Developmental Disability Services
Self-Determination
Facilitation Handbook (2018)
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1.
Overview of Self Determination

What is Self-Determination?

Self-determination is control of services shifts from professionals to the individual served. Self-Determination includes development of a fixed budget which allows the individual served to purchase supports intended to mitigate the effects of disability. According to California's SB 468 (Emmerson) which created the statewide program.

The Self-Determination Program enables participants (or their parents or legal representatives) to have more control over selecting their services and supports including developing and having control of a specific budget to purchase the services and supports that they need. Participants may choose their services and pick which providers deliver those services. Participants can choose services that are not vendored by regional center. They are responsible for staying within their annual budget.

There are five "principles of self-determination," which in the law, Independent Facilitators are be trained in. These are:

- Freedom, the ability to design or influence the individual's own life plan;
- Authority, the ability to control resources and decide who will provide supports, what they are to provide, when the support is to be provided, how the support is to be provided and how much of each support will be needed;
- Support, the expectation that one's needs will be met;
- Responsibility to use resources wisely and contribute to the community; and
- Confirmation, individuals receiving support should influence the development of the support delivery system.

Because of direct control of services and introduction of a more competitive marketplace, self-determined services offer the potential to provide higher quality support than the traditional system.

Direct control is offered to the individuals who experience support services firsthand. Under the principle of Authority, effective support moves away from professional opinion and is based on the individual's values and level of satisfaction.

Providers will compete for services. Client satisfaction (not regional center) will hold greater influence, and service providers that offer significantly better services will be more preferred.It is a significant change from tradition system.

Under the Responsibility principle, the duty to insure that services are appropriate, helpful and effective shifts to the individual and his or her natural circle of support, all volunteers with the professional community reporting directly to the individual and his or her team. It is a shift in oversight of services.

With accountability now directly to the individual, providers will offer services that will be of value to the client's life. Duplicative and other "wasteful" activities can be eliminated, and rates charged can reflect the quality and cost of services more accurately.

Along with its potential benefitsthere are also concernswith SDP. Therefore it is important Independent Facilitators and Financial Service providers to be alert, knowledgeableabide by the five principles, and be pro-active.

One of the motivators for the self-determination program has been a sense among many advocates that the traditional system overvalues professional expertise and undervalues the understanding of individuals and their loved ones. There is a risk of reversing the error. An Independent Facilitators and Financial Management Services must balance the needs of the

individual and team with the realities of arranging supports within and outside the developmental support system. Successful Independent Facilitation requires expertise. The individual's needs and preferences will be the main drives of service planning, but arranging for theright staff with the right values, and offering the right services at the right price will also be required regardless of the program plan.

The statewide program will unfold after sixteen years of pilot testing SDP in five regional center catchment areas. Each of these pilot programs were different in some respects from one another and all of them were different from the statewide program. As this new program rolls out It's important Facilitators remain open and flexible to the rules and regulations that will emerge and be understanding of best practices that emerged in the pilot programs.

2. Required Department of Developmental Service Training and Orientation

Process

The Self-Determination statute states consumer and family training is required to assure understanding of the principles of self-determination, the planning process, and the management of budgets, services, and staff.

The process of enrolling individuals for the initial roll out of Self Determination in California requires a two-step enrollment process. To be placed on an interest list, an individual or family member needs to attend an Informational Meeting and request their name be placed on the interest list. If selected to participate in self-determination individuals and families then need to attend an Orientation and confirm their willingness to participate.

Informational Meetings

SDP Informational Meetings are for interested individuals and/or their families to learn more about the SDP and to help them decide whether it is right for them. For the initial roll out of Self Determination in California a SDP Informational Meeting is required for individuals to be added to the candidate list from which the Department will randomly select the first 2,500 SDP participants.

The informational trainings are hosted by regional centers, and can be hosted by local consumer or family-run organizations, and community-based organizations interested in voluntarily conducting SDP Informational Meetings in their region. A community-based organization is a public or private organization of demonstrated effectiveness that is

representative of a community, or significant segments of a community, and provides educational or related services to individuals in the community. To manage the Informational Meeting outreach and insure a smooth, safe, and secure process of acquiring individual's names to be placed on the interest list, regional centers are working in cooperation with the local Self Determination Advisory Committees. Committees put in place procedures and methods to assure privacy of those who have added their names to the interest list.

Providers of Training

Each regional center shall be responsible for implementing the Self-Determination Program. As part of implementing the program, the regional center shall collaborate with the local consumer or family-run organizations to jointly conduct training about the Self-Determination Program. The regional center shall consult with the local volunteer advisory committee and the local volunteer advisory committee may designate members to represent the advisory committee at the training. The Department of Developmental Services has led several train the trainer programs throughout the state in 2017. Staff at regional center and many members of Self Determination Advisory Committees throughout the State have attended these trainings. These trainers both lead and offer further trains the trainer opportunities.

Orientation

Participants selected for self-determination from the roll out or those and for those who want to participate in self-determination upon its full implementation must attend an orientation. At the orientation the principles of self-determination, the role of the independent facilitator and the financial management services provider, person-centered planning, and development of a budget will be reviewed. Upon completion of the orientation and final confirmation of wanting to participate in self-determined services individuals begin work with the regional center service coordinator to develop, plan, budget and implement self-determined services and supports.

3. <u>Person Centered Planning</u>

"PersonCentered Planning" or "PCP" refers to a plan of service that is based on the assets, skills, challenges, aspirations, preferences, style of learning, etc. of the individual served.Person-centered services arespecified in SB-468. "Person Centered Services" can generally be defined as highly individualized in their methods and objectives and typically include a learning process by the service provider that assumes services can get better as the person served is better known. Studies demonstrate there is correlation between quality of life and person centered services.

In the traditional support system, there is an emphasis on program design which implicitly places organizational style ofworking with the people served. The Independent Living movement seeks to shift away from an organizational style of service delivery to one that focused on the person.Although within the developmental services system a person-centered focus and orientation is the language used when discussing services, a bias toward traditional supports systems from funding /oversight organizations that operate through regulations remains. Self-determination by-passes the disincentivesexisting in the traditional support system.

