PRACTICE - TALKING TO PARENTS WITH INTELLECTUAL DISABILITIES

P - Persistence
R - Respect
A - Acceptance
C - Clear information
T - Truthful
I - Increase skills
C - Creativity
E - Encourage

Parents with Intellectual and/ or Developmental Disabilities

The presence of an intellectual and/or developmental disability[1] does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities.

Issue

The history of discrimination toward individuals with intellectual and/or developmental disabilities includes the denial of rights and opportunities to have and to raise their own children. This history has included segregation and involuntary sterilization of adolescents and adults. After birth, infants have been removed immediately from parental care, and through legal provisions, parents have been denied the opportunity to raise their children in their home.

Examples of social and social service biases and discriminatory practices include:

- Presumption of incompetence, that is, a general belief that people with intellectual and/ or developmental disabilities are unfit to be parents;
- Limited supports to parents with intellectual and/or developmental disabilities;
- Professional emphasis on limitations of parents with intellectual and/or developmental disabilities to the point of weakening parents' sense of competence and potential for success;
- Public resources primarily focused on crisis-driven support;
- Lack of trust of service providers or government officials by parents with intellectual and/or developmental disabilities based upon fears of losing their children and their vulnerability to arbitrary authority; and
- Disproportionate representation of parents with intellectual and/or developmental disabilities in child custody proceedings, where, their competence as parents is held to higher, less flexible and more frequently applied standards than those applied to other parents.

Despite research which documents the ability of many parents with intellectual and/or developmental disabilities to raise a child successfully with appropriate and effective supports, access to these supports continues to be limited, fragmented and

uncertain. Few specialized programs exist. Many family support and early intervention programs are not equipped to provide the intensive and ongoing supports that parents with intellectual and/or developmental disabilities and their children are likely to require.

Position

All adults, when provided access to appropriate and effective supports as needed to fulfill the basic responsibilities of child rearing, are more likely to be effective in their roles as parents.

Parents with intellectual and/or developmental disabilities and their children deserve social and health supports that:

- Recognize the need of parents to be viewed as unique individuals able to learn and improve in their skills and to respond to the needs of their children;
- Distinguish the effects of the family's living conditions and economic status independently from assessing ability to perform a parenting role;
- Build a trusting relationship between the parents, child, and those who provide formal and informal supports to them;
- Recognize, include, and engage the informal supports of family members, neighbors, and their community members to assist parents and the family as a whole;
- Recognize that as the needs of children change, parenting skills must evolve and may require new forms of support for parents and children;
- Respond to the unique learning needs of parents with intellectual and/or developmental disabilities;
- Assist parents in becoming actively engaged in their children's school and community;
- Reflect the full range and multiple components of effective support programs including, as needed:
  - in-home visits to teach parenting skills;
  - assistance with daily living skills;
  - access to nutritional resources such as "ready to feed" formula;
  - child care, early intervention services, and counseling;
  - basic academic education for parents;
  - assistance in accessing public benefits as appropriate;
  - crisis intervention services, availability of intensive supports as needed, and volunteer mentoring programs; and
- Assure that access to parent supports and to the environments and programs in which parental participation is beneficial to the child and family are provided with proper consideration of Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and related accommodations.

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities support adoption of the United Nation's Convention on the Rights of Persons with Disabilities. Article 23, "Respect for Home and the Family,"

Obligation 4 states that "Parties shall ensure that a child shall not be separated from his or her parent against their will, except when competent authorities subject to judicial review determine, in accordance with applicable laws and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents."

Rev'd 2013
Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

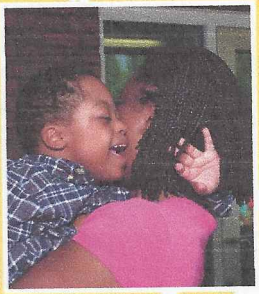
[1] "People with intellectual disability and/or developmental disabilities" refers to those defined by AAIDD classification and *DSM IV*. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by *DSM IV*.

