

**Recommendations for a Self-determination
Process in Colorado for Persons with
Developmental Disabilities**

Submitted to
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Submitted by
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Introduction

There has been increasing interest and need in Colorado to develop a Self-Determination initiative for persons with developmental disabilities. As reflected in the Human Services Research Institute (HSRI) evaluation of the Division for Developmental Disabilities (DDD) Systems Change Project, Colorado is well positioned to take the next logical step toward Self-determination. Much has been learned through the implementation of the Supported Living Services program in Colorado and, in general, the provision of greater choice in service delivery. Along with these experiences has come recognition of potential problem areas to be avoided in the future or addressed upfront in the development of any Self-determination models in Colorado.

Based on this, the Division for Developmental Disabilities formed an Ad Hoc Committee to review models that can and should be considered for implementation. Fred DeCrescentis, Director of the Division for Developmental Disabilities, provided the following direction to the committee:

Purpose:

1. To explore viable models, inclusive of The Arc of Colorado's proposal entitled: "Direct Funding for Consumer Directed Services With Payment to Family Members for Direct Services"; and
2. To recommend to the Director for Developmental Disabilities a model or models for implementation that can be funded under Medicaid.

Parameters:

The model must be consistent with:

1. Providing reasonable assurances or safeguards regarding the health and safety of individuals participating;
2. Providing reasonable assurances that decisions made by the individual or his/her guardian are informed, reasonable and responsible;
3. Core values of the Department of Human Services and the Division for Developmental Disabilities; and
4. Medicaid funding regulations.

The committee met approximately twice a month between April 2003 and September 2003 to develop a set of recommendations for the State. The committee was comprised of self-advocates, family members, community centered boards, provider agencies, advocacy organizations, national experts, and other state agencies. Each member of the committee brought a unique set of expertise and experiences that were invaluable to a full deliberation of the strengths, weaknesses, opportunities and threats for a Self-determination model in Colorado.

A wide range of information was considered by the committee, including: evaluations of national Self-determination pilot programs that have been implemented in recent years, as well as experiences within Colorado with local community centered boards and other state agencies Self-determination projects; models that have been used in other States, such as Connecticut, New Hampshire, New Mexico, Ohio, Oregon and Utah; national organizations, such as the Center for Self-determination and the Human Services Research Institute (HSRI); and experiences gained with the implementation of the DDD Systems Change Project in Colorado.

The committee recognized that an enormous amount of information about Self-determination would have to be filtered through and narrowed down to what would be useful for persons with developmental disabilities in the State of Colorado. The committee did not find that there was any one particular approach being used elsewhere in the country that could be transplanted to Colorado without some amount of revising. Given Colorado's long standing interest in home-rule and local control, current economic and political conditions, and its history of community-based services, the committee felt strongly that a model needed to be developed that was specific to Colorado's needs.

The committee also believed strongly that Self-determination should embrace the entire range of ability in Colorado where everyone, adults, as well as the families of children with a developmental disability has the right to participate in Self-determination to whatever level they are able to. Throughout this document, references to persons receiving services includes the families of children with a developmental disability and children's programs. The person receiving services, including the families of children, should be presumed to be able to make their own decisions. At the same time, due to nature of the developmental disabilities population, a system of checks and balances should be in place to ensure that persons with developmental disabilities are indeed self-determining and that they have the necessary supports to do so.

The committee also agreed that Self-determination should be approached as a set of Core Values and a Process, and not as a single program. This meant that the committee had to consider the potential impact on almost all areas of the developmental disabilities system. Due to the expansiveness of the changes envisioned that would overlay the entire developmental disabilities system, the committee recommends that the State carefully and thoughtfully consider how to provide good upfront training to all interested and involved parties. Since Self-determination should not be a single program, people should be informed about what Self-determination is, what it can offer in terms of creating a life for a person with developmental disabilities, and how self-directed services can facilitate achieving such an outcome. The committee recognizes that this may mean a more fluid and dynamic process for implementation, but the need for upfront training is critical to the success of any Self-determination model in Colorado.

This report is presented not as much as a definitive programmatic model, but as a guide to be used by the State in determining how the various functions from informed choice, to plan development, to service delivery can be implemented in such a way as to not only support but also facilitate a Self-determination process for persons with developmental disabilities. While there are some areas that have greater detail in the recommendations than others, there are some general themes that promote Self-determination and are important for the State to consider as the details are developed. These themes include:

- ▶ Choice and control should be the predominant themes that penetrate all aspects of Self-determination. There should be flexibility for individuals to exercise the amount of choice and control they choose or are able to do. There should not be just one standard for self-direction.
- ▶ Full discussion of information and options should be mandatory, and all procedures should be transparent in order to promote informed choice.
- ▶ The Life Plan should be the center piece that explores all means by which a person's disability and non-disability related needs can be met, including the use of paid and unpaid supports, and the use of private and public resources.
- ▶ Regulations should be kept to a minimum to preserve the intent of Self-determination.

Vision

All citizens with developmental disabilities in Colorado are provided the necessary supports and accommodations related to their disabilities that help them to lead more productive and self-sufficient lives with interdependent and meaningful relationships.

Purpose

The purpose of Self-determination in Colorado is to provide opportunities for adults with developmental disabilities to live the life of their choosing, and for families with children with developmental disabilities to have greater control over the supports they receive.

