Real Choice Systems Change Grant Program

Third Year Report: Progress and Challenges of the FY 2002 and FY 2003 Grantees

(October 1, 2003 - September 30, 2004)

U.S. Department of Health and Human Services
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Final Report

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EXECUTIVE SUMMARY

Over the past two decades several states have led the way in creating long-term care (LTC) systems that enable individuals with disabilities or long-term illnesses to live in their own homes or in other residential settings and to have more control over the services they receive. The enactment of the Americans with Disabilities Act (ADA) and the 1999 Supreme Court decision in Olmstead v. L.C. have reinforced states' efforts by giving legal backing to this policy direction. Recognizing that states face difficult challenges in their efforts to fulfill their responsibilities under the ADA, Congress, as part of President George W. Bush's New Freedom Initiative, appropriated funds for Systems Change grants in fiscal years (FY) 2001, 2002, 2003, and 2004.

The Centers for Medicare & Medicaid Services (CMS) has awarded approximately $188 million in Systems Change Grants for Community Living to 50 states, the District of Columbia, and two U.S. territories. In all, 225 grants—not including technical assistance grants—have been awarded during the four funding cycles. These grants are specifically intended to help states and others build the infrastructure that will result in effective and enduring improvements in community-integrated services and long-term support systems that enable individuals of all ages to live in the most integrated community setting suited to their needs, to have meaningful choices about their living arrangements, and to exercise more control over the services they receive.

Grantees who received funding in FY 2001 are completing their grant projects in the coming months. Accomplishments of these Grantees were highlighted in *Real Choice Systems Change Grant Program: First Year Report* and *Real Choice Systems Change Grant Program: Second Year Report*. RTI will prepare a final report on their activities in 2006. Because the FY 2004 Grantees did not receive their grants until September 30, 2004, the end date of the reporting period for this report, their activities are not covered in this publication.

This report describes the FY 2002 and FY 2003 Grantees' accomplishments and progress, using information provided by the Grantees during the reporting period October 1, 2003 to September 30, 2004 (Year Two of the grant period for FY 2002 Grantees and Year One of the grant period for FY 2003 Grantees). The report describes grant activities in four major LTC systems areas:

- **Access to Long-Term Care Services and Supports**—efforts to ensure that consumers have access to the full range of currently available home and community services and supports, such as creating "one-stop shopping" or "no-wrong door" information and referral systems.

- **Services, Supports, and Housing**—efforts to create new community services and supports or to modify or improve currently available community services and supports (e.g., changing regulations to allow service provision outside the home, working to change nurse delegation rules).

- **Administrative and Monitoring Infrastructure**—efforts to design, implement, and maintain systems and processes that enable and support home and community services, such as the creation of data systems needed to allow flexible budgeting and reimbursement and development of comprehensive quality assurance and quality improvement systems covering LTC.

- **Long-Term Care Service and Support Workforce**—efforts to improve the recruitment, training and retention of direct service workers.

For each of these focus areas we describe Grantees' accomplishments, including the development of products such as training manuals and assessment protocols, if applicable, and any enduring changes made, such as the enactment of new legislation and policies. We also provide examples illustrative of the challenges faced by Grantees as they implement grant activities and the various roles consumers and consumer partners have taken on in the implementation and evaluation of grant activities.

The principal source of data for this report is the Year Two annual reports of the 49 FY 2002 Grantees and the Year One annual reports of the 47 FY 2003 Research and Demonstration Grantees, which were submitted electronically using a Web-based reporting system. Data from the 25 FY 2003 Feasibility Grantees' Year One annual reports were also analyzed and included.

Information contained in this report is subject to the limitations of the data and the technical approach used. Specifically, the content of this report depends on both the quality and thoroughness of each Grantee's information in their annual report and their responses to follow-up inquiries. Some Grantees' activities span more than one systems area, and RTI exercised judgment in assigning activities to a particular area and categories within these areas. At each step of the analysis, RTI exercised judgment to determine the key activities and issues to highlight in this report. Staff eliminated duplicative information and prepared concise summaries. Consequently, descriptions of activities may not contain some information that individual Grantees consider important. Also, this report covers only 1 year of grant activities, and only the first year of activities for the FY 2003 Grantees. Grantees may not have reported on the full range of activities being implemented because they had not been initiated during the reporting period.

Grant Initiatives

Grantees in the majority of states made progress in at least one of the four major systems change areas during the reporting period. Grantees in almost half the states are focusing on

increasing access to and improving the quality of LTC supports and services, primarily by increasing consumers' knowledge of available services. Most also have initiatives underway to improve LTC services, supports, and housing. Many are working on initiatives related to personal assistance services, for example, increasing options for consumer-directed personal assistance services. Several states have Grantees who are also working to develop the administrative and monitoring infrastructure needed to support home and community services, for example, developing reimbursement systems compatible with independent budgets in consumer-directed programs. A few Grantees are undertaking initiatives focused on the long-term care workforce, for example, developing strategies to recruit direct service workers.

Initiatives to Improve Access to Currently Available Services

Grantees in 27 states reported undertaking activities to provide or increase access to existing long-term care services and supports. The initiatives described by Grantees include efforts to improve access by (1) integrating information sources for multiple long-term care services and supports; (2) streamlining financial and functional eligibility determinations; (3) increasing consumers' knowledge of existing service options; and (4) other related activities, including expanding eligibility to new target populations.

The majority of Grantees in these states have initiatives to integrate access to the full range of LTC services, including efforts to create single-point-of-entry systems; develop Web sites and establish toll-free phone lines for access to information; and create dedicated information, referral, and assistance staff positions. Fewer Grantees are focusing on efforts to streamline eligibility determinations for long-term services and supports. These Grantees are undertaking efforts that make intake, assessment, eligibility screening, and programmatic and financial eligibility determinations appear seamless to consumers. For example, Wisconsin (RC) implemented an automated Web-based functional eligibility assessment tool for children's long-term supports, which will become the only tool for waiver level-of-care determination. Several Grantees are improving access to long-term services and supports by providing outreach and education to consumers to increase their knowledge of service options. These Grantees are also making improvements to information systems and/or conducting assessments to determine consumer knowledge and needs.

In addition to the Real Choice Systems Change grant efforts to increase access to available long-term services and supports, the Aging and Disability Resource Center (ADRC) Grants, awarded jointly by the Administration on Aging (AoA) and the CMS, offer states the opportunity to create single points of entry to long-term support services. Primary oversight for these grants resides with AoA, and these grant activities are not covered in this report. However, ADRC Grantees are engaged in many of the same types of activities as the Systems Change Grantees, i.e., they are engaged in initiatives to improve access to

services and supports. These Grantees are primarily focused on activities that will integrate information and referral sources and facilitate access to publicly and privately financed LTC services and benefits. More information about the ADRC grant initiatives can be found in the profiles for each grant at http://www.adrc-tae.org/tiki-index.php?page=GranteeProfilesPublic.

Initiatives to Modify, Improve, or Create New Services and Supports

Grantees in 45 states have reported on initiatives to modify, improve, or create new services and supports. These accomplishments are grouped into six broad categories: (1) personal assistance services and supports, (2) nursing facility transition and diversion, (3) housing, (4) respite for adults and children, (5) community-based treatment alternatives for children, and (6) other initiatives to modify or improve services and supports for individuals with disabilities and long-term illnesses.

Most Grantees in these states are focusing on activities related to personal assistance services, which includes efforts to provide opportunities for consumers to direct their own services. These Grantees are involved in a range of other activities to achieve this goal, including working to incorporate the principles and philosophy of consumer direction into rules and regulations, to develop new consumer-directed waiver programs, and to develop a consumer-owned and consumer-directed worker cooperative. For example, Arizona (CPASS) is working to create a consumer-directed model within the State's home and community-based services (HCBS) 1115 waiver program by developing a consumer-owned and consumer-directed cooperative in which consumers will be the employer of record for direct service workers and will control the dollars spent on services. A few Grantees are focused on developing new or modifying existing home and community services through initiatives such as modifying the nurse practice act to allow for nurse delegation of tasks. A small number of Grantees are focused on other activities related to personal assistance services and supports, such as determining the feasibility of creating a peer support program for elderly persons.

During the current reporting period, Grantees in 21 states described a range of nursing facility transition and diversion initiatives and strategies. For example, Alabama (NFT) identified criteria for residents who are likely targets for transition services in preparation for a pilot nursing home-to-community transition program for individuals with dementia. In Michigan, the MFP Grantee partnered with the NFT Grantee to develop a nursing home transition curriculum that will incorporate planning tools and community resource information using a person-centered planning model for transition under the current LTC system.

Grantees in 10 states have engaged in a number of activities to help individuals with disabilities find accessible and affordable housing. The majority of these Grantees are implementing educational campaigns and outreach aimed at housing authorities and developers, forming collaborative task forces to address housing barriers, and improving access to existing housing through home modifications and helping individuals obtain rental subsidies.

A total of 16 Grantees are engaged primarily in conducting feasibility studies and are exploring ways to either expand services through existing programs or to develop new programs (i.e., respite services for adults and children and community-based treatment alternatives for children). For example, Arkansas (RFC) conducted focus groups and surveyed current respite recipients to identify problems in the current program. The Grantee will use the information obtained through these activities to determine how to improve respite services. Another example comes from the Illinois (CTAC) Grantee, which conducted focus groups with parents, teens, and mental health providers about services. Based on the results of these focus group discussions, the Grantee has made recommendations for program changes, some of which have already been implemented.

Initiatives to Design, Implement, and Maintain Systems and Processes that Enable and Support Home and Community Services

Grantees in 27 states have initiatives to design or implement systems and processes that support home and community services. Grantees' quality assurance and quality improvement (QA/QI) initiatives are grouped into four broad categories: (1) improvement of quality monitoring and management systems; (2) addition of a consumer-focused component to quality monitoring and management systems; (3) development of, or improvements to, remediation systems or processes; and (4) other initiatives to improve the quality of long-term care community services and supports.

A majority of Grantees in states with QA/QI activities are focused on improving or adding a consumer focus to quality monitoring and management systems. For example, Texas (QA/QI) developed a Systems Requirement Document for the design of an integrated information-gathering system that will compile and automate information regarding program provider performance and participant experiences in the State's mental health and mental retardation (MHMR) waiver programs.

Several of these Grantees are involved in activities to develop quality assurance systems with a consumer focus that also measure outcomes. For example, Tennessee (QA/QI) is collecting and analyzing data from consumer satisfaction surveys and will establish a single, functional database that generates useful and timely reports of findings. A few Grantees with quality initiatives described accomplishments in activities designed to correct problems

identified at the individual level, including those to develop or improve components of critical incident reporting systems and the development of coordinated systems for multiple waiver programs.

Grantees in 13 states reported activities to change their budgeting and reimbursement systems. Their initiatives fall into three categories: (1) individualized budgeting, (2) payment rates and methodologies, and (3) Money Follows the Person (MFP). The majority of Grantees in these states reported progress on activities to design or promote individualized budgets. In addition, Grantees in seven states are working on MFP initiatives. As an example, Nevada (MFP) conducted a study of MFP systems in other states and barriers to money following the person in Nevada, and prepared a report for the legislature, which is considering several recommendations from the report.

Initiatives to Improve the Recruitment, Training, and Retention of Direct Service Workers

Although many of the Systems Change Grantees' workforce initiatives were reported in RTI's *Second Year Report* (http://www.cms.hhs.gov/systemschange/report04.pdf) and the *Direct Service Workforce Activities of the Systems Change Grantees* report (http://www.hcbs.org/files/35/1708/CMSWorkforce.pdf), a few Grantees reported additional progress in this area during the current reporting period. Grantees in seven states described accomplishments on workforce initiatives intended to improve the recruitment and retention of workers and the quality of direct care services. These initiatives are categorized into three major areas: (1) recruitment, (2) training and career development, and (3) administrative activities. In a few states, Grantees have undertaken activities to increase the number of workers through recruitment efforts. These initiatives included promotional efforts through Web sites and brochures, career fairs, and worker registries. Grantees in three states developed training curricula (e.g., medication administration and basic skills certification) to improve the skills of direct service workers. Grantees in two states are involved in administrative activities to aid in efforts to increase the availability of personal care workers, including conducting surveys of workers and collecting data about working conditions.

Challenges

Although Grantees have made significant progress initiating and implementing grant activities, most Grantees faced challenges in their implementation efforts. As noted in earlier reports, these challenges generally are unique to their individual efforts to improve the LTC systems in their respective states (e.g., lack of affordable and accessible housing, lack of available community services, and legislative barriers). Grantees also continue to

describe challenges that are administrative in nature (e.g., finding staff for grant activities, state budget deficits, and delays in subcontracting).

Consumer Involvement

The Centers for Medicare & Medicaid Services mandated that consumers be involved in the Systems Change grant activities. In keeping with this mandate, Grantees have involved consumers and consumer partners in both grant implementation and grant evaluation activities. As members of consumer task forces and advisory committees, consumers provide oversight of all grant activities. Consumers are also assisting in grant implementation by providing input on specific grant activities and materials development and by pilot testing grant products. Finally, to assess the grant's impact, Grantees are soliciting consumers' input through consumer satisfaction surveys and focus groups.

Looking Forward

Although the FY 2002 Grantees are nearing the end of their 3-year grant period, many of them have requested no-cost extensions to continue grant activities for a fourth year. This extra time will likely be used by Grantees to complete activities that were late starting (due to the challenges already described), to evaluate their grant activities, and to put in place measures to ensure that grant initiatives are sustained after the grant ends. A report of their final year's activities will be completed during the spring of 2007.

The first year activities of the FY 2003 Grantees demonstrate accomplishments in many areas. We anticipate that these Grantees will make more substantial progress during their second year and that the next annual report, which will be completed in the summer of 2006, will highlight a wider range of successes for these Grantees.

In addition to next year's annual report of the Systems Change grant activities, RTI will prepare a final report of the FY 2001 Grantee accomplishments, which will be completed in the spring of 2006. The source of information for this report will be Grantees' final reports to the CMS as well as interviews with the grant project directors. These reports will highlight each state's accomplishments at the end of the grant period and summarize accomplishments across all the Grantees in specific systems change areas.

SECTION 1
INTRODUCTION

Services and supports that enable persons with disabilities to live independently in the community have, historically, received far less public funding than services provided in institutional settings. Over the past 20 years, many states have led the way in creating long-term care (LTC) systems that enable people with disabilities or long-term illnesses to live in their own homes or in other residential settings and to have more control over the services they receive. These efforts have been reinforced by the 1999 Supreme Court decision in Olmstead v. L.C., which also gives legal weight to this policy direction. However, despite the movement to rebalance LTC systems in virtually all states, in fiscal year (FY) 2004, spending for community-based LTC services (Home and Community-Based Services waivers, personal care, and home health services) accounted for 36 percent of all Medicaid LTC expenditures, compared to 64 percent on institutional services, a marginal increase since FY 2003.[1]

The enactment of the Americans with Disabilities Act (ADA) and the U.S. Supreme Court's Olmstead decision interpreting the ADA are landmark achievements, providing legal support for the rights of persons with disabilities to live as independently as possible in home and community settings. Recognizing that states face formidable challenges in their efforts to fulfill their responsibilities under the ADA, Congress appropriated funds for Real Choice Systems Change Grants for Community Living in fiscal years 2001, 2002, 2003, and 2004. These grants are specifically intended to assist states and others to build the infrastructure that will result in effective and enduring improvements in community-integrated services and long-term support systems.

Overview of Systems Change Grants

Starting in FY 2001, Congress began funding the Systems Change for Community Living Grants program to help states increase access to and availability of home and community-integrated services and to improve their quality. Since 2001, the Centers for Medicare & Medicaid Services (CMS), has awarded approximately $188 million in Systems Change Grants for Community Living to 50 states, the District of Columbia, and two U.S. territories. In all, 225 grants—not including technical assistance grants—were awarded from FY 2001 through FY 2004.

[1] In FY 2003, reported Medicaid spending for nursing home expenditures was $44.8 billion and for intermediate care facilities for people with mental retardation (ICFs/MR) was $11.3 billion. Expenditures for community-based LTC services were $27.8 billion, and HCBS waivers accounted for two-thirds of this spending.

The CMS, as part of the President's New Freedom Initiative, has awarded Real Choice Systems Change Grants for Community Living (hereafter Systems Change grants) to encourage states to make enduring changes in their LTC systems that will enable people of all ages with a disability or long-term illness to (1) live in the most integrated community setting suited to their needs, (2) have meaningful choices about their living arrangements, and (3) exercise more control over their services.

Bringing about enduring change in any state's LTC system is a complex endeavor requiring the involvement of many public and private entities. Recognizing this, the Systems Change grants are intended to be catalysts for incremental change—to support or expand existing activities or to begin new initiatives. The grants' overriding purpose is to enable states to make enduring changes in key areas of systems change, (e.g., access to long-term care services and supports, consumer choice and control, quality management systems, and affordable and accessible housing) and to make enduring changes to the underlying framework upon which the LTC system operates.

Overview of Grant Periods and Reporting Structure

The Systems Change Grants have been awarded in late September of each year since FY 2001. The CMS contracted with RTI to compile a number of reports including (1) an annual compendium that offers a description of each grant, its proposed goals and activities, and contact information; (2) annual reports to detail the progress of the grants at a specific point in time; and (3) a series of final reports to summarize the experience (accomplishments and challenges) of each Grantee for the entire grant period. Following is a brief description of the grantee reporting periods and reporting structure for each cycle of the grants.

FY 2001 Grantees

The FY 2001 grants were awarded September 30, 2001, for a period of 3 years. For many states, the first year of the grant coincided with large state budget deficits, which in many cases delayed the initiation of grant activities due to hiring freezes and other administrative and operational barriers. The original completion date for these Grantees was September 30, 2004, but since all but a few Grantees requested no-cost extensions, these grants will not conclude until September 30, 2005.

The FY 2001 Grantees' interim accomplishments were reported in RTI's *Real Choice Systems Change Grant Program: First Year Report* and *Second Year Report*. Because these Grantees are currently in the final year of their grants, their activities are not included in this *Third Year Report*. Instead, RTI will prepare a final report on FY 2001 Grantees in early 2006 (Grantees' final reports are due to the CMS on December 30, 2005.) This final report will

include a review of each FY 2001 Grantee's accomplishments and outcomes, as well as a summary of accomplishments in key systems change areas across all FY 2001 Grantees.

FY 2002 and FY 2003 Grantees

The FY 2002 grants were awarded on September 30, 2002, and the FY 2003 grants on September 30, 2003. For the FY 2002 Grantees, this report covers Year Two of a 3-year grant period, and for the FY 2003 Grantees, it covers Year One of a 3-year grant period. The report describes Grantee accomplishments during the reporting period October 1, 2003, to September 30, 2004.

