

Moving from SSI to SSDI:

When a Parent Retires

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I have received a number of calls over the past year from families who have been told that their adult child is no longer eligible for Medicaid when they go from receiving SSI to SSDI. SSI is the Supplemental Security Income for folks with disabilities with low income. Many individuals with disabilities access Medicaid through their SSI eligibility. As parents begin to retire, their "adult child with a disability" often becomes eligible for Social Security Disability Income (SSDI) which typically has a higher monthly stipend than SSI. When they lose SSI (can't receive both SSI and SSDI) they are sometimes told that their family member is no longer eligible for Medicaid because their income is now too high. The fear of losing Medicaid eligibility can cause a family significant stress as there is a two-year wait to receive Medicare services (health coverage available through SSDI).

This is not true. There is a provision in federal law referred to as the "Pickle Amendment" – named after our own Congressman Jake Pickle. This amendment states that if an individual's monthly income is over the SSI limit simply because they went from receiving the SSI stipend to the higher SSDI stipend, they maintain their eligibility for Medicaid. This is extremely important to know because, as stated earlier, the Medicare coverage under SSDI has a two year waiting period. Read the two stories below of two parents' experiences with this important process.

Alexander Family:

When my husband began taking Social Security (SS) after retirement, my son was aged 26 and receiving SSI, Medicaid and the CLASS program. So I needed to learn how a parent's SS benefits influence an adult child's eligibility for state funding. Here's what I learned:

Your child will move to SSDI (Social Security Disability insurance) when you disclose having an adult child with disabilities during the process of applying for your own SS. Note that SSI eligibility is based on disability and income/financial assets. SSDI is based on earning history, either a parent's or the person's who has a disability. SSDI will be half of the parent's SS monthly payment, and that's in addition to the full payment the parent will receive. So if the parent receives \$2000 per month based on his or her earning history, SSDI for the adult disabled child will be \$1000. If the SSDI amount is higher than SSI benefits, your child might become ineligible for Medicaid, which automatically comes with SSI. It is important to stay Medicaid

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eligible.

There is another door into Medicaid called the Disabled Adult Children Program that solves this problem. It coordinates SSI and Medicaid so that someone can receive SSDI and stay eligible for Medicaid. It is federally mandated for people 18 and over, onset of disability before age 22 and denied SSI because of SSDI. It provides for Medicaid coverage by excluding increases--it disregards the amount of the benefit to keep Medicaid.

When a parent anticipates starting to draw down Social Security benefits, you should talk to someone in the SS office nearest you to resolve the problem. My own experience was that I started several months before the date when my husband would start receiving SS. I called people at DADS to check my facts then the Social Security office and started a process of alternately acting and waiting. It takes coordination between DADS and SS. We got the application ready but then had to wait for my husband's record to be set up, the trigger to start the process. On the designated day, I got a letter denying SSI and a letter starting SSDI and Medicaid through the new program. I wanted NO TIME to pass, not a moment, when my son was not eligible for Medicaid! It did work. He continued the CLASS benefits without a pause. Furthermore, he has just become eligible for Medicare, which kicks in 2 years after starting to get SSDI.

I hope this helps parents to be aware of the changes that might affect your child's benefits and how to keep your child eligible for benefits.

Rosemary Alexander,

Luzzo Family:

I started the process of applying for Disabled Adult Child benefits several months before Jenna's 18th birthday, knowing the process would take time. I too called SS and made a face to face appointment. In the meantime, I told the representative what my intentions were and I was sent a packet of information that was needed in order to start the process. If the child is over 18, you can start this process on-line at the social security website (www.ssa.gov). The information they needed was letters from a doctor stating diagnosis, medical history, hospital stays, etc. We went prepared when we had our face to face appointment.

For a child to receive SSDI one of the parents must be retired and receiving benefits. In our case Ron retired while Jenna was still in high school, so she was already receiving benefits. These benefits stopped once Jenna reached 18 or graduated from high school. That is where the change came in and we started the process to apply for Disabled Adult Child benefits. Jenna now receives SSDI and will continue to receive this until her death. Benefits will not end after the parent's death. She will also be eligible for Medicare once she turns 20. It is a 24 month waiting period once you have been approved for SSDI.

If a child is receiving SSI, it is not an automatic move over to SSDI. It is my understanding you have to apply for it. In our case, this was true; as Jenna's benefits ended the month she graduated from high school. SSI is based on the person's income and disability, where SSDI is based on the work history of

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the retiree. If a parent is retired, and the child/adult is within the age limits, I would recommend applying for SSDI, as the monthly income is much higher. Also, I have been told once a child/adult reaches 21, they are eligible for Food Stamps. Once the child reaches 21 they look at that person's income, until then they take into account the household income for food stamps. I know some might look at this, and say that is not necessary, but remember, we will not always be here to assist our children. We need to advocate for them now and get all that is available for them now, as in some cases, that won't even be enough.

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Here are a couple of links to more information on the Pickle Amendment:

Pickle Amendment:

http://dpaweb.hss.state.ak.us/manuals/adltc/531/531 deemed under the pickle.htm

Directly from the SS website: https://secure.ssa.gov/apps10/poms.nsf/lnx/0501715015

If this happens to you, contact the regional manager of your Department on Aging and Disability Services local office. Each regional office should have a staff person who is familiar with the provision and can help get these straightened out. If that doesn't work, feel free to contact me at colleen.horton@austin.utexas.edu.

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