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Improving Home and Community- Based Service Delivery Systems for Older Adults and Individuals with Disabilities:

REDESIGNING INFORMATION TECHNOLOGY AND BUSINESS PROCESSES TO SUPPORT
PARTICIPANT CONTROL, QUALITY AND COST EFFECTIVENESS

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Improving Home and Community-Based Service Delivery Systems for Older Adults and Individuals with Disabilities: Redesigning Information Technology and Business Processes to Support Participant Control, Quality and Cost Effectiveness

Federal and state efforts, such as those funded under the US Administration on Aging's (AoA) Choices for Independence Program and the Center for Medicare and Medicaid Services' (CMS) Real Choice Systems Change and Money Follows the Person Rebalancing Initiatives, have focused on increasing the control individuals and families have over the home and community-based supports (HCBS) they receive. These initiatives enjoy widespread support because of the belief that giving greater control to individuals and their families will result in lower cost and greater quality of life. Allowing individuals to direct their own services may result in lower cost because:

- 1) There may be administrative savings associated with shifting functions, such as locating and managing direct care workers from agencies to individuals and their families.
- 2) Unlike providers, who have the incentive to maximize the amount of services they can bill for, individuals and/or their families may be more likely to use only what they need.
- 3) Individuals and families will develop creative support arrangements that will provide savings by reducing the number of hours of support necessary or by using less costly approaches.

Self direction is believed to improve quality of life by:

- 1) Allowing individuals to better match supports to their needs;
- 2) Increasing opportunities for the individual to have better and more meaningful relationships with direct care workers that he or she has chosen; and
- 3) Benefitting the individual's psychological and physical health, and community life through the ability to customize supports within the context of the family structure, available private resources, culture and community norms, and other factors which heavily influence the overall health and welfare of the individual.

There is a large body of research that supports the notion that having greater perceived control has a significant effect on a wide variety of outcomes. The John D. and Catherine T. MacArthur Research Network on Socioeconomic Status and Health summarized the research on the effect of personal control on health:

There is considerable evidence linking sense of control to better psychological health (Rodin, 1986; Rodin, Timko, Harris, 1985; Haidt & Rodin, 1995) as well as evidence of links to better physical health outcomes, including lower incidence of CHD (Karasek et al, 1982, Marmot et al, 1997), better self-rated health and functional status (Seeman & Seeman, 1983; Seeman & Lewis, 1995; Rodin & Langer, 1977), better maintenance of cognitive function (Seeman et al, 1993) and lower mortality risk (Seeman & Lewis, 1995; Rodin & Langer, 1977). However, there is also evidence suggesting that stronger control

beliefs can be associated with poorer health outcomes under certain circumstances (Rodin, 1986; Seeman, 1991; Thompson et al, 1988).

Negative health outcomes have been hypothesized to be more likely to occur when there is incongruity between personal control beliefs and actual situational/environmental "control conditions" (Watson & Bauml, 1967; Thompson et al, 1988; Rothbaum et al, 1982; Evans et al, 1993). Stronger control beliefs would thus be predicted to result in poorer outcomes when there is a mis-match between beliefs and environmental contingencies. Support for this prediction can be found in research from both animal and human studies of physiologic reactivity to environmental control conditions where the greatest reactivity (e.g., increase in cardiovascular or neuroendocrine activity or reduction in immune function) is seen when there is incongruity reflecting a combination of general expectancies for control and actual situational "uncontrollability" or difficulty in controlling outcomes (DeGood, 1975; Houston, 1972; Hokanson et al, 1971; Manuck et al, 1978; Sieber et al, 1992). Data from a study undertaken by the MacArthur Successful Aging Study provide further evidence of such effects, showing that men with strong personal control beliefs who perceive that they were NOT "in control" in a driving simulation challenge exhibited the greatest physiological reactivity. By contrast, individuals with similarly strong personal control beliefs who perceive themselves to be "in control" during the challenge situation exhibited the least reactivity (Seeman, unpublished data). Data such as these suggest that having strong internal control beliefs in situations which do not allow for such personal causation will tend to be detrimental in terms of physiologic activation and, if such a "person-environment" mis-match is relatively chronic, may actually result in increased pathophysiology. Known links between the Type A Behavior Pattern and increased risks for heart disease may be an example of such links. Type A's have been shown to have a strong need for control (Strickland, 1978; Miller et al, 1985), to persist in attempts for control in laboratory situations (Miller et al, 1985; Strube & Werner, 1985) and to exhibit greater physiologic reactivity in the face of uncontrollable situations (Krantz, Glass & Snyder, 1974). Such persistence, in the face of external realities that limit or prevent actual control over outcomes, along with its accompanying physiologic reactivity may contribute to Type A's increased risk for CHD. Personal control beliefs, however, may also contribute to CHD risk, independent of Type A behavior. The presence of stronger personal mastery beliefs, for example, has been found to be associated with greater coronary atherosclerosis independent of other known risk factors (Seeman, 1991). To the extent that such strong mastery beliefs may tend to promote unrealistic expectations for control, they may be associated with patterns of physiological arousal that promote the development of atherosclerosis.¹

The important lesson to be taken from this research is that HCBS delivery systems that provide greater control will likely have a positive effect on the participant's psychological and physical health. However, delivery systems that promise greater control, but have flaws that prevent that control from materializing may do more harm than good.

Whether consumer-directed HCBS results in better outcomes largely depends upon how well the infrastructure that supports the delivery of these services is provided. This paper examines potential approaches to designing this infrastructure.

¹ "Personal Control." Summary prepared by Teresa Seeman in collaboration with the Psychosocial Working Group. Last revised July, 1999. Available at: www.macses.ucsf.edu/Research/Psychosocial/notebook/control.html.

Potential outcomes that the system can support

HCBS is unique in government programs because it rests at the intersection of healthcare and families. Government needs families to be involved because they must capitalize on existing informal/unpaid resources to keep programs affordable. Families need outside assistance because time demands often exceed their capacities and they often lack the technical expertise to support someone who has complex medical conditions or other needs requiring specialized assistance. Thus, to be successful, the system should support the following potential outcomes:

