

# Transitions

A guide to future planning as  
your child with Down Syndrome  
enters adulthood

SIE Center for Down Syndrome  
720-777-6750

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Valid through 2025



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# An Introduction to Transition Planning

For people with Down syndrome, the late teens and early twenties are an important period of transition. They are transitioning from childhood to adulthood, from being students to employees, and from relying on their parents and teachers to becoming more independent and able to advocate for themselves.

In this packet, we refer to transition as all the aspects of your child's life that will change once they become a legal adult. We hope to clarify the process so your child's transition into adulthood is as smooth and effective as possible.

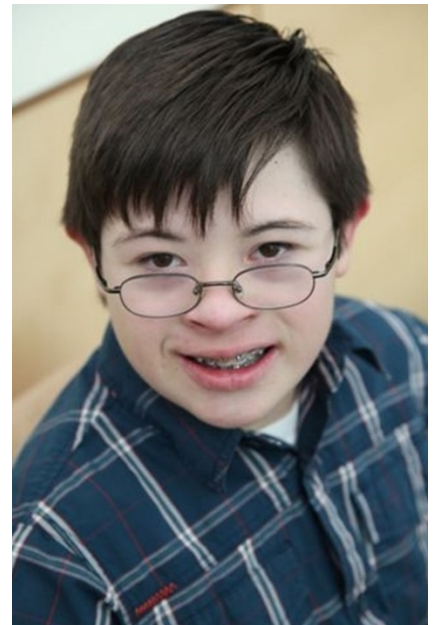
The Individuals with Disabilities Education Act (IDEA) of 1975, guarantees children with disabilities equal access to public education. Under IDEA, schools are responsible for providing the supports and services needed to make sure children with disabilities get a public education, earn their diploma, or ages out of the system at 21. Here, transition means the years between when a student finishes high school and the end of their services from the school district at 21. During this time, students with special needs can attend district-sponsored transitioning education programs.

## What is a transition plan?

The goals of a transition plan is to make sure your child will reach their full potential, be self-sufficient, and happy as an adult. A successful plan must consider employment, community involvement, adult services, postsecondary education/vocational training, independent living, and financial and legal planning.

Everyone will have their own transition plan. A well-constructed transition plan will be:

- **Person-centered.** This is a plan for your child's future. Make it about them. The plan's success depends on how well it meets your child's needs. When possible, include them in the planning process. Take time to talk with them about the things they do well and things they have a hard time with. Discuss their future goals with them so you are both prepared for planning meetings. If your child is nervous about these discussions, a school counselor might help with one-on-one talks.
- **Flexible.** Everything changes over time. The transition plan must be reviewed on a regular basis to make sure that all available public-school resources are being used as needed. As your child gets closer to the age of 21, the transition plan will change as those sources or support end.
- **Long-term.** Being prepared for the unknown is important when planning. Thinking through all situations will help you and your child be ready. Difficult topics such as your aging and death must be talked about and planned for so that your child can cope with the loss. Things to ask include:
  - How will my child be provided for financially?
  - Is there someone else that could take over as caregiver?
  - What services will your child need? Including:
    - Medical
    - Psychological
    - Social



- **Comprehensive.** In addition to your child's career goals, this transition plan should include their social, medical, legal, and financial goals. These include:
  - File for guardianship once they become a legal adult (age 18)
  - Enroll in a postsecondary vocational, transitional, or educational institution
  - Transitioning to an adult health care team
  - How to arrange for their future living situation
- **Realistic, Achievable, and Measurable.** Setting concrete goals that promote independence and achieving life skills will help measure your child's progress. This will help if the IEP changes to match their progress. Finally, establish goals that are realistic based on your child's strengths and weaknesses. Hopefully this will set them up for success.

# Adult Services and Waivers

## What is a Community Centered Board?

A Community Centered Board (CCB) is a non-profit organization that provides the long-term services and public support systems for persons with developmental disabilities. There are twenty different CCBs in Colorado, based on region (page 9). The CCB decides if a person is eligible for disability services, and how the local resources will be managed based on their needs.

## What is a Single-Entry Point Agency?

A Single-Entry Point Agency (SEP) is like a CCB. It provides case management, care planning, and referrals to other resources. They manage different waivers. See the map on page 10 for your SEP.

## What adult services do they provide?

CCBs and SEPs offer adult services through a waiver program, divided into 3 categories:



### Supported Living Services Waiver (SLS)

The Supported living services waiver adds to existing community aid by offering paid supports (see chart on page 8). SLS is for people over the age of 18 who are independent, semi-independent, or get most of their support from their family. It focuses on the independence, individual choice, and community involvement of each adult with disabilities.

### Home, Community-Based Services for Persons with Developmental Disabilities Waiver (HCBS-DD)

Home and community-based services offer Medicaid-funded supports to people over the age of 18. This service offers supports including day programs focusing on community involvement, pre-vocational training, and supported employment. HCBS-DD also offers several residential service options that provide 24-hour access to care and supervision. Based on availability and the person's needs/desires, multiple housing options are available. There are

Group Residential Services and Supports (GRSS) for homes of 4-8 people, Individual Services and Supports (IRSS) for 1-2 people living in host homes, leased homes, or their own home, and Personal Care Alternative programs for those who want to live in a host home or staffed apartment.

### Elderly, Blind, and Disabled Waiver (EBD)

The elderly, blind, and disabled waiver offers in-home services to adults who need long-term care. Recipients must qualify for Long-Term Care Medicaid. EBD services include help with medicine, adult day services, personal care, homemaking services, assisted living, nonmedical transportation, and other services. This is for those who need help to stay in their current living situation, whether that's their family home, or an assisted living facility.

