



The CES *Family Caregiver* Guide

“Options and Choices”

For Colorado citizens with intellectual and developmental disabilities and their families

September 2011



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This guide is distributed through chapters of The Arc in Colorado. The purpose is to give individuals receiving services and their families the information needed to understand the option available under the Family Caregiver Act. The guide was jointly developed by a group of family members, The Arcs, Program Approved Service Agencies and CCBs. While some of the opinions and recommendations in the guide may not be jointly shared by all parties, they are included in order to give a complete perspective of the Family Caregiver option.

PART 1: WHAT IS THE FAMILY CAREGIVER OPTION?

The **2008 Family Caregiver Act** was fully implemented in November 2010. The Family Caregiver Act allows a person already receiving services funded by the Division for Developmental Disabilities (DDD), to receive those services in a place of their choice and by a person of their choice. Family Caregiver is a service option and not a program. The Family Caregiver Act resulted in minimal changes in the way Children’s Extensive Support (CES) Waiver is delivered.

References to “you” or “your” in this guide refers to the parent or legal guardian of the child receiving services.

WORDS TO HELP YOU UNDERSTAND THIS GUIDE

Person with I/DD	Refers to a person with Intellectual or Developmental Disabilities
Family Caregiver	<p>A family member who provides care to the person with an intellectual or developmental disability in the family home.</p> <ul style="list-style-type: none"> • Paid family member who meets the requirements for a qualified Family Caregiver & working through a Program Approved Service Agency or CCB. • Non-Paid family member offers support
Case Manager	Also known as a Resource Coordinator (RC for short), Service Coordinator or Support Coordinator. This is the first person to call and talk to about the Family Caregiver option.
CCB	Community Centered Board (CCB) is the single point of entry for waiver and state funded services for persons with developmental disabilities and is responsible for case management services. Some CCBs have their own Program Approved Service Agency in addition to CCB functions.
CES	Children’s Extensive Support Waiver
CNA	Certified Nurse Aide available through the State Medicaid Plan, not a waiver service
DDD	The Division for Developmental Disabilities (DDD) approves and monitors the CES waiver services for children with developmental disabilities.
Family	A mother, father, brother, sister or any combination, extended blood relatives such as grandparent, aunt, uncle, cousin, an adoptive parent, one or more individuals to whom legal custody of a person with I/DD has been given by a court, a spouse, or the person’s children.
IDT	Interdisciplinary Team includes you, your family members, friends, Case Manager, allies, advocates and providers. Basically anyone of your choice who can assist with making decisions.
Legally responsible person	A parent of a minor child who has legal responsibility for the physical and financial care of their child.
Natural supports	The supports and supervision offered by non-paid persons, related or not.
OHCDs	Organized Health Care Delivery System: Has the ability to do an independent contract in order to deliver services to an individual. The CCB is the OHCDs for the Developmental Disability system.
PASA (Agency)	Program Approved Service Agency. Agency Program Approval is authorized by DDD and is specific to a type of service. Hereafter referred to as the Agency.

SP	Your child's annual Service Plan (SP) is the written document that defines your child's needs and services
Waiver resource	The DD system term for the money allocated to your child for specific services when your child is enrolled in a Medicaid waiver program. It is sometimes called a "slot".

A. WHY WOULD YOU CHOOSE THE FAMILY CAREGIVER OPTION?

Family members, who may or may not be living with your child, can be paid to provide services outlined in your child's Service Plan.

