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Results of the Formative Evaluation of the FY 2001-2004 Systems Change Grants Program: Enduring Changes, Lessons Learned, and Conclusions

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Goal of Systems Change Grants Program

- To help states develop the regulatory, administrative, program, and funding infrastructure to enable people of all ages with disabilities or chronic illnesses to:
 - (1) live in the most integrated community setting;
 - (2) exercise choice and control over their living arrangements, services, and service providers; and
 - (3) obtain high-quality services consistent with their preferences.

CMS Systems Change Strategy

- To encourage and facilitate incremental reforms and improvements in states' LTC systems.
- To jumpstart new initiatives
- To provide funding to supplement existing initiatives to increase their scope
- To provide the impetus for states that have historically lagged in developing strong HCBS systems.

Number of Grants Awarded

- Between FY 2001 and FY 2004, CMS awarded 226 grants in 17 categories.
- Grants awards were for 3 years; almost all Grantees received 1 year or longer no-cost extensions. Grants were completed between September 30, 2005, and September 30, 2008.
- With the exception of the Real Choice and Comprehensive Reform grants, individual awards were relatively modest—averaging between \$300,000 and \$800,000 over a 3- to 4-year period.

Number of Grants by Grant Type: Research and Demonstration Grants

Grant	2001	2002	2003	2004
Community-Integrated Personal Assistance Services and Supports (CPASS)	10	8	8	–
Comprehensive Systems Reform (CSR)	–	–	–	2
Plus (IP)	–	–	12	–
Integrating Long-Term Supports with Affordable Housing (Housing)	–	–	–	8
Mental Health Systems Transformation (MHST)	–	–	–	12
Money Follows the Person (MFP)	–	–	9	–
Nursing Facility Transition–Independent Living Partnership (NFT-ILP)	5	5	–	–
Nursing Facility Transition–State Program (NFT-SP)	12	11	–	–
Quality Assurance and Quality Improvement Systems in Home and Community-Based Services (QA/QI)	–	–	19	9
Portals from Early and Periodic Screening, Diagnosis, and Treatment Programs to Adult Supports (EPSDT)	–	–	–	2
Real Choice	25	25	–	–
Rebalancing Initiative (Rebalancing)	–	–	–	7
Total of Grants by Grant Type	52	49	48	40

Number of Grants by Grant Type: Feasibility Study and Development Grants

Grant	2001	2002	2003	2004
Community-Based Treatment Alternatives for Children (CTAC)	-	-	6	-
Living with , Freedom, and Equality Accounts Feasibility and Demonstration (LIFE)	-	-	-	2
Respite for Adults (RFA)	-	-	4	-
Respite for Children (RFC)	-	-	6	-
Total of Grants by Grant Type	0	0	16	2

Number of Grants by Grant Type: Technical Assistance Grants

Grant	2001	2002	2003	2004
Family to Family Health Care Information and (FTF)	-	-	9	10

Grant Focus Area: Access

Access to Existing HCBS

- Lack of access to HCBS can lead to institutional placement.
- Lack of access can be due to barriers to *existing* services.
- States used several approaches to improve access to existing services and supports.

Access: Enduring Improvements

Access to Existing HCBS

System Improvement	Total States
New or improved assessment tools and eligibility processes	9
Improved or expanded information and referral service	6
New information and referral website, toll-free telephone system, resource center, single point of entry, or network	17
New Family to Family Health Care Information Center	18
New or expanded transportation options	4
New policies and procedures to facilitate transition/diversion	28
New Money Follows the Person policy and infrastructure	7
Increased state transition capacity	11
Increased transition capacity and collaboration	13

Grant Focus Area: Access

Lack of Comprehensive HCBS

- Lack of access can also be due to an insufficient *type and amount* of services.
- States used several approaches to develop new services and expand existing services.

Access: Enduring Improvements

Access to New or Expanded HCBS

System Improvement	Total States
Liberalized financial eligibility criteria for waiver program	2
Expanded coverage for under-65 population in existing waiver program	2
New Section 1115 waiver offering equal access to home and community-based services and nursing homes	1
New funding for transition expenses	23
New funding for non-Medicaid service(s) or program	8
Increased funding for home and community-based services (both waiver and State Plan)	7
Increase in waiver slots for people transitioning	6
Environmental modifications added to waiver program	1
New Program of All-Inclusive Care for the Elderly (PACE)	1
New funding and processes to support youth transitioning to adult services and supports	2
New or expanded community service options for people with psychiatric disabilities	18

Focus Area: Personal Assistance Services and Consumer-Directed Services

Personal Assistance Services and Consumer-Directed Services

- Personal assistance is the key long-term care service that enables individuals with disabilities to live in the community.
- Increasing the availability of personal assistance, improving the delivery of PAS, and increasing the availability of CD services were major goals of the Systems Change grant program.
- About half of the states received Community-Integrated Personal Assistance Service and Supports grants, and many Real Choice Grantees also had initiatives to expand PAS and CD options.

