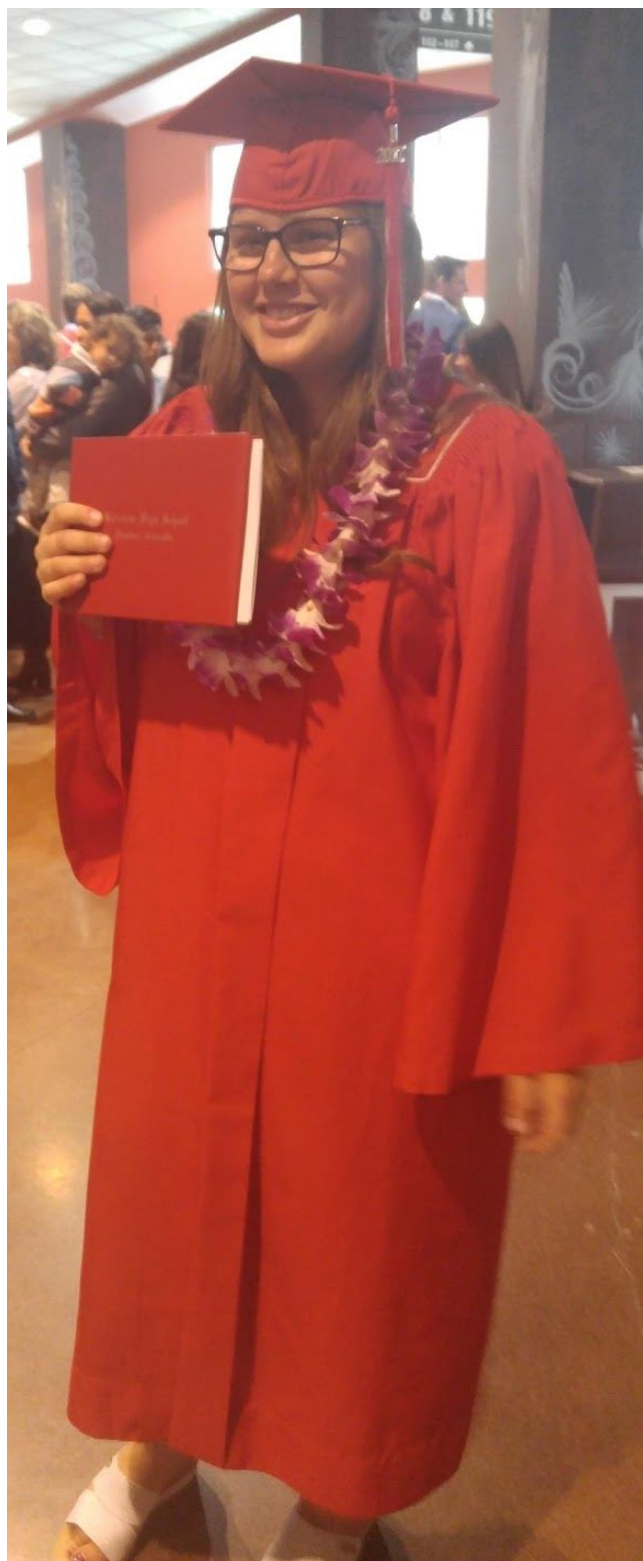


*Parent Led
Transition Cadre*

**Guide to
Navigating
Adult Services
in Boulder and
Broomfield
Counties**

*Resources, tips
and decisions through
personal stories*



Anna Stewart, editor and parent guide

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In this guidebook, parents who have young adult children with Intellectual and/or Developmental Disabilities (IDD), share their personal journeys to accessing and utilizing adult services for their children in Boulder and Broomfield Counties.

Our goal is to share the individual options and decisions that parents and their children have navigated through to work towards a meaningful, engaged and purposeful adult life for their sons and daughters. Adult services for persons with disabilities differ from children's services in that they are based on different criteria for eligibility. So, while everyone who contributed to this guidebook has a young adult that met the state criteria for IDD and was a client of our local Community Centered Board, Imagine!, you will see that we took a lot of different paths. Our children are working, going to college, or participating in day programs, recreation programs and therapeutic programs. Some need full-time attendant care; others are using public buses on their own to get to classes and jobs.

Through our experiences of navigating the bureaucracy, the eligibility requirements, mounds of paperwork, meetings and phone calls, we have learned a great deal about how to navigate those systems in our community. Every one of us has faced challenges on this journey. Some of us hired lawyers, others camped out at the social security offices until our numbers were called, and others, again, struggled and failed to find Medicaid providers to provide the services their kids needed. We are weary and wise. And we want to help the next wave of families finishing high school (and 18-21 transition services) to navigate the support and services of the adult-care systems in our communities.

We joke about the after school experience becoming an “endless summer” for our kids, and that has become very real to us. When we had little kids, and school was out for the summer, we had to plan those 10 weeks to keep our kids safe, active, and engaged until the summer was through. For those of us with adults with IDD, we have to plan like summer for the whole calendar year, every year, until we “fall off the perch.” Unlike our parent peers whose typical high school teens are emancipating, our jobs as parents get a whole lot harder and more involved when our children reach adulthood. As most of us are also near the age of retirement, we have to face the truth, that we are now and forever, full-time case managers for our

children, in addition to being their parents. We have to learn to negotiate new systems that we know nothing about, and we are expected to become instant experts. We face the future with hope, but also with fear and even with some resentment. Just as our kids are eager to become adults, we are facing our elder years and have to confront our own mortality. That means planning for our kids' old age. It truly can feel like an endless summer.

Using our hard-earned expertise and speaking as a collective 'we', we will share our stories and also share information about the agencies that offer services and supports for yours and our kids. These are the main systems we navigate in this document:

- HCBS IDD Medicaid waivers for Adults (Supported Living Services and Developmental Disabilities)
- Social Security (SSI and SSDI)
- Medicaid & Medicare Health insurance
- Division of Vocational Rehabilitation (DVR)
- Probate Courts: Guardianship and alternatives to guardianship
- Transportation

Meet the young adults

Claire (SIS Level 2)

In the past few years, Claire took a class at her local community college, participated in a program for students with disabilities at a university and learned the bus system to get to all her activities. She is employed as a server at a local senior living center. Claire recently discovered a love of theater and performed in *Fiddler on the Roof* with other actors (with and without disabilities.) Claire has great gusto for life's pleasures and enjoys being out and about. Claire also has ADHD, learning disabilities and borderline Intellectual Disability among other issues.

- Supported Living Services waiver
- Supplemental Security Income
- Division of Vocational Rehabilitation
- Medicaid Health Insurance
- Lives with family
- Employed
- Guardianship
- Public bus, bike, walk

Shannon (SIS Level 3)

Shannon is 20 years old and lives with her mother in Longmont. Shannon met all her graduation requirements and graduated on time with her peers. In the 18-21 transition program, she was exposed to a variety of workplaces, did some volunteering, and learned how to ride the city bus. Shannon got her driver's permit at 19 though her significant issues with anxiety prevent her from driving by herself and getting her license. Shannon also has Asperger Syndrome and a painful, chronic gastrointestinal condition. Her dream job is to train horses.

- Supported Living Services waiver
- Supplemental Security Income

- Division of Vocational Rehabilitation
- Medicaid Health Insurance
- Lives with family
- Guardianship

Eli (SIS Level 3)

Eli who is 21, lives with his mother in Longmont. His father died when he was 6, and his sister is attending college in Boulder. One of Eli's passions is farm equipment. His mom took him to visit the John Deere world headquarters in Illinois for a graduation present. He loves the outdoors and wants to work on a farm. He just got a new service dog, Henry who is a wonderful companion. He likes working and hopes to have a real job soon. Eli is a sight word reader who practices daily and he definitely can use a computer. Eli's diagnoses of autism, ADHD, and pervasive learning delays mean he needs supervision and support to access his community.

- Supported Living Services waiver
- Social Security Disability Income
- Division of Vocational Rehabilitation
- Medicaid and Medicare Health Insurance
- Guardianship
- Lives with family

Brett (SIS Level 3)

Brett has two little brothers and lives with them and his mom and dad in Longmont. At 21 years old, he has a clear goal for his life- he wants to become a welder. Brett has autism, learning disability and XXY Syndrome which have affected his ability to read and write. He also has behavioral needs (such as anger, confabulation, obsessed with sex/porn) though he is working on learning more

independent skills. He recently started working at King Soopers and has a new girlfriend.

- Supported Living Services waiver
- Supplemental Security Income
- Division of Vocational Rehabilitation
- Medicaid Health Insurance
- Guardianship
- Employed
- Lives with family

Sabrina (SIS Level 2)

Sabrina recently graduated from high school and enjoyed independently accessing her general education classes in high school as well as competing on the girls' swim team. She lives with her mother, two older brothers, two cats and two dogs in Boulder. Sabrina recently got her first paying job as a server in a senior living center. She is eager to learn independent living skills, so she can live with a roommate in a few years. Her intellectual disability along with her speech issues, do pose some barriers for her to pursue her dreams of saving the planet through teaching people how to reduce, reuse and recycle.

- Supported Living Services waiver
- Supplemental Security Income
- Division of Vocational Rehabilitation
- Medicaid Health Insurance
- Medical Power of Attorney
- Lives with family
- Employed
- Uses bus system and walks

Aaron (SIS Level 3)

Aaron lives with his parents in Louisville. He recently became an uncle and has three older brothers. Aaron is 24 and happily got his first paying part-time job doing data entry for a local non-profit organization. It took several years to find a good employment fit, and he is enjoying working. He likes learning and particularly enjoys music history. Aaron has autism and with it, an anxiety that creates some barriers to his participating independently in his community. He is working on learning to be more self-sufficient, so he can handle the changes that life brings.

- Supported Living Services waiver
- Supplemental Security Income
- Division of Vocational Rehabilitation
- Medicaid Health Insurance
- Medical Power of Attorney
- Employed
- Lives with family

Benjamin T. (SIS Level 6)

Benjamin is a complex young man with a big heart and great curiosity. At 20, he is walking with support at home, but uses a wheelchair to access the community. He has multiple strategies and tools to communicate and works hard at all his therapies. Benjamin contends with a variety of medical issues along with autism and an intellectual disability, and needs 24/7 support. He lives with his parents and a teen-aged cousin who has recently joined their family, in Broomfield. He enjoys swimming, music, stories and people.

