SSI and Medicaid for Students with Intellectual & Developmental Disabilities



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Planning For Adult Life

- ***Planning for Adult Life*** was created to help you and your student navigate the process of preparing for life after they leave school.
- Planning for Adult Life activities, events, and materials are conducted and developed in partnership with The Arc of New Jersey with funding from the New Jersey Division of Developmental Disabilities.
- We offer classes for students in high school (MAPs), community presentations (HOW), Opportunity Expos, Webinars, and extensive website, and the monthly e-newsletter (The Compass).
- Our Help Desk is always available at HelpDesk@PlanningForAdultLife.org or 732.828.0972.



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We Will Discuss

- What is SSI and Medicaid
- Before applying
- Applying
- After Applying
- Why you should apply for this now
- What if you are turned down
- What if your student wants to work



What is SSI and Medicaid?

- SSI is monthly cash payment to meet basic needs for food, clothing, and shelter.
- Medicaid provides health coverage to individuals including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities
- Medicaid is administered by states, according to federal requirements.

Continuation of Parent's Private Health Insurance AFTER age 26

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

Under Age 21, Services from Dept. of Children & Families

- DCF provides limited services through PerformCare. Phone line operates 24/7: 1-877-652-7624.
- Example of services: Respite & summer camp. Families who need a service should call PerformCare to discuss the need
- The child/young adult does not have to have Medicaid to get services but PerformCare will still do the application
- If problems accessing services from PerformCare, contact The Arc – **info@arcnj.org**

PerformCare and a Medicaid "look-alike" number

- When children receive services from PerformCare, they will be assigned a number that looks like Medicaid, but does not provide full Medicaid coverage.
- The "look-alike" Medicaid number is used only for coverage of the PerformCare services. It isn't useful for anything else, and it ends at age 21 when the young adult "ages out" of PerformCare.

To Receive Division of Developmental Disabilities (DDD) Services at Age 21

- **Must be functionally eligible for DDD services and 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. Everyone who receives 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**

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Before Applying

Planning for 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.

Things To Consider When Applying for SSI…



- 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.**

- Person with a disability can't have more than $2,000 in his/her name, with that person's Social Security number.
  - "Assets" includes savings bonds with child's Soc. Sec. number.

Other Things To Consider…

"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 18: No spend-down on food, clothing, shelter – parent's responsibilities.

"Inheritances"

- 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** or **ABLE** account

Achieving a Better Life Experience (ABLE) Act of 2014

- Persons with disabilities can deposit up to $19,000/year in an ABLE tax-exempt savings account (**in 2025**).
- 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 $19,000/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 now available in NJ. Can open ABLE account in this state or another state. https://savewithable.com/nj/home.html
- Visit **the ABLE National Resource Center** website www.ablenrc.org, for 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.

529 accounts for child with I/DD

- 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 I/DD. The student should be the designated beneficiary
- When applying for SSI - as long as **account owner is not the individual with I/DD**, **a 529 account is not counted as asset when SSI applicant is 18 or older.**



529 accounts (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.
- **NEW in 2025**: A rollover provision. Can rollover up to $19,000/yr. into ABLE account. If 529 account had more than $1,000, can do rollover in multiple years.
- Talk to accountant about tax implications of rollover.

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.)
- 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 or Medicaid if parents are divorced

- When parents are divorced, child support is viewed as the child's "income".
- Depending upon the amount of child support, adolescent may not be eligible for SSI or Medicaid, but there is a 1/3 exclusion of child support income.
  - Example: if child receives $1,000/month in child support, only $666. would be counted by Medicaid as "income."

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Applying For SSI and Medicaid

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How to apply for Supplemental Security Income (SSI)

- Information on applying for SSI: www.ssa.gov/ssi/text-apply-ussi.htm
- Can start the disability application process online, as long as this is a first time SSI application.
- Parents can call Social Security at 1-800-772-1213 to make appointment to apply for SSI benefits for son/daughter with I/DD. With appointment, can apply for SSI on the phone or in person at local Social Security office.
- Can visit Social Security office without appointment, however there will be a longer wait time.

