FAQs

1. **Q: I am interested in applying for Supplemental Security Income (SSI). How do I start this process?**

A: The easiest way to learn about the process and to get started is to visit the Social Security administration website at <https://www.ssa.gov/benefits/disability/apply-child.html>.

1. **Q: What qualifies as a disability under Social Security Standards (SSA) standards?**

A: According to the SSA, a person with a disability is defined as someone with “marked and

severe functional limitations. The child’s condition(s) must have been disabling, or be expected to be disabling, for at least 12 months; or the condition(s) must be expected to result in death.”

1. **Q: My family makes too much to qualify for SSI and SSI Medicaid, but my child has a severe disability. Having access to Medicaid would help us so much financially. Are there any other options?**A: Yes! You can try for the TEFRA/Katie Beckett program. The application process can be tedious, but is worth it. Start here <https://medicaid.georgia.gov/tefrakatie-beckett> and I suggest calling the Right From the Start Medicaid Project Centralized Katie Beckett Medicaid Team at 678-248-7449 to make sure you have all the correct and updated forms. Remember, in order to obtain Katie Beckett Medicaid your child MUST meet nursing home/institutional level of medical care. Katie Beckett is intended for the most severe of the severely disabled. A disability that qualifies for SSI is not a guarantee of Katie Beckett approval (for example: ADHD, low birth weight, blindness, deafness). Once approved for Katie Beckett, your child’s eligibility will be reviewed each year (this is the easy part)and medical level of care reviewed every two years (this is the big, lots of paperwork, overwhelming documentation process). See the handy dandy chart below.



1. **Q: My child has Autism and was denied SSI because we make too much money and was also denied Katie Beckett because he does not meet the nursing home level of care requirement. We spend so much money on private therapies, respite, incontinence supplies, etc. Is there anywhere else we can find help?**A: Yes! Check out <http://www.championsforchildrenga.org/give.php>.This is a state and privately funded program specifically for individuals denied the Katie Beckett waiver. You can also apply for DBHDD’s Family Support Services (see next question).
2. **Q: What is DBHDD’s (Department of Behavioral Health and Developmental Disabilities) Family Support Services program?**A: There are a lot of different Family Support Services programs out there! But DBHDD’s Family Support Services (FSS) program provides up to $3000 a year to cover the cost of medical supplies, camps, respite, therapies, etc. It is specifically for children ages 3 and up with intellectual and developmental disabilities. Medicaid is not a requirement, but to qualify a person cannot already be receiving funds through the NOW/COMP waiver. It is also important to remember this program is state funded July 1st-June 30th of each year. The later you apply in the fiscal year, the more likely it is there will be more limited funding and you will be put on a waiting list. To learn more about the program, how to apply, and which agencies in your community are providers, go here: <https://dbhdd.georgia.gov/family-support-services>.
3. **Q: I heard Medicaid will pay for diapers for my child. Is this true?**

A: Yes! Medicaid will pay for incontinence supplies (including diapers) for individuals aged 4 and up who have a diagnosis of encopresis (fecal incontinence) and enuresis (urine incontinence). Remember, payment for diapers is intended for individuals who have a developmental or medical condition as the root cause of the need for diapers past the age of typical toilet training. This is NOT intended for babies or for individuals who might have an accident every now and then. A prescription for diapers is required from a doctor and items must be purchased from a Durable Medical Equipment (DME) company. You cannot go to Wal-Mart and pick up some Pampers and expect Medicaid to pay for it! One DME company you can call is <https://www.uromed.com>. Tell them you are interested in incontinence supplies for your child with a disability and they can walk you through the process. Keep in mind Medicaid will only pay for incontinence supplies until age 21.

1. **Q: What if my child does not have Medicaid or any insurance/is under-documented? Is there any support my child can receive to help meet their special healthcare needs?**

A: Your best bet would be to check out your local Children’s Medical Services (CMS) program. Housed under the state’s Department of Public Health, there are 20 CMS programs throughout the state. CMS can help provide funding for medicines, supplies (like diapers or insulin needles), vaccines, nurse case management and follow up, as well as access to primary care and specialists. Services are available until age 21. There may be waiting list for services. For more information or to find your nearest CMS, go here: <https://dph.georgia.gov/CMS>.

