The Robert Wood Johnson Foundation
Self-Determination Initiative:
Final Impact Assessment Report
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All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Robert Wood Johnson Foundation or any government authority.

What follows are findings stemming from a recent impact assessment of RWJ’s Self-Determination Demonstration for people with developmental disabilities.
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# Table of Contents

SUMMARY OF FINDINGS .........................................................................................................................................5  
CRITICAL SUCCESS FACTORS AND BARRIERS........................................................................................................5  
NATIONAL IMPACT ................................................................................................................................................8  
FUTURE POLICY CONSIDERATIONS ..........................................................................................................................8  

OVERVIEW AND PURPOSE .......................................................................................................................................13  
BACKGROUND ...................................................................................................................................................13  
OVERVIEW OF PROJECTS AND GOALS ....................................................................................................................14  
FINDINGS: YEAR 1 ...............................................................................................................................................17  
THE ORGANIZATION OF THIS REPORT ..................................................................................................................20  

STUDY METHODS ..................................................................................................................................................21  
METHODS: IMPACT ASSESSMENT ..........................................................................................................................21  
  Data Collection: Year One – Impact Assessment ..................................................................................................23  
  Data Collection Strategies: Year One – Impact Assessment ..................................................................................25  
  Year One Constraints and Year Two Revisions .................................................................................................25  
METHODS: IMPLEMENTATION ANALYSIS .............................................................................................................26  
METHODS: FINANCIAL MANAGEMENT ANALYSIS .............................................................................................27  

WHAT WAS LEARNED: SELF-DETERMINATION IS AN EVOLVING CONCEPT ....................................................30  

WHAT WAS LEARNED: FOCUS ON SELF ADVOCATE PERSPECTIVES .................................................................35  
CONVENING OF THE SELF ADVOCACY MEETING ..............................................................................................35  
FINDINGS RESULTING FROM THE SELF-ADVOCACY MEETING ........................................................................37  
SELF-ADVOCATE RECOMMENDATIONS .............................................................................................................39  
CONCLUDING REMARKS ....................................................................................................................................41  

WHAT WAS LEARNED: FINANCIAL MANAGEMENT ANALYSIS .............................................................................43  
SCOPE OF EVALUATION ......................................................................................................................................44  
BACKGROUND INFORMATION ..............................................................................................................................44  
FINDINGS AND OBSERVATIONS ............................................................................................................................46  
  Fund Allocation, Individual Spending Authority and Individual Budget .......................................................................46  
  Rate/Price Setting ..............................................................................................................................................49  
  Billing, Payment and Tracking ............................................................................................................................52  
  Employee Administration ....................................................................................................................................53  
  HCBS Waiver Dimensions .................................................................................................................................54  
  Observations Concerning Resource Requirements ..........................................................................................55  
  Management Information Systems ....................................................................................................................57  
CONCLUSION .......................................................................................................................................................58  

WHAT WAS LEARNED: COMPLEMENTING OUTCOMES AND OBSERVATIONS ....................................................60  
SUMMARY OF RECOMMENDATIONS ..........................................................................................................................74  
REFERENCES .........................................................................................................................................................76  
APPENDIX A: RWJ PROJECT EVALUATION CODING FORM ..................................................................................77  
APPENDIX B: SELF-ADVOCATE INTERVIEW PROTOCOL ......................................................................................86  
APPENDIX C: DETAILED RESULTS OF FINANCIAL MANAGEMENT STUDY ..........................................................90
Summary of Findings

In 1997, the Robert Wood Johnson Foundation invested in a broad range of demonstration activities around the country aimed at exploring the ways in which people with developmental disabilities can influence the character and configuration of the supports they receive through self-determination. The emphasis on the choices and preferences of people, a theme that was at the center of each of the 19 demonstrations, represented a significant departure from conventional practice.

The Foundation allocated over $5 million in support of the demonstrations. Allocations for each project amounted to $400,000 for a 3-year period, $200,000 for a 2-year period, or $100,000 for a 1-year period. While each local project was based on the same broad outline of values and objectives, there were significant differences given the variations in geography, socio-demographic factors, resources, service configuration, and economy. Further, the 19 states represented in the project also differed insofar as the history and evolution of publicly funded services, the extent of reliance on public institutions, the extent of provider acceptance of notions of self-determination, the extent of regulation, and the presence of supportive advocacy and professional/provider organizations.

The lasting impression of the Self-Determination demonstrations was of works in progress – progress toward an understanding of self-determination that yielded a way of working that is capable of surmounting the bureaucratic and structural obstacles that lay in their way. It was also of a positive struggle to surmount, work around, and/or deconstruct the “architecture” of traditional systems to craft individual budgets, ensure choice, and leverage power to people with disabilities and their families. The following discussion summarizes some of the specific observations that flow from the analysis presented in this report.

Critical Success Factors and Barriers

Flexibility Breeds Flexibility

A system that encourages self-determination must be flexible enough to accommodate a variety of life choices. The days of channeling individuals into a limited array of preset service options are over. Once people are set free to imagine other ways of living and to plan for the supports that are needed, systems are challenged to become maximally flexible.
As the RWJ demonstrations unfolded, it became plain that some states were better positioned than others to flex with the varying support needs that individuals have. Some, for example, already were stretching their system to deliver residential, vocational and family support services in innovative ways, and were developing the financing and managing infrastructure to support such flexibility. In other states, however, the available service options were narrower, and so it was more difficult to inject flexibility into an historically rigid system. Simply put, flexibility breeds flexibility.

A more specific example pertains to how states set individual budgets. Sites/states used a variety of methods to assign dollar resources for individual budgets including allocations based on historical costs, allocations within overall ranges, and funding based on individual functional characteristics. Where systematic approaches to budget development (e.g., based on costs, and/or individual characteristics) were already in place (e.g., in Utah and Kansas), the task of making these individual resource allocations was facilitated. For these states, the task was simply to translate the individual “self-determined” budgets into their existing system. Where funding was more categorical (e.g., MA, CT), the task was harder.

Let All Flowers... 

One of the important keys to offering legitimate choice is to ensure that individuals and families can chose from a range of services and supports – both traditional and generic. In some states, contracting policies proved to be barriers to expanding the types and quantities of available providers. Self-determination requires agile procurement systems to accommodate the purchase of services and supports from a wider number of sources than typically is the case in specialized service systems. Those states with tightly controlled RFP processes found it difficult to accommodate individual needs for services not currently part of the “contractor” pool.

Self Determination is Not a Rehearsal

The success of the self-determination initiatives in New Hampshire and Vermont or in Dane and Winnebago Counties in Wisconsin had to do with the fact that leaders there did not treat self-determination as a “project” but rather embedded the approach throughout the system. While the realization of this system-wide ideal did not happen overnight, everyone in the system was put on notice that the direction ahead was clear and that self-determination was the overarching approach. It is also important to note that such a mandate was made more palatable because these were also states where innovation and progressive change was the norm.

Supporting the Supporters

Across the country, the ability to lead a self-determined life was significantly influenced by the availability of direct support professionals. Recruitment sometimes took weeks
and many individuals and families experienced substantial turnover in their supporters. This finding, however, cannot be tied uniquely to the self-determination demonstrations. Human service organizations nationally are feeling the pinch of an apparent worker shortage. In fact, some evidence (e.g., Utah, Kansas) suggests that self-determination practices can make it easier for people to find needed support because the inherent flexibility to the approach may open labor resources that were previously untapped (e.g., as in hiring friends, neighbors or family members to offer sporadic or longer term support). One provider in Kansas who was having trouble recruiting staff remarked that “self-determination could turn out to be his best friend.”

Further, in some states/sites, staff also absorbed more of the “risk” (e.g., not getting benefits, etc.) of self-determination and in ways that should give us pause. For instance, workers could be hired by individuals outside of the traditional service system. The worker may even be offered a higher wage than what might be offered by a local provider. However, the job may not carry health benefits. And in many states workers compensation insurance might not be offered on grounds that the worker is a “domestic employee” and so exempt. Initially, the arrangement might appear more cost effective and empowering to the self-advocate and worker. Yet, it must be understood that the arrangement may not be particularly in the best interest of the workers.

Finally, direct support staff did not always receive the level of training and orientation received by managers, executives, and other providers in person-centered and person-driven practice. In a decentralized system, direct support professionals play an absolutely crucial function and their role should be taken seriously by the system through increased compensation as well as training.

**Leadership Counts**

Leadership at the state and local level and the presence of innovation and momentum within a state were key elements in the success of the self-determination initiative. As noted above, cutting through the bureaucratic underbrush to establish a system based on the principles of self-determination requires stamina and commitment. It is not a task that can be handed off to someone in a marginal relationship to power – power in the state authority, power in the local entity, and power at the provider level.

We observed that often where a site pushed ahead the advance could be traced back to an individual or group of individuals who worked hard to make things work. These leaders modified or tweaked systems, established new alliances, built on past accomplishments, created new operational structures and “spread the word” to self-advocates, family members, provider staff and others whenever they could. These individuals took the risk to think differently and put these new thoughts into action.

We also observed, however, that initial efforts were often primarily grounded in the actions of these relatively few leaders. We understood that the self-determination
initiative would be hard pressed to maintain or expand unless the grassroots constituencies became equally engaged. After all, effective leadership to drive systems change must also include the actions of many -- acting in their own ways as leaders in their own lives and to influence policy. This past year, we observed that this transition in leadership responsibility has begun. Self-advocates, family members and some providers are increasingly coming to expect that their state systems will embrace self-determination principles and practices. Regarding the future for self-determination, their expectations and emerging leadership will certainly count.

**National Impact**

*Speaking for Ourselves*

The demonstrations have resulted in an intensified spotlight on self-advocacy and in some states, an increased allotment of resources to nascent self-advocacy groups. In the first year evaluation, the evaluators did not detect substantial self-advocacy activity. However, in the second round of observations, it was apparent that the juxtaposition of the self-determination demonstrations with the emerging aspirations of people with developmental disabilities combined to spur the growth of organized self-advocacy.

*Person-Centered Doing*

Self-determination gave momentum to the application of person-centered planning by giving it a very specific and instrumental purpose – the creation of individual supports based on individual preferences and taking into account individual budgets. The combination of person-centered planning and self-determination has sharpened the practice of person-centered planning in many states because it provides the “end” that justifies the “means.” In other words it added person-centered “doing” to person-centered “thinking.”

**Future Policy Considerations**

*Keep it Simple*

Dealing with the mechanical elements of consumer budget management and employee administration can be extremely complex. Site staff discovered that moving money between people or organizations did not eliminate needs for tracking money or honoring state and federal tax and labor laws. The task for states/sites was to move these functions “behind the curtain” in ways that simplified the process for people with disabilities and their families. Some states/sites were able to work out practical, economical arrangements to address this dimension including “outsourcing” these functions to fiscal intermediaries of some sort (e.g., to Goodwill in Dane County or Acumen in Utah) at relatively low costs. However, managing the complexity is
something that all entities committed to self-determination will have to be concerned about.

However, while workable solutions were found to many of the logistical and payment challenges, self-advocates in many states still found the experience confusing and intimidating. Such complexity may inadvertently give more power to families and brokers. In the end, if the only people who really understand the process are those other than the person seeking support, then we are left to wonder “who” is the “self” in self-determination?

**To Waive or Not to Waive**

States varied in the extent to which they felt it necessary to modify their Medicaid Home and Community Based waivers to implement practices consistent with self-determination principles. There continues to be uncertainty among the states concerning the interface of self-determination with Medicaid policy.

Such a clarification is important since the Medicaid program now underwrites the majority of community developmental disabilities services. The extent to which self-determination will play an increasingly important role thereby hinges on the extent to which it is sanctioned in federal Medicaid policy. In addition, Medicaid requirements also affect the design and implementation of certain instrumental features of self-determination (e.g., financial intermediaries). For example, there are specific federal Medicaid requirements concerning contracting, billing and payments. These requirements add complexity, cost and effort to operating a financial intermediary.

The federal Centers for Medicare and Medicaid Services (CMS) voiced strong support for the principles of self-determination and is on record as urging states to promote “beneficiary-directed” services. However, to date, CMS has not issued a coherent set of policy guidelines that clearly sanction self-determination as a framework for the provision of Medicaid-funded community services. For example, states have voiced uncertainty about the extent to which Medicaid policy sanctions the use of individual budgets. States also are concerned about potential conflicts between honoring the principles of self-determination and their responsibilities to protect the “health and welfare” of Medicaid waiver participants.

In some cases, the lack of federal policy clarity slowed projects coming on line, led to false starts or caused states to confine their initiatives to individuals who were not receiving Medicaid services. During and after the project period, many states/sites continue to be uneasy about whether their implementation of self-determination on behalf of Medicaid beneficiaries will be the source of compliance problems down the road. At the end of the day, the extension of self-determination would be considerably aided by CMS’ issuing clear policy guidelines to serve as a reliable foundation upon which states could base self-determination.
Managing Information

Whether “self-determination” causes an increase in overhead/administrative costs was unclear. Some of the additional administrative costs can be attributed to costs transferred from provider organizations (e.g., hiring people). One cost that was not reflected in the analysis was MIS expenditures. There is little doubt that for self-determination to become the predominant approach in a state, sophisticated, integrated MIS capabilities will be necessary. For the limited purposes of the demonstrations, States/sites generally put into place workable, ad hoc data systems especially at the local level to support the initiatives in Michigan, Wisconsin, Minnesota, and Ohio. Going forward, however, more comprehensive approaches will be needed. The underlying problem with existing state MIS systems is that they don't track individual costs and service utilization.

From Theory to Practice

The process of developing a theory of self-determination is ongoing and will continue for some time. Given that self-determination is premised on the uniqueness of each transaction, this process of refinement may become a permanent feature. As such, evolving the theory will require continued education and support for people with disabilities and their families.

Further, the accepted wisdom about what is entailed in self-determination has also metamorphosed over time and the original conceptions (e.g., need for a broker, fiscal intermediary, etc.) of what had to be in place have changed. In part these changes are the result of trade-offs between practicalities and the original idea. Specifically, not everyone wants or needs a fiscal intermediary, some individuals may only need a broker at the inception of the process, and other individuals may be content to stay with an existing provider and may not want the responsibilities of management.

Build It and They Will Come

To simplify the process of self-determination, it will be necessary in some states to significantly alter the “architecture” of how public agencies allocate, disperse and track funds. The troublesome complexity noted above is the result of the fact that many states (e.g., MA, PA) have not grappled with a new “business model” that would establish a streamlined system infrastructure that would make it possible to allocate funds, pay for services, and develop budgets on an individual basis. Such changes would entail reforming the RFP process, developing means to track individual allocations, designing assessment methods to establish broad budget ranges, and so forth.
Its All Relative

As the self-determination movement goes forward, it is important to note that not everyone wants the choice to be involved in “backroom” functions (e.g., hiring, firing, recruiting, paying, etc.). In fact in this demonstration as well as in the RWJ cash and counseling demonstration, the minority of people want to be in control of all of the aspects of their support network. There are lots of ways to lead a self-determined life without having to control funds and write checks. For instance, in Vermont, only 250 people were formally using fiscal intermediaries, but that doesn’t mean that they are not leading self-determined lives.

The lesson here is that we should not confuse decision-making over the substance of one’s life with decision-making over backroom operations. People want to control their own lives. They do not necessarily feel an associated need to control all aspects of how a system functions mechanically (e.g., how often workers are paid, how audit trails are constructed and maintained, assuring that federal and states employment taxes are paid).

Managing Case Management

The nexus of self-determination is the brokerage function. It was at this point in most states/sites that the greatest stress was experienced. Because most service brokers were part of the existing case management system in most states, they still had their regular system functions to perform (e.g., monitoring, IHP development, provider negotiations, etc.). The entailments of supporting an individual in a person-centered process is, according to brokers interviewed, a highly labor intensive process. Thus in states such as Massachusetts, the brokers ended up doing two jobs – the conventional job plus the job required to assist an individual to become self-determining. While it can be argued that the SD workload will decline once more flexible procedures have been put into place, the current stress is still considerable. Given the turnover in case managers nationwide, attention must be paid to finding ways to separate administrative from other brokerage functions in order to ensure that adequate attention can be paid to both. Attempts to rectify this problem, such as in Kansas giving an individual’s “circle of support” case management responsibilities met with mixed success.

Conclusion

Given the trends that have driven the developmental disabilities field, clearly we have steadily come to embrace themes to promote community integration and personal empowerment. Prior to these RWJ demonstrations, antecedents to self determination can be found in innovations explored within family support, supported employment and independent living systems. One can argue that “self-determination” is less a
revolutionary concept and more an evolutionary step that the field was already pushing toward.

Yet, what would have happened if the Self-Determination initiative had never been funded? It is of course difficult to speculate and crystal balls only project the future not the past. However, based on the observations and data collection undertaken by the evaluators, it is clear that the presence of these demonstrations definitely hastened the progress toward a more person-driven system of supports — especially in those states/sites where there was already a glimmer of understanding and a hunger to go further.

This hastening process has permanently altered the developmental disabilities field. Even as RWJ funding for these demonstrations has ceased, the talk nationally about self-determination continues. New phrases such as “personal broker,” “fiscal intermediary” and “self-directed supports” have become part of the national dialogue on disability policy. Conferences highlight the topic of self-determination. State leaders continue thinking about how to modify their systems to promote self-determination. New organizations dedicated to promoting self determination have been founded. Federal policy makers at the Centers for Medicare and Medicaid Services are exploring means for keeping Medicaid regulations from undermining efforts to adopt self determination practices. And self advocates in many states are focusing their efforts on teaching other self advocates about self-determination, and are becoming a greater presence at the policy making table.

As we asserted earlier, people with developmental disabilities want to live in and participate in their communities. And they want to control their own lives. These ideals appear to many to be irresistible. Over their one to three year grant periods, the RWJ self-determination demonstrations did not revolutionize state systems in such a way that these ideals could be immediately realized by all. They did, however, achieve their overall goals for testing new ways of doing business and for pushing service systems to promote practices that are consistent with self-determination principles. While these outcomes are noteworthy, much must still be done over time to achieve the larger systems wide goal. The RWJ initiative has given great momentum to this cause -- the idea has been plainly set free across the country. Now, it is up to self-advocates, family members and other self-determination proponents to assure that the idea is put to practical application.
Overview And Purpose

Background

In 1997, the Robert Wood Johnson Foundation invested in a broad range of demonstration activities around the country aimed at exploring the ways in which people with developmental disabilities can influence the character and configuration of the supports they receive through increased self determination. The emphasis on the choices and preferences of people, which formed the heart of each of the 19 demonstrations, represented a significant departure from conventional practice.

The background to this initiative can be traced to the dramatic changes that have taken place in the field of developmental disabilities – changes that have altered both the expectations of professionals as well as people with disabilities and their families. Beginning with the articulation by Wolf Wolfensberger (1972) of the powerful theory of normalization, succeeding theories (e.g., inclusion, community membership, consumer empowerment) have provoked continuing waves of reform. Change in public policy is usually characterized by incremental steps, but in the field of developmental disabilities, the last three decades have seen an almost total shift from large public institutions to increasingly smaller supportive arrangements in communities.

These extraordinary changes have been the result of a partnership between the public and private sectors. The public sector has provided the funds and the private sector has created services to meet the specifications in public contracts. Contracts are based on program “slots” which in turn are allocated by the system’s gatekeepers in line with standard eligibility criteria. This partnership, however, rarely included the participation of people with developmental disabilities and their families in the design of services or in the allocation of resources.

The implicit goal of the Foundation’s self-determination initiative was to move the system to the next – and perhaps most challenging – incarnation. This emerging paradigm was predicated on a significant alteration of power relationships by placing the choices, preferences, and individual gifts of people with developmental disabilities at the center of the system and by encouraging a range of traditional and non-traditional providers to compete for the opportunity to supply needed supports.

An emphasis on the preferences of people with disabilities, however, is not sufficient to change the direction of a service system -- it also requires power over resources.
Already, methodologies for system redesign that are consistent with these themes are taking shape (Agosta, Bradley, Taub, Melda, Taylor, Kimmich, Semple & Kelsch, 1999). The approaches may utilize vouchers, direct cash grants or third party payments. To help assure success, individuals may use: (a) a “broker” or personal agent to develop a plan for purchasing or otherwise acquiring support, and (b) a fiscal or administrative intermediary to handle the resulting paperwork (e.g., receipt of allocated funds, payments, IRS tax reporting requirements, Department of Labor requirements, fiscal accounting).

The self-determination projects also included individually-controlled budgets that can be dispersed based on an agreed upon person-centered plan. Finally, in order to ensure that people with disabilities receive the information necessary to make decisions in their best interests, the demonstrations also included some form of service brokerage ideally carried out by individuals without a direct interest in the choices made by individuals.

Because the changes anticipated in the Foundation’s initiative represent major alterations in the existing approach to providing services, the documentation of the process of implementation as well as the outcomes for individuals was deemed critical to expanding the understanding of the self-determination approach to others in the field. In order to address both key components of success, the Robert Wood Johnson Foundation supported two evaluations – one conducted by Conroy and Associates, which focused on individual experiences and one carried out by the Human Services Research Institute, which focused on implementation, costs and financing, and systems level policy concerns and constraints. The ensuing report describes HSRI’s findings and recommendations based on three years of data collection, interviews, and observations.

Overview of Projects and Goals

In 1997, the Robert Wood Johnson Foundation made grants to 18 states to further the self-determination agenda (New Hampshire previously had such a grant). These projects promoted new configurations of services and the empowerment of individuals with developmental disabilities to gain control over the shape and content of needed supports. The Foundation allocated over $5 million in support of the demonstrations. Allocations for each project ranged from $400,000 for a 3-year period, $200,000 for a 2-year period, and $100,000 for a 1-year period. Since that time several other states (e.g., CA, OK, MO, MT, NC, NY, ID, IL) have also shown an interest in modifying service systems so that they are more consistent with self-determination principles.
### 19 RWJ Demonstration States

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### Four Principles Of “Self-Determination”

1. Individuals have the **freedom** to plan their own lives...
2. Individuals have **authority** or control over one’s own life, including control over resources …
3. Individuals have access to the **support** they need and opportunity for increased community integration…
4. Individuals take on the **responsibility** of living in interdependent communities…

(Nerney & Shumway, 1996)

While each local project was based on the broad outline of values and objectives discussed above, there were also significant differences given the variations in geography, socio-demographic factors, resources, service configuration, and economy. Further, the 19 states represented in the project also differed insofar as the history and evolution of publicly funded services, the extent of reliance on public institutions, the extent of provider acceptance of notions of self-determination, the extent of regulation, and the presence of supportive advocacy and professional/provider organizations.

The 19 state projects ranged in focus from broad-based reform initiatives to programs targeted to a small number of individuals and families. Some projects spanned statewide systems, while others encompassed specific regional, metropolitan, and even neighborhood areas.

A range of geographic, cultural, and socioeconomic backgrounds characterized the consumers and families targeted by the self-determination projects. Examples of such diversity included Arizona, a largely rural state with a focus on the significant Hispanic and Native American population; Massachusetts, which chose to focus on the urban Metro-Boston region, including Latino, African-American, Asian, and Haitian communities; and the State of Washington, which targeted Island County, a rural community centered around a Naval base and its resources.

All 19 state project sites made it their goal to rearrange some or all of their associated state developmental disabilities service systems. The overall intent was to achieve
widespread systems change related to self-determination. Sites differed, however, regarding the projected scope and pace of change.

Review of these goals revealed two distinct strategies for systems change. The first, applied by most states, utilized the RWJ initiative as a limited “learning laboratory” (e.g., Oregon, Massachusetts, Kansas, Pennsylvania). This strategy revolved around starting small, learning a lot, and putting the lessons to work elsewhere over time. States may have articulated a desire to expand the pilots to other sites, but the general intent was to gain experience and work out any technical difficulties with a small number of people before attempting to change over the entire system.

A second strategy, pursued by a few states or counties, was more ambitious. This approach bypassed or accelerated the piloting phase and involved changing entire systems over to a self-determination structure (e.g., Maryland, New Hampshire, Michigan, Vermont, Winnebago and Dane Counties in Wisconsin). The intent was to set broad systems change vision, and align relevant administrative, fiscal and service practices with the new vision.

Aside from differences in strategy, the system centered goals that states planned to achieve included the following:

- Involve self-advocates and family members in policy planning and implementation (e.g., Oregon, Iowa, Massachusetts).
- Create a policy environment favorable to self determination, while eliminating current system barriers to self-determination. This may have included goals related to financing or rules and regulations (e.g. Arizona, Iowa, Michigan).
- Develop a working structure for delivering supports based in self-determination principles, including resolution of any technical difficulties. This was an essential systems goal articulated by all states. States may have included objectives related to setting personal budgets, establishing “broker” or fiscal intermediary functions, exploring news means for assuring quality or re-defining the roles played by the payer, support providers and participants, and establishing new standards for licensing and accreditation.
- Expand system capacity by encouraging use of alternative or informal sources of support (e.g., Massachusetts, Vermont, Iowa).
- Decrease overall costs for delivering services and/or improve cost efficiency (e.g., Arizona, Hawaii, Maryland, Massachusetts, Michigan, New Hampshire, Texas, Wisconsin).
- Decrease wait lists by investing any savings in additional service capacity (e.g, Maryland, Utah).
Thus, any evaluation of these projects of necessity had to address three distinct questions -- 1) whether particular projects, given the idiosyncrasies of each, reached their stated (planned) goals in a cost-effective fashion; 2) what changes took place at the state and local level as well as the constraints and obstacles encountered; and 3) whether the major components of self-determination result in increased choice and power among project participants, and the creation of individual supports (investigation conducted by the Center for Outcome Analysis).

Findings: Year 1

In the initial review of the 19 demonstrations (Agosta et al., 1999), most states made significant progress on many of the stated goals. For instance, self-advocates and family members often were involved in policy planning and implementation, though not at all sites and the level of their participation varied. Likewise, all states succeeded at developing a working structure for delivering supports based in self-determination principles. The structures, however, varied in design and complexity. Additionally, sites worked hard – albeit without decisive impact yet -- to widen the range of supports available to individuals, including use of informal or “non-traditional” supports, and to establish a policy environment more favorable to “self-determination.”

Progress on other goals was more elusive. Goals related to serving specified numbers of people, decreasing costs or wait lists, or establishing a system-wide culture for delivering supports routinely consistent with self-determination were not immediately met during the first year of the projects. States typically made progress at a slower rate than was initially anticipated. This is not surprising since achieving goals like these will predictably take time and much additional effort. Indeed, in many states the planning process alone took up a good part of the first year.

A variety of discrete factors contributed to the initial success of the RWJ Demonstrations. Five, however, stand out:

✓ A clarity of vision and action oriented leadership
✓ A strong commitment among many to make self-determination work
✓ Supportive systems infrastructure
✓ Supportive financing
✓ Supportive history and a proclivity for innovation

The Demonstration Sites also encountered a variety of obstacles in the initial phase of implementation. The major constraints included:
Overview and Purpose

- The relatively short duration of the RWJ grant awards, and for some states the relatively modest amount of the award
- An absence of a sense of urgency for change
- An embryonic and still emerging constituency to support the Demonstrations
- Difficult issues to resolve regarding the mechanics of self-determination
- Difficult and uncertain financing for self-determination
- Day-to-day distractions associated with administering state systems
- Competing local interests

Several preliminary conclusions were advanced in the Year 1 report that are important to keep in mind in reviewing the findings in this final report:

- The ideal of self-determination gives voices to an unexpressed frustration with the current method of administering services.
- States initially relied on the structures that were in place (e.g., case management) rather than erecting new mechanisms.
- Self Determination efforts were relatively small in comparison to the dollars spent across entire service systems. Preliminary findings raised that concern that the demonstrations would result in one more option within the larger system rather than an engine for larger systems change.
- Self-advocates consistently indicated that they very much wanted to be in control of their own lives. Yet, the organized self-advocacy community was not a consistent and engaged partner of the self-determination projects in the initial phases.
- Nuts and bolts concerns included setting individual budgets, managing risk, allocation tracking mechanisms, equitable linkage of resources to need, assuring quality, and the reconfiguration of management information systems.
- In several states, the demonstrations provided a methodology for carrying out parallel initiatives such as the wait list reductions and cost containment.
- The movement toward self-determination is an evolutionary process that will require changes in attitudes and culture as well as in the organization of systems and in the more precise allocation and tracking of resources.
Overview and Purpose

Given the rich experiences of the states and local sites during Year One of the project, HSRI evaluators noted several issues to monitor in the final phase of the analysis:

✓ The extent to which the self-determination initiative stimulates the use of more non-traditional providers, the increased utilization of generic services and the blurring of categorical boundaries in the service system.

✓ The paths states take to resolve the many operational riddles that confounded planners in Year One, including examples such as: (a) the evolution of the role of service broker, its level of independence and authority, and who pays for it, (b) setting person-centered budgets, (c) the diversification of the fiscal intermediary function, the formal roles of this entity, and the auspices under which these roles are carried out, and (d) quality monitoring.

✓ The extent to which the self-determination effort moves beyond a limited demonstration to an approach that develops momentum throughout the system.

✓ The ways in which self-determination initiatives cope with “success” – including how its proponents preserve the person-centered character of the process, deal with provider resistance, and with challenges from emboldened opponents.

✓ The central components of self-determination that can be consistently applied across all settings.

✓ The changes that are actually made in the traditional or existing service system to enable self-determination to be carried out, including what is done to overcome various legal, social, fiscal and administrative barriers.

✓ The presence of sustained leadership at all levels (e.g., state, county, individual) for self-determination.

Based on the discussions of the Project Advisory Committee, we also concentrated on one key implementation issue: the extent to which designers, planners, administrators, and supporters of self-determination initiatives have been successful in involving people with disabilities as trainers, advisors, participants, constituents and evaluators of the self-determination initiative. This focus allowed us to explore the connection between the self-determination initiative and the formal self-advocacy system within a state and the productivity of these relationships.
The Organization of This Report

The final report of the HSRI evaluation brings together in one place a review of all of the analyses undertaken including the impact assessment, cost analysis, and the review of self-advocate participation. The report is organized as follows:

Chapter 2 -- Study Methods -- This chapter provides an overview of the assessment methods that were applied to complete this phase of the assessment.

