

Notes on Self-Determination

Anticipated Power Shifts and Conflicts of Interest

This note summarizes a discussion with people involved in Wisconsin's Robert Wood Johnson Self-Determination Project. The group met on 10 June in Madison and included representatives from each of the three project counties as well as people from guerrilla counties and a number of state DD staff.

Context

Project counties pursue different approaches to self-determination, but each intends to implement at least part of its approach through the more flexible approach to Medicaid funding allowed by the proposed "Consumer Directed Supports" amendment to Wisconsin's HCBS waiver. Counties' different understandings of self-determination and designs for their different self-determination projects have at least one common aspiration: people with developmental disabilities will have significantly more power in their relationships with the service system.

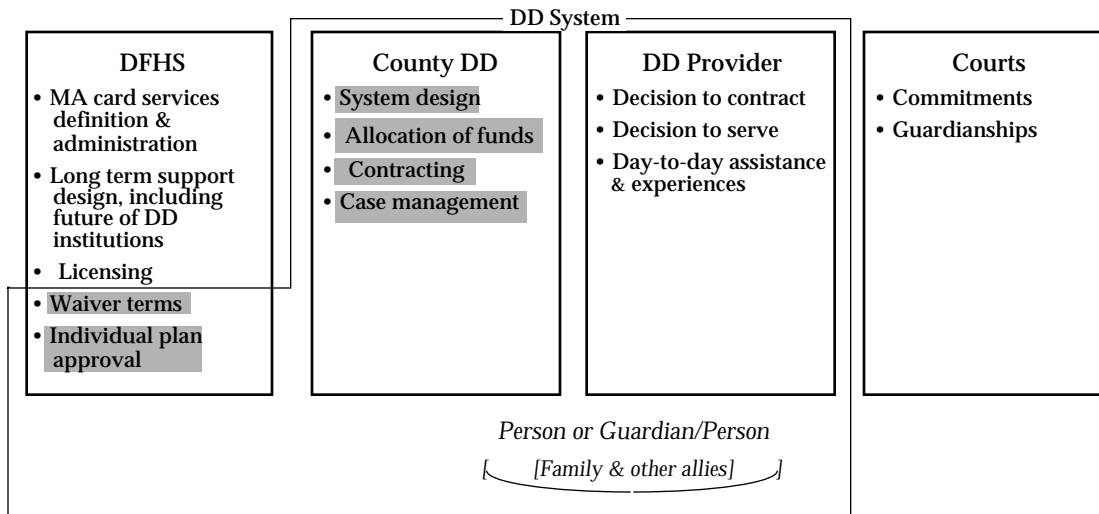
Discussion focused on exploring changes in relationships anticipated as people with developmental disabilities exercise more power. The group first mapped current concentrations of power and the conflicts of interest that influence the present system, then mapped the power concentrations and influential conflicts of interest foreseeable if the self-determination projects succeed, and finally used the contrasts between maps to identify key issues for consideration in preparing the memoranda of understanding that will be necessary to implement Consumer Directed Supports.

Each county in the self-determination project pursues its own strategy; this discussion focused mainly on the issues common to them.

* These are somewhat more my own notes and reflections on the discussion than simply a record of it. I have tried to accurately capture each of the points that participants made, but I have rearranged them in terms of ideas that occurred to me as I prepared to summarize them. I recognize that some of the participants' meaning got lost in my compulsive search for order and would welcome corrections or further thoughts.

Process changes within existing authority structure

The diagram below indicates some of the authorities that control formal decision making in the DD system. The gray bars highlight the decision making processes changed by the self-determination project. The self-determination projects do not change the system's allocation of authority. They represent discretionary choices by county managers to modify –and state DD managers to negotiate to modify– some of the system's processes in order to discover the effects of increasing self-determination project participants* direction of who is paid to provide what supports and services.



* In this paper, “self-determination project participants” refers to people with developmental disabilities or guardians who have legal power to make service decisions and the people for whom they are guardians. It also includes any involved family members and other allies, who may be organized as the person’s support circle. Because self-determination is usually accepted as a good thing for everyone, this note distinguishes the value, self-determination, from the system change effort, the self-determination project. This focuses attention on the narrow question of increasing people’s say over how and for what the system spends its money as a way to improve the quality and efficiency of services rather than on other questions that often arise in discussions of self determination such as whether people will get whatever they ask for at public expense or whether people in service settings get to make choices in the course of their daily routine. This narrower understanding may be unsatisfying to people who have attached higher hopes to self-determination efforts.