It is anticipated that most of the FY 2002 Grantees will request and receive no-cost grant extensions because of delays in initiating their grants due to administrative and operational barriers. As a result, they will not finish their grant activities until September 30, 2006. RTI will prepare a final report on the FY 2002 Grantees after they submit their final reports on December 30, 2006.

The Year Two activities and accomplishments of the FY 2003 Grantees will be reported in the *Fourth Year Report* in 2006, and in a final report after they submit their final reports to the CMS.

FY 2004 Grantees

The FY 2004 Grantees did not receive their grants until September 30, 2004, the end date of the reporting period for this report. Their activities and accomplishments will be reported in the *Fourth Year Report* in 2006, the *Fifth Year Report* in 2007, and a final report in 2008.

Exhibit 1 summarizes the types of grants awarded in FY 2002 and FY 2003, which are the focus of this report.

Organization of this Report

The report has six sections and three appendices. Section 2 describes the data sources used to prepare this report and the technical approach for summarizing and reporting the data. Section 3 presents our findings in the four major areas of systems change on which Grantees are working: (1) initiatives whose goal is to improve access to currently available services; (2) initiatives to modify, improve, or create new services and supports; (3) initiatives to design, implement, and maintain systems and processes that enable and support home and community services, for example, those that allow for flexible budgeting and reimbursement, and (4) initiatives to improve the recruitment, training, and retention of direct service workers. Section 4 describes Grantee challenges to achieving their goals, and Section 5 summarizes consumers' involvement in grant implementation and evaluation

Exhibit 1. Number of Systems Change Grants Awarded, by Grant Type

Grant Type	FY 2002 & FY 2003
Real Choice (RC)	25
Community-Integrated Personal Assistance Services (CPASS)	16
Nursing Facility Transition (NFT)*	16
Research & Demonstration: Quality Assurance/Quality Improvement (QA/QI)	19
Research & Demonstration: Independence Plus (IP)	12
Research & Demonstration: Money Follow the Person (MFP)	8
Feasibility Study: Community-Based Treatment Alternatives for Children (CBTAC)	6
Feasibility Study: Family-to-Family (FTF)	9
Feasibility Study: Respite for Children (RFC)	6
Feasibility Study: Respite for Adults (RFA)	4
Total	**121**

*NFT Grants are of two types—State Program (SP) Grants supporting state initiatives, and Independent Living Partnership (ILP) Grants made to Centers for Independent Living (CILs) to promote partnerships between CILs and states to support transitions to the community. In this report, NFT refers to State Program grants, whereas NFT-ILP refers to the latter.

activities. The final section provides an overview of forthcoming reports of the Grantees' accomplishments.

Appendix A lists the types of grants awarded in FY 2002 and FY 2003 and the total amount awarded to each state. Appendix B identifies the lead agency receiving grants in each state in FY 2002 and FY 2003. Appendix C provides information on the FY 2004 Grantees. Additional information about all the Grantees' initiatives can be found in *Real Choice Systems Change Grants: Compendium, Fourth Edition,* on the CMS Web site (http://www.cms.hhs.gov/systemschange/compendium04.pdf) and on the CMS technical assistance Web site (http://www.hcbs.org/files/60/2991/Compendium4thEdition.pdf).

SECTION 2
METHODS

Data Sources

The Year Two annual reports of the 49 FY 2002 Grantees and the Year One annual reports of the 48 FY 2003 Research and Demonstration Grantees are the principal source of data for this report. In subsequent months, we obtained additional information through e-mail communication and telephone calls with these Grantees. We also analyzed the primary accomplishments reported by the 25 FY 2003 Feasibility Grantees' in their Year One annual reports.[2]

Technical Approach

Grantees submitted their annual reports on October 30, 2004, and their reports were analyzed in the following months. RTI identified four focus areas for classifying major systems change activities, which are broad enough to incorporate the activities of all grant types:

- **Access to Long-Term Care Services and Supports**—efforts to ensure that consumers have access to the full range of currently available home and community services and supports, such as creating "one-stop shopping" or "no-wrong door" information and referral systems.

- **Services, Supports, and Housing**—efforts to create new community services and supports or to modify or improve currently available community services and supports (e.g., changing regulations to allow service provision outside the home, working to change nurse delegation rules).

- **Administrative and Monitoring Infrastructure**—efforts to design, implement, and maintain systems and processes that enable and support home and community services, such as the creation of data systems needed to allow flexible budgeting and reimbursement and the development of comprehensive quality assurance and quality improvement systems covering LTC.

- **Long-Term Care Service and Support Workforce**—efforts to improve the recruitment, training, and retention of direct service workers.

Each area was further divided into categories and, in some cases, subcategories, to better illustrate the range of activities being undertaken in each focus area. For example,

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[2] Four states—Kentucky, Iowa, New Hampshire, and Vermont—did not receive a grant during FY 2002 or FY 2003. Although New Mexico received an FY 2002 grant, a major reorganization of the state's Medical Assistance Division—the lead agency on the grant—prevented it from initiating any activities during the reporting period. Consequently, these five states are not included in this report.

initiatives to improve access to currently available services were broken down into three subcategories: integrating access to LTC systems, streamlining eligibility determinations, and increasing knowledge about service options.

RTI staff analyzed the most recent annual reports for the FY 2002 and FY 2003 Grantees and classified their activities and accomplishments into these four major focus areas and the appropriate category or subcategory. We then selected examples of Grantee activities to illustrate the type and range of accomplishments during the reporting period for each category and subcategory.

Finally, after reviewing the data, we contacted Grantees and technical assistance providers to obtain additional information and to clarify responses.

Limitations of Approach

This report describes the progress Grantees made on their scheduled activities in the reporting period. The description is subject to the limitations of the data and the technical approach used. Specifically,

- The data used in the analysis were reported by Grantees. The content of this report depends on both the quality and thoroughness of each Grantee's information in their annual report and their responses to follow-up inquiries.
- In some cases, activities could be classified in more than one area. For example, nursing facility transition activities could be assigned to both the Access focus area and the Services, Supports, and Housing focus area. In these cases, RTI exercised judgment in assigning activities to a particular focus area and categories within these focus areas. In some instances, different facets of the same initiative are described in more than one focus area.
- At each step of the analysis, RTI exercised discretion to determine which activities and issues to highlight in this report. Staff eliminated duplicative information and prepared concise summaries.
- This report covers only one year of grant activities and only the first year of activities for the FY 2003 Grantees. Therefore, many of these Grantees may not have reported on the full range of activities being implemented, because some activities had not yet been initiated at the time of reporting. Additionally, the FY 2002 Grantees' activities that were completed during the previous reporting period were included in the *Second Year Report*.[3]

[3] The Second Year Report can be found on the CMS Web site (http://www.cms.hhs.gov/systemschange/report04.pdf).

SECTION 3
GRANT INITIATIVES

This section describes Grantees' initiatives in four areas:

- initiatives to improve access to currently available services;
- initiatives to modify, improve, or create new services and supports;
- initiatives to design, implement, and maintain systems and processes that enable and support home and community services; and
- initiatives to improve the recruitment, training, and retention of direct service workers.

Initiatives to Improve Access to Currently Available Services

Ensuring access to the full range of currently available services and supports for persons with disabilities of all ages is a critical component of LTC systems rebalancing. Grantees in more than half the states reported progress on activities to provide or increase access to new or existing services and supports. As shown in Exhibit 2, initiatives to improve access are grouped into four broad categories:

- integrated access to LTC systems;
- streamlined financial and functional eligibility determinations;
- increased knowledge of service options; and
- other related activities, including expanded eligibility.

The majority of Grantees who have access initiatives are working to integrate access to the full range of LTC services. Many are also focusing on improving access through community education. Fewer Grantees are focusing on efforts to streamline eligibility determinations or expanding eligibility for services and supports. In the following sections, we present examples of Grantee's activities in each of the four categories to illustrate the type and range of initiatives they are undertaking.

Integrated Access to Long-Term Care Systems

Grantees in 12 states described efforts to improve access by integrating information sources for multiple LTC services and supports, primarily by creating single-point-of-entry systems; developing Web sites and toll-free phone lines; and creating dedicated information, referral, and assistance staff positions. Examples follow.

Exhibit 2. Number of States with Activities to Increase Access to Services

State	Integrate Access to LTC Systems	Streamline Eligibility Determinations	Increase Knowledge of Service Options	Other
Alabama			●	
Alaska			●	
Arkansas	●		●	
California			●	
Colorado	●			
Connecticut			●	●
Delaware			●	●
District of Columbia	●	●	●	
Florida				●
Idaho			●	●
Indiana			●	
Louisiana	●		●	
Maryland			●	
Montana			●	●
Nebraska			●	
Nevada	●		●	
New Jersey			●	
New York			●	
North Dakota	●		●	
Northern Mariana Islands	●			
Ohio	●		●	
Rhode Island	●		●	●
South Dakota				
Texas	●		●	●
Utah	●		●	
Washington			●	
West Virginia	●		●	●
Wisconsin		●	●	●
Total	**12**	**2**	**24**	**9**

- **Arkansas (RC, CPASS, NFT-SP)** continued development of AR-GetCare, the State's single-point-of-entry online information system (http://www.argetcare.org). The system includes a self-assessment form, extensive resources, educational information, and search options to help consumers and family members locate needed services. The system is organized into six main categories, and each category includes a range of services for older adults and people with disabilities. The categories are in-home care, community health and social services, residential facilities, medical services, caregiver resources, and care coordination and other services. AR-GetCare was scheduled to be rolled out to the public in early 2005.

- **The District of Columbia (RC)**, in preparation for the opening of the Disability and Aging Resource Center, selected a vendor and executed a contract to manage and operate the center. The vendor, Chesapeake Consulting, secured a site for the resource center in a centrally located, low-income neighborhood, making it easily accessible to the target population. To simplify the process of obtaining services, the Grantee plans to staff the Center with intake, information, and assistance staff; care managers; a care manager specialist; and a benefits counselor. Care managers will provide functional assessments or at-risk assessments to determine potential waiver

eligibility and the potential service needs of consumers, and to provide consumers with provider contact information. In addition, a full-time eligibility worker from the Income Maintenance Assistance Department (the District's Medicaid authority) will be on-site to answer questions, take applications, and determine eligibility for Medicaid, Supplemental Security Income (SSI), food stamps, and other programs.

- **Nevada (RC)** worked with other State agencies to increase access to health care and insurance through (1) development of a Web site for children with special health care needs (CSHCN) (http://health2k.state.nv.us/cshcn/) and (2) implementation of a 13-month-long media campaign with public service announcements that began in late 2004. The Web site will provide a single point of access to many of the supports, advocacy groups, and services that parents of CSHCN seek. The media campaign provides basic information on available services and a toll-free number to access those services. As it continues, the media campaign will also address issues raised during the statewide needs assessment, which is now under way.

- **The Northern Mariana Islands (RC)** are partnering with an Administration on Aging (AoA)-sponsored program to provide access to information and referral to support services for persons of all ages. Using space at a local Aging Program office, the Grantee is providing the office equipment and technical support.

- **Rhode Island (RC)** signed an interagency agreement with the Department of Elderly Affairs to purchase information and assistance software for individuals who provide information and assistance to elderly persons and people with disabilities with the intent to improve integration of health and social services. The software will also be used in an Aged and Disabled Resource Center after the Center is established.

- **Texas (RC)** has two subcontracted projects (the Heart of Texas project and the Texoma Real Choice project), both of which have promoted numerous community partnerships with hospitals and health/medical service providers, who have agreed to adhere to the new intake, referral, assessment and follow-up protocols developed by the Grantee. The partnership agreements are the result of outreach and education efforts with physicians, discharge planners, and hospital administrators and will improve LTC system coordination and consumers' timely access to services.

  The grant projects' system navigators (i.e., individuals knowledgeable of the LTC system) have also enhanced and streamlined the work of existing Community Coordination Resource Groups, a group of front-line professionals from a variety of agencies who staff critical cases and attempt to piece together rapid response solutions for the consumer. Real Choice centers in the Heart of Texas project area processed 11,833 inquiries, and navigators served 567 consumers with complex needs, while the Texoma Real Choice project assisted 946 consumers with multiple needs.

- **Utah (RC)**, with assistance from the University of Utah, has completed a statewide survey and conducted focus groups to identify how different stakeholder groups (e.g., consumers, families, physicians, discharge planners, and care coordinators) obtain information, and what information they need to make informed decisions about LTC options. The results, contained in a report completed September 29, 2004, are being used in the development of a statewide LTC Web site with information for the public about available services, including an "eligibility wizard" feature. The State has also finalized a contract with the statewide Information and

Referral 211 agency to provide an access point for caregivers to obtain emergency information regarding available services. The contractor is developing an information and referral information bank.

Streamlined Financial or Functional Eligibility Determinations

Real Choice Grantees in two states described initiatives to administratively streamline financial and/or functional eligibility determinations for Medicaid State Plan and HCBS waiver programs so that intake, assessment, eligibility screening, and programmatic and financial eligibility determinations are seamless to consumers:

- **The District of Columbia (RC)** created and implemented a streamlined financial eligibility redetermination process for waiver clients. First, they created a flag in the Medicaid Management Information System (MMIS) to identify these consumers so that staff will know who is eligible for the streamlined process. The recertification application was simplified, reducing the application from 15 pages to 1 page. In addition, those applying for recertification do not have to provide proof of their assets and income as they do during the initial certification process. Instead, the Income Maintenance Administration (the District's Medicaid authority) will accept self-declaration of assets and income.

- **Wisconsin (RC)** implemented an automated Web-based functional eligibility assessment tool for children's long-term supports; after all agencies are trained in its use, it is expected to be the only tool for waiver level-of-care determination after January 1, 2005. The Grantee has also automated the functional eligibility assessment tool for adults with mental illness, which is being tested for interrater reliability. Pilot counties have also tested the mental illness assessment tool, and the Grantee expects it will be used statewide in 2005. These tools will simplify eligibility determination and access to LTC services.

Increased Knowledge of Service Options

Grantees in 24 states reported activities to increase informed consumer choice and knowledge of LTC service and support options by providing outreach and education and conducting need assessments to determine consumer knowledge and needs, building infrastructure, and/or making improvements to information systems. The majority of Grantees are implementing specific activities to inform consumers about consumer options. These include Family-to-Family (FTF) Grantees, whose initiatives are focused on increasing access to home and community services for families who have CSHCN. Examples follow.

- **The FTF Grantee in Alaska**—the Stone Soup Group—is making progress on a number of initiatives. The Grantee has begun design of a Web site, which will include a listserv for families of CSHCN to communicate with and support each other. The Web site will also have links to existing information and referral sites for families with CSHCN. The Grantee is also collecting and cataloguing resource materials to establish a lending library for families with CSHCN, which will be available by mail for families in rural areas. As part of this process, grant staff will identify outdated resources and update or produce new educational resources.

A third initiative is the development of an interactive, statewide peer-to-peer network and support forum for families of CSHCN. To help recruit participants in this network, the Grantee sent information about the initiative and a survey about support and training needs to rural health networks, public health nurses, and agencies serving families with CSHCN. The distribution of this information has increased awareness of project activities among families and professionals. This process has also forged important partnerships with key agencies such as public health nursing and rural health networks in the State. At the time of the Grantee's report, 35 parents had been recruited to provide peer-to-peer support for families in the State.

- **The FTF Grantee in Colorado**—Family Voices of Colorado—is establishing a statewide network of parents and professionals whose role will be to (1) improve access to information about health care systems and community resources and (2) assist other parents to effectively navigate these systems and use these resources. The Grantee has already trained 12 Family Coordinators and more than 200 parents, providers, and professionals and is planning training sessions in Spanish to reach Hispanic parents.

- **Louisiana (RC)** conducted 10 stakeholder forums to increase consumers' knowledge of LTC services and supports. The State also participated in the governor's State Summit on Health Care, during which 387 stakeholders provided recommendations to improve the State's system of LTC services and supports. This stakeholder input will be used in the State's efforts to make changes to its LTC system.

- **The FTF Grantee in Maryland**—The Parents' Place of Maryland—has established and broadly advertised a toll-free number that consumers can call to obtain information on health care options for families with CSHCN, and has conducted outreach to pediatricians, hospitals, and clinics, which has resulted in increased contacts with parents of CSHCN. The Grantee also (1) developed and distributed e-newsletters containing health and contact information to over 14,000 people; (2) presented information at several health fairs, conferences, and forums; (3) conducted five focus groups with families of CSHCN to determine information needs and is planning additional focus groups with pediatricians; and (4) developed and piloted six workshops related to the health care system, which will be presented in every region of the State within the next year.

  To increase the provision of culturally competent information, the Grantee has expanded outreach to Hispanic/Latino populations by providing a Latino Outreach Coordinator to provide needed information and resources to Spanish-speaking families of CSHCN. The Grantee is also developing a Spanish version of a workshop combining basic healthcare and education information. The Grantee also has an African American Outreach Coordinator who is working to reach traditionally underserved populations.

- **Michigan (MFP)** developed a Consumer Consortium for informing consumers about LTC issues and gathering input from them. The Michigan Disability Rights Coalition developed a presentation on LTC reform and has presented it to groups throughout the State. The contractor is also videotaping consumer stories, developing a Web site for the consortium (http://www.copower.org/mfp/index.php), and compiling fact sheets and other information. A total of 30 presentations to 600 people have taken place, with 50 percent of attendees signing up to join the consortium.

- **The FTF Grantee in Montana**—Parents, Let's Unite for Kids (PLUK)—is using its grant to provide training, data collection, and information services to a statewide constituency to create a Family-to-Family Health Care Education and Information Center. PLUK has provided extensive training for 15 of its Family Support Consultants throughout the state to provide them with the knowledge and skills needed to work with families, recruit volunteers, and provide training sessions throughout the State.

  The Grantee is also working to increase collaboration among public and private entities to ensure that families receive accurate and timely information on health care options available to families of CSHCN. For the past year, grant staff focused on increasing collaboration with agencies and established Associate Boards (similar to advisory committees) throughout the State that directly involve parents and service providers on a collaborative board. The Grantee now has 12 boards in Montana, including one on the Blackfeet Indian Reservation. The Grantee is working to establish Associate Boards on the remaining six reservations.

- **North Dakota (RC)** held consumer awareness information sessions regarding LTC service options in all eight regions of the State. Consumers were instrumental in developing the content for each session and in providing information in each session. As a result, more consumers are asking questions about services and offering suggestions to improve services. The Grantee also distributed information about service rights and LTC service options to all eight Human Service Centers, eight drop-in centers for the seriously mentally ill, four Independent Living Centers and their affiliates, the North Dakota Nursing Home Association and affiliates, and consumers who have contacts with these entities.

- **Rhode Island (RC)** contracted with the New England States Consortium (a collaborative effort of the health and social services agencies of the six New England states) to assist in grant coordination and the development of a Web-based resource directory and benefit screener to increase informed consumer choice. A benefits screener will allow individuals to enter information in a Web-based application that will then screen the information to determine if the individual may be eligible for certain benefit programs and will tell them how and where to apply. The Grantee is negotiating with a community provider to become the content and knowledge base manager for the directory and screener. The Grantee also plans to conduct a conference on community services for persons with disabilities.

