Promising Practices in Long Term Care Systems Reform: Common Factors of Systems Change

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Promising Practices in Long Term Care Systems Reform:
Common Factors of Systems Change

The federal government has encouraged states to reform their long-term support systems in recent years, particularly after the Supreme Court's 1999 decision in *Olmstead v. L.C.* affirmed the right of people with disabilities to live in the most integrated setting appropriate to their needs. Federal efforts have included increasing the flexibility of Medicaid, the largest public payer of long-term care, to support self-directed services and the transitioning of institutionalized people into the community. The Centers for Medicare and Medicaid Services (CMS) also established several grant and demonstration programs to improve state long-term care delivery systems, including the Real Choice Systems Change Grants, to enable people with disabilities of all ages to exercise more control over their lives.

As states consider redesigning their long-term care support systems, they must develop strategies to achieve public and political support for comprehensive systems change. This paper describes eight common factors that have contributed to successful systems change for different populations in eight states that had significantly different political environments.

Medstat identified these common factors of systems change based on a review of organization transformation literature and, more importantly, the experiences of eight state long-term support systems that were the subject of a recent series of case studies on comprehensive system reform (see the table below). These states all implemented two design features that have been essential components of systems reform across the disability spectrum:

- *Single Access Points* to obtain information, advice, and access to services and supports, and
- *Person-Centered Services* that place the person at the center of all planning activities.

Promising Practices in Long-Term Care Systems Reform Case Studies*	
State	**Case Study Populations**
Colorado	Older adults and people with physical disabilities
Michigan	People with developmental disabilities, mental illness, or addiction disorders
New Hampshire	People with developmental disabilities
Oregon	Older adults and people with physical disabilities
Pennsylvania	People with mental retardation**
South Carolina	Older adults and people with physical disabilities
Vermont	Older adults and people with physical disabilities
Wisconsin	Older adults and people with physical or developmental disabilities

* For additional information regarding individual states, see the series of case studies on the Internet at http://www.cms.hhs.gov/promisingpractices/sysreform.asp.
** Pennsylvania has separate systems for people with mental retardation and those with other developmental disabilities.

Factors of Change in Case Study States

1. Effective State Agency Leadership

System change in all of the case study states could not have been successful without experienced, effective, and sometimes visionary leadership from the state agencies. The most influential state agency leader in most of the states managed Medicaid institutional and community services for the populations listed in the above table. The exception was in Wisconsin, which created a new unit to implement the Family Care pilot. This unit was outside of both the agency that manages home and community-based services and the state Medicaid agency (which manages institutional payment policy) in order to achieve consensus across these two agencies.

In some states, one of the first steps in systems change was the creation of a single agency or unit with oversight over both institutional and home and community-based services. The single agency was critical to developing policies to promote common goals across all service settings. For example, Oregon merged the agency that managed the Older Americans Act and community services with the unit of the Medicaid agency that was responsible for nursing home policy and payment to create a single long-term care agency. South Carolina combined the agency that administered Older Americans Act services with the agency that managed Medicaid institutional and community services for older adults. Vermont created the Department of Aging and Disabilities to assume responsibility for all long-term care policy, program, and regulatory functions.

Review of the literature on organizational transformation indicated that trust in agency is essential government agencies to implement lasting, comprehensive systems change (Ingstrup and Crookall, 1998; Osborne and Gaebler, 1992). Several leaders had been in their position for years and had earned the trust of agency staff and other stakeholders. These leaders were a mix of directors in civil service positions and political appointees, including a few appointees who had served through multiple administrations (e.g., Pennsylvania and Vermont).

2. Participant Involvement

Every case study state made special efforts to involve program participants, self-advocates, and family members in the decision-making process to ensure that the reforms would improve participants' experience with the long-term care system. Consumers were involved in system planning, policy development, local program management, and quality assessment. State agency leaders often had to compromise with participants, providers, and other stakeholders to develop a coalition supporting system reform. The literature indicated a coalition of supporters was necessary to generate political support to adopt, implement, and sustain comprehensive reform (Kotter, 1998; Patashnik, 2003; Sapat, 2004; Wilson, 1989).

States facilitated participant involvement in several ways. In some states, consumers served on task forces, work groups, and advisory councils appointed by the governor or the legislature to design broad changes in the long-term support system. Examples include the Governor's Commission on Aging in Oregon, South Carolina's Olmstead Task Force, and the Governor's Community Health Specialty Services Panel in Michigan. State agencies also recruited participants to work groups the agency formed to address specific policy decisions or to

implement part of a system reform initiative. For example, consumers participated in design teams that planned the implementation of Michigan's specialty services managed care model and Pennsylvania's Transformation Project. Each team planned a part of the new model, subject to approval from the state agency. In Oregon, participants were part of stakeholder teams the state formed in 1984 to identify and resolve policy differences between the state, Area Agencies on Aging, providers, and participants.