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Filling Out The 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.

Keep All Records

- 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)



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After Applying and Approved

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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.
- If person receiving SSI is working, must report wages monthly to Social Security.

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When SSI Begins…

- **SSI funds should not 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.
- Select a Medicaid HMO or be auto-assigned.

Representative Payee Information

- This is usually parent or other relative.
- Guide to Representative Payees- https://www.ssa.gov/payee/NewGuide/toc.htm#Proper_Use_Benefits
- Frequently Asked Questions (FAQs) for Representative Payees- https://www.ssa.gov/payee/faqrep.htm



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.

Continuing Disability Reviews and Redeterminations

- After being approved for SSI (or SSDI) parents should expect their child will have continuing disability reviews.
- **Continuing Eligibility Review:** Is the individual still disabled? Frequency is determined by specific disability and symptoms.
- Can be required every 3 years; can be more or less often.
- **Redetermination:** Does individual continue to meet the technical eligibility requirements for SSI/SSDI, including documentation of finances, resources and income.
- Can be required every **6 years**; can be more or less often.

Employment While Receiving SSI

- If person receiving SSI is employed, must report wages monthly to Social Security.
- Substantial Gainful Activity (SGA) - $1,550/mo., gross income (2024).
- 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.”

What is SGA?

- Social Security Administration’s regulation: To be eligible for SSDI benefits, a person must not be able to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount is usually considered to be engaging in SGA.
- SGA maximum for 2024 is $1,550/mo. gross income. SGA is income from employment; does not include SSDI income.
- Report income from employment monthly to SSA.
- If employee with IDD receiving SSDI exceeds SGA: Expect to have SSDI halted and receive a letter from Social Security requiring pay-back for overpayment.
- Important: SSA is months and years delayed in sending notifications that persons with SSDI exceeded SGA level.

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What happens if the SSI application is turned down?

If turned down?

- 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

- SSI is intended for persons with a **severe disability**.
- In doing the SSI application, parents should include all of their child's diagnoses, if applicable. For example: autism, seizure disorder, depression, OCD, etc. with medical documentation of the diagnoses.
- In general, persons with high functioning autism (i.e., Aspergers), will probably be turned down for SSI. They can apply, but they should be prepared for the application to be turned down, and they may want to hire an attorney for representation at a hearing.

If turned down for SSI…

- Parents may want to contact attorney to represent the son/daughter at a hearing with a judge.
- If attorney accepts the case, typically there is no fee, unless the attorney wins the case. Then the fee is a % of the lump sum back payment from Social Security.
- Can contact Community Health Law Project to discuss representation. Can call the County Bar Association's Lawyer Referral Service, and ask for names of three attorneys in your county who do this type of work.

Community Health Law Project

Main Admin - South Orange, 973-275-1175

Essex County - Bloomfield, 973-680-5599
DCF & DDD - Bergen, Essex, Passaic, Sussex, Warren

Union County - Elizabeth, 908-355-8282
DCF & DDD - Hudson, Morris, Union, Somerset
*Hudson County - Jersey City, 201-630-6201

Monmouth County - Eatontown, 732-380-1012
DCF & DDD - Monmouth, Ocean
*Ocean - Toms River, 732-349-6714

Mercer County - Trenton, 609-392-5553
DCF - Burlington, Hunterdon, Mercer, Middlesex
DDD - Hunterdon, Mercer, Middlesex
*Burlington - Mt. Holly, 609-261-3453

Camden County- Collingswood, 856-858-9500
DCF - Atlantic, Camden, Cape May, Cumberland, Gloucester, Salem
DDD - Atlantic, Burlington, Camden, Cape May, Cumberland, Gloucester, Salem
*Atlantic - Galloway, 856-858-9500

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New Jersey State Bar Association Lawyer Referral Service

- The link below is a list of county bar associations that offer lawyer referral services
- http://bit.ly/LegalReferralService
- Ask for 2-3 attorneys that specialize in SSI and Medicaid

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Why Is It Important To Have SSI?