- **The FTF Grantee in South Dakota**—South Dakota Parent Connection, Inc.—has developed three workshops to train Regional and Indian Reservation Coordinators to assist in assessing and responding to the community's need for information about health care and home and community services statewide to persons caring for CSHCN. The workshops are being piloted with various stakeholders around the State. Workshop materials are currently being translated into Spanish, and the Grantee will also translate promotional brochures, posters, and other informational materials.

- **Texas (MFP)** consolidated information for state- and federally funded community care programs available through the Department of Aging and Disability Services and developed educational packets for consumers, which include information about eligibility criteria, services offered, and how to apply for services.

- **Washington (RC)** held a 1-day Real Choice Community Living Conference, sponsored by the Real Choice Consumer Task Force, that provided training,

education, and networking opportunities to over 550 individuals with disabilities and persons interested in community living. During the conference, 22 local councils of self-advocates and families, counties, and State representatives exhibited and distributed materials developed in their local communities to educate individuals on choice and consumer-directed supports and services. The Grantee also assisted in the preparation of literature for doctors and nurses on the needs of children 3 years of age or younger with developmental disabilities.

- **West Virginia (RC)** awarded funding to two demonstration peer support services model programs and will use the information obtained from these models to encourage agency and legislative buy-in for replication. The State also cosponsored a statewide conference for 151 adults and their family members. The conference had six tracks: Employment, Health, Community Services and Supports, Housing, Transportation, and Self-Determination. The Grantee provided funding for 92 adults and families to attend self-determination and advocacy trainings.

- **The FTF Grantee in Wisconsin**—Family Voices of Wisconsin—is working to increase coordination between existing, state-funded information and assistance activities. An interagency planning group is focusing on developing methods for sharing information about what each agency does, current collaborations, and ways in which the information, assistance and advocacy (IA&A) network can interact to improve access to IA&A for people with disabilities in Wisconsin. The group has identified all IA&A providers in the State and has convened several meetings with them. Prior to the first meeting, they conducted a survey of all the organizations to develop a comprehensive summary of information about each organization to distribute to all providers.

Other Initiatives to Increase Access

Several Grantees described additional efforts to increase access to LTC services and supports, primarily by expanding eligibility for Medicaid State Plan or HCBS waiver programs, working to increase transportation options (e.g., adding a new target population), implementing initiatives to foster community integration, integrating health and social services, and engaging in community education activities. Examples follow.

Expanded Eligibility

- **Florida (IP)** helped secure a waiver from the Social Security Administration (SSA) to allow individuals enrolled in the Consumer Directed Care Plus (CDC+) 1115 waiver demonstration to have increased levels of earned and unearned income and assets up to $10,000. The CDC+ program is a cash and counseling program approved to serve 3,350 individuals statewide, and the Grantee has begun to identify consumers eligible for the program.

Transportation

- **Montana (RC)** worked to increase public transportation options for persons with disabilities. Through a contractor (Western Transportation Institute), the Grantee finalized the first version of a countywide coordination and service improvement plan for the Ravalli County–Hamilton area, and implemented a coordination program for several other counties to eliminate overlap in the provision of transportation. The

Grantee also worked with a contractor to conduct a bus service survey in East Helena. Based on the results, the contractor is considering consolidating bus fares for two areas in Helena to provide less expensive and more efficient service. The contractor also plans to recommend changes to Public Service Commission rules, which would require coordination among services and locales to improve rural public transit.

- **West Virginia (RC)** is investigating various methods for increasing access to transportation supports for people with disabilities, which will lead to the development a replicable model within the State. The West Virginia Transportation Alliance, which received funding from the Grantee to assist with achieving this goal, was successful in having the Governor establish a Statewide Transportation Coordination Council; has developed strategies and recommendations for a State transportation plan; and has been examining ways to sustain the program (e.g., through funding from Governor's Council and seeking 501(c)3 status and/or other grant funds).

Community Integration

- **Connecticut (RC)** developed and administered statewide surveys to 260 individuals to assess how persons with disabilities receive an inclusive education, participate in community life, seek and obtain employment and housing, and generally access supports and services needed to maintain independence. The findings will be used to provide feedback to communities on their level of inclusiveness and inform the content of future forums on inclusiveness. The Grantee also sponsored forums for State legislators on disability issues related to housing and transportation.

- **Idaho (MFP)** is conducting an ongoing effectiveness study of how people with disabilities reach their community integration goals, becoming more self-reliant through independent housing, assistive technology, and home access modifications. The study has enrolled 16 participants with physical and mental disabilities to examine their individual experiences and integration issues in using individualized community integration plans to work toward improvements in life areas such as employment, education, and recreation through increased community access. An analysis is planned to provide guidance for future efforts to assist people with disabilities in this process.

- **Rhode Island (RC)** contracted with Yale University to produce a work plan to guide the assessment of youths with serious emotional disturbances transitioning to the community in an effort to expand capacity to provide services to these youths. The University will also track and analyze the demographics, utilization, and outcomes of children accessing residential and community systems of care. The assessment has already led to a reduction in highly restrictive placements, including a 50 percent reduction of out-of-state placements.

- **West Virginia (RC)** is working to ensure that quality education is a part of a community inclusion plan for children with disabilities. The Grantee cosponsored a workshop on transitioning into, through, and out of public education to support parent groups in ensuring that education curriculums meet the needs of children with disabilities. The workshop was attended by 35 parents of children with disabilities.

Integration of Health and Social Services

- **Rhode Island (RC)** signed an interagency agreement with the University of Rhode Island to analyze Medicare data to identify acuity patterns of individuals likely to become dually eligible for Medicaid and Medicare, as part of an effort to better integrate health and social services and coordinate services across multiple delivery systems.

Community Education

- **Delaware (NFT-SP)** trained nursing facility (NF) residents and staff, families, and hospital discharge planners and case managers on community options for transition and diversion, and conducted education and outreach to community health groups.

- **Montana (RC)** provided training classes on advocacy methods to self-advocates, community advocates, and professional staff to promote and strengthen partnerships between families, consumers, human service providers, and state Developmental Disabilities Program staff. Topics included exercising rights, being a member of the individual planning team, managing the individual planning process, and changing the way the systems works. To reach people in their own locales, the Grantee is exploring options that would offer more flexibility to participants, such as video conferencing with online streaming, Web-based training, condensed or module-based training, and train-the-trainer sessions. The Grantee also supported the attendance of self-advocates at a legislative forum presented by a disabilities services coalition. During this conference, gubernatorial candidates were asked about their positions on funding for disabilities services, and their responses were subsequently published in several newspapers across Montana.

- **Rhode Island (RC)** issued a request for proposals (RFP) for Behavioral Health Consultation to develop training modules that instruct caregivers and community support workers in techniques to deal with individuals with adverse behavior. The consultant will also provide a series of train-the-trainer sessions.

- **Texas (RC)** used the Texoma Real Choice project to develop life-planning tools for high school students with disabilities. They also formalized a “Life Plan Tool Kit” for the grant’s system navigators to use when educating individuals and groups about the need for life planning, and to provide guidance while navigators assist individuals in creating a Life Plan for themselves.

- **Wisconsin (MFP)** conducted training sessions to prepare stakeholders for the planned downsizing of ICF/MR facilities, providing information about changes in State statutes, standards for the least restrictive and most integrated community living situations, and the role of guardians and guardians ad litem. The Grantee conducted a separate training for the Members of the Milwaukee County Bar Association focused specifically on the responsibilities of a guardian ad litem.

Aging and Disability Resource Centers

Because long-term support services are often paid for by many different sources and administered by several different agencies—often with duplicative intake, assessment, and eligibility functions—figuring out how to obtain services is difficult for persons with disabilities who need and qualify for services. As a result of these barriers, individuals with

disabilities face the risk of institutionalization. To help states simplify the process of obtaining information on available services, the CMS collaborated with the Administration on Aging (AoA) to award 24 Aging and Disability Resource Center (ADRC) Grants—12 in FY 2003 and 12 in FY 2004. These grants offer states the opportunity to create single points of entry to long-term support services. Primary oversight for these grants resides with AoA.

The ADRC Grantees are engaged in many of the same types of activities as the Real Choice Systems Change Grantees described in this section. They are primarily focused on activities to develop systems that integrate information and referral sources and facilitate access to publicly and privately financed LTC services and benefits. More information about the ADRC Grantee initiatives can be found in the profiles for each grant at http://www.adrc-tae.org/tiki-index.php?page=GranteeProfilesPublic.

Initiatives to Modify, Improve, or Create New Services and Supports

For individuals with disabilities, successful community living depends on the availability of a wide range of services and supports. Without adequate services and supports, many individuals with disabilities can experience increased risk for health problems and secondary disabilities that result in a need for more health and LTC services. A lack of appropriate and adequate services and supports can also lead to unnecessary nursing home placement. To live successfully in the community, consumers—especially those transitioning from nursing facilities and other institutions—must also have affordable and accessible housing.

As shown in Exhibit 3, initiatives addressing services, supports, and housing are grouped into six broad categories:

- personal assistance services and supports,
- nursing facility transition and diversion,
- housing,
- respite for adults and children,
- community-based treatment alternatives for children, and
- other efforts to address long-term services and supports.

The FY 2003 grants include three feasibility grant types. Two of these—Respite for Children and Respite for Adults—were awarded to help states assess the feasibility of developing respite projects for caregivers under Medicaid or other funding streams. A third type—Community-Based Treatment Alternatives for Children—was awarded to help states develop a comprehensive, community-based mental health service delivery system, through

Exhibit 3. Number of States Working in Subcategories of Service, Supports, and Housing

State	Personal Assistance Services and Supports	Nursing Facility Transition / Diversion[1]	Housing	Respite for Adults and Children	Community-Based Treatment Alternatives for Children	Other
Alabama		●		●		
Alaska	●					
Arkansas		●	●	●		
Arizona	●			●		
California	●	●				
Colorado	●	●				●
Connecticut	●					
Delaware			●			
District of Columbia	●					
Florida	●					●
Georgia	●					
Hawaii	●					
Idaho	●					
Illinois					●	
Indiana	●					
Kansas	●	●				
Louisiana	●	●	●			
Maryland				●	●	
Massachusetts	●				●	
Michigan				●		
Minnesota		●	●			
Mississippi	●				●	
Missouri	●				●	
Montana			●			
Nebraska	●	●	●			
Nevada	●	●	●			
New Hampshire						
New Jersey	●	●	●			
New Mexico						
New York	●	●		●		
North Carolina	●	●				
Northern Mariana Islands						●
Ohio	●	●		●		
Oklahoma	●	●				
Oregon	●			●		
Rhode Island		●		●		
South Carolina		●				
Tennessee	●					
Texas	●	●			●	
Utah		●				
Virginia	●					
Washington		●				
West Virginia	●		●			
Wisconsin		●				
Wyoming		●				
Total	**28**	**21**	**9**	**9**	**6**	**3**

[1]This category also includes Grantees other than NFT Grantees (e.g., RC, CPASS, and MFP) who are focused on transitioning and diverting persons with disabilities to the community.

Medicaid, for children with serious emotional disturbance who would otherwise require care in a psychiatric residential treatment facility. These Grantees are exploring ways to either expand services through existing programs or develop new programs. As these Grantees are engaged primarily in a feasibility study, few reported major accomplishments during the first year of their grants, the period covered by this report.

Grantees in 45 states reported accomplishments in their efforts to address issues related to a lack of LTC services and supports, and housing. Most are focusing on activities related to personal assistance services (PAS) and nursing facility transitions (NFT).

Although the CMS awarded grants to eight Grantees in 2004 to focus specifically on housing options, a few FY 2002 and FY 2003 Grantees also have initiatives underway to address housing needs, especially for consumers transitioning from nursing facilities and other institutions. Next, we provide examples of Grantee activities and accomplishments in the five major categories noted earlier.

Personal Assistance Services and Supports

Persons of all ages with all types of disabilities need personal assistance services and supports to exercise control over their lives and to live as independently as possible. Many people with disabilities also want to be actively involved in choosing the services they need to carry out everyday activities and the workers who provide these services. Grantees in about half the states reported progress toward or accomplishments for their goals of providing or improving personal assistance services and supports. As shown in Exhibit 4, these activities can be grouped into four subcategories:

- consumer direction,
- person-centered planning,
- new or modified services, and
- other activities.

The majority are working to provide opportunities for consumers to direct their own services through a range of approaches, including incorporating the principles and philosophy of consumer direction into rules and regulations and developing a consumer-owned and consumer-directed worker cooperative. A few Grantees reported accomplishments in the areas of person-centered planning and developing new or modifying existing home and community services. A small number of Grantees are focused on other methods to increase personal assistance services and supports, such as determining the feasibility of creating a peer support program for elderly persons.

Exhibit 4. Number of States with Activities Related to Personal Assistance Services and Supports

State	Consumer Direction	Person-Centered Planning	New or Modified Services	Other
Alaska	●			
Arizona	●			
California	●		●	
Colorado	●		●	●
Connecticut	●	●		●
District of Columbia	●		●	
Florida	●			
Georgia	●	●		
Hawaii	●		●	
Idaho	●	●		
Indiana	●			
Kansas	●		●	
Louisiana	●	●	●	
Maryland				
Massachusetts	●	●	●	
Michigan		●		
Mississippi	●	●		
Missouri	●	●		
Nebraska	●			
Nevada				●
New Jersey	●			
North Carolina	●			
Ohio		●		
Oklahoma			●	
Tennessee	●			
Texas			●	
Virginia	●			
West Virginia	●			●
Total	**22**	**9**	**9**	**4**

Personal Assistance Services and Supports: Consumer Direction

Grantees in about half the states described activities to create LTC systems that give consumers maximum control over the services they receive. Their activities and accomplishments include education and outreach, training, consumer-direction infrastructure development, and new consumer-directed waiver programs. Examples of Grantee's activities and accomplishments in these areas are presented next.

Education and Outreach

- **Alaska (RC)**, provided outreach and training opportunities for individuals interested in directing their own services and provided consumers with information about how consumer-directed services work. Grant staff also wrote an article for the Partners in Policymaking newsletter to bring awareness to the grant's efforts to design and implement a consumer directed pilot program.

- **Hawaii (CPASS)** is working with the State and local island Developmental Disability (DD) Councils and the Hawaii Real Choices System Change Grantee to conduct outreach to persons with developmental disabilities to ensure they are informed

about the new consumer driven personal assistance (CDPA) waiver option and other resources available for individuals who wish to direct their own services. To further information dissemination and outreach activities, the Grantee plans to develop a Web page on the Department of Health's Web site. Grant staff are also developing a video on consumer direction to be shared with families throughout the State who would like to learn about consumer direction options.

- **Indiana (CPASS)** enabled 150 consumers to participate in a model pilot consumer-directed attendant care program, administered by local Area Agencies on Aging. Consumer-directed attendant care was available to consumers across the State in both rural and urban areas from nine of the State's sixteen Area Agencies on Aging.

- **North Carolina (CPASS)** awarded contracts to four community pilot projects to promote leadership among persons who need personal assistance services to help them direct their own supports, assume personal responsibility, manage risks, and exercise their rights. All four pilots have begun surveys and focus groups in their communities addressing such topics as community openness and awareness of consumer-directed supports.

- **Virginia (CPASS)** developed a general awareness brochure on consumer-directed services for distribution to individuals, family members, providers, consumer-directed services resource networks, case managers, and service facilitators. Grant staff made presentations on consumer direction in three areas of the State reaching approximately 35 family members and providers. They also presented information on consumer-directed services to individuals with disabilities and family members during workshops in two other areas of the State. The Grantee is also developing a Web site for posting information and materials related to consumer-directed services. The Web site will be operational by January 2005.

- **West Virginia (CPASS)** distributed materials on consumer direction, e.g., brochures, PowerPoint presentations, and fact sheets, to consumers, advocates and State agencies to assure consumers have access to information to help them make more empowered decisions about the services they receive. The Grantee will partner with other Systems Change Grantees in the State to develop a multimedia campaign to disseminate information regarding available personal assistance services.

Training

- **California (RC)** initiated plans to conduct a needs assessment of consumers and providers in the In-Home Support Services program to determine their training needs. The process began with extensive consumer focus groups and provider interviews. The training will be designed to enhance the ability of consumers to direct their own care and identify ways improve the quality of care provided.

- **Colorado (CPASS)** trained 79 case managers of the State's single entry point system in principles of consumer direction and the consumer-directed attendant support (CDAS) 1115 Demonstration Project. The State also trained 85 new participants in CDAS about consumer rights and responsibilities. The State developed training materials and a consumer-direction supports curriculum for consumers acting as trainers, and subsequently trained four consumers who had transitioned to become peer trainers. Grant staff revised training materials to reflect the trainees' improved consumer direction knowledge base and changing consumer direction information needs to ensure continuous quality improvement.

- **Connecticut (RC, CPASS)** developed a train the trainer manual and a training manual for consumers who employ personal assistants. The manual has several modules, including: Knowing What You Need and Want; Funding Options and Tax Considerations; Stress Management; and Communication Skills and Additional Resources.

- **Florida (IP)** established developmental disability districts to work with consumers enrolled in the State's 1115 waiver cash and counseling demonstration program, with a working committee in each district responsible for developing a district-wide plan to implement self-determination. The Grantee collaborated with the Center for Self-Determination to identify the content of a training curriculum designed to educate the district committees, support brokers, advocate groups, providers and policymakers about consumer direction, self-determination, and the broad authority provided under 1115 waivers, with a specific focus on the waiver of the SSA income and asset rule that was secured by the Grant.

- **Georgia (RC)** created a peer support curriculum and implemented peer support pilot training programs for consumers to learn how to direct their own care. Fourteen people with mental illness participated in one peer support training program and 32 people with developmental and physical disabilities participated in two other programs.

- **Idaho (IP)** completed training for three regional teams of self-advocate trainers, and the training group has evolved into an on-going "Self-Advocate Leadership Network" statewide group. Three additional regional teams have been identified and have begun their training. Self-advocate trainers have presented consumer-direction information to several consumer, parent, and provider groups and are scheduling additional presentations.

- **Kansas (CPASS)** worked with individuals with developmental disabilities and/or their families in three pilot regions to develop management skills and maximum consumer control over all aspects of personal assistant services. Staff delivered seven trainings on all aspects of self-direction for consumers, representatives, and families. They also hosted a six-hour statewide "Training Material Extravaganza" on the same topic attended by 25 consumers and service providers.

