Real Choice Systems Change Grant Program

First Year Report
(October 1, 2001 -September 30, 2002)

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First Year Report

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ES.1 INTRODUCTION

Historically, the majority of public long-term care (LTC) funding has paid for the provision of LTC services in institutional settings. Over the past 20 years, many States have led the way in creating 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. The 1999 Supreme Court decision in Olmstead v. L.C. gives legal weight to this policy direction.

However, in virtually all States, the majority of funding for LTC services continues to be spent on institutional care. This imbalance is due, in part, to the existence of policies, regulations, and programs that present barriers to the provision of home and community services, and to assuring optimal consumer control over their services.

To help States bring about the infrastructure changes needed to remove these barriers and create more consumer responsive LTC systems, the Centers for Medicare & Medicaid Services (CMS) awarded approximately $70 million in Real Choice Systems Change Grants for Community Living to 37 States and Guam.

Fifty-two Grants were awarded in September 2001:

- 25 Real Choice Systems Change (RC) Grants,
- 10 Community-Integrated Personal Assistance Services and Supports (CPASS) Grants, and
- 17 Nursing Facility Transition (NFT) Grants. NFT Grants are of two types—State Program (SP) Grants supporting SP initiatives and Independent Living Partnership (ILP) Grants made to Centers for Independent Living (CILs) to promote partnerships between CILs and States to support NFTs.

The purpose of this report is to describe the progress fiscal year (FY) 2001 Grantees have made on their activities during the first year of the three-year Grant period (October 1, 2001 through September 30, 2002.)[1]

ES.2 SOURCES OF INFORMATION

This report summarizes findings from the Year One annual reports of the 52 FY 2001 Grantees. The reports included a description of Year One activities and Grantees' ratings of their progress on Grant activities.

We reviewed each report and spoke with Grantees to obtain missing information and clarify ambiguities. We prepared a summary for each content area covered in the annual report and

selected examples of Grantees' activities in several key areas of systems change to illustrate the type and range of activities Grantees undertook in Year One.

ES.3 BUILDING THE INFRASTRUCTURE TO BRING ABOUT CONSUMER RESPONSIVE LTC SYSTEMS

Grantees are embarking on a multi-year effort to build the infrastructure necessary to bring about consumer responsive LTC delivery systems.

To build this infrastructure, Grantees are undertaking a wide range of activities, including:

- changes in reimbursement mechanisms to facilitate consumer-directed services;
- changes to incorporate a more person-centered approach in assessment and service planning processes;
- changes in oversight mechanisms to assure health, safety, and quality without compromising consumer choice;
- changes to assure that the work of agencies serving the same populations are effectively coordinated; and
- development of resource centers to provide information about community services and supports, which can facilitate informed choice and help prevent unnecessary institutionalization.

The Grant solicitation allowed Grantees exceptional flexibility in selecting the type of investment that they believe will yield the most significant improvement in the state's home and community service system.

ES.4 GRANTEES HAVE MADE SUBSTANTIAL PROGRESS, DESPITE FACING MAJOR OBSTACLES

In the first year of funding, Grantees faced many challenges initiating Grant activities. These challenges included reductions in their original budgets, State budget crises, staffing problems, and travel restrictions. The most frequent reason cited for late initiation or completion of Grant activities was staffing problems.

In the context of these challenges, in many States, the Grants are playing an even more important role than originally envisioned. Several Grantees stated that Grant funding has been a particularly important catalyst for initiating and continuing systems change activities that would otherwise not have been possible.

Grantees have initiated about 81 percent of all activities scheduled to start in Year One. Of these, Grantees anticipate that almost two thirds will be completed on schedule.

The NFT Grantees are well on their way to achieving the goals they have set. The 17 NFT Grantees have a combined goal of transitioning almost 1400 consumers during the three-year Grant period. In the first year of Grant activities, Grantees have successfully transitioned 370

consumers in community settings. Another 321 consumers are in the process of transitioning, and Grantees have contacted 867 consumers about transitioning to the community.

The CPASS and RC Grantees have also made substantial progress towards their goals, as illustrated by the following examples:

- Maryland (RC) has collaborated with multiple State and local agencies (Departments of Aging, Human Resources, and Education) on workforce recruitment efforts. Additionally, the State's Fire and Rescue Institute is providing reduced-cost CPR and First Aid training at workforce recruitment fairs.

- Alabama (NFT-ILP) created an on-going consumer advisory committee to advise not just the Grant, but the State's Medicaid LTC director on policy issues. This committee will assure that consumers' perspectives inform systems change.

- In Georgia (NFT-ILP), Centers on Independent Living worked with the local Public Housing Authorities to obtain Section 8 set-asides for people with disabilities and those transitioning from institutionalized settings.

- Nevada (CPASS) is working with a private developer and the State Division of Housing to establish the State's first Low Income Housing Tax Credit assisted living development for people with disabilities.

- Montana (CPASS) conducted focus groups with consumers and attendants to help determine the content of a website to provide resources for caregivers and consumers.

- As part of Maine's (RC) efforts to integrate State data, the Assistant Attorneys General and other counsel have worked with the Grantee to identify confidentiality constraints when integrating data across departments.

- Rhode Island (CPASS) began developing certification standards for a new PASS program. Consumer members of a Personal Assistance Services and Supports (PASS) workgroup provided input and recommendations to help guide their development.

- In Delaware (RC), a number of banks and financial institutions have participated in a work group looking at establishing a low interest loan program for funding assistive technology.

- Florida (RC) is working with the Department of Elder Affairs and the Florida Housing and Finance Corporation to develop a preliminary database of affordable and accessible housing units and public housing authorities. When completed, it will be the first data base of its kind in Florida, and will act as a single-point of entry for housing information for consumers and providers.

At the end of the First Year, most Grantees are still in the process of bringing about systems change. However, several reported the completion of activities that have resulted in enduring change, including:

- Kentucky (RC) Grant activities were instrumental in getting the Kentucky Housing Corporation to change its policy to require use of Universal Design principles.

- As a result of Maryland (NFT-SP) Grant activities, the Department of Housing and Community Development has agreed to modify the weight factor in its Qualified Allocation Plan (QAD) as an incentive for developers to set aside a percentage of housing units for people with disabilities. Additionally, three Public Housing Authorities have included a commitment to set aside Section 8 vouchers for participants in Medicaid Waiver programs in their HUD funding applications.

- In Connecticut (NFT-SP) a Center for Independent Living formalized the first partnership with a local housing authority.

- In Georgia (NFT-ILP), two Centers for Independent Living (CILs) obtained Memos of Understanding with their local Public Housing Authorities that guarantee priority for housing to persons transitioning from a nursing facility.

These examples illustrate the wide range of activities that Grantees are undertaking to bring about the infrastructure changes needed to create consumer responsive LTC service systems.

ES.5 NEXT STEPS

During Year Two—October 1, 2002 through September 30, 2003—Grantees are continuing their activities with a specific focus on ensuring systems changes that will endure beyond the three-year Grant period.

Grantees who experienced some delay in initiating Grant activities are now working with CMS Project Officers to assure that their projects are back on schedule by the end of Year Two.

The next RTI reports documenting Grantee progress will focus on two key issues that many Grantees are addressing: increasing the availability of affordable, accessible housing and workforce recruitment, training, and retention. These reports will be available in late Fall 2003.

The Year Two annual report documenting progress in Year Two will be available in March 2004. A companion report documenting Year One progress of the Grantees who first received funding in FY 2002 will also be available in March 2004.

1.   Introduction

1.1   BACKGROUND

In May 2001, the Centers for Medicare & Medicaid Services (CMS) invited applications from States and others to obtain Real Choice Systems Change Grants for Community Living Grants (hereafter, the Grants). The purpose of the Grants is to encourage States to make enduring changes in their long-term care (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 the services they receive.