## How can I apply for adult services?

Each waiver has a different application process. You should contact either your CCB or SEP to start the process. You'll need to include your child's medical and behavioral history and the services or therapies they receive. A functional needs assessment may also be needed.

Applicants can apply for multiple waivers but may only receive service from one at a time. In Colorado, there can be long wait lists for some waivers due to limited resources. It's best to apply when your child is 14 to reduce the wait time when they turn 18. Applying early may not guarantee benefits once your child turns 18, but it can help with the wait time.

Currently, there is no wait list for the HCBS-EBD or SLS waivers. If needed, your child can receive these services while on the wait list for the HCBS-DD waiver.

## Who qualifies?

Having Down syndrome automatically qualifies your child to be put on the wait list. With the SLS and the DD waiver, applicants must be 18 or older and meet Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID) level of care based on the functional needs assessment. Applicants must also meet the financial requirements. The person's income must be less than 300% or three times the Supplemental Security Income (SSI) allowance per month and countable resources less than \$2,000 for a single person or \$3,000 for a couple.

Visit [www.ssa.gov/OACT/COLA/SSI.html](http://www.ssa.gov/OACT/COLA/SSI.html) for current information on SSI allowance.

## Why should I apply for adult services?

The services and supports offered through the CCB are important for adults with developmental disabilities. If your child doesn't need these services once it's their turn, you can decline them without losing your place. The application isn't binding and can be canceled by you or your child. It's better to take your name off the list than to add to it.

## Medicaid Waivers for Adults with Down Syndrome

	HCBS – SLS Supported Living Services Waiver	HCBS – DD Persons with Developmental Disabilities Waiver	HCBS – EBD Persons who are Elderly, Blind, and Disabled Waiver
Purpose of waiver	To offer people with developmental disabilities supported living services in their home or community	To offer people with developmental disabilities services and supports which help them stay in the community	To offer a home or community-based alternative to nursing facility care for people who are elderly, blind, and living with a disability
Who is served?	People, who live independently with limited supports or who already have that high level of support from other sources	People who need services and supports 24 hours a day to live safely and take part in the community	Elderly people with a functional impairment (aged 65+) or are blind or physically disabled (aged 18-64)
Where do you apply?	Community Centered Boards (CCB)	Community Centered Boards (CCB)	Single-Entry Point (SEP) Agencies
Services offered	<ul style="list-style-type: none"> <li>Assistive Technology</li> <li>Behavioral Services</li> <li>Buy-In for Working Adults with Disabilities</li> <li>Consumer Directed</li> </ul>	<ul style="list-style-type: none"> <li>Behavioral Services</li> <li>Day Habilitation (Specialized Habilitation, Supported Community Connections)</li> </ul>	<ul style="list-style-type: none"> <li>Adult Day Services</li> <li>Alternative Care Facilities</li> <li>Buy-In for Working Adults with Disabilities</li> </ul>

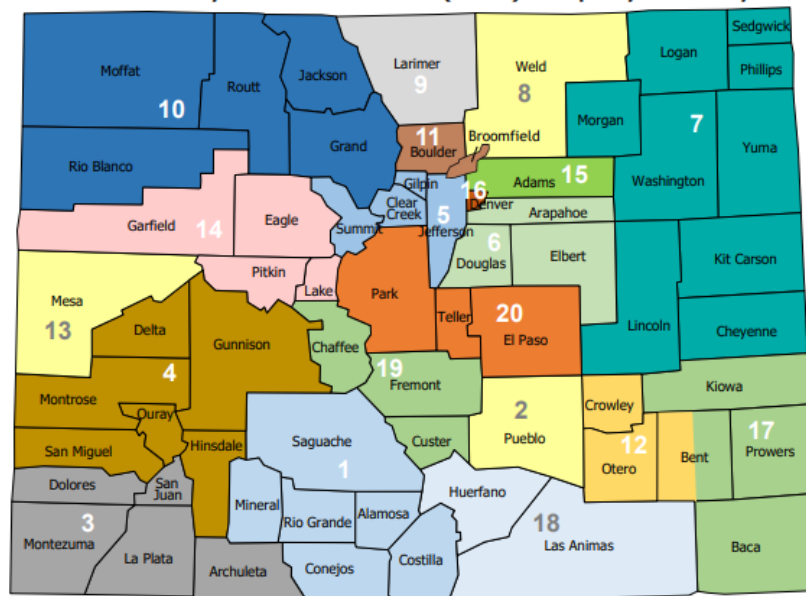
	<ul style="list-style-type: none"> <li>Attendant Support Services (CDASS)</li> <li>Day Habilitation Services</li> <li>Dental Services</li> <li>Health Maintenance Activities</li> <li>Home Delivered Meals</li> <li>Home Modifications</li> <li>Homemaker Services</li> <li>Life Skills Training</li> <li>Mentorship</li> <li>Non-Medical Transportation</li> <li>Peer Mentorship</li> <li>Personal Care</li> <li>Personalized Emergency Response System (PERS)</li> <li>Prevocational Services</li> <li>Professional Services (Includes Hippotherapy, Massage &amp; Movement Therapy)</li> <li>Remote Supports</li> <li>Respite Services</li> <li>Specialized Medical Equipment &amp; Supplies</li> <li>Supported Employment</li> <li>Transition Set Up</li> <li>Vehicle Modifications</li> <li>Vision Services</li> </ul>	<ul style="list-style-type: none"> <li>Dental Services</li> <li>Home Delivered Meals</li> <li>Non-Medical Transportation</li> <li>Peer Mentorship</li> <li>Prevocational Services</li> <li>Residential Habilitation Services (24-hour individual or group)</li> <li>Specialized Medical Equipment &amp; Supplies</li> <li>Supported Employment</li> <li>Transition Set Up</li> <li>Vision Services</li> </ul>	<ul style="list-style-type: none"> <li>Consumer Directed Attendant Support Services (CDASS)</li> <li>Home Delivered Meals</li> <li>Home Modifications</li> <li>Homemaker Services</li> <li>In-Home Support Services (IHSS)</li> <li>Life Skills Training</li> <li>Medication Reminder</li> <li>Non-Medical Transportation</li> <li>Peer Mentorship</li> <li>Personal Care</li> <li>Personal Emergency Response System (PERS)</li> <li>Remote Supports</li> <li>Respite Care</li> <li>Specialized Medical Equipment &amp; Supplies</li> <li>Transition Set Up</li> </ul>
Waitlist	No	Yes	No
Website	<a href="https://hcpf.colorado.gov/supported-living-services-waiver-sls">hcpf.colorado.gov/supported-living-services-waiver-sls</a>	<a href="https://hcpf.colorado.gov/developmental-disabilities-waiver-dd">hcpf.colorado.gov/developmental-disabilities-waiver-dd</a>	<a href="https://hcpf.colorado.gov/elderly-blind-disabled-waiver-ebd">hcpf.colorado.gov/elderly-blind-disabled-waiver-ebd</a>