- **Tennessee (CPASS)** developed a series of products and a lending library to educate and prepare consumers to direct their own services. The library contains a User's Guide to help consumers recruit, hire, train, manage, and terminate workers and a checklist for addressing pre-employment and employment issues. The Grantee developed a brochure describing the products, and a self-assessment tool to help consumers document their needs, develop a daily schedule, and write a job description. Grant staff also developed a job description that lists core competencies consumers should expect workers to possess and a Mentor's Guide. The Mentor's Guide is for consumers providing peer to peer mentoring as well as for self-advocates to mentor agency staff during in-service trainings. The Mentor's Guide also contains a training curriculum with materials promoting consumer direction.

Consumer-Direction Infrastructure Development

- **Alaska (RC)**, with assistance from the Grant's Consumer Task Force, developed a service brokerage model for the waiver program to support individuals who wish to direct their own services.

- **Colorado (IP)** conducted 42 key informant interviews and organized and facilitated six focus groups with users of attendant services. The purpose was to identify the strengths and weaknesses of the current consumer-directed programs from the consumers' point of view, find out how consumers would define a critical incident, and obtain input for developing a statewide emergency backup system. A consultant compiled the findings into a report, "Voices of Attendant Support Users," which provided recommendations on how to improve the consumer-directed programs infrastructure.

- **Georgia (IP)** conducted over 20 stakeholder group meetings to discuss individual budgeting, key operations and master plan development, and quality assurance/quality improvement system changes. In the process, the Grantee identified activities that needed to be undertaken and infrastructure that needed to be developed to fully implement a consumer-directed system. The meetings to date have resulted in proposals related to the coordination of individual budgeting with person-centered planning, procedures for individual budget formula development, incident management, and access to consumer-directed services.

- **Idaho (IP)** has formed a workgroup to (1) identify qualifications and requirements for support brokers and fiscal employer agents and (2) define their responsibilities in providing support to individuals with developmental disabilities.

- **Louisiana (IP)** is conducting an analysis of the State's existing emergency backup systems to determine if they are effective. Individuals selecting the consumer direction waiver option are being tracked, and anecdotal information and incident reports related to emergency backup issues are being reviewed to determine the effectiveness of individual emergency backup plans.

- **Missouri's (IP)** grant task force, which is composed mostly of self-advocates and parents along with direct support professionals and State agency staff, conducted an internal review of Missouri's current financial intermediary system and reviewed the backup systems for individuals with mental retardation and developmental disabilities (MR/DD) in Missouri and other states. These reviews were part of the Grantee's efforts to plan and develop elements for an accessible statewide consumer-directed choice system.

Consumer-Directed Waiver Programs

- **Alaska (RC)** convened a subcommittee to design and plan the implementation of a consumer-directed waiver program. As a result of the committee's work, the consumer task force recommended to the State that it pursue a new 1915(c) Independence Plus waiver. Grant staff began writing the waiver application in September 2004.

- **West Virginia (CPASS)** worked on the design of a consumer-directed model within the 1915(c) Aging and Disabled waiver. The State applied for and was awarded a Robert Wood Johnson Cash and Counseling grant to support the expansion of the consumer-directed model beyond the grant period. Grant staff are continuing their involvement in the State's efforts to implement a consumer-directed model, are in the final stages of developing a PAS training curriculum for consumers, and are developing a fiscal management system for the consumer-directed program. Additionally, the Grantee plans to recruit consumers to the program and train resource consultants.

Other Consumer Direction Initiatives

- **Arizona (CPASS)** is working to create a consumer-directed model within the State's home and community-based services (HCBS) 1115 waiver program by developing a consumer-owned and consumer-directed cooperative in which consumers will be the employer of record for direct service workers and control the dollars spent on services. The Northern Arizona Human Services Cooperative (HSC) has been established as a certified provider agency, a Board has been established, and board members have been trained. The Board has developed its mission and vision statements and launched an official membership campaign to recruit members to provide personal assistant services. The Grantee has also developed a resource library that will facilitate the development, operation, and management of additional HSCs.

- **Connecticut (RC)** completed and disseminated a report describing the extent to which key State agencies and bureaus serving individuals with disabilities have included principals of self-determination and consumer direction into their mission statement and professional development.

- **Indiana (RC, CPASS, NFT)** combined funds from the Real Choice, CPASS, and NFT grants and used the funds to provide minigrants to offer consumer-directed care to individuals diverted from or transitioned out of a nursing home. Grants were awarded to 10 communities that demonstrated innovative ways to deliver consumer-directed services and supports.

- **Kansas (CPASS)** recommended to the State Medicaid agency that waiver regulations be changed to allow for more consumer direction. Grant staff and advisory committee members participated in the statewide Developmental Disability Waiver Re-write Task Force to incorporate consumer direction and update other existing policies to incorporate the philosophy of consumer direction.

- **Nebraska (CPASS)**, led by the Department of Health and Human Services, succeeded in revising the State's personal assistance regulations, which the governor signed into law. The regulatory revisions include adding consumer-directed care, eliminating the requirement for physician assessment, and creating an assessment tool based on self-reported needs. They also conferred with regulations and licensure experts in developing personal assistance organization specifications. Their goals were to (1) ensure that these organizations are distinct from home health agencies so that they will not be subject to home health agency regulations and (2) assure appropriate quality standards.

- **North Carolina (CPASS)**, through a contractor, has completed a preliminary report that identifies barriers to consumer-directed services and supports and makes recommendations for removing them. The report also addresses the need to both provide consumer safeguards and promote consumer direction and autonomy.

Personal Assistance Services and Supports: Person-Centered Planning

The CMS requires Medicaid-funded consumer-directed programs to include person-centered planning. Person-centered plans are designed to enable and assist individuals of all ages with disabilities to achieve their personal life goals and to obtain the LTC services and supports they need. Grantees in nine states reported progress on activities to incorporate

person-centered planning in service planning, which primarily involved designing and implementing person-centered planning pilot initiatives. Examples follow.

- **Georgia (QA/QI)** is developing two person-centered planning pilot programs, which will be implemented in the grant's second year. One pilot will target 10 children transitioning from school to adulthood, and the second pilot will target 10 adults with developmental disabilities living with aging parents. Groups of consumers and their supports will meet up to four times throughout the year to monitor progress and identify obstacles that consumers may be encountering in implementing their person-centered plans. Speakers will be invited to educate the groups on various topics, including, but not limited to, vocational rehabilitation, special trust funds, and communication devices.

- **Idaho (IP)** recommended to the State's Medicaid agency a basic design for a person-centered planning process to give individuals with developmental disabilities personal choice and control over their community support services. A task force of consumers, grant partners, and key stakeholders formed infrastructure construction workgroups to complete program designs, identify qualifications and requirements and define responsibilities for support brokers and fiscal employer agents, and develop quality assurance and improvement methods.

- **Michigan (MFP)** conducted over 20 presentations to LTC providers across the State to inform them about person-centered planning. The presentations combined training on the State's new screening tool for nursing home and MI Choice Waiver eligibility, with a presentation on person-centered planning. The Grantee noted that the State was awarded a Robert Wood Johnson Cash and Counseling grant that will be used to pilot self-determination in the MI Choice Waiver program and support the principles of person-centered planning.

- **Mississippi (RC)** initiated plans to create a model for systems change by training stakeholders in the person-centered planning (PCP) process and applying the PCP process in four selected mental health regions. Training is being provided in several areas, including accomplishing employment goals, building relationships, identifying/developing recreational opportunities in the community, and using peer support and advocates.

- **Missouri (IP)** established a consumer-directed task force that identified qualifications for person-centered planning facilitators by reviewing existing requirements, MR/DD person-centered planning guidelines, and requirements of other states that have implemented consumer-directed services and supports. The task force developed the components and guidelines for a consumer-directed, person-centered support program pilot, for which the training curriculum is being finalized and recruitment of pilot participants is under way. The Grantee intends to pilot person-centered planning with 30 participants from 8 to 60 years of age in five urban and rural areas throughout the State. To date, 12 pilot participants have been identified.

Personal Assistance Services and Supports: New or Modified Services

Grantees in nine states have initiatives to modify existing services or create new services. These Grantees are undertaking activities to expand opportunities for consumer direction in existing waivers or offer consumer-directed options to additional populations (e.g., persons

with mental disabilities), allow services to be provided outside the home, and modify the nurse practice act to allow for nurse delegation of tasks (e.g., medication administration). Examples follow.

- **Colorado (CPASS)** developed infrastructure and protocols for implementing a new consumer-directed service offered under the State's existing 1915(c) HCBS Elderly, Blind and Disabled waiver. The State developed basic recruitment materials aimed at consumers eligible for these services and prepared specialized recruitment and outreach documents for consumers, single-entry-point case managers, and providers.

- **Kansas (CPASS)** worked to increase the availability of personal care workers to meet consumers' needs at home, at work, and anywhere else that those needs occur by drafting a definition of "personal attendant" that allowed the State to provide services in work settings. This definition was adopted by the task force charged with rewriting the developmental disability waiver. Other accepted modifications to the waiver included (1) eliminating the requirement that a client reside in their home of birth in order to receive services, (2) cashing out residential and day services to support consumer-direction, and (3) holding 15 percent of each consumer's budget in a reserve to cover backup coverage as needed and additional services if consumers' needs increase during the year.

- **Louisiana (CPASS)** conducted a survey at mental health centers across the State to identify the scope of PAS that individuals with severe and persistent mental illness would find beneficial. The Grantee plans to use the survey results to develop and pilot new PAS or new service approaches in existing PAS programs for this population.

- **Oklahoma (RC)** worked on several activities to improve the availability, reliability, adequacy, and quality of PAS. A partnership of consumers and state agency staff developed a proposal to reform the State's PAS program to allow for nurse delegation of tasks, including medication administration and therapeutic treatments. The proposal also includes reforms to increase monitoring and accountability to ensure that authorized services are provided.

Nursing Facility Transition / Diversion

The majority of Grantees with nursing facility transition (NFT) and diversion initiatives are NFT-SP and NFT-ILP Grantees, but several states are also supporting NFT efforts through RC, CPASS, and MFP grants. These Grantees described a range of transition and diversion initiatives and strategies:

- creating transition assessment tools;

- developing outreach materials and conducting outreach;

- providing workshops and training for hospital staff and other community providers involved in the transition and diversion process;

- amending waiver programs to give priority for waiver slots to those able to transition;
- developing intervention plans and protocols;
- increasing housing availability and accessibility through the use of HUD vouchers, home modifications, and other means;
- establishing peer support, local community, and service provider networks—e.g., CILs and Area Agencies on Aging (AAAs); and
- providing small grants to consumers for transition costs.

We first provide examples of activities and accomplishments reported by the FY 2002 NFT Grantees, followed by examples reported by other FY 2002 and FY 2003 Grantees.

NFT-SP Grantees

- **Alabama (NFT)** has identified criteria for residents who are likely targets for transition services in preparation for a pilot nursing home-to-community transition program for individuals with dementia. The Grantee has also implemented an intervention to facilitate better communication between AAA Elderly and Disabled Medicaid Waiver staff and hospital discharge planners. A purple sticker on a client's Medicaid card identifies Medicaid waiver participants and prompts hospital discharge planners to explore home and community service options. Through identifying these clients, the Grantee seeks to help waiver staff and discharge planners work together to facilitate the clients' transition to the community.
- **Arkansas (NFT)** launched its first Fast Track waiver eligibility project in partnership with a hospital in Jonesboro, Arkansas, aimed at reducing the eligibility wait time for Medicaid waiver applications. From January to July 2004, the project processed 15 referrals from the hospital, five of which were found eligible for waiver services and were diverted from an institutional placement upon discharge. The Fast Track project was able to determine eligibility for these individuals in an average of 14 days rather than the usual 45+ days. Due to a low volume of referrals at the Jonesboro hospital, the project is moving to a Little Rock hospital in hopes of obtaining more referrals and acquiring more data to evaluate the project's outcomes.
- **Delaware (NFT)** developed (1) a system to identify clients with the potential for transitioning, (2) a transition guide, and (3) a standardized process for transitioning residents to the community. The Grantee also collaborated with the **Delaware NFT-ILP** Grantee to develop a curriculum to teach independent living skills to nursing facility residents to assist them in successfully transitioning to the community. In addition to engaging in transition activities, the Grantee is an active member of the seven subcommittees of the Governor's Commission on Community-Based Alternatives for People with Disabilities and as such participated in the following two successful legislative initiatives:

  (1) SB 261 (Nurse Practice Act) is now a law and allows delegation of some services to nonprofessionals under the supervision of licensed nurses. This enables those who need these services to be served in the community at a more affordable cost.

  (2) HB 373 MFP created a legislative task force to study the feasibility of the Money

Follows the Person (MFP) concept as a means to address administrative requirements that cause delays in service delivery when someone is discharged from a nursing facility. Grant staff also submitted recommendations to the Commission to encourage vocational, technical, and higher learning institutions to incorporate independent living skills and disability-related courses into their curricula.

- **Louisiana (NFT)** is developing a video to inform the general public about community alternatives to nursing homes. The Grantee also used two nursing facility transition coordinators to provide information and training about transitioning nursing facility residents to the community to individuals, families, nursing home residents and administrative staff, social workers, doctors, and other health care service persons statewide. In addition, the Grantee participated in the development of a single-point-of-entry system and was instrumental in the having the State adopt and incorporate a standard assessment system for LTC—the Resident Assessment Home Care Assessment System–Minimum Data Set Home Care (MDS-HC). The MDS-HC assessment will be used for the State's LTC assessments and will capture the needs of individuals as they assess their LTC options through the single-point-of-entry system.

- **New Jersey (NFT)** staff visited all of the State's nursing facilities and rehabilitation hospitals to explain the transition initiative to individuals and facility staff and encourage support for patients in the transition process. Ongoing activities include providing information through brochures and a project Web site, providing assistance to hospital patients at highest risk of nursing home placement, connecting mentors in the community with nursing facility residents interested in community living, training consumers and families to make meaningful choices and obtain quality services, and sharing expertise and knowledge with community organizations.

- **North Carolina (NFT)** established NFT work groups comprising nursing facility staff, health and human service providers, and consumers and their families to raise awareness about community living options in 53 of the State's 100 counties; completed and disseminated a transition fact sheet designed to inform providers, counselors, and consumers about transitioning; and conducted outreach efforts to regional nursing facilities. The Grantee also conducted successful information and exchange forums with nursing home providers in each of the regions that resulted in over 35 additional referrals to the transition program.

  The State developed transition assessment and planning tools for counselors working in the State Independent Living Rehabilitation Program and Centers for Independent Living to aid in transition efforts and increase coordination and collaboration between these counselors. Additionally, the State is developing a Data Usage Agreement so it can use data from the CMS Minimum Data Set to analyze characteristics of residents who successfully transitioned into the community. Grant staff supported a funding increase for the Community Alternatives Program for Disabled Adults waiver by $28 million and received approval to give priority for waiver slots to transition candidates.

- **Ohio (NFT)** created a pilot program in four counties that identifies and supports the transitioning of individuals from nursing homes into integrated community settings. To support the process, the State hired peer coaches to meet regularly with transitioning individuals. As part of the transition process, the Grantee will assess consumer's satisfaction with the new living arrangement and obtain suggestions for improving the program.

- **Rhode Island (NFT)** exceeded the target of reaching 200 people by the end of the grant period to ensure that institutionalized individuals of all ages and their families, as appropriate, receive information on community service options for which they are eligible. The Grantee provided transitional assistance for incidental purchases necessary for transition to occur and successfully targeted assistance to individuals with more complex needs for transitions. The Grantee reported plans to develop a day program for transitioned individuals and is in the process of obtaining approval from the licensing authority to issue a day program RFP. Additionally, the Grantee held a training session in February 2004 for discharge planners, nursing facility staff, and HCBS waiver coordinating staff regarding community service options, to illustrate the range of services available and thus encourage transitions and diversions. As part of the training, the Grantee developed a discharge planner curriculum. The State has been collecting detailed data on individuals served, and plans to conduct a satisfaction survey of all participants at end of the grant period. The State also committed to review a summary of cost/benefit data from the transition initiative to guide decision making on whether to include transition services in the waiver program.

- **South Carolina (NFT)** provided training on transitioning to AAA staff, nursing facility social workers, and community LTC staff and conducted 23 onsite training visits for nursing facility staff. The Grantee also provided financial assistance to consumers to cover one-time transition expenses. Grant staff reported successfully amending the South Carolina Elderly/Disabled waiver to include a nursing home transition service that will continue after the grant ends. The State has developed a mechanism that allows for real-time access to the community LTC case management database, which permits timely identification of residents who have the potential to transition to the community. The State also received approval for a 30-day bed hold agreement allowing residents to return to the same nursing facility in the event of an unsuccessful transition.

- **Wyoming (NFT)** helped craft legislation that led to the addition of 150 HCBS Medicaid Waiver slots to support the transition program (Project OUT). The State ombudsman is partnering with grant staff to provide information about transitioning to residents of LTC facilities, and the grant project's transition specialist partnered with the Veteran's Administration (VA) to obtain supports for several consumers participating in the transition program. Project OUT has also worked with tribal authorities to obtain assistance with housing and home repairs and modifications for Native American consumers and to address unique issues for Native American consumers who are transitioning. In addition, grant staff provided the impetus for the development of Vulnerable Adult Abuse Training, which provides training for families, communities, agencies, and others who support the transition of individuals into their homes and communities. The kits and the resources developed will be used to increase awareness of the abuse, neglect, and exploitation of vulnerable adults and the importance of reporting cases of abuse.

NFT-ILP Grantees

- **California (NFT-ILP)** conducted outreach in nursing facilities to identify and receive referrals for consumers interested in transitioning. As part of the transition process, consumers can participate in the Peer Support Mentors Team program in which staff provide direct advocacy on behalf of consumers and assist them in developing independent living skills (e.g., self-advocacy, personal assistant management, budgeting, interacting with agencies, and social skills). The Grantee also organized a

Transition Task Force composed of consumers, service providers, advocates, and project staff to develop a systematic statewide outreach plan to increase community awareness of the NFT program.

- **Delaware (NFT-ILP)** reported working one on one and in group workshops to equip individuals transitioning with the skills needed to live independently in the community. The Grantee also collaborated with nursing facilities in discharge planning, assisted individuals wanting to transition in acquiring housing, and provided assistance with the physical transition and post-transition follow-up. The Grantee funded one-time transition expenses through a $5,000 minigrant awarded by the Developmental Disabilities Council.

- **Minnesota (NFT-ILP)** focused largely on diverting individuals from institutional placement, but also transitioned 49 individuals from nursing facilities. In addition, the grant's community living specialists from the State's eight centers for independent living engaged in 220 direct contacts/trainings, including working with consumers to plan their move into the community, assisting in teaching independent living skills, and providing peer/mentor relationships and advocacy support. The Grantee distributed 1,810 consumer handbooks and/or brochures and 51 videos to consumers, service providers, and vendors—providing information about transition services and the development of independent living skills.