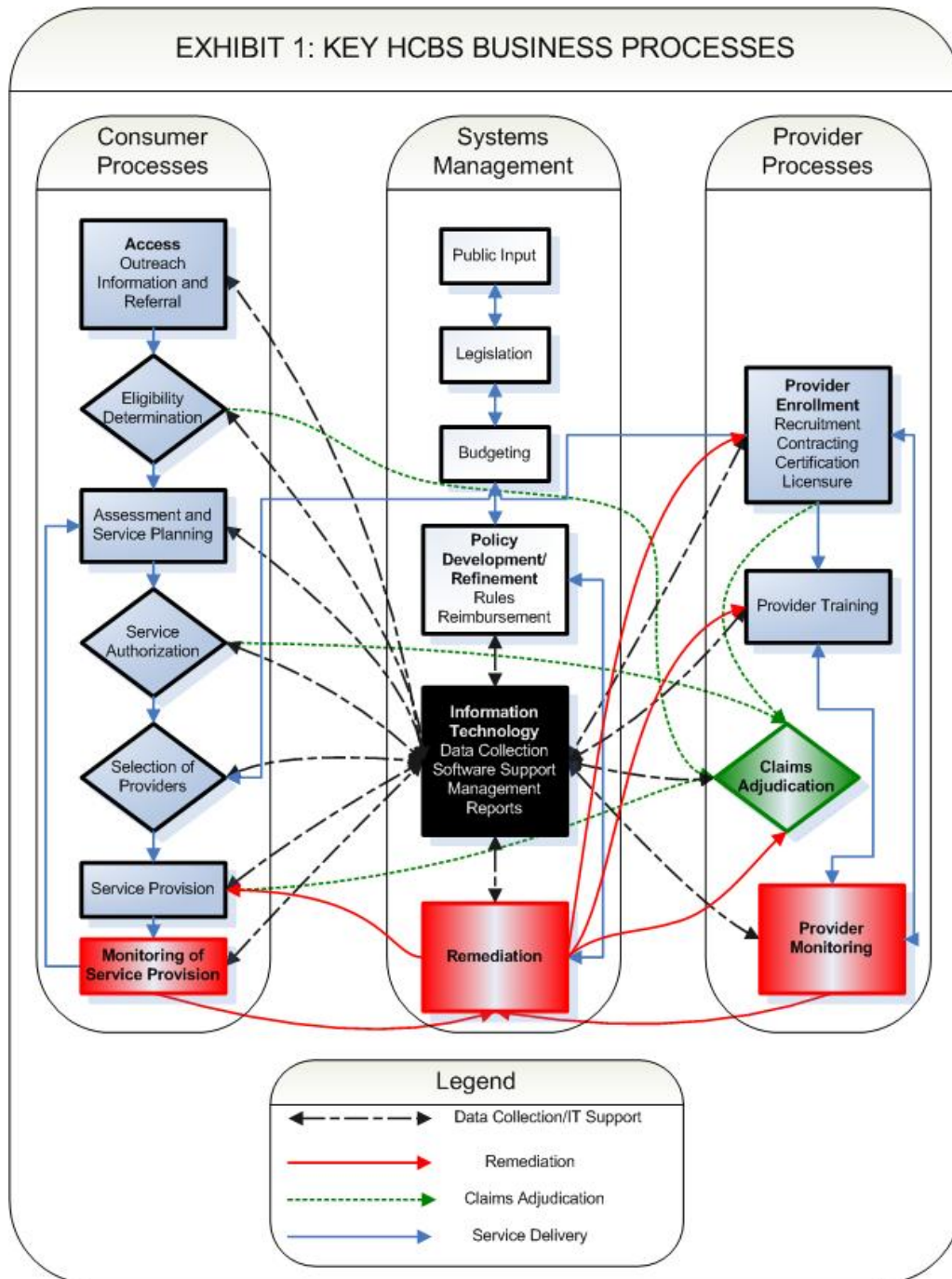
- Consumer-direction
- Community integration and participation
- Familial involvement/responsibility
- Cost containment
- Health status maintenance/improvement

Most states have made or are in the process of making the first change necessary to build a consumer-directed system, adopting a philosophy that identifies consumer-direction as a primary goal. To date, States have developed systems that rest upon the assumption that the consumer will be a somewhat passive in directing or managing the services provided by an agency. In contrast, increasing consumers' ability to direct and control their supports and decreasing dependence upon traditional agency providers involves removing responsibility for some or all of the functions typically performed by the agency provider. States must then decide who will assume responsibility for these functions. Thus, they must build infrastructure that either allows the consumer to perform the function or develop new types of providers that will assume the functions. Many states are responding to this change by developing new providers that assume the functions of paying staff, including managing taxes and benefits. The providers, commonly known as fiscal intermediaries, remove a major barrier, making it easier for consumers to manage pay staff and comply with Internal Revenue Service (IRS) regulations and assure that cash flows to the individuals providing direct care. In many cases states have expanded the role of the fiscal intermediary to include some of the other functions listed above.

States generally have not recognized how fundamental a shift consumer-direction is in changing all of their business processes. The remainder of this paper is devoted to discussing how states can alter their core business processes and maximize technology tools to assist in this shift in responsibility.

Key HCBS business processes and the use of IT support to facilitate consumer-direction and greater efficiency

Exhibit 1 provides an overview of key HCBS business processes. This flowchart demonstrates the overall complexity of the basic delivery system, summarizes the overall process by which individuals access and receive supports, and incorporates the means of monitoring those supports. (Later exhibits provide greater detail on specific processes. This paper also includes a discussion regarding how IT can be used to support each of these business processes as well as facilitate the ability of both agency-provided and consumer-directed supports.)



The framework presented in *Exhibit 1* examines HCBS delivery systems from the following three perspectives: 1) individuals trying to access and receive services (consumer processes); 2) entities trying to become enrolled and act as service providers (provider processes); and individuals trying to monitor and manage the support delivery system (systems management).

The color blue is used to refer to key processes that are necessary for an individual to receive supports. The color red is used for processes whose core function is to monitor and ensure the quality of these services. The color green is used to show core functions necessary to ensure that providers are paid (i.e., claims adjudication).

The black box at the center of the diagram represents the IT systems that may be used to support each of the business processes. This box may include the following:

Software that supports key functions, such as an automated assessment tool that informs eligibility determinations and support planning;

Databases of raw information, such as client and/or provider characteristics;

Mechanisms for exchanging data electronically between different IT systems and among partnering organizations; and

Mechanisms for summarizing information so that it is more useable, such as the creation of data warehouses that match data from multiple databases and management reports that extract key pieces of data in a manner that can be acted upon (e.g., summarizing the number of critical incidents for a particular provider and if that number exceeds a set threshold, an investigation is triggered).

It is important to note that not all programs follow the sequential order included in this diagram. For example, Minnesota's Comprehensive Assessment purposefully moves back the eligibility determination until after the assessment to try to eliminate a bias towards having funding streams, rather than assessed needs and preferences, driving the assignment of supports. Many states also set an authorization for a budget based on a more limited assessment and then require that case managers gather more detailed information and craft a service plan that fits within that authorized amount.

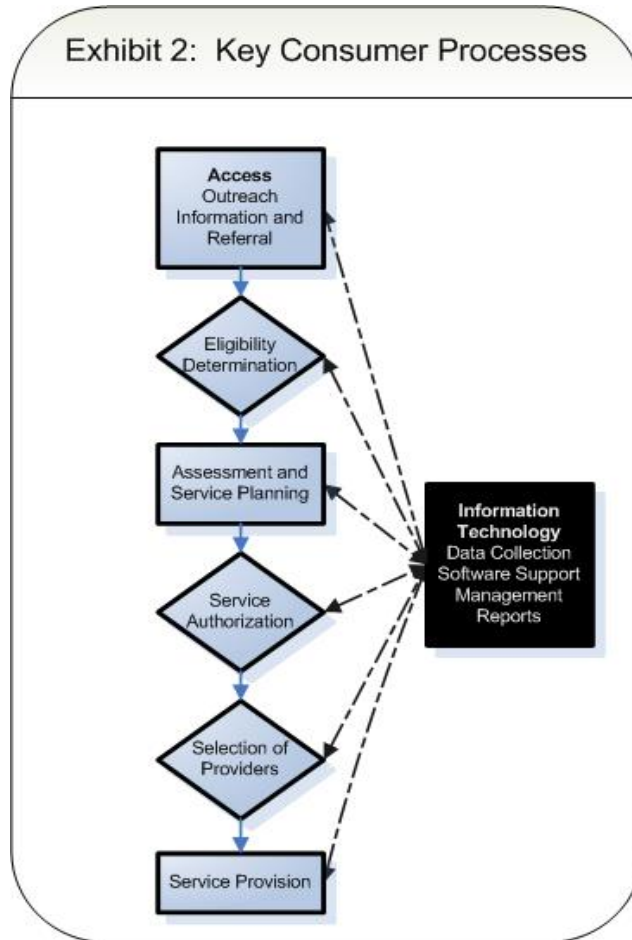
Key Consumer Processes

Exhibit 2 shows key processes that allow an individual to identify and obtain supports. We discuss all of the processes included in this flowchart with the exception of Service Provision, which is discussed in the next section, Key Provider Processes.

Access

Individuals in need of supports must be able to find them. State efforts can be broadly broken down into two key functions: outreach and information and referral (I & R). For purposes of this discussion, we will define outreach as efforts to inform individuals who could benefit from supports or entities that have contact with these individuals (e.g., physicians, hospitals, social service agencies, etc.) about the availability of these supports. Examples of outreach include educating hospital discharge planners about HCBS that is available or providing pamphlets at a health fair that describe a specific program. We define I & R as being the process through which individuals who express

interest in receiving services are provided information about what is available and appropriate and how to access those services.



IT systems can support a variety of access functions. A database program could be used to track outreach efforts. This database could be tied to another database that tracks contacts received including the source of that contact to assess whether the outreach efforts were successful. A database with up-to-date information about available programs and their requirements is essential in making appropriate referrals.

