#### 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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To sign up for listserv:

www.mainstreamingmedicalcare.org



#### The Arc of New Jersey 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 (<u>www.thearcfamilyinstitute.org/resources/camp-funding-applications.html</u>)
- Family support services (ex:. Respite, assistive technology)

#### The Arc of New Jersey: Free Advocacy Services

Mainstreaming Medical Care www.mainstreamingmedicalcare.org

New Jersey Self-Advocacy Project www.njselfadvocacyproject.org

Criminal Justice Advocacy Program www.cjapnj.org

Planning For Adult Life www.planningforadultlife.org

The Family Institute 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
- Camp Jaycee: (Private pay or funding through PerformCare or DDD)

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).



www.TheArcFamilyInstitute.org

# Main topics to be discussed in this presentation include:

- Medicaid "Unwinding"
- When a parent is planning to collect Social Security retirement benefits.
- Why SSI for son/daughter changes to SSDI.
- Social Security's official definition of a Disabled Adult Child (Section 1634 DAC).
- □ NJ WorkAbility (Medicaid).
- □ ABLE Accounts.
- Medicare and persons with IDD.

#### MEDICAID UNWINDING FROM THE PUBLIC HEALTH EMERGENCY (PHE)

### Medicaid "Unwinding"

- 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 Medicaid.
   Medicaid Unwinding should not apply to people with SSI & Medicaid.
- If receiving NJ 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: <u>www.mainstreamingmedicalcare.org</u>

### Medicaid "Unwinding" (cont.)

#### What you can do prior to the end of PHE:

- Don't exceed Medicaid's maximum allowable resources (usually \$2,000). This maximum also applies if receiving SSI.
- <u>Exception</u>: If received a back-payment from Social Security 9 months to spend-down.
- □ Consider ABLE account, if appropriate.
- 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!

## Current Status of the Public Health Emergency (PHE)

- On October 13, 2022, the PHE was renewed by the US Department of Health & Human Services.
- Medicaid members will continue to remain enrolled as they have since March 2020.
- The next possible date for the PHE to end would be January 11, 2023. The federal government has promised at least 60 days' advance notice, so we should know in mid-November whether or not the PHE will actually end on January 11th.
- □ It is possible the PHE will be renewed again.

### MANY DIFFERENT TYPES OF MEDICAID IN THE AGED, BLIND, DISABLED (ABD) CATEGORY

#### Many Types of Aged, Blind, Disabled (ABD) Medicaid

- □ SSI and Medicaid.
- DAC Medicaid (per the DAC flyer).
- □ NJ WorkAbility.
- Non-DAC Medicaid via DDD Waiver Unit.
- NJ Care Special Medicaid Program (Community Medicaid).
- MLTSS.
- If not sure about whether son/daughter has ABD Medicaid or NJ FamilyCare/Medicaid expansion: Can call Health Benefits Coordinator and ask. 1-800-701-0710.

### WHEN A PARENT IS PLANNING TO COLLECT SOCIAL SECURITY RETIREMENT BENEFITS

#### 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

# 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 on work credits. A Section 1634 "DAC" is a disabled adult child who receives SSDI from the parent's work record.

#### WHAT HAPPENS TO SSI & **MEDICAID FOR SON/DAUGHTER** WHEN A PARENT STARTS TO **COLLECT SOCIAL SECURITY RETIREMENT BENEFIT (OR WHEN** A PARENT BECOMES DISABLED **OR PASSES AWAY)?**

#### **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.

#### **Important Information!**

- Previously: When a person with IDD had SSI and then a parent retired, became disabled, or passed away – the switch to SSDI and DAC status was automatic.
- Currently: Parents are being told they need to do a new application to Social Security before DAC status takes place.
- Some reports of denial for DAC status because sufficient information was not provided to Social Security to "prove" disability status before age 22. Very troubling!
- Important to <u>save all medical & IEP documents from</u> when SSI is approved, to provide during a Social Security re-application process!

### **More Important Information!**

- If your son/daughter needs DDD services, then they must have NJ Medicaid. Therefore, when SSDI starts, their resources cannot exceed \$2,000.
   This is a Medicaid rule, not a Social Security rule.
- Some confusion: Social Security employees don't know that NJ Medicaid is required for DDD services. Do <u>not</u> pay attention if Social Security employee says there is no resource maximum for people who receive SSDI.

### SOCIAL SECURITY'S OFFICIAL DEFINITION: SECTION 1634 DAC – (DISABLED ADULT CHILD)

#### 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 ignored.

#### **Official Definition: Section 1634 DAC**

DAC = Disabled Adult Child. See Section 1634 DAC flyer developed by NJ DHS. <u>Flyer was revised, Sept. 2021.</u>

- □ 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



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

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

#### For individuals ENROLLED in the DDD Supports Program or Community Care Program:

DDD will send 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 will receive a Final Determination letter.