B. HOW FAMILY CAREGIVER WORKS IN THE CES WAIVER

1. Your child must already have a resource in order to use the Family Caregiver option. Participation in Family Caregiver does not change the current funding available. It is no more or no less. Funding changes only occur when your child's needs change, the state changes the established rates or the Colorado budget changes. For current information contact your child's Case Manager.
2. Your child's services and supports must be identified in his or her annual Service Plan.
3. Your child's IDT makes the recommendation to use the Family Caregiver option. His or her Case Manager or some members of the IDT may not agree with using Family Caregiver. There may be really important reasons for this and you need to ask them exactly why they disagree. You can always ask for help from different people:
 - a. Call the person who supervises the Case Manager
 - b. Call DDD and talk to the person who manages Family Caregiver in that office
 - c. Call your local chapter of The Arc
 - d. Call the Legal Center
4. A paid Family Caregiver must be able and willing to meet any requirements of employment specific to an Agency or an independent contractor specific to the CCB.
5. There may be times the paid support person cannot be there because of an illness or emergency. Your family and the Agency need to have a backup plan to support your child.
6. Any Agency can have additional requirements based on their policies and procedures. The Agency should share all of that information prior to your choice of an Agency.
7. It is the responsibility of everyone involved in your child's life to ensure he/she is free from abuse, neglect, mistreatment & exploitation, and that your child's rights are not violated. Everyone must understand this process and know to whom and how to report any concerns.
8. If you decide you don't want to use the Family Caregiver option after trying it out, you can just choose a different service delivery option. Your child keeps the waiver resource and stays in services while the change is being made.

PART 2: THE BASICS

A. SERVICE INFORMATION

1. CES does not allow the utilization of a Legally Responsible Person (parent of a minor child) to provide services under this waiver. A parent of a CES enrolled minor child is considered a Legally Responsible Person. While federal Medicaid allows this option, Colorado did not include it.

DDD's reasoning for this decision is because the parent of a minor child has a legal responsibility to provide care and supervision to their child, regardless of whether or not the child has disabilities. The CES waiver is intended to support, not supplant naturally occurring resources and parental responsibility. Additionally, all children enrolled in the CES waiver require "extraordinary care", as the targeting criteria for the CES waiver includes the need for extraordinary care for exceptional medical and/or behavioral issue.

2. In CES any family member (except a parent), who may or may not be living with your child, can be a paid Family Caregiver. They can be hired and paid to deliver any allowed CES services including
 - a. basic homemaker
 - b. enhanced homemaker
 - c. personal care
 - d. respite

The following services in the CES waiver cannot be provided by a paid Family Caregiver:

- a. Behavioral Services
 - b. Professional Services (Hippo-Therapy, Movement or Massage Therapy)
 - c. Home Accessibility/ Vehicle Modifications / Assistive Technology
 - d. Adaptive Therapeutic Recreation & Equipment
 - e. Vision Services, Dental Services, Specialized Medical Equipment and Supplies
 - f. Personal Emergency Response System
3. Not everyone needs all of these services. They are based on your child's needs, priorities and available funding.
 4. The maximum funding for a child in the CES waiver is \$35,000 per year. The specific funding available for each child is determined by the IDT in the annual Service Plan. It is based on your child's needs. This option doesn't change the funding level for your child's services.
 5. All CES allowable services have established reimbursement rates. The rate for the service and any limitation on specific service amounts stay the same. If you want rates for specific services in CES please contact your Case Manager. These rates do not reflect the hourly rate negotiated between the paid Family Caregiver and Agency.

B. HOW CAN MY FAMILY MEMBER GET PAID TO SUPPORT ME?

1. A paid Family Caregiver, who may or may not be living with you, can work for an Agency. You will need to choose an Agency. Your child's Case Manager is not permitted to refer you to any specific agency but can send information to Agencies on your behalf. You can also call Agencies directly. The Agency is responsible for hiring, training, determining salary and supporting paid staff. Anyone paid to support your child has to be at least 18 years old. The rate of pay is established by the Agency.
2. You may have a family member who decides to take the steps to become an agency like some other families in Colorado have done. If you are interested, please contact DDD at (303) 866-7450.
3. Your family member may become an independent contractor with the CCB (as the OHCDs). The CCB is not required to offer this option. There are several external requirements that must be

met as an independent contractor for which the CCB is held responsible. You will need to have this discussion with your CCB. Currently, a Program Approved Service Agency (PASA – the Agency) is not able to do an independent contract with a family member. For updated information or further clarification, call DDD.

All of these options may require Background Checks.

C. COLORADO MEDICAID STATE PLAN BENEFITS

If you are receiving services in CES, your child is covered under Colorado Medicaid. Colorado Medicaid is your child's health insurance plan (also known as State Plan benefits). Along with coverage for your child's medical care there are skilled nursing care, CNA and home health services available if your child meets the eligibility criteria for those specific services. You are also eligible for the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services. It is a health care benefit package for all Medicaid enrolled children under 21 and all pregnant women.