Participants also served on the boards of local organizations that administer long-term supports in several states. New Hampshire, for example, mandates that participants comprise at least one-third of Area Agency board members, and Wisconsin requires that consumers comprise one-fourth of board members on the county-level Resource Centers and Case Management Organizations that administer Wisconsin's Family Care. In Colorado, participants serve on regional Community Advisory Committees charged with identifying opportunities to increase the community support system's capacity. Vermont's local long-term care coalitions, which identify unmet needs and develop and implement local delivery system improvements, also include participants.

In addition, some states held public forums to solicit consumer input. For example: the Michigan Department of Community Health organized a series of public hearings with key stakeholders, including participants and advocates; South Carolina held a series of 13 public forums for older adults; and Vermont awarded funds to five Area Agencies on Aging to gather community input from consumers and other stakeholders into the design of a new long-term care system.

3. A Shared Vision

Defining a vision and establishing broad consensus on goals and values to guide systems redesign was an essential step in systems change. As the literature suggests (Kotter 1998; Ingstrup and Crookall, 1998; Osborne and Gaebler, 1992; Wilson, 1989), an inclusive process for developing a vision or a set of system values was critical to build support for system change among stakeholders and within the state agency.

State and local program staff, participants, advocates, and community and institutional providers typically participated in work group meetings to establish a vision or a set of goals and principles for the long-term care system. Vermont created a state-level coalition with all relevant stakeholders to achieve consensus on policy goals. This consensus eventually led to a sweeping reform of the long-term care system, beginning with passage of Act 160 in 1996. This law expanded HCBS programs and participant-directed supports and encouraged nursing facilities to focus on people with more severe impairments. Pennsylvania's Planning Advisory Committee to the Office of Mental Retardation put its vision of people with mental retardation living mainstream lives within their communities into a 1991 document called *Everyday Lives.* In Wisconsin, stakeholders and state staff consolidated shared goals and values into "guiding principles" before developing the details of what was then a proposed Family Care pilot program.

Having a shared vision for the system did not end policy debates. Rather, in some states it provided a framework for policy development and subsequent discussions with stakeholders.

For example, Oregon has continued to be guided by the principles developed by the Governor's Commission on Aging in 1981 as the system has evolved and faced new challenges. These principles are particularly enduring because the state legislature enshrined them into state law in 1981 when it authorized a long-term care plan proposed by the Commission on Aging. Pennsylvania's Office of Mental Retardation, meanwhile, has connected its recent Transformation Project to a 1991 vision document, *Everyday Lives.*

4. Precipitating Event or Crisis

The organization transformation literature indicates a key challenge in systems change is creating a sense of urgency to make changes (Bridges 1991; Kotter 1998; Osborne and Gaebler 1992). In most case study states, events beyond the state agency's control helped build this sense of urgency, which made political decision-makers receptive to systems reform and hastened consensus between stakeholders. Groups with opposing interests became more willing to compromise to address pressing mutual concerns.

Some of these events, such as state fiscal crises and a class action lawsuit settlement, are common among state long-term support agencies. For example, during state budget crises in Oregon and Vermont, the state agency, participants, advocates, and providers persuaded the governor and the state legislature that proposed system reforms would slow the rapid growth of nursing facility expenditures. New Hampshire developed its community support system for people with developmental disabilities after a 1980 court order that Laconia State School residents must live in the least restrictive setting possible. In Pennsylvania, momentum for changing the system increased after a CMS review identified significant quality concerns regarding Pennsylvania's largest MR/DD waiver. Stakeholders were concerned about the possibility of losing federal funding for waiver services in the future. Finally, Michigan's managed care model for services for serious mental illness, developmental disabilities, and addiction disorders was developed in response to a proposal to incorporate these services into a comprehensive Medicaid managed care program. State staff and others were concerned that existing Health Maintenance Organizations were not experienced in providing these services.

5. Political Champion

In each state, systems change required legislative approval for appropriation of funds and for enabling legislation to create new programs and establish new long-term care policies. Some states had political champions – the governor or individual legislators – who put long-term supports on the public policy agenda and guided reform measures toward enactment. The governor's support was particularly important because it enabled reform proposals to be part of the governor's budget and legislative package. Gubernatorial support also enabled state agencies to openly support the proposals. A few governors also used their office to highlight long-term support initiatives or the need for system change. For example, Oregon's governor called on the Commission on Aging to develop a proposal for reorganizing the long-term care system in 1980. The legislature enacted the plan the following year. Also, Wisconsin's governor proposed the Family Care demonstration in his 1998 "State of the State" message, and the proposal was adopted a year later.

