

What is a developmental disability?

by Jeff Konrade-Helm

What is a developmental disability? What does it mean to have a developmental disability?

These are the questions the state Division for Developmental Disabilities (DDD) is asking.

The definition of developmental disability (DD) will, in a way, define the division and its purpose for the foreseeable future. More importantly, however, is that the answers to these questions now will likely determine the future of Colorado's DD policies for a very long time.

On Monday September 8, DDD is convening its Developmental Disability Definition Task Force to begin discussing and researching this issue to help inform and help shape Colorado's future policy in this area. At this point, the Division intends to conclude this effort by mid-December of this year.

While not specifically stated by the Division, the timing of developing the Task Force's recommendations by the end of the year would likely allow the state to pursue any necessary changes to legislation in the 2009 session of the General Assembly.

Background:

Since 1908, the American Association on Mental Retardation (AAMR) (now American Association on Intellectual and Developmental Disabilities (AAIDD)), has published a definition for mental retardation and now intellectual and developmental disabilities in its landmark publication: "Mental Retardation: Definition, Classification, and Systems of Supports which is currently in its 10th revision (2002). Over the past century, this book has been a guide for providing services to individuals with mental retardation and developmental disabilities throughout the United States and much of the rest of the world.

In the 1970s, the United States saw a movement away from traditional views of "mental retardation" (as defined almost entirely by a low IQ score) and started to take a more inclusive or expansive view toward its definition to include those with more adaptive behavioral (functional) challenges who may not have fit the classic definition for mental retardation.

In 1985, the Colorado General Assembly passed a law to reflect this societal change (see Colorado's DD Definition) and state agencies created rules to implement the new law.

In 1995, the Department of Human Services sought to clarify/change its (then) existing rule to what has been and will be in effect until October 1, 2008. By most accounts, at that time, it was a more restrictive interpretation of the 1985 statute.

Over the past 13 years, there has been considerable disagreement over the interpretation of the 1995 rule resulting in numerous questionable service terminations and subsequent appeals as well as discrepancy in final appeal decisions by administrative law judges.

In March 2008, one of Colorado's 20 Community Centered Boards (CCBs) received a Declaratory Order they had sought from an Administrative Law Judge asking what should be the correct interpretation of the rule (See Declaratory Order). The Declaratory Order in one way gave a broader interpretation of the rule by allowing for a higher IQ score; but in another way, it more closely tied Colorado's definition for developmental disability to IQ scores. The Declaratory Order also encouraged the Division to seek a rule change from the Human Services Board (HSB).

On August 1, 2008, the HSB voted to change the rule defining developmental disabilities in Colorado tying it more closely to intellectual (not functional) ability and used substantially lower IQ scores effectively restricting who may qualify for DD services and supports even further.

< Additional Resource: http://www.aaidd.org/Policies/faq_intellectual_disability.shtml >

Despite anything you may have heard, at this point there is nothing on the table. That is a good thing because it also means that at this time, nothing has been removed from the table for consideration. Because of the Division's commitment to addressing this issue in this way, Coloradoans have a unique opportunity to deliberate over and shape DD policy in Colorado from a fresh perspective. Instead of the very minor, gradual and, in many cases, accidental changes, we have an opportunity to influence the policy from scratch if that is what we want to do. I'm not saying we should scrap everything and start over. I'm just trying to stress that anything is possible.

But the reality is that not EVERYTHING is possible.

No matter what happens with Amendment 51 (DD funding) in the election on November 11, there will always be limited resources available and there will be some very hard decisions to make. The recommendation that comes out of the DDD Task Force will likely be based on meeting the needs for most but not all individuals whom members of the committee would like to provide state services. That is just the harsh reality.

Some have suggested that Colorado adopt the federal definition for developmental disabilities or something similar that Colorado law specifically excludes at this time (see Federal DD Definition).

That makes it even more important for this committee to be aware of as many issues of this nature as possible. We need to hear the stories of children and adults who have suffered because they didn't receive services. We need to hear about the fears families may have for what the future may hold for their loved ones.

But that's not all; we need to hear the success stories, too. If you or a family member has been helped by the DD system and is living a fulfilling and productive life, we need to hear that, too.

And we're also going to need to hear that you are willing to tell the legislature your stories, too. Because no matter how well-intentioned, this group can only recommend a course of action but the General Assembly and the Governor will *decide* the course of action that will become Colorado's future DD policy.

I don't know how the DDD Task Force is going to receive testimony. The meetings it holds will have to be open to the public by law. But at the time of this writing, there has been no announcement of how it will engage in such a public discourse.

I will continue to keep readers updated in ***The Source*** and on the *autism-co*, *p2p-co* and *pad-co* listserves (among others). If you do not subscribe to one of these lists yet, please do it now to be able to keep up with the latest developments on this and other important issues to the Developmental Disability community.



Jeff Konrade-Helm, advocate
Individual Disability and
Education Advocacy Services, LLC
9017 Grove Street
Westminster, CO 80031-3362
720-275-0053
720-379-3977_fax
jeff@SpEd-HELP.com | www.SpEd-HELP.com