



## SSI and Medicaid for Individuals with Intellectual and Developmental Disabilities

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**The Arc of New Jersey**

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



The Arc of NJ is the State's leading advocacy and service organization for children and adults with intellectual and developmental disabilities (IDD) and their families.

The Arc consists of a State office, 20 Local County Chapters and a National office in Washington, DC.

The Arc of NJ is primarily an advocacy organization, conducting public policy work, community outreach and information and referral.

The Arc of NJ also runs several programs including:

- Project HIRE
- Planning for Adult Life
- The NJ Self-Advocacy Project
- The Criminal Justice Advocacy program
- The Arc of NJ Family Institute
- Mainstreaming Medical Care
- Training & Consultation Services
- NJ Camp Jaycee

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email list at  
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- DDD – NJ Division of Developmental Disabilities
- DDS – NJ Division of Disability Services
- DHS – NJ Department of Human Services
- IDD – intellectual and developmental disabilities
- SSA – Social Security Administration
- SSDI – Social Security Disability Income (based on work history)
- SSI – Supplemental Security Income (not based on work history)

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

- All young adults can stay on parent's health insurance until age 26.
- Adult children with disabilities can stay on their parent's health insurance indefinitely, with some exceptions.
- **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.

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## Why do we focus on applying for Medicaid?

Because Medicaid is a critical benefit for individuals with disabilities to access services and supports.

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

- **Must be functionally eligible for DDD services and must have Medicaid.**
- **Best way to have Medicaid: Apply for Supplemental Security Income (SSI) at age 18. Everyone who receives SSI will also get Medicaid.**
  - SSI is the cash benefit. Medicaid is the health insurance benefit and the gateway to DDD services.

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## Rule #1 – Age Matters!

When the individual with a disability is *under 18* years old, determination for Supplemental Security Income (SSI) is based on the *family* income.

When the individual is *over 18*, the determination is based on the *individual's* income.

Apply as soon as possible after the individual's 18<sup>th</sup> birthday.

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## Rule #2 – Money Matters!

If the individual has “too much” they won’t be eligible.

- Person with a disability **can’t have more than \$2,000** in his/her name (assets). This includes anything with that person’s Social Security number.
- 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 – these are considered the parent’s responsibilities.
- Income can be earned or unearned – there are also some issues if someone has too much income (we’ll talk about this later!)

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- If applicable, consider a Special Needs Trust (SNT). **Hire a professional who specializes in SNT!**
- Set up an ABLÉ Account (Achieving a Better Life Experience)
  - Persons with disabilities can deposit up to \$17,000/year in an ABLÉ tax-exempt savings account.
  - Age of onset of disability must be before age 26
  - Must be receiving SSI or SSDI; or with medical documentation, someone can deposit money into ABLÉ as spend-down *before* applying for SSI.
  - ABLÉ accounts won't affect continuing financial eligibility for SSI, Medicaid and other public benefits, until the account reaches \$100,000.

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- ABLÉ accounts are available in NJ.  
The individual can open an ABLÉ account in this state 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 with educational webinars and state-by-state comparisons.

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## Applying for SSI or Medicaid if parents are divorced

- When parents are divorced, child support is viewed as the child's "unearned 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 "unearned income."

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## Rule #3 – Be prepared!

As you are getting ready to complete the application, start collecting:

- Evaluations and assessments
- Schools: Name, address, IEPs and Progress Reports
- Disabilities: names of conditions/diagnoses; onset date
- Doctors and therapists: Name, address, phone, dates first and last seen, specialty, diagnosis
- Medications: Name, prescribing physician, date and dosage when started as well as most recent date and dosage
- Employment: Name, address, phone, supervisor name, position held, date and pay when started, last date of work and pay
- Division of Vocational Rehabilitation Services information

Put together a file or binder as well as creating electronic files, if possible.

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## Start thinking about the questions.

- What is the individual's disability?
- How does it affect the individual?
- What is keeping them from working?
- Can they complete tasks and activities independently?
- What does a typical day look like?
- What steps have been tried previously to work? What happened?

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- Be prepared to talk about the individual's disability.
  - Decide who is the best person to be "in charge".
  - Consider how you will answer questions about the individual's disability, *including when you are discussing their disability with them present.*

Prepare the individual to talk about their disability.

- Let them know they will be asked questions, when appropriate.
- Help them to describe how they feel or how their disability affects their daily life.
- Help them to feel as comfortable as possible.

A diagnosis alone does not mean there is a severe impairment that entitles the applicant to SSDI or SSI benefits, and the burden of proof is on the applicant.

While the diagnosis may be very compelling, Social Security still needs to know what the actual **impact of the condition is on this applicant's ability to do work-related activities.**

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## Ready to apply?

- Information on applying for SSI: [www.ssa.gov/ssi/text-apply-ussi.htm](http://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.
- 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.

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<http://Secure.ssa.gov/ICON/main.jsp>

**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:**    
[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**

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Keep in mind that if you do the application online, you can always stop, save it and go back to it later. This is very helpful if you find yourself getting distracted or tired.

