

# *Parents with Intellectual Disability*



## *Who Are Parents with Intellectual Disability?*

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 Disability?*

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 disability, 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 disability 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 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 Disability Capable of Raising Their Children?*

Contrary to what many people think, people with intellectual disability 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 Disability?*

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 disability
- 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 disability. Half of these adults had intellectual disability themselves. They conclude that the children's destinies are not fixed by having a mother or father with intellectual disability. 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.
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- 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

March, 2011





## The HOPE Initiative

Parenting - Families

### Phone

303-362-0990

### Address

PO Box 350458, Westminster, CO 80035

ALL RESOURCES  
(PROGRAMS/STU  
DENT-FAMILY-  
OUTREACH/RESO  
URCES)

## 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 Criteria

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.



COLORADO DEPARTMENT OF HEALTH CARE POLICY AND FINANCE,  
DIVISION FOR INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (DIDD)  
and the COMMUNITY CENTERED BOARD SYSTEM (CCB)

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Colorado Division for Intellectual and Developmental Disabilities (DIDD)  
1570 Grant Street  
Denver, CO 80203  
(303) 866-2993

**Purpose:**

State agency responsible for services for people who have a developmental disability with an IQ  $\leq$  70 and adaptive behavior needs. The Division for Developmental Disabilities contracts with private not-for-profit agencies in local communities who are designated as community centered boards and who determine eligibility and provide services, either directly or through purchases of services. Each of the community centered boards throughout Colorado has a designated geographical service area. This is the only agency that can provide long-term support.

**Eligibility:**

Based on the presence of a developmental disability.

Appears before age 22.

Creates a substantial handicap which results in decreased general intellectual and adaptive functioning.

Can be the result of mental retardation, cerebral palsy, epilepsy, autism or other neurological conditions.

Services: Offered through organizations designated as CCBs and service agencies throughout the state:

- Family support services
- Case management
- Adult vocational and community day services
- Individual and group residential services
- Transportation
- Community supported living arrangements
- Supported employment services

Application process and timeline: Eligibility must be determined. Waiting lists for services can be very long. Individuals can be added to the wait list at the age of 14 for services which start at 18 or later.

**Local Agency Information:**

Organization \_\_\_\_\_

Contact \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_ Email \_\_\_\_\_



**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

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[www.colorado.gov/hcpf](http://www.colorado.gov/hcpf)





must devise conflict of interest protections and receive approval from the Centers for Medicare & Medicaid Services.<sup>1</sup>

## 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

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|---|---|
| <p>(1) <u>Blue Peaks Developmental Services</u><br/>703 Fourth Street<br/>Alamosa, CO 81101<br/>(719) 589-5135</p> <p>(2) <u>Colorado Bluesky Enterprises</u><br/>115 West 2nd Street<br/>Pueblo, CO 81003<br/>(719) 546-0572</p> <p>(3) <u>Community Connections</u><br/>281 Sawyer Drive, #200<br/>Durango, CO 81303<br/>(970) 259-2464</p> | <p>(11) <u>Imagine!</u><br/>1400 Dixon Avenue<br/>Lafayette, CO 80026<br/>(303) 665-7789</p> <p>(12) <u>Inspiration Field</u><br/>612 Adams Avenue<br/>La Junta, CO 81050<br/>(719) 384-8741</p> <p>(13) <u>Mountain Valley Developmental Services</u><br/>700 Mount Sopris Drive<br/>Glenwood Springs, CO 81602<br/>(970) 945-2306</p> |
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| <p>(4) <u>Community Options</u><br/>336 South 10th Street<br/>Montrose, CO 81402<br/>(970) 249-1412</p> <p>(5) <u>Developmental Disabilities Resource</u><br/><u>Center</u><br/>11177 W. 8th Avenue<br/>Lakewood, CO 80215<br/>(303) 233-3363</p> <p>(6) <u>Developmental Pathways</u><br/>325 Inverness Drive South<br/>Englewood, CO 80112<br/>(303) 360-6600</p> <p>(7) <u>Eastern Colorado Services</u><br/>617 South 10th Ave.<br/>Sterling, CO 80751<br/>(970) 522-7121</p> <p>(8) <u>Envision</u><br/>1050 37th Street<br/>Evans, CO 80620<br/>(970) 339-5360</p> <p>(9) <u>Foothills Gateway</u><br/>301 Skyway Drive<br/>Fort Collins, CO 80525<br/>(970) 226-2345</p> <p>(10) <u>Horizons Specialized Services</u><br/>405 Oak<br/>Steamboat Springs, CO 80477<br/>(970) 879-4466</p> | <p>(14) <u>North Metro Community Services</u><br/>1001 West 124th Ave.<br/>Westminster, CO 80234<br/>(303) 252-7199<br/>or (303) 457-1001</p> <p>(15) <u>Rocky Mountain Human Services</u><br/>9900 E. Iliff Ave.<br/>Denver, CO 80231<br/>(303) 636-5600</p> <p>(16) <u>Southern Colorado Developmental Services</u><br/>1205 Congress Drive<br/>Trinidad, CO 81082<br/>(719) 846-4409</p> <p>(17) <u>Southeastern Developmental Services</u><br/>1111 South Fourth Street<br/>Lamar, CO 81052<br/>(719) 336-3244</p> <p>(18) <u>Starpoint</u><br/>700 South 8th Street<br/>Canon City, CO 81215<br/>(719) 275-1616</p> <p>(19) <u>Strive</u><br/>950 Grand Avenue<br/>Grand Junction, CO 81502<br/>(970) 243-3702</p> <p>(20) <u>The Resource Exchange</u><br/>418 South Weber<br/>Colorado Springs, CO 80903<br/>(719) 380-1100</p> |
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## COLORADO