- Developmental Disabilities Waiver
- Supplemental Security Income
- Medicaid & Private Health Insurance
- Guardianship
- Lives with family

Griffin (SIS Level 6)

Griffin is 19 and lives with a host home provider in Lafayette. He settled in well in his new home and sees his mom and dad weekly. Griffin has a younger sister and three adult siblings. Griffin loves being outdoors as much as he enjoys his IPAD and movies. He also loves salad, popsicles and Power Rangers. He uses an augmentative communication device. Griffin requires 24/7 supervision to keep him safe and engaged. He has ADHD and autism along with an intellectual disability caused by a genetic disorder.

- Developmental Disabilities Comprehensive Waiver
- Supplemental Security Income
- Medicaid Health Insurance
- Guardianship
- Lives in host home

Benjamin J. (SIS Level 6)

Benjamin is a dapper dresser who lives with his mother in Arvada. He has three adult siblings whom he wishes he could see more often. Ben is 21 and attends day programs where he has made new friends and gets to go places and do things every day. Ben has Down syndrome along with hearing loss, some physical issues and a severe underbite due to cleft lip and palate, which makes his speech almost unintelligible. Ben is a fan of birthdays and often communicates via Touch Chat on his IPAD.

- Supported Living Services Waiver
- Supplemental Security Income
- Medicaid Health Insurance
- Guardianship
- Access-a-ride
- Lives with family

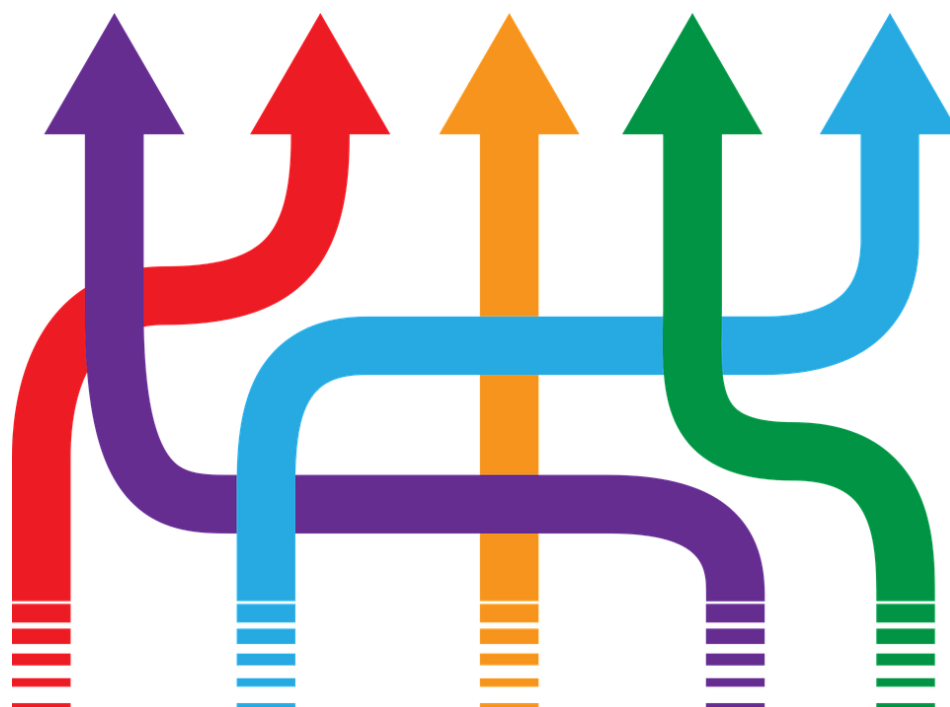
Kammie (not using IDD waivers currently)

Kammie is a world traveler who also happens to have a genetic disorder (Trisomy 18), which many doctors consider incompatible with life. At age 21 and just back from a three-week road trip, Kammie would have to disagree. Kammie's genetic make-up has resulted in an intellectual disability along with her being non-verbal, non-ambulatory and G-tube fed. She loves music, lots of action, cute boys, horseback riding as well as being out and about every day. Kam requires constant supervision which is sometimes provided by her service dog Ilya.

- Elderly, Blind and Disabled waiver (EBD)
- Supplemental Security Income
- Medicaid Health Insurance
- Lives with family
- Has one live-in caregiver and employs others
- Guardianship

How did we choose the best waiver?

In Colorado, we have a waiver system that is funded through federal and state Medicaid dollars. Like most states, the criteria for being eligible for those services means meeting the state requirements for having an Intellectual or Developmental



Disability. The local Community Centered Board (see [What is a Community Centered Board?](#)) determines eligibility at any age. Once a person turns 18 and is eligible for services, families need to look at what options are available for their young adult. There are also waivers for specific issues such as Traumatic Brain Injury or Mental Health issues. For this guidebook, we are only looking at options for adults with IDD in Boulder or Broomfield Counties. Those are:

1. SLS (Supported Living Services Waiver)
2. DD (Developmental Disabilities/Comprehensive Waiver)
3. EBD (Elderly, Blind and Disabled Waiver)

Right now, there is no waitlist for SLS or EBD. There is a large waitlist for DD, and no one can say when that will change. There are efforts in the state to simplify the waiver system and combine SLS and DD into one system, so people can tailor their allotted funds more directly towards what their young adult needs, but that requires additional funding that is not available at this time.

We want to share with you how several groups of families whose adult children have similar level of needs, chose to use their funding and services.

For those with lower funding (SIS levels 1-3), most seek some paid employment along with ways to be out in the community, having their young adults do what they want to do safely. These young adults all want more independence with a goal of moving out of their family homes eventually. None of these young adults (Claire, Shannon, Eli, Brett, Aaron or Sabrina) were eligible for children's support waivers (CES/HCPS) when they were minors, and none have a qualifying physical disability that makes them eligible for the EBD waiver. The only waiver they were eligible for was the SLS.

The goal of the SLS waiver is to help adults with disabilities work towards more independence. The services that SLS offers target involve teaching independent living skills (cooking, cleaning, shopping, laundry, and banking) as well as gaining mentors who can help with networking, making connections, and also helping the young adults advocate for themselves in the community. Behavioral therapists may be engaged to reduce behaviors that may get in the way of goals. Respite services give young adults and their parents a break from each other. Pre-vocational and supported employment services provide experiences and facilitate skills in preparation for integrated, paid employment. Programs paid through Medicaid such as Imagine!'s Out & About offer a variety of recreational and community-based opportunities during the day, at night, and sometimes also on the weekends.

The following young adults (Benjamin J., Griffin, Benjamin T. and Kammie) have more significant support needs (SIS 5-6) and may be eligible to more than one funding stream. However, everyone with a disability in Colorado can only use one waiver, so families do have to choose between waivers. Kammie uses the EBD waiver as she has high attendant care needs, and most day programs are not a good match for her interests and needs. Benjamin J declined his EBD waiver offer in favor of the SLS waiver, so he could attend day programs. Benjamin T was on the Children's Extensive Support waiver (CES) as a minor, and was therefore moved right into the DD waiver when he came of age. Ben J was not on the CES prior to

age 18 (because he lived in another state), so even though he also has extensive needs, he is only on the waitlist for the DD waiver, and currently he accesses the day services of the SLS waiver. Griffin was also on the CES waiver as a child, and therefore moved straight into the DD system when he turned 18. He is using his 24/7 funding to live in a host home.

Lene is Benjamin J's mom. The two live together in Arvada. She is a college professor and a single mom who has guardianship of Benjamin. She manages his funding, his schedule, and his activities. She wrote about how she made the decision to use the SLS waiver instead of the EBD waiver to support Benjamin.



Here is her story:

EBD or SLS -- A choice

I did not know anything about long term Medicaid waivers till my son was 13 or 14. His previous schools, elementary and middle, never mentioned the waiver and since Ben was born in Michigan and lived there till he was seven years old, I never had a formal introduction to any sort of support by the state when we moved to Colorado. In fact, when we first moved to Colorado in 2003, Benjamin was put on a waitlist for the basic children's Medicaid health care waiver that just helps with medical insurance support. (And that was tough for about 3 years!! He was on a special formula that cost \$1000 per month.)

In this piece I will limit myself to discussing the EBD and the SLS waivers.

Wait Lists

It did not occur to me that the state of Colorado would not just pick Benjamin up for long term care automatically, because I assumed things worked in Colorado the same way they had worked for us in Michigan. What I did not know, and what I now regret, is that my son--as severe as his disabilities were at the age of 7 would immediately have qualified for CES, which then on turning 18 would have automatically qualified him for a comprehensive DD waiver, something that he is currently waitlisted for. -- I did not search for the information, and none of our connections to the state (doctors, hospitals, therapists and), not even the lady who came out annually to assess his needs for the health insurance part of Medicaid, ever mentioned it. Neither did any of the teachers at the St Vrain Valley schools he attended during those years speak to me of any availability of waivers to support him. It is, in a sense, a bitter pill to swallow because he would have been covered comprehensively at this point with so much more funding, had I known this. But, it is what it is, so we move on and make the best of what is available to us.

At any rate, when I enrolled my son in Broomfield High School in 2012 and went back to work after a long hiatus of staying home with my son, his teacher not only urged me to put him on the (THEN) 5-10 year state wait list for long term care waivers, but she also met with me to fill it in appropriately. I am forever grateful to her. Never ever try to complete these applications alone. Always bring a support person along, someone who is experienced in how you need to express the disability to the state. Your disabled adult's funding level depends on all these forms being filled in optimally.

The waitlist, once I became aware of it, scared me. All sorts of thoughts flew through my head of how I would keep a job and find a place for my over 18 son to exist in while I was at work.

That lead me to explore the EBD waiver (the Elderly, Blind, and Disabled waiver). The biggest question was, would he qualify?

Diagnoses

At this point, I think I need to step back and discuss some of my son's diagnoses in order to make it clear why he might qualify. Also, I need to make it clear what his needs are.

My son was born with Down syndrome, a severe congenital heart defect (common to Down's) and also cleft lip and palate. That means, of course, he has a cognitive disability as well as physical disabilities. I won't go over the many ancillary illnesses and complications that stemmed from those three diagnoses, rather, I will mention the results and the on-going issues we faced when he neared the age of 18.