There are several models for person centered planningwith tools meant to assist service providers to develop person-centeredpolices, services, and supports. Along with being instrumental in the development of Person Centered Plans, Independent Facilitators will need to educate the individual, family, and circle of support about person centered thinking to promote development of innovative services and supports.

Principles of Person-Centered Planning

1) Presume competence. The first influence in any planning discussion should come from the individual served and other viewpoints should address the preferences of that individual. For many of the purposes of service planning, there is no expert greater than the individual.
2) Behavior is communication. For all individuals, but especially those who do not communicate traditionally, it is important to consider behavior, body-language and sounds within the context of what is being discussed and for the purpose of tailoring the plan to the individual's preferences.
3) Respect cultural diversity: Culture provides much of any individual's preferences so one reason to be respectful of an individual's heritage is that it can streamline the process of getting to know and understand them. Another reason to seek cultural understanding is that it honors the individual. It might be controversial to say so but planners who share a cultural heritage with an individual will often have an easier time understanding. One aim of Self Determination is to reduce the disparity in service delivery that is entrenched within the traditional system of delivery.
4) Maintain Health and Safety for Life: There is a very simple metaphor "respect a person's choices but don't let them jump in front of a bus." It's a good rule but very complicated to implement except when taken literally. In some ways this principle stands against the first one and at best cautions the planning team to consider safety while filtering the goals and preferences of the individual.

5) Support individuals in their own choices. This is the ultimate goal of a person-centered plan.

The life domains to include in person centered planning are:

1.) Health and Safety: where medical concerns are present. Include information in the plan so that support workers are aware of signs of particular concern, trained to provide routine care, and be considerate of any physical or emotional sensitivity. For example, we want all staff who routinely interact with a g-tube trained to do so safely. Different supports, especially hygienic ones might become routine to the staff but embarrassing to the individual. Such considerations belong in a person-centered plan and should be subject to frequent review and amendment to assure the individual is able to express discomfort or concern.Creation of a "one-pager" health and care summary is encouraged as a means of having ready access to health and safety information by first responders and health care professionals.

1) Learning Style: different people learn differently.It's important to describe effective communication styles: verbal, gestural, and emotional. For example, explain preference if someone seems to be a strong tactile learner and is likely to be the predominant teaching method. Essential Lifestyle Planning (ELP,) as an example, includes tools for refining communication and training strategies over time.

2) Focus on Person's Strengths: expectations of progress should be ambitious relative to the individual so that no potential progress goes to waste and no needless frustration gets stirred up. A fair, honest and frequently updated assessment of the recipient's functional strengths, skills and challenges helps to measure expectations, share among service providers, and prioritize appropriately.Along with identifying strength based strategies to train and build skills, also discern what supports can be put in place to reinforce a cycle of accomplishment. Evaluate progress. Too often a goal remains in place without progress and becomes more a disincentive that inhibits progress.

3) Lifestyle Preferences: the person's environment in the home, in the neighborhood, and across a broader community should be included in the plan for safety, social, vocational and other opportunities. In person centered planning, the individual is seen as a valued member of the community who is to contribute through work and volunteerism as do all others. Different communities include people with disabilities according to different customs. Local circumstances can and should influence individual plans either in selecting strategies for inclusion or in the decision to move. Within any community are natural supports to seek

out and enlist for integration and independence and not be completely dependent on providers within the service system. The local availability of resources should be considered in a person-centered plan.

4) Relevance: goals and objectives should be ones that matter, are purposeful and based on the person's values. The traditional system never fails more reliably or expensively than when it addresses challenges of no interest to the person being "served." Indicators of success will include engagement and be beneficial to the person those near him and the community around him

Existing person-centered systems:

Essential Lifestyle Planning was developed in an open-source-like manner by Michael Smull of the University of Maryland, Helen Sanderson of the United Kingdom and many others. Essential Lifestyle Planning (ELP) includes a variety of tools for person-centered planning and process improvement. Their emphasis has been on "good paper," the concept that formal learning devices can be helpful and derive their value from their helpfulness. As such, the Essential Lifestyle Planning (ELP) systems offer many forms which can be put to use not only in person-centered planning but in quality improvement and learning.

Examples of templates produced by the group include person-centered plans, tools for determining which activities should be done creatively versus rigorously, evolving glossaries for individuals with communication challenges and many others. A good portal for learning about ESP is *http://www.learningcommunity.us/home.html*. There is training and certification process for ELP and California has several excellent trainers. Helen Sanderson and Associates has a good collection of tools for person-centered planning, thinking and service at http://www.helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/.

PATH uses a graphic approach to person-centered planning. The product of a day or more, a PATH plan begins in one corner with an illustration of the individual's current circumstance and in another corner with that individual's ideal life. In between are shown resources, steps from one corner to the opposite one, challenges, barriers, supports and skills. A well-done PATH plan can be especially helpful to visual learners and for sequencing objectives. PATH was principally developed by John O'Brien, Jack Pierpoint and Marscha Foresst. Good starting points for learning more about PATH are here:
http://inclusive-solutions.com/person-centered-planning-using-path-and-maps/

http://www.communityworks.info/pathcf.htmhttp://inclusionnetwork.ning.com/profile/JohnOBrien.

There are a great deal of other systems for person-centered planning with other authors and the systems above are not meant to create an exhaustive list. Sally Burton-Hoyle (*http://www.emich.edu/univcomm/releases/release.php?id=1333054993*) has done and published a great deal of good work on person-centered planning, particularly with people on the autism spectrum.

Key practices in creating a person-centered plan

The individual served plays a leading role in creating the plan. Independent Facilitators should expect to facilitate person-centered planning meetings and there are a few key practices which should be honored.