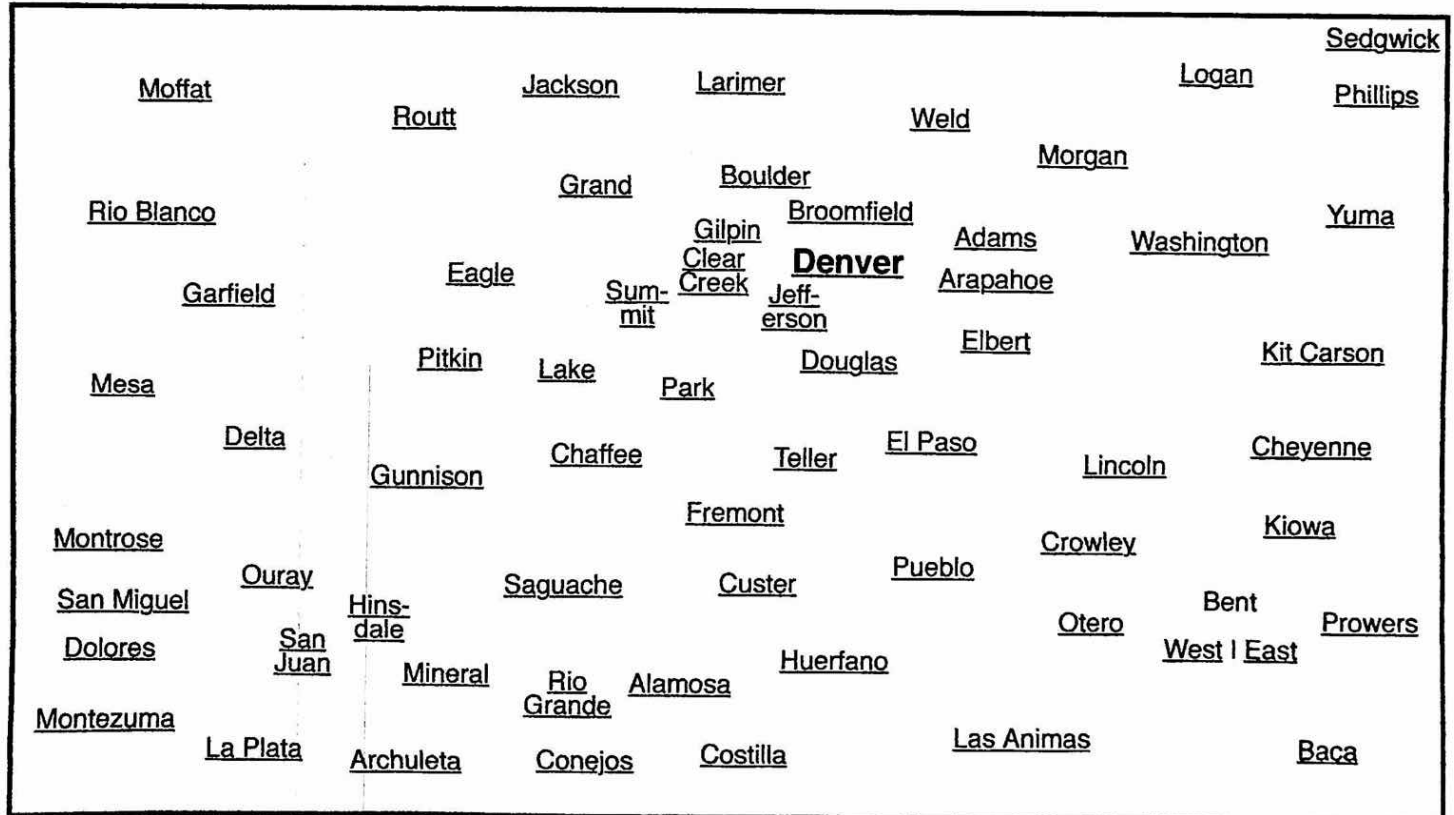
Department of Health Care  
Policy & Financing

# Community Centered Boards

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.

Formal, confidential complaints regarding Community Centered Board transparency may be submitted directly to the Department of Health Care Policy and Financing via our [Community Centered Board Transparency Complaint Form](#).

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



**Adams**North Metro Community Services

1185 W. 124<sup>th</sup> 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

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**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**DenverRocky 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 / TellerThe Resource Exchange

6385 Corporate Drive, Suite 301

Colorado Springs, CO 80919

**Main Phone: 719-380-1100**[Back to Top](#)Grand / Jackson / Moffat / Rio Blanco / RouttHorizon Specialized Services

405 Oak Street

Steamboat Springs, CO 80477

**Main Phone: 970-879-4466**

Huerfano / Las Animas	
<u>Southern Colorado Developmental Services</u> 1205 Congress Drive PO Box 781 Trinidad, CO 81082	Main Phone: 719-846-4409

Larimer	
<u>Foothills Gateway</u> 301 Skyway Drive Fort Collins, CO 80525	Main Phone: 970-226-2345

Mesa	
<u>Strive</u> 950 Grand Avenue Grand Junction, CO 81502	Main Phone: 970-243-3702

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Pueblo	
<u>Colorado Bluesky Enterprises</u> 115 West 2nd Street Pueblo, CO 81003	Main Phone: 719-546-0572

Weld	
<u>Envision</u> 1050 37th Street PO Box 200069 Evans, CO 80620	Main Phone: 970-339-5360