Pointing to self-determination projects as a set of discretionary process changes does not discount the potential importance of these changes to the quality of people's lives. Indeed, it argues for...

... boldness in making the most possible control available to those people with disabilities within the project as soon as it is reasonable to do so

... discipline in learning rapidly by actively looking for, understanding, and repairing difficulties in project implementation and identifying and amplifying positive changes from the self-determination projects

... thoughtfulness about exercising whatever positive influence is possible on the political contingencies that could strongly affect project outcomes

EXAMPLE: County Commissioners could reverse or revise a project they come to see as uneconomic or as generating too many complaints from families (who might be acting on the perceptions of threatened providers)

EXAMPLE: some people could be stressed and disadvantaged by uncertainties and denials imposed through prior authorizations and limits on medicaid card services regardless of the success of the self-determination project, this will color their sense of satisfaction with the system

EXAMPLE: the self-determination project could be overwhelmed by long term care redesign

EXAMPLE: the decisions of guardians and judges will only reflect the principles of self-determination if they are persuaded of the benefits these principles offer them

...care in enrolling people with disabilities and their guardians, family members, and friends in the self-determination project so that they understand the projects purpose and their responsibilities to other people who could benefit from the project

The self-determination project modifies decision making processes.

- It shifts how counties may choose to use HCBS waiver funds and (maybe) how state staff monitor individual plans.
- It may reduce the number of regulations and safeguarding procedures the county and providers respond to in favor of people exercising increased voice in negotiating and paying for services and the option for people to exit undesirable services.
- It changes how counties deal with providers and how service planning and coordination gets done.
- Counties still decide who waits for what services.

- Counties still control the amount of money allocated to each person’s individual budget.
- The self-determination project is a context within which county authorities discharge their responsibility to assure the availability of necessary services of good quality. It is not a vacation from accountability for system design, which will take new urgency when participants with individual budgets ask, “What if what I want is unavailable?” and “What is ‘off the menu’ of possible choice?”
- Providers still have the power to negotiate with consumers and the responsibility to assist people in what they believe to be reasonable and effective ways; consumers can no more compel providers to serve them in a particular way than consumers can compel an electrician to follow a particular procedure in installing a new electrical entrance

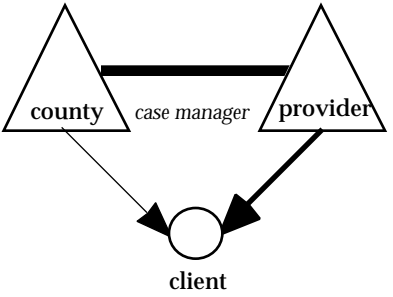
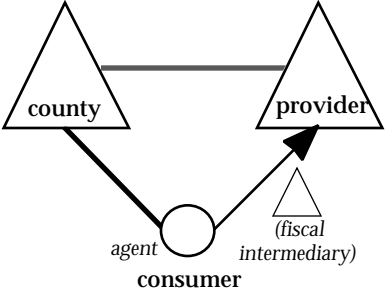
When implemented, these process modifications position the county’s authority differently for participants in the self-determination project* than for people outside the project. Within limits, some of which are negotiable, the county agrees to be bound by decisions made by self-determination project participants.

<i>Outside self-determination projects</i>	<i>For participants in self-determination projects</i>
County contracts with providers for a number of program slots at defined rates; once a provider has a contract, it is likely to keep the contract with marginal adjustments.	County authorities determine allocation of funds by developing an individual budget which is open to negotiation; individual agreements replace contracts for blocks of places

* When a county considers everyone it serves to be part of the self-determination project, a person’s decision to initiate a change in present service arrangements activates the possibilities created by the self-determination project on that person’s behalf. For now at least, people who remain quiet about current arrangements are in a similar position to people in other counties who do not join the self-determination project.