Core Values

Across the country, there is emerging a common set of core values that are consistently connected to Self-determination. These core values provide the essential context from which a Self-determination process in Colorado should be implemented. Self-determination for persons with developmental disabilities must result in the following:

- ▶ **Freedom**
to choose a meaningful life in the community
- ▶ **Authority**
over a specific amount of public dollars
- ▶ **Support**
to organize resources in ways that are life enhancing and meaningful to the individual with a disability
- ▶ **Responsibility**
for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities
- ▶ **Confirmation**
of the important leadership role that self-advocates must play in any system that is designed to provide services and supports for them and support for the self-advocacy movement

Guiding Principles

A Self-determination process provides an opportunity for persons with developmental disabilities to act in partnership with a variety of paid and unpaid support networks. This joint venture should be reliant on the recognition of interdependence among all the parties. As the committee worked through a myriad of issues, there were several occasions when they believed that specific guidance should be provided to all stakeholders in order to guide the behavior of the system in everyday practice. The committee has initially identified several guiding principles that provide a context for how Self-determination should be implemented in Colorado. The State, however, may find that additional principles may prove useful as a Self-determination process evolves.

► Informed Choice is Fundamental to Self-determination

The person receiving services, including families of children, should have the opportunity to have sufficient information and experience from which to make a decision. Informed choice should be actively promoted by the developmental disabilities system through full disclosure of options and transparency of system procedures. It should also be supported through training for self-advocates, families, providers and other involved persons. It should be recognized that some individuals will need to have actual experience with different options in order to exercise informed choice. A system of checks and balances should be embedded within the Self-determination process to assess the extent to which full disclosure of options is provided.

► A Free Market System Facilitates Self-determination

Choice and Control should be predominant themes of a Self-determination model. Individuals should be encouraged to dream about the life of their choosing and supported to obtain that life. The opportunity to individually develop or recruit new providers and/or other resources or means to meet a person's needs or to access existing providers allows the person to exercise greater control over their life circumstances.

► Services must be for the Best Interest of the Consumer

The living arrangements and types of services selected by the consumer should be provided for the best interest of the person receiving services. At times, there may be secondary

benefits to primary care givers, but services should first be in the best interest of the person and intended for the success of their Life Plan. Additionally, there should be a balance between an individual's desire to self-direct services and the State's interest to ensure the person's health and safety, and to promote its core values.

► Opportunities for Community Contribution

During life planning activities, the person and their support network should give primary consideration to what opportunities are available for the person to be an active member of their community. Contribution to a person's community can take many different forms, such as employment or other means for the production of income, volunteer activities, or other activities that promote a positive societal-image and/or self-image for persons with developmental disabilities. When determining what opportunities are available, consideration should be given to the person's preferences, age (i.e. retirement, minor under age 18), and abilities of the persons (e.g. medical condition).

Accessing Self-determination

The only "eligibility" that needs to be determined is if an adult or child has a developmental disability. Pursuant to C.R.S. 27-10.5-102 (3) and 105, Community Centered Boards are authorized to determine eligibility for DDD funded services. This function needs to occur separate from how to access Self-determination.

In order for Colorado to realize the vision and purpose of Self-determination, DDD should adopt an overall philosophy and process that supports the right of all adults and the parents of children to exercise the level of control they are comfortable with over the services that are provided. Within the developmental disabilities Self-determination model in Colorado, the full range of decision-making abilities should be honored, inclusive of persons who can totally self-direct to persons who require some assistance to persons who require significant support. The range of ability might best be illustrated through examples that apply to individuals, as well as parents of children.

- For individuals who desire and are able to do so, they can choose to literally self-direct all aspects of plan development and plan implementation, such as control over a specific

amount of funds, developing highly tailored services to meet their unique needs, and the hiring and firing of specific individuals who provide the services (not just which agency).

- ▶ Some individuals may choose to use someone who knows, or gets to know, them well and can act on their behalf to assist with decision-making, hiring of staff, monitoring use of their budget, etc. Such a person is sometimes referred to as a personal agent.
- ▶ For still other individuals, self-determination may take the form of less direct detailed control but still retain personal choice. For example, a person may determine that choosing from an agency's existing menu or package of services is more in line with their personal choice. That agency would be responsible to provide the staff, training, activities, etc. for the services purchased. While exercising less direct control, it still supports the person's right to self-determine.
- ▶ There will also be individuals who may have lesser ability to direct all aspects of their life, but they can and should be supported to direct whatever portions they are able to direct. In these situations, self-determination may present itself as an expression of immediate preferences or personal choice. Longer term planning or budgeting may be done on behalf of the person by a personal agent who knows, or gets to know, the person well and can effectively act on their behalf.

Unless restricted by legal action, the ability to self-determine should be available to ALL adults and parents of children with developmental disabilities, and to ALL forms of developmental disabilities, without regard to living situations or funding sources.

A Review of Key Planning Functions

The creation of a person-centered Life Plan based on the individual's dreams for a good life is, perhaps, the characteristic that most distinguishes Self-determination from other service models. There are a host of planning functions that support an individual or families of children to create a life of their choosing. The following presents a series of discrete functions that, while they can be performed independently of each other, are inter-related and necessary in order for a person or families of children and the system to engage in Self-determination. Separating these planning

functions into discrete activities allows a person receiving services to individualize how the planning process can best work for them. A person should be able to elect to perform many of these functions themselves or they may involve others, either paid or unpaid, to help them. If others are enlisted to help, these functions should only be provided to the level desired or needed by the person receiving services. These discrete functions should be able to be combined and performed by the same person or agency if agreed to by the person. Anytime an individual or agency performs a function(s) for which they may have a conflict of interest, the consumer should be informed ahead of time and provided with a clear understanding of what potential conflicts may exist, what is being done to protect the consumer from the conflict of interest, information about what other options exist, and how to change providers, at any time, should the consumer believe that the conflict of interest is no longer manageable.

