

# *Free at Last, Oh Lord, Free at Last: Self-Determination in Colorado*

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As the state once again embarks on developing a new system of delivery of supports to persons with developmental disabilities, self determination in this case, it is critical that our constituents look at the idea with a close magnifying glass to: 1) determine why we cannot or have not currently implemented the changes necessary to the proposed outcome, 2) define what the expected outcome is so that we are not using different phrases to describe the same thing or worse yet, the same phrase to describe something different, and 3) project the potential unintended consequences so as not to repeat the past perversions of previous system change.\* We can bring to mind the initial concepts of both the family support program and supported living services to note the current reality of the programs (dependence) vs. the original well-intended descriptors of the programs (independence).

Many states across the U. S. are implementing the idea of “self-determination” within their D.D. Systems. The four basic tenets of the idea are freedom, authority, responsibility, and individual choice. If any of our readers have been through system changes in the 1970’s they might reminisce on the terms from Normalization theory: social integration, equal treatment, dignity of risk, and respect. We have all been working for many years toward the ideal of participation in the community on an equal playing field, i.e. the concept is not new. The reality is that control by families and individuals in major decisions that affect their lives has been a goal for as many decades as I can remember. “Nothing about us without us” has been on our individual plans for a long time without even a short-term objective having been met – just carry over from year to year onto next years’ plan. We change the terms we use, but the substance is still void in this arena. The idea of self-determination once again will attempt to bring to reality this goal. It is possible that we are using strategies that are not/have not worked or, as Norman Kunc so clearly proposes, “We are using a refrigerator to get to the grocery store when we really should be using a car.”

It is critical to identify prior to implementation not only how we define self-determination, but also to have markers along the way that can identify perversions as they occur and make changes as needed. A friend recently indicated that a member of her son’s planning team called to say that the dream page was not in the file and could it be faxed over as soon as possible. How soon will it be that we are trivializing and requesting that the “freedom” and “choice” pages are faxed over for the files because an auditor from CMS is on their way on July 13?

There is an assumption that as we develop the “new” idea of self-determination there will be some obfuscation along the way. The attached chart hopefully helps delineate the potential differences in interpretation. The reader may note that many of the differences in the two-columns relate to fiscal issues and control over how funds are used.

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We may all agree on the outcome of ‘choice’ and ‘freedom’ but there could potentially be issues relative to strategy, control and who implements the option in addition to who gets how much money from whom for what. If there are staff members whose tasks are vestigial, who gets the cost savings?

On a practical front, the idea of self-determination/direct funding is that a person with a disability will direct their services personally, have the ability to hire and fire those who provide their supports, be that a job coach, a home health aide who assists with daily living tasks, or a provider of residential supports. Thus far all of Colorado’s self-determination projects have left out individuals with cognitive disabilities, however, current proposals allow such individuals to get support from family and friends as they participate. The individual will not receive money directly themselves, however, there is a more direct line between an individual and the money in that a fiscal intermediary will cut the check to the support person or place, thus easing out the expensive middle persons we have currently in many systems and agencies.

Central to the idea of self-determination is the use of a fiscal intermediary for the purposes of dealing with the IRS, FICA, workman’s compensation, performing the role of employer of record, buying liability insurance, and cutting checks to people and places that families and individuals have chosen to serve them. The determinant in families choosing an intermediary is one of who will do this for the least amount of money and how quickly the support services can be reimbursed for their work. In essence, it is more of a cash subsidy model than the current layered system. Please check **Arc of Colorado’s website** [www.thearcofco.org](http://www.thearcofco.org) for their current proposal to the state to implement a direct funding model in the state.

\* “System change” voted favorite oxymoron of 2000 by Values in Action.

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