

# *When Parents Collect Social Security: How Parents' Social Security Benefits Impact Their Adult Loved One with IDD*

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The Arc of New Jersey

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# 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
- 
- A decorative graphic consisting of several thick, light gray, wavy lines that flow from the bottom left towards the top right, partially overlapping the text area.

# 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).



**When a parent is thinking  
about collecting Social Security  
retirement benefits.**

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# Social Security for parents -- “full” retirement age

- If born between 1943 and 1954 – age 66 for full retirement benefit for the employee.
- If born between 1955 and 1960 – the age increases gradually beyond 66.
- If born 1960 or later – age 67 for full benefit.
- Parent can collect Social Security as young as age 62, with reduction in benefit; if wait to age 70, increased benefit.
- See this retirement planner link from SSA.gov
- <https://www.ssa.gov/benefits/retirement/planner/agereduction.html>

# How to contact local Social Security office by phone



**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

**What happens to SSI and Medicaid for son/daughter with IDD when a parent starts to collect Social Security retirement benefit (or when a parent becomes disabled or passes away)?**

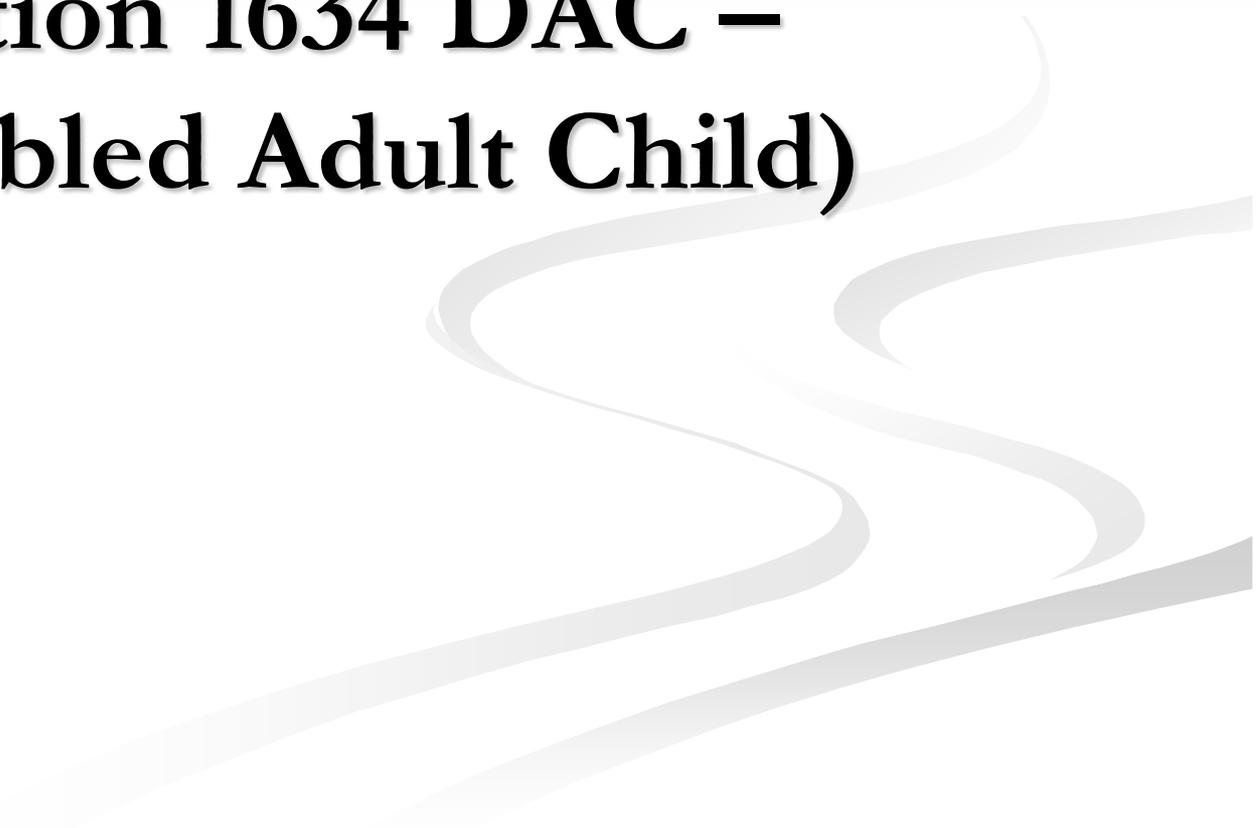
# What is the difference between SSI and SSDI?

- **SSI is Supplemental Security Income.** The determination is based on having a severe disability and very limited income and resources.
- **SSDI is Social Security Disability Insurance.** It is based on Social Security's determination of a disability and also work credits. A "DAC" is a disabled adult child who receives SSDI from the parent's work record.

# SSI and Medicaid in NJ

- Majority of adults (18 and older) with IDD have SSI and Medicaid.
  - When individuals have SSI, they have Medicaid automatically, without a separate Medicaid application.
- There are changes to the son/daughter's SSI & Medicaid when a parent collects Social Security retirement, or if parent becomes disabled or passes away.