In September 2001, CMS awarded approximately $70 million in Grants to 37 States and Guam. Fifty-two Grants were awarded:

- 25 Real Choice Systems Change (RC) Grants,
- 10 Community-Integrated Personal Assistance Services and Supports (CPASS) Grants, and
- 17 Nursing Facility Transition (NFT) Grants. 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.

A list of the fiscal year (FY) 2001 Grantees is provided in Appendix E.

Historically, the majority of public LTC funding has paid for the provision of LTC services in institutional settings. Over the past 20 years, many States have led the way in creating 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. The 1999 Supreme Court decision in *Olmstead v. L.C.* gives legal weight to this policy direction.[2] However, in virtually all States, the majority of funding for LTC services continues to be spent on institutional care—71 percent in 2001.[3]

Certain features of States' LTC policies and programs may present barriers to the provision of home and community services and to assuring optimal consumer control of the service they receive. The Real Choice Systems Change Grants for Community Living are intended, in part, to remove these barriers.

1.2   PURPOSE AND ORGANIZATION OF REPORT

The purpose of this report is to describe the progress FY 2001 Grantees made during the first year of the three-year Grant program, (*hereafter*, Year One.)

- Section 2 describes our data sources and technical approach.

- Section 3 describes the challenges Grantees faced initiating Grant activities.

- Section 4 describes Grantee progress in Year One.

- Section 5 provides information about reports we will prepare describing about Grantees' progress during Year Two.

2. Sources of Information

2.1 DATA SOURCES

Our principal source of data was the Year One annual reports of the 52 FY 2001 Grantees. (A copy of the annual report format can be found in Appendix D). Grantees' reports included: a description of Year One activities and Grantees' ratings of their progress on goals and activities as described in summaries of their revised Grant applications.[4] Grantees rated their progress using a scale provided in the annual report format.

2.2 TECHNICAL APPROACH

We first reviewed each report and spoke with Grantees to obtain missing information and clarify ambiguities. We next prepared a summary for each content area covered in the annual report. We then compared the summaries to the Grantees' original reports to assure that they retained the substance of their responses.

Finally, we selected examples of Grantees' activities in several key areas of systems change— such as workforce development and housing—to illustrate the type and range of activities Grantees undertook in Year One.

2.3 LIMITATIONS OF THE APPROACH

This report describes the progress Grantees have made on their scheduled activities in Year One. The description is subject to the limitations of the data and the technical approach used. The specific limitations are:

- The data we used are the self reports of the Grantees. Our description is dependent on the thoroughness of each Grantee's responses in their Annual Reports.

- In some instances, we exercised judgment in deciding which activities were linked to a particular content area. In some cases, the activity might be linked to multiple content areas.

- At each step of our analysis, we exercised judgment to determine the key points to highlight in this report. We also eliminated duplicative information and prepared concise summaries. Consequently, our description may not contain some information that individual Grantees consider important.

3. Building the Infrastructure to Bring about Consumer Responsive LTC Systems

Grantees are embarking on a multi-year effort to build the infrastructure necessary to bring about consumer responsive LTC delivery systems.

To build this infrastructure, Grantees are undertaking a wide range of activities, including:

- changes in reimbursement mechanisms to facilitate consumer-directed services;
- changes to incorporate a more person-centered approach in assessment and service planning processes;
- changes in oversight mechanisms to assure health, safety, and quality without compromising consumer choice;
- changes to assure that the work of agencies serving the same populations are effectively coordinated; and
- development of resource centers to provide information about community services and supports, which can facilitate informed choice and help prevent unnecessary institutionalization.

The Grant solicitation allowed Grantees exceptional flexibility in selecting the type of investment that they believe will yield the most significant improvement in the state's home and community service system.

The implementation period for the FY 2001 Grants is three years. This report describes activities undertaken in Year One—from October 1, 2001 through September 30, 2002.

Due to an overwhelming response to the Grant solicitation, CMS awarded a greater number of Grants with lower levels of funding than requested. Consequently, Grantees initially had to scale back their proposed activities to match their Grant awards. To do so, they worked with the consumer, public, and private partners who helped to develop the original Grant application to determine priorities.

In many instances, budget cuts necessitated changes to the original project. For example, Michigan (NFT-SP) had to reduce the scope of some Grant activities from statewide to selected geographic regions.

The revised workplans were due to CMS on December 1, 2001. Thus, the actual timeframe for implementing Year One Grant activities was 10 months.

3.1 CHALLENGES INITIATING GRANT ACTIVITIES

Grantees faced many unanticipated challenges when initiating Grant activities. The Grants were initiated during a time of great fiscal challenge for all States. Due to a national recession, State tax revenues have fallen dramatically, causing budget deficits of crisis proportion. In

response, many States reduced staff through hiring freezes, layoffs, and the offering of early retirement options.[5]

These actions slowed Grant implementation and progress in many States, because most Grants are staffed with State personnel. Additionally, many Grant activities require collaboration with State agencies and community providers who also rely on State funding. In South Carolina (RC) budget cuts prevented one Grant partner from working on the project entirely.

Hiring staff was the greatest challenge. Twenty-seven Grantees stated that Grant initiation was affected by staffing problems. In some cases, lead project staff could not be hired for up to 10 months after the Grant's were awarded. In one case, Grant activities were not initiated until the end of the first year. Rather than deal with continuing staffing problems, this Grantee decided to outsource most Grant activities.

Grantees in Michigan (CPASS and RC), New Jersey (RC), and Maryland (NFT-SP) reported that early retirement options and hiring freezes left them short staffed. Remaining staff were left with heavy workloads. Minnesota (RC and CPASS) experienced an employee strike that delayed hiring and interfered with Grant implementation activities.

Job insecurity in many States made it difficult to recruit senior people, who, in many cases, were reluctant to change jobs for term-limited employment funded by Federal Grants (sometimes without health insurance and other benefits.) To bypass staffing difficulties, some States decided to outsource all or some Grant activities, but finding appropriate subcontractors was also time consuming.

State budget problems affected Grant implementation in other ways. At least two Grantees faced travel restrictions even though travel under the Grant is supported by federal, not State, funding. State personnel working on Grants have in some cases not traveled to avoid the appearance of disregarding State employee travel restrictions. Montana (CPASS) cancelled a planned trip when the State travel budget was cut by 25 percent. In Minnesota (RC), travel restrictions limited outreach to outlying areas.

In the context of these challenges, in many States the Grants are playing an even more important role then originally envisioned. Several Grantees stated that Grant funding has been a particularly important catalyst for initiating systems change activities that would not otherwise have been possible. Maine (RC) reported that without its RC Grant, the State would have been unable to respond meaningfully to its *Olmstead* Workgroup's recommendations on consumer choice and control, housing, and the personal assistant workforce. Additionally, the Grant has helped to reinvigorate some initiatives that had lapsed due to lack of State resources.

4. Grantees Have Made Substantial Progress in Year One, Despite Facing Major Obstacles

4.1 OBTAINING BUY-IN AND BUILDING CONSENSUS

Both the Congress and CMS emphasized the importance of stakeholder involvement—consumers and public and private entities—in the Grant planning and implementation process. CMS listed partnership development as an evaluation criterion in its Notice of Funding Availability and required all Grantees to assure meaningful involvement of consumers, their families and their advocates in all stages of program development, planning, implementation, monitoring, and evaluation.

All Grantees have included numerous stakeholders in Grant activities, including:

- individuals with disabilities and their families,
- consumers of long-term services and supports and their families,
- consumer advocates and organizations,
- representatives from agencies and organizations that provide services to individuals with disabilities,
- educational institutions,
- service providers,
- advocacy groups, and
- commissions and task forces addressing disability and LTC issues.