1) Listen the way the individual communicates. Spend time to learn the purpose of a person's behavior. People communicate in their own styles and the variations likely increase the more atypical the individual's communication works. It is very important to observe and defer to things like slow responses, to differentiate between someone struggling to find the right language and someone who is feeling pressure to respond, to pay attention to body language whether the individual is speaking or can't.
2) Every feature of the planning meeting has an impact. Sally Burton-Hoyle advocates one or several pre-meetings as a way knowing the individual and insuring that the planning meeting has the right people, location, atmosphere and schedule. People can have very idiosyncratic sensitivities and the purpose, to develop a workable plan of support for authentic goals; a thoughtful, skilled approach is required. Some individuals need a parent's support to express themselves fully while others may be unable to express themselves in front of a parent. Be as aware as possible of how and why decisions regarding the environmental features of the meeting get chosen. Person Centered Planning is better thought of as a Person Centered Process that includes pre-meetings, planning, IPP development, implementation, and revision.
3) Find the right objectives: Support programs undermined by the individual are key indicators of poor planning. Self-Determination has great potential to improve outcomes at lower cost just by harmonizing the objectives of the supports with those of the individual. But this will not always happen naturally and older individuals in the system may have had their objectives chosen by others so often that it will take time and attention to create person-centered plans that choose appropriate objectives in the order the individual would want to pursue.

4) Work to find the right circle of support: Person-centered planning typically involves planning not only with the individual but with those who have insight into the character of the person. Generally speaking, person-centered plans comprise brainstorming, debate and discussion. Although this may sound like a step away from person-centeredness, most who call what they do "person-centered planning" follow this step. What makes the plan nonetheless person-centered is that the individual should have final say on who participates and shows up.
5) Planning with this focus takes time, and it is helpful to see it as a process where the final planning meeting is the culmination of insights and decisions discovered, reviewed, and agreed to prior to the meeting.

Moving from Person Centered Planning to an Individual Program Plan

A Priority within the traditional service system isemphasis on the Individual Program Plan. Because a signed IPP is the legal agreement required between the regional center the individual that describes the services to be provided, the focus on the Person Centered Plan may be downplayed or seen as having secondary importance. The presumption is untrue. The IPP should be understood in the context of Person Centered Planning, which should be understood in the context of Person Centered Thinking.

A facilitator will take on the roll one who is skilled in Person Centered Thinking who approaches and works with the individual based on a respect toward the individual not often seen within the traditional system. Planning begins at the moment of introduction, and all interactions where the facilitator includes assessing and identifying values, character, and wants of the individual. The Person Centered Meeting and Plan comes later in the process where the information gathered through a variety of assessments and other tools is composed into a variety of documents that clearly describes the person and his or her preferences. The IPP meeting and plan fits into the Person Centered Plan as the work agreement with the goals, objectives, methods, procedures, and review of services. It is a step by step description of services. Although a legal document and vital to the delivery of services, the IPP is a part the larger Person-Centered plan.

Person center thinking, process, and planning continues beyond the IPP meeting to include service delivery, continued discovery, and continued effort to have the individual be assisted in all that is needed to fully express themself.

Circle of Support / IPP Team

Regardless of disability, people interact in a broad network of family, friends, neighbors, community members, and professional service providers. There are both formal and informal connections. Connections with individuals occur in a variety of settings that can include church, club, store, or online communities. The interaction of one to the other is how individuals become members of the community and participants in the broader society.

Historically, this natural style of interaction has been denied to people with developmental disability. Because traditional service delivery follows a custodial model, those with developmental disability have experienced segration, have come to depend on professionals to care for them, and are "siloed" into services that often do not overlap. Ostensibly for the purpose of health and safety, restrictions on a person's right to associate with others have been highly restricted to the point of institutionalization.

To shift from a custodial model of care to an empowerment one, it is important to return to reliance on natural community interactions. By way of the person, as well as the person's family system, it is likely there are a number of individuals from the natural community interacting with the individual. In Person Centered Planning, those associated with the individuals are seen as essential supports for the person to succeed in the community.

A role of the Facilitator will be to identify those involved with the person's daily life. Considering the degree of association with the individual, people involved in the person's life can be visualized into circles of support. Closest family, friends, and relatives, comprise the first circle, the circle radiates outword based on closeness of the relationship and move from friends, associates, on to service providers such as clerks, bus drivers, and it continues outward to occasional contacts or associates, such as health care professionals.

Along with identifying the circle of support the Facilitator needs to identify the role these people play in the person's life and how they may provide support to the individual. Facilitators also need to educate and solicit these people to work with and identify strategies to assist the individual with achieving his or her personal goals. For example a neighbor may know someone who administers contracts at a local business who is seeking a service that can be accomplished by the individual. The neighbor's effort to promote the introduction of the contract administrator to the individual could lead to an employment opportunity. A facilitator will seek and arrange such opportunities.

Members of the circle of support are most likely to have informal connections with the individual. Something as simple as an invitiation to a movie, or dinner at a restaurant can significantly increase the person's inclusion in the community.

Person Centered Planning will require a facilitator to identify members of the circle of support and where appropriate meet with, and invite them to appropriate planning meetings. The roll of these people is three fold: to offer information about the person, to offer informal supports for the person, to connect the person to contacts, leads, and an ever increasing community network.

4. <u>Facilitation:</u>

According to statute[1], "'Independent facilitator' means a person, selected and directed by the participant, who is not otherwise providing services to the participant pursuant to his or her IPP and is not employed by a person providing services to the participant. The independent facilitator may assist the participant in making informed decisions about the individual budget, and in locating, accessing, and coordinating services and supports consistent with the participant's IPP. He or she is available to assist in identifying immediate and long-term needs, developing options to meet those needs, leading, participating, or advocating on behalf of the participant in the person-centered planning process and development of the IPP, and obtaining identified services and supports. The cost of the independent facilitator, if any, shall be paid by the participant out of his or her individual budget. An independent facilitator shall receive training in the principles of self-determination, the person-centered planning process, and the other responsibilities described in this paragraph at his or her own cost."

Key points from this definition:

- The Independent Facilitator shall not be in another professional relationship with the client shall not work or gain income from a program or service utilized by the individual.
- The Facilitator shall be trained in principles of self-determination, person-centered planning and other responsibilities undefined.
- The responsibilities are broad and can be done for free or as part of the individual's SDP budget.

The definition above is broad. The participants and the Facilitator will define the role in many different ways.