Adapted from Colorado Department of Health Care & Financing July 2022 Adult Waivers



## Map of CCBs in Colorado

Community Center Board (CCB) Map by County

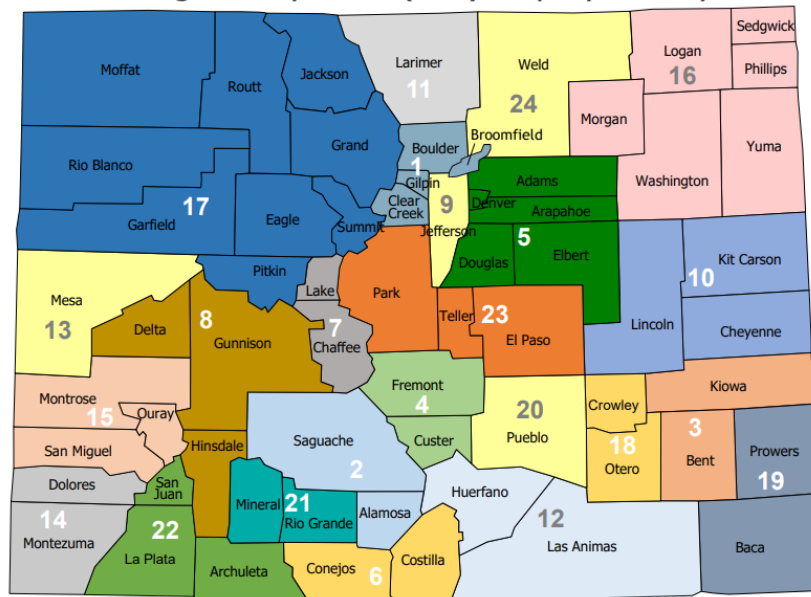


October 2021

- |   |  |   |
|---|--|---|
| 1. Blue Peaks Developmental Services<br>719-589-5135          | 8. Envision<br>970-339-5360                                | 15. North Metro Community Services<br>303-252-7199 or<br>303-457-1001 |
| 2. Colorado Bluesky Enterprises<br>719-546-0572               | 9. Foothills Gateway<br>970-226-2345                       | 16. Rocky Mountain Human Services<br>303-636-5600                     |
| 3. Community Connections<br>970-259-2464                      | 10. Horizons Specialized Services<br>970-879-4466          | 17. Southeast Developmental Services<br>719-336-3244                  |
| 4. Community Options<br>970-249-1412                          | 11. Imagine!<br>303-665-7789                               | 18. Southern Colorado Developmental Services<br>719-846-4409          |
| 5. Developmental Disabilities Resource Center<br>303-233-3363 | 12. Inspiration Field<br>719-384-8741                      | 19. Starpoint<br>719-275-1616   |
| 6. Developmental Pathways<br>303-360-6600                     | 13. Strive<br>970-945-2306                                 | 20. The Resource Exchange<br>719-380-1100                             |
| 7. Eastern Colorado Services<br>970-522-7121                  | 14. Mountain Valley Developmental Services<br>970-945-2306 |   |

## Map of SEPs in Colorado

Single Entry Point (SEP) Map by County



- |  |  |   |
|--|--|---|
| 1. Adult Care Management, Inc.<br>303-439-7011                 | 9. Kit Carson County Health and Human Services<br>719-346-7158         | 16. Northwest OLTC<br>970-963-1639                                |
| 2. Bent County Public Health<br>719-458-0555                   | 10. Larimer County Dept. of Human Services<br>970-498-6300             | 17. Otero County Dept. of Human Services<br>719-383-3166          |
| 3. Starpoint<br>719-458-0888                                   | 11. Las Animas County Dept. of Human Services<br>719-946-2276          | 18. Prowers County Public Health and Environment<br>719-336-8721  |
| 4. Rocky Mountain Human Services<br>1-844-790-7647             | 12. Rocky Mountain Health Plans<br>970-244-7892                        | 19. Pueblo County Dept. of Social Services (OLTC)<br>719-583-6857 |
| 5. Rocky Mountain Health Plans<br>719-982-6025                 | 13. Montezuma County Public Health Dept.<br>970-564-4772               | 20. Rocky Mountain Health Plans<br>833-420-2077                   |
| 6. Chaffee County Health and Human Services<br>719-530-2500    | 14. Montrose County Dept. of Health and Human Services<br>970-252-5000 | 21. Community Connections, Inc.<br>970-259-2464                   |
| 7. Delta County Dept. of Health Human Services<br>970-872-1000 | 15. Northeast CO Area Agency on Aging<br>970-867-9409                  | 22. The Resource Exchange<br>719-380-1100                         |
| 8. Jefferson County Dept. of Human Services<br>303-271-1388    |  |   |