The purpose of stakeholder involvement is to obtain buy-in and build consensus—two necessary first steps in bringing about systems change. Grantees made considerable progress in these areas during Year One, bringing together stakeholders to work on cross-cutting issues, many of whom had not previously worked together. Many Grantees stated that the Grant planning and implementation process has increased the number of stakeholders involved in systems change. New Hampshire (RC) noted that one of the Grant's most significant accomplishments was the ability to get all parties at the table working together to solve very complex issues.

A primary method of assuring buy-in and building consensus is having stakeholders provide input to, and oversight of, Grant activities through task forces and advisory boards. Another method is having stakeholders participate in work groups charged with implementing specific Grant initiatives. For example, in Massachusetts (RC), an Interagency Leadership Team responsible for improving interagency program coordination has assigned agency staff to participate in Grant work groups.

Several Grantees specifically noted the value of cross disability representation on task forces and advisory boards. Consumers, regardless of age or disability, often have the same or similar concerns about access to, and the availability, quality, and value of the LTC services they need. Several Grantees found that bringing consumers of different ages and with different types of disabilities together to discuss common concerns helped to achieve consensus.

For example, the Michigan (CPASS) Grantee noted that participants in consumer task force meetings and focus groups consistently commented on the similarity of issues across programs, service settings, and populations. In one of their focus groups, the parent of a child with developmental disabilities commented to an elderly beneficiary on how similar their concerns were: the need for competent, caring, and reliable caregivers.

The role that advisory and oversight bodies play in assuring buy-in and consensus is expanded in many States through cross membership on boards, councils, and advisory groups for other projects. For example, consumers and advocates serving on Grant advisory bodies and work groups take ideas and information about Grant activities to other councils and boards they serve on, and then return to Grant meetings with council and board comments and reactions. This process is repeated, serving to help bind Grant activities to other disability and LTC projects and programs. In addition, members alert project staff about related activities requiring coordination.

In Year One, members of advisory and oversight bodies have reviewed and provided input on a wide range of Grant activities. For example:

- In Arkansas (CPASS) and Oregon (RC), consumers were involved in hiring decisions for Grant staff positions.
- In Guam (CPASS), consumers provided input regarding the conceptualization and content of its Individualized Budgeting initiative. This initiative will permit consumers who are directing their own services to have more input into how their services dollars will be allocated.
- In Colorado (NFT-SP), a State Resource Team, comprising consumer, private and public partners, provided input on: drafts of a letter to consumers in nursing facilities and from the State to the nursing facilities; a flyer to be used for outreach and other activities; and drafts of transition protocols.

Some Grant Task Forces have multiple roles, as in Iowa (RC), where the Consumer Task Force oversees not only Grant activities but all of the State's *Olmstead*-related activities. Several States with two or more Grants—Arkansas, Oklahoma, Maine, and New Hampshire (not a complete list)—use a common consumer oversight body for all of the Grants, thereby enabling coordination and integration of related activities.

Some Grantees have sought to increase buy-in and build consensus by involving stakeholders in addition to those serving on the Grant's advisory and oversight bodies and workgroups. For example:

- Minnesota (CPASS) conducted extensive outreach to recruit members for a Quality Design Commission and a Project Design Team. Staff used postal mailings, media, and

e-mail to provide information to consumers and public and private entities, and made presentations to large advocacy groups. These efforts resulted in 80 applications for membership on the Quality Design Commission.

- In Florida (RC), the Consumer Task Force (CTF) held a statewide public hearing to solicit input from other consumers and interested parties. The hearing, attended by several hundred citizens, gave a large number of consumers the opportunity to voice their opinions on disability issues in Florida, and informed subsequent Grant activities. In addition to assuring citizen participation, the hearings provided formal documentation of their views on issues and problems.

- Hawaii (RC) held a three-day strategic planning meeting with 100 participants (approximately 51 percent self-advocates or their representatives) to obtain input regarding its proposed single entry point website. Experts, professionals from various State and private agencies, and State and City and County departments were also invited and asked to assess the user-friendliness and usefulness of the proposed information system.

- Nebraska (RC) held town hall meetings with local facilitators to help assure buy-in, and provided respite services for caregivers to encourage participation. They held meetings during times when consumers could more easily participate, and publicized the meeting through brochures and newspaper announcements.

Assuring involvement and achieving consensus among a wide range of consumers and public and private partners can be very challenging, particularly when the issues to be addressed affect a wide range of age and disability groups, agencies, and funding streams. Some Grantees used trained facilitators to assure participation by all meeting attendees, increase productivity, and help achieve consensus.

In response to consumers' request, North Carolina (RC) hired a professional facilitator for the Grant's Consumer Task Force meetings. The Grantee stated that the facilitator maximized Task Force workgroup effectiveness, guided deliberations, and assisted in consensus building. The Grantee noted that using Grant funds for this purpose was cost-effective because the facilitator planned and prepared the meetings, and provided meeting minutes, tasks that Grant staff would otherwise have had to perform.

There was a consensus among Grantees that stakeholder involvement—particularly, consumer involvement—was and will continue to be extremely important to the success of Grant initiatives. Several Grantees stated that obtaining the input of stakeholders—particularly consumers—gave them a full and accurate understanding of the issues on which they were working. Others credited consumer involvement as a key catalyst and facilitator in bringing about systems change. For example:

- Rhode Island (CPASS) noted that consumer involvement was a critical element in the success of the first phase of the redesign of its service system for children with special health care needs.

- Idaho (RC) stated that consumers provided a "real life" perspective on a number of its Grant activities: (1) what should be included in its anti-stigma campaign, (2) how questions should be worded in a needs and resources assessment survey to reduce participant burden, and (3) how the surveys should be made accessible to consumers.

Several Grantees noted that the Grants—and in particular, the receipt of two or more Grants by one State—have been a catalyst for getting agencies that serve different populations to work together on common issues. For example:

- Maryland (NFT-ILP), Michigan (NFT-SP), and Wisconsin (NFT-SP) noted that the Grants have led to an increase in interagency cooperation.

- Maine (RC) noted that the Grant is helping to build cross-departmental relationships and the capacity to develop policy that crosses traditional boundaries.

- Georgia (NFT-SP) noted that it had developed a new model of collaboration by having all interested stakeholders at the table: providers, consumers, advocates and public agencies. Centers for Independent Living are beginning to work more closely with State agencies as a result of Grant funding, a development that is a key factor for assuring enduring systems change.

- Texas (NFT-ILP) said that Grant funding had enabled Centers for Independent Living and State agency staff to develop or strengthen relationships, and to collaborate with Area Agency on Aging groups on "local access" strategies for LTC services.

- Alaska (NFT-SP) and Wisconsin (NFT-ILP) reported that as a consequence of Grant activities, their State agencies were working more closely with CILs.

- Arkansas (RC) reported that the Divisions of Aging and Adult Services and Developmental Disabilities Services have begun to work together on several common issues, a change from past dynamics when the service populations of the two Divisions were seen as being very different and without overlapping interests.

The importance of stakeholder collaboration to create enduring systems change cannot be over-estimated, particularly when it involves entities that historically have not interacted or have even been on opposing sides of issues. Many Grantees stated that the Grants have played and will continue to play a key role in fostering this collaboration.

- Several NFT Grantees stated that success in transitioning individuals from the nursing home to the community depends in large part on involving nursing facility staff in the process. To ensure their involvement, CIL staff in Colorado (NFT-SP) contacted a number of nursing facilities to recruit someone to work on the Grant project. As a result, a nursing home administrator is now a part of the Grant team and has provided valuable information and perspectives that the Grantee has found to be useful in achieving project goals.

- Connecticut (NFT-SP) said that the level of open communication and willingness to work together is unprecedented in the State.

- New Hampshire (RC) reported that there was an increase in coalition building and cross-disability work on critical issues facing older adults and persons with disabilities.

- New Hampshire (RC) stated that one of the Grant's most significant accomplishments was the creation of a structure for getting all parties at the table to work together to solve very complex issues.