Most Aging and Disability Resource Centers (ADRCs), the joint AoA/CMS initiative to streamline access for older adults and individuals with disabilities, have or plan to use at least one IT solution to facilitate access. An April 2007 technical assistance paper on this effort described many of the initiatives.² Hennepin County, Minnesota provides an example of one of these initiatives. The

² Chapman and Carrie Blakeway, “Moving Forward: Opportunities for Information Technology Advances

county developed a short series of questions that are asked by all the different departments within the county to determine to which area of the county the person should be referred. This “no wrong door” approach provides information about eligibility and program contact information. This helps ensure that no matter where within the county the initial contact is made, the person will be routed to the most appropriate place. Many ADRCs are implementing IT systems that allow for data sharing across different platforms and organizations. These data sharing systems help break down traditional barriers between service networks and providers and make it easier for organizations to work together to serve individuals and their families. Electronic referral systems allow for information that is collected during an initial contact to be shared electronically with the appropriate partnering agency or service provider without the person seeking services having to answer the same set of questions over again. Positive outcomes include: fewer people getting lost in the transition between agencies, less frustration for the individual needing services, and quicker initiation of services.

ADRCs are using IT to provide consumers with greater control over accessing services, primarily by increasing their ability to make informed choices. In the traditional system, most of the information about the availability of HCBS lay with people connected to the aging and disability network of service providers or the government agency responsible for overseeing the program. Individuals in need of supports needed to somehow come into contact with one of these entities and then rely on the information that was provided. This information was typically limited to the funding streams, programs, and providers with which their contact point was familiar. ADRCs are using IT to develop databases of programs’ corresponding eligibility requirements, and providers offering services, in order to facilitate the ability of individuals to make informed choices. Ideally, an individual contacting an ADRC could answer a few questions which would then be entered into a software program that included algorithms to identify programs and funding streams that might be appropriate for that individual. The individual would then be able to make an informed choice about how to move forward from a range of options. Similarly, a database of resources and providers, especially one that included information about their capabilities, availability and indicators of the quality of their service, could allow individuals to make informed choices across a range of providers.

Eligibility Determinations

After finding out about services, the next step is typically to determine if the individual meets the financial and functional and/or medical criteria for entering the program. For 1915(c) waivers, this means that they must meet the level of care criteria (LOC) for the institution that serves as the comparison for cost neutrality purposes (i.e., nursing facility, intermediate care facility for individuals with mental retardation (ICF-MR), or hospital). However, most states have other programs for which the individual may be eligible, such as Medicaid funded personal care or programs funded with state or local dollars only.

in the Aging Network.” Available at <http://adrc-tac.org> .

In most cases, States have had separate processes for determining the eligibility for different funding streams or benefits within the same funding stream. For example, the department on aging might determine eligibility for the Medicaid 1915(c) waiver, while the Medicaid agency would determine eligibility for the Medicaid State Plan personal care benefit. ADRCs and other efforts to build single point of entry have made great strides at trying to integrate some of these processes.

Integrating eligibility determination processes has become more important as potential funding streams have multiplied. This increase in complexity is attributable to the following:

In many States, subsets of individuals demonstrate needs that meet the criteria of multiple waivers and State Plan services. These individuals typically have a combination of disabilities which may include cognitive, physical, and/or medical conditions. Where there are waiting lists for waiver services, these individuals will elect State Plan services while waiting even though the State Plan service may not entirely meet their need for habilitation or rehabilitation. Similarly, individuals may elect to enroll in a waiver program that is less likely to provide the array of services and funding for the range/scope of their disabilities, due to waiting lists or caseload growth priorities (such as first serving people leaving institutions) in another waiver.

There has been a broadening of the types of services that are offered under the Medicaid Health Rehabilitation Option, so that many individuals with disabilities and older adults could potentially benefit from these services.

The Deficit Reduction Act of 2005 (DRA) creates two major new funding streams that are applicable for these populations: state plan HCBS (1915(i)) and state plan consumer-directed personal care (1915(j)).

Thus, to determine which program and funding stream is most appropriate, the following must be considered:

- For which programs does the individual meet the functional and/or medical eligibility requirements;
- For which program does the individual meet the financial eligibility requirements and which will allow the individual to retain the most of her or his income (this becomes even more complicated if the individual is employed);
- What types of services are offered by each funding stream and what is the availability and quality of the providers that participate in each funding stream;
- What is the waiting list for each funding stream (this is more complicated when the waiting lists give priority to individuals meeting certain conditions); and are there regulatory requirements to use one funding stream first (e.g., generally state plan services be used before waiver services)

The level of complexity created by these multiple decision points is daunting for both the individuals trying to navigate the system and those trying to assist them. IT can be of great assistance in navigating this maze. The basic approach for using IT as a tool involves codifying the key pieces of

information about eligibility, waiting lists, and provider availability and developing a decision tree that will assist in making key decisions throughout the process.

For example, the first decision point might be for which programs is the person eligible. Key information necessary to make a determination for a variety of programs is entered (most likely information about functional impairment, limited information about acute or skilled nursing need, key diagnoses, IQ, and assets and income). The software would then indicate a preliminary determination of which eligibility criteria the individual is likely to meet. Next, the software program could lay out key information necessary to choose among programs and funding streams, such as: the types of services offered under each program/funding stream, which programs/funding streams could be combined or are mutually exclusive, waiting lists, and provider availability.

This information will facilitate the ability of the individual (and those assisting) to make an informed choice about which services and funding are most appropriate to meet the needs and are compatible with the personal goals of the individual.

Assessment and Service Planning

The process of assessing an individual's needs and developing a corresponding service plan, (also known as a support plan, an individualized support plan (ISP), a care plan, and other names), differs dramatically across states. The overall purpose of this effort is to better understand an individual's needs and develop a plan for meeting those needs.

There is considerable pressure on states to standardize assessments and support plans. Language in the DRA mandates that, for the new 1915(j), consumer-directed personal care budgets must be based on assessments. CMS audits of 1915(c) waivers are likely to examine case files to determine if there is sufficient documentation in the assessment materials to justify services. In addition, the new CMS 1915(c) waiver application requires that states make assurances in key areas. Data from standardized assessments may form a core of performance indicators that will assist a state in making these assurances.

The main thrust of trying to make this process more person-centered is to reshape the process to not only look at needs, but to also look at strengths, preferences, and the ongoing availability of informal supports that could be used in combination with services. The DRA mandated that assessments for the 1915(j) option examine strengths and preferences in addition to need.

In developing its Comprehensive Assessment, Minnesota decided to incorporate this philosophy into its assessment in a number of ways. First, the assessment begins with a mandatory person-centered interview that addresses issues such as the individual's personal history, hopes and goals, and expectations for supports. Stakeholders in Minnesota expressed a strong desire for this to be upfront because they felt that in current assessments, individuals were only asked what they wanted late in the support planning process. They argued that at that point, "the train had left the station and it's hard to change the destination." The idea behind the new assessment protocol is to use it to bias the rest of the support planning process to reflect the wishes and strengths of the individual.

Second, questions and prompts about preference and strengths are embedded within many of the other areas. This is especially relevant for the assessments of activities of daily living (ADLs) and instrumental activities of daily living (IADLs). For example, the assessment not only addresses what assistance the person requires when eating, but examines food preferences and whether an individual is capable of doing portions of the activity, such as cutting food. This information is intended to be then provided directly to the individuals and/or agency providing personal care. In addition, reassessments can address whether the personal care provider actually respected these preferences and strengths.

The development of a support plan builds off the conversation started during the assessment to add the following:

- Identification of specific outcomes to be achieved through the provision of services;
- Special provisions for how health and welfare will be monitored and evaluated;
- A plan for how services will supplement and enable the continuation of available unpaid/informal supports;
- Provisions for back-up if appropriate; and
- An agreement about and a plan for the scope and duration of services, special training or expertise to be required, and a list of specialized equipment to be secured.

