



# Colorado Cross-Disability Coalition

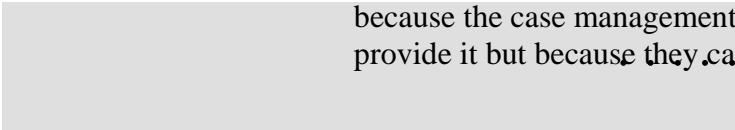
February 1, 2010

Comments on the DD Definition:

The Colorado Cross Disability Coalition is pleased to be able to submit comments on this important rule. As the only organization in Colorado that is statewide and run by people with disabilities composed of people with all types of disabilities we have a unique perspective on this issue. On one side, there is the urge to support as broad an interpretation as possible in the interest of serving as many as possible in the system that is without a doubt the most generous and most flexible when run as intended. On the other side there is the urge to narrow the definition to protect those who are currently served, to prevent the system from feeling even more overwhelmed, and to serve those considered most in need or most severely disabled. Put this in the context of a system that is overwhelmed, in flux and stressed anyway and in the context of a desire to make all waivers more similar and you have a perfect conflict with no easy answer.

For any HCBS waiver one must meet the financial criteria, the level of care required to receive services in a facility (ULTC 100.2) and the target criteria for that specific waiver. For a DD waiver that means meeting the state definition of developmental disability, for the MI waiver that means having one of a list of diagnosis for mental illness, for the BI waiver that means being in the hospital where you received your brain injury (for the initial approval) and continuing to meet that very high standard for continuing review. The only waiver where one simply has to be disabled, blind or elderly is the EBD waiver. The attached document compares the various waiver programs, quality standards and levels of oversight. While there is a move to make the waivers more similar there are significant differences at this time. The main differences include but are not limited to

- ✓ No program in the EBD for people with any sort of difficult behavior
- ✓ Only residential option in EBD is assisted living which provides minimal support and usually no supervision. Assisted living facilities can discharge for any reason at any time. The few assisted living facilities that do work with people with difficult behavior are under scrutiny for violation of the IMD rule that does not permit grouping of people with “mental diseases” in facilities using Medicaid dollars.
- ✓ No human rights committees overseeing issues like use of psychotropic drugs
- ✓ Extremely limited case management in all non-DD waivers. This is not because the case management agencies (Single Entry Point) do not want to provide it but because they cannot provide it. . . . .



If someone is found ineligible for the DD waivers they will then look towards the other waivers. Assuming that they will qualify under level of care (which would be required for the DD waivers) they will likely end up in the MI or EBD waiver. If the person has a family member available to coordinate services and if the person has a someone to act as the authorized representative under the Consumer Directed Attendant Support Services (CDASS) program and the SEP provides enough hours of personal care (which is difficult under the current definitions if the main issues are psychiatric, cognitive or supervision related) then they can probably make it work. For reasons outlined below it is not feasible to consider the typical HCBS providers for this population. However, the respite process in the non-DD systems make using respite in a community based sense close to impossible, particularly if the client is already on CDASS. In addition to a coding nightmare, there is great confusion and the only agencies allowed to do respite are HCBS personal care agencies. These companies are allowed to hire people who have significant criminal histories, often do not speak English and have minimal training. Pairing typical personal care provider agencies in the EBD world with people who have any sort of issue with behavior or communication is a recipe for disaster. There is no real way in the non DD waivers to access things like technology, at least not without going to hearing.

So that leaves the DD system as the better system to serve these folks—mostly people with some form of autism but will also include people with dual disabilities such as childhood onset mental illness coupled with severe learning disabilities. We have many people who have low IQ (70-90), coupled with other issues including but not limited to mental illness, medical illnesses (usually that could be treated if there were some supports in place), and history of chaotic living situations. These are the folks who fall through all of the cracks in the system. Someone with a **very** low IQ will not be left to fend for his or herself. Once the IQ gets to a certain level, however, they are left on their own without the intellectual or emotional abilities to survive. Often these folks develop maladaptive coping mechanisms from their years of being left without adequate supports. If by some miracle we can get these folks eligible, they are usually terminated from services due to behavior, not showing up for appointments, and other “failure to comply” type issues. They almost never get the help they need learning new coping mechanisms or support with essential life functions like communication, accessing resources, problem solving, managing relationships, etc.