The increased level of consumer involvement and stakeholder collaboration fostered by the Grants has also increased the level of enthusiasm for and attention and commitment to bringing about systems change, which some Grantees mentioned as a critical factor in creating enduring changes. For example:

- Maine (RC) said that Grant funding has been a key element in sustaining the energy and vision that resulted from the Work Group's planning process, and has fostered a shared vision for promoting community integration among State agencies and among consumers.

- Kentucky (RC) stated that virtually all of the State and local agencies and organizations focused on people with disabilities have become energetically involved with Grant and *Olmstead* planning activities.

- Wisconsin (NFT-ILP) noted that the Grant has increased the dedication of the CILs to de-institutionalization.

- Maryland (NFT-ILP) noted that the attention paid to the Grants has provided a lot of exposure for disability issues and helped to make these issues a part of the local political agenda.

- Florida (RC) said the availability of pilot site funding through the Grant has sparked the creation of community coalitions to bring about systems change.

4.2   IMPLEMENTING GRANT ACTIVITIES

4.2.1 Overview of all Activities

Grantees plan to initiate 657 major project activities over the three-year Grant period; 543 were scheduled to begin in Year One. As part of their annual reporting requirements, Grantees identified progress on these activities.

We categorized the 543 Year One activities into 14 topic areas initially identified in the report on *Goals, Objectives and Activities: Comparative Analysis of FY 2001 Systems Change Grantees.*[6] Exhibit 4-1 presents the number of Grant activities in each topic area and their completion status.

By the Fall of 2002, approximately 81 percent of Year One activities had been initiated; of these, 56 percent were being completed on schedule and 25 percent were *not* expected to be completed on schedule. Approximately 19 percent of activities had not yet been initiated. Additional information about progress on Grant activities, presented by topic area, can be found in Appendix B.

When activities were not initiated or were not progressing on schedule, most Grantees cited several reasons for the delay. These reasons are presented in Exhibit 4-2, which also shows the number of Grantees who cited that reason. Staffing issues were the primary reasons for delays.

4.2.2 Overview of Nursing Facility Transition Grant Activities

By the end of the three-year Grant period, the 17 NFT Grantees plan to transition or divert almost 1,400 individuals from nursing facilities.

Exhibit 4-3 presents transition and diversion information for Year One. Eleven Grantees have already successfully transitioned 370 consumers to community settings, and Michigan (NFT-SP)

and West Virginia (NFT-SP) have successfully diverted three consumers from nursing home placements. Eight Grantees identified 321 consumers in various stages of transition, and nine Grantees contacted an additional 867 consumers about transitioning to the community.

Exhibit 4-1. Year One Activities by Topic Area and Completion Status in Fall 2002

Topic Area	Number of Activities in Topic Area	Percentage of Activities on Time	Percentage of Activities That Will Be Completed Late	Percentage of Activities Not Yet Initiated
Workforce Recruitment, Retention, and Training	89	58	18	24
Education/Advocacy	81	51	27	21
Housing	56	59	27	13
Consumer Direction, Choice, and Control	46	72	13	15
Information, Referral, Assessment, and Outreach	48	73	21	6
Nursing Facility Transitions and Diversions	46	67	20	13
Policy, Planning, and Management	43	51	28	16
Quality Assurance and Improvement	38	47	26	24
Person-Centered Planning	19	32	37	26
Research on Effectiveness, Costs and Related Issues	21	45	35	15
Interagency Coordination	16	50	31	19
Personal Assistance Services and Supports	15	53	20	20
Assistive Technology (AT)	13	23	54	23
HCBS Waiver Program Improvement and Development	13	31	62	8

Exhibit 4-2. Reasons Cited for Not Starting Individual Activities or Delays in Activities

Reasons Cited*	Number of Grantees Who Cited Reason
Lack of staff or staffing turnover	15
Lengthy State contracting procedures	7
Activity more complex than first thought	7
Dependent on other tasks not yet completed	5
State budget problem	5
State election issues	3

*Some Grantees cited more than one reason.

- Of the Grantees who have not yet make any transitions planned for Year One, two—Indiana (SP) and Massachusetts (SP)—experienced delays in initiating Grant activities. Both have begun outreach activities and plan to begin transitions in Year Two.

- The Maryland ILP Grantee did not plan to make transitions itself, but to use a peer mentor outreach program to identify nursing facility residents who may be interested in returning to the community. The 150 transitions identified by the Maryland SP Grantee were, however, facilitated by the activities of the ILP Grantee.

Eleven NFT Grantees cited the lack of affordable, accessible, and readily available housing as a major problem for consumers wanting to transition to the community. For example:

- Massachusetts (NFT-SP) noted that low-income housing is becoming increasingly scarce.

- Connecticut (NFT-SP) noted that younger people had difficulty finding housing because many housing complexes were designated for elderly people only.

- Maryland (NFT-ILP) noted that rent for housing is more expensive than what HUD vouchers cover, fair market value is too high for HUD payment standards, and the State has a low housing vacancy rate.

Exhibit 4-3. Nursing Facility Transition Activities in Year One

Name of NFT Grantee	Successfully Transitioned	Successfully Diverted[4]	In the Process of Transition	Contacted by the Transition Program
Alabama ILP	2	n.a.	14	29
Alaska SP	2	n.a.	1	7
Colorado SP	17	n.a.		
Connecticut SP	1	n.a.		
Georgia SP *and* Georgia ILP[1]	30			
Indiana SP				
Maryland SP	23	n.a.	81	251
Maryland ILP	n.a.[2]	n.a.	35	232
Massachusetts SP		n.a.		4
Michigan SP	88	3	126	225
New Hampshire SP	n.a.[3]		2	2
Texas ILP[5]	n.a.	n.a.	n.a.	n.a.
Washington SP	12	n.a.		
West Virginia SP		3	27	39
Wisconsin SP	159			
Wisconsin ILP	36	n.a.	35	78
Total	**370**	**6**	**321**	**867**

[1]In Georgia, the SP and ILP Grantees work very closely together and reported that the successful transitions in Year One were the result of their combined efforts.

[2]Maryland-ILP is working only on outreach for transition purposes and does not plan to transition any individuals.

[3]New Hampshire-SP did not plan to transition individuals in Year One. In Year One, they set up the transition infrastructure, implemented their wrap-around team concept, and built connections with the housing community.

[4]Not applicable for Grantees who do not plan to divert individuals from nursing facilities.

[5]Transitioning consumers is outside the scope of work for the Texas ILP grantee.

NFT Grantees in Maryland, Michigan, Texas, and Wisconsin noted limitations posed by HUD rules for Section 8 housing vouchers and difficulties coordinating with public housing authorities. For example:

- Michigan (NFT-SP) stated that persons over age 62 are not eligible for Section 8 Access Vouchers.

- Wisconsin (NFT-ILP) had difficulty getting the local housing authorities to accept referrals.

Several NFT Grantees who experienced setbacks initiating Grant activities offered suggestions for addressing the delays and eliminating the barriers. They include enhanced communication between HUD and CMS, giving priority for public housing to nursing home residents wanting to transition, and additional Grant funding to permit Grantees to hire more full-time staff.

4.2.3 Type and Range of Activities Implemented in Year One

Grant activities aim to bring about systems change by addressing problems and issues in 14 topic areas. This section provides examples of the types of activities implemented in each of these areas, which are listed in Exhibit 4-1.

Workforce Recruitment, Retention, and Training

- In Georgia (NFT-SP), consumers assisted in the development of the curriculum for a direct service worker training program.

- Maryland (RC) has collaborated with multiple State and local agencies (Departments of Aging, Human Resources, and Education) on recruitment efforts. Additionally, the State's Fire and Rescue Institute is providing reduced-cost CPR and First Aid training at workforce recruitment fairs.

- Montana (CPASS) has subcontractors working on specific Grant tasks including: (1) the design and development of a regional training center to recruit and train individuals to become direct service workers; (2) the development of a public relations campaign aimed at increasing awareness of direct service workers; and (3) the development of a website designed to provide personal assistance resources to consumers, caregivers and family members.

