

**Supplemental Report**  
to the  
Recommendations for a Self-determination  
Process in Colorado for Persons with  
Developmental Disabilities

Submitted to  
Fred DeCrescentis, Director  
Division for Developmental Disabilities  
Colorado Department of Human Services

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**Submitted by Members**  
of the  
Ad Hoc Committee on Self-determination

**Members of the Ad Hoc Committee  
Indorsing this Supplemental Report**

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## Introduction

The Ad Hoc Committee on Self-determination (the “Committee”) has worked very hard since its appointment in April of 2003 to develop recommendations for a self-determination process and/or model for Colorado to submit to the Division for Developmental Disabilities (the “Division”). The final report Recommendations for a Self-determination Process in Colorado for Persons with Developmental Disabilities, dated September 25, 2003 (the “Report”) by the Committee has now been submitted to the Division. The Report is comprehensive and captures the essence of the many discussions by the Committee from April through September 2003. The Report without a doubt encompasses a self-determination process essential to improving the quality of life for persons with developmental disabilities. The foundation of the self-determination process described in the Report is choice and control for persons with developmental disabilities.<sup>1</sup> It can be fairly emphasized that without exception the Committee supports choice and control as the core of any self-determination model.

The Report empowers persons with developmental disabilities (hereinafter referred to as “Person(s)” or “Individual(s)”) to choose and access the level of self-determination with which they are comfortable.<sup>2</sup> The Person has the choice and control over developing their Life Plan and budget,<sup>3</sup> living where and with whom they desire,<sup>4</sup> coordinating services and supports identified in the Life Plan,<sup>5</sup> choosing their Personal Agent to assist them in making decisions,<sup>6</sup> choosing their Fiscal Intermediary,<sup>7</sup> choosing their Support Broker,<sup>8</sup> choosing who will provide their services and supports<sup>9</sup> including the authority to hire and fire,<sup>10</sup> and choosing the Employer of Record, or acting in that capacity themselves<sup>11</sup>. But the Committee did not come to consensus on providing the Individual with a choice of what entity would assume certain Managing Service Organization (“MSO”) and Case Management functions, such as resource allocation<sup>12</sup> and monitoring for quality of services and health and safety,<sup>13</sup> functions that are currently controlled by the Community Centered Board (“CCB”) in the CCB service area where the Individual resides.

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<sup>1</sup> Report, at page 6

<sup>2</sup> Report, Accessing Self-determination, at page 9

<sup>3</sup> Report, Plan Development, at page 12

<sup>4</sup> Id.

<sup>5</sup> Report, Decision-making, at page 11

<sup>6</sup> Report, Decision-Making, at page 11

<sup>7</sup> Report, Fiscal Intermediary, at page 19

<sup>8</sup> Report, Service Brokerage, at page 20

<sup>9</sup> Report, Provider Selection, at page 20

<sup>10</sup> Report, Employer of Record, at page 22

<sup>11</sup> Report, Employer of Record, at page 22

<sup>12</sup> Report, Resource Allocation, at page 17

<sup>13</sup> Report, Accountability-Monitoring, at page 25

## **The Paradox**

Choice, but no choice! Individuals and/or their families may have the choice and control as is supported in the Report, but all of this choice and control in reality will be controlled by a single CCB entity that ultimately has always controlled an Individual's life in Colorado's Developmental Disabilities system through resource allocation and monitoring. In other words, all of the authority to make decisions as set forth in the Report is compromised by prohibiting the Individual to select who will set the funding parameters and oversee the decision. This can best be illustrated by the following hypothetical.

Bill has a resource of \$20,000.00 and has had this resource for 5 years. Bill has been receiving occupational therapy, speech therapy, in home personal assistance, and community personal assistance to facilitate and develop a network of friends and natural community supports. He submits his individualized budget of \$20,000.00 to his CCB after his annual review of his Life Plan.

Bill's CCB has just lost two Individuals who moved out of state and who had combined resources of \$45,000.00. Bill's CCB has just approved two additional Individuals for services off of the waiting list. Their individualized budgets are a combined \$50,000.00 and their Life Plans include the same services as Bill's.

Over the years Bill has not gotten along with his CCB. He has written many letters to the State regarding the staff his CCB has provided to serve him and he can not find other service providers in his area. Bill has filed several grievances and appealed through the State appeals process, but lost. He is still unhappy with the direct care staff providing him community personal assistance.

Bill's CCB convenes its resource allocation committee that manages the reinvestment pool and Bill is not invited. Bill gets a call from his CCB's case manager and is told that because of the increased funding needed for others, and because of the resource allocation committee's belief that Bill does not need all of the community personal assistance in his individualized budget, the resource allocation committee is reducing Bill's resource in the amount of \$5,000.00.

First, it is clear that the CCB controls Bill's Life Plan, not Bill. Second, it is clear that the CCB is making the decision on what the most needed supports are, not Bill. Control of Bill's Life Plan is squarely in the hands of Bill's CCB.