1. **Q: Why is my child turning 21 such a big deal?**

A: Turning 21 is not a big deal. It is a HUGE deal! I cannot stress enough how huge of a deal 21 is, especially for young adults with severe and profound intellectual disabilities and/or medical complexities. Age 21 marks the end of the EPSDT (Early, Periodic, Screening, and Treatment) Medicaid mandate. This is a federal law requiring each state’s Medicaid program to pay for services and specialized medical supplies deemed medically necessary by a medical doctor. This includes incontinence supplies (diapers), feeding tube formula, occupational, speech, and physical therapies, and both unskilled (caregiving) and skilled nursing services. Get my drift? That’s right! **At 21, Medicaid will no longer pay for diapers, feeding tube formula, therapies, or formula.** Or dental care. Another thing to keep in mind is most pediatric specialists will no longer see pediatric patients once they turn 21. A few might, but not forever. Also, your child with medical complexities is probably used to going to Children’s Healthcare of Atlanta (CHOA). Your relationship with CHOA will end at 21. CHOA is a children’s hospital and at age 21 your child is considered an adult. It is very difficult to find adult medical providers, especially specialists, who understand the intricacies of having a patient with severe/profound intellectual disabilities AND medical complexities/fragilities. Prepare for this now. **Know and understand life after 21 will be different and full of new challenges.**

1. **Q: My child just turned 21. All of his calories and nutrition come from a feeding tube as he is at risk of aspiration if he were to eat by mouth. He is also incontinent and diaper dependent. He has SSI Medicaid, but his Medicaid will no longer cover the cost of his feeding tube formula or his diapers. This is A LOT of money each month and we are going to go broke! He gets SSI money, but we use that to cover the cost of wipes, chuck pads, over the counter medications, and gas to get to all of his medical appointments each month. HELP!**

A: First, is your child already on the waiting list for NOW/COMP? See question 11. If not, see question 10. Secondly, see question 12. And also make sure you read question 5. That’s all I got for you. Turning 21 is rough!

1. **Q: What is the NOW/COMP Medicaid Waiver?**

A: The NOW (New Options Waiver) and COMP (Comprehensive) waiver are actually two different waivers available to individuals with the most severe disabilities. The state Department of Behavioral Health and Developmental Disabilities (DBHDD) oversees the programs. NOW typically is funding less than $25,000 a year and COMP is for funding over $25,000 a year. To be eligible for NOW/COMP waiver funding, an individual must have a diagnosis of developmental disability, intellectual disability, or related disabilities including cerebral palsy, seizure disorder, Autism, or other neurological disabilities that impact cognitive abilities. This program is intended to keep individuals with intellectual disabilities out of nursing homes, hospitals, or other institutions. NOW/COMP is not intended for individuals who have mental health disabilities such as bi-polar or schizophrenia as a primary diagnosis or those with mild intellectual disabilities. NOW/COMP may provide funding for all the things Medicaid stops paying for at 21. This includes formula, diapers, other incontinent supplies, skilled and unskilled nursing, etc. The program also is what pays for supported employment, respite, day programs, group homes, and host homes. There is a long and extensive waiting list for services and the chances of getting the waiver before 21 is pretty slim. If your child is eligible for NOW/COMP (especially if they have severe or profound disabilities), it is imperative your child is on the waiting list by the time they are 16 years old. I am a big proponent of getting on the waiting list at a very early age. The waiting list is not first come, first served. Waiver slots/funding is determined based on who is at the most risk for out of home placement/institutionalization. So why is it important to get on the waiting list? Because the more people that are on the waiting list, the more obvious it is to the People in Charge that there is a BIG need for services and funding. To learn more about NOW/COMP waiver or to apply, go here: <https://dbhdd.georgia.gov/applying-dd-services>. Now, see questions 11.