▶ **Decision-making**

The person receiving services should be presumed and supported to be able to make his or her own decisions. Consistent with the guiding principles described earlier, the person receiving services should have the opportunity to have sufficient information and experience from which to make a decision. However, there is no known standard means by which to assess whether an individual has either sufficient information or experience by which to make a decision. It should be incumbent on those in the person's support network to assist the person to determine the best means by which decision-making can take place.

A person may enlist the (paid or unpaid) help of others to ensure that they are making informed decisions. This type of service should be included within the cost of a person's Life Plan, if needed. Help from others might include:

- ▶ General decision-making and planning
- ▶ Developing a Life Plan, including a budget
- ▶ Coordinating services and supports identified in the plan
- ▶ Assessing the quality of services provided
- ▶ Assuring that health and safety needs are addressed

The level of involvement of support for decision-making should be based upon the level of need of the person with developmental disabilities (i.e. no more and no less than what is necessary to ensure that actions taken are informed and in the person's best interest). There should be some type of checks and balances in place to monitor that ongoing decision-making remains in the person's best interest. Such a system should be objective and involve review by persons who are not directly connected with plan development or ongoing implementation of services.

People who help someone make decisions, sometimes called a personal agent, must demonstrate an ongoing effort to know the person with developmental disabilities well, and to act solely in the best interest of the person.

► **Plan Development**

Self-determination should use a plan that is developed by the person, and those close to him or her, that considers all aspects of a person's life (not just publicly funded services), and that provides for control by the person or their designee over all aspects of the person's plan (except for any rights suspensions). The planning process should promote open-ended thinking about what is possible in a person's life and be applied consistently around the state so that everyone has the same opportunity. A systemic shift in focus from needs-based thinking to outcome-based thinking will be needed. A Life Plan, for example, should address the following:

- The desired outcomes for the person in Major Life Areas:
 1. Where and with whom a person lives
 2. Contribution to a person's community, such as generating income or volunteering
 3. Community and relationships
 4. One-time costs
 5. Additional support staff
- Assessment of any health and safety concerns based on a uniform risk assessment and other information as appropriate

- ▶ Services and Supports, both DDD funded and other, necessary to achieve planned outcomes or ongoing supports
- ▶ Individual Budget (both DDD funded and other sources)
- ▶ A description of how monitoring of health and safety, and services will occur based on the individual's needs and preferences

The State may want to consider use of a standardized format in order to improve statewide consistency and to help support people who are new to the process. Regardless whether a standard format is used, there are elements that should be done consistently throughout the state, including:

- ▶ The same minimum life areas should be covered in all Life Plans.
- ▶ The types of services and supports needed to achieve a person's identified Life Plan goals should be broadly defined and related to addressing the impact of a developmental disability that is above and beyond what others without disabilities experience.
- ▶ Training should be available and ongoing to persons receiving services, families, CCB's, providers, etc. to ensure that plans are developed that address the minimum life areas for all persons.
- ▶ A statewide uniform risk assessment process should be part of the planning process. It should be completed for everyone and used to determine a person's health needs, vulnerability to abuse, neglect, exploitation, mistreatment, as well as their ability to deal with emergency or dangerous situations that might cause harm to the person. (see Risk Assessment and Safety Net below for more information.)

► **Risk Assessment and Safety Net**

- *Choice is not a reason for a person to live in an unsafe place.*
- *Choice is not a reason for a person to live in filth.*
- *Choice is not a reason for a person to smell bad.*
- *Choice is not a reason for a person to inflict self-harm.*

– *John O'Brien*

A statewide uniform risk assessment process should identify a person's level of vulnerability and the critical health and safety areas to be addressed. Based on the assessment, a person's Life Plan should address what safety net options are necessary and available to the person. The more vulnerable the person, the more checks and balances that need to be in place. A risk assessment may trigger the need for rights suspensions to address personal and community safety. The State should implement a policy that health and safety is a priority concern and that when a plan is being developed, the expectation is that health and safety will be addressed first. The following should be key elements of the risk assessment.

- The risk assessment should be completed by an objective third party as one means to ensure a system of checks and balances. For example, this could be part of the case management monitoring function to ensure that health and safety areas are addressed no matter who develops the Life Plan.
- It is important that individuals who are responsible for completion of the risk assessment be well trained and knowledgeable about the vulnerabilities of people with developmental disabilities, including adults and children.
- At a minimum, any identified areas of concern regarding health and safety must receive priority attention in the development of a person's Life Plan.
- The cost for this assessment should not be part of the person's Life Plan, rather this should be a built-in function for anyone receiving services.

Additionally, the committee recommends that the Division for Developmental Disabilities work with the Department of Health Care Policy and Financing to assess the impact of the federal requirement to provide 24-hour back-up services.

▶ **Allowable Services and Supports**

If a person has a legitimate need related to their disability, then it should be allowable to direct available funds to that need. The State should write any necessary federal waiver applications or rules in such a way as to provide the broadest latitude for service definitions. It should be possible to address the major life areas identified in the person's Life Plan by reimbursing a person to perform a needed task related to a disability, or to purchase a device or modification to address an adaptation need.