[1] California WIC, Title XVII, 4685.8 (c) (2)

The Independent Facilitator's role has often been to provide those skills needed by the participant to successfully implement their program and which are not available in the circle of support. Some participants will have relatively simple needs to meet; while many will have complex programs to run. Some people with developmental disabilities and their family members can facilitate their own plans, and they may have excellent skills and instincts for managing people, vendors and for achieving goals. However, for a variety of reasons the choice of a participant or family may be to hire an Independent Facilitator to attend the program plan. . Because each individual and family need is different a Facilitator will require a wide-ranging skill set and prepare for many different approaches to the work.

5. <u>Financial Management</u>

According to SB 478[2], "'Financial management services' means services or functions that assist the participant to manage and direct the distribution of funds contained in the individual budget, and ensure that the participant has the financial resources to implement his or her IPP throughout the year. These may include payroll and bill paying services and activities that facilitate the employment of service and support workers by the participant, including, but not limited to, fiscal accounting, tax withholding, compliance with relevant state and federal employment laws, assisting the participant in verifying provider qualifications, including criminal background checks, and expenditure reports. The financial management services provider shall meet the requirements of Sections 58884, 58886, and 58887 of Title 17 of the California Code of Regulations and other specific qualifications established by the department. The costs of financial management services shall be paid by the participant out of his or her individual budget, except for the cost of obtaining the criminal background check specified in subdivision (w).

The key point from the statute is that the FMS is the primary professional point of accountability to the regional center in a self-determination program and that these are mandatory. The FMS will be vendored by the regional center and have responsibility for insuring that the other requirements of the statute and waiver are complied with in the overall program. Being vendored, FMS will have reporting responsibility to the regional center.

Service Navigation

As stated previously, the IPP is the agreement between the individual, his or her team, and Regional Center for provision and payment of services. The role of an Independent Facilitator

will be to work with the participant and team to navigate through the process and create an IPP that assures preferences within the Person Centered Plan will be pursued.

For children, the primary services paid for by the regional center is respite care. Most other needs are for education or health of the child. The school's special education program, and child's health insurance are the generic resource paid by resources from other service systems that are not included in the waiver funding of self-determination. Traditional funding of such services will remain in place. For children, along with a Facilitator having knowledge about respite, they may also be active in advocating of other services to promote inclusion of the child. Such services may focus on recreation, socialization, and behaviors. Knowledge of IDEA and Special Education can be helpful.

For adults, services shift away from education more toward least restrictive community based, independent living. Independent Facilitators will have a responsibility to inform, and advocate for participants as they navigate the adult service system. A participant's life will be ordered around what they do during the day, be it a work or training activities, and where they stay at night, be it living with parents or in anotherresidential care setting. It's fair to expect an Independent Facilitatorswill work with the individual and circle of support to arrange these types of services, as well as social / recreational, transportation, therapeutic, health and safety, financial, and others that maximize community involvement. A Facilitator will need to have an understanding of system navigation, how regional center services are paid for through self determination and can be woven in with generic services so the individual is living a full and preferred life.

Presently, there is a greater emphasis on securing employment activities for adults with developomental disability. Under the termEmployment First, services are to be explored and arranged to find work activities where a person receives pay. Along with traditional employee and employer arrangement, jobs can be customized and can include contract, fee for service, sales of goods, business ownership, and negotiated work opportunities. Independent Facilitation requires innovative ideas and planning for the individual when identifying work activities, vocational training activities, or acquisition of toolsnecessary to find employment.

Developing the Budget:

Budgeting may have already taken place before the facilitator becomes involved, but in other cases the Independent Facilitator may have an important role to play in developing the budget with the individual. The mechanics of the budget (discussed below) are relatively simple but

skills are needed (also discussed below) to making the budget robust, proactive and as constructive as possible.

The budget is typically produced on a grid. The main data are how much is the annual budget and how that will be month and by category as below

Table 1

Client Name:	**First W. Example**		**UCI#**	**xxxxxx**	**Budget Year:**	**2016**	**Budget Amount:**	**$24,000**					
Category	January	February	March	April	May	June	July	August	September	October	November	December	**Total**
FMS	129	129	129	129	129	129	129	129	129	129	129	129	1548
IF	80	80	80	80	80	80	80	80	80	80	458	80	1338
Home Health	1200	1200	1200	1200	1200	1200	1200	1200	1200	1200	1200	1200	14400
Advocacy												400	400
Com. Int.	400	400	400	400	400	400	400	400	400	400	400	400	4800
Travel	45	45	45	45	45	45	45	45	45	45	45	45	540
Total	1854	1854	1854	1854	1854	1854	1854	1854	1854	1854	2232	2254	**23026**

Options are available to build flexibility into the design of the budget, empowering the individual to use their self-determination funds as efficiently and effectively as possible. Here are helpful techniques that emerged in the pilot.

A category is not exactly a service*:* Although the Medicaid Waiver application added some definition to what can be covered within a category (see and study Addendum C to the waiver,) many of the categories still have broad definitions. While in the traditional system use of vendor codes set sharp parameters around services, under self-determination, these parameters fade. To give an example, an individual might begin the year wanting some basic assistance at home, having high hopes for an expanded social life and wish to find a job with assistance. That individual might hire an agency to help with finding and keeping a job (under

Community Integration/Vocational,) an individual to provide assistance at home (under Personal Assistance) and pay a third person to help her join a book club under Advocacy.

Over the course of the year, perhaps the individual finds social events unrewarding and chooses to quit. The supported employment agency she hired has not come up with a position after four months. In this case, the person hired for home health can also assist setting up a microenterprise at home. It does not have to be the case that transferring funds from one service to another requires changing the original categories as long as the service rendered reasonably fits the definition of that category.

As individuals learn more about meeting their own needs through self-determination, they can do so with increasing efficiency and improving satisfaction. A well-crafted budget can facilitate that by concentrating spending on the least flexible categories to the benefit of the more flexible categories. In this example, one could do this by always billing time spent with the companion to Community Integration whenever the pair are away from home or at home working on a vocational activity. In this way, the money spent on wages for her all-purpose companion could, in the example above, rise by 1/3 without reaching the 10% threshold.