Consumer involvement (or involvement of family) in this planning process should always be one of active engagement. However, in a consumer-directed process, it is the consumer who directs and leads the development of this plan. The case manager's role is one of guide and facilitator, meant to advise the consumer about the legal parameters of programs and funding streams, and to assist the consumer and/or family in ensuring that all salient issues are included within the plan.

A well designed automated system can improve the case managers' ability to perform their job in the following ways:

- Information can be easily retrieved and used to inform or reduce time spent on reassessments;
- If linked to a data base used for initial contact and intake, case managers will save time during the assessment process by not having to repeat requests for information already gathered during earlier stages of the consumer process;
- Inconsistencies can be more easily identified and clarified during the assessment process, providing more accurate information for the service planning process;
- Case managers can be given prompts about functions that need to be done ("ticklers"), such as reassessments;
- If linked with a claims database, the case manager can potentially obtain important pieces of information such as inpatient hospital visits and diagnoses;
- Case managers can more easily retrieve information from past assessments;
- The automation can include guidance to train case managers about key policies or best practices; and
- Case files can be more easily shared and understood by other case managers who need to assume responsibility for a person.

Automating the assessment and support planning process can assist the state in managing the program in ways such as the following:

- Data can be electronically analyzed to identify trends and potential quality issues;
- Key performance indicators could be identified to develop a performance driven system and comply with CMS assurances; and
- The system could help ensure compliance with regulations, such as not allowing the assessment to be considered complete until key information is gathered.
- Automation can assist in further the goal of consumer-direction in the following ways:
- Individuals could be allowed to access parts of their assessment and support plan and be provided mechanisms to enter information themselves, making the process more collaborative and transparent;
- Individuals and/or families could be provided access to the same tools available to case managers so that they could assume the primary case management role, while the case manager shifts to an advisory role; and
- The process can be structured to ensure that preferences and strengths are incorporated into the assessment and accompanying support plan.

Service Authorization

States have some sort of process for determining what an appropriate budget is for an individual and then authorizing that budget and/or the set of services within a support plan. This process differs across states with some simply setting an overall cap under which any proposed support plan must fall, while others establish benchmarks or budget levels that are based on a set of characteristics.

A second component to this function is the prior authorization of these services, typically in the state's Medicaid Management Information System (MMIS). Examples of how this is done include inserting an edit within the MMIS that will reject claims for units of service that exceed a preset cap (e.g., no more than 8 hours of personal care in one day) and giving an authorization number that must be included on billings before payment is approved.

The primary challenge with determining what budgeted amount is appropriate and completing the prior authorization process is that, unless parameters are set fairly broadly (e.g., an overall cap for a person or an edit that limits the number of hours), it can be time consuming to sustain these efforts and monitor for needed adjustments. The downside of setting broad parameters is that they less accurately reflect what a particular individual wants and needs. Variations are more likely to occur for which the justification is less apparent than it should be within a well managed system.

In addition, if the process of prior authorizing services is time consuming, case managers tend to react by authorizing everything the individual potentially might need rather than authorizing what the person actually needs and then updating these authorizations as circumstances change.

Automation can assist in alleviating these issues in a number of ways. One, having more detailed assessment data that can be tied to service usage and benchmarks from other state or national data

will eventually allow a state to create more sophisticated cost profiles to guide the establishment of budgets. Once established, these cost profiles can be translated into algorithms that are built into the software allowing case managers to obtain information on budgets at the time they are developing support plans. The data from these assessments could also be monitored to identify whether individuals are being scored as being more impaired on their assessments to qualify for a higher budget.

Two, the software could incorporate logic to better ensure that the support plan is directly related to the assessment. For example, personal care could not be authorized unless an individual needed assistance with an ADL, and increases in personal care would only be justified if there were a change in the level of impairment or deterioration in the availability of informal (unpaid) caregivers. The challenge will be to develop a series of decision trees to guide when supports are justified and then to automate the logic behind these trees. This does not mean that the system needs to become rigid and unable to reflect circumstances that were not anticipated. States could develop standards for exceptions or exceptions processes that would evaluate when other services should be authorized.

Three, prior authorization of services could be done directly from the support plan. Thus, once someone updates a support plan, corresponding prior authorizations would also be updated and notices (most likely emails) could be sent to providers. This could help ensure that changes in services are supported by changes in the individual's needs or circumstances and are reflected in the support plan. In other words, three separate processes—assessment, support planning, and service authorization—would be combined into one process.

Allowing budgets and service authorizations to be more flexible may improve consumer control. Assuming the assessment is person-centered; having budgets and service authorizations that have the flexibility to follow and change with these assessments could allow these consumer-oriented assessments to better influence budgets allocated for services.

Selection of Providers

To some degree, most states have compiled lists of available providers from which a consumer can choose. The utility of these lists depends on how frequently they are updated, whether they include all providers, and whether they include other crucial information that would assist a person in identifying potential providers that are a good match. Thus, information about whether providers have the capacity to support the individual, hours during which they provide supports, service areas, and areas of specialization are all helpful. In addition, having potential indicators of the quality of the provider, such as the information contained within CMS' Nursing Home Compare could also be useful, not only in selecting providers, but creating market forces that would reward good providers.

Most states and local case management agencies have created simple databases that contain basic provider information. The next level of automation would involve building simple queries that would allow for sort based on criteria relevant to needs and circumstances of the consumer. This can be an extremely valuable tool for a case manager who is trying to develop a support plan.

The simplest way to use this tool to advance the goal of consumer-direction is to make an easily searchable database available to the public. The potential transformative effect of this database increases as quality measures are included.

This quality information can also include measures of the degree to which a provider supports an individual's ability to direct their own services and has adopted a person-centered philosophy. This could create market forces that would reward these providers with a larger amount of business.

In addition to relying on statistically valid instruments that tap into the person centered constructs, such as the Participant Experience Survey (PES) and some of the measures developed by the Center for Outcomes Analysis³, online searchable databases of providers could allow consumers to add ratings and descriptions of their experiences with providers, similar to the customer reviews used by websites such as Amazon.com.

Building direct care worker registries is a prominent example of how IT can facilitate consumer-direction. States including California and Washington have built electronic registries that facilitate the ability of individuals and families that manage their services and workers who provide direct personal care to individuals to find each other. These databases can play a crucial role in making consumer-directed care feasible for a wider variety of individuals and helping to overcome shortages of direct care workers.⁴