There are some limitations that are established via statute, such as the maximum size of group living situations not being more than eight persons. The committee researched and developed some general guidelines that should be considered when making a determination of allowability:

- ▶ Rates should be reasonable given current market prices.
- ▶ The service or support should be a cost effective means to meet the need.
- ▶ The service or support should provide a safe environment and/or ensure the health, welfare and safety of the person.
- ▶ Any adaptations should meet Uniform Building Codes, as adopted by the State of Colorado, and meets local building codes.
- ▶ The service or support should not be solely for personal comfort of the consumer or provider.
- ▶ The service or support should not be experimental.
- ▶ The service or support should not be excluded by state or federal regulation.

The committee recommends that the State not expand upon what is minimally excluded by the federal government. Known federal exclusions include:

- ▶ Anything that is illegal.
- ▶ Adaptations or devices for the person's environment which are not associated with a direct medical or remedial need of the individual such as carpeting, roof repair, central air conditioning, regular clothing, etc.

- ▶ Cost of admission to professional or minor league sporting events (e.g. football, baseball games), movie, theater or concert tickets.

Whatever limitations may be developed by the State, careful consideration should be given as to the absolute necessity for any rule (i.e. don't regulate to the exception). The State should develop other mechanisms to address exceptions and to promote best practices.

▶ **Resource Allocation**

This was unquestionably the most difficult area for the committee, as well as other states, to address. There does not appear to be a nationally recognized uniform instrument, process or other mechanism to establish plan amounts. The most common approaches included:

- ▶ A fixed pre-set amount could be established for each person to begin services, and then adjusted over time.
- ▶ A managed care approach could be used to negotiate individualized amounts up to a pre-set maximum based on identified needs.
- ▶ An assessment tool, such as a modified Colorado Comprehensive Services Assessment Tool (CSAT), Wyoming DOORS instrument, I-CAP, etc. could be used to establish funding ranges for individuals, such as a tiered high, medium, low category.
- ▶ Persons who are already receiving services could use their historical utilization patterns as a starting point.
- ▶ A pool of funds should be developed in each service area to provide options for mid-year reviews, adjustments, and emergencies. To the extent possible, written objective criteria and procedures that are widely available for review should be used to describe the circumstances and justifications for either increasing or decreasing previously established funding amounts.

The committee did have consensus that the developmental disabilities system should be used to flow funds to the local level. The State or its designee should approve plan amounts and the types of services that would be provided with DDD funds. The State or designated

approving agency should act as a gatekeeper. They should be authorized to operate within broad definitions to approve or deny requested services. It should not be the role of the State or approving agency to approve a person's entire Life Plan. If developed as envisioned, a Life Plan may well address areas of a person's life that do not and should not involve oversight by the State. Only those services and supports that require DDD funding should be reviewed for approval. It is expected that there will and should be overlap between DDD funded services and other areas of a person's life. The interplay between these areas may need to be considered when the State or approving agency is reviewing a Life Plan.

There was agreement that the resource allocation process should be transparent. However, there was no consensus from the committee on 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 allocation, such as standardizing the initial amount of funds available to an individual or requiring outside agency participation in the process.

The ultimate goal should be to provide individuals and families with a full range of options, full disclosure of their options, and an objective and fair allocation process that does not directly or indirectly bias one person or family over another as a result of their choice of service providers. No matter the process selected by the State, it should require approving agencies to provide full written disclosure about:

- ▶ How resource allocations are determined
- ▶ The type and frequency of utilization information to be provided to consumers

- ▶ The processes to be followed to request initial or additional funding for an individual's budget
- ▶ Usual and customary rates for services within a service area
- ▶ Appeal rights

In addition to the immediate need to develop an allocation process, the committee recommends that the State investigate options regarding room and board expenses and the impact on persons receiving services. Currently, room and board expenses are not allowable under federal Medicaid regulations. Removing this barrier would allow a more robust opportunity for all persons with developmental disabilities to develop comprehensive Life Plans.

▶ **Incentives**

One of the Core Values of Self-determination is Responsibility for the wise use of public funds. The committee believes that the State should create incentives to be cost effective in the use of funds that are approved for Life Plans. Other states, as well as Colorado through the Consumer-Directed Attendant Support program for example, have developed incentives that allow a person to retain a portion of any savings from their plan. The committee agrees with this approach and recommends that the State consider a similar approach for Self-determination for persons with developmental disabilities. There are some general parameters that the committee identified, including:

- ▶ Half of the unused funds should be available to the person for more services, lower prioritized services or services that may be unallowable under Medicaid.
- ▶ Half of the unused funds should go the local managed service organization to develop a reinvestment fund for emergencies, for more services, to address one-time high cost items, and, when possible, to address waiting list but only if services, once started, can be maintained long term.
- ▶ A person's plan amount should not be reduced in the current year due to underutilization the previous year. A clear pattern of underutilization should be established over multiple years to demonstrate that the level of funding exceeds the

need rather than the person being cost effective. The incentives should also promote long range planning that may require multiple years to accumulate sufficient funds.

- ▶ There should be a cap, such as a percentage of an individual's or agency's budget on the total amount a person or agency could accumulate through incentives.