- **New Jersey (NFT-ILP)** has implemented a statewide system of round table discussions for consumers who are in the transition process, in which ILC staff and State personnel meet jointly with transitioning individuals to assist in planning and implementing the transition process. Peer mentors, who are being trained and are beginning to work with individuals in nursing facilities, are also involved in these discussions, as are the consumer's family and any other individuals participating in the consumer's life. This system provides the consumer with the opportunity to express their preferences and facilitates cooperation between ILC and stage agency staff in assisting the consumer.

- **Utah (NFT-ILP)** provided community living skills training for 197 LTC residents, 62 of whom transitioned from nursing homes to community living during FY 2004. The Grantee is training 30 peer mentors, 12 of whom have begun meeting with participants. Peer mentors in the Salt Lake area have formed a local peer support group that meets weekly. The Grantee has organized six Advocacy Alliances comprising representatives from 80 groups or agencies to support transitions. These Alliances are currently active in each of the six grant service areas. In addition, the Grantee has developed and disseminated a transition manual that details statewide resources and contains a section on resources unique to each local service area. The manual has been used to train grant personnel throughout the State to ensure that accurate information is provided statewide to nursing facility residents contacting ILCs for transition services.

As stated previously, several states with RC, CPASS, and MFP grants are also involved in transition and diversion efforts, including transitioning and diverting individuals, identifying potential candidates, targeting transition outreach to persons with mental illness and developmental disabilities, and increasing community transition supports. Examples follow.

- **Colorado (RC)** began a study focusing on the appropriateness of placements of people with mental illnesses in nursing facilities. A contractor began interviewing and

evaluating individuals currently residing in nursing facilities throughout the State to help determine whether there were those who could live in the community with LTC and mental health supports. The contractor will make recommendations for possible changes to the State's screening procedures to ensure that only individuals truly in need of nursing facility care are admitted.

- **Michigan (MFP)**, in conjunction with the NFT Grantee, is developing a nursing home transition curriculum that will incorporate planning tools and community resource information using a person-centered planning model for transition under the current LTC system.

- **Nevada (MFP)** identified 40 consumers for transition; 22 made the transition and remain in the community, 15 are awaiting transition, and 3 have declined community placement. From the grant's Community Transition Fund, 10 individuals received assistance with expenses that are not Medicaid reimbursable. To supplement grant funding for this transition fund, the Northern Nevada Center for Independent Living obtained additional resources from the State Independent Living Council and the Northern Nevada Center for Independent Living Home Modification Program.

- **New York (RC)** has provided funding for five regions across the State to create consortiums of LTC stakeholders. Together, these consortiums have developed and initiated the implementation of person-centered plans to transition seven individuals with developmental disabilities from intermediate care facilities.

- **Kansas (RC)** increased consumer involvement in the transition screening process for nursing home residents with mental illness. Community-dwelling consumers accompanied reviewers to encourage residents to consider community living. This practice has been picked up permanently by the State reviewing agency.

- **Oklahoma (RC)** obtained approval from the CMS and the State Medicaid agency to cover transition services under the HCBS waiver, including skilled nursing for personal care planning, case management, medical equipment, supplies, and environmental modifications provided within 120 days of discharge from an institution. The Grantee also developed (1) a consumer outreach brochure to educate potential transition applicants and (2) a tool to evaluate the transitioned individuals' experience with the person-centered planning process. In addition, the Grantee will conduct a Participant Experience Survey to learn about participant living experiences before and after transition.

- **Texas (MFP)** contracted with The Center on Independent Living (COIL) to establish voluntary nursing facility transition workgroups in each of the State's 10 regions (one region at a time). Three workgroups have been established and trained so far, and they are conducting monthly meetings to assess and coordinate services for individuals needing assistance with their transition. Local housing authority representatives have joined the transition workgroups to help resolve housing issues.

  COIL has developed a Money Follows the Person Web site for workgroup members to share best practices, communicate across regions, and obtain project-related data. The project has conducted training with the Department of Aged and Disabled Services staff, regional staff who interact with clients, independent living center staff, consumers, advocates, and other stakeholders in 3 out of 10 regions. Training has included teaching relocation specialists and agency case managers to develop transition plans using a person-centered approach.

- **Wisconsin (RC)** drafted and submitted a 1915 (c) waiver application to the CMS to provide home and community services to persons with serious mental illness currently in nursing facilities, in order to eliminate an existing system barrier in providing community-based services to this population.

Exhibit 5 presents transition and diversion information for the reporting period October 1, 2003, to September 30, 2004, for FY 2002 NFT Grantees. A total of 16 Grantees in 14 states reported successfully transitioning a combined total of 597 consumers to community settings and diverting 392 consumers from entering nursing facilities or other institutions. The majority of NFT Grantees are focused on establishing transition processes and a transition system, rather than diversion activities—Minnesota (ILP) accounts for 364 of the 392 diverted.

Exhibit 5. Individuals Transitioned to Community Settings and Methods Used to Disseminate Information, by State (FY 2002 NFT Grantees Only)

State (Grantee)	Number Transi-tioned[√]	Number Diverted[√]	Number Who Received Informa-tion	Methods of Information Dissemination					
				Personal Contact	Social Worker	Facility Staff	Bro-chures	Toll-Free #s	Other[*]
Alabama	n/a	5	-	•	•	•	•		•
Arkansas	n/a	5	-						
California (ILP)	4	2	210	•	•	•	•	•	•
Delaware	4	n/a	14	•	•	•	•		•
Delaware (ILP)	4	n/a	1,152	•	•	•	•	•	•
Louisiana	0	n/a	30,450	•	•	•	•	•	•
Minnesota (ILP)	49	364	1,810	•	•	•	•		•
Nebraska	86	n/a	500,000[†]	•	•	•	•		•
New Jersey	94	4	500	•	•	•	•		•
New Jersey (ILP)	27	3	59	•	•	•	•	•	
North Carolina	37	n/a	55	•	•	•	•	•	•
Ohio	3	n/a	18	•	•	•	•		
Rhode Island	156	n/a	207	•	•	•	•		
South Carolina	24	n/a	79	•	•	•	•		
Utah (ILP)	62	9	135	•	•	•	•		•
Wyoming	47	n/a	112	•	•	•	•	•	•
Total	**597**	**392**	**534,801**	**15**	**15**	**15**	**15**	**6**	**11**
Percent	—	—	—	***94%***	***94%***	***94%***	***94%***	***38%***	***67%***

[*] This category includes, but is not limited to, presentations, advocacy groups, peers, e-mail, medical professionals, facility staff, ombudsmen, Web sites, and waiver program staff. Several Grantees reported using multiple methods of dissemination under the "other" category.

[†] The 500,000 figure is based on published radio market share and newspaper readership statements.

[√] n/a indicates that the Grantee did not plan to transition or divert individuals during the reporting period.

However, it is important to note that the relative success of NFT grant initiatives should not be judged on the basis of the number transitioned. Some Grantees had a goal at the outset

to transition a large number of individuals, while others focused more on developing the infrastructure needed to sustain the transition process once the grant ended.

In addition to reporting the number transitioned, Grantees reported that they provided transition information to 534,801 individuals. Two states account for the majority of these contacts: Louisiana (NFT) reported reaching 30,450 persons and Nebraska (NFT) 500,000. Nebraska (NFT) is engaged in an ongoing communication/marketing strategy in partnership with AAAs, whose territories are located in the State's high-population centers. The State derived this large figure from published radio market shares and newspaper readership figures, and the pilot project partner AAAs' Web sites, presentations, and other marketing activities. Since it is likely that the overwhelming majority of the 500,000 people in Nebraska and the 30,450 in Louisiana who were exposed to the marketing campaigns were not in nursing facilities and likely did not have relatives in nursing facilities, this number is not comparable to those reported by the other states, which are based on one-on-one contacts with nursing facility residents and staff.

Most Grantees reported using multiple methods for disseminating information about transitions and diversions to the community, generally through personal contact, brochures, and social workers and NF staff, and less frequently through the use of toll-free numbers.

Housing

Home and community services and supports are of little use to persons with disabilities if they have no place to live. Individuals with disabilities face major challenges when attempting to secure affordable and accessible housing. While housing initiatives are the primary focus of a number of FY 2004 Grantees, who are not included in this report, several FY 2002 and FY 2003 Grantees reported housing-related activities and accomplishments.

As shown in Exhibit 6, Grantees in 10 states engaged in a number of activities to help individuals with disabilities find accessible and affordable housing. These activities can be grouped into three subcategories:

- increasing awareness and knowledge of housing issues,
- improving access to existing housing, and
- developing new housing.

The majority of these Grantees are implementing educational campaigns and outreach aimed at housing authorities and developers, forming collaborative task forces to address housing barriers, and improving access to existing housing through home modifications and helping individuals obtain rental subsidies. The following sections provide examples of Grantees' activities to improve access to affordable housing for persons with disabilities.

Exhibit 6. Number of States with Activities to Increase Access to Housing

State	Increasing Awareness and Knowledge of Housing Issues	Improving Access to Existing Housing	Developing New Housing
Arkansas	●	●	
California	●	●	
Delaware		●	
Louisiana		●	●
Minnesota	●		
Montana			●
Nevada		●	
New Jersey	●		
Ohio	●		●
West Virginia	●	●	●
Total	**6**	**6**	**4**

Housing: Increasing Awareness and Knowledge of Housing Issues

In the policy arena, where multiple issues compete for attention, issues with the greatest visibility often have an advantage. Consequently, six Grantees are engaging in activities to increase awareness of the difficulties individuals with disabilities face when looking for accessible affordable housing. Activities include developing educational materials to bring attention to the problem, collecting data to support requests for more housing, creating a database of available housing, and developing a long-term plan to create affordable housing. Examples follow.

- **Arkansas (NFT-SP)** developed materials to educate housing authorities in an effort to expand their understanding of the housing issues that affect elderly persons and individuals with disabilities. By educating and establishing partnerships with local public housing authorities, the Grantee aims to support more individuals in choosing home and community services options as an alternative to nursing facility placement.

- **Minnesota (NFT-ILP)** developed and field-tested a survey instrument to collect information about the housing market in one region of the State. Based on the results of this test, they developed and field-tested a housing assessment model for use in all of the State's regions. The data details the type of housing that would meet the needs of consumers and what is currently available for metro, urban, and rural populations. Findings from the housing assessment will be presented at a statewide community forum that will include county services staff, nursing home relocation staff, ILC staff, nonprofit providers, and others. The report is also targeted to legislators and will provide the data needed to identify and create incentives that will lead to more accessible, affordable housing.

- **New Jersey (NFT-SP)** organized a Housing Work Group to bring together several State organizations and disability groups. Bringing together the stakeholders and State organizations has resulted in a greater dialogue to identify housing opportunities, understand housing and service needs, and stimulate efforts to develop affordable, accessible housing for people with disabilities. The Division of

Disability Services, a partner agency to the Grantee, is working to create an interactive Web site that will provide an inventory of available housing that meets the needs of the disability community. It is hoped that this inventory will help identify locations in need of additional housing.

- **West Virginia (RC)** is investigating ways to increase housing available for people with disabilities and collaborated with the West Virginia Legislative Oversight Commission to organize a Fair Housing Summit attended by more than 200 housing providers. The Grantee also collaborated with the Commission to create a housing and services taskforce to assist in the development of a 10-year housing plan for the State, focused on community living options, and obtained additional funding to create a housing resource data base. The housing database will be available in printed form, as well as electronically in the Real Choice online Resource Directory.

Housing: Improving Access to Existing Housing

It is sometimes more feasible to increase access to existing affordable and accessible housing than to increase the supply of affordable and accessible housing. Grantees in six states have initiatives designed to help persons with disabilities use the existing housing within their communities, primarily through the provision of information about available housing, rental assistance, and home modifications. Examples follow.

- **Arkansas (NFT-SP)** referred 23 individuals who qualified for waiver services to the Bridge Rental Assistance Fund, which was set up by the Arkansas Development Finance Authority (ADFA) to help individuals remain in or return to the community. The ADFA is responsible for administering state and federal low-income housing tax credits and other affordable housing initiatives. ADFA set aside $300,000 of its annual HOME program allocation for bridge rental subsidies to be used for individuals who had applied for a Section 8 voucher and were placed on a waiting list. Funds are used to bridge the gap between the actual cost of the housing and what the tenant would pay with a voucher. Federal HOME program funds are targeted to low-income residents and are administered by HUD. They are available through Rental Housing Programs, Homeowner Housing Programs, and Tenant Based Rental Assistance Programs.

- **Delaware (NFT-SP)** is collaborating with the Delaware State Housing Authority, Wilmington Housing Authority, Dover Housing Authority, and the Delaware Housing Coalition to increase the number of available rental assistance vouchers; create a comprehensive database of safe, affordable, integrated, and accessible rental units; and create a comprehensive registry of individuals with disabilities in need of housing. The Grantee is also coordinating with the Homeless Planning Council to identify overlaps and gaps in services.

- **Nevada (MFP)** hired a Housing Development Specialist (HDS) who has developed a down payment assistance program, similar to the Home of Your Own program, with $200,000 received from the HOME Investment Partnership Program, a block-grant program in Nevada. The Nevada Developmental Disabilities Council has supplemented this funding with a $50,000 grant to a local nonprofit organization to administer the program. A policy manual, “My Home,” has been created to help clients use the program, which is designed to help low-income clients with physical or mental impairments secure housing.

- **Rhode Island (NFT)** is collaborating with the Rhode Island Housing Resources Commission, an organization that provides a link to available housing for individuals in need and assists transition coordinators in working with public housing authorities (PHAs) to find suitable housing for transitioning individuals.

Housing: Developing New Housing

Grantees in four states have initiatives to increase the supply of affordable and accessible housing through new housing development.

- **Louisiana (RC)** has developed a draft housing policy for the Department of Health and Hospitals to provide guidelines for departmental employees to use when advocating with housing developers, community planners, and others for the development of affordable, accessible, integrated housing. Also, a developer worked with a local Community Housing Advocacy Network (CHAN) to plan a multifamily development that will include several accessible units. The Grantee is also working to increase participation of persons with disabilities in local CHANs.

- **West Virginia (RC)** supported the State's Home of Your Own Project (HOYO) with funding, which helped the organization build three homes for individuals with developmental disabilities. The Grantee also collaborated with the Legislative Oversight Commission to write a new bill on Universal Design for introduction during the 2005 legislative session.

Respite for Adults and Children

Caring for a family member with a disability or long-term illness can be stressful and time consuming. Of the services available to families caring for a loved one with a disability or long-term illness, respite is the service most often requested. Grantees in 9 states are involved in initiatives to assess the need for and discern how to best provide quality respite services. These Grantees are primarily conducting feasibility studies, including the use of surveys and focus groups, to explore various means and cost models of providing respite for caregivers of adults and children. Examples follow.

- **Arkansas (RFC)** conducted focus groups and surveyed current respite recipients to identify problems in the current program(s); met with program directors to review current policies, procedures, and problems; and met twice with a parent advisory group to discuss problems with current respite program(s). The Grantee will use the information obtained through these activities to determine how to improve respite services.

- **Maryland (RFC)** is conducting an analysis of the State's current respite system through provider surveys and a review of existing regulations. The Grantee is also developing family and provider surveys. The provider survey will provide information about referral and capacity issues, types of respite provided, funding mechanisms and system capacity. The Grantee is also developing an implementation and evaluation plan for the proposed demonstration, including the development of outcomes measures.

- **The Northern Mariana Islands (RC)** successfully supported the passage of respite care legislation. Respite care funding will become available in 2006. The Grantee also selected a daycare center to provide respite services for children with developmental disabilities.

- **Ohio (RFA)** is examining the feasibility of providing respite services as part of the State's PASSPORT (Pre-Admission Screening System Providing Options and Resources Today) program—the 1915(c) Medicaid waiver for seniors. The Grantee has contracted with the SCRIPPS Gerontology Center at Miami University (Ohio) to conduct the study. SCRIPPS has researched information throughout the country to gain an understanding of how different states approach and implement respite programs. They have also conducted eight different focus groups and key informant interviews to obtain information about adult respite in Ohio. The information obtained will be used to inform remaining grant activities.

Community-Based Treatment Alternatives for Children (CTAC)

Grantees in six states are conducting feasibility studies to investigate community-based alternatives to residential treatment or institutionalization for children. These Grantees are conducting focus groups, evaluating the feasibility of expanding community-based alternatives, and developing implementation and evaluation plans for community-based treatment alternatives. Examples of Grantee accomplishments follow.

- **Illinois (CTAC)** conducted focus groups with parents, teens, and mental health providers about services and reviewed the results with a larger consumer group from which the focus group participants were drawn. The Grantee has made recommendations for program changes, some of which have already been implemented.

- **Maryland (CTAC)** is developing a capitated program for children with serious emotional disorders to provide home and community-based services in lieu of residential treatment. The program will pool Medicaid funds with funds from other state agencies such as the child welfare agency and juvenile justice and education systems to provide community alternatives to residential care. The Grantee is also working with residential treatment facilities to help them plan for a shift to increased community-based treatment and help the experienced workforce make the transition to providing community treatment. Working with a consultant and other national experts, the Grantee used a consensus-building process to develop a standardized process model for individualized service planning and implementation.

- **Massachusetts (CTAC)** is evaluating the financial feasibility of expanding community-based alternatives for children with serious emotional disturbances (SED) and has begun discussions with stakeholders and garnered interest from family members and the community. To assist them in their efforts, the Grantee has consulted with three states that have 1915(c) waivers for SED youth—Indiana, Vermont, and Kansas—and has obtained the waiver applications from these states for guidance on developing waiver services, determining eligibility, and calculating cost neutrality.

  The Grantee is also evaluating services currently provided and reimbursable as State Plan services under existing Medicaid guidelines and those that are "State only"

funded. They have collected information on the range of Psychiatric Residential Treatment Facilities across the State including Inpatient Programs, Intensive Residential Treatment Programs, Clinically Intensive Residential Treatment Programs, Behavioral Intensive Residential Treatment Programs, Community-Based Acute Treatment Programs, and Transitional Care Units. Additionally, the Grantee is collecting demographic and service data on existing programs that serve youth who could potentially be served through a waiver program.

- **Missouri (CTAC)** has completed a detailed feasibility study, which describes the client population and explores various financing mechanisms to provide community-based mental health services.

Initiatives to Design, Implement, and Maintain Systems and Processes that Enable and Support Home and Community Services

Providing home and community services that meet consumer needs in an efficient and responsive manner often requires infrastructure changes because LTC systems infrastructure has been designed generally to support the provision of institutional services.

Many Grantees have initiatives to bring about changes in the LTC infrastructure. Their initiatives are grouped into two broad categories:

- quality monitoring and management and
- budgeting, reimbursement, and administrative systems.

Grantee activities and accomplishments in each of these areas are presented next.