Chapter 3 -- What Was Learned: Self-Determination Is An Evolving Concept -- This chapter illustrates that “self-determination” is a concept that is evolving across the states with resulting variance in definition and operations.

Chapter 4 -- What Was Learned: Self Advocates Are Becoming More Involved During our Year One Impact Analysis we observed that self-advocates were not generally playing a strong role in the demonstrations. This chapter focuses on this issue and provides findings of a focus group on self-advocacy and self determination.

Chapter 5 -- What Was Learned: Financial Management Analysis -- This chapter reveals findings stemming from an analysis of financial management strategies associated with the demonstration projects.

Chapter 6 -- What Was Learned: Complementing Outcomes & Observations -- This chapter presents addition findings related to the site demonstration sites, offering comparison to Year One impact assessment findings and other new observations.
This chapter describes the methods used for three separate components of the evaluation: (1) Impact Assessment – a system-level policy analysis of the demonstration projects, conducted in Year One and Year Two; (2) Financial Management Analysis – a study of seven demonstration states, conducted in Year Two; and (3) Implementation Analysis – a study of the role self-advocates played in the demonstrations, conducted in Year Two. The table below indicates which states were included in each component of the assessment. Specific analytic methods used in Year Two will be described separately for each component.

<table>
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<th>States Included in Analyses, by Year and by Component</th>
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**Methods: Impact Assessment**

Given the diversity of the self determination projects, as indicated in the previous chapter, the HSRI evaluators assumed that the methodology should ensure that the
Self-Determination Is An Evolving Concept

outcomes observed were in fact a reflection of the successful implementation of the self-determination paradigm or theory rather than some other intervention or construct. Thus, the evaluation team initially proposed an evaluation methodology that would document both the theory or model of how the program is supposed to work, as well as the process followed by the demonstration sites and the process outputs. It was assumed that this approach would ensure that the planned outcomes could legitimately be attributed to the original conception.

The first step in the evaluation process was to articulate the program theory. In the case of the self-determination projects, one theory that was advanced was that a system in which individuals with developmental disabilities and their families are given control over resources and the ability to make choices about the nature of their supports, is more cost effective and responsive than conventional service systems. It was posited that such a model should lead to proximal outcomes that would include more individually tailored supports, and the use of a broader array of natural as well as specialized services. The ultimate outcome, it could be argued, should include more cost effective services, higher customer satisfaction, and improved consumer participation and inclusion in communities. The demonstration effort also anticipates changes in state systems (quality assurance, resource allocation, Medicaid policy, etc.) designed to allow consumer choice.

The next step was to enumerate the elements to be implemented in order to test the theory. In this context, such ingredients would include an agent or service broker, person-centered planning approaches, flexible funding or vouchers, assessment and intake procedures, and so forth. These elements may be somewhat different in each setting. With respect to the success of each individual project, documentation of the particular implementation details was deemed to be important. For instance, were service brokers trained in the fashion that was originally anticipated? Were individual budgets developed as originally contemplated?

Further, those elements that one might hypothesize to be associated with successful outcomes (e.g., training, technical assistance, leadership, client characteristics) were seen as critical data elements if the evaluators were to understand the context within which the implementation of self-determination efforts is going forward. Given that the Foundation anticipated changes at the state level, it was important to document key variables in the state context including extent of institutionalization, historical use of Medicaid waiver, level of support among key policy makers, and provider configuration.

The approach proposed for the evaluation involved two major components. The first was the development of logic models for the self determination initiative as a whole as
well as for each individual project. The second portion of the evaluation involved the development of a “project data base” which would capture the variables associated with each project and which could be linked with outcome and cost (quantitative) information during the analysis phase.

Data Collection: Year One – Impact Assessment

In the first phase of the study, the HSRI team collected information to flesh out the logic model, including: (a) a variety of contextual factors (i.e., mediating or moderating variables), as well as, (b) the precise actions that were taken by the project to evoke the desired results (i.e., independent variables). To complete the picture, the team is also collected data related to the outcomes of the project (i.e., dependent variables).
Each of these variable types is shown below, along with the primary topics of interest that fall under each. Examples include: (a) the characteristics of and impacts on individuals served by the projects (tracked separately by COA), and (b) cost implications (tracked separately by COA and HSRI).

1. Mediating Variables
   - **Contextual factors**: the existing developmental disabilities services system.
   - **Local program design and underlying program theory**: the values or principles that underlie the project and the project’s structure.

2. Independent Variables
   - **Participant planning & individualized budgeting**: practices used to develop a plan for providing the individual with services and supports and the procedures used to decide what amount of money each participant receives.
   - **Service brokers**: agency structure and staff activities associated with “brokering” functions.
   - **Fiscal intermediaries and other allocation mechanisms**: the structure and functions of organizations that are used to manage the budgets that are allotted to participants.
   - **Advisory Councils**: the presence and responsibilities of advisory committees, including the participation of self-advocates in council deliberations.
   - **Training and education**: efforts to provide participants and family members with information about the project and how to participate effectively.
   - **Regulatory relief**: efforts to eliminate, waive or alter rules or regulations.
   - **Identification of non-traditional resources**: efforts to access additional money or other sources of support for participants.

3. Dependent Variables
   - **Participant Outcomes**: impact on people with developmental disabilities.
   - **System Outcomes**: impact on the overall developmental disabilities system.
   - **Service Outcomes**: impact on the traditional service provider system.
   - **Project Specific Outcomes**: unique impacts anticipated by particular Projects.
Data Collection Strategies: Year One – Impact Assessment

To amass the information necessary to describe all of the above variables, project staff developed a data collection protocol and collected information from the following activities:

- Records and literature review involving analysis of secondary data
- Telephone interviews
- On site visits and interviews

A project database was developed and the data from the above activities was entered and subsequently reported in HSRI’s Year One report.

Year One Constraints and Year Two Revisions

While the results presented in the Year One report provided a useful picture of the 19 self-determination projects and the variables surrounding their implementation, there were constraints that caused the HSRI evaluation team to rethink the approach. Some of the reasons for revisions in the second phase included:

- In some states, the “intervention” was so weak (meaning the amount of time and money for the demonstration) that the impact – as might be expected – was not significant.
- The states all took varying lengths of time to start up, making cross site comparisons very difficult.
- The expectations and scope varied even more widely than initially anticipated.
- The ability to identify “success” given the widely varying scope and intensity of change was hampered.
- A definition of the target group for the self-determination pilots became very difficult especially in states like New Hampshire and Maryland where the approach was said to have expanded system-wide.

Finally, the ability of the team to link the quantitative impact data with the individual outcome data developed by COA was not possible given the limited numbers of individuals for whom data was available at each site.

The recognition of these constraints suggested that a strict quantitative approach would not be appropriate for the final phase of the evaluation. As a result the project made the following revisions:

- Selection of 10 states out the 19 on which to concentrate data collection activities. The 10 states included New Hampshire, Massachusetts, Michigan, Vermont, Ohio, Wisconsin, Kansas, Oregon, Utah and Maryland. The criteria for
selection included the momentum for change in those states, the length of the demonstration activity, and geographical distribution. In other words, states were selected because there was a “critical mass” of activity to observe and document.

- Revision of the interview protocol to reflect implementation issues and the change process rather than to glean a quantitative picture of the project processes and outcomes (e.g., numbers of people served, etc.). The Year Two protocol is included in Appendix A of this report. The aim became to glean insights from selected sites that had gone forward regarding the process of moving a system toward a more self-determined and consumer-driven approach.

- In both Year One and Year Two, interview protocols were used to gather information from a variety of informants at each demonstration site. The format of data collection included direct interviews with state and local/county project directors, and focus groups with service coordinators and other project team members. Interviews were conducted both on-site and by telephone.

**Methods: Implementation Analysis**

During the Year One Assessment, a range of topics was explored, including the role that self-advocates had played in the demonstrations. At the time of that assessment (See Agosta et al., 1999, p. 57), we found that:

…self-advocates and family members were typically, but not always, involved with project planning and advisement. [But that] associated enthusiasm for the project … did not easily or readily spread out among broader numbers of people. This was especially noticeable among self-advocates as we observed that as an organized constituency self-advocates played a limited role in the Demonstrations.

In making this observation, the evaluation team cautioned that this finding was “not meant to suggest that individuals with developmental disabilities do not want to control their lives… Nor suggest that the individuals associated with the Demonstrations were unaware of the need to engage self-advocates and family members in the change process” (p. 56). We also speculated that the extent of their involvement in the projects could well increase in years two and three.

As part of the Year Two Impact Assessment, we proposed to focus part of our efforts on any changes in the role self advocates play in influencing policy and practice related to self-determination. As a result, in the fall of 2000, we convened a two-day meeting of two self-advocates and a support person from each of seven states to: (a) discuss the role that self advocates have played in their state’s self-determination effort, and (b) to make recommendations for promoting increased self-advocate participation. The purpose of this preliminary report is to document our actions to convene the meeting and its outcomes.
Methods: Financial Management Analysis

Individually centered and controlled procurement of services and supports is a critical feature of self-determination. Through self-determination, people with developmental disabilities and their allies have decision-making authority over the dollars allocated to them, including the selection of services and providers. In addition, consumers are positioned to direct the day-by-day delivery of supports, including directing the community workers who furnish services. Self-determination positions individuals, their circles of support and families to direct and manage the purchase of publicly funded services and supports.

Consumer-managed/directed procurement of services and supports stands in contrast to standard "provider-direct" procurement methods employed by state and local developmental disabilities authorities/funders to contract and pay for services. Provider-direct methods do not engage consumers actively and directly in procurement. Although consumers usually have a say in the selection of qualified individuals and/or organizations to furnish services that they have been authorized to receive, they rarely have little direct involvement in deciding how much to pay for supports, authorizing payment or day-to-day management of services.

In order to clear the way for consumer-managed/directed procurement, state and local developmental disabilities authorities must develop and implement new procurement and financial management mechanisms in support of self-determination. Whereas "standard" procurement methods are bilateral in nature (i.e., between the funder and the service provider), consumer-managed/directed methods on face are more complex since they must accommodate multiple interactions among consumers, service providers, funders and financial intermediaries. These methods also must comply with a wide-range of funder-imposed accountability requirements as well as state and federal tax and labor law requirements.

This evaluation looked at procurement methods and processes in the following RWJ demonstration states: Kansas, Minnesota, Maryland, Michigan, Vermont, Utah, and Wisconsin.

The evaluation of selected RWJF self-determination demonstration site consumer-managed/directed procurement methods was conducted through site visits and interviews with state and project site staff along with the review of relevant documentation. Site interviews focused on understanding the flow of funds/transactions and documenting related procedures for tracking and controlling funds and payments. HSRI staff also explored the perceived efficacy, operational problems, and constraints associated with each arrangement. Where possible, project staff also sought to estimate as best as possible the number of staff involved in the management of funds at the demonstration sites vs. non-demonstration activities and distinguish between "recurring" and "non-recurring" costs of implementing new procurement methods in conjunction with self-determination.
Since the site visits generally took place when the demonstration sites were in the early stages of designing/implementing new procurement methods, it typically was not possible to make exact determinations concerning whether the use of consumer-directed/managed procurement methods was more or less resource intensive than procuring services through standard bilateral, provider-direct methods. Isolating changes in procurement costs either way proved difficult, especially because other factors often were concurrently affecting procurement (e.g., making baseline financial management data systems Y2K compliant). As a consequence, the evaluation was more qualitative than originally hoped.

Originally, this study included a second task - to verify the accuracy of the expenditure and individual budget figures obtained by the Center for Outcome Analysis. Early on in the project, it was determined that completing this task would not be feasible due to (1) the size and distribution of the sample of participants with individual budgets and (2) the discordant timelines of the two data collection activities.

Certainly a central focus of the evaluation was to examine the interplay between consumer managed/directed procurement methods and the use of Medicaid dollars as a source of financing for community services and supports for people with developmental disabilities. In particular, especially over the past ten years states have aggressively employed the Medicaid home and community-based services (HCBS) waiver program to underwrite a greater proportion of community services and supports for people with developmental disabilities. In 2000, about 291,000 people with developmental disabilities nationwide participated in the HCBS waiver program. Medicaid dollars obtained through the HCBS waiver program have become the cornerstone for financing community services and supports in almost all states, including the states selected for this evaluation. Going forward, the HCBS waiver program will play an even larger role in underwriting community services and supports for people with developmental disabilities.

As the financing and delivery of community services and supports become increasingly intermeshed with the HCBS waiver program, the design of consumer-directed/managed procurement methods must take into account federal statutory requirements that affect contracting and paying for Medicaid-funded services. HCBS waiver programs operate under limited waivers of federal Medicaid law. However, these waivers do not extend to various key statutory provisions that affect payments and contracting. By and large, present federal Medicaid law is structured around provider-direct procurement methods. With some exceptions, present law dictates that each provider have enter into a contractual agreement with the state Medicaid agency (per §1902(a)(27) of the Social Security Act) and that payments for Medicaid services flow from the state directly to the provider of services (per §1902(a)(32). Moreover, when Medicaid dollars are involved, certain alternatives are precluded (e.g., making cash payments to consumers).
Consumer managed/directed methods frequently employ contracting methods (e.g., employment agreements between workers and consumers) and transaction/payment schemes (e.g., the use of financial intermediaries) that depart from Medicaid's conventional vendor-based procurement model. A focus of this evaluation was to examine how the demonstration states/sites designed and implemented consumer managed/directed procurement methods that met federal Medicaid requirements.
What Was Learned: Self-Determination Is An Evolving Concept

People with developmental disabilities want to live their life in the community. They also want to control their own lives. In pursuing goals like these, self-advocates often tell us that they want to be in control of the support they receive, because playing such an empowered role offers them the greatest chance to live the life they want. The RWJ self-determination initiative sought to stimulate change in service systems that would be consistent with these demands.

At the start, there was a generally defined idea associated with four guiding principles coupled with a rudimentary understanding of the elements that were thought to be needed to turn the principles into real operations. In fact, our plan for assessing the impact of the RWJ Demonstrations was based on a presumption that the demonstrations would generally stay “on track,” developing and implementing differing yet generally similar project structures. (See the graphic on the following page)

Past this starting point, however, it soon became clear that the encouraged innovation resulted in a variety of strategies for establishing a system based on the four self-determination principles. At every turn local planners needed to think through complex mechanical issues, and finally arrive at a workable solution. Along the way, these solutions ultimately needed to be judged favorably against the guiding principles. Additionally, local pragmatic requirements would need to be met (e.g., maintaining an audit trail, following Medicaid waiver rules, assuring health and well-being of self-advocates). Finally, any solution must also have mustered sufficient political backing, even while stakeholders (e.g., self-advocates, family members, funders, providers) may have not always agreed.
Self-Determination Is An Evolving Concept

Moving From Definition To Principles To Operations...

One Early Definition Of Self-Determination...
Self-determination is a national movement to redesign long-term care for individuals with developmental disabilities that eschews traditional program models and facility placement approaches. ... Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities. Public dollars need to be used strategically to support existing family and community relationships as well as help create them where they do not now exist (Nerney, 1998).

Four Principles Of “Self-Determination”
1. Individuals have the freedom to plan their own lives...
2. Individuals have authority or control over one’s own life, including control over resources ...
3. Individuals have access to the support they need and opportunity for increased community integration...
4. Individuals take on the responsibility of living in interdependent communities...
(Nerney & Shumway, 1996)

Anticipated Elemental Program Structures To Include...
Participant planning & individualized budgeting: practices used to plan out needed supports & procedures to decide what amount of money each participant receives.
Service brokers: agency structure and staff activities associated with “brokering” functions.
Fiscal intermediaries: the structure and functions of organizations used to manage individual budgets.
Advisory Councils: the presence and responsibilities of advisory committees.
Training and education: efforts to provide with information about the project.
Regulatory relief: efforts to eliminate, waive or alter rules or regulations.
Non-traditional resources: efforts to access other money or sources of support.
(Principal “Independent Variables” explored in HSRI’s Year One Impact Assessment)

O’Brien (2001) draws on his knowledge of “complex adaptive systems” to explain this outcome further. He notes that innovative systems take form when many players adapt to each other’s actions within circumstances that make it difficult to predict what the outcome may be. Centralized planning inevitably runs aground as individuals engage one another to push down this or that path. Policy makers cannot easily control these actions, but “do what they can to harness three interlocking processes: variation, interaction and selection.”
• **Variation** means that many agents pursue different strategies to get what they want in a shared environment. Strategies are the ways agents respond to their environment and pursue their goals. … Variation raises two key system design questions: (1) What is the right balance between variety and uniformity? and (2) How can the number of agents be increased to create variety that could matter? …

• **Interaction** makes a complex adaptive system come alive as agents create exchanges, make use of things, and inform themselves about other agents’ strategies and thus shape social patterns. Interaction raises two key system design questions: (1) What kinds of interactions should be able to happen and when? and (2) What rules will allow useful patterns of interactions to emerge?…

• **Selection** promotes adaptation by determining which strategies should be copied and which strategies should be abandoned. Selection raises three key design questions: (1) What criteria will define success? (2) How, and how frequently, will success and failure be attributed? and (3) How will successful strategies be copied and recombined into new strategies? …” (O’Brien, 2001, p. 9-10)

The questions O’Brien asks are good ones, although at this point are unfortunately not easily answered. Just as stakeholders interact to create a variety of innovation from state to state, their continued interaction will likely also lead to variety in how questions like these are addressed.

Given the complexity of the task set before the 19 RWJ Demonstrations and an awareness of how complex adaptive systems interact, it is not surprising to observe that the idea of “self-determination,” while grounded in a well publicized definition and guiding principles, took on many shapes and forms as time went on. In fact, beyond variation in project structure, sites have modified the criteria used to define concretely what “is” self-determination.

Illustrating this point, the National Program Office on Self Determination (Moseley, 2000) undertook a survey of RWJ demonstration sites (including the 19 initial sites and an addition 10 others who received smaller subsequent grants) to track the status of each project with respect to the number of individuals involved in self-determination activities, and record how each state defines self-determination.

The findings proved very difficult to aggregate in great part because sites had come to define “self-determination” and its associated mechanics in such different ways. There was general consensus about some of the most important features of a self-determination system structure, such as the presence of an individual budget, individual exertion of control over decision making with respect to their budget, presence of a
support broker hired by the individual, and having a person-centered plan funded through a fiscal intermediary.

General consensus, however, should not be mistaken for unanimity. Respondents did not completely agree on whether these features were essential to a self-determination structure. Further, within these categories variance in project design was apparent. As was found in HSRI’s Year One Impact Assessment, these survey findings reveal that there are differences in how particular system elements are defined and put into practice.

Ultimately, such differences became apparent in how “self-determination.” Was defined in operational terms. Consider these examples:

- **Kansas** indicates that for a person to be considered to be living a “self determined life” he or she must:
  - have an individual budget,
  - be controlling all of the supports he or she is receiving, and
  - must be receiving funding through a fiscal intermediary.

- **Michigan** considers a person to be living a self determined life if he or she:
  - has an individual budget,
  - is actively managing the budget,
  - is controlling some or all of the supports received,
  - receives the assistance of a support broker employed by themselves as the employer of record, or by a service providing agency, and
  - receives funding through a fiscal intermediary, or an agency/governmental entity that does not provide services or an agency/governmental entity that does provide services.

- **Vermont** views the determination of whether or not a person is living a self-determined life to be primarily a subjective decision of the individual and as such may vary from one person to another. In Vermont, most of the people receiving support have an individual budget. A person is considered to be self determining if he or she:
  - controls all or some of the decisions regarding the supports received (whether or not the individual has an individual budget),
  - receives assistance from a support broker employed by the state, which does not provide services, or by the individual themselves, and
  - has a plan of care that is funded through an independent fiscal intermediary or through an agency that does not provide services.

- **New Jersey** considers a person to be “self determining” if he or she:
Self-Determination Is An Evolving Concept

- has an individual budget,
- is actively managing his or her individual budget,
- has a support broker hired by the consumer, and
- receives funding through a fiscal intermediary.

Review of definitions like these suggest that thought there are great similarities between them, there are obvious differences. In one state, an individual may be thought to be living a “self-determined life,” while in another state -- with differing criteria -- the same individual may not may not be thought of in the same way.

We are not suggesting that any particular way is the “right way” to define self-determination. Participants at the 19 RWJ Demonstration Sites embarked on a journey to explore the notion of “self-determination” and in doing so were encouraged to be innovative … to “think outside the box.” In face of the complex decisions they were required to make and as the study of “complex adaptive systems” may have predicted, their cumulative efforts assure that self-determination will continue to evolve in concept and practice.
What Was Learned: Focus On Self Advocate Perspectives

During the Year One Assessment, a range of topics pertaining to the self-determination demonstrations was explored, including the role that self-advocates had played in the demonstrations.

At the time of that assessment (See Agosta et al., 1999, p. 57), we found that:

...self-advocates and family members were typically, but not always, involved with project planning and advisement. [But that] associated enthusiasm for the project ... did not easily or readily spread out among broader numbers of people. This was especially noticeable among self-advocates as we observed that as an organized constituency self-advocates played a limited role in the Demonstrations.

In making this observation, we cautioned that this finding was “not meant to suggest that individuals with developmental disabilities do not want to control their lives... Nor suggest that the individuals associated with the Demonstrations were unaware of the need to engage self-advocates and family members in the change process” (p. 56). We also speculated that the extent of their involvement in the projects could well increase in years two and three.

As part of our Year Two Impact Assessment, we wanted to focus part of our efforts on any changes in the role self advocates play in influencing policy and practice related to self-determination. One action we took was to convene a two-day meeting of two self-advocates and a support person from each of seven states to: (a) discuss the role that self advocates have played in their state’s self-determination effort, and (b) to make recommendations for promoting increased self-advocate participation. The purpose of this preliminary report is to document our actions to convene the meeting and its outcomes.

Convening Of The Self Advocacy Meeting

On October 24-25, 2000 we convened a meeting in Baltimore, MD to discuss the role that self-advocates have and could play in shaping self-determination policy and practices in the states. Two self-advocates and a support giver were invited from each of seven states, including Maryland, Massachusetts, Michigan, Oregon, Utah, Vermont, and Wisconsin. Additionally, two self-advocates, Teresa Moore and Joseph Meadours, facilitated the meeting with support provided by HSRI staff.
These states were selected based on preliminary work and discussion, suggesting that in these states self-advocates were relatively active within the policy arena and the self-determination initiative had taken root.

Prior to attending the meeting, all self-advocate participants were asked to interview five other self-advocates in their states. In this way, we anticipated that the participants would attend the meeting with the thoughts and opinions of others to complement their own. Participants were supplied a ten-question interview protocol along with instructions for carrying out the interviews (See Appendix B). It should be noted that self-advocates were paid for conducting these interviews as well as a stipend for attending the meeting.

### Meeting Participants

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<td>Kevin Duckworth</td>
<td>Bryon Murray</td>
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<td>Tracy Wright</td>
<td>Stacey Callahan</td>
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<td>Kathy Vecchioni &amp; Nancy Berger (support)</td>
<td>Denise Winslow (support)</td>
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<td>Kelly Mendel &amp;</td>
<td>Natalie Sinkew</td>
</tr>
<tr>
<td>Christopher Goss</td>
<td>Nina Moore</td>
</tr>
<tr>
<td>Rebecca Attinga &amp; Ken Staples (support)</td>
<td>Karen Topper (support)</td>
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<td>Charlotte Williams</td>
<td>Arlyn Sandow</td>
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<tr>
<td>Tom Williams</td>
<td>Don Lund</td>
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<tr>
<td>Maureen Cahalan &amp; Deathra Johnson (support)</td>
<td>Roxanne Price (support)</td>
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<td>Teresa Moore</td>
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<tr>
<td>Dayna Davis</td>
<td>Joseph Meadours</td>
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<td>Diane Duerscheidt (support)</td>
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During the meeting, self-advocates were asked to explore these four questions:

1. What is the status of self-determination?
2. Where is self-determination going?
3. How well are self-advocates included in policy and planning in self-determination?
4. What should be done to fix any problems or make things better?

In doing so, discussions focused on what was learned during the in-state interviews and on the opinions of the self-advocate participants. The support-givers who attended the meeting were required to maintain their silence for most of the time, speaking only to
help clarify what a self-advocate was saying. Specific time, however, was set aside for support givers only to voice their thoughts.

**Ten Interview Questions Used By Self-Advocate Participants In Their States**

1. What does self determination mean to you?
2. From what you know, how well is self-determination working in your state?
3. What is it about self-determination that is working best?
4. What is it about self-determination that is not working?
5. If you could change one thing about how self-determination works in this state, what would you change and why?
6. If you could recommend something for other states to do the same as this state, what would that be and why?
7. How much have self-advocates been involved in deciding things about self-determination in our state?
8. What kinds of ways are self advocates involved in deciding things about self-determination in our state?
9. What must be done to make sure that self-advocates are involved in self-determination?
10. Is there anything else you’d like to tell me about self-determination or self-advocacy?

**Findings Resulting From The Self-Advocacy Meeting**

We took extensive notes during the meeting. What follows is a summary or synthesis of the general themes that emerged during the discussion. Note that these themes were reviewed and approved by meeting participants before adjourning.

**Self-Advocate Observations**

**What is Self-Determination?**

- I am a person like all people: My life is my own.
- I speak for myself… “I speak up” “I stick up for myself”.
- I make my own choices.
- I am the boss of my own life.
- I make my decisions in my own life.
♦ I do for myself… and not depend on others so much.

**Self-advocates said…**

♦ People don’t know what self-determination is or have enough information about it (what is available or how is done in the state). This includes: self-advocates, staff, moms and dads… many people.

♦ Teaching people about self-determination is OK, if the teachers live it.

♦ There are projects going on in our state to support self-determination (e.g. Intermediary Service Organization (ISO) in MA or the Self-Determination Resources Inc. (SDRI) in Oregon)

♦ Some things are going pretty well.

→ There is an awakening about self-determination…. County and state people are waking up. Self-advocates are waking up too. There is evidence of this.

→ Self-advocates are participating on boards, committees and task forces locally and at the state level.

→ States and counties are putting money into self-advocacy.

→ Self-advocates are becoming issues based and finding a voice… and listeners.

→ Self-advocates and others are working better together as the “Network” (in Utah).

→ States are becoming more flexible in how money is spent

♦ Some things are not going so well.

→ There are problems with the doing:

  • Caseworkers don’t allow people to make their own decisions.
  • People know about self-determination, but don’t know how to do it.
  • Not enough staff to give support… can’t find workers.
  • People don’t really have control of personal budgets.

→ There are problems with controversy or arguing.

  • Agencies say they believe in self-determination but then don’t want to give up the money (or the power)
  • Agencies don’t want to get us the supports we want

We need to define self-determination better… We know the principles but people don’t get it… It’s problems with the doing that trips people up.
There are problems with feelings about it (fear, respect, dignity)

- People promote self-determination but there is an expectation of failure. Agencies also “set things up” for it to fail (the amount of money we get is less than the amount agencies get… so we can’t get good staff)
- Professionals or staff not talking directly to us… talking to others instead of us.

There are problems inside of agencies.

- People are not always being responsive.
- Agencies can work better together.

There are problems that don’t have a lot to do with self-determination.

- Not enough staff to give support (staff shortages).
- Not using the available money in the right way (building sports stadiums instead of supporting people).

People don’t always know what self-determination is.

“Service coordinators” don’t always allow people to make their own decisions.

Agencies say they believe in self-determination but then don’t want to give up the money (or the power).

Agencies don’t always want to get us the supports we want.

People promote self-determination but there seems an expectation of failure. Agencies can “set things up” for it to fail by making it too hard to do.

Professionals or staff do not always talk directly to us… they talk to others instead of us.

Self-Advocate Recommendations

Working in groups and then together, self-advocates considered what state policy makers could do to assure that self-advocates could play a stronger role in shaping policy and practice related to self-determination. They placed their recommendations in the form of a letter to state directors of developmental disability services. This letter follows below.

Dear Mr. or Ms. Director,

We [I] represent [name of self-advocacy group].
As you know self-advocates are concerned about a number of issues affecting people with disabilities. For example, we believe that institutions should close. We feel strongly that people should live and work in the community, not in institutions. We believe that states need to eliminate waiting lists and that people who need support or services should get what they need. We believe that people should direct their own services by choosing their own staff, training them and paying them directly. We feel the money ought to go to the person and not be wasted in the state system. We want more choices, and we want to be able to buy any kind of services. AND

We believe that self-advocates should have a real say over policies and rules in our state about self-determination.

We know that helping people to have a real say over the policies and rules is a hard thing to do. Here are some of the things we think state directors can do to make sure that we have a real say over policies and rules about self determination:

• When there are meetings to decide things about self-determination, we want self-advocates to be part of these meetings: Nothing about us without us! We think it is extremely important that the self-advocates must be at these meetings to represent self-advocates in the state. Therefore, the self-advocacy organization should choose the self-advocates to attend, not staff people who work for the state or program.

• One way to make sure it is not token representation is to support a State Self-Advocate Council consisting of representatives of all self-advocacy groups or organizations to make recommendations on an on-going basis about state-wide self-determination and policy. This council should report back to the self-advocacy community so that they are informed of the council’s activities, and can continue to make recommendations through their council representative.

• People who are new to advocacy or who don’t often have the opportunity to make important decisions might worry about personal consequences. Please be sure that people who speak their minds will not be retaliated against.

• Please always make sure that meetings are held in accessible places. We can help you decide whether the meeting place (like an office, hotel or conference center) is accessible by checking
the place out or telling you about our experiences with that location.