▶ **Fiscal Intermediary**

Once resources have been assigned to a person's individual budget, the person should be provided with options for how and by whom the funds will be administered. The committee could find no compelling benefit for the State to identify a single entity or to limit the number of entities who could perform this function. Rather, the consensus was that persons receiving services should be able to select from any qualified agency to act as a fiscal intermediary. A fiscal intermediary agency would be hired by the person receiving services and could be changed at any time by the person. Fair market competition should help to ensure that the cost of such services remain reasonable. A fiscal intermediary function could be combined with other functions, such as the employer of record. Functions provided by fiscal intermediary agencies should include, at a minimum, any combination of the following:

- ▶ Payroll (including tax withholdings, insurance, benefits)
- ▶ Paying bills
- ▶ Billing services
- ▶ Utilization tracking
- ▶ Regular reporting to the person receiving services about utilization

▶ **Service Brokerage**

The person receiving services should be presumed and supported to act on his or her own behalf to ensure that their Life Plan is being implemented. The individual should be able to provide this function directly or to build into his or her plan a brokering function that would be provided only to the level requested or needed. Help from others might include:

- ▶ Finding funding sources (not just DDD-funded) to pay for services and supports identified in the Life Plan

- ▶ Providing knowledge and expertise about what's available within the person's community
- ▶ Finding or developing providers
- ▶ Interviewing and selecting staff
- ▶ Negotiating the terms of a contract (e.g. rates, frequency, times, etc.)

As with other planning functions, a person who helps to ensure implementation of a person's Life Plan, sometimes called a Support Broker, may also provide other functions. If purchased, this function should only be provided to level needed or desired by the person receiving services.

Funds authorized in an individual budget should be used for their intended purpose as identified in the person's Life Plan. Adjustments can be made, but funding for the adjusted plan should still be prior approved. Individuals should be able to negotiate all types of purchase of services agreements (e.g. hourly, daily, weekly, monthly, outcomes, pre-set package of services).

▶ **Provider Selection**

There are numerous factors in Colorado and most other states that are driving the need for alternative sources for finding direct service professionals, including limited availability of qualified providers, high turnover rates, and the cost of service provision. The person receiving services and/or their personal agent should have the broadest consideration of possible providers available and the authority to determine who provides a service, as long as provider qualifications are not otherwise regulated by state statute or rules for a specific type of service. Options for provider selection¹ should include approved service agencies, professionals, generic community vendors, individuals, friends, etc., as well as payment of family members for providing services for which they are qualified to provide. If a family member is paid to provide a service, then the same expectations as other similarly qualified providers should apply to them.

Some general guidelines for provider qualifications should include:

¹ Consideration should be given to the impact of Colorado's Guardianship law (CRS 15-14-310).

- ▶ A provider must meet certification or licensure requirements when required by state statute or rules, such as certification or licensure for therapists, physicians, dentists, etc.
- ▶ When certification or licensure is not required, the provider should be able to demonstrate training or existing competencies commensurate with the required job duties. This should apply to family members as well.
- ▶ The Risk Assessment should provide some amount of guidance as to what qualifications might be appropriate.
- ▶ A background check process should be utilized for any person who has direct unsupervised contact with persons receiving services with the exception of generic services, such as plumbers, housekeepers, or delivery persons.
- ▶ There should be no pre-set limitations on the types of services that can be provided by a qualified provider.
- ▶ The rate for payment should be in-line with usual and customary rates for the region and type of service being provided.
- ▶ The State should use statewide data to establish ranges for different services. This could address two issues: 1) to allow the State to monitor the reasonableness of rates, and 2) to provide a guide for consumers to inform them of typical costs for services in their service area.

There may be some events outside of the consumer's control that might impact the ultimate outcome for who can be used as a provider. For example, an employer of record (EOR) may refuse to hire a particular individual, and the consumer would not have the authority to require the EOR to do so. However, the consumer could opt to try another EOR. Also, the State could ultimately refuse to use State funds for a provider for whom it cannot be demonstrated to the State's satisfaction that the provider is qualified or for whom a pattern of questionable service delivery is documented. This series of checks and balances would allow the person and/or their personal agent to have the benefit of first consideration in selecting a provider while still recognizing certain basic hiring practices may influence the ultimate outcome. An override of a person's choice should only happen within appropriate safeguards to prevent arbitrary denial of a provider.

While a person should be able to select the provider of their choice, if they act as the "supervising employer" either directly or through an employer of record, they must abide by applicable federal, state and local laws governing employment, including but not limited to:

- ▶ Title VII of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000e, *et seq.*
- ▶ Age Discrimination in Employment Act, 29 U.S.C. §§ 621, *et seq.*
- ▶ The Americans With Disabilities Act, 42, U.S.C. §§ 12101, *et seq.*
- ▶ The Family and Medical Leave Act, 29 U.S.C. §§ 2601, *et seq.*
- ▶ The Fair Labor Standards Act, 29 U.S.C. §§ 201, *et seq.*

Other federal, state, and local statutes and/or regulations may also apply.

▶ **Employer of Record**

The ability to hire and fire specific staff is one of the elements of Self-determination that promotes choice and control. However, performing this function within fair labor standards requires the individual or agency to have knowledge about employment regulations. Colorado should use an open free market system regarding employers of record. An individual should be able to elect to be the employer of record directly or to purchase this service from other who have the necessary expertise. The functions to be performed by a purchased employer of record should be negotiated for each situation so that a person can better control costs and the level of support they need. Individuals should be provided with information about what usual and customary practices are for employers of record, along with the cost for such services. Some examples of employer of record functions include:

- ▶ Hiring and firing
- ▶ Background checks
- ▶ Tax withholdings
- ▶ Workman Comp
- ▶ Liability coverage
- ▶ Employee training

- ▶ Compliance with applicable state and federal employment laws

Regardless who the employer of record is, including the person receiving services if they elect to be the EOR, minimum standards applicable to all employers should be met (i.e. workers comp., tax withholdings, liability insurance, etc.).

