOWN FOR SSI, CAN THE PERSON WITH IDD GET MEDICAID AND HAVE DDD SERVICES?



If Denied SSI Because Disability is not "Severe"...

- Can wait a year and try to apply for ABD Medicaid from NJ (will require medical documentation of disability), or
- Apply for <u>Medicaid expansion</u> regular NJ
 FamilyCare/Medicaid. But if son/daughter with IDD
 is a dependent on parent's tax return or has Medicare –
 NOT eligible for Medicaid expansion.
- If parent wins the case at Social Security hearing, the son/daughter receives SSI and Medicaid, and lump sum back payment. But this process can take a long time.



WHAT HAPPENS IF A STUDENT WITH IDD IS NOT ABLE TO HAVE SSI BECAUSE OF TOO MUCH INCOME FROM SSDI OR CHILD SUPPORT?



What Happens if Unable to Get SSI Due to SSDI Benefits or Child Support Income?

- Depending on the amount of income, students age 18 and older may be able to apply for NJ Medicaid.
- If the gross monthly SSDI benefit (on parent's work record) is below \$1,133/mo. (in 2022), can apply for NJ Care Special Medicaid Program (also called Community Medicaid).
- Can have up to \$4,000 in resources. Having this type of Medicaid is okay for DDD services.



Medicaid Through the DDD Waiver Unit (known as "Non-DAC")

- A person viewed as a "Non-DAC" is <u>not eligible</u> for Medicaid from the County Board of Social Services.
- Example: Never had SSI as an adult (age 18 or older) and receives Social Security Disability Insurance (SSDI) on the parent's work record, due to retirement, disability or death of the parent. If the amount of the SSDI benefit is above \$1,133/month (in 2022), the student is not eligible for NJ Care Special Medicaid Program..
- Maximum income: \$2,523/month in 2022.



More on DDD Waiver Unit and Non-DACs

- Most notices say that Medicaid is required to apply for DDD services. Individuals with IDD can obtain Medicaid through DDD Waiver Unit process, if not eligible for other Medicaid categories.
- The Arc of NJ has fact sheet on Non-DAC status.
- IMPORTANT: Having "Non-DAC" status does NOT provide Medicaid immediately. In the future, the person who has Non-DAC status from DDD will be eligible for Medicaid from DDD Supports Program.



Medicaid Eligibility Problem Form (or DDD's Troubleshooting

Revised 01/2017



The Arc of New Jersey's Mainstreaming Medical Care Program Medicaid Eligibility Problem Form

Individual's Name:	DDD Client	? Yes No	Date of Birth	1:	Age now:
	CCW? Yes No Social Secu		rity#		
Address:			County:		
Name of Contact Person:	Contact Person	n's Telephone:		Email:	
Relationship to Individual:					
Assats Amount of money in the bank in the name of the individual: \$ Any other assets in the name of the individual (e.g., stocks, bond if there are assets in the name of the individual, was a special in Comments:	ds)? \$ eeds trust ever de		□No		
Supplemental Security Income History Has the individual evil fyes, monthly amount: \$ At what age did SSI start? If no, at what age did person stop receiving SSI? Do you know the circumstances that caused the person to lose to Comments:	_ Is the pe	rson still receiving	SSI? Yes	□No	
Do you know why Medicaid ended? Yes No If yes, pleas If the person has never received Medicaid, did he/she ever apply If yes, explain why Medicaid was denied: If no, explain why no application was ever made to Medicaid: Comments: Social Security Disability? Yes No If yes, month Did he/she begin receiving benefits from Social Security based of	Approximate age se explain: y for Medicaid? [Yes No At what	approximate ag		
Medicare? Yes No					
Employment Status of Parents Mother: Working?	_ Re De Dis	Father: Working?			
Individual's Employment Questions Currently employed?	bility Program ☐ mount of unemplo ☐No If yes	Yes No Com yment income: \$_ amount of SSDI	per mor		om any
		erson's applying fo	or Medicaid:		
Miscellaneous If applicable, Please mention any other issues that you think are					

*Electronic Signature accepted: Typed signature with date indicates electronic verification of the information provided.



Continuation of SSDI at age 18

- Children, under age 18, with or without IDD receive SSDI when a parent passes away, is disabled or collects retirement benefit.
 - Known as a Survivor's Benefit if parent passes away.
- This benefit is scheduled to end at age 18 (or 19 if still in school) for all youths.
- When student has IDD, parent will need to initiate a new Social Security application with documentation of the IDD (IEPs, medical reports, etc.).
 - If denied, parent should appeal; may want to hire an attorney.