<p>County places people based on an individual plan prepared by an interdisciplinary team that includes the client and guardian.</p>	<p>Participants, with needed assistance from someone who acts as their individual agent (maybe a county system employee or a broker independent of the county system), negotiate with any legitimate provider for the specific assistance they require, whether or not a contract currently exists between the county and that provider. Based on the agreement arising from this negotiation, county (or the county's agent) pays providers on an individual basis for satisfactory performance as judged by participants. Some form of fiscal-intermediary may facilitate this process.</p>
<p>County defines individual planning process in compliance with state regulations. A case manager by who acts as the county's agent, coordinates services and (if CIP funded) the plan is overseen by state staff.</p>	<p>Participants can assume control of designing their individual plans with the help of their agent, and participants have responsibility for deciding on trade-offs created by scarcity of funds or other resources. EXAMPLE: a person might manage with fewer paid hours of assistance in order to pay assistants higher wages</p>

These changes in how counties use authority shifts the source of demand for services from the county agency to a growing number of individual self-determination project participants, who are backed by the county's authority. By making it easier for people with developmental disabilities to switch providers and by expanding the range of agencies and people from whom a participant can purchase assistance with county money, the self determination project shifts the logic of alliances in the system.

<i>Outside self-determination projects</i>	<i>For participants in self-determination projects</i>
	
<p>County allies with service provider to develop programs that will improve quality of life for people with developmental disabilities by changing them, primarily through a professionally defined program of treatment coordinated by a case manager</p>	<p>County allies with people with developmental disabilities to improve their quality of life by changing the ways providers support them and the mix of available providers, primary through economic influence facilitated by a personal agent (and perhaps a fiscal intermediary)</p>

Until large numbers of people become active self-determination project participants, counties and providers will be part of two demand systems. Moreover, as the number of participants in the self-determination projects increase, the number of separate agreements providers have to negotiate and manage increases. The costs of multiplying transactions with individual customers are unknown and might be substantial. Over time, these costs may be offset by finding services under the “Consumer Directed Supports” category, if memoranda of agreement significantly reduce the costs of complying with medicaid regulations and procedures

- Providers will perceive more threat from the self-determination project the more ...
- ... satisfaction the provider derives from holding a unique position in the lives of the people served (“We are the only ones who truly accept and understand them.”)
- ... provider staff identify themselves with professional careers in clinical disciplines (“Our career satisfaction depends of delivering state of the art interventions.”)
- ... money a provider has sunk in buildings that serve people in groups (“Our living is tied to the mortgage on this building.”)

Providers retain the power to say no to serving a person. As the logic of the system shifts to consumerism from paternalism and clinicalism, with its presumptions of commitment to people or observance of professional ethics, providers may see new obligations to calculate the costs and benefits to them of serving people who may challenge or inconvenience them. Because providers have to consider the possible effects of individuals leaving and taking their money with them, they may find it necessary to demand higher prices from people whose needs have been met by a sort of averaging of support over a number of people. If self-determination budgets prove insufficient to meet the full price, a provider may reasonably argue that it would be a disadvantage to other individual consumers to subsidize these people. Provider refusals to make offers to serve people will highlight the county's responsibility to provide good quality services to eligible, funded consumers.

Culture change: the project's challenge

To preserve relationships, programs, and investments they value—and to minimize transaction costs – providers have strong incentives to reduce the uncertainties created by the self-determination project, for example by...

- Using their influence with self-determination project participants to minimize the difference between what they currently offer and what their newly defined customer demands from them. Such an approach would probably involve appealing to people's loyalty, making small changes that people find attractive, and highlighting the advantages of familiar routine over the risks involved in doing something new. It might also involve offering relief from having to face the difficulties and threats of change to guardians and influential family members.
- Marketing the advantages of group purchasing to self-determination project participants and their agents. For example, a day program might approach families whose children are graduating from special education with an offer of a lower price if several students agree as a group to select their program as is.
- Negotiating contracts that tie consumers to them, for example by offering discounts for longer commitments or exacting penalties for cancellation.
- Avoiding consumers who frequently switch providers or charging them a premium.
- Building good relationships with the people who act as agents for participants in the self-determination project, especially those agents who represent more than one participant. Such relationships can have important benefits: for example, a provider who makes a consistent effort to go the extra mile with a difficult person deserves the good will of that person's agent, who otherwise might have to help the person cope

with at least temporary exclusion from service. It may also create the possibility of conflict of interest for agents: agents who cannot find providers for the people they represent are unlikely to make a living.