Funding

The committee discussed general parameters of Self-determination and how a variety of funding options might apply. Overall, however, the committee found too many pros and cons to be able to offer a single recommendation. Virtually all options offer something. Ultimately, since Self-determination really reflects a process and not a specific program, the committee believes that the choice of funding mechanism is secondary to how it supports the values and intent of Self-determination. The committee does have several guidelines that the State should consider when selecting a funding option.

- ▶ The State should stay focused on choice and control for persons with developmental disabilities.
- ▶ The State should consider the length of time involved (e.g. amendments to existing Medicaid waivers may be faster and easier than a whole new waiver).
- ▶ The State should balance flexibility with complexity of operation. For example, the trade off for flexibility may not be worth the additional paperwork, utilization tracking, or general reporting (i.e. cost benefit should be a major consideration).
- ▶ If a new Medicaid waiver is needed, the committee suggests writing the Medicaid waiver as broadly as possible to maximize flexibility for implementation within Colorado.
- ▶ The State should remember that Self-determination and Life Planning are intertwined with blended funding. Hopefully, a person will not be reliant on only one source of funding to meet all of their needs, therefore, the ability of DDD funding to be used jointly with other sources is important.

The committee did review a proposal by Thomas Nerney that looks at removing certain barriers between Social Security Administration benefits, Medicaid and personal income. Given that it is a proposal only, there were too many unknowns, length of time for implementation being one. The committee recommends that the State investigate this option further to determine if it might further support Self-determination in the future.

Accountability

Accountability is everyone's business. There are many approaches that can be used to ensure accountability, including monitoring, assessing outcomes, reviewing paper compliance, etc. The intent of oversight activities for accountability is to provide a system of checks and balances to ensure that what is supposed to be happening, is indeed happening. The types and scope of review under Self-determination may be different from current practices due to the individualized nature of the model, open-ended planning and service options, the variety of skill level involved in plan development and implementation, etc. Information should be gathered at all levels of the system and results made available at all levels of the system. While accountability should address a wide range of specific issues, the overall goals should be to determine whether: systematic monitoring is occurring, the person receiving services is achieving stated Life Plan goals, health and safety issues have been addressed, the process of Self-determination is transparent to the customer, uniformly available and applied statewide, and DDD funds were used appropriately.

► Monitoring

Monitoring should take place at multiple levels from the individual person to broad systemic trends.

- The individual should be able to monitor services and directly impact the quality of services through the hiring and firing of staff directly or through the freedom to choose the agency from which to receive services. Monitoring should be done, however, the frequency and method of how monitoring will be done on an individual basis should be negotiated through the planning process, One area of particular interest for monitoring should be when a provider acknowledges a conflict of interest to which the person receiving services agrees to.

- ▶ Monitoring at the local level should ensure that the person's health and safety are addressed, that Self-determination is indeed occurring, and that DDD funds are used for their intended purposes. 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 monitoring, such as requiring outside agency participation in the process.
- ▶ The State should still have the ability to monitor the delivery of services through state level program quality assurance surveys, and through the use of local entities to ensure the overall health and safety of persons receiving services and that funds are being used for their intended purpose.

▶ **Achieving Stated Life Plan Goals**

The State should not rely on one method to assess whether a person is achieving the stated Life Plan goals. A system of checks and balances should be used, such as:

- ▶ Assessing how a person exercises control over their life and services.
- ▶ Assessing the person and not just the paper (i.e. find out what's happening in the person's life, interview people, find out what a typical day is like for the person).
- ▶ Using a variety of formal and informal means to collect information, including unannounced visits.
- ▶ Looking to see if the outcomes identified in the plan are being achieved (e.g. make a summary of the previous year's outcome a requirement as part of the annual plan review).

- ▶ Making information about all provider's performance available generically to all, including deficiencies.
- ▶ Using regular satisfaction surveys.
- ▶ Using available evaluation tools, such as Core Indicators.

The nature of Self-determination may require the State to review how a dispute resolution process might apply. Since the person should have greater control over services and who provides the services, there may need to be some adjustments for what triggers a dispute resolution process.

When a dispute resolution is needed, the committee recommends that the same types of dispute resolution processes be used as are currently available. Individuals, and their families, should be afforded the opportunity for resolution in the most expeditious manner possible. This process includes:

- ▶ Informal negotiations at the local level,
- ▶ Third party mediation services,
- ▶ Formal resolution at the local level,
- ▶ Formal resolution at the state level (both CDHS and HCPF), and
- ▶ Federal review for Medicaid.

Final resolution of unresolved disputes should not rest with the same entity as where the dispute originated.

▶ **Health and Safety Issues are Addressed**

The general satisfaction of the services should be up to the individual to determine, and his or her personal agent, if needed. However, the bottom line is that the system should have the means to detect, address and monitor trends involving health and safety regardless of the service model. The approving agency should have authority as part of the planning process to approve or deny services based on health and safety needs not being met first. The State or its designee should have ultimate responsibility to ensure that quality and services meet health and safety needs.

It is believed that necessary and targeted rights suspensions can occur to the benefit of the person and the community in conjunction with self-determination to address potential harm to self, others or property, or to prevent illegal activities. A person should be able to self-determine all other areas of their life that do not warrant a rights suspension. The State should ensure that information and training is available about the following:

- ▶ How a rights suspension review would be triggered (e.g. part of the planning process, part of the risk assessment process, etc.);
- ▶ Who would ultimately approve and oversee a rights suspension (i.e. absent the Interdisciplinary Team (IDT) will the role of the Human Rights Committee (HRC) be elevated); and
- ▶ How such suspensions, the services necessary to address the suspension, and the costs would be incorporated into a person's Life Plan.