The bottom line is that we have a social question of not only resources but asking what categories of folks should we service and what does each category deserve. It is certainly easier to blame the folks with higher IQ’s who look as if they are able to care for themselves. It is easy to tell them to just suck it up and get a job. It is easy to tell them, just pay attention and don’t ignore your mail, learn from your mistakes and don’t let strangers come live in your apartment, etc. However, they are often no more able to do these tasks without supports, than a paralyzed person is able to climb a flight of stairs.

Those who are concerned about the capacity of the systems have good cause to be concerned. There is not capacity and the folks in this new category are people who may not fit well in existing services. They don't fit well in the existing EBD system either. Nevertheless *they are no less deserving of services than people who are born with lower IQs or those whose parents are savvy* enough to keep them in the better system. Rather than convening more work groups to discuss the definition, why not use the energy and resources to convene a workgroup to determine how to best serve this new and emerging population?

I would also argue that while the expanded definition would definitely strain existing resources in some cases resources could be diverted from other systems. CCDC is currently working with a woman who has been living at Fort Logan for more than two years at a cost of approximately \$500 a day. She fits in this group—was determined ineligible by her CCB but a consulting CCB said she should be eligible. Requests for reasonable modification of policy have been delayed by HCPF and ignored by DDD making this a matter that may require litigation. This is not the only such case where the definition change would help not only divert resources but would cause a substantial savings. Until an analysis of that sort is done one should not assume that there are insufficient resources. Have we studied how many of the long term inmates at Fort Logan and Pueblo have an IQ below 85? How many in our prison system would qualify under this definition and would they not have been in that system had they had appropriate supports? What about our long term clients on the Aid to the Needy Disabled program? These are the programs where our members who fit this definition tend to end up in and they are not only inappropriate, in some cases they violate Olmstead because the state is not providing services in the most integrated setting appropriate to their needs.

Finally, this is typical of the system where one CCB says that she should be eligible and another says no. Federal regulations require that services and eligibility be consistent statewide unless we specifically request and receive a waiver of that requirement. Colorado has no such waiver for the DD system.

**For all of the reasons cited above and with due consideration to the issues of resource and system capacity CCDC supports keeping the definition consistent with the declaratory order.** However CCDC also supports the development of a workgroup to determine what is the best way to serve this emerging population. Perhaps a new waiver that is a hybrid between the EBD and DD waivers needs to be developed that has more supervision than the EBD or MI system but less than the DD system. Perhaps a revised version of SLS with the flexibility and case management but fewer benefits and lower cap would fit? The DRA expanded the existing ability of the states to design waiver programs that fit the needs of the specific population. Without study we don't know that this population needs the richness of benefit offered to the entire DD community. Maybe they do but until we take a honest and critical look at this we will not know. We have the flexibility to design different systems to fit the needs of different populations.

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CCDC would encourage DDD to include in any such workgroup people who are in this population—people living with IQ's between 70 and 85. This should include people with diagnosis on the autism spectrum but should also include people with psychiatric and medical diagnosis and people on AND. These folks often cannot get on SSI because they do not have the capability to follow the complex SSA instructions and because they are not identified as DD so receive no help from any system. This workgroup should also include people from mental health and from Centers for Independent Living and county social services as these are the folks most often dealing with this group. CCDC would also like to be included. The group should of course include others in the DD system including PADCO, P2P and Empower.

Finally, as a matter of basic fairness and due process whatever you decide you should grandfather people. If you go with a more narrow definition you should not re-assess people who have been assessed under the declaratory order and throw them out. This is unfair by any standard.