Personal Assistance Services and Consumer-Directed Services: Enduring Improvements

Personal Assistance Services and Consumer-Directed Services

System Improvement	Total States
New education and training materials for consumers and/or providers	11
Policies and procedures to enhance PAS provision	6
Policies, procedures, or entities to enable or facilitate consumer-directed services	17
New infrastructure for consumer-directed services	14
New or expanded consumer-directed services option	27
New methods to recruit and retain workers (training, certification, career ladder, benefits)	12
New worker registries and support organizations	8

Focus Area: Quality Assurance & Quality Improvement Systems

Quality Management Strategies

- Helping states to improve their quality management systems was a major CMS goal.
- CMS awarded 28 QA/QI grants over two grant cycles.
- Many states also used their Real Choice grants to work on QA/QI initiatives.
- Grantees addressed different components of quality management systems.

QA/QI: Enduring Improvements

Quality Assurance and Quality Improvement

System Improvement	Total States
New quality management system (indicators, provider standards, monitoring tools/processes)	19
New/improved methodology/tool/indicators to measure participant outcomes	23
New quality management infrastructure, including electronic system components	18
New/improved complaint and critical incident reporting/remediation process	10
New methods to involve participants in QA/QI processes and policy development	16

Focus Area: Housing

Affordable and Accessible Housing

- Increasing access to affordable accessible housing was not a primary focus of the Systems Change grant program because the federal authority for doing so lies with HUD.
- However, because lack of affordable accessible housing is a major barrier to community living generally and NFT specifically, many of the NFT and other Grantees had initiatives to address the lack of housing.
- In FY 2004, CMS awarded 8 grants to (1) improve access to affordable, accessible housing that is coordinated with long-term services & supports and (2) to help states develop methods to better coordinate or provide LTC services & supports in subsidized housing.

Housing: Enduring Improvements

Housing Infrastructure, Policy, and Funding

System Improvement	Total States
New funding for affordable and accessible housing targeted to people with disabilities	7
Improved housing accessibility	3
Increased access to services and supports	4
New infrastructure to link housing and services sectors	5
Policy and regulatory reform to promote community living	11

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Planning for Sustainability From the Start

- Although a detailed sustainability plan may not be developed until later in a project, project staff and stakeholders need to plan for sustainability from the beginning.
- Sustainability is important not just for policies and programs but also for the processes required to bring about systems change.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Building on Existing Systems Change Efforts

- Link initiatives to ongoing high-profile state initiatives or other change efforts, to ensure that their goals and objectives are an integral part of a state's reform plan for its LTC system.
- States with QA/QI initiatives should combine their data system development projects with data systems and projects related to financial systems or other mandated reporting systems to ensure ongoing financial and technical support.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Enlisting the Support of Key Leaders

- Strong leadership from the executive and legislative branches is needed. Without high-level support, it is unlikely that resources will be committed to a new initiative and that information about systems changes will be communicated to those whose work will be affected by them.
- Strong executive leadership, in particular, is needed to ensure the cooperation and collaboration among multiple agencies and organizations that is needed to bring about systems change.
- Even with strong leadership, education is sometimes needed to obtain the commitment of relevant government entities to bring about systems change.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Obtaining Buy-in From All Relevant State Agencies

- Many Grantees found it difficult to obtain commitment from and meaningful collaboration among multiple state agencies to work on common goals and noted that the current system provides few incentives for such collaboration, particularly on comprehensive systems change initiatives that require multi-year efforts.
- Working with state agencies to obtain their buy-in takes a lot of work and patience even with support from the executive branch and it should be done prior to initiating systems change activities.
- Executing Memoranda of Understanding or other formal agreements can help to ensure that agencies provide promised support.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Developing Effective Communication Strategies

- Comprehensive systems change efforts need an effective strategy for ongoing communicating with key leaders and stakeholders.
- Successful strategies generally require multiple communication methods, such as meetings, e mail, postings on state department websites, and teleconferences.
- Having a full-time project manager can help states to develop a comprehensive and coordinated communication strategy.
- Staff should have ongoing contact with legislators and policy makers to keep them informed about the project and to provide data about its success or cost savings.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Coordinating Multiple Systems Change Initiatives