Although some allowances may be necessary for those living in family homes, the same requirements should apply under a Self-determination model as would apply under other models of service delivery.

▶ **Uniformly Available and Applied Statewide**

As with the entire Self-determination process, evaluation should examine discrete functions. Examples of discrete functions might include:

- ▶ Monitoring for compliance (i.e. were the rules followed, are providers qualified).
- ▶ Evaluating for quality (i.e. how satisfied are people, are best practices being used, looking beyond the paper compliance to the impact on the person).
- ▶ Assessing responsible spending (i.e. are funds being used for their intended purposes, are rates reasonable).
- ▶ Reviewing the availability and choice of providers.
- ▶ Determining how well information and options are being fully disclosed.
- ▶ Evaluating how transparent the system's processes are.

- ▶ Assessing how successful a Life Plan has been from year to year. Such an assessment should look at needed adjustments to achieve any desired outcomes not previously met.
- ▶ Collecting standard demographic and utilization data to monitor trends.
- ▶ Comparing rural vs urban needs to ensure that Self-determination is available statewide.

▶ **State Funds were Used Appropriately**

As part of a Utilization Review process, the approving authority should be responsible to ensure that DDD funds and associated services that were prior approved in the plan are ultimately used for allowable services. If funds are misused, the level of infraction should determine what an appropriate response should be.

The State should also consider evaluating how other (non-DDD) resources are being utilized to determine the level of systems dependency as things change over time.

The committee also had some general recommendations regarding accountability and efficiency. First, given the scope of the change anticipated with the implementation of a Self-determination model in Colorado, the committee recommends that any evaluation process take into account that this change will occur over time to varying degrees around the state. Second, the State should focus on what is the minimum amount of documentation necessary to ensure accountability yet maximize time spent on providing the actual service. Third, the committee recommends that the State consider maximizing utilization of an electronic/ paperless system (i.e. the assumption should be paperless, the need for hard copies should be justified). The manner in which this committee envisions Self-determination being implemented in Colorado will require a very fluid process of information transmission. In order to keep the cost down and improve the timeliness of information, use of available electronic media should be exploited to the greatest degree possible.

Training and Information

The importance of good upfront training and information for both the initial start up of Self-determination and ongoing needs was a constant theme throughout the development of this report. Applying a Self-determination model (i.e. process) across the entire developmental disabilities system will mean that consumers, families, providers, advocates, etc. will all be getting up to speed at different rates. It also means that a large amount of training and information material will need to be developed. The State should develop multi-layered training and information materials that will allow the reader to absorb the amount of information desired or necessary depending on where they are in the process. For example, general information brochures and briefing materials should be generally distributed. More detailed information materials and training modules should be available as the person and others are ready. DDD should make all information readily available in multiple media formats, such as written training materials, web-based applications, Power Point presentations, etc. Training and materials should be supportive of full disclosure of information and options so that, whenever possible, a person should be provided the opportunity for informed choice about using existing providers or developing new options.

There has been much discussion throughout that State about different Self-determination models. Once a final decision is made on the approach to be used, the State should make a concerted effort to ensure that everyone knows what model has been formally adopted by the State.

In order to create opportunities for each person to individually determine their own life's goals, and to develop and implement a Life Plan for achieving those goals, the "process" for Self-determination should be approached as a set of individualized functions that can be mixed and matched together as needed and desired by the person. Individuals with developmental disabilities, their families, and the developmental disabilities system in general may be used to having established groupings of functions. This means that everyone at all levels of service delivery should understand what functions are fundamental to Self-determination and how they work together to support choice and control for the persons receiving services.

The committee has a variety of recommendations that cover many different elements of a Self-determination process. The recommendations are categorized into Systemic Structures, and Individual and Family.

► **Systemic Structures**

1. The State should establish a Training Steering Committee early on in the process. One of the central roles of the committee should be to track who is doing what types of training in order to ensure that all necessary areas are covered and to minimize duplication of effort.
2. The State should consider having a minimal level of core training materials or guidelines that could be expanded upon and tailored to local needs. Consideration should be given to best practices mentoring. Those individuals or agencies who are doing quality work should be recognized and used to help teach others. Trainings should involve a wide variety of presenters, such as persons with developmental disabilities, family members, providers, advocates, local and national experts, etc.
3. The State should maintain its minimum provider standards, such as basic CPR training, procedural requirements (e.g. billing, incident reporting). In addition, for individuals or agencies who are fiscal intermediaries and employers of record, the State should require that necessary training be provided (i.e. the provider should be expected to know how to perform those functions).
4. The committee recommends that the State ensure that training is provided to further the understanding of those functions that are fundamental to the process of Self-determination. Much of this understanding should be available to the entire system prior to, separate and apart from receiving services. While the committee did not have a strong recommendation as to whether such information should be uniformly developed by the State or whether local agencies might be able to do this, there was absolute consensus that training should be effective and consistently available statewide on an ongoing basis.