He is intellectually disabled due to the Down's, with an IQ in the mid to high forties. He has a swallowing disorder, though he is no longer tube fed. He has a moderate hearing loss, a severe underbite, slurred and largely unintelligible oral speech, his immune system is weak, he wears AFOs (Ankle and Foot Orthoses) on his legs, hearing aids, and on top of it all he acquired as a teen an additional diagnosis of obsessive compulsive disorder. Ben has endured many surgeries and hospitalizations.

EBD Waiver

In order to qualify for the EBD waiver a person has to be either elderly, blind, or disabled. The catch here is that the disability has to be PHYSICAL not intellectual. The disability also cannot be related to mental health.

A person, like my son, who has both an intellectual disability, a mental health disability, and physical disabilities can be difficult to diagnose with regards to qualifying for the EBD waiver because the three distinct types of disabilities feed into each other. Say, for example, he can't tie his own shoes. Is this because he has an intellectual disability and cannot sufficiently master the skill of wrapping laces

around and through each other in such a way that they actually form a bow? Or is this because his thumbs have limited mobility – a physical disability?

We went through a lengthy process in terms of paperwork and interviews to determine the exact extent of the PHYSICAL aspects of his disabilities. His AFOs, his heart problems, his lung issues, his digestive issues, his risk of aspiration, etc. And in the end, he was offered a slot on the EBD waiver.

I cannot detail the steps and number of interviews we had to obtain the EBD waiver. It has been too long, and I do not remember any hurdles, just a couple of interviews with a couple of people, some paperwork. I remember thinking that he was not significantly disabled physically to get the waiver, so I did not think he would be accepted in the program, but they met for a determination, and once they sorted his intellectual disabilities and his mental diagnosis away from all his challenges, they determined that on the basis of the physical disabilities he had that he did qualify.

I drew a sigh of relief, and proceeded to look into the waiver to see what it had to offer. And while I was super happy that the state had granted us funding, I quickly found out that while he qualified for EBD, the structure of this waiver--where it allowed funding and the things it supported--were not the things we needed most. The EBD waiver naturally focuses on physical needs, and while my son has a slew of physical disabilities in terms of his overall health, he really has progressed in his late teens into a relatively stable, robust, walking, self-feeding young man, whose needs are not to be cared for by nursing staff or nurses' aid staff throughout the day.

What we really needed once he was done with school were

1. Respite during the day so I can work or
2. Meaningful employment for him or
3. Stimulating day programs that continue to challenge and stimulate him and connect him with people who can be his friends, as well as
4. Transportation to get him from one activity/job to another so I can work an

8-hour day and not have to transport him myself.

The four points above are totally related. I put respite first because without me working, our home will not function at all. However, respite is the bare minimum requirement. That simply keeps him safe at home or in someone else's home or in some group respite situation.

Beyond respite I look for what would make him what we all want to be; a productive member of society, a person who is growing and learning and enjoying the good things in life, and finally a person with friends and connections beyond the immediate family.

EBD would meet our needs well during weeks when he might be down with a lower respiratory infection where he would be confined at home or during times when he would be suffering with some bodily issue where regular skilled care would be needed. Those days and weeks are thankfully rare for us.

I will address the final piece of the puzzle, transportation, later in this document.

SLS Waiver

To my delight, the week after we were getting ready to start with the EBD waiver, the week before my son turned 18, by some miracle, the state of Colorado had begun to increase its funding for SLS waivers, another type of Medicaid waivers specifically tailored to service developmentally disabled adults. Ben was offered an SLS slot, I took a look at the SLS waiver and subsequently turned down the EBD waiver. An individual can only use one waiver at a time, regardless of needs.

SIS Evaluation

In order to determine the level of support a person gets on the SLS waiver, a couple of hoops have to be jumped through. One is the SIS evaluation ([Supports](#)

[Intensity Scale](#). The SIS evaluation is done with a person from your local HCBS, the community-based board that manages the waiver funds in your area. The person who interviews you (your child's caregiver) has a tabulated list of questions to go through. Your answers to each question will be scored 1 - 4, and at the end of the interview (several hours long) a score is compiled, and that score (ranging from 1 - 7) determines the level of funding available to your child.

What I always heard from my son's teacher, when reporting on anything to do with his disabilities, is to answer all questions as if it were his very worst day. The funding needed for your child should be the level of funding he would need on his worst day (in terms of behavior, physical illness, and cognitive functioning). My son was evaluated at a 6, in part thanks to the fact that his public school teacher came along with me, and she very much knew him, she had seen many of his worst days, and was better at advocating for the level of funding he needed than I was.

Let me add to the SIS experience, that had I known or foreseen the level of negative talk regarding my son that would take place at the SIS interview, I would've had my son picked up by someone after the assessor had verified his existence. As it was, the interview greatly upset him. He basically sat with his back to us the entire interview muttering under his breath and shouting at the wall. On the other hand, one might argue that his total lack of cooperation, his emotional outbursts and his general impossible demeanor might have helped the SIS evaluator to score him at a level 6 (almost the top you can get), and so perhaps his greatly frustrated self was the best self-advocacy he could have handed the state in favor of maximum funding.

SLS Offerings

SLS offered a combination of respite and day programs and supported employment. My son has been on the SLS waiver since September 2014, just after he turned 18, and we used the waiver services while he was still in school.

During school years, he had services of group respite events, where he would get picked up after school and taken to an afternoon program where they would swim, do art, explore the community, do dances, walk dogs for the Humane Society etc. I also had and still have a private respite-care friend, who takes him two afternoons per week after school. Nowadays, she takes him after his Monday through Thursday day programming. During the school year as well as in the summer, he participates in day programs at a local day program facility, a structured program where he is out in the community every day and where he has friends in the neighborhood we live in.

Now that he is not in school or transitions any more, my initial plan for him was to do a combination of supported employment, day programs and respite. As it turns out, we are doing 100% day program and respite after the program instead, because supported employment is 125% of the day program cost, and since I am already paying a significant portion to keep him in programs and respite-- more than the SLS waiver allots, even at a SIS level 6. I do not, at this point want to pay even more for even one day of supported group employment. This may change with time.

Transportation

The transportation piece has worked out well for us, also. His day program picks him up four mornings per week and drops him at home on two afternoons. I do not need to be there right when he gets home because he can use a key and let himself into our home and is safe being there for up to one hour or so on his own. For the other days, he has an Access-a-Ride pass with RTD, and I call twice a week to the Access-a-ride reservations to schedule his transportation from day programming to his respite provider and back home. It works wonderfully. They provide door to door services and are generally reliable to get him to and from (occasionally they run a touch late). He loves Access-a-Ride, since he gets to go out and come home on his own. The nice thing about the SLS waiver is that the Access-a-ride tickets are not taken out of his base level 6 pay. It comes out of an additional \$10,000 that is provided through the SLS waiver only for transportation and equipment needs. SLS best meets Benjamin's needs.

Conclusion

Well, my son's physical needs are less (though still significant in terms of hearing aids, AFOs, many doctor's visits, glasses, swallowing issues, hearing issues, and also ongoing chronic health problems), but since he is as healthy as he is most of the time, he is completely able to attend day programs and be functional on most days. His most significant disability at this point, the one that impacts daily living and functioning is a combination of his intellectual disability and his mental health issues, with his intellectual disability clearly taking the front seat in terms of what impairs his progress and independence.

He needs employment, day programs, respite care (because he cannot come home alone or be left alone for long), and transportation to function in the daily grind, and the SLS Waiver while it is not fully adequate to pay for all his needs, goes a long way towards providing him with services daily and weekly that keep him functioning as well as his trio of disabilities (physical, mental, and intellectual) allow him to function. What we have works for us, so far. He functions well and is happy, I am able to go to work, not have to pick him up after work (which is HUGE!), and he is able to have some nights out with friends, also through these programs.

It is a good life, not perfect, but far far from deprived, difficult or despondent. We rejoice in the strides he has made, we are grateful that there now, in Colorado is funding for adults with developmental disabilities that they can access to live meaningful lives after the school years.

Ok. So now what?



Currently, Imagine is calling families whose child is already eligible for Imagine services a few weeks before their 18th birthday to ask if the family wants adult services. After answering yes, in order to keep your child on the waitlist for DD, you will start the long process for determining your child’s support needs and SIS level and then you will develop an Individual Plan (IP) for how you want your child to use Medicaid services as outlined in the state documents [The SLS Family Caregiver Guide “Options and Choices”](#).

The process has several steps:

1. [ULTC 100.2 Initial Screening and Intake](#) home visit by case-manager
2. [SIS interview](#) with certified interviewer from Imagine
3. Meeting to discuss plan with Imagine case-manager
4. Case-manager writes plan and submits to state for approval
5. Family sent plan along with list of providers
6. Family looks for providers
7. Family looks more for providers
8. Introduction meetings are arranged

9. Weeks later, after family calls and emails, someone is contracted to provide services
10. Case-manager approves services
11. Hopefully services begin

Remember, we have all been through this process and we are here to tell it like it was for us. The reality is that parents become the general manager for their child. We parents do everything. No one else is going to coordinate between the funding agencies or contract for services with the providers. No one else will speak up when our children wander off from a group activity and get lost, or when my child hits someone on the special transit bus. (Ben J. did that on a bus because the other person was making an unfamiliar sound that made him anxious and the only way he knew to stop it was to hit that person.). No one else will search for a dentist who will sedate your child so your child can get his or her teeth cleaned. No one else will find an adult physician who can treat an adult patient who is the size of a child (as in Kammie's case). No one else will drive your kid to their meeting with the DVR job coach, then to hippotherapy, then to EXPAND swim practice.

When other parents are blissfully facing an empty nest, we are filling ours with a whole new flock of folks. Now we have to have adult nurses, adult mentors, adult behavioral therapists, adult physicians, as well as job coaches, day program managers, respite workers, social security staff, Imagine case-managers as well to manage. Most of us are trying to plan both for our own future and for our children's future. Add to that that there are serious flaws in the systems we rely on to service and support our adult children. It is not an easy path, which is why, we want to share our experiences in this document. So, hold on to your seats and we will walk you through the process.