# Education and Social Options

For most adults, having a job, being active in their community, and having positive social relationships are very important. Below are some programs and activities for adults with special needs. This isn't a complete list.

## Athletic/Social Opportunities

- **Special Olympics Colorado (SOCO)** offers social, physical, and emotional benefits. There is no age limit. They host year-round athletic events for competitors to train for and compete in. SOCO promotes physical fitness, team relationships, and the excitement of playing sports.
  - Please visit [specialolympicsco.org](http://specialolympicsco.org) or call 720-359-3100 for more information.
- Most **park and recreation districts** offer adaptive recreation programs. Many districts reserve places and offer lower fees to in-district residents. Visit your local district to see the programs they offer.
- **National Sport Center for the Disabled** offers a wide variety of outdoor recreational opportunities for individuals with disabilities of all ages and skill levels. Programs include summer camps, therapeutic horseback riding, cycling, hiking, rafting, skiing, snowboarding, and various other sports camps and clinics.
  - Please visit [www.nscd.org](http://www.nscd.org) or call 303-316-1518 for more information.
- **Adam's Camp** hosts week-long Adventure Camps for youth and young adults. Hosted at YMCA of the Rockies- Snow Mountain Ranch, this camp provides many outdoor activities to promote fun, challenge, and adventure. With low counselor to camper ratios, Adam's Camp provides a safe environment for campers to relax and enjoy themselves.
  - Please visit [www.adamscamp.org/](http://www.adamscamp.org/) or call 303-563-8290 for more information.



## Educational/Job Training

Many vocational schools, community colleges, and some four-year colleges sponsor programs for students with intellectual and developmental disabilities. Each program offers different skills and counseling services, as well as the degrees or certificates.

Your child has the right to an education through your Local Education Agency (LEA) or school district until they are 21 years of age. Transition planning starts during the IEP when child turns 16. During this IEP, the school will work with you and your student to establish post-secondary goals including post-secondary education and vocational training, independent living, and employment. These goals will help with yearly IEP goals and class registration. They will also help connect your child with outside agencies, including:

- **Local Community Centered Boards (CCB's)** offer job training and independent living skill courses. They provide services to both children and adults who have special needs. Their resource coordinators help determine which programs best suit the interests and needs of each person and family.
  - Contact your regional Community Centered Board at [hcpf.colorado.gov/community-centered-boards](http://hcpf.colorado.gov/community-centered-boards) for information.
- The Rocky Mountain Down Syndrome Association sponsors a class called **Higher Visions for Education**. It explores topics including self-esteem, safety, community involvement, and health. The class focuses on teaching the skills needed to increase independence.
  - Please visit [www.rmdsa.org/higher-visions-for-education/](http://www.rmdsa.org/higher-visions-for-education/) or call 303-797-1699 for more information.
- The **Colorado Division of Vocational Rehabilitation (DVR)** helps people with disabilities join the workforce. The Colorado DVR offers services such as vocational training, career counseling, and job placement. The application involves multiple steps so that its services are tailored to the needs of everyone. As of March 2013, there is a waiting list for new applicants.
  - Please visit [dvr.colorado.gov/job-seekers](http://dvr.colorado.gov/job-seekers) or call 303-866-4150 for more information.
- **Project Search** is a high school transition program including a yearlong, school-to-work transition that happens in the workplace. Project Search offers a unique combination of classroom instruction, career exploration, and relevant job-skills training through internships. To take part in Project Search, participants must still be enrolled in the public school system. Check with your local school district to see if placement is available. Out-of-district students may apply, but preference is given to in-district students.
  - Please visit [www.projectsearch.us/](http://www.projectsearch.us/) for more information
  - For more information on CHCO's Project Search program and application process, visit: [www.childrenscolorado.org/about/careers/students/project-search/](http://www.childrenscolorado.org/about/careers/students/project-search/)
- **Day Programs** are available to provide individuals with developmental and intellectual disabilities both support and a meaningful social outlet. Depending on the goals of their managers, they can encompass different activities and provide different degrees of service/care.
  - Contact your local Community Centered Board at [hcpf.colorado.gov/community-centered-boards](http://hcpf.colorado.gov/community-centered-boards) for information about day programs available in your area.
- **Think College!** is an online resource for college options for people with learning and developmental disabilities.
  - Please visit [www.thinkcollege.net](http://www.thinkcollege.net) for more information
- The **College Living Experience** hosts programs for students with special needs at colleges and vocational schools in the Denver area. They also offer a three-week summer program that helps with the transition to independent adulthood. This program is for students who have recently graduated high school and would like to gain skills to either live independently or continue to an institute of higher education.
  - Please visit [experiencecle.com/locations-2/denver-colorado/](http://experiencecle.com/locations-2/denver-colorado/) for more information.