- In Montana (CPASS), a consumer workgroup provided input for the development of back-up worker models and mechanisms to support the personal attendant workforce.

Education and Advocacy

- In Minnesota (RC), the Grant's Quality Design Commission provides input for The Long-term care Task Force, which is made up of legislators and commissioners who are looking specifically at making legislative changes to the State's LTC system.

- In Arkansas (RC), to begin building a network of advocates who are knowledgeable about aging and disability issues and have the necessary skills to influence policy makers, the Grantee conducted an *Introduction to Advocacy* seminar. Both aging and disability advocates attended the seminar, which provided information on the basics of advocacy, and stressed the importance of collaborating on common issues, as well as supporting each other.

- Alabama (NFT-ILP) created an on-going consumer advisory committee to advise not just the Grant, but the State's Medicaid LTC director on policy issues. This committee will assure that consumers' perspectives inform systems change.

Housing

- Florida's (RC) housing group (1) created a cross-disability leadership group to advocate for new and expanded affordable and accessible housing resources; (2) brought together housing developers and service providers; (3) is seeking project-based subsidies; and (4) made presentations to Public Housing Authorities statewide about the *Olmstead* decision and potential strategies for increasing affordable and accessible housing for people with disabilities.

- In New Jersey (RC), a team of mental health consumers and State agency staff attended a two-day Housing Forum in Arlington, VA conducted by the Center for State Health Policy.

- In Georgia (NFT-ILP), CILs worked with the local Public Housing Authorities to obtain Section 8 set-asides for people with disabilities and those transitioning from institutionalized settings.

- Nevada (CPASS) is working with a private developer and the State Division of Housing to establish the State's first assisted living development for people with disabilities funded through a Low Income Housing Tax Credit.

Consumer-Direction, Choice and Control

- In South Carolina (RC), a subcommittee of the Grant's advisory committee provided input for the revision of the National Association of State Units on Aging's Consumer Direction Tool for use in South Carolina. The subcommittee also provided input for the development of the consumer-directed waiver application.

- A Montana (CPASS) workgroup reviewed and provided input on the content of consumer-directed policy rules, as well as consumer and personal attendant surveys.

- In Virginia (RC), the Virginia Commonwealth University has an interagency agreement to conduct focus groups to find out what people want to know regarding consumer direction, to develop training modules, and to conduct trainings.

Information, Referral, Assessment, and Outreach

- In Montana (CPASS), consumers and attendants participated in a focus group to help develop the content of a website to provide resources for caregivers and consumers.

- In Maine (RC), consumers reviewed and provided feedback about a website being developed, and participated in an all-day conference to develop a consumer guide regarding transportation resources.

- Hawaii (RC) hired AssistGuide, Inc., a for-profit organization, as the lead technical contractor for the development of a web based Real Choices information system. The organization also participates in all workgroups and Governing Council meetings as a resource for technical assistance.

  To assure sustainability of the website, AssistGuide is currently working with employers such as hospitals, unions and utility companies, to encourage them to include the Real Choices website as part of their benefits package.

- In Connecticut (NFT), many of the private partners, including the statewide nursing facility associations, participated in the Grant's communication plan by putting Grant information and updates on their websites.

- In Michigan (RC), consumers helped to field-test an on-line self assessment instrument.

- Montana (CPASS) has subcontractors working on specific Grant tasks including: (1) the design and development of a regional training center to recruit and train individuals to become direct service workers; (2) the development of a public relations campaign aimed at increasing awareness of direct service workers; and (3) the development of a website designed to provide personal assistance resources to consumers, caregivers and family members.

- In some instances, Grantees are partnering with both private and public partners on a single Grant activity. For example, Vermont's (RC) *Options Educations* project is a partnership between the State's Department of Aging and Disabilities and the Visiting Nurse Association Health Systems, a private non-profit group representing Certified Home Health Agencies in Vermont. The home health agencies provide highly trained options educators to advise families and consumers applying to a nursing home about all community LTC options.

Nursing Facility Transitions and Diversions

- In Connecticut (NFT-SP), the Office of the Ombudsman arranged a workshop for transition coordinators focused on discharge planning in nursing facilities, and arranged and facilitated a meeting with the directors of Connecticut's statewide nursing facility associations.

- The Maryland Department of Rehabilitation Services has designated one caseworker in each county to work on the NFT-ILP Grant.

- In Washington (NFT-SP), the Division of Vocational Rehabilitation Independent Living Program supplemented Grant funding for individuals who wished to transition but required more extensive supports than could be provided through the Grant.

- In Wisconsin (NFT-SP), the LTC Ombudsman Program identifies individuals in nursing facilities who are candidates for discharge and provides advocacy for those who wish to relocate to the community.

- Alabama (NFT-ILP) former nursing home residents provided information and encouragement to help consumers prepare for a possible transition.

- Connecticut (NFT) a member of the Steering Committee, who is an administrator of a nursing facility, was instrumental in the development of the Grant's nursing home survey and piloted the base line assessment of nursing facilities with a few of her colleagues.

- Alabama (NFT-ILP) staff have met with members of two large rural churches to discuss applying for Robert Wood Johnson Foundation Grants to establish Circle of Friends groups to help nursing home residents transition to the community.

Policy, Planning, and Management

- As part of Maine's (RC) efforts to integrate State data, the Assistant Attorneys General and other counsel have worked with the Grantee to identify confidentiality constraints when integrating data across departments.

- Idaho (RC) partnered with the Idaho Health Care Association, the Idaho Nursing Home Association, the Idaho Housing Finance Association, and AARP to construct a needs and resources assessment. These organizations also served in advisory capacities on the statewide anti-stigma campaign.

Quality

- In Maine (RC), consumers participated in focus groups to identify themes and domains for defining quality.

- Kentucky (RC) has subcontracted with the ARC of Kentucky to review the Federal and State requirements for monitoring service providers under the Medicaid Home and Community Based Waiver for individuals with mental retardation and developmental disabilities. The ARC also convened the first meeting of the Quality Steering Group, which will focus on development of a plan for consumer and family involvement in monitoring waiver service providers.

Person-Centered Planning

- Oregon (RC) is drawing upon experience with person-centered planning for persons with mental retardation and other developmental disabilities (MR/DD) to develop the same service approach for persons with psychiatric disabilities. The Grantee will be working with the Oregon Technical Assistance Corporation, which has several years experience working on person-centered planning for persons with developmental disabilities.

Research on Effectiveness, Costs, and Related Issues

- In Tennessee (RC), Grant staff have had preliminary discussions with Eli Lilly, a pharmaceutical company, regarding potential partnership opportunities for an anti-stigma media campaign. The Grantee is seeking funding from Eli Lilly to evaluate the media campaign's effectiveness.

Interagency Coordination

- Maine (RC) works with staff representatives from five State departments who participate on the Steering Committee for Community Living, some of whose members also work on Grant Work Groups. The Steering Committee is currently discussing ways to continue inter-departmental collaboration and sustain project initiatives beyond the funding period.

Personal Assistance Services and Supports

- Rhode Island (CPASS) began developing certification standards for a new PASS program. Consumer members of a Personal Assistance Services and Supports (PASS) workgroup provided input and recommendations to help guide their development.

- Michigan (CPASS) conducted an analysis of the its current PASS system. To assure the input of consumers, the Grantee surveyed consumers (of whom 202 completed the survey), and conducted focus groups with 16 consumers.

Assistive Technology

- In Delaware (RC), a number of banks and financial institutions have participated in a work group looking at establishing a low interest loan program for funding assistive technology.

Waiver Program Improvement and Development

- New Hampshire (CPASS) has been working to implement the consumer-directed personal care option for the State's waiver program.

During the first year, Grantees developed many products for outreach, training, and general informational purposes, many of which will continue to be used after the Grant ends. A summary description of these products can be found in Appendix C.