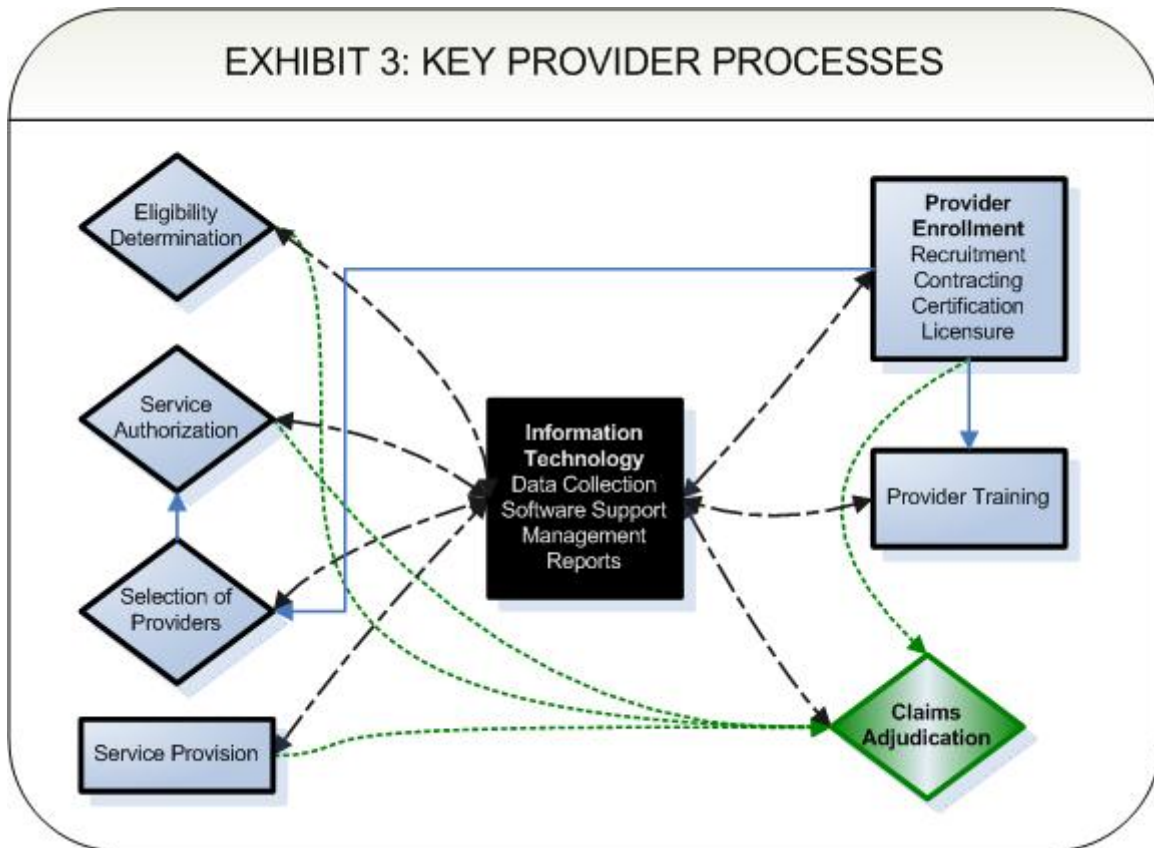
Social networking websites, such as MySpace and Facebook or similar ones focused on caregivers and people needing support, may offer an approach to assisting individuals to recruit both paid and non-paid supports. These sites allow individuals to display information about themselves and find information about other people who have compatible or complementary interests. The sites also allow users to integrate other programs within their framework. A state could create a simple program that outlines an individual's goals and their need for supports. This could be integrated into a social networking page that offers a profile of the person. Similar pages for individuals interested in offering support could also be created. For example, an older adult who needs assistance with instrumental activities of daily living (IADLs) such as chores, housework, and shopping and who has a spare room in their house could use this site to find a college student who would be willing to provide this support in exchange for rent. These sites might be even more powerful for facilitating integration into the community. The purpose of these sites is to support the development of relationships around common interests. Individuals with disabilities, their family members or their case managers could use these sites to locate and recruit people who have interests that coincide with the individual's personal goals and outcomes.

³ <http://www.outcomeanalysis.com/>

⁴ A description of these efforts can be found at: <http://www.betterjobsbettercare.org/page.asp?pgID=172>.

Key Provider Processes

Exhibit 3 provides an overview of the key business processes states use to enroll and manage providers. Providers are affected by many of the consumer business processes. Before a vendor begins providing supports, the individual must be deemed eligible, the provider must be selected, and the service authorized. As discussed earlier, an IT solution can assist in making all of these processes more efficient.



Service Provision

Consumer-direction involves shifting responsibility for many of the processes necessary to provide services from an agency to an individual and/or family member. These processes include:

- Identifying and hiring workers;
- Managing payroll for workers, including paying taxes and insurance;
- Recruiting clients and/or payment sources, such as becoming enrolled as a Medicaid provider;
- Training workers;
- Monitoring the quality of supports provided by staff and intervening when issues arise;

- Coordinating schedules to ensure that all client needs are met and all workers are fully utilized, including providing substitute or back-up staff when staff are not available or fail to show up;
- Evaluating, promoting, and firing staff;
- Ensuring workers have transportation to the work site;
- Managing the provision of services to ensure they do not exceed pre-authorized limits;
- Billing for services; and
- Maintaining programmatic and financial documentation necessary to comply with state and federal requirements.

States typically rely on independent providers to fulfill these functions with two major exceptions. States often offer training to providers and their staff on certain issues (see section on provider training below for a greater discussion on this) and the states share the responsibility for managing the quality of the services with the agency (see sections on Service Monitoring and Provider Monitoring).

States can facilitate consumer-direction in two general ways. One, they can encourage or mandate that providers modify the functions listed above to improve consumer control. Common examples of this include the following:

- Allowing the consumer to select staff;
- Hiring family members or other individuals selected by the consumer;
- Incorporating person-centered principles into training or allowing the consumer to be a central player in providing the training; and
- Using input from the consumer as a component of a performance evaluation.

Two, states can bypass providers altogether and allow consumers to control a budget. Individual budgets that consumers manage that are available through the Cash and Counseling and Independence Plus programs are examples of these arrangements.

Facilitating consumer-direction will involve determining how to promote the ability of individuals and families to assume the key business functions that agency providers now assume. Most states have not built significant infrastructure to do this with one major exception. Most states do offer the services of a fiscal intermediary who will take on the role of managing payroll, including paying taxes and workers compensation. This removes a major barrier for most potential program participants. However, most programs offering individual budgets leave it up to the individual to assume the rest of the functions, such as recruiting, hiring, training, and managing staff. The remainder of this section will include examples of how states can and are altering their existing infrastructure to rectify this and make consumer-direction feasible for a larger number of people.

Provider Enrollment

Every state must have a mechanism by which a provider becomes eligible to receive payments from the Medicaid program. This effort often has two components: 1) efforts to recruit or develop new

providers to ensure there is an adequate range of providers and 2) mechanisms to enroll providers within the Medicaid program.

Mechanisms for enrolling providers include the following:

- Allowing any qualified provider that meets certain criteria to enroll;
- Requests for Proposals (RFP), Quotations (RFQ), etc.; and
- Human Services Agreements.

These arrangements usually require that the entity be certified by the Medicaid agency to meet certain requirements. Often times, this certification includes or is replaced by licensure requirements for particular provider types.

States can facilitate consumer-direction in two ways. One, states can try to identify barriers that individuals and their families face in trying to have the provider of their choice enrolled in the Medicaid program. Actions states have taken to facilitate this range from removing prohibitions on agencies from hiring family members of individuals receiving personal care to allowing individual direct care staff to enroll as a personal care provider. Two, states can recruit a broader range of providers, thus facilitating greater choice.

IT can play a role in facilitating both efficiency and choice by allowing providers to apply online and update information about their capabilities. Integrating the process of provider enrollment and building a searchable database of provider capabilities into one system may help to achieve both goals. A perceived barrier with creating an online database of provider capabilities is the burden of ensuring the information in that database is complete and accurate. However, if structured correctly, this barrier may be easily overcome. If case managers and consumers use a database to decide which provider to use, providers have a strong incentive to participate in that system and ensure that information is up to date. RTZ Associates' GetCare system allows providers in Arkansas to enter and update their information online and they report that provider compliance has not been a problem. States can further ensure accurate information by using a database as a key component of their certification process. For example, a state could require that the information for annual recertifications be entered into the database and restructure its recertification review to verify the accuracy of the information entered.

Linking the process of enrolling providers to the process of facilitating provider selection is one of the most tangible benefits of examining business processes as part of a larger system rather than standalone efforts. In this case, an effort to automate enrollment can result in even greater efficiencies by allowing case managers and individuals to make more informed decisions about their selection of providers.

Provider Training

Prior to the introduction of CMS' new application for the 1915(c) waiver, many states would have viewed training as a key provider business process, but not a key business process that the state must oversee. However, the instructions for the new waiver application include the following language:

“Conduct training and technical assistance concerning waiver requirements.

The performance of this function may include activities such as providing training to case managers concerning best practices in the development of service plans, acquainting waiver providers with waiver service documentation and billing requirements, and furnishing technical assistance to improve waiver operations. This function does not include training providers in order to assist them to qualify as waiver providers.”⁵

“The State implements its policies and procedures for verifying that training is provided in accordance with State requirements and the approved waiver.