After your child is determined eligible by Imagine! (something you should have done when they were little – if you have not, call Imagine! NOW!), and you finally get the call, those young adults who were not on CES will likely be offered a home visit from their new Imagine case-manager. Rarely do the case managers explain what they are looking for during that home interview, nor that is the meeting part of determining eligibility. Most case managers ask a bunch of questions about what

your child can and cannot do independently, including (but not limited to) all the intimately personal issues like hygiene. The case managers usually take notes. What they are actually doing is determining via the UTC 100.2 whether your child is sufficiently disabled to merit services. Think of it as a screener.

TIP: Throughout the process of eligibility and determining needs, you must answer all questions as if 1. You are not present, 2. Your child is not in your home and 3. Some stranger in some unfamiliar home is caring for your child. 4. It was their worst day ever? What would someone who did not know your child have to do?

If your child is on the CES waiver, most of the time, case-managers will do the evaluation by going straight to the SIS (Support Intensity Scale). This is a critical assessment (for all young adults with disabilities) which determines the level of need. With that level of need comes a specific level of funding. A SIS level 2 gets about \$17,600 a year of services. A SIS level 6 gets about \$36,000 a year. The SIS interview is done once at age 18, whatever level that interview determines becomes the level your young adult has for life. (You can appeal a SIS level you disagree with and possibly get the level changed. Also, if new issues arise, you may request a new interview. The state folks decide whether the SIS interview will be repeated, not your child's case-manager from Imagine). In short, the SIS interview is a very important interview.

The certified interviewer must meet your child. If you do not have guardianship, then they also must sign the consent forms. After that, have someone take them out of the room. No person should sit through hearing all of the things they can't do in excruciating detail. Having your child in the room also tends to make you the parent more positive. You may want to portray your child as perhaps more capable than your child really is. It is important on the SIS to portray your child on his or her worst day, without you, in the care of strangers.

The SIS interview usually lasts about 2 hours, though some have gone much longer. We have attached the questionnaire and highly recommend you and anyone

else planning to join you for the SIS answer all questions ahead of time. Do not forget to include justification and examples to illustrate. Anyone who knows your child can be a respondent and you may want to bring a support person, however, the more people you bring, the more discussion there will be, and the longer it takes. We have had teachers, family friends, siblings and siblings of the parents come.

Another consideration for the SIS interview is if there are two parents. Often one parent prefers to see the child has more capable and has a hard time expressing the child's true needs or viewing the child on 'the worst day'. Both parents do not have to attend. However, if there is a court-appointed guardian, they do have to attend.

The SIS level usually is scored and reported to the parents within a couple of days. The scale is 1-7 though it is very rare to score a 7. The Medical and Behavioral Needs sections are weighted and higher numbers there will increase the score. Section 2 does not count towards the SIS score but is used in developing the IP plan if there are needs in that section.

TIP: Request a copy of the interview questions and scoring sheet for your records from your case-manager ahead of time.

Your Imagine case-manager will now set up a meeting and using the answers will work with you to develop an IP. Then the case-manager will work up a plan with hours and submit it to the state. That usually takes a few weeks.

Finding providers

The case-manager will give you a list of agencies and the kind of services they provide. Now comes the fun part (insert sarcasm here). While you can ask your case manager to send out a Request for Proposals (RFP), we see very little response to those requests. The reality is you will have to start calling agencies and asking if they are accepting new clients, and if they are, do they have staff to provide the services you want.

“We usually found our Medicaid providers by word of mouth (mostly from my parent group) and sometimes by looking at the Medicaid website. We only had one response to an RFP and they were bad.”- Megan

We have found that SLS services such as respite care, homemaker services, personal care and mentorship are the most difficult to find, then to make work, then to keep. They also tend to be young people who are busy with school or other things. In short, respite care workers don't tend to last long in any one position.

Other options such as [Out & About](#) and Day Habilitation are easier to get and keep since they are not 1:1 services.

Out 'n' About offers classes and outings in the community. The mission of Out & About is to make a positive difference in the lives of people with developmental disabilities and their families by providing positive instruction and community-based services within a therapeutic framework.

Claire, Eli, Benjamin J. and Brett all enjoy Out & About.

Claire says, “I like that Out & About treats everyone equally and if you're having a hard time with someone or something they try to help you. I like Friday Nights Out and Market and Music because

you get to know and see your friends from Out 'n' About and they try to make everything fun.”

Day Habilitation options are varied in Boulder and Broomfield Counties. There are some that are focused on vocational training such as [Hearts 'n' Hands Work Enrichment](#) whose mission is “to create vocational training and business skills development in the community for people with intellectual and developmental disabilities with the intention of empowering them to live more independent, purposeful, and meaningful lives.” (The [Roost Training Center](#) has a similar mission). Participants there make items to sell (dog treats, wood sculptures, jewelry, etc.)

Others, such as [CORE](#) (In Boulder and Longmont) and [F.R.I.E.N.D.S. of Broomfield](#), have classes (music, art, computer, social skills, etc.) and opportunities for supported employment. Day programs provide transportation and offer some flexibility in the number of days a participant attends.

It will take phone calls and visits to determine if day programs are the right fit for your young adult. Some questions to ask include:

1. Ratio of staff to participants (usually the lowest is 1:3 and often much higher)
2. How they handle issues between participants
3. How they deal with behaviors
4. How they deal with hygiene and personal care
5. Safety protocols (what do they do when a participant wander off?)
6. Path through pre-vocational to supported to independent employment

Skilled Nursing Services

Many adults who qualify for IDD waivers have extensive health and medical needs which may require skilled nursing services.

Skilled nursing services are those listed in the person's plan of care and need to be provided by a registered professional nurse, or licensed practical or vocational nurse under the supervision of a registered nurse, licensed in Colorado. Services could include:

- Evaluating health status through the collection and assessment of health data
- Health teaching and health counseling
- Providing therapy and treatment that is supportive and restorative to life and well-being either directly to the patient or indirectly through consultation with, delegation to, supervision of, or teaching of others
- Executing delegated medical functions
- Referring to medical or community agencies those parents who need further evaluation or treatment
- Reviewing and monitoring therapy and treatment plans.

Note: Our group does not have expertise in this area so if you have tips or information to share, please contact Anna at advocatigwith@gmail.com so we can fill this section out.

What the day looks like for those with a SIS Level 6

Young adults who are at a SIS Level 6 use their funds in a variety of ways depending on their own goals as well as what their parents can and cannot provide.

You heard from Lene, a single mother, how she utilized Benjamin's services to meet his needs through a consistent routine by enrolling him at Friends of Broomfield. He also used Out & About which Lene pays for out-of-pocket because all his funds are used up in the Day Programming. Benjamin is on the waitlist for the DD waiver which would give him funding for residential services (can be at the family home, in a group home or in a host home).

From Benjamin T.'s mom Sara

Benjamin has the DD waiver. I am his mother, Sara, and I am his primary caregiver, as well as managing his therapeutic and medical needs. I am paid to support him through the DD waiver, along with other employees of PASCO, the Program Approved Service Agency (PASA) that administers Benjamin's DD waiver.

Benjamin is accessing some of BVSDs 18-21 services, on Tues and Thurs. Because we didn't know anything about the BVSD Transition program when Benjamin was leaving high school, and we had pretty low expectations for public education based on his previous experiences, we only signed him up for 2 days per week. This was a big mistake! Because the goal is transition out of school and into the community, adding additional days isn't an option. BVSD Transition turned out to be a really great fit for Benjamin. I now recommend to the parents I know that they request all 4 allowable days, and reduce them later if they need more time for therapies or other activities.

Benjamin also attends a day program on Mon and Wed afternoons, and on occasional evenings for social events.

A typical day for Benjamin looks like this: He wakes at around 7, and needs full assistance with all of his personal needs, eating, and medications. Then he gets on

the schoolbus (Tues and Thurs), or gets ready for physical, occupational, or behavioral therapies, or exercise at the community pool (Mon, Wed, Fri, Sat, Sun). He comes home for lunch, except on Tues or Thurs, and then heads out for day program or more therapy. On Saturday and Sunday afternoons he stays home and relaxes with his family. Benjamin comes home on the bus from day program on Mon and Wed at 3:30. I pick him up from his Transition job at arc Thrift on Tues and Thurs. I transport and accompany him to all his therapies and activities. All of the driving around may sound tiresome, but it's usually quite relaxing for me. Benjamin loves riding in the van, so I can just enjoy the radio while he is happy in the back seat.

Benjamin generally stays home in the evenings, though he sometimes goes to a show or concert. There are many more sensory performances these days, that allow Benjamin to enjoy the events without being shushed. After dinner, Benjamin relaxes and listens to music or television or a book until it is time for a shower and getting ready for bed. He goes to bed and quickly falls asleep at 11, as long as he has had a busy day. If he hasn't had enough to do to make him tired, he sometimes stays awake for hours.

It is our intention to have Benjamin stay in his home after my husband and I are too old and tired to take care of him. We have spent years and lots of dollars adding physical accessibility to this house that is tailored to Benjamin's particular needs, and he functions well here. We are exploring many different options to make this work for him, while also trying to figure out how we will get by.

Griffin's day

Griffin, who also has the DD waiver is now living in a host home while attending a super senior year at his high school. The host home providers are kind and attentive providers and he is thriving in their home. Having more adults directly involved in his daily care, has lightened the load for each person. His parents get more quality time with him since they don't have to manage all his needs, all the time. Host home caregivers fill a critical role by providing a home but not as

parents. Griffin's host home providers take their role seriously and are very attentive to his health and well-being, physically and emotionally.

Griffin's typical day looks like this:

Wakes at

Assisted to dress, complete hygiene, feed breakfast

District bus picks up for high school (doing a super senior year)

Bus back to host home at 3:30

Snack

Watches favorite shows

Dinner

Providers shower and shave and prep for bed

Bed at 9 PM (sleeps well, room locked for safety)

Kammie would likely be a SIS Level 6 but her family opted to use the Elderly, Blind and Disabled waiver to provide her with attendant care in their family home. Kammie is also on the DD waitlist. For now, while she completes her final year of 18-21 services, her full-time caregiver has an apartment in the family home. Once she is out of school, the family will likely hire additional caregivers. Kammie needs an attendant with her at all times. The family has to personally pay for all other expenses (other than those covered by her Social Security Income).