5. Examples of systemic training and/or materials that should be available and funded outside of a person's Life Plan cost (i.e. established as a basic part of the system's infrastructure) include:

- ▶ Basic Self-determination 101 (e.g. Core Values, Guiding Principles)
- ▶ What does transparency of systems procedures mean
- ▶ How to ensure that individuals are provided with full disclosure of their options
- ▶ Roles and responsibilities of a personal agent
- ▶ How to develop a Life Plan
- ▶ How to focus on Outcomes
- ▶ How to complete a risk assessment
- ▶ Roles and responsibilities of a service broker

▶ **Individual and Family**

Training should not be mandatory for consumers or families. However, all information should be readily accessible. The extent to which a family member is paid to provide services or key functions, such as Life Plan development may necessitate training per the provider requirements or demonstrated competency to perform the job. In addition to the general systemic training and information that should be available, examples of training and materials for individuals and families should include:

- ▶ Self-advocacy on an ongoing basis
- ▶ What responsibility means for the individual
- ▶ How to select a personal agent
- ▶ How to assess available services and resources, and evaluate options
- ▶ How to develop a Life Plan
- ▶ How to hire and fire staff

Planning for Transition

The thought of switching the entire developmental disabilities system, both adults and children, over to a Self-determination process can be overwhelming. Already, there has been much angst and questioning occurring throughout the State around Self-determination. There are some who are ready and waiting for the change, and others who are leery and would like to take a slower pace. The committee does not recommend a “pilot” status for a Self-determination process in Colorado. Much work has been done around the country and good information is available to support the benefit of using a Self-determination process. What will be important is how the statewide transition is managed.

The transition to Self-determination will likely occur over an extended period of time, therefore, local, regional and statewide trainings should be provided on a regular basis once a specific model is selected by the State. The committee recommends that the State and the Community Centered Boards start now preparing individuals, staff, provider agencies, and others. This can be done through information sharing of the Core Values and other central elements of Self-determination. The State should lay out clear ground rules ahead of time so people know what to expect (i.e. role model transparency of action and full disclosure of information).

Although process is fundamental to Self-determination, the State should begin now educating all constituents that the focus is on the outcomes for people’s lives. The Self-determination process is only a tool to help make that happen. CCB’s should probably work first with those with high interest levels who may be able to also help other individuals/families.

The committee recommends that C.R.S. 27-10.5 not be amended unless there is language that creates a specific barrier to implementing Self-determination for persons with developmental disabilities in Colorado. If there is a need identified that would require additional language added, the State should do so through legislation that would make conforming amendments to C.R.S. 27.10.5. All other changes should be done through the rule making process. The State may wish to consider general legislation that would solidify the State’s interest in using a Self-determination model across all human service systems.

Ongoing Input from the System

The committee recommends that the State develop a formal mechanism that provides for a State level constituency reviewing of the implementation of Self-determination. The State should form a committee similarly comprised as the Self-determination Ad Hoc Committee to provide the State with advice specific to the Self-determination process in Colorado. The State should consider an ongoing 6 month review process to reassess how it's going. Such a review should include participation at all levels of the systems. The State may also wish to establish a systems review work group to critically evaluate where there is duplication of documentation.

Summary

Self-determination is a philosophy, it is a process, and it is an opportunity for a person to achieve their Life Plan goals. Colorado is well positioned to take the next logical step toward Self-determination. Much has been learned through the implementation of the Supported Living Services program in Colorado and, in general, the provision of greater choice in service delivery. The committee believes that the parameters outlined in this Self-determination report provide persons with developmental disabilities and families of children with developmental disabilities not only greater choice but control over their lives. Successful implementation will be dependent on the State's ability and willingness to adhere to the Core Values and Guiding Principles. There will no doubt be distractions along the way, but the State should hold to the core values. Additionally, due to the nature of the developmental disabilities population, the State should pay particular attention to the degree to which persons with developmental disabilities are in fact self-determining. There have been concerns raised in other parts of the country about a shift in decision-making going more toward surrogates and not to the person directly.

The committee also believes that the building blocks that will create the systemic opportunity for choice and control lie in the separation of the planning functions. Whether a person chooses to keep the functions separate or combine them through one provider important, however, more important is the fact that the basic structure of the system provides the opportunity for all to exercise choice and control.

One theme that permeated all committee discussions was “don’t rule by the exception”. In order to prevent ruling by the exception, the committee recommends that the State set high standards for determining when something is a systemic problem as opposed to an exception. Rules should only be added after a need has been identified (i.e. don’t anticipate a problem that may not ever occur or be so minute that it should not skew the whole system).

Finally, the committee reviewed what it believes would facilitate Self-determination in Colorado for persons with developmental disabilities. Although Self-determination touches on all aspects of a person’s life, there are two critical areas for adults that warrant immediate upfront cross system’s coordination (i.e. the production of income and housing) and one for children (i.e. coordination with Part C regarding Self-determination).

For adults, the better situated a person is regarding the production of income and their housing, the more successful Self-determination is likely to be.

▶ Production of income

- ▶ The committee recommends that DDD work closely with other entities to determine how to facilitate the production of income for persons with developmental disabilities, such as through employment or micro-enterprises.
- ▶ Examples of entities to coordinate with might include: the Division of Vocational Rehabilitation, Workforce Centers, SSA Ticket to Work, Thomas Nerney proposal for a Medicaid/SSA waiver, the Colorado Department of Education transition from school to adult services, and Services for Senior Citizens through Aging and Adult Services.

▶ Housing

- ▶ The committee recommends that DDD work to improve dissemination of information for HUD grants and homeownership, as well as facilitate more people with developmental disabilities to have greater control over their living environments.
- ▶ Examples of entities to coordinate with might include: CDHS Supportive Housing, City and County HUD offices, Mortgage companies, and others.

For children and families, the implementation of Self-determination will offer the next step from choice of services to choice and control over services. The committee recommends that DDD work closely with the Colorado Department of Education, Part C to ensure that Self-determination is fully available to children and families.

The committee appreciates the opportunity to provide recommendations to the State regarding Self-determination for persons with developmental disabilities in Colorado.