Why is it Important to Have SSI?

- When parent of person with I/DD retires, becomes disabled, or dies, the son/daughter receives a Social Security Disability (SSD) benefit on parent's work record.
- Monthly SSD on parent's work history is often too high to get Medicaid.
- **But, when persons with disabilities previously had SSI, they are "Disabled Adult Children: Section 1634 DACs", as defined by the Social Security Admin. They are eligible to get Medicaid again, after they start receiving SSD on parent's work record, from county Board of Social Services. The amount of the SSD benefit is disregarded.**

Official Definition: Section 1634 DAC

- **DAC = Disabled Adult Child. See Section 1634 DAC flyer developed by NJ DHS.**
- Social Security Admin. (SSA) definition of a DAC:
  - A person who was receiving Supplemental Security Income (SSI) benefits (and Medicaid) and who 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 SSI based on blindness or disability; and
  - Has lost SSI due to the receipt of Social Security benefits on a parent's record due to the retirement, death, or disability of a parent.
- Also, the person cannot have more than $2,000 in resources in his/her name

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.

Disabled Adult Child (1634 DAC) Flyer, from NJ DHS



Disabled Adult Children (§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.

*If an individual meets all of the above criteria, they 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.

What should an individual do if they lose their SSI benefits and Medicaid coverage because they are now receiving Social Security Disabled Adult Child (DAC) benefits, resulting in their income exceeding the SSI income limit?

The individual should have received a letter from the Social Security Administration (SSA) verifying that he/she may continue to be eligible for Medicaid coverage under this eligibility group (§1634 DAC). If the individual did not receive or no longer has this letter, contact the Social Security Administration at 1-800-772-1213 (Monday–Friday from 7am–7pm) 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.



To obtain Medicaid Eligibility for individuals expected to be enrolled in the Community Care Waiver (CCW) Program:

Individuals must complete and submit the Medicaid Only-Community Care Waiver Application that is sent to them. They also must submit all necessary documents, including the letter from the SSA verifying that the individual may be eligible for DAC status for consideration of Medicaid eligibility under Section 1634 of the Social Security Act (regarding DAC).

To obtain Medicaid Eligibility for individuals expected to be enrolled in the Supports Program:

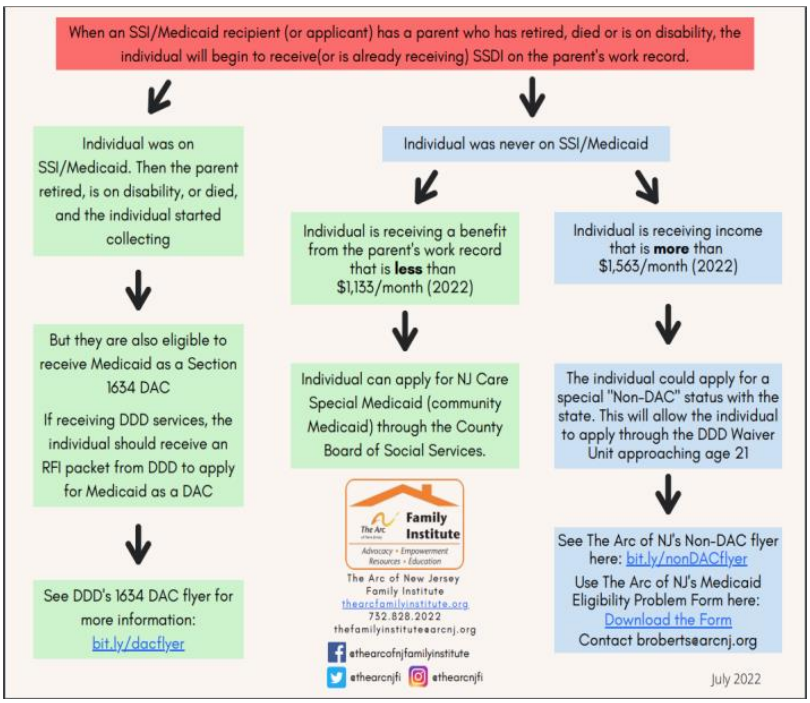
Individuals must complete the NJ FamilyCare Aged, Blind, Disabled (ABD) Medicaid Application. They must submit the completed ABD Application and all necessary documents to the County Welfare Agency, including the letter from the SSA verifying that the individual may be eligible for DAC status for consideration of Medicaid eligibility under Section 1634 of the Social Security Act (regarding DAC). The ABD Application is available at:

www.state.nj.us/humanservices/dmahs/clients/medicaid/abd/ABD_Application_Booklet.pdf