A typical Tuesday for Kammie looks like this:

Wake at 8 AM

She is dressed, tube-fed, gets her hearing aids in, has hygiene cared for

Gets on bus to 18-21 Transition program at 9 AM

Spends day going to work experience and classes

Takes bus home at 3

Tube fed at 4, hygiene

Acupuncture from 4:30 to 5:30

Participates in a community activity (park, downtown, street fair, farmers market, etc.)

Tube fed at 7, hygiene

Bathing at 9:30

Goes to bed 10 or 10:30 (requires assistance at least once a night)

What the day looks like for those with a SIS of 2 or 3

The young adults in our cadre who have SIS Levels of 2s and 3s also have different looking lives. None of this group has the DD waiver, they only have SLS waiver services.

Eli lives with his mom and since she works full-time, he is enrolled at Core Labor Source day program in Longmont. They have had difficulty finding qualified providers for him over the past few years but have slowly built a life that works for him, for now.

A typical day for Eli looks like:

Wake at 7:30

Get dressed, take medications, eat breakfast, make his bed, and make his lunch

Van picks up at 9 AM to go to CORE

CORE 9-3 (he likes hiking and outside days the best)

Van brings him home by 3:30

Computer time, watch a movie, have a snack

Shower and shave

Dinner

More computer time or movie

Get ready for bed

Reading

10 PM bedtime (he mostly sleeps well)

Brett lives with his mom and dad and two little brothers. He recently aged out of St Vrain School District 18-21 services. He attends Imagine's Out & About program 4 mornings a week as well as a couple of evenings. He is working with the DVR and DVR Vendor, Steiner SILS to find a part-time job. His typical day looks like this:

Wakes self at 7:30 AM

Showers, dresses and eats on own with lots of reminders

Is ready to be picked up for Imagine activity, usually dressed appropriately for the activity and weather or goes to work at King Soopers 20 hours a week.

Dropped off at home around 12:20 PM

Fixes his own lunch

Is reminded what the rest of his day looks like and if he has chores to complete

Two days a week, his mom drives him to ABA (Applied Behavioral Analysis) therapy for 2 hour sessions

He sometimes will make himself dinner but not for rest of family

He cleans up after family dinner

Personal time

9 PM, showers and gets ready for bed with reminders

Sleeps well

Sabrina is one of the younger adults in the cadre and just finished high school. She is in BVSDs 18-21 transition program four days a week and is just starting her first part-time job.

Her typical day looks like:

Wake self at 7:15 (later on some days)

Get herself dressed, groomed and her own breakfast

Is ready for bus with purse, lunch and sweater/coat on own

Does classes (self-advocacy, employment skills, etc.) or at work sites from 9-2:30

RTD or district bus home by 3:15

Gets her own snack, cleans out lunch box, checks on her dog

Goes to work from 4-7 or from 7-3 (three days a week)

Either takes RTD or family picks up and brings home

Dinner (she cooks some and does all the dishes)

Personal time

Gets herself ready for bed, goes around 11 PM, sleeps well



Checklist for Medicaid Waiver system

1. Apply to Imagine! as a minor
2. Get call from Imagine near child's 18th birthday
3. Say yes to Comprehensive/Developmental Disability waiver waitlist
4. Say yes to receiving long-term disability services through SLS (or DD if offered)
5. Case-manager assigned will call to come to home, meet child and conduct UTC 100.2
6. Complete Medicaid paperwork (will not need to do if already receiving Medicaid such as Medicaid Buy-in or CES waiver)
7. Review SIS interview, answer all questions, have examples ready
8. Complete SIS interview (2 or so hours typically). Have someone take child after they meet and greet interviewer!
9. Get SIS Level, set up meeting to discuss IP.
10. Casework submits IP to state for approval

11. Start looking for providers
12. Sign up for Out 'n' About, Day programs, etc.
13. Track spending
14. Manage providers, look for new ones

At the same time, you and your child are going through this process, you also have to consider:

1. Applying for Social Security benefits
2. Whether to apply for guardianship, conservatorship or Powers of Attorney
3. Apply to the Division of Vocational Rehabilitation if your child is ready for integrated employment
4. Post-secondary IEP goals and enrolling in 18-21 transition program through school district (possible up to the semester the child turns 21)
5. Consider applying to college programs that serve students with IDD or traditional community college
6. Finding a doctor for your adult child
7. Figuring out Transportation to all activities, jobs and programs

Are you tired yet?



School based Transition Services

All of our kids participated in their districts 18-21 transition services programs while they were getting services/supports through a waiver. That is the intention of transitions-to thoughtfully use school services while trying different services through the waivers over several years so when our kids turn 21, we have

adult services already in place (though as we well know, things will always be changing).

In Boulder Valley School District (BVSD) the focus of 18-21 services is to prepare young adults for the next chapter of their lives. Using the post secondary goals (PSG) of the IEP (Individual Education Plan), students spend 2-4 days a week taking classes (cooking, self-advocacy, career exploration, job skills, etc) along with going out to various job sites to gain work experiences. Staff collects data about skills, preferences, successes and challenges and use that data to customize next steps.

St.Vrain Valley School District also uses the PSG goals to determine services. Currently, they have a shorter school day and are not using community based work experiences. Other districts that intersect with parts of Bromfield County also offer 18-21 services with a wide variety of programming.

Kammie and Benjamin T. are planning to continue some of the work they started under BVSD as they transition out of 18-21 services. Sabrina has an entry level job in the community and is working with BVSD Transition services to build her skills to achieve her career goals.

Guardianship and Alternatives

Let's talk about [guardianship](#) choices and alternatives. If you do nothing when your child turns 18, then they are considered an adult in the legal system. That means you can't talk to their doctors or make medical decisions for them. You can't represent them in any way unless they give you written permission (such as a HIPPA form). Knowing your choices and having a clear plan of action is critical to maintaining their health and safety.

The decision to request to the Probate Courts to be given guardianship over your child is an individual choice. There is no one way to do this.

In general, if your child needs direct care in all life areas and is dependent on you and other caregivers to provide basic needs, they are likely a good candidate for requesting guardianship. Guardianship requires a petition to the courts that document that your child is not able to make their own decisions. It does not require an attorney to file the petition through there are attorneys that can help you. The basic process is:

1. Complete paperwork for your state
2. Gather medical documentation of your child's disability
3. File with Probate Court (fees vary, usually around \$300)
4. Arrange for court-appointed representative to come to your home and meet your child (you also pay for this, fees vary)
5. Court date with judge to make determination (child must be present)
6. File paperwork annually with court

In the cadre, most parents have been granted guardianship. But a couple families have opted for other options.

Aaron and Sabrina parents both have filed notarized [Medical Power of Attorney](#) paperwork with their child's doctors. In Colorado, this is a simple two-page form that gives decision making authority to whomever is listed on the form. Aaron and Sabrina were both able to understand what they were signing and agreed to give their parents decision making rights. The parents also stressed that they would

always keep them fully informed along with their doctors. The POW does not remove a person's rights.

This brings up a movement within discussion about guardianship (which does remove most rights- in Colorado, a person can still vote and marry but in other states, those rights belong to the guardian) which is that of [Supported Decision-Making](#) (SDM).

SDM started as an alternative to guardianship to allow an individual with a disability to work with parents and caregivers to make his or her own choices about their own life. It's working with the person, not for the person.

SDM is part of the push at the state, local and personal level to always engage the person with the disability in a way that is person-centered. This is a change from the medical model which says that professionals or other authorities, including parents, know what is best for the person and makes decisions for them. We are still learning that this is another way to 'dehumanize' a person with a disability.

No matter who the person is and what skills they have, all decisions that affect them, must include them and that includes people who have a guardian.

Financial protections can also be put in place for a person who does not have a guardian. The simplest way is to have joint checking & savings accounts and monitor spending.

All of the cadre parents also are "Representative Payees" for their child's social security (the real name is Supplemental Security Income) but everyone calls it Social Security. That means the rep payee is authorized by SSA to receive and manage their child's income.

[Conservatorship](#) is another legal way to have financial control. A conservator is in charge of managing your estate. Most attorneys recommend that option only when you have a lot of funds to manage (such as getting an inheritance or life insurance payout).

Since we are on the subject of money, let's talk about finances.



Financial

Though all of our kids have qualified to receive Social Security benefits, their journey there has varied a lot.

To get social security income (which at this point is a max of \$735/month) an adult has to meet the criteria for:

1. Having an eligible, documented disability that prevents them from being able to work enough to support themselves, and,
2. Not have assets worth over \$2000 and not have an income

The SSA determines disability eligibility first, then they do the income part. Our kids all have an Intellectual or Developmental Disability that easily qualifies them. There are many 'listings' for other issues which can be found on their [website](#).

The basic process to apply for SSI is:

1. Call the SSA or local office to set up an intake appointment. These are usually booked at least two months out. Call the month after your teen turns 18.
2. Bring to that appointment:
 - a. Your child (they must attend no matter what)
 - b. Current IEP
 - c. Colorado identification card or drivers' license
 - d. Letter from Imagine stating child's disability
 - e. Medicaid number
 - f. Letter from pediatrician documenting disability
 - g. Copy of trust and all bank statements for the trust
 - h. Copy of current bank statements that have your child's name on them (they will tell you at meeting what additional ones they need)
 - i. Letter saying what you are charging your child for rent and utilities
 - j. If receiving child support, will need to show documentation of how much.
 - k. Guardianship papers if you have them
 - l. Patience and good humor

3. Wait a few months, get a letter from SSA that shows they have made an appointment with a psychiatrist for you and how to confirm that appointment (not everyone is sent to a psychiatrist and there does not seem to be any predictability about who is sent!)
4. After appointment, (which is to verify the disability) and child is eligible, get another letter or sometimes a phone call, with request for additional paperwork (typically bank statements for the months since the in-person appointment.)
5. Wait some more
6. One day, get a check in the mail or see a deposit in the “Rep Payee” bank account you set up (need to have proof of being a rep payee for most banks to set up account with your name on it as the rep payee for...)
7. Think all is well until something happens such as...
 - ❖ *Your child earned income through a job*
 - ❖ *SSA randomly sets up a meeting while you are out of the country*
 - ❖ *They think you need to give them back the money because your special needs trust is missing a sentence and therefore is an asset*
 - ❖ *They decided that the college savings account you have for your child is your child’s asset (it’s not if you are the owner)*
 - ❖ *They deny that your child is disabled, and you finally get a hearing 2 ½ years later*
 - ❖ *You got a settlement from an accident that took place 6 years ago and just paid out and is now a big asset*
 - ❖ *You had \$2004 in your bank account for one day and they stopped SSI payments*

And yes, these all actually happened to members of the Parent Cadre!

