

# ***The Basics of SSI and Medicaid: What You Need to Know for Your Adult Loved One with IDD***

**Beverly Roberts**

Director, Mainstreaming Medical Care

October 19, 2021

**[BRoberts@arcnj.org](mailto:BRoberts@arcnj.org)**



# The Arc of New Jersey

[www.arcnj.org](http://www.arcnj.org)

- Largest non-profit advocacy organization for people with intellectual and other developmental disabilities and their families
- Parent directed membership organization founded in 1946
- Chapters in all 21 counties
- Affiliated with The Arc of the United States
- Governed by a volunteer Board of Directors

# The Arc of New Jersey Local County Chapters

**20 chapters of The Arc in New Jersey, serving all 21 counties, providing direct supports and services, including:**

- Early intervention/children programs
- Group homes and other community based residential programs
- Day programs
- Supported and competitive employment
- Recreation programs
- Camps ([www.thearcfamilyinstitute.org/resources/camp-funding-applications.html](http://www.thearcfamilyinstitute.org/resources/camp-funding-applications.html))
- Family support services (ex.: Respite, assistive technology)

# The Arc of New Jersey: Free Advocacy Services

- **Mainstreaming Medical Care**  
[www.mainstreamingmedicalcare.org](http://www.mainstreamingmedicalcare.org)
- **New Jersey Self-Advocacy Project**  
[www.njselfadvocacyproject.org](http://www.njselfadvocacyproject.org)
- **Criminal Justice Advocacy Program**  
[www.cjapnj.org](http://www.cjapnj.org)
- **Planning For Adult Life**  
[www.planningforadulthoodlife.org](http://www.planningforadulthoodlife.org)
- **The Family Institute**  
[www.thearcfamilyinstitute.org](http://www.thearcfamilyinstitute.org)



# The Arc of New Jersey (cont.)

- **Project HIRE:** (Free to families; must be tied to a funding source such as IEP, DVRS, etc.)  
[www.ProjectHire.biz](http://www.ProjectHire.biz)
- **Camp Jaycee:** (Private pay or funding through PerformCare or DDD)  
[www.campjaycee.org](http://www.campjaycee.org)

# The Arc of New Jersey Family Institute

Provides families with the necessary resources and education to access the appropriate supports and services for their loved one with an intellectual and developmental disability (IDD).



# To Receive 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. 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”.**

# Planning to apply for SSI

The background of the slide features several light gray, wavy, horizontal lines that sweep across the lower right portion of the image, creating a sense of movement and depth.

# 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.

# When Applying for SSI: Resources

- When student is younger than 18, family income is considered. On 18<sup>th</sup> 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.
- Inform relatives not to leave money in their will to the individual with I/DD. They can leave assets in their will to a Special Needs Trust that parents have set up.

# When 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.
  - 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.



# How to apply for Supplemental Security Income (SSI)

- Information on applying for SSI: [www.ssa.gov/ssi/text-apply-ussi.htm](http://www.ssa.gov/ssi/text-apply-ussi.htm)
- Call local Social Security office to make appointment to do the SSI application on the phone. Because of COVID pandemic, SSA offices are closed to the public.
- Parents can use the Social Security office locator to get phone number for the local office.

# Social Security Office Locator



Social Security

The Official Website of the U.S. Social Security Administration

## Social Security Office Locator



**We are OPEN to receive your calls**

On Tuesday, March 17, 2020, we suspended face-to-face service to the public in our field offices and hearings offices nationwide until further notice. However, we are still able to provide critical services via phone, fax and online.

Find the Office for this ZIP Code.

ZIP:



Locate

[Zip Code Look Up](#)  
[Services Outside the United States](#)

Using our online services, you can:



- Apply for most types of benefits
- Estimate your future benefits
- Do so much more

To learn more, visit [What You Can Do Online](#).