Remember – if you begin to answer questions just to “get them over with”, it’s time to stop and take a break.

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Once you have finished the Application and Disability report, Social Security will review the financial information you provided and make an assessment of whether your applicant meets financial eligibility for an SSI application.

If they do, the case will be moved over to DDS where a Claims Adjudicator will be assigned for the medical review. (That should take about 10 days, but it has been taking longer.)

If you do not receive any forms or other communications within a month after the application has been taken, call the District Office and ask for a status report.

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## Functional Reports

- Don't do the Function Report Adult *for* your child (SSA-3373)
  - Let your child do whatever they can. If you help in any way, be sure to note that in the comments section.
- Complete the Third Party Function Report (SSA-3380)
  - Answer honestly and with insight
  - When the question does not ask for the information you want to give, answer it as if it does
  - Once completed, re-read the entire report
  - If you think it is lacking anything, ask someone who knows your child well to read it
  - Make a copy, paper and scanned, before mailing
  - Mail receipt requested

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## After approval for SSI

- Always respond in timely way to official requests for information. 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, you must report wages monthly to Social Security.
- Social Security: Substantial Gainful Activity (SGA) - **\$1,470/mo., gross income (2023).**

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## When SSI begins...

- Parents should open new bank account, jointly with individual with IDD, with child's Social Security number first.
- Consider a representative payeeship for the funds.
- SSI checks to be deposited electronically into this new joint bank account.
- Can't have more than \$2,000 in assets!
- If receiving lump sum back payments, you have 9 months to spend down. After 9 months, assets cannot exceed \$2,000 in the individual's name. Open ABLE account or start a SNT, if needed.
- Select a Medicaid HMO or be auto-assigned.

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## 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:
  1. Horizon NJ Health
  2. United Health Care Community Plan
  3. Amerigroup
  4. Fidelis Care (formerly WellCare)
  5. Aetna Better Health

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## 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.
- If there is a rep payee, they need to fill out an annual financial report.

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## 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**.

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

▪ **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.
- Parents may want to contact attorney to represent the son/daughter at a hearing with a judge.

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## 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>

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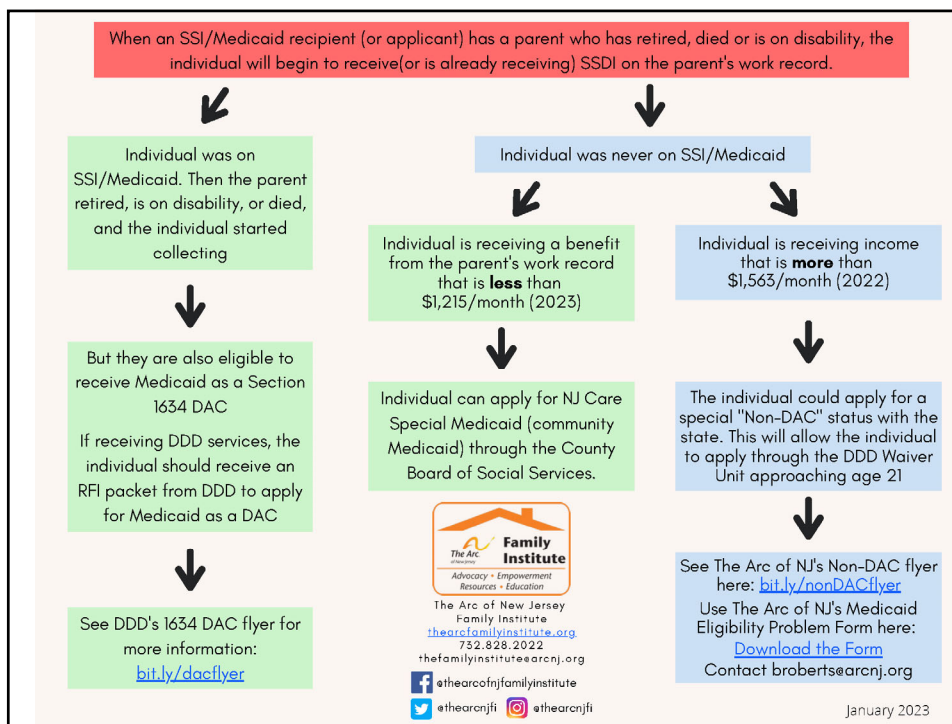


## Other avenues to accessing Medicaid



There are instances where the individual may not receive SSI (the cash benefit) but they can still receive Medicaid.

- The applicant is receiving a Social Security benefit because their parent, died, is retired or is collecting Social Security Disability themselves.
- The applicant has high unearned income such as child support.
- The applicant has a job.