4.3 ASSURING SUSTAINABILITY AND ENDURING CHANGE

The primary purpose of Grant funding is to bring about enduring changes in States' LTC programs and policies that will improve access to, and the availability, quality, and value of home and community services and supports.

One method to help assure that effective changes will endure after the Grant ends is to build upon—or coordinate and integrate Grant activities with—past or current efforts and initiatives. Several Grantees are taking this approach. For example:

- Alabama (RC) is building on two current initiatives. The first is with a United Way agency working to set up a 211 telephone line that will provide referrals for health and social services. The Grantee is providing the agency with information about services, and the agency is seeking funding to sustain the 211 line when the Grant ends.

  The second builds on an existing community volunteer program—the *Care Team Network*—in which volunteer care teams support persons with serious illness, the frail elderly, or persons with special needs.

  Grant funds were used to sponsor a Care Team Leadership Training Conference attended by more than 80 people representing a variety of churches and community organizations. The Alabama Department of Senior Services is committed to expanding the Care Team Network in AAA regions.

- Montana-CPASS is working with two caregiver support groups that have been operated by a Caregiver Advocacy Network for over two years. The caregiver support groups are primarily for paid caregivers, but some involve family caregivers as well. The State plans to use Grant funds to formalize the operation of other groups throughout the State.

  The Grantee is also working with the Aging Services Bureau on a website project. After the Grant's subcontractor develops the website, it will be turned over to the Senior and Long-Term Care Division for maintenance.

- Florida (RC) is working with the Department of Elder Affairs and the Florida Housing and Finance Corporation to develop a preliminary database of affordable and accessible housing units and public housing authorities. When completed, it will be the first data base of its kind in Florida, and will act as a single-point of entry for housing information for consumers and providers.

- Nebraska (RC) used the results of previously conducted statewide conferences, research studies, and a pilot 211 project in developing recommendations for a statewide coordinated structure of resource data to be used by consumers, family members, and providers.

North Carolina (RC) provides an example of a successful integration effort. When looking for existing initiatives that were complementary to Grant activities, Grant partners identified two individuals in two different parts of the State who were working to generate interest in creating a State association for direct service workers, which is a key Grant activity. One person is a direct service worker and the other a professional staff member in a home care agency that participates in a multi-county workgroup to address direct care workforce issues.

Grant staff are now collaborating with partner organizations already working to support these individual efforts and are working to combine the two efforts so that all parties involved will be working together to develop a common plan and strategy to promote a State-level direct service worker association. This collaboration and integration has prevented costly duplication of effort and will help to assure the success and sustainability of the initiative.

At the end of the First Year, most Grantees are still in the process of bringing about systems change. However, several reported the completion of activities that have resulted in enduring change, including:

- Minnesota (CPASS) proposed and the legislature approved statutory changes permitting consumers who use the Personal Care Assistance Choice option to use *Shared Care*. *Shared Care* is a program that gives two consumers the opportunity to share a personal assistant. For example, if two consumers want to go shopping together, a personal assistant can work for both and get paid one and-a-half times the regular rate. The cost is divided between the two consumers, resulting in a savings for the State.

- Kentucky (RC) Grant activities were instrumental in getting the Kentucky Housing Corporation to change its policy to require use of Universal Design principles.

- Maryland (NFT-SP) reported a number of enduring changes achieved as a result of Grant activities.

  (1) The Department of Housing and Community Development has agreed to modify the weight factor in its Qualified Allocation Plan (QAD) as an incentive for developers to set aside a percentage of housing units for people with disabilities.

  (2) Three Public Housing Authorities have included a commitment to set aside Section 8 vouchers for participants in Medicaid Waiver programs in their HUD funding applications.

  (3) One county has set aside existing vouchers for applicants to the Medicaid HCBS waiver program.

- In Connecticut (NFT-SP), a Center for Independent Living formalized the first partnership with a local housing authority.

- In Georgia (NFT-ILP), two Centers for Independent Living (CILs) obtained Memos of Understanding with their local Public Housing Authorities that guarantee priority for housing to persons transitioning from a nursing facility.

5. Next Steps

During Year Two—October 1, 2002 through September 30, 2003—Grantees are continuing their activities with a specific focus on ensuring systems changes that will endure beyond the three-year Grant period.

Grantees who experienced some delay in initiating Grant activities are now working with CMS Project Officers to assure that their projects are back on schedule by the end of Year Two.

The next RTI reports documenting Grantee progress will focus on two key issues that many Grantees are addressing: increasing the availability of affordable, accessible housing and workforce recruitment, training, and retention. These reports will be available in late Fall 2003.

The Year Two annual report documenting progress in Year Two will be available in March 2004. A companion report documenting Year One progress of the Grantees who first received funding in FY 2002 will also be available in March 2004.

ENDNOTES

[1] The grants were awarded for a 3-year period from September 28, 2001, to September 27, 2004. For convenience, we will report on their activities to coincide with the federal fiscal year calendar.

[2] *Olmstead v. L.C.*, 119 S.Ct. 2176 (1999).

[3] Burwell, B., S. Eiken, and K. Sredl. "Medicaid Long-Term Care Expenditures in Fiscal Year 2001" (Internal memorandum, Medstat Group. Cambridge, MA, May 2002).

[4] In 2002, RTI and its subcontractor, MEDSTAT, prepared summaries of each Grantees' goals, objectives, and major activities, which Grantees reviewed and approved. These activities were categorized by topic into 14 categories in the RTI report *Goals, Objectives and Activities: Comparative Analysis of FY 2001 Systems Change Grantees,* September 2002, page 3-3. This report was prepared under contract to CMS, and can be found at http://www.hcbs.org.

[5] State Budget Update: April 2003. National Conference on State Legislatures. http://www.ncsl.org/programs/press/2003/030424.htm

[6] *Goals, Objectives and Activities: Comparative Analysis of FY 2001 Systems Change Grantees,* September 2002. This report can be found at http://www.hcbs.org.

Appendix A:

Acronym List and State Abbreviations

Acronyms and State Abbreviations

AAA	Area Agencies on Aging
AT	assistive technology
CIL	Center for Independent Living
CMS	Centers for Medicare and Medicaid Services
CPASS	Community-Integrated Personal Assistance Services and Supports
CTF	Consumer Task Force
FAQ	Frequently Asked Questions
FY	fiscal year
HCBS	home and community-based services
HUD	Housing and Urban Development
ILP	Independent Living Partnership
LTC	long-term care
NFT	Nursing Facility Transition
PAS	personal assistance services
PHA	Public Housing Authority
RC	Real Choice
SP	State Program
AL	Alabama
AK	Alaska
AZ	Arizona
AR	Arkansas
CA	California
CO	Colorado
CT	Connecticut
DE	Delaware

DC	District of Columbia
FL	Florida
GA	Georgia
HI	Hawaii
ID	Idaho
IL	Illinois
IN	Indiana
IA	Iowa
KS	Kansas
KY	Kentucky
LA	Louisiana
ME	Maine
MD	Maryland
MA	Massachusetts
MI	Michigan
MN	Minnesota
MS	Mississippi
MO	Missouri
MT	Montana
NE	Nebraska
NV	Nevada
NH	New Hampshire
NJ	New Jersey
NM	New Mexico
NY	New York
NC	North Carolina
ND	North Dakota

OH   Ohio

OK   Oklahoma

OR   Oregon

PA   Pennsylvania

RI   Rhode Island

SC   South Carolina

SD   South Dakota

TN   Tennessee

TX   Texas

UT   Utah

VT   Vermont

VA   Virginia

WA   Washington

WV   West Virginia

WI   Wisconsin

WY   Wyoming

Appendix B:

Progress on First Year Grant Activities by Topic Area

Progress on First Year Grant Activities by Topic Area

This section categorizes the 543 the Year One activities into 14 topic areas and describes Grantee progress in each area.