The QMS [Quality Management Strategy] specifies:

- The discovery processes that are conducted to ensure that training is provided and that the state takes action when providers do not meet the waiver's training requirements, who conducts discovery and with what frequency;
- Who reviews the results (data and information) from ongoing discovery activities to determine whether the performance of the system meets the assurance;
- Types of information used to measure performance of the system, including relevant quality indicators; and,
- The frequency with which system performance is measured.”⁶

Thus, the state and any agency that has been delegated authority for operating a waiver have responsibility for conducting a limited amount of training and assuring that providers and their staff have met training requirements set in the service definitions. States can use IT to respond to these mandates in the following ways:

- Establishing a database to track whether providers met training requirements. A state could develop a template that would document whether staff had met certain training requirements using a program such as MS Excel or Access and request that providers complete the template for each staff member and send an electronic version to the state. The state would then merge these files to track whether providers met training requirements. Alternately, a state could develop a web-based database which would allow providers to document that staff met training requirements online.

⁵ Application for a §1915(c) Home and Community-Based Waiver [Version 3.4:] Instructions, Technical Guide and Review Criteria. Centers for Medicare and Medicaid Services. November 2006, pg. 60. Available at: http://www.cms.hhs.gov/HCBS/02_QualityToolkit.asp#TopOfPage .

⁶ Ibid, pg. 232.

- Developing web-based training tools. These tools can provide online training and also keep track of who completed the training.

States can facilitate consumer-direction by making these options available to individual who are managing their own supports and the staff that are supporting them, as well as traditional providers. As stated earlier, one of the challenges of consumer-direction is that responsibility for training is shifted from an agency to individuals and/or their families. Providing access to web-based training tools could make assuming this responsibility more feasible.

Claims Adjudication

The last provider process include in the flowchart is claims adjudication, which is the process by which a state decides that a claim to reimburse for services provided is justified. Typically, adjudicating a claim involves determining the following:

1. The provider is a certified Medicaid provider in good standing;
2. The individual to whom a service was provided is an eligible Medicaid recipient and eligible to receive this service; and
3. The service was provided in a manner that is consistent with the states regulations and policies and procedures, including any prior authorization requirements (e.g., if the state plan limits personal care to 8 hours a day and the provider bills for 12 hours, the claim will be rejected).

Typically, claims adjudication has been automated. In most states, claims adjudication is handled by the MMIS. In some states, waiver programs have established their own claims adjudication system that then feeds information back into the MMIS.

A state will build in “edits” into the MMIS to ensure that claims that violate certain policies are rejected. However, the ability to build these edits depends upon the information that is in the MMIS. For example, a state could build an edit that prevents a provider from billing for more than 8 hours of personal care in a day, but could not build an edit that ensures that those hours were actually provided.

Automating other business processes, such as assessment and service monitoring, can improve a state’s ability to ensure that services were provided in the prescribed manner. Information from these other automated systems could be imported into the MMIS to make enforcement more comprehensive. For example, if a state had a telephone verification system or an automated mechanism that consumers could sign off that a service had been provided, this information could be used by the MMIS as a consideration in adjudicating a claim.

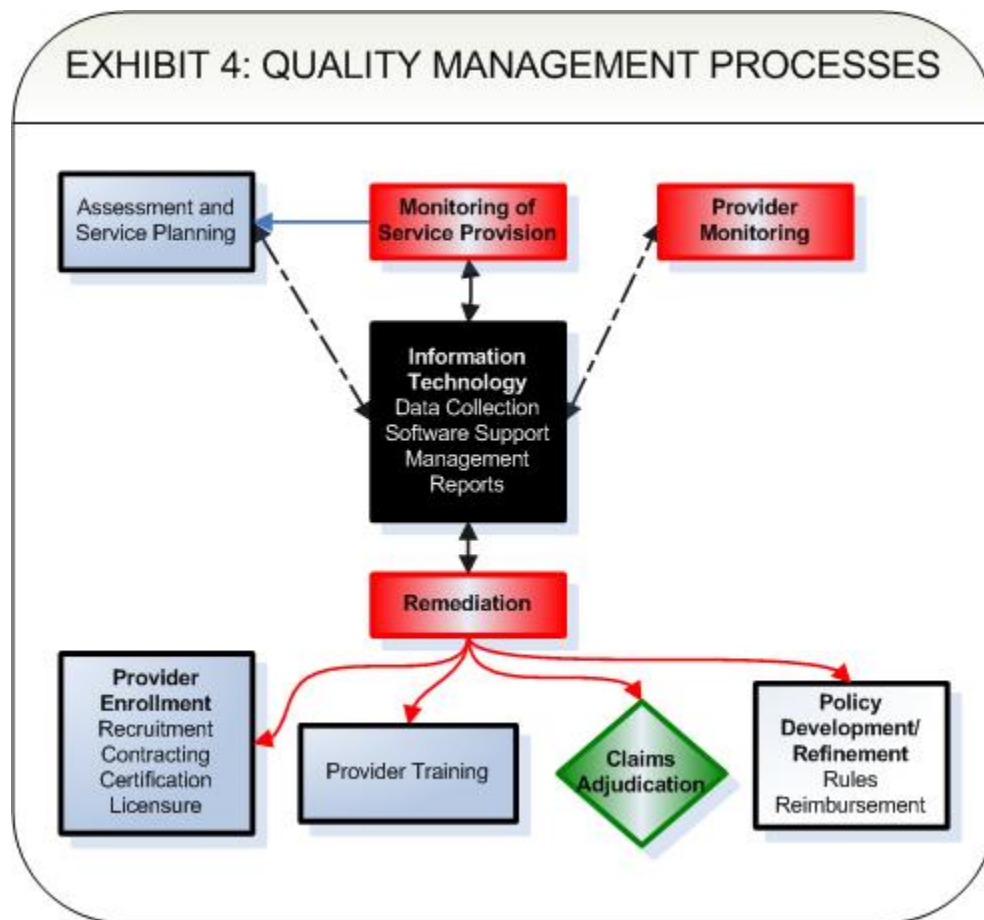
In addition, information from the MMIS could flow to other systems to improve their efficacy. For example, information included on claims such as type of service (e.g., inpatient hospitalization) and diagnosis could be linked with an assessment and case management system.

States have made a lot of progress in this area in facilitating consumer-direction by establishing fiscal intermediaries. These services typically remove the necessity of having the consumer interact directly with the claims adjudication system, thereby removing a major potential barrier to consumer-direction.

Key Quality Management Processes

Exhibit 4 provides an overview of key quality management business processes that states operate. We make a distinction between two major types of monitoring:

- Monitoring of services provided to a particular individual. This is typically a primary case management function.
- Monitoring of providers. This is typically a licensure or certification function that involves examining whether a provider is complying with program requirements.



Service Monitoring

Once supports are authorized and provided, states must verify that services have been provided and have been provided in a manner that is consistent with the support plan and the individual's preferences. Operationally, this area can be broken into ensuring that: 1) providers have filed claims for services in the support plan; 2) services for which claims were filed were actually provided; and 3) services were provided in a manner consistent with the individual's needs, preferences and strengths.

Matching support plans and claims. A simple check on whether the support plan was fulfilled is to crosscheck that plan with filed claims. Finding that individuals were receiving substantially fewer services than they were authorized to receive could indicate that there was a shortage of appropriate providers or that a different service mix should be used.

The seemingly simple task of comparing a support plan with filed claims necessitates extracting information on filed claims that typically resides in the MMIS with information gathered from the support plan. If the support plan is not entered into an electronic database, a printed extract from the MMIS must be manually compared with the support plan. The ideal solution would be to have an automated support plan that is linked with the claims authorization database and reports that were generated that compared supports and claims.

Interpreting this cross-check is often complicated when case managers over-authorize services to avoid having to make adjustments when needs increase. In this case, one would expect that authorized services would always be substantially greater than claimed supports. The challenge would be to establish a threshold that would indicate when this gap was so large that it could indicate that the individual was being underserved.

Ensuring that services were provided. States have taken a variety of approaches to ensure that services were actually provided. These approaches do not necessarily need to take advantage of IT. For example, Illinois requires that parents whose children receive nursing services under the Medically Fragile Technology Dependent waiver sign each nurses' time sheet and that these timesheets be submitted with billings. However, this approach requires someone to manually review these timesheets and match them up with a claim before that claim is paid.