- **Accessibility is the building block of our participation.** If places where decisions are going to be made are not accessible, the department or project may have to put up some money to make it immediately accessible to us so that we can be a part of important meetings.

- **Accessibility is not just about buildings and rooms.** For meetings to be accessible to us, we may need help preparing for and participating in the meeting. Please make sure there is money to pay support people so we can understand the agenda at meetings and that there is money to pay for training and conferences so we can understand the issues and be fully prepared when making decisions.

- Please make sure we have transportation when we need it and better communication about transportation.

If you and the other state directors could do these things, self-advocates would have real opportunities to shape the rules and policies about self-determination in their states. We feel that self-determination truly works when self-advocates are at the table and making the important decisions about their lives. Nothing about us without us! We hope that you take our recommendations to heart and ensure that self-advocates have a real say.

Sincerely Yours,

Names or Names
Self Advocacy Group

**Concluding Remarks**

A primary goal of self-determination is to place self-advocates squarely in control of their own lives, and in ways that make for more efficient spending. Of course, as with other citizens, limits on individual preferences are imposed by a variety of factors, such as civil law or one’s personal budget.

As these changes unfold, however, one thing has become clear – **self-advocates must have a powerful voice in influencing change.** To play a strong role, self-advocates must develop effective leadership skills and know something about the forces and policies at work. They must be expressive about their want for self-determination, community integration and participant-driven supports. They must understand how they can be most effective in their own life and in the policy arena. And **they must have opportunity** to act, individually and together.
In this context self-advocates already have done much themselves to organize as a constituency to be reckoned with. Dybwad & Bersani (1996) document the steady growth and changes within the self-advocacy movement in the United States and elsewhere. People First of Oregon was established in 1973 and is recognized as the first formalized self-advocacy organization in the United States. By 1974, 16 such organizations existed and now there are about 750 self-advocacy organizations sprinkled across the nation. Braddock (1996) estimates the number of participants in formal self-advocacy groups to be in excess of 17,000.

At first, however, these fledgling organizations acted more as social clubs than as centers for directed advocacy and change. The 1990s, however, brought a change in this focus as self-advocates showed a stronger interest in influencing policy and practice. Accenting this transformation, in 1995 a national organization, Self-Advocates Becoming Empowered (SABE), was officially incorporated and began sounding its message for change. Dybwad (1996) concludes that “self-advocacy in the 1990s has become a policy forming reality in public and private efforts to deal with the challenges posed by persons with intellectual limitations” (p.15-16).

Within this context, RWJ initiated its Self-Determination Demonstrations, and promoted discussion and systems change consistent with self-determination principles. Yet our Year One Impact Assessment found that self-advocates -- while emerging as a public policy force -- were not immediately involved with leading or shaping the desired change. In our Year One report, we offered several potential explanations for this finding and speculated that, as the Demonstrations took root, the self-advocacy movement might embrace the Demonstrations and self-advocates would help lead the way.

Our two-day discussion with self-advocates from seven states supports suggests that self-advocates are indeed taking on such leadership roles. Meeting participants offered insights into the workings of self-determination in their states, including observations over what is and is not working well. Additionally, they provide sound advice for what state policy makers might do to assure that self-advocates participate meaningfully to influence and shape self-determination policy and practice. The challenge to policy makers, and all others involved with the self-determination initiative, is to take the advice offered and act decisively to provide opportunity for self-advocates to participate in setting state developmental disability policy.

Many professionals are at a loss to describe the phenomenon of self-advocacy, especially by people who were said to have “mental retardation.” We were comfortable when they were social clubs. Some were bemused by their growing interests in organizational skills. Today, we cannot ignore the emerging power.

What Was Learned: Financial Management Analysis

A central feature of self-determination is direct consumer control of an individual budget. Conceptually, the individual budget is a powerful device to shift power and authority from the “system” to people with developmental disabilities and their allies. The power to decide how dollars are used enables the individual or family to select services and supports that they judge to be the most valuable and position them as purchasers. It also serves as a platform for empowering consumers to directly manage the procurement of services and supports and supervise their delivery.

Consumer-managed/directed procurement of services and supports stands in contrast to the standard "provider-direct" procurement methods employed by state and local developmental disabilities authorities to contract and pay for services. Provider-direct methods do not engage consumers actively in managing dollars and procurement. Although consumers usually have a say in the selection of qualified individuals and/or organizations to furnish authorized services, they rarely are directly involved in deciding how much to pay for supports, authorizing payment or day-to-day service management. "Standard" procurement methods are bilateral in nature: they revolve around agreements and transactions between the funder and service providers to which the consumer is not a direct party.

Providing for individual budgets and enabling consumer-managed/directed procurement demands that state/local developmental disabilities authorities have in place supportive procurement and financial management mechanisms. Consumer-managed/directed methods on face are more complex since they must support multi-lateral interactions among consumers, support brokers, service providers, funders and financial intermediaries. Methods must comply with a wide-range of funder-imposed accountability requirements as well as comport with an especially complex maze of state and federal tax and labor law dictates. Finally, in light of the rapidly expanding role that the Medicaid program plays in underwriting community services and supports for people with developmental disabilities, consumer-managed/directed methods also must adhere to federal Medicaid law and regulations affecting procurement and payments.

The face complexity of consumer-managed/directed procurement methods stands in contrast to the nominal simplicity of standard bilateral arrangements. Accommodating consumer-managed/directed procurement methods thereby poses significant system management challenges for state and local authorities. Each project had to confront designing and implementing new business processes to allocate dollars to individuals and families as well as support their management of the individual budget, including the procurement of services and supports. These “mechanical” elements had to be
addressed in order to clear the way for consumers to take charge of selecting, directing and managing their own services and supports.

**Scope of Evaluation**

This aspect of the evaluation looked at individual budget determination and procurement methods and processes in seven demonstration states: Kansas, Minnesota, Maryland, Michigan, Vermont, Utah, and Wisconsin. This dimension of the evaluation concentrated on the following topics:

- Each state’s baseline “procurement architecture” – how the state contracts for services, including its policies concerning provider certification;
- Methods employed to determine the individual budget/spending authority;
- Alterations in rate-setting and service pricing schemes to accommodate individual and family management of services and supports;
- Experiences in establishing financial intermediaries and the use of other payment schemes;
- Employee administration arrangements;
- The extent to which states modified their Medicaid home and community-based services (HCBS) waiver programs to accommodate self-determination;
- The potential effects of the use of consumer-managed/directed models on system overhead costs; and,
- The interplay between consumer-managed/directed procurement methods and management information systems.

In conducting this evaluation, we made site visits to the seven states during which key informants were interviewed, telephone follow-up, and document review.

**Background Information**

There are similarities and differences among the seven states with respect to their baseline service system architecture. Two states (Minnesota and Wisconsin) have county government-run systems. There, county entities perform system intake, service planning and authorization. Maryland and Utah operate “state administered” systems. The state agency contracts and pays for services directly. In the case of Utah, the state agency also is responsible for intake and continuing support coordination. In Maryland, a non-profit entity performs these functions in most areas of the state. Vermont and Kansas operate their systems through designated, largely non-governmental local entities. These organizations serve as the “single point of entry” for services, generally conduct ongoing support coordination for individuals and families and have significant financial management responsibilities. Michigan’s system operates through designated local public entities that have been reformulated as managed care organizations.

There are some differences among these states in terms of their eligibility criteria but significant differences with respect to system access as measured by the number of
individuals who have been wait-listed for services (e.g., Vermont’s waiting list historically has been very small while Utah has struggled with a large and persistent waiting list).

There are differences in each state’s baseline “procurement architecture.” In general, these differences stem from the extent to which financial management responsibilities have devolved to local authorities and the extent to which state laws and policies dictate that certain practices must be followed (e.g., the mandatory use of Request for Proposals (RFPs) to award contracts versus the use of open-ended contracts or provider agreements).

With respect to provider certification, the states themselves typically regulate and certify agencies that furnish conventional residential and daytime supports. There are differences among the states with respect to their treatment of “individual providers” (e.g., individuals who furnish personal assistance or respite care). Some states have processes in place to certify and contract with such providers on a freestanding basis. In others, the services of such providers must be procured through licensed or certified “agency providers.”

All the states earmark the majority of their dollars for community services and supports. Large state-run facilities play no or minimal roles in most of the states. The utilization of ICF/MR services in these states generally is below nationwide norms. Each state has operated a Medicaid HCBS waiver program for people with developmental disabilities since the 1980s. Since 1998, Michigan has had what is termed a Section 1915(b)/1915(c) “combination” waiver program that wraps around almost all long-term services for people with developmental disabilities. There are differences among the states in terms of the types of services and supports each state offers through its HCBS waiver program, the emphasis of each program, and the program’s inherent “flexibility” and funding levels.

The states also differed with respect to their self-determination initiatives. The Vermont and Utah initiatives were statewide in scope rather than principally site-based. There also were differences among the site-based initiatives concerning the extent to which individuals and families could and did opt to direct and manage their services and supports. Generally, individuals and families already receiving services voluntarily could opt into self-determination. In the case of people new to services, states/sites sought to start people out employing self-determination. The states also varied with respect to which there already was a “person-centered” culture in place. In some cases, the self-determination project ramped up side-by-side with other major system change activities (e.g., Maryland’s multi-year waiting list reduction initiative). In other cases, the state’s initiative was carried out in a less turbulent environment. In some cases, projects were able to build on antecedent efforts to promote person-centered supports, including flexibility in selecting services and supports on behalf of and in collaboration with
individuals and families. Elsewhere, projects also had to spend more time establishing a foundation for self-determination.

Findings and Observations

Here, we describe the experiences of the state and local sites in designing and implementing several of the essential dimensions of self-determination and consumer-managed/directed procurement methods.

Fund Allocation, Individual Spending Authority and Individual Budget

A linchpin of self-determination is that each individual has an amount of dollars over which the person and his/her allies (circle of support) have decision-making authority. With individual spending authority, the person/circle/family is positioned to make decisions about deploying dollars to best meets his/her needs and preferences. These decisions are translated into an individual budget/plan that records the services and supports the person will purchase and creates a framework for ongoing management of the budget. The individual budget also serves as a device that enables funders to interconnect billings/payments to the services and supports authorized in each person’s budget/plan.

The challenge the individual budget concept poses for states and local authorities lies in developing methods to establish the individual spending authority. Provider-direct procurement methods are specific to particular services/service agencies. Funding is not conceived in individually centered terms. Self-determination requires decoupling dollars from specific service categories or providers and assigning spending authority to each person so that individuals have maximum authority and flexibility in managing their own resources.

Another challenge stems from the very nature of the individual spending authority. In broad brush, when payments are tied to providers/services, providers have the latitude to manage and balance dollars across all the individuals they serve. Segmenting funding by individual causes “risk” to emerge as a major concern – the potential that the amount assigned to a person may not be correct or unforeseen circumstances may arise that cannot be accommodated. This results in the need to consider using devices such as “risk reserves” (either person-by-person or collectively) in order to create a funding safety net in the event that the individual’s circumstances change.

In developing strategies for determining individual spending authority amounts, funders necessarily must strive to assure equity and fairness across current and future consumers. Funders obviously also must be concerned with the adequacy of the individual spending authority. Too low amounts will defeat the aims of self-determination. Too high amounts have other consequences, including tying up dollars that might be used for other objectives (e.g., reducing waiting lists or enhancing quality).
Each state/site adopted somewhat different approaches to determining the amount of the individual spending authority. Beyond determining the amount, funders also used different approaches to managing dollars overall across all persons who have individual budgets (i.e., how unspent dollars are treated and the use of risk reserves to address changes in circumstances).

Among the seven states, the following methods to determine the individual spending authority amount were observed:

- **Adaptation of Pre-Existing Formulaic Methods.** Predating self-determination, Kansas and Utah operated funding systems that assigned dollars to individuals based on formulaic methods. In each case, overall funding levels are determined by taking into account various functional assessment results and dollar amounts are assigned to individuals on a uniform basis. In each instance, these states simply provided that the amount determined through the existing method would be available to individuals who opted to direct their own supports. In Kansas, the practice was adopted of reducing the amount of authorized dollars by 10% to fund a risk reserve. In Utah, the predetermined funding amount serves as a point of reference when each person’s support plan is developed; regional personnel have some leeway in adjusting the amount above or below the mid-point value. The use of formulaic methods assures that individuals who opt for self-determination will have no more or less dollars than if they received conventional services. However, when formulaic methods were used, some problems were identified. In particular, the use of formulaic methods in provider-centered systems implicitly permits the provider to balance resources across many individuals whereas their application in a person-centered system makes such balancing difficult without resorting to devices such as risk reserves. Formulaic methods ensure equity across consumers but pose potential problems when translated into an individual spending authority.

- **Development of New Methods.** Participation in the self-determination initiative prompted some sites to develop *de novo* methods. This was the case in Wisconsin’s Dane County where extensive analysis was undertaken to develop a method to assign dollars based on consumer support needs that reflected spending patterns for persons already in the system. Dane’s approach was designed to assure that individuals new to services would have an amount of dollars that more or less matched the dollars spent on behalf of current consumers with similar support needs and circumstances. In the Dane approach, there is leeway in terms of authorizing additional dollars. A somewhat similar but less elaborate approach was developed in Minnesota’s Dakota County.

- **Continuation of Non-Formulaic Methods.** In Vermont, funding had been support-plan driven and individualized for many years. Individualized funding reflected essential person-centered guidelines and was keyed to state allocations to local authorities. Via self-determination, individuals may opt to directly manage their authorized funding. Vermont’s practice of individualizing funding was facilitated by
the fact that the state has long emphasized the use of very small living arrangements and other highly individualized/personalized supports.

- **Use of the Historical Baseline.** In the case of individuals already receiving services, it was common to base the individual budget on the amount currently expended on the person’s behalf. At some sites (e.g., Wisconsin's Winnebago County), implementing this approach sparked funders to obtain more in-depth information about the exact costs of supporting individuals than they heretofore had, especially persons supported in group living arrangements or facility-based day services. Basing the individual budget on the historical baseline led funders to recognize that they lacked critical information about individual costs. While the use of baseline spending amounts seems simple enough, some sites (e.g., Michigan's Wayne Community Living Services) developed processes to address situations where the historical funding amount proved insufficient to meet a person’s essential needs. There were relatively few cases where funders set individual spending authorizations in order to capture savings up-front by discounting the amount authorized from the historical baseline. Where the budget was discounted from the historical baseline, the dollars typically were set aside for individual or collective risk reserves.

In nearly all cases, determining the amount of the individual spending authority was strongly influenced by predecessor funding systems or funding levels. Sites sought to ensure that individuals would not be disadvantaged in terms of the dollars available to them by virtue of their decision to opt into self-determination. Funding equity was a common concern. However, funding equity could be a double-edged sword, especially when existing funding levels are problematic or premised on individuals being served in congregate service arrangements.

At none of the sites did an entirely new approach emerge to determine the individual spending authority amount independent of current baseline funding levels. In one fashion or another, current funding levels (either overall or an individual basis) served as the overall constraint on the amounts authorized. In some projects, little experience was accumulated concerning the individual funding levels for people who do not live with their families, people who require especially intensive supports or persons in transition from institutional settings. However, elsewhere the use of individual budgets was relatively widespread.

As self-determination becomes more widespread, continuing to anchor determination of the individual spending authority on antecedent fund allocation methods (including historical baseline costs) likely will prove more problematic, especially in states and localities where existing methods have spawned disparate funding amounts for similarly situated individuals.

At two sites (Dane County and Utah), methods were developed to interrelate the individual funding authority and funding sources. At both sites, the individual funding authority was expressed in terms of state and/or local dollars. The full amount of dollars
available to a person hinged on decisions concerning the use of Medicaid services or accessing services through other state or local programs. At these sites, state and/or local dollars could be used to leverage other dollars. Utah developed software to support budget development to take into account whether Medicaid services would be used or not.

**Rate/Price Setting**

In provider-based procurement, payment rates (prices) are set in various ways but typically are not often “individualized.” Instead payments span the entire group of individuals for whom a provider furnishes a specific service. For example, a facility that furnishes HCBS day habilitation services often receives a uniform payment for each person served. Payments for group-based residential services also are usually standardized, either by provider, site or category. States employ a variety of methods in determining prices for such services. Some vary payments to take into account “case mix” and consumer characteristics. Others base payments on each provider’s specific costs.

Self-determination focuses on the individual. The services and supports each person receives are expected to be different, not standardized. The volume of a type of support might vary from period-to-period, a factor that makes the use of per diem rates difficult. Furthermore, pricing schemes must accommodate portability and consumer choice. That is, if a person decides to change providers, then he or she should expect to pay about the same price for the service or support. In some respects, portability can be enhanced when prices are standardized.

With self-determination, participants often live with their families or have their own living arrangement. They may have jobs and/or need supports to participate in community activities they value. Some may require support around the clock and others may not, due in part to the availability of natural supports. As a consequence, pricing schemes tend to employ the “hour” as the unit of service. The use of Medicaid HCBS waiver funding also dictates that pricing schemes be unit based since payment for services requires documenting services specific to each person by date of service and provider.

With self-determination, there is interest in positioning consumers to negotiate or specify prices for at least some services. For example, instead of paying a state-determined rate, families may want the leeway to negotiate a lower or higher rate for a service such as personal assistance. If an acceptable attendant can be found at a low hourly cost, dollars become available for other services or a higher volume of personal assistance services can be obtained. It is well documented that personal assistance services typically can be obtained at a lower price when consumers hire assistants directly than when they obtain them through provider organizations. Alternatively, the ability to pay a higher wage might be critical in obtaining a personal assistant who has especially valued skills or ensure that the assistant will not look for a job elsewhere.

It was not the purpose of this evaluation to describe or analyze the methods that states and localities use to set rates or prices for all types of services but more to concentrate
on the extent to which self-determination caused changes in practice or identify instances where a state/site has established pricing schemes that appeared to facilitate self-determination. Thus, in this section, we do not discuss rate/price setting state-by-state but instead identify specific practices that one or several states have employed.

- **Variable pricing for services furnished by individual worker/employees.** Several states/sites where families or individuals (and their circles) are actively involved in recruiting individual workers gave consumers or support brokers the authority to negotiate wage rates. In Utah, for example, families have the latitude to negotiate hourly wage rates anywhere from the minimum wage up to a statewide maximum. Utah’s individual budgeting software can accommodate variable wage rates and fiscal intermediaries assist in translating the hourly wage into an hourly cost, taking into account benefits. Kansas also provided for negotiating individual worker wage rates. Consumers often had the authority to negotiate wage rates whenever they have been positioned as the employer of record for their workers.

- **Individualizing rates/prices.** Especially when individuals are receiving more or less continuous supports (including habilitation, supervision and other services) in their living arrangement from a provider agency, sites employed methods aimed at crafting individualized payment rates that take into account the particular needs and situations of individuals based on the person-centered plan. More and more, these rates are being developed utilizing standardized pricing methods. For example, Maryland has shifted from person-by-person negotiation of payments for community supported living arrangement services to employing standardized pricing methods based on each person’s plan and unique requirements. Utah also has a standardized pricing scheme for persons who live in supported living arrangements. The strength of these methods is that they yield a customized per diem payment amount (which simplifies billing and record keeping). They also enhance portability (the same amount of dollars will be paid if a person changes provider).

- **Breaking Out Individual Costs.** In Minnesota and Wisconsin in particular, the shift to self-determination lead to counties working with providers to break down the costs of services for each person served in group arrangements or for whom a uniform payment had been made. The aim is to develop “true” rates (costs) for each person served. In each instance and especially in order to identify the amount of dollars that should be attributed to each person, it was necessary for all parties to obtain a more accurate understanding of how many dollars were spent to support each person. This is particularly important because, if as a result of self-determination, a person leaves a program/site, funding for the individuals who remain also will be affected. As a consequence, it is in everyone’s best interest to have a clear picture of the resources committed to supporting each individual.

- **Revamping Existing Rates.** The trend among states is to revamp their rate/pricing methods to standardize payments in a fashion that takes into account differences in the intensity of the services and supports that individuals require. Both Utah and Kansas had taken steps in this regard prior to the advent of self-determination. For
core day and residential services, **Maryland** sets rates based on the level of supervision required, health and medical needs. **Minnesota** is working toward revising its fee structure for certain types of day services along similar lines with the aim of replacing a “one size fits all” uniform fee negotiated with each provider by the state. Taking steps such as these arguably results in more accurate pricing when individuals opt to receive more or less conventional services and increases the portability of dollars across providers.

- **Wrap-around Rates.** Administratively, it can be simpler all around if a person’s individual budget can be converted to a single daily or monthly payment amount. This simplifies transactions between the state and a locality or a lead provider agency. So long as the person or family retains control over the details of the budget, this method of rate setting does not undermine self-determination. In this vein, the method developed in **Minnesota** to enable counties to bill expenditures for consumer-directed supports is especially simplified. The “rate per month” is the same as the expenses per month incurred during the spend-out of the individual budget. In a similar vein, **Vermont**’s use of a wrap-around HCBS waiver service definition also serves the purpose of simplifying transactions while maintaining individualization, consumer control and accountability.

- **Upper Limits.** Another device that enables flexibility in pricing while maintaining orderliness in payment rates is establishing price/rate upper limits. As noted previously, **Utah** employs such upper limits in the case of services like personal assistance. **Minnesota** also establishes upper-limits for various services. Such upper limits enable flexibility in setting prices but also prevent unduly high prices to be charged for services. These upper limits also are labeled “fee-screens.”

There is little concerning rate/price setting that is especially unique to self-determination. Most considerations that arise in a self-determination context also apply to provider-direct procurement methods. In the main, the principal result of self-determination was to push funders/payers to accommodate multiple rates/prices for services, either in the form of variable pricing for a specific service by vendor or individualized payment rates. As rates/prices proliferate and become increasingly tied to specific individuals, new challenges can emerge in the arena of billing and payment, especially with respect to Medicaid services in reconciling charges to pre-approved rates/prices. In some instances, data systems had to be reprogrammed to accommodate variable pricing. The use of variable or individualized rates/prices also can result in increased effort in pre-auditing billed charges to make sure that they match up with the amounts that have been authorized for each consumer.

Going forward, a major emerging concern among the states/sites is the federal Health Insurance Portability and Accountability Act (HIPAA). A central thrust of HIPAA is “administrative simplification.” However, there was considerable concern that the implementation of HIPAA will work at cross-purposes with the aim of promoting flexibility in the provision of Medicaid home and community services by requiring the use of
billing/procedure codes that may not be sufficiently flexible to accommodate variability in service definitions and therefore in prices/rates.

**Billing, Payment and Tracking**

Consumer management of the individual budget dictates providing for certain essential capabilities. These include: (a) budget status reporting (i.e., actual versus planned or authorized spending); (b) consumer authorization of payments for services received; and, (c) payment to vendors. These tasks frequently are intertwined. The main way these tasks are addressed is by employing "financial intermediaries." The need for intermediaries stems from several factors, including Medicaid prohibitions against making cash payments to individuals, the need to ensure accountability with respect to payments for services rendered by providers, reducing administrative burdens for consumers, and, frequently, accommodating arrangements for individuals or families to be the employer of record of community workers. Financial intermediaries serve an *instrumental* role in support of consumer management of the individual budget.

In some respects, financial intermediaries conduct tasks (e.g., billing for services rendered and approved by the consumer) that otherwise are internalized within provider agencies in conventional provider-direct procurement systems. However, in other respects, the role that intermediaries play is unique, especially in supporting direct consumer management of dollars and payments.

The sites varied in how they provided for carrying out billing, payment and tracking tasks. Some sites (e.g., Kansas and Vermont) opted to contract with intermediary organizations to carry out the full-range of responsibilities. Elsewhere, tasks were separated. For example, Winnebago County contracted with a local CPA solely to keep track of spending against the individual budget. Typically but not universally, sites outsourced the financial intermediary function to other entities and organizations rather than conducting these functions internally. Outsourcing overcame problems with funders having to design and operate new payment systems or took advantage of capabilities already in place (e.g., the intermediary selected by Vermont already had considerable experience in the arena of consumer-directed personal assistance services). By and large, the costs associated with such outsourcing were modest in comparison to typical provider agency overhead charges. In Utah, for example, the intermediary charged 6½% of billed charges. In Vermont, a flat payment of $25-35 per month was paid to the intermediary. The costs of intermediary services were a function of the range of tasks that the intermediary conducted.

During the period of the initiatives, there were some changes in arrangements at some of the sites. In Utah, the state changed from employing a single intermediary organization to contracting with several organizations. In Dane County, a limited "fiscal conduit" organization was supplemented by contracting with another organization that offered a fuller range of services to consumers. While the sites varied in terms of financial intermediary arrangements, by and large each site/project was able to make practical arrangements to obtain such services economically.
A few sites tested alternative arrangements for billing and payments, principally in the form of consumer/funder joint checking account arrangements. Such arrangements enable the consumer to write a check directly to a provider to pay for services. These accounts clearly establish that the consumer is the purchaser of services while maintaining a transactional audit trail. However, the use of such accounts posed various issues, including the workload associated with account reconciliation and funders having dollars available to deposit funds in advance into such accounts.

The use of intermediaries to direct pay providers also surfaced cash management issues at some sites. Where an intermediary furnishes payroll services and makes payments to providers, it obviously must have funds available to make such payments. However, especially with respect to Medicaid-funded services, the recovery of dollars from funders for such payments occurs after a service is rendered and only when the claim for payment has been processed by the state. At some sites, floating the cash flow necessary to operate intermediary arrangements was problematic and limited the number of persons who could manage their services through an intermediary arrangement. Elsewhere, funders were in a position to float the necessary dollars.

At the end of the day, states/sites generally were able to put into place workable arrangements to address the mechanical issues associated with budget tracking, billing and payments. Outsourcing proved to be a practical and useful strategy. Individuals and families were brought into the loop in authorizing and approving payments albeit in some instances families themselves had to expend considerable effort in meeting paperwork requirements.

**Employee Administration**

Closely related but distinct from billing and payments is the topic of employee administration. When provider agencies/organizations furnish services, the service agency/organization is responsible for hiring, firing, supervising and paying workers. These activities take place behind the scenes and the associated costs are simply part of the agency’s “cost of doing business.”

When the provision of services and supports shifts from buying them from a service agency/organization to direct consumer management and management extends to individuals and families becoming the employer of record, then provision has to be made for handling employee administration tasks. These tasks include withholding and paying taxes, making unemployment compensation payments, and securing workers compensation coverage. In the absence of assistance, such tasks fall on the consumer/family employer and are especially burdensome/complex and fraught with potential liability. Or these tasks can be accomplished in other ways, including through financial intermediaries or by way of other arrangements whereby another entity agrees to be the employer of record but while still affording the consumer or the family a high level of authority in hiring workers and directing them.
For various reasons, government funders are reluctant to serve as the implicit or explicit employers of consumer-selected workers due to the associated financial liability. Absent an employment arrangement between the worker and the consumer or the worker and an employment agency, consumer-management/direction takes the form of workers becoming providers in their own right and consumers simply exercising their authority under Medicaid law to freely choose from among all qualified providers. While some states have been able to achieve reasonably high levels of consumer control using this model (e.g., offering provider agreements to consumer-recruited workers), the model poses some difficulties, especially for workers. Ensuring high levels of consumer control over workers requires mechanical solutions that substitute for the employment of workers by provider agencies.

In general, the projects/sites addressed employee administration issues either by wedding the necessary functions with financial intermediaries or working out arrangements with employment agencies. In some projects/sites, the scope of the arrangements was relatively limited with the intermediary functioning as a “fiscal conduit” and the consumer (individual or family) shouldering considerable burden and risk liability exposure by becoming the employer of record. Elsewhere, arrangements were more full-featured and less burdensome with the intermediary taking on a wider range of responsibilities on behalf of consumers. There were marked variations in the extent to which projects/sites furnished training and other assistance to consumers to play the employer role or made consumers aware of potential liabilities they faced. In a few cases, problems surfaced around some aspects of employee administration. For example, in Utah securing workers compensation coverage for family-employed workers was and continues to be a problem due to state law.

The states/sites generally were able to make suitable arrangements to address employment administration tasks. However, some sites encountered difficulties in finding organizations that were willing to serve as the employer of record due to liability concerns. Projects/sites varied with respect to the distribution of burdens and responsibilities between individuals/families and the organizations used to facilitate employment administration, principally with respect to how the employer of record issue was addressed.

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HCBS Waiver Dimensions

As noted earlier, the Medicaid HCBS waiver program plays a linchpin role in underwriting the costs of community services and supports for people with developmental disabilities in nearly all states. The widespread use of HCBS waiver financing introduces additional issues that have to be addressed in promoting self-determination. Medicaid law and rules contain dictates regarding service planning,
authorization, contracting and payments. Fitting self-determination to these dictates can be more complicated than when only state or local dollars are used to pay for services.

Among the seven states, only Minnesota, Utah and Wisconsin made changes to their HCBS waiver programs expressly to facilitate self-determination. Minnesota and Wisconsin added the coverage of “consumer-directed supports” to serve as a vehicle for promoting self-determination. Utah made several changes to its HCBS waiver program to reflect the principles of self-determination. Elsewhere, states carried out their initiatives employing their already approved HCBS waiver programs. For example, Vermont’s waiver provided for the coverage of an individually-centered “flexible support plan” cluster of services and supports. State officials regarded this coverage as sufficiently congruent with the principles of self-determination and hence found that they had no need to further modify their program to accommodate self-determination.

The use of Medicaid HCBS waiver funding did present various issues for states/sites and consumers and constricted the use of some options. As noted previously, because Medicaid payments are made post-service delivery, Medicaid dollars cannot be employed to pre-fund consumer budgets or checking accounts. In addition, the use of Medicaid funding eliminates the use of direct cash transfers to individuals and can even pose problems for approaches where consumers are reimbursed for their direct outlays for services even when such services are obtained from approved sources. Some states encountered problems in conforming consumer employer of record arrangements to Medicaid requirements concerning provider agreements between the state Medicaid agency and service providers and found that accommodating such arrangements led to added administrative burdens. Working out arrangements to compensate financial intermediaries also posed problems for some sites, as did fitting intermediaries into the Medicaid claiming/payment loop. In one or another, states/sites worked around these issues.