These services may be provided in conjunction with CES services, however, they cannot happen at the same time of the day, nor can duplicate services be provided through the CES waiver. Your Case Manager can help you understand how both of these services work. Neither state plan benefits nor EPSDT services are part of any waiver.

PART 3: IF FAMILY CAREGIVER SOUNDS LIKE A GOOD OPTION, WHAT NEXT?

A. THESE ARE SOME QUESTIONS YOU SHOULD ASK:

1. Do I have family members (grandparent, aunt, uncle, sister, brother etc...) that will help support my child?
2. Am I asking other siblings or relatives to commit to something that they really do not want to do or can't do for a variety of reasons?
3. Are they able and willing to meet any requirements of the Agency as an employee? Are they willing to have a background check?
4. Is the Independent Contractor option under the CCB a better option? It still has requirements.
5. There are pros and cons to any option. Which is better **for your child** and your family?

B. CALL YOUR CHILD'S CASE MANAGER and ask for an IDT to discuss this option and the changes you need to make. If you don't have a copy of your SP, just ask your Case Manager. Who you want to help you should be based on your child's needs, your preferences and personal goals.

C. IF A FAMILY MEMBER DECIDES TO GO THROUGH AN AGENCY, HOW DO WE CHOOSE?

1. Do you have any agency specific requirements besides those defined by DDD?
2. How many hours of direct service can the Agency provide?
3. Do I, as the parent, have any input or say so about who the Agency hires to provide the services?
4. What kind of insurance does the Agency have for staff?
5. What kind of training does the Agency have for paid family members?
6. Do you have any training options for the non-paid Family Caregivers?

You can also ask other people for information about the Agency, such as the Arcs, PAD-CO, Parent to Parent, CCBs and DDD. They are all listed in PART 4.

PART 4: WHO TO CONTACT FOR ADDITIONAL INFORMATION CONTACT

- Your Case Manager
- Your Agency
- Your CCB
- Your Local/State chapter of The Arc
- Division for Developmental Disabilities at (303) 866-7450 or <http://www.colorado.gov> (type Developmental Disabilities in the search bar). PASAs are listed on the DDD web page under the Service Provider link.
- Colorado Cross Disability Coalition (CCDC) (303) 839-1775 or 1 (800) 817-1435
- PAD-CO (Parents of Adults with Disabilities in CO) padcoweb@aol.com
- P2P (Parent to Parent) 1 (877) 472-7201
- The Legal Center (303) 722-0300 or 1 (800) 288-1376

Colorado Chapters of The Arc are privately funded Independent Advocacy Organizations supporting persons with intellectual and developmental disabilities and their families.

Advocacy Denver (303) 831-7733	The Association for Community Living in Boulder County (303) 527-0888
The Arc of Adams County (303) 428-0310	The Arc of the Pikes Peak Region (719) 471-4800
The Arc of Aurora (720) 213-1420	The Arc of Pueblo (719) 545-5845
The Arc In Jefferson County (303) 232-1338	The Arc of Weld County (970) 353-5219
The Arc of Larimer County (970) 204-6991	The Arc of Colorado (303) 864-9334
The Arc of Mesa County (970) 245-5775	
The Arc of Arapahoe & Douglas (303) 220-9228	

Colorado Community Centered Boards (CCBs)

Arkansas Valley Community Center (719) 384-8741	North Metro Community Services Developmental Disabilities Resource Center (303) 457-1001 (303) 233-3363
Foothills Gateway (970) 226-2345	Southeastern Developmental Services (719) 336-3244
Blue Peaks Developmental Services (719) 589-5135	Developmental Pathways (303) 360-6600
Horizons Specialized Services (970) 879-4466	Southern Colorado Developmental Services (719) 846-4409
Colorado Bluesky Enterprises (719) 546-0572	Eastern Colorado Services (970) 522-7121
Imagine! (303) 665-7789	Starpoint (719) 275-1616
Community Connections (970) 259-2464	Envision (970) 339-5360
Mesa Developmental Services (970) 243-3702	The Resource Exchange (719) 380-1100
Community Options (970) 249-1412	
Mountain Valley Developmental Services (970) 945-2306	
Denver Options (303) 636-5600	