In the self-determination system, crossing allocations for a single service, as long as that service reasonably fits the definition of both categories is both legal and efficient. This is one of the ways self-determination can produce better outcomes for the same level of funding that is not available through traditional funding.

To build the budget so that is as flexible and empowering as possible, consider the basic elements of the person-centered plan. Where those elements can (and this will be often) fit two or more categories, it helps to allocate more to the most broadly defined category and less to the more narrowly defined one.

10% is an annual threshold. Taking the example above, if the individual served gave up on the supported employment agency in the sixth month, then 20% could be reallocated monthly for the remainder of the year without exceeding 10% overall. Transferring money from underspent categories to more needed ones should get easier as the budget year advances. If an initial plan seems to not require the full amount in the budget, you can empower later decision making by *budgeting any extra funds to the end of the year* when they will be easier to move.

Unanticipated needs: If the elements in the person-centered plan can be purchased for less than the full budget amount, the extra monies can be allocated to meet unanticipated needs. This amounts to budgeting funds you may not spend rather than spending funds you do not

need. It helps to budget everything available simply to prevent unforeseen traumas and useful epiphanies which may change needs from simultaneously requiring an additional and potentially exhausting bureaucratic step.

An example from the pilots: it was not unusual for individuals to discover that managing is much more challenging than previously thought. When conflict and performance issues emerge, especially for individuals who use a lot of direct care staffing, an intervention may be needed. In the pilots, staffing crises weren't uncommon and were usually remedied by regional center staff, advocates, or the Independent Facilitator/Support Broker. The other common source of needed change followed a traumatic event or an illness. Unspent funds should be allocated according to the risks which seem likeliest for the individual. So, for example, if an individual will have a large number of staff they will manage themselves and has not done so in the past, allocating extra funds at the end of the year to the Independent Facilitator category will help with frequent staff meetings, person centered planning, recruiting and hiring or other functions likely to be needed. If the individual is being staffed through an agency with a good track record but has known health risks or loved ones at risk for serious health events, the extra funds can be allocated so extra companionship will be available.

These moneys are important to track, though. In the example above, $1200 per month was expected to cover the individual's home health needs. An additional $974 was added to that line. When circumstances call for extra expenditures in that category, it will be important to track how much has been used to avoid overspending the budget. In the pilots, knowing that some extra funding was available and how much spent was an occasional point of comfort. Not knowing how much extra was available can increase confusion instead. This also makes it helpful to allocate any remainders in the last month of the fiscal year, so that FMS statements comparing actual expenditures to budgeted expenditures reflect the underlying plan.

It's important to recognize that if the plan includes expenditures equal to the budget, that unforseen events may cause extra turbulence as services intended have to be depleted to meet the needs of the crisis. Although the plan budget should allocate every dollar in the budget, it is wise to first cost out the plan to make sure there is an available reserve.

A big advantage gained by SDP over the traditional system is the opportunity to, over time, allocate funds more efficiently. In the traditional system, greater independence reduces funding over time, making the service itself less sustainable. In the case of the self-determination program, services that become less needful become more sustainable. Take this example, an individual who needed 200 hours per month of support for assistance cooking, cleaning, taking medications and pursuing a social life. If he or she learns to cook simple meals,

do basic cleaning and track his or her own medications might be able to double the pay of a trusted person who made a great difference and taught many things, focusing a lower level of service on greater challenges like social learning or developing job skills. In this way, the individual can transfer monies spent on basic sustenance to a more reliable or more effective staffing. Alternatively, the individual could maintain the rates for remaining basic supports and invest in more ambitious challenges participants are unlikely to attempt through the traditional system. A hybrid approach is even more likely where effective service providers can receive raises in hourly compensation while new services are purchased.

After the first budget, as with the traditional IPP, it is worth looking at whether all the services in the previous year's plan remain necessary. Unlike the traditional IPP, the goal is not to reduce support as possible, but to reallocate that support to goals of greater value.

Over time, more effective and productive support providers should be able to charge higher rates and, in the meanwhile, there will be a new incentive to deliver support with denser progress. For those who have tarried in the traditional system a long time, the possibility of rewarding effectiveness, sequential goal-setting and more selective attention to the development of the individual are key features of the self-determination program. Planners have an important role to play in making sure that resources which can be better used will be.

Although self determination allows for flexibility, efficiency, and progress driven services. Appropriate accounting and reporting methods must be used. It is important to demonstrate responsible use of funds, and demonstrate dollars spent were for authorized activities. Red flags subject to any review will include co-mingling of funds or services. Be sure through expenditure reporting and accurate recording of services that all funds utilized and services rendered are accounted for.

Sustainable IF and FMS Services

During the roll-out period for California's Self-Determination Program, the market for Independent Facilitation services and Financial Management Services might be in some ways easier and in some ways harder than it should eventually become. Over the longer period, the market should begin to work with facilitators competing on cost, quality, specialty and skills. Furthermore, there may yet be some regulations which will set parameters on how and how much an Independent Facilitator or FMS can charge.

Prior to that, it will be worth setting prices which are both competitive and sustainable. In all likelihood, the first clients in self-determination will begin to learn what they need from their

infrastructure services. The discovery period may be long and it is not clear whether price will be the prime determinant, source of the referral or other qualifications. But over the long-term, we should expect simpler models of care to be price-sensitive and more elaborate services to command a larger share of the self-determination budget.

For the first Independent Facilitators into the market, it might be worthwhile to experiment a little with different methods of pricing services, fiddle with a menu of options or set a simple price. An example of how a menu might be drawn up is below:

Table 2

Menu	Price
Basic subscription- Lowers cost of other interaction, up to 5 emails and one phone call per month, returned within 24 hours	$15/Month
Enhanced subscription- Lowers cost of other interactions and includes up to three hours involvement per month at no additional cost	$100/Month
Recruit one individual or agency	$200/provider or $100 with subscription or $50 with enhanced subscription
Develop person-centered plan and budget	$450 or $400 with basic subscription or free with Enhanced Subscription for one year.
Facilitate staff meeting, other	$250/half day or $400/day (200,350 with basic subscription, 150, 300 with enhanced) plus $.54/mile.
Emergency home visit	$300/$200/$150
Home visit	$150 plus $.54/mile ($125,100)
Online only membership	$125/year

A partial list of potential business models include working as a consultant, working as a heavy partner involved in day-to-day management of services (Program Director of Fortune) or even as a convener, online or in person, of crowd-sourced problem-solving. Self-determination creates a lot of opportunity to innovate new ways of bringing value to individuals and families affected by developmental disabilities.

