

**Addressing Potential Conflicts of  
Interest Arising from the Multiple  
Roles of Colorado's Community  
Centered Boards**

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UNIVERSITY OF  
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**Addressing Potential Conflicts of Interest  
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Community Centered Boards**

**Report to Colorado Department of Human Services  
Division of Developmental Disabilities**

**December 2007**

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# Addressing Potential Conflicts of Interest Arising from the Multiple Roles of Colorado's Community Centered Boards

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## EXECUTIVE SUMMARY

**INTRODUCTION:** The Division of Developmental Services (DDD), within Colorado’s Department of Human Services (the “Department”), administers three 1915(c) Medicaid waiver programs providing home and community based services to persons with developmental disabilities. Central to the delivery of these services is the community centered board (CCB), which plays multiple roles in connecting people to needed services. Over the past two decades, a variety of stakeholders have objected to the role of the CCBs and the potential for conflict of interest. More recently, the Centers for Medicare & Medicaid Services (CMS) and the Office of the State Auditor have inquired about the potential for conflict of interest, with CMS expressing concern that the Department implement more safeguards or alter the role of the CCB. In response to these concerns, DDD asked the Muskie School to assist in defining appropriate safeguards and protections related to potential conflicts of interests arising from the multiple roles of community centered boards.

This document summarizes the information we gathered, our analysis of potential conflicts of interest, and recommendations for addressing opportunities for improvement. The information we gathered is based on document review, input from stakeholders, and a review of practices in four other states. See the APPENDICES for more detail on these sources of information. Our findings are a “point-in-time” view of the policies and infrastructure in place and may not reflect some of the many reforms recently or soon to be implemented in the Department.

**THE ROLES OF THE CCB:** The CCB is at the center of the delivery system. CCBs are private non-profit organizations. Colorado statute designates the CCB as the single entry point to the long-term service and support system for persons with developmental disabilities within a designated service area. Colorado currently contracts with 20 CCBs, with each CCB serving a non-overlapping geographic region of one to ten counties and from 90 to 1,800 individuals each.

The CCB plays a series of central roles:

- *Single Point of Entry (SPOE):* As the SPOE for developmental disability services and supports, the CCB provides information and referral, determines eligibility for services, and manages waiting lists.
- *Case Management Agency:* In this role, the CCB develops individualized plans (IPs), manages the provider selection process, and advocates on behalf of the participant.
- *Organized Health Care Delivery System (or Provider Contractor):* An OHCDS provides a mechanism for reimbursing providers without requiring every provider to enter into a Provider Agreement with the Medicaid agency. As an OHCDS, the CCB is responsible for services provided through subcontracted providers. Providers can benefit from participating in an OHCDS because the CCB can provide a steady cash flow and reduce financial risk connected to unexpected costs. In return, a CCB can set rates for services, permitting the CCB to pay a provider more or less for a service than the CCB receives from Medicaid. Provider agencies are not required to participate in an OHCDS. Providers who do not participate in the OHCDS can still bill through the CCB or can bill Medicaid directly.

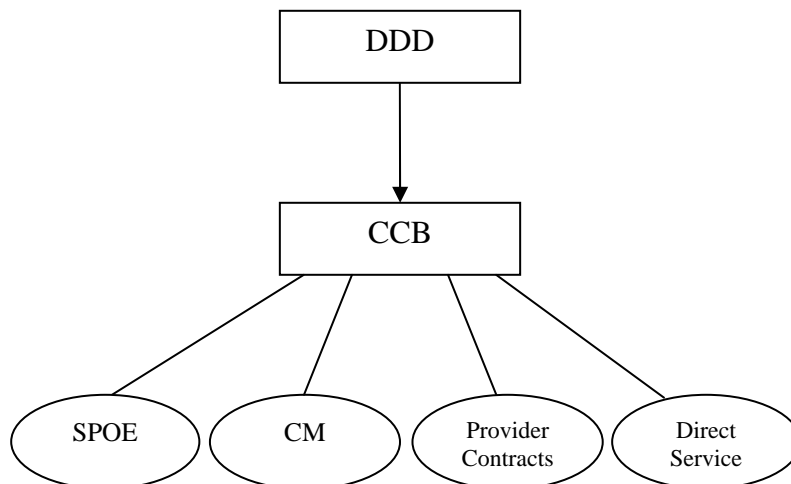
- *Service Provider:* Under statute, the CCB is authorized to act as a direct service provider. Almost all CCBs do provide direct services. The CCB is often the only major service provider in rural areas.

Embedded in these roles are two others:

- *Quality Assurance:* In its capacity as case management agency and as an OHCDS, the CCB plays several quality assurance roles. It monitors IP implementation; it reviews the overall quality of services and supports provided in its service area; it provides access to the complaint system; and it addresses allegations of abuse, mistreatment and neglect,
- *Overseeing Provider Entry:* Recent policy changes have significantly reduced the role of the CCB in overseeing provider entry. Under the new policy, the CCB reviews a service agency’s application for completeness and makes recommendations to DDD for approval or disapproval. As part of its review, the CCB makes a site visit for a new group home or facility-based day program. Once approved to provide a specific service, a provider agency can provide that service in other parts of the State without obtaining further approval.

The chart below depicts an OVERVIEW OF CCB ROLES.

### Overview of CCB’s Roles



**IDENTIFYING CONFLICTS OF INTEREST:** A “conflict of interest” is a “real or seeming incompatibility between one’s private interests and one’s public or fiduciary duties.”<sup>1</sup> A CCB’s *public duty* is defined by statute, regulation and contract. As an agent of the State, the CCB has a

<sup>1</sup> BLACK’S LAW DICTIONARY, Eighth Ed., Thomson West, St Paul, MN (2004).

duty to adhere to and promote the Department's programmatic goals for quality, here defined to be:

Every person meeting the State's eligibility criteria for developmental disability services has equitable access to services that meet individual needs and preferences, are consistent with federal and state law, and are within existing resources.

The CCB's *private interests* are those natural to any business (including any other provider) interested in its own survival in a competitive environment. In particular, the CCB has an interest in maximizing revenue (*e.g.*, by increasing the number of people it serves and the amount it is paid for services), minimizing costs (*e.g.*, minimizing the costs associated with meeting the needs of the people it serves), and improving its competitive position relative to others (*e.g.*, promoting awareness of its service).

The CCB's private interests may be in conflict with its public duty in a variety of ways. For example, to minimize costs, a CCB might have an incentive to avoid serving more costly individuals. Acting on that incentive would be adverse to its duty to promote equitable access to services.

A CCB is not unique in having public duties and private interests in potential conflict. However, because of the multiple roles a CCB plays, there is naturally a greater opportunity for role confusion for a CCB, as well as more opportunity for a CCB to act on its private interests. The table on the next page, A CCB'S OPPORTUNITIES TO ACT ON PRIVATE INTERESTS AS A DIRECT SERVICE PROVIDER, identifies:

- The different roles the CCB plays and the functions performed as part of those roles.
- The CCB's public duty in fulfilling its role.
- The CCB's private interest as a provider that might be in conflict with its duty.
- A listing of some of the ways a CCB could act on its private interests as a service provider (without drawing conclusions about whether it does) when performing its functions in other roles.

Our conclusions about the existence of these opportunities are based on our understanding of how the delivery system works, which we have developed through document review and stakeholder interviews.<sup>2</sup> We have also relied on stakeholder input to get a better understanding of how a conflict might play out, if acted upon by a CCB. For the purpose of this analysis, we do not draw conclusions about whether one or several or all CCBs act upon a conflict, only whether or not a CCB has an incentive and opportunity to do so.

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<sup>2</sup> See the appendices for a listing of REFERENCE DOCUMENTS and SUMMARY OF STAKEHOLDER INPUT.

A CCB'S OPPORTUNITIES TO ACT ON PRIVATE INTERESTS AS A DIRECT SERVICE PROVIDER			
Other CCB Role	CCB's Public Duty as Agent of State	CCB's Private Interest as Provider	Opportunities to Act on Private Interests
Single Entry Point <ul style="list-style-type: none"> <li>▪ <i>I&amp;R</i></li> <li>▪ <i>Eligibility Determination</i></li> <li>▪ <i>Managing Waiting List</i></li> </ul>	<ul style="list-style-type: none"> <li>• Allow choice of provider</li> <li>• Ensure equitable access.</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Minimize costs</li> <li>• Maximize revenue</li> </ul>	<ul style="list-style-type: none"> <li>• Publicize CCB services, but not other service providers to limit access to information about other service providers?</li> <li>• Loosen interpretation of eligibility criteria and level of care to fill available provider slots?</li> <li>• Use eligibility criteria to screen out high cost users?</li> <li>• Move people up on the waiting list who match openings in CCB provider agencies?</li> </ul>
Case Management Agency <ul style="list-style-type: none"> <li>▪ <i>Service Planning</i></li> <li>▪ <i>Provider Selection</i></li> </ul>	<ul style="list-style-type: none"> <li>• Allow choice of provider</li> <li>• Ensure equitable access</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Minimize costs</li> <li>• Maximize revenue</li> </ul>	<ul style="list-style-type: none"> <li>• Develop service plans that favor CCB services?</li> <li>• Use service planning or provider selection process to steer participants toward CCB services in order to fill open service slots?</li> <li>• Use the provider selection process to steer low cost participants to CCB services &amp; high costs participants to other providers?*</li> </ul>
OHCDS	<ul style="list-style-type: none"> <li>• Allow choice of provider</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Maximize revenue</li> </ul>	<ul style="list-style-type: none"> <li>▪ Negotiate low rates with other providers, while offering favorable rates to own provider agencies?*</li> </ul>
Quality Assurance <ul style="list-style-type: none"> <li>▪ <i>Monitoring Services</i></li> <li>▪ <i>Complaints</i></li> <li>▪ <i>Incidents</i></li> </ul>	<ul style="list-style-type: none"> <li>• Assure provider/ service quality</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Minimize costs</li> </ul>	<ul style="list-style-type: none"> <li>• Suppress complaints against CCB?</li> <li>• Suppress incidents connected to CCB?</li> <li>• Less rigorous monitoring of CCB services; resistance to interventions?</li> <li>• Less rigorous advocacy on behalf of participant or family?</li> </ul>

\* With the introduction of standardized rates, the Department expects the opportunity for conflict here to fade.

**EXISTING SAFEGUARDS AND OPPORTUNITIES FOR IMPROVEMENT:** Having identified the range of opportunities a CCB has to act on its private interests as a provider, when performing its other public duties, we reviewed DDD’s existing strategies for mitigating these opportunities.

Our analysis focuses on:

- *Safeguards:* Here defined as a policy, procedure or system that works to deter a CCB from acting contrary to the goals of the program. In evaluating existing safeguards, we assessed whether the safeguard adequately addresses the potential conflict and whether there are barriers to the effectiveness of the safeguard.
- *Discovery Methods:* It is not enough to define a policy or procedure. The Department must design and implement methods for assessing a CCB’s performance against the standards on an ongoing basis. Is there a method to assess the effectiveness of the safeguard in eliminating or reducing the conflict (e.g., oversight method)?
- *Design Features:* Design features include roles, responsibilities and organizational structures that either produce or eliminate the potential for conflict. Changes to program design features may be warranted where no effective safeguards exist, where there are substantial barriers to their effectiveness, or where oversight methods are weak or unavailable to confirm that the safeguard is working.

The formal safeguards we analyzed build on the most obvious and effective safeguard against any conflict: the professional, personal and contractual commitment of the CCB to program goals and the pursuit of quality outcomes for participants. Reports from many stakeholders suggest that this safeguard is present and leads to very positive experiences within the CCB. We also heard that the CCB’s multiple and blurred roles can undermine the effectiveness of this safeguard or confidence that it is working.

In general, our analysis showed a number of opportunities for improvement and proposed a number of enhanced safeguards and some design options. This analysis is documented in the full report, EXISTING SAFEGUARDS AND OPPORTUNITIES FOR IMPROVEMENT.

**CONCLUSIONS AND RECOMMENDATIONS:** To address the opportunities for improvement, we identify a series of strategies for addressing the conflicts of interest inherent to the existing delivery system. The options we propose would impose varying levels of disruption to the existing delivery system, with varying degrees of effectiveness:

- The first set of strategies are the least disruptive to the existing delivery system but are also the least likely to effectively safeguard against conflicts of interest. This set of recommendations assumes the CCB continues to play the same roles it does currently but would minimize the opportunity for acting on a conflict of interest by imposing standards for requiring greater consistency and accountability.
- The second set of strategies considers a range of design options, separating out some of the roles currently fulfilled by the CCB. In all of these options, at a minimum, the direct service role is separated from the case management and single entry point role. These design options impose different levels of disruption on the system but are also the most likely to be effective at minimizing the potential for a conflict of interest.



- The third set of strategies is not directly related to the multiple roles played by the CCB but have a significant impact on the quality of services. These issues were surfaced in our discussion with stakeholders and information we gathered from other states. We include them here because of their potential benefit to the Department.

Moving forward with any of these strategies must involve careful consideration of the costs and consequences relative to the expected benefit. We heard the same theme from many families: “Do not fix a problem for someone else by creating problems for me. Do not add an extra administrative cost that means less money for services. If it’s not broke, don’t fix it!”

While the Department may be reluctant to disrupt what is working well, it may find compelling reasons to do so. We suggest a balancing test, where any remedy for a conflict is weighed against its cost and disruption to the system. If the scope and severity of a problem is minor, ideally the cost and consequence of the remedy should be minor. However, if the problem has a significant negative impact on quality, the cost of the remedy will have more justification. Weighing the costs and benefits of the status quo against a proposed remedy involves a range of competing priorities. The Department also needs to balance local control (familiarity and responsiveness to the local community) and state level interests in equity, minimizing inconsistent and duplicative burden on participants and providers; and compliance with state and federal law. Deciding what weight to give competing priorities is a judgment call,<sup>3</sup> ideally based on information and stakeholder input.

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<sup>3</sup> At least where there is discretion. Compliance with federal or state law, for example, would have greater weight than the cost and availability of services.

## ■ INTRODUCTION

The Division of Developmental Services (DDD), within Colorado’s Department of Human Services (the “Department”), administers three 1915(c) Medicaid waiver programs providing home and community based services to persons with developmental disabilities. Medicaid funded targeted case management services are also provided to this population group. Central to the delivery of these services is the community centered board (CCB), which plays multiple roles in connecting people to needed services. Over the past two decades, a variety of stakeholders have objected to the role of the CCBs and the potential for conflict of interest. More recently, the Centers for Medicare & Medicaid Services (CMS) and the Office of the State Auditor have inquired about the potential for conflict of interest, with CMS expressing concern that the Department implement more safeguards or alter the role of the CCB. In response to these concerns, DDD asked the Muskie School to assist in defining appropriate safeguards and protections related to potential conflicts of interest arising from the multiple roles of Community Centered Boards.

As part of our work, we have:

- Conducted document review
- Gathered stakeholder input
- Developed an operational definition of “conflict of interest”
- Reviewed approaches used in other states
- Evaluated existing safeguards and identified opportunities for improvement.

This document summarizes the information we gathered, our analysis of potential conflicts of interest, and recommendations for addressing opportunities for improvement.

We discuss the information we gathered in the context of our analysis. Much more detail can be found in the reference documents we reviewed (listed in the APPENDICES) and in our SUMMARY OF STAKEHOLDER INPUT (also in the APPENDICES). In particular, the SUMMARY OF STAKEHOLDER INPUT provides a much deeper understanding of the range of stakeholder perspectives than we document in our analysis.

This document must be read as a “point-in-time” view of the policies and infrastructure in place. The Department is currently moving from quasi-managed care to a fee-for-service reimbursement system. With this reform comes a new standardized assessment tool for determining payment rates, a standardized rate schedule, new supporting information systems and policies. In addition, the Department has recently upgraded some of its oversight functions. The Department will be submitting waiver renewal applications for its three waivers reflecting these changes. However, at this point in time not all of these changes are documented or reflected in program rules. While this document attempts to reflect changes made subsequent to our review, we anticipate that some have been omitted or their potential impact not fully captured.

## DELIVERY SYSTEM OVERVIEW

This section describes the basic elements of Colorado’s delivery system for persons with developmental disabilities.

### **Oversight and Direction of Developmental Services**

DDD provides leadership for the direction, funding and operation of services for persons with developmental disabilities. DDD serves through its Medicaid and state funded programs a total of approximately 12,400 adults and children with developmental disabilities.

DDD partners with the Colorado Department of Health Care Policy and Financing (HCPF), the state Medicaid agency, to develop policy for DDD services funded through Medicaid. As the designated single state Medicaid agency, HCPF is responsible to CMS for assuring that Medicaid-funded services comply with federal requirements. HCPF is responsible for overseeing DDD’s administration of its Medicaid funded programs.

### **Home and Community Based Waivers**

DDD administers three waiver programs for persons with developmental disabilities:

#### ***Comprehensive Services Waiver (HCB-DD)***

Comprehensive waiver services serve those adults who require extensive supports to live safely (including access to 24-hour supervision) and who do not have other sources for meeting those needs. Services available under the HCB-DD waiver include individual and group residential services and supports, day services and employment services. Currently, HCB-DD services cannot be provided in the family home. The service agency is responsible for the living environment, which it may own or is owned by the individual or a “host home,” also known as adult foster care. Approximately 3,790 adults currently receive services under this waiver. The number of Medicaid-funded resources for comprehensive waiver services is 3,806 (with 66 state-funded resources).

#### ***Supported Living Services (SLS)***

The Supported Living Services waiver provides assistance and support to meet daily living and safety needs of persons who are responsible for their own living arrangements in the community. Services are intended to augment available supports for those adults who either can live independently with limited supports or who, if they need extensive support, are getting that support from other sources, such as their family. *DDD Rule 16.611*. Services available under the SLS waiver include personal assistance, day services and employment services. SLS services can be provided in the family home. Approximately 2,676 adults currently receive services under this waiver. The number of Medicaid-funded resources for supported living waiver services is 2,892 (with 692 state-funded resources).

#### ***Children’s Extensive Services (CES)***

Children’s Extensive Services provide enhanced in-home supports for those children considered to be most in need because of the severity of the disability. CES services are intended to provide for the stability of the family setting in order to allow the child to continue to remain in the

home. Approximately 323 children currently receive services under this waiver. The number of Medicaid-funded resources for children's extensive services and supports is 395.

## **Providers**

Services under these three waivers are provided through CCBs, direct service providers, and Regional Centers. The role of each type of provider is described below:

### ***Community Centered Boards (CCBs)***

The CCB is at the center of the delivery system. CCBs first emerged in the 1960s in response to parents and advocates seeking alternatives to institutional services for children with developmental disabilities. CCBs are private non-profit organizations. Colorado statute designates the CCB as the single entry point to the long-term service and support system for persons with developmental disabilities within a designated service area. *27-10.5-102. C.R.S.* CCB designation is for a 12-month period. DDD reviews a CCB's application for designation, evaluating the CCB based on a range of factors, including how well the CCB has encouraged competition. DDD is required to purchase service and support coordination services through the CCB, except under specified conditions relating to the CCB's failure to provide or purchase the service, or because of poor quality. *27-10.5-104 C.R.S.* DDD regulations govern the process when DDD chooses to purchase services without involving the CCB. *DDD Rule 16.225.* Colorado currently contracts with 20 CCBs, with each CCB serving a non-overlapping geographic region of one to ten counties and from 90 to 1,800 individuals each. Resources for services are allocated to each service area based on historical experience and the legislative process. *DDD Rule 16.226.* In addition, some CCBs supplement state funding with mil-levy funding, dedicated funding collected from local taxes.

### ***Service Agencies***

Service agencies are defined to include "individual service agencies" (*i.e.*, an individual person under contract with a CCB or another service agency); "developmental disabilities service agencies," which provide services predominantly to persons with developmental disabilities; and "typical community service agencies," which provide services predominantly for persons without developmental disabilities. *DDD Rule 16.221.* With the approval of the DDD, both the developmental disabilities service agencies and the "typical community service agencies" can provide comprehensive (residential) services. These service agencies can also provide in-home supports under the SLS or CES waiver (and in the case of "typical" service agencies, a variety of other services and supports). The "individual service agencies" would include in-home support providers providing services under the SLS or CES waiver.

### ***Regional Centers (RCs)***

Regional Centers are essentially state operated and licensed intermediate care facilities for persons with mental retardation (ICFs-MR), providing waiver services to persons with developmental disabilities having the most intensive needs. Access to RC services is through the CCB. A Referral and Placement Committee within each service area is responsible for reviewing and recommending a placement in a RC. Criteria limit referral to a RC to those instances when all reasonable alternatives have been exhausted. Prior to the person entering the RC for long-term placement, an order from a district court is required (although there are some residents that were voluntarily admitted to the RC many years ago.) RCs provide a number of

waiver services including: 24-hour supervision, residential services, day programming, habilitation, medical, training and behavioral intervention, plus short-term emergency/crisis support to the community system. RC case managers provide case management for all persons receiving waiver services at the RC, although CCBs will be taking over this role in the coming months. Colorado has three RCs (Grand Junction, Pueblo and Wheat Ridge). All three are under the direct administrative authority of DDD, with state employees providing services.