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

#### For individuals <u>NOT</u> ENROLLED in the DDD Supports Program or Community Care Program:

- Your local County Board of Social Services should send you the NJ FamilyCare Aged, Blind, and Disabled Programs <u>Request for Information (RFI) Packet</u> 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 will receive a Final Determination letter.
- If you do not receive the RFI Packet from the County BOSS, contact that office to request it:

www.nj.gov/humanservices/njsnap/home/cbss.shtml

#### 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 resources with these exceptions:
  - □ Funds in ABLE account (up to \$16,000 deposited per year)
  - Funds in a Special Needs Trust
  - If back-payment received from Social Security: Nine months to spend it down.

Important: During the pandemic no one should lose Medicaid, but the pandemic will end eventually. <u>Do not</u> 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.

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**

NOTE: Important legislation signed by Governor Murphy, (Jan. 2022) to improve NJ WorkAbility but not implemented yet! Hope for implementation early in 2023.

#### □ Current NJ WorkAbility regulations:

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

#### NJ WorkAbility: Difference between "earned" & "unearned" SSDI income

# THIS WILL CHANGE WHEN THE LEGISLATION IS FULLY IMPLEMENTED:

<u>"Unearned" income – if over \$1,133/month (2022),</u> not eligible currently for NJ WorkAbility.

Example of unearned income: <u>SSDI from a</u> <u>parent's work record.</u>

<u>"Earned"</u> income from SSDI from person's own work record is permitted for NJ WorkAbility.

## IMPORTANT: WHAT TO KNOW WHEN A SON/DAUGHTER WITH IDD RECEIVES SSDI AND IS EMPLOYED

#### What is SGA?

- Social Security Administration's regulation: To be eligible for SSDI benefits, a person must <u>not</u> 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 2022 is \$1,350/mo. gross 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 behind in sending notifications that persons with SSDI exceeded SGA level

#### **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.
- 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. <u>https://savewithable.com/nj/home.html</u>
- 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.

# MEDICARE AND PERSONS WITH IDD

# When will Medicare start for person with IDD?

- Important Note: If a parent is age 65 and collecting Medicare, that does <u>not</u> automatically result in person with IDD having Medicare.
- Medicare for person with IDD starts only due to having SSDI for 24 months.

# Medicare starts after 24 months of SSDI benefit

- When a person with IDD has been receiving SSDI for two years, Medicare starts automatically.
- □ Two ways for person with IDD to have SSDI:
  - From work record of parent who collects Social Security retirement or disability, or who has passed away.
  - From the work record of the person with IDD after they have SSDI for two years.
- When person has both Medicare and Medicaid, Medicaid pays the Medicare Part B premium (after a couple of months).
- Person with IDD won't receive Medicare without having SSDI for two years (or turning age 65, with a sufficient work record).

# Having both Medicare and Medicaid (dual eligibility)

- Can have both Medicare and Medicaid with an ABD (Aged, Blind Disabled) type of Medicaid.
- □ DAC Medicaid = ABD Medicaid.
- Cannot have both Medicare and Medicaid with non-ABD NJ FamilyCare (Medicaid expansion).
- □ Most people with IDD have an ABD type of Medicaid.

#### Medicare Part B for dual eligible

- Without Medicaid, the cost of Medicare Part B premium: \$164.90/mo. in 2023. (Slight decrease from 2022 premium.)
- Having both Medicare and Medicaid: NJ Medicaid pays the cost for Medicare Part B monthly premium. 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.

### Private insurance and Medicare Part B

- Suggest <u>not</u> declining Medicare Part B even though person with IDD also has private health insurance from parent. Medicaid pays the Part B premium.
- What happens if Part B was turned down and then private insurance ends?
- When ready to start Medicare Part B: The parent who has that health insurance MUST have a letter from employer documenting continuous, creditable coverage from the date when the person was first eligible to have Medicare Part B, but refused it because of the private health insurance.
- This letter is also needed if employee has a spouse covered by employer's private insurance who declined Part B.

#### 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 a good drug benefit (called "creditable" coverage) need to "opt out" from Medicare Part D. Call 1-800-Medicare.
- The Arc of New Jersey's free webinar on Medicare Part D in 2023: Thursday, November 3<sup>rd</sup> at 1:30

# 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)

# DUAL ELIGIBLE SPECIAL NEEDS PLANS (D-SNPs)

#### Horizon. 📲 🖤 + Even More Benefits.



#### Get extra benefits for \$0. Call us today at 1-866-928-5922 (TTY 711) Or visit

01 00044650

HorizonBlue.com/DualPlan2.