- **Colorado Initiative for Inclusive Higher Education (IN!)** works to make sure that all Colorado students can continue their academic career in Colorado. IN! currently supports programs on three campuses: UNC, UCCS, and ACC with plans to expand to additional campuses in the future.
  - Please visit [inclusivhighered.org/](https://inclusivhighered.org/) for more information.

## Transportation

Public transportation can help adults with intellectual and developmental disabilities take part in services and opportunities they wouldn't be able to enjoy if they had to rely on their parents or caregivers.

- Public transportation, such as the bus or LightRail, is an option if both the routes and a person's independent capabilities make this possible. .
- If using public transit isn't an option, carpooling or RTD's Access-a-Ride may be a good fit. RTD's Access-a-Ride is available to "any individual with a disability who is unable, as a result of a physical or mental impairment to board, ride, or disembark from any vehicle on the system which is readily accessible to and usable by individual with disabilities."
  - Please visit [www.rtd-denver.com/services/accessaride](https://www.rtd-denver.com/services/accessaride) for more information.
- Via Colorado offers classes for Access-a-Ride users on how to use the RTD system. An instructor rides with the adult until they can ride safely and independently.
  - Please visit [viacolorado.org/services/travel-training/](https://viacolorado.org/services/travel-training/) or call 303-447-2848 ext. 1048 for more information

# Guardianship and Power of Attorney

When a person turns 18, they legally become an adult. This means they can make their own decisions and are legally responsible for the consequences of their actions. At this stage, parents can't access confidential medical and school information without permission. Once your child starts the transition process, it's important to think about whether guardianship or medical durable power of attorney is appropriate.

## What is guardianship?

Guardianship is a legal process where an adult is appointed by the court to handle the personal matters and decision-making of a minor or an adult who is "incapacitated." An incapacitated adult is someone "who is unable to effectively receive or evaluate information or both or make or communicate decisions to such an extent that the individual lacks the ability to satisfy essential requirements for physical health, safety, or self-care, even with appropriate and reasonably available technological assistance" (C.R.S. 15-14-102(5)). A person under guardianship is called a "ward."

The guardian, who must be 21 years of age or older, is responsible for managing their ward's estate, legal decisions, and medical treatment, and making sure their daily needs are met based on their ward's needs and values. A person can have multiple guardians. This can happen if the guardian can't fulfill their duties. A guardian is **not** required to care for a ward with their own funds and aren't legally responsible for their ward's actions or behaviors.

## What is the process for guardianship?

Establishing guardianship is a long process that can take up to six months. It involves completing multiple legal forms and submitting to the court. You should start this process before the child turns 17. This is done through the District Court in the county where the person may become a ward. This process can be expensive. The cost of establishing guardianship consists of a petitioning fee, court visitor fee, certified copy of court's order, and legal fee if you use a lawyer. If appropriate, the court may waive these fees if the petitioner can't pay.

- The forms for guardianship can be found on the Colorado Courts website: [www.courts.state.co.us/Self\\_Help/adultguardianship/](http://www.courts.state.co.us/Self_Help/adultguardianship/)
- A medical and psychiatric evaluation is needed to note the level of competency and get a baseline of functioning. The letter or report must be from a doctor, psychologist, or another professional that is trained to evaluate the patient's impairment and decision-making abilities.
- The evaluation must include:
  - The date of the assessment.
  - A description of the patient's specific cognitive and functional deficits.
  - An evaluation of the patient's mental and physical condition.
  - If needed, a statement about the patient's learning abilities, adaptive behavior, and social skills.
  - A prognosis for improvement and a recommendation for a treatment plan.
  - Caregivers must understand all the duties placed on them by the court when they become a guardian.



- Caregivers may choose to file the court paperwork on their own, hire an attorney, or seek help. Filing the petition by yourself can take a long time and be very confusing so we encourage you to get help if you need it. Support is available through the Colorado Medical-Legal Partnership at Children's Hospital Colorado. The Guardianship Alliance of Colorado also offers classes to guide families through the process.
- After the petition has been filed, a court visitor will assess the need for guardianship. They will meet with the ward in person, and file a report either recommending or disputing the need for guardianship. Typically, the court visitor has a background in psychology, sociology, or law.
- Notices of the hearing date are announced. The incapacitated person must be at the hearing with the petitioner (unless excused by the court for an approved reason).
- The naming of a guardian happens within 30 days of the hearing.
- The court may change who the guardian is if they aren't meeting the ward's needs, or they are abusing their powers.
- Guardians must file periodic reports about the status and care of their ward. This is to make sure that their power is not being abused.
- Guardianship ends when a ward dies or if the ward no longer needs guardianship.

## **What is Medical Durable Power of Attorney (MDPOA)?**

A MDPOA is an advance medical directive made in writing by an adult (18 years and older) who can make this decision, that gives another adult (age 21 or older) the power to act as their "healthcare agent" and make medical decisions on their behalf. If you don't think your child requires guardianship, another option is to establish durable legal power of attorney. This option is for people who can live independently, make day-to-day decisions on their own, and are in the process of establishing guardianship. People naming a MDPOA must be able to understand the power they are giving to that person. Typically, this isn't appropriate for someone who has significant developmental delays or intellectual impairments. Legal power of attorney is much quicker to establish and may be useful to have in an emergency while you are waiting to be granted guardianship. Legal power of attorney is different from guardianship in several ways:

- First, a person can grant legal power of attorney to another person by filing the appropriate legal documents. Unlike guardianship, this process starts with the person, not the court. They don't need to be declared incapacitated like a ward and can choose to take back the MDPOA later.
- Second, the agent who is given legal power of attorney has a more limited scope of decision-making ability. They can only exercise the power given to them in the document and only make decisions based on the preferences and desires of the person. They can't override the person's wishes. The 2 types of power of attorney are medical durable power of attorney, where the agent is given the authority to make medical and personal decisions and general durable power of attorney, where the agent is given the authority to manage finances and property.
- And third, this agent doesn't need to file any further reports once they have been granted legal power of attorney. Unlike guardianship, there is no further court oversight.