Sincerely,

Julie Reiskin  
Executive Director

**Program quality standard comparison document to follow:**

*Nothing about us without us---ever*

Program Quality Standard Comparison

Issue	DD	EBD/MI/BI
Case manager training	Responsibility of CCB BA at least 5 years in DD field combination of education and experience appropriate to position; Must have organized orientation and training program <i>(DDD regulations, DDD survey tool, DD statute outlines some)</i>	Responsibility of SEP-1. Background information on the development and implementation of the Single Entry Point system 2. Mission, goals, and objectives of the Single Entry Point system 3. Regulatory requirements and changes or modifications in federal and state programs; 4. Contracting guidelines, quality assurance mechanisms, and certification requirements; and 5. Federal and state requirements for the Single Entry Point agency. <i>(Volume 8)</i>
Case manager duties	Eligibility determination, Process to select service providers for each client, coordinate team that does care plan, implement care plan, develop services if none exist and assure client choice in service providers, resolve disputes among clients and providers (Legislation) *SLS clients expected to pay separately for service coordination, e.g. finding providers, etc.	Establish eligibility, determine care plan, arrange for services care plan, assure choice of provider/program, do prior authorizations, call quarterly at visit 2 x year to determine if services are working, resolve disputes between clients and providers. SEP supposed to do resource development but this not monitored or enforced. (Legislation) *No service coordination available outside of what case managers can do. *Expectation that clients who have families will have family members do service coordination
Case manager service oversight	CCB	SEP
Care Plan Development	IP-developed by a team, team given information to make appropriate plan, person centered, focus on strengths, preferences included, how services will meet specific needs <i>(DDD survey tool and 10)</i>	Developed by case manager, has one section on strengths, client makes one goal statement, only identifies waiver and related services <i>(ULTC and related guidance)</i>
Care Plan Requirements	Signed by client and reviewed annually, indicates choice of provider and understanding of complaint process <i>(DDD survey tool and legislation)</i>	Signed by client and reviewed annually. Indicates choice of provider and understanding of complaint process <i>(Care plan on line with ULTC)</i>
Complaints	Clients have mediation option	Client can file formal complaint

	<p>Case manager required to intervene if problem with provider, client dumping prohibited or if it happens CCB must find a new provider. Client can complain to DDD about CCB <i>(DDD survey tool, legislative requirement for system and direct advocacy experience)</i></p>	<p>client can complain to HCPF about SEP. Client complaints about providers do not have assurance that client will be able to continue services. Regulation does say that providers must document how they tried to resolve problem prior to discharge but no requirement that documentation show reasonable efforts. <i>(Volume 8 and direct advocacy experience)</i></p>
Abuse reporting	<p>All levels of system responsible-either to law enforcement or DPHE, <i>(DDD regulations)</i> Law gives clients right to be free from abuse and excessive medications</p>	<p>If in assisted living per <i>DPHE regulations</i>; case managers to report suspected abuse to APS <i>(HCPF regulations)</i></p>
Occurrence reporting	<p>All providers must report occurrences <i>(DDD and DPHE regulations)</i> Group home occurrences on internet No occurrence reporting for community based services but DDD addresses in regulations and survey tool.</p>	<p>Assisted living complies with <i>DPHE regulations</i> Assisted living occurrences on internet No occurrence reporting for community based services</p>
Living environment	<p>Standards for residential facilities monitored by DPHE case manager also must assess home <i>(DDD and DPHE regulations for Comp and DD regulations and survey tool for SLS)</i> <i>Formal connection with law enforcement required in legislation</i></p>	<p>Standards for assisted living and BI supported living monitored by DPHE. Case manager assesses home for home modifications, assessment case manager notes home environment problem but only option is to call APS –No formal connection between APS law enforcement and SEP <i>(DPHE and HCPF regulations)</i></p>
Selection of provider agency	<p>CCB selects and sometimes develops, CCB may also be provider agency, case manager may pair appropriate client with agency and may refuse to refer to agencies that have quality problems <i>(legislation)</i></p>	<p>SEP is not allowed to be provider agency unless they have a waiver (very rare and only in most rural areas) Any willing provider and SEP must rotate referrals unless client specifically chooses agency. SEP not allowed to cease referrals to problem agency <i>(practice, this last issue is not addressed in regulations)</i></p>
Direct care staff selection	<p>Per agency</p>	<p>Per agency</p>
Direct care staff training requirement	<p>DD statute outlines that there must be training, DD survey tool requires, DPHE requires agency to establish training as follows: orientation for all new</p>	<p>20 hours for unskilled or pass test; C.N.A. per nurse practice for skilled <i>(Volume 8)</i></p>