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TYPES OF NJ FAMILYCARE/MEDICAID ELIGIBILITY IN NJ			
AGED, BLIND, OR DISABLED (ABD)		NJ FAMILYCARE/ MEDICAID EXPANSION	
<b>Supplemental Security Income (SSI) Medicaid</b> 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: <a href="http://bit.ly/ssaooffices">bit.ly/ssaooffices</a>	<b>Disabled Adult Child (DAC)</b> 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. <a href="http://bit.ly/dacmedicaid">bit.ly/dacmedicaid</a>	<ul style="list-style-type: none"><li>• Eligibility is based on income, not on the individual having a disability.</li><li>• The maximum monthly income limit increases each year.</li><li>• The maximum gross income for a single adult in 2023 is \$1,677/month.</li><li>• The individual cannot be listed as a dependent on their parent's tax return.</li><li>• The individual cannot receive Medicare.</li><li>• ABD is a better route if eligible.</li></ul>	
<b>Medicaid Only</b> For individuals with IDD who do not receive monthly SSI, but meet SSI income and resource limits. <a href="http://bit.ly/medicaidonly">bit.ly/medicaidonly</a>	<b>New Jersey Care... Special Medicaid Program</b> For individuals with IDD with income below \$1,215/month. Contact your County Board of Social Services: <a href="http://bit.ly/njcbss">bit.ly/njcbss</a>		
<b>NJ Workability</b> Offers healthcare to individuals with IDD ages 16-64 who are employed and whose income would disqualify them from other forms of Medicaid. <a href="http://bit.ly/njworkability">bit.ly/njworkability</a>	<b>Long Term Services and Supports</b> Applies to younger individuals who need significant support, such as private-duty nursing, etc. <a href="http://bit.ly/longtermsupport">bit.ly/longtermsupport</a>		
<b>HOW TO GET IT</b> Apply for SSI at age 18 <a href="http://bit.ly/Apply4SSI">bit.ly/Apply4SSI</a> ABD Medicaid Application <a href="http://bit.ly/ABDApplication">bit.ly/ABDApplication</a>	<b>QUICK FACT</b> 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 guaranteed.	<b>HOW TO GET IT</b> <i>Applicants must have financial eligibility.</i> NJ FamilyCare Quickstart <a href="http://bit.ly/njfamilycare">bit.ly/njfamilycare</a>	<b>QUICK FACT</b> 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.
<b>WHAT'S COVERED?</b> Doctor visits, prescriptions, x-rays, dental, lab testing, eyeglasses, mental health, hospitalization, specialist visits, hearing aids, Personal Care Assistant (PCA), Personal Preference Program (PPP)	<b>WHAT'S COVERED?</b> Doctor visits, prescriptions, x-rays, dental, lab testing, eyeglasses, mental health, hospitalization, specialist visits, hearing aids, Personal Care Assistant (PCA), Personal Preference Program (PPP)	<b>WHAT'S COVERED?</b> Doctor visits, prescriptions, x-rays, dental, lab testing, eyeglasses, hospitalization, mental health, preventative screenings, regular checkups	
For specific questions about Medicaid or the application process, contact The Arc of New Jersey at <a href="mailto:info@arcnj.org">info@arcnj.org</a> .			



January 2023



January 2023



## Can I Work While on SSI/Medicaid?

If an individual with IDD is working and they earn too much to be eligible for Medicaid through other means:

- NJ WorkAbility provides Medicaid for people with disabilities who are employed and over age 16.
- Persons with disabilities, working PT or FT, are eligible.
- Can earn as much as \$73,932/yr. (2023).
- There are no asset limits!
- However, if **unearned income** exceeds \$1,215/mo. (2023) due to parent's work record, they are **not** eligible for NJ WorkAbility. **SSI income from parent is considered "unearned income."**
- **Caution: If the person becomes unemployed, NJ WorkAbility ends.**

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## Free Help Ticket to Work

- Ticket to Work Helpline 866-968-7842
- Project HIRE – Ticket to Work  
[ccollick@projecthire.biz](mailto:ccollick@projecthire.biz) or 732-246-7605
- In Northern NJ – Goodwill Industries  
<https://goodwillnynj.org/people-with-disabilities/>

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## 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.
- Difference between PCA and PPP.

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## Medicaid “Unwinding”

- ❑ COVID pandemic started in March 2020, and the federal government declared a Public Health Emergency (PHE) and “continuous Medicaid enrollment”. No one was terminated from Medicaid since March 2020.
- ❑ Continuous Medicaid enrollment ended **starting in April 2023.**
- ❑ This process has been called **“Unwinding” from the continuous Medicaid requirement.**

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## Medicaid “Unwinding”

- ❑ Medicaid unwinding does not apply to people who receive SSI and Medicaid.
- ❑ But sometimes Social Security does redeterminations for disability beneficiaries. Respond promptly to any requests for information from Social Security or Medicaid!

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## New Medicaid Unwinding Web Site

[www.arcnj.org](http://www.arcnj.org) -- **look for the red writing at the top of the page!**

- ❑ These materials, and more, can be found on our new Medicaid Unwinding web page.

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



# Questions?



**info@arcnj.org**

More information can be found at  
[www.arcnj.org](http://www.arcnj.org) under the page for the  
Mainstreaming Medical Care Program or  
at [www.TheArcFamilyInstitute.org](http://www.TheArcFamilyInstitute.org)

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