## ■ THE MULTIPLE ROLES OF THE CCB

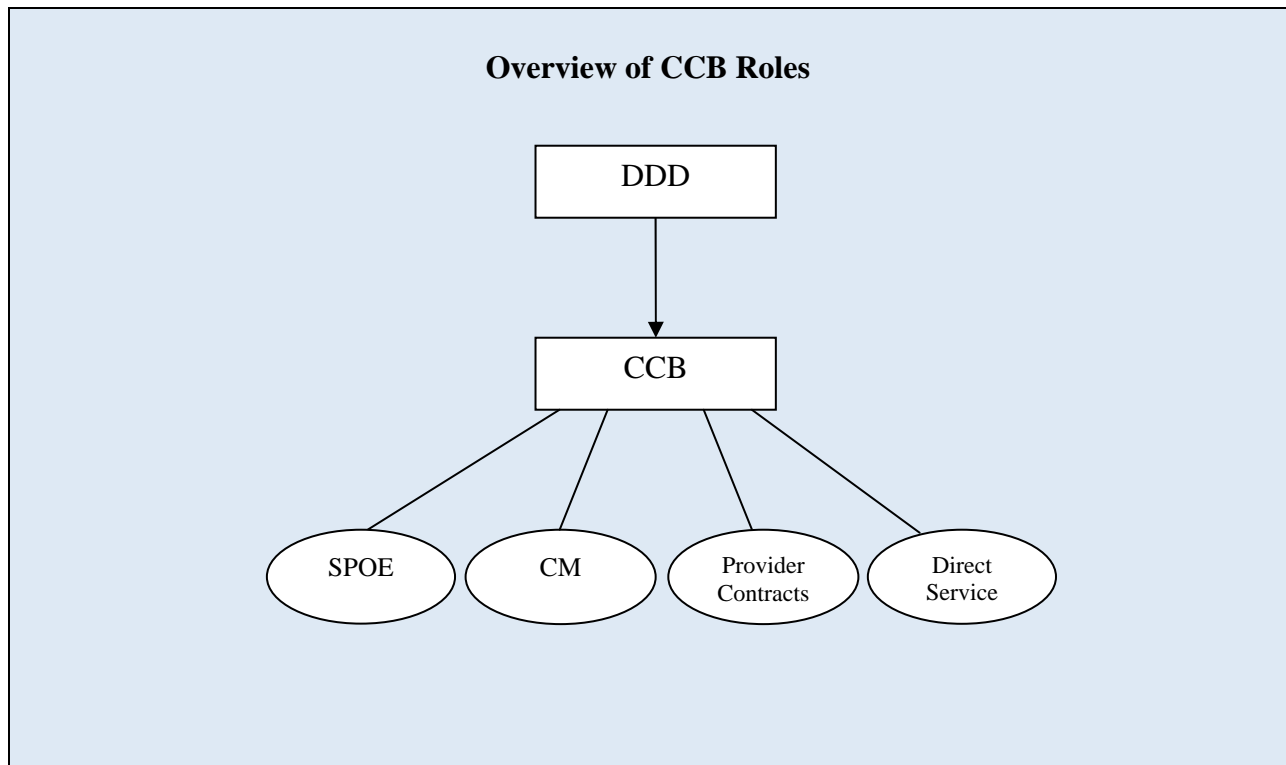
The CCB plays, or can play, a wide range of roles in the DD delivery system, including:

- Serving as the single entry point for DD services
- Providing case management services
- Providing direct services
- Serving as an Organized Health Care Delivery System (or provider contractor)

Embedded in these roles are two others:

- Overseeing the provider entry process
- Assuring the quality of services and providers

Each of these roles is described below. Please refer to the Summary of Stakeholder Input for a better understanding of the nature of these roles and how they are experienced by different people.



## **The CCB's Role as Single Point of Entry**

As the designated Single Point of Entry (SPOE), the CCB performs a number of functions.

Colorado statute gives the CCB responsibility for cultivating services in its catchment area:

- The CCB is required to annually submit a long-range plan to address the needs of the people in its service area. The annual plan is to be developed through “collaborative community efforts, facilitated by the CCB, and shall include an annual public forum.” *DDD Rule 16.210.*
- DDD rules require that the CCB: use existing service agencies, social networks and natural sources of support; encourage competition; and establish new services and supports for the prevention of institutionalization. *DDD Rule 16.210.* The CCB's performance on this standard is to be assessed as part of the CCB's annual application for redesignation as a CCB.

A number of stakeholders discussed the role of the CCB as the community “face” for developmental disability services. It is readily identifiable as a resource and community partner for addressing issues affecting persons with DD.

In addition to its community role, the CCB has responsibility for a range of individualized services including information and referral, eligibility determination and managing the waiting list for services.

### ***Information and Referral***

The CCB has responsibility for providing information about available services, including public and private services, and state and local services, supports and resources. *DDD Rule 16.410.* Many parents identified the important role a CCB can play in this capacity, particularly for parents who have just learned that their child has a disability and do not know where to start.

### ***Eligibility Determination for DD Services***

The CCB is responsible for determining whether or not an individual has a developmental disability, within the State's definition of that term. This process is governed under DDD Rule 16.420. Each CCB is required to have a Referral and Placement Committee to determine when an individual has a developmental disability and to make referrals for Medicaid waiver services. *DDD Rule 16.450.* An individual can appeal the determination under the CCB's complaint and grievance process. *DDD Rule 16.420.*

### ***Eligibility Determination for Medicaid Waiver Services***

The CCB determines whether a person is eligible for home and community based services under the HCBS-DD waiver. Specifically, the CCB determines if the person has a developmental disability as defined in HCPF Medical Assistance Staff Manual, 8.761.1, and administers the ULTC 100.2, the standardized assessment used to determine level of care (LOC) and individual needs. *HCPF Medical Assistance Staff Manual, 8.401.17.* The LOC assessment is used to determine whether HCBS-DD waiver services are an appropriate option. *HCPF Medical Assistance Staff Manual, 8.405.32.* An individual has a right to appeal this determination.

*HCPF Medical Assistance Staff Manual, 8.401.204 and 8.057.* The LOC determination is also used to determine the level of services an individual can receive under the HCBS-DD waiver. *HCPF Medical Assistance Staff Manual, 8.403.* These determinations can also be appealed. *HCPF Medical Assistance Staff Manual, 8.402.53 and 8.057.*

### ***Managing Waiting Lists for Services***

The CCB is required to establish a waiting list for services and supports for people eligible for services but for whom funding is not available. The waiting list is to be maintained in accordance with DDD guidelines and HCPF policies. *DDD Rule 16.450.* The CCB submits waiting list data to a database maintained by DDD. The CCB must manage the waiting list according to the immediacy of the need for services: as soon as available, safety net (*i.e.*, if current supports are lost or change), or by a specific date (*e.g.*, turn 21, graduation). Individuals and families must be made aware of their waiting list status and any changes that would affect the length of wait. DDD guidelines also define date of placement on the waiting list. It is up to the CCB to decide whether to consider the service needs of someone already receiving services before a person not receiving services. The guidelines specify exceptions to the “First Come First Served” rule including: the person is homeless, in an abusive or neglectful situation, a danger to others, or a danger to him or herself. When the pool of available funds do not permit the next person on the waiting list to be served, or under other circumstances, the CCB can ask for an exception to First Come First Served. Also, if a resource becomes available because a person is placed in a RC, a person from the RC must be placed in the community. A person has a right to dispute a CCB’s management of the waiting list. *DDD Guidelines for Management of Waiting Lists.*

As a service agency, the CCB has the authority to determine to whom they will or will not provide direct services; however, before a person can be denied services the CCB needs to document that services have been sought and that there is no willing provider to provide the needed service. *Directive Memorandum to CCB Directors, DDD, March 27, 2001.*

### **CCB’s Role as Case Management Provider**

As case management provider, the CCB has a number of other responsibilities, including developing individualized plans, managing the provider selection process, advocating for the people they serve, and overseeing implementation of the individualized plan.

#### ***Developing Individualized Plans***

The CCB is responsible for developing individualized plans (IPs), in coordination with an interdisciplinary team (IDT). *DDD Rule 16.440.* The IDT includes the person receiving services, the parent or guardian, and others as determined by the needs and preferences of the individual. *DDD Rule 16.16.120.* Currently, DDD does not prescribe a specific tool for assessing an individual’s service needs and resources. The IP must document the individual’s strengths, preferences, desires and needs; the services and supports appropriate to meet needs; the planning process; IP goals; authorized services and supports funded by DDD, in sufficient detail so provider agencies have a clear understanding of expected responsibilities and performance. *DDD Rule 16.440.*

The DDD is currently implementing the Supports Intensity Scale (SIS) to measure the frequency, intensity and volume of support that individuals need; funding allocations will be linked to this

measurement. The CCBs are administering the SIS; DDD monitors the results for conformance with an expected pattern.

### ***Managing the Provider Selection Process***

For comprehensive waiver services, the CCB is responsible for developing and implementing a process for selecting service agencies to meet the needs and preferences of individuals seeking services. The CCB is required to provide information concerning all existing agencies approved to provide comprehensive services. If the person knows which service agency they wish to choose, they may do so.<sup>4</sup> If the person does not have a preference, the CCB must notify approved and prospective service agencies and solicit their interest. For those agencies expressing interest, the CCB issues an RFP profiling the individual and the anticipated services and supports to be provided. The CCB is to evaluate all proposals submitted in response to the RFP, including its own, according to the same criteria. Those approved by the CCB are offered as options to the person seeking services. *DDD Rule 16.228*. Upon request, the person can review those proposals not selected by the CCB.

For SLS services, a participant or the participant's family has the freedom to choose providers from approved service agencies.<sup>5</sup> *DDD Rule 16.227*.

### ***Advocating for Participants and Families***

The CCB must identify who within the CCB will assist a person in filing a complaint or grievance. *DDD Rule 16.326*. The case manager is responsible for promoting a person's ability to engage in self-advocacy. *DDD Rule 16.460*. In addition, under the Medicaid rule for Targeted Case Management, case management includes advocating on behalf of their clients to access the services and support programs identified in their individualized plan. *HCPF Medical Assistance Staff Manual, 8.761.14*.

### **The CCB's Role as Service Provider**

The CCB is also authorized to act as a direct service provider. *27-10.5-104. C.R.S.* Almost all CCBs do provide services. In rural parts of Colorado, the CCB may be the only service provider. One CCB executive reported that his CCB became a service provider only because it had previously been "held hostage" by service providers when negotiating over rates and placement. Other CCB representatives that we talked to said that, if forced to choose, they see themselves as a direct service provider before they are a case management agency.

### **The CCB's Role as Organized Health Care Delivery System (OHCDS)**

The CCB can also operate as an Organized Health Care Delivery System (OHCDS). Pursuant to a CMS policy statement made in a letter to State Medicaid Directors (dated December 20, 1993), an OHCDS provides at least one Medicaid service directly but also contracts with other qualified providers to furnish other covered services. An OHCDS provides a mechanism for reimbursing providers without requiring every provider to enter into a Provider Agreement with the Medicaid agency; this mechanism is helpful where a state wants to promote the use of non-traditional

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<sup>4</sup> Although DDD rules currently condition an individual's choice of provider on the CCB's approval, DDD reports that this requirement is no longer operative under the new standard fee structure. *Communication from Matthew Solano, October 2007*.

<sup>5</sup> Again, DDD rules condition individual choice on DDD concurrence; DDD reports this requirement is no longer operative under the new standard fee structure.



providers (*e.g.*, a housecleaning or laundry service) or individual providers, such as family member or neighbor providing personal assistance services.

The OHCDS is responsible for the services provided by the subcontracted provider. 42 CFR 434.6(c). Providers can benefit from participating in an OHCDS because the CCB can provide a steady cash flow and reduce financial risk connected to unexpected costs (*e.g.*, costs associated with a psychiatric crisis or an adaptation not reimbursable under Medicaid). In return, a CCB can set rates for services, permitting the CCB to pay a provider more or less for a service than the CCB receives from Medicaid.

Technically, all CCBs are OHCDSs. CMS' Freedom of Choice policy requires that an individual seeking services have their choice of any qualified provider who chooses to provide services to the individual. An individual, therefore, cannot be limited to OHCDS providers and approved providers are not required to participate in an OHCDS in order to provide services. The OHCDS is also not required to accept all providers as part of the OHCDS. The CCB can charge providers fees for processing claims.

The CCB may also act as a business agent for the service provider, *i.e.*, only providing billing services for the agency and not fulfilling the other roles that an OHCDS can serve. Under the SLS and CES waivers, the CCB serves as the Support Coordinating Agency, and is authorized to provide services directly or to sub-contract with other service agencies. *DDD Rule 16.611*. Currently, service agencies must contract with the Support Coordinating Agency to provide any waiver services under the SLS and CES waivers.

Thus, provider agencies have three options for billing and payment: the agency can obtain a Medicaid provider number from HCPF and bill Medicaid directly; the agency can subcontract with the CCB as part of an Organized Health Care Delivery System; or the agency can use the CCB or some other entity as a business agent for billing services. Per CMS requirements, DDD and HCPF have taken steps to ensure all service providers are aware that the service agency may bill Medicaid directly. The CCB has a very limited role in monitoring claims payments and billings for those service provider agencies billing Medicaid directly, limited only to confirming that the person is receiving the services specified in his or her service plan.

### **The CCB's Role in Managing Provider Entry**

Previously, the CCB played a strong role in controlling provider entry into its service area, for all developmental services agencies and any typical community service agency planning to provide comprehensive services. *DDD Rule 16.222*. The regulations specified minimum criteria for a CCB selecting and approving a provider. A provider had to obtain the approval of the CCB in every service area in which it wanted to operate.

Pursuant to a policy directive issued in March 26, 2007, the CCB's role has been significantly reduced. The CCB reviews a service agency's application for completeness. The CCB makes recommendations to DDD, to inform DDD's approval decision. However, it must document the basis for any recommendation to disapprove. As part of its review, the CCB makes a site visit for a new group home or facility-based day program. Once approved to provide a specific

service, a provider agency can provide that service in other parts of the state without obtaining further approval.

## **The CCB's Role in Assuring Service Quality**

In addition to monitoring implementation of an individualized plan, the CCB has several other roles connected to quality assurance, including monitoring the overall performance of a service provider, responding to complaints, and addressing critical incidents and allegations of abuse and neglect.

### ***Monitoring Individualized Plan Implementation***

As the case management agency, the CCB is responsible for monitoring the delivery and quality of services and supports, the health, safety and welfare of the participant, and the participant's satisfaction with services and choice of service provider. In addition, the CCB is responsible for promoting the individual's ability to engage in self-determination, self-representation, and self-advocacy. *DDD Rule 16.460.*

### ***Monitoring Overall Provider Performance***

In its capacity as an Organized Health Care Delivery System, the CCB is also responsible for reviewing the overall quality of services and supports provided in its service area, including general satisfaction with services, general practices of service agencies regarding health, welfare and safety of the people it serves, fiscal compliance related to implementing the IP, and the nature and frequency of complaints connected to service agency. *DDD Rule 16.460.* DDD Program quality standards require each CCB to develop and implement a written CCB monitoring plan to describe monitoring activities, frequency, documentation, etc.

### ***Providing Access to a Complaint and Grievance Process***

The CCB is required to have procedures for resolving disputes related to: a decision that an applicant is not eligible for services, a decision to provide, modify, reduce or deny services or supports as specified in the IP; a decision to terminate services or supports; and a decision that the person receiving services is no longer eligible for services. *DDD Rule 16.322.* The grievance is heard by an impartial decision maker. An "impartial decision maker" is someone who has not been directly involved in the specific decision at issue and may be a CCB executive director. The duties of the impartial decision maker are defined; the impartial decision maker may not talk to either party about the dispute without the other present. *DDD Policy: Conducting an Effective Evidentiary Meeting as Part of the Developmental Disabilities System's Dispute Resolution Process. (September 2000).* CCB decisions can be appealed to DDD. *DDD Rule, 16.322.* (These dispute resolution processes supplement but are not a prerequisite to an individual's right to a Medicaid fair hearing.)

The CCB is also required to have a process for timely resolution of grievances or complaints. DDD provides that use of the grievance procedure will not prejudice a person's right to services. *DDD Rule 16.326.*

### ***Addressing Incidents and Allegations of Abuse, Mistreatment and Neglect***

The CCB and service agencies are required to have written policies and procedures for timely reporting, recording and reviewing of incidents. Allegations of abuse, mistreatment, neglect,

exploitation, or injuries that require emergency medical treatment or result in death, must be reported to the CCB within 24 hours. *DDD Rule 16.580*. In addition, all provider agencies, CCBs and Regional Centers are required to report to law enforcement any allegations which may indicate a crime has been committed; reports about at-risk adults must be made to the county adult protective units.

The CCB is required to establish a Human Rights Committee (HRC) as a third-party mechanism for protecting the rights of participants. The HRC is advisory; it reviews the practices of the CCB and service agencies to make sure practices are consistent with protecting participant rights. The HRC is required to include two professional persons trained in the application of behavioral development techniques, three representatives of persons receiving services, their parents, legal guardians or authorized representatives. No employee or board member of a service agency within the CCB's service area can serve on the HRC. *27-10.5-105.5 C.R.S.* The CCB provides staff support to facilitate HRC functions. *DDD Rule 16.550*.

## IDENTIFYING CONFLICTS OF INTEREST

### Defining Conflict of Interest

A “conflict of interest” is a “real or seeming incompatibility between one’s private interests and one’s public or fiduciary duties.”<sup>6</sup> A CCB’s “public duty” is defined by statute, regulation and contract. As an agent of the State, the CCB has a duty to adhere to and promote the Department’s programmatic goals for quality, here defined to be:

Every person meeting the State’s eligibility criteria for developmental disability services has equitable access to services that meet individual needs and preferences, are consistent with federal and state law, and are within existing resources.

The CCB’s “private interests” are those natural to any business (including any other provider) interested in its own survival in a competitive environment. In particular, the CCB has an interest in maximizing revenue (*e.g.*, by increasing the number of people it serves and the amount it is paid for services), minimizing costs (*e.g.*, minimizing the costs associated with meeting the needs of the people it serves), and improving its competitive position relative to others (*e.g.*, promoting awareness of its service).

The CCB’s private interests may be in conflict with its public duty in a variety of ways. For example, to minimize costs, a CCB might have an incentive to avoid serving more costly individuals. Acting on that incentive would be adverse to its duty to promote equitable access to services.

In talking about a conflict of interest, it is important to distinguish between the existence of a conflict of interest and whether or not a CCB acts upon that conflict. Our analysis focuses only on the ways in which a CCB’s roles create opportunities for acting on private interests, not

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<sup>6</sup> BLACK’S LAW DICTIONARY, Eighth Ed., Thomson West, St Paul, MN (2004).

whether a CCB does act upon those interests. In the next section, EXISTING SAFEGUARDS AND OPPORTUNITIES FOR IMPROVEMENT, we will evaluate whether existing safeguards effectively prevent a CCB from acting upon a conflict.

### **Opportunities to Act on a Conflict of Interest**

A CCB is not unique in having public duties and private interests in potential conflict. However, because of the multiple roles a CCB plays, there is naturally a greater opportunity for role confusion for a CCB, as well as more opportunity for a CCB to act on its private interests. The following discussion reviews these multiple roles and the increased opportunity to act on a conflict. Our discussion focuses primarily on the CCB's private interests as a service provider and how that role, when combined with other CCB roles, creates incentives and opportunities to act on the CCB's private interest. We also briefly discuss how the CCB's private interests as a case management agency or an organized health care delivery system (OHCHDS) interacts with other roles.

Our conclusions about the existence of these opportunities are based on our understanding of how the delivery system works, which we have developed through document review and stakeholder interviews.<sup>7</sup> We have also relied on stakeholder input to get a better understanding of how a conflict might play out, if acted upon by a CCB. Again, we do not draw any conclusions about whether one or several or all CCBs act upon a conflict, only whether or not a CCB has an incentive and opportunity to do so.

#### ***The CCB's Role as Direct Service Provider***

The CCB role creating the most incentive to act on a conflict of interest is the CCB's role as service provider. The interaction of this role with each of the CCB's other roles is discussed below.

##### ***Dual Role: CCB as Service Provider and Single Point of Entry***

As the single point of entry, the CCB has the opportunity to operate in its self-interest when providing information and referral services, determining eligibility for services, and managing the waiting list.

As the single entry point, the CCB can create a competitive advantage for itself by providing information and referral services that favor its own services over other providers. Some of the ways in which a CCB might fail to adequately perform its information and referral obligations because of its conflict of interest:

- Sponsoring informational meetings or publishing newsletters where only the CCB's services are presented or advertised.
- Giving participants and families the option between the CCB's services or a list of providers to sort through on their own, without CCB assistance.
- Failing to provide information about other service providers.