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 DDD Case Manager or Support Coordinator, or send an email to DDD's Medicaid Eligibility Help Desk: DDD.MediEligHelpdesk@dhs.state.nj.us.

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When an SSI/Medicaid recipient (or applicant) has a parent who has retired, died or is on disability, the individual will begin to receive(or is already receiving) SSDI on the parent's work record.

Individual was on SSI/Medicaid. Then the parent retired, is on disability, or died, and the individual started collecting

But they are also eligible to receive Medicaid as a Section 1634 DAC

If receiving DDD services, the individual should receive an RFI packet from DDD to apply for Medicaid as a DAC

See DDD's 1634 DAC flyer for more information: bit.ly/dacflyer

Individual was never on SSI/Medicaid

Individual is receiving a benefit from the parent's work record that is **less** than $1,133/month (2022)

Individual can apply for NJ Care Special Medicaid (community Medicaid) through the County Board of Social Services.

Individual is receiving income that is **more** than $1,563/month (2022)

The individual could apply for a special "Non-DAC" status with the state. This will allow the individual to apply through the DDD Waiver Unit approaching age 21

See The Arc of NJ's Non-DAC flyer here: bit.ly/nonDACflyer

Use The Arc of NJ's Medicaid Eligibility Problem Form here: Download the Form

Contact brobertsearcnj.org

The Arc Family Institute
Advocacy • Empowerment
Resources • Education

The Arc of New Jersey Family Institute
thearcfamilyinstitute.org
732.828.2022
thefamilyinstitutesearcnj.org
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#thearcnjfi #thearcnjfi

July 2022

Medicaid Eligibility Problem Form or DDD's Troubleshooting Form



The Arc of New Jersey's Mainstreaming Medical Care Program
Medicaid Eligibility Problem Form
www.mainstreamingmedicalcare.org
Date of Report:

Individual's Name:	DDD Client? ☐Yes ☐No CCW? ☐Yes ☐No	Date of Birth:	Age now:
		Social Security#	
Address:			County:
Name of Contact Person: Relationship to Individual:	Contact Person's Telephone:		Email:

Assets
Amount of money in the bank in the name of the individual: $____
Any other assets in the name of the individual (e.g., stocks, bonds)? $____
If there are assets in the name of the individual, was a special needs trust ever developed? ☐Yes ☐No
Comments:

Supplemental Security Income History Has the individual ever received SSI? ☐Yes ☐No
If yes, monthly amount: $____ At what age did SSI start? __ Is the person still receiving SSI? ☐Yes ☐No
If no, at what age did person stop receiving SSI? __
Do you know the circumstances that caused the person to lose SSI? Please explain: ____
Comments:

Medicaid History Has the individual ever received Medicaid? ☐Yes ☐No
If yes, approximate age when Medicaid started: __ Approximate age when Medicaid ended: __
Do you know why Medicaid ended? ☐Yes ☐No If yes, please explain: ____
If the person has never received Medicaid, did he/she ever apply for Medicaid? ☐Yes ☐No
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, monthly amount: $____ At what approximate age did SSD start? ____
Did he/she begin receiving benefits from Social Security based on parent's work history? ☐Yes ☐No If yes, please explain: ____
Medicare? ☐Yes ☐No

Employment Status of Parents

Mother: Working? ☐Yes ☐No
Retired? ☐Yes ☐No If yes, approx. age when mom retired: __
Deceased? ☐Yes ☐No If yes, approx. age when mom died: __
Disabled? ☐Yes ☐No If yes, approx. age when mom became disabled: __