Some states were able to recruit champions by addressing an elected official's interests or an issue receiving several legislators' attention. For example, Colorado's agency released a long-term care reform plan in 1989, the same year that a legislative long-term care task force began working on a legislative reform package that included many elements of the state agency's proposal. The legislature subsequently enacted most of this package. Pennsylvania's agency proposed to modernize its management information systems when the governor strongly supported improving the Commonwealth's information technology. The governor supported project funding for several years as the initiative evolved to include transforming the service system. As mentioned earlier, Oregon and Vermont enacted laws to decrease reliance on institutional care and increase home and community-based services when the states faced significant budget constraints and legislators were interested in slowing the growth of long-term care expenditures.

6. A Plan for Change

Several states developed plans to achieve – or at least move toward – the shared vision or the common goals for redesigning the long-term care system. Some of these plans recommended specific policy changes. Others detailed the implementation of long-term support reforms that the state legislature had approved. Some states developed both types of plans. Colorado's state agency, for example, recommended the creation of Single Entry Point agencies and other system reforms in two reports. After the legislature authorized many of these changes, the state released a detailed implementation plan for establishing Single Entry Point agencies. Pennsylvania's Planning and Advisory Committee developed a *Multi-Year Plan* that called for many policy changes. The state agency then implemented many of these recommendations during its Transformation Project. Almost all of the case study states' plans were developed with significant input from consumers, state and local staff, advocates, providers, and other stakeholders.

7. Staff Preparation

As is true for any comprehensive reform of a government agency and its operations (Ingstrup and Crookall 1998; Kotter 1998; Stewart and Kringas 2003; Wilson 1989), system change in the case study states required major changes in the way state staff, case managers, and providers did their jobs. States spent significant amounts of time and money preparing state and local staff to incorporate the system reforms into their daily work. For example, New Hampshire and Pennsylvania provided support coordinators with extensive, ongoing training on person-centered planning. South Carolina trained providers and case managers to use the Care Call system, a telephone monitoring system that creates a record of each service visit. Michigan and Wisconsin invested in training and technical assistance to enable local service agencies, or coalitions of local agencies, to develop managed care organizations.

8. Multiple Changes over Several Years

All the case study states implemented multiple rounds of systems change. While most of the case studies described dramatic, comprehensive initiatives, smaller incremental reforms both set the stage for these initiatives and followed them. Michigan, for example, had gradually expanded the responsibilities of community mental health agencies over decades to include

hospitalization authorization as well as community treatment, which positioned these agencies to implement the state's managed care model. Since it started its community support system in the 1980s, New Hampshire has steadily provided smaller residential settings for people with developmental disabilities. The state has closed its institutions and is currently phasing out group homes with up to four participants and increasing the number of available community residences for only one or two participants. Colorado has expanded the responsibilities of its Single Entry Point agencies to include authorization of Medicaid state plan home health care as well as other long-term services for older people and people with disabilities.

States that implemented multiple program or policy changes over time usually did not use a multi-phase plan (Pennsylvania is an exception). Instead, new initiatives emerged as the state and various stakeholders identified new problems or better ways to support older people and people with disabilities. The emergence of new initiatives after major system change was common among other government agencies that implemented major reorganizations or reforms according to the literature (Ingstrup and Crookall 1998; Osborne and Gaebler 1992; Patashnik 2003).

Discussion

Agencies interested in changing their long-term support systems, including agencies that administer Systems Change grants, may want to consider the eight factors that contributed to systems change in other states.

1. Effective State Agency Leadership
2. Participant Involvement
3. A Shared Vision
4. Precipitating Event or Crisis
5. Political Champion
6. A Plan for Change
7. Staff Preparation
8. Multiple Changes Over Several Years

State agencies can influence, but not completely control, these factors. For example, while agencies cannot choose their leaders, they can recommend the type of agency that led long-term support reform in most case study states: one with oversight over both institutional and community supports. Similarly, state agencies do not want to create a crisis, but they can raise awareness of events or crises that need to be addressed.

Several elements require the commitment of other entities including participant groups, providers, local agency staff, and elected officials. After all, agencies cannot force participant groups or other stakeholders to get involved and to reach consensus on a vision of the system. However, agencies can create an environment of participation, valuing stakeholder views. This environment would go a long way to encouraging participant groups and other stakeholders to get involved. Agencies also need adequate internal and external resources to properly plan for change and to prepare staff for it. Good working relationships between agency leaders, stakeholders, and political decision-makers can be a strong foundation for systems change.

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