	<p>employees prior to unsupervised contact with Residents; job training specific to the needs of the residents for each staff person. Such training shall</p> <p>Be related to the health, safety and services for the resident. Such training shall include, But not be limited to, resident rights, individual resident's care issues, abuse and neglect Prevention, and the community residential home's policies and procedures to be completed</p> <p>In the first ninety (90) days of employment.</p> <p>DDD regulations also address training</p>	
<p>Oversight of direct care staff</p>	<p>Per agency, some regs in DPHE, mostly in regulations <i>DD act gives DDD authority set specific requirements, the requirements in DDD rules and DDD quality survey tool</i></p> <p><i>Regulations speak more to skill set and process and outcomes and does not direct specific topics for training outside of DPHE process</i></p>	<p>Orientation of staff to agency policies and procedures.</p> <p>B. Arrangement and documentation of training.</p> <p>C. Informing staff of policies concerning advance directives and emergency procedures.</p> <p>D. Oversight of scheduling, and notification to clients of change or close communication with scheduling staff.</p> <p>E. Written assignment of duties on a client-specific basis.</p> <p>F. Meetings and conferences with staff as necessary.</p> <p>G. Supervisory visits to client's homes at least every three months, or more often as necessary, for problem resolution, skills validation of staff, client-specific or procedure-specific training of staff, observation of client's condition and care, and assessment of client's satisfaction with services. At least one of the assigned personal care staff must be present at supervisory visits at least once every three months.</p> <p>H. Investigation of complaints and critical incidents.</p> <p>I. Counseling with staff on</p>

		<p>difficult cases, and potentially dangerous situations.</p> <p>J. Communication with the cas managers, the physician, and other providers on the care plan, as necessary to assure appropriate and effective care.</p> <p>K. Oversight of record keeping by staff. (Volume 8)</p>
Termination of provider agency	Per CCB for cause (Legislation and DDD regulations)	For specific reasons outlined in volume 8 related to improper billing or improper administrative issues
Direct care staff background checks	Required (Legislation and regulations)	Not required (Lack of legislation-attempts to create this have failed several times over the years due to cost concerns)
Medication reminder	DD medication training protocols-in DD regulations, statute and NPA	Can formally only be done by electronic system or a nurse, unskilled person can give reminder but cannot assist client with actually taking medication. Rules are conflicting regarding ability of client (nurse practice act and informal directives by DPHE)
Challenging behavior	<p>Providers are expected to deal with disability (and even non-disability) related behaviors. Providers get more money for taking difficult clients. If provider refuses to serve CCB responsible for getting alternative providers in Comprehensive program but always in SLS. Law requires specialized training and prohibits restraints (27-10, D survey tool and direct advocacy experience)</p> <p>Clients labeled sex offenders treated differently per state law</p>	<p>If client cannot behave in way that pleases staff client likely not to receive services. There is no accommodation for disability related behaviors. Some assisted living or supported living facilities may deal with some behaviors but provider has sole discretion as to what behaviors they will or will not tolerate. No specialization or ability to pay more for difficult clients.</p> <p>(Practice direct advocacy experience) Regulations in Volume 8 state that provider must document what was done resolve the problem that led to discontinuation of services—if provider documents efforts are not evaluated.</p>
Support for employment	Seems to be emphasis on working but more in theory than in practice—however there is definite obligation for client to have something to do during	None-assume if client is working client should not be getting Medicaid supports. Only exceptions are for clients that can independently negotiate SSA