- Highlighting the potential difficulties faced by county staff if providers are unwilling or unable to serve (many) people under new conditions.
- Diversifying to serve people without developmental disabilities who will be less demanding to serve because their funding sources have less expectation of consumer control.
- Concentrating on services to people with little interest in the self-determination project.

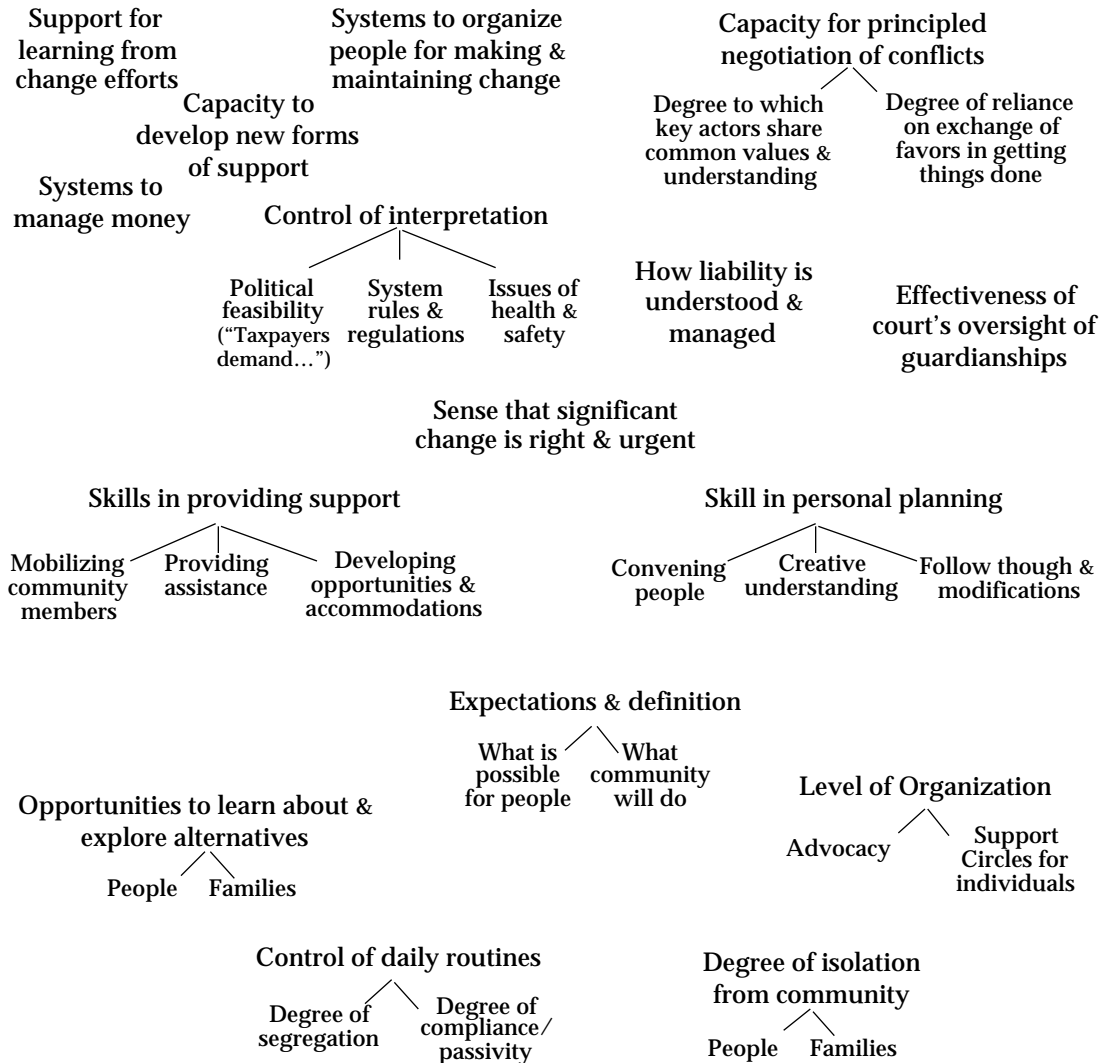
Each of these tactics is consistent with the logic of consumerism, and some offer self-determination project participants a wider choice of benefits. However, leaders who adopted the self-determination project as a way to major change may find this level of change significantly less than the transformation they had visualized.