Some members of our cadre are accessing [Social Security Disability Income \(SSDI\)](#) due to having a parent who is deceased or retired who paid into the Social Security system. Monthly payments vary depending on the previous income of the deceased or retired parent but is usually more than the \$750 that SSI pays currently.

Those on SSDI will also be getting [Medicare](#) after age 21. Medicare becomes the primary insurance with Medicaid becoming secondary. In theory everything should be covered but the two systems have different rules and different coverage, so it can be frustrating to navigate between them, especially if your child's prescriptions are not covered under Medicare (but should be under Medicaid.)

Employment and SSI

Too many people do not encourage people with IDD to work due to fear of losing their SSI benefits. It's true that it is a hassle to report income and not be sure if the accounting will affect this month or next month's payment. Working has so many of its own rewards, including being able to have an income greater than the current \$750/month that SSI gives, and there are ways to keep benefits.

There are programs to encourage working without losing Medicaid and one is called the Working Adults with Disabilities program. The individual needs to have a determination of disability from Social Security and then can earn up to the sliding scale for poverty level) and not lose their Medicaid health insurance or Medicaid waiver services. If income continues to rise, they can use the [Colorado Medicaid Buy-In program](#) which subsidizes Medicaid on a sliding scale. There are income limits to receive waiver services (adjusted income around \$2,200/month). The person still cannot have more than \$2000 in assets unless they are in an ABLE account or special needs trust.



ABLE Accounts (Achieving a Better Life Experience)

ABLE Accounts are now available in Colorado at [Coloradoable.org](https://coloradoable.org). These are tax-advantaged saving accounts that do not affect SSI or Medicaid benefits.

Basically, you enroll online (no physical banks) as long as the person meets the criteria. Eligible individuals can open the account for themselves, or an authorized individual can open an account on their behalf. There are a few requirements that individuals with disabilities must meet to be able to have an account.

You're eligible if:

- You're entitled to SSI or SSDI because of your disability; and
- Your disability was present before age 46.

Not everyone with a disability needs an ABLE account. They work best if family members or friends want to offer financial support to a person with a disability or if the person with the disability is employed and wants to save more than the \$2000 limit that SSA sets. Some other points to note:

- Contributions from all sources to an ABLE account have a limit of \$15,000 a year and at \$100,000, Social Security benefits are suspended. At \$400,000, Social Security benefits are denied.
- Regular 529 Education Savings accounts can be rolled into an ABLE (ABLE accounts are a form of a 529 account).
- Funds from a trust can be transferred to an ABLE Account and used for more things (such as housing) that is not always available through a trust.
- Upon the death of the person who has the ABLE account, the remainder after debts and burial go back to Medicaid.

There are folks who can help answer questions about these accounts through the coloradoable.org website.

Special Needs Trusts

Special Needs trusts are a specific, legal tool to protect financial assets, particularly inheritances or financial gifts so that they remain an accessible benefit for the person with the disability.

They differ from a regular trust as the legal language allows a person with a disability to have assets over the \$2000 that Social Security limits. A special needs trust is the place to have large assets such as a home or life insurance policy when parents die. If you don't have a special needs trust and your child receives anything that puts their assets over \$2000, they are in jeopardy of losing Social Security income or benefits and losing the Medicaid waivers and Medicaid/Medicare health insurance. So if you plan to leave your estate to your child, you will need to set up a trust.

There are three types of special needs trusts-private first party trusts, third party trusts and pooled trusts.

First party trusts can be set up by the person with a disability or by a family member. These are designed to hold the person with a disabilities assets that belong to them. They can be funded at anytime and can include being a place for inheritances to be distributed. One of our parents had to set this type of trust up when her adult daughter received a settlement for an accident many years earlier.

When the person dies, Medicaid can request any funds left after burial and funeral costs and debts, by paid to them.

Third party trusts are different from first party in that they are funded with money that never belonged to the person with the disability such as a home they are a beneficiary of in a parent's will. It's what those of us with limited resources

who own a home, usually set up for our kids. Unlike first party trusts, since the money never belonged to the beneficiary, when they die, the money does not go to Medicaid but to a designated recipient. It's important to note that the person with the disability cannot contribute to this trust or it violates the third party criteria. If your son or daughter starts to work and build their own assets, then consider opening an ABLE account. If they receive a settlement, it cannot go in here either-you would have to set up a first-party or put it in a pooled trust to protect the funds and the person with the disability. Because the legal language is critical and it must meet the exact language in Colorado (trusts cannot be moved across states), all of us in this group have used an attorney to set up our trusts.



Pooled trusts are group trusts that are run by a non-profit association. In Colorado, that is [Colorado Fund for People with Disabilities](#). This type is helpful when you don't have someone to be the trustee or you don't have enough money to justify creating a private trust. There are costs incurred on an annual basis but it may be much less than the cost of a lawyer to draft a first person trust. Individuals with disabilities are allowed to open their own accounts and they must also be below the age of 65.

Employment

Most of our kids spent their years in school thinking about and getting ready for a job. It's one of the sections in the Post-Secondary Goals in the IEP. Having a job, showing up and making a contribution is something everybody wants at some level. Thankfully, there are more opportunities for adults with IDD to get the support needed to enter and stay in the workforce. Locally, places like [Blue Star Recyclers](#) (located inside EcoCycle) tries to hire people with autism and other developmental disabilities. And [Ramble on Pearl](#), a local retail clothing store on Pearl street trains adults in the store and when they are masters, works with job coaches to secure integrated employment in the community.

The first place to go is the [DVR](#) for anyone looking for support to find a job. DVR is the Division for Vocational Rehabilitation and they currently have no waiting list to serve adults like our kids. Their website is very informative so it's a good place to gather information. Your young adult will apply and have an intake interview with a DVR caseworker. They will direct their questions to your child, not you so be ready for that. DVR is for people ready to work at a regular job so if your child can't handle or respond to the intake meeting at least some, they may not be ready for DVR services.

Once you have a case open, then you can work with a job coach through a DVR vendor and that coach is your main contact. Some of our kids, like Claire, Aaron and Sabrina did some assessments with the job coach in order to develop a "plan of employment." These varied from a couple hours at a couple places of employment

(like a grocery store, office, and child care center) to try some of the skills and interest needed for an entry level job.

Ideally this should happen when they are in 18-21 transition services. A good transition program has students out at a variety of job sites to learn what they like and don't like, to learn new skills, to be exposed to a variety of job sites and to develop a resume of experiences. The job sites need to be actual places people work and not made-up work. Sabrina is interested in office work, so she files and alphabetizes at one of the Human Resource offices at CU through BVSD transitions. Claire did some client shopping for a grocery store and worked in a school cafeteria. Now she is employed as a server at a senior center.

Once there is a starting place of a realistic entry level job, then the job coach will meet regularly to develop a resume, help with online applications, talk to prospective employers, go to interviews and be there on the first day of work. In our group, Claire, Aaron and Sabrina are working between 6 and 17 hours a week and Shannon is actively looking for a job! Claire found and learned her job with a job coach and now works completely independently. She also knows how to get to and from her job on RTD or on bike. Sabrina is on her second week and her job coach is starting to fade his support as she becomes more independent. Her next step is to learn how to get to work on RTD. Aaron's job coach is usually at work with him.

Once they are comfortable in the job, the coach will close the DVR case. But that does not mean that support ends. Within the SLS waiver, there are supported employment services. So technically, if the DVR vendor is also a Medicaid

provider, the same job coach can continue to provide on-site support. The SLS waiver will limit the number of hours per week-typically 1-3 per week. The idea is to be there if there is a new task to learn or a new supervisor or some other change that needs outside support.

We also want you to know that first jobs are just that and too often are the only job a person with IDD ever has. If your adult wants to try something else or get some training or go to school to pursue a career, he or she can reopen a case with DVR. First job does not have to be only job.

Supported Employment

If your child is not quite ready for integrated (meaning independent in the community with people without disabilities at minimum wage or above) they may need to start with supported employment. Supported employment is offered only through a Medicaid provider. The agency, such as CORE Labor Support in Boulder and Longmont, works with individuals to match their areas of career interest with an opportunity to develop work skills in actual employment settings. That means going to places such as Celestial Seasonings, General Electric, local thrift stores, and other business in the community with paid staff to practice skills. The range of tasks varies though they are usually predictable and routine (sorting, packaging, boxing, washing and cleaning). A good program will add skills to an individual as they are able, so that people are not stuck sorting the same things for months or years. We find parents need to ask for reports and if you can, go to see what people in supported employment options are actually doing. Because the

'jobs' are real, the adults with IDD are usually paid a small amount. They are allowed to pay below minimum wage because the person is doing less than someone without a disability could do. Sometimes they are paid at a piece-rate which is a calculation of the rate of completion they do against what someone who held that job would be expected to do. Eli has worked at General Electric through CORE Labor but reports that they are not able to consistently have work for him on the days he is supposed to be working which is frustrating for him.

The low rate also helps prevent reductions in SSI payments (to a point as [Nolo](#) describes below) which is an issue for anyone receiving SSA income and working.

Earned Income Exclusion

Earned income means money you are paid from working. If you have earned income, the SSA will exclude the first \$65 (if you don't have any unearned income, \$85 will be deducted instead), plus half of the remainder amount over \$65 that you are paid each month. This reduces your countable income, which will help minimize the effects of your work on your benefit amount.

For example, if you make \$1,465 per month, the SSA will subtract \$65 (to get \$1,400) and then half of the amount over \$65 (to get \$700). That \$700 is your countable income from work, and it will be subtracted from your monthly SSI payment (which is \$735 without a state supplement). You would still get an SSI payment of \$35. In a nutshell, you can make about \$1,550 a month before your SSI benefit is reduced to zero.