The main point is that people working in this self-determination will need to compete, to earn enough from their services to make their focus sustainable, and to provide real value to the programming of the individual served.

It is worth noting that with a standard of around 15% administrative fees, it should be easy for individuals to spend less than that for professional expertise and have funding left over to raise incomes for direct care staff, invest in new services and/or find new services unobtainable through the traditional system. As a best guess for how to set prices, roughly 10-15% of the SDP budget for Independent Facilitation and Financial Management Services combined seems like a reasonable portion to include in a business plan. There is some chance that FMS costs will be fixed either through market forces or regulation, so Independent Facilitators can use the remainder of the tenth part as a first-guess guideline.

But it is critical to remember that IF and FMS fees compete with the wages of direct-care staff and the funds for needed services and supports. A low cost in a sustainable range will generally be the right price. This can be achieved through very light interactions at very low cost to many clients or by charging enough for a great deal of involvement with a few.

Arranging and Negotiating with Regional Center, Providers, and Service Providers:

Two principles will apply when regional center and the planning team build a budget. SB 468 (Emmerson) requires the Self Determination budget is to be based on the previous 12months expenses for the individual. Also, for needs that have emerged that have not been accounted for in the previous year's services, regional center will base the cost on the average costs for such services. When negotiating a budget Independent Facilitators will need to support the requests of the person and team and advocate for funds that accurately reflect the cost of services. Facilitators will have an awareness of prevailing wages for services within and outside of the developmental service system. Where the 12 month expenditures do not reflect the actual cost of services, the Facilitator will need to advocate for more accurate funding and provide justification. Often there is a time lag between referral and provision of services. No billing occurs during this lag, and if it has occurred within the previous 12 months its important the lag does not figure into the accounting.

When determining services and costs it's important to keep in mind a founding principle of the Lanterman Act is treatment and habilitation services and supports to foster the most independent, productive, and normal lives possible. Such services shall protect the personal liberty of the individual and shall be provided with the least restrictive conditions necessary to

achieve the purposes of the treatment, services, or supports. This principle can offer guidance when negotiating with regional center the plan and budget.

The vendor arrangement between provider and regional center remains the business model for developmental services since the inception of the regional center system. This arrangement will remain in place after the roll out of self-determination. However, among service providers, there is a tradition of private pay arrangements with the individual or individual's family not utilizing regional center services. Self-determination funding arrangements should fit into the private pay standards of any provider. When negotiating rates with a provider, keep in mind reporting requirements, hours of services, number of services, level of administration, etc. can be individualized and rates adjusted / negotiated to reflect actual expenses.

Always, Independent Facilitators are not allowed to arrange any services with a provider they are associated with or draw an income from.

Implementation, Monitoring, and Reviewing the Plan

The scope of work for Facilitation includes implementation, monitoring and reviewing the Person Centered Plan, the Individual Program Plan, and Personal Budget. Within the plan, and any agreement between the Facilitator, and the Individual and Planning team the level of intervention should be made clear.

Timely activation of supports, consistent service delivery, positive interactions between staff and individual and team, accurate invoicing and remittance for services, effective communication between all participants including the FMS and regional center, and overall consumer satisfaction are indicators of successful implementation of the self determination plan. To assure success a Facilitator should maintain consistent contact with the individual and team. A facilitator should be open to performance review and employ work habits that assure good quality. The Self Determination Plan is an "active" document. Plan reviews should be regularly scheduled, and strategies be in place if adjustments are necessary.

Review of the expenses is important to assure funds for services be available throughout the term of the plan. Oversite of expenditures is essential. There is a 10% allowance for funds to be adjusted between line items. Effective financial oversite enables a Facilitator to respond proactively as needs develop.

Strong oversite of the self determination plan enables an Independent Facilitator to identify emerging issues. If needs should surmount the expectations with the self determination plan,

responsible facilitation will require notification of members of the planning team and if necessary request a meeting be reconvened to address the needs and problem solve.

6. Assessing for Quality

With any program, there is a definition of quality which can be expressed in terms of how life will be different through successful support than it would be with unsuccessful support. Defining, describing and measuring what quality will mean for an individual brings focus to planning, to staffing, to training, to budgeting and with selecting which practices should be continued and which should change.

In the traditional system, quality is typically defined at the program level only. As such, there is a real opportunity for Independent Facilitators to work with clients on developing their own Continuous Quality Improvement programs so that their programs can serve better and better with less and less wasted money, time, energy and effort.There are standardized measurements that can be implemented.

The National Core Indicators Project: NCI (*http://www.nationalcoreindicators.org*) has been developed in Amherst, Massachusetts and utilized across the United States and internationally. They have developed a list of outcomes which they have tested to ensure validity and reliability. Choosing a few indicators of particular value to the individual served might be a good way to begin to begin thinking about quality on an individualized but systematic basis.

Community-Based Ideas of Quality: If community integration is important to an individual, then it is important to determine success partly through changes in the community. Are the neighborhood or the city and its institutions more receptive and accessible to people with disabilities? Several organizations have sought to develop quality-measurement systems that look at the community. For individuals in self-determination, it can be useful to identify those businesses, offices or other parts of the community which the individual most wishes to participate in and keep track of how that is going. A couple organizations doing good work in this area are the Council on Quality and Leadership (http://www.c-q-l.org) and the Asset-Based Community Development Institute (http://www.abcdinstitute.org.) Whether or not these organizations or their tools will be part of a particular Independent Facilitator's practice, they are good to know and to think about.

Lean Systems, Value-Streaming, Learning systems: Many of the philosophical under-pinnings of self-determination come from business theory. These theories can add a lot to the process of

facilitation and to understanding its purpose. Two books worth reading: *The Fifth Discipline*, by Peter Senge and *Lean Thinking*, by James Womack and Daniel Jones (also *lean.org*).