During our interviews with project managers and other officials involved in promoting self-determination, some expressed uncertainty concerning whether the practices they had put into place in fact comported with federal Medicaid requirements. Some expressed frustration about the lack of clear federal policy guidance to sanction various practices and concern about the potential that the practices they were employing might be found to be non-compliant.

Observations Concerning Resource Requirements

It is not unreasonable to ask is whether self-determination “causes” system overhead and other costs to increase or decrease. Another important question is: if costs increase, is the increase the result of non-recurring expenses or recurring expenses? The answers to these questions proved hard to come by, although the sentiment expressed at most sites was that self-determination involves a greater commitment of
resources to some activities and functions. The need for additional resources concentrates in the “overhead” arena because of the nature of person-centered supports. Tasks once embedded in provider agency operations shift elsewhere (e.g., employment administration). There also is a greater need for support coordination resources when the services and supports that people want are highly variable, change frequently, and are obtained from alternative sources.

For example, there is little doubt that person-centered planning is more resource intensive than service planning that revolves around finding the best fit for individuals among limited existing service alternatives. Following its shift to person-centered planning, Utah DSPD boosted the number of hours for service coordination in its HCBS waiver program. At one site, the observation was made that furnishing support coordination on behalf of individuals who live with their families is much more resource intensive than conducting case management for people in provider-operated community residences (where the provider agency frequently shoulders direct case management responsibilities).

There are other “costs” that arise with person-centered supports that did not arise in predecessor “provider-centered” systems. For example, in one Minnesota county, time was set aside to conduct consumer education and training classes for people new self-determination. At a Kansas site, considerable energy was devoted to unraveling rules and regulations as a result of individuals and families “thinking outside the box.” Major investments also were made in supporting individuals and families to manage and direct their own supports, including contracting with financial intermediaries and employment agencies, at least some of the costs of which involve paying for activities that provider agencies bore in the past. Fees paid for intermediary services ranged from 2 to 10% of direct program costs, depending on the site and the scope/nature of the services being purchased from intermediaries.

There also is no doubt that self-determination strained government agencies, especially in the financial management arena, with additional workload being piled atop current workload without the benefit of added staff. In nearly all cases, self-determination did not completely displace the “old way of doing business” and at most sites only a relatively small percentage of individuals were participating in self-determination. This meant that old and new ways of doing business were operating in parallel, a costly proposition. Clearly, there have been considerable “ramping up” costs in all the states/sites to get self-determination off the ground and moving along, costs that were borne only in part by the RWJF grants.

But, even though nearly all the individuals with whom we spoke believe that self-determination led to increased system overhead costs, most were optimistic that some of these costs would decline, due either to implementing new IS solutions or as a result
of individuals and families themselves gaining more confidence and experience in managing and directing their own supports.

Left unanswered, however, is the extent to which an increase in infrastructure/“overhead” resource requirements might be counterbalanced or more than offset by changes in service and support costs themselves. For example, while the cost of fiscal intermediary services might be around 5%, that cost is markedly lower than the 10-15% or more paid to provider agencies in the form of administrative overhead expenses for conventional services. There continues to be strong evidence that the “self-determination model” itself makes more efficient use of scarce public dollars than provider-centered systems. As a consequence, if infrastructure/overhead costs increase with self-determination (in the form of increased expenses for support coordination/service brokerage or paying intermediaries), it is not necessarily the case that these increased costs lead to increased total costs in supporting individuals and families. There is little doubt that supporting people “one person at a time” requires a strong and responsive infrastructure. However, that infrastructure may yield offsetting savings down the road.

The relatively short duration of the projects and the fact that many fully ramped up late in the project period made it virtually impossible to gauge the effects on system costs. Even if costs increased overall, that result must be assessed in broader terms, including the extent to which self-determination contributes to consumer satisfaction and prompts the more effective deployment of public dollars overall in both the short and long-term.

Management Information Systems

Without exception, the states/sites pointed out the added information requirements associated with self-determination. Agencies went from simply having to track and control only the numbers of clients served (slots), to the tracking and control of services and supports provided with the expansion of fee for service systems, to the tracking and control of services and supports and individual expenditures against individual budgets in the case of self-determination.

The only way the sites with large numbers of consumers were able to manage was through automation. Most sites turned to off-the-shelf software as the quick solution: specifically, accounting, spreadsheet and database software. Some custom-developed their own systems in-house or through contract, e.g. a system to manage individual checking accounts. All agreed that without the increased use of automated information systems, they would not have been able to handle to manage the increased information-processing load associated with the individualized processes associated with self-determination.
Ad hoc, make-do solutions serve for a time or frequently they are best that can be achieved given the limited IS-resources available to states/sites. Most certainly, one of the major problems in this arena is that many state developmental disabilities system are well-behind in shifting from IS systems principally geared to tracking program/service use and payments to systems that can readily extract information about service use and expenditures on an individual consumer basis, the dimension upon which person-centered supports and self-determination operate. In addition, state service systems increasingly must link to Medicaid payment systems. In addition, there is mounting recognition of the need to intermesh state, locality and even provider IS systems in order to achieve resource-efficient IS solutions, including pulling together all the varied information and data necessary to support procurement and other financially-related tasks that accompany self-determination. In many respects, the IS challenges that arise from self-determination require tackling broader systemic issues and engaging in redesign of baseline systems. This was recognized in Minnesota, for example, where a multi-phase redesign is underway, including developing the capability within the Department of Human Services information system to support individual budgets and facilitate state and county data sharing rather duplicate data and/or avoid compiling information manually. Similar redesigns are underway in other states, including Pennsylvania and Rhode Island, again prompted by self-determination.

For sure, self-determination exposed material weaknesses in state and local information systems. At first blush, it should not be a daunting task to keep track of individual budgets, payments and service use person-by-person. But the reality is that the task is less simple than it seems absent integration across multiple systems at multiple levels. What has been discovered is that, absent IS redesign efforts, there was a steep price to paid in maintaining ad hoc systems or substituting labor for computing power.

**Conclusion**

Ramping up self-determination posed many challenges to states/sites in the arena of financial management. New ways of allocating dollars had to be designed and put into place. Fundamental business processes also had to be developed and implemented. Often times, these efforts took place in the midst of carrying out other major initiatives that competed for attention. States/sites started at different places in terms of their orientation to furnishing person-centered supports. In some cases, states/sites faced the daunting task of having to accommodate self-determination while continuing to operate predecessor systems side-by-side.

The states/sites were able to design and put into place an infrastructure in support of self-determination. One way or another, they worked out solutions to many of the mechanical challenges of implementing self-determination. The specific solutions varied from site-to-site as a result of local considerations and, in some cases, due to more fundamental differences in state service delivery system organization and structure. The
fact that different solutions emerged furnishes evidence that addressing the mechanical aspects of self-determination hinge mainly on local considerations. It also supplies evidence that self-determination can work within a variety of structures.

The first stage experience with self-determination and its consequences for financial management and business practices also brought to the fore various issues that likely will need to be addressed in future stages. These include continued examination of methods to set individual spending authority amounts, the extent to which federal Medicaid policy might need to be revamped in order to sanction various practices, and the implications of consumer-directed/managed arrangements across business processes, including IS.
In our First Year Impact Assessment Report, we observed that “the RWJ Demonstration Sites took great strides toward achieving goals related to systems or policy change, individual planning and outcomes, and education and training” (p.64). Primarily, first year efforts were consistent with efforts to bring about significant, if not radical, change in the role of people with developmental disabilities in determining how resources will be allocated on their behalf. We observed further that the Demonstrations were aided or hindered by a variety of factors. We noted that these factors were not equally observed in all sites, and that, where present, they acted within a dynamic systems context. It was impossible to predict which factors would eventually gain sway, pushing a state’s effort to advance further, stall or retreat.

### Factors Aiding Or Hindering the RWJ Self-Determination Demonstrations (Year One Findings)

#### Factors Aiding the RWJ Demonstration Sites

- A clarity of vision and action oriented leadership.
- A strong commitment among many to make self-determination work.
- Supportive systems infrastructure (e.g., quality assurance, information management, service providers that were prepared to change the way they worked).
- Supportive financing, especially a supportive Medicaid Home and Community-based waiver that could finance a wide range of service choices.
- Supportive history and a proclivity for innovation.

#### Factors Hindering the RWJ Demonstration Sites

- The relatively short duration of the RWJ grant awards, and for some states the relatively modest amount of the award.
- An absence of a sense of urgency for change
- An embryonic and still emerging constituency to support the Demonstrations.
- Difficult issues to resolve regarding the mechanics of self-determination (e.g., how to set personal budgets, distinguishing between the role of “brokers” and “case managers,” establishing a “fiscal intermediary”).
- Difficult and uncertain financing for self-determination
- Day-to-day distractions associated with administering state systems (e.g., wait list suits, Olmstead planning, resistance offered by various stakeholders).

Source: HSRI First Year Impact Assessment
In fact, this list held up favorably over the past year and can still be used to assess circumstances in any particular state. Given time and the added perspective of having collected additional information, however, we offer these four complementing observations pertaining to the current status of the RWJ Demonstrations:

1. While staff at the sites uniformly worked hard to make their self-determination demonstration work, in some sites momentum for the initiative seemed to melt away, while in others it gained strength and spread, either right from the start or eventually.

2. The role self-advocates play nationally to promote self-determination is growing.

3. Troublesome implementation issues related to translating self-determination principles into actual practice persist and pose significant obstacles to advocates and policy makers alike.

4. As self-determination policy and practice evolve, a gritty question concerning “who is the ‘self’ in self determination?” has emerged and has no easy answer.

We want to be clear that this observation in no way reflects poorly on the efforts of the individuals hired locally to staff the RWJ Demonstrations. As we noted in our previous report, we found these staff to be extraordinarily hard working and committed to the idea of self-determination. Their efforts, however, did not always result in strong and enduring outcomes for self-determination. We cannot be certain, but we suspect that several of the hindering factors listed above could be used to explain this finding.

For instance, the short duration and relatively small amount of some of the grants likely affected how states performed. States were granted one, two or three year grants and allocated between $100,000 - $400,000 per year. For instance, Florida, Pennsylvania and Washington received grants of $100,000 for 1 to 1½ years while Hawaii, Wisconsin Maryland, Texas, Kansas, Minnesota, Ohio and Vermont received about $400,000 for three years.

We understand that early on that the RWJ National Program Office was aware of the risks associated with their strategy of spreading the available resources unevenly across 19 sites rather than concentrating more substantial resources on fewer places. From a national perspective, the strategy may have paid off because the concept of “self-determination” became, and remains, a very popular topic of discussion across the country. Yet, at the local level, the momentum tied to the smaller or more time limited grants may have created an initial stir, but over time could not be maintained in face of other pressing concerns within the state.
Likewise, several other hindering factors may have played into how sites eventually fared. Uncommitted or changed state leadership, absence of an urgent need to change, tricky financing, unresolved implementation issues, and other difficulties all took their toll so that in several sites (e.g., WA, TX, FL, PA, FL, AZ) the early momentum appeared to dissipate.

To contrast, in some sites the initiative appeared to gain momentum over time (e.g., OR, MI, Winnebago & Dane counties in WI, Delaware county in OH, VT, NH, CT). In Hawaii and Utah, in fact, the initiative seemed to have withered away entirely only to rebound strongly given changes in state or local leadership. Meanwhile, in Massachusetts the initiative seemed to maintain a steady but very low-key pace, but has more recently grown and become more visible.

In Michigan, the RWJ Demonstration came at an important time, given the state’s plan for incorporating managed care concepts into its long term services system. The state secured two new Medicaid Home and Community based waivers (Section B & C waivers) from the Health Care Finance Administration. These waivers permitted the state to offer a more flexible range of supports to individuals within the context of greater personal control over these supports, and to channel these individuals through local single portal service points. Overall, this financing structure helped policy makers to proceed with plans for integrating self-determination principles into the system.

Likewise, circumstances in Oregon also warrant special attention. This Demonstration initially focused on Multnomah County which encompasses the state’s largest city, Portland. Its goals were relatively modest to start, seeking only to affect about 60 people over three years, but to serve primarily as a “learning laboratory.” Early on, the site exceeded its performance goals, though efforts were tied primarily to individuals living home with family members. In May 2001, however, the state developmental disabilities office issued a statewide Request for Proposals for “Support Service Brokerages.” Based on the principles of self-determination and the lessons learned from the Demonstration, the “goal is to develop a sufficient number of Brokerages whereby... all eligible adults with developmental disabilities, in every part of the state, will have access to the services provided by the Brokerages” (p.4).

Ohio is another state that has achieved significant expansion, growing from four sites to over thirty counties statewide. Committed project leadership, perseverance, and a combination of local efforts and state-level support has provided the initiative with the continuous energy needed to develop and expand. Their strong and steady incremental approach has proved successful.

In sites like these, we cannot say for certain what specifically prompted success. These sites struggled with the same hindering factors as the others, and still struggle with a variety of unsettled implementation issues. However, two facilitating factors stand out:
(a) a clarity of vision and action oriented leadership, and (b) a supportive history and a proclivity for innovation.

Where a Demonstration site has done exceedingly well, we can usually identify a team of individuals who shared a common vision for self-determination and worked deliberately to put the vision into practice. This team, however, often benefited from working within a supportive environment for change -- acting on a historical proclivity for innovation. Michigan, for instance, was an early leader in the move to establish community-centered responses to disability. Dane County in Wisconsin regularly wins national awards for its innovation (e.g., in family support, supported employment). New Hampshire and Vermont have no public institutions and have a national reputation for progressive service practices. Oregon has steadily downsized its institutional census, recently closing its largest center at Fairview, and also has a history for supporting innovative service practices.

In addition to these favorable factors, individuals across these more accomplished sites revealed a common theme: that success was related to thinking about and presenting “self-determination” as a way -- the way -- of doing things rather than as a temporal demonstration project. This position sent a strong message throughout the system that policy makers were not interested in simply testing a new model or layering it into the existing system, but were committed to pushing past the demonstration phase and reforming the entire system based on self-determination principles. This strategy was plainly revealed early on in Dane County, WI. We asked staff there if they had produced any specialized media (e.g., video, brochures) to publicize the “project.” They had not, and explained that to do so would highlight the effort as something separate from the overall system. Instead, they were steadily going about a reform of their entire system, integrating self-determination practices into “how we do business.”

The role self-advocates play nationally to promote self-determination is growing.

In our First Year Report we wrote that: “Self-determination is thought by many to be an irresistible concept that requires no argument or justification. It is. Yet ... we did not observe a widespread constituency for the systemic changes sought by the Demonstrations. Energy for the effort was young and still emerging ... This was especially noticeable among self-advocates as we observed that as an organized constituency self-advocates played a limited role in the Demonstrations” (p. 56-57). We explored several potential explanations for this finding and decided to focus some of our subsequent effort on this topic. Chapter 4, for instance, presents findings of a special self-advocate focus group we convened to explore the issue.

In addition, our talks with self-advocates nationally reveal that self-advocates are becoming increasingly engaged in advising policy making in general, and in particular for promoting self-determination. For example, the national organization -- Self
Advocates Becoming Empowered -- is increasingly injecting itself into discussions pertaining to disability policy, including talk related to self-determination. Likewise, the national Alliance for Self-Determination, anchored at the Center for Self-Determination at the Oregon Health Science University is facilitating efforts to coordinate actions keyed to self-determination across disability groups and stakeholders.

Locally, state self-advocacy organizations are also finding their political footing. For instance, the Utah Self-Advocacy Network is partnering with other stakeholders, to educate self-advocates and others about self-determination. Likewise, in Oregon, Texas, New Hampshire and elsewhere self-advocates are organizing to “spread the word” about self-determination. Many demonstration sites have since recognized the importance of the emergence of self-advocacy and have taken active steps to support its development. For example, Michigan awarded $100,000 in small grants for the development of local self-advocacy groups, and Ohio is making a strong effort to link with their relatively young statewide People First group in conducting many of the self-determination activities. As mentioned earlier, Vermont is unique in its involvement of self-advocates as a core component of their project.

Consider, for example, these selected statements compiled by self-advocates from New Hampshire who were participating in “Project LEAD: Promoting Personal Leadership” through the Institute on Disability at the University of New Hampshire. These self-advocates met to learn about self-determination, respond to four related questions, and set plans for talking with other self-advocates. What follows is a portion of what these self-advocates compiled:

“We are self-advocates who are participating in Project LEAD. We are working hard for self-determination. ...This meeting involved over 20 self-advocates from the Concord, NH area. Like any other person, each of us wants to be in control of our own life. The services and supports we receive should help us to do that. What follows are answers to questions that we asked ourselves about self-determination. This is our voice ..."

1. What does self-determination mean?
   - Speaking for yourself and taking control of your own life.
   - Not letting other people speak up for you about how to live your life in the community.
   - Live on your own to do what you want, like taking charge of your own money.
   - Fighting for your rights, like for getting your own house.
   - Being able to live where I want.
Complementing Outcomes And Observations

- Being able to get around to do the things I want, like take the job I want.
- Being determined to learn new things and have the opportunity to learn.
- Be determined to stand up for my right in life and live the way I want to.
- Nothing about me, without me.
- Being asked what I want and then agencies putting money behind it.

2. What kinds of things help you to control your own life?
- Being able to stand up and telling people how I feel.
- Keeping telling people, like the case manager, about the things I want to do.
- Having control over what I want to do.
- Being out on my own and making my own decisions... making my own choices without having people making choices for you.
- Having the support I need.
- Going to the state capitol to testify to tell legislators what we want them to do.
- Knowing and fighting for my rights to get what I want.
- Trying to stop state agencies from interfering in people’s lives, like interfering with families.

3. What gets in the way of controlling your own life?
- People telling me what to do or what not to do, or where to go.
- State agencies that interfere in people’s lives, like when people with disabilities who have children.
- My case worker... she doesn't listen to where I want to move, or she tells me who I can and can't have for friends.
- Parents. They don't always let me do it on my own. They treat me like a little kid.
- State workers get in the way. They don't always tell the truth.
- People don't work with you... and tell us that we can't do it.
- My own temper gets me in trouble, and my confusion gets in the way.
- Well-intended staff who think they know best for me. They cannot control our lives.
• Having to do things that are against my beliefs because we are forced too, like where to live or who to live with.

• Sometimes there is a conflict between what a self-advocate wants and what his or her legal guardian wants. It can put staff right in the middle. Self-advocates can be left not getting what they want.

4. What can Self-Advocates DO to overcome those barriers?
• Call my case manager to explain the problem so she can fix it or refer me to someone else who can.
• Speak up for ourselves.
• Get some other people to advocate with us. Get an advocate to help.
• Work together to help change certain laws.
• Doing things to call attention to an issue or problem, if people don’t listen. This could mean going “right to the top” to ask for change, or conducting information pickets, or making a petition… This action must “make noise.”

5. What CAN PARENTS OR OTHERS DO to overcome those barriers?
• Staff should think of themselves as our employees.
• Though you might care about us, we need you to stand behind us or beside us, not in front of us and get in the way.
• Let us make our own decisions
• Help us to vote.
• Back off and see how far I can fly and how tough I can be.
• Put yourself in my place and see how you feel.
• Listen to a person to live and do what they want in the community.
• Tell us what the truth is… each of you tells me something different… don’t jerk me around.

Overall, statements like these, and the actions of self-advocates nationally illustrate that a constituency for self-determination is growing. At issue is whether or not such momentum can be maintained. Certainly, the demonstration projects have advanced the growth of self-advocacy groups in many places around the country.
On a promising note, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 contains strong language pertaining to the role Developmental Disability Planning Councils must play to support self-advocates. Specifically, Part B; Section 124 requires that State Plans include a goal for each year to: (a) establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities; (b) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and (c) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions. We understand that self advocates in several states (e.g., OR, NH, UT, OK, MA, MO, NC, IL) are already using this language to convince Planning Councils in their state to invest more in self-advocacy, leadership development and self-determination.

3 Troublesome implementation issues persist related to translating self-determination principles into actual practice.

In our First Year Report we identified several implementation issues that challenged the Demonstrations. These included:

- The means for compiling person centered plans and budgets. Settling on the role and functions of the "service broker" as opposed to traditional "case management" or "service coordination."
- Determining the most efficient means for managing and accounting for person-centered budgets and resulting spending.
- Working through the legal and tax implications of individuals managing their own budgets, and the structure and responsibilities of fiscal intermediaries.
- Deciding on what to do with any savings that may be realized from the initiative.
- Settling and growing comfortable with the new roles that must be played by government, individuals, families and providers
- Deciding on how to manage financial and personal risk.
- Thinking through and developing new ways to manage information and assure health and safety of individuals, and monitor supports quality.

Certainly, over the past year progress has been made pertaining to several of these issues. While there is still resistance to the idea of ceding authority to self-advocates, such resistance is receding given greater familiarity with the idea and successful experience. Service providers, for example, though not uniformly enthusiastic are increasingly showing favorable interest. Illustrative of such awareness, the Center for Accreditation of Rehabilitation Facilities (CARF) has highlighted self-determination at its
last two annual meeting of its community services division, focusing on what providers might do participate in self-directed systems.

Other issues, however, resist easy solution. For instance… what is the best way to set a person centered budget? One school of thought maintains that budgets should be set “one person at a time” based on personal conversations. Yet how do we distinguish between needs and wants? What about equity? And what would be the cost of applying this approach to hundreds of people in a state as opposed to a few dozen in a Demonstration effort? An alternative approach calls for use of systematic assessment whereby individuals are assigned to varying budget tiers based on their scores. Yet, while potentially more equitable, doesn’t this strategy undercut the idea of a “person centered” approach? And what happens when a budget is set too high or too low? To date, this debate seems without a satisfying end and policy makers are still probing for a winning solution.

Likewise, given a self-directed system where self-advocates increasingly call on non-traditional sources of support, how can the health and well-being of the individual be assured? Within the current system, great effort is made to assure that the supports people receive meet a standard of some kind and that the individual’s well being is looked after. Surely, present “quality assurance” systems are not free of criticism and significant effort is continually placed into rethinking and reforming these systems. Yet, self-determination poses a special problem.

In present systems, access to the individual and his or her service provider is generally assumed and there is a resulting confidence that personal circumstances can be adequately monitored. In self-directed systems, however, such access is not guaranteed, especially where non-traditional supports are used. Parties seeking to “check up on” non-traditional providers such as neighbors, friends and others will not have it so easy. Some argue that these circumstances can place people with disabilities at greater risk of harm, and so suggest that some amount of personal authority must be relinquished so that system representatives may assure the health and well-being of self-advocate participants. But what amount of personal authority must be ceded? And what practices, precisely, will be applied to assure health and well being?

To contrast, some Demonstration sites have worked through knotty issues pertaining to the complementing yet potentially differing roles of “brokers” and “case managers.” There was no single solution that won out over all. In some instances, site staff decided to keep these roles unified within a single position, having case managers, for instance, expand their traditional roles to take on broker functions. In other instances (e.g., OR, MN) the roles were systematically delineated into two separate staff positions.

Similarly, sites have found ways to how to manage and account for personal allocations. In specific, “fiscal intermediaries” have been utilized to fill this precise niche. In some instances the intermediary role is played through an existing business entity (e.g., a C.P.A. firm), provider agency (e.g., Goodwill Industries in Dane County, Wisconsin) or regional entity (e.g., area agencies in New Hampshire and Vermont and Kansas). In
other sites, such as in Oregon, intermediaries were established locally. In some instances, local entities were established seek to expand their operations out-of-state. For example, Acumen Fiscal Agent and in Utah and one operated through the Public Consulting Group in Massachusetts began operations locally and now seek to offer their services nationally.

At first glance, it would appear that issues pertaining to the broker and intermediary functions have been resolved. However, second generation issues have emerged. Can parents serve as effective brokers for their adult family member? Do they have an inherent conflict of interest? Are they representing their family member’s preferences or their own? If we establish a broker to stand along side a case manager, how do we pay for the added position? For the cost, is there significant added benefit? Or are we simply tacking on added administrative costs.

Likewise, how do we justify any added expense for managing money through a fiscal intermediary? Where do the funds come from? If administrative costs are added to accommodate the intermediary, are equivalent costs subtracted from the overall system administrative equation?

What role, precisely, will the intermediary play? Will this entity simply assure that resources are invoiced and distributed, assure that taxes are paid and provide an audit trail? Or is the intermediary expected to play an expanded role, checking prospective employee criminal records and immigration status, or offering health benefits or workers compensation?

And if a self-advocate retains an individual to provide supports, who -- after all -- is the employer of record? The quick answer is “the person with disabilities.” However, an employer of record carries certain legal responsibilities such as detailing job responsibilities, directing employee actions and assuring that they are paid appropriately. If the person with disabilities has a severe cognitive disability, is that individual truly acting as an “employer of record?” Or is some other party (e.g., a parent, the broker) acting as the real employer of record? And if so, is this third party aware of his or her legal responsibilities and the associated risks?

Policy makers may choose any number of ways to respond to questions like these. An obvious outcome is that systems that promote self-determination are quite varied in their approach. In addition, we note that there is a dynamic rhythm to the respective roles played by the self-advocate participant, his or her broker, the fiscal intermediary and other interested individuals, such as family members. The “dance” between these parties can play out differently at a systems level across sites, and at an individual level from person to person.

Considering these circumstances, Terry Cote, who serves in a state leadership capacity in Connecticut, remarked that there is no easy solution to issues like these. Rather, the best one can do is to weigh all the options and find the solution that: (a) stays truest to the principles of self-determination, and (b) musters sufficient support from stakeholders
so that the initiative can go forward. For these self-determination demonstrations, this is the system’s “sweet spot”. The resulting system structure may not be perfect from all accounts, and shortcomings may be soon exposed. The structure, however, provides a suitable platform from which the demonstration could advance.

In great part, while the resolution of issues like these can involve technical innovation, finding a “sweet spot” often requires stakeholders to agree on how “risk” in a service system will be managed. “Risk” refers to the possibility that something could go wrong. Many stakeholders in a service system bear risk. For instance, financial officers are worried about maintaining audit trails and keeping in line with funding rules and the law. Case managers want to be sure that the individuals they support receive services from reputable providers. Service providers must offer assurance that no harm comes to their customers while they provide quality supports. They are also charged with assuring that their employees are paid adequately and have safe working conditions. State directors bear responsibility for assuring that the entire system works efficiently and effectively, and within budget.

The present system already has well defined means for managing the variety of risks associated with supporting people with developmental disabilities. Risk is distributed among set players (i.e., funders, system administrators and providers) and articulated within set policy and procedure. Establishing a system based in participant-driven or self-determination principles upsets these arrangements.

The following graphic illustrates what is occurring. Ultimately, changes in the flow of control and power imposes change in how risk is managed. Planners must cope with contextual variables while considering how to re-distribute risk among players and/or utilize a variety of risk management tools. The needed negotiation among players requires exploration of new ideas, and can involve vigorous disagreement. Given that agreement can be reached, the outcome is a new system with new risk management guidelines.
Self-Determination, Managing Risk and Systems Change

**Context**
- Trouble with Financing
- Uncertain Policy Direction
- The “Consensus Trap”
- The Gap Between Status Quo and Preferred System
- Overall System Re-structuring
- Historical Tension Among Players
- Tough Procedural Issues

**Players**
- Participants
- Brokers
- Fiscal Intermediaries
- State Agencies
  - Local Administrative Agencies (regional entities)
- Traditional DD Providers
- Alternative Providers

**Risk**
- Tax Liability
- Civil Liability
- Criminal Liability
- Payroll Issues
- Labor Issues
- Day-to-Day Personal Support Issues
- Budget Issues
- Accountability
- Impacts on the Provider Market
- Medicaid Implications

**Risk Management Strategies**
- Avoid Risk By Steering Clear
- Modify Risk To Make things “Safer” Through Policy, Practice and Procedure
- Transfer Risk to Another Player
- Retain Risk And Prepare for Consequences (e.g., buy insurance)

**New Solution For Managing Risk**
- Involving...
- Redistribution of Risk Among Players... and
- Use of Risk Management Strategies
“Who is the ‘self’ in self determination?”

As self-determination policy and practice evolve, a gritty question concerning “who is the ‘self’ in self-determination?” has emerged and has no easy answer. Often, when we ask this question, the quick response is “the person with disabilities, of course.” Our conversations with self-advocates, however, make us wonder. We wonder if systems to promote self-determination are subtly shifting significant authority not to self-advocates but instead to other players, such as family members, brokers or intermediaries. Indeed, our conversations with self-advocates repeatedly illustrate this concern.

Given this emerging issue, we note that:

- Self-determination administrative structures can become remarkably complex. Ironically, the simple idea that people should be in charge of their own lives, can be quite difficult to translate into practice given the numerous implementation issues to resolve. As an individual who attended our self-advocate focus group (See Chapter 4) noted, the result is a system that may be too complex for self-advocates to easily negotiate, and so requires system guides that invariably subtract decision-making authority from self-advocates.

- Family members are often cast as co-decision-makers with self-advocates. Often, literature and brochures detailing the workings of self-determination describe a shift of decision-making authority to “self-advocates and families.” What is left unsaid is how authority is distributed between family members and self-advocates. Again, our conversations with self-advocates reveal a certain fear that family members are acquiring authority within self-directed systems that should more squarely sit with self-advocates.

This concern may play out on a systems level, for instance, over what the composition of an advisory panel should be. How does a requirement of 51% self advocates and family members actually get distributed between these stakeholders? On a personal level, self-advocates are quick to point out the inconsistency between the ideal of self-determination and the reality of imposed guardianship. Meanwhile, while parents may believe that they can and should be able to act as their family member’s broker, self-advocates do not particularly agree. One self-advocate in Alabama remarked that “You love us, but you don’t always listen to us.”