## **How do I establish legal power of attorney?**

When establishing power of attorney the individual is involved and doesn't need to be declared incapacitated to grant powers of attorney. Both parties should keep a copy of the documents granting legal power of attorney.

- Attorneys who specialize in probate and estate law can help you with the necessary documents at a cost. The fee for consultation and drafting a legal power of attorney varies. However, an attorney isn't necessary for this process, as free templates for the documents are available online by searching for example "legal power of attorney template."

- If the online forms are drafted and you don't use an attorney, the cost is much lower. In Colorado, a notary doesn't need to witness the documents, but it's recommended. If you use a notary, there is a cost. Notaries are available at most banks and courts.
- No document should be signed or put into effect unless both parties involved fully understand the implications and consequences of establishing legal power of attorney. This document must be signed, dated, and notarized before it can be put into effect.

## Which is better for my child?

Both guardianship and power of attorney limit your child's ability to lead an independent life. While independence should always be a goal, you should think about the individual needs and capabilities of your child. Complete, or even partial, legal independence may not be practical or safe for some people with Down syndrome. For others, limiting their independence can have long-term consequences. If your child will be attending a college or post-secondary program, you both should visit each school to discuss the level of guardianship your child might need. Ultimately, the decision to establish guardianship or power of attorney depends on the personal capabilities and best interests of your child.

	Cost	Time Frame	Application	Role of Self-Advocacy	Powers Granted
<b>Guardianship</b>	\$300-\$500	Can take up to 6 months	Application can be lengthy and complicated. Can be found at <a href="http://www.courts.state.co.us/Self_Help/sultguardianship/">www.courts.state.co.us/Self_Help/sultguardianship/</a>	Must be deemed an "incapacitated adult" by the court	Decision-making authority over various areas, equivalent to a parent over a minor child; must submit periodic reports to the court
<b>Legal Power of Attorney</b>	\$0-\$5	Immediately once signed/notarized	1-2 pages and is a simple form. Attorney can draft it for a fee or caregiver can search online ie "adult power of attorney template"	Individual chooses to grant decision-making powers to another adult/agent	Decision-making authority in whatever areas specified in the document



## Where can I go for more information and help?

- Colorado Courts: guardianship paperwork and instructions can be found at [www.courts.state.co.us/Self\\_Help/adultguardianship/](http://www.courts.state.co.us/Self_Help/adultguardianship/)
- Guardianship Alliance of Colorado: for classes and training information, check out [www.abilityconnectioncolorado.org/guardianshipallianceofcolorado/](http://www.abilityconnectioncolorado.org/guardianshipallianceofcolorado/)
- Medical Power of Attorney letter template: [powerofattorney.com/medical-power-attorney/](http://powerofattorney.com/medical-power-attorney/)

Note: Many county courts and local legal agencies offer legal clinics that may offer legal support/consultation regarding guardianship for adults (or probate matter).

# Supplemental Security Income and Medicaid

Supplemental Security Income (SSI) is not the same as Social Security. It provides monthly payments to meet basic needs for food, clothing, and rent. In most states, people who get SSI will also get Medicaid to cover healthcare costs.

The amount of SSI you get each month is based on your living arrangement and countable income. You may get **more** if you live in a state that adds money to the SSI program and **less** if you have other income such as wages, pensions, or Social Security benefits. You may also get less if someone pays your household expenses or if you live with a spouse and they have income.

SSI requires that recipients have less than \$2000 in cash and assets including money in the bank, stocks, gifted money, and inheritances. You need to carefully check the amount of money that is in your child's name so they can continue to collect these benefits. Please see page 21 for more information on specialty bank accounts.

In Colorado, Community Center Boards require that teens/adults apply for SSI and Medicaid also be eligible for adult Medicaid Waivers.

## Who is eligible for SSI?



**Non-Mosaic Down syndrome** (Trisomy 21) automatically qualifies legally as a disability. **Mosaic Down syndrome** is harder to qualify because studies have shown these patients have a higher average IQ than people with Trisomy 21. This means that government agencies don't always treat the 2 diagnoses the same. To get Social Security Disability benefits for Mosaic Down syndrome, extra information must be submitted to show it prevents them from being able to work. If your application for SSI is denied, you can appeal the decision.

## How do I apply for SSI?

You can apply online or at your local social security office. Parents or guardians can apply for children under 18 who are blind or have a disability. Parents/guardians should help teens apply around age 17.

- Apply online: [www.ssa.gov/benefits/ssi](http://www.ssa.gov/benefits/ssi) or call 1-800-772-1213 to make an appointment with your local Social Security office. TTY number: 1-800-325-0778.

Have this information ready when applying:

- Social Security number
- Birth certificate or other proof of age
- Home information, such as a mortgage receipt or lease and landlord's name
- Payroll slips, bank books, insurance policies, car registration, burial fund records, and other information about income and resources
- Names, addresses, and telephone numbers of doctors, hospitals and clinics, a karyotype if one has been performed
- Proof of U.S. citizenship or noncitizen status
- Checkbook or other papers that show your bank, credit union, or savings and loan account number

For people with disabilities, a medical decision must be made by the state disability determination service. If your claim is denied, you have 60 days to appeal the decision.