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<sup>7</sup> See the appendices for a listing of REFERENCE DOCUMENTS and SUMMARY OF STAKEHOLDER INPUT.

The CCB can also create a competitive advantage for itself by blurring the distinction between its single point of entry and case management roles and its role as service provider by using the same name or co-locating services.

In determining eligibility and level of care, a CCB might want to screen out people it finds hard to serve or screen in people to fill openings with its service agency. A CCB's decisions about who should move up on the waiting list could be influenced by who on the waiting list might best fit into an opening in the CCB's service agency.

***Dual Role: CCB as Service Provider and Case Management Agency***

As the case management agency, the CCB has the opportunity to act on its self-interest when developing an individualized plan and when overseeing the selection of providers.

When developing the IP, a CCB can steer participants and individuals into CCB services. For example, the case manager could refer a person down the hall to the CCB's provider, or the CCB representatives participating in the meeting could offer to provide the services during the planning meeting circumventing the need for an RFP process. The CCB could also shape the individualized plan to match the services it has available.

The CCB can use the provider selection process to create a competitive advantage for itself and to maximize its revenue and minimize costs. Some of the ways the CCB could act upon these conflicts include:

- Steering participants to CCB services. "Steering" could be the result of intentional (e.g., questioning a participant's choice of another provider) or unintentional acts (e.g., a case manager is more familiar with the CCB's services and can offer less information about the other options available).
- Failing to solicit interest from a range of providers. Failing to fairly evaluate proposals submitted by other providers.
- "Cherry picking" the easier to serve and steering high-cost participants to other providers.

Again, co-location of case management and other services can create a competitive advantage for the CCB: the path of least resistance leads across the hall to the CCB's employment services or day habilitation provider.

***Dual Role: CCB as Organized Health Care Delivery System***

When a CCB is both acting as a provider and is responsible for setting rates as an Organized Health Care Delivery System, the CCB has the opportunity to establish rates that are favorable to its own service agencies. (The Department expects this conflict to fade with the introduction of standardized rates.)

***Dual Role: CCB as Service Provider and its Quality Assurance Role***

The CCB's quality assurance functions could be influenced by its role as a provider.

- When serving as the impartial hearing officer for resolving disputes over access to services, or when addressing complaints and grievances, the CCB has the opportunity to make decisions that favor its provider agency.
- The case manager has the opportunity to dissuade or discourage complaints against the CCB's provider agency.
- The CCB has the opportunity to suppress, minimize, or inadequately address incidents, or allegations of abuse, mistreatment, neglect, etc.
- When monitoring provider and service quality, the CCB has the opportunity to hold itself to a lower standard than its competitors. One case manager described the subtle effect of personal relationships developed by working in the same location. "They're in the lunchroom together every day," making it more difficult for the case management side of the CCB to challenge the performance of the provider side.

***Dual Role: CCB as Service Provider and its Role Managing Provider Entry***

Recent policy changes significantly reduce the opportunity for a CCB to limit competition from other providers. We assume that this role has been sufficiently reduced to no longer pose a significant opportunity to inappropriately limit provider entry.

The table, CCB'S OPPORTUNITIES TO ACT ON PRIVATE INTERESTS AS A PROVIDER on the next page summarizes the ways in which the CCB's other roles provide an opportunity for the CCB to act on its private interest and against its public duty.

- The first column identifies the different roles the CCB plays and the functions performed as part of those roles.
- The second column identifies the CCB's public duty in fulfilling its role. For example, as the single entry point, a CCB has a public duty to ensure equitable access to services.
- The third column identifies the CCB's private interest as a provider that might be in conflict with its duty. For example, the CCB's interest in minimizing cost might be in conflict with its duty to provide equitable access if it wants to avoid serving high cost individuals.
- The fourth column identifies a range of possible ways a CCB could act on its private interests as a service provider (without drawing conclusions about whether it does) when performing functions in its other roles. This list is meant to be illustrative and does not represent all of the ways a CCB might act on a conflict, as identified by stakeholders. See the SUMMARY OF STAKEHOLDER INPUT for more.

***The CCB's Role as Case Management Agency***

As a case management agency, a CCB has a similar set of private interests that, when combined with its other roles, also create increased opportunities for the CCB to act on its private interests. For example, as both single entry point and case management agency, the CCB can use the eligibility determination process to screen out high cost users or reduce the number of people on the waiting list. It can also loosen eligibility criteria to increase the number of people it provides case management services to.

A CCB'S OPPORTUNITIES TO ACT ON PRIVATE INTERESTS AS A DIRECT SERVICE PROVIDER			
Other CCB Role	CCB's Public Duty as Agent of State	CCB's Private Interest as Provider	Opportunities to Act on Private Interests
Single Entry Point <ul style="list-style-type: none"> <li>▪ <i>I&amp;R</i></li> <li>▪ <i>Eligibility Determination</i></li> <li>▪ <i>Managing Waiting List</i></li> </ul>	<ul style="list-style-type: none"> <li>• Allow choice of provider</li> <li>• Ensure equitable access.</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Minimize costs</li> <li>• Maximize revenue</li> </ul>	<ul style="list-style-type: none"> <li>• Publicize CCB services, but not other service providers to limit access to information about other service providers?</li> <li>• Loosen interpretation of eligibility criteria and level of care to fill available provider slots?</li> <li>• Use eligibility criteria to screen out high cost users?</li> <li>• Move people up on the waiting list who match openings in CCB provider agencies?</li> </ul>
Case Management Agency <ul style="list-style-type: none"> <li>▪ <i>Service Planning</i></li> <li>▪ <i>Provider Selection</i></li> </ul>	<ul style="list-style-type: none"> <li>• Allow choice of provider</li> <li>• Ensure equitable access</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Minimize costs</li> <li>• Maximize revenue</li> </ul>	<ul style="list-style-type: none"> <li>• Develop service plans that favor CCB services?</li> <li>• Use service planning or provider selection process to steer participants toward CCB services in order to fill open service slots?</li> <li>• Use the provider selection process to steer low cost participants to CCB services &amp; high costs participants to other providers?*</li> </ul>
OHCDS	<ul style="list-style-type: none"> <li>• Allow choice of provider</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Maximize revenue</li> </ul>	<ul style="list-style-type: none"> <li>▪ Negotiate low rates with other providers, while offering favorable rates to own provider agencies?*</li> </ul>
Quality Assurance <ul style="list-style-type: none"> <li>▪ <i>Monitoring Services</i></li> <li>▪ <i>Complaints</i></li> <li>▪ <i>Incidents</i></li> </ul>	<ul style="list-style-type: none"> <li>• Assure provider/ service quality</li> </ul>	<ul style="list-style-type: none"> <li>• Gain competitive advantage</li> <li>• Minimize costs</li> </ul>	<ul style="list-style-type: none"> <li>• Suppress complaints against CCB?</li> <li>• Suppress incidents connected to CCB?</li> <li>• Less rigorous monitoring of CCB services; resistance to interventions?</li> <li>• Less rigorous advocacy on behalf of participant or family?</li> </ul>

\* With the introduction of standardized rates, the Department expects the opportunity for conflict here to fade.

### *The CCB's Role as Organized Health Care Delivery System*

The CCB role as an Organized Health Care Delivery System (OHCDS) also creates a very similar array of private interests, potentially playing out when the CCB performs its other roles. For example, when serving as the single point of entry or the case management agency, the CCB might have an incentive to steer people to OHCDS providers, to less rigorously monitor the quality of OHCDS providers, etc. To the degree that the CCB is able to steer people to particular providers, the CCB can create an inappropriate incentive for providers to participate in the OHCDS (in addition to the services and protections that appropriately come with being part of the OHCDS).

## **EXISTING SAFEGUARDS AND OPPORTUNITIES FOR IMPROVEMENT**

In this section, we evaluate whether potential conflicts are adequately addressed through existing safeguards, whether safeguards can be enhanced, or whether a change to program design features is desirable.

We define “safeguard” to mean:

A policy, procedure or system that works to deter a CCB from acting contrary to the Department’s programmatic goals for quality.

While we understand that CCBs may impose their own safeguards to promote appropriate behavior, this section focuses on safeguards that are or could be imposed by the Department. To assess the adequacy of a safeguard, we raise two questions:

- Does the safeguard adequately address the potential conflict? Are there barriers to the effectiveness of the safeguard?
- Is there a method to assess the effectiveness of the safeguard in eliminating or reducing the conflict (e.g., oversight method)?

Changes to program design features may be warranted where no effective safeguards exist, where there are substantial barriers to their effectiveness, or where oversight methods are weak or unavailable to confirm that the safeguard is working.

We define “design features” as:

Roles, responsibilities and organizational structures that either produce or eliminate the potential for conflict.

The most obvious and effective safeguard for any conflict is the professional, personal and contractual commitment of the CCB to program goals and the pursuit of quality outcomes for participants. While we offer an appraisal of safeguards to eliminate conflicts or mitigate their impact, none can succeed without the integrity and commitment of the CCB. Reports from many stakeholders suggest that this safeguard is present and leads to very positive experiences within the CCB. We also heard that the CCB’s multiple and blurred roles can undermine the effectiveness of this safeguard or confidence that it is working.



In addition, while in the previous section we talked about a number of incentives that can operate against quality, we have not itemized those instances that operate to promote quality. Examples cited by the CCBs include the CCB's interest in assuring quality to avoid liability, or the costs connected to a crisis. We do not attempt to assess the possible impact of these "natural" safeguards, but note that they are also likely to play a positive role.

Our analysis below reflects findings from a review of four states that allow the same entity to perform case management and service provision (OH, SD, VT and WY). A full review of their practices with respect to waiver functions is presented in APPENDIX B.

The following tables examine the adequacy of current safeguards and oversight methods for potential conflicts deriving from the CCB's interest as a service provider and its other roles (see TABLE: A CCB'S OPPORTUNITIES TO ACT ON PRIVATE INTERESTS AS A DIRECT SERVICE PROVIDER, page 14).

- POTENTIAL CONFLICT summarizes the nature of the conflict. Potential conflicts are organized according to roles described in the first column of the TABLE on page 14.
- EXISTING SAFEGUARDS identify protections currently in place in Colorado to reduce the likelihood of a CCB acting on a conflict or mitigating its impact.
- PROPOSED SAFEGUARD ENHANCEMENTS identify additional safeguards or enhancements to existing safeguards proposed by the authors.
- PROPOSED DESIGN FEATURES identify changes to program design proposed by the authors.
- DDD OVERSIGHT METHODS describe existing processes and tools used by DDD to assess whether a safeguard is working as intended. Oversight methods listed in *italics* are processes and tools proposed by the authors to supplement existing oversight methods.
- BARRIERS TO EFFECTIVENESS identify the authors' understanding of issues that may undermine the adequacy of a given safeguard or oversight method.

## Information and Referral (I&R)

<p><b>POTENTIAL CONFLICT:</b> The CCB is the focal point for participants and families to learn about available services and supports in the community in an objective and comprehensive manner. As a direct provider of care, the CCB has the discretion to limit access to information about other service providers or to bias information in favor of its own providers.</p>		
Existing Safeguards	Oversight Method <i>(Italics = proposed)</i>	Barriers to Effectiveness
CCB required to provide information on all available services and supports that may be available to persons with DD	<ul style="list-style-type: none"> <li>• <i>Participant survey to assess understanding of available resources to support persons with DD.</i></li> </ul>	<ul style="list-style-type: none"> <li>• CCB might not provide assistance to participant in sorting through the service provider options.</li> <li>• CCBs may withhold information about available service providers</li> </ul>
Statewide referral list of approved service agencies in the CCB's designated service area is posted on the Department website.	<ul style="list-style-type: none"> <li>• <i>Participant survey to assess understanding of available resources to support persons with DD.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Website viewed as not user-friendly, insufficient information to inform decisions on quality.</li> <li>• CCB less knowledgeable about other community resources that could address needs of clients.</li> </ul>
Proposed Safeguard Enhancements		
Department protocol defining CCB's handling and documentation of I&R activities	<ul style="list-style-type: none"> <li>• DDD conducts onsite quality reviews of CCB performance <i>including review of I&amp;R activities, on more frequent basis.</i></li> <li>• <i>Log of I&amp;R requests and actions taken by CCB.</i></li> <li>• <i>Participant survey to assess understanding of available resources</i></li> </ul>	<ul style="list-style-type: none"> <li>• Administrative burden of maintaining a log of requests and actions.</li> <li>• DDD onsite quality review does not focus on role of CCB in I&amp;R.</li> <li>• DDD onsite quality review happens infrequently.</li> </ul>
Prohibit promotion of CCB service providers at the exclusion of other community providers and resources.	<ul style="list-style-type: none"> <li>• DDD conducts onsite quality reviews of CCB performance <i>including review of promotional activities.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Role in I&amp;R can be confused with opportunities to promote CCBs own service providers</li> <li>• No separation of CCB identity as single entry point and service provider (e.g., co-located, same name)</li> </ul>
<p><b>Proposed Design Feature:</b></p> <ul style="list-style-type: none"> <li>• Remove I &amp; R from CCB responsibility in all or some (e.g., urban) CCBs</li> </ul>		

Current safeguards focus on requirements that the CCB fully inform participants of the array of services and resources in the community to serve persons with developmental disabilities and a state referral list that standardizes information about available qualified DD providers. Neither of these safeguards sufficiently embrace the CCB's broader role in promoting service integration and awareness among all service providers, including those not specific to the DD population but which may affect their lives or wellbeing (e.g., vocational rehab services or housing subsidies).

Two safeguard enhancements could strengthen the role of I & R and engage the CCB beyond its more narrow perspective as service provider. A comprehensive guide or protocol for conducting the I&R function, combined with more regular reporting to and review by the Department of

activities, would enhance CCB understanding of its responsibilities to promote and refer to a broad community of resources beneficial to participants. A safeguard prohibiting the CCB from promoting its own services at the exclusion of others would help to distinguish its obligations for community outreach and awareness building from marketing its own services. Each of these safeguards has barriers to effectiveness.

Removing the I&R function from the CCB eliminates role confusion but also has potential costs and consequences. Rural areas, in particular, may lack the infrastructure and knowledgeable staff to establish I&R functions outside the CCB structure.

## Eligibility Determination

<b>POTENTIAL CONFLICT:</b> The CCB conducts the level of care determination and assesses whether an individual meets the target population criteria for the waiver program. These functions give the CCB discretion to limit equitable access to services by screening people out who are hard to serve or giving advantage to others.		
Existing Safeguards	Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
CCB is required to use a prescribed tool (ULTC-100.2) and criteria and to document decisions on a web-based database maintained by Medicaid.	<ul style="list-style-type: none"> <li>• BUS runs internal system error check verifying eligibility based on reported information</li> <li>• DDD Medicaid staff reviews ULTC 100.2, final Service Plan and IP cover sheet for internal consistency</li> <li>• DDD conducts onsite quality reviews of CCB performance, including review of appropriateness of eligibility determinations, every 3 years</li> <li>• Medicaid conducts periodic review of LOC for conformance with state and federal assurances</li> <li>• <i>Conduct focused study of LOC determinations by CCB</i></li> </ul>	<ul style="list-style-type: none"> <li>• Variability in interpretation of determination criteria by the CCB.</li> <li>• Infrequency of DDD onsite quality reviews</li> </ul>
Participant has a right to appeal CCB decisions to the Department.	<ul style="list-style-type: none"> <li>• <i>Participant survey to assess awareness of appeal process</i></li> <li>• <i>Review frequency of appeals on LOC/waiver denials</i></li> <li>• <i>Review frequency of appeals upheld</i></li> </ul>	<ul style="list-style-type: none"> <li>• Access to advocate to assist during appeal process</li> <li>• Fear of retaliation</li> <li>• Intimidating, formal process</li> </ul>
Proposed Safeguard Enhancement		
Reduce interpretive variation in LOC determinations among CCBs through enhanced training	<ul style="list-style-type: none"> <li>• Medicaid conducts periodic review of LOC for conformance with state and federal assurances.</li> </ul>	
<b>Proposed Design Features:</b>		
<ul style="list-style-type: none"> <li>• CCB conducts LOC and waiver eligibility review; Department approves determinations.</li> <li>• Department conducts and approves LOC and waiver eligibility determinations.</li> </ul>		

Under existing safeguards, the Department has a standardized instrument and process for conducting LOC determinations and a database documenting LOC decisions made by the CCB. Federal rules allow entities other than Medicaid to make LOC determinations but the Medicaid agency must oversee the performance of the entity, including ensuring that applicable level of care criteria have been properly applied. These provisions require the Department to

independently assess the quality of LOC reviews performed by the CCB. Currently, onsite quality reviews are the only oversight method for validating LOC documentation. In an agreement with DHS, Medicaid requires that a statistically valid sample of participant functional assessments be shared with the agency for review. While these reviews are able to assess the completeness and timeliness of LOC determinations, they are unable to assess their validity. We are concerned that the onsite quality review, which includes meeting with participants and comparing their functional status with the LOC assessment, is conducted only once every 3 years.

Of the states reviewed for this study, all four require the state to make final determinations with respect to LOC determination. The accountability placed on Medicaid for LOC determinations suggests to us that more careful study is needed to determine whether this function is being appropriately conducted at the CCB level. Unless onsite quality reviews are conducted on a more regular basis, we are concerned that there is insufficient information upon which to show ongoing evidence of compliance with CMS assurances. The optional design feature proposes to insert the Department directly in the eligibility determination process, a remedy that while solving the problem, has significant cost implications.

### Administration of the Waiting List

<p><b>POTENTIAL CONFLICT:</b> Each CCB is responsible for managing the waiting list within its catchment area. This role gives discretion to the CCB to favor individuals in providing more rapid placement or to fill openings in its service agency.</p>		
Existing Safeguards	Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
Persons are selected for services from the waiting list according to criteria and interpretive guidelines established by the Department.	<ul style="list-style-type: none"> <li>• CCB is required to enter waiting list documentation into CCMS, a web environment designed and accessible to DDD</li> <li>• DDD conducts onsite quality reviews of CCB performance, including management of waiting list</li> </ul>	<ul style="list-style-type: none"> <li>• Discretion in how to apply criteria.</li> <li>• Infrequency of state onsite quality reviews</li> </ul>
Proposed Safeguard Enhancement		
Strengthen guidance on decisions related to waiting list allocations, especially in cases of emergency.	<i>More timely review by DDD of cases where individuals are placed on the waiver out of sequence with their eligibility date.</i>	
<p><b>Proposed Design Options:</b></p> <ul style="list-style-type: none"> <li>• CCB recommends slot allocations from the waiting list; the Department approves</li> <li>• Centralize management of the waiting list.</li> </ul>		

The central statewide data base on the waiting list provides useful information to DDD on the movement of individuals on and off the waiting list by catchment area. We would suggest that this information be more carefully monitored, especially with respect to decisions where individuals are taken out of sequence for placement when a waiver opening becomes available.

Two of the states reviewed (SD and WY) maintain the waiting list at the State level and allocate available slots centrally. Two states (OH, VT) delegate responsibility for the waiting list to the local entity, requiring routine reporting to the State on its status.

Strengthening review of outliers is an important safeguard enhancement but, as long as authority for allocating slots remains with the CCB, the Department is placed in a reactive role to correct inappropriate decisions. Two design options remove decision-making authority from the CCB, thus eliminating the basis of the conflict.

## Service Planning

<p><b>POTENTIAL CONFLICT:</b> The CCB case manager, together with the participant and interdisciplinary team, develops an individualized plan specifying the scope and frequency of services required in response to a participant’s needs and preferences. This role gives the CCB discretion to identify service needs that benefit its own service providers or to steer participants into its own services.</p>		
Existing Safeguards	DDD Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
The Department specifies elements that must be addressed in the IP and the process and timelines for its completion.	<ul style="list-style-type: none"> <li>• Select elements from IPs entered into state database for review</li> <li>• DDD conducts onsite quality reviews of CCB performance, including IP development, every 3 years</li> <li>• DDD reviews 20% sample of IPs on day programs, residential and SLS/CES, every 3 years</li> <li>• Medicaid reviews all initial IPs</li> <li>• Medicaid reviews IPs for consistency with state and CMS assurances</li> </ul>	<ul style="list-style-type: none"> <li>• CCB bias in identifying service needs based on its own service provision</li> </ul>
The CCB is required to convene an interdisciplinary team (IDT) to facilitate service planning.	<ul style="list-style-type: none"> <li>• DDD conducts onsite quality reviews of CCB performance, including composition of ID,</li> </ul>	<ul style="list-style-type: none"> <li>• Limited check on CCB influence over IDT composition</li> <li>• Composition can be driven by CCB service agency</li> </ul>
Support Intensity Scale (SIS) to reduce variations in service planning.	<ul style="list-style-type: none"> <li>• Medicaid conducts periodic review of IPs for conformance with state and federal assurances</li> </ul>	<ul style="list-style-type: none"> <li>• Perceived to be subject to gaming and variations across CCBs</li> </ul>
Proposed Safeguard Enhancements		
Enhance training and oversight of case manager’s role as neutral facilitator of IP.	<ul style="list-style-type: none"> <li>• <i>Participant survey to assess IP development process.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Neutrality of CCB.</li> </ul>
Required composition of IDT to include external providers	<ul style="list-style-type: none"> <li>• Medicaid conducts periodic review of Plan of Care for conformance with state and federal assurances</li> </ul>	<ul style="list-style-type: none"> <li>• Can be inconsistent with participant choice and control</li> </ul>
<p><b>Optional Design Features:</b></p> <ul style="list-style-type: none"> <li>• Provide option for independent case manager to develop IP or resource person to attend IP development meeting.</li> <li>• No longer allow case management agency to provide direct services.</li> </ul>		

The development of an effective IP rests on the ability of a case manager to provide guidance grounded solely on the interests of the participant. This relationship must be built on trust and confidence that other considerations do not interfere with decisions relative to what is best for the participant within available resources.