MEDICAID MANAGED CARE



Medicaid Managed Care

- Everyone enrolled in Medicaid must be enrolled in Medicaid managed care. Can select the managed care org. (MCO), and switch at any time for "good cause."
- Health Benefits Coord. for Medicaid questions: 1-800-701-0710.
- Care management available, upon request, from the MCO.
- If son/daughter has private insurance, it is primary payer and Medicaid may be needed only to access DDD services.
- Five Medicaid MCOs in NJ:

Horizon NJ Health, United Health Care Community Plan, Amerigroup, WellCare, Aetna Better Health



Personal Care Assistance (PCA) and Personal Preference Program (PPP)

- To be eligible, Medicaid enrollees must need assistance with activities of daily living (ADLs) e.g., dressing, bathing, feeding, grooming, toileting, etc.
- PCA and PPP are free from NJ Medicaid, but requires doctor's prescription and MCO nurse assessment to approve the eligibility and the number of hours per week that Medicaid will cover.
- Contact MCO care manager to get started.
- Personal Preference Program (PPP) allows flexibility. Parents decide who will provide the care and be paid. Can be a parent, adult sibling, a family friend, etc. Recordkeeping requirement.



DIFFERENT MEDICAID CATEGORIES



Two Major Medicaid Categories

1. Aged Blind and Disabled (ABD): Must have a disability. Most people with IDD are enrolled in ABD Medicaid/NJ FamilyCare.

2. NJ FamilyCare – Medicaid Expansion: eligibility based on income not on disability.

TYPES OF NJ FAMILYCARE/MEDICAID ELIGIBILITY IN NJ

AGED, BLIND, OR DISABLED (ABD)

Supplemental Security Income (SSI) Medicaid

Provided automatically when a person with IDD is approved for SSI benefits. Apply for SSI at age 18 or above through your local SSA Office here: bit.ly/ssaoffices

Medicaid Only

For individuals with IDD who do not receive monthly SSI, but meet SSI income and resource limits. bit.ly/medicaidonly

NJ Workability

Offers healthcare to individuals with IDD ages 16-64 who are employed and whose income would disqualify them from other forms of Medicaid. bit.ly/njworkability

HOW TO GET IT

Apply for SSI at age 18
bit.ly/Apply4SSI
ABD Medicaid Application
bit.ly/ABDapplication

Disabled Adult Child (DAC)

For persons whose SSI ended because they received benefits from a parent who retired, became disabled, or died. Request for information(RFI) is for people who have DDD. bit.ly/dacmedicaid

New Jersey Care... Special Medicaid Program

For individuals with IDD with income below \$1,133/month. Contact your County Board of Social Services: bit.ly/njcbss

Long Term Services and Supports

Applies to younger individuals who need significant support, such as private-duty nursing, etc. bit.ly/longtermsupport

QUICK FACT

Medicaid is an entitlement-based program. Anyone who is determined eligible by the Medicaid Office has the right to receive Medicaid and its related services. Eligibility is not quaranteed.

NJ FAMILYCARE/ MEDICAID EXPANSION

- Eligibility is based on income, not on the individual having a disability.
- The maximum monthly income limit increases each year.
- The maximum gross income for a single adult in 2022 is \$1,563/month.
- The individual cannot be listed as a dependent on their parent's tax return.
- The individual cannot receive Medicare.
- ABD is a better route if eligible.

HOW TO GET IT

Applicants must have financial eligibility.

NJ FamilyCare Quickstart

bit.ly/njfamilycare

QUICK FACT

Adults must have legal resident status for 5 years to be eligible. Children and pregnant women with legal resident status are eligible, regardless of length of residency.

WHAT'S COVERED?

Doctor visits, prescriptions, x-rays, dental, lab testing, eyeglasses, hospitalization, mental health, preventative screenings, regular checkups

WHAT'S COVERED?

Doctor visits, prescriptions, x-rays, dental, lab testing, eyeglasses, mental health, hospitalization, specialist visits, hearing aids, Personal Care Assistant (PCA), Personal Preference Program (PPP)

For specific questions about Medicaid or the application process, contact Beverly Roberts at broberts@arcnj.org or 732-246-2567.





Resources • Education



IMPORTANT: Continuation of Parent's Private Health Insurance AFTER age 26

- All young adults can stay on parent's health insurance until age 26.
- **BEFORE** child's 26th birthday parent requests a form from employer's Human Resources Dept.
- Special process for young adults with disabilities who are not capable of self-sustaining employment to stay on parent's employer's health insurance.
- Can have private health insurance *and* Medicaid. Medicaid is always payer of last resort.
- The Arc of NJ's fact sheet on private insurance.



Contact Information

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Mainstreaming Medical Care Program

The Arc of New Jersey

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To sign up for our listserv:

www.mainstreamingmedicalcare.org

The Arc of NJ website: www.arcnj.org



Questions?