- For more information, [visit www.socialsecurity.gov](https://www.socialsecurity.gov) or call toll-free 1-800-772-1213.
- SSI Packet - [www.ssa.gov/pubs/EN-05-11000.pdf](https://www.ssa.gov/pubs/EN-05-11000.pdf)

If approved for SSI, funds will be sent by direct deposit, through the Direct Express® card program, or by Electronic Transfer Account.

- For more information, visit [www.GoDirect.org](https://www.GoDirect.org).

## Medicaid

In Colorado, if someone is eligible for SSI, they automatically qualify for Medicaid. Medicaid is a federal and state-sponsored public health insurance. People on Medicaid may still need to pay co-pays and some out-of-pocket expenses. These costs are often small, and Medicaid will cover most of the cost of mandatory medical care and approved therapies.

## Things to consider:

- Sometimes private insurance is the best option for your child/family. Look at all options before making a choice.
  - Most children can stay on their parents' policy until they turn 26. Some insurance companies allow children with disabilities to stay on their parents' policy after this date, but each company is different. Private insurance companies may be able to provide better medical coverage for your child.
- If Medicaid is your best insurance option, make sure your child's doctor accepts it.
- To learn more about Medicaid services in Colorado for adults with disabilities, please visit: Programs for Adults | Colorado Department of Health Care Policy & Financing  
[www.hcpf.colorado.gov/programs-adults](https://www.hcpf.colorado.gov/programs-adults)

Some people with Down syndrome may also qualify for **Social Security Disability Insurance (SSDI)** if they have had a paying job and pay into social security. You can have both SSI and SSDI at the same time if you qualify.

- To learn more about the rules for SSDI and how to apply, please contact your local Social Security office, or visit [www.ssa.gov/pubs/EN-05-10029.pdf](https://www.ssa.gov/pubs/EN-05-10029.pdf) or I Benefits for Adults | SSA  
[www.ssa.gov/benefits/ssi/adults.html](https://www.ssa.gov/benefits/ssi/adults.html)
- Easterseals Colorado offers consultation and webinar trainings (for a fee) on SSI/SSDI. Check out Easterseals Colorado | Disability Benefits Services (DBS) [www.easterseals.com/co/our-programs/work/disability-benefits-services/](https://www.easterseals.com/co/our-programs/work/disability-benefits-services/)

# Special Needs Trusts (SNT) and Achieving a Better Life Experience (ABLE) Accounts

A special needs trust (SNT) is a trust set up by the guardian of a person with disabilities where the disabled person will inherit the money. An SNT should be created instead of gifting the funds in an inheritance after a death. This can help avoid a loss of Medicaid/SSI benefits if the beneficiary has too many assets. The SNT will help the beneficiary have lasting financial support.

An SNT is meant to supplement rather than make up the income of the beneficiary. There are specific requirements about the proper usage of funds. In general, the funds should be used for nonessential items such as things that aren't covered by SSI and Medicaid.

There are two types of special needs trusts: revocable and irrevocable.

**Revocable Trust:** the creator of a revocable trust is called the grantor. The grantor can withdraw any funds they deposit. A revocable trust can't be turned into an irrevocable trust.

**Irrevocable Trust:** The funds of an irrevocable trust can't be taken out once they've been deposited. A revocable trust can be turned into an irrevocable trust.

Special needs trusts are expensive to set up and may not be an option for some families. Talk with a financial advisor or lawyer about which type makes the most sense for your child.

## What is an Achieving a Better Life Experience (ABLE) account?

An Achieving a Better Life Experience (ABLE) account is a tax-advantaged savings account for an individual with a disability. You can use an ABLE account to save funds for many disability-related expenses. Anyone, including the account owner, family, and friends can contribute to the ABLE account.

**The account owner of an ABLE account must:**

- Be eligible for SSI based on disability or blindness that began before age 26
- Be entitled to disability insurance benefits, childhood disability benefits, or disabled widow's or widower's benefits, based on disability or blindness that happened before age 26
- Have a certification that disability or blindness happened before age 26

The money in the ABLE account doesn't count as a resource under SSI rules. You can use this money to pay for certain qualified disability expenses, such as education, housing, transportation, employment training, employment support, assistive technology, and related services.

- Visit [www.ablenrc.org](http://www.ablenrc.org) to get more information on ABLE accounts.

Please see the Special Needs Trust/ABLE Account handout for more detailed information.



# Transitioning to Adult Health Care

## Why is it necessary to transition to an adult primary care provider (PCP)?

Health care as an adult is very different from child health care. If your child has Down syndrome, it's especially important for them to see a health care team that specializes in age-appropriate care.

## What specific health concerns do adults with Down syndrome face?

In addition to the basic health concerns, your child is more likely to have other conditions. These can include hearing or vision loss, Type II diabetes, mental illness, Alzheimer's disease, and become obese. Your child should see their adult health care team on a regular basis to monitor their health and well-being.

## What time is the best time to transfer to an adult health care team?

This depends on the medical needs of your child. Most pediatricians will see patients until they are 18-21. Transition talks should start early so you and your child are ready when the time comes. When you are ready to move to an adult care team, ask for a copy of your child's medical records or have your child's doctor's office send a copy to their new care team. Start asking your child's specialist teams about transition care at the age of 16-17 if they will transition to adult specialist teams.

## Are there doctors in Colorado who specialize in caring for adults with Down syndrome?

Yes, Dr. Barry Martin is the Medical Director of The Denver Adult Down Syndrome Clinic at Denver Health offers annual medical evaluations. This can help you get an overview of your child's health and an understanding of the medical conditions that can happen with Down syndrome. This evaluation is only meant as a consult. This shouldn't replace your child's primary care team.