Still there are many with developmental disabilities who have significant cognitive disabilities and caring families who know their family member well and want the best for him or her. In these instances, parents argue that they should take the lead to interpret the individuals preference’s and craft an appropriate support plan. This is a difficult position to argue with.

We do not anticipate that this issue will be satisfactorily resolved soon. Family members and other stakeholders have traditionally wielded significant power within developmental disability systems and in the personal lives of self-advocates. More
recently, self-advocates are finding their footing as political activists and pressing for authority over their personal lives. The RWJ self-determination demonstrations have helped to legitimize this trend and push it along.

- The ideal of “self-determination” does not apply identically to children and adults with developmental disabilities. It is true that parents ideally wish for their children to grow up into responsible self-determining adults. In this context, the self-determination ideal applies to all.

Yet its application is age sensitive. Parents are expected to exert significant authority over their young children, including those with disabilities. Accordingly, family support systems emphasize “family empowerment themes.” In this context, “self-determination” as applied to families of children with disabilities seems more accurately to resemble a reformed family support structure… one that still emphasizes family empowerment themes only with a new spin.

As the child ages into an adult, however, family empowerment must eventually give way to personal empowerment. For adults with developmental disabilities, the “self” in self-determination must unmistakably refer to the individual, not his or her parents.

Complicating matters, thousands of adults with developmental disabilities live at home with their families. As state systems respond to their needs, it is difficult to sort through how to support these families while also honoring the individual’s want to live a self-determined life. In these circumstances, policy makers seem caught between a historical bias for offering supports within the framework of a family empowerment theme and a purposeful want to explore alternative approaches to promote self-determination.

The preceding overview was meant to offer a summary of four persistent and emerging issues faced by the RWJ Demonstrations. While the Demonstrations have not resulted in “radical change” in all 19 sites, an enduring mark was left in each and in several the Demonstrations have taken strong root and have spread.

Certainly, difficult issues remain and second generation issues are emerging. Most promising, however, has been the strong resolve among many to push forward -- to find the “sweet spot” to work from -- and the growing awareness and commitment of self-advocates to self-determination. This emergent constituency is still finding itself and will likely play an increasingly important role in shaping disability policy for self-determination.
In this final chapter, we summarize our recommendations for future work and development efforts in self-determination.

Design self-determination structures and implementation strategies to “fit” within the context and culture of where services are being delivered. There is no one way to “do” self-determination. In fact, our analysis of demonstration projects leads us to conclude that there are many different models and individual components that work, depending on the local service system. We saw successful efforts in both urban and rural areas, in statewide projects and in individual counties. Be true to the principles but don’t be rigid about the structures necessary to implement self-determination.

Self-determination can be implemented gradually, but it should be the long-term vision for the “way of doing business” in the system, not just another program option.

Expand leadership opportunities for self-advocates. Several distinct recommendations came out of the implementation analysis, including:

» Ensure self-advocate representation at all meetings where decisions about self-determination are being made.

» Support statewide self-advocacy councils (drawn from the various self-advocacy groups within that state) that can make recommendations on an ongoing basis.

» Hold meetings in accessible places.

» Support meaningful self-advocate participation by providing training and technical assistance.

» Provide transportation support so that self-advocates can attend meetings.
Continue to study the effects of self-determination on Direct Support Workers. Studying the direct support workforce was not a major focus of the demonstration projects, but it is critical to begin to explore these issues in greater depth. Conduct training on the principles of self-determination and promote “person-centered doing” as well as person-centered planning. Look at job design, salary, benefits, and retention issues and how they differ when services are delivered within a framework of self-determination.

Keep financial management and administrative strategies as simple as possible. These systems do not have to be overly complex in order to work and to be accessible to people who want to self-manage their services. A detailed analysis of financial management strategies is provided in the Appendix to help others learn from the demonstration activities.

Continue to develop fair and accurate methods of establishing individual spending amounts.

CMS should define clear policy guidelines on the use of waiver funds for self-determined services.

Bring management information systems up to speed by developing individual cost tracking and service utilization capabilities.

Separate support brokerage and administrative/case management functions.

Continue to examine how self-determination is being defined. If the power is shifting, is it moving toward self-advocates or to another player in the mix?

Continue to study how risk will be managed and distributed among different players, and develop new solutions and strategies to handle the shifting risks.
References


Appendix A: RWJ Project Evaluation Coding Form
1. Systems Level Questions:

**Overall Support for Self Determination:**

- To what level is the self determination effort supported by state level officials? Or is it more driven by local proponents (area agencies, county agencies…)? What indicators are there that state level officials are/are not supporting self-determination approaches?

- To what level is the self determination effort supported by self-advocates and family members? What is the overall level of awareness? What indicators are there that a constituency for self-determination approaches is/is not taking form?

- To what level is the self determination effort supported by service providers? What is the overall level of awareness? What indicators are there that providers are/are not supporting self determination approaches?

- Have there been issues raised related to staff unions? Explain...

**People Participating:**

- How many people are being served? Age range? Residential status? Level of disability?

- Of this number, what number are “slot conversions” or individuals who were receiving supports from a traditional dev disabilities provider (e.g., group home, sheltered work…)?

**Financing:**

- What has or is being done to assure that Medicaid financing will be effectively used to support the effort? New HCBS waiver? Amendments? Pending application or amendments? Ongoing negotiation with HCFA?

- What barriers have states faced in utilizing Medicaid?

- Have any new administrative layers been added as a result of the self-determination demonstration (e.g., fiscal intermediary, brokers)?

- If so, have other existing layers been modified as a result -- that is -- have existing layers been “downsized” reduced as a function of these new layers taking on duties?

- Or has the system simply added administrative functions (and cost)? If so, where has the financing for these layers come from?
Self Advocacy

- How have self-advocates been involved with setting policy or guiding practice for your state’s RWJ self-determination project? (Mark all that apply)

- They are not involved
- Self-advocates who represent self-advocacy organizations are members of our state and/or local advisory committees
- Individual self-advocates who are not representing a self-advocacy organization is under contract to our project to help us in various ways (e.g. produce materials, provide training, mentor other self-advocates)
- An individual self-advocate(s) is under contract to our project to help in various ways (e.g. produce materials, provide training, mentor other self-advocates)
- Other:

- What barriers have made it difficult for self-advocates to influence policy and practice related to the RWJ self-determination project?
- What actions have been taken or could be taken in the future to increase the participation of self-advocates in setting policy and practice related to the RWJ self-determination project?
- Regarding the RWJ self-determination project, rate how active and influential self-advocates have been in shaping the project’s policies and practice (Circle the number from 1-5 that best applies)
  
  not active/influential somewhat very active/influential
  1..................2..............3..............4......................5

- Since the RWJ project’s inception, the role played by self-advocates in shaping project policies has… (Circle the number from 1-5 that best applies)
  
  decreased significantly stayed the same increased significantly
  1..................2..............3..............4......................5

Advisory Councils

- Do you have an advisory council or project committee?
  
  __ (0) = NO, no council or committee (SKIP TO NEXT SECTION)
  __ (1) = Yes
• What proportion of your members are people with disabilities?
  ______%  
• What proportion of your members are families?
  ______%  
• How often does the group meet?
  Check one:
  ___ (1) = monthly  ___ (3) = semiannually
  ___ (2) = quarterly  ___ (4) = annually  
• Do participants receive any of the following types of compensation?
  Check all that apply:
  ___ Stipend  ___ Lodging  ___ Meals
  ___ Mileage  ___ Child care  ___ Other
• What is the substantive nature of the role played by the advisory council?
  Check all that apply:
  ___ Advises on training
  ___ Participates in evaluation
  ___ Assists in revising goals/objectives
  ___ Recommends state or local policy changes
  ___ Other
• What types of policy related decisions can the Council make?  
• What types of policy related decisions can’t the Council make?  
• What training to Council participants receive? Is it mandatory?  
• What challenges has the project faced related to the Council?  

Management Information Systems
• What limitations have been found, if any, related to existing management information systems related to administering a self-determination structure?  
• What information is required that is not presently being collected?  
• What is being / has been done to assure that needed information is being collected?  

Provider Market
• What have providers been doing to retool to participate in a self-determination system?
• Is training being routinely offered to provider staff or their boards? -- say as part of a “required” training regimen?

• Have or are providers considering or acting on developing “provider networks” or Managed Service Organizations?

• What innovative business opportunities have providers identified related to self-determination?

• Overall, how has the self-determination demonstration affected the provider market?

• Overall, are alternative providers (e.g., generic community providers, informal support givers) being more or less utilized within the self-determination demonstration? Explain…

• One crucial issue facing the field pertains to the lack of availability of direct support staff… What impact, if any, has the self-determination demonstration had on this issue -- tied to specific participants?

**Changes in control**

• Of the services and supports provided through the project, estimate the percentage of funds that are: (a) under the control of participants or (b) distributed directly to providers through contracts with state or county funders.

  (a) participants:_____%  (b) providers:_____%

  Last year’s data:

<table>
<thead>
<tr>
<th></th>
<th>Average % funds controlled by participants</th>
<th>Average % funds distributed directly to providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>At onset of project:</td>
<td>20% (N=15)</td>
<td>81% (N=18)</td>
</tr>
<tr>
<td>At end of year one:</td>
<td>41% (N=16)</td>
<td>65% (N=19)</td>
</tr>
</tbody>
</table>

**Marketing/PR**

• Have you conducted any of the following types of marketing and public awareness activities?

  Check all that apply:

  __ Articles in local media, including Arc newsletters   __ Brochures
  __ Presentations at "professional" meetings    __ Videos
  __ Presentations targeted to community audiences   __ Internet
  __ Letters to potential participants                 __ Other

  Last year’s data:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Presentations</td>
<td>32/38 (84.2%)</td>
<td></td>
</tr>
<tr>
<td>Articles</td>
<td>28/40 (70.0%)</td>
<td></td>
</tr>
<tr>
<td>Brochures</td>
<td>27/39 (69.2%)</td>
<td></td>
</tr>
</tbody>
</table>
Rating the Challenges faced by the projects...

- Last year we identified a series of challenges faced by the demonstrations. With a year more of work now completed, rate these challenges in terms of their present relevance to the demonstration: And Explain…

<table>
<thead>
<tr>
<th></th>
<th>No Problem</th>
<th>Great Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>o The short duration of some projects</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o Absence of a sense of urgency for change</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o A young and just emerging constituency</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o Difficult problems to resolve regarding the mechanics of self-determination</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o Tricky and uncertain financing</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o Day-to-day distractions associated with administering state systems</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o Competing local interests</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

2. Setting Person Centered Budgets

- Are individuals told the amount of money (a budget) allotted to them before they plan? After they plan? Not at all?

- How is a budget figure arrived at? Person by person negotiation based on stated needs? Historical rates? Assessment tied to tiered rates? Combination? Last years data…

  Use historical budget, adjust according to supports listed in plan. 23/29 (79.3%)
  Aggregate costs of supports listed in plan. 14/28 (50.0%)
  Two-tiered approach: start with base amount, add more if needed. 8/28 (28.6%)
  Use assessment measure to determine budget. 6/29 (20.7%)

- What is done to assure equity or fairness in budget setting across people?
• What is done, if anything, to establish risk reserves? Are budgets discounted before planning person by person? Is a flat rate set aside based on the overall aggregate budget?

• Are there concerns that these allocated budgets may be spent on supports that are not reimbursable by Medicaid? Does this concern influence how budgets are set?

• How are budget amounts “certified” as reasonable? And sufficient for meeting an individual’s needs? Does a “broker” make this certification? Case manager? How are the funder’s interests represented?

3. Participant Planning  (Thought of often in tandem with the budget setting process)

• How is the Plan of Support put together?

• Is a “planner” (i.e., broker) involved? What are this person’s responsibilities?

• Is the broker also a case manager? Who does the broker work for (provider agency, state/county agency, independent)? Can parents be brokers for their own children?

• How are conflict of interest issues managed?

• Are brokers expected to receive training? What is the nature of the training? Must they be certified?

• Is anything being done to establish a routine “way of doing things” for brokers? Are their standardized planning forms to complete? Other routine protocol?

• Are broker services Medicaid reimbursable? As a HCBS waiver service tied to the individual? As a targeted case management service?

• What differences, if any, are there between broker and case manager duties?. Are such duties specified ands on paper?

• What risk, if any, is carried by the broker?

• May the broker be housed within the same administrative structure as the Fiscal Intermediary?

4. The Fiscal Intermediary

• Are Fiscal intermediaries being used or are traditional third party reimbursement systems sufficient?

• If there is an FI… what is it’s structure?
  o For profit company or non profit?
  o What is it? (Last year’s data)

  ▪ Community org 10/13 (76.9%)
  ▪ Vendor created for project 3/13 (23.1%)
- Government agency 1/13 (7.7%)
- Microboards 0/13 (0%)
- Purchasing alliances 0/13 (0%)

- But what is it exactly? (CPA, employee leasing company, bank, payroll/fiscal agent company...)

- Is the FI considered the employer of record? Is it shared with the participant? Is the participant the sole employer of record?

- If there is an FI… what are it’s functions? (Here are last year’s findings)

  - Pay staff 13/14 (92.9%)
  - Pay employ taxes 13/14 (92.9%)
  - Reimburse provds 13/14 (92.9%)
  - File workers comp 8/11 (72.7%)
  - Liability insurance 6/11 (54.5%)
  - Hiring/firing staff 1/14 (7.1%)

  Others???? See below...

- More specifically, outside of using traditional providers.... who/what entity is responsible for the following employer related functions (the participant, the FI or some other?...

  - Obtain an Employer Identification Number
  - Complete an Immigration & Naturalization Service Form 9 (INS-9) on all workers to assure their eligibility to work in the United States
  - Keep proper records for each person employed
  - Pay workers appropriately (e.g., minimum wage, frequency of pay) & keep proper records
  - Observe Department of Labor wage requirements regarding minimum wage and overtime pay
  - Notify workers of eligibility for Earned Income Credit (use IRS form W-5 for eligibility)
  - Withhold Medicare and Social Security taxes (FICA) from worker’s pay, if required
  - Pay federal unemployment taxes (FUTA) from worker’s pay, if required
  - Withhold state income tax from worker’s pay, if required
  - Pay state unemployment taxes (SUTA) from worker’s pay, if required
  - Make federal tax deposits (IRS Schedule H annually)
  - Make state tax deposits quarterly or monthly (using appropriate state forms)
o (Optional) Withhold state/federal income taxes (based on worker’s IRS form W-4)

o Issue IRS form W-2 to all workers and submit it to the proper authorities by February 1 of the year following the work year. Also, submit IRS form W-3 to the SSA by March 1.

o Pay workers compensation insurance premiums for workers, if required

o Pay disability insurance premiums for workers, if required

o Keep all proper records on workers, the hours worked, their pay, reports made and tax payments

What risks does the FI carry if these duties are not performed?

5. Receiving Supports

- Are there any types of supports that are “off the menu?” Such as? What if… (probe)…
- What is done to assure that the final support plan is reasonable, sufficient and within budget?
- How are “unusual requests” managed?
- What level of control to individuals have over their allocated budgets?

6. Assuring Quality, Safety and Well Being

- What strategies are being used to assure that the health and well being of participants is assured?

- Have there been any significant undesired events involving participants. If so.. probe.

- How are existing QA practices able/unable to assure quality?

- Are there concerns over civil liability associated with the potential of injury or harm befalling a participant? What is being done to manage concerns over liability?

- What grievance mechanisms are provided to participants?

Check one:

__ (1) = governed by regular grievance process

__ (2) = process tailored to self-determination

__ (3) = no formal grievance process

__ (4) = other
Appendix B: Self-Advocate Interview Protocol
Questions For Self-Advocates To Ask Other Self-Advocates

Instructions:

• Call a friend on the telephone or make a time when you could talk in person.

• Explain to your friend why you are asking these questions. Tell her or him that you are going to meeting with self-advocates from 6 other states. You will be talking to everyone there about self-advocacy and self-determination.

• The purpose of the meeting is to find out what more can be done to help self-advocates have a say in self-determination. Before you go to the meeting you want to hear what her or his opinion on a few things.

• Explain that there are 10 questions that you want to ask. Say that you will be taking some notes so you can remember what she or he says.

• Ask if this is OK. If it is not, then you should thank your friend for their time, but you will have to ask someone else.

• If your friend says that it is OK, you can go ahead and ask the questions.

• Ask your friend these 10 questions one at a time.

• When they answer a question, take notes about their answers. Write what they say in the space under the question. This will help you remember what they said later. You may need to ask someone for help to do this.

• When you are done with a question, ask the next question. Keep going until you are finished with all the questions.

• When you are finished, thank your friend for helping.

• Remember -- you should talk to at least 5 people!
Questions For Self-Advocates To Ask Other Self-Advocates

_______________________   Your Name
_______________________   First Name of the Person You Are Talking To
_______________________   The Date

1. What does self-determination mean to you?

2. From what you know, how well is self-determination working in our state?

3. What is it about self-determination that is working the best?

4. What is it about self-determination that is not working?

5. If you could change one thing about how self-determination works in this state, what would you change and why?
6. If you could recommend something for other states to do the same as this state, what would that be and why?

7. How much have self-advocates been involved in deciding things about self-determination in our state?

8. What kinds of ways are self advocates involved in deciding things about self-determination in our state?

9. What must be done to make sure that self-advocates are involved in self-determination?

10. Is there anything else you’d like to tell me about self-determination or self-advocacy?
Appendix C: Detailed Results of Financial Management Study

This Appendix contains detailed findings from the financial management analysis. The purpose of this study was to describe and compare as best as possible the efficacy of traditional service procurement methods to the consumer managed/directed methods that emerged in conjunction with the self-determination initiatives that were unfolding in several states and localities. In other words, what ramifications do the use of consumer managed/directed methods have for procurement, including financial management arrangements and associated resource requirements? The focus of this analysis was financial management and not program management, case management, quality management, or other related areas.

The first part of this Appendix describes profiles of the seven states. The second part discusses findings and observations by state on the following topics: Fund Allocation, Individual Spending Authority, and Individual Budget; Rate/Price Setting; Billing, Payment and Tracking; Employee Administration; Management Information Systems; and Observations Concerning Resource Requirements.

State Profiles

Before launching into the analysis of procurement methods and issues in the demonstration states, we provide brief background information concerning each state’s self-determination initiative, relevant details about their HCBS Waiver Program, and basic information concerning each state’s overall service delivery and financial management architecture. For purposes of comparison, we define two categories of financial management activities as follows:

- **Procurement Architecture** describes the constellation of activities related to contracting for services, determining the amount to be paid for services and supports, and the related processes of billing, payment approval and making payments.

- **Provider Certification** refers to processes used to determining whether an agency or individual is qualified to render services and supports to individuals with developmental disabilities and thereby may furnish and be paid for services furnished to individuals.

There are similarities and differences among the seven states with respect to their service system architecture. Two states (Minnesota and Wisconsin) operate their systems through county government. Maryland and Utah operate what may be labeled as state-administered systems. Vermont and Kansas operate their systems through designated, largely non-governmental local entities. Michigan’s system operates
through designated local public entities that have been reformulated as managed care organizations.

1. Kansas

In Kansas, the Health Care Policy Office of Community Supports and Services, Department of Social and Rehabilitation Services administers services and supports for people with developmental disabilities. Locally, twenty-eight Community Developmental Disabilities Organizations (CDDOs) manage services across Kansas. CDDOs are both public (county) and private, non-profit entities. They are the single points of entry to the state’s developmental disabilities system. Kansas has adopted as its baseline eligibility criteria the broad-based definition of developmental disabilities spelled out in the federal Developmental Disabilities Act and Bill of Rights. Eligibility is determined by a CDDO using the child or adult versions of the Eligibility Determination Instrument (EDI) to determine whether individuals meet the functional criteria upon which the federal definition is based. A second-tier process is used to determine whether individuals who meet the state’s criteria also are eligible for the HCBS waiver program.

CDDOs were established in 1995 via the enactment of the Developmental Disabilities Reform Act. CDDOs manage state, federal and county funds for developmental disabilities services. CDDOs operate under contract with Health Care Policy. Their specific responsibilities include the provision of services (directly or via subcontract), eligibility determination, identification of available services and service providers, case management (directly or via subcontract) on request, local system planning, and new provider development.

Procurement Architecture

Kansas’s procurement architecture is structured in and around CDDOs as local managing entities. The state employs a “tiered” fund allocation system for its HCBS waiver program. CDDOs are responsible for managing the provision of services within their allocations. Services are furnished by CDDOs, other service organizations that have affiliation agreements with CDDOs or from other provider entities. Providers directly bill and are reimbursed by the state.

HCBS Waiver Program

Kansas has furnished HCB waiver services to people with developmental disabilities since the early 1980s. About ten years ago, Kansas split services for people with developmental disabilities out of an omnibus, multi-target population waiver program into a distinct program for people with developmental disabilities.

In 2000, 5,442 individuals participated in the HCBS waiver program. Relative to population (e.g., number of individuals who participate in the waiver program divided by state population), Kansas operated the 7th largest HCBS waiver program for people with developmental disabilities among all states (Smith 2001). In Kansas, 202 individuals per 100,000 in the general population participated in the HCBS
waiver program versus 103.7 individuals per 100,000 weighted average for all states.

In 2000, HCBS waiver expenditures totaled $169.4 million. Kansas HCBS waiver expenditures per participant during 2000 were $32,068, a little lower than the nationwide average of $34,891 (Smith 2001). Kansas furnishes HCB waiver services to children age five and older and adults with developmental disabilities. Services and supports are furnished to individuals (children and adults) who live with their families or in community living arrangements. Over the past decade, Kansas has reduced its utilization of ICF/MR services considerably, both through the community placement of persons from its public facilities as well as reducing the number of people served in large ICFs/MR operated by non-state organizations.

Through its HCBS waiver program, Kansas offers respite, habilitation (day and residential), supportive home care, supported family living, wellness monitoring (by registered nurses), home modifications, van lifts, communication devices, night support, and medical alert devices. In general, the present array of HCB waiver services and supports has been in place for several years. Kansas has made no special modifications to its HCBS waiver program to accommodate self-determination. The benefits available through the state’s program are flexibly defined and state officials have been willing to interpret the benefits broadly to accommodate consumer needs and preferences.

Consumers may opt to self-determine/direct HCB waiver services and supports or may appoint someone to manage the supports on their behalf, e.g. family members or another member of their circle of support. Specifically, they can request assistance in the following areas: recruitment and selection of staff, referring staff for payroll registration, pre-screening applicants, staff supervision, staff assignment and scheduling, staff evaluation, staff dismissal, arranging for back-up staff, maintaining records of work performed/time spent, and communication with a payroll agent. Consumers/families interested in and accepted for the demonstration usually are those for whom the traditional system would not work or is not working and who are looking for non-traditional services and supports.

**Provider Certification**

Health Care Policy Office of Community Supports and Services licenses providers of adult residential and day services. The Kansas Department of Health and Environment licenses out-of-home residential arrangements for children. Kansas provides for the certification of individual workers as HCBS waiver providers.

**Self-Determination Initiative**

The Kansas self-determination initiative built on the considerable efforts that already had taken place in the state to promote person-centered services and supports. During the 1990s, Kansas leaders emphasized creating a “person-centered culture”, including making heavy investments in systemwide essential lifestyles planning training and promoting consumer outcomes. The self-determination initiative gave Kansas the
opportunity to take the additional step of testing/implementing direct consumer management of services and supports.

Health Care Policy manages the overall Self-determination Project. There are five self-determination project sites. This analysis focuses on the original two sites: Topeka and Wichita. The Topeka ARC operates the Topeka project. There were 10 participants at the time of the site visit. COMCARE operates the Wichita project. There were 30 participants at the time of the site visit. The aim of these projects was to create an infrastructure and demonstrate a process by which persons with disabilities have the power to determine where and how the funds that they have been authorized are spent. Participants are to have a wide range of choices in terms of who provides their services and supports -- from traditional providers, to other business entities, to families and friends. Most project participants utilize HCBS Waiver funds and a few utilize state funds.

A regional project coordinator or manager oversees each project and works with the individual’s service coordinator1 and serves as a change agent for self-determination. As the projects unfolded, project managers devoted more and more of their time to seeking the administrative and regulatory system changes necessary to achieve the objectives of the self-determination project.

Persons enter the MR/DD System generally and the self-determination project through the CDDOs. The regional manager or staff member helps form a circle of support typically comprised of individual, family member/guardian, friends, service coordinator and staff. The circle meets and develops a life plan and budget.

2. Maryland

In Maryland, the Developmental Disabilities Administration (DDA – Maryland Department of Health and Mental Hygiene) is the state developmental disabilities authority. DDA manages both community and institutional services. There are DDA regional offices located around Maryland. Maryland’s community service system can be characterized as “state administered.” DDA also operates the state’s HCBS waiver program for people with developmental disabilities.

As its baseline eligibility criteria, Maryland employs the broad-based federal definition of developmental disabilities contained in the Developmental Disabilities Act and Bill of Rights as its first tier eligibility criteria. In the case of the HCBS waiver program, eligibility is limited to individuals who have mental retardation or a related condition and need more intensive services and supports. In order to receive services, an eligible individual also must fall into one of three priority service categories, based on urgency of need. Persons who do not fall into one of these categories are assigned to a “future need” registry and their situation is periodically reviewed. Persons who fall into one of three priority service categories are accreted to the “official” waiting list. Individuals who need comprehensive services are screened for eligibility for HCBS waiver services. Persons determined not to require comprehensive services instead may be offered

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1 Participants may choose not to have a service coordinator in which case any necessary case management duties fall to a circle of support.
state-funded Family and Individual Support Services (FISS). Via FISS, people who live with their families or independently are able to receive limited continuing or one-time services and supports.

Procurement Architecture

DDA contracts with licensed providers to furnish services to people with developmental disabilities in Maryland. DDA contracting must comport with Maryland state procurement rules and regulations. Those rules and regulations generally require that contracts be let through an RFP process and rebid periodically. At least historically, complying with state procurement rules has caused difficulties in Maryland in acquiring services and supports on as needed basis or from generic sources. Maryland's basic procurement architecture differs from the Medicaid procurement framework wherein there is open-ended certification of qualified providers and payments are based on the volume of services that each provides. The procurement architecture does not accommodate direct contracting with individual providers (e.g., personal assistants). Such individual providers must affiliate with licensed providers. Payments for “mainstream” community services (residential and day supports) are determined employing a payment determination method that includes factors related to the characteristics of individuals served by each agency. DDA has some latitude to enter into “innovative service” agreements to acquire services and supports. This capability was established as a result of the state’s participation in the Medicaid Community Supported Living Arrangements (CSLA) program in the early 1990s.

HCBS Waiver Program

Maryland has operated an HCBS waiver program for people with developmental disabilities since the early 1980s. Historically, Maryland's HCBS waiver program has served principally as a vehicle for acquiring federal Medicaid dollars to pay for a package of community residential and daytime services, including community services for persons re-entering the community from the state's public institutions. Maryland has confined the availability of ICF/MR services to its public institutions. In the community, provider-managed residential services mainly take the form of three-person "Alternative Living Units" (ALUs). CSLA services continue to be offered through the HCBS waiver program.

In 2000, about 5,000 persons participated in Maryland’s HCBS waiver program for people with developmental disabilities. Maryland ranked 29th among the states in terms of HCBS waiver utilization relative to state population (Smith 2001). The average per capita costs of HCBS waiver services in Maryland were $68,798, second highest among the states (Smith 2001). Maryland’s per capita costs historically have been among the highest nationwide because the HCBS waiver program has been used extensively to underwrite the community placement of individuals from large public facilities and because almost all participants receive out-of-home residential services.

Maryland’s HCBS waiver program offers case management services, residential and daytime habilitation services, environmental modifications, respite, intensive behavioral management, personal assistance, support services, emergency assistance, community
integration training, assistive technology and adaptive equipment. The bulk of case management services in Maryland are furnished via contract with The Arc of Frederick County, an independent service coordination entity that provides no direct services. Maryland’s HCBS waiver was modified in 1995 to enable continuation of services that were offered through the CSLA program. Maryland last renewed/modified its HCBS waiver program in 1998. Maryland has made no specific modifications to its federally-approved HCBS waiver program to accommodate self-determination.

Provider Certification

In order to furnish services to individuals, providers must be licensed. Another Department of Health and Mental Hygiene operations unit performs licensing. Only licensed providers may furnish HCB waiver services. Providers may furnish one or many services. DDA has been engaged in extensively revising the state's underlying service regulations to bring them into better alignment with essential person-centered principles and values. However, the combination of state procurement rules and licensing requirements often has made it difficult in Maryland to procure services from individuals or generic sources except through licensed provider organizations.

Self-Determination Initiative

Several factors propelled Maryland's self-determination initiative. One was the concern that Maryland might fold long-term services and supports for people with developmental disabilities into a managed health care plan. Self-determination was seen as offering a better alternative. In addition, Maryland leaders also regarded self-determination as an integral element of a broader system reform effort featuring: (1) support brokers replacing service coordinators; (2) individual budgets controlled by recipients instead of DDA-controlled contracts with providers; and, (3) the creation of Independent Resource Agencies to assist individuals in decision-making and in accessing natural and community supports. A key “selling point” for the initiative in the minds of state budget makers was the announced aim to save 10% or 15% of current service costs — savings that could be reprogrammed to serve people on the waiting list.

Maryland’s Self Determination Initiative (SDI) is a collaboration of DDA and the Arc of Frederick County. The initiative began in February of 1998 as a pilot project in two DDA regions, encompassing four counties: in Central Region, suburban Howard County; and in Western Region, rural Allegany County, suburban Washington County, and rural Garrett County. Three groups of consumers were originally targeted: people currently receiving services but wanting a change; people on the waiting list; and, youth transitioning from school to DDA services.