Did you know that you may qualify for even more benefits than what you currently have - at no cost to you? Horizon NJ TotalCare (HMO D-SNP) combines all your Medicare and Medicaid benefits (including prescription drug benefits) in one plan. We can also check to see if your doctors and specialists are in Horizon's strong network, so you can keep getting the same high-quality health care.

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We have an exciting addition for 2023 - the Extra Benefits Card. It's an easy-to-use card that comes loaded with:

Up to \$1,600/year for Over the-Counter (OTC) purchases. That's \$400 every 3 months. Increased for 2023!

Spend it on select items at participating retailers, like Walmart, CVS, Dollar General, Stop &

Shop, Acme and Rite Aid. Shop online or in-store.

Eligible members may also use this benefit to buy eligible healthy food items."

Up to \$1,080/year for OTC Benefit Catalog purchases. That's \$270 every 3 months. Increased for 20231

Spend it on items from our catalog, like toothpaste, vitamins, denture cleaner and more. Shop online, by telephone or via mail order.

Eligible members get up to an extra \$300/year (\$75 every 3 months) to help pay your electricity, water or gas utility bills.\* (Gasoline is not included with this benefit).

Plus, you can also earn up to \$235/year in rewards for completing a routine health survey and health screenings. Once you confirm a screening is complete, your rewards will be automatically loaded onto your Horizon EXTRA Benefits Card.

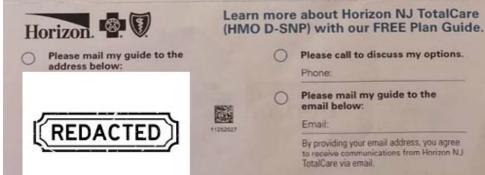
You'll also have these additional benefits:

· No referrals needed for network doctors

- · \$0 Monthly premium
- S0 For all covered prescriptions
- · SU Home delivery of meals for up to 14 days following a qualifying inpatient hospital stay\*\*
- · SO Copay to talk to doctors via phone, video or online chat 24/7 with Horizon CareOnline<sup>SM</sup>

Don't miss out on these extra benefits - all at no cost to you! Call us today or visit HorizonBlue.com/GetStarted. We'll even help you enroll.

✓ DETACH ✓







\* The benefits mentioned are a part of special supplemental program for the chronically iii. Not all members qualify.
\*\* Meals are offered following surgery and inpatient stay and must be coordinated by Horizon Care Managers. Eligible to receive up to 28 meals over a 14 day period. Limited to two occurrences per year.

Members must use an in-network provider. Members must use an in-network DME (Durable Medical Equipment) supplier. Members must use an in-network pharmacy. Members will be enrolled into Part D coverage under this plan and will be automatically disentalled from any other Medicare Part D or conditable coverage plan in which they are currently enrolled. There are no referrate required to see an in-network doctor or specialist. ATTENTION: If you speak a language other than English, language assistance services, free of charge, are available to you. Call 1-800-543-5656 (TTY 711). This document is also available in other languages, as well as other formats, such as large print and Braille. Herizon VI. Totalcare HMD D-SNP) complies with applicable Federal civil rights laws and does not discriminate against nor does it exclude people or treat them differently on the basis of race, color, gender, national origin, age, disability, pregnancy, gender identify, sex, sexual orientation or health status in the administration of the plan, including enrollment and benefit determinations.

Spanish (Español): Para ayuda en español, llame al 1-800-543-5656 (TTY 711), Chinese (中文): 如要中文協助, 請致電 1-844-498-9393 (TTY 711).

Horizon NJ Health has a Medicare contract and a contract with the State of New Jarsey Medicaid Program to offer Herizon NJ TotalCare (HMO D-SNP), an HMO Medicare Advantage Dual Eligible Special Needs plan. Enrollment in Horizon NJ TotalCare (HMO D-SNP) depends on contract renewal. Products are provided by Horizon NJ Health. Communications are issued by Horizon Blue Cross Blue Shield of New Jarsey in its capacity as administrator of programs and provider relations for all its companies. Both are independent licensees of the Blue Cross Blue Shield Association. The Blue Cross Blue Shield and Blue Shield<sup>6</sup> names and symbols are registered marks, and Thar's the Benefit of Blue<sup>6</sup> is a service mark of the Blue Cross Blue Shield<sup>6</sup> names and symbols are registered marks, and Horizon CareOnline<sup>60</sup> is a service mark of Horizon Blue Cross Blue Shield of New Jarsey. © 2022 Horizon Blue Cross Blue Shield of New Jarsey Orios.

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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.
- 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**

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To sign up for our listserv:

www.mainstreamingmedicalcare.org

The Arc of NJ website: <u>www.arcnj.org</u>

# **Questions?**