Quality Monitoring and Management

Comprehensive and integrated quality management is an essential component of a state's LTC system. A major challenge for states is designing, implementing, and maintaining effective quality assurance and quality improvement (QA/QI) systems that are well-suited to community living. Grantees in 27 states have initiatives to improve QA/QI systems. Many other Grantees are implementing activities to improve the quality of services as part of other initiatives, for example, conducting consumer surveys to determine satisfaction with nursing facility transition services and newly implemented consumer direction programs.

Grantees' QA/QI initiatives are grouped into four broad categories:

- improvement of quality monitoring and management systems,
- addition of a consumer-focused component to quality monitoring and management systems,
- development of or improvements to remediation systems or processes, and

- other QA/QI initiatives.

As shown in Exhibit 7, the majority of Grantees with QA/QI activities are focused on improving or adding a consumer focus to quality monitoring and management systems. In the following sections, we present examples of Grantee activities in the three major categories to illustrate the type and range of initiatives they are undertaking.

Exhibit 7. States with Quality Assurance/Quality Improvement Activities

	System Improvements	Adding Consumer-Focused Components	Remediation	Other
Arkansas		•		
California		•		
Colorado	•	•	•	
Connecticut	•	•		
Delaware		•		
Idaho		•		
Indiana	•	•	•	
Kansas		•		
Louisiana		•		
Maine	•		•	
Minnesota		•	•	
Mississippi		•		
Missouri		•		
New Jersey		•		
New York	•			
Ohio	•			
Oklahoma	•			
Oregon	•			
Pennsylvania	•			
Rhode Island				•
South Carolina	•			
Tennessee		•		
Texas	•	•	•	•
Virginia		•		
Washington	•			
West Virginia	•	•		
Wisconsin	•	•		•
Total	**14**	**18**	**5**	**3**

Quality Monitoring and Management: System Improvements

Grantees in 14 states reported initiatives to improve their quality monitoring and management systems, including developing new or improving existing data systems, developing quality indicators, and improving coordination of quality management and improvement activities for home and community services. Examples follow.

- **Colorado (QA/QI)** is working on a number of quality initiatives to improve data systems. The Grantee is standardizing critical elements of the participant/family survey conducted by the Department of Human Services Division for Developmental Disabilities Community Centered Boards for statewide application. As part of this work, the Grantee reviewed current family satisfaction measures and held several focus groups in urban and rural areas to ask families what information would help

them choose service providers. They also sought input from families about how to measure satisfaction with services and supports.

As part of an effort to improve the timeliness and efficiency of data reporting, the Grantee obtained technical equipment and software to enable participant/family survey forms and regulatory survey forms to be scanned rather than having to enter the data manually. The Grantee has also begun development work for a Web site that will provide information to consumers and their families about provider performance.

Grant staff have started outlining Web-site considerations and used input from several focus groups held in urban and rural communities to obtain information from families on the types of information that would be helpful to them.

- **Maine (QA/QI)** formalized a structure to improve staff communication and coordination surrounding quality management and improvement activities for home and community services. As part of an effort to coordinate quality management and improvement for HCBS waiver programs, the Grantee also developed a quality matrix for mapping quality assurance activities across departments.

- **Oklahoma (RC)**, as part of its effort to develop and implement an infrastructure to support continuous quality improvement activities, developed indicators for its Aged and Disabled waiver program to measure the quality of two processes: (1) consumer due process when the consumer withdraws from the waiver and (2) level of care determinations to prevent inappropriate removal of persons from the waiver. The Grantee also convened a provider task force to develop an enhanced continuous quality improvement model that will incorporate the CMS Quality Framework. Additionally, the Grantee developed and implemented quality enhancements for case management, disease management, and recognizing plan of care implications for its Waiver Management Information System data warehousing reporting function, which will allow the State to develop reports on the performance of providers, administrative agents, and the Oklahoma Department of Human Services.

- **Oregon (QA/QI)** reviewed quality assurance systems currently being used in senior, physical disability, and developmental disability services throughout the State and created an integrated inventory of source documents, processes, and supporting information systems related to key indicators. This information will be used to develop critical tools and implementation procedures focusing on (1) assuring health and safety and (2) risk management for individuals receiving in-home supports.

- **Texas (QA/QI)** developed a Systems Requirement Document for the design of an integrated information-gathering system that will compile and automate information regarding program provider performance and participant experiences in the State's Mental Health and Mental Retardation (MHMR) waiver programs. The Grantee also wrote a rationale for developing a critical incident system and presented it to management, resulting in the convening of an agency workgroup to facilitate coordination of grant activities with the Department of Aging and Disability Services' initiatives.

  Further, the Grantee has collaborated with the Texas CPASS Grantee on the development of a quality management framework for the new Service Responsibility Option (SRO) that is being piloted by the Texas CPASS grant. The Grantees plan to

use the same quality/consumer satisfaction measures, which will be used to establish a baseline for continuous quality improvement.

- **West Virginia (QA/QI)** established a Quality Improvement Team and a Quality Assurance & Improvement Council for the Aging and Disabled Waiver Program. These entities will provide guidance and oversight of a QA/QI process for HCBS waiver services. The Grantee contracted with the University of Southern Maine to provide training on the CMS Quality Initiative, the CMS Quality Framework, and methods to improve the quality of home and community services. The university developed a Resource Manual containing these materials and distributed it to the Council and Team members.

- **Wisconsin (QA/QI)** is conducting a review of departmental program requirements and protocols for local QA/QI programs to identify areas where local programs can be improved and increase their focus on consumer outcomes. The Grantee also created a "Cross-unit Quality Management Team" of department staff from quality management sections within the State Department of Health and Family Services. The team will be a focal point for sharing information on quality management practices and for developing quality-management policy recommendations, and will be an ongoing unit within the department.

Quality Monitoring and Management: Adding Consumer-Focused Components

A frequently expressed concern about quality assurance systems is their lack of a consumer focus and their failure to measure outcomes important to consumers. Grantees in 18 states are addressing this concern in a number of ways, such as involving consumers and families in quality assurance initiatives, developing consumer satisfaction surveys, and using the CMS Participant Experience Survey (PES). Examples follow.

- **Arkansas (NFT)** developed an ombudsman program for HCBS waiver clients (called *Your Voice, Your Choice*) to address consumers' issues and complaints, which will be used to identify areas for quality improvement. This program was developed at the beginning of the grant period. Subsequently, the Grantee developed a manual and marketing materials, and a marketing campaign to promote the ombudsman program now underway.

- **Colorado (QA/QI)** is working to promote more active and effective involvement of consumers and families in quality assurance and quality improvement initiatives for home and community services through a number of initiatives. They developed and released an RFP and subsequently awarded grants to six self-advocate and family advocacy groups in urban and rural communities to help them establish Advocacy Growth Projects to strengthen self-advocacy and family advocacy through technical assistance, cash, and in-kind support. They also established a statewide committee of self-advocates to provide input directly to the Division for Developmental Disabilities Director regarding policy and QA/QI issues, which will continue after the grant ends.

- **Indiana (QA/QI)** trained nine quality monitors to administer the PES. The monitors will conduct face-to-face surveys with a minimum of 20 percent of waiver recipients annually to obtain current information and individuals' perspective about services and providers.

- **Kansas (CPASS)** is developing a method for collecting consumer satisfaction data regarding their services from persons with developmental disabilities and their families in order to make program improvements. Grant staff are evaluating a self-direction measurement tool for use with consumers, family members, and case managers to determine progress on self-direction in specific areas of the State. The Grantee anticipates that some key variables or perhaps sections of this tool will be incorporated into the State's Quality Assurance model.

- **Minnesota (QA/QI)** worked with its Consumer Quality Design Team to adapt the CMS PES, to include measures related to maintaining and enhancing social roles and relationships, caregiver outcomes, and additional items applicable in consumer-directed services. The revised PES will be piloted with 100 Elderly Waiver consumers.

- **Missouri (IP)** is developing a pilot consumer-directed, person-centered service model program, which will include facilitators, support brokers, and individual budget and fiscal management services. A Grantee-established, self-directed task force—composed of self-advocates or parents, direct support professionals, and State agency staff—reviewed and evaluated the State's current QA framework for services for the mentally retarded and developmentally disabled (MR/DD) to ensure that it fulfills the QA requirements of the pilot program. The Grantee is also developing an evaluation process for the pilot with four tools to measure consumer satisfaction with program supports and services.

- **Tennessee (QA/QI)** is collecting and analyzing data from consumer satisfaction surveys and will establish a single, functional database that generates useful and timely reports of findings. Grant staff designed a consumer satisfaction instrument and recruited and trained consumers and family members to administer it. They also implemented the first stages of a management system to track data collection. The Grantee modified its survey and related processes based on findings from the first year's activities.

- **Virginia (CPASS)** developed and piloted a survey instrument to obtain feedback from consumers regarding satisfaction with and the processes for obtaining consumer-directed personal assistance services. To ensure inclusion of all consumers in the survey process, the Grantee included in the survey instrument specially developed materials to solicit input from individuals with cognitive disabilities.

- **West Virginia (CPASS)** is partnering with the QA/QI Grantee to use the PES to collect data from a sample of consumers who receive services through the consumer-directed model and those receiving services through the traditional model. The data will be used to establish a baseline measure of the quality of current services in the State's Aged and Disabled Waiver, which will be compared to measures of service quality in the new consumer-directed program once it is implemented.

- **Wisconsin (QA/QI)** is implementing the PES to examine consumer-experience outcomes. Sites have been selected for administration, and the PES has been introduced to the sites. Data entry software, including options for entering time, expenses, and comments, has been developed for the PES DD version, designed for use with adults with mental retardation/developmental disabilities. Interviews have begun, with 32 of 50 interviews completed at one of the sites at the time of reporting. Through the survey, the Grantee is working toward identifying and

adopting key consumer-experience outcomes and establishing a means of measuring them comparably across waiver programs.

Quality Monitoring and Management: Remediation

An essential component of a quality assurance system is the ability to collect and evaluate information in a timely manner to remedy problems expeditiously and effectively. Remediation, an essential component of the CMS Quality Framework, includes activities designed to correct identified problems at the individual level. Five Grantees reported initiatives in this area including those to develop or improve components of critical incident reporting systems, and the development of coordinated systems for multiple waiver programs.

- **Colorado (QA/QI)** completed an analysis of current critical incident reporting systems (Web-based and non-Web-based) as part of an initiative to standardize elements of critical incident reports for statewide application.

- **Indiana (QA/QI)** completely redesigned the State's Web-based complaint database. Training about the new system for QA/QI department staff and education of consumers by case managers was initiated during the reporting period. In addition, QA/QI grant staff collaborated with the Indiana RC Grantee to develop a quality assurance and oversight process at the State level that will lead to implementation of a new, more comprehensive, more efficient complaint and incident reporting policy.

- **Maine (QA/QI)** is working to develop a coordinated incident management system for all its HCBS waiver programs. As part of this work, the Grantee is evaluating existing reporting and incident management systems and examining existing policies, contracts, and procedures and applications. The Grantee (1) completed an assessment of key elements of an incident reporting system for persons with mental retardation, (2) developed draft incident reporting categories for the Elderly and Disabled Waiver, and (3) collected information for 1 month on the most commonly reported incidents.

- **Minnesota (QA/QI)** established a Vulnerable Adults Design Team to fully integrate county-level Adult Protection units into the Vulnerable Adults Report Tracking System. The team created/redesigned forms for vulnerable adult report and investigation data collections and submissions, and outlined and reached consensus on interagency processes.

- **Texas (QA/QI)** reviewed eight survey tools and recommended that the Department of Aging and Disability Services use the National Core Indicators (NCI) tool to measure participants' experiences in waiver programs. The Grantee further recommended that the Department work with consultants to develop additional questions about self-determination to add to the NCI tool.

Budgeting and Reimbursement Systems

Long-term care budgeting and reimbursement systems have been institutionally biased for many years, but states are modifying these systems to better reflect the desires of persons

with disabilities to be served in home and community settings and to have more control over their services. Modifying budgeting and reimbursement systems can be a complex undertaking, requiring planning and changes by several agencies within a state to ensure fiscal efficiency and accountability.

Grantees in 13 states reported activities to change their budgeting and reimbursement systems. As shown in Exhibit 8, these activities are grouped into three categories:

- individualized budgeting,
- payment rates and methodologies, and
- money follows the person (MFP).

Exhibit 8. Number of States with Budgeting and Reimbursement Activities

State	Individualized Budgeting	Payment Rates and Methodologies	Money Follows the Person
California			•
District of Columbia		•	
Georgia	•		
Idaho			•
Louisiana	•		
Maine	•		
Michigan	•		•
Montana	•		
Nevada			•
Pennsylvania			•
Texas			•
Washington	•		
Wisconsin			•
Total	**6**	**1**	**7**

Only one Grantee reported accomplishments on initiatives related to payment rates and methodologies. States periodically review their payment mechanisms and modify them to accommodate changes in services and consumer need and to address provider concerns. These changes have often been driven by the implementation of consumer-directed demonstration programs. One Grantee—the District of Columbia (RC)—reported activities in this area. The Grantee retained a contractor to work on rate development for independent provider/consumer-directed care.

The majority of Grantees reported progress on activities to design or promote individualized budgets or to implement MFP initiatives. We provide examples of Grantees' accomplishments in these two categories below.

Budgeting and Reimbursement: Individualized Budgeting

Grantees in 6 states are developing individualized budgets to support initiatives to allow consumers to direct their own services. A key goal of these initiatives is to help states estimate the resources needed to meet various levels of need within and across services and populations served. Most of the Grantee activities on individualized budgeting centered on developing tools and methodologies, with only a few activities focusing on data collection or training. Examples follow.

- **Georgia (IP)** created a database of service use, needs, and cost data to develop a uniform methodology to calculate all individual budgets in the State. This is part of the larger effort to develop consumer-directed home and community-based services and supports for elderly people and individuals with disabilities.

- **Maine (IP)** expanded and organized a stakeholder work group comprising consumers, family members, providers, and the Department of Human Services to guide development of the IP self-directed waiver program for adults with mental retardation or autism. Additionally, the Grantee is developing Maine's approach to individual budget development and will use a companion MFP Systems Change grant to further the development and implementation of individual budgeting tools.

  The Grantee also began negotiations with subcontractors to participate in the development of training materials and to design a co-instructional (instructor–self-advocate) model for training of support brokers and waiver participants. Consumer groups, AAAs, and families are providing input into the development of these materials.

- **Maine (MFP)** is developing standardized rates but has delayed adoption of an individual budgeting tool for mental retardation waiver services due to legislative pressure. The Maine Department of Behavioral and Developmental Services has convened a stakeholder group to provide input on revising service definitions to support standardized rates. Another advisory group will provide a consumer and family perspective on service definitions.

- **Montana (IP)** conducted focus groups with 73 participants in three pilot sites to obtain their views on the essential features of a cash and counseling service model. The Grantee also developed a screening tool to determine consumers' readiness to participate in the consumer-directed program and developed and disseminated an informational brochure on the program.

- **Montana (RC)** helped self-advocates participate in a meeting with the Developmental Disability Program to discuss individualized budgets based on a person's services need to promote and strengthen partnerships between consumers, providers, and agency staff. The Grantee is also developing a new software program to enable the State to provide consumers with individualized budgets.

- **Michigan (IP)** completed a statewide survey to identify the lead person for self-determination and IP design activities in each of the 46 Community Mental Health Services Programs and to identify their most immediate needs for technical assistance. They found that issues requiring technical assistance include understanding self-determination and Medicaid alternatives, education and training

on self-determination, liability issues, and fiscal intermediary issues. The Grantee also developed guidelines for fiscal intermediary services.

- **Washington (MFP)** formed a Real Choices Advisory Committee comprising self-advocates, family members, a county representative, representatives of advocacy organizations, providers, and case managers to give recommendations regarding the development of an assessment tool that accurately measures a consumer's needs, determines the resources needed for appropriate services, and fairly determines the funds needed to actually allow individual choice.

Budgeting and Reimbursement: Money Follows the Person

States are making changes to their budgetary infrastructure so that funding designated for institutional settings can "follow" consumers who elect to be served in the community. Grantees in seven states reported developing or implementing activities to allow "money to follow the person." These activities include developing pilot programs, assessment tools, waiver applications, legislation, fiscal system changes, and information and training initiatives. Many of these initiatives are in the early stages of development. Examples follow.

- **Nevada (MFP)** conducted a study of MFP systems in other states and barriers to MFP in Nevada, and prepared a report for the legislature, which is considering several recommendations from the report. One recommendation under consideration would facilitate the transition and diversion of patients from nursing facilities to the community by extending to 180 days the waiver of patient liability for Medicaid consumers entering nursing facilities. Other recommendations, which have been approved by a legislative committee, call for a feasibility study of increasing the financial eligibility criteria for Medicaid to 300 percent of SSI for institutionalized consumers transitioning to the community, and a study of county and State payment programs for institutional and community services, to examine the potential impact of a state MFP program on state, county, and nursing facility budgets.

- **Texas (MFP)** has completed outreach education and training activities to ensure that all services and supports are considered for individuals transitioning to the community and to increase awareness of Texas's MFP policy, which allows nursing facility residents who are transitioning to bypass waiting lists for the waiver program.

- **Wisconsin (RC)** drafted legislation for a "Life Lease" mechanism that will allow funds to follow individuals moving from nursing homes to community settings, thereby removing a barrier to consumer choice of community-based services. Originally introduced in the last session of the State legislature, the legislation will be reintroduced as part of the 2005–2007 budget.

Initiatives to Improve the Recruitment, Training, and Retention of Direct Service Workers

Many states face a shortage of direct service workers to meet consumer demand. Continuing turnover is also a problem given demanding working conditions, low salaries, lack of training, and limited potential for advancement. Recruitment and retention problems directly and indirectly affect access to and the quality of services. While many of the

Systems Change Grantees' workforce initiatives were reported in RTI's *Second Year Report* and *Direct Service Workforce Activities of the Systems Change Grantees* (which can be found at http://www.hcbs.org/files/35/1708/CMSWorkforce.pdf), a few Grantees are undertaking activities related to workforce during the current reporting period (October 2003–September 2004). As shown in Exhibit 9, Grantees in seven states have workforce initiatives in three major areas:

- recruitment,
- training and career development, and
- administrative activities.

Exhibit 9. Number of States with Workforce Activities

State	Recruitment	Training and Career Ladders	Administration and Planning
Connecticut	•		
District of Columbia	•		
Georgia		•	
Kansas			•
Louisiana	•	•	
Northern Mariana Islands		•	
West Virginia			•
Total	**3**	**3**	**2**

Most of these activities focus on recruitment and training development. States have been slow to develop initiatives to improve wages and benefits for workers, primarily because of fiscal crises faced by legislators in many states who are watchful of increases in Medicaid spending. However, the District of Columbia (C-PASS) Grantee did analyze wage rates within the District and surrounding areas, and identified options to increase wages to direct service workers, should Medicaid funding for wage increases become available.

In the following sections, we present examples of Grantee activities in each of the three categories to illustrate the type and range of initiatives they are undertaking.