Not long after SDI began, Governor Glendening and the Maryland Legislature stepped forward to provide $118 million (over 5 years) to reduce the number of persons waiting for services in Maryland. DDA’s waiting list had climbed to over 5,000 individuals and thereby was one of the largest nationwide relative to state population size.

The waiting list initiative greatly affected how SDI unfolded in Maryland. DDA moved quickly to offer services and supports to individuals on the waiting list. In turn, this led to a substantial increase in The Arc of Frederick County’s service coordination workload at
the same time that SDI was ramping up. On a practical basis managing both initiatives at once led to Maryland’s concentrating on people who had been waiting for services rather than persons already receiving services who wanted to change. Managing the waiting list initiative also delayed the state’s pursuing some of its other SDI objectives.

3. Michigan

In Michigan, the Department of Community Health (DCH) manages services and supports for people with developmental disabilities. At the local level, services and supports are managed by Community Mental Health Services Programs (CMHSPs) that are responsible for serving individuals who have a mental illness, a developmental disability, or a substance abuse problem. CMHSPs are the single points of entry into Michigan’s system. CMHSPs serve single or multi-county catchment areas. Michigan serves fewer than 300 individuals in large public facilities. Technically, developmental disabilities services are a managed care “carve out” within Michigan’s Medicaid program. Medicaid eligible individuals access services via the CMHSPs that, in turn, determine whether the person is eligible for the services and supports provided in the “carve out.” CMHSPs must furnish essential services to all eligible persons.

**Procurement Architecture**

Michigan is unique among the states because it operates its developmental disabilities service system employing a managed care framework. In 1998, Michigan gained HCFA’s approval to operate what is termed a Section 1915(b)/Section 1915(c) combination waiver program. In broad brush, Michigan’s system now is structured for the state to make capitation payments to CMHSPs to furnish community services and supports to people with developmental disabilities. CMHSP responsibilities are spelled out contractually, including performance standards and benchmarks.

CMHSPs, in turn, are responsible for furnishing or arranging for services through providers in each CMHSP service provider network. CMHSPs determine rates/prices for services and pay for services out of the monthly capitation payments that they receive from the state. Individuals may freely select from among providers within each CMHSP service provider network.

**HCBS Waiver Program**

Under the Section 1915(b)/Section 1915(c) combination waiver, Michigan continues to operate an HCBS waiver program for people with developmental disabilities. The effect of the combination waiver that Michigan operates was to enable the state define a unitary package of benefits for all Medicaid beneficiaries with developmental disabilities, regardless of whether individuals participate in the HCBS waiver program. Prior to the combination waiver, Michigan made extensive use of other Medicaid funding streams (ICF/MR, personal care, clinic services and targeted case management) to underwrite community services and supports for people with developmental disabilities.

The combination waiver option enabled the state to pull together all its Medicaid funding into a single funding stream and furnish a unitary package of benefits rather than
structure the provision of Medicaid long-term services for people with developmental disabilities by Medicaid service category. For example, one outgrowth of the combination waiver was to remove the often artificial distinction between ICF/MR group home services and other types of residential services and supports. Michigan leaders sought to establish a Medicaid funding mechanism that would support person-centered services by enabling greater flexibility in how Medicaid dollars could be employed and, hence, align Medicaid funding to changes in state law that dictated systemwide adoption of person-centered practices. HCFA reviewed the operation of both Michigan waiver programs last year and has approved their continued operation.

**Provider Certification**

The state has retained responsibility for the certification and licensure of residential services. Generally speaking, CMHSPs are responsible for certifying and credentialing other providers. DCH oversees CMHSP performance, including CMHSP compliance with the terms and conditions of the performance contract.

**Self-determination Initiative**

Michigan received a full, three-year grant from RWJF for its self-determination project. An overarching goal of Michigan’s project was to “replicate” what was done in New Hampshire, with an urban focus rather than a rural one. The project was conducted across four local project sites: Allegan and Van Buren CMHSPs, Midland-Gladwin CMHSP, Washtenaw CMHSP, and Detroit-Wayne CMHSP (through a contract agency, Wayne Community Living Services – WCLS).

Like Maryland, Michigan was a participant in the CSLA program (specifically, Allegan, Midland-Gladwin, and Washtenaw counties were CSLA sites). The CSLA experience, together with earlier legislative mandates around supported living and person-centered supports and pioneering family-directed family supports and respite care options, provided a strong foundation for the self-determination initiative. The implementation of managed care through the redesigned combination waiver is the central system change that has allowed the self-determination demonstrations to progress and expand to other areas of the state.

4. **Minnesota**

The Minnesota Department of Human Services administers the state’s system of services for people with mental retardation and related conditions. The Department’s Division of Community Supports for Minnesotans with Disabilities administers the state ICF/MR, HCBS waiver program and most other services for persons with developmental disabilities. In Minnesota, county government plays a central role in administering the provision of human services, including services and supports for people with developmental disabilities. County human services agencies serve as single points of entry into the service system and are responsible for intake, eligibility determination, and service authorization. Minnesota counties are “agents” of the state for the purpose
of administering Medicaid services. This means that counties determine eligibility and contract with providers for services.

**Procurement Architecture**

With respect to HCBS waiver services, counties have the status of “agents of the state” and thereby have the authority to contract with providers and set most payment rates within state limits.

Minnesota uses a supplemental grant agreement that designates counties as the state’s fiscal agents for the purposes of governing the allocation and expenditure of HCBS waiver dollars for people with developmental disabilities. Each year the Counties prepare plans and component grant applications as required by the state’s Community Social Services Act, including the HCBS waiver program. The plans include program goals and outcome indicators, eligibility policies and service fee schedules to be used by the County, and a description of the quality assurance activities that counties are undertaking with respect to the HCBS waiver program.

**HCBS Waiver Program**

Minnesota’s HCBS waiver program for people with developmental disabilities has been in operation since the early 1980s. It furnishes services to persons with mental retardation and other related conditions. In 2000, 7,948 individuals participated in the program, making Minnesota’s program the 13th largest among the states relative to state population (Smith 2001). In 2000, Minnesota furnished HCBS waiver services to 161.1 persons per 100,000 or about 56.3% greater than the all states weighted average. Total expenditures were $408 million and per capita outlays were $54,429, 7th highest among all states (Smith 2001). At one time, Minnesota had a very large ICF/MR service sector. Over the past eight years, ICF/MR utilization in Minnesota has declined by 45%, as a result of the termination of services in large state-run facilities and additional reductions in the use of non-state ICFs/MR.

The HCBS waiver program for people with mental retardation and related conditions is but one of many programs available to support people with severe disabilities in Minnesota. Minnesota’s Medicaid program includes a broad-based personal assistance benefit. There also are extensive other state and county-funded benefits available to individuals and families, including cash grants for families.

Minnesota’s HCBS waiver program for persons with mental retardation and related conditions offers the following services and supports: case management, homemaker, respite, habilitation services (including supported employment), environmental accessibility adaptations, crisis respite, 24-hour emergency assistance, specialist services, caregiver training and education, adult day care, housing access coordination, assistive technology and personal support.

In 1997, Minnesota submitted and HCFA approved an amendment to the HCBS waiver program to add chore services, “consumer-directed community supports”, transportation, extended personal care assistant, live-in caregiver and consumer
education and training. The addition of consumer-directed community supports along with consumer education and training was the direct outgrowth of Minnesota’s self-determination initiative. The amendment also contained several changes to make the state’s program more flexible, including permitting family members/relatives to furnish certain services, relaxing various regulatory constraints and boosting the maximum allowable amounts that could be spent on certain services. The role that the consumer-directed community supports HCBS waiver coverage/benefit plays in Minnesota will be discussed in more detail below. The majority of individuals who participate in the HCBS waiver program are persons who no longer live with their families.

**Provider Certification**

Minnesota has especially extensive rules and regulations governing the licensure and certification of provider agencies. Provider requirements are spelled out in detail in state law and DHS regulations. However, licensing and certification rules do not prevent contracting with individuals as providers of services.

**Self-determination Initiative**

Three Minnesota counties served as RWJ demonstration sites: Dakota, Olmsted, and Blue Earth. All three counties shared the objective of serving all persons with developmental disabilities using a self-determination model. At the time of the site visits, Dakota was farthest along in ramping up self-determination. In terms of the overall number of people receiving services, Dakota also served the most individuals.

The Minnesota self-determination initiative for people with developmental disabilities is but one of several steps the state is taking to promote consumer-managed/directed services. For example, the state also launched a Community Support Grant program to enable people with disabilities to manage directly home care and personal assistance funds.

5. Utah

The Division of Services for People with Disabilities (DSPD – Utah Department of Human Services) is the state developmental disabilities authority. DSPD also administers services for persons with non-developmental disabilities, including individuals who have had a head injury or who have severe physical disabilities. DSPD personnel out stationed in regional offices furnish service coordination. Regional offices also manage regional budget allocations and conduct ongoing monitoring of services. Utah’s service system is state-administered and managed. There is one large public facility – the Utah State Developmental Center at American Forks where 236 individuals were served in June 2000. Approximately another 520 persons are served in larger ICFs/MR operated by non-state entities.

There is a three-tiered eligibility structure for DSPD services. Utah follows the federal definition of developmental disabilities contained in the Developmental Disabilities Act and Bill of Rights except that Utah does not limit eligibility by age of onset. This reflects DSPD’s broader charge to serve people with non-developmental disabilities. With
respect to people with developmental disabilities, Utah operationalizes the federal
definition by limiting eligibility to persons who have an IQ of 70 or less and a score of 70
or less employing the Inventory for Client and Agency Planning (ICAP) tool to determine
overall functional limitations. Lastly, in order to obtain HCB waiver (or ICF/MR) services,
an individual must meet federal requirements with respect to having mental retardation
or a related condition.

Intake and eligibility determination occur at the DSPD regional offices. At the regional
offices, individuals also go through what is termed a “Critical Needs Assessment” (CNA)
assessment process. The CNA process is geared to determining extent/urgency of
need and yields a score. One role the CNA process plays is to prioritize people who are
waiting for services. Another role it plays is in determining dollar allocations for people
who live with their families (discussed in more detail below).

**Procurement Architecture**

DSPD contracts for, determines rates or sets prices for community services and
supports for people with developmental disabilities. DSPD contractors also have a
provider agreement with the single state Medicaid agency. In the case of group living
arrangements, a level of care payment structure has been in use for several years.
Providers transact with DSPD, which serves as conduit for claims for HCBS waiver
services. With self-determination, various changes have been taking place in the state’s
procurement architecture that will be described in more detail below.

**HCBS Waiver Program**

Utah’s HCBS waiver program has been in operation since the 1980s. In 2000, 3,152
people participated in Utah’s program. Utah’s program is the 20th largest among all
states relative to state population. In Utah, HCBS waiver services were furnished to
140.2 persons per 100,000 in the population or 36.0% greater than the all states
weighted averaged (Smith 2001). Outlays for HCB waiver services were $74.3 million in
2000 or $24,730 per full year participant. Utah’s costs per participant are about 29%
below the all states weighted average, due in part to the fact that Utah has employed its
HCBS waiver program more extensively than most states to pay for family support
services.

Utah’s HCBS waiver program offers support coordination, community living, personal
assistance, personal emergency response system, environmental accessibility
adaptations, chore and homemaker, supported employment, site and non-site based
day supports, senior supports, “latch key” services, family assistance and support,
respite, self-directed supports, educational, assistive technology, specialized medical
equipment and supplies, and specialized supports. In 1999, the state extensively
revised its HCBS waiver program to broaden and make more flexible services and
supports available to people with developmental disabilities. The 1999 waiver
amendment included a clear statement of the state’s person-centered service
philosophy. Some of the changes also were related to the state’s self-determination
initiative. In 2000, the state submitted its application to renew its program. In June 2000,
HCFA approved the renewal. The renewal carried forward the 1999 changes.
**Provider Certification**

For the HCBS waiver program, DSPD conducts provider certification activities. For many years, DSPD has followed an approach to provider certification that emphasizes valued outcomes for people with developmental disabilities. DSPD also makes available to consumers and families information about provider performance. Utah provides the certification of individuals as providers of various services, including personal assistance.

**Self-Determination Initiative**

Utah’s self-determination initiative was one of the few predicated on achieving system change statewide. Utah did not follow a site-based, demonstration approach. In Utah, DSPD established a foundation for self-determination by having adopted person-centered planning methods systemwide well in advance of the initiative. In addition, the state’s family support program already incorporated consumer managed/directed features (including the use of a financial intermediary). As a consequence, Utah leaders regarded self-determination as a way to further advance an already person-centered approach to supporting individuals in the community, including supporting individuals in being better able to pursue their personal vision. DSPD staff in collaboration with the regions has managed the self-determination initiative.

At the beginning of the demonstration, implementation of self-determination revolved around families who support a person with a developmental disability. Starting last year, efforts to commenced to extend self-determination to adults who no longer lived with their families. Utah also has taken various steps with respect to funding to create a solid foundation for self-determination.

6. **Vermont**

In Vermont, the Division of Developmental Services (DDS) in the Vermont Department of Developmental and Mental Health Services manages services for people with developmental disabilities. Locally, there is a Designated Agency (DA) for each geographic region. The DAs are responsible for ensuring that needed services are available through local planning, service coordination, and monitoring outcomes. DAs also serve as the single points of entry to the service system. Vermont does not operate a public institution.

**Procurement Architecture**

Services are contracted through Vermont’s DAs and what are termed Specialized Service Agencies (SSAs). DAs and SSAs may furnish services if they are certified providers. Other organizations certified by DDS also may furnish services via contract or subcontract with a DA or SSA. Individual providers must work for a certified provider or under the auspices of a certified provider. DDS allocates state dollars to DAs. Claims for Medicaid payment are made in order to obtain federal funds.
**HCBS Waiver Program**

Vermont’s HCBS waiver program for people with developmental disabilities has been in operation since the early 1980s. In 2000, 1,684 Vermonters with developmental disabilities participated in the program. Vermont’s program was the 2nd largest among all states relative to state population (Smith 2001). HCBS waiver spending was $60.0 million in 2000 or $37,230 per full year participant, slightly above the all states weighted average. Vermont provides only very limited ICF/MR services. Almost all people in the community participate in the HCBS waiver program.

Vermont’s HCBS waiver program offers three services: (a) service coordination; (b) supported employment; and, (c) “flexible support plan”. The flexible support plan is defined as:

“The service or array of services determined and documented through a planning process, including a services coordinator or designee, necessary to help an individual with developmental disabilities and his/her family, if applicable, avoid institutional level of care the person. Includes provision of assistance and resources to individuals with developmental disabilities and their families in order to improve and maintain the individual’s opportunities and experiences in living, working, socializing, recreating, education and personal growth, safety and health in the communities where they live. Includes such services as home supports, family supports, community/social supports, crisis supports, etc. Transportation, therapies, environmental modifications, adaptive equipment, etc. are provided as component parts of the flexible support plan. The costs of these components are included in the rate paid to providers for the flexible support plan.”

This coverage permits customizing services and supports to each individual. Vermont’s service system is especially noteworthy because it stresses very small living arrangements and the state has an especially strong track record in securing integrated employment for people with developmental disabilities.

**Provider Certification**

Providers are certified by DDS employing a uniform set of standards. Any service provided must be under the auspices of a certified provider, even if an individual is self-managing his or her services. A certified agency is responsible to the state for the proper use of funds. The certified agencies must ensure that Medicaid regulations are followed and must report to the MCIS (managed care information system). Non-certified agencies contract with certified agencies.

**Self-Determination Initiative**

Vermont’s self-determination initiative is statewide in scope. Vermont’s aim is make self-determination available to all individuals who wish to direct their own services. Through the initiative, Vermont is supporting people and families in this endeavor, including contracting with an organization (Alpha One) to serve as fiscal intermediary. Vermont’s
self-determination initiative in many respects simply is the continuation of the state’s long-established policy direction to promote person-centered supports.

The Vermont initiative took a unique approach of creating four Regional Facilitation Teams, each one composed of a consumer, a family member, and a provider. The teams are responsible for responding to referrals from individuals, families, or agencies interested in self-determination. Unlike other states, Vermont did not specify a target number of participants in its grant application. The project received full, three-year funding from RWJF and is open to everyone.

7. Wisconsin

In Wisconsin, services and supports for people with developmental disabilities principally are managed by the Bureau of Developmental Disabilities, Division of Supported Living, Wisconsin Department of Health and Family Services. The Bureau administers the state’s HCBS waiver programs for people with developmental disabilities and persons who have had a brain injury along with family support and other services and supports. Like Minnesota, at the local level, services for people with developmental disabilities are managed by county human services agencies. Wisconsin counties are legally recognized agents of the state for the purpose of determining eligibility for Medicaid services and contracting for services. The State of Wisconsin operates three large public ICF/MR facilities. There also are several large ICFs/MR operated by non-state organizations. However, utilization of ICF/MR services has declined considerably in Wisconsin over the past several years.

Counties conduct intake and eligibility determination for Medicaid and other state-funded services. Wisconsin has adopted the federal definition of developmental disabilities contained in the Developmental Disabilities Act and Bill of Rights. By state law, traumatic brain injury has been deemed a developmental disability. Against the backdrop of the state’s relatively broad eligibility criteria, eligibility for Medicaid ICF/MR services and the HCBS waiver program is based on somewhat narrower level of care criteria as dictated by federal law and regulations.

**Procurement Architecture**

Wisconsin manages its HCBS waiver program by allocating dollars and waiver “slots” to counties. Counties contract with provider organizations to provide services through the HCBS waiver program. The state itself does not set rates/prices for HCBS waiver services. Counties determine rates within the limits of overall state dollar allocations.

Providers bill and are paid for services by the counties. The counties then move claims forward to the state for Medicaid processing. This type of arrangement is relatively standard in county-administered service systems.

**HCBS Waiver Program**

Wisconsin has operated HCBS waiver program(s) for individuals with developmental disabilities since the early 1980s. In 2000, 9,547 individuals participated in these
programs. Relative to state population, Wisconsin ranked 10th with respect to the size of its HCBS waiver program (Smith 2001). Also in 2000, the state expended $273.0 million for HCB waiver services for people with developmental disabilities or $30,466 per full year participant, an amount slightly below the all states weighted average.

The services offered under Wisconsin’s HCBS waiver program for people with developmental disabilities include the full gamut of residential, day, employment and other services. In 1998, following Minnesota’s lead, Wisconsin amended its HCBS waiver program to include the coverage of “consumer-directed supports” in order to build self-determination into its HCBS waiver program. However, the state limited the availability of this benefit to counties that executed a Memorandum of Understanding with the Department. Under the terms of the MOU, a county had to demonstrate various capacities to assist people with developmental disabilities to direct and manage their own supports. This approach is regarded as overly burdensome and state officials are seriously considering modifying it.

As is the case in Minnesota, Wisconsin also furnishes relatively robust personal assistance/personal care benefits via its Medicaid program. There are other state and local programs/services also available to children and adults with developmental disabilities. In Wisconsin, counties play a large role in funding services for people with developmental disabilities. Many counties earmark additional local tax dollars over and above local matching requirements to supplement state funding.

**Provider Certification**

The state of Wisconsin licenses and certifies various types of residential services settings. Certification of other types of services/providers has been devolved upon the counties, which ensure that basic state minimums are met.

**Self-Determination Initiative**

Wisconsin’s self-determination initiative revolved around three demonstration counties (Dane, Lacrosse and Winnebago) but also involved additional, non-demonstration “guerilla” counties as well. Winnebago County set the objective of having all the individuals it supports participate in its project. In Dane County, self-determination targeted individuals new to services or persons who expressed an interest in directing their own supports. In May 2000, about 300 adults were directing their own services and supports.

The self-determination initiative has unfolded against the backdrop of Wisconsin’s longstanding and widely recognized efforts to establish a person-centered culture system wide. Part of the impetus for self-determination was the state’s positive experience in participating in the Community Supported Living Arrangements (CSLA) program during the early 1990s. Participation in the CSLA program sparked stakeholders to think “more outside the box” in how they supported people with developmental disabilities. Self-determination furnished a coherent framework to take
person-centered supports a step further to embrace consumer-managed/directed supports.

Findings and Observations

This section examines the experiences of states and local sites in designing and implementing various aspects of consumer-managed/directed procurement methods.

Fund Allocation, Individual Spending Authority and Individual Budget

A central feature of self-determination is that each individual has an amount of dollars over which the person and his/her allies (circle of support) have decision-making authority. With individual spending authority, the person/circle/family is in a position to make decisions about applying dollars in a fashion that best meets his/her needs and preferences. These decisions are translated into an individual budget/plan that records the services and supports the person intends to purchase and furnishes a framework for ongoing management of the budget. The individual budget also serves as a device that enables funders to interconnect billings/payments to the services and supports that have been authorized in each person’s budget/plan.

The challenge this dimension of self-determination poses for states and local authorities is to development methods for assigning dollars to establish the individual spending authority. Provider-direct procurement methods are specific to particular services/service agencies. They are not individually centered. Self-determination demands decoupling dollars from specific service categories so that individuals have maximum flexibility in managing their own resources. Determining the dollar amount that is assigned to an individual independent of the services the person receives requires that funders reframe procurement around consumers instead of providers/program category/service type.

Another challenge arises as a result of the very nature of the individual spending authority. In broad brush, when payments are tied to providers/services, providers usually have the latitude to manage dollars across all the individuals they serve. When dollars are allocated directly to individuals and are under their control, it is less obvious how to balance resources and needs. This causes the need to consider employing devices such as “risk reserves” to create a funding safety net in the event that the circumstances of individual services change. As will be seen, creating such risk reserves is a relatively common practice.

In developing strategies for determining individual spending authority amounts, funders necessarily must be concerned with assuring equity and fairness across all consumers, including current and future consumers. Funders obviously also must be concerned with the adequacy of the individual spending authority. Amounts that are too low will defeat the aims of self-determination. Amounts that are too high lead to other consequences, including encumbering dollars that might be devoted to other objectives (e.g., reducing waiting lists).
Each of the states and localities has adopted somewhat different approaches to addressing the question of determining the amount of the individual spending authority. Beyond determining the amount, funders have developed different approaches to managing dollars overall across all persons who have individual budgets (i.e., how unspent dollars are treated and the use of risk reserves to address changed circumstances). Determining the amount of the individual spending authority is complex in its own right. But there also is considerable complexity in managing dollars across large numbers of consumers who are managing their own budgets.

1. Kansas

Predating self-determination, Kansas developed the Tier System\(^2\) for making fund allocations to CDDOs for individuals. The Tier System provides for five levels of payment corresponding to the functional assessment scores of individuals derived from the administration of the Developmental Disabilities Profile (DDP), an instrument developed by the New York Office of Mental Retardation and Developmental Disabilities. The Tier System was implemented in Kansas to assure equitable funding across all CDDOs based on observable differences (measured by the DDP) among the persons served by each CDDO. The DDP is administered at intake and then yearly thereafter. DDP scores result in the person’s assignment to funding tier(s). There are tier rates for residential and day services and tier rates for being developed for supportive home care. These amounts serve as a dollar limit on the amount that will be paid for services under the HCBS waiver program. The amounts are not based on an individual’s receiving a specific modality of day or residential services.

In self-determination, the tier amounts also serve as the individual budget authority. Consequently, the Kansas strategy is to equalize dollars between persons not involved in self-determination and those who are. As a rule, the individual and his/her circle of support must make the amount available work. The paramount issue with any arrangement is the individual’s health and safety. An analysis of participant expenditures at TARC to-date shows that 88% of the dollars are used to purchase personal attendant services. In the case of individuals eligible only for limited state funds, a high percentage are able to fund participation in other community activities, e.g. art classes, health club memberships.

The practice has been adopted in Kansas of reducing the tier dollar amount by 10% in order to fund a risk reserve. This risk reserve enables meeting unforeseen needs that might arise over the course of the year for any of the individuals participating in self-determination project. Every six months, a CPA contracted by TARC reconciles individual funds and expenditures. Unspent funds may be retained in the person’s individual account so long as they are earmarked for a specific purpose, e.g. contingency funds for emergency staffing or the purchase of adaptive equipment. These unspent dollars constitute a type of individual risk reserve.

\(^2\) Persons not eligible for Waiver funds, are covered using state grant funds at a rate of $26.32 per day.
The Kansas approach to setting the individual spending authority assures that people who participate in self-determination have access to the same amount of dollars as individuals who do not participate. The tier system itself is a mechanism for setting an individual funding amount and, consequently, could be adapted readily for purposes of self-determination.

However, there are concerns in Kansas about the use of the tier system for self-determination. When individuals are served in the “mainstream,” provider-based system, changes in a person’s tier assignment (and therefore funding level) can be balanced across all individuals served by the provider. Changes in funding up or down do not necessarily result in abrupt changes in the services that people receive. With self-determination, changes in funding (e.g., a decrease) have direct consequences for the person and cannot be balanced among all self-determination participants, except possibly through the risk reserve device.

2. Maryland

Maryland has not developed a distinct methodology for determining the individual spending authority. There is not a funding/allocation method in Maryland that is akin to the Kansas Tier system.

Fund allocations in Maryland are budget/initiative based and relate to different purposes and target populations. The DDA Central Office defines the criteria to be used by the regional offices in allocating these funds and the procedures for managing them. The Regional Offices prepare corresponding spending plans. There are four main pools of dollars: (a) dollars tied to the Waiting List initiative; (b) funds set aside for resolving individual and family crises; (c) the transitioning youth initiative; and, (d) dollars to facilitate the community placement of individuals from state-run facilities to the community.

The determination of the individual spending authority in Maryland revolves around the preparation of a person-centered plan within the broad parameters of regional budget management. Maryland’s contracting and procurement requirements dictate seeking out provider agencies that will offer to implement the person-centered plan and entail negotiating with such agencies over the cost of implementing the plan. The challenge for the Regional Offices presently—and possibly for the resource agencies in the future—is making sure that the total amounts in the individual spending plans don’t exceed the amounts allocated. This requires reconciling the individual spending (funding) plans with the total amounts available in each allocation given the various criteria associated with the use of each of the funds.

Resource coordinators help consumers and families locate appropriate services and possible providers. One or more of the providers selected by the consumers and families then are asked to submit a support plan specifying the services and supports to be provided, their rationale and cost to the regional office.

The individual budgeting/spending authorization processes in the Central and Western Regions differ somewhat. In Central Region, the Service Coordinator reviews the
budget and sends it with comments in a cover memo to the Regional Office for review. The Community Services Team, comprised of members of the program units in the Region Office assesses and passes on the cost-effectiveness and appropriateness of the plan.

Resource coordinators have budget negotiation responsibility as well. Providers send their proposed budgets to the coordinator who then negotiates with providers. Consumers and families are shown all the proposed support plans offered by providers, but without an attached budget so that decisions are not made based on money.

Both the DDA Western and Central regional offices, as part of the demonstration, were directed to transfer their responsibilities for individual budgeting and negotiating provider budgets to resource coordinators within the resource agencies established under the auspices of The Arc of Frederick County in the four pilot counties. Budget negotiation still rests largely with the regions, even in the Pilot sites--more specifically, with specialists in each of the program areas who are liaisons with the provider agencies. At present, the job of these specialists is to help resource coordinators understand what services and supports are allowable within each funding category, what prices are reasonable and what are not. The plan is to shift even more budgeting responsibility to resource coordinators.

Ultimately, Maryland’s aim is to establish a network of local resource agencies responsible not only for individual planning and budgeting but for area-wide planning and administration of DDA funding in their area. The agencies will house resource coordinators who will assist individuals and their families in designing and purchasing services and supports. The agencies will not be service providers. The majority of members of each Board of Directors are to be people with disabilities and family members. Because of the structural activity in the pilot counties, emphasis has been placed on assisting individuals in converting from traditional services to customized supports; 120 individuals are actively involved in this process in the pilot counties.

A number of administrative, legal and political constraints have slowed this transition and for the time being have stalled efforts to establish the resource agencies as originally conceived:

- Administratively, the sharp increase in the numbers of individuals served as a result of the Waiting List initiative escalated regional office and service coordinator workloads. It has been a challenge to mesh individually centered plans and budgets with the labyrinth of "categorical" funding rules and regulations. Not only must provider budgets continue to be established and amended and corresponding expenditures tracked and controlled as always, but individual budgets must now be established and amended and corresponding expenditures tracked and controlled. Several regional staff commented on the limited negotiating knowledge and know-how of service coordinators in the budgeting arena and the difficulties in making the time to prepare service coordinators to negotiate budget amounts -- most particularly concerning the maze of rules and regulations that constrain the different funding streams and the knowledge of the programs, operations and related costs of the different
providers with whom they are expected to negotiate.

♦ Service coordinator vacancies and turnover have further hindered the planned transfer of responsibilities to service coordinators. With caseloads that have risen as high as 85, coordinators have had hardly enough time to get to know the individuals served, let alone the providers serving them.

♦ Politically, state policy-makers and administrators are hesitant to decentralize decisions concerning spending authority entirely. DDA funds are limited; insuring that their distribution is fair and equitable is an important concern. There is also the concern over whether private non-profit entities are capable of managing the funds.

♦ DDA does not have the legal authority, state or federal, to vest separate agencies with spending authority. This poses significant problems in decentralizing resource management.

As self-determination has unfolded in Maryland, it has brought to the fore some of the difficulties that states face in shifting from provider-direct to consumer-managed/directed procurement methods. In Maryland, procurement is tied to DDA-certified agencies/providers. Hence, individual budgets ultimately entail negotiation with provider organizations that are willing to submit budget proposals. Resource coordinators and regional office staff are thrust into the midst of the individual budgeting process and triggers considerable back-and-forth among all parties along several fronts. As a consequence, preparing an individual budget is complicated by Maryland’s procurement rules and contracting policies. This problem is well-understood by Maryland officials. Disentangling this situation will depend in large part on the extent to which the local resource agencies can be ramped up and whether they will have greater flexibility in procurement.