**Social Security's  
Official Definition:  
Section 1634 DAC –  
(Disabled Adult Child)**

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# Why is it Helpful to Have SSI?

- When parent of person with IDD retires, becomes disabled, or dies: If the son/daughter has SSI, they are able to receive Social Security Disability Insurance (SSDI) income on parent's work record, instead of SSI.
- Monthly SSDI on parent's work record is often too high to get Medicaid.
- **But, when persons with IDD 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 SSDI on parent's work record. The amount of the SSDI benefit is disregarded.**

# Official Definition: Section 1634 DAC

- **DAC = Disabled Adult Child. See Section 1634 DAC flyer developed by NJ DHS. Flyer was revised, Sept. 2021.**
- 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 (not including a Special Needs Trust or ABLE account).

## 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.





## 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](http://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](mailto:DDD.MediEligHelpdesk@dhs.nj.gov)

# How to obtain Medicaid after becoming a Section 1634 DAC, and SSI benefits end

## Per DDD's DAC flyer, revised 9/2021

**For individuals ENROLLED in the 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 (*or it may be sent via email during the COVID pandemic*) 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.

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# When applying for Medicaid...

When SSI/Medicaid is ending due to parent's retirement (or due to parent's disability or passing away):

- Son/daughter with IDD cannot have more than \$2,000 in assets with these exceptions:
  - Funds in ABLE account (up to \$15,000 deposited per year)
  - Funds in a Special Needs Trust

**Important: During the pandemic no one should lose Medicaid, but pandemic will end eventually. Do not delay in doing a Medicaid application.**

# Special Needs Trusts (SNT)

- If setting up SNT, be sure the attorney is very experienced with this type of trust for Medicaid beneficiary.
- If the SNT has been funded, Medicaid will want to review the document.
- Whenever there are expenditures from SNT, save all receipts. Follow Medicaid regulations.

# Important information!

- Previously: When a person with I/DD had SSI and then a parent retired, became disabled, or passed away – the switch to SSDI and DAC status was automatic.
- Recently: Some parents are being told they need to **do a new application to Social Security** before DAC status takes place.
- Two recent reports of denial for DAC status. Very unusual and troubling!
- **Important to save all medical & IEP documents from when SSI is approved, to provide during a Social Security re-application process, if necessary!**

**Some people with IDD who are employed have NJ WorkAbility Medicaid. What can change with NJ WorkAbility when a parent collects Social Security retirement benefit?**

# NJ WorkAbility

- Eligibility: Persons with permanent disabilities, who are working PT or FT, between ages 16 and 64.
- In 2021: Individual's gross *earned income* can be much as \$64,596/yr, or \$5,383/mo. Can have \$20,000 in personal assets and still qualify.
  - IRA & 401K personal retirement accts are not counted for eligibility!

# NJ WorkAbility: Difference between “earned” & “unearned” income

## Unearned income:

- **Examples of unearned income: SSDI from a parent’s work record; unemployment income; investments.**
- **In 2021: Unearned income threshold cannot exceed \$1,073/mo.**  
If unearned income exceeds that amount, not eligible for NJ WorkAbility.

**Earned income:** SSDI income from individual’s own work record.

**NOTE: LEGISLATION TO FIX THIS UNFAIR POLICY IS BEFORE THE NJ LEGISLATURE.**

# NJ WorkAbility (Cont.)

- At present: What can cause termination of NJ WorkAbility Medicaid?
  1. No longer employed.
  2. Receiving unearned income above the threshold (\$1,073/month in 2021)
  3. Has 65<sup>th</sup> birthday.

# If son/daughter has NJ WorkAbility and then a parent collects Social Security...

- At present, if SSDI for son/daughter with IDD is more than \$1,073/mo., they would lose that type of Medicaid.
- If receiving DDD services and have NJ WorkAbility: Person with IDD can apply for a different type of Medicaid through DDD Waiver Unit, **but total income can't exceed \$2,382/mo. (2021).**
- **No one should be terminated from any type of Medicaid during the coronavirus pandemic.**

# **ABLE Accounts**

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# Achieving a Better Life Experience