The introduction of the SIS and documentation of individualized plans on the BUS enhances standardization and review by the Department to assure consistent development of IPs within and across CCBs. The Department's onsite quality reviews offer the best opportunity to validate the accuracy and fairness of IPs. These are conducted at the CCB and service agency levels every 3 years. While this results in a significant overall sample of IPs being reviewed each year (estimated to be approximately 800), it does not necessarily mean that IPs are reviewed for each CCB on an annual basis. We understand the resource intensity of conducting onsite reviews and, if annual reviews are not possible, we suggest that data available through the BUS and other sources be used to assess trends that may suggest inappropriate service planning by CCBs on an ongoing basis.

Revising composition requirements for the IDT to include persons outside the employ of the CCB could help neutralize the potential for conflict. Imposing requirements on IDT membership, however, may undermine participant's voice in the planning process.

Our four-state review revealed several strategies for addressing this conflict. Protections in these states fall into 3 major categories:

- Frequent and prescribed assessment by the state of the local service planning process and its conformance with guidelines (OH, SD, VT, WY).
- The establishment of a uniform assessment process that limits discretion and eases periodic review for conformance to guidelines (VT)
- The introduction of an independent party to participate in plan of care meetings (WY)

We believe that the proposed design feature of introducing an independent party during IP development offers a solution for those participants who avail themselves of the resource. The design feature of eliminating case management agencies from delivering direct service restores objectivity to the process for all participants.

## Provider Selection

<p><b>POTENTIAL CONFLICT:</b> The CCB case manager is responsible for assuring that participants are fully informed of all qualified providers in an area and overseeing the selection of providers with the participant. The CCB has the discretion to steer participants to the agency’s providers or those favored by the agency.</p>		
Existing Safeguards	Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
CCBs are required to follow a process of developing a participant profile and soliciting provider interest through a RFP.	<ul style="list-style-type: none"> <li>• DDD conducts onsite reviews of CCB performance, including sample review of participant profiles and RFPs to determine consistency with policy</li> <li>• <i>Written acknowledgement by participant of receipt of provider information</i></li> </ul>	<ul style="list-style-type: none"> <li>• Not all participants or their families know to ask to see their profiles to assure its accuracy.</li> <li>• Transparency of process for soliciting provider interest and reviewing provider proposals.</li> <li>• Infrequency of state onsite quality review</li> <li>• Steering to CCB services before selection process is initiated.</li> </ul>
Referral list provided by the Department for approved services in a service area.	<ul style="list-style-type: none"> <li>• <i>Participant survey to assess adequacy and comprehensiveness of referral list</i></li> </ul>	<ul style="list-style-type: none"> <li>• Updates and accuracy of referral list</li> <li>• Limited information for assessing quality</li> <li>• Case manger’s lack of knowledge or unwillingness to assist with. sorting options</li> </ul>
Proposed Safeguard Enhancements		
Six month review of provider choices with participants.	<ul style="list-style-type: none"> <li>• <i>Written acknowledgement by participant that case manager reviewed service options</i></li> </ul>	<ul style="list-style-type: none"> <li>• Administrative burden</li> <li>• Potential disruption to service delivery</li> </ul>
More prescriptive standards for provider selection process.	<ul style="list-style-type: none"> <li>• DDD conducts onsite reviews of CCB performance, including review of provider selection process</li> </ul>	
Standard profile of provider attributes and quality performance	<ul style="list-style-type: none"> <li>• <i>Participant survey to assess usefulness of provider profiles</i></li> </ul>	<ul style="list-style-type: none"> <li>• Timely access to accurate and consistent data.</li> </ul>
<p><b>Proposed Design Features:</b></p> <ul style="list-style-type: none"> <li>• State employs/contracts with independent case managers as an option for participants during provider selection process.</li> <li>• Centralize provider selection process through a state or independent entity.</li> </ul>		

Central to the waiver program and federal assurances is a person’s freedom to select among qualified providers. The lack of transparency in the process and a standard means for monitoring adherence to the Department protocol undermine trust that the system is working as it should.

The four study states all retain responsibility for facilitating provider choice at the case manager level. Three have safeguards to reduce potential conflict. Vermont involves the State in decisions when the designated agency disagrees with the participant on his or her choice. Wyoming requires case managers to review provider choices with the participant every six months and to have the participant attest to the discussion. Ohio is developing a user-friendly website on certified providers for use by participants and families to make them more informed and engaged in the provider selection process.

Current safeguards and enhancements all have significant barriers to their effectiveness. The design feature for participants to work with an independent case manager eliminates the conflict for those opting to use it while raising cost and logistical issues that we have not considered. This option creates some additional conflicts of interest for the CCB, which may have an incentive to limit access to information about this option or refer difficult to serve participants to the alternative case management agency. Eliminating the provider selection process from the role of the CCB is a more comprehensive design feature that removes the question of bias for all participants, but with obvious cost implications.

## Rate Negotiation

<b>POTENTIAL CONFLICT:</b> When acting as an organized health care delivery system (OHCDS), a CCB can set rates for services, permitting the CCB to pay its own provider agencies for the same service more than it does other providers.		
<b>Existing Safeguards</b>	<b>Oversight Methods (<i>Italics = proposed</i>)</b>	<b>Barriers to Effectiveness</b>
State rules govern purchase service rates and allowable fees for services provided to network providers.	<ul style="list-style-type: none"> <li>• DDD conducts onsite reviews of CCB performance, <i>including review of rate determinations.</i></li> <li>• <i>Department review of methods for determining rates and fees in advance of their adoption by the CCB.</i></li> </ul>	<ul style="list-style-type: none"> <li>• No opportunity for public comment</li> <li>• Different rates within and across CCBs may result in variations in services and quality.</li> </ul>
Dispute resolution process.	<ul style="list-style-type: none"> <li>• <i>Dispute resolution findings reported to Department.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Fear of retaliation</li> </ul>
<b>Proposed Safeguard Enhancement</b>		
More specific guidance on allowable withholds for administrative fees.	<ul style="list-style-type: none"> <li>• DDD conducts onsite reviews of CCB performance, <i>including review of rate determinations</i></li> </ul>	
<b>Proposed Design Feature:</b>		
<ul style="list-style-type: none"> <li>• Separate OHCDS from the CCB.</li> </ul>		

Existing safeguards leave discretion to the CCB to negotiate service rates with their network providers, notwithstanding a State-established rate for each Medicaid service. While we understand this to be a business transaction with provider partners that is an acceptable and legal practice, it has the potential to lead to inequities in service delivery and therefore should be the subject of regular Department oversight. The dispute resolution process for providers introduces independent review of the arrangement and mitigates against unfair practices. Our review did not include an analysis of the federal OHCDS rules to determine the constraints that may be imposed on the negotiation. Nor did we examine how this practice affects Medicaid rules requiring that payments for waiver services (like other Medicaid services) be consistent.

Separating the OHCDS from other CCB roles eliminates this conflict. An alternative, more fully explored in the conclusions, would have the Department separately solicit entities to organize one or more OHCDS systems and prohibit service providers from qualifying.



## Monitoring Services

<p><b>POTENTIAL CONFLICT:</b> The CCB is responsible for monitoring implementation of the individualized plan by provider agencies. This role places discretion within the CCB case manager to enforce a different standard of quality among service providers.</p>		
Existing Safeguards	Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
State requires each CCB to have a written protocol for case management monitoring that addresses general guidelines established by the Department.	<ul style="list-style-type: none"> <li>• DDD conducts onsite reviews of CCB performance, including review of provider monitoring activities.</li> </ul>	<ul style="list-style-type: none"> <li>• No prior review and approval of monitoring protocol by the Department.</li> <li>• State guidance does not address incentive to favor own providers</li> <li>• Lack of transparency in monitoring process.</li> <li>• Lack of consistency within CCB service area.</li> <li>• Service providers subject to multiple reviews.</li> <li>• Limited enforcement authority when problems are found.</li> </ul>
CCBs required to develop a monitoring tool for use in assessing performance of area providers.	<ul style="list-style-type: none"> <li>• Monitoring tool submitted to Department.</li> <li>• <i>Findings of CCB monitoring submitted to Department and other CCBs working with the Service Provider</i></li> </ul>	<ul style="list-style-type: none"> <li>• Inconsistent monitoring practices among CCBs and within their service network.</li> <li>• Lack of transparency in results of monitoring</li> <li>• Lack of effective enforcement tools when problems are identified.</li> </ul>
Proposed Safeguard Enhancements		
Standard tool and protocol for monitoring IP implementation and conducting programmatic reviews	<ul style="list-style-type: none"> <li>• <i>Periodic findings of case management review submitted to the Department.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Lack of transparency</li> <li>• Incentive to favor own providers</li> <li>• Lack of consistency across CCBs in monitoring practices.</li> </ul>
<p><b>Proposed Design Features:</b></p> <ul style="list-style-type: none"> <li>• Include peers or independent case manager when monitoring IP implementation at the CCB's own service providers.</li> <li>• No longer allow case management agency to provide direct services.</li> </ul>		

An essential role of case management is to assure the quality, appropriateness and timeliness of services identified in the IP. This task requires case managers to review the performance of all service providers, including the CCB's own.

Colorado's current safeguard results in inconsistency across CCBs and imposes no rigorous standard on the role of the case manager when monitoring services delivered by CCB providers. The establishment of a standard tool and protocol, combined with submittal of monitoring findings to the Department and to other CCBs that may also be working with the service provider, could enhance safeguards but does not limit the potential for bias.

Wyoming's use of area resource specialists (ARS) is one approach for neutralizing this situation. The state-employed ARS periodically attends IP meetings to monitor plan implementation. The Department also conducts random samples of a participant's services to assess compliance with the terms of the plan of care.

One design feature separates direct service from the role of case management, thus eliminating the conflict. Another optional design feature requires the addition of peers or an independent case manager whenever a CCB case manager monitors services within his or her own agency. We expect this option would be cumbersome to implement and potentially unrealistic given the frequency with which this situation arises.

Department rules speak to a programmatic function assumed by the CCB with respect to overseeing a provider's overall performance, unrelated to any one IP. Although monitoring tools are submitted to the Department, there is no formal review and approval process by the Department. Lack of a standardized template for conducting programmatic monitoring and a forum for reviewing findings with the Department for possible follow up weakens the impact of this programmatic review function and its fairness.

## Complaints<sup>8</sup>

<p><b>POTENTIAL CONFLICT:</b> The CCB is responsible for establishing a process through which individuals and family members can voice concerns and expect a speedy and fair resolution. At the same time, the Case Manager, employed by the agency also providing service, has potential conflicts in acting as a strong, objective advocate.</p>		
Existing Safeguards	Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
Self advocacy or through guardians or family members	<ul style="list-style-type: none"> <li>Participant survey to assess willingness to complain</li> </ul>	<ul style="list-style-type: none"> <li>Not everyone is comfortable or has the ability to advocate</li> <li>Reluctance or fear of retaliation</li> </ul>
Professional advocates (e.g., ARC, The Legal Center)	<ul style="list-style-type: none"> <li>Participant survey to assess how to access professional advocates</li> </ul>	<ul style="list-style-type: none"> <li>Ability to access advocate when needed</li> </ul>
State standards governing the CCB's complaint process.	<ul style="list-style-type: none"> <li><i>Routine collection of CCB complaint logs to assess trends and timely resolution</i></li> </ul>	<ul style="list-style-type: none"> <li>Case manager's ability to act as advocate for individual against employer</li> <li>CCB's neutrality in responding to complaint.</li> </ul>
CCBs are required to maintain and analyze a complaint log to determine trends and need for system improvement.	<ul style="list-style-type: none"> <li><i>Routine collection of CCB complaint logs to assess trends and timely resolution</i></li> <li>DDD conducts onsite reviews of CCB performance, including review of complaint log and responses</li> <li>Department conducts investigations on complaints brought to its attention</li> </ul>	<ul style="list-style-type: none"> <li>No standard format for tracking complaints</li> <li>No standard plain language guidance to participants on how to voice complaints</li> <li>Reluctance or fear of retaliation to make complaint to CCB</li> </ul>
Rule/policy protecting individuals against retaliation	<ul style="list-style-type: none"> <li>Participant survey to assess participant fear of retaliation</li> </ul>	<ul style="list-style-type: none"> <li>No written process/protocol has been implemented</li> </ul>
Proposed Safeguard Enhancements		
Plain language brochure on how to voice complaints	<ul style="list-style-type: none"> <li>Participant survey to assess participant understanding of complaint process</li> </ul>	
Case manager training/protocol on how to respond to complaint and document.	<ul style="list-style-type: none"> <li><i>Survey of case managers to determine their</i></li> <li><i>understanding of their role in handling complaints.</i></li> </ul>	<ul style="list-style-type: none"> <li>Case manager turnover</li> <li>Requires promotion at all levels of the CCB</li> <li>Case manager's independence from the CCB.</li> </ul>
<p><b>Proposed Design Features:</b></p> <ul style="list-style-type: none"> <li>Establish an independent pathway or ombuds program for voicing complaints.</li> <li>Augment existing complaint system with opportunity to complain directly to the Department.</li> </ul>		

Active complaint systems are considered by many as the hallmark of a good quality management program in that (when functioning effectively) they provide a timely means for detecting and remedying quality problems. Existing safeguards provide no uniform check and balance on how

<sup>8</sup> Complaint Systems are distinct from the two formal dispute resolution mechanisms available to persons with developmental disabilities through the Medicaid Fair Hearing Process or the Dispute Resolution System.

well complaint systems are working within the CCBs or aggregate trends across CCBs. Nor do they offer formal recourse for voicing concerns outside of the CCB.

Ohio requires their County MRDD Boards to submit all complaints to the State for review. Wyoming, in addition to complaint systems maintained by local entities, has established a state process for receiving complaints directly from participants.

Safeguard enhancements may improve access to the complaint system by building participant awareness of the complaint process. But this improvement does not provide an independent agent with authority to investigate problems that may involve the CCB. The optional design feature for establishing an independent pathway for registering and resolving complaints removes the fear of retaliation and creates an objective and fair atmosphere for resolving problems but may have access barriers. On the other hand, the development (and promotion) of a state-sponsored complaint system offers ready access to persons in authority to act on the problem in a fair and neutral manner.

### Incident Reporting System

<b>POTENTIAL CONFLICT:</b> The CCB is responsible for establishing policies and procedures for reporting and examining incidents and to work to prevent their re-occurrence. In this role, the CCB has the discretion to minimize incidents or otherwise limit follow-up investigations.		
<b>Existing Safeguards</b>	<b>Oversight Methods <i>(Italics = proposed)</i></b>	<b>Barriers to Effectiveness</b>
The CCB must establish policies to ensure prompt notification of specific events determined by the State (e.g., abuse, neglect, death, serious injuries) and others identified by the CCB.	<ul style="list-style-type: none"> <li>• Complaints entered into web-based reporting system (CIRS) maintained by the Department including status of all follow up activities made by the CCB</li> <li>• DDD conducts onsite quality reviews of CCB performance, including reviewing of its incident reporting system, every 3 years</li> <li>• DDD reviews critical incident practices on all service agencies at least every 2 years.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of transparency to the public</li> <li>• Sufficient state staff to adequately follow up on incidents</li> </ul>
Each CCB is required to have a Human Rights Committee on issues of abuse, neglect and other serious incidents	<ul style="list-style-type: none"> <li>• DDD reviews HRC activities during quality onsite reviews (every 3 years) and during program surveys of all service agencies (every 2 years).</li> <li>• <i>Recommendations of HRC submitted to Department for review.</i></li> </ul>	<ul style="list-style-type: none"> <li>• Membership appointed by CCB</li> <li>• HRC findings only advisory to CCB</li> <li>• Information and staff support provided by CCB.</li> </ul>
<b>Proposed Safeguard Enhancements</b>		
Guidelines, protocol and forms for submitting root cause analyses via the State's CIRS.	<ul style="list-style-type: none"> <li>• Routine reporting via CIRS of all required root cause analyses.</li> </ul>	
<b>Proposed Design Feature:</b>		
<ul style="list-style-type: none"> <li>• Critical incidents are reported directly to the Department for analysis, investigation and follow up rather than to the CCBs.</li> </ul>		

Effective quality management systems are designed to detect problems quickly, remediate the individual situation, and determine whether and how system improvements can be made to avoid their reoccurrence. Critical incident reporting is a major protection within the HCBS system to assure quick and proper notification and follow up action for the most serious of events affecting participants.

All four states in our study require the immediate reporting of all critical incidents to the State, three (OH, SD and VT) via the local entity and one (WY) directly to the State. Vermont is in the process of developing a system that will provide web-based reporting simultaneously to the local entity and the State.

Current safeguards have made the Department a more active partner in understanding and resolving critical events occurring within the system. Recent guidance should help to limit variations in a CCB's interpretation of when an event is subject to reporting and the required accompanying documentation. The system should be accompanied by dedicated Department personnel to follow up and assure that comprehensive and accurate assessments of the problem have been made and that systemic changes have been instituted to avoid their reoccurrence in the future. Unclear in the current guidance is the extent to which the CCB and Department will work collaboratively to investigate problems. The web-based system does not resolve this question and, without further directives, may lead to confusion on who is in charge of determining when adequate remedies have been put into place.

## Structural Safeguards

The Department also has adopted several overarching safeguards designed to reduce the potential for conflict.

Structural Safeguards	Oversight Methods <i>(Italics = proposed)</i>	Barriers to Effectiveness
CCB Governing Board membership	<ul style="list-style-type: none"> <li>• <i>Review of CCB Bylaws to determine method of selection</i></li> </ul>	<ul style="list-style-type: none"> <li>• No required public process for selection of board.</li> <li>• Independence of Board members from influence of CCB Executive Director</li> <li>• Independence of CCB Executive Director from influence of Board members</li> </ul>
Rules requiring separation of case management from service provision.	<ul style="list-style-type: none"> <li>• DDD conducts onsite quality reviews of CCB performance, <i>including review of I&amp;R activities, on more frequent basis.</i></li> <li>• <i>Log of I&amp;R requests and actions taken by CCB.</i></li> <li>• <i>Participant survey to assess understanding of available resources</i></li> </ul>	<ul style="list-style-type: none"> <li>• CCB and service providers have same name and location</li> <li>• Public perception does not recognize organizational distinctions</li> </ul>
Annual designation of CCB	<ul style="list-style-type: none"> <li>• Findings of designation process.</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity for public input into designation process</li> </ul>
Two-way Agreement between DDD and CCB specifies conflict of interest standards	<ul style="list-style-type: none"> <li>• CCB required to submit to Department written code of standards</li> <li>• CCB required to submit to Department disclosure statement</li> </ul>	<ul style="list-style-type: none"> <li>• Variability across CCB on how standards are implemented</li> <li>• Does not address multiple roles served by CCB and potential for conflict.</li> </ul>
<b>Proposed Safeguard Enhancement</b>		
	<ul style="list-style-type: none"> <li>• Enhance transparency of designation process and operations of CCB.</li> </ul>	

Current structural standards all have barriers to their effectiveness and offer minimal guidance on the fundamental question of conflict as it plays out in the daily operation of the CCB. Despite the presence of these structural safeguards, potential conflicts continue to exist. Underlying our analysis of structural standards is the question of transparency and the process used to engage the broader community in decisions with respect to the organization and operations of a CCB. Each of the above safeguard enhancements also could include an opportunity for public disclosure and/or input. In our CONCLUSIONS AND RECOMMENDATIONS we examine in detail proposed design features to alter the current structure.