The power of these incentives to minimize the impact of the self-determination project depends on how much it is possible to change the effects of system culture on the way power is distributed and exercised. Culture can be understood to include: accepted understandings, habits and familiar tools of practice, norms and expectations, patterns of relationships and associations, and informal political processes. Culture defines the ways in which power works in the system. Unless people reflect on and work to change cultural patterns, the effects of modifications in decision-making process on the experience of people with developmental disabilities will be far more limited than necessary.*

The diagram below maps some of the sources of power whose interplay will influence the amount and kind of changes that will result from the self-determination project.

* Those who enjoy reading management books will find many interesting ideas on this sort of change in R. Daft & R. Lengel (1998). *Fusion Leadership: Unlocking subtle forces for change*. San Francisco: Berrett Koehler. They distinguish the effects of “strong forces”, such as shaping structure, financial incentives, and enforcement of rules, from the effects of “subtle” forces such as building common understandings of purpose, persuasion, and displaying courage and compassion in risking defeat or opposition.

Some Cultural Influences on the Level of Power People with Developmental Disabilities Can Exercise Through Participation in Self-Determination Projects



These elements of system culture cluster and affect each other in mutually reinforcing and mutually inhibiting ways. For example, participants with a history of isolation and passive compliance who lack encouragement to explore new things and the organized support of other people may confirm low skilled personal planners and low skilled support providers: "We did the person-centered plan and she's chosen to stay right where she is." This ratified request for more of the same will do little to generate urgency for change and the kinds of conflict that could challenge timid interpretations of what regulations or prudent management of liabilities will allow. In fact, it will turn self determination projects into complacency generators.

On the other hand, a critical mass of people could notice that their work is bound by unfulfilling norms and decide to challenge these norms in collaboration with participants in the self-determination project. They could choose principled negotiation of conflicts and bold interpretations of the possibilities offered by changes in the medicaid waiver instead of acting inside boxes created by following such unwritten rules as “Everyone feels they have no power.” and “With all the layers of rules, it’s easier and safer to say ‘no’ than to say ‘yes’.” Such people will bring different ears and eyes to the core task of listening to participants and provide a higher level of energy to problem solving than people who are caught in the old norms.

As tracing these simple interactions suggests, the point is not to be overwhelmed by the complex interactions of these multiple aspects of culture. The point is the act courageously and thoughtfully, in small steps, in ways that nudge multiple aspects of culture, remembering the time delays between action and rippling effects. When stuck in one aspect of culture, look for ways to make a difference in another: blocked by an unyielding and political influential provider, increase the occasions people with disabilities have to organize for advocacy.

The importance of culture to the outcomes of the self-determination project underscores the centrality of the human and the importance of understanding the facilitation of personal self-determination as an art. The self-determination projects will have better results if...

- ...system managers create opportunities for people to deepen their understanding of and commitment to people’s right to choose their own life paths with the active support of people who care about them and the active assistance of people who are paid to support them
- ...people, regardless of role, share responsibility for exercising leadership in making changes and learning from their successes and failures
- ...system managers model risk taking, for example by explicitly increasing the responsibility and authority assumed by self-determination project participants and the people who directly assist them
- ...service providers recognize their opportunity to develop and refine their capacity to assist people
- ...guardians see their responsibility to explore the potential benefits of change in the assistance that structures their ward’s opportunities for satisfaction and growth
- ...personal agents realize the centrality of integrity in relationships to their work; unless they perfect the art of practicing power with the participants they represent – actively

encouraging exploration and high expectations, creatively negotiating conflicts, thoughtfully dealing with risks– the project will offer very limited benefits

Over time, the self-determination projects should lead to substantial investment in improving the process for developing and selecting personal agents and service providers.