3. Michigan

WCLS had contracts with four fiscal intermediaries at the time of the interview. Two were local Arcs and two were “traditional” providers who branched out to offer “staffing agent” services. Individual budget plans are facilitated by the support coordinator. The historical amount is used as a base, but the budget is determined around the person’s needs. Consumers/families are told the base amount if they ask. All budgets must be approved by the finance department. If the amount is at or under the historical budget, it is automatically approved. If the amount is above the historical budget, a “self-determination lab” is conducted. This process involves bringing people together to review the costs and brainstorm about creative ways to save money. If the lab exhausts all ideas and the budget is still over, the amount stands. Washtenaw County started with individuals who already had in-home support budgets as part of the CSLA project. In Allegan county, budgets are set by pre-authorizing 75% of current costs as the target amount. All budgets must be approved by the Project Director.

4. Minnesota
In Minnesota, the self-determination demonstration counties have developed their own approaches to setting the individual budget authority amounts within the broad framework of how the state allocates dollars to the counties. The State of Minnesota itself has not dictated the precise method that a county must follow in determining the individual budget authority.

The state has taken various steps to rationalize the allocation of HCBS waiver dollars to the counties. Over the years, different allocations had been made based on particular initiatives or circumstances. In the mid-1990s, the state started down the path of seeking to equalize dollar allocations. For persons participating in the waiver program in 1995, a blended rate was developed based on actual service utilization and costs. In addition, a set of four rates for people new to services was developed based on extensive research. These rates differentiate among four groups of consumers on the basis of functional and behavioral characteristics statistically related to level of service need. As more and more individuals enter the waiver program over time, fund allocations will become more equalized across counties and consumers.

Minnesota’s 1997 HCBS waiver amendment to incorporate self-determination into its program also has facilitated counties in operationalizing self-determination. In essence, under the amendment and its implementing procedures, counties are able to bill to the state the total amount expended on behalf of each person in a month for authorized/approved services actually received (under the consumer-directed supports waiver category) rather than billing on a service-by-service by service basis. This enables counties to tie claims for and receipts of state reimbursements to each person’s individual budget authority rather than having to reconcile service-by-service. Since the counties maintain the requisite documentation of services delivered and paid locally, accountability for Medicaid dollars is assured.

Counties are authorized to furnish consumer-directed community support services when they execute a Memorandum of Understanding with the Department. In practice, the HCBS waiver “consumer-directed community supports” benefit is an umbrella service category that includes chore services, consumer training and education services, extended personal care attendant services, live-in personal caregiver expenses, respite and transportation and related services and supports that represent a cost effective alternative to institutionalization.

Within the broad framework of how the state allocates dollars to counties, the three demonstrate site counties are employing roughly similar approaches to setting individual spending authorizations. Authorization amounts are based on whether the individual is presently receiving services or is new to the service system. As an aside, the state permits a county to set aside 5% of total dollars to establish a risk pool. However, the dollars in the risk pool cannot carry over from year to year.

In the case of people currently receiving services, Dakota, Olmsted and Blue Earth use historical costs as the basis of the individual spending authorization. As a rule, Dakota and Blue Earth counties authorize spending at 100% of current spending but Olmsted is authorizing at 90% of current service costs. Olmsted puts 5% of current funding into a risk pool for unplanned needs and the other 5% aside to reduce its waiting list.
Each county uses an “allocation tool” to set a beginning individual spending authority to start off the service and support planning for each individual new to the system. The budget amount may change in the course of the planning. Different levels of review and approval are required depending if and by how much the amended budget exceeds the beginning budget amount.

In Dakota County, the first to develop an allocation tool, everyone eligible for services and supports receives a “general needs grant” or floor amount that increases with age. The amounts are: $3,000 for children under age 18; $6,000 for youth ages 18-22 in transition; and, $16,000 for adults over age 22. Additional funds are added as a function of various levels of supervision needs and whether the individual lives in or out of the family home.

The Olmsted County allocation tool for individuals new to services is based on an analysis of the costs of supporting individuals in different categories for different styles of support, functional level and natural supports. As in Dakota County, all individuals receive a floor amount. Floor amounts vary by age and whether the person lives with their family or not. About 75% of individuals receive individual spending authority amounts based on a standard funding matrix. In the case of the remaining 25%, amounts are determined on an exception basis as an outgrowth of the individual planning process.

Blue Earth County also uses an allocation tool to arrive at a beginning budget for everyone except children living at home. In the case of children, there is no fixed beginning budget amount. Blue Earth officials are comfortable with this approach because needs tend to be low cost but not very predictable since they are heavily dependent on family situations.

For others, budgets are expected to fall within what the typical residential service would cost for an individual with comparable supervision needs. There are four levels of need (supervision): 1) person needs less than four hours of supervision; 2) person needs more than four hours of supervision but no overnight supervision or care; 3) person can be independent only a few hours each day; and, 4) person needs support around the clock. In the case of the final group, additional dollars may be budgeted to address special medical, mobility, communication and behavior needs.

In all the counties individual plans and expenditure plans (budgets) are prepared by the individuals, family members, county case managers, and others invited participants. The counties continue to hone these protocols for identifying service and support variations pursuant to plan objectives through experience and training. Participants are made aware of the allocated amounts at the start of the planning process.

In summary, the Minnesota counties base the determination of individual spending authority amounts for self-determination participants on: (a) the amount presently expended on the person’s behalf if the person already is receiving services or (b) an allocation tool that is employed in the case of people new services with the allocation
tool itself more or less based on spending patterns for like individuals already receiving services.

5. Utah

In some important respects, there are marked similarities between Utah and Kansas with respect to setting the individual spending authority amount. Dating back several years, funding for community services in Utah has been tier/level-based. For example, payments for group home services in Utah were tied historically to consumer functioning level as measured by the ICAP instrument. Self-determination has prompted DSPD officials to accelerate and better articulate a tier-based approach to funding that assures equitable dollar allocations across all persons receiving services and thereby also serves as a ready basis for establishing individual spending authority amounts for persons who opt for self-determination. The Utah approach assures equitable funding between persons who receive provider-managed services and individuals who decide to direct/manage their own services.

In particular, DSPD has developed an Authorized Spending Limit (ASL) matrix. This matrix has five funding tiers. For each tier, distinct ASLs have been established for: (a) individuals who live with their families, broken down by children, adults, and adults who require extensive supports and (b) individuals who receive supports outside the family home (persons receiving less than 24 hours supports, persons who require 24 hour supports, and youth who require 24 hour supports). Individuals are assigned to a tier based on ICAP results (except in the case of children who live with their families where the Critical Needs Assessment tool is employed) and to a cell within the tier based on living arrangement. Each cell within the ASL matrix has an associated dollar range. The dollar range is based on the range of expenditures for people presently receiving services in each cell and associated tier.

In Utah, dollars for community services and supports are managed by the DSPD regions. One of the responsibilities of each region is to make sure that overall spending remains within appropriated amounts. Dollars are apportioned to the regions based on statewide averages. Regions employ these averages as starting points for establishing a person’s final ASL. Individual ASLs may fall within the tier/cell range (above or below the average). As a result, individual support planning takes place within a known ASL range.

Utah ASLs are expressed in both state general revenue dollar terms and total dollar terms, with state general fund dollars serving as the budget control point. In constructing service plans, consumers may select from services and supports offered through the HCBS waiver program or decide to allocate dollars for needs not covered by the HCBS waiver program (e.g., housing or cash assistance in the case of families). As individuals make choices about services and supports, the ASL amount is affected by the mix between Medicaid and non-Medicaid services. In essence, consumers and families have direct control over state general fund dollars and in working out support plans they can decide whether they prefer to use their dollars to leverage Medicaid funds or earmark state general fund dollars for other purposes.
To support the development of individual budgets, DSPD has developed a computer software application that supports interactive costing of consumer support plans. The software identifies all services and supports (Medicaid and non-Medicaid) that may be included in a support plan as well as the standard prices established for such services, where applicable. It also provides for variable pricing of certain services (e.g., personal assistance) where individuals have the latitude to negotiate pay rates with individual providers. The software also permits the entry of service volume/frequency information. Employing this software, individuals and support coordinators may interactively work through permutations and combinations of support strategies with the software continuously informing them of where they stand against the state general fund ASL limit and the total amount taking into account the availability of Medicaid matching dollars through the HCBS waiver program.

The development of this software is a positive step. In Utah, the ASL is an upper budgetary limit. The “individual budget” apportions the dollars available under the ASL to distinct types of services and supports. Decision-making with respect to the individual budget typically is iterative as individuals and families balance support strategies and needs against the ASL. The role of Medicaid funding adds additional complications to individual budget development. The DSPD software makes it appreciably less burdensome to develop an individual budget since the necessary calculations are built into the software. This software also makes the calculation of individual budgets less prone to error.

6. Vermont

The state is not directly involved in the planning process. The consumer and family/guardian are in charge of this process, based on guidelines distributed by the state for developing an individual support agreement (ISA). This unique guide is designed with consumers and families in mind, rather than professionals. The state also conducts a quality review process, where two teams of six reviewers continually check to see if planned services were in fact delivered.

7. Wisconsin

Setting the individual spending authority in Wisconsin parallels the methods employed in Minnesota. As in Minnesota, the state is not directly involved in setting the individual spending authority. Counties set the individual spending authority within the broader context of the dollars allocated by the state. State guidelines concerning this topic are general in nature.

Among the Wisconsin demonstration counties, Dane County had invested the most time in developing a framework for setting the individual spending authority amount. In advance of ramping up self-determination, county staff conducted a study of current spending on behalf of persons presently receiving services. From this study, county staff was able to garner information concerning present spending levels in relation to the hours of supports an individual required/ received. This study formed the basis for the development of a budget allocation method for individuals new to the system.
In Dane County, individuals already receiving services who opt for self-determination carry forward the dollars presently spent on their services and supports. Persons new to the system are assigned an individual spending authority amount at intake based on expected hours of support. Individual budgets are developed based on this amount. Plans can vary from the amount so long as they fall within a predetermined range. The individual spending authority encompasses “county funds.” County funds include state allocated Medicaid CIP waiver dollars, “state aids” (COP) dollars and county tax dollars. Additional dollars available to the individual (e.g., non-waiver Medicaid personal assistance dollars, SSI payments, or employment dollars from vocational rehabilitation) are treated as supplements to the assigned individual spending authority. As a consequence, to the extent that other funding sources can be accessed on behalf of the person, more of the county dollars are available to purchase county-funded supports.

The individual budget that is developed is a total budget that takes into account all potential sources of funds along with possible uses of funds. In Wisconsin there are multiple funding streams for community services and supports. In addition, by employing a total budget approach, the Dane County individual budget approach also aids in ensuring that individuals have sufficient dollars to meet their living expenses. Dane County has developed an “individual financial plan” format that captures key information concerning sources and uses of funds that also ensures that the amount of county funds that are used balance with the individual spending authority amount.

In Winnebago and Lacrosse Counties, less elaborate methods are employed. Winnebago has taken the step of assigning all individuals presently receiving services an individual spending authority amount. This entailed county staff working with providers to isolate the current costs of supporting each consumer. As a consequence, each person has an individual spending authority and thus is able to realign services and supports.

**Summary**

Among the states/sites, the exact methods of setting the individual spending authority vary. In Kansas and Utah, methods have been developed that are highly generalized and formulaic. Elsewhere, the strategy most typically employed was to simply convert existing expenditures on behalf of people already receiving services to the individual spending authority amount and permit people to redeploy these dollars if they wish. In the case of persons new to services, individual spending authority amounts typically are set based on observed costs of persons who have similar needs and life situations.

In one fashion or another, the methods employed are rooted in present funding practices and levels. In no instance has there been in-depth evaluation of the effects of the methods employed to assess the adequacy of the amounts or determine the extent to which actual expenditures match up with the individual spending authority or the associated individual budgets.

In each instance, the individual spending authority frames the development of each person’s individual budget. The individual budget details how the dollars available to the person are deployed. As illustrated by the Utah individual budgeting tool and the Dane
County individual financial plan, the preparation of the individual budget can be complicated in its own right due to funding considerations.

From an administrative resource consumption standpoint, there is little doubt that self-determination and especially the development and preparation of individual budgets causes increased workload for service system infrastructure components (e.g., support coordinators). However, it remains unclear whether managing the interplay between individual service authorizations and budgets causes a net increase in systemwide overhead costs. To some extent, self-determination causes some aspects of budget development/management to shift from service provider organizations to individuals, service coordinators and/or support brokers. System infrastructure components must bear and accommodate costs that heretofore were borne by service provider organizations. System support coordinators are more heavily involved in the details of putting together support plans in collaboration with individuals and families where as in provider-direct systems internal agency staff had these responsibilities. Hence, costs may not be so much increasing as shifting.

**Rate/Price Setting**

In provider-based procurement, payment rates (prices) are set in various ways but typically are not “individualized.” Instead payments span the entire group of individuals for whom a provider furnishes a specific service. For example, a facility that furnishes HCBS day habilitation services receives a uniform payment for each person served. Payments for group-based residential services also are usually uniform, either by provider or site. States employ a variety of methods in determining prices for these kinds of services. Some vary payments to take into account “case mix.” Others base payments on each provider's specific costs.

Self-determination focuses on each individual. The services and supports each person receives are expected to be different, not standardized. The volume of a type of support might vary from period-to-period, a factor that makes the use of per diem rates difficult. Furthermore, pricing schemes must accommodate portability and consumer choice. That is, if a person decides to change providers, then he or she should expect to pay about the same price for the service or support. Portability is enhanced when prices are standardized.

With self-determination, participants often live with their families or have their own living arrangement. They may have jobs and/or need supports to participate in community activities they value. Some may require support around the clock and others may not, due in part to the availability of natural supports. As a consequence, pricing schemes tend to employ the “hour” as the unit of service. The use of Medicaid HCBS waiver funding also dictates that pricing schemes be unit based since payment for services requires documenting services in a manner that is specific to each person by date of service and by provider.

With self-determination, there also is interest in consumers being positioned to negotiate or specify prices for at least some services. For example, instead of paying a
state-determined rate, families might want the leeway to negotiate a lower or higher rate for a service such as personal assistance. If an acceptable attendant can be found at a low hourly cost, dollars are made available for other services or a higher volume of personal assistance services obtained. For example, it is well documented that personal assistance services typically can be obtained at a lower price when consumers hire assistants directly than when they obtain them through provider organizations. Alternatively, the ability to pay a higher wage might be critical in obtaining a personal assistant with an especially good skill set or to ensure that the assistant will not look for a job elsewhere.

It was not the purpose of this evaluation to describe or analyze the methods that states and localities use to set rates or prices for all types of services but more to concentrate on the extent to which self-determination has caused a change in practice or identify instances where a state/site has established pricing schemes that seem to facilitate self-determination. Thus, in this section, we do not discuss rate/price setting state-by-state but instead identify specific practices that one or several states have employed.

♦ Variable pricing for services furnished by individual worker/employees. Several states/sites where families or individuals (and their circles) are actively involved in recruiting individual workers give consumers authority to negotiate wage rates or service coordinators/support brokers negotiate on behalf of consumers. In Utah, for example, families have the latitude to negotiate hourly wage rates anywhere from the minimum wage up to a statewide maximum. The Utah individual budgeting software has the capability to accommodate variable wage rates and fiscal intermediaries assist in translating the hourly wage into an hourly cost, taking into account benefits. Kansas also provides for negotiating individual worker wage rates. Consumers typically have the authority to negotiate wage rates whenever they have been positioned as the employer of record for their workers.

♦ Individualizing rates/prices. Especially when individuals are receiving more or less continuous supports (including habilitation, supervision and other services) in their living arrangement from a provider agency, states are employing methods aimed at crafting individualized payment rates that take into account the particular needs and situations of individuals based on their person-centered plan. More and more, these rates are being developed utilizing standardized pricing methods. For example, Maryland has shifted from person-by-person negotiation of payments for CSLA services to employing standardized pricing methods based on each person's plan and unique requirements. Utah as well has a standardized pricing scheme for persons who live in supported living arrangements. The strength of these methods is that they yield a per diem payment amount (which simplifies billing and record keeping). They also enhance portability (about the same amount of dollars will be paid if a person changes provider).

♦ Breaking Out Individual Costs. In Minnesota and Wisconsin in particular, the shift to self-determination lead to counties working with providers to break down the costs of services for each person served in group arrangements or for whom a uniform payment had been made. The aim is to develop “true” rates (costs) for each person served. In each instance and especially in order to identify the amount of
dollars that should be attributed to each person, it was necessary for all parties to obtain a clearer, more accurate understanding of how many dollars were being spent to support each person. This is particularly important because, if as a result of self-determination, the person leaves a program/site, funding for the individuals who remain also will be affected. As a consequence, it is in everyone’s best interest to have a clear picture of the resources committed to supporting each individual.

♦ **Revamping Existing Rates.** The trend among states is to revamp their rate/pricing methods to standardize payments in a fashion that takes into account differences in the intensity of the services and supports that individuals require. Both Utah and Kansas had taken steps in this regard prior to the advent of self-determination. For core day and residential services, Maryland sets rates based on the level of supervision required, health and medical needs. Minnesota is working toward revising its fee structure for certain types of day services along similar lines with the aim of replacing a “one size fits all” uniform fee that has been negotiated with each provider by the state. Taking steps such as these arguably results in more accurate pricing when individuals opt to receive more or less conventional services and increases the portability of dollars across providers.

♦ **Wrap-around Rates.** Administratively, it can be simpler all around if a person’s individual budget can be converted to a single daily or monthly payment amount. This simplifies transactions between the state and a locality or a lead provider agency. So long as the person or family retains control over the details of the budget, this method of rate setting does not undermine self-determination. In this vein, the method developed in Minnesota to enable counties to bill expenditures for consumer-directed supports is especially simplified. The “rate per month” is the same as the expenses per month incurred during the spend out of the individual budget. In a similar vein, Vermont’s use of a wrap-around HCBS waiver service definition also serves the purpose of simplifying transactions while maintaining individualization and consumer control.

♦ **Upper Limits.** Another device that enables flexibility in pricing while maintaining orderliness in payment rates is establishing price/rate upper limits. As noted previously, Utah employs such upper limits in the case of services like personal assistance. The state of Minnesota also establishes upper-limits for various services. Such upper limits enable flexibility in setting prices but also prevent unduly high prices to be charged for services. These upper limits also are labeled “fee-screens.”

There is little concerning rate/price setting that is especially unique to self-determination. Most of the considerations that arise in the context of self-determination also apply to provider-direct procurement methods. In the main, the principal result of self-determination is to push funders/payers to accommodate multiple rates/prices for services, either with respect to variable pricing for a specific service by vendor or individualized payment rates. As rates/prices proliferate and become increasingly tied to specific individuals, new challenges can emerge in the arena of billing and payment, especially with respect to Medicaid services in reconciling charges to pre-approved rates/prices. In some instances, data systems need to be reprogrammed to
accommodate variable pricing. The use of variable or individualized rates/prices also can increase level of effort in pre-auditing billed charges to make sure that they match up with the amounts that have been authorized for each consumer.

Going forward, a major emerging concern in this arena is the federal Health Insurance Portability and Accountability Act (HIPAA). A central thrust of HIPAA is “administrative simplification.” However, there is considerable concern that the implementation of HIPAA will work at cross-purposes with the aim of promoting flexibility in the provision of Medicaid home and community services by requiring the use of billing/procedure codes that may not be sufficiently flexible to accommodate variability in service definitions and therefore in prices/rates.

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**Billing, Payment and Tracking**

As observed in the introduction, provider-direct procurement methods are essentially bilateral in nature. A provider furnishes an authorized service, bills the payer and receives payment directly from the funder. In Medicaid HCBS waiver programs, billings and payments are screened pre or post against consumer plans of care. Under federal law, a state only may obtain federal financial participation in the cost of furnishing a service to an HCBS waiver participant if the service has been included in the individual's approved plan of care. In this sense, the HCBS waiver program can be described as operating in a prior authorization framework.

Consumer-managed/directed methods engage individuals and families in a wide variety of ways in the procurement process and, indeed, in many important respects, change procurement in important ways. For example:

- In combination, the individual spending authority and the individual budget have important implications with respect to putting into place tracking capabilities. Consumer management dictates that individuals and families know where they stand in spending down their individual spending authority. The same is true for funders. In addition, the need arises to ensure that provider billings comport with the individual budget.

- Consumer management/direction also frequently takes the form of individuals, circles of support and families wanting to have hands-on roles in procurement. This includes paying providers directly or approving provider billings for services before the funder can issue payment to the provider. Another alternative of high interest to consumers is the use of “vouchers” that enable consumers to “shop” for services among vendors and providers. In self-determination, many consumers want to be highly involved in procurement. Moreover, when the aim is to position individuals and families as employers of community workers, steps must be taken to demonstrate that the individual or family in fact is authorizing the payment of wages to the worker.

These dimensions fundamentally alter procurement. Transactions still take place between funders and providers. But, these transactions no longer are bilateral. Additional capabilities frequently are required to accommodate consumer-
managed/directed methods. One such accommodation is furnishing consumers assistance in the form of "support brokers" to provide help (if desired) in managing the budget. Another important accommodation is the use of financial intermediaries to support consumer management and reduce the burden on public agencies in administering some aspects of consumer-managed/directed supports.

The state/site experiences along this dimension are of considerable interest. Along some dimensions (e.g., tracking the individual budget), economical, common sense solutions have been implemented. Experiences have been mixed along other dimensions (e.g., employing vouchers). Some problems have been unearthed with respect to some types of consumer-control devices (e.g., the use of consumer-controlled checking accounts). Questions also have arisen with respect to the interplay between consumer-managed/directed procurement methods and Medicaid policy with respect to billing and payment.

1. Kansas

In Kansas, there are two systems of billing and payment that directly engage consumers and families. One is designed to meet the requirements of the State’s Medicaid payer, Blue Cross/Blue Shield. Payments are made for residential and day encounters reported by consumers or their representatives as proof that they have received residential and/or day supports. The second is designed to attend to the individual needs of the consumer; payments are made for actual services and goods delivered according to the individual’s life plan.

In the first system, a member of the consumer’s circle of support (family member, consumer, service coordinator or staff person) is responsible for submitting encounter data to the CDDO twice each month using a Medicaid Encounter data card. Project participants report only residential and day encounters since, at present, these are the two sources of HCBS waiver funding used to finance the costs of participant services and supports. These encounter data trigger payment from the state to the CDDO.

With the encounter data in hand, the CDDO bills BC/BS using the tier rates authorized for each individual for residential and/or day services. The BC/BS electronic claims processing system checks the billings against the individual’s Plan of Care (amount authorized). So long as funds are available within the individual's authorization (Plan of Care), payment is made to the CDDO. These claims and payments may be billed at any time. Typically, they are billed semi-monthly and amount to 1/24th of the individual's annual residential and/or day tier rates.

On average, six weeks elapse between the time the service is rendered to when payment is received by the CDDO and then dispersed. Most certified service agencies of any size have built-up sufficient working capital or have lines of credit sufficient to carry expenses until payment is received. However, there have been problems with respect to payments to individual attendants and other services where neither workers nor individual consumers/families have sufficiently deep pockets to carry the expenses. Consequently, the CDDOs have had to advance funds to cover consumer staff payrolls and other consumer expenses until payment is received from BC/BS. Both TARC and
COMCARE have used individual risk reserves for this purpose. The Project Managers at both CDDOs observe that, because there is the need to advance funds for self-determination project participants and because there are limited funds for this purpose, the number of participants that the CDDOs can afford to accept into the project is limited.

Except when so-called “pre-paid” arrangements are employed, federal Medicaid policy does not permit a state making payments in advance of when services are rendered. Payments are made post-delivery. In most cases, this means that Medicaid providers must have sufficient funds on hand to carry expenses until payment is received. When individuals who are providers or small organizations that rely heavily on Medicaid payments furnish services, the time lapse between furnishing services and receiving payment can be a major problem. A similar problem arises when individuals and families pay vendors directly and are reimbursed from an organization like a CDDO that, in turn, must wait to make the reimbursement until it receives payment from the state. Absent other arrangements, cash flow problems arise (either for the worker or the consumer/family). In order to mitigate these problems, some other entity needs to carry the costs. As noted above, in Kansas the CDDOs have been carrying some of these costs but have limited capacity to do so. Elsewhere state government implicitly has shouldered these costs (e.g., state funds are advanced and replenished when Medicaid payments are received). This problem is more acute in systems where an intermediary organization is the Medicaid billing agent than in systems where service providers bill the state directly for Medicaid services because frequently less time elapses between when the service is rendered and payment received.

In the second Kansas system, the individual’s life plan is approved by the CDDO and ratified by the State. To-date, the vast majority of expenditures under life plans have been for personal attendants who work for the consumer. Most of the other expenditures are for different sorts of activities in the community.

At TARC, some individuals choose to pay these other expenses (e.g. YMCA membership) from their own checking accounts. The amount that will go into the individual’s checking account to cover such expenses is decided at the time of the life planning process. Individuals are instructed to keep record of these expenses. Some do it well; others don’t. The TARC self-determination managers at TARC are asking consumers/families to keep receipts for possible review.

At TARC, money must get in and out of individual accounts quickly, not accumulate. So long as individuals use the checking account money for authorized purposes, the dollars that go into the account are non-taxable. If participants use the checking account for purposes other than those authorized (e.g. rent), the funding counts as taxable income and thereby can also jeopardize eligibility for SSI and food stamps.

Each CDDO contracts with a fiscal intermediary to help administer the payments required in carrying out the individual life plans. All individuals participating in the demonstration are required to use a fiscal intermediary.
A Certified Public Accounting (CPA) firm is used at each site as the fiscal intermediary. The CPAs are not expected to judge the appropriateness of expenditures. They do not do criminal checks for consumers on staff that consumers are considering hiring. Other than employee pay, expenditures handled by the fiscal intermediary may include memberships, part-time participation in traditional day programs, and so forth. The CPAs are not permitted to be a service provider during or following the contract period.

In the future, the COMCARE CPA might coordinate paid benefits for consumer employees such as health insurance, disability insurance, and retirement; however, at present consumers are not offering employees paid benefits due to budget restrictions. A few full-time employees get paid vacation and holidays but most are part-time, and money is built into individual budgets to cover whatever stand-in help might be needed on vacation, holiday and sick days.

By contract, the fiscal intermediaries are liable for malfeasance, misfeasance and non-feasance in connection with their duties. However, one of the fiscal intermediaries does not carry professional liability insurance. Neither is bonded. The CDDOs found the cost of the insurance too high and could find no entity interested in bonding the CPAs.

The CPAs cut all checks to and for consumers for employee payroll and for other non-payroll expenses. At TARC individuals can pay non-payroll program expenses through their own checking accounts. At TARC the fiscal intermediary sends checks to the individuals to replenish their accounts. The number of employees and corresponding payroll checks that must be cut by the CPAs vary from person to person as do the number of expense checks for such items as appliances, recreational activities, medical supplies, and adaptive equipment.

At TARC, there is a three-party agreement among the CDDO, the fiscal intermediary and the individual/guardian that sets forth their respective responsibilities, including those pertaining to checking account maintenance. The responsibilities of the fiscal intermediary are:

- Pay for all services and supports, consistent with the approved budget, incurred on behalf of the eligible person in a timely manner.
- Pay wages to employees of the eligible person as designated.
- Pay all applicable employment taxes.
- Retain all documentation of submitted bills.
- Transfer amount designated in individual budget into eligible person’s checking account.
- Report to TARC information that serves as a record of services provided as established in the Preferred Life Plan.
- Assist TARC in the audit of funds received and expended by the fiscal intermediary at times determined by TARC.
- Report quarterly to TARC, with reconciliation of funds every six months.
• Return unexpended funds to the TARC risk pool.
• Report to appropriate agencies and TARC any suspicions of abuse, neglect, exploitation or fiduciary abuse.

At COMCARE the responsibilities are defined in a two-party agreement between the CDDO and CPA.

• Develop accounting procedures and information systems necessary to establish consumer accounts based on each individual’s budget. Generate and maintain a record of all money disbursed on behalf of each consumer.
• Pay vendor bills and invoices for goods and services rendered to consumers. Process vendor invoices within three working days of receipt of the bill. Maintain documentation of each consumer’s expenses.
• Prepare and distribute payroll checks to all of the staff of each consumer based on time sheets submitted by staff.
• Manage the tax reporting, filings and payments for all staff hired by the consumer and paid for by the consumer’s budget in accordance with State and Federal Statutes. Manage all aspects of employment tax filings and deposits in accordance with IRS Code, including income tax withholdings for federal and state income tax, social security and Medicare taxes, federal and state unemployment insurance, workers compensation and other paid benefits a consumer might offer employees, and corresponding deposits in accordance with IRS Code. Maintain all tax records.
• Conduct Immigration and Naturalization Service (INS) Employment Eligibility Verification Process for all workers.
• Maintain a record for each consumer employee including at a minimum: the enrollment forms and information needed to process payroll and administer benefits.
• Manage worker’s compensation for consumer employees and the payment of employment tax rebates for those consumers that do not meet the annual income limits for FICA, FUTA / SUTA under the SSDERA.
• Ensure the rate of pay for consumer employees comports with state requirements for minimum wage and overtime.
• Issue an accounting to consumers or their designees every other week and to the CDDO outlining consumer expenditures and payroll information for consumer staff including any benefits. List the hours of service provided in the month by all staff for each consumer and the hours of service by each individual staff person.
• Provide an accounting every other week to the CDDO describing all activities and expenditures.

The TARC fiscal intermediary serves as a fiscal agent only, not as an employer of record. Consumers are considered the employers of record. As the employer of record, each consumer must pay the up-front workers compensation payments for staff in their employ.
In Wichita, the CPA is the employer of record. Thus, in addition to the responsibilities outlined above, the COMCARE CPA is obligated to pay worker's compensation, federal unemployment tax and state unemployment tax for all consumer employees; these payments are made from the individual budgets. As the employer of record, the COMCARE CPA must also attend any workers compensation hearings, unemployment hearings and other legal events.