	<p>day. System provides transportation for whatever client does during day and there is no penalty for client working. Services must not duplicate DVR-expectation to coordinate with DVR. (Various documents survey tool)</p>	<p>work incentive programs like 1619. In MH system clients encouraged to work and often lose Medicaid as result because of no support to deal with SSA and reporting. No HCBS support for needs that occur at work. Only option for any support at work is for pure attendant care under the CDAS program, but client will not get extra hours for working. Non-medical transportation cannot be used for anything related to employment. No mention or expectation of coordination with DVR but in some cases this does occur. (Direct advocacy experience-employment not mentioned in formal regulations or documents)</p>
<p>Goals of program</p>	<p>The mission for Colorado's Division for Developmental Disabilities is to join with others to offer the necessary supports with which all people with developmental disabilities have their rightful chance to: <u>Be included</u> in Colorado community life. Make increasingly <u>responsible choices</u>. Exert greater <u>control</u> over their life circumstances. Establish and maintain <u>relationships</u> and a sense of <u>belonging</u>. Develop and exercise their <u>competencies</u> and <u>talents</u>. Experience personal <u>security</u> and <u>self-respect</u></p> <p><b>DDD homepage</b></p>	<p>To provide cost effective care for eligible low-income clients, to provide alternatives to nursing homes (HCPF home page)</p>
<p>Responsibilities of state</p>	<p>Assuring individuals free from abuse, neglect, mistreatment, protecting rights, accountability for money, assess performance of service providers, quality assurance</p>	<p>Assure rules are followed, assure quality improvement program in place, assure requirements of waiver are met, accountability funds, assure health and safety waiver participants</p>
<p>Oversight of OSDS</p>	<p>On site reviews every three years, plans of correction, more frequent review if necessary, review paper and interview clients and providers. Review also may be done following complaints. Public process, community knows when reviews are occurring and for what programs (DDD survey and quality documents)</p>	<p>On site review every three years, plans of correction, more frequent review if necessary, paper review no interview of clients or providers, state staff follows up on individual complaints but complaints do not trigger full review. Public may find out about this through open records request (Open records review)</p>

Community involvement	Statutory requirement for consumers on board, board meetings open to public, human rights committees must have some autonomy and must get staff support; family support funding also must be run by family council Statutory validation of the right of people receiving services to influence policy. Community notified of CCB reviews and in some cases are involved in reviews <i>(Legislation, direct knowledge receipt of notifications)</i>	Advisory committee is required but no requirement to let client know where and when meetings are; no real enforcement for not having active advisory committee. No notification of when SEP is going to be reviewed and no client involvement in review process <i>(Regulation and legislation requiring advisory committee, direct knowledge and open records verification of process)</i>
State level involvement/consumer advocate involvement	DD policy advisory committee federally funded DD planning council, regular meetings by DD administrator with self advocacy groups, regular meetings with provider groups CCB's highly organized, two associations with paid lobbyists <i>(Direct knowledge and notice of meetings)</i>	SEP agencies formed an association a couple years ago; no paid representation, SEP was terminated in 2001 for sending clients letter telling them to call Governor if they were unhappy with budget cuts, Most SEP are part of county government; This is not a SEP advisory council, consumer or advocate involvement; clients involved in project for example were involved with re-design of tool are currently involved with establishing quality measures, active in systems change activities but not ongoing. Clients can get on interested person list to review rules <i>(direct knowledge and active participation in CBLTC issues)</i>
Funding	Per appropriation –out of overall appropriation for DD services assumption of 15% for case management and administrative, not fee for service. Audits must be done but not sure if there are allowable costs or requirement to spend all money in same year.	SEP gets rate per client found eligible, however costs are also audited and must refund for both unallowable costs and for client over-counted, what is and is not allowable cost changes and audits are often more than year after the fact. <i>(direct knowledge, board member of SEP)</i>
Right to vote	Service agencies must provide assistance to assure right to vote (27-10) CCB must assist with voter registration per Motor Voter- <i>(State and federal legislation)</i>	SEP must assist with voter registration per Motor Voter-notice support for clients to vote\ <i>(Federal legislation)</i>
Right to Medical Care	DD statute outlines specific right to receive medical care, inferring obligation of CCB to make sure client receives such	Clients are entitled to receive state plan benefits under Medicaid, if dual eligible client must negotiate Medicare system

	care-clients still must use state plan benefits under Medicaid <i>(DD statute)</i>	Some SEP case managers assist clients with finding and keeping doctors. No specific obligation to make sure client gets medical care <i>(Direct advocacy experience)</i>
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