## ■ CONCLUSIONS AND RECOMMENDATIONS

We conclude this report with a synthesis of our findings that can serve as a framework for the Department as it moves forward. We identify a series of strategies for addressing the conflicts of interest inherent to the existing delivery system, with varying degrees of effectiveness:

- The first set of strategies are the least disruptive to the existing delivery system but are also the least likely to effectively safeguard against conflicts of interest. This set of recommendations assumes the CCB continues to play the same roles it does currently but would minimize the opportunity for acting on a conflict of interest by imposing standards for requiring greater consistency and accountability.
- The second set of strategies considers a range of design options, separating out some of the roles currently fulfilled by the CCB. In all of these options, at a minimum, the direct service role is separated from the case management and single entry point role. These design options impose different levels of disruption on the system but are also the most likely to be effective at minimizing the potential for a conflict of interest.
- The third set of strategies are not directly related to the multiple roles played by the CCB but have a significant impact on the quality of services. These issues were surfaced in our discussion with stakeholders and information we gathered from other states. We include them here because of their potential benefit to the Department.

Moving forward with any of these strategies must involve careful consideration of the costs and consequences relative to the expected benefit. We heard the same theme from many families: “Do not fix a problem for someone else by creating problems for me. Do not add an extra administrative cost that means less money for services. If it’s not broke, don’t fix it!” For example, equitable access to services suggests greater standardization in the eligibility and budgeting process. Greater standardization, however, can (but does not always) mean less flexibility to individualized services.

While the Department may be reluctant to disrupt what is working well, it may find compelling reasons to do so. We suggest a balancing test, where any remedy for a conflict is weighed against its cost and disruption to the system. If the scope and severity of a problem is minor, ideally the cost and consequence of the remedy should be minor. However, if the problem has a significant negative impact on quality, the cost of the remedy will have more justification. Weighing the costs and benefits of the status quo against a proposed remedy involves a range of competing priorities. The Department also needs to balance local control (familiarity and responsiveness to the local community) and state level interests in equity, minimizing inconsistent and duplicative burden on participants and providers; and compliance with state and federal law.

Deciding what weight to give competing priorities is a judgment call,<sup>9</sup> ideally based on information and stakeholder input. We do not have all of the information (*e.g.*, impact on cost) or stakeholder input that are needed to draw definitive conclusions.

### **Incremental Strategies to Reduce Conflict or Strengthen State Oversight**

In our identification of incremental strategies, we focused on aspects of the program that did not require statutory changes, major expenditures or significant implementation time but which could strengthen program quality and oversight to safeguard against conflicts of interest.<sup>10</sup> These strategies were identified with the pending waiver renewals in mind as an opportunity to move forward in the near term.

#### ***Develop Comprehensive Operational Protocols for Waiver Programs***

The multiple roles served by the CCB and related opportunities for conflict heighten the need for the Department to be particularly clear about its expectations. The current system allows significant discretion by the CCB to conduct its business contrary to the goals of the program. We believe that the Department cannot preserve the current structure without being more prescriptive about program operations and expectations.

A major task for DDD and Medicaid staff is to thoroughly document current waiver policies and practices in a format that is easily accessible to program managers, CCBs, provider agencies and program participants. Clear and unambiguous language should be used to identify the operational protocol for CCBs, including required processes, tools and documentation, in the implementation of waiver policy. Experience in other states indicates that the preparation of a waiver renewal application is a good opportunity to conduct this exercise and to involve stakeholders in its review.

In earlier sections of this report, we identified safeguard enhancements, many of which could be addressed through an Operational Protocol. Some of these may be more easily implemented than others. While we do not have adequate information for assessing the viability of implementing the following enhancements in the short term, they are listed below for the Department's consideration:

- Handling and documentation of requests for information and referral
- Guidelines for preventing the CCB from promoting its own service agency at the exclusion of others
- Criteria for administration of the waiting list
- Composition and documentation of an inter-disciplinary team (IDT)
- Methods and tools for use by case managers in monitoring implementation of individualized plans

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<sup>9</sup> At least where there is discretion. Compliance with federal or state law, for example, would have greater weight than the cost and availability of services.

<sup>10</sup> This report assessed the design and operation of Colorado's waiver programs for persons with disabilities at a point in time. Our description of the waiver program came largely from rules, policies and documents gathered during our study period. We understand from the Department that substantial changes were made subsequent to our study period. Consequently, some of the strategies proposed in this section may already have been proposed or implemented.



- Review and approval of monitoring tools for CCB oversight of service providers within OHCDIS
- Policy or guidance on retaliation<sup>11</sup>
- Investigation and analysis of critical incidents by the CCB
- Protocol for provider referral and selection process

### ***Document Oversight Methods and Quality Indicators used by the Department to assess CCB Performance***

The potential for conflict due to the multiple roles of the CCB creates the need for greater accountability to assure that standards for quality are met. It is not sufficient to establish standards in an Operational Protocol; the Department must design and implement methods for assessing CCB performance against the standards on an ongoing basis. Under the present system, state oversight is the mechanism for restoring confidence that the program is working as intended and that consistent standards for monitoring and improving performance are applied across the State.

Our conversations with CMS underscored the importance of documenting in detail how the State routinely detects and addresses problems. Ohio in particular was identified as having documented its discovery methods and data sources for each major waiver function and assurance. We concur with CMS on the importance of aligning oversight tools, methods and measures with CCB functions, including quality indicators, responsible entity and frequency of oversight. This seems especially relevant given the substantial changes that have and are occurring within the Department with respect to its oversight methods and the pending waiver renewals.

Listed below are oversight methods identified in previous sections that were proposed for development or improvement:

- State-sponsored participant survey to assess experience under the waiver program (see previous section for specific areas identified for inclusion)
- State-sponsored survey of case managers to assess their experience in providing case management services under the waiver
- Documentation and reporting of information and referral requests and actions
- Documentation and reporting of waiting list decisions and rationale
- Written acknowledgement by participant that the case manager has reviewed all service options
- Written acknowledgement of provider referral and selection process
- Submittal and review of recommendations of the Human Rights Committee
- Focused review of level of care determinations
- Standard tool for monitoring IP implementation

### ***Enhance the Visibility and Leadership Role of Medicaid and DDD***

The discretion of the CCB to act in ways that place private interests over public interests undermines the integrity of the program and its accountability to the Department. A perception

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<sup>11</sup> The Department cites a technical assistance paper, *Handling Consumer Complaints: Pushing the Service Quality Envelope, Growing Quality Services (March 2001)*, as guidance on identifying and preventing retaliation. This document provides a thoughtful analysis of retaliation and suggested strategies for responding to complaints. However, as technical assistance rather than policy, we do not view this document as regulating CCB behavior.

held by many stakeholders is that CCBs are the arbiters of how waiver policy is implemented, as illustrated by variations across CCBs in how core processes are conducted (e.g., selection of qualified providers to meet a participant's needs).

We encourage the Department to exert its authority and oversight of the waiver programs in more tangible and visible ways so that variations in practice are minimized and accountability is centralized. The development of Operational Protocols and oversight methods are steps in this direction. In addition, the Department could sponsor training programs or communicate directly with providers and consumers on issues of statewide concern. Areas identified in our study include:

- Training to enhance consistent interpretation of criteria for determining Level of Care
- Training on the development of individualized plans and provider selection process
- Training on handling and documenting complaints
- Plain language brochure for consumers on how to voice concerns and make complaints

### ***Move Towards a More Transparent System***

Lack of transparency in how the system works and performs may be contributing to frustrations expressed by providers and parents. We believe that Operational Protocols and documentation of oversight methods and processes will be an initial step in reducing ambiguities in people's perceptions of how the program is intended to work. Disclosure of audit findings and performance assessments may be another opportunity to inform stakeholders of the Department's commitment to a fair and comprehensive quality oversight system and to engage them in the design of improvement initiatives.

### **Options for System Re-design**

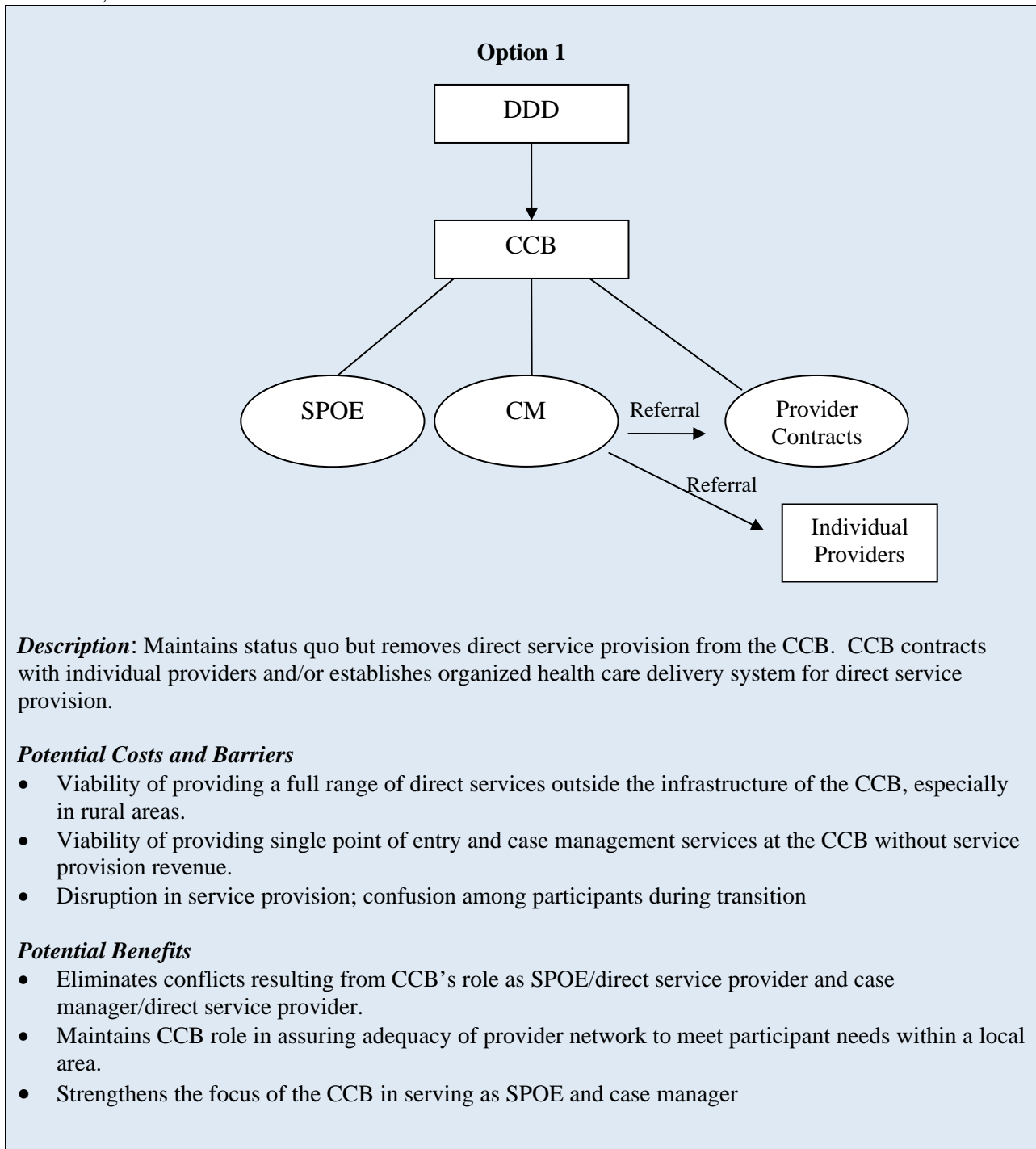
We do not anticipate that the safeguards identified in the previous section will eliminate the opportunity for conflict, given the many roles of the CCB. Most of the safeguards we identified monitor, but do not prevent, the exercise of a conflict of interest. The compounded effect of the CCB's multiple roles is still likely to confuse participants, families, and even the CCBs, on which hat the CCB is wearing at any given point in time (especially when the CCB is co-located and shares a name with its provider agencies). In addition, the ability of participants, families and providers to challenge a CCB – an important check on the CCB's ability to act on a conflict – is inhibited when so much control rests in the hands of the CCB. In this section we present three design options aimed at eliminating, reducing or mitigating the potential for conflict by reducing the number of roles the CCB plays. At a minimum, all of these options separate direct service from other roles currently performed by the CCB.<sup>12</sup> Under each option, we examine potential costs and barriers as well as potential benefits.

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<sup>12</sup> Some have suggested that pursuing a less intrusive design option, in which the Department would contract with an independent case management agency, other than a CCB, to serve those people who would like an alternative to the CCB in their service area. This option appears to invite some of the same opportunities for conflict of interest that already exist: As the single entry point to services, the CCB is likely to have the same incentive to limit access to information about a competing case management agency. Alternatively, it is has the same incentive to refer difficult to serve participants to its competition.

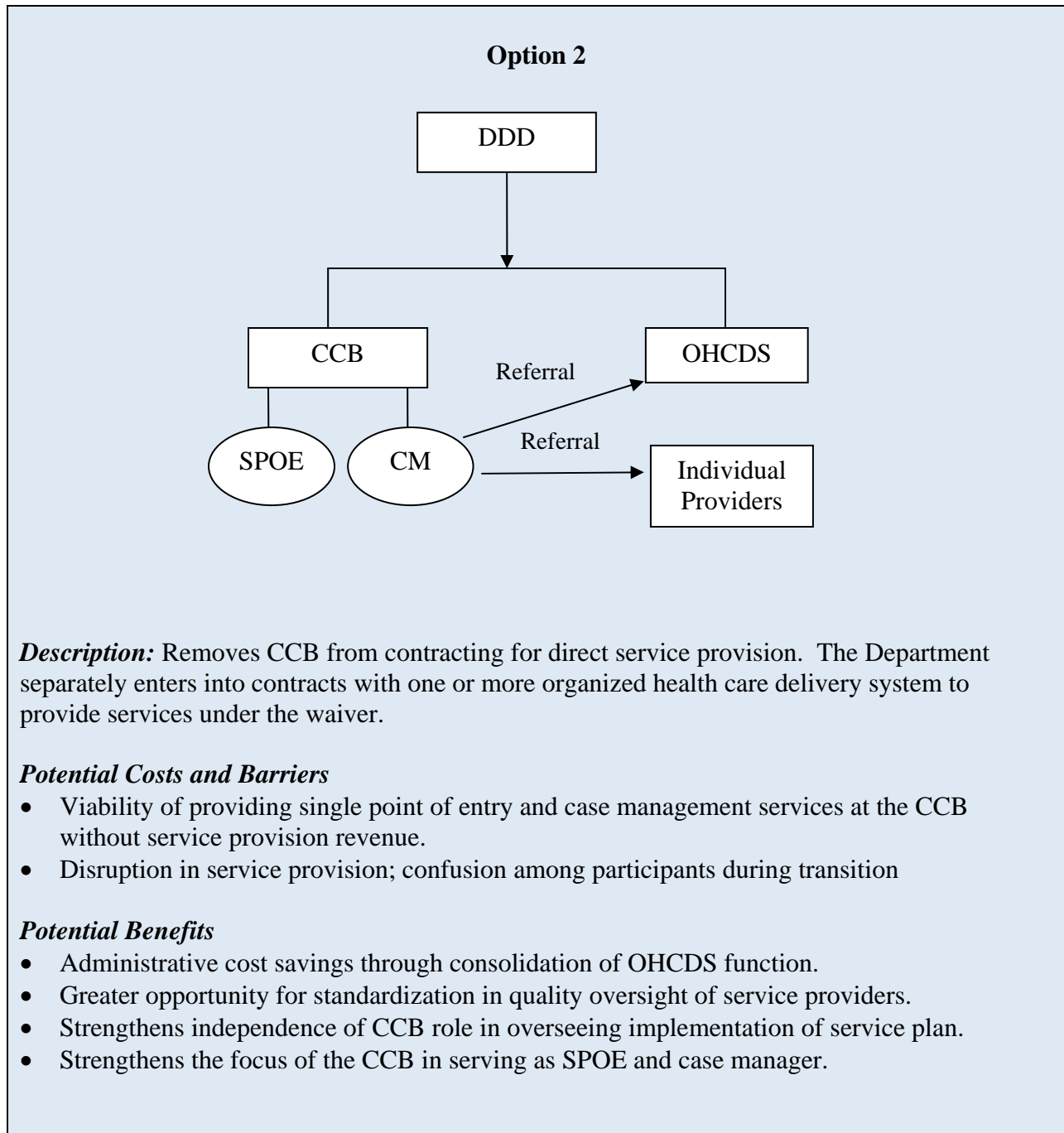
**Option 1: Direct Service Separated from Other Roles**

The role that most compromises the ability of the CCB to be seen and to act as a neutral agent in the performance of its functions under the waiver program is the provision of direct services. Option 1 would separate direct service provision from other functions performed by the CCB. All service provision would occur through an organized health care delivery system and/or direct contracts with providers. The organizational entity serving as the CCB would maintain its current role as the single entry point and case management provider, or opt to provide direct services, but not both.



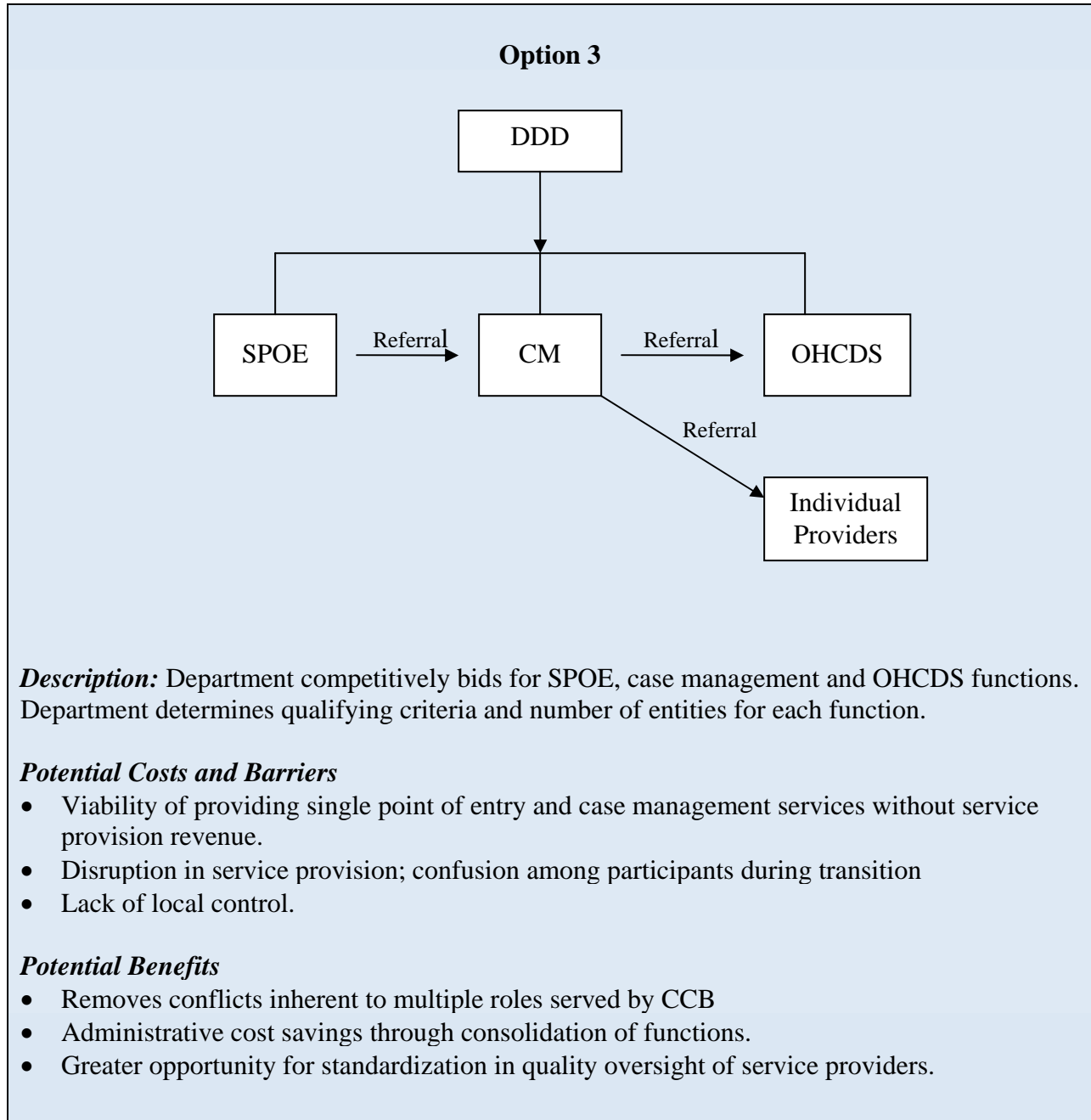
**Option 2: Provider Contracts (OHCDS) and Direct Service Separated From Other Roles**

The second option for redesign de-couples the CCB from all provider contracts and limits its role to referral for service delivery. Under this option, the Department would enter into direct contractual relationships with one or more organized health care delivery systems to provide direct services under its waiver programs. The organizational entity serving as the CCB would maintain its current role as the single entry point and case management provider, or opt to serve as the OHCDS/direct service provider, but not both.