1. **Q: My child is over 21 and has been on the waiting list for NOW/COMP for several years, but I have not heard anything from DBHDD in years. I thought once my child turned 21 it would be an “automatic” approval for funding. What do I do?**

A: No waiver service or program is ever “automatic”, no matter what anyone tells you. It is important to remember there are literally thousands of other people on the waiting list for NOW/COMP. It is your job to make sure DBHDD knows about your child, their needs, and how their life will be impacted negatively without access to funding. This will be difficult. This means you will have to call your local DBHDD regional office and “remind” them of your child. Often and regularly. You will need the Planning List Navigator’s phone number and email address and you will have to email her and call often. She or he may not respond. Be prepared for this to be difficult. Do not be afraid to “go up” the chain of command at your county’s regional DBHDD office. In this case, the squeaky wheel gets the grease. Always remember NOW/COMP’s primary goal is to prevent institutionalization. It is NOT to make you (the parent) have an easier time managing your child’s disability. It is not so your adult child has a babysitter so you can work. When requesting service, ALWAYS state how not having funding will increase your child’s risk of institutionalization. For instance, once your child graduates from school at 22, he will be home alone all day with no one to watch him because you work outside the home. This is dangerous and he cannot stay home alone. If you have to quit your job, there will not be income to ensure stable housing and your child will be homeless.

1. **Q. My child just turned 18 years old. We applied for Adult SSI and he was approved. With SSI, he receives “traditional” Medicaid and a stipend each month. However, he is not receiving the full federal benefit of $771. He is only getting about $500 a month. He really needs the full amount to help pay for his supplies and expenses. I know any and all money he can get will be helpful once he turns 21 and Medicaid stops paying for formula and supplies. Or maybe even to help pay for a day program once he ages out of school and is still on the waiting list for NOW/COMP. How can we get the full benefit?**

A: Most likely, the reason your adult child is not receiving the full federal benefit is because when he applied for SSI at age 18 he had no indication of having any household expenses/bills. If your adult child lives in your home and does not pay rent or contribute to household expenses, he is considered to be receiving “in kind” support. This will mean your child will only receive about a 3rd of the federal benefit rate of $771. In order to get the full benefit amount, your adult child will have to have documentation he is either paying rent or his fair share of household expenses. Please see below for “living at home” letter options. If paying their fair share amount is the best option, write a letter stating the amount the individual is required to pay each month. Remember to write and keep a monthly receipt. The living at home letter will need to be submitted to your local Social Security Administration (SSA). Please keep in mind the folks are the Social Security Administration’s job is to ask questions. So be prepared to answer questions such as “So what would you do if your child gets behind on rent or his fair share?” Your response should be honest and indicate your adult child will be held responsible for their living needs. Just like other adults. It is important to maintain an accurate and legitimate record of monthly payments. So give your child a receipt each month and keep it in a folder. Also note if the rent option is chosen, it may count as income and impact your taxes. Another note of interest, if your child has private health insurance this may also impact his eligibility to receive the full federal benefit. Generally, it is best to wait until a full 30 days AFTER your child turns 18 to apply for SSI.

“Living at Home” Options:



1. **Q: What is the GAPP program?**

The GAPP program stands for Georgia Pediatric Program and is a Medicaid based program housed under the Department of Community Health (DCH). In theory, it should not matter what kind of Medicaid (SSI, Amerigroup, Wellcare, etc) your child has. The program serves children aged 0-21 who have medical or developmental needs that impact their ability to meet their daily living needs. GAPP provides both medically necessary skilled (an RN or LPN) and unskilled (usually a CNA) nursing services. A doctor will need to prescribe skilled/unskilled nursing services in order for it to be a medically necessary service. Typically, to qualify for skilled nursing, a child will need to have chronic, multi-system medical diagnosis impacting their ability to function. Typically, children who qualify for skilled nursing require suctioning, frequent breathing treatments, feeding tubes, epilepsy, and are trach/vent dependent. Having just one of these needs may not qualify for skilled nursing. However, GAPP also covers unskilled nursing. An unskilled Certified Nursing Assistant (CNA) is not legally able to assist with any skilled nursing tasks such as dispensing and administration of medication, breathing treatments, or tube feedings, etc. However, a CNA can assist with daily living needs such as grooming, dressing, toileting, and light housekeeping. Once approved for GAPP, the individual is typically allotted weekly hours of either skilled or unskilled hours or even a mix of both. The need for hours is reviewed every 3-6 months. Because of this, it is VERY important you communicate regularly with your GAPP agency and update them on ANY medical changes/challenges your child experiences. Any unplanned ER visit, unplanned pediatrician sick visit, extra use of PRN medications, etc needs to be reported and documented to the GAPP agency. This will help them get the most accurate information when submitting paperwork for GAPP renewal. It may seem as though the more medically stable your child is, the more likely his GAPP hours will be cut. He is probably more stable because he has a GAPP nurse. If the hours are cut, he may become more unstable. It is a cycle. The more medically unstable a child is, the more likely he is to maintain his GAPP hours. Keep all this in mind while making the best medical decisions for your child (should we go to the ER? Do I need to call the doctor? Should I wait?). To start the GAPP application program, simply reach out to a GAPP provider agency and request to start the process. There are multiple provider agencies throughout the state. A complete list can be found in Appendix U of the GAPP Provider Manuel. At the time this was written, the website link on the DCH website was down. Naturally! Some GAPP providers to check out include Pediatria Healthcare for Kids <https://www.aveanna.com>, Pediatric Services of America (PSA) [www.psahealthcare.com](http://www.psahealthcare.com), and Advanced Care Partners [www.advancedcarepartners.com](http://www.advancedcarepartners.com). Be mindful it may take 30-45 days for all the paperwork to be processed and approved. Also keep in mind GAPP ends at 21. The only way (that I know of) to obtain SKILLED nursing services via a LPN or RN after the age of 21 is via the NOW/COMP waiver. However, to obtain unskilled nursing services (usually a Certified Nursing Assistant or CNA), see question 14.

1. **Q: My child recently turned 21. He has CP that has led to severe physical disabilities. He is wheelchair dependent, diaper dependent, and eats pureed foods. He is getting too heavy for me to lift, even with a hoyer lift, and it is increasingly difficult for me to take care of him all on my own with limited support from my family. Is there any help I can get?**

A: You are in luck! Yes! He may be eligible for the SOURCE program or CCSP ( Community Care and Support Program). These are Medicaid waiver programs housed under the DCH (Department of Community Health) and are available to individuals over the age of 21 with documented physical disabilities. A significant physical disability meeting a nursing home level of care is the primary diagnosis needed to qualify. Cognitive disabilities are not a basis for approval for this Medicaid waiver. Medical documentation about significant mobility impairment and contractures are warranted.

1. **Q: So what’s the difference between SOURCE and CCSP?**

A: The SOURCE program is intended for people over the age of 21 who have a significant physical disability that was acquired after birth. This includes traumatic brain injuries or CP due to accidents, near drownings, etc. after birth. This is not for congenital birth defects. Another key difference between SOURCE and CCSP is the medical providers. SOURCE’s primary goal is to provide primary care for those with physical disabilities in order to avert preventable ER visits or hospitalizations. This basically means your listed primary care provider will have to be a SOURCE provider. I have heard it is not difficult to become a SOURCE medical provider, but some doctors may be against the process. If you are really attached to your primary care provider, and they are not willing to become a SOURCE doctor, SOURCE may not be for you. Keep this in mind. In general, the services available via CCSP are the same as SOURCE. Again, thee two biggest differences are CCSP is intended for those who have a congenital (at birth) disability and CCSP does not require a CCSP medical provider. Both of these programs also provide case management! The good news is it is not really up to you to decide if your adult child is more appropriate for CCSP or SOURCE. Both of these programs provide other services as well, such as day health and group homes. **But keep in mind these programs are really intended for the elderly and disabled and not the young and disabled.** You can apply for CCSP or SOURCE up to 90 days before turning 21; there may be a brief(ish) waiting list. The application process typically takes 30-45 days. If you are interested in learning or applying, go here: <https://medicaid.georgia.gov/sites/medicaid.georgia.gov/files/related_files/document/17CCSP.pdf> or <https://medicaid.georgia.gov/sites/medicaid.georgia.gov/files/related_files/document/17SOURCE.pdf>.