The Arc

For people with intellectual and developmental disabilities

Achieve with us.

Parents with Intellectual Disabilities



What Is The Arc's Position?

The presence of an intellectual and/or developmental disability does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals soley on the basis of intelellectual and/or developmental disabilities. Read the entire Position Statement at http://www.thearc.org/page.aspx?pid=2375.

Who Are Parents with Intellectual Disabilities?

Parents with intellectual disability or developmental disabilities (I/DD) have various levels of cognitive impairment. An intellectual disability occurs before age 18 and is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills (AAIDD, 2011). Mild cognitive limitation describes individuals who may have been diagnosed with an intellectual disability at some time in their lives. They have lower than average learning, communication, judgment and understanding abilities (Tymchuk, Lakin & Luckasson, 2001). Their eligibility for service varies from state to state, because they do not qualify for services based on having an intellectual disability.

Why Is The Arc Concerned about Parents with Intellectual Disabilities?

The right to marry and raise children have long been recognized as fundamental under the Constitution of the United States. While these rights apply to parents with intellectual disabilities, their parental rights are sometimes terminated solely upon the determination that a parent has an intellectual disability. Often, there is no assessment of the parents' actual abilities or the likelihood that they could successfully parent with appropriate supports.

The Arc's position statement on sexuality states that people with I/DD have the right to make decisions about having and raising children and to have access to the proper supports on an individual basis to assist them in raising their children within their own home (The Arc, 2008). While parents without disabilities often receive support and ideas from other parents, those with I/DD typically are unable to obtain and develop such relationships that provide natural support. Other supports provided through government programs or non-profit agencies are also scarce in most communities.

Parents who have intellectual disabilities may be closely scrutinized for any sign or symptom of abuse or neglect to their children. Parents live in fear of having their children taken away. Many whose children have been removed

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don't understand why or how to prevent it next time. Many others are not identified as having an intellectual disability and try to hide their disability, depriving themselves of any opportunity for accommodations. For those parents whose children have been taken from them, the reunification plan usually requires parents to attend counseling sessions and parenting classes that are not cognitively adapted, which dooms most to failure.

Are Parents of Children with Intellectual Disabilities Capable of Raising Their Children?

Contrary to what many people think, people with intellectual disabilities can be good parents. Field and Sanchez (1999) suggest that the ability of a parent to provide adequate child care cannot be predicted on the basis of intelligence alone. As with parents without disabilities, the ability to parent successfully depends on a wide range of factors. Grayson (2000) reviewed studies attempting to identify factors contributing to successful parenting. These factors include: higher IQ (greater than 50 or 60), being married or living with the child's grandparents or daily support from a high functioning adult, having fewer children or only one, adequate motivation and willingness to accept support from service providers or informal sources, training in the home to enhance generalization, appropriate parent models during childhood, good physical and mental health, adequate finances and low stress and adequate education and reading skills.

What Are Strategies for Successful Supports to Parents with Intellectual Disabilities?

McConnell, Llewellyn & Bye (1997) surveyed service providers and identified four principles associated with effective services to parents with I/DD. These are:

- Services need to be responsive to the parents' individual needs and focus on the whole family to ensure that interests of both parents and children are served.
- Services must include long-term, ongoing supports because the needs of children change and parenting skills must change as children mature.
- Services must consider the special learning needs of the parent. Learning must occur in the home, be repetitive, use demonstration and use resources that require little or no reading.
- Services must assist parents in becoming part of their community.

What Kinds of Supports Are Needed?