Workforce Initiatives: Recruitment

Grantees in three states described activities to increase the number of workers through recruitment efforts. These initiatives included promotional efforts through Web sites and brochures, career fairs, and worker registries.

- **Connecticut (RC, CPASS)** developed a Web site designed to attract and recruit Personal Assistants (http://www.rewardingwork.org/States/Connecticut/Default.asp). During the first year, 75 prospective employees registered on the Web site. In addition, grant staff designed and test-marketed a recruitment brochure to be used as part of an outreach campaign to one-stop career centers and Community Colleges.

- **The District of Columbia (C-PASS)** made several efforts to increase the supply of personal care providers, including encouraging the State Health Planning and Development Agency to relax a moratorium on new home health agencies, and holding career fairs for nursing students sponsored by the Office on Disabilities and Aging and the University of the District of Columbia.

- **Louisiana (RC)** is working to establish a statewide database registry of workers who support persons with developmental disabilities as part of a workforce development project.

Workforce Initiatives: Training and Career Ladders

Three Grantees developed training curricula to improve the skills of direct service workers. The training topics included medication administration, basic skills certification, community outreach, and various competencies.

- **Georgia (RC)** developed a curriculum for a medication administration program designed to certify direct support workers to distribute medications. This program is intended to be a more cost-effective method for supporting individuals with mental illness and/or developmental disabilities in the community through the substitution of direct service workers for nurses who now administer medications. The recommended policies and regulations developed during the first year of the grant and the proposed curriculum are on hold until legislative changes to the Nurse Practice Act are made in the 2005 Legislative Session.

  The Grantee also developed a direct support professional certificate program training curriculum requiring completion of two courses within two quarters for direct service workers who provide care to people with mental illness and developmental disabilities. Topics covered in the curriculum include person-centered planning, the discovery process, family supports, personal wellness, medications, and medical supports. Four pilot programs are operating with a total of 56 participants.

- **Louisiana (RC)** developed a direct service worker training curriculum and has provided competency-based training to 237 individuals, including direct service providers, family members, and consumers. To date, 70 trainees demonstrated competence in the required curriculum areas, and 29 individuals became trainers after completing the direct service provider competency-based curriculum and train-the-trainers sessions. The Grantee is planning to continue to work with community colleges and vocational-technical schools to make training more accessible.

- **The Northern Mariana Islands (RC)** worked with the local college to develop a certificate program for personal care attendants using a curriculum developed in Oregon.

Workforce Initiatives: Administration and Planning

Grantees in two states conducted administrative activities to aid in future planning efforts. These activities included a survey of workers and data collection about working conditions.

- **Kansas (CPASS)**, to increase the availability of personal care workers, conducted a survey of personal attendants and consumers on a range of issues, including job satisfaction, hours worked, wages, and training, and shared the results with the grant's advisory committee and Kansas Medicaid.

- **West Virginia (CPASS)** staff are collaborating with the Nursing Facility Transition Project and Real Choice Grantees to gather data on the working conditions of personal assistance workers. The data will assist statewide agencies in developing and implementing a long-term strategy for improving recruitment and retention of personal assistants. Consumers have been instrumental in these efforts by providing anecdotal information regarding recruitment and retention issues.

SECTION 4
GRANTEE CHALLENGES

The types of challenges cited during the current reporting period are similar to those reported in previous years. Grantees primarily described administrative challenges and budget constraints.

Grantees also reported challenges specific to their particular grant efforts. Not surprisingly, they cited lack of affordable housing, lack of available community services, and resistance from agency providers as challenges to implementing systems change within their respective states. This was especially true for Grantees engaged in NFT initiatives. The following sections highlight the types of challenges Grantees reported.

Administrative and Budgetary Challenges

States' budget crises continue to affect their ability to make progress in efforts to rebalance their LTC systems. For example, several Grantees reported that new waiver services or transition programs could not be implemented because of the lack of funding to support the efforts. Others attributed delays in subcontracting and the changes in staffing to their respective states' budget crisis. Examples of challenges faced follow.

- **Maine (MFP)** reported that due to the State's budgetary process, the Maine Department of Behavioral and Developmental Services made significant changes to services and policies for persons with brain injury that significantly delayed the Grantee's early efforts to develop its pilot project. As a result of these changes, the State reported that several major service providers ceased operations.

- **Nebraska (NFT)** gained approval to use waiver funds for rent and utility deposits, and basic furniture and appliance purchases for consumers transitioning back to the community. However, the service remains unfunded due to the State's ongoing budget shortfall. In addition, the Grantee has developed an effective model for identifying and assisting individuals to leave nursing facilities that has been piloted by two AAAs. These two AAAs are ready to provide training on best practices to the rest of the State. However, due to State budget reductions, the remaining AAAs are reluctant to replicate the program, fearing they will not have the resources to adequately assist consumers in the community who currently receive facility care. This has effectively placed statewide implementation of the grant's transition model on hold.

- **Oregon (QA/QI)** expressed concerns that the ongoing State budget crisis will not support new information management system development or substantial revisions to current systems.

- **Utah (NFT-ILP)** reported that project staff turnover was high because most transition staff are employed part-time due to the original request for funding being cut. The staff positions are also time limited, although each of the six CILs are in the process of trying to locate funding to continue the positions after the grant ends.

Challenges Specific to Grantees' Initiatives

A total of 11 Grantees, most of whom are NFT Grantees, cited lack of affordable and accessible housing as the biggest barrier to systems change, even when rental assistance vouchers are available, and most noted that vouchers were difficult or impossible to obtain. Pennsylvania (NFT) cited lengthy waiting lists that caused delays in transitional planning for individuals who need housing placement upon discharge, and Delaware (NFT-ILP) and North Carolina (NFT) reported additional, unforeseen problems for consumers with previous bad credit or criminal backgrounds. In addition to lack of affordable and accessible housing, Grantees reported challenges to systems change ranging from lack of available community services to provider resistance and legislative barriers. Examples of the range of difficulties faced by Grantees follow.

- **Delaware (NFT-SP)** noted that the limited number of service hours under the waiver program can discourage some nursing facility residents from transitioning because they are concerned about losing the 24-hour availability of services.

- **The District of Columbia (RC)** is working to include assisted living as a waiver service, but cannot progress until the Health Regulatory Administration, which is the licensing body, develops definitions and certification guidelines for assisted living. The Grantee has also drafted regulations to cover medical case management as a waiver service, but the CMS has informed them that a demonstration waiver is required.

- **Louisiana (RC)** faced difficulties negotiating a workers' compensation policy for direct service workers with the fiscal agent, which delayed the implementation of the grant's consumer direction project. The State has high rates for workman's compensation, and after researching less expensive alternatives, grant staff were able to secure a better rate for workers' compensation, allowing them to move the initiative forward. The Grantee also reported that legislation that would have implemented MFP on a pilot basis and would have created a single-point-of-entry for developmental disabilities services was defeated.

- **Mississippi (RC)** reported that both consumers and providers of mental health services find it difficult to accept consumer-directed services in a very traditional service delivery environment. Individuals are returning to the hospital because they are not accustomed to the freedom that the consumer-directed service approach allows.

- **Utah (NFT-ILP)** reported that no new waivers or housing assistance programs have been initiated to support the grant project, nor is there funding for transition costs. Project staff have to rely on connecting people to existing community resources that are scarce and have waiting lists. Four of the six CILs working with the project have experienced difficulty matching peer mentors with people wanting to transition. No public transportation exists in most of the State's rural areas, and even in urban areas transportation services are often difficult to access for people with mobility impairments.

- **Wyoming (NFT)** reported that age and cost restrictions in assisted living settings prevent some younger consumers from leaving nursing facilities. The Grantee also cited mental health issues as a challenge. About 70 percent of the consumers they have transitioned have an identifiable mental health problem, but it is difficult to secure services and supports to address their needs in the community.

SECTION 5
CONSUMER INVOLVEMENT IN SYSTEMS CHANGE ACTIVITIES

Consumer involvement in Systems Change grant activities is mandated by the CMS. Grantees reported that consumers and consumer partners were actively involved in grant activities, participating in both grant implementation and evaluation. As members of consumer task forces and advisory committees, consumers provide oversight of all grant activities. Their specific roles are described below.

Consumer Involvement in Implementation Activities

Grantees in all states indicated that consumers were involved in implementation activities in a variety of ways during the period covered by the report, such as (1) the design and implementation of assessment and evaluation tools and educational and outreach materials and (2) participation in pilot programs, surveys, and formative and summative evaluation activities. Grantees in almost all states involved consumers or consumer partners on advisory boards, consumer task forces, or advisory committees during grant implementation. Of the more than 2,500 members serving on task forces or advisory committees, about 40 percent are individuals with disabilities, and approximately one-quarter are consumer advocates.

During the reporting period, consumers and consumer partners were most often involved by participating in planning meetings, participating as members of committees, and reviewing grant products such as outreach material. Exhibit 10 shows the range of activities in which Grantees involved consumers and the number of states reporting each type of activity.

Examples of implementation activities in which consumers were involved follow.

- **Alaska (RC)** collected informal survey and interview data from consumer task force members and other grant staff as part of its formative evaluation activities. The data are being used to ensure that grant implementation proceeds in a timely and efficient manner and that the project goals are met.

- **California (MFP)** consumers provided feedback on the design of the Preference Survey, a uniform assessment tool and protocol for care planners to assess service needs and service availability for persons interested in transitioning.

- **Colorado (QA/QI)** involved consumers and family members in focus groups to provide feedback on the types of information that should be available on a Web site that is being created to provide information on system navigation, provider assistance and performance, and other resources that support participants and inform consumer choice.

Exhibit 10. Consumer Involvement in Grant Activities

Activity	Number of States
Performed grant activities	38
Participated on committees	44
Reviewed grant products	42
Reviewed outreach materials	40
Developed outreach materials	30
Developed evaluation	21
Pilot tested outreach materials	27
Pilot tested grant products	20
Participated in planning meetings	44
Participated in focus groups	27
Responded to surveys	26
Served as peer mentors	19
Attended Grantee-sponsored conferences	27
Other	17

- **Idaho (IP)** established a task force involving consumers, partners, and key stakeholders to collaboratively design the components of a consumer-directed system of care.
- **Massachusetts (CPASS)** conducted extensive outreach activities to increase representation of culturally and ethnically diverse consumers and parents on their coordinating council and ad hoc committees to ensure that program development addresses the needs of the broad population of consumers and parents.
- **Washington's (RC)** Consumer Task Force planned and implemented the Real Choice Community Living Conference that provided training, education, and networking opportunities to individuals with disabilities and persons interested in community living.

Consumer Involvement in Evaluation Activities

Involving consumers in formative evaluation activities provides Grantees with information on the changes that need to be made in processes used to implement grant activities. Many Grantees involved consumers in different types of formative evaluation activities during the reporting period. As members of consumer task forces or advisory boards, consumers provided input on the progress made in meeting grant goals and objectives, recommended changes in activities required to meet grant objectives, and provided input on the future direction of the grant. Additionally, Grantees involved consumers and consumer partners in developing and revising consumer satisfaction survey instruments. Grantees also conducted interviews, surveys, and focus groups with consumers and consumer partners to assess the grant's progress toward meeting goals and objectives.

Several Grantees reported plans to involve consumers in summative evaluations, but very few reported that they had initiated evaluation activities during the reporting period. Examples of the range of formative evaluation activities in which Grantees involved consumers follow.

- **California's (QA/QI)** quality assurance work group members completed the annual progress report on grant activities and presented lessons learned to the grant's steering committee. The committee used the report to inform decisions about changes needed to achieve grant goals.

- **Colorado's (QA/QI)** Project Advisory Committee members meet quarterly to report on progress implementing the grant's workplan. The Advisory Committee also meets on a regular basis to discuss grant progress and challenges and to develop solutions that will further the grant's goals. The Committee also provides input on the Grantee's annual report to the CMS.

- **Mississippi (RC)** conducted satisfaction surveys and functional assessments to assess the impact of person-centered planning (PCP) on individuals in the program. Each individual and family member that goes through the PCP process gives the Advisory Committee direct feedback about what is working, what is not working, and what needs to be changed.

- **Ohio (NFT)** conducted consumer satisfaction surveys to assess consumer satisfaction with the transition program. As information and data are received, parts of the program will be evaluated and changed as necessary.

SECTION 6
LOOKING FORWARD

The CMS awarded the Systems Change grants to states and other entities as seed money to support efforts to build the infrastructure needed to provide consumer-responsive LTC systems. The findings of this third annual report—summarizing the second year activities of the FY 2002 Grantees and the first year activities of the FY 2003 Grantees—demonstrate that states are engaged in a wide range of activities to improve access to and the availability of home and community services. In addition, many states are creating the infrastructure to allow consumers to have more control over their services and to assure that quality monitoring and management systems are responsive to consumers' needs and concerns.

Though the FY 2002 Grantees are nearing the end of a 3-year grant period (September 2005), it is anticipated that many will request no-cost extensions to continue grant activities for a fourth year. Because many Grantees started their activities late, this extra time will likely be used to complete activities, evaluate their activities, and undertake activities to ensure that grant initiatives are sustained after the grant ends.

Exhibit 11 lists the report schedule for the Systems Change grants program, both those completed and those forthcoming.

Exhibit 11. Reports for the Systems Change Grants Program

	Annual Report of First Year's Activities	Annual Report of Second Year's Activities	Final Report*
FY 2001 Grantees	*Completed*	*Completed*	Spring 2006
FY 2002 Grantees	*Completed*	*Completed*	Spring 2007
FY 2003 Grantees	*Completed*	Spring 2006	Spring 2008
FY 2004 Grantees	Spring 2006	Spring 2007	Spring 2009

* The final report covers the third year of grant activities. For Grantees with no-cost extensions, the final report will cover the third and fourth years of grant activities. The dates assume that the majority of Grantees will receive no-cost extensions to cover a fourth grant year.

The final reports will be based on information provided in Grantees' final reports to the CMS and interviews conducted with the project directors. These reports will highlight each state's accomplishments at the end of the grant period and summarize accomplishments across all the Grantees in specific systems change areas.

APPENDIX A
STATE AWARDS BY GRANT TYPE AND TOTAL AWARD AMOUNT, FY 2002–2003

Table A-1. State Awards by Grant Type and Total Award Amount, FY 2002–2003

State	Community PASS		NFT – State	NFT – ILP	Real Choice	Respite for Adults	Respite for Children	Community-Based Treatment Alternatives	Quality Assurance / Quality Improvement	Independ-ence Plus	Money Follows the Person	Family to Family	Total $ Amount Awarded
	2002	2003	2002	2002	2002	2003	2003	2003	2003	2003	2003	2003	
Alabama			•				•						$870,000
Alaska					•							•	$249,991
Arizona		•											$600,000
Arkansas			•				•						$673,444
California				•	•	•			•		•		$3,072,344
Colorado	•				•				•	•		•	$2,886,135
Connecticut		•			•				•	•			$2,496,849
Delaware			•	•					•				$1,188,474
District of Columbia	•				•								$2,110,000
Florida										•			$501,801
Georgia					•				•	•			$2,292,108
Hawaii	•												$725,000
Idaho										•	•		$1,249,642
Illinois								•					$100,000
Indiana	•				•				•			•	$2,760,000
Kansas	•				•								$2,110,000
Louisiana		•	•		•					•			$2,949,073
Maine									•	•			$1,750,000
Maryland							•	•				•	$350,000
Massachusetts		•						•		•			$1,179,170

(continued)

Table A-1. State Awards by Grant Type and Total Award Amount, FY 2002–2003 (continued)

State	Community PASS		NFT – State	NFT – ILP	Real Choice	Respite for Adults	Respite for Children	Community-Based Treatment Alternatives	Quality Assurance/ Quality Improvement	Independ-ence Plus	Money Follows the Person	Family to Family	Total $ Amount Awarded
	2002	2003	2002	2002	2002	2003	2003	2003	2003	2003	2003	2003	
Michigan							•			•	•		$1,324,649
Minnesota				•					•				$899,880
Mississippi					•			•					$1,484,000
Missouri								•	•	•			$1,027,282
Montana					•					•		•	$2,034,963
Nebraska		•	•										$1,200,000
Nevada					•						•	•	$2,284,999
New Jersey			•	•								•	$1,150,000
New Mexico					•								$1,385,000
New York					•	•			•				$1,955,096
North Carolina	•		•						•				$1,800,100
North Dakota					•								$900,000
Northern Mariana Islands					•								$1,385,000
Ohio			•		•	•			•	•			$3,058,594
Oklahoma					•								$1,385,000
Oregon		•					•		•				$1,139,394
Pennsylvania					•				•		•		$2,581,861
Rhode Island			•		•	•	•						$2,185,000
South Carolina			•						•				$1,100,000
South Dakota												•	$150,000

(continued)

Table A-1. State Awards by Grant Type and Total Award Amount, FY 2002–2003 (continued)

State	Community PASS		NFT – State	NFT – ILP	Real Choice	Respite for Adults	Respite for Children	Community-Based Treatment Alternatives	Quality Assurance / Quality Improvement	Indepen-dence Plus	Money Follows the Person	Family to Family	Total $ Amount Awarded
	2002	2003	2002	2002	2002	2003	2003	2003	2003	2003	2003	2003	
Tennessee	•								•				$1,177,636
Texas		•			•			•	•		•		$3,308,785
Utah				•	•								$1,785,000
Virginia		•											$513,557
Washington					•						•		$1,993,008
West Virginia	•				•				•				$2,538,991
Wisconsin					•				•		•	•	$2,771,772
Wyoming			•										$600,000
Total	**8**	**8**	**11**	**5**	**25**	**4**	**6**	**6**	**19**	**12**	**8**	**9**	**$75,233,598**