The place of guardians

A substantial number of people have guardians, which disturbs self-determination when others who know the person conclude that a guardian makes little or no effort to know their ward personally and in depth, to look carefully at things from their ward’s point of view, to use their ward’s resources in ways that directly benefit their ward, and to actively seek the best for their ward’s quality of life. Guardians might be roughly sub-grouped in terms of the extent of their personal involvement with their ward and their level of interest in using the self-determination project as a way to improve life for their ward.

		Personal engagement in ward’s day-to-day life	
		Low	High
Interest in the self-determination project as a means of improving ward’s life	High	4 ?	1
	Low	3 ?	2 ?

- Guardians (1) who are personally engaged with their wards and interested in using the self-determination project as a way to improve the quality of their ward’s lives are probably valuable allies. They may have differences of opinion with others in the person’s life about what is possible or desirable, but they are likely to be willing to join in the project’s learning.
- Guardians (4) who are interested in the possibilities of the self-determination project but have little personal engagement with their ward will probably trust the advice of

people who demonstrate caring or expertise. A person who has other allies interested in change has a good chance to benefit from the self-determination project.

- Guardians (2) who are highly involved and little interested in change offer the self-determination project a choice: will their wards be...
 - ...left outside the self-determination project
 - ... included in the self-determination project with the assurance that the self-determination project will accept their choice to preserve the status quo without question
 - ... actively invited to consider positive changes that the self-determination project makes possible; that is, can the project help them shift to Guardian (1) or maybe to Guardian (3) by agreeing to stand aside and endorse the judgments of others.
- Guardians (3) who have little involvement and little interest in self determination pose the biggest challenges to the self-determination project.
 - One challenge is practical. If a guardian's position is to manage their ward's affairs in a way that minimizes their own contact and effort by choosing services that maximize stability, protection, and control, can people committed to self-determination find effective ways to persuade the guardian to entertain proposals for change from others who know and care about the person; that is, to shift to the position of Guardian (4).
 - The second challenge is conceptual: are there people whose guardianship situation should exclude them from participation in the self-determination project? In what sense can a person be said to exercise self-determination if that person (a) has a guardian with a narrow view of his/her possibilities and a disposition to say 'no' to changes and (b) has no other allies who act on the basis of personal commitment?

Of course, guardianship problems exist regardless of the self-determination projects. In fact, some participants in the discussion have had troubling and deeply frustrating experiences with guardians, some of whom act in ways that seem neglectful, exploitative, or abusive of their wards. Difficulties with such guardians are compounded by judges who habitually defer to guardians, probably because of these judges' own limited expectations for people with developmental disabilities.

The self-determination projects offer a somewhat different context for struggling with these enduring issues, though they probably cannot be expected to offer the means to resolve them. It does seem that culture change efforts related to self-determination projects could have positive influences of the issues, especially those efforts aimed at...

- ...organizing and strengthening self-advocacy
- ...encouraging the development of circles of support
- ...strengthening the capacity for principled negotiation of conflicts
- ...increasing opportunities for positive news to move through personal contact from family-to-family and person-to-person
- ...improving the skills of personal planning
- ...building service provider understanding of and commitment to the values at stake in self-determination projects

Who has standing to question?

At the base of self-determination projects are at least four premises about the relationship between choice and quality of services:

- Responsibility for choice and control over the pattern of assistance a person relies on is a good in itself. Given the same (insufficient) resources, a service system that makes more room for this kind of choice and control is of better quality than a service system that places more limits on choice and control.
- The quality of services is best defined by the contribution those services make to the quality of life of the people who rely on them.
- Quality of life is best defined by people themselves and judgments about the quality of services are best made by people themselves, in terms of their individual understanding of what works best for them.
- Over time, people's choices will lead to better quality services by directing the efforts of service providers to the things that matter most to them.