Examples of supports that help parents provide appropriate care and stimulation to their children include:

- In-home visits to teach parenting skills and to assess parenting competency
- Parent training adapted for parents with intellectual disabilities
- Help with shopping and money management
- Service coordination
- Health care, learning to deal with doctors
- Child care, early intervention services
- Mental health counseling
- Counseling for substance abuse and other addictions
- Basic academic education for parents
- Transportation for families
- Play groups for children and parents
- Crisis intervention services

Parents may need varying kinds and levels of support at different times in their child's life. Grandparents, aunts and uncles, friends and other family members often provide a lot of the help and support. Early intervention and/or Head Start can link families of young children to community and natural supports. However, the family may not even qualify for case management services, which means someone needs to be creative in helping the family find positive environments and help for the child. There is a great need for community service agencies to create and provide individualized services based on each family's needs.

How Are These Supports Provided?

Several service approaches have been shown to be effective

individually and in combination in supporting parents and teaching parenting skills. These include home visiting programs, parenting groups, center-based programs and shared parenting models described below (Anderson & Lakin, 1998).

In-home programs provide an opportunity to model and teach parenting skills in the setting where parents will use them. This makes the skill easier for the parents to learn. The service providers can provide appropriate supports focusing on nutrition, cleanliness, safety issues and other issues related to the home.

Parenting groups can instruct families meeting together on such topics as discipline techniques, child development, health and safety issues and decision-making skills. Studies show that parents consistently gain skills in this type of instruction. They are most successful when the class is followed by home visiting. This allows parents to practice in the home what they have learned in class under the support and observation of their instructor.

Center-based programs provide a variety of services to parents and children at a program site. They can provide services to the parent and the child jointly and separately at the same site. They are most effective when supplemented with in-home training. They typically offer a variety of services and instruction such as parenting skills, cooking, financial management, etc.

Shared parenting provides full-time support when the parent and child live in foster care together. The foster provider acts as a "co-parent" to ensure the needs of children are met.

What Are the Effects on the Child's Development of Having a Parent with an Intellectual Disability?

Booth & Booth (1997) interviewed 30 adults brought up in a family headed by a parent or parents with intellectual disabilities. Half of these adults had intellectual disabilities themselves. They conclude that the children's destinies are not fixed by having a mother or father with intellectual disabilities. Their experiences in leaving school to adult life were similar to other people from the same social class and neighborhoods. Most of them maintained a valued relationship with their families. There was little evidence of them assuming responsibility for "parenting their parent."

Protective factors that fostered resilience in the children are personality characteristics, such as responsiveness to others and an outgoing nature; family characteristics, such as warmth and mutuality and stability; and external supports, such as supportive relationships outside the home and involvement in the wider community.

References:

American Association on Intellectual & Developmental Disabilities. (2011). Intellectual Disability: Definition, Classification, and Systems of Supports, 11th Edition. Washington, DC: American Association on Intellectual & Developmental Disabilities.

Anderson, L. & Lakin, K.C. (1998).Parents with cognitive limitations: What do we know about providing support? Impact: 11(1), 6-7.

Booth,T. & Booth, W. (1997). Growing up with parents who have learning difficulties. York, England: Joseph Rowntree Foundation.

Field, M.A. & Sanchez, V.A. (1999). Equal Treatment for People with Mental Retardation: Having and Raising Children. Cambridge: Harvard University Press.

Grayson, J., ed. (2000). Parents with mental retardation. Virginia Child Protection Newsletter. Vol. 57

McConnell, D., Llewellyn, G., & Bye, R. (1997). Providing services to parents with intellectual disability: Parent needs and service constraints. Journal of Intellectual and Developmental Disability, 22(1), 5-17.

Tymchuk, A.J., Lakin, K.C. & Luckasson, R. (2001). The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations. Baltimore: Paul H. Brookes Publishing Co.

The Arc. (2008). Position Statement on Sexuality. On-line: http://www.thearc.org/page.aspx?pid=2375

Revised 3/1/11

COLORADO
Department of Health Care Policy & Financing

Community Centered Boards

What is a Community Centered Board?