IT is increasingly being used to verify that supports were actually provided. States including Arizona, California, Ohio, and South Carolina have built IT systems that electronically verify and track whether personal care was provided. For example, South Carolina has implemented Care Call,

a toll-free telephone check-in and check-out system for in-home personal care attendant, companion, and nursing providers.⁷

Ensuring that services were provided in a manner consistent with needs, preferences and strengths. Determining that services provided were done so in a manner consistent with what the individuals with a disability and/or family would want is a more complicated task. This requires that the individual and/or family express or are given an opportunity to express how supports should be provided to the direct care provider and that whomever is monitoring the provision of supports uses this information as the basis of that monitoring.

States typically have one or more of the following mechanisms to inform them about the quality of supports provided:

Incident management systems. Many states have established requirements that providers report critical incidents to the agency operating a waiver. A 2004 survey found that 85% of programs supporting individuals with developmental disabilities and 50% of programs supporting individuals with physical disabilities and/or older adults had such a system.⁸ The new CMS quality requirements have probably caused other additional waiver programs to build incident management systems.

Data collected from case managers. Case managers are typically in the best position to obtain this information from the consumer and ensure that providers are complying with these requirements. Most of this monitoring will frequently be gathered during conversations and kept in case notes. A case manager who has the time and the will can use this information to play an important quality management role.

External case reviews. A 2004 study found that 83% of waivers surveyed had a process by which reviews were done on a sample of cases to determine how well service plans had been implemented. These reviews included observation and interviews with the program participants.⁹

Participant surveys. States often gather information using satisfaction surveys or other measures of the individual's experience, such as the Participant Experience Survey (PES) developed by MedStat with funding from CMS. While these tools can be important in understanding the overall effect of the program, when they can be related back to specific individuals and/or specific providers the tools can be used as mechanisms for changing the way supports are delivered.

⁷ More information about these initiatives can be found in the AARP report, *Bridging the Gaps: State and Local Strategies for Ensuring Backup Personal Care Services*, available at: http://assets.aarp.org/rgcenter/il/2006_19_pcs.pdf.

⁸ Gary Smith and Beth Jackson. (January 2004). "Summary of Results: National Quality Inventory Survey of HCBS Waiver Programs." Prepared for Centers for Medicare and Medicaid Services (CMS). Available at: <http://www.cms.hhs.gov/HCBS/downloads/sumnatqinvreport.pdf>.

⁹ Gary Smith and Beth Jackson. (January 2004). "Summary of Results: National Quality Inventory Survey of HCBS Waiver Programs." Prepared for Centers for Medicare and Medicaid Services (CMS). Available at: <http://www.cms.hhs.gov/HCBS/downloads/sumnatqinvreport.pdf>.

There are two challenges in trying to translate these data into a coherent strategy that ensures that supports are consistent with needs, preferences, and strengths. One, information from all of these sources must be analyzed, integrated and shared in a manner that can be acted upon. For example, incident reports must be shared with case managers and trend analyses of these incidents could be used to identify problematic providers. Ideally, all of this information could be summarized into reports that case managers and individuals and their families could use to select providers.

Two, what are an individual's preferences, strengths, and needs and whether a particular support has met them must be specific enough to facilitate the creation and use of performance indicators. Minnesota's Comprehensive Assessment is attempting to do this for ADLs and IADLs. In each case, an individual is not only asked about level of impairment, but preferences and strengths. *Attachment 1* provides an example of how this is used for the eating ADL. Minnesota intends that this information will be directly shared with whoever is providing personal care. In addition, case managers will ask at reassessment whether supports are being provided in a manner that is consistent with these stated preferences and strengths. IT will play a crucial role in that it will make previous assessments available and facilitate the comparison of what is happening now with what had been expected to happen at previous assessments. In addition, the state can track consistency between stated preferences and strengths and supports delivered as a quantifiable outcome measure.

Provider Monitoring

For many community-based services, states have processes for reviewing the performance of individual providers that are separate from the monitoring typically done by case managers. States are more likely to have a formal licensure process for residential supports, such as group homes, and daytime supports that are offered in a facility specifically designed for individuals with disabilities and older adults (e.g., "brick and mortar" day treatment program, adult day care, etc.). States often have a certification process and/or annual review process for other supports.

This monitoring typically involves a protocol that includes items that will be examined during the review. In some cases, these items have been translated into checklists. In others, narrative descriptions are used. In the past, states maintained paper file records. States are now moving towards creating databases into which this information is entered.

CMS' new quality requirements push states into identifying components of these reviews that can be used as performance indicators. Ideally, states would gather quantifiable data on these performance indicators and enter this information into a database that uses these data for program improvement.

Relatively simple database programs, such as MS Access, could be used to create these databases, though some states have created more sophisticated systems. However, the efficacy of these reviews is limited because they rely on data that are only collected annually and are gathered by individuals who have limited contact with the actual delivery of supports, in comparison to the direct care providers, the case managers, and the individuals themselves.

Combining the information gathered during the provider reviews with the data sources described in the Service Monitoring section provides a much more robust picture of provider performance. An added benefit of trying to coordinate these two review processes is that it is likely to identify where these two efforts are working at cross purposes. States are learning that empowering individuals and allowing them to live in the most integrated setting must be balanced against perceived risks to health and safety. Provider monitoring, especially licensure reviews, tend to focus solely on health and safety. If these reviews are necessary for a provider to continue to participate in the Medicaid program, the balance may be thrown off in favor of excessive attention to only health and safety. Trying to integrate the two processes could result in changes to the provider review process that alleviates this bias.

This is a good example of where IT must be accompanied by reforms to business processes. Establishing an automated process that identifies every issue and requires follow-up for a licensure process that solely focuses on health and safety and does not consider choice and integration could cause case managers and providers to restrict choice and integration. Only reforming the underlying business process to create an appropriate balance will improve the system.

Remediation

States must identify ways to use the information gathered from the service and provider monitoring efforts. States typically have a variety of methods to address problematic providers. The 2004 survey cited earlier identified the following approaches:

- Corrective action plans (96% of all programs responding to the survey),
- Preventing the provider from serving additional program participants (82%),
- Fines/financial penalties (42%),
- Transferring program participants to other providers (92%), and
- Terminating the provider (79%).¹⁰

In addition to these approaches, states may act upon problematic indicators by changing or increasing training and/or modifying program rules or reimbursement structures.

The changes to the monitoring processes described earlier could lead to better information to be addressed in the remediation process. By selecting person-centered indicators, remediation can be used to further the goal of building a consumer-oriented system.

IT systems can then be used to track the impact of remediation activities. For example, a report could be developed that will monitor the performance of providers who received a training intervention.

¹⁰ Gary Smith and Beth Jackson, Ibid.

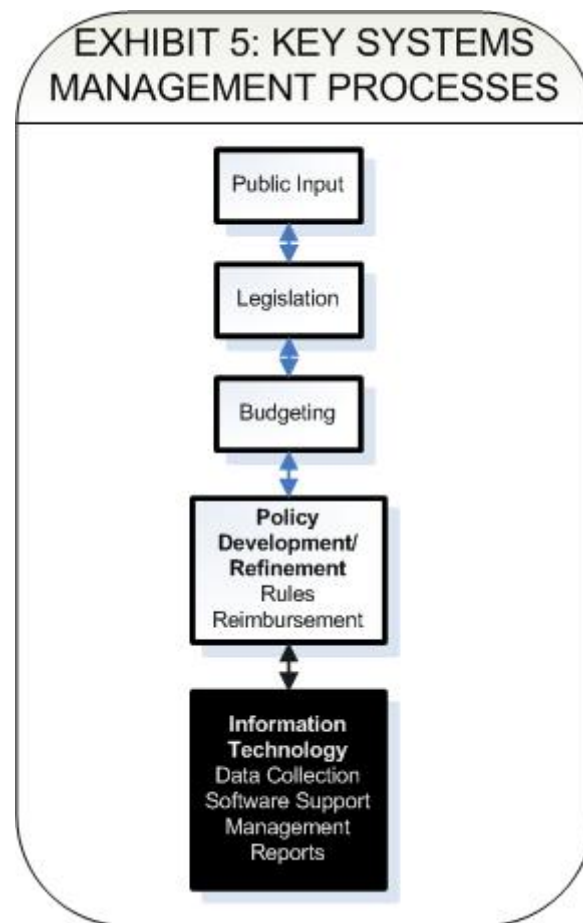
Key Systems Management Processes

Exhibit 5 provides an overview of key systems management processes. In this system, information on program performance gathered from all of the processes above is used to guide the development of policy, shape the budgeting process, inform legislation and inform the public.

