

Changes to Colorado Rules Regarding Definition of Developmental Disabilities and —Effective August 1, 2013

The state of Colorado Human Services Board recently approved amendments to Colorado rules regarding how a determination of a developmental disability is made for eligibility for Developmental Disability (DD) services. (2CCR 503-1, 16.120 and 16.124). The amended rules are consistent with state law (C.R.S. 27-10.5-102 (11) (a) that defines a developmental disability and eligibility for services as substantial impairment of general intellectual functioning OR substantial adaptive behavior limitations. State law has not changed. The rule changes, which took effect August 1, 2013, will allow people who may not meet the intellectual criteria but who have adaptive behavior limitations to be determined eligible for DD services.

The following information addresses some of the commonly asked questions about the amended rules.

1. Why were the rules changed?

Colorado law, enacted in the mid 80's, defines a developmental disability as a disability that is demonstrated by impaired intellectual functioning (generally measured by an IQ of 70 or less) OR substantial adaptive behavior limitations. The disability must occur before the age of 22 and must be related to a neurological condition. (More about this in # 6)

While the law is clear that a developmental disability could be defined using IQ or adaptive behavior limitations, CO rules were not consistent with statute. In 2007, an administrative law judge ruling determined that the rules could be interpreted to include **adaptive behavior** limitations. This ruling prompted a request for a Declaratory Order from CDHS. A final agency decision was issued agreeing that without more specific guidance in rules, it could be interpreted to include adaptive behavior limitations. The Colorado Department of Human Services Division for Developmental Disabilities (CDHS—DDD) enacted emergency rules to define a measurement for adaptive behavior limitations, it also agreed to engage the developmental disability community in a broader discussion.

Two work groups of stakeholders met throughout 2008 and 2009 to review the rules and the law for the purpose of making recommendations to change either or both. The work groups agreed that the definition in law at the time was acceptable but that changes were needed in rules to ensure that a developmental disability could be based on either a substantial intellectual impairment OR substantial limitations in adaptive behavior. Draft rules were submitted to the Colorado Department of Human Services—Division for Developmental Disabilities and circulated for public input in 2011 and 2012.

The State Board of Human Services approved the amended rules which became effective August 1, 2013; people may be determined to have a developmental disability **due to either a substantial intellectual impairment OR substantial limitations in adaptive behavior**. The rule change only applies to applicants five years of age and older.

2. What is meant by “adaptive behavior?”

In general, adaptive behavior means behaviors and skills needed for people to live independently and function safely and appropriately in daily life. Adaptive behavior includes skills such as grooming,

dressing, behaving safely in the home and community, following rules, managing money, making friends, and taking personal responsibility for one's actions.

A person's adaptive functioning can be affected by many factors including age, education, social or cultural background, personality, motivation, family and school expectations, and community setting.

A standardized test must show that the person's adaptive behavior is substantially limited, meaning a score of 70 or below. Such a score represents a significant impairment; fewer than 2% of the population will meet this criterion.

3. What do the rule changes mean for people who want to find out if they are eligible for DD services?

The amended rules mean that some people, who may have previously been determined ineligible because of an IQ score above 70, may be eligible for services if assessments for adaptive behavior indicate a need.

To find out if a person has a developmental disability, application must be made through a Community Centered Board (CCB). Click here <http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251586997819> for a listing of CCB's. Ask for the intake coordinator or whichever department is responsible for eligibility. The CCB is responsible for reviewing the available information to determine if a person meets the requirements:

- Documentation that the onset of the disability occurred prior to the age of 22
- Medical information that demonstrates that the disability is due to "mental retardation or related conditions such as cerebral palsy, epilepsy, autism, or other neurological condition."
- If a person doesn't have a specific diagnosis, a written statement from a licensed medical professional may be used. (See # 6 for more information) **AND**
- The results of a standardized Intellectual Quotient (IQ) assessment showing a score of 70 or below. At least one intellectual assessment must have been completed for applicants between five (5) and eighteen (18) years of age. For individuals over age eighteen (18), if there is only one assessment available, the assessment must have been completed when the individual was at least eighteen (18) and within ten (10) years of the request.
OR
- The results of a standardized assessment for adaptive behavior showing an overall score of 70 or below. The overall (or composite) score is a result of the assessments in several areas of adaptive functioning. The assessment must have been completed within three (3) years of the application date. Limitations in adaptive behavior cannot be attributed **ONLY** to a physical or sensory disability or a diagnosed mental illness.

4. What kinds of assessments are needed?

Colorado has identified the Wechsler Intelligence Scale and the Stanford-Binet Intelligence Scales as the most commonly accepted assessments for IQ. Other comparable norm-referenced, standardized assessments for general intellectual functioning may be used. The test must be administered by a licensed clinical psychologist or a school psychologist.