1. **Q: What is the Independent Care Waiver Program (ICWP)?**

A: ICWP is a state Medicaid program intended for individuals ages 21-64 with severe physical disabilities who have the mental capacity to manage their own care. It is also available to those with Traumatic Brain Injuries, in which case the ability to manage their own care is not a requirement. However, this program is not intended for those with severe intellectual disabilities. ICWP can provide an aide to assist with daily living needs such as grooming, hygiene, feeding, etc. This waiver has been known to provide college students with physical disabilities a support person to assist them while attending college and living in a dorm. There is a very limited number of slots available and there is often a waiting list for the program. For more information, go here: <https://dch.georgia.gov/sites/dch.georgia.gov/files/IndependentCareWaiverProgram_FY14_Final_0.pdf>

1. **Q: My 21 year old child is on the waiting list for NOW/COMP, but we recently were approved for CCSP. CCSP will provide an aide to help bathe, dress, and take care of him while I am at work. This is such a huge help to me, especially as we prepare for him to age out of school at 22. How will having another waiver impact his chances of getting NOW/COMP? CCSP is great, but NOW/COMP will best fit his needs in the long term.**

A: So, honestly, this situation basically puts you between a rock and hard place. CCSP (or any other Medicaid wavier aside from NOW/COMP) helps your adult child tremendously in the short term, but probably challenges him in the long run. When DBHDD, the agency that oversees NOW/COMP, sees that he has CCSP, they will probably question why he needs to transition to NOW/COMP. Remember, the goal of any Medicaid waiver is to prevent institutionalization. If CCSP is “doing its job” by preventing out of home placement, why does he need NOW/COMP? Yes, CCSP is only meeting a very basic need, but NOW/COMP would meet a whole bunch of needs. So your chances of transitioning from one waiver to another can be very challenging. But not impossible! Your job is to help DBHDD understand why your adult child needs NOW/COMP vs another waiver. It might be easier to get the waiver if you don’t have ANY waiver when requesting it, but then you wouldn’t have the support you need to live day to day. The grass isn’t greener on the other side. Every program comes with challenges and disappointments. Your job is just to plant the grass so people know what your child needs. And to keep cutting it till someone sees what beautiful grass you have and gives it the attention it deserves and is entitled to receive. Remember, you can only have one waiver at a time.

1. **Q: I am considering adopting a child with severe needs from foster care, what do I need to consider? What if the child ages out of foster care instead?**

A: So, the first thing you really need to understand is this child you are considering adopting will never be able to live on their own. They won’t turn 18 and go off to college, or turn 21 and move out to their first apartment, or turn 27 and get married. They will need you forever. Their whole life. To feed them, bathe them, dress them, change their diaper, give them medications, lift them in and out of their wheelchair, turn them so they do not get infected bed sores, take them to medical appointments, and to be able and willing to take them to the emergency room if they become medically unstable, and to hold their hand and love them while their hospitalized. This is a life-long commitment and is very different than adopting a child with other special needs such as Autism, ADHD, or mental health disorders. This is a whole other kind of love. You must think LONG TERM. Yes, she is a cute little girl with CP now. But in a few years she will be a teenager who is 60 pounds heavier and requires more appointments and more medications. And you will be older and probably with more back and shoulder pain. And then another few years she will be middle aged, even heavier, and with declining health. Again you’re older and it is near impossible to lift her on your own. You have supports in the home, but no one is there 24 hours a day to help you care for her or turn her over at 3am. Is this something you are willing to commit to? For the long haul? Not just while she is cute and little? This is what you need to consider. Don’t let anyone make you feel bad about asking questions. You love her, that is why you are asking questions and making difficult decisions. The other thing to think about is the hard truth that if your foster child ages out of foster care at 21, she has a much higher chance of getting NOW/COMP sooner rather than later. This is because she will have nowhere to go and will likely end up institutionalized. With NOW/COMP, she could have a place to live, access to specialized medical supplies, nursing, unskilled nursing, respite, etc. Where as if you adopt her, you will then face the same challenges accessing NOW/COMP as every other parent of a child with severe needs faces. It is a battle. Before you sign any adoption paperwork, you need to ask questions about how to obtain SSI Traditional Medicaid instead of adoption assistance Medicaid. I am not clear on how this might impact Adoption Assistance, but Medicaid will be imperative for the child’s well-being in the long run. ASK QUESTIONS about Medicaid. Your child will need Traditional (Aged, Blind, and Disabled) Medicaid, not foster care Medicaid. Figure this out with the right people.