- Contact: Adult Down Syndrome Clinic at Denver Health call 303-602-0002, Option 3

Ask your pediatrician if they have any recommendations for adult care teams in your area, specifically, teams who see patients with Down syndrome.

For more support on transitioning healthcare, please visit:

- Got Transition at: [www.gottransition.org/](http://www.gottransition.org/)

For healthcare guidelines for adults with Down syndrome, please visit:

- Global Down Syndrome Medical Guidelines: [www.globaldownsyndrome.org/medical-care-guidelines-for-adults/](http://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/)

# In Conclusion

The goal of this transition plan should be to help your child be as independent as possible. Independence is an important part of living a full, happy life. They must be responsible for being their own self-advocate, speaking for themselves, and asking for what they need. These skills are important in all areas of life including at the store, at work, and at the doctor. In addition to all the other aspects of their transition plan, these independent living skills must be included as much as possible. They start with teaching your child to make logical, responsible decisions- a process that's never too early to learn. The influence parents have on their child's future quality of life is very important.

While many state services can be valuable supports in your child's adult life, they should not be relied upon too heavily. As well-intentioned as these programs can be, they are run by paid workers, who can't replace family and friends as advocates for an adult with Down syndrome. There will be bumps along the way, but what is important is that you keep fighting for your child's best interests.

We hope this packet has helped you prepare for your child's transition and has calmed some of the stress. We know this process can be overwhelming, but the future has never been brighter for adults with Down syndrome.

# Transition Timeline

13-15

- Contact CCB to be put on waiting list for adult services
- Begin talking to school about future planning and transition services
- Talk to the care team to find out what age they stop seeing patients, and who they refer to

16-17

- Decide if guardianship or power of attorney are right for you
- Apply for Supplemental Security Income (SSI) and Medicaid
- Decide if you will establish a special needs trust (SNT) or ABLE account
- Attend an open house to look at any higher education or post-secondary programs. Decide if you will use district resources or explore other options.

18

- Complete legal requirements (guardianship/power of attorney)
- Prepare to transfer to adult healthcare
- Apply to higher education programs (if senior and not using district services)
- Apply for a driver's license or Colorado State ID. Visit [dmv.colorado.gov](http://dmv.colorado.gov) for more information
- Register to vote. Visit [www.vote.gov](http://www.vote.gov) for more information.
- Register for Selective Service if needed. Visit [www.sss.gov](http://www.sss.gov) for more information.

19-21

- Find alternatives for involving adult in the community for when district resources end
- Connect with Department of Vocational Rehabilitation for employment options if not employed and there is a desire to be employed
- Explore leisure, social, and exercise programs for health and enrichment

# Healthcare for Teens/Young Adults with Down syndrome

Age	13	14	15	16	17	18	19	20-29
Usual preventative care <sup>1</sup>								
Heart tests <sup>2</sup>						CV ECHO	CV ECHO	CV ECHO
Hearing tests								
Eye exam								
Labs: Thyroid (TSH & T4)								
Neurologic exam								
Dental exam								
Reproductive health <sup>4</sup>								
Mental health <sup>5</sup>								
Nutrition and weight management								
Facilitate transition <sup>6</sup>								

- <sup>1</sup> Common medical issues include heart issues, sleep apnea, eye/progressive vision issues, progressive hearing loss, hypothyroidism, Alzheimer's, obesity, aspiration symptoms, celiac disease
- <sup>2</sup> Listening to the heart to find mitral valve prolapse and aortic regurgitation; having an echocardiogram at ages 18 to 22
- <sup>3</sup> Check for spinal cord compression from synovial joint (neck) instability test gait (how they walk), tone, Babinski responses, deep tendon reflexes, and clonus (muscle cramping). Check for neck pain, new incontinence (bladder leaking), problems walking, spasticity, and weakness. Help the family/caregiver report results to the physician.
- <sup>4</sup> Check the need for birth control/period control to stop possible pregnancy, help with hygiene issues, premenstrual behavior problems, recommend routine gynecologic care and exam under anesthesia if needed. Perform testicular exam. Help patient and family understand the increased risk of sexual exploitation.
- <sup>5</sup> Periodic screening to check development, depression, and stress. Assessment should include occupational, physical, and speech therapists as needed. If there is a loss of function, check thyroid function, depression, stress, Alzheimer's disease, sensory deficits, sleep patterns suggestive of sleep apnea, possible regression.
- <sup>6</sup> Guardianship, financial planning, behavioral problems, school transition, vocational training, independence, hygiene and self-care, community living, work settings, and adult programs



# Resources

## Books

Wright, H. (2013). The Complete Guide to Creating a Special Needs Life Plan: A Comprehensive Approach Integrating Life, Resource, Financial, and Legal Planning to Ensure a Brighter Future for a Person with a Disability. Jessica Kingsley Publishers.

Couwenhoven, T. (2007). Teaching children with Down syndrome about their bodies, boundaries, and sexuality: A guide for parents and professionals. Bethesda: Woodbine House.

McGuire, D., & Chicoine, B. (2010). The guide to good health for teens and adults with down syndrome.

McGuire, D. E., & Chicoine, B. (2006). Mental wellness in adults with Down syndrome: A guide to emotional and behavioral strengths and challenges. Woodbine House.

## For information about transitioning a child with autism:

- [www.autismspeaks.org/family-services/tool-kits/transition-tool-kit](http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit)

## Notes

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