In Colorado, the Department of Health Care Policy & Financing (the Department) oversees the states' 20 Community Centered Boards (CCBs). CCBs support access to long term services and supports (LTSS) through Medicaid waivers for Home and Community Based Services (HCBS). Specific waivers require CCBs to coordinate services to clients in the least restrictive setting possible with the goal of keeping them in their homes and communities as an alternative to institutional care.

CCBs serve individuals with intellectual and developmental disabilities. Colorado has designated CCBs as the access point for the following HCBS waivers:

- Home and Community Based Services Children's Extensive Support Waiver (HCBS-CES)
- Home and Community Based Services Waiver for Persons with a Developmental Disability (HCBS-DD)
- Home and Community Based Supported Living Services Waiver (HCBS-SLS)

Case Management & Other Responsibilities

CCBs currently provide case management, entry point functions and HCBS services for individuals with intellectual and developmental disabilities. The responsibilities of a CCB case manager include assessing a client's long-term care needs and developing and implementing a LTSS support plan for the client. Once a plan is developed, the case manager is responsible for authorizing, coordinating and monitoring delivery of the services, evaluating their effectiveness and periodically reassessing the client's needs.

CCBs have also been designated as the utilization review contractor that have the responsibility to determine functional eligibility for LTSS programs for individuals with intellectual and developmental disabilities.

Because CCBs provide case management and HCBS services, they are required to adhere to federal person-centered planning rules. Under the rules, HCBS providers or those who are employed by or have an interest in an HCBS direct service provider, may not provide case management or develop a person-centered service plan unless the state demonstrates that there are no other options available. In which case, the state

must devise conflict of interest protections and receive approval from the Centers for Medicare & Medicaid Services.[i]

How are CCB Services Funded?

Administrative contracts between the Department and the CCBs fund eligibility determinations, Support Level Determinations, and quality assurance activities. Funding is a combination of approximately 50% federal funding and 50% state General Fund revenue. These administrative services include eligibility determinations, Support Level Determination, and quality assurance activities. CCBs bill fee-for-service rates for Targeted Case Management, which is a State Plan Benefit.

CCB Regulations Relevant to No Wrong Door

CCB regulations can mostly be found at 10 CCR 2505-10, section 8.600 *et. seq.* Regulations relevant to No Wrong Door are highlighted in the table below.

Relevant Regulations	
Rule Citation	**Rule Topic**
8.606.1	Administrative Services, including the process for designation as a CCB
8.607.2	Determination of developmental disability
8.607.3	Service and support coordination

Colorado's Community Centered Boards

(1) Blue Peaks Developmental Services
703 Fourth Street
Alamosa, CO 81101
(719) 589-5135

(2) Colorado Bluesky Enterprises
115 West 2nd Street
Pueblo, CO 81003
(719) 546-0572

(3) Community Connections
281 Sawyer Drive, #200
Durango, CO 81303
(970) 259-2464

(11) Imagine!
1400 Dixon Avenue
Lafayette, CO 80026
(303) 665-7789

(12) Inspiration Field
612 Adams Avenue
La Junta, CO 81050
(719) 384-8741

(13) Mountain Valley Developmental Services
700 Mount Sopris Drive
Glenwood Springs, CO 81602
(970) 945-2306

(4) **Community Options**
336 South 10th Street
Montrose, CO 81402
(970) 249-1412

(5) **Developmental Disabilities Resource Center**
11177 W. 8th Avenue
Lakewood, CO 80215
(303) 233-3363

(6) **Developmental Pathways**
325 Inverness Drive South
Englewood, CO 80112
(303) 360-6600

(7) **Eastern Colorado Services**
617 South 10th Ave.
Sterling, CO 80751
(970) 522-7121

(8) **Envision**
1050 37th Street
Evans, CO 80620
(970) 339-5360

(9) **Foothills Gateway**
301 Skyway Drive
Fort Collins, CO 80525
(970) 226-2345

(10) **Horizons Specialized Services**
405 Oak
Steamboat Springs, CO 80477
(970) 879-4466