### ***Option 3: All Roles Separate***

Options 1 and 2 alter the role of the CCB but guarantee an ongoing role of the CCB in programs providing home and community based services to persons with developmental disabilities. Option 3 makes no such assumption, leaving the delivery of SPOE, case management and service provision to a competitive bidding process. The Department would establish qualifying criteria.



## Issues outside the Scope of the Study

In our conversations with stakeholders we identified a series of other issues that may contribute to tensions connected to the CCBs' role. While these issues are not directly related to a conflict of interest, we highlight them here for consideration by the Department as it looks to strengthen the system of services for persons with developmental disabilities.

- The lack of a consumer-directed model that enhances consumer choice and control over services exacerbates frustration with the CCBs. Greater consumer choice and control can itself be a safeguard. We understand that the Department's efforts to introduce greater choice and control were delayed by state legislation. We encourage the Department to move forward with its plans.
- We heard from a number of stakeholders frustrated by the control their CCB exerts over local service options and their lack of influence and voice. We encourage the Department to revisit the statutory and regulatory requirement that the CCB develop a long-range plan for the development and coordination of services and supports. The plan is to be developed "through collaborative community efforts." Few of the stakeholders we asked were familiar with this plan or the required annual public forums for updating the plan. The planning process may be a missed opportunity for engaging in public dialogue regarding new directions for the service system. Defining expectations for the components of the plan and updates, as well as the "collaborative community efforts" and the required annual public forum could provide an opportunity for great public voice in delivery system design, providing a chance for participants and families to shape services that are more responsive to the needs and preferences of the people served.
- We heard several comments on the quality of case management services that suggest opportunities for improvement. For example, one parent mentioned that information and referral should include more "generic," or not DD, supports (*e.g.*, the YMCA) that promote inclusion and integration. Others expressed their concern that, while a CCB is required to provide information and referral to all services and supports, some case managers only refer people to those funded through DDD. People on waiting lists must find their own way to housing supports (*e.g.*, Section 8) and vocational rehabilitation services. As the Department establishes its operational protocol, it may wish to consider greater specificity in the definition of the case management function.
- Mil-levy funding was raised in our stakeholder meetings as a major support for enhancing services to a community's population with developmental disabilities and was viewed by others as creating service disparities across the State given that not all CCBs have access to this funding. Some questioned whether mil-levies were being used to subsidize a CCB's own service providers rather than support all persons in the community with developmental disabilities as required by legislation.
- Stakeholders expressed concern that the Adult Protective Service system is inadequate to meet the need of the population, causing them to defer to the CCB for investigations. CCBs confirmed that they were having to step in where APS lacked the resources to adequately respond to problems.

## ■ APPENDICES

- **A: Listing of Reference Documents**
- **B: Summary Grid: Approaches in Other States**
- **C: Summary of Stakeholder Input**

## Appendix A

### Reference Documents

Colorado Statutes, Title 27, Article 10.5.

Developmental Disabilities Services Rule 16.

Health Care Policy and Financing Medical Assistance Staff Manual, §§8.400–401; §§8.402-8.416; §8.500, §8.760

Interagency Agreement between Department of Health Care Policy and Financing and the Department of Human Services (July 1, 2006).

3-Way Contract Template between Department of Health Care Policy and Financing; the Department of Human Services, Division of Developmental Disabilities, and Community Centered Boards (contract period of July 1, 2007 to June 30, 2008).

Program Quality Standards for On Site Surveys: CCB Administration and Case Management Services, with Interpretive Guidelines. Division of Developmental Disabilities, Office of Adult, Disability and Rehabilitation Services, Colorado Department of Human Services (Revised December 2001).

DDD Complaint Policy.

DDD Guidelines: Management of Waiting Lists (Revised January 1995).

DDD Policy: Conducting an Effective Evidentiary Meeting as Part of the Developmental Disabilities System's Dispute Resolution Process (September 2000).

Directive Memorandum to CCB Directors re service denial policies, DDD (March 27, 2001).

Directive Memorandum to CCB Directors re revised statewide program approval process (March 26, 2007).

Advisory Memorandum to CCB Directors, DDD re critical incident reporting system (December 4, 2006)

Letter to Cindi Stetson, Office of the State Auditor, State of Colorado from Fred L. DeCrescentis, Director, Division of Developmental Disabilities (February 15, 2007).



Letter from Fred DiCrescentis, Director, Division of Developmental Disabilities to Barbara Prehmus, Director, Medical Assistance Office, Department of Health Care Policy & Finance (April 23, 2007).

Letter from Barbara Prehmus, Director, Medical Assistance Office, Department of Health Care Policy & Finance, to Diana Friedli, Centers for Medicare and Medicaid Services (March 21, 2007).

Handling Consumer Complaints: Pushing the Service Quality Envelope, Growing Quality Services, Division of Developmental Disabilities, Office of Adult, Disability and Rehabilitation Services, Colorado Department of Human Services (March 2001)

Strategic Plan: 2003-2008 for the Colorado Developmental Disabilities Service System Division of Developmental Disabilities, Office of Adult, Disability and Rehabilitation Services, Colorado Department of Human Services (July 1, 2003).

Special Report to the Joint Budget Committee on the History of Community Centered Boards and the History of the Controversy Surrounding Separation of Case Management (or Managed Care Duties) From Direct Service Provision, Developmental Disabilities Services, Office of Health and Rehabilitation Services, Colorado Department of Human Services (January 18, 1996).

Report from Legislative Audit Committee (1987)

Memorandum from Colorado Legislative Council Staff to Interim Committee on Long-term Care Services and Supports for Persons with Developmental Disabilities. (August 29, 2007).

**Appendix B**  
**Review of Select State Practices Pertaining to Potential Conflicts**

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Program Overview</b>			
<p>88 County Boards are the primary agents of the MRDD waiver’s administration. County MRDD Boards provide intake and referral, case management, program planning, some direct services, and monitoring of plan implementation within the county. Persons applying for the waiver must select a Support Services Administrator (SSA) employed by the County Board.</p>	<p>The SD Division of Developmental Disabilities certifies 19 non-profit Adjustment Training Centers (ATC) to provide case management and, at a minimum, day habilitation services to persons with mental retardation or developmental disabilities within a defined geographic area. ATCs are required to be re-certified by the State no less often than every 2 years.</p> <p>Each consumer must have a designated service coordinator responsible for monitoring the implementation of a service plan. If the service coordinator is responsible for any direct implementation of the consumer’s plan, another service coordinator or staff member, designated by the ATC, shall conduct quarterly observations of those services.</p> <p>A pilot project is underway to develop an independent case management option external to the provider network.</p>	<p>10 Designated Agencies (DA) are responsible for ensuring needed services are available for persons with developmental disabilities in Vermont. The DA is responsible for local planning, service coordination and monitoring outcomes of the region they serve. DAs must provide services directly or contract with other providers to deliver supports and services. DA is responsible for intake and referral, assessing individual needs and assignment funding, developing support plan, providing regional crisis response services, and providing or arranging for comprehensive service network within its region.</p> <p>In addition 5 Specialized Service Agencies (SSA) have been designated to provide distinctive, specialized services.</p> <p>Re-designation of DA and SSA is conducted every 4 years by the State</p>	<p>The WY Developmental Disabilities Division purchases services for persons with developmental disabilities from programs that provide case management, direct service or both. A core group of programs are accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) and provide both case management and direct services.</p> <p>Area Resource Specialists (ARS) work for the State to provide initial assistance to consumers in accessing waivers; assure freedom of choice in selecting a case manager from list provided by the State; attend plan of care meetings, and be the contact on local level to address concerns.</p>

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Level of Care (LOC) Determination</b>			
County MRDD Bds complete initial assessment packet for waiver enrollment. Eligibility Unit in Medicaid reviews assessments and recommends formal LOC determination.	Using standardized ICAP form, ATC submits data for LOC determination for State approval. ICAP is part of the information used by State to also determine rate within which service plan is developed.	LOC review conducted by DA and approved by State.	The Case Manager schedules the ICAP screen which is conducted by state contractor and assembles information for LOC and waiver eligibility determination. Information is submitted to State for review and approval.
<b>Service Planning, Funding and Monitoring</b>			
The SSA is responsible for completing the OH Developmental Disabilities Tool (ODDP) that generates a standardized score based on service needs. The ODDP links the assessment to a funding range that allows individuals with similar needs to access comparable waiver services throughout the State. An Individual Service Plan is developed by the SSA, with no prescribed tool required. The ISP process identifies the actual services needed by the individual, and develops a funding level based on the funding range. The SSA monitors implementation of the service plan.	ATC case manager develops and approves plans of care within funding levels established by the State. No prescribed service plan tool required although policies on its content established.	Service planning and funding level determined by DA using a standard assessment tool. DA responsible for monitoring service plan implementation. Funding levels >\$100,000 approved by State.	Case manager is responsible for the development of the plan of care, subject to State approval, and ongoing monitoring of plan implementation. Funding levels determined by State. A State Extraordinary Care Committee can authorize funding for emergency requests.  ARS periodically attends plan of care meetings to monitor plan implementation process.  Survey/Certification staff review random sample of participants' services to assess implementation of plans of care.

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Freedom of Choice of Providers</b>			
<p>State rules require individuals to have access to contact information about all certified providers; website being modified to include user-friendly provider info for consumers and families.</p> <p>State conducts quarterly reviews of sample service plans to confirm that individuals are afforded choice of providers and case manager conform to state requirements associated with consumer choice of provider.</p>	<p>Providers are required to provide consumer with a list of available providers of interest to the consumer whether at host ATC or other provider.</p>	<p>The DA must help consumers learn about service options, including all providers in the region that can respond to their needs. The recipient may choose to receive services from any certified provider. If the DA disagrees with the choice, the consumer is notified and the Director of the State DD Division reviews the issue and makes a final decision.</p>	<p>Case manager provides consumer with current service provider list. The consumer signs a “Notice of Choice” document to confirm that he/she has been informed of choices available.</p> <p>Case manager required to review provider options with individual and confirm preferred choice every 6 mos.</p>
<b>Governance of Sub-State Entity</b>			
<p>Composition of County MRDD Boards determined by the county.</p>	<p>Each ATC must adopt bylaws that provide for a rotating board of directors; establish term limits not to exceed 3 years and no more than 3 consecutive terms; provide opportunity for consumers and family members to be on the board; provide that members of the board serve without pay; and provide that no financial benefit accrue as a result of membership on the board.</p>	<p>Majority of Board members are comprised of consumers and family members. Composition of the Board is confirmed by organization’s independent audit.</p> <p>Local Program Standing Committee (a minimum of 5 members, majority of which are consumers and family members – and 25% must be consumers) reports to the Board and is responsible for: hiring key management of DA, quality assessment, and development of local system of care plan.</p>	<p>No requirements for required composition</p>

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Quality Management and Improvement</b>			
<p>The State is moving toward a data-driven quality management system with participation by local agents and consumers.</p> <p>A State Quality Management Advisory Council (QMAC) guides the development and implementation of a Quality Management system for the MRDD waivers. Using data reported by County MRDD Bds, recommendations for system changes will be made.</p> <p>The QMAC will help design data reporting requirements for County MRDD Bds that may in the future be reported publicly.</p>	<p>ATC must apply a Life Quality Review process for maximizing an individual's outcomes in the areas of choice, relationships, lifestyle, health and well being, rights and satisfaction.</p>	<p>All service providers are required to have internal Quality Management Plans approved by State and demonstrated data information systems to properly assess and report performance. DAs and SSAs are reviewed every 2 years.</p>	<p>No specific provider level quality management program required.</p>

Ohio Individual Options Waiver	South Dakota Comprehensive DD Waiver	Vermont Waiver for Persons with DD	Wyoming Adult DD Waiver
<b>Critical Incident Reporting</b>			
<p>Incidents are reported to the County MRDD Bd which reports the information to the State. County MRDD Boards are responsible for immediate action, investigations, and prevention planning for each incident.</p> <p>The State <i>Major Unusual Incident and Registry Unit</i> reviews all critical incidents. The State provides TA to providers and counties and conducts annual assessment of each County MRDD Board's incident response system.</p>	<p>The ATC must submit an incident report to the State within 48 hours or the next working day whichever occurs first of becoming aware of the incident. The Division of Developmental Disabilities conducts investigations and sometimes receives assistance from the protection and advocacy agency. A report on aggregate incident data is published annually by the State.</p>	<p>Critical incidents received over past 2 yrs are examined prior to Quality Service Review to identify trends and areas for improvement.</p> <p>Web-based reporting system under development.</p>	<p>Critical incidents are reported to State via electronic incident reporting system. Regional Survey/Certification Unit required to review and conduct incident investigations as needed.</p>
<b>Complaints and Grievances</b>			
<p>The County MRDD Bd must have a complaint resolution process that includes the submittal of complaints to the Director of the State Office of MRDD.</p> <p>The Medicaid office administers the state hearing process and analyzes requests for hearings to identify the frequency and types of requests.</p>	<p>Each provider is required to inform each participant at their annual meeting that if they have any questions, they can contact the division.</p> <p>The ATC must have a grievance process approved by State that allows an individual to appeal any decision or action by the ATC that affects the individual. Aggregate data regarding grievances is not collected at this time.</p>	<p>Plain language brochures on <i>How to File a Complaint</i> and <i>How to Appeal A Decision</i> are broadly disseminated. [Note: these brochures are currently being revised in accordance with new regulations.]</p> <p>Grievance policy addresses issues of confidentiality, retaliation, and mediation.</p> <p>Grievance data received over past 2 yrs is examined prior to agency Quality Services Review.</p>	<p>Providers required to have complaint process with timeframes for response. In addition, the State has its own process for receiving complaints directly and maintains data base for tracking resolution.</p> <p>Providers are not required to submit complaint log to State. State reviews provider complaint process during onsite reviews.</p>

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Oversight of Entity</b>			
<p>The State conducts comprehensive field reviews of each waiver at least as often as the waiver comes up for federal renewal. Based on face-to-face interviews and record reviews for samples of about 400 consumers, the State assesses performance and compliance in regard to all federal waiver requirements, issues reports, and requests corrective actions if needed.</p> <p>Quarterly reviews of a sample of service plans to assess adequacy, completeness and appropriate implementation.</p> <p>The State monitors and accredits County MRDD Boards; accreditation is given for period of from 1 to 5 years. The State also certifies and registers county board employees; certifies HCBS providers; and licenses residential facilities.</p> <p>The State delegates responsibility for some provider compliance monitoring to county MRDD Bds; however, if the county board identifies any concerns during monitoring activities, the State is notified, reviews the concerns, and issues any findings or citations that are warranted.</p>	<p>Biennial reviews conducted by State to assess conformance of ATC with state requirements. Biennial surveys also include a medical and programmatic review for 5% of enrolled individuals.</p>	<p>State team (including at least 1 consumer) conducts Quality Services Review of DA every 2 years thru consumer interviews, record reviews, observation and discussions with agency staff. DA required to submit Quality Action Plan according to state-defined template.</p>	<p>State Survey/Certification Unit is responsible for completing initial certification of new providers and annual recertification of waiver providers.</p> <p>In addition, agencies are subject to CARF review every 1-3 years based on findings. Findings of CARF review submitted to the State for follow up on issues pertaining to health, safety and individual rights.</p>

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Quality Improvement Plans</b>			
<p>County MRDD Bds must submit a corrective action plan in response to issues identified in the accreditation review. Service providers are required to submit corrective action plans as a result of issues identified in the State’s compliance review.</p>	<p>The State requires the ATC to have a Quality Life Review conducted by the State or the Council on Quality and Leadership. The review focuses on a sample (2/3 selected by State; 1/3 selected by ATC) of individuals to determine presence of desired outcomes. At least 17 of the total 25 outcomes must be met for re-certification. All 19 providers are accredited by CQL. The ATC must submit a Plan of Enhancement to State specifying actions to findings of biennial review and Life Quality Review.</p>	<p>State staff assists service providers in development and implementation of Quality Action Plans resulting from Quality Services Review.</p> <p>TA also given to help providers and consumers (who self direct) develop internal quality management strategies.</p>	<p>A quality improvement plan is required for each recommendation made during a provider certification including action steps, responsible parties, and dates of completion for each recommendation</p> <p>Surveyor/Certification staff are responsible for review and tracking of QIPs. .</p>
<b>Public Reporting</b>			
<p>The State is coordinating the development of an interagency set of waiver performance measures which will become a basis to examine performance across waivers and over time, to identify and replicate best practices, etc.</p>	<p>The State publishes an annual report showing aggregate findings of the performance of its waiver programs.</p>		<p>Agency-specific results of CARF and State reviews published on the website.</p>



<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Waiting Lists</b>			
<p>Waiting lists are managed at the county level. Counties are responsible for inputting waiting list data into a State database.</p>	<p>There is a minimal waiting list that is managed by the State. The State reports that they usually know which providers have openings or funding available to serve someone and have ready means for locating services for people in crisis situations.</p>	<p>Each DA maintains a waiting list. The State specifies criteria for waiting list and requires the DA to submit monthly updates via a secure website to assure appropriate allocations.</p>	<p>The State maintains a central waiting list. Rules require that the State alternate between funding the person with the most severe needs based on their service and funding the person who has been on the waiting list the longest.</p>

<b>Ohio</b> Individual Options Waiver	<b>South Dakota</b> Comprehensive DD Waiver	<b>Vermont</b> Waiver for Persons with DD	<b>Wyoming</b> Adult DD Waiver
<b>Stakeholder Involvement</b>			
<p>Consumers participate on the State Quality Management Advisory Council (QMAC) and are otherwise involved in waiver renewals and grant activities pertaining to the waiver program.</p>	<p>The State has program workgroups involving consumers. In addition, consumers participate in designing a pilot project to develop a method to offer consumers a choice with service coordination.</p>	<p>State Program Standing Committee appointed by Governor includes 9-15 members (majority are disclosed consumers and family members). Responsible for hiring key state management, evaluation of quality, development of State System of Care Plan, Policy, Review of aggregate complaints and grievances for trends.</p> <p>Majority of members of Local (DA) Program Standing Committee must be consumers or family members.</p> <p>DA must document consumer/family inclusion in reviews of services delivered, requests for services, quality monitoring, and evaluation of agency program effectiveness.</p>	<p>The Division has an Advisory Council that includes representatives from the regional service providers, independent providers, participants/family members, Governor’s Planning Council for People with Developmental Disabilities, Protection &amp; Advocacy, Wyoming Institute for Disabilities, Developmental Preschools and the Department of Education. The Council meets at least twice a year and reviews the Division’s strategic plan, suggests changes to rules, regulations and policies, and reviews aggregate data on the service delivery system to identify gaps and make recommendations for changes.</p> <p>Division has a Working Group process where stakeholders are invited to participate in working groups that work on development/updating of rules, changes to current procedures or forms, and other special projects.</p>

## Appendix C

### ■ Summary of Stakeholder Input

- ▶ **Keep What's Working**
- ▶ **The CCB as Single Point of Entry**
- ▶ **Eligibility Determination & Resource Allocation**
- ▶ **Waiting Lists**
- ▶ **Case Management Services**
- ▶ **Provider Selection Process**
- ▶ **Consumer Choice & Control**
- ▶ **Participant Complaints**
- ▶ **Pressures on System**
- ▶ **Provider Entry**
- ▶ **The CCB as Organized Health Care Delivery System**
- ▶ **The CCB's Quality Assurance Role**
- ▶ **Accountability**
- ▶ **Consistency and Local Control**
- ▶ **Political Context**
- ▶ **Issues and Comments Outside of Scope**

## ■ Summary of Stakeholder Input

The following narrative summarizes information gathered through:

- A series of face-to-face interviews with ARC representatives, CCB trade associations, CCBs, parents, and participants conducted in Colorado, August 22 and 23, 2007.
- Phone conversations with parents, case managers, provider representatives, Colorado's protection and advocacy organization over the month of September.
- Email communications from parents and some providers received during the month of September.

This summary should be read with the understanding that we do not know the answers to the following questions:

- Are the comments we received a fair representation of the views held by participants, parents, providers, etc.? In fact, it is unlikely that the experience of the participants we interviewed fully represent the typical experience of the people served by CCBs. In particular, we expect that many of the participants we met with had a relatively low level of service need; their relationship with their CCB is therefore likely to be less intensive than other participants might experience. In addition, many of the participants we met with received state funded, not Medicaid funded services.

We also heard concerns that some people are afraid to express their opinion for fear of retaliation. In addition, some parents questioned whether the process for soliciting input was selective.

- Are the positive and negative comments predominantly connected to just a subset of CCBs or can they be generalized across many? A number of people we talked to, including advocates and CCB representatives, seemed to agree that the problems identified were associated with only three or four CCBs, although we do not know if they agreed on which CCBs. We also heard complimentary comments about particular CCBs.
- Is the information gathered an accurate representation of a problem, or is it skewed by that person's understanding of the problem? There may be cases where we can answer this question but not generally.

### **Keep What's Working**

We heard from many parents that any changes to the system should not interfere with what's working. Said one parent: "If it works, don't fix it!"

