



# **The SLS *Family Caregiver* Guide**

## **“Options and Choices”**

*For Colorado citizens with intellectual and  
developmental disabilities and their families*

September 2011



*Achieve with us.*

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 (including a family member living with them). Family Caregiver is a service delivery option and not a program. The Family Caregiver Act resulted in minimal changes in the way Supported Living Services (SLS) Waiver is delivered.

**References to the “you” or “your” used throughout this guide refers to the person receiving SLS.**

### WORDS TO HELP YOU UNDERSTAND THIS GUIDE

<b>Person with I/DD</b>	Refers to a person with Intellectual or Developmental Disabilities
<b>Family Caregiver</b>	<p>A family member who provides care to the person with an intellectual or developmental disability where the person lives.</p> <ul style="list-style-type: none"> <li>• Paid family member who meets the requirements for a qualified Family Caregiver &amp; working through a Program Approved Service Agency or CCB</li> <li>• Non-Paid family member who offers support</li> </ul>
<b>C.R.S.</b>	Colorado Revised Statute or Colorado law can be accessed at <a href="http://www.michie.com/colorado">www.michie.com/colorado</a> .
<b>Case Manager</b>	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.
<b>CCB</b>	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.
<b>CNA</b>	Certified Nurse Aide available through the State Medicaid Plan, not a waiver service
<b>DDD</b>	The Division for Developmental Disabilities (DDD) approves and monitors the SLS waiver services for adults with developmental disabilities.
<b>Family</b>	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 your children.
<b>IDT</b>	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.
<b>Least Restrictive Environment</b>	Details in PART 1 Section C.
<b>Legal guardian</b>	It is based on court action appointing a Legal Guardian for a person 18 years of age or older. Legal Guardianship does not mean legal responsibility to provide care for a person or financial responsibility for their physical care. A Legal Guardian is not held legally responsible for a person's actions. A Legal Guardian is responsible for making decisions in accordance with the terms of the guardianship.
<b>Legally responsible person</b>	Spousal relationships are considered responsible to share in the physical and financial care of one another. Therefore, federal Medicaid defines a spouse as a legally responsible person. A court appointed legal guardian is not considered a legally responsible person.

<b>Natural supports</b>	The supports and supervision offered by non-paid persons, related or not.
<b>OHCDs</b>	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.
<b>PASA (Agency)</b>	Program Approved Service Agency. Agency approval is authorized by DDD and is specific to a type of service. Hereafter referred to as the Agency.
<b>SIS</b>	Supports Intensity Scale used by Colorado to determine individual's level of need.
<b>SLS</b>	Supported Living Services Waiver
<b>SP</b>	Your annual Service Plan (SP) is the written document that defines your needs, desires and services.
<b>Waiver resource</b>	The DD system term for the money allocated to you for specific services when you are enrolled in a Medicaid waiver program. It is sometimes called a "slot".

**A. WHY WOULD YOU CHOOSE THE FAMILY CAREGIVER OPTION?**

Family members, who live with you or not, can be paid to provide services outlined in your Service Plan.

**B. HOW FAMILY CAREGIVER WORKS IN THE SLS WAIVER**

1. You must already have a resource in order to use the Family Caregiver option. The funding level for your services is based on your SIS level. Participation in Family Caregiver does not change the current funding available. It is no more or no less. Funding changes only occur when your needs change, the state changes the established rates or the Colorado budget changes. For current information contact your Case Manager.
2. Your services and supports must be identified in your annual Service Plan.
3. The IDT makes the recommendation to use the Family Caregiver option. Your Case Manager or some members of the your 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. The Family Caregiver option must meet the Least Restrictive Environment criteria in PART 1 Section C.
5. Your Individual Rights as defined in Colorado Statutes must be assured. (Ask your Case Manager if you don't have a copy of your rights.)
6. You and your family must choose an approved service agency willing to support the Family Caregiver option or a CCB willing to use the independent contractor option.
7. A paid Family Caregiver must be able and willing to meet any requirements of employment specific to the Agency or an independent contractor specific to the CCB.
8. There may be times your 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 you.
9. 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.
10. It is the responsibility of everyone involved in your life to ensure you are free from abuse, neglect, mistreatment & exploitation, and that your rights are not violated. Everyone must understand this process and know to whom and how to report any concerns.

11. 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. You keep your waiver resource and stay in services while you are making the change.

**C. LEAST RESTRICTIVE ENVIRONMENT and Typical Patterns of Daily Living**

Your life should be a lot like other people your same age. It is important to consider all aspects of your life when you think about this. You should have typical times you go to bed, participate in routine activities, go shopping or do recreational activities. Your choices include:

1. Choosing your activities and what you want to do in the community (e.g. recreation, getting together for meals, attending places of worship).
2. Receiving help for activities such as cooking, shopping, laundry and housekeeping, etc. that lets you be as independent as possible.
3. Help with your personal care activities, e.g., bathing, dressing, etc., to promote independence and ensure appropriate hygiene, grooming and dress.

This is required in Colorado law C.R.S. 27-10.5-102 (24)

**D. LEGAL GUARDIANSHIP AND THE FAMILY CAREGIVER OPTION**

In April 2011, Colorado law changed and legal guardians of adults can now be paid Family Caregivers without having to return to the court. DDD is in the process of reviewing the September 18, 2010 Advisory Memorandum about the dual role of guardianship and paid Family Caregiver responsibilities. DDD will make revisions as necessary.