It seems worth limiting the scope of the discussion about honoring people's choices to the terms of the self-determination projects. The self-determination projects give participants an individual budget and the ability and support to negotiate with any legitimate provider for services and supports that match the persons requirements. This limitation sets aside some distractions (such as questions arising from the assumption that self-determination means making wishes come true with public dollars or the notion that self-determination somehow evaporates a service provider's ability to negotiate with a person over what supports and services they will and will not offer). It also sets aside some important issues about how a person's assistants should respond day-to-day when a person expresses interest in doing something illegal or dangerous: serving a person in a self-determination project does not relieve the person's assistants of their

ethical and legal obligations and the many dilemmas these can cause. These limits may be too neat: some people may try firing providers as a way to happiness.

At least three questions trouble these premises of self-determination.

- History shows that people with developmental disabilities are deeply vulnerable in many ways.
 - Is individual choice of services and supports an adequate safeguard for people who may be seen as trapped in isolation and habits of compliance to conditions that most people would view as neglectful or abusive?
 - If a guardian expresses satisfaction with their ward being locked in her room and deprived of food as punishments for bad behavior, are the managers of a self-determination project absolved from worrying about the situation?
 - If not in this latter case, then what if a person is satisfied with what some people see as the slower acting poison of segregation and habituation to compliance?
 - Do counties have a serious conflict of interest between stability in their system at current levels of expenditure and the long term interests of significant numbers of people who could benefit from active encouragement to pursue more integrated and personalized supports, and isn't it possible that focus on self-determination veils this conflict?
- Many people with developmental disabilities have limited horizons of possibility because they have grown up in settings shaped by low expectations of their capacities and at least some people come out of these experiences with poor judgment because they have had very little opportunity to exercise choice. When and how, if ever, is it reasonable to disapprove of a person's choice of services and supports?
- Participants in self-determination projects are directing the expenditure of public money; what limitations and obligations follow from this?
 - If a county has chosen, as a matter of public policy, to reduce expenditures on congregate services, should participants be able to purchase such services if their purchase would increase the number of people in a congregate setting?
 - What conditions on who can be paid and for what are legitimate?
 - Are there any limits or conditions that cannot be specified and monitored in the process of assigning and implementing individual budgets? What are reasonable and respectful procedures for auditing participant compliance with county requirements?

The self-determination projects also face practical questions around the memoranda of understanding required to implement the Consumer Directed services amendment to the waiver. The amended waiver calls for participating counties to describe how they will deal with issues of health, safety, and quality for self-determination participants in waiver funded services. In negotiating these memoranda, should counties assume a blank page, or does the state believe that people's interests are best served by identifying non-negotiable provisions of the memoranda. For example, will state staff continue to exercise oversight on waiver plans as a matter of policy or will counties have the option to include them in their plans or not, based on their own approach to safeguards?

In thinking about this question, it seems helpful to distinguish among...

- ... county authority to set and check conditions for participating in the self-determination project
- ... responsibility to report and to act on reports of neglect and abuse
- ... requirements on providers to observe applicable rules of licensure
- ... efforts to inform or persuade participants of what involved people see the pros and cons of a choice of their particular configuration of services and supports
- ... the power to override a decision about a person's selection of services and supports made within the county's conditions of participation

The foundations for the first three interventions seem straightforward, though some people would strongly advocate that conditions for participation should leave people as much room for choice as possible, and some people would raise questions about the capacity of licensed programs to offer participants personalized supports or the adequacy of licensing as a safeguard. Persuasion differs from command and raises the question of how those who want to persuade participants can respectfully enter their lives and effectively make their case. This will be a valuable theme to explore as the self-determination projects continue.

Overriding a participant's decision about who offers support and how offers the greatest potential for learning about the possible limits of the self-determination project. One instance has already arisen of a person and closely involved family members choosing to return to a setting from which the person had been removed because of serious problems. Reflection on this situation offers important learning: involved staff believe that better supports could be had and that the participant has chosen an unnecessarily restrictive situation. However, no clear way to overrule the participant (both guardian and consumer) presents itself. The participant tried an alternative that seemed better to involved staff, but, after trying the alternative, asked to return to a

setting that seemed to offer what the guardian and the person valued more: closeness to family and family confidence in the provider, who has cleared up licensing violations. In this sort of complex situation, what seems to matter is first to work affirmatively to identify problem situations and then to struggle together to improve them. As experience with different real situations grows, reflection will produce important learning for the self-determination projects.