(14) **North Metro Community Services**
1001 West 124th Ave.
Westminster, CO 80234
(303) 252-7199
or (303) 457-1001

(15) **Rocky Mountain Human Services**
9900 E. Iliff Ave.
Denver, CO 80231
(303) 636-5600

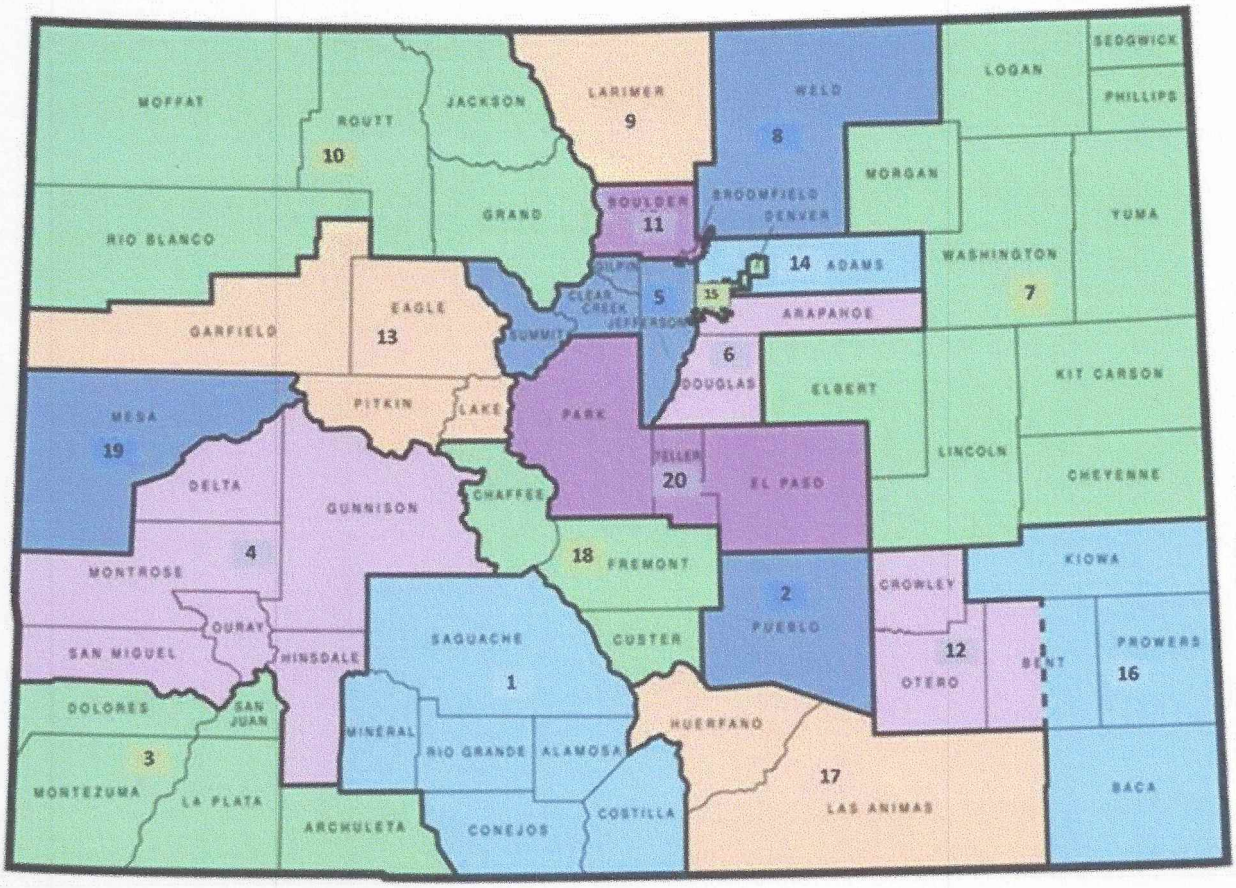
(16) **Southern Colorado Developmental Services**
1205 Congress Drive
Trinidad, CO 81082
(719) 846-4409