<b>PART 2: THE BASICS</b>
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**A. SERVICE INFORMATION**

1. SLS does not allow a Legally Responsible Person (spouse of the individual receiving services) to be paid to provide services under this waiver.
2. All other family members can be hired to deliver any allowed SLS services including:
  - a. personal care
  - b. basic & enhanced homemaker
  - c. mentorship
  - d. respite
  - e. day habilitation
  - f. supported employment
  - g. non-medical transportation
3. Day Habilitation Services and/or Supported Employment are provided outside of your home. If you are requesting these services take place in your home, the Agency must provide evidence that it is necessary because of your medical or safety needs.
4. The following services in the SLS waiver cannot be provided by a paid Family Caregiver:
  - a. Behavioral Services, Vision Services, or Dental Services
  - b. Professional Services (Hippo-Therapy, Movement or Massage Therapy)
  - c. Adaptive Therapeutic Recreation & Equipment
  - d. Home Accessibility/Vehicle Modifications/Assistive Technology
  - e. Specialized Medical Equipment and Supplies
  - f. Personal Emergency Response Systems
5. Not everyone needs all of the services available in this waiver. They are based on your needs, your priorities and available funding.

6. Individual funding limits called SPALs (Service Plan Authorization Limit) are the same as currently exist under the SLS waiver. Current levels are:

<b>SLS: Funding Limits</b>	This table lists the funding limits based on an individual's SIS level.	
	SIS Level	Service Plan Authorization Limit (SPAL): Annual Total
	1	\$12,193
	2	\$13,367
	3	\$15,038
	4	\$17,296
	5	\$20,818
	6	\$27,366
	7	\$35,000 : limited to individuals at this level effective July 1, 2010

7. All SLS 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 SLS 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 approved Agency. Your 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, and supporting paid staff to provide you direct supports. Anyone paid to support you 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 three of these options may require Background Checks.

**C. COLORADO MEDICAID STATE PLAN BENEFITS**

If you are receiving services in SLS, you are covered under Colorado Medicaid. Colorado Medicaid is your health insurance plan (also known as State Plan benefits). Along with coverage for your medical care there are skilled nursing care, CNA and home health services available if you meet the eligibility criteria for those specific services. These services may be provided in conjunction with SLS services, however, they cannot happen at the same time of the day, nor can duplicate services be provided through the SLS waiver. Your Case Manager can help you understand how this works. State Plan Benefits are not part of any waiver.

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

#### **A. THESE ARE SOME QUESTIONS YOU SHOULD CONSIDER**

If you are the person receiving services **ASK YOURSELF** these questions:

1. Do I want my family members to provide my supports? Why do I want to do this?
2. Who do I think is the best person in my family to do this?
3. Do I have family members (parents, grandparents, aunt, uncle, sister, brother etc..) who will help me out?
4. Is the whole family in agreement with this decision? Am I asking other people to do something that they really do not want to do or can't do for a variety of reasons?
5. There are pros and cons to any option. Which is better for me and my family?

If you are the family member of the person receiving services **ASK YOURSELF** these questions:

1. Why do I want to do this? Is it because I feel I have to? Does my family want to do this? Do they feel like they have to?
2. Is the whole family in agreement with this decision? 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?
4. Would it be better to consider the Independent Contractor option under the CCB? There will still be requirements that have to be met.
5. Am I willing to have a background check completed on me and/or other family members?
6. As a paid caregiver you will actively participate to assist your family member to achieve their own personal goals and objectives as identified in the Service Plan. You probably already help your family member to learn and grow. This new role would mean a more written and documented process to accomplish their goals. Is this something you want to do?
7. There are pros and cons to any option. Which is better for your family member?

- B. CALL YOUR 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, or don't know your SIS level and rate, just ask your RC. The available rates for the SIS Levels are in PART 2 Section A #6.

#### **C. IDT DISCUSSION ITEMS**

1. What do you want? Your choices should be honored. Your choice about who provides you supports should truly reflect your wishes, needs and personal outcomes.
2. Is the use of your parent or a family member as a paid staff always age appropriate? Sometimes having a family member around may be fine. Other times may not be. Your IDT is always responsible to look at your choices and what you want as long as it can meet your needs. The IDT should think about how you can meet different people and find new friendships.

#### **D. IF A FAMILY MEMBER DECIDES TO GO THROUGH AN AGENCY, HOW DO I CHOOSE?**

Here are some questions you should consider asking the Agency.

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. If a family member does not want to be the paid Family Caregiver, do I or my family member, 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. Will you negotiate the rate of pay for people I think would work best with me?
6. Is there any training for the non-paid Family Caregiver?

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

- 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 Aurora	(720) 213-1420	The Arc of the Pikes Peak Region	(719) 471-4800
The Arc In Jefferson County	(303) 232-1338	The Arc of Pueblo	(719) 545-5845
The Arc of Larimer County	(970) 204-6991	The Arc of Weld County	(970) 353-5219
The Arc of Mesa County	(970) 245-5775	The Arc of Colorado	(303) 864-9334
The Arc of Arapahoe & Douglas	(303) 220-9228		

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