- Large state agencies with multiple grants should coordinate activities across grants to prevent duplication of effort and ensure that grant activities in one area are compatible with and complement those in other areas.
- Using grants synergistically enables states to leverage resources to improve their long-term care system.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Developing Realistic and Achievable Goals

- Because systems change is a time-intensive process, states should focus grants on a limited number of clearly defined goals rather than multiple, complex issues.
- It is better to commit to a few major systems change initiatives rather than several to avoid spreading staff and resources too thinly.
- It is unrealistic to try to introduce changes in multiple agencies at the local, regional, and state level—particularly in a large state—in a short period. A more practical approach is to pilot a new initiative at the local or regional level to enable project staff to work out operational issues before expansion.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Building in Flexibility

- Planning is essential for unanticipated events that may require changes in goals and methods.
- Always develop contingency plans—both to take advantage of emerging opportunities and to address insurmountable barriers identified through formative evaluation.
- Planning may be difficult because of new leadership, agency reorganizations, budget restrictions, and staff turnover, and staff need to allow time to overcome and/or accommodate inevitable delays.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Building in Flexibility

- Because systems change requires significant state agency involvement, staff should be assigned full time to grant implementation and their usual duties reassigned to other staff for the duration of the grant.
- Using senior staff as primary grant staff ensures integration of grant goals into existing systems and structures, resulting in more enduring systems improvements.
- Staff working on different grants and initiatives should meet regularly to ensure collaboration and the efficient use of resources; a specific individual should be given responsibility for ensuring that this happens.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Involving Stakeholders

- Involving all stakeholders in the planning, development, and implementation of HCBS systems change initiatives is essential.
- Input and participation from stakeholders should involve more than serving on an external advisory committee. Providing stakeholders with real decision-making roles in developing program goals, as well as program design, implementation, and evaluation, is most likely to pay off in building long-term support for systems changes.
- Involving consumers early on is particularly important, providing a valuable “reality check” for program and policy initiatives and can help drive systems change in ways that state staff cannot. Staff time and financial resources are needed to ensure meaningful consumer participation.

Ensuring Sustainability of Systems Change Initiatives: Lessons Learned

Involving Stakeholders (continued)

- It is essential to ensure broad, strategic participation of stakeholders with the authority and responsibility to bring about change. Enlisting the support of top administrators and securing the commitment of relevant leaders can help ensure that needed resources will be committed for a new initiative.
- Hiring professional facilitators to work with stakeholder groups can ensure objectivity, help all stakeholders participate, keep groups moving forward with their agendas, and help reach consensus.

Continuing Challenges & Barriers to Community Living

- The first four cycles of Systems Change grants enabled states to make significant improvements in their long-term care systems, but many challenges and barriers remain.
- Much needs to be done to continue transforming states' long-term care systems so they can better support individuals with disabilities in their communities.

Conclusions

- With few exceptions, Grantees achieved at least some of their goals, and many implemented programs and made changes that improved their states' LTC system.
- In many states, the incremental reforms achieved through the grants have enabled additional reforms.
- For states that have lagged behind in offering HCBS, the federal commitment to promoting HCBS provides an important impetus—and an antidote to continuing resistance among many service providers and state policy officials to achieving a better balance in expenditures between HCBS and institutions.

Conclusions

- The Systems Change grant program is based on the belief that infrastructure development is crucial to improving access to and the quality of HCBS.
- States often need to develop complex policies and procedures to implement HCBS waivers, CD services, NFT programs, and quality measurement initiatives, but lack the funding to do so.
- Grantees uniformly endorsed the continuation of the Systems Change Grants Program, many declaring that without the grants they would not have undertaken their initiatives.

Conclusions

- Systems change strategies provide policy makers with the opportunity to remake the LTC system rather than simply expanding the current inadequate system to meet increased need.
- Infrastructure grants are an incrementalist reform approach that provides extra resources to help states move towards a more balanced delivery system.
- However, states themselves must be willing to invest more in HCBS for systems change to occur.

Conclusions

- Many continuing challenges and barriers to community living cannot be addressed with infrastructure development grants and recommendations to address them cannot be implemented without significant increases in state spending.
- Lack of state funding is the major barrier to both increasing HCBS & undertaking activities to improve the LTC system.
- Lack of funding was a significant factor in the inability of some states to sustain Systems Change grant projects after the grants ended.

Conclusions

- Given the economic downturn, states are not likely to allocate limited funds to LTC systems change efforts.
- Additional funding and technical assistance from the federal government may be needed to continue the progress being made under the Systems Change Grant Program.