For many, the system is working well. Many fear how change will impact services that they depend on. More than one parent shared the view that: "Without the funding we have received...we would be lost." Parents were worried about the potential for added costs and

administrative burden reducing the amount available for services. One person also worried that the familiarity of existing relationships would be lost if the current system were disrupted.

### **The CCB as Single Point of Entry**

The CCB serves as the single point of entry for people who want to access DD services in their service area. We asked stakeholders about the advantages and disadvantages of having the CCB serve as the single entry point to services.

A number of stakeholders identified the positive roles a CCB can play:

- The CCB is a “soft place to land” for parents just learning that their child has a disability. Several parents described the valuable role a CCB can play in helping parents adjust.
- The CCB serves as the “face” of developmental disabilities in their community. One parent cited the role that the CCB plays in building community connections, with the CCB as the known point of contact for working with the local community to address problems affecting the DD population.
- Also because the CCB is known in the community, a CCB representative noted that CCBs serve as a primary contact for responding in an emergency situation.
- Several stakeholders said the advantage of the CCB was having one place to go to get answers. Some parents mentioned that the CCBs provided access to and information about the service and provider choices available to them. One parent said “I like having one central place to coordinate placement, provider organizations, and other services for those with developmental disabilities.”
- A case manager suggested that having a single point of entry for developmental disability services made it easier to coordinate with other single points of entry (*e.g.*, the elderly, blind, disabled waiver).

CCBs appear to vary in how they comply with the statutory requirement for an annual public meeting and annual plan. One CCB reported combining the annual public meeting with a provider fair.

Others questioned whether or not CCBs were visible access points:

- Several parents thought that entry through the CCB is not obvious for people who are new to Colorado. (This is compared to a number of parents reporting they were quickly linked to services when their child was born in Colorado.)
- One advocate reported that the educational system does not always know to refer to a CCB; she saw this as a problem given that the educational system is responsible for educating the school system about how to access services.

There seemed to be some consensus that the visibility of the CCB, and its effectiveness as a single entry point depended on whether or not the CCB was located in a rural or urban community.

People also worried about how much control the CCB had because it served as the single entry point:

- One parent said that because the CCBs have a “captive audience” they are not motivated to provide objective information on available services.
- One parent said the CCB “limits our options and puts us at the mercy of their effectiveness and bureaucracy.”
- A case manager said the downside to having only one entry point in a service area was being stuck with the “personality” of your CCB.
- A number of stakeholders said the CCB does not have an incentive to “think outside the box” to develop creative service solutions.

Stakeholders discussed different strategies for addressing concerns about the CCB’s single entry point role:

- The idea of providing independent information and referral was not seen as useful in rural areas, where the CCB is the only provider. At the same time, one parent suggested that information and referral should be done by a provider who would make referral to generic supports (e.g., the YMCA); this parent said when information and referral is provided by a disability provider, referrals tend to be toward disability-specific services.
- Several stakeholders, including parents, advocates, and CCB representatives, discussed the need for other options. In Colorado, if a person is dissatisfied with his or her CCB, that person can request case management services from another CCB. However, it was agreed that there were some serious logistical problems associated with that option. First, the other CCB can deny the request. Also, particularly in rural areas, the closest CCB can be a long distance away.

### **Eligibility Determination & Resource Allocation.**

The CCB is responsible for determining whether a person is eligible for developmental disability services. They also administer the level of care assessment for determining whether or not a person is eligible for waiver services. CCBs are responsible for assessing an individual’s need for services in order to develop a service plan.

One case manager said that the Level of Care (LOC) determination is subject to interpretation. Some CCBs are more liberal and others conservative. Some people believe the CCB uses the eligibility determination process as a tool for screening people out if they are hard to serve. One advocate said some CCBs are frequently overturned on appeal; while others apply the eligibility

criteria much more loosely. This advocate speculates that some CCBs are tightening up how they interpret eligibility to keep down their waiting lists.

CCB representatives reported that the eligibility determination process has recently become muddied because a number of decisions have been overturned on appeal. The CCBs believe that their determinations have followed the letter of the law but the administrative law judges (ALJs) have not. They believe the ALJs need better training or the Department needs to clarify that it has changed its eligibility criteria.

Many agreed that Colorado's plans to use a standardized assessment tool for allocating resources was a positive step in the right direction and would address some concerns around consistency. Many, including representatives of the CCBs, agreed that administering the SIS should be done by someone other than the CCB. Advocates believed the CCBs would game the SIS. Some CCB representatives believe they would be asked to game the SIS or would be accused of gaming the SIS, and wanted to stay away from that problem.

Advocates, many parents, and some CCB representatives were comfortable with the idea of taking the functions for eligibility determination, level of care determination and the allocation of resources out of the CCB. One parent noted that people have to go through the county to apply for Medicaid anyway, so it makes sense to have the county be the single entry point. (Another parent had experience with both the Elderly, Blind, Disabled (EBD) waiver and the DDD HCBS waiver. To this person, access to the EBD waiver system was very concrete and straightforward. For the DDD waiver, access is more complicated, vague, and "murkier.")

A number of parents and others worried that reassigning these functions would add another administrative layer and more costs, creating more bureaucracy and reducing the money for direct services.

### **Waiting Lists**

A number of stakeholders expressed concern about how waiting lists are managed. Some perceive the CCB playing favorites, moving board members, employees or favored parents up the list faster. Some parents were dissatisfied with the case management services available to them while on the waiting list; that the CCB makes no effort to connect a person to services outside of those within the CCB's domain.

The CCBs say that they are not paid to manage waiting lists and are paid very little for case management services for those on the waiting list.

Some thought that there needed to be more transparency and consistency in the way waiting lists are managed. The idea of centralizing the management of waiting lists would raise concerns if that meant that all CCB waiting lists were merged into one: some were concerned that people in rural areas would essentially be shut out of services, given the higher volume in cities.

### **Case Management Services**

Parents had a lot to say about the quality of case management services. Many parents see their case manager as having their child's best interests at heart. A number of people were able to

describe the personalized and effective role that a case manager had played in addressing their child's needs:

- “The people we dealt with at every level were kind, caring and professional individuals.”
- “[My son’s case managers] are caring, meticulous and sensitive to the needs of both the clients and families of the client!”
- “I find that the case managers for my ward consistently place his needs before those of the agency by whom they are employed and ensure that the his needs are met, his rights as an individual are protected and that he is given the opportunity to succeed as an individual.”
- [Our CCB] stepped in...and provided very caring, skilled representatives who helped us navigate some difficult territories.”
- “[Our care manager] was right there the whole time working with our schedule and making sure that [our son] received the required help.”
- “I am certain my life has been repeatedly graced by the endurance, tension holding and sustained focus of [my son’s] numerous case managers....
- They have always been helpful and conscientious in their work. We find that they are the most client-friendly of any agency we deal with.”

One parent noted that her child’s case manager was not familiar with her child’s condition but was willing to learn. Some parents said their own skills as an advocate for their child left a minimal role for their case manager, but they could turn to their CCB when they had a problem. One parent said she and her case manager would not always agree but they work as a team and make the best decisions under the circumstances. She said she is comfortable challenging decisions with her case manager’s boss. One parent described the role her CCB played in teaching her to be an advocate for her child, providing funding and respite so that she could attend training and support groups.

Other parents had less favorable things to say about their case manager. Several described their case manager as “not very helpful,” or inexperienced, or nonresponsive. Some parents shared stories about instances in which their case manager’s failure to give them correct information had resulted in lost funding or a lost opportunity to access services. Another parent said his child has had six case managers in the last year and half. This parent said these case managers have not observed his child in any other context except in the case manager’s office, so do not have a good understanding of his child’s needs.

Others comments include:

- “[H]ere is what is missing in case management: Plans that have goals and solutions in them with direction on where to apply for what is needed. We are on the wait list so our



case manager really is only supposed to meet with us twice a year to discuss what we will do with family support funds (which is a couple hundred dollars a month). Nobody talks to us about what we can do outside the CCB system. There is no plan. No direction at all, when there could be. Some people could end up not even needing supported living and comp services if they did that because there are other resources. So a plan should include how to apply for Section 8 vouchers, how to connect with Voc Rehab for job services, etc., to address the needs of an adult who wants to live on their own and work! I am constantly learning new things from other people, not my case manager. (I found out my son did not have to use Ticket to Work to work with Voc Rehab again – and that now I am wasting his Ticket to Work money!) I told my case manager that my son wanted more education. She sent me a list of community colleges, etc. But I told her when I met with her recently that what she doesn't know about that is that my son (because he has an IEP) can't be in a degree program, can't get the accommodations he needs, etc. So those schools may work with people in wheelchairs, etc., and my son could audit classes, but to what end? How does that translate into a job?...[N]obody seems to be understanding that all resources should be considered for each individual and a plan should be based on what is available to them at the time to achieve their goals...so they don't wallow away in quiet desperation....”

- “My daughter’s case manager has been changed 7-8 times in the last 10 years at least. And not to different people [because of] turnover, but switched around to the same 3-4 people over and over. And she isn’t a difficult case at all. We get contacted once a year, when it’s time for her IP. But these will be the people the state and the CEO will listen to when it comes time to make decisions about her care.”
- “I don’t get a lot of input from my worker as to what is out there for my son. I have to be on top of it, I have to be the one to search for resources.” This parent said the CCB’s role is not “personal.” It is playing a “clinical” or “administrative” role.

Parents also identified some of the problems impacting case managers and suggested additional supports:

- Some parents recommended better training for case managers.
- One parent mentioned the importance of a good supervisor.
- Parent representatives also identified poor pay as a factor contributing to the quality of case management, with poor pay contributing to turnover.
- Parents and CCB representatives cited the additional administrative burden created by recent reforms as another factor affecting the quality of case management services and turnover rates.

CCB representatives report that case managers are leaving their jobs because of the added bureaucracy resulting from recent reforms.

Other parents talked about own their role as advocates for their children as a way to complement the services provided by their case manager. They said the family or participant needs to take responsibility for exploring all the options. Some thought that strong parental advocacy was important for getting their child what was needed, while at the same time saying that it shouldn't matter who you are or what you know, everyone should be treated the same.

For the participants interviewed, the role of the case manager appears to be very limited. Participants reported that they meet with their case manager only once per year, when it is time to develop their IP. Case managers can also be involved "when there's a problem," but they were not the first person called by any of the participants interviewed. (It should be noted that the utilization patterns of the people interviewed are very possibly not representative of those receiving services.) Not all participants were happy with their case managers. One member objected to the barrier that her case manager and her guardian presented when it came to choosing services based on her preference.

One advocate reported that the State used to have annual case meetings for case managers, which was a way for the State to stay connected. That program has been continued and no other mechanism exists for maintaining contact with case managers.

### **Provider Selection Process**

Advocates, CCB representatives, parent representatives and participants all had a similar understanding of the provider selection process as it should work: The case manager works with the individual to identify needed services and identifies available providers. For those that do not already have a preference for providers, the case manager drafts a profile of the individual. The profile is used to solicit interest among providers. Providers participate in an RFP process and the case manager helps the individual learn more about potential providers in order to make an informed choice.

Many reported experiences consistent with the ideal process:

- All of the participants interviewed had a favorable impression of the provider selection process. All recognized that a participant is not limited to the services offered by a CCB (unless the CCB is the only provider in the area). Some reported that their case manager identified potential providers and set up interviews, so that they had an opportunity to meet with different providers before choosing.
- Some parents reported that their CCB had been extremely helpful and helped them navigate a difficult process. Several described the important role their case manager played in helping to develop a list of questions for prospective providers, so that they could make an informed choice.
- One parent said her case manager helped her identify a range of providers that were better at serving people with her son's needs. A packet was sent to all of these agencies, and the parent and case manager interviewed the providers together. The case manager had helped her develop questions for these interviews and identify what to look for given her son's specialized needs. The case manager did not sway her in her decision. One of

the service agencies under consideration was part of the CCB. She said her case manager helped her come to the conclusion that the CCB's service agency did not have the right capacity to serve her son.

For others, the provider selection process has not worked as well. Some parents reported that they were guided to the CCB's services and that they had a hard time finding out about other options. Some parents said their CCB publicized only their own services so that people, not knowing about any other options, come to the CCB with a preference for CCB services. (When an individual already has a preferred provider, an RFP to other providers is not required under DDD rule.)

- One parent described a meeting held by her CCB as follows: "The meeting was advertised as parent information on the [comprehensive] waiver. I was particularly interested in going to the meeting to find out what housing options were available. When it got to that part of the meeting addressing housing options, I noticed that one particular housing community that I knew about wasn't mentioned. Since this was my first foray into exploring the possibilities for my child, I was a little confused that I didn't hear the name of the provider I was aware of. I specifically asked if there were any other housing options. The answer was no, these are the ones we have (a technically correct answer, as these were the residential options managed by the CCB--but not really the answer I was seeking). After the meeting, I asked about the housing option I was aware of, and the presenter said that this meeting was for the services offered by the CCB. It was stated that there would be a meeting at a different time with information on other providers (which I have never seen a flyer about - and it has been almost a year since the meeting I attended.) It is possible that I missed the notice for the additional meeting."
- One parent raised questions about a newsletter advertising one of the CCB's service programs. This parent wondered if that service agency had paid for advertising in the CCB's newsletter or whether other service providers had been offered a similar opportunity to advertise in the newsletter.
- Another person, objecting to a flyer inviting parents to a forum about the CCB service programs, expressed the view that it is inappropriate for a CCB receiving public funding (including mil-levy funding) to provide access to services to spend that public funding on advertising only for its own services. This person wondered if this CCB would be distributing information about other providers.
- One parent said tracking down information about providers was confusing. She did not know if she had a complete list of providers, which included only 40 service agencies while she knew her CCB contracted with over 100 independent contractors.
- The provider listing on DDD's website was seen as a positive move, but some did not think it was sufficiently family friendly or publicized. Discussing the lack of clarity in the listing, one parent said: "It would be great to have a 'yellow pages' service directory for the CCBs. Then I could look under transportation and here are all the providers, and

here are the day programs and here are the residences and here are the providers that do community access.”

- Some parents were frustrated by the fact that the CCB could only hand them a list of providers but could not tell them about their quality. They saw the need for tools to help the parent evaluate provider quality. One provider suggested that CCBs hand over the list without more support as a way to steer people into the CCBs services: people are given the option of the CCB’s services or handed a list to sort through on their own.

Case managers had mixed experience with the provider selection process. One said that as long as you keep in mind the needs of families and participants, it is not a problem to be objective in the provider selection process. One case manager said it is sometimes easier to identify the weakness of the CCB providers than other agencies.

Another case manager found it very difficult to be objective. She reported that case managers at her CCB were pushed to fill openings for the CCB’s service providers. She said clients are only occasionally given a list of all available providers. She said that if a participant or family member comes in preferring another provider, the IP meeting is about why they did not choose the CCB’s services. She reported that the administrative office manages the provider selection process; she does not know which providers are solicited; she does not know if she sees all responses or if they have been screened. The case manager’s job primarily is to process claims and monitor service plan implementation. This case manager reported working at other CCBs and not experiencing the same pressure. She reported that there is very little separation administratively between the service agencies and case management services; nor is there separation in the eyes of the consumer walking in the door. Case management and the service providers are located in the same building, and sometimes across the hall from each other.

A provider also talked about the blurred lines between the case management services and other services. Often, without other information to clarify the relationship, people are referred to the CCB’s services as the only option available to them. In questioning the effectiveness of the “firewall” between case management and direct services, this provider said: “If you still have the ability to confuse people, how good is your firewall?”

Other concerns about the provider selection process:

- Advocates and parents reported that they were not given an opportunity to review the individual profile before it was shared with providers. Some parents said the profile should be strengths based but is often negative.
- A number of stakeholders expressed concern that the CCB bypasses the RFP process by selectively referring people to their own service providers. A provider reported her understanding that the planning meeting involves the CCB’s “sales people,” who when a need is identified, say “We can take care of that” and the individual is never given a list of other options. Or, in response to a request for employment services, a case manager says: “Let me put you in touch with our Employment Services.” One case manager reported a specific example of a CCB bypassing the RFP process. The CCB legitimately

placed people in residential services in an emergency and then kept them there without opening up the long term placement to other providers.

- Advocates believe the CCBs are selective in who they solicit interest from, rewarding providers in the CCB's "good graces" and steer people to the CCB's own services. From their perspective, CCBs reward providers who do not complain about rates or make referrals to the ARCs.
- Some saw the CCB redirecting the harder to serve to other service providers. The advocates see case managers as responsible for limiting the CCB's liability, and "cherry picking" the easier to serve, rather than finding the best match between participant and provider.

Other comments on the provider selection process:

- Some people saw themselves as having the right to advocate for more choice.
- Some people thought the problem was less about lack of information about choices than it was the lack of choices, or service options, for people with specialized needs.
- One parent objected to the perceived premise underlying the provider selection and RFP process. For this parent, the CCB should be developing a program to meet a participant's needs rather than finding the program the participant fits into best. The individualized plan is supposed to be unique, with needs met through a variety of service agencies. Instead, standard services are offered "as close as we can get" to individualized need. Another parent agreed, saying provider selection is about "what's most convenient," even if it means fitting a round peg into a square hole. Other parents saw it easier to be flexible and individualize services in rural areas.
- One parent thought that providers don't have enough information to decide whether to respond to an RFP because the amount of funding allocated to an individual is not specified. This concern may be addressed by the standard rates to be implemented by the Department.
- Some parents said they had a lot of provider choices but have trouble finding quality providers. Some said quality was an issue for rural areas

CCB representatives agreed that there may be inconsistency in how the provider selection process plays out for different CCBs. They agreed that there was a need for consistent standards for how to document adherence to this process. Some of their suggestions:

- Standardize the provider selection process and create more transparency in RFP process.
- Standardize what the case manager says in the provider selection process; require participant to sign a document to acknowledge that they were informed about options.

- Standardize what the case manager says about participant rights and advocates; require participant to sign a document to acknowledge that they were informed about options.

CCB representatives refute the claim that CCBs cream the easiest to serve. CCB representatives see the CCBs as the “provider of last resort,” serving the hardest to serve participants. One CCB representative reported that his CCB decided to provide services only because previously his CCB had been “held hostage” when negotiating with service providers over rates and placement. Another CCB representative offered to produce data showing that his case managers refer to other service providers at a much higher rate than to services provided by his CCB.

CCB representatives do not believe that CCBs play favorites among providers. One CCB representative reported that his CCB has been accused of favoritism even when it was not providing a competing service. In his eyes, the case manager provider is always susceptible to that claim.

In rural Colorado many CCBs are the only service provider. One rural CCB representative reports that he would welcome other providers in his community; he reports, however, that previous attempts have failed because he is not able to guarantee sufficient numbers of participants. (One provider mentioned the challenges of expanding to a rural community if the CCB is unwilling to work with the new provider.)

### **Consumer Choice and Control**

The issue of consumer choice and control came up in a number of different ways.

Some parents mentioned their own experience with consumer directed services and the State’s plans for expanding these options:

- Parents and participants discussed an earlier taskforce which had issued a series of recommendations for consumer directed services. Parents saw CMS’ interventions as sidelining these recommendations. Parent representatives said they would like to see consumer direction as part of every waiver.
- One parent expressed disappointment that the person centered planning pilot project in her area had come to an end. She saw the use of person centered planning and direct funding as ideal for her son. Now he participates in the traditional annual IP meeting, where “almost everyone but my son has input and say in the plan.” Also, the funding for services is reduced with the administrative costs associated with traditional services.
- Another parent described her arrangement under the SLS waiver, saying that she had complete control over how her daughter’s funds are spent and what providers work for her. Her CCB serves as the employer of record and processes payroll. She “orders” services online each month. She can select among approved providers, including family-recruited providers. This parent believed that expanding this model to other parts of the State would “address some of the conflict issues and create competition that should drive quality and innovation. A completely consumer-driven model without CCB intervention should also be made available to participants/families who want to take on the

Some parents report that some CCB directors discourage people from the idea of consumer directed services, suggesting that there will be no recourse if there is a problem. A provider said that CCBs do not want families to know that they can be their own case manager under the SLS waiver; they tell them that emergency funds will not be available if there is a problem.

A number of stakeholders shared the view that the lack of a consumer directed option strengthened the CCB's hold on the system; participants are bound to the case management and referral practices of their CCB.

One parent cautioned that self determination will work for some people but not others and that other options should be available.