We break policy development into two major categories:

Rules. States implement policy or create policy regarding the operation of services through the promulgation or issuance of standards, instructions, and guidance to the stakeholders in the system. These instructions are conveyed in a variety of ways, ranging from published regulations to policy manuals and letters sent to providers.

Reimbursement. How a state pays for supports also has a strong effect on how the system operates. This category includes rates and rate methodologies for individual services as well as other financial architecture, such as establishing a capped budget for an individual or a particular area.



All of the information gathered through the other business processes discussed in this paper could be used to inform the development of these policies. The challenge is to have useable data that can inform the process and summarize the data so that it will inform rather than overwhelm policy development.

CMS' quality framework that emphasizes the development and use of performance indicators provides a sound framework for achieving both of these objectives. States must select meaningful performance indicators, gather accurate and complete data on these indicators, summarize this information into readable reports and distribute this information.

Examples of how this process can be used include the following:

A state could select as an indicator the percentage of personal care hours identified in a support plan that was actually provided. A lower percentage in extremely rural areas could suggest a provider shortfall that may be attributable to the long travel distances not being adequately compensated. The State could then consider a reimbursement approach which adjusts for the additional costs of doing business in less populated areas or which provides other incentives for providers to offer services in harder to reach locations.

A state could select the degree to which individuals believe they control their supports as a key indicator. Examination of circumstances in which individuals score low on this indicator could reveal biases or problems in requirements for certain supports. For example, several individuals may wish to pool their income and buy a house together and move out of a group home. However, no provider may be willing to serve them because it could be perceived as violating licensing requirements. This could cause the State to change licensing requirements to either create variances in these circumstances or to clarify the definitions related to when licensing is required.

Similar processes could be used to inform the budgeting and legislative processes. In addition, states could make this information available to the public at large. This could result in the public input process becoming more of a two-way process in which stakeholders input is informed by key information about how a program is performing.

IT can be of great assistance to states in overseeing their programs. It could help States identify areas where action is needed sooner.

Conclusion: Key Principles for a Successful HCBS Information Technology (IT) effort

The discussion above illustrated numerous ways in which states can and do use IT to improve the efficiency of their HCBS delivery systems and promote the goal of consumer-direction. In addition to the successful examples included in the earlier discussion, almost every state can provide an example of a failed IT effort. While the increasing complexity and scope of HCBS delivery systems has made IT support more necessary, the changing nature of these delivery systems also complicates the task of building an IT system. IT is intended to automate and support key underlying business

processes, but IT systems will also reflect any ambiguity and inefficiency that exist in underlying business processes.

Another paper funded under the Aging and Disability Resource Center Technical Assistance Exchange (ADRC-TAE) discussed the challenges in building IT systems:

A not-so-well-kept secret in the computer industry is that many software projects fail, and there are a fair number of spectacular, budget-busting failures that have ruined careers and organizations. Software projects are different than most other projects in which things are built, because they sometimes produce absolutely nothing of value to their sponsors, even after absorbing a lot of money and time. For this reason it's reasonable to be wary about the claims of vendors and technology boosters. Even with the amazing things we see computers doing today, there are always examples of colossal and embarrassing failures.

There is an entire field of specialty in keeping a software project on time and on budget, and it's important for organization managers to know something about this field, in order to hold a vendor accountable or to find a vendor with reasonable and expert terms of service. A good track record of past performance is often the best measure of likely success. Success in the same domain of service is also a good sign. A vendor that emphasizes the importance of planning and understanding a task to be computerized is likely to be more successful than a vendor who emphasizes the technology. How many personnel are dedicated to a project is often a good indicator too, because, contrary to popular belief, good software is usually the product of a very small team of competent people. Researchers have demonstrated that the more people involved in a software project the more likely it is to fail or to extend far past its deadline.

The most important element in whether or not a software project succeeds is whether or not the client has a good understanding of what they want to do, and can communicate this effectively to system developers. Getting the functional model of a software project right is often 80% of the work. Using flow-charts and business process modeling techniques can help clarify this portion of the task.¹¹

A client seeking to build an IT system can improve the likelihood that they can clearly communicate their needs to developers if the following is kept in mind when designing the system:

First identify the outcomes. The starting point of any effort to develop an IT system should be to clearly delineate the expected outcomes (e.g., consumer control, community integration, etc.) of the program and determine how each of the business processes supports these outcomes. Any business process that is crucial to the delivery of services will impact these outcomes.

Identify and involve stakeholders. The effort to build a better system should include the identification of all stakeholders (e.g., state officials, case managers, individuals, family members, etc.) who could impact the system and a determination of who they will interact with in each of the

¹¹ Gary Chapman and Carrie Blakeway (April 2007). Moving Forward: Opportunities for Information Technology Advances in the Aging Network. Available at: http://adrcetae.org/tiki-index.php?page=p_DevelopTools.

business processes and accompanying IT support. Each of these stakeholders potentially can play an important role in determining the cost and quality of services. IT can support the ability of all of these players in improving the system if it is designed to do so.

Allow people who know your system enough time to guide the automation. Automating business processes requires close collaboration between people who know IT and people who know what is supposed to be automated. This typically requires a substantial commitment by state staff and a select group of outside stakeholders. Because of the complexity of building these systems, it may be preferable to establish a small group of state staff and stakeholders who can devote the time to delve into the details of the developing IT system.

Clarify the business processes to be automated. The development of an IT system should not be separated from the careful examination and development of the underlying business processes described above. The IT system is designed to support key business processes. If the business process is faulty or poorly defined, the IT system will reflect and possibly compound those failings. The best IT system in the world cannot correct a fundamentally flawed business process. Using flowcharts that clearly delineate these processes is essential to this process.

Paper-based business processes should change with automation. Even if sound paper-based processes exist, the processes should be reexamined and changed to reflect the new possibilities allowed by an IT system. The most common mistake is to use an IT system simply to make the creation, processing, and recording of forms easier. In almost all cases, an electronic record can be created that will greatly reduce administrative burden.

Consider starting off with simple IT solutions. Very often states are not sure what they want in an IT system until they build one and it becomes apparent what they do not like about the system and what it is missing. Often, relatively simple database programs can provide many, if not most of the capabilities that are being sought. These programs can be used as starters to identify and better understand what the more complex automated system should include. However, even small investments in IT should be made while keeping an eye toward longer-term needs and goals. Any new database should be built using accepted open data standards, such as XML, to facilitate interoperability and data sharing within and between partnering agencies and networks. Siloed IT systems can pose as much of a barrier to building consumer-centered systems as siloed funding streams.

Build in the ability for the system to evolve over time. The rapid evolution of HCBS shows that even the best IT system will soon fall out of date. States should anticipate that these systems will change and incorporate mechanisms to allow the IT systems to keep up with the evolution. Efforts such as Wikipedia (Wikipedia.org) provide a framework for how this might be accomplished. Wikipedia is an online encyclopedia in which the content is provided by users who are interested in a particular subject. In the case of an IT system, the individuals who use the system are in the best position to provide guidance regarding how it can be improved. For example, Minnesota's plan for automating their IT system incorporated feedback buttons in which everyone conducting an



assessment can suggest improvements to the tool. Current plans are for this feedback to be summarized into a table and reviewed by the state on a quarterly basis.

In summary, IT holds to promise to radically change how HCBS is delivered and managed. However, IT is only a powerful tool; it is not a standalone solution. Agreement regarding what goals the system should be trying to achieve and an in-depth understanding of the best ways of achieving these goals are essential to using these tools well.