7. Case management and Record Keeping

Self Determination and private pay arrangements are not under obligation to maintain the same records required by the regional center under vendor agreements and other regulations. However, there are standards for case management and record keeping that are important to adhere to assure professional and confidential delivery of service. Appropriate record keeping documents the hard work being completed on behalf of the individual. Along with maintaining the most current identifying and contact information, records need to be available to assure the health and safety of the inviduals. Contracts, agreements, program plans, emergency information, releases, and other required documentation need to be properly maintained to demonstrate the working relationship between individual and Independent Facilitator. Assessments, data records and casenotes are essential to verify completion of work. Budget, invoices, and other financial statements verify payments made and pending. A strong rule of thumb to consider: direct service represents only half the work completed, documentation of the service represents the second half.

Independent Facilitators benefit from developing policies and procedures surrounding record keeping. Individual and planning team access to records will require consideration. Legal and ethical standards, including HIPPA require documentation of intervention. Appropriate records include the documentation of significant decisions and events occurring in provision of services.

Key Elements of Recordkeeping:

The record should include person centered plans with the assessment of individual needs that outline services to be provided. No single formula for documentation exists. Facilitator notes and records should reflect observations and explanation regarding services provided, decisions discussed, plans made, and any changes to the person-centered plan.

Records shall be maintained, in either a written or electronic format, for a minimum of seven years from the date facilitation was terminated. If the person receiving services is a minor, the records shall be retained for a minimum of seven years from the date the client reaches eighteen years of age.

Records need to be stored, transmitted, and/or disposed of in ways that protect confidentiality. When storing records, it is necessary to secure hardcopies in a locked file cabinet or drawer.

Access to electronic records should be password-protected and a backup should be made and stored in a safe and secure manner.

Necessary Forms and Documents
Facilitators should ensure that they have the following forms/documents available for use:

- Intake/informed consent/disclosure forms
- Release of information form
- Service Agreements (Person Centered Plan, IPP, Facilitator Plans) Financial agreement forms
- Forms or lined paper, etc. for the purpose of writing progress notes. Notes need to be signed and dated.
- Forms or logs for the purpose of noting payments made
- Billing forms

8.Standards of Conduct

Insurance
A facilitator should consider professional liability insurance coverage.

Distinguish Your Practice & Develop Areas of Expertise
To assure transparency, a facilitator should identify their skills and expertise and identify the unique qualifications they offer a client as well as areas where a facilitator has limited knowledge and expertise and methods to address such limitations.

Identify Your Business Entity
As a facilitator; you may organize your business as either a sole proprietorship or a professional corporation.

Fictitious Business Names ("DBA")
In some instances, a facilitator may want to attach a fictitious business name (also known as a "DBA," or "doing business as") to his or her business, for advertising purposes. This is entirely up to the individual and a DBA may be obtained for use by sole proprietor or a corporation.

To operate a business under a name other than the name of the individual proprietor, a fictitious business statement must be filed with the county where the principal place of business is located. It is necessary to contact the county clerk, and/or recorder where the principal place of business is located for information about filing or registering a DBA. The

intended business name must not be one that is already registered in the county, and it must be renewed periodically, in accordance with local rules.

Obtain a Federal Tax ID ("EIN")

It is advisable for a facilitator to obtain a Federal Tax ID, also known as an Employer Identification Number ("EIN") for use in relation to his or her business. A practitioner must include his or her Federal Tax ID when submitting a claim to an insurance company. In most instances, it is also necessary for a Federal Tax ID number to be included on a statement, or billing form that is provided to a client as a receipt for their use in seeking reimbursement. By obtaining an EIN from the IRS, the facilitator is relieved from having to utilize his or her Social Security Number for such purposes. An EIN is issued by the IRS and may be applied-for on the IRS website. According to the IRS, it takes approximately 4-5 weeks to receive the EIN.

Initial Inquiries and Requests for Service

A facilitator should plan to respond to initial phone inquiries and requests for service. Generally speaking, there is a need to provide information to the caller and to gather information regarding his or her needs. The basic goal when responding to the initial phone inquiry is to make a preliminary determination as to the person's needs and the likelihood that the facilitator would be able to assist him or her.

It is recommended that facilitators have a consistent approach when speaking to potential clients about

- Appointments and expectations
- Expected completion of paperwork during, or prior to, the initial visit
- Other information which the facilitator may wish to share about him or herself, including, but not limited to skills, experience, etc.

Intake Procedures

Facilitators should develop intake procedures applicable to every client. Facilitatorshave a fair amount of latitude in developing the procedures and systems of documentation that will be utilized in his or her work.

Required Disclosures

It is good practice to disclose the following.

- Prior to the commencement of services, information concerning the fee to be charged for the facilitation, or the basis upon which that fee will be computed.

- If the business is conducted under a fictitious business name, it is necessary to inform the person, prior to the commencement, of the name and experience of the owner or owners of the business.
- Information concerning the limits of confidentiality, including, but not limited to, mandated disclosures for child, elder and dependent adult abuse.
- Information relevant to the treatment of minors regarding issues such as confidentiality, consent, access to records, and writing reports
- Emergency Procedures/Information about the facilitator's availability and how best to communicate.
- Procedures to express dissatisfaction and or register a complaint.
- HIPPA disclosures and compliance as required.

Fee-Related Policies and Procedures

All fee arrangements should be clarified with the individual. Policies should include payment by the third-party FMS, and the amount of payment expected during the first visit and subsequent visits, and the acceptable form(s) of payment.

At the time of the initial visit, person should also be provided with clear written policies regarding missed appointments, cancellation fees, and any other payment-related issues that a facilitator deems worthy, including co-payments and receipt of gifts.

To raise fees for continuing clients, a facilitator should give reasonable notice. It is recommended that clients be informed of policies about raising fees in writing, at the outset of facilitation. Such statements should include the possibility that the fee may be raised; the percentage the fee may be increased by; how often the increase may occur; and how much notice clients will be given.

Conflict of Interest

It is a conflict of interest and inconsistent with good practices if a facilitator arranges services for an individual, resign and then be hired or work for a provider of the service.