Is the CCB getting back at Bill for all the trouble he has caused it, or is it making a prudent decision regarding resource allocation from its limited reinvestment pool? What do you believe Bill thinks? It makes no difference because Bill has no other choice of an entity to provide these MSO and Case Management functions. He is not self-determining his life, his CCB is, whether or not the conflict is real or perceived. But Bill has no option.

This hypothetical is all too real in Colorado’s developmental disabilities system. Many Individuals currently receiving services, and/or their families, would prefer not to be associated with CCBs with respect to the provision of some, or all, of their services or functions. These Individuals and/or families have concerns regarding conflicts of interest, either real or perceived, and some Individuals, and/or their families, fear reprisals or retribution from CCBs if they become too aggressive or assertive in advocating for services or resources. If these Individuals and/or families are truly to self-determine the life of an Individual, they must trust the system through alternative choice as to who will be determining resource allocation, authorizing services, and monitoring for health and safety, and quality of services.

### **Supplemental Report Recommendation**

Those who endorse this Supplemental Report believe that for the introduction of self-determination for persons with developmental disabilities in Colorado to be successful, and for systems change to actually occur, Individuals and/or their families will be the ones that will make it work. Historically, and although the mechanisms have been in place, self-determination through the use of the current Community Centered Board system has not worked in Colorado as has been documented by the Division. It will be successful, and it will occur, when those who receive the services, not the ones who provide them, have autonomy with respect to choice and control of their destiny. In order for this to come about, Individual’s and/or their families must have an alternative to the use of the current Community Centered Board system for resource allocation, service authorization and monitoring of health and safety, and quality of services.

The Report reflects disagreement among the Committee with respect to the choice an Individual should have regarding the entity that provides resource allocation, service authorization and monitoring of health and safety and quality of services. The Report states:<sup>14</sup>

“There was no consensus from the committee about how to best address perceived conflicts of interest related to resource allocation. There were several options discussed and the State may wish to explore alternatives for how this function might be handled, such as:

- ▶ Use of the current Community Centered Board system
- ▶ Use of the Regional Center in closest proximity to where the person lives
- ▶ Use of an entity independent of the CCB/RC system
- ▶ Have the State manage resource allocations directly through the DDD office
- ▶ Consider other system modifications and controls to minimize possible conflicts of interest when it comes to individual resource

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<sup>14</sup> Report, Resource Allocation, at page 17

allocation, such as standardizing the initial amount of funds available to an individual or requiring outside agency participation in the process.”

Similar language appears with respect to monitoring for health and safety and quality of services.<sup>15</sup> However, those who endorse this Supplemental Report believe that the State must not only explore alternatives, but in order to shift power and control to the Individual, it must in fact develop an alternative choice to the “use of the Current Community Centered Board system” for resource allocation, service authorization and monitoring for health and safety and quality of services.

The alternatives apparent to those endorsing this Supplemental Report are for the State itself to undertake these responsibilities, or for the State to purchase these services from an independent entity separate from the current Community Centered Board or Regional Center system, or to use Regional Centers that are in the closest proximity to where the Individual resides.

It would be an easy transition for the State to assume these responsibilities. The State currently has an understanding of resources and how they are allocated to Individuals receiving services. Additionally, the State currently conducts monitoring through quality assurance surveys and entertains issues relating to authorized services.

State Regional Centers, all of which provide community based services, currently provide all of these functions. By rule and regulation, State Regional Centers maintain all of the MSO and Case Management functions that CCB’s maintain. Since the self-determination model ultimately introduced by the State must include, at the least, those receiving community based services in the Regional Center system, as well as the Community Centered Board system, there would be no alteration of current Regional Center functions.

By adopting the Committee’s recommendations, the State will be required to purchase services from others outside of the CCB system for fiscal intermediary services<sup>16</sup> (currently a CCB MSO function) and service coordination and service brokerage<sup>17</sup> (currently a CCB Case Management function). In making these changes, it would be consistent for the State to engage private entities outside of the current CCB system to provide the additional limited functions of resource management and allocation, service authorization, and monitoring of health and safety and quality of services.

For any one of these options, necessary funding is available from administrative and/or management fees, and Case Management fees, currently provided CCBs. Funding can

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<sup>15</sup> Report, Accountability-Monitoring, at page 25

<sup>16</sup> Report, Fiscal Intermediary, at page 19

<sup>17</sup> Report, Service Brokerage, at page 20

also be drawn from a percentage of the managed reinvestment pool or the Individual's resource itself. In addition, resource allocation committees can be organized from volunteers to minimize cost.

## Conclusion

It is extremely important to understand and accept this Supplemental Report with respect to the spirit and intent with which it is offered. It is not intended to disparage or malign Community Centered Boards. It is understood that some Individuals will want to continue with services provided by their CCBs, while others will not. The intent is to provide the most favorable mechanism to make self-determination a success in Colorado, and to create an environment within which systems change will in fact occur. The intent is to create true choice and control. For Colorado to provide leadership in developing a self-determination model for the rest of the country to admire and emulate, it would be a mistake to create a facade of choice and control with respect to persons with developmental disabilities, because without genuine choice and control for Individuals and/or their families, the current system will not change.

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