(17) **Southeastern Developmental Services**
1111 South Fourth Street
Lamar, CO 81052
(719) 336-3244

(18) **Starpoint**
700 South 8th Street
Canon City, CO 81215
(719) 275-1616

(19) **Strive**
950 Grand Avenue
Grand Junction, CO 81502
(970) 243-3702

(20) **The Resource Exchange**
418 South Weber
Colorado Springs, CO 80903
(719) 380-1100



[i] 42 CFR 441.301(c)(1)(vi)

Coronavirus Disease 2019 (COVID-19) in Colorado: State & National Resources

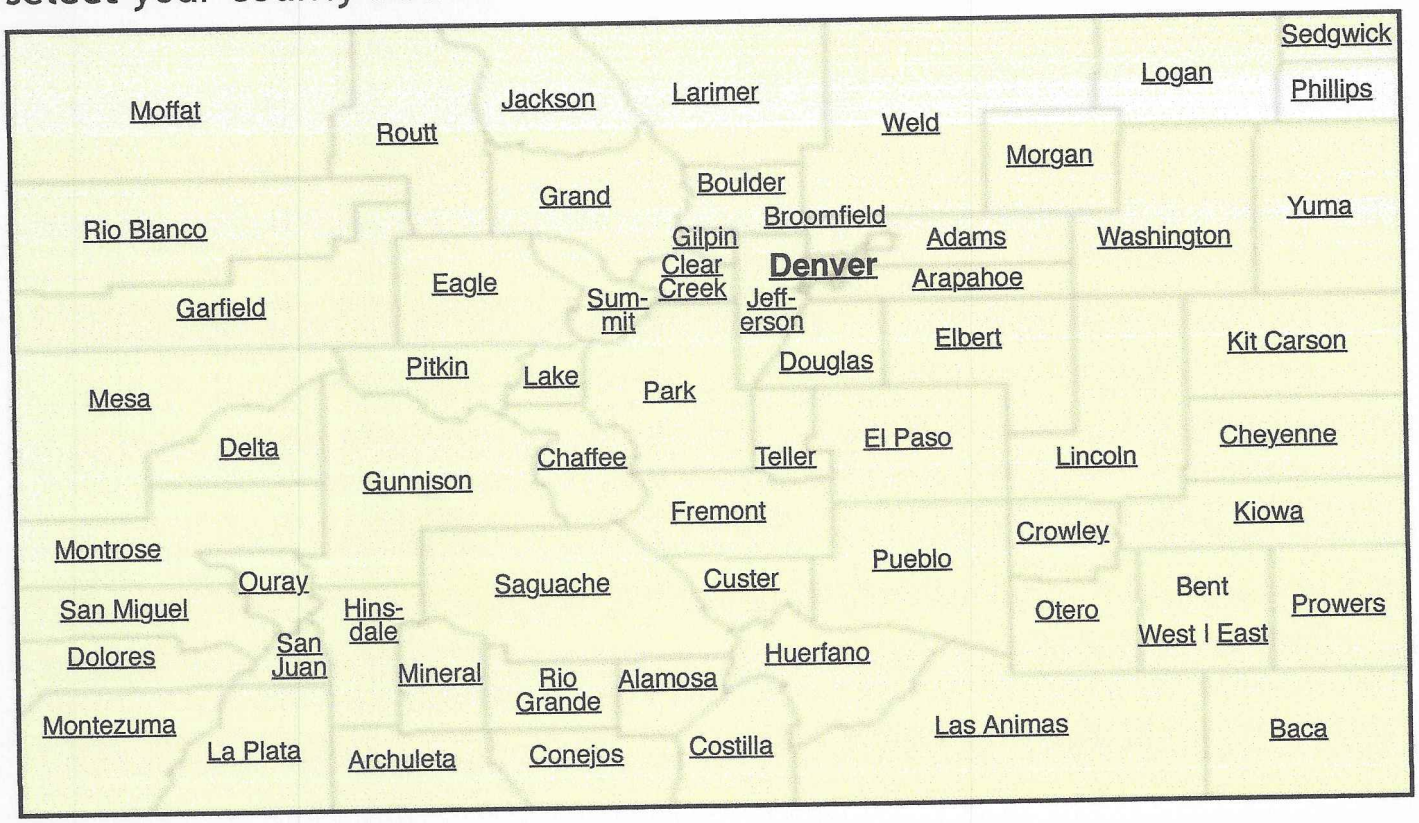
Community Centered Boards

Formal, confidential complaints regarding Community Centered Boards transparency may be submitted directly to the Department of Health Care Policy and Financing via our Community Centered Boards Transparency Complaint Form.

Case Management Services assist a person in accessing necessary services and supports to meet his or her needs. Services include intake, eligibility determination, service plan development, arrangement for services, delivery of services, service and support coordination, monitoring, any safeguards necessary to prevent conflict of interest between case management and direct service provision, and termination and discharge from services.

CCBs By County Printable Map - July 2020

To find the Community Centered Board (CCB) Agency in your area, select your county below:



Adams	
North Metro Community Services 1185 W. 124th Ave. Westminster CO 80234	**Main Phone:** 303-252-7199 or 303-457-1001

Alamosa / Conejos/ Costilla / Mineral / Rio Grande / Saguache	
Blue Peaks Developmental Services 703 Fourth Street Alamosa, CO 81101	**Main Phone:** 719-589-5135

Arapahoe / Douglas / City of Aurora	