Workforce Recruitment, Retention, and Training. Eighty-nine activities (16 percent of total activities) relate to workforce recruitment, retention and training. Some Grantees have been slower to get these activities started. Approximately three-quarters of the activities in this group were initiated, with approximately 58 percent of all activities expected to be completed on schedule.

Education of Consumers, Providers, Agency Personnel/Advocacy with the General Public on General or Specific Disability Issues. Eighty-one activities (15 percent of total activities) relate to education and/or advocacy. Grantees have been slow in getting these activities started. About 79 percent have been initiated, with 51 percent of all activities expected to be completed on schedule. One activity requires technical assistance for completion.

Housing. Fifty-six activities (10 percent of total activities) relate to housing. Nearly 86 percent of these activities were initiated. Of the housing activities that began in the first Grant year, approximately 59 percent are anticipated to be completed on schedule. Only one housing activity requires technical assistance to be completed.

Consumer Direction, Choice, and Control. Forty-six activities (9 percent of total activities) relate to consumer direction. The majority of Grantees were progressing well in this area. Approximately 85 percent were initiated in Year One, and about 72 percent of all activities are expected to be completed on schedule.

Information, Referral, Assessment, and Outreach. Forty-eight activities (9 percent of total activities) relate to information, referral, assessment and outreach. The majority of the Grantees are progressing well in this area. Approximately 94 percent of the activities in this topic area have been initiated, and three-fourths of all activities are expected to be completed on time.

Nursing Facility Transitions and Diversions. Forty-six activities (9 percent of total activities) relate to nursing facility transition and/or diversion. Grantees were progressing well in this topic area. Approximately (87 percent) have been initiated, and 67 percent of all nursing facility transition/diversion activities are expected to be completed on schedule.

Policy, Planning, and Management. Forty-three activities relate to policy, planning and management (8 percent of total activities). Grantees are progressing well in this area, with approximately 79 percent of activities initiated, and half of these are expected to be completed

on schedule. There were two activities for which Grantees specifically requested technical assistance.

Quality Assurance and Improvement. Thirty-eight activities (7 percent of total activities) relate to quality assurance and improvement. Some Grantees have been slower to get these activities started. Approximately three-quarters of these activities have been initiated, although only 47 percent of these are expected to be completed on time. One activity requires technical assistance.

Person-Centered Planning. Nineteen activities relate to person-centered planning (4 percent of total activities). Many Grantees have faced delays in this area. While thirteen (68 percent) of these 19 activities commenced in the first Grant year, Grantees expect only one-third of these activities to be completed on schedule. One activity in this topic area requires technical assistance.

Research on Effectiveness, Costs and Related Issues. Twenty activities (4 percent of total activities) relate to research on effectiveness, costs and related issues. Many Grantees have faced delays in this area. Four-fifths of these activities were initiated, with about 45 percent of the 20 activities expected to be completed on schedule. One of the activities in this topic area requires technical assistance for completion.

Interagency Coordination. Sixteen activities (3 percent of total activities) are related to interagency coordination. About four-fifths of these activities were initiated, but only half of the 16 activities are expected to be completed on schedule.

Personal Assistance Services and Supports. Fifteen activities (3 percent of total activities) relate to personal assistance services and supports. Grantees have been slow in getting these activities started. Three-quarters of the activities in this topic area have been initiated and approximately 53 percent of all activities are expected to be completed according to schedule. One activity in this topic area requires technical assistance for completion.

Assistive Technology (AT). Thirteen activities (2 percent of total activities) relate to assistive technology. While most of these activities have been initiated, few will be completed on time. Ten (77 percent) of these activities were initiated, although only 23 percent are on schedule.

Home and Community Services (HCBS) Waiver Program Improvement and Development of Additional Waivers. Thirteen activities (2 percent of total activities) relate to waiver programs. While most of these activities have been initiated, few will be completed on time. Nearly all of these 12 activities (92 percent) were initiated in the first Grant year, but only 31 percent are expected to be completed on schedule.

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Appendix C:

Products Developed by Grantees

Products Developed by Grantees

During Year One, Grantees developed many products for outreach, training, and general informational purposes. This section provides a summary overview of these and other products Grantees have developed.

Outreach Products. Twenty-five Grantees developed outreach products. The most common types include:

- Websites (8 Grantees)
- Brochures (8)
- Conference, workgroup, and PowerPoint presentations (8)
- Flyers (5)
- Newsletters (5)
- Materials for fairs, seminars, meetings, conferences (4)
- Posters (3)
- Guidebooks (3)

Websites, brochures, and presentations were the most frequently used methods for outreach. Website content included information about services [NH (CPASS)], direct care workforce initiatives [NC (RC)], the Olmstead decision and NFT activities [GA (NFT-ILP)], work group reports [ME (RC)], and general Grant information and materials [MI (NFT-SP)], [NE (RC)], [TX (NFT-ILP)], and [WV (NFT-SP)].

Grantees developed brochures to communicate general information about Grant activities as well as information about specific Grant initiatives. For example, the Center for Accessible Living in Kentucky (RC) produced two brochures for use in assisting individuals to transition from nursing homes to the community. One describes the availability of transition/ diversion services and the second gives a detailed description of transition/diversion services.

Grantees made presentations to communicate information about Grant activities to consumers and other stakeholders. Similar to the use of brochures, presentations were used to communicate general information about the Grant and specific information about Grant activities. For example, Arkansas (RC) developed presentations for its *Introduction to Advocacy Seminar*, Nebraska (RC) made presentations at town hall meetings, South Carolina-RC made presentations at public awareness sessions and consumer-directed care workshops, and NH (CPASS) made presentations at a Peer Support Conference.

Some Grantees developed unique outreach products, including wallet cards, videos, public service announcements, media packets, news releases, recruitment materials, letters, Frequently Asked Questions (FAO) materials, and vouchers.

Educational Products. Eighteen Grantees developed educational and training products [AR (CPASS), GUAM (CPASS), MT (CPASS), NH (CPASS), OK (CPASS), AL (RC), DE (RC), ID (RC), IL (RC, KY (RC), NC (RC), OR (RC), SC (RC), VA (RC), VT (RC), NH (NFT-SP), WA (NFT-SP), WV (NFT-SP)]. They include: PowerPoint presentations; educational booklets; manuals; packets of materials; courses and sessions; websites; videos; and FAQs.

For example, Kentucky (RC) developed Personal Advocate recruiting and training materials. Delaware (RC) developed resource information on assistive technology that outlines processes, funding, and service provision sources. Other topics addressed in educational materials include housing, problem solving, rights and responsibilities, how to be a strong self advocate, and being part of the community.

Some Grantees provided educational courses and sessions. For example, Delaware developed a 12-module course on assistive technology. Other forms of educational products include new-hire and consumer orientation information packets, websites, interview skill training videos, and FAQs for staff.

Technical Products. Twenty-one Grantees developed technical products [AR (CPASS), MI (CPASS), NH (CPASS), OK (CPASS), DE (RC), FL (RC), IL (RC), MI (RC), MN (RC), NC (RC), NE (RC), OR-(RC), VT (RC), CT (NFT-SP), GA (NFT-SP), MD (NFT-ILP), MD (NFT-SP), NH (NFT-SP), TX (NFT-ILP), WI (NFT-ILP), WV (NFT-SP)]. Technical products were primarily measurement tools, assessment instruments, and informational materials.

Several Grantees developed survey instruments and assessment tools. Surveys were the most common type of technical product, developed to obtain information on a range of topics, including:

- Personal Assistant Services and Supports [MI (CPASS)]
- Consumer back-up coverage [NH (CPASS)]
- Consumer satisfaction [NH (CPASS)]
- Housing Needs Assessment Survey in [IL (RC)]
- Mental Health Drop-In Centers and CILs [OR (RC)]
- Residents in nursing facilities who want to transition to the community [GA (NFT-SP)]
- Service providers [TX (NFT-ILP)].