APPENDIX B
LEAD AGENCIES RECEIVING GRANTS, BY STATE

Table B-1. Lead Agencies Receiving Grants, by State

State	Grant Type	Grantee Organization
Alabama	NFT-ILP	Mid-Alabama Chapter of the Alabama Coalition of Citizens with Disabilities, DBA Birmingham Independent Living Center
Alabama	NFT-SP	Alabama Department of Senior Services, State Unit on Aging
Alabama	RC	Alabama Medicaid Agency, Long-Term Care Division
Alabama	RFC	Alabama Department of Mental Health and Mental Retardation
Alaska	CPASS	Department of Administration, Division of Senior Services
Alaska	FTF	Stone Soup Group
Alaska	NFT-SP	Department of Administration, Division of Senior Services
Alaska	RC	Department of Health and Social Services, Division of Mental Health and Developmental Disabilities
Arizona	CPASS	Arizona Department of Economic Security, Division of Developmental Disabilities
Arkansas	CPASS	Department of Human Services, Division of Developmental Disabilities (DDS)
Arkansas	NFT-SP	Department of Human Services, Division of Aging and Adult Services
Arkansas	RC	Department of Human Services, Division of Aging and Adult Services
Arkansas	RFC	Arkansas Department of Human Services
California	MFP	California Department of Health Services (DHS)
California	NFT-ILP	Community Resources for Independence
California	QA/QI	State of California
California	RC	California Department of Social Services
California	RFA	California Department of Mental Health
Colorado	CPASS	Department of Health Care Policy and Financing
Colorado	FTF	Family Voices of Colorado
Colorado	IP	Colorado Department of Health Care Policy and Financing
Colorado	NFT-SP	Department of Health Care Policy and Financing, Office of Medical Assistance
Colorado	QA/QI	Colorado Department of Human Services, Division for Developmental Disabilities
Colorado	RC	Department of Health Care Policy and Financing
Connecticut	CPASS	Department of Social Services
Connecticut	IP	Department of Mental Retardation
Connecticut	NFT-SP	Department of Social Services, Health Care Financing
Connecticut	QA/QI	Connecticut Department of Mental Retardation
Connecticut	RC	Connecticut Department of Social Services
Delaware	NFT-ILP	Independent Resources, Inc.
Delaware	NFT-SP	Delaware Health and Social Services, Division of Services for Aging and Adults with Physical Disabilities
Delaware	QA/QI	Division of Developmental Disabilities Services (DDDS)
Delaware	RC	Delaware Health and Social Services

(continued)

Table B-1. Lead Agencies Receiving Grants, by State (continued)

State	Grant Type	Grantee Organization
District of Columbia	CPASS	Department of Health, Medical Assistance Administration
District of Columbia	RC	Department of Health, Medical Assistance Administration
Florida	IP	Florida Department of Children and Families
Florida	RC	Florida Department of Management Services, Americans with Disabilities Act Working Group
Georgia	IP	Georgia Department of Human Resources
Georgia	NFT-ILP	disABILITY LINK
Georgia	NFT-SP	Georgia Department of Community Health, Division of Medical Assistance, Aging & Community Services
Georgia	QA/QI	Georgia Department of Human Resources
Georgia	RC	Georgia Department of Human Resources
Guam	CPASS	Department of Integrated Services for Individuals with Disabilities
Guam	RC	Department of Public Health and Social Services, Division of Public Health
Hawaii	CPASS	State of Hawaii, Department of Health
Hawaii	RC	Department of Human Services
Idaho	IP	Idaho Department of Health and Welfare, Division of Medicaid
Idaho	MFP	Idaho Department of Health and Welfare, Division of Family and Community Services
Idaho	RC	Department of Health and Welfare, Division of Family and Community Services; Idaho State University Institute of Rural Health
Illinois	CTAC	Illinois Department of Human Services
Illinois	RC	Illinois Department of Human Services
Indiana	CPASS	Family and Social Services Administration
Indiana	FTF	The Indiana Parent Information Network, Inc. (IPIN)
Indiana	NFT-SP	Family and Social Services Administration
Indiana	QA/QI	Indiana Family and Social Services Administration/Division of Disability, Aging, and Rehabilitative Services
Indiana	RC	Family and Social Services Administration
Iowa	RC	Iowa Department of Human Services, Division of MH/DD
Kansas	CPASS	The University of Kansas Center for Research, Inc.
Kansas	RC	Department of Social and Rehabilitation Services, Resource Development
Kentucky	RC	Kentucky Cabinet for Health Services
Louisiana	CPASS	Department of Health and Hospitals
Louisiana	IP	Louisiana Department of Hospitals
Louisiana	NFT-SP	Louisiana Department of Health and Hospitals
Louisiana	RC	State of Louisiana Department of Health and Hospitals
Maine	IP	Department of Behavioral and Developmental Services (BDS)
Maine	MFP	Maine Department of Behavioral and Developmental Services
Maine	QA/QI	Maine Department of Human Services
Maine	RC	Maine Department of Human Services, Bureau of Medical Services

(continued)

Table B-1. Lead Agencies Receiving Grants, by State (continued)

State	Grant Type	Grantee Organization
Maryland	CTAC	Mental Health Administration, Maryland Department of Health and Mental Hygiene
Maryland	FTF	The Parents' Place of Maryland
Maryland	NFT-ILP	Making Choices for Independent Living, Inc.
Maryland	NFT-SP	Department of Human Resources (DHR), Office of Personal Assistance Services
Maryland	RC	Department of Mental Health and Hygiene
Maryland	RFC	Mental Hygiene Administration, Maryland Department of Health and Mental Hygiene
Massachusetts	CPASS	Massachusetts Department of Mental Retardation
Massachusetts	CTAC	Executive Office of Health and Human Services
Massachusetts	IP	University of Massachusetts Medical School
Massachusetts	NFT-SP	Department of Mental Retardation, Division of Systems Integration
Massachusetts	RC	Center for Health Policy and Research, University of Massachusetts Medical School
Michigan	CPASS	Department of Community Health, Long-Term Care Initiative
Michigan	IP	Michigan Department of Community Health
Michigan	MFP	Michigan Department of Community Health
Michigan	NFT-SP	Department of Community Health, Long-Term Care Initiative
Michigan	RC	Department of Community Health, Long-Term Care Programs
Michigan	RFC	Division of Mental Health Services for Children and Families, Michigan Department of Community Health
Minnesota	CPASS	Department of Human Services, Continuing Care for Persons with Disabilities
Minnesota	NFT-ILP	Metropolitan Center for Independent Living
Minnesota	QA/QI	Minnesota Department of Human Services, Continuing Care Administration
Minnesota	RC	Department of Human Services, Continuing Care for Persons with Disabilities
Mississippi	CTAC	Division of Medicaid
Mississippi	RC	Department of Mental Health
Missouri	CTAC	Department of Mental Health
Missouri	IP	Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities
Missouri	QA/QI	Department of Health and Senior Services
Missouri	RC	Department of Social Services
Montana	CPASS	Department of Public and Human Services, Senior & Long-Term Care Division
Montana	FTF	Parents, Let's Unite for Kids (PLUK)
Montana	IP	Department of Public Health and Human Services
Montana	RC	Department of Public Health and Human Services
Nebraska	CPASS	Nebraska Department of Health and Human Services
Nebraska	NFT-SP	Department of Health and Human Services, Finance and Support
Nebraska	RC	Nebraska Department of Health and Human Services, Finance and Support

(continued)

Table B-1. Lead Agencies Receiving Grants, by State (continued)

State	Grant Type	Grantee Organization
Nevada	CPASS	Department of Employment, Training & Rehabilitation, Office of Community Based Services
Nevada	FTF	Family TIES (Training, Information, and Emotional Support) of Nevada, Inc.
Nevada	MFP	Nevada Department of Human Resources
Nevada	RC	Nevada Department of Human Resources
New Hampshire	CPASS	Granite State Independent Living
New Hampshire	NFT-SP	DHHS, Elders Division
New Hampshire	RC	Department of Health and Human Services
New Jersey	FTF	Statewide Parent Advocacy Network of New Jersey, Inc (SPAN)
New Jersey	NFT-ILP	Resources for Independent Living, Inc. (RIL)
New Jersey	NFT-SP	Department of Health and Senior Services
New Jersey	RC	New Jersey Department of Human Services
New Mexico	RC	Human Services Department, Medical Assistance Division
New York	QA/QI	New York State Department of Health, Office of Medicaid Management
New York	RC	New York State Department of Health
New York	RFA	New York State Department of Health
North Carolina	CPASS	Department of Health and Human Services
North Carolina	NFT-SP	North Carolina Department of Health and Human Services
North Carolina	QA/QI	North Carolina Department of Health and Human Services
North Carolina	RC	North Carolina Department of Health and Human Services
North Dakota	RC	State of North Dakota
Northern Mariana Islands	RC	Governor's Council on Developmental Disabilities
Ohio	IP	Ohio Department of Mental Retardation Developmental Disabilities (ODMRDD)
Ohio	NFT-SP	Ohio Department of Job and Family Services
Ohio	QA/QI	Ohio Department of Mental Retardation Developmental Disabilities
Ohio	RC	Ohio Department of Job and Family Services
Ohio	RFA	Ohio Department of Aging
Oklahoma	CPASS	Oklahoma Department of Human Services, Aging Services Division
Oklahoma	RC	Oklahoma Department of Human Services, Aging Services Division
Oregon	CPASS	Oregon Health and Science University
Oregon	QA/QI	Oregon Department of Human Services, Seniors, and People with Disabilities
Oregon	RC	Oregon Department of Human Services
Oregon	RFC	Oregon Department of Human Services, Seniors, and People with Disabilities
Pennsylvania	MFP	Department of Public Welfare
Pennsylvania	QA/QI	Department of Public Welfare
Pennsylvania	RC	Department of Public Welfare
Rhode Island	CPASS	Department of Human Services

(continued)

Table B-1. Lead Agencies Receiving Grants, by State (continued)

State	Grant Type	Grantee Organization
Rhode Island	NFT-SP	Department of Human Services, Center for Adult Health
Rhode Island	RC	Department of Human Services, Center for Adult Health
Rhode Island	RFA	Rhode Island Department of Human Services (DHS)
Rhode Island	RFC	Rhode Island Department of Human Services (DHS)
South Carolina	NFT-SP	Department of Health and Human Services, Office of Senior and Long-Term Care
South Carolina	QA/QI	South Carolina Department of Disabilities and Special Needs
South Carolina	RC	Department of Health and Human Services
South Dakota	FTF	South Dakota Parent Connection, Inc.
Tennessee	CPASS	Department of Finance and Administration
Tennessee	QA/QI	Tennessee Department of Finance and Administration
Tennessee	RC	Department of Mental Health & Developmental Disabilities
Texas	CPASS	Texas Department of human Services
Texas	CTAC	Texas Health and Human Services Commission
Texas	MFP	Texas Department of Human Services
Texas	NFT-ILP	Austin Resource Center for Independent Living (ARCIL)
Texas	QA/QI	Texas Department of Mental Health and Mental Retardation
Texas	RC	Texas Health and Human Services Commission
Utah	NFT-ILP	Utah Independent Living Center
Utah	RC	Department of Human Services
Vermont	RC	Agency for Human Services
Virginia	CPASS	Partnerships for People with Disabilities, Virginia Commonwealth University
Virginia	RC	Department of Medical Assistance Services, Long-Term Care & Quality Assurance
Washington	MFP	Washington State Department of Social and Health Services (DSHS)
Washington	NFT-SP	Department of Social and Health Services
Washington	RC	Department of Social and Health Services
West Virginia	CPASS	West Virginia University Research Corporation
West Virginia	NFT-SP	Department of Health and Human Resources
West Virginia	QA/QI	West Virginia Department of Health and Human Resources
West Virginia	RC	Department of Health and Human Resources
Wisconsin	FTF	Family Voices of Wisconsin
Wisconsin	MFP	Department of Health and Family Services
Wisconsin	NFT-ILP	Great Rivers Independent Living Center
Wisconsin	NFT-SP	Department of Health and Family Services, Division of Supportive Living
Wisconsin	QA/QI	Department of Health and Family Services
Wisconsin	RC	Department of Health Family Services, Division of Supportive Living
Wyoming	NFT-SP	Wyoming Department of Health, Aging Division

APPENDIX C
FY 2004 GRANTEES

APPENDIX C
FY 2004 GRANTEES

The CMS awarded more than $30 million in Systems Change Grants for Community Living in FY 2004. The awards build on the roughly $158 million in grants awarded in the previous 3 years to help states improve their community-based services. The CMS awarded a total of 51 grants across three broad categories—Research and Demonstration, Feasibility, and Technical Assistance—a total of 8 grant types.[4]

Exhibit C-1. Comprehensive Systems Reform

Purpose: To assist states to decrease their reliance on institutional services and increase the level of supports that are controlled by the individuals that receive them by supporting a comprehensive planning, design, and implementation effort to reform their LTC systems. This grant opportunity is distinguished from the Rebalancing Initiative grant opportunity in that it is intended to assist states in developing a comprehensive reform plan rather than a targeted rebalancing plan.

State	Organization	FY 2004 Award
Vermont	State of Vermont Office of Health Access	$2,089,863
Wisconsin	Wisconsin Department of Health and Family Services	$5,500,000
COMP Total Awarded:		**$7,589,863**

Exhibit C-2. Integrating Long-Term Supports with Affordable Housing

Purpose: To remove barriers that prevent Medicaid-eligible individuals with disabilities of all ages from residing in the community or in the housing arrangement of their choice. This grant will assist states to create the infrastructure necessary to increase access to and the capacity of affordable and accessible housing, and to coordinate supports funded through State Plan services, waiver services, or other service agencies.

State	Organization	FY 2004 Award
Arkansas	Department of Human Services	$900,000
District of Columbia	District of Columbia Department of Mental Health	$812,004
Mississippi	University of Southern Mississippi	$720,000
New Hampshire	University of New Hampshire	$899,954
North Carolina	North Carolina Department of Health and Human Services	$775,123
Oregon	State of Oregon Department of Human Services	$828,232
Pennsylvania	Pennsylvania Governor's Office of Health Care Reform	$893,340
Vermont	Vermont Agency for Human Services	$900,000
HOUSE Total Awarded:		**$6,728,653**

[4] CMS awarded Technical Assistance grants to two organizations in FY2004. These Grantees will not be included in next year's annual report and have not been included here.

Exhibit C-3. Quality Assurance and Quality Improvement in HCBC

Purpose: To assist states to (a) fulfill their commitment to ensure the health and welfare of individuals who participate in the state's home and community-based waiver programs; (b) develop effective methods to meet statutory requirements and the CMS expectations by the use of ongoing quality management strategies; and (c) develop methods to involve program participants and community members in active roles in the state's quality assurance systems.

State	Organization	FY 2004 Award
Alaska	Alaska Department of Health and Social Services	$417,849
Arizona	Arizona Department of Economic Security	$500,000
Arkansas	Arkansas Department of Human Services	$500,000
Florida	Florida Department of Children and Families	$475,000
Massachusetts	University of Massachusetts Medical School	$499,226
Nebraska	Nebraska Department of Health and Human Services	$470,000
New Hampshire	New Hampshire Department of Health and Human Services	$498,988
New Jersey	New Jersey Department of Human Services	$475,000
Vermont	Agency of Human Services, Department of Aging	$499,709
QA/QI Total Awarded:		**$4,335,772**

Exhibit C-4. Mental Health: Systems Transformation

Purpose: To provide funding to improve the ability of states to offer evidence-based and recovery-oriented services to consumers with mental illnesses. In July 2003, the President's New Freedom Commission on Mental Health finished its work and published its final report: *Achieving the Promise: Transforming Mental Health Care in America*. This grant opportunity will assist states to address recommendations made in this report to further align their mental health system with recovery orientation of mental health practice.

State	Organization	FY 2004 Award
Delaware	Delaware Department of Services for Youth and Their Families	$300,000
Maine	Maine Department of Health and Human Services	$262,318
Massachusetts	University of Massachusetts Medical School	$300,000
Minnesota	Minnesota Department of Human Services	$300,000
New Hampshire	State of New Hampshire, Division of Behavioral Health	$300,000
North Carolina	North Carolina Department of Health and Human Services	$293,769
Ohio	Ohio Department of Mental Health	$300,000
Oklahoma	Oklahoma Department of Mental Health and Substance Abuse	$299,820
Oregon	Portland State University	$300,000
Pennsylvania	Pennsylvania Department of Public Welfare	$300,000
Virginia	Virginia Department of Mental Health, Mental Retardation, and Substance Abuse	$300,000
MHST Total Awarded:		**$3,255,907**

Exhibit C-5. Rebalancing

Purpose: To reform the financing and service designs of state long-term support systems to decrease reliance on institutional care and increase the utilization of community-based long-term supports. These rebalancing strategies are likely to include systems for increasing access to HCBS and transitioning individuals out of institutions. This grant opportunity is intended to assist states in developing a targeted rebalancing plan rather than a comprehensive reform plan.

State	Organization	FY 2004 Award
Illinois	Illinois Department of Aging	$300,000
Louisiana	Louisiana Department of Health and Hospitals	$300,000
Mississippi	Mississippi Department of Mental Health	$282,700
North Carolina	North Carolina Department of Health and Human Services	$249,500
North Dakota	State of North Dakota	$300,000
Tennessee	State of Tennessee, Bureau of TENNCARE	$291,382
Virginia	Partnership for People with Disabilities	$300,000
REBAL Total Awarded:		**$2,023,582**

Exhibit C-6. Family-to-Family Health Care Information and Education Center

Purpose: To enable organizations to develop statewide family-run centers that will (a) provide education and training opportunities for families with children with special health care needs; (b) develop and disseminate needed health care and HCBS information to families and providers; (c) collaborate with existing Family-to-Family Health Care Information and Education Centers to benefit children with special health care needs; and (d) promote the philosophy of individual and family-directed supports.

State	Organization	FY 2004 Award
Arizona	Raising Special Kids	$150,000
Kentucky	The Arc of Kentucky, Inc.	$150,000
Louisiana	Family Voices of Louisiana, Inc.	$150,000
Massachusetts	Federation for Children with Special Needs	$150,000
New Mexico	Parents Reaching Out for Help, Inc.	$150,000
New York	Parent to Parent of New York, Inc.	$150,000
North Carolina	Exceptional Children's Assistance Center	$150,000
North Dakota	Family Voices of North Dakota, Inc.	$150,000
Utah	Utah Parent Center	$150,000
West Virginia	WUPTI, Inc.	$150,000
FTF Total Awarded:		**$1,500,000**

Exhibit C-7. Portals from EPSDT to Adult Supports

Purpose: To assist states to address the needs of children with disabilities who receive community health services through EPDST and who are re-determined to be eligible for SSI/Medicaid at age 21 (or younger at the discretion of the state). These grants will assist states in (a) developing and implementing a State Plan amendment, (b) developing a waiver or demonstration application to provide new supports to this population and implement enrollment into the waiver or demonstration, or (c) developing a waiver amendment application to expand either services or slots in the state's existing targeted disability waiver(s).

State	Organization	FY 2004 Award
District of Columbia	District of Columbia, Department of Mental Health	$499,649
Nebraska	Nebraska Department of Health and Human Services	$500,000
PORT Total Awarded:		**$999,649**

Exhibit C-8. LIFE Accounts Feasibility and Demonstration

Purpose: To enable states to assess the feasibility of establishing and maintaining a savings program of individual savings accounts within which eligible Medicaid participants can build savings without affecting their eligibility or benefit levels for the state's Medicaid, Supplemental Security Income (SSI), Social Security Disability Income (SSDI), or any other Federal assistance program. The LIFE Account savings program is intended to enable people with a disability or chronic condition to become more independent by allowing eligible participants the opportunity to save for needed supports without losing their health coverage.

State	Organization	FY 2004 Award
New Hampshire	University of New Hampshire	$99,999
Wisconsin	State of Wisconsin Department of Health and Family Services	$100,000
LIFE Total Awarded:		**$199,999**