Father: Working? ☐Yes ☐No
Retired? ☐Yes ☐No If yes, approx. age when dad retired: __
Deceased? ☐Yes ☐No If yes, approx. age when dad died: __
Disabled? ☐Yes ☐No If yes, approx. age when dad became disabled: __

Individual's Employment Questions
Currently employed? ☐Yes ☐No If yes, Number of hours/week: ____ Salary: $____ per month
If currently employed: Did individual apply for Medicaid's Workability Program ☐Yes ☐No Comments: ____
Receiving unemployment income? ☐Yes ☐No If yes, amount of unemployment income: $____ per month
Receiving SSDI because of individual's work history? ☐Yes ☐No If yes, amount of SSDI per month $____

Does individual receive any other income not listed above? (including child support, pension from a parent or income from any other source) ☐Yes ☐No
If yes, what is the other income and amount, per month? ____

Miscellaneous
If applicable, Please mention any other issues that you think are relevant to this person's applying for Medicaid: ____

I give permission for this information to be forwarded to The Arc of New Jersey, and also give permission for it to be forwarded to the NJ Division of Medical Assistance and Health Services (NJ Medicaid) and/or the Division of Developmental Disabilities (DDD).
*Signature: Date:

Please email or fax the completed form to Beverly Roberts at broberts@arcnj.org / fax (732)246-2567 or Jennifer Lynch at jlynch@arcnj.org / fax (732)784-6397. We will get back to you as soon as possible.
*Electronic Signature accepted: Typed signature with date indicates electronic verification of the information provided. Revised 8/'08

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Immigrants with I/DD and Medicaid

- Immigrant with I/DD must have been living in the USA, with a green card, for 5 years or more to qualify for Medicaid.
- Unfortunately, Non-DAC process is not applicable to students who are immigrants and don't meet above criteria for Medicaid.
- **COVER ALL KIDS Initiative-**If the child (under 19 years old), then they may qualify for NJ Family Care regardless of immigration status and how long the person has been in the U.S. (http://nj.gov/coverallkids/)

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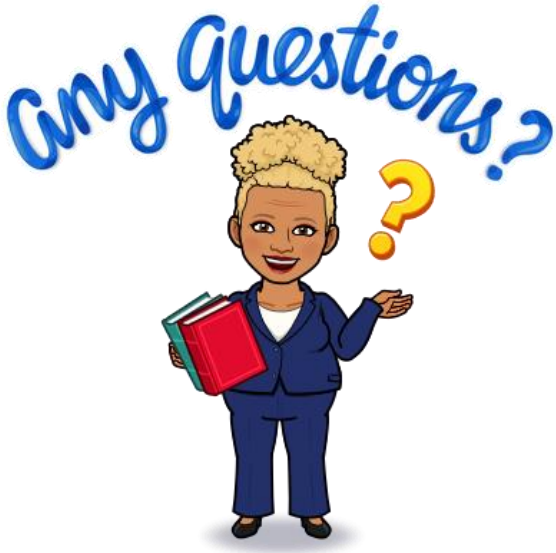
How Can Someone Work and Receive SSI?

Medicaid Thru NJ WorkAbility

- NJ WorkAbility provides Medicaid for people with disabilities who are employed ages 16 and up.
- Persons with permanent disabilities, working part-time or FT are eligible.
- Can earn as much as $73,932/yr. or $6,161/month(2024). Can have $20,000 in personal assets and still qualify.
- IRA & 401K personal retirement accts. – not counted for eligibility
- DDS Workability webpage: https://www.nj.gov/humanservices/dds/programs/njworkability/

Other types of Medicaid –Special situations

- Sometimes there are special situations, and another type of Medicaid may be appropriate for a person with I/DD who is not eligible for SSI.
- The Arc of New Jersey can provide individualized information to those families.
- Contact: The Arc of NJ Health Care Advocacy Program healthcareadvocacy@arcnj.org



Contact Information:

helpdesk@planningforadultlife.org
732-246-2525 x21
www.PlanningForAdultLife.org



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