National 800 Number

**Toll-Free: 1-800-772-1213**

# 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."

# When SSI begins...

- Parents should open new bank account, jointly with individual with I/DD, with child's Social Security number first.
- SSI checks to be deposited electronically into this new joint 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. May open ABLE account, if needed.
- Select a Medicaid HMO or be auto-assigned.

# 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.
- If person receiving SSI is employed, must report wages monthly to Social Security.
- Social Security: Substantial Gainful Activity (SGA) - **\$1,310/mo., gross income (2021).**

**What happens if the SSI  
application is turned down?**

The background of the slide features several light gray, wavy, horizontal lines that sweep across the lower right portion of the image, creating a sense of motion or a stylized landscape.

# What happens if 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](http://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 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), may 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.
- Some attorneys specialize in this type of representation.
- Can call the County Bar Association's Lawyer Referral Service, and ask for names of attorneys in your county who do this type of work.

# 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>

# **ABLE Accounts**

The background of the slide features several light gray, wavy, horizontal lines that sweep across the lower right portion of the image, creating a sense of movement and depth.

# Achieving a Better Life Experience

## (ABLE) Act of 2014

- Persons with disabilities can deposit up to \$15,000/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 \$15,000/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>
- Visit the **ABLE National Resource Center website**  
[www.ablenrc.org](http://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.**

# What to do if parents opened a 529 account 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.**

# What to do if parents opened a 529 account for child with I/DD? (cont.)

- If person with I/DD 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 \$15,000/yr. into ABLE account. If 529 account had more than \$15,000, can do rollover in multiple years.
- Talk to accountant about tax implications of rollover.



# **Why is it helpful to have SSI?**

(Will be discussed at webinar  
on Oct. 26, 2021)

**If turned down for SSI, can the person with IDD get Medicaid and have DDD services?**

The background of the slide features several light gray, wavy, horizontal lines that sweep across the lower half of the image, creating a sense of movement and depth.

# If denied SSI because disability is not “severe”...

- If there is a Social Security hearing and you win, the son/daughter receives SSI and Medicaid, and lump sum back payment.
- Wait a year and try to apply for ABD Medicaid from NJ (will require medical documentation of disability), or
- Apply for Medicaid expansion – regular NJ FamilyCare/Medicaid. But son/daughter with IDD **cannot** be a dependent on parent’s tax return.

**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 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 \$1,073/mo. (in 2021)**, 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.**

# What is a “Non-DAC”?

- A non-DAC *never had SSI as an adult (age 18 or older)* and now 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 \$1,073/month (in 2021),** the student is not eligible for NJ Care Special Medicaid Program.
- Other situations may also qualify for DDD’s Non-DAC status.

# More on Non-DACs

- Families may be confused because most DDD-related notices say that Medicaid is required. Most individuals with IDD can obtain Medicaid.
- **Families should know that “Non-DAC” status is an exception to DDD’s Medicaid requirement!**
- **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 Form



## The Arc of New Jersey's Mainstreaming Medical Care Program

### Medicaid Eligibility Problem Form

[www.mainstreamingmedicalcare.org](http://www.mainstreamingmedicalcare.org)