At COMCARE, consumer employees submit timesheets to the CPA every other week for payment; at TARC, twice each month. The CPA translates this information into dollar requests to the CDDO. Unlike TARC, requests or bills for non-payroll payments go first to COMCARE. The CDDO reviews the individual’s budget and expenditures to-date to ensure that there are adequate funds available to meet the person’s current and future needs before approving the requests. The CDDO does this for all participating consumers, then forwards the approved bills and requests to the CPA for payment together with funds sufficient to cover the approved non-payroll expenses and payroll expenses for two weeks at COMCARE, a half-month at TARC.

2. Maryland

Pending the shift to resource agencies and other changes in Maryland’s funding/contracting systems, billing/payment for services remains “provider-direct.” This means that various aspects of consumer-managed/directed procurement are internalized within service providing organizations rather than dealt with through “external mechanisms” such as financial intermediaries.

The DDA Regional Office translates the provider support plans into fiscal packets specifying the funds to be used to pay for the plans. The packets are sent to DDA headquarters to certify the availability of the funds specified and to make the necessary adjustments to the contracts of the providers involved. These contract actions then must be approved by the Department of Health and Mental Hygiene's (DHMH) Division of Contracts. In certain circumstances when dollar thresholds are exceeded (e.g. new contracts in excess of $100,000), the State Board of Public Works also must approve. The process can take three months.

In order to expedite contract approvals to accommodate the wave of new admissions under the Waiting List Initiative, the DDA was able to engineer an Expedited Payment Process (EPP). The expedited payment process consolidates 800 to 1,000 separate requests into one consolidated request. A blanket approval of the consolidated requests is granted twice a year by the Board of Public Works.

The Comptrollers Office makes payments after authorization by Department of Health and Mental Hygiene. Payments are not made directly to the resource coordination agencies. DDA pays providers directly and providers must sign an authorization for the State to act as their billing agent for Medicaid services.

Regardless of the method of payment, the DDA advances providers approximately 25% of their projected annual contract amounts each quarter—in the first quarter, the state
actually advances the provider's funds to cover four months of the contract and reduces the fourth quarter payment accordingly. Advances are reconciled quarterly and annually with actual provider costs by the DHMH Program Cost and Analysis Division.

In Maryland, present state procurement and contracting requirements trigger a high volume of work for DDA in order to implement initiatives such as self-determination or the waiting list initiative. Structurally, Maryland remains a “provider-direct” procurement state and, hence, is less well-positioned than some other states to implement external mechanisms to facilitate consumer-managed/directed procurement.

3. Michigan

WCLS contracts with approximately 60 agencies. At the time of the interview, WCLS was working to clarify relationships between fiscal intermediaries, consumers, and providers. If a consumer decides to contract directly for residential services, the provider becomes the “staffing agent” whereby the consumer is able to select the staff. Monthly reports are prepared by the fiscal intermediary, and the supports coordinator reviews individual budgets with consumers on a monthly basis. There is a master contract between the fiscal intermediary and WCLS (with a listing of clients) and a direct contract between the person and the provider of services and supports. Previously, there were general contracts between WCLS and providers on a cost reimbursement basis – providers were given monthly advances, which were reconciled quarterly with actual expenditures. The state now mandates fee-for-services payments for services rendered.

Washtenaw county now tracks actual costs and will base further contracts on these data. The contract with the fiscal intermediary is for a period of three years. The fiscal intermediary handles payroll, tax reports, power of attorney, and employee identification numbers. They may pay rent, transportation, and other costs for consumers. Fiscal intermediaries prepare monthly statements of expenditures relative to budget. In addition, they provide technical assistance to consumers around payroll issues. While individuals may serve as their own fiscal intermediary, they must be using a provider agency to do so. Washtenaw currently has a panel of 15 agencies with whom individuals may contract for in-home supports. These are open contracts in the sense that they have no dollar amounts committed to them. They are planning to expand this time of contracting in the future. The plan is to have most services pre-authorized. The authorized individual budget will be used as a control, and annual and quarterly reports will replace monthly reports. Per diem rates that average the costs of the individual over a period of time will be used.

In Oakland County, only public dollars are tracked by the fiscal intermediary. Individuals must use the fiscal intermediary so long as they are expending public funds. Oakland is paying for the fiscal intermediary administratively. The children's waiver is still on a fee-for-service basis. The fiscal intermediaries in this case will generate bills using the HCFA 1500s. It is the responsibility of fiscal intermediary to withstand audits. The fiscal intermediary is allowed to move dollars across line items within individual budgets, but cannot exceed allowed budget levels. They advance the fiscal intermediary one twelfth
of the funds monthly and reconcile annually. Initially they advanced the fiscal intermediary two months worth of cash to cover start-up costs.

4. Minnesota

In Minnesota, a provider can be paid only if the County has a service agreement with the provider authorizing the provision of the service. There are three entities whom providers may bill for waiver services: 1) the state 2) the county, and 3) consumer.

To bill the state directly, a provider must be Waiver-certified, i.e. licensed by the state. Providers of day training and habilitation services, semi-independent living services (SILS) must be licensed (certified) by the State. In the past, the counties paid certified providers. The state Medicaid Management Information System (MMIS) took over these payments in order to centralize and thereby streamline the process of claims payment. Instead of paying providers directly, the counties now act as local intermediaries preparing and processing claims through the MMIS system. Providers bill monthly on a fee for service basis. The MMIS system is a reliable, well-managed system that generates timely payments.

If the provider is authorized to provide services and supports to individuals with DD served by the County but not certified to provide waiver services, the provider bills the county and the county as a certified waiver provider may file claims for these services. Non-certified providers include individuals and smaller organizations offering specialized services, e.g. behavioral, respite, personal support and others that do not have the interest or capability to file Medicaid claims directly. County agreements with these individuals or organizations serve as Medicaid provider agreements. The more informal and natural the supports, i.e. the more supports are provided by individuals and organizations whose principal occupation is not the provision of supports, the more likely it is that the county pays and then bills for the Waiver-funded supports through the MMIS.

At the time of the visit, in Olmsted and Blue Earth Counties, all certified providers bill the state directly. This was not the case in Dakota County where consumers may elect to pay certified as well as non-certified providers themselves using county-backed checking accounts taken out in their names. In Olmsted and Blue Earth Counties, consumers may elect to pay only non-certified providers themselves.

“County-backed” checking accounts were pioneered in Dakota County. They also are used in Olmsted and Blue Earth, except these counties were not employing them for persons receiving HCBS waiver dollars. At the time of the visit, there were 52 people in Dakota County who had county-backed checking accounts and county officials were hoping to increase the number to 100.

County-backed checking accounts are a device to put consumers directly into the transaction loop with service providers. People and families who have consumer-backed checking accounts pay for goods and services directly. County-backed checking accounts also avoid the problem that arises when people/families pay for services directly but then must wait to be reimbursed by the funder (as discussed with respect to
the Kansas demonstration). Consumers do not have to carry the costs of services. These accounts as labeled as “county-backed” for two reasons: the account is co-owned by the county and the county assumes responsibility for overdrafts.

It took some time to operationalize the checking account payment scheme. HCFA had to be convinced that county advances should not be treated as individual assets when determining Medicaid eligibility as the accounts are owned by the counties. It took time to locate willing banks. Counties appealed to smaller banks where the promise of future accounts represented enough of a float to be attractive. Larger banks were not interested.

The counties periodically deposit funds in each individual’s account and assume responsibility for any overdrafts. Time is required setting up the individual accounts with the consumers or families. County staff must also look at every check and match the check expenditure to the waiver categories for claiming. Maintaining these accounts is labor intensive. Training is required to make sure that the families record the correct waiver category name on the check. One county provides the account holder with a wallet size card listing the categories as an aide. A very small percent of individuals and families (2%) have proven to be poor managers of their accounts.

County officials see possible difficulties with these accounts down the road. They worry that providers may be unwilling to bill individually given the added time required on their end unless they are able to develop more efficient billing systems. There is also the issue of cash flow. Each quarter Dakota County replenishes individual accounts at 25% of the spending amount authorized through the checking account with County funds. County funds, rather than Medicaid Waiver funds, must be employed because Medicaid funds cannot be obtained in advance of when a service is rendered.

Of the 52 families that had checking accounts, 29 used certified providers and 20 of them had elected to pay the certified providers through their accounts. Because the service costs and corresponding payments to certified providers (e.g. residential and day) tend to be on the high side, there is concern that as the number of checking accounts grows and as families become more comfortable paying providers directly, the size of the total cash advance may become politically untenable or financially infeasible. Reportedly obtaining the cash needed to advance deposits into these accounts is already problematic in some counties. These difficulties notwithstanding, consumer checking accounts offer a number of practical benefits in addition to the fact that they embody the self-determination principles.

Families and consumers can themselves track their bank balances rather than the counties having to do it. While the Counties have to do the monthly check reviews, the accounting system has to reckon with only one check versus the ten-to-twelve checks that an average family or individual might write each month. Case aides can do these reviews.

The cancelled checks also provide an audit trail. The county gets a copy of the individual checking account statement, and the county makes a copy for the case manager and for the family--Olmsted County does not send a copy out to the family.
Counties favor having as much information available for audit as needed, but minimizing the reporting requirements. The three Minnesota counties have been less active in employing external fiscal intermediary arrangements than sites elsewhere. The counties have tended to internalize functions such as budget tracking. However, external agents are employed to support consumers who are employers.

5. Utah

Predating self-determination, Utah already was employing a financial intermediary in conjunction with its family-directed, family support program. This intermediary (Acumen) enabled families to become the employer of record for in-home support workers as well as handling payroll and billing chores and tracking the use of family support dollars both families and the state. In 2000, DSPD expanded this capability by signing up additional organizations to provide financial intermediary services, thus providing families with a wider range of choices. DSPD issued an RFP to secure these services. The RFP and the related contract were especially well-drawn in spelling out financial intermediary responsibilities.

Financial intermediaries in Utah – at the time of the visit – supported only families in directing and managing in-home support workers (e.g., personal assistance or respite workers). Other services that individuals received were not being handled by the intermediaries but instead were being direct-billed for payment. As previously noted, it has been only recently that Utah has extended self-determination to adults living outside the family home.

Financial intermediaries in Utah are responsible for receiving and processing family-approved worker time cards. These time cards also must be accompanied by documentation prepared by the family concerning the services furnished by workers. This documentation parallels the documentation that provider agencies must generate in order to receive Medicaid payment. Once the time cards and documentation are received, the intermediary sends billing information upstream to DSPD. Once payment is received from DSPD, the intermediary prepares and dispenses payroll checks to the workers. The intermediary also keeps track of expenditures for the services for which it makes payment against authorized amounts on behalf of consumers and DSPD.

The costs of intermediary services in Utah are pegged at 6-¼% of the dollar value of services for which the intermediary makes payments. These costs are added onto charges billed to DSPD. This method of setting the charges for intermediary services stands in contrast with practices in other states where charges are pegged to the number of checks issued or a monthly fee is paid. In comparison to charges for roughly similar services elsewhere, Utah’s payment for financial intermediary services are relatively economical.

In the past, Utah claimed federal reimbursement for these charges at the Medicaid “service rate” since they were included in the billed service charges. However, the HCFA regional office directed Utah to claim federal reimbursement for these charges at the “administrative claiming rate.” Because Utah’s service rate is about 20% higher than
the standard 50% administrative claiming rate, complying with HCFA’s directive had the effect of requiring DSPD to earmark more state funds to pay these expenses. To no avail, Utah officials advanced the argument that these costs were integrally related to the provision of the underlying Medicaid service and, hence, were appropriate for service rate claiming. They also pointed out that conventional Medicaid providers include precisely the same costs of employment administration in their billing rates and, hence, de facto federal financial participation for these costs are being paid at the service rate. HCFA, however, based its ruling on its view that the activities for which federal financial participation was sought are more closely akin to payment processing and, thus, were administrative in nature.

Utah’s use of financial intermediaries as vehicles for consumer-managed/directed procurement mainly supports positioning consumers as the employer of in-home workers rather than encompassing all types of services and supports.

6. Vermont

The state contracts with an organization called Alpha One to be the intermediary service organization (ISO). Alpha One is an Independent Living Center in Maine that has been acting as a fiscal intermediary for personal care attendant (PCA) services for many years in Maine. Alpha One replaces ARIS, a provider network that was created several years ago in anticipation of managed care and served as the interim fiscal intermediary until the RFP process was completed.

The fee paid to the ISO is between $25-35 per month; the cost decreases as the number enrolled goes up. At the time of the interview, the maximum contract amount was set at $291,000 for the year. The state pays for the fee through waiver.

The ISO handles cash flow. There are two types of payments made to the ISO: one payment is made to them for their services on a monthly basis; a second payment is for the payroll and bills they must pay for consumers/families. These two billing and payment processes are described below.

- **Fees for service (per person per month)**

  Fees for service are paid once per month. The $291,000 is allocated to the Designated Agencies (DAs) based on the maximum number of participants that might sign up. The DAs bill EDS for each individual served. The fee is built into everyone’s rate. The state pays the bill, then later bills the DAs. The state allows Medicaid to be billed twice per month, on the 16th and on the 1st. A person’s rate is equal to his/her individual budget/365.

- **Payroll and non-payroll expenses**

  Payroll and non-payroll expenses are paid once every two weeks. The ISO bills the DAs, and the DAs reimburse the ISO. The ISO gets reimbursed once they make payments. Payment is through electronic transfer within three business days. The ISO maintains a bank account in Vermont.
The ISO’s responsibilities include:

- Making payments to contractors for approved goods and services
- Paying employees
- Reporting expenditures back to the consumer and the DAs

Alpha One does not pay workman's compensation as it is not required in Vermont. However, they are checking into private group plan options.

7. Wisconsin

The Wisconsin demonstration sites were employing varied alternatives in support of consumer-managed/directed procurement. One county – Winnebago – provides for county-backed checking accounts. Counties also were contracting with CPAs to assist consumers and the counties themselves in keeping track of expenditures against individual budgets. In Winnebago County, the charge for this service was quite economical -- $5 per month per consumer. The Wisconsin sites also tended to look toward outsourcing as a principal means of supporting consumer-managed/directed procurement to the extent feasible. For example, in Dane County, individuals can select from two arrangements with respect to handling employment-related activities, including payroll functions. In Wisconsin as well there was a relatively long history of employing consumer-managed/directed procurement methods that predated self-determination. As a consequence, Wisconsin county officials had had experience with such arrangements and, thus, were relatively comfortable with respect to their operation.

In addition, county officials in Wisconsin (as in Minnesota) also recognized that consumer-managed/directed procurement creates substantial time and resource demands in tracking budgets and payments. They were quick to point out that they were unlikely to be able to secure additional personnel to perform these functions and that county data processing systems likely could not be modified to provide the required capabilities. Hence, outsourcing functions was seen as the most feasible/realistic alternative.

Summary

By and large, the evaluation found that the sites had found and developed common sense and reasonably economical approaches to handling the billing, payment and budget plan tracking elements of consumer-managed/directed procurement. Wisely, most sites decided to use non-governmental entities in order to put into place the necessary infrastructure and supporting capabilities rather than attempting to tackle these tasks internally. Much the same has been the case in other states that have ramped up self-determination.

The experiences at these states/sites also sparks some additional observations. In particular:
Where the aim is that consumers be involved in financial transactions directly, it is feasible to use such devices as county-based checking accounts or paying consumers back for the expenses that they have incurred with their own dollars. So far as we can tell, neither alternative runs afoul of federal Medicaid law for a very simple reason: such transactions do not involve the use of Medicaid dollars themselves and, hence, do not run afoul of the long-standing federal prohibition against making cash payments to Medicaid recipients. The transactions enter the Medicaid billing/payment stream after the fact and claims for Medicaid payment are not different than conventional claims. However, the experiences in Kansas and Minnesota clearly point out that the use of such devices can pose difficulties with respect to cash flow (either for consumers, workers, or intermediary agencies like counties). Hence, the broad-based feasibility of such devices appears to hinge on some funding entity absorbing the "opportunity cost of money" in order to float the necessary cash flow. The same problem can arise in provider-direct procurement. However, at least in the case of larger providers, there are more options to float necessary dollars out of accumulated reserves and/or lines of credit.

Also, there are some less visible ramifications of consumer-managed/directed procurement methods that are beginning to surface in this arena. In some states/sites, consumers are shouldering without compensation or other assistance some burdens as the "price" of self-determination. Medicaid procurement policies dictate a high level of effort with respect to documentation. Provider agencies can recoup the costs of meeting such requirements but families are expected to do so without compensation. Furnishing support brokers and personal agents may assist in addressing this issue (and the somewhat parallel issues that arise with respect to employee administration). Clearly, the use of financial intermediaries also reduces the burden on individuals and families but not entirely (since consumers often times must feed information to the intermediary). The burdens on individuals and families that accompany consumer-managed/directed procurement methods may have subtle ramifications with respect to the willingness to opt for self-determination.

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**Employee Administration**

Closely related to but still distinct from billing and payments is the topic of employee administration. When provider agencies/organizations furnish services, the service agency/organization is responsible for hiring, firing, supervising and paying workers. These activities take place behind the scenes and the associated costs are simply part of the agencies "cost of doing business."

When the provision of services and supports shifts from buying them from a service agency/organization to direct consumer management and management extends to individuals and families becoming the employer, then provision has to be made for handling tasks that are associated with the employer function. Such tasks include withholding and paying taxes, making unemployment compensation payments, and securing workers compensation coverage. In the absence of assistance, such tasks fall on the consumer/family employer and are especially burdensome/complex. Or these...
tasks can be accomplished in other ways, including through financial intermediaries or by way of other arrangements whereby another entity agrees to serve as the employer of record but still affords the consumer or the family a high level of authority in directing services.

For various reasons, government funders are reluctant to serve as the employers of consumer-selected workers. When government funders have done in this in past by deeming such workers as "independent contractors" they have found themselves exposed to all manner of financial liabilities. Absent an employment arrangement between the worker and the consumer or the worker and an employment agency, consumer-management/direction takes the form of workers becoming providers in their own right and consumers simply exercising their authority under Medicaid law to freely choose from among all qualified providers. While some states have been able to achieve reasonably high levels of consumer control using this model (e.g., offering provider agreements to consumer-recruited workers), the model poses some difficulties, especially for workers.

The self-determination states/sites have addressed this topic in various ways.

1. **Kansas**

See the previous section for information concerning how the Topeka and Wichita sites addressed employment administration. In addition, we note that the TARC CPA is paid at a flat rate of $65 / month per person. The COMCARE CPA is paid $7.50 for each payroll check cut and $4.00 for each non-payroll check. If required to attend a hearing in conjunction with his role as the employer of record, the would be paid at a rate of $75 per hour ($150 maximum).

Any individual or organization having an annual payroll to non-relatives in excess of $20,000 must provide workers compensation for employees. Because the Wichita CPA is designated as the employer of record for all of the persons employed by consumers participating in the Self-determination Project, he must make pay workers compensation for all. This amounts to 4.22% of all wages. In contrast, in Topeka, the individual consumers are designated as the employers of record, and must pay the rates determined by their insurance companies. However, most of the consumers are not required to pay-in at all; they are exempt either because they are employing relatives and relatives or because they don't have annual payrolls in excess of $20,000. Consequently, even though some consumers, as new employers are required to pay the maximum rate of 6%, most pay nothing; the average amount paid by consumers is only 2%.

All employers are required to pay the state and federal unemployment taxes as well. The federal tax rate is 0.8% of the first $ $7,000 of a person's pay. The state unemployment tax rate is 6.0% of the first $6,000 of a person's pay with the percentage decreasing over time to the extent that an employer builds up a reserve, i.e. contributes more than is used. As the Wichita CPA has a good employment history and has built a sizeable reserve, he has had to pay nothing to date. However, because of the added
consumer employees a larger reserve is now required. Starting in the year 2000 he must pay 1.56%.

2. **Maryland**

In Maryland, a small number of families in one area of the state employ individuals directly in support of their family members. In these cases, the Arc of Frederick performs employer-related Internal revenue Service (IRS) obligations and other fiscal functions on behalf of the individual. Otherwise, these functions devolve on providers in Maryland.

3. **Michigan**

At WCLS, some participants have chosen to hire their own support staff, through the individual planning and budgeting process and using the fiscal intermediary. Staff or personal assistants who are hired in this way can negotiate their own pay and hours and work with specific individuals. In Van Buren, individuals can contract with the staff person directly as employer of record.

4. **Minnesota**

In Dakota County, if the provider is working as an employee of the consumer, the consumer must complete a number of administrative tasks associated with employing the provider: a background check prior to hiring, employee payroll, and related tax filings. They may do this themselves or may contract with a fiscal agent or employer of record to handle one or more of these functions. No consumers in Dakota County or at the other two sites have elected to use a fiscal agent. Employers of record, unlike fiscal intermediaries, can assume liability -- an important feature to the counties and consumers.

The counties require all consumers and families who are paying non-certified providers (individuals) more than $600 -- the level above which an employer is required to withhold FICA -- to use the Employer of Record to handle the payroll, tax withholdings (federal and state unemployment, FICA, federal and state payroll taxes) workman’s compensation and liability insurance.

In Olmsted County, only one organization was willing and able to serve as an Employer of Record, Possibilities of Southern Minnesota. Possibilities receives 22% of the monies earmarked in the individual plan for these individual supports. Approximately 17% covers the payroll taxes, withholdings and insurance. Possibilities nets approximately 5% for its services.

Dakota and Blue Earth Counties each have an agreement with MRCI -- an established, non-profit service provider -- to serve as an employer of record for consumers and families. MRCI does background checks, provides for workman’s comp and liability insurance, and does payroll processing and tax filings for employees serving consumers and families directly. The agency assures that employees complete time sheets and records of expense. MRCI gets 25% for all costs (including employee withholding) and
nets about two percent of total expenditures to furnish this service. The county issued an RFP for other agencies to serve as Employers of Record. The bids were 36 to 46% as opposed to MRCI’s 25%.

As it now stands, MRCI bills the county, and the county in turn bills the state. Dakota County is currently negotiating with MRCI to bill the state directly for waiver services. This would streamline the process by eliminating the county as the middle person with respect to these payments.

5. Utah

As previously noted, the financial intermediaries in Utah principally were established to facilitate families becoming the employer of record for in-home workers. The Utah intermediaries are not employers of record. Also as previously noted, the net fee for this service in Utah is set at 6 ½ % based on the dollar volume of transactions that an intermediary processes. The intermediaries make sure that all the requisite employment-related paperwork has been completed by the family or the worker, takes in and processes worker time sheets, sends billings upstream to DSPD and writes payroll checks, including withholding and paying federal and state taxes. The intermediaries provide limited assistance to families with respect to worker supervision and employee management.

In Utah, the main unresolved issue with respect to families being the employers of record revolves around the inability to secure workers compensation insurance at an economical rate. The minimum cost for worker compensation insurance in Utah is $300, irrespective of the number of employees. Hence, a family interested in securing workers compensation coverage faces what is in effect a very high rate. As a consequence, most families have relied on their homeowners’ liability insurance coverage, a not especially reliable form of insurance. Efforts during the past legislative session to change Utah law with respect to workers compensation to permit families to obtain lower cost coverage came to naught. By all reports, this problem is unique to Utah and how it structures its workers compensation program.

6. Vermont

Alpha One has a prepared information packet for anyone (including consumers) interested in becoming an employer of record. Each DA has a person specially trained to help people fill out the forms. The DAs and Specialized Service Agencies (SSAs) do the criminal background checks on behalf of the employer of record. They do not actively assist people with hiring and firing of employees.

7. Wisconsin

Again, principally due to Wisconsin’s relatively long history with consumer-managed/directed services, few problems have been encountered in setting up the requisite employment administration mechanisms. In Dane County, for example, there is an employer of record agency that has been available to individuals since the beginning of the project. More recently, a service provider has stepped forward to offer
a fuller range of services to consumers, including assistance with recruitment, employee screening, training in worker supervision, and so forth. This approach contrasts with less full-featured models that primarily address the technical aspects of employment but leave it to families and individuals to go it alone with respect to managing and supervising workers, finding workers or working out back-up arrangements.

Summary

The states/sites generally were able to make suitable arrangements to address employment administration tasks. In some states/sites, the arrangements are limited (e.g., fiscal agent) and individuals/families thereby are expected to be very active supervisors/managers. It seems clear that, in many cases, families and individuals prefer to be able to use an organization that is willing to serve as the employer of record due to liability concerns. However, it was not always the case that it was possible to find such entities.

Management Information Systems

Without exception, the states/sites pointed out the added information and control requirements associated with self-determination. Agencies have gone from simply having to track and control only the numbers of clients served (slots), to the tracking and control of services and supports provided with the expansion of fee for service systems, to the tracking and control of services and supports and individual expenditures against individual budgets in the case of self-determination.

The only way the sites with large numbers of consumers have been able to manage has been through automation. Most sites have turned to off-the-shelf software as the quick solution: specifically, accounting, spreadsheet and database software. Some have custom-developed their own systems in-house or through contract, e.g. a system to manage individual checking accounts. All agree that without the increased use of automated information systems, they would not be able to handle the increased information-processing load associated with the individualized processes associated with self-determination. Here we illustrate some of the activities underway at two of the sites.

Ad hoc, make-do solutions serve for a time or frequently they are best that can be achieved given the limited IS-resources available to states and local sites. Most certainly, one of the major problems in this arena is that many state developmental disabilities system are well-behind in shifting from IS systems that principally are geared to tracking program/service use and payments to systems that can readily extract information about service use and expenditures on an individual consumer basis, the dimension upon which person-centered supports and self-determination operates. In addition, state developmental disabilities systems increasingly must intermesh with Medicaid payment systems. In addition, there is mounting recognition of the need to intermesh state, locality and even provider IS systems in order to achieve resource-efficient IS solutions, including pulling together all the varied information and data necessary to support the procurement and other financially-related tasks that
accompany self-determination. In many respects, the IS challenges that arise with respect to self-determination require tackling broader systemic issues and engaging in redesign of baseline systems. This is well recognized in Minnesota, for example, where a multi-phase redesign is underway, including developing the capability within the Department of Human Services information system to support individual budgets and permit the state and the counties to share rather duplicate data and/or avoid compiling information manually. Similar redesigns are underway in other states, including Pennsylvania and Rhode Island.

For sure, self-determination has exposed material weaknesses in state and local information systems. At first blush, it should not be a daunting task to keep track of individual budgets, payments and service use person-by-person. But the reality is that the task is less simple than it seems absent integration across multiple systems at multiple levels. What has been discovered is that, absent IS redesign efforts, there is a steep price to paid in maintaining ad hoc systems or substituting labor for computing power.

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**Observations Concerning Resource Requirements**

A not unreasonable question to ask is whether self-determination “causes” system overhead costs to increase or decrease? Another important question is: if costs increase, is the increase the result of non-recurring expenses or recurring expenses? The answers to these questions are hard to come by, although the sentiment expressed at most sites is that self-determination involves a greater commitment of certain types of resources. The need for additional resources concentrates in the “overhead” arena because of the nature of person-centered supports. Tasks once embedded in provider agency operations shift elsewhere (e.g., employment administration). There is a greater need for support coordination resources when the services and supports that people want are highly variable, change frequently, and are obtained from alternative sources.

For example, there is little doubt that person-centered planning is more resource intensive at a systems level than when service planning revolved around finding the best fit for individuals among existing service alternatives. For example, following its shift to person-centered planning, Utah DSPD boosted the number of hours for service coordination by 20% in its HCBS waiver program. At one site, the observation was made that furnishing support coordination on behalf of individuals who live with their families is much more resource intensive than conducting case management for people in provider-operated community residences (where the provider agency frequently shoulders direct case management responsibilities).

There are other “costs” that arise with person-centered supports that did not arise in predecessor “provider-centered” systems. For example, in one Minnesota county, time is set aside to conduct consumer education and training classes for people new self-determination. At a Kansas site, considerable time and energy has been devoted to unraveling rules and regulations as a result of individuals and families “thinking outside the box.” Major investments are being made in supporting individuals and families managing and directing their own supports, including contracting with financial
intermediaries and employment agencies, at least some of the costs of which involve paying for activities that provider agencies have born in the past. Fees paid for intermediary services are ranging from 2 to 10% of direct program costs, depending on the site and the scope/nature of the services being purchased from intermediaries. There also is no doubt that self-determination has strained government agencies, especially in the financial management arena, with additional workload being piled atop current workload without the benefit of added staff. In nearly all cases, self-determination has not replaced the "old way of doing business" and at most sites only a relatively small percentage of individuals were participating in self-determination. This meant that old and new ways of doing business were operating in parallel, a costly proposition. Clearly, there have been considerable "ramping up" costs in all the states/sites to get self-determination off the ground and moving along, costs that were borne only in part by the RWJF grants.

But, even though nearly all the individuals with whom we spoke believe that self-determination has led to increased system overhead costs, most were optimistic that some of these costs would decline, due either to implementing new IS solutions or as a result of individuals and families themselves gaining more confidence and experience in managing and directing their own supports.

Left unanswered, however, is the extent to which an increase in infrastructure/"overhead" resource requirements might be counterbalanced or more than offset by changes in service and support costs themselves. For example, while the cost of fiscal intermediary services might be about 5%, that cost is markedly lower than the 10-15% or more that is paid to provider agencies in the form of administrative overhead expenses for conventional services. There continues to be strong evidence that the "self-determination model" itself makes more efficient use of scarce public dollars than provider-centered systems. As a consequence, if infrastructure/overhead costs increase with self-determination (in the form of increased expenses for support coordination/service brokerage or paying intermediaries), it is not necessarily the case that these increased costs are leading to increased total costs in supporting individuals and families in the community. There is little doubt that supporting people "one person at a time" requires a strong and responsive infrastructure. However, that infrastructure may yield offsetting savings down the road.