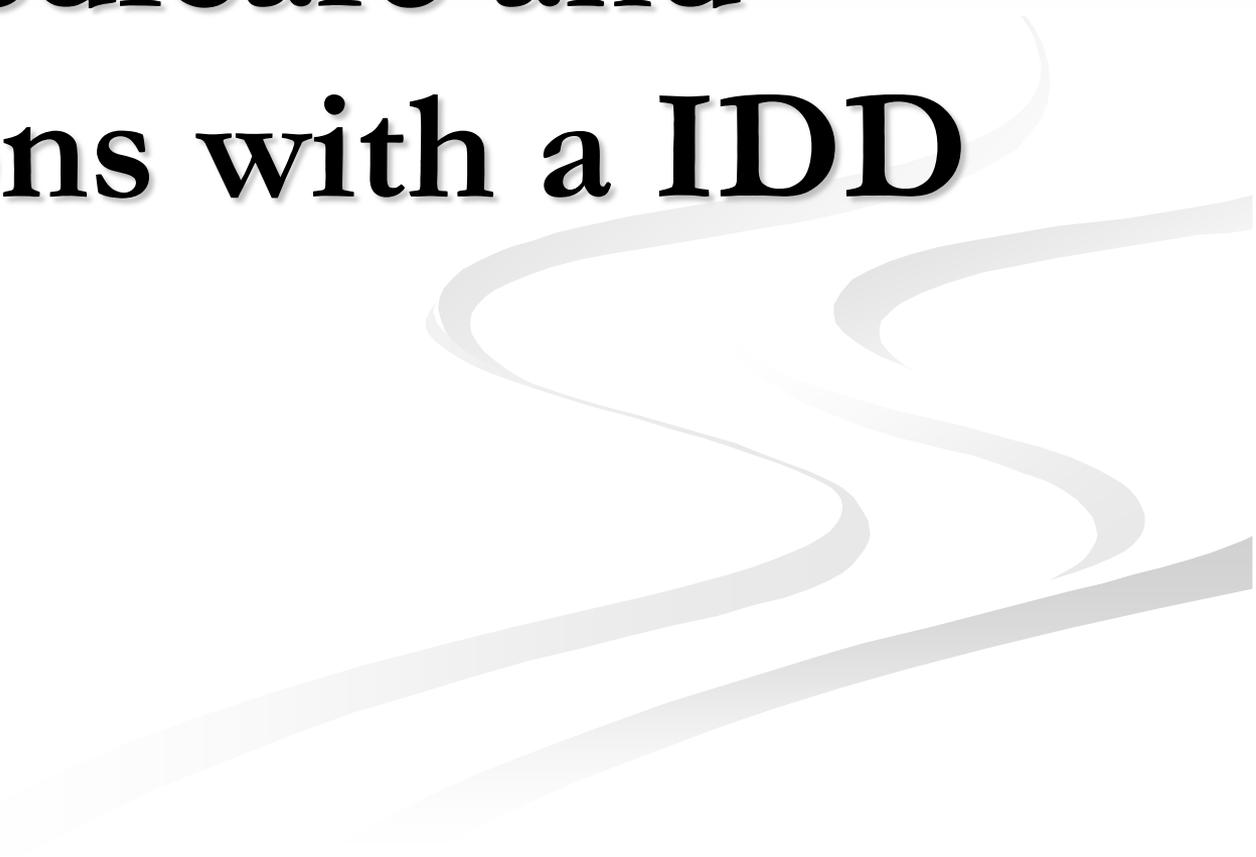
## (ABLE) Act of 2014

- ❑ Persons with disabilities can deposit up to \$15,000/year in an ABLE tax-exempt savings account (in 2021).
- ❑ Eligibility: Must be receiving SSI or SSDI; Age of onset of disability must be before age 26.
- ❑ After SSDI starts (if difficulty spending the additional money), opening an ABLE account may be helpful.
- ❑ ABLE accounts won't affect continuing financial eligibility for Medicaid, SSI and other public benefits.

# ABLE Accounts (cont.)

- Can open ABLE account in NJ or another state.  
<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.

# **Medicare and Persons with a IDD**

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# Obtaining Medicare after 24 months of SSDI benefit

- When a person with IDD has been receiving SSDI for 24 months, Medicare starts automatically.
  - Medicare also occurs due to person with IDD's own work record – if they have SSDI for 24 months.
  - When person has both Medicare and Medicaid, Medicaid pays the Medicare Part B premium.
- Cannot have Medicare without having SSDI for 24 months (or turning age 65).

# Having both Medicare and Medicaid (dual eligibility)

- **Can have both Medicare and Medicaid** with ABD (Aged, Blind Disabled) Medicaid. Most people with IDD have an ABD Medicaid category!
  - **DAC Medicaid = ABD Medicaid.**
- ***Cannot*** have both Medicare and Medicaid with “regular” NJ FamilyCare (Medicaid expansion).

# Medicare Part B for dual eligibles

- Without Medicaid, the cost of Medicare Part B premium: \$148.50/mo. in 2021; cost increases yearly.
- Having both Medicare and Medicaid: NJ Medicaid pays the cost for Medicare Part B. But for the first 2 or 3 months, the Medicare fee will be deducted from Social Security benefit. Then the problem should be corrected automatically.
  - If Medicaid is not covering Medicare Part B cost after 3 months, let me know.

# Medicare Part D – drug benefit

- When person has Medicare and Medicaid, prescription drugs provided through Medicare Part D.
- If person also has private health insurance with good drug benefit, need to decline Medicare Part D.
- The Arc of NJ does a free webinar each year on Medicare Part D and changes that start Jan. 1<sup>st</sup>. This year's webinar will be **Mon., Nov. 15<sup>th</sup> at 10 am.**

# Three Fact Sheets from The Arc of New Jersey

**Understanding what happens when a person with IDD who receives Medicaid becomes eligible for Medicare.**

- [FAQ- Dual Eligibles General Information](#)
- [FAQ- Dual Eligibles and Prescription Medication](#)
- [FAQ- Dual Eligibles and Special Needs Plan \(D-SNPs\)](#)

# 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)