Developmental Pathways 325 Inverness Drive South Englewood, CO 80112	**Main Phone:** 303-360-6600

Archuleta / Dolores / La Plata / Montezuma / San Juan	
Community Connections 281 Sawyer Drive #200 Durango, CO 81303	**Main Phone:** 970-259-2464

Back to Top

Baca / Bent / Kiowa / Prowers	
Southeastern Developmental Services 1111 South Fourth Street Lamar, CO 81052	**Main Phone:** 719-336-3244

Boulder / Broomfield	
Imagine! 1400 Dixon Avenue Lafayette, CO 80026	Main Phone: 303-665-7789

Back to Top

Chaffee / Custer / Fremont	
Starpoint 700 South 8th Street Canon City, CO 80212	Main Phone: 719-275-1616

Cheyenne / Elbert / Kit Carson / Lincoln / Logan / Morgan / Phillips / Sedgwick / Washington / Yuma	
Eastern Colorado Services 617 South 10th Avenue Sterling, CO 80751	Main Phone: 970-522-7121

Clear Creek / Gilpin / Jefferson / Summit	
Developmental Disabilities Resource Center 11177 W. 8th Avenue Lakewood, CO 80215	Main Phone: 303-233-3363

Crowley / Otero / Bent	
Inspiration Field 612 Adams Avenue La Junta, CO 81050	Main Phone: 719-384-8741

Delta / Gunnison / Hinsdale / Montrose / Ouray / San Miguel	

Community Options 336 South 10th Street PO Box 31 Montrose, CO 81402	**Main Phone:** 970-249-1412

Denver	
Rocky Mountain Human Services 9900 E. Iliff Avenue Denver, CO 80231	**Main Phone:** 303-636-5600

Eagle / Garfield / Lake / Pitkin	
Mountain Valley Developmental Services 700 Mount Sopris Drive Glenwood Springs, CO 81601	**Main Phone:** 970-945-2306

El Paso / Park / Teller	
The Resource Exchange 6385 Corporate Drive, Suite 301 Colorado Springs, CO 80919	**Main Phone:** 719-380-1100