Other stakeholders talked about the need for more control over decision making generally:

- At least one parent expressed frustration about the CCBs and their case manager's "unilateral control" over decisions, in which the parent is informed "here's what's been done" without an opportunity to weigh in.
- Another parent wrote: "[My CCB] has had a stranglehold on services for as many years as I can remember. It is the one stop where you get told what services they provide, which services you can have (regardless of what you might NEED) and where you can get them."
- Another parent said "I'm tired of being told that a stranger, someone who is paid to be in my daughter's life, knows more about what is good for her than I do. Someone with no relationship with her can come in and make decisions for her, and her family for that matter, without even knowing them."
- One parent talked about the fact that families are left out of the loop in managing their child's budget. She does not review the provider contracts, get a monthly statement, see payment rates or bills. Nor does she know whether a worker has been paid. This parent thought this information would be helpful for better managing how her child's resources are managed.
- Advocates reported that the CCB, having control over access to services, can place demands on participants and deny services when a person does not meet those demands. They saw this as one strategy for limiting the CCB's liability for "difficult" participants. One advocate cited the example of a person presumed to be sexually dangerous who was denied services because the individual refused to participate in a behavioral program.

A number of parents and advocates talked about how the lack of consistency across CCBs limits consumer choice and control. Because eligibility, resource allocation, and payment rates decisions vary across CCBs, when a person wants to move from one catchment area to another, “everything changes.” The uncertainty connected to whether or not a person will lose services, inhibits a participant’s choice to move.

### **Participant Complaints**

Many people talked about the ability of participants and families to make complaints. An advocate noted it is often very difficult for a person with developmental disabilities to advocate for him or herself. As a result, it is important for people with developmental disabilities to have someone who can help them navigate or connect them into the complaint process. While some were satisfied with the way things worked, others saw problems.

The participants interviewed talked about their own experiences advocating for themselves. While many people agreed that it is was important to speak up, many found it hard to so: some participants reported that they are afraid to speak up. Some reported that they are shy, or don’t know how to say what they want to say, they are afraid of saying something wrong, or they are afraid what they say will “come back at them later.” One person said it is intimidating speaking up to people in higher positions. Another person said if they speak up, they are afraid they will be “mowed down.”

Many parents also talked about their fears about speaking up:

- A number of parents discussed their fear of retaliation. One parent said that there are no checks and balances on the CCB, and parents are reluctant to “bite the hand that feeds you.” One parent saw the participant profile, used to solicit interest among providers, as one mechanism for retaliating against a parent that complains. The CCB will negatively describe your child to discourage responses. In her case, she reported that provider agencies often reported that her son was not as challenging as the CCB had described him in his profile.
- Some said parents are either “in or out” with the CCBs or the Department, depending on how much trouble they are. If you are out, you do not receive notices, you are not invited to be on boards, you do not move up on the waiting list, etc.
- One parent said that concern about retaliation is greater in the adult service system where services are not an entitlement and can be more easily pulled.

From the CCB perspective, the allegations of retaliation are particularly frustrating. They see themselves as unable to address complaints when they are made anonymously, but the complainant will not come forward for fear of retaliation. CCB representatives acknowledge that there must be fear of retaliation among some participants and families but have not seen documented evidence. They reported that only a very small fraction of complaints last year included allegations of retaliation. They also noted that some people will perceive retaliation when services are terminated or reduced, even when the reduction in services is related to budget cuts not retaliation.



One advocate said that the complaint process is not an adequate safeguard for developmental disability services. This advocate said people with developmental disabilities often need assistance in advocating for themselves or need someone to advocate on their behalf. A number of people discussed what can be an uncomfortable role for a case manager who is advocating on behalf of a participant and challenging the CCB. Advocates see case managers as intimidated by their employers, the CCBs, limiting their freedom to advocate on behalf of the people they serve. The advocates wonder why more case managers are not filing appeals to help get services; they report that a case manager is put in the position of appealing to his or her boss to not reduce services. One advocate said only a handful of case managers are willing to stand up for their client.

The challenges of advocating against their employer were confirmed by a number of case managers interviewed. We heard from more than one person about how difficult it is to advocate on behalf of a participant against the CCB; that the participant is left without a strong advocate. At the same time, one case manager, finding no satisfaction from her CCB brought her concern to the State. She acknowledged that others might not feel comfortable with that approach.

Some sources said that CCBs also discourage access to external advocates, including the ARCs:

- According to an ARC representative, at least one CCB has told providers in its service area to stop calling the ARC, that they should call each other to figure things out. The advocates report that the CCBs do their own investigations into abuse and neglect and believe the local social services agency blesses their findings.
- One parent reported that a CCB tried to cancel a provider's contract accusing the provider of being a disruptive force by inappropriately advocating for its clients. In the eyes of the provider, it was a matter of holding the CCB accountable.

Many also identified problems with the way complaints are resolved.

- Advocates report that the review at the CCB level is potentially biased by the fact that CCB directors appoint themselves as the impartial hearing officer, based on the understanding that they were not directly involved in the underlying dispute.
- Some parents reported that appearing before the administrative law judge is intimidating.

The CCB representatives noted that the mediation process recently developed has hardly been used. Several people advocated that there needed to be a different, independent pathway for making a complaint, so that the complaint does not fall back on the head of the person making the complaint.

Of the participants interviewed, none said they called their case manager as their first step in addressing a problem. In general, people go to their provider or their family and friends, before they go to their case manager. At least one person reported that the anticipated delay in response time was one reason why she did not call her case manager. In addition, it's likely that because

this group only met with their case manager once a year, they did not see their case manager as the place to go for help with a problem.

### **Pressures on the System**

Many stakeholders talked about the challenges presented by the shortage of funding for services. Funding shortages were blamed for a number of problems:

- **Waiting lists:** CCB representatives reported that there are very long waiting lists for services (reportedly ranging from 10-20 years to 150 years).
- **High caseloads:** CCB representatives reported that case managers have very high caseloads and that the CCBs get paid very little relative to the services provided. One CCB representative reported that he subsidizes his case management services with other funding sources, including the mil levy. He said the State pays to provide case management to 300 people and he is able to provide case management to 900. CCB representatives reported that they do not get paid for managing waiting lists.
- **Unhappiness:** CCBs say that funding shortages mean they have to make hard choices which lead to unhappiness. They see rural CCBs as having an easier time being flexible, since the problem of creating precedent is less where there are fewer people. A number of parents reported that satisfaction with services is very likely tied to whether or not your child is receiving services as an adult or child. The range of services is greater for children so parents tend to be more satisfied. The pressure of finding services for an adult creates greater frustration with the system.

A number of families described the challenges they face while they wait for services or because needed services are not available, including therapies, employment support, respite, etc. One parent shared her gratitude for the progress her son had made because of the early intervention services he had received and explained that, had her son been born a year later, he would not have received the same services because of funding cuts. She said children are now going without needed early intervention services. One parent noted that the waiting lists are so long you need to be poor or in crisis in order to get services.

### **Provider Entry**

Previously the CCB had a role in controlling provider entry into their catchment area. That policy was changed recently so that the CCB is responsible for reviewing a provider application for completeness and submitting it to DDD for approval.

Prior to the recently policy change, providers objected to the inconsistent criteria used by CCBs for approving or disapproving a provider's entry into its service area. In some cases, a provider would be approved by one CCB and denied by another. The recent policy change does not eliminate the variation in a CCB's criteria for approving a provider. However, with recent changes, a provider approved by one CCB is now approved to provide services throughout the State.

One provider said a CCB's unwillingness to work with an approved provider can be another effective barrier to provider entry in rural areas. The CCBs believe that recent changes have minimized their role relative to approving provider entry. They see the role of the CCB as purely an administrative pass through of the required paper work. They see this change as having a negative effect on their ability to assure the quality of providers in their service area. The ability of a provider to expand to other service areas is viewed as a negative, with questions raised about the adequacy of state review of expansion letters. CCB representatives say it is in the CCB's interest to have a lot of service options in their area, mitigating any incentive to block entry.

### **The CCB as Organized Health Care Delivery System**

Although recent reforms have reduced the role of the organized health care delivery system (OHCDS), a provider representative reports that providers see several advantages to joining an OHCDS. The CCB provides a billing service attractive to smaller providers unequipped to manage billing under Medicaid. Billing through the CCB also offers greater security on cash flow, as compared to direct billing to Medicaid. Also, the OHCDS is viewed as a buffer in the event that problems arise, because the CCB is the accountable entity. Providers also believe that participation in an OHCDS puts them in a favorable position for receiving referrals and for benefiting from mill-levy funding. One provider said fear of retaliation is the primary reason for participating in an OHCDS; she said providers are afraid that the small amount of referrals they do get will go away if they do not participate.

Some CCB representatives saw this shift as a short-term policy change made in response to direction from CMS. These representatives thought the service system would move back to an OHCDS model, believing CMS and states would find fee-for-service unsustainable over time. For this reason, one CCB representative believed there is still value for a CCB to maintain the OHCDS relationships developed before the reforms were implemented. CCBs also see a contractual relationship as the most expedient mechanism for addressing quality issues. In the absence of a contract, which can be pulled for a violation, the CCB has to wait for the State to intervene. The State often is more cautious in making interventions. At the county level, the social service agencies are seen as understaffed and not able to make timely responses.

One person provided an example of how a CCB favored itself in establishing reimbursement rates. In this case, a provider had requested an adjustment to negotiated rates in response to a change in a client's conditions. The CCB denied the request and as a result, the provider was no longer able to meet the individual's needs and the contract was terminated. The client was then referred to a CCB provider agency and the rates were increased to cover the additional services needed. Many agreed that Colorado's effort to develop standardized rates would address some concerns around consistency and transparency.

CCB representatives reported that they are limited on the fees that they charge for SLS and that audits would show noncompliance with these limits. On the other hand, according to CCB representatives, service providers submit financial statements but CCBs do not know how service providers spend their money.

## **The CCB's Quality Assurance Role**

The CCB is responsible for overseeing the quality of service agencies, including its own service agencies. The CCBs saw themselves as having a strong role in regulating themselves. Some see the “corporate culture” as an important determinant of quality: there needs to be a top down message from leadership that the participant is at the center of services. They also said CCBs can (and do) take responsibility for bringing up the quality of other CCBs, by sharing best practices.

The CCBs identified a series of QA mechanism that they use to monitor quality including: independent satisfaction surveys, trend reports on incidents, investigations (which provide direct reports to the CCB board), complaints, and spot surveys.

We heard from a number of stakeholders about concerns that CCBs were very good at addressing quality concerns for other service agencies, but were less responsive when it was their own service agency. A provider suggested that CCBs can use the quality assurance function to retaliate against providers, by nit picking. She said the company she contracts with is her direct competitor; as a result she is held to a different standard. One case manager said, when it comes to monitoring services, other service agencies are very responsive but she has little leverage to make things happen with the CCB's providers; she often experiences a lot of resistance to making changes she proposes; this case manager said the CCB she works for suppressed something that should have been a reported incident, saying “Let's move forward.” Another case manager described the subtle effect of personal relationships developed by working in the same location. “They're in the lunchroom together every day,” making it more difficult for the case management side of the CCB to challenge the performance of the provider side. We also heard concerns that CCBs favor contracted providers (providers billing through the CCB, and paying a fee for that service) over independent providers (providers billing directly to the State).

A provider representative expressed concern about the lack of consistency across CCBs. CCBs are required to submit their monitoring plans to the Department but providers note there is no standard process or format for these plans. Agencies can be monitored by multiple CCBs, with potentially different expectations and potentially different outcomes and issues raised. This person said there is also variation in the requirements coming from the different Human Rights Committees associated with each CCB. Some require major documentation and others minimal evidence in others. In the eyes of this provider, CCBs have been delegated authority with limited standardization and transparency, leading to significant variations in practice. They are viewed by providers as quasi-regulatory, without strong central oversight. This person believes that the State should take a stronger role in imposing standards and insisting on transparent practices in operation and quality oversight.

Advocates thought the CCB should not have a quality assurance function over its own service agencies or other service agencies.

CCB representatives thought it was very important for the CCB to have some control over the quality of providers operating in their catchment area. The CCBs see themselves as playing an important QA role, providing technical assistance and monitoring services. CCBs also reported that the CCB has a strong incentive to be on top of the quality of all providers, whether its own,

contracted, or independent. When providers fail the CCB is held responsible for finding alternative services and can be held liable for any injury resulting from a poor quality provider. In the eyes of the CCBs interviewed, the CCB holds itself to a higher level of accountability when it also provides services. They also report that their own case managers are some of the toughest critics of services provided by the CCB and that the division between case management is very real within the CCBs represented. CCB representatives believe that the DDD onsite survey would catch any favoritism were it to exist. They are not aware of any documented cases of favoritism toward contracted providers.

Advocates see the Human Rights Committee as a “rubber stamp” for CCB actions. They report that only the information provided by the CCB is provided to the HRC. Also, advocates reported that those members who challenge the CCBs are “uninvited” as continued members. Some parents also reported that there are some parents that are “in” with the CCBs that get invited to participate on the HRC or board but that those parents that are not “in” never receive an invitation. One person reported that, as a member of a Human Rights Committee, he was in position to pass judgment on the care provided for many of the CCB’s clients; he said the CCB regularly proved itself to be an excellent provider.

Some CCBs saw the need for a stronger hand from DDD. Some of the improvements suggested by CCB representatives include:

- Greater DDD involvement in incident investigations; DDD should be reviewing incident reports.
- DDD should respond to legitimate issues and questions raised by families and participants.
- Faster response from DDD in emergencies; the CCB has to write a report and can wait 1-3 weeks for a response from the State, during which the situation is not corrected. The CCBs see themselves as the party held accountable.
- Stronger leadership from DDD; more willingness to take the heat. DDD should have a wider range of tools for regulating CCBs; right now DDD has only a big stick or no stick.
- DDD conducts all satisfaction surveys, so that the surveys are seen as independent of CCB influence.

Advocates regretted changes to DDD’s onsite survey process. In the past advocates participated in these surveys. Advocate representatives saw value in having an independent set of eyes to identify potential problems. Also, advocates reported that the participant evaluation of services is facilitated by the case manager or the service provider, creating a potential barrier to accurate and honest participant feedback. They report that there is anecdotal evidence that the participant evaluations are manipulated.

## **Accountability**

We heard a wide range of comments from parents and advocates encouraging more transparency and accountability for CCBs.

- One parent thought it was important for the salaries of CCB executive directors to be publicly available, making the board of directors more accountable for salary decisions. Several parents raised concerns about the salaries of executive directors, expressing concern about how tax dollars were being spent and who makes decisions about salaries.
- One parent identified a series of concerns about a CCB's accountability. Beginning with her concern that her CCB provided full day programs to the children of employees, she asked: "How do services get divvied out? Who makes those decisions? It feels like those committees, there to protect us, are hand picked by those who are holding the purse strings. How about a more fair selection process? Who is monitoring the hand picked committees....? When asked for documentation on how the services or funding is divided, they don't provide policies/procedures—even though they will tell you they do. Same thing when asked for a copy of the budget, it's not available, can't have it, can't get it."
- A number of comments relate to how funding decisions are made: "We constantly hear the problem is with funding. However, why won't they show us where the money comes from and where it goes?" "[T]here is no transparency in the finances so it is hard to tell the cost of the services being provided or how much has been spent." One parent reported having to cut back on services although the amount of money available to his child is the same. He attributed this reduction to higher charges from his CCB.
- One parent suggested that families receive an Explanation of Benefit, so they can monitor what is being claimed for services. Access to this information would also make it easier to manage the choices they are making.

One parent objected to the recent changes connected accountability. While recognizing the need for accountability, she believes the CCB must be able to serve its clients without the accountability process interfering. She hopes her CCB will not have to continue to say "Mother may I?" for routine fiscal decisions, including approval of a \$50 recreational class for her son. This parent was confident that her CCB had adequate internal accountability mechanisms in place before these recent reforms were made.

Some CCB representatives agreed that there is a need for greater standardization and transparency in how CCBs operate.

## Consistency and Local Control

More than once Colorado's CCB delivery system was described as "twenty different systems operating in twenty different ways." Said one parent: "It's the luck of the drawer where you live."

Some of these differences are procedural, *e.g.*, how eligibility criteria are applied, how waiting lists are managed, how the provider selection process is managed. One person reported that one CCB, responsible for determining eligibility for the CES waiver, had determined that no child in its region met CES waiver requirements. She reported that she knew that not to be the case and her organization helped to get this waiver implemented in this area.

Other differences seem to be philosophical. One parent described making a choice about where to live based on one CCB's practices relating to segregated, rather than integrated, services.

Others are cultural. To a large extent, cultural differences appear to be driven by the urban or rural nature of the community. Many parents talked about the flexibility and responsiveness of CCBs in rural communities. One parent having personal experience in both urban and rural settings, described urban services as "overwhelming." Participants are "almost treated like a number," with the question being what they can provide not what is available in the community. In the rural area where he now lives, services are responsive and personalized, and the CCB and the local community have taken creative approaches to develop employment opportunities and fundraise.

The quality and availability of services was also identified as another difference. Some saw this, too, as connected to whether in a rural or urban community. For example, one parent said it is generally harder to find employment opportunities for participants in rural areas. Some parents complained that quality providers are harder to find in rural areas.

Many advocated for greater standardization across CCBs. CCB representatives also recognized the need for great consistency and transparency. At the same time, a number of parents and CCB representatives expressed strong preference for preserving the local presence of a CCB and ability of a CCB to be flexible and responsive to individual needs. This preference seemed particularly strong among those living in rural areas.

Many also discussed Colorado's strong preference for "local control." The need for local control was explained by the diversity of needs across Colorado. Because some CCBs operate in urban centers and others in large tracts of rural land, they encounter very different community resources and provider costs. State government was described as "detached." CCB representatives believe that regional delivery of services would be a "disaster" for rural services areas.

According to one advocate, the public sees the CCB as a local community agency and do not believe the government should be able to tell it how to do business; but the CCB is providing a government service and needs to comply with federal and state law.. In this advocate's eyes, many CCBs operate as fiefdoms.

## **Political Context**

In every interview, the role of politics was raised. The trade associations rely on former legislators as lobbyists. The CCBs include legislators on their boards. The advocates call on legislators (and CMS or Health Care Policy and Finance) to step in when other avenues fail. Participants agreed that if you really need to be heard, you have to go to the legislature. Some parents reported that they have been “shamed” for not going to the CCB first.

The dialogue between advocates and CCBs was described as “toxic,” and interviews with each included allegations of inappropriate conduct on the others’ part. Many saw the toxicity as tied to personalities. In at least one case, however, the combative history between the ARC and the CCB seems to have carried over, even with changes in leadership and personalities. Advocate, CCB, and provider representatives expressed their belief that DDD’s ability (or willingness) to influence the political dialogue is limited and needs to be more active.

Not all relationships between CCBs and ARCs are adversarial. At least one CCB includes ARC representation on its board and CCB representation on the ARC board. One CCB representative reported that he would welcome an ARC in his region, since it would relieve him of some advocacy responsibilities with, e.g., school districts. However, previous attempts to start an ARC in his region have failed, probably because a critical mass of discontent does not exist in his region.

Among parents there were also expressions of mistrust. Some parents expressed fear of retaliation from parents who were also CCB board members or employed by the CCB. On the other side, some parents reported that they did not feel free to speak up in front of parents who are strong critics of the CCBs. One parent suggested that many parents resent outspoken critics of CCBs (such as herself) because “They are very worried they will lose the little morsels of help they do get.”

CCB representatives report that close to 50% of board membership is composed of participants or parents or others interested in the field. One parent said there were three to four parents on his CCB’s board, including him. He said the board had diverse representation and good dialogue, with parents comfortable expressing their opinion. Some parents believe that parents who are board members get preferential treatment, including moving up waiting lists faster.

The CCBs cite improved relations between HCPF and DDD as a positive change and believe that many of the changes currently being implemented are correcting problems created by historically poor communication between the two agencies.

## **Issues and Comments Outside of Scope**

The following issues and comments are outside the scope of our analysis. They are recorded here for the benefit of the Department.

- Advocates opposed using historical billing to set standards rates. They believe CCBs have creamed the easiest to serve and have paid themselves the highest rates; assuming a CCB’s historical rates reflect their costs will inappropriately inflate their rates.



- Advocates raised the question of whether a CCB providing only case management services “can make a go of it.”
- CCB representatives identified the need for emergency back up from the state. They said they can’t get someone into a Regional Center without agreeing to take someone else out. Currently there are no psych beds in Colorado; people are “treated” or restrained in emergency rooms.
- Advocates reported that some people with a high level of need are refused services by the CCB and end up in prison even when the individual has not been convicted of crime.
- One parent reported that a parent dissatisfied with the quality of services in a group home had been told that leaving the group home meant going to the bottom of the wait list.
- One parent expressed concern about DDD spending money on systems change, new layers of bureaucracy and administrative costs.
- Several parents mentioned problems connected with SSI.
- One parent would prefer the CCB spend money on services, not bricks and mortar.
- One parent advocated for more flexibility in tailoring services to need or changing need, with fewer layers of approval and paperwork.
- A number of parents talked about their need for respite services.
- One provider raised concerns about case managers who pick up extra work providing direct support to their clients, through another provider agency. In that situation, the relationship between the case manager and service provider are so interconnected that the case manager cannot provide an independent assessment of case management and the service agency is in a difficult position monitoring the services provided by the person responsible for monitoring its services.