Facilitators should refrain from accepting goods, services, or other non-monetary remuneration from clients in return for facilitation. Such arrangements often create conflicts and may lead to exploitation or distortion of the professional relationship.

Facilitators should notoffer or accept payment for referrals, whether in the form of money or otherwise.

9.Common Management Topics

Based on experience in the pilots, there are some management issues which recur and which might be appropriate for Independent Facilitator guidance. A prospective facilitator should be well served understanding or researching the following matters.

1.) The benefit of independence: Successful self-determination improves independence. With a set and stable budget, outgrowing specific needs provides more resources for either attempting new challenges with previously unavailable support or to stabilize and improve remaining supports through higher wages. On the other hand, doing without needed and, especially, preventive support can easily reduce welfare.

This risk-and-opportunity potential really doesn't exist in the traditional system where increased independence tends to also lower the quality of service available. When hours of service are commoditized, as they are in the traditional system, a client who achieves new levels of independence also receives reduced funding, undermining the support they still need and reducing the ability to pursue new goals. In self-determination, because of the fixed and ongoing budget, the opposite is true.

For example, a client who uses 100 hours per month of assistance with meal preparation and 100 hours per month of assistance with medical and sanitary needs could, having learned to cook, double the wages of the home health aide or purchase intensive vocational support. However, if doing so leads to frequent stomach ailments which, in turn, have negative physical and mental health consequences, it might have been more efficient to retain the cooking assistance. Working with clients to think critically about where, what, when and how they can reduce supports provides for much better outcomes, more stability and greater efficiency. Be ready to introduce this opportunity and help the client consider both the risks and the rewards of reducing services.

2.) How much an employer?Self-Determination program beneficiaries have several options available for how to receive personal assistance of various kinds. They can:

- Hire individuals using a sole employer model where they are fully the employer,
- Using a co-employer model where they share liability, responsibility and management authority or
- Hire a staffing agency.

From A through C, the model becomes less direct and the individual gives away both authority and responsibility. Likewise, as the individual moves from A through B to C, the wage of the employee likely decreases which can reduce stability and reasonable expectations of the person providing the service.

On the other hand, as the employment model becomes more assisted, there will be less risk of a staffing emergency, less risk of law-suits or other employment related challenges and a better chance of alternative staff being available to cover missed shifts. There is also less risk of an employment law transgression and a greater likelihood of savings from other forms of compensation like medical insurance.

So the basic trade-off is authority, customization, higher wages and greater responsibility versus greater support, better non-wage compensation and more available support staff.

The skill set of the Independent Facilitator can make an important difference in finding the right mix. An experienced program manager can facilitate a more direct approach to employment, moderating the risks and enhancing the benefits.

Another important consideration is available support. One open question right now is whether the FE/A model, in which the FMS provides a purely administrative and technical support while the client is for all practical purposes the sole employer, will be viable under California law at any likely price. So it will be possible that the real range of options for individuals using direct care support through self-determination will be co-employment with the FMS or to hire an agency to provide staff.

The personality and communication style of the individual should also guide the choice. People who are easily frustrated, emotionally volatile or who have trouble with confusion, in every population, often have trouble as employers, creating or experiencing environments which lead to bad outcomes. Bossy Type A visionaries in every field can achieve great things as managers as well as chaotic calamities. For people likely to run into trouble in the work of supervision, some kind of intermediary can be very helpful.

That intermediary can be a very good Independent Facilitator who will not have the right to discipline staff in the client's stead. For many clients who have a very hard time communicating or really just can't bring themselves to do the work of managing direct-care staff, hiring an agency to provide staff will often be the best choice. In every case,

the individual should retain the right to select, guide and instruct their staff, the right decision of how much to be an employer really depends on how much management support is needed.

10. <u>Other Ethical Considerations</u>

According to the statute, an Independent Facilitator may not provide other services to the individual or be employed by a paid provider of other services to the individual. This rule should reduce the opportunity for conflict-of-interest and the appearance of such. But it may not go far enough. For example, it does not prevent someone resigning as Independent Facilitator and then providing other services. If it were to become commonplace that Facilitators often resign after writing the plan and become staffing providers to the same individuals, that would confer a strong appearance of misconduct. In some locations where services are scarce, that might even be a desirable outcome. A useful discussion could consider whether, for example, there should be an ethical standard that Independent Facilitators do not provide services in the same county where they provide other services. Or if there should be a two-year waiting period between when someone terminates as Independent Facilitator and begins offering other services to the same individuals.

Another question along these lines goes to whether Independent Facilitators and Financial Management Services should have some parameters around making referrals to one another. The FMS is the principle quality assurance provider to DDS for the self-determination program and to receive referrals from other providers might bring their objectivity into question. Independent Facilitators, at least in the pilots, can be very influential on the decision of which FMS should be used. Sometimes these referrals can be based on useful experience (a grizzled old support broker might know in depth which FMS agencies do great work and the cost of one that does not.) A solution might include allowing referrals but only for IF's and FMS' that agree not to accept payments from one another.

In the traditional system as well as through the Self Determination Program, a constant challenge is how to ensure maximum input from beneficiaries who do not communicate by typical methods. As a consequence, planners can often be placed in an ethically challenging situation vis-a-vis individuals who rely primarily on paid service providers for advocacy. Some self-imposed standards of identifying when self-determination is practically too fraught to provide and a voluntary threshold for when an Independent Facilitator or FMS will not serve might be appropriate. Of course, such a policy would also deny self-determination to some individuals who might benefit from it.

Should there be limits on the cost of Independent Facilitation? The final regulations will likely impose price constraints on FMSes and may do so for Facilitators. The author has argued against such limitations, on the grounds that complex programs might be efficiently served by expert services delivered at high cost. Another problem with price caps will be that there are so many ways of setting prices (by subscription, by the hour, by the day, by the task, by some unit not yet devised) that such regulations may not be effective.

But there are reasons against that argument and first among these comes this one: The Independent Facilitator often touches the plan and budget before anyone else and nobody has more opportunity for mismanagementthan the facilitator. A voluntary code of ethics around pricing might be help