Back to Top

Grand / Jackson / Moffat / Rio Blanco / Routt	
Horizon Specialized Services 405 Oak Street Steamboat Springs, CO 80477	**Main Phone:** 970-879-4466

Huerfano / Las Animas

Southern Colorado Developmental Services 1205 Congress Drive PO Box 781 Trinidad, CO 81082	**Main Phone:** 719-846-4409

Larimer

Foothills Gateway 301 Skyway Drive Fort Collins, CO 80525	**Main Phone:** 970-226-2345

Mesa

Strive 790 Wellington Avenue Grand Junction, CO 81501	**Main Phone:** 970-243-3702

Back to Top

Pueblo

Colorado Bluesky Enterprises 115 West 2nd Street Pueblo, CO 81003	**Main Phone:** 719-546-0572

Weld

Envision 1050 37th Street PO Box 200069 Evans, CO 80620	**Main Phone:** 970-339-5360

COLORADO
Department of Health Care Policy & Financing

Programs for Individuals with Physical or Developmental Disabilities

Snapshots are **informational only.** You must apply to find out what programs or waivers you qualify for.

If you are not looking to find coverage for an individual with physical or developmental disabilities, please choose another category. Click on the program names below to learn more.

Do you have Physical or Intellectual/Developmental Disabilities?

Do you need Behavioral Health Services?

Are you an American Indian or Alaska Native?

Are you a Veteran?

Programs For Children with Disabilities

- Brain Injury Waiver (BI)
- Children With Autism Waiver (CWA)
- Children With Life Limiting Illness Waiver (CLLI)
- Children's Extensive Support Waiver (CES)
- Children's Habilitation Residential Program Waiver (CHRP)
- Children's Home and Community-Based Services Waiver (CHCBS)
- Family Support Loan Fund
- Family Support Services Program (FSSP)

Health First Colorado (Colorado's Medicaid Program)

Health First Colorado Buy-In Program for Children with Disabilities

Programs For Adults with Disabilities

Brain Injury Waiver (BI)

Colorado Choice Transitions (CCT)

Colorado Indigent Care Program (CICP)

Community Mental Health Supports Waiver (CMHS)

Developmental Disabilities Waiver (DD)

Elderly, Blind, & Disabled Waiver (EBD)

Family Support Loan Fund

Family Support Services Program (FSSP)

Full Benefit Medicare/Medicaid Enrollees

Health First Colorado (Colorado's Medicaid Program)

Health First Colorado Buy-In Program for Working Adults with Disabilities

Health Insurance Buy-In Program (HIBI)

Participant Directed Programs

Medicare Savings Program - Qualified Medicare Beneficiary (QMB)

Medicare Savings Program - Qualifying Individual (QI-1)

Medicare Savings Program - Qualified Disabled and Working Individual (QDWI)

Medicare Savings Program - Specified Low-Income Medicare Beneficiary (SLMB)

Spinal Cord Injury Waiver (SCI)

Supported Living Services Waiver (SLS)

Waiting Lists and Enrollment

Adams 12 Five Star Schools

The HOPE Initiative

ALL RESOURCES (PROGRAMS/STUDENT-FAMILY-OUTREACH/RESOURCES)

Parenting - Families

Phone
303-362-0990

Address
PO Box 350458, Westminster, CO 80035

Hands on Parenting Education

We believe that every individual has a fundamental right to family life. We believe that the ability to parent should be based on skill level rather than I.Q. It is the mission of The HOPE Initiative to provide individualized education, training, and supports to parents with intellectual disabilities and cognitive limitations in order for them to exercise their right to family life.

Service Critera

At least one parent must have an intellectual disability cognitive limitation, or learning limitation. HOPE does not require IQ testing, since many parents with intellectual disabilities are not identified. We accept any parent who

it appears would benefit from hands on, individualized, repetitive learning environment with information presented in a concrete repetitive way.

PayForIt

safe2tell