Customized Employment

Written by Bob Lawhead, Colorado Employment First

As stated on the Office of Disability Employment Policy website, "Customized Employment is a flexible process designed to personalize the employment relationship between a job seeker and an employer in a way that meets the needs of both." The Customized Employment process is not a single strategy, service, or

support but rather a flexible blend of strategies, services, and supports designed to increase employment options for job seekers with complex needs through voluntary negotiation of the employment relationship. Customized Employment can be useful for all job seekers, including those without disabilities, who have unique circumstances affecting employment. It builds on proven principles, services and supports, and strategies — such as supported employment — that have resulted in success for job seekers with complex needs. It is appropriate for job seekers and existing employees whose changing circumstances require negotiation to customize employment tasks, expectations, or working conditions.

The following principles are fundamental to Customized Employment:

The employer voluntarily negotiates specific job duties or employee expectations.

The negotiated employment relationship meets both the unique needs, strengths, and interests of the job seeker or employee and the discrete needs of the employer.

The job seeker is the primary source of information and decides the direction in which to explore the job market.

The job seeker controls the Discovery process that captures his/her preferences, interests, and connections in the community.

Exploratory time during Discovery is essential to uncover the job seeker's unique needs, abilities, and interests. More formal or traditional assessment may supplement this exploratory phase if necessary, but it should not be used as the primary source of information for planning.

Customized Employment results in jobs that fit the individual and therefore have the potential for advancement for job seekers who have been chronically unemployed or underemployed. It can only be successful if the job seeker is treated as an individual who is free to make choices about his or her life's direction; is afforded respect and dignity; is assumed to have competencies that, if not readily obvious, can be discovered; is given access in natural settings with minimal intrusion; and is provided with high quality employment opportunities and services.

Customized employment will often take the form of:

Task reassignment: Some of the job tasks of incumbent workers are re-assigned to a new employee. This reassignment allows the incumbent worker to focus on the critical functions of his/her job (i.e., primary job responsibilities) and complete more of the central work of the job. Task reassignment typically takes the form of job creation, whereby a new job description is negotiated based on current, unmet workplace needs.

Job carving: An existing job description is modified — containing one or more, but not all, of the tasks from the original job description.

Job sharing: Two or more people share the tasks and responsibilities of a job based on each other's strengths.

Discovery is the first of four components of Customized Employment which include, Discovery, Job Search Planning, Job Development and Negotiation, and Post-Employment Support. Discovery involves the gathering of information from the job seeker, family, and others who know the job seeker to determine the job seeker's interests, skills, and preferences related to potential employment that guide the development of a customized job.

Adapted from information on the Office of Disability Employment Policy website accessed at <http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/practical/indicators.htm> and a document entitled *Customized Employment Competency Model* produced under U.S. Department of Labor Contract No. GS-10F-0042M, 4 DOLQ089428184 accessed at <http://www.dol.gov/odep/pdf/2011cecm.pdf>

Kammie and her family are looking for ways to do some kind of customized employment. She is very social and loves to be out and about. Her caregiver would be with her in any employment setting.

You will most likely hear about two other employment programs- [SWAP \(School to Work Alliance Program\)](#) and [Workforce Boulder County](#). These are both wonderful options, but they are geared to young people with mild to moderate needs. If your child needs attendant care, these two programs will not be able to support them. If they are independently employable and will need an on-site job coach initially and checking in regularly, then these two programs will not be able to support them. If they only need help with writing a resume and preparing for interviews, either of these programs will be the right fit.



Higher Education for Students with IDD

Most of us in the cadre did not get a message when our kids were in public school that college would be an option for them. If we had a 529 College Savings Account for them, we transferred it to our child without disabilities or put it in a special needs trust.

Thankfully, times have changed and there are college options now in Colorado. Many other states have had college programs for students with IDD for years. In 2016, Governor Hickenlooper signed Senate Bill 16-196 which partially funds a four-year pilot initiative to build the structure for inclusive higher education pathways at three college campuses in Colorado. [Colorado Initiative for Inclusive Higher Education](#) led the initiative. The **University of Northern Colorado**, the **University of Colorado at Colorado Springs** and **Arapahoe Community College** are in their second year of educating students with IDD beside their peers. Metropolitan State is starting a program and there are some ‘taste of college’ programs at CSU and others.

These programs are partially funded but it is still an expensive option. Because students are not receiving a traditional college degree, most of the scholarships and grant programs are not available, including FAFSA. IN! is aware and looking for

ways to reduce the cost so that more young people could access college through these programs. The original intention of these programs was to provide an age-appropriate setting for students to work on employment skills as well as social and independent skills along with academic skills. DVR is a partner in many states that offers on-site job-coaching.

Currently UNC is the only program offering residential options. Here is their blurb about their program which they call [GOAL](#)

GOAL stands for "Go On And Learn" and is a fully-inclusive, 4-year, non-degree program for students with mild intellectual and/or developmental disabilities to attend courses and live on campus at the University of Northern Colorado.

UNC GOAL is an opportunity for students with intellectual disabilities to attend UNC with their peers. Students complete a four-year program that is individualized to their interests and strengths. Students then work with the GOAL team to design an individualized course of study complete with classes that are modified to their skill level.

Check out the others at their website - [Colorado Initiative for Inclusive Higher Education](#)

Claire is on her third class at Front Range Community College. She needed remedial classes to start so she took two remedial language arts classes. As part of disability services there, she had two hours of tutoring a week which helped her pass both her classes. Now she is taking a regular college class on Early Childhood Education. She continues to access the tutor and gets accommodations through the Front Range Disability Services department. Because she can only handle one class

at a time, she is ineligible for college scholarships or financial aid putting the financial burden on her and her family.



Transportation

Transportation is one of the biggest obstacles to employment for our young adults. For instance, Eli did an internship at Community Cycles that went really well and was a good fit for him. But in order to continue as a potential employee, he needed to get to and from Longmont to Boulder at different times. He is not quite ready to be fully independent on RTD and the schedule changes make it hard to use Access-a-Ride; if there were a gap (they were late, didn't show, he forgot to call, etc.) he would miss work.

Aaron's mom provides his transportation (he works two 3 hours shifts a week) as his company is too far to walk but there aren't close bus routes.

Lene writes about how she has resolved the transportation issue for Benjamin:

One aspect of having a young adult with special needs that can be taxing is transportation. For several years I drove for two, both morning and evening. 1. Taking my young adult to his daily activities, then taking myself to work. 2. Going from work to pick up my young adult, then both of us going home.

I sat in my car about 2.5 hours per day, a lot of precious time in addition to working overtime every week.

Nowadays, my young adult is picked up for his day program from home and he is also delivered home after his program. All I have to do is be there when he leaves and when he returns.

Two options are available to us in our situation in terms of transportation, and both are wonderful in terms of letting my young adult be more independent in that he comes and goes without my having to bring him or return him.

1. His day program picks up and returns. They have a bus that goes around the neighborhood to get many of the participants. For that to be possible, you need to live within whatever radius they are willing to pick up within. That is one of the reasons we picked a program close to home.
2. On Mondays and Wednesdays I stay at work later, so my young adult needs additional care and supervision after the day program is over. We have a wonderful friend with a daughter with a disability, and my son takes RTD's Access-a-ride to her house both afternoons, and also he goes on Access-a-ride back home around 6 pm.

How does [Access-a-ride](#) work?

Access-a-ride is a travel option for persons with disabilities who live within the Denver-Metro RTD area. It is for individuals who cannot access the fixed-route bus and rail system. It is to help them be independent and still get around in their communities.

Transportation is absolutely key to independence. Our young adults who do not have transportation miss many events and programs that they otherwise might have attended, since many of us caregivers have full time jobs and cannot switch gears in the middle of the day when most day programs end (between 2 pm and 3 pm) to get our young adults to their next destination for the rest of the afternoon.

Access-a-ride is available during the day and run during the same hours as the RTD bus and rail system runs.

You need to apply online at the link above, or call 303 299 2960, turn in an application, and take your young adult for an interview where an RTD Access-a-ride employee will assess whether your young adult will qualify for an Access-a-ride pass or whether your young adult should do bus training with RTD.

Travel Training - can your young adult take the regular bus alone?

We did both. We applied for an [Access-a-ride](#) pass and got it, and my son also did RTD bus training with a super friendly and helpful person who met with him every week for about 6 months, seeing whether my son could bus train well enough to be able to take a bus from point A to point B with a responsible adult on either end to put him on the bus and take him off the bus. Our conclusion was that since he fell asleep on the bus when left on the bus alone, we were better off with Access-a-ride.

I have other friends, however, whose young adults with disabilities have learned to access RTD buses and rail services well enough to transfer buses and get to and from their jobs.

[VIA Travel training](#) is free for your young adult. We utilized travel training to work on routes where my son was already going. It was very useful even though he did not ultimately use the bus alone. The trainer is highly qualified, knows how to assess your young adult, works on specific traffic awareness skills, and has several stages for the training. The trainer reports back to you after each training session, and you get a good sense of your young adult's strengths and weaknesses in being out in the community traveling.

How does Access-a-ride work?

You may still want both Access-a-ride and RTD travel training for travel flexibility, so I will talk about Access-a-ride. There are two parts to Access-a-ride.

1. Access-a-ride
2. Access-a-cab

[Access-a-ride](#)

Access-a-ride rides for your young adult need to be scheduled. You can call as early as 3 days in advance and as late as the day before. You tell the operator your young adult's Access-a-ride ID number, tell the operator where your young adult is

going, where he or she needs to be picked up from, and then you give a half hour window in which you would like your young adult to be picked up.

My son takes Access-a-ride Monday, Wednesday, Friday, and Sunday. I have a reminder in my calendar to call Sunday at noon to schedule Monday and Wednesday. And I have another reminder in my calendar to call Tuesday for his Friday ride, and then again, I call Friday to schedule his Sunday ride. In my experience they tend to come towards the latter half of the window I give them, most of the time.

The price for a local Access-a-ride ride is \$4.70, and for a regional it is \$8.50. We get Access-a-ride tickets from my son's SLS budget. It does not take away from his day programming. The Access-a-ride tickets he gets come out of an additional \$10,000 or so that he gets for equipment, adaptive clothing and shoes, and transportation. All I have to be sure of is that his wallet (tethered with a lanyard to the backpack he always carries with him) has his Access-a-ride picture ID and enough tickets to complete the trips for the day. He himself is fully trained to show ID and to pull out a ticket every time he travels. I no longer need to remind him of that.