Date of Report: \_\_\_\_\_

Individual's Name: _____		DDD Client? <input type="checkbox"/> Yes <input type="checkbox"/> No	Date of Birth: _____	Age now: _____
Address: _____		CCW? <input type="checkbox"/> Yes <input type="checkbox"/> No	Social Security# _____	
Name of Contact Person: _____		Contact Person's Telephone: _____	County: _____	
Relationship to Individual: _____		Email: _____		
<b>Assets</b> 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? <input type="checkbox"/> Yes <input type="checkbox"/> No Comments: _____				
<b>Supplemental Security Income History</b> Has the individual ever received SSI? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, monthly amount: \$ _____ At what age did SSI start? _____ Is the person still receiving SSI? <input type="checkbox"/> Yes <input type="checkbox"/> 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: _____				
<b>Medicaid History</b> Has the individual ever received Medicaid? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approximate age when Medicaid started: _____ Approximate age when Medicaid ended: _____ Do you know why Medicaid ended? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please explain: _____ If the person has never received Medicaid, did he/she ever apply for Medicaid? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, explain why Medicaid was denied: _____ If no, explain why no application was ever made to Medicaid: _____ Comments: _____				
<b>Social Security Disability?</b> <input type="checkbox"/> Yes <input type="checkbox"/> 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? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please explain: _____ <b>Medicare?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No				
<b>Employment Status of Parents</b> <b>Mother:</b> Working? <input type="checkbox"/> Yes <input type="checkbox"/> No Retired? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approx. age when mom retired: _____ Deceased? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approx. age when mom died: _____ Disabled? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approx. age when mom became disabled: _____ <b>Father:</b> Working? <input type="checkbox"/> Yes <input type="checkbox"/> No Retired? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approx. age when dad retired: _____ Deceased? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approx. age when dad died: _____ Disabled? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, approx. age when dad became disabled: _____				
<b>Individual's Employment Questions</b> Currently employed? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, Number of hours/week: _____ Salary: \$ _____ per month If currently employed: Did individual apply for Medicaid's Workability Program <input type="checkbox"/> Yes <input type="checkbox"/> No Comments: _____ Receiving unemployment income? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, amount of unemployment income: \$ _____ per month Receiving SSDI because of individual's work history? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, amount of SSDI per month \$ _____				
<b>Does individual receive any other income not listed above? (Including child support, pension from a parent or income from any other source)</b> <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, what is the other income and amount, per month? _____				
<b>Miscellaneous</b> 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](mailto:broberts@arcnj.org) / fax (732)246-2567 or Jennifer Lynch at [jlynch@arcnj.org](mailto: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 01/2017



# 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, and 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 permitted.

*Becky Thomas will do a webinar presentation on PPP  
on Nov. 17!*

# **Different Medicaid categories**

The background of the slide features several light gray, wavy, horizontal lines that sweep across the lower half of the image, creating a sense of movement and depth.

# Two Major Medicaid Categories

- **Aged Blind and Disabled (ABD):** Most people with IDD are enrolled in ABD Medicaid/NJ FamilyCare
- **NJ FamilyCare – Medicaid expansion:** eligibility based on income not on disability.

# Medicaid Thru NJ WorkAbility

- NJ WorkAbility provides Medicaid for people with disabilities who are employed and between ages 16 & 64.
- Persons with permanent disabilities, working PT or FT are eligible.
- Can earn as much as \$64,596/yr. Can have \$20,000 in personal assets and still qualify.
  - IRA & 401K personal retirement accts. – not counted for eligibility

# Free Help from NJ WINS when Person with I/DD is Employed

- Some additional Medicaid-related complications are possible when person who has SSI or SSDI is employed.
- **Substantial Gainful Activity (SGA) max. for 2021 - \$1,310/month, gross income.**
- Free help available from NJ WINS for persons with disabilities who are planning to work, or are already employed, and want to know if they can maintain SSI, SSDI, and Medicaid while working.
- Website: [www.njwins.org](http://www.njwins.org) The “contact us” page lists the staff contact info by county, including company cell number and e-mail address.

# Other types of Medicaid – special situations

- Sometimes there are special situations, and another type of Medicaid may be appropriate for a person with IDD who is not eligible for SSI.
- The Arc of New Jersey can provide individualized information to families.
- Contact: Beverly Roberts: [broberts@arcnj.org](mailto:broberts@arcnj.org)



# 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 26<sup>th</sup> 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 – for as long as parent has the 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

Beverly Roberts, Director

Mainstreaming Medical Care Program

The Arc of New Jersey

[Broberts@arcnj.org](mailto:Broberts@arcnj.org)

To sign up for our listserv:

[www.mainstreamingmedicalcare.org](http://www.mainstreamingmedicalcare.org)

The Arc of NJ website: [www.arcnj.org](http://www.arcnj.org)

# Questions?