The state has identified the Vineland Scales of Adaptive Behavior as the most commonly accepted measurement of adaptive behavior. Major skill areas include: Communication, Activities of Daily

Living, and Socialization. The Vineland Scales also measure Motor Skills and Maladaptive Behavior. Other norm referenced assessments of adaptive behavior similar to the Vineland may be used. These assessments must be administered by a qualified professional. The Vineland Scales do not require a psychologist to be the administrator. The rules do specify that a 90 percent confidence interval should be used when reporting results. The manual for the Vineland Scales recommends this interval for most users. The confidence interval varies by age and domain being tested. For the Vineland Scales composite score this means that the true score may be plus or minus four to seven points higher or lower than the obtained score.

You may also consult your Primary Care Physician to refer you to professionals qualified to administer an IQ test or adaptive behavior assessment.

5. Who pays for the assessments?

In Colorado, a person (or guardian) seeking a determination of developmental disability under Colorado statute must present required documentation (see #3) to the CCB within 90 days of application.

School and medical records often provide evidence of the needed assessments. Schools sometimes administer IQ or adaptive behavior assessments to determine educational supports that students need.

In other cases, it may be necessary to have a new assessment. Persons eligible for Medicaid may be able to access assessments from qualified professionals who accept Medicaid. Families or guardians of people under the age of 20 who are enrolled in the state Medicaid plan should consult their Medicaid case manager to see if the assessments can be covered through Early Periodic Screening, Diagnosis and Treatment (EPSDT) services. Individuals receiving Medicaid who are over 20 years of age, who can demonstrate onset before 22 years of age may be able to receive payment under Medicaid.

If there is no documentation to demonstrate either an intellectual impairment (IQ below 70) or a substantial adaptive behavior limitation, then the applicant (or guardian) may have to pay for the assessment in order to meet the 90 day requirement to present documentation. A physician, physician's assistant or nurse practitioner must request the assessment and stipulate that it is a medically necessary service in order for Medicaid to pay. The medical necessity is the fact that the assessments are essential to determine the types of services and supports a person needs.

Some private insurance plans may cover these assessments.

6. What is meant by a "neurological condition?"

Colorado law requires that a person's developmental disability be related to some type of neurological condition. Neurological conditions are those affecting the brain, spinal cord, nerves or muscles. Some neurological conditions are difficult to define but licensed medical professionals can affirm that the impairment is the result of a nonspecific neurological condition. Consultation with a neurologist is not required.

7. What do the rule changes mean for someone who was determined NOT to have a developmental disability because of an IQ of 70 or higher but who may have substantial adaptive behavior limitations?

Anyone may re-apply for a determination of a developmental disability using the results of an adaptive behavior assessment. The rule clarification will have an impact for people with autism spectrum disorder who may have previously been denied eligibility for services and for others who have substantial adaptive skill limitations but with higher IQs.

8. If a person is now determined eligible for DD services because of adaptive behavior assessment, will they be able to access services?

Not necessarily. Colorado has waiting lists for most all services for people with an Intellectual or a Developmental Disability, these services include Family Supports Services Program (FSSP) as well as the Medicaid waivers: Children with Autism, Children's Extensive Support (CES), HCBS DD (comprehensive 24-7 support), and Supported Living Services (SLS). It is more than likely that a person who has not previously been determined eligible for services will be placed on a waiting list until a resource is available or if conditions change that make emergency placement necessary.

We strongly encourage people to move forward with applying for an eligibility determination. It is critical that we have data about the scope of the true number of people eligible for services. In 2013, the state budget authorized a significant number of new resources for the CES waiver and the waiting period for that level of support may not be as lengthy as in past years.

Additionally, eligibility determination is needed to access ANY services available for persons with IDD including Family Support. Some CCBs also provide non-Medicaid waiver support for people on the Waiting List.

9. What is the difference between being determined to have a developmental disability and being eligible for a specific service?

A person must first be determined to have a developmental disability as explained in # 3 and then must meet the criteria for a specific program. Having a developmental disability means that a person has a substantial intellectual impairment or substantial limitations in adaptive behavior and must still meet the requirements for programs such as age, living arrangements, or level of need.

For example, people under the age of 18 would not be eligible for the HSBS-DD waiver or the Supported Living Services waiver and an adult with an Autism Spectrum Disorder would not be eligible for the Children with Autism waiver.

10. Are there any other changes in the law or in CO rules coming up that could affect the definition of developmental disability or eligibility for services?

The current Colorado law was enacted more than 25 years ago and reflected the professional and legal thinking of the time. Since then, many things have changed—not the least of which—are changes to the language we use to describe a developmental disability. In the past two years, the term “mental retardation” has been eliminated from many federal laws and rules and from professional literature. The term that has been substituted is Intellectual Disability. We hope to make that change in CO laws in the very near future.

Additionally, many advocates in the disability community would prefer to have eligibility determination processes and systems of support designed around the functional needs of individuals not their diagnoses. Such a profound shift takes time.

11. Where can I get more information?

If you have additional questions, contact:

- a local chapter of The Arc or The Arc of CO if you live in an area not served by a local chapter <http://www.thearcofco.org/about-the-arc/colorado-arc-chapters>, or
- The Legal Center for People with Disabilities <http://www.thelegalcenter.org/> or
- the CCB in your community: <http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251586997819>

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