Access-a-ride goes door to door. If you are not out, they come knocking on your door to say they are there. They wait as much as 6 minutes from the time they arrive for your young adult to board the bus. They will knock on doors where they arrive too, though my son is well trained with a key and walks up the stairs and lets himself in, unlocking the two locks we have on our front door, waves at the Access-a-ride driver and walks in. — Access-a-ride considers their responsibility over so soon as your young adult has entered the house of his or her destination.

Sometimes Access-a-ride is late. It is rare, but once or twice it has taken 2 hours for my son to get to a destination that should only have taken 30 minutes. Both times the issue was a combination of traffic and other passengers with high needs slowing the process down. It has never been a problem for me. If he is supposed to be home at 6 pm and he does not show up till 6:30 pm, my son wears a watch called a Gizmo gadget

<https://www.verizonwireless.com/connected-devices/lg-gizmogadget/> (Verizon's version of a combination watch-phone-messaging system-GPS for kids), and I can simply look at the app on my phone and see where he is at. I can also call and talk with him on the Gizmo, so I always have peace of mind with where he is when he travels alone. (Except for the one time when he turned the Gizmo off :))

[Access-a-cab](#)

Access-a-cab is a yellow cab service which you can call for same day service. It is only \$2 for a shorter trip, and more for longer trips. Your young adult has to have an Access-a-ride bus card to ride with Access-a-cab.

In addition, you and your young adult can — with his or her RTD Access-a-ride card — ride free together on the RTD bus and rail system any time.

Transportation = Independence

Lastly, my son also attends Out & About for adults via Imagine! And their programs provide transportation door - to - door (or you can pick up or drop at base sites). We use the door to door and we live just about as far away as they go. It is super convenient to have my young adult attend, for example, go to Friday Night Out and be picked up at home, and coming home at 10:30 pm on his own with the Out & About team cars.

In short, my son loves being independent, and nothing says independent more than him being able to walk out the door, saying “goodbye, Mom” and shutting the door behind himself without me needing to lift a finger. Nothing says independence more than saying, “Mom, I am leaving with my friends now”, or coming home late Friday night, unlocking the door on his own, coming inside to the family, grinning ear to ear and telling everyone what a great time he had (all by himself without family assistance).

Thanks to Access-a-ride, Access-a-ride-cab, Out & About, RTD, and his local program's morning and afternoon bus, he is able to BE more independent, and I spend about 8 hours less in the car every week than I otherwise would have.



Housing

We put this section at the end for two reasons; it is usually the last thing we set up and there are very few options. Since most of us have young adults on the SLS waiver (which does not include residential), our kids live with us. For some, that works pretty well and for others, both young adults and parents are in conflict. Like other young adults, our kids want to be able to make their own decisions, not live with their parents, and be more independent. Unlike other young adults, they may not have all the necessary skills to keep themselves safe, make good decisions and live on their own. So, they take their frustrations out on their parents.

Unfortunately, this might create some decrease in independency as their feelings and emotions override their reasoning skills.

Part of the frustration all of us are experiencing is the huge gap in housing options. Beside living with family, or having a family member buy a condo or apartment for them, the only other option is to try and get a [Housing Choice Voucher](#) (also referred to as Section 8 housing voucher). The HCV Program is a rent subsidy program funded by the U.S. Department of Housing and Urban Development (HUD). The program assists individuals and families with very-low income, including seniors and people with disabilities. Assistance is provided on behalf of the participants, who secure their own housing within the community, with rent payments split in portions between the Housing Authority and the household.

That part sounds good, but the reality is that vouchers are given through a lottery system. In the best cases, counties have one or two days a year that people can

apply and then only a fraction actually get a voucher. So, it can take years before you get one.

Then the next issue is finding a landlord or housing authority who will accept the voucher. Boulder County continues to see rents go up, so landlords can pick and choose, and they often don't pick our kids. So much fun!

DD Waiver options

If you are one of the few to get the DD Waiver, you also get funding for residential services. There are three options:

1. Host homes
2. Group homes
3. Family Caregiver

Host homes are essentially adult foster care. Through an agency and with Medicaid waiver funding and Social Security income, families can solicit and find a willing host home provider for their adult child.

Host home providers provide a bedroom and cover all expenses related to caring for your adult child. They get paid through the waiver and SSI. The family does not get any of the funding- it goes to the host home providers and some to the agency that provides the oversight for the host home.

One advantage of this arrangement is that the person is living in a regular home with their own bedroom, so it is a familiar arrangement. Griffin is living in one and it is working beautifully for his parents, for him and for his lovely host home providers. His parents see him weekly, take him out to do things and partner with the host home providers to take care of his health, safety, recreation and access to his community. Host homes usually have between 1 and 3 adults with IDD.

A **group home** differs in that it may be a house, but the agency owns the house and provides staff to come in and out to care for multiple adults. The staff do not live in the home with the residents.

One disadvantage is that group homes tend to create one schedule for everyone. For example, breakfast is between 7:30 and 8 whether or not you are awake or hungry. It has more oversight but a reduction in relationships as the turnover tends to be high. The group home model, like the host home, means all the funding for residential services and the income for food and shelter from Social Security go to the group home agency.

In Boulder County, we are seeing many group homes closing so there are very few options. The reason they are closing is costs- it is expensive to own and maintain a house in Boulder County and the Medicaid dollars just don't stretch enough.

The third option for DD waiver funds is Home-based services which allows you to be paid by a Medicaid approved agency to provide services in your home. This option is for families who want to keep their adult child in their home. This does not mean in the home all day.

The funding from the waiver also covers day services (you would make an individual plan). This is called the Family Caregiver option. One disadvantage of the Family Caregiver plan is a significant loss of privacy. Your home becomes subject to a lot of state regulation, and you can be "inspected" at any time. There are lots of people coming into your home from your Program Approved Service Agency (PASA). These may include your PASA case manager, nurses, and the other PASA employees who will be helping your son or daughter when you aren't. You need to plan, document, and practice fire drills on a regular basis. (That is not necessarily a bad thing.) There is a vast amount of paperwork to keep up with, especially that dealing with medications and medical appointments. If you choose the Family Caregiver option you need to choose your PASA carefully. All have different types of support, services, compensation, and benefits.

The DD waiver works pretty well under the Family Caregiver program. It provides funding for the most expensive parts of Benjamin's life: Medical: Residential, which is supposed to cover everything needed to support Benjamin's basic needs; Day Habilitation, which includes both day program and personnel to assist in accessing the community; and Behavioral Services, even though that is severely cut back from the behavioral services that were available in the CES waiver. But

there is not nearly enough money to cover 24 hour supports and we depend heavily on what is known as “natural supports” to get Benjamin everything he needs. As near as I can tell, “natural supports” means the family provides or pays for the support. I am doing my best to figure out how this is going to work after Benjamin no longer has family to support him. When Benjamin was younger we believed that the DD waiver was the magic solution that would ensure care for Benjamin after we were no longer able to. Now that Benjamin has one, it is clear that we aren’t that much closer to a solution that will allow us to get old and die in peace.

There are some private options in Broomfield and Boulder Counties such as [Glory Community](#) which is a faith-based Christian environment and family-oriented community. They are not a Medicaid provider so work outside of that system.

CADRE TIPS

1. Make copies of everything, including online forms (many of us have had agencies, especially Social Security, lose paperwork.)
2. Be patient. Everything takes much longer than you think it will. Think in months and years.
3. Double check information. (Many well-meaning case-managers have incorrect information.)
4. Bring everything to all appointment (see how to organize paperwork.)
5. Track and document all phone calls, meetings and conversations.
6. Track the hours that your child receives services.
7. Join a parent group to share information and resources and also how to engage with the agencies.
8. Be prepared for any interviews or meetings (know the goals, process and purpose)

None of the Above but Important Stuff

1. [Colorado Identification card](#) before 18 and after 18.
2. Voting
3. [Selective Service \(draft\) registration](#) for males
4. Letter of Intent/Vision for the Future

Colorado ID cards

Every resident of Colorado is required to have state approved identification by age 18. You can't apply to Social Security without an ID. The easiest way to do this is to make an appointment online for the office nearest you. It makes the process much faster. Know that your child will be asked to remove hats, glasses and to have their hair behind their shoulders. The staff do not always know how to accommodate a person who uses a wheelchair and cannot stand on their own for the picture so be prepared!

Voting

Every resident has the right to vote and we encourage you to help your son or daughter to get registered. Like everyone else, they do not need to know all the ballot issues to be able to vote. If they only want to vote for the governor or president, they can and leave the rest of the ballot empty. Our kids are not heard in the political arena in part because they often don't vote. Here is the link to register in [Boulder](#) and [Broomfield](#).

Selective Service Registration

Under current law, all male US citizens between 18–25 years of age are required to [register](#) within 30 days of their 18th birthday. Since this registry has not been used for decades, the chance you will have to do anything about it is unlikely.

Letter of Intent/Vision for the Future

The Letter of Intent serves as the foundation of a comprehensive life plan. It is not a legal document, but it provides invaluable guidance to those who will support your son or daughter. It also includes your hopes and dreams so that those supporting your child continue to fulfill your wishes.

Your child should be involved in developing the Letter of Intent. It should reflect his or her unique preferences as well as needs in every aspect of life. It is a big undertaking and most of us put this off. But as we age and our children age, writing a letter of intent becomes more important.

Here are some examples to use. A Letter of Intent can be written or can be videotaped or some combination of the two. There are also a couple of local groups that offer workshops and consulting for letters of intent along with other special needs planning:

[Loose Ends or Legacy](#)

Lehman Disability Planning

Samples:

<https://www.specialneedsalliance.org/the-voice/letter-of-intent-3/>

<http://www.bridges4kids.org/letter-of-intent-form.pdf>

http://www.mimianddonamovie.com/wordDoc/Writing_Letter_of_Intent_FORM-April%202014.docx

Additional resources

Wright's Law <http://www.wrightslaw.com/info/future.plan.index.htm>



From graduation to employment!

Sabrina in her uniform.