Assessment instruments that Grantees developed include a baseline assessment for nursing facility staff and self-assessment tools for nursing facility residents in Connecticut (NFT-SP), and a transitions assessment, household checklist, and planning tools in Wisconsin (NFT-ILP).

Informational Materials. Grantees produced manuals, guides, inventories, directories, and databases on a wide range of topics:

- Provider technical assistance [NH (CPASS)]
- Transitioning to the community [MD (NFT-ILP)]

- Housing [TX (NFT-ILP)]

- Guide to community services and supports [WV (NFT-SP)]

- Home modification inventories [IL (RC)]

- Service and support needs inventories [TX (NFT-ILP)]

- Resource directories include employee and consumer training directories, directories of advocacy groups, service provider directories, and directories containing community activities [MI (RC)]

- Databases with information on direct service workers [NC (RC)]

- Database on cutting edge systems change efforts [NE (RC)].

Appendix D:

Annual Report Form

SYSTEMS CHANGE GRANTS FOR COMMUNITY LIVING

ANNUAL REPORT
FY 2002 (OCTOBER 1, 2001 – SEPTEMBER 30, 2002)

Please submit a complete response to the following questions no later than **November 29, 2002**.

Your answers should be limited to activities that occurred in the last Grant year. Include responses and return this form via email to:

CMS Project Officer:

Regional Office Contact:

Grants Officer:

RTI/MEDSTAT Formative Research Contractor:

Grant Information:

Grant Number:

Grant State:

Name of Grantee:

Title of Grant:

Type of Grant:

Amount of Grant FY 2001:

Contact Information:

First Name:		**Last Name:**
Title:		**Phone:**
Street Address:		**E-mail:**
City:	**State:**	**Zip:**

I. MAJOR MILESTONES / ASSESSMENT OF CURRENT STATUS

A. After the Grant awards were made, Grantees were asked to confirm their final goals, objectives, and activities. These are listed in the attached document. **(Not shown)**

> **Next to each <u>activity</u> in the attached document please indicate your progress using the following letters:**
>
> **A   you have initiated the activity and it is being completed on schedule**
> **B   you have initiated the activity but believe it will not be completed on schedule**
> **C   you have not initiated the activity**
> **D   you need assistance from a CMS technical assistance provider to initiate or complete the activity**
> **E you were not scheduled to undertake the activity in this Grant year.**

For activities not on schedule, please indicate an estimated revised due date and describe the steps you are taking to complete activities timely.

B. Please describe the type of activities that consumer partners, private partners, and public partners have been involved in over the past six months (e.g., participation in advisory or oversight meetings, reviewed Grant related materials, engaged in planned Grant activities, etc.).

Please describe activities separately for each type of partner:

1. Consumer partners

2. Private partners

3. Public partners

C. Please describe how Grant activities are being coordinated or integrated, if applicable, with other disability or long-term care programs (i.e., housing, transportation, vocational rehabilitation, etc.) within the State.

D. Please indicate if your project has produced any outreach, education, technical assistance materials, or other such products.

E. Please describe the major challenges you have faced in implementing Grant activities.

F. Have you had to revise any of your goals based on difficulty initiating or completing activities? If so, please describe any changes you have made.

G. Is there specific assistance that the CMS Central Office, your CMS Regional Office, or CMS Technical Assistance Providers could provide to help you achieve the goals specified in your Grant?

H. Please describe any specific systems change issues that your project addressed through a particular approach or activity that you would recommend to others. Include a description of any critical steps or partners in the approach you recommend, any pitfalls to avoid, and any particular activities that facilitated success.

I. ***For Nursing Home Transition Grantees***: Please provide any information you have on individuals who have been transitioned to the community using Grant funds (e.g., age, gender, ethnicity/race, level of care need, primary diagnosis, activities of daily living needs, numbers of months in the nursing facility prior to transition and/or months in the hospital or other institution prior to diversion.

J. Is there anything else you would like to tell us about your project's activities in the last year?

II.   TECHNICAL ASSISTANCE

A. During the last six months, what technical assistance did your project receive from the Community Living Exchange Collaborative: A National Technical Assistance Program (formerly known as The National Technical Assistance Exchange for Community Living) or another source?

B. What changes, if any, would you suggest in the way that technical assistance is being provided to make it more effective or timely?

C. Please describe the technical assistance that would be helpful as you enter the second year of your Grant's activities.

III.   ENDURING SYSTEMS CHANGE

A. As a result of your Grant activities to date, has your State made any enduring changes to its community long-term services and supports systems? If so, what are they?

For example, if existing programs or policies have been changed as a result of Grant activities, describe those changes.

Please provide any other information about how Grant activities have changed the environment, policies or processes in your State.

Appendix E:

FY 2001 Grantees by Grant Type and State

List of States with FY 2001 Grants, by Grant Type

Community-Integrated Personal Assistance Services and Supports Grants (CPASS)

ALASKA
ARKANSAS
GUAM
MICHIGAN
MINNESOTA
MONTANA
NEVADA
NEW HAMPSHIRE
OKLAHOMA
RHODE ISLAND

Nursing Facility Transition Grants (NFT)

ALABAMA (ILP)
ALASKA
COLORADO
CONNECTICUT
GEORGIA (ILP)
GEORGIA
INDIANA
MARYLND (ILP)
MARYLAND
MASSACHUSETTS
MICHIGAN
NEW HAMPSHIRE
TEXAS (ILP)
WASHINGTON
WEST VIRGINIA
WISCONSIN (ILP)
WISCONSIN

Real Choice for Systems Change Grants (RC)

ALABAMA
ARKANSAS
DELAWARE
FLORIDA
GUAM
HAWAII
IDAHO
ILLINOIS
IOWA
KENTUCKY
MAINE
MARYLAND
MASSACHUSETTS
MICHIGAN

MINNESOTA
MISSOURI
NEBRASKA
NEW HAMPSHIRE
NEW JERSEY
NORTH CAROLINA
OREGON
SOUTH CAROLINA
TENNESSEE
VERMONT
VIRGINIA

List of States with Grants, in Alphabetical Order

ALABAMA (NFT-ILP)
ALABAMA (RC)
ALASKA (CPASS)
ALASKA (NFT-SP)
ARKANSAS (CPASS)
ARKANSAS (RC)
COLORADO (NFT-SP)
CONNECTICUT (NFT-SP)
DELAWARE (RC)
FLORIDA (RC)
GEORGIA (NFT-ILP)
GEORGIA (NFT-SP)
GUAM (CPASS)
GUAM (RC)
HAWAII (RC)
IDAHO (RC)
ILLINOIS (RC)
INDIANA (NFT-SP)
IOWA (RC)
KENTUCKY (RC)
MAINE (RC)
MARYLAND (NFT-ILP)
MARYLAND (NFT-SP)
MARYLAND (RC)
MASSACHUSETTS (NFT-SP)
MASSACHUSETTS (RC)
MICHIGAN (CPASS)
MICHIGAN (RC)
MINNESOTA (CPASS)
MINNESOTA (RC)
MISSOURI (RC)
MONTANA (CPASS)
NEBRASKA (RC)
NEVADA (CPASS)
NEW HAMPSHIRE (CPASS)
NEW HAMPSHIRE (NFT-SP)
NEW HAMPSHIRE (RC)
NEW JERSEY (RC)
NORTH CAROLINA (RC)
OKLAHOMA (CPASS)
OREGON (RC)
RHODE ISLAND (CPASS)
SOUTH CAROLINA (RC)
TENNESSEE (RC)
TEXAS (NFT-ILP)
VERMONT (RC)
VIRGINIA (RC)

WASHINGTON (NFT-SP)
WEST VIRGINIA (NFT-SP)
WISCONSIN (NFT-ILP)
WISCONSIN (NFT-SP)